The Tube
Al Toman

Though I don’t “tube” anymore, I often think back to when I did. Some might consider it a small happening, an inconvenience, a pain in the butt (or the gut), but mostly I think of it as something that needed to be done. I keep one of my old G-tubes on a shelf above my desk to remind me how fragile but resilient we are.

I believe I keep it also because my tube adventures cost me over $10,000. More than once, the balloon (used as an internal bolster) burst and the tube fell out. Consequently, I had it replaced more than once. Maybe someday I’ll auction it and recover some of the expense. Unrealistic? I guess I’ll write about it instead.

Beginning at the End

At one of my checkup visits, Dr. S— (a head and neck surgeon) asked if I didn’t think it was time to remove the tube. By then, it had become a part of me. I told her I wanted to think about it. It had become so easy to pour cans of goo down the tube. It was fast and efficient. And at that time, I had nothing else to eat but my cans of goo.

“I picture this petite woman grasping onto the tube, with both feet on my chest, yanking it out.”

I immediately recalled when radiation started making its mark on my oral cavity and the only thing I could get down was Boost or Ensure. I hated the stuff! I think they were partially why I had decided to do the tube. Sitting across the table from me as I used my tube, my son-in-law would ask, “What are we having tonight? Meatloaf? Steak?” My can of goo could become anything I wanted it to become.

Putting a Face to Short Bowel Syndrome

On October 16, Oley Executive Director Joan Bishop and several Oley members entered the FDA building in Silver Springs, Maryland, to address the task at hand: to showcase the challenges and struggles that accompany the diagnosis of short bowel syndrome (SBS) before an FDA Scientific Advisory Committee. At the end of the day, this committee would decide whether or not to recommend that the FDA approve Short Bowel Syndrome, cont. pg. 10 ». 

Paul Roser

Paul, who is unable to swallow due to surgery, often shares tips and news with a “cancer survivor” e-mail list that he maintains. He recently wrote that he was going to “make the most of the holidays this year.” So we asked him what he planned on doing. Here’s his reply.

“We (my wife and I) enjoy the holidays, but just “differently.” We usually do a Christmas Eve church service someplace (New Year’s Eve, also) and big sit-down dinners with friends or families—though the meal portion is really pretty brief. It’s mostly anticipation… I used to love the crisp turkey skin, and often nibble on a small piece of it for the flavor. I keep a small green...”

Our Holidays, cont. pg. 10 »
The Tube, from pg.1

It’s a four-hour drive to and back from UNC Medical Center in Chapel Hill North Carolina where I see Dr. S—. The trip home allowed me plenty of time to think. That night I popped open a can of goo and poured it into a glass. Plenty of time to think. That night I popped open a can of goo and poured it into a glass. I placed it in front of me.

End of the Tube

Three months later, in my next visit with Dr. S—, I told her to pull the tube. A can of goo went down sooo smooth and tasted sooo good (though normal people can’t stand to either smell or taste it). I told her I had stopped using the tube the evening of my last visit. The nursing director was in the room when I told Dr. S— to take it out. He laughed and said, “Now you’ll have two belly buttons!” I had never, ever given it any thought. Two belly buttons? No one tells you these things.

You have to picture Dr. S—. She is petite (but also a larger-than-life, strong, and dedicated woman, who saved my life). She went to her cabinet and retrieved a small syringe. I pulled up my shirt and she looked at the tube, surprised that there was no place to put the syringe to deflate a balloon. I told her that the last time my balloon-type tube fell out, Dr. T— had replaced it with a fixed mushroom type—with no balloon to burst. If it hadn’t stunned me, causing tears to run down my face, I would have been rolling on the floor laughing when the tube was extracted. I picture this petite woman grasping onto the tube, with both feet on my chest, yanking it out. Her hands were literally shaking as she forced the tube to pop out of my chest (yes, my chest; it was just below my sternum). [See comments on page 13 about tube removal.]

And that was that.

Me and Cooking

I’ve always been a utility eater, which has turned out to be a blessing. Many people feel sad or become depressed that they most likely will never again eat pizza and drink beer, or have lobster or a big piece of chocolate cake. I have yet to become depressed over not being able to eat solid foods even after being off the feeding tube.

Actually, I had always hated to cook, but now I enjoy grocery shopping and cooking or grilling. Of course I can’t eat any of it, but I love to cook for others and make them eat the stuff. During my recovery—after the surgeries, radiation, and chemo—I was watching TV and saw Oprah interview Grant Achatz, who manages the award-winning Alinea restaurant in Chicago. He battled tongue cancer and has an incredible story to tell. (Don’t we all?) I wrote him a letter thanking him for the inspiration. He actually wrote me back! Maybe he helped turn my hatred of cooking around?

How It All Began

No one tells you definitively that you’ll need “The Tube”—well, that is, you will need it if you want to eat. Yes, they mention it, but as a cancer victim, you’re in a fog. Thoughts like “I just want to stay alive” are spinning around in your head, and nothing else registers. I really gave no thought to the tube until about the third week into radiation therapy.

Radiation affects the oral cavity tissues and glands. Your saliva becomes radically reduced. Your mouth feels like the burning pits of hell. Swallowing becomes almost nonexistent. And you’re supposed to shovel food into this? Not going to happen.

I finally told Dr. G—, my oncologist, that it was time for the tube. He arranged for its insertion the following day. I signed in at the local hospital (an hour away) as an outpatient.

As it happened, the procedure was new to the radiology department. I was apparently one of its first victims. I stripped down, got into a gown, and was placed onto a bed on wheels. I was poked, prodded, questioned, and, best of all, given a warm blanket out of the microwave. They then rolled me down the never-ending maze of hallways into their den of horrors, where people were standing with their hands in latex gloves above their shoulders, looking at me with wide grins underneath their face masks, waiting to take possession of my body. Well, not really, but that’s what my mind sees.

The radiology department used the CRT to image my belly as they properly located the incision to my gut. They used a local anesthesia, so I was awake watching all the technicians. Without further ado, I exited the tube, with both feet on my chest, yanking it out. Her hands were literally shaking as she forced the tube to pop out of my chest (yes, my chest; it was just below my sternum). [See comments on page 13 about tube removal.]

And that was that.

The mushroom-type bolster inside Al’s intestines in the prepyloric region.
**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 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.

