Self-Monitoring for HPN Consumers

Marcia Boatwright, RN, CRNI; Kristyn Maixner, RN

Participants at the recent Oley conference frequently heard speakers discuss the importance of self-monitoring for those on enteral and parenteral nutrition (PEN) therapy. What is self-monitoring? It is the gathering and recording of important health information, and it will enable you to assist your care team in providing optimal nutrition therapy outcomes.

The body provides subtle indicators that when recognized early can prevent potentially serious medical conditions and complications. No one knows your body better than you, which is why self-monitoring is the most important thing you can do for yourself and your well-being.

The following self-monitoring parameters can help you identify your baseline and recognize early the signs your body presents. They will also enhance your participation in your medical plan of care.

While receiving home PN, the important key factors to monitor are weight, temperature, blood glucose, urine output, hydration status, stool/wound/ostomy output, and the appearance of your catheter or port site. Please turn to the “Nutrition and You” column on page 4 of this issue for a discussion on hydration; the other topics are discussed below. HEN consumers: we hope to present more information regarding self-monitoring specific to enteral feeding in a future issue of the Lifeline Letter.

**Body Weight**

Weigh yourself at the same time every day on the same scale, wearing the same amount of clothing (or lack thereof). Should you see a decrease, or even an increase, of more than two pounds in a day, or five pounds in a week, it is important to notify your physician.

**2010 Conference Exceeds Expectations**

What can you expect from an Oley annual conference? In a nutshell, learning opportunities—formal and informal—and a chance to meet and share stories with other home parenteral and enteral (HPEN) consumers and families. The presentations offered at the conference (and there are many!) are coordinated to bring HPEN consumers and their families information on topics as diverse as basic care to the latest research and coping to pain management, while the social activities bring attendees together in easy, comfortable, fun settings.

**One attendee's story:**

I started on home parenteral nutrition (HPN) about seven years ago, initially as a temporary measure to obtain bowel rest. Over the years it evolved into a more permanent form of nutrition. I discussed the pros and cons of HPN with my family and I remember feeling a little lonely, as if I were the only one in this situation.

After I’d been on HPN about two years, my aunt found out about the Oley Foundation and told me about the Web site. I started reading about all the programs Oley has to offer and the profiles of other people who live on HPN, including some who’d been on for thirty plus years! I shared this information with my wife, who was also excited, and we both decided we wanted to meet other Oley members at the annual conference. For one reason or another we were unable to attend until the 2010 conference in Minneapolis, MN.

**Attendees respond enthusiastically at 2010 Oley conference**

**2011 Oley Conference**

**Hope to see you there!**

Attendees respond enthusiastically at 2010 Oley conference.
Conference, from pg. 1

Saratoga Springs. This was indeed an amazing opportunity for us.

The conference was unique and multi-faceted, and it addressed the various needs of the consumers—whether the needs were emotional, physical, or medical based. Upon arriving at the conference, we found the Oley members to be friendly and inviting. They made us feel very welcome.

It was an amazing opportunity to meet and interact with other people in similar circumstances. It was the first time we were able to socialize and not feel confined or restricted by my condition. In addition to the wonderful consumers, the medical faculty was truly remarkable. From their care and compassion to their expertise, it was a great opportunity to learn about the latest medical advancements in the world of HPEN.

My wife and I both felt very comfortable discussing our concerns and asking our questions to medical staff and consumers alike, as they appeared to genuinely care about our well-being and were able to relate well to our situation. The interaction between faculty and consumers appeared to be based on a partnership; consumers contributed valuably and played an active role in their care.

Upon the conclusion of the conference we felt more empowered to cope with the situation we have been dealt. It taught us what is required to balance my HPN needs while leading a normal and fulfilling lifestyle. It was truly encouraging for us to meet people who live rich and rewarding lives while dealing with similar health issues. We were able to learn many valuable tips from consumers and faculty and staff alike, and have made several life-long friends. I hope that one day soon I am able to share some of this information with other new HPEN consumers. My wife and I now understand that we are truly not alone.

— Gerald L.

Travel Scholarships

A limited number of travel scholarships are available each year for those who would like to attend the conference for the first time. If you think you might be interested, we encourage you to submit a paragraph or two now, telling us about yourself—or your HPEN-dependent family member—and why you think you’d benefit from attending the conference. This will help us inspire potential funders to support our travel scholarship fund. We hope your heartfelt stories will compel our sponsors to support this program. (Your letter will be considered an application for a scholarship to the 2011 meeting in Minneapolis; we will accept applications through May 1, 2011.)

Conference on Demand

Couldn’t attend the conference? Main sessions and some breakout sessions are videotaped each year and are available on DVD. Please call the Oley office at (800) 776-6539 or visit www.oley.org/video_dvd.html to borrow DVDs from the Oley library.

Walk-a-Thon Walkers

The 2010 Oley Walk-a-Thon raised just under $4,000 for Oley programs. Many thanks to the following individuals who participated in the event: Jameson & Leah Atkinson; Felice Austin; Gerardo & Deon Balli; Mike, Robin, & Andrew Bodnar; Gail & Chuck Brenenstuhl; Faye Clements; Team Coram; Roz Dahl; Louise Delgado; Stacy, Amanda, & Sheldon Fleming; Mikey Freese; Todd Friedman; Mary Friel; Tammy Hodder; Rose Hoelle; Kishore Iyer; Michele & Devon Juda; Michelle Lambert; Jack Leibee; The Lopez Family; David Lukasiewicz; Yvonne MacMillan; Chris & Kathy Mannino; Michael & Eli Medwar; Lisa Metzger; David & Sharon Million; Kay Oldenburg; Dee & John Pappas; Thomas Perez; Sadie Pierce; The Sinkus Family; Bob Smithers; Rex Speerhas; Rob & Tammie Stillion; Cheryl Thompson; Jim & Sarah Wittmann; Donna, Peter, & Audrey Yadrick; and Aliza, Leigh, & Phil Zaleo.
Take Care of Your Skin

If the skin could talk, I think it would sing one of Elvis Presley’s favorite lines: “Don’t be cruel”!

The average adult has 3,000 square inches of skin. Its main function is to protect from harsh chemicals and bacterial and viral organisms, as well as the sun. The skin also prevents dehydration, regulates temperature, and allows sensory communication.

Layers of the Skin

The skin is divided into three distinct layers: epidermis, dermis, and hypodermis (subcutaneous layer). The epidermis is the outermost layer and is avascular, meaning there are no blood vessels in this layer as it is nourished by the dermis. This layer is renewed approximately every two months. Its thickness depends on where it is on the body.

