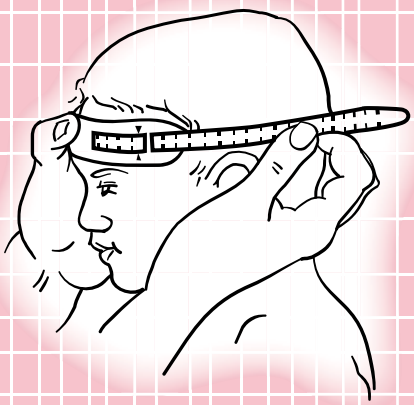

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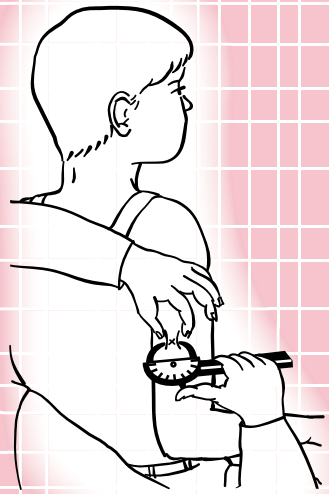
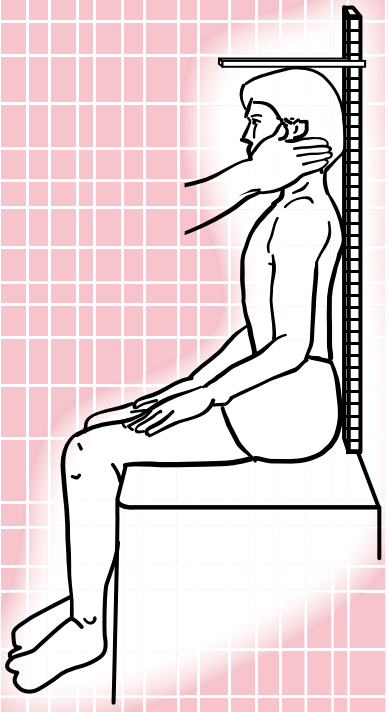
Third Edition, 2010





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Contents

Appendices

Acknowledgements

There are several key groups who made this third edition of the *Nutrition Interventions for Children with Special Health Care Needs* possible.

We would like to thank the authors who contributed their time and expertise to update the information and references. We offer our deepest appreciation for the contribution of editors who have spent hours attending to the many details. Thanks also to registered dietitians who have reviewed and provided comments on this edition. We would also like to extend our appreciation to registered dietitians and others who worked on the first and second editions.

The CSHCN Program deserves acknowledgement for supporting staff that had continual involvement in this project. The Washington WIC Program provided the funding for closure on the project, including the final printing and CDs. WIC must also be acknowledged for its key role in the distribution of the resource to WIC Clinics throughout Washington State and for its consistent integration of information from this resource into statewide training plans and curriculum for community-based WIC nutritionists.

This project was undertaken to meet the needs of nutritionists serving children with special health care needs in Washington, but we know there will be interest from others around the country. We are happy to add this book to the national pool of resources for providers working with children with special health care needs and hope that others continue to do the same.

Lastly, we acknowledge the users of this resource who will have a critical role in implementing the nutrition intervention strategies outlined in the book to improve the nutritional status of children with special health care needs. We would also like to extend our appreciation to our colleagues from other disciplines and caregivers with whom we work as partners to help children with special health care needs reach their full potential.

Introduction

Maria Nardella

Updated by Yuchi Yang

Background

The original edition of *Nutrition Guidelines for Children with Disabilities and Chronic Illnesses* was published in 1989 in response to an assessment of needs for nutrition services in Neurodevelopmental Centers and local health departments throughout the state of Washington.

The primary users in Washington were members of a statewide network of registered dietitians/nutritionists who provide services to children with special health care needs. In 1996, this group was surveyed to determine how useful the book still was as a resource and if there was enough interest and need to warrant a revision. The overwhelming results were to initiate a revision process.

An Advisory Committee was formed and a part time Coordinator/Editor was hired to revise and expand the 1989 version. It was intended to be a contribution to existing tools and nutrition resources for dietetic practitioners that serve to guide or define the provision of nutrition care for children with special health care needs in multiple service settings. It was an expensive endeavor even though hundreds of hours of work were generously donated by the 30 unpaid authors of the various chapters and their employers. It took four years to complete (2001), and the name of the new publication was changed to *"Nutrition Intervention for Children with Special Health Care Needs."* In 2002, a second edition and second printing was done which included minor corrections and additions.

New Edition

For the past few years, the CSHCN Program has received numerous requests for a new edition. The work on the third edition was initiated in 2008. Again, many authors, editors and reviewers have come forward and contributed their expertise and donated hundreds of unpaid hours for the completion of the third edition.

This edition includes three new chapters, which makes the publication more comprehensive. These chapters include breastfeeding, physical activity, and autism spectrum disorders.

Population

"Children with special health care needs" refers to children with or at increased risk for a broad range of chronic illnesses or disabling conditions who require intervention beyond basic, routine, pediatric care.

Organization of the Book

The book is divided into three sections.

Section 1 "Determination of Nutritional Status" outlines the recommended procedures for nutrition screening, and assessment; and addresses the prerequisite steps to take in the development of a nutrition intervention care plan.

Section 2 "Problem-Based Nutrition Interventions" addresses the nutrition-related problems that are more common across a wide range of diagnoses.

Section 3 "Condition-Specific Nutrition Interventions" addresses nutrition management related to specific diseases and disorders that have strong nutrition components.

Intervention strategies with evaluation/outcomes are presented in each chapter based on the following screening and assessment components:

- Anthropometric
- Biochemical
- Clinical/Medical history
- Dietary
- Feeding
- Socioeconomic characteristics

Each chapter contains a "Nutrition Interventions" table that addresses steps to take in assessment, appropriate interventions to consider, and achievable outcomes. Some material is intentionally repeated in the summary table for each chapter, recognizing that users of this book may want to utilize individual chapters as "free standing" documents. This is also why references are included with each chapter versus one list at the end of the book.

Lastly, there is an extensive Appendix that provides more detailed supportive information for the topics presented in the earlier sections and includes many useful tools.

It is hoped that this book will enhance the development of the following skills:

- Comprehensive nutrition assessment
- Nutrition assessment of abnormal growth patterns
- Advanced nutrition assessment and counseling for special diets
- Appropriate uses of special formulas
- Interpretation and application of objective data
- Development of nutrition intervention strategies to produce outcomes
- Participation as a team member to provide interdisciplinary care

Most nutrition and feeding problems of children with special health care needs can be improved or controlled, but often are not totally resolved. These children will require ongoing and periodic nutrition assessment and intervention. This book is a resource that will be needed time and again.

CHAPTER 1

Nutrition Screening and Assessment

Janet Gilliam, MS, RD, CD and Sandi Laney, RD, CD
Updated by Roseann Torkelson, MS, RD, CD

Nutrition disorders and compromised nutritional status are common among children with special health care needs. As many as 40% of infants and children with special health care needs are at nutritional risk (1). A survey of children from birth to age three years with developmental delays in early intervention programs found 70-90% had one or more nutrition risk indicators (2). Indicators of nutritional risk include altered growth, increased or decreased energy needs, medication-nutrient interactions, metabolic disorders, impaired ability to utilize nutrients, poor feeding skills, and partial or total dependence on enteral or parenteral nutrition (1). A well-nourished child has increased alertness and stamina to participate in therapies, educational activities, and social interactions and benefits from fewer illnesses and improved coping skills. Improved nutritional status and feeding skills may increase the level of independence the child is able to achieve. It can improve the child's perception of self and the caregivers' perceptions of their abilities to meet the child's needs (2).

Screening and assessment of nutritional status are integral components of pediatric health care (3). Screening is a preliminary survey of factors associated with nutritional status that is undertaken to identify infants and children who appear to have nutrition problems or who are at risk for developing a nutrition problem (4). Nutrition screening should be routinely performed for all children with special health care needs. Screening provides general information that can be used in the more comprehensive Nutrition Care Process of nutrition assessment and diagnosis, leading to nutrition intervention, monitoring, and evaluation (5).

Nutrition Screening

Nutrition screening has a variety of functions, requirements, and benefits. Screening consists of the collection of preliminary data in one or more of the following categories:

- anthropometric parameters
- clinical (medical history and diagnosis)
- biochemical laboratory data

- diet
- developmental feeding skills
- behavior (related to feeding)
- socioeconomic characteristics

The screening activities in each of these categories are described in Table 1-1.

Nutrition screening can be effective without including all the categories or all suggested data within a category. The screening protocols must be adapted to the setting and according to staff availability and other resources (6). Nutrition screening should be brief and easy to administer. Parent-administered questionnaires and/or interview methods can be effective tools for obtaining screening data. Screening can be successfully completed by a variety of individuals such as the parent or caregiver, public health nurse (PHN), clinic nurse, therapist, social worker, family resource coordinator (FRC), primary care provider (PCP), registered dietitian (RD), or dietetic technician (DTR). Nutrition screening can be incorporated into initial early intervention screenings so that concerns can be identified and referred for an assessment. Infants and children need to be screened on a regular basis to monitor growth and nutritional status over time. Sample screening forms are included in Appendix A.

When a child is identified as having one or more nutritional risk indicators, referral for nutrition assessment with an RD is needed. Nutrition risk indicators need to be clearly defined to avoid over-identification or under-identification of those at risk. Refer to Table 1-1 for examples of risk indicators and sample criteria. In addition to red flags identified by nutritional risk indicators, parental concerns should be carefully listened to and considered.

Nutrition Assessment

Once a nutritional risk indicator is identified through screening, a nutrition assessment serves to obtain all information needed to rule out or confirm a nutrition-related problem. Nutrition assessments should be completed by an RD, preferably with pediatric expertise and/or specialized training for children with special health care needs and developmental disabilities.

Nutrition assessment consists of an in-depth and detailed collection and evaluation of data in the following areas: anthropometrics, clinical/medical history, diet, developmental feeding skills, behavior related to feeding, and biochemical laboratory data (2). During the assessment, risk factors identified during nutrition screening are further evaluated and a nutrition diagnosis can be made. The assessment may also reveal areas of concern such as oral-motor development or behavioral issues that

require referral for evaluation by the appropriate therapist or specialist. The nutrition assessment is one of the essential elements of a comprehensive interdisciplinary team evaluation and intervention plan. Table 1-2 provides parameters for completing nutrition assessments and indicators for nutrition intervention.

Nutrition Intervention

Planning and providing nutrition care and intervention for children with special health care needs is often complex because many factors interact to affect nutritional status. Optimal nutrition care involves consultation and care coordination with professionals from a variety of disciplines. The interdisciplinary team may consist of the child and family, PCP, occupational therapist (OT), physical therapist (PT), speech language pathologist/ therapist (SLP), RD, behavior specialist, social worker, PHN, and home health care providers. Other community agencies such as schools, early intervention programs, hospitals, specialty clinics, the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), Head Start, day care, Division of Developmental Disabilities, and Child Protective Services may also be involved.

The team approach consists of professionals working in a family-centered partnership to coordinate services and provide continuity of care for the child and family. With input from team members, a specific plan of nutrition intervention is developed. The nutrition intervention step of the Nutrition Care Process should be culturally-sensitive and have a preventive emphasis. Nutrition care goals and objectives (or outcomes) can become a part of the child's Individual Education Plan (IEP) or Individualized Family Service Plan (IFSP) (See Chapter 12). Reassessment should occur at regular intervals to monitor the child's nutrition status, and evaluate the effectiveness of the nutrition intervention. Based on the reassessment, nutrition goals and objectives may be modified to meet the needs of the child and family (5).

Table 1-1: Nutrition Screening [3-7] Repeat screening in 6 to 112 months if no nutritional risk factors are identified.

Screening Activities	Nutrition Risk Indicators
Anthropometric	
Measure and weigh using standardized techniques and appropriate equipment* Plot on standard growth charts† • Height or length for age • Weight for age • Weight for height (or length) • Head circumference (under age 3 years) • Body Mass Index (BMI) (over age 2 years) Compare current measurements to reference data and to previous measurements available.	Refer for nutrition assessment if any of the following exist: • Height or length for age less than 10th percentile • Weight for age less than 10th percentile • Weight for length (or height) less than 10th percentile • Weight for length (or height) greater than 90th percentile • BMI less than 10th or greater than 90th percentile • Change in weight or length of 2 or more percentile channels • Inadequate growth or weight gain for more than one month (under age two)
When doing anthropometrics, observe for signs of neglect or physical abuse.	If signs of neglect or physical abuse are noted, contact Child Protective Services (CPS).
Biochemical Laboratory Data	
Obtain lab data from medical record, WIC program, or primary care provider: • Hematocrit (Hct) or hemoglobin (Hgb) • Other pertinent lab data: serum albumin, serum prealbumin, if available	Refer for nutrition assessment if abnormal lab values of nutritional significance.
Clinical/Medical History	
Review past medical history and current health status and diagnosis	Refer for nutrition assessment if any of the following: • Anemia • Anorexia and/or bulimia nervosa • Autism or Pervasive Developmental Disorder • Cardiac, pulmonary, or renal disease (See Chapters 16, 18,19) • Chronic constipation or diarrhea (See Chapters 6 and 7) • Chronic diseases such as diabetes, cancer, HIV/AIDS • Cystic fibrosis (See Chapter 17) • Feeding problems, poor appetite or refusal to eat (See Chapters 8 and 9) • Fetal alcohol syndrome or fetal alcohol effects • Food allergies or intolerances • Frequent or recurring infections

Screening Activities	Nutrition Risk Indicators
	• Gastrointestinal disorders, reflux, vomiting • History of poor growth or excessive weight gain (See Chapters 13 and 14) • Long-term use of laxative, diuretic, anticonvulsant, steroid, or stimulant medications (See Chapter 5) • Malabsorption syndromes • Metabolic disorders, ie, PKU, galactosemia (See Chapter 21) • Myelomeningocele (spina bifida) • Neurological conditions, ie, cerebral palsy, anoxia, trauma • Oral or facial anomalies that affect nutrition (See Chapter 8) • Prader-Willi syndrome (See Chapter 13) • Significant dental problems • Special or therapeutic diet • Tube feeding (See Chapter 10)
Dietary	
Interview caregiver(s) to determine • Concerns about food intake, feeding, and nutrition • Child's typical feeding pattern (types of foods eaten and how often, aversions, and preferences) • Use of oral supplements • Use of vitamin/ mineral supplements • Use of herbal products or alternative nutrition or other therapies	Refer for nutrition assessment if: • Inadequate or inappropriate dietary intake, i.e., NPO or hypocaloric intake for more than 3 days • Alternative or special diet: vegan, macrobiotic, or other restricted diet • Consumes only liquid, pureed, or ground food after age 2 • Pica (intake of non-food items, ie, clay, dirt, starch) • Use of supplements, including vitamin / minerals exceeding 100% of the DRI without physician recommendation
Developmental Feeding Skills‡	
Interview caregiver(s) to determine child's feeding skills: • Oral-motor control • Frequency and duration of feedings • Consistency of foods eaten • Self-feeding skills • Typical fluid intake by breast, bottle, and/ or cup • Concerns about progression of feeding skills Review health records for signs of delays or abnormalities in the development of feeding skills.	Refer for nutrition assessment if: • Abnormal sucking pattern (arrhythmic, disorganized, lack of initiation) • Swallowing difficulties (gagging, choking, coughing, noisy breathing after feeding) • Difficulty with chewing • Inability to drink from a cup at appropriate age • Lack of progression in food textures • Not self-feeding after two years of age • Feeding routinely takes longer than 45 minutes per meal

Screening Activities	Nutrition Risk Indicators
Interview caregivers about child's behavior during feeding. Review health records for signs of behavior problems related to feeding.	Refer for nutrition assessment if signs of behavior problems related to feeding including: • Disruptive behavior at mealtime • Refusal to eat • Voluntary gagging on foods
Socioeconomic Characteristics	
Obtain by interview or review of health records: • Family size and income level • Cultural and familial food patterns • Adequacy of food resources • Participation in food and community programs: WIC, Food Stamps, school food program, food banks	Refer for nutrition assessment if inadequate or inappropriate food pattern: • Insecure food supply • Inadequate housing • Abusive home situation • Financial difficulties Refer to appropriate social services, nutrition programs, and/or food resources.

*See Chapter 2
†Correct for prematurity up to 36 months. See Chapters 2 and 13.
‡See Chapter 8 for appropriate developmental milestones

Table 1-2: Nutrition Assessment [4, 5, 7-10]

Assessment Activities	Indicators for Nutrition Intervention
Anthropometric*	
Measure and weigh using standardized techniques and appropriate equipment. For difficult to measure children, arm span, crown-rump, or sitting height may be appropriate methods to estimate stature. Plot on CDC Growth Charts: United States and specialized growth charts as indicated:† • Height or length for age • Weight for age • Weight for length (or height) • Head Circumference (under 3 years) • Body Mass Index (BMI, over age 2 years) Measure and calculate, if skilled in these techniques: • Mid-upper arm circumference • Triceps skinfold • Subscapcular skinfold • Arm muscle area • Arm fat area Compare all current measurements to reference data and previous measurements. Use of incremental growth charts may be helpful.	Nutrition intervention indicated if any of the following: • Weight for height or length less than 5th or greater than 95th percentile • Length or height for age less than 5th percentile • BMI less than 5th or greater than 85th percentile • Deviation of more than 2 channels from established pattern of growth • Triceps skinfold less than 5th or greater than 95th percentile • Subscapular skinfold less than 5th or greater than 95th percentile (ages 2 to 18 years) • Mid-arm circumference (MAC), Upper-arm muscle area (AMA), and Upper-arm fat area (AFA) less than 5th or greater than 95th percentile
When doing anthropometric measurements, observe for signs of neglect or physical abuse.	If signs of neglect or physical abuse are noted, contact Child Protective Services (CPS).
Biochemical Laboratory Data	
Recommend or obtain the following lab tests as indicated by anthropometric, clinical, and dietary data. Consult with child's primary care provider or clinic physician for appropriate tests. • Complete blood count (CBC) • Tests for anemia, including hematocrit, hemoglobin, erythrocyte protoporphyrin • Tests for iron status, including serum iron, serum ferritin, total iron binding concentration, and percent saturation • Tests for malabsorption • Tests for specific nutrient deficiencies	Nutrition intervention may be indicated by abnormal lab test results.

Assessment Activities	Indicators for Nutrition Intervention
Clinical/Medical History	
Complete a health history by interviewing caregiver(s) and reviewing medical records. Pay special attention to nutrition risk factors identified in nutrition screening. Include the following in data collection: • Medical diagnosis • Frequency of infections • Reflux/ vomiting not able to be managed with routine precautions (medications, positioning, etc.) • Elimination patterns‡ • Maturation stage, age of onset of puberty • Possible medication-nutrient interactions∫ • Family history of diseases • Family growth history • Dental health Physical observation of hair, skin, nails, eyes, oral (tongue and gums), lips and mucus membranes, overall musculature, and adipose stores for signs of deficiencies or excesses. (See Reference 7, Table 4-18)	• Nutrition intervention indicated if any unresolved nutrition concern. • Refer to primary care provider for follow-up and referral to appropriate medical and pediatric feeding specialist(s).
Dietary	
Assess dietary intake by a 3 to 7-day food record and diet history. When requesting a food record, provide both oral and written instructions. When interviewing for a diet history, include both the child and caregiver(s) if possible. Obtain the following data: • Type, brand name, and amount of food, beverage, or formula eaten or tube-fed • Preparation method for cooking foods and for mixing formula • Time of each meal, snack, or feeding • Cooking facilities available • Location of feedings (e.g., daycare center, school, home, restaurant) • Dietary supplements (e.g., vitamins, minerals, energy dense liquids) • Complementary and alternative therapies/supplements • Intake of non-food items (pica) Adequacy of food intake may be determined by comparison with age-appropriate food group plan or by computer analysis and comparison with DRIs for age and sex.	For nutrient recommendations for specific conditions and disorders, refer to appropriate section in this manual.

Assessment Activities	Indicators for Nutrition Intervention
Consider: • Level of physical activity or ambulation. • Cultural and familial food practices. • Pertinent historical data related to feeding: breastfeeding, amount of formula milk used, age of introduction of solid foods, variety of solids provided. • Influences on the validity of food record (e.g., illnesses, meals eaten away from home, losses from reflux).	
Feeding Skills[**] and Behavior[††]	
Complete a feeding history by interviewing caregiver(s) and reviewing health, therapy, and assessment records. Observe child while eating or being fed. Consider the following factors: • Positioning of child • Appropriateness of feeding environment • Oral-motor development and coordination • Self-feeding skills • Behavior problems related to feeding • Child-caregiver interactions during feeding[‡‡]	Multi-disciplinary intervention with pediatric feeding specialists such as speech pathologist, occupational therapist, registered dietitian (RD), public health nurse, behaviorist, and/or social worker indicated if any of the following: • Delayed or abnormal feeding skills • Neurological or oral-motor problems • Behavior problems interfering with feeding • Suboptimal scores on feeding assessment tools

*See Chapter 2
†Correct for prematurity up to 36 months. See Chapters 2 and 15.

[‡]See chapters 6 and 7

[ʃ]See Chapter 5

[**]See Chapter 8
[††]See Chapter 9

[‡‡] Assessment tools for documenting inappropriate or at-risk child-caregiver interactions during feeding are the NCAST Feeding Scale[9](up to age 1) and the CHATOOR Feeding Scale[10] (up to age 3).

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CHAPTER 2

Anthropometrics

Karen Murphy, MS, RD, CD
Updated by Sharon Feucht, MA, RD, CD

The term anthropometry refers to comparative measurements of the human body. The primary measures used as indices of growth and development include stature (length or height), weight, and head circumference (for young children). The secondary measures used to estimate body composition include triceps skinfold thickness, subscapular skinfold thickness, and mid-upper arm circumference. Growth is an important index of a child's nutritional status and should be monitored on a regular basis.

Stature (length or height), weight, and head circumference are typically evaluated by comparing individual measurements to population data, represented by percentile curves on a growth chart. Current charts for assessment of growth have been constructed from cross-sectional studies in which large numbers of healthy children representing the racial and ethnic diversity of the US were carefully measured at various ages and the data ranked in percentiles. These charts are intended as clinical tools to assess nutritional status and general health of infants, children, and adolescents. To assess and monitor the nutritional status of a child with special health care needs who does not necessarily meet the criteria of the growth charts, it is necessary to carefully evaluate a pattern of measurements obtained at regular intervals. The CDC Growth Charts: United States are currently in use in the United States (1).

For the typically developing child, atypical growth is suspected when height or weight for age is either below the 5th percentile or above the 95th percentile, and when weight for height, weight for length, or body mass index (BMI) is below the 10th percentile or above the 90th percentile. The CDC suggests using BMI for age percentiles to identify atypical growth (<5th percentile to indicate underweight, >85th percentile to indicate risk of overweight, and >95th percentile for overweight) (1). The more recent work from the Expert Committee recommend that 85-94% be identified as overweight and >95th percent be identified as obese (2).

For the child with special health care needs, these parameters may not be reliable indicators of atypical growth. However, they are useful in screening for children who are at risk for growth problems. For some children with special health care

needs, poor growth or excessive weight gain must be confirmed with longitudinal measurements and, in many cases, additional anthropometric parameters to estimate body composition. Furthermore, the growth patterns characteristic of the particular disease or disorder and the child's growth history must be considered.

For anthropometric parameters to be valid indices of growth status, they must be highly accurate. This requires precise measurement techniques. Appropriate use of growth charts requires that measurements be made in the same manner in which the reference data were secured (3,4). In order to measure a child accurately, the individual performing the measurement must be properly trained, and reliable equipment must be available. For some children with special health care needs, it can be challenging to make accurate measurements because of factors such as contractures and low muscle tone.

This chapter provides information on recommended equipment and measuring techniques including special considerations for obtaining measurements from the child with special health care needs. Guidelines for measuring and interpreting length, crown-rump length, height, sitting height, arm span, mid-parent height, weight, BMI, head circumference, triceps skinfold, mid-upper arm circumference, and subscapular skinfold are also provided. The concepts of growth as an index of nutritional status and ideal body weight (IBW) are also discussed. Information on specific equipment is listed in Appendix B. Measurement techniques, equipment required, advantages, and limitations are summarized in Table 2-1.

Primary Measures

Head Circumference (3,4)

Head circumference is an important screening tool in infants and young children because it is closely related to brain growth. A rapid increase in the rate of growth may indicate hydrocephalus. A decrease in the rate of head growth may indicate a developmental delay. Decreases in the rate of head growth have been seen in children who are severely undernourished. Children with slow head growth frequently have poor linear growth as well. Head circumference should be measured routinely

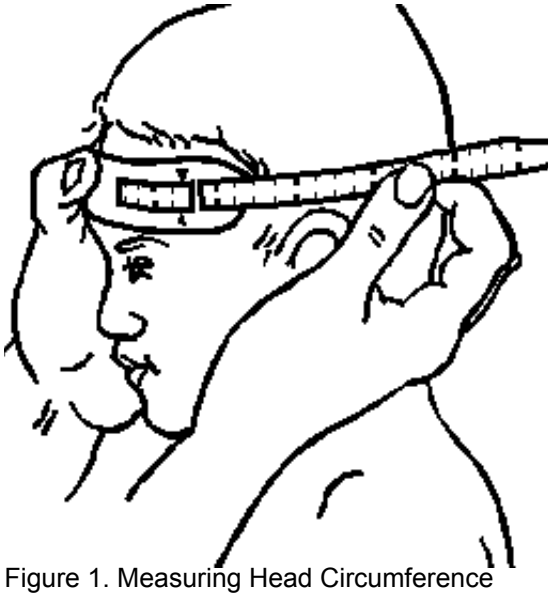

Figure 1. Measuring Head Circumference

until at least 36 months of age. Parental head circumferences of infants whose head circumferences are atypical should also be measured, as head circumferences of parents and their offspring are typically closely associated. The proper technique for measuring head circumference is shown in Figure 1.

Equipment and technique for measurement of head circumference

1. Use a flexible, non stretchable measuring tape.
2. Position the child standing or in a sitting position in the lap of her caregiver. Remove any barrettes or braids in the child's hair.
3. Place the lower edge of the measuring tape just above the child's eyebrows, above the ears, and around the occipital prominence at the back of the child's head.
4. Pull the tape snugly to compress the hair. The objective is to measure the maximal head circumference.
5. Read the measurement to the nearest 0.1 cm or 1/8 in.
6. Repeat the measurement twice or until two measurements agree within 0.2 centimeter (cm) or 1/4 inch (in).
7. Record the numeric value and plot it on the appropriate growth chart.
8. If the measurement appears larger or smaller than expected when plotted, check the accuracy of plotting and recheck the measurement. If there is a rapid increase in the child's head circumference, she should be seen by her physician.

Guidelines for Interpretation of Head Circumference

The CDC percentiles for head circumference for children ages 0 to 36 months are the most readily available, as they are printed with the CDC percentiles for length, weight, and weight for length. However, the Nellhaus head circumference percentiles may be more useful for some children because they include percentiles for children ages 0 to 18 years and were developed from international, interracial data (See Appendix C) (5). Premature infant growth charts include percentiles for head circumference as well as for length and weight (See Appendix J). When monitoring head growth, it is important to consistently plot measurements on the same chart and to look for consistent patterns in head growth.

Stature (Length and Height)

Stature is measured in two ways: recumbent length for the child younger than 36 months of age and standing height for children older than 24 months (4). Alternative measurements (e.g., crown-rump length, sitting height, and arm span) can also provide information about a child's stature.

Contractures about the hips, knees, and ankles can interfere with an accurate stature measurement. Crown-rump length or sitting height measurements are often useful estimates of stature for children with contractures of the lower body. These measurements will not correlate directly with height or length, but can indicate a child's rate of growth when plotted on CDC growth charts. Although the measurements will be below the 5th percentile for age, they will show whether or not the child is following a consistent growth curve. The stature of children with involvement of the lower body only (e.g., some children with myelomeningocele) can be estimated by using arm-span measurements. However, for children with contractures of the upper extremities such as in cerebral palsy, accurate arm span measurements are also difficult (6). For those children who have contractures of the arm, tibia length, though less accurate, is sometimes used with a formula to estimate stature (7).

Length

For children who are younger than 24 months of age and children 24 to 36 months of age who are unable to stand independently, measure recumbent length. Older children who are unable to stand may also be measured in the recumbent position; however, it should be noted on the growth chart that the measurement is length, not height.

Equipment for Length Measurement

In order to have accurate recumbent length measurements, it is important to have a good quality length-measuring device. The infant length board should have a fixed headboard and a movable footboard that are perpendicular to the surface on which the child is lying. A measuring tape, marked in millimeters or 1/8 inch segments, is needed along one or both sides of the table, with the zero end at the end of the headboard (3,4). The required features of an infant length board are shown in Figure 2. The proper technique for measuring length is shown in Figure 3.

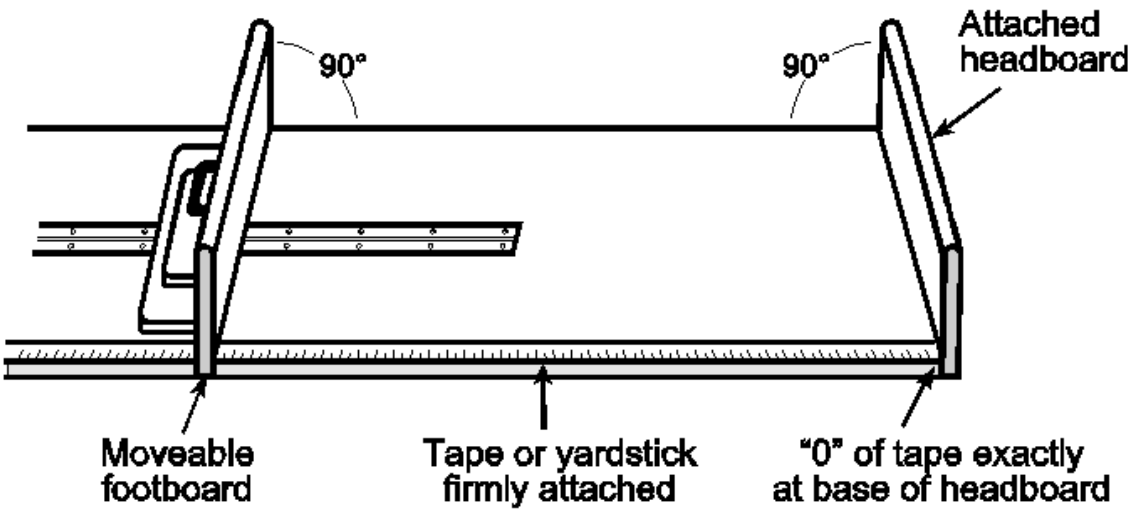

Figure 2. Infant Length Board

Technique for Length Measurement (3,4)

Clothing that might interfere with an accurate measurement, including diapers, should be removed. Two people are required to measure length accurately as shown in Figure 3.

Person A

1. Hold the child's head with the crown against the headboard so that the child is looking straight upward.
2. Make sure that the trunk and pelvis are aligned with the measuring device.

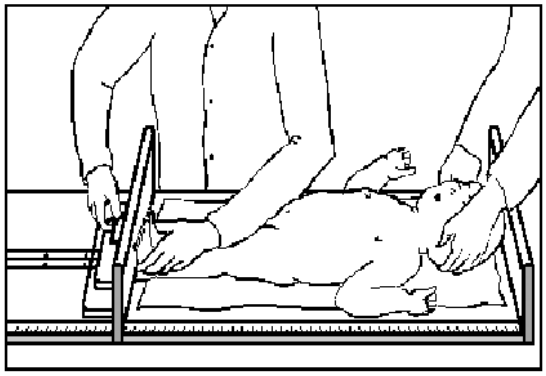

Figure 3. Measuring Infant Length

Person B

1. Straighten the legs, holding the ankles together with the toes pointed directly upward.
2. Move the footboard firmly against the soles of the child's feet.
3. Read the measurement to the nearest 0.1 cm or ⅛ in.
4. Repeat the measurement until two measurements agree within 1 cm or 1/4 in.
5. Record the numeric value and plot length for age on the 0 to 36 month growth chart appropriate for age and sex.

Technique for Length Estimation: Crown-Rump Length

Use the same equipment and technique as that described for measuring length, except bend the child's legs at a 90-degree angle, and bring the footboard up against the buttocks. The proper technique for measuring crown rump length is shown in Figure 4.

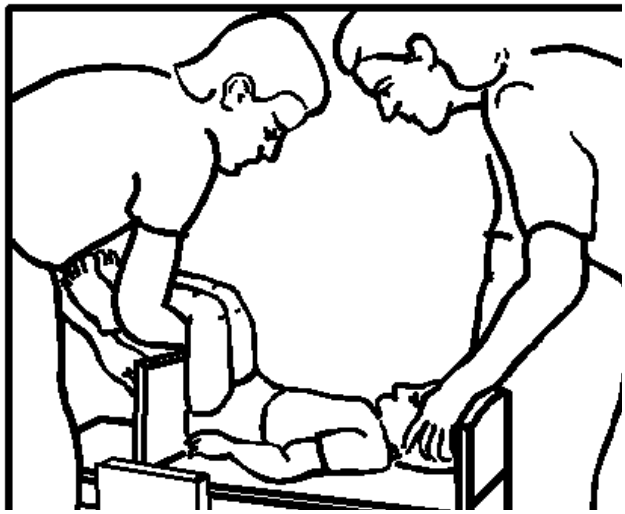

Figure 4. Measuring Crown-Rump Length

Height

Children 2 to 3 years of age may be measured either in the recumbent or standing position, depending on their ability to stand unassisted. It is important to plot standing height measurements on the growth charts for 2 to 20 year olds, because the percentiles are adjusted for the difference between recumbent length and standing height. Children over 3 years of age who are able to stand should be measured standing.

Equipment for Height Measurement

Use a measuring board with an attached, movable headboard (stadiometer). If this is not available, use a non stretchable tape measure attached to a vertical, flat surface like a wall or a door jam with no baseboard and equipment that will provide an accurate right angle to actually take the measurement. The movable measuring rod that is attached to a platform scale is too unsteady to ensure accurate measurements. The features of an accurate stadiometer are shown in Figure 5.

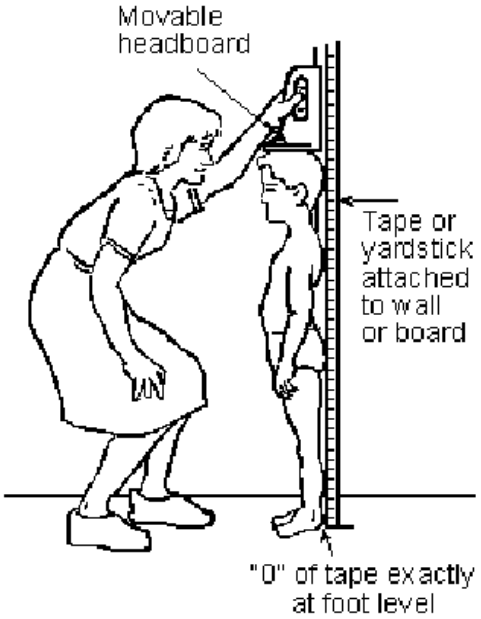

Figure 5. Stadiometer

Technique for Height Measurement (3,4)

Two people may be required for accurate measures of younger children, however, usually only one measurer is required for compliant older children.

1. Measure the child with underclothes only, if possible, or with non-bulky clothing and no shoes.

2. Have the child stand with heels together and touching the floor, knees straight, arms at sides, shoulders relaxed, and shoulder blades, buttocks, and heels touching the wall or measuring surface.

3. Have the child look straight ahead with her line of vision perpendicular to the body.

4. Lower the headboard or right angle onto the crown of the child's head.

5. Read the measurement to the nearest 0.1 cm or 1/8 inch. When reading, make sure your eyes are level with the headboard.

6. Repeat the measurement until two measurements agree within 1 cm or 1/4 in.

7. Record the numeric value and plot height for age on the appropriate growth chart.

Technique for Stature Estimation: Sitting Height

Use the same equipment as that described for measuring standing height, except have the child sit on a box of known height and subtract the height of the box from the measurement obtained. The box should be high enough so that the child's legs hang freely. Sitting height should not be measured with the child sitting on the floor or on a box with legs extended outward in a 90° angle (3). The proper techniques for measuring sitting height are shown in Figure 6.

Figure 6. Measuring Sitting Height

Technique for Stature Estimation: Arm Span (7)

Arm span is defined as the greatest distance between the tips of the extended middle fingers of the right and left hands when the arms are fully extended to the sides at right angles to the body and the back is straight. Measurement of the arm span is useful for estimating the stature of persons with lower extremity contractures or lower body

paralysis. For the typically developing child over age six, the ratio of arm span to height has been found to be 1:1. This may not be the case for the child with special health care needs; however, monitoring an individual's arm span measurements over time can provide some information about growth.

Arm span is not an adequate substitute for stature in persons with contractures of the upper extremities (e.g., in spastic quadriplegia) because these individuals cannot fully extend their arms and fingers. Also, arm span cannot accurately estimate stature in young children (younger than 5 to 6 years) because the proportions of limb length and trunk length to total body length are different for younger than older children.

Equipment for Arm Span Measurement

Arm span measurements are made with an anthropometer, a stainless steel detachable rod approximately seven feet long with etched gradations to 0.1 cm or 1/8 inch and one movable sleeve (7). The proper technique for measuring arm span is shown in Figure 7.

Technique for Arm Span Measurement

Two people are needed to measure arm span

Person A

1. Have the child sit in an erect position with arms outstretched.
2. Hold the fixed end of the anthropometer at the tip of the middle finger of one of the child's hands.

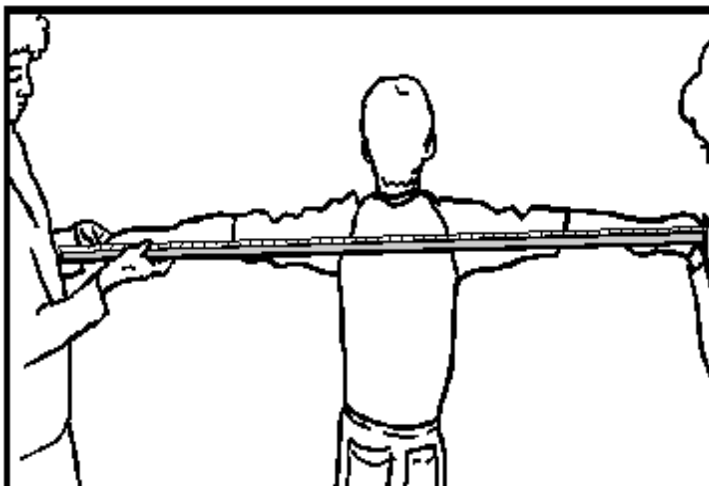

Figure 7. Measuring Arm Span with Anthropometer

Person B

1. Position the sleeve at the tip of the middle finger of the child's other hand with the anthropometer going across the child's back.
2. Have the child stretch her arms while the movable sleeve is adjusted to the maximum arm span.

3. Repeat the measurements until two measurements agree within 0.1 cm or 1/8 inch.

4. Record the actual numeric value, and plot as height for age on the appropriate growth chart. On the chart, note that arm span was the technique used to estimate stature.

Weight

Infants and toddlers less than 12 kg or 25 lbs can be accurately weighed on an infant scale. An accurate measure of weight is critical—it is more valuable to obtain an accurate bi-annual weight than a series of inaccurate monthly weights.

Equipment for Weight Measurement

Use a calibrated beam balance scale with non-detachable weights or a digital scale with a "strain-gauge" mechanism. To weigh infants and young children who cannot stand, use a pan-type or bucket seat-type pediatric scale that is accurate to within 0.01 kg or ¼ oz. For older children who can stand, use a platform beam scale, or an electronic scale that is accurate to within 0.1 kg or ¼ lb. Do not use a spring type bathroom scale which, with repeated use, will not maintain the necessary degree of accuracy. For children who are too large for the infant scale, but cannot stand, use a platform scale on which a wheelchair can be placed, or a bed scale. Since this type of specialty scale is not available in many communities, it can be difficult to regularly monitor the weight of children with special health care needs. An alternative is to weigh the child's caregiver holding the child, weigh the caregiver alone, and subtract the caregiver's weight from the weight of both individuals. If this method is used, it is important to note this on the growth chart. If the child can sit independently, but is not able to stand, use a chair scale.

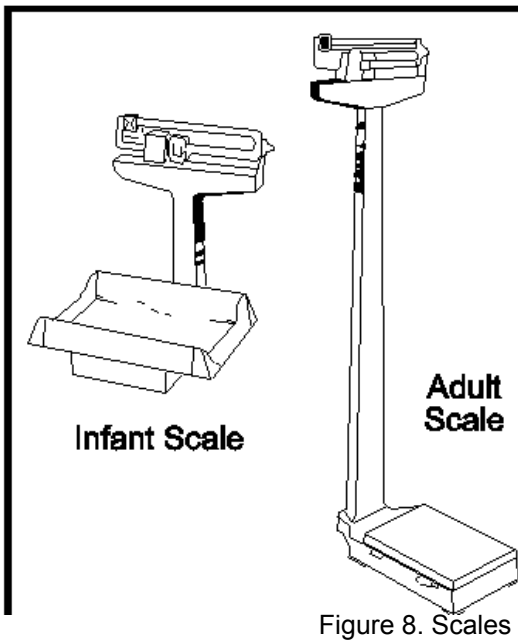

Figure 8. Scales

Frequently check and adjust the zero weight on the beam scale by placing the main and fractional sliding weights at their respective zeros and moving the zeroing weight until the beam balances at zero. If a pad or diaper is used to make the pan more comfortable, place it in the pan before the zero adjustment is made; otherwise, the weight of the pad or diaper must be subtracted from the weight of the child each

time a measurement is made. At least two or three times per year have the accuracy of the scale checked with a set of standard weights by a local dealer or an inspector of weights and measures. Equipment for measuring weights is shown in Figure 8.

Technique for Weight Measurement (3,4)

Infants

1. Remove the infant's clothing and diaper.
2. Center the infant in the scale tray.
3. Weigh infant to the nearest 0.01 kilogram (kg) or ½ ounce (oz).
4. Repeat the measurement until two measurements agree to within 0.1 kg. or ¼ pound (lb).
5. Record the numeric value and plot weight for age and weight for length on the appropriate growth chart(s).
6. Record any information about conditions that might have interfered with an accurate weight measure (e.g. infant was moving).

Children (able to stand)

1. Weigh the child with only lightweight undergarments or a hospital gown and no shoes.
2. Have the child stand in the center of the scale's platform touching nothing and with heels together.
3. When the child is standing still, read the scale to the nearest 0.1 kg or ½ oz.
4. Repeat the measurement until two measurements agree to within 0.1 kg or 1/4 pound.
5. Record the numeric value and plot weight for age and weight for height on the appropriate growth chart(s).
6. Record any information about conditions that might have interfered with an accurate weight measure (e.g. child was moving).

Guidelines for Interpretation of Length, Height, and Weight

Various growth charts have been developed from reference data for length, height, and weight. The growth charts produced by the Centers for Disease Control (CDC) are the reference used for growth assessment in the United States. There are separate charts for girls and boys ages 0 to 36 months; they include weight for age, recumbent length for age, and weight for length. There are also separate growth charts for girls and boys ages 2 years to 20 years that include weight for age, height for age, weight for height (for children 77-121 cm only), and BMI for age. These charts are most useful if measurements are accurately obtained and plotted on a regular basis so that the child's growth pattern can be observed.

Information about the CDC 2000 growth charts and downloadable versions of the charts can be found on the CDC website (8). The 0-36 month charts are based primarily on data from the third National Health and Nutrition Examination Survey (NHANES III 1988-94) and represent the racial/ethnic diversity of the US. The data set includes both formula-fed and breastfed infants, and data collection methods were standardized. Values from preterm and very low birth weight (VLBW) infants were not included. The revised charts for 2-20 year olds are based on data from the five previous NHANES data, and also represent the racial diversity of the US. NHANES III data was not used for weight and BMI for age percentiles for children over age 6 years because of the trend toward obesity in this age group.

On the CDC 2000 charts, Body Mass Index (BMI) replaces the weight for stature curves for children over age 2 years. A separate weight for height chart is available for children 77-121 cm tall (approximately 2-5 years of age). Charts that include the 3rd and 97th percentiles for weight and stature for age are also available. An 85th percentile line has been added to the BMI for age chart to aid in assessing risk of overweight.

The World Health Organization (WHO) has produced global child growth standards for infants and children up to the age of 5 years. These charts vary from the CDC charts in that the WHO charts describe how children should grow (prescriptive) regardless of time and place. The CDC charts describe how children do grow (descriptive) in a particular time and place. Currently in the United States there is no definitive recommendation to use the WHO charts to evaluate growth. Several groups are evaluating use of these charts in the United States (9).

Body Mass Index (BMI) (8,10,11,12)

Body mass index (BMI) is a calculation that is used to assess obesity in children over 2 years of age. It has been recommended as a non-invasive and clinically convenient

measure. BMI is expressed as a ratio of weight in kilograms to height in meters squared:

$$BMI = \frac{\text{weight in kilograms}}{(\text{height in meters})2}$$

OR

$$BMI = (\text{weight in kilograms}) \div (\text{height in meters}) \div (\text{height in meters})$$

BMI can also be calculated using English units (8):

$$BMI = [\text{Weight (pounds)} \div \text{Height (inches)} \div \text{Height (inches)}] \times 703$$

The calculated BMI adds a useful dimension to the assessment of body composition if accurate stature (length or height) and weight measurements are obtained. This index of weight relative to length or stature can be used to monitor changes over time. With this addition, clinicians can compare a child's BMI to the BMI of her peers. Because growth parameters change, no single BMI is ideal during childhood and adolescence.

Incremental Growth Charts

Incremental growth charts used with charts for weight and stature can be helpful in assessing deviations in growth and response to intervention (9,10). These charts show changes in growth velocity over a 6 month period and are more sensitive to deviations in growth than charts with length or height and weight attained. For example, a child weighing 7 kg at 12 months of age and 8.8 kg at 18 months plots below the 5th percentile for weight for age on the CDC charts, but shows a growth velocity near the 90th percentile. This child, although below the 5th percentile for weight for age, is demonstrating rate of weight gain that is faster than the mean. Copies of incremental growth charts are provided in Appendix D (13).

Specialty Growth Charts

Growth charts for premature infants that attempt to reflect intrauterine growth rates have been produced by several different researchers; each set has benefits and drawbacks. However, instead of premature infant charts, many practitioners use the CDC growth charts and correct for the child's prematurity. It is important to document that measurements of age are corrected for prematurity. It is best to continue to correct for prematurity until the child's growth is plotted on the charts for 2-20 year olds.

Other growth charts that are useful in assessing growth are those for children with Down syndrome, William's syndrome, cerebral palsy (quadriplegia only), Turner syndrome, achondroplasia and charts for measuring crown rump and sitting height. (See Table 2-2). These charts should be used as an additional tool for interpretation of growth after data have been plotted on the CDC charts. They are based on the growth of small groups of children with specific disorders and do not necessarily reflect ideal rates of growth. Many children with Prader Willie syndrome now receive growth hormone beginning as early as 6 months of age. The Prader-Willi growth charts do not reflect growth patterns in those children with PWS who receive growth hormone.

Charts and tables available for interpretation of growth of children with special health care needs, as well as the advantages and limitations of these charts and tables are summarized in Table 2-2. Copies of these charts are included in Appendices G-M.

Midparent Height

Adjustment of length or height to reflect parental stature may help to explain unexpected growth. These adjustments help remove the influence of genetics from the child's measurement and make it easier to recognize potential growth problems. Tables of adjustment have been developed based on the research of Himes, Roche, and Thissen (14). Midparent height adjustments should be applied when the child is below the 5th percentile or above the 95th percentile in length or height for age and both parents are very tall (mother taller than 5'9" and father taller than 6'4") or very short (mother shorter than 5' and father shorter than 5'5") (3,15). The technique for parent-specific length or height adjustment is recorded on the table included in Appendix E.

"Ideal" Body Weight

Because children grow at different rates, it is impossible to quantify an absolute "ideal" weight based solely on age. Obviously, the desirable weight for a 108 cm, 6 year old girl is not the same as for a 120 cm, 6 year old girl, although both children's growth rates can be described as typical. Some sources suggest using the weight that would place the child at the 50th percentile for weight for stature as an "estimated desirable weight" or "ideal" body weight. This may help to make identification and classification of malnutrition more quantifiable, but must be carefully considered. Many children are more satisfactorily described in terms of "degree of malnutrition." However, classifications are generally arbitrary and thus may not be consistent.

Mild malnutrition has been defined as 80-89% of expected weight for stature (15). This roughly corresponds with the 5-10th percentile on the weight for stature charts. Moderate malnutrition has been defined as 70-79% of expected weight for stature, and severe malnutrition as less than 70 percent. Both of the criteria correspond to less than the 5th percentile on the weight for stature charts.

Secondary Measures

Triceps Skinfold and Mid-Upper Arm Circumference (2,3)

Together, triceps skinfold thickness and mid-upper arm circumference are used to calculate arm muscle circumference, arm muscle area, and arm fat area, which are indicators of body fat and muscle stores when compared to population percentiles (3,7). For typically developing children, the calculations of arm muscle circumference, arm muscle area, and arm fat area provide a better estimate of body composition than triceps skinfold alone.

Accurate measurements of triceps skinfold thickness and mid-upper arm circumference are difficult to obtain by an inexperienced or untrained measurer. Measurement error is likely to be higher when measuring young children because it is difficult to maintain the child in the proper position while the measurement is being performed. It is also difficult to separate fat from muscle tissue (7). These secondary measurements are useful only if obtained with precise and accurate technique that is developed with training and practice. In the course of training, the measurements must be validated by a person experienced with skinfold thickness techniques. Only calibrated calipers should be used for measuring skinfold thickness; plastic calipers are not accurate. For further information on these measurements see Frisancho (16), Guiney (17) Tanner (18), and Cameron (19).

Recommended guidelines for interpretation have been published, and an individual's measurements can be compared to population reference data (16). These interpretations, however are based on assumptions of the bone diameter and the distribution of muscle and fat around the bone of typically developing persons; these assumptions may be inaccurate for persons with physical abnormalities. The best use of these measurements for children with special health care needs is for assessing changes over time (e.g., increases in fat and muscle stores in the undernourished child and decreases in fat stores in the overweight child). Skinfold measurements are not appropriate for children with subcutaneous edema.

Equipment and Technique for Triceps Skinfold Measurements (3, 7,17)

1. Use an accurate skinfold caliper, such as the Lange or the Holtain, and a flexible, nonstretchable tape measure.

2. On the child's right side find the acromion process and the olecranon process (tip of elbow). These processes are shown in Figure 9. The child's elbow if flexed at 90 degrees.

3. Using a tape measure, find the midpoint between the acromion process and the olecranon process and mark it with a pen as shown in Figure 9.

4. Position the child with his right arm completely relaxed and hanging by his side.

5. Pick up the skinfold overlying the triceps muscle, 1 cm above the midpoint mark.

6. At the midpoint mark, apply the jaws of the caliper to the skinfold while continuing to hold the skinfold above the mark, as shown in Figure 9.

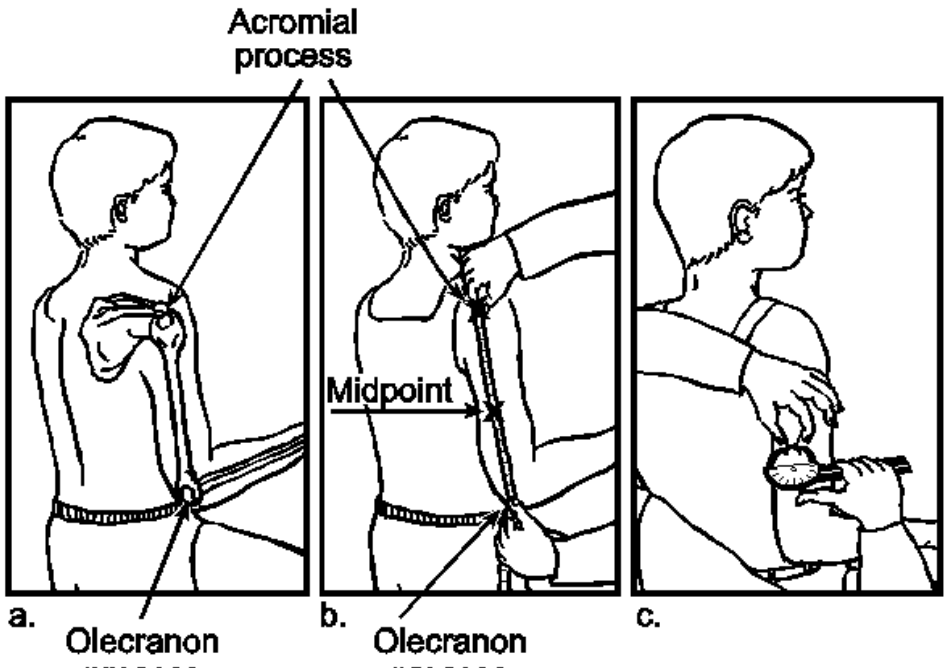

Figure 9. (a) Locating the acromion and olecranon processes; (b) measuring the midpoint, and (c) measuring triceps skinfold thickness.

7. Permit the jaws of the caliper to exert full strength as the trigger lever is released, without "snapping" it.

8. Read the dial to the nearest 0.1 mm. Record the measurement.

9. Re-position the child and re-measure the skinfold. Make sure there is not tissue compression with the repeated measurement.

10. Compare the measures; they should agree within 0.2 cm

11. Record the numeric value and compare it to reference data and/or previous measurements.

Equipment and Technique for Mid-Upper Arm Circumference (3,7)

1. Use a flexible, nonstretchable tape measure.

2. Position the child with his right arm completely relaxed and hanging by his side.

3. Measure the circumference of the right arm at the midpoint mark (midway between the acromial and olecranon processes as shown in Figure 9.)

4. Wrap the tape around the arm so that it is touching the skin but not perpendicular to the long axis of the arm.

5. Measure to the nearest 0.1 cm.

6. Repeat the measurement until two measurements agree within 0.2 cm.

7. Record the numeric value and compare it to reference data and/or previous measurements.

Calculating Arm Muscle Circumference, Arm Muscle Area, And Arm Fat Area (3,16)

The mid-upper arm circumference (C) is converted to mm (c) and used with triceps skinfold thickness (T) to calculate upper arm area (A), upper arm muscle area (M), and upper arm fat area (F). Equations for these calculations are provided below. A nomogram is also available (15).

- Upper arm area (mm^2) = $\left[\frac{\pi}{4}\right] \times \left[\frac{c}{\pi}\right]^2$
- Upper arm muscle area (mm^2) = $\frac{(c-\pi T)^2}{4\pi}$
- Upper arm fat area (mm^2) = A – M

Guidelines for Interpretation of Upper Arm Indices of Fat and Muscle Stores

Percentiles for triceps skinfold, mid-upper arm circumference, arm muscle circumference, arm muscle area, and arm fat area for Caucasian males and females 1 to 75 years have been published by Frisancho (16) and are shown Appendix F. These indices are appropriate for assessing an individual's fat and muscle stores, but it is important to remember that these are reference data for typically developing Caucasians.

Subscapular Skinfold

Subscapular skinfold thickness is a useful measurement for estimating fat stores, especially when used in conjunction with triceps skinfold thickness and mid-upper arm circumference. Percentiles for subscapular skinfold thickness for typically developing males and females ages 0 to 19 years have been developed by Tanner and Whitehouse (18). It has been suggested that the best use of the subscapular skinfold measurement in managing children who are overweight or underweight is to evaluate individual change over time.

Equipment and Technique for Subscapular Skinfold (7)

1. Use an accurate skinfold caliper, such as the Lange or the Holtain.
2. Pick up the subscapular skinfold just under the shoulder blade, following the natural fold of the skin. The arm and shoulder should be relaxed
3. With a pen, mark the midpoint of the fold.
4. Holding the skinfold approximately 1 cm from the midpoint mark, apply the jaws of the caliper to the skinfold so that the mark is midway between the jaws, as shown in Figure 10.

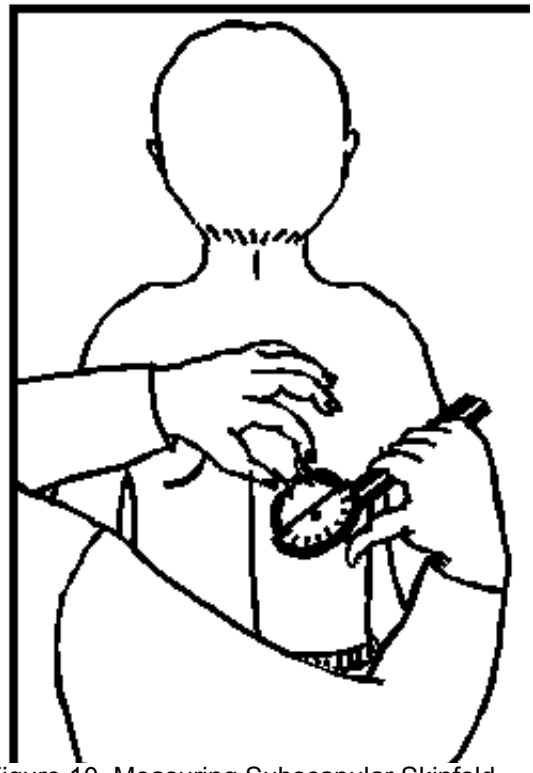

Figure 10. Measuring Subscapular Skinfold Thickness

5. Permit the jaws of the caliper to exert full strength as you release the trigger lever, but do not allow them to “snap” and pinch the child.

6. Take the reading right after the first rapid fall. Read to the nearest 0.1 cm.

7. Repeat the measurement. The measurements should agree within 0.2 cm.

8. Record the value.

Table 2-1: Measurement Techniques

Technique	Equipment	Advantages	Limitations	Tolerance Levels*
Stature				
Length	Length board	Direct measure of stature	Hard to do if contractures	1 cm[4]
Height	Stadiometer	Direct measure of stature	Hard to do if contractures	1 cm[4]
Stature Estimation				
Crown-rump	Length board	Provides estimate of stature	Limited data available	0.1 cm
Sitting height	Stadiometer, sitting box	Provides estimate of stature	Must be able to sit independently	0.1 cm
Arm span	Arm spanner	Provides best estimate of stature; 1:1	Requires full arm extension	0.2 cm
Upper arm length	Anthropometer	Provides estimate of stature	Difficult to interpret	
Knee height	Anthropometer	Provides estimate of stature	Useful if contractures, difficult to interpret	
Tibia length	Anthropometer	Provides estimate of stature	Not used if <2 years old, difficult to interpret	
Weight	Calibrated Scale			0.1 kg[4]
Skinfolds				
Subscapular	Caliper	Provides estimate of total body fat	Difficult to maintain technique; inappropriate for obese; not for <1 year	0.2 cm
Triceps	Caliper, flexible tape	Provides estimate of percent body fat	Difficult to maintain technique; inappropriate for obese; not <1 year	0.2 cm
Circumferences				
Head	Flexible tape	Direct measure of head circumference	None	0.2 cm[4]
Mid-arm	Flexible tape	Estimator of body fatness	May be difficult to interpret	0.2 cm

*The measure should be reproduced with a difference no greater than the value in this column.

Table 2-2: Charts/Tables Used to Monitor Growth of Children With Special Health Care Needs*

Growth Chart	Study Sample Information	Ages	Parameters	Limitations	Use With CDC
CDC (2000)[1]	Previous data plus NHANES III data; 3rd-97th %iles	0-3 years	• weight/age • length/age • OFC/age • weight/length		
CDC (2000)[1]	Previous data plus NHANES III data; 3rd-97th %iles	2-20 years	• weight/age • height/age • weight/height (2-6 years) • BMI/age		
Crown-rump[20]	~75 females, 75 males			Longitudinal data	Use with CDC weight/ age
Sitting height[21]	NCHS 1977 population	1-18 years	• sitting height/age	Caucasian and African American children onl	Use with CDC weight/ age
Knee height[22,23]	13,821 ambulatory children NHES I,II,III, 1960-70	6-12 years	• knee height/age	Use equation for race (85% Caucasian children); Difficult to do	Use with CDC weight/ age
Incremental growth[13]	Children who grew "close" to NCHS 1977	6-36 mos 2-18 years	• weight/age • stature/age	Caucasian children only	Use with CDC for weight/age, length or height/age, weight/ length or height
Triceps skinfold thickness, upper arm circumference[24]	NCHS 1977 population	2-18 years	• triceps skinfold/age • upper arm • Use after age 2 years, Caucasian children only	Use after age 2 years, Caucasian children only	Use with CDC weight/age, length or height/age, weight/ length or height, or BMI/ ageagecircumference/age
Mid-arm circumference; triceps skinfold, subscapular skinfold thicknesses[16,17,18]	NCHS 1977 population	2-18 years		Use after age 2 years	Use with CDC weight/age, length or height/age, weight/ length or height, or BMI/age
Parent-specific adjustment for length/ stature[14]	586 parent-child pairs (Fels data) and 16,000 serial length and height measurements	0-36 mos 3-18 years		Note parent height on chart	Use with CDC weight/age, length or height/age, weight/ length or height, or BMI/age

Growth Chart	Study Sample Information	Ages	Parameters	Limitations	Use With CDC
Achondroplasia[25]	189 males 214 females	0-18 years	• height/age • height velocity/age • upper, lower segment lengths/ age • OFC/age	Small sample size, especially children over 10 years	Compare to CDC weight/ age, length or height/ age; use with CDC for weight/ length or height or BMI/ age
Cerebral palsy[26]†	360 children (males and females), 0-120 months with spastic quadriplegia	0-10 years	• length/age • weight/age	Both longitudinal and cross-sectional data, small sample size, for spastic quadriplegia only	Use with CDC weight/age, length or height/age, weight/ length or height or BMI/age
Down syndrome[27]	Longitudinal data; 400 males, 300 females; 1960-1986	1-36 mo 2-18 years	• weight/age • length or height/ age	Included children with congenital heart disease, reflects tendency to be overweight	Use with CDC weight/ age, length or height/ age, weight/ length or height, BMI/age
Noonan syndrome[28]	64 males, 48 females	0-20 years	• height/age	Small sample size	Compare to CDC; use CDC for weight/age, length or height/ age, weight/length or height or BMI/age
Prader Willi syndrome[29]	56 males, 36 femalesNote – sample did not receive growth hormone	3-24 years	• height/age	Longitudinal and cross-sectional data, small sample size, do not use if individual received growth hormone	Compare to CDC; use CDC for weight/ age, weight/ height, BMI/age
Turner syndrome[30]	366 females; pooled data; no hormone treatment	2-19 years	• height/age	Small sample size, unequal age distribution	Use with CDC for weight/age, height/ age, weight/height, BMI/age
Williams syndrome[31]	61 females, 47 males	0 to 18 years	• weight/age • height/age • OFC/age	Retrospective and croos	Use with CDC for weight/length or height, BMI/age

*All charts have sex-specific versions for male and female children (except for Turner syndrome charts).
†These growth charts should be used only with children who have cerebral palsy with spastic quadriplegia and may underestimate the growth for a child with mild cerebral palsy or without spastic quadriplegia. More information about growth and children with cerebral palsy can be found at the North American Growth in Cerebral Palsy Project website: http://www.healthsystem.virginia.edu/internet/nagcepp/

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Suggested Readings

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CHAPTER 3

Physical Activity for Children with Special Health Care Needs

Kathleen Washington, PT, PhD and Kay Kopp, OTR/L

Introduction

A 2005-06 survey conducted by the Centers for Disease Control and Preventions' National Center for Health Statistics showed that 13.9 percent of US children have special health care needs, and 21.8 percent of households with children include at least one child with a special health care need (1). These children are at greater risk than peers without disabilities to develop poor health, including obesity, cardiovascular disease, and musculoskeletal limitations because they are not appropriately physically active and fit.

The most frequently identified barriers to participation of these children in sports and physical activities are the child's functional limitations (18%), high costs (15%), and lack of nearby facilities or programs (10%) (2). The child's perceived self-competence, time, social support from schools and communities, and family and child preferences are additional factors influencing participation. Families who engage in physical activities are more likely to encourage similar participation for their children with special health care needs. Interestingly, environmental and family factors seem to be more significant determinants of participation than characteristics of the children themselves (2).

The primary goals for increasing physical activity in these children are to reverse deconditioning secondary to impaired mobility, optimize performance of functional activities, and enhance well-being. Regular physical activity is essential for the maintenance of normal muscle strength, flexibility, and joint structure and function, and may prevent, minimize, or slow the loss of function often associated with disabling conditions. Other benefits of physical activity include improvements in confidence and self-esteem (3).

Definitions and Types of Physical Activity

The term "physical activity" describes many forms of movement that involve the large skeletal muscles and require significant energy expenditure. Physical activity is

defined by its duration (amount of time), intensity (rate of energy expenditure), and frequency (number of sessions per time period). As described in Bright Futures in Practice: Physical Activity (4) there are several types of physical activity:

1. Aerobic: Light to vigorous intensity physical activity that requires more oxygen than sedentary behavior and thus promotes cardiovascular fitness and other health benefits (e.g. jumping rope, playing soccer or basketball)

2. Anaerobic: Intense physical activity that is short in duration and requires a breakdown of energy sources in the absence of sufficient oxygen. Energy sources are replenished as an individual recovers from the activity. Anaerobic activity (e.g. sprinting during running or biking) requires maximal performance during a brief period.

3. Lifestyle: Physical activity typically performed on a routine basis (e.g. walking, climbing stairs, raking the yard) which is usually light to moderate in intensity.

4. Physical activity play: Play activity that requires substantial energy expenditure (e.g. playing tag, jumping rope)

5. Sports: Physical activity that involves competition, scorekeeping, rules, and an outcome that is not known in advance. Sports can be divided into categories such as individual (e.g. gymnastics, swimming) dual (e.g. tennis) and team (e.g. basketball)

Most of the above are weight-bearing activities, which contribute to the growth of healthy bones in children and adolescents, and provide numerous other health benefits. Many children and adolescents choose not to participate in competitive team sports but can still gain health benefits by participating in individual activities such as biking or yoga. One of the most important criteria for promoting physical activity for children and adolescents is that it is enjoyable for them.

Two broader categories of physical activity for children and adolescents are lifestyle and structured (4). Examples of lifestyle physical activities are walking, playing, and doing chores. Structured physical activities consist of 1) physical education (PE) programs at school and 2) extracurricular activities (e.g. baseball team), which can occur in either in school or non-school settings. Structured physical activities generally provide more intense physical activity than lifestyle activities, and are more likely to help maintain weight and result in improved strength and cardiovascular fitness.

The Importance of Physical Activity in Health Promotion

The role of physical activity in the prevention of disease and health promotion for all children and adults has been advocated by many organizations. In 2008, the U.S. Department of Health and Human Services published their Physical Activity Guidelines for Americans (5). The guidelines for all children and youth call for moderate-intensity and vigorous-intensity physical activity for periods of time that add up to 60 minutes or more each day. Children with disabilities are urged to meet these guidelines when possible. Other organizations, such as the American College of Sports Medicine (6) and the National Center on Physical Activity and Disability (7) have promoted the health benefits of physical activity, and articulated the public health concerns that inactivity presents. As CSHCN are at serious risk for additional health consequences such as obesity and musculoskeletal impairments as a result of a more sedentary lifestyle, increasing their levels of physical activity should be a life-long objective.

The International Classification of Functioning, Disability and Health, known more commonly as ICF, is the framework developed by the World Health Organization (WHO) for measuring health and disability at both individual and population levels (8). The ICF is a classification of three domains of human functioning: body structures and functions, activities, and participation. (See Fig. 1) Body functions refers to the physiological function of body systems, while body structures refers to anatomical body parts, such as organs and muscles. Activities refers to a person's performance of tasks such as getting dressed, walking, or running. Participation refers to the nature and extent of a person's involvement in daily life situations, such as attending school, socializing, or playing sports (recreation). A primary goal of health care professionals is to assist children with special health care needs in participating as fully as possible in the life of their family and community. Since an individual's functioning and disability occurs in a context, the ICF also includes personal factors (e.g. personality, age, lifestyle) and environmental factors (e.g. physical, economic,

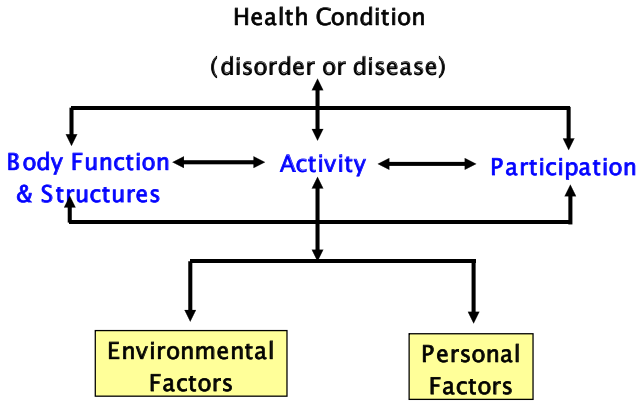

Figure 1: The International Classification of Function, Disability and Health (ICF)--World Health Organization, 2001. For more information on ICF, visit: http://www.who.int/classifications/icf/en/index.html

social). These contextual variables allow a more holistic view of disability on the person's functioning.

Note that the ICF framework is not a linear model. Within the ICF model, a child with a health condition such as cerebral palsy may have impairments in body structures (e.g. spasticity). However, this does not necessarily mean that the child will have a participation restriction. While the child may not be able to play on the school basketball team, he can participate in the sport of wheelchair basketball through the local Special Olympics organization. Similarly, while he may not be able to walk, his use of a manual wheelchair affords him mobility and access to his home and community. Nutritionists and other health care professionals have an important role in preventing or minimizing the degree of restrictions in activities and participation, thus minimizing the degree of disability.

Benefits of Physical Activity for Children with Special Health Care Needs

The benefits of physical activity for children with special health care needs have been demonstrated in a growing body of scientific literature, as documented in the studies cited below. Incorporating regular physical activity into their lifestyles will hopefully increase the likelihood of improved health in adulthood for CSHCN, as well as reduce secondary conditions such as cardiovascular disease and osteoporosis. Equally important are the psychological benefits of physical activities including opportunities to form friendships, express creativity, and develop self-esteem and confidence (3). However, there are important health-related conditions, such as high blood sugar in children with diabetes or cardiac defects in children with Down syndrome, that may be affected by participation in physical activity. Thus, screening and assessment of CSHCN, conducted by appropriate members of the individual's health care team, is recommended prior to participation in physical activity.

Benefits of Physical Activity for Children with Obesity

Currently, 11% of children and adolescents in the United States are affected by obesity, as defined by a body mass index (BMI) at or greater than the 95th percentile. There are many societal factors presumed to contribute to the increased prevalence of childhood obesity, including less time playing outdoors and in physical activities, increased "screen" time (computer, video games, TV), increased consumption of high calorie fast foods, and the decline of family meals (9). In addition to an increased risk of obesity in adulthood, there are a number of diseases

associated with childhood obesity that can impact one's health for a lifetime. Into adulthood, obese children and adolescents can have associated conditions including asthma, Type 2 diabetes, hypertension, musculoskeletal complications, psychosocial stigmas, and sleep apnea (10).

In addition to healthy eating habits and decreasing sedentary activities, regular physical activity is a primary strategy for preventing obesity. Of the limited studies on the use of both exercise and nutrition education as an approach to addressing childhood obesity, efficacy of this combination has been reported. An important finding was that an educational approach focusing on exercise and nutrition empowers both children and their families to make better lifestyle choices around activity participation and food selections. Improved lifestyle choices equate with improved health over a lifetime (11).

Benefits of Physical Activity for Children With Asthma

Another group likely to experience limitations in exercise and physical activity is children with asthma, one of the most prevalent disorders in childhood. To avoid the common unpleasant feelings of shortness of breath and exercise-induced bronchospasm (EIB), some children with asthma self-limit their physical activities. Restricting physical activities can contribute to muscle deconditioning and lowered levels of fitness, as well as limit participation in play and recreation with peers.

By preventing or managing EIB, many children and adolescents with asthma can safely participate in physical activities and sports. Prevention and management strategies may include identification and control of triggers (e.g. allergens, prolonged physical activity [especially in cold weather], respiratory tract infections), medications, and modification of physical activities. Modifications may include longer warm-up and cool-down periods, modifying activity intensity, training and conditioning to prepare for physical activity, and monitoring the environment to minimize asthma triggers. A team approach to asthma management is recommended, with all the adults involved in the care of the child participating. An asthma-management plan should also include the physical education (PE) teacher at school, as modifications may be necessary for participation and enjoyment.

Research shows that physical activity for children with asthma not only improves fitness, but may also have a positive effect on perceived physical competence and coping with asthma (12,13). Study participants tolerated the training programs well, and led the authors to recommend organized sports activities with short and intense bouts of muscle work for children with stable asthma. Parents of children in

the experimental groups reported their children had more success and pleasure in sports, and that they played with other children for longer periods of time (13).

Benefits of Physical Activity for Children with Neuromotor Disabilities

The benefits of physical activity for children with neuromotor disabilities such as Down syndrome and cerebral palsy (CP) have been documented in the literature, as cited below. However, some children may require a health screening from a primary care provider prior to participating, and some activities may have to be adapted to ensure that the child or adolescent has a safe, positive experience.

Common physical characteristics of children with Down syndrome include hypotonia, decreased muscle strength, and ligamentous laxity, which can limit endurance and restrict participation in physical activities, including play. In addition to these musculoskeletal impairments, there are other associated medical and health issues that can affect physical activity including congenital heart defects, atlantoaxial instability (i.e. an abnormally large space and excessive motion between the first and second cervical vertebrae), and a tendency toward obesity. All health care providers should discuss with families the risks that certain physical activities (i.e. gymnastics, horseback riding) involving neck hyperflexion or hyperextension may pose for individuals with atlantoaxial instability. Parents in turn need to consult with their child's primary care provider before these types of activities are initiated. As long as medical and health issues are monitored, participation in moderate- to vigorous intense activity is recommended for children with Down syndrome to reduce their tendency toward obesity, enhance social opportunities, and promote lifelong health (14).

For many children with CP, impairments such as muscle weakness, muscle spasticity, and balance deficits make it difficult to participate in sport and play activities at sufficient levels to develop and maintain normal physical fitness levels (15). However, a substantial body of evidence has documented that muscle strength can be improved in children with CP, and that improved strength can translate into functional gains such as improved walking efficiency (16,17). Thus, the child's participation in physical activities should be encouraged by all members of the individual's health care team.

Given the appropriate guidance and supervision, children and adolescents with neuromotor disabilities can improve fitness and physical activity levels at community fitness facilities. This option not only allows these children to participate in

community-based settings, but also promotes their involvement in fitness activities with other family members. Programs in the community also offer the possibility of transitioning children from individual physical therapy or occupational therapy sessions to lifelong fitness programs (15). In one study evaluating a conditioning program of aerobic exercise, flexibility exercises and weight training for adolescents with CP, significant improvements in strength were documented (18). However, an unanticipated outcome of the program was a dramatic change in self-perception for the participants, with some participants gaining enough confidence to enroll in a regular aerobics class after the study. This self-initiation represents an important step in health promotion for these adolescents.

Other benefits of community based activity programs for children with special health care needs are the positive effects on motivation and compliance. Many individuals, including both children and adults, are more motivated to exercise in a group setting. Parents reported difficulties in getting their young children with physical disabilities to comply with home exercise programs (HEP) (19). But when involved in a group fitness program incorporating strength and endurance training, attendance and adherence to the exercise program was high, prompting parents to request continuation of the program. Improvements in many of the outcome measures such as energy expenditure, strength, fitness, and self-perception were also documented for the study subjects.

The Role of the Nutritionist in Promoting Physical Activity for CSHCN

The role of the nutritionist is to collaborate in the development of an overall physical activity plan for the child through the following activities:

- perform screening as indicated in Table 3.1
- provide information regarding the benefits of physical activity and contraindications
- make referrals to other health care professionals when appropriate
- provide appropriate resources
- facilitate partnerships among other health care professionals, families, and community agencies (e.g. schools, YMCA)
- serve as an advocate
- provide support and encouragement

One of the most important benefits a nutritionist can provide to these children and their families is anticipatory guidance to help prevent complications of inadequate nutrition and inactivity. Once family activity patterns are identified, guidance about

limiting sedentary behaviors (e.g. watching TV, playing computer games) may be indicated. Education regarding proper nutrition, weight management, and exercise is vital to making choices about a healthy lifestyle. Establishing healthy eating habits and exercise as a part of one's lifestyle when a person is young will help ensure they carry over the behaviors into adulthood.

The Following Case Study Illustrates How the Nutritionist, Using a Family-Centered Approach, Helps Facilitate a Physical Activity Program for a Boy With Cerebral Palsy.

Charlie is a 10-year-old boy with a history of premature birth at 28 weeks gestation. He has a diagnosis of spastic diplegic cerebral palsy (CP). Charlie is a friendly, social boy, and his cognitive skills are within the average range. He presently ambulates with Lofstrand crutches for short distances at home and at school, but uses a manual wheelchair for community access. The family has recently moved to the area, and Charlie was just enrolled in the 5th grade at a new school. At the first well-child appointment with his new primary care provider, Charlie's growth parameters met the criteria for obesity. His primary care provider made a referral to the nutritionist at the public health department.

During an interview with Charlie's mother, the nutritionist learned that Charlie's inactivity, coupled with excessive caloric intake, was contributing to his obesity. In addition to his short-distance crutch walking, his primary form of physical activity was limited to a home exercise program (HEP) of stretching developed by his previous physical therapist. Charlie's mother reported that he was not motivated to perform his HEP, and that she was tired of nagging him. She was interested in learning about alternative physical activities that might be more appealing and motivating for Charlie. A follow-up visit was scheduled to design a plan.

At that visit, the nutritionist, Charlie, and his mother collaborated to make a plan to decrease Charlie's caloric intake, as well as increase his physical activity level. The nutritionist discussed some of the questions in Table 3.1 with Charlie and his mother to identify family recreation interests. Charlie was fortunate to be part of a family that valued fitness. The nutritionist learned that Charlie was more motivated to participate in recreation activities with his family than play in adapted team sports. Because of the family's interest in skiing and cycling, the nutritionist suggested contacting Outdoors for All, a local organization providing year round instruction in outdoor recreation and modified sporting equipment for people with physical, developmental, and sensory disabilities. To help maintain weight and promote overall fitness and conditioning, the nutritionist recommended checking out some of the local fitness clubs for a family membership. She also suggested that Charlie's new physical therapist may be able to consult with the trainer at the club to develop

a strengthening and conditioning program for him that would meet the Surgeon General's recommendation for physical activity a minimum of 60 minutes, most days of the week (20).

Screening Guidelines

Children and adolescents with special health care needs vary in their ability to participate in physical activities. Individual screening or assessment should be conducted by appropriate health care professionals, including the nutritionist, before a child begins a program of physical activity. To help the family select appropriate and beneficial physical activities, health care providers need to consider the individual's health status, interests, cognitive skills, and available community resources. Most importantly, working with the family to identify their specific physical activity goals for their child and their current physical activities as a family will help tailor recommendations.

Tables 3.1 and 3.2 provide guidelines for screening of children with special health care needs and appropriate interventions to promote physical activity.

Table 3-1: Suggested Screening Questions About Physical Activity

1. What physical activities does your family currently participate in?
2. What are your child's interests related to physical activity?
3. Does your child participate in physical activities at school? If so, which ones? How often?
4. What are your priorities for your child's participation in a physical activity? (e.g. an activity other family members enjoy, for socialization, weight management)
5. How does your child's health impairment limit his/her participation in physical activities? What type of activities should be avoided?
6. How does your child understand and follow instructions and rules?
7. Has your child had any experience participating in structured group physical activities, such as a gymnastics class, T-ball team, or group setting?
8. What modifications might be necessary for your child to participate in a physical activity? (e.g. adapted equipment, modification of rules, simplified instruction, protective equipment)

Table 3-2: Interventions to Promote Physical Activity in Children with Special Health Care Needs

Screen/ Assessment	Intervention	Evaluation/Outcome
Obtain current medical/ health information	Review current medical/health information	Child will participate in activities that are compatible with current health status
Assess nutritional status	Develop a nutrition plan to include physical activity to promote growth and well-being	Child will maximize their nutritional status and participate in appropriate physical activity
Review current medications	Discuss with parents any side effects of medications (e.g. diarrhea, constipation, sleepiness) that may effect physical activity participation	Child will participate in activities that are compatible with medication side effects
Probe for current physical activity levels at home, school (i.e. sports, PE class) and community	Refer to Table 3.1 Educate the family regarding community resources for physical/recreation opportunities for child Provide guidance re: limiting sedentary activities	Child will participate in physical/ recreational activities geared towards his/ her interests and abilities Family will identify and participate in community physical activities with child
Probe for contraindications to physical activity	Discuss with parents and/or contact primary care provider to inquire re: contraindications to physical activities PCP or family member write a cautionary statement to provide to community organizations re: child's limitations and/or contraindications	School and community physical activity providers will have knowledge of child's restrictions and/or adaptations regarding safe and appropriate physical participation Eliminate/minimize possibility of injury for child during physical activity
Inquire if parents have any concerns around child's motor skills and if child is receiving any occupational therapy (OT) or physical therapy (PT) services	Refer to pediatric OT or PT to evaluate motor status and determine if direct OT or PT services are needed to improve motor skills for participation in physical activities	Child will develop necessary motor skills to participate in selected physical activities

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Resources

American College of Sports Medicine, www.acsm.org/ (go to link: Physical Activity and Public Health Guidelines)

Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, www.cdc.gov/nccdphp/dnpa

City of Seattle Parks & Recreation & Special Populations Programs, www.seattle.gov/ parks/specialpops/index.HTM

Healthy People 2010, www.healthypeople.gov/

King County Specialized Recreation, http://www.metrokc.gov/parks/ the newer site is at http://www.kingcounty.gov/healthservices/health/chronic/getactive/activities/disabilities.aspx

The National Center on Physical Activity and Disability, www.ncpad.org

Office of Disease Prevention and Health Promotion, http://odphp.osophs.dhhs.gov/

Outdoors for All, www.outdoorsforall.org

President's Council on Physical Fitness and Sports, www.fitness.gov/

Special Olympics, www.specialolympics.org

Special Olympics of Washington, www.sowa.org

Summer Camps and Programs for Children with Special Needs (WA State), www.cshcn.org

Surgeon General of the United States, www.surgeongeneral.gov/

United States Dept. of Health and Human Services – " I Can Do It, You Can Do It!" Nation-wide initiative supporting physical activity for children with disabilities; includes on-line mentoring program with 50 organizations participating. www.hhs.gov/od/physicalfitness.html

The Kid's Activity Pyramid, Penn State College of Agricultural Sciences Publications, http://pubs.cas.psu.edu/freepubs/pdfs/uk076.pdf

The Kid's Activity Pyramid, International Diabetes Center, Park Nicollet HealthSource, http://www.parknicollet.com/healthinnovations/search/search.cfm

CHAPTER 4

Breastfeeding for the Child with Special Health Care Needs

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The nutritional benefits of breastfeeding and breast milk for the typically developing infant are undisputed (1). These benefits are also important for the infant with special health care needs (2). However these babies may reap additional benefits from breast milk due to their initial medical problems. The anti-infective properties found in breast milk often play a crucial role in the baby's recovery from medical complications and support their health in the early months of infancy.

For the typically developing infant, exclusive breastfeeding is considered to be getting all nutrition at the breast. For the infant with special health care needs, a broader definition should be considered. Breastfeeding can be seen on a continuum from full nutrition directly from the breast through receiving breast milk either fully or partially from a bottle or tube feeding. For this reason, attention to the adequacy of the mother's milk supply is crucial. In particular, the first few weeks of life will be vital to the mother's ability to provide her baby with enough breast milk for growth over the next six to twelve months. For all infants who are receiving mother's milk recommended supplements include a single shot of Vitamin K at birth, use of a Vitamin D supplement started within a few days of birth, and a supplement of iron introduced in the first few months of life.

If the infant is not able to feed at the breast within two hours after birth, the mother should be assisted to begin pumping using a hospital grade pump. The first two weeks after birth are a crucial time for the establishment of a full milk supply (3). Encourage the mother to ideally pump a minimum of eight times per day, spaced at 2-3 hour intervals during the day with a break of no longer than 4-5 hours at night. The aim is to produce at least 16 oz or more of breast milk per day at two weeks after birth.

Pumped expressed breast milk can be stored for five days in the back of the refrigerator or frozen and kept for 3-6 months in the freezer of a refrigerator with a separate door for the freezer. If the mother is struggling with her milk supply even though she is pumping regularly, a referral to a lactation consultant (LC) is indicated. The LC, in conjunction with the mother's primary medical doctor, (PMD) might

recommend galactogogues to help boost milk supply. These are medications and herbs that can increase the mother's rate of milk production and help her pumping efforts (1).

Many mothers worry that their baby is not getting enough milk at the breast. This may reflect a new mother's lack of confidence, but can be an indication that the mother's milk supply is low, or that the baby is having trouble transferring milk from the breast (4). If the baby has inadequate growth or appears to be hungry even after feeding, a detailed assessment is indicated to identify the problem. Issues with breastfeeding can reside with the mother, infant or both. Careful evaluation by a registered dietitian, a lactation consultant, and an occupational, physical or speech therapist with a specialty in breastfeeding can determine the problem and develop treatment strategies.

The most common reasons mothers have low milk supply are related to delay in the start of pumping after birth if the baby is unable to feed at the breast, incomplete milk removal by the baby, and/or low frequency of pumping (3). Mothers may also have hormonal issues such as hypothyroidism, retained placental parts or hypoplastic breast development during pregnancy that can be linked with poor milk supply (3).

Once the contributions from mother-sided issues are determined, more detailed evaluation of the infant's role can occur. Assessment of the infant's oral motor control as it relates to the ability to latch to and remove milk from the breast is an important first step (5). When observing a mother/baby breastfeeding, a pre-post breastfeeding weight is the only reliable method to determine intake from the breast. The amount of time spent at the breast is an extremely inaccurate measure of milk transfer. In addition to pre/post weights, observing the infant's sucking pattern and rate of swallowing can give some indication of the baby's ability to breastfeed also known as efficiency of milk transfer. Frequent weight checks to monitor overall weight gain and growth velocity will also provide valuable data on which to base a treatment plan.

How satisfied the baby appears after nursing and the length of time between feedings can also provide clues to the adequacy of milk transfer from the mother to the infant. Health professionals should be aware, however, that there are babies who are "happy to starve," so that behavioral cues alone may not accurately reflect the amount of nutrition the baby is receiving at the breast. Infants with special health care needs may be particularly vulnerable to under-eating, as they may have diminished endurance from their primary medical conditions.

Many infants will require additional calories, beyond what they are capable of taking each day, in order to grow adequately. The RD's individualization of the care plan

for each infant and mother should be done in a manner that ultimately leads to full breastfeeding and/or use of the mother's milk supported by methods to preserve the mother's supply. The energy density of a mother's expressed breast milk (EBM) can be increased by the use of powdered formula and/or additional modules. See Appendix S. The increased energy dense breast milk can be given by a supplemental nursing system (SNS) or by use of the bottle for 1 or 2 feedings a day with the goal of full breastfeeding and/or use of all breast milk. Careful evaluation of the infant's growth will be needed. Merely taking the fully breastfed baby off of the breast, having mother pump her milk, fortifying it and then giving it by bottle can quickly lead to the cessation of breastfeeding, and possibly a severe reduction in breast milk supply.

Even babies who require nasogastric or gastrostomy tube feedings can gain breastfeeding benefits. They may breastfeed for a portion of their nutrition, with tube feeding volumes adjusted to account for intake (as measured by pre-post weights). Optimally, as much EBM as possible will be provided during tube feedings. Babies who take low volumes from the breast or who are unsafe to breastfeed can still nurse at a "dry" breast or participate in skin-to-skin care. These feeding experiences can have a beneficial influence on milk production.

Contraindications for breastfeeding and/or use of human breast milk are present in children with special health care needs. The most obvious is that for infants identified with galactosemia or other inborn errors of metabolism (See Chapter 21). For other contraindications to breastfeeding and/or the use of breast milk see The American Academy of Pediatrics *Pediatric Nutrition Handbook* (6).

For the infant with special health care needs, breastfeeding may look differently for each mother/baby pair. The primary goal is for the baby to receive as much breast milk as possible, with the secondary goal of achieving at least some feeding at the breast. Treatment strategies must support the mother in maintaining her milk supply, and support the mother and baby in moving toward breastfeeding. The intensity of the physical and emotional experience for the mother beginning breastfeeding with an infant with special health care needs should be acknowledged. The team of professionals working together can help balance competing medical goals, provide emotional support, and offer practical guidance to ensure the baby's optimal growth. In the process, we may redefine "breastfeeding" in a way that is unique to each mother/baby pair.

Table 4-1 presents guidelines for the assessment, intervention, and outcome/ evaluation for several breastfeeding concerns.

Table 4-1: Nutrition Interventions for Breastfeeding

Assessment	Intervention	Evaluation/Outcome
Is maternal milk supply adequate? A mother may have low milk supply if any of the following are observed: • Infant has inadequate weight gain or slow growth velocity • Insufficient number of feedings or length of feeds/day • Quantify milk supply through pre/post breastfeeding weights or pumping log • History of no change in breast size prenatally or within 1-2 weeks after birth • Infant appears hungry after feeding or eats more often than every 2 hours • Infant requires supplemental formula feeds for growth	If low milk supply is observed, refer mother to a lactation consultant (LC) for further evaluation and intervention. Mother should begin pumping with a hospital grade pump, at least 8-10 times per day. Consider beginning a galactogogue	Infant will demonstrate age appropriate growth. Mother will maintain milk supply
Is milk transfer effective? In a mother with good milk supply, if latch is effective there should be clear evidence appropriate milk transfer, such as: • Active sucking throughout most of a 10 -20 minute period at one or both breasts (baby should not be mostly sleepy) • Most sucking with "long draws" (not short, rapid sucks) • Evidence of swallowing after every 1-2 sucks • Baby satisfied when comes off of the breast • Pre-post weights using digital scale (accurate to +/- 2 grams) show adequate intake. • There should not be significant pain Remember: the amount of time spent at the breast is not an accurate indication of the amount of milk the baby is getting	If milk supply is clearly good (high pumping volumes), but baby is not transferring milk effectively: Improve latch: • optimize position • asymmetric latch techniques Referral to LC if: • changes to position/latch not helping • suspect problem with baby's sucking • Mother has significant pain	Baby receives adequate nutrition from breastfeeding for optimal growth

Assessment	Intervention	Evaluation/Outcome
Should breastfeeding be supplemented? If the baby is not gaining adequately on exclusive breastfeeding, there is other evidence of inadequate milk transfer, or the baby's medical condition requires it, supplementary feeding should be provided. The amount and type will be based on: • Mother's current milk supply • Baby's current success with breastfeeding and milk transfer • Prediction of future potential for breastfeeding • Baby's medical condition • The primary goal should be as much nutrition as possible from breast milk, with the secondary goal of successful feeding at the breast	Schemes for providing supplementation: Baby is primarily non-orally fed: • Tube feeding required • Maximize amount of breast milk provided • Support skin to skin care (kangaroo care) • Support non-nutritive or low volume nutritive experience at the breast; support from LC as needed Baby is partially orally fed: • Tube feeding as necessary. • Breastfeeding based on baby's ability (for nutrition versus for practice); support from LC as needed. • Use of other oral supplementing devices as needed (see below) • Maximize use of expressed breast milk. Baby is fully orally fed: • As much nutrition as possible at the breast (balance needs of baby, mother and family) • Work with LC to build breastfeeding skills • Use of appropriate oral supplementing devices (see below) to support current goals and needs. • Maximize use of expressed breast milk given by supplementary method Oral supplementing devices can include: • Finger feeding • Tube and syringe or commercial supplementer at breast (SNS, Hazel Baker finger feeder or Lact-Aid) • Binky trainer • Bottle (select one to provide characteristics similar to breastfeeding, if possible)	Baby receives adequate nutrition using a variety of methods that provide as much breast milk as possible, and work toward breastfeeding as is desired by the family and seems appropriate for the baby

Assessment	Intervention	Evaluation/Outcome
Is fortification needed? Babies may require fortification to provide extra calories for growth if: • The baby is not able to take adequate volume at the breast, or with breast + supplement • There are additional caloric or nutritional requirements specific to the baby's medical condition.	If fortification is needed, try to rely on breastfeeding and/or breast milk as much as possible: • During pumping, separate hind milk, and use this as a supplement. • Add energy enhancement to expressed breast milk • Balance feedings at the breast with energy enriched bottle feedings • Breast feed using a energy enriched breast milk through a tube feeding device (i.e. supplemental nursing system)	Infant will show growth in all parameters at an appropriate rate

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CHAPTER 5

Medication-Nutrient Interactions

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Medications and nutrients are known to interact, sometimes with detrimental effects. Medications can affect nutritional status in the following ways:

- altering the absorption, metabolism, and/or excretion of specific nutrients
- causing gastrointestinal disturbances and/or anorexia, thereby decreasing overall nutrient intake
- increasing appetite which can result in obesity
- interacting with nutrients prior to ingestion (e.g. when mixed with food or formula before administering)

Additionally, specific foods and nutrients are known to interfere with the action of certain medications by altering the absorption or metabolism of the medication. Children with special health care needs are at risk for medication-nutrient interactions, especially when medications are used long-term, multiple medications are prescribed, and nutrient intake is marginal (1). Other issues to consider include interactions between medications and vitamin and mineral supplements and the timing of medication administration related to meals and snacks. This section discusses ten types of medications that have documented effects on nutrients and are commonly used in the treatment of children with special health care needs (2).

Anticonvulsants

Children with neurologic impairments often have secondary seizure disorders that are treated with anticonvulsant medications. Long-term use of anticonvulsant medications places a child at risk for deficiencies of vitamin D, folic acid, and possibly other vitamins, including vitamins B6 and B12 (3,4). Routine assessment for vitamin deficiencies is an important component of comprehensive health care for these patients. Some anticonvulsants can cause side effects such as nausea, vomiting, diarrhea, and lethargy (3). Other side effects include weight loss or gain (5).

Vitamin D

Long-term use of anticonvulsants has been associated with vitamin D deficiency, resulting in rickets or osteomalacia (1). The effects of anticonvulsant therapy on vitamin D status are multiplied by the following factors (1,4):

- multiple medication regimens
- inactivity
- little exposure to sunlight
- dark skin
- poor dietary intake of vitamin D

The anticonvulsants most frequently implicated in vitamin D deficiency are phenytoin (Dilantin), phenobarbital, and carbamazepine (Tegretol). Primidone (Mysoline) and valproic acid (Depakene/Depakote) have also been shown to be associated with vitamin D deficiency and decreased bone mineral density (1,3,4).

Recent research on vitamin D has shown that optimal levels are much higher than previously thought (>30ng/mL versus >20 ng/mL). Vitamin D deficiency has been found to be widespread in the normal population, especially for those living at greater than 45 degrees latitude (north or south) (5,6). It is imperative that vitamin D levels are evaluated and deficiencies treated at time of initiation of anticonvulsant therapy, and regularly thereafter. Children on anticonvulsant therapy who have normal vitamin D levels should be given a prophylactic dose of up to 2000 IU vitamin D daily. Those with documented deficiencies will need pharmacologic doses prescribed by their physicians (7).

Folic Acid

Longterm use of anticonvulsants has also been strongly associated with folic acid deficiency and possibly with deficiencies of other B vitamins and vitamin C. Folic acid deficiency has been observed with phenytoin alone and in combination with other medications; the strongest effects have been observed with multiple medication regimens. There is some indication that folic acid supplementation may result in more frequent seizures. However, supplementation with Dietary Reference Intake (DRI) levels of folic acid and close monitoring of seizure activity is appropriate to prevent folic acid deficiency (1). Folic acid deficiency is associated with hyperhomocysteinemia which in turn increases risk for heart disease. Supplementation with folic acid has been shown to both replete folic acid levels and decrease homocysteinema levels in individuals on anticonvulsants (8,9).

