2009 Conference: Wet and Wonderful

Smiles were bright at the Oley annual conference in St. Petersburg, Florida, this June, even if the sun wasn’t. The daily rains didn’t seem to dampen anyone’s spirits and—to look at the bright side—kept most of us from having to worry about sunburns (most, but not all!) and dehydration. Conference sessions were stimulating and well received, the social activities and fundraisers were great successes, and many friendships were made and/or cemented.

At our welcome reception on Monday, we looked back at Oley’s past as we celebrated Joan Bishop’s twenty-fifth anniversary with the organization, and at the Town Hall meeting on Thursday, we looked to Oley’s future as many members contributed ideas and suggestions for next year’s conference and Oley programs. In the two days sandwiched in between, we chose between presentations by over thirty experts in the homePEN field, visited the booths of more than twenty-five exhibitors, swung to the beat of the steel drums, built boats from cardboard boxes, and walked on the beach.

Zac Colton and Jameson Atkinson give two thumbs up for this year’s conference.

Oley conferences, and especially the annual conference, offer a unique opportunity to learn, whether you’re in a formal presentation or in conversation at the buffet line. We learn from each other, as well as from the presenters and exhibitors, and we offer each other support. But don’t just take it from me. Read Conference, cont. pg. 9 ➤

Living a Normal Life with HomePN: Results from a Qualitative Research Study

Marion F. Winkler, PhD, RD, LDN, CNSC

Home parenteral nutrition (HPN) provides life-sustaining intravenous nutrition for individuals who have impaired gastrointestinal (GI) function. One goal of HPN is to improve quality of life (QOL) for these individuals. Yet poor QOL has been consistently reported in studies comparing HPN-dependent individuals to healthy adults. It is not clear whether this poor QOL is related to the underlying medical condition, HPN technology, or the individual’s beliefs, values or life experiences. Among HPN consumers, factors that may influence QOL include underlying health diagnoses, depression, marital status, access to support systems, and financial security.

The aim of this qualitative study was to define QOL and describe how HPN influences a person’s QOL. Knowing how HPN consumers view QOL may enhance care and may also provide groundwork for the development of a patient-reported outcomes questionnaire, which could further enhance care.

The summary that follows provides a general overview of this research. A full report of the study findings will be published in the Journal of Parenteral and Enteral Nutrition (JPEN).

Research Methodology

The study was conducted using audiotaped telephone interviews in which participants told stories about living with HPN and answered questions about QOL and the meaning of food. The interview transcripts were analyzed by grouping words, phrases, and paragraphs together to identify similar experiences and themes. The study received approval from the Institutional Review Boards of Rhode Island Hospital and the University of Medicine and Dentistry of New Jersey.

Study Participants

Participants were recruited from announcements sent to HPN programs and the Oley Foundation Web site. Twenty-three of the twenty-four HPN-dependent adults who were interviewed for this study had a diagnosis of short bowel syndrome due to resection for Crohn’s disease, mesenteric ischemia, or radiation enteritis. The other participant was diagnosed with stage 3-4 breast cancer with metastasis to the liver and lung.

The study included seven participants with resection for Crohn’s disease, four participants with mesenteric ischemia, and one participant with radiation enteritis. The median age of respondents was 45 years old (range 28–71 years old), and the median time since diagnosis was 7 years (range 0–25 years).

Normal Life, cont. pg. 2 ➤
Normal Life, from pg. 1

was diagnosed with dysmotility. Half of the participants had an ostomy.

Eighteen of the participants were female and sixteen were married. Half of the participants were disabled or on a medical leave of absence; five were retired; four were working part time; and three were working full time. The length of time the study participants had been receiving HPN ranged from four months to twenty-six years (with an average of eight years). They infused between two and seven times per week (average six), from nine to twenty-four hours (average twelve). Only thirteen of the participants were involved or familiar with the Oley Foundation.

Defining QOL

Study participants defined QOL as how much one enjoys life; being happy, satisfied, or content with life; and “being able to do what you want to do when you want to do it.” They all noted activities they wanted to be able to do, including: working or doing household chores; attending community or church events; socializing with friends and family; various sports and leisure activities; traveling; and eating or dining out. Their ability to participate in these activities was affected by their health, stamina, and GI symptoms.

The HPN consumers interviewed felt having diarrhea or worrying about an ostomy leak had greater impact on their lifestyle than infusing HPN. The unpredictability of diarrhea interrupted life; they were unable to plan around it. A few of the participants with ostomies said the ostomy gave them more freedom because it was no longer necessary to be close to a bathroom; others said the ostomy caused disrupted sleep and made swimming, traveling, and choosing clothing difficult. One participant described good QOL as “one where you can go out freely, you don’t have to worry about infection, you don’t have to carry one thousand things with you, and you don’t have to run to the bathroom.”

Measuring QOL

While published reports have associated HPN with poor QOL, twenty-one of the study participants viewed their own QOL as “good,” “pretty good,” “very good,” or “wonderful.” The remaining three reported unsatisfactory QOL, but one attributed this to frequent infections and the other two attributed it to factors unrelated to HPN.

When describing their QOL, participants discussed how important it was to be pain free and to have health and enough energy to be mobile and “to get up and go.” Fatigue due to health issues, immobilizing diarrhea, aging, and lack of sleep interfered with enjoyment of life. Some participants noted that “some days things are more important to you than other days,” and good QOL “depends on how you are feeling.” Faith, having a supportive spouse, the ability to work or be productive, and financial security also influenced their QOL.

