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Conference videos and slides are at www.oley.org/2017conferendocs.

LifelineLetter

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

Oley Conference First Impressions

“As a new program associate for the Oley Foundation, I attended my first annual Oley conference in Greenwich, Connecticut, July 5–8. I was very impressed with overall cordiality, in combination with a sense of purpose and commitment towards bettering the lives of those on HPEN. The information was presented thoroughly and professionally.

“The social activities and dining allowed me to meet many consumers and to broaden my awareness of their experiences. The silent auction was great fun and the ‘family’ feeling at the walkathon was quite inspiring. Working alongside the Oley staff to host the conference was a joy, and I am already looking forward to next year’s annual conference.”

—Phil Kellerman

“I enjoyed the conference and learned a great deal. I thought I knew a lot heading in but getting to know others and their stories was enlightening. It gave me a sense of renewed hope and a feeling of fitting in with other non-eaters.”

—Pam S.



First-timers and returning attendees find camaraderie at the annual conference.

“As a first-time conference attendee, I was blown away. The speakers were wonderful and informative. I also enjoyed meeting fellow ‘tubies.’”

—Diana D.

By the Numbers

- 5: FDA representatives attending
- 6: Awards presented
- 6: Countries represented by attendees
- 29: States represented by attendees

Conference Impressions, cont. pg. 14 ➤

Resource for Parents of Schoolchildren

Is your child heading to school with parenteral nutrition and/or tube feeding? A new article in *Nutrition in Clinical Practice*, “Resources for the Provision of Nutrition Support to Children in Educational Environments,” and the online toolkit that complements it, can help make this a more positive and safer experience.

A project of the American Society for Parenteral and Enteral Nutrition’s Home and Alternate Site Care Section, the article and toolkit were developed by a panel of several clinicians and parents with years of experience with HPEN, including Oley board members Shirley Huang, MD, and Betty Bond, RN. Shirley and Betty bring both clinical and personal experience and insight to the project. The article outlines the needs of children requiring nutrition support; the suggested roles of caregivers and the school; the complications associated with central venous catheters and feeding tubes; and more.

It is a valuable tool that provides information and can facilitate discussion. As stated in the article, “For children who require nutrition support therapy, a need

School Resource, cont. pg. 12 ➤

HomePN Research Prize

Congratulations to this year’s winners of the HomePN Research Prize. Thank you to Nutrishare for underwriting this important effort to highlight upcoming advances affecting home parenteral nutrition consumers.

Central Venous Catheter Infections in Home Parenteral Nutrition Patients: Outcomes from Sustain: American Society for Parenteral and Enteral Nutrition’s National Patient Registry for Nutrition Care

Vicki M. Ross, RN, PhD, CNSC

Home parenteral nutrition (HPN) is a complex nutrition support therapy that requires the use of central venous catheters. Central line-associated bloodstream infections (CLABSIs) are among the most serious risks of HPN. Sustain: American Society for Parenteral and Enteral Nutrition’s National Patient Registry for Nutrition Care (Sustain registry) provides the most current and comprehensive data for studying CLABSI among a national cohort of HPN patients in the U.S. For this study, the researchers analyzed data from the Sustain registry for HPN patients followed from 2011 to 2014.

Results: Of the 1,046 HPN patients from twenty-nine sites across the U.S., 10.7% experienced 194

HomePN Research Prize, cont. pg. 2 ➤

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The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically.

The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

HomePN Research Prize, from pg. 1

CLABSI events during 223,493 days of HPN exposure, for an overall CLABSI rate of 0.87 episodes/1,000 PN-days. Although the majority of patients were female (59%), adult (87%), white (75%), and with private insurance or Medicare (69%), CLABSI episodes per 1,000 PN-days were higher for men (0.69 vs 0.38), children (1.17 vs 0.35), blacks (0.91 vs 0.41), and Medicaid recipients (1.0 vs 0.38 or 0.39). Patients with implanted ports or double-lumen catheters also had more CLABSIs than those with peripherally inserted or central catheters or single-lumen catheters. Staphylococci were the most commonly reported pathogens. These data support findings of smaller studies about CLABSI risk for children and by catheter type and identify new potential risk factors, including gender, race, and insurance type.

Conclusion: Additional studies are needed to determine effective interventions that will reduce HPN-associated CLABSI.

This research was published in the *American Journal of Infection Control* (44 [2016] 1462-8). Watch for more about this data in an upcoming issue of the *LifelineLetter*.

Outcomes from a 12-Week, Open-Label, Multi-center Clinical Trial of Teduglutide in Pediatric Short Bowel Syndrome

Beth A. Carter, MD

The objective of this study was to determine the safety and pharmacodynamics/efficacy of teduglutide in children with intestinal failure associated with short bowel syndrome (SBS-IF). This was a twelve-week, open-label study. It enrolled patients aged 1 to 17 years with SBS-IF who required parenteral nutrition (PN) and showed minimal or no advance in enteral nutrition (EN) feeds. Patients were enrolled into three teduglutide cohorts (dosage of 0.0125 mg/kg/d; 0.025 mg/kg/d; or 0.05 mg/kg/d) or received standard of care.

Results: All of the patients in the study experienced one or more treatment-emergent adverse event; most were mild or moderate. No serious teduglutide-related treatment emergent adverse events occurred. Between baseline and week 12, prescribed PN volume and calories (kcal/kg/d) changed by a median of -41% and -45%, respectively, with 0.025 mg/kg/d teduglutide and by -25% and -52% with 0.05 mg/kg/d teduglutide. In contrast, PN volume and calories changed by 0%

and -6%, respectively, with 0.0125 mg/kg/d teduglutide and by 0% and -1% with SOC.

