

What's Inside:

Tube Talk

Page 3

Equipment/Supply Exchange

Page 3

Micronutrients Update

Page 3

Parent Resources

Page 3

On the Move

Page 4

Kyle Noble Scholarship Fund

Page 4

Meet Your New RC

Page 5

Grieving Parents

Page 6

Biography of an HPNer

Page 7

Recall Notices

Page 7

Looking Back, Moving Forward

Page 8

☆ **2008 Oley Award Nomination Form** ☆

Pages 9–10

In Memory of Tracy Phelan

Page 11

Contributor News

Pages 12–15

Toll-free Networking

Page 16

LifelineLetter

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

My 25-Year History with TPN

Davria Cohen

Twenty-five years ago, Davria (Davi) Cohen went on parenteral nutrition (PN) as a consequence of injuries she sustained in an automobile accident. We asked Davi to share her experiences from her early years on PN and more recently, as an Oley Regional Coordinator. It seemed appropriate as Oley, too, celebrates its twenty-fifth anniversary in 2008!

Historical notes: Davi refers to her therapy as total parenteral nutrition (TPN). In the early years, many of us also knew the therapy as hyperalimentation or hyperal. While these terms are probably familiar to most readers, now the preferred term is parenteral nutrition (PN). It is no longer thought that the therapy can always provide all necessary nutrients ("total nutrition") to the consumer, and the idea of hyperalimentation, or administering more than optimal amounts of nutrients, is no longer seen as beneficial.

Davi also talks about receiving the LifelineLetter in the early 1980s. The newsletter was started by Lee and Marshall Koonin, founders of the Lifeline Foundation. Soon after Oley was founded, the Lifeline Foundation was merged into Oley and Oley took on the responsibility of publishing the newsletter. (See "How It All Began," LifelineLetter, March/April 2003, available at www.oley.org or by calling 800-776-OLEY.)



Beverly Mello and Davi Cohen at the 2007 Oley Annual Conference in Hyannis, Massachusetts.

June 18, 1982, was the day my life became divided into before and after: before the accident and after the accident. We had been in Annapolis that evening, and as we headed home from our seven-year-old daughter's ballet rehearsal, a man ran a red light and plowed his car into ours.

25 Years on TPN, cont. pg. 2

Connect at Conference!

Join us **June 26–30** for an outstanding opportunity to learn more about the therapy that sustains you. Network with top clinicians from across the country and meet others who have similar challenges.

The conference will be held at the **Marriott San Diego Mission Valley**—where we can offer a great room rate! The hotel has extended Oley conference-



goers (excepting exhibitors) a discounted rate of \$126/night (\$142 with taxes), and Oley is further reducing this rate with a \$27 subsidy, bringing the total to **\$99/night** (\$115 with taxes). To take advantage of the discounted Oley rate, you must indicate the Oley conference code: **olyolya**. The \$126 rate will appear in the Marriott reservation system (and will be the rate

Conference, cont. pg. 4

Tysabri Approved

In mid-January, the FDA issued regulatory approval for the use of the multiple sclerosis drug Tysabri (natalizumab) for the treatment of moderate to severe Crohn's disease on a limited basis. The drug was approved for use in patients with evidence of inflammation who have had an inadequate response to, or are unable to tolerate, conventional Crohn's disease therapies.

"The addition of Tysabri to the treatment options for sufferers of Crohn's disease is important, but one that carries serious risks," said Daniel Shames, director of the Division of Gastroenterology Products for the Center for Drug Evaluation and Research.

Because of the risks, Crohn's disease patients using the drug must be enrolled in a special restricted distribution program called the Crohn's Disease–Tysabri Outreach Unified Commitment to Health (CD TOUCH) Prescribing Program. Under this program, patients are evaluated after three months of treatment to determine if they have improved on Tysabri. If not, patients should discontinue treatment.

Patients who are taking steroids for Crohn's disease Tysabri, cont. pg. 3

25 Years on TPN, from pg. 1

A policeman at the accident scene saw my bleeding forehead, assumed I had sustained a head injury (I had merely bumped it on the dashboard), and sent for a medevac helicopter to take me to what is now the R Adams Cowley Shock Trauma Center in Baltimore—a decision that saved my life. My seatbelt had severed my mesenteric artery and perforated my intestines. Shock Trauma, the model for

our modern trauma centers, was pioneered by the late Dr. Cowley. Dr. Cowley revolutionized emergency medicine with his concept of “the Golden Hour”: if you could get severely injured people to treatment by trauma specialists within an hour, their chances of survival vastly improved.

After two operations, I was left with very little small bowel and only two-thirds of my colon. It was a dark time for me and my family, but my husband, Steve, tried to brighten things up. He would, for example, hang signs in my hospital cubicle, such as “Excuse my restin’, I lost my intestine!”

In the months to come, there would be many things to adjust to, including chronic, persistent diarrhea. I received TPN continuously during most of my nearly seven weeks at Shock Trauma. After several weeks I was coaxed to drink two unpleasant-tasting elemental beverages, alternating one with the other every two hours. A discharge planning nurse told me about a congresswoman who infused TPN at home; she said this might eventually be an option for me. However, at discharge my nutrition consisted solely of the elemental drinks.

Home, Sweet Home

Going home was wonderful, but I was so weak that reading a story to my two year old—one of the normal, everyday things of my life that I had so missed while I was hospitalized—exhausted me. And I was tormented by the wonderful smells of food when my mother cooked. I remember once trying to escape the aroma by going outside, but that was worse: my neighbors were barbecuing! Also, it became increasingly difficult to get the elemental drinks down. I found them so unpalatable—no matter what we mixed them with—that merely lifting the glass to my mouth made me gag.