**Further Advice on Traveling with Tube Feeding**

I read with interest the article in the latest Oley newsletter about traveling with a feeding tube [“Tube Talk,” September/October 2012]. I’ve never used a bag except in skilled nursing, and I hated it. Traveling is much easier using gravity feed syringes, 8 oz cans of formula, and bottled water. If one has a faraway destination in mind those things can be shipped ahead. For shorter jaunts of a week or less everything can be carried in your vehicle with the supplies diminishing from day to day.

—Shirley C., Sun City, CA

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**Book Corner**

*My Tubey: A Day in the Life of a Tube Fed Girl*, by Rhiannon Merritt-Rubadue

**Review by Nancy Sinkus**

The picture book *My Tubey: A Day in the Life of a Tube Fed Girl*, by Rhiannon Merritt-Rubadue, portrays some very basic mechanics of feeding tubes, told as a young girl with a feeding tube goes through her day. Ms. Merritt-Rubadue wrote the book so her own daughter could see another child with a feeding tube like herself.

My son J. D. has had a "tubey" for nearly all of his eight-plus years of life due to swallowing difficulties. We’ve always tended to emphasize to J. D. that no one else he knows well has a feeding tube—that it’s not the norm—because we want him to increase his oral feeds. It took us by surprise to see how excited he was to see the girl illustrated in the book with what looks exactly like his low-profile feeding tube (or button). J. D. has definitely taken ownership of the book, continuing to be interested each time he picks it up, telling us the title, pointing out the tubey picture.

The book is great for kids for its very simple explanation of how a tube works. It would make a great show-and-tell for a tube-fed child in preschool or the primary grades. The same simple explanation, along with the glossary of feeding tube terms listed in the back, would also work as a great primer for the adults in J. D.’s life who were previously unfamiliar with feeding tubes. Well-meaning but uninformed family and friends would get a quick lesson in the basics, all while just doing a good deed by reading J. D. a book. He will happily sit through another reading of the book with the “tubey” girl just like him.

Nominate Someone Who Inspires You!

The five awards Oley presents this year recognize those in our community who have earned our respect, inspired us, and taught us. **We are pleased to have added a second LifelineLetter award** (see details below)! Nominate someone today, following the criteria listed below. We've provided a form you can use as a guideline when submitting your nomination(s). Nominations must be received by March 18, 2013.

Awards will be presented at the 2013 Oley Consumer/Clinician Conference and the awardees will be spotlighted in the LifelineLetter. Four of the awards include a partial travel grant to the conference (tentatively scheduled for the last week in June in Hyannis, Massachusetts). Recognition is given to all nominees.

### The Awards and Criteria

**LifelineLetter Award, HPN**
*In honor of Nutrishare, Inc., Gold Medallion Partner*
- 19 years of age or older
- Home parenteral (HPN) consumer or caregiver for 5 years or longer
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN
- Winner will receive a partial travel grant to the Oley annual conference

**LifelineLetter Award, HEN**
*Sponsored by Abbott Nutrition, Benefactor Level Partner*
- 19 years of age or older
- Home enteral (HEN) consumer or caregiver for 5 years or longer
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN
- Winner will receive a partial travel grant to the Oley annual conference

**Child of the Year Award**
*In honor of ThriveRx, Gold Medallion Partner*
- 18 years of age or younger
- HPEN consumer for 1 year or longer
- Shows a positive attitude in dealing with illness and therapy which encourages and inspires others
- Winner will receive a partial travel grant to the Oley annual conference

**Celebration of Life Award**
*In honor of Coram Specialty Infusion Services, Gold Medallion Partner*
- Any age
- HPEN consumer for 3 years or longer
- Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.
- Winner will receive a partial travel grant to the Oley annual conference

**Nan Couts Award for the Ultimate Volunteer**
- Clinician (physician, nurse, dietitian, etc.) practicing in the field of HPEN or related field (psychology, interventional radiology, pain management, etc.)
- Demonstrates a willingness to give of themselves, above and beyond their regular work hours, to educate, empower, and improve the quality of life for HPEN consumers

### 2013 Oley Award Nomination

1. **Provide the following information:**

   I am pleased to nominate the following individual for the 2013:
   - LifelineLetter Award, HPN
   - LifelineLetter Award, HEN
   - Child of the Year Award
   - Celebration of Life Award
   - Nan Couts Award for the Ultimate Volunteer

   Nominee's name: _______________________________________
   Age: ______ Daytime Phone: (______) _______ - _________
   E-mail: ____________________ @ ________________________
   Primary diagnosis: _____________________________________
   No. years on HPEN ______
   Your name: ___________________________________________
   Daytime Phone: (______) _______ - _________
   E-mail: ____________________ @ ________________________

2. **Tell us why you are nominating this person.**

   Cite specific examples of how the nominee meets the award criteria. Please limit length to one page (attach).

3. **Submit nomination to:**

   The Oley Foundation
   214 Hun Memorial, MC-28
   Albany Medical Center
   Albany, NY 12208
   Fax (518) 262-5528
   E-mail harrinc@mail.amc.edu

   **Questions? Call (800) 776-OLEY**
Tube Feeding Pump Update

In October, Abbott Nutrition announced that it will no longer manufacture, lease, or sell “enteral device products” (i.e., tube feeding pumps, feeding sets, tubes, and tubing) in the United States. “This decision,” they write, “allows us to focus...on bringing innovation to our oral and enteral nutrition portfolio of products” (including enteral formulas). How will Abbott's decision impact you, as a home enteral nutrition (EN or tube-feeding) consumer, and what action—if any—do you need to take?

Abbott Pumps

The greatest impact will be on those who use EN pumps and feeding sets or tubing manufactured by Abbott Nutrition (formerly known as Ross), including the Patrol, Quantum, Companion, and Clearstar pumps. Any EN consumer who is using one of these pumps will need to transition to a non-Abbott pump by the end of April 2013, when Abbott will discontinue selling the disposable sets, tubes, and accessories related to these pumps.

Many of you—probably most—will be supported in this transition by your home care company. If you have questions, you should turn to them first. You can also call the Abbott Nutrition Pathway Reimbursement HelpLine at (800) 558-7677 to speak to specialists about insurance reimbursement, or visit abbottnutrition.com/reimbursement.

Abbott writes, “Abbott Nutrition is committed to providing support through the discontinuation of our device business.”

If you own an Abbott pump, you will be asked to return your pump to the company once you have transitioned to a new pump. Abbott has set up a program for buying back pumps that were purchased within the past three years, at a depreciated price. Again, your home care company should be able to help you make these arrangements.

