Weaning Preparation for Children Fed by G-Tube
Joan Arvedson, PhD, CCC-SLP, BC-NCD, BRS-S, ASHA Fellow

Infants and children with feeding and swallowing problems may need to receive some or all of their nutrition and/or fluids via gastrostomy tubes (G-tubes). Depending on the etiology of the child’s problem and his or her development, the child may need to be tube fed for several months, years, or indefinitely. It is usually the goal, however, at some point to wean the child from tube feeding, or to at least have the child take as much nutrition and fluid orally as possible in ways that are safe and pleasurable. This article will focus on what parents can do to prepare their child for weaning from a G-tube (other types of tubes are not covered in this article).

Looking Ahead
Some of these children are kept “nil per oral” (NPO, or nothing by mouth) when medical or surgical issues are prominent, and gastrointestinal (GI) issues or the risk for aspiration make oral feeding difficult or impossible. In these cases, most children should tolerate at least minimal “tastes,” which may help the child adapt to oral feeding later. The parent should check with the child’s health care team. The child may reach a point where safety of swallowing and GI issues are no longer barriers to oral feeding, and it may be possible for the child to eat and drink orally. When this day comes, parents may expect their child to be interested in eating and drinking, but that is not likely to be the case.

Similarly, a child who receives supplemental nutrition and/or fluid through tube feeding may one day be able to eat and drink enough food and liquid to meet nutrition needs so the tube can be removed. This child, however, may be very limited in what she will consume orally, or may have other difficulties with eating and drinking.

A child who has been tube fed for an extended period...

My New Self
Paul Serchia

When that guy whispered “Plastics” in The Graduate, he was foretelling my future, not Benjamin Braddock’s. I lived the first half-century of my life as a full-fledged Homo sapien. Then I began an unexpected drift toward becoming something other than fully human. At the piecemeal pace that I’m moving, by the time I file my next income tax return or fill out a census form, I may be checking a box beside the word “Android.”

New Pearly Whites
My teeth were the first part of my body to surrender. Around the time of my fiftieth birthday, a dentist declared my mouth a disaster area. He set me on the path to replacing the teeth I still had left with a set of upper and lower dentures. I took possession of my...
may not want, or know how, to eat and drink orally. A child’s oral skills are one of several issues that must be considered in preparing her for oral feeding. There are a number of ways parents can help children and infants develop oral skills to prepare them for feeding by mouth, even if weaning is not predicted in the near future. Oral sensorimotor stimulation, with or without tastes, can promote improved oral skills. Some oral sensorimotor stimulation strategies are discussed below.

Readiness

If your child’s health care team has given the okay for your infant or child to eat or drink by mouth, you can ask the following questions to determine whether he is ready for small “tastes” by mouth or for larger-volume true oral feeding.

1. Does your child tolerate bolus tube feedings (where the amount of formula for the total feeding is given over a period of 20 to 30 minutes) without vomiting or other kinds of stress (for example, gagging or retching during or after tube feedings)?

Children who cannot tolerate bolus feedings and require slow, continuous feeds — even when the tube feeds are given overnight and turned off during the day — are not likely to demonstrate signs of hunger or an appetite for oral feeding. Facilitation or promotion of hunger is understood to be primary in transitioning from tube feeding to oral feeding. Hunger forms the base for advancing a child’s oral skills and expanding the types of food a child will accept. If your child cannot tolerate bolus feedings, he is probably not ready for total oral feeding. He may still be receptive to tastes of food or liquid.

2. Does your child have gastroesophageal reflux (GER) or some other GI tract problems?

Gastrointestinal tract discomfort, from whatever underlying cause(s), can make it more difficult for the child to enjoy oral taste experiences. In these cases, it is more difficult to help the child learn the oral skills typical of children of the same developmental age. When the child’s nutrition status, overall medical/surgical status, and safety of swallowing support an advance of oral feeding, she may not be ready to increase the amount of food or liquid, and expand textures and types of food. Parents are encouraged to be sensitive to the child’s discomfort and seek guidance to reduce the pain or discomfort. A child needs to “feel good” in order to be interested in eating and drinking by mouth.

Close medical monitoring is important. Physicians and dietitians may make recommendations for adjusting the tube feeding; these could include changing the timing, formula, or volume per tube feeding. These changes may be needed as a basis for advancing oral feeding.

3. Does your child have frequent respiratory problems?

It is important that children have stable respiratory status in order to become oral feeders. It is also important that children get tastes of food or liquid in structured situations with no stress on the child or the parent on a regular basis. Frequent upper respiratory infections, repeated pneumonias, and upper airway obstruction (including enlarged adenoid and tonsils) can interfere with advancing functional oral feeding in developmentally appropriate ways. In this context, “functional” means the skills learned can be applied to “normal” eating experiences, such as eating with family, at school, and so on.

4. Has your child been made NPO? Does he drool frequently, or does he consistently swallow saliva?

It is not unusual for children who are NPO to be inefficient in swallowing their saliva. Total NPO should be rare. Small, perhaps miniscule, tastes should help stimulate purposeful swallowing. Increasing the frequency with which the child swallows his saliva can potentially reduce the possibility of the child’s aspirating on saliva or secretions that may be sitting (pooling) in his upper airway. Without purposeful stimulation, some children don’t seem to get the sensory cues they need to realize they should swallow their saliva. Healthy lungs are most important, and taste experiences or real feeding must never interfere with pulmonary status.

5. Does your child show interest in different tastes? Is she interested in food or liquid other family members are having?

Young infants who show interest in drinking often do well with a pacifier dipped into pumped breast milk or formula. After the infant has sucked several times and swallowed, the pacifier can be eased out of her mouth and dipped into the liquid again. The process can be repeated several times. It is usually best to keep practice times to about five minutes, and to start just before tube feeding or as the tube feeding is getting started, providing there are no obvious signs of discomfort and stress with tube feeding. If the child has negative experiences with tube feeding, it is best to keep the oral taste practice apart from the tube feeding. All oral experiences should be happy times for any child, and not related to pain or discomfort anywhere in the body.

Weaning, cont. pg. 10
**Tube Talk**

Send your tips, questions, and thoughts about tube feeding to:

*Tube Talk*, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or e-mail metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

---

**Be A.W.A.R.E. Campaign Promotes Safety**

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) has launched a new campaign to promote safety with tube feeding. Directed at clinicians, the 2010 Be A.W.A.R.E. Campaign features a poster focused on the proper delivery of medication through enteral feeding tubes.

Last year A.S.P.E.N. ran a similar campaign, Be A.L.E.R.T., focused on educating nurses to help prevent enteral misconnections and improve enteral nutrition safety. Tubing misconnections can be extremely dangerous, as when enteral formula is administered through an IV line.

Download the Be A.L.E.R.T. and Be A.W.A.R.E. posters from www.nutritioncare.org (select “For Patients and Caregivers,” then “Patient Safety Information” near the bottom of the page), or call (800) 776-OLEY to request a copy. They can be useful at home or in hospital. More information about enteral misconnections and other enteral topics is also available on A.S.P.E.N.’s “Patient Safety Information” page.

---

**New Airline Restrictions**

We’ve had questions from members about flying with homePEN since new restrictions went into place in December 2009. In particular, members have asked how to handle the limited access to bathrooms at the end of flights, and whether fluids (medications and ostomy bag contents) are a problem when going through security. Please contact Roslyn Dahl (dahlr@mail.amc.edu, 800-776-OLEY) if you have experience to share.

If you are planning a trip, you can find updated information about airline travel at www.oley.org/New_Airline_Restrictions.html, as well as general advice about traveling with homePEN at http://www.oley.org/traveltips.html. Bon voyage!
Ongoing Research Trials

Study for Parents of Children with Undiagnosed Medical Condition

If you have a child with a medical condition that has been ongoing for longer than two years and for which you have not received a conclusive diagnosis, you are invited to participate in a research study sponsored by the National Human Genome Research Institute, one of the National Institutes of Health.

The study involves filling out a forty-minute survey that asks for your thoughts and feelings about having a child or children with an undiagnosed medical condition, as well as questions about your everyday life. There are no personal benefits to you from taking part in this study. However, by sharing your experiences you may help improve health care and counseling for other parents of children with undiagnosed medical conditions.

