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# LifelineLetter

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

## Newly Formulated Multi-Trace Element Injection

Vanessa J. Kumpf, PharmD, BCNSP, FASPEN, Clinical Pharmacy Specialist, Vanderbilt University Medical Center

In July 2020, the U.S. Food and Drug Administration (FDA) approved a new multi-trace element injection formulation, Tralement™. In October 2020, American Regent announced its availability for use. Tralement is designed to meet daily trace element requirements as recommended by the American Society for Parenteral and Enteral Nutrition (ASPEN) and is indicated in adult and pediatric (weighing at least 10 kg) patients requiring parenteral nutrition.

This new product contains zinc 3 mg, copper 0.3 mg, manganese 55 mcg, and selenium 60 mcg per mL. Compared to the current combination trace element product used in adults (Multitrac®-5 Concentrate), Tralement is lower in zinc, lower in copper, much lower in manganese, and provides no chromium. Compared to the current combination trace element product used in pediatrics (Multitrac®-4 Pediatric), Tralement provides selenium (not found in

Multitrac®-4 Pediatric) and does not provide chromium. It provides equivalent doses of zinc, copper, and manganese when using weight-based dosing. Of note, chromium is not considered an essential component of a multi-trace element formulation.

### What This Means for HPN Consumers

1. If you are receiving Multitrac®-5 Concentration, it will be replaced with Tralement. Multitrac®-5 Concentrate is being phased out and supply will no longer be available. Overall, the new product is good news for home nutrition support (HPN) consumers because it better meets trace element requirements with less risk of toxicity.

2. If you are receiving individual trace element components (i.e., zinc, copper, selenium) added to your PN, you may be able to switch to Tralement. Tralement

may provide a safe and effective option to meet trace

**Multi-Trace Element Injection, cont. pg. 10** ➤



Tralement™ multi-trace element injection

## On Your Behalf

Lisa Crosby Metzger

In terms of advocacy (and really, all around), 2020 was a busy year for the Oley Foundation. We advocated on your behalf on several issues, as noted below, and asked



you to advocate for yourself on several of them as well. As with all of our programs, our primary focus in legislative and regulatory issues is on those that directly affect the use of home parenteral (IV) and enteral (tube feeding) nutrition. This year, especially, though, we have also been focused on patient access to medication and medical care more generally.

**Your voice and your story are what carry the day** with both legislators and regulators. Please share your experiences with us regarding any of the issues below, many of which are ongoing, and regarding new issues as they emerge in the coming year. In the past, Oley members have spoken before the FDA and other agencies, and your stories have been presented to legislators and others—sometimes by you personally, sometimes by Oley staff and volunteers. You can contact us at any time at (518) 262-5079 or metzgel@amc.edu and bishopj@amc.edu.

**On Your Behalf, cont. pg. 6** ➤



Carol has had a feeding tube since after her stroke.

## Unexpected Blessings

Carol Falk

My grandmother used to say that sometimes God would make you lie down to look up. I am very grateful that he did just that to me. I have met some incredible people along the way, and I have learned some valuable lessons about myself that I would not have learned had he not gotten my attention.

### An Aneurism

My lying down came when I had a brain aneurism, which led to a stroke. I spent one year in five different

**Unexpected Blessings, cont. pg. 12** ➤

## 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 24,000+ 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

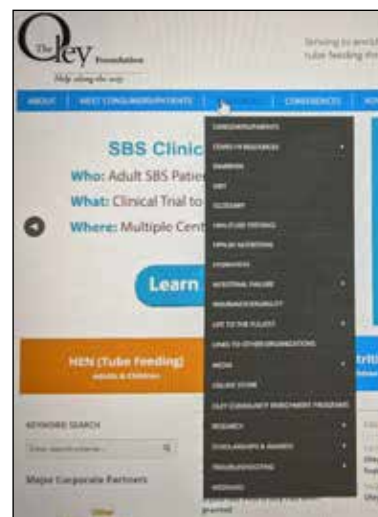
- *LifelineLetter*
- Peer to Peer Support
- Conferences and Webinars
- Resources to Promote Living Well on Tube Feeding and IV Nutrition
- Equipment Supply Exchange
- Advocacy and Awareness

## Resource Spotlight:

The Oley Foundation website contains a wealth of information. In particular, the “Resources” tab is a goldmine. On the Resources menu, you will find our ever-evolving glossary; a landing page with a long list of other organizations—from medical air lift services to insurance resources to disease-specific websites, and more—that we think are helpful, with links; landing pages for specific topics, such as COVID-19, diarrhea, diet, hydration, intestinal failure, insurance, and more; an item called “Life to the Fullest,” where we provide information on things like swimming and traveling with HPEN, products to help make your life with HPEN more manageable, and stories about other Oley members; information about research in HPEN and related fields, including a list of studies currently accepting participants; troubleshooting aids; and a landing page where all of our webinars are listed, both those to come, and those that have passed (with links to recordings). Explore and enjoy!

## How to Support Oley

Donations are tax deductible and are accepted at [www.oley.org/donations](http://www.oley.org/donations) or at the street address on left.



# Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to [metzgel@amc.edu](mailto: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 Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



## O-ring Syringes

We recently received the following email from an Oley member asking us to call attention to an older “Tube Talk” tip that she found invaluable. Below, Marla’s email and the tip from LifelineLetter (July/August 2012).

Please figure out a way to let more people know about the o-ring syringes. They are a miracle. I would bet if you took ten or even one hundred people who had been using the ordinary syringes for a little while and asked them to try the o-ring ones, they would feel it saved them from insanity. The only place that I found any information about them is the one post on your site [see below]. I was feeding myself outside because of the mess until I got the great o-ring syringes. I don’t know how to let people know, but I feel you do. You just need to know how much of a difference it makes.

—Marla S.

## “Tube Talk” tip, from LifelineLetter (July/August 2012) and online at [www.oley.org/O\\_Ring\\_Syringes](http://www.oley.org/O_Ring_Syringes)

I used to have a love/hate relationship with the 60 ml syringes provided by my home health care company. I was constantly battling the rubber tips. I washed them. I oiled them. I sprayed them. But no matter what, they performed like a city taxi driver: abrupt stops and abrupt starts. Not only that, you must have super-human strength to get them going. I loved them because my son couldn’t live without them.

But now, it’s nothing but love! I discovered silicone o-ring syringes over the Internet. Prices vary considerably and there are many types. I like the 60 ml catheter tip and the 60 ml slip tip syringes. The slip tip will fit right into a low-profile feeding tube device. Instead of a rubber stopper on the plunger like ordinary medical syringes, the plunger is solid plastic with a silicone o-ring around it to make the seal. The silicone does not degrade with washing and use like rubber does. It remains always easy to push. Their tip is a little more narrowly tapered and sits better in the extension tube.

