Integrative Medicine

Ellen Wilson, PT

At the Oley Consumer/Clinician Annual Conference in June, Ellen Wilson led a breakout session called "Urban Zen" with a team from UCLA Medical Center that included Tara McColeman, RN; Julie Walden, RN; Lynn Leslie, RT; and Katie Anderson, RN. Conference attendees loved it. One commented, “Wonderful! I think every medical model should consider adopting it.” Another said, “I believe I have found my calling. I want to be trained to do this and volunteer my time at the hospitals. This is great!”

The session was so popular, we asked Ellen to tell us more about Urban Zen and how the program is implemented at UCLA. For more information on the UCLA program and several research articles about integrative therapies, visit www.rehab.ucla.edu; for the Urban Zen Foundation, visit www.urbanzen.org or call (212) 414-8520.

UCLA Health System has a long history of integrative medicine offerings, including the Center for East West Medicine, the Sims/Mann Integrative Oncology Center, and the Mindfulness Awareness Research Center. Recently, UCLA added to these services for inpatients through an innovative collaboration with the Urban Zen Foundation.

The Urban Zen Integrative Therapy program was founded in part by designer Donna Karan. She was impressed by the profoundly effective complementary therapy techniques provided to her husband when he was undergoing treatment for lung cancer. Seeing how these techniques complemented traditional medical care, Ms. Karan made it

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Our Journey as Parents

Shirley Huang, MD, and James Yoo, MD

I am a pediatrician working in an academic children’s hospital where I see predominantly children with special health care needs. My husband, Jim, is a colorectal surgeon. Together, we have a daughter, Janie, with short bowel syndrome who is dependent on home parental nutrition (HPN). We would like to share our journey as physician parents with you.

Imaginings

Life changed dramatically for us when we became parents. Two years after our son, Ryan, was born, we had a second child, our daughter, Janie. During both pregnancies, we enjoyed imagining what our child would be like. All parents have hopes and dreams for their children.

Troubleshooting Tube Feeding

Looking for suggestions for a leaky tube? Or advice on avoiding nausea when feeding? Try the Oley Foundation’s new Tube Feeding Troubleshooting Guide. Based on the popular HEN Complication Chart, the guide features a new section for beginning tube feeders, is easy to read and print, and is completely updated with current medical best practices.

Clinicians and home care providers are invited to share this educational resource with their patients. Copies can be downloaded from www.oley.org; or ordered by calling (800) 776-OLEY. Consumers are encouraged to discuss suggestions with their physician before making any changes in their care.

We are most thankful for the authors/editors: Pat Agre, RN, EdD; Pat Brown, RN, CNSN, OCN; and Kerry Stone, MS, RD, CNSC; and the sponsors: the Daniel F. and Ada L. Rice Foundation.
Parent Journey, from pg. 1

When you have a child with special needs, those hopes and dreams change. We used to wonder: Would Janie be smart or funny? Would she be good at sports? Will she get along with her big brother? As she got sicker and sicker, the questions we asked about Janie changed. We wondered: How big will her scar be? Does she really need a stoma? Will she ever be able to eat? Will she live? Does she know how much we love her?

Realities

Janie was born premature at thirty-four weeks gestation, shortly after being diagnosed as small with no amniotic fluid. She weighed just three pounds at birth. Initially, besides being small, she appeared normal. Within a day, however, she was diagnosed with a distal ileal atresia.

Janie underwent her first of six surgeries at four days of life. We were relieved that they were able to resect the area and reconnect the bowel, “solving” her problem with the initial surgery. She remained in the neonatal intensive care unit (NICU) for two months as a “feeder and grower,” off and on PN.

When we were discharged, she was quite jaundiced and we were scheduled to come back daily for studies and weight checks. Despite this, we were thrilled to have her home with us, and to finally have her big brother meet her. Ryan was less than two years old at the time and had not been allowed in the NICU to visit her.

Complications

Over the next two months, we were in and out of the hospital for failure to thrive and malabsorption. Sometimes, we would be home for less than a day, sometimes we would make it for a week. Finally, when Janie was almost four months old and still weighing about six pounds, the decision was made to take her back to the operating room (OR) for a resection of her initial anastomotic site, which was thought to be the cause of her difficulties.

We hoped this would solve her problems and would allow us to go back to a normal life. We anticipated a simple resection and re-anastomosis like her original surgery, but instead she came back from this surgery with a central venous catheter, a G-tube, and an ileostomy.

Unfortunately, things became more complicated when, within a day, she was taken back to the OR. They found the majority of her bowel was necrotic, requiring a massive resection and jejunostomy. We thought Janie would die that night. She was made DNR (“do not resuscitate”) and after her return to the NICU, we were left to spend time with her behind draw curtains.

Janie managed to pull through, but in addition to severe liver disease, jaundice, and failure to thrive, she now had short bowel syndrome.

Alternatives

This is when we began looking into Omegaven®. We had heard about it in passing from one of the neonatologists, but it was not available in our city at the time. When we realized it had originally been used at Boston Children’s Hospital, I thought perhaps I would know the investigators as I had completed my pediatric residency there. As luck would have it, the primary investigator was a pediatric surgeon, Dr. Mark Puder, who had been Jim’s senior resident when Jim was an intern.

We contacted Dr. Puder ourselves, looked into the published research, and spoke with medical colleagues at other institutions with clinical experience in Omegaven. Some of our own doctors discouraged us and told us we were searching for miracles. We were. We took a chance and had Janie transferred to Boston Children’s Hospital, a difficult decision that involved moving our family across the country.

We spent the next six months in Boston, where Janie was treated with Omegaven. Slowly, her liver failure improved and Janie got better. We stayed there until she was well enough to come back home with us. As parents and as physicians, we have no doubt that Omegaven saved Janie’s life, and we look forward to the day when it will be available, anywhere, for any child who needs it. [See editor’s note page 10.]