Carnitine

Numerous studies have shown that plasma carnitine levels are significantly lower among patients taking valproic acid than among controls (10). Carnitine deficiency in epilepsy results from a variety of etiologic factors including underlying metabolic disease, inadequate nutrient intake, and specific medication effects (6, 7). The relationship between carnitine deficiency and valproic acid-induced hepatotoxicity is unclear. Carnitine treatment does not always prevent the emergence of serious hepatotoxicity, but it does alleviate valproic acid-induced hyperammonemia (4,11).

Medications for Treatment of Attention Deficit and Attention Deficit Hyperactivity Disorders

Attention Deficit Disorder (ADD) and Attention Deficit Hyperactivity Disorder (ADHD) is commonly treated with stimulant medications such as methylphenidate (Ritalin, Ritalin SR, Metadate CD, Metadate ER, Concerta), dextroamphetamine (Dexedrine) and amphetamine mixture (Adderall). Automexetine (Strattera) is a non-stimulant drug used to treat ADD/ADHD. Studies have shown that all of these medications are associated with depressed appetite in children, often resulting in a slower rate of weight gain and growth. Other studies have shown that effects of stimulant medications on appetite or growth are temporary and dose related; after one to two years of treatment, a tolerance is developed, and growth and appetite are no longer depressed. A 1996 study found small but significant differences in height between children with ADHD and controls (12). These height differences were evident in young children, but not older adolescents and were unrelated to the use of psychotropic medications (13,14).

Diuretics

Diuretics are frequently prescribed for children with cardiac defects or chronic lung disease. Many diuretics such as furosemide (Lasix) increase the excretion of potassium, calcium, sodium, zinc, chloride, and magnesium; other diuretics such as spironolactone (Aldactone) spare potassium, but increase the excretion of calcium and magnesium (2). The diets of patients on diuretics must provide adequate replacement of the minerals that are excreted. Diuretics can also contribute to anorexia and gastrointestinal distress (15).

Corticosteroids

Glucocorticoids are used as replacement therapy in adrenal cortical deficiency states and for anti-inflammatory and immunosuppressive effects in the treatment of many disorders, including asthma. Side effects of glucocorticoids include decreased bone mineral density, and decreased absorption of calcium and phosphorus; poor linear growth; increased appetite often leading to excessive weight gain; sodium and water retention occasionally leading to hypertension; muscle catabolism; increased glucose leading to insulin resistance; and increased lipolysis (16,17). Inhaled corticosteroids are now more commonly used than systemic corticosteroids. Their side effects are minimal compared to oral corticosteroids, but they can have similar effects when used long term.

Antidepressants

Tricyclic antidepressants (TCAs) are used to treat mental depression, as an aid in the temporary treatment of nocturnal enuresis in children over the age of six years, and as a treatment for ADHD for some young adults and children over six years of age. Although the exact mechanism of action in the treatment of depression is unclear, TCAs have been thought to increase the synaptic concentration of norepinephrine and/or serotonin in the central nervous system. Nutrition-related side effects of TCAs can include an increased appetite and weight gain, dry mouth, nausea and vomiting, constipation, and diarrhea.

The relatively new antidepressant medications, selective serotonin reuptake inhibitors (SSRIs) may cause dry mouth and GI disturbances such as nausea and vomiting, dyspepsia, diarrhea or constipation (18,19).

Antibiotics

Antibiotics are used to treat infections. They are sometimes used long-term on a prophylactic basis. Side effects that may interfere with an adequate nutrient intake include mouth and tongue sores, diarrhea, nausea, and vomiting (1). With long-term use, gut flora can be altered, decreasing vitamin K production (20). Monitoring of nutritional effects is indicated.

Anti-Inflammatory Medications

Anti-inflammatory medications (e.g. sulfasalazine for ulcerative colitis and Crohn’s disease) can cause nutrition-related side effects including anorexia, nausea, vomiting, taste changes, diarrhea, gastric distress, and abdominal discomfort (20).

Anti-Gastroesophageal Reflux Disease Medications

These medications are used to treat heartburn due to gastroesophageal reflux disease (GERD) by increasing GI motility. This acceleration of gastric emptying could affect the rate of absorption of other medications (21). A wide range of nutritional side effects may also occur, including constipation, diarrhea, nausea, vomiting, and abdominal pain and discomfort.

Antispasmodics

Antispasmodic medications are prescribed for bladder instability, e.g., with myelomeningocele. Some of the nutrition-related adverse effects include nausea, dry mouth, constipation, abdominal pain, anorexia, dysgeusia, and difficulty with swallowing (22).

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome for nutrition assessment, intervention, and evaluation/outcome for specific medication-nutrient interactions.

Table 5-1: Medication—Nutrient Interactions

Assessment	Intervention	Evaluation/Outcome
In addition to the Nutrition Assessment described in Chapter 1, complete the assessment indicated below	See the intervention below for each type of medication	
ANTICONVULSANTS Examples: Any of the following alone or in combination with other anticonvulsants: phenobarbital; phenytoin (Dilantin); carbamazepine (Tegretol); primidone (Mysoline); valproic acid (Depakene/Depakate)		
Assess diet for overall nutrient intake. Check specifically vitamin D, folic acid, other B vitamins, vitamin C, Vitamin K, and calcium Monitor for weight gain, weight loss, diarrhea, and constipation	If intake of any nutrient is less than the DRI/RDA: • Counsel caregiver/patient about food sources of nutrients • Recommend multivitamin/mineral supplement at DRI/RDA levels • Monitor for weight changes	Dietary intake of all nutrients is adequate
Assess indicators of bone mineralization: • Serum 25 (OH) vitamin D • Serum calcium (Ca) • Serum phosphorus (P) • Serum alkaline phosphatase (Alk Phos)	If vitamin D is low, supplement with pharmacologic doses of vitamin D3 until it is well within normal limits While pharmacologic doses of vitamin D are being given, monitor for vitamin D toxicity weekly or bimonthly by checking serum Ca level (High serum Ca may indicate vitamin D toxicity) If vitamin D is normal, give up to 2000 IU/day of vitamin D to maintain stores If Ca or P is low, and vitamin D is normal, supplement with Ca or P. If Ca or P is low and vitamin D is low, insure DRI levels of Ca and P while vitamin D is being repleted If serum Ca, P, and Alk Phos are normal, re-assess 1-2 times per year	Indicators of bone mineralization are within normal limits
STIMULANTS Examples: methylphenidate (Ritalin); dextroamphetamine (Dexedrine, Adderall); pemoline (Cylert)		
Assess dietary intake when medication first prescribed	If diet is low in any nutrient, counsel appropriately. Instruct caregiver(s) to offer meals before giving the medication and later in the day when the medication action is minimal or absent. Collaborate with school to make sure child gets meal or snack before medication at school, if appropriate (see Chapter 12)	Dietary intake of all nutrients is adequate

Assessment	Intervention	Evaluation/Outcome
Assess growth (height or length and weight) every 3 months	If rate of growth (height/length, or weight) is slowing, re-assess dietary intake and counsel appropriately	Weight and height (or length) are increasing in appropriate percentiles
Reassess dietary intake with a 3-to-7-day food record (if possible) and a diet history	If diet is adequate, but growth rate continues to slow, refer to physician to evaluate need for a change in medication or dose	
DIURETICS Examples: furosemide (Lasix); spironolactone (Aldactone); triamterene (Dyrenium*); thiazides (Diuril, Hydrodiuril, Naqua, Hygroton, Hydromox, and Diamox)		
Consider effect of diuretic on excretion of potassium (K), magnesium (Mg), and calcium (Ca) Assess diet for K, Ca, and Mg	If intake of K, Ca, or Mg is lower than the DRI counsel regarding dietary sources. Consider mineral supplements, especially K	Dietary intake of all nutrients is adequate
If use of diuretics has been long-term, assess electrolyte and mineral status	If mineral deficiency is evident, counsel on dietary sources and provide mineral supplement	Lab indicators of electrolyte and mineral status are within normal limits
CORTICOSTEROIDS Examples: **Systemic**-dexamethasone, hydrocortisone, methylprednisolone, prednisolone, prednisone **Inhaled** - triamcinolone acetonide (Azmacort)		
Assess for indigestion or mild GI intolerances that may occur Assess if patient receiving prolonged therapy with pharmacologic doses	Administer oral or inhaled dosage forms with food Consider need for sodium restriction and/or potassium supplementation	GI distress is decreased Fluid retention and electrolyte disturbances are minimized
Assess protein intake to ensure adequacy	Ensure adequate intake of protein and encourage physical activity	Muscle catabolism is minimized.
Assess vitamin and mineral intake	Supplement any vitamins and minerals that are deficient in diet. Supplement Calcium to insure intake of 150% DRI[22] and 400 to 2000 IU vitamin D	Intake of vitamins, calcium, and phosphorus is adequate
Assess linear growth	Discuss possibility of decreased dose and/or alternate days on/off medication with physician.	Effect on growth is minimized
Assess bone density—use bone densiometry to diagnose osteoporosis if long term corticosteroid treatment	If condition permits, exercise or physical therapy will reduce risk of osteoporosis	Bone loss is prevented/ minimized

Assessment	Intervention	Evaluation/Outcome
ANTIDEPRESSANTS Examples: **Tricyclic antidepressants (TCAs) -** amitriptyline (Elavil); amoxapine (Asendin); clomipramine (Anafranil); desipramine (Norpramin); imipramine (Tofranil); nortriptyline (Aventyl, Pamelor); protriptyline (Vivactil); trimipramine (Surmontil); **Selective Serotonin Reuptake Inhibitors (SSRIs)** -fluoxetine (Prozac); sertraline (Zoloft)		
Assess if patient on tricyclic antidepressants (TCAs) or selective serotonin receptor inhibitors (SSRIs)	Monitor for dry mouth, taste changes, GI distress Take in morning without regard to meals Monitor weight	Decreased GI distress. Appropriate rate of growth and weight gain
Assess if problem with gastric irritation	Take medication with or immediately after food to lessen irritation (for TCAs)	Decreased GI distress
Assess if patient on amitriptyline or imipramine	Requirements for riboflavin may be increased/may interfere with the biochemical assessment of riboflavin's effect or induce riboflavin depletion.	Adequate riboflavin intake
ANTI-ANXIETY Examples: diazepam (Valium)		
Monitor for dry mouth, nausea, constipation, hypoalbuminemia (with usage over 4 weeks)	Increase free water as needed Check serum albumin every 6 months Ensure protein needs are met; modify protein intake as needed	Serum albumin is within normal limits Problems with dry mouth, constipation are minimized
ANTIBIOTICS Examples: cefazolin (Ancef, Kefzol); cefotaxime (Claforan); cefotetan (Cefotan); ceftizoxime (Cefizox); ceftriaxone (Rocephin); penicillin; vancomycin		
Assess for anorexia or GI distress	Anorexia – Suggest small, frequent meals GI distress - If appropriate, suggest medication be taken with meals	Rate of growth and weight gain is appropriate GI distress is minimized
ANTI-INFLAMMATORY Examples: sulfasalazine (Asulfidine)		
Assess for GI distress Assess fluid intake Assess folate intake	Take with water after meals or with food Ensure output of 1500 cc/day Folate supplement (1 mg/day) recommended Take folate separately from medication	Decreased GI distress Sufficient urine output Prevent folate deficiency

Assessment	Intervention	Evaluation/Outcome
ANTI-GASTROESPHAGEAL REFLUX DISEASE (GERD) Examples: ranitidine (Zantac)		
Assess for GI distress	Take with meals and/or bedtime snack Bland diet may be recommended Limit caffeine	Decreased GI distress
ANTISPASMODICS Examples: oxybutynin (Ditropan), tizanidine (Zanaflex), baclofen (Lioresal), dantrolene†† (Dantrium)		
Assess for GI distress	Take consistently with or without food (food increases maximum concentration and decreases time to peak concentration).	Decreased GI distress

*Spironolactone and triamtere are potassium-sparing diuretics. Avoid salt substitutes that are high in potassium. Do not supplement with potassium unless serum K low and only under close supervision.

†With dentrolene, monitor for GI bleeding and dysphagia.

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CHAPTER 6

Nutrition Interventions for Constipation

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Constipation is defined as incomplete or infrequent passage of stool persisting for 2 or more weeks. The presence of hard, dry fecal material with difficulty in defecation, even if passed frequently, may also be considered constipation (1). Most authorities agree that a stool frequency of less than three times per week would be diagnostic of constipation in any age group (2).

Management of constipation is important because it can cause physical and emotional complications. Chronic constipation can lead to impaction and stretching of the rectal wall resulting in fecal soiling. Painful bowel movements might result in withholding behavior or encopresis (3,4). Urinary tract infections and other urinary pathology are reported in 30% of children with constipation, relating to fecal flora entering the urethra or the dilated rectum pushing on the bladder causing spasms (4). Decreased quality of life has been reported in children with chronic constipation and in their families. About one third of children never outgrow it (4,5). Signs of constipation include abdominal pain, abdominal distention, decreased oral intake and irritability (1).

There are many causes of constipation with specific relevance for children with special health care needs, and these are listed below. In some cases, reasons for the constipation cannot be determined. When no organic cause for constipation is identified, this is termed functional constipation (1).

Causes of Constipation Seen Commonly in Children With Special Health Care Needs

- Abnormal anatomy or neurologic function of the intestinal tract (e.g. anal stenosis, Hirschsprung's disease, and neurogenic bowel associated with myelomeningocele)
- Abnormal muscle tone (hypertonia or hypotonia) leading to impaired function of the intestinal tract

- Decreased activity (e.g. due to prolonged illness, body cast, impaired motor skills, immobility or paralysis)
- Lack of routine toileting habits or the inability to attain an upright position for toileting
- Coercive toilet training (excessive parental involvement and/or fear of punishment with fecal soiling).
- Medications, e.g. codeine; methylphenidate HCl (Ritalin), phenytoin (Dilantin), imipramine, anticholinergics that may be used to treat neurogenic bladder (1,3) and excessive or long-term use of laxatives, suppositories, or enemas, which can affect bowel motility or muscle tone and lead to more constipation and reliance on medications
- Unable to communicate need
- Behavioral withholding (encopresis)
- Excessive fluid losses (e.g. due to constant drooling, chronic vomiting, or fever)
- Inadequate fluid intake
- Inadequate fiber intake
- Underfeeding or malnutrition
- Cow milk protein allergy. This has not been well documented and requires further confirmation with double-blind studies (6). A time limited trial of a cow milk protein free diet is only recommended when other medical interventions and behavioral strategies have been exhausted (1,3).

The treatment of chronic constipation can involve increased intake of dietary fiber and fluids, a routine toileting schedule and proper positioning, increased exercise or massage, and use of stool softeners or laxatives (1,3). Evacuation of the bowel, usually accomplished with enemas or suppositories, is necessary in cases of impaction (3). A list of laxatives and description of mechanisms is provided in Table 6-1.

When using any form of laxative, it is recommended to gradually decrease the amount of laxative required over a period of two to three months to a level that maintains one stool/day and prevents pain or straining (1). In a period of three to six months, discontinuation of the laxative is possible in about 50% of patients, with normal elimination then maintained via dietary and toileting practices (1,3).

Several controversies exist regarding the use of a high fiber diet in children, the use of mineral oil, and the use of highly osmotic liquids such as corn syrup. The following briefly summarizes the issues and conclusions.

High Fiber Diet for Children

There have been concerns that a high fiber diet may have adverse effects on total energy intake and nutrient absorption in children. However, current research is inadequate to support a recommendation for fiber supplementation in children, and instead the recommendation is a balanced diet including whole grains, fruits and vegetables (1,3). The American Dietetic Association released a position statement in 2008 on dietary fiber, citing: "Appropriate kinds and amounts of dietary fiber for children, the critically ill, and the very old are unknown". Reference Intakes are set at 14 grams of fiber per 1000 calories (7). Unfortunately, these recommendations may not be applicable to children with special health care needs consuming individualized diets, such as a low energy diet or tube feeding. Other recommendations have been followed with successful outcomes in bowel management for healthy children and children with special needs.

The American Academy of Pediatrics recommends 0.5 g fiber/kg for a general healthy intake, with an upper limit of 35 g/day (8). Another method for estimating fiber requirements is "age plus 5 g," as established by the American Health Foundation for children over age 2 years (e.g. a child who is 3 years old: 3 plus 5 g = 8 g fiber/day) (9,10). It is important to realize that children with chronic constipation may require fiber in amounts greater than the usual recommendations, along with increased fluid, to maintain normal elimination. However, it is recommended that levels above "age plus 10 g" be avoided (9). Children who are not able to consume adequate amounts of fiber from food often benefit from the use of supplemental fiber products. Examples of these include Unifiber®, Benefiber®, and Metamucil®. (See Appendix S.)

Mineral Oil

Another controversy in the treatment of constipation involves the use of mineral oil. Mineral oil serves to soften the stool and provide lubrication for easier elimination. However, there have been concerns that it may bind fat-soluble vitamins and thus cause nutrient deficiency. This controversy began with a study done in 1939 that showed a decrease in serum carotene after six months of high-dose mineral oil use. However, the participants in this study never developed serum levels in a deficient range (11). Two recent studies have demonstrated no adverse effects of mineral oil use on fat-soluble vitamin status (2,11).

Mineral oil is not appropriate for infants less that 1 year of age secondary to concerns for gastroesophageal reflux and immature swallowing skills that may lead to aspiration (1,3). The risk for lipoid pneumonia also exists for children with history

of aspiration or swallowing difficulties. Alternatives suggested for infants are sorbitol, naturally found in pear, apple, and prune juices, glycerin suppositories, and lactulose.

Corn Syrup

Corn syrup has been commonly used to treat constipation, on the theory that its high osmolarity will draw more water into the intestinal tract by osmosis. Although this seems to work in some cases, high osmolarity liquids have not been shown to be effective in treating constipation (2).

The remainder of this section (Table 6-1 and 6-2) presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with constipation.

Table 6-1: Laxatives

Instructions on packages should be followed. Contact physician if age-appropriate instructions are not available. Encourage families to report additions or changes in routines and medications so this information may be considered in prescribing medications and monitoring progress.

Laxative Type	Onset of Action (hours)	Site of Action	Action	Comments	Brand/Common Name
Saline Magnesium Sulfate Magnesium Hydroxide Magnesium Citrate Sodium Phosphate	0.5-3	small and large intestine	Attracts/retains water in intestinal lumen, increasing intraluminal pressure; cholecystokinin release	• May alter fluid and electrolyte balance • Sulfate salts are considered the most potent • May decrease tetracycline absorption	Epsom salts Milk of magnesia
Sodium Phosphate/ Biphosphate enema	0.03-0.25	colon			Fleets enema®
Irritant/Stimulant Cascara Danthron Senna Phenolphthalein Casanthranol	6-10	colon	Direct action on intestinal mucosa; stimulates myenteric plexus; alters water and electrolyte	• Cascara and senna may cause yellow-brown urine; alkaline urine may turn pink-red or red-violet • Bile must be present for phenolphthalein to have effect • Do not give Biscodyl tablets within 1 hour of antacids or milk products • May prefer castor oil when complete evacuation is required	Cascara Senokot® Ex-Lax® Dulcolax® Fletcher's Castoria®
Bisacodyl Tablets	0.25-1				
Bisacodyl Suppository Castor Oil	2-6				
Bulk-Producing Methylcellulose Psyllium Polycarbophil	12-24 (up to 72 hr)	small and large intestine	Holds water in stool; mechanical distention; malt soup extract reduces fecal pH.	Safest and most physiological Do not give with salicylates, digitalis, or cardiac glycosides May cause obstruction if passage is stopped	Citrucel® Hydrocil® Metamucil® Chronulac® Malt supex®
Lubricant Mineral oil (1-2 tsp/ day) Oil enema (1-4 oz)	6-8	colon	Lubricates intestine; retards colonic absorption of fecal water; softens stool	Not for infants less than 1 year of age or children with history of aspiration. Administer on empty stomach	Mineral oil
Surfactants Docusate sodium (do not use if mineral oil given)	24-72	small and large intestine	Detergent activity; facilitates admixture of fat and water to soften stool.	Beneficial when feces are hard or dry, or in anorectal conditions where passage of a firm stool is painful	Colace® Doss®

Laxative Type	Onset of Action (hours)	Site of Action	Action	Comments	Brand/Common Name
Miscellaneous Glycerin	0.25-0.5	colon	Local irritation; hyperosmotic action	Sodium stearate in preparation causes the local irritation, can moisten suppository in water to reduce irritation	Glycerin
Lactulose	24-48	colon	Delivers osmotically active molecules to colon	Also indicated in portal systemic encephalopathy	Lactulose Cephulac® Chronulac®
Polyethylene glycol	1-4	colon	Osmotic agent, causes stool to retain water		Miralax®

Compiled from *Drug Facts and Comparisons*, 1999 Edition, J.P. Lippincott Company.

Table 6-2 - Nutrition Interventions For Constipation

Assessment	Intervention	Evaluation/Outcome
Clinical		
Obtain stool history. Differentiate between acute and chronic conditions. Determine: • Stool frequency and consistency • Toileting techniques • Primary diagnosis (e.g. Down syndrome, cerebral palsy, Hirschsprung's disease)	Work with family to establish regular toileting schedule and appropriate positioning. Include a physical or occupational therapist to assist with appropriate positioning techniques, and assess the need for any special equipment.	Regular toileting is established and followed. Re-evaluate frequently until regular bowel movements are occurring every 1-2 days, with a normal consistency.
Work with child's primary care physician or a medical consultant to rule out anatomic or neurologic disorder. Obtain the following as needed: • Rectal exam • Abdominal x-ray • Barium enema • Intestinal biopsy/rectal manometrics • Colonoscopy (From early infancy, children with spinal cord anomalies, e.g. myelomeningocele, need close medical assessment and monitoring for bowel problems.)	Provide medical management for physiologic disorders (e.g. a child with myelomeningocele who has a neurogenic bowel, which may require surgery) [1] Use the following treatments with care: laxatives (including prunes and prune juice), stool softeners, suppositories, and enemas. Certain treatments may be hazardous with long-term or excessive use, or if there is impaction or megacolon. [1,3] Some of these may result in dependency. See Chapter 5 for more information or see reference 9.	Medical contributors to constipation are controlled. When a potentially correctable underlying cause of constipation exists, re-evaluate need for medications on a regular basis. If possible, discontinue and manage with other methods. (Children who have neurogenic bowel or who are immobile often need medications indefinitely.)
Assess level of physical activity.	Increase physical activity as tolerated. Obtain OT/PT consult for instruction on infant/child massage.[10]	Recommended activity schedule is followed. Appropriate massage occurs.
Dietary		
Assess fluid and fiber intake. Use food record and/or interview. Determine food textures that are well-tolerated.	Counsel caregivers regarding appropriate dietary changes.[11] Advise the following as needed: Increase fluids, especially water and juice. For the child who cannot easily swallow thin liquids, try the following:	Intake of fluid and fiber is increased. Re-evaluate diet frequently until stools are of normal consistency and frequency.

Assessment	Intervention	Evaluation/Outcome
	• Juices thickened with pureed fruit, infant cereal, or a commercial food thickener • Gelatin • Increase foods with high water content if fluid intake is suboptimal. (Fruits and vegetables are about 90% water.) [1,3] Increase dietary fiber with the following foods: • Unprocessed bran (add 1-3 Tbsp per day to foods. Provide adequate fluid.) • Whole grain cereals, breads, and crackers • Raw, cooked, or dried fruits (especially prunes and prune juice) • Raw or cooked vegetables • Legumes (beans, split peas, lentils) Consider use of supplemental fiber products (e.g. Benefiber®, Unifiber®, Metamucil®). For tube-fed individuals, advise the following: • Increased water • Try prune juice Try formula with added fiber, such as PediaSure with Fiber®, Compleat Pediatric®, and Nutren Jr. with Fiber®	

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CHAPTER 7

Nutrition Interventions for Diarrhea

Naomi Katsh, MD

Diarrhea is the sudden increase in frequency and looseness of stools. Diarrhea is sometimes described as the passage of more than three watery stools in 24 hours or three times the normal number of stools in 24 hours (1,2,3). The best indicator of the severity of diarrhea is the frequency. If severe or chronic, this condition has a high potential for morbidity (and mortality, especially in developing countries). It is estimated that two million deaths occur annually in children under age 5 as a result of diarrheal diseases (1,4).

The main complication of diarrhea is dehydration from the loss of fluid and electrolytes with the stools. Nutritional complications may also develop, especially in chronic situations. Depending on the severity, chronicity, and underlying medical condition, evaluation and treatment of diarrhea may require input from many different health professionals including nurses, registered dietitians (RDs), primary care providers, and gastroenterologists.

Although there is not always a clear distinction, the subject of diarrheal illness can be approached as either an acute or chronic problem.

Acute Diarrhea

Acute diarrhea refers to a self-limited illness usually of less than 2-3 weeks duration. Acute diarrhea may lead to electrolyte imbalance and dehydration, which can be life threatening. Infants and young children with diarrhea are more susceptible to dehydration than older children and adults because of their smaller intravascular volume and a lower capacity to concentrate urine (2). Children who have disabilities that affect oral-motor function are already at risk for dehydration and may be at even greater risk because of difficulty replacing the fluids lost through diarrhea.

Causes

There are many causes of acute diarrhea. Some common causes include:

- Infection: Diarrhea in children is usually caused by a viral infection of the lining of the intestine (gastroenteritis) and can be accompanied by vomiting, fever, and

abdominal pain. Types of infection include:

1. viral: (e.g., Rotavirus, enteric adenovirus). In the United States, viruses account for at least 3040% of episodes of acute gastroenteritis.
2. parasitic: (e.g., Giardia)
3. bacterial: (e.g., E. coli 0157, Salmonella, Shigella, Campylobacter)
4. non-gastrointestinal infection: Diarrhea can accompany otitis, pneumonia or urinary tract infection

- Medication side-effect (frequent with some antibiotics)
- Food intolerance

Nutritional Complications

Nutritional complications from acute diarrhea may not always be evident. Nutrient deficits are uncommon among previously healthy children with self-limited gastroenteritis. Dehydration is the most concerning complication of acute diarrhea. In the literature there are multiple different definitions of degrees of dehydration. Table 7-1 describes one approach to the assessment of dehydration for those with acute diarrhea.

Table 7-1: Assessment of Dehydration (1,2,5,6)

	Percent Body Water Lost	Signs and Symptoms
Minimal dehydration	1 to 2%, subclinical	Increased thirst and mild oliguria (decreased urine output)
Mild dehydration	3 to 5%	Increased thirst, oliguria, mucous membranes slightly dry
Moderate dehydration	6 to 9%	Marked thirst, urine output <1mL/kg/hr, dry mucous membranes, decreased or absent tears, sunken fontanel, sunken eyes, delayed capillary refill, may have increased heart rate, may be listless and/or irritable
Severe dehydration	10%	All the signs of moderate dehydration and may have hypotension, thready pulse, bradycardia or tachycardia, cool, cyanotic extremities, severe lethargy

After rehydration is started, refeeding the intestinal tract is recommended as the appropriate dietary management (1-3,5,7,8). There are multiple physiologic effects when the gastrointestinal tract receives no enteral nutrition. Starvation has been shown to cause atrophy of the gastrointestinal mucosa, decreased production of

digestive enzymes, and increased permeability of the mucosal barrier. All of these effects can lead to decreased ability of the gut to absorb nutrients (7,8).

Some children who have chronic illnesses or who are medically fragile may suffer nutrition deficits from repeated bouts of mild acute diarrhea even when appropriately managed.

Treatment

Mild acute diarrhea requires no special treatment. Adequate fluid intake should be a priority, but a strict clear liquid diet is no longer the treatment of choice. Recent data indicates that feeding with the usual diet is appropriate for most cases of acute diarrhea (1-3, 5-9). If an infant is breastfed, this should be continued on demand and other fluids given if needed for supplementation. Breast milk contains substances which may stimulate and protect the gastrointestinal mucosa (7). Formula-fed infants also should be continued on their routine formula. Milk and milk-based formulas have historically been avoided during episodes of diarrhea. There may be mucosal damage during the illness that creates temporary lactase deficiency. However, at least 80% of children do not have worsening of diarrhea from this temporary lactase deficiency and can safely be continued on milkbased formula or milk (7,8). Change to a lactose-free formula is only recommended if stool output increases on a milk-based formula (3).

Previous recommendations for treatment of acute diarrhea were for a period of "bowel rest" with clear liquids only, then gradual re-introduction of first diluted, then full strength formula or milk along with a very limited diet of solid foods. Diluted formula is no longer recommended. Current information has demonstrated that early feeding of a routine diet leads to a better overall outcome. Specific beneficial effects are decreased duration of illness, improved weight gain, and improved nutritional state (5,7,8).

There is discussion in the medical literature as to what constitutes the most appropriate mixed diet for feeding during acute diarrhea. Historically, the BRAT diet (banana, rice, applesauce and toast/tea) was recommended. This very restricted diet is high in carbohydrates but very low in calories, fat, fiber, protein, calcium, and Vitamins A and B12 (8). Current broad guidelines for an appropriate mixed diet are for food that is palatable, inexpensive, culturally acceptable, and easily digested (5,7). This may include complex carbohydrates (rice, wheat, potatoes, bread, cereal), lean meats/poultry, eggs fruits, vegetables, and yogurt (5).

Medications are generally not prescribed or recommended for infants or children with acute diarrhea. Viruses are the predominant cause of acute diarrhea, especially in developed countries; therefore antibiotics are not indicated when treating acute diarrhea illnesses. Very few studies regarding medications have been done with children to demonstrate safety or efficacy. The potential risks of medications, including antispasmodics and anti-motility agents are felt to greatly outweigh any potential benefits (1,2,5,7).

Mild (3-5%) to moderate (6-9%) dehydration resulting from acute diarrhea can be treated with oral rehydration. There are commercially available preparations (e.g., Pedialyte®, Rehydralyte®) for oral rehydration. In developing countries childhood deaths from diarrheal illness, while still unacceptably high, has decreased dramatically due to oral rehydration solution (ORS) programs for treatment and prevention of dehydration.

Since 1975, The World Health Organization (WHO) and the United Nations Children's Fund (UNICEF) have recommended the formulation of ORS used in developing countries. Since 2002 there has been a new recommendation for a lower osmolarity ORS. This new preparation has been found to be more effective for acute, noncholera diarrhea in children and causes fewer cases of hypernatremia (high sodium). Adult cholera patients may still need higher sodium preparations in some instances (4).

Osmolality is a major factor in determining the efficacy of Oral Rehydration Solutions. In general, juice, broth, carbonated beverages, and sports drinks should not be used for oral rehydration because their high osmolalities may induce osmotic diarrhea and the electrolyte content is not appropriate (1-3,5,7,8). Diluted juice, broth, and sports drinks can be used for some children if other, more appropriate rehydration fluids are not available. Cereal-based oral rehydration therapy has also been proposed as a method of rehydration which also provides some nutrients (4,7). There are no commercially available cereal-based products at of the time of this writing.

HERE IS A RECIPE FOR CEREAL-BASED ORT (ORAL REHYDRATION THERAPY) SOLUTION

½ - 1 cup dry infant rice cereal
2 cups (16 oz) water
¼ teaspoon table salt

Measure salt and dissolve in water. Gradually add cereal to the water until the mixture is as thick as is drinkable. Mix well. Discard after 6 to 8 hours or if it becomes too thick to drink (4).

Intravenous rehydration (in an outpatient or inpatient setting) may be required when oral rehydration attempts have failed or when dehydration is greater than 10% and/

or associated with uncontrollable vomiting, shock, or severe lethargy. The contents of the intravenous solution and the rate of administration are calculated based on percentage dehydration, rate of ongoing losses, and serum electrolyte values.

Chronic Diarrhea

Diarrhea is considered to be chronic if one episode lasts longer than three weeks or if there are multiple episodes with only a few weeks or months between.

Causes

Some of the same factors that cause acute diarrhea may also result in chronic diarrhea. In addition, there are other etiologies of chronic diarrhea. Some of the more common ones include:

- Carbohydrate intolerance (e.g., lactose, fructose)
- Other food/formula intolerances, improper formula preparation, tube-feeding complications
- Chronic nonspecific diarrhea (This is a term used for diarrhea of at least 3 weeks duration, greater than 3 loose stools per day, no evidence of malabsorption or enteric infection.)
- Cystic fibrosis (see Chapter 17)
- Celiac disease (Glutensensitive enteropathy)
- Short bowel syndrome (see Chapter 20)
- Inflammatory bowel disease (Crohn's disease and ulcerative colitis)
- HIV/AIDS and other immune deficiencies
- Constipation/obstipation with encopresis
- Pseudomembranous colitis (Most often related to antibiotic use)
- Micronutrient deficiency (e.g., zinc deficiency can be both a cause and a complication of chronic diarrhea (8)

Nutritional Complications

Compromise of nutritional status is much more likely to occur with chronic diarrhea than with acute diarrhea. Malnutrition can result both from chronic loss of nutrients and fluid through the gastrointestinal tract and from overzealous attempts at dietary eliminations to determine the cause of chronic diarrhea (8). In turn, this malnutrition can lead to additional diarrhea secondary to alteration of mucosal absorptive ability and decreased enzyme activity (8). Children who have chronic diarrhea may have decreased appetites and therefore decreased intakes of nutrients.

Treatment

Treatment of chronic diarrhea depends on the cause of the diarrhea and the results of a total assessment. Malnourished infants with diarrhea present a significant challenge for successful treatment and need energy replacement in addition to rehydration. Energy requirements of infants or children with chronic diarrhea may be as high as 200 kcal/kg/day (2). Enteral feedings may be attempted orally or by slow continuous nasogastric tube feeds. For children who are severely malnourished or who have poor gastrointestinal function for other causes (e.g., short bowel syndrome), parenteral nutrition may be required. Medications may have some role in treating chronic diarrhea. Pancreatic enzyme replacement is required in cystic fibrosis and other pancreatic disorders. Sulfasalazine and corticosteroids may be used in inflammatory bowel disease. If there is a specific protein or carbohydrate intolerance or enzyme deficiency, avoidance of the offending foods is the treatment of choice. Many children affected by chronic diarrheal conditions may require nutrition evaluations and follow-up throughout infancy and childhood. Special formulas and dietary supplements may be needed.

Diarrhea is a very common occurrence in childhood. Frequency of the stools and duration are two variables used to determine what, if any, evaluation is needed. The remainder of this section presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with acute (Table 5-2) and chronic (Table 5-3) diarrhea.

Table 7-2: Nutrition Interventions for Acute Diarrhea

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for height (or length) or BMI • Head circumference (under 3 years) Compare current measurements to available previous measurements. If there are recent weights, this can be helpful in assessing amount of dehydration. Repeat height/length, weight and OFC measurements at every clinic visit.	Adjust recommendations for energy intake based on growth data.	Child maintains growth pattern.
Clinical		
Obtain information about clinical history. Include child's age, other diagnoses (prematurity, congenital disorders, prior surgery), medications, possible exposures through day care attendance, camping, or foreign travel. Food record is helpful to evaluate possible causes of diarrhea. Obtain information about stool history, including duration of illness, stool frequency, consistency, and presence of blood or mucus.	Attempt oral rehydration to prevent need for hospitalization and parenteral fluids. Oral rehydration therapy with a glucose-electrolyte solution is only required if there is dehydration. 50-100 ml/kg of body weight of solution is given over a 4-hour period. Ongoing losses can be estimated at 10 ml/kg for each stool.[5]	Treatment for medical causes of acute diarrhea is identified.
Work with primary care provider or medical consultant. Medical evaluation may include some of the following when indicated: • Physical examination especially assessment of hydration status (see Table 7-1 for clinical description of degrees of dehydration) • If diarrhea is very frequent, prolonged or bloody, tests may be indicated including stool culture for bacteria, tests for rotavirus or parasites, and stool white blood cells. • Blood tests for electrolytes may be done especially if hospitalization is required.	Treatment depends on the cause of diarrhea. Provide medical management and appropriate nutrition intervention for diagnosed diseases/disorders. Generally anti-diarrheal medications are not recommended.	Appropriate medical and dietary recommendations are followed. Physical signs of dehydration should resolve and diarrhea should gradually decrease in severity. If diarrhea does not resolve, further medical testing and management may be indicated.

Assessment	Intervention	Evaluation/Outcome
Dietary		
Obtain a diet history and compare with stool history to determine possible relationships between foods and diarrhea. If further information is needed, request a 3- to 7-day food record and a 3- to 7-day stool record.	Use prepared glucose electrolyte solutions for rehydration if needed. High carbohydrate drinks are inappropriate. Rapid refeeding of usual diet is recommended.	Dietary triggers of diarrhea are identified and eliminated from food pattern. Food pattern provides adequate amounts of energy, protein, and vitamins and minerals.

*See Chapter 2

Table 7-3: Nutrition Interventions for Chronic Diarrhea

Assessment	Intervention	Evaluation/ Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for height (or length) or BMI • Head circumference (under 3 years) Calculate rate of weight gain and linear and OFC growth (It is very important to know if there has been weight loss or slowing of weight gain.) Repeat height/length, weight and OFC measurements at every clinic visit.	Adjust recommendations for energy intake based on growth data.	Child maintains growth pattern.
Clinical		
Obtain information about clinical history. Include child's age, other diagnoses (prematurity, congenital disorders, prior surgery), medications, possible exposures through day care attendance, camping, or foreign travel. Food record is helpful to evaluate possible causes of diarrhea. Obtain information about stool history, including duration of illness, stool frequency, consistency, and presence of blood or mucus. Specific emphasis should be placed on the characteristics of the stool and if there is a family history of gastrointestinal disorders. A careful review of systems must be done to see if other body systems are involved (e.g., respiratory tract symptoms might be the clue that cystic fibrosis is the cause of chronic diarrhea).	Treatment of chronic diarrhea is dependent on the cause. Medical and dietary management is available for many of the disorders that cause chronic diarrhea.	Treatment for medical causes of chronic diarrhea is identified.

Assessment	Intervention	Evaluation/ Outcome
Work with primary care provider or medical consultant. Medical evaluation may include different studies, depending on the clinical situation, diagnosis (if known), and duration and severity of diarrhea: • Stool cultures and studies may be done for infectious causes and fat content • Blood tests may be done for electrolytes, specific micronutrients: vitamin E and B12 (if problems with ileal absorption), total protein, albumin, d-xylose, carotene • Sweat test • Gastrointestinal x-rays and/or sigmoidoscopy or colonoscopy and biopsy Physical examination to include not only assessment of hydration status, but also assessment of nutritional status.	Medication may be indicated in some cases (e.g., pancreatic enzymes in cystic fibrosis, sulfasalazine or corticosteroids in inflammatory bowel disease).	Close, frequent follow-up is indicated to see if appropriate medical recommendations are being followed or are effective in decreasing the amount or frequency of diarrhea.
Dietary		
Obtain a diet history and compare with stool history to determine possible relationships between foods and diarrhea. For example, evaluate whether or not onset of diarrhea coincides with introduction of cow's milk or cow's milk protein formula (cow's milk protein sensitivity, lactase deficiency); cereals or bread (gluten-sensitive enteropathy); foods with table sugar added, (sucrase deficiency). Consider obtaining a 3-7 day food record and a 3-7 day stool record.	If food allergy or intolerance is suspected, try eliminating specific foods that seem to be related to the diarrhea. Caution must be taken that an elimination diet is not so extreme that it leads to inadequate nutrient intake. Provide instruction about special diets when indicated (such as lactose-free diet for lactase deficiency, gluten-free diet for gluten-sensitive enteropathy, low fructose for fructose intolerance, etc.) [6-8] Close, frequent follow-up is indicated to see if appropriate dietary recommendations are being followed or are effective in decreasing the amount or frequency of diarrhea.	Dietary triggers of diarrhea are identified and eliminated from food pattern. Food pattern provides adequate amounts of energy, protein, and vitamins and minerals.

Assessment	Intervention	Evaluation/ Outcome
Evaluate ratio of energy from fat and carbohydrate in the diet (low fat diet may contribute to nonspecific diarrhea)[3,9] Evaluate volume of liquids ingested and amount of fruit juice consumed.[3,9]	For chronic nonspecific, diarrhea consider decreased fruit juice intake and increased fat and fiber intake [9,10]	Food pattern does not contribute to diarrhea.
If child is tube-fed evaluate the type and preparation of formula, rate of feeding, tube position (gastric or small bowel), care of feeding bags and tubes, etc. Consider changing to a formula with added fiber[3,10]	Consider adjustments to tube feeding formula, rate, as indicated.	Tube feeding does not contribute to diarrhea.

*See Chapter 2

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CHAPTER 8

Oral-Motor Feeding Problems

Robin P. Glass, MS, OTR/L and Lynn Wolf, MOT, OTR/L

Children with neurodevelopmental disorders or developmental delays frequently have oral-motor and swallowing problems. These feeding difficulties influence the child's ability to consume a nutritious intake in a variety of ways. The child may have inefficient or abnormal oral-motor patterns, making ingestion slow or labored. Oral-motor difficulties may limit the types of foods the child can eat. In addition, swallowing dysfunction may severely restrict the type of food textures that are safe for the child to eat. Most frequently, swallowing dysfunction affects the child's ability to drink liquids. This may not only compromise the child's overall nutrition but also his hydration status (1). Some factors associated with oral-motor and feeding problems include:

- abnormalities in muscle tone and delays in motor development
- oral-facial defects that interfere with feeding (such as cleft palate)
- delayed oral motor development or abnormal oral motor patterns (e.g., a tonic bite reflex)
- hypersensitive responses to touch and/or temperature in and around the mouth
- dental problems such as severe dental cavities or acquired malalignment of the jaws and teeth
- inability to properly coordinate feeding, swallowing, and breathing due to chronic medical conditions or central nervous system damage
- related medical conditions such as gastroesophageal reflux that may affect willingness to eat
- prolonged length of feeding sessions which tax both the child and the caregiver

If feeding difficulties such as these are observed, a thorough feeding evaluation is indicated. A pediatric occupational, speech, or physical therapist skilled in feeding disorders can perform this type of evaluation.

Complete evaluation of oralmotor and swallowing deficits in children with neurodevelopment disorders involves assessment of a wide range of factors beyond assessment of the level of oral-motor control. These include assessment of:

- basic postural control and level of motor development as it relates to feeding
- tactile sensitivity in the oral area and throughout the body

- the child's ability to achieve and maintain an appropriate behavior and state of alertness for feeding
- the stability of the child's physiologic functions to support feeding (e.g., stability of heart rate or respiratory rate)
- coordination of feeding, swallowing, and breathing
- swallowing function using videoflouroscopic swallowing study (VFSS), if indicated (2)

Difficulties in parent-child interaction may also be associated with oral-motor feeding problems. It is often difficult to differentiate between physical, behavioral, and interactional problems. Thus, it is necessary to consider all three when evaluating a child for oralmotor feeding problems (3).

In addition, related medical problems such as gastroesophageal reflux (GER) may influence the child's feeding ability. If the child associates eating with the pain that often accompanies GER, the child may be resistant to feeding and food intake may decline dramatically. If GER is suspected, further evaluation by the child's primary physician or a gastroenterologist is indicated.

Since most feeding problems have multiple underlying factors that contribute to the overall nutritional and feeding deficits, a team approach is the most effective method to thoroughly assess and intervene with the oral-motor feeding problems. In addition to the occupational, speech, or physical therapist, this team should include a registered dietitian (RD), a pediatrician, or other primary health care provider and the caregivers. The team may often also include a nurse or social worker to address the psychosocial issues that frequently occur concurrently with the feeding problem (see Chapter 9).

Appropriate interventions can significantly improve the child's basic feeding skill as well as improve the ease of feeding for the caregiver. Mealtimes can become more satisfying for the child and family promoting better growth and nutrition. Intervention may include:

- proper positioning during feeding
- specific therapeutic activities to improve basic oral motor skills
- specific food types or textures to support the child's level of oral motor control and swallowing function while ensuring adequate nutrient intake
- adapted feeding utensils
- specialized feeding techniques (4)

If the child is still unable to consume an adequate intake and/or it is unsafe for the child to eat, partial or full nutrition may need to be given via a nasogastric or gastrostomy tube.

Planning and implementation of any feeding interventions should be done in collaboration with the caregivers and the other members of the team. Treatment strategies should be arranged so that they support caregiver priorities, improve nutrition and improve underlying oral-motor and feeding problems.

Table 8-1 describes the developmental sequence of oral-motor and self-feeding skills. Table 8-2 presents guidelines for nutrition assessment, intervention and evaluation/ outcome for children with oral-motor feeding problems.

Table 8-1: Developmental Sequence of Oral-Motor and Self-Feeding Skills

Age	Reflexes	Jaws and Cheeks	Lips	Tongue	Swallowing	Self-Feeding
Term to 1 month	• Palmomental • Rooting • Gag • Phasic bite	• Fat pad present • Primary jaw movement downward during sucking	• Upper lip exerts more pressure than lower in sucking • No lateral lip closure • Lips closed at rest	• Fills oral cavity • Provides compression and suction during sucking	• Suck-swallow sequence 1:1 at start of feed; 2-3:1 toward end of feed • Air swallow common	• Hand-to-mouth activity
1-2 months	See above	• Fat pad thinning	• Lateral borders close on nipple			• Expects feeding at regular intervals
3-4 months	• Palmomental and phasic bite disappearing	• Buccal cavity begins to develop	• Smacks lips • Protrudes lips to surround nipple	• Tongue protrudes in anticipation of feeding or if nipple touches lip • Ejects food voluntarily	• Visual recognition of nipple • Pats bottle or breast • Can voluntarily inhibit suck to look or listen	
5-6 months	• Rooting begins to diminish • Gag elicited farther back in mouth	• Buccal cavity developed • Up and down munching and biting • Inner cheeks draw inward during eating • Positions mouth for spoon	• Draws in lower lip when spoon removed • Upper lip active in cleaning food from spoon • Purses lips at corners	• Tongue moves in up and down manner with pureed foods; no lateralization • Tongue still in anticipation of food • Tongue protrudes before swallow	• Choking rare on breast or bottle • One sip at a time from a cup • No gagging on pureed food	• Begins finger feeding • Plays with spoon

Age	Reflexes	Jaws and Cheeks	Lips	Tongue	Swallowing	Self-Feeding
7-8 months	• Mature gag	• Munching continues • Jaw closes on solid then sucks it • Jaw held closed while a piece of soft solid is broken off	• Blows "raspberries" • Upper lip moves downward and forward to actively clean spoon	• Tongue begins lateral shift when food is at side of mouth	• Does not gag on ground foods or soft semisolids	• Feeds self cracker • May hold bottle
9 months		• Munches with diagonal movements as food is transferred from center to sides • Voluntary biting on food and objects	• Lips active with jaw during chewing • Briefly closes lips on cup rim	• Lateral movements to transfer food from center to sides of mouth	• Drinking from cup • Takes 1-3 sucks before stopping to swallow and breathe	• More precise finger feeding • Reaches for spoon, may insert crudely in mouth
12 months		• Controlled, sustained bite on soft cookie • Begins rotary chewing movements	• Lips closed during swallow with no food or liquid loss • Lower lip is drawn inward to be cleaned by upper gums	• Lateralizes from center to sides • Licks food from lower lip • Intermittent tongue tip elevation	• Taking increased amount of liquids from cup • Takes 4-5 continuous swallows • Swallows ground, mashed or chopped table foods without gagging	• Finger feeds ependently • Holds and lifts cup but has spillage • Brings spoon to mouth but inverts spoon before mouth • Fills spoon poorly

Adapted from Glass, RP and Wolf, LS. *Approaches and Strategies for the Occupational Therapist in Early Intervention*, p. 132.

Table 8-2: Nutrition Interventions for Oral-Motor Feeding Problems

Assessment	Intervention	Evaluation/Outcome
Inability to ingest age appropriate food textures and liquids Inability to take age-appropriate amount of food/ liquids for adequate growth in a reasonable length of time (see Chapter 1) Presence of abnormal oral motor patterns (See Table 8-1 Developmental Sequence of Oral-Motor and Self-Feeding Skills)	If observed, refer to a pediatric occupational, physical and/or speech therapist for further evaluation and intervention	The feeding therapist evaluates feeding skills and develops an intervention plan. Improvements may be observed in basic oral-motor skills, volume of food ingested, decreased feeding times and/or safer feeding.
Observe swallowing function: coughing, choking, wet sounding breathing during feeding, difficulty catching breath during feeding; frequent respiratory infections	If observed, refer for a clinical feeding evaluation and possible videofluoroscopic swallowing study (VFSS).	Diet modifications to increase safety or ease of feeding may be made based on results of these interventions. If oral feeding is unsafe, tube feeding may be necessary. See Chapter 10.
Observe sensory responses: gagging with food or feeding tools; resistance to touch around face and mouth; excessive selectivity of food tastes/ textures.	If observed, refer to occupational, physical or speech therapist for an in depth sensory and sensory integration assessment.	Improvements noted in acceptance of age-appropriate food textures, an increase in volume and more timely food ingestion
Feeding resistance or refusal is observed. Differentiate underlying cause; consider medical (GER, swallowing or respiratory problem) versus parent/child interaction versus sensory issues.	Interactional: see chapter 9 Medical: Refer to PCP or specialist such as gastroenterologist Sensory: Refer to feeding specialist	Greater ease of feeding for parent and child.
Observe Parent /Child dynamics: this includes behavioral interactions; parent expectations, and emotional tone of meals; mealtime structure.	If problems are noted with either parent/child interaction or feeding behaviors, see Chapter 9. Referral to a behavior specialist may be indicated.	Improvements in parent/child interactions and feeding behaviors.

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CHAPTER 9

Behavior Issues Related to Feeding

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Updated by Kelly Johnson, PhD

Behavior challenges can be a significant factor in oral feeding dysfunction. Sometimes these challenges are obvious, such as when a child turns away, refuses to eat, or has tantrums at mealtime. At other times the behavioral concerns are much more subtle, as when gagging and arching accompany reflux in an infant. It is best to address maladaptive behaviors as they are just beginning to develop.

Even when food refusal is well entrenched, a behavioral plan can help children achieve their feeding goals. When behavioral concerns significantly impede progression towards feeding goals, they should be addressed carefully and accurately. A generalized approach can do more harm by inadvertently strengthening the very behaviors targeted for decrease.

This chapter will discuss the importance of incorporating a technically accurate behavioral approach in the treatment of feeding dysfunction. Understanding the role of aversive conditioning and environmental variables will help to avoid common mistakes and allow appropriate referrals. Examples will be given of ways to restructure the adult-child interaction to decrease the challenging behaviors of food refusal and resistance to therapeutic activities. Methods to increase the replacement behaviors of food acceptance and participation in therapeutic activities will also be reviewed. Appropriate analysis and sample treatment protocols will be considered which should enable individuals to roughly evaluate the quality of behavioral services as they are provided (1).

The Role of a Behavior Analyst

The role of a behavior analyst in the treatment of feeding dysfunction, as well as other behavioral challenges, is to analyze the functions or goals of challenging behaviors and develop interventions based on these analyses. This process is referred to as functional assessment, and is the standard of care in the field of applied behavior analysis.

Some areas of concern in the realm of feeding include:

- Understanding what the child is trying to achieve with the challenging behavior
- Understanding how difficult behaviors are developed in the first place
- Understanding how the current situation is maintaining those behaviors
- Developing strategies to prevent the development of food refusal behaviors
- Implementing effective and technically accurate interventions that change the current structure to reinforce desired behaviors and eliminate the reinforcement that is currently in place for the behaviors to be decreased
- Developing behaviorally sound instructional goals and strategies for replacement behaviors that will facilitate progression of oral-motor skills, food acceptance, and other therapy goals

How Food Refusal Behaviors Develop

Understanding the variables involved in the development and maintenance of difficult behaviors always precedes developing an effective intervention. Behaviorists, social workers, or counselors are often consulted on a feeding team when a child actively, vocally, and consistently refuses food. Tantrums and aggression may accompany this behavior. While this is an excellent situation for utilizing the skills of a behaviorist, it is very late in the development of the behavioral sequence. By understanding how food refusal develops, other professionals can make a referral earlier in the aversive conditioning phase, preferably before the behavior has a chance to develop at all.

Classical Conditioning

Behaviors can be developed (learned) by what occurs before or during the behavior. This is called classical conditioning (2). Classical conditioning occurs when a neutral stimulus is paired with another stimulus. In feeding, such conditioning occurs when food presented to the mouth is paired with pain or satiation. The neutral stimulus becomes a discriminative stimulus that a punisher or reinforcer will occur. For example, a nipple in the mouth becomes a signal or warning that pain or satiation is about to occur.

Operant Conditioning

Behaviors can also be conditioned by what occurs *after* the behavior. This is called operant conditioning. Operant conditioning occurs when a behavior (eg, sucking) is followed by a response (eg, pain/satiation) that punishes or reinforces the behavior (3). A behavior results in a predictable response that reinforces or punishes the occurrence of that behavior. For example, sucking results predictably in pain/satiation that increases or decreases sucking in the future. A behavior has been reinforced if

it occurs with greater frequency in the future. It has been punished if it occurs with decreased frequency in the future. Even a response which appears to be pleasant (offering a bottle) can be a punisher if it causes a response (pain) that decreases the behavior in the future.

In feeding, aversive conditioning occurs when the child associates a negative or painful event with a neutral feeding stimulus. This aversive conditioning can be triggered by medical, physical, sensory or environmental stimuli. For example whenever the nipple is presented, pain is experienced concurrently (operant). The nipple comes to represent pain, although reflux, not the nipple, causes the pain. In time, this conditioned response results in avoidance behavior such as arching to refuse the nipple. Refusing the nipple does not reduce the pain, but arching does (classical). This scenario describes a combination of classical and operant conditioning.

Case: Aversive conditioning developed as a result of medical/physical concerns

Jonathan was a young infant who had reflux and arched in pain, pulling away from the nipple repeatedly throughout feedings. Eventually he ate very small quantities and then fell asleep. In this scenario, the child experienced pain regularly during feeding and began to associate the two. Ultimately, feeding was equated with pain in his mind and he chose to avoid it altogether. The association could be diagrammed as follows:

Classical Conditioning: feeding = pain → pull away

Operant Conditioning: pull away (food refusal) → pain reduction (escape)

That pain occurred concurrently with the feeding is an example of classical conditioning. Operant conditioning occurred when the behavior (food refusal) was followed by a reinforcing event (pain reduction) that increased the likelihood that behavior would occur again in the future. Both classical and operant conditioning occurred, as is usually the case.

Results of Non-Treatment

In the example above, the situation was treated as a medical concern only. This is typical when reflux is the only presenting concern, because many children with no other complicating factors outgrow reflux with time. By using medication to reduce the reflux episodes, only the classical conditioning had an opportunity to be reduced.

The operant conditioning was still in place. When food refusal was well established and the child was formally diagnosed with failure to thrive, he was referred to a feeding team with a behaviorist. At this point a long and arduous process of systematic desensitization, reinforcement, escape extinction, and careful pain management was needed to progress his oral feeding.

Case: Aversive conditioning as a result of sensory and motor concerns

Charlotte was a young child with sensory, physical, and environmental factors that conditioned her to avoid eating. Charlotte came from a poor socio-economic background. She was never evaluated for developmental concerns. Because she was significantly underweight, she was referred for a behavioral feeding evaluation. The physician saw no need for a developmental or sensory evaluation because there were many foods that "she ate when she felt like it."

A comprehensive evaluation was conducted according to the policy of the feeding team. During the evaluation, Charlotte initially refused to eat. She turned her head and tried to get out of her chair. Her mother talked to her, gently encouraging her to eat and trying to play games to amuse and distract her during the feeding trial. She eventually ate several very large bites of soft foods, and then began to refuse all food again. She avoided hard and crunchy foods and smooth foods, like whipped cream and ranch dressing. She sat very straight in her chair and her fingers splayed when smooth foods were introduced. She didn't chew very effectively and "pocketed" foods in her cheeks. Several very subtle gags were noted, as was a hypoactive gag response during an inter-oral examination.

Observation during play suggested poor quality of movement. A sensory history was taken and a developmental observation was completed which revealed significant sensory processing difficulties, inability to move in flexion, and poor oral motor skills. A diagram of Charlotte's feeding behaviors includes:

food textures = discomfort

swallowing = gag/panic

eating = gag/panic/discomfort

refusal behaviors=attention/toys/escape

For Charlotte, as with many children, there were sensory and physical reasons for her food refusal. At the same time, her caregivers had adapted to her behavior in a way that provided for environmental reinforcement for her food refusal. Once again,

both classical and operant conditioning were well established by the time the referral was received. The next section will explore how Charlotte's environment served to strengthen her refusal behaviors, although it did not cause them.

Environmental Reinforcement

While there are often physical, medical, or sensory causes for a child's initial food selectivity and refusal, what happens in the environment as a result of that food refusal is equally important. There are four environmental variables that tend to maintain both positive and negative behaviors (1). By observing what happens immediately before and after food refusal and food acceptance, we can begin to get an idea of how these variables might be influencing behavior.

1. Attention as a reinforcer for food refusal

Although Charlotte had developmental and sensory reasons for avoiding food, other variables were operating. Charlotte received more attention for food refusal than for food acceptance. In the research literature, attention has been proven to be a powerful reinforcer of both desirable and undesirable behaviors across many settings and populations. Attention, for these purposes, is defined as eye contact, touch, speech, or increased proximity. When Charlotte was being fed by her mother, the following pattern occurred repeatedly:

- Mom puts the food on Charlotte's tray (neutral)
- Charlotte turns her head (food refusal)
- Mom holds up the spoon and says, "Take a bite honey" (attention: eyes, speech)
- Charlotte turns her head (food refusal)
- Mom leans forward (attention: increased proximity)
- Mom looks, turns Charlotte's chin back (attention: touch)
- Mom looks Charlotte in the eye (attention: eye contact)
- Mom says, "Take a bite honey" (attention: speech)
- This pattern is repeated several times (attention for food refusal)
- Charlotte takes a bite (food acceptance)
- Mom turns from Charlotte to reload the spoon (removal of attention)

Charlotte's story is very common. The unintended misuse of attention contributes to the maintenance of many feeding difficulties. Attempts at encouraging, coaxing and reminding can all result in behavior that is maintained by high levels of attention. Once the child takes a bite, parents tend to give themselves and the child a "break," thereby reducing attention for the very behavior they would like to see increased.

Parents and professionals routinely and inadvertently reward non-compliance and food refusal with attention, and punish compliance and food acceptance through the withdrawal of attention (1).

2. Escape: the avoidance of a non-preferred task

Almost all children treated for feeding dysfunction have already developed refusal behaviors. Avoiding something unpleasant is a powerful reinforcer. In many situations, this escape, also called negative reinforcement, will maintain the avoidance behavior regardless of how well contingent attention is utilized (3,4). (Negative reinforcement is defined as increasing a behavior by removing something aversive, contingent upon the occurrence of the behavior.) An illustration follows:

- Sarah turns her head when a spoonful of food is presented (food refusal)
- Mom removes the spoon, and removes a little of the food (escape)
- Sarah looks at mom again (pre-skill for feeding)
- Mom presents the spoon (punishment for looking at mom)
- Sarah turns her head again (food refusal)
- Mom coaxes Sarah (attention for food refusal)
- Mom takes Sarah's chin and forces the food into her mouth (aversive conditioning)
- Sarah swallows the bite (food acceptance)
- Mom presents another bite (punishment for food acceptance)

It is difficult to avoid reinforcing food refusal with escape. Force-feeding merely increases the aversive conditioning. Allowing the child to avoid the food gives the child escape, thereby reinforcing food refusal. When we tell a child, "You may leave time-out when you are quiet," we are using negative reinforcement (escape from time-out) contingent upon the occurrence of the target behavior (quiet behavior) (3).

3. Tangible reinforcement of food refusal: providing an item or activity when the child engages in avoidance of a non-preferred feeding task (1)

During feeding, this type of reinforcement usually occurs in combination with escape or attention. When a child refuses to eat, the parent allows her to leave the feeding setting and then provides a comfort toy or a comfort food. For Ben, the tangible reinforcer was a cloth diaper that he used as a security blanket. He had severe reflux as an infant and the cloth diaper was used to clean his mouth. Every time the reflux ended, the diaper was presented. He began to act as though the diaper caused the reflux to end. During a reflux episode, he would reach for the diaper. Later, he received a g-tube and a fundoplication. During any stress, including the presentation of food, Ben reached for the diaper and covered his mouth with it. This diaper itself

was a positive tangible reinforcer, and it also allowed him to escape the food, thereby operating as a negative reinforcer. For many children, the tangible reinforcer is the bottle. This is offered whenever they refuse other foods, because the parents are rightly concerned about providing adequate nutrition.

4. Internal events as reinforcers of food refusal: Unobservable events, not occurring in the external environment, which occur immediately following a feeding behavior.

The most common example of internal reinforcement in feeding dysfunction is a self-injurious behavior such as self-induced vomiting. If a child is experiencing significant gastrointestinal pain, self-induced vomiting often results in comfort. Such behaviors occur with equal frequency whether or not there are other possible reinforcers available. The "litmus test" for an internal reinforcer is its occurrence when the child is alone and the behavior causes no change in the external environment, ie, no one comes or even notices that the behavior has occurred. Another hallmark is its resistance to change based on any behavioral interventions (1). A painful or unpleasant internal event can be overlooked or misinterpreted because of the child's response.

Case: Self-injurious behavior

> Nina had spina bifida and banged her head every time she was put into the highchair to eat. She also refused most foods. To make the headbanging stop, her parents removed her from the highchair and removed the food. This would appear to be a classic example of escape as the function of the head-banging behavior. She also banged her head randomly throughout the day and sometimes at night. She headbanged when she was angry or frustrated as well. Several different behavioral plans were put in place to address the different functions of her behavior. They successfully eliminated most of her headbanging except that which occurred in the highchair. Ultimately it was discovered that her shunt needed to be replaced and that her position in the highchair increased the pain caused by the intercranial pressure of the mal-functioning shunt. After the shunt surgery, headbanging in the highchair only occurred when she was finished eating or was presented with a non-preferred food.

The example above highlights the need for an interdisciplinary approach to treating behavioral issues. The medical concerns of children with special needs are too easily misinterpreted. A summary of the most typical reinforcers for food refusal and their indications is included in Table 7-1.

Collecting Data for a Functional Assessment

A functional assessment is a data-driven approach that is based on the response of the child to variables in the environment. These variables include, but are not limited to attention, escape, tangible items, environmental structures, timing and pacing, individuals present, and internal events such as pain or reflux. It is a methodical approach that identifies what the child is trying to achieve through the behavior, and builds an intervention around that information. Data is collected in an ongoing manner to carefully chart progress, and adjustments are made based on the data collected. Strategies are individualized to the needs and abilities of the family while remaining technically accurate. This approach presupposes that the primary caregivers are both able and willing to follow through with recommendations. It is a goal-oriented, time-limited, and cost-effective approach for the right population (5).

Taking a comprehensive history and conducting a complete and thorough developmental and sensory evaluation are essential components of a functional assessment for feeding dysfunction. It is important to listen carefully to parents as they describe what mealtimes look like and how they differ from each other and from mealtimes in the past. It is also necessary to observe one or more feedings to gather data on the observed behaviors and interactions. This is called a structured observation. During these observations, which are typically videotaped, a team often utilizes a simple ABC chart to collect information on the function of the target behavior (6,7). A sample chart is provided as Table 9-2. The "A" stands for antecedent and refers to what occurred immediately before the target behavior. The "B" stands for the behavior, carefully and objectively defined. The "C" stands for consequence and refers to what occurred immediately after the target behavior. Using Charlotte as an example, behavior can be charted as follows:

Antecedent	Behavior	Consequence
Mom puts the food on Charlotte's tray	Charlotte turns her head (food refusal)	Mom holds up the spoon and says, "Take a bite, honey" (attention)
Mom presents spoon	Charlotte turns her head (food refusal)	Mom leans forward and turns Charlotte's chin, looks her in the eye and says, "Take a bite, honey." (attention)
Mom points to some food on the tray and says, "Yummy!"	Charlotte turns her head (food refusal)	Mom leans forward, turns Charlotte's chin, looks her in the eye, and says, "Come on, you can do it! It's easy!" (attention)
This pattern repeats itself with minor variations about 6 times.		
Mom points to the food	Charlotte takes a bite (food acceptance)	Mom turns from Charlotte to reload spoon (removal of attention)

The likely function of the behavior becomes clear when an ABC chart is used. At this point we have a strong hypothesis that attention is one of the reinforcing variables. The fact that Mom did not remove the spoon suggests that escape may not be the primary function of the behavior. However, when Charlotte turned her head, she did in fact avoid taking a bite. The hypothesis of escape as one of the functions of her refusal behavior is supported by her medical and developmental history. There was reported information that indicated sensory and motor problems that have the potential to make feeding unpleasant. That which is unpleasant is often avoided. Her behavior resulted in both escape and attention. On a practical level, we must operate as though both reinforcers are helping to maintain the behavior and our intervention would address both escape and attention (1).

Since several reinforcers may be operating, an appropriate intervention will address all functions suggested by the data. For example, an intervention for Charlotte would need to include components from the protocols for internal events, attention, and escape. Below are several examples of interventions based on the hypothesized function of the food refusal. Because escape is a likely function in almost all feeding dysfunction, the most complete sample intervention is included under its heading.

Developing Intervention Plans

Intervention plans are developed with data gathered during the functional assessment process. The interventions are based on teaching and reinforcing replacement behaviors so that, theoretically, the child drops the old behavior because it no longer works as efficiently and effectively as the replacement behavior (1). Steps 1-4 below are included in all interventions.

1. Baseline data must be collected to identify the tasks and the duration of trials that a child can tolerate without becoming distressed. Task analysis is then used to break the goal behavior down into many smaller steps, called sub-skills. Individual intervention is begun at a subskill that is easy for the child and unlikely to trigger severe escape behaviors.

2. Seating, positioning, food selection, oral-motor skill development, medication, and other components specific to the child must be addressed to reduce the aversive (punishing) elements of the mealtime setting.

3. An assessment must be conducted to identify highly preferred reinforcers (8). When reinforcers are varied and rotated randomly, their effectiveness is enhanced. Identified reinforcers, on a random rotation basis, are used to reward behaviors already in the child's repertoire. This builds behavioral momentum

and helps maintain the child's interest in the process. Only after reinforcing easy behaviors, does work begin on the targeted behaviors. Sometimes the only behavior the child can exhibit without displaying distress is to look at the food or to touch a small piece of food. This is then referred to as a previously mastered behavior. The next subskill that the child needs to master is referred to as the targeted behavior.

4. The next step is to elicit the targeted behavior from the child through modeling and a least-to-most prompting paradigm. This entails giving the least amount of assistance required to gain the targeted response. Demonstrating, tapping the item, touching the child's elbow, guiding the child's hand, or using hand-over-hand modeling are all different levels of prompting. The therapist must be careful not to provide attention or a delay in the completion of the behavior, otherwise, she risks reinforcing avoidance through escape or contingent attention.

Examples of interventions for specific behavior challenges are described below.

Internal Events: avoiding the development of food refusal when pain or discomfort accompanies feeding.

In the first example, baby Jonathan refused food because of pain triggers. Without behavioral intervention, attention or escape may end up maintaining or strengthening this behavior even if the medical conditions causing the pain are resolved. Rather than waiting for entrenched food refusal to develop, treatment could have been started at the first refusal of food during a feeding, the first episode of pulling away. With careful data collection and analysis of the data, a behaviorist would have determined the antecedents, cues, frequency, latency and duration of pain episodes. Steps would have been taken to identify medications, positions, times, settings, and duration of feeds that decreased the frequency of pain episodes.

The feeding could have been structured to maximize the likelihood that pain would have occurred primarily when the child was off the nipple. When a pain episode did occur during a feeding, pain management strategies could have been implemented that did not include escape from the nipple. Examples of pain management strategies include changes in positioning, in the rate of flow from the nipple, and movement during feeding. Increasing the social and sensory reinforcers available during a feeding would have helped to maintain the nippling behavior. In combination, these strategies often reduce or eliminate the development of food refusal behaviors while the reflux is treated or the child outgrows it.

Tangible Maintained Behavior: changing the timing.

Ben was given a clean cloth diaper as a comfort item after each episode of reflux or other anxiety. His mother was taught to make the cloth available additionally as a reinforcer for allowing touch to his mouth and oral stimulation activities. In this way the reinforcing properties of the cloth were transferred to other therapeutic activities. Ben learned to tolerate many of the subskills he would need to progress to oral feeding in the future when his medical condition was resolved. We avoided allowing him to develop an escape response to touch to his mouth (1).

Attention-Maintained Behavior: providing attention for food approach and ignoring food refusal.

For Charlotte, attention was more pleasant than food. Refusing food had become a powerful way to gain attention. One appropriate response to this difficulty is to use contingent attention accurately. Contingent attention is powerful. It involves paying attention to the behaviors targeted for increase, and ignoring the behaviors targeted for decrease (1).

In Charlotte's situation, the therapist or parent would be directed to avert their eyes and stop talking until Charlotte displayed some type of approach response to food. This response might be defined initially as looking at the food or touching the food. Her most preferred foods would be used at first to make this approach response an easy one. Enthusiastic and specific praise would occur immediately upon the occurrence of the behavior. "Charlotte! You touched the bread! Good for you!" The therapist (or parent) would continue to talk to her and would touch her (if she found touch pleasant) as long as she continued to interact with the food. Over time, the required response would change based on the task analysis of the target behavior. Attention would be delivered only when she picked up the food, smelled it, licked it, or held it in her mouth. These types of carefully graduated changes are called shaping techniques. Eventually, only swallowing would be reinforced (3).

Modeling would be utilized to prompt each new targeted behavior. Hand-over-hand prompting or some lesser degree of prompting would be utilized if Charlotte did not exhibit the targeted behavior independently. Such prompting would be appropriate only if it was determined that the target behavior was an appropriately small change and that prompting it was unlikely to trigger significant anxiety. Adding a tangible reinforcer to the contingency, such as access to a preferred toy for brief intervals, can strengthen the effects of contingent attention (3).

Understanding contingent attention is simple. Using it correctly, however, is more difficult than it first appears. It goes against the typical parenting response, which is to instruct, explain, remind, and encourage. Few parents or professionals are able to master the subtleties of delivering contingent attention accurately without hands-on training.

Escape-Maintained Behavior: quantifying the task, breaking the task down into manageable steps, building behavioral momentum, reinforcing with escape, adding attention and/or tangible reinforcers, extinguishing escape.

Escape must be extinguished. This entails ensuring that avoidance behaviors do not result in a delay or removal of the task demand. If touch to the lips is the targeted behavior, the therapist's finger must remain on or near the lips even during head turning. If a bite of food is presented, it is not removed until a bite is taken. This is only possible when the target behavior is a very small step up from a previously mastered behavior. The child should find that compliance with the task demand is easier than waiting, and that the reinforcer is powerful enough to override the conditioned aversion.

Using escape extinction in isolation can trigger intense anxiety and a fight or flight response on the part of the child. Escape extinction should only be implemented within the context of a complete intervention package which includes a functional assessment, task analysis, targeted replacement behavior, an intense reinforcement plan and behavioral momentum paradigm (9).

Since escape is a likely reinforcer for many children who engage in food refusal, it is important to demonstrate to the child in a concrete way, exactly what is required to gain escape. This is called quantifying the task. If the child is cooperative, therapists tend to try to get "just a little more" progress. This punishes the child for cooperating. A more effective approach is to make the goal very small and attainable, and then indicate to the child how long, or how often she must exhibit the behavior to gain escape. Singing a phrase from a song while providing oral stimulation indicates that the task is over when the song phrase is over. Stopping at the end of the song builds confidence in the child that escape can be attained through cooperation fairly easily. Using a timer, singing, and counting are all methods of quantifying the duration of a single task. Always stopping a trial at the expected interval builds predictability and therefore, cooperation in the child.

If the goal is to have the child touch a food item, the therapist can have a plate clearly visible to the child, with a small number of pieces of food. The food item is removed as soon as the child touches it.

Reinforcement is most powerful when it is delivered instantly. If escape is provided quickly when the child exhibits the targeted behavior, the behavior following the target behavior (which may be an avoidance response such as crying, head turning, or gagging) is not reinforced.

As a general rule, reinforcement should be five times more powerful than the targeted behavior. Implementing this can be somewhat subjective. The reinforcer can be made to last five times longer, or it can be delivered with a great deal of enthusiasm, or the quality of the reinforcer can be increased. However, a child should not struggle for three minutes to swallow a new taste or texture and then be given only a five second interval of reinforcement in the form of social praise.

Once the child exhibits the first targeted behavior without hesitation, on eight out of ten trials, for three consecutive sessions, it is time to change the targeted behavior. A trial may last only seconds or the entire length of a session. A session may last from 3 to 30 minutes depending on the targeted behavior. Perhaps the first targeted behavior was to accept touch from the therapist's finger to the lips for five seconds. The second targeted behavior may be to increase the duration of the touch, or it may be to move the touch from the lips to the teeth, or it may be to have the child accept the same touch from the parent (1).

The protocol above is a simplified explanation of what an effective intervention might look like. Developing such a program should be done with the collaboration of a behaviorist experienced in treating feeding dysfunction. A quick behavior plan checklist is included in Table 7-3 to help evaluate whether or not the most obvious needs are included in an intervention plan.

It is important to note that, for some families, carefully designed intervention strategies and adequate training in their implementation are not sufficient. Sometimes there are significant family dynamic issues that prevent the parent from having the ability or motivation to follow through with recommendations. Other times, a parent is motivated to maintain the current situation for reasons outside the feeding arena. In these situations there are usually multiple difficult behaviors present in the environment and multiple providers frustrated with an inability to make progress in any area of concern. With these circumstances, we have found it most effective to refer the family to a counselor or a social worker with a family therapy approach to deal with other underlying issues. Most family counselors and social workers utilize a family systems or cognitive-behavioral approach which is different from the applied behavior analysis and functional assessment approach. Once the family is more stable, a highly focused behavior approach can be used to address the specific behaviors causing feeding dysfunction. A skilled pediatric psychologist with expertise in feeding may be able to provide intervention that

addresses both dysfunctional family dynamics as well as implement a behavioral feeding intervention. If nutritional status, failure-to-thrive, or other medical issues are significantly problematic, inpatient treatment for the child may be indicated. While feeding may initially be handled by an inter-disciplinary team of hospital clinicians, the primary caregiver should ultimately receive direct practice in utilizing new feeding patterns with the child prior to discharge (10).

Table 9-1: Typical Reinforcers for Eating or Food Refusal

Example	Most likely to occur when…	Least likely to occur when…
Reinforcer: Tangible		
• getting a kiss • getting a new toy • distraction • changing of activities • bandaid • food/drink • comfort item	• this is the most effective way to ensure that the tangible item will be provided • the tangible item has been provided in the past for this behavior • the tangible item is not readily available • something in the environment leads the child to believe that the item is about to become less readily available	• the tangible item is readily available • the item has never been provided after this behavior • there is an easier and equally reliable way to gain access to the item
Reinforcer: Internal – Generally, no pattern to occurrence or the pattern is relative to sleep or medication schedule.		
• facial grimace • muscle contraction/ extension • random self-injurious behavior • behaviors designed to access deep pressure (in the form of physical assistance or restraining)	• child is alone and no one is likely to respond • no pattern to occurrence • in the midst of a preferred, low demand, high attention activity • high level of sensory input • low level of sensory input	

Example	Most likely to occur when…	Least likely to occur when…
Reinforcer: Attention		
(Adult's Behavior) • encouraging • looking at the child • talking to the child • explaining • approaching • touching • taking to time-out • helping • wiping nose or eyes • repeating • asking • scolding	• attention is diverted from child • adult is occupied with a task • attention was briefly removed • a more high quality attention can be gained • another individual enters who has diverted attention in the past • some change occurs in the environment which signals the child that attention is about to be diverted • it has resulted in attention in the past	• child is receiving one-on-one attention • the environment is free of anything that might lead the child to believe that the attention might be interrupted • high quality attention is as reliably, easily, and quickly available through some other low-effort behavior and the child has used it often in the past
Reinforcer: Escape		
(Child's Behavior) • ignoring • not doing the task • screaming • being sent to time-out • turning away • being passive • doing it poorly • self-injury • aggression • charming behavior • asking questions • changing positions • going to the bathroom • vomiting	• a non-preferred activity is occurring • a task is presented • a request is made • something in the environment leads the child to believe a task or request will be presented • the environment is unpleasant to the child (sensory overload) • a non-preferred activity has occurred in the setting in the past • the behavior has resulted in escape in the past	• the child is engaged in an activity of his own choosing • the environment is free of anything that might lead the child to believe that a request will be made or a non-preferred activity might occur • there is an alternative way to avoid or escape the setting, activity, or task that is just as reliable, quick, and easy…and the child has used it effectively in the past

Table 9-2: ABC Worksheet

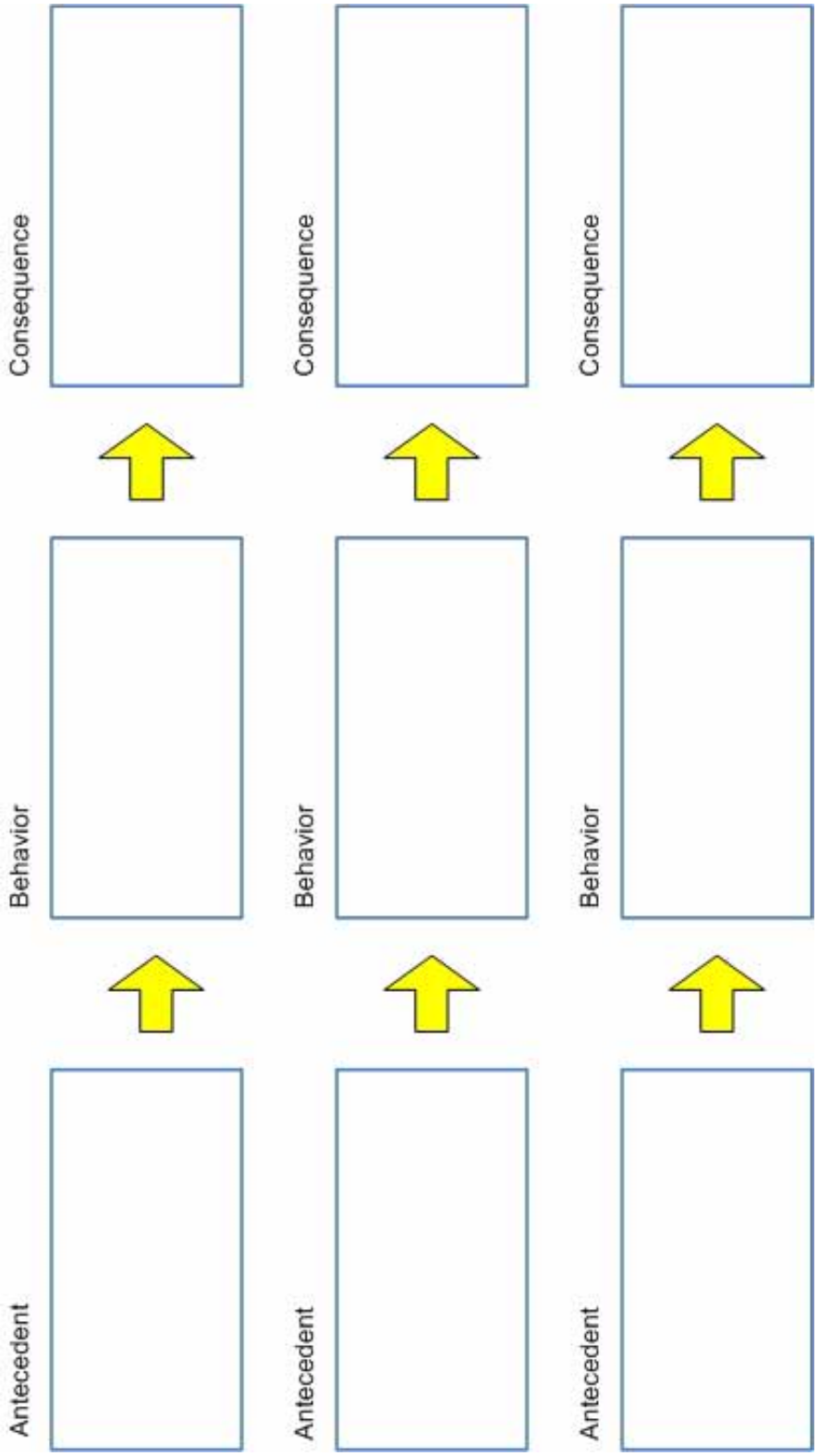

Table 9-3: Quick Behavior Intervention Plan Checklist for Feeding Dysfunction

- [ ] Have you defined the target behavior and the behavior you would rather see instead?
- [ ] Have you considered how often, when, where, and with whom the behavior does/doesn't occur most frequently?
- [ ] Have you considered medical complications?
- [ ] Have you attempted to reduce or eliminate the punishing aspects of the feeding as much as possible through changes in position, medication, mealtime, volume, taste, texture, and timing of tubed boluses?
- [ ] Do you have a hypothesis about the goal of the behavior? Does your intervention match all of your hypotheses?
- [ ] Do you plan to teach and reinforce the replacement behavior with developmentally appropriate strategies, which may include prompting, modeling, mirroring, and/or representational play?
- [ ] Do you know what the child really likes and is willing to work for?
- [ ] Is the reinforcement plan appropriate? (intensity, duration etc.)
- [ ] Are your reinforcers novel and powerful enough to compete with the reinforcer(s) currently maintaining the misbehavior?
- [ ] Does the child know how long the task will take?
- [ ] Does the child know how many times s/he will have to repeat the task?
- [ ] Do you avoid punishing good behavior through an increase in demands?
- [ ] Do you wait 15 seconds for compliance?
- [ ] Can you change the environment to reduce opportunities for misbehavior?
- [ ] Are you providing choices, structure and routine to give the child appropriate opportunities to exercise control?
- [ ] Have you faded your supports and prompts gradually to ensure success?

- ☐ Does this child have the necessary subskills?
- ☐ Are you reinforcing easy tasks to build momentum during each session, before moving to the target task?
- ☐ Are you moving through the subskills slowly enough to ensure success and compliance?
- ☐ Are you careful not to inadvertently ignore appropriate behavior?
- ☐ Are you careful not to talk or make eye contact during misbehavior?
- ☐ Are you careful not to repeat instructions when you get no response?
- ☐ Are you careful to ignore misbehavior without allowing escape?
- ☐ Do you know this child's escalation pattern?
- ☐ Do you intervene early in the escalation cycle by reinforcing previous subskills to rebuild momentum?
- ☐ Do you give enough time/space for de-escalation between trials?

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Resources

The Association for Applied Behavior Analysis International (ABAI), 550 W. Centre Ave., Portage, MI 49024-5364; Phone: (269)492-9310, FAX (269)492-9316; email: mail@abainternational.org; http://www.abainternational.org

The Association for Applied Behavior Analysis International can provide a list of colleges and universities that have strong behavioral programs as well as information on locating a behaviorist in specific areas. The Association of Professional Behavior Analysts is another potential resource, http://www.apbahome.net. As with any profession, the quality of services provided by those performing behavior analysis, certified or uncertified, varies greatly.

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CHAPTER 10

Enteral Feeding (Tube Feeding)

Annette Pederson, MS, RD, CD

Enteral tube feeding is used for infants and children who have a functioning gastrointestinal tract but are unable to meet their nutrition needs orally. Conditions that may require enteral feeding are numerous:

- Gastrointestinal disorders, such as disorders of absorption, digestion, utilization, secretion, and storage of nutrients; and including anatomic disruptions such as tracheoesophageal fistula
- Inability to meet nutrition needs orally or safely by mouth, including neuromuscular disorders, such as muscular dystrophy, spinal cord defects, and cerebral palsy or damage to the central nervous system that can cause oral-motor problems
- Increased energy/nutrition needs due to cardiopulmonary disorders and other conditions, such as cystic fibrosis, burns, cancer, prematurity, chronic lung disease, catch up growth, and failure to thrive

Enteral feeding can play a role in both short-term rehabilitation and long-term nutrition management. The extent of its use ranges from supportive therapy, in which the tube delivers a portion of the needed nutrients, to primary therapy, in which the tube delivers all the necessary nutrients. Most children who receive tube feedings can continue to receive oral feedings to fulfill the pleasurable and social aspects of eating. All infants and young children require oral-motor stimulation for developmental reasons.

Tube feeding benefits the child by improving growth and nutritional status and frequently improves the primary condition. By ensuring that the child's nutrient needs are being met, tube feeding can free the family from anxiety and therefore improve quality of life. Additional benefits can include improved hydration, improved bowel function, and consistent medication dosage. Tube feeding is an important therapy for the child who cannot orally feed safely and needs to be fed by enteral tube to protect his airways and prevent or decrease the risk of aspiration. Tube feeding is a safer and less expensive alternative to oral feeding than total parental nutrition (1).

There are disadvantages to enteral feedings. If a child has gastroesophageal reflux, aggressive enteral feeding may increase his risk of aspiration or vomiting.

Other possible physical disadvantages are diarrhea, skin breakdown, or stoma site granulation/infection. Mechanical disadvantages can be a dislodged or occluded feeding tube (1-6).

Children who are either malnourished or at high risk for becoming malnourished can benefit from tube feeding. When one or more of the following factors are identified, tube feeding should be considered after other aggressive oral interventions have been tried (1,6):

- Inability to consume at least 80% of energy needs by mouth
- Total feeding time more than four hours per day
- Inadequate growth or weight gain for more than one month (under age 2 years)
- Weight loss or no weight gain for a period of three months (over age 2 years)
- Weight for length or Body Mass Index (BMI) less than 5th percentile for age/sex
- Triceps skinfold less than 5th percentile for age

An interdisciplinary team should decide whether or not to begin tube feeding. At a minimum, the team should include the child's caregivers, the primary physician, the surgeon, and the registered dietitian (RD). If the child has oral motor feeding problems, the team should also include an occupational or speech therapist. Before tube feeding is started, the child needs a medical work-up for the following purposes:

- To rule out contraindications for enteral feeding (e.g., malabsorptive disease)
- To diagnose possible gastrointestinal problems (e.g., gastroesophageal reflux, risk of aspiration)
- To determine the optimal delivery site for the feeding (e.g., stomach, duodenum, or jejunum)
- To determine an appropriate program for oral-motor stimulation

The feeding tube may be placed through the mouth or nose such as for gavage or nasogastric (NG) feedings. A gastrostomy is placed surgically or by percutaneous endoscopic gastrostomy (PEG). The choice of placement depends on many factors (1-6):

- Expected duration of the need for tube feeding (generally, NG feeding tubes are used for short periods of time only)
- Local resources for dealing with possible complications
- Family's ability to learn the feeding technique required by the particular placement
- Preference of the caregiver(s)

Oral-motor problems may improve with development, time, and treatment. All enteral feeding techniques are reversible. Discontinuation of enteral feedings requires the same careful planning and often the same detailed work-up that go into the decision to start it.

The remainder of this section is presented in two parts: guidelines for determining when enteral feeding is necessary (Table 10-1) and guidelines for evaluating the patient who is being tube-fed (Table 10-2). The details of the enteral feeding process, including possible complications, are discussed in Appendix N.

Table 10-1 Guidelines for Determining When to Use an Enteral Tube Feeding

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for length or BMI for age • Head circumference (under 3 yr) Measure: • Triceps skinfold • Mid-upper arm circumference • Subscapular skin fold Calculate: • Arm muscle area • Arm fat area Obtain and plot all previous anthropometrics that are available Compare all current measurements to reference data and previous measurements	Consider tube feeding if either of the following: • Inadequate rate of growth or weight gain (for 1 month, under age 2 years; for 3 months over age 2 years) OR decreased rate of weight gain such that weight percentile has dropped continuously over past 6-12 months. • Skinfold thickness and arm fat area OR indicators of muscle mass have decreased or are below 5th percentile	Caregiver(s) and interdisciplinary team decide either to tube feed, or to continue oral feeding alone with reevaluation at later specified date Consistent growth pattern is established
Clinical/Medical		
Obtain the following: • Medical history • Review of body systems • Physical exam • Supportive laboratory work and/or X-ray (individual indications)	Consider tube feeding if any of the following: • Aspiration pneumonia (g-tube) • Anatomic abnormality in airway, upper intestinal tract, cranium, or face • Medical conditions characterized by hypermetabolic state (e.g., cardiopulmonary diseases) • Neurologic abnormality that prevents efficient oral feeding; feeding video-fluoroscopy swallowing study (VFSS) may document severity	Tube-feeding is initiated, if appropriate, without development of complications

Assessment	Intervention	Evaluation/Outcome
Dietary†		
Assess dietary intake by diet history and food record Assess adequacy of energy intake based on growth records Estimate energy needs Estimate fluid needs and assess adequacy of fluid intake	Consider tube feeding if either of the following: • Oral feeding providing less than 80% of required energy • Oral feeding not meeting fluid needs	Intake of fluid, energy, protein, and other nutrients is adequate to support growth
Feeding		
Estimate number of hours per day spent feeding child. Assess oral-motor skills to determine ability to take solids and liquids Assess ability to swallow to determine risk of aspiration (e.g., VFSS)	Consider tube feeding if: • Caregivers spending more than 4 hr/day feeding (less time, if few caregivers) • Oral-motor skills preventing adequate oral intake of foods in a reasonable length of time • Risk of aspiration when eating or drinking	Increased time is available for parent-child interaction, without the pressure of oral feeding Oral foods offered in addition to tube feeding are appropriate for the child's swallowing ability

*For reference data and guidelines for taking accurate measurements, see Chapter 2.

†For more information, see Chapter 1 Nutrition Screening and Assessment.

Table 10-2 Guidelines for Evaluating the Patient on an Enteral Tube Feeding

Assessment	Intervention	Evaluation/Outcome
Once the decision is made to tube feed, have a gastrointestinal work-up done to document intestinal motility, anatomic integrity, and presence/absence of gastroesophageal reflux	Determine most appropriate feeding route: • Site of formula delivery (i.e., gastric, duodenal, or jejunal) • Tube placement (i.e., nasal or surgical)	Caregiver(s) and all involved medical professionals contribute to decisions regarding feeding route
Have a medical/surgical assessment done	Determine requirements for the following: • Fluid • Energy • Protein • Vitamins • Minerals • Electrolytes	Patient is receiving a nutritionally adequate feeding
Before starting tube feeding, do a complete nutrition assessment:* • Anthropometric • Biochemical • Physical • Dietary	Determine most appropriate type of formula and supplements. Determine most appropriate method of formula delivery (i.e., bolus, continuous drip or combination)	
	Instruct caregiver(s) about the following:† • Obtaining the formula and supplements • Preparing the formula • Giving feedings and using the pump • Daily skin/stoma care • When to call physician	Caregiver(s) obtain appropriate formula and supplements Caregiver(s) demonstrate appropriate techniques for feeding and stoma/skin care Caregiver(s) know when to call MD

Assessment	Intervention	Evaluation/Outcome
Once tube feeding has begun, monitor closely: • Tolerance of tube feeding; maintain frequent contact with family by phone or clinic visits; check for vomiting, diarrhea, constipation, and other adverse reactions • Growth and indicators of fat and muscle stores, every 1 - 2 months until weight gain has been stable for 2 months	As necessary make changes in: • Type of formula • Amount of formula • Method of delivery • Additional supplements • Once child achieves appropriate weight for height (or length), evaluate need for reducing energy intake to compensate for low energy needs due to immobility or paralysis	Child tolerates feeding regimen and formula well (no gastrointestinal disturbances or other signs of formula intolerance) Weight gain is stable and adequate
Once weight gain has been stable for 2 months, re-evaluate every 6 months (more often in periods of rapid growth, such as infancy and adolescence): • Growth and indicators of fat and muscle stores • Nutrient adequacy of formula • Method of formula delivery • Tolerance of formula	Make changes in formula and delivery method as indicated by nutritional status.	Weight is appropriate for height (or length) Formula meets requirements for energy, protein, vitamins, minerals, and electrolytes Fluid intake is adequate

*For more information, see Chapter 1 Nutrition Screening and Assessment.

†See Appendix N Technical Aspects of Enteral Feeding.

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   NOTE – A process was described for updates of these guidelines in *J Parenter Enteral Nutr*. 2009; 33:255-259. Future updated guidelines will be published as separate chapters and will be available at the A.S.P.E.N. website (www.nutritioncare.org) with access to all.

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CHAPTER 11

Community Monitoring of the Patient on Home Parenteral Nutrition

Kathryn L. Hunt, RD, CD

Parenteral nutrition (PN) is needed when the patient's gastrointestinal tract will not sustain life or when a child is unable to tolerate enteral feedings for a significant period of time. PN may be administered for weeks or months, as may be required for children with nutritional depletion from certain diseases, or for years, as may be required for children with severe short bowel syndrome (1). However severe or significant the need, PN is now an accepted form of therapy with life-saving capacities for pediatric patients. Indications for home parenteral nutrition for pediatric patients are listed below.

- Short bowel syndrome
- Intestinal motility disorders (e.g., pseudo-obstruction)
- Inflammatory bowel disease (e.g., Crohn's disease, ulcerative colitis)
- Hypermetabolic states (e.g., severe burns and trauma)
- Acute and chronic pancreatitis
- Special circumstances (e.g., hepatic failure, cancer, congenital villous atrophy)
- Unexplained intestinal malabsorption syndromes

The goal of the health care team in managing the pediatric patient on PN is to provide a solution of carbohydrate, protein, and fat that will achieve a positive nitrogen balance for growth, increase the patient's weight, and improve clinical outcome. The solution should also contain appropriate amounts of electrolytes, vitamins, minerals, and trace elements to maintain balance within the patient's body and prevent nutrient deficiencies (2). Despite its life-saving capacities, PN has risks and potential consequences, including liver damage from overfeeding, biliary sludge from absence of enteral nutrition, and catheter-related sepsis (3). To minimize these risks and to prevent other complications, the patient receiving PN should be transitioned to enteral feeding at the earliest opportunity (4). This requires close monitoring and regular re-evaluation by the health care team.

In general, PN regimens (including solution composition) are established in the hospital, where the patient's metabolic response and tolerance can be monitored closely (5). After discharge, it is important to continue to monitor response to PN

and regularly re-assess nutrient needs. Guidelines for the technical aspects of PN, including complications of PN, are provided in Appendix O.

The remainder of this section presents the basic guidelines for monitoring a child on home PN Regular assessment and monitoring by a team of health care professionals, physician, pharmacist, and registered dietitian (RD), with PN experience is essential. Coordination of care between the ordering physician, and home care company is vital.