The most economical place I have found for these syringes is a squirrel feeding supply company! Go to Squirrels and More, [www.squirrelsandmore.com](http://www.squirrelsandmore.com), and search for “60 cc oring catheters.” I have used the same syringe for four months now. I am very pleased with the purchase. They have saved my wrists and my sanity!

—Susan

## Editor’s Notes:

- Remember that the “Tube Talk” tip above is from 2012, and some of the information may be dated.
- The Squirrels and More website says syringes are for “veterinary use only.” Further, they note, “the ink on the syringes will not stay on with multiple cleanings. After inquiring about

this issue,” they continue, “it has come to our attention that the ink has been changed due to toxicity of the prior inks used on o-ring syringes. Our o-ring syringes will outlast most other syringes that are available. All of our o-ring syringes are a product of Denmark, they are BPA free and sterile.”

- In regard to the problem with the ink wearing off, we have had members suggest using clear nail polish over the numbers to preserve them.
- ENFit® o-ring syringes are available from several sources online, without a prescription.

Sample o-ring syringes, cath tip and ENFit connector



## Update on Cardinal Tube Feeding Administration Set Supply

In mid-November, Cardinal Health provided the following updates on the situation with their supply of Kangaroo™ ePump and Joey enteral feeding pump sets, and announced the launch of a website dedicated to providing information on the shortages. Visit [www.cardinalhealth.com/byyourside](http://www.cardinalhealth.com/byyourside) for more information and updates.

## Impacts of COVID-19

Cardinal notes that COVID-19 has created increased demand for pump sets, because of an increase of intubated patients. Initially, COVID-19 also caused a decrease in production volume as staffing was reduced, due to both the pandemic itself and government mandates related to social distancing. Cardinal notes that since June 2020, staffing has steadily improved, with a resulting increase in pump set production.

Cardinal reports that in September, production levels were stabilized to 100 percent of pre-COVID-19 volumes. In October, Cardinal activated new machinery and produced the highest volume of pump sets yet, exceeding pre-COVID-19 production rates.

## The Future

Beginning in November, Cardinal anticipates a monthly increase in production. By February 2021, they anticipate monthly production quantities to exceed monthly demand for the highest volume items.

They note that these recovery dates are estimates only and are affected by changes in demand.



# Nominate Someone Who Inspires You!

The five awards Oley will present in 2021 recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone today at [www.oley.org/nominations](http://www.oley.org/nominations). Alternatively, you can use the form below as a guide and submit nomination(s) by email or US mail. Nominations must be received by **March 24, 2021**. Please notify the person that you are nominating them for the award.

*Awards will be presented during the conference, to be held virtually, in summer 2021. Winners will receive a \$750 grant to attend the next in-person meeting, and will be spotlighted in the LifelineLetter. Recognition is given to all nominees.*

## The Awards and Criteria

### Innovator/Advocator Award

*Sponsored by Avanos*

- Current home enteral nutrition (HEN) consumer or caregiver for one year or longer, **OR** Current home parenteral nutrition (HPN) consumer or caregiver for one year or longer
- Any age
- Sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care

### LifelineLetter Award, HPN

*Sponsored by Nutrishare, Inc.*

- Current home parenteral nutrition (HPN) consumer or caregiver for one year or longer
- 19 years of age or older
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN

### LifelineLetter Award, HEN

*Sponsored by Nestlé Health Science*

- Current home enteral nutrition (HEN) consumer or caregiver for one year or longer
- 19 years of age or older
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN

### Child of the Year Award

*Sponsored by Abbott*

- Current home enteral nutrition (HEN) consumer for one year or longer, **OR** Current home parenteral nutrition (HPN) consumer for one year or longer
- 18 years of age or younger
- Shows a positive attitude in dealing with illness and therapy which encourages and inspires others

### Celebration of Life Award

- Current home enteral nutrition (HEN) consumer for three years or longer, **OR** Current home parenteral nutrition (HPN) consumer for three years or longer
- Any age
- Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.

**HEN = home enteral nutrition = tube feeding**

**HPN = home parenteral nutrition = IV nutrition, TPN**

## 2021 Oley Award Nomination

### 1. Provide the following information:

I am pleased to nominate the following individual for the:

- ☐ Innovator/Advocator Award
- ☐ LifelineLetter Award, HPN
- ☐ LifelineLetter Award, HEN
- ☐ Child of the Year Award
- ☐ Celebration of Life Award

Nominee's name: \_\_\_\_\_

Age: \_\_\_\_\_ Daytime Phone: ( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

E-mail: \_\_\_\_\_ @ \_\_\_\_\_

Primary diagnosis: \_\_\_\_\_

Number of years on HEN (enteral, tube feeding) \_\_\_\_\_ and/or

Number of years on HPN (parenteral, IV nutrition) \_\_\_\_\_

☐ I've notified this person that I am nominating them for an award.

Your name: \_\_\_\_\_

Daytime Phone: ( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

E-mail: \_\_\_\_\_ @ \_\_\_\_\_

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

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

### 3. Submit nomination by March 24 to:

The Oley Foundation  
Albany Medical Center, MC-28  
99 Delaware Avenue  
Delmar, NY 12054

Fax (518) 262-5528

E-mail [andreaguidi.oley@gmail.com](mailto:andreaguidi.oley@gmail.com)

**Questions? Call (518) 262-5079**

## Noble Memorial Scholarship

In 2007, the Noble family established the Kyle R. Noble Scholarship to further the educational goals of individuals relying on home parenteral and/or enteral nutrition for their primary nutritional needs. Each academic year, a \$2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered.

### Applicant Should Submit:

1. Cover letter with name, address, daytime phone, email address, age, diagnosis, HPN and/or HEN, and years on therapy.
2. A one- to three-page essay wherein the applicant describes how he or she has overcome obstacles/challenges posed by HPEN and inspired others to live life to the fullest.
3. A letter from an advisor or teacher supporting applicant's educational pursuits.
4. A letter from a clinician or homecare company reflecting the applicant's need for HPEN.
5. Applicants must submit their transcripts at the end of the semester of study in order to receive the second half of the scholarship amount.

**Deadline is March 24, 2021.** Details and application online at [www.oley.org](http://www.oley.org) or call the Oley Foundation at (518) 262-5079.

## Apply for HPN Research Prize: \$7,500 in Awards!

The Oley Foundation encourages researchers to apply for an HPN Research Prize. Oley will award \$2,500 prizes to each of the three clinical research papers best aligned with the foundation's mission to enhance the lives of HPN patients, and that generate interest among HPN patients and improve their well-being.



