

# Kids with Tubes News

A newsletter connecting parents and caregivers of  
tube-fed children

## Letter from the Editors

I remember my mom telling me to drink my milk and clean my plate so that I would grow up big and strong. Of course I want my children to grow up big and strong, but I wasn't sure if this was exactly the advice I'd follow since my knowledge of nutrition had grown over the years: I was aware of the idea of a healthy diet by keeping fat grams and cholesterol low. Well, throw that all out the window. Now I have a child with a g-tube. Suddenly a healthy diet has become secondary to oral eating and fat grams have become desirable. As our family strives for a healthy diet for each one of its members, I am constantly revising and learning more about what constitutes a healthy diet.

The editors of this newsletter have endeavored to provide an overview of nutrition for the tube-fed child. Our children are different in their ages, abilities, diagnoses and prognoses. Most are meeting some or all of their caloric and fluid needs with formula. Many, but not all, Kids with Tubes families are working toward transitioning to oral eating. Food allergies seem to be more commonplace in the general population today as well as in the Kids with Tubes population. (At some point, haven't we all at least suspected a food allergy as our children's problem?)

Nutrition Basics for Children (page 2) is an overview of caloric needs (as well as protein, vitamin and mineral, and fat needs) and serving sizes. Fluid Requirements for Children (page 4) provides the conventional calculation method for fluid needs as well as some factors that may affect fluid needs. A case for choosing water over other fluids is presented in Water Intake for Health and Well Being (page 5). Nutritional Considerations for Tube Feedings (page 6) discusses many factors that must be considered when choosing formula for your child. An overview of diagnosing and managing a food allergy is presented in the article entitled Food Allergies (page 8). Pertinent information regarding vitamins and minerals is discussed on page 10. For your reference, we have also included a recipe for homemade formula (page 13), a list of calorie enhancers (Beyond Butter, page 13), and a list of books (page 15) and websites (page 14) discussing nutrition and related topics.

The difficulty involved in putting this newsletter together was not apparent when we began. Finding interested and qualified writers that understood the nutritional needs and concerns of a tube-fed child turned out to be a challenge. We hope that the information presented here will help you get your arms around nutritional concepts so that you can further your work toward providing a healthy diet for your child. Please remember, the information presented here is largely an overview. Our children are greatly different. It is important to work with your child's medical team, including a nutritionist, before making any changes to your feeding regimen.

A special thanks goes to the professionals who contributed articles for this newsletter, including Lilah Al-Masri, Suzanne Evans Morris, Jennifer Murphy, Patricia Murray, and Heidi Quinn.

Nancy Kolb with  
Jill Crisman  
Amanda Loftus  
Irene Walborsky  
Sue Wolff

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## *Nutrition for the Tube-Fed Child*

### *Our shared principles:*

- *Each child with a feeding tube is unique – what works for one child and family may not work for another.*
- *Always check with your child's doctor(s) and/or therapist(s) before using any information presented in this newsletter for your child's treatment or care.*
- *All information that is learned through any Kids with Tubes forum is to be treated with complete respect and confidentiality.*
- *Some children will outgrow the need for a feeding tube, others will have a tube for their lifetime; we seek to support all parents and caregivers of tube-fed children, whatever their experience will be.*

# Nutrition Basics for Children

## Lilah Al-Masri, MS, RD, LDN

Everyday we hear a new nutrition tip on the news or in the paper or from a friend. One tip tells us to eat something because it will be good for us and the next day we hear that it is bad for us. What do we do? What *should* we eat? Better yet, what *should* our children be eating? This article outlines general nutritional requirements for children.

A healthy lifestyle is based on good nutrition and physical activity. The food pyramid is a wonderful tool to help guide one to eat well. It can be found on cereal, bread, and cracker boxes. The food pyramid uses six food groupings: bread, cereal, rice and pasta; fruit; vegetable; milk, yogurt and cheese; meat, poultry, fish, dry beans, eggs and nuts; and fats, oils and sweets. Food items in each group can be further broken down into their contents that include carbohydrates, protein, and fats.

Carbohydrates are the body's preferred energy source. Carbohydrates provide the body with fuel to function properly. Carbohydrates include sugars (simple carbohydrates), starches (complex carbohydrates), and fiber. Fiber has several important functions in the body including maintaining bowel function, providing bulk, and delaying gastric emptying time. For children, the recommended amount is:

$$\text{AGE} + 5 = \text{Total grams fiber/day.}$$

Good sources of fiber include fruits, vegetables, 100% whole wheat bread, whole grain cereal and beans.

Protein is used by the body for maintenance, growth and tissue repair. Protein helps to regulate the body's immune system and regulate the body's processes. In addition to meat, poultry, fish, dry beans, eggs, and nuts, protein is found in many other foods including vegetables, breads and cereals.

Fats are the body's second energy source (carbohydrates are the primary source). Fats have several functions in the body including acting as a carrier for fat solu-

ble vitamins (A,D,E,K), regulating body temperature, protecting internal organs, providing satiety and flavor to the diet. Fats are essential for growth of skin, hair, and nails. Monounsaturated fat is found in both plant and animal products, usually liquid at room temperature.

Monounsaturated fats include nuts, peanut butter, avocado, and vegetable oils (peanut, olive and canola). (Eat more foods high in monounsaturated fats!)

Polyunsaturated fats are found in plant and animal products. Liquid vegetable oils-safflower, sunflower, corn and soy oil are high in polyunsaturated fat. Polyunsaturated fats are also found in fish such as tuna, salmon and mackerel.

Saturated fats are found primarily in foods of animal origin, generally solid at room temperature. Foods high in saturated fats include chicken skin, red meats, whole milk and 2% milk and products made from them, butter and cheese. Five vegetable fats are saturated: coconut oil, palm oil, palm kernel oil, cocoa butter, and hydrogenated vegetable oil. These are often found in processed baked goods, non-dairy cream substitutes, and frozen desserts. (Eat fewer foods that contain saturated fats!)

In addition, foods we eat contain vitamins and minerals that assist our bodies growth in many ways including regulation of metabolic processes. If one eats a wide variety of foods, a vitamin and mineral supplement is unnecessary. Certain clinical conditions may be an exception. Please see your physician or registered dietitian for specific supplement information.

**Remember—Every child is different.** Your child may need more or less depending on weight, height, activity level and/or medical status. Children's appetites will vary. They have a unique way of regulating their bodies and may eat well one day and poorly the next. This is normal. Food jags are quite common among the pediatric population.

If your child experiences food jags or refuses to try new foods, getting him/her involved in food preparation may be helpful. Food preparation is a great way for a child to spark interest in new foods and gain the confidence to try something new. This may be especially important for a child who has been solely or partially tube fed. q

*Lilah Al-Masri, MS, RD, LDN is a Pediatric Dietitian at The Franciscan Children's Hospital and Rehabilitation Center in Boston, MA. If you have any questions you may call her at 617-254-3800 x1350.*

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### Energy and Protein Requirements

Age	Calories per	Calories per	Protein gm/
	lb	kg	kg
0 to 1/2 year	49.0	108.0	2.2
1/2 to 1 year	44.5	98.0	1.6
1 to 3 years	46.0	102.0	1.3
4 to 6 years	40.9	90.0	1.2
7 to 10 years	31.8	70.0	1.0
11 to 14 years			
Male/Female	25.0/21.3	55.0/47.0	1.0/1.0
15 to 18 years			
Male/Female	20.4/18.0	45.0/40.0	0.9/0.8
19 to 24 years			
Male/Female	18.0/17.0	40.0/38.0	0.8/0.8