The second layer, the dermis, is the thickest layer; it is very vascular. It contains many important structures, including: blood vessels, hair follicles, fat cells, nerve endings, sweat glands, sebaceous glands, and connective tissue.

The third layer, the hypodermis or subcutaneous layer, contains fat cells, lymph vessels, and larger blood vessels that protect the muscles and bones.

Protecting Your Skin

One of the biggest challenges is to keep the skin clean, dry, and free from harm, especially when the skin has been broken by a tube or a stoma. In the case of a tube, leakage and tube mobility are factors. In the case of a stoma, leakage, an improper fitting flange, harsh drainage, or unprotected peristomal skin are risks. However, there are steps you can follow to promote skin health.

The most important issue in maintaining skin health is to hydrate and nourish the skin. Adequate proteins, minerals, vitamins, and calories keep the skin supple and well fed. Keep your skin clean and dry but not dried out. Soaps that have a high acidity to them will remove the protective acid mantle. If your skin is dry, use a moisturizer; conversely, if your skin is wet, dry it.

Examine your skin each day. Check all around the tube site or the stoma site, especially underneath by using a mirror. Stabilize the tube by using a holder or a tube stabilizer. Clean the area with warm water and dry well.

For stoma care: clean the peristomal skin with warm water only. Dry the skin well. Some may use a barrier wipe before placing the wafer (flange).

We need to protect the skin at all costs; it is time well spent keeping away complications.

—Betty Brady, RN, CWOCN
Nutrition and You

Short Bowel Syndrome: Quenching Your Thirst

We often think and talk about the heat, especially with picnics, baseball games, and all of the fun associated with being outside in warmer weather. But consumers with short bowel syndrome (SBS) and other types of malabsorption are at greater risk of dehydration at all times of the year, so it is important to know how to stay hydrated. Fluid intake and output is always important!

Body Composition

Water is the single largest component of the body, contributing between 50 and 70 percent of total body weight. Water is obtained by eating and drinking. The body also makes water.

We lose water in our urine and stool and through our skin and respiratory tract. If you have SBS, you can lose a lot of water in your stool or ostomy output. In warm weather, people tend to lose more water through increased sweating.

In order to be well hydrated, fluid intake must equal output. So, should you drink water, sports drinks, or oral rehydration solutions?

Selecting a Beverage

Believe it or not, water isn't the best beverage for a person with SBS or other types of malabsorption. If your gastrointestinal tract has to try extra hard to absorb fluid—like in SBS—you should drink a beverage that is low in sugar and contains sodium, and sometimes one that contains potassium and bicarbonate. These drinks are called oral rehydration solutions (ORSs). You can buy these or make your own. Check the Oley Web site for some recipes and ideas.

Oral Rehydration Solutions

Why an ORS? The consumer with SBS must consider the osmolarity of the beverage he or she has chosen. Osmolarity refers to the concentration of a liquid, or the number of particles in it. The more particles there are, the higher the osmolarity.

Hyperosmolar solutions contain many particles of glucose and little to no sodium. They are very concentrated and cause fluid to be pulled into the intestinal tract to dilute the concentration of the drink; this causes watery diarrhea. Examples of hyperosmolar beverages include: fruit juices, regular soda pop, lemonade, and fruit smoothies.

Hypoosmolar solutions contain little to no particles of glucose and sodium. They are not very concentrated and do not pull fluid into the intestinal tract. But they are not always absorbed entirely. Examples include: water, ice, decaffeinated coffee and tea, sugar-free soda pop, sugar-free powdered drinks, and sugar-free flavored water.

Isoosmolar solutions contain sodium, potassium, and glucose in the same concentration as blood and extracellular fluid. These will not cause fluid to shift into the intestinal tract and will therefore help to minimize stool output. An example of an isoosmolar solution is the World Health Organization ORS.

Working with your dietitian or physician, you can choose an appropriate oral fluid tailored to your bowel function and anatomy in order to best manage your fluid balance. If you have SBS and your colon is connected, you will most likely do best with isoosmolar or hypoosmolar fluids. If you have SBS ending in an ostomy, you will most likely tolerate isoosmolar, high-sodium ORSs.

Preventing Dehydration

Drink an appropriate volume of fluid slowly throughout the day to meet both your baseline needs and to cover your losses. This means drinking no more than one cup over one hour—and take the hour to do it! Drinking oral fluids quickly will typically worsen dehydration by causing increased stool output and causing you to feel thirstier.

When in doubt, consult with your health professional as soon as you have identified the signs and symptoms of dehydration, which include thirst, dark-colored urine, decreased frequency of urination, lightheadedness (especially upon standing), fast heart rate (pulse), and sudden weight loss. Prevention is the best treatment. So stay well hydrated and enjoy the warm weather!

This column has been compiled and reviewed by Laura Matarese, PhD, RD, LD, FADA, CNSD; Carol Ireton-Jones, PhD, RD; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC.
We received the following e-mail in response to the article “Too Much to Carry” in the May/June 2010 LifelineLetter. Thanks, Jack, for taking the time to write. This is a great suggestion!

Dear Lifeline Editor,

My home care provider has shipped my HPN supplies for the past five years. Whether I’m on business or traveling for pleasure, they ship overnight. I have them ship to my hotel and then call the hotel and ask them to put the package in a refrigerator until I arrive. They use UPS overnight shipping and use this same service to deliver the HPN to my house every week.

I suggest you let your readers know to check with their supplier first when traveling [before trying to make other arrangements to have medical supplies shipped] as the cost to them may be $0.

— Jack
jleibee@hotmail.com

Fran Culp, who wrote “What Health Care Reform Means to HomePEN Consumers” in the May/June issue of LifelineLetter has offered to try to answer your questions about health care reform. Send them to us at metzgel@mail.amc.edu. We look forward to hearing from you!

Go Green, Go Electronic

• Help Oley save printing costs and trees.
• Receive notices, alerts, invitations, and newsletters quickly.
• Preserve your newsletters electronically.

Write harrinc@mail.amc.edu or call (800) 776-6539 to learn more, or to convert to electronic delivery of the LifelineLetter.

The Board of Trustees meeting in June marked the end of Michael Medwar’s second three-year term on the board. Michael, who has been an HPEN consumer on and off for many years, was presented with a certificate as the Board acknowledged his rotation off the board and thanked him for the great service he has provided Oley. At the same meeting, HPN consumer Mary Patnode was elected Vice President.

Exhibit your strength

The Oley annual conference, Rob and Tammi Stillion were donned King and Queen of the Equipment-Supply Exchange for their outstanding volunteer management of this vital program.

