Swimming with Lines and Tubes: It’s a Team Effort

Kathleen M. Gura, PharmD

This article is based on a presentation by Dr. Gura at the Oley annual conference in Orlando, Florida, in June, and on an article that appeared in Nutrition in Clinical Practice (“Going with the Flow or Swimming Against the Tide,” February 2014).

Swimming is an excellent form of aerobic exercise and a great social activity, as well as being enjoyable. Many consider recreational swimming to be a rite of summer, but for some, the risk may outweigh the benefit. Individuals who require long-term parenteral nutrition (PN) support or have an enteral (EN) feeding tube have to consider swimming options carefully.

Central venous catheters (CVCs) and EN feeding tubes may be portals for infection. Patients with CVCs may be predisposed to exit site, tunnel, and catheter-related bloodstream infections (CRBSIs) from water submersion. Those with recently placed percutaneous endoscopic gastrostomy (PEG) tubes may get an infection if they go swimming before the tract fully heals.

So what should you do? My colleagues and I recently conducted a literature search on swimming and surveyed several home PN programs about their policies. Here I share the results, as well as some approaches to keeping your line or feeding tube safe.

The Risks

Despite the growing number of individuals with CVCs, the risk of infection after swimming has not been well studied. There is currently no strong evidence concluding that swimming has caused an increase in catheter-related infections;

Tips for Managing PN Component Shortages

Beverly Holcombe, PharmD, BCNSP, and Peggi Guenter, PhD, RN

Shortages of parenteral nutrition (PN) components or ingredients are not new to consumers of parenteral nutrition (PN) or health care professionals who provide this therapy. Shortages have been ongoing since the intravenous (IV) adult multivitamins shortage in 1988. Shortages were intermittent and usually short-lived. However, since 2009 almost every PN component has been in short supply.

A number of factors have contributed to the shortages of sterile injectable drugs, which includes PN components. Sterile injectable drugs are produced by only a few manufacturers. Some manufacturers have shut down and others have had quality issues requiring corrective actions. When one company is unable to manufacture a drug, it increases demand on another company, which cannot keep up with the demand for the drug.

The shortage of IV adult, pediatric, and neonatal multi-trace element products and individual trace elements is particularly concerning, as administering
PN with less than optimal amounts of trace elements has been associated with deficiencies and patient harm. The Food and Drug Administration (FDA) has approved only two U.S. manufacturers of these trace element products (American Regent and Hospira, Inc.) and release of products has been hindered and sporadic due to manufacturing delays. In 2013, the FDA approved importation of multi-trace and single element products in order to fill the patient need and gaps in the market.

The Clinical Practice Committee Nutrition Product Shortage Subcommittee of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) was interested in learning more about how clinicians have been managing the prolonged shortage of IV trace elements and evaluating the impact of these shortages on their patients. The Shortage Subcommittee developed a survey to give clinicians who provide PN to adult, pediatric, and neonatal patients the opportunity to share their clinical experiences and shortage management strategies. Less than half of the survey respondents have the U.S. commercially available IV multi-trace element products. When these products are available and prescribed, rationing and conservation dosing regimens are common.

Managing Trace Elements Shortages

Since May 2013, imported European IV adult and pediatric multi-trace element products have been available in the U.S. Although these imported European products are available, they are not widely used by clinicians who are unable to obtain the U.S. products. Even when the imported European product is available to clinicians, not all administer a full dose daily in PNs. About one-third of clinicians responding to the survey indicated they do not use the imported European IV multi-trace element products because individual trace element products are available. For others, the most common reasons for not administering the imported European IV multi-trace element products are concerns about the trace element profile and concerns about compatibility/stability with PN admixtures. Other reported reasons for not using imported products include inability to obtain from supplier/wholesaler or outsource compounding pharmacy, and concerns about the expense.

Approximately half of all clinicians responding to the survey indicated they monitor their patients for trace element deficiencies by assessing clinical signs and symptoms and/or laboratory tests. Although there have been reports of deficiencies in the scientific literature, many of the clinicians responding to this survey did not report any adverse events or suboptimal patient outcomes, even when monitoring for deficiencies.

The lack of observed adverse events/deficiencies and the potential cost savings associated with “partial” dosing of trace elements should not be the impetus to continue this practice of less than optimal dosing of trace elements. Now is the time to evaluate current practices for dosing IV trace elements, review IV trace element requirements for patients/consumers receiving PN therapy, and implement daily dosing regimens to meet the trace element needs for all patients receiving PN.

Questions Consumers Should Ask Their Physician, Homecare Provider, and/or Homecare Team

• Are the shortages of PN ingredients affecting my PN prescription?
• What am I missing as a result of the shortages?
• Are you out of any PN ingredients? Which ones?
• Have you notified my physician you are out of these ingredients?
• Do you currently have U.S. IV multi-trace elements?
• Do you currently have imported European multi-trace elements?
• If you do not have multi-trace elements, do you have individual trace elements such as copper, zinc, and selenium?
• Do I receive a correct daily dose of trace elements necessary for my condition?
• What is your plan to make sure I receive the correct amount of PN ingredients? Have you notified my physician of your plan?

Beverly Holcombe, PharmD, BCNSP, is Clinical Practice Specialist, and Peggi Guenter, PhD, RN, is Senior Director of Clinical Practice, Quality, and Advocacy, American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). The A.S.P.E.N. Trace Elements Shortage Survey report is available at www.nutritioncare.org/Professional_Resources/Trace_Element_Shortage_Survey_Report.
Further Updates on Blenderized Diet Use with the New Enteral Connectors

Peggi Guenter, PhD, RN, and Don McMichael

In the May/June issue of the Lifeline Letter, Tom Hancock from GEDSA wrote “Enteral Connector Changes: FAQs for Blenderized Diet and Other Patient/Caregiver Concerns.” One of the questions posed was, “Will thicker formulas and blended foods pass through the new ENFit connector?” As a follow-up to this question, GEDSA, Kimberly-Clark engineering staff, and A.S.P.E.N. staff developed a protocol and conducted experiments, which were carried out after the May/June issue was published. We'd like to share the results here.

The testing purpose was to determine the flow rate of blenderized diet formulas through various available feeding tube components and systems, comparing current feeding tube systems with those with a proposed ENFit connector system. Testing was performed with commercially available viscous formulas, water, applesauce, and a commercially prepared blended diet. All fluids were meant to replicate what is used in practice. Each test was done ten times with each tube and results were averaged.

