Bidding Farewell, Welcoming Oley Officers

The Oley Foundation would like to welcome the Board of Trustee's new Executive Committee, including Beth Gore, who has been elected president, and would like to extend thanks to Bob and Mary Smithers, former co-presidents, and others who have rotated off the board.

New Officers
Beth Gore, PhD, MBA, who joined the Oley Board of Trustees in 2016 and formerly served as vice-president, has been elected president. Beth is a national patient advocate with a background in training, communication, and business. She works for the Association for Vascular Access (AVA), collaborating with other organizations to help provide safe vascular access and heading up AVA's Patient Education and Advocacy Committee. Beth is also

Advocacy Updates

Your voice matters in legislative and regulatory issues—and you don't need to travel to Washington, D.C., to use it. Understanding the importance of educating policy makers and regulators and developing your advocacy skills are the first steps in becoming an effective advocate.

Two years ago in this newsletter, Oley Ambassador and board member Joy McVey Hugick eloquently wrote,

Oley members constitute a community of sophisticated consumers, caregivers, and clinicians who can communicate the home parenteral and enteral nutrition (HPEN) consumer experience incredibly well. While we may differ in our diagnoses, we are united by HPEN therapy and we all face challenges regarding access to care and availability of treatment options. Participating in Oley's advocacy efforts is a great opportunity to have our voices heard and allows us to play an important role in the public policy process. By translating for decision makers how their policies impact our day-to-day lives, we can help inform them to improve access to, and reimbursement for, our national health care system.

A Lifelong Journey

Swapna Kakani

I was born seven weeks premature, and shortly after was diagnosed with multiple intestinal atresias (which led to short bowel syndrome). I was immediately transferred to Children's Hospital of Alabama, where I had my first surgery as a two-day-old baby. In the same surgery, I received a central line in my chest and a gastrostomy tube (G-tube) in my stomach, becoming dependent on parenteral and enteral nutrition (HPEN, or IV nutrition and tube feeding).

In my twenty-eight years, I have had sixty-five surgeries, including over thirty central line placements, a Bianchi lengthening surgery, a STEP lengthening surgery, and, most recently, four years ago, an isolated small intestine transplant. The goal from the beginning was for me to be free of IVs and tubes.

School Days
Growing up, I was determined to live a life similar to the lives my peers were living, although my daily routines were starkly different. From kindergarten through college, I went to school with two backpacks—one for my school books and one for my enteral (EN) feeds. In the evenings, unlike my peers, I would end the day by hooking up to my parenteral nutrition (PN) and EN

Swapna has been dependent on nutrition support her whole life.
You Don’t Know What You Don’t Know

Central Line Repair Kits
Michelle Barford

Many times, those who are going to have a line placed for the administration of home parenteral (IV) nutrition (HPN) do not know what to ask, or don’t have time before the line will be placed to consider what their questions might be. Too often the line placement is done due to an emergency, and the only things you want to know are: (1) How is this going to affect my situation?; (2) How long will I need to be in the hospital?; and (3) What more do I need to learn?

You are told you need to have a central line placed and what type of line you’re going to have, and arrangements may have already been made for the placement, which is often done in interventional radiology (IR). This can be at a hospital or a physician’s office that has its own IR department. It can also be done in the operating room (OR).

When you have a central line placed, a number of considerations need to be made beforehand. These include the type of line and the location of the exit site. Other considerations include how active you are and whether you need to have more than just HPN infused. Another consideration should be whether the line is repairable, or if it will have to be replaced if it fractures or becomes occluded. Whether HPN is new to you or you are “just” getting a new line placed, there are certain parts of this scenario that you need to beware of:

1. If there is enough time, you should be able to have a voice in all of the considerations mentioned above.
2. There are tunneled central lines that can be repaired. This means that if they fracture or break, they may be able to be repaired instead of being replaced. This is so much better for you because (a) repairs to a central line may be done in your doctor’s office or the emergency department (ED); and (b) when you have a central line removed, the vein may be damaged or can collapse, making it unusable in the future, which will limit your options for future line placement. You should discuss your central line options with your health-care provider.
3. If your central line can be repaired, your infusion company may be able to provide a repair kit for you. There may be an extra charge for you if it isn’t covered in the “per diem” they receive for your HPN supplies. You can appeal this decision if there is an out-of-pocket expense.
4. There are several different kinds and brands of central lines available, including Broviacs, Hickmans, Groshongs, PICCs, and ports. One thing they all have in common is the need for you to obtain additional knowledge beyond what’s offered at the doctor’s office and hospital.

Remember that you will have your hands full dealing with getting a central line placed and definitely will need the support of family and friends to assist you in learning all there is to know about your new line. Organizations like Oley can assist you and your caregiver in obtaining information about HPN, your central line, and the care of your central line. Even if you’ve had one before, receiving a new line will require you to reacquaint yourself with what the aftercare of the new line is, so you won’t overlook something important!

Most important of all, know that YOU ARE NOT ALONE!
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.

Tips for Declogging a Tube

These tips and reference images come from Cynthia Reddick, RD, CNSC, who presented information about tube feeding at the 2018 Oley Consumer/Clinician Conference.

**Push-Pull Technique:**
1. Fill a 60 ml syringe halfway with warm water.
2. Connect the syringe to the feed port of the feeding tube.
3. Grasp the end of the plunger and gently rock it back and forth as you first pull it out, then push it into the barrel of the syringe in an effort to loosen and dislodge the clog in the tube.
4. Take a break as needed, then try again. Work on it for a few minutes. It may take some time and patience.