Per patient diary data, EN volume increased by a median of 22%, 32%, and 40% in the 0.0125, 0.025, and 0.05 mg/kg/d cohorts, respectively, and by 11% with SOC. Four patients achieved independence from PN; 3 were in the 0.05 mg/kg/d cohort and 1 was in the 0.025 mg/kg/d cohort. Study limitations included its short-term, open label design, and small sample size.

Conclusions: Teduglutide was well tolerated in pediatric patients with SBS-IF. Teduglutide 0.025 or 0.05 mg/kg/d was associated with trends toward reductions in PN requirements and advancements in EN feeding in children with SBS-IF.

This research was published in the *Journal of Pediatrics* (2017;181:102-11) and Dr. Carter wrote about it for the January/February issue of the *LifelineLetter*.

Taurolidine Locking Prevents Catheter-Related Bloodstream Infections in Patients on HPN

Yannick Wouters, MD, PhD-student

Note that at this time, taurolidine is not approved for use in the U.S. Dr. Wouters is from the Netherlands

Patients on HPN are exposed to a life-long risk for developing catheter-related bloodstream infections (CRBSI) that pose a threat to catheter and patient survival. Both taurolidine 2% and saline 0.9% solution are used as catheter lock solutions (CLS) to prevent CRBSI, but the optimal agent for this purpose remains unclear.

This multicenter double-blinded randomized clinical trial assigned HPN patients to use either taurolidine 2% or saline 0.9% as CLS for one year. Primary outcome was the number of CRBSI/1,000 catheter days.

Results: Of 105 randomized patients, 102 were enrolled as modified intention-to-treat population. With taurolidine, 5 CRBSI occurred during 15,318 catheter days, while in the saline arm 18 CRBSI occurred over 12,493 catheter days. CRBSI/1,000 catheter days were 0.33 and 1.44 for taurolidine and saline, respectively. Time to CRBSI in the taurolidine group was prolonged compared to saline 0.9%. The number of patients with a catheter removal due to CRBSI was two (4%) in the taurolidine group and eight (16%) in the saline arm. Time to catheter **HomePN Research Prize, cont. pg. 12**

Tube Talk



Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@mail.amc.edu. Information shared in this column represents the experience of the individual and 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.

Tube Feeding Through an Ostomy Bag

Most physicians see important advantages to a patient using his or her gastrointestinal tract, even if accessing it is somewhat complicated. For example, tube feeding is sometimes done through a small bowel ostomy that is the site of some secretions and requires an ostomy bag. This might happen if the patient has a loop small bowel ostomy and feeding into the more distal segment of the bowel is desirable, or if the patient has a Roux-en-Y feeding jejunostomy.

The ostomy bag is essential so the secretions from the proximal bowel do not irritate the skin, so the challenge is to insert the feeding tube through the ostomy bag and into the distal segment for feeding. This can be achieved by following the directions below. To see larger versions of the photos, and/or another approach to this task, go to www.oley.org/Feed_Thru_Ostomy_Bag.

Please discuss this idea with your physician before you try it.



1–2. Cut the top off a baby bottle, leaving the cap, nipple and threaded part. Separate the three pieces.

3. Put the threaded cut-off bottle top inside the ostomy or fistula bag. Make a small hole (a tiny "X") in the plastic of the bag in the center of the threaded part. Pull the tube through the hole in the bag with a clamp.



4–6. Put the nipple on the tube. Alternatively, and more easily, only change the nipple when you change the tube. You can, then, feed the small end of the tube through the nipple, rather than the bulkier end.

7. Put the baby nipple cap around the nipple.



8. Put white Teflon plumbers tape inside the threads either side of the baby bottle's cut-off top or cap.

9. Screw the baby bottle top to the threaded cut-off part of the baby bottle. Be sure the entire hole in the plastic bag is inside the nipple ring. Tighten the nipple ring with needle-nose pliers.

10. Reinforce the catheter nipple junction with silk tape.

Viola! You are finished and ready to feed.



Bright Idea

PICC Line Cover

The name of this product says it all: PICCPerfect. These PICC line covers truly live up to their name. Not only are they beautiful, but the fabric is extremely comfortable and they actually protect your PICC line—which is of utmost importance.

The sleeve was designed with two pre-cut slots for your lumens to slip through. This allows access to your line for infusions or blood draws without needing to remove the sleeve, which is very convenient. And it fits well under long-sleeved clothing, too! If you have a PICC line, PICCPerfect is a must. For more information go to www.mighty-well.com.

—Betsy C.



Close-up of the cover shows the two, pre-cut openings.

Join Oley in Phoenix

Saturday, September 16, 2017
Sheraton Grand Phoenix, 340 N 3rd Street, Phoenix, AZ
9:30 a.m.–4:30 p.m.

The Oley Foundation, working with the Association for Vascular Access (AVA), is presenting a free one-day regional conference filled with education and networking. Learn more about vascular access, current treatments in intestinal failure, diet and intestinal failure, tube feeding complications, infection prevention, and more.

Lunchtime provides an opportunity to network with vendors, and learn about vascular access products and services. Enjoy great food and conversation while asking questions and sharing experiences. In the evening you can visit the exhibit hall at the AVA conference.

Continental breakfast and lunch provided. Parking: onsite garage, \$8 for self-parking; \$12 for valet.