Table 11-1: Community Monitoring of the Pediatric Patient on Home Parenteral Nutrition

Assessment	Intervention	Evaluation/Outcome
Anthropometric after hospital discharge*		
Measure and plot on appropriate growth chart • Weight for age (weekly for infants, 2 times per month for older children) • Length for age (0-3 years) (every 2 weeks for infants <12 months of age, once per month for 13-36 month olds) • Height for age (2 years and older) (every 1-3 months, depending on clinical status) • Weight for length or BMI • Head circumference (0-3 years) (monthly)	If weight loss or no weight gain, increase energy provided by PN solution. If rate of weight gain exceeds recommended guideline on 2 consecutive visits, decrease energy provided by PN solution.6	Steady, stable weight gain to maintain normal growth curve. Consistent linear growth. Consistent increase in OFC in usual growth channel.
Measure (2 years and older) every 1-3 months, depending on clinical status: • Triceps skinfold • Mid-upper arm circumference • Subscapular skinfold Calculate: • Arm muscle area • Arm fat area	Use information in assessing child's energy and protein needs	Restore muscle and fat reserves to normal or >10th percentile
Biochemical		
Frequency of monitoring biochemical indicators depends on the child's clinical condition and the protocol established by the institution. Once the medical condition is stable, labs are generally done every 1-3 months or when PN solution is adjusted: • Electrolytes • Blood glucose • Calcium, phosphorus, magnesium • Creatinine, BUN • CBC, platelets • Prealbumin, albumin (See next page for continuation)	Work with PN team to monitor biochemical indicators and assess need to adjust PN solution.	Biochemical indicators in the normal range

Assessment	Intervention	Evaluation/Outcome
• Triglycerides • Prothrombin time • Zinc, copper, selenium, vitamin B12 • Ammonia • Liver function tests: SGPT, SGOT, GGT, and direct bilirubin • Alkaline phosphatase • Cholesterol • Fat-soluble vitamins (A, E, D)		
Clinical		
Observe child for signs of PN-related complications: • Infections (e.g., catheter or line sepsis): indicated by fever, redness at catheter site, elevated triglycerides or glucose levels, lethargy • Mechanical (e.g., catheter occlusion): indicated by clot or thrombus, failure to maintain line patency, formation of fibrin sheath outside catheter, fat deposition or mineral (calcium and phosphorus) precipitates • Metabolic abnormalities (e.g., electrolyte imbalances, glucose instability, elevated triglycerides, elevated liver function tests) indicated by abnormal lab values	Immediately alert physician and PN team of signs of complications	Complications are identified and treated
Dietary/Feeding		
Assess feasibility of enteral (tube-feeding or oral) trial. Evaluate: • Developmental readiness • Medical readiness • Readiness of family • Level of oral stimulation	Make referral to occupational therapist in advance of starting enteral feeding, for oral stimulation, prevention of future feeding aversions Gradually begin oral or tube feeding when feasible	Transition to enteral (tube or oral) feedings is begun (or postponed)

Assessment	Intervention	Evaluation/Outcome
Once transition from parenteral to enteral nutrition is begun, assess adequacy of PN and enteral intake: energy, protein, vitamins and minerals. During transition, monitor weight closely.	As enteral intake approaches 30% of estimated energy needs (and is absorbed), begin decreasing energy provided by PN solution.[7] Consider: • Reduce rate of PN infusion by 1 mL for every 1 mL tube feeding rate increase • Eliminate lipid infusion when 50-60% energy needs are met enterally and weight is stable • Reduce number of hours of PN infusion • Discontinue PN when 75-80% energy needs met orally or enterally and there is adequate nutrient absorption	Fluid, energy, protein, and micronutrients provided by parenteral and enteral nutrition meets child's estimated needs for growth and weight gain

*For reference data and guidelines for taking accurate measurements, see Chapter 2

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CHAPTER 12

Accommodating Children With Special Dietary Needs in School Nutrition Programs

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It has been estimated that 15% of all students have special health care needs (1). Case studies conducted in eight school districts have shown that most school food service managers serve at least one student with special nutrition needs in their school on a regular basis (2).

Some students attend special education classes due to developmental disabilities, while others with arthritis, pulmonary disease, lactose intolerance, diabetes, and inborn errors of metabolism (e.g. PKU, galactosemia) may attend regular classes. The medical conditions reported most frequently by schools include food allergies, diabetes, and a variety of disorders that require modifications to the texture of food (2).

Legislation

Several federal laws have been passed with the intent of ensuring that all enrolled students, regardless of disability, have access to meals served at school and, that those students eligible for free or reduced-price meals receive them. Under Section 504 of the *Rehabilitation Act of 1973* and the *Americans with Disabilities Act* (ADA),

a "person with a disability" is defined as anyone who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment (3).

Major life activities covered by this definition include caring for one's self, eating, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working (3).

One effect of these laws and the *Individuals with Disabilities Education Act* (IDEA, 1990) has been an increase in the number of children with disabilities who are being

educated in regular school classrooms. Often, the disability prevents the child from eating meals prepared for the general school population. Students with special nutritional needs usually have the same or greater nutritional needs as students without physical disabilities; however, they may have a difficult time meetings those needs (1).

School Food Service Requirements

Students who may need modified or special meals can be classified in two major categories: 1) those who are unable to eat regular school meals because of a disability and 2) those who have a chronic medical condition but are not determined to have a disability. A sample order form that a physician or recognized medical authority may use for students with disabilities or a chronic medical condition to modify a diet is included (Appendix P).

Students with Disabilities

The US Department of Agriculture's (USDA) nondiscrimination regulation (4), as well as the regulations governing the National School Lunch Program (5) and School Breakfast Program (6), make it clear that substitutions to the regular meal must be made for students who are unable to eat school meals because of their disabilities when that need is certified by a statement or order signed by a recognized medical authority.

The order must include (3):

- The student's disability and an explanation of why the disability restricts diet
- The major life activity affected by the disability
- The food or foods to be omitted from the student's diet and the food or choice of foods to be substituted

Students with Chronic Medical Conditions

For a student without a disability, but with a chronic medical condition that requires a special diet, an order signed by a recognized medical authority must be provided. (In Washington State a recognized medical authority is defined as a physician, licensed physician's assistant, an advanced registered nurse practitioner (ARNP), or a licensed Naturopathic Physician).

This order must include:

- Identification of the medical or other special need which restricts the child's diet
- The food or foods to be omitted from the child's diet and the food or choice of

foods that may be substituted (e.g. texture changes and foods substitutions) (7)

Other items that may be included in orders for children with disabilities or chronic medical conditions are:

- Whether the allergy/medical condition is temporary or permanent. (A permanent note will relieve the family from updating this information every year.)
- The location for maintaining this documentation to ensure that it accompanies the student should she transfer to another school or district

Students with Other Special Dietary Needs

Schools may make food substitutions, at their discretion, for individual students who do not have a disability, but who are medically certified as having a special medical or dietary need. Such determinations are made only on a case-by-case basis and must be supported by a statement or order that specifies the food substitution needed and is signed by a recognized medical authority.

This provision covers those children who have food intolerances or allergies, but do not have life-threatening reactions (anaphylactic reactions) when exposed to the foods to which they are allergic. Generally, children with food allergies or intolerances do not have a disability as defined under USDA's regulations and school food authorities may, but are not required to, make substitutions for them.

However, when in the physician's assessment, food allergies may result in severe, life-threatening (anaphylactic) reactions, the student's condition would meet the definition of disability and the substitutions ordered by the physician must be made (6).

Schools are not required to make modifications to meals due to personal opinions of the family regarding "healthful" diets.

Students with Individualized Education Plans

Many students with special needs will have an Individualized Education Plan (IEP) or an Individualized Family Service Plan (IFSP). These are plans for students receiving special education and related services to help the student benefit the most from the school program. The services described in the IEP or IFSP may include special meals, supported by a diet order. The food service director or manager is responsible for providing meals as described in the diet order, but is not responsible for revising, changing, or interpreting the diet order (7). Examples of IEP nutrition-related goals that are written in collaboration with the child's nutrition team and parents are outlined in Appendix Q.

Section 504 of the *Rehabilitation Act of 1973* specifies that food service program administrators must serve special meals at no extra charge to students whose disability restricts their diet (8). There is no provision for additional federal reimbursement for the added expense. However, these costs are legitimate program costs that can be paid for out of the food service account, which includes federal reimbursement for meals served for these students. If federal reimbursements are insufficient, alternative funding sources may also be available from Medicaid and special education to cover some of these costs. School officials should explore all possible funding sources.

Nutrition Team

The team for a student with special nutritional needs often includes the principal and teachers, the food service director and/or staff, the child's parents, and other health professionals and specialists. The team considers the needs and abilities of the individual student. The food service staff:

- applies basic guidelines for food preparation to meet those needs
- refers to resources, including parental input, on the proper techniques for preparing regular menus in a special way
- with the rest of the team, evaluates whether or not the meal plan is meeting the special needs of the student

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CHAPTER 13

Nutrition Interventions for Overweight and Obesity

Betty Lucas, MPH, RD, CD

National surveys indicate that the prevalence of obesity in children in the United States has increased dramatically over the last four decades. About 17% of school-age children and 12% of preschool children are obese, using body mass index (BMI) of >95th percentile (1). An equally high percentage of the pediatric population is also overweight, defined as BMI between the 85th-94th percentiles. These national studies also show a shift of the heaviest children being markedly heavier now than in the past. The increase in childhood obesity is influenced by environment and genes, but the contributing factors are very complex (2).

The newer BMI percentiles and categories for children are (2):

<5th	underweight
5th-84th	healthy weight
85th-95th	overweight
>95th	obesity

The most recent consensus recommendations for childhood obesity focus on prevention, thorough assessment, and intervention (2).

For most children, weight for length/height at the 50th percentile is considered ideal, with an acceptable range of 10th to 90th percentile, depending on body composition and stability in the percentile over time. Although using the above criteria will identify most obese children, some children whose weight for height is at or above the 95th percentile may be highly muscular and not obese. Others with weight for height percentiles in the acceptable range could actually be "overfat". For a child with cerebral palsy, the reduced muscle mass may result in a BMI of 10th-25th percentile, which may be appropriate considering the child's altered body composition. In this example, BMI at the 50th percentile may reflect excess fat stores, and obesity should be assessed when BMI reaches the 75th percentile. On the other hand, for a pre-school or school-age child with Prader-Willi syndrome, a stable weight for length or BMI within the 75th to 90th percentile range is considered clinically acceptable.

An accurate diagnosis of overweight and obesity requires measurements of length or height, weight, a visual assessment, and previous growth data to determine rates of weight gain over time. This data can then be compared to norms, although interpretation requires professional judgment with certain conditions and diagnoses, since standards are not available for children with special health care needs. Either weight for length or BMI should be used to determine overweight or obesity along with other data and history. Each child's individual diagnosis and body composition should be considered when evaluating overweight and/or obesity.

Overweight and obesity in children with disabilities may impair their mobility, balance, and ability to progress in gross motor skills. As a consequence, the child's energy needs may be further reduced. Overweight children who are not ambulatory also require greater physical effort from family and other caregivers in their daily activities.

Children who have short stature and/or limited mobility are more prone to excessive weight gain than their typically developing peers. For non-ambulatory children, energy needs are 25 to 50% lower than those of ambulatory children (3). Additional factors that may contribute to obesity include: a family history of obesity; family eating patterns that result in excess energy intake; frequent snacking or lack of structured meals and snacks; use of food as a bribe or reward; and limited opportunities for physical activity (4).

Children with Prader-Willi syndrome are at high risk for obesity unless diet management and control of food access is consistently implemented. The risk of weight gain in most other conditions associated with overweight, such as spina bifida or Down syndrome, is related directly to the factors of short stature, limited activity or mobility, and energy intake. Due to the common characteristic of short stature in many children with developmental disabilities, assessment of energy intake and determination of energy needs for weight maintenance or loss should be based on height, e.g. kilocalories per centimeter (3,5).

Routine periodic monitoring of growth parameters allows the identification of a pattern of weight gain likely to result in obesity. This allows early intervention to correct the factors contributing to excessive weight gain before obesity is established. Frequent growth monitoring is especially important for children who are at risk for obesity.

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with obesity.

TABLE 13-1: NUTRITION INTERVENTIONS FOR OVERWEIGHT AND OBESITY

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Anthropometric*		
Measure and plot on appropriate growth chart: • Length/height for age • Weight for age • Weight for length or BMI • Head circumference (<3 years) Obtain and plot previous anthropometric data available. Compare all current measurements to reference data and to previous measurements. Note visual signs of obesity. Collect data from medical records, caregivers, and child (if possible): • Growth history • Recent pattern of weight gain • Family history of obesity	For child who is moderately obese, set goal of weight maintenance or decreased rate of weight gain. For child who is significantly obese, set goal of slow weight loss (no more than 2 lb/mo)[6]. For adolescent (with any degree of obesity) who has attained adult height, set goal of weight loss at 0.5-2 lb/wk. Monitor weight and length/height at least once per month. EXCEPTION: For a child in a wheelchair with no available equipment for measurements, if monthly measurements not feasible, do as often as possible.	Growth rate and body composition are appropriate.
Clinical/Medical		
Refer to primary care provider to rule out physiologic and metabolic contributors to obesity.		Physiologic and metabolic contributors to obesity are ruled out or addressed.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Determine activity level and physical capability for increasing activity.	If child is ambulatory and able to follow instructions, develop with caregivers and child a plan for increasing daily activity.[7] Consider: • weight-bearing activities • work up to 30 minutes of aerobic activity • activities that are enjoyable • done with a partner or friend • Special Olympics program for children >8 years of age If child is in wheelchair or has some degree of physical disability, refer to physical or occupational therapist regarding a plan for increasing activity. Reduce television and media viewing time[8] If child is quadriplegic or unable to move voluntarily, manage weight by diet alone. See Chapter 3 for more information about physical activity.	Caregivers, educators, and others involved in child's daily care report increased activity.
Dietary†		
Interview caregivers and child (if possible) to get the following information: • Typical content and time of snacks and meals • Types of foods and methods of preparation usually available to child at home, school, and/or day care • Access to food away from home (school, other homes, stores) • Assess to food used for rewards Obtain a 3- to 7-day food record. Calculate average daily energy intake.	Estimate energy needs based on the following factors: • Current energy intake (kcal/cm height) • Degree of obesity • Activity level (Examples of energy needs based on diagnosis: *Prader-Willi syndrome* –10-11 kcal/cm for maintaining growth in channel; 8.5 kcal/cm for weight loss[5] *Spina bifida* -- 9-11 kcal/cm for maintenance; 7 kcal/cm for weight loss)[5]	Subsequent food records or interview indicate appropriate energy intake for current body size and activity level. Child and caregivers report dietary practices consistent with nutrition care plan. Re-evaluate nutrition care plan according to changing energy needs due to growth, changes in body composition, and activity level

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
	Develop individualized nutrition care plan based on the following: • Estimated energy needs • Child's food likes, dislikes, allergies, and intolerances • Family's and child's eating patterns • Child's feeding skills and mode of feeding (oral or tube) • Family's financial resources Provide counseling to family regarding positive feeding interactions, support for self-regulation of food intake, allowing for choices, and avoiding unnecessary rigidity or "rules" related to food[8] Help design reinforcement strategies at home and school that do not involve food Obtain periodic food records or diet history as indicated. Assess average daily energy intake.	
Family/Social		
Determine: • Family's feelings about child's weight status • Previous attempts to control weight • Family's pattern of reinforcement for eating and any use of food as rewards	If family does not consider child's weight a problem, arrange for all health care providers to meet and agree on an appropriate message to be reinforced by all.	Family acknowledges need for weight management and agrees to work with RD and other health providers to achieve appropriate weight.

*For reference data and guidelines for taking accurate measurements, see Chapter 2.
† For more information about dietary assessment, see Chapter 1.

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CHAPTER 14

Nutrition Interventions for Failure to Thrive

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Updated by Sharon Feucht, MA, RD, CD and
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> "It seems to me that our three basic needs for food, security, and love, are so mixed, mingled, and intertwined that we can not think of one without the other."- M.F.K. Fisher

Introduction

Children with special health care needs are at risk for failure to thrive for a number of reasons. Poor or delayed growth is associated with some diagnoses, and conditions may have developmental problems that can interfere with an adequate intake or can increase energy needs. The stress of a serious medical condition can put a strain on the parent-child feeding relationship, further placing the child with special needs at risk for problems with growth.

Definition of Failure to Thrive

Failure to thrive (FTT) is a medical term frequently used to describe children, generally up to 3 years of age, who demonstrate a downward deviation in growth when compared to expectations from the Centers for Disease Control (CDC) growth charts (1,2). There are no universally accepted diagnostic criteria for FTT, and there remains confusion about definitions currently used to describe this condition. Definitions range from vague descriptions of children whose weight is delayed in comparison to stature, to specific criteria such as weight moving downward across two standard deviations for age. While these descriptions may help identify a slow rate of growth, it is important to recognize that they depict anthropometric parameters only and offer little understanding to the overall complexity of the issues which have contributed to the diagnosis of failure to thrive (1,2).

Often pediatric undernutrition and growth failure originate from multiple physical and psychosocial factors that change over time and are most effectively treated by an interdisciplinary team. Growth experts warn against a broad use of anthropometric

descriptions which often steer practitioners toward an oversimplified and ineffective treatment approach. Until there are more useful diagnostic criteria, early age undernutrition and growth failure can be more accurately conceptualized as a clinical syndrome related to dynamic multifactorial issues within a child/family's functioning that require interdisciplinary treatment. In this way early age growth failure is similar to eating disorders of older age groups (1,3).

In contrast to the confusion around definitions and diagnostic criteria for FTT, physiologic risk factors associated with pediatric undernutrition and the benefits of early intervention are clear. When a child's nutritional intake is compromised, slowed weight gain is the first notable growth problem. Generally this is followed by a decline in the rate of linear growth and head circumference if the degree of malnutrition is significant or prolonged (4). The potential long-term effects of these delays include short stature, developmental delays, and/or suppressed immune function (1). Despite normal variations among children's growth, the risk of undernutrition and the benefit of early intervention warrant further evaluation when one of the following is noted in a child's growth pattern (1,2,4):

- failure to maintain previously established growth curve
- weight for length or height persistently below the 5th percentile.

A special situation to consider when evaluating early age growth patterns is a child born prematurely with a weight or length below the 5th percentile that persists beyond two years of age. Although a premature infant's weight or length may remain significantly low for a long period of time, growth velocity may be accelerated, and the child's nutrient intake may be adequate (2). Some children born small for gestational age (SGA) also may remain below the 5th percentile for weight or length. Catch-up growth potential will vary and, in part, is dependent upon the duration and cause of the growth retardation.

Caution is warranted when predicting a child's growth outcome by using specific ethnic group charts. Data used to formulate growth charts for various ethnic populations can be misleading, particularly when used for children who have immigrated to the United States. Research has shown that immigrant children raised in the United States with increased access to food, grow taller than family members brought up in their country of origin (5). This phenomenon is also true for American children whose parents may have short stature in response to nutritional deprivation during their childhood (6). Thus, it is important to use the CDC growth charts when assessing the growth of children in the US.

The Cause of Growth Failure

Historically, the origins of early age growth failure have been dichotomized as organic or non-organic FTT (1,2). Although this view has evolved into the complex understanding of mixed etiology, practitioners tend to oversimplify issues of cause as static rather than interrelated and evolving (1). It is important to recognize that the majority of children who fail to thrive do so because of multiple, interrelated factors that may result from the child, the parent, the parent-child relationship, and the many influences of extended family, culture, and community (1,2,7-10).

As the development of feeding and growth problems is better understood, the integral relationship between feeding and emotional development becomes clear. Early on, most infants positively connect internal feelings of hunger with the satisfying outcome of eating (8-10). Similarly, young infants begin to positively connect their desire for socialization and comfort with reciprocated parental gestures, eye contact, and soothing verbal praise. The infant who repeatedly looks into the blank, expressionless face of a detached, depressed parent may, over time, make fewer, less sustained bids for her parent's attention even at feeding.

As the infant's ability to communicate different needs improves, parents are better able to read and respond to their child's cues. Both the parent and the child come to trust the positive outcome of having the infant's needs met and the parent's satisfaction in doing so. The benefits of such attunement reach beyond early infancy to the time when the child begins her own struggle for autonomy. Success in this early relationship lays the foundation for ongoing healthy interactions between a parent and child as they navigate future developmental stages (2,8-10).

There are numerous factors within both a parent and child's life that may negatively impact early associations with food and a child's desire to express hunger and need for comfort (2,7). Examples of factors pertaining to the child include prematurity, developmental delays, or various illnesses. Infants born prematurely often have immature lungs, compromised gastrointestinal absorption, and/or weak oral motor skills. Infants with these complications fatigue easily during feedings and are often unable to take in an adequate volume of food or absorb all nutrients required for growth without nutritional support. Other infants with low tone or developmental delays may be unable to communicate hunger discomfort in order to elicit a consistent parental response and establish a positive connection to feeding tasks or food. Parents of such children often report a history of a baby who seldom cries and does not express hunger or discomfort for other reasons.

Other common conditions include cardiac anomalies that can cause a child to fatigue easily during feedings and/or require restriction of fluid intake in order to avoid

further heart failure. Many children also suffer from varying degrees of neurological impairments that hinder their ability to focus on feeding tasks and/or may cause adverse experiences with various tastes, textures, and environmental changes. Finally, there are many children with feeding and growth complications who have or have had gastroesophageal reflux. This is a significant problem that, if left untreated, causes great discomfort with a child's every attempt to feed. Many of these conditions occur during the first year of life and may easily bring about a negative association between hunger and feeding for the child. When the negative impact related to feeding is prolonged, infants and young children learn to ignore internal hunger cues and may continue to refuse food long after the initial problem has been resolved (6,11). (See Chapter 9.)

The challenges parents face when their child begins to reject food and doesn't gain weight cannot be overstated. At the most primitive level parents fear being unable to adequately nurture their youngster (8,12). The child's poor growth can bring on feelings of inadequacy, frustration, fear, and anger. In an effort to reverse their child's growth problem, parents may resort to feeding techniques, both forceful and/or overwhelmingly playful (8,9). Despite the parents' best intentions, fears and feelings of inadequacy may cause them to override the child's cues for hunger and comfort (9,10,12). The stress of a child's feeding problem and weight loss can challenge a parent and family system and bring on complex relationship issues that are difficult to reverse (8).

There are also a number of issues within the parents' own experiences that may set the stage for discord in the parent-child relationship. Consider the mother who does not think of a meal as a pleasurable experience, but instead finds it a source of anxiety, tension and inner conflict. Whether consciously or unconsciously, she may avoid or minimize her time at the table (8,12). The child does not know the source of the mother's conflict, but will register the tension relative to the presence of food and the act of eating. Unresolved issues from the mother's past being played out in the present are so common they are referred to as "ghosts in the nursery" (8). Consider also the mother who is trying to lose weight. Her preoccupation about her own needs and internal hunger-satiety may prevent her from seeing the child separately, and/or distinguishing her child's expression of hunger and satiety from other emotional states such as distress (8,12). This mother may inadvertently limit the child's food choices or portions. In many cases eating becomes one of several parent-child interactions affected by the parent's inability to view the child as an individual with separate needs (8). For example, a well-intended parent whose father died of a heart attack may provide low fat foods regardless of the child's needs for an energy-dense diet or the child's hunger cues resulting from a low energy intake.

Assessment and Treatment of Growth Failure

Primary care providers are encouraged to seek comprehensive evaluation from feeding and growth experts when a feeding or growth problem is suspected (1,7). The most effective assessment and intervention for growth failure is by a team of professionals in pediatric medicine (physicians and nurses), developmental feeding (specialists from occupational therapy or speech pathology), psychosocial services (behaviorists, social workers, psychologists, psychiatrists), and nutrition (registered dietitians) (1-3,7). This interdisciplinary team, along with parents/caregivers, can identify the factors influencing growth and prioritize interventions for the family and child (7). Effective intervention can focus on educating parents with regard to their child's needs and modeling a positive interactive response to a child's behavior. Parents may also need support to identify issues that negatively impact their ability to implement a treatment plan consistently (7). Intervention should also include the identification of issues related to the nutrition, medical and developmental needs of the child and selection of appropriate interventions from the family and community.

ASSESSING MEDICAL CONTRIBUTORS

A detailed medical history of both the child and the parents can be compared to a child's growth history to identify possible medical and developmental issues that may negatively impact a child's emotional and feeding development (1). Examples of common medical contributors (2,13):

- gastrointestinal—gastroesophageal reflux, malabsorption
- neurological—problems with sucking, chewing, swallowing
- respiratory—increased energy needs, difficulty coordinating suck-swallow-breathing pattern
- cardiac—increased energy needs, fluid restrictions
- endocrine—alterations in appetite, increased energy needs, coordination of meals and insulin

See reference 1 for a more detailed review of the medical concerns related to growth failure.

ASSESSING A FEEDING SITUATION

When a growth problem is noted, it is important to observe a typical feeding situation (1,2,7,11). Growth evaluations completed without a feeding observation are limited to the parent's perception of feeding and interaction problems. Feeding observations may take extra time and expertise, but provide a more accurate picture of an individual situation. They are ideally performed in a home setting,

though valuable information may be obtained in the clinical setting (1,2,7). The feeding can be videotaped to replay for further evaluation, as well as to illustrate problematic feeding behaviors and behaviors a parent may need to alter. Particular attention is given to the child's feeding pace, suck, chewing, and swallowing skills, feeding independence, and ability to focus and communicate hunger and satiety. Other factors to assess include the parent's understanding of the child's needs, ease of interaction, ability to read the child's cues, and meal preparation skills (1,2,11). Feeding specialists skilled at determining a child's feeding ability and able to distinguish between productive and nonproductive parent-child interactions can provide interventions to help a child begin to unlearn negative associations with food and feeding (7,11). (See Chapter 9.)

ASSESSING NUTRITIONAL STATUS

A comprehensive nutrition evaluation by the registered dietitian (RD) who has experience in growth and feeding dynamics can provide insight to the origins of the child's food struggles and the relative risk of physiological complications associated with undernutrition (1,2,7). The RD evaluates a child's growth pattern, comparing an individual's rate of growth and body composition to reference data. The RD can then determine reasonable growth goals and provide guidance about how to accomplish specific goals. In addition to the growth assessment, a history of feeding development should be obtained, including information about feeding skills, readiness for independent feeding, and ease of transitions to new tastes and textures (1,2,7). For infants, breast and bottle feeding frequency, feeding duration, suck strength, and formula preparation are evaluated. A 3-day diet record for the infant or toddler gives an approximate nutrient intake, provides information with regard to meal and snack routine, and can indicate the family's use of specific diets (e.g., vegetarian), supplements, or alternative therapies (1,2,14). A comparison of a diet recall the day of a clinic visit and a three-day diet record prior to the visit may also indicate differences between the parent's perception of the child's diet and the actual eating pattern.

Once the initial team evaluation is complete, a conference with the family allows for the development of a plan that the family can use with follow-up from the team (7). Nutrition therapy may be as simple as instructing the parent on the child's needs for greater energy density, limiting juice intake, or offering developmentally appropriate foods (2,7,15). Other situations may require further education and support in order to help parents avoid erratic feeding patterns and move toward more appropriate meal and snack organization (10). The RD who is experienced with eating disorders may also provide nutrition therapy in conjunction with psychosocial intervention for

parents who may need help distinguishing between their own fears and anxieties about food and their child's nutritional needs.

ASSESSING PSYCHOSOCIAL CONTRIBUTORS

An initial assessment by the psychosocial professional is often key to other interventions. It can allow parents to learn about their child's needs and also implement complex treatment plans consistently (7,8). Unfortunately, the involvement of a psychosocial professional with experience in early age eating and growth disorders is often viewed as the final intervention, sought only after all other attempts have failed.

Families may need varying levels of support/therapy. Psychosocial professionals are able to help parents separate their own struggles from their child's needs and gain confidence in their own ability to bring about change (7). For most families, change is difficult to sustain. Emotional support provided by psychosocial professionals provides parents with an opportunity to meet their own needs so they can better meet their child's needs.

Summary

FTT is a complex disorder related to multiple issues within a family system that change over time. While the initial growth problem may be associated with factors brought on by either or both the child and the parent, the continuing challenge of a child's food refusal and poor growth may act to maintain feeding and growth problems over a long period of time. Once a feeding or growth problem is suspected, practitioners are encouraged to refer for interdisciplinary assessment and intervention in order to evaluate and treat effectively all factors influencing growth.

An interdisciplinary approach is critical even when a specialized team is not available. Practitioners faced with this situation are encouraged to collaborate with experienced providers in the community. In this way they can assess and prioritize treatment goals as a team as well as evaluate progress over the course of treatment. It is helpful to designate one provider as a primary contact person for both the family and other team members in order to minimize confusion about the intervention.

The remainder of this chapter (Table 14-1) presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with failure to thrive.

TABLE 14-1: NUTRITION INTERVENTIONS FOR FAILURE TO THRIVE

Assessment	Intervention	Evaluation/ Outcome
Anthropometric:*		
Measure and plot on appropriate growth chart (for infants born prematurely use corrected age) • Height or length for age • Weight for age • Weight for length or BMI • Head circumference (under 3 years) Determine height-age, weight-age,† and ideal weight for height.‡ Compare current weight to ideal weight for height. Obtain all available previous growth measurements. Compare all current measurements to reference data for chronological age and to previous measurements. Calculate rate of weight gain and linear and OFC growth. Use percent ideal body weight (%IBW) to determine relative risk for physiologic complications associated with malnutrition. Classification of malnutrition:[16] (% IBW) (Classification) 80-89% Mild 70-79% Moderate <80% Severe Repeat height/length, weight and OFC measurements at every clinic visit.	Collaborate with all disciplines to develop and prioritize a comprehensive treatment plan according to the individual needs of each child and family. A regular team meeting can help keep communication clear throughout the course of treatment.[1,2,3] If %IBW ≤ 75%, temporary hospitalization for nutrition support and hydration may be required.[4]	Weight gain is appropriate. Normal to accelerated weight gain and linear growth demonstrated. Improved growth parameters: • Weight for length or BMI between 25th-75th%ile • % IBW >85% (mild to normal) • % IBW >100% may be required to reverse linear stunting

Assessment	Intervention	Evaluation/ Outcome
Measure: • Triceps skinfold • Mid upper arm circumference Calculate: • Arm muscle circumference • Arm fat area Indicators of inadequate stores: • Muscle and fat stores ≤5% may suggest long-term inadequate intake • Normal muscle with fat stores ≤5% often suggests acute energy deficiency Repeat mid upper arm circumference and triceps skin-fold at least every 3 to 6 months	Adjust recommendations for energy and/or protein intake, as appropriate.	Upper body muscle and fat stores between 10-90th%.
Biochemical		
Monitor for iron deficiency as indicated by CBC, and diet record. Suggest nutrition panel (albumin, prealbumin, vitamins A and E, zinc and retinol binding protein), as appropri-ate.	Offer nutrient-dense foods, emphasizing specific nutrients identified to be at risk. Use supplements as needed to augment the child's diet.	Biochemical indicators of specific nutrients within normal limits.
Check serum electrolyte levels. Assess for metabolic acidosis, indicated by low CO2.	Refer to physician to treat electrolyte imbalance.	Serum electrolyte levels are within normal limits.
Clinical		
Review medical history for medical reason for growth problems. Acidosis, renal insufficiency, "mild" cystic fi-brosis can present as failure to thrive.	Refer to physician if medical problem is suspected.	Medical causes of failure to thrive are addressed.

Assessment	Intervention	Evaluation/ Outcome
Dietary		
Determine parents' knowledge of child's feeding development and nutritional needs. Evaluate parents' perception of child's intake and daily patterns vs. child's experience described in diet recall and 3-day diet record. Note parents' ability to read child's cues and ease of interactions during office visit. Note parental affect, communication of fear, frustration, and/or hopelessness, and ability to sort family issues and focus on child's current needs. Refer to information gained by other disciplines to prioritize nutritional education and amount of information to be provided (typically 1-3 educational points at one time).[18]	Prioritize nutrition intervention to provide information and recommendations for the family that are non-threatening. Nutrition Counseling:[17] • Provide unconditional positive regard to establish trust with the parents • Convey empathetic understanding to parent's fears and frustration by acknowledging the difficulty of the situation • Use initial interview and the parent's perspective on health and nutrition for the educational starting point. Point out challenges the child brings to the feeding situation • Correlate nutrition education with healthy physiologic feeding cycles and social development • Help parents prioritize efforts to maintain healthy eating habits (meal/snack frequency, limit juice, food/beverage selection, balance of fluid/solid volume, variety) • Move to new concepts when the parent has experienced success and is confident in their ability to implement recommendations • Revert to initial educational information as needed with setbacks • Avoid using specific numbers for goal weight gain and energy intake; speak in terms of working toward healthy feeding patterns and growth Compliment parent on efforts to try new ways and implement intervention	Parent/caregiver's knowledge of child's nutritional needs. Parents are able to read their child's cues accurately and provide for their needs in a consistent nurturing manner. Nutrient intake improves. Frequency of ad-lib feeding and drinking is appropriate. Daily dietary pattern approximates foods offered every 2-3 hour interval about 5-6x/day. Fluid intake is balanced to provide nutrient density and allow for adequate intake of nutrient dense solids (for example, 16-24 oz milk or other nutrient dense fluid plus solids to meet needs for catch up growth).

Assessment	Intervention	Evaluation/ Outcome
Estimate energy requirements:[18] For normal weight gain and proportional linear growth: • Determine basal metabolic rate (BMR) from WHO chart (see below). BMR is expressed in kcal, W is weight (kg). • Calculate estimated daily energy needs (DEE): BMR x 1.5 to 1.8 Estimated BMR Age (years) Females Males 0-3 61W-51 60.9W-54 3-10 22.5W+499 22.9W+495 10-18 12.2W+746 17.5W+651 18-30 14.7W+496 15.3W+679 Sample calculation for a 10 year old girl who weighs 26 kg: • BMR = 12.2(26) + 746 = 1063 • DEE = 1063(1.6) = 1700 For catch-up weight gain and growth: • Determine BMR based on ideal body weight (IBW)‡ • Calculate estimated daily energy needs: IBW(BMR) x 1.8 to 2.0	For infants: • Concentrate infant formula to >24 kcal/oz using appropriate guidelines. See Appendix T • Fortify pumped breast milk with infant formula to >24 kcal/oz, and/or supplement breast-feeding with infant formula concentrated to >24 kcal/oz • Add Polycose®, Moducal®, margarine, corn oils, and other high fat additives to strained baby foods as tolerated • Avoid juice in excess of 4 oz/day unless temporarily needed to relieve constipation Enhance appetite/satiety awareness for infants >10 months of age:[10,19] • Encourage gradual change to regular, planned feedings consistent with physiological needs. Emphasize feeding intervals, typically every 2-3 hours 6x/day, rather than rigid times • Optimal feeding period lasts up to 20-30 minutes • Allow the child to determine how much food/beverage is eaten. Offer only slight encouragement after the child expresses satiety • Avoid forceful and other overwhelmingly invasive feeding techniques • If the infant is fearful of food from past experiences, refer to OT/PT or behavior therapist for recommendations and potential positive use of feeding distractions • Introduce new foods one at a time with foods the child enjoys. Food variety is not a primary goal until the child is comfortable and is eating regularly.	Energy intake is adequate to meet estimated needs. Growth is appropriate.

Assessment	Intervention	Evaluation/ Outcome
Estimate protein requirement by using RDA for age. Estimate fluid requirement (adjust with weight gain): • For 0-10 kg: 100cc/kg • For 10-20 kg: 1000cc + 50cc/kg (over 10 kg) • For 20 kg: 1500cc + 20cc/kg (over 20 kg)	Enhance energy density of foods offered: • Identify and encourage energy-dense foods/beverages enjoyed by the child • Increase the energy density of foods/beverages by adding whole milk, powdered milk, cream, half and half, instant breakfast powders, avocados, sour cream, soy powders, peanut butter, margarine, oils, and yogurt • Avoid frequent intake of foods with low energy density (e.g., broth, Jell-O®, popsicles, rice cakes, etc.) Offer a multiple vitamin and/or other supplement to avoid nutrient deficiencies. Manipulate fluids to improve appetite and satiety in children ≥1 year of age: [10] • Encourage a gradual change in fluid consumption to approximate 16-24 oz whole milk or other calcium fortified, nutrient dense beverage • Together, juice, fruit drinks, and soda should be limited to ≤6-8 oz/day For thirst between meals and snacks, offer water.	Intake of protein is adequate. Intake of energy is adequate.
Feeding		
Refer to findings from parent-child feeding evaluation from feeding specialist (OT/PT, or speech pathologist) and psychosocial professionals to gain insight on all factors effecting a child's feeding.[7] Note: • Threatening and non-threatening aspects of feeding techniques and environment for both the child and parent • Parent-child interactions • Child's feeding skills and other obstacles in the past or present	Incorporate recommendations from feeding specialist and psychosocial professionals into intervention plan.	Parents are connected to an appropriate support system and /or individual to help separate their needs from the child's needs and prioritize adequately. Non-threatening feeding techniques and feeding environment is provided for the child consistently.

Assessment	Intervention	Evaluation/ Outcome
• Issues related to the family's life and environment that may negatively impact ability to provide for child in a nurturing manner and to implement nutrition education and overall treatment plan consistently		

*For reference data and guidelines for taking accurate measurements, see Chapter 2.
†Height age is the age at which the child's current height (or length) would be at the 50th percentile on the growth chart. Weight age is the age at which the child's current weight would be at the 50th percentile.
‡Ideal weight is the weight that would place the child in the 50th percentile weight for height (or length).

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CHAPTER 15

Nutrition Interventions for the Premature Infant After Discharge

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Advances in neonatal intensive care, including respiratory management and nutrition support, have contributed to a dramatic increase in the survival of infants born prematurely and of low birth weight (LBW). See Table 15-1 for definitions. These infants may experience prolonged hospitalization and medical and nutritional complications commonly associated with their immaturity. Increasing numbers of "late or moderately preterm infants" are being discharged home before their due date. However, these infants represent considerable diversity. Some are discharged without any major medical complications related to prematurity. Others experience continuing health problems and emerging neurodevelopmental sequelae after discharge from the hospital. Medical and developmental complications present at discharge or that emerge in the post discharge period may further impact the needs of individual infants (1-3).

Table 15-1: Categories of Infants by Birth Weight & Gestational Age

TERM	DEFINITION
Prematurity	<36 weeks gestation
Late or moderately preterm infant	33-36 weeks gestation
Low birth weight (LBW)	≤2500 grams or 5.5 lbs
Very low birth weight (VLBW)	≤1500 grams or 3.3 lbs
Extremely low birth weight (ELBW)	≤1000 grams or 2.2 lbs
Small for gestational age (SGA)	Birth weight <10th percentile
Appropriate for gestational age (AGA)	Birth weight 10th-90th percentile
Large for gestational age (LGA)	Birth weight >90th percentile

Medical and Developmental Factors

Preterm infants exhibit increased morbidity and mortality when compared to term infants (1-3). The risk for increased morbidity and mortality is inversely related to

gestational age and size. Morbidity associated with the late preterm infant includes temperature instability, hypoglycemia, respiratory distress, feeding difficulties and growth failure in the immediate post discharge period (3). Complications that may affect nutritional needs and growth outcome are listed in Table 15-2.

Table 15-2: Complications That May Affect Nutritional Needs & Growth

Physiological System Affected	Possible Complications	Reference in this volume
Respiratory	Bronchopulmonary dysplasia (BPD) Reactive airway disease (RAD)	Chapter 16
Cardiac	Congenital heart disease (CHD) Patent ductus arteriosus (PDA) Cor Pulmonale	Chapter 18
Renal	Nephrocalcinosis	Chapter 19
Gastrointestinal	Gastroesophageal reflux (GER) TPN-induced cholestasis Short bowel syndrome (SBS)	Chapter 8 Chapter 11 Chapter 20
Neurodevelopmental	Developmental delays Cerebral palsy Learning disabilities Vision and hearing	Chapter 8 Chapter 8 Appendix R
Hematological	Anemia	
Immunological	Susceptibility to repeat infections, illnesses, and rehospitalizations	
Nutrition	Alteration in growth Osteopenia Feeding difficulties	Chapter 2 Chapter 5 Chapter 8

Growth Expectations and Assessment

During hospitalization, it is common practice to strive for "in utero" rates of growth (15 g/kg/day weight gain, 0.5-1.0 cm/week increase in length). After hospital discharge, it is unclear what represents optimal growth for the preterm infant. Growth data should be plotted according to the infant's age corrected for prematurity. See example below for calculating corrected age:

Corrected age (CA) = Chronological age (CH) – number of weeks premature

Example: An infant is born at 28 weeks gestation and is now 6 months past his date of birth:

Step 1: 40 – 28 = 12 weeks or 3 months premature
Step 2: 6 months – 3 months = 3 months CA

A number of growth charts have been developed for monitoring growth in preterm infants. See Appendix D for copies of these growth charts. The CDC growth charts developed for term infants are also used for monitoring growth of preterm infants after hospitalization. When using the CDC growth charts, growth should be plotted according to corrected age until approximately 2 years of age (4). See Table 15-3 for weight gain expectations for the first year of life.

Table 15-3: Weight Gain Expectations Using Age as a Guide[14]

Age	Population	Percentile	Weight Gain: Male	Weight Gain: Female
Birth-6 mos (using CA)*	Premature infant		20-30 g/day	20-30 g/day
Birth-6 mos	Term infant†	10th percentile	22 g/day	19 g/day
		50th percentile	23 g/day	21 g/day
		90th %ile	28 g/day	23 g/day
6-12 mos (using CA for preterm infants)*	Preterm and term infants†	10th percentile	12 g/day	12 g/day
		50th percentile	13 g/day	13 g/day
		90th percentile	15 g/day	14 g/day
>12 mos (using CA for preterm infants)*	Preterm and term infants†	10th percentile	7 g/day	7 g/day
		50th percentile	8 g/day	8 g/day
		90th percentile	9 g/day	9 g/day

* CA = corrected age
† Calculated from CDC growth charts (10th-90th percentile)

Follow-up studies suggest that when growth parameters are plotted according to corrected age (CA), VLBW and ELBW infants may not achieve percentiles comparable to term infants of similar age; they remain smaller and lighter (4-8). Most studies demonstrate little "catch-up growth" for the VLBW infant between 1-3 years of age. Infants with chronic medical conditions may not experience "catch-up growth" until school age (7,8). It is important to note that the term "catch-up growth" is often used in a non-traditional sense, to identify infants who achieve $\geq$ 10th percentile on growth charts. More correctly, "catch-up growth" describes an infant who demonstrates accelerated rates of growth following a period of growth failure. The infant who continues to gain 20-30 g/day after 6 months of age, or the SGA infant

who is more than twice his birth weight by 4 months of age, may be demonstrating a pattern of accelerated growth even though he remains <10th percentile in growth parameters.

VLBW and ELBW infants are also at increased risk for "failure to thrive" (FTT)(9,10). The term FTT in the traditional sense refers to failure to gain in weight and length at expected rates. One study identified a 21% incidence of FTT in VLBW infants in the first 36 months of life. The incidence of FTT peaked between 4-6 months of age. Preterm infants are at risk for being misidentified as having FTT when the term is applied in other ways (i.e., weight or length <5th percentile).

ELBW and infants with severe intrauterine growth retardation (IUGR) may demonstrate periods of accelerated rates of weight gain and remain ≤10th percentile in weight and length for several years. Therefore, the rate of growth and weight gain should be evaluated.

Nutrition Practices Associated With Growth Outcomes

Preterm infants are discharged from the hospital when they weigh approximately 1800-2000 grams (4.0-4.5 lbs), are nippling all feedings, and can maintain their temperature outside an isolette. It is usual practice to transition these infants to standard infant feedings (breastmilk or term formula). Infants with increased energy needs, history of postnatal growth restriction, or feeding difficulties may continue on a higher caloric density feeding (24 kcal/oz).

Although some studies have demonstrated improved growth rates in infants fed a nutrient-enriched formula after hospital discharge there is insufficient evidence to support routine use for all preterm infants (11-15). Factors to consider in feeding choices for the preterm infant include individual nutrient needs, tolerance, parental choice, cost and availability. Practices that were associated with poor growth outcomes in a group of VLBW infants include: (10).

- introduction of solids prior to 6 months CA
- introduction of cow's milk before 12 month CA
- use of low fat milk

Feeding Difficulties

Preterm infants who have attained an age at which oral-motor maturity supports nipple feeding may continue to have feeding issues. Factors such as

immature maintenance of physiological stability, disorganized suck-swallow-breathing, decreased strength and endurance, cardiorespiratory compromise, and neurodevelopmental complications may contribute to alterations in feeding behavior and ultimately feeding success (16,17). Infants who experience unpleasant feeding experiences (choking, respiratory distress, GER) may begin to demonstrate aversive feeding behaviors. Evaluation of preterm infants with growth concerns and/or reports of feeding difficulties should include a careful history and description of feeding behaviors and observation. In observing a feeding, attention should be given to document control, organization, coordination of suck-swallow-breathing, length of time to consume adequate volume, evidence of distress, signs of choking or changes in respiratory status. Infants who demonstrate evidence of feeding difficulties should be referred to the appropriate disciplines for further evaluation and treatment. See Chapters 8 and 9.

Nutrient Needs

The nutrient needs of preterm infants after hospital discharge and throughout the first year have not been clearly established. Common practice is to view the nutrient needs of the preterm infant to be the same as the term infant when the preterm infant achieves a weight of 2.0-2.5 kg (4.5-5.0 lbs). Some follow-up studies raise questions about this practice (10-12). Infants fed a nutrient-enriched formula after discharge show improvements in growth and mineral status. Follow-up studies have also demonstrated decreased bone density in VLBW infants one year after discharge (18-20). Some preterm infants may continue to be at risk for inadequate bone mineralization after discharge. These infants may need higher mineral intake and monitoring after hospitalization. Currently there are no standardized practices to treat these infants and a variety of strategies have been used without clear identification of an optimal approach (13). Often, the transition to breastfeeding occurs after discharge from the hospital. These infants may continue to receive supplemental bottles of formula or breast milk until the transition to total breastfeeding is complete. To facilitate transition, follow-up is essential. This follow-up can be provided by a hospital or community lactation specialist.

Standard infant formulas are designed to meet the DRI for vitamins and minerals for term infants when the infant consumes approximately 32 oz/day. Infants discharged from the hospital weighing 4.5-5.0 lbs may only consume 10-12 oz/day. This volume may be adequate to meet fluid, energy, and protein needs. However, a multivitamin supplement is needed to meet the DRI for infants until the infant or child consumes 24-30 oz/day. Soy formulas are not recommended for preterm infants, particularly those at risk for osteopenia, secondary to decreased bioavailability of calcium and phosphorus (13).

Preterm infants often demonstrate adequate weight gain when consuming 110-130 kcal/kg/day. The VLBW and ELBW infants often need higher energy intakes to support appropriate weight gain. Factors that alter energy needs, absorption, or utilization in infants will also impact the energy requirements of preterm infants.

Preterm infant formula and human milk fortifiers are designed to meet the increased vitamin and mineral needs of the preterm infant taking smaller volumes than the term infant consumes. Continuation of the preterm infant formula and human milk fortifiers in infants who weigh more than 2.5-3.0 kg will result in increased intakes of several vitamins, including vitamins A and D. Case reports of hypervitaminosis D suggest that these products should be discontinued when the infant is exceeding the recommend intakes for fat-soluble vitamins.

Preterm infants are at risk for iron deficiency anemia. Preterm infants require 2-4 mg iron/kg/day by 2 months of age. This may be provided as an iron supplement or with the appropriate volume of iron-fortified formula. In general, this iron should be continued until 12 months of age (CA) (13).

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome after discharge from the hospital for children who are born prematurely. Additional references and resources are included at the end of this chapter.

Table 15-4: Nutrition Interventions for Premature Infant After Discharge

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure: • Length for age • Weight for age • Weight for length • Head circumference Plot on appropriate growth chart: • Premature growth curves • CDC charts using corrected age (CA) up to 2-3 yrs	Consider further assessment of intake and medical conditions that may impact growth if growth is less than expected: • weight/length <5th percentile • no weight gain • weight loss • decline in growth across channels	Rate of linear growth: • 0.5-1.0 cm/week up to 6 months of age • may decline 6-12 months, compare to expected rates for term infants using CA Note: Infants who do not demonstrate equivalent decreases in growth rate after 6 months of age may demonstrate "catch-up growth." Rate of weight gain: • 20-30 g/day up to 6 months of age • may decline 6-12 months, compare to expected rates for term infants using CA
Dietary		
Assess adequacy of fluid intake for age and size.	If fluid intake not adequate to meet fluid needs: • check for feeding difficulties • consider changes in feeding frequency, volume, position or environment as appropriate	Infant is well hydrated.
Assess adequacy of energy intake. Assess adequacy of formula volume for energy needs.	If feeding difficulties and/or growth concerns, but fluid intake is adequate, consider increasing energy density of formula. See Appendix T.	On 20 kcal/oz formula, 2.75 oz of formula/lb of infant weight (180-190 cc/kg/d) provides 120 kcal/kg/day.

Assessment	Intervention	Evaluation/Outcome
Assess appropriateness of vitamin/mineral intake.	When intake is <24 oz, provide multivitamin supplement. Breast fed infants should continue receiving a vitamin supplement for Vitamin D and Iron Provide 2-4 mg/kg iron (in formula or as supplement) for first year or until 12 months CA.	Infant receives appropriate amounts of vitamins and minerals.
Check appropriateness of type of feeding.	Recommend appropriate type of feeding.	Breastmilk or standard infant formula to 12 months CA. (Soy formula is not recommended for premature infants at risk for osteopenia.) If on non-standard formula, vitamin/ mineral intake is within recommendations for age and size.
Check appropriateness of feeding transitions for developmental age (use CA).	For infants with history of growth or other nutrient deficiencies, consider selection of transitional foods that will meet specific needs of infant. For infants having difficulty making feeding transitions: • evaluate developmental readiness • consider referral to appropriate specialty for evaluation	Infant shows progress in feeding related to appropriate developmental level.
Assess for feeding difficulties: • oral-motor problems • behavioral problems	Refer to appropriate specialist for feeding evaluation. See Chapters 8 and 9.	

* For reference data and guidelines for taking accurate measurements, see Chapter 2.

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CHAPTER 16

Nutrition Interventions for Respiratory Disease

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Causes of abnormal respiratory function in infancy are shown in Table 16-1. Nutritional implications are dependent on the nature of the disorder, clinical manifestations, treatment modalities, compensatory mechanisms, and the presence of other underlying conditions. Compensatory mechanisms are designed to maintain normal ventilation and include: increased respiratory rate, increased work of breathing, grunting, and nasal flaring. The consequences of these mechanisms include increased effort, increased energy expenditure, and exhaustion. Normal infant activities such as feeding and growth may be impaired.

Table 16-1: Causes of Respiratory Disease in Infancy[1]

Cause	Example
Infections	Viral (respiratory syncytial virus-RSV, parainfluenza), bacterial
Bronchopulmonary dysplasia (BPD), Chronic Lung Disease (CLD)	prematurity, aspiration, meconium aspiration, infection
Congenital anomalies of heart and lung	Tracheomalacia, laryngomalacia, congenital heart disease (CHD), diaphragmatic hernia, hypoplastic lung, congenital cysts or tumors
Congenital Syndromes	Beckwith-Wiedeman, CHARGE association, Pierre Robin, Treacher Collins, Trisomy 18, deLange, Mobius sequence, cleft lip and palate

Bronchopulmonary dysplasia (BPD) has been described as a "chronic pulmonary disorder that is the consequence of unresolved or abnormally repaired lung damage" (2). BPD is seen primarily in preterm infants requiring respiratory support in the first 2 weeks of life. However, chronic lung dysfunction can occur in full term infants with respiratory distress syndrome, meconium aspiration, congenital heart disease, congenital neuromuscular disease, or respiratory infections (3). Although advances in clinical practices may be associated with reductions in the incidence and severity

of BPD due to lung injury, particularly in the larger more mature infant, a "new BPD" has been described consistent with an arrest of pulmonary development and disruption of alveolarization (2-5).

The classic diagnosis of BPD may be assigned at 28 days of life if the following criteria are met (6):

- Positive pressure ventilation during the first 2 weeks of life for a minimum of 3 days
- Clinical signs of abnormal respiratory function
- Requirement for supplemental oxygen for longer than 28 days of age to maintain PaO2 (partial pressure of oxygen, a measure of arterial oxygen tension) above 50 mm Hg
- Chest radiograph with diffuse abnormal findings of BPD

Dissatisfaction with the definition and diagnostic criteria to describe BPD resulted in the National Institute of Child Health and Human Development/National Heart, Lung and Blood Institute expanding the definition to reflect differing criteria for infants less than or greater than 32 weeks gestation. This expanded definition includes different diagnostic criteria for mild, moderate, and severe disease and recognizes that BPD represents a continuum of lung disease (3,4,6). It has been suggested that the term "chronic lung disease of infancy" (CLD) be used to describe infants who continue to have significant pulmonary dysfunction at 36 weeks gestational age (GA). In current clinical practice, these terms are often not clearly differentiated, but infants with significant pulmonary dysfunction at 36 weeks GA are likely to be those who require ongoing nutritional support after initial hospital discharge.

This chapter will cover concerns that are specific to the infant with chronic pulmonary dysfunction (BPD/CLD).

Growth and Nutritional Support

The overall goal for infants with BPD/CLD is to promote growth and development. As infants grow, lung function improves and risk of severe cardiopulmonary sequelae, morbidity, and mortality with respiratory infection declines. Cornerstones of treatment are pulmonary support to maintain optimal oxygen saturation and prevent complications and nutrition support to promote growth.

GROWTH

Growth in infants and young children with BPD may be compromised by several factors. These include respiratory limitations, altered nutrient needs, drug-nutrient interactions, and feeding difficulties. Documented studies of growth in patients with

BPD/CLD show reduced rates of growth and reduced percentile ranking during the first 1-2 years of life. Long-term follow-up, however, suggests that catch-up growth from post-natal growth restriction may occur by age 3, or in the case of moderate to severe BPD/CLD by 7-10 years of age (7,8,9).

Persistent hypoxemia is recognized as a cause of poor growth as well as feeding problems in children with BPD (2,10,11). Inappropriate discontinuation of oxygen therapy for these children has been reported to cause an abrupt drop in growth rates. Maintaining adequate oxygenation improves growth (8). Infants with BPD who are not on oxygen therapy may experience oxygen desaturation with feeding after hospital discharge. Oxygen saturation should be assessed when growth falters or when fatigue and aversive behaviors are observed during feeding (12,13,14).

Medications used in the management of BPD/CLD may contribute to feeding intolerance, nutrient utilization, or nutrient needs. Through these interactions, growth may be negatively impacted. Medications frequently used in the treatment and management of BPD/CLD include diuretics, steroids, methylxanthines, and bronchodialators. Many oral medications are hyperosmolar and when added to feedings can contribute to nausea and feeding intolerance. Some medications may increase metabolic rates and result in increased energy needs. Long term use of steroids negatively impact linear growth and alter mineral status. Diuretics increase urinary losses of electrolytes and calcium. A thorough history should include medications and identify specific monitoring needs (8,13).

Growth faltering due to inadequate intake in infants with BPD/CLD has been documented. Factors contributing to inadequate intake include feeding difficulties, recurrent illness, and increased energy needs (3,8,9).

NUTRITIONAL SUPPORT

Nutrition is critical for prevention, treatment, and recovery from BPD/CLD. Antioxidant nutritional therapies, including Vitamin A, Vitamin E, selenium and n-acetylcysteine, have been proposed for the prevention of BPD. It has also been proposed that inositol may aid in the prevention of BPD by enhancing the production of surfactant (13). These therapies require further investigation. Recovery from BPD occurs with growth of new lung tissue. Supportive therapy, therefore, depends on the provision of adequate nutrients to support growth (2,5,13).

Higher energy needs have been proposed as a cause of growth failure in infants with BPD/CLD. It has been suggested that infants with respiratory dysfunction may experience increased energy expenditure associated with increased work of breathing (WOB). Studies, however, have not demonstrated this consistently (13). Some

infants with BPD experience increased energy needs (7). The reasons for this are not entirely clear, but increased work of breathing, catecholamine release due to stress, increased energy requirements for feeding, and the effects of medications probably all play roles. Energy requirements of 120-160 kcal/kg/d have been reported (8). A number of factors contribute to energy expenditure in individuals, including genetics, activity, and severity of respiratory distress. Correlating growth with energy intake is the best indicator of adequacy.

It may be difficult to provide adequate energy to infants and young children with BPD. They may have ongoing fluid restrictions due to concerns about pulmonary edema. They may experience fatigue with feeding. Increasing the energy density of formula or breastmilk using a combination of components may be helpful (see Appendix T). For infants with BPD it is inappropriate to use only carbohydrate to increase energy density. A high carbohydrate load increases production of CO_2. At the same time, the addition of excess fat may delay gastric emptying. Delayed gastric emptying may contribute to gastroesophageal reflux. The addition of vegetable oils that may separate out from formula or breastmilk may be problematic as they may increase the risk of aspiration pneumonia. Since infants with BPD are at also risk for more frequent and serious illnesses in the first months of life, it is important to teach caregivers how to assess hydration status during illness, especially when infants are receiving an energy-dense formula.

Nutritional care for the infant with BPD must be individualized. Feeding concerns, nutrient needs, and growth outcomes are different for each infant. Variables that influence the nutrition care plan include initial severity of BPD, presence of other medical problems, and characteristics the infant and caregiver bring to the feeding relationship. Infants and young children with severe BPD may require ongoing mechanical ventilation and a tracheostomy, medications with nutrition implications such as corticosteroids and diuretics (see Chapter 5), gastrostomy tube feedings (see Chapter 10), and frequent hospitalization. Some infants with milder forms of BPD may continue to require medical/nutritional interventions post discharge including supplemental oxygen, medications, and tube feeding. Some infants with CLD may experience exacerbations of respiratory dysfunction with illness, and have feeding difficulties without ongoing need for oxygen, medications, or tube feeding.

FEEDING DIFFICULTIES

Feeding problems are common among infants with moderate or severe BPD. These infants benefit from an interdisciplinary team approach to assess and treat feeding issues. Problems found in infants with BPD include poor coordination of suck, swallow, and breathing, swallowing dysfunction with silent microaspiration, oral-

tactile hypersensitivity, and aversive behavior associated with unpleasant oral and feeding experiences. Assessment of feeding problems with feeding observations, swallowing studies, and measurements of oxygen saturation during feeding may be helpful. Infants with BPD may also experience gastroesophageal reflux and/or delayed gastric emptying. The feeding situation may show significant improvement if these conditions are diagnosed and treated with changes in feeding patterns, positioning, or medications (9,14,15,16) (See Chapter 8).

The growth and development of infants with BPD is also influenced by family characteristics. Taking care of these infants can present many challenges. Feeding issues may contribute to the stress of caring for an infant with BPD. Feeding infants with moderate and severe BPD may require several hours each day (9,11,14). Nighttime feedings may last for several months. Health care professionals and the families themselves may put excessive emphasis on weight gain increments and establish problematic feeding behavior patterns. Infants with BPD are often rehospitalized. They are at high risk of serious illness during the respiratory syncytial virus (RSV) season from November through March, and families are usually told to keep their babies at home. Many caregivers report a sense of social isolation. Assuring that family needs for social, emotional and financial support are met is an essential component of good care for these infants and young children.

The remainder of this chapter presents guidelines for nutritional assessment, intervention, and evaluation/outcome for children with broncopulmonary dysplasia.

TABLE 16-2:

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Anthropometric:*†		
Measure and plot on appropriate growth chart using corrected age: Length for age • Weight for age • Weight for length (or height) or BMI • Head circumference (under 3 years) For infants and children with mild and moderate BPD these values should be obtained monthly for the first 4 months after hospital discharge and every 3 months thereafter for the first year of life, more often if weight gain is less than 15 g/day. For infants with severe BPD, measure length bimonthly, weight weekly (use incremental growth charts[11]), and head circumference monthly.[2] Infants relying on tube feeding should have frequent weight checks to adjust feeding rates with growth, initially every 1-2 weeks, then monthly. While some infants and young children with BPD will exhibit catch-up growth (growth that shows increasing percentiles on growth charts), those who were very small at birth and those who have moderate to severe illness may not show catch-up growth for several years. All infants and children with BPD should have at least a steady growth pattern that follows established growth percentiles.	Further assessment is required to determine potential causes of inadequate growth. Intervention may be a combination of dietary, feeding, behavioral and medical interventions.	Maintain established growth pattern for weight and length for age.
For older toddlers and children with moderate to severe BPD, especially those on corticosteroid therapy, assessment of mid-arm circumference, mid-arm muscle circumference, and triceps skinfold every 2 months can be useful to assess fat stores and protein status.[2,12] Triceps skinfold <5th percentile or >85th percentile or arm muscle area <5th percentile indicates a need for intervention.	Very inactive children and those dependent on steroids or mechanical ventilation may develop excessive fat stores and energy intake may need to be reduced.	Fat and muscle stores within normal parameters for age, gender, and medical condition.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Several classification systems for describing poor growth and malnutrition have been developed. These have not been developed for VLBW infants with growth that is compromised with illness. However, these classifications may be useful in some clinical settings: Mild malnutrition - weight between 80-89% of expected weight for length or height Moderate malnutrition – weight between 70-79% of expected weight for length or height Severe malnutrition - weight <70% for expected weight for length or height.	Excessively thin or wasted infants and children will require interventions as described in dietary section of this table.	
Biochemical [2,12,13,14,15] See laboratory standards for normal values		
Iron Status: Measure hematocrit, hemoglobin, or erythrocyte protoporphyrin at least every 3 months.[2] Samples taken when child is sick may give false positive readings for iron deficiency and should be repeated.	If lab values indicate possible iron deficiency anemia, assess dietary and supplemental iron intake and apply dietary methods to increase iron intake and absorption and/or consider trial dose of increased iron supplement.	Indicators of iron status are within normal limits.
Bone mineralization: For infants at high risk of osteopenia of prematurity (those on long-term diuretics or corticosteroid therapy and those fed unfortified human milk, term formula, or soy formula before achieving weights of 2000 gm) measure alkaline phosphatase, calcium, and phosphorus every two months.	If lab values indicate risk of osteopenia: • consider supplementing with calcium, phosphorus, and vitamin D • discuss possibility of changing dosing patterns (e.g., every other day) or methods of delivery (e.g., inhaled vs. systemic) of corticosteroids with primary care provider	Indicators of bone mineralization are within normal limits.
Electrolyte balance: For infants and children on diuretics measure electrolytes, calcium, phosphorus, magnesium every two months[2].	Consider supplementing with electrolytes or minerals. Discuss possibility of changing type or dose of diuretics with primary care provider.	Indicators of mineral and electrolyte status are within normal limits.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Protein status: If long-term growth is poor, consider monitoring for protein status with measures of serum albumin, prealbumin, or transferrin.	Assess dietary intake, feeding skills, and feeding interactions. Plan interventions based on assessment. Possibilities include increased energy density of breastmilk or formula and foods (see Appendix T), initiation of tube feedings (see Chapter 10), referral for caregiver counseling and support, and referral for therapies and treatment of problems such as reflux, aspiration, and compromised oxygen status.	Growth and laboratory values improve in response to intervention.
Clinical		
Oxygen status: Periods of hypoxemia or marginal hypoxemia should be suspected whenever infants with BPD fail to grow.[1,5,6] Previously undetected hypoxemia has been reported during sleep and during and after feeding. [8,16,] Oxygen status should be assessed with pulse oxymetry during feeding, sleeping, and crying. SaO_2 $\geq$92% during feeding, sleeping, and crying is recommended.[1,6] Values in the range of 95% have been reported to increase growth.[1]	Provide oxygen therapy as needed. This may include oxygen support only at feeding and sleeping or increased flow rates at these times.	Growth is appropriate. SaO_2 remains $\geq$92%.
Fluid restriction: Fluid restriction may be prescribed for infants with severe BPD in first months of life.	Plan diet that provides adequate energy and nutrients with limited fluid intake. May need to concentrate formula. See Appendix T.	Growth is appropriate.
Gastroesophageal reflux (GER): Assess presence of GER symptoms: regurgitation with gagging/coughing/repeated swallowing between meals, red and teary eyes, excessive vomiting, esophagitis (post prandial pain, anemia), respiratory symptoms (pneumonia, wheezing), neurobehavioral symptoms (irritability, crying, feeding refusal, seizure-like attack).	If symptoms indicate need for further assessment, refer to primary care provider for arrangements for diagnostic tests. Interventions for GER include: • medication • positioning • dietary (e.g.smaller more frequent feedings) • surgical (reflux unresponsive to above treatments may require surgical intervention)	Meal times and post-prandial period are pleasant and pain free. Respiratory symptoms improve.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Dietary		
For infants: assess intake of energy, protein, carbohydrate, vitamins, minerals. In infancy, protein intake may be compromised if intake of infant cereal, high carbohydrate baby food, or glucose polymers are excessive. Protein should provide 8-12% of energy for infants. Excessive protein and high renal solute load may result if formula is concentrated to greater than 24 kcal/oz without the use of modular products.	For infants with mild BPD, appropriate growth, and good feeding skills, provide standard infant formula. For infants with moderate or severe BPD, ongoing fluid restriction, or feeding problems that interfere with adequate intakes, a 22 kcal/oz formula may be used or formula may be concentrated to 24-30 kcal/oz following guidelines in Appendix T. Guidelines for infants receiving tube feedings are found in Chapter 10. Small infants with limited energy needs may require additional supplements to meet DRI/ RDA requirements for vitamins and minerals if sufficient formula is not taken. Attention should be paid to iron, calcium and phosphorous intakes of all VLBW infants (see Chapter 15).	Growth is adequate. Intakes of vitamins and minerals are at DRI/RDA levels. For infants, iron intakes are those recommended by the American Academy of Pediatrics.
Assess introduction of non-milk feedings (solids). Foods are sometimes introduced to the infant with BPD according to chronological age since birth. This is not nutritionally or developmentally appropriate. Infants with growth and feeding difficulties should begin the transition to solid foods using high nutrient dense foods. This can be accomplished by reading labels for jar baby foods, using infant cereal mixed with breast milk or formula, and when appropriate making baby food from table foods.	Foods should be introduced as the infant is developmentally ready. See Chapter 8.	Foods are introduced to the child when developmentally appropriate.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Assess intake of energy, protein, vitamins, and minerals of young children.	If energy needs remain high past early infancy, foods should be chosen to provide optimal energy and nutrients. Suggestions include yogurt, pudding, cottage cheese, pancakes, hot cereals, tuna or meat salad, scrambled egg, cheese, and mashed avocado. High fat foods such as butter, margarine, mayonnaise, cream cheese, and cream can be added to other foods to increase energy content. Homemade milkshakes, fruit slushies, and instant breakfast products can be used as an energy-dense snack or bedtime beverage. Commercial pediatric enteral feeding products may also be used for this purpose. Meals and snacks should be offered at regular times 5-6 times each day in a pleasant, non-coercive environment. Tube feedings are sometimes required for infants with BPD, especially those who continue to depend on mechanical ventilators. The type of enteral feeding is usually changed at about 1 year of age. (See Chapter 10). Tube-fed infants should continue to receive oral stimulation and to have social interactions at feeding times.	Young children are growing adequately and achieving DRI/RDA levels of vitamin and mineral intake.
Feeding skills: Feeding problems are common in infants with BPD. Feeding should be assessed by a feeding observation and careful questioning of caregivers.	A team approach to feeding problems and referral for additional assessment and therapy may be indicated. (See Chapter 8)	Problems with feeding are addressed.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Fatigue: Consider fatigue as a feeding issue if the infant stops feeding before ingesting adequate energy. Family may be spending several hours each day feeding infant and may feel inadequate in light of meeting energy requirements.	Check with primary care provider about provision of additional oxygen at feeding times and/or use of bronchodilators before feedings. Increase energy concentration of formula or other foods. (See Appendix T) Manipulate the feeding schedule to increase efficiency. Shorten feeding times and end when feeding becomes less efficient. Try smaller, more frequent feedings. Consider gastrostomy tube placement. (See Chapter 10)	Child ingests adequate energy to support growth. Family is able to enjoy feeding interactions with child.
Poor coordination of swallowing: Feeding observation may show abnormal sucking patterns with short irregular sucking bursts with long pauses and rapid breathing.	See Chapter 8. Help infant to "pace" feeding. Consider interventions listed in fatigue section (above). Refer for feeding therapy.	Infant feeds without distress and demonstrates coordination of suck-swallow-breathe.
Swallowing dysfunction due to aspiration: Infants with BPD are at risk of aspiration due to airway damage caused by intubation as well as reduced ability to use pulmonary air to clear the larynx. Suspect aspiration with episodes of respiratory deterioration or wheezing with feedings, and refer for testing and intervention. Aspiration can be assessed with videofluoroscopic swallowing study (VFSS)	Dependent on findings of specialist. May include changes in texture or temperature of foods and beverages. In severe cases it may not be safe to feed orally.	Feeding is not associated with adverse pulmonary consequences.

ASSESSMENT	INTERVENTION	EVALUATION/OUTCOME
Oral-tactile hypersensitivity: Infant becomes agitated, pulls back, gags, or vomits when oral feeding is attempted. Infants and young children with BPD are at increased risk due to aversive oral experiences early in life. This situation often requires the intervention of specialists in pediatric feeding therapies.	See Chapter 8. Avoid aversive oral experiences as much as possible. Gradually introduce pleasant oral-tactile experiences into daily care routines. Encourage oral exploration.	Child displays pleasure with feeding and oral exploration.
Behaviors: Infants and children with BPD are at risk for developing inappropriate feeding behaviors and interactions.	See Chapter 9.	Problems with feeding behaviors are addressed.

* For reference data and guidelines for taking accurate measurements, see Chapter 2.

† For information about correcting for prematurity, see Chapter 13.

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CHAPTER 17

Nutrition Interventions for Cystic Fibrosis

Susan Casey, RD, CD

Cystic fibrosis (CF) is a complex, multi-system disorder characterized by abnormally thick secretions from the exocrine glands that impair the function of the lungs and digestive system. It is one of the most common genetic disorders in children. The incidence is highest among Caucasians, approximately one in 3200 persons in the Caucasian population (1).

The median age of survival for persons with CF today is greater than 31 years, quite an improvement over 1950 when the average life expectancy was one year. The primary cause of morbidity and death in patients with CF is progressive pulmonary disease (2).

The major clinical manifestations of CF include chronic lung disease; increased levels of sodium, potassium, and chloride in the sweat; and exocrine pancreatic insufficiency, which is a reduced or absent production of digestive enzymes and a reduced secretion of bicarbonate. The child with untreated CF may have growth failure, malnutrition, chronic pulmonary symptoms, bulky, foul-smelling stools, and abdominal cramps. Typical pulmonary symptoms are chronic cough, asthma-like symptoms, recurrent pneumonia, nasal polyps, and chronic sinusitis (3).

The diagnosis of CF is confirmed by two positive sweat chloride tests (Gibson-Cook method), properly performed and interpreted. Every person with CF should have this diagnosis confirmed in a facility that is approved by the Cystic Fibrosis Foundation. The approved Cystic Fibrosis Centers are required to maintain the highest diagnostic and treatment standards. Since the gene responsible for cystic fibrosis was identified in 1989, genotyping with two identifiable alleles has also met the requirement for diagnosis in the presence of an ambiguous sweat chloride test or a quantity-not-sufficient sweat chloride test (4). Two positive genotypes for CF can also be considered diagnostic.

CF Newborn Screening is available in all states. In Washington, all infants are tested for IRT (Immunoreactive Trypsinogen) at birth. Infants with two positive IRT's are

referred for a sweat chloride by their pediatrician. Infants with a positive sweat chloride are sent to a CF Clinic.

All patients should be followed by an interdisciplinary team at a Cystic Fibrosis Center. The clinical practice guidelines for Cystic Fibrosis, published by the Cystic Fibrosis Foundation, require a coordinated, interdisciplinary approach for the diagnosis and management of patients with CF who have diverse needs and complex treatment plans (4). Typically, the treatment involves professionals in the following areas:

- medicine
- nursing
- nutrition
- physical therapy
- respiratory therapy
- social service
- psychologist

The nutrient needs of a person with CF are often difficult to meet because of both increased nutrient requirements and decreased food intake. The energy requirement is increased because of hypermetabolism intrinsic to the genetic defect, increased losses of nutrients attributable to pancreatic insufficiency and chronic pulmonary infection, as well as in some instances, sinusitis. Decreased intake is the result of emesis due to coughing, increased work of breathing, anorexia from both GI and pulmonary symptoms and psychosocial issues (2,5).

Pancreatic insufficiency is controlled with the use of pancreatic enzymes containing lipase, protease, and amylase. There are several brands and doses of products available. Generic enzymes are not approved for patients with CF. Powdered enzymes are also no longer recommended. Enzymes are administered via capsules with acid resistant coated microspheres released in the alkaline pH of the duodenum. It is recommended that the enzymes be taken prior to meals, snacks and enteral feedings either in the intact capsule form or with the enteric-coated microspheres mixed with an acidic food (2,6,7). Recommendations from the Cystic Fibrosis Foundation are to limit the amount of lipase to 2500 IU lipase per kg per feeding or meal.

Because of the increased median age of survival of patients with CF today, secondary illnesses are more common. These include CF-related diabetes, liver disease, and osteoporosis, which require specific interventions as well (2). The effects of the disease on growth are more noticeable. Adequate health care for these patients requires close attention to their nutritional needs. The goal of nutrition intervention is to promote normal growth and development and optimal resistance to infection.

Current research is showing that deterioration of pulmonary function can be reversed and catch-up growth achieved by means of nutrition support (8,9).

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with cystic fibrosis. Nutrition assessment for CF includes the components listed in the table four times per year and is performed by the registered dietitian (RD) in the Cystic Fibrosis Center. The following is included to clarify the information to community RDs who concurrently see patients with CF who are managed at a designated CF center. The community RD and CF Center RD will need to work together to coordinate care and avoid duplication of services.

Table 17-1: Nutrition Interventions for Cystic Fibrosis

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for height (or length) or BMI • Head circumference (under 3 years) Determine height-age,† weight-age, and ideal weight for height (IBW).‡ Compare current weight to ideal weight for height. **CF standards for malnutrition[5]** The CF Foundation has set standards for all patients with CF to have a Wt/Ht or BMI at the 50th percentile or greater. • 10th-50th percentile BMI or Wt/Ht=at risk • 5-10th percentile BMI or Wt/Ht=malnourished • <5th percentile BMI or Wt/Ht=severely malnourished	Adjust recommendations for energy intake, based on growth.	Child gains and grows to genetic potential, follows curve of growth chart.
Calculation of stunting Actual height ÷ height at 50th percentile for age 50th percentile height for age Classification of stunting • 95-100% Normal • 90-94% Mildly stunted • 85-90% Moderately stunted • <85% Severely stunted Repeat measurements 1-4 times per year.		

Assessment	Intervention	Evaluation/Outcome
Measure: • Triceps skinfold • Midupper arm circumference Calculate: • Arm muscle circumference • Arm fat area Repeat measurements 1-4 times per year. Obtain all available previous measurements. Compare all current measurements to reference data for chronological age and to previous measurements.	Adjust recommendations for energy and protein intake based on measurements.	Indicators of fat and muscle stores within normal limits.
Biochemical		
The following are yearly labs for patients with CF ordered by the CF center following the patient:[4] • complete blood count with differential • serum vitamin A • serum vitamin E • serum vitamin D • liver function tests • casual glucose (random) • oral glucose tolerance test (>10 years of age) • urinalysis	Recommend supplemental vitamins A, E, and K, as appropriate. Adjust recommendations for other nutrients, as appropriate.	Normal serum vitamins A, E, and prothrombin time. Liver function tests, hemoglobin A1C, glucose tolerance within are normal limits.
Other labs, which may be ordered based on clinical symptoms: • 72-hour fecal fat test • Fecal elastase (on all newborns) with positive CF newborn screens • prothrombin time • albumin • bone mineralization status • oral glucose tolerance test (<10 years of age)	Adjust recommendations for nutrient intake (fat, fat-soluble vitamins, protein, calcium, etc.), as indicated by labs.	Fecal fat, prothrombin time, albumin levels are within normal limits. Bone mineralization and glucose tolerance are normal.

Assessment	Intervention	Evaluation/Outcome
Clinical		
Assess for • stool (frequency, consistency, size, and color) • abdominal cramping or pain • use of pancreatic enzymes (product name, dose, and frequency) • use of over-the-counter medications as alternative nutrition therapies Rule out dehydration.	Adjust pancreatic enzyme dose to achieve optimal absorption and prevent constipation without the risk of fibrosing colonopathy (sometimes associated with an excessive dose or abrupt discontinuation of pancreatic enzymes). Rule out distal intestinal obstruction syndrome (DIOS), which has similar symptoms to obstipation or constipation. (Patient needs to be seen in a CF center.)[10]	Fewer stools (2/day) and normal consistency Fewer stomach aches No rectal prolapse Re-evaluate pancreatic enzyme dosage at each clinic visit.
Identify possible medication-nutrient interactions, including nausea, vomiting, or diarrhea, possibly attributed to antibiotic therapy.	Address medication-nutrient interactions. (See Chapter 5)	Medication-nutrient interactions are identified and addressed.
Assess effects of chest physio-therapy on intake (can cause vomiting).	If chest physio-therapy causes vomiting, complete meals at least 1 hour before therapy or delay meals until ½ hour after.	Therapy does not interfere with adequate intake.
Assess effects of difficulty with breathing on energy intake (difficult breathing can interfere with ability to chew and swallow).	Consider energy-dense liquid supplement.	Difficulty with breathing does not interfere with adequate energy intake.
Nutrition		
Assess intake by diet history. Determine intake of energy, protein, carbohydrate, fat, vitamins, and minerals with 24 hour recall or food record. Specific guidelines are provided below. Determine use of supplements, enteral products, calorie additives, vitamins, and minerals. Identify product name, amount, and frequency. Obtain exact formula recipe used by the family.	Provide recommendations for adequate nutrient intake. Specific guidelines are provided below. Diet should have no limitations for fat, carbohydrate, or protein.	Patient is tolerating a nutritionally adequate diet without experiencing gastrointestinal symptoms.

Assessment	Intervention	Evaluation/Outcome
Caloric intake is estimated to be at 130%-150% of the RDA for age and Ideal Body Weight. RDA is continued to be used by most CF centers as the DRI for energy does not meet the needs for people with CF.	If energy intake is lower than estimated needs, increase energy intake.[5] **For infants:** Increase energy intake by concentrating formula to ≥24 kcal/oz. (or higher if necessary) When strained baby foods started, add Moducal®, Polycose®, Scandical®, or margarine Avoid foods and drinks that have a low ratio of nutrients to energy (e.g., commercial dinner combinations and fruit drinks) **For children**, increase energy intake by the following means, used in combination: Increase the energy density of usual foods as much as possible without increasing the volume of food Identify and encourage intake of readily available energy-dense foods enjoyed by the patient Formulate recipe for homemade milkshakes, according to individual preference. Include ingredients such as milk, powdered milk, half-and-half, cream, breakfast powders, corn oil, fruits, and/or syrups Use commercial supplements; ie, complete enteral products such as Scandishake®, Ensure®, Ensure Plus®, or Boost®, if acceptable to patient or modular products; i.e., Polycose®, Moducal®, or Scandical®[11]	Intake provides an adequate amount of energy for growth. Caregiver and/or patient increase energy in usual diet by selecting energy-dense foods. Energy-dense products are used appropriately to supplement regular diet.

Assessment	Intervention	Evaluation/Outcome
	All CF centers have patient education materials (written, video) for increasing energy density If patient cannot orally consume adequate energy to maintain weight and nutritional status, consider enteral feedings (i.e., gastrostomy or nasogastric tube).[12,13]	
Estimate individual protein needs.[5] Protein needs may be as high as 150-200% RDA for age for ideal body weight. Infants (less than 12 months): 4.0 g/kg/d Children (1-10 years): 3.0 g/kg/d Males (11 years and older): 2.5 g/kg/d Females (11 years and older): 2.0 g/kg/d	Provide recommendations for an adequate intake of protein.	Intake provides an adequate amount of protein for growth.
Evaluate fat intake. Fat may supply 30-50% of total energy. Fat intake will vary according to weight gain, pulmonary status, and fat tolerance. (There is no limit on dietary fat intake.)	Encourage use of foods containing essential fatty acids (e.g., safflower, corn, sunflower, and sesame oils).	Intake provides an adequate amount of fat for growth.
Evaluate intake of vitamins and minerals.[5] (Specific vitamins and minerals are recommended by CF center RD.) Specific brands are: Sourcecf, Aquadeks and Vitamax.	Provide conventional vitamin/mineral supplements daily (dosage based on DRI/RDA for age). When indicated by lab test results, dietary data, or clinical data, use CF-specific vitamins (Sourcecf, Aquadek, or Vitamax)[14]	Intake of vitamins and minerals is adequate. Caregiver demonstrates appropriate use of vitamin/ mineral supplements.
Evaluate intake of sodium chloride.[4]	Provide salt adequate to meet individual needs. Infants will require supplementation with sodium chloride (table salt). An appropriate and safe dose is 2-4mEq/kg/d. This amount can be provided as ⅛ teaspoon table salt per day.	Intake of sodium chloride is adequate. No episodes of heat exhaustion or dehydration.[4]

Assessment	Intervention	Evaluation/Outcome
Evaluate consistency and appropriate use of enteric-coated pancreatic enzymes.[7] Enzyme dosage is the responsibility of the patient's CF center. Recommendations are to use 2000 to 3000 IU lipase/ kg/meal as the upper limit of dosage, although the patients' needs vary. The most commonly used products include Ultrase, Ultrase MT12, MT18, MT20; Pancrease MT4, MT10, MT16, MT 20; Creon 6, Creon 24, Creon 24., Pancrecarb MS4, Pancrecarb MS8 & Pancrecarb MS16.	Instruct caregivers to • Give enzymes with all foods and drinks (exception: some children may be able to eat simple carbohydrates without symptoms of malabsorption). • Give an adequate number of enzyme capsules. Adequate replacement varies from patient to patient. The required number of capsules may vary, depending upon: a) amount of food eaten b) protein, fat, and carbohydrate content of foods c) stool size, frequency, and consistency • Carry enzymes at all times for convenient use. Keep enzymes at child's bedside when in hospital, if approved by the hospital. • Check enzymes for freshness. When out-of-date or exposed to temperature extremes, enzyme beads may shrivel and turn a darker beige color. **For infants**, instruct caregivers: • Open capsules to be taken and place in small amount (1/4 tsp) strained fruit or yogurt. • Give enzymes by spoon at the start of each feeding. • Enzymes are effective for approximately 1 ½ hours. • Check baby's mouth to see that no beads remain under tongue or between gums and cheeks. Beads may cause tissue breakdown and discomfort if left in mouth.	Enzymes are provided in an appropriate dose and are used consistently.

Assessment	Intervention	Evaluation/Outcome
	• Do not crush beads; enteric coating will be destroyed. • Do not add beads to baby's bottle. Beads will block the nipple opening. **For children**, **instruct**: • Swallow enzymes in capsule form, once they are able to safely swallow capsules. • Do not chew beads; enteric coating will be destroyed.	

* For reference data and guidelines for taking accurate measurements, see Chapter 2.

† Height-age is the age at which the child's current height (or length) would be at the 50th percentile on the growth chart. Weight-age is the age at which the child's current weight would be at the 50th percentile.

‡ Ideal weight is the weight that would place the child at the 50th percentile for weight for height (or length).

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CHAPTER 18

Nutrition Interventions for Congenital Heart Disease

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Congenital heart disease (CHD) refers to cardiovascular defects that are present and usually evident at birth. Most commonly, these defects include ventricular or atrioventricular septal defects, Transposition of the Great Arteries, Tetralogy of Fallot, Coarctation of the Aorta or a single ventricle. With improved detection, diagnosis, medical management, and surgical techniques, the number of children surviving with congenital heart disease is increasing (1). Presently, surgical repair in this population is often delayed in order to permit increased weight gain (2). Surgery is performed when a patient reaches an ideal weight and age, or when failure to thrive precludes further waiting (2). See Table 18-1 for a list of congenital cardiac anomalies.

Children with CHD often demonstrate slow growth, which becomes apparent early in life. Depending on cardiac status, many factors may cause poor growth:

- Chronic deficit of oxygen in cyanotic patients
- Decreased food intake due to poor appetite, fatigue, or oral aversions
- Decreased gastrointestinal absorption
- Increased energy needs due to increased cardiac workload
- Increased susceptibility to infection with frequent illnesses
- Decreased gastric/intestinal motility and associated reflux disease.
- Increased resting metabolic rate
- Poor cardiac output resulting in decreased splanchnic blood flow which may lead to early satiety, nausea and vomiting

Congestive heart failure (CHF) may be a result of CHD due to the heart having to work harder than usual. CHF is a serious condition in which the overworked heart becomes strained and does not pump blood efficiently. As the heart works harder, the metabolic rate rises, and energy requirements increase. Further contributing to the increased energy requirement is a decrease in the rate of gastrointestinal absorption resulting from reduced cardiac output (3,4,5).

In CHF, the heart's inefficient pumping causes fluid to back up into the lungs, the liver, and other organs. Therefore, children with CHF often require fluid restriction

and/or modification of dietary sodium. When a child's fluid intake is limited, it becomes difficult to provide adequate energy intake (4,5). See Appendix T for information about increasing the energy density of formula.

CHF can affect either side of the heart. In children with CHD, right-sided CHF is the most common. Children with right-sided failure may have gastrointestinal malabsorption, vomiting, and diarrhea mimicking the common symptoms of milk allergy or formula intolerance. Children with left sided failure may have tachypnea (rapid breathing), tachycardia (rapid heart beat), and/or diaphoresis (sweating) (4). Infants with both types of failure tend to tire easily and may not be able to breastfeed or bottle-feed without developing shortness of breath (4, 5).

Malabsorption has been suggested as a cause for growth failure. Some studies report fat and/or protein malabsorption in infants with CHF while others report varying degrees of fat malabsorption in infants with all types of CHD (2,4). Protein losing enteropathy is a condition reported in patients with increased right-sided heart pressures, especially those young children who have undergone the Fontan or Bidirectional Glenn procedure (6).

Decreased perfusion to the gastrointestinal (GI) tract often leads to delayed gastric emptying, vomiting and gastroesophageal reflux (GERD) in infants and children with moderate to severe heart failure (6). Reflux can be managed with medications and/or an adjustment to the infant's feeding (6). Surgical intervention (gastric fundoplication) is effective in managing severe reflux in order to promote weight gain in children with severe congenital heart defects (7).

Reduced blood flow to intestinal tract may occur when the body shunts blood away from the gut to preserve heart and brain function in the child with moderate to severe heart failure (6). This reduction in blood flow can cause early satiety, nausea and vomiting which in turn may result in decreased nutrient absorption (6).

Often, complications can arise after cardiac surgery. One such complication is the formation of a chylothorax. When the thoracic duct or tributaries are injured during extra pericardial operations, chyle can accumulate in the pleural spaces. This is especially common in surgeries involving mobilization of the aortic arch or coarctation of aorta as well as with a Blalock-Tausig shunt. A chylothorax can also occur spontaneously due to increased pressures within the heart itself (8,9). Conservative nutrition treatment of a chylothorax includes the use of very low fat diet. Infants and young children may require specialized formulas containing high amounts of medium chain triglycerides (MCT) (6). Medium chain triglycerides by-pass the lymphatic system and are directly absorbed into the bloodstream via the portal venous system; therefore, reducing chyle production and slowing/eliminating

the chylous drainage (8). Depending on the long chain fat content of the diet or formula used, it may be necessary to supplement long chain fatty acids to prevent essential fatty acid deficiency.

Nutrition goals for infants/children with CHD (6):

- Provide adequate calories and protein, taking into account potentially increased needs.
- Promote normal weight gain and growth velocity.
- Promote oral feeding as able. Chronic illness or extended hospitalization may result in oral feeding challenges.
- Maintain normal/near normal electrolyte levels. Watch closely for abnormalities if the child is on highly concentrated enteral feedings or certain medications.

If a child has documented growth failure or is having difficulty meeting nutrition needs with an oral diet, supplemental tube feedings may be considered for additional energy and protein (4,10). There are several factors to consider before deciding if a temporary or permanent feeding tube should be placed. These factors include the length of time, ease of care, appearance and the risks of nasogastric versus gastrostomy tube feeding. A percutaneous endoscopic gastrostomy tube (PEG) is a safe and reliable technique to support enteral nutrition in children with severe CHD (10). This technique allows enteral nutrition support without the disadvantages related to long term nasogastric tube feeding (10).

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with CHD (Table 18-2).

TABLE 18-1: CONGENITAL CARDIAC ANOMALIES

Defect	Description	Symptoms	Treatment	Growth/Developmental Implications
Cyanotic/ Hypoxic	R to L shunts	See specfic anomaly below.	See specfic anomaly below.	Tend to be more severely growth retarded overall; generally work within their internal limits of oxygen availability; more developmental delays compared to children with acyanotic defects
Tetralogy of Fallot	R ventricular outflow obstruction; ventricular septal defect (VSD); narrowed pulmonary valve; thickened R ventricular wall; displaced aorta	Cyanosis; dyspnea	Primary repair	Moderate growth failure, especially with regards to weight
Transposition of the Great Arteries (TGA)	Two parallel and separate circulatory systems exist, one pulmonary and one systemic	Cardiomegaly; cyanosis	Arterial switch	Growth retardation in 30-50% of patients.
Pulmonary Atresia	Complete obstruction of pulmonary artery resulting in total diversion of blood from R ventricle to aorta	Murmur; CHF; not compatible with life unless there is an inter-atrial communication and pathway for entry of blood into pulmonary circulation (ie, patent ductus arteriosus (PDA)	Systemic to pulmonary shunt; may also have a pulmonary valvulotomy or pulmonary outflow patch (later in childhood)	Poor feeding and growth

Defect	Description	Symptoms	Treatment	Growth/Developmental Implications
Tricuspid Atresia	Absence of any communication between R atrium and R ventricle; blood from R atrium passes through atrial septal defect (ASD) into L atrium, mixes with oxygenated blood returning from lungs, flows into L ventricle, and is sent into circulation; VSD usually present.	Slightly increased heart size	Staged surgical repair: Stage 1: Cavo-Pulmonary Shunt or "Glenn". Connects superior vena cava (SVC) to R pulmonary artery to direct blood from upper circulation to lung w/o return to heart Stage 2: Fontan (later in childhood). SVC and inferior vena cava (IVC) are connected to pulmonary artery so that lung circulation operates w/o separate ventricle (which is too small to do its job)	40% of children have marked weight and height growth retardation
• Hypoplastic Left Heart	L side of heart poorly formed and cannot support main circulation; L ventricle and aorta are small; syndrome including severe coarctation, severe aortic valve stenosis or atresia, and severe mitral valve stenosis or atresia	CHF; heart murmur in 2/3 of patients	Staged surgery - mortality high even with surgical intervention: Stage 1: Shunt from R arm artery to R pulmonary artery for blood flow to lungs Stage 2: Cavo-Pulmonary Shunt or "Glenn" (see above). Previous shunt removed Stage 3: Fontan (if needed-see above)	Poor feeding, growth, and failure to thrive after surgery; nutritional status deteriorates post-op
Acyanotic	L to R shunts	Dyspnea	See specific anomaly below	Poor feeding; typically affects weight rather than length (except for Coarctation of the Aorta and Pulmonary Stenosis)
PDA (Patent Ductus Arteriosis)	Failure to close the fetal communication between the pulmonary artery and aorta	Heart murmur	Fluid restriction; pharmacologic closure (Indocin or Ibuprofen); surgical ligation	Weight negatively affected prior to duct closure; growth acceleration following closure

Defect	Description	Symptoms	Treatment	Growth/Developmental Implications
VSD (Ventricular Septal Defect)	Most common heart defect - "Hole in heart"; abnormal opening between the right and left ventricle	CHF	Primary closure	Highest frequency of severe growth failure (>2 std dev below mean); poor feeding; slow weight gain
ASD (Atrial Septal Defect)	Abnormal opening between the right and left atria	Asymptomatic or mild respiratory symptoms; may not be detected until school age	Direct closure of defect or patch graft	Normal growth unless lesion is severe, then poor weight gain
Aortic Stenosis	Obstruction to the left ventricular outflow; aortic valve is thickened and narrowed leading to ↑ pressure in L ventricle	Variable presentation; narrowing worsens with growth.	Valvotomy	Growth failure noted in 16% of patients
Coarctation of the Aorta	Narrowing of the aortic lumen	Elevated upper extremity blood pressure; congestive failure	Medical management, balloon angioplasty, or surgical repair	Growth normal with simple defect; linear growth affected more than weight
Interruption of Aortic Arch	Part of aorta absent leading to severe obstruction of blood flow to lower part of body; PDA initially allows flow but after closure BP in lower circulation inadequate	Difficulty breathing; impaired renal function	Surgical repair	Poor feeding; slow weight gain
Pulmonary Stenosis	Obstruction to R ventricular outflow	Variable presentation	Valvotomy	Normal growth unless lesion is severe; linear growth affected more than weight

TABLE 18-2: NUTRITION INTERVENTIONS FOR CONGENITAL HEART DISEASE

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for length or BMI • Head circumference (under 3 years) Repeat height/length, weight and OFC measurements at every child visit	Adjust recommendations for energy intake, based on growth	Rate of weight gain and growth are appropriate
Measure: • Triceps skinfold • Mid-upper arm circumference Calculate: • Arm muscle circumference • Arm fat area Obtain all available previous measurements. Compare all current measurements to reference data for chronological age and to previous measurements	Adjust recommendations for energy, protein intake based on measurements	Indicators of fat and muscle stores within normal limits
Biochemical		
Evaluate iron status: • MCV (mean corpuscular volume) • Serum transferrin saturation	If iron deficiency is evident, supplement with iron while carefully monitoring hematocrit, hemoglobin, MCV, and serum transferring saturation: Note: hematocrit and hemoglobin are often elevated because of an increased number of red blood cells (polycythemia) to compensate for the cardiac defect; iron deficiency may exist even if hematocrit and hemoglobin levels are high; children with congestive heart failure may have chronic constipation, which can be aggravated by iron supplements	Serum transferrin saturation and MCV are within normal limits

Assessment	Intervention	Evaluation
Clinical/Medical		
Evaluate possible medication-nutrient interactions (e.g. diuretic-induced potassium, magnesium, and/or calcium excretion). Monitor weight gain and edema	If concerns about medications-nutrient interactions exist, consult with primary care physician; also see Chapter 5	Concerns about medication-nutrient interactions are addressed
Evaluate water retention (need for fluid and/or sodium restriction)	If sodium restriction is indicated: • For infants, evaluate sodium content of infant formula Low sodium infant formula such as Similac®, Similac PM60/40®, or Good Start® may be needed • For infants, commercial baby foods or homemade baby foods without added salt should be used • For children, diet with no added salt should be used Counsel caregivers on: • Measurement of liquids • No added salt diet	Excessive weight gain and edema are minimized
Evaluate malabsorption (diarrhea, or ›0.5% reducing substances in stool)	If malabsorption, vomiting or diarrhea is evident: • Decrease concentration of formula • Try small, frequent feedings and/or continuous nasogastric drip feedings If malabsorption, vomiting, or diarrhea persist change to hydrolyzed protein formula (e.g., Alimentum®, Nutramigen®, Pregestimil®) or semi-elemental formula (e.g., Peptamen Jr.®, Vital®) or elemental formula (e.g. Elecare®, Neocate®, Vivonex Pediatric®) or "fat free" formula (e.g., Tolerex®) or high MCT formula (e.g., Lipistart®, Portagen®,) or added MCT oil to diet in place of other fat **Note:** MCT oil can cause diarrhea, start with very small amounts and increase slowly	Malabsorption, vomiting, or diarrhea improved

Assessment	Intervention	Evaluation
Dietary		
Obtain diet history and/or 3 to 7 day food record; assess intake of energy, protein, vitamins, minerals, and electrolytes • Energy needs for infants may range from 120-180 kcal/kg/ day • Energy needs for older children may be significantly higher than normal, 120-150 kcal/kg/day for toddlers Recommended distribution of energy: • 8-10% from protein; protein should be given at a minimum of the recommended for age • 35-65% from carbohydrate • 35-50% from fat	Recommend adequate energy intake including: • Increased concentration of infant formula (if urine osmolarity is maintained below 400mOsm)[3] • Increased energy in food or infant formula by adding carbohydrate (e.g., Moducal® or Polycose®) or fat (e.g., vegetable oil, margarine, MCT oil)+ • Counseling about dietary supplements • Fortified breast milk (adding formula or modular®) • Separation of hind milk from fore milk for pumped breast milk; use hind milk for feedings • Consideration of tube feeding if a child has documented growth failure and/or having difficulties with oral feeding • Consider speech/and or occupational therapy consult if poor oral intake	Nutrient intake is adequate

*For reference data and guidelines for taking accurate measurements, see Chapter 2

† For more information about products to increase energy see Appendix S and for guidelines to increase energy in formula see Appendix T.

