Finding the Life I Didn’t Realize I Was Missing

Julie M. Andolina

This year, I attended Oley’s annual conference in Lincolnshire, Illinois. It was the first time in over a decade that I’d been to an Oley conference, and I can honestly say that I intend not to miss any more! When I was a child living with short bowel syndrome and needing home parenteral and enteral nutrition (HPEN) to survive, my family found Oley to be a fantastic source of support and education. Growing up, I didn’t know many other children in my position, and frankly, I had been so normalized that I didn’t want to know anyone else. But, as I’ve grown up and come to understand that I will most likely be on HPEN for my entire life, I’ve come to embrace Oley and the work that they do.

Learning New Things

With every passing minute at the Oley conference, I picked up new and useful information. From the exhibitors, I learned of a new g-tube that indicates when its balloon needs to be refilled; I saw the different types of enteral formula that are available to me, some of which may have the potential to provide me with better nutrition; I was able to speak to a Transportation Security Administration (TSA) agent about how to travel with HPEN supplies. Oley put in so much work to be able to provide me with those resources that I never even thought I could use.

Oley’s unique conference schedule allowed for a wide range of presentations given by clinicians and consumers alike. However, even more valuable to me than the main presentation sessions were the breakout sessions. These sessions allowed for the presentation of useful tricks of the trade and covered a wide range of topics, all while keeping group size small enough to allow for an intimate experience.

Sitting in groups of five, ten, max fifteen consumers to one or two clinicians or consumers leading the

Goldsmith Awarded Scholarship

Oley is excited to award Derick Goldsmith with this year’s Kyle R. Noble Scholarship. Established in memory of Kyle, the scholarship helps further the educational goals of a home parenteral and/or enteral nutrition (HPEN) consumer who embodies the qualities for which Kyle is remembered.

Derick, who is 20 and has recently completed high school, has been accepted into a program to become a human services assistant at a college near his home. His mom, Mitzi, writes that they only accept fifteen students a year into this program.

2019 HPN Research Prize Winners

Exciting research regarding lipids, catheter repair, and a faster way to diagnose bloodstream infections was presented at the Oley conference by the winners of the 2019 HPN Research Prize. Sponsored by Nutrishare, Inc., the prize was established in 2007 to encourage clinical studies focused on improving the quality of life for home parenteral nutrition (HPN) consumers.

The award winners presented their findings during the main session on Saturday, and later led round tables. See tinyurl.com/Conf2019Sat (the first research presentation starts at approx. 1:15 on the video) and www.oley.org/2019confpresentations (for slides).
**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 21,000+ 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

**Check Out This Resource:**

**Tube Feeding Troubleshooting Guide**

Hot off the press! Download the newly updated *Tube Feeding Troubleshooting Guide* at tinyurl.com/OleyTFTG, or call (518) 262-5079 for a paper copy. The guide has practical advice on everything from bathing with a tube, to avoiding clogs and dealing with skin care issues. The guide was created and reviewed by Oley medical advisors.

Clinicians and home care representatives: This is an especially good resource for those who are new to tube feeding. It’s also a good refresher for those who are experienced with tube feeding. Feel free to request multiple copies to share with your patients.

**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.

Need Help Caring for the Skin Around Your Tube?
Many Oley members inquire about caring for the skin around their tube site. These resources are a good place to begin your journey.

Webinar
• “Practical Management of Home Tube Feeding,” Cynthia Reddick, RD, CNSC
  www.oley.org/webinars

PowerPoint Presentations
• “Skin/Wound Issues Why Things Go Wrong,” Dane De Luca, RN, BSN, WOCN
  tinyurl.com/Oley-DeLuca
• “Comfort and Care of Ostomies and Feeding Tubes: It’s the Little Things,” Susan Hamilton MS, RN, CCRN, CWOCN
  tinyurl.com/Oley-Hamilton
• “Tool Kit for Tube Care,” Teri Williard, BSN-RN
  tinyurl.com/Oley-Williard

Articles, Publications
• “Tips for Dealing with Skin and Stoma Issues,” Dane De Luca, RN, BSN, WOCN
  www.oley.org/TipsForSkinandStoma
• “Site Irritation and/or Tube Leaking” section of Oley’s Tube Feeding Troubleshooting Guide
  tinyurl.com/OleyTFTG

Get Professional Help—Find a WOCN
• What Wound, Ostomy, and Continence (WOC) and Enterostomal Therapy (ET) Nurses Do
  www.oley.org/WOCN_ET_Nurses
• Find a WOC Nurse at Wound, Ostomy and Continence Nurses Society, www.wocn.org (select “Patient Information” then “Find a Nurse in Your Area”)

Kangaroo™ Connect Enteral Feeding System NOW WITH WIRELESS CONNECTIVITY
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Oley Announces 2019 Award Winners

The Oley Awards Program recognizes home parenteral and enteral nutrition (HPEN) consumers and caregivers who exhibit courage and perseverance in overcoming the adversity of illness and are generous in helping others. The stories clinicians, family members, peers, caregivers, and patients relay in the nominations are truly inspiring.

The award winners are chosen by a panel of previous award winners, Oley board and committee members, and, if there’s a tie, Oley staff. It is a difficult job to select just one winner for each award from the outstanding pool of nominees! We congratulate everyone who was nominated for an Oley award.

Please consider nominating someone who inspires YOU. There are so many worthy candidates! Nomination forms will be available in an upcoming issue of the LifelineLetter, January through April at www.oley.org or by calling (518) 262-5079.

We hope you will enjoy reading about this year’s winners. Awards were presented at the Oley/UI Health Combined Conference in Lincolnshire, Illinois, in June.

**LifelineLetter Award, HEN**
*Sponsored by Nestlé Health Science, Benefactor Partner
Lauren Reimer-Ethridge*

The LifelineLetter Award, HEN, recognizes an HEN consumer or caregiver, 19 years old or older, who demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN. This year, the award was given to Lauren Reimer-Ethridge.

