

What's Inside:

Tube Talk:
Alternatives for Bolus
or Gravity Feeding,
Stoma Dilation
Page 3

Camp Scholarships
Help Oley Kids Grow
Page 4

Welcome Oley's
Newest Ambassador
Page 5

Life Without Limits:
Owen and Mal
Page 6

Rotary Rewards
Page 14

Donor News
Pages 14–15

Oley Calendar
Page 16

Teal Pumpkin Project
Page 16

Open Enrollment
for Health Insurance
Marketplace
Page 16

LifelineLetter

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

Fifty Years on Nutrition Support: Yesterday, Today, and All of My Tomorrows

Sharon Rose

Based on a presentation Sharon gave at the annual Oley Consumer/Clinician Conference in June 2018, in Memphis, Tennessee. Find a link to Sharon's moving presentation at www.oley.org/2018confdoc (under "Videos," choose "Monday Main Session"). At the end of the talk, the audience fittingly honored Sharon with a standing ovation.

In 1968, I had just graduated from nursing school. I had my first apartment, my first job, and things were wonderful. Then I developed abdominal pain. I ignored it until one day the pain came and didn't go away. To make a long story short, blood clots had blocked the flow of blood to my small bowel. My small bowel became gangrenous, then

ruptured, and, in the end, most of the bowel was removed surgically.



Oley Co-founder, Dr. Lyn Howard, with Sharon at the 2018 conference.

the cycle would begin again. I steadily lost weight and eventually ended up back in the hospital.

Fifty Years on Nutrition Support, cont. pg. 8 ▶



I was young and healthy and I recovered from this surgery quite rapidly. I was home in nothing flat. The only instruction I was given on discharge was to eat a bland diet. I ate a peanut butter sandwich, which I loved. It, however, didn't love me. I became horribly ill—nausea, vomiting, steatorrhea. After I'd purged everything out of my body, though, I'd feel good. Then I'd eat another peanut butter sandwich—or something else—and

Ohio Oley Conference

In September, long-time Oley member Luke Vohsing opened our Regional Conference in Columbus, Ohio, by sharing his personal story with a captive audience of home parenteral and enteral (HPEN) consumers and professionals. Luke has been on tube feeding since he was a child, as a result of injuries he sustained in a car accident.

A busy schedule followed, with presentations by Dr. Ezra Steiger on his 50 years of experience being an HPN physician; Kelly Green Corkins, with a dietitian's take on the "ins and outs" of enteral nutrition; Gail Egan, an interventional radiologist speaking on central lines; Dr. Teresa Cutts speaking on GI motility disorders (via webinar); and Maria Karimbakas and Cassandra Pogatschnik, both dietitians, on diet for short bowel syndrome and emerging therapies in gut rehabilitation, respectively. Many thanks to our sponsors: Shire, Soleo Health, and ThriveRx. ¶



Luke Vohsing with his wife, Jennifer, and their two boys.

PTSD: Tell Me What It Means to Me

Stephanie Torres and Tiffany Taft, PsyD

This article is based on a ThriveRx podcast recording. Our thanks to ThriveRx for sharing it with us.

Stephanie Torres (ST): I am a consumer advocate with ThriveRx. I have been diagnosed with gastroparesis, had a feeding tube, and am currently on home parenteral nutrition (HPN). I understand what it's like to live with a chronic condition, and to manage daily medical care, complications, hospital visits, and feelings of fear and isolation.

I am talking with Dr. Tiffany Taft about trauma associated with these challenges, how to recognize the signs of post-traumatic stress (PTS), and steps we can take to manage trauma and PTS. Dr. Taft has a doctorate in psychology. She is a leading expert in GI psychology, and has been practicing for more than ten years. She is on the faculty at Northwestern University Medical School where she does research on the emotional and social aspects of chronic digestive conditions.

Dr. Taft, what sparked your interest in this area?

PTSD, cont. pg. 2 ▶

LifelineLetter

September/October 2018
Volume XXXIX, No. 5

Publisher:

The Oley Foundation
Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054
(518) 262-5079, Fax: (518) 262-5528
www.oley.org

Executive Director:

Joan Bishop • BishopJ@amc.edu

Editor, LifelineLetter; Director, Community Engagement:

Lisa Crosby Metzger • MetzgerL@amc.edu

Communications & Development Director:

Roslyn Dahl • DahlR@amc.edu

Administrative Assistant:

Cathy Harrington • HarrinC@amc.edu

Executive Assistant:

Andrea Guidi • andreaguidi.oley@gmail.com

Program Associates:

Philip Kellerman • philkellerman.oley@gmail.com

Mary Wootten • marywootten.oley@gmail.com

Science & Medicine Advisor:

Darlene Kelly, MD, PhD

Medical Director/Co-Founder:

Lyn Howard, MB, FRCP, FACP

Oley Board of Trustees:

Bob and Mary Smithers, Co-Presidents; Beth Gore, PhD, MBA, Vice President; Joy McVey Hugick, Secretary; James Senese, BS Pharm, MS, Treasurer; Lynn M. Anderson, LLD; Rhonda Arends; Lillian Harvey Banchik, MD, FACS, CNSC, FASPEN; Elizabeth Bond, RN; Debbie Fox, MS, RD, LD; Shirley Huang, MD; Jerry Mayer; Manpreet Mundi, MD; Laurie Reyen, RN, MN; Kelly Tappenden, PhD, RD

Oley Advisory Council:

Jane Balint, MD; Lynda Bosworth; Alan Buchman, MD, MSPH, FACN, FACP, FACC, AGAF; Frances Culp, MA; Marcia Denenholz; Terry Edwards; Jocelyn Hill, MN, RN, CVAA(c), OCN, CRNI, VA-BC; Kishore Iyer, MBBS, FRCS, FACS; Swapna Kakani; Barbara Kapuscinska Kelly, MD; Sue Koprucki; Vanessa Kumpf, PharmD, BCNSP; Jack Leibee; Laura E. Matarese, PhD, RDN, LDN, CNSC, FADA, FASPEN; David F. Mercer, MD, PhD, FRCS; Russell J. Merritt, MD, PhD; Ann Michalek, MD; Jay M. Mirtallo, MS, RPh, BCNSP, FASHP, EASPEN; Vicki Ross, RD, PhD, CNSC; Trish Skiendziel, RD, LD, CNSC; and Ezra Steiger, MD, FACS, FASPEN

Subscriptions:

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

PTSD, from pg. 1

Tiffany Taft (TT): Like you, I have personal experience with chronic digestive illness, having been diagnosed with Crohn's disease and eosinophilic esophagitis (EoE). I have that unique perspective as a patient and then the expert perspective on the social, emotional, and psychological toll from my work at Northwestern. We started looking at trauma in inflammatory bowel disease (IBD) last year, and realized there had been only one other study done. We wanted to dig in to find the rates of post-traumatic stress disorder (PTSD) in patients with IBD and identify some of the potential risk factors for a patient's developing PTSD from their medical experience. We work with Dr. Steve Hanauer, who is probably the leading expert in IBD and Crohn's. He brought the idea to us from observing symptoms of PTSD in his patients in the clinic.

ST: At what point does stress become trauma and eventually turn into a diagnosis of PTSD?

TT: Trauma, by our definition in psychiatry and psychology, is the experience of intense fear or perceived threat to your life or someone else's life. (We will talk later about the trauma caregivers can have from watching their loved ones go through all of this.) The good news is only about one-third of people who experience a traumatic event will go on to develop PTSD.

There is a window between experiencing trauma and when we would say someone has PTSD. Historically that has been about four months, per the manual we use to make these diagnoses. But in the most recent revision of that manual, the time was shortened to one to two months—I think so people won't go too long living with these symptoms before we offer them help. So there is an acute stress period where most people are able to get ahead of it and don't go on to develop PTSD.

ST: That's hopeful. How might someone know they are experiencing acute stress? Are there specific signs to watch for?

TT: We group post-traumatic stress or acute stress symptoms a couple different ways. One is what we call re-experiencing or reliving of the event. This includes repeated nightmares about what happened, or repeated intrusive thoughts you can't get out of your head, or images to the point where it feels like you're reliving the experience. It can be normal for

this to happen a few days or even a couple of weeks after something that is particularly stressful and traumatic, but if this keeps going, those are red flag warning symptoms.

Other things are physical reactions like heart pounding, almost like having feelings of a panic attack without anything to really explain that; feeling keyed up in general, kind of jumpy, on edge, super watchful and guarded; and starting to avoid things that might trigger you to remember the situation. So if it happened at the hospital, you might stop going to your doctor's appointments and avoid any activities that might remind you of what happened.

Another symptom is feeling emotionally cut off, numb and distant, not really getting much out of what you would normally enjoy. Those are some of the warning signs. Again, they are normal within a couple of days or weeks, but beyond that window we get concerned.

That first couple of weeks provides the window of opportunity to talk to someone about your experience. It doesn't have to be a professional; it can be a trusted friend or family member. I can't emphasize this enough. If you try to just avoid it and not think about it and push it aside, the brain won't necessarily process it in the way that it should. That's when we can get into trouble. So, as unpleasant as it is, however much you don't want to talk about it, if you walk away with one thing today it is talk about it, write about it, blog about it, journal about it. Communicating about trauma helps us process it and put it where it belongs in our memories.

ST: It sounds counterintuitive. When you are dealing with trauma, it seems more common to hide, to isolate yourself, but you're saying communication is what's going to get you through it.

TT: It is. We recognize how hard that is, but it's probably the most important thing you can do.

ST: In your research, are you finding similarities between those with IBD or digestive disease generally, and others, like returning vets, who experience PTSD?

TT: We have looked at IBD, IBS (irritable bowel syndrome), and breast cancer. We chose

PTSD, cont. pg. 10

Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@amc.edu. Information shared in this column represents the experience of the individual and, while medical information is reviewed by an advisor, should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



Alternatives for Bolus or Gravity Feeding

Members have recently shared with us information about two products that can be used in place of syringes for administering tube feeding formula or blenderized diet through a G-tube.

bFed System

The bFed System was created as an enteral delivery system. The Bolee Bag component of the system is a 375mL reusable food container that works with commercial formula, homemade blenderized nutrition, and water.

Once the bag is filled with formula or blenderized nutrition, it is connected to the feeding tube or bolus extension set with the Bolink™ Large Cap to deliver. The Bolink Large Cap has a five-inch-long large-diameter tube with a clamp to control flow. A small cap connector is also available to deliver pureed fruit and vegetable baby food pouches. The system uses ENFit® connectors. More information at www.udelivermedical.com.



Bolee bag being used for a feeding.



Bolee bag with connectors.

“The new bFed™ System is easy to use and easy to understand. Both the small cap and the large cap gravity feeding sets worked well. The large cap fit easily on the Bolee™ Bag and it was easy to infuse formula from the bag through my feeding tube.”

—Rick D.

Squeasy Gear

According to their website, Squeasy Gear was developed to provide “easy feeding on the go.” They write, “We wanted to make the best silicone food pouch on the market.” As their products became more popular, they started hearing from parents who were using their products to administer tube feeding. “One of the issues many of [the parents] were encountering was air in the feeding tube, generated by the syringe they have to use to get the food into the tube.... They discovered... that Squeasy’s



Squeasy bottle being used for a feeding.

patented one-way valve eliminates air from the tube.” Squeasy Gear is developing an extra, optional spout that will be ENFit compatible. More information at www.squeasygear.com.

“[In the lower left corner] is a picture of me using a Squeasy Gear bottle to tube a cappuccino at a convenience/gas station store. I use Squeasy Gear when I’m on the go. When I am sitting at a table or other places where I’m feeding in front of the world, it doesn’t have as much of a medical appearance as a syringe does. That’s a good feeling for a tube feeder. I can also lay it in my lap and squeeze it, or roll it up. The bottle works well. Just hook up the funnel on your tube or extension to the bottle.”

—David R.



Close up of the Squeasy bottle.

Stoma Dilation

I want to share an experience we had with re-inserting a G-tube button after it had been out for too long. Our 26-year-old son, Will, woke us up at 4:00 a.m. one day to say that his button had come out at some point overnight. We jumped into action to put a new one in, but the stoma had tightened too much. We didn’t have a small enough Foley catheter at home to insert either, so we headed to the emergency department (ED).

Thankfully the nurses there got us into a room quickly and gave us a small Foley catheter that we were able to insert to keep the stoma from closing further. Also thankfully, the doctor there agreed that the right process is to insert a small catheter, then move to a bigger one to re-open the stoma. They inflated the balloon along the way to open the stoma further.

The doctor offered pain relievers for the process, but our Will toughed it out. It was not fun and was definitely uncomfortable for him. My takeaway: From now on, we will make sure we have a small Foley catheter at home that we can insert if the button has come out and we don’t immediately know about it. No doubt further closure had occurred during the two hours between finding the button was out and getting the small catheter in at the hospital.

I thought this was a tip worth sharing with families. Of course, you have to be comfortable doing this and knowledgeable about how to carefully do it, but I expect most families living with a G-tube long term get there.

—Valinda W.

Editor’s Note:

Valinda also brought the following article to our attention: “Replacement of Dislodged Gastrostomy Tubes after Stoma Dilation in the Pediatric Emergency Department,” S. Bhambani, T. Phan, L. Brown, and A. Thorp (*Western Journal of Emergency Medicine*, April 19, 2017; westjem.com/original-research/replacement-of-dislodged-

Tube Talk, cont. pg. 14

Camp Scholarships Help Oley Kids Grow

Natalie Wins Cooking Award

Mary Wootten

Natalie Wootten, 10, a recipient of the Oley Tim Weaver Camp Scholarship this year, attended two camps this summer: she spent one week at Camp MasterChef in Kent, Connecticut, and another at The Hole in the Wall Gang Camp in Ashford, Connecticut.

Natalie is mostly tube fed, and has been since she was sixteen months old, due to failure to thrive and dysmotility. Surprisingly, she has a strong interest in cooking and baking, as well as creating new recipes. Natalie was the first child with a feeding tube to attend Camp MasterChef! She spent her days with other children, chefs, and MasterChef winners learning new techniques and recipes, and safety in the kitchen. Although Natalie does tube feed, she can and does eat a small amount of food orally. Nurturing Natalie's love for feeding others is vitally important to keeping her own interest in oral intake alive. She learned to make tiramisu, ratatouille, guacamole and chips, and more, and she won the Top Spud Award!



Natalie with her award.

Camp MasterChef provided wonderful medical care for Natalie during her stay. She was able to receive all of her tube feedings, medications, and treatments right on schedule.

The Hole in the Wall Gang Camp is part of the SeriousFun Children's Network. It was founded by Paul Newman in 1988 and, to quote their literature, is "dedicated to providing 'a different kind of healing' to seriously ill children and their families throughout the Northeast" and celebrating "the fun, friendship and spirit of childhood." Natalie enjoyed horseback riding and spending time with friends she met there last year, as well as meeting new kids. Camp is a safe place where she can just be a kid, doing all the typical camp activities in a way that fits her needs, and where she doesn't need to explain her feeding tube or backpack with pump and all of her medications.

Thank you to the Oley Foundation and Fresenius Kabi USA for providing the scholarship to help pay for the tuition and travel costs for these wonderful camps. The memories she made this summer will last a lifetime.

Zach Learns New Skills

Gary Solomon

I dropped Zach off at camp with a bit of trepidation—not so much for him, but for my sanity regarding the medical attention he would receive. I spent a couple of hours with the medical staff going over the detailed notes and organization of his medical care. The staff was amazing at paying attention to my directions and thanked me for having his supplies so organized and directions easy to follow; it made me feel a bit more at ease about the upcoming week. I was given a tour of the camp with descriptions of all the wonderful experiences Zach was going to have. Knowing he was in good hands, I gave him a kiss and wished him a great time, and said I would see him in a week.

On Tuesday, I had a phone call with his counselor and all signs were positive! I received a photo of his woodworking expertise (his favorite activity of the week). He made a 12 x 12 x 12" box to hold his video games. The furthest thing from his mind was wondering how we were going to take that box back on the plane!

On the following beautiful, sunny Sunday morning, I returned to camp for camper pickup. Kids' laughter could be heard coming from the mess hall as the campers exchanged pictures, signed each other's shirts, and hugged goodbye. I could see the energy Zach had as he bounced between his friends. Zach greeted me with a smile the size of Connecticut.

While Zach whirled around getting signatures and pictures, the counselors regaled me with stories about Zach and the incredible energy and radiant affection he showed at camp. His positive energy and flexibility provided an incredible experience for everyone. Honestly, watching him and hearing the counselors' feedback made me tear up and my heart swell for the opportunity he had had to experience this kind of camp.

We finished up our goodbyes and made our way to the infirmary to gather his suitcase and supplies. Then we made our way slowly out of camp and down the highway back to Boston to catch our flight. Zach took the next two hours to delight me with stories from the week—foods (his primary focus), woodworking, tennis, treehouses, archery, arts and crafts, theater night, horseback riding, the cabin, and on and on. There were even two other kids that he knew from his Oley conferences who bunked in his cabin every night! We discussed his survival for a week without his phone or a soda! He did share that his favorite breakfast was waffles and ice cream, of course!

I asked if he wanted to go to camp again next summer. His face lit up and he said FOR SURE! He said there were other camps like this in other cities and could he go to one every week of summer next year? I used the patented parent answer: "We'll see!" We are so grateful for the outpouring of support that made this camp experience happen for Zach, including the Oley Tim Weaver Camp Scholarship.



Zach shows off the box he made at camp to hold his video games.

APPLY TODAY! Oley Tim Weaver Camp Scholarship

Sponsored by Fresenius Kabi, USA, the \$1,000 Oley Tim Weaver Camp Scholarship was created to provide youth on home parenteral and/or enteral nutrition (HPEN) the chance to experience summer camp, building self-confidence, independence, courage, and creativity in a safe environment.

Applicants must be on HPEN, aged 7–18, and qualify for a camp that provides appropriate HPEN medical support. First-time campers will be given first consideration. Applications are accepted on an ongoing basis. For details, go to www.oley.org/campscholarship.

Welcome Oley's Newest Ambassador

Meet Emily, one of our newest Oley Ambassadors. As part of a growing network of volunteers, she will help spread the word about the Oley Foundation to home parenteral (IV) and enteral (tube feeding) nutrition (HPEN) consumers and health care professionals, and provide peer support for consumers—in person, by phone or e-mail, or through social media.

Contact Ambassadors with your questions, or for an understanding ear. We are so grateful for their efforts to meet our members' needs! For a complete list of Ambassadors, representing a range of ages, diagnoses and experiences, visit www.oley.org under "Meet Consumers/Patients," or call (518) 262-5079.

Note that Oley Ambassadors are not medical professionals and they do not offer medical advice. Oley Ambassadors should not be contacted for **solicitation, marketing, or research purposes.**

Please join us in welcoming Emily!

Emily Parks

Emily has been dependent on home parenteral nutrition (HPN) since age six and has overcome obstacles such as multiple intestinal surgeries and IV placements, open heart surgery, and acute kidney failure. She jokes that at the tender age of six months she decided life was "too boring," so she focused really, really hard and gave herself intestinal pseudo-obstruction, "you know, just to kick it up a notch and be a major over-achiever."



Emily Parks

Emily was born and raised in a small Missouri college town. Growing up, she says, "I never knew anyone else on HPN; I didn't know anyone who knew anyone who was. Many of my doctors were new to HPN as well. My Missouri hospital was a good hospital, but it wasn't large enough to be equipped with protocols to handle a patient like me. As much as I was learning, they were, too. I'm sure my health care team spent endless nights poring over research and hours calling colleagues.

"There were mistakes, open conversations, and test runs without a guaranteed success, but I was most definitely a part of my own health team. I always knew what was happening, why it was happening, and what was happening next. My voice mattered. I experienced the best person-centered care there, because of the people I worked with. Even if a line infection didn't die, I was taught critical tools I needed to advocate and care for myself."

Emily graduated from Boston University, Boston, Massachusetts; studied abroad in Sydney, Australia; works full-time; and lives independently. Currently, Emily resides just outside of the Washington, D.C., area, and is pursuing a career in behavioral health and patient advocacy. In her free time, she interns with a Harvard-based podcast, explores Washington, and talks politics with her golden retriever. As she likes to say, "she's a million-dollar baby cause she's one in a million, baby."

Emily can be reached at emilyprk@bu.edu or (573) 864-4656.

Coram

♥CVS specialty infusion services

We're here for
you every step
of the way

The CoramSM Nutrition Support Program is dedicated to making home nutrition therapy easier. You can count on our team of experienced specialists to help you achieve success and independence throughout your therapy.

- Individualized therapy
- Ongoing education
- Customized support
- Personalized care

For more information, talk to
your doctor or call Coram at
1-800-423-1411.

Coram CVS SpecialtySM Infusion Services
©2018 Coram, LLC. All rights reserved. 75-16762A 091318

Life Without Limits

Three Oley members have generously offered to share their experiences and answer your questions in a new column. Fran, Mallory, and Michelle each bring something different to this space. Fran offers a willingness to address your personal issues—from dating, to non-eating etiquette, to...who knows?—and to do so with humor and grace. Mallory, who has been on home parenteral nutrition (HPN) all of her life, will address the myriad issues young home parenteral and enteral (HPEN) consumers face as they move from being a child, to teenager, to adult, and all of the unique transitions growing-up-while-dependent-on-HPEN entails. Michelle says, “You don’t know what you don’t know,” and she wants to share information that she has learned—sometimes the hard way—to make life on HPN a bit more manageable. Here, we introduce Mallory—who, by the time you read this, will be married to Owen!

Fran, Mallory, Michelle, and Oley staff hope you will share your experiences, too, and your questions. We welcome guest authors, questions, and suggested topics! Send comments, ideas, and questions to the editor at metzgel@amc.edu. *Information shared in this column represents the experience of the individual and, while medical information is reviewed by an advisor, should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.*



Owen and Mal Mallory Cyr

I was not the kind of girl who had my wedding all planned out at the age of ten. My Barbies were career driven, and when I was old enough to know what dating was, all it took was one look around my high school for me to know I was just going to focus on getting good grades.

I wasn’t anti-social by any means. My family made all possible efforts to make sure I was included growing up, regardless of my health needs. I had tons of friends and I hung out with lots of guy friends in high school and college, but I knew I wasn’t going to settle. My plan was to graduate college, move to a big city, and write my book à la Carrie Bradshaw. But life is what happens when you’re making other plans, right?

It’s important to mention that since I’m on home parenteral nutrition (HPN) and have been my entire life (thirty-three years), I wasn’t interested in, and was pretty set against, dating anyone with a disability. I didn’t need to add anybody’s “stuff” when I had my own to manage.

Enter Owen

Owen and I met in 2011. I was a keynote speaker at a youth transition conference at the University of Las Vegas. Speaking of “managing stuff”...right before the conference, I was in the hospital for a central line infection, and wasn’t sure I would even be able to go. I was terrified to tell the people organizing the conference, because the year before, I was supposed to present when it was in Reno but there was a horrible storm in Washington, D.C., that affected my flight, and I had to present on Skype. All day.

I didn’t want to let them down or have to resort to my virtual self again. I was determined to make it happen. Luckily, all the timing worked out, and I was off to Las Vegas on IV antibiotics. If I have learned anything throughout my life on HPN, it’s that, if at all possible, the show must go on.

I had made a decision before the conference that I was not there to meet a guy. I was there to work, and if it worked out, have some fun on the strip. The first day of the conference, people kept trying to introduce me to Owen. At the time, he was the youth coordinator who worked

for the family organization that had put on the conference. I couldn’t understand why everyone kept trying to get us to meet. I clearly was not interested. He lived on a ranch in Nevada, and was a wheelchair user! I learned that he had spina bifida and had been a wheelchair user his whole life.



Owen and Mal out on the town.

Throughout the conference, Owen and I did get to spend some time together. I discovered he was not only funny, but he had a gentle, quiet wisdom about him. When it was time for me to go back to my hotel, I jumped out of the van and with a quick goodbye to Owen and a “You have my number! Use it or don’t!” I disappeared into the glittering lobby of Planet Hollywood.

Well he did use it. He texted me that evening. A short, respectful, grammatically correct message: “It was great to meet you. I hope we get to see each other again. You’re amazing.”

Long-distance Dating

The first year of our relationship, we were long distance. Owen lived in Nevada and I lived in Maine. We both lived with our parents. This situation came with both blessings and challenges.

The good part was, all we could do was TALK. And we did. For a whole year. On the phone, on Skype, on Facetime. We talked about everything. I remember we used to Google search “get to know you questions,” or “questions to ask someone you’re dating.” Because of this, we learned a LOT about each other, and it was so refreshing to talk to someone who was willing to have deep conversations about our values, our goals, and what we wanted our lives to look like.

When we decided we wanted to “be official” after spending a few days in Vegas for my birthday, we promised each other we would always communicate honestly, and not waste time with “drama.” Our communication has stayed strong through our entire relationship. The year of being long distance and learning everything about each other proved helpful, for when we moved in together the following year (yes, we went straight from living in each other’s phones, to living together in a 500-square-foot studio apartment), we had already covered the bases and discussed the tough stuff.

The difficult part of being long distance was that we didn't really get to ease into the whole dating thing. In order to spend time together, we had to travel. With most of the people I have spent time with, I would gradually disclose different aspects of my "health life," as I felt comfortable, but in this situation our first months together were spent in small hotel rooms in Vegas and the guest room at his parents' house.

Not only did I have to schedule my HPN to be shipped to wherever we were staying, I had to coordinate with Owen's family, whom I had just met, to make sure my HPN delivery arrived safely, and that they put everything in the refrigerator once it arrived. Since I did not want to appear high maintenance, I wasn't sure how this first impression was going to come off. At the time, I needed help setting up my HPN for the night. Whereas most couples get to know one another over movies and pizza nights, Owen and I quickly established trust as he helped me set up my HPN.

Supporting One Another

Once we moved in together, we had lots of conversations about our needs, and how we could support each other in the relationship. As two people with disabilities and complex medical needs, we both would have qualified for additional support services, or people to come into our home to help us with medical or household tasks. Early on, we decided that we didn't want to pursue these options and that we would support each other in whatever ways necessary. There is absolutely nothing wrong with having additional help, and it works great for some people, but this was what worked for us. Many people are surprised when they hear that we navigated life, work, and my three years of grad school without additional in-home support.

In the seven years we have been together, Owen has become an expert in managing HPN. He handles the weekly delivery that arrives and is on a first-name basis with our Fed Ex delivery person. If my home supply company can't reach me, they call him without hesitation. We both have our chores, and we work together to cook meals, pay bills, and do everything to keep our lives running smoothly.

Truthfully, I knew Owen and I would get married when, four months after moving in together, I was hospitalized. It took a long time for the doctors to figure out what was wrong, and I was sicker than I had ever been. My parents drove down from Maine to Boston to be with us. As my mom prepared to stay overnight with me, Owen said, "It's Ok. I'm going to stay with her." And he did. He slept on the small couch in my hospital room for ten nights. He held my oxygen monitor and pushed my IV pole so I could go to the bathroom. He never left my side. Five years later, after many trials and tribulations, in our first Denver apartment, Owen asked me to be his wife. We get married in mid-October.

Our story isn't short. It's not simple, and it's taken a lot to get to our "happily ever after." In the beginning I was opposed to being with someone who had their own "stuff." In the end, though, we each found someone whose "stuff" aligned with our own, and we understood each other on a level that nobody else would.

To learn more about Mallory, follow her blog: www.curbcutsand-cocktails.com. Or follow Owen and Mal at their Facebook page: www.facebook.com/OwenandMal. ♡

#GET TO KNOW GATTEX

Don't wait.
Talk to your doctor
and visit gattex.com
to learn more.

MISA, GATTEX PATIENT

Gattex
(Teduglutide (rDNA origin)) for Injection

Shire is not responsible for the terms and conditions, privacy policy, or content of any website not owned by Shire. Shire has no control over and does not endorse the results or content of any hashtag search or the use of hashtags on social media.

Shire

GATTEX® is a registered trademark of Shire-NPS Pharmaceuticals, Inc. SHIRE and the Shire Logo are trademarks or registered trademarks of Shire Pharmaceutical Holdings Ireland Limited or its affiliates. ©2018 Shire US Inc. All rights reserved. S4083 05/18

Fifty Years on Nutrition Support, from pg. 1

This was a good-sized city hospital, but they didn't know what to do with me. They gave me IVs—the usual sugar, water, and electrolytes—and they gave me an occasional bag of plasma, but that wasn't enough. I was going downhill when one of the doctors told me a doctor at the university center who had some expertise in nutrition had agreed to take over my care. I moved to Cincinnati University Medical Center under the care of Dr. Richard Bozian. Dr. Bozian was, and still is, a wonderful human being. He is currently in his mid-nineties, but is still very active in the community.

The first thing my new doctor did was absorption studies, to see how much I actually could absorb. It wasn't much. Then he sat on my bed and talked to me about this new therapy called hyperalimentation (which is what total parenteral nutrition—TPN—was called in those days). From the very beginning he told me he'd never used TPN on anybody, but that he had read about it and there was a doctor in Texas who had successfully treated several patients with it. He felt it was what I needed. I agreed.

The Process

My doctor explained that TPN had to be rapidly diluted in a large vein, so I got my first central line. It was placed at the bedside. They placed a large-bore needle into the subclavian vein. Through the center of that needle they threaded a little, thin, hard, plastic catheter. After the catheter was in the vein, they took the needle out, but they couldn't get rid of it because it was all one piece. The needle was taped to my chest and the catheter stayed in the vein.

The catheter never got soft or compliant with my body. It was rigid, and when you moved, like if you moved your arm, it would ride in and out of the skin. Consequently, it became infected rather easily. To add insult to injury, we didn't have nice clear occlusive dressings like we do now. I just had gauze and tape. Thus I had my central line.

The TPN

Making the TPN was a problem. My doctor couldn't call the pharmacy and say he wanted it. Nobody knew what it was. Luckily, my doctor had been a pharmacist before he got his MD. He went down to the pharmacy and together, he and the pharmacist figured out how they were going to compound this solution that would give me everything I needed. In those days, the TPN came from the pharmacy in glass bottles.

Luckily, my doctor was familiar with 0.2 micron filters, and he wanted a filter on my IV because he recognized that it had great potential for growing bacteria. However, you couldn't infuse fluid through the filter without it being pumped, and there were no IV infusion pumps back then. That afternoon Dr. Bozian came into my room pushing a cart, and on it was a heavy metal box, about 10 to 12 inches square. It was a Harvard infusion pump. This pump was meant for laboratory use, not for patient care. It had no safety

features, no bells and whistles. It had an on and off switch and a rheostat. You turned the dial up, the pump went faster; you turned it down, the pump went slower. That was the extent of it.

The sterile tubing that went with the pump was not IV tubing, so I had to create something that would work. I would take sterile IV tubing, clean the outside with betadine, and cut it with sterile scissors. I would do the same thing with the pump tubing, then I'd take the two and tape them together. That was my IV tubing.

I did not change my tubing every day. I kept using it until, well, usually it exploded. With no safety features, the pump pumped regardless. If something was blocked, like maybe the tubing was kinked or the filter was clogged with precipitate, it kept pumping anyway, and the pressure would get so great that the tubing would pop apart and there would be TPN in every corner of the room.

The 0.2 micron filter was a lifesaver. Once it was wet, air could not go through it. There were no alarms on the pump, and if a bottle ran dry and I wasn't paying attention, it would pump air. The filter prevented that air from

being pumped into me. Pressure would build up behind the filter and there were times when I would look over and see the latex part of the tubing blowing up like a balloon before it would come apart.

Going Home on TPN

This was basically my life for two years. I more or less lived at the university center. I did occasionally get out. If a line went bad, for example, I could go home for a few days. In those days, we still hoped that if I really, really pushed oral feedings—eating small amounts constantly of the appropriate stuff—that I maybe could make it orally. But it didn't work and I would end up back in the hospital.

After about two years, my doctor started talking about me going home and doing this. That set up a roar among his colleagues because they felt it was entirely too dangerous to let a patient go home with a central line. Thank goodness my doctor never gave up. He started brainstorming with some of the surgeons and they came up with the idea of creating AV fistulas for me to infuse my TPN through.

An AV fistula is the same thing a dialysis patient has in their arm. They surgically connect the artery and the vein in the arm. Having the arterial flow pushed through this vein causes the vein to become engorged and have a very rapid blood flow. And that's what they did. I would put a little needle in my arm every night, and infuse my TPN during the night, then take the needle out in the morning and be free.

I infused TPN using a fistula for six years, but it involved many, many, many surgeries, because although this vein had rapid blood flow, it still couldn't really handle the TPN. Over time the vein would become irritated and clot off. They would go in and remove the clot and put in an artificial vein graft. They did this consistently, going up both arms until they could go no further.



At the end of the talk, the audience fittingly honored Sharon with a standing ovation.

Finally, I got my first silastic catheter. It wasn't cuffed; it was just a thin, soft, little catheter. They had to open my chest and managed to thread it through a small intercostal vein to get it up to where it should be. And it worked!

Because it was a very soft catheter and because the route was so convoluted, at night I had to lay flat with my arms at my sides. I could not move my arms, or tilt my head, my shoulder, or even a hip. If I moved, the catheter would kink off. Believe it or not, I was kind of happy two years later when that catheter went bad.

I did eventually get the type of catheter we are all familiar with today. I now have a Hickman. Getting a catheter in me can be challenging, as all the major vessels in my chest have clotted off.

I wondered, why am I so lucky? ... I didn't know the answer then, and I still don't know the answer, but I'm thankful.

I have led a full life.

Throughout my body, small vessels have taken over the flow of the large veins that have been blocked off through the years. With our advances, however, it has become easier. Interventional radiologists can get a catheter into a turnip. They are wonderful. So life has gotten easier.

We encountered a lot of problems through the early years. For example, it took me six years to

get any lipids, and then I only got them as a research patient, because although lipids were being used in Europe with no problems, the FDA would not approve them. By the time I got lipids, my essential fatty acid levels were very low. I'd lost all my hair and the musoca in my mouth, nose, and vagina was like raw meat.

Everything was "learn as you go." When I was home doing it myself, I used to reuse my tubing. I'd pack it in formaldehyde, then rinse it out and use it again. In those early days, I didn't get TPN already premixed. I mixed it from scratch, and I did it in my bathroom. Doesn't that make you cringe?

A Blessed Life

After I'd been on TPN about five years, my doctor told me Dr. Wretlind, a Swedish MD who was one of the pioneers in IV nutrition, was visiting from Europe and would like to meet me. Intralipid was his formula. Dr. Wretlind and I had a nice lunch together, during which he kept asking me rather everyday questions about what it was like living on TPN. I was surprised and said, "Certainly you know the answers, as one of the fathers of TPN." He looked at me and said, "I've never talked to anybody who has lived on TPN. In Europe, we only use it as a temporary measure while people are recovering from surgery."

That was a real moment for me. I wondered, why am I so lucky? Why am I so blessed? I didn't know the answer then, and I still don't know the answer, but I'm thankful. I have led a full life. I was married, I have twin boys and five grandchildren, and I worked full-time as a critical care nurse.

I have seen a lot of changes in the fifty years I have been on TPN and have seen many improvements. We improve so much every year. I want us all to have hope that it's only going to get better. ¶

Diplomat Specialty Infusion Group is more than just a pharmacy.

Our nutrition division, ThriveRx, helps reduce parenteral nutrition dependence and improve quality of life.



We provide:

- Clinical excellence
- Customized care
- Consumer advocacy



CONTACT US

888.684.7483

infothriverrx@diplomat.is

thriverrx.diplomat.is



Copyright © 2018 by Diplomat Pharmacy Inc. Diplomat, Diplomat Specialty Infusion Group, and ThriveRx are either trademarks or registered trademarks of Diplomat Pharmacy Inc. All rights reserved. 0545-190274-9910



HPN Consumer Education Seminar

An Advanced Program for the
Sophisticated HPN Consumer

Next Stop

Redondo Beach, CA
Saturday,
December 8, 2018

HomePN.com
or 1 800 HOME TPN
For more information

Award Winning HPN Specialists
Nutrishare[®]
1 800 HOME TPN

PTSD, from pg. 2

breast cancer because a lot of PTSD research has been done with that patient group, and we wanted to compare IBD and IBS with another medical group versus war veterans. The IBD patients came in right at 29% (roughly one-third, as has been shown with war vets), IBS at 26%, and breast cancer at 20%, consistent with prior research in breast cancer. The IBD group is significantly higher than breast cancer, so there is something unique going on in digestive illnesses that we are maybe not seeing in cancer patients.

ST: Do you have thoughts on why that might be?

TT: We asked questions about hospitalizations and surgeries. The IBD and breast cancer patients looked similar in terms of rates, but I think the types of surgeries that are done in IBD differ from those done in cancer. A lot of people with IBD end up with emergency surgeries, or a critical surgery like having their colon or parts of the small bowel removed, whereas in breast cancer, it might be more planned out. I'm not saying surgery for breast cancer is not difficult, but I think there is something about having sections of your bowel removed, to the point of sometimes having to go on total parenteral nutrition (TPN), that is different than a breast cancer experience.

ST: How might nutrition support, like TPN, complicate things?

TT: When you get to the point of requiring TPN or nutrition support, you may have already had some surgeries. In the IBD world we see short bowel syndrome, and people who may not tolerate food. So not only is something happening to your body surgically or disease process-wise, but now food is being taken away and you are left to basically sustain yourself via IV or other types of nutrition delivery. Existentially and psychologically, this is a huge blow that will compound your experience. We are resilient as human beings, but it is almost like a one-two punch when getting TPN added on top of everything else that has happened.

ST: I think it's hard for people to understand the psychological aspect of not having food if they are not living in that world.

Can something that is traumatic for one person, for example a line infection which can be life threatening, also feel traumatic to another? Is it the event, the individual, or maybe a combination of both?

TT: Let's look at vets coming back from active duty. Two vets may be in the same unit and see the same things, but one gets PTSD and the other does not. That points to more of the whole life experience, with the psychological makeup of the person being important. We know some things make us more prone to developing PTSD, with number one being repeated trauma.

If you had a pretty good experience most of your life or you grew up in a relatively calm environment, with maybe some minor things but nothing you would deem traumatic—no abuse, no crime committed against you—and you go to combat, you are less likely to get PTSD than if you lived in a rough neighborhood, watched people get shot, maybe

Not only is something happening to your body surgically or disease process-wise, but now food is being taken away....psychologically, this is a huge blow.

had an abusive relationship at some point. That person is more likely to not be able to withstand another trauma. That is our number one predictor.

The situation of the line infection definitely is traumatic, but I think what you bring into the situation makes it complicated. And that is not me blaming anybody. It's just what it is in terms of your life experience, and it can unfortunately make it harder to bounce back from something like that.

ST: Sometimes people can get multiple infections. Maybe the first time wouldn't be traumatic, but infection number five would be different.

What are the common treatments used for PTSD? Are some proven to be more effective than others?

TT: Yes, absolutely.

I can't emphasize enough the need to work with an experienced, trauma trained therapist. There are many excellent therapists

out there that are trained in what we call evidence-based treatments of PTSD. The two main treatments are cognitive processing therapy and prolonged exposure therapy. Just as what I said earlier about talking about the trauma in our window of opportunity, when you come in for one of those treatments the therapist will ask you to retell the trauma to them either in written exercises or in the office. But prior to doing that, the therapist will teach you how to relax your body, how to use “grounding techniques” to bring you out of a flashback. Here’s an example of grounding: I’m sitting in the office looking at the computer screen, at my phone on the floor—just looking at what’s around me—to think I’m not back in the hospital, I’m present where I am. It’s retelling it in a way that feels safe. It’s a tough treatment but the good news is it works about 70 percent of the time. People don’t like the treatment very much because it’s hard, but when they get going with it their symptoms really do improve considerably. A strong therapeutic relationship with the therapist is important.

ST: So literally facing those fears?

TT: Yes. With PTSD, you really want a therapist who knows what they are doing. Look for these two specific terms—cognitive processing or prolonged exposure therapy. You can ask the therapist if they do either of those treatments before you even see them. There are other therapies out there that I would not advocate using.

In terms of medications, there are only two approved for PTSD. They are in the antidepressant SSRI class. We do not recommend that someone experiencing PTSD take benzodiazepines, which are fast-acting anti-anxiety medications. Those are contraindicated. If you want to take them you can, but a psychiatrist trained in treating PTSD will know which ones are good and which to avoid.

ST: Earlier you mentioned that caregivers and even spouses can also feel the effects of trauma. Parents of children with chronic illness and who are on nutrition support, for example, go through a lot. Would treatment for them be similar to what we’ve discussed?

TT: Yes, it would be very similar. Sometimes more of a subclinical PTSD is more common in caregivers and spouses, but either way the treatment would be the same: retelling, talking about it, getting it out.

ST: There can be negativity associated with seeking help, like we might be “weak” or “not trying hard enough” to deal with things on our own.

TT: Unfortunately, that’s true. The U.S. has a long history of stigma towards mental health and mental illness. People actively avoid going to see a therapist for even depression or anxiety. When you get into PTSD, which is very difficult to live with and scary—sometimes people think they are going crazy or losing their mind—it can be harder. It’s natural to be worried about what might go in your medical record, about what it means for the future, like insurance, or having it out there. People don’t like that. We are also a very stoic society, with a “pull yourself up by your bootstraps” attitude, and that is often detrimental. In my opinion, it is very brave to face PTSD and seek help because I know how hard the treatment is. You are not weak at all if you go in to get the help you need.

PTSD, cont. pg. 12 ◀

katefarms®
The Higher Standard for Oral & Tube Feeding Nutrition
THE ONLY PLANT-BASED PEPTIDE FORMULA
For Kids Ages 1–13 Years

- ✓ People on Kate Farms experienced improved symptoms of GI intolerance*
- ✓ Our formulas don't contain common allergens

ALSO AVAILABLE:
 Kate Farms Pediatric Standard 1.2

Flows smoothly for tube feeding
 Coded to be covered by insurance

Get Started on Kate Farms
 VISIT KATEFARMS.COM

ALLGOODTHINGS®
*National survey of healthcare professionals who have prescribed Kate Farms Peptide 1.5. Conducted April 2018. N=92.

PTSD, from pg. 11

ST: I agree it is brave.

Those of us living with nutrition support or caring for someone who does often hear about others' experiences, whether through support groups or in conversation. There is fear, frustration, and anxiety, and often for very good reasons. People are not being taken seriously, often feel dismissed, are being told "you look fine" or that it's "all in your head."

People share that visits to the ER tend to be most traumatic, both for the reasons just mentioned and also a fear of anyone touching their lines or bodies due to risk of infection and past trauma. What are some tips we can use to communicate with our care teams or anyone we need to seek medical help from? How can we help them better understand why we might be in tears, or are scared or upset?

TT: I want to validate this feeling. Even as a health-care provider myself, I avoid the ER like the plague. I get it. You feel helpless to communicate, and terrified they are not going to take you seriously. It's also hard being a female in the medical system. We are not taken as seriously as men; we are more likely to be dismissed. Thankfully, that is getting more discussion, but it's still a thing, so we are up against a lot of potential problem areas.

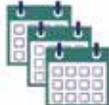
Find your voice if you can, and/or have someone there that can speak for you. I have a friend with Crohn's and we are each other's person. I take her to her ER visits or procedures and she takes me to mine. I can talk about things with her that I can't talk about with my husband.

Also, kind of decide you really don't care what this ER doc thinks of you, or that you really need help and will be assertive. There is a fine line between assertion and aggression. It's tough, but say, "No, I don't agree with that. Can I speak to the attending?" if you're seeing a fellow or trainee.

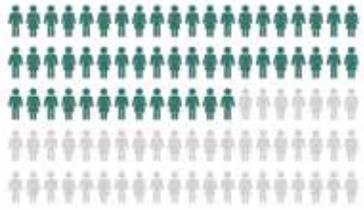
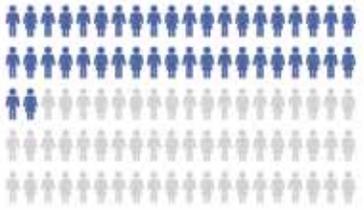
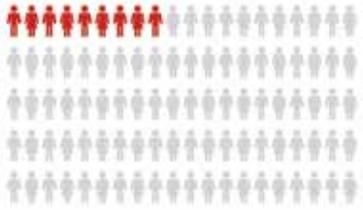
Try to advocate best you can. When not feeling well it's tough. If you are in tears you can say, "I've been through a lot of traumatic times with this and it's bringing up a lot of stuff for me. If my emotions seem out of proportion to you, I hope you can understand they are not out of proportion to me."

ST: Sometimes as we do our best to get through what has happened, we must also live with what is currently going on and anticipate what may come that is not always in our control. How does treatment work for something that may always be present?

THE BEST TREATMENT FOR PTSD: The evidence is in.

 **Trauma-focused psychotherapy is the first-line treatment for PTSD.**
It lasts only about three months, and research shows that for most people its effects last long after treatment is over.

 **Did You Know?**

 Trauma-focused Psychotherapy	 Medication	 No Treatment
53 OUT OF 100	42 OUT OF 100	BUT ONLY 9 OUT OF 100
people who receive trauma-focused psychotherapy will no longer have PTSD after about 3 months of treatment.	people who take medication will no longer have PTSD after about 3 months of treatment.	people who don't get treatment will no longer have PTSD after about 3 months.
		

Reprinted from the National Center for PTSD, www.ptsd.va.gov

TT: If PTSD is occurring and it's associated with a particularly bad hospitalization, surgery, or infection, we would address that first to try to get that traumatic memory stored in a way that's not causing flashbacks and nightmares. It's not ever going to be completely resolved, but we'll strive to get to where it's contained, it's not causing a lot of impairment, and the person feels empowered to handle it.

Every day I ask the people I see, "How do you cope? How do you tap into your resilience?" We are paying a lot of attention to resilience and to normalizing the ups and downs—the rollercoaster ride that is a chronic illness—and teaching people skills so they can go back up the hill after they've gone down it and to maybe make some of those hills a little bit smaller. Focusing on what you can do and what you can control, maybe letting go of what you can't, is another important step when you have a chronic illness.

ST: As a therapist, are you helping build that resilience? While working with someone, is there anything we can do on our own to continue that?

TT: I came out of a training program that was really strength based. I look for what skills you already had before you came in to see me. You are out in the world functioning, you have been through a lot. Even kids are super resilient.

When we get overwhelmed we often predict the worst, and that if it happens we're not going to be able to handle it. I'll ask my patients, "When you thought that, did that really come true?" And they will tell me, "No, I was able to figure it out. It wasn't pleasant, but I made my way out the other end." So we leverage the skills that someone already has and then, where there are gaps, try to teach them new ones. The idea is that you can do a lot more than you feel or think you can do when you're at your lowest point.

ST: That's a great approach. A lot of us hear how brave we are. It's easy to dismiss that and say I'm doing what I have to do. A lot of strength can come out of the hardships we go through and if you can build on that, it sounds like a positive way to work through and prepare for things that may come.

TT: Yes, and I think a part of that is having a good support system—and by good I don't mean big. Even one person that really gets it can be with you in the messy times, in addition to when you are doing well. I mentioned my friend with Crohn's. We talk about all sorts of things I would never talk about with other people. It doesn't mean I like her more, it just means we have that connection.

Sometimes, unfortunately, chronic illness changes our social relationships and that person isn't who you would expect it to be. It's not your best friend but an acquaintance that gets it. Don't ignore that person. Take them up on their offers to sit and cry and laugh with you. I'm a big proponent of humor. If you can laugh, please do. That is part of resilience. It keeps you going too when you feel like you can't.

ST: Many people reach out on social media for support these days. However, this can also come with a downside, like seeing pictures

of people who are sick in the hospital, hearing how unwell others are, and not only feeling sad for them, but also thinking, "Wow, this could possibly happen to me." Do you see any problems with this type of support? Is it helpful because of the connections or can it also be hurtful by leaving us overly exposed to others' experiences and our constantly retelling our own?

TT: The answer is both. For some, their only support is online, and that's okay as long as that support circle is what I have described: it's reciprocal, and you're not constantly the one taking on someone else's issues and problems. We are good at turning into caregivers ourselves when connected to people online, thinking I don't have it as bad as "Joe" over here, so I'm going to set my stuff aside to try and help. Then you feel burned out from helping because Joe doesn't say, "OK, I've talked enough. Let me hear how you are doing." You really want it to be reciprocal.

Model your online relationships with ones you would want to have in the real world, not taking on too much and limiting your time in terms of social media, message boards, and checking in with yourself. If you are starting to feel particularly tense—say if your shoulders are up to your ears as you are reading various messages online—it might be time to step away from the screen.

Online support is great when using these types of guidelines and limiting it if you feel overwhelmed. For example, if someone on Instagram is posting really graphic pictures, you might need to unfollow them because it's just too much for you to see and you are getting vicarious trauma from them and priming yourself for that kind of hyperarousal I talked about earlier.

PTSD, cont. pg. 14

We are paying a lot of attention to resilience and to normalizing the ups and downs—the rollercoaster ride that is a chronic illness.



bio scrip®
Infusion Services

Proud supporter of the **Oley Foundation**, home nutrition support consumers, and their caregivers.

Evidence-Based
Condition-Focused
Outcomes-Driven

Enhancing the Lives of Those
We Care for Each Day.

Tube Talk, from pg. 3

gastrostomy-tubes-after-stoma-dilation-in-the-pediatric-emergency-department.html). The authors conducted a retrospective medical record review of children up to 18 years old who came to one pediatric ED “with a dislodged GT [G-tube] that required stoma dilation by pediatric emergency physicians with serially increasing Foley catheter sizes prior to successful placement of the GT.”

They “reviewed a total of 302 encounters in 215 patients, with 97... encounters requiring stoma dilation prior to replacing a GT. The median amount of dilation was 2 French between the initial Foley catheter size and the final GT size. There was a single complication of a mal-positioned balloon that was identified at the index visit. No delayed complications were encountered.”

They conclude that the practice “is generally successful and without increased complication.” They continue, “All patients received at least one form of confirmation for appropriate GT placement with the most common being aspiration of gastric contents.” ¶

Thanks Corporate Partners!

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

ThriveRx, Inc.

ThriveRx, a division of Diplomat Specialty Infusion Group, is proud to be a Gold Medallion Partner of the Oley Foundation. The company is dedicated to providing customized care for the home enteral and parenteral nutrition consumer. Its mission is to empower patients and their families. Learn more at thriverrx.diplomat.is.

Rotary Rewards

A \$400 check created by proceeds from the “Loose Change” donation jar was presented this spring to Joan Bishop, executive director of the Oley Foundation, and club member and Oley program associate, Phil Kellerman.



If you or your loved one is a member of a rotary club, please consider spreading the word about the Oley Foundation’s good work and what it means to you. It’s a great way to raise awareness of tube feeding and/or IV nutrition in your community, and may result in financial support for Oley programs as well!

Joan Bishop and Phil Kellerman receive a check from the Southern Rensselaer Rotary Club.

PTSD, from pg. 13

ST: You’re saying really pay attention to yourself and how you are feeling and how your body is reacting. Do you have any tips for finding a good therapist to work with that might be trained with this?

TT: If you feel like you have some symptoms, not full-blown PTSD, the best resource is the Department of Veteran Affairs’ wonderful, comprehensive website.* It’s obviously geared towards combat, but the principles are the same. That is where we take our guidance from in treating PTSD. You can fill out screener questionnaires and it will tell you your score and if you should seek care. If you have a potential diagnosis of PTSD, you will want to look for a trauma therapist.

I also direct people to the searchable Psychology Today therapist directory.** The caveat to that is some people will say they do everything, and that is a warning sign when you are looking for someone for a specific thing. But any good therapist will answer your questions before they schedule with you, so come up with a list of questions—ask about those treatments I mentioned, how many patients with trauma they see or what percentage of their practice is based on trauma—and weed out ones who shouldn’t be working with you.

In terms of GI psychologists, I’m happy to say the ROME Foundation, which is the functional digestive illness foundation, will be putting out a searchable directory of GI psychologists and therapists. If you want someone who focuses more on digestive illness and maybe you have some signs but not full PTSD, a GI psychologist would be qualified to treat that and work with you on the digestive illness and TPN. So there are two answers depending on how severe the symptoms are.

Any good therapist will answer your questions before they schedule with you, ... [ask] what percentage of their practice is based on trauma.

ST: Are there resources available for medical professionals when they come across a patient who needs further help?

TT: I would recommend they also view the VA website,* watch the videos, and ask questions of any patient who seems on edge or is avoidant (maybe not following their treatment plan or canceling appointments), especially if the patient has had a particularly rough hospitalization or complications. I know and appreciate that doctors and nurses might be afraid to open a can of worms in a short appointment when they need to focus on medical topics, but they should get comfortable with it and also get comfortable with saying, “I can see you are really struggling here and I recommend you see this person or that person.”

They should have names of therapists they have a relationship with before they bring it up with a patient, because if they bring it up and then say they are going to find one, the patient might feel a bit overwhelmed. A minute or two spent on this could really make a big difference. I recommend doctors get to know at least one psychologist in the community they can refer patients to. ¶

*www.ptsd.va.gov
 **Psychology Today therapist directory, www.psychologytoday.com/us/therapists/trauma-and-ptsd

Notable Individual Gifts

Among the contributions we receive, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from May 12 through September 20, 2018. Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.

Memorials: *In memory of* Lawrence Carter; Michelle DeHart; Clifton Dodge, Sr.; Jeff Dutton; Judith Ervin; Tim Leahy; Nina Marino; Heidi Martin-Coleman; Gregory Medwar; Brittney Salinas; Josh Shapiro; Paula Southwick; Bob Sweet; John Tucker; Bruce Wolf; Liz Wolfson

Tributes: *In honor of* Dr. Jane Balint “and the amazing gifts she gave to short gut kids and their families”; Hadar Birger-Bray’s birthday; Thomas Bjurbo; Lynda Bosworth; Dan Guerrero; Lyn Howard and Jack Alexander’s eightieth birthdays; Megan Hundt; Phil Kellerman; Aidan Koncius; Michael Luebbehusen; the birth of Cameron Walter Banchik Morpeth; Jeffrey Schesnol; twelve years on HPEN; Lynn and Eli Wolfson; and in support of continuing education

Matching Gifts: The GE Foundation; Johnson & Johnson

Fund-raisers: Amazon Smile; Facebook; GoodDoneGreat.com

Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference by calling (518) 262-5079 or visiting www.oley.org/plannedgifts.

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

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their strong commitment.



TITANIUM LEVEL PARTNER (\$150,000+)

Shire

GOLD MEDALLION PARTNER (\$50,000–\$69,999)

ThriveRx, Inc.

SILVER CIRCLE PARTNERS (\$30,000–\$49,999)

Coram / CVS Specialty Infusion Services
Nutrishare, Inc.

BRONZE STAR PARTNERS (\$20,000–\$29,999)

Avanos
Baxter International Inc.
Cardinal Health, Inc.
Fresenius Kabi USA
Option Care

BENEFACTOR LEVEL PARTNERS (\$10,000–\$19,999)

BioScrip Infusion Services
BriovaRx Infusion Services
Nestlé Health Science
Real Food Blends

PATRON LEVEL PARTNERS (\$5,000–\$9,999)

Applied Medical Technology, Inc.
Apria Healthcare
Cook Medical
Functional Formularies
Soleo Health

Learn more at www.oley.org/IndustryLandingPage

LifelineLetter

The Oley Foundation

Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 687
ALBANY, N.Y.



HPN Awareness Week
October 15–19, 2018

Oley Calendar

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

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

October 15–19: HPN Awareness Week

February 3–8, 2019: Feeding Tube Awareness Week

March 2–3, 2019 (tentative dates): Digestive Disease National Coalition, (DDNC) Washington, DC

March 9–13, 2019: Oley exhibiting at National Home Infusion Association (NHIA) Conference, Orlando, FL

March 23–26, 2019: Oley attending and exhibiting at ASPEN 2019 Nutrition Science & Practice Conference, Phoenix, AZ

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

Additional Meetings of Interest

January 17–18, 2019: Feeding Matters' Pediatric Feeding Disorders Conference, Glendale, AZ

May 18–21, 2019: Digestive Disease Week, San Diego, CA

Halloween Is Almost Here!

Support kids who cannot eat the usual candy treats by participating in the Food Allergy Research & Education's Teal Pumpkin Project®. It's as simple as buying inexpensive non-food treats, such as glow sticks or small toys, and placing a teal pumpkin on your doorstep to show non-food treats are available.

You'll find details and lots of free resources at www.tealpumpkinproject.org, including:

- a free poster to hang in your window (if you don't have a teal pumpkin);
- directions for adding your home to the interactive map, making it easier for kids to find your house;
- ideas for non-food treats; and
- tools and tips to help spread the word via social media!



November 1–December 15

Open Enrollment for 2019 Health Insurance Marketplace

Important: 2019 Open Enrollment is only a few weeks. If you don't act by December 15, you can't get 2019 coverage unless you qualify for a Special Enrollment Period. Plans sold during Open Enrollment start January 1, 2019. Go to www.healthcare.gov/get-coverage.