A list of the affected products and more information is available at www.AbbottEnteralTransition.com.

Moog/Zevex Pumps

In the past, Abbott was a distributor of the EnteraLite® Infinity® pump, manufactured by Moog Medical Devices Group. Recently, Moog purchased all EnteraLite Infinity pumps distributed by Abbott Nutrition and has assumed all rights and obligations under the lease agreements that you or your home care company may have had with Abbott Nutrition. Abbott will no longer serve as a distributor of these pumps. Moog states, “We want to assure you that the decision by Abbott to exit the feeding pump business will not impact your ability to access...the EnteraLite Infinity line of pumps and feeding sets.”

The transition of this agreement will be handled by Moog and your home care company, so your service should continue without any apparent changes. If you do have questions regarding your Infinity pump, you can call Moog at (800) 970-2337.

Other Suppliers


We have been assured that other manufacturers are building up production to meet the demand as Abbott leaves the devices market.
A Banner Year for Travel
Sandy Schwarz

Everyone needs something that gets them excited, that makes their day and gives them a reason to live. Having a central line of some sort and being on parenteral nutrition (PN)—or having a tube and being on enteral nutrition (EN)—can put a kink into some of those passions or dreams. And having a disease or multiple diseases sometimes leads you to be a little more resourceful or slightly lower your expectations. BUT—the happiness one gets from an activity sometimes involves taking chances.

Fortunately or unfortunately, my lifelong interest has been traveling. Not the fancy type, but where you try to blend in and learn more about another culture. Thankfully those opportunities are practically endless. I should mention that I would probably be described as chronically ill—Crohn's disease, colectomy, ileostomy, gastroparesis, separate PEG and J tubes, constant pain and nausea, etc. My doc tries to tell me I am fragile; I reply by totally ignoring that description. But you get the idea. I spend most of my time in a fetal position on my bed trying to work on my art when I can. Most everyone wonders how I manage to travel as much as I do and to where I do. My answer is adrenaline.

China

My most memorable year was probably 2010. (I should mention that we all thought that this was the safest time for me to travel to China and India since I would be on PN with extra boluses of fluid, and would have no need to drink or eat anything in either country.) At the start of the year, I had just returned from Kauai, Hawaii. A few days later I spent a month in Atlanta with a very close friend, who is also my travel buddy. During that visit we decided we would go to the Galapagos and Machu Picchu, Peru.

Just as we were on the phone to book the trip for about two months later, we saw news reports about torrential rains at Machu Picchu. The rains had washed away the train tracks and part of the trails. Needless to say, the trip was cancelled; it would be months before things would be fixed and it would be open to tourists again.

On to plan B. We surveyed the world and travel companies and decided on a trip to China. So with visas acquired, off we went to Beijing, Xian (site of the buried hidden sculpted army), and finally Shanghai. I loved the trip, but not the big tourist sites—the Great Wall, Tiananmen Square, Forbidden City, and so on. I loved the places a few blocks behind the hotels, and walking in the various neighborhoods in the cities we visited. I love interacting as much as possible without knowing more than three or four words—and a smile—and showing respect.

We found the hutongs—the old neighborhoods being torn down—very interesting and totally unlike other places people live. Apartment buildings are being built in those spaces and a whole new way of life is being forced on these people. We also loved the parks, watching and being forced on these people. We also loved the parks, watching and being on these people.

Europe

After China I slept for six weeks—till the next trip. I scraped myself off my bed and on to England. Liverpool, to be exact. My aunt and

Doorway in a preserved part of the town of Xian.

many relatives live there. I have definitely been to Liverpool more often than anywhere else. We visited a friend in London for a week, then back to Liverpool and on to Germany, where we now have a number of friends, after a number of visits to one little spot in northern Bavaria. Eventually we made it back home to Seattle.

I slept a few more weeks. I was starting to feel a bit crummiest, but I flew to Los Angeles to a friend's house, where I slept for a few more days (Fourth of July now—views of the fireworks from high in the hills looking down on the Hollywood Bowl). We then drove to Point Reyes (San Francisco). We stayed a few days, drove back down to LA, and then flew home.

Questions & Answers on International Travel

Thanks to Sandy Schwarz and Todd Friedman for this segment, much of which was published in Todd’s “Sweet TPN Times.” The questions are Todd’s, answers are Sandy’s.

1. How did you plan ahead to ensure that your PN and supplies would arrive safely overseas?
   I carry all my supplies myself—no shipping by anyone. I carry on all my medications and a couple of days of PN with an ice pack or two, since I use freshly made PN at the beginning. Since I last traveled overseas, many airlines are only allowing one free checked bag. I find it very unfair since some equipment used for visually obvious disabilities are still free (wheelchairs, etc.). This change greatly increases the cost of traveling overseas. Hopefully airlines will understand the lack of options and the necessity for people on PN and EN to bring multiple heavy bags of life-sustaining, medically necessary bags with them. [Editor’s note: Some airlines will not charge for extra baggage containing medical supplies; we suggest you check with the individual airline regarding its policy.]

2. How do you ensure that your PN, supplies, and pump get through customs?
   I have never had ANY problems, ever. I always have a few letters with me, one from my doc and the other from my home infusion division. I am always polite and calm, and carry my letters with me. I let them do whatever they want (there has never been anything outrageous, though full body scans DO confuse them). Also, at some airports there
with Parenteral Nutrition

is now a separate line for security for families and people traveling with babies, wheelchairs, and carrying medical liquids. I have used that line about four times now in different cities. It lets you skip most of those endless lines.

3. Do you mix your own PN once you are at your destination?
I now use a product by Baxter called Clinimix or Clinimix E. It does not need refrigeration. It comes in a foil-like wrapper with a multichamber in the middle. You roll the bag, which breaks the seal and mixes the amino acid side with the dextrose side. It will never be exactly your formula, but if your medical provider thinks it is okay for a week or two—or longer—it is great. There are no lipids.

4. Have you encountered any challenges in keeping your PN cold?
This has not been applicable in the last few years. Before three years ago, we found ways to keep my PN cool—collapsible coolers or staying in rented apartments or other places with refrigeration. There are no ice machines in any place I have stayed outside this country (which shows my level of accommodations). It is easy to keep small vials of things like vitamins and other additives cold by being creative. Clothing is a great insulator, frozen peas work, and there are bags with chemicals that when combined become an ice pack (we’ve all used them in the hospital, etc.).