If you would like to fill out the survey online, go to www.surveymonkey.com/SurveyExperienceUncertainty. The password to enter the survey is: Uncertainty. For more information or if you would like to complete a paper copy of the survey, contact Anne C. Madeo, MS, CGC, Principal Investigator; National Human Genome Research Institute; National Institutes of Health; (301) 443-2635; Anne.Madeo@nih.gov.

Note that you will not be paid for participating in this study, and the study is completely anonymous.

The research study listed above has been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee; however, the Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.

Information on these studies is available by calling (800) 776-OLEY or visiting our Web site at www.oley.org. Clinicians interested in having their study listed should complete the form at www.oley.org or fax the same information to (518) 262-5528.

HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org.

Mount Sinai Medical Center, New York, NY

Since the days when Dr. Burell Crohn first described inflammatory bowel (“Crohn’s”) disease at Mount Sinai Medical Center in New York, the center has had a tradition of GI and transplant excellence. It was one of the earliest intestinal transplant centers in the country, with the first intestinal transplants in New York State performed there in 1997. Twelve years and 120 intestinal transplants later, under the current directorship of Kishore Iyer, MBBS, FRCS, FACS, intestinal transplantation is placed firmly within a multi-disciplinary Intestinal Rehabilitation Program. At a time when intestinal transplant volumes at Mount Sinai continue to grow, transplant represents less than 20 percent of the Intestinal Rehabilitation Program’s activity.

The program’s successes over the last two years, with a new but mature team, relate to comprehensive multi-disciplinary representation. The adult gastroenterology/hepatology services are led by Tom Schiano, MD, and Lauren Schwartz, MD, with specific expertise and training in liver disease and advanced nutrition support. Pediatric GI/liver services are led by Tamir Miloh, MD, backed by a team of pediatric hepatologists led by Frederick Suchy, MD. The program’s nursing and nutrition coordinators are led by Christine Chamberlain, RN. A team of social workers that understands the complexities of intestinal failure provides support for families and consumers. Consultants in closely allied services like infectious disease and interventional radiology are integral parts of the program.

An active child-life program provides respite, distraction, and stimulation for younger patients. For families coming from out of state, a subsidized Transplant Living Center is available as a “home away from home.”

New! Telephone Networking

Oley’s peer-to-peer, toll-free phone lines program has been revised to include three toll-free lines. All lines will be staffed by consumers or caregivers, willing to share their experiences.

- (888) 610-3008 will be devoted to HPN (intravenously infused nutrition).
- (888) 650-3290 will be devoted to HEN (tube feeding).
- (877) 479-9666 will be devoted to HPEN consumers in their teens and twenties.

We hope you’ll use this opportunity to explore options and share ideas. The connections will put you in a better position to cope with day-to-day issues and handle complications.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.
From the Desk of Joan Bishop, Executive Director

A Focus on Gratitude

With many people wanting better health or less pain it’s easy to center our thoughts on things we cannot have or don’t like in our lives. It’s much healthier to shift the focus to the things we are grateful for. This helps to elevate our mood and brings a different perspective to our lives.

At Oley, we mourn the recent deaths of several of our members, including Lee Koonin and Colyn Woods. Although it’s not always possible and instant, we do need to shift our thoughts to try to focus on how extremely grateful we are for the time we shared with them and how much they enhanced the lives of everyone they touched. I admit that these situations require all of our strength.

Oley trustees and staff realize the need for more programs but turn to the impact that our existing efforts have had on Oley members. We’re grateful for all of the help we have received and look forward to a future centered on People Helping People.

In Memory of Colyn Woods

Colyn Taylor Woods was 15 years old when he passed away on Thursday, January 14, 2010, from complications of a mitochondrial disorder. Colyn was the youngest of Patty and Darrell Wood’s five children.

He was diagnosed at age 11 by Dr. Boles at Childrens Hospital Los Angeles with a maternally inherited Mitochondrial Disease. He had suffered undiagnosed for years with a disorder that had affected multiple systems in his body, including his stomach, immune system, and lungs.

Throughout his life, Colyn maintained a positive attitude that encouraged and inspired others. He made a tremendous impact on everyone he came in contact with. Colyn often reached out to people who were struggling to offer them hope. He wanted others to know that no matter the circumstances, it was okay. His strength often exceeded that of those around him, despite his physical challenges.

For his many wonderful qualities, Colyn received the 2007 Celebration of Life Award. He made many friends of all ages at Oley conferences, and was quick to bring a smile to Oley staff members.

Colyn loved life, lived it with courage and loved others around him. Words cannot express how much we will miss him.

In Memory of Colyn Woods

Colyn Taylor Woods was 15 years old when he passed away on Thursday, January 14, 2010, from complications of a mitochondrial disorder. Colyn was the youngest of Patty and Darrell Woods’ five children.

He was diagnosed at age 11 by Dr. Boles at Childrens Hospital Los Angeles with a maternally inherited Mitochondrial Disease. He had suffered undiagnosed for years with a disorder that had affected multiple systems in his body, including his stomach, immune system, and lungs.

Throughout his life, Colyn maintained a positive attitude that encouraged and inspired others. He made a tremendous impact on everyone he came in contact with. Colyn often reached out to people who were struggling to offer them hope. He wanted others to know that no matter the circumstances, it was okay. His strength often exceeded that of those around him, despite his physical challenges.

For his many wonderful qualities, Colyn received the 2007 Celebration of Life Award. He made many friends of all ages at Oley conferences, and was quick to bring a smile to Oley staff members.

Colyn loved life, lived it with courage and loved others around him. Words cannot express how much we will miss him.

In Memory of Colyn Woods

Colyn Taylor Woods was 15 years old when he passed away on Thursday, January 14, 2010, from complications of a mitochondrial disorder. Colyn was the youngest of Patty and Darrell Woods’ five children.

He was diagnosed at age 11 by Dr. Boles at Childrens Hospital Los Angeles with a maternally inherited Mitochondrial Disease. He had suffered undiagnosed for years with a disorder that had affected multiple systems in his body, including his stomach, immune system, and lungs.

Throughout his life, Colyn maintained a positive attitude that encouraged and inspired others. He made a tremendous impact on everyone he came in contact with. Colyn often reached out to people who were struggling to offer them hope. He wanted others to know that no matter the circumstances, it was okay. His strength often exceeded that of those around him, despite his physical challenges.

For his many wonderful qualities, Colyn received the 2007 Celebration of Life Award. He made many friends of all ages at Oley conferences, and was quick to bring a smile to Oley staff members.

Colyn loved life, lived it with courage and loved others around him. Words cannot express how much we will miss him.
Combine the Oley Conference with a Camp Experience

If you've considered sending your homePEN-dependent child to summer camp and you're planning to join us in Saratoga Springs for the 25th annual Oley conference, you might want to think about combining the two. The Double H Ranch in Lake Luzerne (a Hole in the Wall camp) is situated approximately twenty-five miles from the conference site. It is reserving five slots for HPN kids in each of two camp sessions: June 25–30 and July 3–8. HEN kids are also welcome.

The Oley conference, June 28–July 2, will overlap the first session and finish just before the second session begins. With the two locations so convenient to one another — and plenty for a family to do in upstate New York, before or after the conference — this might be a wonderful opportunity for your child to attend camp.

To learn more about the camp or to request an application packet, visit www.doublehranch.org or call (518) 696-5676. To speak to other families who have experienced Double H hospitality, contact Joan Bishop at Oley, (800) 776-6539 or bishopj@mail.amc.edu. You can also read about one camper's and a mom's impression of the camp at http://oley.org/lifeline/Camping.htm.

Other Options

If you can't make either of the sessions above, we've rounded up some other possibilities for you to consider. Several of the programs listed below are free, very inexpensive, or offer scholarships. Application deadlines vary; many are accepting applications now and will continue accepting them until camp opens or fills to capacity. Camps are listed alphabetically by state.