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CHAPTER 19

Nutrition Interventions for Chronic Kidney Disease

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Chronic kidney disease (CKD) in children may be due to congenital anatomical defects (e.g., urologic malformations, or dysplastic kidneys), inherited disease (e.g., autosomal recessive polycystic kidney disease), or metabolic disorders which eventually result in renal failure (e.g., cystinosis or methylmalonic aciduria). CKD may also be due to acquired causes such as untreated kidney infections, physical trauma to kidneys, exposure to nephrotoxic chemicals (including some medications), or illnesses that damage the kidneys (e.g., hemolytic uremic syndrome or glomerulonephritis). CKD is a progressive disorder, which may lead to End Stage Renal Disease (ESRD) which is less than 5 10% renal function. ESRD requires some type of renal replacement therapy (dialysis or kidney transplant). Depending on the cause of CKD, a child may be polyuric or oligo/anuric. The child with polyuria may "waste" electrolytes (sodium, potassium), while the child with oligo/anuria may retain electrolytes. Many children with CKD have other concurrent medical problems (e.g., heart, lung, or liver problems). The former premature infant with CKD may have lung disease and be on steroids and diuretics. In all cases, treatment must be individualized depending on weight gain, growth, laboratory values, hydration status, and other patient specific issues.

Poor weight gain and growth are major issues for most children with CKD. These problems are caused by a variety of factors: (1-6)

- Anorexia, resulting in inadequate nutrient intake
- Uremia
- Renal osteodystrophy (bone disease)
- Electrolyte and mineral imbalances (sodium, potassium, calcium, phosphorus)
- Metabolic acidosis
- Anemia
- Abnormal growth hormone metabolism
- Nutrient losses on dialysis
- Psychosocial factors resulting in poor nutritional intake

Normal growth and development depends on many factors, the main one being adequate nutrition support. Nutrition management of children with CKD involves meeting nutrient needs while avoiding excesses of substances that accumulate because of renal insufficiency. A child with CKD needs to receive adequate energy for weight gain and at least the DRI for protein. Protein restriction below the Dietary Reference Intake (DRI) has not been found to be beneficial for children with CKD (7). Sodium may be restricted if hypertension is a problem. Sodium, potassium, and phosphorus are restricted if blood levels are high and increased if levels are low. There is not one specific diet that meets the needs of all children with CKD.

CKD is staged by a combination of age, height, and creatinine level. The glomerular filtration rate (GFR) is estimated by the Schwartz formula for children 2 years of age and older. Confirm CKD stage with nephrologist(8).

GFR (ml/min/1.73m²) = (0.413 x height (cm)/creatinine (mg/dL))

Table 19-1 Stages of Chronic Kidney Disease

Stage	Description	Glomerular Filtration Rate (Gfr)	Action
	At increased risk	>90 with CKD risk factors	Screening. CKD risk reduction
1	Kidney damage with normal or increased GFR	>90	Diagnose & treat. Treat comorbid conditions. Slow progression. Cardiovascular disease risk reduction
2	Mild decrease in GFR	60-89	Estimate progression
3	Moderate decrease in GFR	30-59	Evaluate and treat complications
4	Severe decrease in GFR	15-29	Preparation for kidney replacement therapy
5	Kidney failure	<15 or dialysis	Replacement, if uremia is present

Supplemental nasogastric or gastrostomy tube feedings are necessary to meet energy and protein requirements in the majority of infants and young children with CKD (3). Commercial formulas have been designed to meet the special needs of infants, children and adults with CKD. These can be used alone or with modular products to meet an individual's needs. Both low and high protein "renal" enteral formulas are available. They are energy-dense and can be diluted. The formula can be used separately or combined to achieve specific energy and protein goals. For example, a child with CKD, not yet on dialysis, may need a high energy, low protein supplement (e.g., Suplena Carb Steady®, Abbott). A child on peritoneal dialysis may need a high energy, high protein supplement (e.g., Nepro Carb Steady®, Abbott; Nova Source Renal®, Nestle).

Even with adequate nutrition, a child with CKD will not grow unless metabolic acidosis is corrected and bone disease is treated. Metabolic acidosis (diagnosed by a low serum bicarbonate level) is a major factor in failure to thrive and contributes to bone demineralization; it is generally corrected by giving sodium bicarbonate.

The biggest factor in bone demineralization is 1,25(OH)2 vitamin D deficiency. Vitamin D is activated in the kidney. As kidney function decreases with CKD, activation of 25 (OH) vitamin D to1,25 (OH)2 vitamin D is decreased. This results in decreased intestinal absorption of calcium and subsequent hypocalcemia. Hypocalcemia stimulates the production of parathyroid hormone (PTH), which results in release of calcium from the bone. Deficiency of 25(OH) D is also common in children with CKD and should be corrected prior to treatment with activated Vitamin D. In the early stages of CKD, correction of 25(OH) Vitamin D levels may result in a normal PTH level.

Another factor in bone disease is retention of phosphorus in the blood. This also stimulates production of parathyroid hormone, further increasing mineral loss from the bone. Bone disease is prevented and treated by giving vitamin D2 or 3 if 25 (OH) Vitamin D level is low, as well as 1,25 (OH)2 vitamin D (calcitriol, paricalcitol) based on PTH levels. It is also necessary to limit phosphorus in the diet and give phosphate binders with meals. Calcium carbonate, calcium acetate and sevelamer are the most commonly used phosphate binders. The calcium based binders also serve to supplement calcium. With vigilant attention to treatment, bone development can be fairly normal (1).

Anemia is a major problem for all patients with significant CKD. The main cause of anemia is decreased production of the hormone erythropoietin by the kidneys. Erythropoietin stimulates the bone marrow to produce red blood cells. Anemia is treated by giving erythropoiesis-stimulating agents (ESA’s), such as epoetin alpha or darbepoetin, subcutaneously or parenterally up to 2 to 3 times per week. In order for ESA’s to work to produce red blood cells, adequate amounts of iron must be given. Iron stores are quickly depleted when ESA’s are started, and hematocrit is rapidly increased (5). It is often necessary to give IV iron to patients on ESA’s to keep up with the demand for production of red blood cells (1).

Despite early medical intervention and adequate nutrition support, children with CKD often continue to exhibit slow growth and rarely achieve catch-up linear growth without the use of recombinant growth hormone therapy (1,4,5,9). Long-term growth hormone treatment of growth retarded children with CKD results in significant improvement in linear growth with few side effects. Many children with CKD treated with growth hormone from a young age are able to reach their genetic potential.

Although difficult to measure, psychosocial factors can be major contributors to poor growth and malnutrition. Chaotic home life, poverty, poor coping function of parents, as well as low self esteem, and/or depression in the child with CKD all compromise ability to comply with the complex medical and nutrition therapies necessary for successful treatment of CKD (1). The registered dietitian (RD) must work closely with the social worker to optimize family compliance with regimens to meet nutrition needs.

The remainder of this chapter presents basic guidelines for nutrition assessment, intervention, and evaluation/outcome for children with CKD. It is impossible to give guidelines for every situation one could see in an infant or child with CKD; it is critical that clinical judgment be used in providing nutrition intervention for these children. Due to the complexities of CKD, regular assessment and monitoring by a pediatric renal team (nephrologist, nurse, RD, and social worker) is essential for comprehensive care of a child with CKD.

Table 19-2 Nutrition Interventions for Chronic Kidney Disease in Children

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for length or BMI • Head circumference (under 3 years) Determine height-age,† weight-age,‡ and ideal weight for height. Compare current weight to ideal weight for height.ʃ Calculate rate of weight gain and linear and OFC growth. Repeat height/length, weight and OFC measurements at every clinic visit.	If weight for stature and/or rate of weight gain is low, increase energy intake. If weight for stature is high and rate of weight gain is high, decrease energy intake. If length or height is <5th percentile, and/ or rate of linear growth is less than 50th percentile, growth hormone therapy may be considered.	Weight for stature between 25th and 75th percentiles Weight and height (or length) increase appropriately. (Expect much higher rate of growth if patient receiving growth hormone and is getting adequate nutrition).
Measure: • Triceps skinfold • Mid upper arm circumference Calculate: • Arm muscle circumference • Arm fat area Repeat mid upper arm circumference and triceps skinfold at least every 3 to 6 months Obtain all available previous measurements. Compare all current measurements to reference data for chronological age and to previous measurements.	Use arm muscle and fat calculations, together with weight, length or height, and OFC in determining nutritional status and developing intervention plan.	Arm muscle circumference >25th percentile for age Arm fat area between the 10th and 75th percentiles for age. *Note: Arm anthropometry is limited by differences of intra-operator measures and fluid overload and is not routinely recommended for children with CKD. However, serial measurements by the same clinician performed on children without fluid issues may provide useful information.*
Biochemical		
Monitor all blood values every 3 to 6 months for CKD patients, monthly for ESRD patients on dialysis.	All changes in diet, or medications, based on labs should be done in coordination with physician managing patient's care.	

Assessment	Intervention	Evaluation/Outcome
Sodium (Na)	High or low serum Na, indicates fluid balance problems and/or high or low sodium intake. Determine dietary responses in consultation with physician.	Normal serum sodium:* 135 145 mEq/l
Potassium (K)	If serum K is high, restrict K intake: 1-3mEq/kg/day (1meq = 39mg) Consider K supplement if K is low.	Normal serum potassium:* 3.5-5.5 mEq/l
Creatinine (Cr)	Cr is a measure of kidney function. Normal values increase with increased skeletal muscle. Cr will be high in CKD. Knowing Cr helps the RD to know how advanced the CKD is.	Normal serum creatinine: ≠ 0 - 1 week 0.2 - 1.1 1 week - 2 months 0.1 - 0.6 2 month - 2 years 0.1 - 0.4 2 years - 10 years 0.1 - 0.6 10 years - 14 years 0.2 - 0.9 >/= 14 years 0.2 - 1.1
Blood urea nitrogen (BUN)	BUN is a measure of protein waste products in the blood. If BUN is very high (>80-100), it may be a major indication for initiation of dialysis. Protein intake may need to be reduced to the DRI for age or slightly less if BUN is high and dialysis cannot be immediately started. BUN >80-90 on dialysis may indicate need for decrease in protein intake, or change in dialysis regimen. BUN <10 times Cr or in the normal range indicates inadequate protein intake; need to evaluate current protein intake and increase it.	Normal BUN: 6-20 mg/dl*

Assessment	Intervention	Evaluation/Outcome
Albumin	Serum albumin may be low in patients "spilling" protein in urine, with elevated C-reactive protein (CRP) and in setting of fluid overload. Evaluate albumin and BUN together to determine need for increased protein intake.	Normal serum albumin:* • Newborn, infant: 2.9-5.5 gm/dl • Child and adult: 3.8-5.4 gm/dl
Phosphorus (P) Calcium (Ca)	If serum P is high and serum Ca is within normal limits or low: • Restrict phosphate intake by limiting dairy to 1-2 servings per day (1 serving = 1 cup milk, which provides ~230 mg phosphorus) • Use a phosphate binder such as calcium carbonate or calcium acetate taken with meals (e.g., Tums, Oscal 500, PhosLo) If serum Ca is low: • Provide supplemental Ca as calcium carbonate • Evaluate calcitriol (activated vitamin D), consider increasing If serum P is low and serum Ca is low: • Increase P in diet, allow more milk products, alter tube feeding formula to increase P, or provide P supplements (e.g., Neutra-Phos or IV form of Na PO4, given enterally/orally) • Evaluate calcitriol, consider increasing • Decrease calcium carbonate or calcium acetate and replace with calcium gluconate or calcium glubionate (have less of a P-binding effect), give calcium apart from meals	Normal serum phosphorus:* • Newborn: 4.5 - 9.0 mg/dl • Child: 4.0-6.0 mg/dl • Adult: 2.5-4.9 mg/dl Normal serum total calcium:* • Infant (full term): 7.5 - 11.0 mg/dl • Child - Adult: 8.7-10.7 mg/dl

Assessment	Intervention	Evaluation/Outcome
	If serum Ca is high: • Decrease Ca intake and temporarily discontinue or decrease calcitriol (vitamin D) If serum Ca is high AND serum P is high: • Strictly limit dietary P; if on tube feeding, further decrease P • Temporarily discontinue calcitriol • Temporarily give a non-Ca containing P binder such as Renagel® (inert binder made by Genzyme) or aluminum hydroxide, (if Renagel® unavailable)	
Intact Parathyroid Hormone (iPTH)	High iPTH indicates loss of Ca from the bones. If Vitamin D 25(OH) is normal, increase calcitriol to suppress iPTH (if serum Ca is not high). If serum Ca is high, give Hecterol® (oral) or Zemplar® (oral or IV), vitamin D derivatives which have less effect on serum Ca.	Normal Intact Parathyroid Hormone:◇ 10–65 pg/mL <1 yr Unlikely to differ significantly from 9-59 but values have not been established. 1 - 9 years 9 - 59 10 - 13 years 11 - 74 14 - 17 years 9 - 69 Concern in CKD if >100, or increasing Goal for ESRD 2-3 times normal level
Bicarbonate	If serum bicarbonate is low, add or increase bicarbonate supplement.	Normal serum bicarbonate level:≠ 18-27 (desired range: ≥22)
Iron studies: • Serum iron • Total iron binding capacity (TIBC) • % saturation • Hemoglobin • Hematocrit	If iron stores are low, increase oral iron supplements or consider IV iron. If hemoglobin is low, recommend increase in ESA.	Iron Studies, use laboratory normal values≠ • Serum Fe: 20-123 ug/dL • TIBC: 250 – 400 ug/dL • % Saturation: 15-50% • Hemoglobin: 11.5-15.5 ug/dL • Hematocrit > 30% in patient with CKD

Assessment	Intervention	Evaluation/Outcome
Clinical		
Check blood pressure.	If blood pressure is high, restriction of sodium intake may be necessary. Sodium restricted diet is 2 to 4 mEq/kg/day (1 mEq = 23mg).	Normal diastolic blood pressure: • Infants < 65 mm Hg • 2 6 yr < 75 mm Hg • Over 6 yr < 80 mm Hg • Goal <90th percentile for height-age and sex
Nutrition Intake		
Obtain detailed food intake history and/or 3 to 7 day food record to estimate intake of energy and protein. Compare to DRI for age and size and to patient's rate of weight gain and growth.	Provide adequate energy and protein to achieve a weight for height or BMI between the 50th and 75th percentiles If necessary for optimal growth, provide a nutrition supplement orally or via tube to provide adequate energy and protein. Early in course of disease, discuss with caregivers the possibility that tube feedings may be needed to promote growth. Energy: In general, provide DRI for height-age. Consider the following: • Some infants and children may need less energy due to low activity level • Peritoneal dialysis patients usually need less than DRI energy, due to dextrose absorbed from dialysate • Many infants and children have increased needs due to other medical problems or increased activity level	Child is gaining weight appropriately for age and condition (catch up weight gain if underweight; slowed weight gain if overweight). Child's linear growth rate is appropriate for age (greater than normal if he is receiving growth hormone). Serum albumin is within normal limits, and BUN is at least 10 times creatinine to indicate adequate protein intake.

Assessment	Intervention	Evaluation/Outcome
	Protein: In general, provide: • 1-1.4 times DRI for IBW (CKD stage 3) • 1-1.2 times DRI for IBW (CKD stage 4-5) • DRI+0.15-0.3 g/kg (ESRD peritoneal dialysis) • DRI+0.1 g/kg (ESRD hemodialysis)	Child is gaining weight appropriately for age and condition (catch up weight gain if underweight; slowed weight gain if overweight). Child's linear growth rate is appropriate for age (greater than normal if he is receiving growth hormone). Serum albumin is within normal limits, and BUN is at least 10 times creatinine to indicate adequate protein intake.
Assess food intake information for sodium, potassium, calcium and phosphorus intake, as indicated by lab values.	See clinical and biochemical sections for interventions regarding when to adjust sodium, potassium, calcium, or phosphorus intake.	Serum sodium, potassium, calcium, and phosphorus are within normal limits to indicate adequate, but not excessive intakes of these nutrients.

*For reference data and guidelines for taking accurate measurements, see Chapter 2.
†Height-age is the age at which the child's current weight would be at the 50th percentile on the growth chart.
‡Weight-age is the age at which the child's current weight would be at the 50th percentile of the growth chart.
∫Ideal weight for height is the weight that would place the child at the 50th percentile weight for height (or length).
◇Seattle Children's Hospital Laboratory normal levels, 2009.

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CHAPTER 20

Nutrition Interventions for Short Bowel Syndrome

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Definition of Short Bowel Syndrome

Short Bowel Syndrome (SBS) is defined as malabsorption resulting from anatomical or functional loss of a significant length of the small intestine. This occurs most commonly after bowel resection in the newborn period (e.g., secondary to necrotizing enterocolitis, mid-gut volvulus, gastroschisis, or intussusception). SBS can also result from trauma to the bowel (e.g., with an auto accident or fall, or with severe non-accidental trauma). The amount of bowel that must be lost to produce malabsorption is variable and depends on which sections are lost and whether or not the ileocecal valve is preserved. The normal length of small intestine is approximately 300-850 cm for an adult, 200-250 cm for an infant over 35 weeks gestation, and approximately 100-120 cm for a premature infant less than 30 weeks gestation. Loss of greater than 80% of the small bowel is associated with increased requirement for parenteral nutrition support and decreased overall survival. When the ileocecal valve is lost, the resulting risk for bacterial contamination of the small intestine from the colon mandates more small intestine for tolerance of oral/enteral feeding (1,2,3).

The small intestine consists of the duodenum, jejunum, and ileum. (See Figure 1) The majority of carbohydrate and protein absorption takes place in the duodenum and jejunum. Fats and fat-soluble vitamins are absorbed in the ileum. Bile salts are excreted from the liver into the duodenum and are required for the absorption of long chain fatty acids and fat-soluble vitamins in the ileum. Vitamin B12 binds to intrinsic factor (produced in the stomach) and is absorbed in the terminal ileum. Fluids and electrolytes are predominantly absorbed in the ileum and in the colon. When the duodenum and/or jejunum are resected, the ileum can largely adapt to perform their absorptive functions. The duodenum and jejunum, however, cannot adapt to perform the functions of the ileum. Thus, resection of the duodenum or jejunum is generally much better tolerated than resection of the ileum.

The ileocecal valve is the main barrier between the small and large intestine. It helps regulate the exit of fluid and malabsorbed nutrients in small bowel. It also helps

keep bacteria from the large bowel from refluxing into the small bowel. Resection of the ileocecal valve results in decreased fluid and nutrient absorption, and increased bacterial overgrowth in the small bowel (2,3).

Nutritional Support in Short Bowel Syndrome

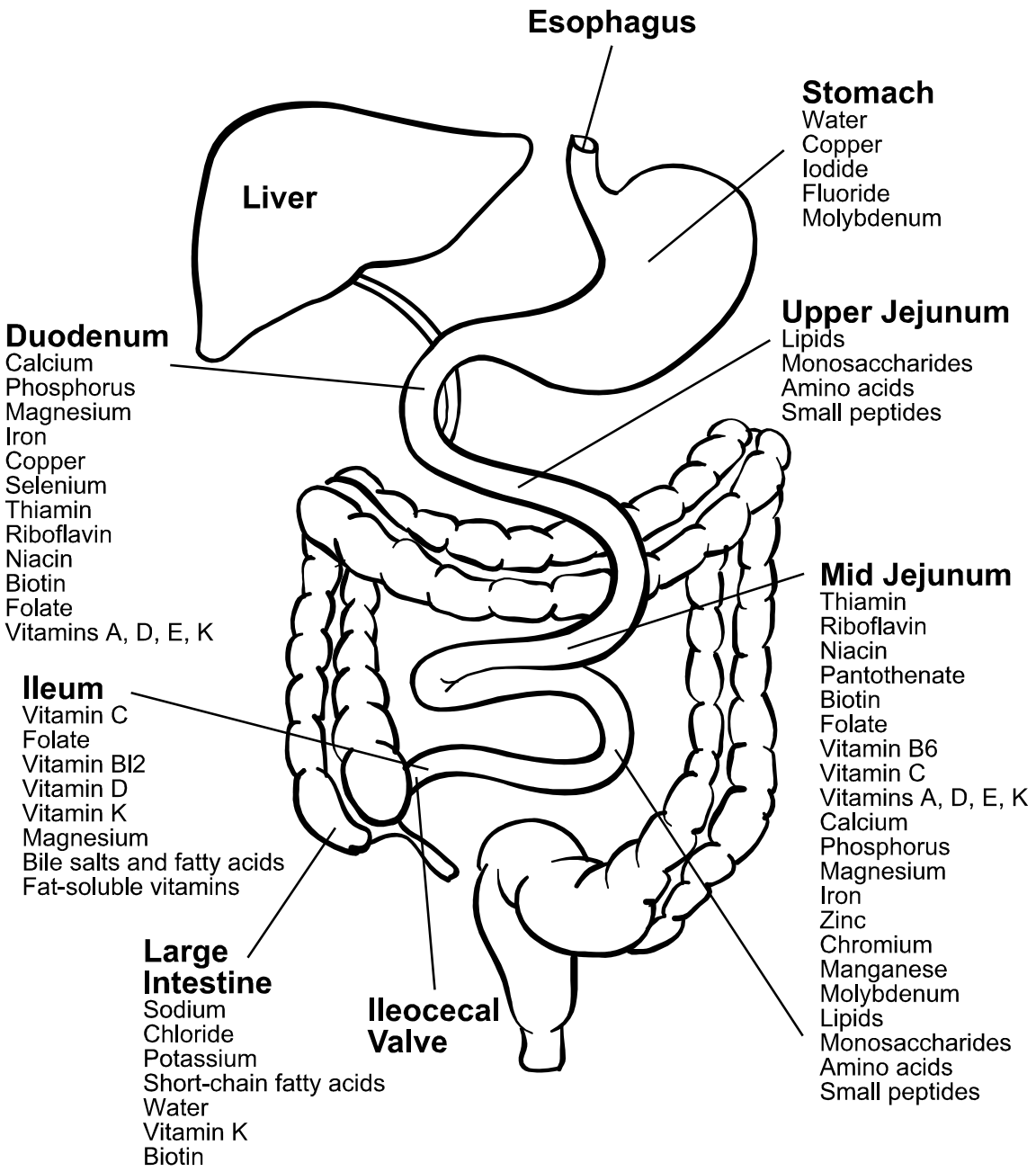
Immediately after a bowel surgery which results in short bowel syndrome, total parenteral nutrition (TPN) is required until bowel function returns (bowel sounds are detected and stool is produced). Depending on the severity of short bowel syndrome, full enteral/oral nutrition may be achieved in a matter of weeks, months, or may never be achieved.

It is important that a patient be given as much enteral/oral nutrition as possible to facilitate bowel growth and increased absorption of nutrients and to decrease the deleterious effects of TPN on the liver (2,3). Patients may require specialized enteral formulas with altered fat, protein, or carbohydrate. Infants are typically given hydrolyzed protein or amino acid-based formula to decrease risk of allergy-like reactions, common with a compromised gastro-intestinal tract (3). If the ileum is resected, fat malabsorption is likely, and fat may be provided as part medium chain triglycerides (MCT) and part long chain fat. Medium chain triglycerides do not require bile salts for absorption and can be absorbed anywhere in the small intestine. Even with fat malabsorption, it is essential to provide some long chain fatty acids, as they are important for gut adaptation after resection (3). Carbohydrate often needs to be decreased to less than that contained in standard formulas, as its malabsorption is a significant problem with a shortened bowel and decreased nutrient transit time. Carbohydrate malabsorption results in an increased osmotic load in the colon and thus watery diarrhea, with increased fluid and electrolyte losses. This can actually be more of a problem than fat malabsorption, because malabsorbed fat does not increase colonic osmotic load and increase fluid and electrolyte losses (2). There are many commercially available formulas that contain free amino acids or peptides for protein and medium chain triglycerides for a portion of the fat. The carbohydrate content of formula varies; choosing the lowest carbohydrate formula available that also meets protein and fat criteria is often helpful in decreasing osmotic diarrhea. Very low carbohydrate modular formulae can be prepared if carbohydrate malabsorption is severe.

Introduction of oral feedings are important for development and prevention of oral feeding aversion. Small boluses of oral feedings of breast milk, formula or an electrolyte solution should be introduced as soon as an infant is stable and increased as tolerated. Solid foods should be introduced when developmentally appropriate (typically by 6 months of age). Foods such as strained meats may be better tolerated

than the cereals, fruits or vegetables due to decreased intestinal transit time and resulting carbohydrate malabsorption (2).

Figure 1. Intestinal Tract - Sites of Nutrient Absorption



Long-Term Nutritional Concerns in Short Bowel Syndrome

Micronutrient Deficiencies

Once a child is on full enteral or oral feeds and parenteral nutrition has been discontinued, adequacy of micronutrient absorption becomes a concern. This is especially important when a significant portion of the ileum is missing. Ileal resection can result in fat and fat-soluble vitamin malabsorption; it is frequently necessary to give fat-soluble vitamins in a water-soluble form. These are available in individual vitamin preparations or in multivitamin preparations (e.g., ADEK's®), which contain water and fat-soluble vitamins, all in a water-soluble form. Additionally, children with ileal resection may need vitamin B12 injections every 1 to 3 months. It can take from several months to several years for a vitamin B12 deficiency to develop; therefore, long-term, regular monitoring of B12 status is necessary. Vitamin B12 is often given routinely to prevent deficiency when the terminal ileum has been resected (4).

Minerals that may be malabsorbed include calcium (often due to vitamin D malabsorption), iron, magnesium, and zinc. These nutrients need to be monitored periodically, especially in the months just after parenteral nutrition is discontinued, and whenever a patient develops a prolonged diarrheal illness or has bacterial overgrowth (4).

Bacterial Overgrowth

Children with short bowel syndrome often have poor intestinal motility and dilated segments of the small intestine. This, plus absence of the ileocecal valve, contributes to the development of bacterial overgrowth (3). Bacterial overgrowth is present when the bacteria in the small bowel exceed normal levels. Bacterial overgrowth results in malabsorption by causing inflammation of the bowel wall and deconjugation of bile acids. This results in rapid reabsorption of bile, leaving very little bile for fat absorption. Symptoms include very foul smelling stools and flatus, bloating, cramps, severe diarrhea, gastrointestinal blood loss, and accumulation of D-lactic acid in the blood. Bacterial overgrowth can be diagnosed by breath hydrogen test either fasting or after an oral glucose load, by aspiration and culture of small bowel contents or by blood test for D-lactic acid. Bacterial overgrowth is treated with oral antibiotics. In many cases it is necessary to give cyclic antibiotics for the first five days of every month. For some patients continuous antibiotics are necessary; in these cases,

antibiotics are rotated every two to three months to avoid overgrowth of resistant bacteria (3,5).

Liver Disease

Parenteral nutrition-associated liver disease (PNALD) is a common complication for children with short bowel syndrome who depend on long term TPN. PNALD affects 40-60% of infants with prolonged PN and it has a significant effect on mortality. Risk factors for development of PNALD include premature birth, extremely short bowel (<15 cm), ileal-cecal valve resection, bacterial overgrowth, early or recurrent catheter-related sepsis, and high parenteral carbohydrate, protein and/or fat administration. Prevention strategies include early introduction of enteral feeding, reduction of PN and prevention of catheter related sepsis by using strict aseptic care techniques. There is some evidence that oral administration of ursodexoxycholic acid (ursidiol) may improve bile flow and reduce gallbladder stasis and thus PNALD. Recent data suggests that parenteral fats enriched with omega-3 fatty acids may benefit children with PNALD; studies are ongoing (1,6,7)

Conclusion

Children with short bowel syndrome require vigilant nutritional care. Those children who are dependent on TPN are generally well monitored. However, it is easy for those who have advanced to oral/enteral nutrition to "fall through the cracks," if their parents and health care providers are not aware of the potential nutritional problems associated with short bowel syndrome. These children need immediate medical care any time they have an illness resulting in increased stool or ostomy output, since they are at very high risk for dehydration and fluid and electrolyte imbalances. They need long term, regular nutrition monitoring to prevent problems associated with macro-and micronutrient malabsorption, which can result in poor weight gain and growth, and nutrient deficiency syndromes.

The remainder of this chapter presents guidelines for nutrition as assessment, intervention, and evaluation/outcome for children with short bowel syndrome.

Table 20-1: Nutrition Interventions for Short Bowel Syndrome

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart (for infants born prematurely, use corrected age until 2 years old): • Height (length) for age • Weight for age • Weight for height (length) or BMI • Head circumference (<3 years) Determine height-age (length),† weight-age.‡ Determine "ideal" weight.ʃ Obtain and plot all previous anthropometric data that are available. Compare current data to previous measurements. Calculate incremental weight gain, linear growth and head circumference growth since last measurements obtained and compare to reference data for age.[8]	If poor weight gain, evaluate need to: • increase energy and protein intake • alter intake to decrease stool or ostomy output. If weight gain is excessive, evaluate need to decrease energy intake (this is most often an issue with patients on parenteral nutrition). If poor linear or head growth with normal weight gains, refer to physician for medical evaluation of poor growth.	Weight for height (length) is between 10th and 90th percentiles. Child is gaining weight and growing at a normal rate for age (or corrected age).[8]
For children over 2 years of age measure: • Triceps skinfold • Mid upper arm circumference Calculate: • Arm muscle circumference • Arm fat area Compare to reference data for age.[9]	Use information from assessment of muscle and fat stores to help in assessment of nutritional status. Concerns: • low muscle and/or fat stores (often an indication of long term inadequate energy intake) • high fat stores with normal or low muscle stores (often an indication of overfeeding with TPN)	Muscle and fat stores within normal limits for age.

Assessment	Intervention	Evaluation/Outcome
Biochemical		
If receiving parenteral nutrition, see Chapter 11 and Appendix O. After parenteral nutrition is discontinued and enteral or oral feedings are sole source of nutrition, monitor serum levels up to once every 4 weeks until levels are within normal limits. Once stable, measure every 6 to 12 months.	If intestinal loss is in ileum, give a water soluble form of fat soluble vitamins (e.g., ADEK's® multivitamin;1mL liquid/day for infants < 1 year; 2 mL liquid/day for children 1-3 years; 1 chewable tablet per day for children 3-10 years; 1-2 chewable tablets per day for children >10 years) Dosages for specific vitamin and mineral supplements will vary depending on a child's age, size, and degree of deficiency; consult the child's physician and pharmacist for appropriate dosage of vitamin and/or mineral to treat deficiency.	Child's micronutrient needs are met and biochemical indicators are within normal limits.
Vitamin A	If deficiency, give additional vitamin A in water-soluble form. Monitor levels every 1-2 weeks while giving high doses of vitamin A to avoid toxicity.	Indicators of vitamin A status are within normal limits.
Vitamin E	If deficiency, give additional vitamin E in water-soluble form. Monitor levels every 2-4 weeks to avoid vitamin E excess.	Indicators of vitamin E status are within normal limits.
Vitamin D, calcium, phosphorus, alkaline phosphatase	If vitamin D deficiency, give high dose vitamin D. Make sure child is receiving at least DRI of calcium and phosphorus. Check serum calcium at least 1 month after high dose vitamin D is started and monthly thereafter to monitor for vitamin D toxicity. Recheck serum vitamin D three months after high dose supplement is started. Once serum vitamin D is within normal limits (32 to 80ng/mL); give maintenance vitamin D of 18 IU/kg/day. Continue to monitor serum 25(OH)D every 3 to 6 months.[10, 11, 12] If serum calcium or phosphorus are low, and vitamin D levels are normal, give supplements of calcium and/or phosphorus.	Indicators of vitamin D, calcium, phosphorus, and alkaline phosphatase are within normal limits.

Assessment	Intervention	Evaluation/Outcome
Magnesium	If deficiency, give Magnesium Protein Complex	Indicators of magnesium are within normal limits.
Zinc	If deficiency, give zinc supplement	Indicators of zinc are within normal limits.
Monitor serum level of vitamin B12 every 6 to 12 months for 3 to 5 years. (It can take years for vitamin B12 deficiency to develop.)	Once vitamin B12 levels are in the low-normal range, begin intramuscular shots of vitamin B12 (cyanocobalamin) every 1 to 3 months.	Indicators of vitamin B12 status are within normal limits.
Clinical		
Assess stool or ostomy output: • If stooling though anus, obtain information regarding number and size of stools per day • If child has ileostomy or colostomy, obtain information regarding approximate volume of output each day	If stool output is high, consider: • need for medical evaluation • need for intravenous fluid (patients with SBS are at high risk for malabsorption and dehydration) Evaluate need to alter feeding: • may need to decrease carbohydrate and/or long chain fats • infants may need to use a modular formula so that carbohydrate and fat content can be manipulated If stool output is high, child may have bacterial overgrowth and need antibiotics. If severe, TPN may be necessary until bacterial overgrowth resolved. Child may have a viral gastroenteritis; therefore, needs careful management of fluid status until gastroenteritis resolves.	Stool or ostomy output is less than 40—50 mL/kg/day.[2]

Assessment	Intervention	Evaluation/Outcome
Dietary		
Obtain diet history or 3 to 7 day food intake record, and analyze for energy and protein. If on parenteral nutrition, calculate energy and protein in parenteral nutrition solution, check contents of vitamin and mineral additives. (See Chapter 11 and Appendix O) Compare intake to DRI for age and to growth and weight gain. Consider: • energy and protein needs of infants and children with short bowel syndrome who are eating or receiving tube feedings are often greater than the DRI • infants and children on TPN may need up to 10% less energy than those fed enterally/orally because of decreased needs for diet-induced thermogenesis. It essential to avoid over feeding, as over feeding is associated with excessive fat deposition, and TPN-induced liver failure.[10] • parenteral protein needs will be the same as for enteral/oral feeding.	Adjust recommendations for nutrient intake.	Energy and protein intake is adequate to promote growth.

*For reference data and guidelines for taking accurate measurements, see Chapter 2.
†Height-age is the age at which the child's current height (or length) would be at the 50th percentile on the growth chart.
‡Weight-age is the age at which the child's current weight would be at the 50th percentile.
ʃIdeal weight is the weight that would place the child at the 50th percentile weight for height (or length).

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CHAPTER 21

Nutrition Interventions for Children With Metabolic Disorders

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Most inherited metabolic disorders are associated with severe illness that often appears soon after birth. Neurologic impairment and mental retardation may occur. However, effective newborn screening programs and advanced diagnostic techniques and treatment modalities have improved the outcome for many of these infants (1,2,3).

Advances in newborn screening technology offer the potential for earlier diagnosis, prevention of neurologic crisis, and improved intellectual and physical outcomes. When tandem mass spectrometry techniques are used in newborn screening laboratories, infants with a broader range of metabolic disorders can be identified, and identification can be earlier than ever before (3).

The goal of treatment for inborn errors of metabolism is to strive for correction of the biochemical abnormality. The approach to treatment for each disorder depends on the enzyme(s) affected and the metabolic consequences of that effect (1,2). Without effective nutritional therapy many children with metabolic disorders would not survive infancy or would have severe cognitive and physical problems. Outcome of treatment for metabolic disorders is variable and depends on early diagnosis and intensive intervention (1,2,3).

For children with metabolic disorders, appropriate growth reflects the achievement of metabolic balance. In addition to a limited energy intake, inadequate weight gain may reflect a chronic elevation in ammonia levels or chronic acidosis. If growth and development are to proceed normally, energy and all required nutrients must be provided in adequate amounts. At the same time, controlling the biochemical abnormality necessitates the restriction of nutrients specific to the disorder to the requirement level (4,5,6).

Most children with metabolic disorders require the restriction of one or more nutrients or dietary components. These restrictions are specific to each disorder

and include, for example, the restriction of specific amino acids or total protein, fatty acids, simple sugars, or total carbohydrate (1,2). In general, the strategies for treatment focus on reducing the negative impact of the affected enzyme and normalizing biochemical status. These goals can be achieved by using one or more dietary modification or intervention strategies, depending on the disorder:

- reduce the substrate
- provide the product(s)
- supplement co-factors
- enhance elimination of excess nitrogen

The protein and amino acid restrictions require the critical assessment of protein and energy intakes; particular attention must be paid to the protein-energy ratio of these prescribed diets. See Table 19-1 for nutritional restrictions and modifications for selected metabolic disorders.

The nutrient needs of each individual must be carefully considered and the dietary prescription based on the individual genetic and biochemical requirements for nutrients. If the specific nutrient needs of an individual are ignored or misunderstood, mental retardation, metabolic crisis, growth failure, neurologic crisis, organ damage, or death may occur.

For many metabolic disorders, especially those involving amino acid metabolism, it is extremely difficult to correct the metabolic imbalances caused by the disorder and meet the nutritional requirements for growth, maintenance, and activity without the use of a specialized semi-synthetic formula or medical food. The formulas are generally supplemented with small amounts of high biological value (HBV) protein to supply the restricted amino acid(s) to the requirement level. These formulas provide 75-80% of the total protein intake for the individual. Nitrogen-free foods are often needed to provide an appropriate energy intake, such as low protein pasta, bread, and other baked goods (4,5,6).

Maintaining metabolic balance for these children requires frequent and intensive monitoring of biochemical parameters specific to the disorder and those indicative of normal nutritional status. The goal is to achieve biochemical levels at or near the normal range. Laboratory parameters that are frequently monitored include:

- plasma amino acids
- hematological status
- protein status
- electrolytes
- blood lipid level
- ammonia

Table 21-2 describes general biochemical monitoring guidelines for selected disorders.

Other considerations in management of metabolic disorders include monitoring (6,7,8):

- Hydration status: Dehydration in children with metabolic disorders often causes severe metabolic imbalance. Fluid intake and requirements must be carefully monitored. Constipation is also of medical significance.
- Illness: The "usual childhood illnesses" often cause the child with a metabolic disorder to lose metabolic balance and become seriously ill. Frequently, children require hospitalization and the administration of intravenous fluids to prevent metabolic "crisis". During infection or illness that results in catabolism, protein-containing formula is often refused. Continued administration of some form of energy and fluids assists in rehabilitation.
- Feeding: Some children who have neurological difficulties develop oral-motor problems that interfere with the provision of adequate nourishment. A hyperactive gag reflex is a frequent problem. Some providers use nasogastric or gastrostomy tubes as a feeding adjunct to prevent metabolic crisis.

The crucial role of nutrition support cannot be disputed in the treatment of these disorders. Effective treatment requires the expertise of a team, generally comprised of a geneticist, registered dietitian (RD), genetic counselor, psychologist, and neurologist. This team of experts is familiar with the nuances of current treatment for metabolic disorders and will incorporate new treatment innovations as they are deemed appropriate. However, the complex nutritional and medical management of these children cannot occur without the follow-up and support of the community teams. Communication between the team at the tertiary center, the community teams, and the family is crucial.

Table 21-1: Some Metabolic Disorders Amenable to Nutritional Therapy*

Disorder	Enzyme: missing or inactive	Biochemical features	Nutritional treatment	Adjunct treatment
Amino Acid Disorders				
Phenylketonuria	Phenylalanine hydroxylase	↑↑ blood phe ↑ phenylketones in urine Progressive, severe MR, which can be prevented by early treatment	Food: low protein Specialized formula: without phenylalanine, supplement tyrosine	
Tyrosinemia type I	Fumaryl-acetoacetate hydrolase	Vomiting; acidosis; diarrhea; FTT; hepatomegaly; rickets ↑ blood/urine tyrosine, methionine; ↑ urine parahydroxy derivatives of tyrosine; Liver cancer	Food: low protein Specialized formula: without tyrosine, phenylalanine, and methionine	Nitisinone†
Homocystinuria	Cystathionine synthase or similar	Detached retinas; thromboembolic and cardiac disease; mild to moderate MR; bone abnormalities; fair hari, skin; ↑ methionine, homocysteine	Food: low protein Specialized formula: without methionine, supplement L-cystine	Betaine, folate, vitamin B12, ?vitamin B6 if folate levels are normal
Urea Cycle Disorders				
Ornithine transcarbamylase deficiency	Ornithine transcar bamylase	Vomiting; seizures; sometimes coma → death. Survivors usually have MR, ↑ plasma ammonia, glutamine	Food: low protein Formula: without non-essential amino acids	L-carnitine, phenylbutyrate,‡ L-citrulline, L-arginine Hemodialysis or peritoneal dialysis during acute episodes

Disorder	Enzyme: missing or inactive	Biochemical features	Nutritional treatment	Adjunct treatment
Citrullinemia	Argininosuccinate synthetase	↑ plasma citrulline, ammonia, alanine *Neonatal*: vomiting; seizures; coma → death *Infantile*: vomiting; seizures; progressive developmental delay	Food: low protein Formula: without non-essential amino acids	L-carnitine, phenylbutyrate,† L-arginine
Carbamyl phosphate synthetase deficiency	Carbamyl phosphate synthetase	Vomiting; seizures; sometimes coma → death Survivors usually have MR, ↑ plasma ammonia, glutamine	Food: low protein Formula: without non-essential amino acids	L-carnitine, phenylbutyrate,† L-citrulline, L-arginine Hemodialysis or peritoneal dialysis during acute episodes
Argininosuccinic aciduria	Argininosuccinate lyase	↑ plasma argininosuccinc acity, citrulline, ammonia *Neonatal*: hypotonia; seizures *Subacute:* vomiting; FTT, progressive developmental delay	Food: low protein Specialized formula: lower protein without non-essential amino acids	L-carnitine, phenylbutyrate,† L-arginine
Arginase deficiency	Arginase	Periodic vomiting; seizures; coma Progressive spastic diplegia, developmental delay ↑ arginine, ammonia with protein intake	Food: low protein Specialized formula: lower protein without non-essential amino acids	L-carnitine, phenylbutyrate†

Disorder	Enzyme: missing or inactive	Biochemical features	Nutritional treatment	Adjunct treatment
Organic Acid Disorders				
Methylmalonic aciduria	Methylmalonyl-CoA mutase, or similar	Metabolic acidosis; vomiting; seizures; coma; often death, ↑ organic acid, ammonia levels	Food: low protein Specialized formula: lower protein without isoleucine, methionine, threonine, valine	L-carnitine, vitamin B12 IV fluids, bicarbonate during acute episodes
Propionic aciduria	Propionyl-CoA carboxylase, or similar	Metabolic acidosis; ↑ ammonia, propionic acid; ↑ methylcitric acid in urine	Food: low protein Specialized formula: lower protein without isoleucine, methionine, threonine, valine	L-carnitine, biotin IV fluids, bicarbonate during acute episodes
Isovaleric acidemia	Isovaleryl-CoA dehydrogenase	Poor feeding; lethargy; seizures; metabolic ketoacidosis; hyperammonemia	Food: low protein Specialized formula: without leucine	L-carnitine, L-glycine
Ketone utilization disorder	2-methylacetoacetyl-CoA-thiolase, or similar	Vomiting; dehydration; metabolic ketoacidosis	Food: low protein Specialized formula: without isoleucine Avoid fasting, emphasize high complex carbohydrates	L-carnitine, bicitra
Biotinidase deficiency	Biotinidase, or similar	In infancy, seizures, hypotonia, rash, stridor apnea; in older children, also alopecia, ataxia, developmental delay, hearing loss		Supplemental oral biotin

Disorder	Enzyme: missing or inactive	Biochemical features	Nutritional treatment	Adjunct treatment
Maple syrup urine disease	Branched chain ketoacid dehydrogenase complex	Seizures; acidosis Plasma leucine, isoleucine, valine 10x normal	Food: low protein Specialized formula: without leucine, isoleucine, valine	L-carnitine, ?thiamin
Fatty Acid Oxidation Disorders				
Long chain acyl-CoA dehydrogenase (LCAD) deficiency	Long-chain acyl-CoA dehydrogenase	Vomiting, lethargy, hypoglycemia	Low fat, low long chain fatty acids, avoid fasting	MCT oil, ?L-carnitine
Long chain 3-hydroxy-acyl-CoA dehydrogenase (LCHAD) deficiency	Long-chain 3-hydroxy-acyl-CoA dehydrogenase	Vomiting, lethargy, hypoglycemia	Low fat, low long-chain fatty acids; avoid fasting	MCT oil, ?L-carnitine
Medium chain acyl-CoA dehydrogenase (MCAD) deficiency	Medium-chain acyl-CoA dehydrogenase	Vomiting, lethargy, hypoglycemia	Low fat, low medium chain fatty acids, avoid fasting	?L-carnitine
Short chain acyl-CoA dehydrogenase (SCAD) deficiency	Short-chain acyl-CoA dehydrogenase	Vomiting, lethargy, hypoglycemia	Low fat, low short chain fatty acids, avoid fasting	MCT oil, ?L-carnitine
Very long chain acyl-CoA dehydrogenase (VLCAD) deficiency	Very-long-chain acyl-CoA dehydrogenase	Vomiting, lethargy, hypoglycemia	Low Fat, low very long chain fatty acids, avoid fasting	MCT oil, ?L-carnitine
Carbohydrate Disorders				
Glycogen storage diseases (Type Ia)	Glucose-6-phosphatase	Profound hypoglycemia; hepatomegaly	Low lactose, low fructose, low sucrose, low fat, high complex carbohydrates, avoid fasting	Raw cornstarch, iron supplements
Hereditary fructose intolerance	Fructose-1-phosphate aldolase	Vomiting; hepatomegaly; hypoglycemia, FTT, renal tubular defects after fructose introduction ↑ blood/urine fructose after fructose feeding	No sucrose, fructose	

Disorder	Enzyme: missing or inactive	Biochemical features	Nutritional treatment	Adjunct treatment
Galactosemia	Galactose-1-phosphate uridyl transferase	Vomiting; hepatomegaly; FTT; cataracts; MR; often, early sepsis ↑ urine/blood galactose	Eliminate lactose, low galactose, use soy protein isolate formula	

*Table adapted from reference 6
† 2-(2-nitro-4-trifluoro-methyl-benzoyl)-1,3-cyclohexanedione which is an inhibitor of 4-hydroxy-phenylpyruvate dioxygenase
‡ Sodium phenylbutyrate and phenylacetate are chemicals administered to enhance waste ammonia excretion; other compounds producing the same effect are also used.

Table 21-2: Biochemical Parameters to Monitor in Children with Metabolic Disorders*

Disorder	Parameter	Frequency
All disorders	Hematocrit, hemoglobin, ferritin	Twice per year, depending on age and health status
	Prealbumin	Twice per year, depending on age and health status
	Length or height, weight, weight/height, head circumference, BMI	At each clinic visit
	Intake of medical food and foods as contributors of critical nutrients	Monthly, at each clinic visit
	Protein, energy, fat, nutrients critical to specific metabolic disorder	Monthly, at each clinic visit
Phenylketonuria (PKU)	Plasma phenylalanine, tyrosine	Monthly, if child is well, more frequently if ill
Tyrosinemia	Plasma tyrosine, phenylalanine, methionine	Monthly, if child is well, more frequently if ill
Maple syrup urine disease (MSUD)	Plasma leucine, isoleucine, valine, alloisoleucine	Monthly, if child is well, more frequently if ill
Urea Cycle Disorders, eg, Ornithine transcarbamylase deficiency (OTC), Carbamyl phosphate synthetase deficiency (CPS), Argininosuccinic aciduria (ASA)	Plasma ammonia, electrolytes, plasma carnitine, plasma amino acids	At each clinic visit, more frequently if ill or illness is suspected
Organic acidemias, eg, Methylmalonic aciduria, Propionic aciduria, Isovaleric aciduria	Urine organic acids, electrolytes, plasma carnitine, plasma amino acids	At each clinic visit, more frequently if illness is suspected
Ketone utilization disorder	Urine organic acids, plasma carnitine, electrolytes, serum ketones	If illness is suspected
Galactosemia	Galactose-1-phosphate	At each clinic visit

*Table adapted from: Trahms CM, Ogata BN. Medical nutritional therapy for genetic metabolic disorders. In: Mahan LK, EscottStump S, eds. *Krause's Food, Nutrition, and Diet Therapy,* 12th ed. Elsevier; 2008[6].

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CHAPTER 22

Ketogenic Diet for Seizure Disorders

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The Ketogenic Diet (KD) is an established, effective nonpharmacologic treatment of many types of epilepsy. It is a high fat, adequate protein, and low carbohydrate diet. Ketosis occurs when the body's carbohydrate intake is limited and fat from the body or diet becomes the primary energy source for the body. The exact mechanism of the diet's anticonvulsant and antiepileptic effects is not known. However, it has been proposed that changes in cellular metabolism resulting in increased metabolic enzymes modifies the cell and decreases hyperexcitability, and hence a less epileptiform state. Another speculation is that the antiepileptic effect is exerted via neuroprotection. This may involve protection from free oxygen radicals or prevention of apoptosis (1,2,3,4,5).

The beginning of the specific use of the KD dates to 1921 (5,6). The Mayo Clinic's 1921 article suggested that a high fat diet, adequate in protein and low in carbohydrate could mimic the effects of starvation, thus producing seizure control. The diet fell out of favor in 1938 when phenytoin (Dilantin) was discovered leading to the era of medication treatment for epilepsy (5). Revival of the KD began in the early 1990's with a Hollywood producer and writer, Jim Abrahams and his son Charlie. Charlie's seizures were refractory to medications and other treatments. Abrahams read about the KD, and took his son to Johns Hopkins Hospital to start the diet. Charlie's seizures stopped completely soon after starting the diet. Abrahams created the Charlie Foundation, published a book about the KD, created a Dateline TV program about the KD in 1994, and a made-for-television movie called, "First Do No Harm".

There are four KD approaches being practiced around the country (6). They are

1. Long chain triglyceride diet (classic or traditional KD diet)
2. medium chain triglyceride (MCT) diet
3. Modified Atkins diet
4. Low Glycemic Index Diet.

This chapter will focus on the traditional KD. The traditional KD is based on an exact ratio of fat to combined protein and carbohydrate. For example, a 4:1 ratio would have 4 grams of fat to every 1 gram of protein and carbohydrate combined. (1,4,7,8) At the 4:1 ratio, fat contributes 90% of calories. Protein and calorie requirements are established based on current DRI with the goal of meeting needs for growth. Heavy whipping cream is usually the foundation of all meal plans, followed by butter, oil, and mayonnaise. Fluid restriction does not play a role in seizure control, and is no longer recommended (8,9). Vitamins and minerals as well as fiber are inadequate in the KD, and must be supplemented (6,8).

The diet can be implemented on an outpatient or inpatient basis (6). The Johns Hopkins inpatient protocol for initiating and maintaining the KD has been gradually modified at Johns Hopkins and other centers, and is continually evolving. Some centers observe a fasting protocol of approximately 24 hours. Others observe an overnight fast with no food consumption after midnight (3). Extended fasting does not produce better results.

Two approaches are observed with respect to starting the diet. The first approach starts at a lower ratio with full calories, such as a 2:1 ratio. The ratio is to be increased based on patients' tolerance.. The second approach is to provide the diet at a set ratio, such as a 3:1 or 4:1 ratio, but starting with 1/3rd calories, increasing daily until full calories are tolerated.

The outpatient approach does not involve fasting. The diet can be started at a lower ratio such as a 2:1 ratio then progressed in 3-5 day increments to a 3:1 ratio then 4:1 ratio. Hypoglycemia, acidosis, nausea, vomiting and lethargy can be minimized or avoided by implementing the diet according to this protocol.

The KD is particularly effective in controlling absence, atonic, myoclonic seizures and infantile spasms. However, it may be tried as a therapy with any child who has refractory seizures (10). The diet is usually prescribed for children over the age of one year. Children younger than one year of age have more difficulty maintaining ketosis and experience a higher incidence of hypoglycemia. However, it is offered as a therapy at Johns Hopkins in infants with infantile spasms. Infants should be assessed on an individual basis to determine if KD therapy is appropriate. Historically, the diet has been felt to be most effective in children ages 2 to 5 years of age. Children and young adults alike have had success in controlling their seizures with the KD (9). The diet will control seizures in approximately one-third of children who have been unable to control them with medications. Of the remaining number of children, one-half will have some degree of improvement in their seizures and/or anticonvulsant medications reduced (2,4,8,11,14). Because of issues of non-compliance, older children may have more difficulty maintaining adequate ketosis

and diet control. The motivation to control their seizures can be enough to keep compliance adequate (11,13).

The KD is best initiated under the supervision of an experienced KD team. A team is best defined as a physician or epileptologist, nurse, registered dietitian (RD) and social worker who all have experience with the KD (8,10,14). A pharmacist can also be a valuable part of the KD team. The KD is not an exact science, and since all children are different, an individualized approach based on current best practices is advised. Much is learned through experience, and by adjusting the diet as needed. RD's are charged with the job of translating the science of the diet into a palatable form. The advent of the Nutricia Ketocalculator and the Stanford Ketocalculator have decreased the time involved in calculating menus. KetoCal (http://www.shsna.com/pages/ketocal.htm), new sugar-free products (http://waldenfarms.com/) and even low carbohydrate noodles made from mushroom fiber (http://www.miraclenoodle.com) have expanded diet options for the diet.

The availability of the team, especially the RD during the diet initiation and the first three months of the diet are crucial to the success of the diet. It is difficult for families to absorb all of the information during the hospital admission, and they need constant guidance from the KD team in order to address their concerns.

The remainder of this chapter presents guidelines for nutrition assessment, intervention, and evaluation/outcome for monitoring a child on the ketogenic diet.

Table 22-1: Ketogenic Diet for Seizure Disorders

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Height or length for age • Weight for age • Weight for height (or length) or BMI • Head circumference (under 3 years) Identify ideal body weight (IBW).† Compare all current measurements to reference data for age and to previous measurements. Measure weight weekly (at home). Weight should be reported to RD.	Adjust recommendations for energy intake, based on growth, activity level. Goal is to allow for child to continue to grow according to current weight/height channels • To ensure accurate calories, obtain three-day food record. Evaluate average daily calorie intake. • Caloric adjustments are made slowly, and not combined with a ratio adjustment.	Child's growth continues appropriately. Weight maintenance for the first full year on the diet (maintenance defined as staying within weight channel) Weight loss can result in hyperketosis and vomiting. Consistent energy intake is important. Weight gain can result in a loss of ketosis, resulting in loss of seizure control.
Biochemical		
MD to order the following serum lab tests (pre-diet and monthly for the first months). MD will determine schedule depending on how stability of the child.		
Total cholesterol Triglycerides	Modification of fat sources may be needed if increased levels do not decline or stabilize. Adding fish oil is an effective therapy to decrease serum triglycerides. Converting some of the fat from heavy whipping cream and butter to olive oil or canola oil is also helpful.	Mild elevations of cholesterol and triglycerides are acceptable. After initial increase in cholesterol and triglycerides (during first 6 months), levels will stabilize or return to baseline.

Assessment	Intervention	Evaluation/Outcome
Free carnitine Esterified carnitine Most children become deficient at some point on the diet, especially at the higher ratios. Deficiency can decrease effectiveness of the diet to control seizures. Depakote can deplete carnitine. Recommend adding L-carnitine before diet start as the combination of the two can deplete stores more rapidly.	Begin supplementation with L-carnitine if needed.[4]	Normal carnitine levels
Electrolytes	Monitor for severe dehydration. Recommend using table salt to taste when cooking. Consider use of potassium chloride (salt substitute) to maintain normal serum levels if needed. Bicarbonate of soda (baking soda) may be used to normalize low serum carbon dioxide. Low serum carbon dioxide can contribute to vomiting, especially during the initiation phase.	Normal electrolyte levels
Creatinine BUN Magnesium Phosphorus Calcium Protein Vitamins E, D Vitamins A /Retinol binding protein	Minor abnormalities may not need to be corrected. Consult with ketogenic diet team. • Maintain normal vitamin and mineral intake by using appropriate supplemental vitamin with iron. • Start supplement before starting the diet. • Antiepileptic medications (AED's) interact with vitamin D; generally any child on an AED needs a vitamin D supplement. Vitamin D low in almost all cases at start of diet • The diet is low in calcium; supplementation to equal the DRI is recommended.	Serum creatinine, BUN, magnesium, phosphorus, calcium, protein levels, Vitamins A, E, D and retinol binding protein within normal limits. • Maintain Vitamin D supplementation; profound drop in D serum values seen when MVI not taken by child.

Assessment	Intervention	Evaluation/Outcome
Albumin, Prealbumin	If albumin is low, increase protein intake.	Albumin levels within normal limits.
AED (antiepileptic medication) levels	Some anticonvulsants can have an increase in medication level when a state of ketosis is present.	• MD to determine if decrease in anticonvulsants is indicated
Aspartate aminotransferase (AST) Alanine aminotransferase (ALT)	Fat absorption/metabolism may be decreased in liver disease - KD can alter liver function due to high load of fat • High AST and ALT may indicate the need to • decrease ratio	Normal AST and ALT levels
Complete blood count	Close physician supervision is necessary to evaluate. • Provide iron supplement if anemic. • Elevated hemoglobin and hematocrit may indicate fluid deficit; obtain fluid intake history, tease out possible causes, recommend/re-teach family as appropriate	• Maintain normal hematocrit and hemoglobin. • Maintain adequate hydration, based on fluid needs in mLs per kilogram
Urine ketone levels • Checked at same time twice daily, useful at the beginning of the diet. • After initial start, only a good indicator of dehydration or hyperketosis in the context of decreased oral intake of fluids or food.	Ideally, urine ketones should be checked every morning and afternoon. If ketones are checked just once per day, then afternoon or evening is necessary. Caregivers should log ketone levels daily along with seizure activity to help evaluate the success of the diet.	• AM Ketones: consistent level, individualized for each child • PM Ketones: consistent level, individualized for each child • Discontinue once child has stabilized on the diet • Can be useful to check for hyperketosis, and to check the effects of foods eaten that are not allowed on the diet (lower ketosis than usual).
Betahydroxybutyric Acid Large ketone body found in serum, considered the most reliable method for determining level of ketosis		Consistent range depending on child's response to the KD.

Assessment	Intervention	Evaluation/Outcome
Selenium If not deficient before starting the diet, most will become deficient during the course of the diet. Deficiency seen with use of the AED Depakote.	Selenium supplementation, start with 40 mcgs, recheck serum values Increase dose as needed until serum levels are normal.	Maintain selenium within normal serum limits.
Zinc Low serum value	Supplement with 15 mgs zinc, recheck serum values. Increase dose if needed until serum levels are normal.	Maintain zinc within normal serum limits.
Clinical: Monitor side effects of diet		
Acute symptoms: Lethargy	May be seen within the first couple of weeks of diet initiation.	Transient lethargy is normal. Normal activity returns.
Acidosis	An expected side effect In the presence of low carbon dioxide, giving ¼ tsp. baking soda may help if child is vomiting.	pH within normal range
Nausea/vomiting	May be a sign of hyperketosis. Give 15-30 cc orange juice if ketones are >80 mg/dL in AM or >160 mg/dL in PM and nausea or vomiting is a problem. Baking soda, ¼ tsp. can also be used to relieve symptoms. Encourage patient to take all of daily fluid allowance. Dehydration can occur quickly with moderate to severe vomiting. If no improvement within 24 hours or vomiting is severe, contact MD.	Ketones within normal limits based on child's normal values. Nausea and vomiting are diminished. Ketone levels remain within acceptable limits.

Assessment	Intervention	Evaluation/Outcome
Hypoglycemia	Hypoglycemia is common and does not require treatment. Symptomatic hypoglycemia is very rare when initiating the diet without a fasting period. Hypoglycemia may not occur until the second or third day of the diet initiation when using a non-fasting start. Symptoms include: • Pallor and fatigue • Nausea • Excess drowsiness • Diaphoresis • Confusion • Seizures • Jitteriness • Tachycardia Symptomatic hypoglycemia should be treated.[11] Usually 15-30 mLs of orange juice is given.	Blood glucose levels remain within acceptable limits without symptoms of hypoglycemia.
Effects of medications	Some anticonvulsants (especially barbiturates, e.g., phenobarbital) can have an increase in medication level when a state of ketosis is present.[15]	Medication levels remain within the therapeutic ranges.
Chronic Effects		
Hyperlipidemia	No long-term cardiovascular side effects are known. If triglyceride levels are constantly rising and do not subside, the risk of complications versus the benefit of the diet must be considered. Phenobarbitol can increase serum triglycerides.	Serum triglyceride and cholesterol in acceptable range. Slight elevation is acceptable. Evaluate if trending upward if previously stable.
Vitamin or mineral deficiency	All patients should be given a sugarless multivitamin/ mineral and calcium supplement. The diet is inadequate for most vitamins and minerals. Anticonvulsant medication-nutrient interactions are common. See Chapter 5 for specific assessment and intervention guidelines.	Child receives adequate amounts of vitamins and minerals.
Growth	Some slowing in growth may occur on the diet. Catch-up growth is likely when the diet is discontinued.	Growth should be plotted at each follow-up visit.

Assessment	Intervention	Evaluation/Outcome
Constipation • Determine pre-diet bowel pattern • Intervene if child is constipated before start of diet	Due to the lack of fiber in the diet, many children require intervention. Miralax, Dulcolax, Colace, glycerine suppository, Benefiber and milk of magnesia may be used. Use of lower carbohydrate fruits and vegetables (10% fruits and group A vegetables)‡ should be encouraged in order to maximize the serving size of fiber-containing foods.	Bowel movements should be achieved at least every 1-2 days.
Kidney stones Increased risk if family history or use of AED Topamax or Zonegran	Evaluation by a renal specialist is preferred. Continuation of the diet may be possible with increase in fluid intake. Calcium intake greater than the DRI is discouraged.[2,4,8]	
Noncompliance	This is the most common problem. It is more prevalent in older children and poorly organized families. Decreased k betahydroxybutyrate and increased seizures are typical. Diet calculations should be rechecked for miscalculation or excessive energy. Possible errors in food preparation should be discussed. More often than not, family has added an extra snack or meal. Sometimes they change the ratio by giving additional protein or carbohydrate which changes seizure control. Not giving all of the fat in meal plan can also cause increased seizures. Caregivers must be encouraged to be "sleuths" in looking for possible mistakes or extra carbohydrate in the diet (medications, toothpaste, and "sugar-free" beverages).	Strict adherence to the diet for at least 3 months for adequate evaluation of diet success on seizure control. Continued strict adherence to the diet is necessary to maintain seizure control.
Dietary		
Obtain diet history and/or 3 day food record, including all food preferences.	Review intake.	Intake is appropriate, with consideration of nutrients discussed below.
Review all medications and nutritional supplements currently used. Assess amount of carbohydrate provided by supplements and medications. Ketocalculator contains the carbohydrate content of many common supplements and medications.	Medications should be converted to lowest carbohydrate-containing form. Nutritional supplements should be evaluated and coverted to the lowest carbohydrate form. In general, no pediatric formulations, chew tabs or liquids should be used. Contribution of carbohydrate from medications and supplements should be under 1000 mgs. Otherwise, values greater than 1000 mgs. should be calculated into the meal plans.[11]	Follow medication list at each clinic visit. Make sure nothing has been used or added that is not on the approved list. Breakthrough seizures can occur.[16] For example, three teaspoons of liquid augmentin yields 1914 mgs of carbohydrate. Families have reported breakthrough seizures with use of high sugar formulations such as this.

Assessment	Intervention	Evaluation/Outcome
Assess energy needs	Daily energy goal—using IBW, a starting point of 75-100% DRI for age is appropriate unless current energy intake is significantly greater or less than the DRI[4,11]. Adjust recommendations for energy intake, based on rate of weight gain. Excessive weight gain can negate the effects of the diet. Slow weight gain may be appropriate if ketosis is achieved.	Slow weight gain, maintain BMI percentile, stable betahydroxybutyrate (no extreme fluctuations up or down.)
Assess protein needs	Daily protein goal—protein should be kept at DRI per kilogram IBW if possible, with a minimum 1.0 g/kg for children less than 7 years of age and a minimum 0.8 g/kg for children 7 years and older. Maintaining adequate protein levels can be difficult in children with low energy needs.[4,11]	Normal protein status is maintained.
Assess fluid needs	Daily fluid goal—60-70 cc per kg IBW or 1 cc/kcal. Consistent fluid must be spaced out evenly throughout the day. Educate the caregivers on signs and symptoms of dehydration.[4,11].	Fluid will not affect ketosis. Maintain adequate hydration status. High hemoglobin and hematocrit may indicate mild dehydration.
Develop diet prescription and meal plans	Establish meal schedule—3 meals/day is standard, but smaller, more frequent meals may be needed. If tube-fed, determine tube-feeding regimen. Both bolus and continuous regimens can be achieved.[11]	Maintain steady ketosis by eating evenly spaced meals and consistent carbohydrate, protein, and fat at each meal.

Assessment	Intervention	Evaluation/Outcome
Develop diet prescription and meal plans 1. Caloric needs based on three-day diet history 2. Dietary preferences based on preference survey	Establish ratio (defined as grams of fat to grams of protein and carbohydrate combined). Consult with KD Epileptologist to determine starting ratio, and best plan for KD start. This will be dependent on age of child, and overall caloric need. Some programs start with a 24-hour fast or longer, some only fast after midnight the day before the diet start. Start: 1. Consistent ratio, increase calories over three days, 1/3, 2/3, then full calories. 2. Progressive ratio ramp-up, 1:1, 2:1, 3:1 for example. 3. Outpatient diet initiation program - start with the lowest ratio, then ramp up the ratio every 3-5 days until the desired ratio is achieved. Lower ratios may be necessary for children with very low energy needs in order to maintain adequate protein in the diet.	Ketogenic diet ratio sufficient to maintain consistently high ketosis, and optimum seizure control. Betahydroxybutyrate within consistent range.
	Recommend using Ketocalculator or Stanford calculator. Computer programs give more accurate information and are faster. Both programs are free. Families can be trained to calculate meal plans when appropriate.	Families should be given at least 10-15 meal plans to initiate diet. Caloric needs are met, providing weight maintenance or slight gain to maintain BMI percentile. Big fluctuations can cause hyperketosis, with symptoms, or hypoketosis resulting in decline in seizure control.

Assessment	Intervention	Evaluation/Outcome
Determine education needs	Ketogenic Diet education—caregivers come with different levels of understanding and preparation regarding the diet. Education program should include: • History of the diet • Theoretical basis • Expectations of the diet • Possible complications • Expectations of the program • Resources needed • Ketone testing • How to handle illness • Importance of compliance • Monitoring requirements • Nutritional guidelines—energy, protein, carbohydrate, fat, fluids, vitamins, and minerals • Meal planning—eating consistently, using a gram scale, careful measuring, recipe suggestions, and meal preparation Give caregivers as much written information as possible in an organized format for home reference. Education on an outpatient basis may be achieved with a one-day class. The outpatient approach allows an education environment that is lower in stress and free from interruptions common with hospital admissions.	Caregivers plan, prepare, and measure meals with 100% accuracy as demonstrated in class and follow-up visits. Ketosis is stable as demonstrated by stable betahydroxybutyrate. Weight gain consistent with defined parameters.
Assess appropriate time and regimen for weaning the diet	Ideally, a child will remain on the diet for 2 years or for one year after becoming seizure-free. This is individualized based on the child's needs as determined by the KD Epileptologist. The diet is then weaned over a one-year time period, with decreasing ratio every 3-6 months. If seizures increase, the diet can be reversed. Not all children have total seizure control, or become medication-free.	Seizure control remains during and after weaning from the diet.

*For reference data and guidelines for taking accurate measurements, see Chapter 2.

†Ideal weight is the weight that would place the child at the 50th percentile for weight for height (or length).

‡See Freeman JM. The Epilepsy Diet Treatment: An Introduction to the Ketogenic Diet, 2nd Edition, p.39 for more information.

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Additional Resources

Charlie Foundation

Jim and Nancy Abrahams, Charlie's Parents
1223 Wilshire Blvd., #815
Santa Monica, CA 90403-5406
800/3675386
www.charliefoundation.org

The Charlie Foundation is an education resource for the ketogenic diet. The Foundation was established by Jim and Nancy Abrahams, whose son Charlie had become seizure free on the ketogenic diet. The Foundation provides several videotapes free of charge for education purposes.

Epilepsy Foundation of America

National Office
4351 Garden City Drive
Landover, MD 207852267
800/3321000
http:www.efa.org

This is a national organization that provides information about epilepsy to professionals and persons with epilepsy. Families can obtain information about local resources and supports. The foundation also offers research and training grants.

Nutricia North America

This is the website sponsored by Nutricia North America. Subscription is free to dietitians that work in centers that use the Ketogenic Diet as a therapy for seizure control. Parents may have access to this program by starting the diet through a center that uses the ketocalculator and by obtaining online access to their personal account. Parents and professionals can sign up for a quarterly newsletter. There is also specific information for dietitians, as well as current research which is updated on a regular basis.

Ketogenic Diet Ketocalculator

http://www.ketocalculator.com
http://www.myketocal.com

Stanford Ketogenic Calculator

Families or professionals may download this calculator. It is in an excel spreadsheet format. This is a free resource, but its calculations are not as exact as the Ketocalculator. http://www.stanford.edu/group/ketodiet.

Books

The Ketogenic Diet: A Treatment for Children and Others with Epilepsy

Freeman, J. et al.
Demos Medical Publishing, 2006.
386 Park Ave. South, Suite 210
New York, NY 10076
800.532.8663

This is a good basic book for professionals and families alike who are interested in learning more about the diet. This following is a link to read an excerpt of the book online. To read an excerpt from the book, go to the Amazon.com website, under department, select books, and type in Ketogenic Diet.

Keto Kid: Helping Your Child Succeed on the Ketogenic Diet

Snyder, D, Freeman, J. et al.
Demos Medical Publishing, 2006.
386 Park Ave. South, Suite 210
New York, NY 10076
800.532.8663

This book was written by a family physician whose child is on the Ketogenic Diet. It provides recipes, as well as helpful hints for families to promote success while on the diet. To read an excerpt from the book, go to the Amazon.com website, under department, select books, and type in Ketogenic Diet.

CHAPTER 23

Nutrition Interventions for Autism Spectrum Disorders

Betty Lucas, MPH, RD, CD

Autism Spectrum Disorders (ASD) is the broad category of developmental disorders with primary impairment in social development. The ASD spectrum includes: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder (1). The prevalence of ASD is about 1 in 91 children (based on a 2007 parent survey), which is higher than in the past (2). It occurs more in males than females, approximately 75 percent have some cognitive delay (children with Asperger's have normal IQs), and about 30 percent eventually have seizure disorders. Although the specific etiology of ASD is not known, about 10-15 percent may be related to genetic disorders. Future research will yield more information on the causes of ASD.

Although children with ASD reflect a wide range of behaviors and severity, ASD is identified by behavioral features in three categories:

- Impaired social interactions
- Impaired verbal and nonverbal communication
- Restricted and/or repetitive behaviors

Common behaviors in children with ASD include: difficulty with transitions, impaired communication skills, social interaction difficulties, easily overwhelmed or over-stimulated, short attention span, limited range of interests, and need for routine. Since there are no biological markers for autism, diagnosis is made by behavioral assessment. Red flags identified by screening children under 3 years of age include problems with eye contact, joint attention, nonverbal communication, pretend play, paying attention to one's name, and language development, as well as regression in skills. If screening is positive, a comprehensive evaluation is indicated, including medical, cognitive, and communication assessments. With diagnosis of ASD, referral should be made for early intervention services, special education, and related therapies, such as speech/language therapy, occupational therapy, and behavior management (3).

Nutrition and Feeding

The unique nutrition-related aspect for children with ASD is their selective food choices that often result in a narrow list of foods accepted. Parents frequently report "picky" eating, although this behavior is more persistent than the transient picky eating typically seen in young children. This diet selectivity is influenced by the same range of general behaviors seen in children with ASD. See Table 23-1.

Although most parents report that their infants fed well and generally accepted baby foods, the transition to table foods after the first year tends to be more problematic. A frequent pattern is a preference for dry, crunchy foods; and refusal of soft, smooth textures, e.g. mashed potatoes and cooked cereal. Typically, finger foods are preferred to using eating utensils. Foods frequently reported in the diets of children with ASD include dry cereal (eaten as a finger food; no milk added), crackers, chicken nuggets, pizza, bread, hot dogs, and plain pasta, while intake of vegetables and fruits tends to be minimal. Over time, some children narrow their food acceptances even more, to fewer than 10-15 items; within that restriction, only certain brands or methods of preparation are allowed.

It is easy to understand that families become anxious when their children continue to refuse foods, despite being offered a variety of foods. Eventually, parents respond by giving their child foods they know he/she will eat. This leads to different and sometimes separate meals for the child, and if behavior is an issue, less participation in family mealtime.

Table 23-1 Feeding Behaviors of Children with Autism

Autism Concerns	Feeding Characteristics
• Difficulty in transitioning to textures • Increased sensory sensitivity • Restricted intake due to color, texture, temperature, odor • Decreased acceptance of foods over time; refusal of "new" foods • Difficulty with changes in mealtime routines, tantrums	• Preference for dry, crunchy foods (no milk on dry cereal) • Food groups most likely refused or limited – vegetables and fruits • Often adequate intake of protein (though limited selection) and dairy foods • Often prefer finger foods (sensory issues?) • Refusal of vitamin/mineral supplements

Children with ASD tend to have growth parameters within normal limits, although overweight and underweight can be seen secondarily to feeding behaviors. Energy needs are usually met, although the food sources may be limited or an entire food group omitted. Due to their selective eating behaviors, the micronutrient intakes of these children may be minimal or inadequate. A recent report of preschool children with ASD indicated nutrients most at risk were vitamin A, vitamin E, fiber, and

calcium (4). In addition, elimination diets increase the risk of inadequate nutrient status. There have been reports of impaired bone growth in boys with autism, as measured by bone cortical thickness (BCT) (5). These changes were seen in boys whether they were on a restricted diet or not, but there was lower BCT in those on a gluten-free, casein-free diet.

Alternative Nutrition Interventions

There are many diet-based interventions to treat ASD, although scientific evidence confirming their efficacy is limited. Sophisticated marketing, testimonials, and claims have prompted many parents to adopt dietary changes and supplementation regimens for their children with ASD. The plethora of information available to parents and families on the Internet provides added challenges to RD's and other health care providers.

The most common nutrition interventions include:

- Gluten-free/casein-free diet
- Specific carbohydrate diet (SCD)
- Yeast-free diet
- Vitamin supplement for ASD, i.e. "Super Nu-Thera®"
- Specific nutrients – B6, magnesium
- Fatty acid supplements
- Probiotics
- Enzymes
- Dimethylglycine (DMG)

Gluten-free/casein-free (GFCF) diet

The GFCF diet is the most popular dietary treatment intervention for children with ASD. The "leaky gut syndrome" (also called the opiate theory) is part of the basis for using the diet, and was originally developed by researchers in Europe (6,7). The theory is that children with ASD cannot properly digest the casein and gluten in dairy and wheat foods, leaving partially broken down polypeptides. With more permeable or "leaky" intestines, these polypeptides are believed to enter the circulatory system, passing through the blood-brain barrier. There they form compounds with endorphin receptors in the brain, causing some of the characteristics and behaviors seen in children with ASD. Removal of casein and gluten from the diet is therefore a treatment.

Gastrointestinal symptoms, such as constipation and diarrhea, seen in some children with ASD have also led to use of the GFCF diet. And some studies, mostly in vitro, have demonstrated GI inflammation and other abnormalities, in children with ASD, whether they were on a GFCF diet or not (8).

Nutrients at risk in the GFCF diet include calcium, vitamin D, zinc, and many B vitamins. Most of the positive reports of the diet have been anecdotal, and randomized, well-controlled studies and systematic reviews have not found the diet to be effective. The Cochrane Database found only two small, randomized controlled trials (RCTs) that were well-controlled, and small positive treatment effects in some of the children (9). Many families still want to try the GFCF diet for their children, and there is need for large scale, quality RCTs. The role of the RD is to discuss the known effectiveness with the family, and then help them provide a GFCF diet that is adequate in nutrients and energy to promote good growth and development.

Specific Carbohydrate Diet (SCD)

This diet is more restrictive than the GFCF diet as it eliminates grains, dairy, sucrose, and complex carbohydrates; and limits vegetables and fruits. Originally intended for irritable bowel syndrome, ulcerative colitis, and Crohn's disease, it is supposed to combat bacterial and yeast overgrowth. There is no evidence to support the diet in any disease, and the diet is likely to be inadequate.

Supplements

Specific vitamin-mineral supplements, such as Super Nu-Thera®, and single supplements such as vitamin B6, magnesium, and fatty acids, are common in children with ASD. Although there are few well-controlled studies of these supplements, the evidence that exists does not support any effectiveness (10,11). Caregivers do not always realize that the components in multivitamin mixtures can also be found in other supplements their child is taking. Families should be counseled as to the tolerable upper limits (ULs) now set for most vitamins and minerals, and should be encouraged not to exceed these levels.

Understanding the nature and scope of alternative therapies is important in providing the best quality family-centered care. Families who are searching for effective treatments for their child are often unable to discriminate between anecdotal reports and research-based scientific evidence. RD's and other health professionals must be able to evaluate information about alternative nutrition therapies for ASD, and use

evidence-based practice. Open dialogue between the RD and the family is critical, as is understanding of the family's desire for an effective treatment (12).

Feeding Behaviors

The persistent picky eating and related behaviors that limit the food intake of a child with ASD can be very challenging to all who work with the child. For many, the self-limited diet is outside the typical developmental picky eating and neophobia. Working on these eating behaviors is most effective when intervention is provided by a team, including feeding therapists and/or behavior specialists. Interventions can be incorporated into a child's educational goals e.g., Individualized Family Service Plan (IFSP), Individual Education Program (IEP). This requires coordination between the school, family, and the RD.

Using an applied behavior analysis (ABA) approach is effective for many children, and can be used in feeding at school, daycare and home. Setting small goals, using a step-wise system, to increase food acceptance is likely to be more successful (6). See Fig 23-1.

The remainder of this section presents guidelines for nutrition assessment, intervention, and evaluation/outcome for children with ASD.

Table 23-2: Nutrition Interventions for Autism Spectrum Disorders

Assessment	Intervention	Evaluation/Outcome
Anthropometric*		
Measure and plot on appropriate growth chart: • Length/height for age • Weight for age • Weight for length or BMI • Head circumference (<3 years) Compare all current measurements to reference data and to previous measurements Collect growth history from medical records and caregivers	If underweight or overweight, work with family to change child's energy intake by type of foods offered, energy-density of foods, frequency of eating, adapting feeding environment, and addressing behavior problems (see Dietary below).	Growth and weight-for-length or BMI are appropriate
Clinical/Medical		
• Biochemical data, including screening for lead exposure if pica behavior is present • Developmental history • History of GI disease or infections • Constipation, diarrhea • Medications used • Oral health care, i.e. toothbrushing, dental care	Address any dietary interventions for constipation or diarrhea (see chapters 6 and 7) Determine any medication-nutrient interactions, and adjust any nutrient supplements and/or food choices, consulting with primary care provider as needed. Provide education re: food and snacks that are less cariogenic; encourage regular dental care and exams	No symptoms of GI disorders Any negative medication-nutrient interactions are compensated by food or supplements Child receives daily oral care and routine dental exams
• Determine usual activity level • Assess any constraints on physical activity due to safety or other issues • Assess amount of time spent at computer, TV, video, games, etc (screen time)	• Support daily, safe physical activity, i.e. 30 minutes of aerobic activity; encourage weight-bearing activities and sports appropriate to age, development, and need for supervision • Special Olympics program for children >8 years of age • Reduce screen time, if greater than 2 hours per day, if appropriate for child's overall program	Caregivers, educators, and others involved in child's daily care report appropriate and safe physical activity.

Assessment	Intervention	Evaluation/Outcome
Dietary		
Assess: • Typical food intake, timing of snacks and meals, and eating environment • Methods of preparation, preferences, i.e. brands, presentation, color, shape, temperature • Early feeding development history • Food aversions, refusals • Use of food as a reward • Feeding behaviors -- current and past • Previous dietary interventions • Use of special diets, i.e. GFCF, SCD, and nutrients at risk, i.e. calcium, Vit D, folic acid • Vitamin and/or mineral supplements, herbals, etc • Other complementary and alternative medicine (CAM), i.e. enzymes, probiotics • Determine usual energy and nutrient intake Obtain a 3- to 7-day food record.†	• If child is overweight or underweight, adjust energy intake by altering portion sizes, increasing or decreasing snacks, and changing beverage volume and/or energy-density. Plan should accommodate child's food limitations and preferences as much as possible. See chapter 13 or 14. • For nutrient inadequacies, collaborate with family to find alternative food sources that might be acceptable, i.e. for those on GFCF diet consider calcium-fortified soy milk and cheese • Provide vitamin-mineral supplements if needed; work with family regarding form (chewable, liquid, crushed), color, taste, etc. Treat supplements as "medicine" or using behavior approach to increase compliance • Provide family education and counseling regarding ULs for supplements, evidence-based effectiveness, and any dangers of toxicity or negative side effects • Discourage use of food as a reward in all environments; work with family and professionals to identify other reinforcers • Support family meals and regularly-scheduled meals and snacks	Subsequent re-evaluation or food records indicate appropriate energy and nutrient intake from a variety of foods Caregivers report dietary practices consistent with nutrition care plan.
Family/Social		
Determine: • Family's concerns about child's nutrition and feeding, and current goals for change • Child's behaviors that limit or alter food intake • Previous attempts to improve diet and intake, and their outcomes • Use of CAM therapies and family's expectations	• Nutrition counseling for caregivers, educators and others to set small goals, with expectation that progress will be slow.[6] Food exposures should be step-wise, i.e. child tolerates, smells or touches food, but does not eat. See Fig. 23-1 • Refer for feeding therapy by OT, SLP, and/or behavior specialist at early intervention, school, or other program (with consultation from RD) • Consider feeding group therapy for preschool children	Child makes slow, but consistent progress with food acceptance and improvement in feeding behaviors. Periodic re-assessment of family's concerns and goals

**For reference data and guidelines for taking accurate measurements, see Chapter 2.*

† *For more information about dietary assessment, see Chapter 1.*

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Resources

Autism Society of America, http://www.autism-society.org/

American Academy of Pediatrics, Committee on Children with Disabilities. Counseling families who choose complementary and alternative medicine for their child with chronic illness or disability; Pediatrics. 2001;107(3):598-601.

Autism Awareness Project. Washington State Department of Health, Children with Special Health Care Needs Program. http://www.doh.wa.gov/cfh/mch/Autism/Autism.htm

Centers for Disease Control and Prevention, Autism Information Center http://www.cdc.gov/ncbddd/autism/

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Maternal and Child Health Library Knowledge Path: Autism Spectrum Disorders, http://mchlibrary.info/KnowledgePaths/kp_autism.html

National Institutes of Health, Office of Dietary Supplements, http://ods.od.nih.gov/

National Institutes of Health, National Center for Complimentary and Alternative Medicine, http://nccam.nih.gov/

National Institutes of Mental Health, Autism Spectrum Disorders, http://www.nimh.nih.gov/health/publications/autism/

Medline Plus: Complementary and Alternative Therapies, http://www.nlm.nih.gov/medlineplus/complementaryandalternativetherapies.html

Western Maternal Child Health Nutrition Partners. Nutrition and Autism. http://www.mchnutritionpartners.ucla.edu

Fig. 23-1 Autism, Nutrition, and Picky Eating…

Some common behaviors in children with autism can cause problems around food and eating. (Your child may or may not have these behaviors.)

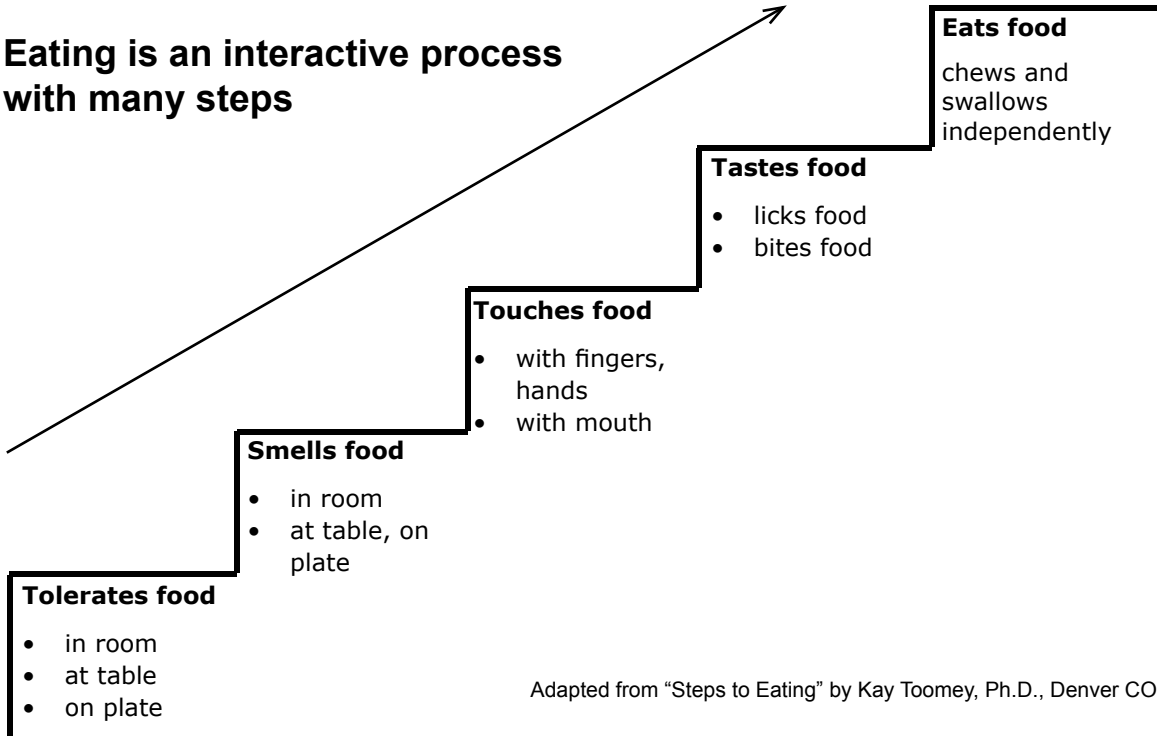
BEHAVIOR	HOW IT MIGHT RELATE TO CHILDREN'S EATING
Hypersensitivity to texture, smell, taste	Refuses to eat foods with specific textures, smells, tastes
Need for routine	Refuses to eat food that looks "different"… or is in a new bowl … or is at a different place at the table
Overstimulated or overwhelmed by the environment	Distracted from meal and does not eat

Typically developing children may need **10** or more exposures to a new food before they will eat it.

… **children with autism who are especially sensitive to tastes, textures, smells, or new things may need even more exposures!**

Eating (and enjoying food) is **not** as simple as it looks.

It is natural for children to refuse to eat some foods at **some** times. This is one way to show independence and to make decisions.



Adapted from "Steps to Eating" by Kay Toomey, Ph.D., Denver CO

Picky eating can be a nutrition risk when:

- one or more food groups is excluded from a child's food pattern
- "not enough" food leads to weight loss or lack of weight gain
- fights over eating (or not eating) put a strain on parent-child relationships

WHAT MAY WORK ...but not in the long run	**WHY THIS IS NOT IDEAL**
"Bribing" your child to eat a food. *("If you eat your vegetables, you can have some candy.")*	Teaches your child that he/she shouldn't like vegetables as much as candy, because vegetables are less desirable
Forcing your child to *"take a bite"* or *"have at least one taste."*	Creates negative associations with food and eating. Takes control away from your child.

Suggestions to help your child enjoy new foods

Avoid overwhelming your child with too many changes:

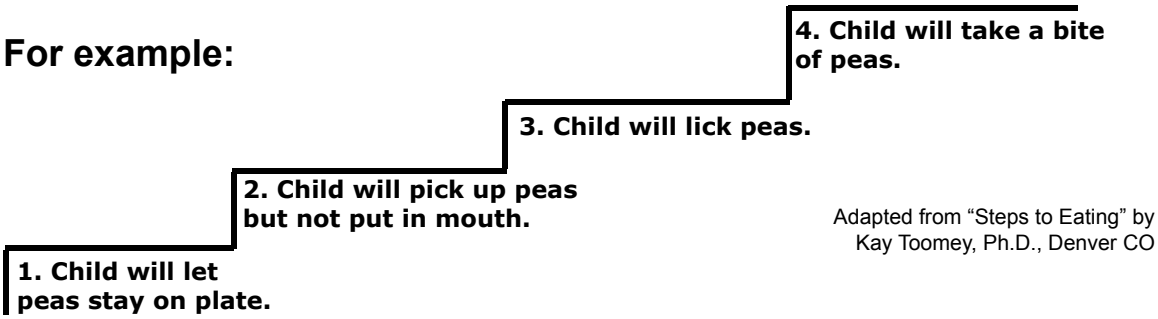
1. Keep mealtimes constant. Use the same plates and utensils. Eat at the same place and at the same time.
2. Offer small servings of a few (2-3) foods at one time…avoid offering TOO MUCH FOOD and TOO MANY CHOICES.
3. Offer new foods along with foods your child already likes to eat.

Introduce foods in forms that are similar to foods your child already eats, and make changes gradually.
For example, if your child eats crackers, but not sandwiches:

- First, offer sandwiches made with crackers
- Then, offer sandwiches made on toast
- Finally, offer sandwiches made with bread

Expect slow changes. Follow your child through the steps of the process… set realistic goals.

For example:



Adapted from "Steps to Eating" by Kay Toomey, Ph.D., Denver CO

Ask your child's teacher for help.

1. Pick one "goal food" to offer at snack time and/or lunch. Offer this same food at home.
2. Use non-food reinforcers. Using food as a reinforcer teaches your child to value this food—and can teach your child not to value other foods.
3. Incorporate eating behaviors into your child's token reward system—a token for a "goal behavior," such as leaving peas on plate. Remember NOT to use food as the end reward!

Developed by Beth Ogata, MS, RD and Betty Lucas, MPH, RD

Center on Human Development and Disability, University of Washington, Seattle, WA
September 1999

APPENDIX A

Children With Special Health Care Needs

NUTRITION SCREENING

Dear Parent or Guardian:

Nutrition services are offered to all children in Spokane County attending Spokane Guilds' School by the Children with Special Health Care Needs Program. I will contact you soon if you have a nutrition concern and set up a convenient time to meet with you.

Please complete this Nutrition Screening form for your child. Today's date _____

Child _____ Age _____ Birth date _____ Sex: M F (circle)

Premature? yes ____ no ___ If yes, number of weeks _____ Birth weight _____

Your Name _____ Relationship to child _____

Phone number _____ Zip Code _____

Diagnosis _____

CURRENT NUTRITION CONCERNS ABOUT THIS CHILD: (Please check all that apply)

	YES	NO	UNSURE
Seems underweight	_____	_____	_____
Seems overweight	_____	_____	_____
Food intolerances/allergies, to what? _____	_____	_____	_____
Frequent constipation	_____	_____	_____
Frequent diarrhea	_____	_____	_____
Frequent throwing up/vomiting	_____	_____	_____
On a tube feeding	_____	_____	_____
Takes a long time to eat	_____	_____	_____
Has trouble eating textured or chunky foods	_____	_____	_____
Has difficulty taking liquids: formula/water/juice	_____	_____	_____
Often chokes and gags on foods	_____	_____	_____
Is a picky eater	_____	_____	_____
On a special diet, specify: _____	_____	_____	_____

My child takes the following medicines: _____

Vitamin/mineral supplements taken: _____

What kind of milk or formula does your child drink? _____

How much per day? _____

Uses bottle _____ cup _____ both _____ other _____

Please list any other nutrition concerns you have:

_____

Ethnicity: (circle one)

Black/African American
Hispanic
Caucasian
Native American
Asian/Pacific Islander
Other

Community Programs currently enrolled in: (circle all that apply)

CSHCN
Food Stamps
SSI
CHAMPUS
DDD
WIC
Medicaid
Private Insurance
Foster Care

Thank you for providing this important information about your child. Please return this form to

_____.

For office use only:

Evaluation by therapists: _____Completed by _____

Describe child's feeding skill level:_____

Observations of parent-child interaction_____

Additional comments: _____

Nutritionist: _____Completed by _____

Weight _____ Height _____ Head Circumference _____

Weight/age _____% Height/age _____% Weight/Height _____% OFC_____%

COMMENTS: _____

_____

_____

_____

Action taken: _____

_____

_____

_____

_____

Nutrition Screening Questionnaire

Today's date _____ Parent _____ Home Phone _____

Address _____

How is your Child Eating and Growing? *(Please circle yes or no in response to the following questions)*

1. Is it easy to tell when your child is hungry or thirsty? Yes No
2. Do you worry about his/her eating or growing? Yes No
3. Have you received any special directions for feeding your child? Yes No
4. Does he/she take vitamins or minerals? Yes No If yes, what?_____
5. Does he/she take medications? Yes No If yes, what? _____
6. Does your child eat anything that is not food, such as paint or dirt? Yes No
7. Do you have trouble buying or making your child's food? Yes No
8. Is your child on the WIC program? Yes No If yes, where?_____
9. Does your child go to a daycare or school? Yes No If yes, where?_____
10. Is your child fed by any other people? Yes No If yes, who? _____

What Does Your Child Eat and Drink?

11. Where do you usually feed your child? _____
12. How many meals and snacks does he/she eat most days? _____ Meals _____ Snacks
13. How long does it take your child to eat? _____ Minutes
14. Please check what your child eats:

___ Breastmilk ____ Baby Cereal ____ Ground Meats/Finely Ground Table Foods

___ Formula ____ Strained Baby Foods ____ Cut Up Meats/Soft Table Foods

___ Cow's Milk ____ Junior Foods ____ Finger Foods

15. Circle the foods that you feel your child does not eat enough of:

    1. milk and milk products 2. meat, beans, eggs 3. fruit and vegetables 4. breads and cereals

16. How much does your child usually drink in one day (24 hours):

    Water _____ Sweet drinks _____ Juice _____ Cow's milk _____

Baby formula _____ What kind of formula? (with/without iron?) _____

How do you mix the formula? _____

Are Any of These a Problem for Your Child? *If yes, please check.*

___ vomiting	___ gagging and choking	___ eating too slowly
___ diarrhea	___ chewing	___ refusing to eat
___ constipation	___ cup drinking	___ spitting out food
___ sucking on nipple	___ finger feeding	___ getting upset at meals
___ holding up head	___ not eating solid foods after 1 yr.	___ poor appetite/picky eater
___ sitting up alone	___ bad teeth/sore mouth	___ not self-feeding
___ swallowing	___ food allergies	

Other concerns: _____

_____

_____

_____

PHN please complete

DX _____

Height _____ Weight ____ %tiles: Ht/age _____ Wt/age _____ Wt/Ht _____

Birthweight (≤ 2 years) _____ OFC _____ Hematocrit ___ % Hemoglobin _____ Gm/dl _____

Comments: _____

_____

Medical Care Provider _____ Phone _____

PHN _____ Clinic _____ Phone _____

Name _____

DOB _____Patient I.D.# _____

Seattle-King County Department of Public Health
CS #13.19.87 Rev. 5/90
NUTRQUES.PM3

APPENDIX B

Sources of Anthropometric Equipment

Sharon Feucht, MA, RD, CD

Listed below are manufacturers of specific equipment. Some manufacturers sell directly to the public and/or through distributors while others only sell through distributors. For information about a specific product contact the manufacturer. For distributors you can search for the equipment piece using the web or search your local yellow pages for a supplier.

Equipment Selection

When you consider equipment purchase, consult Chapter 2 (Anthropometrics). Ensure that measurement tolerances are available (i.e. the length or height can be measured in 0.1 centimeters or 1/8 inch (or less) increments; the weight can be measured in 0.01 kilograms or ½ ounce (or less) increments).

