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LifelineLetter

Living with home parenteral and/or enteral nutrition (HPEN)

A Journey through Life Unexpected

Carol A. Pelissier

Life's challenges can become so intense that some days it is difficult even getting out of bed. When people look at you, they can't physically see anything, so they make statements like, "Oh, you look good. You should feel good." (If they only knew.) It can take a whole lot of effort to do a normal everyday task. It takes courage, strength, energy, and attitude to be able to live in a world where one is chronically ill.

The Beginnings

At the age of nine, I suffered with severe abdominal pain, vomiting, and exhaustion. It was not until the age of nineteen, at my first surgery, that I was officially diagnosed with endometriosis. I had infertility issues for six years and underwent nine surgeries before I was blessed with my son (now twenty-eight years old).

As if that were not enough, I was stricken with a second chronic condition, and it took longer to get a diagnosis than my first ordeal. I would go weeks without bowel movements (despite taking every kind of laxative known to man). It could be up to sixteen



Carol finds purpose, happiness caring for Slim.

weeks before I had any results, and then it would start all over again. I was unable to eat because of nausea and vomiting, and my abdomen would blow up like I was nine months pregnant.

I had endless tests performed over the years. Some were painful, humiliating, and uncomfortable, and **Journey through Life, cont. pg. 2** ➤

See Oley Grow!

The Oley Foundation is in a growth spurt! We now have over 12,250 members across the world. Thank you to everyone who has helped share information about the organization and had a hand in this growth!

In addition, and with some overlap, Oley's online forum now has over 2,000 members. It seems like yesterday that we were researching how to set up an online resource that would be secure and private. Inspire offered Oley an answer, and in 2008 we teamed up with Inspire to create the Oley forum—a free online community for anyone on tube or IV feeding, and their families, friends, and caregivers. It is a place where people can find and support one another, share stories, and build a network of online friends.

Membership in the forum isn't automatic when you sign up as an Oley member, and vice versa. Both memberships have unique value. Your membership in the Oley Foundation enhances Oley's ability to advocate for the HPEN community, and to contribute to



See discussion on page 11.

Oley Growing, cont. pg. 11 ➤

Drug Shortages and You

This article has been written by Oley staff in close collaboration with the American Society for Enteral and Parenteral Nutrition (A.S.P.E.N.). It quotes heavily from "Parenteral Nutrition Product Shortages: The A.S.P.E.N. Strategy," by Jay Mirtallo, Beverly Holcombe, Marty Kochevar and Peggi Guenter (Nutrition in Clinical Practice, April 2012), with permission from A.S.P.E.N.

What's in your home parenteral nutrition (HPN)? Are you missing anything? And would you know if you were? With an increasing number of sterile injectables (such as those used in the preparation of PN) in short supply, it is perhaps more important than ever to know what is in your bag and what your doctor has prescribed. It's not just PN that is affected by drug shortages, by any means. "Drug shortages have affected every drug product category, including chemotherapeutic, antimicrobial, and gastrointestinal agents," says Jay Mirtallo et al in a recent article in *Nutrition in Clinical Practice* ("Parenteral Nutrition Product Shortages: The A.S.P.E.N. Strategy," April 2012).

Shortages Affect Patients

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) has requested that their members

Drug Shortages, cont. pg. 12 ➤

Journey through Life, from pg. 1

others were not so bad. I underwent gastric emptying (where my stomach did not empty properly); sigmoidoscopies; endoscopies; manometry studies; barium enemas; CT scans; MRIs; blood work; small bowel follow-throughs; sitz marker studies (for motility); and more. As my symptoms continued and

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got worse, I knew a big part of my life was going to be changed and uncertain.

A Diagnosis

Eighteen years later, I was diagnosed with chronic intestinal pseudo-obstruction (CIP), severe dysmotility, colonic inertia, delayed gastric emptying, and gastroesophageal reflux disease (GERD). I was scheduled to have a total colectomy (removal of my entire colon).

The recovery from bowel surgery was long. I was vomiting, had severe abdominal pain and nausea, and was unable to eat. I began to lose weight. Several times I was brought to the hospital or to my physician's office because the pain was unbearable. At one of many visits to my gastroenterologist (due to being malnourished), I was admitted for evaluation. I was not prepared for the impact of the next phase of this debilitating disease.

Nutrition Support

I had a procedure done so I could be started on parenteral nutrition (PN) to support my nutritional needs. They also inserted a nasogastric (NG) tube so they could see what enteral (EN) formulas I would tolerate. Once they determined what formula was right for me, I had a gastrostomy-jejunostomy (G-J) feeding tube placed.

I knew at that time this was how I was going to consume my nutrition. Through the G-J tube, I receive all the necessary vitamins, minerals, calories, etc. I need to survive.

Physician/Patient Relationship

As many of you well know, living with a chronic condition forces you to develop a very different relationship with your physician. Unlike others who are treated for acute illnesses and then move on, the chronically ill patient will develop a life-long relationship with and depend on their physicians, no matter what crisis arises.

I am thankful every day for my physician. He sees me as a person with feelings who needs understanding, and not as just another patient with a disease or symptoms. He allows me to gain some sense of control over my medical treatment. He shows me that my opinion

regarding my health matters, and we always work together to decide what is the best care and treatment.

Coping with all the ups and downs of a chronic condition is difficult, but when you have a physician in whom you can put your trust, it makes everything much easier to deal with. Search for a physician you feel comfortable with, even if you have to see several. It is well worth it.

Sidelined

I have always tried to accept everything I had to go through without too much effort, but when things kept building up and there was no reprieve, frustration set in. There were so many obstacles I could not stop. I had to have an ileostomy eight years ago due to megarectum and loss of control of my anal sphincter muscles. This

was a huge adjustment in my life. I had to take control and learn what it meant to have an ileostomy.

I continued to work for a five-physician OB/GYN office while being hooked up to IV hydration and my PN/EN feeding. It was quite a challenge to maneuver everything and work a full-time job. That went on for four years. I dropped to 89 pounds and my physician saw how I was failing. He more or less made the dreaded decision for me to retire. At the age of forty-one, I was forced to go on disability. I now had to direct my life in a different direction.

It was clear now what my limitations were, but not what my possibilities were. Not long after I stopped work, my physician gave me information on the Oley Foundation, for consumers who live as I do. I attended conferences over the years and I learned as much as I could. I was so glad I reached out to Oley. It has been a tremendous help in being supportive and there for me. I eventually became a Regional Coordinator (RC) in the New Hampshire area to reach out to others with gastrointestinal/digestive problems.

Step by Step

Every day I face unexpected challenges associated with CIP. I prepare formulas and

Journey through Life, cont. pg. 7 ➤



Carol and her dog, Dante, playing out in the snow.