I began nightly feedings through an NG tube. Generally, a nurse came out each evening to insert the tube. On Labor Day, however, when no one was available, I had to insert the tube myself!

Still I was losing weight, and these enteral feedings did not always stay down. I was again hospitalized, and this time, to my surprise,

I was allowed to eat real food. I celebrated my thirty-third birthday in the hospital on September 12 with my family and a cake my mother baked according to my special diet. There was much reason to celebrate that day: my two-year-old son, who had been in a body cast for weeks following the accident, had taken his first steps that morning. I went home a few days later.

Time for Change

It was nice to be eating again, but the diarrhea was relentless; no medication worked to slow it down. Further, I just did not have enough remaining bowel to absorb sufficient nutrients and fluids from the food that I ate. By March, my weight had dropped from about 110 pounds to a dangerous 77. Yet the gastroenterologist I saw did nothing. It became clear that a change in doctors was necessary.

With the new doctor came a new plan: TPN. Since I already knew

about the congresswoman who infused TPN at home, I readily accepted it as being a good therapy for me.

In 1983, there was no local home care company. A nurse based in Philadelphia delivered TPN and supplies to my Maryland home weekly. My pump, heavy and pole-mounted, was rudimentary; it could not be programmed to ramp up or down. Each night at 5 a.m., after most of my TPN had run in, I had to reset the pump to infuse at a slower rate for two more hours. I was rarely very alert at that time of day, so I am amazed that I never did any serious harm to myself!

Another down side was that, once hooked up, I felt trapped. There was no way I could go downstairs, and it was difficult to get to my son when he awoke crying in the night. I had to unplug the pump and push the pole down the hall over thick shag carpeting. Usually, by the time I got there he had fallen back asleep.

After I was on TPN for several years, we moved into a one-story house, and shortly after the move, I got my first portable, fully programmable pump.

An Intro to Oley

On her second visit, the nurse from Philadelphia brought an issue of the *LifelineLetter*, then

25 Years on TPN, cont. pg. 6

LifelineLetter

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The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

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.

Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.



Securing a Tube, Preventing Leakage

One of my biggest initial concerns—and challenges—as a new tube user was how to safely secure my dangling tube between feedings. The second was how to prevent fluid loss from a leaking port. My first two tubes did not leak from the port, so I didn't see that challenge coming. I now use two low-tech methods to keep my tube secured in place and keep it from leaking at the port.

To contain the feeding tube and give it a safe zone, I use an abdominal binder that I wear all the time. It is a stretch band and attaches with Velcro. After I have cleaned around the stoma, I wrap the 3" binder around my abdomen, securing my tube under it. Binders can be purchased in varying widths. Mine started out as a 9" binder with 3" sections stitched together in a way that they could be cut apart and not ravel. I wrap it around my abdomen next to my skin, under all my other clothing. That way the tube is never left dangling. Even using the toilet does not disturb it.

My binder is made by Dale (www.dalemed.com/prod/abdominal-binder.html). You should also be able to find a binder through your hospital pharmacy or rehab supplier. I have normally sensitive skin and my binder does not irritate me. Also, I cut mine apart at the sections, so I have three washable binders that I wear constantly. Repeated washings make them softer.

Leaking Port

Now, my solution to the leaking port. Between feedings (or meal times!), I use a twister/tie, like the ones that come on bread bags and with garbage bags. I crimp my tube, twist the tie onto it, put the tube back under my binder and I am set. The twisters that are wire with paper over them work better for me than the plastic. They can be twisted tighter. With practice I have even become adept at reusing them by sliding them on and off. The crimping of the tube has not damaged it, and I retain my fluids and nutrition! As a bonus, the crimping even eliminates the dangling during showers.

—Marie Latta, latta@mindspring.com

(Editor's Note: While Marie hasn't had problems, we are not sure if the wire in the twister/tie will cause damage to the tube over time.)

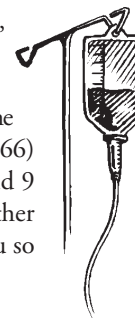
Tysabri, from pg. 1

should begin tapering steroid doses while on Tysabri. Treatment should be discontinued if steroids cannot be fully tapered within six months.

You can obtain more information about Tysabri from the FDA at 888-INFO-FDA or www.fda.gov/cder/.

Equipment/Supply Exchange

There is an abundance of formula, particularly Isosource, available through the Oley Foundation equipment/supply exchange program. For details on what's available and how to acquire it, visit www.oley.org or contact the coordinator, Ben Hawkins, at benhawkins@fuse.net or (866) 454-7351 (toll free). Please call Ben between 9 a.m. and 9 p.m. EST. Note: It is important to let Ben know whether or not you have taken the item(s) he has offered to you so they don't go to waste.



Micronutrients Get Attention

Dr. Lyn Howard, Oley co-founder and Medical and Research Director, and Dr. Alan Buchman, Oley trustee, have been named co-chairs of the 2009 Clinical Nutrition Week Research Workshop which will address the parenteral requirements for micronutrients (trace elements, vitamins, and small additives such as choline and carnitine). Hat's off to these two focused and devoted clinicians, and the A.S.P.E.N. Research Committee for proposing the project. Watch for more news as the program develops!



Parents!

