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# LifelineLetter

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

## Disabled Couple Is Doing It All

**Tina Jackson**

A small embroidered pillow reading, "Grow old with me, the best is yet to be," sits on our sofa. The sentiment is one that Mark and I have taken to heart. Since our marriage twelve years ago, we have worked together to overcome obstacles that would defeat most couples. But overcoming obstacles is a way of life for both of us, as we each had to learn to overcome physical and medical challenges long before we married.

### Individual Struggles

In 1980, when Mark was a high-school football player, he was seriously injured in a motorcycle accident. He was comatose and in the hospital for six weeks. He suffered permanent brain damage that affected his speech and limited his balance, fine motor skills, and mobility. He worked for months to regain the ability to speak and walk, and he was able to discard his wheelchair in time to walk across the stage with his high-school graduating class in 1982. Mark attended Moody Bible Institute for a time and completed a vocational training program in small-engine repair.

I was born with cerebral palsy with left hemiplegia (which means I have very limited use of my left hand



*Tina and Mark Jackson out for a ride on their trikes.*

and a slightly shorter left leg, resulting in a limp) and a slight speech impediment. Empowered by my mother, though, I have had a drive to be independent all my life and was able to be mainstreamed through school. I have earned two degrees—a bachelor's in social work from Northern Kentucky University in 1977 and a medical-records associate's degree from Central Piedmont Community College in Charlotte, North Carolina, in 1994.

**Disabled Couple, cont. pg. 2**

## Make Your Plans!

### Oley Annual Conference, July 5-9, Bloomington, MN

Plans are under way for the 2011 Oley Annual Conference, and the Sheraton Bloomington is ready to accept your reservations. The rate is \$99/night for single/double or \$109 for triple/quad. Access these rates by calling (866) 837-4278 and mention you are with Oley, or by visiting [www.starwoodmeeting.com/Book/oley](http://www.starwoodmeeting.com/Book/oley). The cutoff date for reservations is June 12; requests received after this will be handled on a space and rate availability basis.

Conveniently located in the heart of Bloomington, Sheraton Bloomington Hotel, Minneapolis South is just ten minutes from the airport and the Mall of America. The 564 guest rooms and suites set the stage for an enjoyable stay. Parking is complimentary. The hotel shuttle offers transportation to and from the



accept your reservations. The rate is \$99/night for single/double or \$109 for triple/quad. Access these rates by calling (866) 837-4278 and mention you are with Oley, or by visiting [www.starwoodmeeting.com/Book/oley](http://www.starwoodmeeting.com/Book/oley). The cutoff date for reservations is June 12; requests received after this

**Conference, cont. pg. 8**

## Advocating on Your Behalf

### Working with the Transportation Security Administration

As noted in the Nov/Dec issue of the *LifelineLetter*, Oley has joined with twenty-three other organizations in a dialogue with the Transportation Security Administration (TSA) regarding the special needs of people traveling with central lines, tubes, ostomies, or other medical devices.

In December, this group sent a letter to TSA Administrator John Pistole. "We believe," the letter states, "that more information and training about how to be sensitive to travelers' medical conditions

is needed. This is especially true because ostomies and other medical conditions and devices that previously



**TSA, cont. pg. 10**

### Disabled Couple, from pg. 1

While I was working as a social worker in 1980, I began having seizures, which led to a stroke when I was twenty-four. The drive to be independent that had carried me through life to that point was tested again later, when the stroke eventually took away my ability to

speak and eat without aspiration.

#### Love Blooms at Bible Study

Mark and I met at church and then again at an annual bicycle touring event. I was a volunteer and Mark was a cyclist. We began dating after I started attending a weekly Bible study held in Mark's home.

He endeared himself to me when he found a three-wheel tricycle and altered it to accommodate my balancing problems. He attached a large seat and a lawn-mower steering wheel. We married in 1998.

#### Maintaining Independence

In 2000, I was told I would have to depend on a feeding tube for the rest of my life, due to worries of aspiration. I was afraid the tube would limit my activities and I refused to have one inserted. I took speech therapy for a year, trying to regain the ability to eat, but I was slowly starving to death. After a year I agreed to have the tube inserted into my stomach.

When I came home from the hospital, I had an intravenous pole with a pump attached for tube feeding. I now faced a new challenge to my independence: I could not manage to feed myself with one hand.

The bond between us and the value we place on independence inspired Mark to create a device that would give me more independence in feeding myself. After four or five versions, he came up with the Jackson PEG-tube stand. It is a portable, adjustable device that holds a feeding tube, and it can be used with one hand.

Often enteral bags are held on IV poles for gravity drips, or the formula and a pump are carried in a backpack. Neither of these options is very easy to use with one hand. When I first used the stand Mark developed, I knew I would be okay and could start planning for a future. Needing help every time I ate was unthinkable to me.

#### A New Venture Is Born

Mark and I formed Jackson PEG Tube Stands, LLC, in 2003 and began to explore the possibility of patenting and marketing the stand. We worked with the University of Kentucky Center for Manufacturing to improve upon the product's design and make prototypes with a grant from the Rural Innovation Fund, which supports new business ventures.

We are excited about the possibility of marketing the device, but are more excited about the impact it may have on those who rely on bolus PEG-tube feeding.

The stand has improved my quality of life because I don't have to rely on someone else to feed me. It has allowed me to travel and take meals wherever I go.

#### Bike Tour E-mail Takes a Detour to the Oley Foundation

Mark and I attended the annual Oley Foundation conference for the first time in 2010. However, it was not our first contact with Oley and its staff. Shortly after I got my PEG tube, I was searching the Internet for information on living with a tube. I came across the Oley Foundation and the e-mail address for Ellie Wilson, then the outreach staff member. I stored Ellie's e-mail address in my address book for future reference.

In 2005, I was e-mailing cyclists in our

## LifelineLetter

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#### Subscriptions:

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

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



Tina and Mark share a laugh with Ellie Wilson (center) at the 2010 Oley Conference.

region on updates for another bike tour when I accidentally included Ellie in the mailing. One of the cyclists was named Ed Wilson and his e-mail address was similar to Ellie's. When all the bike tour e-mails were dutifully sent, we waited for cyclists to respond. It did not take long to receive a reply from Ellie.

Ellie politely explained she would not be participating in the bike tour. Could I please take her name off the mailing list? she asked. When I saw she was writing from Oley, I realized my mistake and took the opportunity to explain I was on a PEG tube and was in the process of developing an assistive device for PEG users. We exchanged a few e-mails about the irony of the error.

## 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](mailto: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.

### Washable Pads Wick Moisture Away

I am a pediatric home care nurse and I care for a little guy with a G/J-tube. We now use Calmoseptine® cream on his site to address the irritation around the tube from drainage/leakage. We then put a washable G-tube pad over the site, which wicks the moisture away. I make them for him and his site is so much better!