A portion of each prize (\$1,000) will be designated to cover the researcher's time for preparing a presentation about their research and sharing it at the Oley Foundation's annual conference (which will be virtual in 2021). We are grateful to Nutrishare, Inc., for sponsoring the prizes.

To apply, researchers must submit their abstracts to the Oley Foundation by **March 24, 2021**. The abstract must have been accepted for poster or oral presentation, or publication by a respected, relevant professional association such as ASPEN, ESPEN, INS, AGA, etc. between July 2020 and March 2021.

For additional details and application go to [www.oley.org/HPN\\_ResearchPrize](http://www.oley.org/HPN_ResearchPrize). Questions? Email the prize coordinator at [andreaguidi.oley@gmail.com](mailto:andreaguidi.oley@gmail.com), or call Andrea at (508) 460-1707 or the Oley office at (518) 262-5079.

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

\*Not yet approved in any country.

Talk to your doctor to learn  
more about the STARS trial

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## On Your Behalf, from pg. 1

Here are some of the things the Oley Foundation did in 2020 on your behalf, though note that we have been involved with many of these issues and all of the groups listed for many years. More information on all of these can be found at [www.oley.org/legislation](http://www.oley.org/legislation) or obtained by contacting us.

This year, the Oley Foundation has:

- **Continued supporting initiatives to make changes to Medicare coverage guidelines for home parenteral (IV) and enteral nutrition** (tube feeding) (HPEN) that date back to 1984. When changes were announced in late 2020, they were to take effect very quickly and they raised some concerns. The Oley Foundation sent a request to the Centers for Medicare and Medicaid Services (CMS) asking that the new regulations be delayed until these concerns could be addressed, and for a six-month moratorium on discontinuing HPEN for people already on the therapy, to give clinicians time to better understand the new rules. *Watch for updates on this issue.*
- Formally **supported creation of unique ICD-10-CM codes for short bowel syndrome (SBS) and intestinal failure (IF)** for

use in the United States. ICD-10-CM stands for “International Classification of Diseases, Clinical Modifications,” and these codes are used to identify medical diagnoses. Also, importantly, they are needed for insurance reimbursement. ICD-10-CM codes for SBS and IF would help health care professionals, researchers, and others better understand SBS and IF, which could lead to improved care. Changes to the ICD-10 code set will be announced in spring 2021. *Watch your email, [www.oley.org](http://www.oley.org), and this newsletter for updates on this issue.*

- **Issued a call to action** by email and social media **for Oley members to provide comments regarding their experiences with telehealth** to the CMS as it considered changes to its policies (September 2020).
- **Solicited member stories regarding IV ethanol locks**, and shared these stories with the FDA, asking the FDA to consider suitable alternatives, if ethanol locks continue to be unavailable to many home parenteral nutrition consumers (March 2020). *This is ongoing. We continue to share these stories, and communicate with FDA regularly regarding the patient experience.* Contact us at [metzgel@amc.edu](mailto:metzgel@amc.edu) and [bishopj@amc.edu](mailto:bishopj@amc.edu) or (518) 262-5079.
- **Solicited member stories regarding IV selenium and issued a communication to American Regent regarding price and stability** (November 2019). One outcome was being invited to and participating in a stakeholders’ meeting (February 2020). Price increases for and subsequent problems in obtaining IV selenium and ethanol are related to the U.S. Food and Drug Administration (FDA) Unapproved Drug Initiative (UDI). *See below and left for update on IV selenium and the UDI, and page 7 for a call to action regarding the UDI (for patients, healthcare providers, industry, and other stakeholders).*
- Issued a call to action by email **asking members to provide comments to the FDA on a Memorandum of Understanding (MOU)** regarding the compounding of solutions (including parenteral nutrition) and

### \*Update on FDA Unapproved Drug Initiative:

In late November, the U.S. Department of Health and Human Services (HHS) announced termination of the FDA’s Unapproved Drug Initiative (UDI). Based on guidance issued in 2006 and 2011, the FDA had started the UDI to reduce the number of unapproved drugs on the market. The UDI granted the first company to obtain approval of a previously unapproved drug (IV selenium, for example) a period of market exclusivity (where their product was the only one of its kind available) before other companies could obtain approval for the product.

According to the Federal Register, HHS is withdrawing the 2006 and 2011 guidances for several evidence-based reasons. One reason is that after the UDI began, reports emerged that patients were paying significantly more for prescription drugs approved through the UDI than they had paid previously—as has been the case with IV selenium and ethanol.

To quote the Federal Register further, “In 2017, scholars from the Yale School of Medicine and the University of Utah published a peer-reviewed study corroborating the previous reports....The study also linked the UDI to drug shortages, which the authors defined as ‘a supply issue that affects how a pharmacy prepares or dispenses a drug product that influences patient care when prescribers must use an alternative agent.’... Finally, the authors considered whether the UDI generated new clinical data evidence for older drugs. The authors found that, of the nineteen drugs that obtained FDA approval during the study period, only two were supported by ‘new clinical trial evidence.’ The other seventeen drugs ‘were supported by literature reviews and bioequivalence to older drug products.’ Therefore, the Department has concluded that while the UDI began with laudable goals, it has had numerous negative, unintended consequences on Americans’ access to prescription drugs and generated very limited benefits.”

### \*Update on IV Selenium:

In the September/October 2019 issue of this newsletter, we reported on the (then) newly formulated and FDA-approved intravenous selenium product, Selenious Acid Injection, USP for Parenteral Nutrition (American Regent). At that time, the Oley Foundation and the American Society for Parenteral and Enteral Nutrition (ASPEN) were asking American Regent to clarify the stability of the new product, to make it clear whether the product could be added to the parenteral nutrition (PN) by the pharmacy, or if it needed to be added separately, just before use.