Similar to findings in other published research, participants who had short bowel syndrome because of Crohn’s disease or radiation enteritis described poor QOL before starting HPN. These participants noted substantial improvement following initiation of HPN and attributed the change to gains in energy, strength, stamina, and weight. One female participant who had been on HPN for six and a half years explained: “Initially it wasn’t good and at times poor, but I’ve been out of the hospital for three years, and family members say I look healthier. And when you look at it that way, and I look in the mirror, I can see the difference. Overall I would say my quality of life now, it’s very good.” Another female participant with Crohn’s disease said, “Before HPN I would say my quality of life was poor. I was having massive diarrhea. I was spending literally the entire day on the toilet. The wonderful part of HPN was, I went from feeling really awful, from being malnourished for many years, to having strength and stamina.”

Previously healthy participants who developed short bowel syndrome acutely because of mesenteric ischemia, however, described a better QOL before the need for HPN. One male participant who had been receiving HPN for less than a year following massive resection for ischemia recalled, “Up until I got sick, I was active and out playing golf and going out to eat more often”; and one female participant who had emergency surgery for gangrenous bowel noted: “Before, I could eat everything, everything without worrying about diarrhea. I mean it was a normal good life. I used to do, including: working or doing household chores; attending community or church events; socializing with friends and family; various sports and leisure activities; traveling; and eating or dining out. Their ability to participate in these activities was affected by their health, stamina, and GI symptoms.

The HPN consumers interviewed felt having diarrhea or worrying about an ostomy leak had greater impact on their lifestyle than infusing HPN.
**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 E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that 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.

**Pill Crushing Solution**

I keep stainless steel pliers with my supplies, put the pills in a small plastic bag, crush with pliers, then put crushed pills into a small container and dissolve with water. Works great.

— Marie Latta
latta@mindspring.com

**Packable Pole**

At the Town Hall meeting at the Oley annual conference, a member asked about IV poles short enough to fit into a suitcase. We received the following e-mail from one of our Regional Coordinators in response.

The Pitch-It® IV pole Model No 30003 collapses to less than 28” x 3” and is very lightweight (aluminum). Because it is so lightweight (and relatively thin) it is not as sturdy as the standard IV pole. However, I just attached an old pump clamp without a problem and I think this pole would work for a variety of purposes. It will not fit in a 24” carry-on suitcase, but it could very easily be carried onto a plane in its own box. This pole is listed on many Internet sites.

— Steve Cohen
cohennet@verizon.net

**Hike-a-thon: Grand Canyon**

Join Oley President Rick Davis as he hikes 50 miles across the Grand Canyon, October 6 to 11, 2009, to raise money for the foundation. Rick has been 100 percent dependent on tube feeding since a stroke in December of 2000 left him unable to swallow. For details on the hike, contact Rick at rickdavis320@comcast.net or (904) 710-9159.

Also, please consider making a corporate or individual donation to support Rick’s “hike-a-thon” for Oley. All donations will go toward Oley Foundation programs, like this newsletter.

You can donate by credit card at www.oley.org, or write a check to “The Oley Foundation” and send it to 214 Hun Memorial, Albany Medical Center MC-28, Albany, NY 12208. Please indicate the gift is in honor of Rick’s hike-a-thon.

Meet your tube-feeding needs with Jevity® 1.2 Cal and Enteralite® Infinity™ Pump

With Jevity 1.2 Cal and the Infinity Pump you can be assured you are receiving complete, balance nutrition.

Jevity has a unique fiber blend to promote normal bowel function. Concentrated calories and protein help you gain and maintain a healthy weight.

The Infinity Pump offers safe, simple operation and the flexibility of ambulatory use.

Contact your home medical equipment supplier or visit Abbott Nutrition.com for more information.
LifelineLetter Annual Award
In honor of Nutrishare Inc., Oley Platinum Partner
Mariah Abercrombie • Henderson, NV

The LifelineLetter Annual Award is given to a homePEN consumer or caregiver, aged nineteen or older, who has demonstrated courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN.

This year the award was presented to Mariah Abercrombie.
Mariah was diagnosed with pseudo-obstruction syndrome when she was only three years old, and has had a central line, a G-tube, and an ileostomy most of her life. Today, despite ongoing health issues, setbacks, and a dependence on home parenteral nutrition (homePN), Mariah is a senior in college who hopes to go on to get a master’s degree. Mariah is only two semesters away from a diploma, and last semester she made the dean’s list.

Celebration of Life Award
In honor of Coram Specialty Infusion Services, Oley Golden Medallion Partner
Robin Lang • Friendship, ME

We were pleased to present the Celebration of Life Award to Robin Lang at the annual conference. “If you have the pleasure of knowing Robin Lang,” says one of her friends, “you know what celebrating life is all about….Robin is here to live life to the fullest.” Robin has been on home parenteral nutrition (homePN) for almost thirty years, but she hasn’t let it, or her underlying health issues, stop her. She is known for her great sense of humor (and in fact was a professional clown for twenty years), her concern for others, and her many interests and hobbies.
Robin served as one of the original Oley volunteers and has been to many Oley conferences. In 1986, Robin, as Peaches the clown, entertained everyone at an Oley picnic. For her activities as an Oley Regional Coordinator, Robin received the

Child of the Year Award
In honor of ThriveRx, Oley Golden Medallion Partner
Emily Koprucki • Williamsville, NY

“Emily Koprucki is a wonderful young lady who has always dealt with the issues surrounding her homePEN with a smile and a determined attitude,” says a Koprucki family friend. Now fourteen, Emily has learned how to manage her own care and to advocate for herself wherever she is—at school, at the hospital, or while participating in Girl Scout trips and activities.
“I have tried really hard to never let my medical stuff get in the way,” writes Emily. “Last year, I hit a really big road block. I started needing IV hydration more during the day, and my school district was not ready to have a kid walking the halls of the middle school infusing! My mom, my doctor, the school nurse, and my guidance counselor all understood how important this was for me, but everyone else was

Nan Couts Award for the Ultimate Volunteer
Coordinated by Judy Peterson, RN, MS
Linda Gravenstein • Tomball, TX

Throughout her life Nan Couts volunteered for many groups, including the Red Cross. She founded Grossmount Hospital in San Diego in the 1950s. Nan taught her granddaughter Judy Peterson the meaning of volunteerism, beginning with having Judy help out at a senior home when she was ten. Judy says this is when her interest in nursing began. We are proud to honor clinicians in the homePEN or related field who demonstrate willingness to give of themselves—beyond their regular work hours—with an award in Nan's name.

