

# LifelineLetter

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

## What's Inside:

Tube Talk *Page 3*

Auction Items Needed *Page 3*

Life after Intestinal Transplantation *Page 4*

A Day in Washington *Page 5*

Nutrition and You *Page 5*

Center of Experience *Page 7*

Volunteers Wanted for Research Studies *Page 7*

Equipment Exchange *Page 10*

Tribute to Suzanne Rosenthal, Linda Aukett *Page 11*

Contributor News *Page 11*

Awareness Week Recap *Page 12*

## Connecting with Others Helped Me...

...See Life's Promise Once More

I have been on home parenteral nutrition (HPN) and hydration for almost two and a half years due to a serious accident. My husband and I were in the desert for four days without food or water. Very, very near death, we were saved...by human and divine miracles. Later I was saved by medical miracles at the hands of University of Arizona doctors, the miracle of HPN and hydration, and the emotional miracles of family, friends, home health care, and the Oley Foundation.

### Help from My Friends

My fabulous sister Bonnie and two very old girlfriends of mine attended the Oley Annual Consumer/Clinician Conference in Minneapolis, June 2011. Notes were taken—but better yet, Bonnie met Mary P., Dr. Darlene Kelly, Oley staff members, and many consumers who shared their stories of life after HPN. All the information Bonnie brought to me from the

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conference—and my talking to other consumers by phone during the Minneapolis conference—was the “kick in the butt” I needed to put on my big girl panties and strive to be as normal as I could once again.

I learned to do the HPN with hydration on my own. (I had been very fearful of bubbles in the tubing.) I decided my home health nurse could stop coming (love her as I do), and—wow—I was driving again and going to Pilates. I took my first overnight. I didn't go alone, but I was doing it. In 2012, I was feeling confident enough to drive with my sister from Tucson to Redondo Beach, California, for the 2012 Oley Consumer/Clinician Conference.



Lynda Bosworth

Oley Conference, cont. pg. 6

## Support Groups

Lisa Crosby Metzger, Joan Bishop, and Lyn Howard, MB, FRCP

*In the January/February issue of this newsletter, we ran Part 1 of “Support Groups,” a chapter the Oley Foundation was asked to contribute to the textbook Clinical Management of Intestinal Failure. If you missed it, we'd be happy to send it to you. Contact us at harrinc@mail.amc.edu or (800) 776-6539.*

*Do you think Oley could improve in any of the areas mentioned below? Do you have a different impression of Oley's role? Or do you have a story about how peer support has made a difference in your life? We welcome your feedback.*

### Part Two

#### Oley Foundation Programs

Oley Foundation membership and all of the programs the group offers are free to HPEN [home parenteral and enteral] consumers and their families or caregivers. Any program that brings consumers together offers both learning and networking opportunities.

Why is networking so important? One long-term HPEN consumer says, “I've talked to an awful lot of people who just got out of the hospital or have been

Support Groups, cont. pg. 2



Tara Smith (right) at the Oley meeting in Phoenix discusses her experience parenting a youth on HPEN.

## Meeting to Learn

Oley Foundation members, Oley staff, and professionals involved with home parenteral and enteral nutrition (HPEN) met for an afternoon of sharing in Phoenix, Arizona, on February 9—an Oley-style warm-up to the annual conference of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) scheduled to begin that evening (more on the A.S.P.E.N. meeting on page 12).

While a snowstorm on the East Coast kept a few from attending, those who were able to make it en-

Meeting, cont. pg. 12

### Support Groups, from pg. 1

home for a few months, and they're telling me the same things that I've heard for 35 years: they talk about feeling like they're the only one, of being isolated, that it's very difficult to explain [about HPEN to other] people. That after five minutes of explaining, it doesn't seem

## LifelineLetter

March/April 2013 • Volume XXXIV, No. 2

### Publisher:

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### Subscriptions:

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

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

worth talking any longer...It's unrealistic to expect [friends, family, and acquaintances to] just grasp it all."

In the following dialogue, three mothers, all Oley members who manage HPEN-dependent children, echo this sentiment:

**L.M.:** I think that for the first couple of years, I really wanted somebody outside my immediate family to "get it." And I really invested in that....People said, "Oh, you're home? You don't work? Can you babysit my kids?" After about the sixteenth person said,

"Oh, you're so lucky.

Can you babysit?" I realized they aren't going to get it. And I finally stopped trying to make them understand our life. Because...unless somebody lives with you—and even then it's iffy—they're never

going to get it. And just because they don't get it, doesn't mean they don't love you... S.K., I remember your approach from our [online] support group helped me as well. You said that when family members were less than understanding during a crisis, it helped when someone close to you said, "Why are you expecting a normal response? They are incapable."

**S.K.:** Yes, [this was when my daughter] perforated her bowel....It pushed me off the edge. But once I came to that understanding, I've been able to deal with it.

**L.M.:** I think the second I let that go I was much better emotionally. I do not need anyone to get it because I can go to Oley and they get it, and that's all I need.

**A.W.:** But if you don't have that there's a need. I can clearly remember thinking I had to tell everybody the whole story and try to make them understand. And I reached the point where I didn't explain things and then situations cropped up when I realized, Oh yeah, I suppose you really need to know. Because honestly, if you look at...many of the kids, you would have no clue...that they have anything going on.