Check out the First Hand Foundation at www.firsthandfoundation.org. This not-for-profit organization offers grants to help pay for children's health-related expenses that are not covered by insurance. The foundation can also be reached by phone, at (816) 201-1569.

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On the Move

Several medical program changes and doctor relocations have come to our attention over the last several months. We'll share such updates with you when we receive them.

Ohio

In January 2008, the Cleveland Clinic Intestinal Rehabilitation and Transplant Program began offering small bowel and multivisceral transplants. Cristiano Quintini, MD, a transplant surgeon with experience in liver and intestinal transplants, is spearheading the integration of surgical options to manage intestinal failure. Dr. Quintini joined Cleveland Clinic in August 2007 after training in multiorgan abdominal transplant surgery in Modena, Italy, and Miami, Florida. He will be supported by John Fung, MD, PhD, Bijan Eghtesad, MD, and Charles Miller, MD.

Cleveland Clinic will be the only transplant center in Ohio and among a dozen in the nation to offer an adult and pediatric small bowel transplant program. The program will provide a range of expertise, combining techniques to enhance intestinal adaptation and nutrition support with surgical treatment of intestinal failure, including intestinal transplantation. For more information about Cleveland Clinic's Rehabilitation and Transplant Program call (216) 445-2090.

Tennessee

Effective February 1, 2008, Douglas L. Seidner, MD, is the director of the Center for Human Nutrition at Vanderbilt University Medical Center (VUMC) in Nashville, Tennessee. He was previously the director of the Nutrition Support Team at the Cleveland Clinic and as such was involved in one of the largest home parenteral nutrition programs in the country. Dr. Seidner will direct the program for home parenteral and enteral nutrition at VUMC and will develop a program for intestinal rehabilitation for patients with severe malabsorption. To contact Dr. Seidner, call (615) 936-1288.

On the Move, cont. pg. 5

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Kyle R. Noble Memorial Scholarship

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In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a \$1,000 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 educational pursuits) and a medical reference (from someone on the applicant's health care team — physician, nurse, dietitian — verifying the medical situation) are required. The scholarship will be distributed at the end of the school year after a copy of the recipient's transcript of his/her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference. Applications for the June 2008 scholarship must be received by April 25, 2008. Complete details posted on www.oley.org.



Kyle Richard Noble
11-10-98 to 12-29-06

Conference, from pg. 1

on which you are taxed), but at checkout your bill will reflect a credit of \$27/night. It is important to us that you completely understand the Marriott's process. If you have questions, please do not hesitate to contact us. For more information about lodging visit www.sandiegomarriottmissionvalley.com or call (619) 692-3800.

It's also worth mentioning that **many of your meals are covered at the conference** (continental breakfast and lunch Friday and Saturday, dessert at the silent auction, dinner at the town meeting, and a great lunch at the picnic).

Opportunities you won't want to miss include:

- Celebrating Oley's 25 years at the reception Thursday evening
- A silent auction with plenty of great items to bid on
- A town meeting dinner to learn more about Oley activities
- A walk-a-thon and picnic

More details will be published soon in the conference registration packet. To speed up delivery of your packet by as much as three weeks, send your e-mail address to harrinc@mail.amc.edu.

The value of attending is best described by former attendees. About one session, a 2007 attendee wrote, "*Terrific presentation. I appreciate the comments from the various people in the audience as well as the presenters.*"

Last year's attendees also commented, "*Appreciate touching on the issues of chronic illness, loss, and coping with chronic grief—that accompanies chronic illness...[The session was] very moving and inspirational.*"

Please contact us if you have any questions, need more information, or have suggestions regarding a topic or speaker. We're listening! ☛

New Ohio Regional Coordinator

We are excited to introduce you to Oley's newest Regional Coordinator volunteer, Norman Benway. Norman was born and raised in Toledo, Ohio, where he now lives with his wife, Maryanne. Norman and Maryanne have three children and three grandchildren.

Norman first showed symptoms of what would later be diagnosed as an esophageal motility disorder in late 2004. By 2006, Norman was hospitalized; weighing only 93 pounds, he was soon introduced to the world of tube feeding. He underwent many tests, swallowing studies, and therapies, but ultimately returned home unable to eat or drink and entirely dependent on his new PEG tube for nutrition.

With the help of a trusted dietician, Norman has been able to adapt to his new lifestyle. He's gaining weight back and is currently working two jobs! For thirty years before all of this, Norman worked as the custodial supervisor for Lucas County; he also has experience working in an assisted living facility.

Norman is determined to help himself and other people who are dependent on nutrition support. He is extremely motivated and plans to establish a support group. Please contact Norman if you live in the Toledo area and want to be involved in the support group, or if you just want to talk. Norman can be reached at (419) 531-4427.

Becoming an RC

Do you, like Norman, wish Oley had a bigger presence in your area? Would you like to be able to attend a homePEN support group? You can make it happen. Call Kate Swensen at (800) 776-6539, or e-mail her at Swensek@mail.amc.edu, to learn more about the Oley Foundation Regional Coordinator program. As a Regional Coordinator, you can also support homePEN consumers and families just by picking up the phone or shooting out a quick e-mail! We'll work with you to establish professional connections and to develop support groups or educational meetings. If you'd like to talk to other Regional Coordinators before making up your mind, check out their Web page, www.oley.org/volunteers.html, for photographs, biographies, and contact information. Make 2008 YOUR year to help Oley help others!

