

LifelineLetter

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Subscriptions:

The *LifelineLetter* is a bi-monthly newsletter sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your healthcare provider prior to actual use. Correspondence can be sent to the Editor at the address above. Medical/scientific content contained herein has been peer reviewed by an Oley advisor or trustee.

Our Mission

...is to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

The Oley Foundation provides its 26,000+ members with critical information on topics such as medical advances, research, and health insurance. The Foundation is also a source of support, helping consumers on home IV nutrition and tube feeding overcome challenges, such as their inability to eat and altered body image. All Oley programs are offered FREE of CHARGE to consumers and their families.

Oley Foundation Programs

- *LifelineLetter*
- Peer to Peer Support
- Conferences and Webinars
- Resources to Promote Living Well on Tube Feeding and IV Nutrition
- Equipment Supply Exchange
- Advocacy and Awareness

Resource Spotlight:

Kidz Klub, a virtual extension of the annual Jammin' Jammies, is a program for kids on IV nutrition and/or tube feeding and their siblings, and kids who have a loved one on nutrition support. We have virtual scavenger hunts, do arts and crafts and science experiments, show and tell, and share jokes. Kids can ask the other kids about their life with nutrition support, but we mainly focus on having fun in a safe virtual setting, where the kids don't feel obligated to explain their backpacks, beeping pumps, lines, and tubes. Children of all ages can participate, but we ask parents of younger children to be close by in case they need help with the activity. Please email Mary at marywootten.oley@gmail.com if you have questions about this program, and to RSVP. Meetings are typically held quarterly.



How to Support Oley

Donations are tax deductible and are accepted at oley.org/donations or at the street address on left. We appreciate your support!

Tube Talk

Send your tips, questions, and thoughts about home tube feeding (home enteral nutrition, or HEN) to metzgel@amc.edu. Information shared in this column represents the experience of the individual and, while medical information is reviewed by an advisor, should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



Tube Feeding (Enteral) Formula: Navigating Outages, Recalls, and Finding Alternatives

Cynthia Reddick, RD, CNSC, gave an excellent presentation at the Oley Foundation's April Mini Meeting titled "Enteral Formula in Homecare: Navigating Outages, Recalls, and Finding Alternatives." In her presentation, Cynthia gives basic information on the different types of tube feeding formula, with an in-depth discussion of what "plant-based" means in terms of enteral formula.

She also helps us better understand what causes backorders and shortages of both formula and supplies, and discusses the recall by Abbott earlier this year of lots of Similac, Alimentum, and EleCare powder formula manufactured in Sturgis, Michigan—and the impact that recall had on the availability of other formulas.

To wrap up, Cynthia gives some practical tips you can use at home to anticipate backorders, supply chain issues, or shortages of tube feeding formula or supplies. These include making sure your prescriber provides an equivalent formula, when possible, in case the first choice is not available; that you get timely refills ("be proactive," Cynthia advises); and have a buffer or backup—be prepared, as you would be for an emergency or natural disaster.

For a link to Cynthia's presentation, go to oley.org/2022minimeetingspresentations.

Cynthia Reddick, RD, CNSC, is National Tube Feeding Manager for Coram/CVS Specialty Infusion Services.

Mailbox From Feeding Tube Awareness Week

I am an oncology dietitian at a small outpatient cancer care center in Massachusetts. Over the past seven years, I have been building a special program for our adult patients diagnosed with cancers of the head/neck area. Their treatment course of chemotherapy, radiation and/or surgery is often challenging, painful, and stressful. We have developed a multidisciplinary approach for this special population including early nutrition and swallowing interventions. Many patients do require placement of a feeding tube for maintaining nutrition and hydration during and after treatment.

One of my favorite days working as an oncology dietitian usually involves helping my patients practice feeding themselves through their new G-tubes. They feel empowered and relieved to be able to feed through their tube when eating is too difficult or painful. Another awesome day comes a few months later when I can be a cheerleader on G-tube removal day! We often work with the Oley Foundation's equipment and formula exchange program, too!

This year for Feeding Tube Awareness Week, I ordered and handed out fifty+ buttons for our staff and patients. I shared professional experiences, common myths, and quotes from patients. In the years to come, I hope to continue improving this program and spreading awareness around using feeding tubes.

I am very proud of and inspired by our patients as well as their supportive caregivers. Their inspiration fuels all of us in healthcare to keep moving forward and helping others.

—With love, Rachel S.

(oncology dietitian & tube feeding ambassador)

Thanks to everyone who participated in Feeding Tube Awareness Week in February 2022.

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Welcome New Oley Ambassadors

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit oley.org or call (518) 262-5079. Note: Ambassadors volunteer to provide peer support for home IV nutrition and tube feeding patients and family members. They are not medical professionals and do not offer medical advice. Please do not contact Oley Ambassadors for solicitation, marketing, or research purposes.

Meet our newest Oley Ambassadors.

Amber Cox joins the Oley Ambassador network as a caregiver. Her son, Mark, was diagnosed with megacystis-microcolon-intestinal hypoperistalsis syndrome (MMIHS) when he was six months old and has been on home IV nutrition (HPN) since 2014. He has a tunneled central line and an ileostomy. Amber writes, “The beginning days of HPN, central line, and ostomy care were extremely overwhelming, but as time goes by it becomes easier, especially with a support network.”

Amber (along with her husband and son) attended her first Oley conference in 2015. Amber writes that she “was immediately grateful for the incredible knowledge and support. It was heartwarming to hear our son, at two years old, say, ‘look line like me.’ It was the first time he ever met other kids that had similar needs to him.”

In her spare time Amber enjoys reading, camping, and going for Jeep rides with her family. She believes we are better and stronger when we go through life’s challenges with a support network to lean on.

Amber lives in San Bernardino, California, and can be reached at amnelson77@gmail.com or (909) 744-7491.

Kathy Griffin was diagnosed with scleroderma in 1995 after experiencing slow-moving stomach and intestines, tightening of her esophagus, and other symptoms. In 2001, when she could no longer swallow food and her stomach and intestines had almost come to a standstill, her gastroenterologist put her on home parenteral (IV) nutrition (HPN). Kathy was on and off HPN until she had a blockage in 2021, when she went back on HPN. She expects to be on it for the rest of her life.