...[When our son was] about 18 months old...we went to visit [my mother-in-law. We] sent the supplies ahead. One of the first nights we were there she told us, "You could try your best to explain everything to me, but when the supplies came to my house—three

boxes full—and I started putting stuff in the refrigerator and started putting stuff away and seeing all the stuff, I had to sit down and cry. Because it just overwhelmed me. What you deal with. You couldn't have told me."

"The general population as a whole," says one of these mothers, "doesn't grasp the nature of a chronic condition. They don't grasp the fact that it is up and down. I certainly experience it at work. Many people just expect your kid to be sick and then you move on and life is fine. And you learn that it's not like that.

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"The general population as a whole, doesn't grasp the nature of a chronic condition."

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I remember early on one of the social workers talking to us in the NICU about chronic conditions. We grieve and re-grieve all the time. You never heal because the condition never goes away. We certainly celebrated the

time that [our son] came off HPN [home parenteral, or IV, nutrition]. Being on tube feeds for many people would not be considered a happy life, but for us it was phenomenal. Then to go back [on HPN] and have this bumpy road that we've had for the past two years—we long for just tube feeds. Stability is nice. With a chronic condition the best you can hope for is stability."

### Conferences

At the large annual Oley Foundation Consumer/Clinician Conference and the smaller, regional conferences Oley sponsors, consumers and their families, clinicians, and industry representatives meet in large and small groups and one-on-one, in both educational and social settings.

The mother of a fourteen year old tells how her daughter was more comfortable with her HPEN after attending an Oley Foundation conference: "[My daughter's] perspective started to change a little bit when we started meeting more people....What really did it for her was when we went to [the Oley conference in] Cape Cod....At the time she had gone through a stage where she didn't want to be seen in public infusing. [She was] body conscious...And I remember, a couple of weeks [after the conference] she says, 'I've decided I'm going to go out in public.' I said, 'Well, why is that?' And she [told me how another teen] was infusing the entire evening that [the

**Support Groups, cont. pg. 8** ◀

## Tube Talk

Send your tips, questions, and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or metzgel@mail.amc.edu. Information shared in this column represents the experience of the individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.



Here are two products that Oley has become aware of that may be helpful for members.

### Cloth Med Port Covers

Kristi Potts makes Med Port Covers (patent pending). The fabric cover snaps around the medicine port of a feeding tube. Kristi says, "It keeps the medicine port from accidentally popping open and little fingers from playing with it (stop feeding the bed at night!)." Kristi also makes cloth diapers for older children, fleece diaper covers to help stop nighttime leaks (for use over cloth or disposable diapers), and waterproof underpads for car seats, wheelchair seats, etc. Contact Kristi at [www.TUBEaliciousTushies.com](http://www.TUBEaliciousTushies.com) or (712) 621-4501.

### Bamboo G-Tube Pads and More

Patchwork Peddler sells bamboo feeding tube pads, belts, medicine port covers, and other accessories. Bamboo, Patchwork Peddler says, "is antimicrobial, antibacterial, hypoallergenic, antifungal, odor resistant, and environmentally friendly." The company also takes custom orders. A percentage of every sale goes to the United Mitochondrial Disease Foundation. Their Web site is [www.PatchworkPeddler.com](http://www.PatchworkPeddler.com).

## Auction Items Needed

The silent auction held at the annual conference has raised thousands of dollars, helping to keep all Oley programs free for you. Your help in gathering items is key! The possibilities are endless, including handmade quilts and scarves, collectibles, DVDs, books, photos, paintings, gift certificates, time-share units, concert or sporting event tickets, electronics, etc. Any energy you can give towards making this year's event successful is much appreciated!

A solicitation letter describing Oley and the auction is available at [www.oley.org/documents/Silent\\_Auction\\_letter\\_2013.pdf](http://www.oley.org/documents/Silent_Auction_letter_2013.pdf), or call (800) 776-6539 for copies. If you'd like, we can send you Oley brochures as well.

You can bring items with you to the conference, or you can ship items directly to the address below. Please plan for the items to arrive by June 25. Thank you!

Cathy Harrington, Guest  
Hold for Arrival on 6/25/13  
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## Life after Intestinal Transplantation

*The Reid family came to the United States when Matisse was a toddler, knowing Matisse would require intestinal transplantation and it would not be available to her in their native country. Matisse received a transplant in December 2011, and two years later, in December 2013, the family returned to New Zealand.*

*Jodee and Matisse Reid have been active members of the Oley Foundation community for several years. Even from New Zealand, Jodee will serve as an Oley Regional Coordinator. (So if you'll be visiting New Zealand...)*

*For those who haven't had the privilege of meeting them, we wanted to introduce you; for those who do know Matisse, here's an update from December 2012, just before the family left for New Zealand. Matisse has been an inspiration to us. She and the rest of her family have exhibited tremendous strength and courage.*

### **Oley: Jodee, how is Matisse doing, two years post-transplant? What are her daily routines?**

**Jodee:** Matisse is doing really well. Small bowel transplant is one of the most complicated of all transplants and recovery is the most lengthy. Two years on and we are still in recovery phase and still learning “the new normal” for Matisse. However, compared with pre-transplant, Matisse is 100 percent better.