**Med Port Technique (for tubes with med ports):**
1. Fill a 6 or 10 ml syringe halfway with warm water.
2. Connect the syringe to the smaller med (medication) port of the feeding tube.
3. Gently and slowly attempt to flush the med port with the water.
4. Do not force the flush or attempt a “power flush.”
From the Desk of Joan Bishop, Executive Director

’Tis the Season

As we approach the end of the year, it is always gratifying for me to look back and remember some of our accomplishments during the year and to give thanks. The Oley Foundation’s success is possible only because of our members and their exceptional generosity!

- **Members** are always willing to help us help others by providing input on requests that come to us regarding personal challenges, coping issues, sending kids off to school, and so on. The peer-to-peer support is unmatchable!

- **Corporate Partner donations and gifts from individuals** are very generous and provide the financial underpinning that keeps us financially healthy and in forward-thinking and planning mode. The above-and-beyond support to meet the needs of our members is overwhelming. It’s hard to find words to express our gratitude.

- **Contributors to our annual and regional conferences, webinars, and newsletter** deserve a huge nod for their willingness to share their expertise and experience and help attendees and readers understand what’s new and what contributes to “living better” while on home parenteral and/or enteral nutrition (HPEN) or caring for a loved one who is on HPEN.

- We thank the many **volunteers who staff Oley exhibit tables** at meetings across the country, giving us exposure to professionals who can then share Oley information with HPEN consumers—increasing opportunities for others to join Oley, to share and benefit.

- **Oley Equipment-Supply Exchange Program volunteer coordinators** Betty Marie Bond and Robin Bodnar give tirelessly throughout the year handling thousands of requests from those who are underinsured or uninsured in search of tube feeding and related supplies. Their energy and enthusiasm for helping people is remarkable. We couldn’t run this program without them!

- Being thankful includes a nod to the wonderful **Oley Board of Trustees** who provide us with direction and support and the fantastic **Oley staff** who go above and beyond to meet the needs of each and every Oley member.

Our goals for 2019 are energetic! We are planning for an annual conference offering CME’s, more regional meetings (with the first to be held in Dallas, Texas, on February 9), additional webinars, outreach activities, Oley presentations at professional meetings, the sharing of Oley slides with our community to increase exposure, and more. Stay tuned to the Oley calendar and your email for notifications! Be sure to keep your contact information updated in our database. Need help? Visit www.oley.org/page/help.

Excitement builds as we approach the 20,000th-Oley-member mark. It’s mind-blowing, especially for those of us who were here when we were serving a community of 300 members. Wow, have things changed!

We can only hope to be the recipient of your kindness and generosity again next year. Whether you can write a check or share a talent, we need your support. We simply cannot do what we do without you.

On behalf of all of us here at Oley headquarters, I send the most sincere best wishes for a wonderful holiday season and all of the best in 2019!
Reach Out and Touch Someone

Lynn Wolfson

We all want to feel like valuable members of our community. However, many times we are held back by personal issues, lack of time, or just a complete lack of knowledge on how to contribute to help others. Those who have not had the experience may not know the emotional elation that one gets by helping others.

Let me tell you a little about myself. I was born with a genetic disease that prevents my digestive track from functioning as it should. Consequently, I am fed through my heart (with home parenteral nutrition), I defecate in a bag glued to my abdomen (my ostomy), and I catheterize to urinate four times a day. It took me years to accept and learn to take care of all of this medical equipment on my own. However, once I accepted, learned, and had my independence back, I wanted to give back to my community.

Getting Involved

I started by participating in my local ostomy support group. I attended national ostomy conferences and met many people who also had ostomies. I then joined the Digestive Disease National Coalition (DDNC) in Washington, DC, and learned how to lobby for bills that are needed for the digestive disease community on Capitol Hill. There I met many people active in the digestive disease community, and learned of and joined the Oley Foundation.

After several years of attending national conferences with the United Ostomy Associations of America (UOAA), the Oley Foundation, and DDNC, I decided to create my own support group. I named it the Weston Ostomy Tube Feeding Group. The group meets monthly from August to May (in Weston, Florida) and discusses issues that are important to people with ostomies and/or who depend on enteral and/or parenteral nutrition.

Local Opportunities

Then I decided I wanted to help my local community. I started going to the Jewish Community Center (JCC) and learning how to knit hats for cancer patients. I had not knitted since I was a little girl. I was not too optimistic since I have tremors. However, the ladies in the group taught me how to knit on a loom. I now make beautiful hats that I donate weekly to cancer patients. I was really feeling proud of myself.

One week there was a senior fair in the ballroom at the JCC while I was in my knitting group. I took a break from my knitting to go and check it out. While walking around the fair, I saw “Jet Express” and I stopped and asked about it. I was told this is a service the Goodman Jewish Family Services provides to seniors for $100 a year. The service is to pick up seniors and bring them to medical appointments, shopping, or social engagements. They needed volunteers to pick up these seniors. This sounded like fun to me. I called Pam at Jet Express and signed up.

Since signing up, I have enjoyed taking seniors to medical appointments, the beauty salon, and shopping, and just spending the afternoon with them, going wherever they would like. I find the seniors so interesting. I visit with one senior who has lived in Florida since the 1950s and she tells me what South Florida was like when she first came.

