

What's Inside:

Tube Talk: Clogged
Tubes and Pill
Crushers
Page 3

Meet Our Newest
Ambassador: Miranda
Einstein
Page 4

In Memoriam: Jane
Golden
Page 4

Oley Regional
Conferences
Page 4

Remote Learning to
Benefit Patients
Page 5

HPN Awareness
Week
Page 6

Webinar: Superbugs
Page 6

Donor News
Page 11

Oley Calendar
Page 12

Your Privacy Is
Paramount
Page 12

LifelineLetter

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

Oley Glossary

Here are a few of the words we are adding to our online glossary. At www.oley.org/ResourcesGlossary, you can find an ever-growing glossary of terms related to or associated with home parenteral and enteral nutrition (HPEN), and the many medical conditions that can create a need for it. The definitions are focused on what the term means in the world of HPEN, and don't necessarily repeat the definition you would find in the dictionary (see "additive," for example). If it's a term you've seen in the newsletter or on the Oley website, we'll be adding it to the glossary. What do you think? Is there a term you think we should add? Please contact Lisa at metzgel@amc.edu.

Note: Any word or phrase that is underlined here will also be included in the glossary.

abdominal adhesions (ab-DOM-i-nul ad-HEE-zhuhnz): bands of fibrous tissue that can form; they can cause abdominal tissues and organs to stick together. Abdominal adhesions can kink, twist, pull, or compress the intestines and other organs in the abdomen, causing symptoms and complications, such as intestinal obstruction or blockage.

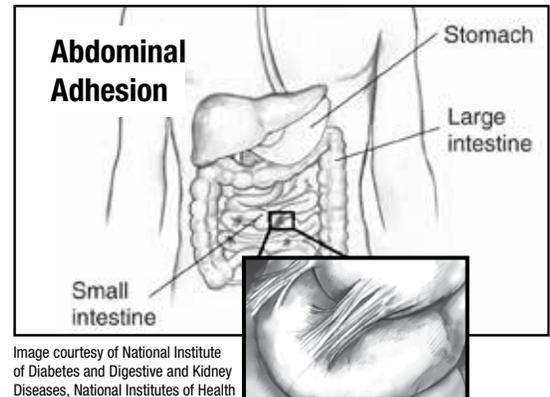


Image courtesy of National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health

abdominal wall (ab-DOM-i-nul waul): the lining of the abdomen. It consists of some bone, but mostly muscle.

absorption (ab-SORP-shun): the way nutrients are taken up by the digestive system.

additive (AD-it-iv): something that is added to a bag containing parenteral nutrition solution. Examples include vitamins and minerals.

Glossary, cont. pg. 7

Consortium Promotes Gastroparesis Research

Michael Smith

I was diagnosed with both chronic intestinal pseudo-obstruction and gastroparesis in 1987, when I was a child. This has given me a frame of reference for comparing where we were then regarding these conditions with where we are today. Now, thirty-three years later, I feel we have made hopeful progress (though at times it may not seem that way) in the fight to better diagnose, treat, and cure these and other conditions of digestive tract paralysis.

Perhaps the most important landmark in this fight was the creation of the National Institutes of Health (NIH) Gastroparesis Clinical Research Consortium (GpCRC). It is often quite difficult for private enterprises, or even private philanthropic organizations, to effectively fund entities that can perform the basic, translational (bench to bedside) research—and even certain aspects of clinical care—necessary to better diagnose, treat, and eventually cure gastroparesis and similar maladies of the neurologic function of the di-

Gastroparesis, cont. pg. 10



Rebekah celebrating becoming a registered nurse.

From Adversity to Patient Advocacy

By Rebekah Urbonya

In July 2014, I was hospitalized for two months due to severe gastroparesis and intestinal dysmotility. Despite many interventions, I had stopped tolerating tube feeds through my gastrostomy-jejunostomy (G-J) tube, which had been placed just a few months prior. I had signs and symptoms of malabsorption, was unable to eat or drink fluids at all, and had become drastically

Rebekah, cont. pg. 8

LifelineLetter

July/August 2020 • Volume XLI, No. 4

Publisher:

The Oley Foundation
Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054
(518) 262-5079, Fax: (518) 262-5528
www.oley.org

Executive Director:

Joan Bishop • bishopj@amc.edu

Editor, *LifelineLetter*; Director, Community Engagement:

Lisa Crosby Metzger • metzgel@amc.edu

Communications & Development Director:

Roslyn Dahl • dahlr@amc.edu

Administrative Assistant:

Cathy Harrington • harrinc@amc.edu

Executive Assistant:

Andrea Guidi • andreaguidi.oley@gmail.com

Program Associates:

Philip Kellerman • philkellerman.oley@gmail.com

Mary Wootten • marywootten.oley@gmail.com

Intern: Julie Andolina

Science & Medicine Advisor: Darlene Kelly, MD, PhD

Medical Director/Co-Founder: Lyn Howard, MB, FRCP, FACP

Oley Board of Trustees:

Beth Gore, PhD, MBA, *President*; Joy McVey Hugick, *Vice President*; Lillian Harvey Banchik, MD, FACS, CNSC, FASPEN, *Secretary*; James Senese, BS Pharm, MS, *Treasurer*; Rhonda Arends; Elizabeth Bond, RN; Jerry Mayer; Manpreet Mundi, MD; Laurie Reyen, RN, MN; Kelly Tappenden, PhD, RD

Oley Advisory Council:

Leah Atkinson; Jane Balint, MD; Kevin Baskin, MD; Melissa Bill; Lynda Bosworth; Alan Buchman, MD, MSPH, FACN, FACP, FACG, AGAF; Frances Culp, MA; Marcia Denenholz; Terry Edwards; Paula Foiw-Washesky, RD, LDN, MBA; Madalyn George-Thiemann, RN, CNS; Kathleen Gura, PharmD, BCNSP, FASHP, FPPAG, FASPN; Jocelyn Hill, MN, RN, CVAA(c), OCN, CRNI, VA-BC; Shirley Huang, MD; Kishore Iyer, MBBS, FRCS, FACS; Swapna Kakani; Barbara Kapuscinska Kelly, MD; Sue Koprucki; Vanessa Kumpf, PharmD, BCNSP; Jack Leabee; Laura E. Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; David F. Mercer, MD, PhD, FRCS; Russell J. Merritt, MD, PhD; Ann Michalek, MD; Jay M. Mirtallo, MS, RPh, BCNSP, FASHP; Vicki Ross, RD, PhD, CNSC; Trish Skiendziel, RD, LD, CNSC; Michael Smith; Bob and Mary Smithers; and Ezra Steiger, MD, FACS, FASPEN

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 22,000+ 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: *Hope and Harmony Hour*

This spring, to help provide relief and entertainment and to bring the community together during the pandemic, the Oley Foundation started *Hope and Harmony Hour*, a Facebook Live event where you can meet fellow Oley members and share in their talents. *Hope and Harmony Hour* is held every two weeks, on Wednesday evenings at 7:00 pm ET. Watch www.oley.org, your email, and the Oley Facebook page for updates.

You don't need to have a Facebook account to join us. Just follow the link provided in the email announcing the event, and it will bring you directly to the live video once it begins streaming. See you there!

How to Support Oley

Donations are tax deductible and are accepted at 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. 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.



Clogged Tubes*

Having a clogged or blocked tube is a common problem for tube feeders. Some reasons why the tube may be clogged include:

- Medication not given properly.
- Tube not flushed properly.
- Putting soda through the tube.
- Putting in items that are too thick, sticky, or large to pass through tube.
- Tube clamp is closed.
- Infusion rate is too slow.

What should you do when you have a blockage?*

IMMEDIATE ACTION:

- Make sure the tube clamp is open.
- Do not force formula or medication into a clogged tube.
- Try to flush the tube with a syringe filled with warm water. Pull the plunger back on syringe. Try flushing again with warm water. If flushing doesn't work, call your doctor to discuss alternative options.

What can you do to minimize clogs due to medication?*

- Ask your pharmacist, doctor, or nurse to review medications and how to give medications via a tube.
- Give each medicine by itself. Flush with water before and after it is administered.

- Do not mix any medicine with formula.
- Liquid medicines should be diluted with 30 mL of water before administering. Note: The high osmolarity of liquid medications may cause cramping and/or diarrhea.
- Tablets should be thoroughly crushed, then dissolved in 30 mL water before administering.
- Capsules should be opened and their contents poured into a syringe. Add 30 mL water and allow a slurry to form (usually within 20 minutes) before administering.
- Time-release medicines should not be given via a feeding tube.

Pill Crushers

Two pill crushers that have been recommended recently by a clinician experienced with tube feeding are **RxCrush** (Resolve Designs, www.rxcrush.com) and **Silent Knight** (Medline, www.medline.com/jump/product/x/Z05-PF10902;_1). RxCrush was cited as especially useful for more hands off and fine crushing.

More Information

- Go to www.oley.org for instructions on giving medications by tube.
- Go to www.ismp.org/recommendations/do-not-crush for a list of medications that should not be crushed.

*Adapted from Oley's Tube Feeding Troubleshooting Guide (tinyurl.com/OleyTFTroubleshooting)

katefarms®

**Plant-Based, Organic,
Nutritionally Advanced.**

Formulas for tube feeding or drinking.

- ⊘ No dairy, soy, gluten, corn, or artificial sweeteners
- ⊕ Clinically-effective functional ingredients
- ✦ Eligible for insurance coverage

**Our Customer Care Team offers
personal help to get started:**

support@katefarms.com or 805.845.2446
katefarms.com

Introducing **AMT ONE Source**™
a NEW educational app!



App Store

Google Play

AMT
ONE Source™

Up-to-date product information, FAQs, and How-To Videos – Now available at your finger tips!



Welcome Miranda, 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 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 Miranda, our newest Oley Ambassador.