Manufacturer	Description of Equipment
Manufacturers of Equipment to Measure Height or Length	
Ellard Instrumentation Ltd. Toll free: 1-800/Ellard-1 Phone:360/805-5406 http://home.earthlink.net/~eiltd/Stadiometers.html	• Premie length board • Newborn length board • Pediatric length board • Adult recumbent length board • Portable stadiometer
Perspective Enterprises Toll free: 800/323-7452 Phone: 269/327-0869 http://www.perspectiveent.com	• Infant length boards • Stadiometers • Individual head boards • Flat, metal measuring tapes • Scales • Test weights and calibration rods

Manufacturer	Description of Equipment
Weigh and Measure LLC Toll free: 877/900-9007 Phone: 301/774-9006 http://www.weighandmeasure.com	• Infant length board • Infant/child height measuring board (length and height) • Infant/child/adult measuring board • Scales • Calipers
Manufacturers of Equipment to Measure Weight*	
Detecto, A Division of Cardinal Scale Manufacturing Co. Toll free: 800/641-2008 http://www.detecto.com/	Digital and mechanical infant and pediatric scales; chair scales and adult scales Sell direct or through distributors
Health o meter Sunbeam Health Division Toll free: 800/672-5625 http://www.healthometer.com	Balance beam scale and infant scale Sell direct or through distributors
Seca Toll free: 888/879-8582 (Western USA) 800/542-7322 (Eastern USA) http://www.secacorp.com	Digital and mechanical infant and pediatric scales; infant length board Sell only through distributors
Tanita Corporation of America, Inc. Phone: 847/640-9241 http://www.tanita.com	Digital and mechanical infant and pediatric scales Sell only through distributors
Manufacturer of Equipment to Measure Skinfolds	
Seritex, Inc. Phone: 973/472-4200 http://www.seritex.com	Distribute Holtain caliper in the USA; also sell Lange calipers; anthropometer (for measuring body segments); infant length board, stadiometer, pediatric/adult supine measuring table; sitting height table
Beta Technology Toll free: 800-858-2382 http://www.beta-technology.com/	Manufacturer of Lange caliper; can be purchased through manufacturer or other distributors of medical equipment

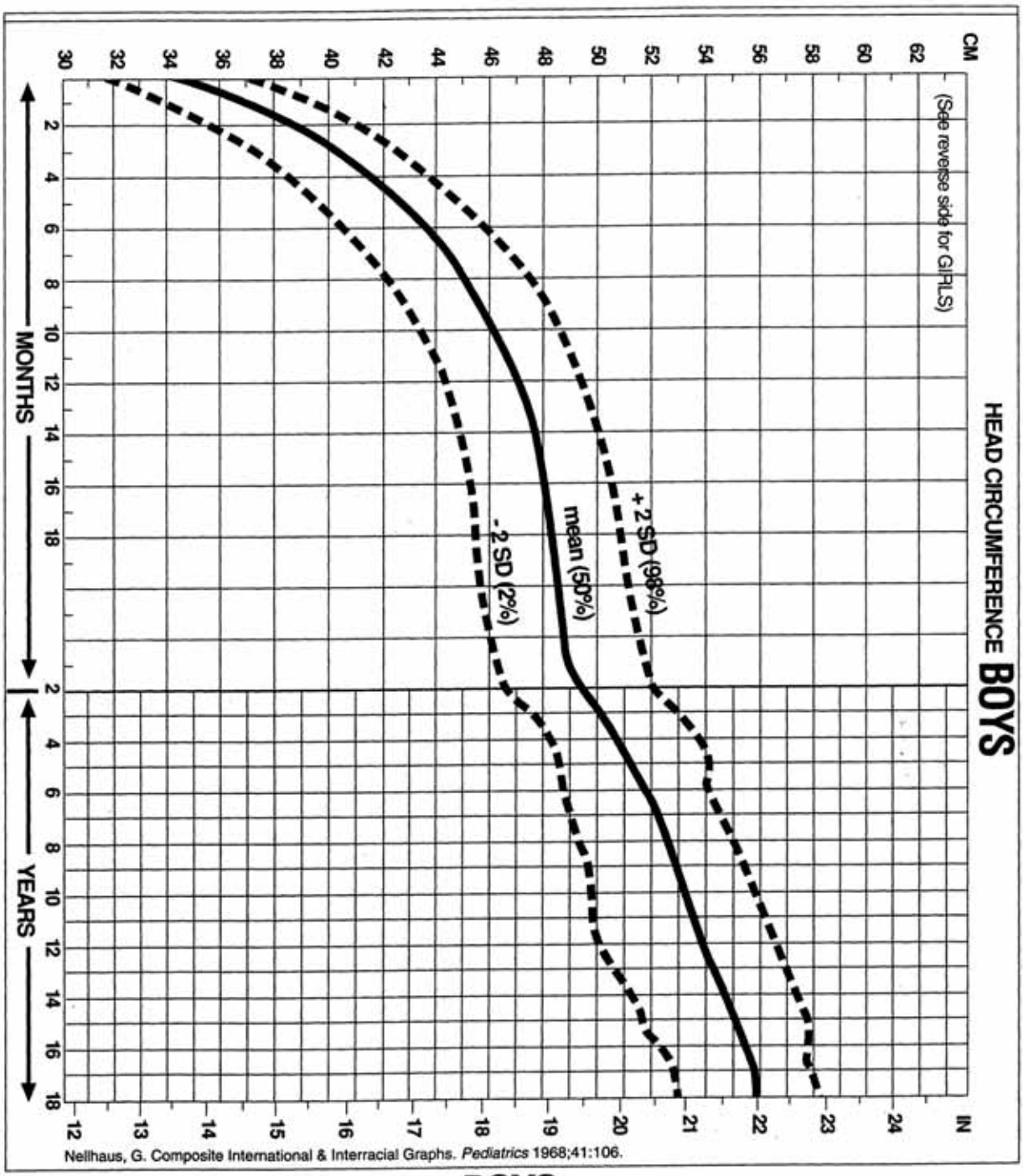
*Scales should be calibrated at regular intervals to ensure accuracy. A local supplier may offer this service with a purchase or calibration weights can be obtained.

Name _____

Birth Date _____

Notes:

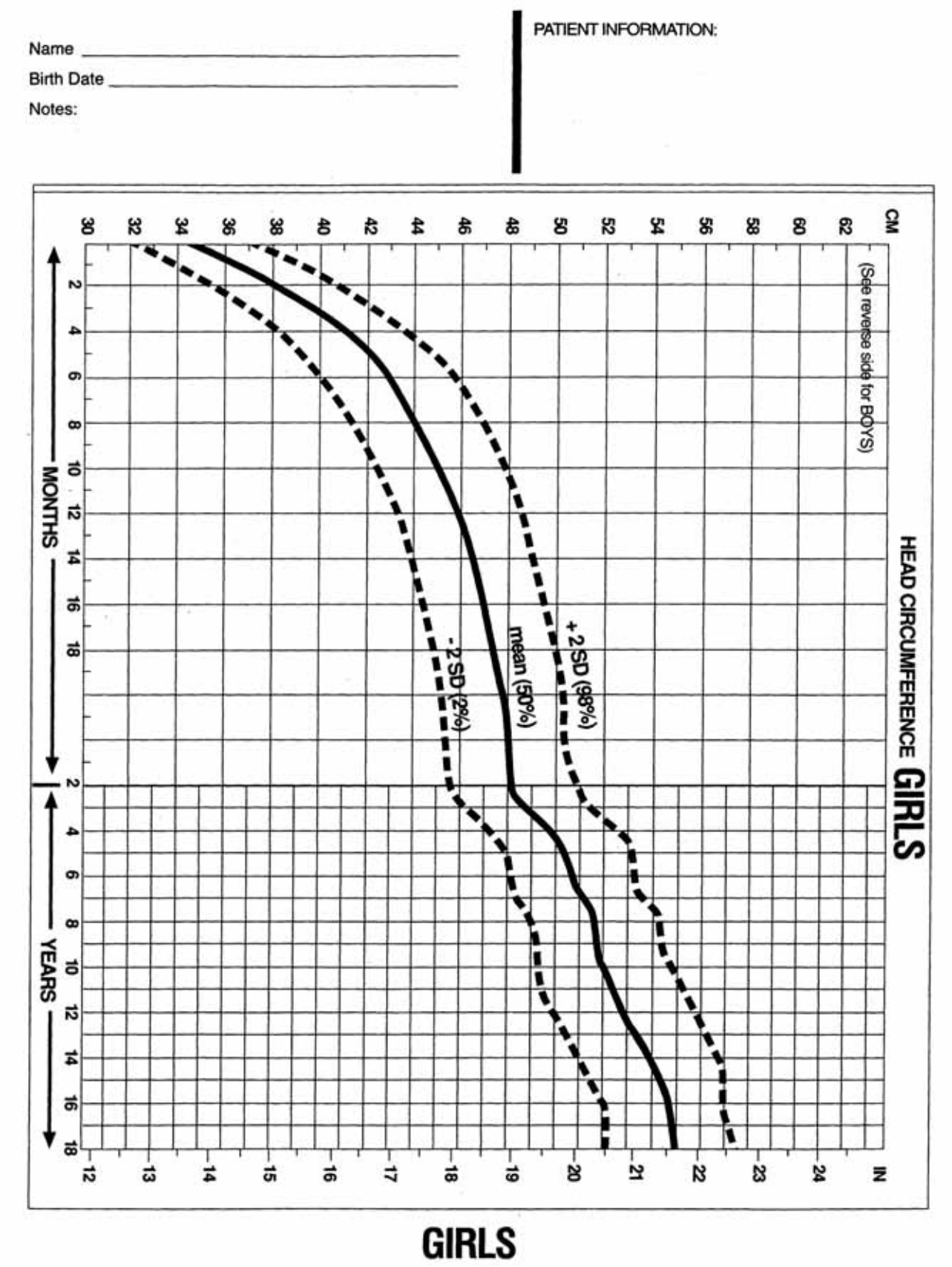
PATIENT INFORMATION:



BOYS

Provided Courtesy of Enfamil Family of Formulas™ Mead Johnson Nutritionals™

LB11 REV 9/97


Name
Birth Date
Notes:
PATIENT INFORMATION:
CM
IN
(See reverse side for BOYS)
HEAD CIRCUMFERENCE GIRLS
+ 2 SD (98%)
mean (50%)
- 2 SD (2%)
MONTHS
YEARS
GIRLS

Ross
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Development
Program

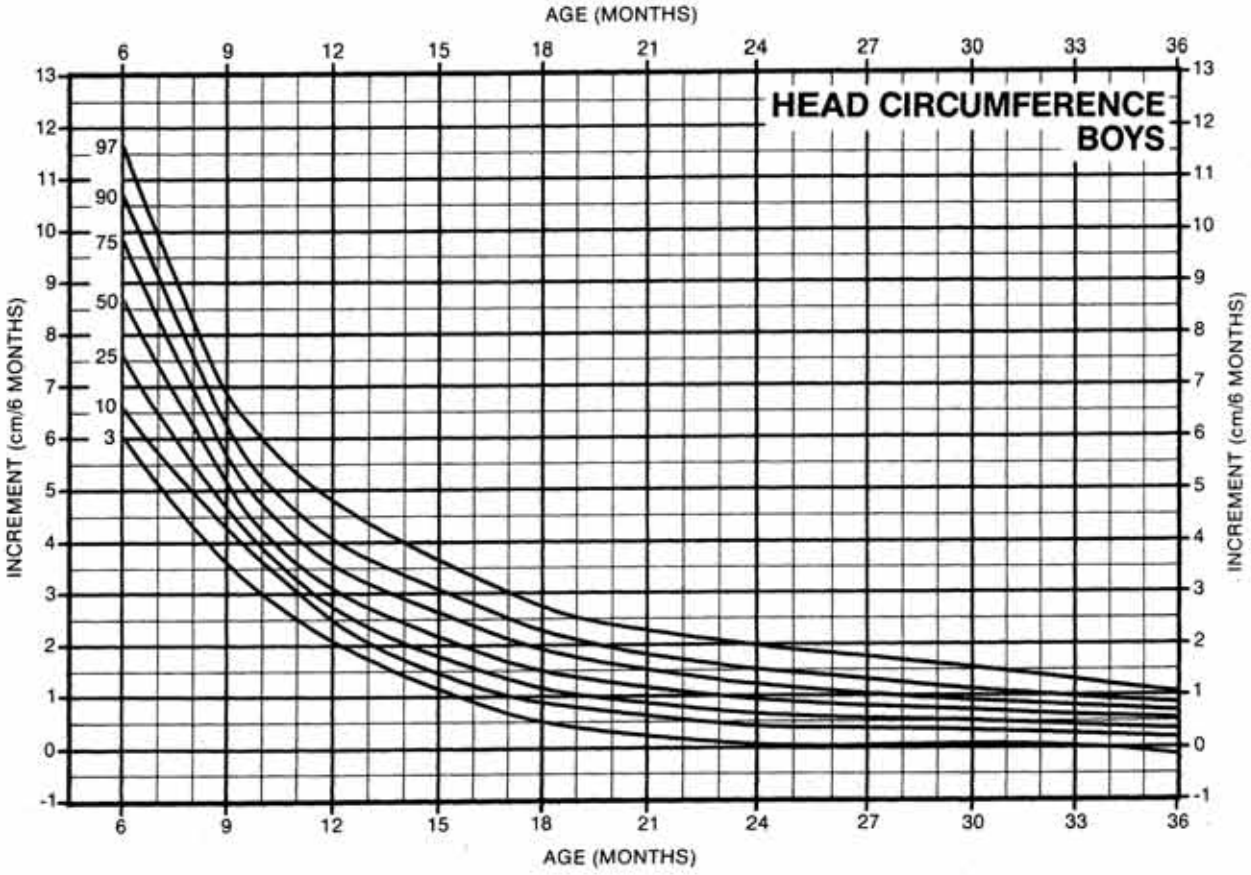
INCREMENTAL GROWTH CHARTS—BOYS

Growth charts such as those that display the National Center for Health Statistics (NCHS) percentiles are used for routine assessment of physical growth.[1] Occasionally, growth rate (growth velocity or increment divided by time between measurements) should be assessed, eg, when an infant or preadolescent child is found to be at an extreme percentile or when a substantial shift of percentile has occurred on an NCHS growth chart. The accompanying incremental growth charts are useful for assessing growth rates. They do not replace written records of growth data or NCHS growth charts.

These incremental growth charts have been prepared from serial data for white US children whose growth is very close to that of children from whom the NCHS percentiles were derived.[1,2] Highly standardized anthropometric methods that conform to current recommendations were used to make all measurements.[3] Weight was measured as, or corrected to, nude weight. Recumbent length and stature were measured without shoes. Appropriate use of the incremental growth charts requires that similar methods be applied. Ideally, the same person should measure a child at the beginning and end of an interval.

References:

1. Hamill PVV, Drizd TA, Johnson CL, Reed RB, Roche AF, Moore WM: Physical growth: National Center for Health Statistics percentiles. *Am J Clin Nutr* 32: 607-629, 1979.
2. Roche AF, Himes JH: Incremental growth charts. *Am J Clin Nutr* 33: 2041-2052, 1980.
3. Fomon SJ: *Nutritional Disorders of Children. Prevention, Screening, and Follow-up*. Washington, DC: DHEW Publication No. (HSA) 76-5612, 1976.



INSTRUCTIONS

1. Measure the child at the beginning and the end of a 6-month interval, if possible.
2. Subtract the initial measurement from the follow-up measurement to obtain the increment.
3. If the interval between measurements is not exactly 6 months (182 days), divide the increment by the interval in days and multiply by 182 to obtain the adjusted 6-month increment. The Table of Consecutively Numbered Days can be used to determine the interval between the measurements. If measurements are made in different years, add 365 to the day of the year for the follow-up measurement. Extrapolating increments from intervals of 3 months or less is not recommended.
4. Locate the intersection of the increment and the child's age at the ***end*** of the interval to determine the 6-month incremental percentile.

Interpretation: The accompanying charts permit definition of growth rate (growth velocity) relative to current reference data. Further investigation is indicated for children growing at rates markedly different from the 50th incremental percentile or for children whose incremental percentile changes rapidly.

Example 1 Boy at 5th NCHS* percentile at ages 6 and 12 months; aged 12 months at follow-up measurement.

Measurement	Length	Date	Day**
Follow-up	71.7 cm	August 10, 1981	222
Initial	63.4 cm	February 9, 1981	40
Increment =	8.3 cm	Interval =	182

His increment is 8.3 cm/6 months.
His increment is just below the 50th percentile.
He is short but growing at a normal rate.

* National Center for Health Statistics
** From Table of Consecutively Numbered Days

Example 2 Boy, aged 8 years at follow-up measurement.

Measurement	Stature	Date	Day*
Follow-up	119.1 cm	February 10, 1981	406**
Initial	118.0 cm	September 24, 1980	267
Increment =	1.1 cm	Interval =	139

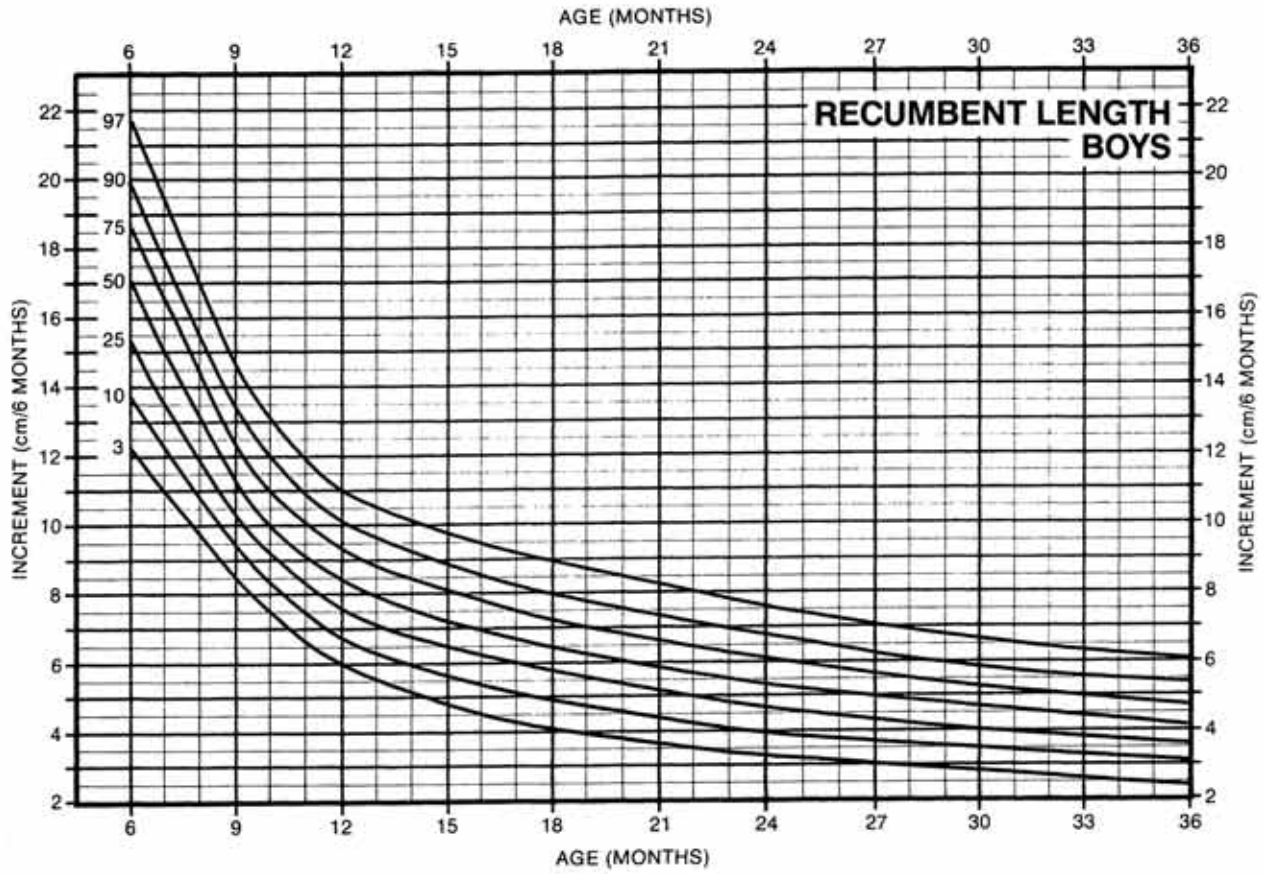
His adjusted 6-month increment is $\frac{1.1 \text{ cm}}{139} \times 182 = 1.4$ cm.

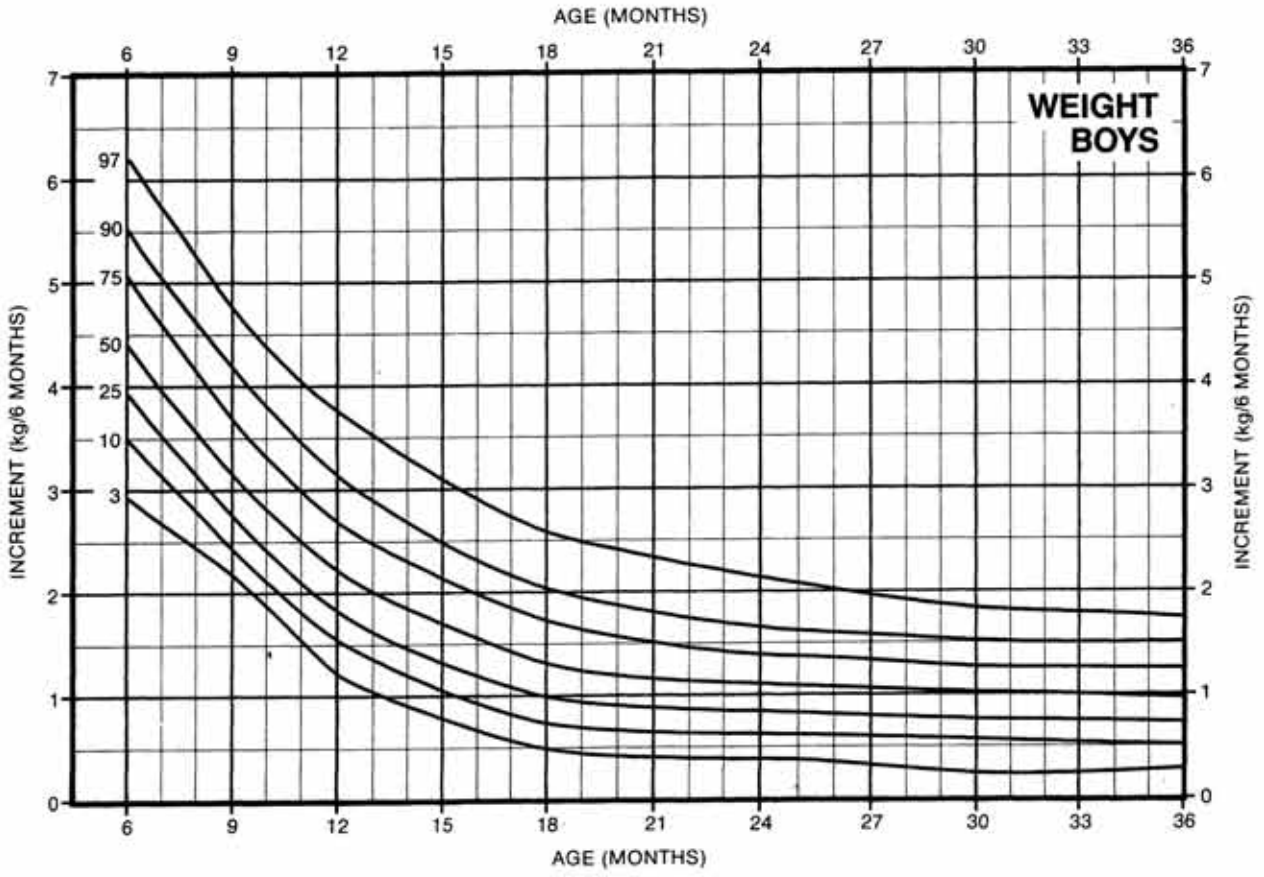
His increment is below the 3rd percentile.
Further investigation is indicated.

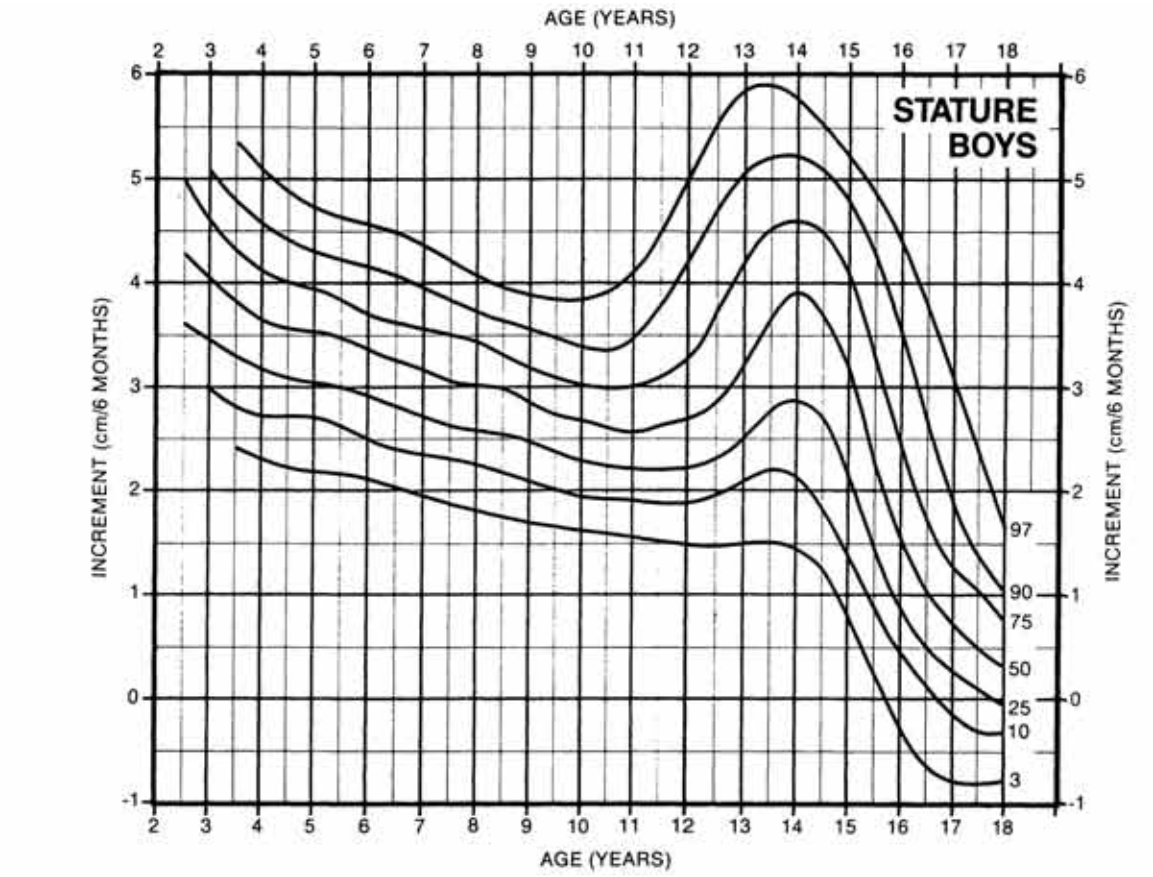
* From Table of Consecutively Numbered Days
** February 10 is day 41, to which 365 is added because follow-up measurement is in a different year (41 + 365 = 406).

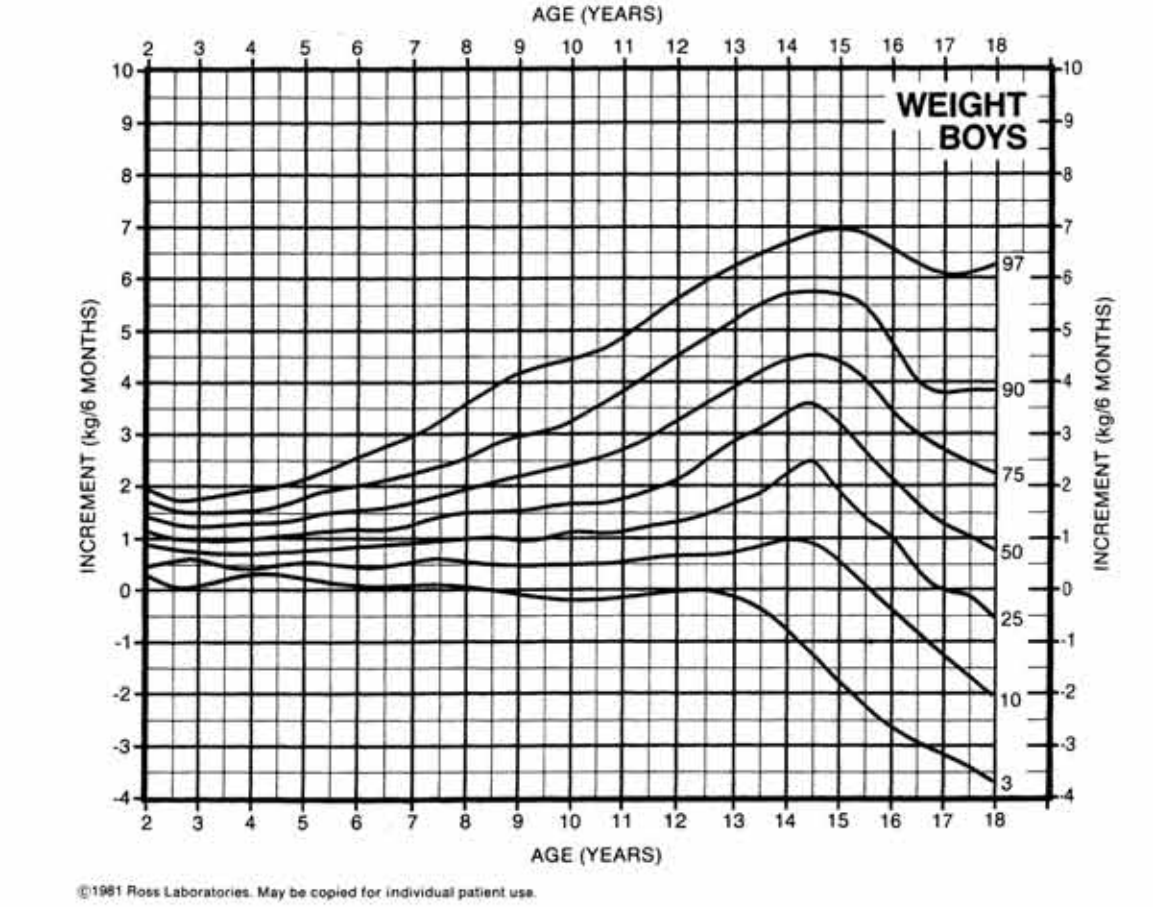
Table of Consecutively Numbered Days

Day	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	Day
1	1	32	60	91	121	152	182	213	244	274	305	335	1
2	2	33	61	92	122	153	183	214	245	275	306	336	2
3	3	34	62	93	123	154	184	215	246	276	307	337	3
4	4	35	63	94	124	155	185	216	247	277	308	338	4
5	5	36	64	95	125	156	186	217	248	278	309	339	5
6	6	37	65	96	126	157	187	218	249	279	310	340	6
7	7	38	66	97	127	158	188	219	250	280	311	341	7
8	8	39	67	98	128	159	189	220	251	281	312	342	8
9	9	40	68	99	129	160	190	221	252	282	313	343	9
10	10	41	69	100	130	161	191	222	253	283	314	344	10
11	11	42	70	101	131	162	192	223	254	284	315	345	11
12	12	43	71	102	132	163	193	224	255	285	316	346	12
13	13	44	72	103	133	164	194	225	256	286	317	347	13
14	14	45	73	104	134	165	195	226	257	287	318	348	14
15	15	46	74	105	135	166	196	227	258	288	319	349	15
16	16	47	75	106	136	167	197	228	259	289	320	350	16
17	17	48	76	107	137	168	198	229	260	290	321	351	17
18	18	49	77	108	138	169	199	230	261	291	322	352	18
19	19	50	78	109	139	170	200	231	262	292	323	353	19
20	20	51	79	110	140	171	201	232	263	293	324	354	20
21	21	52	80	111	141	172	202	233	264	294	325	355	21
22	22	53	81	112	142	173	203	234	265	295	326	356	22
23	23	54	82	113	143	174	204	235	266	296	327	357	23
24	24	55	83	114	144	175	205	236	267	297	328	358	24
25	25	56	84	115	145	176	206	237	268	298	329	359	25
26	26	57	85	116	146	177	207	238	269	299	330	360	26
27	27	58	86	117	147	178	208	239	270	300	331	361	27
28	28	59	87	118	148	179	209	240	271	301	332	362	28
29	29	—	88	119	149	180	210	241	272	302	333	363	29
30	30	—	89	120	150	181	211	242	273	303	334	364	30
31	31	—	90	—	151	—	212	243	—	304	—	365	31
Day	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	Day









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INCREMENTAL GROWTH CHARTS—GIRLS

Growth charts such as those that display the National Center for Health Statistics (NCHS) percentiles are used for routine assessment of physical growth.[1] Occasionally, growth rate (growth velocity or increment divided by time between measurements) should be assessed, eg, when an infant or preadolescent child is found to be at an extreme percentile or when a substantial shift of percentile has occurred on an NCHS growth chart. The accompanying incremental growth charts are useful for assessing growth rates. They do not replace written records of growth data or NCHS growth charts.

These incremental growth charts have been prepared from serial data for white US children whose growth is very close to that of children from whom the NCHS percentiles were derived.[1,2] Highly standardized anthropometric methods that conform to current recommendations were used to make all measurements.[3] Weight was measured as, or corrected to, nude weight. Recumbent length and stature were measured without shoes. Appropriate use of the incremental growth charts requires that similar methods be applied. Ideally, the same person should measure a child at the beginning and end of an interval.

References:

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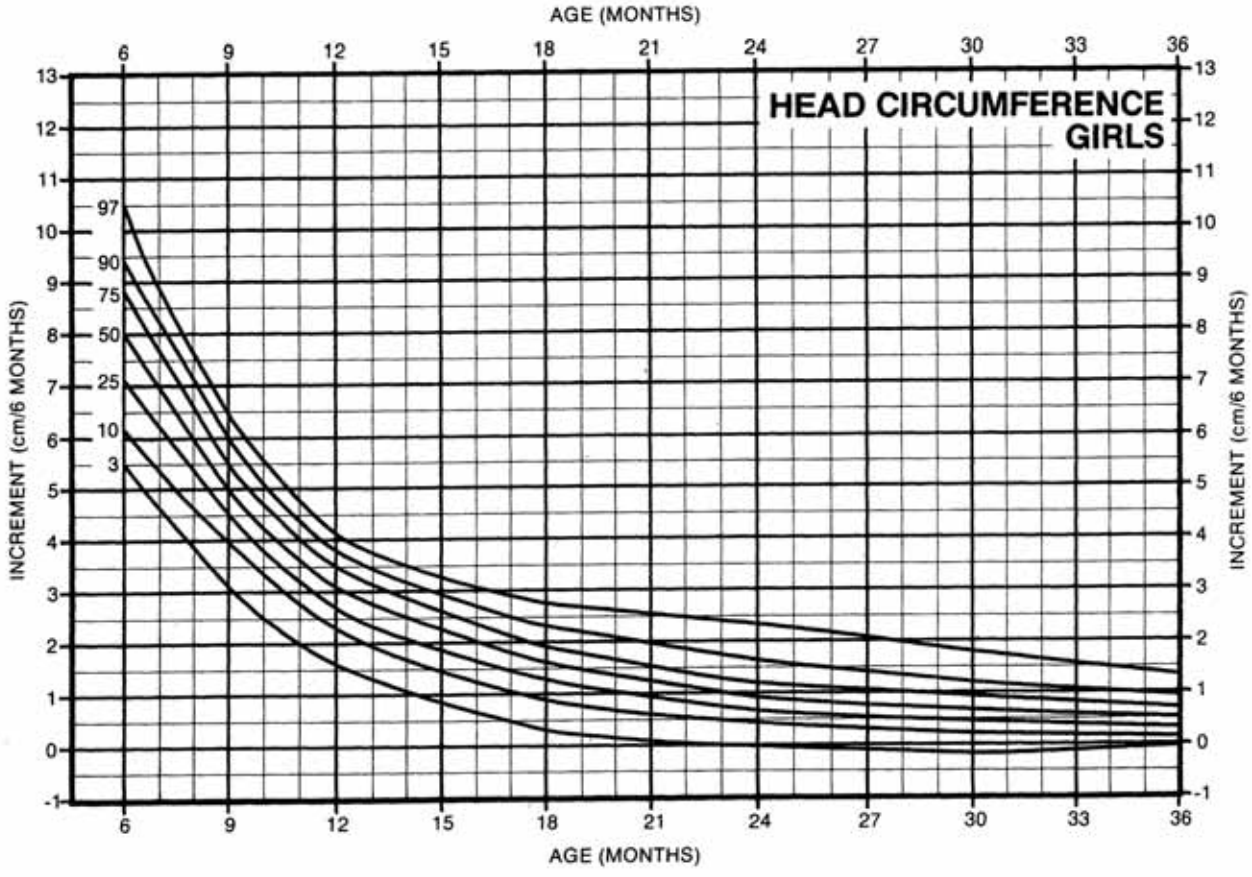
2. Roche AF, Himes JH: Incremental growth charts. *Am J Clin Nutr* 33: 2041-2052, 1980.
3. Fomon SJ: *Nutritional Disorders of Children. Prevention, Screening, and Follow-up.* Washington, DC: DHEW Publication No. (HSA) 76-5612, 1976.



INSTRUCTIONS

1. Measure the child at the beginning and the end of a 6-month interval, if possible.
2. Subtract the initial measurement from the follow-up measurement to obtain the increment.
3. If the interval between measurements is not exactly 6 months (182 days), divide the increment by the interval in days and multiply by 182 to obtain the adjusted 6-month increment. The Table of Consecutively Numbered Days can be used to determine the interval between the measurements. If measurements are made in different years, add 365 to the day of the year for the follow-up measurement. Extrapolating increments from intervals of 3 months or less is not recommended.
4. Locate the intersection of the increment and the child's age at the ***end*** of the interval to determine the 6-month incremental percentile.

Interpretation: The accompanying charts permit definition of growth rate (growth velocity) relative to current reference data. Further investigation is indicated for children growing at rates markedly different from the 50th incremental percentile or for children whose incremental percentile changes rapidly.

Example 1 Girl at 5th NCHS* percentile at ages 6 and 12 months; aged 12 months at follow-up measurement.

Measurement	Length	Date	Day**
Follow-up	69.8 cm	July 16, 1981	197
Initial	61.8 cm	January 15, 1981	15
Increment =	8.0 cm	Interval =	182

Her increment is 8.0 cm/6 months.
Her increment is between the 25th and 50th percentile.
She is short but growing at a normal rate.

* National Center for Health Statistics
** From Table of Consecutively Numbered Days

Example 2 Girl, aged 8 years at follow-up measurement.

Measurement	Stature	Date	Day*
Follow-up	118.0 cm	April 22, 1981	477**
Initial	116.9 cm	November 21, 1980	325
Increment =	1.1 cm	Interval =	152

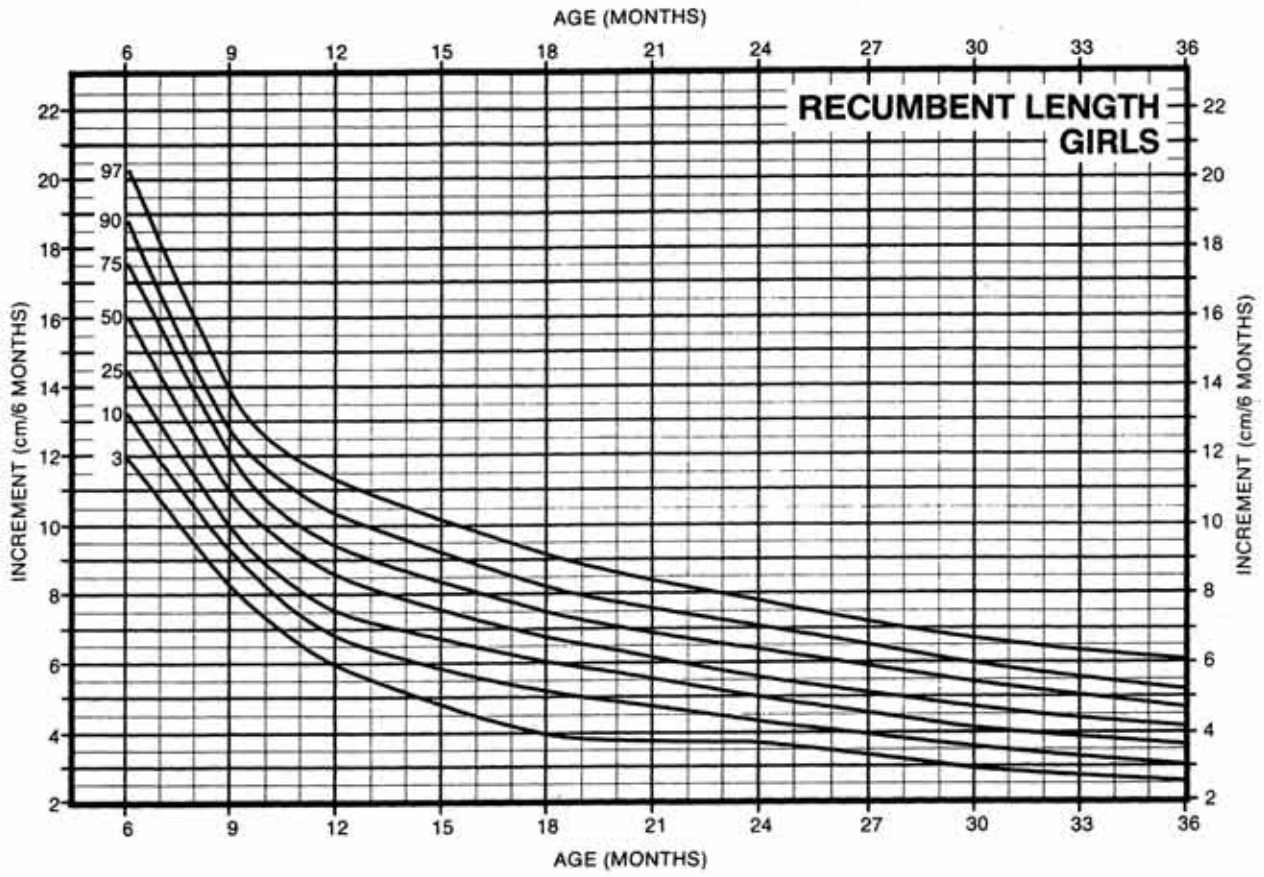
Her adjusted 6-month increment is $\frac{1.1 \text{ cm}}{152} \times 182 = 1.3$ cm.

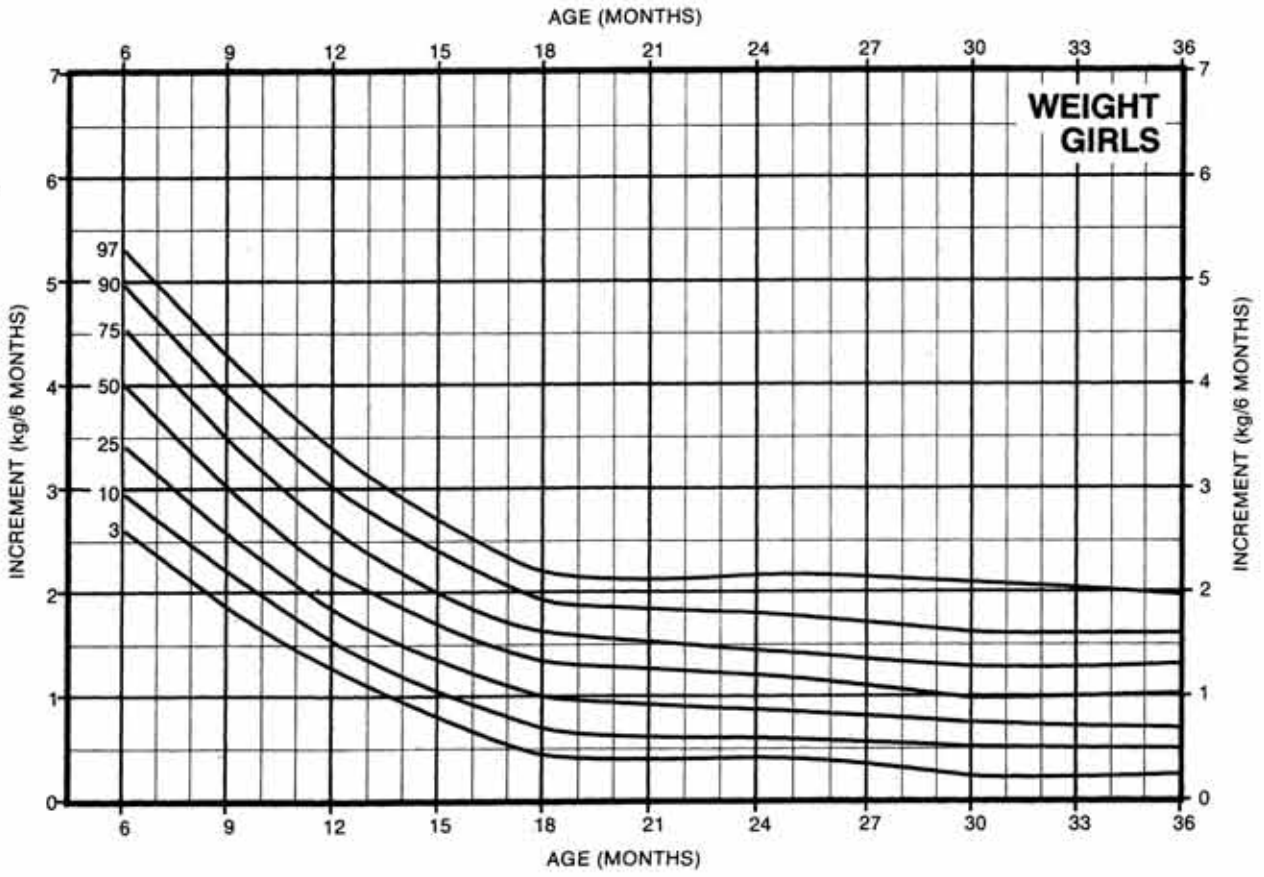
Her increment is below the 3rd percentile.
Further investigation is indicated.

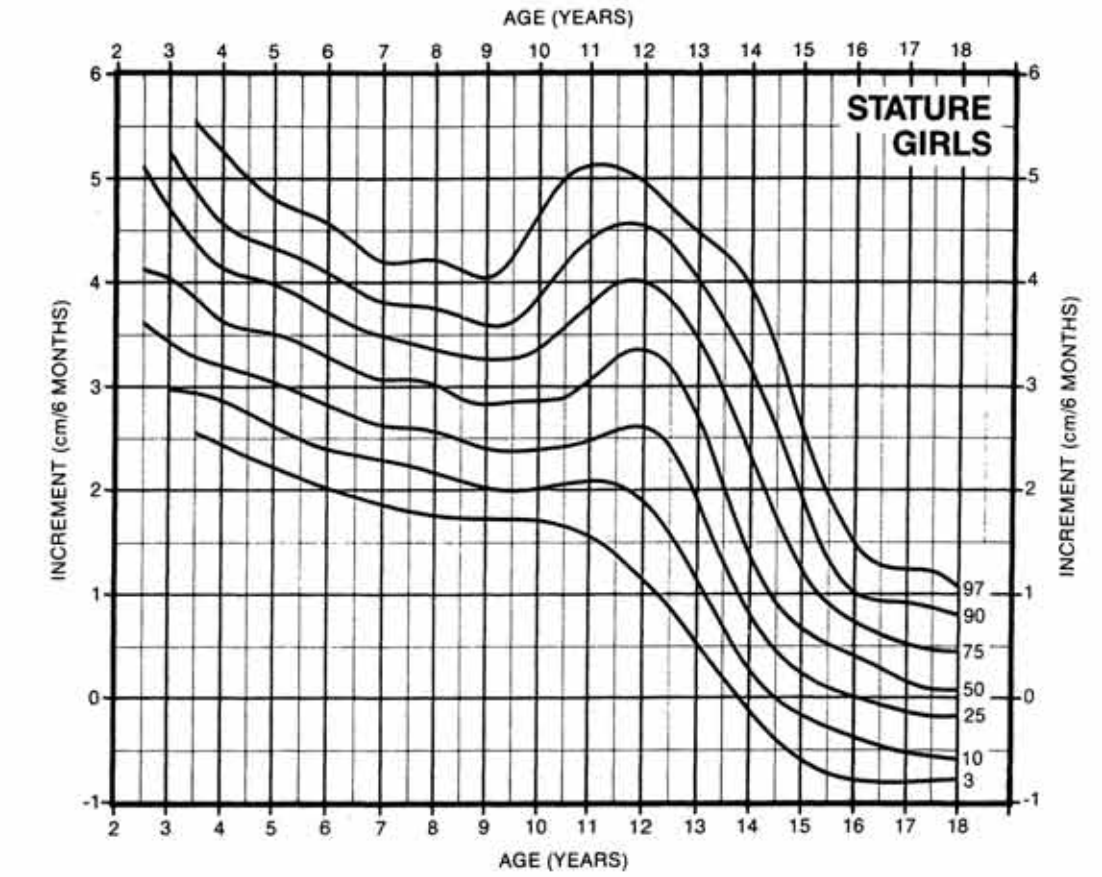
* From Table of Consecutively Numbered Days
** April 22 is day 112, to which 365 is added because follow-up measurement is in a different year (112 + 365 = 477).

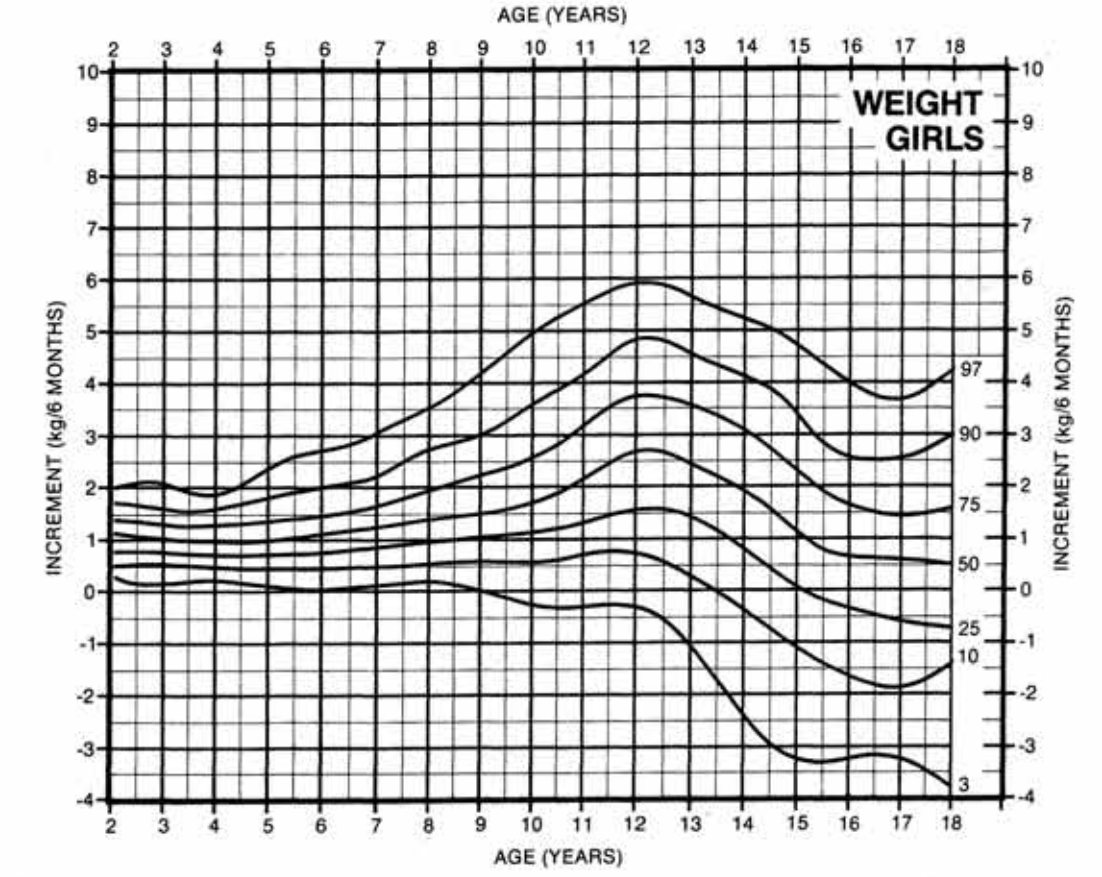
Table of Consecutively Numbered Days

Day	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	Day
1	1	32	60	91	121	152	182	213	244	274	305	335	1
2	2	33	61	92	122	153	183	214	245	275	306	336	2
3	3	34	62	93	123	154	184	215	246	276	307	337	3
4	4	35	63	94	124	155	185	216	247	277	308	338	4
5	5	36	64	95	125	156	186	217	248	278	309	339	5
6	6	37	65	96	126	157	187	218	249	279	310	340	6
7	7	38	66	97	127	158	188	219	250	280	311	341	7
8	8	39	67	98	128	159	189	220	251	281	312	342	8
9	9	40	68	99	129	160	190	221	252	282	313	343	9
10	10	41	69	100	130	161	191	222	253	283	314	344	10
11	11	42	70	101	131	162	192	223	254	284	315	345	11
12	12	43	71	102	132	163	193	224	255	285	316	346	12
13	13	44	72	103	133	164	194	225	256	286	317	347	13
14	14	45	73	104	134	165	195	226	257	287	318	348	14
15	15	46	74	105	135	166	196	227	258	288	319	349	15
16	16	47	75	106	136	167	197	228	259	289	320	350	16
17	17	48	76	107	137	168	198	229	260	290	321	351	17
18	18	49	77	108	138	169	199	230	261	291	322	352	18
19	19	50	78	109	139	170	200	231	262	292	323	353	19
20	20	51	79	110	140	171	201	232	263	293	324	354	20
21	21	52	80	111	141	172	202	233	264	294	325	355	21
22	22	53	81	112	142	173	203	234	265	295	326	356	22
23	23	54	82	113	143	174	204	235	266	296	327	357	23
24	24	55	83	114	144	175	205	236	267	297	328	358	24
25	25	56	84	115	145	176	206	237	268	298	329	359	25
26	26	57	85	116	146	177	207	238	269	299	330	360	26
27	27	58	86	117	147	178	208	239	270	300	331	361	27
28	28	59	87	118	148	179	209	240	271	301	332	362	28
29	29	—	88	119	149	180	210	241	272	302	333	363	29
30	30	—	89	120	150	181	211	242	273	303	334	364	30
31	31	—	90	—	151	—	212	243	—	304	—	365	31
Day	JAN	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	Day









Ross
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PARENT-SPECIFIC ADJUSTMENTS FOR EVALUATION OF LENGTH AND STATURE — BOYS

Recumbent length and stature (standing height) are affected by both genetic and nongenetic factors. The genetic component should be considered when concern arises that diet or disease may have retarded or accelerated growth. Adjustment of length or stature to take parental stature into account may help identify or explain the nature of a growth problem. Such adjustment may prompt diagnostic studies or suggest a genetic basis for the growth problem.

Parent-specific adjustment procedures have been developed for US children by Himes, Roche, and Thissen.* The accompanying tables of adjustments are adapted from their research. Parent-specific adjustments need not be done routinely but should be considered when a child has unusual length or stature. As a guideline for applying parent-specific adjustments, "unusual" may be defined as below the 5th percentile or above the 95th percentile in length or stature for age.

Occasionally, a child's length or stature may appear normal, but the parents (one or both) are very tall or very short. Under such circumstances, parent-specific adjustment also is appropriate. Rapid decrease or increase in a child's percentile for length or stature generally is not an indication for applying parent-specific adjustments because the cause is more likely to be nongenetic than genetic.

*Himes JH, Roche AF, Thissen D: *Parent-Specific Adjustments for Assessment of Recumbent Length and Stature*. Monographs in Paediatrics. Basel, Switzerland: S Karger, 1981, vol 13.

Table 1. Metric Equivalents (cm) for Length and Stature

INCHES	0	¼	½	¾	INCHES	0	¼	½	¾	INCHES	0	¼	½	¾
12	30.5	31.1	31.7	32.4	36	91.4	92.1	92.7	93.3	60	152.4	153.0	153.7	154.3
13	33.0	33.7	34.3	34.9	37	94.0	94.6	95.2	95.9	61	154.9	155.6	156.2	156.8
14	35.6	36.2	36.8	37.5	38	96.5	97.2	97.8	98.4	62	157.5	158.1	158.7	159.4
15	38.1	38.7	39.4	40.0	39	99.1	99.7	100.3	101.0	63	160.0	160.7	161.3	161.9
16	40.6	41.3	41.9	42.5	40	101.6	102.2	102.9	103.5	64	162.6	163.2	163.8	164.5
17	43.2	43.8	44.4	45.1	41	104.1	104.8	105.4	106.0	65	165.1	165.7	166.4	167.0
18	45.7	46.4	47.0	47.6	42	106.7	107.3	107.9	108.6	66	167.6	168.3	168.9	169.5
19	48.3	48.9	49.5	50.2	43	109.2	109.9	110.5	111.1	67	170.2	170.8	171.4	172.1
20	50.8	51.4	52.1	52.7	44	111.8	112.4	113.0	113.7	68	172.7	173.4	174.0	174.6
21	53.3	54.0	54.6	55.2	45	114.3	114.9	115.6	116.2	69	175.3	175.9	176.5	177.2
22	55.9	56.5	57.1	57.8	46	116.8	117.5	118.1	118.7	70	177.8	178.4	179.1	179.7
23	58.4	59.1	59.7	60.3	47	119.4	120.0	120.6	121.3	71	180.3	181.0	181.6	182.2
24	61.0	61.6	62.2	62.9	48	121.9	122.6	123.2	123.8	72	182.9	183.5	184.1	184.8
25	63.5	64.1	64.8	65.4	49	124.5	125.1	125.7	126.4	73	185.4	186.1	186.7	187.3
26	66.0	66.7	67.3	67.9	50	127.0	127.6	128.3	128.9	74	188.0	188.6	189.2	189.9
27	68.6	69.2	69.8	70.5	51	129.5	130.2	130.8	131.4	75	190.5	191.1	191.8	192.4
28	71.1	71.8	72.4	73.0	52	132.1	132.7	133.3	134.0	76	193.0	193.7	194.3	194.9
29	73.7	74.3	74.9	75.6	53	134.6	135.3	135.9	136.5	77	195.6	196.2	196.8	197.5
30	76.2	76.8	77.5	78.1	54	137.2	137.8	138.4	139.1	78	198.1	198.8	199.4	200.0
31	78.7	79.4	80.0	80.6	55	139.7	140.3	141.0	141.6	79	200.7	201.3	201.9	202.6
32	81.3	81.9	82.5	83.2	56	142.2	142.9	143.5	144.1	80	203.2	203.8	204.5	205.1
33	83.8	84.5	85.1	85.7	57	144.8	145.4	146.0	146.7	81	205.7	206.4	207.0	207.6
34	86.4	87.0	87.6	88.3	58	147.3	148.0	148.6	149.2	82	208.3	208.9	209.5	210.2
35	88.9	89.5	90.2	90.8	59	149.9	150.5	151.1	151.8	83	210.8	211.5	212.1	212.7

INSTRUCTIONS

1. Measure and record mother's stature.
2. Measure and record father's stature.
3. When one parent's stature cannot be measured, the measured parent's estimate of the other parent's stature (in cm) can be substituted for measured stature, and midparent stature can be calculated as in instruction 4. Alternatively, the measured parent's perception of the other parent's stature (short, medium, or tall) can be used to determine midparent stature directly from Table 4.

Table 4. Midparent Stature (cm) When Measured Parent Reports Other Parent's Stature as Short, Medium, or Tall

Measured Parent's Stature (cm)	Midparent Stature (cm)* When Mother Reports Father's Stature as Short†	Medium†	Tall†	When Father Reports Mother's Stature as Short‡	Medium‡	Tall‡
146	156	162	166	150	154	158
148	158	162	166	152	156	160
150	158	164	168	152	156	160
152	160	164	168	154	158	162
154	160	166	170	154	158	162
156	162	166	170	156	160	164
158	162	168	172	156	160	164
160	164	168	172	158	162	166
162	164	170	174	158	162	166
164	166	170	174	160	164	168
166	166	172	176	160	164	168
168	168	172	176	162	166	170
170	168	174	178	162	166	170
172	170	174	178	164	168	172
174	170	176	180	164	168	172
176	172	176	180	166	170	174
178	172	178	182	166	170	174
180	174	178	182	168	172	176
182	174	180	184	168	172	176
184	176	180	184	170	174	178
186	176	182	—	170	174	178
188	178	182	—	172	176	180
190	178	184	—	172	176	180
192	180	184	—	174	178	182
194	180	—	—	174	178	182
196	182	—	—	176	180	184
198	182	—	—	176	180	184

* All midparent statures are rounded to the nearest 2 cm to facilitate use of Tables 2 and 3.
† Values for father's stature used in calculations of midparent stature: short, 167.6 cm (5 ft 6 in.); medium, 176.3 cm (5 ft 9½ in.); tall, 185.4 cm (6 ft 1 in.).
‡ Values for mother's stature used in calculations of midparent stature: short, 154.9 cm (5 ft 1 in.); medium, 162.8 cm (5 ft 4 in.); tall, 170.7 cm (5 ft 7¼ in.).

4. Calculate midparent stature by adding the mother's stature and the father's stature in cm and dividing by two. Metric equivalents for stature are shown in Table 1.
5. Measure, record, and plot the boy's length (birth to 36 months) or stature (3 to 18 years) in cm on the appropriate growth chart that displays the National Center for Health Statistics (NCHS) percentiles. Metric equivalents for length and stature are shown in Table 1.
6. Calculate the boy's adjusted length or stature by using the parent-specific adjustments from Table 2 for length or from Table 3 for stature:
   a. Locate the age closest to that achieved by the boy.
   b. For that age, locate the horizontal row that includes the boy's length or stature.
   c. Locate the vertical column closest to the midparent stature for the boy's mother and father.
   d. The parent-specific adjustment (in cm) appears at the row-column intersection.
   e. Add the parent-specific adjustment to the boy's length or stature if the factor has no sign; subtract the adjustment if it has a minus sign.
7. Determine the boy's parent-specific adjusted percentile by plotting adjusted length or stature on the appropriate NCHS growth chart. Clearly label plotted measurements as being actual or adjusted values.

Interpretation: A boy at a low percentile for actual length or stature whose parents are short probably is genetically short. However, his shortness, particularly if it is extreme, may have additional contributing factors that should be considered.

If the boy's adjusted percentile is low, his growth probably has been slowed by nongenetic factors and diagnostic studies should be considered. If the parents are tall, the boy's adjusted percentile will be lower than his actual percentile and his shortness is more likely due to malnutrition or disease.

A boy at a high adjusted percentile for length or stature most often will be found to have accelerated maturation. Rarely, a specific disorder such as Marfan's syndrome or pituitary gigantism may be responsible for the boy's unusual length or stature.

Follow-Up: Counseling may be advisable when a boy is judged to be genetically short or tall. Additional contributing factors should be considered and growth monitored to confirm the relative stability of the boy's length or stature percentile.

Further investigation and modification of diet or specific therapy is indicated for a boy with unusual length or stature due to malnutrition or disease. Growth should be monitored to evaluate the effectiveness of dietary management or drug therapy.

Example #1. Boy aged 12 months, length 28 in., mother's stature 60½ in., and father's stature 65¼ in.

Son's actual length in cm is 71.1 (from Table 1).
Son's actual percentile is below the 5th (from NCHS growth chart).
Mother's stature in cm is 153.7 (from Table 1).
Father's stature in cm is 165.7 (from Table 1).
Midparent stature is $\frac{153.7 + 165.7}{2}$ = 159.7 cm.
Adjustment is 2 cm (from Table 2).
Son's adjusted length is 71.1 cm + 2 cm = 73.1 cm.
Son's adjusted percentile is between the 10th and 25th (from NCHS growth chart).
Interpretation: Probably genetically short. Consider additional contributing factors.

Example #2. Boy aged 8 years, stature 47¼ in., mother's stature 68½ in., and father's stature reported as "tall."

Son's actual stature in cm is 120.0 (from Table 1).
Son's actual percentile is 10th (from NCHS growth chart).
Mother's stature in cm is 174.0 (from Table 1).
Midparent stature is 180.0 cm (from Table 4).
Adjustment is −7 cm (from Table 3).
Son's adjusted stature is 120.0 cm − 7 cm = 113.0 cm.
Son's adjusted percentile is below the 5th (from NCHS growth chart).
Interpretation: Probably nongenetically short. Further investigation is indicated.

Table 2. Parent-Specific Adjustments (cm) for Length of Boys From Birth to 36 Months*

Age (Months)	Length (cm)	Midparent Stature (cm)																	
		150	152	154	156	158	160	162	164	166	168	170	172	174	176	178	180	182	184
Birth	40.0– 43.9	2	1	1	1	1	1	1	0	0	0	0	0	0	−1	−1	−1	−1	−1
	44.0– 52.9	2	2	1	1	1	1	1	0	0	0	0	0	0	−1	−1	−1	−1	−1
	53.0– 56.9	2	2	1	1	1	1	1	1	0	0	0	0	0	−1	−1	−1	−1	−1
1	40.0– 44.9	2	2	1	1	1	1	1	0	0	0	0	−1	−1	−1	−1	−1	−2	−2
	45.0– 48.9	2	2	2	1	1	1	1	0	0	0	0	0	−1	−1	−1	−1	−2	−2
	49.0– 52.9	2	2	2	1	1	1	1	1	0	0	0	0	−1	−1	−1	−1	−2	−2
	53.0– 56.9	2	2	2	2	1	1	1	1	0	0	0	0	−1	−1	−1	−1	−1	−2
	57.0– 62.9	2	2	2	2	1	1	1	1	1	0	0	0	0	−1	−1	−1	−1	−2
3	52.0– 56.9	3	2	2	2	1	1	1	1	0	0	0	−1	−1	−1	−1	−2	−2	−2
	57.0– 60.9	3	2	2	2	2	1	1	1	0	0	0	0	−1	−1	−1	−2	−2	−2
	61.0– 66.9	3	3	2	2	2	1	1	1	1	0	0	0	−1	−1	−1	−1	−2	−2
	67.0– 68.9	3	3	2	2	2	2	1	1	1	0	0	0	0	−1	−1	−1	−2	−2
6	62.0– 64.9	3	3	2	2	2	1	1	1	0	0	0	−1	−1	−1	−2	−2	−2	−3
	65.0– 66.9	3	3	3	2	2	2	1	1	1	0	0	−1	−1	−1	−2	−2	−2	−3
	67.0– 73.9	3	3	3	2	2	2	1	1	1	0	0	0	−1	−1	−1	−2	−2	−2
	74.0– 76.9	4	3	3	3	2	2	2	1	1	1	0	0	0	−1	−1	−1	−2	−2
9	66.0– 68.9	3	3	3	2	2	1	1	1	0	0	0	−1	−1	−2	−2	−2	−3	−3
	69.0– 72.9	4	3	3	3	2	2	1	1	1	0	0	−1	−1	−1	−2	−2	−2	−3
	73.0– 76.9	4	3	3	3	2	2	2	1	1	0	0	0	−1	−1	−1	−2	−2	−3
	77.0– 80.9	4	4	3	3	3	2	2	1	1	1	0	0	0	−1	−1	−2	−2	−2
12	67.0– 71.9	4	3	3	2	2	2	1	1	0	0	−1	−1	−1	−2	−2	−3	−3	−3
	72.0– 74.9	4	4	3	3	2	2	1	1	1	0	0	−1	−1	−1	−2	−2	−3	−3
	75.0– 78.9	4	4	3	3	2	2	2	1	1	0	0	0	−1	−1	−2	−2	−3	−3
	79.0– 82.9	4	4	3	3	3	2	2	1	1	1	0	0	−1	−1	−1	−2	−2	−3
	83.0– 84.9	4	4	4	3	3	2	2	2	1	1	0	0	−1	−1	−1	−2	−2	−3
18	73.0– 75.9	4	4	3	3	2	2	1	1	0	0	−1	−1	−2	−2	−2	−3	−3	−4
	76.0– 80.9	4	4	3	3	2	2	2	1	1	0	0	−1	−1	−2	−2	−3	−3	−4
	81.0– 84.9	5	4	4	3	3	2	2	1	1	0	0	−1	−1	−2	−2	−3	−3	−3
	85.0– 88.9	5	4	4	3	3	2	2	1	1	1	0	0	−1	−1	−2	−2	−3	−3
	89.0– 92.9	5	5	4	4	3	3	2	2	1	1	0	0	−1	−1	−2	−2	−2	−3
24	78.0– 82.9	5	4	4	3	3	2	2	1	0	0	−1	−1	−2	−2	−3	−3	−4	−5
	83.0– 86.9	5	5	4	4	3	2	2	1	1	0	0	−1	−2	−2	−3	−3	−4	−4
	87.0– 92.9	6	5	5	4	3	3	2	2	1	1	0	−1	−1	−2	−2	−3	−3	−4
	93.0– 96.9	6	5	5	4	4	3	3	2	1	1	0	0	−1	−1	−2	−3	−3	−4
30	85.0– 88.9	6	5	5	4	3	3	2	1	1	0	−1	−1	−2	−3	−3	−4	−4	−5
	89.0– 92.9	6	5	5	4	4	3	2	2	1	0	0	−1	−2	−2	−3	−3	−4	−5
	93.0– 96.9	6	6	5	4	4	3	3	2	1	1	0	−1	−1	−2	−3	−3	−4	−5
	97.0–100.9	7	6	5	5	4	3	3	2	2	1	0	0	−1	−2	−2	−3	−4	−4
36	88.0– 90.9	6	6	5	4	3	3	2	1	1	0	−1	−1	−2	−3	−4	−4	−5	−6
	91.0– 94.9	6	6	5	4	4	3	2	2	1	0	−1	−1	−2	−3	−3	−4	−5	−5
	95.0– 98.9	7	6	5	5	4	3	3	2	1	1	0	−1	−1	−2	−3	−4	−4	−5
	99.0–102.9	7	6	6	5	4	4	3	2	1	1	0	−1	−1	−2	−3	−3	−4	−5
	103.0–106.9	7	7	6	5	5	4	3	2	2	1	0	0	−1	−2	−2	−3	−4	−4

*Adapted from Himes JH, Roche AF, Thissen D: *Parent-Specific Adjustments for Assessment of Recumbent Length and Stature.* Monographs in Paediatrics. Basel, Switzerland: S Karger, 1981, vol 13, Table XII, pp 36-37.

Table 3. Parent-Specific Adjustments (cm) for Stature of Boys From 3 to 18 Years

Age (Years)	Stature (cm)	Midparent Stature (cm)																		
		150	152	154	156	158	160	162	164	166	168	170	172	174	176	178	180	182	184
3	86.0– 87.9	7	6	5	5	4	3	2	1	1	0	−1	−2	−3	−3	−4	−5	−6	−7
	88.0– 97.9	8	7	6	5	4	4	3	2	1	0	−1	−1	−2	−3	−4	−5	−5	−6
	98.0–106.9	8	8	7	6	5	4	4	3	2	1	0	0	−1	−2	−3	−4	−4	−5
4	90.0– 93.9	7	6	5	4	4	3	2	1	0	−1	−1	−2	−3	−4	−5	−5	−6	−7
	94.0–103.9	8	7	6	5	4	3	3	2	1	0	−1	−1	−2	−3	−4	−5	−6	−6
	104.0–112.9	8	8	7	6	5	4	3	3	2	1	0	−1	−1	−2	−3	−4	−5	−6
5	96.0–103.9	8	7	6	5	4	3	2	1	0	0	−1	−2	−3	−4	−5	−6	−7	−8
	104.0–113.9	9	8	7	6	5	4	3	2	1	0	0	−1	−2	−3	−4	−5	−6	−7
	114.0–122.9	9	9	8	7	6	5	4	3	2	1	0	0	−1	−2	−3	−4	−5	−6
6	102.0–111.9	8	7	7	6	5	4	3	2	1	0	−1	−2	−3	−4	−5	−6	−7	−8
	112.0–121.9	9	8	7	7	6	5	4	3	2	1	0	−1	−2	−3	−4	−5	−6	−7
	122.0–130.9	10	9	8	7	6	6	5	4	3	2	1	0	−1	−2	−3	−4	−5	−6
7	108.0–117.9	9	8	7	6	5	4	3	2	1	0	−1	−2	−4	−5	−6	−7	−8	−9
	118.0–127.9	10	9	8	7	6	5	4	3	2	1	0	−1	−2	−4	−5	−6	−7	−8
	128.0–136.9	12	10	9	8	7	6	5	4	3	2	1	0	−1	−2	−4	−5	−6	−7
8	114.0–115.9	10	9	8	6	5	4	3	2	1	−1	−2	−3	−4	−5	−6	−8	−9	−10
	116.0–125.9	11	9	8	7	6	5	4	2	1	0	−1	−2	−3	−5	−6	−7	−8	−9
	126.0–135.9	12	10	9	8	7	6	5	3	2	1	0	−1	−2	−4	−5	−6	−7	−8
	136.0–144.9	13	12	10	9	8	7	6	5	3	2	1	0	−1	−2	−4	−5	−6	−7
9	120.0–121.9	11	9	8	7	6	4	3	2	1	0	−2	−3	−4	−5	−7	−8	−9	−10
	122.0–131.9	11	10	9	8	6	5	4	3	1	0	−1	−2	−3	−5	−6	−7	−8	−10
	132.0–141.9	12	11	10	9	7	6	5	4	2	1	0	−1	−2	−4	−5	−6	−7	−9
	142.0–150.9	13	12	11	10	8	7	6	5	4	2	1	0	−1	−3	−4	−5	−6	−7
10	124.0–127.9	11	10	9	7	6	5	3	2	1	−1	−2	−3	−5	−6	−7	−9	−10	−11
	128.0–137.9	12	11	10	8	7	6	4	3	2	0	−1	−2	−4	−5	−6	−8	−9	−10
	138.0–147.9	13	12	11	9	8	7	5	4	3	1	0	−1	−3	−4	−5	−7	−8	−9
	148.0–158.9	14	13	12	11	9	8	7	5	4	3	1	0	−1	−3	−4	−5	−7	−8
11	128.0–133.9	12	10	9	8	6	5	4	2	1	0	−2	−3	−5	−6	−7	−9	−10	−11
	134.0–143.9	12	11	10	8	7	6	4	3	2	0	−1	−2	−4	−5	−6	−8	−9	−10
	144.0–153.9	14	12	11	10	8	7	5	4	3	1	0	−1	−3	−4	−5	−7	−8	−9
	154.0–162.9	15	13	12	11	9	8	7	5	4	3	1	0	−2	−3	−4	−6	−7	−8
12	132.0–141.9	12	10	9	8	6	5	4	2	1	0	−2	−3	−4	−6	−7	−8	−10	−11
	142.0–151.9	13	11	10	9	7	6	5	3	2	1	−1	−2	−3	−5	−6	−7	−9	−10
	152.0–161.9	13	12	11	9	8	7	5	4	3	1	0	−1	−2	−4	−5	−6	−8	−9
	162.0–170.9	14	13	12	10	9	8	6	5	4	2	1	0	−2	−3	−4	−6	−7	−8
13	136.0–139.9	12	10	9	8	6	5	4	2	1	−1	−2	−3	−5	−6	−7	−9	−10	−12
	140.0–149.9	12	11	10	8	7	6	4	3	1	0	−1	−3	−4	−6	−7	−8	−10	−11
	150.0–159.9	13	12	10	9	8	6	5	4	2	1	−1	−2	−3	−5	−6	−7	−9	−10
	160.0–169.9	14	13	11	10	8	7	6	4	3	2	0	−1	−3	−4	−5	−7	−8	−9
	170.0–178.9	15	13	12	11	9	8	6	5	4	2	1	0	−2	−3	−5	−6	−7	−9
14	142.0–145.9	13	11	10	8	7	5	4	2	1	−1	−2	−4	−5	−7	−8	−10	−11	−13
	146.0–155.9	14	12	11	9	8	6	5	3	1	0	−2	−3	−5	−6	−8	−9	−11	−12
	156.0–165.9	15	13	11	10	8	7	5	4	2	1	−1	−2	−4	−5	−7	−8	−10	−11
	166.0–175.9	15	14	12	11	9	8	6	5	3	2	0	−1	−3	−4	−6	−7	−9	−11
	176.0–184.9	16	15	13	12	10	9	7	6	4	3	1	−1	−2	−4	−5	−7	−8	−10
15	148.0–151.9	14	13	11	9	7	6	4	2	0	−1	−3	−5	−7	−8	−10	−12	−14	−15
	152.0–161.9	15	14	12	10	8	7	5	3	1	0	−2	−4	−6	−7	−9	−11	−13	−14
	162.0–171.9	17	15	13	11	10	8	6	4	3	1	−1	−3	−4	−6	−8	−10	−11	−13
	172.0–181.9	18	16	14	13	11	9	7	6	4	2	0	−1	−3	−5	−7	−8	−10	−12
	182.0–190.9	19	17	16	14	12	10	9	7	5	3	2	0	−2	−4	−5	−7	−9	−11
16	156.0–163.9	17	15	13	11	9	7	5	3	1	−1	−3	−5	−7	−9	−11	−13	−16	−18
	164.0–173.9	19	17	15	13	10	8	6	4	2	0	−2	−4	−6	−8	−10	−12	−14	−16
	174.0–183.9	21	19	17	15	12	10	8	6	4	2	0	−2	−4	−6	−8	−10	−12	−14
	184.0–192.9	23	21	19	17	14	12	10	8	6	4	2	0	−2	−4	−6	−8	−10	−12
17	162.0–165.9	17	15	13	11	9	7	4	2	0	−2	−4	−7	−9	−11	−13	−15	−17	−20
	166.0–175.9	20	17	15	13	11	9	6	4	2	0	−2	−4	−7	−9	−11	−13	−15	−18
	176.0–185.9	22	20	18	16	13	11	9	7	5	3	0	−2	−4	−6	−8	−11	−13	−15
	186.0–194.9	25	23	20	18	16	14	12	9	7	5	3	1	−1	−4	−6	−8	−10	−12
18	160.0–165.9	18	16	13	11	9	6	4	2	0	−3	−5	−7	−10	−12	−14	−17	−19	−21
	166.0–175.9	20	18	16	13	11	9	7	4	2	0	−3	−5	−7	−10	−12	−14	−17	−19
	176.0–185.9	23	21	19	16	14	12	9	7	5	3	0	−2	−4	−7	−9	−11	−14	−16
	186.0–194.9	26	24	22	19	17	15	12	10	8	6	3	1	−1	−4	−6	−8	−11	−13

Ross
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PARENT-SPECIFIC ADJUSTMENTS FOR EVALUATION OF LENGTH AND STATURE — GIRLS

Recumbent length and stature (standing height) are affected by both genetic and nongenetic factors. The genetic component should be considered when concern arises that diet or disease may have retarded or accelerated growth. Adjustment of length or stature to take parental stature into account may help identify or explain the nature of a growth problem. Such adjustment may prompt diagnostic studies or suggest a genetic basis for the growth problem.

Parent-specific adjustment procedures have been developed for US children by Himes, Roche, and Thissen.* The accompanying tables of adjustments are adapted from their research. Parent-specific adjustments need not be done routinely but should be considered when a child has unusual length or stature. As a guideline for applying parent-specific adjustments, "unusual" may be defined as below the 5th percentile or above the 95th percentile in length or stature for age.

Occasionally, a child's length or stature may appear normal, but the parents (one or both) are very tall or very short. Under such circumstances, parent-specific adjustment also is appropriate. Rapid decrease or increase in a child's percentile for length or stature generally is not an indication for applying parent-specific adjustments because the cause is more likely to be nongenetic than genetic.

*Himes JH, Roche AF, Thissen D: *Parent-Specific Adjustments for Assessment of Recumbent Length and Stature*. Monographs in Paediatrics. Basel, Switzerland: S Karger, 1981, vol 13.

Table 1. Metric Equivalents (cm) for Length and Stature

INCHES	0	¼	½	¾	INCHES	0	¼	½	¾	INCHES	0	¼	½	¾
12	30.5	31.1	31.7	32.4	36	91.4	92.1	92.7	93.3	60	152.4	153.0	153.7	154.3
13	33.0	33.7	34.3	34.9	37	94.0	94.6	95.2	95.9	61	154.9	155.6	156.2	156.8
14	35.6	36.2	36.8	37.5	38	96.5	97.2	97.8	98.4	62	157.5	158.1	158.7	159.4
15	38.1	38.7	39.4	40.0	39	99.1	99.7	100.3	101.0	63	160.0	160.7	161.3	161.9
16	40.6	41.3	41.9	42.5	40	101.6	102.2	102.9	103.5	64	162.6	163.2	163.8	164.5
17	43.2	43.8	44.4	45.1	41	104.1	104.8	105.4	106.0	65	165.1	165.7	166.4	167.0
18	45.7	46.4	47.0	47.6	42	106.7	107.3	107.9	108.6	66	167.6	168.3	168.9	169.5
19	48.3	48.9	49.5	50.2	43	109.2	109.9	110.5	111.1	67	170.2	170.8	171.4	172.1
20	50.8	51.4	52.1	52.7	44	111.8	112.4	113.0	113.7	68	172.7	173.4	174.0	174.6
21	53.3	54.0	54.6	55.2	45	114.3	114.9	115.6	116.2	69	175.3	175.9	176.5	177.2
22	55.9	56.5	57.1	57.8	46	116.8	117.5	118.1	118.7	70	177.8	178.4	179.1	179.7
23	58.4	59.1	59.7	60.3	47	119.4	120.0	120.6	121.3	71	180.3	181.0	181.6	182.2
24	61.0	61.6	62.2	62.9	48	121.9	122.6	123.2	123.8	72	182.9	183.5	184.1	184.8
25	63.5	64.1	64.8	65.4	49	124.5	125.1	125.7	126.4	73	185.4	186.1	186.7	187.3
26	66.0	66.7	67.3	67.9	50	127.0	127.6	128.3	128.9	74	188.0	188.6	189.2	189.9
27	68.6	69.2	69.8	70.5	51	129.5	130.2	130.8	131.4	75	190.5	191.1	191.8	192.4
28	71.1	71.8	72.4	73.0	52	132.1	132.7	133.3	134.0	76	193.0	193.7	194.3	194.9
29	73.7	74.3	74.9	75.6	53	134.6	135.3	135.9	136.5	77	195.6	196.2	196.8	197.5
30	76.2	76.8	77.5	78.1	54	137.2	137.8	138.4	139.1	78	198.1	198.8	199.4	200.0
31	78.7	79.4	80.0	80.6	55	139.7	140.3	141.0	141.6	79	200.7	201.3	201.9	202.6
32	81.3	81.9	82.5	83.2	56	142.2	142.9	143.5	144.1	80	203.2	203.8	204.5	205.1
33	83.8	84.5	85.1	85.7	57	144.8	145.4	146.0	146.7	81	205.7	206.4	207.0	207.6
34	86.4	87.0	87.6	88.3	58	147.3	148.0	148.6	149.2	82	208.3	208.9	209.5	210.2
35	88.9	89.5	90.2	90.8	59	149.9	150.5	151.1	151.8	83	210.8	211.5	212.1	212.7

INSTRUCTIONS

1. Measure and record mother's stature
2. Measure and record father's stature.
3. When one parent's stature cannot be measured, the measured parent's estimate of the other parent's stature (in cm) can be substituted for measured stature, and midparent stature can be calculated as in instruction 4. Alternatively, the measured parent's perception of the other parent's stature (short, medium, or tall) can be used to determine midparent stature directly from Table 4.

Table 4. Midparent Stature (cm) When Measured Parent Reports Other Parent's Stature as Short, Medium, or Tall

Measured Parent's Stature (cm)	Midparent Stature (cm)* When Mother Reports Father's Stature as Short†	Medium†	Tall†	When Father Reports Mother's Stature as Short‡	Medium‡	Tall‡
146	156	162	166	150	154	158
148	158	162	166	152	156	160
150	158	164	168	152	156	160
152	160	164	168	154	158	162
154	160	166	170	154	158	162
156	162	166	170	156	160	164
158	162	168	172	156	160	164
160	164	168	172	158	162	166
162	164	170	174	158	162	166
164	166	170	174	160	164	168
166	166	172	176	160	164	168
168	168	172	176	162	166	170
170	168	174	178	162	166	170
172	170	174	178	164	168	172
174	170	176	180	164	168	172
176	172	176	180	166	170	174
178	172	178	182	166	170	174
180	174	178	182	168	172	176
182	174	180	184	168	172	176
184	176	180	184	170	174	178
186	176	182	—	170	174	178
188	178	182	—	172	176	180
190	178	184	—	172	176	180
192	180	184	—	174	178	182
194	180	—	—	174	178	182
196	182	—	—	176	180	184
198	182	—	—	176	180	184

* All midparent statures are rounded to the nearest 2 cm to facilitate use of Tables 2 and 3.
† Values for father's stature used in calculations of midparent stature: short, 167.6 cm (5 ft 6 in.); medium, 176.3 cm (5 ft 9½ in.); tall, 185.4 cm (6 ft 1 in.).
‡ Values for mother's stature used in calculations of midparent stature: short, 154.9 cm (5 ft 1 in.); medium, 162.8 cm (5 ft 4 in.); tall, 170.7 cm (5 ft 7¼ in.).

4. Calculate midparent stature by adding the mother's stature and the father's stature in cm and dividing by two. Metric equivalents for stature are shown in Table 1.
5. Measure, record, and plot the girl's length (birth to 36 months) or stature (3 to 18 years) in cm on the appropriate growth chart that displays the National Center for Health Statistics (NCHS) percentiles. Metric equivalents for length and stature are shown in Table 1.
6. Calculate the girl's adjusted length or stature by using the parent-specific adjustments from Table 2 for length or from Table 3 for stature:
   a. Locate the age closest to that achieved by the girl.
   b. For that age, locate the horizontal row that includes the girl's length or stature.
   c. Locate the vertical column closest to the midparent stature for the girl's mother and father.
   d. The parent-specific adjustment (in cm) appears at the row-column intersection.
   e. Add the parent-specific adjustment to the girl's length or stature if the factor has no sign; subtract the adjustment if it has a minus sign.
7. Determine the girl's parent-specific adjusted percentile by plotting adjusted length or stature on the appropriate NCHS growth chart. Clearly label plotted measurements as being actual or adjusted values.

Interpretation: A girl at a low percentile for actual length or stature whose parents are short probably is genetically short. However, her shortness, particularly if it is extreme, may have additional contributing factors that should be considered.

If the girl's adjusted percentile is low, her growth probably has been slowed by nongenetic factors and diagnostic studies should be considered. If the parents are tall, the girl's adjusted percentile will be lower than her actual percentile and her shortness is more likely due to malnutrition or disease.

A girl at a high adjusted percentile for length or stature most often will be found to have accelerated maturation. Rarely, a specific disorder such as Marfan's syndrome or pituitary gigantism may be responsible for the girl's unusual length or stature.

Follow-Up: Counseling may be advisable when a girl is judged to be genetically short or tall. Additional contributing factors should be considered and growth monitored to confirm the relative stability of the girl's length or stature percentile.

Further investigation and modification of diet or specific therapy is indicated for a girl with unusual length or stature due to malnutrition or disease. Growth should be monitored to evaluate the effectiveness of dietary management or drug therapy.

Example #1. Girl aged 12 months, length 27¼ in., mother's stature 60½ in., and father's stature 65¼ in.

Daughter's actual length in cm is 69.2 (from Table 1).
Daughter's actual percentile is below the 5th (from NCHS growth chart).
Mother's stature in cm is 153.7 (from Table 1).
Father's stature in cm is 165.7 (from Table 1).
Midparent stature is $\frac{153.7 + 165.7}{2}$ = 159.7 cm.
Adjustment is 2 cm (from Table 2).
Daughter's adjusted length is 69.2 cm + 2 cm = 71.2 cm.
Daughter's adjusted percentile is between the 10th and 25th (from NCHS growth chart).
Interpretation: Probably genetically short. Consider additional contributing factors.

Example #2. Girl aged 8 years, stature 46¾ in., mother's stature 68½ in., and father's stature reported as "tall."

Daughter's actual stature in cm is 118.7 (from Table 1).
Daughter's actual percentile is 10th (from NCHS growth chart).
Mother's stature in cm is 174.0 (from Table 1).
Midparent stature is 180.0 cm (from Table 4).
Adjustment is −6 cm (from Table 3).
Daughter's adjusted stature is 118.7 cm − 6 cm = 112.7 cm.
Daughter's adjusted percentile is below the 5th (from NCHS growth chart).
Interpretation: Probably nongenetically short. Further investigation is indicated.

Table 2: Parent-Specific Adjustments (cm) for Length of Girls From Birth to 36 Months*

Age	Length	Midparent Stature (cm)																	
(Years)	(cm)	150	152	154	156	158	160	162	164	166	168	170	172	174	176	178	180	182	184
Birth	40.0-42.9	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-1
	43.0-50.9	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	-1
	51.0-54.9	1	1	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
1	46.0-56.9	1	1	1	1	1	1	0	0	0	0	0	0	0	0	-1	-1	-1	-1
	57.0-58.9	1	1	1	1	1	1	1	0	0	0	0	0	0	0	-1	-1	-1	-1
3	52.0-54.9	2	2	1	1	1	1	1	0	0	0	0	0	-1	-1	-1	-1	-2	-2
	55.0-60.9	2	2	2	1	1	1	1	1	0	0	0	0	-1	-1	-1	-1	-1	-2
	61.0-66.9	2	2	2	2	1	1	1	1	0	0	0	0	0	-1	-1	-1	-1	-1
6	58.0-60.9	3	2	2	2	1	1	1	1	0	0	0	-1	-1	-1	-2	-2	-2	-3
	61.0-63.9	3	3	2	2	2	1	1	1	0	0	0	-1	-1	-1	-2	-2	-2	-2
	64.0-68.9	3	3	2	2	2	1	1	1	1	0	0	0	-1	-1	-1	-2	-2	-2
	69.0-72.9	3	3	3	2	2	2	1	1	1	0	0	0	-1	-1	-1	-1	-2	-2
9	64.0-66.9	4	3	3	2	2	2	1	1	0	0	0	-1	-1	-2	-2	-3	-3	-3
	67.0-70.9	4	3	3	3	2	2	1	1	1	0	0	-1	-1	-1	-2	-2	-3	-3
	71.0-73.9	4	4	3	3	2	2	2	1	1	0	0	0	-1	-1	-2	-2	-2	-3
	74.0-76.9	4	4	3	3	3	2	2	1	1	1	0	0	-1	-1	-1	-2	-2	-3
12	66.0-68.9	4	4	3	3	2	2	1	1	0	0	-1	-1	-2	-2	-3	-3	-4	-4
	69.0-72.9	4	4	3	3	2	2	1	1	1	0	0	-1	-1	-2	-2	-3	-3	-4
	73.0-77.9	5	4	4	3	3	2	2	1	1	0	0	-1	-1	-2	-2	-3	-3	-4
	78.0-82.9	5	5	4	4	3	3	2	2	1	1	0	0	-1	-1	-2	-2	-3	-3
18	74.0-76.9	5	4	4	3	2	2	1	1	0	0	-1	-1	-2	-2	-3	-4	-4	-5
	77.0-80.9	5	4	4	3	3	2	2	1	1	0	0	-1	-2	-2	-3	-3	-4	-4
	81.0-84.9	5	5	4	4	3	3	2	2	1	0	0	-1	-1	-2	-2	-3	-3	-4
	85.0-88.9	6	5	5	4	4	3	2	2	1	1	0	0	-1	-1	-2	-2	-3	-4
24	77.0-80.9	5	4	4	3	3	2	1	1	0	0	-1	-2	-2	-3	-3	-4	-5	-5
	81.0-84.9	5	5	4	4	3	2	2	1	1	0	-1	-1	-2	-2	-3	-4	-4	-5
	85.0-88.9	6	5	5	4	3	3	2	2	1	0	0	-1	-1	-2	-3	-3	-4	-4
	89.0-92.9	6	6	5	4	4	3	3	2	2	1	1	0	-1	-2	-2	-3	-3	-4
	93.0-94.9	7	6	5	5	4	4	3	2	2	1	1	0	-1	-1	-2	-2	-3	-4
30	83.0-84.9	6	5	4	4	3	2	2	1	0	0	-1	-2	-2	-3	-4	-4	-5	-6
	85.0-89.9	6	5	5	4	3	3	2	1	1	0	-1	-1	-2	-3	-3	-4	-5	-5
	90.0-94.9	7	6	5	5	4	3	3	2	1	1	0	-1	-1	-2	-3	-3	-4	-5
	95.0-97.9	7	6	6	5	4	4	3	2	2	1	0	0	-1	-2	-2	-3	-4	-4
36	87.0-88.9	6	5	5	4	3	3	2	1	0	0	-1	-2	-2	-3	-4	-5	-5	-6
	89.0-92.9	6	6	5	4	4	3	2	1	1	0	-1	-2	-2	-3	-4	-4	-5	-6
	93.0-96.9	7	6	5	5	4	3	2	2	1	0	0	-1	-2	-3	-3	-4	-5	-5
	97.0-100.9	7	7	6	5	4	4	3	2	1	1	0	-1	-1	-2	-3	-4	-4	-5
	101.0-104.9	8	7	6	6	5	4	4	3	2	1	0	0	-1	-1	-2	-3	-4	-4

* Adapted from Himes JH. Roche AF, Thissen D: *Parent-Specific Adjustments for Assessment of Recumbent Length and Stature*. Monographs in Paediatrics, Basel, Switzerland: S Karger, 1981, vol 13, Table XIII, p. 38.