Some seniors are here alone. Their children live out of state and they are lonely. I take one senior out to lunch weekly. I find I learn so much from these seniors and I bring them home so happy. As happy as they feel, I always feel happier that I could do this for them.

I then found out about the Cupboard, a kosher pantry that services individuals or families who cannot afford groceries and Holocaust survivors. The Cupboard is also part of the Goodman Jewish Family Services. I go to the Cupboard weekly to take grocery orders from the clients and help deliver the groceries. Since I cannot carry due to my medical equipment, I have a partner who can carry the groceries when I am delivering. I do the driving. Again, I really enjoy meeting and talking with all the clients. They are so appreciative of everything we do for them!

Many of the clients who are having a difficult time—emotionally, physically, or financially—are so elated when they see us, as they know they are not alone. I know for myself that each one of us was given a “deck of cards” in life and no one has received a perfect deck. We all have “rotten” cards. Those people that can overcome these “rotten cards” will be the most successful and happiest. However, as humans, we all need a hand helping us to overcome our individual challenges.

Once we can master our personal challenges, there is no greater joy than giving back to others. Helping others helps each of us to love life even more and appreciate our individual gifts. Life is a matter of attitude. Those with a positive attitude can not only overcome their own challenges, but also help others do the same.
Nominate Someone Who Inspires You!

The five awards Oley will present in 2019 recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone today at www.oley.org/nominations. Alternatively, you can use the form below as a guide when submitting your nomination(s).

Nominations must be received by March 15, 2019. Please notify the person that you are nominating them for the award.

Awards will be presented at the conference, to be held June 21–24 in Lincolnshire, Illinois. Winners will receive a $750 grant to attend the meeting, and will be spotlighted in the LifelineLetter. Recognition is given to all nominees.

The Awards and Criteria

Innovator/Advocator Award
- Current home enteral nutrition (HEN) consumer or caregiver for one year or longer, OR Current home parenteral nutrition (HPN) consumer or caregiver for one year or longer
- Any age
- Sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care

LifelineLetter Award, HPN
Sponsored by Nutrishare, Inc., Silver Circle Partner
- Current home parenteral nutrition (HPN) consumer or caregiver for one year or longer
- 19 years of age or older
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN

LifelineLetter Award, HEN
- Current home enteral nutrition (HEN) consumer or caregiver for one year or longer
- 19 years of age or older
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN

Child of the Year Award
Sponsored by Kate Farms
- Current home enteral nutrition (HEN) consumer for one year or longer, OR Current home parenteral nutrition (HPN) consumer for one year or longer
- 18 years of age or younger
- Shows a positive attitude in dealing with illness and therapy which encourages and inspires others

Celebration of Life Award
Sponsored by ThriveRx, Gold Medallion Partner
- Current home enteral nutrition (HEN) consumer for three years or longer, OR Current home parenteral nutrition (HPN) consumer for three years or longer
- Any age
- Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.

HEN = home enteral nutrition = tube feeding
HPN = home parenteral nutrition = IV nutrition, TPN

2019 Oley Award Nomination

1. Provide the following information:
I am pleased to nominate the following individual for the:
- Innovator/Advocator Award
- LifelineLetter Award, HPN
- LifelineLetter Award, HEN
- Child of the Year Award
- Celebration of Life Award

Nominee’s name: ____________________________
Age: _____ Daytime Phone: (_____ ) _____ - ______
E-mail: ___________________ @ ______________________
Primary diagnosis: __________________________________
Number of years on HEN (enteral, tube feeding) _____ and/or
Number of years on HPN (parenteral, IV nutrition) _____
☑ I’ve notified this person that I am nominating them for an award.
Your name: ______________________________________
Daytime Phone: (_____ ) _____ - ______
E-mail: ___________________ @ ______________________

2. Tell us why you are nominating this person.
Cite specific examples of how the nominee meets the award criteria. Please limit length to one page (attach).

3. Submit nomination by March 15 to:
The Oley Foundation
Albany Medical Center, MC-28
99 Delaware Avenue
Delmar, NY 12054
Fax (518) 262-5528
E-mail andreaguidi.oley@gmail.com

Questions? Call (518) 262-5079
Noble Memorial Scholarship

In 2007, the Noble family established the Kyle R. Noble Scholarship to further the educational goals of individuals relying on home parenteral and/or enteral nutrition for their primary nutritional needs. Each academic year, a $2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered.

**Applicant Should Submit:**

1. Cover letter with name, address, daytime phone, email address, age, diagnosis, HPN and/or HEN, and years on therapy.
2. A one- to three-page essay wherein the applicant describes how he or she has overcome obstacles/challenges posed by HPEN and inspired others to live life to the fullest.
3. A letter from an advisor or teacher supporting applicant's educational pursuits.
4. A letter from a clinician or homecare company reflecting the applicant’s need for HPEN.
5. Applicants must submit their transcripts at the end of the semester of study in order to receive the second half of the scholarship amount.

**Deadline is March 15, 2019.** Details and application online at www.oley.org or call the Oley Foundation at (518) 262-5079.

Apply for HPN Research Prize

The Oley Foundation encourages researchers to apply for an HPN Research Prize. Oley will award $2,500 prizes to each of the top three clinical research papers best aligned with the foundation's mission to enhance the lives of HPN patients, and that generate interest among HPN patients and improve their well-being. A portion of each prize ($1,000) will be used to cover travel expenses to bring the winning prize recipients to the Annual Oley Consumer/Clinician Conference to present their research. We are grateful to Nutrishare, Inc., for sponsoring the prizes.