Today she is taking all her medications in pill form, which is huge for a kid who did not eat for ten years. She recently came off overnight tube feeds, which were started soon after transplant and have been slowly reduced over the past two years to the point where we were just supplementing daily oral intake. Matisse gets all her nutrition from food—and boy does she love to eat!

I think we are all enjoying the freedoms we now have. Hooking up to home parenteral nutrition (HPN) every single day for ten years was a big commitment and one that we got used to, but Matisse's chronic pain and bilious vomiting ruled our lives. Even if we did make it to an event or a dinner, or just a gathering with friends, we often left in a hurry when things turned sour for Matisse—and they always turned sour. If Matisse made it school, I would be there every day to administer IV pain medication and more often than not, to pick her up early due to illness.

Since transplant, Matisse has enjoyed the freedom to swim, the energy to ride a bike, and the ability to sleep over at a friend's house and even attend camp. She feels well enough most days to go to school and we've even on occasion been the last family instead of the first to leave an event.

Of course, post-transplant is not a walk in the park and we now have other issues we need to be aware of and monitor. Matisse still has an ostomy and always will due to a separate issue with her anal sphincter. We need to ensure her output is not too high, which could

signify rejection. Any fever needs to be addressed immediately, as infection could cost her her life, just like in her HPN days. We need to monitor her immune suppression levels to make sure they are not too high or too low, and like the days of HPN we need to ensure she is not exposed to flu and viruses. So it is still a juggling act.

I had always described transplant as swapping the devil we know for the devil we don't, and I stick to this. We knew intestinal pseudo-obstruction well; we knew Matisse well. Now we are getting to know post-intestinal transplant and how it affects Matisse's life. This devil is certainly kinder to her, but she will always be medically fragile and under doctors' care.

### **Oley: Could you tell us about Matisse's passion for cooking?**

**Jodee:** Once we learned that Matisse would never eat, we made a decision to make food a healthy part of her life. It seems strange, I know. However, food is a huge part of life of which we did not want to exclude her.

Matisse did not realize she could not eat for many years. We never stopped her from putting food in her mouth. Sometimes she would chew and swallow, but mostly her instincts told her not to. Food caused her tremendous pain and she soon learned that. She learned to chew and spit, which helped give her a taste without the pain. When Matisse was small, like most other littlies she owned teas sets and toy

kitchens. I packed her school lunches when she started school and she would have great input into acceptable food—which, of course, all came home uneaten.

When Matisse was around age six, she really took a liking to cooking and would help me prepare family meals. Also at this age she started watching cooking shows on TV and became almost obsessed. Matisse would entertain herself on the many days of being at home, too sick to leave the house, by chopping up vegetables, making marinades, and concocting all sorts of recipes using real food and ingredients.

### **Oley: How did the column with *Cooking Light* come about?**

**Jodee:** Matisse made headlines after her transplant predominately because of our coming from New Zealand. However, as she did so well, she was a poster child for Children's Hospital of Pittsburgh transplant program. Reporters were obsessed with the fact that this kid who could not eat for ten years was now not only eating and cooking, but her favorite food was squid. Here's this kid who could never eat, but who has this very sophisticated pallet. She cooked for all the reporters, one of whom happened to be married to the editor of *Cooking Light Magazine*.

### **Oley: Any advice you'd like to share with parents with a child on**



*Jodee and Matisse Reid two years post-intestinal transplantation.*

### the transplant list? Or for parents who may be facing this option for their child?

**Jodee:** I will always be honest and tell you the good, the bad, and the ugly. I welcome anyone waiting for transplant to contact me if you need some support. It's not an easy ride, but neither is what you are going through now. For us, it has been the greatest blessing. We waited four years for organs and for two years, Matisse has predominately done well. We don't know what the future holds but remain hopeful and positive that Matisse will be well for a very long time.

Everyone's experience is different; there is no cookie-cutter version, so don't get bogged down on the negative stories. Look for the positive, as well. Educate yourself, and once the decision has been made, know that it is right for you at this point in time. None of us know what the future holds; we all just do our best with the knowledge and tools we have today.

**Oley:** We are sorry to see you go, and hope to see you and Matisse again in person some day. In the meantime, we are grateful that through the Internet we'll be able to keep track of Matisse as she grows into a teen and young woman.

**Jodee:** I am happy to be "friended" on Facebook by any Oley member. Just mention you are an Oley member if you send me a request. Or visit us on [www.caringbridge.org/visit/matissereid](http://www.caringbridge.org/visit/matissereid). ♣

## A Day in Washington

On Monday, March 4, Oley Executive Director Joan Bishop and several Oley members (HPEN consumers and professionals) visited legislators on Capitol Hill as part of the Digestive Disease National Coalition (DDNC) Public Policy Forum. Members of Congress and the Senate were asked to consider key issues of NIH and FDA funding; the Medicare Home Infusion Therapy Coverage Act; ongoing drug shortage issues; disease prevention and treatment concerns, i.e. early colon cancer screening; and more. Joan reports, "It was an extremely stimulating experience!"



## Nutrition and You

### A Heartfelt Thank You

From the first "Nutrition and You" column in 2009 until recently, Marion Winkler, PhD, RD, LDN, CNSC, FASPEN, and Cheryl Thompson, PhD, RD, CNSC, have been extraordinarily generous in sharing their expertise. Busy with other projects, Marion and Cheryl have resigned as part of the team that writes and reviews the column. We cannot thank them enough for their contributions. They will be sorely missed. We also wish to thank Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN, FASPEN, and Laura Matarese, PhD, RD, LDN, FADA, CNSC, FASPEN, who will continue to write and review "Nutrition and You."