For more information and to register, visit www.oley.org/event/Phoenixregional, email andreaguidi.oley@gmail.com, or call (518) 262-5079. To receive notices about events like this electronically, make sure we have your current email address!

Shopping Online?

Don't forget to list the Oley Foundation as your charity of choice at AmazonSmiles, www.iGive.com/oley, www.GoodShop.com or another favorite charity-supporting online retailer.



Important Update: New Phone Numbers for Oley

As of August 16, 2017, the Oley Foundation has discontinued its toll free numbers. Our carrier has discontinued this service and when looking to replace it, we realized our toll free numbers are being used less and less frequently. Eliminating them allows us to use these funds more effectively.

To reach the Oley office:

- Call (518) 262-5079
- Email oleyfoundation@gmail.com
- For individual staff members, visit www.oley.org/Staff_Profiles

To access Equipment Supply Exchange Program:

- Call (518) 262-2230

We typically respond to messages within two business days.

- Visit www.oley.org/Equipment_Exchange

Please update our number in your records. We appreciate your ongoing support. Thank you.



ESPAÑOL

Speak Spanish?

If you are a Spanish-speaking patient on home parenteral nutrition (HPN) or home enteral nutrition (HEN), or care for such a patient, the Oley Foundation can help. Phil Kellerman, Program Associate, speaks Spanish. He can be contacted Monday–Wednesday, 9 a.m.–2 p.m., at 518-262-5079. Email: philkellerman.oley@gmail.com.

Oley would like to acknowledge and thank Guiller B., too, who has been helping people who speak Spanish when they call us through our Equipment-Supply Exchange program. We would be lost without her help!

¿Habla A Español?

Si usted es un paciente de habla español y depende en nutrición parenteral (HPN) o nutrición enteral (HEN) o tiene cuidado de tal paciente, la Fundación Oley puede ayudar. Phil Kellerman, Asociado de Programa habla a español. Puede ponerse en contacto con Phil los lunes–miércoles de 9:00 a.m.–2 p.m. por teléfono, número 518-262-5079. Correo electrónico: philkellerman.oley@gmail.com.

También nos gustaría reconocer y darle gracias a Guiller B. quién ha estado ayudando a la gente que habla español cuando nos llaman a través de nuestro Programa de Intercambio de Suministro de Equipos. ¡Estaríamos perdidos sin su ayuda!




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IMPORTANT SAFETY INFORMATION

WARNING: DEATH IN PRETERM INFANTS
See full prescribing information for complete boxed warning

- Deaths in preterm infants have been reported in literature.
- Autopsy findings included intravascular fat accumulation in the lungs.
- Preterm and low-birth-weight infants have poor clearance of intravenous lipid emulsion and increased free fatty acid plasma levels following lipid emulsion infusion.

INDICATIONS AND USAGE

• Smoflipid is indicated in adults as a source of calories and essential fatty acids for parenteral nutrition when oral or enteral nutrition is not possible, insufficient, or contraindicated.

Limitations of Use

The omega-3:omega-6 fatty acid ratio and Medium Chain triglycerides in Smoflipid have not been shown to improve clinical outcomes compared to other intravenous lipid emulsions.

DOSAGE AND ADMINISTRATION

- For intravenous infusion only into a peripheral or central vein.
- The usual daily dosage in adults is 1 to 2 grams/kg per day and should not exceed 2.5 grams/kg per day.

CONTRAINDICATIONS

- Known hypersensitivity to fish, egg, soybean, or peanut protein, or to any of the active ingredients or excipients.
- Severe hypotension or severe disorders of lipid metabolism with serum triglycerides >1,000 mg/dL.

WARNINGS AND PRECAUTIONS

Monitor for signs or symptoms of:

- **Hypersensitivity Reactions:** Discontinue infusion if reactions occur.
- **Infection, Fat overload, Hepatobulbarretaria, and Metabolic Complications:** Monitor laboratory parameters.
- **Respiratory Toxicity:** Patients with renal impairment, including preterm infants, are at increased risk.
- **Parenteral Nutrition-Associated Liver Disease:** Increased risk in patients who receive parenteral nutrition for extended periods of time, especially preterm infants. Monitor liver function tests. If abnormalities occur, consider discontinuation or dosage reduction.

To report suspected adverse reactions, contact Fresenius Kabi USA, LLC, at 1-800-551-7176 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.
Please see full Prescribing Information, including **Boxed Warning**, for Smoflipid at www.smoflipid.com.

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Congratulations to
RUBY BARRIOS,
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Kyle Noble Scholarship



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A Sincere Thank You for Your Help

What a whirlwind week we had in Old Greenwich, Connecticut, at the 32nd Annual Oley Consumer/Clinician Conference! From the Oley Ambassador Workshop and Welcome Reception on Wednesday, July 5, through the Breakfast and Brainstorming session on Saturday, July 8, we were constantly on the go... listening, learning, networking, and enhancing our understanding of homePEN.

The unique combination of volunteers, faculty, exhibitors, and sponsorships all contributed to one of the best conferences ever. Over 420 people attended, and we received extremely positive feedback. We could not be more pleased with the outcome! And we couldn't have done it without you. From start to finish, your dedication, hard work, and commitment was apparent. We thank you for your time, energy, and resources. We've set the bar high for future conferences.

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GEDSA
G-PACT
Gus Gear, LLC
Halyard Health
Kate Farms
Medtronic
Mighty Well
Mito Action



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Thank You, cont. pg. 14 ➔



#WithCoramICan

Take a trip of a lifetime!

My husband Bill always wanted to see Alaska. But how could we do this with a gastric tube and the need for daily enteral nutrition supplies?



