2018 HomePN Research Prize Winners

Congratulations to the winners of the 2018 HomePN Research Prize, sponsored by Nutrishare, Inc. Prize winners Marianne Opilla, RN, BSN, CNSC, and Yannick Wouters, MD, presented their research at the Oley annual conference in Memphis in June. Their slides and presentations, which provide more information on the studies, are posted at www.oley.org/AnnualConference. Unfortunately, prize winner Siri Tribler, MD, was unable to attend.

Our thanks to Nutrishare for underwriting this important effort to highlight research affecting home parenteral nutrition consumers. Below, please find edited versions of all three research abstracts.

Central Venous Catheters for Home Parenteral Nutrition: Characteristics and Outcomes of Devices in Place for Five Years or Greater
Marianne Opilla, RN, BSN, CNSC

Purpose: Intestinal failure patients may require home parenteral nutrition (HPN) for a lifetime. HPN is administered through a central venous catheter (CVC), and an important goal is to extend the dwell time of the CVC many years without complications leading to loss. The aim of this study was to examine a group of HPN patients and report characteristics and outcomes of CVCs in place for at least five years.

Methods: All charts of adult and pediatric patients from one home infusion pharmacy were retrospectively reviewed for CVCs in place for at least five years. Data collected included CVC type, days in place, number of lumens, material, and if removed, reason for loss. HPN regimen was also reported, including infusion days per week, cycle time, volume infused, and intravenous lipid emulsion (ILE) administration. Care routines were studied, such as use of protective alcohol cap; lock therapy; antimicrobial site patch; Omegaven, cont. pg. 14 ➔

Oley Foundation: Port in a Medical Storm
Rosana Shah
This year my daughter, Parri, and I had the honor and privilege of being able to attend our very first Oley conference (it was my husband’s second Oley conference).

Of course, there was acute apprehension regarding the travel and stay. The mum in me was worried about all the “what ifs.” What if she caught a cold! What if she caught C. diff! What if she caught HFM (hand, foot, and mouth disease)! You get the idea….My brain wouldn't switch off.

I reached out to my friend Ann W. She tried to allay my fears somewhat, but they remained in the recesses of my mind until I let my guard down. The Oley Foundation, however, made every effort to allow caregivers to have some peace of mind. Knowing that

Oley Foundation: Port in a Medical Storm, cont. pg. 14 ➔
Research, from pg. 1

dressing type; lab draw method and frequency; and identification of primary caregiver. Demographic data included age, gender, diagnosis for HPN, and years on HPN.

**Results:** Sixty-one patients, age 13 to 91 years, were identified as having at least one CVC lasting at least five years. Sixty-two percent of these patients were female. The primary diagnosis was short bowel syndrome (70.5 percent). Total HPN years were 1495, averaging 24.5 years. HPN averaged six days per week, 2050 ml over a ten-hour cycle, and 85 percent infused ILE at least one day per week.

With fifty-one tunneled CVCs, this was the most common type. There were nine infusion ports and one PICC. Most CVCs were single lumen (95 percent) and made of silicone (87 percent). Total CVC days were 241,219, with an average of 3954 days (10.8 years).

Twenty of the sixty-one devices were still in place at the completion of the data collection. Looking at the other forty-one CVCs, catheter-related bloodstream infection (CRBSI) was the most frequent complication resulting in CVC loss (n=20). The infection rate was 0.08 per 1000 CVC days. The second most frequent cause of CVC loss was catheter material damage (n=8), and the third was skin site failure (n=7). There were no obvious CVC losses related to infusion regimens.

The most frequently used CRBSI prevention strategy was the antimicrobial site patch (34.4 percent), followed by protective alcohol caps (18 percent), and alcohol lock (11.4 percent).** The majority of the patients did their own HPN administration and site care (self-care, 85.2 percent) and used transparent dressings (75.4 percent). Labs were drawn from the CVC 41 percent of the time, but none more frequently than once per month.

**Conclusion:** This cohort demonstrates that CVCs can remain in place at least five years without complications requiring removal. CRBSI was the most frequent reason for CVC loss, the CRBSI incidence was very low, and about a third of the patients used CRBSI preventative strategies. Use of transparent dressings and self-care may have impacted CRBSI incidence, but more studies would be needed to confirm this finding. The years of lived experience, education, and acquired catheter care knowledge in this unique group of HPN patients probably contributed to the low CRBSI rate. The material damage and skin site breakdown may be attributed to wear and tear as the CVC aged. HPN infusion regimens, thrombosis, occlusion, and blood draws from CVC did not appear to impact the CVC dwell time. Silicone, single-lumen tunneled CVCs provided the greatest longevity with the fewest complications, making this device the best choice for most HPN patients.

*"n means “number”

**The site patch is placed around the exit or insertion site of the CVC and remains in place under the dressing for up to seven days. It provides continuous release of chlorhexidine to the site as a preventive measure for site infection. CRBSI can occur when bacteria enter the CVC during manipulation at the hub with flush or infusion connections. Protective alcohol-embedded end caps cover the CVC when it is not in use to prevent skin or environmental bacteria from entering at the hub. Lock therapy sterilizes the internal CVC lumen to reduce bacterial load that may be present in biofilm.


Siri Tribler, MD

**Background:** In patients with intestinal failure receiving home parenteral nutrition (HPN), catheter-related bloodstream infections (CRBSIs) entail a risk of frequent need for replacements of the tunneled central venous catheters (CVCs). Implementation of a catheter-salvage strategy is important to preserve safe and long-term central venous access.

**Methods:** This retrospective study investigated the short- and long-term consequences of a catheter-salvage strategy in the Department of Medical Gastroenterology, University Hospital of Copenhagen (Rigshospitalet), Denmark. We evaluated all CRBSIs occurring in patients followed and treated in our tertiary intestinal failure unit from 2002 to 2016 by extracting data from the Copenhagen Intestinal Failure and Microbiological databases. Catheter salvage was defined by successful antimicrobial treatment with a retained CVC at discharge after a CRBSI episode. CRBSIs with reappearance of same microbial species...
Support the Medical Nutrition Equity Act

The Oley Foundation is part of the Patients & Providers for Medical Nutrition Equity Coalition (see www.medicalnutritionequityfor.us). The coalition has been meeting with members of Congress to ask that they co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587), which would provide public and private insurance coverage for medically necessary foods (including vitamins) for digestive and inherited metabolic disorders. Medically necessary foods would be covered under Medicaid, CHIP, Medicare, FEHBP, and private insurance if they are prescribed by the patient's provider.