American Regent recently announced an updated package insert for Selenious Acid Injection. The updated information includes the following extended stability information: the admixture should be stored under refrigeration from 2°C to 8°C (36°F to 46°F) and limited to a period of time no longer than 9 days. This extended stability (9 days) will allow home infusion pharmacies to continue to add selenium in the clean room during the compounding process.

the distribution of those solutions across state lines (June 2020). This MOU could have a large impact on many home parenteral nutrition consumers. *This issue is ongoing. Watch your email, [www.oley.org](http://www.oley.org), and the newsletter for updates as they become available.*

- **Participated in two public policy forums held by the Digestive Disease National Coalition (DDNC)**, of which Oley is a board member, and on a panel to review a DDNC white paper entitled, “Patient Access to Care and Treatments in the Cost-Shifting Era: Preserving the Patient-Provider Decision-Making Relationship.” The paper explains some of the ways the cost of medications and treatment are shifted back to the patient, including step therapy, quantity limits, medication tiers, non-medical switching for drug treatments and medical supplies, prior authorization, and co-pay accumulator programs). (See [www.oley.org/Resources/Glossary](http://www.oley.org/Resources/Glossary) for brief explanations of these terms.) In March, just before travel advisories were issued, Oley staff and several members participated in the DDNC Spring Public Policy Forum, attending a workshop on Sunday and visiting congressional offices on Monday, and in November, staff and members participated in the virtual Fall Forum. The focus was on patient access, drug shortages, *Medical Nutrition Equity Act*, and *Safe Step Act* (see below). *These efforts are ongoing. Watch your email, [www.oley.org](http://www.oley.org), and this newsletter for updates.*
- **Advocated in support of the *Medical Nutrition Equity Act* (S.3657/H.R.2501)**, as part of the Patients and Providers for Medical Nutrition Equity Coalition. This bill expands coverage under Medicare, Medicaid, other specified federal health-care programs, and private health insurance to include foods, vitamins, and individual amino acids that are medically necessary for the management of certain digestive and metabolic disorders and conditions, including enteral nutrition (tube feeding formula). *This issue is ongoing. Watch your email, [www.oley.org](http://www.oley.org), and this newsletter for calls to action.*
- **Represented Oley members’ needs and circumstances to the Transportation Security Authority (TSA)** as part of their Disability Coalition. *Watch for updates on the TSA in an upcoming issue of the newsletter.*
- **Represented the patient voice as a member-at-large on the board of directors of the National Board of Nutrition Support Clinicians (NBNSC)**, which administers the Certified Nutrition Support Clinician (CNSC) certification for physicians, dietitians, pharmacists, physician assistants, nurse practitioners, and nurses. The CNSC credential is the most widely accepted, visible nutrition support certification, and is recognized nationally and internationally.
- **Advocated for passage of the *Safe Step Act* (S.2546/H.R.2279)**, which requires a group insurance plan to establish an exception to a medication step-therapy protocol in specified cases. “Step therapy” refers to a specific sequence in which prescription drugs will be covered by insurance. The bill also requires a group insurance plan to implement and make easily available a clear process for an individual to request an exception to the protocol. *This effort is ongoing. Watch for calls to action on this issue.*

On Your Behalf, cont. pg. 14 ➤



## Call to Action: Request for Information about Pre-1938 Grandfathered and GRASE Drugs

From the Federal Register: “When Congress enacted the FD&C [Food, Drug and Cosmetic] Act in 1938 and later amended the Act in 1962, it exempted certain drugs from the FDA approval requirement. [It]...excludes from the definition of ‘new drug’ certain drugs marketed prior to June 25, 1938 and drugs generally recognized as safe and effective, or GRASE. ... In a 1980 version of the Orange Book, FDA stated that ‘[t]he law also permits drugs to be legally marketed without such fully approved applications under certain circumstances,’ including ‘drugs marketed prior to 1938 that are not subject to the pre-market clearance procedures of the law’ and ‘drug products marketed between 1938 and 1962 that were approved for safety but not effectiveness.’... The agency went on to identify specific products, noting ‘commonly used large volume intravenous products are not included on the List [of FDA-approved drugs] (e.g., dextrose 5% with water, dextrose 10% with water, sodium chloride 0.9% injection),’ since ‘all of these drug products came on the market in glass containers before 1938 and have not been required to obtain an approved new drug application as a condition of marketing.’”

### Request for Information

Currently, the Department of Health and Human Services (HHS) is reviewing whether certain drugs might qualify as exempt from the FDA approval requirement. To aid that effort, *HHS asks patients, health care providers, industry, and other stakeholders to provide information on any of the topics below:*

1. Lists of drugs marketed prior to June 25, 1938, that are currently available on the market.
2. The extent to which drugs marketed prior to June 25, 1938, or drugs that might qualify as GRASE, have regulatory approvals in countries outside the United States.
3. Whether there would be adverse clinical or economic consequences to deeming as GRASE those drugs previously approved by the FDA for which patent and regulatory exclusivity have expired.
4. Any published literature reviews or clinical studies related to any drugs potentially exempt from the new drug approval requirement.

Responses must be submitted electronically, and should be addressed to [Import@hhs.gov](mailto:Import@hhs.gov). In the subject line of the email message, submissions should include “GRASE RFI Response.” For further information contact [import@hhs.gov](mailto:import@hhs.gov).



## LIFT-ECHO Intestinal Failure Videos Available

Recognizing that many patients don't have access to medical teams with extensive experience in intestinal failure, Dr. Kishore Iyer, Mount Sinai Hospital, New York, New York, launched the Learn Intestinal Failure Tele-ECHO clinic (LIFT-ECHO) in spring 2019. As described on the LIFT-ECHO website, it "is an online community of medical professionals dedicated to supporting the treatment and management of patients with intestinal failure. LIFT-ECHO utilizes the ECHO® model, which links specialist teams at academic 'hubs' with primary care clinicians or other non-specialists in local communities (the 'spokes' of the model)." (See more about ECHO on page 11.)

Hubs and spokes meet twice a month during scheduled web-based HIPAA-compliant teleECHO clinics. Non-specialist clinicians are invited to present patient cases to the specialist teams and each other, "discuss developments relating to their patients and together determine the best course of treatment." There is no cost to participating clinicians. If you are a patient with intestinal failure and you think your clinician would be interested in learning more or presenting a case, send them to [www.liftecho.org](http://www.liftecho.org). The more your clinician knows about intestinal failure, the better it is for you!