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### Oley Conference, from pg. 1

The conference offers a chance to interact with a group of people who know, care, and want to help. The knowledge gleaned from consumers, staff, and medical connections is up-to-date, and they understand what a change of life we all experience. I like to say, being part of Oley is like being in a soft hammock or a bunting.

#### In My Own Time

I was told about Oley by the coordinator for the nutrition support team at the University of Arizona Medical Center in 2010. I didn't want to, care to, or have the energy to get involved at that time, but when I was ready—about one and a half years after my major, major surgery—I was ready to be helped, and to help myself. My husband Tom and I, as well as my sister Bonnie and the friends who have always been there for me, are grateful for Oley's existence.

—Lynda Bosworth

#### ...Build a Support Network

What could be bad about a weekend in Boston? That's how I rationalized my late wife Esther Ann's suggestion that we attend something called an Oley Conference. I personally had no desire to spend a summer weekend at a convention talking about ostomy and J-tube products. Much to my surprise, the convention was a wonderful experience!



**Esther Ann Brown Adler**

handling issues like ours and working on solutions.

Esther Ann and I both were very happy that we had made the decision to attend an Oley conference and I would strongly urge others in our position to do the same.

*Arthur's wife, Esther Ann Brown Adler, passed away in 2010 from a motility disorder.*

—Arthur Adler

#### ...Find Myself Again

It seems not so long ago that I first heard of Oley. With time, I discovered the many wonderful benefits of being a member. I had support through the Internet, newsletters, referrals, research studies, and more. In a time that seemed so dark for me, learning to accept the new challenges I faced each day, I was able to turn to Oley and its

many members for advice—or just an ear to listen.

When I heard about the yearly conference, it seemed like the perfect opportunity for me to find myself again. I could finally meet so many of the individuals that had helped me in online forums; I could be in a place where everyone knew what "it" was like, and for a few days, I could feel like it was okay to ask questions, stop hiding, and feel the love of a community that was overwhelmingly accepting.

#### Open Doors, Open Arms

My biggest obstacle was getting from Boston to Los Angeles, where the conference was going to be held. With generous donations from my local Kiwanis Club, and an open door from my cousin, who lived not far from the hotel where the conference was held, I made my way to Oley for the first time.

From the very first steps I took into the hotel lobby, up until the Farewell Picnic on the last day, I was flooded with hugs and lots of love. I had left Boston with some extremely difficult medical decisions to make, and after returning home from the conference, I had figured out—with the help of new friends—what was right for me when it came to taking charge of my health care.

#### Becoming Involved

Without a doubt, I knew I would be returning to the annual conference. When I discovered it was going to be held practically in my back yard, I wanted even more, and to be as involved with the planning process as possible. A combination of what I had learned the previous year, along with various things I saw that could use a little "sprucing up," parts of my experience that I couldn't wait to re-live, and ideas I had of my own that I wanted to contribute, I jumped on board, going from just an Oley member to an active one.

It has been an incredible year for me, with plenty of ups and downs. This coming June, I am looking forward to an even better experience than the last conference. Oley is truly the face of HPEN, comprised of the most wonderfully spirited people that make it so special. I look forward to seeing familiar faces, as well as welcoming new, as we once again share laughs and stories, and attend great classes, events, and all the fantastic things Oley has to offer!

—Amanda Singer



*Amanda Singer with Michael Medwar at the picnic, 2012 Oley conference.*

*We've had a generous outpouring to support patient travel to the meeting from families, industry, and the Daniel F. and Ada L. Rice Foundation. Patients who have never attended the annual conference are encouraged to **apply for a \$500 travel grant**. Details are available at [www.oley.org/annualconf.html](http://www.oley.org/annualconf.html), by emailing [harrinc@mail.amc.edu](mailto:harrinc@mail.amc.edu) or by calling (800) 776-OLEY. ¶*

## Center of Experience

*Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our readers strictly as an informational tool. For a listing of other experienced centers visit [www.oley.org](http://www.oley.org) or call (800) 776-OLEY.*

### Children's Hospital of Los Angeles, Los Angeles, California Intestinal Rehabilitation Program

The multidisciplinary team of the Intestinal Rehabilitation Program at Children's Hospital of Los Angeles provides comprehensive care for children with intestinal failure or related conditions through the Division of Gastroenterology. The team's goal is to help patients move from intravenous to tube feeding to an oral diet while supporting normal growth and development. The team coordinates care with other services in the hospital and with home care agencies that provide products and nursing care in the home setting. The home parenteral nutrition (HPN) service was established in 1978 by Russell Merritt, MD, PhD, and has been offering full intestinal rehabilitation services since 2008.