Kathy is active with the Scleroderma Foundation, where she volunteers for the Delaware Valley Chapter, is a support group leader and board member, and serves as the patient caregiver outreach chair.

She also has experience with beauty pageants. She says she had always wanted to be in a pageant when she was a child, but was shy about speaking in front of a big crowd. Finally, in 2018, she gathered the confidence to follow this dream. She competed for the title of Ms. New Jersey New England States, and she won. She went on to compete in a larger, national pageant in 2022, where, she says, she was nervous to appear before a full audience in a bathing suit, after having undergone more than twenty intestinal surgeries. Kathy



Amber Cox



Kathy Griffin

says she felt fulfilled after the experience, where, out of fifty women, she won Miss Congeniality.

Kathy lives in Sicklerville, New Jersey. She can be reached at (609) 519-1770 or kathyann3761@yahoo.com.

Tonya Henry was born and raised in the rural Piedmont area of North Carolina. She now lives in Killeen, Texas. Tonya joined the military right out of high school, but left due to multiple medical issues. She is divorced, with two young grandchildren.

Tonya has experience with both tube feeding and home parenteral (IV) nutrition (HPN). She first had a jejunal (J) tube (2016), then a gastrojejunal (G-J) tube, and finally a gastric (G) tube, which she uses for draining and venting. Tonya also has a port; she has been HPN dependent since 2019.

Tonya says, “I have a heart for service,” and this is evident in the volunteer work she does. She has served on the Relay for Life committee; as a greeter, children’s choir assistant, and second-grade volunteer at church; at Camp Care a Lot; and as moderator for a Central Texas women veterans group. She also volunteers to help the homeless. “Due to health and Covid-19,” she says, “my efforts are done by coordinating through texts and social media.” She also does a homeless hygiene drive annually.

Tonya concludes, “I may be a disabled veteran with multiple rare and non-rare conditions, but I love doing what I can for others. I am ready to start working as an Oley Ambassador.”

Tonya can be reached at vette2375@peoplepc.com or (254) 220-8844.

Pilar Rigau lives in Barcelona, Spain, with her husband and their three sons. Their son Albert, born in 2009, was diagnosed with necrotizing enterocolitis (NEC) when he was six days old. Most of his bowel had to be removed, leaving him with ultra-short bowel syndrome. Albert has been dependent on parenteral (IV) nutrition (PN) since that day. Pilar says, “It has been a long journey and I cannot be thankful enough to all the people who have helped us along the way. At first, it was just a Yahoo group (which later became a Facebook support group) that allowed me to know more and more about our son’s condition. In our country, we are a bit behind in terms of bowel rehabilitation, oral nutrition to improve any condition, and considering well-being of the patient as one of the main parts of their lives.”

Pilar continues, “We have always been fighting to give Albert a full life. He goes to school, has friends, eats really well, and we even travel as often as we can. Oral nutrition is really important. I studied and became a nutritionist to learn how to help Albert through food.” Pilar adds that she is “into everything natural,” such as exercise, meditation, and integrative psychology—“and everything that may help going through rough times.”



Tonya Henry



Pilar and Albert Rigau

Pilar looks forward to helping others, especially with issues related to nutrition or a patient's well-being. She says she would also enjoy talking to anyone coming to Spain, or Europe generally. Pilar can be reached at personal@pilarrigau.com.

Barbara Rudzin was first diagnosed with autoimmune disorders in 1998 and has been dealing with chronic illnesses ever since. Barbara says she is thrilled to become an Oley Ambassador (and we are thrilled to have her, and all of our newest Ambassadors, join us!).

Barbara has had a low-profile gastrojejunostomy (GJ) tube since September 2020 after scleroderma and GERD had made it difficult for her to swallow. In addition, Barbara has gastroparesis and esophageal dysmotility. She is NPO (takes nothing by mouth) and says she probably will be for life. She has been on IV nutrition (parenteral nutrition, or PN) and had various types of feeding tubes since 2020.

Barbara says, "I feel the tube saved my life because before it was placed, I would eat and would not be able to keep food down; I would drink and get sick; and I would take medication and get sick. Now, I have energy, strength, and motivation to live life to the fullest. I never viewed myself as 'sick' and I never will."

Barbara has recently moved from Chicago, Illinois, to Peoria, Arizona. She can be reached at barbara525@gmail.com or (847) 224-5200.

Monique Stith started her journey with short bowel syndrome and home IV (parenteral) nutrition (HPN) in 1976. In what Monique feels was a reflection of the times, when much less was known about short bowel syndrome or long-term HPN, her parents were told she would not live past her third birthday. During her time on HPN, Monique has had numerous central line placements and hospital stays, and, she notes, "countless uncomfortable and embarrassing situations." She continues, "Growing up I felt lonely and isolated. I had no knowledge of Oley or other people going through my situation. I'm sure if I had had some HPN peers the situation would have been slightly easier to bear."

Monique attended college and graduate school and went on to build a career. She went ten consecutive years without HPN. "As I marked that day as a triumph," she writes, "I ended up crashing and in the hospital, back on PN temporarily. I've been on and off HPN three times since my ten-year stint. During the time I was not on HPN and as the disease progressed, I experienced a diminished quality of life while watching myself slowly starve to death."

After many years of struggling, in September 2021 Monique had intestinal surgery. She writes, "I am adjusting and adapting to a new way of eating and thinking about food while watching my body again go through a growth spurt. I will always have short bowel, but I am hopeful that with this procedure I can provide for my nutritional requirements without HPN and can begin to rebuild my quality of

life. By sheer determination, hope and a strong faith in Jesus and a supportive and encouraging family I am where I am today. Today I hope to share my experiences and encourage others who use HPN."