Miranda Einstein

Miranda is a mother to Ariel, who has been on parenteral nutrition since birth due to necrotizing enterocolitis. Miranda lives in Sydney, Australia. She says she is fortunate to have found the Australian and New Zealand home parenteral nutrition (HPN) consumer support organization, Parenteral Nutrition Down Under (PNDU), at the beginning of her HPN-carer journey. Knowing how important that support has been to her, she is grateful for the opportunity to pay-it-forward as the secretary of PNDU and as an Oley Ambassador.



Miranda Einstein

Former lawyer, current commercialization manager, and would-be filmmaker, Miranda enjoys creating PNDU’s annual (and sometimes nutty) awareness videos. Miranda says she makes her own spare time by not sleeping and spends it in the ocean as often as she can.

Miranda and PNDU are happy to support any consumers travelling to Australia and New Zealand with information regarding facilities and procedures in its corner of the world. Contact Miranda at contactpndu@gmail.com. For more information about PNDU, please visit www.pndu.org.

A Nutrishare Facebook Group

HPN TALK
Tune in!

Nutrishare

HPN Educational Podcasts • HPN Consumers Stories

Join at hpntalk.com

In Memoriam

Jane Golden, a long-time Oley Foundation Ambassador and former member of the Board of Directors, passed away on June 12 at Waterbury Hospital, Waterbury, Connecticut. Jane had been on and off of home parenteral nutrition (HPN) and IV hydration since 1993, due to short bowel syndrome.



Jane Golden

Jane felt strongly that, as she put it, “survivors of short bowel syndrome need other survivors to talk to and see, since it is difficult for others to truly understand the lifestyle and concerns of people with the syndrome.” Putting this to practice, she volunteered as an Oley Foundation Regional Coordinator (later called an Ambassador) for over thirty years—from 1997 until her recent death. Jane also served on the Oley Board of Directors, from 2004 to 2008.

Those who knew Jane enjoyed her sense of humor, and appreciated her great love for animals. Jane was active in training and showing horses through adulthood, even during her career with IBM, where she worked for many years. As time went on, she began showing miniature horses. Jane also loved her many pets, and in her later years volunteered at animal shelters.

Jane and her husband of seventeen years, John, enjoyed going to concerts and dances, and going for drives. Her family says, “Jane lived life to the fullest measure and fought to live that life always.” She will be greatly missed.

Oley Regional Conferences

Due to concerns for your health and the pandemic, plans for the **September Regional Conference will be shifted from an in-person to a virtual event, with the date to be determined.**

Meeting supported by:

* * * * *

We are **closely monitoring** the situation in **Charlotte, NC**, for the conference scheduled for **Saturday, November 14, 2020**. We will keep you posted as decisions are made.

Meeting supported by:

For updates go to

- www.oley.org/oleyregionals
- or contact Andrea Guidi (508) 460-1707, andreaguidi.oley@gmail.com

Remote Learning to Benefit Patients

Marjorie Nisenholtz, Clinical Research Coordinator, Recanati/Miller Transplantation Institute, Mount Sinai Hospital

In the wake of the coronavirus pandemic, the “new normal” of instructional education relies heavily, if not entirely, on video-conferencing software. Platforms such as Zoom or Microsoft Teams are now household names in the global effort to streamline learning while maintaining social distance. However, many do not realize that technology-based education has been playing an important role in public health efforts for nearly two decades.

Project ECHO (an acronym for “Extension for Community Healthcare Outcomes”) is a global healthcare movement that strives to increase access to specialty care in rural and underserved communities. Dr. Sanjeev Arora, a liver disease specialist in New Mexico, launched Project ECHO (echo.unm.edu) in 2003, originally in response to the scarcity of hepatitis specialists in the southwest United States. Since then, roughly eight hundred additional ECHO projects have followed suit, with satellite clinics in over thirty-nine countries addressing a wide range of diseases and disorders.

Project ECHO expands access to specialty care by modernizing the approach to medical education and disease management. Using widely available Zoom conferencing technology, non-specialist clinicians can freely join regularly scheduled meetings with specialists and other healthcare professionals. These ECHO sessions are Socratic in nature; providers of all different backgrounds and disciplines hone their knowledge of a disease by discussing patient cases in real time. Through this type of unique, interactive collaboration, non-specialists in underserved communities gain the expertise they need to treat patients who otherwise would not have access to specialty care.

Applying ECHO Principles to Intestinal Failure

In 2019, Dr. Kishore Iyer, an intestinal transplant surgeon in New York City, started an ECHO project for the treatment and management of intestinal failure (IF) called LIFT-ECHO. LIFT-ECHO (or “Learn Intestinal Failure Tele-ECHO,” www.liftecho.org). It is the first ECHO to focus specifically on what is known as an “orphan disease”—a disease considered rare by FDA standards (affecting less than 200,000 people nationwide, by definition). Due to their rarity, orphan diseases often present unique challenges to both affected patients and their treating physicians. “We’re talking about a devastating disease,” says Dr. Iyer, referring to IF. “Forty thousand patients around the country, and maybe thirty or forty programs that have real expertise in this.”

This scarcity in knowledge means most patients must travel far distances and wait long periods of time to seek the advice of an expert in the field, for example, a surgeon or gastroenterologist. However, often the issues that patients seek consultations for could easily be managed by a local clinician, if only he or she were equipped with the proper knowledge.

