A Regular Guy: My First Oley Conference
Stephen Alan Boyar

On board the plane from JFK Airport to Orlando with my wife, Melba, waiting to take off for my first Oley conference, I sigh. I will never overcome my anxiety about getting through Security. I remember the scene from two hours ago.

There's Something Wrong with Me

I’m certain I will be thrown in jail as a suspected terrorist. To defuse the tension I know I should announce to the TSA (Transportation Security Administration) agent ordering me to step into the body scanner that I have a feeding tube. I don’t want to. But I do—even though it’s none of his or anyone else’s business that I have a hole in my stomach and a tube hanging out of it.

Again the agent barks, “Step into the scanner.”

Either he didn’t hear me or chose to ignore me. I tell him I have a letter from my doctor. He takes it but doesn’t read it, doesn’t even look at it.

“Move into the scanner.”

They’re going to freak out when they see the tube looped and secured by a tube holder taped to my chest.

School Days
Michele Horton

Many parents feel apprehension and concern when their kids complete preschool. The thought of sending our precious children off into the big world of kindergarten is enough to make any parent panic. Add special medical needs into the mix, and the apprehension and concern turn into absolute fear.

The thought of sending my (g-tube fed, peanut and milk anaphylactic) son to a public school was overwhelming. Someone other than me or my family would be responsible for feeding him? I could not get comfortable with this. No one could do as good of a job as I could. And how would the school accept him?

I dreaded school for years. I knew the day would come, and I spent many, many years fearing it.

SF Meeting, Marathon

The Oley Foundation will be coordinating several one-day regional conferences for 2014–2015, with support from NPS Pharma. We were inspired to hold the first conference in San Francisco in July when Oley member Emma Tillman, PharmD, PhD and home parenteral nutrition (HPN) consumer, notified us she was signed up to run the San Francisco Marathon. That’s 26.2 hilly miles, and Emma was determined to—and did—run it, along with several others comprising “The Oley Running Team” and about 20,000 strangers (running the full or a half-marathon).
My First Conference, from pg. 1

and so, he tells me, he's taking me to a private room. How thoughtful.

He walks ahead of me, fast, slowing down to kibbutz with a coworker. He's not paying attention to me. I could run back, grab my wife, and flee to the safety of home. She's overseeing the testing of each and every medicine bottle, can of food, bottle of water, syringe, and plastic cup in my medicine wheely. She is practiced at remaining calm and checking that every item is returned intact so I won't go crazy on the flight from hunger, thirst, or the lack of pain medicine.

I was ambivalent about going to an Oley conference anyway because I don't want to be identified with people who I see as disabled. I didn't want to see myself—or allow anyone else to see me—as anything less than perfect. A gift of my upbringing.

But this year I had a change of heart. I'd been to another organization's conference, also focused on illness, and one of the presenters has since been instrumental in changing my life for the better. I believe in education.

So, back at the airport, scratch the escape plan. I really want to go to the Oley conference—see what I've been missing. I say to the agent's back, “Do I really need to be without shoes?”

He stops, looks at my feet, and says, “I didn't know you left them behind.” It's my fault.

“Go back and put your shoes on.” What am I, his kid?

In the private room, I feel like the next step is a cell. Another agent joins us. I guess he's the witness who will make sure the first agent behaves according to the rules. Or the two of them are in cahoots, happy for the opportunity to steal... what? They wouldn't want to yank the tube out of my stomach. I doubt they could find a fence interested in hot feeding tubes.

I tell No. 2 I have a letter from my doctor. “Go back and put your shoes on.” What am I, his kid?

At the conference on Monday I join a company that makes nutritional products, also focused on illness, and one of the presenters has had similar experiences. I wonder how many other to see me—as disabled. I didn't want to be identified with people who I see as disabled. I didn't want to see myself—or allow anyone else to see me—as anything less than perfect. A gift of my upbringing.

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At the conference on Monday I join a company that makes nutritional products, also focused on illness, and one of the presenters has had similar experiences. I wonder how many others as well if they receive the newsletter electronically.

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

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

Subscriptions:
The LifelineLetter is sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically.
**Stand Offers a “Third Hand”**

Since being on a feeding tube for two years, I have found myself facing many challenges and always searching for easier ways to do things. I am bolus feeding using a PEG tube, and I use the gravity system through a 140 cc syringe. As you may know, when gravity feeding, you pour formula or blended food into a syringe and then hold the syringe in one hand while formula flows in through your tube. Eating like this can take a long time, and your arm can become very tired in this position.

This was very frustrating to me as I only had one hand left to do the things I wanted to do while feeding, such as use the computer, read the newspaper, etc. It’s so much easier to do these things with two hands.

After I had been on the tube for one year, I was searching the Internet one day and found a syringe holder and clamp. I was thrilled by this discovery and ordered one immediately. When it arrived, I was excited and amazed at how well it worked. Now, I don’t know how I lived without it!

It’s such a great tool to have. You can use various sizes of syringes (i.e., 60 cc, 70 cc, 140 cc, etc.), and it helps to alleviate spillage. It’s like having a third hand!