This year the Nan Couts Award for the Ultimate Volunteer was presented to Linda Gravenstein. Linda currently works as a consumer advocate with the home healthcare company Coram Specialty Infusion Services. She has many years of experience with homePEN as the mother of a young woman,
Lenore Heaphey Grassroots Education Award
Sponsored by Kimberly-Clark, Oley Blue Ribbon Partner
Davria and Steven Cohen • Crofton, MD

Lenore Heaphey was hired when the Oley Foundation was founded in 1983. She brought with her many years of administrative experience and an unmatched amount of energy and enthusiasm. Lenore quickly recognized the importance of our Regional Coordinators as the "face of Oley" in different regions of the country. When Lenore left Oley to pursue a law degree, it seemed only fitting to name an award in honor of her outstanding contributions.

This year we were pleased to present the Lenore Heaphey Grassroots Education Award to a husband and wife Regional Coordinator team, Davria and Steven Cohen. Davria (Davi) has been on homePEN for over twenty-five years. She has short bowel syndrome due to injuries sustained in an automobile accident. She and Steve are always available to reach out and educate others about Oley, and about what it means to be dependent on homePEN. They have spoken at Oley conferences, as well as at meetings of the National Association of Vascular Access and the American Society for Parenteral and Enteral Nutrition, and often volunteer to answer calls to the Oley toll-free phone lines.

Davi and Steve are also utilizing another, relatively new venue to offer help and support to homePEN consumers and caregivers: the Oley Foundation online forum. The forum is proving to be very popular, and is a great way for people to connect. "Davi and Steve are very active in the forum discussions, frequently offering support and advice," an Oley member said in nominating them. "It's appropriate that their screen name is daviandsteve as the two of them together make a formidable pair." Davi is willing to share her extensive knowledge of the nutritional and general health issues confronting long-term homePN consumers, and Steve is always willing to listen and talk to spouses and/or caregivers.

As Davi received the award, she commented, "This award means a lot to me, because Oley means a lot to me. So many Oley RCs have inspired me. They have reached out to me and given me advice and comfort. I am an RC because I want to give back to the community." Steve added, "Oley should be an acronym for 'Organization for Learning to live Effectively,' with the 'y' for 'You,' all of you who have become part of our family."

To quote the nomination form, "We are thrilled to have them give their great insight and energy to Oley members." Thank you, and congratulations!

Nominees:
Bettemarie Bond, Anna Cyr, Carla Truman

Awards Coverage, cont. pg. 6
Kyle R. Noble Memorial Scholarship
Coordinated by Donna & Richard Noble
Kailee Brown • San Francisco, CA

Kyle R. Noble’s enthusiasm for life affected many positively, and he is remembered widely with affection and admiration. Kyle passed away in 2006 at the age of eight. In 2007, the Noble family established the Kyle R. Noble scholarship to recognize others who share the admirable qualities for which he will be remembered. This year’s recipient, announced at the Oley Conference in St. Petersburg, Florida, is Kailee Brown.

Kailee is a full-time nursing student at Dominican University, near San Francisco, California. She has had to cope with gastroparesis and malabsorption issues all of her life. As a child, Kailee’s parents managed to keep her healthy enough with diet modifications and supplements. In high school, however, she started to be sicker more frequently. “I was so sick every time I ate,” she remembers, “eventually I no longer wanted to eat at all.” Kailee ended up in the hospital. It was the first of many hospital stays, some of which lasted months.

“Growing up, my mother used to tell me that everything happens for a reason, but sometimes we do not know what that reason is. I have found, however, that over time, sometimes that reason presents itself,” Kailee says. “The time I did spend in the hospital changed my life….When it came time for me to enter college I decided I would rather be a nurse than an orthodontist.”

In 2006, after finishing all of the prerequisites at a junior college, Kailee applied to and was accepted at Dominican University. She struggled with nausea, exhaustion, and pain her first year, and underwent surgery for a PEG-J tube as soon as finals were over. “It has been two years since I had my tube put in, and as I stood by the bedside of my patient…crushing her pills and starting her tube feeding, I knew I had finally found the meaning in why all of the ‘bad’ things that have happened to me medically have happened: they made me a better nurse. I know what it feels like to have to spend time laying in hospital beds and I know what it is like to be scared. When my patients tell me that they are scared, I can say with honesty that I know what they are going through, that I know how they feel….I like being able to tell my patients that I have been there and that I overcame my obstacles to stand bedside instead of being in the bed.”

Kailee has maintained a 3.8 GPA and will apply to the honors society for nursing students next year. “Kailee is an extraordinary student who has earned my respect and admiration,” says one of her clinical instructors. “Kailee has so much to give to nursing…. She will touch many lives.” Congratulations, Kailee!
**Nutrishare HomePN Research Prize**
*Sponsored by Nutrishare, Inc., Oley Platinum Partner*

Marianne Opilla, RN, BSN, CNSC
Nutrishare, Inc., Midlothian, VA

"Reduction in Catheter-Related Bloodstream Infections with Weekly Dosing of 100 Percent Ethanol Lock Therapy in Chronic HPN Patients"

Ethanol lock therapy (ELT), in various frequencies and with various strengths of ethanol, has been reported as a successful strategy to reduce the incidence of catheter-related bloodstream infection (CRBSI) in HPN patients. The aim of this study was to determine the incidence of CRBSI before and after initiation of weekly dosing of 100 percent ELT in a group of frequently infected HPN patients. The researchers noted a nearly fivefold decrease in CRBSIs and no adverse effects during the study period in this cohort of patients. Additional measures to decrease CRBSIs were not reported but may have contributed to the results.

