

# Nutrition Focus

*for children with  
special health care needs*



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## Nutrition Issues in Children with Myelomeningocele (Spina Bifida)

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### WHAT IS SPINA BIFIDA?

Myelomeningocele, or spina bifida, is the most common neural tube defect (NTD). NTDs are caused by abnormal fetal development of the neural tube when the opening in the spinal cord fails to close by the 28th day after fertilization of the egg, often before a woman knows she is pregnant. During this stage the neural groove folds over to become the neural tube, which becomes the spinal cord and vertebral arches. If a portion of the groove does not close, it results in a sac on the spine that contains meninges and spinal nerves.<sup>1</sup> The location of the NTD on the spine affects the motor function and level of sensation in the lower parts of the body. A higher lesion corresponds to greater paralysis.<sup>2</sup>

Children with spina bifida have complex and lifelong medical care needs.<sup>3</sup> A team of providers, including the registered dietitian (RD), provides optimum care by using a comprehensive, coordinated, multidisciplinary approach.<sup>4-6</sup> The child and his/her family form the core of the interdisciplinary team. The primary care provider (PCP) functions as the "medical home" and supports the family in advocating for the child from the time of entry into the practice, through adolescence and the transition to adult providers.<sup>1</sup> The PCP's central and unique role includes coordinating the required ongoing communication and management with pediatric medical and developmental sub-specialists including RD, orthopedist, urologist, neurosurgeon, nurse specialist, speech therapist, physical therapist (PT), occupational therapist (OT), social worker, and other community providers.<sup>3</sup>

### Conditions associated with spina bifida

- Hydrocephalus affects approximately 85% of children with myelomeningocele.<sup>1</sup> This is usually treated by sur-

gical placement of a ventriculoperitoneal shunt to drain excess fluid from the ventricles in the brain into the peritoneal cavity. Without treatment, the excess pressure can result in mild to severe intellectual disabilities.

- Arnold Chiari type II malformation typically occurs in children with spina bifida above the sacral level.<sup>2</sup> This results in a brain stem malformation which may result in weakness, atrophy of neck and arm muscles, intellectual disabilities, and laryngopharyngeal palsies (e.g., bulbar palsy), and ultimately, dysphagia. Children who have Arnold Chiari II malformation can have several symptoms indicative of dysphagia, as discussed in a later section.
- Neurogenic bowel and bladder occurs in almost all children that have a lesion above the sacral nerves at level S2-S4. This requires a proactive approach to achieve continence through dietary changes and medical management.
- Epilepsy (seizure disorder) has been reported in approximately 15% of patients with myelomeningocele, frequently requiring long-term management with medications.<sup>3</sup>

### Etiology

Spina bifida, anencephaly, and other NTDs occur as a result of defective neurulation. A lesion that involves elements of the spinal cord as well as the meninges within the sac is termed myelomeningocele.<sup>1</sup> The cause of NTDs remains uncertain, with biological (e.g., febrile illness, maternal diabetes), environmental (e.g., geography, exposure to chemicals, poverty, poor maternal nutrition), biochemical (e.g., amphetamines, anticonvulsants), and genetic factors (e.g., ethnicity) potentially playing a role.<sup>1,3</sup>

NTDs occur in fewer than one in every 1,000 live births.<sup>1,7</sup> A decreased incidence of NTDs is thought to be the result of improved prenatal nutrition, food fortification, and supplementation through the use of prenatal vitamins and minerals.<sup>1,8</sup> The Centers for Disease Control and Prevention (CDC) estimates that the number of NTD-affected pregnancies in the United States declined from 4,000 in 1995-1996 to 3,000 in 1999-2000.<sup>9</sup> A woman who has had a child with a NTD has a 20-fold higher risk of having another child with an NTD.<sup>1</sup> Although some risk factors are known, causes of NTDs are not yet fully understood and continue to be researched.

In September 1992, the United States Public Health Service issued recommendations that “all women of childbearing age in the United States who are capable of becoming pregnant should consume 0.4 milligrams (mg) of folic acid per day for the purpose of reducing their risk of having a pregnancy affected with spina bifida or other NTDs...”<sup>10</sup> They also recommended that women who had prior pregnancies affected by NTDs be encouraged to consult with their physicians to discuss folic acid supplementation (up to 4 mg of folic acid per day beginning one to three months prior to conception and through the first three months of pregnancy).<sup>11</sup>

See the last page of this newsletter for a reproducible handout titled “Folate Facts” that summarizes information about the importance of folate as well as food sources. Subscribers can reproduce this handout for their clients.

## Prevention of Neural Tube Defects

Women of childbearing age should routinely consume foods that are good sources of folate or fortified with folic acid. If a woman does not consume adequate folate in her diet, then she should take a daily multi-vitamin/mineral supplement containing folate. Most multi-vitamin/mineral supplements contain 0.4 mg (400 micrograms [mcg]) folic acid. Since the neural tube closes before most women know they are pregnant, an adequate intake of folate or vitamin/mineral supplementation is a critical prevention measure.<sup>11,12</sup> In 1996, the United States Food and Drug Administration released regulations requiring the addition of folic acid to fortify and enrich breads, cereals, flour and other grain products in an effort to reduce the risk of neural tube defects.<sup>13</sup> In January 1998 mandatory fortification of cereal grain products went into effect.<sup>9</sup>

## Vitamin B12

In addition to folic acid, vitamin B12 plays an important role in the prevention of NTDs.<sup>14,15</sup> Folate is required for production and maintenance of new cells, for DNA and RNA synthesis, and to carry carbon groups for methylation and nucleic acid synthesis. It has been hypothesized that the embryo might be vulnerable to folate deficiency because of the differences in enzyme function during embryogenesis.

Vitamin B12 is an important receptor in folate metabolism, and studies have shown a deficiency in vitamin B12 can contribute to NTD risk.<sup>16</sup>

## NUTRITION SCREENING

All children with spina bifida should be screened on an annual basis using a valid and reliable nutrition screening questionnaire that can identify common nutrition risk factors (e.g., overweight, underweight, short stature, delays in feeding skills, constipation, chronic use of medications, diet inadequacy, special diet or food supplements, food allergies). Such a tool can provide reliable data for initiating nutrition assessment and intervention. Development of a screening and assessment protocol in any specialty pediatric clinic where nutrition is a concern should be coordinated with the clinic medical director and interdisciplinary team. See Box on page 3 for development of one nutrition screening tool.

In 1994 Children's Hospital Los Angeles validated a nutrition screening questionnaire with 81 children in the Spina Bifida Clinic.<sup>17</sup> The parent-completed nutrition screening questionnaire (English and Spanish) is contained in the *Nutrition Strategies for Children with Special Needs Manual* and can be accessed on pages 6 and 7 at [http://www.uscucedd.org/index.php?option=com\\_content&view=article&id=166&Itemid=230](http://www.uscucedd.org/index.php?option=com_content&view=article&id=166&Itemid=230). Please see RESOURCE #2 for access to the entire manual and additional information.

## NUTRITION ASSESSMENT

A thorough nutrition assessment should be conducted by the RD if a child is found to exhibit one or more nutrition risk factors, based on screening and the policies and procedures defined by the clinic. The purpose of the nutrition assessment is to obtain, verify, and interpret data needed to define the child's nutrition-related problem(s), and to use this information to develop the plan for nutrition intervention.<sup>18,19</sup> The Academy of Nutrition and Dietetics (AND) has defined five categories for collection of nutrition assessment data listed in Table 1 on page 4. This provides a standardized process for providing nutrition care and a standardized language for dietetics.<sup>19</sup> Once data are compared to standards, norms and evidence-based criteria, the RD interprets these findings and develops an individualized patient intervention plan. Ongoing re-assessment is a critical component of the nutrition care process, with data used to:

1. define patient outcomes in reaching intervention goals
2. define new or unmet needs and establish new goals.

Ongoing monitoring and evaluation is critical in measuring the impact of patient care.

### Information Regarding Development of the Children's Hospital of Los Angeles Nutrition Screening Tool<sup>17</sup>

In a 1994 study Bujold reported a nutrition screening questionnaire that was a reliable and valid instrument for all but a few variables examined. Nutrition risk factors which were accurately identified included: underweight, use of daily medications, constipation, dental problems, food allergy, non-oral feeding, vomiting, diarrhea, special diet and anemia. Six variables which were not accurately predicted by the parent included: overweight, short, eating a balanced diet, picky eater, food intolerance and feeding difficulty/delay. Use of a parent-completed, low literacy questionnaire can provide a quick method to identify children who have nutritional risk factors while screening out unnecessary referrals for more effective use of the Registered Dietitian's time. A reliable and valid screening protocol could contribute significantly to the ability of specialty clinics to identify children who have the greatest need for nutrition intervention. A parent/care-giver-completed questionnaire relieves the professional from taking the time required to administer. To identify nutrition risk factors found to be unreliable, The study author suggested that:

1. all children should be weighed and measured and data compared to the BMI tables
2. use a separate method to evaluate diet intake and adequacy for example, a food frequency questionnaire or 24-hour diet recall
3. feeding difficulty and delay should be evaluated by the occupational or speech therapist skilled in feeding evaluations who is a member of the interdisciplinary team.

