Easing Your Trip through Airport Security

Representatives from the Transportation Security Administration (TSA) joined the Oley Foundation for our annual conference in Redondo Beach, California, in June. Jeremy Buzell, the Acting Manager of TSA’s Disability Branch in the Office of Civil Rights and Liberties, Ombudsman and Traveler Engagement, met conference attendees during roundtable sessions and while handing out materials at a booth. We asked him to provide us with more information based on his experience at the conference.

Q: How did TSA become familiar with the Oley Foundation and the people it serves?
A: TSA works with a coalition of more than fifty organizations representing individuals with disabilities and medical conditions. These organizations provide TSA with valuable feedback about the concerns of the people they serve. The Oley Foundation has been an active member of this coalition for years. The Disability Branch was grateful for the invitation to attend this year’s conference because, even though we interact with representatives of Oley on a regular basis, we learn a lot from hearing about the individual passenger experience.

Q: What did you learn from the attendees you met?
A: We had many very positive conversations with attendees who understand the role that TSA plays in protecting travelers. We also were asked many questions and heard many concerns about TSA’s screening procedures for passengers with medically necessary liquids, medical equipment, and medical devices such as ports and feeding tubes. It gave us a lot of insight regarding the challenges that passengers face when traveling with homePEN supplies.

Nominate a Consumer

The Lyn Howard Nutrition Support Consumer Advocacy Award is given on an annual basis to a patient/family member/caregiver who has advocated for other patients, families, or caregivers of consumers who require parenteral nutrition (PN) or enteral nutrition (EN). The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) established this award in order to recognize individuals who perform admirable activities and heroically advocate for others like themselves and their families.

Advocacy efforts include such activities as lobbying for legislation to improve care or reimbursement, developing educational tools, fundraising for PN or EN research, starting or sustaining support groups, being a consumer advocate, or teaching others about PN or EN.

The award is named in honor of A.S.P.E.N. member and Oley Foundation co-founder Lyn Howard, MB, FRCP. The winner receives a plaque and travel grant to A.S.P.E.N.’s Clinical Nutrition Week meeting. Please consider nominating a consumer, caregiver, and/or family member. Nominations are due by October 15th. For more information or a nomination form, go to www.nutritioncare.org/Membership/Awards/Lyn_Howard_Award or call (610) 649-7994.

Refreshed, Renewed by Oley Conference

Malik Saunders
Journal Entry: Thursday, Redondo Beach, CA

So today my three-day journey ends. I leave the conference refreshed, with new confidence, a new attitude, and new friends. Honestly, I didn’t know how I was going to fit in. To my surprise, I felt at home—actually, better than at home. I felt this is where I was supposed to be. I felt safe, safe in the arms of experienced people who had stories like mine, if not worse. I wasn’t the only one running to the bathroom…
Airport Security, from pg. 1

Q: Based on what you learned, what advice do you have for passengers who are preparing to travel by air?

A: First, we want to encourage everyone who requires homePEN to contact TSA Cares before they fly. TSA Cares is a dedicated, toll-free helpline for passengers with disabilities and medical conditions and their loved ones. Passengers who call TSA Cares can get the latest information on screening for passengers with disabilities and medical conditions. But, more importantly, we often can work with the airport to provide advance notice or get assistance for the passenger at the checkpoint. Calling TSA Cares does not exempt a passenger from screening, but it can help prepare the airport for your arrival and will facilitate a positive screening experience.

It is very helpful if passengers call at least seventy-two hours before they fly (or earlier if they are flying on a weekend) in case we need to work with the airport. Travelers may call the TSA Cares helpline toll free at (855) 787-2227, Monday through Friday, 8 a.m. to 11 p.m. EST, and weekends and holidays, 9 a.m. to 8 p.m. EST.

Second, it is very important for passengers to get to the airport early. Aside from normal wait times, screening of medically necessary liquids and medical devices can take extra time. The screening experience is less stressful for everyone if there is enough time to get through it without worrying about whether a flight will be missed.

The screening also will go more smoothly if passengers are prepared to communicate openly and clearly. It is very helpful if they inform TSA personnel up front that they have medically necessary liquids, or medical equipment, or a device like a port or feeding tube and where it is located. Let TSA personnel know of any areas that are painful or dangerous to touch, as well as any information they need to safely handle your equipment or liquids.

Lastly, pack your carry-on property with screening in mind. Separate all of your medically necessary liquids and equipment from your other belongings so they can be quickly and easily identified and accessed for screening.

Q: What should passengers who use homePEN expect at the TSA checkpoint?

A: Every passenger’s screening experience will differ based on the kinds of devices, and amounts and kinds of liquids that a passenger may have. Similarly, how a passenger’s screening is conducted can sometimes depend on the configuration of the checkpoint and the technology being used. Lastly, TSA actively employs random and unpredictable screening in order to thwart terrorists who try to game the system.

In general, however, medically necessary liquids are allowed through a checkpoint in any amount once they have been screened. Supplies that are associated with medically necessary liquids and gels, such as IV bags, pumps, and syringes, are allowed through the checkpoint once they have been screened by x-ray or a hand inspection.

Liquids are screened by x-ray, and those in excess of 3.4 ounces will receive additional screening. Accessories required to keep liquids cool, such as freezer packs or frozen gel packs, are treated as liquids unless they are frozen solid at the checkpoint. If these accessories are partially frozen or slushy, they are subject to the same screening as other liquids.

A passenger could be asked to open the liquid for screening. A Transportation Security Officer (TSO) will not touch the liquid during this process, however. If the passenger does not want a liquid, gel, or aerosol x-rayed or opened, he or she should inform a TSO before screening begins. If the liquid cannot be opened or x-rayed for screening, additional screening of the passenger and his or her property may be required; this may include a pat down.