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.



Have (Mini) Blender, Will Travel

When I travel for work, I used to bring my Blendtec blender with me to prepare my foods for tube feeding. But then I discovered the little Oster "My Blend." It cost about \$30 and came with a 20 oz. smoothie bottle. It's not a replacement for my main blender (I don't think it would hold up to the abuses of every meal, every day), but it is very easy to haul around, and almost a year later it is still working well.

I put my food and liquid in the bottle, screw on the cap with the blades, then twist-lock the bottle into the base. A couple of minutes later, I have a liquidized meal. I did have to modify the My Blend a little



Everything fits neatly into the small traveling bag.

to help it blend my meals. I had to sharpen the blades using a diamond file. It made the blades razor sharp. This really helps when I am blending coleslaw and black bean salad. It works well on chicken and beef, too. You can overload the blender by not adding enough liquid, but once you get the right mix it works well.

I put the blender in a little tool bag I picked up. The bag holds the blender, bottle, strainer, and pump. So far, the Transportation Security Authority (TSA) has let me through the security check with no questions asked about the blender.

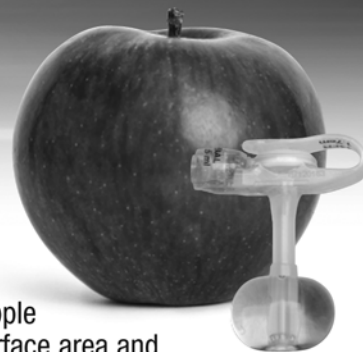
As an aside, I am on tube feeding after a radical neck dissection due to cancer in the base of my tongue and thorax. I cannot swallow without severe aspiration issues. Unable to tolerate canned formulas, I switched to a blended diet and have thrived on it. A blended diet fits me to a T.

—Steve
stevewelch47@gmail.com

Thanks to Steve for adapting and updating this entry from an Oley forum entry (www.oley.org/forum.htm).

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Nutrition and You

When is tube feeding a bad idea?

Enteral nutrition or tube feeding is a way to sustain life when food cannot be taken orally. Technology continually leads to improvements in this therapy: smaller tubes; low-profile tubes; backpacks for carrying formula and pumps; and smaller, more convenient pumps. Perhaps it isn't optimal, compared to eating orally, but you can achieve health and well-being and receive all the nutrition you need.

How many of you receiving enteral (EN) or parenteral nutrition (PN) have had someone say to you, "I should go on that therapy. Then I won't have to worry about what I eat!" It may have been said jokingly, but now—as many of you know—there is a new "diet" being marketed that uses short-term nasogastric feeding for weight loss! Called the "K-E Diet," it provides a specialized high fat, high protein, very low carbohydrate (or ketogenic) diet.

The physician who is promoting this "diet" places a feeding tube into the "normal" person's stomach. The tube is kept in place for ten days and the person infuses a special powdered ketogenic EN formula that has been mixed with water. This very low calorie (800/day) and low carbohydrate (~zero) formula causes the body to create ketones as it has to metabolize its own energy stores for calories. The formula is provided twenty-four hours per day using a pump. The physician who is offering this in Florida advertises that one can lose twenty pounds in ten days—all for only \$1,499!

The facts:

- A ketogenic diet has been used in children with seizures, but is very closely monitored.
- Certain low carbohydrate oral diets have been used for years for weight loss. The major drawback is immediate weight gain when carbohydrates are added back into the diet.
- A diet with less than 80 to 100 grams of carbohydrate is dangerous since the brain needs glucose (carbohydrates) to function.
- When calories are severely decreased, water weight is lost, followed by muscle. With a ten-day weight loss program, the weight loss is not permanent.
- \$1,499 is a lot of money—hire me and I will nag you not to eat for ten days!

Here is what some of the experts have said:

Laura Matarese, PhD, RD, Oley Board member, and Associate Professor of Gastroenterology at East Carolina University: "Enteral nutrition is a life-saving technique for those who are unable to eat by mouth. However, this is not an appropriate methodology for weight loss. The K-E Diet (short for Ketogenic Enteral Diet) was developed to induce quick weight loss. So what's wrong with this approach? Plenty! This could be the most shocking, controversial diet ever developed, in my opinion. It is a drastic and extreme regime which amounts to controlled starvation. You will, of course, lose weight rapidly on such restricted calories—but no one should slim down that quickly. Additionally, the psychological and emotional reasons for overeating need to be addressed, which this plan fails to do. And there are potential side-effects. For example, constipation is common due to the total lack of fiber in the formula. The ketones, which are created when your body burns its own fat, are expelled via the urine and breath, so another side-effect is bad breath. Although feeding tube placement is

generally considered safe and 'low risk,' it is not totally benign. There are potential complications, such as tube misplacement in the lung or perforation of the stomach. Bottom line: save this therapy for those who cannot eat by mouth."

Lillian Harvey-Banchik, MD and nutrition support physician: "A person who, without a valid medical reason such as drug resistant epilepsy, voluntarily goes on a ketogenic enteral diet is playing Russian roulette with their life. The potential risks to both short-term and long-term health, including renal damage and cholelithiasis from rapid weight loss, negates any short-term weight loss benefit, especially since the lost weight is normally regained rapidly once the diet is stopped."

Cheryl Thompson, PhD, RD, and EN researcher "For HPEN consumers and clinicians, the thought of using a medical therapy as a fad/crash diet is understandably upsetting. Tube feeding is intended to promote and restore the health of those unable to eat—not provide an unhealthy formula with the potential risk of causing health problems. It is also distressing that a physician (who is bound by the oath to first do no harm) would claim patients will 'get used to the KE-tube within just a few minutes' and 'apart from being 20 lbs lighter will be in the perfect place to continue a more healthy relationship with your food'—to lure people into paying for a ten-day diet. Yet the real tragedy is that some overweight people are so desperate and gullible they are resorting to such drastic measures—often for vanity alone.

"Consumers who have posted on the Oley Facebook page have been quite vocal and quite right, I especially like what Lisa K. had to say: 'As a person who has to rely on a feeding tube to survive, I find this diet for vanity absolutely appalling.'"

All of the nutrition experts agree: Effective long-term weight control, without surgery, can only be achieved by lifestyle modifications, including changes in both eating and exercise habits. Weight loss in the range of two pounds per week is considered safe and allows the individual to learn to manage their food and drink intake.

Those of you who are receiving HPEN because you need it to survive are the best examples of how well this therapy works. It is from you that we receive our inspiration!

This column has been compiled by Carol Ireton-Jones, PhD, RD, LD, CNSC, FACN; and reviewed by Laura Matarese, PhD, RD, LDN, FADA, CNSC; and Cheryl Thompson, PhD, RD.



Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation's Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? No Internet access? Contact Oley volunteers Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.

7th International Pediatric Intestinal Failure Symposium

September 6–8

Omni William Penn Hotel
Pittsburgh, PA

This symposium is designed for health professionals and parents/guardians who care for children with short bowel syndrome and small bowel intestinal transplants.

On Thursday, September 6, a family program (as well as a “Primer for Medical Professionals”) will be offered. Main session topics in the family program include nutritional management, social work support, cognitive outcomes after transplant, and parenting a child with a chronic condition. In the afternoon, a series of workshops on intestinal failure and intestinal transplantation topics will be offered.

On Friday and Saturday, the focus will be on “Integrated Care for Intestinal Failure, Adaptation, and Transplantation: Common Themes and Challenges.”

Registration fees for families are \$75 for Sept. 6, Family Day, only; and \$100 for the full meeting, Sept. 6–8 (after July 1, \$150).

For more information or to register, go to www.chp.edu/CHP/PIFR+Symposium.

Bears Bring Comfort

Tubie Friends™ was started by a group of families who have had experience with tube feeding. Volunteer “Tubie Friends surgeons” adapt stuffed animals to have feeding tubes (and maybe other devices, such as a trach), and then give the stuffed animals to children who have or are getting tubes.

Tubie Friends co-founders Cheryl and Shannon write, “Having a Tubie Friend that ‘looks just like me’ helps normalize tube feeding for children through play therapy and provides comfort during procedures, surgeries, and hospital stays. Tubie Friends also help spread awareness, acceptance, and are a relatable teaching tool for siblings, caretakers, family, teachers, and classmates.”

The stuffed animals, feeding tubes, and medical supplies are all donated to the group. As a fund raiser, special (also adapted) stuffed animals are available for purchase. For more details or to donate unwanted supplies, go to www.tubiefriends.com or e-mail them at tubiefriends@gmail.com.



Abby with Bear. Abby's mom writes, "Abby doesn't know any other children with the combination of a g-j tube, trach and port, so it helps her to have something so similar to her to play with. Bear goes everywhere with her, even outside to play."

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Meet Oley's Newest Regional Coordinator Volunteers

Oley Regional Coordinators (RCs) help extend Oley's reach. They bring Oley to you, whether in person, by phone, or online. They answer questions, share their experiences, and sometimes just listen. Please reach out to them when you want to connect—they look forward to hearing from you!

Here we welcome some of our newest RCs. For a complete list of RCs, or information on becoming an RC, please go to oley.org or call (800) 776-6539.

Michelle Barford (HPN, SBS)

After being a nurse for over thirty years, Michelle became the patient in 2008 when she went to the ER with acute abdominal pain. She and her husband had just moved to the Memphis area and knew no one, especially in the medical field. When Michelle woke up from surgery, she learned she had carcinoid cancer of the small intestine. Because it was so widespread, they closed her up after a second surgery and sent her home on hospice. Michelle says, "I have a T-shirt from *Spamalot* that says, 'I'm not dead yet,' and that became one of my many mantras. Many times when I was discharged from the hospital I would wear that shirt home!"

"There isn't any treatment for carcinoid," Michelle continues, "except to cut it out. So I discharged myself from hospice in 2009 and had the 'big' surgery where 90 percent of my intestine was removed. Before that, I had never heard of short bowel syndrome (SBS), but after a year or more of denial I finally got my groove back! I have since tried to live every day to its fullest. I still have good days and bad days. My husband, Mark, is very supportive, but says a silent prayer every time we hit the road. The nurse/teacher in me wants to give back and I am looking forward to being an RC!"

Michelle lives in Germantown, Tennessee, and can be reached at (901) 755-8924 or mbarford@comcast.net.

Rosana Shah (family caregiver, HPEN)

Rosana and Nilam Shah live in Denham Springs, Louisiana, where Nilam works as a field service technician and Rosana is a stay-at-home mother. Their daughter, Parri, was born at twenty-seven weeks gestational age in 2006. Three weeks into her life, Parri developed necrotizing enterocolitis (NEC), which left her with 17cm of small bowel and no ileocecal valve. Parri came home in October 2007, after a year and a half in the hospital—with her mother always by her side.

Now five years old, Parri is on home parenteral and enteral nutrition (HPEN). Despite the HPEN, oxygen dependency, and many infections, Parri is a very active little girl. She is being followed by Duke University.



Michelle Barford



Rosana Shah

Rosana and Nilam write that when they discovered the Oley Foundation Web site, they found it "extremely beneficial." With Rosana as an Oley Regional Coordinator, they hope to "help other families to feel confident and comfortable with their child's medical dependency needs."

One of the issues of immediate concern to Rosana and Nilam is the problem of drug shortages. They write, "We are extremely grateful that the Oley Foundation is actively involved in addressing drug shortages, which directly impact our daughter's care."

Rosana can be reached at (225) 667-8233 or parri814@gmail.com.

Jennifer Thiesse (HPN, Gardner's syndrome, SBS)

Jennifer has been on home parenteral nutrition (HPN) since 1982, when she was diagnosed with FAP/Gardner's syndrome. She has had a total proctocolectomy (removal of colon and rectum) with a continent ileo reservoir/Koch Pouch type ileostomy. She writes, "I have had benign tumors along my small intestine, desmoid tumors, and adhesions as part of my Gardner's syndrome, which the doctors had to remove. In the end, I have short bowel syndrome (SBS) and motility problems. Ten years ago, I got leukemia, too. I have been in remission since my chemo treatments—praise the Lord!"

Jennifer has a master's degree in rehabilitation counseling and works part time as a cashier at a local grocery. She is active in her church, and also enjoys flower gardening, golfing, computer games, and reading. Jennifer, who has always been ready to help individuals with questions and problems with their HPN, has been part of Oley since 1987.

Jennifer lives in Minneapolis. She can be reached at (507) 934-4865 or jenitc@live.com.

Eve Thomas (off therapy, GP)

Eve was diagnosed with idiopathic gastroparesis in 2004. She has been on both enteral (EN) and parenteral (PN) nutrition, but is currently off both. "I have quite a bit of experience with both HEN and HPN," she writes, "and am free to answer questions anyone has. I have had a lot of experiences with gastroparesis (and other chronic illnesses), PICC lines, and central lines, as well." Eve, who is twenty-eight years old, also has a G-tube for venting.