**Example:** Calculate the needs for a 5 year old boy who weighs 19 kg/41.8 lb.

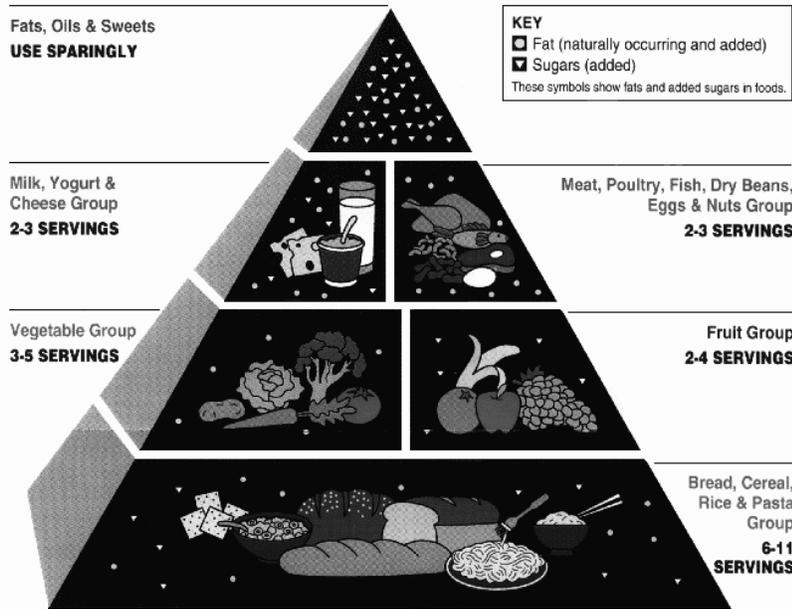
**Calorie needs:** 19 kg x 90 calories/kg = 1710 calories/day

**Protein needs:** 19 kg x 1.2 gm protein/kg = 23 gm protein/day

Adapted from the Manual of Pediatric Nutrition, Twin Cities Dietetic

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**The USDA Food Pyramid**



**Understanding Fat**

Children need fat for growth and development. Fat builds healthy cells and brains. Fat helps the body use vitamins, make hormones and provides for healthier skin. From birth to age two, 50% of a child’s caloric intake may come from fat calories. The American Dietetic Association recommends that between ages two and five, the total fat calories in a child’s diet be reduced from 50 to 30%, the same recommended intake as adults (*Complete Food & Nutrition Guide*, Duyff, 1996). Not all fats are created equal. Diets high in fat, especially saturated fat, have been found to contribute to heart disease, some types of cancer, diabetes and obesity (*Family Nutrition Book*, Sears, 1999). The Nutrition Basics article on page 2 discusses unsaturated, polyunsaturated, and saturated fat. This article discusses what many consider the best fat (Omega-3 fat) and the worst fat (trans fat from hydrogenated oils).

**“Good” fat.** Linolenic (Omega –3) acid is essential fat that your body does not produce. The American diet is generally high in fat consumption but low in Omega-3 fat consumption. Omega-3 fats are needed to manufacture healthy brain cells. Research suggests that Omega-3 fats may reduce the risk of heart at-tack by lowering potentially harmful substances in the blood. Omega-3 fats can be found in flax seeds, cold water fish such as salmon and tuna, canola oil, soybeans, walnuts, and eggs.

**“Bad” fat.** Processed foods including some margarine, shortening, cookies, crackers, fast food, snack foods and other foods contain trans fatty acids in the form of hydrogenated oils. Trans fatty acids are made when food processors chemically alter unsaturated fat by adding hydrogen, making the fat more stable, and extending shelf life. Trans fatty acids also are found naturally in some foods (beef, pork, lamb, milk, butter). These trans fatty acids act like saturated fats in the body, causing increased cholesterol levels. Some studies suggest that trans fat may inhibit the body’s ability to synthesize essential fats needed for brain function (*Feeding Your Child for Lifelong Health*, Roberts and Heyman, 1996). Since nutrition labels do not yet include trans fat, look for the terms hydrogenated or partially hydrogenated oil in the ingredient list of food products to determine if the product includes these fats. The Food and Nutrition Board of the Institute of Medicine (which provides input to FDA and other US nutrition policy makers) and the Center for Science in the Public Interest (a consumer nutrition watchdog group) agree: there is no nutritional value in trans fat and its intake should be limited. Both groups also recommend reducing overall saturated fat consumption, which will likely result in decreased trans fat consumption.q

**Serving Sizes for Children**

Food Group	1 to 3 years	4 to 6 years	7 to 10 years
<i>Grains</i> 6 to 11 daily servings	½ slice bread ¼ C cooked cereal, rice, pasta 1/3 C dry cereal 2 to 3 crackers	½ slice bread 1/3 C cooked cereal, rice, pasta ½ C dry cereal 3 to 4 crackers	1 slice bread ½ C cooked cereal, rice, pasta ¾ to 1 C dry cereal 4 to 5 crackers
<i>Vegetables</i> 2 to 3 daily servings	¼ C cooked vegetables	¼ C cooked vegetables ½ C salad	¼ C cooked vegetables ½ C salad
<i>Fruits</i> 2 to 3 daily servings	¼ C cooked or canned fruit ½ piece fresh fruit ¼ C juice	¼ C cooked or canned fruit ½ piece fresh fruit 1/3 C juice	1/3 C cooked or canned fruit 1 piece fresh fruit ½ C juice
<i>Dairy</i> 2 to 3 daily servings	½ C milk ½ oz cheese 1/3 C yogurt	½ C milk 1 oz cheese ½ C yogurt	1 C milk 1 oz cheese ¾ to 1 C yogurt
<i>Protein</i> 2 daily servings	1 oz meat, fish, poultry, tofu ¼ C dried, cooked beans ½ egg	1 oz meat, fish, poultry, tofu 1/3 C dried, cooked beans 1 egg	2 to 3 oz meat, fish, poultry, tofu ½ C dried, cooked beans 1 to 2 eggs

Source: *American Academy of Pediatrics Guide to Your Child’s Nutrition* by W.H. Dietz and L. Stern

## Is My Child Malnourished? A Parent's Perspective

Our family is going through the weaning process now with our daughter. It is amazing to me how little she eats, even when tube-fed supplementation is cut back or eliminated. Even though we butter everything, I know her daily caloric intake is less than what we or our feeding team would like to see. And with food jags and refusals of whole categories of foods, like fruit, I worry that her diet is not well balanced. Worse yet, I worry that her small stature is a sign that she is malnourished.

Fortunately, our feeding team is quick to step in and remind us that her weight to height ratio is around the 25th percentile, so although she is small for her age, she still is proportional for her height. They also remind me that she is (generally) healthy and active, which a malnourished child is not. She also has shiny hair and a glowing complexion, two other indicators that her system is getting the nutrients it needs. Could she do better? Yes. Is she malnourished? No.

During this time as we work toward weaning from the g-tube, we are supplementing her diet with a vitamin and mineral supplement as well as calcium (since she does not drink milk). I look forward to the day when I can count on her good eating to provide the nutrients she needs. In the meantime, our feeding team (feeding therapist, dietician, pediatrician, GI doctor) continues to assess her growth and eating habits to ensure good nutritional status. q

## Fluid Requirements for Children Jennifer Murphy, MS, RD, LDN

So how important is water in a child's diet? More often than not, water is the forgotten nutrient. When we think in terms of nutritional needs we tend to think about calories, protein, fat, vitamins and minerals. But what about water or any other fluid for that matter? Adequate fluid intake is crucial in maintaining hydration status. Water, juice, or any other fluid that does not contain caffeine or alcohol can be used to maintain hydration. Water is often recommended over juice due to the high sugar content in juices. Too much juice may result in diarrhea, abdominal pain, bloating and flatulence. It also can contribute to increased dental cavities when taken by mouth.

Fluid requirements in children are based on body weight according to the Holliday-Segar method. Fluid requirements are better estimated by weight than age, to take into account the possibility of an underweight or overweight child. The table below shows the baseline requirements for a normal healthy child. It is important to note fluid requirements are higher with increased losses (i.e. fever, diarrhea, vomiting, sweating, etc.). Fluid restrictions may be required in some medical cases and those children should be carefully

monitored by their physician. It is important, however, to maximize fluid intake within this restriction.