If a passenger cannot or chooses not to be screened by advanced imaging technology (AIT) or a walk-through metal detector, the passenger will be screened using a thorough pat-down procedure. A pat-down procedure is also used to resolve any alarms of a metal detector or anomalies identified by AIT. If a pat down is required in order to complete screening:

- The pat down will be conducted by a TSO of the same gender. Sometimes passengers must wait for a TSO of the same gender to become available.
- The passenger can request a private screening at any time and a private screening should be offered when the TSO must pat down sensitive areas. During a private screening, another TSA employee will also be present and the passenger may be accompanied by a companion of his or her choosing.
- A passenger may ask for a chair if he or she needs to sit down.
- The passenger should inform TSOs of any difficulty raising his or her arms; remaining in the position required for a pat down; or any areas of the body that are painful when touched.
**HEN Tips**

- A passenger should not be asked to remove or lift any article of clothing to reveal a sensitive body area.

If a passenger has a port, feeding tube, or other similar device, it may receive additional screening. This may include, but is not limited to, an inspection of the device if it is not in a sensitive area, and a pat down of the device followed by testing for traces of explosives. If explosive material is detected, the passenger will have to undergo additional screening. For more information about the technology used to test for explosive material, please visit www.tsa.gov/approach/tech/etd.shtm.

**Q: What should a passenger do if he or she has a difficult time during screening?**

**A:** It is best to try to resolve any problems right at the checkpoint. So, the first thing a passenger should do is ask to speak with a supervisor while still at the checkpoint. The supervisor should help to explain any procedures or resolve any issues. If the supervisor cannot do so, many airports also have Customer Service Managers that passengers can ask to speak with either during or after their screening.

If an issue cannot be resolved at the checkpoint, a passenger can file a complaint with the Disability Branch by sending an e-mail to TSA. ODPO@tsa.dhs.gov. It is extremely helpful if the passenger sends it as soon as possible after the event and includes as much detail as possible in the description of what happened.

Our thanks to the TSA and Jeremy Buzzell for sharing these tips. We'd like to share a few other thoughts on air travel that we gleaned from roundtable participants:

- On documentation: We usually recommend that homePEN consumers travel with documentation from their health care provider(s). Note that while this may be helpful in communicating with TSA personnel, it will not exempt you from screening. See the “Travel Tips” section on www.oley.org for sample documentation and other advice on traveling with home parenteral and/or enteral nutrition.

- On TSA Cares: If you've called TSA Cares, you should be contacted by someone from the airport before you get to the airport, or the people at the TSA checkpoint will be watching for you.

- On pat downs: If a medical device is in a sensitive area or should not be touched by a TSO, you may be asked to do a “self pat down,” after which your hands will be tested for explosive materials.

---

**Tube Talk**

Send your tips, questions, and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or e-mail metzgel@mail.amc.edu.

Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

**O-Ring Syringes Easy to Use**

I used to have a love/hate relationship with the 60 ml syringes provided by my home health care company. I was constantly battling the rubber tips. I washed them. I oiled them. I sprayed them. But no matter what, they performed like a city taxi driver: abrupt stops and abrupt starts.

Not only that, you must have super human strength to get them going. I loved them because my son couldn’t live without them.

But now, it’s nothing but love! I discovered silicone o-ring syringes over the Internet. Prices vary considerably and there are many types. I like the 60 ml catheter tip and the 60 ml slip tip syringes. The slip tip will fit right into a low-profile feeding tube device.

Instead of a rubber stopper on the plunger like ordinary medical syringes, the plunger is solid plastic with a silicone o-ring around it to make the seal. The silicone does not degrade with washing and use like rubber does. It remains always easy to push. Their tip is a little more narrowly tapered and sits better in the extension tube.

The most economical place I have found for these syringes is a squirrel feeding supply company! Go to Squirrels and More, www.squirrelsandmore.com, and search for “60 cc o-ring catheters.” I have used the same syringe for four months now. I am very pleased with the purchase. They have saved my wrists and my sanity!

—Susan, susan@thebuttonbuddy.com

---

**When I travel, I make sure the agents use clean gloves when handling my supplies. I make sure I clearly explain what I am carrying with me and why I need it. I offer letters of medical necessity to validate my claims.**

“Most people don’t know and understand HPEN. They won’t know what I need if I don’t take the time to explain it. Additionally, they will be much more willing to accommodate and help me out when I take the time to explain and when I respect them.

“Regardless of what the agents want to do, I realize it is important to be patient and respectful. These people ultimately get to decide if I am allowed to take my flight or not. I understand they are trying to protect all of us traveling and are just trying to do their job.”

—Tim Weaver, HPEN consumer
Nutrition and You
Medication and Nutrient Interaction Awareness: How to Play It Safe

Home enteral and parenteral nutrition (HPEN) consumers must be always mindful of possible medication interactions, ever striving to minimize the number of medications used. Since it is not possible for any health care professional to recognize all medication interactions, the HPEN consumer can play a weighty collaborative role in identifying and understanding interactions.

The following suggestions will help you identify and potentially avoid medication-medication or medication-nutrient interactions.

Maintain a List

Be vigilant in updating the list of all your medications, prescription and over-the-counter (OTC). Make a master list of these medications, including all HPN prescriptions (keep a label or ask the provider to provide a copy) and HEN regimens.

Keep a Diary

Consider keeping a perpetual diary (as timely and as continuous as practical), so you can note changes that may be helpful in determining when a probable medication interaction impacts on well-being. Diary entries should include not only significant changes, but all deviations from the norm. These entries can more easily be incorporated into your existing daily record keeping (i.e., weight, temperature, pulse, blood pressure) using automation (i.e., computers, voice recognition software, recorders). Medication interaction screening can be more adequately evaluated if the consumer or caregiver has collected accurate information.

Write down and record any changes in OTC or prescription medications, medication administration, dosing, herbas, and foods. The quantity and ingredients of food or drink intake should be meticulously noted, especially if taken with medications or outside the normal ingestion. Remember that all changes may be significant, so even social activities, mood, stress, seasonal changes, weather, or body cycles (menstrual, menopause) need to be indicated.