Kimberly-Clark 18fr/20fr feeding tube systems were used for this testing, including:

- a low-profile feeding tube system with “bolus” extension set
- a silicone balloon retained G-tube
- a PEG tube (an initial placement feeding tube with solid silicone bolster and attachable feed head)
- a G-J tube (a dual lumen, balloon retained, jejunal feeding tube with a gastric decompression lumen)

The Testing

Three types of testing were conducted. First, the viscosity of each fluid or formula was measured to determine the thickness of each; the higher the number, the thicker (more viscous) the formula. The blended formula was thick, but not as thick as the Japanese formula or the applesauce (see Figure 1).

The second type of testing was designed to determine how much pressure was required to dispense or push the formulas through a 60mL syringe (catheter tip and ENFit). Figure 2 (on page 13) demonstrates the pressure (or pounds of force) it took to push the formulas through the two syringes and tube delivery system at room temperature. The blended diet was tested just coming out of the refrigerator to simulate clinical conditions. It took about 8 to 10 pounds of force to push the blended formula through the system, but was actually easier with the ENFit connector. The results for all of the tubes were similar in that there was no significant difference in the amount of pressure needed to push through the new ENFit connector.

The third type of testing was designed to check gravity flow through the connectors. Formulas were allowed to flow through a feeding tube system with a minimal (18”) pressure head. Figure 3 (on page 13) demonstrates how much formula or fluid would flow through each of the systems in mL/ minute. Comparing the standard catheter tip syringe and the new ENFit connector, there was little difference in the gravity flow of the blended diet through two types of gastrostomy tubes when using formula right from the refrigerator.

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Announcing 2014 Oley Award Winners

LifelineLetter Award, HPN: Mary Patnode and Harlan Johnson
Sponsored by Nutrisure, Inc., Silver Circle Partner

This year we recognize a husband and wife team, Mary Patnode and Harlan Johnson, as the LifelineLetter Award, HPN recipient. Mary has been described as “petite but a dynamo package with a big personality,” and Harlan as “Mary’s lighthouse, standing firm, a ray of positive light, and Mary’s ‘go to’ strength.”

Mary had Crohn’s disease and short bowel syndrome and had been a home parenteral nutrition (HPN) consumer for over thirty-two years. In an article she wrote for the Journal of the American Association for Vascular Access (2012), Mary noted that, thanks to HPN, she “was able to pursue a career, finish an advanced degree, work full time, buy a home, participate socially, get married, and enjoy a family that came complete…with children and grandchildren.”

Mary served as an Oley Ambassador (formerly Regional Coordinator) for almost thirty years. When she retired from her position as a psychologist in special education, she joined the Oley Board of Trustees as well. Retirement, Mary had said, meant “more time to give and choices to make about where to place my efforts. Serving on the Oley board will be an opportunity…to contribute to the supportive network that is so important to HPN consumers.” She joined the board in 2008 and became president in 2012. She continued to serve in this capacity until her death in April of this year.

Darlene Kelly, MD, states, “Mary was known for her sincere compassion and her conscientious organizational ability, and as one who seeks out the opinions of others, representing them without bias.” She brought these characteristics to her positions at Oley and contributed the much valued consumer perspective to the board. Mary has been an invaluable part of the Oley community.

Harlan was a source of boundless encouragement, love, and support for Mary throughout their twenty-two years of marriage. Oley Executive Director Joan Bishop says, “Harlan has been a rock of support for Mary, and through this support both personally as a caregiver and as husband of the Oley President, his contributions to our community are endless.” Harlan has assumed responsibility for various jobs at several annual Oley meetings and has helped Oley gain access to the team of a US senator from Minnesota in order to discuss drug shortages.

Mary and Harlan have truly enjoyed life to the fullest, spending time at their lake cabin, traveling, visiting with family and friends, enjoying their grandchildren, and playing cards with their lake neighbors. Mary and Harlan will continue to inspire the Oley community with the positive strides they have made throughout the years.

Congratulations to the nominees:
Donna Noble, Lisa Phipps, Carla Root

LifelineLetter Award, HEN: Carol Pelissier
Sponsored by Abbott Nutrition, Benefactor Level Partner

This year’s LifelineLetter Award, HEN goes to Carol Pelissier. A friend describes Carol as “never complaining.” Carol, she continues, “thinks of others before herself and no matter how difficult the challenges may get, she…always finds a way to get through…regardless of how she may be feeling.”

Carol’s story starts years ago. She began going weeks without bowel movements; nausea and vomiting left her unable to eat; and her abdomen would expand to the point of extreme discomfort. Countless tests drained her emotionally and physically, yet she would not give up hope. Many years later she was diagnosed with chronic intestinal pseudo-obstruction, severe dysmotility, colonic inertia, delayed gastric emptying, and gastroesophageal reflux disease.

Carol has undergone a total colectomy (removal of her colon) and ileostomy. For years she has been on enteral feedings and hydration, with periods of time on parenteral nutrition. “I have faced several challenges through life, but it has only strengthened me to make me the person I am today,” she says.

Carol was a physician coordinator in a busy OB/GYN office, but was forced to retire due to her health. Carol says, “It was the hardest thing for me to agree to because I did not have a choice. I loved what I was doing and I was good at it. My life took a 360 degree turn and I had to focus on other things and different ways to do things.” Carol became an Oley Ambassador, focusing on helping others on nutrition support or with problems similar to hers. Preparing formulas and medications, infusing IV hydration, undergoing tests, and dealing with infections is a constant battle. This gives her great understanding of her challenges may get, she…always finds a way to get through…regardless of how she may be feeling.”

Carol feels enjoying life is the best medicine. In 2007, her five sisters took her horseback riding for her fiftieth birthday; since then she has been hooked. Her husband bought her the horse she rode on her birthday; and Carol also takes care of the police horses in Manchester, New Hampshire. This has provided her with purpose and makes her happy.

Carol also thrives because of the emotional support she receives from her family. Married for thirty-six years, Carol and her husband have a son and daughter-in-law; in October 2013, they celebrated the birth of their first grandson.

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Celebration of Life: Patricia Melland
In honor of Coram CVS/Specialty infusion services, Gold Medallion Partner

On January 24, 2009, Tricia Melland was a very happy, healthy, and active ten-year-old girl who loved all sorts of food. On January 25, Tricia picked up a virus that landed her in the hospital. Eventually, she was diagnosed with viral mesenteric lymphadenitis, visceral hyperalgesia, reflex neurovascular dystrophy (CRPS), autonomic neuropathy, hematuria, myopathic pseudo-obstruction, intestinal failure, mitochondrial disease, and more. She was put on parenteral nutrition (PN). Since then, Tricia has spent as much time in hospitals and doctors offices as she has spent out of them. However, she continues to foster a “can do” attitude.

Despite missing several weeks to several months of school each year from fifth grade through ninth grade, Tricia manages to maintain a 97 percent grade point average in college prep–level classes. She plans on using the experiences she has gained in doctors’ offices and hospitals to pursue a career in medicine.

