Drug Shortages Hit Home

Nicole Gerndt, MS, LCPC

I recently discovered the Oley Foundation, which has been helpful to me as I’ve been learning more about IV drug shortages that have been impacting my son, Finley, as well as others.

Finley was born in July 2010. He has been parenteral nutrition (PN) dependent since he was just a couple of days old.

Baby Finley

Finley was born full-term. Until he was born, we had no idea he had a congenital, chronic medical condition. My husband and I were blindsided by it, and had no idea what was in store for the three of us just a little over twenty-four hours after our his birth. It was a whirlwind. To condense a long story a bit, our...
Drug Shortages Hit Home, from pg. 1

son, who initially took to breastfeeding like a champ, began to vomit bile and did not pass his first stool (meconium).

He was in for surgery within his first week of life. He was given a high ileostomy and his first stool. They hoped that over time, he would be able to tolerate a slow rate of enteral feedings— even though we had been having little to no success with bolus, NG-, or NJ-tube feedings.

Going Home

Eventually we were sent home. We struggled to manage everything— hooking our infant son up to PN fifteen hours a day, running GJ-tube feedings at night, changing his ostomy bag multiple times each day, and dealing with the chronic vomiting that resulted from his inability to tolerate the GJ feedings.

In the early days of GJ feedings, hospitalizations occurred as Finley would become distressed and full of bile that was not emptying out of his small intestine. Over time, we learned how to vent his G-tube when needed and use a catheter to help drain stool from his ileostomy. This has helped him tolerate small oral feedings and thankfully avoid an oral aversion, but he could never survive on what little nutrition he takes in orally.

In May of 2011, following a mortality study at Children's Hospital of Wisconsin, we were told by our GI team that Finley would always be PN-dependent. Due to his severe to moderate level of hypoganglionosis (which means he has too few ganglion cells throughout his entire GI system, and the few that he does have are immature/not fully developed) and because of the lack of migrating motor complexes (MMC's), Finley will not be able to rely on oral and/or G-tube feedings to meet his primary nutritional needs. We initially perceived this as devastating news, although it wasn't surprising to us; we had watched Finley struggle with both oral and enteral feedings and absorption issues since birth.

Our Normal

It took some time, but eventually, over the last couple of years, our family has found our "normal" and our routine. Our "normal" involves Finley being connected to his PN for ten hours overnight. The bulk of his nutritional needs are met through the PN. We are now extremely grateful for home PN (or HPN), as without it our son would not be flourishing as he is today. Even more bluntly, he would not be alive. We are also grateful to have had the assistance of a wonderful in-home health nurse who has worked with Finley since he was about six months old.

If you saw Finley in the midst of his usual daily routine, you would see a cheerful, friendly little fella who loves to play in the dirt with his trucks. You'd never know that he has a chronic life-threatening medical condition. We have been fortunate to have a dedicated GI team that watches his lab work closely and that has made adjustments to his PN as needed.

During our first four weeks in the NICU at the hospital where Finley was born, I was erroneously told by multiple medical professionals that Finley wouldn't be able to live on HPN past a couple of months. I was told he likely could die due to liver failure and/or while waiting for transplantation. It wasn't until we transferred to another hospital and met with our current GI team that we started to hear that this was not the case, and that many people survive and thrive while on HPN. It has taken me some time to let go of that terrible fear I first felt, and to trust and believe what I was later told and able to observe, having met others who have survived and done well on HPN.

I am well aware that we will always need to monitor his liver functioning extremely closely in case of detrimental impact to this and other vital organs. We will also always need to be wary and take precautions to prevent central line infections, as these could prove life-threatening.

Calcium and Multivitamin Shortages

Up until recently, we have been able to get what Finley needed in his HPN. Approximately a year ago, we experienced a brief shortage of calcium. Gratefully, this did not last too long, as I am unsure how much Finley

Drug Shortages Hit Home, cont. pg. 9
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 the 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.

More Tips for Granulation Tissue
In the article on skin care issues that begins on page 1, there is a discussion of granulation tissue and treating it with silver nitrate. Here are two other options Oley members have suggested.