Common signs and symptoms of an interaction are: anorexia (loss of appetite), polyphagia (increased appetite), cough, dry mouth, edema, fever, headache, insomnia, quickening or slowing of food in the intestinal tract, urinary excretion, lethargy, itching, rash, nausea, vomiting, or diarrhea. If these symptoms are associated with a change in medication or a change in how the medication is being applied, vomiting, or diarrhea. If these symptoms are associated with a change in medication or a change in how the medication is being applied, the intestinal tract, urinary excretion, lethargy, itching, rash, nausea, vomiting, or diarrhea. If these symptoms are associated with a change in medication or a change in how the medication is being applied, ingested or injected, speak to your physician and/or pharmacist.

Nutrient-Medication Interactions

One of the most widely studied food-medication interactions concerns grapefruit. It is clear that grapefruit and especially grapefruit juice can increase medication blood concentrations up to fifteenfold with high doses of grapefruit, and twofold with lower doses in some medications (i.e., statins).

It is also important to know that other juices will have varying effects. For example, lime, star fruit, and pomegranate juice may also inhibit intestinal enzymes. (Note: orange juice does not have a similar effect.) This means that some drugs will not be broken down by the enzymes and may be absorbed in a more potent form than necessary. Always ask about any interactions with your medication, especially if grapefruit juice is a common component of your diet.

Speak to your doctor, pharmacist, or dietitian about your medications and your diet to be sure you are playing it safe. Although dramatic advances have been made in the study of medication interaction mechanisms, there is much to learn. The consumer and his or her health care team must work together to recognize beneficial, and avoid adverse, medication-nutrient interactions.

Resources

The Internet is a valuable tool for both the patient and the clinician to provide confirmation for any proposed interactions. Although Internet domains that are government (.gov) or educational (.edu) are preferred, there are numerous other credible domains (see table below for some recommended sites).

Making Changes

Finally, all suspected interactions should be discussed with your primary health care providers before any curtailment of medications or changes in diet are made.

Written by Thomas G. Baumgartner, PharmD, MEd, RPh, RCPPh, FASHP, President and Chief Executive Officer of Consultant Pharmacists of America, Inc. Reviewed by Carol Ireton-Jones, PhD, RD; Laura Matarese, PhD, RD; and Cheryl Thompson, PhD, RD. References are available upon request.

Table 1. Selected Medication Interaction Web Sites

- www.cdc.gov
- www.med.unc.edu/medicine/edursrc/drug_int.htm
- www.ext.colostate.edu/pubs/foodnut/09361.html
- www.drugs.com/drug_interactions.html
- www.hanstenandhorn.com

Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? No Internet access? Contact Oley volunteers Tammi and Rob Stillion at oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.
A Look Back: Sunday

Mariyah (my fiancée /caregiver), her beautiful, spirited daughter Annie, and I got in Sunday evening, June 25. The hotel was beautiful. Our room was a little far, but worth the walk. We checked in and hit the beach.

We found a fresh seafood restaurant, Captain Kidds. You can pick out your own seafood and they will cook it right there for you. As we ate dinner, I gazed out the window and thought, “Wow, the Oley Foundation picked a beautiful place.” The weather was perfect, and I was surrounded by fresh seafood. Mmmm. We turned in early so we could be up and ready for registration.

Monday

The next morning I meet Cathy Harrington at the registration table. She greets me with a smile and says, “We have been waiting for you. Glad you could make it.” Lisa Metzger greets me with a warm smile, too, and makes me feel comfortable instantly.

I receive my name badge with my green ribbon for first-time attendees and a brown ribbon for being an award nominee. Now you can see who is actually here for the conference by show of the name tags. I take a minute to look over the schedule, and I am overwhelmed by all the information. Mariyah tells me to take a deep breath and relax—we made it! Everything will be OK.

Meeting people who have been on TPN over twenty years with very few blood infections and normal liver numbers inspired me to live each day with passion.

Tuesday

And everything is better than OK. I have met some amazing people who are Living, living Life to the fullest. In the past seven years, on more than a few occasions, I was told of the five-year mark—meaning statistically, after five years of HPN my mortality rate goes down. I didn’t really listen to that too much because I believe when God calls, He calls! Meeting people who have been on TPN over twenty years with very few blood infections and normal liver numbers inspired me to live each day with passion.

I met people like the beautiful Lynda Bosworth, who has that movie star quality about her. Lynda and I met after an inspiring breakout session and we instantly made a connection. Her sister was with her, and you could see and feel the love they share. Her sister said, “She is a movie star,” pointing at Lynda. To myself I said, “I knew it.” Lynda began to tell me her story.

Lynda and her husband were on a picnic in the Arizona desert mountains when their jeep hit a rock and flipped over. They were stuck in the desert for four days. Theirs is a story of perseverance and true love. It was featured on a reality show called “I Shouldn’t Be Alive” (Animal Planet). The title of the show was “Till Death Do Us Part.”

Thank you, Oley Foundation for a wonderful time. And a special thank you to the sponsors and the people who donate to the Oley Foundation. We might not have been able to make this trip without an Oley travel grant. I appreciate you and I thank you. We are patiently waiting for next year… ¶
27th Annual Oley Consumer/Clinician Conference Highlights

Redondo Beach was a spectacular location for this year’s Oley conference. As one attendee noted, “Southern California weather is always the best!” Total conference attendance this year set a new record for us. Of the 394 people who came, 89 were home parenteral and/or enteral consumers (68 adults, 21 pediatric) and 132 were family members and caregivers. The rest of the attendees were clinicians and exhibitors.

The conference presentations were outstanding and informative. Many of the powerpoint shows are available at www.oley.org, and several of the sessions will be available on DVD this fall. Forty-nine children rotated through child care and the youth activities! The kids had the opportunity to enjoy a “faux” campout with Painted Turtle camp staff, make stuffed animals, tour on a glass-bottom boat, race Big Wheels, and visit the marine center to learn about ocean ecology, while the adults stayed inside to learn about better managing their, or their loved one’s, nutrition therapy.