The team works with hospitalized patients to ensure that their nutritional needs are met; prepares patients and their parents to use nutrition therapies at home; and cares for children who need at-home nutrition support (including tube feeding and intravenous nutrition). It also offers educational activities in the hospital and the community, and research and quality of care initiatives. The team includes physicians, nurses, occupational therapists, a dietitian, and a social worker. For further information or an appointment, contact the nurse coordinators at (323) 361-5694 or [ccox@chla.usc.edu](mailto:ccox@chla.usc.edu). ¶

## Volunteers Wanted for Research Studies

### Phone Interviews about HPEN and Oley

The purpose of this study is to learn more about the aspects of membership in the Oley Foundation that are of most value to home parenteral and enteral (HPEN) consumers. Volunteers will be asked to participate in telephone interviews lasting about one hour, with one fifteen-minute follow-up phone call.

To be eligible, you must: receive HPEN; have joined the Oley Foundation within the past two years; be willing to speak about your experiences with HPEN and your involvement with the Oley Foundation; be over 18 years old; live in the United States; have an e-mail address and telephone; and speak English. All information obtained will remain confidential.

For more information or to indicate your interest in participating, e-mail graduate student Katelyn Chopy at [oleystudy@etal.uri.edu](mailto:oleystudy@etal.uri.edu) and include your name, telephone number with area code, and best time to reach you.

### Study on Use of Mobile Technologies

This NIH-funded study involves the use of mini iPads and will test how connecting from home to Internet information, professionals, and peers will impact your home parenteral nutrition (HPN) management and how monthly iPad messages about healthy living activities impact your health outcomes. An iPad will be loaned to each family with no connection costs for eight to twelve months. The iPads are for personal use, as well as for the monthly study contacts.

Your iPad and your training guide to using it will be delivered to your home, and the study will take place from your home. Two study iPad meeting sessions will be coordinated using encrypted multisite connections with conferencing capability. Previous studies with HPN families found that picture phone meetings were highly valued and connections to other HPN peers and families increased quality of life and resulted in less depression.

You may or may not benefit from participating in this study, but investigators hope that the information from this study may help you feel better about managing HPN, and help you to feel better informed and more confident about home care management. To learn more and/or register, contact Carol Smith, RN, [csmith@kumc.edu](mailto:csmith@kumc.edu) or (913) 588-3392. ¶



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### Support Groups, from pg. 2

two of them] were together... And she didn't realize it until 45 minutes before the end of the evening. She said, 'Mom, I keep thinking people see it. I should have noticed it and if I didn't notice it...'

Another mother of an HPEN-dependent child tells this story about attending an Oley Foundation conference soon after her son had his first central line placed (at age three) because of short bowel due to infarction from malrotation. Previously she and her husband had been told that their son probably would not survive:

"For forty days our son had fevers at night. We were brand spanking new, so we didn't know what to do. We stood over our son, who was vomiting and had a temperature of 105, and I remember my husband saying, 'We might need to bury our child. He might die.'...

"Then we were in the hospital and in walked [a health care provider who had] overheard me talking to the social worker. She said, 'You need to contact Oley.' I was too overwhelmed, but my mom contacted our local [Oley regional] coordinator, who said, 'We just happen to have the annual conference right near you in June.' So for the seventh time in four months our son was discharged. He was then re-admitted with another fever. This time he grew out a bacterial line infection. It was also fungal. They pulled the line. Everything was going on, including the Oley conference. On the first day we gathered family and friends and split up to cover as many presentations [at the conference] as possible. Later we met in 'headquarters' upstairs in the hotel room, and everybody starts looking at each other saying, 'You know what? You can live on HPN. Our doctor and nurses said you die on HPN! They said he'd never eat. He can eat. You know what? We're not being sterile with the line, and you're not supposed to have a cap with lipid crud coming out the top.'... We actually met a man who had been on HPN for twenty years!

"Later, I went downstairs and met a woman who said, 'The two best things I've ever done in my life were to go to a different home care company and switch to Dr. [so and so at the other hospital].' So I went to the home care company booth, which was at the conference.... I told them how our first seven months on HPN had been. One of the representatives said to his colleagues, 'Come over here and listen to this story.' I remember thinking, 'What do you mean listen to me? Nobody listens to me. I'm the crazy mom!'

"After the Oley sessions were over, we took [our son] out of the hospital on a day pass to go ride the rides at Knott's Berry Farm with other Oley families at the Oley picnic. Our son saw the other [HPEN] kids, all his cousins saw the other kids, and everybody was so excited. We were like, 'Oh my gosh, I think he's going to live.'

"And that was when we switched to [another hospital. Our son] had been inpatient seventy days, with probably six line infections, none of which grew out because the nurses kept pulling what should have been

the culture and throwing it out as 'waste.' That was the last time we were in the hospital, pretty much.... Because we were able to attend the Oley conference, we talked to the HPN pharmacist, took notes, switched home care companies, switched doctors. It's been really stable ever since.... In our first seven months the hospital days were seventy and now there have been seven in-patient days in eight years.... His central line is now over seven years old! The Oley conference saved his life, there is no question. And it changed our lives because all the new people we met didn't look at us like we were crazy."



*Members share information and friendship at an Oley gathering.*

About the learning opportunities at an Oley conference, one member writes, "I underwent a subtotal gastrectomy for an abdominal tumor in 1995. Along with numerous other complications, I developed gastroparesis. I struggled for ten years, depending on oral nutrition, motility meds, and little amounts of food. I became very malnourished, which led to severe neurological symptoms. In 2006, I went on HPN via a PICC line. I had amazing results, but developed too many infections and went through five [lines] in one year. I went to my first Oley conference in June 2006. I learned so much, that by that August,

I had a jejunostomy button inserted by a physician I learned of at Oley. I am now living the best quality of life [I have had] in fourteen years."