Insurance coverage for medically necessary food varies widely, and many people do not have coverage. Even if your enteral formula is covered by your insurance, please join us in advocating for passage of this legislation.

What You Can Do

Legislators say they need to hear from constituents before they will co-sponsor this bill. Please contact your members of Congress and ask them to become a co-sponsor before the end of August. Here are some easy steps you can take:

• Call the DC office of your elected official.* A staff person will answer and ask where you live (to verify you are a constituent) and why you are calling. Tell them you want the Senator or Representative to co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587).

• Email your elected official. On the official's website*, you will find a link to "contact Senator/Congressman X." There will be a place to give your name and address (to verify you are a constituent) and another for you to write your message. If you are asked for a "message topic," select "health care" or write in "Medical Nutrition Equity Act." There will also be a space for you to write a message. Write a few sentences about why this bill is important to you and then make sure you include the "ask": "Please co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587)." If the "send a message" page will allow you to send attachments, send them one of the fact sheets from the coalition website** (under "For Policy Makers").

• Tweet at your members of Congress. Make sure you include their twitter handle (e.g., @senatorA) and the coalition hashtags: #MedicalNutritionEquityNow and #PPMNE.

Sample tweets include:

Co-sponsor the Medical Nutrition Equity Act today [elected official's twitter handle--e.g., @senatorA] #MedicalNutritionEquityNow #PPMNE

Dear [elected official's twitter handle--e.g., @senatorA], we need your support now as a co-sponsor on S. 1194/H.R 2587! #MedicalNutritionEquityNow #PPMNE

• Submit your story to the coalition website.** It will be used in our efforts to get Congress to move the bill. Once your story is on the coalition's website, you can print a nicely formatted copy and email or mail it to your congressional offices.

• If your Senator or Representative is already co-sponsoring the bill (see coalition website, under "For Policy Makers"), contact them to say thank you for their support.

Keep doing these activities until you see your elected officials listed as a co-sponsor on the coalition website. Ask your friends and family to reach out to their elected officials too. Remember, the squeaky wheel gets the grease!

Please share your efforts and stories with Oley (contact Lisa, metzgel@amc.edu or 518-262-5079). When there is a need in a specific region or an event planned in D.C., it is helpful to know who has been active on or is interested in this issue!

*Find contact information for your elected officials at www.medicalnutritionequityfor.us/join-us/#lookup, or by calling the Congressional switchboard at (202) 224-3121.

**Patients & Providers for Medical Nutrition Equity Coalition, www.medicalnutritionequityfor.us.
Congratulations 2018 Oley Award and Scholarship Winners

The annual Oley awards program recognizes home parenteral and enteral nutrition (HPEN) consumers and family members or caregivers who exhibit courage and perseverance in overcoming the adversity of illness and are generous in the effort of helping others. We are continually impressed by the stories clinicians, family members, peers, caregivers, and consumers relay as they nominate the people who’ve inspired them.

The award winners are chosen by a panel of previous award winners, Oley board and committee members, and Oley staff, and awards are presented each year at the Oley conference. It is a difficult job to select just one winner for each award! It is an outstanding pool of nominees, and we congratulate each of them, as well as the winners.

Please consider nominating someone who inspires YOU for any of these awards next year. Nomination forms will be available in an upcoming issue of the LifelineLetter; from January to April online at www.oley.org; or anytime by calling (518) 262-5079.

LifelineLetter Award, HPN
Sponsored by Nutrishare, Inc., Silver Circle Partner
Kristi Roach

This award is given to a person who has been a home parenteral nutrition (HPN, or IV nutrition) consumer for one year or longer, or his or her caregiver, who demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN.

Kristi Roach’s perseverance and positive attitude have allowed her to not only overcome the challenges of her disease, but to continue to grow and thrive. In 2012 Kristi started on home enteral nutrition (HEN) due to severe gastroparesis. By 2014 she was no longer able to tolerate her enteral feedings and began on home parenteral nutrition (HPN). Kristi refused to allow this to hinder her lifestyle. Despite her illness, hospitalizations, and discouragement from her instructors, Kristi continued her nursing education. She was determined to do something that would make a difference in the lives of others.

Kristi not only reached her goal of completing her education—she graduated on time. She is now a registered nurse in a cardiac unit. She feels her personal health experiences with central lines and feeding tubes have given her unique insight into her patients, unparalleled by other nurses. Her nursing schedule can be physically demanding, but Kristi has met that challenge head on.

Kristi remains selfless with her time, always giving to others in hopes of improving their lives. She is an active resource on social media for others diagnosed with gastroparesis and those who are HPN dependent. She loves hiking and being outdoors, and feels spending time with nature is very relaxing and a perfect way to relieve stress. Her love of the outdoors combined with a passion for running helped motivate her to finish her first half marathon last fall. Kristi is a true testament that anything is possible if you believe in yourself.

Congratulations to the nominees:
Mariah Abercrombie; Michelle Barford; Tiffany Dodd; Brenda Gray; Saira Grisales; Debbie Hansard; Sean May; Hayley Miller; Linda Psomas; Sara Ringer; Vicky Sedano; Samantha Smith; Tammi Stillion

Celebration of Life Award
Sponsored by ThriveRx, Gold Medallion Partner
Lauren Hood

This award recognizes someone who has been on parenteral and/or enteral nutrition for three years or longer and who lives life to the fullest (traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.).

Lauren Hood epitomizes living life to the fullest. She has been dependent on home parenteral nutrition (HPN) her entire twenty-four years of life and she has never let that stop her from pursuing her dreams. Lauren has had fifty-one surgeries since she was diagnosed with Hirschsprung’s disease at two days old. Lauren went to school, played soccer and softball in high school, and is now working full-time in her dream job as a pediatric intensive care nurse.

She has used all her experience from being a child with medical issues and HPN dependency to excel in her caring and connection with patients and their families. Lauren loves her work and is very passionate about her patients and families.

Lauren also has a full and active life outside of her career. She is happily married to her best friend, Kyle, and says she is so thankful to have such a supportive husband. She loves “doing life with him” (from traveling, to doing grocery shopping), and says when she is in the hospital, he is her biggest advocate. Lauren and Kyle recently visited St. Lucia in the Caribbean where they went four-wheeling in the rainforest and snorkeling in the ocean. Lauren is also an avid runner. She completed her first half marathon in December.