By the way, traveling with it is very easy. It’s very portable. The base will fit on any standard table and some chairs, and it has a flexible arm. I highly recommend this product to give you a more useful and comfortable way to feed. For more information go to www.jofas.net.

—David Rowland, cdrowland@comporium.net

**Feeding Tube Connector (ENFit) Updates**

Are you up-to-date with the changes coming to feeding tube connectors? Products with the new ENFit connectors are scheduled to go on the market as early as this winter.

The first products to be released with the new connectors will be administration/feeding sets, next will be syringes, and last will be the feeding tubes themselves. Everyone on tube feeding will see changes.

GEDSA (www.stayconnected2014.org), the Oley Foundation (www.oley.org/EN_Connector_Articles.html or 800-776-OLEY), and individual manufacturers have educational resources available to help you transition to the new products. We encourage you to inform yourself and discuss these changes with your homecare provider. The more you know, the more comfortable you will be with yourographies.

**Necessity Is the Mother of Invention**

I have been on a feeding tube since June 2011, after cancer surgery, chemo, and radiation left me unable to swallow. I had a nose tube, then a J-tube, and now a G-tube that has to be replaced every three months.

At first, I struggled with the stomach feeding tube when I was not using it to get nourishment. The medical advice given to me was to tape it to my skin. This irritated my skin and didn’t hold well. I needed to find a better way. I researched alternatives. When I couldn’t find anything to help me, my determination led me to create a feeding tube holder and feeding tube clamps.

Both are simple, functional, and easy to use. For over two years now, I have been wearing the holder and making improvements to it. It holds the feeding tube up and keeps it away from my waist. I use the clamp when I need to close off the tubing while I am taking nourishment. The clamp is gentle on tubing.

After four surgeries and many doctors and nurses telling me they have patients who could benefit from the holder, I am making them available for purchase. I want to share with others who need a feeding tube to stay alive. The holders and clamps are available at www.easyfeedingtube.com.

—William Langford, Okeechobee, Florida
Standing in the Shadow of Death

Gail Farhood

I have been battling Crohn’s disease for thirty-eight years. I have had fourteen operations and spent half my life in hospitals. This has obviously restricted me from doing what I really wanted to do in life, but I can now say I have come full circle with this dreaded disease and also state that every breath I take is a Godsend.

You really can’t give up (even though the thought has crossed my mind on more than one occasion). You just have to keep fighting and fighting. You can’t beat Crohn’s, but you can control it and go on to a better life. It is all in your mind.

No Light for Me

We have all heard about near-death experiences, where people tell you, “I saw the light,” or “I was going through a tunnel,” or “My parents were there to greet me.” Well, last March, I was incredibly sick and was later told I had been standing in the shadow of death. But I didn’t see the light, a tunnel, or my parents. So, I say laughingly, I just knew it wasn’t my time! How lucky was I?

My son and my close friends who were there to witness my so-called demise told me what had happened. I don’t remember much. It’s a long story, so I’ll just share some of it.

Just a Tunnel

At the time this happened, I was in the hospital. I had actually been in the hospital for quite a while, but I didn’t know where I was. One night I was in so much pain that the GI surgeon who was on call sent me for a full body scan.

He discovered that my Crohn’s disease had caused perforation of the bowel, and toxins were going through my body at a rapid pace. They called my son and asked permission to operate immediately. If they didn’t, they told him, I was going to die. They operated on March 1, 2013. I ended up with my third ileostomy and four fistulas.

I spent some time in the ICU, then some time in step down. I was in an induced coma for a while, as I had been subconsciously pulling out the IVs and pulling off my breathing mask.

I finally woke up in a hospital bed to see my son looking at me. That was quite unnerving, I could hardly talk and I still had difficulty breathing. I felt I was broken. I asked my son quietly, “What happened?”

He asked me what my last memory was. I told him what I remembered. There was a gap, events I don’t remember at all. He told me they kept telling him they “didn’t think I would make it…”

But I had made it. The journey had been long and grueling—and it wasn’t over. I thought, I have to get out of this place! Though my determination was fierce, I soon realized that’s easier said than done.

Recovery

At that time I weighed 80 pounds. My son told me I couldn’t just lay there—I had to start moving. “Start with rotating your feet to get your circulation going a bit,” he said. “Try and move your legs, Mom.” Then he would help me. Bit by bit, I started to come back. I wasn’t giving up. I could have, but I didn’t.

I lay on my back for almost two months, as I was very weak. I was too weak to eat in the beginning and they were feeding me with parenteral nutrition (PN). Then they stopped. I started to eat slowly, hoping to gain a bit of weight and to gain the strength I needed to get on the road to recovery.

After two months the physical therapist came to get me started on some exercises. I was afraid, but I knew I had to start somewhere. I wish I could have just swung my legs over the side of the bed and walked out of there, but that would be a while yet.

The nurse and the therapist came every day and we all took baby steps. I started with sitting at the side of my bed; then they stood me up to walk a few steps and get my legs in motion. Every day I managed a few steps more. Four steps the first day, eight steps the next, and so on. I was eventually able to walk with a walker, with a nurse at my side.