Tea Tree Oil, an Easy Option
Tea tree oil works wonderfully on granulation tissue. Mix fifteen drops of tea tree oil to five ounces of water and apply to the granulation tissue a couple times a day with a Q-tip.

—Kayjay35
Oley-Inspire Forum (www.oley.org)

Skin Protectants and Dressings
I went to a wound center because of skin breakdown caused by leaking around my tube, and they gave me Marathon™ Liquid Skin Protectant. This is the first thing that has stayed on long enough to help and is thick enough. It's sort of painted on using a single-dose applicator so it's easy to cover skin areas that are not smooth, and it's okay to use it on irritated skin. I was able to get it on Amazon. I'll admit it's a little pricey, but it's been well worth it for me.

They also gave me super-absorbent pads called Optilock™ non-adhesive wound dressing. The Optilock can't be cut (or the special insides burst out and make a mess… I speak from experience!), but I folded it around my J-tube and could just lay it flat over the site. The skin protectant was great in protecting my skin, but the dressing helped absorb the intestinal leakage.

I also use Mepilex® Lite wound care foam dressings with Safetac®. They are wonderful and easy to use since they stick right to the skin and I can cut them to go around the J-tube. They are actually easier (for me, anyways) to use than the Optilock dressing, but Optilock absorbs better. I was blessed that the wound care center nurses gave me some to try. They are somewhat expensive to purchase even via Amazon, but they are well worth it.

—Cindy L.
lovingartist28@yahoo.com

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.

For more information on Abbott Products, visit www.abbottnutrition.com.
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Nutrition and You

Starting Gattex: How to Work with Your Health Care Provider

Home parenteral nutrition (HPN) allows people to not only survive, but thrive. However, it carries potential complications, and for some it can be cumbersome and limiting. While it would be great to take even one day each week off of HPN, not everyone can do that. We’d like to discuss some options that may allow you to reduce your HPN.

The first option is to visit with your nutrition support team to optimize your diet and medications. In some cases specialized surgical procedures may be appropriate. Another option is a new medication called Gattex® (NPS Pharmaceuticals).

About Gattex

All medical interventions involve a partnership between the consumer and the clinician. It cannot be a one-way street. So, what do you need to know and what do you need to do when starting Gattex?

1. Know what the drug does and how it is administered. Gattex is an analog of GLP-2 which increases absorption in the small intestine. It is administered as a daily injection. You (the client) or your caregiver will administer this in your own home.

2. This drug should be used only under the guidance and monitoring of skilled clinicians with a substantial knowledge of short bowel syndrome (SBS) and HPN.

3. Be aware of the potential complications. For example, as absorption through your intestine is increased, you may start retaining more fluid. You will be able to tell by an increase in body weight, puffiness around your feet, ankles and hands, or even shortness of breath. If this occurs, call your health care provider immediately so he or she can adjust your PN volume. If there are any adverse reactions, the dose of the Gattex may have to be adjusted.

4. And what about diet? Does Gattex mean you can eat whatever you want when you want it? Well, not necessarily. Many will be able to eat normally and enjoy most foods. But you may be able to maximize absorption and the Gattex therapy if you follow a diet that is based on your own special gastrointestinal anatomy (see “Dietary Management for Short Bowel Syndrome: What You Eat Does Matter” and “Dietary Recommendations for Patients with Intestinal Failure,” LifelineLetter, Sep/Oct 2008 and July/Oct 2004 respectively*). It will be helpful to work with a knowledgeable dietitian who can assist you with food choices and monitor the process of weaning from HPN. There are many centers with experience in managing HPN and SBS that can be helpful in this process (see Oley’s Centers of Experience list*).

If you haven’t worked with your nutrition support team to ensure that your HPN, diet, and medication regimen is optimal, talk with your nutrition support team members. This is always the first step. When the standard therapies have been exhausted, then it is time to consider Gattex in partnership with your health care provider. ¶

* Articles and Centers of Experience list are available at www.oley.org in the “Resources” menu or by calling the Oley office at (800) 776-6539.
Submitted by Laura Matarese, PhD, RD, LDN, FADA, CNSC, FASPEN; reviewed by Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN.
Remembering Sheila Messina

This May the Oley Foundation lost a good friend, colleague, and former trustee, Sheila Messina, RN, MA, CLNC.