Geert Wanten, MD, PhD, Msc
Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

"Taurrolidine versus Heparin Lock to Prevent Catheter-Related Bloodstream Infections in Patients on HPN: A Prospective Randomized Trial"

Taurrolidine, an antimicrobial agent without known side effects, holds promise as an effective catheter lock to prevent catheter-related bloodstream infection (CRBSI). This study was undertaken to evaluate the effect of using a taurrolidine versus heparin catheter lock on the occurrence of CRBSI in patients who had recently developed an episode of catheter sepsis. The study concluded that using a taurrolidine lock dramatically decreased CRBSI when compared with heparin in this group of HPN patients. Of note, no catheter occlusions were observed either in controls or in the taurrolidine group in the study.

Marion F. Winkler, PhD, RD, LDN, CNSC
Rhode Island Hospital, Providence, RI

"Relationships among HPN, Food and Eating, and Quality of Life"

The aim of this research was to explore the meaning of food and eating from the perspective of adults receiving HPN as their primary form of nourishment and to describe how living with HPN and the ability to eat influences QOL. All study participants could eat. The researchers came to several conclusions: HPN helped participants maintain weight and strength without the pressure of having to eat to survive, and being able to enjoy food was an important component of good QOL. Participants employed eating strategies to minimize gastrointestinal pain and diarrhea and adopted a healthier orientation around food. They achieved satisfaction from cooking, providing food for others, and participating in family events. Social isolation was not evident as participants recognized the importance of being together regardless of whether or not they ate a “normal” meal. The researchers suggest nutritional counseling should include not only the nutrient content of food and management of diarrhea, but the social and emotional aspects of food and eating. (See related article on page 1.)

The research from all three studies was presented at the Oley conference in June. Slides from the presentations are available at www.oley.org.

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**Oley Conference 2010: A 25th Anniversary Celebration**

With one annual conference just behind us, we eagerly look forward to the next. And we hope you do, too!

Save these dates: June 28 to July 2, 2010.

Next year marks twenty-five years since the Oley Foundation held its first meeting in Saratoga Springs, New York. In time these gatherings have grown from half-day events to the four-day conferences we now enjoy. To celebrate this anniversary, we bring the conference back to Saratoga, at the historic Gideon Putnam Resort, www.gideonputnam.com. Take a virtual visit, then mark your calendar for the real thing.

Come early, stay later, and enjoy all that this area has to offer. Plan on golfing with us (watch for details on a tournament!), boutique shopping downtown, visiting Saratoga’s famous mineral baths, dance museum and race course, and just plain relaxing. Saratoga is practically in our back yard, and we’ll be so glad to welcome you to our neighborhood.

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**Oley Exhibits, Help Needed**

In an effort to reach more consumers and professionals, we have reserved exhibit space at several upcoming conferences. We could use your help at our booth. Be the face of Oley! You’ll be asked to hand out information and answer questions, and you’ll also have an opportunity to visit other exhibits. For exhibit times and other details, contact Kate Swensen at swensek@mail.amc.edu or call the Oley office at (800) 776-6539.

- Association for Vascular Access (AVA) Annual Scientific Meeting, Riviera Hotel and Casino, Las Vegas, Nevada, September 14-17
- Colorado Chapter ASPEN, The Radisson Hotel Denver Stapleton Plaza, Denver, Colorado, September 25
- American College of Gastroenterology (ACG) 2009 Annual Scientific Meeting, San Diego Convention Center, San Diego, California, October 23-28
- Virginia Chapter ASPEN, Crowne Plaza Hotel, Williamsburg, Virginia, November 13-14
NutriThrive Changes Name to ThriveRx

Still the same great company, just with a new name!

NutriThrive, focused on highly customized care for individuals requiring intravenous nutrition and tube feeding, is changing its name. The new name, ThriveRx, was chosen to better reflect our holistic approach to care, and to provide synergy with the parent company, BioRx.

ThriveRx’s consumers will continue to receive superior clinical care, individualized supplies, responsive service, and the same dedication to excellence that they’ve come to rely on from NutriThrive.

NutriThrive
Improving Life on Nutrition Support

THRI
Formerly NutriThrive

1-888-6-THRIVE (888-684-7483)
or info@thriverx.net
www.thriverx.net
Mailbox: Trust in the Balance

Full disclosure: I have control issues and am somewhat anal-retentive. When I read Laura Bailey’s article in the May/June issue of LifelineLetter, it struck a chord with me. Early on in our child’s care, I had many feelings similar to those Laura expressed as she stated what she felt were the benefits of being the only person to care for her child’s central venous line. I think what Laura has done borders on super-human—but I feel there needs to be a balance struck on quality of care and caregivers’ quality of life. I feel there is a need to allow a couple of people into the circle of care and still maintain continuity.

Unlike Laura, my background is not in nursing, so everything was new and scary to me when my son was born with Hirschsprung’s. Our insurance provided little nursing coverage, which put a lot of responsibility on my husband and me once we were home. While I truly was the primary caregiver, I found it beneficial to have my DH [dear husband] as a back up. Whether it be illness, injury, or just a need for a break, I knew there was someone there I could depend on.

And while I agree not all medical professionals are as careful with our children’s lines as we would be, I believe that rather than avoid them we should treat each interaction as a teaching opportunity. We can do so either by preemptively informing staff of our protocol or addressing issues as they come up. If their protocol is different than ours, I try to find out why. Over the years we have seen many changes in how things are done. Most often they are supported by some recent study—regarding types of flushes, types of caps, scrub time, dry time, and the list goes on—but I also understand the “if it ain’t broke, don’t fix it” approach.