Monique lives in Spencer, Oklahoma and can be reached at candy-cornhotpickles@gmail.com or (405) 551-3024. ¶

New Role, Responsibilities

We are pleased to announce that Program Associate Mary Wootten, in addition to other responsibilities, will be serving as the staff liaison for the Oley Ambassador program. We thank Mary for her six years of volunteering as an Ambassador and know that that experience will serve her well in this role. As staff liaison, Mary will be able to help Ambassadors achieve their goals and make the program thrive. Mary says, "I look forward to embracing this new role. I will continue to be a resource to Oley members and Ambassadors, as well as being available to help OAs to achieve their goals and visions." She invites all Oley members to reach out to her with any questions. Mary can be reached at marywootten.oley@gmail.com or (518) 262-5079.

In addition to being a great listener and organizer, Mary knows what it is like to live with home nutrition support. One of Mary's three children, Natalie, has had a feeding tube since 2009 due to failure to thrive, slow motility, and visceral hypersensitivity. Mary is also knowledgeable about Oley programs and resources, and, as a Daisy Girl Scout leader and New York Rare Action Network Volunteer State Ambassador with the National Organization for Rare Disorders (NORD), she knows about the joys and challenges of serving as a volunteer. ¶



Barbara Rudzin



Monique Stith



Mary Wootten

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Thanks to the following corporations, foundations, and organizations for their generous gifts (\$500+) for specific Oley programs in FY 2021. These gifts extend support beyond their corporate partner pledges.

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To those who supported the Oley Foundation in FY 2021

- **with in-kind gifts:** Timothy Arends/Dorsey & Whitney LLP; Jaihui and John Dalton; Roy George; MagicWig Productions, Inc.; Nancy Pickett; Lingxia Sun
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Enhancing the Oley Equipment Exchange Program

Oley staff is excited to announce plans to modernize the process we use to connect people who have products that they no longer need with people who can put them to good use. We recognize how fortunate we have been to have had Phil Kellerman at the helm of this program, and our dedicated volunteers, Bettemarie Bond and Robin Bodnar.

With Phil's retirement (see page 11), we are working to coordinate an online process to facilitate the exchange of products. The result should be a positive experience for everyone, with 24/7 access to the list of available items and the forms for donating products!

The downside of shifting to an online platform (and with Phil's retirement) is that we are only able to offer the donation forms and the listing of available products in English. Everyone accessing the exchange program, whether to donate or with hopes of accessing products, will need to do so in English. We are hoping that those who will find this change challenging will be able to identify friends or family members to assist them.

Stay tuned to oley.org/Equipment_Exchange for updates on our progress.

President's Perspective

As you probably already know, in 1983, what would ultimately become the Oley Foundation began with one doctor, Dr. Lyn Howard, and one patient, Clarence "Oley" Oldenberg. Who could have foreseen we would have over 26,000 members in 2022?



Beth Gore, PhD, MBA

Pandemic

Just like the rest of the world, Oley had to make adjustments during the pandemic. Following the recommended guidelines, most of the staff went from working out of Albany Medical Center to primarily working remotely. The annual conferences shifted from in-person to virtual. Yet our membership never stopped steadily increasing. Our educational offerings continue to reach record numbers of members.

Two years after the pandemic lockdowns, we continue evaluating and navigating how to best work towards meeting our mission: *Striving to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.*

Staffing

As the membership grows, the staffing needs also continue to evolve. In 2013, Andrea Guidi stepped in as Executive Assistant; her title was later changed to Director, Educational Programs and Initiatives. Her primary responsibilities included helping coordinate the Oley annual conference, mini meetings (formerly called regional conferences), and awards, and much more.



Andrea Guidi

In April 2022, Andrea began a position elsewhere, and she no longer works for Oley. We are sad for Oley because she brought zest, professionalism, skills, a can-do attitude, and a heart to help. But we are thrilled for Andrea

and wish her utter success in her next adventure. We know she will be an asset to her new organization. You might still see her around as a piece of her heart still belongs to Oley. Join us in wishing her success in her new role.

Phil Kellerman has been working since 2017 with the Equipment Exchange program. Phil, too, has brought skills, a can-do attitude, and a heart to help. Phil has helped us serve several hundred consumers. At the end of April 2022, Phil will be retiring. Please join us in wishing him well in his retirement.

As a result of Andrea and Phil's departures and the ever-increasing program demands, the Oley Foundation Board of Trustees voted to evoke a clause in the Bylaws to hire the President of the Board as Interim Chief Operating Officer (COO) to Oley. That's me. On February 28, I began working part time to help fill in the gaps. I have extensive experience with organizational development, non-profits (from the board, staff, and executive sides), and overall management experience. My most im-



Phil Kellerman

working alongside Joan Bishop, Executive Director, as well as the rest of the capable Oley staff members of Roslyn Dahl, Communications and Development Director; Cathy Harrington, Administrative Assistant; Lisa Metzger, Editor, *LifelineLetter*, and Director of Community Engagement; and Mary Wootten, Program Associate.

Strategic Direction

The Oley Board will be meeting to discuss the strategic vision of the Oley Foundation in 2023 and beyond. We are excited to begin to map out "now what?" How do we best continue to reach towards our mission? How do we best serve our members? We will be utilizing the Member Survey data collected to help us navigate the next steps. If you have not completed that survey, there's still time and we would love to hear from you. Visit surveymonkey.com/r/OleyProgramSurvey.

I personally am grateful that someone had that vision decades ago to be a voice for the consumers of home IV nutrition and tube feeding (parenteral and enteral nutrition). Now it is time to look to the future of Oley. We want the Oley Foundation to be around for many more decades of enriching the lives of those on home IV nutrition and tube feeding.

—Beth Gore

*Oley Board of Trustees President
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ENFit Syringes, from pg. 1

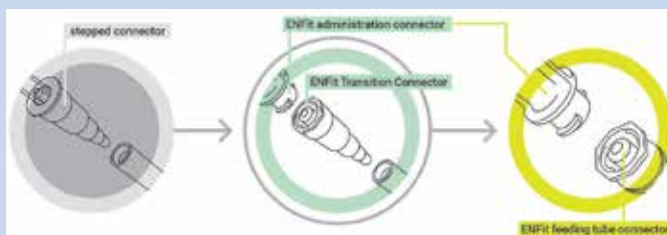
To prevent misconnections from repeatedly happening, the medical device community is standardizing several small-bore connector designs under ISO 80369. ISO 80369-3 covers enteral (tube feeding) connectors. FDA recognized this standard in 2016. Medical device manufacturers started to make enteral devices such as feeding tubes with connectors that conform with ISO 80369-3 around the same time. A popular design that follows this standard is known as ENFit®.