“I get patients who sometimes drive up to eight or nine hours to see a transplant surgeon because they don’t have somebody closer by who can provide them with the medical oversight that they need,” says Dr. Iyer. Short bowel and IF patients are suffering, and even dying, simply because they are waiting to receive basic care.

Cue: Project ECHO. As Dr. Iyer recognized, the ECHO model was designed to address this exact issue. However, with no history of the model’s application to an orphan disease, there was question as to

whether there would be enough non-specialist clinicians interested in learning about IF to sustain the project.

LIFT-ECHO

The first LIFT-ECHO clinic was held in May 2019. The LIFT-ECHO team opted to organize the curriculum into “modules”—groupings of eight meetings, held twice a month, loosely united by a common theme in IF management. At each meeting, a case presentation is followed by a didactic lecture. Since its launch, LIFT-ECHO has completed three full modules. Across all modules, the group was comprised of roughly 50% dietitians, 20% physicians, 10% pharmacists, and 20% miscellaneous (nurses, PhDs, physician assistants, etc.).

Most other ECHO projects have somewhere between fifteen to twenty participants per session, a realistic attendance goal for LIFT-ECHO prior to its start. Upon conclusion of the first module in early September 2019, the average number of LIFT-ECHO participants across those first eight sessions was forty-five. During the second module, that average rose to sixty-five. By the end of the third module, which held its eighth session in June 2020, the average head count held steady at one hundred clinicians per meeting. Participants have dialed in from thirty-two states, as well as eleven countries in addition to the US.

Given the rarity of the disease, these numbers came as a surprise to some—a 55% increase in participation within the first year and a participant count five times that of the average ECHO. However,

ECHO, cont. pg. 6 ◀

ECHO Update

This summer, Project ECHO (Sanjeev Arora, New Mexico) was selected as one of six finalists for the prestigious MacArthur Foundation’s 100&Change competition. The winner of the competition, which will be announced in spring 2021, will receive a \$100 million grant “to fund a single proposal that promises real and measurable progress in solving a critical problem of our time” (from www.macfound.org/programs/100change).

Oley’s Role in LIFT-ECHO

Recognizing the value of having intestinal failure experts available to more patients, the Oley Foundation has been supportive of LIFT-ECHO since it was first proposed, offering a small grant to help fund the program initially and contributing the patient perspective when and where we can.

Patient’s Role

While patients are not directly involved in the LIFT-ECHO clinic, the clinics benefit patient care overall. Please tell your clinicians about LIFT-ECHO and encourage their participation (for details on dates and topics, visit www.liftecho.org/web/join-the-conversation/session-schedule). By participating, clinicians may receive expert consultation and continuing education that may benefit them, but their patients will benefit as well. The LIFT-ECHO network, based on the ECHO model of care to share “right knowledge at the right place and right time,” is expected to improve management of complex IF in the US.

HPN Awareness Week: October 12–16, 2020

For many Oley members, home parenteral nutrition (HPN) is part of life. But many people don't know what parenteral nutrition is, why it is used long-term, how it helps, and what struggles and challenges it brings.

HPN Awareness Week is meant to bring some light to these things. It is a chance to share your stories; to build bridges to HPN consumers who aren't yet connected to a community; to increase understanding and empathy; to provide hope to others; and an opportunity to talk about the challenges.



How can you help raise awareness?

- Once again, we'll kick off HPN Awareness Week with our annual "Alive with HPN" video. Please send us a photo of you or your child, along with a sentence or two saying what you would like people to know about home parenteral nutrition (HPN). Photos that show you in a favorite place or doing a favorite activity are welcome!
- If you are comfortable sharing your story, reach out to your local media. Share an event in your life (an HPN anniversary, a graduation or wedding, etc.) around which they can build a story. Someone in your community may be encouraged by learning about your experiences.
- Request your free HPN Awareness pin now! Share them with friends, family, clinicians.
- Use social media to share news of HPN Awareness Week, of the Oley Foundation, and, if you choose, part of your story—your challenges, your successes, your life day-to-day...

- Watch the webinar: *Superbugs: Knowledge Is the Best Defense* (see details below)
- Answer the following questions in one or two words, and send to Lisa at address below (results will be shared in aggregate):
 - What does HPN mean to you?
 - What has led to your/your loved one's need for HPN?
 - Why do you want to raise awareness of what HPN represents?

Submit photos to Lisa at metzgel@amc.edu by September 21, 2020—the sooner, the better! For free pins, visit our online store, e-mail Lisa, or call Oley at (518) 262-5079. Give us a call if you'd like help with a press release.

Thanks to Baxter Healthcare for underwriting the pins and promotional materials for HPN Awareness Week, and thanks to Coram for underwriting the webinar.



Superbugs: Knowledge Is the Best Defense

Featuring Kamna Giare-Patel, MS, RN

October 13, 1:00–2:00 pm EDT

Go to www.oley.org/webinars for details and to register.