## Anthropometrics

Weight-for-age, length- or height-for-age, weight-for-length or Body Mass Index (BMI)-for-age, and head circumference (OFC)-for-age (<2 or 3 year olds) should be plotted on the appropriate growth charts, with values compared to the child's previous measurements to assess growth patterns. Growth charts should be used with careful interpretation, as children with spina bifida were not included in the reference population. Spina bifida growth charts are available<sup>20,21</sup> and include an analysis of growth data related to lesion level and ambulatory status.<sup>20</sup> These charts can be helpful to use in addition to standard growth charts when evaluating growth of children with spina bifida.

Children with spina bifida are typically shorter than their peers, and this is related to the slowing of linear growth that usually begins around 2 years of age. This is also the time when weight gain may begin to increase at a faster rate than linear growth. Standardized procedures for obtaining OFC, height/length and weight measurements should always be followed and can be found in RESOURCES #2 and #3 and at <http://depts.washington.edu/growth>.

Weight should be measured on a consistent, calibrated scale, and the child should be dressed in light clothing without shoes, braces, or other items that may add additional weight. Length should be obtained on a length board, or by measuring recumbent length in young children and children who cannot bear weight. If a child is able to stand, a wall-mounted stadiometer should be used. It can be very difficult to obtain an accurate length/height measurement due to scoliosis, contractures, or other differences in body habitus. Although arm span measurements have been used in children with spina bifida<sup>22</sup> they are not reliable for use in children with a high lesion that are not expected to have typical growth in their lower extremities. However, arm span measurements can be reliable in children who are prescribed growth hormone to treat an underlying deficiency.<sup>23,24</sup>

Children with spina bifida have an increased risk of obesity related to their reduced amount of lean body mass and higher amount of body fat.<sup>25-27</sup> Body Mass Index (BMI) is calculated for children 2 years of age and older for use as a screening tool in conjunction with the CDC growth charts. BMI is not the most accurate measurement for practitioners to use to assess underweight/overweight/obesity in children with spina bifida due to the differences in body composition and distribution of lean body mass and fat mass.

Alternative measurements, such as skinfold measurements, can be tracked over time in addition to height, weight, and BMI to monitor changes in body composition and growth.<sup>28</sup> An experienced clinician can also measure humeral length, mid arm circumference (MAC), and triceps skin fold (TSF). Reference percentiles are available for these techniques.<sup>29</sup> However, since the data consist of measurements of nondisabled children, it is best to track an individual's measurements over time, using each child as his or her own control. It is important to use the same techniques for anthropometric measurements at each visit and to note specific techniques in the child's medical record for future reference to assure consistent techniques by all members of the healthcare team.

## Energy needs

In children with spina bifida, the goal is to have a pattern of growth that is predictable, and results in a body that is proportionate (i.e., BMI-for-age between the 10th and 85th percentiles). Energy needs are frequently based on kilocalories per centimeter height (kcal/cm) in children with spina bifida to prevent overnutrition and resultant obesity. Table 2 on page 4 shows methods to calculate energy needs in children with spina bifida. These equations are intended for use as a starting point, as each child's energy needs are unique; their ambulatory status, lesion level, and activity level all factor into their level of energy expenditure. The lower amount of lean body mass and higher fat mass<sup>25,26,30</sup> leads to a 20-25% reduction<sup>26,31</sup> in total energy expenditure that can result in obesity without a proactive approach.



**Table 1 – Nutrition Assessment**

Nutrition Care Process (NCP) Assessment Category	Assessment Components Examples
Food/Nutrition History	Diet intake, vitamin/mineral supplements, nutrition supplements, knowledge and beliefs about food, food availability, physical activity, fast food consumption, frequency of meals
Anthropometric Measures	Height, weight, skinfold measures, alternative measures, growth and weight history
Lab Data, Medical Tests, Procedures	Lab test results compared to standards, swallowing studies, surgical procedures, G-tube placement
Nutrition-focused Physical Findings	Patient appetite, feeding skills, chewing and swallowing abilities, level of support needed for eating or drinking, physical appearance, wounds/pressure sores, visible muscle and fat stores
Client-reported History	Social history, family composition and level of support, medical history, medication history, where meals are eaten, school support for nutrition, access to community nutrition programs

Table adapted from the *Pocket Guide for International Dietetics & Nutrition Terminology (IDNT) Reference Manual*, Academy of Nutrition and Dietetics, Fourth Edition, 2013.

**Table 2 – Energy Requirements for Children with Spina Bifida<sup>32</sup>**

Age Group	Calorie Requirements
Infants	RDA for age
After Infancy	approximately 50% RDA for age
After Age 6 years	weight maintenance: 9-11 kcal/cm
	weight loss: 7 kcal/cm

From: Grogan CB, Ekvall SM. Body composition of children with myelomeningocele, determined by <sup>40</sup>K, urinary creatinine and anthropometric measures. *J Am Coll Nutr.* 1999;18:316-323.

factor in constipation due to the resulting bowel hypomotility.<sup>33</sup> Additional factors include inactivity, a low fiber diet, inadequate fluid intake, and medications which may slow intestinal motility (e.g., anticholinergics used to treat neurogenic bladder). Blood loss through the stools when a child is constipated may also result in an iron-deficiency anemia and requires monitoring. A bowel management program which includes dietary intervention, regular toileting, and medical intervention where indicated, is important for the prevention and treatment of constipation. See RESOURCE 4 for a previous issue of NUTRITION FOCUS addressing constipation.

## NUTRITION-RELATED ISSUES

There are many nutrition related issues that can impact children with spina bifida. Table 3 on page 5 summarizes these issues and provides intervention strategies. Selected nutrition related issues are discussed in detail below.

### Short Stature

Short stature is common in children with spina bifida, and the causes can be multifactorial. Growth hormone deficiency, atrophy of the lower extremities, abnormal vertebral growth, musculoskeletal deformities, renal disease, and failure to thrive can result in impaired linear growth. As mentioned earlier, children with documented growth hormone deficiency can experience gains in linear growth velocity when treated with growth hormone.

### Neurogenic Bowel/Constipation

Constipation or fecal incontinence of varying degrees is seen in over 90% of individuals with spina bifida. The constipation may be associated with several interacting factors. Neurogenic bowel (abnormal nervous system control of the bowels) is a common complication and a primary

### Obesity

Children with spina bifida, especially those with reduced mobility and ambulation, are at increased risk for obesity, metabolic syndrome, insulin resistance and dyslipidemia.<sup>2,34</sup> The reduction in the metabolic rate due to reduced lean body mass, combined with inactivity due to non-ambulation and possible overeating can result in acceleration in weight velocity at an early age. Limited nutrition knowledge, boredom, depression, and/or food rewards can also result in an accelerated rate of weight gain. Regular monitoring of all growth parameters and use of weight/length or BMI using the growth chart, is critical to identify children who would benefit from early prevention of obesity.