#### Regional Coordinator Program and Toll-free Phone Lines

The Oley Foundation also supports networking with an extensive Regional Coordinator (RC) program. Over sixty HPEN consumers and/or caregivers have volunteered to represent the foundation in their regions. These volunteers answer phone calls and e-mails, make visits, reach out through the Oley online forum, and generally support other members. Some of them have established support groups that meet regularly in their areas (a list of groups and meeting schedules can be found at [www.oley.org](http://www.oley.org)). The foundation also maintains three toll-free phone lines that are staffed by different consumers and/or caregivers each month (in addition to a toll-free line to the foundation offices).

The toll-free numbers and RC network are valuable for one-on-one, peer-to-peer support. An Oley RC, talking to another RC, tells how important it is for her to be able to communicate with a peer (both of these RCs have HPEN-dependent children): "There are things that are difficult to say out loud to other people.... If I share my fears with you, I know that you know how heavy they make my heart. People just don't comprehend or grasp that. It's just nice to know there are people out there who understand what I say." Further, she adds, "When I say to you, 'Four liters of output,' you understand the magnitude. I get these blank looks from people at work. I say, 'You know the two-liter pop bottles? Two of them. Two of them in three hours!'"

For online networking, the Oley Foundation started a forum in 2008. The community of users grew quickly. One forum user writes, "This forum has been like a lifeline for me—who knew there were others out there like me? I thought I was a medical mystery." For those who are unable to attend a conference for health or financial reasons, the

forum provides a good alternative. The forum can be accessed through the Oley Foundation Web site.

#### Newsletter

The bimonthly newsletter features a medical article and a personal consumer/caregiver coping or biographical article. It also regularly carries a column with practical tips for HEN consumers; information about major HPEN and/or intestinal management centers; pertinent clinical trials; and any new research or information deemed of interest to HPEN consumers/caregivers/clinicians. For many members, the newsletter is the Oley Foundation's most conspicuous program.

An article about how to write an effective insurance appeal letter is an example of a typical "coping" article. After reading the article, a member wrote, "I was inspired to start the appeal process with Medicare. Medicare was refusing to pay for my hydration and supplies (I have short bowel). It took four appeals, but I finally received a favorable decision...With the well-needed letter from my doctor...and Medicare rights' knowledge...I had [my home care company] reimbursed for great work and care: \$12,000."

#### Information Clearinghouse

Since its inception, the Oley Foundation has collected, compiled, and distributed the most current information available about HPEN and related issues. Foundation staff answer hundreds of information requests each month via e-mail and phone calls. When needed, staff refer members' questions to medical advisors. The information clearinghouse also includes educational videos and DVDs, which members may borrow. Many of the DVDs cover educational sessions from Oley conferences, allowing more members to benefit from the knowledge imparted by the expert speakers.

The newest educational tool being developed by the foundation is MY HPN, an online program where members can learn more about managing their parenteral nutrition (PN) in the comfort of their home at a time that is convenient to them. Topics range from becoming a more active health care partner, to understanding the nutritional content of a PN solution, to avoiding HPN-related complications.

#### Research

The Oley Foundation is well known for the North American Home Parenteral and Enteral Nutrition Patient Registry (1987–1994), which is the largest registry of HPEN consumers to date and which allowed researchers to assess outcome on HPEN for different underlying diseases and different age groups. Outcome was measured by mortality on therapy, duration on therapy, complications on therapy, and quality of life (QoL) on therapy.

More recently, the Oley Foundation supported the research workshop at the American Society of Parenteral and Enteral Nutrition's 2009 meeting (Clinical Nutrition Week), titled "Micronutrients in Parenteral Nutrition: Too Little or Too Much?" "In 1979, and again in the mid-1980s, the American Medical Association established guidelines regarding micronutrients in PN. Concerned that these guidelines and the resulting Federal Drug Administration recommendations are outdated, Dr. Lyn Howard and Dr. Alan Buchman located funding for the workshop and invited specialists from around the world to present the most up-to-date research on several micronutrients where new data or controversy exists." (*LifelineLetter* 2009 Mar/Apr;4–5) The research proceedings have been published as a supplement to *Gastroenterology* (2009 Nov). "We hope," said Dr. Howard, "this research workshop

**Support Groups, cont. pg. 10** ◀

## America's Premier HPN Pharmacy

### Created Exclusively for Long-term Home TPN Consumers



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Opportunities for our 'Family of Consumers' to network with each other.

Gold Partner of  
The Oley Foundation

*Helping our family of consumers reach a greater quality of life*

### Support Groups, from pg. 9

will lead to an FDA multi-trace element reformulation and the availability of safer commercial products.”

Currently [2012], the foundation is coordinating the U.S. portion of a large international HPN QoL study in conjunction with the Home Artificial Nutrition workgroup of the European Society for Parenteral and Enteral Nutrition. Among other things, this research will provide a valuable tool in assessing QoL on HPEN versus QoL after intestinal transplant.