Lauren is very close to her family and says that her village has helped her excel and live such a full life. She enjoys connecting with families with children who have an ostomy and/or are HPN dependent to help show them they can still live a full life and follow their dreams.

Congratulations to the nominees:
Tyler Ashcroft; Jenna Banville; Gunner Bowlin; Matthew Cech; Lauren Ethridge; Brenda Gray; Melea Hart*; Nina Marino; Sean May; Ellen Meade; Hayley Miller; Sally Moore; Sharon Rose; Tammi Stillion
Innovator/Advocate Award
Sarah Palya

This award is given to a home parenteral or enteral nutrition consumer or caregiver of any age who sets an example by promoting innovation in nutrition therapy or by advocating for themselves or someone in their care.

Sarah Palya's inspiration and innovation first started with her son, who has been on nutrition therapy for eleven years. While raising a child on nutrition therapy, Sarah recognized there were challenges associated with his medical appliances and keeping them safe. Instead of waiting around for someone else to create something to help, Sarah got creative and began making accessories to secure her son's ostomy and G-tube. Soon other parents were inquiring about the accessories and Sarah started making them for others. Quickly this evolved into a complete line of medical accessories called Gus Gear, affectionately named after her son.

Creating everything from central line wraps to pump bag covers, Sarah has helped this community manage their nutrition therapy and medical needs. Sarah feels her products give people their quality of life back while allowing them to be active and engage with their peers. Sixteen hospitals in the United States and Canada now buy Gus Gear’s central line wraps for their patients. Sarah won the New England Pediatric Device Consortium’s 2017 Target Challenge for Catheter Securement.

Sarah continues to give back to her community through her advocacy and public speaking events. She was selected to speak at the Association for Vascular Access national conference in September. She remains optimistic, loving, and incredibly supportive of her son, daughter, and husband.

Congratulations to the nominees:
Brenda Gray; Saira Grisales; Ruth Hamilton; Heather Hanna; Andrew Jablonski; Luke Johanson; Jack and Carol Leibee; Carolyn Sue MacKinnon; Tammy Martin; Ellen Meade; Linda Pomas; Vicky and David Sedano; Tomas Thompson; Maggie Vladyka

Lifeline Letter Award, HEN
Sponsored by Kate Farms
Jennifer Dunegan

This award is given to a person who has been a home enteral nutrition (HEN, or tube feeding) consumer for one year or longer, or his or her caregiver, who demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN.

Award Winners, cont. pg. 6
Jennifer Dunegan was diagnosed with cerebral palsy, epilepsy, and food allergies at birth. She was weaned from HEN when she was three years old, but she has continued to experience feeding issues throughout her life. In 2014, Jennifer received a diagnosis of gastroparesis, and, due to complications, she was placed on parenteral nutrition (PN) for a period before being placed on HEN again last year.

Jennifer has faced the challenges associated with her medical conditions and HEN with a positive attitude and willingness to help others. She and her husband founded the non-profit organization Gastroparesis Support Services, Inc. (GSSI), which supports individuals who are undergoing testing and treatment for gastroparesis. Jennifer provides support, resources and information, including information about the Oley Foundation.

Jennifer believes we need to find effective methods to educate medical professionals about gastroparesis. One of her goals is to educate emergency doctors about her condition.

Jennifer is a lifetime member of the Girl Scouts, having received the Gold Award. She was also named a Kentucky Colonel, the highest title of honor bestowed by the Governor of Kentucky in recognition of an individual’s noteworthy accomplishments and outstanding service to the community, state, and nation. Jennifer’s selfless generosity has enriched the lives of many.

Congratulations to the nominees:
Sarah Dame; Brittany Detrick; Melea Hart*; Nina Marino; Ellen Meade

Child of the Year Award
Alex Beckwith

This award is given to a youth who has been a home parenteral and/or enteral nutrition consumer for one year or longer and who shows a positive attitude in dealing with illness and therapy which encourages and inspires others.

Alex Beckwith’s journey through life has been filled with doctors, hospitals, surgeries, tubes...G-tube, J-tube, and central lines. Through it all he has remained an encouragement to everyone around him. Shortly after he turned three years old, Alex was diagnosed with mitochondrial disease. He is dependent on home parenteral nutrition (HPN), yet he continues to inspire others with his joy for life and desire to give back.

Alex is the 2018 Children’s Miracle Network Hospitals Champion for Cook Children’s. He represents them by speaking and attending kickoffs, campaigning, and helping bring awareness to their hospital. He has raised money for the Extra Life program and spoken for the Make-A-Wish Foundation of America.

Alex enjoys playing video games, golf, theater, and volunteering with church, and is also a Boy Scout. He plays the violin, takes an acting class, is part of an improv group, and participates in a theater workshop each summer. This year he was Bert Healy in Annie, Jr. Above all, Alex is an amazing big brother and mentor to his sister, who also suffers from mitochondrial disease and relies on home enteral nutrition (HEN, or tube feeding). Alex’s courage, strength, and determination are apparent in everything he does.

Alex’s mom says, “I do not know anyone who exhibits more courage on a daily basis. Despite his life-threatening illness, almost forty doses of medication, and chronic pain, Alex lives every day to the fullest.”

Congratulations to the nominees:
Tyler Ashcroft; Gunner Bowlin; Alejandra Castellanos; Matthew Cech; Zachary Daugherty; Emma Dean; Olivia DeKold; Evelyn Delmenico; Hope Knight; Ansley McCormick; Maddie Morris; Alexander Mounayar; Melody Purkey; Kinzi Schneider; Michael Smith; Sydney Zimmerman

*We are sorry to share that Melea Hart has passed away since she was nominated for the LifelineLetter, HEN, and Celebration of Life Awards.
Kyle R. Noble Memorial Scholarship
Damarius Ingram

In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a $2,000 scholarship is awarded to an applicant who embodies the qualities for which Kyle is remembered.

This year, the scholarship was awarded to Damarius Ingram, a seventeen-year-old student who wants to pursue art. Meet Damarius:

My name is Damarius. At the age of fourteen I was diagnosed with multiple sclerosis, which changed my life. I was always a healthy individual, so when I became sick it was very hard for me to process it. For two years I suffered in silence with my family, trying to deal with being sick. I got into art, which really helped me cope and discover that things can get better. This is why I decided to major in art.