Tricia loves the arts. At her community theatre group, she has participated in several musicals, despite being on either PN or J-feeds 24/7. Even when she had a nasojejunal (NJ) tube taped to her face, she gave it her all. That “can do” attitude helped Tricia prove that even a person on a feeding tube could springboard dive, too. Tricia became active in diving at the age of seven and despite her chronic pain and low energy, she was on the local dive team. Although she is no longer able to dive, she is looking forward to the time when she can get back into it if/when she is able to come off PN.

Although Tricia is unable to eat, she feels socializing during meals is important in the world and she refuses to miss out on that aspect of it. She enjoys baking for others, especially “FROG” cookie cakes. “FROG” stands for “Fully Rely on God.” Tricia eagerly shares Oley information with others in hopes of easing their transition. She is always willing to lend her support and knowledge to anyone in need.

Tricia has managed to travel to several states in the past few years and likes to share funny stories about the challenges she has run into. To allow others to better understand her journey and to increase awareness about mitochondrial disease, Tricia created a video for Mito Awareness Week. Tricia has also submitted photos for use in the Oley Foundation’s Feeding Tube Awareness and HPN Awareness videos (online on Oley’s YouTube channel). Congratulations Tricia!

Congratulations to the nominees:
Jameson Atkinson, Ana Maria Bennett, Tiffany Dodd, Melissa Drake, Brenda Gray, Virginia Holland, Kendall Hollinger, Natalie Holmes, Dylan Lenburg, David McMahill, Madelyn Morris, Carol Pelissier, Donna Pugh, Melody Purkey, Tegan Watkins, and Natalie Wootten

Awards, cont. pg. 6
Awards, from pg. 5

Child of the Year Award: Kendall Hollinger
In honor of ThriveRx, Gold Medallion Partner

This year, the Child of the Year Award goes to Kendall Hollinger. As an infant Kendall was diagnosed with an anaphylactic reaction to 95 percent of all food. Still allergic and now seventeen years old, Kendall inspires and raises awareness for others who have food allergies.

Kendall thrives in all areas of her life. She started skating at the age of six and has never looked back. At age nine, she won the Ice Skating Institutes World Championship; now she competes in United States Figure Skating (USFS) at the intermediate level. Currently, she is taking some time off for health reasons.

Kendall also snowboards, wakeboards, water skis, and does about anything else she sets her mind to. When she bought her first guitar three years ago, Kendall says, “everything fell into place.” She enjoys singing and performing at Parkcrest Lakewood Church in Lakewood, California, and is currently working on pre-album production with Harmony Studios.

She attributes her love of music to her grandfather (a gospel opera singer) and her grandmother (a concert pianist).

Lola, Kendall’s peanut detection service dog, is by Kendall’s side at all times. Lola is trained to sniff for peanut residue in the air or on surfaces. “Lola has helped alert me to things and potentially saved my life many times. Having her around makes my life a little easier. I will be going to college in a year and will need her to be with me there,” says Kendall.

In 2011, Kendall was the National Teen Ambassador for the Food Allergy and Anaphylaxis Network (FAAN). That same year FANN awarded her the Teen Hero Award, and honored her at a Disney Gala in Los Angeles. She says, “It was by far the most incredible night of my life!” Every year she participates in the FAAN Walk to Save a Life. She is now a National Teen Ambassador for the Food Allergy & Anaphylaxis Connection Team. Hoping her story can help make a difference in someone else’s life, Kendall has spoken on shows such as “ABC7” and “Good Morning America.”

“I am so honored and excited to receive the 2014 Child of the Year Award,” Kendall says. “I am blown away….Oley has helped my parents and me so much growing up. My goal is to show people everywhere that your medical illness cannot keep you from achieving your dreams. This award means so much to me and I am forever grateful.” Congratulations, Kendall!

Congratulations to the nominees:
Ethan Abramowitz, Markus Bachman, Lyla Ann Baisden, Caylee Barton, Madison Beckner, Ana Maria Bennett, Ellie Brogan, Delilah Garrison, Natalie Holmes, Hope Knight, Dylan Lenburg, Madelyn Morris, Logan Urbina, Grace VanTuyl, Caleb Walsh, Tegan Watkins, and Natalie Wootten

Innovator/Advocator Award: Shannon Goldwater
In honor of BioScrip, Platinum Partner

This year the Oley Foundation established a new award to recognize a home parenteral and/or enteral nutrition (HPEN) consumer or caregiver who sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care. This award goes to Shannon Goldwater, founder of Feeding Matters.

Shannon’s triplets were born four months premature. They overcame life-threatening infections and many surgeries, but once home, feeding became a challenge. The infants would cry, arch, and often turn blue during feedings. Desperate for help, Shannon reached out to anyone who would listen. She was dismissed several times as being an over reactive mom, but she knew something was wrong. She later learned the babies were psychologically unable to eat and were avoiding eating to avoid pain.

They lived in and out of hospitals and sought specialist after specialist for three years. When two of the triplets regressed, Shannon was told feeding tubes would be vital for their development. With this, she felt she had been given permission to finally relieve her children of the suffering they had been experiencing in their effort to eat orally.

Shannon found the triplets had benefitted in different ways from each of several different feeding programs. This, and insights gained from other families, inspired her to found P.O.P.S.I.C.L.E. in 2006. Now called Feeding Matters, the organization seeks to bring pediatric feeding struggles to the forefront so infants and children are identified early, families’ voices are heard, and medical professionals are equipped to deliver collaborative care.

Currently the Board Chair, Shannon continues to advocate for the hundred-plus families she has mentored through Feeding Matters’ Power of Two Program, which matches parents who are dealing with their child’s feeding struggle with other parents who have been through a similar experience.

The triplets are now contented twelve year olds. Megan is a full oral eater; Will and Lee still require tube feedings, but are starting to find joy in eating. Chris Linn shares, “Shannon and her family are extremely grateful the Oley Foundation exists to support individuals who are dependent on feeding tubes. With all that she and her family have been through, Shannon still finds a way to...impact the lives of infants and children who struggle to eat. She constantly advocates in the community that pediatric feeding struggles are real and parents should not be blamed, and she does this by...gathering medical experts who bring credibility and knowledge with them.”

Congratulations to the nominees:
Meenakshi Aggarwal, Markus Bachman, Beth Gore, Brenda Gray, Lance Hansard, Vicky Jacque, Robin McGee, Tricia Melland, and Mary Beth Wootten

In honor of ThriveRx, Gold Medallion Partner

In honor of BioScrip, Platinum Partner
Nan Couts Award: Brenda Gray, PharmD, BCNSP, CNSC

Inspired by Judy Peterson, RN, MS

This year the Nan Couts Award for the Ultimate Volunteer goes to Brenda Gray, PharmD, BCNSP, CNSC, in recognition of her willingness to give of herself beyond her regular work hours to educate, empower, and improve the quality of life for home parenteral and enteral nutrition (HPEN) consumers. Brenda has been active in the nutrition support community for several years as a clinician and patient advocate. Along with her inpatient and outpatient clinical services, she has also been very active in consumer and professional nutrition support organizations.