The pads are made from two wicking fabrics, like fleece and hemp terry, and then covered with a layer of waterproof polyurethane laminated fabric (PUL) so that the drainage doesn't leak onto clothing. The fleece is usually the fabric closest to the skin. The pads are circular with a slit halfway up to allow the pad to be placed around the tube. It is then secured by a plastic resin snap. I make them in 2.5" and 3" sizes and sometimes add an extra absorbent layer for heavy drainage. The edges are secured with an overlock stitch to prevent fraying.



**Cher's Washable G-tube Pads**

The pads are machine washable and can be put in the dryer. He's been using them for a year, and his pads are still holding up pretty well! If someone wants to purchase pads, or wants information on how to make them, they can e-mail me.

Also, if someone has a special request for something to be created to solve a problem, they could contact me with the specifics. I really enjoy helping solve some of the problems these special little ones have!

—Cher Hall, [cherlad55@hotmail.com](mailto:cherlad55@hotmail.com)

*Editor's note: Another version of a G-tube pad is available at My ButtonBuddies, [www.mybuttonbuddies.com](http://www.mybuttonbuddies.com). Like Cher's pads, ButtonBuddies are circular, absorbent cloth pads designed to be worn around a G-tube; are washable and reusable; and are approximately 2 to 2.5 inches in diameter. The ButtonBuddies Web site notes, "Because ButtonBuddy pads are so cute and colorful, they make the G-tube 'button' look less scary than white medical gauze to the G-tube child, his/her playmates and anyone the child interacts with. ButtonBuddies look less like a bandage or a 'boo-boo.'*

*With ButtonBuddies, children with G-tubes can have something special for themselves in a happy and positive way." The Web site also notes that ButtonBuddies are available in various flesh tones for adults.*



**ButtonBuddies**

My e-mail communication with Ellie continued for five years. We explored the Oley Web site and would discuss issues with Ellie. When we were finally able to attend our first Oley conference this year, we were thrilled to meet Ellie and other Oley staff in person. Ellie is no longer on the Oley staff but she came to spend a day at the conference and to meet us.

### Struggles Continue

As hard as we have worked to be together and live a full life, it has come at a high price for Mark. When we got married, Mark lost his Social Security and medical coverage from the state. My Social Security Disability payments are above the limits allowed for him to qualify for any assistance.

Mark is concerned about what would happen if he got seriously injured or ill. To remedy the situation he has opened his own lawn-care business and files taxes each year. This will eventually allow him to qualify for Social Security disability benefits. The work is demanding on his body, though, and he is exploring his eligibility for assistance from Social Security. He is working toward a solution.

### Living Life to the Fullest

What do we do with our time? Besides marketing our invention, we have served as organizers for the annual Appalachian Bike Tour at Yatesville Lake for about seven years. The event is a fundraiser for a local college scholarship, which is awarded to a high school senior each spring. I also helped organize and research a book on the history of First Baptist Church, where I am a member and Mark serves as deacon. Mark was recently appointed by the governor of Kentucky to serve on the statewide Council for Vocational Rehabilitation.

*The Jackson PEG Tube Stand is patented and is available for purchase at [www.jacksonpegtubestands.com](http://www.jacksonpegtubestands.com).*

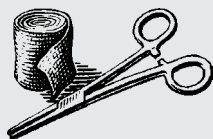


*Tina tube feeding independently, using the stand Mark created for her.*

## Equipment-Supply Exchange

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

Questions? Contact Oley volunteers Tammi and Rob Stillion at [Oleyequipment@aol.com](mailto:Oleyequipment@aol.com), or call toll-free, (866) 454-7351 between 9 a.m. and 4 p.m. EST.



## HomePN Research Prize: \$7,500 in Awards

Don't miss this opportunity to gain recognition for your homePN research, and win thousands of dollars in prize money! Apply for an Oley Foundation 2011 *Nutrishare HomePN Research Prize*.

Oley will award \$2,500 for each of the top three clinical papers dedicated to helping parenteral nutrition consumers. A portion of each prize (\$1,000) will be used to cover travel expenses to bring the winning recipients to the Oley Conference in Bloomington, Minnesota, July 5-9, 2011, where they will present their research.

Details on the award criteria and application process are available at [www.oley.org](http://www.oley.org) or by calling (800) 776-OLEY. Many thanks to Nutrishare, Inc., for sponsoring the awards.

**Hurry! Deadline for submissions is April 1.**

## Kyle R. Noble Memorial Scholarship

*To further the educational goals of individuals relying on HPN or HEN for their primary nutritional needs.*

In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a \$2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered. Applicants are asked to write a one- to three-page essay describing how he or she has overcome obstacles/challenges posed by HEN and/or HPN and inspired others to live life to the fullest. An educational reference (letter from an advisor or teacher supporting the applicant's educational pursuits) and a medical reference (from someone on the applicant's health care team — physician, nurse, dietitian — verifying the medical situation) is required.



**Kyle R. Noble**  
11/10/98–12/29/06

The scholarship will be distributed at the end of the school year after a copy of the recipient's transcript of his or her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference this summer in Bloomington, Minnesota.

Applications for the 2011 scholarship must be received by April 1, 2011. Send applications to Kyle R. Noble Memorial Scholarship, c/o The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208; or e-mail to [BishopJ@mail.amc.edu](mailto:BishopJ@mail.amc.edu).

## GLP-2 Analog May Reduce PN Dependency

New research results show that adult patients with short bowel syndrome (SBS) needed less parenteral nutrition (PN) after being treated with GATTEX® — a recombinant analog of human glucagon-like peptide 2 (GLP-2), also called teduglutide. Teduglutide is a peptide protein involved in the rehabilitation of the intestinal lining.

The 24-week, randomized, double-blind study, known as STEPS, was designed to compare the efficacy, safety, and tolerability of GATTEX to placebo. According to the manufacturer, NPS Pharmaceuticals, Inc., 27 out of 43 patients (63 percent) who received GATTEX achieved a 20 percent or greater reduction in weekly PN volume at weeks 20 and 24 in the study. In comparison, 13 out of the 43 patients (30 percent) treated with a placebo met the same end point. On average, patients who received GATTEX experienced a 4.4 liter reduction in weekly PN volume from a pre-treatment baseline of 12.9 liters; patients who received a placebo experienced a 2.3 liter reduction from a pre-treatment baseline of 13.2 liters. (More information about the study is available on the Oley Web site, [www.oley.org/Gattex2.html](http://www.oley.org/Gattex2.html).)

“The STEPS results suggest teduglutide helps restore normal intestinal function in patients with short bowel syndrome, thereby reducing dependence on parenteral nutrition and potentially improving their quality of life,” said Palle Bekker Jeppesen, MD, associate professor, Department of Medical Gastroenterology, Rigshospitalet, University Hospital of Copenhagen, Denmark. “These findings bring us closer to an important new therapeutic option for patients with this debilitating condition.”

