The Oley Foundation
Help along the way

SEPTEMBER/OCTOBER 2020

LifelineLetter

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

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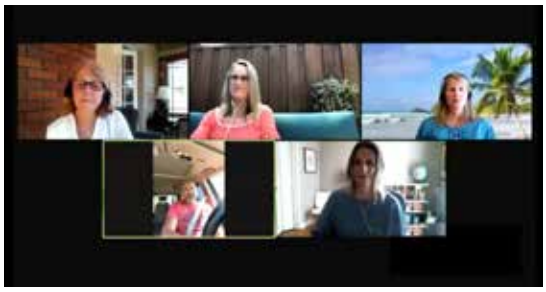
Oley 2020 Conference a Virtual Success!

At the start of this year, we were planning our annual conference, to be held in June in California. With COVID-19, however, it became clear that we could not bring together hundreds of Oley members. We needed to go virtual. The bonus was that this would open up the conference to many people who would not have been able to travel—even without COVID.

We chose a platform where we could offer a variety of presentations, giving attendees more options for learning about topics important to them, as well as hold small-group sessions where attendees could interact. Plus, it offered a virtual exhibit hall.

We learned a lot along the way, and even more during the conference itself and from your feedback. After Monday's session, for example, Oley staff members made several changes to improve the experience attendees would have on Thursday. We appreciate the feedback and emails we received.

Join the Oley 2021 Virtual Conference planning committee by emailing Joan at bishopj@amc.edu.



Speakers in the Q&A for the tube feeding session.

There were two main sessions each on Monday and Thursday, with live question and answer periods. Please see the list of presentations on page 11; all of these can be seen on the Oley YouTube channel. In the afternoon, a variety of breakout sessions and chat sessions were offered, where attendees could interact informally with each other as well as learn from the presenters.

The Oley walkathon went virtual (see page 5), as did Jammin' Jammies (see page 9). We remembered those in our community who have passed away during the

Conference, cont. pg. 11 ☛

HPN Research Prize

Each year at the annual conference, the Oley Foundation presents this award to the three clinical research papers that are best aligned with Oley's mission to enhance the lives of HPN patients and generate interest among HPN patients and improve their well-being. The abstract must have been accepted for presentation or publication by a respected, relevant professional association such as ASPEN, ESPEN, INS, AGA, etc. between July of the previous year and March of the current year. Thank you to Nutrishare, Inc. the award sponsor.

This year, the HPN Research Prize was awarded to the following.

Bone Mineral Composition Among Long-Term Parenteral Nutrition Patients: Postmortem Assessment of Calcium, Phosphorus, Magnesium, and Select Trace Elements

Aubrey L. Galusha, PhD, New York State Department of Health, Albany, New York

Background: Patients receiving long-term parenteral nutrition (PN) treatment are at risk of developing metabolic bone diseases (MBDs). The bone compartment

HPN Research Prize, cont. pg. 10 ☛

Kyle R. Noble Scholarship Winner

In 2007, the Noble family established the Kyle R. Noble Memorial Scholarship to further the educational goals of individuals relying on home parenteral (IV) nutrition or home enteral nutrition (tube feeding) for their primary nutritional needs. The $2,000 scholarship is awarded to the applicant who best embodies the qualities for which Kyle is remembered, including perseverance, determination, a love of life, and a sense of curiosity. Congratulations to this year's winner, Nancy Pickett.

Nancy Pickett

In her freshman year of high school, Nancy was captain of her volleyball team, a leader at her church, and a dedicated volunteer at the local children's cancer foundation. She had near perfect grades and was on track to go to college with little to no adversity. All of that changed during her sophomore year, when she had to take a semester off school to deal with sudden, debilitating symptoms

Nancy, cont. pg. 12 ☛

LifelineLetter
September/October 2020 • Volume XLI, No. 5

Publisher:
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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 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: Oley Website

The Oley Foundation website contains a wealth of information in various formats—articles, PowerPoint presentations, links to videos, links to other organizations and resources, our Equipment Supply Exchange list, an online store for ordering free resources and awareness materials, a glossary, and more. And on hundreds of topics—from care of your G-tube to the latest research on IV access; from grieving losses such as eating, to finding the best way to travel with tube feeding and/or parenteral nutrition supplies.

On the home page, seen here as it looks on a mobile phone, the "HEN (Tube Feeding)," "HPN (IV Nutrition)," and "Clinician" buttons are shortcuts to landing pages where dozens of articles and resources related to those fields—HEN, HPN, or for clinicians—are listed. Try them out!

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.

Survey of Home Tube Feeding (Home Enteral Nutrition, HEN)

Manpreet S. Mundi, MD, and a team of researchers at Mayo Clinic in Rochester, Minnesota, are inviting everyone involved with home enteral nutrition (tube feeding) to participate in an international survey. The results will help them better understand the broad range of practices used by those on home tube feeding, their caregivers, and the healthcare professionals who place and care for these tubes.

With data showing that tube feeding is helpful in many circumstances, its use, especially at home, continues to increase. Yet the practices of people who are tube feeding at home, their caregivers, and their healthcare providers are different, and depend largely on local factors such as the healthcare providers' experience with feeding tubes, what level and types of care and supplies are available, and what a patient's insurance will cover. As an example, the types and size of tubes used often depends on what the healthcare provider who is placing the tube is familiar with or has available to them. Similarly, the formulas used can vary according to what a provider is comfortable prescribing, whether insurance coverage is available, and what the patient prefers.

This diversity can prove challenging as broad changes to the practice of tube feeding are put in place, such as implementation of ENFit®. ENFit refers to a specific type of feeding tube connector that has been designed to connect only to other ENFit tube feeding products. It was designed to make it harder for someone to mistakenly connect something meant for tube feeding to a tube meant for something else (for example, to prevent a syringe containing medication prepared for a g-tube being connected to an IV line).

Tubing misconnections can lead to significant morbidity and mortality. However, the diversity in tube feeding practices raises issues regarding the ability of ENFit to meet the needs of all tube feeding consumers.

With these challenges in mind, Mayo has designed a survey to try and assess the broad range of practices among consumers, caregivers, and healthcare professionals. The goal is to collect data regarding everyone's tube feeding experience, including diagnosis, complications, and types of formulas used, as well as experience with ENFit and during the COVID-19 pandemic.