With ENFit, the connectors on feeding tubes have been redesigned with their orientation changing from a female to a male port. (See figure 1, below.)

Similarly, enteral syringes have undergone redesign in order to offer an ENFit-compatible option. In an ENFit syringe, the orientation is reversed also, from male to female tip (see example in figure 2, below).

Concerns have been raised regarding dosing inaccuracies with the standard ENFit syringe design, especially for low-dose syringes (less than 6 ml), which are more commonly used in pediatric populations. These concerns led major manufacturers to create a newly designed

Figure 1. Legacy and ENFit connectors

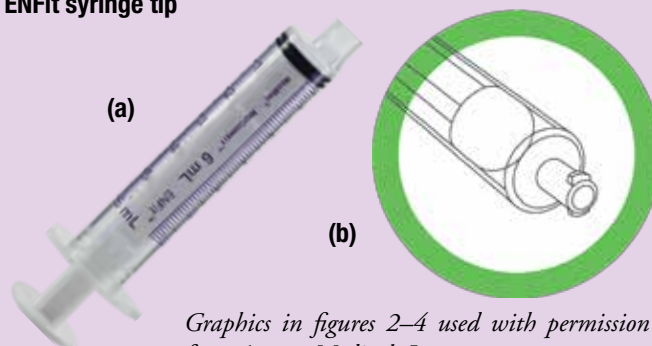


Legacy Feeding Tube
Legacy connectors have a stepped or Christmas tree end that plugs into legacy feeding tubes.

Transition Adaptor
The transition adaptor has an ENFit connector on one end and a stepped connector on the other. This allows an item with an ENFit connector to fit with an item with a legacy connector.

ENFit Feeding Tube
When there is an ENFit connector on both the feeding tube and the administration set, a transition connector is not needed. The ENFit connector will twist and lock into place.

Figure 2. (a) A standard ENFit syringe; (b) illustration of a standard ENFit syringe tip

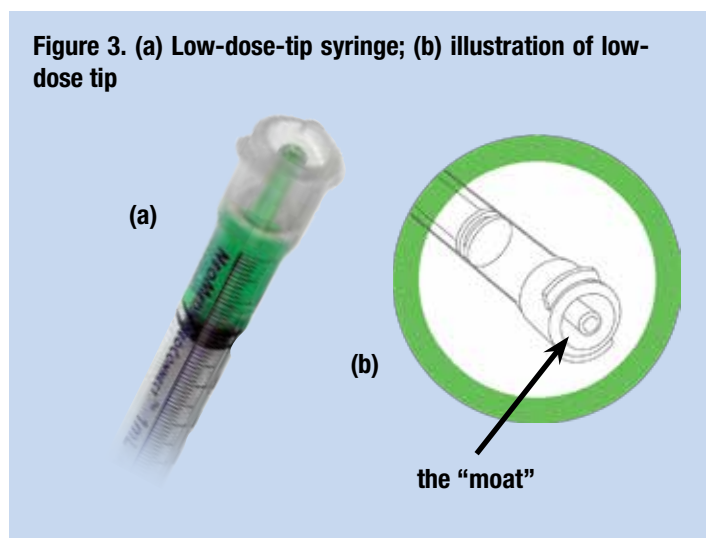


Graphics in figures 2–4 used with permission from Avanos Medical, Inc.

low-dose ENFit syringe, referred to as the low-dose-tip (LDT) syringe. (See example in figure 3, below, and in illustration on page 1.)

Research on Dosing Errors

The FDA recently conducted a virtual evaluation of dosing errors in 0.5 and 1.0 ml legacy (traditional) syringes compared to dosing errors in ENFit LDT syringes of the same volume. This evaluation was carried out with the use of computer-aided design software; it took into account the orientation of the syringe during delivery, as well as any errors caused by spillage and flushing. The FDA found that the dosing error for the 0.5 and 1.0 ml ENFit LDT syringes and legacy syringes was the same (+/- 5%) when there was no medication in the moat area of the LDT syringe. When medication was present in the moat area and the syringes were reused during flushing, the LDT syringe error could range from 1% to 18% for the 1.0 ml syringe and 28% to 35% for the 0.5 ml syringe.



While legacy syringes do not have a moat, errors in technique with legacy syringes can result in dosing errors similar to what happens with LDT syringes. The FDA noted that when the legacy syringe was also used for flushing, the dosing errors could range from -7% to 12% for the 1.0 ml syringes and -9% to 19% for the 0.5 ml syringes.

Recommendations

Based on these findings, the FDA issued the communication mentioned above (see page 1) on October 12, 2021, with recommendations for caregivers as well as healthcare providers, which has been supported by the Global Enteral Device Supplier Association (GEDSA). The FDA also sent letters to manufacturers on October 7, 2021, requesting an update of their labeling and training materials to include expanded instructions for the use of LDT syringes (see [fda.gov/media/152862/download](https://www.fda.gov/media/152862/download)).

Some of the key steps highlighted to prevent dosing errors include:

- Ensure that the syringe is free of air bubbles and the moat of the syringe is free from fluids by tapping or flicking the tip of the syringe before administering the medications.
- Use a filling adapter, such as an ENFit-compatible cap or medication straw, to prevent fluid and medications from entering the moat area of the syringe tip. (See examples in figure 4.)
- Be aware that using a medicine cup to fill an LDT syringe may cause fluid or medications to enter the moat of the syringe and lead to possible overdose.
- Use a new syringe to flush the medication or fluid after administering any medication to prevent overdose due to the dead space (remaining fluid in the tip of the syringe after administration) in the syringe.