NPS reports that GATTEX was well tolerated. Four of the 86 randomized patients discontinued the study due to adverse events, of which one was treated with GATTEX and three were treated with a placebo. Adverse events appear to be consistent with the pharmacological effects of the drug.

GATTEX is not yet available commercially; it is in Phase 3 in the development process. In the second half of this year, the company expects to file for FDA approval of GATTEX as a treatment to reduce PN-dependence in adult patients with SBS. GATTEX is in preclinical development for use in patients with other intestinal failure-related conditions. In 2007, NPS granted Nycomed the rights to develop and commercialize teduglutide outside the United States, Canada, and Mexico. Nycomed expects to submit a Marketing Authorization Application (MAA) to the European Medicines Agency (EMA) for teduglutide in the first half of 2011.

## Attention Facebook Friends

The Oley Foundation facebook page has moved! Please join us at [www.facebook.com/pages/The-Oley-Foundation/100575259989358](http://www.facebook.com/pages/The-Oley-Foundation/100575259989358).

All you have to do is click “Like” and you'll be connected to Oley updates, members, staff, and more via our new Facebook page!

Please tell your friends! E-mail [KSwensen18@gmail.com](mailto:KSwensen18@gmail.com) if you have any questions.



## Book Corner

*The Empowered Patient: How to Get the Right Diagnosis, Beat Your Insurance Company, Buy the Cheapest Drugs, and Get the Best Medical Care Every Time*, by Elizabeth Cohen (Ballantine Books Trade Paperback, \$15.00)

This book is loaded with practical, useable information, from how to communicate effectively with your doctor to how to buy health insurance to how to use the Internet wisely for medical information. Cohen, a medical correspondent with CNN, uses dozens of patient stories to illustrate her points, and often offers a health care provider's perspective or insights as well. She ends each chapter with a "checklist," which makes the book very easy to use.

This book would be a good resource for any of us, whether we are dealing with a chronic illness, caring for someone with a chronic illness, or just looking to become wiser about the health care we receive and the medicines we take.

*The Sound of a Wild Snail Eating*, by Elisabeth Tova Bailey (Algonquin Books of Chapel Hill, 2010, \$18.95)

While bedridden with an illness that is identified in the epilogue as mitochondrial disease, Elisabeth Tova Bailey becomes fascinated by the wild snail that lives in a terrarium at her bedside. Most of the book is focused on the snail—its habits, its life cycle, its characteristics—but along the way the author shares many insights into her own feelings and condition.

"Watching it glide along was a welcome distraction and provided a sort of meditation," Elisabeth writes about the snail. "My often frantic and frustrated thoughts would gradually settle down to match its calm, smooth pace. With its mysterious, fluid movement, the snail was the quintessential tai chi master." Elisabeth writes, too, that as she felt more and more distanced from the busyness that occupied her friends and visitors, the snail offered steady companionship.

*The Sound of a Wild Snail Eating* is a gentle book about a quiet but resilient creature, and the resilient woman who befriends it.

## Call an Expert, 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 will be devoted to **HPN (intravenously infused nutrition)**.
- (888) 650-3290 will be devoted to **HEN (tube feeding)**.
- (877) 479-9666 will be devoted to **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.*



## A Trusted Provider of Home TPN for Over 30 Years

Coram's Nourish Nutrition Support Program™ provides a customized care approach for home TPN and enteral patients. We are dedicated to providing high quality clinical care, nutrition expertise and personal support for nutrition consumers in the home.

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## Nutrition and You

### Searching the Web for Reliable Nutrition Information

Nutrition and health information is widely accessible on the Internet. Health-related searches are the third most popular online activity, and diet and nutrition information accounts for nearly half of all health-related searches. Nutrition Web sites that pop up in search engines may be eye-catching and easy to navigate, but how can you determine if they provide accurate and reliable information?

#### Look for Accuracy

By nutrition accuracy we mean scientific correctness. Questions to ponder include: Is the information or health claim backed up by scientific evidence? Do the materials have reference citations? Are the credentials of the author listed? Has anyone reviewed the information, for example, a qualified health professional or medical expert? Does the site have a scientific or medical advisory board? A nutritionally sound or scientifically accurate Web site should also provide a balanced perspective on the topic, with both positive and negative sides of the story visible.

There are many valuable tools to help you become an informed consumer when you navigate the World Wide Web. These tools help identify accurate and unbiased material and distinguish between fact and commercial bias. Two credible gateways that lead you to high-quality health and nutrition information are: [www.healthfinder.gov](http://www.healthfinder.gov) and the Tufts Nutrition Navigator at <http://navigator.tufts.edu>. Both the National Network of Libraries of Medicine and the National Institutes of Health have wonderful portals to help you evaluate health Web sites. Visit them at [nmlm.gov/outreach/consumer/evalsite.html](http://nmlm.gov/outreach/consumer/evalsite.html) and [www.nlm.nih.gov/medlineplus/healthywebsurfing.html](http://www.nlm.nih.gov/medlineplus/healthywebsurfing.html).

#### Consider the Source

Here are a few tips to help you evaluate the source of a Web site when you explore the Internet on your own. In general, addresses ending in “.org” are sponsored by not-for-profit organizations; those ending in “.gov” are sponsored by governmental agencies; and those ending in “.edu” are sponsored by academic institutions. Most nonprofit and governmental Web sites do not contain advertising and access to the site is usually free.

Private or commercially sponsored sites have addresses ending in “.com.” The primary purpose of many commercial sites is marketing or selling a product or service. Commercial sites often provide nutrition and health information, although this may be a secondary goal. It is important to evaluate who provides funding to the site and whether the source of nutrition information is written or reviewed for scientific accuracy by a health care expert with appropriate credentials, or a scientific advisory board with experts in the field.

#### Some Favorite Sites

A Google search for “nutrition” today yields over one hundred million hits, but this column provides only a brief review of a few of our favorite sites. Future issues of the newsletter will review additional Web sites, especially some reliable “.com” sites.

#### [www.nutrition.gov](http://www.nutrition.gov)

The government’s Nutrition Web site is provided as a service of the National Agricultural Library of the U.S. Department of Agriculture (USDA). The home page provides news feed for current events and spotlights food and nutrition research. The site is easy to navigate and allows searching by topic or browsing by subject. Click on the link for “Nutrition and Health Issues,” where you will find a gateway to Medline Plus (a searchable database with consumer-friendly health information) or on the links to USDA MyPyramid or Dietary Guidelines for Americans.

The “Health Issues” page provides information on: heart health, high blood pressure, diabetes, cancer, weight and obesity, digestive disorders, osteoporosis, eating disorders, food allergies and intolerances, and AIDS/HIV. The “Digestive Disorders” link provides information from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), including a section in English and Spanish called “Your Digestive System and How It Works.” You’ll find plenty of information about gas, heartburn, indigestion, diarrhea, and constipation, too.