The energy needs of nonambulatory children may be 25-50% less than their ambulatory peers. Children with spina bifida may need to consume less than 80% of the daily energy needs recommended for the general population for age to prevent excessive weight gain.<sup>35</sup>

The RD should provide ongoing nutrition education throughout the lifespan to promote good eating habits and optimum nutrient intake with portion size control start-

**Table 3 – Nutrition Related Concerns and Intervention Strategies for the Child with Spina Bifida**

<b>Nutrition Related Concern</b>	<b>Intervention Strategies</b>
<b>Overweight/Obesity</b> Use BMI to screen for potential obesity; diagnosis is based on individual's pattern and other indicators, including rate of weight gain <ul style="list-style-type: none"> <li>• Overweight – BMI-for-age or weight-for-length &gt;85th percentile and &lt;95th percentile</li> <li>• Obese – BMI-for-age or weight-for-length &gt; 95th percentile</li> </ul>	Early intervention and monitoring of growth velocity, education on healthy choices, regular exercise, monitor for risk factors of metabolic syndrome, insulin resistances, and hypertension.
<b>Underweight</b> Use BMI to screen for potential underweight; diagnosis is based on individual's pattern and other indicators, including rate of weight gain <ul style="list-style-type: none"> <li>• BMI-for-age or weight-for-length &lt;5th percentile</li> <li>• Inadequate energy intake</li> </ul>	Increased energy intake, evaluate for possible need for feeding tube or use of nutrition supplements.
<b>Short Stature</b> <ul style="list-style-type: none"> <li>• Length-for-age &lt;5th percentile</li> <li>• Plateauing of linear growth</li> </ul>	Monitor linear growth and energy reserves or weight/height over time. Increase energy intake and provide adequate intake of all nutrients at or above Dietary Reference Intake (DRI) if growth stunting appears to be due to nutritional causes. Evaluate for growth hormone deficiency if nutritional causes of stunting not present.
<b>Constipation</b> <ul style="list-style-type: none"> <li>• Reliance on bowel medications</li> <li>• Inadequate fluid and fiber intake</li> </ul>	Increased fiber, increased fluid, bowel management program, regular exercise.
<b>Urinary Tract Infection</b> <ul style="list-style-type: none"> <li>• Inadequate fluid and fiber intake</li> <li>• Constipation</li> </ul>	Adequate fluid and fiber intake, routine bladder emptying, prophylactic antibiotics.
<b>Feeding Problems</b> <ul style="list-style-type: none"> <li>• Dysphagia</li> <li>• Swallowing difficulty, silent aspiration, pneumonia</li> </ul>	Feeding evaluation by an occupational or speech therapist. May include a swallowing study to assess the child's feeding abilities. Child may require a pureed diet, thickened liquids or enteral feedings to maintain adequate nutrition and hydration.
<b>Wound Prevention</b> <ul style="list-style-type: none"> <li>• Inadequate protein and micronutrient intake</li> <li>• Underweight</li> <li>• Overweight</li> </ul>	Monitor diet for nutritional adequacy. Avoid obesity and undernutrition to minimize the risk of pressure sores. Encourage daily skin inspections.
<b>Osteopenia/Osteomalacia</b> <ul style="list-style-type: none"> <li>• Inadequate calcium and vitamin D intake</li> </ul>	Ensure DRI for age for calcium and vitamin D, evaluate drug/nutrient interactions.
<b>Drug-Nutrient Interactions</b>	Monitor diet for nutritional adequacy. May require certain nutrients above DRI for age.

ing with standardized tools, for example ChooseMyPlate, <http://www.choosemyplate.gov>, and individualizing for each child. Approximately one-quarter of children with spina bifida have mild intellectual disability and may have impairments in executive functioning that may impact their education and self-help skills. Adapting the nutrition intervention plan to recognize the cognitive abilities of the child and the level of support available from the family is important to assure diet adherence.

Increasing physical activity is critical to avoid the health consequences of obesity and related health care costs and

comorbidities.<sup>2, 36,37</sup> A referral to a PT can provide valuable information to the school for modified physical education to ensure children maximize their activity. In addition, Therapeutic Recreation specialists can help families identify leisure activities, such as swimming, local recreation centers/clubs, and hobbies.

## Medications

Children with spina bifida have complex medical issues that may require medication management. Many of the prescribed medications have associated nutrient interac-

**Table 4 – Medications with Nutritional Implications**

Classification	Medication Examples	Side Effects
Stimulants for behavior management (stimulants)	Vyvanse	Anorexia, ↓ weight, ↓ growth, nausea, constipation, diarrhea, dry mouth, limit caffeine, acidifying agents (cranberry) ↑ drug excretion
	Focalin	Anorexia, ↓ weight, ↓ growth, nausea, vomiting, diarrhea, abdominal pain, dry mouth, limit caffeine
Antibiotics for UTI prophylaxis	Bactrim	Anorexia, ↓ folate metabolism, nausea, vomiting, diarrhea, ensure adequate hydration
	Macrochantin	Anorexia, nausea, vomiting, diarrhea, constipation, ensure adequate energy intake, protein intake, B-complex intake
Anticholinergics for neurogenic bladder	Detrol, Ditropan, Enbex, Toviaz, Vesicare	Dry mouth, nausea, vomiting, diarrhea, constipation, ↓ salivation may lead to dysphagia
Anticonvulsants for seizures	Keppra	Anorexia, sedation, irritability, behavioral and mood changes, vomiting, diarrhea, leukopenia
	Topamax	Ensure adequate fluid intake to ↓ risk of kidney stones, ↓ weight, anorexia, ↑ appetite, ↑ weight, dry mouth, nausea, abdominal pain, constipation, diarrhea
	Valproic acid	Sedation, appetite changes, abdominal pain, pancreatitis, pancytopenia, mood changes, take with meals to ↓ GI irritation, ensure adequate calcium and vitamin D intake (or supplement), ↑ appetite, ↑ weight, anorexia, ↓ weight, nausea, vomiting, diarrhea, constipation, flatulence, ↓ vitamin D and bone density
Laxatives for bowel management	Senna	Ensure ↑ fluid and fiber intake, nausea, vomiting, diarrhea, cramps, dependence with long term use, ↓ potassium, ↓ calcium, ↑ glucose, ↑ peristalsis
	Lactulose	Ensure ↑ fluid and fiber intake, nausea, vomiting, diarrhea, cramps, belching, flatulence
	Enemeez	Nausea, diarrhea, gas, cramps
	Bisacodyl suppository	Nausea, diarrhea, abdominal distension, cramps
Anti-ADHD/Antiepileptics for neuropathic pain	Concerta	Ensure adequate energy intake, anorexia, ↓ weight, ↓ growth, nausea, vomiting, diarrhea, abdominal pain, limit caffeine
	Lyrica (antiepileptic) Neurontin (anticonvulsant)	↑ weight, ↑ appetite, anorexia, dry mouth, nausea, vomiting, diarrhea, constipation, flatulence, dizziness, sedation, fatigue, mood changes
Antidepressants	Prozac	Anorexia, ↓ weight, ↑ appetite, ↑ weight, nausea, vomiting, diarrhea, constipation, dry mouth, mood changes
	Zoloft	Anorexia, ↓ weight, nausea, vomiting, diarrhea, constipation, dry mouth, dyspepsia, slight ↑ in cholesterol and triglycerides, mood changes

tions and may increase the child's nutritional risk if given for longer than one month. The most common medications prescribed are for neurogenic bowel and bladder management. Table 4 lists some of the common medications and nutritional side effects.

## Urinary Tract Infections (UTI)

Children with neurogenic bladder are at a high risk of UTIs, as the bladder does not empty completely secondary

to abnormal innervation. In addition, many children have vesicoureteral reflux, in which urine refluxes back up the ureters towards or into the kidneys. UTI risk is increased by constipation, which can result when a bowel program is not followed or effective. A bladder management program may consist of routine bladder emptying (via clean intermittent catheterization, timed toileting, or diaper drainage), anticholinergics, adequate fluid intake, and prophylactic antibiotic treatment (as needed for vesicoureteral reflux). A review by Opperman did not find compelling evidence for

the role of cranberry extract in reducing UTI risk in individuals with spinal cord injury,<sup>38</sup> a group that is most similar to spina bifida in terms of neurogenic bowel and bladder. Pinzon-Arango et al<sup>39</sup> found cranberry juice cocktail can help reduce UTIs by inhibiting biofilm formation, and Cozens and Read<sup>40</sup> reviewed studies that looked at the role of anti-adhesion agents, including cranberries, in treating/preventing bacterial infections. However, neither of these papers specifically looked at neurogenic bowel and bladder or spinal cord injury.

## Wounds

Insensate skin and obesity are the major risk factors for the development of wounds in children with spina bifida. During wound healing, it is important to ensure the child is consuming adequate energy, protein, and micronutrients to heal the wound. Weight loss is not a priority during wound healing. Protein intake recommendations are 2-3 grams/kilogram/day (with monitoring of serum urea nitrogen and creatinine levels), with adequate energy to ensure protein sparing for wound healing.<sup>35</sup> Any child with a wound should be on a multivitamin with iron, as well as supplemental iron and zinc as needed based on diagnosed deficiency via laboratory monitoring.

## Feeding Problems

The inability to suck and swallow effectively due to complications of Arnold Chiari type II malformation can cause failure to thrive, aspiration pneumonia, dysphagia, vocal cord paralysis, and apnea.<sup>2, 35, 41</sup> Dysphagia, defined as difficulties with oral and/or pharyngeal phase of swallow and initiation of swallow, can be indicated with poor weight gain, coughing at mealtime, choking, wet breathing, or food refusal.<sup>6</sup> See Table 5.

Identification of these problems is frequently through screenings performed by an OT, speech therapist, or RD, and where available, an interdisciplinary feeding team. A feeding evaluation performed by either an OT or speech therapist can allow the clinician to evaluate feeding tolerance of solids and liquids, observe feeding interactions/dynamic, and observe positioning for meals. Further evaluation may include a swallowing study to obtain imaging of the oral and pharyngeal phase of the swallow.