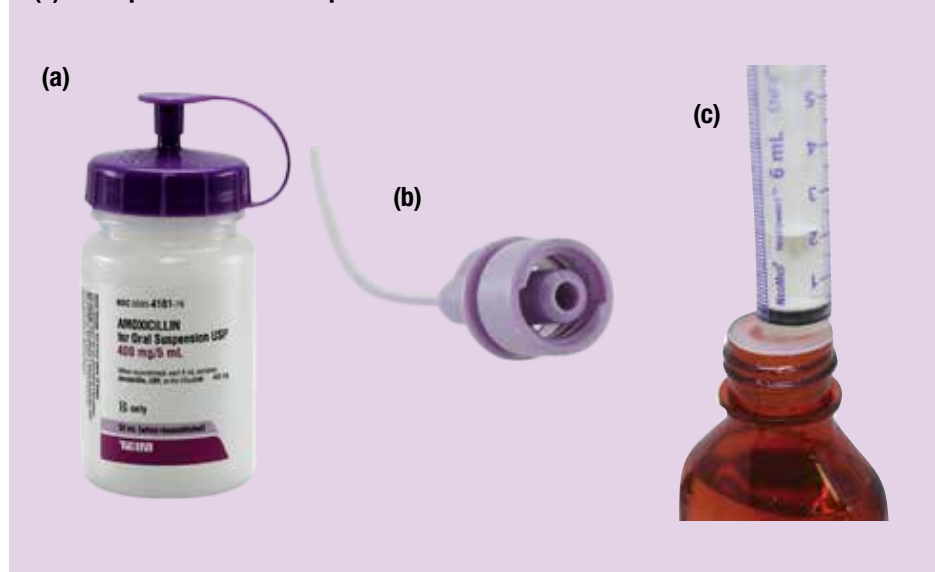
The FDA in their communication also note that if used appropriately and following the above steps, “the dose accuracy of the ENFit LDT

syringes is equivalent to the dose accuracy of traditional syringes.” Additionally, they state, “While the FDA’s analysis has identified a potential for overdose using ENFit LDT syringes, no patient injuries have been reported. In contrast, serious patient injuries and deaths have been reported due to misconnections. Therefore, the FDA continues to recommend the use of enteral devices and syringes that reduce the risk of misconnections, such as ENFit LDT syringes.”

Any problems with ENFit LDT syringes—or any other medical devices—should be reported through the FDA MedWatch Voluntary Reporting Form, at accessdata.fda.gov/scripts/medwatch. ¶

Note: The illustrations used here represent a small sampling of ENFit syringes. Products with ENFit connectors made by other manufacturers may look different from the products shown here.

Figure 4. (a) ENFit-compatible cap on a sample medication bottle; (b) ENFit straw; (c) ENFit press-in bottle adaptor



Education, from pg. 1

over-the-counter antacids to settle his stomach, he had decided to seek help through his primary care physician and find out what was causing his discomfort. Within a few days Frank had an upper endoscopy and was told there was a “malignant-appearing site” on his esophagus. We did not leave the clinic until blood work was done, along with a CT scan of his chest, abdomen, and pelvis. Another appointment was scheduled for later that week to discuss the results of the test. During this appointment, we were told he had cancer of the esophagus.

A diagnosis of cancer was NOT what he was expecting. Statistics were discussed and the decision was made to have a combination of chemotherapy and radiation at a local oncology facility. If surgery was going to happen at a later date, it was suggested that we go to a specialized hospital, since only five or so surgeries of that type had been done in our region within a year.

A week later, we were contacted by the local oncology facility and told that Frank needed to have a PET scan and an MRI to determine the stage of the cancer (stage 1–2.). His team of providers through this journey included his primary care physician, a gastroenterologist, an oncologist, a radiologist, and a variety of other radiologists whose responsibility was to insert a feeding tube (a PEG) if necessary.

The day Frank’s infusions were to begin, we attended a “chemo class” conducted by a nurse from the chemo facility. The class lasted a half day and included reviewing the contents of a well-organized notebook, which took us through the process of having infusions and addressed potential problems that might arise, including the probability of having a port and a PEG tube inserted. Initially, he was NOT going to have a port or a PEG tube installed. After the information was presented and reviewed and questions answered, the first infusion began.

Prior to us meeting the radiologist, we were shown a video, which led us through the entire radiation process. Following the video, our assigned radiologist discussed issues and answered questions. At this point, infusion and radiation began, with radiation every day for six weeks and infusion four days a week with overlapping radiation. It wasn’t long into this process that a port was installed. Shortly after, a PEG tube was installed, because he was not able to eat anything via his mouth.

Note, prior to infusions and radiation, Frank participated in dialogue with medical personnel who explained what was to come with treatment and the opportunity for questions/answers was available. This was NOT the situation he encountered with the PEG tube.

Lack of Preparation for Using A PEG Tube

Frank did not receive face-to-face information about the process of having a PEG tube or how to care for it. It was installed at a local hospital by a radiologist who spoke few words to him. After installation,

a dietitian came to the recovery room. She handed Frank paperwork that showed him how to use the tube, and then gave him the formula for his life-sustaining nutrition. There were no demonstrations on how to use the tube, no tips, no explanation that different formulas were available if problems did arise (which they did—in his case, extreme gas, wound [or stoma] care not addressed, and leakage).

The lack of education was the cause of the majority of the problems he later encountered, not counting the stress of having the diagnosis of esophageal cancer, and relying on a PEG tube for the rest of his life.

Listed below are some of the problems he encountered and some of the reasons why he encountered them:

- No demonstration on how to care for the tube, which led to leakage of stomach acid, which burned his skin and was very painful, and daily leakage, which caused embarrassment with having wet shirts in public, stress, frustration, and high level of anxiety
- Multiple PEG tube replacements due to a variety of radiologists replacing the tube (i.e., going from small tube to large tube to small tube)
- Lack of wound (or stoma) care, until a nurse mentioned that there is a special wound care center that is part of the facility
- Lack of interaction between the radiologist(s) who installed the PEG tube(s) and the oncologist, as they were associated with separate medical facilities
- None of the medical team

working with Frank had heard of the Oley Foundation, which offers a multitude of information along with the opportunity to interact with members to have specific questions answered about PEG tubes by individuals currently living with PEG tubes.

Frank stated that 95 percent of the problems he encountered with PEG tube leakage were due to the medical personnel who were treating him acting as if they had never heard of this problem. Leaking caused stomach acid burns with fear of stomach acid reaching his groin area. Changing shirts multiple times a day due to leakage caused embarrassment in public. Site irritation is another BIG problem, which we found Desitin helped. Tips from feeding tube users, such as turning the tube daily, and learning that products such as Osmolite did not come only in the variety given at the hospital, were a tremendous help.