After the case presentation and discussion, there is a 15- to 20-minute didactic lecture by an expert on a topic related to intestinal failure. While the LIFT-ECHO clinics are not open to patients, these lectures are available to everyone, free of cost, on the LIFT-ECHO website, [www.liftecho.org/web/resources/didactics-archive](http://www.liftecho.org/web/resources/didactics-archive). They include (from newest to oldest):

- *Clinical Significance of Pathological Small Bowel Dilatation*, Mikko Pakarinen, MD
- *Management of Adult Patients with Severe Chronic Small Intestinal Dysmotility*, Jeremy Nightingale, MD
- *Diagnosis and Management of Pseudo-Obstruction and Functional Intestinal Failure in Children*, Nikhil Thapar, MD
- *Overview of Intestinal Failure*, Kishore Iyer, MD

- *Establishing a National Intestinal Failure Service: Lessons from New Zealand*, Helen Evans, MD, and Amin Roberts, MD (Hosts of CIRTA 2021)
- *Enteral Autonomy and Survival in Pediatric Intestinal Failure*, Biren Modi, MD
- *Role of Interventional Radiology in Intestinal Failure*, Rahul Patel, MD
- *Experience with the Acute Intestinal Stroke Unit in Paris*, Olivier Corcos, MD
- *Predicting Enteral Autonomy in Pediatric Intestinal Failure*, Paul Wales, MD
- *Intestinal Failure: Lessons from Latin America (Part 2)*, Gabriel Gondolessi, MD
- *Managing Type 2 Intestinal Failure: The SNAP Approach*, Simon Lal, MD
- *State of Pediatric Intestinal Failure in 2020*, Valeria Cohran, MD
- *Intestinal Failure: Lessons from Latin America*, Gabriel Gondolessi, MD
- *Quality of Life in Home Parenteral Nutrition and Short Bowel Syndrome*, Marion Winkler, RD, PhD, FASPEN
- *Principles of Intestinal Failure Management: The Patient with High Stoma Output*, Jeremy Nightingale, MD
- *Nutritional Rehabilitation: How Do We Wean Parenteral Nutrition?* Carol Parrish, MS, RDN
- *Educating the Patient and Caregiver for Transitioning to Home Parenteral Nutrition (HPN)*, Dejan Micic, MD
- *Transitioning the PN Patient to the Home and Monitoring PN in the Home Setting*, Vanessa Kumpf, PharmD
- *Who Needs Parenteral Nutrition and When?* Carol Semrad, MD
- *Current Status of Intestinal Transplant*, Kishore Iyer, MD
- *Growth Factors Beyond Teduglutide*, Palle Jeppesen, MD
- *Real World Experience with Teduglutide: Lessons Learned*, Francisca Joly, MD
- *Probiotics and Intestinal Adaptation*, Kelly Tappenden, PhD, RD
- *Psychosocial Challenges in IF and Transplant*, Mary Brosnan, LCSW
- *Intravenous Access and Complications of Parenteral Nutrition in Intestinal Failure Patients*, Donald Kirby, MD
- *Diagnosing and Managing Intestinal Failure Associated Liver Disease (IFALD)*, Alan Buchman, MD
- *The Value of Patient Education and Support in Intestinal Failure*, Joan Bishop, Oley Foundation
- *Indications and Outcomes for Intestinal Transplant*, Jang Moon, MD
- *Surgery for Intestinal Failure*, Antonino Morabito, MD, FRCS
- *New Growth Factors in Management of Intestinal Failure*, Lauren Schwartz, MD
- *Medical Management of Intestinal Failure*, Kelly Tappenden, PhD, RD
- *Nutritional Management of SBS/IF*, Maria Karimbakas, RD
- *Clinical and Laboratory Monitoring for Parenteral Nutrition*, Marion Winkler, PhD, RD
- *Prescribing PN 101 and Transitioning to HPN*, Vanessa Kumpf, PharmD
- *Recognizing Intestinal Failure*, Douglas Seidner, MD

### Let's Get Together!

(Virtually)

The **Nutrishare Neighborhood** is our digital platform for gathering together. We learn, craft, chat, and discuss all things HPN with friends.



**Nutrishare**  
1 800 HOME TPN

Join in! We welcome all HPN consumers and caregivers



## Sneak Peek at Webinars

- free of charge
- [www.oley.org/webinars](http://www.oley.org/webinars)

**March 2021** (exact date TBA), **1:00 – 2:00 pm, EST**

*Interview with Allysa Seely, Team USA paratriathlete on HPN, and her dietitian, Jacque Scaramella, MS, RD, CSSD*

**April 6, 2021, 1:00 – 2:00 pm, EST**

*Discussion with Dr. Paul Wischmeyer; Patient and Physician Perspective*

**July 13, 2021, 1:00 – 2:00 pm, EST**

*Motility Disorders Discussion with Dr. Carlo Di Lorenzo*



## Research Study for Adults with Short Bowel Syndrome

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

Glepaglutide (Zealand Pharma) is a long-lasting glucagon-like peptide-2 (GLP-2) analog with weekly dosing with a prefilled syringe.

Clinical studies are currently underway. One study is regarding glepaglutide in the treatment of short bowel syndrome (SBS) in adults (ages 18 to 90) who receive parenteral (IV) nutrition or IV hydration at least three days a week.

The study, “Efficacy and Safety Evaluation of Glepaglutide in Treatment of SBS (EASE SBS 1),” is to learn about how safe this treatment is in adults with SBS, and how effective it is at reducing their need for parenteral support (parenteral nutrition and/or IV hydration). It is a phase 3 international, multicenter trial (a list of centers is on the ClinicalTrials.gov website; see below).

Participants will be randomly assigned to one of three arms of the study. One group will receive glepaglutide injections twice weekly; a second group will receive glepaglutide injections once weekly and a placebo injection once weekly; the third group will receive placebo injections twice weekly. To avoid bias, it is a double-blind study: neither the participant nor the investigator knows which treatment the participant is receiving.

Sponsored by Zealand Pharma, these studies are being done at several centers in the United States and Canada, as well as Belgium, Denmark, France, Germany, Italy, the Netherlands, Poland, and the United Kingdom. To learn more, including criteria and study locations, visit [www.clinicaltrials.gov/ct2/show/NCT03690206](http://www.clinicaltrials.gov/ct2/show/NCT03690206). ¶

## Welcome Ambre, Our Newest Ambassador

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit [www.oley.org](http://www.oley.org) or call (518) 262-5079. Note: Ambassadors volunteer to provide peer support for HPEN 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 Ambassador!

### Ambre Minty

Ambre is a mom, advocate, and writer. She has written about her journey with chronic illness, feeding tubes, and home parenteral nutrition (HPN) on her blog, *Living with Dys*.

Ambre is passionate about body positivity, and home enteral nutrition education. She was diagnosed with gastroparesis in 2016, at just thirty years old. By 2019, she was unable to tolerate food by mouth, and became completely dependent on enteral nutrition (tube feeding). She still struggled due to intestinal motility issues, and as a result, was also placed on parenteral (IV) nutrition (HPN) in April 2020. Ambre has advocated for better education regarding both home enteral and parenteral nutrition (HPEN).

Ambre says her dedication, hope, and motivation led her to become an Oley Ambassador, and as an Ambassador, she will strive to give hope and encouragement to others on HPEN. As an Ambassador, she also hopes to work towards better education regarding HPEN.