On the Move, from pg. 4

Pennsylvania

Gordon L. Jensen, MD, PhD, has relocated to Pennsylvania State University, where he is a professor of medicine and nutritional sciences and head of the Department of Nutritional Sciences. Dr. Jensen has also initiated a malnutrition clinic in State College at Centre Medical and Surgical Associates affiliated with the Mount Nittany Medical Center. He is taking referrals for patients with nutrition support related concerns, including malnutrition, tube feeding, and parenteral nutrition. To contact Dr. Jensen go to www.centremedsurg.com or call (814) 234-8800. ¶



*Norman Benway with grandson
Adam Charles Benway*




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Improving Life on Nutrition Support

25 Years on TPN, from pg. 2

published by the Lifeline Foundation. This *LifelineLetter* was a far cry from the one of today, but it served the same purpose: support and education. I learned that there were others on TPN and that they were thriving, not just coping! When the Oley Foundation began, it took over the newsletter and developed other resources for the HPN and HEN community.

Since then I have called upon Oley for help with several TPN issues. For example, when my doctor recommended a Port-a-Cath® as a replacement for my Hickman catheter, I had many questions and fears; most importantly, I wondered how could I possibly learn to stick myself?! Through Oley I learned of three consumers with ports who were willing to talk to me about their experiences. I called them, and learned that sticking yourself is no big deal; furthermore, they were able to swim and bathe without worrying about infection. Being able to talk to others with ports helped me make a decision that I have been very happy with.

About six years ago, Joan Bishop, Oley's executive director, asked me if I would be willing to serve as a panelist at the National Association of Vascular Access Networks (NAVAN, now the Association for Vascular Access, or AVA) meeting the following month in Alexandria, Virginia. She wanted me to speak about the patient's perspective on using venous-access devices, concentrating on the psychological issues. When we arrived, Joan asked Steve if he would fill in for an absent speaker and address the spouse's perspective. We thoroughly enjoyed talking to the IV nurses and others about coping with a central catheter. We hoped that our comments might ultimately help fellow consumers as well as our immediate audience.

Sharing

After that meeting, Joan encouraged us to become Oley Regional Coordinators (RCs). Since we felt that the time had come to give back to the Oley community, becoming RCs made sense. We enjoy making a difference in peoples' lives by exchanging e-mail messages or having phone conversations with fellow consumers or caregivers. Even if we cannot help in a concrete way, people seem to feel better knowing they are not alone.

Several months ago my dietitian asked if I would contact one of her patients, a woman newly on PN. She sounded so sad and weak when we first spoke. We talked for long time, and as we were about to end the call she said, "My friends stop by and say they'll pray for me, but you really know what it's like!"

Being an RC is not a one-way street. Besides the enormous gratification of helping others, I have learned interesting and useful information.

The next day, I mailed her a thick packet of past *LifelineLetters* and other Oley material. When I called the following month, she sounded stronger and she had even ventured out with friends. She loved the *LifelineLetters*; reading the articles gave her the sense that, although she could not eat and had to be hooked up to this strange, scary equipment, she could still enjoy life.

Recently, we received an e-mail from a woman whose father had lost most of his small bowel and was scheduled for further surgery. She and her family were concerned about his quality of life on PN. She had seen our profiles on the Oley Web site and was encouraged to learn that people on PN can lead active lives.

At her request, we phoned her. The three of us talked for nearly an hour, and when we hung up, I was worried that we had overwhelmed her. I sent her an e-mail several days later asking how her father's surgery had gone. She wrote back saying: "Thank you for the generosity of time and knowledge Steve and you shared with me. You helped my family feel

more confident in my dad's ability to fight back and thrive. I'm not overwhelmed; I am relieved."

As RCs, most of the contact we have with consumers or their families is of short duration, but there are a few people with whom we have developed long-term relationships. Lillian Horn and I have been e-mailing each other for several years. She lives in South Dakota and, although we are separated by many miles and have never met, we regard each other as friends. We share health concerns, but also

news of other things, such as the arrival of her latest great grandchild. I admire her perseverance in working out regularly and am impressed that she enjoys baking for her family, even though she is unable to eat.

At Oley meetings we've met in person friends we had made over the phone and through e-mail. At the 2005 conference in Saratoga Springs, New York, we met Jeff and Tammy Hodder. Since we had exchanged photos beforehand, we recognized one another immediately and hugged and laughed like old friends, which indeed we were.

In March 2006 we manned an Oley toll-free line. One of our callers was Beverly Mello. We were on different therapies and had different underlying diagnoses, but we bonded with one another. We continued our friendship, calling one another every so often. When she learned that the 2007 Oley conference would be in Cape Cod, and within driving distance from her home, she immediately registered; she said she hoped I would go, too, because she wanted to meet me. At the conference, someone pointed me out to her, and I heard a familiar voice say, "I'm Beverly!"

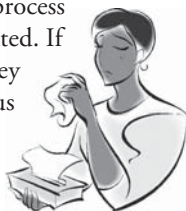
Being an RC is not a one-way street. Besides the enormous gratification of helping others, I have learned interesting and useful information. Lillian told me about a Web site where I could learn to understand my lab test results (try www.amarillomed.com/howto.htm, or do an Internet search for "understanding lab results"). I have also been told about intraluminal brushes and the prophylactic instillation of ethanol alcohol to prevent line infections (the latter therapy is still being investigated).

But the real essence of the RC experience is sharing personal experiences with others who are traveling down the same, occasionally bumpy, highway. ¶

Call Davi and her husband Steve toll-free in March at (888) 610-3008 or anytime at (410) 721-3399.