Crohn's and Colitis Foundation of America (CCFA), Camp Oasis
For children with medically stable Crohn's disease or ulcerative colitis
Various sites and dates; now accepting applications
www.ccfa.org/kidsteens/camp
Information: (888) 694-8872

Hole in the Wall Camps
For children facing serious illness
Various sites and dates
www.holeinthewallcamps.org
Association of Hole in the Wall Camps: (203) 562-1203
Hole in the Wall Gang Camps: (860) 429-3444

Center for Courageous Kids, Scottsville, KY
For the medically fragile child (7–15) and his/her family members; operates year round, offering twenty-two family weekend retreats and nine separate weeks of illness-specific summer camping sessions focused on the child
www.courageouskids.org
Medical center line: (270) 618-2912

Camp Mak-A-Dream, Gold Creek, MT
For children, young adults, and families affected by cancer
Camps include: Kids Camp (ages 6–14), July 31–Aug. 7; Teen Camp (15–18), July 9–16; Siblings Camp (6–17), July 20–27; Young Adult Conference (18–40), June 16–23; and Young Adult Survivor Conference (18–40), June 8–13. Applications now being accepted.

Kids, teens, and young adults can be in or out of treatment.
www.campdream.org
Information: (406) 549-5987

Youth Rally (sponsored by Youth Rally Committee, Inc.)
Xavier University, Cincinnati, OH, July 12–17
For adolescents (11–17) with ostomies, continent diversions and other bowel or bladder management issues, or who are preparing for surgery.
Application deadline: June 1
Scholarships available; also customizable fund-raising Web pages.
www.rally4youth.org
(856) 854-3737

Camp Chihopi, Children's Hospital of Pittsburgh, Pittsburgh, PA, Aug. 13–16
For liver and/or intestine transplant recipients 7–16 years old
Campers arrive in Pittsburgh 8/13 and are transported by bus to the camp, about 100 miles south of Pittsburgh. They return to Pittsburgh 8/16.
Applications available in early March.
(412) 692-6115 or Beverly.Kosmach@chp.edu

Kyle R. Noble Memorial Scholarship

To further the educational goals of individuals relying on HPN or HEN for their primary nutritional needs.

In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a $2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered. Applicants are asked to write a one to three page essay describing how he or she has overcome obstacles/challenges posed by HEN and/or HPN and inspired others to live life to the fullest. An educational reference (letter from an advisor or teacher supporting educational pursuits) and a medical reference (from someone on the applicant’s health care team — physician, nurse, dietitian — verifying the medical situation) is required.

The scholarship will be distributed at the end of the school year after a copy of the recipient’s transcript of his or her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference this summer in Saratoga Springs, NY.

Applications for the 2010 scholarship must be received by April 1. Complete details posted on www.oley.org.
Lifeline Mailbox

Blessings for 2010

As we enter into 2010, I want to wish everyone a blessed and joyful holiday and winter season, however you celebrate it. As I celebrated Christmas, I thought of all of you and the strength and meaningful relationships we develop out of sharing our needs. I pray for each of us that we will feel a sense of joy, peace, and hope amid all the physical and emotional challenges we face in order to survive.

Celebrate 2010 and celebrate life. Participate! That tube or line should not control us but be a tool for life. Live life to your fullest.

Blessings to you that spill over onto others as you become a blessing to them. Cheers for life and breath.

Here’s to a 2010 filled with hope!

—Marie Latta, latta@mindspring.com

National Healthcare Decisions Day, April 16

The Oley Foundation has banded with other organizations to highlight the importance of advance healthcare decision-making on April 16, National Healthcare Decisions Day (NHDD) — and throughout the year. We encourage you to express your wishes regarding your health-care options and to complete advance directives. NHDD organizers are also working with providers and facilities to ensure that individual wishes are respected, whatever they may be.

NHDD has created a Web site with information and tools to encourage conversations about future healthcare decisions and to help you execute written advance directives (healthcare power of attorney and living wills) in accordance with applicable state laws. Visit the NHDD Web site at www.nationalhealthcaredecisionsday.org.

Prize Encourages HPN Research

The Oley Foundation will award $2,500 to each of the top three clinical studies dedicated to improving the quality of life for home parenteral (IV-fed) consumers. Underwritten by Nutrishare, Inc., the HomePN Research Prize was initiated to encourage more research in this area of critical concern to long-term consumers of home intravenous feedings.

Papers must have been accepted for poster/stand-up presentation or publication by a respected, relevant professional association such as ASPEN, ESPEN, INS, or AGA between July 2008 and March 2010. A portion ($1,000) of each prize will be dedicated towards travel expenses to bring the winners to the 2010 Oley conference in Saratoga Springs, NY, to present their research. The deadline for submissions is April 1. Further details and an application are available online at www.oley.org.
new plates in 2008, as spring was turning to summer.

For something crafted in plastic, my new choppers looked pretty spiffy. Once I tried to talk or eat, however, the plates took on a life of their own. It was a struggle to keep them attached to my gums.

I tested every denture adhesive on the shelf, but none of them worked. So I started to bug my dentist to adjust the dentures to get a better fit. Each modification was an improvement, but people couldn’t understand my speech and I didn’t dare use the dentures for chewing.

**New Tube**

Even when not wearing my dentures, I had a hard time swallowing. A Diet Coke addict to the core, I could only ingest a micro-sip at a time. I needed an entire morning to finish one twelve-ounce can. I’m sure that Coca-Cola noticed a sharp slippage in their product’s sales in Southern California.

Getting a meal past my lips was exhausting. Soon, friends and co-workers began to comment on how my body was pulling a vanishing act in slow motion. It’s hard to keep weight loss a secret when you can’t keep your trousers around your waist.

Before long I found myself in the outpatient infusion center of my HMO, being fed intravenously. The next thing I knew I woke up in a hospital recovery room with a brand-new gastronomy tube (G-tube) tethered to my tummy.

I never knew G-tubes existed before I got one of my own. All of you who have one are doing a commendable job at keeping your tubes secret from everyone else. Dick Cheney would be impressed.

Once I got over its freakish presentation, I became very fond of my new rubber appendage. Sure, my G-tube doubled my inventory of artificial body parts, but it also meant that I wasn’t going to starve to death — not as long as I kept pouring cans of formula down the hatch.

**Tube #2**

Dodging the starvation bullet didn’t solve all of my problems, however. Last winter, my tongue began swelling up to Hindenburg proportions, which not only made it more difficult to talk but also threatened my ability to breathe. Even if the rest of my body was in tip-top shape, a blocked airway makes everything else moot.

My doctors dug deeper into their bag of artificial parts. In January, I had a tracheotomy: installation of a plastic cannula into my neck to ensure that air can get into my lungs.

**Cancer**

At the same time the trach was installed, tissue on my tongue was collected for a biopsy. When I awoke in the recovery room at the hospital, I not only had a brand-new fake body part added to my ensemble, I also got a cancer diagnosis. The cancer was anything but fake.

Treatment began almost immediately. In the winter of 2008–2009, I endured three rounds of chemotherapy and thirty-three sessions of radiation therapy. As I write these words, there is little clarity about whether those treatments succeeded or failed. Barring a medical miracle, I may be relying on my trach and G-tube for some time to come — maybe forever.

**Self-imaging**

In a strange way, my tubes have had something of a calming effect on my life.

I’m gay; I’m single; I live in Los Angeles. I don’t know what it’s like in Memphis or Madison, but you can’t walk two feet in this burg without spotting someone sexing up their image to get attention or jogging shirtless down a major thoroughfare to ensure maximum visibility.

The G-tube has released me from pursuit of the six-pack abs I see everywhere I turn. Not that years of labor in the gym ever brought me close to developing a taut, tight tummy, but this tube sticking out of my mid-section has liberated me from pursuing that ideal.

If I were looking for a partner, I’m certain I would find an excuse to raise my shirt soon after saying “hello,” just so he knew exactly what he would be getting into. Then he better not shun the trunk protruding from my torso or pretend it isn’t there. If he knew what was good for him, he’d give it a pet name, like “Babar” or “Dumbo.”

**Uncovered**

The story with the trach is slightly different. After I got the trach, I became paranoid about having it exposed in public. I bought scarves to spare others the shock of seeing a man with a hole drilled into his neck, and friends gave me more to add to my collection.