Eve lives in South Carolina. She can be reached at (843) 422-7606 or evethomas22@gmail.com. She writes, "I am interested in hearing from anyone, and would be glad to lend a helping hand to newly diagnosed individuals. I hope that I can be of help!" Eve is interested in starting a local support group. Please reach out if you are in her area. ♣



Jennifer Thiesse



Eve Thomas

Journey through Life, from pg. 2

medication daily and IV hydration as needed; undergo tests; deal with infections, doctor's appointments, and hospitalizations; care for my G-J tube and ileostomy; and handle the not-so-pleasant situations that arise with an ileostomy (leakage, getting appliances to fit properly, irritations, infections...).

It is a full-time job making sure all my needs are cared for. In September 2011, I had my forty-sixth surgery. I don't know what the future holds for me, but I will continue to put emphasis on my determination and power, and I will keep on fighting.

Through the journey I have traveled so far, I never wanted sympathy or anyone to have pity on me. I did not want to dwell on the things I could not do, but rather on the things I could. Sure there were

Believe in yourself,
redirect your purpose in
life to what makes you
shine, and always have
the courage to prevail.

times I would despair, but I had to reach within myself to find the strength to keep on going. I had to maintain my positive attitude to take control and start being my own best advocate, to learn and search for information about this disease that had taken hold of my life.

The twists and turns in this road I've gone down are unexplainable. Attitude, being strong-willed, and having faith are the keys to moving forward—looking to the future and not looking back. I never know what curves are ahead, and I try to cope and deal the best way I know how.

Back in the Saddle

When you are dealing with a chronic illness, no one can tell you how you should feel unless they are in your shoes (because otherwise they don't know). It does not go away, so we must take one day at a time.

I have had to find the best therapy that works for me. That would be the love I have for horses. My sisters took me horseback riding when I turned fifty in 2007. Shortly after, I started volunteering at the place we had gone riding. I had a special connection with the horse I had ridden that first day, Slim (only not so slim, at 16'3 hands and 1300 pounds). It made me happy to know I had found a purpose.

I then got involved with volunteering to help with the police horses in the city where I reside. I find such solitude and happiness when I am around them. Four years later, I purchased Slim. He was finally mine. He puts a smile on my face whenever I mention his name and start talking about him. Horses are the best medicine!

Strength in Adversity

The most important thing to remember, for those of us who are burdened with a chronic illness, is to remain positive no matter how hard it may become. Believe in yourself, redirect your purpose in life to what makes you shine, and always have the courage to prevail. Thank your illness for giving you inner strength, instead of being angry for the unexpected.

Every challenge you confront can give you the determination and willpower to get through the next hurdle with your health. Remember, we have the upper hand to take control. Never give up. ¶

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Suffering from severe malnutrition, I was so weak, I rarely got out of bed. My physician advised that I start on TPN, and although he wasn't too familiar with its management, thank goodness he referred me to Coram. Five months later, I was dancing at my son's wedding! Eventually, I could transition to enteral feedings. Having a feeding tube has helped me to have a great quality of life. I can do anything I want — or at least try. I volunteer with my therapy dog, Jack, and recently took up golf. Last year we moved to another state and the transition from one state to another was so smooth. The only difference was the change in my address.

My Nourish Nutrition Support Team is my lifeline and will always be. Five years ago, the odds of even being alive today were poor. Now every day is a gift!

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In Memoriam

We regret that there is limited room in the newsletter for memorials. However, we encourage you to send us the names and photos of those who have recently passed so we can remember them during the In Loving Memory ceremony at the annual conference. Email harrinc@mail.amc.edu or call (800) 776-OLEY by June 18.

Marie Latta, of Atlanta, Georgia, was a new Oley Regional Coordinator volunteer when she died in April 2012. As a result of having had bulbar polio in 1949 at the age of eight, Marie had post-polio syndrome, characterized by muscle weakness and severe systemic fatigue. As her swallowing and respiratory became paralyzed, in 2004 she had a



Marie Latta

G-tube and tracheostomy tube placed (her "twin tubes," as she called them). Marie, who relied exclusively on the G-tube for nutrition, was active on the Oley forum, where she enjoyed meeting others who have tubes because of upper body weakness.

Marie was adamant that tube feeding was only one part of her life. She went on with life and just took the alternate way of eating with her. She enjoyed being in a local artists group, and enjoyed traveling. She traveled to Disney a couple of times and wrote

about the experience for the Oley newsletter (see September/October 2010). In December 2011 she went on a Disney cruise and spent several days in Disney World with her son and family. Even though she had some digestive issues sneak in while she was there, she wrote that she had a wonderful time.

Marie's message to herself in 1993, when she started using a wheelchair because her respiratory would no longer support her walking,

was this: "Survivors never quit. We just change our ways." She was an inspiration to many of us, and will be greatly missed.

Kathleen McInnes, from Chicago, Illinois, was a long-time Oley member and had been a Regional Coordinator volunteer since 1998. Kathleen, who died in March 2012, had been married to her husband Larry for forty-four years; they had two children. For many years, Kathleen coordinated meetings of a local Oley support group, fondly known as "The Pumpers."



Kathleen McInnes

Fellow Pumper Cathy Tokarz writes, "Kathleen was always willing to step up and help Oley when there was a person in need of information about enteral nutrition; help in dealing with pseudo-obstruction; support through a difficult time; or just in need of a friendly shoulder to lean on, or cry with. She had a unique perspective on life and always wanted to share with you." Cathy continued, "The members of our support group are very grateful for Kathleen, who was such a wonderful leader of our group. She really exemplified someone who always makes you feel like you have come home to Oley. We have lost a great friend."

Roslyn Dahl, Oley Director of Communication and Development, remembers, "Kathleen had a way of seeing the best in everyone, and was very helpful in addressing the social concerns of tube feeders." Larry adds, "Kathy always had a smile on her face, no matter what her concerns were or the pain she was in. She enjoyed life and helped other people enjoy life."

Bethellen Dilcher was well-known among those with gastroparesis and motility disorders and her BellyBuster support group was a help to many. Bethellen died in February. Oley member Linda Stroshine writes, "Bethellen helped me when I first got my tubes and even went



Bethellen Dilcher

to the motility doctor with me at the University of Michigan. From the time I joined BellyBusters, Bethellen welcomed me and helped me handle my health problems. She was so sick herself, yet she was there to help anyone who was in need."

Bethellen spent many years advocating for those with motility disorders. "Not only did she help many others through her support group," her family writes, "but she also worked with Congressman John Dingell to promote FDA approval of medications that were

proven to be helpful to those with her condition. Even though she was very ill, she continued to work."