Sheila wore shoes that were much too big to be filled by any one person. She had been on home parenteral nutrition for thirty years due to Gardner’s syndrome, and trained consumers and clinicians in safe health care practices. She contributed to Oley and professional associations by writing articles, creating educational training materials, presenting at meetings, and fielding individual consumer queries.

Craig Petersen, RD, CNSD, knew Sheila for many years. He writes, “Sheila inspired me by her continued desire and efforts to productively contribute to the health and welfare of healthcare consumers. She never complained about her extensive personal health and medical hurdles, but instead, actively sought strategies and solutions to address these obstacles. She remained optimistic and positive, refusing to let her medical problems define her.”

In addition to all this, Sheila was one of the wittiest people we’ve known, making any interaction with her that much more of a pleasure. We feel her loss deeply.

Update on Enteral Pumps

*Nestlé Health Science Will Distribute Moog’s EnteraLite® Infinity® Pump*

Nestlé Health Science and Moog, Inc., have announced that Nestlé Health Science will distribute Moog’s EnteraLite® Infinity® Pump, as well as compatible administration sets and accessories. Nestlé will be the exclusive distributor of the pumps in the United States. In Canada both Nestlé Health Science and Maquet Dynamed will distribute the pump.

Nestlé Health Science will continue to sell and support Compat® enteral feeding pumps and administration sets. Nestlé Health Science writes, “Through this partnership…customers gain expanded access to state-of-the-art enteral delivery systems for their adult and pediatric patients in hospitals, home care and alternate site settings.”

This new arrangement has no effect on the products and your use of them. For specific information on the EnteraLite® Infinity® Pump and accessories, please visit www.nestlehealthscience.us/infinitypump.
Skin and Stoma Care, from pg. 1

can become painful, weepy, and eroded, much as with IAD. Some of the same products and techniques are used to treat the skin in both situations.

Treating Skin Breakdown

The role of the WOC nurse—and your goal as a home nutrition support consumer or caregiver—is to prevent skin breakdown; minimize skin exposure to stool, urine, or gastric contents; and promote healing to prevent infection. Key to preventing skin breakdown is a skin care regimen that includes gently cleansing and moisturizing the skin, and applying a skin protectant or barrier ointment.

Cleansing

Cleansing with soap and water is very appropriate if you are not experiencing any skin issues. To minimize skin exposure to irritants, cleanse as soon as possible to keep stool or gastric contents from sitting on your skin.

If there are skin issues, cleansing with a perineal cleanser (for bottoms) or wound cleanser (around a G- or J-tube site) is really beneficial. These products have a pH range that reflects the acid mantle of good, healthy skin (5.4 to 5.9), which helps prevent bacterial or fungal infection. Exposure to stool, urine, or gastric contents can increase the skin pH, which increases the risk of skin colonization by microorganisms and of infection.

Cleansers work by converting dirt and microorganisms on the skin surface into an emulsion so that they can be easily removed with rinsing. No-rinse cleansers use a combination of detergents and surfactants to help loosen and remove dirt or irritants. Many cleansers also contain a moisturizer. Products that contain both a cleanser and moisturizer (which can counteract the effect of dry skin) can save time and money. Cleansers are available as liquids, emulsions, or foams; you can also buy towelettes that already contain the cleanser.

Friction (rubbing too hard to cleanse the skin) can also contribute to skin breakdown. It is important to be gentle when cleansing to reduce friction on the skin, such as around a tube site.

Protecting the Skin

Skin protectants provide a barrier on the skin to protect it from water and the irritants found in stool, urine, or gastric secretions. This type of product includes petrolatum-based ointments, dimethicone-based ointments, zinc oxide creams, and oils. Some brands combine all of these ingredients, and others have just one of them as the main component. Skin protectants can come in the form of a cream, paste, or ointment. Pastes and ointments are thicker and stay in place longer. Skin protectants are also available as lotions, but these are intended for healthy skin.