5. Did you get names of PN doctors in each country you visited in case of an emergency?
I get the names of hospitals, but I try to avoid them by bringing antibiotics and any other meds my doc and I have discussed. Sometimes I get evacuation insurance (like when I went to India), and have decided if I get really sick, I would get the next plane home. I also have e-mail and an iPod touch that I can use to Skype-call my docs, who give me their cell phone numbers.

6. What other challenges have you encountered overseas and how have you dealt with them?
Bring an extra pump and as many extra strong tall people (“sherpas”) as possible. Also, count, recount, have others count too, and go over your supplies and meds as many times as you can and with as many people as you can. My biggest fear traveling is, did I bring enough of my meds? I am on a lot right now, and I use a spreadsheet to calculate how much for how many days.

One of the harder things to navigate is figuring out which and at what time to do your meds, depending on the number of meds and the time difference from your starting point. One of my current luxuries that solves many things is again that iPod touch (fourth generation). I borrowed one for China (good reception if you stand outside the premier lounge in Seoul). I could set multiple alarms for taking meds and hooking up, e-mail my doc, Skype-call my doc and family, carry copies of all my medical records, carry a detailed map—you get the idea. I am not a techie, but I am sure there are endless solutions out there these days.

I spent the next three months in the fetal position getting sicker all the time. I was admitted to the hospital in September for five weeks, with endless docs trying to think of solutions, and was finally discharged with visiting nurses. Meanwhile, I was going ahead with year-long plans for a trip to India for the following December. It took me weeks to get up the nerve to tell my docs. Half thought I was crazy; the other half gave me the thumbs up and gave me ideas to help me.

India

I did go to India for eighteen days. I went with my sister “Sherpa,” and my traveling buddy and her entire family, which is also my family. There were thirteen of us. I went with a slow-growing tunnel infection, so I was on antibiotics the whole time. We all caught a short Norwalk virus type thing. Being me, I got the sickest and it lasted the longest, but I didn’t have to get down a sip of fluids—ah, extra IVs! I was also dealing with low albumin and therefore very swollen feet and legs.

We split the trip into two parts. The first part was to the state of Kerala, which is in southern India on the western coast. It is lush green. Many different cultures have influenced it, and it is very interesting. While there, we went to Munnar, a high station where they grow tea and spices, then went on an overnight houseboat on the backwaters at Alleppey. It was very relaxing despite the heat.

After Kerala we flew to Gujarat—a state that is far west and north, and very different. It is the home region of my friend’s family. I loved seeing my other mom in her element in India. She and I have talked for over thirty years of getting me to India, so in many ways it was a victory for both of us. I found the whole trip fascinating and I don’t regret a thing.

The Future

I haven’t done any “real” traveling since then, due to my health. I’ve tried a few times within the country, but got sick each time. The last attempt was a year ago. But now my traveling buddy, my acupuncturist, and all my docs are on my case to make some travel plans. I am still not back at my baseline so I can’t decide where to go, but soon I will be on a plane somewhere. Croatia maybe? Or South Africa? My bed? Anyone have any ideas?

Several years ago I had stopped traveling for a while. I had had a bunch of surgeries and I sort of gave up the traveling stuff. I kept getting sick. I had multiple bouts of sepsis, tunnel infections, more sepsis with stranger bugs…. And all I was doing was lying on my bed. I then decided I can get sick anywhere at anytime and I wasn’t going to let that rule my life. I would rather live a life than wait for the next medical emergency to come along and guide it.

I now focus on being calm and open minded, and “going with the flow.” Stressing about relatively insignificant things will most likely ruin my trip—and my traveling companions’ trip. An interesting vacation has many ups and downs; the ability to smile and laugh about it later is the key.

Happy travels.

P.S. My next trip is to Turkey—at the end of next spring. I admit I am more nervous about this trip than any others, but I have a number of months to get this body (and mind) ready.

Sandy can be reached at skookstuff@comcast.net if you have any comments or questions.
Tips for Better Living

Tube Tips and Bright Ideas

Over the years, Oley members have shared hundreds of tips and ideas for making life with IV and/or tube feeding more manageable. We’ve published these in the newsletter and have collected them on our Web site. In anticipation of a new year and to help make our Web site easier to navigate, we’re updating and recategorizing those ideas and tips. We’ll toss those that are outdated, repeat those that are timeless, and add what’s new. Watch for this column throughout 2013, and check www.oley.org periodically for updates.

We’re starting with ideas to secure your lines and tubes. We know there are other ideas and options available. Got one? Send it to Lisa Metzger at Oley and we will add it (e-mail and mailing addresses are on page 2)! We’d love to expand this useful resource.

Note that the information provided here is designed to support, not replace, the relationship between the HPEN consumer and his or her physician. All issues, ideas, suggestions, etc. should be discussed with your health care provider prior to use. Medical information is reviewed by clinicians in a relevant field, but inclusion here does not imply endorsement by the Oley Foundation.