The researchers thank you in advance for your participation. Your answers will help them continue to improve the care people on home tube feeding receive.

To take the survey, please visit: https://redcap3.mayo.edu/redcap/surveys/?s=TFFMHWL9LJ

Note that no personal data will be collected and responses will be presented as part of a total of all responses, not individually.

BD Update

In a letter to customers this June, Becton Dickinson (BD) announced that it was no longer planning to release the BD UniVia™ RightFit Syringe, an ISO 80369-3 compliant "non-proprietary male syringe enteral system that seeks to avoid misconnections."

Their decision not to develop or launch an ISO 80369-3 compliant system, they note, was based in part on technical challenges with the syringe that they felt "would impact [their] ability to bring to market an ISO 80369-3 solution within a timely manner."

On their website, BD also notes that they "took into consideration health care provider concerns around the disruption of therapy and care continuity that may result in carrying two disparate ISO 80369-3 enteral feeding systems." The other ISO 80369-3 feeding system being referred to here is ENFit.

BD will continue to manufacture and supply BD UniVia™ oral/enteral syringes. These syringes, they note, "do not misconnect to Luer devices (e.g. IV devices) and comply with applicable U.S. medical device regulations."

For more information, see https://go.bd.com/Enteral-Feeding.html.

Life During a Pandemic: Oley Member News

Have you had to uniquely or remotely share a special birthday, a wedding, an anniversary, or another momentous event due to the pandemic? Or has COVID affected you in other ways? Send us your news. We will recognize it in the Oley newsletter.

We would also like to recognize your losses. If you have had to say good-bye to someone since the pandemic began—or due to COVID—and possibly without being able to gather to mourn, please share that with us, too. This is a difficult time. We are in it together! Contact Lisa, metzgel@amc.edu. Photos welcome.

New Traditions for COVID Birthday

I had a fantastic birthday on April 27th. My caregivers made it a wonderful day by getting me flowers and a balloon and turning my living room into a movie theater where we rented online movies that I had wanted to see in the theater but didn't have a chance to! My family and friends FaceTimed me throughout the day and sent me videos of themselves singing happy birthday and dancing.

—Allison T.

Missing Energy Because of Missed Treatments

Bette on the sofa with her nieces.

The past two months have been very rough. I have been unable to do much, but lay on sofa. [My nieces] were so wonderful. They hung out with me on the sofa, just at my pace.

I did not get needed treatment due to all the stuff going on and it caused issues. Finally, in September I got two of the treatments, and they are starting to take effect. It's great I'm able to send emails today. That's a big difference.

—Bette B.

Oley Members Remembered

We were saddened to learn of the passing, due to COVID-19, of long-time Oley members Sharon and Dr. Barry Sakowitz, 74 and 75 years old, respectively.

Sharon and Barry loved to travel.

Dr. Sakowitz was a practicing pulmonologist until his death on March 31. Sharon, an HPN consumer, passed away on March 27. Our hearts go out to the Sakowitz family.

—Oley staff

GI Motility Specialist Remembered

Dr. Hyman, pediatric GI motility specialist, recently passed away due to COVID. Dr. Hyman saved [my daughter's] life as an infant and is responsible for her excellent quality of life over the past thirteen years. When Maddie was two months old, we transferred to KUMC after overhearing the rounding NICU doctors at [our previous hospital] say that they "had given up feeding her." Upon our first discharge from KU I was in tears. I told Dr. Hyman that I didn't know how to thank him for saving her life, and not giving up on her. He replied, "You just did."

Dr. Hyman would sit in Maddie's hospital room with us for hours after her diagnosis and just wait for us to ask him questions and carefully answer each one (even the ridiculously stupid ones). Everything he said would happen, happened. No one knew more about intestinal psuedo-obstruction than he did. He taught us, "You must become a strong advocate for your child because you are the only ones who will." We took his words to heart and it absolutely gave us permission to question, research, and go anywhere we needed to go to get her the care she needs.

Maddie, thriving today thanks to Dr. Hyman's care.

He was protective of her complex medical condition. He once stated, "Nobody messes with Maddie." And we still say it.

We were devastated when he moved from Kansas City, three and a half hours from our home, to head up peds GI at New Orleans Children's. Over the last thirteen years we would email him with questions and concerns, and within hours he would email us back, even though we hadn't seen him in years.

His expertise was invaluable and his compassion boundless. He was always willing to share his knowledge with other providers. "Have them call me directly," he would say and graciously give out his cell phone number. The world has lost a pioneer and a giant in the pediatric GI motility field and the best doctor our family and countless others have been blessed to have.

—Tammy M.

Oley 2020 Virtual Walk

When it became clear that we were not going to be able to meet in person this year for our annual conference and we'd be "going virtual," we decided to go virtual with the annual walkathon as well. We invited people to register, to download a walk bib from our website and get a photo of themselves, and walk, run, bike, do yoga—whatever they wanted to do to get moving—all in the safety and comfort of their own communities and homes.

Monica and her husband, Luis, took their kids for a stroll.

Cathy enjoyed a spin bike ride.

Thank you to the many who took advantage of this opportunity to raise funds or make donations to the Oley Foundation. Those who raised or donated $25 or more received an Oley t-shirt. Together, the walkers raised over $8,700! A special shout-out to two Oley Ambassadors who went above and beyond in their fundraising efforts. Facebook proved to be a very good platform for raising money. [If you'd like to set up a Facebook fundraiser—for a birthday, next year's walkathon, or another special event—and need some help, please call the Oley office at (518) 262-5079. It's super simple.]

We hope you will join us for the 2021 walkathon.

Lillian, Cameron, and Brenda walked with their dogs.

Michael walked around a track.

Walkers/Bikers/Runners/Hikers/All Movers and Shakers

Lillian Harvey Banchik and Cameron Morpeth Banchik; Hadar, Mel, Emma, and Jason Birger-Bray; Joan Bishop; Brad B.; Lauren Chevalier; Heather Coover; Amber and Mark Cox; Marcia and Howard Denenholz; Ari Dennis; Tiffany Dodd; Luis Escobar and Monica Reynolds-Escobar; Madeleine Feder; Whitney Garner; Brenda Gray and Mollie (dog); Lauren Hortin; John Mahalchak and John Mahalchak Jr; Michael Medwar; Lisa and Ron Metzger; Elaine Nell; Katie and Robert Peters; Javier Ramirez; Dovev Rappel; David and Carolyn Rowland; Tracy Schweyer; Gillian Simons; Cathy Tokarz; Candace Verners

Katie and Robert did their walk at the Detroit Zoo.