Lauren developed GI issues at a young age and was diagnosed with visceral myopathy chronic intestinal pseudo-obstruction at the age of thirteen. She has been on HPN since then. She has experience with feeding tubes, as well, as she uses them to vent her stomach and intestine. Even in her early years, Lauren didn’t let these things hold her back from enjoying life. Now, Lauren is a blogger, photographer, and advocate for a home infusion company. She lives in Fayetteville, Arkansas, with her husband, Anthony, and puppy dog, Elway. She loves spending time with her little family and friends, vintage eyeglasses, creating engaging social media content for the chronic illness community, and spontaneous phone calls.

Lauren spends lots of time communicating with those in the online chronic illness community, and often shares tips and tricks on her blog. She also volunteers with the Mid-South Chapter of the Make-A-Wish Foundation, taking photos of wish reveals and fundraising events, and helping coordinate the fulfillment of children’s wishes.

In nominating Lauren for this award, several people wrote about the many ways Lauren reaches out to others. Her father cites this example: “Last summer, Lauren participated in an unusual event hosted by the library in Fayetteville. It was called the Human Book Library Day. A number of people were ‘human books’ and people could ‘check out’ a human book for a fifteen-minute interview. The subject of Lauren’s ‘book’ was ‘Living with a Chronic Illness.’ By participating in events like this, Lauren has reached out to the general population in an effort to educate them about living with a chronic illness.”

Lauren has been involved with the Oley Foundation for the past several years. She attended her first annual conference in 2016 and says she was blown away by the amazing community. She finds that Oley is great at connecting a rare group of humans who all have something huge in common, and for that, she says, she is beyond grateful.

She adds, “Receiving this award meant so much to me, as I know there are many just like me living this life with courage, perseverance, and a positive attitude. I hope to bring light to those people in the years to come through nominating them and letting their light shine a little brighter by being recognized for it.”

**Congratulations to the nominees:**
Irina Chaykowsky; Joyce Clay; Tiffany Dodd; Diana Donnarumma; Jennifer Glanden; Brenda Gray; Gaby Luna; Michael Sherels; Stephanie Torres; Jessica West; Bill Wu; Linda Zarella; Sasha Zolik

**LifelineLetter Award, HPN**
*Sponsored by Nutrishare, Inc., Silver Circle Partner
Lauren Reimer-Ethridge*

The LifelineLetter Award, HPN, recognizes a home parenteral nutrition (HPN) consumer or caregiver, nineteen years old or older, who demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN. This year, the award was given to Lauren Reimer-Ethridge.

Lauren developed GI issues at a young age and was diagnosed with visceral myopathy chronic intestinal pseudo-obstruction at the age of thirteen. She has been on HPN since then. She has experience with feeding tubes, as well, as she uses them to vent her stomach and intestine.

Even in her early years, Lauren didn’t let these things hold her back from enjoying life. Now, Lauren is a blogger, photographer, and advocate for a home infusion company. She lives in Fayetteville, Arkansas, with her husband, Anthony, and puppy dog, Elway. She loves spending time with her little family and friends, vintage eyeglasses, creating engaging social media content for the chronic illness community, and spontaneous phone calls.

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She adds, “Receiving this award meant so much to me, as I know there are many just like me living this life with courage, perseverance, and a positive attitude. I hope to bring light to those people in the years to come through nominating them and letting their light shine a little brighter by being recognized for it.”

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**LifelineLetter Award, HEN**
*Sponsored by Nestlé Health Science, Benefactor Partner
Patrick Dunegan*

The LifelineLetter Award, HEN, recognizes an HEN consumer or caregiver, 19 years old or older, who demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN. This year, the award was given to Patrick Dunegan.

In nominating Patrick for the LifelineLetter Award, HEN, his wife, Jennifer, notes that Patrick...
“goes above and beyond to take care of me.” He is, first and foremost, a caregiver, and, as Jennifer notes, “being a caregiver is very stressful. [Patrick] works a forty-hour a week job and takes care of me….Over the years [he] has educated himself about my conditions. So even though he himself does not have gastroparesis, diabetes, or a feeding tube (j-tube), he knows how to care for me and knows the signs and symptoms of when things are going wrong….He tries to make life a little easier if possible.”

Patrick gives of his time, knowledge, and experience to help Jennifer and others. He and Jennifer run Gastroparesis Support Services Inc. 501c3 (GSSI). According to its website (www.gpsupportservices.com), GSSI “aims to fill the gap in service by providing hotel rooms, food, and transportation for patients and their families” that travel to University of Louisville GI Motility Clinic in Louisville, Kentucky. Guests are referred to GSSI by the University of Louisville GI Motility Clinic.

Patrick is also a Kentucky Colonel and Volunteer State Ambassador for the National Organization for Rare Disorders (NORD), and in 2019 was commissioned by the governor to chair the Kentucky Rare Disease Advisory Council. He spends much of his free time advocating for the rare disease community in Kentucky. “There is no reason that someone diagnosed with a rare condition should [have to] face the same struggles that my wife and I had to,” Patrick says. “Alone we are rare. Together we are strong,” he continues, quoting NORD’s trademark phrase.

Congratulations to the nominees:
Brianne Coffey; Kimberly Dalen; Abbie Esterline; Maddie Feder; Krista Hobson

Celebration of Life Award
Sponsored by ThriveRx, Silver Circle Partner
Nathaniel Ross

The Celebration of Life Award recognizes someone who has been a home parenteral and/or enteral nutrition consumer (HPEN) or caregiver for three years or more and who lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, and so on. This year, the award was given to Nathaniel Ross.