To apply, researchers must submit their abstracts to the Oley Foundation by **March 15, 2019.** The abstract must have been accepted for poster or oral presentation, or publication by a respected, relevant professional association such as ASPEN, ESPEN, INS, AGA, etc. between July 2018 and March 2019. For additional details and application go to www.oley.org/HPN_ResearchPrize. Questions? Email the prize coordinator at andreaguidi.oley@gmail.com, or call Andrea at (508) 460-1707 or the Oley office at (518) 262-5079.

Drawing All Talent

Got a knack for drawing? We’re looking for artwork from our younger members (eighteen and under) to be considered for the front of Oley greeting cards. Please submit no more than four designs per artist, along with a paragraph about the artist that could be used on the back of the card. We’ll ask our Advisory Council to help us select a variety for publication.

Submit to the Oley Foundation, 99 Delaware Ave., Delmar, NY 12054 or harrinc@amc.edu.
Officers, from pg. 1

an Oley Ambassador. Beth is the mother of six adopted children, one of whom, Manny, has been dependent on both tube feeding (enteral nutrition) and IV (parenteral) nutrition. We are excited she is willing to share her many strengths with us.

Joy McVey Hugick has been elected vice-president, after formerly serving as secretary. Joy has been on the board since 2016. After serving patient populations during her career in public health at the Centers for Disease Control and Prevention, Joy became a patient herself in 2010, when she had an acute onset of GI symptoms. Joy’s symptoms were diagnosed as post-viral gastroenteropathy, which caused severe dysmotility throughout her GI tract. After some time on parenteral nutrition, Joy was transitioned to tube feeding. She continues to rely on tube feeding for most of her daily nutrition. Like Beth, Joy is also an Oley Ambassador and is very active in our community.

Lillian Harvey Banchik, MD, FACS, CNSC, FASPEN, who joined the board in 2017, has been elected secretary. Lillian is a board-certified surgeon with a special interest and advanced certification in nutrition support. During her residency in surgery at Mt. Sinai in New York City, Lillian did research in nutrition at Memorial Sloan Kettering Cancer Center, investigating ways to minimize chemotherapy-induced gastrointestinal issues by changes in the diet. This research started her lifelong interest in nutrition support. Lillian has long been involved with Oley, and also with the American Society for Parenteral and Enteral Nutrition (ASPEN). Most recently Lillian has been actively involved in ASPEN’s Public Policy Committee.

Jim Senese, BS Pharm, served as Oley’s treasurer and as a board member from 1997 to 2001, and rejoined the board as treasurer in 2016. Jim has over thirty-five years of experience in the medical field with a broad background in practice management, operations, and medical sales. Jim is currently Director of Network Development for the Oncology Circle (a division of Flatiron Health), a data-sharing collaborative of best-in-class oncology practices, dedicated to clinical and operational excellence through the scientific collection and use of data. In 2014, Jim became a cancer survivor and a short-term (nine months) enteral nutrition consumer. He volunteers with a variety of non-profit organizations, in addition to Oley.

We are grateful to Beth, Joy, Lillian, and Jim for their willingness to serve on the Oley Executive Committee.

To learn more about these and other board members, visit www.oley.org/Board.

Giving Thanks

We’d like to take this opportunity to offer our sincere thanks to Bob and Mary Smithers, who together were elected to serve as co-presidents of the board. Bob and Mary served as Oley’s first couple on the board—“two people, one vote, no fighting,” as the board liked to joke. They have been part of the Oley community for many years, and we are grateful both for the service they have provided and that they will continue to stay close to Oley as Ambassadors and as members of the Oley Advisory Council.

We’d also like to thank Lynn M. Anderson, LL.D, for her service. We are grateful for the unique perspectives and insights each board member brings to the group.

Join Jana and her Oley friends in supporting Oley programs.

Don’t Forget Your Annual Donation

If you have sent your annual gift to the Oley Foundation already, thank you! If not, you can use the envelope enclosed in this issue of the newsletter; or donate through Oley’s secure online web portal at www.oley.org/donations/donate.asp?id=13882 (scan the QR code on right for a direct link).

Are You Missing Out?

If Oley doesn’t have your email address, you’re missing conference news, event invitations, HPEN FDA Alerts, and other timely updates. Remedy this today: email harrinc@amc.edu.
Thank You Volunteers for Putting Oley on the Map This Fall!

Ashleigh Bond (above), and her grandmother, Betty, spread the word about Oley to clinicians at the American College of Gastroenterology meeting in Philadelphia, PA, October 5–10.

Tiffany Dodd (right) and her partner Javier Ramirez graciously pitched in to help at the Rare New England meeting in Ayer, MA, on November 10.

Oley Trustee Shirley Huang, MD, speaking at the Oley regional conference in Waltham, MA, on October 6. Sixty-nine people attended. Thanks to ArTana, Shire, and ThriveRx for sponsoring this event.

Not Shown:
Oley Executive Director Joan Bishop and Executive Assistant Andrea Guidi networked with clinicians at the Association for Vascular Access meeting in Columbus, OH, on September 15–18 (after the Oley regional meeting in the same location). Joan also represented Oley at the Pediatric Intestinal Failure Symposium in Pittsburgh, PA, September 20–22.