We asked our Coram dietitian, Rhonda Knecht, for help. Within a week, she called to say the details were in place to ship, store and transport Bill's supplies. Because of Coram, the entire trip was a breeze!

We saw grizzly bears catching salmon, gorgeous glaciers and many whales. We couldn't have made any leg of the trip without Coram's help. Thank you Rhonda and Coram for creating a terrific plan that allowed us to see Alaska our way.

— Bill Weida and Jane Davis Weida

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Congratulations 2017 Oley Award and Scholarship Winners

LifelineLetter Award, HPN

Sponsored by Nutrishare, Inc., Silver Circle Partner

Kathryn Bundy

This award is given annually to a person who has been a home parenteral (HPN) consumer for five years 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.

At the annual conference, we were pleased to give this award to Kathryn Bundy. Kathryn is known to give of herself—her knowledge, experience, and resources—far beyond what someone would expect of her. She is selfless with her time, always giving to others. Kathryn visits patients, for example, and helps them to deal with medical and personal issues related to their care.

Kathryn is in her thirty-second year of HPN, having developed Crohn's disease at age seven. She was left with only 15 percent of her intestines after a radical resection in 1985 due to extensive disease and no medical treatment. From the first week on HPN, Kathryn has pursued her acting career, along with a lengthy stint in live graphic design for TV shows and sports events and post-production for film and graphic design. You may have seen her in many national commercials and television shows, such as *Men of a Certain Age*, *CSI*, *New York Love Stories*, and feature films, including *Relax* and *The Ones*. She has also done stand-up comedy in New York City. After a ten-year hiatus focused on medical issues, Kathryn will be rejoining her career in 2018.



Kathryn Bundy

Having spent most of her life with Crohn's and short bowel syndrome (SBS), Kathryn has joined forces with other patients to create the SBS Cure Project to help find a cure for SBS and intestinal failure.

Kathryn always maintains a positive attitude and spirit. Her favorite "life hacks" are:

- Sleep as much and as often as you can.
- Keep your support system close and cherish them.
- Take days off to just do nothing but recharge.
- Don't compare your life to anyone else's.
- Find someone who knows everything about insurance.
- Most of all, don't give up!

Congratulations to the nominees:

Julie and Thomas Gilcrease; Kimberly Kaufmann; Linda and Paul May

LifelineLetter Award, HEN

Sponsored by Trovita Health Science

Mary Beth Wootten

This award is given annually to a person who has been a home enteral nutrition (HEN) consumer for five years 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.

We were pleased to present this award to Mary Beth Wootten at the annual conference. Mary is the mother of three beautiful children—Natalie (9), Oliver (7) and Quinn (5), and an inspiration to all.

While pregnant with Natalie and living in Connecticut, Mary and her husband, Nathanael, were told that Natalie was small for gestational age and had essentially stopped growing. As a result Mary was induced early and Natalie was born.

After countless pediatrician visits and specialist referrals for various health issues, it became clear that Mary's mission was going to be ensuring that Natalie received the best care possible, that diagnoses were understood, and that treatment plans were put in place. A feeding tube was placed when Natalie was sixteen months old. As a result, Natalie has lived as normal a life as possible and has been able to pursue many interests, such as Girl Scouts and gymnastics.

Mary has demonstrated an incredible amount of courage and perseverance over the past nine years. Despite many setbacks and challenges, she always has a positive outlook.

Mary embodies service by dedicating a generous portion of her time serving as an Oley Ambassador in New York's Capital Region, offering peer-to-peer support to others with HEN. Whether it is visiting a young mother with an infant who has had a feeding tube placed and is afraid to leave her home, or an elderly patient who is seeking guidance, Mary is happy to share what she has learned. In addition to volunteering for Oley, she also assists her local Girl Scout Troop



Mary Beth Wootten



and is a Reiki Master Teacher. Mary has also recently joined the Oley staff, working part-time as a Program Associate.

Mary says she is guided by a quote from Mother Teresa: “It’s not how much love we give, but how much love we put into giving.”

Congratulations to the nominees:

Ellen Renee Evans; Tracy Nagy; Pam Winter

Child of the Year Award

Sponsored by ThriveRx, Gold Medallion Partner

Ally Winter

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

Congratulations to Ally Winter, this year’s recipient of the Child of the Year Award!

When Ally was four years old, she had two tumors that twisted her bowel. She lost all but 25 cm of her small intestine. However, Ally has always been a resilient girl, with a smile and kind words for all around her.

Ally has rebounded from tough situations many times—from complete home parenteral nutrition (HPN) dependence with seven liters output, to severe d-lactic acidosis, to months of not being able to walk or eat. Each medical crisis has shown her strength in character and heart. She strives to be her own personal advocate. For example, when she felt she wasn’t being taken seriously by her GI doctor, Ally responded by writing the physician a letter.

Ally’s willingness to help others despite her illness is inspiring. She bakes cookies at the Ronald McDonald House, serves at church, and takes care of neighbors’ animals. Ally manages an Instagram account involving makeup design, and is a great sister to her foster brother and sister.

Ally’s family has a photo of Ally holding a school binder that she decorated, with a picture of an intestine. The caption reads, “You don’t need guts to be brave.”

Congratulations to the nominees:

Ethan Abramowitz; Zachary Daugherty; Emma Dean; Treyson Garcia; Lidia Hout; Albert Otero Rigau; Oliver Shattles-Moore; Maria Stamos; Natalie Wooten; Janie Yoo

Celebration of Life

Malisa Matheny

This award recognizes someone who has been on parenteral and/or enteral nutrition (HPEN) for three years or longer and who lives life to the fullest.