Since he was little, Nathaniel has battled health problems, including eosinophilic esophagitis, gastroparesis, Ehlers-Danlos syndrome, and postural tachycardia syndrome (POTS). His mom says, “You would think all of this and being TPN [or HPN] dependent would slow him down. Nope!...He is graduating with a 5.0 GPA and is class valedictorian….He has volunteered over 450 hours in the last four years. He has worked with special needs baseball, helped run blood drives, is a gallery interpreter at the Museum of Natural History, collects musical instruments for our local children’s hospital, and the list goes on. He is a tap dancer, involved in the drama team at his high school, vice president of the National Honor Society [chapter], and City of Mesa student of the Year.” Nathaniel, says his mom, “has told others his health battles have just made him stronger.”

We received several nomination forms for Nathaniel, some from the parents of teenagers a bit younger than him who look up to him. One parent writes, “Even though we are states apart, Nathaniel taught my son how to play yo-yo via Skype. The night before my son got his feeding tube, Nathaniel Skyped with my son and told him what to expect and was honest about the pain, nausea, etc., all while reassuring him that it would be okay. He even showed my son what his tube looked like.”

By his example, Nathaniel offers parents hope for their children. Through his compassion, kindness, creativity, and determination, he lets others know they are not alone. Another of Nathaniel’s accomplishments is writing a book about eosinophilic esophagitis. One parent wrote, “My son still reads that book. It makes him feel like he is not alone….Nathaniel is a role model for my son and so many more, whether they are living with chronic illnesses or not. He is a hard-working, dedicated, and compassionate young man.”

Another parent wrote that Nathaniel “is an exemplary student who is devoted to finding cures and improving the lives of others with chronic illnesses. In addition, he is charismatic and so fun….No disease will stop him. If anything, he is inspired by the thought of all he can accomplish in spite of the medical limitations he may have. I can’t wait to see how high he will fly!” We can’t wait to see, either!

Nathaniel writes, “I am honored to have received this award and thankful for all of the people who nominated me. I hope to continue to inspire people to keep fighting and to never let life’s challenges get in the way of achieving your dreams.”

Congratulations to the nominees:
Leighanne Boone; Irina Chaykowsky; James DeLano; Tiffany Dodd; Ellen Evans; Gideon Floresca; Jennifer Glanden; Brenda Gray; Kenneth Martin, Jr.; Kathy Patterson; Michael Smith; Jennifer Stoffel; Debbie Gilbert Taylor; Shellee Tedrick; Lynne Tower-Clark; Lynn Wolfson

Award Winners, cont. pg. 6

Nathaniel Ross
Child of the Year Award
Sponsored by Kate Farms, Bronze Star Partner

James DeLano

The Child of the Year Award recognizes a current home parenteral and/or enteral nutrition consumer (HPEN) who is eighteen years of age or younger and who shows a positive attitude in dealing with illness and therapy which encourages and inspires others. This year, the award was given to James DeLano.

James is an extraordinary young man living with mitochondrial disease, hemophagocytic lymphohistiocytosis (HLH), and severe eosinophilic esophagitis. Over the last eleven years James has overcome many obstacles with chronic illness, including nine years of enteral nutrition and four years of parenteral nutrition. Throughout his journey he’s remained positive, always looking for the good and sharing his experiences to help others. James has maintained his thirst for knowledge and a desire to be a vital part of his family and active contributor to his community through volunteer work.

In his free time, James enjoys volunteering for organizations that have helped him and his family. His volunteer service includes yearly donation drives for the Ronald McDonald House of the Carolinas (his family’s home away from home), helping his family raise service dog puppies-in-training for Canine Companions for Independence, working at his local library, helping out at the barn where he does equestrian therapy, organizing blood drives in his community, and speaking in public to share his story whenever possible. James logged over 150 hours of community service this past school year.

James not only feels compelled to help others within his local community, he also enjoys attending conferences to expand his learning and to meet others. While at conferences, James is known to reach out to the younger or less experienced children on parenteral or enteral nutrition and share his experiences. He has a way of instantly making others comfortable by relating to their story and showing genuine compassion for those managing life with similar struggles.

One nominator has written about the wonderful example James is to their son: “He knows James can get sick easily and cannot eat like most kids do, but he doesn’t see James as a weak or sick person. He sees James as a smart and kind kid. He looks up to James for his creativity and he sees James volunteering in the community… He sees the power and perseverance in his friend. He knows he is loved by James and he thinks James is one of the coolest kids in the world. James inspires my son and other kids around him to look outside themselves and whatever they may be going through and to continue to connect with the world around them to make life better for others.”

James’ loving smile and warm hugs are the outward signs of his strength of character and goodness of his heart. James is a true example of strength and perseverance, and he inspires others with his determination and passion for increasing awareness about managing life with a rare disease.

James says, “I am enormously honored to have received this award. I was surprised to have received this honor and never considered there would be any reward beyond the work itself.” About the conference, James says, “The Oley conference was overflowing with loving and supportive people.”

Congratulations to the nominees:
Tommy Adams; Easton Anderson; Gabriella Ecdao; Emma Foster; Hannah Jordan; Norah Kerr; Ellie Kuntz; Samyuel McKee; Streeter Petrizzo; Bryleigh Roop; Michael Smith

Innovator/Advocator Award
Sponsored by Avanos, Bronze Star Partner

Misti and Will Staley

The Innovator/Advocator Award was established to recognize a home parenteral and/or enteral nutrition consumer (HPEN) or caregiver who sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care. This year, the award was given to Misti and Will Staley.

After losing their son Freeman in 2016, Misti and Will turned their grief into a passion to help others. Misti and Will have created a feeding tube holder, named the FreeArm Tube Feeding Assistant in honor of Freeman; have been instrumental in the creation of a handicapped-accessible playground in Arkansas; and provide supplies to school children.