The Oley Foundation...research committee reviews research protocols pertinent to HPEN consumers. If the committee deems it appropriate, these protocols are briefly described in the Oley Foundation newsletter and on the Web site so consumers can find out more about these studies and decide whether they'd like to participate. [Note: see page 7 of this newsletter for two new studies.]

#### Equipment-Supply Exchange

The Oley Foundation maintains a database of equipment and supplies that consumers no longer need and wish to donate for someone's use. The foundation facilitates contact between the donor and recipient, who arrange for the delivery of the equipment or supplies. This program is especially popular with HEN consumers, and as a whole, saves participants thousands of dollars each year in out-of-pocket expenses.

#### **Consumers' Needs Change Over Time**

The amount of experience an HPEN consumer has with his or her therapy affects their relationship to the Oley Foundation as a support group and as a source of information, as evidenced in this dialogue between three long-term HPEN consumers:

**A.D.:** The role of Oley has changed for me through the years. In the beginning it was...just awesome, like kids say, both in terms of learning about real basic stuff, like a new portable pump, and [losing the sense of isolation]. [Dr. H.] has been a wonderful physician and she took care of ... me for many years, but you're sitting with [her] once every three or four months if you're stable, and she takes a lot of time, but how much information can she convey? There's just so much that you learn at the Oley conferences that's amazingly empowering. That was one part of it. And the other part was losing the sense of isolation—talking to other people about how they cope with a lot of the basics, and just knowing that there were other people like you out there. Both of those were amazing, at least for me, in the early stages of my relationship with Oley.

Now my relationship with Oley is...the newsletter, in terms of what I get out of it....Every once in a while I get an in-depth article that's

really relevant to me, [in a format] where I can sit and digest it and really get a lot out of it—probably in some ways even more than I can if I go to a conference where...it's hard to absorb it all.

**L.T.:** I think that's true. [My home care company] people actually got me to Oley in 1989, and...it was really nice to see other people who were on HPN. That was really wonderful. Plus learning all the new information and everything.... [Now], I think [it has become] more a case of wanting to give back and help other people who are in the situation I was in all those years ago. But also, I find that when I come to a conference I always learn at least one thing that has changed, or that's new, or something I didn't know yet.

**D.Y.:** Absolutely. The Oley Foundation started in '83...We're a ways down the road now, and...I guess what...I really get—ham that I am—is a great deal of satisfaction when people I don't know come up to me at the conference, after I've spoken, and say you've been a real inspiration to me. L., you just said you're kind of coming to the point where you're giving back. And that element is very important now....But I find, especially now that [my physician] is retired, that the information I get, the technical information, either comes from Oley, or if I [go] to a Crohn's and Colitis meeting and hear somebody speak.

#### **Conclusion**

It is well documented that dependency on HPEN affects the consumer's quality of life. Yet many of the issues that influence a consumer's quality of life often fall outside the scope of services clinicians and/or intestinal rehabilitation centers can—or have time to—provide. The support and information available from peers and independent support groups can be invaluable. As researcher Carol Smith notes, “Any intervention that can improve the patient's quality of life and ability to manage at home and reduce expensive complications offers significant benefit to patients, payers, and health care professionals” (Smith et al, JPEN 2002;26[3]:159).

“I think not knowing—anything, whether it's dealing with HPN or even things outside of that realm—I think typically people's imagination is much worse than reality,” says a long-term HPN consumer. “You know the old saying, knowledge is power? That's absolutely true. But also, ... in any situation where people are dealing with life-threatening illnesses, they feel the sense of isolation. It isn't coincidental that there are cancer survivor or cancer support groups all around the world.... There are all kinds of support groups out there. There's a reason these things develop, and that's because there's a need....It's very important to me that Oley survive and thrive because of what it did for me [and] knowing that other people are going to continue to need it.”

Between them, D.Y., L.T., and A.D. estimate they have over seventy-five years' experience on HPEN. At the end of an Oley teleconference, D.Y. concluded: “Here L.T., A.D., and I have just spent a nice [hour] talking on the phone, chatting. It was a really great conversation. Wouldn't it be nice if that person just coming out of the hospital, one week with a catheter heading home, could realize that this is what your future could be. That twenty, or thirty, or thirty-five years from now you could be sitting around talking to friends that you met. And yeah, you've been through a lot. But here we are.” ¶

*For a list of other support groups and organizations that might be of interest to home parenteral and enteral consumers, please contact the Oley office or go to [www.oley.org/links.html](http://www.oley.org/links.html).*

## Equipment-Supply Exchange

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

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

## Tribute to Suzanne Rosenthal, Linda Aukett

Don Young, Founding Oley Trustee

We are saddened by the passing of two women who were leaders in the field of education, patient support, and self-help. Suzanne Rosenthal was the founder of the Crohn's and Colitis Foundation. I met her in the late 1970s when we both testified before a panel selected by President Carter to discuss what it was like to live with IBD and what the role of government should be in helping those afflicted. She told of her appearance on *The Today Show* and how she was told not to mention diarrhea or constipation because people were eating breakfast at this time of day—kind of like talking about the ocean without mentioning water.



Linda Aukett with Suzanne Rosenthal 2009.  
Photo courtesy of DDNC.

I met Linda King Aukett when she was president of the Albany, New York, area United Ostomy Association. She offered to assist me in starting a branch of UOA in my area, Saratoga County. Linda later co-founded the United Ostomy Associations of America (UOAA).