"Now I am trying to carry on Bethellen's mission and am an Oley Regional Coordinator," Linda continues. "I try to help others with their parenteral and enteral nutrition needs. I am paying it forward and it is in honor of Bethellen." ¶



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Bookshelf

Lisa Crosby Metzger

Memoirs from the 5th Floor, Fighting for My Life by Blatant Guyon

Blatant (a pseudonym) was in a near-fatal car accident and lost most of his large and small intestines. He is now dependent on parenteral nutrition (PN). “By the grace of God,” he says, “I am still here. I’m here to share my testimony and be a blessing to others.” In this book, the second volume in a “set of five different hospital journals,” Blatant does share his testimony, as well as his regrets from the past and his hopes for the future. After the accident, he writes, “I am like a baby learning to crawl. I had a near death experience and these are my accounts, my thoughts.” The book—as you might expect from a journal—moves from past to present to future as the author’s thoughts flow. Sometimes it’s a little confusing, sometimes it’s a little upsetting, but there is real heart and feeling in the book, and it’s a compelling read. The book is available at barnesandnoble.com, amazon.com, or publishamerica.com (\$19.95).

Complete Tube Feeding

by Eric Aadhaar O’Gorman

As the title promises, this book is thorough. Eric has drawn on his own experience as the “happy owner of a feeding tube,” as well as others’ experiences and research, to craft a great basic resource. This book should be useful whether you are new to tube feeding or have experience. Part one, “The Tube Basics,” covers the history of tube feeding; types of tubes; feeding methods; tube, equipment, and site care; common complications; the emotional aspects of tube feeding; and more. Part two, “Tube Food and Nutrition,” has a short section on commercially available enteral formulas, and a lot of information on blending “real food” for tube feeding (what Eric calls “a blended diet”), from “pros, cons, and controversies” to almost thirty pages of recipes. More information (including how to order, for \$21.99) at completetubefeeding.net.

NF2 Living, Win the Challenge and Who Am I?

by Jane E. Wilson

Jane has written several books of poetry, and in 2005 wrote an autobiography, *Who Am I?* Jane tells about being diagnosed with neurofibromatosis type 2 (NF2) and how she matter-of-factly faced this and other challenges in her life. She writes with wit and never self-pity. Throughout the book, Jane offers scriptures that have inspired her, poetry, and advice on living with NF2.

NF2 Living, Win the Challenge (2006) is almost a how-to book—how to live, and improve your quality of life, with NF2. In the preface, Jane writes, “This book is to shed light on your life to change chores into challenges and win...Please never give up because you never know what awaits you around the next bend in life’s road.” Many Oley readers will be drawn to the chapter “Fodder for the Feeding Tube,” where Jane describes how she made a successful transition from “7 cans a day of...liquid medical foods” to a blended diet. While Jane’s diet is specific to her medical condition, she offers useful, concrete tips on blended diets in general. The books (\$10 and \$12 respectively) are available directly from the author at 2501 Mt. Pleasant St., Apt. 16, Burlington, IA 52601, or poetgirl52@q.com. ♣



Inspired Giving

Motivated by...

“Oley was the first place I found support and hope.”—J.R.

...Roz is giving up a family movie night

\$40



Knowing that...

“Oley gave us expertise—unprecedented access to leading clinicians and research that directly affected our son.”—L.M.



...Cathy is giving up her favorite take-out treat

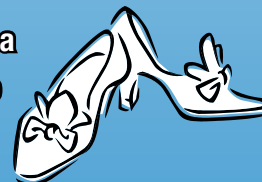
\$5

This inspired Joan...

“Oley has made my life easier, helped me be healthier, and to avoid complications!”—T.H.

...to forgo a shopping trip

\$50



Recognizing that...

“I would never have survived without this community”—R. T.



...Lisa is giving up a hobby project

\$25

What will you give up for Oley this week?

Use the enclosed envelope or go to www.oley.org

Every little bit counts!

Oley Supports Important Patient Safety Measure in California

Carrie Hartgen, Vice President, State Government & Regional Affairs, AdvaMed

The Oley Foundation recently engaged in an important patient safety measure in the state of California. The California General Assembly, in a rush to try to address the problem of inadvertent tubing misconnections, got ahead of itself by mandating that non-interchangeable connectors be used in the state before their designs were standardized. The goal is to create connectors that would make it much more difficult for someone to mistakenly administer enteral nutrition (EN), for example, through tubing (a catheter) intended for parenteral nutrition (PN), or vice versa.

While this mandate was well-intentioned, Oley and other groups, including the Advanced Medical Technology Association (AdvaMed), the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the Infusion Nurses Society, the National Patient Safety Foundation and the Institute for Safe Medication Practices, argued that it was imperative that connector design first be standardized so that California did not create unintended consequences that could also harm patients. On April 18, Oley members Kathy and Charlie Cleberg testified before the Assembly Health Committee on the importance of this issue to EN consumers. The bill passed the Assembly and is expected to be heard before the Senate Health Committee on June 6.

Assembly Bill 1867, sponsored by Asm. (Dr.) Richard Pan (D-Sacramento), extends California's existing mandate to ensure that the International Organization for Standardization (ISO) will have sufficient time to create standardized designs for various connectors. The ultimate goal of AB 1867 is to continue to promote patient safety through the creation of publicly available designs for each unique connection, but to do it thoughtfully and correctly through globally designed and recognized standards.

Not only will new connectors allow for standardization in all hospital environments—which is especially important when nurses,



From left: David Johnson, representing industry, Carrie Hartgen, from AdvaMed, and Charlie and Kathy Cleberg, consumer and parent.

doctors, and patients move between departments within a hospital, among different hospitals, or even from state to state or across national border—they will also eliminate confusion that could be created with new equipment and training requirements.

Under AB 1867, the deadline for non-interchangeable connectors in California would be January 2016. This new deadline allows sufficient time for the ISO to complete the rigorous and critical standardization process, while also allowing time for device makers to get FDA approval of the new designs and bring their products to market. The impending common design formats are worth waiting for and will give consumers and their families peace of mind.

If California does not grant an extension that allows these new design standards to be developed, it could foster unintended consequences. It could create new risks, or a solution that could be too complicated for consumers to use or for companies to manufacture cost effectively. ¶

Have You Heard the Latest?

If the Oley Foundation doesn't have your e-mail, chances are you are missing out. We use e-mail for breaking news and timely invitations. For example, we share FDA alerts and product recalls, and recruit participants for focus groups through e-mail. Focus groups provide valuable insight to companies who are developing products for "our" community. It's worth mentioning that Oley generates income by coordinating these types of activities and that participants (you!) are also compensated for participating. And the true beneficiaries are the consumers that will use the new and improved products in the future. It's win/win/win/win for everyone.

Don't delay. Send or update 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.

As always, we promise to respect your privacy and to not clog your box with unnecessary mail. Thanks a million!