As Misti fed Freeman breast milk through a G-tube—simultaneously adding medications and trying to keep a hand free to turn him over to keep him from aspirating when he would throw up—she realized she needed another hand. To address the need, she and Will devised an L-shaped arm out of wood that attached to Freeman’s bed to hold the feeding tube up high enough to allow for gravity feed. This makeshift arm was helpful, but only when Freeman was in bed.

After Freeman passed away, Misti continued to stay in touch with other moms she had met during his nine-month stay in the ICU.
Seeing a continued need, Misti began to think about ways to make a version of Freeman's feeding tube holder that would be portable and could be used with strollers, car seats, at the dining room table, at home or when traveling—whenever and wherever. After researching their ideas, Misti and Will designed the FreeArm, a lightweight, portable, bendable tube feeding “stand” that clamps to just about anything and holds a syringe, feeding bag, and/or pump. Today the FreeArm is being sold throughout the United States and abroad.

Misti and Will’s actions in their home community show a deep commitment to the youth and children in the impoverished Mississippi Delta region where they live, just south of Memphis, as well. Misti raised over $250,000 to create and build the Freeman Playground in Helena, Arkansas, to address the need for a handicapped-accessible playground for children and families in their area. In addition, they provide backpacks and school supplies for children returning to school, and Misti and Will work with local youth to paint murals conveying positive messages.

Misti and Will say they love their tube feeding community and find comfort knowing that their experiences are shared by many other inspiring people. In expressing their gratitude for being given the Innovator/Advocator Award, they write, “We met so many amazing, thriving, and inspiring people at the Oley conference. We are honored to be a part of such a kind community of people.”

**Congratulations to the nominees:** Peyton Buhler; Irina Chaykowsky; James DeLano; Maggie English; Brenda Gray; Melinda McIntire; Nancy Pickett

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HPN Research Prizes, from pg. 1

deficiency (EFAD). The pro-inflammatory nature of soybean oil is a potential factor in parenteral nutrition associated liver disease (PNALD) development. An ILE containing four types of oils (soybean oil, medium-chain triglycerides [coconut oil], olive and fish oil) is now approved for use as a calorie and fatty acid source. Studies in HPN patients have shown mixed results with regard to changes in liver function tests and fatty acid profiles while receiving a four-oil ILE.

**Purpose:** This study was conducted to evaluate the association between a four-oil ILE and PNALD-related laboratory values in adult HPN patients with baseline abnormal liver function tests.

**Methods:** Eligible subjects were adult HPN patients from twelve branches of a home infusion pharmacy in nine states with baseline abnormal alkaline phosphatase (ALP), aspartate aminotransferase (AST), alanine aminotransferase (ALT) or total bilirubin (T bili) and receiving a four-oil ILE (Smoflipid®). One of these values was required to be at least 1.5 times the high normal limit. There were 77 adult patients enrolled in the study; 62 (80.5%) were receiving a soybean oil–based ILE prior to starting a four-oil ILE. Data were retrospectively collected at: Baseline, 1 Month, 2 Months, 3 Months, 6 Months, and 12 Months. Laboratory sampling coincided with the patients’ routine lab monitoring and included ALP, ALT, AST, T bili, triglycerides (TG) and triene:tetraene ratio. Reports of physical manifestations of EFAD were collected. Primary outcome measures were changes between time points in ALP, ALT, AST, and T bili. Secondary outcome measures included changes in TG and EFAD manifestation between time points.

**Results:** Overall, ALT, AST, ALP, T bili and TG decreased from Baseline to Month 12. A statistically significant decrease in ALT and AST was first detected between Baseline and Month 1, and a statistically significant decrease in ALP was first detected between Baseline and Month 2. ALT, AST and ALP all showed statistically significant decreases between Baseline and Month 12. There were two reports of physical manifestations of EFAD (dry, flaky skin) at the Baseline (n=1) and Month 1 (n=1) in the same patient. Of note, this patient had been receiving a soybean oil–based ILE prior to changing to a four-oil ILE. No triene:tetraene ratio results were reported for any subject at any time point.

**Conclusions:** Use of a four-oil ILE is associated with a clinically and statistically significant decrease in ALT, AST, and ALP in the subject population. Clinical significance is supported by the return from abnormal AST and ALT values at Baseline to a normal reference range at the Month 1 and Month 2 time points, respectively. There were also statistically significant decreases in ALP and clinical significance supported by a decrease toward normal values. Overall, the use of a four-oil ILE may provide benefit over traditional ILE in adult HPN patients with PNALD-related laboratory values.

Saketh Reddy Velapati, MBBS
Mayo Clinic, Rochester, Minnesota

Safety and Effectiveness of Catheter Repair in HPN

**Background:** Patients with chronic intestinal failure (CIF) who require long-term PN rely on central venous catheters (CVCs) for access to nutrition and hydration. With prolonged use, complications such as central line associated bloodstream infection (CLABSI), damage to CVCs, and central venous thrombosis (CVT) can threaten the availability of life-preserving access. Due to this, all efforts should be made to preserve CVCs with techniques such as catheter salvage in case of CLABSI and catheter repair when damaged.

**Purpose:** The study was conducted to evaluate the effectiveness and safety of catheter repair in our hospital patient population.

**Methods:** We conducted a retrospective review in 1253 adult patients who received HPN at Mayo Clinic between 9/1/1997 and 4/30/2018. The incidence of CLABSI and CVT were determined in patients who underwent CVC repair in that period.

**Results:** A total of 55 CVC repairs were done in 36 patients whose mean age at catheter placement was 57.05 ± 16.96 years and 64% were female. Most common indication for HPN was short-bowel syndrome (53%). Median duration a catheter was in place was 1552 days (interquartile range 905-2413). During the study period, a total of 14 catheters (25.45%) were complicated with 24 episodes of CLABSI; we observed the...
2019 Walkathon Raises Awareness, Program Funds

Our thanks to everyone who walked in this year's Walkathon, to those who supported the walkers, and to the walk sponsors. Together these walkers raised more than $8,000, and matching gifts are still coming in as we go to press!