Lisa and Ron showed their support by going for a run.

Hadar and Mel got out with their children, Jason and Emma.

Joan Bishop, Oley's Executive Director, and Brad rode bikes.

Congratulations 2020 Oley Award Winners

Child of the Year Award

Ellie Brogan

Ellie Brogan was born in April 2006 in Rhode Island. She was missing 90% of her small bowel and 30% of her large bowel, and her intestines were not connected to each other. She was transferred to Yale–New Haven Hospital in Connecticut, where the doctors connected her intestines and diagnosed her with jejunal atresia and short bowel syndrome (SBS).

Ellie was transferred again, to Boston Children's Hospital, where she was put on Omegaven, a fatty acid emulsion made out of fish oil. She was the twenty-third child to be put on Omegaven in the U. S.

Ellie Brogan

Ellie underwent multiple surgeries and ended up with a central venous line and a g-tube. She was released in December, after 206 days in the hospital. Ellie says, "I had a wonderful team of nurses, and my parents stayed with me the whole time."

Towards the end of her stay at Boston Children's, the doctors put an ostomy at the end of her small bowel, but with her colon still connected. The ostomy made it easier for her intestines to act as actual intestines, a job they were not used to because they were disconnected when she was born. When she was three, Ellie's intestines were strong enough for her to live without an ostomy and her intestines were reconnected.

Ellie was on tube feeds for many years, but as she grew, she did better by just eating food. She has been on IV nutrition (HPN) or IV hydration every night her whole life.

Going to Hole in the Wall Gang Camp, a sleep-away camp for kids with medical disabilities and conditions, has helped her while growing up with SBS. "The Oley conferences and Hole in the Wall Gang Camp make it easier for me to cope with having short gut," she says, "because they give me a chance to meet other kids, and adults, who are like me, which is rare."

Ellie has learned that she can help herself live with her condition by speaking up and advocating for herself. Advocating for herself with her medical team, she says, can give the doctors an inside view of what her life is like, and how their decisions affect her and make her feel.

Ellie wants young people like her to know they can speak up and need to advocate for their health like she does. "You can speak up about how your treatments affect you and about things like how your central line dressing should be changed or how your central line care should be done, especially if it is being done by someone new," she says, adding, "Because these things all impact your lives."

Ellie lives west of Boston with her parents, her brother Will, and her dog Tillie. She likes to play video games with her family, watch movies, chat with friends, draw, and write stories. She likes to snow ski and go to the beach. A freshman in high school, she is active in theater and plays the viola. She also loves to travel.

Nominees

Jordyn Barker; Lucy Barnes; Matthew Cech; Hope Knight; Judson "Jud" Lein; Ricardo Jesus Nuño-Moreno; Akhil Puppala; Albert Otero Rigau; Samantha Schlemmer; Michael Smith; Kyra Thomas; Isaac Toenies; Tegan Watkins

LifelineLetter Award, HPN

Sponsored by Nutrishare, Inc., Silver Circle Partner

Tiffany Dodd

Tiffany Dodd faced obstacles from an early age: failure to thrive; surgery for a hernia; eye surgeries; and multiple respiratory infections, which led to her being bullied.

After struggling with repeated infections, in 2004 Tiffany was diagnosed with common variable immune deficiency (CVID) hypogammaglobulinemia. She suffers from debilitating migraines, severe anemia requiring frequent transfusions, and gastrointestinal (GI) symptoms including vomiting, abdominal pain, and severe nausea. Tiffany has a J-tube for medications, a G-tube for twenty-four-hour drainage, and a central line for medications and IV nutrition (HPN). Tiffany has also been diagnosed with gastroparesis. She describes the process of getting a diagnosis to explain some of her GI issues as long and frustrating, due to a lack of awareness of gastroparesis.

In 2013, Tiffany attended her first Oley conference, where, she says, "I overheard a young lady sharing her story. It sounded so familiar. This changed my life. I finally realized I was not alone. After attending that conference, I used the resources the Oley Foundation provided to find my own voice and take charge of my journey. I needed to speak up more and be my own advocate. I realized I needed to get my story out there."

She continues, "I now understood that if I felt this way, there had to be others with a similar story, going through a similar journey. I hoped that sharing my story could inspire others to find their voice, to realize they are not alone, and to provide them with the support they need to find their voice."

Tiffany Dodd

Tiffany has become an Oley Ambassador in order to offer support and help others on HPEN. "I love attending the yearly Oley conference," she says. "I gain more and more every time. I take all the knowledge I gain to my social media and do a live event and share what I've learned." Tiffany has also used social media to raise money for Oley and gather donations for Oley's silent auction.

The mother of a child who is on HPN writes, "Tiffany was the first adult on HPN that I met through this journey with my son, who is three years old and on HPN since birth. She has provided great support and insight on what life on HPN is like as an adult. By her sharing her story she has given my family hope, especially at a time when we were very new to life on HPN."

Tiffany lives in Massachusetts, where she enjoys spending time with her seven nieces and nephews; being a New England sports fan; photography; scrapbooking; and reading in her hammock. "I am lucky to have a great support team," she says. "My mom has been my rock and Javier is my soulmate. We have been together for over ten years."

"Please don't be afraid to speak up and tell your story as I have," Tiffany advises.

Nominees

Jana Daigle; Gaby Luna; Teresa Poindexter; Sara Ringer

Celebration of Life Award

Sponsored by ThriveRx, Silver Circle Partner

Samantha Schlemmer

Samantha was not able to help us create a biographical sketch of her life. Instead, we are sharing the sketch presented to us in the nomination form, condensed and edited with permission of the nominator.

I've known Sami her whole life as our dads are old friends. Our families have bonded even more over the years through similarities in our health struggles. In the early stages of Sami's health decline, she was very little and nervous about getting her first feeding tube placed. I showed her my feeding tube and tried to ease her nerves. We performed surgery on her favorite teddy bear that day and have been soul sisters ever since.