Back on the home page, consumers may also enjoy browsing the link for “Shopping, Cooking & Meal Planning,” where you’ll find resources on such topics as food labels, recipes, ethnic cooking, and food safety and storage. In addition there are links for “Dietary Supplements” and “Food Assistance Programs.” Overall the government’s nutrition Web site is informative and current.

#### [www.hsph.harvard.edu/nutritionsource](http://www.hsph.harvard.edu/nutritionsource)

The Nutrition Source Web site is maintained by the Department of Nutrition at the Harvard School of Public Health. It is designed to help you achieve the healthiest diet possible and to provide timely information on diet and nutrition. The Web site is colorful and easy to navigate. You will find links to healthy eating, including tips for eating right and for fitting more activity into your day.

The site is searchable for nutrition topics, provides recipes, news, answers to frequently asked questions, and answers from experts on a variety of current “hot” topics in nutrition. The site includes a disclaimer that the information provided is not intended to offer personal medical advice; it does not mention any brand names and does not endorse products.

#### [www.eatright.org](http://www.eatright.org)

The American Dietetic Association offers “Food and Nutrition Information You Can Trust.” Click on the link “For the Public” and you will find numerous resources and nutrition education materials. Stay informed by reviewing the “Tip of the Day,” the “Question of the Day,” and the latest food and nutrition updates.

Currently the Web site includes a review of popular diet books on the best-seller list, each reviewed by a Registered Dietitian (RD). Learn about fighting childhood obesity and read all about the new Kids Eat Right campaign. The Web site has a body mass index (BMI)

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A nutritionally sound or scientifically accurate Web site should provide a balanced perspective on the topic, with both positive and negative sides of the story visible.

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calculator and videos on a variety of food and nutrition topics.

[www.nutritioncare.org](http://www.nutritioncare.org)

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is an organization for “helping professionals advance nutrition support.” The home page of the Web site announces current news on topics related to parenteral and enteral nutrition and also provides information for patients and caregivers. You will find patient education materials in English and Spanish, including fact sheets titled “What is Nutrition Support Therapy?,” “What is a Nutrition Support Professional?,” “What is Enteral Nutrition?,” “What is Parenteral Nutrition?,” and Oley’s home enteral and parenteral nutrition complication charts. A.S.P.E.N.’s new patient safety initiatives may also be of interest to Oley consumers. While many of these resources assist your health care practitioners in providing you the best care, there are also downloadable posters for the “Be A.W.A.R.E.” and “Be A.L.E.R.T.” campaigns to prevent enteral misconnections and improve enteral nutrition safety.

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

ClinicalTrials.gov is a registry of federally and privately supported clinical trials conducted worldwide, offered through the National Institutes of Health. This site allows you to search for clinical trials by topic. We recently performed a search of parenteral nutrition and found over 100 studies currently open to enrollment. Similarly, we found 180 studies for enteral nutrition. It is encouraging to see so many research studies focused on nutrition therapies.

Stay tuned for reviews of more Web-based nutrition information, including a few reliable “.com” sites, in future issues of the newsletter.

*This column has been compiled and reviewed by Marion Winkler, PhD, RD, CNSC; Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN; Laura Matarese, PhD, RD, LD, FADA, CNSD; and Cheryl Thompson, PhD, RD, CNSD.*

## Prepare for Power Outages

“Shamrockmom” posted a valuable notice on the Oley Forum about her electric company’s Critical Care Program. You may want to see if your electric company offers such a program and what it entails. In her case, the company said once it was notified about life-support equipment, it would call the customer if a severe storm was anticipated so the customer “can make advanced preparations.” Further, they noted, “If an outage does occur, every effort will be made to restore the electricity as soon as possible.” Here’s Shamrockmom’s posting:

*“I found out and applied for the Critical Care Program thru my electric company here in New York (Long Island). The program is free. All I did was send them a letter from my doctor stating I am on a feeding tube. I had to complete a short form that can be downloaded from the electric company’s Web site.*

*“I also purchased an ‘inverter’ that allows me to plug my feeding pump into my car cigarette adapter to charge during a power failure.”*



## Thanks to Our Consumers for Helping Us Give Back...

ThriveRx sponsors several consumer support groups with donations and educational support.

 CROHN'S & COLITIS  
FOUNDATION OF AMERICA



 UNITED  
MITOCHONDRIAL  
DISEASE  
FOUNDATION.  
HOPE. ENERGY. LIFE.

 The Oley  
Foundation

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To be a part of the solution, contact us at  
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## New Resources @ www.oley.org

Brand new on the Oley Web site are interactive programs that help HPN consumers manage their fluid and sugar levels. Part of the MY HPN series, *Module 3: Fluid Balance* and *Module 4: Glucose Control*, teach patients and caregivers about common symptoms, prevention steps, and standard treatment for dehydration and over-hydration, as well as maintaining appropriate glucose levels.

The MY HPN series is the first of its kind to teach HPN consumers how to better manage their own home parenteral nutrition. Modules one through four are available, free of charge, at [www.oley.org](http://www.oley.org). Module 1 teaches consumers how to become active participants in their health care team. Module 2 covers catheter-associated infection. Future modules will cover such topics as nutrition, lab testing, liver and bone disease, catheter issues, and eventually transitioning off of HPN.

Many thanks to Oley trustee, Cheryl Thompson, PhD, RD, CNSD, for developing the modules, and to her husband, Greg Thompson, MD, MSc, for his technical assistance. We are also grateful to Baxter International, Inc., for sponsoring these modules, and for the many volunteers who helped review them.

### Other Neat Stuff @ www.oley.org

Looking to learn more about diet, hydration, and short bowel syndrome? You'll find helpful information at [www.oley.org/Diet\\_Hydration\\_Nutrition.html](http://www.oley.org/Diet_Hydration_Nutrition.html).

Oley staff members find dozens of articles in the popular press each week that may interest you. Go to [www.oley.org](http://www.oley.org), click on "More News," then click on "News Coverage of Tube and IV Feeding." You'll find links to articles on health care reform, profiles of people with stories that may be similar to yours, what people have to say about the TSA, articles on the value of social networking for people with chronic illness, and much more.

You can find articles from our own *LifelineLetter* online, too. There's a link to the latest issue at [www.oley.org](http://www.oley.org), or select "Newsletter" from the "Resources" menu to find previous articles and issues. It's a great way for you to learn more about topics relevant to you. Check them out!



## On HPN? Get Your Provider Involved with a Valuable Database!

A little data on home parenteral nutrition (HPN) can go a long way. That's why the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is encouraging HPN consumers to tell their providers about Sustain™, LLC, its new online patient registry for nutrition support therapy in the United States.

Sustain offers an unprecedented opportunity for HPN providers to help A.S.P.E.N. collect valuable data about consumers who are on HPN. The information entered into the registry will ultimately help organizations make better-informed patient treatment decisions, support the appropriate use of nutrition support therapy, and help improve patient outcomes.