Table 3: Parent-Specific Adjustments (cm) for Stature of Girls From 3 to 18 Years

Age	Length	Midparent Stature (cm)																	
(Years)	(cm)	150	152	154	156	158	160	162	164	166	168	170	172	174	176	178	180	182	184
3	82.0-83.9	6	5	4	4	3	2	1	1	0	-1	-1	-2	-3	-3	-4	-5	-6	-6
	84.0-93.9	6	6	5	4	3	3	2	1	1	0	-1	-1	-2	-3	-4	-4	-5	-6
	94.0-102.9	7	7	6	5	4	4	3	2	2	1	0	-1	-1	-2	-3	-3	-4	-5
4	92.0-93.9	6	6	5	4	3	3	2	1	0	0	-1	-2	-3	-3	-4	-5	-6	-7
	94.0-103.9	7	6	6	5	4	3	2	2	1	0	-1	-1	-2	-3	-4	-4	-5	-6
	104.0-112.9	8	7	7	6	5	4	3	3	2	1	0	0	-1	-2	-3	-3	-4	-5
5	100.0-101.9	8	7	6	5	4	3	2	1	1	0	-1	-2	-3	-4	-5	-5	-6	-7
	102.0-111.9	8	7	6	6	5	4	3	2	1	0	-1	-1	-2	-3	-4	-5	-6	-7
	112.0-120.9	9	8	7	7	6	5	4	3	2	1	1	0	-1	-2	-3	-4	-5	-6
6	106.0-109.9	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6	-7	-8
	110.0-119.9	9	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6	-7
	120.0-128.9	11	10	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6
7	112.0-117.9	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6	-7	-8
	118.0-127.9	10	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6	-7
	128.0-136.9	11	10	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6
8	116.0-123.9	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-6	-8	-9
	124.0-133.9	10	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-7	-8
	134.0-142.9	11	10	9	8	7	6	5	4	3	2	1	0	-1	-2	-3	-4	-6	-7
9	122.0-131.9	10	9	8	7	6	5	3	2	1	0	-1	-2	-3	-4	-5	-6	-7	-9
	132.0-141.9	11	10	9	8	7	6	4	3	2	1	0	-1	-2	-3	-4	-5	-7	-8
	142.0-150.9	12	11	10	9	8	6	5	4	3	2	1	0	-1	-2	-3	-5	-6	-7
10	126.0-127.9	10	9	7	6	5	4	3	2	1	0	-1	-2	-3	-5	-6	-7	-8	-9
	128.0-137.9	10	9	8	7	6	5	4	2	1	0	-1	-2	-3	-4	-5	-6	-7	-8
	138.0-147.9	11	10	9	8	6	5	4	3	2	1	0	-1	-2	-3	-4	-5	-7	-8
	148.0-156.9	12	10	9	8	7	6	5	4	3	2	1	0	-1	-3	-4	-5	-6	-7
11	130.0-133.9	10	9	8	6	5	4	3	2	1	0	-1	-2	-3	-4	-6	-7	-8	-9
	134.0-143.9	10	9	8	7	6	5	4	3	1	0	-1	-2	-3	-4	-5	-6	-7	-8
	144.0-153.9	11	10	9	7	6	5	4	3	2	1	0	-1	-2	-3	-5	-6	-7	-8
	154.0-162.9	11	10	9	8	7	6	5	4	3	1	0	-1	-2	-3	-4	-5	-6	-7
12	134.0-139.9	10	9	8	7	6	5	3	2	1	0	-1	-3	-4	-5	-6	-7	-8	-10
	140.0-149.9	11	10	9	7	6	5	4	3	2	0	-1	-2	-3	-4	-6	-7	-8	-9
	150.0-159.9	12	10	9	8	7	6	5	3	2	1	0	-1	-3	-4	-5	-6	-7	-8
	160.0-168.9	12	11	10	9	8	6	5	4	3	2	0	-1	-2	-3	-4	-5	-7	-8
13	140.0-145.9	10	9	8	7	6	4	3	2	1	0	-1	-3	-4	-5	-6	-7	-8	-10
	146.0-155.9	11	10	9	7	6	5	4	3	2	0	-1	-2	-3	-4	-6	-7	-8	-9
	156.0-165.9	12	10	9	8	7	6	5	3	2	1	0	-1	-3	-4	-5	-6	-7	-8
	166.0-174.9	12	11	10	9	8	6	5	4	3	2	1	-1	-2	-3	-4	-5	-7	-8
14	146.0-149.9	10	9	8	6	5	4	3	2	1	0	-1	-3	-4	-5	-6	-7	-8	-9
	150.0-159.9	11	9	8	7	6	5	4	3	1	0	-1	-2	-3	-4	-5	-7	-8	-9
	160.0-169.9	11	10	9	8	7	6	5	3	2	1	0	-1	-2	-3	-5	-6	-7	-8
	170.0-178.9	12	11	10	9	8	6	5	4	3	2	1	0	-2	-3	-4	-5	-6	-7
15	146.0-151.9	10	9	8	7	5	4	3	2	1	-1	-2	-3	-4	-5	-6	-8	-9	-10
	152.0-161.9	11	10	9	7	6	5	4	3	1	0	-1	-2	-3	-4	-6	-7	-8	-9
	162.0-171.9	12	11	10	8	7	6	5	4	2	1	0	-1	-2	-4	-5	-6	-7	-8
	172.0-180.9	13	12	11	9	8	7	6	5	3	2	1	0	-1	-3	-4	-5	-6	-7
16	146.0-151.9	11	10	8	7	6	5	3	2	1	-1	-2	-3	-4	-6	-7	-8	-10	-11
	152.0-161.9	12	10	9	8	7	5	4	3	2	0	-1	-2	-4	-5	-6	-7	-9	-10
	162.0-171.9	13	12	10	9	8	6	5	4	3	1	0	-1	-3	-4	-5	-6	-8	-9
	172.0-180.9	14	13	11	10	9	7	6	5	4	2	1	0	-2	-3	-4	-5	-7	-8
17	148.0-153.9	11	10	9	7	6	5	3	2	1	0	-2	-3	-4	-6	-7	-8	-10	-11
	154.0-163.9	12	11	10	8	7	6	4	3	2	0	-1	-2	-4	-5	-6	-8	-9	-10
	164.0-173.9	13	12	11	9	8	7	5	4	3	1	0	-1	-3	-4	-5	-6	-8	-9
	174.0-182.9	14	13	12	10	9	8	6	5	4	2	1	0	-1	-3	-4	-5	-7	-8
18	148.0-149.9	10	9	8	7	5	4	3	2	1	-1	-2	-3	-4	-6	-7	-8	-9	-10
	150.0-159.9	11	10	8	7	6	5	4	2	1	0	-1	-3	-4	-5	-6	-7	-9	-10
	160.0-169.9	12	11	9	8	7	6	4	3	2	1	0	-2	-3	-4	-5	-6	-8	-9
	170.0-178.9	13	11	10	9	8	7	5	4	3	2	1	-1	-2	-3	-4	-5	-7	-8

Percentiles for Triceps Skinfold for Whites of the United States Health and Nutrition Examination Survey I of 1971-1974

Age group	Triceps skinfold percentiles (mm^2)															
	n	5	10	25	50	75	90	95	n	5	10	25	50	75	90	95
	Males								Females							
1-1.9	228	6	7	8	10	12	14	16	204	6	7	8	10	12	14	16
2-2.9	223	6	7	8	10	12	14	15	208	6	8	9	10	12	15	16
3-3.9	220	6	7	8	10	11	14	15	208	7	8	9	11	12	14	15
4-4.9	230	6	6	8	9	11	12	14	208	7	8	8	10	12	14	16
5-5.9	214	6	6	8	9	11	14	15	219	6	7	8	10	12	15	18
6-6.9	117	5	6	7	8	10	13	16	118	6	6	8	10	12	14	16
7-7.9	122	5	6	7	9	12	15	17	126	6	7	9	11	13	16	18
8-8.9	117	5	6	7	8	10	13	16	118	6	8	9	12	15	18	24
9-9.9	121	6	6	7	10	13	17	18	125	8	8	10	13	16	20	22
10-10.9	146	6	6	8	10	14	18	21	152	7	8	10	12	17	23	27
11-11.9	122	6	6	8	11	16	20	24	117	7	8	10	13	18	24	28
12-12.9	153	6	6	8	11	14	22	28	129	8	9	11	14	18	23	27
13-13.9	134	5	5	7	10	14	22	26	151	8	8	12	15	21	26	30
14-14.9	131	4	5	7	9	14	21	24	141	9	10	13	16	21	26	28
15-15.9	128	4	5	6	8	11	18	24	117	8	10	12	17	21	25	32
16-16.9	131	4	5	6	8	12	16	22	142	10	12	15	18	22	26	31
17-17.9	133	5	5	6	8	12	16	19	114	10	12	13	19	24	30	37
18-18.9	91	4	5	6	9	13	20	24	109	10	12	15	18	22	26	30
19-24.9	531	4	5	7	10	15	20	22	1060	10	11	14	18	24	30	34

From: Frisancho RA. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*, 1981; 34:2540-2545.

Percentiles of Upper Arm Circumference (mm) and Estimated Upper Arm Muscle Circumference (mm) for Whites of the United States Health and Nutrition Examination Survey I of 1971-1974

Age group	Arm circumference (mm)							Arm muscle circumference (mm)						
	5	10	25	50	75	90	95	5	10	25	50	75	90	95
Males														
1-1.9	142	146	150	159	170	176	183	110	113	119	127	135	144	147
2-2.9	141	145	153	162	170	178	185	111	114	122	130	140	146	150
3-3.9	150	153	160	167	175	184	190	117	123	131	137	143	148	153
4-4.9	149	154	162	171	180	186	192	123	126	133	141	148	156	159
5-5.9	153	160	167	175	185	195	204	128	133	140	147	154	162	169
6-6.9	155	159	167	179	188	209	228	131	135	142	151	161	170	177
7-7.9	162	167	177	187	201	223	230	137	139	151	160	168	177	190
8-8.9	162	170	177	190	202	220	245	140	145	154	162	170	182	187
9-9.9	175	178	187	200	217	249	257	151	154	161	170	183	196	202
10-10.9	181	184	196	210	231	262	274	156	160	166	180	191	209	221
11-11.9	186	190	202	223	244	261	280	159	165	173	183	195	205	230
12-12.9	193	200	214	232	254	282	303	167	171	182	195	210	223	241
13-13.9	194	211	228	247	263	286	301	172	179	196	211	226	238	245
14-14.9	220	226	237	253	283	303	322	189	199	212	223	240	260	264
15-15.9	222	229	244	264	284	311	320	199	204	218	237	254	266	272
16-16.9	244	248	262	278	303	324	343	213	225	234	249	269	287	296
17-17.9	246	253	267	285	308	336	347	224	231	245	258	273	294	312
18-18.9	245	260	276	297	321	353	379	226	237	252	264	283	298	324
19-24.9	262	272	288	308	331	355	372	238	245	257	273	289	309	321
Females														
1-1.9	138	142	148	156	164	172	177	105	111	117	124	132	139	143
2-2.9	142	145	152	160	167	176	184	111	11	119	126	113	142	147
3-3.9	143	150	158	167	175	183	189	113	119	124	132	140	146	152
4-4.9	149	454	160	169	177	184	191	115	121	128	136	144	152	157
5-5.9	153	157	165	175	185	203	211	125	128	134	142	151	159	165
6-6.9	156	162	170	176	187	204	211	130	133	138	145	154	166	171
7-7.9	164	167	174	183	199	216	231	129	135	142	151	160	171	176
8-8.9	168	172	183	195	214	247	261	138	140	151	160	171	183	194
9-9.9	178	182	194	211	224	251	260	147	150	158	167	180	194	198
10-10.9	174	182	193	210	228	251	265	148	150	159	170	180	190	197
11-11.9	185	194	208	224	248	276	303	150	158	171	181	196	217	223
12-12.9	194	203	216	237	256	282	294	162	166	180	191	201	214	220
13-13.9	202	211	223	243	271	301	338	169	175	183	198	211	226	240
14-14.9	214	223	237	252	272	304	322	174	179	190	201	216	232	247
15-15.9	208	221	239	254	279	300	322	175	178	189	202	215	228	244
16-16.9	218	224	241	258	283	318	334	170	180	190	202	216	234	249
17-17.9	220	227	241	264	295	324	350	175	183	194	205	221	239	257
18-18.9	222	227	241	258	281	312	325	174	179	191	202	215	237	245
19-24.9	221	230	247	265	290	319	345	179	185	195	207	221	236	249

From: Frisancho RA. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*, 1981; 34:2540-2545.

Percentiles for Estimates of Upper Arm Fat Area (mm^2) and Upper Arm Muscle Area (mm^2) for Whites of the United States Health and Nutrition Examination Survey I of 1971-1974

Age group	Arm muscle area percentiles (mm^2)							Arm fat area percentiles (mm^2)						
	5	10	25	50	75	90	95	50	10	25	50	75	90	95
Males														
1-1.9	956	1014	1133	1278	1447	1644	1720	452	486	590	741	895	1036	1176
2-2.9	973	1040	1190	1345	1557	1690	1787	434	504	578	737	871	1044	1148
3-3.9	1095	1201	1357	1484	1618	1750	1853	464	519	590	736	868	1071	1151
4-4.9	1207	1264	1408	1579	1747	1926	2008	428	494	598	722	859	989	1085
5-5.9	1298	1411	1550	1720	1884	2089	2285	446	488	582	713	914	1176	1299
6-6.9	1360	1447	1605	1815	2056	2297	2493	371	446	539	678	896	1115	1519
7-7.9	1497	1548	1808	2027	2246	2494	2886	423	473	574	758	1011	1393	1511
8-8.9	1550	1664	1895	2089	2296	2628	2788	410	460	588	725	1003	1248	1558
9-9.9	1811	1884	2067	2288	2657	3053	3257	485	527	635	859	1252	1864	2081
10-10.9	1930	2027	2182	2575	2903	3486	3882	523	543	738	982	1376	1906	2609
11-11.9	2016	2156	2382	2670	3022	3359	4226	536	595	754	1148	1710	2348	2574
12-12.9	2216	2339	2649	3022	3496	3968	4640	554	650	874	1172	1558	2536	3580
13-13.9	2363	2546	3044	3553	4081	4502	4794	475	570	812	1096	1702	2744	3322
14-14.9	2830	3147	3586	3963	4575	5368	5530	453	563	786	1082	1608	2746	3508
15-15.9	3138	3317	3788	4481	5134	5631	5900	521	595	690	931	1423	2434	3100
16-16.9	3625	4044	4352	4951	5753	6576	6980	542	593	844	1078	1746	2280	3041
17-17.9	3998	4252	4777	5286	5950	6886	7726	598	698	827	1096	1636	2407	2888
18-18.9	4070	4481	5066	5552	6374	7067	8355	560	665	860	1264	1947	3302	3928
19-24.9	4508	4777	5274	5913	6660	7606	8200	594	743	963	1406	2231	3098	3652
Females														
1-1.9	885	973	1084	1221	1378	1535	1621	401	466	578	706	847	1022	1140
2-2.9	973	1029	1119	1269	1405	1595	1727	469	526	642	747	894	1061	1173
3-3.9	1014	1133	1227	1396	1563	1690	1846	473	529	656	822	697	1106	1158
4-4.9	1058	1171	1313	1475	1644	1832	1958	490	541	654	766	907	1109	1236
5-5.9	1238	1301	1423	1598	1825	2012	2159	470	529	647	812	997	1330	1536
6-6.9	1354	1414	1513	1683	1877	2182	2323	464	508	638	827	1009	1269	1436
7-7.9	1330	1441	1602	1815	2045	2332	2469	491	560	706	920	1135	1407	1644
8-8.9	1513	1566	1808	2034	2327	2657	2996	527	634	769	1042	1383	1872	2482
9-9.9	1723	1788	1976	2227	2571	2987	3112	642	690	933	1219	1584	2171	2524
10-10.9	1740	1784	2017	2296	2583	2873	3093	616	702	842	1141	1608	2500	3005
11-11.9	1784	1987	2316	2612	3071	3739	3953	707	802	1015	1301	1942	2730	3690
12-12.9	2092	2182	2579	2904	3225	3655	3847	782	854	1090	1511	256	2666	3369
13-13.9	2269	2426	2657	3130	3529	4081	4568	726	838	1219	1625	2374	3272	4150
14-14.9	2418	2562	2874	3220	3704	4294	4850	981	1043	1423	1818	2403	3250	3765
15-15.9	2426	2518	2847	3248	3689	4123	4756	839	1126	1396	1886	2544	3093	4195
16-16.9	2308	2567	2865	3248	3718	4353	4946	1126	1351	1663	2006	2598	3374	4236
17-17.9	2442	2674	2996	3336	3883	4552	5251	1042	1267	1463	2104	2977	3864	5159
18-18.9	2398	2538	2917	3243	3694	4461	4767	1003	1230	1616	2104	2617	3508	3733
19-24.9	2538	2728	3026	3406	3877	4439	4940	1046	1198	1596	2166	2989	4050	4896

From: Frisancho RA. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*, 1981; 34:2540-2545.

PHYSICAL GROWTH IN MALES WITH ACHONDROPLASIA

Name ..... Birthdate ..... Record # .....

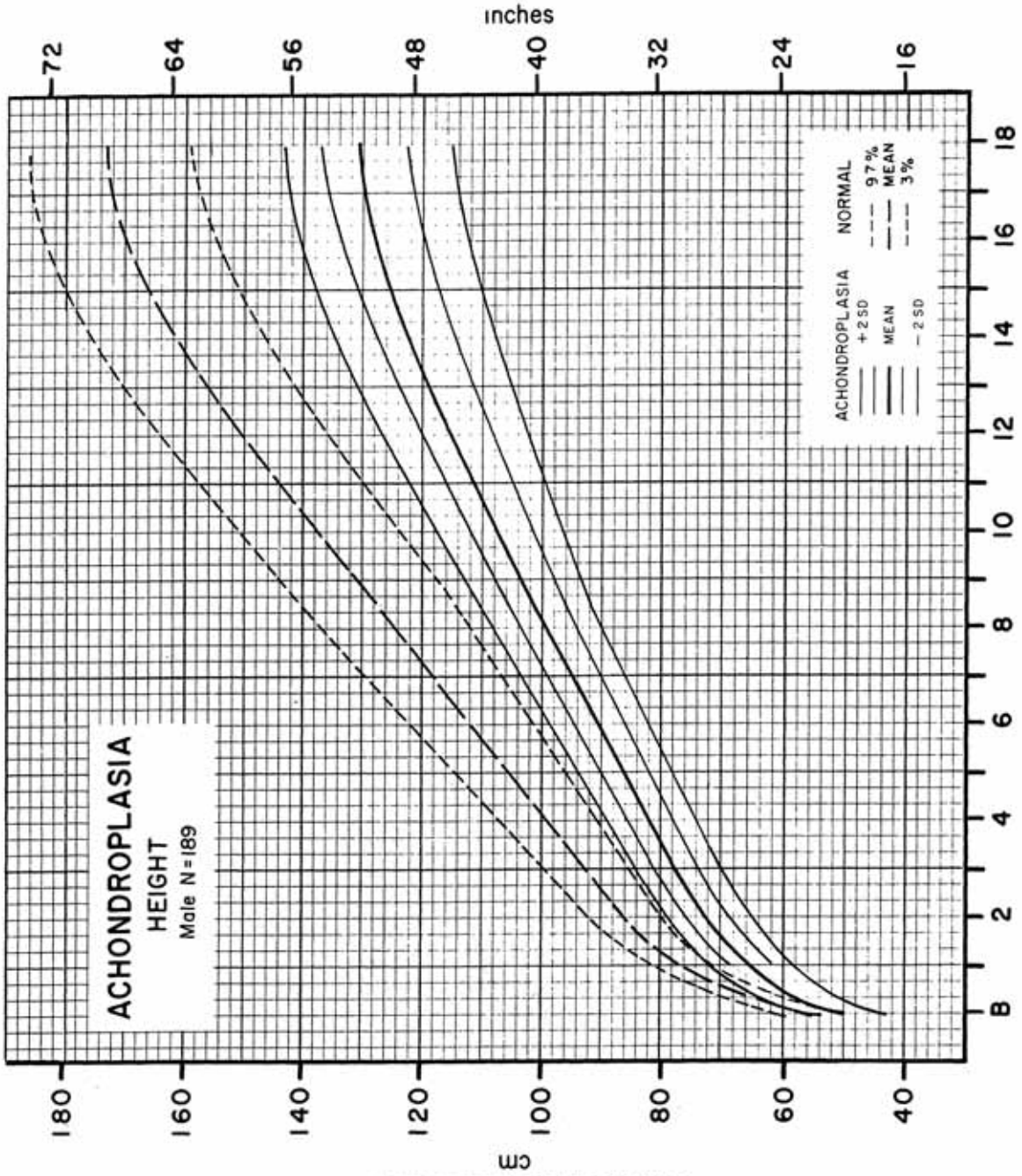

Figure 1A: Height for males with achondroplasia (white area-mean ±2 S.D.) compared to normal male standard curve.

NOTES ON THE USE OF STANDARD CHARTS

Measurements: Supine length with full extension of legs and infant on back is used up to 2.5 years, thereafter standard standing height without shoes is employed. Height velocity is calculated over a full year period (not less) and plotted at the midpoint of that year. Lower segment lengths are measured from the superior pubic ramus to the floor and upper segment lengths obtained by subtraction from total height. Head circumference is measured as the maximum occipital-frontal circumference. All values are represented as means (dark line)± standard deviations with ±2 S.D. represented by the white area. Normal standards are represented as mean (bold dashed line), ±2 S.D. (light dashed lines), except height which is mean, 3rd and 97th percentiles.

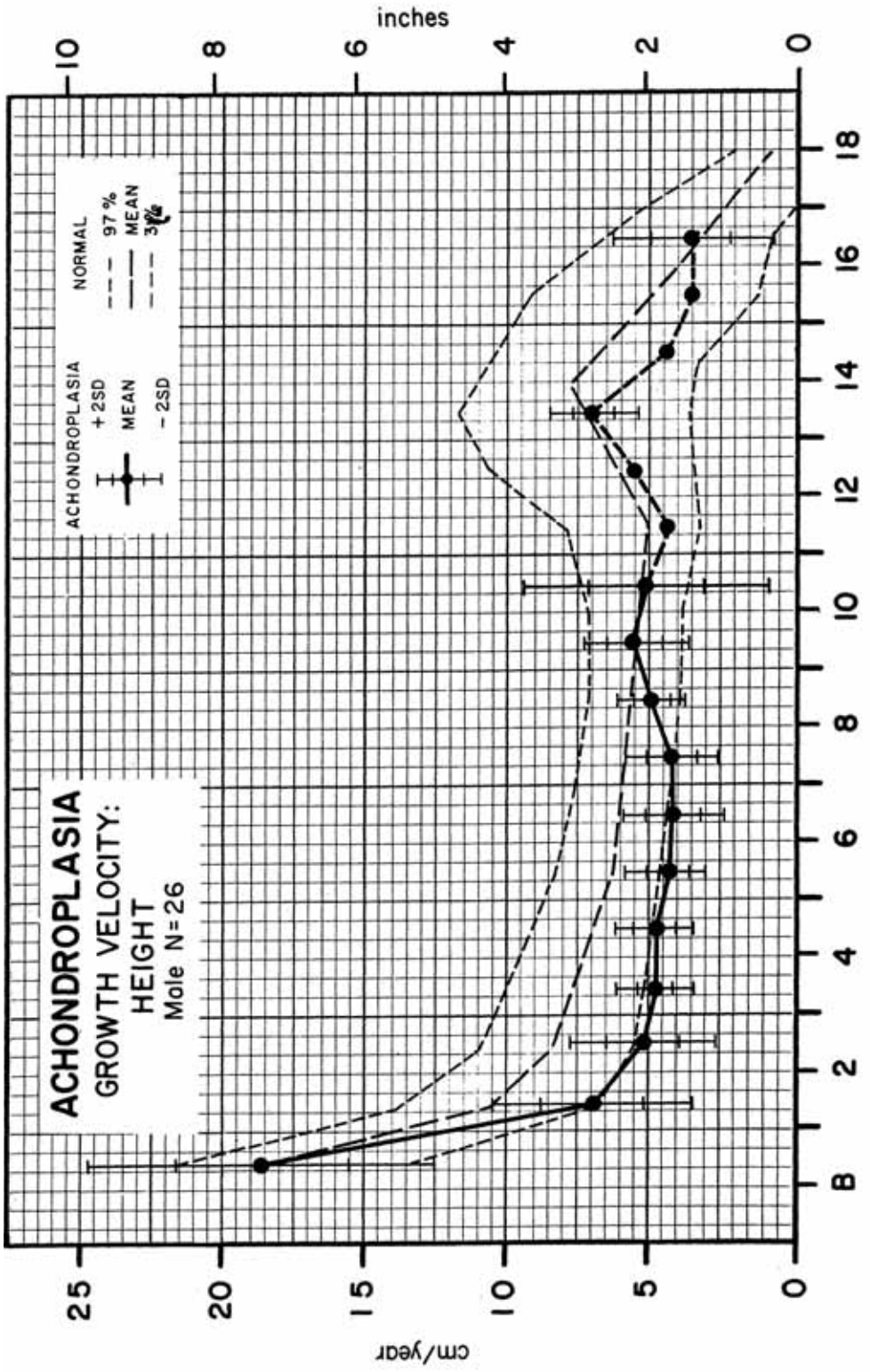

Figure 2A: Height velocity for males with achondroplasia (heavy line-mean ±2 S.D.—bars) compared to normal male height velocity standard.

NOTES ON THE USE OF STANDARD CHARTS

Data Source: Male (n=189) and female (n=214) achondroplasts obtained through Short Stature Clinics at the Harbor-UCLA Medical Center, University of Texas Medical School-Houston, and University of Washington School of Medicine as well as the National Meeting of the Little People of America. Cross-sectional and longitudinal data are pooled. All patients met strict diagnostic criteria, and were excluded if growth accelerating agents used or previous CSF shunting performed. Reference: J. Peds., 93:435-438, 1978.

Standards for Normals: Height and height velocity per Tanner, J. M. and Whitehouse, R. H.: Growth and Developmental records, Bull Plain, Herford, England, 1975, Creaseys Ltd. Upper to lower segment ratio standards per McKusick, V.A.: Heritable Disorders of Connective Tissue, St. Louis, 1972, The C. V. Mosby Co., p. 73-74. Head circumference standards per Nellhous: Peds., 41:106, 1968.

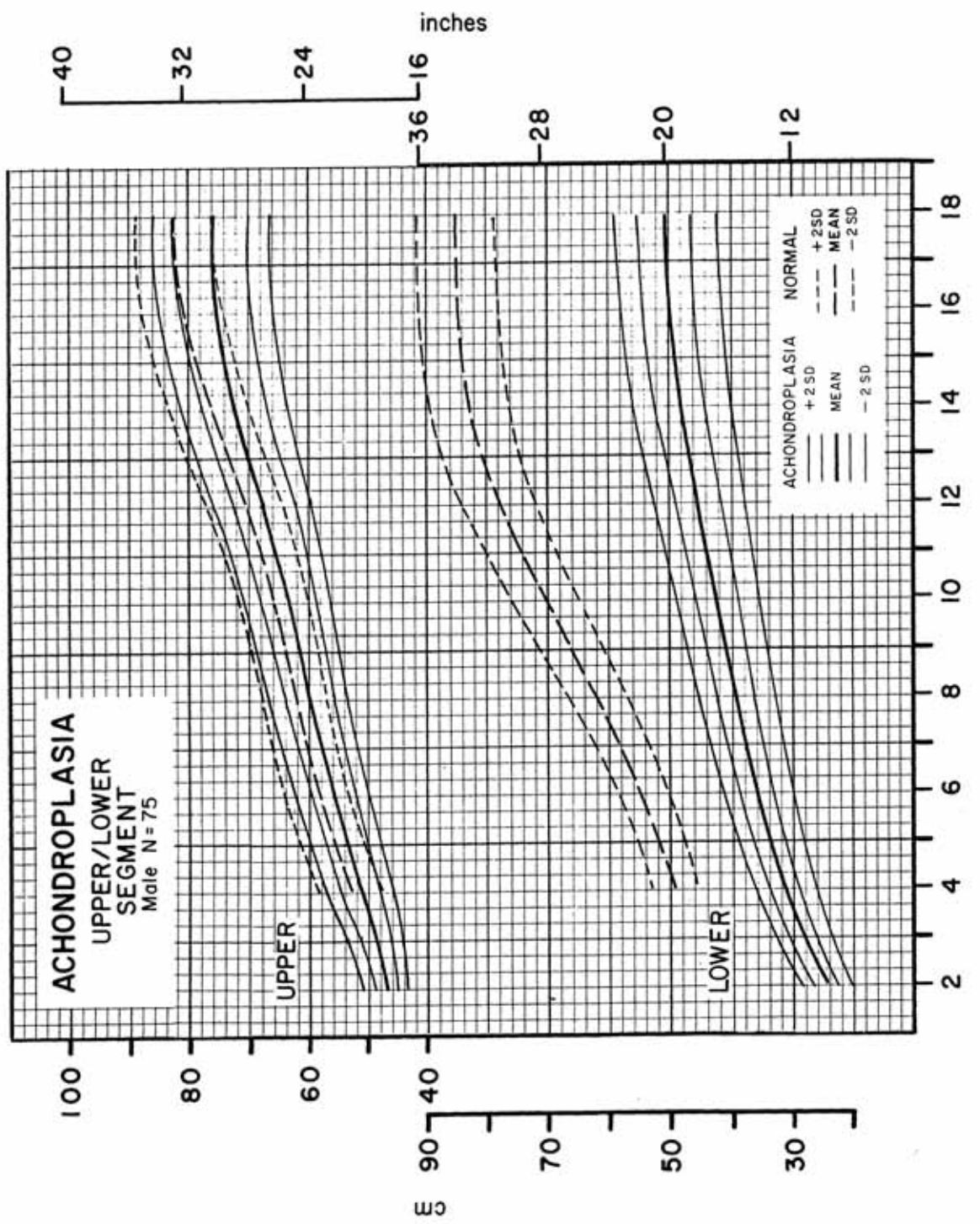

Figure 3A: Upper and lower segment lengths for males with achondroplasia (white area-mean ±2 S.D.) compared to normal male upper and lower segment lengths.

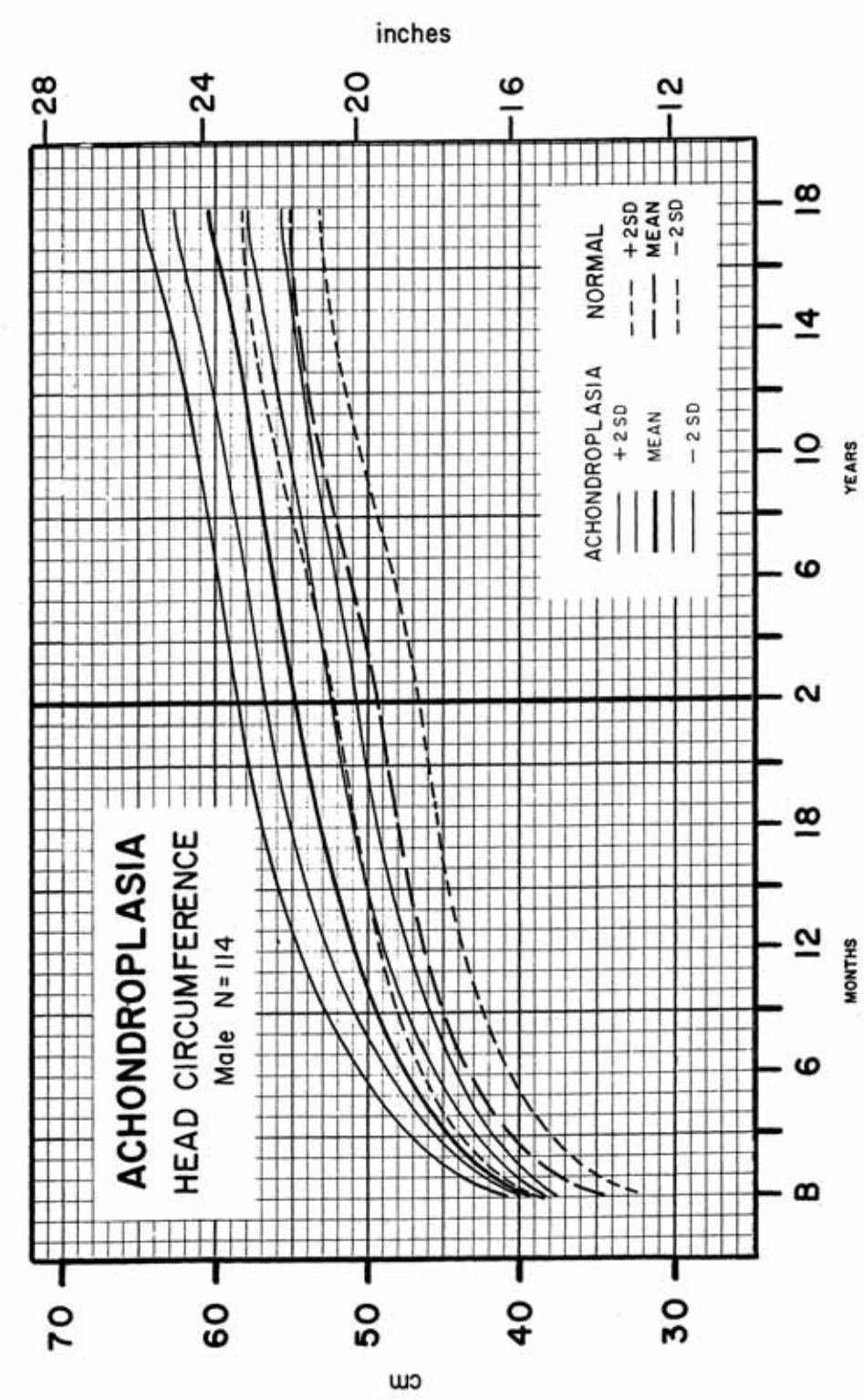

Figure 4A: Head circumference for males with achondroplasia (white area-mean ±2 S.D.) compared to normal male head circumference.

ACKNOWLEDGEMENTS

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Prepared by the Division of Medical Genetics, Harbor-UCLA Medical Center, 1000 West Carson Street, Torrance, California, 90509.

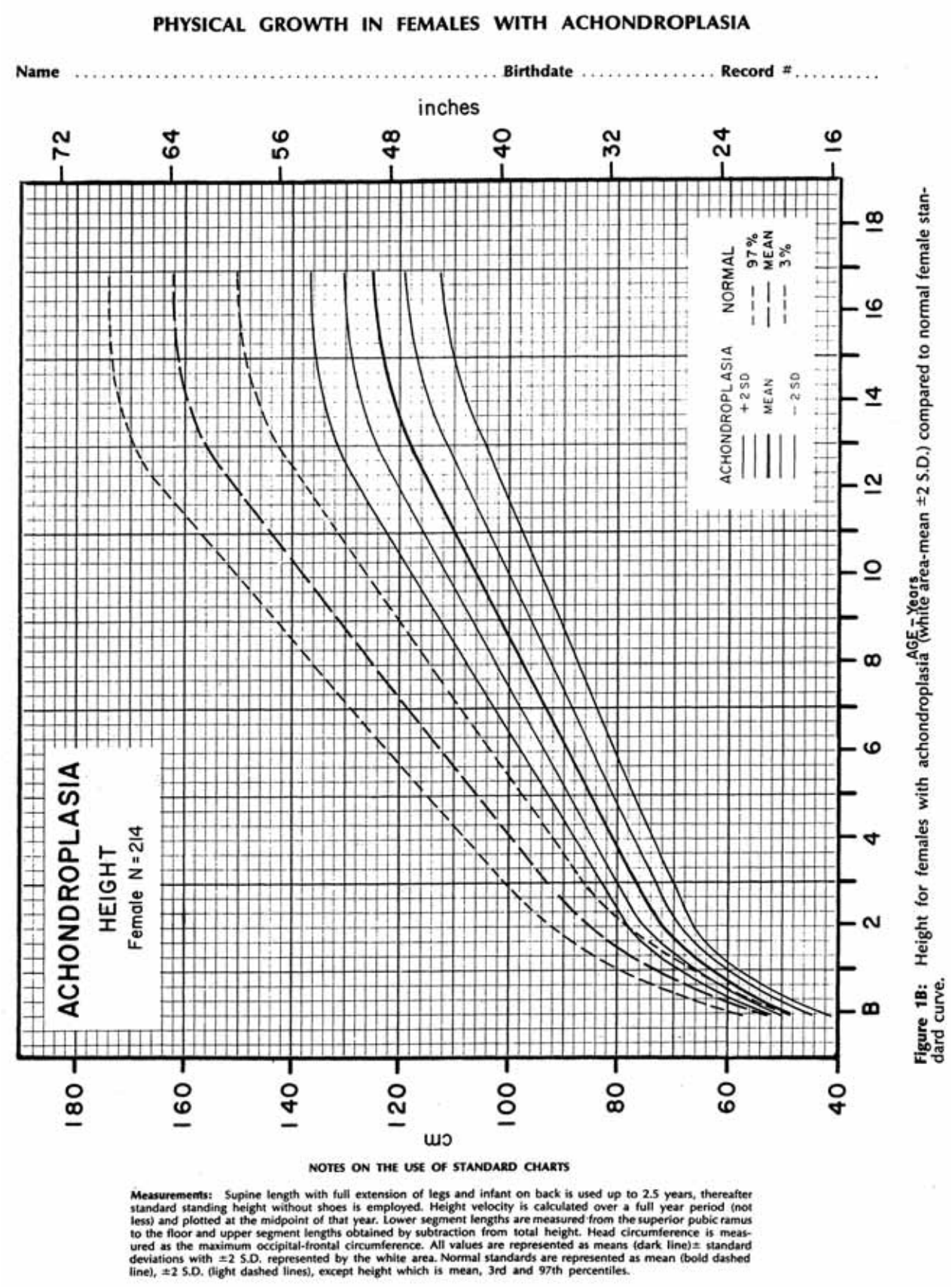


Figure 1B: Height for females with achondroplasia (white area-mean ±2 S.D.) compared to normal female standard curve.

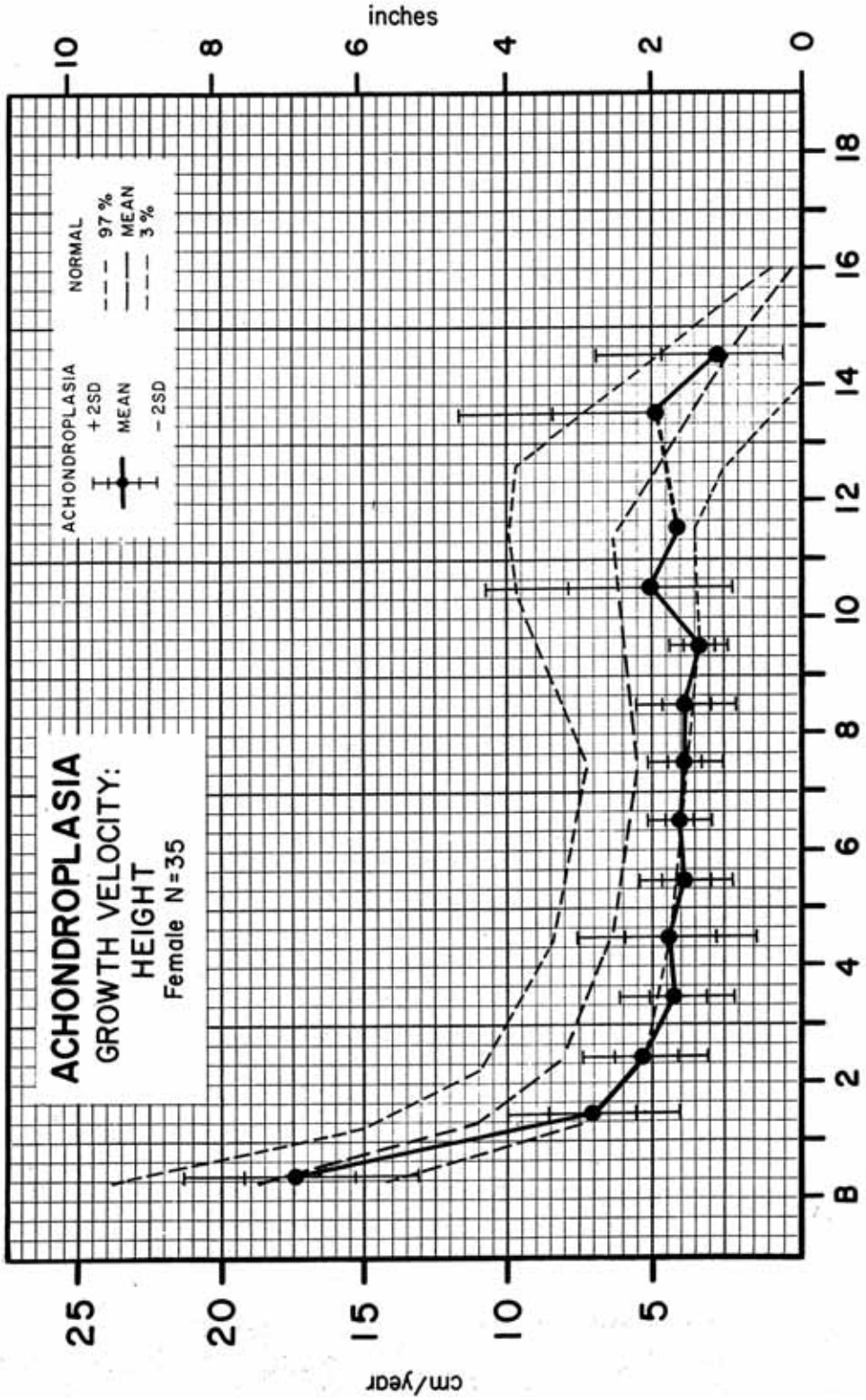


Figure 28: Height velocity for females with achondroplasia (white area-mean ±2 S.D.) compared to normal female height velocity standard.

NOTES ON THE USE OF STANDARD CHARTS

Data Source: Male (n=189) and female (n=214) achondroplasts obtained through Short Stature Clinics at the Harbor-UCLA Medical Center, University of Texas Medical School-Houston, and University of Washington School of Medicine as well as the National Meeting of the Little People of America. Cross-sectional and longitudinal data are pooled. All patients met strict diagnostic criteria, and were excluded if growth accelerating agents used or previous CSF shunting performed. Reference: J. Peds., 93:435-438, 1978.

Standards for Normals: Height and height velocity per Tanner, J. M. and Whitehouse, R. H.: Growth and Developmental records, Bull Plain, Herford, England, 1975, Creseeys Ltd. Upper to lower segment ratio standards per McKusick, V.A.: Heritable Disorders of Connective Tissue, St. Louis, 1972, The C. V. Mosby Co., p. 73-74. Head circumference standards per Nellhous: Peds., 41:106, 1968.

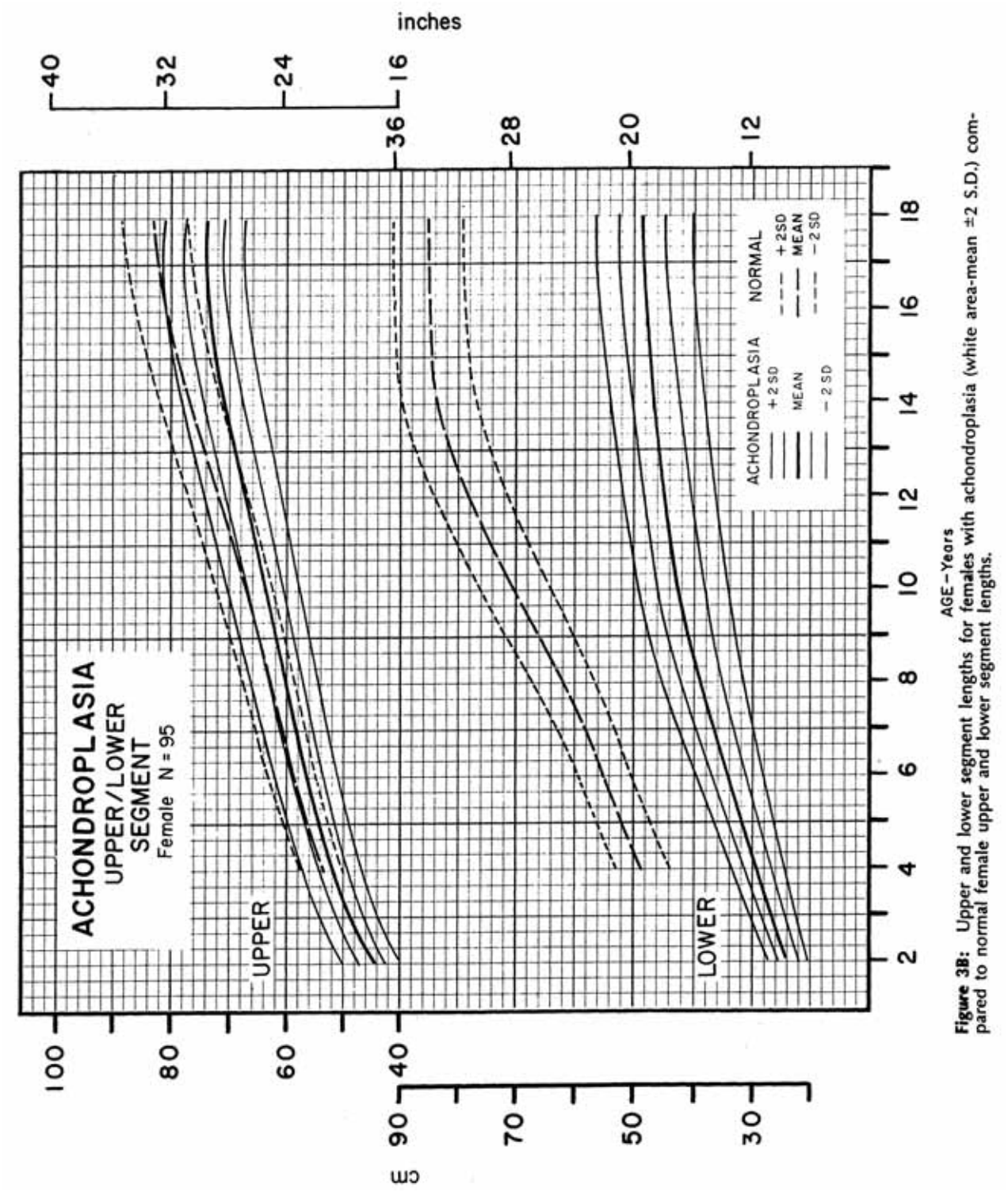


Figure 38: Upper and lower segment lengths for females with achondroplasia (white area-mean ±2 S.D.) compared to normal female upper and lower segment lengths.

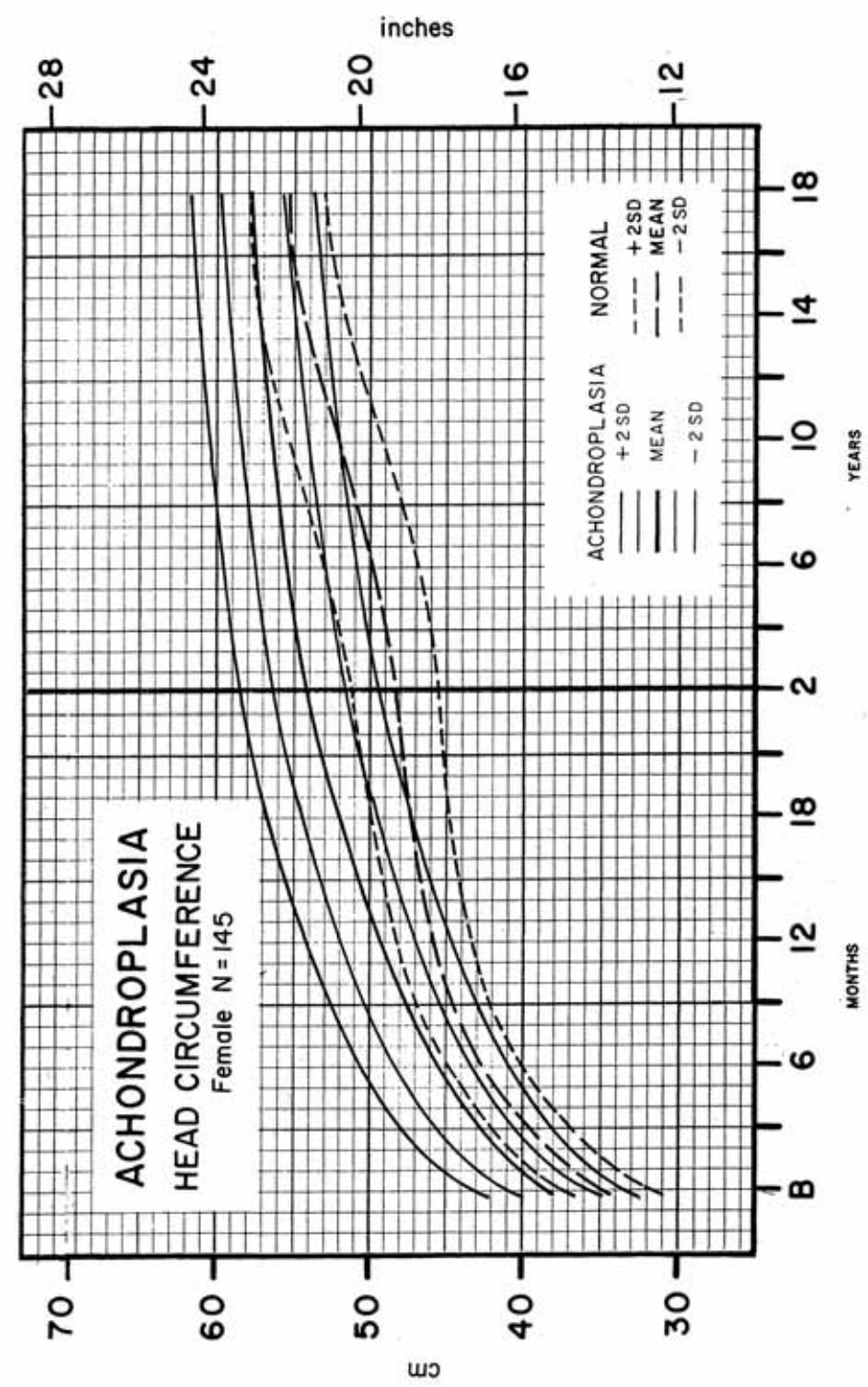
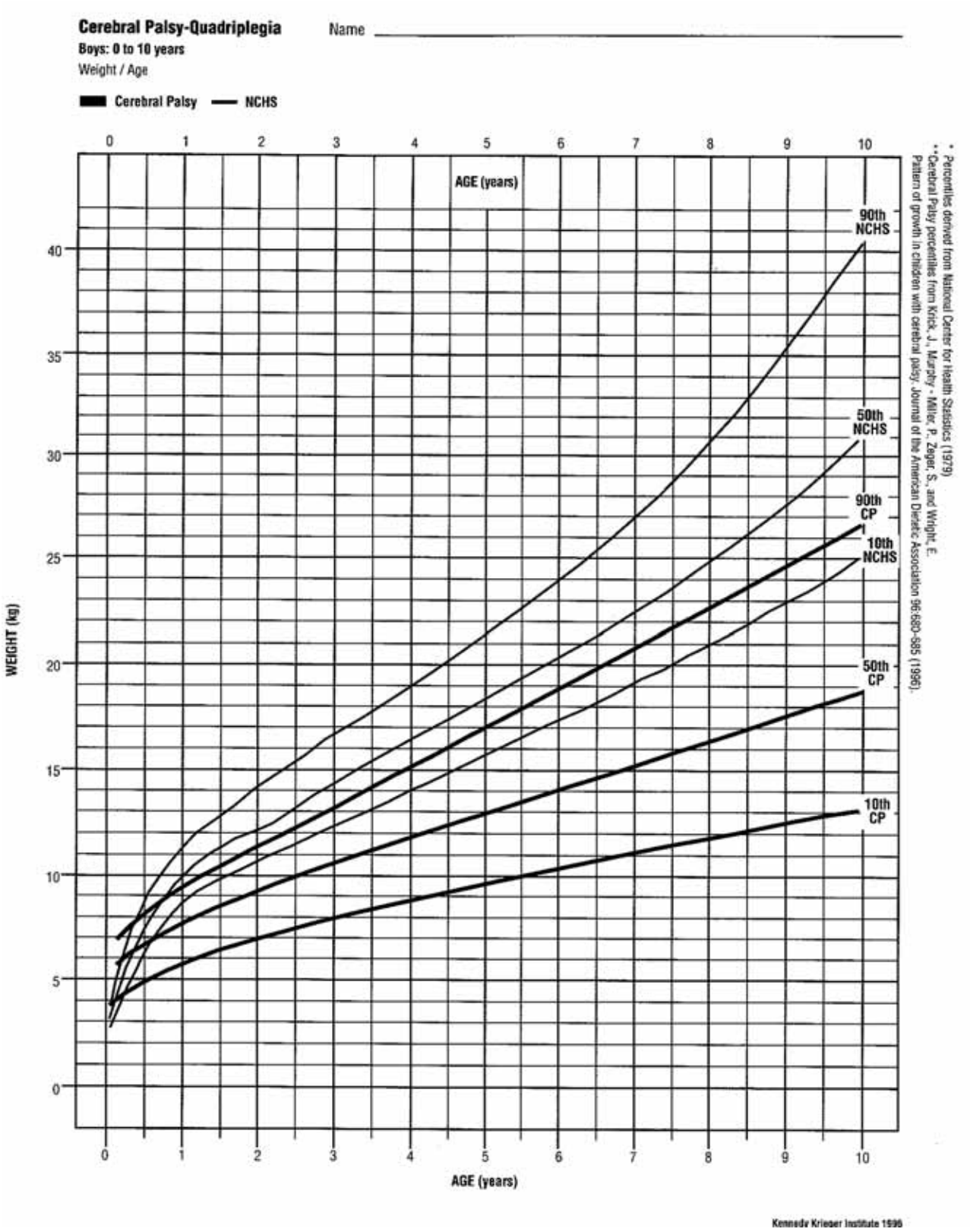


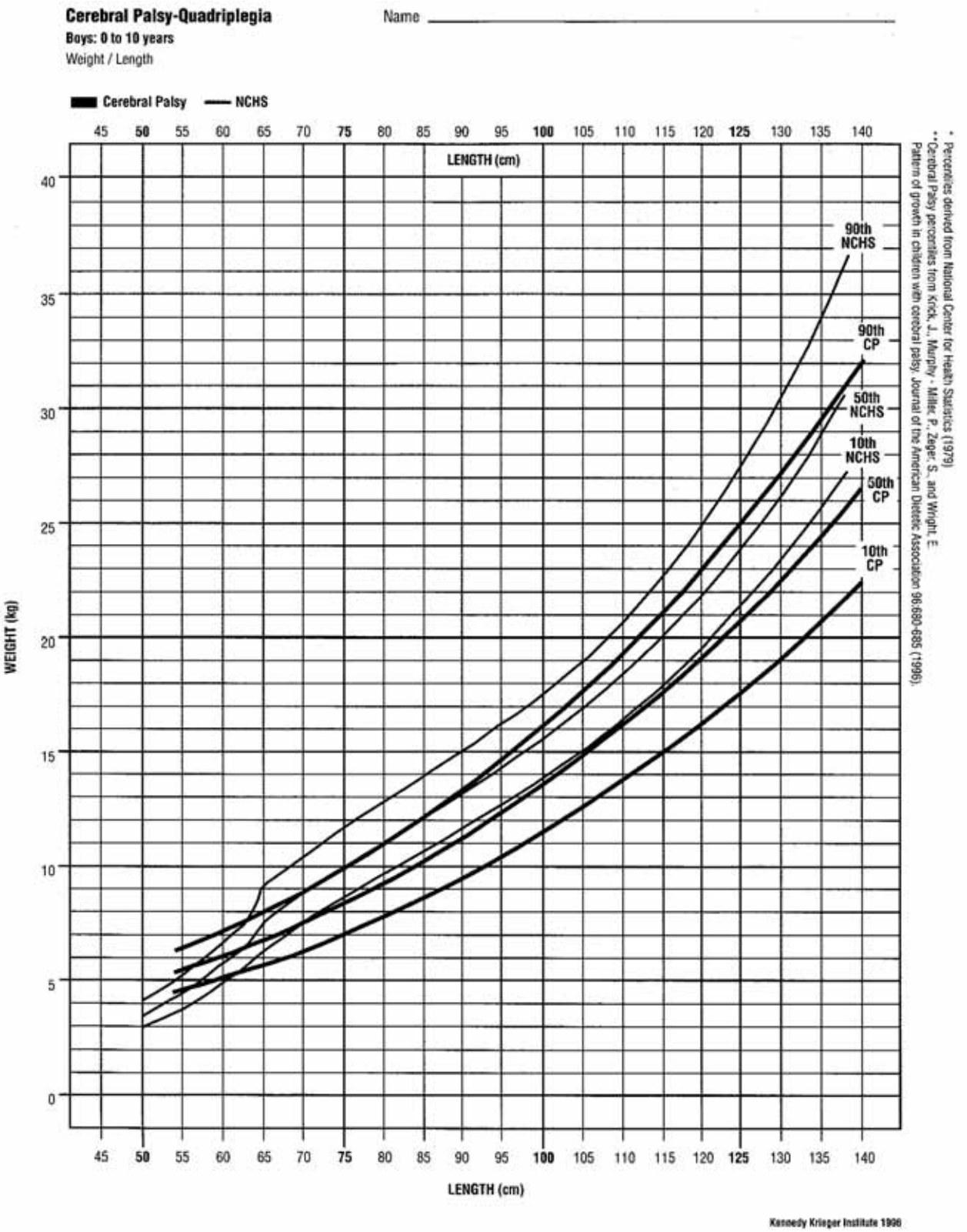
Figure 4B: Head circumference for females with achondroplasia (white area-mean ±2 S.D.) compared to normal female head circumference.

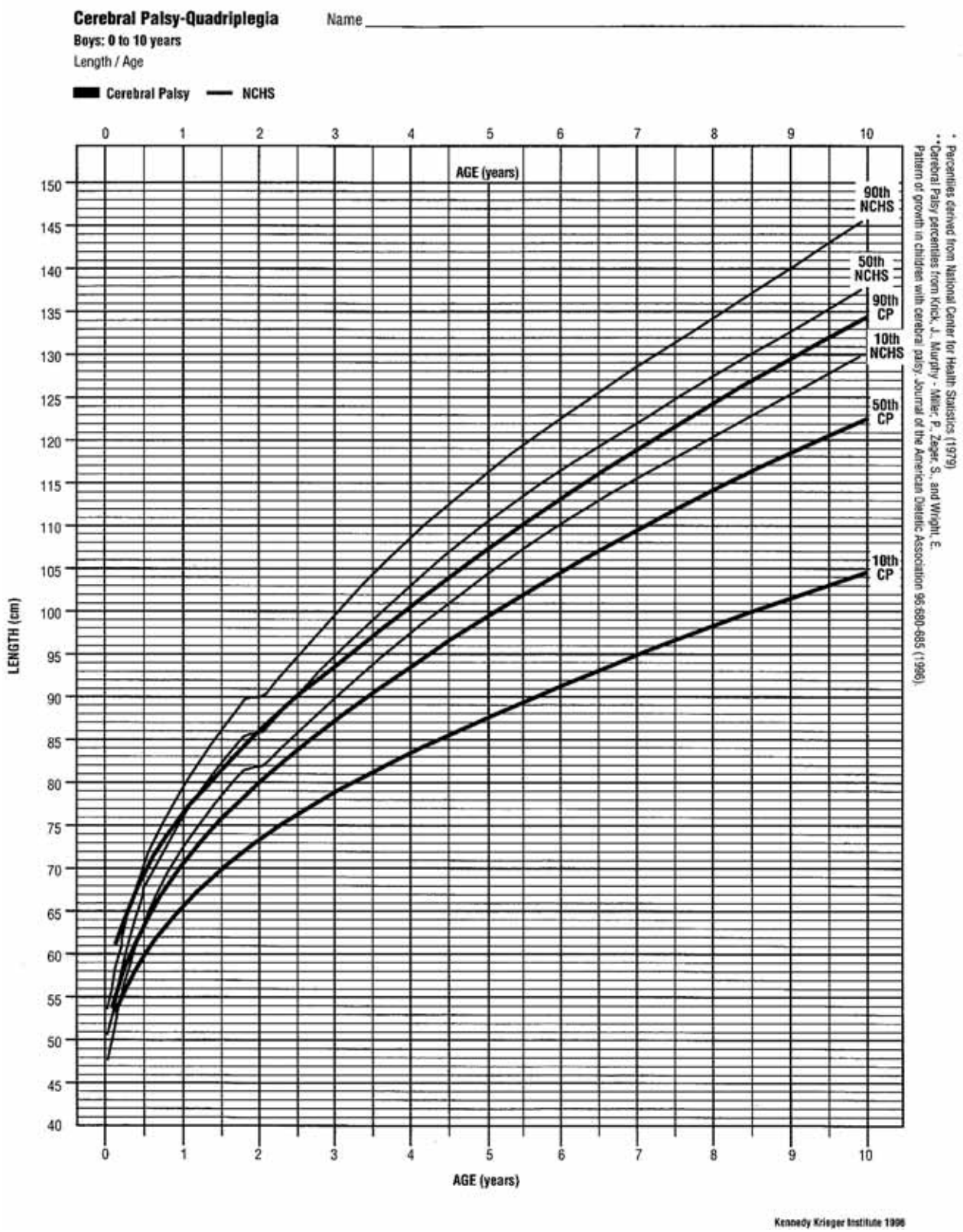
ACKNOWLEDGEMENTS

Supported in part by research grants from the USPHS, (NIH-HD11966) and The March of Dimes Birth Defects Foundation.

Prepared by the Division of Medical Genetics, Harbor-UCLA Medical Center, 1000 West Carson Street, Torrance, California, 90509.


Cerebral Palsy-Quadriplegia
Name
Boys: 0 to 10 years
Weight / Age
Cerebral Palsy
NCHS
AGE (years)
WEIGHT (kg)
90th NCHS
50th NCHS
90th CP
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
** Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1996


Cerebral Palsy-Quadriplegia
Name
Boys: 0 to 10 years
Weight / Length
Cerebral Palsy
NCHS
LENGTH (cm)
WEIGHT (kg)
90th NCHS
90th CP
50th NCHS
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
** Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1996


Cerebral Palsy-Quadriplegia
Name
Boys: 0 to 10 years
Length / Age
Cerebral Palsy
NCHS
AGE (years)
LENGTH (cm)
90th NCHS
50th NCHS
90th CP
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
**Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1996

DATE	AGE	LENGTH	WEIGHT	COMMENT

Notes

Growth References for Children with Quadriplegic Cerebral Palsy

These population specific references for children with quadriplegic cerebral palsy will facilitate uniformity in your clinical appraisal of growth and nutritional status. Deviations in growth may be the first or only signal of a more serious underlying health problem that requires assessment. This chart will also help you to educate families about the issue of growth and aid in evaluating the efficacy of your intervention strategies.

The estimate of ideal body weight is in part determined by the severity and topography of cerebral palsy. For those children with quadriplegia, ideal body weight should accommodate the principles of assuring good health by maintaining adequate fat and muscle stores and allow for ease in daily physical care and management.

Krick J, Murphy-Miller P, Zeger S, Wright E.
Pattern of growth in children with cerebral palsy.
Journal of the American Dietetic Association, 1996;
96:680-685.

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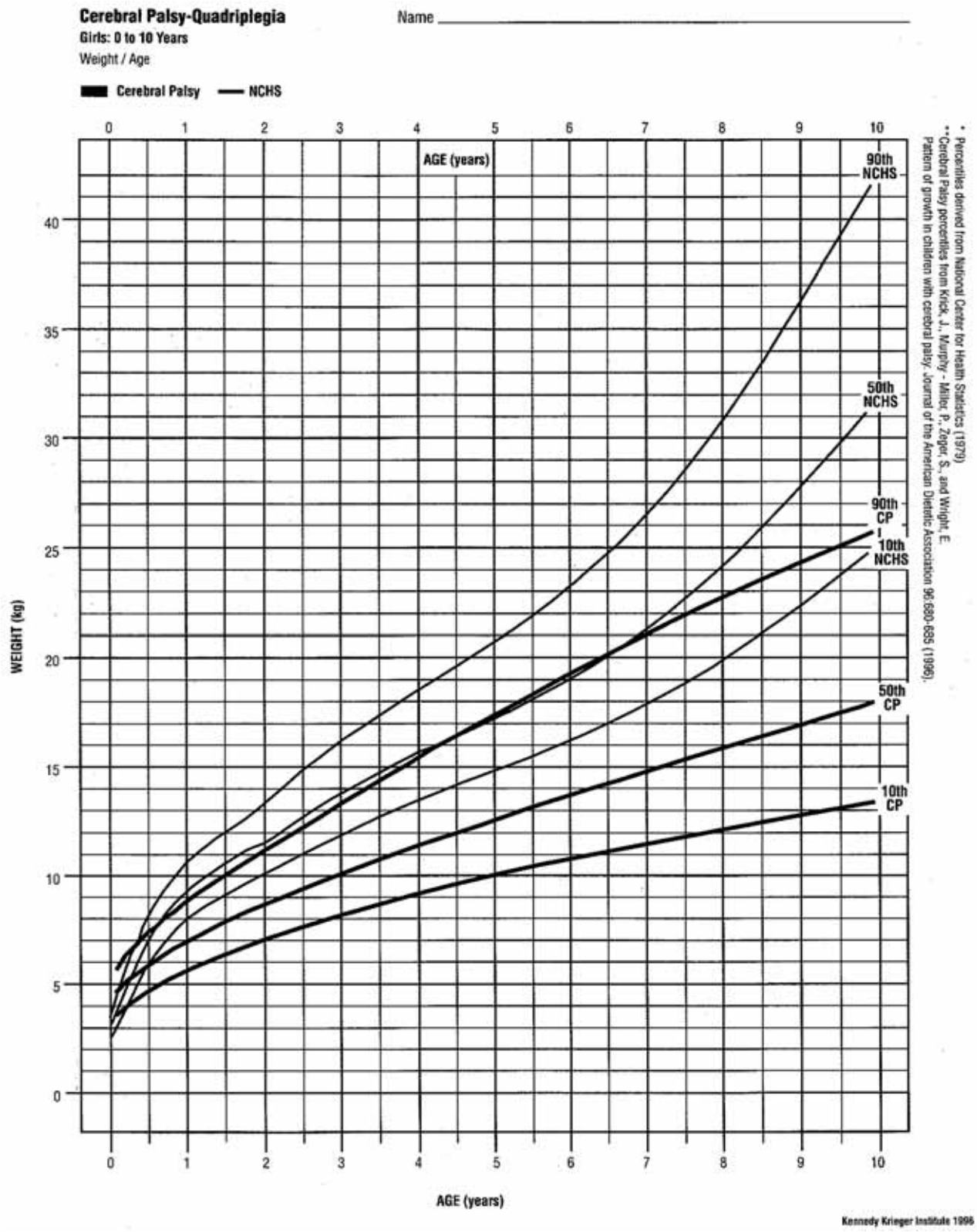
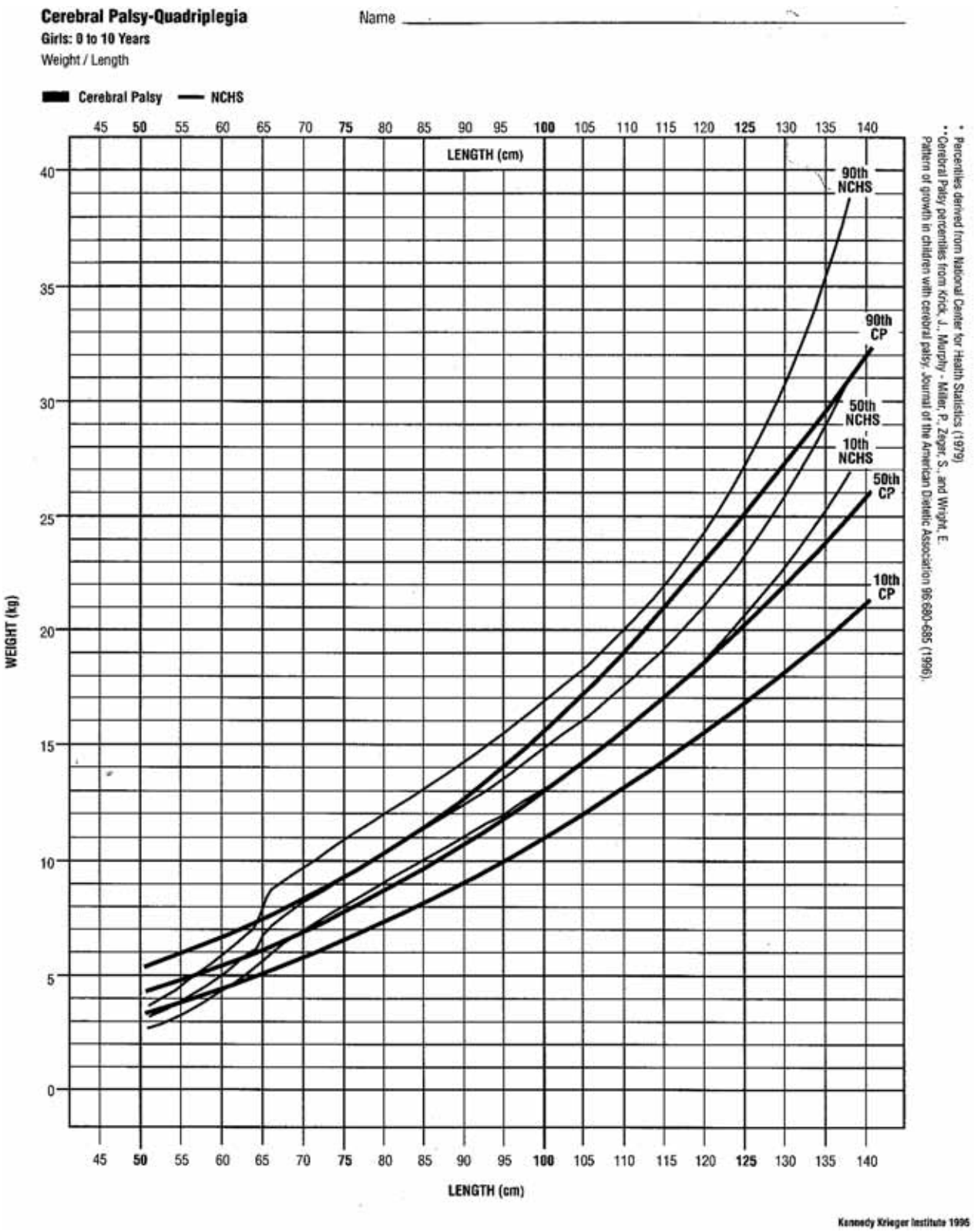
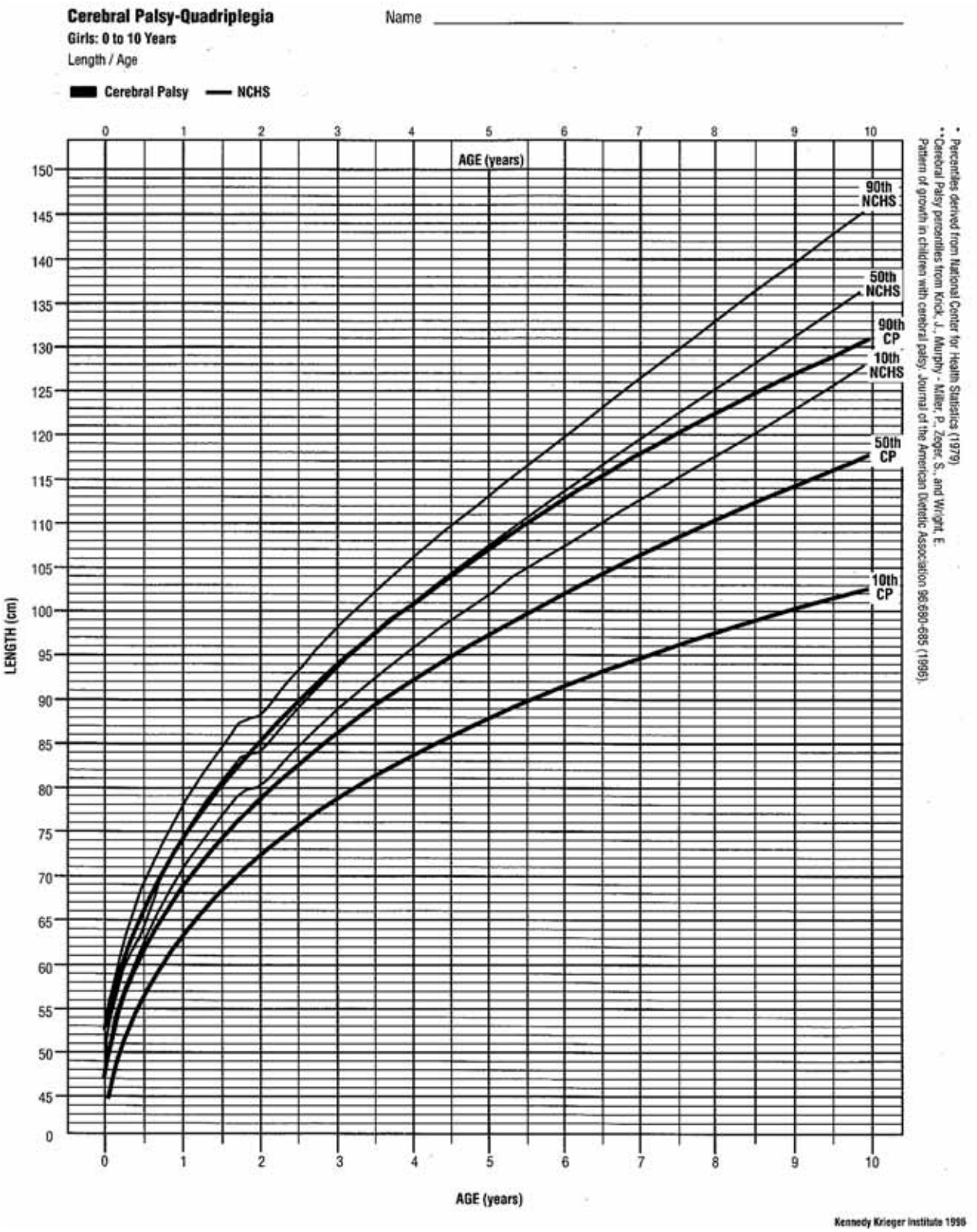

Cerebral Palsy-Quadriplegia
Name
Girls: 0 to 10 Years
Weight / Age
Cerebral Palsy
NCHS
AGE (years)
WEIGHT (kg)
90th NCHS
50th NCHS
90th CP
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
** Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1996


Cerebral Palsy-Quadriplegia
Name
Girls: 0 to 10 Years
Weight / Length
Cerebral Palsy
NCHS
LENGTH (cm)
WEIGHT (kg)
90th NCHS
90th CP
50th NCHS
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
**Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1995


Cerebral Palsy-Quadriplegia
Name
Girls: 0 to 10 Years
Length / Age
Cerebral Palsy
NCHS
AGE (years)
LENGTH (cm)
90th NCHS
50th NCHS
90th CP
10th NCHS
50th CP
10th CP
* Percentiles derived from National Center for Health Statistics (1979)
** Cerebral Palsy percentiles from Krick, J., Murphy - Miller, P., Zeger, S., and Wright, E. Pattern of growth in children with cerebral palsy. Journal of the American Dietetic Association 96:680-685 (1996).
Kennedy Krieger Institute 1996

DATE	AGE	LENGTH	WEIGHT	COMMENT

Notes

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Journal of the American Dietetic Association, 1996;
96:680-685.

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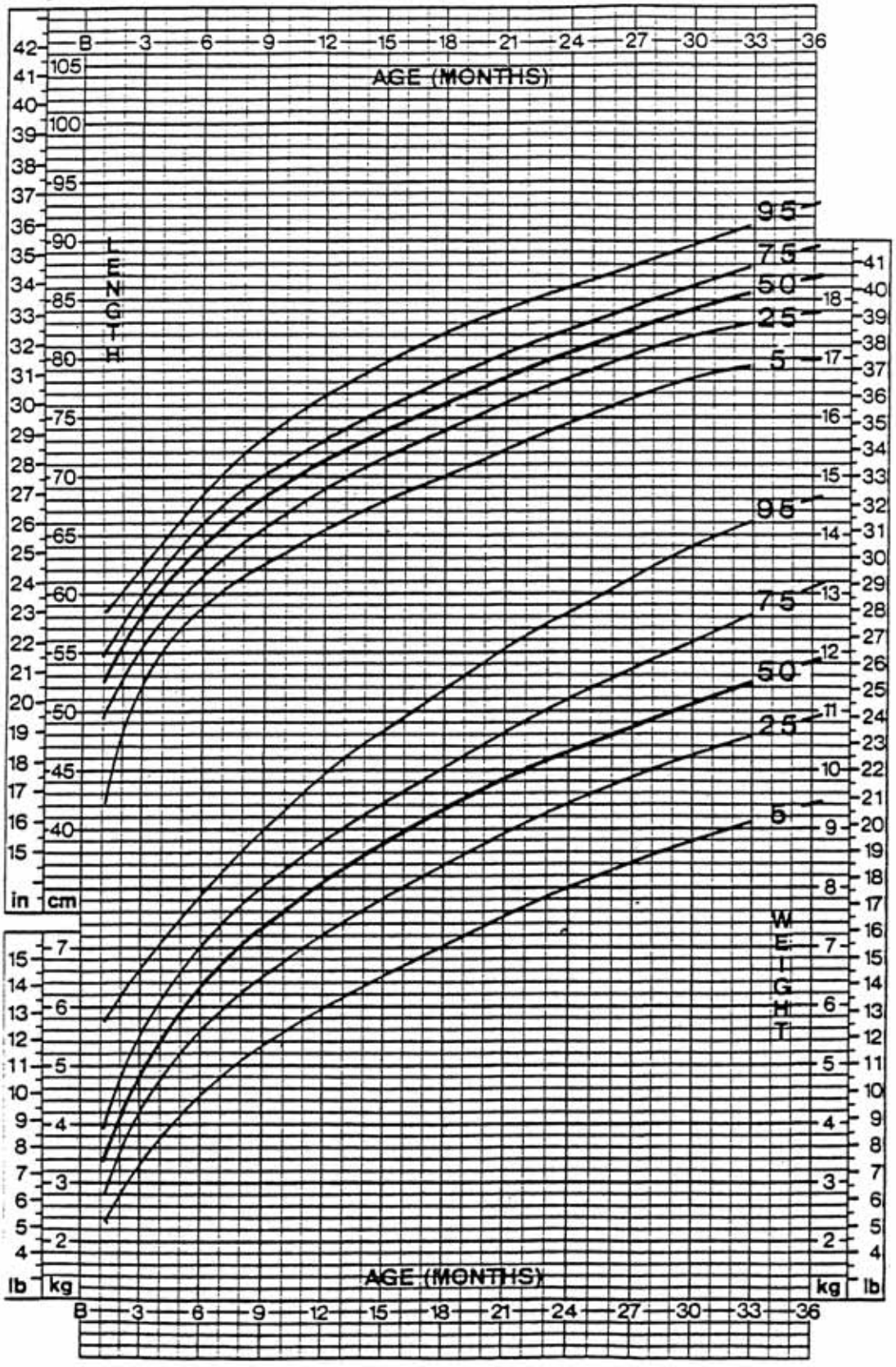
Boys with Down Syndrome:
Physical Growth: 1 to 36 Months



Growth Charts for Boys with Down Syndrome 1 to 36 Months

This chart provides reference percentiles for boys with Down syndrome one to 36 months of age. It is based on mixed longitudinal data for approximately 400 boys with Down syndrome born between 1960 and 1986 and reared at home. Children with congenital heart disease are included in the sample. The centile rank for a given child indicates the relative position he would hold in a series of l00 boys with Down syndrome. For example, a boy at l0th centile is larger than 10% and smaller than 90% of boys his age with Down syndrome. Fiftieth (50th) centile is the midposition, and equivalent to "average" height or weight for a boy with Down syndrome.

These charts correct for the smaller size and slower growth rate of boys with Down syndrome. A boy with Down syndrome would be expected to conform better to centile channels on this chart than those on the NCHS charts. However, because deficiencies in growth rate occur at varying times, and are of widely different magnitudes, a child may not remain in a single growth channel on this chart. Downward centile shifts are common between 6 and 36 months of age.

Children with moderate or severe heart disease show greater growth deficiencies than those without or with only mild heart disease during the first three years of life. On the average, boys with significant cardiac disease are 2 cm smaller than those without or with only mild heart disease beginning in the first six months of life..As with normal children with heart disease, catch-up growth may occur following surgical repair or spontaneous closure of the lesion.

Weight gain for children with Down syndrome is more rapid than height growth. This often results in overweight by 36 months of age. The etiology of this problem is not well understood, but may relate to decreased activity level. Because the present chart reflects this tendency to overweight, it should always be used in conjunction with charts for normal children when assessing body weight.

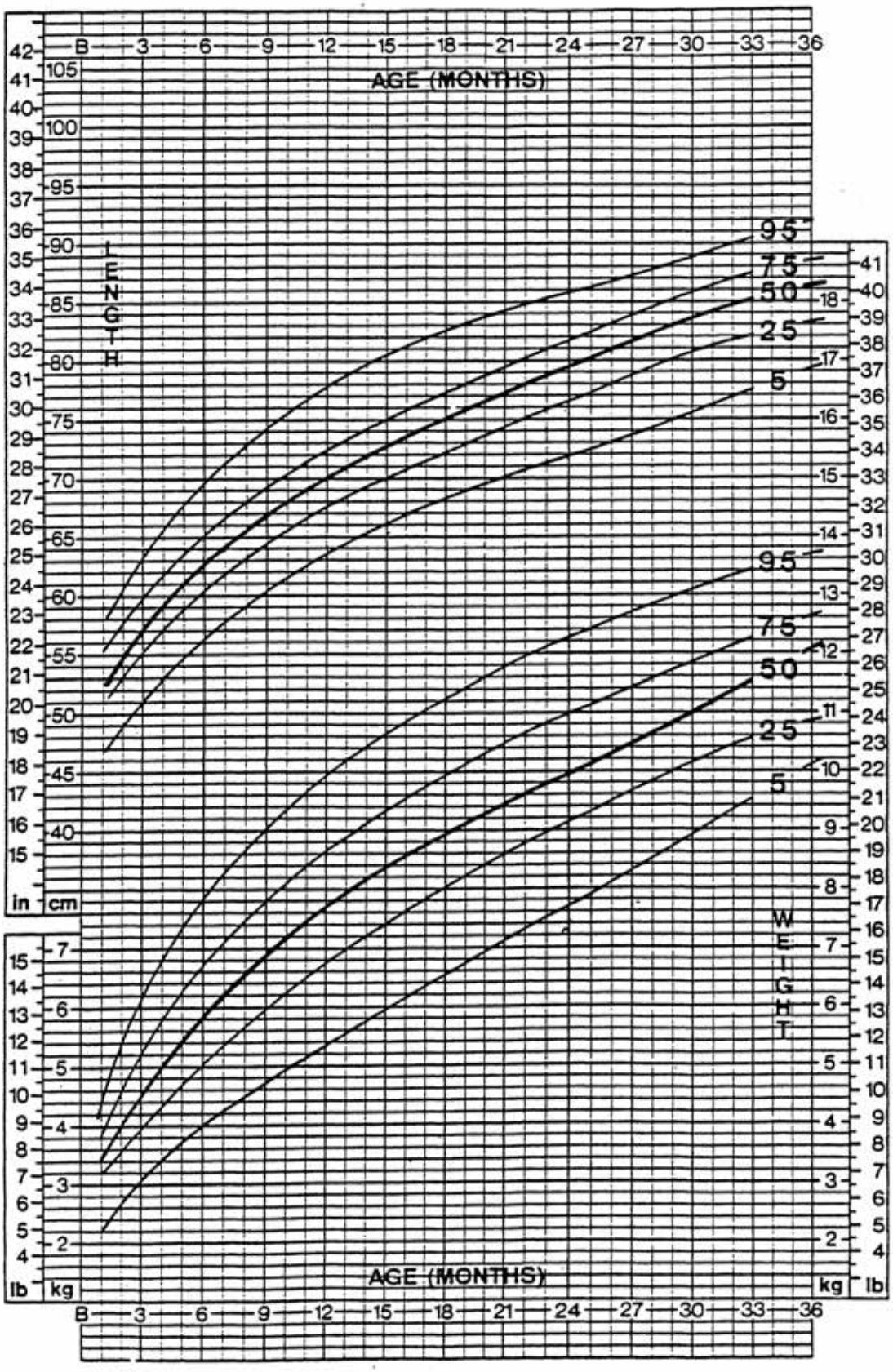
Growth Record

Date	Age	Height	Weight	Date	Age	Height	Weight

Based on data from the Developmental Evaluation Clinic of the Children's Hospital. Boston, The Child Development Center of Rhode Island Hospital, and the Clinical Genetics Service of the Children's Hospital of Philadelphia
Supported by March of Dimes grant 6-449.

Cronk C, et al. Growth charts for children with Down syndrome one month to 18 years of age. *Pediatrics.* 1988; 81:102-110.

Girls with Down Syndrome:
Physical Growth: 1 to 36 Months



Growth Charts for Girls with Down Syndrome 1 to 36 Months

This chart provides reference percentiles for girls with Down syndrome one to 36 months of age. It is based on mixed longitudinal data on approximately 300 girls with Down syndrome born between 1960 and 1986 and reared at home. Children with congenital heart disease are included in the sample. The centile rank for a given child indicates the relative position she would hold in a series of 100 girls with Down syndrome. For example, a girl at l0th centile is larger than 10% and smaller than 90% of girls her age with Down syndrome. Fiftieth (5Oth) centile is the midposition, and equivalent to "average" height or weight for a girl with Down syndrome.

These charts correct for both the smaller size and slower growth rate of girls with Down syndrome. A girl with Down syndrome would be expected to conform better to centile channels on this chart than those on the NCHS charts. However, because deficiencies in growth rate occur at varying times, and are of widely different magnitudes, a child may not remain in a single growth channel on this chart. Downward centile shifts are most common between 6 and 36 months of age.

Children with moderate or severe heart disease show greater growth deficiencies than those without or with only mild heart disease during the first three years of life. On the average, girls with significant cardiac disease are 1.5 cm smaller than those without or with only mild heart disease beginning in the first six months of life. As with normal children with heart disease, catch-up growth may occur. following surgical repair or spontaneous closure of the lesion.

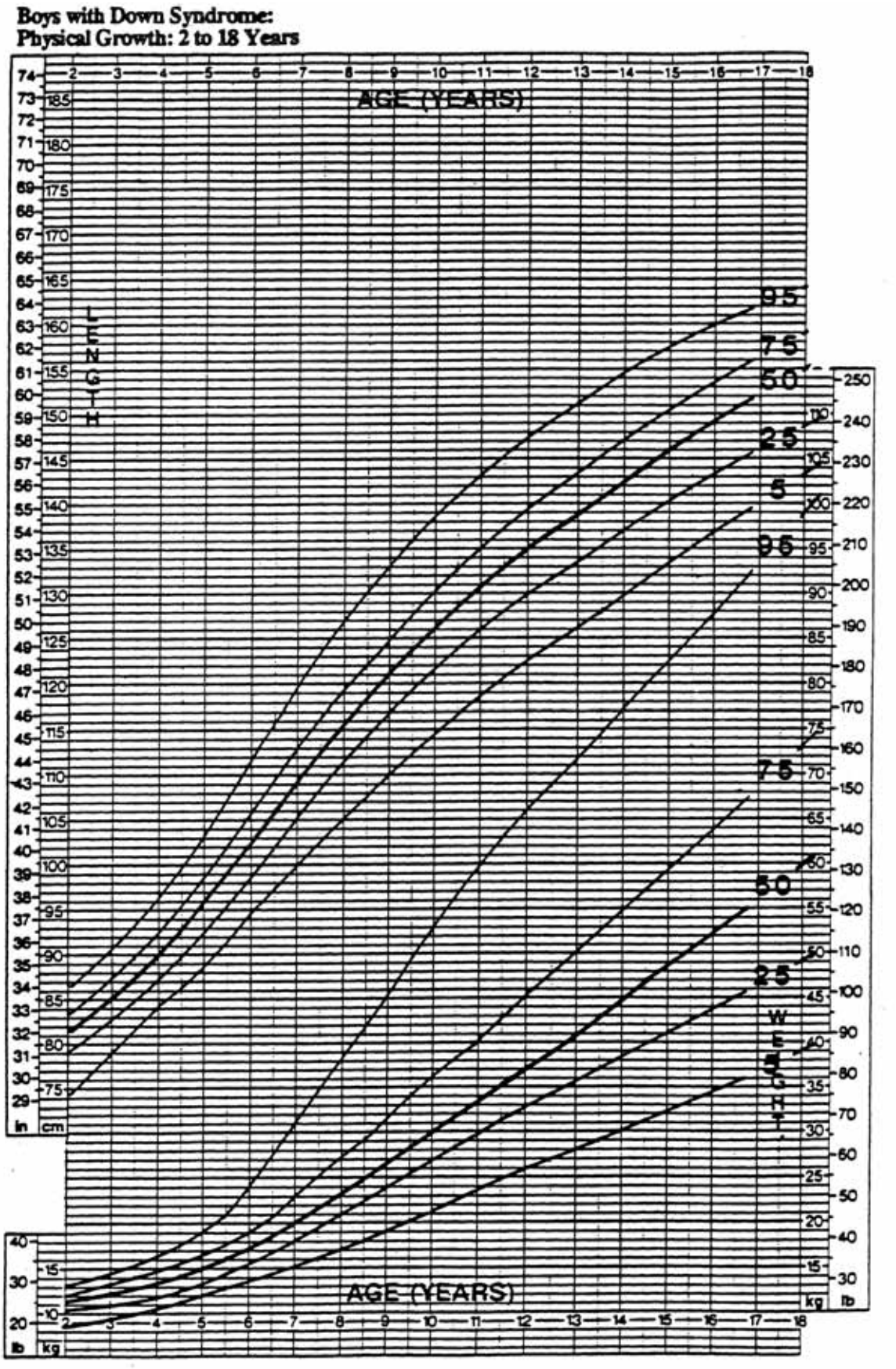
Weight gain for children with Down syndrome is more rapid than height growth. This often results in overweight by 36 months of age. The etiology of this problem is not well understood. but may relate to decreased activity level. Because the present chart reflects this tendency to overweight, it should always be used in conjunction with charts for normal children when assessing body weight

Growth Record

Date	Age	Height	Weight	Date	Age	Height	Weight

Based on data from the Developmental Evaluation Clinic of the Children's Hospital. Boston, The Child Development Center of Rhode Island Hospital, and the Clinical Genetics Service of the Children's Hospital of Philadelphia
Supported by March of Dimes grant 6-449.

Cronk C, et al. Growth charts for children with Down syndrome one month to 18 years of age. *Pediatrics.* 1988; 81 :102-110.


Boys with Down Syndrome:
Physical Growth: 2 to 18 Years
AGE (YEARS)
LENGTH
95
75
50
25
5
95
75
50
25
WEIGHT
AGE (YEARS)
in
cm
lb
kg
kg
lb

Growth Charts for Boys with Down Syndrome 2 to 18 Years

This chart provides reference percentiles for boys with Down syndrome 2 to 18 years of age. It is based on mixed longitudinal data for approximately 400 boys with Down syndrome born between 1960 and 1984 and reared at home. Children with congenital heart disease are included in the sample. The centile rank for a given child indicates the relative position he would hold in a series of 100 boys with Down syndrome. For example, a boy at 10th centile is larger than 10% and smaller than 90% of boys his age with Down syndrome. Fiftieth (50th) centile is the midposition, and equivalent to "average" height or weight for a boy with Down syndrome.

These charts correct for both the smaller size and slower growth rate of boys with Down syndrome. A boy with Down syndrome would be expected to conform better to centile channels on this chart than those on the NCHS charts. During the childhood years, boys with Down Syndrome grow very similarly to normal boys. However at adolescence, their growth spurts tend to occur slightly later than normal, and are not as dramatic as those seen in normal boys. A small percentage of boys with Down syndrome do not have an adolescent growth spurt.

Children with moderate or severe heart disease show greater growth deficiencies than those without or with only mild heart disease during the first three years of life. On the average, boys with significant cardiac disease are 2 cm smaller than those without or with only mild disease beginning in the first six months of life and continuing up through the adolescent period. As with normal children with heart disease, catch-up growth may occur following surgical repair or spontaneous closure of the lesion.

Weight gain for children with Down syndrome is more rapid than height growth. This often results in overweight by 36 months of age which is often enhanced during adolescence. The etiology of this problem is not well understood, but may relate to decreased activity level. Because the present chart reflects this tendency to overweight, particularly in values for the 90th and 95th centiles, the chart should always be used in conjunction with charts for normal children when assessing body weight.

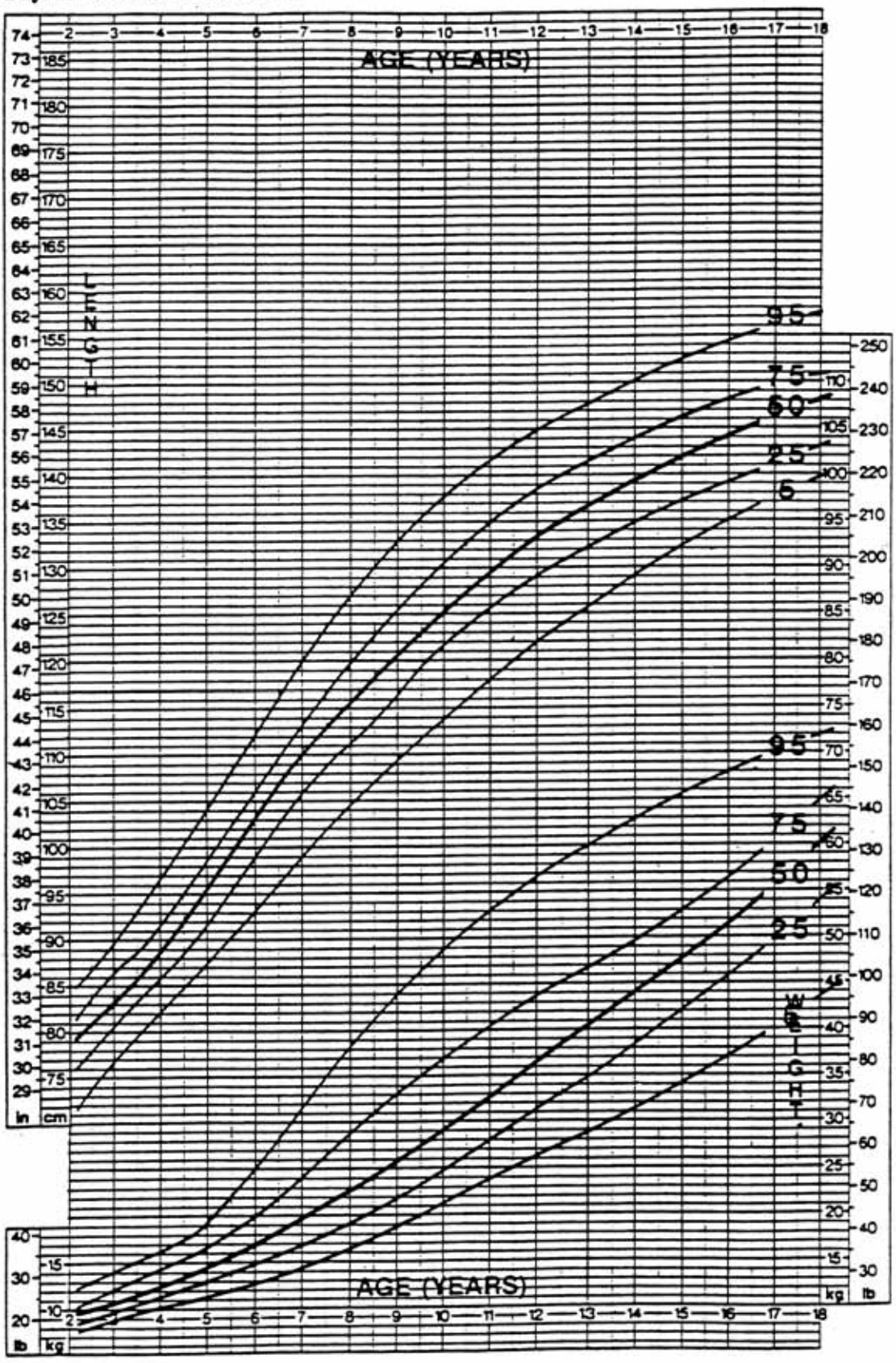
Growth Record

Date	Age	Height	Weight	Date	Age	Height	Weight

Based on data from the Developmental Evaluation Clinic of the Children's Hospital, Boston, The Child Development Center of Rhode Island Hospital, and the Clinical Genetics Service of the Children's Hospital of Philadelphia
Supported by March of Dimes grant 6-449.

Cronk.C, et al. Growth charts for children with Down syndrome one month to 18 years of age. *Pediatrics*. 1988; 81:102-110.

Girls with Down Syndrome:
Physical Growth: 2 to 18 Years



Growth Charts for Girls with Down Syndrome 2 to 18 Years

This chart provides reference percentiles for girls with Down syndrome 2 to 18 years of age. It is based on mixed longitudinal data on approximately 300 girls with Down syndrome born between 1960 and 1984 and reared at home. Children with congenital heart disease are included in the sample. The centile rank for a given child indicates the relative position she would hold in a series of 100 girls with Down syndrome. For example, a girl at 10th centile is larger than 10% and smaller than 90% of girls her age with Down syndrome. Fiftieth (50th) centile is the midposition, and equivalent to "average" height or weight for a girl with Down syndrome.

These charts correct for both the smaller size and slower growth rate of girls with Down syndrome. A girl with Down syndrome would be expected to conform better to centile channels on this chart than those on the NCHS charts. During the childhood years, girls with Down Syndrome grow very similarly to normal girls. However at adolescence, their growth spurts tend to occur slightly later than normal, and are not as dramatic as those seen in normal girls. Some girls with Down syndrome do not exhibit an adolescent growth spurt.

Children with moderate or severe heart disease show greater growth deficiencies than those without or with only mild heart disease. On the average girls with significant cardiac disease are 1.5 cm smaller than those without or with only mild disease beginning in the first six months of life and continuing up through the adolescent period. As with normal children with heart disease, catch-up growth may occur following surgical repair or spontaneous closure of the lesion.