If the skin is weepy, you can dust a protective powder on the compromised skin and seal it with a skin sealant or liquid barrier film product (composed of polymers and a solvent). With a liquid barrier film, the solvent evaporates after application, leaving the polymers to dry and form a protective film on the skin. Then you can place the ointment on top of the treated skin.

Recently I saw a little baby whose skin was very red and weepy around the perineal area. She was crying from the pain of the IAD. Because the skin was actually eroded, I applied a protective powder for moisture absorption and dusted that off, then put a liquid barrier film product over it. I did that twice to give it a dry surface, then covered it with a skin protectant.

Sometimes ointments can end up on the sheets or in the diaper. On the buttocks, our trick to avoid this is plastic wrap. After we put a barrier ointment in place, we cover it with a piece of plastic wrap. If necessary, we’ll cut two sheets of plastic wrap and put one on each buttocks cheek. The plastic wrap helps the ointment to be absorbed and keeps it on the compromised skin.

With skin that is significantly irritated by leakage around a feeding tube, I might put a special dressing on it to help absorb the drainage around the tube. (See “Product Examples,” next page.) Or we might pouch the site to help it heal (see “Pouching,” next page).

Antifungal powders are used similarly to protective powders (to help dry up a weepy area) except that they contain an antifungal agent. In these cases, when we want the powder to stay in place, we sprinkle the powder down, then cover with a liquid barrier film product.

Hypergranulation Tissue

Hypergranulation tissue is beefy red, raised, spongy tissue that forms around the tube insertion site. The most common cause of hypergranulation tissue is chronic leakage around the tube; excessive tube motion can also cause or increase the tissue formation. Hypergranulation tissue can bleed easily and secrete a yellowish ooze.
Treatment includes silver nitrate, where the tissue is cauterized and the hypergranulation tissue is brought down to skin level. This promotes healing. Silver nitrate application should initially be done and taught in the doctor's office; after the initial demonstration it can be done at home. Your skin may burn or sting for a few minutes after silver nitrate is applied, and it may look discolored. [More on hypergranulation tissue in “Tube Talk,” page 3.]

After treatment, preventing the tube from moving is beneficial. To secure a tube, you could use a protective barrier sheet. We use this in ostomy care as well. If you have to put some sort of a dressing around an ulcer near a G- or J-tube, you could put the dressing down, then put a barrier sheet on top of it to seal the dressing. The collar of the tube would sit on top of the barrier sheet. (See “Product Examples” on right for other tube holder ideas.)

**Gastric Stoma**

Sometimes you can get what I’m going to call a “gastric stoma.” This is when the actual stomach lining migrates up around the tube and matures at the skin level. It can cause major leakage problems and it becomes very challenging to keep the tube in place because the stoma has a wet mucosa that is constantly making the tube move in and out.

Treatment options include tube holders; pouching of tube site with or without the tube in place; taking the tube out; cauterization; or surgical relocation of the tube.

There are a few products available to keep a tube in place, and many Oley members have come up with homemade “tube holders” (see “Product Examples,” on right, and “Tube Feeding Tips” on www.oley.org).

**Pouching**

If the tube site is terribly enlarged or painful, we may have to take the tube out and the WOC nurse could apply an ostomy pouch to contain the drainage. “Pouching” the site allows the skin and tract to heal. In such a case, replacing the tube with a larger tube may also be appropriate.

If we have to keep the tube in, we can still apply an ostomy pouch to the site, but this is more complicated and would be a temporary solution. It would require the skill of a nurse to initiate and manage.

**Conclusion**

There are many great over-the-counter ointments and skin protectants available. Pharmacies and hospital supply companies carry skin care product lines by many manufacturers. We mention a few products on the right to give you an idea of what is available, and we found the Web site ostomycaresupply.com had an extensive list of products. Some manufacturers will provide samples upon request. Reimbursement for skin care products is dependent on your insurance and home care coverage; it may be worth asking if something is covered.

When applied with some of the techniques WOC nurses use routinely, these products can help you prevent or care for skin breakdown associated with IAD or G- or J-tube problems.