When I was sixteen I started to experience gastrointestinal (GI) related issues. I was diagnosed with gastroparesis and median arcuate ligament syndrome. I needed a feeding tube and gastric pacemaker. I was tired of suffering in silence, and I decided to create a blog that showed people you can live despite being ill.

Stories are powerful and sharing those stories change lives. I started living by this quote that I made: “I believe we live for each other in this chronic illness community. We live for those who can’t right now and they live for you while you can’t.” In this chronic illness community, we live for one another and we inspire one another to live. Illness doesn’t mean you have to stop living; it just means you have to start living differently.

I’m no longer the girl I was before I became ill. I’m a new, stronger version of my old self, though the journey of rediscovery didn’t happen overnight. It took me two years to see that all the obstacles I’ve faced were never meant to break me, but were meant to keep that fighter within me alive, so I would be able to inspire others with my story.

I am so thankful to be receiving the Oley Foundation Kyle R. Noble Memorial Scholarship this year and plan to keep inspiring others to always keep fighting and to never give up.

Ask Us!

In the last issue, we introduced our help/support/advice column. We plan to run this as often as possible, alternating “You Don’t Know What You Don’t Know,” by Michelle; “Life Without Limits,” by Mallory (watch for an article about Mal and her husband-to-be Owen in the next issue, space allowing); and a surprise offering from Fran, about dating, non-eating etiquette, or who knows?

Send your questions, concerns, comments, tips, ideas, experiences to the editor at metzgel@amc.edu or the Oley Foundation, Albany Medical Center MC 28, 99 Delaware Ave., Delmar, NY 12054. We welcome guest authors and suggested topics!
The Oley Foundation presents two Regional Conferences coming to you!

Saturday, September 15, 2018
Hilton Columbus Downtown
401 North High St.
Columbus, OH 43215
Register at www.oley.org/event/columbusregional

The Oley Foundation and Association for Vascular Access (AVA) come together again this year to present a regional conference filled with education and networking.

With support from…

Saturday, October 6, 2018
Bentley University
175 Forrest St.
Waltham, MA 02452
Register at www.oley.org/event/walthamregional

The map above shows where conference attendees came from. We’ve included the U.S. and Canada, but didn’t have room to show the home countries of attendees from Japan, Denmark, Netherlands, and Ireland.

Oley Conference Summary

By the Numbers
5: Awards presented
6: Countries represented by attendees
20: Funded travel grants
27: Breakout sessions (including Tube Feeding Workshop)
36: Exhibits in exhibit hall
36: States represented by attendees
38: Faculty (presenters)
43: Children, from 1 to 18 years old
47: Award nominees recognized
115: First-time attendees
391: Total attendance. Includes HPEN consumers (64 adults and 20 children); family members/caregivers (88 adult and 23 children); clinicians (45 dietitians; 11 nurses; 10 physicians; 8 pharmacists; 16 other); and exhibitors (106).

Beyond the Numbers—Attendee Feedback on Main Sessions
• My 49+ Years on HPN: Yesterday, Today, and All of My Tomorrows, by Sharon Rose
  “What an amazing story and person! It was great to hear Sharon speak about how things were (makes our TPN routine now seem so easy!), and I appreciated her positive attitude about all that she went through.”
  —Kathryn
• Adherence to Prescribed Therapy, by Emma Tillman, PharmD, PhD
  “Appreciated the patient experience and practical tips.”
  —Aletha
• Coping with Chronic Illness, Therapies, Etc., by Heather Eisele, PhD
  “Great info. Our daughter suffers a lot with several aspects of what Heather spoke about. Good to hear she’s ‘normal’ the way she feels.”
  —Jon
• The Trend to Blend—Things to Consider, by Lisa Epp, RDN, LD
  “A hot topic for a good portion of our community. Well done.”
  —Anonymous

Videos Online
Videos and slide presentations of these talks and others are available to view, free of charge at: www.oley.org/2018confdoc.
Explaining HPN
Your images will help!

2018 HPN Awareness Week is October 15–19. What can you do?

• Be in the movies! Send us your photo for a cameo appearance in an Oley video, or star in your own video and share it on the Oley You Tube channel. We’ll kick off HPN Awareness Week with our annual “Alive with HPN” video. Send us a photo of yourself, doing what you like to do (action photos welcome), along with a sentence or two telling everyone what you would like them to know about home parenteral nutrition (HPN).

• Contact your local newspaper, or radio or TV station. Reach out if you are comfortable sharing your story. Share a noteworthy event in your life (an HPN anniversary, a graduation or wedding, etc.) around which they can build a story. There may be someone in your community who will be encouraged by reading an article about your experiences.

• Wear your free HPN Awareness pin! Share them with friends, family, your clinicians...and help raise awareness!

Submit photos or videos to Lisa Metzger at metzgel@amc.edu or The Oley Foundation, Albany Medical Center MC-28, 99 Delaware Ave., Delmar, NY 12054, by October 5 (the sooner, the better!). For free pins, go to www.oley.org, e-mail Lisa, or call Oley at (518) 262-5079.

Give us a call if you’d like help with a press release.

Thanks to Baxter Healthcare for underwriting the pins and promotional materials for HPN Awareness Week 2018.

Art & HPN

In addition to photographs, feel free to share HPN-inspired art you’ve made. Above left: Pamela, on HPN for many years. Above right: Pamela’s painting number seven in a twelve-painting series of “women warriors” she created to depict her journey. Art therapy provided Pamela with a means of self-expression that helped her work through the difficult transition to life with chronic illness and pain. Her goal is to work towards the creation of art therapy centers (may include music, painting, drawing, dance, or other endeavors) at hospitals around the country. “Where there is a will, there is a way,” she says.
Table 1: Patient demographics and hazard risk ratios for subsequent CRBSIs.