If you have Internet access, you can see the list of available items on the Oley Web site. This list is updated every Monday, so check frequently.

See something you want, or have something to donate? Contact Tammi or Rob at Oleyequipment@aol.com, or call toll-free, (866) 454-7351, 9 a.m. to 4 p.m. EST. They’ll treat you like royalty!

Equipment-Supply Exchange

See something you want, or have something to donate? Contact Tammi or Rob at Oleyequipment@aol.com, or call toll-free, (866) 454-7351, 9 a.m. to 4 p.m. EST. They’ll treat you like royalty!

Have Your Questions Answered

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 HPEN consumers in their teens and twenties.

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.
Medical Update

Self-Monitoring, from pg. 1

Weight is not only a measure of your nutritional status, but it can also be an indicator of your hydration state. Losses or gains as noted above could be a sign of dehydration or overhydration.

Temperature
As an HPN consumer, it is critical that you check your temperature to monitor for infection. Check your temperature before starting your HPN infusion for the day to determine your baseline. Check your temperature again one to two hours into your infusion period. If your temperature has increased by 1.5 degrees Fahrenheit or more, contact your attending physician immediately. It is important to check your temperature with a thermometer as you cannot accurately “estimate” your temperature, and whether you have a fever.

Do not wait to see if your temperature continues to rise or goes away as a fever alone can be a sign of a life-threatening blood infection. Any episodes of chills or flu-like symptoms during your HPN infusion must be taken seriously; they require immediate medical assessment at the nearest emergency department. A delay in obtaining medical care for a fever, chills, or flu-like symptoms could have serious consequences on your health and may require removal of your vascular access catheter or port.

Note: Mercury thermometers are hazardous (see sidebar below).

Blood Glucose (Blood Sugar)
Parenteral nutrition formulas can contain a high level of dextrose to provide calories. This dextrose is sometimes referred to as “sugar.” It is important to monitor your blood glucose for hyperglycemia (high blood sugar) and hypoglycemia (low blood sugar). A recommended time to check your blood glucose level is approximately one hour after beginning your HPN infusion and again one hour after the HPN infusion period has been completed.

Hyperglycemia (blood glucose over 200 for HPN consumers) symptoms may include one or more of the following: drowsiness; nausea; confusion; fruity, sweet-smelling breath; and increased thirst. If your blood glucose is 200 or greater, notify your healthcare provider.

Hypoglycemia (blood glucose under 70 for HPN consumers) symptoms may include one or more of the following: weakness; blurred vision; shakiness; irritability; sweating; and headache. Hypoglycemia can quickly become a serious complication and is most easily treated by taking a simple sugar in the form of glucose gel or dissolving tablets. These are available at any pharmacy; take as directed by your healthcare provider.

Important note: Read and review blood glucose monitor directions carefully. Use the glucose monitor and test strips as directed by the manufacturer. When using test strips, it is important to always close the test strip container tightly immediately after removing a test strip.

Beware Mercury Thermometers
Marcia Boatwright RN, CRNI

A mercury thermometer is made of glass with silver liquid (mercury) in the bulb at one end. While mercury has proven useful in measuring devices, it is a toxic substance that can harm both humans and our environment, and mercury thermometers are no longer considered safe by many municipalities. Mercury can affect the human brain, liver, kidneys, and spinal cord. In the environment, mercury can contaminate lakes, rivers, and wildlife for years to come. As of October 2, 2008, thirteen states have laws that limit the manufacture, sale, and/or distribution of mercury fever thermometers.

Besides not being safe, a mercury thermometer more that two years old is not considered accurate. It may not register a fever even if one is present.

Safe and Proper Disposal
The American Hospital Association and the United States Environmental Protection Agency made a commitment in 1998 to virtually eliminate mercury from hospital waste. To help protect yourself and your community, never throw a mercury thermometer in the garbage or trash burn barrel, or pour liquid mercury down the drain or toilet.

If a mercury thermometer breaks in your home, follow these steps:
• Have everyone else leave the area; don’t let anyone walk through the mercury on their way out.
• Remove pets from the area.
• Open all windows and doors to the outside; shut all doors to other parts of the house.
• Do not allow children to help you clean up the spill.

• Do not vacuum up the broken thermometer. The heat from the vacuum cleaner can evaporate the mercury and disperse it throughout your house.
• Do not use a broom as the bristles can collect the mercury beads and also spread them throughout your house.
• Wear latex or rubber gloves to clean up the spill. Use a flashlight to locate the beads of mercury. Use stiff paper to push all mercury beads together into a wide-mouth sealable container and seal the container. Pick up remaining small beads with sticky tape, such as duct tape. Carefully place all articles in a heavy plastic bag, placing your gloves in last. Label the bag as “mercury waste” and place the bag into a second bag; label this as “mercury waste” also. Take it to the nearest hazardous waste collection center immediately.
• If a mercury thermometer breaks on carpet in your home, contact your local (or nearest) fire marshal, who can identify safe corrective action.

Disposal
You can find collection programs in your area by logging on to earth911.com and typing in “thermometer” or “mercury,” along with your zip code. You’ll get a list of programs that accept mercury-containing thermometers.

Safe Alternatives
A variety of safe thermometers are available at your local pharmacy or food store. Digital thermometers are very inexpensive, easy to use, and easy to read. Some now have large digital number readouts to make them even easier to read.

Check your thermometer now, while it is fresh on your mind.
Keep test strips in the container provided. Never use blood glucose monitoring strips that are outdated.

**Urine Output**

The amount of urine passed each day is an indication of your body’s hydration status and kidney function. Dehydration stresses the kidneys, and adequate fluid balance is important to prevent kidney failure. You cannot truly or accurately estimate your urine output when you urinate; you need to measure it.

Record your urine output for a twenty-four–hour period while noting the color and concentration. Urine should be clear and yellow in color, and an adult should have at least 1000 ml. output within a twenty-four–hour period. Notify your attending physician of any urine that is concentrated or darker in color.

**Stool/Wound/Ostomy Output**

Any sudden change in stool, abdominal wound, or ostomy output—whether a decrease or increase in amount, or a change in consistency, color, drainage, or odor—should be recorded and reported to your healthcare provider. These various output changes can be of significance and may affect the amount of urine output on a day-to-day basis.

Make note to discuss with your physician any changes of color or shape, bleeding, protrusion, or retraction of an ostomy stoma bud. Early detection of these changes can decrease potential complications.

Important notes: Avoid having your vascular access catheter dangling or positioned over wounds, a G-tube, or an ostomy. Avoid caring for a vascular catheter site and a wound or ostomy site within a close period of time. These actions can help prevent cross-contamination of bacteria to your vascular catheter. To prevent infections, it is essential that you wash your hands after you’ve handled stool, wound, or ostomy output!