Giare-Patel, MS, RN



LivingWithSBS
www.livingwithSBS.com

Stories told by SBS patients from their own perspective

ECHO, from pg. 5

the data is reflective of a sobering reality with orphan diseases, such as IF: the experience is often isolating, not only for the patients and their families, but for the clinicians as well.

"I am the only physician who treats predominantly short bowel/intestinal failure patients in my state and I feel like an island," said one participant. "This [is] great connection, and great discussion."

It is a sentiment shared by many LIFT-ECHO attendees. The initiative serves to not only support IF clinicians intellectually (participants who regularly attended LIFT-ECHO showed a 15% increase in quiz scores relative to those who had never attended a session), but socially and emotionally as well. LIFT-ECHO possesses a humanizing quality not often seen in medicine; one that reminds healthcare workers faced with uncommon challenges that they are not alone in their fight against SBS and IF.

As LIFT-ECHO enters its fourth module, the initiative continues to grow and evolve. On July 14, 2020, Dr. Iyer launched a monthly pediatric LIFT-ECHO clinic, specifically designed to help pediatric patients with IF. Roughly 170 clinicians from around the world attended the first session. ¶

Glossary, from pg. 1

biofilm (BY-oh-film): a colony of bacteria that attach to each other and form a sticky protective layer. These bacteria grow in wet environments and can be found on natural surfaces, such as teeth, and medical devices, such as central lines and artificial joints. Bacteria growing within biofilm are hard to treat with antibiotics.

blenderized food (blen-DUR-eyezd food): solid foods that have been mixed with liquids and blended to a consistency thin enough to be fed through a feeding tube. The blended food may replace or supplement tube feeding formula. Blenderized food can also be consumed orally. Also called *blended diet*, *BD*, or *blenderized tube feeding* (BTF).

bowel obstruction (boul UB-struk-shun): partial or complete blockage of the small or large intestine due to mass, narrowing, or inflammation. Liquids, food, and digested materials are not able to pass through the blockage, causing stomach pain, bloating, and a feeling of fullness.

bowel prep (boul prep): the process of emptying and cleaning out the bowels and colon before a test or surgery. It may involve drinking a liquid that causes diarrhea and continuing with the drinking until the diarrhea runs clear, or by administering an enema. Your doctor will tell you which prep is best for you and give you written instructions to follow. Also called *lavage*.

colostomy (koh-LOSS-tuh-mee): a stoma (opening) created from a part of the colon. For this surgery, the surgeon brings the colon through the abdominal wall and makes an opening (the stoma) to drain stool. An appliance (bag) is placed over the opening. It may be temporary or permanent.

endoscopy (en-DOSS-kuh-pee): a procedure that uses an endoscope to see inside the body, such as inside the upper GI tract (stomach or small intestine).

feeding pump (FEED-ing puhmp): a machine that is used to help control the flow of tube feeding formula.

feeding set (FEED-ing set): a specialized container or bag and the tubing that attaches to it through which enteral formula or blenderized diet is delivered. The tubing ends with a connector that is attached to the G-tube, J-tube, or G-J tube.

Foley catheter (FOH-lee KATH-it-ur): a flexible tube placed in the body to drain and collect urine from the body. Also called *urinary catheter*.

gravity tube feeding (GRAV-it-ee toob FEED-ing): a feeding method that uses a feeding set with tubing and an attached bag that holds the enteral formula. Gravity pulls the formula through the feeding set. It is used for intermittent feeding (feeding given in short periods of time throughout the day).

hydrolyzed formula (HY-droh-LYZD FOR-myoo-luh): a type of formula that is predigested (broken down) and easily absorbed. It contains proteins broken down into small units (peptides/amino acids), simple carbohydrates, and a small amount of either oil or a blend of medium chain triglycerides (MCTs) and oil. Also called *predigested*, *monomeric*, *elemental*, or *oligomeric formula*, or defined by their chemical components.

Find more at www.oley.org/ResourcesGlossary. ¶

The advertisement features a goldfish in the upper right corner and another goldfish swimming in the lower left. A fishing hook is positioned in the center, holding a blue rectangular sign. The sign contains the following text:

Fresenius Kabi
caring for life

Fresenius Kabi is a pioneer
in the use of fish oil
and omega-3s in
parenteral nutrition (PN).

Angling for more
information on
omega-3s?

Catch us online at
www.freseniuskabinutrition.com.

©2020, Fresenius Kabi USA, LLC. | All rights reserved. | 07/20



option care health®

Safely starting Nutrition Support patients in the home setting
following evidence-based protocols

Access to a dedicated team of nutrition support dietitians, pharmacists and nurses

Virtual visits when appropriate, reducing person-to-person contact

Proactive monitoring and intervention during therapy to prevent clinical issues that could result in hospitalization

Timely delivery of supplies and routine communication regarding product changes



For more information, call 866.827.8203 or visit optioncarehealth.com

HHA numbers are available to view at optioncarehealth.com. ©2020 Option Care Health, Inc. All rights reserved. 200CH07030

Rebekah, from pg. 1

underweight. Dehydration and malnutrition had become an urgent issue. After seemingly exhausting all options, I was started on total parenteral nutrition (TPN), which delivers nutrients intravenously through a central line. I was sent home after being trained how to administer the parenteral nutrition at home and care for my central line.