Walkathon Participants

Asher Arandela; Rhonda Arends; Quinn Avis; Cody Baio; Hanne Bak; Deon and Gerardo Balli; Lillian Harvey Banchik; Johanna Barrington; Team Baxter: Amy Arnhold, Mary Hise Brown, Rohit Burju, Amber Burnett, Ryan Callahan, Joe Callen, Deniz Cigerci, Gordon Drewes, Marie Colette Galea, Valery Gallagher, Jun Greninger, Hameed Hirani, Peter Hoagland, Julie Jakubowski, Toni Kaaechele, Stephanie Khin, Matt Kloss, Amy Knighton, Kathleen Kula, Rex Kuriger, Caitlin Laystrom, Tony Looper, Lindsey Mansfield, Kristine Moore, Will Morrison, Mansi Mehta, Faith Ottery, Sanjay Patel, Josh Pham, Kaleem Qureshi, Mary Russell, Yuri Salido, Marion Sammut, Sue Schwabe, Sue Seme, Jessica Servon, Moulik Shah, Becky Strauts, Eric Tatro, Jorge Vasseur, and Steven Wyrwa; Hadar, Melanie, Jason, and Emma Birger-Bray; Joan Bishop; Ashleigh Bond; Kyleigh Bond; Bette Bond; Betty and Buddy Bond; Amy Braglia-Tarpey; Laura Castro; Roslyn Dahl; Howard and Marcia Denenholz; Tiffany Dodd; Donathan Donley Jr.; Becky Edwards; Todd Friedman; Mara Golden; Brenda and Mollie Gray; Andrea Guidi; Linda and Coleman Gulden; Karen Hamilton; Bushra Hassan; Daulton and Rachel Heisey; David Helgeson; Marcia Heuss; Jeff Hoelle; Joy McVey Hugick; Arianna Jordan; Asia Jordan; Tanya Jordan-Jackson; Phil Kellerman; Sandra Kleier; Rhonda Knecht; Emily and Sue Koprucki; Colleen Lucy; Kathryn Mackercher; John Mahalchak; John Mahalchak, Jr.; Melissa Mambrot; Don McMichael; Michael Medwar; Randy Menk; The Moreno-Nuno Family; Gretchen Otermat; Bob and Katie Peters; Team Pfizer: Mary Baker, Jerry Boesch, Glenda Cardenas, Lisa Dunbar, Caleb Hart, Chris Hernandez, Melissa Kean Smetana; Stacie, Jason, Connor, and Morgan Poole; Javier Ramirez; Cynthia and Laney Reddick; Denise Richardson; David Rowland; Mary Salerno; Don, Linda; and Marlo Santagata; Bob and Mary Smithers; Rob and Tammi Stillion; Jennifer and Ethan Stoeffel; Jennifer Thiesse; Cathy Tokarz; Pam and Ally Winter; Mary and Natalie Wooten; Molly and Rich Yeselson; and Lis Zimmermann.
Finding the Life, from pg. 1

I no longer see my tubes as limitations on my life, I no longer accept my body, I love it. I no longer answer questions, I educate about them freely in a public setting. From a single Oley conference, I have become empowered. I no longer think of Oley as something to hide, to flaunting them by the poolside and speaking an impossible thing to realize. I went from seeing my tubes and scars as something to hide, to flaunting them by the poolside and speaking about them freely in a public setting.

From a single Oley conference, I have become empowered. I no longer accept my body, I love it. I no longer answer questions, I educate through them. I no longer see my tubes as limitations on my life, I see them as the sole reason I can live it, and Oley has shown me that through them. I no longer see my tubes as limitations on my life, I no longer accept my body, I love it. I no longer answer questions, I educate about them freely in a public setting. From a single Oley conference, I have become empowered. I no longer think of Oley as something to hide, to flaunting them by the poolside and speaking an impossible thing to realize.

Impact of Meeting Others

The greatest part about the Oley conference for nearly everyone—consumers, caregivers, clinicians, corporate representatives, and myself—is meeting the other members of the HPEN community. Getting to share stories and relate to other people when you have a rare disease—or any affliction—is so, so important. I met someone who had been on HPEN for decades, but this was her first conference. Watching this person learn and grow over a period of four short days is an experience I will never forget. She went from thinking a life on HPEN wasn't a life at all, to being excited for the days to come and about the bonds she'd made. This is the impact that Oley has on its members.

Before the conference, I hadn't communicated with another HPEN consumer in at least a decade. I didn't think I had to—I didn't want to become my disease. But coming to the conference and seeing all of these consumers gathered together made me realize that being a part of Oley doesn't make me my therapies. Instead, it shows me the amazing things I can do because of it, and as a teenager, that can be an impossible thing to realize. I went from seeing my tubes and scars as something to hide, to flaunting them by the poolside and speaking about them freely in a public setting.

From a single Oley conference, I have become empowered. I no longer accept my body, I love it. I no longer answer questions, I educate through them. I no longer see my tubes as limitations on my life, I see them as the sole reason I can live it, and Oley has shown me that there is a lot of life out there to live.

Scholarship, from pg. 1

Derick has a learning disability and, his mom tells us, worked hard with a speech therapist to put his life into his own words when applying for this scholarship. He did a wonderful job with it, and, as you read Derick’s story, it becomes clear why he and his parents are so excited he will be attending his program.

“I became aware that I was different from other kids when I was very young,” Derick says. “At about six years old, I realized that my brothers and sister didn't have tubes. I played on a special needs soccer team with my best friend Kyle, a special needs baseball team, and in some local Special Olympics events. My friends Kyle and Isabelle, who were in my age and had the same issues as me, both died when I was eight years old.