Securing Lines and Tubes

• PICC Cover Fashions™: A stretchable sleeve that slips up over the arm and into desired position; available in many fabrics and in two lengths (full-arm or bicep). www.castcoverfashions.com or (201) 953-3160
• Design for Your Life Medical Privacy Sleeves: PICC line covers for adults or children, in a variety of fabrics (including a water-resistant fabric) and designs. www.designforyourlife.com or (888) 479-4687
• Kevin’s Covers: Machine-washable, adjustable cover sleeves to prevent PICC lines from getting caught or tugged. www.kevinscovers.com or (919) 327-6697
• Surgilast®, from Derma Sciences: A tubular elastic stretch net designed to apply gentle pressure to keep bandages or medical devices (including IV tubes) securely in place without adhesive tape; available in a range of sizes. Available through several medical supply companies.
• Pediatric Central Line Protector™ (formerly “Summer’s Lifeguard”): A tape-free way to secure a central venous catheter in infants and toddlers and protect the surgical site. www.healthfullyhealing.com or (866) 219-3113
• Joey Pouch™: A small, soft pouch made by a U.S. company to hold a central line; the pouch adjusts around the neck, and can be worn under clothing. www.joeypouch.com or (630) 310-4366
• Joey Pouch™: This U.K. company makes pouches to hold catheter tubing, pumps, colostomy bags, and more; the central line pouch adjusts around the neck. www.joeypouch.co.uk or 01872 571208
• MyPokit™: A specially designed pocket to wear under clothing to protect a feeding tube and/or other infusion lines. www.mypokit.com or (248) 342-9448
• Pediatric G-tube Protective Belt by Benik Corp.: A neoprene belt to cover a low-profile g- or j-tube. The belt has a hole through which you can access the tube; a flap covers the hole when you want to protect the tube, and can be removed when you want to access it. www.benik.com/peds/strap/g-tube or (800) 442-8910
• My Tubie Jammies: One-piece pajamas for infants and toddlers with a “tube extension ring” that allows tubes/catheter to pass through the chest or leg of the PJs. Custom orders available. Look for My Tubie Jammies on Facebook.
• Kozie Clothes: Machine-washable adaptive clothing for babies and children, plus large onesies with patch for tube; design allows access to feeding tube/tubing without undressing child. www.kozieclothes.com or (484) 624-5751
• Gus Gear: Custom covers for ostomy bags, feeding tubes and central lines, feeding pump bags, and more. www.gusgear.net or (724) 513-4497
• bundlebaby: Baby clothing that provides discreet and easy access to feeding ports and lines; available in a variety of styles and colors. www.bundlebaby.com or (443) 878-9822
• TodBods® from Essential Whites: Short-sleeve, long-sleeve, and sleeveless bodysuits in many sizes, including 2T, 3T, 4T, 5T, and 6T. www.essentialwhites.com or (866) 648-8488
• Olivia’s Peek-a-Boo Pocket: Sleeveless, cotton T-shirts with a slit to allow a central line to thread through into a pocket on the outside of the shirt; available in five children’s sizes. Contact Judy Daniel or Wendy Costa at 55 Laguna Grande Ct., Monterey, CA 93940; wendy-cost@comcast.net, or (831) 375-4655 (Judy).

Water Protection for Swimming/Bathing

For general information about swimming with a tube or catheter, go to www.oley.org/Swimming.html or call us at (800) 776-6539.

• AquaGuard® from Cenorin LLC: Dressing provides watertight seal over catheter site; available in several shapes and sizes; latex and DEHP free. www.aqua-guard.com or (800) 426-1042
• BathGuard™ from MedGuard LLC: A washable, reusable, protective covering for PICC line dressings; latex free; available in adult and pediatric sizes. www.medguard.net or (800) 713-1133
• Design for Your Life Medical Privacy Sleeves (see “Securing Lines and Tubes”)
• Dry Pro’s PICC Line Protector™: Vacuum-sealed watertight cover for PICC line dressings; latex free. www.drycorp.com or (888) 337-9776 (US); www.drypro.ie or 00353 86 8766707 (UK)
• LiquaShield: A waterproof, latex-free clear film with a medical grade adhesive tape around the edges that is water resistant when in contact with the skin. www.liquashield.com or (425) 652-0193
• Seal-Tight®: Reusable covering for PICC line dressings; latex free. www.brownmed.com or (800) 843-4395
• XeroSox®: Waterproof, vacuum-sealed protection for upper-limb PICC sites. www.xerosox.com or (877) 937-0769

8 — LifelineLetter • (800) 776-OLEY November/December 2012
Center 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 readers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org or call (800) 776-OLEY.

MedStar Georgetown Transplant Institute

The Center for Intestinal Care and Transplant at MedStar Georgetown Transplant Institute offers comprehensive care of patients with intestinal insufficiency and intestinal failure. Patients are of all ages, ranging from infants to adults, and include those who have not achieved optimal outcomes during previous attempts at intestinal rehabilitation or who may have no reasonable chance for nutritional independence. Children include those with short bowel syndrome as well as other forms of intestinal failure requiring parenteral nutrition (PN) support, such as pseudo-obstruction and congenital secretory diarrhea syndromes. Adult patients include those who have lost all or much of the gastrointestinal tract due to severe Crohn’s disease, blood vessel thrombosis, tumors, traumatic injury, and complications of previous surgery.

Comprehensive assessment and treatment are provided by a multidisciplinary group consisting of physicians, surgeons, dietitians, nurses, and social workers, carried out inside and outside of the hospital. For both adults and children, a combination of medical, surgical, and nutritional interventions, or investigational studies, alone or in combination, may be utilized. MedStar Georgetown Transplant Institute is among the most active centers of intestinal transplantation in North America. As such, they indicate, “this option may be offered to those with little or no other chance for recovery.” You can contact the center at (202) 444-3700.

Call a Peer, Toll Free!

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley’s peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

• (888) 610-3008 for HPN (intravenously infused nutrition).
• (888) 650-3290 for HEN (tube feeding).
• (877) 479-9666 for parents of HPEN consumers.

We hope you’ll use this opportunity to improve your quality of life.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

What would you tell someone who is considering joining Nutrishare?

“Best move you will ever make! You will not regret it.”

“Nutrishare has changed my life. I no longer have to be concerned with delivery & supplies, part of family not just a number.”

“Do it, you won’t be sorry!”

“I have told quite a few other consumers that this is the best individualized care I’ve ever had, after being on TPN almost 30 years.”

“Run don’t walk! You will not find a group of people anywhere that are more concerned with helping you achieve your best health possible, educate you regarding your condition and the care you require and supporting you in any way they can, making sure you have a life worth living!”

“What is taking you so long?”

“Think of the best care you could wish for. Then think of care beyond the best. That’s Nutrishare. They provide leading edge knowledge, equipment, supplies & service with a smile. You can’t find a better health-care provider…”

“If you want a company that will not only treat the problems that arise but that will be a resource to help prevent problems beforehand then Nutrishare is the company to be with.”

Nutrishare is a proud partner of The Oley Foundation

Serving Home TPN Consumers Across the Country

nutrishare.com

1 800 HOME TPN
Our Holidays, from pg. 1

Fulfillment without Food
Marie Latta
Adapted from a posting on the Oley Inspire Forum November 20, 2011, and reprinted with permission of Marie’s daughter, Gina.

We have got such a variety of reasons for not being able to eat orally... and for all of us, just as many different feelings about a diet that doesn't include "real" food.

Yes, we have lost this one biggee, not by choice. But maybe we do have some positive choices. How many of our lives have been saved because we are on a formula or parenteral nutrition?

When I think of food-oriented holidays, I wonder what else is a part of these big days. What else is there on holidays or other celebration days?

Fellowship. I need it. I think we were created for community. Fellowship fills my heart.

Family. I need to be with them.

Friends. Even just a few faithful friends. Or what about even one life-long friend?

Favorite things. Maybe it is just hugging someone’s new baby when they arrive for dinner.