With our son’s frequent hospitalizations we’ve gotten to know many of the nurses over the years. We have had several come home and care for our son so that my husband and I could get away—something I think is needed in every relationship, but especially when there is so much added stress.

As parents it is our challenge to care for our children to the best of our abilities while at the same time creating independence as they grow. Even at a young age they can begin to advocate for themselves. We teach “stranger danger” to young children, and we can similarly teach basic line safety.

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As parents it is our challenge to care for our children to the best of our abilities while at the same time creating independence as they grow. Even at a young age they can begin to advocate for themselves. We teach “stranger danger” to young children, and we can similarly teach basic line safety.

As our children grow we need to continually entrust them to their own care. Last year I sent my son to camp with a very new central line—after him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears. A conversation with the nursing director, where I learned about her familiarity with him not having a line for seven years—and while I was hesitant, I believed the benefit of the camping experience far outweighed my fears.
and “washing up before going to bed.” They associated HPN with being “hooked up,” or “tied down,” yet noted they were “happy to be alive.” Although they described being “tethered” and having to “drag around the backpack or pole,” they, as one participant phrased it, “just put up with it.”

Some individuals were flexible in planning their HPN infusion schedule around the activities in which they wanted to participate. They would change the infusion hours or skip an infusion to accommodate a social situation. Other participants were much more structured with the infusion schedule and opted to miss activities. Overall, the benefits of HPN were seen to outweigh the burden of the HPN technology.

A Nutritional Safety Net
The study participants saw HPN as unquestionably a life-sustaining therapy. They recognized that without the ability to receive nutrition intravenously, they might not survive. They felt secure knowing their nutritional needs were being met by HPN and that they were able to gain weight and strength even without the ability to digest and absorb food. This view affected their attitudes toward food, which was another of several themes that emerged in the interviews.

All of the study participants ate food. They felt less pressure to eat, however, because they perceived HPN as a nutritional safety net. They saw eating as a QOL issue and, in the words of one participant, defined good QOL as “being able to eat what I want, when I want.”

Eating for Survival, Health, and Pleasure
Participants who had short bowel syndrome because of resections due to Crohn’s disease or radiation enteritis reflected on their struggle to survive and maintain weight. Prior to receiving HPN, they had to constantly focus on eating and drinking. For example, one participant noted: “I had to spend so much time always just thinking, trying to keep my nutrition up.” This struggle led to feelings of desperation, anxiety, and futility. These participants described a poorer QOL before starting HPN because they were unable to work or participate in social activities due to their diarrhea, weight loss, and malnutrition.

With HPN as a nutritional safety net, participants changed their eating behaviors and focused instead on the health and immune benefits of food. They tried to eat small amounts of food to stimulate the bowel and promote intestinal adaptation. The possibility for intestinal adaptation and the hope of decreasing HPN dependency was very important to them.

Participants also discussed the importance of eating for pleasure. They described being content and feeling satiated by small amounts of food and they discussed food as a gathering point for families, especially around holidays. Enjoyment and satisfaction were achieved through socializing, shared meals, and family get-togethers. They associated this pleasure with belonging, whether or not they were eating. The degree to which the participants enjoyed what they ate varied. Those who had less diarrhea or GI distress ate more frequently than those who had diarrhea or pain, yet only a few said they did not enjoy food and that it was no longer appealing or fun.

Achieving a Sense of Normalcy
Many participants discussed the importance of having a positive attitude and adjusting life goals and priorities. They appeared to accept the changes associated with their illness, surgery, and HPN. Even though participants were resentful of the medical circumstances that caused them to need HPN and admitted they “would love not to have it,” they understood how necessary it was to their survival.

Although participants may have been left with no choice but to accept HPN, they learned to endure the consequences associated with serious illness, surgery, or technology dependence. The strong view of HPN as a life-sustaining therapy and a nutritional safety net contributed to acceptance of a new way of life. Ultimately, they realized attaining a sense of normalcy was a matter of personal responsibility and of taking charge.

“HPN actually gave me more control over something that I really felt I had no control over—to be able to take care of myself and to make decisions about my care.”

Participants sought knowledge from home care professionals, the Oley Foundation, local support groups, and other people who received HPN. One said, “Until I found the support group I had nobody to ask, no references; the doctors really didn’t even know what to tell me.” The realization that other people lived under similar circumstances helped participants perceive their own situation as normal. “I felt like I was the only one in the world until I found somebody else like me.” Participants shared their own experiences living with chronic disease or HPN through volunteer service, visits to new HPN patients, or involvement with the Oley Foundation. Doing so helped them to establish a sense of normalcy and enhanced self-identity.

When asked what HPN means to them, one participant answered: “A normal life. It’s just that simple.” Another said, “I try to live as normal a life as possible.” These individuals had redefined “normal” in the face of their current life circumstances and health status. “It’s changed our whole lives,” one said, “our whole outlook, our whole being, you know the two of us, we’re together at this.” Another stated, “HPN means life, but yet it’s not life as you knew it before and it’s a whole different world.”

Good QOL Possible
The findings from this study demonstrate that it is possible to have good QOL while receiving HPN. The study participants wanted others to hear their stories and life experiences, and hoped to provide the message that living with HPN was “really not a big deal.” They also hoped their stories would enlighten health care professionals and encourage them to talk with their patients about some of the “nonmedical things in life.”

“I appreciate it when people recognize me for the person I am and not just the disease process or the therapy,” said one woman, “cause if you get to know somebody and you know what they want to achieve in their life and who they are as a person, then you’re going to make an extra special effort to make sure they’re healthy enough to be able to do those things.”