<table>
<thead>
<tr>
<th>Patient and central venous catheter characteristic</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Total HPN patients (female/male)</td>
<td>715 (395/320)</td>
</tr>
<tr>
<td>Age at HPN commencement (mean ± SD)</td>
<td>57.14 ± 15.47</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>240 (33.6%)</td>
</tr>
<tr>
<td>Complications to non-IBD surgery, non-cancer abdominal surgery</td>
<td>185 (25.9%)</td>
</tr>
<tr>
<td>Inflammatory bowel disease (IBD)</td>
<td>139 (19.4%)</td>
</tr>
<tr>
<td>Mesenteric vascular disease</td>
<td>93 (13%)</td>
</tr>
<tr>
<td>Other causes of intestinal failure</td>
<td>44 (6.2%)</td>
</tr>
<tr>
<td>Complications to gastrectomy</td>
<td>14 (2%)</td>
</tr>
<tr>
<td><strong>Underlying reason leading to intestinal failure (pathophysiological group)</strong></td>
<td></td>
</tr>
<tr>
<td>Short bowel syndrome</td>
<td>416 (58%)</td>
</tr>
<tr>
<td>Dysmotility</td>
<td>85 (11.9%)</td>
</tr>
<tr>
<td>Mucosal disease</td>
<td>70 (9.8%)</td>
</tr>
<tr>
<td>Mechanical obstruction</td>
<td>23 (3.2%)</td>
</tr>
<tr>
<td>Fistula</td>
<td>24 (3.4%)</td>
</tr>
<tr>
<td>Combined</td>
<td>97 (13.6%)</td>
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<tr>
<td>Tunned CVC (n)</td>
<td>2006</td>
</tr>
<tr>
<td><strong>Total tunneled CVC days (years)</strong></td>
<td>735,708 (2014.3)</td>
</tr>
<tr>
<td><strong>CRBSI incidence in tunneled CVCs</strong></td>
<td>1.83 CRBSIs/1000 CVC days</td>
</tr>
<tr>
<td><strong>No. of CRBSI-related deaths</strong></td>
<td>5</td>
</tr>
<tr>
<td><strong>CRBSI-related mortality rate</strong></td>
<td>0.007 deaths/1000 CVC days</td>
</tr>
<tr>
<td><strong>Cox regression analysis with hazard risk (HR) ratios</strong></td>
<td></td>
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<tr>
<td><strong>CVC replacement versus retained CVC</strong></td>
<td></td>
</tr>
<tr>
<td>HR ratios for a new CRBSI (95% CI / p-value)¹</td>
<td>0.86 (0.74, 0.99/p=0.03 )²</td>
</tr>
<tr>
<td><strong>Salvaged CVCs—risk of any new CRBSI according to infection-type</strong></td>
<td></td>
</tr>
<tr>
<td>HR ratio for poly-infection versus mono-infection¹</td>
<td>1.36 (1.03, 1.79/p=0.03)²</td>
</tr>
<tr>
<td><strong>Salvaged CVCs—risk of CRBSI with same microbial species and identical antibiogram (recurrence)</strong></td>
<td></td>
</tr>
<tr>
<td>HR ratio for poly-infection versus mono-infection¹</td>
<td>1.92 (1.23, 3.0/p= 0.004)²</td>
</tr>
<tr>
<td><strong>Salvaged CVCs—risk of CRBSI recurrence with same microbial species and identical antibiogram</strong></td>
<td></td>
</tr>
<tr>
<td>HR ratio for <em>Enterobacteriaceae</em> versus <em>S. aureus</em>¹</td>
<td>4.45 (1.28, 15.5/p=0.02)²</td>
</tr>
<tr>
<td>HR ratio for CoNS versus <em>S. aureus</em>¹</td>
<td>1.97 (0.55, 7.03/p=0.30)²</td>
</tr>
<tr>
<td>HR ratio for <em>Enterobacteriaceae</em> versus CoNS¹</td>
<td>2.26 (1.08, 4.75/p=0.03)²</td>
</tr>
</tbody>
</table>

**Legend:** The Cox proportional hazard regression model was used, with p values testing the null hypothesis, no difference between groups, two-sided p value of < 0.05 was considered statistically significant. CoNS, coagulase-negative *Staphylococcus*.

¹ Evaluating all CRBSI events in our population, a frailty factor (patient-specific-effect) was incorporated, a statistical factor to account for recurrent events and overrepresentation of some patients and the total patient-risk-time scale was applied (the time from insertion of first tunneled CVC after 2002 and until HPN termination, death or censoring, was the risk-time applied).

² Adjusted for patient-age (10/year) and CVC age at CRBSI (per one year).
defined as a relapse (<30 days) or recurrent (30–100 days) infection.

The statistical analysis was performed with the Cox regression analysis, an analysis that gives a probability of experiencing an event (CRBSI) at a particular time-point. Furthermore we included a random effect. We thereby accounted for the fact that some patients are overrepresented in the dataset with repetitive CRBSIs.

Results: Seven hundred and fifteen adult HPN patients covering 2014.3 CVC years and with use of 2006 tunneled CVCs presented with a CRBSI incidence of 1.83 per 1000 (n=1350) (0.67 CRBSIs per CVC year) and a very low patient mortality rate of 0.007 per 1000 CVC days (n=5) in relation to a CRBSI episode. The mean salvage rate was 55.3% (SD±5.5%), varying according to infection-type (mono-infections [62.9±4.4%] and poly-infections [58.6±17.3%]); and causative microorganism (coagulase-negative Staphylococcus [CoNS] [68.1±9.4%], methicillin-sensitive Staphylococcus aureus [42.6±17.5%] and Enterobacteriaceae [54.3±16.7%]). (See tables 1 and 2.)

The overall risk of CRBSI relapse was 7.5% and the risk of CRBSI recurrence was 7.3%. The probability (hazard ratio [HR]) for a subsequent CRBSI was 14% lower in a replaced (=new CVC) versus retained CVC (p=0.03). The probability (HR) of experiencing a new CRBSI after catheter salvage was 36% higher after poly-infections (more than one microorganism detected) compared to mono-infections (only a single microorganism detected) (p=0.03).

Microorganisms in the microbial group called Enterobacteriaceae demonstrated an increased risk of CRBSI recurrence compared to both the group of microorganisms called coagulase-negative Staphylococcus (which is skin commensal microorganisms) (p=0.03) and the more virulent microorganism Staphylococcus aureus (p=0.02). No significant difference in risk was observed between the coagulase-negative Staphylococcus versus Staphylococcus aureus (p=0.30).

Conclusions: In adult intestinal failure–HPN patients, high catheter salvage rates were achievable and safe in relation to CRBSIs in single-lumen tunneled CVCs within a broad range of microorganisms. However, salvage inflicts an increased risk of CRBSI relapse or recurrence.