Brenda has helped many consumers in their desire to return to work, go to school, and pursue interests such as camping, canoeing, and traveling. She has helped consumers make their dreams of taking special trips or dancing at a family event come true. Brenda also works with students and in new practitioner training, and serves as a consultant to develop student and resident educational experiences in clinical and practical aspects of nutrition support, including understanding patient advocacy.

Brenda continues to put her concern and compassion for the nutrition support community first by serving on national committees for several organizations and as a member of the National Board of Nutrition Support Certification Board of Directors. She serves in leadership roles in several areas for the American Society for Parenteral and Enteral Nutrition and the American Society of Health-System Pharmacists and has presented educational programs for the National Home Infusion Association. She serves as President-elect for the Florida Society of Parenteral and Enteral Nutrition and is an active member of the Oley Foundation.

Last year Brenda made a life-changing transition from clinician to nutrition support consumer. Willing to sharing her experiences, Brenda authored an article for Infusion magazine entitled “When the Clinician Becomes the Patient” (Infusion, July/August 2013). She never misses an opportunity to educate the public on the needs of the nutrition support consumer and shares her knowledge, education, and experiences with all, from the TSA, to airlines and hotel staff, in order to inform and advocate for the nutrition support community.

Brenda strives to not let life on nutrition support define her. She continues to work, travel, and enjoy camping, hiking, beach trips, and cruises. At the forefront she remains a constant consumer advocate, providing the ultimate “help along the way.” Congratulations, Brenda!

Congratulations to the nominees:
Martha Barnard, PhD; Tamara Donnelly, RD, CD; Karen Geraci, RD, CD, LD; Karen Hamilton, MS, RD, LD, CNSC; Kevin McNamara, PharmD, CNSC; Anita Shelley, BSN, RN, CWOCN, WOCN; and Kimberly Terrell, RN, ETNS

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Kyle R. Noble Scholarship: Lauren Moore

Coordinated by Richard & Donna Noble

Lauren Moore was born with Hirschsprung’s disease. Her parents were told she would probably not survive past one year. “This was unacceptable to my parents, who strove to help me be and do all I could possibly do,” says Lauren. “Through lots of research and care, I grew into a strong young girl. I never gave up no matter what the circumstances were.” Today, Lauren is studying to be a pediatric nurse. She has just completed her sophomore year of college.

“Growing up, I never allowed my medical condition to hinder me,” says Lauren. She took ballet, tap, and dance classes, was a cheerleader, played softball. “I went to school like a ‘normal’ child, though I missed many days because of hospital stays and surgeries. Despite this, I was very involved in school. I was on the National Honor Society, FCA, Student Ambassador, BiSci club, and Interact. I was also on the varsity high school soccer and softball team. My senior year I was captain of my varsity soccer team, which was a huge accomplishment.”

One of Lauren’s college professors writes that Lauren performs many skills with “competency and beyond.” But, he notes, “the real lessons I have learned from her are the ones that spring from the way she deals with HEN/HPN. Lauren first began educating me on this with a freshman research paper and presentation. I think of it as her awareness campaign. She was so matter-of-fact about her condition. On one hand she would tell me the stories about being a guinea pig for new medical instruments all the while smiling and relentlessly positive about her life.”

He continues, “Her positive energy is not one that comes from denial of the facts of her life. She faces them squarely. She clearly is not defined by her adversity. She walks her own path with family and friends by her side. She recognizes how much she depends on her support network, but it is equally clear that she is master of her condition. I cannot tell you how rare and inspiring that is.”

Lauren can only absorb about one-third of the nutrients she consumes orally, and depends on home parenteral nutrition (HPN) for the balance of her nutritional needs. She has had forty-nine surgeries to date, and has spent almost half her life in the hospital. Yet her philosophy leads her to always have a smile on her face.

“I am thankful to be alive,” Lauren says. “We never know when our last day is and I believe we need to never take life for granted. My medical condition has helped me persevere and inspire many people. My medical condition will not hold me back or define me…I want to be a pediatric nurse and help other children overcome obstacles in their life.”

Congratulations, Lauren!
Thanks for Helping at the Oley Conference!

Many thanks to the following companies and individuals for their generous contributions of time, money, and expertise.

2014 Oley Awards
Abbott Nutrition; BioScrip; Coram CVS/specialty infusion services; Nutrishare; ThriveRx. Program: New York Press & Graphics.

Ambassador Workshop
NPS Pharma. Lynn Anderson; Ron Metzger; Bob Smithers

Ask Me, I'm a Dietitian
Penny Allen, RD, LD, CNSC; Elaine Arthur, RD, LD-NH, LDN; Charlene Compher, PhD, RD, FADA, CNSC, LDN; Carol Ietron-Jones, PhD, RDN, LD, CNSC, FASPEN; Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; Elizabeth Pash, MS, RD, LDN; Craig Petersen, RD, CNSD; Cynthia Reddick, RD, CNSC; Marion Winkler, PhD, RD, LDN, CNSC, FASPEN.

Breakfast
Tuesday: Walgreens Infusion Services

Child Care
Nutrishare, Inc.; Jackson Bishop; Kiley Bishop; Rachel Metzger; Kirsten Pifer; Marjorie Quinn; Denise Richardson, RN; Giuliana Valenti

Commemorative T-shirt
Kimberly-Clark

Co-chairs
Paula Johns, RN; Bob & Mary Smithers

Conference Badges
BioScrip

Conference Program
Coram CVS/specialty infusion services

Elevator Wrap
Nutrishare, Inc.