Please reach out to Ambre with your questions or just to talk. She can be reached by mail at 5745 SW 75th St #169, Gainesville, Florida; by phone at (352) 316-7990; or by email, [ambre.minty@chronicallystrong.org](mailto:ambre.minty@chronicallystrong.org). ¶



Ambre Minty



## Multi-Trace Element Injection, from pg. 1

element requirements at a lower cost. You should discuss with your infusion provider or physician what product is best for you.

3. If your child is receiving Multitrace-4 Pediatric, it may or may not be replaced with Tralement. It will likely make sense for most pediatric consumers to utilize Tralement since it has the advantage of providing selenium. However, as of this writing, the Multitrace-4 Pediatric product will remain available. You should discuss with your infusion provider or physician what product is best for your child.

4. Tralement is not indicated for neonates or pediatric patients weighing less than 10 kg. Multitrace-4 Neonatal will remain available.

5. Has long-term stability of Tralement been tested? Tralement can be added to the PN by your infusion pharmacy and safely stored up to nine days when refrigerated. Of note, this is the first trace element product that has been tested for long-term stability. Even though the practice of adding trace elements (both combination and individual components) to the PN bags of HPN consumers has been in place for years, it has not been tested until now. This is good news for HPN consumers and reflects an appreciation by manufacturers to meet your unique needs. (See also "Update on Selenium," page 6.)

ADULT TRACE ELEMENT DOSING		
Trace Element	ASPEN Adult Standard Daily Requirement	Tralement™ per 1 mL
Zinc	3-5 mg	3 mg
Copper	0.3-0.5 mg	0.3 mg
Manganese	55 mcg	55 mcg
Selenium	60-100 mcg	60 mcg
Chromium	<1 mg	0 mcg

Chart courtesy of the manufacturer, American Regent.

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## Higher Protein in New Premixed PN Formulas

In September 2020, the U.S. Food and Drug Administration (FDA) approved new formulations of Clinimix (amino acids in dextrose) and Clinimix E (amino acids with electrolytes in dextrose and calcium; both Baxter Healthcare, Illinois) for patients requiring parenteral nutrition (PN). These are multi-chamber PN products that contain protein and dextrose with or without electrolytes in a single bag. The new formulations of Clinimix and Clinimix E provide higher doses of protein (up to 80 g/L) than previously available.

Guidelines from the Society of Critical Care Medicine (SCCM) and the American Society for Parenteral and Enteral Nutrition (ASPEN) recommend between 1.2 and 2.0 grams of protein per kilogram of body weight per day for a critically ill adult patient, and note that many patients may benefit from protein supplementation. These patients may also have other nutritional considerations, like controlling blood glucose levels and restricting fluid intake. When compared to currently available multi-chamber PN products, the higher protein formulations are designed to better meet the nutritional requirements of hospitalized patients, in general.

In addition to these new higher protein formulations intended for patients with moderate to high protein needs, Baxter will continue to provide existing formulations of Clinimix and Clinimix E for patients with lower protein needs.

Consumers of home parenteral nutrition (HPN) often have unique nutritional requirements that preclude use of these premixed multi-chamber PN products. However, these do offer the advantage of room temperature storage. Some HPN consumers have utilized multi-chamber PN bags for short-term use to accommodate periods of time when refrigeration is not available, such as during travel. For more information, you can discuss use of these products with your home infusion provider or clinician.

—adapted from a Baxter Healthcare press release



## Need a Restroom Urgently?

Many members have experienced the need to get to a toilet immediately. This can be uncomfortable when you are at a store that doesn't have a public restroom. Showing an employee the Oley Bathroom Access Card can make it easier to ask permission to use the restroom. The card reads: "I have a digestive disorder that means sometimes I need the bathroom urgently. Please allow me to use your facilities." Order your FREE card at [www.oley.org](http://www.oley.org) or by calling (518) 262-5079.





## ECHO® Receives \$50k Award

In November, Dr. Sanjeev Arora, director and founder of Project ECHO® (Extension for Community Health Outcomes), received the prestigious, \$50,000 Brock Prize in Education Innovation. This award “is built upon the belief that the most important thing we do in life is to educate the next generation. Our mission,” the Brock Prize organization writes, “is to reward ideas proven to enhance education.”

Project ECHO, the model upon which LIFT-ECHO (see page 8) is based, “uses technology to connect underserved communities with experts in their fields of interest, creating networks for knowledge sharing, mentoring, and best practices. Started in New Mexico for one disease, Hepatitis C, ECHO now has 205 partners in 28 countries addressing over 100 key problems affecting lives and livelihoods. Through Project ECHO, Arora is realizing his goal of improving the lives of 1 billion people by 2025.” Read more about Dr. Arora and the ECHO project at [www.brockprize.org/laureate/sanjeev-arora](http://www.brockprize.org/laureate/sanjeev-arora) or <https://hsc.unm.edu/echo>.



**Sanjeev Arora, MD**

## Transplant Unwrapped, A New Resource

Transplant Unwrapped is a newly formed 501(c)(3) nonprofit organization with the mission to educate clinicians, patients, caregivers, and the general public about intestinal rehabilitation and intestinal and multivisceral transplantation.



**Transplant  
UNWRAPPED**

Transplant Unwrapped has a comprehensive educational website on the topics of intestinal rehabilitation and transplant, including sections on:

- Total Parenteral Nutrition (TPN) and Short Bowel Syndrome (SBS)
- Intestinal Rehabilitation
- Steps of Intestinal Transplant for both Adults and Pediatrics
- Kids Korner, with Resources Geared Specifically for Younger Children
- Young Adults Page for Teens
- Clinicians Section for General Practitioners
- Moderated Patient and Caregiver Forum for an Online Support Groups
- Numerous Downloads including Handbooks on a Variety of Topics
- Information on Organ Donation and Allocation
- Life After Transplant
- Patient Stories and Videos
- Webinars and Q & As with Experts in the Field

They have also announced they will have a Transplant Unwrapped Ambassador Program to connect pre-transplant patients with post-transplant patients.

Check out their website at [www.transplantunwrapped.org](http://www.transplantunwrapped.org).

**Gattex**  
(teduglutide) for injection

**“It’s important to find a network  
of people who have been through this—  
people with whom you don’t have to be  
anything, but who you are.”**

PEGGY, GATTEX PATIENT

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### Unexpected Blessings, from pg. 1

facilities recovering. I was unconscious for the first five months, had last rites said over me, was paralyzed on my right side, had my head shaved three different times, and, in 2010, had a feeding tube inserted into my stomach so I could get fluids and nutrition. I have a shunt in my head and two pins. I had pneumonia several times, which left me in isolation. I would not get a bed bath for days at a time.