But the scarves started to get unwieldy and bothersome. They had a way of getting caught in my zipper, slammed in my car door, or, yes, even dipped into the toilet bowl. Scarves required too much attention and maintenance. Sometimes they even made me feel that I had a boa constrictor coiled around my neck.

You need a certain élan or foppishness to pull off wearing a scarf. Mick Jagger has it; Charles Nelson Reilly had it; Thurston Howell III had it. I do not.

Now when I go out in public, I usually go commando as far as neckwear is concerned. Aside from one occasion when a woman dropped a veil over her baby’s face when I got in line behind them at the supermarket, exposing my trach hasn’t upset anyone or triggered a stampede of fear.

That’s not to say that my trach doesn’t capture attention. People are always staring at me, and I can follow their gaze to directly below my chin. But their curiosity sometimes leads to some interesting exchanges and “teachable moments.” On several occasions, my trach has provided an invitation for people to tell me about a loved one in their life who has or had a trach as well.

**At Peace**

Are there more artificial parts in my future? Who knows — I can’t imagine what the next one would be. If I’m destined to develop man boobs, I’d prefer to acquire them the natural way rather than by silicone implants.

But I am at peace with the fake body parts I have. Not a day passes when I don’t praise each breath of fresh air I inhale through my trach, or tell myself “Cheers” as I watch another can of formula trickle down my G-tube.

Sure, I would happily shed these tubes if my doctors said it was safe to do so. But if that day never comes, well, I’m OK with that.

In a way, being partly fake only makes life more real.
Nutrition and You

Got Sunshine?

This is the first of a two-part series on vitamin D (cholecalciferol).

Scientists are reporting glowing news about vitamin D, the “sunshine vitamin,” and bringing to light its many health benefits.

Its Importance

Vitamin D is primarily known for its role in maintaining the balance of calcium and phosphorus essential to building (and maintaining) healthy bones. A vitamin D deficiency causes hypocalcemia, secondary hypoparathyroidism, rickets (in children), and osteomalacia (in adults).

Recent studies have revealed a surprising number of potential additional effects of vitamin D. For example, adequate vitamin D status is important for muscle performance (e.g., it may help prevent falls) and to help regulate the immune system. In addition, people with adequate blood levels of vitamin D may be less likely to develop diabetes, cardiovascular disease, and several types of cancer, including colon, prostate, and breast.

Its Source

For most people, there are three ways to get vitamin D: (1) sun exposure, which converts pre-vitamin D in the skin to a usable form; (2) food sources, which include oily fish (e.g., salmon, sardines, or tuna) and fortified milk products/cereals; (3) oral vitamin D supplements. This can present a challenge for home parenteral and/or enteral (HPEN) consumers. Some of you may not feel like going outside, and many people cannot get enough sun anyway, at least part of the year; the food sources are limited and may not be tolerated, or perhaps you just cannot eat; and finally, vitamin D supplements require absorption by the GI tract — which may be a problem.

Measuring It

Assessing your blood level of vitamin D is the only way to determine if your intake from sunshine, food, and/or HPEN is adequate, and screening blood levels of vitamin D should be part of the routine blood tests for everyone. When evaluating vitamin D status, your clinician should order a test for 25-hydroxy vitamin D levels. Although there is no agreement on the optimal level for good health, a general guideline is that a plasma hydroxy vitamin D > 30 ng/mL is desirable, while Dr. DeLuca and others suggest a level of 40-60 ng/mL may be associated with disease prevention.

Getting Enough

You are getting enough vitamin D when your 25-hydroxy vitamin D levels reach the desired level. How you reach these numbers depends on many factors, including your age, your size, how much you can eat and absorb, and how much sun exposure you get. Several organizations have recommended intakes for healthy populations (i.e., those with adequate fat digestion/absorption and liver and kidney function necessary to activate vitamin D from sunshine or food). The 1997 Recommended Dietary Intake (RDI) suggested an adequate intake is 5 mcg (200 IU) from birth to age 50; 10 mcg (400 IU) ages 51–70; and 15 mcg (600 IU) for age > 71. The American Academy of Pediatrics later recommended 10 mcg (400 IU) per day for pediatric and adolescent populations.

Now, emerging science tells us that the recommendations we have always followed for the amount of vitamin D are really too low. The RDI is being updated, and current recommended amounts for adults are at least 25 mcg (1000 IU) per day.

The amount recommended is based on oral/enteral intake. Enteral feedings contain vitamin D, but an oral supplement may still be required. An adult parenteral multiple vitamin supplement (e.g., MVI-12) typically provides 5 mcg (200 IU) vitamin D per day, while the pediatric formulation provides 10 mcg (400 IU). This may or may not be adequate to meet the consumer’s needs. The only way to really determine if your vitamin D intake is adequate is by testing your 25-hydroxy vitamin D levels. If you are an HPN consumer and your vitamin D levels are low, you may need to bring them up with UV exposure, as there is no parenteral form of vitamin D other than in the intravenous multivitamin.

This column has been compiled and reviewed by Carol Ireton-Jones, PhD, RD; Laura Mattarese, PhD, RD, LDN, FADA, CNSD; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC. Their next column will include risk factors for vitamin D deficiency, and benefits and risks of vitamin D supplementation.

Equipment-Supply Exchange

Contact the Oley Equipment-Supply Exchange coordinators Tammi and Rob with donations, requests, or questions at oleyequipment@aol.com or (866) 454-7351 between 9 a.m. and 4 p.m. EST.

A list of equipment-supplies available for “adoption” can be viewed at www.oley.org/equipexchange.html. Be sure to look through the list regularly as new formula is added weekly. Also, consider talking to your doctor or nutritionist to see if you can use a different formula; it may give you more options.

2010 Oley Awards

Oley presents five awards each year to recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone today. Forms are available at www.oley.org, or by calling (800) 776-OLEY.

Awards will be presented at the 2010 Oley Consumer/Clinician Conference and the awardees will be spotlighted in the LifelineLetter. Several of the awards include a partial travel grant to the conference (to be held June 28-July 2, in Saratoga Springs, NY). Recognition is given to all nominees. Hurry! Nominations must be received by April 1, 2010.
Beyond infancy (defined as the first six months of life in typically developing infants or at that level of functioning for pre-term infants or others with developmental delays), a child is more likely to show interest in food and liquid from the family table than in pureed baby foods. She may prefer strong, sour, tart flavors rather than bland food. One example is flavored water (a couple drops of lemon, cranberry, or pickle juice [per a parent suggestion]), usually presented to the child by spoon so you can control the amount. Sauce is another example. You might try spaghetti sauce, ranch dressing, soy sauce, or other foods typically eaten by the rest of the family. You can dip your finger into the sauce, or present it to your child on a spoon; place your finger or the spoon first on the lower lip, and then into your child’s mouth at mid-tongue as she “gives permission.” The primary goal is nonstressful and pleasurable practice. Do not focus on the amount of food or liquid, or even on the number of trials.

**Oral Sensorimotor Stimulation**

Research supporting the importance of specific oral sensorimotor intervention procedures is limited. Research has shown that children have “critical and sensitive periods” in their development for advancing to chewable food. In a nutshell, children should be exposed to foods that require chewing by the time they are one year of age (or if global development is in that range) if the swallowing is safe. If parents and therapists wait until the child is 18 to 24 months of age, it may become much more difficult. He is likely to lack the skills and may have become aversive to attempts to get him to eat.

A fundamental principle when transitioning to oral feeding is that the child should find the experiences pleasurable, or at least not stressful. There is no evidence to suggest that activities for stimulation of the mouth and face help advance oral feeding by themselves. They may be helpful for some children who find oral stimulation with vibrators and special brushes to be pleasurable; they smile, vocalize, and reach for the object to “help.” However, other children turn their heads away, clamp their lips together, and fuss, all of which clearly communicate they do not like what is being done to them. A child should never be tricked. No one, for example, should ever sneak a spoon into a child’s mouth when she is not looking, or while she is crying with her mouth open. The child should know what to expect. The goal is functional eating and drinking, even if little volume.