Grieving the Loss of a Child

Over the years, we've experienced the loss of several children in the Oley family. Grieving is a difficult process at best, and much worse when you feel isolated. If you would like to be connected with other Oley members who have lost a child, please call us at (800) 776-OLEY. We are hoping to host an online discussion forum for grieving members soon.



Biography of an HPNer

In 1970, intestinal blood clots left Judy Taylor unable to eat. Judy was facing a slow death by starvation when she was introduced to Dr. Khursheed Jeejeebhoy, who was researching artificial feeding methods. The recently released book *Lifeline: The Judy Taylor Story*, by Shireen Jeejeebhoy, recounts Judy's journey as the first person to receive parenteral nutrition (PN) as her sole means of sustenance.

Shireen, the book's author and Dr. Jeejeebhoy's daughter, writes that, in 1970 "most doctors still considered long-term intravenous feeding to be science fiction." Over the next twenty years, Dr. Jeejeebhoy worked closely with Judy to understand, develop, and fine-tune the procedures for parenteral nutrition. This book tells about Judy's struggles, and en route, gives a history of the development of parenteral nutrition (PN).

Judy's story is compelling—she was a courageous and determined woman—as is the story of the science of creating a balanced artificial nutrition therapy. But Judy's trials were difficult, and this book is not a light read. From the beginning, Judy's medical conditions are described graphically, and the description of Judy's last days (Judy died in 1991 of sepsis) is particularly difficult. At the Oley offices, Judy is remembered as a vital, fun, life-loving, and generous woman, and several readers found it hard to read of her suffering.

Yet this book validates the chronic pain that some consumers experience, and it touches on several difficult but real topics, such as how chronic illness and homePEN can affect family relationships and the issue of getting good care when there are few experts in this field. The book also shows how Judy's courage, positive attitude, and self-advocacy made a difference in her life. Judy wanted to watch her young daughters grow into young women, and with the help of PN, she was able to.

You can buy *Lifeline: The Judy Taylor Story* at www.iuniverse.com/bookstore. More information about the book is available at <http://jeejeebhoy.ca>. If you read the book and have questions or wish to discuss it, HPNer Don Young, who knew Judy personally, has expressed his willingness to talk about it; call him toll-free at (866) 454-7309. Several Oley staff members have also read the book and are available to chat at (800) 776-OLEY.

Recall Notices

Please note the following recalls issued in January 2008:

—**All lots of both heparin and saline prefilled flushes distributed under the brand names Sierra Pre-Filled Inc. and B. Braun.** The products are sold in 3ml and 5ml sizes for heparin, and 3ml, 5ml, and 10ml sizes for normal saline. Two lots of heparin IV flush syringes were contaminated with *Sierratia marcescens*, which has resulted in patient infections.

Sierra Pre-Filled Inc. can be reached at (919) 331-2039; B. Braun can be reached at (800) 227-2862.

—**A voluntary recall of certain lots of heparin vials by Baxter Healthcare** as a precaution due to an increase in reports of adverse patient reactions associated with these lots. The lots are: Heparin Sodium Injection 1000 units/mL 10mLVial, Lot #'s 107054 and 117085; and Heparin Sodium Injection 1000 units/mL 30mL Vial, Lot #'s 047056, 097081, 107024, 107064, 107066, 107074, and 107111.

Recall, cont. pg. 11

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- ▶ Vital Jr. is appropriate for oral and tube feeding; sole-source or supplemental nutrition.

Contact your home medical equipment supplier
or visit Ross.com for more information.

*The ChefsBest™ Award for Best Taste is awarded to the brand rated highest overall among leading brands by independent professional chefs.

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THE OLEY FOUNDATION

The Pharmacy that treats its consumers like Phamily



HomeTPN.com
Home TPN Specialists

Nutrishare, Inc.
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www.nutrishare.com

Looking Back, Moving Forward

The Town Meeting at the Oley Annual Conference in Hyannis in June 2007 provided Oley staff and trustees with an opportunity to outline our state of affairs and to engage members in a discussion to help us plan for the future. Not knowing what to expect, we reserved a medium-sized room and ordered food for a medium-sized crowd. Much to our surprise, we filled a huge room, and subsequently ordered much more food. The energy flowed!

Rick Davis, Oley President, described our financial situation as outstanding, thanked everyone for their contributions, and acknowledged staff for hosting and faculty for participating in a most informative and well-organized conference. Darlene Kelly was recognized for years of service as an Oley trustee as she stepped down, and Marion Winkler, Cheryl Thompson, and Gail Sansivero were welcomed as new trustees. Then we began the discussion.



Rick Davis hands Darlene Kelly a plaque to recognize her efforts.

Ideas Into Action

Based on a lively afternoon conference session coordinated for young adults transitioning to independence, we received a request to establish an online forum to provide Oley members—particularly teens—with an opportunity to communicate with one another. It was also suggested that Oley consider allowing the young adults representation on the Oley board of trustees.

Update: Watch for the launching of forums on www.oley.org soon. Register, observe, and participate! The forums are for everyone. Young adult representation on the board is being considered.

The topic of reaching others in your community was approached. “What can we bring to our local hospitals?” “How can I introduce Oley to my physician?” And “are there materials prepared specifically to pass along to others?” were a few of the questions asked of Oley staff. Traditionally, such requests have been handled on a one-by-one basis.

Update: We have developed packets, complete with letters to clinicians that have been endorsed by Oley trustees to legitimize the introduction, for the purpose of connecting consumers to Oley services. We are in need of YOUR help to get the word out! Contact Kate at (800) 776-6539 or swensek@mail.amc.edu to order a supply of informational materials—or pass along names and addresses of your clinicians and we'll mail packets from the Oley office.