Please note that **patient privacy is a priority**. The registry constitutes a Limited Data Set under HIPAA requirements and all patient identifiers under those requirements are not entered into the dataset. All persons using or receiving access to the data must sign a data use agreement through which he or she agrees to protect the privacy of the information received.

Currently, in the United States little is known about the annual use of HPN. Sustain will help generate data about therapy utilization, outcomes, and patient demographics, which will help all consumers, present and future.

A.S.P.E.N. needs your HPN providers to get involved with Sustain. Institutions, home infusion company providers, and U.S.-based clinicians who discharge patients from the hospital or care for them at home can join this patient registry program.

Share this information with your provider today! Visit the Sustain Web site at [www.nutrition-care.org/sustain](http://www.nutrition-care.org/sustain) or contact Peggi Guenter at [peggi@aspen.nutr.org](mailto:peggi@aspen.nutr.org) for more information.

### Conference, from pg. 1

airport (schedule will be posted) as well as the Mall of America!

Conference registration is free for consumers and their family members. And with several of your meals included with registration (complimentary continental breakfasts two days, lunch each of two days, at least one dinner and a few receptions), your out-of-pocket expenses can be minimal. Factor in the tremendous learning experience and the value of gathering with others who sustain themselves similarly, and we're sure you'll agree that the conference is a win/win journey for you and your family.

Last summer, one family member wrote, "While at the Oley conference this year [2010] I had a sense of walking among great people! What a privilege it was to attend!"

Another attendee wrote, "The 2010 Oley Foundation conference was better than we had imagined. We left with information and contacts that will enhance [my husband's] quality of life." This family described meeting others who shared their situation, which helped them to feel less isolated. They left with hope that some of the problems they had thought couldn't change can be addressed.

In another compelling testimonial, a parent said, "Our son did not want to leave. It was the first time since he was put on HPN and HEN that he felt normal. He made friends that understand what he is going through."

Please call us with questions, stay tuned to [www.oley.org](http://www.oley.org) for updates, and send suggestions for topics and speakers to [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu) or call (800) 776-6539.

A limited number of travel grants are available for "first time" annual conference attendees. Write two paragraphs describing how you believe attending the conference will affect your life. The ideal candidate will include plans to share information learned at the meeting with consumers and/or clinicians back home. Send to [harrinc@mail.amc.edu](mailto:harrinc@mail.amc.edu) or to Oley headquarters by May 15.

We hope to see you there!

## 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 consumers strictly as an informational tool. For a listing of other experienced centers visit [www.oley.org](http://www.oley.org) or call (800) 776-OLEY.

### Intestinal Support Service, Nationwide Children's Hospital, Columbus, Ohio

The Intestinal Support Service (ISS) at Nationwide Children's Hospital was established in 2004 with the goal of providing exemplary care to a select group of patients who have had significantly impaired intestinal function. This includes those with short bowel syndrome, necrotizing enterocolitis, intestinal atresias, abdominal wall defects, volvulus, long-segment Hirschsprung's disease, and other disorders that have resulted in the need for parenteral or enteral nutrition support.

Nationwide offers a dedicated inpatient service staffed by members of the ISS as well as comprehensive outpatient care. In addition to pediatric surgical and interventional radiology expertise, Nationwide has a nationally recognized motility team. While there is not an intestinal transplant program at Nationwide Children's Hospital, they have a close relationship with several transplant programs, which allows children and families to remain closer to home prior to transplant and once they are stable following transplant.

Since its inception, the ISS has provided care for more than two hundred patients. The majority of children Nationwide has cared for are able to wean from parenteral nutrition to either all oral or a combination of oral and enteral feedings. The time it takes to reach this goal varies from one person to another.

ISS core team members include Jane Balint, MD; Molly Dienhart, MD; Steven Teich, MD; Sandra Jacobs, CNP; Patti Kegley, RN; Lia Headings, RN; Mary Kay Sharrett, RD; Steve Plogsted, PharmD; Lynn Gutches, MSW; and Mindy Johnson.

Contact the ISS by calling Mindy Johnson at (614) 722-3485 or through their Web site, [www.nationwidechildrens.org/intestinal-support-service](http://www.nationwidechildrens.org/intestinal-support-service).

## 2011 Oley Awards


Oley presents five awards each year to recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone today. Forms are available at [www.oley.org](http://www.oley.org), or by calling (800) 776-OLEY.



Awards will be presented at the 2011 Oley Consumer/Clinician Conference and the awardees will be spotlighted in the *LifelineLetter*. Several of the awards include a partial travel grant to the conference (to be held July 5-9, in Bloomington, MN). Recognition is given to all nominees.

Hurry! Award nominations must be received by April 1, 2011.

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TSA, from pg. 1

had not shown up in security screenings will show up more frequently in full body scans.”

“Clearly,” the letter concludes, “a one-size-fits-all approach for screening has not worked for people living with ostomies and those who use medical appliances and devices.” (To obtain a copy of the complete letter, go to [www.oley.org/Air\\_Travel\\_Security.html](http://www.oley.org/Air_Travel_Security.html) or call us at 800-776-6539.)



In response to the letter, the TSA coordinated a meeting for late January, providing representatives from this group with an important opportunity to outline issues of concern to our respective members. We then sent an e-mail to every Oley member who has registered an address with us, requesting that you share your TSA experiences (a benefit of being on our e-mail list—the opportunity for quick correspondence!).

### Sharing Member Experiences

The response to our request was overwhelming, and offered Oley Foundation Executive Director Joan Bishop a greater understanding of your needs. Joan shared these experiences with John Pistole and his staff at the January 25th meeting. Oley, the TSA, and the other organizations involved agreed this meeting was a great starting point, a partnership and work in progress to meet the needs of this government agency charged with “keeping us safe” and of the public traveling with special needs. We’ll keep you updated on [www.oley.org](http://www.oley.org), and encourage you to stay tuned to the TSA Web site as you make your travel plans.

The comments in the box on right, many gleaned from this meeting, should help you navigate your way through airport security.

Please keep the feedback coming! We can only move forward if you continue to contribute. ¶

## Tips for Navigating Airport Security

- Before you go to the airport, **visit the TSA Web site** and read the pages devoted to traveling with disabilities and medical conditions ([www.tsa.gov/travelers/airtravel/specialneeds/index.shtm](http://www.tsa.gov/travelers/airtravel/specialneeds/index.shtm)) or call the TSA Contact Center at (866) 289-9673 for a copy of the most recent guidelines and/or with your questions and concerns.

- Download or call for a copy of the **TSA card**, [www.tsa.gov/travelers/airtravel/specialneeds](http://www.tsa.gov/travelers/airtravel/specialneeds) (just above the additional resources section), and use it to discreetly call attention to your medical condition to Transportation Security Officers (TSOs).