**Strategies to Use with a Child Who Does Minimal Oral Feeding**

Offer taste experiences two to three times per day for about five minutes (and no more than ten minutes). These tastes are likely to be most successful when offered just prior to starting a tube feeding (for a child on bolus feeds) or at a time of day when you think your child will be most open to the practice.

For an infant, dip a pacifier into breast milk, formula, or water and let him suck on the pacifier or your finger (as discussed above).

If the child is six months (developmental skill status) or older, a well-supported high chair can be a good seating system. Introduce a dry spoon. If the child demonstrates fear when the spoon approaches her face, start by touching her arm and work toward her face. Tell the child what you are doing in simple, short sentences. For example, say, “Here comes the spoon,” “I’m going to touch your lip,” or “Time for
a bite.” Place the flat bottom of the spoon against your child’s lips. Do not try to get into her mouth. Repeat a few times. The prediction is that she will open her mouth to give permission for the spoon to go into her mouth.

Do not force a spoon or other utensil into a child’s mouth. The child should open his mouth in anticipation of the spoon. This action signals that the child is giving permission for the spoon to be placed on his tongue. Bring the spoon out of his mouth with the bottom of the spoon on his tongue.

Do not ask, “Do you want to eat?” If your child says “no” in any way, the session is over. You must respect the response your child gives when she has been asked and given the opportunity to say “no.” Choices can be useful. If you ask, “Do you want water or milk?” you give your child a choice within your control. Further, you should end the session on your terms, not with your child getting fussy and escaping by fussing. Sessions should end on a positive note at the parent’s decision.

Strategies for a Child Who Appears Ready to Wean from G-tube Feeds

First, it is very important that the “whole child” is considered when deciding if the child is ready for weaning from a G-tube. This typically requires a team approach. Adequate nutrition and hydration (fluids), stable pulmonary status, minimal to no GER managed well by doctors, knowledge of aspiration risks with oral feeding, and level of function for oral skills must all be considered.

Second, knowledgeable and highly skilled therapists can be extraordinarily helpful to parents and children. Frequency and intensity of therapy are worked out with parents and therapists figuring out a realistic plan. Remember: More is not necessarily better. The primary opportunities for practice will occur with you and your child for a few minutes at a time, likely two to three times per day. The best times for most children are just before the tube feedings, or, if a child is on slow and continuous feeds, when you determine he is likely to be most receptive to practice.

If a child can drink the formula that is given by tube feeding, trade-offs can be direct. The child can drink whatever volume is handled efficiently and without stress, and the rest can be given through the tube. In that way, a “mealtime” schedule is maintained. Some children will make gradual transitions from tube to oral feeding without needing any intensive intervention. Some formulas given by tube do not taste good to children — or to adults either. Children on such formulas should not be expected to drink the tube feeding formula.

Intensive behavioral-focused intervention becomes appropriate for some children once they are medically stable (with or without major medical/surgical issues in the past), nutritionally sound, and swallow safely (not at risk for pulmonary problems with oral feeding). Diverse approaches may be carried out. There is “no one size fits all” approach. Details regarding such programs are beyond the scope of this article.

Parents/Caregivers: What Not to Do

• Do not “force feed.” For example, never hold a child’s face to “sneak” a spoon into her mouth.
• Do not fill the spoon too full. Some parents think that if there is more on the spoon, they can get more food in with fewer presentations. That approach may lead to gagging for some children, requires

Feeding Programs

This list includes some of the multi-disciplinary programs in the U.S. aimed at helping children overcome food aversions or feeding problems. They are listed alphabetically by state. More details and updates are posted at www.oley.org.

Los Altos Feeding Clinic
Los Altos, CA • (650) 237-9111

Marcus Institute
Atlanta, GA • (404) 785-9437

Univ. of Iowa Children’s Hospital
Iowa City, IA • (319) 353-6976

St. Mary’s Hospital and Medical Ctr.
Evansville, IN • (812) 485-7425

Kennedy Krieger Institute
Baltimore, MD • (443) 923-2740

Munroe-Meyer Institute, Univ. of Nebraska Medical Ctr.
Omaha, NE • (402) 559-8863

St. Joseph’s Children’s Hospital
Paterson, NJ • (973) 754-4300

St. Mary’s Hospital for Children
Queens, NY • (718) 281-8541

Duke University Health System
Durham, NC • (919) 684-3733

Cleveland Clinic Children’s Hospital
Cleveland, OH • (216) 448-6024

Good Shepherd Rehabilitation Network
Allentown, PA • (888) 447-3422

Penn State Hershey Children’s Hospital
Hershey, PA • (800) 243-1455

S. June Smith Center
Lancaster, PA • (717) 299-4829

The Hospital at the Children’s Institute
Pittsburgh, PA • (412) 420-2400

Monroe Carell Jr. Children’s Hospital at Vanderbilt
Nashville, TN • (615) 322-0466

Univ. of Virginia Children’s Hospital, Kluge Children’s Rehab Ctr.
Charlottesville, VA • (434) 924-8242

Children’s Hospital, Pediatric Specialty Care of Richmond
Richmond, VA • (804) 228-5818

Children’s Hospital of Wisconsin
Milwaukee, WI • (414) 266-6169

Other Resources:

Hovannesian Feeding Foundation
www.feedingfoundation.org

Mealtime Notions
www.mealtimenotations.com

No Tube (offers Net coaching)
www.notube.at
Donor Profile: Rick Davis

Rick Davis recently hiked across the Grand Canyon to raise money and awareness. His story will kick off our Donor Profile series in a big way. In the future, however, we expect this column will be shorter, and not necessarily focused on a single experience.

Nine years ago, when I was 57 years old, I was disabled by a stroke that weakened my right side, impaired my balance, and paralyzed my esophagus. Initially, I could not raise my right arm and my right leg would not support me. Through physical therapy, I relearned how to walk within a few weeks. After weight training and walking for more than a year, I regained normal strength on my right side. I now maintain muscle tone and strength on my right side through workouts at the gym. The muscles of my esophagus, however, are part of the autonomic nervous system and I cannot improve their functioning at the gym. I will never recover the ability to swallow. For nine years, I have used a G-tube for 100 percent of my nutrition and hydration.

Before my stroke, I enjoyed hiking, skiing, and mountain biking. After my stroke, I used walking and hiking to manage my balance impairment and regain my strength. Each year, I was able to hike longer and steeper trails. I also relearned how to ski at a training center for disabled athletes and even regained my ability to ride a bike. It took nearly four years before I felt I was back to my normal physical abilities. At the same time, I was learning to manage my home enteral therapy more effectively. I learned the best ways to infuse my nutrition on trails, ski slopes, and biking paths. Lacking any sensation of thirst, I had to be diligent about hydration, especially when exercising. Armed with these new tube-feeding skills, and encouraged by the recovery and maintenance of my strength and endurance, I decided to attempt a hike across the Grand Canyon last October. I believed I could do it in one day.

The Big Adventure

It is not an easy hike. The trail between the South Rim and the North Rim is 24 miles long. It descends from 6,680 feet above sea level at the South Rim to 2,400 feet at the Colorado River. National Park rangers, signs, and hiking guides are blunt: “The Grand Canyon has some of the steeps and most rugged terrain on earth.” “If you are not in good shape, you should not even think of hiking down into the Canyon.” “DO NOT attempt to hike from rim to rim in one day.” One sign features a photo of a young, fit man in hiking gear. The caption reads, “Every year, we rescue hundreds of people from the Canyon. Most of them look like him.”

The inner canyon is a hot, dry desert. The steep-sided gorge was carved out by the Colorado River over 17 million years. Summer temperatures at the bottom of the canyon often exceed 110 degrees. The North Rim (at 8,250 feet) is closed because of snow and cold from mid-October to mid-May. It is a place where unprepared hikers can die.

As the volunteer president of the Oley Foundation, I thought it would be cool to do the hike as a fund-raiser for Oley. The fact that an old guy who can’t even eat or drink without a feeding tube would even try such an improbable feat would arouse some interest and encourage my friends to motivate me with their donations. I asked hundreds of my friends, family, and Oley members to sponsor my hike with donations of $10 per mile. My home care company, ThriveRx, was a major sponsor. A ThriveRx dietician, Paul Armiger, age 36, hiked with me.