Toddlerhood

At fifteen months of age, we returned to
Getting Out

When I first had a tube, it went into my nose and down to the stomach. I used it all of the time with a feeding bag and it sufficed for everyday feeding. When I went to the hospital for hyperbarics, I took the bag along and I would find a room I could use for feeding. This was a daily event until the doctor said I was healed and didn’t need hyperbarics anymore.

Later, when I was going for a checkup, my wife and I would stop and get a meal at a fast food place for my wife. Then we would pull into an area off the beaten path and I would take a pole that I carried in the van, put the bag on it, and sit at the back of the van with my wife and feed. When I was finished, I would use water from a large container that I carried to rinse the bag and tubes and everything was fine.

As a matter of fact, we would also travel to various malls and shop. When lunchtime would come I would get my wife a meal and we would go to the van. At one mall there was an outside place that had a pole permanently in place that had a hook on it we used. At other times we would ride around and do the same thing at roadside covered tables.

One day I was home feeding and something went wrong. I didn’t want to throw the formula away so I poured it into a big glass and used the syringe to feed. That was how the feeding bag got relegated to the home. It was time to get a low-profile feeding tube put in, and I started to use the syringe more frequently. We started to go to restaurants and I started ordering a glass of water and an empty glass. We find ourselves using the syringe more frequently. We started to go to restaurants and I started ordering a glass of water and an empty glass. We find ourselves at restaurants quite frequently.

Vacation

Now this may seem to be enough adventure, but every year the family goes to the Outer Banks for vacation and I use this method of eating on the way down, when we go out to eat, and on the way back. It is no problem because the van has room to carry several cases of liquid nutrition. We have been many places, like the Thomas Jefferson home and Myrtle Beach.

It gets sticky when you are flying someplace. On a trip to Disney World with two of our daughters and their families, I stopped after getting off the plane and before arriving at the motel and got my necessary nutrition at Wal-Mart. I had a large bag that I could put on like a belt [a fanny pack] and had the meal with me.

Another time one of my daughters invited us to go along to the Grand Canyon. That was too good to turn down, so we flew to Phoenix. I got enough nutrition to go to the canyon and made many stops between there and Lake Powell. We also toured the Gulf Coast on a trip to Mississippi, and later to Pensacola, Florida.

We decided to take a cruise with another of our daughters and her husband. I can’t say enough about the service on these cruises and they provided me with nutrition for the whole time. It certainly was different, especially our stopover in Belize. They had some pyramids and we ate in a small town. Another stop was Key West. We had a magnificent time, and I had my lunch in a famous bar/restaurant.

We made another trip with our fourth daughter who needed a ride to Vermont to see her sister-in-law. It was apparent we were going to be there for several days, so we decided to head north and visit Montreal. We had a good time and took a tour of the city. Afterward I was walking and found a way to get down under the city. I had several of my meals at restaurants in this part of the city.

Being Resourceful

What do you do when it is time for you to eat but you will not get home for several hours and you don’t have your formula? It happened to me. I took my wife into a fast food restaurant and ordered a glass of water and a vanilla milkshake. When it came it was thick, so I got a pint of milk and stirred it in. When it was a proper thinness that I could get it in the syringe, I fed that way. The glass of water was very handy to get the shake through the tube and to clean out the tube and syringe.

Conclusion

It doesn’t matter where you are and what the native language is. You can always get a meal, even if it is one you carry yourself, because you can always order a glass of water and an empty glass. I just hope you get the idea that you don’t have to stay home any more.

One more tip: When staying at a motel or other strange place, be sure you include an “S” shaped hook, as you may use it to hang your bag from the curtain rod in the room. Or you can do as I started to do, and just use the syringe.

Editor’s note: Bolus feeding (using a syringe) isn’t an option for everyone, nor can everyone with a g-tube tolerate milkshakes. Please consult with your health care provider before making changes to your feeding regimen.

—Michael B., brady1202@comcast.net

Makeshift IV Pole

When traveling, we often use an old-fashioned ironing board for an IV pole. Turn the padded side next to the wall, hang the bag from the ironing board leg, and attach a pump clamp to the lower part of the leg. You can wedge the ironing board between the bed and wall or the nightstand and wall for support. You can also open the legs a bit for support and to lower the height. Lots of hotels now have ironing boards in each room.

—Jane H.
Regional News

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 or call (800) 776-OLEY.

The Children’s Intestinal Rehabilitation Center at LeBonheur Memphis, Tennessee

Nutrition-based clinicians at LeBonheur Children’s Hospital and the University of Tennessee Health Science Center have managed inpatient and home parenteral and enteral nutrition (HPEN) in children with short bowel syndrome (SBS) and other gastrointestinal and surgical disease states for more than thirty years.

The Children’s Intestinal Rehabilitation Center at LeBonheur (CIRCLe) was established in 2007. It is a multidisciplinary and interprofessional team, representing pediatric gastroenterology and surgery, neonatology, clinical pharmacy, clinical nutrition (dietitians), and nursing. CIRCLe’s stated primary goal is to standardize and optimize clinical management of patients with SBS through an evidence-based, integrated, and interprofessional approach to patient care.

Major CIRCLe initiatives are intestinal rehabilitation through surgical interventions, enteral feeding success, and continual assessment; and management of long-term PEN to sustain growth while decreasing catheter-related infections and hospitalizations, intestinal failure–related liver disease, and nutrient deficiencies. SBS patients in the community are managed through the CIRCLe clinic and the team comes together monthly to discuss management of all SBS patients, inpatient and outpatient, and their progress toward intestinal rehabilitation.