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My PN Support Program

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Oley Growing, from pg. 1

research about HPEN. And as most of you know, with membership, you receive the newsletter and e-blasts with FDA recall notices, focus group opportunities, conference updates, and more. If you are new to Oley, be sure to check out Oley's other programs, including the conferences, online modules, Regional Coordinator network, information clearinghouse, Equipment-Supply Exchange, and more. (To join or for more information, visit oley.org or call 800-776-6539.)

Your membership in the forum gives you further access to a network of friends. As one participant says, "This is my number one forum because people are extremely helpful and nice, and provide encouragement, above and beyond suggestions." (See sample discussion below, reprinted with permission from the participants.) More information is available at oley.org ("forum").

Sample of the Support New Members Find on the Forum

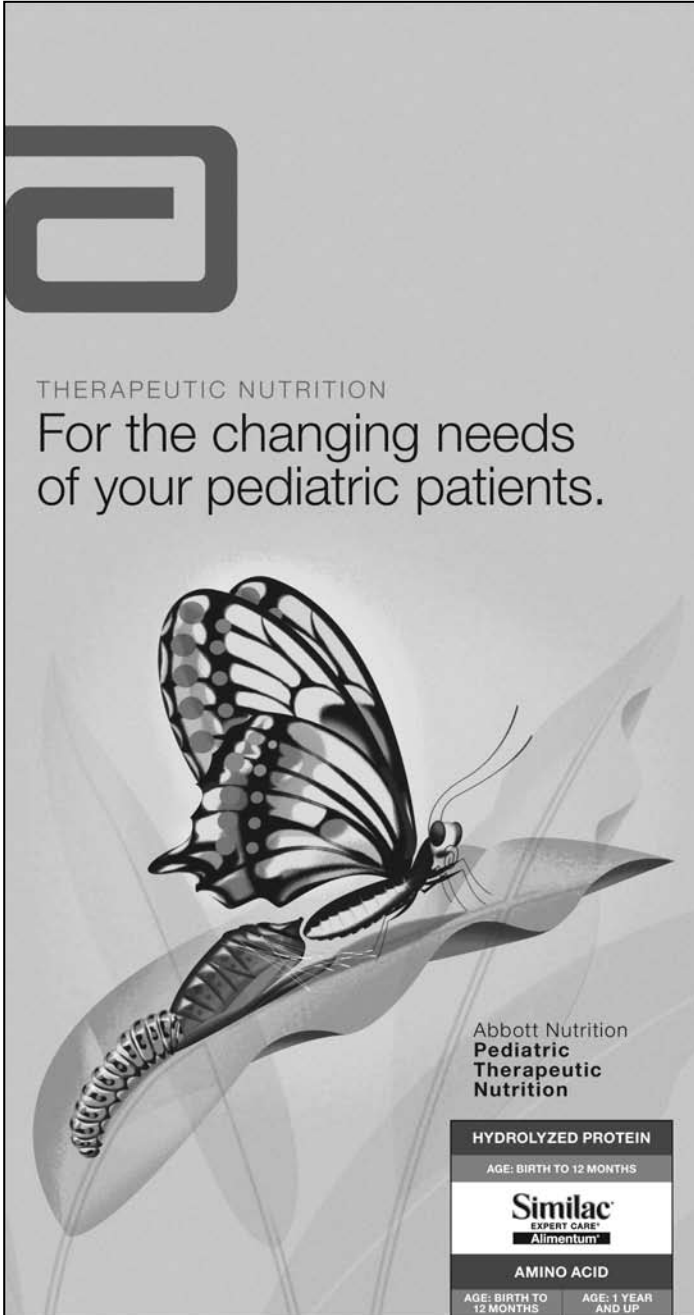
- A** "Since I am new I don't know all the ropes here yet, so if anyone has any info for me on how this forum works I would greatly appreciate it :)"
- B** "Welcome to the group, though sorry you have to be here! Basically we come on here to ask questions, vent, get feedback, etc. We also come here to support and learn from each other."
- A** "I really can't wait to get to know people here, as this illness can be rather isolating. I'm really glad this resource is here."
- C** "Welcome aboard! We are here to support you. So feel free to ask or talk about anything that is on your mind. I've had a g-tube for over 5 years and this forum has been a blessing to me."
- D** "Welcome! What would you like to know about tube feedings? Everyone here has lots of experience and helpful suggestions, so ask away. No question is a dumb question."
- A** "Thank you guys for the warm welcome. I've been reading posts and there is such strength coming from you guys as you all battle your individual challenges. My hope is that I will become as knowledgeable and resilient as you guys :)"

Other Ways to Give

Looking for ways to stretch your donation, without writing a bigger check? We remind you to explore alternate giving options, such as:

- employer matching grants (extremely worthwhile!)
- payroll deductions (United Way)
- friends and family who might add Oley to the list of organizations they support
- planned gifts (include Oley in your will, etc.)

Your support will ensure that the Oley Foundation remains healthy and strong as we move into the future.



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Abbott Nutrition

Drug Shortages, from pg. 1

(health care professionals) share their experiences with shortages, in particular the shortage of nutrition products. Here are some of their responses:

- “The ‘rolling’ shortages have especially created an unsafe practice environment in home TPN with the need for frequent rewriting of orders” [to work around the shortage of first one PN component, then another, and possibly others].
- “PN patients have had to accommodate multiple shortages at once. It can be confusing to them to remember one change from the next.”
- “[The] home care company [is] not notifying [the] ordering institution that they have a shortage and just stop[ped] preparing with the component in shortage.”

What you can do: Know what your PN prescription is and how to read your PN label. Keep a copy of your PN label. Note any inconsistencies and ask questions.

Consequences of Shortages

Clinicians noted increased hospital and home care company staff time spent filling orders; increased expense of preparing HPN; and restrictions on who gets what when. Several noted that they are only administering MVI (IV Multivitamins) three times a week instead of every day. Others, like this respondent, note deficiencies: “PN dependent patients have low serum or plasma levels [of] Se [selenium] and Cu [copper]. Some of our patients cannot take Se PO [by mouth] and therefore the clinical deficiency persists.”

Mirtallo et al note: “The complexity of PN formulations predisposes patients to many real or potential safety issues when products are not available.” The worst outcome was reported in 2011 when nineteen patients were infected with, and nine died from, *Serratia* linked to a contaminated amino acids product manufactured by an infusion pharmacy because commercial amino acids were in short supply. “In addition to the complications outlined [in the table below], infectious problems are likely when venous catheters are used more frequently for electrolyte replacements.” Hospitalization to treat electrolyte disorders or infections is also likely, he notes.

“The PN system is very complex and has many processes prone to errors even without the shortage issue,” Mirtallo continues. “PN product shortages have demonstrated how fragile this system is related to safe provision of care.”

What you can do: Be aware that increased monitoring (of your blood or serum levels, for example) may be necessary as PN formulations are adjusted. Discuss with your health care provider.