I had to give up food, a biggee, but I don’t have to give up everything. Do I want to live a frustrating lonely life or a fulfilling life? I choose fulfillment.

I hope each of us is able to fight our way through the desire for food and forge our way into a fulfilling life... and a fulfilling joyful holiday season.

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 home tube and/or IV feeding (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 in Hyannis, Massachusetts, in late June 2013.

Applications for the 2013 scholarship must be received by March 18, 2013. Send applications to Kyle R. Noble Memorial Scholarship, c/o The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208; or e-mail to BishopJ@mail.amc.edu.

Short Bowel Syndrome, from pg. 1

Gattex® (teduglutide), an adult SBS treatment being developed by NPS Pharmaceuticals.

It was a full day! Medical evidence was presented in the morning, followed by patient testimonials in the afternoon. The testimonials were extremely powerful in outlining the need for treatment for those affected. The general consensus was that consumer efforts had had a huge impact on the panel. Later that evening, we learned the FDA advisory committee had voted unanimously to recommend that the FDA approve Gattex. The advisory committee’s recommendation will be taken into consideration by the FDA when it completes its review of Gattex.

Joan sends a huge thank you to those who sent letters for her to read at this meeting and to those who traveled to Silver Springs to participate. Your contributions were invaluable!

Note that Gattex is not an FDA-approved therapy; it is not yet available. Stay tuned to www.oley.org and the Oley newsletter for updates and more information on Gattex.
Oley Welcomes New Regional Coordinator

The Oley Foundation is happy to introduce Jackie Salzwedel, from Sioux Falls, South Dakota, as a new Regional Coordinator (RC) volunteer. Jackie went to school for cardiac ultrasound and is currently a pediatric and adult cardiac sonographer at a hospital in Sioux Falls. Her interests include reading, shopping, her family, and now, she adds, “most recently, a way to give back and to be a support system for other families who are walking the feeding-tube journey.”

Jackie’s daughter Brynlee, who recently turned one year old, is fed most of her calories through her G-tube. Jackie says, “Brynlee started out with an NJ-tube, but quickly progressed to a G-tube due to continued poor feeding. She also has a Nissen fundoplication, with her main diagnosis being reflux.”

Jackie started a blog at brynleethesupertubie.blogspot.com. It is, she says, “a way for friends, family, and whoever may be interested to stay up-to-date on the happenings of our little tubie. I am also using it as a way to keep track of information and to help spread feeding tube awareness!”

Jackie says, “I am so excited to be a Regional Coordinator for Oley and am looking forward to meeting new people!” She can be reached at (605) 376-3202 (phone calls or texts, she says) or jackie.salzwedel@gmail.com. She is located in the Central time zone. Please help us welcome Jackie, and don’t hesitate to reach out to her with your questions!

Oley Needs Your E-mail

If the Oley Foundation doesn’t have your e-mail, you are likely missing breaking news like FDA alerts and product recalls. You also miss the opportunity to participate in focus groups and other exciting projects. Don’t delay. Send your e-mail address to Cathy Harrington at harrinc@mail.amc.edu. Indicate whether you’d like to receive a link to the LifelineLetter (instead of a hard copy in the US mail) or if you’re just interested in receiving bulletins and invitations. We promise to respect your privacy and not to clog your box with unnecessary mail. Thank you for making communication easier!

Demystifying Health Reform

With the elections behind us, it seems clear that the Affordable Care Act (ACA) is here to stay. The ACA has been a source of uncertainty and concern for many of us, and introduces new vocabulary and health care concepts. What, exactly, is the ACA, and how it will affect you personally? You are not alone in asking. In 2013, we’ll be inviting experts to help us demystify the ACA—and shed light on other legislation that may be of interest to you. Watch for the inaugural column in the January/February issue. Topics and questions are welcome! Call or write Lisa, at (800) 776-6539 or metzgel@mail.amc.edu.
The real fun began after radiation and chemo. In recovery mode, I became tired of watching eggs on TV. I wanted to do! I took over my feeding. I began working outdoors. The cans of goo had gained me back fifteen of the nearly thirty pounds I had lost. Life was good!

The cans of goo were costing me about $800 a month. Many of the cans I received were so damaged, they wouldn't even stand up. I listened to my wife arguing with our supplier on the phone. I finally said enough is enough. I searched the Internet and bought the exact same product from a reputable source online for under $150 a month.

The UPS delivery people noticed there was something wrong with me and would carry the cases into the house. I only had to carry them into the kitchen and stack them. I later learned that this placed a stress on the tube, causing it to eventually fall out.

**A New Tube**

One evening, I felt something slithering down my belly and dropping to the floor. The tube was no longer attached. I stood there staring, like, OMG! It was 9:00 p.m., and I didn't know what to do. My wife, Joan, started calling all over, getting answering services, pager numbers—you know the routine. Aware that the belly button would start closing up, I stuck the darn tube back into its little hole.

There! Then it fell out again. Wait! I needed to inflate the balloon. I scavenged through all the junk delivered by the supplier and found the 3 ml syringe I needed to inflate the balloon. So, that's what I did. (Later, I learned I needed to fill it up with water, not air.) We then taped the tube and finally got hold of Dr. G—, who set me up with an appointment for the next morning.

That morning, when I entered the room where I had originally gotten the tube, my mind started freaking out. The last time I was here it cost me $4,000. I had anticipated I would only need to get a new tube, stick it in, inflate the balloon, and walk out. That didn't happen.

When the nurse told me to get into a gown, I said, “I need to speak with the doctor.” They ignored me until I started to really make some noise. They got Dr. G— on the phone. Standing in the outpatient room where there were several other patients, I yelled on the phone that I was not about to spend another $4,000 for a tube. He asked, “What do you want me to do?” I couldn't think of what to do but submit.

They once again did their poking, prodding, and questioning, then rolled me into a room other than radiology. I was in a super-sized room, with two masked females in front of computer monitors, jiving to the rock music that was playing. Both said, “Hi.” There were two males alongside the table with seven—yes, seven—monitors near the ceiling around the table.

I was transferred to the table and watched as they did their thing. The doctor entered the room and washed at the sinks. As he approached, they colored my abdomen brown-yellow and turned on the monitors. The doctor jiggled a wire into my second belly button while one of the techs walked to the wall where several tubes were hanging; he selected one. He gave it to the doctor who then inserted it and walked away. One of the technicians inflated the balloon with 20 ml of water. He then injected the tube with a dye, which showed it was actually in my stomach and not leaking into my body cavity. I was transferred and rolled back to outpatient, where I had to wait two long hours.