Research endeavors have been directed toward altering the progression of intestinal failure through innovative therapies, improved nutrient absorption, and reduced complications. The center does not perform intestinal transplantation. For more information contact CIRCLe Coordinator, Ila McDonald, RN at (901) 287-6392.

Call a Peer, Toll-Free!

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley’s peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

• (888) 610-3008 for HPN (intravenously infused nutrition).
• (888) 650-3290 for HEN (tube feeding).
• (877) 479-9666 for parents of HPEN consumers.

We hope you’ll use this opportunity to improve your quality of life.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.
Appetite for Life: An HPEN Experience in Poland

Marek Lichota

I will briefly present only a few facts concerning my disease because I think the majority of LifelineLetter readers have experienced a lot in their lives and would prefer to read something optimistic, that will build positive emotions.

I am thirty-two years old and live in Cracow, Poland. Since 2002 I have suffered from Crohn’s disease. At the beginning the disease was taking its normal course, but this was not something I could expect for my future. I had surgery in 2005. I got married, became a father, and worked.

Unfortunately, my life changed when I had a disease flare-up in 2008. Due to abundant intestinal hemorrhage, I had four operations, which resulted in multiple enterectomies. After a month-long struggle to stabilize my condition, I was left with approximately 80 cm of small intestine and a stoma.

The Appetizer

In the beginning after the surgery, functioning was very difficult. Daily eighteen-hour parenteral nutrition (PN) and the need to live with a stoma caused changes in my life. It took me a long time to accept the situation. Then I started to focus on things that I could do, while trying to forget the obvious limitations resulting from my poor state of health.

Dr. Dudrick engaging with Marek during a visit to Cracow

Fortunately, the coming months brought a gradual improvement of my health, so after one and a half years of treatment I could undergo another operation. Its aim was to restore intestinal continuity. Although I could not avoid complications, eventually the operation was a success. This step enabled me to look optimistically into the future.

It’s unbelievable, but in six months after this surgery, I had managed to put on over 10 kg (22 pounds) of weight. This has strengthened not only the need to consume more food taken orally, but has also allowed me to feel the proverbial “appetite for life.”

The Entrées

Since that time I have decided that I will try—to the maximum possible extent—to realize my life plans regardless of PN. One of the first manifestations of this idea was my participation in the EFCCA Youth Meeting in Norway in 2010. EFCCA is the European Federation of Crohn’s and Colitis Associations, which supervises a number of initiatives and projects aimed at improving quality of life among patients with inflammatory bowel disease (IBD) in Europe. It was the first time I had to arrange the air transport of my PN bags. Generally, I experienced more kindness and help from the airport.

Appetite for Life, cont. pg. 6
service people than trouble and unnecessary problems. In the end, I can consider the entire five-day trip very successful. I gained knowledge that has helped me during subsequent visits.

In June 2010, I set out together with my wife and daughter on another trip, to spend a lovely week on the shores of Lake Garda in Italy. This time we traveled by car with a mobile fridge in which we kept nutrition medicaments. During this journey we gained even more experience, as due to some damage we had to leave our car at a service station and look for a rental. I will also not forget another experience I had during this trip: my first dip in a pool after nearly three years (a break associated with a period of disease complications).

Undoubtedly, an appetite for life wasn’t missing during a trip to the Polish mountains with a group of other people suffering from IBD, and the ascent of a 1,300-meter peak, after a nearly three-hour-long approach. I also couldn’t give up my favorite winter discipline, which is skiing. At the first opportunity, I went to a ski resort located 100 km from my house to enjoy snow for the first time after a long time. Although the effort I made was out of proportion to the result, it gave me a lot of satisfaction. Shortly after this week, I decided to spend the winter holidays skiing in Slovakia with my family.

These tours, as well as the opportunity to spend my thirtieth birthday with my family, friends, and colleagues, intensified my optimism in life. I try to exploit every second I am given and I set myself far-reaching goals.

The Side Dishes

Further evidence of this was my trip to Minneapolis, Minnesota, in 2011 for the “Alive, Well, and Even Better” Oley Foundation annual conference for parenteral and enteral nutrition consumers. There I obtained a huge dose of information that will pay off in future treatment. The Oley conference gave me an extra dose of positive energy and allowed me to get to know many interesting people.

Because I had been considering bowel transplant before the doctors restored intestinal continuity in 2009, I’ve visited Prof. Kareem Abu-Elmagd at the University of Pittsburgh Medical Center in Pittsburgh, Pennsylvania. It has been another great experience, because Dr. Abu-Elmagd welcomed me warmly and we have discussed all possible options for intestinal rehabilitation. I have been so amazed with his attitude that my journey to Pittsburgh will last in my memory for a long time. [Note: Dr. Abu-Elmagd is now director of the Intestinal Transplant Program at the Cleveland Clinic, Cleveland, Ohio.]

In addition, I can also boast of a British accent. I spent two weeks of my 2011 holidays traveling by camper through England, Scotland, and Ireland. In order to enjoy the natural beauty of the Cumbria Lake District, Highlands, Isle of Skye, and Cliffs of Moher, I agreed with my doctor to have a batch of nutrition bags sent to the airport in Dublin via courier, because the ones I took with me could only be stored in the refrigerator for one week. Although on our return our luggage looked like a come-back from six months rather than a two-week expedition, the enormity of positive memories and impressions of this trip will long remain in my memory.

PN in Poland

I think it could be interesting for you to know how I deal with my PN at the moment. Every week I get three 1.7 liter nutrition bags from my hospital (my PN provider). The bags have to be kept in cooling conditions and additional vitamins and a few other medicines must be added before I infuse. All this is done by me or by my wife. Our health care staff is responsible for our training and examination, and for providing all necessary medicines and IV accessories.