Enteral feedings are sometimes necessary for safe and adequate nutrition. Optimal follow-up includes routine management of enteral feedings by the RD.

## Bone Health

Many factors can increase the risk of osteopenia/osteomalacia in children with spina bifida, including ambulation status, anticonvulsant medications, reduced sensation, obesity, limited sun exposure, hypotonia, malabsorption, and diets that are low in calcium and vitamin D.<sup>35</sup> Ensuring

**Table 5 – Common Signs and Symptoms of Dysphagia in Arnold Chiari II malformation<sup>35</sup>**

Problems sucking and swallowing
Difficulty positioning for feedings
Respiratory symptoms, stridor
Difficulty forming seal on nipple
Refusal of cup/sippie cup
Loss of food from mouth
Nasal regurgitation
Long feeding times
High number of formula changes to improve formula tolerance
Perceived lack of satiety
Refusal to advance textures/increase variety
Delays in self-feeding
Choking with feedings
Poor salivary control
Aspiration
Weight loss/growth failure

adequate calcium and vitamin D intake through a combination of foods and supplements to meet the Dietary Reference Intake (DRI) for age is critical and should be monitored with laboratory data and diet evaluation.

## Latex Allergies

There is a higher risk of latex allergy in children with spina bifida. The most common food allergies are banana, avocado, and kiwi. Many children also need to avoid latex in the environment if they are latex allergic.<sup>42</sup>

## NUTRITION EARLY INTERVENTION AND SCHOOL SETTINGS

Important tools that can be utilized to obtain health-related nutrition services in schools or early intervention programs are the Individualized Family Service Plan (IFSP), Individualized Education Plan (IEP), and/or 504 Accommodation Plan. These tools provide a management plan for individuals receiving special education and related services, serve as a vehicle for ensuring that a child's special nutrition needs are met, and establish a system in which families of children with spina bifida work as part of a team to access health-related services for their child. See Table 6 on page 8 for examples of nutrition goals and school accommodations that can be developed to assure optimum nutrition for the child with spina bifida requiring school support. The US Department of Agriculture's (USDA) nondiscrimination regulation (7 CFR 15b), as well as the regulations governing the National School Lunch Program and School Breakfast Program, make it clear that substitutions to the



regular meal must be made for children who are unable to eat school meals because of their disabilities. The guidance is based on the policy guidelines outlined in the FNS Instruction 783-2, Revision 2, Meal Substitutions for Medical or Other Special Dietary Reasons. The request for special dietary modifications must be requested by a licensed physician. The IEP is a written statement that is developed, reviewed, and revised yearly. The IEP details the child's education plan, including goals and objectives and special education and related services to be provided.

Section 504 provides for accommodations for individuals as requested by a qualified health care physician. For modifications to the school meal, the physician's statement must identify:

- The child's disability
- An explanation of why the disability restricts the child's diet
- The major life activity affected by the disability
- The food or foods to be omitted from the child's diet, and the food or choice of foods that must be substituted.

Please see NUTRITION FOCUS, Volume 26, #1, Jan/Feb 2011 for a discussion related to the inclusion of nutrition services in the IFSP and IEP.

**Table 6 – General Areas of IFSP, IEP or Section 504 Accommodation Plan Nutrition-Related Goals/ Outcomes<sup>18</sup>**

**Accommodations:**

- Feeding equipment to optimize intake and allow for greater self-feeding
- Feeding setting and length of feeding time
- Level of feeding support required
- Modified food texture and thickened fluids as needed
- Defined communication mechanism with student and behavior reinforcement

**Nutrition goals:**

- Identify and communicate nutrition needs
- Improved self-feeding skills
- Texture or consistency modifications
- Energy modifications
- Mealtime length
- Improved growth rate and weight gain

DeVore J, Shotton A, eds. Pocket Guide to Children with Special Health Care and Nutritional Needs. Chicago, IL: Academy of Nutrition and Dietetics. 2012.

## SUMMARY

Meeting the nutrition needs of children with spina bifida is a challenging task which is best approached by an interdisciplinary team of health care professionals and the family working with the child's medical home to provide comprehensive care and treatment. All team members should understand the complexity of the condition and the importance of early intervention and ongoing screening and education. The RD plays a key role as a member of the multidisciplinary team. Attention to growth, feeding and nutrition needs of children with spina bifida through a family-centered, community-based, coordinated, and culturally-sensitive system of services is essential.

## CASE STUDY OF KB

KB is a 4 ½-year old female diagnosed with mid-thoracic level myelomeningocele, hydrocephalus, VP shunt, neurogenic bowel and bladder, failure to thrive, Chiari II malformation, dysphagia with the recommendations of nectar thick liquids, and history of chronic gibbus wound. She lives with her parents and is the third of four children. KB is nonambulatory and uses a manual wheelchair for mobility. The family has limited financial resources, and KB has both WIC and Medicaid funding.

(Editor's note: A gibbus wound occurs at a rounded, curved, or humped area on the thoracic or lumbar part of the spinal column. The rounded area can result in a sharp angulation; the skin over this area is typically very thin and breaks down.)

KB came to clinic when she was 4 years old with a worsening gibbus wound and a 1.6 kg weight loss. She began to come to clinic weekly for wound care and follow up with the RD. During this time, her Pediasure<sup>®</sup> with fiber was increased to 2 cans daily with no changes in her weight. When her wound on her gibbus progressed to a stage 4 wound in addition to a plateauing of weight velocity, she was admitted to the hospital for comprehensive wound care, including a nutrition consult.

Upon admission, her estimated length (due to gibbus making an accurate length difficult to obtain) was 91 cm, and her weight was 12.75 kg, both <5th percentile. Her growth chart (Figure 1 on page 9) shows she previously followed the 10th to 25th percentile for weight with the use of 1 can of Pediasure<sup>®</sup> with fiber daily. Length measurements were variable, but did follow a curve just below the 5th percentile when outlying measurements were not used.

When KB was admitted for wound care, her diet order was for cohesive/mashed solids with nectar thick liquids in addition to 2 cans of Pediasure<sup>®</sup> with fiber taken orally daily. KB had a swallow study earlier in the year that showed aspiration of thin liquids and a delayed swallow response with solids and liquids. Recommendations were made to thicken all liquids to nectar consistency, limit bite size to ½ teaspoon or ½ inch and to monitor and pace KB at meals.