**Vascular Access Catheter or Port Site**

Complete vascular access catheter or port site care and dressing changes as instructed by your healthcare provider. During site care it is important to feel the catheter track or port pocket for any tenderness, swelling, or drainage, which may indicate an infection. Watch closely for skin irritation, rashes, skin blisters, redness, or oozing at area. Complete dressing changes after swimming, sauna, hot tub, tanning, showering, or heavy perspiration. Avoid adhesive build up on your catheter or port site, but avoid using acetone products near the catheter. These measures will help to prevent catheter or port infections.

Monitor the integrity of your vascular access catheter by watching for cracks, ripples, bulges, or worn clamps on the catheter or the catheter hub. You can help prevent catheter leaks, breakage, or ruptures by promptly reporting any of these catheter defects. Other important observations—such as your catheter looks longer or shorter than usual; the catheter cuff is seen at the exit site; you’re having difficulty accessing the port or flushing the catheter or port needle; any resistance flushing the catheter or port; any discomfort or pain during PN infusion; neck, arm, or shoulder swelling or discomfort—should be reported to your healthcare provider as soon as possible as these experiences require medical evaluation and care.

Last but not least, thorough hand washing is a critical component in the prevention of catheter and port infection.

As always, the articles in the LifelineLetter are not intended to substitute for medical advice or medical care. Please discuss your individual issues and questions with your healthcare provider. Here’s to your health! ☺
2010 Oley Foundation Awards

Tammi Stillion, The LifelineLetter Annual Award, In Honor of Nutrishare Inc., Oley Golden Medallion Partner

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. Tammi Stillion has demonstrated these qualities well, and we were pleased to present her with this year’s LifelineLetter Award at the annual conference.

Tammi has been on HPN since 2001, after surgery to remove a tumor left her with short bowel syndrome. Tammi and her husband, Rob, learned about the Oley Foundation not long after, and in 2009 they volunteered to manage the Oley Foundation’s Equipment-Supply Exchange. Their contribution has been invaluable. One person who talks to Tammi regularly through the exchange notes, “Through their own experiences, Tammi and Rob truly understand what it’s like to be on the other end of the phone. Tammi makes herself available, even if she may be otherwise busy or the dogs are begging for her attention. I find her story touching and her laugh infectious.” She continues, “For those who call, Tammi and Rob are more than volunteers, they are friends.”

“Tammi is an amazing person,” Rob writes. “She enjoys talking to other consumers [through the Equipment-Supply Exchange or Oley’s Toll-free line] and helping consumers with getting what they need. She will spend as much time as necessary on the phone with someone to get them every possible bit of information she can….While she is doing this she is on her HPN and still finds time for sewing and quilting.”

“I nominated Tammi for the LifelineLetter award,” Rob said recently, “after seeing her interact with other consumers on the telephone. When we took over the exchange, we didn’t know a lot about the program, or about tube feeding in general (Tammi is on HPN). But we have begun to learn that there is a lot to learn about tube feeding and there is a great need out there. It sometimes gets disheartening when we hear about people whose insurance won’t cover expenses or who have an extremely high deductible. But Tammi never gets down or upset. Instead, she does all she can to help the consumer. She has spent much time on the phone just talking about whatever the caller needs to talk about. I feel that is the true meaning of being a volunteer. Her dedication to the Equipment-Supply Exchange has spilled over to us being Regional Coordinators (RCs) and has allowed us to become even more involved with Oley.”

As RCs, Tammi and Rob are also active in a support group that meets in the Toledo, Ohio, area, and often volunteer to answer calls through Oley’s Toll-free Number program. This program allows homePEN consumers and/or caregivers to speak to another homePEN consumer/caregiver one on one, toll-free, anywhere, (almost) anytime (see page 5).

We are grateful for Tammi’s generosity and example. Congratulations!

Congratulations to the Nominees:
Susan Agrawal, Pam Belmonte, Mark Jackson, Michele Juda, Sendy Perez, Mary Smithers, Linda Stroshine, Jim Wittmann

Tim Weaver, Oley Foundation Child of the Year Award, in Honor of ThriveRx, Oley Golden Medallion Partner

At the annual conference in Saratoga Springs this June, Tim Weaver was presented with the Child of the Year Award for his positive attitude in dealing with illness and home nutrition therapy, and the wonderful ability he has to inspire others. “Tim Weaver is a young man of great triumph who does not allow his physical limitations to overcome him. Rather, Tim approaches life with poise and determination. I have witnessed the vigor and passion with which Tim fights,” says a nurse who has worked closely with Tim. “He never ceases to amaze me with his uncanny ability to inspire.”

Tim was diagnosed with Hirschsprung’s disease when he was three days old and has been on nutrition support ever since. “While he has never experienced life without nutrition support,” says his mother, Ann Weaver, “he rarely, if ever, mourns for what he does not have or what life could have been.”

Tim plays tuba and guitar, and performs with his high school’s wind ensemble, brass ensemble, and jazz lab bands. He also participates in monthly meetings of the local ostomy association and runs a monthly raffle to raise funds for the Youth Rally, a camp for kids with ostomies.

Tim has also worked with a counselor from Double H Ranch to organize a golf tournament; the Double H Ranch is a camp for children with chronic health issues. As a member of the Kids Advisory Board of Children’s Memorial Hospital, Tim attends monthly meetings and serves as an ambassador for the hospital at various functions.

Judy Smith, the nurse at Tim’s high school, notes, “Tim has a great sense of humor and is very easy going, witty, and pleasant. He has an uncanny ability to find the positive, humorous side of everything in the classroom.” A nurse from camp agrees, noting, “It astounds me the way Tim continually brightens campers’ days with his dry wit and consistent smile. His calm demeanor and ability to be comfortable in his own skin allow him to be a strong leader.”

We see all these qualities in Tim at our Oley gatherings, as well. Tim often attends the annual conference with his mother, who is active as an Oley Regional Coordinator in the Chicago area. Tim is willing to talk to others about his illness and therapy, and is a ready friend to other conference-goers. He has also participated in panels at the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), where he has shared the homePEN consumer’s perspective with clinicians. Congratulations Tim!