Eventually I was able to walk again, after repeated painful physical therapy sessions. I had occupational therapy to teach me how to hold my head up straight, to use my arms and hands, and to write and spell again. The most important of these classes was on how to apply make-up again! I also had an aide from Jamaica who showed me how to properly tie a scarf on my head to look good. I have about fifteen scarves to date, and hats as well!

At first it was exhausting just to be out of bed; my head would spin. My body had to re-acclimate to the everyday experiences. Before this, I had been diagnosed with polymyositis, a muscle disease that attacked my extremities, heart, lungs, and throat. I took chemotherapy in pill form for ten months, and became single again after thirty years of marriage. I had decided then that when you change the way you look at things, things will change. I had decided I was going to be a fighter.

#### Recovering

I was finally released to go home after the aneurism and stroke, but was only allowed to go somewhere where there would be constant supervision. I went to stay at my mother's home and began the long road to gaining back my independence. I had actually believed I would miraculously heal once I was home. I was wrong, but I did enjoy having privacy and quiet again. I had endured listening to machines beeping and sirens; interruptions throughout the night; lack of sleep; grueling physical therapy schedules; and fear, loneliness, and depression.

I had missed my dog's companionship. Her name was Sandy. She was a rescued Shar-Pei. I had had her for thirteen years before she developed a large mast tumor and I had to have her put down. I was happy I got to enjoy her a little more before it ended. I now have a much smaller dog. He is also a rescue and his name is Rudy. He is a Chiweenie and he is the best friend/companion. Being a smaller breed, he is much easier for me to handle.

A friend told me that my first day of recovery began the day I got home—not in the hospital. I did not want to believe her then, but she was right. The one thing I can tell you is that family and friends are prone to believe that you are recovered by the time you're discharged, and don't call or come to see you. You get this feeling of being abandoned or left behind. I would cry when I thought about this because I was trying so hard to regain my independence.

I live alone now with my dog Rudy and I am grateful to all of the doctors, nurses, aides, therapists, friends, and family that helped me get here. I thank God for allowing me to live and to recover to the point that I have today. I still have a feeding tube (a low-profile J-tube), but I have learned how to process food in the blender that I can use with it. I still struggle to keep my weight up, but I can eat a variety! I believe that even though you tube feed, you do not have to have a boring diet.

#### Blenderized Tube Feeding

In 2011, I started blending my own tube feeding, after one of my mother's neighbors suggested blended food would give me more energy. I simply put what I wanted in the blender and processed it until it was smooth enough to administer through my feeding tube. I started gradually and with a bland diet, so it wouldn't upset my stomach, then worked my way up. It took me about six months, but it certainly has given me more energy. I was walking better, performing my tasks better, and even sleeping better. *[Editor's Note: Please check with your healthcare provider before beginning a blenderized diet. Everyone's circumstance is unique, and what works for one person won't necessarily work for another.]*

Once I learned that I could taste, I started adapting recipes for tube feeding with taste, as well as nutritional content, in mind. For me, taste comes from reflux, one of the side effects I have from my feeding tube. How wonderful it is. I don't feel as cheated as I did before I knew this little tidbit. I can have almost anything, I just have to be patient and blend first.

I look at it like this: it is human nature to want what you cannot have and since I cannot eat food, I have a love for preparing it. I have a library of recipes that I have collected over the last few years, and I'm adapting them for tube feeding. I know that no matter who you are, you must avoid certain foods if they have

the potential of harming you, and with tube feeding it is no different. All cooks and bakers adapt recipes to their specific likings and needs, and I've discovered this can be easy and fun. As I have said, just because some of us must tube feed doesn't mean that our diet—or our lives—have to be boring.

### Holidays Ahead

I am looking forward to this holiday season. In September, there was a "Birthday Bash"; in October, Halloween. Then Thanksgiving and, next, Christmas. I absolutely love this time of year because of the baking, the crafts, and the holiday decorating. I could complain about not being able to consume and enjoy all of the different treats randomly like most others, but I choose to be gracious instead.

I try to choose joy each day, though there are days when I struggle to find something to be happy about. Occasionally, I have a small pity party, but I try to keep those to a minimum. I think to myself, what if Jesus had given up or got frustrated and stopped for awhile? Where would I be then? I can still enjoy some of the special treats, just later, instead of sooner. I think that instant gratification is way overrated.

I long to be as physically fit as I used to be, but I can still watch and laugh at the silly holiday activities and participate in the less-demanding ones. Patience and gratitude are a blessing and grace is handed down by God. I focus on what I can do instead of what I cannot. I remember to choose joy each morning as I am giving thanks to God for the upcoming day.

I would tell anyone and everyone to not take anything for granted. Have love, which will give you faith. Have faith, which will give you strength. Never give up, because the only one who suffers is you. You are a child of God. God made you and God can heal you.

Let your wishes be known to your family so they are not faced with the stress of making your decisions for you. It is the only sure way to be treated the way you want to be treated. While this seems like a depressing subject, it is really one that should be looked at with love. I encourage everyone to write everything down and keep these documents in a safe place because someday, God may make you lie down to look up.

### Final Thoughts

I want to share a final thought: Not only as you get older do your thoughts and feelings go deeper, but also once you have experienced a life-changing trauma. I know this is what has happened to me. I have become more empathetic and understanding. I can now see that a person's view of a certain situation is guided by their own past. I can only see one part of the story, but I am sure there is much more that I don't know about in every situation.

I no longer get angry that others have been ugly to me. Instead, I feel sad. I know that we will all have to answer for our own actions and wonder how they will respond. I also hope and pray that I have not done a similar thing to another in the past.

I can now look at an injury that has changed someone's life and have empathy for them, even though that same thing may not ever happen to me. I don't really know how it is to be in their shoes and I have not experienced their particular injury, so I shouldn't judge their reaction. We are not supposed to judge anyway. Is this weird or more compassionate? I think we could all stand to be more tolerant of one another. ¶ *Extracts from Carol's book, I Am Not Broken (written under her pen name Jo M), and her blog, Blending In (falkway.blogspot.com), edited and reprinted with permission of the author.*

## Blenderized Tube Feeding Videos

The American Society for Parenteral and Enteral Nutrition (ASPEN) has released a series of educational videos about blenderized tube feeding. The series is supported by Real Food Blends and is available on ASPEN's YouTube channel. See video list below.