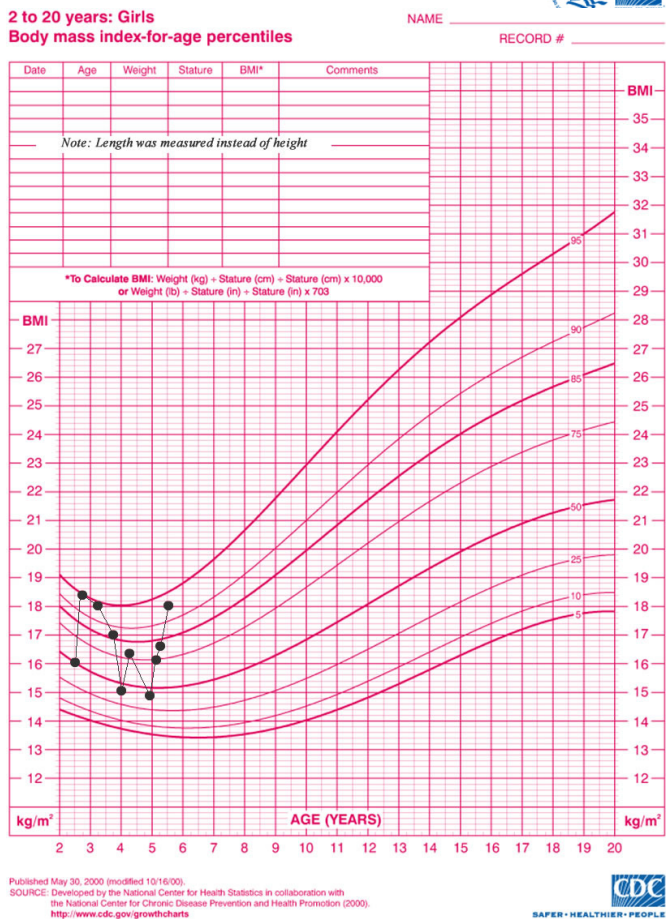
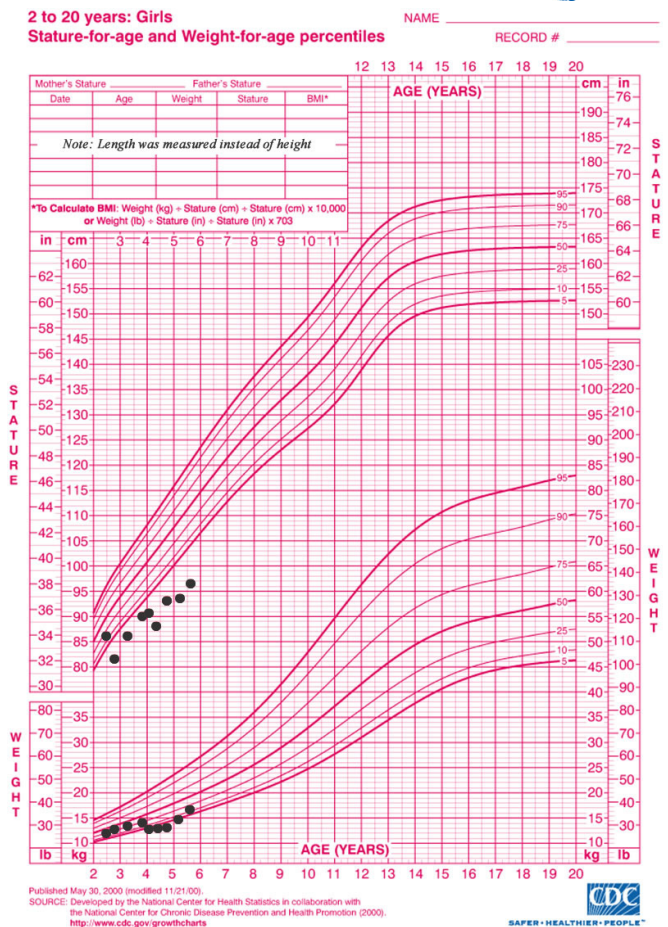
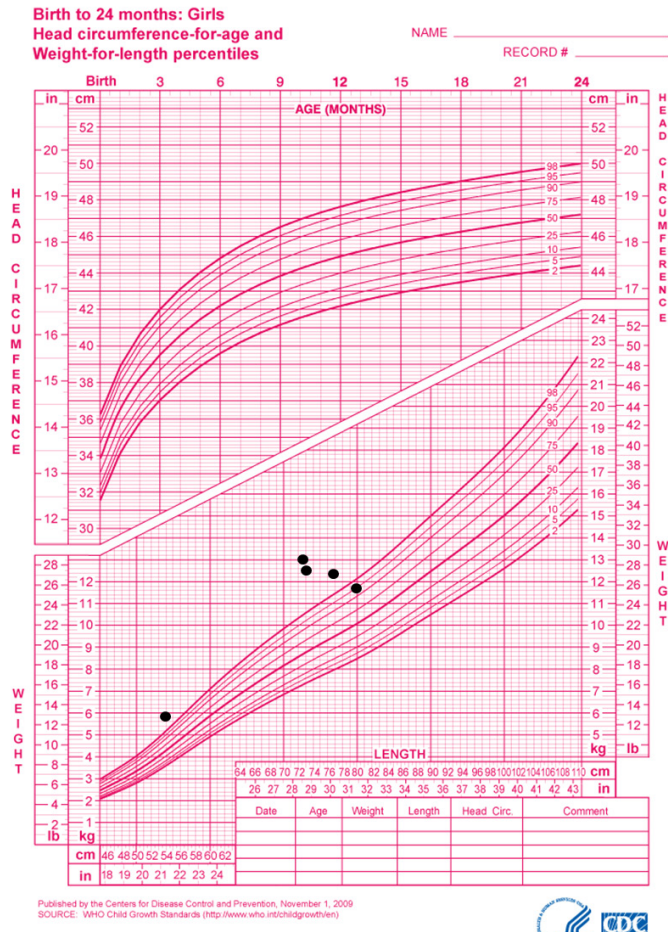
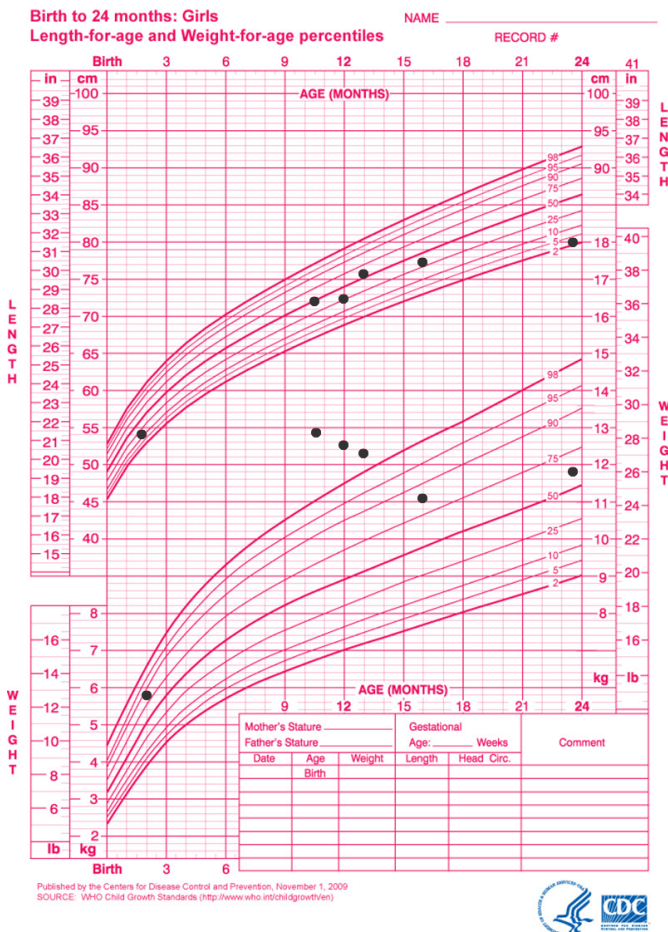


Figure 1. KB's growth charts - Top: Weight-for-age and length-for-age (left), weight-for-length (right); Bottom: weight-for-age and stature-for-age (left), BMI-for-age (bottom)



Her energy needs were estimated at 1000 kcal/day (11 kcal/cm of estimated height); protein needs were estimated at 25 g/day (2 g/kg/day). The RD noted that KB was only consuming 50% of the meals offered and 4 oz of Pediasure® with fiber daily. In addition, the nurses on the unit reported that it was difficult to get KB to drink 3 oz of liquids 5 times daily. When the RD met with mom, she reported that it had been taking KB a long time to drink the Pediasure® with fiber because she was easily distracted and ate slowly. Within one week of admission, the recommendation was made for gastrostomy placement to ensure adequate energy and protein intake to promote wound healing. KB underwent gastrostomy placement and began enteral feedings of Pediasure® with fiber towards a goal of 3 cans/day spaced out among 3 feedings to provide 720 kcal/day and 21 g protein (1.6 g/kg/day), and to allow for oral intake. The RD worked with the family on a schedule that allowed for meals and enteral feedings so that KB could continue to eat orally. Over time, the RD noted that KB's oral intake consisted mostly of non-nutrient dense foods, such as chips and cookies. The RD educated the family on nutrient dense foods they could provide for KB to eat by mouth to support weight gain and wound healing.

KB showed excellent tolerance of her enteral feedings, resulting in a 0.6 kg weight gain when she was discharged 6 weeks after her gastrostomy placement. Her wound was a closing stage 4 wound with granulation tissue. Upon discharge, the recommendations were to continue with 3 cans of Pediasure® with fiber daily in addition to consuming 350 kcal by mouth daily. The diet plan was scheduled so that KB had 3 enteral feedings and 3 oral feedings daily. KB continued to drink nectar thick liquids that were thickened with a commercial gel thickener (Simply Thick®) and mashed solids.

One month later her weight had increased to 13.6 kg, a gain of 0.1 kg. The RD recommended increasing to 3.5 cans Pediasure® with fiber/day and continuing oral feedings. KB returned to clinic 2.5 months later and had gained 0.9 kg on this regimen, which provided 840 kcal/day and 25 g protein (1.8 g/kg/day) in addition to po intake. Three months later, her weight increased another 0.7 kg to 15.2 kg, and no changes were made to the enteral regimen. However 8 months after gastrostomy placement, her weight had increased to 16 kg, and her BMI-for-age was between the 85th and 90th percentiles. KB's weight-for-age was at the 10th percentile. Mom stated KB had consistently been consuming 500-600 kcal/day from oral solids and liquids. In light of KB's catch-up weight gain and healed gibbus wound, and to allow for increasing oral intake, the RD recommended reducing the Pediasure® with fiber to 3 cans/day. KB will continue to be followed in the spina bifida clinic every 3-6 months to monitor her gibbus wound, growth velocity, and intake so that adjustments to her enteral and/or oral feedings can be made.