“I'm OK with who I am and feel no shame about my disabilities. I've never known any different and don't expect people to treat me differently. Anytime someone asks, I will show and talk about my tubes. My online username for Xbox is ‘Mitomaniac. Za’ because I have a mitochondrial deficiency. If a friend asks, I explain why I chose this name.

“There have been many people at school who I inspire. My intent was to help them with their needs, but it turned out to be fun. My friend Matthew had an NG tube and was getting a G tube. He was nervous about it. So, I talked to him about how it was not a big deal. My friend Johnny has a talking device. I always talk the same with him as any other kid because he understands what you say.”

Andy Guy, an intervention specialist who has worked with Derick at school, writes, “Derick quickly rose to the top of the class as our most dedicated, hard-working, and responsible student. He was eager to be in school, to learn, and to make new friends. He was a model student from the beginning…[T]he way he bonded and connected with other students…really began to captivate me as a teacher. I began to notice how his classmates loved him, how they would crowd around him just to be near him and interact with him. I began to notice how kind, patient, and nonjudgmental he was towards them. It wasn’t long before students were asking Derick for help before they would ask their teachers.”

Andy continues, “[Derick’s] presence and modeling in the classroom was helping all of my students perform better. When the kids were having fun, they would have more fun with Derick. When the class was working at their maximum potential, they found a way to work even harder with Derick. When the kids would laugh, they always seemed to laugh a little louder with Derick. This young man was lifting the spirits of those around him. He was bringing joy, hope, excitement, and enthusiasm to his friends and classmates.”

“Helping kids in the classroom is something that I like to do,” says Derick. “When the kids are agitated, I give them something to do. I help them stay focused on the activity so they can calm down. This also helps the teachers so they can attend to the other kids. I see and treat all kids for who they are rather than focusing on whether or not they have a disability. It is important to me to interact with everyone the same way. That is why I’m so excited to get my Human Services Assistant Certificate and be able to help kids like me.”

Conference News

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July/August 2019
Oley Conference Summary

By the Numbers
5: Awards presented
7: Countries represented by attendees
14: Funded travel grants
16: Oley Ambassadors attended
26: Breakout sessions (including Tube Feeding Workshop)
35: States represented by attendees
39: Exhibits in exhibit hall
42: Children, from 1 to 18 years old
42: Faculty (presenters)
45: Award nominees recognized
165: First-time attendees (includes faculty)
435: Total attendance. Includes HPEN consumers (76 adults and 24 children); family members/caregivers (107 adults and 18 children); clinicians (41 dietitians; 14 nurses; 19 physicians; 10 pharmacists; 3 other); exhibitors (105); and volunteers and staff (18).

Videos Online
Videos and slide presentations of conference talks are available to view free of charge at: www.oley.org/2019confpresentations.

Oley Regional Conferences Coming Soon!

October 4
Las Vegas, Nevada
— and —

November 9
Ft. Lauderdale, Florida

Go to www.oley.org/event to
• Register free of charge
• Read information on topics and speakers

...or contact Andrea Guidi at (508) 460-1707, andreaguidi.oley@gmail.com.

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• Once you are signed in, go to “Edit bio” to update your information.

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You need to sign in to access our online store.
This is where you request donated tube feeding supplies (formula, bags, syringes, etc.) or Oley publications and awareness materials (brochures, awareness buttons, etc.). Signing in also makes it easier to register for Oley events.

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Thank You to All Who Contributed to the Oley Conference

Our heartfelt thanks to the many who contributed to make the Oley/ UI Health conference a success. To UIUC staff for partnering with Oley to host the meeting, to volunteers who helped at the registration desk, in Kidz Klub, and all around; to the faculty who prepared and presented information without compensation; to the exhibitors who made the exhibit hall such a fun place to be; to the corporate and individual sponsors who helped make the meeting possible; and to all the attendees who opened their hearts and arms to each other—a huge thank you.

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

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Actuated Medical, Inc.; Applied Medical Technology, Inc. (AMT); Aristacare Health; American Society for Parenteral and Enteral Nutrition (ASPEN); Avanos; Baxter; Ben Guard Healthcare Solutions LLC; BioScrip Infusion Services; Boston Scientific; BriovaRx Infusion Services; Cardinal Health; Chronically Fit; CoapTech LLC; Cook Medical; Coram/CVS specialty infusion services; Covalon Technologies; Feel Good, Inc.; FreeArm Tube Feeding Assistant; Fresenius Kabi USA; GEDSA; Interra; Intestinal Rehabilitation and Transplant Center at UI Health; Kate Farms; Medline Industries Inc.; Mighty Well; Moog Medical; MVP Medical Products; NeoMed; Nestlé Health Science; Nutrishare, Inc.; Option Care; Real Food Blends; SBS Cure Project; Soleo Health; Takeda Pharmaceuticals; ThriveRx; Transportation Security Administration (TSA); U Deliver Medical; Zealad Pharma