Malisa Matheny has fought hard to overcome the obstacles pseudo-obstruction and now mitochondrial disorder have presented, and

she has not let these obstacles hold her back from living life to the fullest. It was an honor to have Malisa attend the conference to receive this award.

Malisa has been on home parenteral nutrition (HPN), and sometimes home enteral nutrition (HEN), since 1993. She was one of the first teenagers to become an Oley Regional Coordinator (now the Oley Ambassador program). Growing up on HPN, Malisa knew the challenges one faced gaining independence when having a chronic medical condition, so, in addition to helping others as a Regional Coordinator, she helped create a program for teens and young adults with chronic health issues at the Children’s Hospital of Philadelphia.



Malisa Matheny

Determined not to let HPN hold her back, Malisa went to Temple University and graduated with a nursing degree. While in college, she met her future husband. They were married in 2005. Then, for the next four years, she experienced a decline in her health and was hospitalized frequently. A severe GI virus in 2009 left Malisa bedridden for years.

Despite her medical problems, and though many felt it could affect her health negatively, Malisa desired to be a mom. In September 2007, she underwent in vitro fertilization to create five embryos and in September 2008, one of the embryos was transferred to a surrogate. On May 27, 2009, her daughter, Julianna Hope, was born. In 2012, Malisa became part of a clinical trial.

“Now,” Malisa says, “it seems because of that drug, I have the strength to hold Julianna in my arms and to play with her. I’ve visited New York

Oley Awards, cont. pg. 10 ◀



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References: 1. September 2013 - August 2014 patient satisfaction data, survey of 207 EN patients and 205 PN patients.

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118A #20858095, 118A #20855096, 118A #209991670, 118A #209991580, 118A #209991202, 118A #209994066, 118A #209994066

Oley Awards, from pg. 9

City and done a zip line! Before, the muscle strength required to turn corners in a car was too exhausting and I couldn't tolerate it. I am so grateful the research group didn't give up on me, and that I didn't give up, feeling isolated and lost in the dark hole of the medical system."

Malisa is full of love, compassion and empathy, and has given of herself many times to help others on HPN. Over the years, Malisa has been managing an online health journal and sharing her experiences with others. She has blogged, made phone calls, and has been active through Oley. She stays in touch with a large network of HPEN consumers by writing cheerful messages and sending care packages. No matter how restricted, Malisa finds ways to celebrate special moments with her daughter and loved ones.

Congratulations to the nominees:

Jameson Atkinson; Jack Leibee; Sally Moore; Pamela Schepis; Maria Stamos

Innovator/Advocator Award

Julie and Tony Bombacino

This award is given to a home parenteral or enteral (HPEN) 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.

Congratulations to Julie and Tony Bombacino, winners of this year's Innovator/Advocator Award. As parents to five-year-old special needs tube-fed child AJ, and in their life work as the co-founders of Real Food Blends, Julie and Tony are special people.

When AJ was six months old, due to constant constipation and vomiting, doctors determined he needed a feeding tube. Faced with what they felt was a nutritional limitation in traditional formula, Julie set out to research and create a homemade blended diet for AJ. Ultimately, AJ began to thrive and grow, and the Bombacinos

attribute it to the introduction of real food into his diet. In the Bombacino family, the new blended diet allowed AJ to join his parents and sister Luca to make meal time into "family time."

Inspired, Julie and Tony launched Real Food Blends. Their efforts began with Julie researching recipes and standards and creating the framework for the business, while Tony worked to support the family and consulted on various aspects of the business. Now both work full-time with their thriving company.

"We are honored and humbled to receive this award from the Oley Foundation," say Julie and Tony. "From Day 1 of our own tube-feeding journey with our son, AJ, we turned to Oley for information and support. Receiving this award and recognition from them six years later is truly a full circle moment and one that is very special to us."

Julie and Tony have helped introduce an alternative for people who rely on tube feeding. The couple embody what the Oley Innovator/Activator Award is all about.

Congratulations to the nominees:

Ann Alford; LeeAnne Bye; Victoria DeLano; Diana Marie Donnarumma; Sanford Flach; Katherine Franco; Rev. Bruce Hanson; Shawn Householder; Joy McVey Hugick; Andrew Jablonski; Swapna Kakani; Jack Leibee; Lynn Wolfson



Tony Bombacino

Nan Couts Award

Inspired by Judy Peterson, RN, MS

David Mercer, MD, PhD, and the UNMC IRP Team

This award is presented annually to a clinician practicing in the parenteral and/or enteral nutrition HPEN or a related field who has shown a willingness to go "above and beyond" to educate, empower, and improve the life of HPEN consumers.

Dr. David Mercer, professor of surgery in the Liver and Transplant Program and director of the Intestinal Rehabilitation Program at the University of Nebraska Medical Center (UNMC), is a champion for his patients. In nominating him, one of his patients wrote, "He is always looking for ways to improve practices and treatments, and goes above and beyond the call of duty in communicating with his patients and families."

One of Dr. Mercer's patients, Tricia M., has shared her story as an example of his dedication. Tricia had been suffering for years with terrible pain and GI problems. She had been sent to some of the finest medical institutions and specialists in the country but, until she met Dr. Mercer, nobody was able to figure out what was going on. Tricia was life-flighted to UNMC/Nebraska Medicine where Dr. Mercer and his multidisciplinary team were able to get her out of the hospital in just ten days, after she had spent more than six months hospitalized at other facilities.