Sami Schlemmer

What has stood out to me is Sami's incredible will to live and fight through obstacles. I can't count the times that Sami has stared death straight in the face, with fierce hope and unwavering faith. Sami has always been fierce. She stands up for what she believes and fights to bring love and light to others even when she is in the midst of intense chaos herself.

At a young age, Sami wanted to ice skate. Doctors told me I would never skate and I still managed to be a U. S. figure skater for thirteen years. So I helped teach her. Not long after, she was gliding across the ice in her first competition. That's just who Sami is.

Sadly, Sami is no longer able to skate, or, truthfully, walk much. She is hooked up to several machines and in a wheelchair most of the time, but this does not stop her from her mission.

When she was ten years old, Sami started her own nonprofit and created a website to spread hope and relief. She made duck-tape wallets and crafts to raise money for research. She collected donations of pajamas to send to kids in need at hospitals, and she has raised over $30,000 for CHOC Children's Hospital in Orange County, California, through her yearly CHOC Walk Team. Every year Sami leads the team in her motorized wheelchair with a smile on her face.

There have been numerous occasions in the last few years where we almost lost Sami, and we know that with her condition tomorrow isn't promised. Through each of these times Sami has been at peace, and a rock for those around her. Sami is now 17. She can't currently attend school and is back and forth between the intensive care unit and hospice care at home. Still, she spends her life choosing to spread love, faith, and hope. She's the kind of person we all strive to be, but she embodies this lifestyle at just 17.

Sami has every reason to be angry and tired. She has every reason to want to give up, and she could have so many times. But instead, Sami chooses to stay and fight, just so she can live another day to encourage others and accomplish her mission of hope. Sami's is a story of faith, resilience, strength, bravery, and hope.

Nominees

Tommy Adams; Jordyn Barker; Courteney Boyle; Jana Daigle; Ellen Evans; Carol Falk; Kendall Renee; Zeke Retsinas; Sara Ringer; Michael Smith; Jennifer Stoffel; Kyra Thomas; Tegan Watkins

LifelineLetter Award, HEN

Sponsored by Nestlé Health Science, Benefactor Level Partner

Samantha Smith

"There's a lot of story between who I was at the time of my first diagnosis and who I am now," says Samantha Smith. "Receiving my first diagnosis after graduating college, life as I knew it came to a screeching halt. I realized I had a long road ahead, and it wasn't going to be easy."

Having multiple chronic illnesses meant living in a constant state of trial and error. It became ever more difficult for her as new diagnoses were determined. Sam was constantly navigating a new normal, all while becoming sicker. Determined to learn what she could about each diagnosis, she attended conferences and reached out to online communities for support and advice. Thus began her desire to be a part of these communities and to be an advocate for others like herself.

Samantha's first diagnosis, in 2013, was of an autoimmune disease that led to removal of her thyroid. By 2016, due to gastroparesis and other chronic illnesses, Samantha needed home parenteral nutrition (HPN). She was malnourished and underweight, and was struggling.

Samantha Smith

After a few years on HPN and a few bouts of sepsis, she and her doctors tried tube feeds, which were successful. She was able to wean off HPN. Further, she was able to get strong enough to do the thing she loved most: run.

Samantha may not have the life and career she had envisioned, but she has worked hard to make a difference in the world. Samantha began volunteering with the nonprofit organization G-PACT as a writer; she is now the president. She strives to be a strong patient advocate, lobbying Congress, putting together fundraisers, and telling her story. In 2018, Samantha's experience being a runner with a feeding tube was featured in Runner's World online.

To quote one of the nominators, "Life with gastroparesis is often challenging and like other chronic conditions, it can be debilitating. Telling herself to just stay positive never helped Sam. Instead, she keeps perspective and reminds herself that she has made it through 100 percent of the bad days and the scary days, and that's pretty good. Being involved in the things she loves helps her stay optimistic and hopeful."

Samantha's story of resilience has inspired others to continue their own journeys, and to find their passion as well. She shares her accomplishments but doesn't hide the ugly side of living with these illnesses. Besides running, her biggest passion is showing others that if she can do it, anyone can. Samantha says, "These diseases can leave you living in fear, wondering if and when things will get worse. Sometimes they do."

"The proverbial shoe will always drop, but I'm not going to sit around and wait for it," she continues. "Something will always go wrong. Life will always be hard. All I know is, no one can ever say I didn't work my butt off; and that's the legacy I choose to leave."

Nominees

Carol Falk; Susan Keith ; Evelyn Olive ; Kendall Renee; Beth Toenies

Awards, cont. pg. 8 ☛

Awards, from pg. 7

Innovator/Advocator Award

Sponsored by Avanos, Bronze Star Partner

Swapna Kakani

Swapna Kakani is a professional speaker in the area of overcoming personal adversity, and an advocate in the area of healthcare delivery and the patient experience. Her inspirational life story shows her individual resilience and self-determination in the face of constant difficulties, as well as the impact her healthcare advocacy has.

Swapna Kakani

Swapna was diagnosed with short bowel syndrome, a chronic gastrointestinal (GI) rare disease, at birth due to atresia. For thirty years, she has lived with intravenous (IV) nutrition and a feeding tube. In 2014, she had a small intestine organ transplant. She is presently doing well, learning how to eat with her entire small intestine for the first time.

After her transplant, desperate for connection and finding there was no established support group for small intestine transplant recipients, Swapna started an online support group for pre- and post-small intestine/multivisceral transplant patients. The online group now has over five hundred members from around the globe.

Swapna has given presentations across the world to various healthcare companies and associations, and at hospitals and non-profit events. These include the Association for Vascular Access (AVA) and National Home Infusion Association (NHIA) conferences, Stanford Medicine X e-patient, the Cleveland Clinic/HIMSS Patient Experience Summit, and a TEDx talk in 2017.

Swapna does healthcare advocacy work both at the federal and state level. She has been part of various projects to improve care for IV and enteral nutrition consumers, and part of policy and regulation changes to improve the rare disease patient experience.

In 2017, Swapna founded Alabama Rare, a grassroots coalition to unite the state around the rare disease population. Today Swapna directs the coalition, which acts to bring support for individuals and families, educate the broader community, bring awareness to the population's needs, and advocate for necessary change. On behalf of Alabama Rare, Swapna was instrumental in the creation of the Alabama Rare Disease Advisory Council, which now meets quarterly. Also under Alabama Rare, Swapna started the first statewide patient-caregiver annual rare disease symposium, and annual state house advocacy event.