Attempts to stop the leakage from the PEG tube have included:

- Lots and lots of gauze and tape
- Cloth “donut” that snapped (ones with buttons were not as doable)
- Sewing elastic to the cloth “donut” to secure the “donut”
- Binder clamps of various sizes (they worked as long as he did not mind a large protrusion showing through his shirts)
- “Plastic scissors” (may be called a hemostat) which serve as a clamp to prevent leakage worked best. No leakage since he started using this.



Cloth “donuts” by themselves (top) and with an elastic band (bottom).

- *Editor's Note: Some tubes come with a clamp similar to the one shown on right. Otherwise, a side load clamp can be ordered separately through online vendors and added to a feeding tube.*

Helpful Tips

Purchase a journal to keep track of phone numbers of doctors (better still, glue business cards into the journal), appointments, prescriptions, narratives of visits, weight changes, etc.

Join the Oley Foundation, at oley.org or oleyfoundation@gmail.com. Their booklet titled "Tube Feeding Troubleshooting Guide" addresses most of the problems people might face with PEG tube usage.



Order copies through the Oley store, free of charge, or print from oley.org/Troubleshoot_Guide

be reduced by learning ahead of time what to expect, it is essential. For any diagnosis, seek reliable medical associations and foundations to learn the latest information. An educated individual is a confident individual who knows what is in the future and where to get help when needed. ¶

Editor's Note: If you're an Oley Foundation member, reading this may seem like preaching to the choir. However, we too often hear of experiences similar to these that Grace outlines. Please help spread the word that there are resources out there for people on home tube feeding and IV nutrition, including the Oley Foundation and the American Society for Parenteral and Enteral Nutrition (ASPEN). For a positive experience, read the letter on page 3.

Conference, from pg. 1

Both tracks will be recorded to accommodate those with an interest in both therapies. Recordings will be available on oley.org for anyone who wants to watch—or rewatch—a presentation.

Whether you are new to a therapy or a twenty-year veteran, you won't want to miss this!

Watch your email and oley.org/Oley2022 for updates on the conference program and activities—including the Walkathon.



Side Load Tube Clamp

This booklet should be given to all radiologists who insert PEG tubes and also to anyone about to have one installed. Again, education is the key to success with PEG tubes. Through the Oley Foundation you can join an online discussion group (the Oley-Inspire forum) where many ideas are shared and questions can be asked. The Oley Foundation also has Zoom meetings and conferences.

Education is essential for someone facing a health issue. An individual needs to know what to expect and where to go for help. Frustration and stress are ongoing, and if the level can

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May 24 2022 | 1:00 p.m.–2:30 p.m. EST

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(registration coming soon!)

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To access information on upcoming and past Mini Meetings and Webinars, go to oley.org and click on "Conferences" in the blue main menu bar, then scroll down to "Community Enrichment Programs."



Expressing Thanks to Incoming and Outgoing Trustees

We'd like to introduce you to the newest members of the Oley Foundation's Board of Trustees, and to extend our thanks to those who have rotated off the board. The foundation is fortunate to have so many talented people willing to share their skills and knowledge.

New Board Members

Steve and Leah Atkinson, of Watkinsville, Georgia, have two sons. Jameson, their older son, began home IV nutrition therapy in 2001 while in high school. Leah attended Oley conferences and drew on



Steve and Leah Atkinson

the knowledge learned and connections made at Oley meetings to improve care and outcome many years ago, and she and Steve have been avid supporters of the foundation ever since. Steve retired in 2020 after forty years in the consumer goods industry. He spent thirty years with Johnson & Johnson, enjoying multiple roles in engineering, plant management, and supply chain across a variety of Johnson & Johnson companies and locations. Leah is a retired RN who focused on med-surg and geriatrics.

Lisa Epp, RDN, LD, CNSC, is an Advanced Practice dietitian at Mayo Clinic in Rochester, Minnesota, and Assistant Professor in Nutrition at Mayo College of Medicine and Science. She is a member of the American Society for Enteral and Parenteral Nutrition (ASPEN), and currently co-chairs ASPEN's enteral committee. She enjoys speaking at meetings of state and national organizations, such as ASPEN's Nutrition Science and Practice Conference, Academy of Nutrition and Dietetics Food and Nutrition Conference, and the Oley Foundation.



Lisa Epp, RDN, LD, CNSC

Vanessa Kumpf, PharmD, BCNSP, FASPEN, is a Nutrition Support Pharmacy Specialist at the Center for Human Nutrition at Vanderbilt University Medical Center, Nashville, Tennessee. Her practice focuses



Vanessa Kumpf, PharmD, BCNSP, FASPEN

on the outpatient management of adult patients with intestinal failure. Her nutrition support experience includes hospital, home infusion, and outpatient settings. Her interests include safe use of parenteral (IV) nutrition (PN), minimizing complications, and improving quality of life for home IV nutrition patients. She recently completed a term as Chair of the Specialty Council on Nutrition Support Pharmacy Practice, Board of Pharmaceutical Specialties; received ASPEN's Stanley Serlick Award for PN Safety; and was named an ASPEN fellow.

John Mahalchak earned a BS in psychology and neuroscience from Allegheny College and previously worked as a research lab coordinator at the University of Pittsburgh. John was forced to take a medical leave of absence in 2013 to undergo a total pancreatectomy with auto-islet transplant. A few years post-transplant, John was diagnosed with gastroparesis and NASH. He requires tube feeding and IV hydration. In 2017, John attended his first medical conference, and he has been pursuing patient advocacy ever since. He has been volunteering as an Oley Ambassador for several years, and also volunteers with IFFGD and NASH Knowledge. John has also helped bring the patient voice to medical conferences and events on Capitol Hill, and recently joined the Patient and Family Advisory Council for his local academic medical center. He has a passion for helping other patients learn to be effective advocates and to cope with the social and mental aspects of living with a chronic illness.