Congratulations to the Nominees:
Eleanor Brogan, Samantha Bye, Kassandra Delossantos, Aria Korda
James (Jim) Wittmann, Celebration of Life Award, In Honor of Conam Specialty Infusion Services, Oley Golden Medallion Partner

Jim Wittmann has been on home parenteral nutrition (HPN) for much of his adult life, though his trials with Crohn’s disease began in adolescence. “Jim was forced, because of serious Crohn’s disease, to deal with the challenges presented by an ileostomy and successive serious intestinal surgeries during his elementary, high school, and college years,” says Jim’s brother-in-law. Jim “chose not to withdraw into isolation,” he continues, “but rather chose to maintain, as best he could, a normal life. Jim has tackled camping, mountain climbing, hiking down and up the Grand Canyon, water skiing, snow skiing, and even sky diving.”

Jim is known for his extensive volunteer work and generosity. He has delivered meals for Meals on Wheels for twenty years and has served on their board of trustees. He is also very active in his church. On a less formal basis, Jim serves in his community by befriending all he meets. He drives his many friends to doctor’s appointments, community events, or the airport; when needed, he brings them food. Jim goes out of his way to visit people in hospitals, mental health facilities, and nursing homes. He gives generously of his time and himself to help others. He also gives generously of his resources. This year, Jim supported the Friends of Robin Lang Memorial Travel Fund, established to help a homePEN consumer attend Oley’s annual conference for the first time.

“Everyone has limitations and obstacles in their life,” says Jim. “Those obstacles or challenges can and should be used for opportunities to become stronger. We all have a duty to encourage each other in overcoming life’s hurdles.” After Jim received the Celebration of Life Award, his sister, Barbara Blanchard, commented, “Our whole family concurs: ‘He deserves it!’ We have seen his life and been amazed at his service and thoughtfulness for others. By God’s sustaining and enabling grace, Jim is diligent, prayerful, wise, steady, and joyful, despite many trials.”

“My dad knows that his illness is something he has been given so his compassion and empathy for others would be greater,” added Jim’s daughter Sarah.

Gary Hoebelheinrich, who has known the Wittmann family for years, expresses Jim’s attitude well: “Whenever he was unable to fulfill his primary adult aspirations, such as completing a college degree or full-time employment [due to health issues], he merely changed course and established new goals in life. As a result, he has successfully parented two daughters, traveled and participated in recreational sports with extended family, logged thousands of hours in service to his church and community agencies, and finally, nurtured his creativity and generous spirit with a photography pastime that he can share with others.”

We were pleased to present Jim with the Celebration of Life Award at the annual conference. Congratulations, Jim!

Congratulations to the Nominees:
Jameson Atkinson, Debbi Fox, Tina G. Jackson, Aria Korda, Jonathan Lockwood, Lauren Marie Moore, Eleanor Orkis, Mary Smithers, Tammi Stillion, Linda Stroshine, Tim Weaver, Steve Welch (aka “NM Husky”)

June Bodden, Lenore Heaphey Award for Grassroots Education, Sponsored by Kimberly-Clark, Oley Blue Ribbon Partner

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 Award for Grassroots Education to June Bodden. June has been an Oley Foundation Regional Coordinator (RC) since December 1993, and has touched many lives through this long stretch of time as an Oley volunteer. As an RC, June is very active in an Oley support group in Tampa, Florida. In 2008, this group celebrated their twentieth anniversary. Since 1988, June says, people “have come and gone to our meetings, and the encouragement and friendship have grown” (LifelineLetter, March/April 2008).

A member of this group notes, “June has always kept us up-to-date on goings on at Oley and in the world of HPEN. She organizes and conducts our quarterly meetings in Tampa and keeps us informed about the group’s members, and particularly when someone is experiencing a more serious problem than he or she already has. Her regular e-mail postings when someone is sick or hospitalized, or having a particular difficulty not only keep us informed, but show how much she cares about everyone, and how dedicated she is to her work.”

In 2009, the annual Oley conference was held in St. Pete’s Beach, Florida. June’s help in organizing the event was invaluable. June was instrumental in locating the site for the conference, pulling the group together to support the event, identifying speakers, getting home care companies involved, soliciting items for the silent auction, and more.

Thank you for your dedication, June., and for your contribution to the HPEN community. And congratulations!

Congratulations to the Nominees:
Tara Smith, Tammi & Robert Stillion
Awards, from pg. 9

Gerry Hennies, RN III, Nan Couts Award for the Ultimate Volunteer, Coordinated by Judy Peterson

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.

At the annual conference, we were pleased to present the Nan Couts Award for the Ultimate Volunteer to Gerry Hennies, RN III. Gerry has been a pediatric nurse for over thirty years, and says she “always wanted to be a nurse,” since she was a young child. Gerry has worked at Cincinnati Children's Hospital Medical Center in Cincinnati, Ohio, for the majority of her career, and has been involved with homePEN consumers since 1990.

“When I first began practicing in the hospital there was no home care,” Gerry says. “Tunneled central lines had not been around long and children who required parenteral nutrition lived in the hospital. Hospitals were not family friendly, siblings didn’t visit, there were no places for families to sleep or even shower. Several years later, when I met my first HPEN family, I realized these families were responsible for many things I wasn’t sure I could do, as a nurse. Shortly after this our pediatric hospital started its own home care company and I was afforded a unique opportunity to case manage HPEN families. This gave me such an advantage, I felt, to help every family I encountered be successful with HPEN. Seeing families as families, and not as patients, changed the entire thought process of how our team should practice.”

“It was in those first terrifying days [after a surgery left my child unexpectedly dependent on HPEN] that we met Gerry Hennies, who would become an invaluable resource in our family’s life,” says one of the parents with whom Gerry works. “She was pretty blunt in explaining what we had to learn before we could even think about taking our daughter home, but she was also our biggest supporter and cheerleader.” When it was time for their child to be discharged, the parents were excited but apprehensive. “That was a very lonely feeling,” says the mother, “but it was easier knowing Gerry was a phone call away and more than willing to answer our questions, address our concerns, and help us figure out the best way to provide care.”

Gerry currently works in the Intestinal Rehabilitation Center at Cincinnati Children’s, providing case management/nutrition support for these families. It is not unusual to see her at her desk long after the day has ended, returning phone calls to the families she serves. The Intestinal Rehabilitation Center, which also has an intestinal transplant program, sees families from all over the United States.

Congratulations Gerry!

Congratulations to the Nominees:
Faye Clements, RN, BS; Marcia Grandko, RD, LD; Cheryl Thompson, PhD, RD, CNSD

Chelsea Johnson, Kyle R. Noble Scholarship Coordinated by Richard & Donna Noble

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 Saratoga Springs, New York, is Chelsea Johnson.

Chelsea graduated from high school in Charlotte, North Carolina, this spring and is excited about entering university in the fall. “I am excited about living on campus and experiencing dorm life,” she says, “and have declared psychology as my major. I am not sure how I will cope with the snow, as the weather at school will be quite different than Charlotte’s mild winters, but I am really looking forward to all the upcoming changes in my life.”