The important role of the “official” Oley volunteer was outlined and a call for anyone who was interested in serving as an Oley Regional Coordinator (RC) was announced.

Update: Joan Medwar in Sharon, Massachusetts, and Norman Benway in Toledo, Ohio, have recently joined the ranks of Oley RCs, and several more people have expressed interest. Consumers or family members who are interested in learning more about serving in this capacity are invited to contact Kate (contacting information above; also see “New Ohio Regional Coordinator,” page 5). ¶

Recognize Someone Who Inspires You!

Oley Award Nominations

The Oley awards give us each a chance to acknowledge someone in our life who has inspired us by their courage, perseverance, or willingness to help others. Nominate someone who has earned your respect because of what they have overcome or inspired you by how they live.

The significance of being nominated is great by itself, as each nominee will be recognized at the Oley conference in San Diego, CA. Combine this with the potential of a travel grant (see award descriptions), and this is awesome!

Ring your own bell!

Don't resist nominating yourself. Tell your story, and/or share examples of how you have helped others along the way. At the very least, it will motivate others.

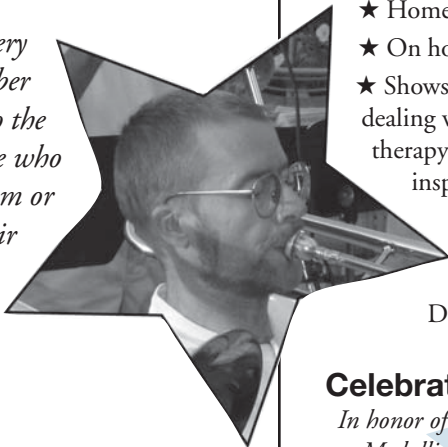
It's FREE and easy!

A simple form (on back side) with three, quick questions is all you need to complete. Technophiles can find it on our Web site: www.oley.org or request a form from Cathy Harrington at harrinc@mail.amc.edu. Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you'd like.

Questions?

Call (800) 776-OLEY.

*Each and every
Oley member
contributes to the
success of those who
walk beside them or
follow in their
footsteps.*



**Nominations must be
submitted by
April 25, 2008**

Award Criteria

The awards will be presented June 27 at the 2008 Oley Conference in San Diego, CA. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a keepsake, are honored at the conference awards program and will be spotlighted in the LifelineLetter. Most awardees will have some of their travel expenses underwritten. Recognition is given to all nominees!



LifelineLetter Annual Award

*In honor of Nutrishare Inc.,
Oley Platinum Partner*

- ★ 19 years of age or older
- ★ HomePEN consumer or caregiver
- ★ Consumer has been on homePEN for at least five years
- ★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
- Winner will receive a partial travel grant to the Oley Conference in San Diego, CA, June 26 to 30

- ★ Lives life to the fullest—traveling, fishing, gardening, volunteering, performing in local theater, spending time with children and grandchildren, etc.
- Winner will receive a partial travel grant to the Oley Conference in San Diego, CA, June 26 to 30

Lenore Heaphey Award for Grassroots Education

- ★ Oley Foundation Regional Coordinator
- ★ Organized an outstanding information and/or education program during 2007
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area

Child of the Year Award

*In honor of NutriThrive, Oley Golden
Medallion Partner*

- ★ 18 years of age and under
- ★ HomePEN consumer
- ★ On homePEN for at least one year
- ★ Shows a positive attitude in dealing with their illness and therapy which encourages and inspires others
- Winner will receive a partial travel grant to the Oley Conference in San Diego, CA, June 26 to 30

Nan Coutts Award for the Ultimate Volunteer

- ★ Clinician (physician, nurse, dietitian, etc.) must practice in the field of homePEN or a related field, i.e. psychology, interventional radiology, pain management, etc.
- ★ Has demonstrated a willingness to give of themselves — beyond their regular work hours — to educate, empower and improve the quality of life for homePEN consumers. For example: a nurse who facilitates an Oley support group on his/her day off.
- Winner will be honored at the Oley Conference in San Diego, CA, June 26 to 30

Celebration of Life Award

*In honor of Coram Inc., Oley Golden
Medallion Partner*

- ★ Enteral or parenteral consumer, any age
- ★ On homePEN for at least 3 years





Oley Foundation Award Nomination Form

Deadline for Nominations: April 25, 2008

The Oley Foundation • 214 Hun Memorial, MC-28 • Albany Medical Center
Albany, NY 12208 • Fax: (518) 262-5528 • e-mail: harrinc@mail.amc.edu

1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2008
(please check one):

- LifelineLetter Award
- Child of the Year Award
- Lenore Heaphey Award for Grassroots Education
- Nan Coutts Award for the Ultimate Volunteer
- Celebration of Life Award

Nominee's name: _____ Age: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (____) ____ - ____ home, (____) ____ - ____ work

E-mail: _____ @ _____

Primary diagnosis: _____ No. years on HPEN _____

2 Fill in your name and contact information.

Your name: _____

Relationship to nominee: _____

Company (if any): _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (____) ____ - ____ home, (____) ____ - ____ work

E-mail: _____ @ _____

Please use this form or an accurate reproduction. Attach **one** additional page if needed. Be sure to type or print legibly using dark ink, since this form will be photocopied. Feel free to submit more than one nomination.