Infant formulas at standard dilution (20 calories/oz) are approximately 95 percent free water. Pediatric formulas at 30 calories/oz are approximately 85 percent free water. *Free water* refers to what remains after any solids are removed from a formula or food. These numbers are crucial in determining if the child is meeting his or her fluid requirement when placed on a particular formula. Water may need to be added to the tube feeding regimen depending on the total volume of the formula given daily. This may be done with water boluses, flushes to avoid clogging and water given with medications.

Too much free water may contribute to over hydration as too little free water can lead to dehydration. Physical symptoms of dehydration may consist of weight loss greater than one percent per day, increased thirst, decreased urine output, highly concentrated urine, etc. It is always important to check with your doctor or nutritionist to determine if you are giving an appropriate amount of fluid to your child. q

### Holliday-Segar Fluid Requirement Calculation

<u>Weight*</u>	<u>Baseline Daily Fluid Requirement</u>
1 to 10 kg (2.2 to 22 lbs)	100 ml/kg
11 to 20 kg (23 to 44 lbs)	1000 ml plus 50 ml/kg for each kg over 10 kg
Over 20 kg (over 44 lbs)	1500 ml plus 20 ml/kg for each kg over 20 kg

\*1 kg = 2.2 lbs, 1 ounce = 29.6 ml

Example: A 30 lb child  
 Convert to kilograms = 30 lbs / 2.2 kg/lb = 13.6 kg  
 Choose formula from above = 1000 ml + (50 ml/kg x 3.6 kg)  
 Calculate = 1000 ml + 180 ml  
 = 1180 ml fluid daily  
 Convert to ounces = 1180 ml / 29.6 ml/ounce  
 = 39.8 ounces fluid daily

## Water Intake for Health and Well Being

An Excerpt from *Gastrointestinal Health and the Child with Feeding Problems, Part 1*

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### Suzanne Evans Morris

It is commonly believed that the body requires a specific level of liquid intake — rather than a specific level of water intake — for health and well being (Batmangheildj 1995). Since children on feeding tubes receive their entire nutrition in liquid form, it often is assumed that they do not need additional water (other than that used to flush the tube). It is also assumed that water will fill them up and reduce their desire and tolerance for the formula. Thus, fear of reduced caloric intake also contributes to the failure to give needed water. Formula is a food — which like most milks, fruits, and vegetables — has a high percentage of water. However, this does not replace the body's cellular need for clear water to provide optimum function of all cells and systems. The digestive system is heavily dependent upon water for efficient function. The chronic "subclinical" dehydration experienced by children and adults who lack adequate water intake, can contribute to reflux and other gastrointestinal problems (Batmangheildj 1995). A child should receive water intake equivalent to two-thirds of the body weight. Thus, a child weighing 30 lbs. should be given 20 ounces of water throughout the day (Batmangheildj 1996). No physician would advise the parents of a typically developing child to drink only milk and juice. Water is recommended for all children and adults.

Lack of adequate water can affect the function of all systems of the body -- especially the gastrointestinal system, which needs water for digestion. Increased water can reduce gastroesophageal reflux, improve digestion, reduce constipation, and cleanse the body through removing toxins. The optimum amount of water varies with the age-range and weight of

the person. Doctors recommend that infants under the age of 6 to 9 months should not receive added water or have their formulas diluted with water. This is because the baby's kidneys have not developed the ability to retain extra fluid efficiently. As a result of the increased water intake there is a risk that the infant's body will release too much urine containing sodium. This can result in a condition known as hyponatremia or water intoxication that can lead to seizures and brain damage. Adding water according to specific weight and age guidelines does not create a risk for older infants and children who are on a formula diet because their kidneys are more mature and can retain and regulate the release of urine and sodium. However, water must be added carefully to the diet of any individual. This is definitely not a case where more is better! Children need the number of ounces equivalent to two-thirds of their body weight (Batmangheildj 1996). A child weighing 36 lbs. needs 24 ounces of water. When children reach the age of 10 to 12 years, their water needs approach that of adults. They need the number of ounces equivalent to half of their body weight (i.e. a child weighing 60 lbs. needs 30 ounces of water). It is commonly stated that adults need a minimum of 6 to 8 eight-ounce glasses of water per day. Juice, milk, tea, and soda do not count toward the daily allotment of water. The body needs clear fluid that is not a food requiring digestion (Batmangheildj 1995).

Water should be introduced very slowly and the total daily amount should be divided into small portions and given approximately 30 minutes prior to each tube-feeding or oral meal. This may be offered by feeding pump, a syringe or gravity bolus feeding, or orally. It is important to begin with an

amount and a rate that is comfortable for the child. This can be very gradually increased over a period of weeks or months. Increments should be very small. For example, if the child is comfortable with 30 cc of water (i.e. 1 ounce), the next increase should be 45 cc (i.e. 1.5 ounces). Monitor the amount of urine output in diapers or trips to the bathroom. As water intake increases, urination should also increase. If there is a history of urinary tract dysfunction or a cardiac problem resulting in water retention, the child's physician should be consulted before fluid intake is increased.

Thirst signals are often unclear to children and adults who are chronically dehydrated. A dry mouth is often the last signal of thirst. A body can suffer from dehydration even though the mouth is moist. Gastrointestinal pain and discomfort can be a major signal that the body is not getting enough water (Batmangheildj 1995).

In his book, *Your Body's Many Cries for Water*, F. Batmangheildj, MD makes a strong case for gastroesophageal reflux (heartburn) as a symptom of inadequate water intake. Copious amounts of water are needed in the stomach for digestion. When we drink a glass of water, it rapidly passes through the stomach and is absorbed in the intestine. Thirty minutes later the stomach secretes the same amount of water through the glandular layer in the mucosa. The water in the stomach is now ready to mix with stomach acids and enzymes and assist with digestion.

The cells in the small intestine would be damaged by acid from the stomach if the pancreas did not secrete a watery bicarbonate solution that changes the environment to a strongly alkaline

(Continued on page 12)

## Nutritional Considerations for Tube Feedings

Heidi Quinn MS, RD, LDN

Parents frequently have questions about what goes into the tube which is the mainstay of nourishment for their child. The following are some commonly asked questions about tube feeding nutrition.

**Q: There are so many different formulas out there. How do we know which one is best for our child?**

**A:** Formula selection depends on several variables including the age and size of the child, absorption capabilities, food sensitivities or allergies, volume tolerance and medical diagnosis. The decision regarding formula selection should be discussed with your child's pediatric gastroenterologist and nutritionist. The following is a brief overview of formula categories based on these variables. Examples of each type within each age category are found in the table on page 7.

**AGE:** Formula selection by age can be categorized as follows: premature, infant, toddler/child, older child/adult. Caloric, protein and vitamin and mineral content are tailored to meet the needs of the child at various ages. There may be slight differences between brands within each specific category, but generally the total nutrient compositions are similar. Most formulas within each age category are tolerated by most children, if there are no issues regarding malabsorption or food allergies. However, some children may be sensitive to slight variations in the amount of fat in a formula even if they don't have specific food intolerances.

**ABSORPTION CAPABILITIES:** Some formulas are designed to be more easily digested through modifications in their protein and/or fat components. Basically the protein and/or fat are broken down into smaller components for easier digestion. There are differences between formulas in this category, with some formulas being

more broken down, or "elemental" as they are called. Some children tolerate a formula which is partially broken down while some need a fully elemental formula. Examples of these are hydrolyzed whey based, casein hydrolysate based, and elemental formulas.

**FOOD SENSITIVITIES / ALLERGIES:** Some formulas are designed to meet the needs of children who have allergies or sensitivities to specific proteins (i.e. milk or soy), fats (soy or corn oil) or carbohydrates (lactose, corn syrup). These formulas may contain soy protein instead of the milk proteins casein and whey, or they may contain an "elemental" protein source (i.e. hydrolyzed proteins or free amino acids). They may be lactose free, that is they contain the milk proteins casein and/or whey, but not the milk sugar, or carbohydrate, lactose.