This procedure only cost me $3,500.

**Number Three**

Several months passed and I continued to gain my strength. I was bush hogging with a blade, shirtless, and the tube was swinging with...
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We asked Douglas Seidner, MD, Oley Trustee, to comment on Al’s tube experiences. He writes:

There is no perfect tube. There are two categories regarding the inner bolster (which secures the tube).

Balloon tipped tubes: Usually changed every three to six months. This is dictated by how long the balloon will last in the stomach, where acid and bile make the silicone stiff and the balloon prone to failure. If it breaks prematurely and the tube falls out, you should have the tube replaced that day so the tract does not close. Some patients can put lubrication on the tube and gently re-insert it to keep the tract open, but they should only do this with their physician’s approval as there are anatomic reasons why this should not be done in all cases. Pros: Less uncomfortable to exchange, and it is possible for a patient/caregiver to be trained to change the tube themselves. Cons: More frequent need to change (expensive, inconvenient), and if it falls out prematurely, the tract may close.

Molded bolsters for external removal: Can last for up to a year or more. I advise patients to come back for a change at one year as the silicone gets brittle and it can be harder to remove (more pain) and, rarely, can break off, which may require an endoscopy to get the part that is left in the stomach. It does hurt to take the tube out, but it is only for several minutes. This is much less than when any tube is initially placed, where the pain lasts for days. The bolster is shaped like a mushroom cap and is the size of a quarter in diameter. I explain to my patients that I have to pull modestly hard to cause it to collapse like an umbrella and come through the tract. Because it is larger than the tract even when collapsed, it will irritate the nerves and cause intense pain (10/10) for a few seconds. The pain will take several minutes to subside. Most patients say it was helpful to know what to expect. Pros: Less frequent need to change. Cons: Removal hurts, and only a clinician can change the tube.

Of note, if the abdominal wall is more than 5 cm (pull up on the tube gently and look at the measurement mark), it can be risky to push a tube back in from the outside, whichever kind of tube it is. The tract can be disrupted and the tube may not make it all the way to the stomach. If your tract is this length or greater, someone with experience should replace it and use imaging to confirm it is in the right place.

Tube Feeding in the Hospital

Months later, I went to my primary care physician for a routine checkup. He took a chest x-ray. After, as I waited in the exam room, the doctor rushed in, asking me how I felt. “I feel great!” I said. He replied, “Your left lung is 50 percent collapsed!” Huh? The same lung had collapsed in 1972 due to a small cyst, but it hadn’t bothered me since.

So, back to the hospital. I was admitted in the evening. They brought me a tray of food, not aware of the tube. I told them, “I can’t eat that. I eat Isosource 1.5.” Oh! A nurse later appeared with a big jug of formula and a 10 ml syringe. I watched as she attempted to syringe out 10 ml of goo so she could syringe in 10 ml of goo. Like this, it would probably take an hour to finish an 8 ounce can. I tried in a nice way to explain if she disappeared, I could feed myself.

In the morning, before the procedure to re-inflate my lung, I got up to go to the bathroom. Yes. As soon as my feet hit the floor, so did the tube. I could NOT believe it. I picked up the tube and ran down the hall to the nurses’ station. Naturally, it was exactly at shift change. There I stood, with tube in hand and no one wanting to assist. Finally, one of the nurses coming on duty stuck a temporary tube in me, securing it with tape. She said this would get me through the lung procedure, and they may just insert a new tube at the same time.

I recovered from the surgery quickly, only to find that the temporary tube was still attached. They finally wheeled me down to gastroenterology, to the same outpatient room I was in when I got my first tube. Fortunately, my gastroenterologist, Dr. T—, was soon at my side. He explained that he’d insert a more permanent type tube, with a rigid mushroom flange instead of a balloon. After the procedure, he gave me photographs of the inside of my stomach. Cool! He also explained that the first tube was improperly placed, I guess to make me happy?

This procedure only cost me $3,200 (for a total of $12,134).
From the Desk of Joan Bishop, Executive Director

As the year draws to an end, I’d like to give thanks to individual supporters and Oley Corporate Partners who have generously supported Oley programs this year AND send a huge nod to those who have already indicated continued or increased support for 2013. This keeps us continually in forward-thinking mode.

The year 2012 has been an active one, with an extremely energetic agenda. From Clinical Nutrition Week (A.S.P.E.N. coordinated) in January to the most recent Italian Paediatric Congress (organized by Un Filo Per La Vita or Thread for Life), we have taken advantage of over forty-four opportunities to exhibit and/or showcase living while dependent upon home nutrition support and distribute Oley materials. As consumers help at these exhibit efforts—putting their positive “faces” to these complicated therapies—it is a win/win situation. Meeting attendees witness the passion of Oley members while they chat about Oley programs; vendors quickly recognize the value of insights gained from the energetic and vocal end users; and consumers learn more about new products and services, and connect to clinicians from across the country. Hats off to everyone who helped in 2012! Stay tuned to the LifelineLetter and www.oley.org for volunteer opportunities in 2013.

Oley in Phoenix

We’ll begin outreach efforts for 2013 in Phoenix at A.S.P.E.N.’s Clinical Nutrition Week (CNW), February 9–11. We’ll kick off CNW with an Oley meeting noon to 4:30 p.m. on February 9, featuring HPEN information and support. Join us, then stay on to help us at the Oley booth, visit other vendors in the CNW exhibit hall, distribute Oley materials, and network with Oley staff and other volunteers. Details on page 16 and www.oley.org.

Market Research

Another win/win initiative is in the market research or focus group arena. Companies recognize the importance of the end user’s experience when developing or upgrading products and services, and they invite Oley to gather participants for market research sessions. Oley is compensated for this effort; participants are compensated for their time and can share their ideas; and the company gains knowledge. The most efficient means of canvassing participants for these sessions is to use electronic media—from e-mail to Facebook. Stay tuned to the Oley Web site, the Oley/Inspire forum, and the Oley Facebook page, and please be sure we have your current e-mail address and telephone number (contact Cathy at harrinc@mail.amc.edu or 800-776-6539).

Advocacy

We have been actively involved with efforts to improve the lives of Oley members—through meetings with the Food and Drug Administration (FDA) and the Transportation Security Administration (TSA); joint efforts with groups such as Digestive Disease National Coalition (DDNC); Feeding Tube and HPN Awareness Weeks, feeding tube misconnection efforts, and more—and will continue to do so. Keep your questions and feedback flowing.