In the evenings and on Thursday, we all came together for the silent auction, town hall meeting, the walk-a-thon, and the picnic. Thanks to everyone who came and helped make this conference a success. We hope you enjoy the photos!
Kudos to the 2012 Award, Scholarship Winners!

Joseph D. Briseno, LifelineLetter Award

In honor of Nutrishare, Inc., Gold Medallion Partner

When Jay Briseno was twenty years old, he was shot by a sniper while on duty in Iraq. Jay was left with a spinal cord injury, as well as traumatic brain injury due to lack of oxygen. Unable to swallow safely, Jay has been dependent on home enteral and/or parenteral nutrition (HPEN) since 2003. Jay’s father, Joseph, is one of his primary caregivers. He is also a selfless advocate for Jay and for other wounded soldiers.

When Jay was first wounded, Joseph reached out to the Christopher and Dana Reeve Foundation where he met Bernadette Mauro, the Director of Information and Resource Services for the foundation’s Paralysis Resource Center. Later, Joseph volunteered as an advocate for the Military Outreach Program of the foundation, working with Bernadette. “Joseph is his son’s voice, as well as the voice for other wounded warriors,” Bernadette says. “He has reached out to other families, soldiers and their caregivers. He shares openly about how they have navigated both the VA and DOD system to get Jay the care and support he needs. If another family needs support, a simple call to Joseph and the family has someone who knows and understands what they are going through.”

Joseph left his job as an engineer to provide twenty-four hour care for his son. He and his wife, Eva, are devoted to Jay, but their commitment doesn’t stop there. “Their love and devotion extends to complete strangers, spouses and family members of other soldiers on HPEN—families uncertain of how they can make it happen at home, who are fearful of the future,” Bernadette continues.

While Joseph acknowledges they have made sacrifices to be home with Jay, he writes, “We are thankful that our Jay is with us, that he is alive and living and with us, in our home, every moment of every day. And little by little, step by step, Jay has regained abilities we were told would be ‘impossible,’ given the extent of his injuries….The impossible is what nobody can do until somebody does it—and in the midst of change in our life, we often discover wings we never knew we had.”

Joseph and his family have been the subject of many articles, including one in USA Today and another on PBS. Their story is inspiring, and we are pleased to welcome them into the Oley community.

Patricia Melland and Aleah Smith, Child of the Year Award

In honor of ThriveRx, Gold Medallion Partner

Patricia (Tricia) Melland

In January 2009, ten-year-old Patricia picked up a virus. After many months in the hospital she was diagnosed with several ailments and started on parenteral (IV) nutrition. Tricia was beginning to recover when she was struck with another virus. Unable to eat, she has been dependent on tube feeding ever since. “Her last meal or real food was in August of 2010,” her mother writes. “[But she] has always had a can-do attitude. She has not let her illness define who she is.”

Even when she had a naso-jejunal (N-J) tube taped in place, Tricia actively participated in a community theater musical production and attended school full time when she wasn’t in the hospital. In August 2011, a gastro-jejunal (G-J) feeding tube replaced the N-J tube.

Tricia recently graduated from eighth grade with her class, despite having missed a great deal of school since fifth grade. She has also traveled a lot this year, visiting eight states. On their trips, her mom says, “She has run into challenges, but nothing she couldn’t deal with and that we don’t laugh about now! [When] she was in Boston, there was a blackout in the hotel for twenty-four hours. She sat in the lobby all night with a super long extension cord running from her pump to a generator outside to keep her pump going! If you are creative enough, you can make anything work.”

Tricia does not let her feeding tube stop her from living her life. After being hospitalized recently with a complication from her illness, she went straight from the hospital to a diving meet, where she impressed the judges with her beautiful high flying dives.

In accepting the Child of the Year Award at the Oley conference, Tricia credited her strength to the support she receives from her strong faith, family, and friends.

Aleah Smith

Aleah was born with such a small amount of intestine the doctors did not expect her to survive. Her parents were given the option of “letting her go” or taking her home and feeding her intravenously. Now seventeen, Aleah has been dependent on parenteral (IV) nutrition and/or enteral nutrition (tube feeding) on and off much of her life. Aleah has undergone numerous surgeries, from when she was just hours old to just last winter.

Despite repeat hospitalizations, chronic pain, and motility issues, Aleah is extremely upbeat and active. She plays flute in concert band, and plays marimba, gong, bass drum—and pretty much whatever is needed—as the section leader for front ensemble in marching band. She was also a member of the winter drum line color guard at Tri-West High School, which won first place at the state competition in 2010. Aleah is in the top 10 percent of her class, keeping up with her schoolwork by going to school part of the day and doing the rest of her work online, with the help of a tutor. She is also on the Children’s Advisory Board at Phoenix Children’s Hospital, and is very involved with church activities.
Michelle Barford, Celebration of Life Award

Michelle had been a nurse for over thirty years when, in 2008, she went to the emergency room with acute abdominal pain. Surgery revealed that she had carcinoid cancer of the small intestine. A second surgery revealed that it was widespread, and the doctors sent her home on hospice. Michelle says, “I have a T-shirt from Spamalot that says, ‘I’m not dead yet,’ and that became one of my many mantras.”

In 2009, Michelle discharged herself from hospice, opting to undergo surgery to have the carcinoid cancer removed—along with 90 percent of her intestine. Since the surgery, Michelle has been dependent on home parenteral nutrition (HPN). She experienced a year or more of denial before, she says, “I finally got my groove back!” Now, it’s hard to slow her down.

Michelle is on the Executive Board of the Special Olympics of Greater Memphis, and in 2010 rappelled a twenty-three story office building to help raise funds for the organization. She also volunteers for the Memphis-Shelby County Court-Appointed Special Advocate Program, where she serves as a court-appointed advocate for children in foster care situations.

Michelle is also an avid traveler. She often accompanies her husband on business trips and visits her family in other states. Last year, Michelle spent three weeks in Australia, Singapore, and Hong Kong. In February, she went on a twenty-nine day road trip, staying in eight states and two Canadian provinces.