Emergency Medical Support
Coram CVS/specialty infusion services

Exhibit Hall Score Card
AMT; Baxter Healthcare; Coram CVS/specialty infusion services; CORPAK MedSystems; Kimberly-Clark; Nestlé; NPS Pharma; Real Food Blends; ThriveRx; Walgreens Infusion Services

Exhibitors
11 Health & Technologies; 3M Health Care; Abbott Nutrition; Applied Medical Technology, Inc; Baxter Healthcare; BioScrip Infusion Services; Boston Scientific; Calmoseptine, Inc; Cera Products, Inc; Coram CVS/specialty infusion services; CORPAK MedSystems; Covidien; Dietitians in Nutrition Support, Academy of Nutrition and Dietetics; Feeding Matters; Functional Formularies; Global Enteral Device Supplier Association (GEDSA); Henry Imagine; Kimberly-Clark Health Care; Lincare Enteral Services; MitoAction; Nature’s One; The Nebraska Medical Center; Nestlé HealthCare Nutrition; NPS Pharma; Nutrishare, Inc; Nutrishare Canada; Patchwork Peddler; Real Food Blends; SBS Cure Project; Short Bowel Syndrome Foundation; ThriveRx; Trendy Tubies; Walgreens Infusion Services; Xeridiem

Faculty
Penny L. Allen, RD, LD, CNSC; Jeffrey A. Bornstein, MD; Kathryn Bundy; Katelyn Chopy, MS, RD; Charlene Compher, PhD, RD, FADA, CNSC, LDN; Mark DeLegge, MD; Marianne Duda, MS, RDN, LD/N, CNSC; Donald George, MD; Roy George; Madalyn George Thiemann, RN; Brandi Gerhardt, RN, BAN; Beth Gore, PhD, MBA; Brenda Gray, PharmD, BCNSP, CNSC; Peggi Guenter, PhD, RN; Kathleen M. Gura, PharmD, BCNSP, FASHP, FPAG; Tom Hancock; Lyn Howard, MB, FRCR; Carol Ietron-Jones, PhD, RDN, LD, CNSC, FASPEN, FAND; Kishore Iyer, MBBS, FRCS, FACS; Paula Johns, RN, MSN; Darlene Kelly, MD, PhD; Maria Karimbakas, RD, CNSC; Barbara Klingler; Lee Klingler; Arlet Kurbchabasche, MD, FACS, FAAP; Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; Daniel M. Marder, MD; Reid Nishikawa, PharmD, BCNSP, FCSHP; Donna Noble; Marianne Opilla, RN, BSN, CNSC; Michelle Park, BA; Craig Petersen, RD, CNSD; Deborah Pfister, MS, RD, CNSC; Stephanie Pitts, MSN, RN, CPN, VA-BC; Michelle M. Romano, RD, LD/N, CNSC; James S. Scapolo, MD; Michael Seres; Amanda Singer; Daniel H. Teitelbaum, MD; Allison Thompson, RD, LDN, CNSC; Ann Weaver; Marion F. Winkler, PhD, RD, LDN, CNSC, FAS-PEN; Donna Yadrich, MPA, CCIR

First-Time Attendee Orientation
Nutrishare, Inc.

General Support
Penny Allen, RD, LD, CNSC; Lynn Anderson; Michelle Carter; Brenda Gray, PharmD, BCNSP, CNSC; Peggi Guenter, PhD, RN; Kody Harlow; Paula Johns, RN; Harlan Johnson; Kathy LeFevre; Lesley & Nina Marino; Michael Medwar; Ron Metzger; Janet Platt; JoAnne Platt; Marjorie Quinn; Stephen Sabol; Diane Seyler; Bob & Mary Smithers; Rob & Tammi Stillion

HomePN Research Prize
Nutrishare, Inc.

Hotel Room Keys
Coram CVS/specialty infusion services

In Loving Memory
Harlan Johnson; Diane Seyler; Mary Smithers; Rob Stillion

Jammin' Jammies
Abbott Nutrition; Kim Butler; Kathy LeFevre; Cory Mulligan; Kelly Strausbaugh

Photography
Kim Butler; Bob Smithers

Picnic
Fresenius Kabi USA

Registration Bags
Nutrishare, Inc.

Registration Bag Inserts
BioScrip; Covidien

Rehydration Station
ThriveRx; Peggi Guenter, PhD, RN; Darlene Kelly, MD, PhD; Laura Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; Ann Michalek, MD; Marion Winkler, PhD, RD, LDN, CNSC, FASPEN

Silent Auction
Kathy LeFevre; Lesley & Nina Marino; Janet Platt; Stephen Sabol…and thanks to everyone who contributed and/or bid on items!

Speaker Support
11 Health & Technologies; Albany Medical Center; Alpert Medical School of Brown University; AngioDynamics; A.S.P.E.N.; Arnold Palmer Hospital; Baxter Healthcare; BioScrip Infusion; Boston Children’s Hospital; Children’s Medical Center, Boston; Cummins Health; Fresenius Kabi USA; Girls Inc.; Good Hope Hospital; GUARDIAN; Hyperion Health; Ibrahim; Irvine Regional Medical Center; Knowles; Larkin Community Hospital; Langley Porter Psychiatric Institute; Lifeline Foundation; Lindy J. McCluggage; Medline; Michael Medwar; Milwaukee Children’s Hospital; The Nebraska Medical Center; Nestlé HealthCare Nutrition; Nutrishare, Inc; Nutrishare Canada; Patchwork Peddler; Real Food Blends; SBS Cure Project; Short Bowel Syndrome Foundation; ThriveRx; Trendy Tubies; Walgreens Infusion Services; Xeridiem

Silent Auction
Kathy LeFevre; Lesley & Nina Marino; Janet Platt; Stephen Sabol…and thanks to everyone who contributed and/or bid on items!
Swimming, from pg. 1

however, there is also no evidence to suggest that this is a safe practice in this patient population. At Boston Children’s Hospital, our interest in the topic arose after a child with intestinal failure in our program suffered a fatal pseudomonas CVC infection within twenty-four hours of swimming in the ocean.

The Centers for Disease Control and Prevention (CDC) documented a total of 134 recreational water-associated outbreaks from thirty-eight states and Puerto Rico in a two-year period, which resulted in 13,966 cases in the general population (Hlavsa, et al. Surveillance for Waterborne Disease Outbreaks and Other Health Events Associated with Recreational Water, US, 2007–2008, Surveillance Summaries 2011; 60 [12]:1–73). The majority of the outbreaks (86.6%) were associated with treated recreational water (e.g., swimming pools). Proper maintenance of recreational water may play an important role in minimizing outbreaks, as many of the outbreaks occurred in pools that were in violation of maintenance standards.

Common sense suggests that lakes and ponds that are stagnant in nature will more likely be contaminated with fecal matter from birds. Unfortunately, there is also an abundance of evidence showing the presence of human pathogens in the ocean and in chlorinated pools. These include methicillin resistant Staphylococcus aureus, E. coli, Pseudomonas aeruginosa, Cryptosporidium, and Enterococci, as well as viruses (adenovirus, norovirus, echovirus, hepatitis A virus, coxsackie viruses), which can cause potentially fatal illnesses when given direct access to the bloodstream.

The presence of E. coli in many recreational water areas indicates that swimmers themselves often introduce fecal matter into pool areas. Other warm-blooded animals can introduce E. coli in the same manner. In addition, P. aeruginosa often inhabits biofilms on moist surfaces, such as pool walls and filters. These findings suggest that swimming is not a completely safe activity for the general public, let alone for patients with a CVC who are already at great risk of acquiring a serious infection. These factors, along with potential host immunosuppression, can place patients at increased risk of acquiring catheter-related infections.