Paul and I began our hike from the South Rim at 6:30 a.m. on October 7. It was overcast, with light showers in the forecast. In about two hours we reached the Indian Garden Campground, 4.6 miles down the trail and 3,100 feet below the rim. It is the first of three campgrounds along the trail, and one of seven rest stops with drinking water. At 11:00 a.m. we reached the Colorado River and crossed over the churning rapids on a footbridge. We stopped at nearby Phantom Ranch for “lunch.”

“Eating” on the Trail

Lunch for me was powdered formula mixed with water. I infused this three times during the hike, getting about 500 calories each time. I had infused one liter of formula before the hike, with 1,500 calories; I infused another soon after we finished the hike, with another 1,000 calories. I also infused drinking water at each of the seven rest stops—a total of more than two gallons. Each time I “drank,” I added a rice-based rehydration powder, which replaced electrolytes and supplemented the carbohydrates in the powdered formula. As most readers know, preparing the equipment, flushing appropriately, and doing bolus feeding with a syringe takes more time than eating a sandwich and gulping some water. But I had fun explaining what I was doing to the curious hikers who stopped to watch and ask, “What in the world are you doing?”

From Phantom Ranch, Paul and I began the uphill hike to the North Rim. For the next seven miles, the trail was relatively easy. It ran parallel with Bright Angel Creek and gradually rose from 2,400 feet to 4,000 feet at the Cottonwood Campground, the fifth rest stop along the way. The most difficult part of the trail was ahead. We had hiked 18 miles in ten hours; it would take us four more hours to hike six miles up to the North Rim, 4,280 feet above us.

The sun went down at 6:30. We still had two miles to go, with another 2,200 feet up. It had snowed that morning at the North Rim and the trail was steep and slippery. We used flashlights to follow the trail and avoid the steep drop-offs. Our feet were blistered and our legs were burning. The air was thin; we were breathing hard. The cold was bone chilling. I think Paul realized the hike was a little more difficult than he had thought, but he was motivated to keep up with the old guy. I was motivated by the hundreds of people who had made donations to Oley on my behalf. Both Paul and I had committed ourselves to the hike and we had to finish. We had no other choice.

The last two hours were brutal. But we made it. We slept well that night. The next morning, we looked down into the canyon and ten miles across to the South Rim. It was hard to believe that we had actually hiked all the way across. We had a huge feeling of accomplishment. In total, we raised more than $15,000 for the Oley Foundation.

I’m going to hike across the Grand Canyon again next May. Would you like to come along? See details at www.oley.org. ¶
Thank You for Your Support in 2009!

The following list represents everyone who generously contributed toward Oley’s efforts in 2009. We also want to thank all of those who are not listed below, yet have supported the Foundation by volunteering their time and talents.

**Ambassadors ($2,000+)**
- Jarol Boan, MD
- Geoffrey O’Burney
- Dianne J. Davis
- Doris R. Johnson
- Darlene Kelly, MD, PhD

**President’s Circle ($1,000–$1,999)**
- Marcia Boatwright, RN, Anovations, Inc.
- The Andolina Family
- Milton Abercrombie
- Andrea Wolcott, ThriveRx
- Cheryl Thompson*, PhD, Margaret Taber
- Lenore Heaphey
- Thomas Henderson & Paulette Machara
- Jeff Hoeffe
- The Kozushin Family
- Jack Leibee
- Mindy Levin-Reinstein
- Mann Wireless, Ltd.
- Sheila Messina
- Krista Middlebrooks
- Mary Patnode**, MS, Ed, LP
- Lynn & Kurt Patton
- Dr. & Mrs. Doug Seidner
- The Ezra Steiger Trust
- Steve & Edithte Swensen

**Benefactors ($500–$999)**
- Access IV
- Anonymous
- Robert & Laura Andolina
- Paul Armiger & Friends / Employees of ThriveRx
- Steven & Leah Atkinson
- W. Gaines Bagby
- John W. Broviac, MD
- W. Gaines Bagby
- Steven & Leah Atkinson
- W. Gaines Bagby
- John W. Broviac, MD
- Dale & Martha Delano
- Mr. & Mrs. Richard Dillion
- John & Gloria Dimino
- Joanne Hilferty
- Marion Hirschler
- Nagarani Kanumui
- Kenneth Knapp
- Nancy & Peter Kudan
- Lap for Life
- Deborah Pfister
- Janet Platt & Christopher Hatky
- Mark Simpson, Jr.
- Margaret Taber
- Cheryl Thompson*, PhD, RD, CNSN
- ThriveRx
- Andrea Wolcott

**Sponsors ($250–$499)**
- Milton Abercrombie
- The Andolina Family
- Anovations, Inc.
- George Blackburn, MD
- Marcia Boatwright, RN, CRNI
- Barrett Burns
- Ann & Paul DeBarberici
- Laura Ellis*, PhD, RD
- Emmaus Medical, Inc.
- Larry Dean Evans
- Grand Canyon Lodge
- Peter Grundfossen
- Lenore Heaphey
- Thomas Henderson & Paulette Machara
- Jeff Hoeffe
- Lyn Howard, MB, FRCP
- Kishore Iyer*, MD
- Mr. David & Elinor Jackson
- Stuart Kay
- The Kozushin Family
- Jack Leibee
- Mindy Levin-Reinstein
- Mann Wireless, Ltd.
- Sheila Messina
- Krista Middlebrooks
- Mary Patnode**, MS, Ed, LP
- Lynn & Kurt Patton
- Joan & Frank Scheib
- " & Mrs. Doug Seidner
- The Ezra Steiger Trust
- Steve & Edithte Swensen

**Patrons ($100–$249)**
- Sharon Alger-Mayer, MD
- Helen Lu Anderson
- Caroline Apovian
- Matthew & Jennifer Banderman
- Dr. & Mrs. Thos Baumgartner
- Pamela & Matthew Belmonte
- Raymond D. Benge, Jr.
- William Binger
- Lacy Blackwell, PharmD
- June Boddren**
- Chuck & Bobbie Breaux
- Gail & Chuck Brenenstuhl
- Maizie Brown
- Jerry & Delmar Burkett
- Mary Caruso
- Cherry Casey
- Cera Products
- Mr. Albert Chambers
- Davia & Steven Cohen**
- Bert Crosby
- Rick Davis**, DNP
- Marie Debarbieri
- Sheila & Robert Dille
- Joseph & Dana Elliott
- Herb & Joan Emich
- Beverly Engle
- Randall & Daphne Falck
- Michael Faughn
- Stacey Fenton
- Mr. & Mrs. W.W.
- Fitzpatrick, Sr.
- Todd Friedman
- Patricia Fuhrman
- Louise Gabel
- Janet M. Gatti
- Lee Glanton
- Seymour Goldfarb
- James & Mary Good
- Stuart Gordon
- Nella & Bernd Gravenstein
- Charlene Gray
- Jon Grove
- Judith Gussler
- George & Marsha Hanover
- Peggy Harlow
- Iline Hathaway
- Eric Hill
- Dana Hilton
- Portia & Wallace Hutton
- Robert Hydorn
- Erik Jacobson
- Arthur Jodoin
- Janis Johnson
- Jesse Jones
- Carol Jorgensen
- Barbara Kapuscinska Kelly
- Deborah Karff
- Duane & Susan Knaurer
- John Kotouc
- Robin Lang
- Little Eric Shoes
- Charles MacMullen
- Bernard & Jane Manderville
- John McHale
- Kathleen** & Larry McNees
- Joan** & Eli Medwar
- Michael Medwar*
- Stella & Bill Melville, Dean & Mindy Melville, Milley
- Kay & Bill Baldwin
- Lois Moran
- Mr. & Mrs. Edward Morrisey
- Frank & Lucille Mozdziack
- Mt. Carmel West Hospital, Nutrition Support Team
- Alyce & Andy Newton
- Mrs. Josephine Oakley
- Lou & Martha Pacilio
- Robert Paskinkoff
- Jacquelyn & John Pender
- Vincent & Helen Pici
- Ellen Pierce
- James & Kathryn Price
- Dr. & Mrs. Douglas Prince
- Professional Nutrition Therapists, LLC
- David Prunas
- Barbara Ralph
- Mary Russell
- Judi Schwarz
- Billy & Cecile Shields
- Marlene & Julian Sloter
- The Smith Family
- Rex Sperhas*, RPh, CDE, BCNSP
- Kendall & Lynn Starkweather
- Betty Stone, Debbie
- Gaffney, Patty Ethridge, and Carolyn Behrens
- Josie Stone
- Mr. & Mrs. Richard Stone
- Fred Stuto
- Patricia Taverna
- Mary Susan Thomas
- Robert & Karyn Thomas
- Cathy Tokarz
- Carmen Tuilloux
- James Vaughan
- Jeff & Mary Jo Walch
- Robert & Patricia Warrington
- Ann** & Michael Weaver
- Chris White
- Bobbiejo Winfrey
- Marion Winkler, PhD, RD, SNAC*
- Rosalie** & Bill Wu
- Charles & Catherine Yamarone
- Allan & Cheryl Yelner
- Don Young
- Sheryl Young