Consumers can initiate discussions with their health care providers about how they define QOL and their goals, priorities, and expectations about HPN. Such discussions may help identify behaviors and coping strategies that promote adaptation and a sense of normalcy.
**Bright Ideas**

**Bigger, Better Bodysuits**
I have had difficulty finding larger one-piece bodysuits for my daughter Madelyn, who is twenty-one months old and has a central line and a G-J feeding tube. After searching the Internet I found some that go all the way up to size 5T! The long- and short-sleeve bodysuits come in four colors, while the sleeveless ones only come in white. They are very reasonably priced at under $10 each, although I would probably pay twice that. They are made well, fit well, and wash well. These are available at www.essentialwhites.com or (866) 648-8488.

—Tammy Morris
Fayetteville, AR

**Cover Me Beautiful**
Gus Gear offers custom covers for ostomy bags, feeding tubes and central lines, feeding pump bags, and more! Contact the company at www.gusgear.net or (724) 513-4497.

—Sarah Palya
spalya@gusgear.net

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**Participate in Major HPN QOL Study**

You are in a unique position to help the medical field understand the impact that home parenteral nutrition (HPN) has had on your life. Because you experience this therapy on a day-to-day basis, we are asking you to participate in a widespread study of the effect of HPN on quality of life.

The Oley Foundation is collaborating with the European Home Artificial Nutrition Workgroup in this study. The study will promote understanding of the issues that are important to you, the consumer, and will hopefully make HPN practices better for you, as well as for those elsewhere. It may also make it possible to compare the effects of techniques such as small intestinal transplantation with life on HPN to allow consumers to make more informed decisions, and to compare HPN practices in the United States with those in European countries.

Developing this understanding further could also help us make Oley of greater benefit to you.

**How to Participate**
This study is open to all adult HPN consumers. You do not have to be an Oley member to participate. We heartily encourage your participation. For details and/or to participate, contact the Oley office at 800-776-OLEY or e-mail Cathy Harrington at harrinc@mail.amc.edu details. All responses will be kept confidential. This study has been approved by the Albany Medical Center Institutional Review Board (IRB).
Thank You for Helping with the 2009 Oley Conference!

Many thanks to the following companies and individuals for their generous contributions.

2009 Oley Awards:
Coram Specialty Infusion Services; Kimberly-Clark; Nutrishare, Inc.; ThriveRx (formerly NutriThrive)

Beach Party:
Lowe’s of Clearwater, FL

Child Care:
Nutrishare, Inc.; Volunteers: Ron Metzger; Sarah Metzger; Kelsey Noble; Marjorie Quinn; Aleah Smith; Kevin Smith; Tara Smith; Guiliana Valenti; Rachel Winkler

Conference Badges:
Coram Specialty Infusion Services

Conference Bags:
Nutrishare, Inc.

Conference Co-Chairs:
June Bodden; Meg Cass-Garcia RN, MSN, CNSC; Marianne Duda, MS, RD, LD, CNSD

Conference Registration:
Volunteers: Stephen Boatwright; Jeff Hoelle; Guiliana Valenti

Conference T-shirts:
Coram Specialty Infusion Services

Exhibitors:
Abbott Nutrition, Abbott Laboratories; Alcavis HDC, LLC; Ambient Healthcare, Inc.; American Society for Parenteral & Enteral Nutrition; Applied Medical Technology; Baxter Healthcare; Cera Products, Inc; Clarian Transplant; Coram Specialty Infusion Services; Covidien; Emmaus Medical, Inc.; G-PACT; InfuScience; International Foundation for Functional Gastrointestinal Disorders; Kimberly-Clark; MitoAction; MOOG, Inc.; MSD, LLC; Nestlé HealthCare Nutrition, Inc.; Nutrishare, Inc; The Pediatric Adolescent Gastroesophageal Reflux Association; PromptCare Home Infusion, LLC; ThriveRx (formerly NutriThrive); United Mitochondrial Disease Foundation; Walgreens-OptionCare

Faculty:
Marcia Boatwright, RN, CRNI; Bettemarie Bond; Abby Brogan; Margaret Cass-Garcia, RN, MSN, CNSC; Faye Clements, RN, BS; Mark H. DeLegge, MD; Marianne Duda, MS, RD, LD, CNSD; Don George, MD; Megan Gravenstein; Kathleen Gura, PharmD, BCNP, FASHP; Carol Ireton-Jones, PhD, RD, LD, CNSC, FACN; Kishore R. Iyer, MBBS, FRCS, FACS; Darlene G. Kelly, MD, PhD, FACP; Vanessa Kumpf, PharmD, BCNP; Kristyn Maixner, RN; Jay Mamel, MD, FACP, FACC, FASN; Lesley Diane Marino; Laura E. Matarrese, PhD, RD, LDN, FADA, CNSD; Stephen A. McClave, MD; Reid Nishakawa, PharmD, BCNP, FCSHP; Donna Noble; Marianne T. Opilla, RN, BSN, CNSC; Sarah Peseski, MPH, RD; Deborah E. Pfister, MS, RD, CNSD; Steven Plogsted, PharmD; Doug Seidner, MD, FACP, CNSP; Rex Speerhas, RPh, CDE, BCNP; Ezra Steiger, MD; Jody Strain; Elizabeth Tucker; Cindy Van Eldijk; Renate Vissers; Marion F. Winkler, PhD, RD, LDN, CNSC; Don Young

General Conference Support:
Pat Brown, RN, CNSN, OCN; Ann & Paul DeBarbieri; Portia & Wallace Hutton; Kimberly-Clark; Lesley Marino; Kathleen & Larry McNees; Joan & Eli Medwar; Sheila Messina, MA, RN; Cheryl Thompson, PhD, RD, CNSD; Donna Macan Yadrich, MPA, CCRP; Volunteers: Lesley Marino; Nina Marino; Marjorie Quinn

In Loving Memory:
Co-sponsor: ThriveRx (formerly NutriThrive); Volunteer: Richard Noble

Jammin’ Jammies:
Abbott Nutrition-PediaSure; Volunteer: Mike Cyr

Kyle R. Noble Scholarship:
Abbott Nutrition; Donna and Richard Noble

Medical Support:
Coram Specialty Infusion Services

Oral Rehydration Solution:
Cera Products, Inc.