A recent literature review demonstrated the abundance of human pathogens that have caused infectious outbreaks in the general population in all types of recreational water, including lakes, oceans, public swimming pools, water parks, and more. Human pathogens that have been identified as etiologic agents involved with recreational water outbreaks include those listed above, as well as Shigella and Giardia. These have resulted in primarily gastrointestinal infections. Moreover, it has been shown that Cryptosporidium can live up to ten days in a properly chlorinated pool. This suggests that such environments may not be optimal for patients with CVCs, and that controlled environments such as private swimming pools may theoretically minimize the risk of catheter-related infections in patients choosing to swim. However, this may be a false sense of security as infections that occur as a result of swimming in a contaminated private pool will not be reported to health authorities.

Water Quality

If you are going swimming, it is extremely important to check the contamination levels of the water on the day you plan on swimming (see table 1 for resources). Runoff from recent rains can contaminate lakes and rivers. Pools can be improperly chlorinated. Some bacteria have even adapted so they thrive in salt water.

For the water quality of public or hotel pools, check with the people who are responsible for maintaining them. Ideally, daily testing should be considered the minimum standard. Many facilities test multiple times per day and will close the pool if results exceed a certain threshold. In some states, such as Florida, public pool testing results are posted online.

Table 1: Useful Web sites for Determining Water Quality

<table>
<thead>
<tr>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centers for Disease Control</td>
</tr>
<tr>
<td><a href="http://www.cdc.gov/healthywater/swimming">www.cdc.gov/healthywater/swimming</a></td>
</tr>
<tr>
<td>Environmental Protection Agency</td>
</tr>
<tr>
<td>water.epa.gov/type/oeceb/beaches/beaches_index.cfm</td>
</tr>
<tr>
<td>Association of Pool and Spa Professionals</td>
</tr>
<tr>
<td>asp.org</td>
</tr>
<tr>
<td>Nemours Hospital</td>
</tr>
<tr>
<td>kidshealth.org/parent/firstaid_safe/outdoor/water_safety.html</td>
</tr>
</tbody>
</table>
Even if pools are maintained properly, however, other people may be swimming when they shouldn’t (for example, when they have diarrhea). Allowing infants and toddlers who are not toilet trained in the water can also result in recreational water illness.

Proper maintenance and testing is also important with private pools. Make sure your guests stay out of the water if they aren’t feeling well; the same goes for infants or toddlers who aren’t toilet trained. Swimming diapers are great, but they haven’t been tested for efficacy.

What the “Experts” Say

In 2013, a survey was performed to determine the practices of home PN programs in the United States regarding this controversial question. Twenty-five home PN programs were identified through the Oley Foundation Web site. Each program was contacted via e-mail and asked: (1) Do you allow your patients with CVCs to go swimming? If yes, what bodies of water are allowed (ocean, lake, pool, etc.)? (2) Are your patients required to use dressings/coverings? If yes, which product(s)? and (3) Are there any other rules the patients must follow?

Sixteen of the programs responded. For the programs that did allow swimming, two programs allowed any body of water; two programs allowed oceans or pools; one program allowed oceans, pools, and private hot tubs; six programs only allowed pools; and one program did not specify. (Table of results available at www.oley.org.) Dressings or line covers varied among the programs and there was no consistency in the products recommended, but Tegaderm® and AquaGuard® were both mentioned. All programs that allowed their patients to go swimming recommended cleaning the site and changing the dressing immediately after swimming.

Protecting Your Site

Consumers and caregivers looking for guidance as they struggle with the decision of whether they should go swimming with a CVC or G-tube should visit the Oley Foundation Web site (www.oley.org) for additional information. The Oley Foundation advises performing site care immediately after swimming (i.e., dressing changes) and lists several products such as AquaGuard®, Dry Pro™ PICC, XeroSox®, Tegaderm®, or OpSite® that may be used for protecting catheter sites. It is important to remember that these products do not replace the primary dressing; they simply attempt to keep the site dry.

Latex-sensitive individuals need to use caution as some products may contain latex or rubber. For example, older versions of the Dry Pro system, which uses a vacuum seal over a PICC or IV line, may contain latex. Proper sizing is also important. In order to size the Dry Pro for PICC lines, for example, you must accurately measure the circumference of the forearm and the bicep. In some cases, the protective sleeve can be trimmed to fit. AnchorDry Water Resistant Barrier is a relatively newer single-use product that is designed to keep surgical sites clean and dry, but also to cover and protect PICC lines, stomas, dressings, and CVC sites. This product is both latex and DEHP free.

It is important to remember these products are not FDA approved for swimming use. Most may have been evaluated for showering only and not the rigors of swimming. Furthermore, these evaluations should not be confused with traditional studies; oftentimes they are simply product evaluations conducted at a hospital by staff before the product becomes part of the hospital inventory. Some individuals will utilize Glad “Press ‘n Seal” to wrap around their line before or after applying one of these other dressing covers. Remember, what works for one individual may not for another.

Special outfits have also been created for this purpose. A dry suit is a fairly expensive, custom-designed outfit that features gaskets at the wrist, neck, and ankles to keep water out. This should not be confused with a wet suit, as wet suits are designed to let some water in (to keep the individual warm) and would be totally inappropriate for this purpose. See table 2 for several product ideas.

Ostomies and Tubes

Care should also be taken to keep ostomy sites dry. One device developed for this indication is the Dry Pro Waterproof Ostomy Protector. This device is made from surgical latex and uses the Dry Pro pump to create a vacuum seal. Once the ostomy protector is put in place, the vacuum pump sucks out the air so that device cannot come off and the ostomy pouch stays dry and secure. Unlike many covers that are designed for one time use, the Dry Pro for ostomy is reusable.

A recently created PEG tube site should also be kept dry when swimming. Individuals should wait at least four to six weeks after placement, when the site is healed, before swimming. The cap and/or clamp should be closed, and to prevent accidental dislodgement, the PEG tube should be tucked into a bathing suit. A T-shirt or a one-piece bathing suit will help prevent pulling by the tube getting caught on something. The tube should be securely taped to the abdomen with waterproof tape as an additional precaution.

More Information

Although many individuals seek guidance from online blogs, these blogs may send mixed or even incorrect messages. Anyone interested in healthy swimming should visit the CDC’s Healthy Swimming Program Web site (see table 1, page 10). The site provides information for the public, public health and medical professionals, and aquatics staff on how to minimize risks and maintain sanitary swimming.