- **A letter from your physician/clinician** describing your medical condition and the supplies you are traveling with is crucial in expediting the security screening process (sample on [www.oley.org/Travel\\_letters.html](http://www.oley.org/Travel_letters.html)).

- You might want to seriously **consider a full body scan**. Catheters, tubes, ostomy and drainage bags, etc. will be detected immediately and are likely to be foreign to screening officers. They will need to be investigated. However, once you have been through the body scanner you have opened the door for a **self pat-down**. You will be asked to touch your own catheter, ostomy bag, etc., then have your hand scanned with the wand used to detect explosives.

- **If the full body scan is declined, a full pat-down will happen**. You have the right to be patted down by someone of the same gender (note that this could take extra time). You also have the right to ask for the pat-down to be conducted in a private place and to have someone else present. Children are not to be separated from a parent!

- Passengers with disabilities can **contact a TSA Customer Support Manager**, prior to arriving at the airport, to discuss the best possible way to be screened. Details are posted at [contact.tsa.dhs.gov/talktotsa/talktotsa.aspx](http://contact.tsa.dhs.gov/talktotsa/talktotsa.aspx).

- A “reasonable” amount of “**medical foods**” can be carried on board. This is the terminology used in the training of the TSOs, so it would be best to identify your supplies in this way. Documentation from your clinician or homecare provider that outlines “your” reasonable amount may help. Additional screening may apply.

- You have right to **request a fresh set of gloves** when being screened.

- **Cameras are positioned** throughout screening areas. While they do not capture everything, it’s worth noting.

- If you feel your experience has been mishandled, please note the name of the airport, city, state, flight number, time, gate, name of TSO, and as much information as possible. **File a report** to help the TSA follow up regarding retraining, corrective action, etc.

- The **safety-related studies** pertaining to the use of Advanced Imaging Technology can be found at [www.tsa.gov/approach/tech/ait/safety.shtm](http://www.tsa.gov/approach/tech/ait/safety.shtm)



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## Medicare Is Looking for Feedback from Tube Feeders

Are you a Medicare recipient on home enteral nutrition (tube feeding) who has been affected by the Medicare Competitive Bidding Program? “Round One” of this program was put into effect on January 1, 2011, in nine communities across the U.S. (“competitive bidding areas,” or CBAs, as well as details of the program, are listed below). Now Medicare would like to know how it’s going.

If your old supplier is not a contract supplier (see below), you have probably had to choose a new supplier. If you are on multiple therapies (for example, tube feeding and oxygen), you may have had to choose one supplier for one therapy and another for a second therapy. So how has this affected you?

Are you getting your supplies in a timely manner? Are you able to get what you need? If you have had to choose a new supplier, has the transition gone smoothly? Please share your experiences with us, or directly with Medicare. Medicare has asked for input. Contact Joan Bishop at [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu) or (800) 776-6539; or Medicare at [www.cms.hhs.gov/DMEPOSCompetitiveBid](http://www.cms.hhs.gov/DMEPOSCompetitiveBid) or (888) 990-0499.

### Competitive Bidding Program Background

In brief, the program involves durable medical equipment, prosthetics, orthotics, and supplies (DMEPOS) covered under Medicare Part B—which includes enteral nutrition. The stated program goal is to lower costs for Medicare and for beneficiaries—you—by using the local, competitive marketplace to lower the costs for DMEPOS

for beneficiaries who use the Medicare-contracted suppliers for these items. Because you pay coinsurance on the cost of DMEPOS, you will directly benefit from the savings.

Medicare states that contracts were awarded to suppliers who offered the best price; met Medicare’s eligibility, quality, and financial standards; and are accredited by an independent accrediting organization. (You can find a list of contract suppliers in your area at [www.cms.gov/DMEPOSCompetitiveBid/01A2\\_Contract\\_Supplier\\_Lists.asp](http://www.cms.gov/DMEPOSCompetitiveBid/01A2_Contract_Supplier_Lists.asp) or by calling 800-MEDICARE.)

### CBAs and Product Categories

The areas covered in Round One are: Charlotte/Gastonia/Concord (NC and SC); Cincinnati/Middletown (OH, KY, and IN); Cleveland/Elyria/Mentor (OH); Dallas/Fort Worth/Arlington (TX); Kansas City (MI and KS); Miami/Fort Lauderdale/Pompano Beach (FL); Orlando/Kissimmee (FL); Pittsburgh (PA); and Riverside/San Bernardino/Ontario (CA).

The items covered include: enteral nutrients, equipment, and supplies; oxygen, equipment, and supplies; standard power wheelchairs, scooters, and related accessories; complex rehabilitative power wheelchairs and related accessories (Group 2 only); mail-order diabetic supplies; continuous positive airway pressure (CPAP) devices; respiratory assist devices (RADs), and supplies and accessories; hospital beds and accessories; walkers and accessories; support surfaces (Group 2 mattresses and overlays in Miami/Ft. Lauderdale/Pompano Beach only).

---

Are you getting your enteral supplies in a timely manner? Are you able to get what you need?

---

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| Len Merewitz, in honor of<br>Alan Robinson                            | Davria & Steven Cohen<br>Shirley Corbin   | Good Search<br>Joan Gordon  |  |  |
| Lisa & Ron Metzger, in<br>honor of Lyn Howard,<br>MD                  | Ralph & Roseann Crafts<br>Carol Daquano   | Sophia Gutherz<br>Brenda Hansen   |  |  |
| Ann Michalek, MD  | Louise Delgado<br>Teri Dool   | Gayle L. Johnson<br>Charles Karnack   |  |  |
| Linda Morotini  | Robert & Anastasia Fenton<br>Janelle & Delbert Fortin, in<br>honor of Jonathan Nelson | Tina Kerrigan<br>Pauline Kubizne, in honor<br>of Ann DeBarbieri                       |  |  |
| Elizabeth Pemble  | Good Search<br>Joan Gordon  | Anne-ophie Labossiere<br>Marie Latta  |  |  |
| Paul & Donna Peot, in<br>honor of Ryan's 16 yrs<br>on PN              | Sophia Gutherz<br>Brenda Hansen   |   |  |  |
| Karen L. Ramagnano, in<br>memory of Seymour<br>Goldfarb               | Gayle L. Johnson<br>Charles Karnack   |   |  |  |
| M. Virginia Roland, in<br>honor of Benji Carroll                      | Tina Kerrigan<br>Pauline Kubizne, in honor<br>of Ann DeBarbieri                       |   |  |  |
| Thomas E. Sanford   | Anne-ophie Labossiere<br>Marie Latta  |   |  |  |
| Jacqueline Schesnol, in<br>honor of Jeffrey Schesnol                  |   |   |  |  |
| Vi Schultz  |   |   |  |  |
| Tracy Scott   |   |   |  |  |
| Karen Sexton-Hamilton   |   |   |  |  |
| Amy, Jay, & Kevin<br>Shearrow, in honor of<br>Colorado State Infusion |   |   |  |  |
| Suzanne B. Skidmore   |   |   |  |  |
| Roseanne Sobieski   |   |   |  |  |
| Wanda Stone, in memory<br>of Sallie Simpson                           |   |   |  |  |
| Enrica Thure  |   |   |  |  |