**VOLUME TOLERANCE:** Some formulas are more calorically dense than others. Standard infant formulas have 20 calories per ounce, though some infant formulas have more (22-24 calories/oz.). Modular components (i.e. additional fat, protein or carbohydrate sources) can be added to increase the caloric density of infant formulas as needed. Toddler/child formulas typically have 30 calories per ounce, though these can be modified for increased caloric density with modular components also. Older child/adult formulas are available as 1.0, 1.5 and 2.0 calories per ml, i.e. 30, 45 or 60 calories per ounce. Generally, a formula with higher caloric density is used to meet the needs of children who have very high caloric requirements but cannot tolerate high volumes of formula due to vomiting or fluid restrictions.

**MEDICAL DIAGNOSIS:** Some formulas are designed to meet the needs of children with specific medical issues such as diabetes, cardio-pulmonary is-

sues, renal/liver issues, HIV. Variations in these formulas include alterations in their protein, fat and/or carbohydrate content.

**Q: What about homemade formulas? Are they better for my child than formulas that come from a can?**

**A:** The decision to use homemade formulas vs. commercially made formulas can be very significant for some families. Nurturing our children through what we feed them is a natural response. There are several things to consider when making the decision to use homemade formulas. First of all, obtaining a balance of foods to provide the needed calories, protein, fat, vitamins and minerals in a volume that is tolerated by the child can be challenging. The volume issue is an important one, because frequently the blended foods need to be processed with additional water to make them thin enough to go through the tube. Providing adequate nutritional balance in a volume that can be tolerated by the child requires close collaboration with a pediatric nutritionist. Tube size is also a factor. Blended foods will have to be thinner, i.e. more dilute, to fit through a smaller tube. Food safety and sanitation is also an important consideration. It is very important that foods be prepared under safe, sanitary conditions and stored properly to maintain their nutritional value. Keeping all of the above in mind, it is possible for some children to use homemade blended foods as their tube feeding. It should also be noted that there are commercially available food based formulas called Compleat Pediatric (ages 1-10) and Compleat Modified (over 10 years) for those families who want the convenience and standardized nutritional composition of commercially made formula. A recipe for homemade formula is included in this newsletter on page 13.

**Q: How long can my child stay on a single formula? Should we be changing the formula periodically?**

A: Several factors should be considered when making the decision to change formulas including whether the child is on a specific formula for medical diagnosis, allergy or malabsorption concerns, and whether there are volume tolerance issues. Some children are more sensitive to changes in formulas, and it would not be wise to change the formula if they are currently tolerating it well. It is not clear that there is necessarily any benefit to changing formulas to provide a more varied diet intake. However, for children who do not have allergy or absorption issues, parents who feel they would like to rotate formulas to provide variety in their child's intake can be reassured that this practice is not harmful. It may be complicated to work out in terms of prescriptions and home care company deliveries. Formulas should be changed from an infant formula to a toddler formula to an adult formula as the child gets older. Formulas may also need to be changed due to changes in the child's medical status and/or changes in tolerance.

**Q: How do I know my child is getting the right amount of formula?**

A: Generally, the best indicator of adequate formula intake is the child's growth pattern. If the child is gaining weight and showing consistent linear growth, formula intake is adequate in terms of calories and protein. However, the volume of formula that is required to meet the child's caloric needs may be lower than the volume needed to meet fluid and/or vitamin and mineral needs. Caloric needs may be reduced due to decreased activity levels, de-

creased muscle mass, or due to neurological issues. Fluid needs are generally based on a child's body weight and should also take into consideration excessive losses through drooling, excessive sweating, diarrhea (refer to Fluid Requirements for Children on page 4 for additional information). Additional fluid can be provided through water flushes/boluses as needed. Vitamin and mineral supplements can also be provided to help meet nutrient needs for those children with reduced calorie requirements (See the vitamin article on page 10 for additional information on supplementation). Formula volume should be modified based on a child's rate of growth. For this reason, it is important to monitor a child's growth regularly. Changes in weight and

height should be monitored at least every 3-6 months for a child who is tube-fed. This is especially important during periods of transitional feeding, i.e. when transitioning from fully tube feeding to oral feeding or from fully oral feeding to supplemental feeds. q

**Heidi Quinn M.S.,R.D., L.D.N.** was Director of Nutrition for the Developmental Evaluation Center at Children's Hospital in Boston for 11 years, providing nutrition and feeding consultations for children with special needs. She currently works as a consultant to several schools for children with special needs and consults to the Down Syndrome Program at Children's Hospital in Boston.

**Examples of Formula Types by Age**

<u>Formula Type</u>	<u>Infant</u>	<u>Toddler/Child</u>	<u>Older Child/Adult</u>
Cow Milk Based	Enfamil Premature* (Mead Johnson) Similac Special Care* (Ross) Similac (Ross) Similac PM 60/40 (Ross) Enfamil (Mead Johnson) Gerber (Gerber) Lactofree (Mead Johnson)	Kindercal (Mead Johnson) Pediasure (Ross) Nutren Junior (Nestle) Compleat Pediatric (Novartis) Follow Up (Carnation) Enfamil Next Step (Mead Johnson)	Ensure (Ross) Boost (Mead Johnson)
Soy Based	Isomil (Ross) Isomil DF (Ross) Prosobee (Mead Johnson) Asoy (Carnation)	Follow-up Soy (Carnation) Enfamil Next Step Soy (Mead Johnson)	Isocal (Mead Johnson) Isosource (Novartis) Jevity (Ross) Ultracal (Mead Johnson)
Hydrolyzed Whey Based	Good Start (Carnation)	Peptamen Junior (Nestle) Resource for Kids (Novartis)	Peptamen (Nestle) Vital (Ross)
Casein Hydrolysate Based	Pregestimil (Mead Johnson) Nutramigen (Mead Johnson) Alimentum (Ross)	Criticare HN (Mead Johnson)	
Elemental/Hypoallergenic	Neocate (SHS America)	Neocate One Plus (SHS America) Pediatric Vivonex (Novartis)	Vivonex (Novartis)

\* For premature infants

Note: This table is intended as example only and is not complete. All labels should be read to ensure that the appropriate formula is selected.

# Food Allergies

## Patricia Murray, RD, MEd

Food allergy or sensitivity is reported in four to eight percent of the pediatric population (Anderson, 1994.) Food allergies may be difficult to diagnose in the pediatric population, since children’s symptoms are exceedingly diverse. This article will define a food allergy, describe symptoms, define the different diagnostic tests for food allergy testing, and discuss treatment.

**What is a food allergy?** “A food allergy is any adverse reaction to an otherwise harmless food or food component that involves the body’s immune system” (AAAI, 1993). It is not to be confused with other types of adverse reactions to foods, such as food intolerance (e.g. lactose intolerance). Food allergy or sensitivity occurs only when the immune system is involved in causing the reaction. “A food allergen is the part of a food that stimulates the immune system of food-allergic individuals. A single food can contain multiple food allergens, the majority of which are likely to be proteins, not carbohydrates or fats” (AAAI, 1993).

**Who is most likely to develop a food allergy?** The ability to become allergic is often inherited, though a child can also develop a non-inherited food allergy. Children with one allergic parent have twice the risk of developing food allergies as children without allergic parents. If both parents are allergic, then the chances are quadrupled for their children (AAIA, 1993). However, a child may have a completely different food allergy than that of the parent. For example, a parent who is allergic to peanuts may have a child who is allergic to milk, but not allergic to peanuts.