Orientation for New Attendees:
Rick Davis

Pediatric Workshop:
Co-sponsor: ThriveRx (formerly NutriThrive)
Silent Auction:
Thanks to all who donated or purchased items, or helped at the event. Volunteers: June Bodden; Jeff Hoelle; Rose Hoelle; Lesley Marino; Richard Noble; Janet Platt

Speaker Support:
Ambient Healthcare; Children’s Hospital Boston; Cleveland Clinic; Coram Specialty Infusion Services; Lee Moffitt Cancer Center; Mayo Clinic; Medical University of South Carolina; Mount Sinai Medical Center; Nationwide Children’s Hospital; Nemours Children’s Clinic; Nestlé HealthCare Nutrition; Nutrishare, Inc.; Rhode Island Hospital; ThriveRx (formerly NutriThrive); University of Kansas School of Nursing; University of Louisville School of Medicine; University of Pittsburgh Medical Center; Vanderbilt University Medical Center; Walgreens-OptionCare St. Petersburg branch

Sunscreen for Your Protection:
Ocean Potion & NO-AD; Volunteer: Barb Klingler

Travel Scholarships for Consumers:
Anonymous; Jarol Boan, MD; Melissa Chaney Memorial Fund; Coram Specialty Infusion Services; Critical Care Systems; Bruce Groeber Memorial Fund; Janet Platt & Christopher Hlatky

Tube Feeding Workshop:
Co-sponsor: Daniel F. and Ada L. Rice Foundation

Videotaping:
Baxter Healthcare; Joel Resnick, Access Medical

Walk-a-Thon:
Coram Specialty Infusion Services; Covidien; Emmaus Medical; Nutrishare, Inc.; ThriveRx (formerly NutriThrive)...and thank you to everyone who walked or otherwise supported the effort! Volunteer: Lesley Marino

Welcome Massage:
Lesley Marino

Youth Activities:
Nutrishare, Inc.; Volunteers: Katie Swensen; Rachel Winkler
Lifeline Award, from pg. 4

Mariah has organized and coordinated several youth activities at past Oley conferences. “I can’t say enough about how important the conference is to me and my family. It is an annual event we look forward to each year,” she says. She has also been a driving force behind Oley efforts to promote the Paul Newman summer camp experiences for Oley members.

At a very young age Mariah began sharing her experiences through formal presentations and roundtable discussions at professional meetings to create a better understanding of the issues and concerns specific to those growing up on homePEN therapies. Her willingness to share has always been extremely helpful for parents who are striving to understand the challenges of being a child/teenager/young adult who is dependent upon homePEN.

“Receiving the Lifeline Letter Award was a great honor,” Mariah says. “I appreciate the recognition. In addition, I am grateful to Oley and the wonderful staff for arranging such a wonderful conference. As always, this year’s conference was both educational and fun. Despite a little rain, I had a wonderful time catching up with old friends and making new ones.” She adds, “I encourage anyone who is thinking about attending to take the plunge. It’s a wonderful opportunity and you won’t regret it. See you in New York in 2010!”

Mariah exhibits all of the qualities the Lifeline Letter Award was designed to recognize. She well deserves it. Congratulations Mariah!

Nominees: Mallory Cyr, Lori Deyarmin, Tammi Stillion

Celebration Award, from pg. 4

Lenore Heaphey Award in 2000. She also received the Lifeline Letter Award, in 1997.

Lately Robin has been busy having her dream house built in Friendship, Maine; settling into her new home; and planting gardens. Now an established member of her new community, Robin planted a flower garden for the local church, of which she is also now a member. To keep the garden growing, Robin is starting a gardening group at church.

If Robin isn’t in the garden, she might be in the kitchen or in the woods near her home. She enjoys cooking for friends and neighbors, exploring the outdoors with her dog, Doodle, and traveling. She also enjoys painting. Several of her watercolors were included in a community art show on Friendship Day, and a watercolor she donated was the object of heavy bidding at our silent auction at the annual conference.

One of Robin’s nurses noted, “Despite illness, Robin always has a smile and is genuinely interested in the lives of those around her, extending herself to console, consult, and listen.” Robin is quick to acknowledge the support she has received through the years, and to show gratitude, as shown in the comments she made when she received the award: “I’d like to thank my Oley family,” Robin said, “and Joan, Cathy, and Roz [Oley staff] for years of support. I get my strength through my Oley family, and I have been able to go to school while on line every since. No one notices, unless I start beeping, of course!”

“For it!” We’re so proud to have you as part of the Oley community, Emily, and we’re very pleased to congratulate you on receiving the Child of the Year Award!

Nominees: Bonnie Burch, Maisy Cyr, Olivia DeKold, Benjamin Dennison, Jonathon Harris, Chelsea Johnson, Lauren Moore, Rowan Windham

Child Award, from pg. 4

afraid to let me do it. I ended up meeting with the director of nursing for our district, and once I showed her that I was more than able to do this, she was willing to help us fight. We finally got it approved, and I have been able to go to school while ‘on line’ every since. No one notices, unless I start beeping, of course!”