Chelsea has been on HPN since she was six years old; she also has a G-tube and a J-tube to help alleviate symptoms associated with motility issues. “During my first ten years on HPN,” she says, “I was hospitalized with several line infections, had 90 percent of my colon removed, and endured a variety of invasive tests. But throughout, I have always attended public school, have a close network of friends, and have maintained a high GPA in my coursework.”

In addition to her schoolwork and friends, Chelsea keeps busy by volunteering in her community. Chelsea is a member of the Family, Career and Community Leaders of America and has helped collect winter clothes for children in need. She also visits senior citizens at a local nursing home and helps with recreational activities there.

“The most positive lesson I have learned in dealing with chronic illness is that I can not only adapt to almost any setback, but I can excel!” says Chelsea. “My illness has made me view each day as a gift, to focus on the things I can control, and to turn challenges into opportunities.” Her goal is to become a therapist “to help others and to share my life lessons.”

“Chelsea has enriched the lives of those around her in many ways,” writes one of Chelsea’s high school teachers. She “finds a way to spread her optimism and cheer everywhere she goes. I have never met someone with the uncanny ability to make those around her laugh and smile so frequently.”

Congratulations Chelsea!

Past Recipients:
Mariah Abercrombie, Kailee Brown, Alicia Hoelle
Nutrishare Research Prize Winners, Sponsored by Nutrishare Inc., Oley Golden Medallion Partner

The Clinical and Psychometric Validation of a Questionnaire to Assess the Quality of Life of Adult Patients Treated with Long-Term Parenteral Nutrition
Janet P. Baxter, PhD, Ninewells Hospital and Medical School, Dundee, UK

The purpose of this study was to test a newly developed questionnaire designed specifically to measure quality of life for the home parenteral nutrition patient (HPN-QoL©). A provisional questionnaire was prepared following recognized guidelines and was subjected to field-testing. After it was administered to one hundred adult HPN consumers, the results were analyzed and the questionnaire was adapted. The resulting tool, the HPN-QoL questionnaire, has been rigorously prepared and demonstrates psychometric and clinical validity to assess the QoL of long-term HPN patients. [Editor’s note: The Oley Foundation is presently looking for adult HPN consumers to participate in a QoL study using, in part, this questionnaire. Please visit www.oley.org or contact the Oley office at (800) 776-6539 for more information.]

Parenteral Fish Oil–Based Lipid Emulsion Improved Lipid and Fatty Acid Profiles in Parenteral Nutrition–Dependent Patients
Hau D. Le, MD, Children’s Hospital Boston, MA

The objective of this study was to describe the changes in fatty acid and lipid profiles of patients with parenteral nutrition (PN)–associated cholestasis who were treated with a fish oil–based lipid emulsion (FOLE, or Omegaven®). Lipid and fatty acid profiles of seventy-nine pediatric patients who developed PN-cholestasis while on standard soybean oil–based lipid emulsion (SOLE) were examined before and after switching to FOLE. All patients received PN with the FOLE at 1 g/kg/day for at least one month. The FOLE was used under a compassionate use protocol. The study concluded that switching from SOLE to FOLE in PN-dependent children was associated with significant improvement in PN-cholestasis and lipid profiles.

Self-Care and Blood Drawing Practices May Be Predictors for Central Venous Access Device (CVAD) Longevity in a Home Parenteral Nutrition (HPN) Population
Marianne Opilla, RN, CNSN, Nutrishare, Midlothian, VA

The aim of this survey was to determine if self-care and blood drawing practices affect CVAD longevity. A multiple-choice survey was mailed to all HPN consumers from one home infusion provider; questions included years of HPN, number and duration of CVADs, caregiver information, and blood drawing practices. Returned surveys were divided into two groups based on CVAD duration and the groups were compared. The results of this survey confirm that patients receiving HPN can maintain the same CVAD for many years. Self-care limits CVAD exposure to multiple handlers, and the results indicate this may contribute to CVAD longevity. The results also indicate frequent blood draws from a CVAD may increase incidence of CVAD dysfunction leading to removal. Also, venipuncture rather than catheter blood draws and less frequent lab monitoring were associated with longer CVAD life in this cohort of HPN patients. These factors may be predictors for CVAD longevity.

For more details on these studies, please visit the Oley Foundation Web site (www.oley.org/Nutrishare_Research.html).

Helping TPN consumers live independently

I’m stubborn and my husband says I’m a pain in the butt.
We’ve been married 29 years and are more in love than the day we married. I love my friends, enjoy gardening, traveling and partying. Right now I am into redecoring everything.

Message to others on TPN
You have to breathe, you have to sleep, you have to do TPN. It’s just another thing you do. Get over it, get it done and move on to the fun stuff. Every moment is a gift.

About Nutrishare
Nutrishare brings my stress level way down. They take care of my needs as if they were their needs. And if a problem or crises comes up Nutrishare is all over it like sugar on a doughnut.

Nutrishare®, Inc.
1 800 HOME TPN
www.nutrishare.com

I AM NUTRISHARE

SUSAN O’BERSKI

Proud Platinum Partner of The Oley Foundation

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(800) 776-OLEY • LifelineLetter — 11
Thank You for Making the 2010 Conference Possible

We are grateful to the following companies and individuals for supporting this year’s conference.

2010 Oley Awards:
Coram Specialty Infusion Services; Kimberly-Clark; Nutrishare Inc.; ThriveRx

Childcare and Youth Activities:
Doris Johnson
Volunteers: Emily Andolina; John Bishop; Ashley Blanchard; Nancy Ellett Crosby; Stefanie Harrison-Bishop; Jayne Justice; Harrison Kendersky; Kate Letzelter; Michael Medwar; Sarah Metzger; Kelsey Noble; Marjorie Quinn; Guilliana Valenti; Peter Yadrich

Conference Badges:
Coram Specialty Infusion Services

Conference Bags:
Nutrishare, Inc.