John Mahalchak

David Mercer, MD, PhD, FRCSC, FACS, is Professor of Surgery and Director of the Intestinal Rehabilitation Program at the University of Nebraska Medical Center in Omaha, Nebraska. Originally from



David Mercer, MD, PhD, FRCSC, FACS

Edmonton, Canada, he came to Nebraska to be trained as a liver and intestine transplant surgeon. He developed a love for intestinal rehabilitation during his training and it has become the main focus of his clinical career. Dr. Mercer heads a specialized program that looks after hundreds of children and adults who are dealing with complex intestinal problems. His team of dietitians, nurses, social workers, and gastroenterologists provides comprehensive nutritional, medical, and surgical management of patients ranging from simple IV nutrition and tube feed management to difficult nutritional scenarios. He is involved in all major clinical trials in the field, and lectures on the role of intestinal rehabilitation programs in getting people off of parenteral nutrition, surgical strategies in short bowel syndrome/complex intestinal problems, the role of the gut microbiome in human health, and all aspects of intestinal transplantation.

As of 2022, **Sharon Rose, RN**, has sustained herself on home IV nutrition for over fifty-three years, and she's still counting. She has raised a family and worked fulltime while on HPN. She has a vast reservoir of personal experience and knowledge, and is always willing to share these to benefit others. Sharon has retired as an RN, and feels volunteering may help fill the void left after so many years of devoting herself to her profession.



Sharon Rose, RN

Our many thanks to all of those who serve on the Oley Board of Trustees for their

willingness to give of their time and talents. To learn more about all of our Oley board members, visit oley.org/Board.

Giving Thanks

We'd like to offer our sincere thanks to Joy McVey Hugick, Manpreet Mundi, MD, and Laurie Reyen, RN. All three joined the Oley board in 2016, with Joy serving from 2016 to 2017 as Secretary, and from 2017 to 2022 as Vice President. As Joy rotates off the board, Kelly Tappenden, PhD, RD, FASPEN, will serve as Vice President. Dr. Mundi will be serving as Oley Science and Medicine Advisor (see below). Joy and Laurie have both been part of the Oley community for many years, and we are grateful both for the service they have provided and that they will continue to stay close to Oley; they have both agreed to serve on the Oley Advisory Council, and Joy will also continue to serve as an Ambassador. ¶

Changing of the Guard

In late March, Drs. Darlene Kelly and Manpreet Mundi were presented with plaques to recognize the great service they have each provided to the Oley Foundation. Dr. Kelly served six years on the Oley Board of Trustees, and more recently as Oley's Science and Medicine Advisor, a position she gracefully accepted soon after she retired from Mayo Clinic, Rochester, Minnesota. We give thanks to Dr. Kelly, and wish her well as she pursues her many interests.

Dr. Mundi was celebrated for completing six years on the Oley Board of Trustees, and was immediately welcomed to fill the position of Science and Medicine Advisor. Among his many responsibilities at Mayo Clinic, Dr. Mundi is Medical Director of Clinical Nutrition, Medical Director of the Home Enteral Nutrition Program, and Associate Program Director of the Home Parenteral and Enteral Nutrition (HPEN) Program.



**Darlene Kelly, MD, PhD, FACP, and
Manpreet Mundi, MD, FASPEN**

Bright Idea: Flavoring Helps ORS

Send your Bright Ideas to Lisa Metzger at metzgel@amc.edu.

For short bowel syndrome (SBS) patients (like me) who make their own oral rehydration solution (ORS), there is a great product for flavoring. It is a flavor packet to add. I make the plain ORS with water, salt, and sugar, and add citrus flavor. The company is TrueLemon.com and the products I use contain no sugar or substitutes. Just citrus flavor. This was helpful for me instead of Crystal Lite as it has no sweeteners included. Plain ORS formula is: 4 cups water, 2 tablespoons sugar, 1/2 teaspoon table salt, and 1–2 citrus flavor packets. (Recipe can easily be halved.)

—MaryAnn N.

Committed to improving
the lives of patients with
short bowel syndrome
and intestinal failure

INTRODUCING

STARS

A Phase III trial
of apraglutide*,
a next-generation,
long-acting GLP-2
analog

Talk to your doctor to learn
more about the STARS trial

VectivBio
Transforming Lives

*Apraglutide is an investigational agent not approved in any region.

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Thank You Corporate Partners!

Please join Oley in thanking the companies that provide unrestricted grants to support the foundation year round. Learn about our most recent corporate contributors in their own words below. For a complete list of corporate partners, go to oley.org/PartnerShowcase.

We are especially excited to welcome Med-IQ as a new partner, and to welcome Zealand Pharma to the Silver Circle Partnership level. These contributions help Oley to continue to grow services for members, and keep them free of charge!

Zealand Pharma—*Now Silver Circle*

Zealand Pharma is changing patients' lives with innovative peptide therapeutics. Patients inspire the company to provide the best possible solutions for gastrointestinal and metabolic disorders. The company is building upon twenty years of expertise in developing treatments for patients with short bowel syndrome.

Fresenius Kabi USA

Fresenius Kabi is a leading global healthcare company that focuses on pharmaceuticals and medical devices used to care for critically and chronically ill patients inside and outside the hospital. Fresenius Kabi products include intravenous specialty and generic medicines, transfusion technologies, infusion therapies, clinical nutrition, and related medical devices.

Kate Farms

Kate Farms was founded in 2011 by parents determined to save their daughter's life and is now the #1 recommended plant-based formula. Kate Farms offers medical formulas for children and adults, to be used as sole source or supplemental nutrition for oral or tube feeding.

Med-IQ—*New Partner*

Med-IQ is a leading provider of clinical, risk management, and patient education, empowering healthcare providers to continuously improve performance and patient outcomes. Med-IQ has delivered unique educational experiences and services and is proud to be one of the most award-winning accredited medical education providers in the United States. www.med-iq.com

Optum® Infusion Pharmacy

Optum® Infusion Pharmacy provides customized HPN therapy with teams of infusion pharmacists, nurses, and dietitians who are Certified Nutrition Support Clinicians. Optum offers ASPEN-based guidelines and standards, ongoing education, and patient liaison support. Together, we're making health care work better for you—so you can live a healthier life.