CI, confidence interval; n, number; SD, standard deviation

Repair of Damaged Central Venous Catheters Is Safe and Substantially Prolongs Catheter Survival in Patients on Home Parenteral Nutrition

Yannick Wouters, MD

Background: Repeated central venous catheter (CVC) loss due to complications, including material breakage, compromises the options to obtain adequate vascular access in home parenteral nutrition (HPN) patients. On average, per patient, there is one damaged CVC every ten years. The most frequent reasons for damage include natural wear of material; rupture due to flushing occluded catheters; damage from sharp objects; repeated clamping maneuvers; and frequent bending.

It remains unclear whether repair of damaged catheters is an effective strategy to extend catheter survival, avoid surgical replacement, and maintain venous access. The aim of this study was to evaluate the efficacy and safety of catheter repair in our cohort of intestinal failure patients.

Research, cont. pg. 12

<table>
<thead>
<tr>
<th>Microorganisms</th>
<th>Episodes with microorganism (mean ± SD)</th>
<th>CVCs salvaged (mean primary salvage rate ± SD)</th>
<th>Relapse infections (relapse rate)</th>
<th>Recurrent infections (recurrent rate)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gram positive bacteria</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CoNS</td>
<td>512 (37 ± 11.3%)</td>
<td>350 (68.1 ± 9.4%)</td>
<td>17 (4.9%)</td>
<td>28 (8%)</td>
</tr>
<tr>
<td>Staphylococcus aureus (no MRSA)</td>
<td>113 (8.9 ± 3.3%)</td>
<td>46 (42.6 ±17.5%)</td>
<td>2 (4.3%)</td>
<td>2 (4.3%)</td>
</tr>
<tr>
<td>Enterococcus species</td>
<td>102 (7.8 ± 2.9%)</td>
<td>51 (3.2 ± 21.3%)</td>
<td>7 (13.7%)</td>
<td>3 (5.9%)</td>
</tr>
<tr>
<td>Streptococcus species</td>
<td>36 (2.6 ± 2.3%)</td>
<td>22 (58.6 ± 39.5%)</td>
<td>1 (4.5%)</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Miscellaneous gram-positive bacteria</td>
<td>76 (7.0 ± 4.2%)</td>
<td>47 (61.1 ± 16.7%)</td>
<td>4 (8.5%)</td>
<td>8 (17%)</td>
</tr>
<tr>
<td><strong>Gram negative bacteria</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enterobacteriaceae</td>
<td>549 (38.4 ± 10.1%)</td>
<td>269 (54.3 ± 16.7%)</td>
<td>25 (9.3%)</td>
<td>20 (7.4%)</td>
</tr>
<tr>
<td>Pseudomonas aeruginosa</td>
<td>32 (2.5 ± 1.9%)</td>
<td>13 (35.2 ± 38.1%)</td>
<td>1 (7.7%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Miscellaneous gram-negative bacteria</td>
<td>89 (6.6 ± 3.0%)</td>
<td>42 (43.6 ± 22.8%)</td>
<td>6 (14.3%)</td>
<td>2 (4.8%)</td>
</tr>
<tr>
<td><strong>Infection type</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mono-infections</td>
<td>913 (67.9 ± 8.5%)</td>
<td>577 (62.9 ± 4.4%)</td>
<td>38 (6.6%)</td>
<td>36 (6.2%)</td>
</tr>
<tr>
<td>Poly-infections</td>
<td>296 (21.1 ± 6.5%)</td>
<td>155 (58.6 ± 17.3%)</td>
<td>13 (8.4%)</td>
<td>16 (10.4%)</td>
</tr>
<tr>
<td>Yeast and Fungi (total)</td>
<td>139 (11.0 ± 5.7%)</td>
<td>12 (5.5 ± 7.3%)</td>
<td>5 (41.7%)</td>
<td>2 (16.7%)</td>
</tr>
<tr>
<td><strong>Total CRBSI (tunneled CVCs)</strong></td>
<td>1350</td>
<td>744 (55.3 ± 5.5%)</td>
<td>56 (7.5%)</td>
<td>54 (7.3%)</td>
</tr>
</tbody>
</table>

Legend: Number of episodes with mean ± SD for the year 2002 to 2016. MRSA, methicillin-resistant Staphylococcus aureus. CoNS, coagulase-negative Staphylococcus. SD, standard deviation.
Methods: We performed a retrospective analysis of all catheter repairs that were performed between 2006 and 2017 at our tertiary referral center for intestinal failure. Primary endpoint was the additional median catheter survival after catheter repair, as calculated with Kaplan-Meier analysis. Survival of repaired catheters was compared with undamaged catheters. Secondary outcomes included risk for catheter-related bloodstream infections (CRBSIs) after repair (thirty days or whole catheter period, pre- versus post-repair), and risk factors for catheter damage, as calculated with Poisson regression analysis.

Results: A total of fifty-eight repairs in forty-one CVCs of thirty-five HPN patients were included in the analysis (see figure 1). The median time to first repair was 452 days (interquartile range [IQR] 206–1134). After repair, catheter survival increased by 316 days (IQR 96–804). Incidence rates were 1.23 and 1.26 CRBSIs per 1000 catheter days for the 30 days pre- and post-repair periods, respectively (relative risk, 1.03; 95%CI, 0.11–9.88; P=0.99). For the whole pre- and post-repair catheter period, incidence rates were 0.12 and 0.59 CRBSIs per 1000 catheter days, respectively (relative risk, 4.73; 95%CI, 1.46–19.98; P=0.006). The overall CRBSI incidence rates in undamaged versus repaired catheters were 0.84 and 0.31 CRBSIs per 1000 catheter days, respectively (relative risk, 0.37; 95%CI, 0.22–0.61; P<0.001). Both a younger age at catheter start and femoral catheterization were independently associated with an increased risk for catheter damage.

Conclusion: Repair of damaged catheters is often successful, and an effective and safe strategy to prolong venous access in HPN patients. Both physicians and patients should be aware of this relatively low-cost strategy to maintain venous access. Identification of risk factors may help educate patients, especially during catheter training, to prevent future catheter damage.

† A Poisson regression analysis compares groups, but corrects for events that occur multiple times. For example, catheters were used multiple times per patient, and CRBSIs occurred multiple times per patient and even per catheter.

†† To clarify, we conclude that repairs are safe (short-term, and overall) because:
• The risk for CRBSIs on the short-term (thirty days) after a repair was not increased and thus safe
• On the long-term (whole catheter period after repair) we observed an increase in CRBSIs. We think that the problem here is that catheters mostly at the end have a complication such as a CRBSI (that’s why they are removed). However, we officially cannot exclude the possibility that the repair itself also played a role for the increase in CRBSI rate.