My determination and stamina were high. “I can do it,” I kept telling myself. “Don’t give up, Gail.” Each day I progressed. I finally got to sit in a chair. I sat for ten minutes to begin with, and then every day it was a little longer. The doctors were amazed at how fast I was recovering. I had told them my goal was to get out of there, and in order to achieve that, I had to work harder.
By Mother's Day I weighed about 96 pounds. Once I could walk without problems, they started thinking about giving me day passes. I was going nuts in the hospital and needed something to occupy my time. They decided to put me back on PN, to help me gain the weight I needed so they could release me from the hospital. That was in May. As I was then getting day passes, I was able to go in to work—after all, the business needed to keep going. Every night my son would drive me back to the hospital to be hooked up for twelve hours with PN.

They felt that in order to release me, I would have to learn how to do the PN myself at home, and they arranged for me to have classes. It was rough going, and really hard to learn. I knew the doctors had gone as far with me as they could, and PN at home was my very last option. The nurse that taught the PN mentioned that maybe it wasn’t for me as I wasn’t catching on fast enough, but after much debate and uncertainty, I went back and completed the course to their satisfaction. The hospital finally released me on August 18, 2013. I weighed 112 pounds.

**The Value of Hope**

Through all the trials and tribulations that I went through, I never gave up hope. “Hope”... that’s the key word. You can’t give up. You can’t let your disease control you, or depress you, or get hold of you.

YOU are the only one who can get over any hurdle you face. The only way to get through it is to survive, to not let go, and to have the determination to live!

I started off with home PN (or HPN) seven days a week on a twelve-hour cycle during the night, so that I had my days free. Gradually I went down to one night off. Now I am at three nights off the HPN and four nights on. I am back to work full time, and I’m happy to be alive. Hopefully I won’t have to be on it the rest of my life, but only time will tell. Since August 2013 I have gained 45 pounds and am feeling great.

My recovery took seven months, whereas normally it takes one to one and a half years. I have had some rough days, but nothing was going to get me down. I just want to tell you, if I can do it, so can you! ¶

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**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? Email Oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.

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*Helping HPEN Consumers Achieve the Quality of Life They Desire*

A few of the ways Coram supports our HPEN consumers:

- Nourish® Nutrition Support Program that provides home TPN and tube feeding support
- Home Nutrition Support Teams that support safe, effective home nutrition therapy
- Registered Dietitians who provide one-on-one diet counseling and therapy weaning support
- Domestic and international travel support
- Consumer webcasts at WeNourish.com/events

To learn about our amazing consumers and how they live to their fullest potential, visit WeNourish.com/Consumers/PatientStories.

*WeNourish.com*  
877.WeNourish

(800) 776-OLEY • LifelineLetter — 5
Internet Resources

There is a lot of information on the Internet! Here are a few resources we’ve identified lately that may interest you. All of these—and many more—are listed on our “Other Organizations” page (under “Resources” at www.oley.org).

For families:

- **Jonah and the Whale Foundation**—provides help for families of disabled and chronically ill children. www.jtwf.org
- **Inheritance of Hope**—provides support for families with a parent who has a life-threatening or terminal illness and young children at home. www.inheritanceofhope.org or (914) 213-8435
- **Chai Lifeline**—helps children and families suffering from serious illness. www.chailifeline.org

Prescription discount cards:

- **Afford Rx**—www.affordrx.com
- **LifeSource Direct**—lifesourcedirect.com/2011/07/lifesourcedirect-rx-drug-discount-card
- **NACo Prescription Discount Card Program**—www.nacorx.org
- **NeedyMeds**—Needymeds.org
- **The Prescription Discount Card**—theprescriptiondiscountcard.com
- **Rx Relief Card**—www.rxreliefcard.com
- **Your Rx Card**—www.yourrxcard.com
- **Rx Access**—www.rxaccess4u.com/rx4u

Miscellaneous:

- **FDA Educational Resources** for Patients, Advocacy Groups, Research Investigators, and Drug Developers—www.fda.gov/ForIndustry/DevelopingProductsforRareDiseasesConditions/ucm385535.htm
- **SwallowSTRONG® device**—Q&A from the National Foundation of Swallowing Disorders, www.swallowingdisorderfoundation.com/advances-in-swallowing-disorder-therapy
- **Home health care resources**—nursingassistantguides.com/leading-home-health-resources
- **Until Death Do We Part**—resources and open forum to change public knowledge, attitudes and behavior towards dying, death and bereavement. www.facebook.com/untildeathdowe?fref=nf

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**Pediatric Feeding Conference**

February 28, 2015, Phoenix, AZ

Hosted by Feeding Matters, the conference will be focused on how coordinated care supports the complexities of a child’s feeding struggles in four areas: medical diagnosis; growth and nutrition; skills and abilities; and family and behavioral psychology.

Parents/caregivers, pediatricians, neonatologists, pediatric GI specialists, allergists, pulmonologists, nurses, dietitians, psychologists, speech and language pathologists, occupational therapists, behavior analysts, and students are encouraged to attend. For more information go to feedingmatters.org/conference or call (800) 233-4658.
Coping with Holiday Stress

Nutrition support therapy and not being able to eat can add layers of stress to what many already consider a stressful time: “the holidays.” How do you cope?

Oley Ambassador Michelle Barford says:

“I guess in my ‘old age’ I don’t get so stressed anymore! And, I no longer work which is a huge part of the equation. But to avoid stress when I did work I used to plan ahead and make lists of things I needed to do and deadlines of when they needed to be done. I was never a procrastinator and because of all the kids we had, biological and foster kids, I had to be organized.

“We still try to go to our favorite traditional holiday festivities. As soon as the schedules come out in the local paper, I put them on the calendar and start planning! My food consumption is greatly reduced, but I don’t let that get in the way of enjoying the holidays. I still cook/bake all the good stuff my family wants and/or expects.

“And I thank God that I’m still here and can do these things that I love to do for my family! I think I must be very much like my mother in that she always did everything and never complained about how it may have affected her. She never whined about having too much to do and too little time or how tired she was... she just did it! And so do I...” ¶

Now, I look back on my emotions and think . . . what an overreaction! School has been great. Not perfect, but great.

Some advice I have found helpful:

• **Communicate EARLY.** Contact school officials long before the start of the school year. There will be many, many forms to complete. Getting these done in advance helps everyone! It may be too late to plan ahead for this school year, but it may help next year.

• **Communicate OFTEN.** Don’t assume no news is good news. Always be sure to ask (and ask often) how things are going.

• **Appreciate EARLY.** Teachers and administrators have many, many responsibilities. On top of all their routine duties, caring for children with special medical needs can be overwhelming. Let them know up front how very thankful you are for their extra effort.

• **Appreciate OFTEN.** Take every opportunity to let the school staff know how much you value their efforts. “Thank you” can go a long way!

• **Prepare EARLY.** Be sure you have covered every “what-if” scenario. Be sure school officials know how to handle any emergency situation. Document everything in writing.

• **Prepare OFTEN.** Revise your plans as necessary. Despite all your planning, something will come up. Treat each scenario as a learning opportunity. ¶
Learning, Sharing at the 2014 Oley Conference

Everyone’s a winner at the awards ceremony!

Patient advocate and caregiver Beth Gore shares strategies.

Remembering members who’ve paved the way before us.

Hands on with consumers and manufacturers at the Tube Feeding Workshop.

The Oley Conference is a great time for the whole family!

Sharing concerns, solutions, and new friendships between sessions.

Attendees welcome time to chat at the Oley picnic.

Attendees find fun activities—as well as the latest products—in the exhibit hall.

Presenters work together to answer attendees’ questions.

Consumers and caregivers alike learn at the conference.

Meeting and greeting at the registration desk.

Connecting with people your own age is a plus!
At the regional conference the day before the marathon, Emma shared her story, and her own inspirations, with everyone who gathered for the event. Other highlights of the conference (detailed below) include presentations by Russell Merritt, MD, PhD, and Gail Egan, MS, ANP, and a series of roundtable discussions.

Emma’s Story

Emma is an assistant professor in the Department of Clinical Pharmacy at the University of Tennessee Health Science Center and a clinical pharmacist in the area of pediatric nutrition and metabolic support at Le Bonheur Children’s Hospital. She has a strong interest in PN-associated liver disease (PNALD). She is a runner, who, with a friend, set a goal of running a marathon in every state.

She ticked off a few states, then, in 2011, she had a major pulmonary embolism. Growing up she had experienced cyclic vomiting, and in recovering from the embolism she developed gastroparesis. For a while, Emma stopped running. Then, she says, in 2014 she met Stanley Dudrick, MD, FACS, FACN, FASPEN, at the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), and he encouraged her to find a way to meet her goals. Emma did just that, and finished the marathon successfully, with some oversight and support from her homecare company. What’s more, with this marathon, Emma raised over $6,000 to benefit Oley! Teammates Jessie Baker, Lisa Metzger, and Gail Egan also ran and raised funds for Oley.

Other Conference Highlights

Dr. Russell Merritt gave a lively and information-packed presentation on managing intestinal failure. He primarily discussed diet and medication, emphasizing that it may be necessary to try a range of things before you find what works for an individual patient. Gail Egan followed with a popular presentation on vascular access, addressing questions such as, “What do I do when my device doesn’t work?” The morning ended with another presentation by Dr. Merritt, in which he discussed future cures for short bowel syndrome and shared a videotaped interview with his colleague, Tracy Grikscheit, MD, who is involved in research on regenerative medicine and tissue engineering.

After a break for lunch, participants broke into small groups to discuss absorption (led by Deb Pfister, MS, RD, CNSC); tube feeding (Cara Larimer, RD); HPN solutions (Marc Stranz, PharmD); pediatric issues (Russell Merritt, MD, PhD); intestinal failure centers (Deborah Andersen, RN, BSN, CCTC); and catheter complications (Reid Nishikawa, PharmD, BCNSP, FCSHP).

Future Conferences, Future Runs

Watch the Oley Web site and your email for invitations to upcoming regional conferences. We have one tentatively set for October 25 in Providence, Rhode Island. You can also call the office (518-262-5079 or 800-776-OLEY) for details.

We also have some members interested in running the Boston Marathon, April 20, 2015. Please let us know if you’d like to run or join us to cheer them on! If you’d like to run it but don’t feel you could meet the qualifying time or need support with training, Achilles International is a great resource (www.achillesinternational.org or 212-354-0300). Their mission is to enable people with all types of disabilities to participate in mainstream athletics. Let them help you meet any of your running goals (from short races to marathons)!

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SF Regional Conference, from pg. 1

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Volume XXXV, No. 5
Increasing Calories in the Enteral Diet

Weight gain and subsequent maintenance are common concerns for the enteral, or tube-fed, patient. Working with your dietitian and physician, you can find ways to increase your caloric intake. Generally speaking, a weight gain of a half-pound to a full pound per week can be achieved with an increase of approximately 250–500 calories per day. When comparing the enteral diet to the oral diet, strategies for increasing calories are quite similar. These strategies include:

Increase the Volume

In an oral diet, you would first simply try eating more. The same idea applies to the enteral diet. If you use the bolus method for tube feeding, the most basic strategy to increase calories is to increase the volume of each bolus meal. Try slowly increasing a meal volume by 30- to 60-mL (1- to 2-ounce) increments. Often, the adult stomach can tolerate a total volume of 240–480 mL per meal. If you are receiving a continuous feed via pump, a slow increase in rate (start with increments of 2–5 mL/hour, as tolerated) can be used to obtain a goal of an additional 120–480 mL per day.

Increase the Frequency

If unable to tolerate additional volume per bolus feeding, you can try increasing the number of feedings per day. Again, an increase of 120–480 mL per day is a practical goal. This can be accomplished by adding an additional meal per day (space meals at least two hours apart). Or, you can add two to three smaller, 60- to 120-mL “snacks” between normally scheduled bolus feedings, or add one smaller feeding at bedtime.

Increase the Density

In terms of food, it is understood that a bite of cheesecake packs more calories than the same amount of fruit does. This concept also applies to various enteral formulas. If an increase in formula volume or frequency is not tolerated, the next strategy is to manipulate the formula density.

Calorie density is noted in the name of most commercial formulas. A “1.0” formula provides one calorie per milliliter. Try increasing the formula density incrementally, using formulas that provide 1.2, 1.5, and 2.0 cal/mL. (Note: High-density formulas contain less water than low-density formulas. If switching to a denser formula, additional water will have to be provided as flush. Consult the formula label to compare total water content in each product. A registered dietitian can help you determine your total fluid needs.)

If using a blenderized formula, you can increase the density by mixing the formula with less water. A variety of products can also be added to enhance nutrition without substantially altering volume. These include powdered products such as a protein module or a liquid MCT (medium-chain-triglyceride) oil. MCT oil is more readily digested than other forms of fat, making it a good choice for those struggling with diarrhea and malabsorption.

Keep in mind that not all interventions are appropriate for every patient. Be sure to talk to your doctor before making any changes to the enteral regimen that has been prescribed for you. Working with your doctor and dietitian to formulate an individualized, balanced approach for increasing calories is the best way to go!

Written by Brittany L. Wright, RD, Enteral Specialist, Coram CVS/Specialty infusion services. Reviewed by Carol Ireton-Jones, PhD, RD, LD, and Laura Matarese, PhD, RD, CNSC. References available upon request.
Vascular Access Certification: An Essential Ingredient

Lois Davis, MSN, RN, and Denise Graham

In this day and age, it is common practice to ensure the people we hire are qualified to administer to our needs—whether they be tradespeople who service our home or vehicle, or professionals who oversee our finances or health. As health care consumers, it is just as important we establish that our health care providers are qualified and certified. This includes not only our physicians and nurses, but any of our vascular access caregivers.

Why?

It is estimated that over 95 percent of hospitalized patients today receive some sort of vascular access device (VAD). According to the Centers for Disease Control, in 2009 we had between 27,000 and 65,000 central line–associated bloodstream infections. These infections carry a 12 to 25 percent mortality rate.

More and more peripheral intravenous devices are being used. In addition, these devices are being kept in for longer periods of time so they need careful monitoring. In an article in Journal of Infusion Nursing (2005), Kokitis notes that peripheral IV insertion has 40 percent success rate on the first attempt, and Barton et al. note in the Journal of Nursing Care Quality (1998) that 27 percent of patients endure more than three attempts. Wolosin notes that fifty-eight percent of patients report being dissatisfied with the skill of the person starting their peripheral IV (in The Press Ganey Satisfaction Report, August 2003). A vascular access professional who routinely performs this service is warranted, rather than a health care professional who occasionally inserts a patient line.

Selecting a certified vascular access health care professional is a measurable way of ensuring the clinician has the knowledge to practice competently within this specialty field, which is especially important when it comes to these high-volume, high-risk procedures. Those who are Vascular Access Board Certified (VA-BC™) have met the standards of the current professional practice. Certification validates that their knowledge is up-to-date and they meet the demand for high safety standards. Certification also demonstrates that their health care facility is committed to board certification.

Next time you or someone you know has a VAD inserted or cared for, ask for a VA-BC clinician. Lois Davis is VA-BC™ Certification Program Director and Denise Graham is VACC Public Board Member. For more information about Vascular Access Board Certification, visit www.vacert.org or e-mail info@vacert.org.

Did You Know?

The LifelineLetter is distributed to more than 14,500 home nutrition support patients, home care providers, and health care professionals in thirty-nine countries. It is also read by many more people online at www.oley.org/newsletter.html.

Coming soon: a supplement for Canadian readers. Send your ideas, suggestions, and articles to metzgel@mail.amc.edu.

Oley Group Meets in Michigan

The first meeting of the Michigan Intestinal Failure Support Group was on May 4, 2014. Organizer and Oley Ambassador Rosaline Wu writes, “Not only did we have a beautiful sunny day, we also had twelve happy people join us. Ann Weaver was our guest speaker. Ann is from the Chicago, Illinois, area and she works for ThriveRx. We had a lively conversation about what’s on everyone’s mind: the shortages of vitamins, minerals, trace elements, and—the latest and most important to everyone—saline.” The group plans to meet, with guest speakers, in September, October, and November. For details, call Rosaline at (734) 464-2709.

Toronto Oley Gathering

The inaugural meeting of the Oley Foundation’s Toronto Chapter on May 3 kicked off with a luncheon sponsored by Baxter Pharmaceutical, offering plenty of opportunities for social networking amongst the attendees. Later, Oley Ambassador Don Lacey introduced a series of professionals who guided the group on a journey from the beginning of home parenteral nutrition (HPN) through to a glimpse into what might be expected in the future. The afternoon ended with a drawing for a number of door prizes provided by PepsiCo Beverages Canada and Cambrian College. The group hopes to gather and celebrate on an annual basis in the spring. Shown left to right are Janet Darwin, Gail Charbonneau, and Sandy Lacey.
Coping Skills

My First Conference, from pg. 2

formula the way I do, by “bolus feeding,” infusing food a few times a day quickly, using a funnel and gravity. I have to carry a can or two of food and supplies when I go out; I have pain intermittently around the tube entry site; I endure day surgery every year or so for a tube replacement. In the future, however, when I am sad about having a tube, I will remind myself of this. If I think I’ve got it bad, most of my new tube colleagues have it worse.

So Many Children

People for whom this is their first Oley conference gather Monday evening for fun and games and tips on how to get the most out of the conference. The atmosphere feels like a birthday party for one of the many children of all ages running around for an hour free of the ever watchful eye of a parent. There are soda and chips, pretzels and candy for those who can swallow safely and for caregivers. Balloons kiss the low ceiling, with ribbons that invite a child to claim ownership.

Three toddlers capture my attention. One, a little girl, maybe three or four, scurries under a table and then around the legs of adults. She’s playing with a boy a little older than she. Wherever she moves, so goes her feeding tube, as if it were the wire of an old-fashioned microphone following a performer. She never trips on it. It’s long enough to go where she goes and somehow stay connected. I want to find her mother and father and tell them I think it’s wonderful they don’t overprotect their daughter, and let her be a child.

The boy wanders near the table where I’m sitting with my two adult partners in a silly but effective game devised to facilitate connections among strangers. The boy tells the woman next to me how old he is, and then asks how old she is. She answers, “Fifty-three,” and he remarks how high this number is. I want to tell him I’m seventy-one—really surprise him—but he only has time to honor me with a hello and smile as welcoming as I’ve ever received. A person with a feeding tube is the same person he or she would be without it.

The third child who captures my attention is a boy in a wheelchair, or maybe it’s a customized stroller. His eyes are big and drink in all that’s happening. I wonder if he’s able to talk because I don’t hear him say anything. His mother treats him as she’d treat any child. She’s to deliver a speech the next morning in which she will share the harrowing journey she and this beautiful boy have been on to keep him in this world.

These children will probably never have the years of pleasure I had before cancer treatment—eating my wife’s glorious cooking, quenching my thirst from a water bottle, bingeing on my mother’s maple walnut cake with thick chocolate icing at every one of my birthdays, even as an adult, until the advent of the tube. I have to carry a can or two of food and supplies when I go out; I have pain intermittently around the tube entry site; I endure day surgery every year or so for a tube replacement. In the future, however, when I am sad about having a tube, I will remind myself of this. If I think I’ve got it bad, most of my new tube colleagues have it worse.

Eye Openers

I think I know all I need to know about my tube and its accessories. But I don’t. I learn a great deal from the talks beginning on Tuesday at the main sessions, at a tube feeding workshop, and during conversations with the people in the Exhibit Hall booths. Here are the highlights.

- **New tube connectors** are coming (transition is expected to be complete by January 2016) to help prevent fluids from being infused into the wrong tube. Now I know to ask my surgeon if my next tube replacement will have a new connector, and my home care company if it has accessories manufactured to the new standards. I’m also happy to learn that the new connector joining my tube with the funnel piece of a 60 mL syringe for bolus infusions will no longer be able to separate. No more accidental spills.

- **Swimming** while on nutrition support can be more dangerous than I ever knew. To allay the worry, you can ask how often a given pool or other body of water is tested and what the contaminant level was at the last reading. Alarmed, I seek clarification from the Oley folks. Swimming is particularly dangerous for people on IV nutrition, because bacteria and viruses from the water can enter the bloodstream through a catheter. However, people with a well-healed g- or j-tube site (such as me) can swim without much worry.

- **One once was delighted to have a low-profile button placed. Gone was the embarrassing bulge—I looked and felt like a regular guy. But that night, after dinner, the button failed. Failed!**

Swimming spewed everywhere. End of dream of not looking to the world like a bionic man. Now I had the privilege of undergoing another procedure to remove the defective button and replace it with a traditional PEG. I was not a happy camper. Swore off buttons, I did. At the conference, however, I’m encouraged to learn from reps of a number of button manufacturers that failure of a button valve is rare. Two reps offer to contact my gastroenterologist to see if my hospital would offer their buttons. One of these vendors is giving away the cutest stuffed bears, each of which has a button in its belly. I choose a brown bear. One grandchild will be very happy. Or maybe I’ll put it on my desk as a reminder to reconsider my prejudice against buttons and one day have one that works under my T-shirt, too.

- **One of the few regrets I have about the Oley conference is that I didn’t speak with the rep from the company that sold the faulty buttons to my hospital. I had filed a report and they promised to investigate and let me know their findings. They never did. Never apologized for putting me through another procedure. Never offered to pay for the second operation.** At the time, I was busy, so I dropped it. Here, at the conference, I could have had their ear. But something held me back. I didn’t want to compound my vulnerability about wearing a tube by being branded a troublemaker. Aaargh!

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the belly, it will compress/squeeze the tissue in-between the external and internal bumpers. This can cause a sharp pain and can lead to complications such as fluid leakage and buried bumper syndrome.]

• I never knew about the possibility of puréed formulas. I might like to try them, so I ask a presenter if Medicare covers these formulas. A fellow participant comes to the audience mic and adds to the presenter’s answer. While Medicare coverage is possible, it usually necessitates a fight—an important piece of information I learn painlessly and quickly.

• One day at lunch, I take advantage of the Oley invitation to talk with a professional sitting at a table with a sign, “Ask Me, I’m a Dietitian.” After I had learned in swallowing therapy how to do swallowing exercises safely, I was given the green light to eat and drink a little for pleasure—applesauce or a few spoons of a smoothie, for example. Starting about a year ago, I’ve been eating a small bowl of oatmeal daily. But I’ve been craving variety. So at the conference I speak with a dietitian, and she gives me some great ideas as alternatives. More importantly, she talks to me like I’m a regular guy, not someone with a disability.

• In a hallway conversation, I learn from a caregiver how to expel air from my stomach out the tube. On the flight home, painful heartburn sends me to the lavatory to try this technique. Although I unintentionally wash the mirror with a squirt of stomach water, I return to my seat heartburn-free.

By the middle of the Oley conference, I sense that I am learning more than practical information—something intangible and as important, if not more important, than the nuts and bolts of living with a feeding tube. But I can’t put my finger on it.

I Want to Win

Wednesday is Raffle Drawing Day, last day for the exhibit booths. In the hotel’s cavern of a lobby, I spot a man lounging near the Oley registration desk feeding himself. He’s holding up, as if it were the Statue of Liberty’s torch of enlightenment, a funnel filled with formula and connected to his tube. I smile. That could be me—is me when I can’t find a private place away from home to feed myself. Always I feel exposed, but he seems unperturbed, as if feeding himself through his PEG is as natural as eating a sandwich. I’d like to ask him if he’s embarrassed doing that when he’s not surrounded by his Oley family. But I don’t. I’m still self-conscious about my tube, still feel it marks me as a freak. And the last thing I want is to risk being asked what the big deal is. I just want to be a regular guy who’s got nothing wrong with him.

Well, at least I’m going to win one of the raffles, maybe two. Great prizes—tablets, gift certificates. While I wait for the drawings to begin, I stop by the booth of the company giving away those bears with PEG buttons in their bellies. I tell the rep my brown bear is lonely—do they have a white bear left over? The rep says the only bears left are the two on display. Someone has spoken for the white one but if I return at two o’clock and it has not been claimed, then I may have it.

I sit with Melba and watch her eat lunch. The prize I really want is to eat again. Yes, I’ve adapted well to my feeding tube, but, really, I don’t like it. I want to eat by mouth. And if I can’t ever again, then I want a new tablet, or another bear, or both.

Soon I spot the same little girl who had been running around at the event for first-time attendees. She’s dancing near her mother, who’s

My First Conference, cont. pg. 14
Donor Thankful for Newsletter

Frances Black, a new Oley member and donor, writes, “I am glad for this opportunity to thank [Oley for its] excellent LifelineLetter publication… Each one has contained helpful information and meaningful human-interest articles. I am an HEN consumer and am interested in keeping current with the latest developments concerning my condition.”

We’re glad to fill this niche for Frances and the thousands of others who depend on the newsletter to keep abreast of medical advances and stories about others living lives similarly to their own.

2014 Oley Walk-a-Thon

Many thanks to the conference Walk-a-Thon participants, who raised $3,340! Proceeds from the walk and other events help keep the conference free of charge for Oley consumers and caregivers.

Registered participants included: Anonymous; Pat Anthony; Elaine Arthur; Felice Austin; Bettemarie Bond; Mark DeLegge; Howard & Marcia Denenholz; Jonathan Dunn; Sanford Flach; Fresenius Kabi USA Team; Brenda Gray; Michelle Guinigundo; Daulton Heisey; Lauren Kaighn; Don & Sandra Lacey; Cathy LeFevre; Ava, Rachael, & Jorge Lopez; Sheila McElwee; Kevin McNamara; Eli Medwar; Michael Medwar; Alyce Newton; Joanne Platt; Marjorie Quinn; Sara Ringer; Christine Roschen; David & Carolyn Rowland; Julie Sahr; Lauren Selby; Mary & Bob Smithers; Rob & Tammi Stillson; Matt Teague; Cathy Tokarz; Miaekia Vincent; Ann Weaver; Tim Weaver; Carolyn Wheatley; Jim & Gloria Wittmann; Samuel & Rachel Zimmerman.

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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 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 July 5 to August 15, 2014:

**In Honor of**
Mariah Abercrombie; and Dale & Martha Delano

**In Memory of**
Pat Brown; Ann DeBarbieri’s birthday; Jeff Dutton; Imagail Gordon; Joyce Hydorn; Mary Patnode; Paula Southwick; Bob Sweet; and Barbara J. Young

**Fundraisers**
In honor of Emma Tillman’s marathon; in honor of Lisa Metzger’s half-marathon
We appreciate all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!

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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.

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

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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.

**PLATINUM LEVEL PARTNERS**
($70,000)
- BioScrip, Inc.

**GOLD MEDALLION PARTNERS**
($50,000)
- Coram CVS/specialty infusion services
- Covidien
- ThriveRx

**SILVER CIRCLE PARTNERS**
($30,000)
- Boston Scientific
- NPS Pharma
- Nutrishare, Inc.

**BRONZE STAR PARTNERS**
($20,000)
- Baxter Healthcare
- Fresenius Kabi USA

**BENEFACTOR LEVEL PARTNERS**
($10,000)
- Abbott Nutrition
- Kimberly-Clark
- Nestlé Health Science
- Walgreens Infusion Services

**PATRON LEVEL PARTNERS**
($5,000)
- Applied Medical Technology, Inc.
- Nutrishare Canada
Alive with HPN—HPN Awareness Week 2014

Thanks to everyone who participated in HPN Awareness Week. Whether you put out a press release, shared the logo on your Facebook page, or planned an event, your efforts are meaningful. Thanks to all of you who submitted photos and shared videos—the “Alive with HPN” video on Oley’s You Tube channel had almost 1000 viewings! (View this and Awareness Week videos by other organizations and members at www.youtube.com/user/TheOleyFoundation.)

We send a big thank you, too, to Baxter Healthcare for a grant to support HPN Awareness Week. Because of this grant, we were able to distribute 3000 Alive with HPN buttons. The Baxter team in Northern Illinois also held a Jeans Day fundraiser to help raise awareness—raising almost $600 for Oley—and NPS Pharma planned a company-wide team-building event that week. Over 150 employees enjoyed a scavenger hunt, lunch, and competition to raise $2,500 to support Oley programs (and $2,500 to support SBS Foundation and HypoPARathyroidism Association, too)! Joan Bishop and Rose Hoelle were on hand to share information about Oley programs and accept the check. A good time was had by all.

What HPN Means

There was a lot of discussion this year about the term “HPN” and what it means, both to you as individuals and in the broad sense. “HPN” stands for “home parenteral nutrition.” It is parenteral nutrition (a nutritional solution delivered intravenously, through the bloodstream) administered at home. Parenteral nutrition is also commonly known as “total parenteral nutrition,” “TPN,” and “hyperal” or “hyperalimentation.”

Why do we use “HPN” instead of “TPN”? We no longer refer to it as “total” parenteral nutrition because the solutions, although life sustaining, do not contain all of the nutrients that are present in our diets. Another reason we do not refer to it as “total” PN is that for many consumers it is not their sole source of nutrition. They may be taking some food by mouth or perhaps supplemental tube feeding.

Further, we want to acknowledge that the situations so many face when they have PN at home, vs. in the hospital, can be very different. We also hope to convey the very important message that people are living their lives at home on PN, and that if PN is a necessary part of your present and future, there are resources available to help you.

There are lots of ways to say it besides “HPN,” including “home PN” and “home TPN,” and we appreciate the insights and suggestions members have offered on the terms and how we use them. It’s an important and helpful dialogue.

On the Oley Facebook page, one mom wrote what “HPN” means to her: “To me HPN includes those who rely on IV nutrition for all their needs (TPN) and those who use IV nutrition to meet some of their nutritional needs, but may also eat or do tube feeds...it also implies that this is a way of life at HOME, which is huge for my daughter!”

What’s YOUR Alive with HPN story?

“At first I found it difficult to schedule my feedings around any kind of social activity, but now if I have something planned during my normal feeding cycle, I just put on my backpack and go. People hardly ever even notice it.... TPN has saved my life—made it possible to have a quality of life that I wouldn't have had without it. I am happy to be ‘Alive with HPN.’”

—Candace, Oley-Inspire Forum