Faculty (donate their time and expertise, with a special nod to conference co-chairs Joan Bishop and Alan L. Buchanan, MD, MSPH, FACN, FACP, FACP, AGAF; Enrico Benedetti, MD, FACS; Joan Bishop; Carol Braunschweig, PhD, RD; Alan L. Buchanan, MD, MSPH, FACN, FACP, FACP, AGAF; Amy Long Carrera, MS, RD, CNSC; Robert Carroll, MD; Valeria Cohran, MD; Maureen Daly; Rick Davis; Mark DeLegge, MD; Lisa Epp, RDN, CNSC, LD; Celia A. Fairbanks; Beth Gore, PhD, MBA; Brenda Gray, PharmD, BCNSP, CNSC; Kathleen M. Gura, PharmD, BCNSP, FASHP, FPPAG; Joy McVey Hugick; Hannah Jordan; Swapna Kakani; Darlene Kelly, MD, PhD; Jack Leibee, MA, MS; Beth Lyman, RN, MSN, CNSC; John R. Mahalchak; Richard McCallum, MD; Russell Merritt, MD, PhD; Ann Michalek, MD; Manpreet Mundi, MD; Emily Parks; Cynthia Reddick, RD, CNSC; Jessica Salgado, RN, BSN, CWOCN; Douglas Seidner, MD, AGAF, FACP, CNSC; Timothy Sentongo, MD; Michael Sherels; Mario Spaggiari, MD; Heather Stanner, MS, RD, LDN, CNSC; Amy Stone, BSN, RN, CRNI, IgCN, VA-BC; Tiffany Taft, PsyD; Kelly Tappenden, PhD, RD; Alexis Turner; Saketh Reddy Velapati, MBBS; Mary Wootten; Yannick Wouters, MD; Linda Zekas, MSN, APRN, CWON, NP

Join Us for Two Oley Webinars with Dr. Taft

“You Should Totally Meditate!”: Realistic, Effective Strategies to Cope with Day-to-Day Life with HPEN (consumer centered) September 10, 1–2 p.m. (EDT)

“You Need Self-Care!”: What Can I Do to Cope with Being a Caregiver to a Loved One on HPEN? (caregiver centered) October 8, 1–2 p.m. (EDT)

Register for free at wwwoley.org/webinars. If you miss the live event, the recording will be available online.

Tiffany Taft, PsyD, is a clinical psychologist from Chicago, Illinois, a research assistant professor and Director of Psychogastroenterology Research at Northwestern University Feinberg School of Medicine, and founder of Oak Park Behavioral Medicine, a private psychology practice specializing in treating patients with chronic digestive diseases. She has published extensively on psychosocial aspects of digestive diseases with interests in stigma, fatigue, and post-traumatic stress disorder (PTSD).

Dr. Taft presented “Psychosocial Issues Related to Intestinal Failure” at the conference in June (video of the session available at https://vimeo.com/343199408; Dr. Taft’s presentation begins approximately 25 minutes into the video) and an edited transcript of an interview with Dr. Taft on the subject of PTSD was published in the Lifeline Letter (Sept-Oct 2018; www.oley.org/PTSD).
Steven Vogler, Newest Oley 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/ambassadorsmain or call (518) 262-5079. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice. Please do not contact Oley Ambassadors for solicitation, marketing, or research purposes.

Meet our newest Oley Ambassador!

Steven Vogler

My wife, Jean, and I live in the Grand Rapids, Michigan, area. We have no children, but do not get us started on Molly, our latest dog. Jean is a retired nurse. I am retired/on disability also. I worked mostly in the technology field, but I also worked about eight years as a certified nursing assistant (CNA) with traumatic brain injury (TBI) patients prior to becoming disabled.

Jean and I have both enjoyed bicycling; she is still actively riding, though I am not. We have had many hobbies through the years and have not allowed our health issues to curtail them. We recently started shooting sports and this has given me renewed strength and helped me regain abilities lost through nephropathy.

I’ve been at this for over thirty years. My story starts less than a year after Jean and I got married—and yes, we’re still married. It started with colon-rectal cancer when I was twenty-six. I lost the rectum and about a foot of large bowel; surgery was followed by radiation therapy. Colon cancer revisited me in 1999, discovered after a routine colonoscopy. This time, I lost my cecum and a foot on either side of it.

I started having a little problem with ostomy output afterwards. Apparently, the small bowel doesn’t care to be radiated and even though it had been twenty years previous, a large portion decided we should part ways in the summer of 2008. Six years later another cancer was discovered in a routine colonoscopy, and the remaining large bowel was removed. Months later it was “discovered” I only have about 90 cm of small bowel left, which led to me being dependent on home parenteral nutrition (HPN). I have been on HPN since 2014 due to short bowel syndrome.

After participating in the Oley conference in Memphis, Tennessee, in 2018, I decided I wanted to be an Ambassador for Oley. I am looking forward to reaching out and helping others with support and encouragement.

You can reach me at stevenvogler@hotmail.com or (616) 881-7192 (text preferred).
Philadelphia Support Group

Hadar Birger-Bray

It all began when I found out that in my small congregation (350 families), there are 5 people that live with a feeding tube and/or parenteral nutrition (TPN). When I realized that the number of people who are in the same boat as I am is higher than what I believed to be, I decided to take action and start a support group.

The Philadelphia Suburbs Feeding Tube/TPN Support Group is open for both consumers and caregivers. The group includes a range of conditions, and what unites us all is the wish to interact face-to-face with someone else that understands what we are going through.

During our first meeting we had a discussion about our relationship with food. It was very interesting to hear and learn how both sides (consumers and caregivers) feel about it. Some of the people said they had a “love-hate” relationship—they love food, but their body doesn’t. From the caregivers’ point of view, the conflict is in enjoying eating while your loved one struggles with it.

With meeting following meeting, we have had a variety of topics. During one of the meetings we were lucky to have Dr. Aleksandar Damevski, a dentist who spoke to us about oral care when you suffer from dry mouth or vomiting or are NPO. He also gave tips to caregivers on how to help a loved one maintain oral health when the person can’t do it on their own.

At another meeting, we had an amazing team of nurses from Einstein Montgomery Hospital come to speak with the group. We had an IV access nurse, an interventional radiology (IR) nurse, and a wound care nurse. They did a phenomenal job and even made a Power Point presentation that covered everything from G-tubes to central lines.

At our July meeting, we were honored to have Linda Gravenstein, an access nurse, an interventional radiology (IR) nurse, and a wound care nurse. They did a phenomenal job and even made a Power Point presentation that covered everything from G-tubes to central lines.