Parenteral nutrition helped me regain some health stability and it also saved my life. But there is a big learning curve in transitioning from tube feedings to IV nutrition and managing care for a central line in the home setting. In addition to tackling that, during my “health crisis,” I grieved a sense of loss that comes with losing the ability to eat and the loss of social interactions surrounding food.

My support system—patient advocates, friends, family, and a team of health professionals—has been essential in helping me cope with long-term home parenteral nutrition and the medical complications that arise. Managing long-term parenteral nutrition is very much a team effort, and my gratitude goes out to the providers and staff—“Team TPN”—who make these medical therapies possible. Meeting other people thriving on long-term nutrition support has also enriched my quality of life.

Setting Goals

Over the past six years, I have infused parenteral nutrition (PN) over twenty hours daily. I still have a G-J tube. The G is for managing chronic nausea and vomiting, and the J is for liquid medications. I’ve worked hard to build a life that incorporates my infusion routine and supports my health needs, versus a life dictated by my daily medical therapies. Quality of life is a top priority.

Remaining involved in meaningful activities and setting realistic goals have helped me to keep moving forward. I frequently challenge myself to “turn pain into passion” by finding constructive ways to transform suffering into motivation to reach my goals. One of my early

goals was to attend a yoga class once per week, which I did accomplish. Eventually, I also resumed my part-time position as a clinical research coordinator. Additionally, I clung to the hope of becoming an aunt. Presently, I am an aunt to my sweet two-year-old niece and two-month old nephew, who bring a lot of joy to my family.

Obtaining a nursing degree was a long-term goal that I had set prior to the significant decline in my health, and I still wanted to fulfill that dream. I took college courses to meet the prerequisites for second-degree nursing programs, and when the acceptance offer came, I went for it! I conquered many health obstacles throughout school, including a hospitalization from sepsis due to a crack in my central line. However, I remained resilient and graduated at the top of my nursing class with a 4.0 GPA.

During my nursing studies, I was registered with the Student Disability Services Office, which was an enormous help. I had academic accommodations arranged for test taking due to remaining connected to my “infusion backpack.” I also had permission for bathroom breaks and was

Navigating Nursing School

allowed to bring in a water bottle. The Student Disability Services staff also helped arrange a meeting with the nursing school administration to implement accommodations in the clinical setting, considering I would need to remain connected to my infusions while providing patient care in the hospital setting.

Some academic programs have flexibility for part-time or full-time enrollment. If you are considering a degree program, this may be a factor to take into account.

Pacing myself throughout my nursing coursework was an essential strategy to maintain a consistent, doable schedule. A concept that helped me was “chunking,” which is breaking down larger tasks into manageable pieces. I would divide nursing coursework/ assignments into parts and schedule specific



“There is a big learning curve in transitioning from tube feedings to IV nutrition.”

days/times when I would complete certain tasks (textbook reading, care plan assignments, reviewing physical assessment skills, listening to recorded lectures, reviewing class power points, etc.).

Whenever possible, I would work ahead in textbook reading assignments. This gave me a buffer to compensate if I needed to rest for a day due to not feeling well or if a medical issue disrupted my routine. When I was hospitalized for one week due to sepsis (a bloodstream infection) the working ahead strategy paid off. I was able to quickly catch up with coursework when I returned to school. It is important to be aware of academic policies for completing make-up exams and assignments and to request supporting documentation from your medical providers.

Working while Infusing

Presently, I work as a registered nurse on an adult inpatient general medicine unit. Due to my twenty-hour PN cycle, I infuse while at work. I use a fanny pack to carry my infusion pump and PN bag at work. I find it works better than a backpack. My fanny packs are covered with a custom-made scrub or cloth

covering, as a required infection-prevention measure. I also infuse IV fluids for hydration before and/or after work, in addition to pushing oral hydration as much as tolerable.

I am a complex patient. Nutrition support is literally the fuel providing 100 percent of my nutritional needs and makes it possible for me to carry out my passion for nursing. My personal experiences strengthen my ability to professionally advocate for patients' needs and, alongside a team of knowledgeable clinicians, help me provide patient education on interventions, including nutrition support. Our collective efforts share the common goal of promoting positive patient outcomes.

Nursing in a Pandemic

As I reflect on completing my first year as a registered nurse, the COVID-19 pandemic stands out as an unpredictable crisis that we've endured. Throughout the pandemic, there have been many valid societal challenges, fears, concerns, and also reminders of gratitude.

While the measures taken are necessary to meet our collective responsibility to protect those most vulnerable, the pandemic has also triggered a mix of emotions in many people. People have felt a sense of loss; uncertainty; vulnerability regarding personal health issues; concern for immune-compromised loved ones; frustration about having fewer resources that are essential to patients' quality of life available; fear about a lack of sufficient personal protective equipment (PPE) at work; and the challenge of adapting to the closure of offices, schools, and universities.