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Dr. Mercer looked at the big picture, consulted with Tricia's mitochondrial specialist, and then, with his team, treated her symptoms. Although a cure for Tricia has yet to be developed, her quality of life has dramatically improved. Tricia graduated high school with honors and now attends the University of Nebraska in Lincoln. Tricia's mother, Wendy, says, "There is no question that Dr. Mercer and his entire Intestinal Rehabilitation Program team have been game changers and lifesavers for my daughter as we have traveled the journey through intestinal failure and the unknown."

This past year Dr. Mercer was awarded the UNMC's Distinguished Scientist Award. This award recognizes researchers who have been among the most productive scientists in the country during the past five years. The work of Dr. Mercer and his multidisciplinary team in successfully treating children with an extremely short length of bowel was recently published in *The Journal of Pediatrics*.



David Mercer, MD, PhD

Asked what is the best advice anyone ever gave him, professionally or personally, Dr. Mercer responded with a quote from Louis Pasteur: "In the fields of observation, chance favors only the prepared mind."

Congratulations to the nominees:

Lyn Howard, MB, FRCP, FACP; Lisa Smith, RD; University of Pennsylvania HPN Team

Kyle R. Noble Scholarship

Ruby Barrios

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

The Oley Foundation is pleased to announce that this year's winner of the Kyle R. Noble Scholarship is Ruby Barrios.

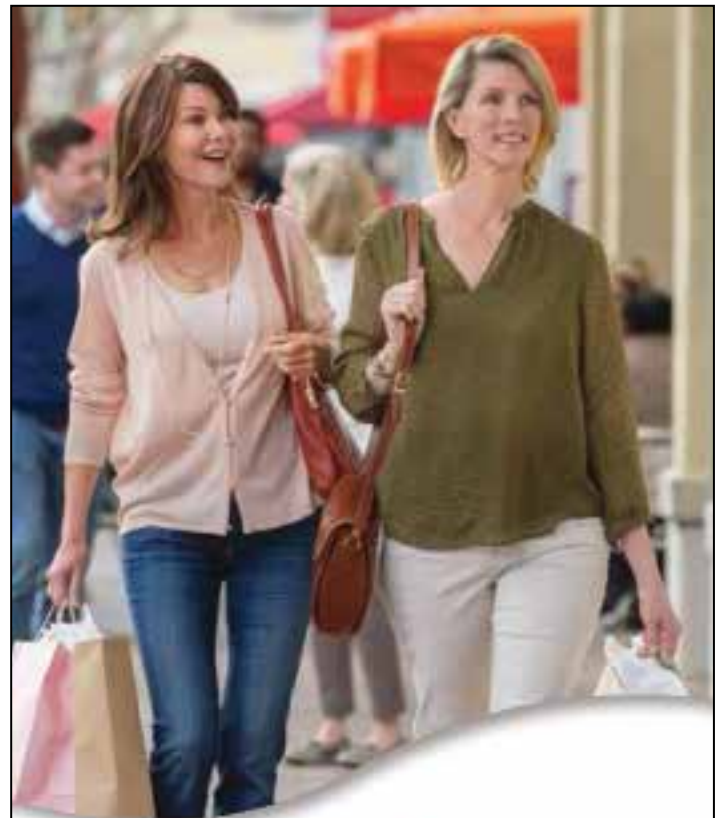
Ruby has proven herself a worthy role model for many children affected by illness. Ruby was diagnosed with gastroschisis prenatally. When she was two days old, she was taken to the emergency room and had a subtotal small bowel resection. She has been dependent on home parenteral nutrition (HPN) her whole life, but it hasn't stopped her from achieving her goals.

Ruby studies theater, dance, choir, and drama. She has written and performed her own monologue. In 2015, Ruby had starring roles in



Ruby Barrios

Oley Awards, cont. pg. 14



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Health Care Reform: ACA Repeal and Replace Efforts

The news on health care reform seems to change daily, and it is tough to keep up with the latest developments. This uncertainty is all the more reason to communicate your needs to the two Senators from your state, now.

The Oley Foundation joins the Digestive Disease National Coalition, the National Organization for Rare Disorders, and other organizations in advocating for health care reform that maintains some of the provisions of the Affordable Care Act (the ACA, or “Obamacare”). Specifically, we encourage bipartisan health care reform that: prohibits pre-existing condition discrimination; prohibits lifetime and annual caps on benefits; limits out-of-pocket costs for patients in a meaningful way; and allows young adults to stay on family coverage until they are twenty-six years old.

How can you take action? Contact your Senators today and share your story. Tell them what is important to you in terms of health care reform, and why.

Take Action

1. Secure the contact information for your Senators by visiting www.senate.gov.
2. Call the office and ask for the Health Legislative Assistant. You can leave a voicemail or request their e-mail address and send them a message using the template below.
3. Politely and occasionally follow up on your request. You should expect that the office will respond to your specific concerns.

Template

Dear _____,

My name is _____ and I am a constituent from _____. I am also an advocate for [your health condition].

I write to urge you to maintain stability for chronic disease patients as you and your colleagues consider health care reform. It is my hope that the Senate will develop a bill that preserves key patient protections and respects the circumstances of those combatting chronic and costly illnesses.

Specifically, please ensure any Senate proposal:

- prohibits pre-existing condition discrimination
- prohibits lifetime and annual caps on benefits
- limits out-of-pocket costs for patients in a meaningful way
- allows young adults to stay on family coverage until they are 26

[Add a paragraph of brief information about your condition. Tell your story.]