Conference T-shirts:
Coram Specialty Infusion Services

Enteral Workshop:
Daniel F. and Ada L. Rice Foundation

Exhibitors:
Abbott Nutrition, Abbott Laboratories; Amazing Kids; American Society for Parenteral & Enteral Nutrition (A.S.P.E.N.); Applied Medical Technology (AMT); Association of Gastrointestinal Motility Disorders, Inc. (AGMD); Association for Vascular Access (AVA); Baxter Healthcare; BioScrip, Inc.; Brooks Health Care, Inc.; CarePoint Partners; Cera Products, Inc; Coram Specialty Infusion Services; Critical Care Systems (CCS); Dietitians in Nutrition Support (DNS); Double H Hole in the Wall Camp; Emmaus Medical, Inc.; G-Pact; Gus Gear; Home Solutions Infusion Therapy; InfuScience; Jackson PEG Tube Stands; Kimberly-Clark; MOOG, Inc.; Nestlé HealthCare Nutrition; NPS Pharmaceuticals; Nutrishare, Inc.; Parent to Parent of New York State; The Pediatric Adolescent Gastroesophageal Reflux Association (PAGER); PromptCare Home Infusion; ThriveRx; United Ostomy Associations of America (UOAA); Walgreens

Faculty:
Linda King Aukett; Michelle Biscossi, MS, ACNP; Jarol Boan, MD; Marcia Boatwright, RN, CRNI; Abby Brogan; Patricia A. Brown, RN, MSN, CNSN, OCN; Faye Clements, RN, BS; Rick Davis; Mark H. DeLegge, MD; Megan Gravenstein; Gil Hardy, PhD; Lyn Howard, MB, FRCP, FACP; Carol Ireton-Jones, PhD, RD, LD, CNSD; Kishore R. Iyer, MBBS, FRCS, FACS; Jennifer C. Jaff, Esq; Michele Juda; Jayne Justice, RN; Darlene G. Kelly, MD, PhD, FACP; Mark G. Klang, MS, RPh, BCNSP, PhD; Hau D. Le, MD; Kristyn Maixner, RN; Laura Matarese, PhD, RD, LDN, FADA, CNSD; Tamir Milor, MD; Frank Murawski; Joseph Nadeau, RPh; Reid Nishikawa, PharmD, BCNSP, FCSP; Donna Noble; Marianne Opilla, RN, CNSC; Deborah Pflister, MS, RD, CNSD; Steven W. Plogsted, PharmD; Sharon Rose, RN; Lauren K. Schwartz, MD; Rex Speerhas, RPh, CDE, BCNSP; Kerry A. Stone, MS, RD, CNSC; Mary T. Tessier, RN; Cheryl W. Thompson, PhD, RD, CNSD; Troy Wallach, RN; Marion Winkler, PhD, RD, LDN, CNSC

General Conference Support:
Patricia Brown, RN, MSN, OCN, CNSN; Ann DeBarbieri; Marilyn Dolan; Portia & Wallace Hutton

Golf Tournament Sponsors:
Photos: Sanford Schimel
Oral Rehydration Solution: Cera Products
15th Hole: Coram Specialty Infusion Services
Hole-in-One Contest: Crescent Healthcare, Inc.
Quenchmobile: ThriveRx
Volunteers: Janis Bariteau; John Bishop; Ron Metzger; Joe Pipereta; Phil Stone; Fred Stuto
Thanks to everyone who played and otherwise supported the game through contests and the 50/50 raffle!

In-Room Refrigerators:
ThriveRx

Jammin’ Jammies:
Abbott Nutrition-PediaSure
Entertainment: Ray Altrock
Volunteers: Harrison Kendersky; Sarah Metzger; Marjorie Quinn

Medical Support:
Coram Specialty Infusion Services

Nutrishare Research Prizes:
Nutrishare, Inc.

Picnic:
Entertainment: Al & Kathy Bain
General: Ben & Jerry’s Ice Cream; Golub Foundation; Bobbie Grober; Sam’s Club; Stewart’s Shops; Walmart

Registration:
Janis Bariteau; Dale Delano (Dots for Diagnosis); Jeff Hoelle; Audrey Yadrich; Britany Young; Janet Young

Room Key Sponsor:
Coram Specialty Infusion Services

Silent Auction:
A big “Thank You!” to volunteers who helped orchestrate the event, and to those who donated and/or purchased items!!
Volunteers: Janis Bariteau; Lars Dahl; Ann Jann & friends; Mary & Charlie Kunz; Joan & Frank Scheib; Fred Stuto

Speaker Support:
The following companies and institutions provided funding and/or faculty for this year’s program.
Advocacy for Patients with Chronic Illness, Inc.; Albany Medical
Camps, Scholarships Databases

NeedyMeds has announced that searchable databases will be available on their Web site (www.needymeds.org) in early August to help families find camps or scholarships tailored toward those with a particular disease or medical condition.

Camps

The camps listing will be sorted by: (1) disease/medical condition; (2) camp name; (3) camp sponsor; and (4) camp location. Each of these searches will produce further information about contact information, application process, eligibility guidelines, Web site, and more. Some of the camps listed may also invite siblings to attend, and many are free or offer financial aid. Most will accept children from anywhere in the country (exceptions will be noted in the summary for the camp).

Scholarships

The scholarships listing will be sorted by: (1) disease/medical condition; (2) scholarship name/organization; and (3) residency of applicant. These searches will lead you to more details about the program, such as contact information, application process, essays that need to be composed and other paperwork, eligibility requirements, scholarship/organization Web site, and more. There will also be some scholarships listed for students who have a parent or a family member with a specific disease.

Add to the List

If you know of a camp or scholarship that is not listed in the database, NeedyMeds would like to know about it. Please contact Robin at robin@needymeds.org. Provide as much information as possible, including the organization’s Web site.

NeedyMeds provides a bounty of other information on its Web site. We recommend you take the time to see if any of their programs might be useful to you, or you can benefit from their NeedyMeds prescription card.

Donor Profile: Pat Brown, RN, MSN, OCN, CNSN

Pat Brown, RN, MSN, OCN, CNSN, former Oley Trustee, has been an active Oley member since the early days. She continues to give generously of her time and treasure.

She writes, “I donate to Oley in memory and in honor of consumers and friends, and my patients here at Memorial Sloan-Kettering Cancer Center who have benefited from the support and educational material provided in the field of parenteral and enteral nutrition.

“I try to pass on to them my philosophy to incorporate HPN/enteral feeds into their lives—to still do all that they can, such as working, traveling, meeting their daily goals, and have the energy to accomplish what is important to them and their family.”

Thanks to Pat for all of her support!
Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

**Coram Specialty Infusion Services**

Coram has been a proud supporter of the Oley Foundation for over twenty-five years and has worked to empower home nutrition consumers through individualized customer service, clinical expertise, education, and support for over thirty years. Coram's local nutrition support teams understand that every consumer is at a different stage of their treatment and their life, and take into account travel plans, work schedules, and nutrition needs in order to develop a therapeutic plan to enhance their quality of life.