In March 2019, Swapna was awarded the Lyn Howard Nutrition Support Consumer Advocacy award by the American Society for Parenteral and Enteral Nutrition (ASPEN). This award is named in honor of Dr. Lyn Howard, who, with her patient Clarence "Oley" Oldenburg, founded the Oley Foundation.

Swapna is proud to have been born and raised in Huntsville, Alabama, where she currently resides. She recently received a Master's in Public Health (May 2020) and now works at the EveryLife Foundation, a rare disease advocacy organization, as their state advocacy fellow.

Nominees

Maggie English-Vladyka; Teresa Poindexter; Kendall Renee; Jayme Scali

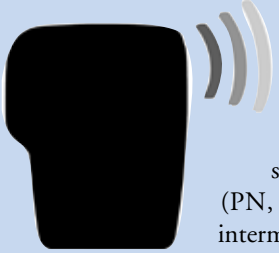
Read more about the Oley 2020 award winners
www.oley.org/2020_Award_Winners

Watch a video featuring the winners
www.youtube.com/TheOleyFoundation

Check out the 2021 Nomination Form
in the next issue of the *LifelineLetter*

Alarm Not Alarming Enough: Consumer Looking for Help

Laurie M. has written us seeking your input on a problem he is having hearing his pump alarm at night. If you have had this problem—whether you've found a solution or not—he'd like to hear from you. And we would, too! Email Laurie (lmcbride40@gmail.com) and Lisa, the newsletter editor (metzgel@amc.edu). We thank you in advance.



Laurie writes:

For those who are hearing challenged and wear hearing aids that are removed at night, when infusion of their parenteral nutrition (PN, or IV nutrition) takes place, the intermittent nature of an alarm (a) is not loud enough (and there is no means of upping the volume of the alarm to permit it being heard); and (b) does not allow alternate work-arounds to function. The same problem may be had with enteral nutrition (EN, or tube feeding) pumps.

I have tried alarm repeaters and under-pillow flappers/vibrators, and they fail to pick up the alarm signal because it is intermittent. It would be appreciated if manufacturers adapted the pump with an accessible option to increase the alarm volume. If other users who suffer from this same challenge have found a satisfactory device to respond to an alarm, please advise. If I heard from others suffering similarly, I would use the number of contacts to pass this request on to manufacturers.

—Laurie M.

Zoomin' Jammin' Jammies

Mary Wootten

Each year at the Oley annual conference, we have an evening event for the kids. Kids are invited to come in something comfy (PJs welcome) and to enjoy the activities that have been planned for them. Sometimes it's a movie, sometimes it's a scavenger hunt and a craft. It's always fun. It's Jammin' Jammies!

This year, Jammin' Jammies was a *virtual* success. Oley staff member and Ambassador Mary Wootten, a mom to young children of her own, created a virtual program that the kids loved using the online platform Zoom. Approximately twenty kids watched magician Jason Verners, participated in an online scavenger hunt, and listened to a story. To keep the fun flowing, they got directions to craft a rainbow (see below), and we mailed them kits to make their own stuffed animals.

Jammin' Jammies got rave reviews from the kids and parents. It was so popular, in fact, we've planned more opportunities for the kids to "get together" on Zoom this fall and winter. Watch for more on the Oley Kidz Virtual Meet in future issues of this newsletter.

A big thanks to Abbott for sponsoring Jammin' Jammies.

518 Rainbow

Since the pandemic began, in the region covered by the 518 area code (which includes the Oley office), families and businesses have made and hung colorful rainbows in response to a Facebook post. The rainbows are all different and fun, and create unity and hope at a time when that is much needed. And they are fun to hunt for!

Parents: Follow the directions below to create a 518 Rainbow with your kids, or use your imaginations! Then email us a picture to add to our collage (marywootten.oley@gmail.com). *By submitting the photo, you are giving us permission to share it in our written and online materials.* ¶

Rainbow Craft Instructions

Materials needed:

- googly eyes (or coloring tools to draw eyes on with)
- glue (or tape)
- scissors
- construction paper in white and a rainbow of colors

What to do:

1. Using scissors, cut a cloud shape from the white construction paper. Kids, you may need a grown-up or older sibling to help with this. You can make your cloud as big or small as you want, or even a different color.
2. Glue on the googly eyes, or draw on eyes, and then make a smile.
3. Using your scissors again (with a grown-up or older sibling if needed) cut strips of the colored construction paper for your rainbow. They can be as wide or thin, short or long as you would like them. Glue or tape them onto the back of the cloud. Now have your grown-up take a picture!

Mailbox: Thank You Oley Foundation Volunteers, Staff

I wanted to take a moment to thank [the volunteers and staff who facilitate the Equipment Supply Exchange Program] and the Oley Foundation. Through the families Oley connected me to, I was able to collect thirty-four cases of formula, an IV pole, syringes, and gravity bags. This amount of formula should last about six months.

…I am working with a 29-year-old Turkish woman, mother of two, who is feeding tube dependent after cancer surgery. This will likely be permanent.

To say Oley has helped this family would be an understatement. Thank you for this amazing organization that connects those who have, with those in need. I know that two of the donors had recently lost a loved one. I am sure that this act of kindness and generosity—donating these supplies—will help to ease some of their grief.

Thank you again. I hope to be able to use this program again.

—Allison J., LICSW

Speaking of the Oley Equipment Supply Exchange Program, look who's helping Bette send out packages!

HPN Research Prize, from pg. 1

serves as a repository for a range of metal(loid)s that are administered intravenously to patients via PN solutions. Thus, the mineral composition of patient bones may be linked to the development of MBDs in this group.

Methods: We measured twelve elements in bone samples obtained post-mortem from seven long-term (2–21 years) PN patients and eighteen control bones obtained from hip/knee replacement surgery. The samples were cleaned and dissolved using concentrated nitric acid for subsequent analysis using a method based on inductively coupled plasma tandem mass spectrometry.

Results: Compared with the control group, bones obtained from PN patients were significantly ($p<0.05$) depleted in calcium (Ca), phosphorus (P), magnesium (Mg), chromium (Cr), and strontium (Sr), and enriched in manganese (Mn), zinc (Zn), barium (Ba), cadmium (Cd), and uranium (U). No differences were observed for cobalt (Co) or lead (Pb).