It has been anxiety provoking to carry a lot of uncertainty while continuing to work as an inpatient nurse. Many hospital-policy changes have occurred daily and even hourly. My co-workers and I have made a conscious effort to ensure

that our patients have felt supported and don't feel alone during the COVID-19 pandemic. These have been among the many professional moments that have brought a sense of purpose during a time of adversity.

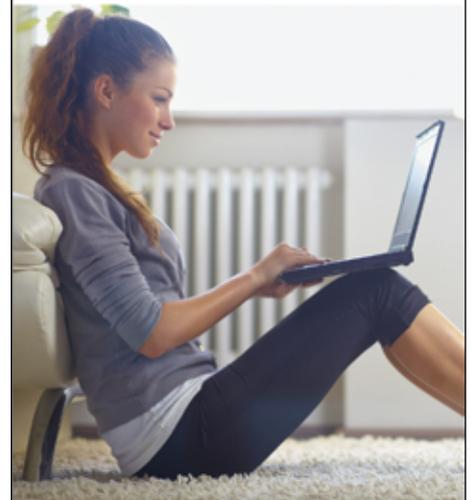
We all have a story and a shared purpose. I'm incredibly thankful for supportive nursing colleagues and to be able to safely contribute how I can. It is rewarding to work as part of a team as well as advocate for patients during vulnerable circumstances. The pandemic is also a valuable reminder of teamwork, which allows us to rise up during challenges and trial innovative solutions. In healthcare, we are stronger and safer when we work together. ¶



Rebekah's first year as an RN was during the pandemic.

Coram[®]

♥CVS specialty[™] infusion services



Help prevent infections, stay healthy

You can depend on us for the support you need to put your health and safety first. Learn how to help prevent catheter infections by attending **Superbugs: Education Is the Best Defense!** on 10/13/20. This webinar is sponsored by Coram and available to you at no cost.

Register now at
oley.org/webinars

©2020 Coram LLC. All rights reserved.
75-52529A 081420



Needed: Your Email Address

If Oley doesn't have your email address, you're missing conference news, event invitations, HPEN FDA Alerts, and other timely updates. Remedy this today: email harrinc@amc.edu.

Gastroparesis, from pg. 1

gestive tract (known as neuroenteric diseases). The GpCRC has grown into the most potent research group and public-private partnership in the fight against these maladies and the fight to find better options for the nearly ten million Americans affected by them.

Previously, research into neuroenteric disease, the single greatest cause of the chronic failure of the digestive tract, had been hindered by disconnected research centers, a limited identified population basis, and a “limited range of clinical and research techniques available to study” (www.repository.niddk.nih.gov/studies/gpcrc). The GpCRC was developed by the NIH’s lead research institute for digestive disease, the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK) to “advance research on the etiology, natural history, and therapy of gastroparesis.” Member institutions of the consortium lead and participate in multicenter clinical trials and seek to provide the infrastructure to make these trials efficient and effective. The GpCRC has also designed national gastroparesis data registries to collect information from gastroparesis patients. This has allowed GpCRC member institutions to further develop projects to research the methods to treat and eventually wipe out this scourge.

Clinical trials developed by the consortium have included:

- Efforts to investigate the **etiology of chronic and persistent nausea** originating from the stomach as well as how to diagnose gastroparesis.
- Methods for **proper and continuous glucose monitoring** to improve insulin pump therapy in the setting of diabetic gastroparesis.
- Efforts to evaluate the **use of neuromodulating and anti-depressant therapies** such as nortriptyline in the setting of gastroparesis.
- Testing of **novel antiemetics** such as aprepitant as well as **next-generation prokinetics** to improve motility and enhance gastric emptying in gastroparesis patients.

The consortium has already published over thirty reports on the progress of their multi-institutional research. The consortium

has been successful in taking down the barriers and silos normally seen in academic and clinical research settings to form the most unified group in U.S. history focused on solving the riddles of neuroenteric disease.

Consortium members include the leading centers for testing, research, and treatment of neuroenteric disease:

- **Baylor College of Medicine** (Houston, Texas): Leaders in the development of a national pediatric gastroparesis registry.
- **Johns Hopkins University** (Baltimore, Maryland): Home to the first gastroparesis clinical research and treatment center under the leadership of Dr. Marvin Schuster, the late past president of the American College of Gastroenterology, and a seminal figure in the field of neurogastroenterology.
- **Massachusetts General Hospital** (Boston, Massachusetts): The leading center for motility disease in New England through the Center for Neurointestinal Health.
- **Temple University** (Philadelphia, Pennsylvania): A long-time leader in the development of a variety of innovative and at times less-invasive testing techniques for the evaluation of chronic GI motility diseases.
- **Texas Tech University** (El Paso, Texas): The preeminent testing and treatment center for neuroenteric disease in the Southwest U.S. under the leadership of long-time motility and electrophysiology expert Dr. Richard McCallum.
- **University of Louisville** (Louisville, Kentucky): Under the leadership of Dr. Thomas Abell, a leading U.S. expert on neuroenteric disease who has done pioneering work with regard to the creation and development of neuroenteric pacing to reset the electrical rhythm of the digestive tract.
- **Wake Forest University School of Medicine** (Winston Salem, North Carolina): Under the leadership of Dr. Kenneth Koch, who is also a seminal leader in the field. Dr. Koch co-authored the *Schuster Atlas of Neurogastroenterology*, the leading foundational text. He is also a lead developer of one of the key pieces of testing equipment, the Electro GastroGram or EGG, which is akin to an EKG to measure the electrical rhythm (and also measure aberrant rhythms) of the stomach.
- **Mayo Clinic** (Rochester, Minnesota) has a long history of research in neuroenteric diseases. Mayo’s newly appointed president, Dr. Giannrico Farrugia, is one of America’s leading currently active GI motility experts.