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**Product Examples**

The products listed here are representative of hundreds of skin care products available. These were highlighted in a presentation the author gave at a recent Oley Foundation conference as products with which she is familiar. There are many manufacturers with complete skin care lines from which to choose. *Listing does not imply endorsement.*

**Cleansers**

- Baza Cleanse and Protect® by Coloplast—“all in one” product; most active ingredient is dimethicone
- Aloe Vesta® Cleansing Foam by Convatec—no-rinse cleanser

**Skin Protectants and Barriers**

- Critic-Aid® Clear by Coloplast—petrolatum-based with dimethicone
- Sensi-Care® by Convatec—zinc oxide–based
- Calmoseptine®—an ointment containing zinc oxide, calamine, lanolin, and menthol (for a little bit of a cooling effect)
- Ilex® by Medcon Biolab Technologies—a white petrolatum-based paste. (It is helpful to apply a layer of petrolatum over Ilex to prevent it from sticking to gauze or a cover dressing.)
- Cavilon™ No Sting Spray Barrier by 3M—alcohol-free formula
- Protective Sheet by Coloplast—a protective barrier sheet that is sticky on one side; it acts like a thick, outer skin

**Protective Powders**

- Stomahesive® by Convatec—powder helps form protective barrier

**Wound Care Products**

- Triad™ by Coloplast—considered a wound dressing, it’s hydrophilic (it’ll absorb the moisture away from eroded or weepy skin); zinc oxide–based
- Aquacel® Ag (Silver) by ConvaTec—goes into the wound bed dry and absorbs drainage; used on areas that are so weepy, nothing will stick. The silver component of it is antimicrobial so it cuts down on infection.

**Dressings**

- Mepilex® by Molnlycke—a multilayered foam pad; the layer against the skin conforms to uneven surfaces and adheres without additional tape. You can put a slit in it and wrap it around the tube to help draw up drainage like a sponge would.
- PolyMem® by Ferris Mfg. Corp.—a pink foam dressing with a surfactant and glycerin. It will absorb drainage and interact with the wound bed. Also comes in a silver form and in a shape that’s made to go around tubes. It does not have an adhesive back, so you have to secure it with tape. (You’re not supposed to clean between dressing changes when you use this product.)

**Tube Holders**

- Flexi-Trak® anchoring device by Convatec—can be opened and closed several times for adjustments; not a “one and done” type of holder.
- Tube holder by Hollister—tighten a loop around the tube and the tube is held in place; adjust the loop to make it tighter or looser. Can be left on for several days.
Advocacy Efforts

End Shortages, from pg. 1

This was very good news to the entire Oley community—to consumers, clinicians, and members of industry alike. However, much to everyone’s surprise and dismay, shortages of critical drugs have continued, and in some cases increased, in spite of the new legislation. This is a critical problem, especially for home parenteral nutrition (HPN) consumers, who are dependent upon these same drugs for vital nutrients and for whom resources are limited in the best circumstances.

Shortages in HPN

Industries providing HPN solutions in this country are managing in day-to-day, triage mode in order to provide the prescribed and necessary nutrients to their consumers. The shortages are not limited to one or two HPN ingredients, but have affected virtually all of the ingredients in HPN. Some drugs are short temporarily or intermittently, while others have been in short supply throughout the crisis. These same shortages have not occurred at all or have occurred with much less frequency and duration in other countries over the last few years.

One pharmacist stated that sterile water was the only ingredient that has not been affected by shortages. This means the HPN supply industry must make decisions about who receives the medicine they need. Who would have guessed that after sweating through the trials of effective medicines, safe techniques, insurance coverage issues, and efficient delivery systems, we would now have to consider availability of needed and sometimes quite common ingredients in this life-saving area of medicine.

“Reach and Teach”

On April 5, Darlene Kelly, MD, PhD, FACP,(recently retired from the Mayo Clinic and now Oley’s Science and Medicine Advisor), Elizabeth Tucker (long-term HPN consumer and advocate), Harlan Johnson (my husband, and an advocate and caregiver), and I (a long-term consumer and Oley Board President) met with the Health Care staffer in Senator Amy Klobuchar’s office in Minnesota. Oley Executive Director Joan Bishop joined us by phone. Senator Klobuchar had previously cosponsored one of the Health Care shortage bills and has been an active supporter of quality health care legislation. We spoke with her aide, Adam Schiff, for almost an hour during a prescheduled appointment about our concerns, and we left written material for him to share with Senator Klobuchar.