Swimming, cont. pg. 12 ☛
Swimming, from pg. 11

conditions. Links to state-specific healthy swimming resources, such as beach monitoring, water quality programs, facts on recreational water illnesses, pool code information, and contacts to local public health authorities are also provided.

Conclusion

The topic of swimming with a CVC, PEG, or ostomy is wrought with mixed messages and little evidence. Unfortunately, due to the limited information available, a firm recommendation cannot be made. Recreational water–associated outbreaks are well documented in the general public, as is the presence of human pathogens even in chlorinated swimming pools.

As a medical team, practitioners can provide information regarding the potential risk, but ultimately the decision lies with the individual. Consumers and caregivers need to have an open and frank discussion with their team to determine what approach is best for them. Due to our experience at Boston Children’s with a fatal event immediately after swimming, we continue to strongly discourage patients with CVCs from swimming. However, if the decision to engage in this popular pastime is still considered worth the risk, we encourage our families to ensure proper line/site maintenance (e.g., dressing and cap change immediately after swimming) and to use products that are specifically designed for this use that may mitigate infection risk. Further studies regarding the risk of swimming with a CVC are needed to make a strong, evidence-based recommendation.

Editor’s Note: A well healed port site with no in-place needle or inflammation from prior needle access may be a good option for teenagers and adults who want to swim. Ideally they would require only intermittent infusions and have learned to insert a needle into their own port as needed.

Table 2: Products That Have Been Used to Protect Lines
(inclusion on this list does mean endorsement)

<table>
<thead>
<tr>
<th>AnchorDry</th>
<th>iMed Technology, Inc.</th>
<th>Dallas, TX 75287</th>
<th><a href="mailto:info@imedtechnology.com">info@imedtechnology.com</a></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aqua-Guard</td>
<td><a href="http://www.aqua-guard.com">www.aqua-guard.com</a></td>
<td><a href="mailto:customer-service@aquaguard.com">customer-service@aquaguard.com</a></td>
<td>(253) 395-2400 or (800) 426-1042</td>
</tr>
<tr>
<td>Design for Your Life Medical Privacy Sleeves</td>
<td><a href="http://www.designforyourlife.com">www.designforyourlife.com</a></td>
<td>(888) 479-4687</td>
<td></td>
</tr>
<tr>
<td>Dry Pro’s PICC Line Protector</td>
<td><a href="http://www.drycorp.com">www.drycorp.com</a></td>
<td>(888) 337-9776</td>
<td></td>
</tr>
<tr>
<td>Hammond Drysuits</td>
<td><a href="http://www.hammond-drysuits.co.uk">www.hammond-drysuits.co.uk</a></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HomePN Research Prize

Sponsored by Nutrishare, Inc., Silver Circle Partner

The HomePN Research Prize, sponsored by Nutrishare, Inc., was established in 2007 to encourage clinical studies focused on improving the quality of life for homePN consumers. The 2014 prizes were awarded at the annual conference to the following individuals:

Katelyn Chopy, MS, RD, LDN
Rhode Island Hospital, Cumberland, Rhode Island

A Qualitative Study of the Perceived Value of Membership in the Oley Foundation by Home Parenteral and Enteral Nutrition Consumers

While research has shown proven benefits to HPEN consumers affiliated with the Oley Foundation, no studies have investigated the perceived value of membership to the consumer or the way in which consumers are introduced to the organization. Analyzing the data obtained from in-depth interviews with several Oley members and identifying common themes, the researchers note the value of Oley lies in programs and resources and the competency, inspiration, normalcy, and advocacy gained from membership, helping individuals adjust to life with HPEN dependency. More than half of participants found the organization through self-initiated Internet searches, but all participants clearly expressed the desire “I wish I knew about it sooner.”

Brandi Gerhardt, RN, BA
The University of Nebraska Medical Center, Omaha, Nebraska

Successful Rehabilitation in Pediatric Ultrashort Small Bowel Syndrome

The objective of this study was to examine treatment outcomes in pediatric patients with ultrashort small bowel (USSB) syndrome in an intestinal rehabilitation program (IRP). Of the 28 patients identified in IRP records from 2001 to 2011, 27 (96%) survived. Almost one-half (48%) of these survivors achieved PN independence with their native bowel. The researchers concluded that enrollment in an IRP provides an excellent probability of survival for children with USSB. The presence of an intact ileocecal valve and colon are positively associated with rehabilitation in this population, but are not requisite.

Michelle Park, BA
Stanford University School of Medicine, Palo Alto, California

A Cognitive Aid “Central Line Care Card” for Central Line Associated Bloodstream Infections in Pediatric Home Total Parenteral Nutrition Patients

Management and outcomes of catheter-associated bloodstream infections (CABSIs) in pediatric home parenteral nutrition (HPN) patients have been inadequately studied. The researchers wanted to see if a “Central Line Care Card” could improve management of CABSIs and patient family satisfaction with central-line associated medical encounters. They gave twenty-eight long-term HPN patients ages 0 to 25 personalized cards with the patient’s diagnosis, details about the central line, and instructions for what to do when the patient went to a medical facility with a fever and potential CABSI. They then tracked patients who sought treatment.

The trend was toward decreased breaches in care of potential CABSIs after the card was presented. Parents also reported that the card impacted their experience positively. These results suggest this low-cost intervention may quickly improve management of potential CABSIs at lower-level healthcare centers that rarely encounter children on HPN.
Tube Talk, from pg. 3

Conclusion

The new ENFit feeding design standards were developed with current practice in mind and specific requirements to avoid any disruption of therapy. Blended formulas are not all the same and tubes vary as well. In this study, with these tubes and formulas, the flow and pressure requirements for ENFit and cath-tip syringes were essentially equivalent. If your formula goes through the cath-tip syringe, it should go through the ENFit connector.

It is recommended that each company perform testing on its tubes with a variety of formulas. For more information or if you have questions about your EN device or delivery system, contact the manufacturer directly and check the GEDSA Web site, www.StayConnected2014.org.

Peggi Guenter, PhD, RN, is the Senior Director for Clinical Practice, Quality, and Advocacy for the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). Don McMichael is Product Development Engineer with Kimberly-Clark Health Care. ¶

Figure 2. Pressure testing

Figure 3. Gravity Flow of Formula

Kangaroo™ products are leading the way to true industry standardization.

The Kangaroo name is synonymous with safe, innovative nutritional delivery products. Recently, the International Standards Organization created ISO CD 80369-3 defining safe design for an enteral feeding connector. Covidien, in collaboration with companies across the industry, helped to develop the ENFit Twist Connection System and the Stay Connected Initiative. By adopting ENFit connections, the complete Kangaroo portfolio will have the added safety of an internationally accepted standard for safe enteral connections.

For more information go to www.covidien.com/safeconnections or www.GEDSA.org.