**Supporters ($50–$99)**
- Cynda Arsenault
- H.S. Ashbaugh
- Mary Barron
- Anthony & Lorraine Bartalo
- Vikki Bedigian
- Dianne Bendersnegel
- Christopher Binger
- Elizabeth Bond
- Sally Bowers
- Patricia & David Bozler
- Judy S.K. Brown
- Lowell & Myrna Buringham
- Susan Carmichael
- George & Margaret Cofer
- Paul & Carol Condit
- Cheryl Conlon
- Dean Cook
- Dave & Bonnie Cox
- Christine & Arthur Dahl
- Victoria Damiani
- Bert Davis
- Jim Davis
- Matthew Davis
- Sara Davis
- Thom Davis
- Lavern Dover
- Scott, Debi, Bryan & Amanda Emery
- Dane Fethering
- Mary Friel
- Leah Funke
- Guadalupe & Virginia Garcia
- Good Search
- The Gravenstein Family
- Peggy Gruenemeier
- Karen Hamilton
- Brenda Hansen
- Bill Hooper
- Martha Hsu
- Portia & Wally Hutton
- Jayne Jeney
- Jesse Jones
- Sheryl Jones
- Heather Kendall
- Janet Kennedy
- Charlene Key
- Janice Kobayaski
- Vanessa Kumpf
- Lucille LaFollett
- Robert Lake
- Christopher & Larissa Lang
- Jacquie & Don Leary
- Carl & Mabel Little
- Eve Longing-Callahan
- Sheryl & Louis Longobardi
- Claire Lupton
- Sarah MacDonald
- Laura Matarese*, PhD, RD, LDN, FADA, CNSD
- David & Theresa Mathiasmeier
- Sharlene Matte

**Donors, cont. pg. 14**
Donors, from pg. 13

Tiffany Matthews, RD
Mary Bea May
Eleline McCarty
Suzanne McQuade
Ron & Dolores Metzger
Ron & Lisa*** Metzger
Mary Miller
Leslie Modena
Glen Morgan
Mr. & Mrs. Donald Nadler
John Nadin
Ronald Noble
Melissa Pariseau, RD
Paul & Donna Peot
Perfromace Physical Therapy
Jo Ann Preston
Karen & William Price
Jim & Donna Quadracci
Marjorie Quinn
Andrea Quinn-Guidi
Nathan Rafferty
Laurie Reyen
Alan Robinson
Cheryl Rusley
Tom & Leslie Sanford
Angelina Schauer
Susan Schesnel
Vi Schultz
Amy & Kevin Shearow
Robert L. Sims, Sr.
John Sindelar & Patricia Homes
Dan & Sue Skelton
Sheldon Sokol
Leonard & Joyce Thompson
Drew Wendt
Mae White
Mark & Andrea White
Marion*, Larry, Pam &
Rachel Winkler
Sharie Youmans, RD
Leigh & Phil Zaleon
Marquette Zeller

Contributors ($30–$49)

Anonymous
Susanne & David Appel
Betty Bailey
Julie Bain
Margaret Bald
Nancy & James Bean
Arthur R. Benanti
Gerald E. Bennett
Patricia Boottom
Joan Bowling
Esther Burch
Mary Burke
Mary Caruso
S.A. Chaney

Coram Houston Branch
Coryn Commare
Mr. & Mrs. Edwin Delong
Donald Emspen
Robera Fost
Sophia Gutterz
Stephen J. Harris
Charles Karnack
James Kellner
Lavina & Pierce Kepple
Pauline Kubizine
Reginald Labossiere
Mr. & Mrs. Jeremiah J. Lynch, Jr.
Philip & Anita Mabardy
Tom Markert
Karen & Millard Mauer
Laura Mulcahy
Joanne Plat**
Jim & Sarah Rausch
Stacey & Bryan Rothmeyer
Carole Ryan
Mr. & Mrs. Charles Sargent
Kathleen Schweitzer
Alan Segal
Ronald & Susan Singleton
Nancy Sinkus
Lori Sirgedas
Clayton Smith
Karen Smollen
Frances Sneider & Beth
Cohen
Lisa Szpak
Enrica Thure
Gregorio Tongol
Michelle Trunick-Sebben
Carrie Whitacre
Eleanor Wilson
Anthony Woodburn
Donna Yadrich

Friends (Up to $30)
The Ackerman Family
Ann Alesse
Jessica Allen
Kathy Allen
Alan & Darlene Amark
Mary & John Annese
Theresa Arewel
Mr. & Mrs. Warren Bales
Joel Ball
Lorraine Barbasz
Joan Barnett
The Bartholomew Family
Joan Bishop***
Bettemarie Bonad***
Mr. William Bonan
Dorothy Booth
Rosemarie Boothroyd
Eileen Bowes
Luciann Boyd Thompson
Johnathan Brodkin
Robert Brown
Dot Buckley
John Cardwell
Kay Carlson
Mr. & Mrs. Joseph Caro
Meg Cass-Garcia, RN,
MSN, CNSC
Gray Chandler
Pamela Chaney
Carol Chapin
Glen & Deanna Clark
Faye Clements, RN, BS
Margaret Cleveland
Judith Elaine Cline
George & Margaret Coker
Drs. Joan & Alan Cohen
Jay Crump, OD., PA
Roslyn*** & Eric Dahl
Donald Darmer
A. Kay Davis
Linda Deane
Gretchen DeKalb
Mark DeLegge, MD
Jean Demichelli
Rose Deveraux
Dawn DeWein
Ted Dudick
James Dunn
Bill Edgeworth
Nathan Egan
Marie Elavich
Thomas Estes
Karen Fish
David Fitch
Theresa Freeman
Andrea Fryd
Nancy Garber
Ms. Joan Gartner
Kathy & Terry Gibson
Jennifer Gniadek
Tiffany Gniadek
Jacqueline Goldman
G. Contanza Gonzalez
Carole Gordon
Helens Grimes
Edward Grissom
Michelle Hadley
Karen Hamilton
Cathryn Hartung***
Vicki Hassen
Zana Hatcher
Raymon & Patricia
Raymon & Patricia
Hawkins
Donna Heald
Keith & Donna Hedlund
Kara Hibler
The Hile Family
Rose Hoelle**
Bob & Blanche Hoffman
Penny Hooper
Ron & Barbara Horsley
Pam Houghes
Dan Hutchinson
Noreen Iacobucci
David Ingram
Carol Irion-Jones, PhD,
RD, LD, CNSD
Alvin & Mary Jackson
Robert & Junta Jacobs
Robert Keane
Deborah & Addison Kellogg
Ron Kibbe
Mary Ann Kovalich
Chris LaPolla
Marie Latta
Michelle Lebaron
Walter Leja
Gail Lindaman
Allison & John Love
Eileen & Richard Lowe
Sherry Lutz
Allan Mabardy
Janice Mabardy & Carol
Valenzano
Paulette Mabardy
Craig, Shannon & Alyssa
MacCormack
Janet Mancini
The Manura Family
Jaime Maul
Charles McDonald
Sue McKellar
Mary Meador
Nora Medwar
Norm Melenson
Pat Meserle
The Metzger Family
Jim Montgomery
Kimberly Morgan
Gerard E. Mullin, MD,
CNSP
Marris & Donna Mummery
Alice Myers
Don V. Nelson
Adolph Neuber
Patricia & Thomas Newton
Doreen Nicholson
La Vonne Nicholson
Linda Nicholson
Josha Paris
Melinda Parker, MS, RD
Indra Patel
Robert Patterson & Kim
Bradly
Dori Pedrioli
Angela & Michael
Petrogeorge
Mary & John Petrsoric
Caroline & Kenley
Woolstenhulme
Tabitha Wunderlich
The Yeager Family
Joe & Carol Yontz
George Young
Aliza Chana Zaleon
Jason & Kelly Zamora
Betty Zeller
The Zimmerman Family