Managing Shortages

A.S.P.E.N. has been proactive in establishing recommendations practitioners can follow when shortages strike. Mirtallo et al write: “Having these recommendations available in this manner allows A.S.P.E.N. to provide timely, accurate recommendations for conserving a product in short supply and alternative to IV nutrient therapy.” These recommendations are available on A.S.P.E.N.’s Web site, nutritioncare.org/Professional_Resources/Drug_Shortages_Update.

Safety Issues Related to Parenteral Nutrition (PN) Product Shortages^a

PN Product	Safety Issue
Macronutrients	
Amino acids	Contaminated PN resulting in infections and death Fluid overload with the administration of PN prepared with less concentrated amino acids and fat emulsions
Intravenous fat emulsion	Hyperglycemia when replacing energy from dextrose for fat
L-cysteine	Inability to provide adequate doses of calcium and phosphorus for neonates
Electrolytes/minerals	Abnormalities when switching to different amino acids or multielectrolyte products
Phosphorus	Diarrhea with use of oral electrolytes for replacement Hypophosphatemia from reduced dose as conservation strategy Hyperkalemia from oral phosphorus product containing potassium Predisposition to refeeding syndrome
Sodium	Hyponatremia
Acetate	Hyperchloremic metabolic acidosis
Vitamins	Thiamin deficiency Vitamin A deficiency Multivitamin deficiency from inadequate profile of oral product or poor patient compliance
Ethanol ^b	Increased infections and hospitalizations due to omission of ethanol locks for central venous catheters

^aSource of these safety issues from the A.S.P.E.N. June 2011 clinician survey on PN shortages.

^bThis product is used as an adjunct to PN therapy and not a product in the PN formulation.

Reprinted from “Parenteral Nutrition Product Shortages: The A.S.P.E.N. Strategy,” by Jay Mirtallo, Beverly Holcombe, Marty Kochevar and Peggy Guenter (Nutrition in Clinical Practice, April 2012) with permission © American Society for Parenteral and Enteral Nutrition 2012.

What you can do: Share these recommendations with your health care provider if you feel it would be helpful. Updates are also posted online at oley.org.

Awareness

A.S.P.E.N. has also formed critical relationships with the Food and Drug Administration (FDA), product manufacturers, the American Society of Health-System Pharmacists (ASHP), and the Institute for Safe Medication Practices (ISMP). Further, “A.S.P.E.N. experts serve as a resource to the manufacturer related to appropriate product use (such as repackaging into smaller volumes to conserve supply) during a shortage,” writes Mirtallo et al. Oley has also been active with the FDA, particularly in FDA workshops, where Oley members have shared their stories of how shortages have impacted them. Oley is also in close communication with A.S.P.E.N. regarding the shortages.

Central to A.S.P.E.N.’s dialogue with the FDA, Mirtallo et al continue, has been “timely information on how the shortages have affected patients and clinicians....It is in this area where A.S.P.E.N. staff, volunteer leaders, and members have the most influence.” This is one place YOU, the HPN consumer, can get involved as well, and it is here that you can have a great impact. It is important that the FDA and decision makers recognize HPN as “medically necessary”—as critical to your health and survival. Oley applauds those who have responded to our appeals to share their stories and/or meet with their elected officials to help put a face to the therapy (we’ve shared several examples in recent past issues of the newsletter) and encourage all members to continue reaching out with their experiences—to Oley, local media, A.S.P.E.N., and local and federal representatives.

Mirtallo et al write, “The information from clinicians about the type of patients seriously affected by the shortage as well as the impact on health systems has greatly assisted A.S.P.E.N. in linking the shortages to real-life situations and accentuated the real or potential safety issues created by PN product shortages. The actions the FDA may take once a product is in shortage is to request other manufacturers of the product to ramp up production to meet the national needs, review products in quarantine, and devise ways that they may be released for use (ie, release product with particulate matter with the requirement that it be filtered). The FDA can also request a manufacturer resume making a product it has discontinued. Finally, the FDA may look into the importation of the product from outside the United States.”

What you can do: Share your stories with Oley, A.S.P.E.N., the FDA, and elected officials. Oley can pass your story on to A.S.P.E.N. and others (anonymously, if you’d prefer).

Proposed Legislation

In previous issues of the newsletter, we have addressed the legislation that has been proposed to address drug shortages. There have been several bills introduced in the House and Senate, such as S 296, Preserving Access to Life Saving Medications, and its companion bill, HR 2245, Preserving Access to Life-Saving Medications Act of 2011, introduced by Sen. Amy Klobuchar (D-MN) and Rep. Diana DeGette (D-CO) respectively; and HR 3839, The Drug Shortage Prevention Act, introduced by Rep. John Carney (D-DE) and Larry Bucshon (R-IN). What has evolved from this push is that the Senate

Drug Shortages, cont. pg. 14 ♣

ACHC Recognition as ‘Center of Excellence’ for Home TPN Therapy

“With Nutrishare I am able to talk with a pharmacist that knows my concerns. Knowing that I have a good company behind me, I can deal with any problem that comes up.”

Mary

“The Nutrishare conferences are very impressive! I am always enlightened from the information I receive.

Sharon



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Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors. Without their support Oley could not provide its many programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

NPS Pharmaceuticals

NPS Pharmaceuticals is developing orphan products for rare gastrointestinal and endocrine disorders. NPS is advancing two registration programs: Gattex® in adult short bowel syndrome (SBS) and Natpara™ in hypoparathyroidism. NPS also has two earlier stage calcilytic compounds with potential in rare endocrine disorders and a royalty-based portfolio. For more information, please visit www.npsp.com.

Walgreens Infusion Services

Walgreens Infusion Services supports the needs of home enteral and parenteral nutrition patients of all ages and conditions. Multidisciplinary teams provide individualized care and comprehensive services designed to achieve optimal health outcomes. Care coordination facilitates a smooth transition from hospital to home. All Walgreens infusion locations are ACHC accredited.

Applied Medical Technology, Inc.

AMT (Applied Medical Technology, Inc.) is a leading developer and manufacturer of enteral feeding devices and accessories. AMT writes, "We have grown into a model for the advancement of G-tube technology by embracing the needs of the patient first." Products include: the Mini ONE low-profile Balloon Button, Mini ONE Capsule Non-Balloon Button, and the new AMT G-JET.

Drug Shortages, from pg. 13

HELP Committee (Health, Education, Labor, and Pension) and the House Subcommittee on Health under the House Energy and Commerce Committee have developed drug shortage language as part of the Prescription Drug User Fee Act (PDUFA) Reauthorization bills, which were just introduced. These are S2516 and HR5651. While the full House and Senate are expected to approve a reconciled bill before the current law expires September 30, 2012, it's critical to show our support now for inclusion of drug shortage legislation in the final version. For more information on drug-shortages related legislation, visit oley.org/Reacting_Recent_Drug_Shortages.html.