Conclusions: Depletion of major components of bone mineral (Ca, P, and Mg) and enrichment in known toxicants (Cd, Mn, U) are concerns for PN patients.

Intravenous Fish Oil Monotherapy as a Source of Calories and Fatty Acids Promotes Age-Appropriate Growth in Pediatric Patients with Intestinal Failure–Associated Liver Disease

Kathleen Gura, PharmD, BCNSP, Boston Children's Hospital, Boston, Massachusetts

Objective: To compare growth in children with intestinal failure–associated liver disease (IFALD) that received a fish oil intravenous (IV) lipid emulsion (FOLE) to those who received a soybean oil IV lipid emulsion (SOLE).

Background: Infants and children receiving prolonged courses of parenteral nutrition containing soybean oil lipid emulsions have been shown to be at risk for developing liver disease. Replacing this lipid emulsion with one that is purely fish oil may be beneficial in reversing this complication. Concerns have been raised, however, that growth may be negatively impacted.

Study design: This multisite, retrospective study pair-matched FOLE (n=82) to SOLE subjects (n=41) using baseline direct bilirubin and postmenstrual age. FOLE subjects received open-label FOLE (1 g/kg/d) until IFALD resolved or parenteral nutrition was stopped. Historical control subjects received SOLE (up to 3 g/kg/d). Growth parameters (changes in body weight, height/length, and head circumference), prealbumin, triglycerides, and glucose were compared between groups over time using the Wilcoxon rank sum test.

Results: Although changes in all of the growth parameters were similar for both groups ($P > 0.05$), FOLE subjects demonstrated overall improved trends in growth. After twenty-eight weeks, FOLE subjects had a mean body weight within a Z-score range of -1 to 1 indicating age-appropriate growth. FOLE subjects consistently had higher prealbumin, lower triglyceride, and more normal glucose concentrations over time compared to SOLE subjects.

Conclusion: Children with IFALD that received FOLE had similar growth and fewer metabolic abnormalities compared to those who received SOLE. Age-appropriate growth can be achieved with FOLE in this population.

The Utility of an Instructional Video Series in Reducing Central Venous Catheter Complications in Children with Intestinal Failure

August Pierik, BA, Medical Student, University of British Columbia, British Columbia, Canada

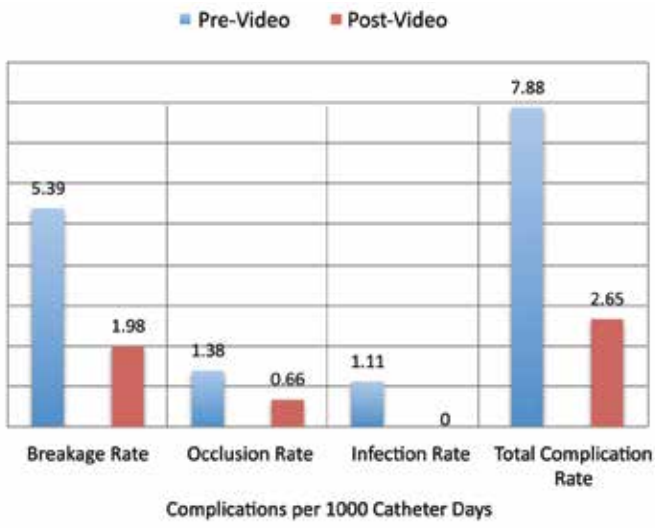
Purpose: Central venous catheters (CVCs) are a source of morbidity for children with intestinal failure receiving parenteral nutrition (PN) at home. Caregivers must remain competent in CVC-related skills to minimize complications. This study evaluates CVC-related complications before and after the introduction of caregiver instructional videos.

Methods: A group of caregivers from one center was surveyed to assess confidence in CVC skill performance. An instructional video series detailing best practices for CVC skills was created by filming two volunteer caregivers performing the skills. It was filmed using only a smart phone and basic editing software. Access to the videos was provided online to the group of caregivers, and feedback was solicited six to twelve months later. CVC-related complication rates were compared for two years prior to and one year following video introduction.

Results: Thirteen caregivers were enrolled, with 80% expressing a need for video and 36% reporting under-confidence in their skills. After viewing the videos, 100% of caregivers reported that the videos facilitated skill acquisition. When comparing CVC complications in these patients for the two years prior to and one year following video introduction, the breakage rate decreased from 5.4/1000 to 2.0/1000 catheter days; bloodstream infection rate decreased from 1.1/1000 to 0/1000 catheter days; and the occlusion rate decreased from 1.4/1000 to 0.7/1000 catheter days. Total line complications decreased from 7.9 to 2.6/1000 catheter days. (See figure 1 below.)

Conclusion: This instructional video series is a simple, cost-effective resource that was well received by caregivers. Complication rates over the year following video introduction were lower than the two years prior. ¶

Figure 1. CVC Associated Complication Rates



Conference, from pg. 1

"In Loving Memory" presentation—complete with virtual candles (see www.oley.org/memorials; this presentation can also be seen on the Oley YouTube channel). We appreciate your support as we have navigated these new waters, and look forward to seeing you at the Oley 2021 Virtual Conference. ¶

Conference Videos Available

Videos of conference talks are available to view free of charge at www.youtube.com/TheOleyFoundation. Slide presentations are at www.oley.org/AnnualConference.

Monday's Presentations

Complexity of Motility Disorders
Challenges in Managing Motility Disorders, Richard McCallum, MD, FACP, FRACP (Aust), AGAF, FACG
The Patient Survey Report, Aylin Tansel, MD
Battling Bacterial Overgrowth, Douglas L. Seidner, MD, AGAF, FACG, FASPEN, CNSC

Management of Short Bowel Syndrome
Surgical and Medical Options for Treating Short Bowel Syndrome, David Mercer, MD, PhD, FRCS, and Kishore Iyer, MBBS, FRCS, FACS
Life after Intestinal Transplantation, Aeisha Reese, small bowel intestinal transplant recipient

Thursday's Presentations

Home Parenteral Nutrition
HPN and Bone Health, Vanessa Kumpf, PharmD, BCNSP
Preserving Vascular Access, Laurie Reyen, RN, MN
Drug Shortages and Your HPN, Penny L. Allen, RD, CNSC, and Beverly Holcombe, PharmD, BCNSP, FASHP, FASPEN

Home Enteral Nutrition
Home Enteral Nutrition Update 2020, Manpreet Mundi, MD, and Lisa Epp, RDN, CNSC, LD
Comfort and Care of Your Feeding Tube, Cynthia Reddick, RD, CNSC
Blenderized Diet: The Good, the Bad, and the Broccoli, Katherine Bennett, RD, MPH, CLE

On Your Behalf

Ethanol Locks
If you typically use ethanol locks, **have you noticed changes** in how often—or whether—you receive them? **Do you have concerns? Please share your experiences with Joan Bishop (bishopj@amc.edu).** Several companies have applied for FDA approval through the FDA's Emergency Use Authorization (EUA) program. **We want to have your stories at hand** to help guide the FDA's decisions. Your communication with us allows us to react quickly to share your needs and concerns.