## CASE STUDY OF GJ

GJ is a 13-year old male with lumbar level myelomeningocele, shunted hydrocephalus, ventriculoperitoneal shunt, neurogenic bowel and bladder, and behavior issues. He has been followed in the spina bifida clinic since birth. He is able to independently ambulate inside and outside his home (i.e., community ambulatory) and wears ankle foot orthotics (AFOs) for support.

His linear growth plotted around the 50th percentile until he was 12 years old, when it increased to the 75th percentile. GJ's weight-for-age has always been >95th percentile. See Figure 2 for GJ's growth chart.

At a 4½ year old follow-up visit with the interdisciplinary spina bifida clinic, his mother reported concerns about his behavior and constipation. GJ's height was 111.5 cm (90th percentile) and his weight was had increased by 2 kg in 2 months to 33.1 kg (>95th percentile). Mother reported she had feelings of depression and had also noticed an increase in aggressive behaviors in GJ. The social worker referred Mom to a local clinic for psychological counseling, and GJ was referred to an Applied Behavior Analysis (ABA) therapist for the aggressive behavior.

Following the 4½ year old visit, GJ's weight gain velocity began to slow. His mother still struggled to manage his behavior, particularly when he was aggressive towards her when she was trying to limit his food intake. GJ's energy needs were calculated to be 1115 kcal/day (10 kcal/cm for weight maintenance). His fluid and fiber needs were estimated at 58 oz/day and 9 g/day, respectively. A 24-hour diet recall revealed a diet high in fat and sweetened beverages and low in overall fluid and fiber. During initial counseling, healthy, low-fat guidelines were reviewed, as well as recommendations to increase fluid intake (such as taking a water bottle to school) and fiber intake. GJ's weight continued to plot above the 95th percentile for several years. The RD regularly met with the family to provide ongoing nutrition education on healthy eating.

Beginning at age 11½, there was a sharp rise in GJ's weight of nearly 5 kg. GJ stated that he was ready to lose weight, as he had been having increasing difficulty with ambulation with his excess weight. GJ's mother felt this was a good time to work on weight management, as his aggressive behaviors had been well managed, and Mom's depression was being treated. The RD reviewed MyPlate and smaller portions and recommended increasing activity level. GJ had a consultation with a Therapeutic Recreation Specialist who was able to find several activities for GJ, including swimming, Boy Scouts, and YMCA afterschool programs. The RD and physician provided school diet and adaptive physical education (PE) orders so that the following recommendations could be incorporated into GJ's IEP: To promote achievement of appropriate weight goals:

1. GJ will be given low fat or non fat milk for school lunch and breakfast

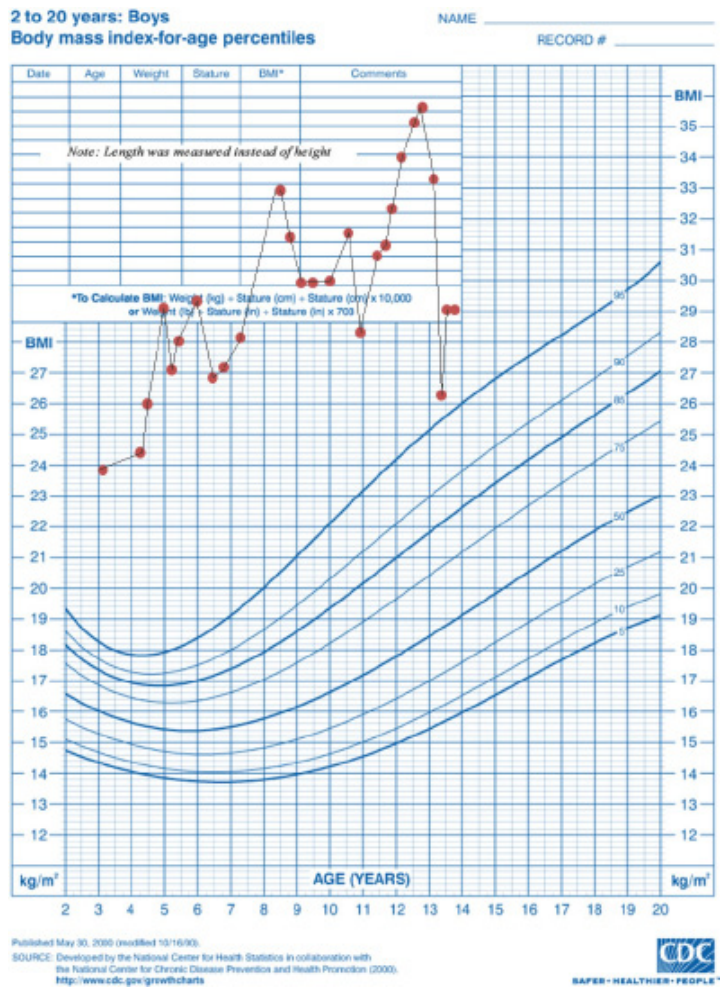
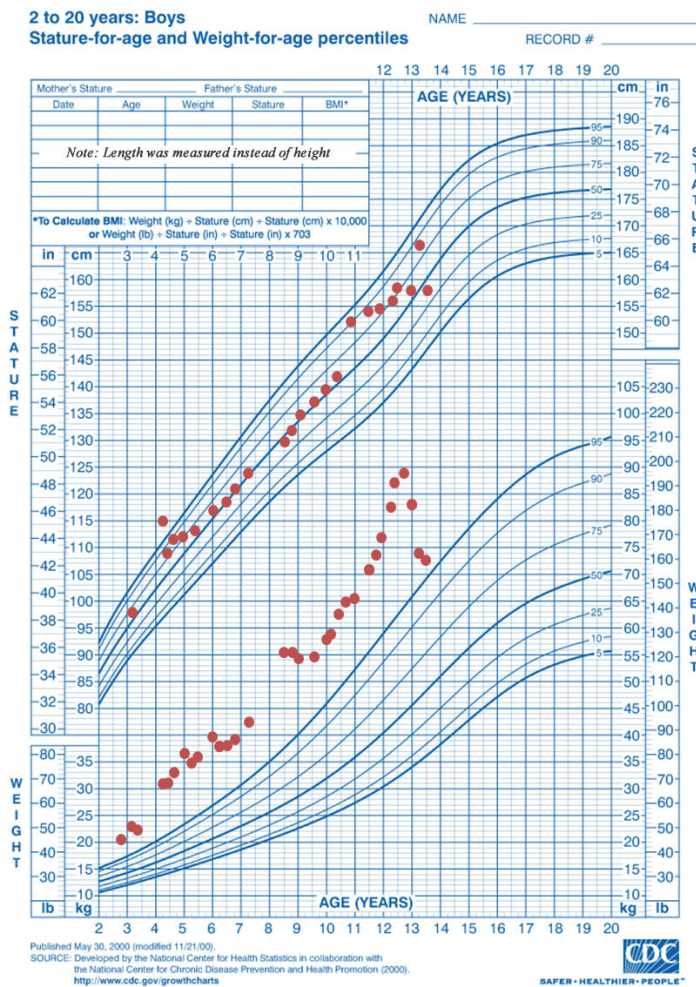


Figure 2. GJ's growth charts: Weight-for- age and stature-for-age (left) and BMI-for-age (right)

2. GJ will be offered one fresh fruit selection at lunch,
3. GJ will participate in adaptive PE class ½ hour per day.

GJ met with the RD twice over the next year to follow up on diet changes and weight changes. When GJ returned to the interdisciplinary spina bifida clinic one year later, he was happy to report that he had lost 10 kg and weighed 73.2 kg, placing his weight-for-age at the 97th percentile. GJ and his mother had made several changes to how they ate at home, but the key to success was GJ making the decision to lose weight. To continue the trend in weight loss, the RD recommended limiting calorie-containing beverages and limiting milk to 3 cups of nonfat milk daily. GJ will continue to see the RD and the interdisciplinary spina bifida clinic time twice a year until he graduates from the program at age 18 years.