Weight gain for children with Down syndrome is more rapid than height growth. This often results in overweight by 36 months of age which is often enhanced during adolescence. The etiology of this problem is not well understood, but may relate to decreased activity level. Because the present chart reflects this tendency to overweight, particularly in values for the 90th and 95th centiles, it should always be used in conjunction with charts for normal children when assessing body weight.

Growth Record

Date	Age	Height	Weight	Date	Age	Height	Weight

Based on data from the Developmental Evaluation Clinic of the Children's Hospital, Boston, The Child Development Center of Rhode Island Hospital, and the Clinical Genetics Service of the Children's Hospital of Philadelphia
Supported by March of Dimes grant 6-449.

Cronk C, et al. Growth charts for children with Down syndrome one month to 18 years of age. *Pediatrics*. 1988; 81:102-110.

IHDP Growth Percentiles: LBW Premature Boys[1,2]

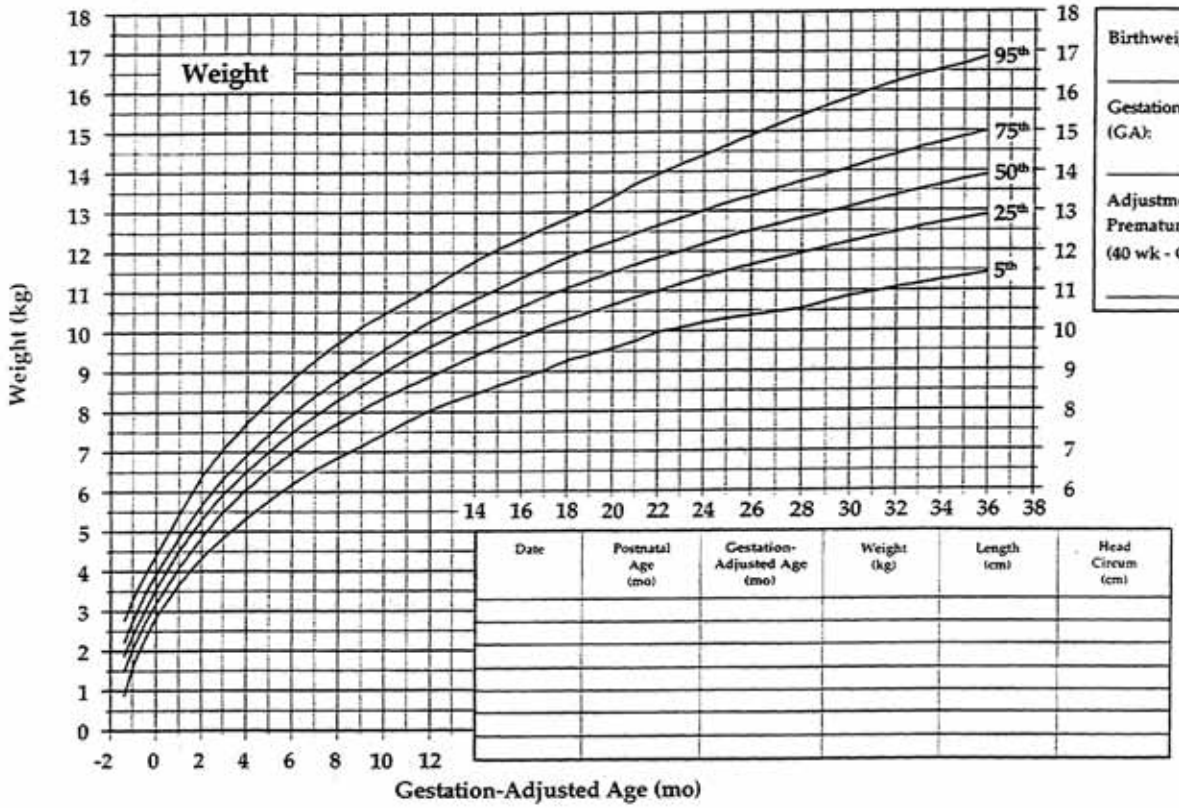
(1501 to 2500 g BW, ≤37 wk GA)

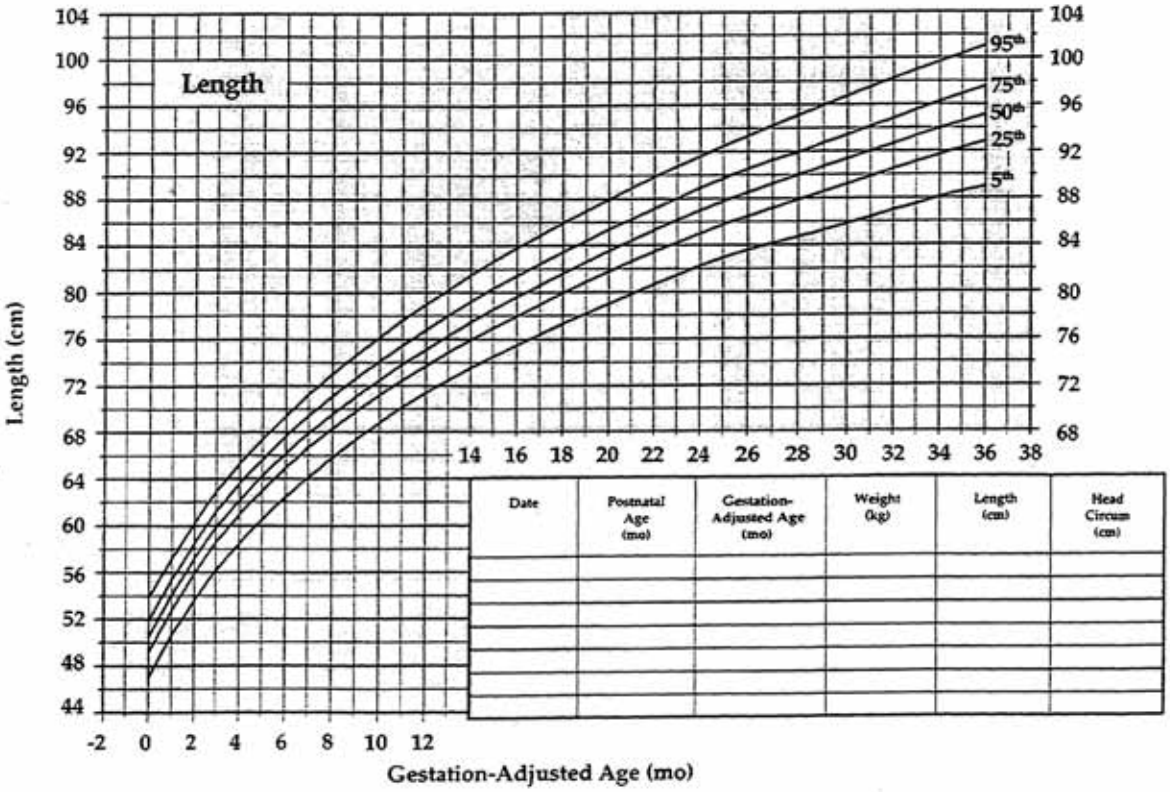
Name_____

Record #_____

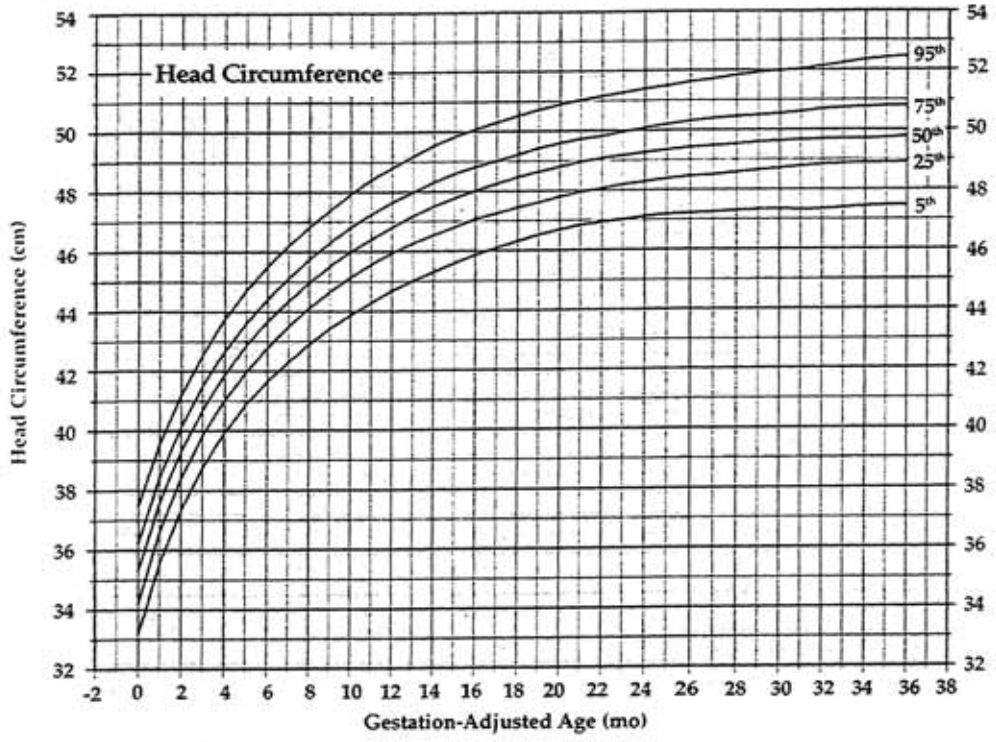
ROSS PEDIATRICS

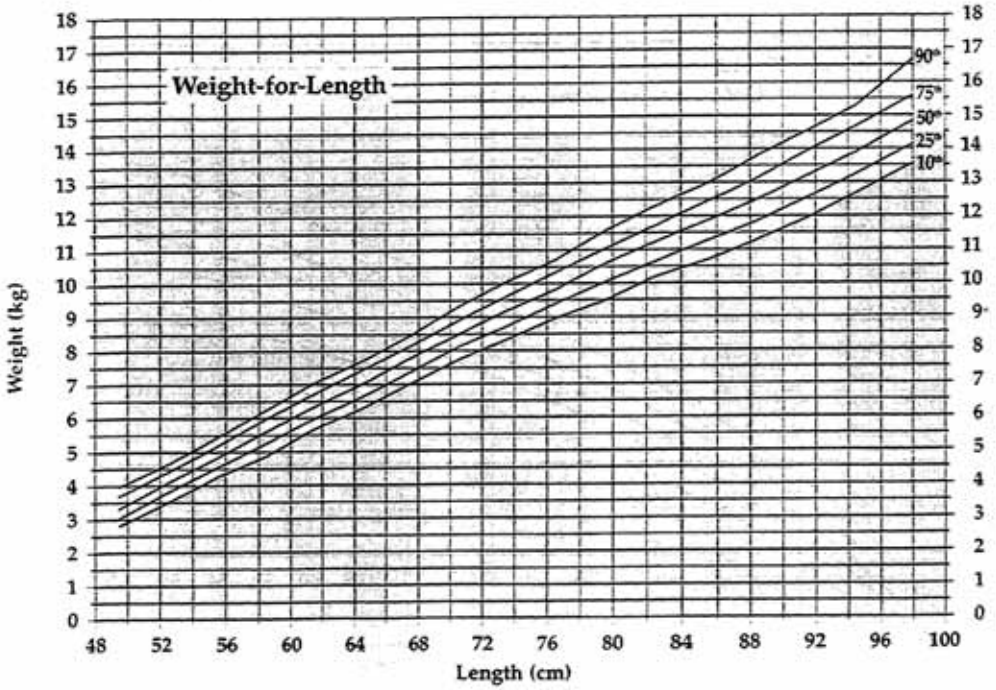
Birthweight (BW):
_____ g
Gestational Age (GA):
_____ wk
Adjustment for Prematurity (40 wk - GA):
_____ wk





IHDP Growth Percentiles: LBW Premature Boys[1,2]





References

1. Guo SS, Roche AF, Chumlea WC, et al: Growth in weight, recumbent length, and head circumference for preterm low-birthweight infants during the first three years of life using gestation-adjusted ages. *Early Hum Dev* 1997;47:305-325.
2. Guo SS, Wholihan K, Roche AF, et al: Weight-for-length reference data for preterm, low-birth-weight infants. *Arch Pediatr Adolesc Med* 1996;150:964-970. Copyright 1996, American Medical Association.

Acknowledgment

IHDP studies were supported by grants from the Robert Wood Johnson Foundation, Pew Charitable Trusts, and the Bureau of Maternal and Child Health, US Department of Health and Human Services. The IHDP growth percentile graphs were prepared by S.S. Guo and A.F. Roche, Wright State University, Yellow Springs, Ohio. IHDP, its sponsors and the investigators do not endorse specific products.

IHDP Growth Percentiles: LBW Premature Girls[1,2]

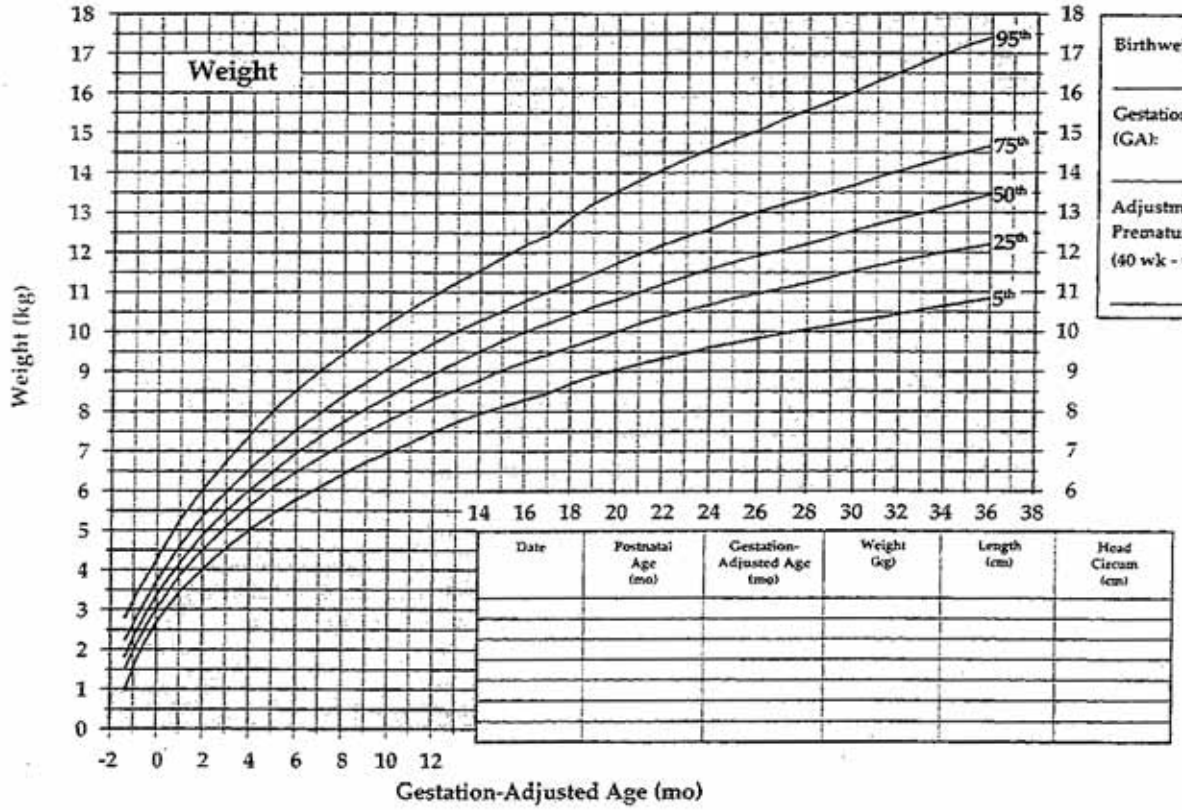
(1501 to 2500 g BW, ≤37 wk GA)

Name_____

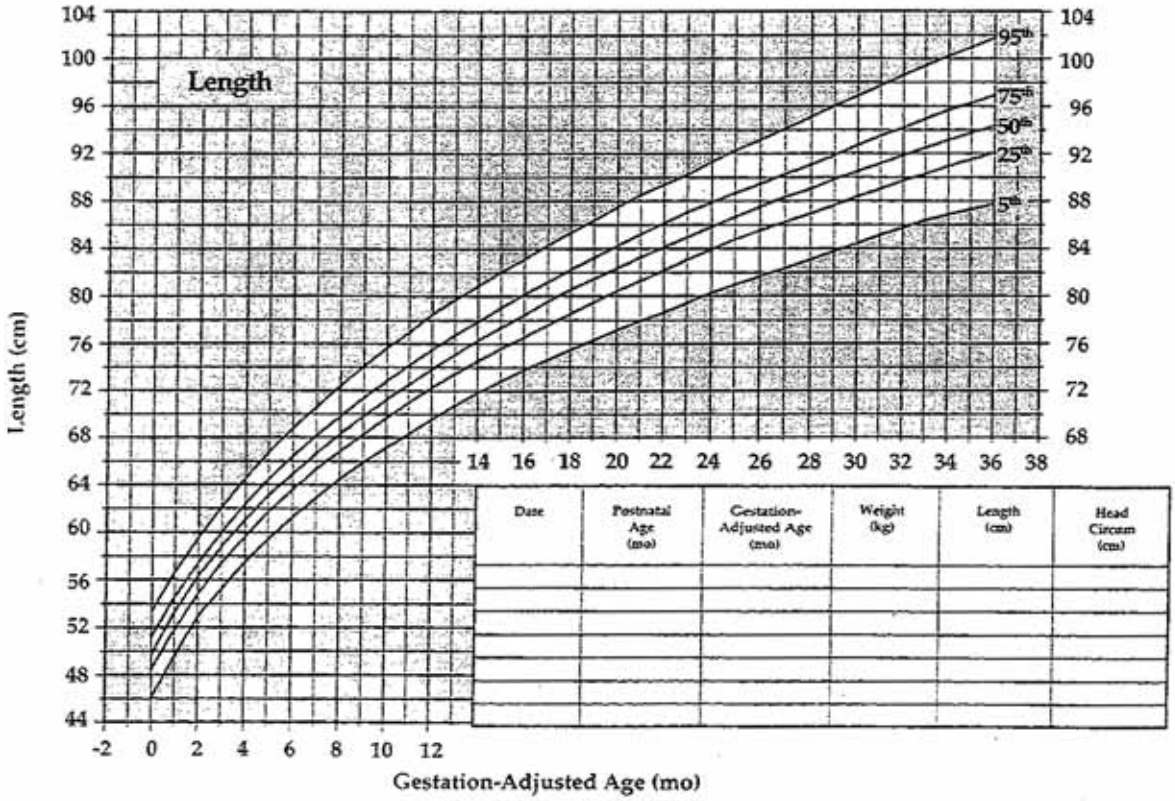
Record #_____

ROSS PEDIATRICS

Birthweight (BW):
_____g
Gestational Age (GA):
_____wk
Adjustment for Prematurity (40 wk - GA):
_____wk

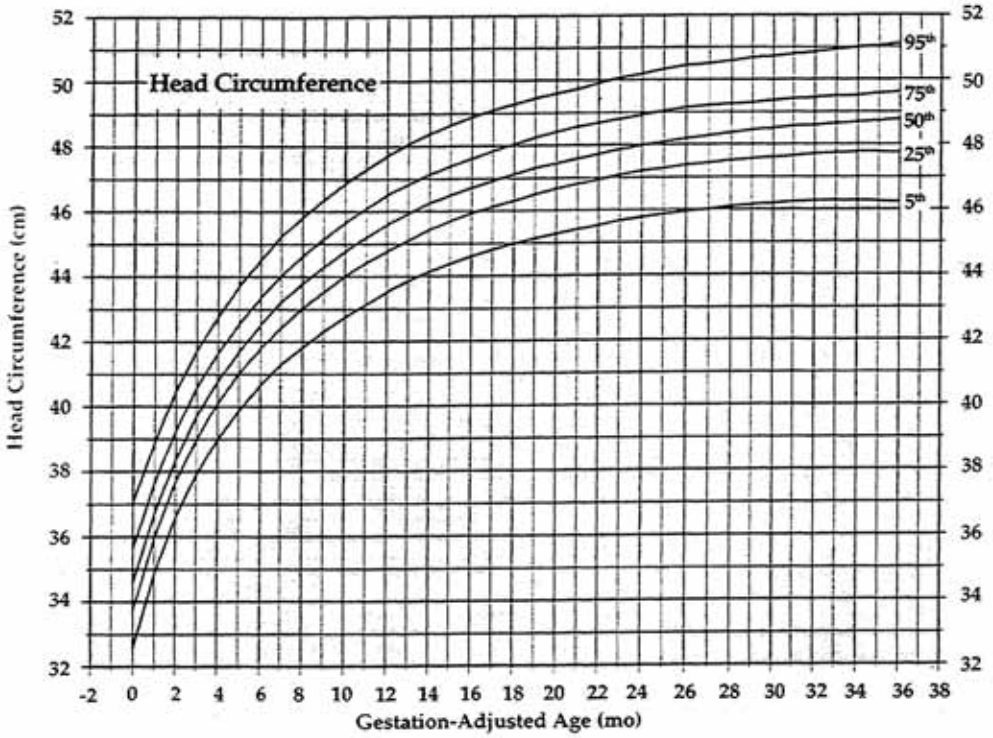


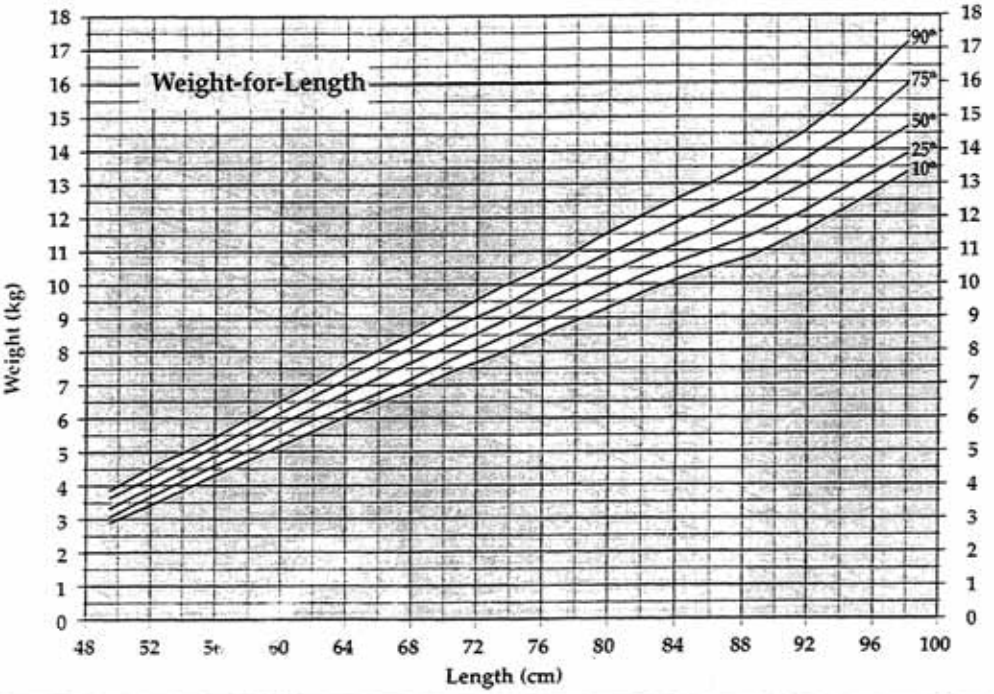
Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)



Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)

IHDP Growth Percentiles: LBW Premature Girls[1,2]





References

1. Guo SS, Roche AF, Chumlea WC, et al: Growth in weight, recumbent length, and head circumference for preterm low-birthweight infants during the first three years of life using gestation-adjusted ages. *Early Hum Dev* 1997;47:305-325.
2. Guo SS, Wholihan K, Roche AF, et al: Weight-for-length reference data for preterm, low-birth-weight infants. *Arch Pediatr Adolesc Med* 1996;150:964-970. Copyright: 1996, American Medical Association.

Acknowledgment

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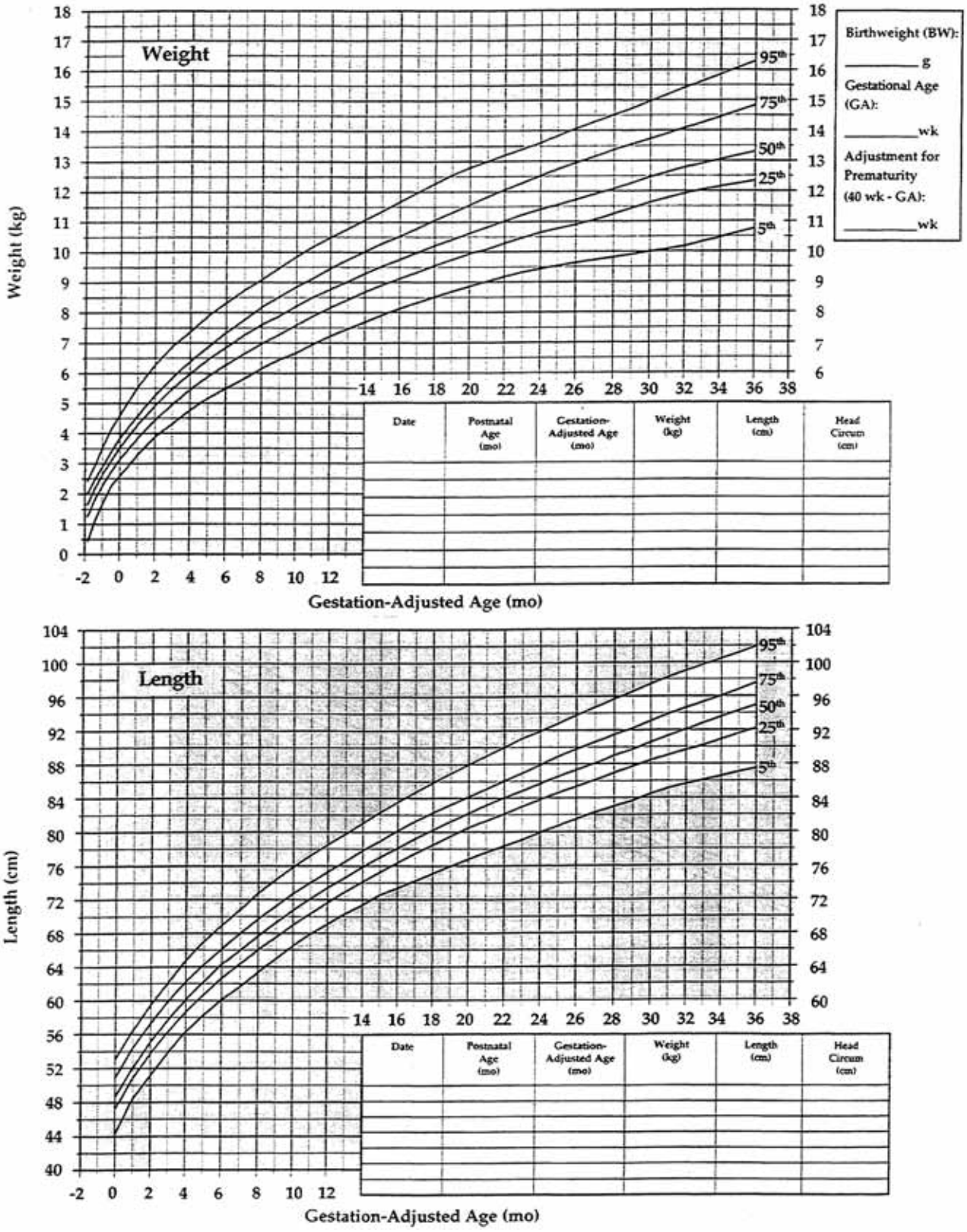
IHDP Growth Percentiles: VLBW Premature Boys[1,2]

(≤1500 g BW, ≤37 wk GA)

Name_____

Record #_____

ROSS PEDIATRICS

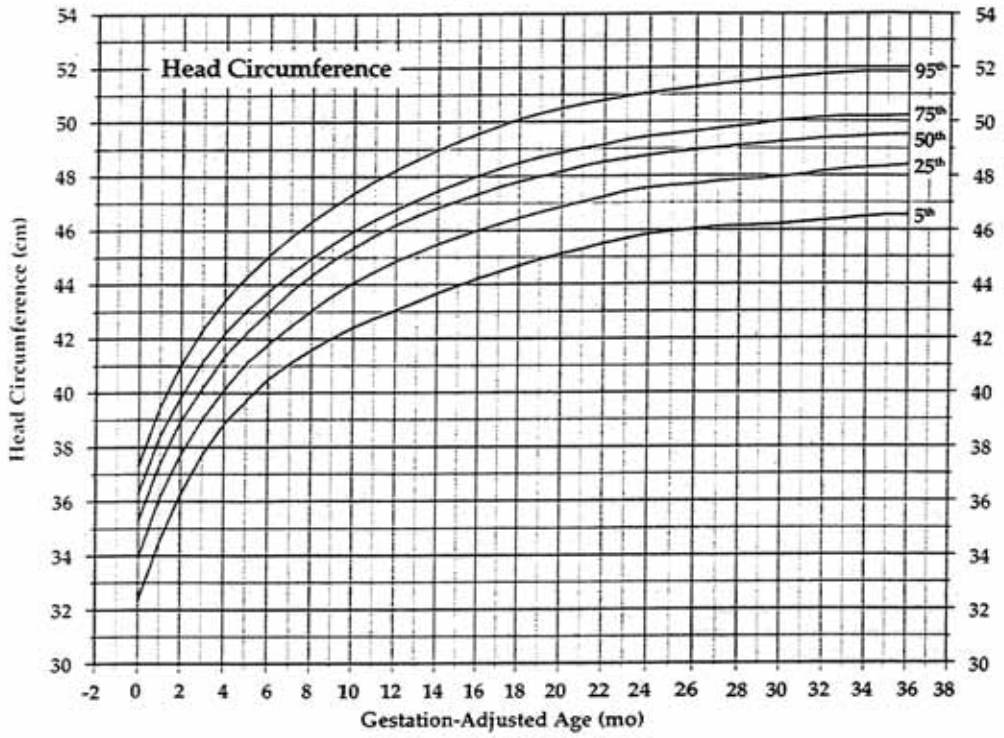


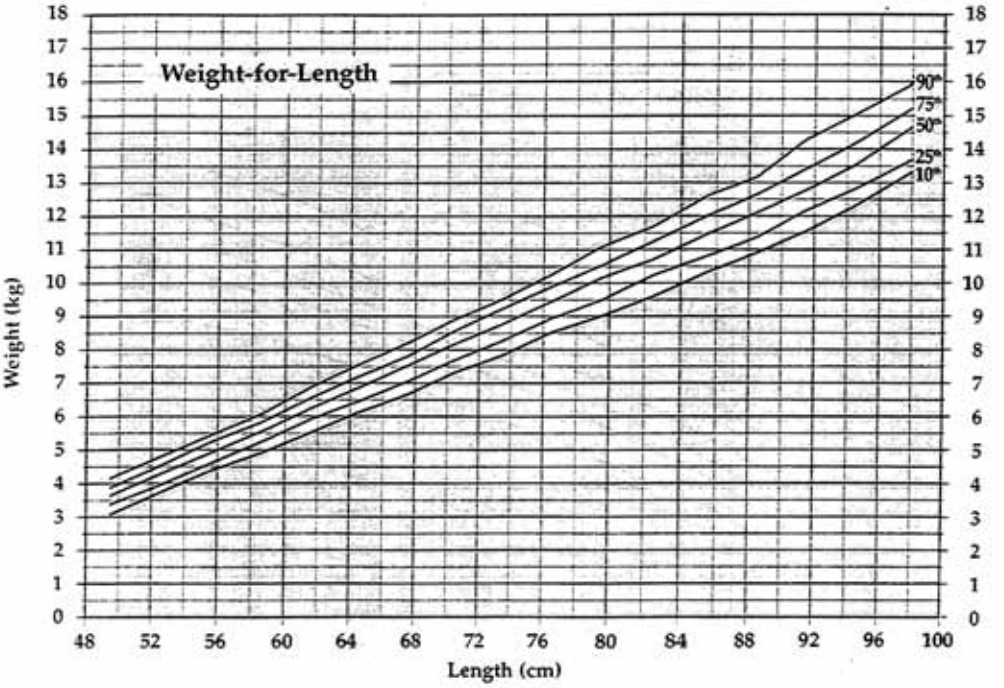
Birthweight (BW):
_____ g
Gestational Age (GA):
_____ wk
Adjustment for Prematurity (40 wk - GA):
_____ wk

Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)

Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)

IHDP Growth Percentiles: VLBW Premature Boys[1,2]





References

1. Guo SS, Roche AF, Chumlea WC, et al: Growth in weight, recumbent length, and head circumference for preterm low-birthweight infants during the first three years of life using gestation-adjusted ages. *Early Hum Dev* 1997;47:305-325.
2. Guo SS, Wholihan K, Roche AF, et al: Weight-for-length reference data for preterm, low-birth-weight infants. *Arch Pediatr Adolesc Med* 1996;150:964-970. Copyright 1996, American Medical Association.

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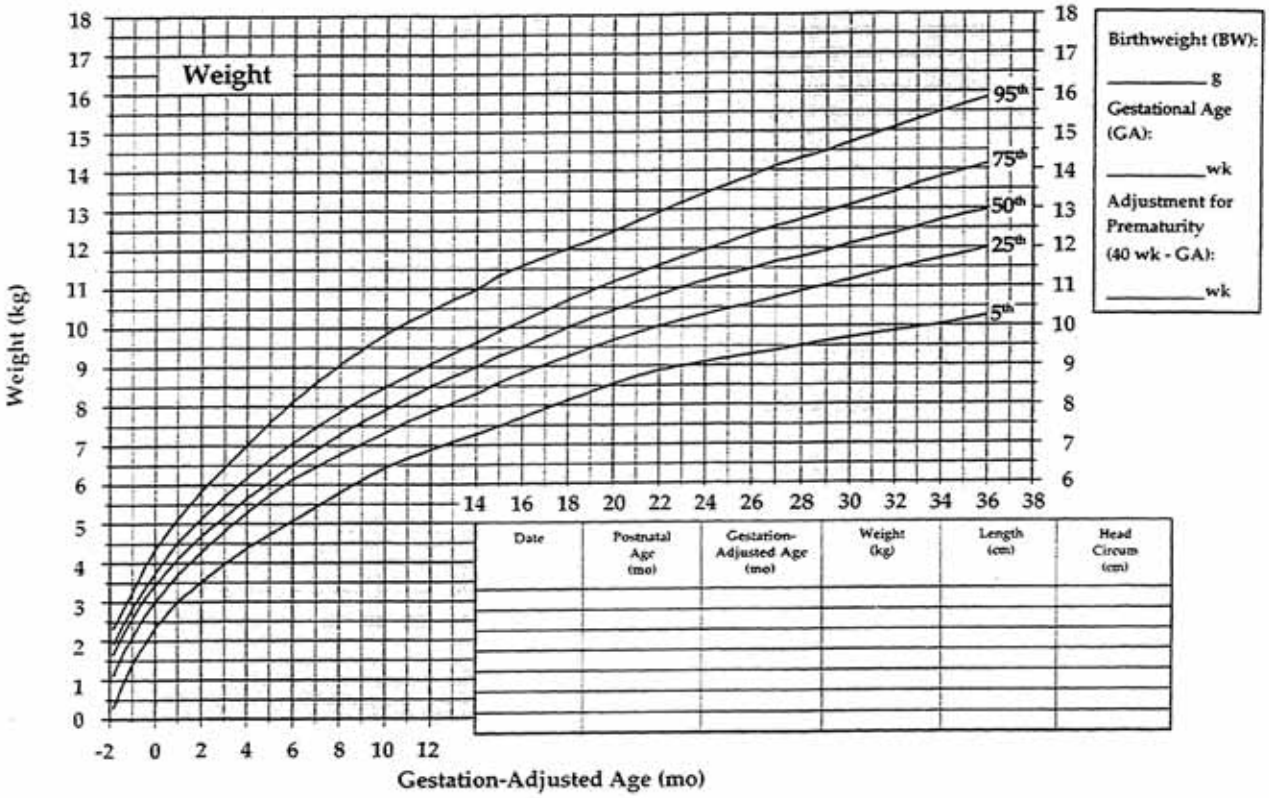
(≤1500 g BW, ≤37 wk GA)

Name_____

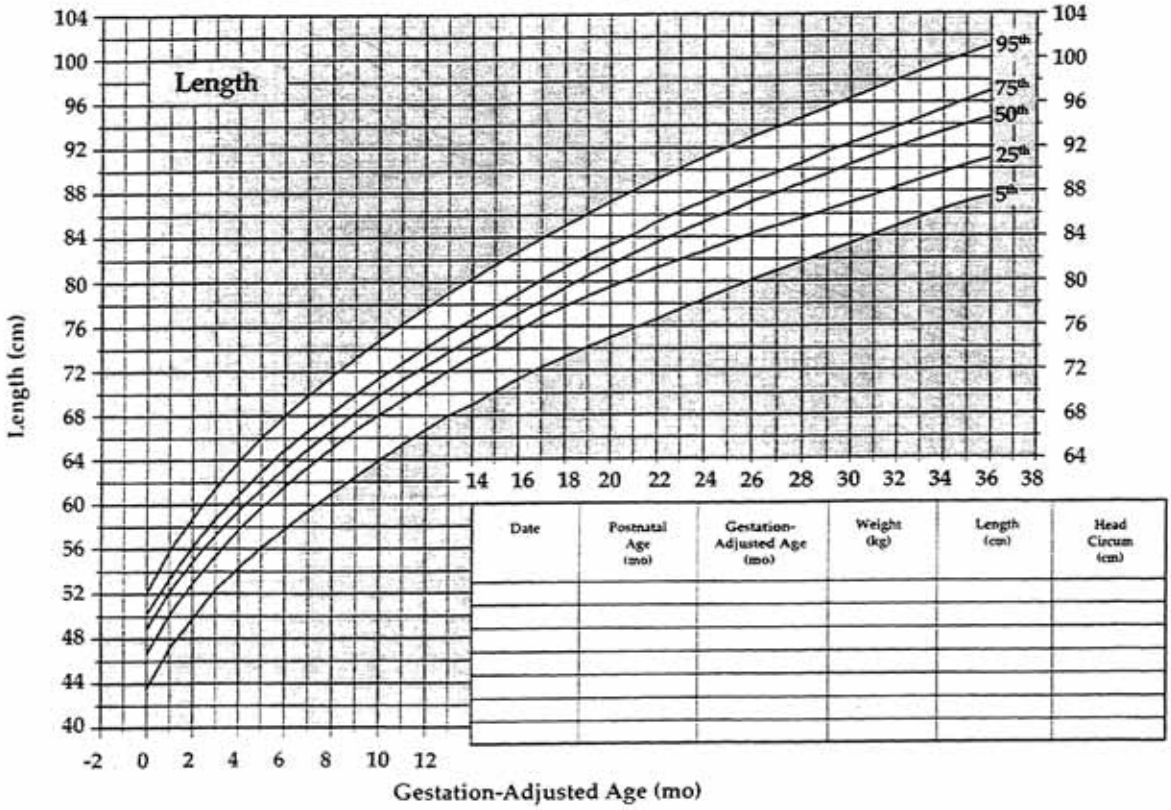
Record #_____

ROSS PEDIATRICS



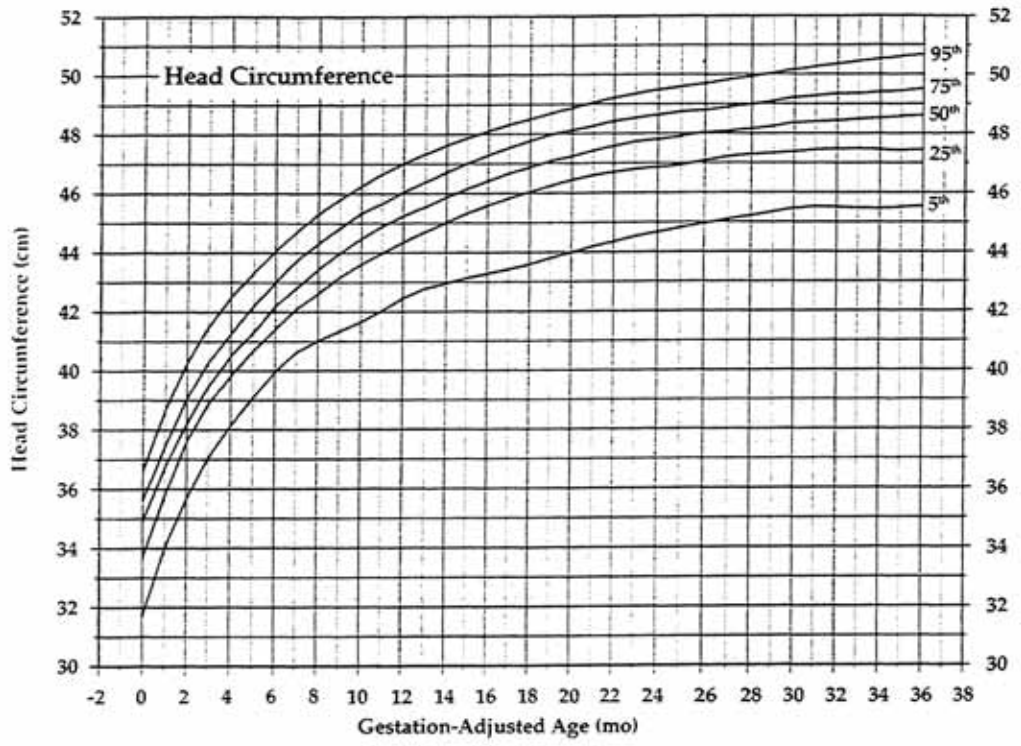
Birthweight (BW):
_____ g
Gestational Age (GA):
_____ wk
Adjustment for Prematurity (40 wk - GA):
_____ wk

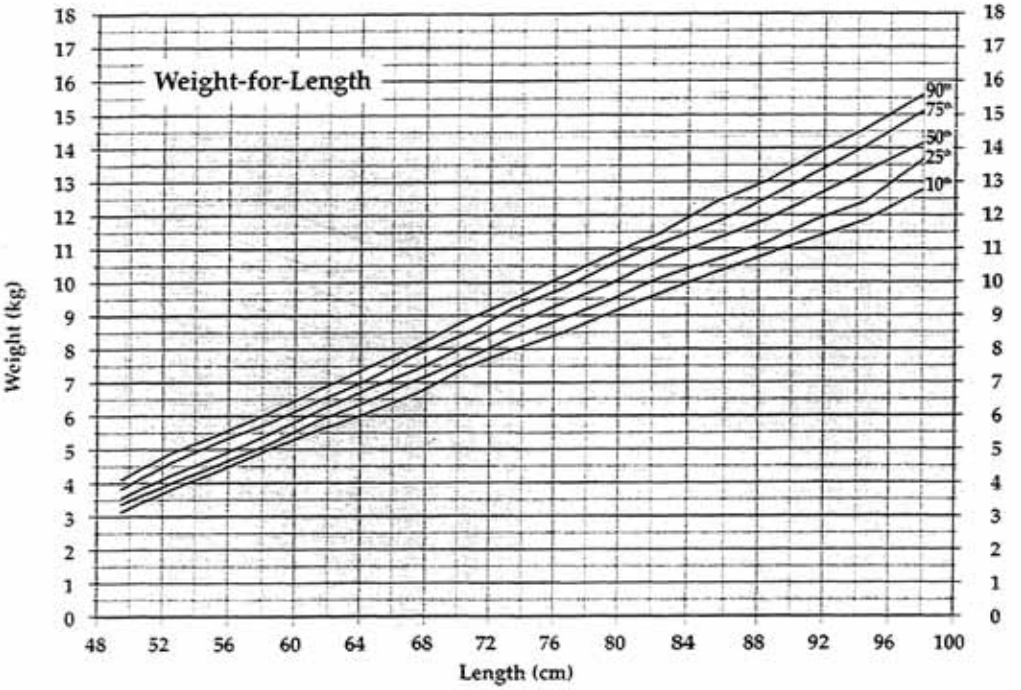
Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)



Date	Postnatal Age (mo)	Gestation-Adjusted Age (mo)	Weight (kg)	Length (cm)	Head Circum (cm)

IHDP Growth Percentiles: VLBW Premature Girls[1,2]





References

1. Guo SS, Roche AF, Chumlea WC, et al: Growth in weight, recumbent length, and head circumference for preterm low-birthweight infants during the first three years of life using gestation-adjusted ages. *Early Hum Dev* 1997;47:305-325.
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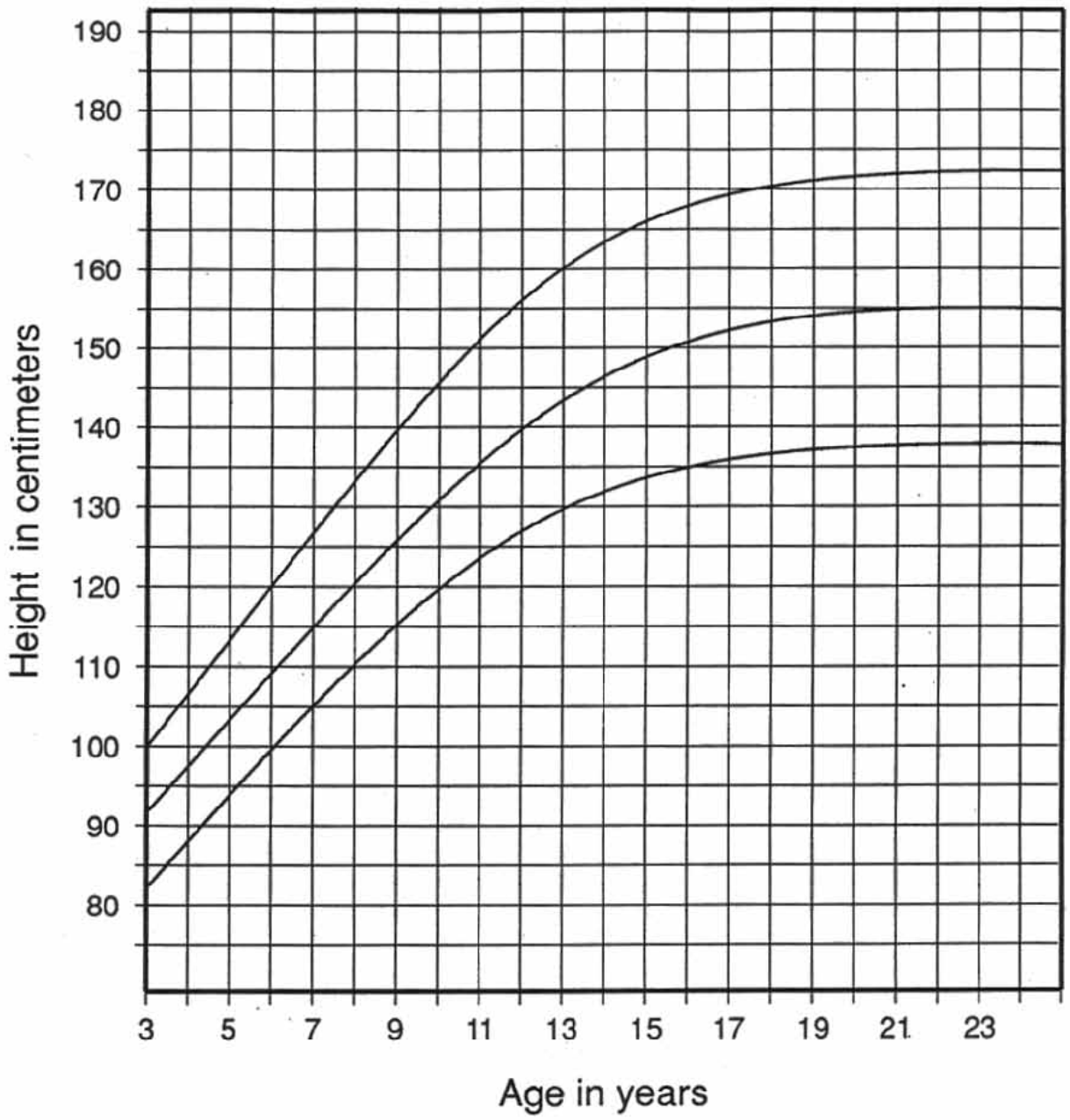
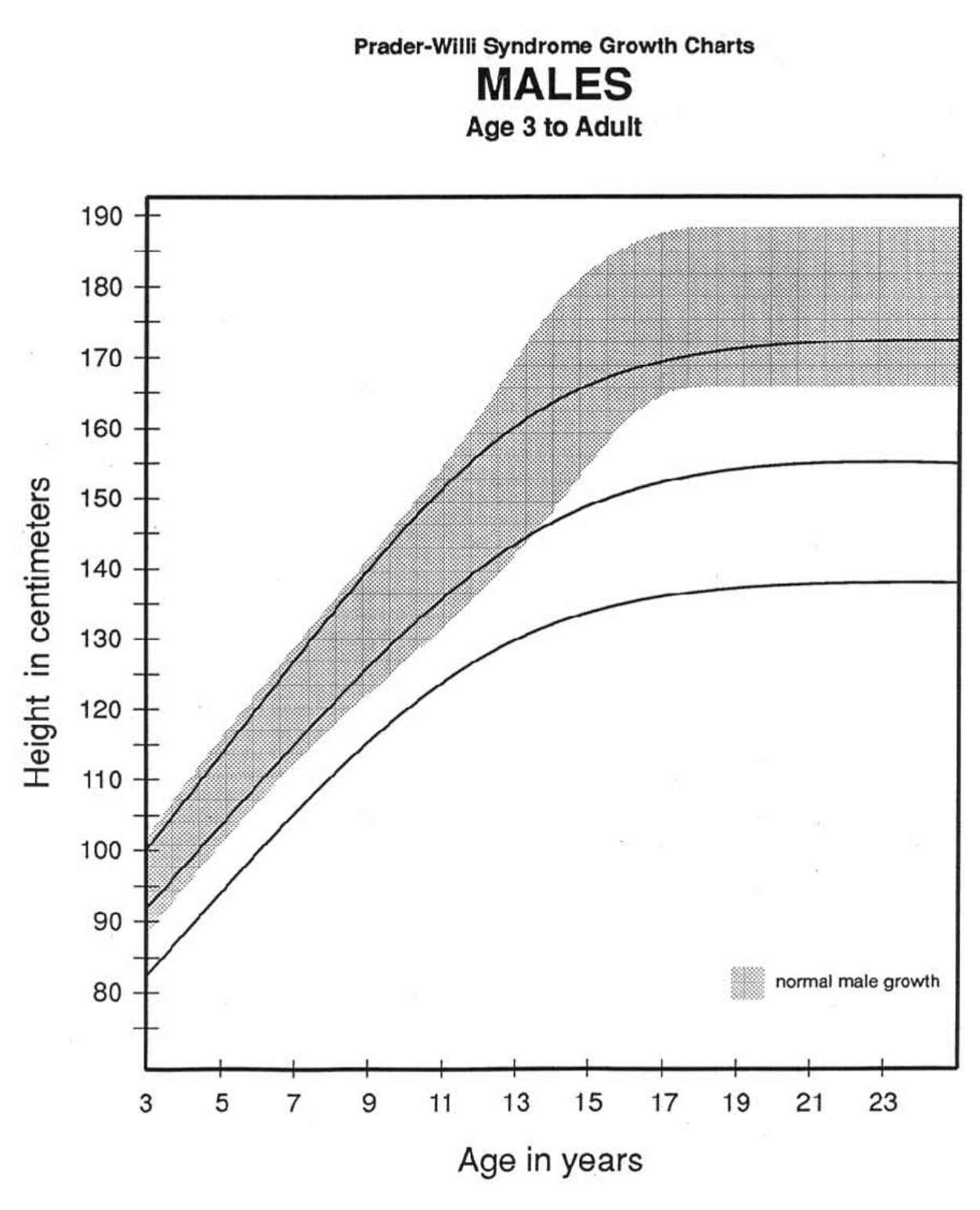
Prader-Willi Syndrome Growth Charts

MALES

Age 3 to Adult



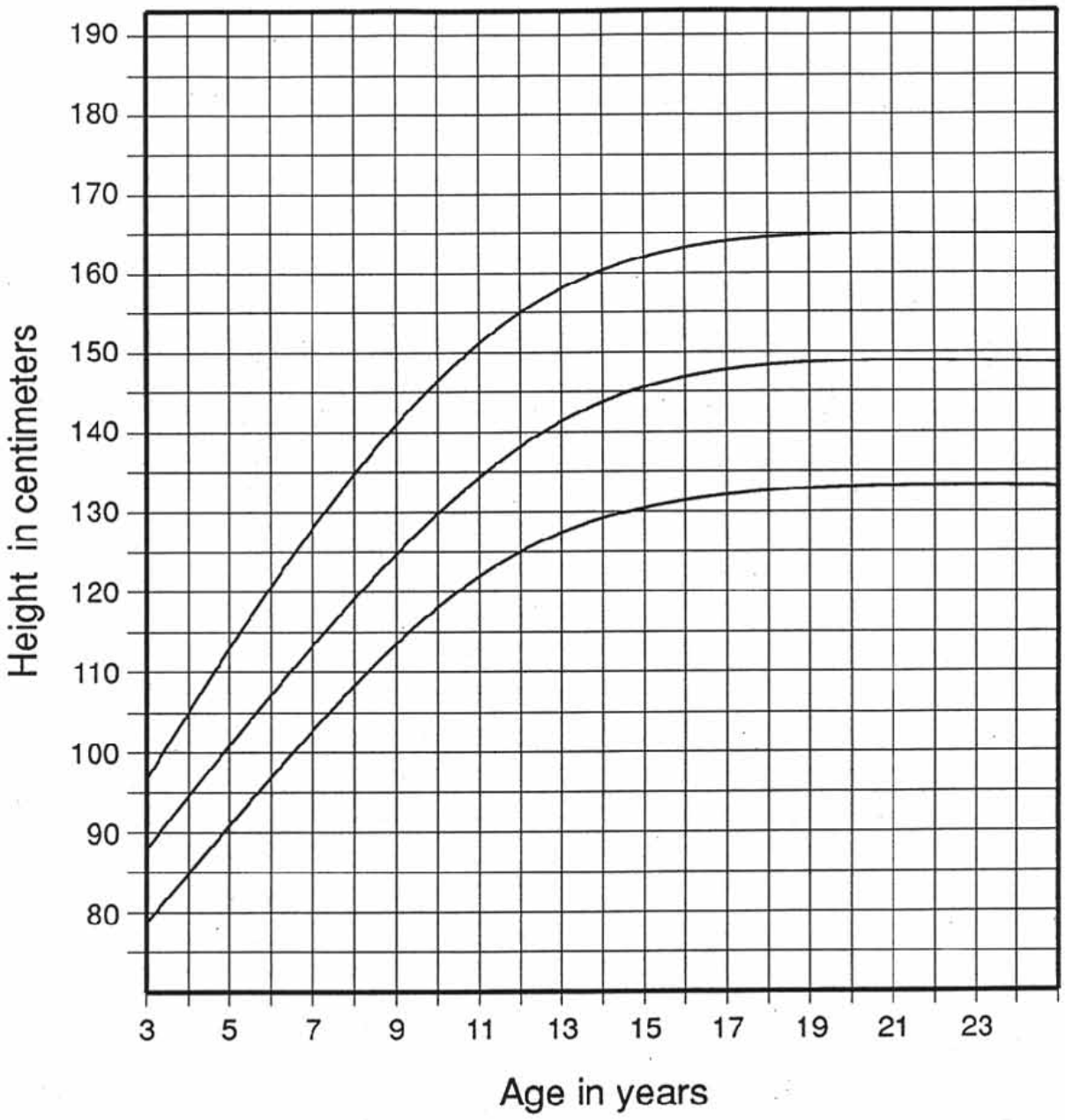
Holm V, et al. Appendix A: Growth charts for Prader-Willi syndrome. In: Greenswag LR, Alexander RD, eds. *Management of Prader-Willi Syndrome*, 2nd ed. The Prader-Willi Syndrome Association. New York: Springer-Verlag. 1995.


Prader-Willi Syndrome Growth Charts
MALES
Age 3 to Adult
Height in centimeters
190
180
170
160
150
140
130
120
110
100
90
80
normal male growth
3
5
7
9
11
13
15
17
19
21
23
Age in years

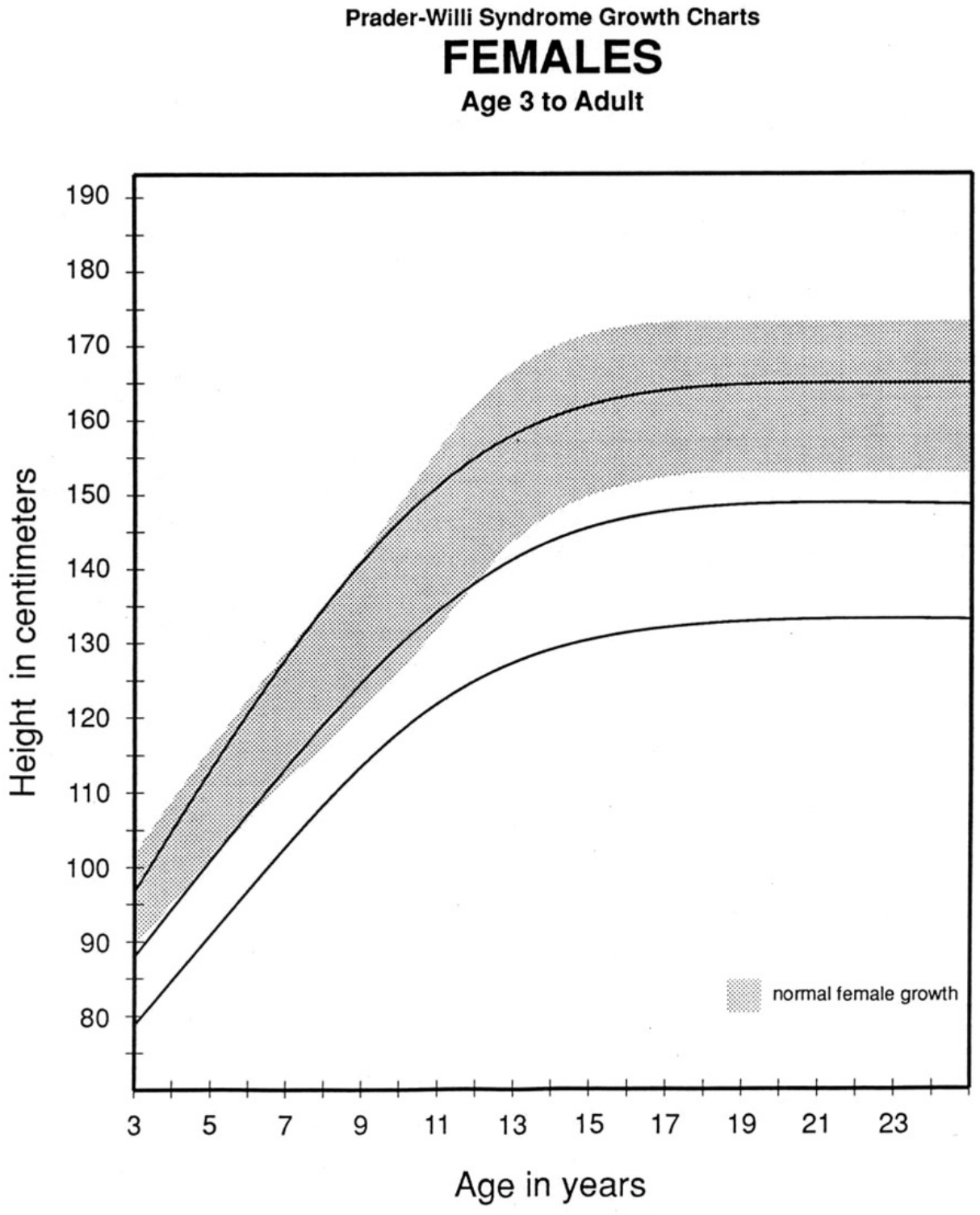
Prader-Willi Syndrome Growth Charts

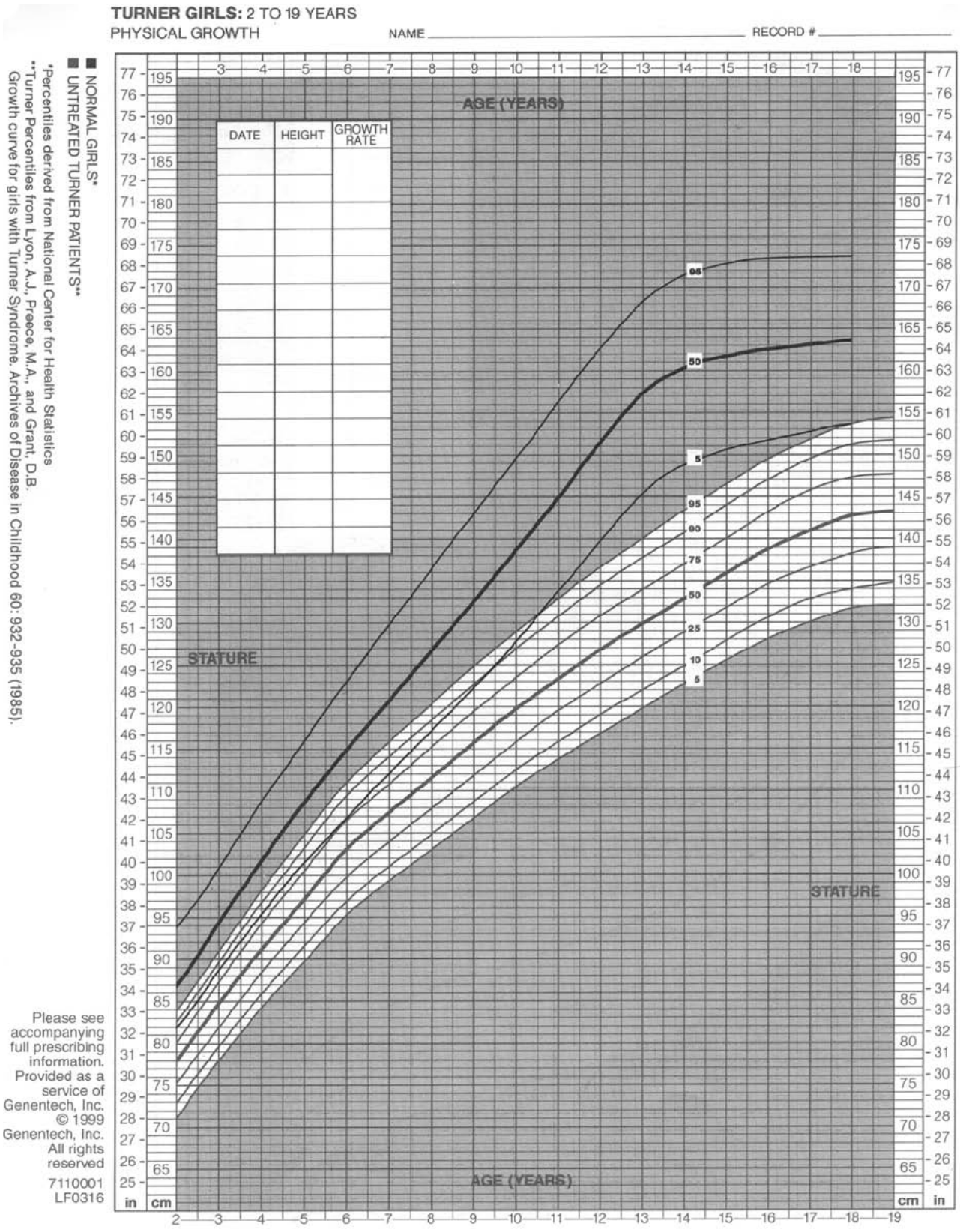
FEMALES

Age 3 to Adult



Holm V, et al. Appendix A: Growth charts for Prader-Willi syndrome. In: Greenswag LR, Alexander RD, eds. *Management of Prader-Willi Syndrome*, 2nd ed. The Prader-Willi Syndrome Association. New York: Springer-Verlag. 1995.


Prader-Willi Syndrome Growth Charts
FEMALES
Age 3 to Adult
Height in centimeters
190
180
170
160
150
140
130
120
110
100
90
80
3
5
7
9
11
13
15
17
19
21
23
Age in years
normal female growth


TURNER GIRLS: 2 TO 19 YEARS
PHYSICAL GROWTH
NAME
RECORD #
■ ■ NORMAL GIRLS*
■ UNTREATED TURNER PATIENTS**
*Percentiles derived from National Center for Health Statistics
**Turner Percentiles from Lyon, A.J., Preece, M.A., and Grant, D.B.
Growth curve for girls with Turner Syndrome. Archives of Disease in Childhood 60: 932-935 (1985).
DATE
HEIGHT
GROWTH RATE
AGE (YEARS)
STATURE
95
50
5
95
90
75
50
25
10
5
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7110001
LF0316
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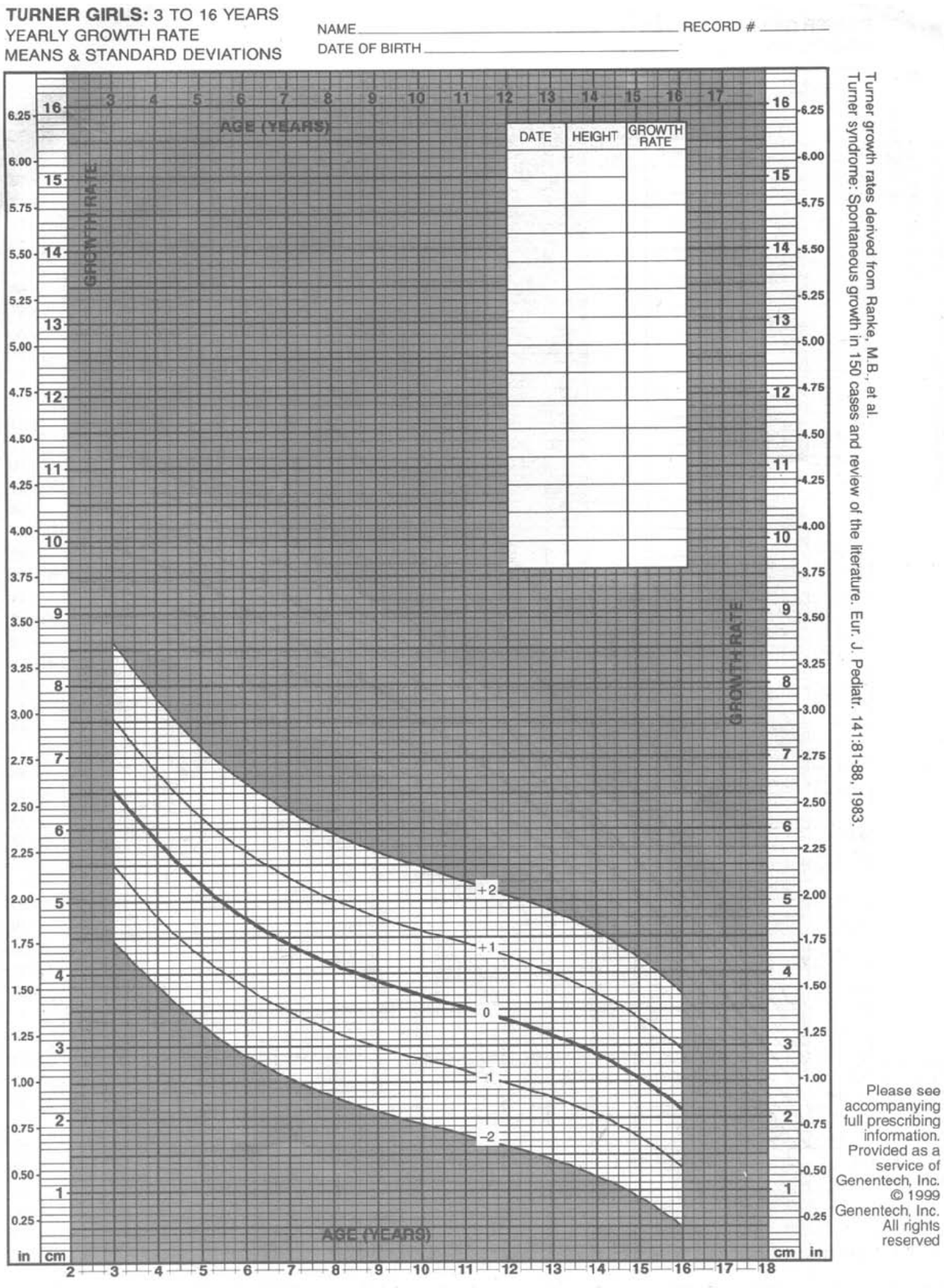
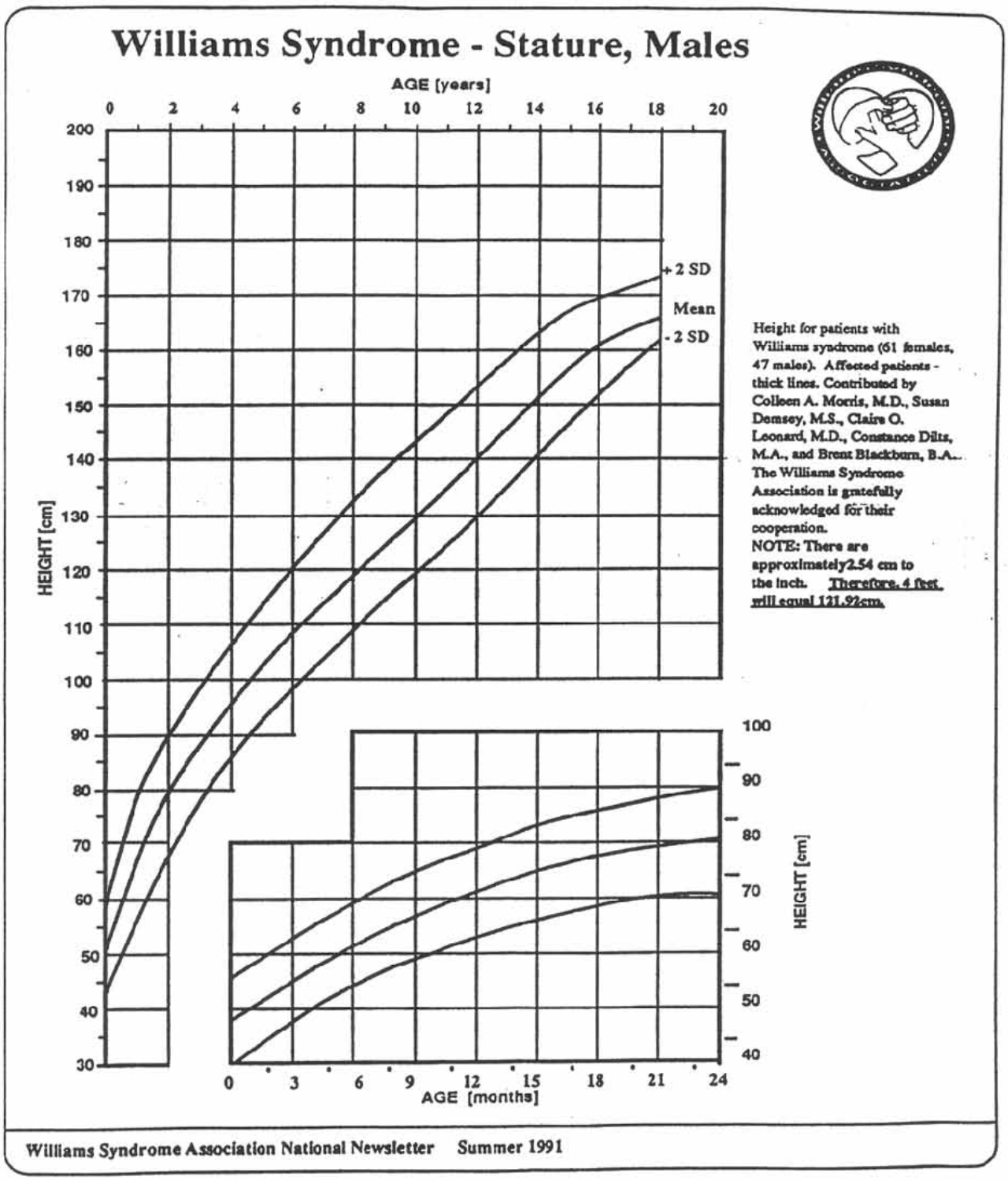
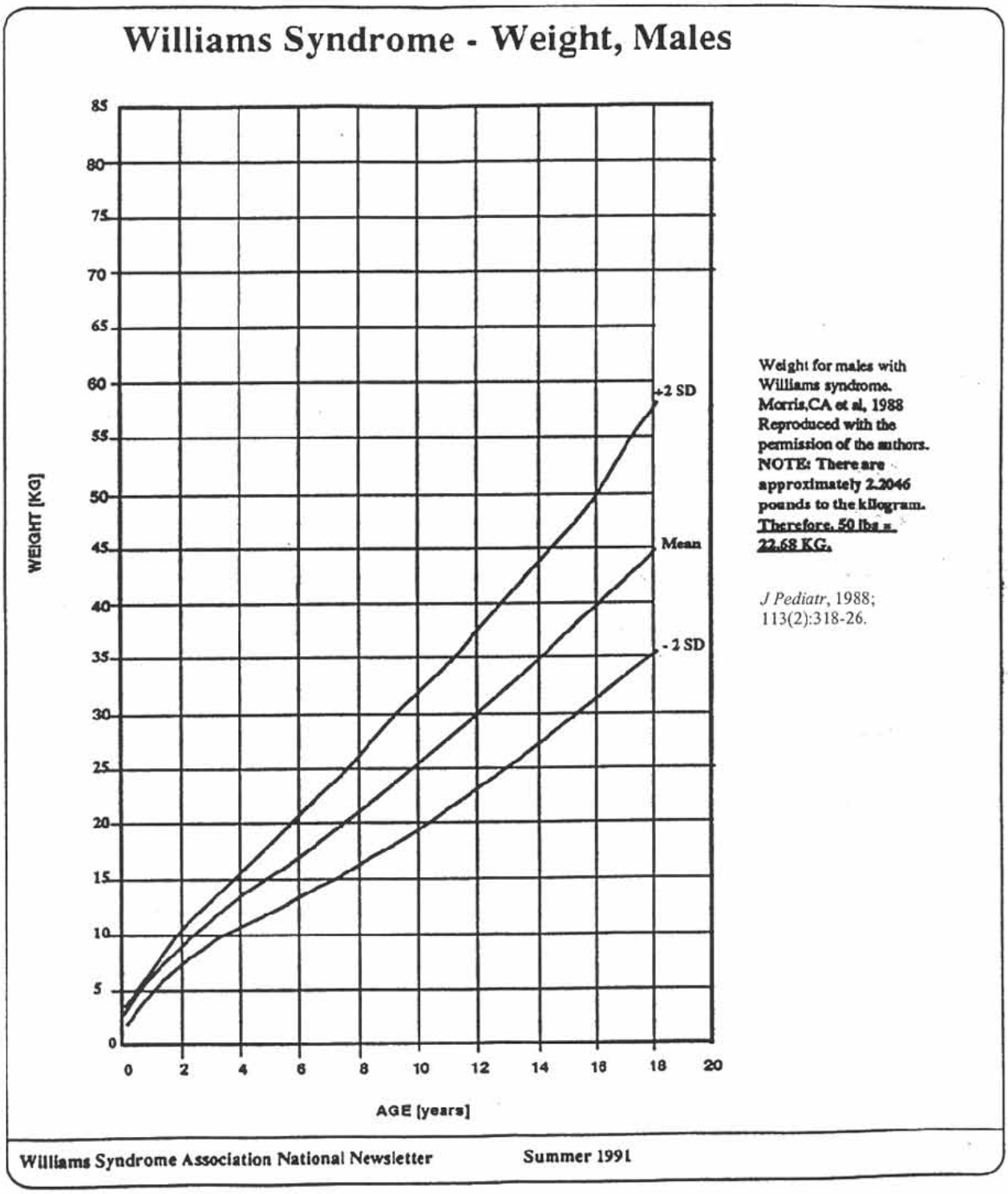
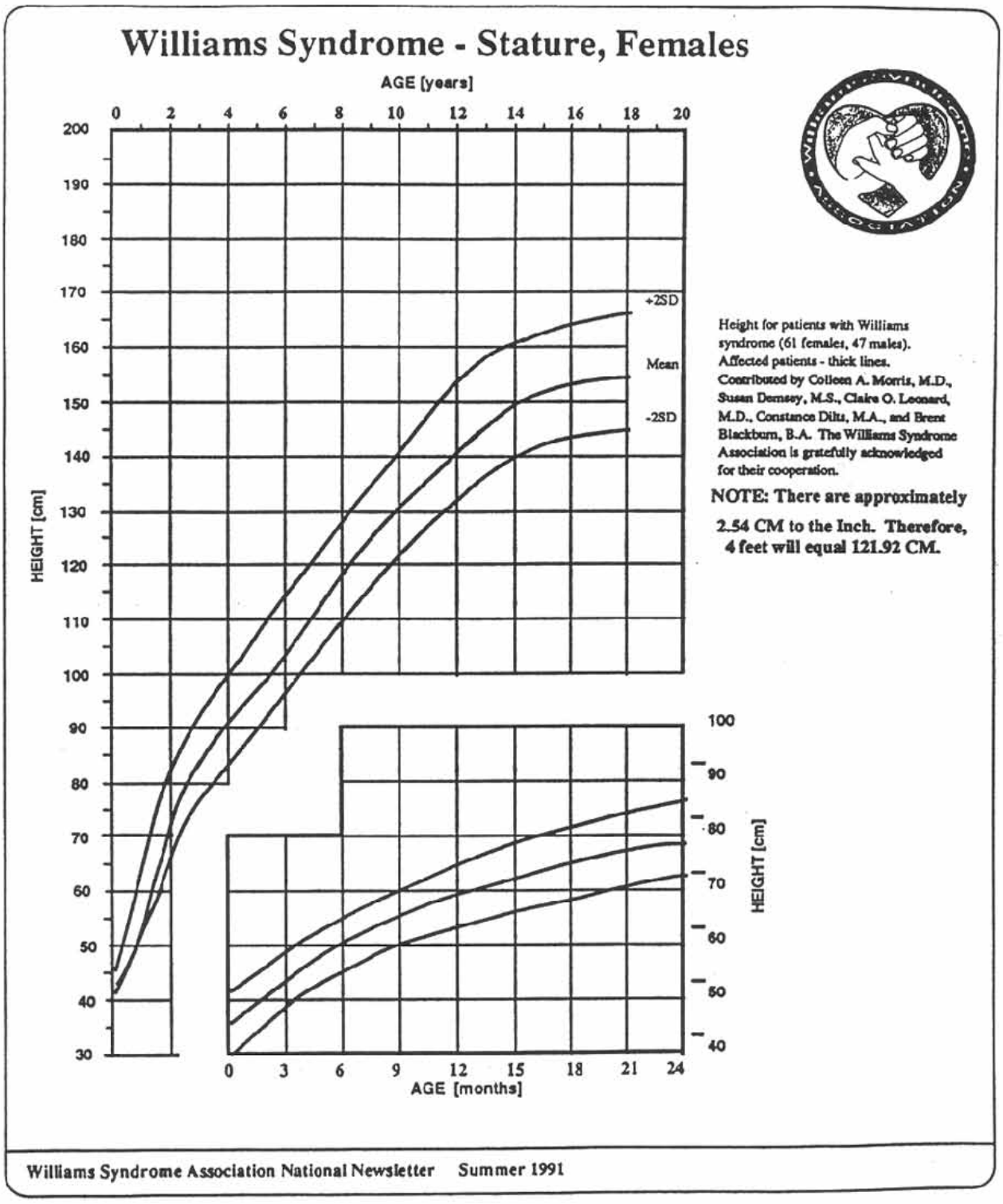


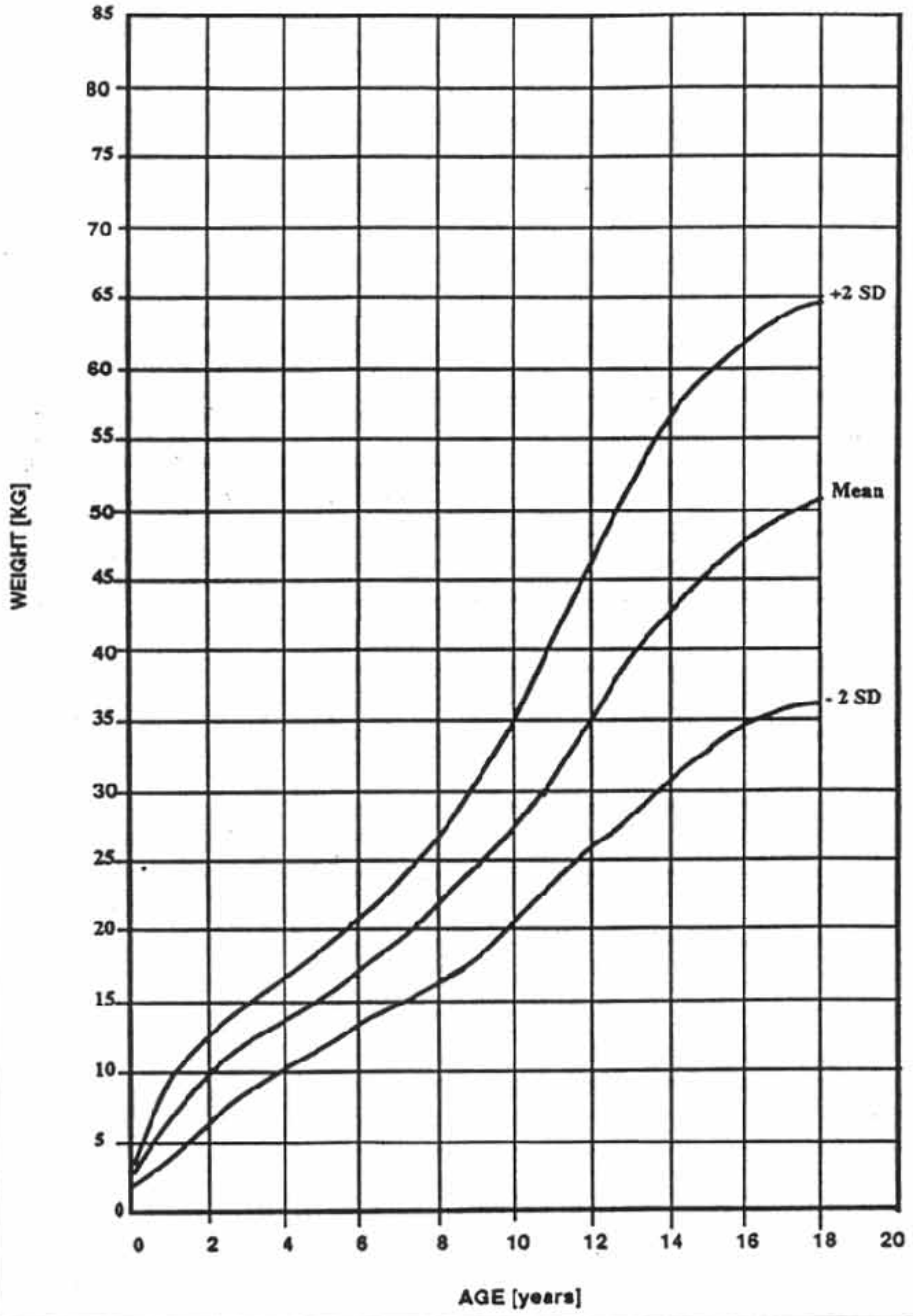
Turner growth rates derived from Ranke, M.B., et al. Turner syndrome: Spontaneous growth in 150 cases and review of the literature. Eur. J. Pediatr. 141:81-88, 1983.


Williams Syndrome - Stature, Males
AGE [years]
0 2 4 6 8 10 12 14 16 18 20
200 190 180 170 160 150 140 130 120 110 100 90 80 70 60 50 40 30
HEIGHT [cm]
+2 SD
Mean
-2 SD
Height for patients with Williams syndrome (61 females, 47 males). Affected patients - thick lines. Contributed by Colleen A. Morris, M.D., Susan Demsey, M.S., Claire O. Leonard, M.D., Constance Dilts, M.A., and Brent Blackburn, B.A.. The Williams Syndrome Association is gratefully acknowledged for their cooperation.
NOTE: There are approximately 2.54 cm to the inch. Therefore, 4 feet will equal 121.92cm.
0 3 6 9 12 15 18 21 24
AGE [months]
100 90 80 70 60 50 40
HEIGHT [cm]
Williams Syndrome Association National Newsletter Summer 1991


Williams Syndrome - Weight, Males
WEIGHT [KG]
85
80
75
70
65
60
55
50
45
40
35
30
25
20
15
10
5
0
0
2
4
6
8
10
12
14
16
18
20
AGE [years]
+2 SD
Mean
- 2 SD
Weight for males with Williams syndrome. Morris,CA et al, 1988 Reproduced with the permission of the authors. NOTE: There are approximately 2.2046 pounds to the kilogram. Therefore, 50 lbs = 22.68 KG.
J Pediatr, 1988; 113(2):318-26.
Williams Syndrome Association National Newsletter
Summer 1991


Williams Syndrome - Stature, Females
AGE [years]
HEIGHT [cm]
+2SD
Mean
-2SD
Height for patients with Williams syndrome (61 females, 47 males). Affected patients - thick lines. Contributed by Colleen A. Morris, M.D., Susan Demsey, M.S., Claire O. Leonard, M.D., Constance Dilts, M.A., and Brent Blackburn, B.A. The Williams Syndrome Association is gratefully acknowledged for their cooperation.
NOTE: There are approximately 2.54 CM to the Inch. Therefore, 4 feet will equal 121.92 CM.
AGE [months]
HEIGHT [cm]
Williams Syndrome Association National Newsletter Summer 1991

Williams Syndrome - Weight, Females



Weight for females with Williams syndrome. Morris,CA et al, 1988 Reproduced with the permission of the authors. NOTE: There are approximately 2.2046 lbs per kilo. Therefore, 50 lbs = 22.68 KG.

J Pediatr, 1988; 113(2):318-26.

Williams Syndrome Association National Newsletter Summer 1991

APPENDIX N

Technical Aspects of Enteral Feeding (Tube Feeding)

Annette Pederson, MS, RD, CD

Types of Enteral Feeding

The types of enteral feedings, or tube feedings, are named according to the feeding route used, the site where the feeding tube enters the body, and the point at which the formula is delivered: nasogastric, nasoduodenal, nasojejunal, gastrostomy, and jejunostomy. The decision as to which type of feeding to use is based on the expected duration of tube feeding as well as physiologic and patient-related factors. The types of tube feeding most commonly used are nasogastric and gastrostomy feedings.

Nasogastric Tube Feeding

The nasogastric (NG) tube is a soft tube that runs through the nose and into the stomach. Nasogastric feedings are typically used when tube feeding will be required for a short time, i.e., less than three months, although in some cases it can be used for several years. The major advantage of nasogastric, nasoduodenal, and nasojejunal feedings is that unlike gastrostomy or jejunostomy feeding, placement does not require surgery. Therefore, they can be started quickly and can be used either for short periods or intermittently with relatively low risk of complication. If the child is safe to feed orally, he can continue to practice feeding skills and improve oral intake.

The disadvantages of NG feeding include nasal or esophageal irritation and discomfort (especially if used long-term), increased mucus secretion, and partial blockage of the nasal airways. Nasogastric feeding may contribute to recurrent otitis media and sinusitis. Two additional disadvantages are the possibility that the tube will perforate the esophagus or the stomach and the possibility that the tube will enter the trachea, delivering formula into the lungs. If formula enters the lungs, severe or fatal pneumonitis can result. Therefore, it is essential to confirm that the NG tube is in the stomach before feeding begins (1,2,3).

Gastrostomy Tube Feeding

A gastrostomy tube places food directly into the stomach. Gastrostomy feedings are preferred as they allow more flexibility with schedule and can mimic normal feeding schedules. These feeding tubes are well suited for long-term enteral feeding. Patient comfort with gastrostomy is an advantage over NG tubes. Gastrostomy tubes do not irritate nasal passages, the esophagus, or the trachea, cause facial skin irritation, or interfere with breathing. The mouth and throat are free for normal feeding if the child is safe to feed orally. There are skin level gastrostomy tubes that are easily hidden under a child's clothing, require less daily care, and interfere less with the child's movement. A gastrostomy with a large-bore tube allows for a more viscous formula and thus a lower risk of tube occlusion. The gastrostomy may be placed surgically. Another alternative is the percutaneous endoscopic gastrostomy, which may be done as an outpatient procedure.

Disadvantages of gastrostomy feeding include the surgery or endoscopy required to place the tube, possible skin irritation or infection around the gastrostomy site, and a slight risk of intra-abdominal leakage resulting in peritonitis. The child with poor gastric emptying, severe reflux or vomiting, or at risk for aspiration may not be a good candidate for a gastric placed tube (1,2,3).

Jejunal Tube Feeding

Jejunal tubes can be placed surgically or via percutaneous endoscopy. Feeding directly into the jejunum (the middle section of the small intestine) is used for children who cannot use their upper gastrointestinal tract because of congenital anomalies, GI surgery, immature or inadequate gastric motility, severe gastric reflux, or a high risk of aspiration. The jejunal tube bypasses the stomach decreasing the risk of gastric reflux and aspiration. If safe to feed, the child can still eat by mouth.

However, even for children with gastric retention and a high risk of aspiration, there are disadvantages to jejunal feeding. Jejunal tubes passed from a gastrostomy to the jejunum and nasojejunal are difficult to position and may dislodge or relocate; their position must be checked by X-ray. A jejunostomy reduces problems of tube position. They usually require continuous drip feeding which results in limited patient mobility and decreased ability to lead a "normal" life. Finally, when compared to gastric feedings, they carry a greater risk of formula intolerance, which may lead to nausea, diarrhea, and cramps. Standard formulas may be given in the small intestine if tolerated, however, elemental or semi-elemental formulas may be required if the child demonstrates formula intolerance (2,4). These elemental formulas are more expensive.

Administration of Tube Feeding: Bolus and Continuous Drip

Tube feedings can be administered as bolus feedings, continuous drip feedings or a combination of the two along with eating orally. The best is a combination of oral and tube feeding that fits into the child/family schedule. Many of the complications of tube feeding arise from improper administration of formula.

Bolus Feeding

Bolus feedings are defined amounts of formula or "meals" delivered four to eight times during the day. Typically, each feeding lasts about 15 to 30 minutes. The advantages of bolus feedings over continuous drip feeding are that bolus feedings are more similar to a normal feeding pattern, more convenient, and less expensive if a pump is not needed. Furthermore, bolus feedings allow freedom of movement, so the child is not tethered to a feeding bag. The parent/caregiver can hold and cuddle the child while feeds are given.

A disadvantage of bolus feedings is that they may be aspirated more easily than continuous drip feedings. For some children, bolus feedings may cause bloating, cramping, nausea and diarrhea. It may not be practical to use bolus feedings with a child when the volume of formula a child needs is large or requires that the child needs to be fed around the clock (4,5).

Continuous Drip Feeding

Continuous drip feedings are a specific amount of formula delivered during a specified time/times during the day. Feeding around the clock is not recommended as this limits a child's mobility and may elevate insulin levels contributing to hypoglycemia. It is common to use drip feedings for 8 to 10 hours overnight with children who cannot tolerate large volumes of formula. This also allows oral feeding to be used during the day. Either gravity drip or infusion pumps deliver continuous drip feeding. The infusion pump is a better method of delivery than gravity drip. The flow rate of gravity drip may be inconsistent and needs to be checked frequently. A child may start out with continuous drip feedings and, as tolerance improves, graduate to bolus feedings or a combination of the two.

Continuous feeding may be better tolerated than bolus feeding by children who are sensitive to volume, are at high risk for aspiration, or have gastroesophageal reflux. Continuous feeding can be administered at night, so it will not interfere with daytime

activities. When feedings are delivered continuously, stool output is reduced, a consideration for the child with chronic diarrhea. Continuous infusions of elemental formula have been successful in managing infants with necrotizing enterocolitis, short bowel syndrome, intractable diarrhea, and Crohn's disease.

A disadvantage of continuous feeding is that although feedings can be scheduled at night and during naptime, the child is "tied" to the feeding equipment during the infusion. However, there are smaller and lighter pumps available to make life easier for the family. Continuous feeding is more expensive because of the cost of supplies including the pump. Management of a pump and its maintenance may be difficult for some families. Finally, a child's medication needs to be considered, as continuous feeding may interfere with serum concentration of some medications (6,7).

Equipment for Tube Feedings

Feeding Tubes

When choosing a feeding tube, the following factors should be considered: the patient's age and size, the viscosity of the formula to be used, and the possible need for a pump.

Nasogastric tubes

For nasogastric feeding, the smallest bore tube in a soft material will minimize child's discomfort. Large-bore tubes partially block the airways, may interfere with the function of the gastroesophageal sphincter, and may irritate the nose and throat. Tubes size 8 French or smaller are usually used for children. The size refers to the outside diameter of the tube; one French unit equals 0.33 mm. Tubes this small cannot accommodate thick or viscous feedings, e.g., homemade blenderized formula or commercial formula containing fiber (1,3,4,5).

Most tubes are made of polyurethane or silicone, both of which remain soft and flexible over time. These tubes are usually weighted at the end for easier insertion. More flexible tubes are difficult to place without using a stylet. Non-weighted tubes may be displaced during gagging, vomiting, or coughing spells; however, they are used regularly and without difficulty for intermittent feedings in newborns.

Gastrostomy tubes

Skin-level gastrostomy feeding devices, such as the Bard® button gastrostomy or the MIC-KEY® button gastrostomy are available. They allow feeding tubes to be attached

only when the child is being fed. These devices are easily hidden under a child's clothes without tubing that extends from stomach. They may be placed surgically or endoscopically in the stomach wall or after a gastrostomy tube has been placed and the stoma site well established. Some gastrostomy tubes have extensions that "lock" into place, so the child is less likely to become disconnected while feeding, e.g., MIC-KEY®. Some parents prefer the flatter fitting tube such as the EndoVive® and Bard®. There are many more gastrostomy tubes available and parents can ask their physician or infusion company for more information. Families should check with their home supply company to determine how many gastrostomy tubes are provided every 6 months. If the child has the balloon gastrostomy tube, e.g., MIC-KEY® or EndoVive®, the parents need to be instructed in what to do if the tube comes out or how to replace with a back up gastrostomy tube.

Pumps

A pump can be helpful in providing a consistent amount of formula to the child, which may improve tolerance. Pumps are designed to be accurate within 10% of the set rate, so determining the accuracy that the patient is actually getting is important. With small infants, a syringe bolus pump will provide more accuracy with a small volume (8).

There are many different enteral infusion pumps, varying in complexity, flow rate, and cost. Pumps can be rented or purchased from a medical supply company. For long-term use, it may be less expensive to buy a pump. When a patient owns a pump he will be responsible for its maintenance, while renting the pump makes the medical supply company responsible for repair and maintenance.

When deciding which type of pump to use, there are various considerations: availability, accuracy, cost, and ease of maintenance. A lightweight, battery operated enteral feeding pump, such as the Zevex Infinity®, will allow the child to attend school or go on outings with formula and equipment fitting neatly into a small backpack. If the child is feed at night only an ambulatory pump may not be needed.

For some families, pumps do not fit into their life. Syringe bolus feeds require less equipment, alarms do not beep in the night, and the syringe bolus feeds may require less instruction time.

Feeding Sets/Extensions

Many of the pumps require specific feeding sets, including a container for the formula and tubing to connect the formula container to the feeding tube. Reuse of feeding sets can help minimize the cost.

After use, the formula container, drip chamber, and tubing should be carefully cleaned. Rinse first with cold water, followed by hot soapy water and then rinse thoroughly to remove the formula residue which can cause bacterial contamination. Using a vinegar or bleach rinse before final water rinse is helpful.