* Oley Trustee
** Oley RC
*** Oley Staff
Acknowledging Your Gifts

Over the years it has been suggested that you would like to see more space in the newsletter devoted to “news you can use,” and less to lists. With this in mind, and with the start of a new year, we would like to introduce a new approach to recognizing and thanking our individual donors. Rather than include a list of donors in each issue of the newsletter, we will publish a short profile piece about a member of the Oley community who has chosen to support the Foundation with a monetary gift (see page 12). It is our hope that this will be a meaningful way to share more personal stories with our readers, while also acknowledging our individual donors. We will continue to publish a comprehensive list of donors in the Jan/Feb issue each year.

We realize that many give to the Oley Foundation to honor or remember a person or special occasion. We will continue to acknowledge these people and occasions. As always, we offer our thanks to the many individuals who have given to the Oley Foundation. Please let Joan Bishop know what you think of the new approach (800) 776-OLEY or bishopj@mail.amc.edu.

Notable Gifts Received from December 2, 2009, to January 20, 2010

In honor of: Mandy Allen’s birthday and 3+ years on HPEN; Julie Andolina; Leslie Bagby; Matthew Banderman’s 30th birthday; Joan Bishop, for her many years of devoted work and hours to Oley; Charlie Cleberg; Colorado State Infusion; Maryellen Costa’s courage; Rick Davis’ Hike-a-thon; Ann DeBarberi; Jackon Merrill Dietel’s birthday; Frances Donohue; Charlie Edim’s birthday; Laura Ellis; Cathy Harrington; home PN and EN consumers; David McGee’s 6 years on HPN; Kathleen McInness & the Chicago Pumpers; Dr. Darlene Kelly; Robbyn Kindle; Mary Kunz; Sebastien Labossiere; Robin Lang; Lina; Eli Medwar; Jonathan Nelson; Dale Parker, 20 year caregiver—what a husband; Ryan Peot’s 16 years on HPN; Ellen Pierce for donating her shipping ice packs; Jay Shearrow; Erin Shore’s birthday; Tanner J. Shuman, off HPN for 7 years; Lia Smollen; Mary Jo Walch’s 19 years on HPN; and Michael Yelner’s 15th birthday and 10 years on HPN.

In memory of: Marilyn & Ronald Baumgartner; Megan Burke; Gene Bussoletti; Kathleen Campbell; Kenneth Crosby (matching gift from the GE Foundation); Norwood Davis; Woody Freese; Richard Gabel; Madalyn Goldfarb; Patricia Gordon; Betty Gray; Nancy Harvey; Joyce Hydeorn; Dorothy Kelly; Inalee Koonin (and “Aunt Lee Bee”); Clare (Becky) Lumpkin; Jyl Elizabeth Marsh; Benjamin Matarrese; Kyle Noble; Susan Parker; Julie N. Patrick; Jane Russell; Becky Schreiner; Willis (Dick) Schultz; Josh Shapiro; Ken Theile; John Ventimiglin; and Colyn Woods.

Oley Horizon Society Blossoms!

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

Alfred Haas
Jeff & Rose Hoel
William Hoyt
Darlene Kelly, MD
Robin Lang
Hubert Maiden

Kay Oldenburg
Judy Peterson, MS, RN
Clemens Pietzner
Abraham Rich
Gail Egan Sansivier, MS, ANP
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnol

Abraham Rich
Catherine Cotter
Jim Cowan
Kishore Iyer, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI

Beverly Promisel
Kimberly-Clark

Andy Fearon
Catharine Cotter
Jim Cowan
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI

Beverly Promisel
Kimberly-Clark

Benefactor Level Partners
($10,000–$19,999)
Abbott Nutrition
InfuScience, Inc.
Nestle HealthCare Nutrition

Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan

Bilevel Systems
($5,000–$9,999)
Bilevel Systems
($5,000–$9,999)
Bilevel Systems
($5,000–$9,999)

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex

Benevolent Basic
Moog Medical Devices Group/Zevex
Reserve Your Room Now!

Join us at the historic Gideon Putnam Resort in Saratoga Springs, N.Y., for the 25th Oley Consumer/Clinician Conference, June 28–July 2. Twenty-five years ago, the Oley Foundation held its first meeting — a half-day picnic — in Saratoga Springs. These gatherings have grown to the conferences we now enjoy, and we are bringing the conference back to Saratoga Springs to celebrate this anniversary.

Reserve your room today at (866) 890-1171 or (518) 584-3000. The rate of $145/night for a single/double room is in effect for reservations made through May 28, and is good from June 27 to July 2. To access the group rate indicate 9N11TG when making your room reservation. See all the Gideon has to offer at www.gideonputnam.com.

Note: To get the group rate, you need to make your reservations by phone.

Come early, stay later, and enjoy all that this area has to offer. Plan on golfing with us (watch for details on a tournament!); boutique shopping downtown; visiting Saratoga's famous mineral baths, dance museum and race course; and just plain relaxing. Sessions at the Double H Ranch (a Hole in the Wall camp) run during and just after the conference — it might be the perfect opportunity for a youth camp experience! (See page 6 for camp details.)

What’s Your Quality of Life Like?

Tell researchers what it’s really like to live with intravenous feeding (HPN). For details call the Oley office at (800) 776-OLEY or visit www.oley.org.

Weaning, from pg. 11

extra, unnecessary effort for the child to swallow, and may lead to food aversions.

• Keep the child in the chair for no longer than ten to fifteen minutes.

• Do not try to get a child to eat or drink all day long. Children should not walk around with food or liquid. “Grazing” does not promote hunger and appetite.

• Try to keep non-feeding/swallowing activities limited when the goal is to get the child to accept a spoon, cup, or finger foods. Keep distractions minimal, with no game playing.

• Do not try to wean a child from a G-tube single-handedly. Most children and their parents/caregivers gain success as they work together with multiple professionals. It is important to make sure the child’s health status supports the plan, swallowing is safe, nutrition is adequate, oral skills can be efficient, and parent-child relationships are positive.

Conclusion

Do you remember the Aesop’s fable “The Tortoise and the Hare”? You know who won the race. The tortoise was slow and steady, and that turns out to be faster in the end. This is the way most children reach the goal of total oral feeding when their medical and developmental status makes it possible for them to wean from G-tube feedings.
What’s Your Quality of Life Like?
Tell Researchers What It’s Really Like to Live on HPN

You are in a unique position to help the medical field understand the impact that home parenteral nutrition (HPN or home intravenous nutrition) has had on your life. Because you experience this therapy on a day-to-day basis, we are asking you to participate in a widespread study of the effect of HPN on quality of life.

The Oley Foundation is collaborating with the European Home Artificial Nutrition Workgroup in this study. The study will promote understanding of the issues that are important to you, the consumer, and will hopefully make HPN practices better for you. It may also make it possible to compare the effects of techniques such as small intestinal transplantation with life on HPN to allow consumers to make more informed decisions, and to compare HPN practices in the United States with those in European countries. Developing this understanding further could also help us make Oley of greater benefit to you.

How to Participate

This study is open to all adult HPN consumers. You do not have to be an Oley member to participate. We heartily encourage your participation. For details and/or to participate, call the Oley office at 800-776-OLEY, e-mail Cathy Harrington at harrinc@mail.amc.edu, or visit www.oley.org. All responses will be kept confidential. This study has been approved by the Albany Medical Center Institutional Review Board (IRB).