3 Tell how the nominee meets the criteria for his or her award (see other side), describing specific examples: i.e. how this person has demonstrated a positive attitude in dealing with his/her illness; lived a full life; organized an excellent educational program; brought information and compassion to homePEN consumers; or generally has helped others live with HPEN. Attach **one** additional page if needed.

In Memory of Tracy Phelan

Robin Lang

Diagnosed with Crohn's at an early age, Tracy Phelan was a 30+ year HPNer. Though initially shy, Tracy warmed up to the Oley family in 1994 at our Memphis conference, and in time he went on to become an Oley Regional Coordinator. He represented Oley at A.S.P.E.N. conferences and pushed the *LifelineLetter* into the hands of many professionals.

Todd Friedman tells how he met Tracy at the Oley conference in Memphis. "At the end of the conference," Todd says, "I remember him telling me what a tremendous difference attending Oley had made for him and that he no longer felt so isolated."



*Robin and Tracy at the 1997
Oley Conference*

Tracy was a good man. His friends remember him and say, "He was such a nice guy! He was easy to like—a great guy to be around and have fun with." He helped anyone wherever he could. He moved to Florida some years ago and helped his parents when they needed it. He and his father painted and roofed houses together.

Tracy opened his home to Lenora Freese when she attended massage therapy school in Gainesville. I accompanied her on that trip. Tracy took us to Silver Springs, orange groves, dinners out—he was happy as long as we were happy. Tracy had a winning smile and an infectious, husky laugh. He was handsome and possessed a special charm.

Tracy's father passed away about two years after I visited, so he and his mother moved back to their hometown of Rockford, Illinois. Not long after, his mom died. But Tracy rallied and kept busy, helping at AA/NA meetings.

Tracy was invited to get a work-up for a multi-organ transplant; he was scared and didn't like the idea. He was running out of access. We discussed it, and secretly stated, "I hope I don't get to that point."

Tracy died suddenly December 26, 2007, from heart failure, after a wonderful Christmas with his family. He will be missed by his many Oley friends.

Recall, from pg. 7

Clinicians can contact Baxter Healthcare Corporation Product Information Center at 800-933-0303; consumers can contact Baxter at 800-4-BAXTER.

FDA MedWatch

The Food and Drug Administration (FDA) has a program called MedWatch through which you can receive alerts, such as these recall notices, by e-mail. We suggest you sign up for these alerts at www.fda.gov/medwatch. To read the complete 2008 MedWatch Safety Summary, which includes both of the above notices with links to the manufacturers' recall notices, go to: <http://www.fda.gov/medwatch/safety/2008/safety08.htm#Heparin>. Recalls may be expanded. If you cannot check MedWatch call (800) 776-OLEY. ¶



Have Home PN. Will travel.

Our consumers don't have to stay put because of their treatment. At least that's what Jerry Fickle believes. He's been on Home PN more than 25 years. In that time he's been on an Alaskan cruise, to wherever Purdue University plays in a bowl game, to Florida, and on bus trips with seniors groups. He plays golf and rides a Jet Ski when he can find the time. Jerry doesn't see why he can't do what he wants. And Coram encourages him, working with him to make it all possible. We got him started, and we'll be there for the long run.



Contact us toll-free at
866.4.HomePEN (866.446.6373)
or visit www.coramhc.com

Coram consumers.
Going places. Doing things. Living life.

Thanks! We Couldn't Have Oley Programs Without You

Following is a list of everyone who contributed in 2007. We also want to thank those who are not listed below, yet have supported Oley by volunteering their time

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Meredith Nelson, in honor of Dr. Darlene Kelly
Kristie Palmer
Elizabeth Pemble
Mary & John Petrscopic
Sarah Rausch, in honor of Julie Andolina
Tom & Leslie Sanford
Alan Segal
Karen Smollen
Enrica Thure, in honor of Greg Tongol and almost 18 years on PN
Mary Till
Bill and Amy Vohsing
James & Susan Wachta
Marianne Weiss

Friends (Up to \$30)

Hannah Abeles
Ann Alesse
Therese Atwell
Joan Barnet
Elda Benotto, in memory of Angelo Benotto
Norman Benway**
Kirk, Ruth, Kyle, & Bret Bye, in honor of Samantha
Marcy Chaney, in honor of all HPEN consumers
S. A. Chaney
Victor Chaney, in memory of Melissa
Colleen Dixon
Geraldine Dougherty
Bill Drenner
Marion Finch
Cleata Francis, in honor of Aidan Fant
Alexandra Golden
LuAnn Harris
Dan Hogan, in memory of Tracy Phalen—he never gave up on life!
Kathleen & John Hogan
Earl & Margie Jones
Marie Latta
Libby Levin, in honor of 12 years on PN
Susan McKallor
Michael Mucciggrosso, thank you!

below, yet have supported the Foundation by volunteering their time and talents.

Donna & Morris Mummery
The Nicholson Family
Roger Niosi
Janet Platt
Gary Rieck
John Schwartz
Doug Seidner, MD*
Charlotte Shore, in honor of
Erin Shore's birthday
Lauren Signer and Michael Faffe
Marilyn & Richard Sobiech
Nancy Stebbins
Jeanne Taylor, in honor of being on
PN 3 years & hydration only 2 yrs
& in memory of Ben Salta
Michelle Trunick-Stebben
James & Mary VanKleunen

Donna Vasilakos
Darlene Vincent
Michael Wenz
Betty Zeller

In Memory of Bruce Grefrath
Phillip Grefrath
Alyce Newton
Don Young

In Honor of Lyn Howard, MD***
Alan Buchman, MD*
Ron & Lisa Metzger***
Robert Warrington

In Memory of Joyce Hydorn
Roslyn*** & Eric Dahl

Noreen Iacobucci
Barbara & Ron Ives
Tom Markert

In Memory of Kyle R. Noble
Roslyn*** & Eric Dahl
Brian Koenig
Roberta Lehman
NutriThrive
George & Katie Timmons
Margaret Zimmer

*Oley Trustee
**Oley Regional Coordinator
***Oley Staff

Thank You for Supporting Oley Programs!