Oley Editor, LifelineLetter, and Director, Community Engagement Lisa Metzger shared the HPEN consumer voice at the Digestive Disease National Coalition’s roundtable in Washington, D.C., on October 30. The discussion was focused on patient health-care access issues and will help inform the coalition’s 2019 policy agenda.

Rosaline Wu (above) and her husband, Bill, represented Oley at the Michigan Society for Parenteral and Enteral Nutrition (MSPEN) meeting in Novi, MI, on November 2.
feeding bags hanging on my personal IV pole. I received EN feedings from a low-profile G-tube sixteen hours a day every day for twenty years; and PN from either a Broviac or Hickman central line or a port for twelve hours a night three to seven times a week for twenty-five years and counting. Despite this extensive routine, I attended school just like my peers. It was my normal.

Every year, the routine would be interrupted with hospitalizations to treat the fearful central line infections. Thankfully, we were able to conquer both the bacterial and fungal culprits, and continue on with our normal. I graduated high school with a love for school, a commitment to community service, and experience as a member of our varsity tennis team. I made aces with my EN feedings running!

I went on to college, away from home, where I learned how to do my own health care while maintaining a demanding academic schedule, without the guidance of my parents. It was one of the best years of my life, physically, emotionally, and mentally. For the first time in my life, I learned how to eat more orally with the social help of my college roommates. Unfortunately, it was quickly evident that my gut could not take the stress of the extra oral intake along with the EN feedings.

After trying different regimens and going through a gut rehab program out of state, my family, the medical team, and I decided to try another modified STEP procedure. This time it would not be with my pediatric surgeon of twenty years, who had done all of my surgeries prior. It would be with a different surgeon, at a different center—my first time to transition from pediatric care to adult care. I was confident this would be my last surgery, and my last hospitalization.

However, the surgery resulted in several complications, and a two-year odyssey of surgeries, second opinions, and more complications, with four different surgeons at four different hospitals around the country. I was left with four fistulas connected from my small and large intestine and bladder to my skin at four different spots on the abdomen. Unfortunately, it was quickly evident that my gut could not take the stress of the extra oral intake along with the EN feedings.

Difficult Decisions

To have the best chance of the fistulas healing and future quality of life, in 2012 I made the hard and bold decision to have a total enterectomy—take out the small and large intestine—the same intestine my family and I had spent my entire life saving. After surgery, I was completely dependent on PN and IV fluids 24/7. My G-tube was no longer used for feedings, but was instead used as a 24/7 gravity drainage tube. Because I had neither a small intestine nor ostomy, I was not allowed to eat any solid food by mouth. I drank clear liquids that came out into my drainage bag or I chewed and spit out solid food.

Despite this new routine, I had quality of life, I had a new normal. For the first time in over a year, I was free of the burning fistulas. I was determined to finish college. I graduated one and a half years later with a bachelor’s degree in psychology (December 2013). With my HPN backpack on, I gave the commencement address.

I was twenty-four years old with a college degree and I received all of my nutrition from an IV. I could not eat solid food. I had quality of life, but I was starving to eat. I spent every free minute watching the Food Channel, reading food blogs, and cooking elaborate meals for my family and friends. That was my life. And medically, there was no getting better; instead, it was either staying the same or getting worse. We had exhausted all of our options. But, in my teens I had decided I would never lose hope, and I would never stop fighting.

After much consideration, a commitment to my faith, and an acceptance of the worst outcome—death—I made the decision to be listed for an isolated small intestine transplant at the Cleveland Clinic. I fortunately only waited fifteen days on the transplant waiting list. On June 18, 2014, I received a small intestine transplant. On June 19, 2014, I woke up for the first time in my life with a fully functioning small intestine and no G-tube! On July 3, 2014, I ate solid food for the first time in three years. In the last four years, I have had milestones I had only dreamed of, and disappointments I could not have anticipated.

Challenges of Eating and Advocacy

My family and I learned that due to my short bowel syndrome journey, I never truly learned how to eat and sustain myself on an oral diet of approximately 2,000 calories/day. It was only after the transplant, when I reached the milestone of no more IVs and tubes, that I realized I needed to learn the routine of how to eat.

Finding Comfort at Food-Centered Gatherings

If you cannot eat at a family or holiday gathering, or you cannot eat what’s being offered, that’s OK! My tip is to be honest with yourself and with others, and to plan ahead.

Be honest with what you can eat and be transparent in a kind way if others ask. I have found, when breaking bread with friends and family, people honestly want others to enjoy food and to see them content in whatever way that means for them. No one wants you to suffer.

If you can eat, but not anything offered on the menu, bring your own “safe” dish or dishes. I have gone to family gatherings on a clear liquid diet. We made soup for me and brought it to our family dinner in a small Tupperware container so I could have a “plate” at the table. Other times I have eaten a more substantial “safe” food meal at home and then snacked lightly at the party.

If you cannot eat at all, maximize your other abilities and roles. I have been to Thanksgiving without being able to eat but because I loved to cook, I baked a dish or I focused on bringing and playing games with my cousins. During the main meal and after grace was said, the family ate in groups so different members could sit with me away from the food.

—Swapna Kakani
What can I eat? What do I tolerate? What is hungry? What is full? When should I eat? With the help of a team of nutritionists and a supportive family, I am learning how to eat and how to sustain myself on the correct amount of calories and fluids. It is my new normal. For the first time, I do not have pain before, during, or after eating, like my normal growing up, and I am able to eat more food, in terms of both variety and quantity, in a day than I was ever able to before. The struggles currently are eating well consistently, absorbing what I eat with a permanent ileostomy, and staying hydrated with no colon.