## 2010 Corporate & Foundation Program Support

*The following corporations and foundations  
gave significant gifts in 2010  
to support specific Oley programs.*

Abbott Nutrition  
Baxter Healthcare  
BioScrip Infusion Services  
Brooks Health Care, Inc.  
Coram Specialty Infusion Services  
Crescent Healthcare, Inc.  
CSL Behring, LLC  
Daniel F. and Ada L. Rice Foundation  
Emmaus Medical, Inc.  
Kimberly-Clark  
NPS Pharmaceuticals  
Nutrishare, Inc.  
ThriveRx  
Walgreens



### Donors, from pg. 13

Keith & Donna Kuhlmann  
Chris LaPolla  
Mary Jane LaPorta  
Kenneth Lighthall  
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Allan Mabardy  
Carol Mabardy  
Sarah MacDonald  
Ron Marshall  
Sue McKallor  
Dona R. McDuff  
Mary Meador  
Carolyn Mesler, in honor of Aleah Smith's birthday  
Joseph & Noel Metzger  
Pat Mielke  
Cathrine Miller, in honor of Jeff Allshouse  
David & Sharon Million  
Gail Moore  
Donna Mummery  
Marilyn Murray, in honor of Bradford Murray  
Stacey Myers  
Joseph Nadeau, RPh  
Meredith Nelson

Howard & La Vonne Nicholson  
Sue Okenck  
Ellie Packer  
John Park  
Brenda S. Parker, in honor of Dale Parker, what a husband!  
Melinda Parker, MS, RD  
Ubolrat Piamjarjakul, PhD, RN  
Sadie Pierce  
P. Plahaerty  
Mary Probus  
Nathan Rameaka  
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Doris Richards  
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Mildred Robidoux & Deborah Pinheiro  
Tom Rohwer  
Tara Rotella  
Janice Roth  
Anita Rothblum  
Lydia Schaefer  
Susan & Jeffrey Schesno, in honor of Jeffrey  
Olivia Seger

Charlotte Shore, in honor of Erin Shore's birthday  
Mary Smithers  
Janet & Brad Spiegel  
Lisa Szpak  
Allison Thompson  
Cheryl Thompson, PhD, RD, CNSD  
George & Katherine Timmons, in memory of Kyle Noble  
Dorothy Townsend  
Jason Valenzano  
Lee & Barbara Van Sluyters  
Carol Walsh, in honor of Mary Ellen Costa  
Brooke Wardrop  
Susan Warren  
Barbara Wennik  
Manuela Wenz  
Helen White  
Bobbiejo Winfrey, in honor of 5 yr transplant anniversary  
Donna Wisnaskas  
Carol Wittlin  
Patricia Wright  
**Matching Gifts**  
Baxter International

FM Global  
The GE Foundation  
National Grid

### In Honor of Rick Davis

Jane Balint, MD  
Sara Davis  
Ross & Ann Heller  
Jacquie & Don Leary  
Robert & Patricia Warrington

### In Honor of Michael Medwar's Birthday

Eileen Bowes  
Mike Hardman & Roseanne Felago  
Craig, Shannon, & Alyssa McCormack  
Stacey Myers  
Janet & Brad Spiegel  
Brooke Wardrop

### In Memory of Linda Gold

Mary Friel  
Kathleen & Larry McInnes  
Cathy Tokarz

### In Memory of

**Floyd Greenman**  
Bob & Renee Resnick  
Richard & Dianna Rice  
Randie Rosenberg  
Janice Roth  
Lee & Barbara Van Sluyters  
Susan Warren

### In Memory of Lee Koonin

Felice Austin  
Davria & Steven Cohen  
James & Kristina Farrley  
Mary Friel  
Mardee S. Jenrette  
Lee & Barbara Klingler  
Marshall Koonin  
Susan Koonin  
Robin Lang  
Alan & Beverly Levy  
Michael Medwar  
Suzanne B. Skidmore

### In Memory of Robin K. Lang

A. L. Prime Energy Consultant, Inc.  
Barbara Blanchard

## Recent 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 are pleased to include a complete list of the contributions received in 2010 on pages 12–15 of this newsletter.

Between November 24, 2010, and January 21, 2011, gifts were received:

### In Memory of

Alma Louise Anderson; Gene Bussoletti; Joy Emich; Arthur & Marjorie Harshbarger; Joyce Hydorn; Tim Joyce; Dorothy Kelly; Shirley, Arnold, & Fred Klein; Robin Lang; Kyle Noble; Dick Rivett; Mary Anne Scellato; Willis (Dick) Schultz

### In Honor of

Mandy Allen; amazing HPEN consumers; Julie Andolina; Leslie Bagby; Bridget Ballard; Joan Bishop; Adele Bitowft's five years on tube feeding; Bettemarie Bond; Bettemarie Bond's loving and supportive family and friends; Colorado State Infusion; Maryellen Costa's courage; Rick Davis, on his tenth anniversary; Ann

DeBarbieri; Jackson Dietel; Jon Fazzaro; Dr. Lyn Howard; Dr. Darlene Kelly; Easton Krumm, three years old; Robert Martino, 9-21-23 on EN for four years; David McGee; Luke Middlebrooks; Rachael Miller; Jonathan Nelson; Oley staff and Regional Coordinators; Ryan Peot's sixteen years on HPN; Ellen Pierce; Jeffrey Schesno; Sandy Schwarz; J.T. Sherrow; Erin Shore's birthday; Lia Smollen; Myrna Stinette's seventy-fifth birthday; Fuad Turfah, MD; Michael Yelner's sixteenth birthday and eleven-plus years on HPN; Don Young

**Matching Gifts** were received from FM Global Foundation and the GE 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!