When we compared repaired catheters with undamaged catheters, we found that repaired catheters (although there was an increase in CRBSI risk, see bullet 2 above) still had a lower risk of CRBSIs compared with undamaged catheters.

††† Physicians should be extra alert for younger patients and warn them to be careful with their catheters. Note that we included only adult patients in this study, and therefore you should, for example, interpret the data as a twenty-five-year-old patient having a higher risk for damage than a fifty-year-old patient.

2018 Walkathon Raises Awareness, Program Funds

Our thanks to everyone who walked in this year’s Walkathon, and to those who supported the walkers. Together these walkers raised $6,216!

Walkers were Aaron and Caleb Aldrich; Kristen Bessett; Hadar Birger-Bray; Mads Bjerringa; Ashleigh Bond; Earl (Buddy) Bond; Elizabeth Bond; Kyleigh Bond; Diane and Leighanne Boone; Charlie, Joe, and Kathy Cleberg; Zachary Colton; Roslyn Dahl; Olivia DeKold; Tiffany Dodd and Javier Ramirez; Celia Fairbanks; Mike Ferguson; Todd Friedman; Gabby Galvan; Andrea Guidi; Michelle Guinigundo; Ethel Hamilton; Karen Hamilton; Judy Hanson; Jeff and Rose Hoelle; Lauren Hood; Melissa Hughy; Joy McVey Hugick; Tonya Jordan-Jackson and family; Babu Kakani; Phil Kellerman; Rachel Loyal; Sue MacKinnon; John Mahalchak; John Mahalchak, Jr.; Sarah Martinez; Ansley McCormick; Eli Medwar; Michael Medwar; Andrew, Patrick, Tricia, and Wendy Melland; Lisa and Ron Metzger; Maddie, Mark, and Tammy Morris; Katie Peters; Robert Peters; Susan Ratner; Cynthia and Laney Reddick; Denise Richardson; Ceciel Roofer; Carolyn and David Rowland; Bob and Mary Smithers; Robert and Tammi Stillion; Dan Szumierz; Amy, Greta, Lucas, and Zach Thompson; Emma Tillman; Misty, Rylee, and Tegan Watkins; Ann Weaver; Ally and Pam Winter; Eli and Lynn Wolfsen; Mary and Natalie Wootten; Maggie and Sheila Zeidler; Lis Broested Zimmermann.
Thank You to All Who Contributed to the Oley Conference

Elsewhere in this issue, you’ll learn about Oley’s 33rd annual consumer/clinician conference in Memphis, Tennessee, through introductions to the Oley award winners, photos, summaries of the HomePN Research Prize–winning papers, and an article about how one of our members felt in attending an Oley conference for the first time. The week was busy and rewarding!

Here, we’d like to thank the many who contributed to make this conference such a success. To the volunteers who helped at the registration desk, in Kidz Klub, and at all around; to the faculty who prepared and presented information targeted to Oley members without compensation; to the exhibitors who made the exhibit hall such a bustling and fun place to be; to the corporate 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)
Abbott Nutrition; Esther Ann Brown Adler Memorial Fund; Albany Medical Center; Anonymous; Applied Medical Technology (AMT); Apria Healthcare; Association for Vascular Access (AVA); Auburn University; Baxter International Inc.; Boston Children’s Hospital; BriovaRx Infusion Services; Cardinal Health, Inc.; Melissa Chaney Memorial Fund; Coram / CVS Specialty Infusion Services; Cova lon Technologies, Ltd.; Fresenius Kabi USA; Fruit of the Earth; GEDSA; Bruce F. Groeber Family; Halyard Health; Interrad Medical, Makers of SecurAcath; Kate Farms; Le Bonheur Children’s Hospital; Jane Lindsay; Mayo Clinic; Memphis Center for Women and Families; Chris Miller; Moog Medical Devices Group; Mount Sinai Medical Center; Nestlé Health Science; Nutrishare, Inc.; Ohio State University College of Pharmacy; Option Care; Riley Hospital for Children; Ryder Science, Inc.; SBS Cure Project; Shire Pharmaceuticals, Inc.; Solo e Health; ThriveRx, Inc.; Transportation Security Administration (TSA); Trifecta Pharmaceuticals; University of Illinois; Vanderbilt Center for Human Nutrition

Exhibitors (exhibit fees help offset conference costs)
Applied Medical Technology, Inc. (AMT); Apria Healthcare; American Society for Parenteral and Enteral Nutrition (ASPEN); ASPEN Rhoads Research Foundation; Association for Vascular Access (AVA); B. Braun Medical, Inc.; Baxter Healthcare; BioScrip; Boston Children’s; Boston Scientific; BriovaRx Infusion Services; Cardinal Health, Inc.; CoapTech; Cook Medical; Coram / CVS Specialty Infusion Services; Cova lon Technologies, Ltd.; Fresenius Kabi USA; Functional Formularies G-PACT; GEDSA; Halyard Health, Inc.; Interrad Medical, Makers of SecurAcath; Kate Farms; Mighty Well; Moog Medical Devices Group; Nestlé Health Science; Nutrishare, Inc.; Option Care; Real Food Blends, LLC; SBS Cure Project; Shire Pharmaceuticals, Inc.; Solo e Health; ThriveRx; Transportation Security Administration (TSA); Trovita Health Science; U Deliver Medical, LLC

Volunteers (give their time and talents)
Kiley Bishop; Ashleigh Bond; Betty Bond, RN; Buddy Bond; Gianna Colburn; Howard Denenholz; Tiffany Dodd; Dotty Fickle; Zoe Fisher; Beth Gore, PhD, MBA; Ray Gravenstein; Melissa Hugh ey; Jeff Hoelle; Rose Hoelle; Joy McVey Hugick; Swapna Kakani; Emily Karimbakas; Barbara Kapuscinska Kelly, MD; Rachel Loyal; Caroline McHugh; Ron Metzger; Emily Parks; Marjorie Quinn; Javier Ramirez; Lan ey Reddick; Denise Richardson, RN; Erin and Greg Smith; Bob and Mary Smithers; Amy Stone; BSN, RN, CRNI, IgCN, VA-BC; Natalie Wooten

… and special thanks to Elvis for his guest appearance, which made the meeting that much more fun!