My story is filled with joys and hardships. I am grateful for the fulfilling life I have been able to lead and the amazing people I have been able to meet on this journey. As a result, I have committed my life to health advocacy and to sharing my story to inspire others to lead a life with hope, determination, and perseverance.

I am a professional speaker and a health-care advocate. I travel around the country giving talks to nonprofits (including Oley), corporations, and medical associations for the purpose of improving health-care delivery and the rare disease patient experience. For example, a common topic I talk about is the importance of central line infection control from the patient perspective. I have also created a Facebook group for pre- and post-intestinal/multivisceral transplant patients (called the “Intestinal and Multivisceral Transplant Support Group”). This closed group, comprised of patients, caregivers, and family members, gives those who are exploring the transplant option an avenue for asking questions to people who have had intestinal/multivisceral transplants, as well as a support group to those post-transplant, because the journey can be unique. The group has strict guidelines and rules, and is closely monitored.

Most recently, I have been very involved in federal and state rare disease advocacy. Last legislative session, I, along with other rare disease advocates, helped get a joint resolution passed to create an Alabama Rare Disease Advisory Council. The council will advise and educate legislators on health policy and initiatives for the almost 500,000 people in the state who have a rare disease.

In the past two years, I created Alabama Rare, a grassroots support and advocacy coalition for the rare disease community in Alabama. We have hosted an annual Alabama Rare Disease Day awareness event at the state capitol, and worked with the governor to pass a law to name February 28 as Rare Disease Day in Alabama and February as Rare Disease Awareness Month. We also hosted the first annual Alabama Rare Disease Patient/Caregiver Symposium. To augment my passion and efforts, in fall 2018 I began graduate school for public health, studying health organization and policy.

Contact Me, I’m an Oley Ambassador

I am excited to expand my advocacy efforts as an Oley Ambassador, where I can continue to pursue my passion for health policy, improvements in health-care delivery, and the importance of speaking up in health-care settings. I have enjoyed meeting so many Oley members and look forward to meeting more. We can support and learn from one another! Please reach out to me with questions about living independently or going to school with HPEN, transplant, advocacy, health-care policy—or anything else. I can be reached by email at info@swapnakakani.com, Facebook, Twitter, or Instagram at @SwapnaSpeaks, or through my website, swapnakakani.com.

Coming Soon! Oley Foundation Regional Conference

February 9, 2019
9:30 a.m.–4:30 p.m.
Southern Methodist University
Dallas, Texas

Go to www.oley.org/event/Dallasregional to
• Register free of charge
• Apply for $200 Travel Grant
• Read information on topics and speakers
...or contact Andrea Guidi at (508) 460-1707, andreaguidi.oley@gmail.com.

With support from:
Recent Advocacy Efforts

What are the issues with which Oley is involved, and where do we stand on them? What motivates us as an organization to advocate for or against a certain bill or rule? How can you get involved? At any given time, a number of legislative and regulatory issues that could have an impact on Oley members are on the table—someone’s table, whether it’s the Food and Drug Administration (FDA), the US Pharmacopeia (USP), or another regulatory body; or a state or the federal legislature.

It’s sometimes difficult to understand how certain regulations or bills might affect different populations, and sometimes something that is good for one reason or to one population has drawbacks for another reason or to another population. Legislation and regulations are seldom simple! Given our small staff, Oley works closely with other organizations—including the American Society for Parenteral and Enteral Nutrition (ASPN), National Organization for Rare Disorders (NORD), Digestive Disease National Coalition (DDNC), the National Home Infusion Association (NHIA), and others—as we determine our priorities and positions.

Here are a few of the issues Oley is working on now, along with some possible actions you, as consumers, caregivers, or clinicians, can take. For more information and to stay updated, visit www.oley.org/HPEN_Drug_Shortages and www.oley.org/Legislation.

IV Drug Shortages

More and more often we are hearing about drug shortages. It’s on the news, in medical journals, and discussed by politicians. The causes and solutions being put forth vary and at this time there is little agreement about either. Oley has sought to offer information and updates to you, home parenteral and/or enteral (HPEN) consumers and caregivers, to help you be aware of the shortages and how they might affect you. Of particular concern to us are the shortages of parenteral nutrition (PN) components.

Some things you can do in regard to IV drug shortages include:

- If you’re a home PN consumer: Check the label on your PN solution to watch for changes and discuss any changes with your home infusion pharmacy and/or health care provider. Is the change due to a shortage? Is there anything you should know about or watch for in regard to the change?
- Let Oley know if you have been affected by drug shortages (PN components or otherwise), so we can speak up on your behalf when regulators, legislators, or the media come to us looking for concrete examples of how our members are affected.
- Look for opportunities to share your HPEN story with legislators and regulators; help them understand that HPEN is your lifestyle and why (an opportunity to submit comments to FDA is listed below).
- Watch “Drug Shortages: Focus on Parenteral Nutrition” by Kathleen Gura, PharmD, BCNSP, at www.oley.org/webinars. Dr. Gura examines why shortages occur, how they affect home PN, and what regulators and health-care providers are doing to minimize the impact on patients.
- If your health-care provider cares for only a few home PN consumers (or even just you), consider sharing ASPEN resources with them. ASPEN offers guidelines for clinicians on how they can minimize negative outcomes created by shortages of PN components. These guidelines, as well as updated information on the availability or shortages of PN components, can be found on the ASPEN website (www.nutritioncare.org/Guidelines_and_Clinical_Resources/Product_Shortages/Product_Shortage_Management and www.nutritioncare.org/public-policy/product-shortages).