In accepting the award at the conference, Michelle said, “You need to conquer your fears and then adapt to your new normal. Live your life as if there may not be tomorrow. Because anything—and I mean anything—you have to do surely beats the alternative.”

Michelle has recently become an Oley Regional Coordinator.

Congratulations to the nominees: Kyler Carlisle; Kendall Hollinger; Mariah Noonan; and Allison Winter.

When she isn’t busy with schoolwork, Aleah enjoys swimming, reading, writing, video games, texting, and hanging out with her best friend. “She loves her cat,” her mother, Tara, adds. “She misses her very much when she is in the hospital.” On a recent Make-a-Wish trip to Hawaii, Aleah and her family enjoyed sailing and Aleah learned how to surf.

When she received the award at the Oley conference, Aleah said a quote Tricia had cited was one of her favorites, too. Both girls agree: “Life is not about waiting for the storm to pass, it is about learning to dance in the rain.”

Congratulations to the nominees: Kyler Carlisle; Kendall Hollinger; Mariah Noonan; and Allison Winter.
Winners of the 2012 Oley Foundation HomePN Research Prize

Sponsored by Nutrishare, Inc., Oley Gold Medallion Partner

The Oley Foundation HomePN Research Prize, sponsored by Nutrishare, Inc., was established in 2007 to encourage clinical studies focused on improving the quality of life for home PN consumers. The 2012 prizes have been awarded to:

**Lisa Johnson, RD, LD/N**  
Coram Specialty Infusion Services, An Apria Healthcare Company • Jacksonville, Florida  
**Electrolyte Impossible: Clinically Navigating through the National Electrolyte Shortage**

**Pam Kruger, PhD**  
Wadsworth Center, New York State Department of Health • Albany, New York  
**Excessive Accumulation of Aluminum in the Bones of Patients on Long-Term Parenteral Nutrition (PN): Post-mortem Analysis**

**Donna Noble**  
ThriveRx • Grove City, Ohio  
**Using the Social Media to Evaluate and Share Insights on Life on Home Nutrition Support**

Abstracts for all three of these studies are available on the Oley Web site, www.oley.org, or upon request (800-776-6539).

---

**Kerry Stone, MS, RD, CNSC, Nan Couts Award**

*Kerry Stone, MS, RD, CNSC, Nan Couts Award*

**Coordinated by Judy Peterson, RN, MS**

Kerry, who currently works as a Nutrition Patient Care Coordinator for KabaFusion in California, has been involved with home parenteral and enteral nutrition (HPEN) for over fifteen years. She has worked in different capacities for different home infusion companies, which has given her a range of experience. Kerry has been a frequent contributor to Oley conferences, has helped with Oley projects (such as the tube feeding complication chart), and is active with the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), where she is the membership liaison for the Dietetic Practice Section.

Patient care is at the center of Kerry’s efforts and interests. In order to provide the best care to the HPEN consumers with whom she works, she stays abreast of new therapies and equipment, and keeps her knowledge base current. She is continually striving to put what she learns into practice. Kerry listens well and helps communicate consumers’ needs to other providers to make sure there is continuity of care. Importantly, she makes sure consumers get the education and support they need to be successful with PEN in their home.

**Congratulations to the nominees:** Jeffrey Rudolph, MD; Ezra Steiger, MD; and Marion Winkler, PhD, RD, CNSC.
Daulton Heisey and Tim Weaver, Kyle R. Noble Scholarship
Coordinated by Richard and Donna Noble

Kyle Noble, who passed away in 2006, is remembered widely with affection. His family established the Kyle R. Noble Scholarship to recognize others who exhibit his enthusiasm for life. This year, the Scholarship Committee selected two recipients, who will split the $2000 scholarship.

Daulton Heisey and Tim Weaver are both good students who are very involved in their schools, extra-curricular activities, and communities, and are both notably kind, warm, mature, and committed. Daulton aspires to be a pediatric nurse when he completes his education, while Tim will study computer engineering.

Daulton started on home parenteral nutrition (HPN) when he was eight years old. He acknowledges that HPN presents challenges, but says, “I try to have a positive attitude. I believe that life is too short to allow yourself to get caught up in the unfairness of your situation; instead, I have picked my feet up and I am determined to make a difference in the world.”

Already Daulton is making a difference. He has coached baseball for younger children; volunteered with his school’s Big Star/ Little Star peer mentoring program and Big Brother program; raised thousands of dollars for the American Heart Association; and served as class treasurer. Daulton has also served on the Advisory Council of Teens at the Penn State Hershey Children’s Hospital.

Tim has had to rely on parenteral and/or enteral nutrition (HPEN) on and off all of his life. He knows what it is like to be on therapy, and to be off. “While some may be disappointed or look at the negative aspects of being on HPEN,” he says, “I look beyond that. I focus on the things I am able to do because I am healthy and feeling well.”

One of the things Tim has enjoyed doing since he was young is going to a camp for children with chronic health conditions. “The ability to enjoy yourself in an environment where people accept you as you are is a rare but wonderful experience,” Tim says. “The camp has had an incredible impact on my growth and ability to care for myself.”

Wanting to make this experience more widely available, Tim joined with camp counselor Matt to set up a Golden Tee (a golf arcade game) tournament as a fund-raiser. Over the past few years, the annual event has raised thousands of dollars and has grown, and Tim has taken on a wide range of responsibilities.

Tim is also on the youth advisory board for his local hospital, and often speaks about what it is like to be on HPEN. “I have spoken to a class of pharmacology students, the suppliers for Baxter, and during a presentation at A.S.P.E.N. All of these times, I have been trying to educate others on what it is like being on HPEN….It gives the doctors [and others involved with HPEN] the ability to understand the daily lifestyle of a consumer and work to improve their quality of life.”