### Food Allergy Symptoms

Foods most likely to cause food allergy or sensitivity are milk and other dairy products, eggs, fish, including shellfish, wheat, soy, peanuts, and other legumes

(split peas, lentils, etc.), and tree nuts such as walnuts, almonds etc. Food allergy symptoms vary greatly in degree, time of onset, location and amount of food eaten. The same food can produce vastly different symptoms in different people. In a person with food allergies, different foods can cause different symptoms. Most documented allergic responses occur within two hours after ingestion of the offending food, although symptoms may be delayed up to 48 hours (Adam, 1987). Food allergies can be mild, moderate, or life-threatening. Anaphylaxis is a potentially fatal condition in which several different parts of the body experience food-allergic reactions at the same time. Symptoms may include severe itching, hives, sweating, swelling of the throat, or breathing difficulty. In very sensitive people, smelling or even touching the allergic food may produce a serious reaction. Most fatalities occur outside the home, when, in spite of an allergy history, no emergency care action plan has been made.

A child may outgrow their food allergy. However a child with asthma and a food allergy is less likely to outgrow the food allergy.

### Food Allergy Diagnosis

As a food allergy may or may not be difficult to diagnose, it is often helpful to have parents keep a food diary to record not only foods but symptoms. An allergy in a young child may be obvious when the child exhibits symptoms such as vomiting, hives and swelling after ingesting the offending food on more than one occasion. The medical diagnosis is based on history of food allergy symptoms, physical examination, tests, trial elimination diets, and food challenge, all of which are done under the supervision of a qualified allergist. Dietitians can provide support to families throughout each of these phases of diagnosis (Adams, 1987).

The two most common food allergy tests are the IgE Rast blood test and skin prick tests. The blood test requires a small sample of blood be sent to the laboratory, where the amount of IgE antibody to the specific food is measured. The result is reported as a numerical value. Skin tests are performed by exposing a tiny area of scratched skin to the suspected food. This is done by pricking the skin with a small needle through a drop of the food

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### Symptoms of Food Allergy

<u>Gastrointestinal</u>	<u>Cutaneous</u>	<u>Systemic</u>	<u>Respiratory</u>	<u>Neurological/ Behavioral</u>
Swelling of lips, mouth or throat	Hives	Failure to thrive	Runny nose	Headache
Abdominal pain	Eczema	Anaphylaxis	Wheezing	Irritability
Distention	Redness		Cough	Tension*
Nausea	Edema		Otitis media	Fatigue*
Vomiting	Itching		Conjunctivitis*	Seizures*
Diarrhea				
Colitis				
Colic*				

\*Still under research, not yet proven.

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extract, or by using a pricking device that has been pre-soaked in the food extract. A positive skin test results in a mosquito-bite-looking reaction at the site of the test within minutes. Both of these tests can result in a false-positive. The tests can not diagnose the level of severity of the allergy.

The only definitive allergy test is the oral challenge; however, this test carries a risk of serious reaction. This test is done by giving gradually increased amounts of the suspect food under a doctor's supervision while observing the child's symptoms. Only trained medical professionals with emergency treatment immediately available should do these tests.

There are also food allergies, such as some gastrointestinal allergies, that are non-IgE mediated (they may be mediated by IgA, IgG, etc.). An oral challenge may be the only definitive method to diagnose such a food allergy (Sicherer, 1998).

Elimination diets can also be used for food allergies that do not cause anaphylaxis. Foods suspected of causing an allergic reaction are eliminated for two to three weeks to determine if symptoms disappear. During this phase it is important to monitor growth and proper nutrition, to prevent growth failure and malnutrition. An elemental formula or hypoallergenic may be beneficial during this phase. After two to three weeks, if improvements are observed, then the suspected foods are gradually reintroduced one at a time to see if symptoms reoccur, and with which foods (Taylor 1987).

### Food Allergy Management

The primary treatment for managing food allergies is eliminating the offending food or foods. A diet should be planned carefully so that the child's

nutrient and calorie needs are met. If a major food group such as dairy products causes an allergy, a supplement or non-dairy formula may need to be added to the child's diet. For a child that is tube-fed, the formula selection should be done with the physician and dietitian to be sure the formula does not contain any of the offending allergen. Elemental or hypoallergenic formulas are available.

An emergency plan should be in place for the child who has anaphylactic reactions or is at risk for anaphylaxis. Treatment is generally a subcutaneous injection of epinephrine (adrenaline), such as EpiPen Jr., followed by an oral antihistamine, such as Benadryl. An identification bracelet should also be worn to alert medical personnel or other caretakers in case the child is unable to advocate for himself. Practice kits to learn how to use epinephrine are available from the Food Allergy Network ([http://www.allergic-reactions.com/consumer/2\\_1.cfm](http://www.allergic-reactions.com/consumer/2_1.cfm)) or your local pharmacy.

Parents must learn to read labels carefully to avoid allergens. Often, the offending food can come in different forms or have a variety of names. For example, a child allergic to milk must avoid whey, a protein found in milk. By law, a food ingredient must be listed on the label, but allergenic components can accidentally get into foods. In addition, food companies may periodically change the ingredients of a food that was originally allergen free. Parents will also need to be watchful when their child is in daycare, school, a restaurant, or at parties. A parent may want to seek assistance from a pediatric registered dietitian familiar with food allergies. Parents also need to be aware that a new method of growing produce, called biotechnology, may pose a risk to the allergic child. Genetic material from peanuts is being transferred to tomatoes and other produce to develop

Consider the following when developing an **Emergency Care Action Plan** for food allergies that may cause anaphylaxis.

- Include directions on when to administer epinephrine. Since epinephrine can cause serious side effects, ask your child's doctors when this life-saving medication should be used.
- Carry EpiPen Jr at all times.
- Alert caregivers of the allergen, and make sure caregivers have an EpiPen Jr and know how to administer it.
- Consider potential use of antihistamines. Ask your physician whether antihistamines should be carried in addition to epinephrine.
- Have your child wear a medical identification bracelet describing their allergies and susceptibility to anaphylaxis. This can help ensure prompt, proper treatment during an emergency.
- Seek emergency medical treatment at once, even after administering epinephrine.

better-looking (but not necessarily better tasting) produce. The FDA is requiring that new products be labeled to identify common allergens (Schepers 1994).

### Breastfeeding and Food Allergies

The literature is controversial, but it appears that while breastfeeding does not prevent food allergies from occurring, it may delay the onset and severity of the allergy. The diet of the mother during lactation would need to be allergen free, because food allergens can be transferred in breast milk (Zeiger, 1994). Breastfeeding is the preferred feeding for infants, including those with allergy to cow and soy milk. When breastfeeding is not possible, the American Academy of Pediatrics recommends use of a protein hydrolysate formula, such as Alimentum, for infants with clinical

*(Continued on page 12)*

## Vitamins and Minerals 101

This article was compiled by Nancy Kolb from information in the referenced nutrition books. The article was reviewed by Heidi Quinn MS, RD, LDN

There are 13 essential vitamins and 15 minerals that work to regulate your body's systems. Vitamins and minerals have no calories and are not an energy source, but assist in metabolizing nutrients in food and are invaluable in keeping your body running smoothly.

Children who receive their nutritional requirements only through tube-feeding probably do not need vitamin and mineral supplementation since formulas are specifically created with children's nutritional needs in mind. In tube-fed children where total caloric needs are limited for medical purposes, or children who are being transitioned to oral eating, additional vitamin and mineral supplementation may be required.

In considering your child's needs for supplementation, please consult your child's nutritionist and consider the following:

- Vitamins and minerals are better absorbed from food sources than

supplements.

- If some is good, more is not necessarily better. Take care when adding vitamin and mineral supplements to the diet, especially Vitamin A, zinc, iron, and copper.
- If choosing a supplement, look for one that provides an amount less than or equal to the Reference Daily Intake

The table of reference daily intakes (RDIs) lists each vitamin and mineral as a complete checklist for your use in choosing a supplement. Additional discussion is provided below on some vitamins and minerals. Please consult your child's nutritionist and the booklist on page 15 to find additional information on vitamins and minerals.