The family needs to know how many extensions, feeding bags and other supplies their insurance company or home infusion company will provide. Usually one feeding bag/day and one connecting tube per week is provided. Families may choose to save money and reuse feeding bags and tubing.

Additional Equipment

To give the child more mobility during continuous feeding, the feeding set can be hung on an IV pole and connected to a long length of tubing. Alternatives are to hang the feeding set on a hook above the bed or crib, on a nail in the wall or bedpost, or on a sturdy lamp or clothes tree. When traveling by car, the pump can be placed on the back seat with the feeding set hanging from the clothes hook. Miscellaneous supplies include syringes, gauze, catheter adapters, and tape.

Nutritional Considerations

In order to determine energy and nutrient needs, nutritional status should be assessed before tube feeding is started. Table N-1 outlines the requirements of normal infants and children for water, energy, and protein; requirements are based on the Dietary Reference Intakes (DRIs). These requirements are useful in formulating tube feedings for children with special health care needs as long as conditions that may alter the child's nutrition needs are taken into account. For example, cardiopulmonary stress may increase energy needs, while decreasing tolerance to fluid volume; infection or the stress from surgery may increase both energy and protein needs; and certain medications may increase the requirement for specific vitamins or minerals. On the other hand, immobility tends to decrease energy needs, and if formula intake is limited calories, there may be deficiencies in protein, vitamins and minerals.

Table N-1: Water, Energy and Protein Requirements for Children[9]

	Water		Energy		Protein	
	cc/kg	cc/lb	kcal/kg	kcal/lb	gm/kg	gm/lb
STEP 1 For first 10 kg or 22 lbs, provide:	100	45	105	48	2.0	0.9
STEP 2 For second 10 kg or 22 lbs, provide:	50	24	50	23	0.9	0.4
STEP 3 For weight over 20 kg or 44 lbs, add to the amount above an additional:	20	10	20	9	0.3	0.2

Energy

The only way to accurately evaluate an individual's energy needs is to regularly monitor weight gain, growth, and actual energy intake. If energy intake is inadequate weight gain will be poor. If energy intake is excessive, weight gain will be higher than that desired for linear growth. Factors that may change energy needs include illness, increased seizures, surgery, increase in therapy or return to school, or changes in medication.

Children who have been chronically underweight while on oral feedings often gain excessive weight when tube feedings are initiated, sometimes to the point of obesity. For these children, two factors may come into play: oral-motor problems that interfere with adequate energy intake by means of oral feeding, and energy needs that are lower than expected. Cases such as these illustrate the necessity of routinely monitoring weight and energy intake in children who are tube-fed, especially after the tube feeding is initiated.

Older children with delayed growth due to inadequate intake may have delayed puberty. With adequate energy provided by tube feeding along with increased body fat, they may begin to experience pubertal growth and body changes into their twenties. These changes need to be assessed when determining energy needs so weight gain is appropriate.

Fluid and Electrolytes

Water must be provided in sufficient quantities to replace fluid losses and allow for normal metabolism. Fluid requirements depend on the following variables: urine output, sweating, vomiting, fever, stool pattern, environment, renal disease, cardiac anomalies, tracheostomies and medications. Constant drooling also contributes to fluid losses. Water requirements can be estimated using Table N-1 as long as the above variables are considered. Indications that fluid intake is not adequate include constipation, decreased urine output, strong smelling or dark urine, crying without tears, dry lips and skin, sunken eyes, weight loss. Symptoms of fluid overload include rapid weight gain, puffy appearance, and rapid or uncomfortable breathing.

Patients who rely on tube feedings as their sole source of nutrients are at risk for electrolyte imbalances, which may result in serious medical complications, e.g., hyponatremia, hypernatremia, hypokalemia, hyperkalemia, dehydration, and cardiac arrhythmias. Sodium, potassium, and chloride status should be evaluated regularly (4,5). The DRIs/RDAs provide guidelines for a safe and adequate intake of electrolytes.

Vitamins and Minerals

To determine vitamin and mineral needs, the DRIs/RDAs for age can be used as a base, unless the child's growth is markedly delayed. For the child with growth delay, the DRIs/RDAs for height age can be used. Children with inadequate energy intakes, decreased absorption, and increased energy needs should be evaluated for supplemental vitamins and minerals.

Vitamin and mineral requirements can be altered by medications (See Chapter 5). Other variables to consider are disease, previous medical and dietary history and biochemical parameters.

Minerals that require special attention are calcium, phosphorus and iron; these are usually not adequate in commercial tube feeding formulas at the energy levels required by many children. Supplemental vitamins and minerals can be given with feedings in the form of a liquid multivitamin with iron or a crushed chewable multiple vitamin/mineral tablet appropriate for age. Children on long-term enteral support are at risk for trace mineral deficiencies. The risk of developing nutrient deficiencies increases with frequent vomiting or gastrointestinal disturbances. Children on long-term tube feedings need to be evaluated for fluoride intake and may need to be supplemented. This will require a prescription from the child's physician or dentist.

Children with cystic fibrosis or anomalies of the distal ileum and ileocecal valve may fail to absorb fat-soluble vitamins or to reabsorb bile salts (See Chapters 17 and 20).

Formulas

A wide variety of commercial formulas are available for tube feeding. See Appendix S for information about the various commercial nutrition products and formulas. Formula selection should be individualized, based on nutrients and fluid requirements, gastrointestinal function and reimbursement coverage.

Standard infant formulas (or specialized infant formulas, if needed) can be given via tube. Pediatric enteral formulas are designed specifically to meet the nutrient requirements of most children 1-10 years of age. These formulas are complete and balanced, i.e., about 1000-1300 ml will meet 100% of the DRI/RDA for vitamins and minerals. These formulas are isotonic and easily tolerated by most children. There are disease specific formulas that may or may not meet pediatric nutrition needs. An adult formula may be used for the older child, however the adult formula may not meet the child's vitamin and mineral needs. The protein and fiber content of adult formulas are higher than a child may require, so special attention is needed to make sure a child receives adequate fluid. One formula may not meet all the needs of a child; 2 or more different formulas may be needed to individualize a specific nutrition plan. When selecting an appropriate formula, the factors to consider include the following:

- Age and medical condition
- Nutrient requirements and goals
- History of food intolerance or allergy
- Intestinal function
- Route of delivery
- Formula characteristics, e.g., osmolality, viscosity, nutrient content, convenience and cost
- Availability of product

The osmolality of a formula has a direct influence on the gastrointestinal (GI) side effects that occur with enteral feeding. Osmolality refers to the concentration of osmotically active particles per kilogram solution of formula, expressed as mOsm/kg. The osmolality of a formula is affected by the concentration of amino acids, carbohydrates and electrolytes. Formula with a higher osmolality than that of normal body fluids produces an osmotic effect in the stomach and small intestine; this hyperosmolality draws water into the GI tract to dilute the concentration of the formula. An influx of water into the GI tract may cause diarrhea, nausea, cramping, and distention. Isotonic formulas are designed to prevent these problems. The

osmolality of full-strength isotonic formulas is similar to the osmolality of normal body fluids, approximately 300 mOsm/kg water.

For infants, the volume of formula provided can be determined by calculating the amount of formula necessary to meet estimated protein needs. If additional energy is needed, fat and/or carbohydrate can be added, See Appendix T. Water must be provided to meet fluid requirements. Another method to determine formula volume for children is to calculate amount of formula needed to meet energy needs and then add supplements to meet other needs. Try to minimize the addition of supplements, for ease of preparation, improved tolerance and decreased risk of error.

Sometimes parents feel that because enteral formulas are not solid food, they are not feeding their child enough. Parents need reassurance that you will help their child to not be hungry and that nutrient needs can be met by formula alone.

Complete or Standard Formulas

Complete or standard formulas are nutritionally complete and made of complex proteins, fats, carbohydrates, vitamins, and minerals. Complete formulas are designed for patients who have normal digestion, but cannot consume adequate energy and nutrients orally. The advantages of complete formulas are that they have low osmolalities and are lactose-free, easy to use, and sterile. Some complete formulas have added fiber.

Elemental Formulas

Elemental formulas are “predigested” formulas made from amino acids or hydrolyzed protein, simple carbohydrates, and fat in the form of medium chain triglycerides and essential fatty acids. They contain all the essential vitamins and minerals. The major advantages of elemental formulas are that little or no digestion is required, stool volume is low, and the stimulation of bile and pancreatic secretions is minimal. Elemental formulas are hyperosmolar however, and if infused too rapidly, may cause cramping and osmotic diarrhea. They are more expensive than standard formulas and offer no advantage to a child whose gut is intact. Clinical indications for the use of elemental formulas include short gut syndrome, malabsorption syndromes, delayed gastric emptying or gastroesphageal reflux, inflammatory bowel disease, gastrointestinal fistulas, cystic fibrosis, and nonspecific malabsorptive states.

Homemade Blended Formulas

Families often ask about making their own blenderized feedings. This may be a less expensive alternative to formula. Many families want to nourish their child with the same foods the family is eating. A commercial alternative, made from blenderized table foods, i.e., chicken, fruits and vegetables, is available (See Appendix S).

Home blended formulas can be less expensive, but more time is consumed to prepare them. Families need to be aware of their child's dietary needs and restrictions. The RD can help support the family by monitoring growth, hydration, and formula tolerance, and can analyze the formula to insure optimal growth and nutrient intake. Parents should understand food safety, to prevent contamination of the formula. When using a home blended formula, supplements may be necessary to meet nutrient requirements.

Milk or infant formula can serve as a base for the blenderized diet, which can contain a variety of foods. A "recipe" should be made to guide food choices and portions to best meet nutritional needs. If the child is able to take oral feeds by spoon, the remainder can be supplemented via tube. Home-blended formulas are best delivered through a gastrostomy tube because these feedings are viscous and may clog a narrow nasogastric tube.

Easy Blenderized Tube Feeding

3 jars (2.5 oz each) strained baby food meat
3 jars (4 oz) baby vegetables – one should be green leafy, e.g., spinach and one orange, e.g., carrots or squash
3 jars (4 oz) baby fruits
2 tablespoons olive oil or vegetable oil
2.5 cups whole milk
6 tablespoons infant rice cereal
7 tablespoons nonfat dry milk powder
1 tablespoon dark corn syrup

Yield = 1500 cc or 50 oz
Energy = 1500 kcal or 30 kcal/oz
Nutrients
66 grams protein (18% of calories)
67 grams fat (40% of calories)
159 grams carbohydrates (42% of calories)
10 grams fiber

100% of DRI for children ages 1-3 years. NOTE - A liquid vitamin or dissolved children's multiple vitamin/mineral supplement may be needed to meet the DRI's for older children. Use of this recipe should be assessed by your child's physician and RD. Additional recipes and details can be found in "Homemade Blended Formula Handbook" (by MD Klein and SE Morris (10).

Modular Products

Modular formulas or products are not nutritionally complete. They contain specific nutrients, which can be added to commercial or home-prepared formulas. Examples of modular products include the following:

- Fats, used for additional energy; medium-chain triglycerides are fats that do not require bile acids and lipase for digestion and absorption. If the child can digest fats, a simple vegetable oil can be used.
- Readily-digested carbohydrates used for additional energy
- Protein and specific amino acid preparations to increase protein intake

Careful monitoring of modulars is important to insure that all nutrient needs are being met and that the formula is tolerated with the additions. See Appendix S for examples of modular products.

Specialized Formulas

Specialized formulas are available for children with specific needs, such as prematurity, renal failure or inborn errors of metabolism. A physician or RD who is familiar with the products and their particular uses should select the formula.

Additional formula thoughts

The more viscous a formula, the slower it will flow through the tube. This may make it more difficult to gravity feed/bolus feed some formula, so parents may add water to "thin" the formula so it will flow faster. Another alternative would be to use an enteral pump for bolus feeds. Formula that is cold is also more viscous and may cause stomach distress.

When instructing parents on formula use written recipes are very helpful along with making sure parents have appropriate measuring utensils. For example, a soup spoon does not equal a teaspoon. Have the parents demonstrate how they mix the formula. Often what is assumed is being delivered to the child is very different from what is actually given.

Cleanliness is very important in preventing bacterial contamination and formula tolerance. Multiple episodes of diarrhea may be bacterial contamination and not viral illness or formula intolerance. Hang times for sterile formula are 8-12 hours with aseptic handling. If you are using powdered formula, the hang time is 4 hours. Please check with the formula company regarding hang time. The American Dietetic Association has published Infant Feeding Guidelines (11).

Administration of Feeding

Formula delivery will depend on tolerance, volume requirements/limits, safety, and the family's home schedule. What works for a hospital setting may not fit into the child's home, school, therapy, and/or daycare schedule. Compliance often relies on making enteral feeding simple for the family.

Children beginning tube feedings may be started on full strength isotonic formulas, given in small volumes (see recommended rate below). Hypertonic formulas should be started at half strength. Some children who have not had oral or tube feedings for a long period of time or have a history of formula intolerance (such as premature infants or children with short gut syndrome) may require half-strength formula initially, with gradual increases to full strength. In general, if a child needs diluted formula, it is best to increase volume to make sure the child meets fluid needs; then gradually increase concentration. Concentration and volume should not be increased at the same time. Frequent adjustments may be necessary as the child adjusts and as the family schedule changes.

Suggested schedule to initiate enteral feedings (3,4):

- Infants 10 ml/hour
- Child 1-5 years 20 ml/hour
- Child 5-10 years 30 ml/hour
- Child >10 years 50 ml/hour

Advance the delivery rate as tolerated to meet the goal for the child's nutrition needs. Increase volume every 4-12 hours, monitoring carefully for tolerance. Tolerance is defined as absence of diarrhea, abdominal distension, vomiting or gagging. If a child is bolus fed, start feeds at 25% of goal volume increasing as tolerated.

The physician may require that residuals be checked when a tube feeding is initiated or when formula or medications are changed. To check residuals, attach syringe to feeding tube and "pull back" stomach contents. If residuals are greater than 25-50% of previous bolus feeding or 2 times the hourly volume for continuous drip feeding, reduce the feeding to the previous volume and advance at a slower rate. Return residual contents to the stomach.

Monitoring

Monitoring home enteral for children varies greatly. Often enteral supplies and formula are delivered to the home, which may be the only contact between a child,

his family, and the home care provider. Children on enteral feeds are a high-risk group that requires closer monitoring. What works best for the child and family is a team of health professionals who work together. In Washington State, nutrition assessment and monitoring is reimbursable for children with Medicaid services. However, for many children with private insurance, enteral formula or assessments may not be reimbursable benefits because enteral feeding is considered food.

Medications and Tube Feedings

The goal for children on enteral feeds is to optimize nutrition therapy and maximize therapeutic response to medications administered through the feeding tube. Children on enteral feedings often have extensive medication regimens; a benefit of tube feeding is delivery of medication by tube. The child does not refuse to swallow, drool or vomit medication, so he receives all of prescribed medication with better efficacy. Feeding tubes may be a convenient avenue for medications, but some medicine may be incompatible, causing the tube to clog, interact negatively with specific nutrients or affect feeding tolerance. Formula or its components can interfere with the absorption, distribution, metabolism or elimination of medication (see Chapter 5). It is important for the pharmacist and physician to know that the child is receiving medication via his gastrostomy tube. The pharmacist and RD can review his medication list for compatibility with enteral feeds.

Medications should not be added to enteral formulas. Avoid mixing medications together. Each medication should be administered separately. Families should be encouraged to give medicine in a liquid form. Elixirs and suspensions can usually be delivered through the feeding tube without a problem. Simple compressed tablets can be crushed and mixed with water or the formula or added to a syringe with water until they dissolve (about 30-60 minutes). In contrast, syrups are incompatible with tube feedings because they tend to clog the tube unless diluted with water. Solid medicines such as sustained-action tablets or capsules or enteric-coated tablets should not be crushed and delivered through the tube; once crushed, their action may be altered or they may cause gastrointestinal distress. Check with the child's physician for another medication preparation.

Medications are a common case of tube occlusion. To maintain patency of feeding tubes, flush regularly with water, before, after, and in between giving medications. Another common side effect with medications is feeding intolerance or GI discomfort. Review medications to determine when it is best to administer each one. Adjustments to the feeding and medication schedules may be needed to improve tolerance and comfort. Table N-2 covers common tube feeding complications. For more information on medications and drug-nutrient interactions, see Chapter 5.

Daily Care of Tube

Contact health care provider regarding care instructions. See Table N-2 for some common complications of tube feeding.

Before feeding:

- Wash hands with soap and water before feeding
- Gather supplies needed for tube feeding; formula should be at room temperature
- Inspect site for skin irritation or leakage
- Check the tube for inward/outward migration
- Clean site with plain water or simple soap and water in circular motion away from stoma site
- Dry site
- If needed, stabilize tube with gauze and tape

Typical Gastrostomy Feeding

Position child with head higher than stomach, upright, or on his side. An infant seat, high chair or propping with pillow or wedge may be helpful. Check residuals if recommended by physician. Residuals may need to be checked with new tube feedings or when switching to a new formula. Residuals may also be checked if the child appears to be, or complains of nausea/fullness before next feeding. To check residuals, attach syringe to feeding tube and "pull back" stomach contents. Return residual contents to the stomach. If residual is okay, flush tube with 10 cc water (10 cc is typical but may vary based on the child's condition). If residual is greater than 50% of previous feeding, wait one hour and recheck. Return residuals to stomach. If there is still residual, contact MD. If residual is okay, flush tube with 10 cc water.

Bolus feeding

A feeding should take 15-30 minutes. If given too quickly, the child may experience sweating, nausea, vomiting, or diarrhea.

- Syringe: Attach syringe to feeding tube, pour formula into syringe. You may need to push with plunger to start flow and fill tubing. You do not want air in tubing. Connect filled tubing to gastrostomy. Control rate of feeding by raising or lowering syringe. Continue adding formula to syringe until total feeding is given.
- Feeding Bag: Clamp tubing, fill bag and tubing with formula. You may need to squeeze bag to start feeding. Control rate of flow with clamp. Hang bag from IV pole.

- The feeding tube may be left in place, unclamped to allow the child to burp, after about 10-30 minutes. If the child has a button gastrostomy, he will need a decompression tube to vent air. To prevent reflux, the child may need to remain with head elevated 30-60 minutes after feeding.
- After formula and burping are finished, flush tubing with 10-30 cc water. Close tube. Tuck gastrostomy under clothing.
- Wash feeding set with hot, soapy water, rinse well and air dry. Feeding sets may be reused.

Continuous drip

- Clamp tubing on feeding bag and fill with formula. Unclamp tubing and fill drip chamber 1/3 full, then fill remaining tubing with formula to minimize air into stomach and clamp. Thread tubing through pump. Connect to gastrostomy tube. Unclamp feeding tube and start pump. The home care supply company will have instructions on how to use pump. Feedings should not hang for more than 4-8 hours. On hot days, ice can be slipped into the pocket of a feeding bag to keep formula cool.
- Children can be cuddled or held during feeding. Include the child at family mealtimes. To distract the child while feeding or doing skin care, play games or music, tell a story, offer toys, etc. Oral motor stimulation is recommended.
- You may want to secure tube connections with tape so they do not come apart. Securing tube to clothing, out of reach of the child is helpful. Tubing can be tucked under clothing (onesies, overalls, tube tops and bandnets are helpful).
- The feeding tube may be left in place, unclamped to allow the child to burp, after about 10-30 minutes. If the child has a button gastrostomy, he will need a decompression tube to vent air. To prevent reflux, the child may need to remain with head elevated 30- 60 minutes after feeding.
- After formula and burping are finished, flush tubing with 10-30 cc water. Close tube. Tuck gastrostomy under clothing.
- Wash feeding set with hot, soapy water, rinse well and air dry. Feeding sets may be reused.

When to Call the Doctor

- If the skin around the gastrostomy is warm, tender, bright red – larger than a quarter
- If excess puffy red tissue is building up around stoma site or persistent bleeding around stoma site
- If there is excess leaking around stoma site or tube, e.g., soaking 2x2 gauze in <4 hours
- If stomach contents are leaking through button

- If child has persistent vomiting, diarrhea or constipation
- If the feeding tube is blocked and you cannot remove blockage
- If the feeding tube is pulled out
- If the child has a temperature >101°F

Common Pump Problems—Check this list if the pump isn't working correctly

- Did the "START" button get pressed?
- Are the clamps open?
- Is the tubing kinked?
- Is the drip chamber too full or not positioned correctly?
- Is the "Pause" button on?
- Is the feeding tube plugged?
- If none of the above, call home care agency.

Social Concerns with Tube Feeding

An important consideration in tube feeding is the family's ability and willingness to carry out the tube feeding program. Concerns include the availability and cost of equipment and formula, home sanitation and family hygiene, family support systems, and other psychosocial factors. Many families have a difficult time deciding to use a tube for feeding their child. When families are asked about tube feeding, their concerns include finding a caregiver to tube feed their child, public ignorance about tube feeding, planning their social life around feeding schedules, and sadness over depriving their child of the pleasure of eating. Reviewing the benefits of tube feeding and allowing them to talk with other parents may help decrease their anxiety. Insurance coverage for formulas and feeding equipment should be determined before the child is hospitalized for tube placement.

Before the child is discharged from the hospital, the caregiver(s) must be prepared for tube feeding. More than one family member or caregiver should be taught about the tube feeding to ensure continuity of the child's feeding program and to prevent isolation of the primary caregiver. Caregivers should be thoroughly instructed on the following aspects of tube feeding: formula preparation, use and care of equipment, insertion of the tube, stoma care and emergency procedures. The caregivers should be encouraged to keep the following records in a notebook, which they should bring to each clinic visit: formula intake, stooling pattern, activity, behavior, medications, and instructions from medical staff. Identify who will provide formula, supplies, and nutrition follow-up. A home care company can provide feeding supplies and

equipment. The Special Supplemental Nutrition Program for Women, Infants and Children (WIC) may provide some formulas to eligible infants and children.

The caregiver(s) should be contacted daily for the first week the child is home, or until they feel secure with the tube feeding regimen. The follow-up can be provided by home visit, clinic visit or telephone. The caregiver(s) should be given a phone number for 24-hour assistance regarding problems with tube feeding.

Family meals offer important learning experiences for children who are tube fed. It is important for the child to associate the satisfying feeling of fullness with the pleasant time of family meals, including social interactions, good smells and appearance of food. Even if the child does not experience the tastes and textures of oral feeding, the social experience can be provided. This is important if the child is to eventually transition from enteral to oral feeding.

Feeding Behaviors

Negative or atypical feeding behaviors may be present before a child is tube fed and additional behaviors may develop while the child is tube fed. See Chapter 9.

School and Tube Feeding

Children with feeding tubes are eligible for expanded nutrition services in schools through Public Law 99-457 and the Americans with Disabilities Act. Tube feedings can be given as a routine activity at school. This presents understandable concern for educators. A team, including the RD, a special educator, a nurse and the family can help facilitate feeding in the school. The objective is to use the same feeding routine, positioning, and oral-motor stimulation at home and at school. Physician's orders, an individualized education plan (IEP) and instruction on when to call the family or physician may be required. See Chapter 12.

Transition to Oral Feeding

Transition to eating by mouth starts when the tube is first placed. All children on tube feeding require oral stimulation for development of feeding skills. (See Chapter 8) The child may need to "re-learn" that food in his mouth can satisfy hunger plus keep his mouth "awake" and ready to accept foods. Transition is generally most successful when the process involves a team; a team might include a pediatrician, RD, feeding therapist, and a nurse. Successful treatment addresses the following questions:

- Can the child eat safely? How are his oral skills?
- Has the child shown appropriate growth on enteral feedings? Often a child will not show hunger until an appropriate weight for height is reached.
- Has the medical condition for which the child had tube placed been corrected?
- Are the parent and child ready to transition? Do they have the time to devote to transitioning?

A common approach to transition is to begin by promoting the child's recognition of hunger cues. If necessary, "normalize" the feeding schedule to include three large and two to three small bolus feedings each day to resemble meals and snacks. This will help the child to recognize hunger and satiety. To stimulate hunger, caloric intake may need to be decreased by 25% and/or night-time feeds discontinued. Oral intake may be minimal so supplemental feedings are offered via the tube after each meal. As the child is able to consume more food orally, the tube feeding can be decreased. It is important to ensure an adequate fluid intake—continue to meet water needs by tube or orally.

It takes time to change feeding behaviors. The longer a child goes without eating by mouth, the longer it will take to transition to oral feeding. Small steps are important so the child feels that she is in control. The child has the benefit of using the feeding tube to meet nutritional requirements (12).

The tube can be removed when the child can eat an adequate amount of food orally to support growth. It may be prudent to wait until the child demonstrates that he does not lose excessive weight with illness. Weaning from tube feeding is often a time when a child may not be meeting nutrition or hydration needs and will require increased monitoring.

Table N-2: Common Complications of Tube Feeding

Complication	Possible Cause	Intervention
Nausea/Vomiting and Diarrhea	Rapid administration of feeding	• For continuous drip feeding, return infusion rate to previous tolerated level, then gradually increase rate • For bolus feeding, increase length of time for feeding; allow short break during feeding; offer smaller and more frequent feedings
	Hyperosmolar solution (energy-dense and/or high protein formulas)	• Switch to isotonic formula • Dilute current formula to isotonic, and gradually increase to full strength • Check that formula is mixed properly • Avoid adding other foods to formula, i.e. baby food, powdered formula
	Medication	• Do not add medication to formula; give between feeding with water or juice • Medications that may cause diarrhea include antibiotics, GI neurologic stimulants, beta blockers, stool softeners, liquid medications with sorbitol • Review medication profile and make recommendations for changes
	Air in stomach/intestine	• Burp child during feedings or allow for short breaks • Use medication to decrease gas, ie, simethicone • Elevate child's head during feeding and for 30 minutes after meal
	Tube migration from stomach to small intestine	• Pull on tube to reposition against stomach wall
	Cold formula	• Warm formula to room temperature
	Rapid GI transit	• Select fiber enriched formula
	Bacterial contamination	• Refrigerate open cans of formula, keep only as long as manufacturer suggests • Clean tops of formula cans before opening • Hang only a 4 hour amount of formula at a time • Be sure feeding sets are cleaned well
	Allergy / lactose intolerance	• Try a lactose-free formula • Try soy formula; if allergic to soy, try elemental or semi-elemental formula
	Excessive flavorings	• Stop using flavorings
	Excessive fat	• Decrease fat in formula or use MCT oil • Refer to physician

Complication	Possible Cause	Intervention
Constipation*	Inadequate fiber/bulk or fluid	• Try formula with added fiber • Increase water • Supplement with prune juice • Try stool softeners, suppositories or enema, as indicated • Refer to physician
Gastroesophageal reflux	Delayed gastric emptying	• Refer to physician • Recommend medication to stimulate movement of GI tract • Elevate child's head (30-45°) during feeding and for 1 hour after meal • Check for residuals before feeding • Try smaller, more frequent bolus feedings or continuous drip feeding • Consider jejunal feeding
Large residuals	Decreased gastric motility	• Elevate child's head during feeding • Use gastric stimulant to promote gastric emptying • Consider continuous feeds
	Hyperosmolar formula	• Switch to isotonic formula
	Medications	• Do not add medications to formula; give between feeding with water or juice. • Refer to physician
Tube feeding syndrome (dehydration, azotemia, and hypernatremia)	Excessive protein intake with inadequate fluid intake	• Refer to physician • Decrease protein • Increase fluids. Monitor fluid intake and output
Hyponatremia	Inadequate serum sodium may be related to excessive water intake, excessive fluid loss (e.g., vomiting and/ or diarrhea), medications, tracheostomies, or fluid retention related to renal or cardiac problems	• Refer to physician • Replace sodium losses • Restrict fluids

Complication	Possible Cause	Intervention
Clogged feeding tube	• Formula residue or coagulated protein • Inadequate flushing of tube • Medication	• Use correct formula • Flush tubes with water after giving formula or medication • Flush every 3-4 hours with continuous drip feeds • Do not mix formula with medication • Irrigate with air, using syringe • Gently "milk" tubing • Dissolve ¼ tsp. meat tenderizer in 10 cc water and flush to dissolve clot • Replace tube
Leakage of gastric contents	• Improper positioning • Tube migration • Increased size of stoma	• Place child upright for feeding • Make sure gastrostomy tube is firmly in place • Stabilize tube with gauze pads, adjust crosspiece • If stoma is too large for tube, insert new tube • Keep skin around stoma clean and dry; use protective ointments and gauze • If leaking out of button gastrostomy, may need to replace device • Refer to physician
Bleeding around stoma	• Excessive movement or pressure on tubing	• A small amount of bleeding is normal • Tape tube securely in place to avoid irritation from movement • Secure tube under child's clothing • Refer to physician
Infection of stoma	• Gastric leakage around tube • Stoma site not kept clean • Allergic reaction to soap	• Correct cause of leakage • Carefully cleanse and protect stoma • If stoma site is irritated, use plain water or change soap used • Refer to physician for culture and medication
Granulation tissue	• Body rejecting foreign body • Poorly fitting tube causing friction • Use of antiseizure medication such as Dilantin	• Keep area clean and dry • Adjust snugness of PEG tube with crosspiece • Stabilize tube using tape, bandnet, ace bandage, tube top • Prevent child from pulling on tube • Apply silver nitrate as directed by physician

* See Chapter 6.

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   NOTE – A process was described for updates of these guidelines in *J Parenter Enteral Nutr*. 2009; 33:255-259. Future updated guidelines will be published as separate chapters and will be available at the A.S.P.E.N. website (www.nutritioncare.org) with access to all.

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APPENDIX O

Technical Aspects of Home Parenteral Nutrition

Kathryn L. Hunt, RD, CD

The American Society of Enteral and Parenteral Nutrition (ASPEN) defines parenteral nutrition (PN) as nutrients provided intravenously. The most commonly used solutions are a combination of dextrose (carbohydrate), amino acids (protein), and fat (lipids). Parenteral nutrition can refer to all three components or the components dextrose and amino acids only. This section describes methods used to determine the components of a parenteral nutrition solution.

Fluid

The initial step in determining the PN solution is the estimation of the patient's fluid needs. General guidelines for fluid management of PN in older infants and children are outlined in Table O-1 (1).

Infants on PN often have increased energy needs due to the natural demands of growth combined with the stress of illness. PN solutions providing "maintenance" levels of fluid may not meet such energy needs and may be too hypertonic. For example, infants with illness or under stress often need between 135-150 mL/kg/day of total fluid to adequately meet their energy needs for growth. Therefore, fluid volumes may be administered in excess of maintenance calculations and then macronutrients may be increased until the solution reaches the desired energy goal.

Table O-1: Estimating Fluid Requirements: Older infant/child

Child's weight (kg)	Fluid Requirements Per Day
0-10 kg	100 ml/kg/day (infants may need up to 135-150 mL/kg/d)
10-20 kg	1000 ml + (50 ml/kg for every kg between 10-20 kg)
>20 kg	1500 ml + (20 ml/kg for every kg > 20)
>40 kg	1500 ml per M2 body surface area

Some conditions increase fluids needs:

- Fever (any degree of fever above normal (37.0-37.4 C) needs immediate medical attention. Fevers are often indicators of line sepsis.)
- Hypermetabolism
- Diarrhea (high ostomy outputs)

Some conditions decrease fluid needs:

- Heart disease
- Renal failure with low urine output

Energy

Parenteral energy needs vary depending upon the activity and stress of the individual child. Because PN requires less energy for digestion and absorption, energy needs may be up to 15 % lower in stable (renourished and not stressed), parentally fed children than for those who are fed enterally. Conversely, an individual's energy needs may be higher than the DRIs during periods of catch-up growth, hypermetabolism, and illness (2,3).

The dietitian must monitor the child's rate of weight gain to ensure appropriate growth. Only by tracking monthly plots on the child's growth chart can the dietitian determine whether to increase energy to maintain the growth pattern or decrease calories to prevent excessive weight gain.

Other Nutrients

Amino acids (AA) provide 4 kcal/g and should provide 6-16% of total energy depending upon the child's energy needs and disease state. For infants and children, AA are typically started at 1.5 g/kg/day and increased by 0.5 g/kg/d increments until the final protein goal is reached (2).

Intravenous (IV) lipids provide a concentrated, isotonic source of energy by which fat is used to supply approximately 30-40% of the child's total calories. The minimum amount of lipid required to prevent essential fatty acid deficiency is 4 – 8% of total calories, while the maximum amount of lipid that may be administered is 60% of total calories. Such IV lipids are available as 20% or 10% emulsions. 20% emulsions provide 2 kcal/ml and is the exclusive solution used in pediatric PN. 10% emulsions are no longer used in the pediatric population due to increased phospholipid content and inferior clearance.

Carbohydrate (dextrose) is typically the major source of non-protein energy and provides 3.4 kcal/g. In general dextrose should provide 40-50% of total energy (3).

Electrolytes and minerals are adjusted in PN solutions based on serum lab values. The team managing the child's PN solution will determine the amounts of electrolytes and minerals to be included in the solution.

Vitamins are added to each bag of PN solution prior to administration. The PN solution is clear until the vitamins are added; the vitamins change the color of the PN solution to yellow. Recommended parenteral vitamin and mineral intake levels are provided in Tables O-2 and O-3 (4).

Trace elements included in the PN solution will vary, depending on the child's age, size, and medical condition. For example, patients with large stool and ostomy outputs may require additional zinc. Again, in general, children are not discharged from the hospital until their medical conditions are stable and PN solutions are firmly established. Recommended trace element intake levels are provided in Table O-4 (4).

Table O-2: Recommended Parenteral Vitamin Intakes for Term Infants and Children[1,4]

Nutrient	Recommended intake
Vitamin A (µg RE/d)	700
Vitamin E (mg α-tocopherol/d)	7
Vitamin K (µg/d)	200
Vitamin D (IU/d)	400
Ascorbic acid (mg/d)	80
Thiamin (mg/d)	1.2
Riboflavin (mg/d)	1.4
Pyridoxine (mg/d)	1.0
Niacin (mg/d)	17
Pantothenate (mg/d)	5
Biotin (µg/d)	20
Folate (µg/d)	140
Vitamin B12 (µg/d)	1.0

Table O-3: Recommended Parenteral Mineral Intakes for Term Infants and Children[4]

Nutrient	Term infants: recommended intake (mg/L)	Children >1 year: recommended intake (mg/L)
Calcium	500-600	200-400
Phosphorus	400-450	150-300
Magnesium	50-70	50-70

Table O-4: Recommended Parenteral Trace Element Intakes for Term Infants and Children [1,4]

Nutrient	Term infants: recommended intake (μg/kg^{-1}/d)	Children: recommended intake (μg/kg^{-1}/d)
Zinc	250 < 3 mos	50
	100 >3 mos	
Copper	20	20
Selenium	2.0	2.0
Chromium	0.20	0.20
Manganese	1.0	1.0
Molybdenum	0.25	0.25
Iodide	1.0	1.0

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NOTE – A process was described for updates of these guidelines in *J Parenter Enteral Nutr*. 2009; 33:255-259. Future updated guidelines will be published as separate chapters and will be available at the A.S.P.E.N. website (www.nutritioncare.org) with access to all.

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APPENDIX P

Diet Order for Meals at School

Student's name _____ Age _____ Grade _____

Disability _____

Major life activity affected _____

or

Nondisabling medical condition _____

Diet Order (check all that apply):

- ☐ Increased calorie #kcal
- ☐ Decreased calorie #kcal
- ☐ PKU
- ☐ Food allergy
- ☐ Other: _____

Texture Modification

- ☐ Chopped
- ☐ Ground
- ☐ Pureed
- ☐ Liquified
- ☐ Tube feeding
  - ☐ Liquified Meal
  - ☐ Formula _____ type

Foods to Omit	Foods to Substitute

I certify that the above-named student needs special school meals prepared as described above because of the student's disability or chronic medical condition.

_____Physician or recognized medical authority signature (circle)

Office phone number _____ Date _____

(Child Nutrition Services 10/97)

Diet Prescription for Meals at School

Section 504 of the Rehabilitation Act of 1973 assures handicapped students access to school meal service, even if special meals are needed because of their handicap. If special meals are needed and requested, certification from a medical doctor must:

1. Verify that special meals are needed because of a disability or medical condition

2. Prescribe the modified diet and/or textures allowed

Name of student for whom special meals at school are requested:

_____

Disability or medical condition that requres the student to have a special diet:

_____

_____

Foods Prescribed:_____

_____

_____

Texture Consistency Required:

_____

_____

Feeding Positioning and Assistance:

_____

_____

_____

Other Information Regarding Diet or Feeding (Please provide additional information on the back of this form or attach to this form.)

I certify that the above named student requires special school meals prepared as described above because of the student's disability or chronic medical condition.

_____ _____ _____

Physician/Recognized Medical Authority Signature Office Phone Number Date

APPENDIX Q

IEP Nutrition Related Goals and Objectives

Goals	Considerations for Writing Objectives
1. To develop or refine self-feeding skills	
• finger feeding • use of feeding utensils • use of a cup or glass	• identify special feeding equipment and level of assistance needed for practicing skills
2. To improve oral-motor function related to eating	
• lip closure: on spoon/fork on cup/glass while chewing at rest • tongue movement (within and outside mouth) laterilization, elevation and depression • chewing pattern • suck through straw • bite off piece of food • oral reflexes, hyperactive gag, tongue thrust • oral sensitivity hyposensitive hypersensitive	• consider exercises to facilitate oral-motor function and specify frequency and dureation of the exercises • consider food texture and consistency changes to facilitate improved oral-motor function • identify positive reinforcement for successful attempts
3. To improve mealtime behaviors	
• inappropriate finger feeding • pace • rumination/regurgitation • food acceptance (textures, types or variety of foods) • neatness • feeding posture/position • self-abusive behavior • staying on task • staying at the table	• identify supervision needed for monitoring mealtime behavior • identify presentation of new foods/textures and situations • identify the appropriate mealtime environment • identify positive reinforcement for appropriate behavior
4. To identify and communicate nutrition needs	
• hunger • thirst • food names • food groups • restricted foods • special nutrients (iron rich foods, etc.)	• identify special instruction or learning activities to teach nutritional needs • identify games/exercises for food or nutrient recognition • identify positive reinforcement for correct responses

Goals	Considerations for Writing Objectives
5. To improve food preparation and meal time skills • open can, box, carton package • make sandwhich • make snack • pour, stir, slice, etc. • set table • clear table • clean table, utensils	• identify practice periods and exercises or steps for skill development • identify supervision needed to monitor skill development • identify positive reinforcement for successful attempts
6. To improve growth rates • weight maintenance with continued linear growth • gradual weight loss with continued linear growth • weight gain and linear growth	• identify person(s) responsible for tracking growth • develop a school weight control program • identify dietary supplements and modifications provided by the school and/or the family • identify extra snacks scheduled during the school day • identify positive reinforcers for growth changes
7. To maintain lab data within normal limits* • blood glucose levels (Diabetes) • phenylalanine levels (PKU)	• identify a method to obtain and communicate specific lab values • identify methods of monitoring this data

*These are very specific nutrition goals which may not be appropriate for the school to monitor. However, other goals may be written which relate to this data.
Example: For the child with diabetes, the goal is to decrease episodes of hypoglycemia.

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APPENDIX R

Selected Disorders Affecting Children With Special Health Care Needs

Cristine Trahms, MS, RD, CD, FADA and Beth Ogata, MS, RD, CSP, CD

Many conditions affecting CSHCN are rare, that is, few children are affected by an individual disorder. However, for these children proper management and nutrition intervention is essential for the best possible outcome, health, and well-being. This table lists disorders of children that may be seen by nutritionists in the community and suggests resources that provide more information. Specific diagnoses and intervention (care plan) information should be obtained for each child. In general, the disorders in this table are organized by "cause" or etiology.

Condition	Description	Nutritional Implications/Problems
Chromosomal		
Trisomy 21 (Down syndrome)[1,2]	Extra chromosome 21, mental retardation, short stature, potential cardiac defects	Oral-motor problems, growth problems, weight gain, dental abnormalities, constipation, hypothyroid, hypotonia, macroglossia
Trisomy 18[2]	Extra chromosome 18, severe mental retardation, survival limited	Oral-motor problems, growth problems, seizures, urinary tract infections
Prader-Willi syndrome[1,2]	Maternal uniparental disomy (UPD) or partial deletion of chromosome 15 (paternal), mental retardation, short stature	Initial feeding and growth problems, then obesity, abnormal food-related behaviors
Angelman syndrome[2,3]	Paternal uniparental disomy (UPD) or partial deletion of chromosome 15 (maternal), mental retardation, hyperactivity, unprovoked laughter	Growth problems, abnormal food-related behaviors
Chondrodysplasias, e.g., achondroplasia[2,3]	Short limbed bone dysplasia, short stature	Oral-motor problems, weight gain
Duchenne Muscular Dystrophy[3]	Partial deletion of locus on X chromosome, progressive hereditary disorder of muscle	Constipation, weight gain
Cranio-facial abnormalities, e.g., cleft lip and/or palate[2,3] (can also be part of syndromes)	Abnormality of lip and palate closure	Oral-motor problems, growth problems
Klinefelter syndrome[2,4]	Male, extra X chromosome, relatively long extremities, infertility	Possible oral-motor problems, obesity, dental abnormalities, adult onset diabetes common
Marfan syndrome[2,3]	On chromosome 15, disorder of connective tissue (fibrillin), tall, detached retina, cardiac disease	Growth problems, possible oral-motor problems
Lowe syndrome[3]	Ocular, CNS, amino acid transport defects, renal tubular disease, hypotonia, mental retardation	Growth problems, oral-motor problems
Turner syndrome[4]	Females, only 1 X chromosome, short stature, infertility	Potential for gaining excess weight
Williams syndrome[3]	Partial deletion of chromosome 7, mental retardation, hyperactivity, cardiac defects	Hypercalcemia, early vomiting, growth problems, oral-motor problems, abnormal tooth development

Condition	Description	Nutritional Implications/Problems
Fragile X syndrome[3]	Fragile site on X chromosome, males, mental retardation, hypotonia, hyperactivity common	Possible oral-motor problems, reflux
de Lange syndrome[3]	Etiology unknown, prenatal poor growth, cardiac defects, severe mental retardation, short stature, dysmorphic features	Growth problems, oral-motor problems
Neurodevelopmental		
Cerebral palsy[1]	Chronic, nonprogressive central nervous system dysfunction leading to problems with tone and posture	Growth problems, oral-motor problems, medication-nutrient interactions seizure disorder, constipation
Neural tube defects, e.g., myelomeningocele[1]	Neural tube defect, immobility, frequently associated with hydrocephaly	Constipation, urinary tract infections, excessive weight gain, medication-nutrient interactions
Spinal muscular dystrophy[1]	Progressive hereditary disorder of muscle	Initial growth problems, then obesity, oral-motor problems
Seizure disorders[1]	Neurological disorders, e.g., epilepsy	Medication-nutrient interactions
Autism and autism spectrum disorders[3]	Abnormal social and communication patterns, stereotypic behaviors	Abnormal food-related behaviors, possible nutrient deficiencies
Rett syndrome[3]	Progressive neurological deterioration in females after normal early infancy, seizures, microcephaly	Oral-motor problems, growth problems, air swallowing
Metabolic		
Smith-Lemli-Opitz syndrome[3]	Abnormality in cholesterol metabolism, multiple dysmorphic features, short stature, abnormal facies, psychomotor retardation, genital abnormalities in males	Growth problems, possible cholesterol supplement, oral-motor problems
Phenylketonuria (PKU)[3]	Deficiency in phenylalanine hydroxylase causes↑ phenylalanine and leads to mental retardation	Need to restrict phenylalanine, supplement tyrosine
Organic acidemias, e.g., methylmalonic acidemia, propionic acidemia[3]	Defect in organic acid metabolic pathways, acidosis	Poor growth, restrict protein and substrate, supplement product of enzymatic reaction, L-carnitine, bicitra, compounds to enhance waste ammonia excretion, possibly biotin, vitamin B_6
Urea cycle disorders, e.g., ornithine transcarbamylase, carbamyl-phosphate synthetase deficiency, argininosuccinic aciduria[3]	Abnormality in urea cycle enzymes,↑ NH_3	Growth problems, restrict protein, supplement L-carnitine, L-citrulline, or L-arginine (except argininemia), and prescribe compounds to enhance waste ammonia excretion
Hereditary fructose intolerance, fructose-1,6-bisphosphatase deficiency[3]	Abnormal fructose metabolism, nausea, vomiting, seizures	Restrict/eliminate sucrose, fructose, possible growth problems

Condition	Description	Nutritional Implications/Problems
Galactosemia[3]	Abnormal galactose-1-phosphate uridyl transferase, possible cataracts, liver disease, developmental delay	Restrict galactose, possible growth problems, use soy formula
Maple syrup urine disease[3]	Abnormal oxidative decarboxylation of branched chain keto acids, can lead to mental retardation, seizures, and death	Growth problems, restrict branched chain amino acids, supplement L-carnitine
Homocystinuria[3]	Abnormal cystathionine-β-synthase, possible mental retardation, detached retinas, thromboembolic and cardiac disease	Restrict methionine, protein, supplement cystine, folate, betaine, possibly vitamin B_6
Tyrosinemia, type 1[3]	Abnormal fumarylacetoacetate hydrolase causes liver disease	Restrict tyrosine, phenylalanine, prescribe nitisinone (Orfadin®)
Nephrogenic Diabetes Insipidus[3]	Hereditary non-responsiveness to antidiuretic hormone	Restrict sodium, protein; increased water requirements, provide chlorothiazide, delayed puberty
Ketone Utilization Disorders[3]	Lack of enzyme(s) necessary to process ketones when catabolic, vomiting, dehydration, ↑ ketones in urine	Restrict protein; supplement bicitra, L-carnitine, avoid fasting
Mucopolysaccharidoses, e.g., Hunter, Hurler, San filippo, Morquio syndromes[3]	Cerebral degeneration and storage of mucopolysaccarides	Oral-motor problems, constipation
Fatty Acid Oxidation Disorders (VLCAD, LCAD, MCAD, SCAD)[3*]	Disorder of β-oxidation of fatty acids of specific chain lengths, vomiting, lethargy, hypoglycemia	Possible oral-motor problems, avoid fasting, need for ↑ CHO, L-carnitine, ↓ fat, avoid non-metabolized fatty acids, supplement with MCT oil for VLCAD, LCAD
Glycogen Storage Diseases (Ia, Ib, III, IV)[3]	Defect in one of several enzymes that affect the use and storage of glycogen, ↑ liver size, severe hypoglycemia, ↑ cholesterol, triglycerides, infections in some types	Supplement raw cornstarch, restrict fat, increase complex CHO, avoid lactose, supplement iron, calcium use soy formula, prescribe granulocyte colony stimulating factor(GCSF) (for type Ib)
Sphingolipidoses, e.g., Gaucher, Nieman-Pick, Krabbe, Tay-Sachs diseases[3]	Storage of GM_2 gangliosides, usually cerebral degeneration	Oral-motor problems, constipation
Wilson's disease[1,3]	Abnormal storage of copper leads to renal, cardiac, pancreatic and liver disease and/or central nervous system manifestations	Oral-motor problems, restrict copper intake
Mitochondrial disorders [3]	A heterogenous group of disorders, result of dysfunction of the mitochondrial respiratory chain, muscle, neurological, GI, cardiac problems, poor growth, developmental delay, seizures	Growth problems, oral-motor problems, air swallowing

Condition	Description	Nutritional Implications/Problems
Environmental/ Teratogenic		
Fetal alcohol syndrome	Excessive fetal alcohol exposure, possible developmental delays, short stature, microcephaly, hyperactivity	Possible growth problems, oral-motor problems
Drug affected, e.g., heroin, cocaine[2,3]	Excessive fetal drug exposure, possible developmental delays and behavior problems	Possible growth problems, oral-motor problems
Maternal PKU [2,3]	Excessive fetal phenylalanine exposure, possible developmental delays	Possible growth problems, oral-motor problems
Other		
Cystic fibrosis[2]	Chloride channel abnormalities, chronic and progressive lung disease, pancreatic insufficiency, liver disease	Growth problems, requires pancreatic enzyme replacement therapy, vitamin therapy, CF-related diabetes
Hirschsprung's anomaly [1,3]	Partial or total intestinal obstruction, enterocolitis	Vomiting, distention, constipation alternating with diarrhea
Central diabetes insipidus [1]	Lack of antidiuretic hormone, polyuria, polydipsia	Possible growth problems, dehydration

*VLCAD Deficiency: Very Long Chain Acyl-Coenzyme A Dehydrogenase Deficiency
LCAD Deficiency: Long-Chain Acyl-CoA Dehydrogenase Deficiency
LCHAD Deficiency:Long Chain 3-Hydroxyacyl-CoA Dehydrogenase Deficiency
MCAD Deficiency:Medium Chain Acyl-Coenzyme A Dehydrogenase Deficiency
SCAD Deficiency: Short Chain Acyl-CoA Dehydrogenase Deficiency

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APPENDIX S

Commercial Nutrition Products

Kim Cooperman, MS, RD, CD

This section contains general information about commercial nutrition products. This table does not list products used in the neonatal intensive care unit or for specific metabolic conditions. Manufacturers and contact information are listed at the end of the table. This information was current at the time of this writing, but manufacturing processes change frequently as do products. Contact manufacturers directly for formula preparation instructions and current nutrient content data. Product information is provided for informational purposes only and is not intended to promote specific products. Store brand versions of some formulas are also available. Generally, these products are manufactured by major formula companies. Information about the manufacturer can be found on the label.

Table S-1: Infant Formulas

Product Manufacturer	Energy (kcal/ oz)	Osmolality (mOsm/kg H_2O)	Comments
Human Milk	20	300	Human milk is ideal for healthy full-term infants
Standard Milk-Based Formulas: Standard milk-based formulas generally contain whey and casein, medium and long-chain fatty acids, and lactose. The mineral and electrolyte content varies with the product. The indicated energy and osmolality are based on a standard dilution.			
Enfamil Premium Enfamil Lipil *Mead Johnson*	20	300	General use for full-term infants; with DHA/ARA; Premium contains prebiotic galactooligosaccharides (GOS)
Enfamil AR Enfamil Restful *Mead Johnson*	20	230 (powdered) 240 (liquid)	These are essentially the same product with different names; milk based protein; added rice starch which thickens in an acidic environment; with DHA/ARA; Enfamil Restful only available as powder
Similac Advance Early Shield *Abbott*	20	310	General use for full-term infants; with DHA/ARA , nucleotides, antioxidants and galacto-oligosaccharides (GOS)
Similac Sensitive *Abbott*	20	180	General use for full-term infants; milk-based, lactose free not galactose-free
Similac Sensitive R.S. *Abbott*	20	180	Milk based, lactose free with added rice starch
Similac Organic *Abbott*	20	225	General use for full-term infants; with DHA/ARA and nucleotides
Soy-Based Formulas: Soy-based formulas contain soy protein isolate, long chain fatty acids, and sucrose or glucose polymers. The indicated energy and osmolality are based on a standard dilution.			
Good Start Soy Plus *Nestle*	20	270	Lactose intolerance; lactose-free, not recommended for infants with cow's milk allergy; with DHA/ARA
Similac Isomil Advance *Abbott*	20	200	Lactose intolerance; milk and lactose-free, not recommended for infants with cow's milk allergy; with DHA/ARA

Product Manufacturer	Energy (kcal/ oz)	Osmolality (mOsm/kg H_2O)	Comments
Similac Isomil DF *Abbott*	20	240	Lactose intolerance; contains soy fiber (6 g/L); for infants > 6 months of age and toddlers
Enfamil ProSobee *Mead Johnson*	20	170	Lactose intolerance; milk, lactose free , not recommended for infants with cow's milk allergy; with DHA/ARA
Partially Hydrolyzed Whey-Based Formulas			
Good Start Nourish Plus *Nestle*	20	250	General use with full term infants; hydrolyzed whey protein
Good Start Gentle Plus *Nestle*	20	250	General use with full term infants; hydrolyzed whey protein with DHA and ARA
Good Start Protect Plus *Nestle*	20	250	General use with full term infants; infant formula with bifidus; hydrolyzed whey protein with DHA and ARA
Enfamil Gentlease *Mead Johnson*	20	220	Reduced lactose and partially digested protein
Specialized Formulas: These formulas are modified for infants with problems of digestion and absorption. The indicated energy and osmolality are based on a standard dilution.			
Similac Alimentum *Abbott*	20	370	Hypoallergenic formula for infants sensitive to intact proteins; lactose free; carbohydrate is corn syrup solids; fat is 55% MCT oil; protein is hydrolyzed casein and taurine
Elecare *Abbott*	20-30	20 cal: 350 30 cal: 560	Elemental: Impaired GI function, allergy. Protein from L-amino acids; fat from high-oleic safflower, MCT oil and soy oil; carbohydrate from corn syrup solids EleCare Unflavored and EleCare Unflavored with DHA/ARA appropriate for infants

Product Manufacturer	Energy (kcal/ oz)	Osmolality (mOsm/kg H_2O)	Comments
Nutramigen Nutramigen with Enflora LGG *Mead Johnson*	20	300	Hypoallergenic formula for infants sensitive to intact milk protein; galactose, lactose and, sucrose-free; carbohydrate is corn syrup solids, cornstarch; fat is palm olein, soy, coconut, sunflower oils; protein is hydrolyzed casein; with DHA/ARA; contains probiotic *lactobacillus rhamnosus* (LGG)
Enfamil Nutramigen AA *Mead Johnson*	20	350	Hypoallergenic formula for infants sensitive to intact milk protein; lactose-, sucrose-free; carbohydrate is corn syrup solids, cornstarch; fat is palm olein, soy, coconut, sunflower oils; protein is free amino acids; with DHA/ ARA
Portagen *Mead Johnson*	30	350	Fat malabsorption; fat is MCT and corn oil; milk based
Enfaport *Mead Johnson*	30	280	Chylothorax or Long Chain 3 Hydroxyacyl CoA Dehydrogenase Deficiency; 84% MCT
Pregestimil *Mead Johnson*	20	320 (powder)	Malabsorption, allergy to cow's milk or soy protein; lactose and sucrose free; carbohydrate is corn syrup solids; fat is 55% MCT oil; protein is hydrolyzed casein, amino acids; with DHA/ARA
Similac PM/60/40 *Abbott*	20	280	Renal insufficiency, low-stress initial feeding for low birthweight infants, congestive heart failure; low renal solute load, low phosphorus (Ca:P=2.1), low sodium (16 mg/100mL); low iron; carbohydrate is lactose; protein is whey and casein
Neocate Infant *Nutricia*	20	375	Hypoallergenic, for infants with cow's milk allergy and food protein intolerance; elemental formula; with or without DHA/ARA
Formulas Post Discharge for Premature Infants			
Similac Neosure *Abbott*	22	250	Premature formula for home use until postnatal age of 9 mo
Enfamil Enfacare *Mead Johnson*	22	300 (powder)	Premature formula for home use until postnatal age of 9 mo

Product Manufacturer	Energy (kcal/ oz)	Osmolality (mOsm/kg H_2O)	Comments
Follow-up Formulas: These formulas are alternatives to cow's milk or soy milk; they are fortified with iron.			
Good Start Gentle Plus 2 Good Start Protect Plus 2 Good Start Soy Plus 2 *Nestle*	20 20 20	265 265 180	Intended for infants 9-24 months who are eating solid foods; with DHA/ ARA; Good Start Protect Plus 2 with bifidus
Enfagrow Premium Next Step Enfagrow Soy Next Step *Mead Johnson*	20	270 230	Intended for toddlers 9-24 months; with DHA/ARA
Neocate Nutra *Nutricia*	175 in 36 grams of powder	N/A	Hypoallergenic, amino acid-based semi-solid food containing essential vitamins and minerals to promote balanced nutrition in children and infants over 6 months of age; powder with added water mixes to a spoonable, semi-solid food item
Similac Go and Grow Similac Go and Grow (Soy) *Abbott*	20 20	300 200	Intended for infants and toddlers 9-24 months who are eating solid foods

Table S-2: Pediatric Formulas

Product Manufacturer	Energy (kcal/oz)	Comments
Standard Pediatric Formulas		
Compleat Pediatric Blenderized *Nestle*	30	Lactose-, soy-, and gluten-free; protein from milk and chicken; fat from canola and MCT oils; carbohydrate from corn starch, cranberry juice cocktail juice, pea, green bean and peach puree; contains fruit and vegetable fiber and Benefiber (6 g/900 ml)
PediaSure Nutripals *Abbott*	18.75	Retail beverage. Lactose free with milk and soy protein. Not nutritionally complete
Boost Kid Essential Nestle	30	Protein from casein, whey; fat from canola, MCT, soy oils; carbohydrate from maltodextrin, sucrose; vanilla flavored
PediaSure (with scFOS and DHA) PediaSure with Fiber (with scFOS and DHA PediaSure Enteral Formula PediaSure Enteral Formula with Fiber and scFOS *Abbott*	30	Lactose-free; protein from casein, whey; fat from high-oleic safflower, soy, MCT oils; carbohydrate from maltodextrin and sucrose ; with fiber contains soy fiber (13.5 g/L), enteral fiber soy and oat (8g/L) a osmolality: enteral = 335-345 mosm/kg water, oral = 480-540 mosm/kg water;
Boost Kid Essential 1.5 Boost Kid Essential 1.5 with Fiber *Nestle*	45	Protein from casein, whey; fat from soy, high-oleic, sunflower and MCT oils; carbohydrate from maltodextrin; vanilla flavored; fiber from hydrolyzed guar gum and soy fiber (9 g/L)
Nutren Junior Nutren Junior with Fiber (with prebiotic) *Nestle*	30	50% whey protein concentrate and milk protein; lactose and gluten free; fiber from pea fiber, digofructose; prebiotic inulin

Product Manufacturer	Energy (kcal/oz)	Comments
Specialized Products		
NeoCate One + (Powder) and Neocate E028 Splash (liquid) and Neocate Junior *Nutricia*	30	Elemental: Impaired GI function, cow and soy milk allergy, multiple food protein intolerance. Protein from L-amino acids; fat from coconut, canola and high-oleic safflower oils; carbohydrate from corn syrup solids(powder), maltodextrin, and sucrose (liquid)
Pepdite Junior *Nutricia*	30	Semi-Elemental: Impaired GI function, malabsorption. Protein from hydrolyzed pork and soy (free amino acids and non-dairy hydrolysates); fat from coconut oil, canola and high-oleic safflower oils; carbohydrate from corn syrup solids
Peptamen Junior Peptamen Junior with Prebio Peptamen Junior Fiber (with Prebio) *Nestle*	30	Semi-Elemental: Impaired GI function; protein from hydrolyzed whey; fat from MCT, soy, canola oils; carbohydrate from maltodextrin, cornstarch; Fiber from oligofructose, pea fiber (fiber version only); prebiotic is inulin; Peptamen Junior versions: unflavored, vanilla, chocolate, strawberry. All others: Vanilla
Peptamen Junior 1.5 with Prebio *Nestle*	45	Semi-Elemental: Impaired GI function; protein from hydrolyzed whey; fat from MCT, soy, canola and tuna oil; carbohydrate from maltodextrin, and cornstarch; fiber from oligofructose; prebiotic inulin
Vivonex Pediatric *Nestle*	24	Elemental: Impaired GI function. Protein from L-amino acids; fat from MCT, soy oils; carbohydrate from maltodextrin, modified corn starch
Elecare *Abbott*	20-30	Elemental: Impaired GI function, allergy. Protein from L-amino acids; fat from high-oleic safflower, MCT oil and soy oil; carbohydrate from corn syrup solids EleCare Unflavored and EleCare Unflavored with DHA/ARA appropriate for infants; both of these products and vanilla flavored version appropriate for children 1 year and older
Vital jr. *Abbott*	30	Semi-Elemental: Impaired GI function. Protein from Whey protein hydrolysate and sodium casienate; fat from interesterified canola and MCT oil; carbohydrate from maltodextrin and sucrose; fiber from fructooligosaccharides (3 g/L). Flavors: vanilla and strawberry
Lipistart *Vitaflo*	22-30	Fat malabsorption, long chain fatty acid oxidation disorders, chylothorax; 40% calories from fat ; 30% MCT, 10% LCT. Fractionated coconut oil, soy oil, AA rich oil derived from fungal sources, whey protein isolate; has adequate essential fatty acid; DHA/ARA; for children 12 months to 10 years of age

Table S-3: Modular Products

Product Manufacturer	Energy (kcal)	Comments
Products to Add Protein		
Beneprotein *Nestle*	16.67/Tbsp (3.57 cal/gm)	Protein from whey protein isolate; add to food or formula; 1 Tbsp contains 4 gm protein, 20 mg calcium, 23 mg potassium, 10 mg sodium and 10 mg phosphorus
Protifar *Nutricia*	15 cal/Tbsp (3.73 cal/gm)	Protein from concentrated milk protein. 1 Tbsp contains protein 3.5 gm, sodium 1.2 mg, potassium 2 mg, chloride 4 mg, , calcium 54mg, phosphorus 28 mg, magnesium .8 mg. Contains soy lecithin
Nonfat powdered milk	15/Tbsp	Inexpensive and readily available; 1 Tbsp contains 1.5 g protein, calcium 94 mg, phosphorus 74 mg, magnesium –mg, Vit D--IU; not recommended for infants because of high renal solute load
Complete Amino Acid Mix *Nutricia*	31.16 cal/Tbsp (3.28 cal/gm)	Protein from L-amino acids, essential and non-essential. 1 Tbsp contains 7.8 gm protein
Essential Amino Acid Mix *Nutricia*	28.44 cal/Tbsp 3.16 cal/gm)	Protein from L-amino acids, essential only. 1 Tbsp contains 7.1 gm protein
Arginaid *Nestle*	35 calories per packet (9.2 gm)	Protein from L-arginine. For healing due to burns, surgery or chronic wounds. Per packet: protein 4.5 grams, carbohydrate 4 gm, sodium 70 mg, potassium 10 mg, vitamin C 155 mg, vitamin E 90 IU. Contains phenyalanine
Resource Glutasolve *Nestle*	90 calories per packet (22.5 gm)	For GI injury or disease. Protein from L-glutamine. Carbohydrate from maltodextrin. Per packet: protein 15 gm, carbohydrate 7 grams
Products to Add Fat		
MCT oil *Nestle*	115/Tbsp	Fat malabsorption; contains medium chain triglycerides; does not provide essential fatty acids; does not stay in solution; can be mixed with juices, salads, vegetables, and sauces, used in cooking; may soften or breakdown containers/ utensils made of certain plastics—use metal, glass, or ceramic
Microlipid *Nestle*	67.5/Tbsp	Emulsified fat from safflower oil; stays in solution longer than vegetable oil

Product Manufacturer	Energy (kcal)	Comments
Vegetable oil	120/Tbsp	Less expensive than Microlipid and MCT oil; add to salads, vegetables, sauces, casseroles, hot cereals, and formula
Products to add fat and protein: Benecalorie *Nestle*	330/serving (1.5 oz)	Fat from high oleic sunflower oil, protein from calcium casienate. Each serving provides: protein 7 gm, fat 33 gm, Vitamin C 60 mg, calcium 100 mg, Vitamin E 30 IU, zinc 3.75 mg
Products to Add Carbohydrate		
Corn syrup	57/Tbsp	Provides a concentrated source of carbohydrate
Honey	61/Tbsp	Provides a concentrated source of carbohydrate. Not recommended for children under 1 year of age. Botulism spores have been associated with infant death due to immature GI systems
Polycose Liquid and Powder *Abbott*	23/Tbsp (powder: 3.8 cal/gm) 30/Tbsp (liquid)	Carbohydrate from glucose polymers; low electrolyte level
Polycal *Nutricia*	29/Tbsp (3.84 cal/gm)	Carbohydrate from maltodextrin
Products to add carbohydrate and fat Duocal *Nutricia*	42/Tbsp (5 cal/gm)	Carbohydrate from hydrolyzed cornstarch; fat from corn, coconut, MCT, oil. 1 Tbsp provides carbohydrate 6.2 gm; fat 1.9 gm
Specialized Products: These formulas are not nutritionally complete		
PFD 2 (formerly Product 80056) *Mead Johnson*	6.9/Tbsp	Protein/amino acid-free diet powder with fat from soy oil and carbohydrate from corn syrup, sugar, modified cornstarch; vitamins and minerals added
Product 3232A *Mead Johnson*	500/100g	Mono- and disaccharide-free powder; protein hydrolysate formula base for use with added carbohydrate; protein from casein hydrolysate; fat from MCT, corn oils; vitamins and minerals added
Pro-Phree *Abbott*	520/100 g	Protein/amino acid-free with fat from palm, coconut, soy oils; carbohydrate from hydrolyzed cornstarch; vitamins and minerals added

Product Manufacturer	Energy (kcal)	Comments
ProViMin *Abbott*	312/100 g	No added carbohydrate (2.0 g/100 g powder); protein from L-amino acids, casein; fat from coconut oil; vitamins and minerals added
RCF (Ross Carbohydrate Free) *Abbott*	81/100 g	Protein from soy, L-amino acids; fat from high oleic safflower, soy, coconut oils; vitamins and minerals added; concentrated liquid
Thickening Products		
Thick-it *Precision Foods*	15/Tbsp (4 g)	Dysphagia/swallowing disorders; made from modified cornstarch and maltodextrin
Thick-it 2 *Precision Foods*	20/Tbsp (4.8 g)	Dysphagia/swallowing disorders; made from modified cornstarch
Thick & Easy *Hormel Health Labs*	15/Tbsp (4.5 g)	Dysphagia/swallowing disorders; made from modified food starch (maize) and maltodextrin
NutraThik *Hormel Health Labs*	20/Tbsp (5 g)	Dysphagia/swallowing disorders; made from modified food starch and maltodextrin; thickens similary to Thick and Easy but has 19 essential vitamins and minerals added. One tablespoon provides 10% of most nutrients
Resource ThickenUp *Nestle*	15/Tbsp	Dysphagia/swallowing disorders; made from food starch modified (corn)
Simply Thick *Simply Thick, LLC*	0/packet of honey or nectar style	Dysphagia/swallowing disorders; made from water, xanthan gum, citric acid, sodium benzoate (preservative), and potassium sorbate (preservative)
Hydra-aid *Links Medical Products, Inc*	0/packet nectar style 5/packet honey style	Dysphagia/swallowing disorders; made from water, xanthun gum, citric acid, sodium benzoate and potassium sorbate
Rice cereal	10/Tbsp	Thickens liquids; inexpensive
Tapioca	36/Tbsp	Thickens liquids; inexpensive; must be heated to attain thickening properties

Product Manufacturer	Energy (kcal)	Comments
Products to Add Fiber		
UniFiber *Alaven Pharmaceuticals*	4/Tbsp	Powdered product from cellulose, corn syrup solids, xanthan gum; does not form a gel when mixed with liquid; 1 Tbsp contains 3 g fiber
Benefiber, institutional and retail *Nestle*	16/Tbsp (institutional) 20/Tbsp (retail)	Powdered product from guar gum (institutional), wheat dextrin (retail); 1 Tbsp (4 grams) contains 3 grams fiber (institutional), 4.5 grams fiber (retail); also available in juice version
Metamucil *Proctor & Gamble*	14/7 g	Powdered product from psyllium husk; 1 tsp (original texture regular) contains 3.4 grams fiber.

Contact Information

Abbott Laboratories, Ross Products Division
Product information at http://abbottnutrition.com/
1-800- 227-5767; M - F, 8:30 a.m. to 5 p.m. EST:
Columbus, OH

Alaven Pharmaceuticals
Toll free: 888-317-0001 x10122
Product information at http://www.unifiber.com
Marietta, GA 30067

Hormel Health Labs
Product information at http://hormelhealthlabs.com
Savannah, GA
1-800-866-7757

Links Medical Products, Inc
Product information at http://www.linksmed.com
Irvine, CA
1-888-425-1149

Mead Johnson Nutritionals
Product information at http://www.meadjohnson.com
Phone: 812/429-5000; M-F 7:30-4:00, Central Time
Toll Free: 800/BABY-123

Metamucil Products
Proctor and Gamble
Product information at http://www.metamucil.com

Precision Foods (Thick It and Thick It 2)
Toll Free: 800/442-5242 x258
Product information at http://www.thickitretail.com
St Louis, MO

Nestle Nutrition
Product information at http://nestlenutrition.com/us
Toll Free: 800/422-ASK2 (2752)
Minnetonka, MN

Nutricia International, North America
Product information at http://www.nutricia-na.com
Toll Free: 800-365-7354
Gaithersburg, MD

Vitaflo USA
Product information at http://www.vitaflousa.com
1-888-VITAFLO
Huntington, NY

APPENDIX T

Increasing Energy Density of Infant Formula

Lori Brizee, MS, RD, CSP, LD
Updated by Susan Casey, RD, CD

General Considerations

It is generally safe to concentrate infant formulas to 24 kcal/oz (0.8 kcal/mL) and to add modular carbohydrate and/or fat products to increase up to 30 kcal/oz (1 kcal/mL). Modular products are used to increase energy content of formula. It is very important that addition of energy sources does not over "dilute" the protein, vitamin, and mineral concentrations of formula. For example:

> An infant with a fluid restriction of 120mL/kg, given a standard infant formula concentrated to 24 kcal/oz, and further fortified with carbohydrate and fat to 30 kcal/oz, will receive 120 kcal/kg, but only 2.0 g protein/kg (goal is 120 kcal/kg and 2.2-3.0 gm protein/kg). By concentrating the formula to 28 kcal/oz, and adding carbohydrate to 30 kcal/oz, the infant will receive 120 kcal/kg and 2.3 g protein/kg in 120 mL formula/kg.

Whenever formula concentration is increased, an infant should be monitored regularly to ensure tolerance of formula and adequacy of hydration, as well as to determine continued need for more energy dense formula.

A common myth about adding fat is that MCT (medium chain triglyceride) oil is the best product to use. This product is intended for individuals who cannot digest and absorb long chain fats (e.g. with short bowel syndrome). It is also an excellent product for very small premature infants with immature digestive tracts; but by the time these infants are ready to be discharged from the hospital, most are able to tolerate long chain fats quite well. If increased fat is needed, it can be added in the form of Micro-Lipid®†(emulsified safflower oil, regular safflower or corn oil, or Duocal®‡ (carbohydrate and fat). MCT oil is very expensive and is more difficult to mix into formulas than other fat sources.

Powdered Formulas

Accuracy in measuring powdered formulas is a major concern, especially when altering energy density. Traditionally, powdered infant formulas have been assumed to contain 40 kcal/Tbsp, and many people have assumed that a scoop is equal to 1 Tablespoon. These assumptions are not necessarily true.

Prior to writing these original guidelines in 2001, two clinical dietitians at Seattle Children's Hospital, Seattle, WA, did an informal study to evaluate traditional methods of preparing powdered formulas.

Study Methods

Tablespoons were measured and weighed for 8 different formulas. Cups and scoops were measured and weighed for 6 of these formulas. Measurements were done using Good Cook® plastic measuring tablespoons and cups, and the scoops included in the formula cans. Weights were done on a pharmacy scale (accurate to 0.0001 gram) and were recorded to the nearest 0.1 gram. The formulas measured were Similac with Iron,®* Similac Neosure,®* Isomil,®* Similac PM 60/40,®* Enfamil with Iron,®† Prosobee,®† Pregestimil,®† and Nutramigen.®† Five measurements were done for each formula using a tablespoon or a scoop, and three measurements were done with a cup. Formula powders were measured "packed" or "not packed" according to manufacturers' directions. The average tablespoon, cup and scoop weight of each formula was used to calculate kcal/Tbsp and kcal/scoop.

Results

The weight of a tablespoon of formula varied by 5-10% for each formula and that of a scoop varied by 3-10% for each formula. The weights of a cup of formula varied by <5% for each formula. The average energy value of 1 Tbsp of formula, measured with a measuring tablespoon, varied from 33.0 to 43.8 kcal. The average energy value of 1 Tbsp formula, measured with a measuring cup, varied from 30.3 to 40.2 kcal/Tbsp. The average energy value of one scoop of formula varied from 40.5 to 50.9 kcal.

*Abbott
†Mead Johnson
‡Nutricia

Conclusions

Assumptions that one tablespoon of infant formula is equal to a scoop and that each contains 40 kcal are not true. Depending on how we prepare "20 kcal/oz" formula, we can get anywhere from 15.2 to 22.8 kcal/oz. (Possible methods of preparation: 1 scoop added to 2 oz of water to make 2.2 oz, or 1 tablespoon plus water to make 2 oz, or 1 cup + water to make 32 oz.) This is not an issue for healthy, normally growing infants, but it could be an issue for infants who have atypical growth and/or who need altered formulas.

Recommendations

When accuracy in measurement is imperative, liquid concentrate formulas are the first choice; if powders must be used, they should be weighed on a gram scale, accurate to the nearest 0.5 gram. Energy value of 1 gram of formula should be calculated by taking the total energy value for 1 can of formula (total ounces formula made per can x kcal/oz = total energy value for 1 can of formula) and divide by the grams formula powder in the can.

> For example: A 400 g can Similac with Iron® Powder makes 105 oz of 20 kcal/oz formula. 105 oz x 20 kcal/oz = 2100 kcal/can; 2100 kcal/400gm = 5.25 kcal/gm formula powder.

If powders must be used, and a scale is not available, use the instructions given by the formula producer to increase the energy density of formula. Most formula manufacturers have written instructions for making altered caloric concentrations of their formulas. Contact the formula company representatives for this information (provided on formula containers; some contact information is provided in Appendix S).

Guidelines for increasing the energy density of liquid concentrate formulas are provided in Table T-1.

Table T-1: Liquid Concentrate Formulas

This table provides guidelines for concentrating liquid concentrate formula up to 24 kcal/oz (0.8 kcal/mL) and using modular components to increase up to 30 kcal/oz. Other modular products are available; this table is not comprehensive.

Liquid Concentrate Formula	20 kcal/oz	22kcal/oz	24 kcal/oz	26 kcal/oz	28 kcal/oz	30 kcal/oz
13 oz (390 mL) can liquid concentrate 1 oz = 40 kcal 1mL=1.34 kcal 1can=520 kcal	13 oz 520 kcal	13 oz 520 kcal	13 oz 520 kcal	13 oz 520 kcal	13 oz 520 kcal	13 oz 520 kcal
Water: Fluid ounces 1 oz = 30 mL Milliliters (mL)	13 oz (390 mL)	10.5 oz (315 mL)	8.5 oz (255 mL)	Add water to get final volume after modular products are added.	Add water to get final volume after modular products are added.	Add water to get final volume after modular products are added.
Polycose (Abbott)® 1 Tbsp=23 kcal (1 gm=3.8 kcal)	----	----	----	1 Tbsp + 2 tsp (10 gm) 38.3 kcal	1 Tbsp + 2 tsp (10 gm) 38.3 kcal	3 Tbsp (18 gm) 69 kcal
Microlipid (Nestle Nutrition)® 1 tsp=22.5 kcal (1 mL=4.5 kcal) OR Vegetable oil 1 tsp=40 kcal (1 mL=8 kcal)	----	----	----	----	2 tsp (10 mL) 45 kcal OR 1 1/8 tsp (6 mL) 45-48 kcal	2 ½ tsp (12.5 mL) 56.25 kcal OR 1 1/2 tsp (7.5 mL) 60 kcal

Liquid Concentrate Formula	20 kcal/oz	22kcal/oz	24 kcal/oz	26 kcal/oz	28 kcal/oz	30 kcal/oz
Final Volume of Formula	26 oz (780 mL)	23. 5 oz (705 mL)	21.5 oz (645 mL)	21.5 oz (645 mL)	21.5 oz (645 mL)	21.5 oz (645 mL)
OR instead of above separate CHO and fat products, use: Duocal (Nutricia)® 1tbsp=42 kcal (1 gm=4.92 kcal)				1 Tbsp (42 kcal) **Final volume** = 21 oz (630 mL)	1 Tbsp + 1 ½ tsp (63 kcal) **Final volume** = 21 oz (630 mL)	2 Tbsp (84 kcal) **Final volume** = 20 oz (600 mL)

APPENDIX U

Nutrition Resources

Betty Lucas, MPH, RD, CD and
Beth Ogata, MS, RD, CSP, CD

Children with Special Health Care Needs

NUTRITION FOCUS for Children with Special Health Care Needs. Newsletter published six times annually. Each newsletter focuses on a specific disorder or condition and includes practical strategies and resources for health care professionals. Back issues are available. $38 per year.

Nutrition Focus Newsletter
Center on Human Development and Disability University of Washington
Box 357920
Seattle WA 98195-7920
(206) 685-1297
http://depts.washington.edu/chdd/ucedd/ctu_5/nutritionnews_5.html

C**hildren with Special Health Care Needs: Nutrition Care Handbook.** (2005) Lucas B, ed. Pediatric Nutrition Practice Group and Dietitians in Developmental and Psychiatric Disorders Practice Group of the American Dietetic Association. A 180-page reference for health care professionals monitoring the nutrition care of children with special health care needs. $30.50, plus shipping (ADA Members), $40, plus shipping (non-members)

American Dietetic Association
http://eatright.org/cps/rde/xchg/ada/hs.xsl/shop_1292_ENU_HTML.htm

Self-study Curriculum - Nutrition for Children with Special Health Care Needs. (2008) Pacific West Distance Learning Network. This continuing education activity is designed for RDs and other health care professionals who see children with special health care needs as part of their clinical practices. The curriculum consists of six modules; each module is approved for 1 CEU from the ADA/CDR. It can be accessed free-of-charge; continuing education credits $10 per CEU.

http://depts.washington.edu/pwdlearn/web

Pediatric Nutrition in Chronic Diseases and Developmental Disorders. 2nd Ed. (2005) Ekvall SW, Ekvall VK. Oxford University Press, Inc. A review of growth and nutrition for children with chronic diseases and developmental disabilities. Attention is given to assessment of nutritional status, as well as to diagnosis-specific issues. 532 pages. $99, plus shipping and handling.

Oxford University Press, Inc.
http://www.oup.com/us

Nutrition Strategies for Children with Special Health Care Needs. (1999) Baer MT, Tanaka TL, Blyler EM. A manual developed to assist programs serving children with special health care needs to include nutrition as a provided service. Includes nutrition screening forms; food guidelines for children 0-18 years; and information, strategies, and handouts for various nutrition concerns. $40 (with binder) $30 (without binder), plus $5 shipping and handling. Also available online, as a pdf:

http://uscucedd.org/index.php?option=com_content&view=article&id=82&Itemid=148

Feeding and Nutrition for the Child with Special Needs: Handouts for Parents. (1994) Klein MD and Delaney T. Therapy Skill Builders. A 601-page manual of 195 reproducible handouts on nutrition and feeding issues. Topics include nutrition guidelines, breast and bottle-feeding, introducing food from a spoon, independent feeding, oral-motor treatment strategies, tube feeding, and family mealtime. $104, plus shipping and handling. Item No. 076164332X

Harcourt Assessment, Inc.
(800) 211-8378
http://harcourtassessment.com/haiweb/cultures/en-us/productdetail.htm?pid=076-1643-32X

Pre-Feeding Skills: A Comprehensive Resource for Feeding Development. (2000) Morris S and Klein M. Therapy Skill Builders. A practical manual for feeding assessment and intervention. $79.95, plus shipping and handling. ISBN: 076-1674-071

Harcourt Assessment, Inc.
(800) 211-8378
http://harcourtassessment.com/haiweb/cultures/en-us/productdetail.htm?pid=076-1674-071

Feeding and Swallowing Disorders in Infancy: Assessment and Management. (1992) Wolf LS and Glass RP. Addresses the diagnosis, evaluation, treatment, and follow-up of infants with varying types of feeding dysfunction. $85, plus shipping and handling. Item No. 0761641904

Harcourt Assessment, Inc.
(800) 211-8378
http://harcourtassessment.com/haiweb/cultures/en-us/productdetail.htm?pid=076-1641-904

Handbook for Children with Special Food and Nutrition Needs. (2006) National Food Service Management Institute. Cloud HH, Bomba A, Carithers T, Tidwell D. The purpose of this resource is to identify developmental disabilities and other health care needs that are frequently seen among children served by food service and provide information related to the type of intervention indicated. Regulations related to school food service are reviewed, and resources are included. It is available online as a pdf:

http://www.nfsmi.org/documentLibraryFiles/PDF/20080213015556.pdf

General Pediatric Nutrition

Pediatric Manual of Clinical Dietetics, 2nd ed. (2003) This American Dietetic Association. A nutrition care resource for health care professionals. The manual presents guidelines for nutrition assessment and care for a general pediatric population, as well as for a variety of specific conditions. $105.50 ADA members, $133 non-members.

American Dietetic Association
216 W Jackson Blvd
Chicago, IL 60606-6995
(800) 877-1600 x5000, Fax: (312) 899-4899
http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/shop_1278_ENU_HTML.thm

An update pack for the 2nd edition is also available ($25, ADA members, 32.50, non-members).

http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/shop_14407_ENU_HTML.htm

Handbook of Pediatric Nutrition, 3rd ed. (2005) Samour et al. Jones and Bartlett Publishers A clinical reference manual on pediatric nutrition for the health care practitioner. Provides an overview of normal growth and nutrition needs for infants to adolescents and addresses therapeutic issues for a variety of chronic and acute conditions. 750 pages. $95.95 plus shipping and handling.

http://www.jbpub.com/

Bright Futures in Practice: Nutrition, 2nd edition (2002). Story M, Holt K, Sofka D, eds., National Center for Education in Maternal and Child Health. The nutrition guide emphasizes prevention and early recognition of nutrition concerns and provides developmentally appropriate nutrition supervision guidelines for infancy through adolescence. The publication is out of print, but pdf files of the material can be downloaded. Additional resources, educational materials, and a pocket guide are also available.

http://www.brightfutures.org/nutrition/

Additional Bright Futures resources are listed on the Bright Futures at Georgetown University website. Links to educational materials, training materials, and other tools related to Bright Futures are listed, including: Social and Emotional Development, Mental Health, Oral Health, and Physical Activity.

http://www.brightfutures.org/georgetown.html

Knowledge Path: Child and Adolescent Nutrition. National Center for Education in Maternal and Child Health (NCEMCH). A selection of current, high-quality resources and tools are compiled on this website. It is aimed at health professionals, program administrators, and researchers.

http://www.mchlibrary.info/KnowledgePaths/kp_childnutr.html

ADA Pocket Guide to Nutrition Assessment. (2008). Leonberg B. American Dietetic Association. This tool is a guide to nutrition assessment and nutrient requirements of infants and children, including screening and risk assessment and assessment of growth, health history and development, diet and feeding, and the family environment. $33 ($25.50 for ADA members), plus shipping.

http://www.eatright.org/cps/rde/xchg/ada/hs.xsl/shop_14406_ENU_HTML.htm

Pediatric Nutrition Handbook, 6th ed. (2009). American Academy of Pediatrics. A reference on the nutritional requirements and the effects of nutrition on the health of infants, children, adolescents, and young adults. $84.95, plus shipping.

American Academy of Pediatrics
http://www.aap.org
www.aap.org/bookstore

How to Get Your Kid to Eat...But Not Too Much. (1987) Ellyn Satter. Bull Publishing. Discusses the impact of child development and parent-child relationships on feeding dynamics from infancy to adolescence. $16.95

Child of Mine, Feeding with Love and Good Sense. (2000) Ellyn Satter. Bull Publishing. A nutrition and feeding reference book for parents of children under six years of age. $16.95

Bull Publishing, (800) 676-2855
http://www.bullpub.com
Also available in most bookstores

Secrets of Feeding a Healthy Family (1999) Ellyn Satter. Kelcy Press. Describes the steps involved in planning and preparing healthy meals and snacks for the entire family. $19.95

Ellyn Satter Associates
4226 Mandan Crescent, Ste. 50
Madison, WI 53711-3062
(800) 808-7976
http://www.ellynsatter.com

GLOSSARY

504 Accommodation Plan	a document outlining the plan for a child who requires health related services (including modified meals) at school, but is not enrolled in a special education program; mandated by the Rehabilitation Act of 1973
Achondroplasia	an inherited problem with the growth of cartilage in the long bones and skull; characterized by short stature
Acromion	the outer part of the scapula; forms the "point of the shoulder" and connects with the collarbone
ADA	Americans with Disability Act, 1990; legislation intended to protect persons with disabilities from discrimination
AGA	(appropriate for gestational age) refers to an infant whose birth weight is between the 10th and 90th percentiles for age
Anthropometry	the science of measuring the human body, including height, weight, and size of different parts; also called "anthropometric measurement"
Antibiotic	a medication that inhibits the growth of microorganisms; used to treat infections
Anticonvulsant	a medication used to prevent or minimize the occurrence or severity of seizures
Antidepressant	a medication that prevents or relieves depression
Anti-inflammatory	a medication that reduces swelling, redness, heat and pain
Antispasmodic	a medication that prevents muscle spasms in certain muscles, including in the digestive system and urinary tract
Arm span	the distance between a child's extended right and left middle fingers, measured across the back; sometimes used as an estimator of stature (length or height)
Applied behavior analysis (ABA)	the science of applying experimentally derived principles of behavior to improve socially significant behavior; identified behaviors are observed and measured, then analyzed, and appropriate interventions are implemented
Aspiration	inspiratory sucking into the lungs of foreign material, including food and liquid
Atonic seizures	seizures characterized by loss of all muscle function

Autism Spectrum Disorders	a broad category of developmental disorders, including Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett's Disorder, and Childhood Disintegrative Disorder; diagnostic criteria include communication problems, ritualistic behaviors, and inappropriate social interaction
Body mass index (BMI)	an indicator of weight and stature proportionality; BMI = weight / height2 (kg/m2)
Bolus feeding	a term used in nutrition support that indicates a feeding administered at one time, typically delivered by gastrostomy or nasogastric tube
BPD	bronchopulmonary dysplasia; a chronic lung disorder that is most common among children who were born prematurely, with low birth weights, and who received prolonged mechanical ventilation; nutritional consequences can include feeding difficulties, slow growth, and increased energy needs
Calipers	an instrument with two hinged jaws used for measuring the thickness or diameter of an object
Catch-up growth	rate of growth that is faster than expected, seen when a child who has experienced stunted growth due to a nutritional insult receives adequate energy and protein
CDC	Centers for Disease Control and Prevention; published CDC Growth Charts: United States 2000 for infants and children 0-36 months and children 2-20 years, with data from NHANES
Cerebral palsy (CP)	a motor nerve disorder caused by injury to the central nervous system; symptoms depend on the area of the brain involved and the severity of the damage; major types include spastic, athetoid, and ataxic quadriplegia or diplegia
Chronic lung disease of infancy (CLD)	a suggested term to describe infants who continue to have significant pulmonary dysfunction at 36 weeks gestational age
Chronic renal failure (CRF)	less than 25% renal function; may be due to congenital anatomical defects, inherited disease, untreated kidney infections, physical trauma or exposure to nephrotoxic chemicals
Chronic renal insufficiency (CRI)	less than 50% renal function; a progressive disorder than can lead to chronic renal failure

Chronological age	the age of an infant stated as the amount of time since birth; also called postnatal age
Congenital heart disease (CHD)	cardiovascular defects that are present at birth; often leads to congestive heart failure; children with CHD are at risk for problems with growth because of increased energy needs and decreased intake and absorption
Constipation	typically characterized as infrequent bowel movements or incomplete emptying of the bowel; symptoms can include a hard stool, straining at stool, a feeling of fullness or pressure, and nausea
Continuous drip feeding	a term used to describe a method of tube feeding where formula is delivered at a constant rate, throughout the day (typically for 20-24 hours per day) or overnight (typically 8-10 hours at night)
Contracture	static muscle shortening resulting from tonic spasm or fibrosis; frequently seen in individuals with cerebral palsy
Corrected age	age from birth, less the number of weeks premature; e.g., an infant born at 32 weeks gestation is born 8 weeks before term; at 12 weeks from birth, this infant's corrected age is 4 weeks.
Crown rump	length between a child's head and buttocks, sometimes used as an estimator of length
Cystic fibrosis (CF)	an inherited disorder of the exocrine glands, primarily the pancreas, pulmonary system, and sweat glands, characterized by abnormally thick luminal secretions
Diarrhea	the sudden increase in frequency and looseness of stools
Diuretic	a medication that promotes the excretion of urine, primarily through effects on the renal system
Down syndrome	trisomy 21; a genetic disorder in which an individual has an extra 21st chromosome; typically characterized by low muscle tone, cardiac problems, GI malformations, and a characteristic facial appearance
DRI	dietary reference intake; reference intakes established by the Institutes of Medicine; include estimated average requirements, recommended dietary allowances, adequate intake levels, and tolerable upper intake levels

Early intervention services	established by Part H of P.L. 97-457 of 1986 (now Part C of the IDEA of 1997); community- based therapeutic and educational services for infants and children under 3 years of age with developmental delays
ELBW	extremely low birth weight; refers to an infant weighing less than or equal to 1000 grams (2.2 pounds) at birth
Encopresis	incontinence of feces not due to organic defect or illness
Failure to thrive	refers to slowed rate of growth, usually describes weight loss, decreased rate of weight gain and/or decreased linear growth; also called undernutrition, delayed growth, growth faltering, and failure to grow
Gag reflex	a normal reflex triggered by touching the soft palate or back of the throat that raises the palate, retracts the tongue, and contracts the throat muscles; protects the airways from a bolus of food or liquid
Galactagogue	Substance that is ingested (foods, herbs, medications, etc), which has the effect of increasing breastmilk supply (induces lactation)
Gastroesophageal reflux (GER)	regurgitation of the contents of the stomach into the esophagus, where they can be aspirated; often results from a failure of the esophageal sphincter to close; commonly leads to feeding problems in infants and children with neuromuscular disorders
Gastroschisis	a birth defect of incomplete closing of the abdominal wall
Gastrostomy tube	a feeding tube surgically placed through an opening from the abdomen to the stomach; tubes can also be placed endoscopically
Gestational age	the age of a fetus or a newborn, usually stated in weeks from the first day of the mother’s last menstrual period
Hypersensitivity	abnormal sensitivity, exaggerated response by the body to a stimulus, such as taste, touch, or smell
Hypoxemia	an abnormal absence of oxygen in the blood; symptoms include increased blood pressure, tachycardia, coma, and an increase in cardiac output that later falls; persistent hypoxemia can lead to feeding problems and poor growth

ICF	International Classification of Functioning, Disability and Health is the framework developed by the World Health Organization for measuring health and disability at both individual and population levels.
IDEA	Individuals with Disabilities Education Act; provides a definition of "disability" and mandates services, such as Early Intervention Programs (Part C), for children with disabilities; originally implemented in 1975 and revised in 1997
IEP	individualized education plan; a contract between the school system and the student/family that outlines specific educational plans and goals, as well as actions and a timeline for implementation that can include plans for special health care needs; in place for all children over age 3 years enrolled in special education programs
IFSP	individualized family service plan; a document that outlines specific educational plans and goals, actions, and a timeline for implementation that can include plans for special health care needs; in place for all children under age 3 years enrolled in early intervention programs
Impaction	the presences of a large, hard mass of stool in the rectum or colon
Intussusception	the "sinking" of one part of the bowel into the next; blockage may include the small intestine, colon, or ileus; surgery is required to clear the blockage
IUGR	intrauterine growth retardation; development of the fetus is delayed relative to gestational age
Jejunal feeding tube	a feeding tube that delivers formula to the jejunum portion of the small intestine; can be placed in the jejunum through an opening in the abdomen or placed in the stomach and passed through the pyloric sphincter into the jejunum
Knee height	the distance from the top of the patella to the bottom of the foot; sometimes used as an estimator of stature (length or height)
Laxative	an agent that promotes bowel movement by increasing the bulk of the feces, softening the stool, or lubricating the intestinal wall
LBW	low birth weight; refers to an infant weighing less than or equal to 2500 grams (5.5 pounds) at birth

Length (recumbent length)	appropriate measure of stature for children under age 3 years; measurement should be done on a length board with a fixed headboard and moveable foot board; infant or child should be nude or without diaper
Length board	a piece of equipment used to measure the recumbent length of infants and young children; many length boards have a fixed headboard and moveable foot board
LGA	large for gestational age; refers to an infant whose birth weight is greater than the 90th percentile for age
Medium chain triglycerides (MCT)	triglycerides with eight to ten carbon atoms. MCTs do not require bile for digestion and are usually easily digested
Megacolon	abnormal widening of the colon that may be inborn or may result from chronic constipation or obstipation
Midarm muscle circumference	measurement used to aid in the estimation and assessment of muscle mass; calculated by subtracting the triceps skinfold measurement from the circumference of the mid upper arm
Midparent height	also known as parent- specific adjustment for evaluation of length and stature, a calculation to estimate a child's eventual height, based on the height of his/her parents
Myoclonic seizures	seizures that are brief, involuntary muscle jerks
Nasogastric feeding	a form of enteral nutrition support; a tube runs through the nose into the stomach; usually used temporarily (e.g., less than 3 months)
Necrotizing enterocolitis	a sudden inflammatory bowel disorder that occurs primarily in premature or LBW infants; causes blood to move away from the gastrointestinal tract, resulting in necrosis with bacterial invasion of the intestinal wall
Nephrocalcinosis	an abnormal condition of the kidneys in which deposits of calcium form in the filtering units
NHANES	National Health and Nutrition Examination Survey; a series of periodic surveys that collects height, weight, and other health information on the American population; data from NHANES was used to construct the 2000 CDC Growth Charts: United States.
Noonan syndrome	sometimes called the "male Turner's syndrome," a disorder marked by short stature, congenital heart disease, webbing of the neck, and characteristic cranio- facial features; equally common in males and females

Obstipation	constipation caused by a blockage, resulting in an accumulation of stool with the development of colon distension; leads to fecal impaction
Oliguria	a reduced ability to make and excrete urine, usually <500 mL/day
Opportunistic infection	an infection caused by microorganisms not usually harmful; infection occurs because of lowered resistance; e.g., by disease or by medications
ORT	oral rehydration therapy; treatment in which patients who are dehydrated are given essential fluids by mouth to correct imbalances of water, glucose, and electrolytes
Osteopenia	decreased calcification or bone density
Parenteral nutrition	nutrition maintained by intravenous injection or other non-gastrointestinal route
PDA	patent ductus arteriosus; an abnormal opening between two arteries (pulmonary artery and aorta) caused by the fetal blood vessel (ductus arteriosus) failing to close after birth
Prader Willi syndrome	a genetic disorder marked by hypotonia, short stature, hyperphagia, and cognitive impairment; when not carefully managed, characterized by obesity
Preterm infant	an infant born at less than 36 weeks gestation
RDA	Recommended Dietary Allowance; the average daily dietary intake level that is meets the nutrient requirements of nearly all healthy individuals
Refractory seizures	seizures that cannot be controlled with treatment
Reinforcer	an individually designed consequence that is generally intended to increase the behavior that precedes it
SBS	short bowel syndrome; a loss of area in the intestine that causes malabsorption
SGA	small for gestational age; refers to an infant whose birth weight is less than the 10th percentile for age
Sitting height	length between a child’s head and buttocks, sometimes used as an estimator of height

Stadiometer	moveable headboard attached to a measuring board, used to measure standing height
Stimulant	an agent that speeds up a body system
Triceps skinfold	measurement of the skin and subcutaneous fat layer around the triceps muscle, used with arm circumference measurement to estimate fat and muscle stores
Turner syndrome	a disorder in females marked by the absence of one X chromosome; typically characterized by ovarian failure, genital tissue defects, heart and circulation problems, and short stature
VFSS	videofluoroscopic swallowing study; a radiologic procedure used to evaluate the swallowing mechanism; foods are mixed with barium and feeding is recorded and observed
VLBW	very low birth weight; refers to an infant weighing less than 1500 grams (3.3 pounds) at birth
Volvulus	a twisting of the bowel that causes intestinal blockage
WIC	USDA Supplemental Nutrition Program for Women, Infants, and Children; a federally- funded community program that provides foods, infant formula, and nutrition education to pregnant women, infants and children under 5 years of age, and breastfeeding mothers
Williams syndrome	a congenital disorder characterized by distinctive facial features, growth and developmental delays, varying degrees of learning disabilities, and sometimes hypercalcemia in infancy

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Index

A

B

C

D

E

F

G

H

I

J

K

L

M

N

O

P

R

S

T

U

V

W

Z