*This document may provide links to third party websites. Covidien has not reviewed any third party website and is not responsible for the content or the privacy policies of any third party website and shall not be liable for any damages or injury arising from that content. Any links to other sites are provided as merely a convenience.

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Through a national network of over eighty-five locations, Coram CVS/specialty infusion services offers comprehensive home infusion services. They provide home parenteral and enteral services through their Nourish™ Nutrition Support Program. With over thirty years of experience, they are dedicated to providing high-quality clinical care and personal support for nutrition consumers.

Boston Scientific

Boston Scientific Endoscopy is a world leader in less invasive medical devices for treating gastrointestinal and pulmonary conditions. The company says it “provides customers unmatched value by combining its clinically proven technologies with superior support to help improve patient outcomes and reduce total cost of patient care.”

Nutrishare

Nutrishare, a home TPN specialty company since 1991, is proud to announce their expansion into Canada. Nutrishare’s team of reimbursement specialists offers personal assistance for all insurance and billing matters. Visit the Nutrishare and Nutrishare Canada websites for more information.

Baxter Healthcare

Baxter Healthcare Corporation has eighty years’ experience in developing parenteral nutrition products that work together to help improve patient outcomes. Baxter offers clinicians and patients parenteral nutrition solutions, IV fat emulsions, and automated compounding systems.

Kimberly-Clark Health Care

Kimberly-Clark—the enteral feeding company—strives to deliver easy and reliable enteral feeding solutions. Kimberly-Clark makes MIC® and MIC-KEY® balloon-retained gastrostomy and transgastric-jejunal feeding tubes. The company says, “these tubes provide safe, reliable nutrition delivery for pediatric and adult patients with more tube options than any other company.”

Nutrishare Canada

Rod Okamoto and Tom Diamantidis founded Nutrishare twenty-three years ago, focusing exclusively on the home TPN consumer. Nutrishare Canada is dedicated to the same standard of excellence and commitment to their Canadian home TPN consumers.

Thank You, from pg. 9

Children’s Hospital; Brody School of Medicine, East Carolina University; Coram CVS/specialty infusion services; CS Mott Children’s Hospital; Florida Network of the Association for Vascular Access; GEDSA; Hasbro Children’s Hospital; Mayo Clinic Florida; Mount Sinai Medical Center; Nutrishare, Inc.; Rhode Island Hospital; St. Joseph’s Children’s Hospital; ThriveRx; University of Florida College of Medicine/Nemours Children’s Clinic; University of Florida Jacksonville; University of Kansas, School of Nursing; University of Nebraska Medical Center; University of Pennsylvania, School of Nursing

Sunscreen

Fruit of the Earth

Travel Scholarships for Consumers

NPS Pharma. Esther Ann Brown Adler Memorial Scholarship; Jarol Boan, MD, MPH; Melissa Chaney Memorial Fund; Friends of Robin Lang Memorial Travel Fund; Bruce F. Groeber Family; Carol Iretson-Jones, PhD, RD, LD, CNSC, FASPEN, FAND; Carol & Jack Leibee; Judy Peterson, RN, MA; Janet Pratt & Christopher Hlatky; Short Bowel Syndrome Foundation; ThriveRx

Tube Feeding Workshop

Sponsored in part by Nestlé

Videotaping of Conference

NPS Pharma

Walk-a-thon

AMT; Baxter Healthcare; BioScrip; Coram CVS/specialty infusion services; Covidien; Fresenius Kabi USA; ThriveRx; Walgreens Infusion Services; Xeridiem

Youth Activity

Wednesday: Walgreens Infusion Services. Amber Barron; Kim Butler; Jackson Bishop; Kiley Bishop; Jonathan Dunn; Noreen Luszcz, RD, MBA, CNSC, Lesley & Nina Marino; Ron Metzger; Marjorie Quinn; Denise Richardson, RN; Julie Sahr; Catherine Smithers; Matt Teague; Guiliana Valenti; Mikaelia Vincent

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Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. A complete list of the contributions received in 2014 will be published in the March/April 2015 issue. We are grateful for the following gifts received from May 10, 2014, to July 4, 2014:

In Memory of
Donald Engle; George T. Linsley; Eleanor Orkis; Mary Patnode

In Honor of
Leroy A. Ferguson, Jr., and all the forgotten middle age and older feeding tube patients; Mary Kunz’s birthday; love; Joanne Platt

Matching Donations
Bank of America Charitable Foundation; FM Global Foundation; GE Foundation

Our sincere apologies to Mariah Abercrombie, whose name was placed in the wrong category in our May/June issue. Our thanks to the donor who gave in honor of Mariah, and our apologies for causing unnecessary stress to our careful readers.

Join the 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 (800) 776-OLEY.

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John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
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Launa Maunsee, PhD, RD, LDN,
CNSC, FADA, FASPEN
Kathleen McIntee
Michael Medowar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
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Suan & Jeffrey Schoenol
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Thank You!
Remembering Pat Brown

Pat Brown, RN, CNSN, OCN, a long-time Oley volunteer and former Oley trustee, passed away June 29. Pat started in nutrition support in 1977 at Memorial Sloan-Kettering Cancer Center working under Maurice E. Shils, MD, a pioneer in parenteral nutrition. She continued in this line of work until very recently, helping consumers meet the challenges of living with home parenteral and enteral nutrition, and the effects of cancer therapy and malabsorption.

Pat had volunteered for Oley since its inception as an advisor, treasurer, conference chair, speaker, board member and friend. Pat was instrumental in creating the HPN and HEN complication charts, and later the “Tube Feeding Troubleshooting Guide.” She also reviewed many articles for the newsletter, and counseled Oley members about their tube feeding issues. In addition, Pat volunteered on medical mission teams that provided surgery and other health care to people in Central America.

Pat was warm and compassionate, and enjoyed sharing a laugh. She was unflappable and always willing to pitch in where needed. When an attendee became ill at an Oley conference, it was often Pat who accompanied him or her to the hospital. And when a consumer needed advice to overcome a hurdle presented by their nutrition therapy, she was there with a practical solution. She was an integral part of the Oley community and will be sorely missed.

Conference, from pg. 1

Another big plus is learning about the newest research and innovations. I learned previously about research on growing your own intestine with stem cells and we heard this year how that is moving forward. But there are other new technologies as well! These things will take years to perfect but are likely to be available during our daughter’s lifetime.

Doctors that are not in this field are still telling families that their short gut children will only live five years. This is what we were told and I hear this all the time…it’s still the standard line for many families new to this disease. The Oley conference gives us the true story and offers hope for our children’s future.

Daniel Teitelbaum, MD, is researching growing small intestines.

Learning opportunities abound at the conference. Here consumers see firsthand how the new ENFit connectors work.