### Vitamins

The Basic Vitamin Information table contains vitamin function, signs of deficiency, and food sources for the 13 vitamins. Vitamins A, D, E, and K are fat-soluble. These vitamins are stored in

your body and may be accumulated to some extent. These fat-soluble vitamins require fat for transport throughout your body. The remaining vitamins are water-soluble. These vitamins are flushed quickly out of your system and need frequent replenishment. In addition, food processing and cooking can easily destroy water-soluble vitamins. In terms of keeping the vitamins in the food, microwaving fresh vegetables retains the greatest number of nutrients. Consider eating the skins and outer areas of vegetables and fruits, since vitamins and minerals are found more abundantly there, not in the centers.

### Minerals

Like vitamins, minerals help regulate your body's processes. They also make up about four percent of your body's structure. Minerals cannot be destroyed by cooking or processing food. While there are 15 essential minerals, calcium, iron and zinc are often of concern in the pediatric population. Recent diet surveys also have reported that more than 50 percent of children in the US consume inadequate amounts of one or more of calcium, iron, and zinc. (Roberts and Heyman, p. 37).

**Calcium.** Essential calcium deposits that strengthen bones and teeth occur almost entirely during childhood and adolescence. Physical activity also will aid in promoting strong bones by sending signals to the body to pull additional calcium from the bloodstream. Children are more efficient at absorbing calcium than adults (Sears p.55), taking around 75 percent of the calcium from food, whereas adults may only absorb 15 percent.

Calcium is abundant in milk products, but if your child doesn't eat or drink milk products, a calcium supplement may be needed. Labels on calcium supplements can be misleading. Only elemental calcium is

### Reference Daily Intakes (RDI)

Vitamin	Children			Minerals	Children		
	Infants	Children Under 4	Over 4 Through Adults		Infants	Children Under 4	Over 4 Through Adults
A	1500 IU	2500 IU	5000 IU	Calcium	600 mg	800 mg	1000 mg
D	400 IU	400 IU	400 IU	Iron	15 mg	70 mcg	18 mg
E	5 IU	10 IU	30 IU	Phosphorus	500 mg	800 mcg	1000 mg
K	**	**	80 mcg	Iodine	45 mcg	70 mcg	150 mg
C	35 mg	40 mg	60 mg	Magnesium	70 mg	200 mg	400 mg
Thiamin (B-1)	0.5 mg	0.7 mg	1.5 mg	Zinc	5 mg	8 mg	15 mg
Riboflavin (B-2)	0.6 mg	0.8 mg	1.7 mg	Selenium	**	**	70 mcg
Niacin	8 mg	9 mg	20 mg	Copper	0.6 mg	1.0 mg	2.0 mg
B-6	0.4 mg	0.7 mg	2.0 mg	Manganese	**	**	2.0 mg
Folate*	100 mcg	200 mcg	400 mcg	Chromium	**	**	120 mcg
B-12	2 mcg	3 mcg	6 mcg	Molybdenum	**	**	75 mcg
Biotin	50 mcg	150 mcg	300 mcg	Chloride	**	**	3400 mg
Pantothenic Acid	3 mg	5 mg	10 mg	Sodium	**	**	2400 mg
				Potassium	**	**	3500 mg
				Fluoride	**	**	**

IU=International Units  
mg=milligrams

\* Also known as folacin and folic acid

available to the body. Calcium carbonate is 40 percent elemental calcium, while calcium glutamate is only 9 percent elemental calcium. Calcium is best absorbed when taken in small amounts throughout the day. Fiber and soft drinks containing citric or phosphoric acid decrease calcium absorption, while vitamin D improves absorption. Calcium should also be given separately from an iron-containing multivitamin, since iron can also hinder absorption.

**Iron.** Iron helps the blood carry oxygen. When children don't get enough iron, they may be fatigued, irritable, and have a difficult time concentrating. Overall poor health is also a possible sign of anemia (anemia is a deficiency in the oxygen-carry portion of the blood). Iron deficiency anemia is one of the most common nutritional problems with children. (Note that there are other causes of anemia besides iron deficiency.) Babies are born with substantial iron stores and receive a small additional amount of iron through breast milk. Many baby formulas are fortified with iron. However, when changing from formula to cow's milk, or from tube to oral feeding, iron consumption may not meet a child's requirements.

Only a small percentage of iron in food is absorbed. Iron from meat, poultry and fish is absorbed better than iron from vegetables or grains (Satter, 485). Foods rich in vitamin C also will help iron absorption, if consumed in the same meal. Cooking in cast iron will also impart iron into the food. High-fiber foods and milk and dairy products hinder iron absorption.

**Zinc.** Many scientists believe that zinc deficiency may be one of the most common hidden health problems in children today since children's zinc levels are not routinely tested. A zinc deficiency may result in appetite loss, skin changes, and reduced resistance to infections (Duyff, p. 102). "This relatively little-known mineral stars in the many enzyme processes that speed up or slow down metabolism. Zinc is an essential partner to more than two hundred of these enzymes. It is especially responsible for

controlling the cell division, growth, and protein synthesis that occur only during childhood. Too little zinc will stop a child from growing. If the deficiency persists, it will cause permanent stunting." (Roberts and Heyman, p. 43) Good sources of zinc are hard to come by, and many children's supplements do not include zinc. Zinc can be found in lean meats, seafood, whole grains, legumes, nuts and seeds, and milk.

**Phytonutrients**

Beyond vitamins and minerals, thousands of phytonutrients or phytochemicals have recently been identified in fruits, vegetables and whole grain cereals. *Phyto* is from Latin meaning plant.

Many of these phytonutrients are believed to protect the body against aging and disease, especially cancer and heart disease. Stay tuned! Science is still discovering these nutrients and continuing to understand the body's nutritional needs. q

References:  
*The American Dietetic Association's Complete Food & Nutrition Guide*, by Roberta Larson Duyff, 1996.  
*Child of Mine, Feeding with Love and Good Sense*, Ellyn Satter, 2000.  
*The Family Nutrition Book*, William Sears and Martha Sears, 1999.  
*Feeding Your Child for Lifelong Health*, Susan Roberts and Melvin Heyman, 1996.  
*The PDR Family Guide to Nutrition and Health*, Medical Economics, 1995.

**Basic Vitamin Information**

Vitamin	Function	Signs of Deficiency	Food Sources
A	Antioxidant, promotes healthy vision, skin, and teeth; boosts immune system	Night blindness, dry eyes, dry, scaly skin, diarrhea, increased susceptibility to infections	Fortified milk, cheese, butter, liver, eggs, dark green leafy vegetables, deep orange fruits and vegetables
C	Antioxidant, help with wound healing, strengthen resistance to infection	Bleeding gums, easy bruising, depressed immune function, infection, anemia	Citrus fruits, broccoli, tomatoes, melons, dark green leafy vegetables, cabbage, strawberries, potatoes
D	Assists in absorption of calcium and phosphorus for strong bones and teeth	Fragile, easily fractured bones and weak muscles -- a condition called rickets	Sunshine stimulates a cholesterol like substance in the skin to make Vitamin D. Dietary sources not necessary as long as skins is exposed to as little as 15 minutes of sunshine 3 times a week. Milk is fortified with Vitamin D.
E	Antioxidant; protects cell membranes against damage	Anemia, neurological damage; effects of deficiency less clear than other vitamins	Vegetable oils, green leafy vegetables, whole-grain products, egg yolk
K	Assists in the blood-clotting mechanism	Bleeding, diminished blood clotting	Green leafy vegetables, cabbage, cauliflower, liver, made by bacteria in intestines
Thiamin (B-1)	Helps cells convert sugars to energy, especially cells in heart and brain	Weakness, nervous system malfunction, heart failure	Pork, organ meats, legumes, nuts, whole grains, enriched cereal
Riboflavin (B-2)	Assists in converting carbohydrates to energy; assists in red blood cell production	Dry, scaly cracked skin; eyes sensitive to bright light; sore red tongue	Dairy products, dark green leafy vegetables, whole grains and enriched bread and cereal
Niacin	Assists in converting carbohydrates to energy, especially in digestive and nervous systems	Dry, cracked, inflamed skin; digestive and nervous system malfunction, loss of appetite, diarrhea, rash	Meat, milk, eggs, poultry, fish, whole grains, enriched bread and cereal, nuts
B-6	Assists in protein metabolism; boosts immune system; assists in building brain's neurotransmitters	Convulsions; muscle twitching; nervous system malfunction; skin disorders	Meat, poultry, fish, whole grains, enriched bread and cereal, legumes, green and leafy vegetables
Folate*	Assists in production of new cells including DNA and red blood cells	Anemia, diarrhea, constipation, delayed growth, infections	Legumes, liver, leafy green vegetables, beans, nuts
B-12	Assists in forming new cells, healthy nervous system	Anemia, nerve damage, fatigue	Seafood, meat, yogurt, milk, cheese, eggs
Biotin	Assists in energy production at the cell level	Rarely a problem, although appetite loss, fatigue, depression or dry skin may rarely occur	Eggs, liver, yeast breads, cereals and many other foods
Pantothenic Acid	Assists in energy production at the cell level	Fatigue, vomiting	Meat, poultry, fish, whole-grain cereals and legumes