On behalf of everyone here at Oley headquarters, I send warm wishes for the happiest of holiday seasons. See the best in 2013!

Donor Profile: Bill Fitzpatrick, Sr.

My family and I have been supporters of the Oley Foundation since it was founded in the early 1980s. Our oldest son, Bill Jr., has been on a tube-feeding regimen for the past thirty years, after complications from emergency gastric bypass surgery terminated his career as a Navy pilot.

Back in 1982, my wife, Marge, and I were desperately searching for help with our son’s nutritional problems as we watched him slowly starving to death from malnutrition and malabsorption after being discharged from active duty with the U.S. Navy. A massive nationwide search for experts in nutrition produced no results until purely by chance, after reading a magazine article, we heard about Dr. Lyn Howard at Albany Medical Center, Albany, New York. Dr. Howard is a co-founder of the Oley Foundation.

One of Dr. Howard’s protégés, Dr. John Jenks, subsequently encouraged us to spend the next three years with our son as a patient of Albany Medical Center and nearby VA Medical Center while we slowly and methodically developed a unique plan to have Bill Jr. insert his own nasogastric tube and feed himself while he slept. So far, he has utilized the procedure about 10,000 times while consuming over 80,000 cans of liquid food supplement. The local aluminum recycling center near where Bill now lives in the Washington, D.C., area eagerly looks forward to his weekly contributions.

Bill Jr. is no doubt one of the most unique enteral patients in the world to the extent he reapplied for active duty with the U.S. military and became one of the first ever to be considered for re-entry as a disabled veteran. No longer able to fly in combat jets, he elected instead to join the ranks of our nation’s premier spy agency, the Central Intelligence Agency (CIA), where he has served with distinction for over twenty-five years. Bill Jr.’s life story is available through Amazon.com in the book Jacob Ryan: Patriot, Medical Miracle, Spy.

Bill Jr., Marge, and I are perennial caregivers to those suffering from nutritional problems and requiring either parental or enteral support. We try to help people from all walks of life, including a prisoner on parenteral nutrition who is serving a lengthy sentence at the Ohio Department of Rehabilitation and Corrections.

Bill Sr., was formerly employed by the Procter & Gamble Co. and several airlines before he retired from Macy’s as an executive. He writes, including the book noted above, and counsels the elderly about retirement options. Both he and his wife, Marge, are in their eighties.
Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2012 in the January/February 2013 issue. Between September 26 through November 20, 2012, gifts were received:

In Honor of
Megan Gravenstein; and BobbieJo’s seventh-year multivisceral transplant anniversary

In Loving Honor of
Jim & Gloria Wittmann’s wedding

In Memory of
Jan Broderick; Werner Gravenstein; Gregory Medwar; and Clarence “Oley” Oldenburg

Matching Gift
FM Global Foundation

We appreciate all gifts and kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!

Join the Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference at (800) 776-OLEY.

Felicie Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Joy Enisch
Jerry Pickle
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Linda Gravenstein
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Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Poria & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maidien
Laura Matarrese, PhD, RD, CNSD
Kathleen McIntire
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clements Pietzner
Beverly Promisel
Abraham Rich
Gail Egan Sansiviero, MS, ANP
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnel
Doug Schedul, MD, FACG, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSD,
& Gregory A. Thompson, MD, MS
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

GOLD MEDALLION PARTNERS
($50,000–$69,999)
- Apria Healthcare / Coram Specialty Infusion Services
- Nutrishare, Inc.
- ThriveRx

SILVER CIRCLE PARTNERS
($30,000–$49,999)
- NPS Pharmaceuticals

BRONZE STAR PARTNERS
($20,000–$29,999)
- Baxter Healthcare
- MOOG, Inc.

BENEFACCTOR LEVEL PARTNERS
($10,000–$19,999)
- Abbott Nutrition
- InfuScience, Inc.
- Kimberly-Clark
- Walgreens Infusion Services

PATRON LEVEL PARTNERS
($5,000–$9,999)
- Applied Medical Technology, Inc.
- Critical Care Systems, Inc.

BLUE RIBBON PARTNERS
($2,500–$4,999)
- Emmaus Medical, Inc.

Thank You!
Give a Gift, Change a Life
If Oley programs have touched you and your family, share that precious gift with others. Make a donation in the enclosed envelope or at www.oley.org.

Tell Us Your Tube Tale
Raise Awareness, February 10–16
Why?
• Help others understand what life with feeding tubes and enteral nutrition are all about.
• Increase tolerance and knowledge.
• Create bridges to people who are feeling isolated by or struggling with tube feeding.

How?
• Send photos and/or videos of yourself to Lisa at Oley (address below), along with a brief statement about what tube feeding means to you, for our Feeding Tube Awareness video. We’ll launch the video on YouTube February 10. Send your photo today!
• During Feeding Tube Awareness Week, share your story in a press release or in your blog. How is tube feeding helping you or your child be active or grow? What do you do if/when you or your child can’t eat? How do you cope with the challenges of tube feeding?
• Join us February 10–16 on Facebook or the Oley forum for daily discussions.
• Talk to your friends and family, or school or church groups. Have a frank conversation about something you find challenging, or that brings you satisfaction.

We are here to help and support you! Contact Lisa at metzgel@mail.amc.edu, (800) 776-OLEY, or The Oley Foundation, 214 Hun Memorial, MC28, Albany Medical Center, Albany, NY 12208.

Join Oley in Phoenix, February 9–11
Reserve February 9 from noon to 4:30 p.m. to join us and learn more about the therapy that sustains you at an Oley-sponsored consumer-focused meeting in Phoenix. Watch www.oley.org for particulars.
After the Oley meeting, join Oley staff in the exhibit hall at Clinical Nutrition Week, the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), February 9–11. Additional information is posted on www.nutritioncare.org, including a list of the many exhibitors who will also be showcasing their products and services. An impressive list of faculty who will be presenting is also posted and worth reviewing.
For more information about these opportunities/programs and to volunteer to help at the Oley booth, contact Joan Bishop at (800) 776-6539 or bishopj@mail.amc.edu.

Save the Dates!
The 28th Annual Oley Consumer/ Clinician Conference is tentatively planned for June 23–29, 2013, in Hyannis, Massachusetts. The meeting provides an excellent opportunity to learn more about improving your health and quality of life on home IV and tube feeding from expert clinicians and experienced consumers/caregivers. Hope to see you there!