Nancy, from pg. 1

that left her unable to eat solid food or stand up for longer than a minute.

As an adolescent female, competitive athlete and musician, and straight-A student, doctors told Nancy she fit the criteria for "amplified muscular skeletal pain syndrome" perfectly. Nancy writes, "They did not perform many tests before enrolling me in a pain clinic for children whose psychological stress manifested as physical symptoms. For several weeks I was encouraged to keep quiet about my symptoms as I pushed through six to eight hours of physical, occupational, and psychological therapy every day."

Nancy plans on graduating in 2021.

While in this program, Nancy eventually lost enough weight that she needed to be evaluated by a gastroenterologist, who discovered that her nausea was not caused by stress, but by a severe case of gastroparesis. Eventually, Nancy was diagnosed with Ehlers-Danlos syndrome. It wreaked havoc on her entire body and caused total digestive tract paralysis. Nancy returned to school with a nasal feeding tube, which was later replaced by a GJ-tube.

Seeing Opportunities

During the first semester of her junior year, Nancy had more than ten emergency surgeries and countless hospitalizations. After a month-long hospitalization at the beginning of her senior year, Nancy was sent home on parenteral (IV) nutrition.

Nancy says, "Everyone expected me to take time off from school and volunteering because of what I was going through, but I didn't want to be defined by my diagnosis. I was motivated to continue volunteering, using my newfound knowledge of the patient experience." Nancy taught kids about feeding tube placements, port accesses, and other procedures that they might find scary, but she was now familiar with.

She helped her children's hospital develop a "teen board" to support age-appropriate child life programming. The program, which is still in action, specifically focuses on teenagers with chronic illnesses. It teaches them how to better advocate for themselves and feel empowered to follow their dreams despite their poor health.

Although Nancy was determined to live life to the fullest, her public school decided they would not allow her to attend the Student Television Network (STN) National Conference while on HPN during her senior year, citing liability concerns. Nancy writes, "So often, schools are so focused on meeting ADA and 504 Accommodation requirements to avoid penalties that they forget the purpose of these protocols in the first place—to give every student equal opportunity for success." Nancy spoke with school leaders about chronically ill and disabled students' potential and shared her own experience with managing HPN as proof of independence and determination.

While her friends were at STN, Nancy created a short documentary about healthcare reform to teach the public about the importance of the Affordable Care Act (ACA) for chronically ill young Americans. "Is Healthcare a Human Right?" was a huge success. In 2017, it won the Mike Wallace Memorial Scholarship, a prestigious award given at the News and Documentary Emmys for excellence in journalism.

Moving West

Nancy graduated from high school with honors and premiered her first feature-length film before moving across the country to attend a prestigious film school in southern California. She found a medical team to manage her HPN in her new community, and then hit the ground running.

Nancy was happy at college. She notes, "It was everything I could have hoped for in a college experience and more."

Unfortunately, Nancy was admitted to the hospital frequently. She finished out the semester and planned on staying in California for the summer. She says, "I was so thankful to have a team of doctors who seemed committed to getting me better." The day after her last final exam, Nancy was admitted to the hospital for blood transfusions due to a Mallory Weiss tear.

Through a series of recommendations from the hospitalist team, Nancy was sedated to let the tear heal, and then transferred to a larger hospital for surgery.

Nancy writes, "My girlfriend's mom hopped on a plane with just a few hours' notice as we prepared for the worst. The worst did happen, but it is not what we imagined. The new hospital said that many patients with Ehlers-Danlos syndrome were actually experiencing factitious disorder, and I did not need surgery." They began weaning her off her medications. Far from family, Nancy relied on her friends to advocate for her. She was transferred back to the original hospital, where she developed sepsis. Eventually, Nancy recovered enough to go stay with friends in Seattle until she was stable enough to fly home to Orlando.

After several months at home, Nancy began coordinating her second cross-country move—this one to Seattle, Washington. Since then, she says, "I have established care with an amazing medical team and leased my first apartment. I am far from healthy, but I have gained back enough strength (and weight!) to enjoy life and live independently." Nancy enrolled in the University of Florida's online program and will graduate in 2021. "My next project," Nancy says, "will be a documentary about the bias faced by adolescent women in healthcare so that no one will have to go through what I went through ever again."

Congratulations, Nancy! ¶

Details on applying for the Kyle R. Noble Scholarship are available at www.oley.org/KyleNobleScholarship.

Oley Foundation Community Enrichment Programs

—Education, Connection, Hope

Oley Mini Meetings

Formerly known as "Oley Regional Conferences," these FREE one-day meetings will offer you the opportunity to learn and connect as experts share the latest information, advocacy, and research.

The conferences are coordinated for consumers and family members/caregivers, but all others are encouraged to attend and learn. All mini meetings will be held virtually until further notice.

Next Scheduled Mini Meeting

- Saturday, November 14, 2020, 10:00 a.m.–3:00 p.m. EST
- Register today!
- For more information, visit www.oley.org/Enrichmentprograms
- With support from

Takeda THRIVERx A DIVISION OF DIPLOMAT SPECIALTY INFUSION GROUP

Oley Webinar Series

- A great opportunity to learn without leaving your home
- Free of charge (we do not offer CEUs at this time)
- Recorded for future viewing
- Watch for the next scheduled webinar, at wwww.oley.org/webinars.

Thank You for Helping with the Oley 2020 Virtual Conference

Our heartfelt thanks to the many people who contributed to make the Oley 2020 Virtual Conference a success. Switching to a virtual platform was no small task for anyone involved. Faculty, exhibitors, attendees, and Oley staff all had to adapt and meet new challenges, and everyone did so admirably.