We wish Daulton and Tim every success as they embark on their new adventures.
Thank You for Supporting the 2012 Oley Consumer/Clinician

Many thanks to the following companies and individuals for their generous contributions and volunteer support, and to all those who unofficially

2012 Oley Awards:
Apria Healthcare / Coram Specialty Infusion Services; Nutrishare, Inc.; ThriveRx. Volunteers: Judy Peterson, RN, MS, and the Awards Committee members.

2012 Awards Programs:
New York Press & Graphics

Breakfast:
Tuesday: ThriveRx
Wednesday: Walgreens Infusion Services

Child Care:
The Painted Turtle. Volunteers: Jessica Bowman; Carmen Carley; Chloe Carley; Collin Carley; Inge Fero; Lou Garcia; Virginia Garcia; Charlotte May; Gabrielle McKenzie; Ron Metzger; Claire Vida, RN; Heidi Wong, RN; Michelle Zadunayski, RN; Sara Zargham

Commemorative T-shirt:
Apria Healthcare / Coram Specialty Infusion Services

Conference Badges/Lanyards:
Apria Healthcare / Coram Specialty Infusion Services

Conference Bags:
Nutrishare, Inc.

Conference Co-Chairs:
Linda May; Laurie Reyen, RN, MN

Emergency Medical Support:
Coram Specialty Infusion Services

Exhibitors:
Abbott Nutrition; Adept Ltd.; American Society for Parenteral & Enteral Nutrition (A.S.P.E.N.); Applied Medical Technology, Inc. (AMT); Apria Healthcare; The Association of Gastrointestinal Motility Disorders, Inc. (AGMD); Baxter Healthcare; BioScrip, Inc.; Brooks Health Care, Inc.; Calmoseptine, Inc.; Corpak MedSystems; Covidiën; Critical Care Systems (CCS); Crohn’s & Colitis Foundation of America; Dietitians in Nutrition Support; Heartland I.V. Care; InfuScience; IveraMedicalCorp.; Kevin’s Covers, a division of Hampton House Medical, Inc.; Kimberly-Clark; LifeCare Solutions; MitoAction; MOOG Medical Devices Group; The Nebraska Medical Center; Nestlé HealthCare Nutrition; NPS Pharmaceuticals; Nutrishare, Inc.; The Painted Turtle; Self Tube Feeder; ThriveRx; Transportation Security Administration (TSA); Walgreens Infusion Services

Faculty:
Penny Allen, RD, LD, CNCS; Katie Anderson, RN; Kanela Artavía, LCSW; Jameson Atkinson; Felice Austin; Mary Baker, PharmD; Abby Brogan; Jeremy Buzzell; Amy Long Carrera, MS, RD, CNCS; Rick Davis; Dane DeLuca, RN, WOCN; Michael J. Erickson, RN; Elana Evan, PhD; Douglas Farmer, MD; Paula Gaida, RN; Joan Gordon, LCSW; Kathleen Gura, PharmD, BCNSP; FASHP; FPPAG; Nancy Hackett, RN, CRNI; Kendall Hollinger; Kim Hollinger; Lyn Howard, MB, FRCP; FACP; Shirley Huang, MD; Carol Ireron-Jones, PhD, RD, LD, CNCS; Hossam Kandil, MD; PhD; Darlene Kelly, MD, PhD; Mark G. Klang, MS, RPh, BCNSP, PhD; Pamela C. Kruger, PhD; Lynn Leslie, RT; Laura E. Mataraese, PhD, RD, LDN, FADA, CNCS; Linda May; Richard W. McCallum, MD, FACP, FRACP (AUST), FACG; Tara Mccoleman, RN; Richard Mokua, RN, CNP; Lynne Murphy, MSN, RN; Reid Nishikawa, PharmD; Neha Parekh, MS, RD, LD, CNCS; Melinda Parker, MS, RD, CNCS; Carol Rees Parrish, MS, RD; Anita Piano, BS, RN, VA-BG; Megan Pike, MS, CCLS; Steve Plogsted, PharmD, BCNSP, CNCS; Michelle Pratt, RN; Laurie Reyen, RN, MN; Dana Russell, MPH, CIC; Jessica Santos; Doug Seidner, MD, AGAF, FACC, CNCS; Rex Speerhas, RPh, CDE, BCNSP; Kerry Stone, MS, RD, CNCS; Jody Strain; Sara Swindle, MS, RD; Brewster Thackeray; Rob Venick, MD; Julie Walden, RN; Ann Weaver; Tim Weaver; Ellen G. Wilson, PT; Marion F. Winkler, PhD, RD, LDN, CNCS; James Yoo, MD; Deborah Zetterholm, RD, LD, CNCS

General Conference Support:
John (Cody) Bakkila; John & Anne Beaman; Ceraproducts, Inc.; Kathryn Cleberg; Fruit of the Earth; Heartland I.V. Care; Heather Hudgins; David & Theresa Mathiasmeier; Ron Metzger; Ralph Valenti. Volunteers: John (Cody) Bakkila; Anne Beaman; Anne & Terry Edwards; Linda & Ray Gravenstein; Jeff Hoelle; Harlan Johnson; Carol Leibee; Ron Metzger; Mariana Osio; Mary Patnode, MS, Ed; Mary Seidner; Bob & Mary Smithers; Karen Speerhas; Tammi & Rob Stillion; Fred Stuto; Giuliana Valenti

Donors and shoppers raised $4800 for Oley Foundation programs at the Silent Auction.
Conference in Redondo Beach, California!

chipped in to help as needed.

Hotel Room Keys:
Apria Healthcare / Coram Specialty Infusion Services

In Loving Memory Service:
Critical Care Systems, Inc. Volunteers: Penny Allen, RD, LD, CNSC; Rick Davis

Jammin’ Jammies:
Abbott Nutrition; Starlight Foundation; Danny Loudon. Volunteers: Maureen & David Denitz; Maureen & Jack Gillespie; Freddi Girard; Cima Kalmanzon; Jennifer Layman; Melissa London; Sarah Lumbert; L.J. Martin; Karen Mewborn; Karen Speerhas; Lou Stratten

Picnic:
Fresenius Kabi; Bobbie Groeber

Registration Brochure & Conference Program:
Nutrishare, Inc.