In addition to the proposed legislation, in October 2011, President Obama issued an executive order aimed at resolving the growing number of shortages. This shows that the administration is taking drug shortages seriously.

What you can do: Contact your U.S. Senators and Representatives to let them know the importance of these bills—and your HPN—to your health and survival. (Sample letter at www.oley.org/sample_letters.html.) Please copy Oley on your letters so we have them as a reference. Also, ask your clinicians and home infusion companies to contact A.S.P.EN. and/or Oley with their stories. Together, we really can make a difference. ¶

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 Jan/Feb 2013 issue. Between March 26 and May 18, 2012, gifts were received:

In Honor of

Eric Green; Mary Kunz's birthday; Jim and Gloria Wittmann's engagement and wedding; Don Young

In Memory of

Ann DeBarbieri; Bethellen Dilcher; Mary Teresa Friel; Loren "Larry" Karacki; Robin Lang; Marie Latta; Kathleen McInnes; Lisa Miller; and Patricia DiAnn Starnes

Matching Gifts

National Grid

Fundraisers

iGive.com (thank you for remembering Oley when you shop online!)

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!

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.

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BRONZE STAR PARTNERS (\$20,000–\$29,999)

Baxter Healthcare

BENEFACTOR LEVEL PARTNERS (\$10,000–\$19,999)

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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!

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. To learn how you can make a difference at (800) 776-OLEY.

<i>Felice Austin</i>	<i>Valerie Gyurko, RN</i>	<i>Rodney Okamoto, RPh,</i>
<i>Jane Balint, MD</i>	<i>Alfred Haas</i>	<i>& Paula Okamoto</i>
<i>John Balint, MD</i>	<i>Shirley Heller</i>	<i>Kay Oldenburg</i>
<i>Joan Bishop</i>	<i>Alicia Hoelle</i>	<i>Harold & Rose Orland</i>
<i>Ginger Bolinger</i>	<i>Jeff & Rose Hoelle</i>	<i>Judy Peterson, MS, RN</i>
<i>Pat Brown, RN, CNSN</i>	<i>Lyn Howard, MD</i>	<i>Clemens Pietzner</i>
<i>Faye Clements, RN, BS</i>	<i>William Hoyt</i>	<i>Beverly Promisel</i>
<i>Katherine Cotter</i>	<i>Portia & Wallace Hutton</i>	<i>Abraham Rich</i>
<i>Jim Cowan</i>	<i>Kishore Iyer, MD</i>	<i>Gail Egan Sansivero, MS, ANP</i>
<i>Rick Davis</i>	<i>Doris R. Johnson</i>	<i>Roslyn & Eric Scheib Dahl</i>
<i>Ann & Paul DeBarbieri</i>	<i>Darlene Kelly, MD</i>	<i>Susan & Jeffrey Schesol</i>
<i>David & Sheila DeKold</i>	<i>Family of Shirley Klein</i>	<i>Doug Seidner, MD, FACG, CNSP</i>
<i>Tom Diamantidis, PharmD</i>	<i>Jim Lacy, RN, BSN, CRNI</i>	<i>Judi Smith</i>
<i>Selma Ehrenpreis</i>	<i>Robin Lang</i>	<i>Steve Swensen</i>
<i>Herb & Joy Emich</i>	<i>Hubert Maiden</i>	<i>Cheryl Thompson, PhD, RD, CNSD,</i>
<i>Jerry Fickle</i>	<i>Laura Matarese, PhD, RD, CNSD</i>	<i>& Gregory A. Thompson, MD, MSc</i>
<i>Don Freeman</i>	<i>Kathleen McInnes</i>	<i>Cathy Tokarz</i>
<i>Linda Gold</i>	<i>Michael Medwar</i>	<i>Eleanor & Walter Wilson</i>
<i>Linda Gravenstein</i>	<i>Meredith Nelson</i>	<i>James Wittmann</i>
<i>Deborah Groeber</i>	<i>Nancy Nicholson</i>	<i>Patty & Darrell Woods</i>
<i>The Groeber Family</i>		<i>Rosaline Ann & William Wu</i>

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What Would You Give Up for Oley?

See page 9 for details on how you can keep Oley programs free of charge for consumers and their families.

Get Hooked Up!

Hook up to HPN Awareness Week August 5–11!

Shawna Forester Smith

You get hooked up every day, so why not share your story with others and help raise awareness about home parenteral nutrition (HPN)?

Here are a few ideas on how to spread the word.

1. Tell somebody about your lifeline. It could be the waiter at a restaurant, a coworker, or your mailman. The more people you tell the more who will know what HPN is. I was at a bridal shower recently and was faced with the infamous “why aren’t you eating?” question. Instead of saying I wasn’t hungry (which is often easier), I shared my story about having multiple bowel resections, which require me to be on HPN. People were interested to hear my story and to learn about HPN. The more people we tell, the more understanding we build, and the more comfortable we become with telling people about our lifelines.

2. Contact your local media. Local media are always looking for human interest stories. Call or e-mail your local media outlets and tell them that it’s HPN Awareness Week and offer to share your story with them. If you are feeling really ambitious, you can draft a press release and send it to the media outlets in your area. Visit oley.org for a template you can use.

3. Update your social media. Put it in your Facebook status! Tweet about HPN Awareness Week! You’d be surprised how many people

you can reach by just updating your social media. Make sure all your Facebook friends and Twitter followers know it is HPN Awareness Week and what HPN is. You can always link to the Oley Web site.

Be sure to download the HPN Awareness Week logo for posting to your favorite social media sites. If you are feeling really creative, you can create a special banner for your Facebook page.

4. Blog about your HPN experience. Several Web sites offer free online blogs: blogger.com, wordpress.com, thoughts.com, and blog.com, to name a few. A blog is a great way to raise awareness and keep friends and family updated about your HPN journey. You don’t have to know HTML to blog! Most Web sites offer user-friendly web publishing platforms that are very simple to use. For inspiration, visit these: gpandme.org, livingwithgp.com, helpme-minx.blogspot.ca, and adventuresoftubegirl.com.

5. Wear your HPN Awareness Week button! The Oley Foundation has HPN Awareness Week buttons. Call (800) 776-OLEY or e-mail harrinc@mail.amc.edu to get yours. Quantities are limited, so act fast!

We hope that these ideas will inspire you to help spread the word during this year’s HPN Awareness Week. Every act, big or small, goes a long way to building awareness about HPN.



**Call for Your Free
HPN Awareness Week Button**