## Water Intake for Health and Well Being

*Continued from Page 5*

solution. Once the bicarbonate solution has been released, the pyloric valve opens to allow stomach contents to pass into the small intestine. These acid contents are then neutralized by the alkaline solution secreted by the pancreas. The manufacturing of the watery bicarbonate solution requires a great deal of water from the body's circulation. When inadequate water is present due to chronic dehydration there is often inadequate production and release of the bicarbonate solution. The pyloric valve does not receive the signals to open and release the stomach's acidic contents into the intestines. This is a self-protective response since the walls of the intestines lack the protective layer against acid that is present in the stomach. The pyloric valve constricts more tightly and the lower esophageal sphincter relaxes. This results in the "anti-peristalsis" that reverses the contractions and sends stomach contents upward into the esophagus (Batmangheildj 1995, p.37-38)

One of the functions of the neurotransmitter histamine is regulation of water distribution to the cells (Batmangheildj 1990, Batmangheildj 1995). When there is inadequate water for all of the cells, the brain secretes more histamine. Histamine

redistributes more water to areas such as the brain whose cells have a high need for hydration, drawing water from cells that have a less critical need. The greater the body's need for water, the more histamine it secretes to try to solve the problem.

Increased production of histamine is one of the major problems in asthma and allergy. This is the reason that the most common medications for these problems are antihistamines. Salt is also a natural antihistamine which can be added to the diet in small amounts to prevent excess histamine production. Sodium (salt) regulates the amount of water that is held outside the cell wall. Through a special filtration system, water can be directed into the cell itself. When we don't drink enough water, the body will retain sodium so that additional water isn't lost. Giving diuretics for water retention just makes dehydration worse. Water itself is an excellent natural diuretic when the body is getting enough.

Problems with thick mucous in the body are also related to chronic dehydration. Batmangheildj states that "Sodium is a natural mucus breaker, and it is normally secreted to make mucous disposable. That is why phlegm is salty when it comes in contact with the tongue. Salt is needed to break up the mucous in the lungs and render it water for its expulsion from the airways." When there is chronic dehydration, the body doesn't want to give up salt to loosen the mucous (Batmangheildj 1995, p. 120).

Constipation is also related directly to inadequate water intake. "One of the main functions of the large intestine is the process of taking water out of the excrements so that too much of it is not lost in the waste matter after food digestion. When there is dehydration, the residue is naturally devoid of the normal amount of water necessary for its easier passage. Also, by slowing down the flow and further squeezing the content, even the final drops of water will be drawn away from the solid residue in the large gut. Thus, constipation will become a complication of dehydration in the body." ((Batmangheildj 1995, p. 34).

Reflux, thick mucous, and constipation are major issues for children with feeding problems. Is it possible to eliminate these problems, by something as simple as increasing their water intake? q

**Suzanne Evans Morris, Ph.D** is a speech-language pathologist with more than 40 years of clinical experience. She is nationally and internationally known for her work in identifying and treating young children with feeding and swallowing disorders. Dr. Morris maintains a practice which includes direct clinical work, continuing education workshops, development of clinical materials, and clinical research. She is the director of New Visions near Charlottesville VA, which sponsors the Mealtime Partners Program a series of family-oriented workshops and clinical services that focuses on mealtime and feeding skills.

**Fereydoon Batmangheildj.** *Your Body's Many Cries for Water.* 1995. Global Health Solutions, Falls Church, VA.

## Food Allergies

*Continued from page 9*

symptoms of allergic sensitivity. (See the table of infant/toddler/older child formula by type on page 7.) Delaying the introduction of solid foods until six to eight months may also be beneficial. Children should avoid highly allergenic foods such as dairy products, eggs, peanuts, soy, fish, and shellfish until 18 to 24 months or older (Kerner, 1989).q

**Patricia Murray** is a pediatric registered dietitian. She consults to the Children with Special Health Care Needs state nutrition program in NH through the Special Medical Services Bureau in Concord, NH and has been in practice for 20 years.

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## Homemade Formula

From The Children's Hospital, Denver, Colorado

The following recipe uses baby food and other readily available grocery items to produce a formula that provides approximately one calorie/cc. The formula contains a variety of foods to provide the calories, protein, vitamins, and minerals your child needs. Depending on your child's daily intake, a vitamin/mineral supplement may be needed. Remember, please consult your child's care team before changing formula or implementing other nutritional changes.

To prepare this formula safely, care should be taken to wash hands, use clean mixing bowls and utensils, and wash food jars and lids before opening.

### Blended Tube Feeding Formula

Makes approximately 1.5 liters containing approximately 1475 calories.

In a large clean mixing bowl or blender, combine the following

- 3 C whole milk (or Soy Milk)
- 2 C fruit juice
- 2 jars strained vegetables (8 oz)
- 2 jars strained meat (5 oz)
- 1/4 C Light Karo syrup
- 1/4 C non-fat dry milk powder
- 1 T vegetable oil
- 6 T baby rice cereal
- 1/2 multi vitamin with minerals

Mix well. Pour into clean bottles, cover and refrigerate. After mixing, the refrigerated formula may be safely used for 48 hours. Any formula left after 48 hours should be discarded.

To provide a more balanced diet, rotate meats, fruits and vegetables included in the formula.

- Strained meat: alternate chicken, turkey, veal, and beef
- Fruit juice: alternate orange, apple, cranberry, grape, and pineapple
- Strained Vegetables: alternate green beans, carrots, peas, squash, and sweet potatoes

Prior to each feeding, the amount of formula needed should be measured into a separate container, covered and warmed slightly. To warm formula, place the container with one feeding into a pan of hot tap water for 15 to 20 minutes or use a microwave on a low setting for approximately one minute. When using a microwave, be sure to shake the formula or stir it with a clean utensil to avoid hot spots. Do not overheat the formula as it may cook, get lumpy and lose valuable nutrients. Because of the chance of bacterial growth and food poisoning, do not use formula which has been removed from the refrigerator for more than two hours. q

## Beyond Butter

The following list includes additives, sauces, spreads, etc. that will add additional calories to foods.

- Olive oil
- Mayonnaise
- Whole milk or cream
- Cream cheese
- Sour cream
- Cheese
- Non-fat dry milk (limit 8T/day)
- Whole milk yogurt
- Pudding or custard
- Pesto
- Baby rice, oatmeal and barley cereals
- Peanut butter
- Nutello
- Wheat germ
- Carnation Instant Breakfast
- Dried fruit
- Nuts
- Creamed avocado or guacamole
- Salad dressing
- Barbeque sauce

Special thanks to Heidi Quinn, Lilah Al-Masri, and the moms who contributed to this list.