Silent Auction:
Volunteers: Anne & Terry Edwards; Jeff Hoelle; Janet Platt; Sanford Schmel; Mary Seidner; Bob & Mary Smithers; Karen Speerhas. A big “Thank You!” to all who donated and/or purchased items!

Silent Auction Vacation Package:
MOOG Medical Devices Group; Walt Disney World

Speaker Support:
The following companies and institutions provided funding and/or faculty for this year’s program: A.S.P.E.N.; Boston Children’s Hospital; Cleveland Clinic; Coram Specialty Infusion Services; Critical Care Systems; East Carolina University; Hospira, Inc.; InfuScience; KabaFusion; Mayo Clinic; Nationwide Children’s Hospital; New York State Department of Health; NPS Pharmaceuticals; Nutrishare, Inc.; The Painted Turtle; Rhode Island Hospital; Shield HealthCare; Sloan-Kettering Institute; ThriveRx; Transportation Security Administration; UCLA Health System; University of Virginia Health System; Vanderbilt University Medical Center

Transitioning to Independence Sessions:
ThriveRx

Travel Scholarships for Consumers:
ANTHEM Health Services; Baxter Healthcare; Jarol Boan, MD, MPH; Melissa Chaney Memorial Fund; Friends of Robin Lang Memorial Travel Fund; Bruce F. Groeber Family; Carol Ireton-Jones, PhD, RD, LD, CNSD; Carol & Jack Leibee; NPS Pharmaceuticals; Nutrishare, Inc.; Melinda Parker, MS, RD, CNSC; Janet Platt & Christopher Hlatky; Shield HealthCare; ThriveRx

Tube Feeding Workshop:
Kimberly-Clark

Videotaping of Conference:
Baxter Healthcare; Joel Resnick

Walk-A-Thon:
Apria Healthcare / Coram Specialty Infusion Services; BioScrip; Critical Care Systems; Fresenius Kabi; InfuScience; MOOG Medical Devices; Nutrishare, Inc.; Shield HealthCare; ThriveRx; Walgreens Infusion Services. Thank you to all of the walkers and everyone who supported the effort!

Youth Activity:
Wednesday: Walgreens Infusion Services
Volunteers Tuesday and Wednesday: Lucia Cimarusti; Rebekah Cleberg; Lou Garcia; Ron Metzger; Janet Platt; Kevin Smith; Paige Turco

Thank You Walk-a-Thon Walkers

Walkers at the 2012 Oley conference raised $4,000! Many thanks to everyone who participated in the event: Penny Allen; Pat Anthony; Felice Austin; Deon Balli; Gerardo Balli; Joan Bishop; Ashleigh Bond; Bettemarie Bond; Betty Bond; Kailee Brown; Vic Brown; Jovaan Clark; Charlie Cleberg; Kathy Cleberg; Rebekah Cleberg; Roslyn Dahl; Peter Daniel; Nick DeCaprio; Anne Edwards; Terry Edwards; Fresenius Kabi Chicago Team; Ray Gravenstein; Michelle Grinzi; Daulton Heisey; Alicia Hoelle; Jeff Hoelle; Hossam Kandil; Marum Kandil; Yosra Kandil; Pamela Kruger; Rachael Lopez; Carlos Martins; Christine Martins; Michael Medwar; Bryan Melland; Patrick Melland; Tricia Melland; Wendy Melland; Lisa Metzger; Ron Metzger; Dee Pappas; Mark Pratt; Michelle Pratt; Clarice Rossignol; Amanda Singer; Bob Smithers; Mary Smithers; Karen Speerhas; Rex Speerhas; Rob Stillion; Tammi Stillion; Cathy Tokarz; Paige Turco; Giuliana Valenti; Craig Wheeler; and Michele Wilson.
Corporate Partner Spotlight

We have much to be thankful for, including the support of our corporate partners. Please join the Oley Foundation in thanking our most recent corporate contributors. Without our partners Oley could not provide its many programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

Apria Healthcare / Coram Specialty Infusion Services
Apria Healthcare and Coram Specialty Infusion Services are proud to support Oley as Gold Medallion Partners. They empower tube feeding and HPN consumers through individualized customer service, clinical expertise, education, and support. Their Nourish Nutrition Support Program (www.wenourish.com) offers thirty-plus years of experience, comprehensive therapy management, consumer advocacy services, online resources, and national coverage and local expertise.

Nutrishare, Inc.
Nutrishare was founded in 1991 by Tom Diamantidis, PharmD, and Rod Okamoto, RPh, with the goal of specializing exclusively in home TPN care. They continue to focus on the needs of their home TPN consumers. Learn more about their team of ‘specialists’ at www.nutrishare.com.

ThriveRx
ThriveRx is proud to be a Gold Medallion Partner of the Oley Foundation. The company is dedicated to providing customized customer service and clinical care for the home enteral and parenteral nutrition consumer. Its mission is to ensure quality care that fosters independence and empowers patients and their families. Visit www.thrivexr.com to learn more about its Short Bowel and iThrive programs.

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. Visit www.clinimix.com to learn about Baxter’s premixed parental nutrition products.

Abbott Nutrition
Abbott Nutrition is one of the world’s leading authorities in science-based nutrition for all stages of life. Explore its portfolio of products, including Vital jr. and PediaSure, to help patients grow and achieve greater well-being. Visit www.AbbotNutrition.com to find product information, patient education materials, clinical research papers, and more.

InfuScience, Inc.
InfuScience, a proud Oley partner, is committed to providing the highest quality infusion service experience for nutrition support consumers. Using individualized care models and coordinated advocacy efforts, InfuScience excels in the delivery of nutrition services, antibiotic and other infusion therapies in the home. Visit them at www.infuscience.com to learn more.