“At school and Girl Scouts, Emily is ready and willing to educate everyone on her condition and homePEN,” says a friend. Emily’s mother tells the story of when an elderly neighbor came home from a serious hospitalization with an ostomy. Emily “decided she needed to go talk to him.” According to the man’s wife, Emily’s “upbeat perspective changed his whole attitude about life as an ostomate. The more Emily reaches out to others,” her mom continues, “the more confident she has become.”

At Oley conferences, Emily helps other teens and children feel welcome and comfortable. She is willing to share her story and to lend an ear, both of which encourage and inspire others. One Oley Regional Coordinator (RC) tells how she spoke with the mother of a nine year old who was on homePEN and had never spoken with or met another child in her situation. The RC remembered being impressed by Emily at an Oley conference and called Emily’s mom, who assured her that Emily would call the girl. Emily already corresponded with several other children on homePEN, she added. “Emily did call the girl,” the RC reports, “and they have been communicating ever since. When I followed up with the girl’s mother, she was very grateful for Emily’s efforts.”

“All I can say,” says Emily, “is if you want to do something—GO FOR IT!” We’re so proud to have you as part of the Oley community, Emily, and we’re very pleased to congratulate you on receiving the Child of the Year Award!

Nominees: Faye Clements, RN, CBS; Marianne Duda, MS, RD, LD, CNSD; Lyn Howard, MB, FRCP, and Alan Buchman, MD, MSPH, FACN, FACP, FACG, AGAF; Gail Sansiviero, MS, ANP
Individual Donors

The following list represents everyone who contributed between May 20 and July 24, 2009. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

**Ambassadors ($2,000+)**
- Darlene Kelly, MD, PhD

**President’s Circle ($1,000–$1,999)**
- The Groeber Family

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- Patricia Brown, RN, CNSN, OCN
- Lap for Life through Angelo Casabianca
- Mark Simpson, Jr., in memory of Susan Parker

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- Robert Hydorn, in memory of Joyce Hydorn

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- Donald Empson
- Sharie Youmans, RD

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- Tiffany Matthews, RD
- Michael Medwar,* in honor of Joan’s*** 25 years with Oley
- Anna Nowobolski-Vasiliou
- Barbara Ralph
- Tom & Leslie Sanford
- Susan Newsom, in honor of Jeffrey's first Father's Day after his successful intestinal transplant

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** Oley RC
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Join Us in Thanking Our Supporters

**Nutrishare, Inc.**

Rod Okamoto and Tom Diamantidis attended their first Oley conference in 1991, the same year that Nutrishare was founded. Nutrishare writes, “The company’s cornerstone principle of focusing exclusively on homePN care and honoring the consumers’ rights to choose their health care providers and the products they use were forged during that remarkable conference in Saratoga Springs, New York, that summer.”

In 2007, Nutrishare, together with the Oley Foundation, launched the Nutrishare Research Prize, designed to recognize and encourage clinical research that will improve the quality of life for homePN consumers and their families. Together, Nutrishare and Oley pioneered Oley’s Platinum Level of corporate support as a tribute to the Oley Foundation’s mission. 2009 celebrates eighteen consecutive years of Nutrishare’s exclusive dedication to the home TPN consumer.

**Moog Medical Devices Group/Zevex**

Moog Medical Devices Group, formerly Zevex, is an advanced medical technology company that manufactures and markets a wide range of medical pump devices including enteral feeding pumps, infusion pumps, and post-operative pain management devices. The company writes that “the EnteraLite Infinity enteral feeding pump is highly portable, +/- 5% accurate, extremely easy to program, and very rugged—it can be washed under running water.” The Infinity weighs less than 15 ounces, has a 24-hour battery life, and can be operated in any orientation due to the elimination of the drip chamber. To learn more about the Infinity and how to remove the traditional barriers to enteral feeding, please visit Moog’s Web site at www.moog.com/medical.

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.

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- ($70,000+)
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  - Moog Medical Devices Group/Zevex

(800) 776-OLEY  •  LifelineLetter — 15
**Chat with Others—Free!**

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers. These volunteers are available to talk about day-to-day issues, ideas on coping, etc. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

**September 2009**

Gail Brenenstahl, on HPN due to short bowel syndrome
Queensbury, NY—EST (888) 610-3008

Karyn Thomas, on HPN due to bowel ischemia/short bowel
Midland, MI—EST (888) 650-3290

**October 2009**

Lynda Yeabower, on HPN since 1992 due to Crohn's disease/short bowel syndrome
Destin, FL—EST (888) 610-3008

Tara Smith, mother of Aleah, currently off HPEN, despite short bowel syndrome
Pittsboro, IN—EST (888) 650-3290

**November 2009**

Lou Pacilio, on HEN due to a swallowing disorder
Leeds, MA—EST (888) 610-3008

Robin Lang, on HPN since 1980 due to short bowel syndrome
Friendship, ME—EST (888) 650-3290

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**Health Care Reform?**

We encourage you to attend your local town meetings to:

- meet your representatives
- learn about the proposed plans
- put a face to home tube/IV feeding
- outline your needs
- ask questions

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**In the Philly Area?**

Please save the date, Wednesday, November 11, for the Oley/PASPEN regional conference in Philadelphia.

The Philadelphia Area Chapter of the American Society for Parenteral and Enteral Nutrition (PASPEN) typically hosts a meeting for their members in the fall, and the Oley Foundation has been hoping to coordinate a gathering for members in this area. Combining the two was a natural! PASPEN and the Oley Foundation will offer lectures and roundtables that:

- discuss safe practices in the field of homePEN,
- share advances in the field of managing these high tech therapies, and
- explore the issues that are meaningful to consumers and healthcare providers.

Meeting notices will be mailed to those in this region and updates will be posted on www.oley.org. For more information, please contact Joan Bishop, bishopj@mail.amc.edu or (800) 776-6539.