FDA Needs Your Comments on Drug Shortages

Now through January 11, 2019, the FDA is accepting comments from patients, health-care providers, and members of industry about drug shortages (“Identifying the Root Causes of Drug Shortages and Finding Enduring Solutions,” Docket No. FDA2018-N-3272). They are asking, for example, about clinical and economic impact on patients, and whether shortages seem to occur in some areas (geographic, demographic, or clinical) or during certain times more than others. In November FDA had a meeting on this topic (see sidebar, next page).

We strongly urge you to submit comments. Share your stories and represent the patient voice. Please share your experiences with us, too, to increase our understanding and to help us represent you to the FDA and others.

Go to www.regulations.gov/document?D=FDA-2018-N-3272-0001 for more information and to post comments; or mail written (paper) comments to Dockets Management Staff (HFA-305), FDA, 5630 Fishers Lane, Rm. 1061, Rockville, MD 20852. Include the docket number and title (see above). Note that FDA will post these written comments on the website listed above. If you wish to submit a comment that contains confidential information, contact the FDA for instructions.

NORD’s State Advocacy Network

Mary Wootten, who both volunteers as an Oley Ambassador and works on staff as a program associate, has been selected by the National Organization for Rare Disorders (NORD) as their New York Rare Action Network (RAN) State Ambassador. RAN Ambassadors are volunteers who help build a strong grassroots network of rare disease volunteer advocates within their state.

Mary has three children, ages 6, 8 and 10, and her two older children have different rare diseases, as well as multiple other health issues. Mary says, “Today rare diseases are getting more attention than ever before, and we have a unique and exciting opportunity to help shape the conversation from the patient and caregiver perspective.”

Mary welcomes all state residents to share with her their experiences as rare disease patients and/or caregivers living in New York. She’d like to know what challenges you’ve faced, what resources or services you think might be useful to others, and if you’d like to get more involved in activities for the New York RAN.

Not in New York? Visit rareaction.org/resources-for-advocates/state-action-center to learn more about the program and your state’s RAN Ambassador. Consider volunteering if your state does not currently have a RAN Ambassador.

Rare Disease Day is February 28. “It’s right around the corner and we need your help!,” says Mary. Think about how you can participate today!
Reimbursement for Enteral Nutrition

It is surprising and discouraging to realize how often insurance does not cover enteral nutrition (tube feeding, or EN), even if it is the only source of nutrition a person receives. Paying for formula out-of-pocket can be a huge financial burden on families and individuals. The Medical Nutrition Equity Act (S.1194/H.R.2587) would provide for public and private insurance coverage for medically necessary foods for certain digestive and inherited metabolic disorders. It is hoped that once this bill is passed, it will pave the way for coverage of medical nutrition for additional diseases/disorders (such as swallowing disorders).

“Medical nutrition” here includes specially formulated and processed products used for the dietary management of individuals who have limited or impaired capacity to ingest, digest, absorb, or metabolize ordinary nutrients or who have other special medically determined nutrient requirements that cannot be sustained by the modification of an ordinary diet. It does not refer exclusively to EN administered through a feeding tube.

Digestive disorders covered by the bill include: inflammatory bowel disease (e.g. Crohn’s disease and ulcerative colitis); eosinophilic digestive disorders; food protein induced enterocolitis syndrome (FPIES); IgE mediated food allergies; and malabsorption due to liver or pancreatic dysfunction or short bowel syndrome.

Inherited metabolic disorders covered include: metabolic disorders on the Recommended Uniform Screening Panel Core Conditions list of the Secretary of Health and Human Services’ Advisory Committee on Heritable Disorders in Newborns and Children; and other genetic metabolic disorders requiring special foods.

The Oley Foundation has joined nearly forty other organizations in the Patients and Providers for Medical Nutrition Equity Coalition (PPMNE) to advocate for this bill’s passage. Other organizations in the coalition include ASPEN, American Academy of Pediatrics, American College of Gastroenterology, Crohn’s and Colitis Foundation, March of Dimes, and NORD.

Beyond-Use Dating for PN

A “beyond-use date” (BUD) is just what it sounds like: the date after which a product should not be used. The label of each bag of sterile compounded PN contains a BUD. It may say, “do not use after” or “use before.”

The BUD for PN and other sterile compounded preparations is set by the US Pharmacopeia (USP), which describes itself as “an independent, nonprofit, science-based organization that…[develops] quality standards for medicines, compounded preparations, [etc.]” These standards are recognized in law and are enforceable by the U.S. FDA.
for medicines and their ingredients imported into or marketed in the United States. (See www.usp.org.)

In the past, the BUD for PN has been as long as seventeen days (from when the preparation was compounded). The BUD was shortened to nine days after a series of serious problems with compounded sterile preparations, including a fungal meningitis outbreak in 2012, where due to contaminated injectable compounded sterile preparations, “more than 70 people died, and 750 cases of infection were reported in 20 states.” (See www.usp.org, “Ensuring Patient Safety in Compounding of Medicines.”)

Many home PN consumers feel the shorter BUD has affected them negatively. It means more frequent PN deliveries, which can interrupt work and other activities, and can limit travel. More deliveries mean increased costs to the health-care system, more packaging and waste, and, for some, greater stress.