Kimberly-Clark
Kimberly-Clark’s priority is to deliver easy and reliable digestive health solutions that help improve outcomes and quality of life. The company’s trusted clinical solutions are utilized more often than any other around the world including its pioneering MIC-KEY™ balloon-retained gastrostomy feeding tube. Visit them at www.mic-key.com.

Critical Care Systems, Inc.
Critical Care Systems is a leading national specialty infusion company providing comprehensive clinical services to pediatric and adult populations through a national footprint of JCAHO-accredited, community-based branches (see www.criticalcasystems.com). It is CCS’s belief that customized nutrition support, “state of the art” HPN standards, and a team of TPN experts, leads to optimal outcomes.

Emmaus Medical, Inc.
Emmaus Medical, Inc. is a specialty pharmaceutical company dedicated to the discovery, development and commercialization of innovative and cost-effective treatments and therapies for rare diseases. The company is completing its Phase III clinical trial for a treatment for sickle cell disease and is also working on regenerative medicine technology products.

Notable Gifts from Individuals
Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2012 in the January/February 2013 issue. Between May 19 and August 10, 2012, gifts were received:

In Honor of
Charlie Cleberg’s 13th birthday; Jane Golden’s birthday; Gaye Lowenstein’s birthday; Mary Patnode

In Memory of
Ann DeBarbieri; Franky Friedman; Mary Friel; Imagail Gordon; James Hudeck; Joyce Hydorn; Larry Karacki; Larry Keating; Sylvia Liebman; Kathleen McInnes; Carol Peirce; Jacqueline Stephens

Matching Gifts
Bank of America Matching Gifts, Baxter International Foundation, and The GE Foundation

Fundraisers
iGive.com (thank you for remembering Oley when you shop online!)

We appreciate all gifts and kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!
$5 Million in Grants!
Vote for Oley, September 6–19

Oley has been nominated to receive a grant from the Chase Community Giving program—now we need votes! From September 6 to 19, you can cast two votes on Facebook (at Chase Community Giving) and another two votes on Chasegiving.com (if you have an online account with Chase). Share a link on your Facebook page, and you could earn another vote.

The 196 charities who receive the most votes will share $5 million in grants! Please vote for Oley, and ask your friends, family members, colleagues, and acquaintances to vote, too! The money would help with Oley’s outreach and educational efforts.

Details on Facebook.com/ChaseCommunityGiving, or call the Oley office at (800) 776-6539 if you have questions.

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 continued interest and strong commitment.

GOLD MEDALLION PARTNERS
($50,000–$69,999)
- Apria Healthcare / Coram Specialty Infusion Services
- Nutrishare, Inc.
- ThriveRx

SILVER CIRCLE PARTNERS
($30,000–$49,999)
- NPS Pharmaceuticals

BRONZE STAR PARTNERS
($20,000–$29,999)
- Baxter Healthcare

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)
- Abbott Nutrition
- InfuScience, Inc.
- Kimberly-Clark

PATRON LEVEL PARTNERS
($5,000–$9,999)
- Walgreens Infusion Services

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. To learn how you can make a difference at (800) 776-OLEY.

---

Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoedle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Lauren Matarrese, PhD, RD, CNSD
Kathleen McInnes
Michael Medwars
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clifford Petterson
Beverly Promisel
Abraham Rich
Gail Egan Sansivero, MS, ANP
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnol
Doug Seidner, MD, FACG, CNSP
Judi Smith
Steve Swensen
Cheryl Thompson, PhD, RD, CNSD,
& Gregory A. Thompson, MD, MSc
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Rodline Ann & William Wu

Thank You!
$5 Million in Online Grants
Your vote will raise money for Oley programs
See details on page 15.

Awareness, Spirits Raised as Consumers Share HPN Stories

There was a flurry of activity in early August as the homePEN community celebrated the second annual HPN Awareness Week. Before the event started on August 5, we had distributed 2000 buttons that read “Alive with HPN,” along with Oley contact information. Members shared these with friends, home care companies shared them with clients, companies passed them out to employees.

During HPN Awareness Week, we watched the numbers soar on the Oley Facebook page (over 13,750 people “reached!”) and YouTube channel (over 1100 viewings of Oley’s “Alive with HPN” video). Several members were interviewed by their local media (stories posted on www.oley.org), while Oley staff joined members to visit Albany-based homecare companies. Members (from as far away as Poland and New Zealand!) sent links to share on Oley’s YouTube channel. Baxter Healthcare, which helped fund the buttons and promotional materials, shared the “Alive with HPN” video with employees, coordinated an HPN consumer panel presentation for employees in Chicago, organized a “jeans” day to raise funds for Oley, and more.

We know many efforts escaped us and we appeal to you to share your experiences with us. And if you haven’t seen the “Alive with HPN” video on YouTube, we think it’s worth a visit to a friend’s house or the library (if you don’t have Internet access at home). Enjoy!

Why Awareness?

Awareness helps create understanding, and understanding helps create compassion. It helps dispel misinformation and assumptions. When you share your stories, you help others see their own situation better. Sometimes your stories offer hope; sometimes people just need to know there is someone else out there like them.

During Awareness Week, we posted a daily question on Facebook. One day we asked, “How long have you been on HPN?” One fan wrote that she had been on for three years. She said, “Amazed reading your posts. I… thought that people couldn’t last long on it. Feel happier now.”

Your Help Needed in 2013!

• HPN Awareness Week, August 4–10, 2013
• Feeding Tube Awareness Week (founded by the Feeding Tube Awareness Foundation), February 3–9, 2013

A photo of you or your loved one for the Oley video will help launch our efforts for 2013. Or create your own video to help people understand life with HPN or feeding tubes. Consider planning an activity, circulating a press release, posting on Facebook, organizing a fund-raiser, etc. We can help!

We’ll start immediately on the video for Feeding Tube Awareness, so please send a photo or contact Lisa Metzger now, (800) 776-6539 or metzgel@mail.amc.edu.

Audrey has mitochondrial disease and uses a doll stroller to carry her pumps and bags. “Despite this, or because of it, she is a happy, thriving girl.”

—Audrey’s mom