At another meeting, we had an amazing team of nurses from Einstein Montgomery Hospital come to speak with the group. We had an IV access nurse, an interventional radiology (IR) nurse, and a wound care nurse. They did a phenomenal job and even made a Power Point presentation that covered everything from G-tubes to central lines.

Future meeting topics include finding the balance between medical and non-medical life, and medical marijuana (please note that medical marijuana is legal in the state of Pennsylvania).

Our group meets once a month (usually the first Thursday of the month) at the Wissahickon Valley Public Library in Blue Bell, Pennsylvania. For details, please contact me at hadarbirger@hotmail.com.

Yannick Wouters, MD

Radboud University Medical Center, Nijmegen, The Netherlands

A New Diagnostic Tool for Rapid Detection of Bloodstream Infections Using Droplet Digital Polymerase Chain Reaction in Patients on HPN

Introduction: Patients on HPN have an increased risk for catheter-related bloodstream infections. Currently, diagnosing bloodstream infections relies on blood cultures in order to identify the causative pathogen(s). Although blood cultures are considered the gold standard, it takes time for blood cultures to become positive (fungi 2–5 days, bacteria 1–2 days), resulting in a significant window before a correct diagnosis is made. A more rapid pathogen detection is critical for patient and catheter care, as well as guidance of early antibiotic treatment. The droplet digital polymerase chain reaction (ddPCR) is a novel culture-independent sensitive molecular technique that allows rapid identification of microbial pathogen DNA in whole blood.

Purpose: The aim of this study was to determine the feasibility and the diagnostic accuracy of the ddPCR to detect bloodstream infections in the HPN setting.

Methods: We analyzed a set of historically collected frozen blood samples from adult HPN patients with a suspected bloodstream infection, and compared these with blood cultures drawn on the same day. Whole blood samples with possible DNA from microorganisms were isolated and analyzed with ddPCR. Study outcomes included the time-to-diagnosis, the detection limit of bacteria and fungi, and the sensitivity and specificity of the ddPCR.

Results: In total, 45 blood samples were collected, of which 15 (33%) had positive blood cultures. Five (33%) blood cultures showed Gram-positive bacteria, three (20%) Gram-negative bacteria, three (20%) contained fungi, and four (27%) blood cultures were polymicrobial. In a short procedure of four hours, blood samples were isolated and analyzed. The ddPCR detection limit was approximately 1 to 5 bacteria and 1 to 2 fungi per PCR reaction (approximately one copy of DNA per 40,000 human cells). The sensitivity of the ddPCR was 80% (95%CI 52–96) and the specificity 87% (95%CI 69–96).

Conclusions: The ddPCR technique has great potential and is able to detect pathogen DNA in whole blood within a short time span of four hours. Currently, the ddPCR has an acceptable sensitivity and specificity for identifying pathogens from whole blood. The ddPCR seems to work especially well in predicting true negative results. A larger prospective study will be conducted to confirm these results.
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 4, 2019, through July 12, 2019.

**Tributes:** In honor of Howard and Marcia Denenholz; Phil Kellerman; Aidan Koncious; Michael Levin’s birthday; Dashiell Lyons

**Memorials:** In memory of Ann DeBarbieri; Jeff Dutton; William Fitzpatrick, Sr.; Linda Franco; Kay Oldenburg; Paula Southwick; Bob Sweet; John Tucker; Elizabeth “Liz” Tucker

**Fund-raisers:** Al Mackay’s Long Trail hike; BriovaRx Infusion Services fund-raiser at ASPEN’s annual conference; Facebook campaigns for Hadar Birger-Bray’s walkathon and Elizabeth Bond’s birthday; Phil Kellerman’s Rotary Club music event and CD sales

**Matching Gift:** The GE Foundation

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.

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Oley Calendar

**Ongoing:** Applications being accepted for Oley Tim Weaver Camp Scholarship

**September 10:** Oley webinar, “You Should Totally Meditate!”: Realistic, Effective Strategies to Cope with Day-to-Day Life with HPEN (consumer centered)

**September 23–27:** Oley participating in Malnutrition Awareness Week

**October 4:** Oley/Association for Vascular Access collaborative education day, Las Vegas, NV

**October 4–7:** Oley exhibiting and participating in Association for Vascular Access (AVA) Annual Scientific Meeting, Las Vegas, NV

**October 8:** Oley webinar, “You Need Self-Care!”: What Can I Do to Cope with Being a Caregiver to a Loved One on HPEN? (caregiver centered)

**October 14–18:** HPN Awareness Week

**October 15–16:** Oley participating in National Organization of Rare Disorders (NORD) Rare Summit, Washington, DC

**November 8:** Oley exhibiting at Michigan Society for Parenteral and Enteral Nutrition (MSPEN) conference, Detroit, MI

**November 9:** Oley Regional Conference, Fort Lauderdale, FL

**March 28–31, 2020:** Oley exhibiting and participating in ASPEN Nutrition Science and Practice Conference, Tampa, FL

For updates or if you are able to help at one of the Oley exhibits listed above, please email harrinc@amc.edu or call (518) 262-5079.

**Additional Meetings of Interest**

**September 27–28:** Le Bonheur Pediatric Nutrition Symposium, Memphis, TN

**October 25–30:** American College of Gastroenterology (ACG) meeting, San Antonio, TX

**November 22:** PNDU social gathering, Adelaide, Australia

**November 23:** AuSPEN HPN Consumer Workshop, Adelaide, Australia

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**Calling Oley?**

If you’ve been with Oley for a while, you may need to clean up your address book! We gave up our toll-free line some time ago. That number now reaches what appears to be a disreputable service. The service is not affiliated with Oley and we have reason to doubt its legitimacy and quality. We do not recommend sharing your credit card information with this service.

Call us at (518) 262-5079. We look forward to hearing from you!