Others are concerned that if the BUD is lengthened and their deliveries occur every two weeks, it will be too much for them to unpack at once and to store in their refrigerators. They note, too, that a longer BUD will mean more waste if their PN formulation is changed.

The USP posted a draft of its revised “General Chapter <797> Pharmaceutical Compounding—Sterile Preparations,” and invited comments from stakeholders through November 30, 2018. The Oley Foundation urged home PN consumers to consider submitting comments to help the USP understand what life on home PN is like and how they feel about the BUD. Oley Ambassador and Advisory Council member Swapna Kakani had started a petition to draw attention to the issue and to urge the USP to consider extending the BUD from nine to seventeen days.

Your comments and signatures in cases like this can be the impetus for change. Such input can help the USP and other decision makers understand why it is important to conduct the research needed to determine if the BUD can be safely extended for PN, and under what circumstances. Such a change is a process, and your voice can help get the process started. We’ll keep you updated as we learn more about revisions to USP <797>.

Other Issues

This is a sampling of the issues with which we are currently involved. Watch for more details online and in future newsletters about these and other important issues, including (but not limited to):

• Memorandum of Understanding (MOU) between FDA and states that could impact delivery of compounded solutions across state lines: Oley is monitoring developments with the MOU and working with NHA and others to minimize negative impact on home PN consumers.
• Patient access to care and insurance coverage: Oley is monitoring legislation that would limit our members’ access to care generally, for example, discrimination against patients with pre-existing conditions, with the DDNC and other groups, and responding accordingly.
• Step therapy (also called “fail first”) and co-pay accumulators: the first is when insurance says you must start with a cheaper medication and if it is not effective (or you “fail”), then you can try another medication. The second is when, if you use a drug co-pay card to help pay for a medication, the insurance company does not count the payment that the card assists with toward the insurance deductible. There is concern against both of these trends. Oley is joining other groups to raise awareness among consumers and decision makers of the practices’ negative impact, and to affect change.
• Functional Gastrointestinal and Motility Disorders Research Enhancement Act (H.R.11897): Oley supports this bill, which would bolster research at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and increase awareness of functional GI disorders.

Feeding Tube Awareness Week, February 4–8, 2019

Help others understand what life with feeding tubes and enteral nutrition is all about. Increase tolerance and knowledge, and create bridges to people who are feeling isolated by or struggling with tube feeding.

Submit your photos for the Oley awareness video now! Looking for photos of you or your loved one “living life” on home tube feeding, with a short explanation we can use as a caption. Watch last year’s video on the Oley You Tube channel for inspiration, then send to Lisa by January 14 (email below).

Be sure to watch the new video on You Tube, and to join the conversations on the Oley Facebook page and Oley-Inspire forum, February 4–8.

We are also still looking for t-shirt designs. We are thankful for the ideas we have received and are continuing to accept submissions. Please send to Lisa by January 14 (email below). See the HPN t-shirt for inspiration at www.oley.org/HPN_Awareness_Week.

If you want to plan an event, reach out to the media, etc., contact metzgel@amc.edu, (518) 262-5079, or The Oley Foundation, Albany Medical Center MC-28, 99 Delaware Ave., Delmar, NY 12054.

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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 September 21 through November 2, 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.

Tributes
In honor of Bobbiejo’s thirteenth multivisceral transplant anniversary; Marcia Denenholz’s birthday; Melissa Hughey’s birthday; Aidan Koncius; the Oley Equipment-Supply Exchange Program

Memorials
In memory of all the losses this year; Clifton Dodge, Sr.; Heidi Martin-Coleman; Nina Marino and her beautiful life; Clarence “Oley” Oldenburg and in honor of his birthday; Mary Patnode

Fundraisers
Amazon Smile, Facebook

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.

Felicie Austin
Jane Balint, MD
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Family of Shirley Klein
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Laura Matanova, PhD, RD, LDN, CNSC, FADA, FASPEN
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Nancy Nicholson
Rodney Okamoto, RPh, & Paula Okamoto
Kay Oldenburg
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Cheryl Thompson, PhD, RD, CNSC, & Gregory A. Thompson, MD, MS
Cathy Tokarz
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Rosaline Ann & William Wu

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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.

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Oley Calendar

**Ongoing:** Applications being accepted for Oley Tim Weaver Camp Scholarship

**February 4–8, 2019:** Feeding Tube Awareness Week

**February 9, 2019:** Oley Regional Conference, Dallas, TX

**February 28, 2019:** Rare Disease Day

**March 3–4, 2019:** Digestive Disease National Coalition (DDNC) Capitol Hill Day, Washington, DC; register by January 29, 2019

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

**March 15, 2019:** Nominations for Oley Awards, applications for Noble Scholarship, and submissions for HPN Research Prize due

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

**April 28, 2019:** National Prescription Drug Take Back Day

**May 6–7, 2019:** Patients and Providers for Medical Nutrition Equity Coalition Capitol Hill Day, Washington, DC

**May 18–21, 2019:** Infusion Nurses Society (INS) conference, Baltimore, MD

**June 21–24, 2019:** Oley Foundation & University of Illinois at Chicago (UIC) conference, Lincolnshire, IL

**October 14–18, 2019:** HPN Awareness Week

Save the Dates!
June 21–24, 2019

--- Will Host ---

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Watch your email and www.oley.org for updates.