To the faculty who prepared and presented information without compensation; to the exhibitors who jumped in and created virtual booths; to the sponsors who helped make the meeting possible; and to all the attendees who signed on and opened their hearts to each other in virtual meetings—a huge thank you.

Oley Ambassador John Mahalchak helped many members access the conference by creating a how-to video.

Contributors *(sponsorships, speaker support, donations, etc. that help offset conference costs)*

Albany Medical Center; Abbott Nutrition; Avanos; American Society for Parenteral and Enteral Nutrition; Baxter International Inc.; Boston Children's Hospital; CHOC Children's Hospital; Cleveland Clinic; Coram / CVS specialty infusion services; Good Nutrition for Good Living; Kate Farms; Managed Care Consultants; Mayo Clinic; Mount Sinai Hospital; Nestlé Health Science; Nutrishare; Optum Infusion Pharmacy; Rhode Island Hospital; Swapna Speaks; Takeda Pharmaceuticals; Texas Tech University Health Sciences; ThriveRx; UCLA Health; University of Illinois at Chicago; University of Louisville; Vanderbilt University Medical Center; VectivBio; Wadsworth Center, New York State Department of Health; Wake Forest School of Medicine; Zealand Pharma

Expo Partners *(exhibits, product showcases that help offset conference costs; available only to Oley Corporate Partners)*

Applied Medical Technology, Inc. (AMT); Avanos; Baxter Healthcare Corporation; Cardinal Health; Coram / CVS specialty infusion services; Fresenius Kabi USA; Kate Farms; Moog Medical; Nestlé Health Science; Nutrishare; Optum Infusion Pharmacy; Real Food Blends; Takeda Pharmaceuticals; ThriveRx; VectivBio

Faculty *(donate their time and expertise; with a special nod to conference coordinator Joan Bishop)*

Thomas Abell, MD; Penny Allen, RD, CNSC; Katherine Bennett, RD, MPH, CLE; Tim Blanchard, DMin; Marcia Boatwright, RN, CRNI; Bettemarie Bond; Elizabeth Bond, RN; Amy Braglia-Tarpey, MD, RD, CNSC; Alan Buchman, MD, MSPH, FACN, FACP, FACG, AGAF; Teresa Cutts, PhD; Brenda Elsagher, CHP; Lisa Epp, RDN, CNSC, LD; Celia Fairbanks; Aubrey Galusha, PhD; Madalyn George-Thiemann, RN, CNS; Kathleen Gura, PharmD, BCNSP, FASHP, FPPA; Beverly Holcombe, PharmD, BCNSP, FASHP, FASPEN; Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN, FAND; Kishore Iyer, MBBS, FRCS, FACS; Swapna Kakani; Maria Karimbakas, RD, CNSC; Darlene Kelly, MD, PhD; Vanessa Kumpf, PharmD, BCNSP; John R. Mahalchak; Richard McCallum, MD, FACP, FRACP (Aust), AGAF, FACG; David Mercer, MD, PhD, FRCS; Manpreet Mundi, MD; Reid Nishikawa, PharmD, BCNSP; Emily Parks; Deb Pfister, MS, RD, CNSC; August Pierik, BSc, Medical Student; Cynthia Reddick, RD, CNSC; Aeisha Reese; Laurie Reyen, RN, MN; Douglas Seidner, MD, AGAF, FACG, FASPEN, CNSC; Janeen Smith, PA-C; Aylin Tansel, MD; Kelly Tappenden, PhD, RD; Kay Tims; Bryan Tims, MS; Marion Winkler, PhD, RD, LDN, CNSC

Special acknowledgement to—

- Kay and Bryan Tims, MS, for sharing their stories with our Corporate Partners
- Brenda Elsager, for her humorous, keynote kickoff
- John R. Mahalchak, for creating a video about the conference website
- Jason Verners, for entertaining the youth in Jammin' Jammies

Oley 2020 Conference — By the Numbers

1: Winner of the Expo scavenger hunt, Brittany D.

5: Awards presented

15: Countries represented by attendees (Argentina, Australia, Canada, Denmark, England, Germany, Ireland, Israel, Italy, Poland, S. Africa, S. Korea, Spain, Switzerland, USA)

20: Oley Ambassadors attended

23: Breakout sessions

24: Children participating in Jammin' Jammies

39: Award nominees recognized

39: Faculty (presenters)

46: States represented by attendees

287: First-time attendees

587: Total attendance—292 adult HPEN consumers; 85 family members/caregivers; 71 clinicians (29 dietitians; 9 nurses; 11 physicians; 6 pharmacists; 2 occupational therapists; 2 social workers; and 12 other); 70 exhibitors; and 69 children.

889: views of Monday's 7 breakout sessions

1,133: views of Thursday's 16 breakout sessions

3,983: views of the main session presentations

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 August 1, 2020 to September 25, 2020.

Memorials: *In memory of* Gisela Barnadas, MS, RD; my stepfather, Dr. Werner (Bill) Berglas; Woody Freese; Lynn Hamilton; Kay Hayden; Susan Denise Kerner; Robin Lang; Eilyne Levy; Jane Lindsay; Michael Loudon; Ansley McCormick; Kyle Noble; the Oley members we've lost, who have left such an impression; Liz Tucker; Colyn Woods; Don Young; Larry Zbanek

Tributes: *In honor of* Hadar Birger-Bray; Phil Kellerman; Aidan Koncius

Matching Gifts: GE Foundation; Johnson & Johnson

Fundraisers: AmazonSmile Foundation; Facebook birthday campaigns: anonymous, anonymous, Hadar Birger-Bray, Francesca Cirillo; Tiffany Dodd's "Taking My 1st Steps as the Empowered Me" Facebook campaign; Phil Kellerman's ongoing political memorabilia fundraiser on eBay

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.

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

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

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Coram / CVS specialty infusion services
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Oley Mini Meeting
November 14, 2020
10:00 a.m.–3:00 p.m. EST
www.oley.org/Enrichmentprograms

2020–2021 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.).*

November 5 (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.

November 14: Oley Mini Meeting, virtual

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

Additional Meetings of Interest

February 27–March 3, 2021: National Home Infusion Association (NHIA) conference, Austin, TX

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

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

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