Usually I get my PN during the night. It takes approximately twelve hours. For two years I’ve been using a Fresenius Ambix Activ portable pump. It enables me to put my nutrition bag into a rucksack and then I don’t have to take my IV stand when I’m going away. That makes my life much easier. Unfortunately, the portable pump is not refundable in Poland, so the patient has to bear the cost of it.

The Dessert

Summing up, implementing all of the plans mentioned above has required a lot of effort and organization from me and my wife. Often it was associated with the pain and discomfort that accompany Crohn’s disease and PN. Never, however, will this outweigh the satisfaction and joy drawn from life on the rightful basis. I think that for all of us it is important to fight with the limitations, and as far as possible to prevent our disease from dominating our lives in any aspect.

That’s why in 2012 I set up an association for home parenteral and enteral (HPEN) consumers in Poland. With the amazing example of and experience from the Oley Foundation and PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy, based in the UK), I hope it will be easier for me now. After just three months of functioning, "Appetite for Life" had more than fifty members, and we’re growing very quickly. I hope we will build a strong community of people who will support each other and share their experience in the nutrition field.

I have had the pleasure of attending a few European physician nutrition courses, to gain new knowledge and represent our association. Again it was a great chance to meet nutrition authorities from Europe and the United States. I met a member of the American Society for Parenteral and Enteral Nutrition’s (A.S.P.E.N.) Board of Directors, Ainsley Malone, MS, RD, with whom I had a nice conversation concerning Oley. The most exciting was the meeting with Prof. Stanley J. Dudrick, MD, who made a great impression on me as an outstanding doctor who gives us a chance to live. His warm personality has also shown me that he is an exceptional man.

Last but not least, I’d like to say I was sorry I was not able to attend this year’s Oley conference. We were expecting a baby! Our son was born in August, and now I am no longer the only man in my family.

Editor’s note: Marek is an Oley Regional Coordinator volunteer and foreign affiliate. If you’ll be traveling in his neck of the woods, be sure to drop him a line at marek.lichota@apetytnazycie.org. ¶
Oley Visits Poland

Joan Bishop, Executive Director

I just returned from Poland, where I was a guest of the Polish Society for Parenteral and Enteral Nutrition (POLSPEN) and Marek Lichota, an Oley member, homePEN consumer, and founder of Appetite for Life. Marek had coordinated a spectacular soccer (football) event to help raise awareness of the need for portable pumps for home parenteral and/or enteral nutrition (homePEN) consumers in Poland. What an amazing man and event! Words cannot describe the crowd, the activities, the soccer match, and the enthusiasm for raising funds to shift folks from stationary pumps to portable pumps and backpacks.

Marek’s passion for improving the quality of life for the homePEN community in Poland is remarkable and contagious. I feel it’s only a matter of time before portable pumps will be available. We’ll stay tuned.

The Event

The festivities took place on Sunday, September 23, with the support of POLSPEN, homePEN consumers and family members, clinicians, and friends in the community. The centerpiece was a soccer match between a team of medical professionals (including Michael Chourdakis, MD, PhD, from Greece, and Alastair Forbes, MD, from England, who made the journey!), and a team made up of members of Parliament, actors, professionals, and Olympic soccer players.

From the start with the ball being dropped from an airplane, to the end when the trophy was awarded, it was apparent that everyone in the stadium was a winner. Food and activities were abundant and a good time was had by all. This was clearly a day that showcased this community of warm-hearted people who have one aim—to help people on homePEN.

Attendees listened as Marek outlined the needs of the homePEN community and introduced them to the Oley Foundation. They were encouraged to donate generously as volunteers circulated with cups. More volunteers sold raffle tickets for a Samsung tablet and other prizes, and a live auction was held during half-time. Inflatable bouncy rides, a giant hamster-ball ride, CPR demonstrations, rides on a firefighter lift, and more rounded out the afternoon’s event. Mission—to inform and entertain—accomplished.

Dedication

For three days following the match, I was Marek’s sidekick. He showed me a few landmarks and we spent time visiting Dr. Klek and Professor Spodaryk and their staff at hospitals in Skawina and Cracow. I couldn’t have been more impressed with the interest, dedication, and passion regarding quality of care and improving the lives of homePEN consumers.

It was a remarkable journey, organized by a remarkable man for an extremely worthy cause. As the Oley Foundation Executive Director, I was proud to have been part of Marek’s effort and hope that in some small way I contributed. Hats off to Marek and his tremendous team of volunteers! We cannot wait to see what they have in store for us next year.

Marek tells us there will soon be a video of the event at www.youtube.com/AppForLife.

Oley Executive Director Joan Bishop gives the thumbs up after the ball dropped from an airplane and landed center field.

Marek Lichota showing the limitations of using a pole-mounted pump with Paulina and her daughter, Emilia.

Observing PN preparation at a hospital in Poland.
Feeding Tube Awareness Week, February 10–16, 2013

Once again, the Oley Foundation will be joining the Feeding Tube Awareness Foundation and other organizations to promote Feeding Tube Awareness Week. But this grassroots effort is really YOUR week. We’ll help provide a platform and structure, but you’re the stars!

Feeding Tube Awareness Week was established to help people understand what life with feeding tubes and enteral nutrition are all about. Who better to increase understanding than you, the home enteral nutrition (HEN) consumer, who has day-to-day experiences with feeding tubes? While increasing tolerance and knowledge, you may also be creating bridges to people who are feeling isolated by or struggling with tube feeding. While you may never know it, others may be inspired by your story, or may reach out for answers and support after hearing about your experiences.

Oley Video Needs You!