## REFERENCES

- Burke R, Liptak GS and Council on Disabilities. Providing a primary care medical home for children and youth with spina bifida. *Pediatrics*. 2011;128(6):e1645-e1657.
- Liptak GS, Dosa NP. Myelomeningocele. *Pediatrics in Review*. 2010;31(11):443-450.
- Liptak GS. Neural tube defects. In: Batshaw ML, Pellegrino L, Roizen NJ. *Children with Disabilities*. Baltimore, MD: Brookes; 2007.
- Liptak GS, Samra AE. Optimizing health care for children with spina bifida. *Developmental Disabilities Research Reviews*. 2010;16:66-75.
- Brustrom J, Thibadeau J, John L, Liesmann J, Rose S. Care coordination in the spina bifida setting: current practice and future directions. *J Pediatr Health Care*. 2012;26(1):16-26.
- American Dietetic Association. Position of the American Dietetic Association: Providing nutrition services for people with developmental disabilities and special health care needs. *J Am Diet Assoc*. 2010;110(2):296-307.
- National Institute of Child Health and Human Development. How many people are affected by or are at risk for neural tube defects? *Neural Tube Defects (NTDs)*. US National Institutes of Health. 2012.
- Oakley GP. The scientific basis for eliminating folic-acid preventable spina bifida: a modern miracle from epidemiology. *Ann Epidemiol*. 2009;19:226-230.
- Centers for Disease Control. Spina bifida and anencephaly before and after folic acid mandate, United States, 1995-1996 and 1999-2000. *Morbidity and Mortality Weekly Report*. 2004;53(17):362-365.
- Centers for Disease Control. Recommendations for the use of folic acid to reduce the number of cases of spina bifida and other neural tube defects. *Morbidity and Mortality Weekly Report*. 1992;41(RR-14):001.
- Milunsky A, Jick H, Jick SS, et al. Multivitamin/folic acid supplementation in early pregnancy reduces the prevalence of neural tube defects. *JAMA*. 1989;262 (20):2847-52.
- Shelke N, Keith L. Folic acid supplementation for women of childbearing age versus supplementation for the general population: a review of the known advantages and risks. *International Journal of Family Medicine*. 2011;1-4.
- Daly S, Mills JL, Molloy AM, et al. Minimum effective dose of folic acid for food fortification to prevent neural-tube defects. *Lancet*. 1997;350(9092):1666-9.
- Molloy AM, Kirke PN, Troendle JF, et al. Maternal vitamin B-12 status and risk of neural tube defects in a population with high neural tube defect prevalence and no folic acid fortification. *Pediatrics*. 2009;123(3):917-923.
- Yang Q, Cogswell ME, Hamner HC, et al. Folic acid sources, usual intake, and folate and vitamin B-12 status in US adults: National Health and Nutrition Examination Survey (NHANES) 2003-2006. *Am J Clin Nutr*. 2010;91:64-72.
- Li F, Watkins D, Rosenblatt DS. Vitamin B-12 and birth defects. *Mol Genet Metab*. 2009;98(1-2):166-172.
- (Kreutzer) Bujold CE. *Validation of a Parent Completed Nutrition Screening Questionnaire for Children with Special Health Care Needs*. University of Washington, Seattle, WA, Master of Public Health Thesis. 1994.
- DeVore J, Shotton A (Eds). *Children with Special Health Care and Nutritional Needs*. Chicago, IL: Academy of Nutrition and Dietetics. 2012.
- Academy of Nutrition and Dietetics. *Pocket Guide for International Dietetics & Nutrition Terminology (IDNT) Reference Manual: Standardized Language for the Nutrition Care Process*, Fourth Edition. Chicago, IL: Academy of Nutrition and Dietetics. 2013.
- Adams RC, Keefover-Hicks A, Browne R, Hardin DS. Growth curves for children with myelomeningocele using longitudinal data. *Dev Med Child Neurol*. 2007;49(Suppl. 111):24.
- Ekvall SW, Ekvall VK (Eds). *Pediatric Nutrition in Chronic Diseases and Developmental Disorders: Prevention, Assessment and Treatment*. New York, NY: Oxford University Press; 2005.
- Duval-Beaupère G, Kaci M, Lougovoy J, Caponi MF, Touzeau C. Growth of trunk and legs of children with myelomeningocele. *Dev Med Child Neurol*. 1987;29:225-231.
- Satin-Smith MS, Katz LL, Thornton P, Gruccio D, Moshang T Jr. Arm span as measurement of response to growth hormone (GH) treatment in a group of children with meningomyelocele and GH deficiency. *J Clin Endocrinol Metab*. 1996;81:1654-1656.
- Trollman R, Strehl E, Wenzel D, Dörr HG. Does growth hormone (GH) enhance growth in GH-deficient children with myelomeningocele? *J Clin Endocrinol Metab*. 2000;85:2740-2743.
- Bandini LG, Schoeller DA, Fukagawa NK, Wykes LJ, Dietz WH. Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Pediatr Res*. 1991;29:70-77.
- Littlewood RA, Trocki O, Shepherd RW, Shepherd K, Davies PSW. Resting energy expenditure and body composition in children with myelomeningocele. *Pediatr Rehabil*. 2003;6:31-37.
- Shepherd K, Roberts D, Golding S, Thomas BJ, Shepherd RW. Body composition in myelomeningocele. *Am J Clin Nutr*. 1991;53:1-6.
- Bellou TF. Skinfold measurements enhance nutrition assessment and care planning for children with developmental disabilities. *ICAN: Infant, Child & Adolescent Nutrition*. 2011;3(3):158-170.
- Frisancho AR. New norms of upper limb fat and muscle areas for assessment of nutritional status. *Am J Clin Nutr*. 1981;34:2540-2545.
- Van den Berg-Emons HJ, Bussmann JB, Brobbel AS, et al. Everyday physical activity in adolescents and young adults with meningomyelocele as measured with a novel activity monitor. *J Pediatr*. 2001;139:880-886.
- Fiore P, Picco P, Castagnola E, et al. Nutritional survey of children and adolescents with myelomeningocele (MMC): overweight associated with reduced energy intake. *Eur J Pediatr Surg*. 1998;8(Suppl. 1):34-36.
- Grogan CB, Ekvall SM. Body composition of children with myelomeningocele determined by <sup>40</sup>K, urinary creatinine and anthropometric measures. *J Am Coll Nutr*. 1999;18:316-323.
- Bischoff A, Levitt MA, Bauer C, et al. Treatment of fecal incontinence with a comprehensive bowel management program. *J Pediatr Surg*. 2009;44:1278-1284.
- Short KR, Frimberger D. A review of the potential for cardiometabolic dysfunction in youth with spina bifida and the role for physical activity and structured exercise. *Int J Pediatr*. 2012;54:1363.
- Wittenbrook W. Best practices in nutrition for children with myelomeningocele. *ICAN: Infant, Child & Adolescent Nutrition*. 2010;2(4):237-245.
- Rimmer JH. Promoting inclusive community-based obesity prevention programs for children and adolescents with disabilities: the why and how. *Childhood Obesity*. 2011;7(3):177-184.
- Kiyoshi Y, Rimmer JH, Lowry BD, Vogel LC. Prevalence of obesity-related health conditions in overweight adolescents with disabilities. *Res Dev Disabil*. 2011;32, 280-288.
- Opperman EA. Cranberry is not effective for the prevention or treatment of urinary tract infections in individuals with spinal cord injury. *Spinal Cord*. 2010;48:451-456.



39. Pinzón-Arango PA, Holguin K, Camesano TA. Impact of cranberry juice and proanthocyanidins on the ability of *Escherichia coli* to form biofilms. *Food Sci Biotechnol*. 2011;20:1315-1321.
40. Cozens D, Read RC. Anti-adhesion methods as novel therapeutics for bacterial infections. *Expert Rev Anti Infect Ther*. 2012;10:1457-1468.
41. Mathisen BA, Shepherd K. Oral-motor dysfunction and feeding problems in infants with myelodysplasia. *Pediatr Rehabil*. 1997;1:117-122.
42. Latex in the home and community. *Spina Bifida Association of America Web site*. <http://www.sbaa.org>. Updated February 2012. Accessed September 17, 2013.