Please join Oley in thanking our corporate donors. This issue we highlight:

Hospira, Inc.

Hospira, Inc., is a global specialty pharmaceutical and medication delivery company dedicated to Advancing Wellness™ by developing, manufacturing, and marketing products that help improve the productivity, safety, and efficacy of patient care. In February 2007, Hospira acquired Mayne Pharma Limited to become a world leader in specialty generic injectable pharmaceuticals.

Baxter Healthcare

Baxter's Nutrition Business manufactures a broad portfolio of parenteral nutrition products including premix parenteral nutrition, amino acids, dextrose, IV fat emulsion, and vitamins. Its business provides parenteral nutrition products and services to all points of care that provide parenteral nutrition to patients requiring feeding via the parenteral route.

Sherwood Clinical

Sherwood Clinical began as the vision of one man. Seeing a need, Charles Sherwood developed a plan to deliver high-quality infusion care in the comfort and convenience of patients' homes, and in 1993 Sherwood Clinical was born. Today, more than a decade and one hundred employees later, Sherwood Clinical provides home-infusion care throughout Georgia, the western Carolinas, parts of Tennessee, and Alabama. Sherwood Clinical provides a wide range of services, including antibiotics; EN and PN therapy for adult and pediatric patients; central line maintenance; IV hydration; IV inotropics; IVIG therapy; pain management; Synagis home injections (for RSV prevention); intermittent therapies; midline catheter placement; skilled nurse visits; and patient and caregiver education. Sherwood Clinical also provides home medical equipment through its partnership with Care Medical, Inc.

Zevex, Inc.

Zevex manufactures and markets the EnteraLite® Infinity enteral feeding pump. The company writes, "The EnteraLite Infinity is highly portable, +/-5% accurate, easy to program, and rugged—it can be washed under running water without fear of damage!" The Infinity weighs less than 15 ounces, has 24-hour battery life, and can be operated in any orientation due to the elimination of the drip chamber. To learn more about the Infinity, and how to remove the traditional barriers to enteral feeding, visit Zevex's Web site at www.zevex.com/infinity.

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.

PLATINUM LEVEL PARTNERS (\$70,000+)

Nutrishare, Inc.

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NutriThrive

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Baxter Healthcare
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Kimberly-Clark
Nestlé Nutrition
Sherwood Clinical
Sigma International

CONTRIBUTORS (\$1,000–\$2,499)

Baxa Corporation
Zevex, Inc.

Toll-Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the United States and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Oley's Regional Coordinators with a better grasp of their region's needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted at www.oley.org. Comments? Call (800) 776-OLEY.

MAR. '08	<p>Davi & Steve Cohen Crofton, MD (888) 610-3008 EST</p> <p>Rose & Alicia Hoelle Gibbstown, NJ (888) 650-3290 EST</p>	<p>Davi has been on TPN for 25 years due to short bowel syndrome resulting from a car accident. She has experience with Port-a-Caths® in subclavian and femoral sites. Davi and Steve have been active at Oley, NAVAN, and ASPEN meetings and are willing to discuss the medical, logistical, and emotional aspects of long-term IV therapy.</p> <p>Alicia (22 y.o.) has been on HPN since birth due to hypoganglionis/NID. She has Crohn's disease too. Alicia is attending college to become a child life specialist. She has enjoyed camp, sports, and other activities. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. Their favorite topics are advocacy, school accommodation, transitioning issues and dealing with long-term HPN.</p>
	<p>Gail Brenenstuhl Queensbury, NY (888) 610-3008 EST</p> <p>Ann Weaver Chicago, IL (888) 650-3290 CST</p>	<p>After numerous surgeries, Gail was left with 60 cm of small intestine and no colon. She has been PN dependent since 2003. She boats in the summer, travels a little, and until she had shingles in the fall, was active in a health club. The shingles has lasted months, but Gail expects to be active again soon and is looking forward to sharing her knowledge and experiences with you.</p> <p>Ann is married and has two sons, ages 20 and 13, the younger of which has SBS due to Hirschsprung's disease. He has been on HEN since birth and has an ostomy. Ann has cared for central line, NG tube, G tube, and ostomy. She looks forward to talking to other parents.</p>
APRIL '08	<p>Bruce & On Braly Davis, CA (888) 610-3008 PST</p> <p>Rick Davis Salt Lake City, UT (888) 650-3290 MST</p>	<p>Bruce and On's son Matthew (now 19) has been on HPN since the age of nine. He has SBS due to malrotation of the gut and uses a CADD pump. They have traveled abroad with HPN and look forward to sharing their experiences with you.</p> <p>Rick knows about tube feeding (HEN). He wants you to call. He is 63, cannot swallow, has been 100% dependent on HEN for 6 years, and is very active. He hikes and skis extensively. He and his wife also travel frequently and enjoy being retired. He looks forward to hearing from you.</p>

LifelineLetter

The Oley Foundation
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Albany Medical Center, MC-28
Albany, NY 12208

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