We kicked off HPN Awareness Week in August 2012 by launching a video on You Tube (look for “Alive with HPN” on You Tube if you’d like to see it). It was a great success, and we are working on a new video for Feeding Tube Awareness Week. We need your photos! Please send them to Lisa at Oley, along with a brief statement about what tube feeding means to you (contact information below).

The Press

It’s worth taking a chance and sharing a press release, if you’re not camera shy. News organizations and bloggers are always looking for interesting stories, and yours is unique and inspiring. How is tube feeding helping you or your child be active or grow? What do you do if/when you or your child can’t eat? How do you cope with the challenges of tube feeding?

For HPN Awareness Week in August 2012, we helped send out just a dozen or so press releases (we’re hoping for more next year!), but each of those press releases generated a story. An article in the Albany, New York, Times Union generated a call from a mother in Maryland, seeking information for her tube-feeding son. With the Internet, even stories in the local press can be far-reaching.

Other Venues

If you’re not up to news coverage, please join us on Facebook or the Oley Inspire forum for daily discussions. During HPN Awareness Week, the Oley Facebook page reached more than 13,000 people! Check out the Feeding Tube Awareness Week Facebook page also—it is bound to be hopping that week. The Oley Inspire forum is a little quieter and more private.

Feeding Tube Awareness Week is also a good time to reach out on a very personal level—to your friends and family, or school or church groups. Maybe you want to have a frank conversation about something you find challenging with a friend, or take the opportunity for “show and tell.”

We’re Here to Help

What you do with Feeding Tube Awareness Week is up to you. We are here to help and support you. Call or write for help with press releases, or to share ideas. We look forward to hearing from you. Don’t forget to send us your photos!

Please send pictures, videos, questions, ideas, etc. to metzgel@mail.amc.edu or the Oley Foundation, 214 Hun Memorial, MC28, Albany Medical Center, Albany, NY 12208.

Like Oley on Facebook

During HPN Awareness Week, Facebook was one of the most effective ways we communicated with Oley members, and members communicated with one another. It’s a quick and easy way for us to get out timely information and to share news and photos. Like us today!
Tribute to Jennifer Jaff

We were saddened to learn in early September that Jennifer Jaff, Esq., had passed away. Jennifer was the founder and executive director of Advocacy for Patients with Chronic Illness, Inc. She was a valuable resource and an impressive advocate, and she will be sorely missed.

As president of Advocacy for Patients with Chronic Illness, Carol Fain Walters knew Jennifer well. Carol has granted us permission to reprint an extract from her blog that pays tribute to Jennifer.

Heavy Heart
Reprinted with permission, advocacyforpatients.blogspot.com, September 19, 2012

Jennifer conceived of and founded Advocacy for Patients because of her extraordinary passion and commitment to ensuring equal rights for those living with chronic illness. She dedicated her life and career to improving the quality of life for others based on her own experience with Crohn's disease.

Her advocacy on a personal level with individuals, in chronic illness arenas for larger disease populations, and in global forums for local and national health care reform was unparalleled in its sophistication, conviction, judiciousness, and honor. Jennifer believed fiercely that this cause was a civil rights issue, and her belief in the worth and rights of every individual with a chronic illness set precedents and models for equality nationwide. Her goal to increase awareness of the need for and the power of advocacy for chronic illness touched all of us who knew her as well as the population at large. She always worked with amazing energy, grace, fortitude and resolve….

We know that Jennifer will always be remembered for her dedication and the actions she took in the pursuit of justice for those with chronic illness. Be assured that the Board of Directors and the Staff of Advocacy for Patients will do everything in our power to promote Jennifer’s great legacy.

CaringBridge.org
Keep Loved Ones Informed

CaringBridge is popular with many Oley members, and you might find it useful, too. The organization provides free Web sites that connect people experiencing a significant health challenge to family and friends. It is their goal to “make each health journey easier.” Go to CaringBridge.org to learn how to create a personal and private CaringBridge Web site. Once you’ve created a site, you can update it as you choose, and family and friends can check in to see how you are doing.
Boston to have Janie’s intestines reconnected. When we returned home, we were finally able to cycle her HPN to run over twelve hours instead of twenty-four. This came just in time, as chasing after a newly walking toddler connected to a backpack on your back all day has its challenges! Luckily, once Janie got going, she didn’t mind balancing and wearing her own backpack. With this time came a lot of hope for us that things were on the upswing, that we had gone through the worst of it, and that she would continue to get better.

Over the next year, there were a lot of bumps. She still wasn’t able to tolerate enteral feeds. We thought she would need another surgery to “fix” a persistently dilated loop of bowel that was believed to be the problem, but ultimately the surgery was canceled. She was changed over to a GJ-tube and tried on another prokinetic medication. We made little progress in advancing her enteral feeds and she was still on full HPN.

Life Today

Though it was a difficult year, we also saw Janie grow and develop. While we continue to hope that someday she may come off HPN, we don’t wait for this day. We look at the big picture and marvel at all the wonderful things that are happening in the midst of our struggles.

When Janie was two and a half years old and our son had his fourth birthday, his birthday wish was for Janie to start talking so they could talk together. Over the past year and a half, she not only began talking, but now talks nonstop with never-ending energy! Ryan may at times regret that birthday wish, but he will never tire of having a sister in his life.

At the end of the day, we have a happy four-year-old daughter. And we have been able to answer many of the questions we used to have about Janie before she was even born. Would Janie be smart or funny? Well, Janie is smart (gifted, actually!), and she is funny. She makes us laugh every day. Will she be good at sports? Not really. Will she get along with her big brother? Usually, and when they do it is a beautiful thing. How big will her scar be? Her scars are big, but that just means she is growing. Will she ever be able to eat? She is eating better and is growing and thriving. Will she live? Life is precious; we take every day as it comes. Does she know how much we love her? Of course she does, because we tell her every single day.