Patients need a transparent, bipartisan effort to stabilize the insurance market, bring down premiums, and retain the protections that are so critical to patients, consumers and their families. I urge the Senate to go back to the drawing board, and work together to find ways to protect patients with serious illness.

Thank you for your time and your consideration of this letter. Please tell me how you have responded to my request.

Sincerely,

[Name]

[Address]

Questions? Contact the Oley staff and we can help get you started: oleyfoundation@gmail.com or (518) 262-5079. ¶



TSA Award

The Oley Foundation was given the Transportation Security Administration Disability and Multicultural Coalition's Community Partnership Award. Oley Executive Director Joan Bishop accepted the award at a ceremony, which was fittingly held during HPN Awareness Week.

Helping to Raise \$\$ for Oley!

Phil Kellerman, who recently joined the Oley staff as a program associate, has a part-time business selling political and historical memorabilia and other collectibles on eBay. “Campaign buttons make up the majority of my sales,” he says.

Phil has enrolled the Oley Foundation on eBay charities and is generously donating to Oley 60% of the proceeds from all sales on his eBay site. Phil asks that you contact him if you have items you would like to give him to sell on his site. You can contact Phil at philkellerman77@gmail.com or (352) 262-5421. Examples of collectibles include political campaign items, stamps, vintage records and toys, jewelry, antiques, old watches, movie posters, and comics. Thank you, Phil!

Note that this is an independent fund-raiser. Items should not be sent to the Oley office and donors will not receive a letter of acknowledgment from the Oley Foundation.

School Resource, from pg. 1

exists for educational settings to provide safe delivery of nutrition beyond the oral route, provide care for feeding access devices, and have a plan for when complications arise.... The purpose of this document is to develop a best practices document and toolkit to raise awareness and provide stakeholders with resources that address nutrition support therapy in schoolchildren.”

You can access the article at <http://journals.sagepub.com/doi/full/10.1177/0884533617718471>. For the toolkit, select “Supplemental Material.” Please share it widely. ¶

HomePN Research Prize, from pg. 2

removal due to CRBSI was significantly prolonged with taurolidine. Exit-site infection and catheter occlusion rates were similar in both groups. These results were corroborated by the per-protocol analysis. Except for occurrence of CRBSI, there was no difference in (serious) adverse events between groups. Drug-related adverse events were rare and generally mild. None of two reported deaths in this study were considered to be drug-related.

Conclusions: Taurolidine 2% decreased almost five times the risk for CRBSI in patients on HPN compared to saline 0.9% locking. In combination with its favourable safety profile and lack of evidence for microbial adaptation, taurolidine 2% locking seems a key strategy for CRBSI prevention and allows implementation of this practice as a standard in HPN care. ¶



HPN Teen Study with iPads

Do visual communications between young home parenteral nutrition (HPN) users make them healthier? Tell us what you think. Test your theory by joining our study!

We are continuing to recruit for a study in which HPN users between the ages of 13 and 30 will meet with peers using a loaned iPad mini. These communications are encrypted audiovisual connections, which protects everyone's privacy. Sharing your opinions in this study can push changes in health practices, insurance reimbursement, and even improvements in gaming apps.

So, let's prove or debunk what you think!

This research study is for HPN-using teens ages 13 to 17 and young adults ages 18–30, and for any person 13 and older who has supported HPN care at home when needed. Research is voluntary.

Would the study be a good fit for me?

It might be, if you are:

- 13 to 30 years old and use a catheter in your vein to deliver nutrition (HPN)
- 13 years or older and experienced in offering supporting care of an HPN user 13 to 30 years old
- English-speaking

What will happen if I take part in the study?

- An iPad mini with health-related game apps will be loaned to you for 8 to 12 months to test connections to peers-based health education and activities
- You will attend one to three audiovisual meetings with your peers from your home using the encrypted secure connection through an iPad mini webcam
- You will complete online opinion surveys every 3 to 4 months for about one year

Each study participant will receive \$50 to thank them for their time. To take part in this research study or for more information, please call or email Cathy Harrington at the Oley Foundation, (518) 262-5079 or harrinc@mail.amc.edu OR complete the contact form at <https://redcap.kumc.edu/surveys/?s=XWJ9HWM48D>

The principal researcher for this study is an experienced HPN nurse, Carol E. Smith, RN, PhD. This research is supported by the National Institutes of Health (1R01NR015743) and the Oley Foundation. ♣

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Thank You, from pg. 7

Jackson Bishop
 Kiley Bishop
 Stephanie Harrison Bishop
 Andrew Bodnar
 Robin Bodnar
 Kim Butler
 Nick Butler
 Katie Coleman
 Nick Coleman
 Anne and Terry Edwards
 Grace Hamilton
 Jeff Hoelle
 Rose Hoelle
 Ellen Iead
 Ron Metzger
 Sarah Metzger, RN
 Marjorie Quinn
 Jackson Reddick
 Laney Reddick
 Denise Richardson, RN
 Bob and Mary Smithers
 Guiliana Valenti
 Nick Viggiani
 Rachel Walsh
 Nicole White ¶

Oley Awards, from pg. 11

her high school plays, *Inherit the Wind* and *You Can't Take It with You*.

Ruby is also active in the Desi Club, which teaches and allows her to perform traditional cultural dances from India. She brings enthusiasm with her every Saturday when she spends time at Inner City Arts, an organization that enriches the lives of children and bridges the cultural and economic divides between them through a total art program. As an employee, she advocates for the program to take on more students like her.