Silent Auction Raises $4000+
Thank you to all who donated to, volunteered at, and supported the Silent Auction this year at our annual conference in Memphis, Tennessee. We raised $1,138.50! Some hot ticket items were a Baby Lock Rachel sewing machine, vacation time in Vieques, beautiful handmade quilts, designer handbags and jewelry, and so much more. We cannot wait to see what next year’s event will bring!
families often had to travel thousands of miles to a center that offered this therapy. To help families obtain this lipid emulsion, Boston Children’s Hospital shared their protocol and disseminated information through Oley’s website and newsletters. Over the years, presentations at regional and national meetings helped to further disseminate information. Despite these efforts, in many cases, it was a hardship for families to reach centers that provided this therapy.

On July 27, 2018, the FDA approved Omegaven® based on data collected from Boston Children’s Hospital, Texas Children’s, and UCLA Medical Center. It will soon become available for children in need. There will be a lag time from approval until it will no longer be a study drug (approximately two to three months), so anyone who currently needs it will continue to receive it only through a compassionate use protocol. In the interim, the manufacturer, Fresenius Kabi, will be approaching insurance providers and pharmacy benefit managers as well as pharmaceutical wholesalers to determine reimbursement and assure patient access to the product.

Oley will work continuously with regulatory agencies and ASPEN to improve access to those patients in need.

Thank You Corporate Partners!

Please join Oley in thanking the companies that support Oley year round. Learn more about our most recent corporate contributor below, as they describe themselves and their products in their own words.

Baxter International Inc.

Baxter Healthcare is a leading provider of parenteral nutrition products and services—from compounding equipment to RTU parenteral nutrition solutions.

Omegaven, from pg. 1

Oley: Port in a Medical Storm, from pg. 1

a forgotten supply or piece of equipment could be replenished or an emergency was planned for, was extremely welcome.

Feeling Welcome and Understood

The conference evidenced what folks have been saying about it for years. It was chock-full of information, collective years of experience from many experts, and most of all people, young and old, with whom my daughter was able to identify.

Years of isolation melted away. All I could see, as people were exchanging stats and information, were nods, smiles, awareness, and insight. There was no need to waste time explaining the elemental stuff. You could say “TPN” without explaining what it was. After years of feeling like we were talking in “tongues” amongst the normals, here we were now with our tribe. No one had that dazed, trance-like expression. We felt heard and seen.

My daughter had the opportunity to forge friendships with kids her age. The conference proved priceless for that reason alone. She had a magnificent time at all the kids’ activities. Kids can be so exhausting and it was a welcome break for us parents! Hats off to Ann, Marjorie, Andrea, Mary, and all of the other volunteers. You are saints!

I was able to meet Facebook friends I’ve been interacting with for years. What a treat! The warmth, understanding, and kinship that you gain in person is not easily expressed online. The investment in the friendship increases exponentially once you meet in person.

It would be remiss of me if I did not mention how beneficial the robust discussions at the breakout sessions were. The interactive format allowed us to get to know one another better and benefit from each other’s experience with our different teams. My only complaint: if only they were longer!

Transforming Lives

As for my fears, we did return home worse for wear. We did not catch anything on my “what if” list. Instead, we caught Oley fever: a yearning to see and interact more with the friends we made. My daughter is already planning her attendance at next year’s conference!

Thank you to the Oley Foundation, donors, corporate partners, and volunteers who make it possible for medically dependent families to have a platform to forge meaningful and transformative relationships. Quality of life and quality of care is positively impacted.

Editor’s Note: Rosana Shah is an Oley Ambassador volunteer, and would be happy to hear from you, or to tell you more about her experience at the conference or raising Parri. You can call Rosana at (225) 326-8844, or email her at Parri814@gmail.com.
Notable Individual Gifts

Among the individual 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 April 6 through May 11, 2018.

Tributes
_in honor of Bettemarie Bond and Family; Aidan Koncius; Aleah Smith

Fund-raisers
Facebook campaigns for John Mahalchak’s birthday; Andy Miller’s birthday; Amy Rash Parson’s birthday; and Lynn Nagin Wolfson’s birthday
GoFundMe campaign organized by Ahilan Ponnusamy

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/plannedgifs.

Felicie 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 & Jay Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Grovenstein
Deborah Groeber
The Groeber Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
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Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD, PhD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Matave, PhD, RD, LDN, CNSC, FADA, FASPEN
Kathleen McNees
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 Riner
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnol
Doug Seidner, MD, FACC, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSG, & Gregory A. Thompson, MD, MS:
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+)
Shire

GOLD MEDALLION PARTNER
($50,000–$69,999)
ThriveRx, Inc.

SILVER CIRCLE PARTNERS
($30,000–$49,999)
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Learn more at www.oley.org/industrylandingPage

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Oley Calendar

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

September 15: Oley Regional Conference, in association with AVA conference, Columbus, OH

September 15–18: Oley attending and exhibiting at AVA conference, Columbus, OH

September 20–22: Oley attending and exhibiting at Pediatric Intestinal Failure Symposium, Pittsburgh, PA

September 24–28: ASPEN Malnutrition Awareness Week

October 5–10: Oley exhibiting at American College of Gastroenterology (ACG) meeting, Philadelphia, PA

October 6: Oley Regional Conference, Waltham, MA

October 6: World Ostomy Day

October 15: International HAN (Home Artificial Nutrition) Awareness Day

October 15–19: HPN Awareness Week

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

Additional Meetings of Interest

September 23: Loma Linda 5th Annual Super Kids Event, Loma Linda, CA

Webinar for Parents, Teens

August 21, 2018
1:00-2:00 p.m. EDT

Pediatric Transition to Adult Care
Featuring Tom Jaksic, MD, PhD

Transition to adulthood is an exciting time. However, as youth with special health needs mature and prepare for independence, they face greater challenges than their peers—including moving to a new set of adult providers, who think and operate very differently than the pediatric providers that have been seeing them all their lives.

Join us for this exciting webinar with Dr. Jaksic, the W. Hardy Hendren Professor of Surgery, Harvard Medical School; Vice-Chairman Pediatric General Surgery, Boston Children’s Hospital; and Surgical Director, Center of Advanced Intestinal Rehabilitation, Boston Children’s Hospital.

Register at www.oley.org/webinars. If you miss the live event, the recording will be available online.

With support from: