Second Chances
Rolf Benirschke

Being a successful kicker in the National Football League (NFL) is a little bit about strength…and a lot about timing. So, when our field goal unit was rushed onto the field on second down, instead of after third down as in normal situations, and didn’t have time to set up properly—I knew we were in trouble. My rhythm was off, and I hooked the ball just left of the goal post.

We were in overtime and the score was now tied 24-24 in a playoff game between my team, the San Diego Chargers, and the Miami Dolphins. Later, this would be called one of the greatest games in NFL history. As I began that agonizing walk back to the sidelines, I was sick with regret, knowing I had let my team down. While the game wasn’t technically over, I believed it was. How often does a kicker get a second chance in overtime? Hardly ever!

The next few minutes were excruciating as I watched the Dolphins march down the field to set their kicker up for what was surely going to be a game-winning field goal. But amazingly, the Miami kicker mishit the kick and the low trajectory allowed our defensive line to block it! The Miami crowd went eerily silent, and I breathed a deep sigh of relief. Then, thanks to our quarterback, Dan Fouts, and our incredible offense, we quickly charged back down the field into scoring position and I actually did get a second chance to kick. This time the field goal unit was ready, the snap was

Oley Community
Enrichment Programs
Education, Connection, Hope

The Oley Foundation is offering many opportunities for consumers and clinicians to learn and connect through meetings (virtual, for now!) and webinars. These Oley events are free of charge, and everyone is welcome to attend. We’ve got exciting programs planned for 2021!

If you miss one of our programs, don’t despair. Visit www.oley.org for a link to the recordings (select “Conferences”; webinars and mini meetings are listed under “Community Enrichment Programs”).

Oley Mini Meeting
April 30, 2021
11:00 a.m.–4:00 p.m. EDT

Join us to hear Swapna Kakani, an HPN consumer and transplant recipient, share her story; Dr. Ann Michalek, on avoiding HPN complications; Penny Allen, RD, CNSC, FASPEN, and Bettemarie Bond, OTR/L, HPN consumer, talk about public policy and

Efficiency of Blenders
Used to Make Formula

M. Mundi, M.D.; L. Epp, RDN; W. Duellman, RDN; J. Davidson; S. Yaramala; R. Hurt, M.D.
Mayo Clinic, Rochester, Minnesota
Adapted with permission from a poster submitted to the American Society for Parenteral and Enteral Nutrition (ASPEN) Nutrition Science and Practice Conference

In recent years the use of blenderized tube feeding (BTF) has gained popularity among home enteral nutrition (HEN) users. [Editor’s note: “Home blenderized tube feeding” is a commonly accepted term for table foods that have been blended for administration through a feeding tube.]

In a recent prospective cross-sectional study it was found that 55.5 percent of adult HEN patients use BTF. The resources available for clinicians and HEN users regarding BTF are still limited, especially in regards to the best blender to prepare BTF. Anecdotal reports state the Vitamix blender is the gold standard. We conducted a study to test the
Our Mission

...is to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

The Oley Foundation provides its 24,000+ members with critical information on topics such as medical advances, research, and health insurance. The Foundation is also a source of support, helping consumers on home IV nutrition and tube feeding overcome challenges, such as their inability to eat and altered body image. All Oley programs are offered FREE of CHARGE to consumers and their families.

Oley Foundation Programs

- **LifelineLetter**
- Peer to Peer Support
- Conferences and Webinars
- Resources to Promote Living Well on Tube Feeding and IV Nutrition
- Equipment Supply Exchange
- Advocacy and Awareness

Resource Spotlight:

Visit the Oley Foundation online! In addition to our website (www.oley.org), the Oley Foundation is online on Facebook, Instagram, Twitter, LinkedIn, and YouTube. There’s also the Oley Inspire online community, with over 30,000 members! Follow us to stay connected to the latest news from Oley and to one another.

Find us at:

- www.facebook.com/The-Oley-Foundation-100575259989358
- twitter.com/oleyfoundation
- www.instagram.com/the_oley_foundation
- www.linkedin.com/company/oley-foundation
- www.oley.org/Forum
- www.youtube.com/user/TheOleyFoundation

React to any of our posts or videos to let us know what you think, and to help us grow.

Are missing another important platform? Let us know!

How to Support Oley

Donations are tax deductible and are accepted at www.oley.org/donations or at the street address on left.
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.

Feeding Tube Pads

We’ve gotten several suggestions and questions regarding feeding tube pads (also sometimes called “tube barriers”) recently. “Tube pads” come in a variety of styles, shapes, colors, and materials, and are available from many sources. When shopping for pads, some things to consider include absorbency; if they are reusable; the design; and variety of sizes.

Below are some examples—along with a DIY option—and some reasons why Oley members find them helpful. Have a favorite source for feeding tube pads? Let us know! Email Lisa at metzgel@amc.edu.

Thanks to Cynthia Reddick, RD, CNSC, for providing these stoma site care tips:

- Keep the skin around the tube clean and dry.
- Change your tube pad or dressing any time it is wet or soiled.
- Clean around your tube between dressing changes using gentle soap and water only, then pat dry. Avoid use of alcohol-based cleaners, hydrogen peroxide, or other harsh chemicals.
- Keep in mind when using tubie pads or dressings that long term exposure to moisture at the stoma site can lead to irritation and/or infection.
- A leaky tube site may be a sign that your tube does not fit properly and may need some adjustment.
- Protect the skin around your stoma site from chronic moisture (i.e., leaky tube not yet resolved) with the use of a moisture barrier cream.
- If your stoma site is clean and dry most of the time, gauze, dressing, or pads are likely not needed at all.

Tubie Pads

Tubie pads help by catching and absorbing stomach acid, sweat, and other gunk that accumulates under the feeding tube and on the skin that can cause irritation and breakdown. My daughter Natalie says that tubie pads feel softer and aren’t as scratchy as gauze pads, and they are better for the environment because you can wash and reuse them.

Natalie also enjoys being able to add a little flare to her tubie by picking tubie pads that have fun colors and designs, as well as characters, or holiday or seasonal themes to them. They come in cotton, fleece, and bamboo. Natalie prefers the softness and natural antimicrobial factor of the bamboo fabric.

Tubie Pads Two

I prefer to use tubie pads because they are less itchy than gauze and absorb more. My tube site “leaks” quite a bit and tube pads prevent that liquid from soaking through my clothes. They also snap on, which makes them less likely to fall off than gauze. Tubie pads come in lots of shapes, colors, and patterns that are fun for kids; as an adult I appreciate having some solid color options to pick from as well.

To clean, I soak my tubie pads in water plus hydrogen peroxide overnight and then put them in a garment bag that can go in the washing machine and dryer with the rest of my laundry.

—Nancy P.

PegPads

PegPads have been a game changer for our five-year-old son, Max. Max has short bowel syndrome (SBS), and gets his nutrition delivered via the J limb of a GJ button. Unfortunately, after many complicated abdominal surgeries, Max has a build-up of scar tissue around his pylorus that causes his stomach to empty very slowly. This delayed emptying also causes excessive leaking out of the GJ stoma.

Last year Max was leaking through gauze dressings, foam dressings, and cotton fabric dressings. Nothing that we tried seemed to absorb the leakage, or block the stoma in such a way that leaking could be prevented.

We were having to change his shirt several times a day, and it was beginning to bother Max and interfere with his daily activities.

A fellow mother of a child with SBS happened to recommend PegPads, and we have never looked back! Not only do the PegPads absorb any leaking, but when they do get wet, they don’t transfer liquid onto Max’s shirt. We’ve even noticed that they fit around his GJ tube so well that they have significantly prevented leaking altogether!

—Katie H.

PegPads can be found at www.etsy.com/PegLeakSolutions/listing/760106188/pegpad-crosshair-10pack-most-absorbent-g.

Do It Yourself Pads

I’m a retired critical care RN, and I’ve created some tube feeding pad digitized embroidery designs. These would be reusable and washable, eliminating the need for disposable split dressings. I’ve posted them on Etsy for anyone who has an embroidery sewing machine. These are created by using a top fabric, a thin cotton batting, and a backer fabric.

—Dru B.

Dru’s designs can be found at www.etsy.com/shop/DrusDesigns (do keyword search for “G tube”).

Max wearing a PegPad.
Welcome Nancy, Our Newest Ambassador

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit www.oley.org/ambassadorsmain or call (518) 262-5079. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice. Please do not contact Oley Ambassadors for solicitation, marketing, or research purposes.

Meet Nancy Pickett

Nancy Pickett (she/her) was diagnosed with GI dysmotility in 2015. She has been fed via NJ-tube, then GJ-tube, and now uses home parenteral (IV) nutrition (HPN) with a continuous G-tube drain. Through her years of being on nutritional support, Nancy has benefitted tremendously from connecting with other patients who have helped her navigate life with a feeding tube and central line. Now she is excited to do the same for others as an Oley Ambassador.

Nancy has experience advocating for medical needs in public school, living on a college campus, moving cross-country, and transitioning between doctors while on HPN. She is currently studying online at the University of Florida, pursuing a master’s degree in Public Interest Communication. She created her first feature-length film, a documentary about pediatric cancer, in high school, and her short film about the Affordable Care Act has been recognized by film festivals across the country, including the News and Documentary Emmy Awards. Her next film will explore disparities in healthcare among different demographic groups.

Nancy can be reached at (407) 212-5893 or npickett7@gmail.com.

Oley Youth a Superhero!

This winter, the Colten Cowell Foundation granted Oley Foundation member Zeke Retsinas a Superhero Experience. Zeke and his family shared an exciting evening exploring the “world-famous crime-fighting cave.” At the end of the event, Zeke presented the Oley Foundation with a $1,000 check. To instill a spirit of giving, the Colten Cowell Foundation invites its superheroes to choose a charity they feel has helped them throughout their journey. The foundation presents the check to their superheroes, who then pass it on to the charity of their choice—in this case, the Oley Foundation.

Our thanks to Zeke and the Colten Cowell Foundation. Learn more about the Colten Cowell Foundation’s Superhero Experience at www.coltcowellfoundation.org/superhero-experience.
advocacy; Sara Seegmiller, RN, BSN, on choosing the right feeding tube; Susan Hamilton, RN, MS, CCRN, CWOCN, on caring for the skin around an ostomy or feeding tube site; Saundra Jain, MA, PsyD, LPC, on wellness-enhancing practices; and more.

_Sponsored by Takeda and Optum Infusion Pharmacy_

**View the full program:** tinyurl.com/Aprilmeetingprogram.

**Register today:** tinyurl.com/Aprilmeetingregistration.

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**Oley Webinars**

**May 19, 2021**

1:00 p.m.—2:00 p.m. EDT

Interview with Allysa Seely, paratriathlete (Team USA) and HPN consumer, and Jacque Scaramella, MS, RD, CSSD, sports dietitian

**July 13, 2021**

1:00 p.m.—2:00 p.m. EDT

Updates on motility disorders with Dr. Carlo Di Lorenzo, Chief of the Division of Pediatric Gastroenterology, Hepatology and Nutrition, Nationwide Children’s Hospital, Columbus, Ohio

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**Oley Annual Conference**

**June 21–25**

Mark your calendar and join us for Oley 2021: A Virtual Experience, June 21–25. We have an exciting lineup of educational programs planned, with a different theme for each day. Sessions will run a maximum of four hours per day and include formal presentations and informal discussions, bringing the Oley Foundation community together for learning and connecting. We look forward to seeing you!

There is no charge for attending Oley 2021. Watch www.oley.org and your email for updates and registration information.

**Daily Themes**

- **Monday, June 21** — _Home Parenteral Nutrition_, sponsored by Option Care Health
- **Tuesday, June 22** — _Home Enteral Nutrition_, sponsored by Kate Farms
- **Wednesday, June 23** — _Managing Gastroparesis_, sponsored by Coram/CVS specialty infusion services
- **Thursday, June 24** — _Short Bowel Syndrome_, sponsored by Takeda
- **Friday, June 25** — _Striving for a Healthier YOU...with Information, Coping, and Connecting with Others_

**Enjoyable evening events planned, too! All times are EDT.**

- **Thursday, June 24** — _Jammin’ Jammies_, 6:30 p.m.—8:00 p.m., sponsored by Abbott
- **Thursday, June 24** — _Young Adult Event_, 6:30 p.m.—8:00 p.m.
- **Friday, June 25** — _Happy Hour_, 4:15 p.m.—5:15 p.m.

**Please share your ideas for conference presentation topics, speakers, activities, etc. with Joan Bishop (bishopj@amc.edu) and Andrea Guidi (andreaguidi.oley@gmail.com).**

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**Why YOU Should Attend a Webinar, Mini Meeting, or Conference**

**Consumers**

Proven Benefits to Patients in Contact with Oley

- Lowers the incidence of catheter-related sepsis
- Reduces reactive depression
- Significantly improves quality of life
- Gives members the tools and confidence they need to manage their therapy
- Enables members to achieve normalcy in their lives
- And More!

- Learn to express your health care needs with assurance
- Access the latest information on nutrition support
- Meet (albeit virtually) others on home tube feeding and/or IV nutrition

**Clinicians**

Unique Opportunity to Learn from Expert Colleagues and Patients

- Learn best management practices for home parenteral and enteral nutrition
- World class speakers
- Unique opportunity to learn from consumers who have managed their own parenteral and/or enteral nutrition for five, ten, even twenty-plus years!
- Become a better resource for your colleagues and patients

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**Oley 2021**

_A Virtual Experience_

**The Nutrishare Neighborhood**

Is our educational platform and your opportunity to interact with other consumers and caregivers. Join us as we learn, chat, and discuss all things HPN with friends.

**ZOOM**

All HPN consumers and caregivers are welcome!

Join at: www.hpnzoom.com

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(518) 262-5079 • LifelineLetter — 5

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**Community Enrichment, from pg. 1**
Calling All Caregivers—Chance to Win $250!

We are appealing to all of the caregivers in our database to answer the questions below to help us update our member records. Respond by June 1 and be entered into a drawing to win $250 gift card!

When we communicate with our members, we want to send the right information to the right people. We send out FDA alerts, free samples, invitations to events and focus groups, and more, based on the nutrition support consumer’s therapy type, age, etc. Further, we use our membership data when we appeal to the FDA or Congress on behalf of our members. And accurate numbers help us attract grant funding.

Contact Cathy at (518) 262-5079 or harrinc@amc.edu with your responses to these questions—by June 1 to be entered in the drawing!

- Your name and email address
- Your phone number
- Patient’s name (first and last), and patient’s date of birth
- Patient’s therapy type (HEN, fed through a tube in the stomach; HPN, IV nutrition directly into the bloodstream; HPEN, both; or oral nutrition)

Not sure you are in our database as a caregiver? Call Cathy in the Oley office for help at (518) 262-5079!

A Rare Award

We’ve got good news to share! Mary Wootten, an Oley Foundation program associate and Ambassador and a National Organization for Rare Disorders (NORD) Rare Action Network Volunteer Ambassador, will be receiving a Rare Impact Award for her work as a patient advocate.

“Despite the pandemic and the challenges we have faced, there are still heroes to be found among us from whom we can draw inspiration and motivation to keep moving forward,” said NORD President and CEO Peter L. Saltonstall, in announcing the awards. “We’re humbled to work alongside them and appreciative of their tenacity and commitment to a brighter future for our community.”

Mary and the other award recipients will be honored for their exceptional work benefiting the rare disease community in a virtual awards program streaming on June 28, 2021, at 7:00 p.m. EDT. More information is available on NORD’s website, www.rarediseases.org.
Feeding Tube Awareness Week Recap

Thanks to everyone who participated in Feeding Tube Awareness Week this year! Please visit www.oley.org/FT_Awareness_Week for a full recap of the week, including more of the photos we shared on social media, and links to the videos and other resources that were shared with us.

Watch (and share!) the Oley Feeding Tube Awareness Week video on the Oley Foundation YouTube channel (www.youtube.com/user/TheOleyFoundation).

Watch (and share!) a recording of our Feeding Tube Awareness Week webinar, “Getting Comfortable with a Feeding Tube,” with Natalie and Mary Wootten, HEN consumer and caregiver; Luke Vohsing, RN, HEN consumer; and Nancy Pickett, HPEN consumer, also on the Oley YouTube channel.

Our thanks to Oley member Nancy Pickett for the outstanding job she did creating videos and social media content for our Feeding Tube Awareness Week campaign, and executing her plan for sharing them.

Researchers poured sample BTF through a stack of sieves in descending order, with the largest on top, to determine particle size.

To go through a feeding tube, BTF must be the proper consistency and particle size.

Ability of five commercial blenders to adequately blend food used for blenderized tube feeding. To be administered through a feeding tube, the BTF must be the proper consistency and particle size.

For our study, five different BTF recipes were prepared using the following brands of blenders: Oster Blender, Cuisinart food processor, Magic Bullet, Mega Kitchen-Ninja System, and Vitamix. Each recipe was blended for 3 minutes and then for 6 minutes. A sample was taken at each interval and tested using sieves of various sizes (4.75 mm, 4.00 mm, 3.35 mm, 2.8 mm, 2.36 mm, 2.00 mm, 1.70 mm, 1.40 mm, 1.18 mm, 1.00 mm, 850 microns, 710 microns, 500 microns, 250 microns).

First, each sieve was weighed dry on a scale. Next, one cup of each BTF recipe was poured on the stack of sieves in descending order, with the largest sieve on top. Each sieve was then weighed with the BTF that would not pass through.

For recipe 1 (1500 kcal nutritionally complete recipe): the Vitamix was better at blending the food at both 3 and 6 minutes, compared to all the other blenders.

For recipe 2 (600 kcal breakfast meal with high amount of liquid): there was no statistical significance between the Vitamix and all the other blenders.

For recipe 3 (500 kcal nutritionally complete dinner meal): when compared to the other blenders, the Vitamix was only statistically superior to the Oster blender at 3 and 6 minutes (p=0.0003/0.0022) and the Magic Bullet at 3 minutes (p=0.0001).

For recipe 4 (1000 kcal nutritionally complete recipe): the Vitamix was statistically better at 3 minutes than the Oster blender (p=0.0140).

For recipe 5: the Vitamix was statistically better than the Oster blender at 3 minutes (p=0.0035) and the Cuisinart food processor at 3 minutes (p=0.0289).

When each blender was compared against itself at 3 and 6 minutes, using all recipes, the Oster blender was significantly better at 6 minutes (p=0.0450) for recipes 1 and 3. The Vitamix was significantly better at 6 minutes (p=0.0140) for recipe 5, and the Magic Bullet was better (p=0.0001) in recipe 3. There was no statistical difference in the other devices between blending for 3 minutes vs 6 minutes.

Overall, the Vitamix seems to lead to smaller particle sizes compared to other blenders, for thicker recipes, with the exception of the Mega Kitchen-Ninja System. There seems to be little benefit in increasing blending time, unless using the Oster blender.
good, and I felt that perfect rhythm return as I hit the ball and watched it soar through the uprights. We had won the game, 41-38, and I had capitalized on my second chance.

**Fighting to Stay in the Game**

I often think of that game as a picture of my life. Two years earlier, I had also gotten a second chance. In that case, it was to live when many did not think I would survive (including me).

Two years into my NFL career, I suddenly began experiencing severe stomach cramps and bad diarrhea along with fever. I thought I had the flu, but my symptoms worsened. I saw a doctor and was diagnosed with Crohn’s disease. Although statistically I was kicking well, my illness was progressing and soon, instead of thinking about trying to make it to the Super Bowl, I was just trying to survive to the end of the season. I was in constant pain; I was hardly able to button my jeans and could just barely endure lacing up my football pants.

Like most inflammatory bowel disease (IBD) patients, I quickly made the connection between eating and the onset of pain...so I stopped eating. As I continued to lose weight and strength, I went from worrying whether I would have the strength to make a long field goal to worrying if I could survive the pain until the next week.

I was determined to keep playing, so the team doctors presented me with an unconventional plan. I would play the game on Sunday afternoon, then be admitted to the hospital and stay there all week while receiving TPN (total parenteral [IV] nutrition). I’d be released from the hospital on Saturday afternoon to spend the night in the team hotel, play the game the next day, and then head back to the hospital for another week.

I’ll never forget that first Sunday after the game when I was admitted to the hospital to receive my first TPN treatment. I was laying on a stiff white sheeted gurney with my head hanging off the end while the nurse struggled to locate a vein in my neck. Soon blood was spurting everywhere; it was like a garden sprinkler had gone off, until the line was finally in place. I returned to my room, wearily dragging my IV pole and wondering what the world I was going to do all week. Determined to stay in shape, I faithfully performed sit-ups and push-ups on the cold linoleum floor while being careful not to dislodge my line. The TPN treatment allowed me to finish out the season and I was incredibly grateful for that...but my problems were just beginning.

**Bad Start to a New Season**

I entered my third season still struggling with my health. The Chargers were pre-season favorites to go deep into the playoffs, and I desperately wanted to be on the team. After our first win, while my teammates celebrated, I sat in front of my locker fighting back tears from the excruciating pain and my fear of the future. Would I let the team down? Would the doctors make me stop playing? And, the most terrifying question of all, would I survive fifteen more games?

The clear answers to my questions came just three weeks later, when I collapsed on the team plane returning from a game against the New England Patriots and “woke up” to my teammates huddled around me, pressing cold compresses to my forehead hoping to lower my raging fever. When the plane landed back in San Diego, I was taken to the hospital, where they performed an emergency surgery to remove part of my colon. Due to complications, I had to undergo a second emergency surgery six days later. When the fog of the anesthesia had cleared, and I woke up in the recovery room, I was 65 pounds below my playing weight, with two ostomy pouches attached my sides, wishing I had died.

When I was finally released from the hospital nearly two months later, I was bitter and discouraged and angry. My abdominal incision was held together by metal wire sutures that reminded me of barbed wire as they sliced into my tender skin. Being back in the care of my parents was depressing and I shuffled around the house, bent over like an eighty-year-old man just barely able to walk unassisted. From my perspective, EVERYTHING I enjoyed about life had been taken from me and the question that haunted me day and night was, “Why me?”

**What Now?**

Since I couldn’t do much in the way of physical activities, I had a lot of time for reading and self-reflection. I was drawn to the plight of prisoners of war (POWs) in Vietnam. I began to read about and study the strategies they had used to survive incredibly horrific conditions that made my ostomy surgery look
like a walk in the park. I decided to apply what they had done to my current situation and focus on taking my life just one day at a time. I couldn’t worry about next month, next week, or even tomorrow. As the days passed and my health stabilized, I slowly began to do a little more each day. Over time, I found my feelings began to shift as I came to accept the situation God had given me. The question “Why me?” turned into “What now?”

Although I believed I was never going to play professional football again, I was still under contract with the Chargers, and they allowed me to recuperate at the team facility under the watchful eyes of the trainers. Having lost one-third of my weight and weighing only 125 pounds, my fitness level was pathetic. I could barely curl a 2-pound dumbbell and walking the length of the football field seemed like running a marathon.

Over the next six months, however, with my diseased colon gone, I began to recover. I steadily gained my weight back. My walking progressed to jogging, then running up and down the stadium steps and sprinting on the field in full-blown workouts. By June I weighed 180 pounds and was feeling strong and fit.

One day falteringly asked the team trainer, “Do you think I might be able to kick again?” He stared at me incredulously and said, “Of course you can kick again! What do you think we have been doing all of this training for?” With that, he grabbed a bag of balls and trotted off to the practice field where I began drilling kick after kick until I proved to myself that I could do this again and that my ostomy bags would stay in place. Miraculously, I was able to earn my job back. I will never forget the euphoria I experienced as I booted the kickoff in our opening game just eight months after leaving the hospital.

Living Life Differently

After my surgery, I learned there are more than three million people in the country who live with Crohn’s disease or ulcerative colitis, and tens of thousands who face ostomy surgery every year—many of whom require TPN treatment at some point during their journey. I received hundreds of letters from patients who identified with my story and who were desperate for hope that they, too, could return to doing the things they enjoyed in life after their own ostomy surgery. Each story I heard was humbling and inspiring and I quickly realized that I needed to try to do something to help others believe that there was life after ostomy surgery…an abundant, fulfilling, and happy life.

I started a program to help uncover the many stories of courageous ostomates. There were police officers, firefighters, marathon runners, triathletes, mountain climbers, beauty pageant winners, and so many others, who refused to accept the parameters of the “restrictive lifestyle box” we ostomy patients think we would be relegated to for the rest of our lives. For the last forty years it has been humbling to work alongside the heroic wound, ostomy, and continence (WOC) nurses and encourage thousands of patients to destigmatize this life-saving surgery. I’ve learned that nothing brings me more joy than connecting with someone facing a difficult health challenge and helping them move from asking “Why me?” to “What now?” as they return to the life they had prior to their surgery.

Whether you have an ostomy and/or live with home parenteral and/or enteral nutrition (tube feeding) (or love someone who does), I hope you know that you are not alone! We understand what it is like to wonder if life is worth living after ostomy surgery, or if you are facing other health challenges. And we also know that there is an opportunity to become changed (for the better) from the experience…but the choice is always up to us.

Through the ongoing work of the Oley Foundation, the United Ostomy Associations of America (UOAA), and other organizations, there are people out there who want to help, and resources. For most of us, the second chance we have been given allows us to live life differently, appreciating the incredible gifts of the people who love us, the days we have been given, and the health that has been returned. Those gifts are priceless.
Thank You Corporate Partners!

Please join Oley in thanking the companies that provide unrestricted grants to support the foundation year round. Funds from our corporate partners help Oley offer programs free of charge even as we continue to grow. We have more than 24,000 members now! Learn more about our most recent corporate contributors in their own words below. Welcome 9 Meters Biopharma, our newest partner!

For a complete list of corporate partners, including a brief description and a link to their websites, go to www.oley.org/PartnerShowcase.

Takeda
Takeda is a global, values-based, R&D-driven biopharmaceutical leader headquartered in Japan, committed to bringing better health and a brighter future to patients by translating science into highly innovative medicines. Visit www.takeda.com.

9 Meters Biopharma, Inc. NEW!
9 Meters Biopharma, Inc., is a rare and unmet needs-focused gastroenterology company that is advancing NM-002, a proprietary long-acting GLP-1 agonist into a Phase 2 trial for short bowel syndrome, as well as larazotide, a Phase 3 tight junction regulator being evaluated for patient-reported symptom improvement in non-responsive celiac disease.

Coram/CVS specialty infusion services
CVS Specialty and Coram provide personalized, compassionate, high-quality infusion care to patients where they live, work, or travel. With more than thirty years of experience and nearly 1,200 skilled clinicians, Coram/CVS specialty infusion services leads with commitment from the heart. The company maintains a 96 percent patient satisfaction rating.

Cardinal Health, Inc.
Cardinal Health, Inc. is a global, integrated healthcare services and products company, providing customized solutions for hospitals, healthcare systems, pharmacies, ambulatory surgery centers, clinical laboratories, and physician offices worldwide. The company provides clinically proven medical products and pharmaceuticals and cost-effective solutions that enhance supply chain efficiency from hospital to home.

Kate Farms
Kate Farms makes plant-based formulas for oral and tube feeding. Its formulas are free of gluten, soy, dairy and corn, and contain no artificial flavors or colors. The formulas provide balanced, ready-to-use essential nutrition and are appropriate for ages one and up; coded to be covered under insurance.

Option Care Health
Option Care Health is a leading provider of home infusion services for nearly forty years. Local, highly experienced teams of pharmacists, nurses, and dietitians provide high touch, comprehensive nutrition support to help prevent and treat malnutrition. Option Care Health supports consumers through its ninety infusion pharmacies across the country.

Optum Infusion Pharmacy
Optum® Infusion Pharmacy provides customized care to those on home parenteral nutrition with infusion pharmacists, nurses and dietitians who are Certified Nutrition Support Clinicians. The program offers clinical standards utilizing current ASPEN guidelines, education and patient liaison support. You can count on Optum for guidance, education, and compassionate care.

Avanos
Avanos is a medical device company focused on delivering complete enteral feeding solutions, from every stage, every age, all in one place. The company develops, manufactures, and markets recognized brands in more than ninety countries. Its recognizable brands are MIC-KEY®, CORTRAK®, FARRELL®, CORGRIP®, MIC® PEG and other enteral feeding accessories.

Nestlé Health Science
Nestlé Health Science is engaged in advancing the role of nutrition to change the course of health for consumers, patients, and its partners in healthcare.

Applied Medical Technology, Inc. (AMT)
AMT is a global manufacturer of enteral feeding devices, cecostomy devices, and accessories. Its products include: MiniONE® family of low-profile g-tubes, traditional-length g-tubes featuring its Capsule Technology, G-JET® family of gastric-jejunal feeding tube, MiniACE® low-profile antegrade enema button, CINCH® tube securement devices, and AMT Bridle™ family of nasal tube retaining systems.
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 January 21, 2021–March 24, 2021.

Memorials:
In memory of Beverly Akers; Michael Aklufi; Fran Culp; Kathy Erdman; Zoe Allison Caulder Hartley; Margaret Kruger; Donald Lacey; Mary Patnode; Steve Saffren; Dr. Barry and Mrs. Sharon Sakowitz

Tributes:
In honor of Mandy Allen; Hadar Birger-Bray; Rick Davis; forty years on HPN; Aidan Koncius; Jeff Nemeth

Matching Gifts:
Johnson & Johnson; Texas Instruments

Fundraisers:
AmazonSmile Foundation; Facebook: Tiffany Dodd’s, Becky Reil’s, and Emily Kratz’ birthday campaigns

Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.

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

TITANIUM LEVEL PARTNER
($150,000+)
Takeda Pharmaceutical

GOLD MEDALLION PARTNER
($50,000–$69,999)
9 Meters Biopharma

SILVER CIRCLE PARTNERS
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Coram / CVS specialty infusion services
Nutrishare, Inc.

BRONZE STAR PARTNERS
($20,000–$29,999)
Abbott
Baxter International Inc.
Cardinal Health, Inc.
Fresenius Kabi USA
Kate Farms
Option Care Health
Optum Infusion Pharmacy
Zealand Pharma

BENEFACCTOR LEVEL PARTNERS
($10,000–$19,999)
Avanos
Baxter International Inc.
Cardinal Health, Inc.
Fresenius Kabi USA
Kate Farms
Option Care Health
Optum Infusion Pharmacy
Zealand Pharma

PATRON LEVEL PARTNERS
($5,000–$9,999)
Applied Medical Technology, Inc.
Cook Medical
MOOG Medical
Soleo Health

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

Felice Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Dale & Martha Delano
Tom Diamanditis, PharmD
Gail Egan, MS, ANP
Selma Ehrenpreis
Herb & Joy Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
Deborah Groeber
The Groeber Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD, PhD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Joyce Madden
Hubert Maiden
Laura Matarese, PhD, RD, LDN, CNSC, FADA, FASPEN
Kathleen McInnes
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 B. Riefer
Roslyn & Eric Scheib Dahl
Susan & Jeffrey Schesnal
Doug Seidner, MD, FACC, CNSP
Judi Smith
Steve Swenssen
Cheryl Thompson, PhD, RD, CNSC, & Gregory A. Thompson, MD, MS
Cathy Tokerz
Eleanor & Walter Wilson
Marion & Larry Winkler
James Wittmann
Patty & Darrell Woods
Rosaline Ann & William Wu

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## 2021 Oley Calendar

COVID-19 has changed how we meet and exchange information. Many of the conferences we usually list in our calendar have been moved to a virtual platform. Dates and venues for events in 2021 are, in some cases, still undecided. Please check www.oley.org or other appropriate websites for the most up-to-date information.

### Ongoing:
Applications being accepted for Oley Tim Weaver Camp Scholarship. Note: scholarships will be honored at a later date in the event of a coronavirus complication (i.e., camp closures, COVID-19 illness, self or mandatory quarantines, etc.).

### April 15:
Oley Tube Feeding/TPN Support Group for Patients and Caregivers, virtual*

### April 19–22:
Oley exhibiting at National Home Infusion Association (NHIA) conference, virtual

### April 29:
Oley Kidz Klub, virtual*

### April 30:
Oley Mini Meeting (see page 1)

### May 3 (and then the first Monday of every month):
Young adult support group, virtual*

### May 6 (and then the first Thursday of every month):
Philadelphia Suburbs Tube Feeding/HPN Support Group, virtual*

### May 19:
Oley webinar “Interview with Allysia Seely, Team USA paratriathlete on HPN, and her dietitian, Jacque Scaramella” (see page 5)

### May 20:
Oley Kidz Klub, virtual*

### June 21–25:
Oley 2021: A Virtual Experience (see page 5)

### June 26–27:
Oley participating in NORD, Living Rare, Living Stronger, virtual

### July 13:
Oley webinar “Motility Disorders Discussion with Dr. Carlo Di Lorenzo” (see page 5)

### October 11–15:
HPN Awareness Week

*For more information on support group and Kidz Klub meetings go to www.oley.org/SupportGroups; for other meetings email harrinc@amc.edu or call (518) 262-5079.

### Additional Meetings of Interest

### May 21–23:
Digestive Disease Week, virtual

### June 7–10:
Nutrition 2021 (American Society for Nutrition conference), virtual

### June 23–26:
United Mitochondrial Disease Foundation (UMDF) conference, Charlotte, NC

### June 30–July 3:
Congress of the Intestinal Rehabilitation and Transplant Association (CIRTA), Auckland, New Zealand

### July 10–13:
Nutrition 2021 (American Society for Nutrition conference), Boston, MA

### September 16–19:
AVA 2021, Orlando, FL