Real Food Blends

Real Food Blends® brings real food and nutritional variety to people with feeding tubes. Their range of meals and more are each made with five to seven real ingredients providing a variety of proteins, fruits, vegetables, grains, and fats. Enjoy the convenience of a true blenderized diet. Covered by many insurance plans.

Amerita, Inc.

Amerita, Inc. employees have been dedicated to providing patient-focused care since 2006. They write, "Our certified nutrition support team is committed to top-notch care for patients regardless of complexity. With a patient satisfaction rate of 96 %, you can expect comprehensive support to help you reach your nutritional goals."

Soleo Health

Soleo Health is an innovative national provider of complex specialty pharmacy and infusion services administered in the home or alternate sites of care. Soleo's interdisciplinary team of experienced pharmacists and registered nurses utilizes a consistent patient management process, which leads to quantifiable clinical and economic value while improving patients' experience.

Join Oley's Growing List of Corporate Partners

Find information on partner benefits, advertising, market research, and sponsorship opportunities at oley.org/IndustryLandingPage.

Notable Individual Gifts

Among the contributions we receive, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from January 13, 2022, to March 10, 2022.

Memorials: *In memory of* Bethellen; Hadar Birger-Bray; Jeff Dutton; Joyce Hydorn; Jeremiah Joseph Lynch; Malisa Matheny; Mary Patnode; Daniel Puga; Irma Jean Shniderson; Paula Southwick; Bob Sweet; John Tucker; Liz Tucker

Tributes: *In honor of* Mandy Allen; Dr. Lyn Howard; Phil Kellerman; Aidan Koncius; Jeff Nemeth; Olivia Scali

Fundraisers: Facebook Giving Tuesday campaigns by Betty Bond and Cathy Harrington

Matching Gifts: CBRE; Discover Financial; FM Global; Johnson & Johnson

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

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 by calling (518) 262-5079 or visiting oley.org/plannedgifts.

Felice Austin	The Groeber Family	Rodney Okamoto, RPh,
Jane Balint, MD	Valerie Gyurko, RN	& Paula Okamoto
John Balint, MD	Alfred Haas	Kay Oldenburg
Joan Bishop	Shirley Heller	Harold & Rose Orland
Ginger Bolinger	Alicia Hoelle	Judy Peterson, MS, RN
Pat Brown, RN, CNSN	Jeff & Rose Hoelle	Clemens Pietzner
Faye Clements, RN, BS	Lyn Howard, MD	Beverly Promisel
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David & Sheila DeKold	Darlene Kelly, MD, PhD	Doug Seidner, MD, FACC, CNSP
Dale & Martha Delano	Family of Shirley Klein	Judi Smith
Tom Diamantidis, PharmD	Jim Lacy, RN, BSN, CRNI	Steve Swensen
Gail Egan, MS, ANP	Robin Lang	Cheryl Thompson, PhD, RD, CNSC,
Selma Ehrenpreis	Joyce Madden	& Gregory A. Thompson, MD, MSc
Herb & Joy Emich	Hubert Maiden	Cathy Tokarz
Jerry Fickle	Laura Matarese, PhD, RD, LDN,	Eleanor & Walter Wilson
Don Freeman	CNSC, FADA, FASPEN	Marion & Larry Winkler
Linda Gold	Kathleen McInnes	James Wittmann
Linda Gravenstein	Michael Medwar	Patty & Darrell Woods
Deborah Groeber	Meredith Nelson	Rosaline Ann & William Wu
	Nancy Nicholson	

Oley Corporate Partners

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

TITANIUM LEVEL PARTNER (\$150,000+)

Takeda Pharmaceutical

GOLD MEDALLION PARTNER (\$50,000–\$69,999)

9 Meters Biopharma

SILVER CIRCLE PARTNERS (\$30,000–\$49,999)

Coram / CVS specialty infusion services
Nutrishare, Inc.
Zealand Pharma

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

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Baxter International Inc.
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Kate Farms
Med-IQ
Option Care Health
Optum Infusion Pharmacy
VectivBio

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B. Braun Medical Inc.
Nestlé Health Science

PATRON LEVEL PARTNERS (\$5,000–\$9,999)

Amerita, Inc.
Applied Medical Technology, Inc.
MOOG Medical
Real Food Blends
Soleo Health



Save the Dates for Oley2022!
August 16–18
Updates at [oley.org/Oley2022](https://www.oley.org/Oley2022)

2022 Oley Calendar

COVID-19 continues to leave us guessing, and to influence when and where gatherings occur. Please check oley.org or other appropriate websites for the most up-to-date information on the events listed below.

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship. Note: *scholarships will be honored at a later date in the event of a coronavirus complication (i.e., camp closures, COVID-19 illness, self or mandatory quarantines, etc.).*

May 5: Oley Kidz Klub* (virtual)

May 5 (and then the first Thursday of every month): Nutrition Group
4 All Feeding Tube/TPN Support Group*. Meetings will be virtual
until otherwise indicated.

May 9 (and then the first Monday of every month): Young adult (ages 18–35) support group* (virtual)

May 12: Oley Tube Feeding/TPN Virtual Support Group for Patients and Caregivers* (virtual)

May 24: Oley webinar on Discussing Your Options, Including Clinical Trials with Your Care Team

August 16–18: Oley2022 Virtual Conference

September 16: Oley Mini Meeting

October 10–14: HPN (Home Parenteral Nutrition) Awareness Week

**For more information on support group meetings go to oley.org/SupportGroups; for Kidz Klub, email marywootten.oley@gmail.com; for other meetings email harrinc@amc.edu or call (518) 262-5079.*

Additional Meetings of Interest

May 21–24: Digestive Disease Week (DDW) conference, San Diego, CA

June 4–17: Infusion Nurses Society (INS) conference, Orlando, FL

June 8-11: United Mitochondrial Disease Foundation (UMDF)
Mitochondrial Medicine Symposium, Phoenix, AZ

June 14–16: American Society for Nutrition conference (virtual)

September 29–October 1: Pediatric Intestinal Failure Symposium,
Ontario, Canada

September 30–October 3: Association for Vascular Access (AVA), Minneapolis, MN