Above and beyond locally available home nutrition support teams for each patient, Coram offers a broad array of in-home and online patient support, a patient advocacy hotline, consumer informational teleconferences, travel programs, and a quarterly support magazine. An in-depth resource for anyone in the parenteral or enteral nutrition community can be found at www.WeNourish.com, which features a consumer blog, extensive resource links, and a host of downloadable educational materials, as well as therapy-specific audio tutorials and educational videos.

**Nutrishare, Inc.**

Nutrishare celebrates its twentieth birthday in 2011! The company's decision to focus exclusively on homePN consumers is the key to its longevity. Nutrishare has carefully built an experienced, Board-certified team of nutrition specialists, who helped pioneer a series of therapeutic solutions to the problems facing the homePNer.

**ThriveRx**

The mission of ThriveRx is to optimize the nutritional well-being of the homePEN consumer through advocacy, clinical care, and education. The company writes, “Advocacy is at the forefront of our agenda, as reflected in our customized products and services, advisory boards, and Consumer Advocate program. Our goal is to empower consumers and their families to live life!”

ThriveRx has put its mission into action as a Golden Medallion Partner. The company contributes financial support to Oley through its Full Circle program: $1 for every day of parenteral nutrition and $1 for every course of enteral nutrition that its patients require nationwide, or a minimum donation of $50,000. ThriveRx is committed to giving back to improve life for those on homePEN.

**Nestlé HealthCare Nutrition**

Nestlé HealthCare Nutrition, part of the world’s largest food company, supports nutrition, health and wellness, and provides a comprehensive line of oral and tube feeding nutrition formulas to the healthcare community for both adults and pediatrics. Through science-based nutrition products and services, Nestlé HealthCare Nutrition helps enhance the quality of people’s lives by supporting health and providing care for specific consumers with special nutrition needs at every stage of life.

Nestlé HealthCare Nutrition, the maker of Peptamen Junior® Complete Elemental Nutrition for Children and Boost® Kid Essentials Nutritionally Complete Drink, is committed to nourishing a healthier generation. Nestlé Nutrition’s vision is to help children grow and develop by delivering innovative, effective, scientifically proven nutrition products.
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 the list of honorees in each issue of the newsletter. A complete list of contributions will be published annually in the January/February issue of the LifelineLetter and in the Oley Annual Report.

Between June 1, 2010, and August 6, 2010, gifts were received:

**In Honor of**
- Alan Robinson, in recognition of his good fight; and Jeffrey Schesnol

**In Memory of**
- Linda Gold; Lee Koonin; Robin Lang; Richard Schaller; Sallie Simpson; Anthony J. Tranchina; and Jonathan White

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

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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.

**Felicie Austin**  
**Jane Balint, MD**  
**John Balint, MD**  
**Joan Bishop**  
**Ginger Bolinger**  
**Pat Brown, RN, CNSN**  
**Katherine Cotter**  
**Jim Cowan**  
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**Tom Diamantidis, PharmD**  
**Selma Ehrenpreis**  
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**Jerry Fickle**  
**Don Freeman**  
**Linda Gold**  
**Linda Gravenstein**  
**The Grober Family**  
**Valerie Gyurko, RN**  
**Alfred Haas**  
**Shirley Heller**  
**Alicia Hoelle**  
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**Lyn Howard, MD**  
**William Hoyt**  
**Portia & Wallace Hutton**  
**Kathleen Iyer, MD**  
**Darlene Kelly, MD**  
**Family of Shirley Klein**  
**Jim Lacy, RN, BSN, CRNI**  
**Robin Lang**  
**Hubert Maiden**  
**Laura Matarese, PhD, RD, CNSD**  
**Kathleen McInnes**  
**Michael Medwar**  
**Meredith Nelson**  
**Nancy Nicholson**  
**Rodney & Paula Okamoto, RPh**  
**Kay Oldenburg**  
**Judy Peterson, MS, RN**  
**Clemens Pietzner**  
**Beverly Promisel**  
**Abraham Rich**  
**Gail Egan Sansivero, MS, ANP**  
**Roslyn & Eric Scheib Dahl**  
**Susan & Jeffrey Scheinol**  
**Doug Seiden, MD, FACC, CNSD**  
**Judi Smith**  
**Steve Swensen**  
**Cheryl Thompson, PhD, RD, CNSD**  
**Gregory A. Thompson MD, MSc**  
**Cathy Tokarz**  
**Eleanor & Walter Wilson**  
**James Wittmann**  
**Patty & Darrell Woods**  
**Rosaline Ann & William Wu**

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**PLATINUM LEVEL PARTNERS**  
($70,000+ )  
- Nutrishare, Inc.

**GOLDEN MEDALLION PARTNERS**  
($50,000–$69,999)  
- Coram Specialty Infusion Services  
- ThriveRx

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

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

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

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

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

**CONTRIBUTORS**  
($1,000–$2,499)

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(800) 776-OLEY • LifelineLetter — 15
Join Oley in Los Angeles!

Oley Southwest Regional Conference
October 30, 2010, 10 a.m. – 4:30 p.m.
(Registration begins at 9:30 a.m.)
Ronald Reagan UCLA Medical Center
B Level Rotunda, 757 Westwood Plaza, Los Angeles, CA

- Don't miss this opportunity to learn from the experts—in both lectures and small breakout sessions—and meet other HPEN consumers and families!
- FREE for HPEN consumers/caregivers/family members; $50 for all others
- Details and registration information are posted at www.oley.org, or call Felice (702) 435-6007 or Cathy (800) 776-6539.

Nominate Now for the Lyn Howard Advocacy Award

Now is the time to nominate a consumer, caregiver, or a family member for the Lyn Howard Nutrition Support Consumer Advocacy Award. This award, named in honor of A.S.P.E.N. member and Oley Foundation co-founder, Lyn Howard, MB, FRCP, acknowledges one patient/family member/caregiver who has advocated for other patients, families, or caregivers of consumers who require parenteral (PN) or enteral nutrition (EN).

Advocacy efforts include such activities as lobbying for legislation to improve care or reimbursement, developing educational tools, fund-raising for PN or EN research, starting or sustaining support groups, being a consumer advocate, or teaching others about PN or EN.

Nominations are due by October 15, 2010. For more information and a nomination form visit the A.S.P.E.N. Web site at www.nutritioncare.org.

The award was established in 2008. Bettemarie Bond was the first recipient, and Lee Koonin received it posthumously in 2009.

“Oley’s” Presence Felt at Conference
Kay Oldenburg (right), widow of co-Founder Clarence “Oley” Oldenburg, is pictured here with Michael Medwar at the 2010 Conference. When asked how she thought Clarence would feel about the meeting, Kay smiled wide and replied, “He’d be proud.”