Our goal was to educate just one of the one hundred senators and to also ask for effective direction to continue our efforts. Adam was receptive to our comments and to our prepared materials. He provided some important recommendations to “reach and teach” as many senators as possible. He said personal stories from consumers are the most effective approach. He also stated that we should target current members of the U.S. Senate Committee on Health, Education, Labor and Pensions, which is the group to decide which bills get attention from the rest of the Senate. Committee members are listed on www.help.senate.gov or call (800) 776-OLEY for a list.

Speaking Up

I have personally benefited from a regular and reliable HPN industry for almost thirty-three years. While my gut might be artificial and my nutrition may be unique, regular access to needed HPN ingredients allows me to live a healthy and fairly normal lifestyle. I am dependent upon the continued availability of all the ingredients in my individual “recipe” and I will continue to attempt to educate those members of Congress who need to provide leadership and boundaries to the drug companies involved. If our needs cannot be met through legislation, perhaps we need to look for alternative, quality standards. Please consider joining our efforts. It is our voices that will get their attention!

Join us in signing the petition

Oley member Ann Weaver has initiated to urge Congress to end shortages. Link at www.oley.org.
is able to absorb enterally, and we needed to give him the calcium through his G-tube.

In the last few months, however, we have been informed that the multivitamin we previously had added each night to his HPN was no longer available. We now have to give a crushed-up multivitamin to him in his G-tube. Again, I worry that he is not getting all of what he needs due to absorption issues. He does not have much intestine, so the vitamins have little chance to be absorbed before they leave his body through his ileostomy.

**Phosphorous and Selenium Shortages**

A couple of months ago, we were told that phosphorous was no longer available for his HPN. Instead we mix a powered phosphorus supplement with two and a half ounces of water twice a day. This may not sound like a lot of fluid, but an extra five ounces a day is a lot for a child with GI issues who can, at his best, comfortably tolerate only one to two ounces at a time. Besides causing him physical discomfort—even when we administer it to him in smaller, divided doses—it has caused his ostomy output to increase. This further adds to our worry that he may be flushing out the essential nutrients and supplements without getting much benefit from them.

Finley, who is relatively used to getting medicine through his G-tube and having to take frequent breaks in his play throughout the day due to the need for ostomy care, now has to experience getting more through his G-tube at least three extra times a day. Most times when he knows it’s coming, he expresses that it hurts and is bothered by it—which, as you can imagine, makes for some very fun moments with an active and strong-willed toddler.

While we have not yet had the problems that I hear others have had (needing to rule out renal failure or going to the hospital because of levels dropping too low), within the last couple of months we received feedback from Finley’s GI dietitian that his phosphorous numbers were “trending down.” I know enough by now to know that “trending down” is generally not good news. Hospitalizations and declining physical health, which can impair his ability to fight off a life-threatening infection, can follow news of numbers and levels “trending down.” We know this through prior experience, when his iron or potassium levels dropped too low.

The most recent shortage to affect Finley is selenium. As of May, we have needed to add crushed up selenium to our daily G-tube routine, and we have to coordinate it so it is not too close to his phosphorous dosage, as it could interfere with the efficacy and absorption.

**Future Trends**

I am afraid of what IV drug shortages may do to my son’s health and physical growth and development should the current shortages continue and if we have additional shortages heading our way.

Having the responsibility and inherent weight of worry caring for a loved one who is dependent on HPN is generally enough, without adding to it the stress of worrying about whether the medication to help them survive will be available and to what extent not having it available may be detrimental to their health.

I want to thank the Oley Foundation for the advocacy efforts and knowledge-sharing they are doing, and would like to offer support by lending our personal experience.
Corporative Partner Spotlight

We have much to be thankful for, including the support of our corporate partners. Please join the Oley Foundation in thanking our most recent corporate contributors. Without our partners 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.