**Blenderized Tube Feeding: Introduction** • Clinical Questions When Administering Blenderized Tube Feeding • **Blenderized Tube Feeding Makes a Comeback: Indications with Adult Enteral Patients** • Basics of Homemade Blenderized Tube Feeding Preparation • **Pediatric Blenderized Tube Feeding: An Update** • Transitioning to Blenderized Tube Feeding: Inpatient/Outpatient Settings and Insurance Coverage

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## Oley Kidz Klub Crafts

Several of our younger members have been gathering virtually for games and crafts as part of the Oley Kidz Klub. This fall Mark, pictured below, and the other kids made “Thankful Trees” out of sticks and paper leaves. They wrote something that they are thankful for, or something that makes them happy, on each leaf. Aren’t they fabulous?!



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## Thank You Corporate Partners!

Please join Oley in thanking the companies that support us year round. Learn more about our most recent corporate contributor in their own words below. For a complete list of corporate partners go to [www.oley.org/PartnerShowcase](http://www.oley.org/PartnerShowcase).

### VectivBio

VectivBio AG is a global biotechnology company developing transformational therapeutics for rare diseases. The company’s lead program is apraglutide for short bowel syndrome, with a pivotal trial expected to begin in late 2020. The company continues to advance this program while building a diverse portfolio of rare disease medicines.

### On Your Behalf, from pg. 7

- **Served as a member of PACIFHAN**, the International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition.
- **Signed the following letters of support**, jointly with other organizations:
  - » Patient community letter to Congress regarding access to charitable assistance programs (March 2020)
  - » Friends of the National Institute of Diabetes and Digestive and Kidney Diseases (FNIDDK) letter to Senate and House leaders regarding funding for NIDDK (April 2020)
  - » Patient community letter to Congress about funding for the Centers for Disease Control and Prevention (CDC) and National Institutes of Health (NIH) during the COVID-19 pandemic (April 2020)
  - » American Gastroenterological Association (AGA) letter urging NIH to continue supporting research on fecal microbiota transplantation (March 2020)
  - » Digestive Disease National Coalition (DDNC) letter to Centers for Medicare and Medicaid Services (CMS) about step therapy and other patient access issues, with a focus on COVID-19 and vulnerable populations (May 2020)
  - » Patient community letter to state governors, insurance commissioners, Medicaid directors and state Boards of Pharmacy regarding patient access, with focus on prior authorization and coverage for home infusion
  - » Patient community letter to Congress encouraging passing of the *Safe Step Act* (December 2020)
- **Elevated Awareness**
  - » Feeding Tube Awareness Week (February)
  - » HPN (Home Parenteral Nutrition) Awareness Week (October)
  - » Participated in days, weeks, or months set aside to raise awareness of things important to our members, for example: Crohn’s disease; cystic fibrosis; emergency preparedness; eosinophilic esophagitis; food allergies; gastroparesis; gastroschisis; head and neck cancer; home artificial nutrition (HAN); inflammatory bowel disease (IBD); irritable bowel syndrome (IBS); malnutrition; mental health; mitochondrial disease; muscular dystrophy; multiple sclerosis; organ donation; ostomies; rare diseases; short bowel syndrome; transplantation; and many more. ¶



## 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 September 26, 2020–November 13, 2020.*

**Memorials:** *In memory of* Dr. John A. Balint; Judge Joseph C. Bruno; Mrs. Elizabeth Gavin; Helen “Kay” Hayden; Dr. Paul Hyman; Peter Michalski, “who would have turned 15 today”; Sharon and Barry Sakowitz; Bob Wolfson

**Tributes:** *In honor of* Hadar Birger-Bray; Bettemarie Bond’s fiftieth birthday; Aidan Koncius; John Mahalchak; and with thanks for a wonderful Virtual Conference

**Matching Gifts:** Johnson & Johnson; National Grid, in recognition of an employee’s volunteer hours at the 2019 Oley annual conference

**Fundraisers:** Facebook campaigns by Hadar Birger-Bray and Tiffany Dodd (“Taking My 1st Steps as the Empowered Me”)

*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 [www.oley.org/plannedgifts](http://www.oley.org/plannedgifts).

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

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

Coram / CVS specialty infusion services

Nutrishare, Inc.

Option Care

ThriveRx

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

Avanos

Baxter International Inc.

Cardinal Health, Inc.

Fresenius Kabi USA

Kate Farms

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

Nestlé Health Science

Optum Infusion Pharmacy

Real Food Blends

Zealand Pharma

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

Applied Medical Technology, Inc.

Cook Medical

MOOG Medical

Soleo Health

VectivBio





## 2021 Oley Calendar

COVID-19 has changed how we meet and exchange information. Many of the conferences we usually list in our calendar have been rescheduled, canceled, or moved to a virtual platform. Dates and venues for events in 2021 are, in many cases, still undecided. Please check the Oley or other appropriate website for the most up-to-date information.

**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.).*

**January 4, 2021:** (and then the first Monday of every month): Young adult support group (virtual), 5:00 pm EST

**January 7, 2021:** (and then the first Thursday of every month): Philadelphia Suburbs Tube Feeding/HPN Support Group, Blue Bell, PA, more info @ [www.oley.org/SupportGroups](http://www.oley.org/SupportGroups). Meetings will be virtual until otherwise indicated.

**January 15, 2021:** Oley participating in Mito Town Hall

**January 28, 2021:** Oley Kidz Klub, 6:00 pm EST

**March 24, 2021:** Deadline for Oley Award nominations, Kyle R. Noble Scholarship applications, and Home Parenteral Nutrition Research Prize submissions

**March 2021 (exact date TBA):** Oley webinar "Interview with Alysa Seely, Team USA paratriathlete on HPN, and her dietitian, Jacque Scaramella"

**April 6, 2021:** Oley webinar "Discussion with Dr. Paul Wischmeyer; Patient and Physician Perspective"

**July 13, 2021:** Oley webinar "Motility Disorders Discussion with Dr. Carlo Di Lorenzo"

For more information, email [harrinc@amc.edu](mailto:harrinc@amc.edu) or call (518) 262-5079.

### Additional Meetings of Interest

**March 20–23, 2021:** ASPEN 2021 Nutrition Science & Practice Conference, virtual

**April 7–9, 2021:** World Congress on Vascular Access (WoCoVA), Athens, Greece

**April 19–22, 2021:** National Home Infusion Association (NHIA) conference, virtual

**May 21–23, 2021:** Digestive Disease Week, virtual

**June 30–July 3, 2021:** Congress of the Intestinal Rehabilitation and Transplant Association (CIRTA), Auckland, New Zealand

**July 10–13, 2021:** Nutrition 2021 (American Society for Nutrition conference), Boston, MA

**September 16–19, 2021:** AVA 2021, Orlando, FL