I am but one of the thousands of people who were touched by these strong, caring women.

*Suzanne and Linda were mentors to the Oley Foundation in its early years. Joan Bishop, Oley Executive Director, says, "They had 'been there, done that,' and were both generous in sharing their experiences with us as we developed our start-up policies and procedures. Linda and Suzanne were tremendous resources to us. They offered insights*

*and thoughts that helped us become the organization that we are today. Either of them would always be on the other end of the line, willing to help, whenever we called. We are extremely thankful to them for their help and example, and, as Don says, deeply saddened by the loss."*

*United in their commitment to patient advocacy, both women had links to the Digestive Disease National Coalition (DDNC) (see "A Day in Washington," page 5). Suzanne was the founder and past president of DDNC, while Linda served a term as DDNC Chair. If you'd like to share your memories of these women, please post to the Oley Facebook page or send to us at 214 Hun Memorial, MC28, Albany Medical Center, Albany, NY 12208. ¶*

### Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2013 in the January/February 2014 issue. From January 9 through March 5, 2013, gifts were received:

#### In Honor Of

Mariah Abercrombie, Gail Brenenstuhl, Dr. Cindy Greenberg, Sean May's Birthday, Brad Murray, Alexander Topping, and Don Young

#### In Memory Of

Wendy Agar, Alma Louise Anderson, W. M. R. Archer, Marie DeLegge, Portia Lyon Hutton, Kathleen McInnes, Gary Rieck, Ruth Heilpean Rosenplatt, and Andrew VanKleunene

#### Matching Donation

FM Global Foundation and Jones Lang LaSalle

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

## Oley Corporate Partners

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

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

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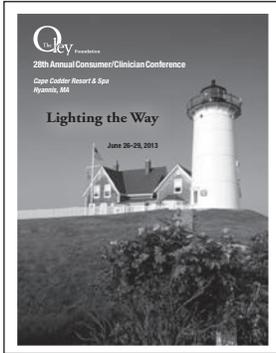
*Thank You!*

## LifelineLetter

### The Oley Foundation

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## Oley Conference Registration Packet Inside

Apply for a \$500 Travel  
Scholarship!

### Meeting, from pg. 1

joyed the camaraderie so common at Oley meetings. During and after lunch, we met in small groups to discuss issues raised by the HPEN consumers and professionals in each group. The time was well spent, and everyone walked away with a new understanding of the challenges different groups face.

The Oley Foundation thanks the following companies for sponsoring this meeting: Cera Products; Coram Specialty Infusion Services; Fresenius Kabi, USA; Sherwood Clinical; ThriveRx; and Walgreens Infusion Services.

### A.S.P.E.N.'s Clinical Nutrition Week

As the Oley meeting broke up, many of us went directly on to Clinical Nutrition Week—A.S.P.E.N.'s annual conference—and to the Oley booth in the exhibit hall. Clinical Nutrition Week is one of the most significant opportunities we have as staff to learn what is new and important in the field of nutrition support. It is also a wonderful opportunity to interact with the “movers and shakers” in this field.

Another highlight of Clinical Nutrition Week is the presentation of the Lyn Howard Nutrition Support Consumer Advocacy Award, which went to Traci Nagy, an Oley member and founder and Chief Executive Momma of Feeding Tube Awareness Foundation. Traci's foundation has heightened awareness of the benefits and challenges of nutrition support through Feeding Tube Awareness Week, and is a wonderful resource, especially for parents of tube fed children. Our congratulations to Traci, and our thanks for all she is doing. (More on Feeding Tube Awareness Week, on right.) ¶



*Traci Nagy and Lyn Howard, MD,  
at Clinical Nutrition Week.  
Photo courtesy of Brandis Goodman.*

## Awareness Week Recap

The Oley Foundation once again joined the Feeding Tube Awareness Foundation in promoting Feeding Tube Awareness Week, held February 10–16. Thanks to all of the Oley members who shared stories, buttons, photos, Facebook comments, and videos. If you haven't yet seen Oley's Feeding Tube Awareness video, it's still on the Oley Foundation channel on YouTube! (Just go to Youtube.com and search for “The Oley Foundation.”) It's not too late to submit your own videos for us to include on the channel.

Traci Nagy, who conceived of and launched Feeding Tube Awareness Week (and who was honored this year with A.S.P.E.N.'s Lyn Howard patient advocacy award—see photo and story on left) told us, “Feeding Tube Awareness Week 2013 was a huge success. By many metrics, the impact of Feeding Tube Awareness Week has tripled since 2012. This year there was greater news coverage, social media reach, more blogs, and video views. There was higher participation among companies, organizations, tube feeders, and caregivers. Well over a million people were reached. Roger Ebert even tweeted about it! However, the most important outcome is joining with others who understand the journey, and feeling less alone in the process.”

You can find links to some of the news stories and videos about Feeding Tube Awareness Week on [www.oley.org](http://www.oley.org) or [www.feedingtubeawareness.com](http://www.feedingtubeawareness.com). If we missed your effort, please let Lisa know at [metzgel@mail.amc.edu](mailto:metzgel@mail.amc.edu) or (800) 776-6539.

Mark your calendar for HPN Awareness Week, August 4–10, and the next Feeding Tube Awareness Week, February 9–15, 2014. ¶