Coram Specialty Infusion Services

Coram is proud to support Oley as a Gold Medallion Partner. Coram empowers tube feeding and TPN consumers through individualized customer service, clinical expertise, education, and support. Coram's Nourish Nutrition Support Program offers thirty-plus years of experience, comprehensive therapy management, consumer advocacy services, online resources, national coverage, and local expertise.

Abbott Nutrition

Abbott Nutrition is one of the world's leading authorities in science-based nutrition for all stages of life. Explore its portfolio of products, including Jevity, Vital, PediaSure Peptide, and EleCare, to help patients grow and achieve greater well-being. Visit www.AbbottNutrition.com to find product information, patient education materials, clinical research papers, and more.

Home Solutions Infusion Therapy

Home Solutions Infusion Therapy is one of the largest independent home infusion providers in the country. Home Solutions says, “Our team understands the importance of a positive patient experience. From the first interaction with the intake department, to the driver; patients feel confident that Home Solutions will perform positively and place their health first.”

Applied Medical Technology, Inc.

Applied Medical Technology, Inc. (AMT) helped develop the PEG tube, and its founder co-invented the first low profile feeding device. AMT continues to make innovative medical devices, including the AMT Bridle™ Nasal Tube Retaining System, the AMT Mini ONE® low profile buttons, and the new AMT G-JET® low profile G-J enteral tube.

Critical Care Systems

Critical Care Systems (CCS) is a leading national specialty infusion company providing comprehensive clinical services to pediatric and adult populations through a national footprint of JCAHO-accredited, community-based branches. It is CCS's belief that customized nutrition support, “state of the art” HPN standards, and a team of HPN experts, leads to optimal outcomes.

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.
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 2013 in the January/February 2014 issue. From March 6 through May 3, 2013, gifts were received:

In Honor Of
Art Commare, for his courage and determination with managing his IBD; Dr. Darlene Kelly; and Ann and Tim Weaver, for their continued support of pharmacy education at Midwestern University

In Memory Of
Mrs. Hamilton

Matching Gifts
Bank of America Charitable Foundation

Fundraisers
iGive.com (online shopping); Planet Green (ink cartridge recycling)

We appreciate all gifts and the 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.

Felice 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 Enich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
Deborah Groeber
The Groeber Family

Valerie Gyurko, RN
Alfred Haas
Shirley Heller
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Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Huston
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Rohin Lang
Hubert Maiden
Lauren Matarrese, PhD, RD, CNSD
Kathleen McNees
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh
& Paula Okamoto
Kay Oldenburg
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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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Thank You!
HPN Awareness Week, August 4–10, 2013

Parenteral nutrition at home (HPN) isn’t easy, but so many people do it! HPN Awareness Week is a chance to help others understand both the challenges and rewards HPN presents. When people understand, they are more supportive. And when people see positive outcomes, they are less discouraged. Help your friends, family, and the community understand what HPN means in your life, and share your story to inspire others who are facing challenges.

Some ideas for sharing HPN Awareness Week:

• **Facebook postings**, casual conversations, **blogs**, and **tweets** will all generate interest and curiosity. One member last year changed her Facebook profile picture to a photo of her HPN bag and supplies and said it sparked lots of questions! Others posted the HPN Awareness Week logo and enjoyed a sense of unity.

• **Contact your local newspaper or radio or TV station.** Look for a sample press release on www.oley.org.

• **Send us photos** for the HPN Awareness Week **video**! See last year’s on the Oley Foundation You Tube page, and contact Lisa at Oley for details on submitting photos for 2013.

• **Request and share HPN Awareness buttons**! Available for no cost through Oley.

• **Ask your home care company** to join in the efforts—to share Oley brochures and HPN Awareness Week buttons, to invite you to speak to their staff about HPN, or to post the event on their Web site.

Ideas? Questions? Button requests? Need help with a press release? Call or write Lisa at (800) 776-6539 or metzgel@mail.amc.edu.

“**Awareness is important to me for several reasons. First, I believe it is extremely beneficial for HPN consumers to know that they are not alone in their journey, that they learn they can integrate HPN into their lives, not the other way around. Second, I think it is critical that others who are not on HPN are aware of this life-saving and life-giving therapy, so that they understand and support the HPN community on things like drug shortages.”**

—Ann W.