Editor’s Note: It is important to realize that Omegaven lipid has not been approved by the Food and Drug Administration (FDA) for release in the United States. Dr. Darlene Kelly, Oley’s Science & Medicine Advisor, adds that there are multiple lipids used in Europe and Asia, but at this point only Intralipid®, a product made of soybean oil, egg
phospholipid and glycerin, has been approved by the FDA. There are current efforts to have alternate lipids reviewed by FDA. Data and clinical experience, primarily from Europe, are promising. There have also been several research studies in the U.S. that have focused specifically on Omegaven (see www.oley.org/Omegaven_Liver_treatment.html).

Omegaven is an omega-3 based lipid solution made from fish oil. Progress is being made in identifying dose requirements, primarily for babies. It must be emphasized that use of this lipid in older children and adults with PN-related liver disease has not been fully explored. The mechanism for development of PN-related liver disease is uncertain; it appears that the type of lipid used, the amount of lipid used, or the frequency of lipid infusion may be related to the pathophysiology of liver disease. Whether the improvement that has been seen in babies and very young children on Omegaven is related to the ability to decrease the Intralipid infusion or to a specific characteristic of the fish oil, Omegaven does seem to play a role in some specific consumers. HPN consumers need to be following the lipid story as it develops over time.

We at Oley are very pleased that this beautiful family (and especially Janie) is doing so well after a difficult course. We were privileged to meet them at the Oley meeting in California this summer, and are happy to say Dr. Huang and Dr. Yoo's presentation is available on the conference DVD (see page 16).

Oley Gains Medical Expertise

The Oley Foundation is pleased to announce that Darlene Kelly, MD, PhD, Oley Trustee, is taking on additional responsibilities at the foundation. Dr. Kelly will share her medical and research expertise with Oley members as she guides Oley projects and serves as Science and Medicine Advisor.

In November, Dr. Kelly will be retiring from her position as Medical Director of the Home Parenteral Nutrition Program, Mayo Clinic, Rochester, Minnesota. Dr. Kelly has served in this position since 1990.

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Equipment-Supply Exchange

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

Questions? No Internet access? Contact Oley volunteers Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST. Be sure to include the details about the items you are donating when you call or email, such as the amount you have, the expiration dates, the size, and/or the order number(s).
one of her goals to spread these techniques to health care and wellness providers across the country.

Techniques

The terms “integrative” and “complementary” refer to practices that treat the whole person—body, mind, and spirit—and which complement traditional western medicine. These natural healing techniques encourage relaxation, focus, and spiritual or emotional balance, all of which can help speed recovery and can provide symptom relief. The techniques used in Urban Zen include in-bed yoga (including restorative poses); Reiki (therapeutic touch); aroma therapy with essential oils; mindfulness/meditation and body scan techniques; and self-care. In addition, patients are taught how to practice these techniques on themselves, to promote self-care and additional strategies for symptom control. Caregivers, too, use the techniques for their own self-care, in order to be calm and more present for their patients or loved ones. Once learned, the techniques can be used for lifelong wellness.

One of our patients who was treated with Reiki said, “That really worked! The Reiki was so relaxing. I feel like that’s the first thing somebody has done for me as a person since I came to the hospital.”

Another wrote, “I was discharged after spending six days receiving continuous infusion chemotherapy for non-Hodgkin lymphoma. The care was excellent, but as part of my treatment I was placed on high dose prednisone, a cardiac monitor, a PICC line, and exposed to frequent interruptions of sleep due to blood draws, ambient hospital noise, and other stimuli. I received Urban Zen techniques on two occasions, which demonstrated basic, effective methods of dealing with the stressors I was encountering as part of my hospital experience. I wish to express my gratitude for the help I received from the Urban Zen program and hope that the program’s true value will be recognized and respected as an instrumental part of providing excellent healthcare.”

Training

The Urban Zen Integrative Therapy program includes an in-depth training curriculum, and UCLA has been able to provide this training to its employees. Training in Urban Zen techniques is offered as an adjunct to the clinical skills the employee already possesses. To be accepted for the training, employees must have direct patient care responsibility and have prior experience with integrative therapy techniques (privately or professionally). Once the employee completes the classroom training and supervised clinical practice, he or she is certified as an Urban Zen therapist and can work independently with patients or their family members.

At UCLA

To comply with hospital requirements, a policy was developed for the program and passed by the medical staff committees. Additionally, initial and annual competency forms were developed, as well as guidelines for ongoing mentoring and support. As more employees are trained, a buddy system will be developed, so experienced Urban Zen therapists can mentor newer ones.

Inclusion criteria and precautions were developed; these allow the bedside nurse to approve a patient’s participation. A physician order is not generally required, unless the patient falls outside the inclusion criteria. Documentation is done by the bedside nurse, and the techniques are provided free of charge.

So far, eighty-six UCLA employees have been trained. Participants have included physicians, nurses, physical therapists, respiratory therapists, social workers, radiology technicians, and others. UCLA’s goal is to have two hundred employees trained, so an Urban Zen therapist will be “available on every floor, every shift, to provide the techniques in the moment patients need it.” Currently, the eighty-six trained cannot keep up with the demand, and there is a waiting list of close to two hundred employees interested in the training. There is interest in providing this care as a routine part of the preoperative area, as well as for the oncology and cardiothoracic populations.

“Imagine a healthcare system where the patient is treated, not just the disease. Imagine a system where eastern healing techniques...are used in combination with western medicine in a holistic approach to patient care....

“The UZIT [Urban Zen Integrative Therapy] program set out to bring dignity to the families, patients, and doctors whose well-beings are ravaged by the confrontation of illness day after day, and often with the uncertainty of what the final outcome might be. The UZIT program was designed to complement the care provided by western healthcare professionals in adding modalities such as yoga, acupuncture, Reiki, bodywork and nutrition to the experience of all individuals involved in dealing with illness.”