Mrs. Patricia A. Brown  
 Mary & Beth Caruso  
 Louise Comeau  
 Danver's Boot Camp Group,  
 c/o Kelly Pszeny  
 Ann & Paul DeBarbieri  
 Emily Foley & Family  
 Barbara Follansbee  
 Joyce Fountain  
 Mary Friel  
 Bobbie Groeber  
 Margaret Kelley  
 Christopher & Larissa  
 Lang  
 Ernest Lang  
 Susan J. Lear  
 Kathy & Rich Malewicki

Dona R. McDuff  
 Kathleen & Larry McInnes  
 Mary Meador  
 Joan & Eli Medwar  
 Mary Miller  
 Mary Probus  
 Doris Richards  
 Mildred Robidoux &  
 Deborah Pinheiro  
 Alan Segal  
 Robert & Karyn Thomas  
 Cathy Tokarz  
 Dorothy Townsend  
 George Walden  
 Marion Winkler  
 James Wittmann  
 Patricia Wright

**In Memory of  
 Colyn Woods**  
 Felice Austin  
 Joan Bishop  
 Mrs. Patricia A. Brown  
 Joseph & Kathryn Cleberg  
 Roslyn Dahl  
 Michael Medwar  
 Lisa Metzger  
 Steve & Edithe Swensen  
 Cathy Tokarz

## 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)

Coram Specialty Infusion Services  
 Nutrishare, Inc.  
 ThriveRx

### BRONZE STAR PARTNERS (\$20,000–\$29,999)

Emmaus Medical, Inc.  
 NPS Pharmaceuticals

### BENEFACTOR LEVEL PARTNERS (\$10,000–\$19,999)

Abbott Nutrition  
 InfuScience, Inc.  
 Kimberly-Clark  
 Nestlé HealthCare Nutrition

### PATRON LEVEL PARTNERS (\$5,000–\$9,999)

Applied Medical Technology, Inc.  
 Baxter Healthcare  
 Critical Care Systems, Inc.  
 Walgreens-OptionCare

### BLUE RIBBON PARTNERS (\$2,500–\$4,999)

Sherwood Clinical

### CONTRIBUTORS (\$1,000–\$2,499)

B. Braun Medical  
 Drink Your Meals

## 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. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

|                                  |                                    |   |
|----------------------------------|------------------------------------|---|
| <i>Felice Austin</i>             | <i>Shirley Heller</i>              | <i>Kay Oldenburg</i>                      |
| <i>Jane Balint, MD</i>           | <i>Alicia Hoelle</i>               | <i>Harold &amp; Rose Orland</i>           |
| <i>John Balint, MD</i>           | <i>Jeff &amp; Rose Hoelle</i>      | <i>Judy Peterson, MS, RN</i>              |
| <i>Joan Bishop</i>               | <i>Lyn Howard, MD</i>              | <i>Clemens Pietzner</i>                   |
| <i>Ginger Bolinger</i>           | <i>William Hoyt</i>                | <i>Beverly Promisel</i>                   |
| <i>Pat Brown, RN, CNSN</i>       | <i>Portia &amp; Wallace Hutton</i> | <i>Abraham Rich</i>                       |
| <i>Katherine Cotter</i>          | <i>Kishore Iyer, MD</i>            | <i>Gail Egan Sansivero, MS, ANP</i>       |
| <i>Jim Cowan</i>                 | <i>Doris R. Johnson</i>            | <i>Roslyn &amp; Eric Scheib Dahl</i>      |
| <i>Rick Davis</i>                | <i>Darlene Kelly, MD</i>           | <i>Susan &amp; Jeffrey Schesno</i>        |
| <i>Ann &amp; Paul DeBarbieri</i> | <i>Family of Shirley Klein</i>     | <i>Doug Seidner, MD, FACC, CNSP</i>       |
| <i>David &amp; Sheila DeKold</i> | <i>Jim Lacy, RN, BSN, CRNI</i>     | <i>Judi Smith</i>                         |
| <i>Tom Diamantidis, PharmD</i>   | <i>Robin Lang</i>                  | <i>Steve Swensen</i>                      |
| <i>Selma Ehrenpreis</i>          | <i>Hubert Maiden</i>               | <i>Cheryl Thompson, PhD, RD, CNSD,</i>    |
| <i>Herb &amp; Joy Emich</i>      | <i>Laura Matarese, PhD, RD,</i>    | <i>&amp; Gregory A. Thompson, MD, MSc</i> |
| <i>Jerry Fickle</i>              | <i>CNSD</i>                        | <i>Cathy Tokarz</i>                       |
| <i>Don Freeman</i>               | <i>Kathleen McInnes</i>            | <i>Eleanor &amp; Walter Wilson</i>        |
| <i>Linda Gold</i>                | <i>Michael Medwar</i>              | <i>James Wittmann</i>                     |
| <i>Linda Gravenstein</i>         | <i>Meredith Nelson</i>             | <i>Patty &amp; Darrell Woods</i>          |
| <i>The Groeber Family</i>        | <i>Nancy Nicholson</i>             | <i>Rosaline Ann &amp; William Wu</i>      |
| <i>Valerie Gyurko, RN</i>        | <i>Rodney Okamoto, RPh,</i>        |   |
| <i>Alfred Haas</i>               | <i>&amp; Paula Okamoto</i>         |   |

*Thank You!*

## LifelineLetter

### The Oley Foundation

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Albany Medical Center, MC-28  
Albany, NY 12208

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## Staff an Oley Booth!

Oley may be exhibiting at a conference in your area! If you can help us by staffing an Oley exhibit booth—handing out information about Oley and sharing your experiences—please call Oley at (800) 776-6539 or contact Katie Swensen at [kswensen18@gmail.com](mailto:kswensen18@gmail.com).

- May 8–10: *Society of Gastroenterology Nurses and Associates*, Indianapolis, IN
- May 15–17: *American Society of Colon and Rectal Surgeons Meeting*, Vancouver, BC
- May 23–25: *Infusion Nurses Society*, Louisville, KY
- November 18–19: *Infusion Nurses Society*, Los Angeles, CA

After Oley member Amelia Coffman helped out at an exhibit in October, she shared this with us: “The main thing I personally wanted to share with these professionals was that we [Oley] are ‘real people’ who are just sharing what has worked for them, with a great staff of regional volunteers and a very comprehensive Web site....”

“I always assumed Oley was very well known, but some of the people visiting the table had never heard of Oley, despite sharing with me that they discharge multiple patients a week with new PEG/G/J/PICC etc. [tubes or lines]. So, there is a message to be shared and we, the ones living with HPEN, are in a place to do that!”

“I, of course, had my backpack with my pump and food, and it was almost startling for some of these professionals to realize that you can lead a pretty normal life on HEN. That I am working on a PhD while on HEN was a revelation to a few I think!”

## Bright Idea

### MoveAround™ IV Buggy

We recently saw an article in a Maryland newspaper about a grandfather who, after watching his granddaughter try to get around while undergoing infant leukemia treatments, designed and built a basic “little shopping cart” for her in his garage.

The invention allowed the child to move around with her IV pole, tubes, bags, and pumps, as well as toys and small stuffed animals. The grandfather, Ralph Lawrence, has joined with his family to create Lawrence Medical, which is now producing the MoveAround™ IV Buggy for other children on IV therapy.

The buggy, which sells for \$350, features a removable IV pole, is pushed like a shopping cart, and offers an adjustable handle to accommodate kids aged eighteen months to teenagers. It features a bin where the child can store personal items, and a cup tray accessory. For more information, contact Lawrence Medical at [www.ivbuggy.com](http://www.ivbuggy.com), (401) 595-4370, or [info@ivbuggy.com](mailto:info@ivbuggy.com).