Ruby has never let her illness stop her from

chasing her dreams of a career in the performing arts. She maintained a GPA of 3.5 or better in high school and she will be attending her dream college, the American Musical Dramatic Academy in Los Angeles, in the fall.

Ruby continues to shoot for the stars, and we offer her our sincere wishes for success in the future.

We also want to congratulate everyone else who applied for the scholarship. We received many outstanding essays and regret that there can only be one winner. Please consider applying next year for the Kyle R. Noble Scholarship! ¶

Conference Impressions, from pg. 1

- 30: Breakout sessions
- 37: Award nominees recognized
- 43: Exhibits in exhibit hall
- 50: Faculty (presenters)
- 58: Children, from 1 to 18 years old
- 69: First-time attendees
- 420: Total attendance. Includes HPEN consumers (52 adults and 24 children);

- family members/caregivers (132 adult and 34 children); clinicians (26 dietitians; 14 nurses; 18 physicians; 7 pharmacists; 1 social worker); staff and volunteers (16); and exhibitors (96).
 - **\$3,262** earned at the Silent Auction
 - **\$6,720** raised by the Walkathon
- Hope you can join us in 2018! ¶



2017 Oley Walkathon Participants

Thank you to everyone who walked or supported the walkers. Walkers were Rhonda Arends; Lillian Harvey Banchik; Hadar and Melanie Birger-Bray; Barbara and Tim Blanchard; Andrew and Robin Bodnar; Buddy Bond; Diane and Leighanne Boone; Kaitlin, Nicholas, and Paul Coleman, and Heidi Martin-Coleman; Roslyn Dahl; Howard and Marcia Denenholz; Tiffany Dodd; Donathan Donly, Jr.; Celia Fairbanks; Sanford Flach; Kelly Ford; Todd Friedman; Mae Godbee; Brenda Gray; Andrea Guidi; Colman Gulden; Mel Halliday; Karen Hamilton; Rose Hoelle; Joy McVey Hugick; Tonya Jackson; Eriq Jordan; Swapna Kakani; Barbara Kapuscinska; Phil Kellerman; Jack and Carol Leabee; Ava, Jorge, and Rachael Lopez; Cheryl and John Mahalchak; John Mahalchak, Jr.; Cesar Marroquin; Brian McCall; Eli and Michael Medwar; Lisa and Ron Metzger; Michael Mondello; the Noble family; the Palya family; Marjorie Quinn; Terry Quinn; David Rowland; Kaaren Ruth; Ann Savattier; the Singh family; Bob and Mary Smithers; the ThriveRx Team; Cathy Tokarz; Ally and Pam Winter; Fiona Winterton; Elizabeth Wittmann; Gloria and Jim Wittmann; Eli and Lynn Wolfson; Mary and Natalie Wootten; Donna Yadrich; the Yoo family

Notable Individual Gifts

Among the individual contributions received, 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 25 through August 3, 2017:

In Memory Of: Ann DeBarbieri; Evan Leibowitz; Lynn Wolfson's father, James Nagin; Don Young

In Honor Of: The late John Balint, MD, founding Oley Trustee; the strength of Jennifer Blons; Gabe Eisenberg; Paul Feyer; the late Leo Kellerman, MD; Phil Kellerman's birthday; Aidan Koncius; Maddie Morris; my son Rick who has Crohn's & the many consumers I work with at Thrive Rx; Jeffrey Schesnol on Father's Day

Fund-raiser: Edithe Swensen charity class at Rockspport Indoor Climbing Gym

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 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.

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Real Food Blends

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Apria Healthcare
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Cook Medical
Soleo Health

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 at (518) 262-5079.

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

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Oley Aug–Nov 2017 Calendar

August 22–26: Oley exhibiting at United Ostomy Associations of America conference, Irvine, CA

September 9–12: Oley attending European Society for Parenteral and Enteral Nutrition (ESPEN) Congress, The Hague, Netherlands

September 16: Oley Regional Conference (in conjunction with AVA meeting), Phoenix, AZ

September 16–19: Oley attending, exhibiting, and presenting at Association for Vascular Access (AVA) conference, Phoenix, AZ

September 29: Oley exhibiting at Mid-Atlantic Society for Parenteral and Enteral Nutrition (MASPEN), Charlotte, NC

October 16–17: Oley attending National Organization for Rare Disorders (NORD) Summit, Washington, DC

October 26: Oley hosting Grand Rounds, Albany Medical Center, Albany, NY

November 3: Oley exhibiting at Michigan Society for Parenteral and Enteral Nutrition (MSPEN), Ann Arbor, MI

November 3–5: Oley exhibiting at Infusion Nurses Society (INS), Atlanta, GA

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

For updates, or if you are able to help at an Oley exhibit, go to www.oley.org, email harrinc@mail.amc.edu or call (518) 262-5079.

Additional Meetings of Interest

October 1: Loma Linda Patient and Family Event, Loma Linda Children's Hospital, San Bernadino, CA

un•whole•y•ness

I lie awake in bed at night
Hoping to fall asleep
To dream...to be whole
The soft whirl of the pump
ka-chunk ka-chunk
Moving liquid nutrients into my heart
And eventually into what's left of my gut

How did I become this creature?
This artificial being in body
While still real and whole in mind and soul

How can the body fail so as to betray
the spirit that drives me?
And how do I go on from here
To fulfill my purpose with such distraction?

Tomorrow is another day
To push through the daily rituals
Until the whirl of the pump once again
Lulls me to sleep...and I become whole

—MaryAnn Neblock