—The Urban Zen Foundation, www.urbanzen.org
Bookshelf

Diagnosing Kourtney, by Laura Najjar
Lisa Crosby Metzger

Kourtney was born in July 2002; in June 2009, she was listed for a multi-organ transplant. This book, written by Kourtney’s mom, is “the story of [their] journey” between these two points. Laura kept a daily record as Kourtney was diagnosed with neurogenic pseudo obstruction, osteopenia, and, finally, intestinal failure, and she shares her journals here “as a help to all parents of children with this condition, and for all families and children who face life threatening issues on a daily basis.” It is a journey many Oley families will recognize, full of ups and downs, strength and frustration, and love. You’ll fall for Kourtney from the moment you see her photo on the cover of the book. The book is available through bellissimapublishing.com or amazon.com ($25.00).

My Complete Caregiving Organizer, by Pat Dranchak
Bob Smithers

My Complete Caregiving Organizer by Pat Dranchak is exactly what it says it is: a comprehensive collection of forms, charts, lists, and ideas to help the caregiver(s) get and remain organized. The author developed this tool from over eleven years of caregiving, and has covered seemingly every aspect of providing care for a loved one. The organizer is available in different formats (see below). I reviewed the spiral binder, which is broken into sections for personal, contact, insurance, and medical information; medications; legal documents; health tracking; care plans; and physician visits. A cover sheet provides a checklist of forms and information to include in an emergency packet, good for doctor or ER visits, or for emergency medical personnel.

The section on medications allows you to compile a list of, and provide detailed information on, medications, and record a daily medications schedule. One thing missing is space to enter e-mail addresses in the provider and support contact sections. My wife and I contact many of our providers, including our home health provider and some physicians, by e-mail. We get a better response for routine business this way.

The organizer is also available as a digital download, e-book, on CD-ROM, and in a three-ring binder (two versions). According to their Web site, the CD-ROM contains the same sections and forms as the spiral-bound version and one of the two binder versions. The second binder version (master system) contains all these sections and forms, plus sections for insurance claim logs, checklists, journal/notes, and more.

The digital download and the CD-ROM versions allow you the convenience of filling in forms on your computer, while in the other versions, you fill in forms by hand. The advantage of the binder versions is that additional forms can be placed in the proper sections, although these versions are much pricier than the others.

The Caregiving Organizer begins with seven well-written pages on using the organizer and structuring your caregiving organization. It should be extremely valuable to those new to caregiving, and will provide reminders and ideas for “seasoned” caregivers. Each section is preceded by a page of information/instructions. Compiling detailed information in one book allows persons other than the primary caregiver(s) to easily access all the information necessary to provide care and handle emergencies. For those of us who have tried to organize all of our information in various places on our own computers, using one of the digital versions of the Organizer would seem to be a tremendous time saver. This organizer should allow even the least organized among us to take charge of the responsibilities of caregiving, and do it safely and efficiently.

My Complete Caregiving Organizer: spiral bound, $24.95; binder (standard), $44.95; master system, $74.95; digital download, $24.95; CD-ROM, $29.95; e-book, $14.95. Available through PLD Caring Solutions, 230 Dorcas Ct., Mount Laurel, NJ 08054; (856) 552-1378; or atmyfingertips.us.com.
Donor Profile: Carol and Jack Leibee

My wife, Carol, and I have been supporters of the Oley Foundation since we first learned about it in 2005. That was the year I was diagnosed with short bowel syndrome (SBS) as a result of a small bowel bypass. All we could do was follow the gastroenterologist’s directions for treating the symptoms. We decided to seek a second opinion, as we had a lot to understand and many decisions to make.

Because my wife and I wanted to make sure I was receiving the best treatment possible, we visited an out-of-town gastroenterologist who had more experience with SBS. His nurse told us about Oley and how they could possibly help us. After looking at their Web site and calling a couple of their patient volunteers, we knew that Oley could be a tremendous help. We weren’t looking for a different treatment regime; we just wanted to know how other people dealt with the myriad of choices one had with respect to type of catheter, diet, preventing line infections, clogged lines, travelling with infusion equipment and supplies, and a lot of other decisions.

Carol attended the first conference in Tampa and came home excited about what she had learned and the people she had met. We asked lots of questions and sought advice from the volunteers and Oley staff. We were always looking for ways to minimize the impact of home parenteral nutrition (HPN) on my organs. We became very proactive in seeking adjustments to my treatment by asking the gastroenterologist about options when it came to the HPN formula, volume, and infusion rate. After five plus years of HPN, I finally got off of it. We believe this is partly due to the help we received from Oley and its family.

Having gotten so much help from Oley and seeing firsthand the benefit of attending its annual conference, Carol and I have been donors for the past five years and plan to continue. We give money directly to Oley for whatever use it sees fit. We also provide money for a travel grant to help a patient go to the annual conference. Because attending the conferences has been so beneficial, we want to provide the opportunity for other patients to take advantage of all it has to offer.

We encourage you to make a donation to Oley, regardless of the amount. Whether or not you, a loved one, or a friend has experienced an illness requiring parenteral or enteral feeding, please consider donating to Oley. Your donation will help make at least one person’s illness a little easier to endure and make their life better.

Shopping Online? Share the Benefits with Oley

When shopping for your friends and loved ones, you can allocate some of the proceeds to the Oley Foundation. It doesn’t need to cost you a cent and helps keep Oley’s programs free of charge for consumers on home IV and tube feeding, and their families. There are several sites to try (listed below). And for that special person who seems to have everything — you could consider making a donation to Oley in their honor. It’s simple and secure at www.oley.org.