Previous Seminar:

## Navigating 504/IEP Process for the Tube-Fed Child

On April 27, 2002 a panel consisting of three mothers, a school administrator of special needs, and a professional advocate shared ideas, experiences and tips on accessing the appropriate level of services for a school aged child with special feeding needs. The distinction between a Medical Plan (504) and an individual Education Plan (IEP) was made. The role of the professional advocate was explained. Families described their experiences advocating for their children in the various school systems. Each family had a different sense of what services their child's feeding needs required. Advocate and families offered tips for getting what they wanted. For a detailed review of this meeting with tips and helpful links, visit the Quarterly Seminars page of our website, [www.kidswithtubes.org](http://www.kidswithtubes.org).

## Websites

The internet contains volumes of nutrition information. The following websites have been recommended by mothers and professionals during the course of this newsletter's preparation.

You can contact a Registered Dietitian by receiving a referral from your pediatrician or by visiting the American Dietetic Association Website, [www.eatright.org](http://www.eatright.org).

[www.cnpp.usda.gov](http://www.cnpp.usda.gov) is the USDA's Center for Nutrition Policy and Promotion and contains pertinent nutrition information and research.

[www.nutrition.gov](http://www.nutrition.gov) contains tomes of nutrition information, including a link to a complete index of government nutrition sites and topics.

[www.askdrsears.com](http://www.askdrsears.com) contains nutrition and other children's health topics through the eyes of a pediatrician.

[www.cspinet.org/reports/chemcuisine.htm](http://www.cspinet.org/reports/chemcuisine.htm) comprehensive list and discussion of food additives from the Center for Science in the Public Interest, a non-profit watchdog.

## Thank You

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## What's in a Name? Dietitian vs. Nutritionist Heidi Quinn, MS, RD, LDN

People frequently ask – what is the difference between a dietitian and a nutritionist? Some practitioners use both titles interchangeably, and some prefer to use one title over the other. Technically speaking, anyone who studies the science of nutrition may refer to themselves as a nutritionist. However, this term does not always reflect a uniform level of knowledge, as the extent of nutrition study can vary significantly. Some “nutritionists” may work at a health food store, while others may have doctorates in the science of nutrition.

Use of the title dietitian, however, implies “registered dietitian” (R.D.). A registered dietitian has completed an undergraduate and/or graduate degree in the study of nutrition and an internship which has been certified by the American Dietetic Association; and also has passed a national exam, i.e. nutrition boards, developed by the American Dietetic Association. Technically, only a registered dietitian can use the term dietitian. Within the area of dietetics there are subspecialties as well, so some practitioners may refer to themselves as a clinical dietitian, or a diabetes

dietitian, or a renal dietitian. Other practitioners may have a degree in Public Health, and refer to themselves as a public health nutritionist.

Some states also have acquired licensure for dietitians and nutritionists. This specific title is L.D.N., indicating licensed dietitian/nutritionist. For registered dietitians (R.D.'s), the licensure was automatic. For new dietitians and nutritionists, passing an exam is required.

It is important that parents ask the nutrition practitioner about their educational background and their experience to ensure that the practitioner is qualified to meet the specific needs of the family.q

## Tube Tip: Easing the Load

For toddlers who require continuous tube-feeds, try having the child carry their own pump in a backpack. Some pump manufacturers provide backpacks for their pumps. You can also find small backpacks in the toy section, sometimes sold with a doll inside. To ease the load, place an inflatable swimming wing (sometimes called *Swimmies*) at the bottom of the pack, beneath the pump. This helps raise the center of gravity, making it easier for your child to manage the extra weight.

## Have You Seen the Kids with Tubes Website?

Our website, [www.kidswithtubes.org](http://www.kidswithtubes.org), includes write-ups of previously held seminars, including detailed summaries from 2002 seminars, Tube Tips and Navigating the 504/IEP Process. The website also has access (using Adobe Acrobat) to previously published newsletters including: The Decision to Place a Feeding Tube, Daily Life with a Tube-fed Child, and Therapies for the Tube-fed Child.

**Check it out!**

## Booklist

The information contained in this newsletter is largely an overview. There are many books available that go into great detail on various nutritional topics. The following have been recommended by moms and dieticians dealing with tube fed children. In addition, we have included cookbooks for toddlers and up, hoping that getting involved in the kitchen (and the garden for that matter) will lead to better eating and nutrition.

- *Child of Mine: Feeding with Love and Good Sense*, by Ellyn Satter. Revised in 2000. An excellent source of solid nutrition information and philosophy of good eating habits.
- *How to Get Your Child to Eat...But Not too Much*, by Ellyn Satter. Discussion about parenting and feeding including: how much your child should eat, discussion of normal eating, and helping your child eat the right food.
- *Cooking Art: Easy Edible Art for Young Children*, by Mary Ann Kohl and Jean Potter. Well-illustrated cookbook that encourages kids to interact with food as they make their own potentially edible creation.
- *The Family Nutrition Book*, by William Sears and Martha Sears. Comprehensive nutritional information including advice on feeding picky eaters, how to tell whether your child is eating enough, understanding fats, deciphering food labels and packing nutritious lunches.
- *Stealth Health: How to Sneak Nutrition Painlessly into Your Diet*, by Evelyn Tribble. Delicious recipes (not always easy to prepare) that pump up the nutritional value of foods that you probably already like — in a way that you won't even notice. Popular examples include adding black beans to brownies and pureeing cauliflower into twice-baked potatoes.

- *5-A-Day: The Better Health Cookbook*, by Elizabeth Pironka and Barbara Berry. 150 recipes to get your five daily servings of fruits and vegetables. Includes substitutions such as baking with applesauce instead of oil, and baby food prunes instead of butter.
- *One Bite Won't Kill You*, by Ann Hodgman. Over 200 recipes to tempt even the pickiest kids on earth and the rest of the family too.
- *Your Body's Many Cries for Water*, Fereydoon Batmangheildj. Discusses in detail the bodies use of water, making a case to choose water over other liquids.
- *Pretend Soup and Other Real Recipes: A Cookbook for Preschoolers and Up*, by Mollie Katzen and Ann Henderson. Delightful recipes with illustrations for the child who does not yet read!
- *Good Enough to Eat, A Kid's Guide to Food and Nutrition*, by Lizzy Rockwell. Charming drawings and good information about food and nutrition for the older preschooler/school age child.
- *Dinosaurs Alive and Well, A Guide to Good Health*, by Laurie Krasny Brown and Marc Brown. Accessible information for the older preschooler/school age child. Covers nutrition as well as other useful topics.
- *Food for Tots*, by Janice Woolley and Jennifer Pugmire. Easy, safe, nutritious, and fun food recipes for children ages zero to five.
- *Super Baby Food*, by Ruth Yaron. Everything you should know about feeding your baby and toddler through age three. How and when to start your baby on solid foods, with detailed information on the best and safest high chair, spoons, bibs, and other feeding equipment.

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## *Kids with Tubes*

support for parents and caregivers of tube-fed children

### Parent Leadership Team

Jill Crisman  
Amanda Loftus  
Nancy Kolb  
Irene Walborsky  
Sue Wolff

### Professional Advisory Committee

Athos Bousvaros, M.D.  
Kara Fletcher, M.S., SLP-CCC  
Lori Parker-Hartigan, R.N.  
Arden Hill, M.S., SLP-CCC  
Patricia Huntley, M.S., OTR/L  
Deirdre Patch, M.S., SLP-CCC  
Heidi Quinn, M.S., R.D., LDN  
Rita Williams, M.S., SLP-CCC

### Mailing Address

Kids with Tubes  
59 Sweetwater Ave.  
Bedford, MA 01730

### Phone

Jill Crisman  
(781) 402-0216

### E-Mail

Info@kidswithtubes.org

### Website

www.kidswithtubes.org

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### **Kids with Tubes**

59 Sweetwater Ave.  
Bedford, MA 01730

Email: [info@kidswithtubes.org](mailto:info@kidswithtubes.org)  
Website: [www.kidswithtubes.org](http://www.kidswithtubes.org)