As you can see, the talents and resources of some of the nation’s leading medical centers have been harnessed. Fueled by the NIH’s decision—under the overall guidance of Dr. Frank Hamilton—to fund the concept of a gastroparesis clinical consortium fourteen years ago, there is hope we will eventually win the fight against neuroenteric disease. At the current moment, this includes development of testing, research, and treatment methods to ensure that COVID-19 does not in any way directly or indirectly impact the proper neurologic functioning of the digestive tract.

An additional challenge now for the consortium is to ensure that COVID-19 doesn’t have sequels in the neuromuscular control and function of the gut. This challenge is being actively addressed.

Learn more about the GpCRC at www.jhuccs1.us/gpcrc/open/patients/patientlinks.htm. ¶

tubefed.com

A NEW go-to resource from the makers of MIC-KEY*
Feeding Tubes for every stage of your enteral feeding journey



Check out www.tubefed.com

AVANOS

*Registered Trademark or Trademark of Avanos Medical, Inc., or its affiliates. 2020 AVNS. All rights reserved.

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 May 15, 2020 to July 31, 2020.

Memorials: *In memory of* Beverly Akers; Jane Golden; Marie Latta; “My mam” Milly Leivovich; Gillian Miller; Jonathan Miller; Sharon Sakowitz and Dr. Barry Sakowitz; Larry Zbanek

Tributes: *In honor of* Hadar Birger-Bray; Rick Davis; Aidan Koncius; “the birth of my grandson,” Hunter Harvey Banchik Morpeth; “Our 44th wedding anniversary”; Lynn Wolfson

Matching Gift: Johnson & Johnson

Fundraisers: AmazonSmile Foundation; Facebook birthday campaigns: Hadar Birger-Bray, Ellie Brock, Michelle Fogel, and Damarius Noelle Ingram; Tiffany Dodd’s “Taking My 1st Steps as the Empowered Me” Facebook campaign; Bowl-a-thon hosted by Southern Rensselaer County Rotary Club

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.

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

Oley Corporate Partners

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



LifelineLetter

The Oley Foundation

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

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 687
ALBANY, N.Y.

2020 Oley Calendar

COVID-19 is changing how we meet and exchange information. Many 2020 conferences have been rescheduled, canceled, or moved to a virtual platform, and information is changing quickly. Please check the Oley or other appropriate website for the most up-to-date information, including information on the two Oley regional conferences scheduled for this fall.

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.).*

September 3 (and then the first Thursday of every month): Philadelphia Suburbs Tube Feeding/HPN Support Group, Blue Bell, PA, more info @ www.oley.org/SupportGroups. Meetings will be virtual until otherwise indicated.

TBA: Oley Regional Conference, Albany, NY

October 12–16: HPN Awareness Week

October 13: Oley webinar, “Superbugs: Knowledge Is Our Best Defense”

November 14: Oley Regional Conference, Charlotte, NC

For updates please email harrinc@amc.edu or call (518) 262-5079.

Additional Meetings of Interest

October 27–30: AVA At Your Fingertips (Association for Vascular Access virtual conference)

Your Privacy Is Paramount

Have you received unsolicited calls, emails, or mail related to home enteral and/or parenteral nutrition? If you have any concerns that they may be related to your membership in the Oley Foundation, please contact us so we can try to determine the source. Oley has never sold its mailing list and never will.

Just recently we held our first-ever virtual conference. It presented a new set of challenges in terms of privacy. Many conference platforms are designed to maximize attendees’ interaction with one another. While connecting members is one of our goals, we can’t use those features on the virtual conference platforms without sharing your names with all other attendees—and we won’t do that.

The experience also reminded us that we can’t control how much information you share, often without realizing it. Some examples, with solutions:

- On Zoom and other virtual platforms, you can change how your name appears. We suggest you use just your first name or a nickname.
- In an exhibit hall (real or virtual), if you share your contact information with a vendor—for example, you sign up to receive information or enter a drawing—you should expect them to follow up with you. If you want them to stop contacting you, tell them.
- When you connect with other Oley members or other HPEN consumers and caregivers, when you join a Facebook group, when you sign up for a webinar or a newsletter, consider that the person or event may have an affiliation with industry.

We would love to hear from you, whether it’s suggestions or concerns regarding your privacy. Please contact Oley Executive Director Joan Bishop at bishopj@amc.edu or (518) 262-5079.