Thank you for supporting Oley Foundation programs!

www.iGive.com/oley
Shop your favorite online stores through iGive.com. Select Oley as your charity of choice, and a portion of your purchase will be donated to the Foundation. If you are new to iGive, when you shop within forty-five days of registering they will donate an extra $5 to Oley!

www.GoodSearch.com
Use GoodSearch for all your Internet searching needs. If you select the Oley Foundation as your charity of choice, a penny is donated to Oley for every search you make—whether you are shopping or researching.

www.GoodShop.com
Use the GoodShop Web mall for shopping, choose Oley as your favorite charity, and up to 37 percent of your purchase will be donated to the Foundation.

www.giftsthatgive.com
Shop your favorite brands, select the Oley Foundation as your charity from the dropdown box in the shopping cart, and 20 percent of your purchase will be donated back to Oley!

Designate Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this by designating the Oley Foundation on your United Way campaign pledge card.

Questions? Please contact Roslyn Dahl or Joan Bishop at the Oley office by calling 800-776-OLEY, or emailing dahlr@mail.amc.edu or bishopj@mail.amc.edu.
Contributor News

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 2012 in the January/February 2013 issue. Between August 12 and September 25, 2012, gifts were received:

In Honor of
Home Health Pharmacy, Lafayette, IN; Rachael Miller; Eleanor Orkis; Aiden Raffe; Susan and Joel Vatsky’s wedding

In Memory of
Esther Ann Brown Adler; June Bodden; Robert Martino; Susan Oberski

HPN Awareness Week Fundraiser
Baxter Employees’ “Jeans Day”

Matching Gifts
Allstate Giving Campaign and GE Giving Foundation

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!

Join the Oley Horizon Society
Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference at (800) 776-OLEY.

Felicie Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Cotter
Jim Cowan
Rick Davis
Ann & Paul DeBarbieri
David & Sheila DeKold
Tom Diamantidis, PharmD
Selma Ehrenpreiss
Herb & Jay Emich
Jerry Pickle
Don Freeman
Linda Gold
Linda Grovenstein
Deborah Grover
The Grover Family
Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kathleen Iyer, MD
Dorri R. Johnson
Darlene Kelly, MD
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Lauren Matarrese, PhD, RD, CNSD
Kathleen Mclnies
Michael Medward
Meridith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Ordand
Judy Peterson, MS, RN
Clement Pietzner
Beverly Promisel
Abraham Rich
Gail Egan Sanisiero, MS, ANP
Rosalyn & Eric Scheib Dahl
Susan & Jeffrey Schesol
Doug Seldin, MD, FACQ, CNSP
Judi Smith
Steve Swensson
Cheryl Thompson, PhD, RD, CNSD,
& Gregory Thompson, MD, MSc
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Roseline Ann & William Wu

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)
Apria Healthcare / Coram Specialty Infusion Services
Nutrishare, Inc.
ThriveRx

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

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

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)
Abbott Nutrition
InfuScience, Inc.
Kimberly-Clark
Walgreens Infusion Services

PATRON LEVEL PARTNERS
($5,000–$9,999)
Allstate Giving Campaign and GE Giving Foundation

BLUE RIBBON PARTNERS
($2,500–$4,999)

Thank You!
Join Oley in Phoenix, February 9–11, 2013

Spend an afternoon learning about the therapy that sustains you at an Oley-sponsored consumer-focused meeting in Phoenix on February 9. Then stay to help Oley at A.S.P.E.N’s Clinical Nutrition Week! Watch the Oley Web site and the November/December issue of the newsletter for details. We’ll be announcing speakers and topics soon!

After the Oley meeting, join Oley staff in the exhibit hall at Clinical Nutrition Week, February 9–11. This is the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), and you’ll meet experts from around the world as you distribute Oley materials at our exhibit booth. You’ll also learn about the newest products and services available in the field of clinical nutrition as you explore the exhibit hall.

Visit the A.S.P.E.N. Web site at www.nutritioncare.org for a list of the many exhibitors who will be at Clinical Nutrition Week, February 9–11. This is the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), and you’ll meet experts from around the world as you distribute Oley materials at our exhibit booth. You’ll also learn about the newest products and services available in the field of clinical nutrition as you explore the exhibit hall.

Give Us Your Feedback!
We’re overhauling the Oley Web site and need your feedback to make it the best site for YOU. Visit www.oley.org and take our brief survey today!

Conference DVDs Offer Easy Way to Learn the Latest

Missed the 2012 Oley conference? Or want to see a presentation again? The main sessions and highlights are available to view at your leisure in your own living room! Borrow the DVDs to hear the experts address critical and timely issues in home IV and tube feeding. Presentations from 2012 included on the DVDs include:

- Managing Short Bowel Syndrome, Carol Parrish, MS, RD
- HPN and Fatty Liver Disease, Hossam Kandil, MD, PhD
- Managing Complications, Doug Seidner, MD, AGAF, FACC, CNSC
- Skin/Wound Issues, Dane DeLuca, RN, WOCN
- Drug Nutrient Interactions, Mark Klang, MS, RPh, BCNSP, PhD
- Advocating for Yourself, Lynne Murphy, MSN, RN
- Our Journey as Parents, Shirley Huang, MD, and Jim Yoo, MD
- From Clinician to Patient–My Personal Perspective, Rex Speerhas, RPh, CDE, BCNSP

DVDs are loaned for a one-week period free of charge on a first-come/first-served basis. Reserve one for a week now! DVDs and/or VHS tapes are also available for past conferences, and on a variety of other topics. See what’s available and make your requests at www.oley.org/video_dvd.html or call the Oley office at (800) 776-OLEY.