## RESOURCES

1. DeVore J, Shotton A, eds. Academy of Nutrition and Dietetics. *Pocket Guide to Children with Special Health Care and Nutritional Needs*. Chicago IL: Academy of Nutrition and Dietetics. 2012. <https://www.eatright.org/Shop/Product.aspx?id=6442467529>
2. *Nutrition Strategies for Children with Special Health Care Needs*. Harris AB, Blyler EM, Baer MT. USC UCEDD at Children's Hospital Los Angeles, 4650 Sunset Blvd, MS#53, Los Angeles, CA 90027. [http://www.uscucedd.org/index.php?option=com\\_content&view=article&id=166&Itemid=230](http://www.uscucedd.org/index.php?option=com_content&view=article&id=166&Itemid=230)
3. Yang Y, Lucas B, Feucht S, eds. *Nutrition Intervention for Children with Special Health Care Needs*, 3rd Edition. Washington State Department of Health. 2010. <http://here.doh.wa.gov/materials/nutrition-interventions>.
4. Feucht S, Ogata B. *Nutrition and Constipation*. Nutrition Focus for Children with Special Health Care Needs. University of Washington, Seattle, WA. 2010;25(3):11-1; Supplement 2 pages.
5. Centers for Disease Control and Prevention (CDC), National Center for Birth Defects and Developmental Disabilities (NCBDDD) provides pamphlets for professionals and the public on prevention of birth defects by assuring an adequate intake of folate when a woman is pregnant or anticipates pregnancy. Materials can be ordered or downloaded as PDFs and are available in English and Spanish. <http://www2a.cdc.gov/ncbddd/faorder/orderform.htm>.
6. The Spina Bifida Association provides materials and information for parents, the public and professionals including PDF documents that can be downloaded and printed for distribution. Local or State affiliate chapter can be identified through the association webpage. <http://www.spinabifidaassociation.org>
7. Recommended Skinfold Calipers - Lange and Harpenden. Various sites and online retailers sell these instruments.
8. Cushing P, Spear D, Novak P, Rosenzweig L, Wallace LS, Conway C, Wittenbrook W, Lemons S, Medlen JG, Academy of Nutrition and Dietetics. Standards of Practice and Standards of Professional Performance for Registered Dietitians (competent, proficient, and expert) in Intellectual and Developmental Disabilities. *Journal of the Academy of Nutrition and Dietetics*, 2012;112(9):1454-1464. <http://www.andjrn.org/article/S2212-2672%2812%2901188-4/fulltext>
9. United States Department of Agriculture, Food and Nutrition Services *Accommodating Children with Special Dietary Needs in the School Nutrition Programs: Guidance for School Food Service Staff*. Washington, DC. 2001. [www.fns.usda.gov](http://www.fns.usda.gov)

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To participate in this continuing education opportunity login to [http://depts.washington.edu/nutrloc/webapps/?page\\_id=844](http://depts.washington.edu/nutrloc/webapps/?page_id=844) to access the quiz related to this issue. You must correctly answer 80% of the questions to pass. Cost is \$20 (subscribers) or \$40 (non-subscribers) for 2 CPEU.

1. A team of providers provides optimum care to children with spina bifida. Often, the primary care provider (PCP) supports the family by advocating for the child, functioning as the:
  - a. specialist
  - b. medical home
  - c. guardian ad libtum
  - d. developmentalist
2. Abnormal nervous system control of the bowels is called:
  - a. Myelomeningocele
  - b. Chronic constipation
  - c. Neurogenic bowel
  - d. Neurogenic bladder
3. The energy needs of non-ambulatory children:
  - a. May be 25-50% less than their ambulatory peers
  - b. May be 80% less than their ambulatory peers
  - c. Are generally the same as ambulatory peers
  - d. Will depend upon the type of spina bifida
4. Which of the following menus would meet folate intake recommendations for women of childbearing age:
  - a. 1 cup rice, 1 cup broccoli, 1 slice bread, 2 cups lettuce
  - b. 3 ounces halibut, ½ cup white rice, 1 cup raw spinach, 1 cup milk
  - c. ½ cup vegetarian baked beans, 1 wedge cantaloupe, 1 cup boiled spinach
  - d. None of the above; most food patterns do not provide enough folate and a supplement is generally recommended
5. Vitamin B12 is important in prevention of neural tube defects (NTD) because:
  - a. It is a receptor in folate metabolism
  - b. It carries carbon groups for methylation and nucleic acid synthesis
  - c. B12 deficiency can lead to secondary folate deficiency
  - d. The mechanism is unknown, but studies have shown B12 deficiency can contribute to NTD risk
6. The best indicator of linear growth for a child with spina bifida is:
  - a. Standing height
  - b. Recumbent length
  - c. None of the above; children with spina bifida are generally shorter than peers, so linear growth cannot be evaluated
  - d. None of the above; the best indicator will depend on the individual
7. Arm span measurements:
  - a. Can be used only for children who have high lesions
  - b. Should be used to evaluate the growth of most children with spina bifida
  - c. Should be used in conjunction with another indicator such as triceps skinfold
  - d. Can be reliable for children who are treated with growth hormone to treat an underlying deficiency
8. Energy needs of children with spina bifida:
  - a. Are typically lower than energy needs of children without spina bifida because of less lean body mass and higher fat mass
  - b. Are typically lower than energy needs of children without spina bifida because of less energy expenditure with ambulation
  - c. Should be monitored regularly to identify problems and prevent obesity
  - d. All of the above
9. The most common medications prescribed for children with spina bifida are for:
  - a. Seizures
  - b. Neuropathic pain
  - c. Behavior management
  - d. Neurogenic bowel and bladder
10. Bone health is a concern for children with spina bifida. Which of the following was suggested to minimize osteopenia/osteomalacia:
  - a. Ensure adequate intake of calcium and vitamin D
  - b. Minimize sun exposure and use of anticonvulsant medications
  - c. Provide a vitamin D supplement to all individuals who use anticonvulsant medications
  - d. Refer to an endocrinologist for further workup

- 
11. Which of the following was NOT recommended for children with wounds:
- a. Ensure adequate energy intake
  - b. Protein intake of about 2-3 g/kg/day
  - c. Multiple vitamin with iron and supplemental iron and zinc as indicated
  - d. Continued weight loss if obesity is a concern
12. Arnold Chiari type II malformation can interfere with feeding because of:
- a. Hydrocephalus
  - b. Seizure disorder
  - c. Neurogenic bowel
  - d. Laryngopharyngeal palsies

# Folate Facts

- Folic acid (also known as folate or folacin) is a B vitamin found in spinach, leafy green vegetables, dried beans, liver, and citrus fruits.
- Cereal products are required to be enriched with folic acid to provide approximately 10% of the Dietary Reference Intake (DRI) per serving.
- Folic acid can be obtained in multi-vitamin/mineral supplements. Most contain 400 micrograms (mcg).
- More than 1 milligrams (mg) (or 1000 mcg) folic acid per day is not recommended unless under the supervision of a physician.
- Women of childbearing age are advised to consume 400 mcg of folic acid daily. Women who have previously given birth to a child with a neural tube defect should consume 4.0 mg folic acid daily<sup>1</sup>
- Most prenatal vitamins contain 600 mcg of folic acid.

## SELECTED FOOD SOURCES OF FOLATE AND FOLIC ACID

Food	mcg DFE *	percent DV **
Beef liver, braised, 3 ounces	215	54
Spinach, boiled, 1/2 cup	131	33
Black-eyed peas, (cowpeas), boiled, 1/2 cup	105	26
Breakfast cereals, fortified with 2% of the DV <sup>+</sup>	100	25
Rice, white, medum-grain, cooked, 1/2 cup <sup>+</sup>	90	23
Asparagus, boiled, 4 spears	89	22
Spaghetti, cooked, enriched, 1/2 cup <sup>+</sup>	83	21
Lettuce, romaine, shredded, 1 cup	64	16
Avocado, raw, sliced, 1/2 cup	59	15
Spinach, raw, 1 cup	58	15
Broccoli, chopped, frozen, cooked 1/2 cup	52	13
Mustard greens, chopped, frozen, boiled, 1/2 cup	52	13
Green peas, forzen, boiled, 1/2 cup	47	12
Bread, white, 1 slice <sup>+</sup>	43	11
Peanuts, dry roasted, 1 ounce	41	10
Wheat germ, 2 tablespoons	40	10
Tomato juice, canned, 3/4 cup	36	9
Orange juice, 3/4 cup	35	9
Papaya, raw, cubed, 1/2 cup	27	7
Banana, 1 medium	24	6
Yeast, baker's, 1/4 teaspoon	23	6
Egg, whole, hard-boiled, 1 large	22	6
Vegetarian baked beans, canned, 1/2 cup	15	4
Cantaloupe, raw, 1 wedge	14	4
Fish, halibut, cooked, 3 ounces	12	3
Milk, 1% fat, 1 cup	12	3

<sup>1</sup> CDC 1992

\* DFE = Dietary Folate Equivalents. The Food and Nutrition Board developed DFEs because folic acid from supplements is more bioavailable than folate from foods (at least 85% of folic acid is bioavailable when taken with food, whereas only about 50% of folate naturally present in food is bioavailable).

<sup>+</sup> Fortified with folic acid as part of the folate fortification program

\*\* DV = Daily Value. DVs help consumers compare the nutrient contents of products within the context of a total diet. The DV for folate is 400 mcg for adults and children aged 4 years and older. At this time food labels are not required to list folate content unless a food has been fortified with folate. Foods providing 20% or more of the DV are considered to be high sources of a nutrient.

ABBREVIATIONS - mg = milligrams, mcg, micrograms

This table is adapted from: <http://ods.od.nih.gov/factsheets/Folate-HealthProfessional>

