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LifelineLetter

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

20th Annual Oley Consumer/Clinician Conference

"One of the best" was the refrain heard from many of the conference attendees as they left Saratoga Springs, New York this year. Over 330 people came for the 20th Oley Conference and what a conference it was!

Tuesday's activities included a hike in the Adirondacks, the regional coordinator workshop and a high-spirited welcome reception in the evening.

Wednesday, we were entertained by the annual awards ceremony, including awards for those on HPEN for 20 years or more and the Match Game with contestants Don Young and Madalyn George-Thiemann, RN, MSN. "Gene Rayburn" looked suspiciously like Mark Klang, PharmD and the panel was filled with medical and consumer experts discussing such topics as avoiding long-term complications and clogged feeding tubes. The afternoon started with visits to our many exhibitors and lunch in the exhibit hall. Everyone then had to make the hard choice of which two breakout sessions to attend. The kids got to spend the afternoon playing laser tag and other games. To top off the day, many people attended the silent



Michael, Cheryl and Amanda Yelner at the picnic.

auction, which had more great items than ever. Thanks to everyone who donated and purchased items, the event raised \$6,500 for Oley programs!

Thursday, we took a few thoughtful minutes to remember those Oley consumers who are no longer with us. This is always a special time. The plenary session speakers included a delightful physician from

Conference cont., pg. 15 ←

Welcome Aboard!

We would like to introduce you to four new Oley Board Members:

Rick Davis has been a HEN consumer for less than five years. He uses enteral nutrition exclusively after a stroke destroyed his ability to swallow anything. He



Rick Davis

struggled for some time and then was introduced to the Oley Foundation. His interaction with both consumers and professionals at an Oley Conference convinced him that he could live a full and active life even if he was on HEN. Rick now travels

again, worldwide, and has been instrumental in bringing the conference to Salt Lake City, his home town, in 2006. He reaches out to stroke victims in his area and other Oley members whenever he can. Being a

Welcome cont., pg. 14 ←

Make It Positive

compiled by Elizabeth Tucker, Deb Pfister and Cheryl Thompson

During the recent Oley Foundation conference, consumers, their families and clinicians met to discuss how to cope with the many challenges associated with HPEN. Suzanne Appel, MD, shared her insights based on her work as a clinical psychiatrist and personal experiences as the mother of children on HPEN. Below are highlights from the two sessions. A DVD of the sessions is available from the Oley Foundation's Video Tape/DVD Library (see form inserted in this issue or call 800-776-OLEY).

Words of Wisdom from Dr. Suzanne Appel

Dr. Appel began both sessions by sharing coping tips. Things she and her family found most helpful are to:

- Attend an Oley Foundation Conference or Regional Meeting. Just the process of attending helped her family realize traveling was possible. Good planning is the key and now they have traveled outside their state and the country. Also, seeing other HPENers doing "normal" things helped shift their thinking from "not being able" to do something to "being able."

Make It Positive cont., pg. 2 ←

Make It Positive, from pg. 1

- Make a conscious effort to shift from thinking “life revolves around HPEN” to “HPEN as just one aspect of life.”

- Use what you have learned to help others. That can be with others who have similar problems to what you have experienced or it could be in another venue entirely. Some examples might be as a regional coordinator

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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 Director of Communications & Development at the address above.

for the Oley Foundation or a volunteer in your local hospital auxiliary. Other ideas might be delivering meals on wheels or volunteering at your local food pantry/food shelf.

- Take an active role in your medical care. Be an advocate for your own or your child's care. Most consumers or parents of consumers have learned the right and wrong ways for things to be done and the times when questions need to be asked. Use your expertise to make your health care experience better.

- Learn to deal with stress using “the relaxation response.” Many people can be unaware of the impact thoughts and emotions, both negative and positive, have on their lives; it is important to understand what triggers stress and have techniques available to use to deal with that stress.

Obviously, some of Dr. Appel's stress could be related to her children's hospitalizations. To counter the “stress response” researchers, such as Dr. Herbert Benson at the Mind-Body Institute at Harvard, feel there is also a “relaxation response” that can be learned. This response can help you resume a more relaxed state. His web site: www.mbmi.org has a number of simple techniques.

One quick technique is: *Making sure you are using your diaphragm to breath, take in a deep breath and exhale out your nose. Counting backwards from ten, do this slowly and deliberately.* It will make a difference. Dr. Benson also has books and tapes available. He says the basic steps to learning a “relaxation response” are repetition, such as focusing on breathing and learning to passively disregard everyday thoughts. By using a relaxation technique, research has shown significant reduction in blood pressure and pulse, and changes in brain activity.

Exercise is another effective method people can use to put their minds into a more relaxed state. Other methods include meditation, tai chi or yoga. In addition, gaining knowledge can be reassuring.

Taking personal responsibility was also discussed at some length. The age of an HPENer was determined to be a most important component.

0 – 4 years = total dependence on a caregiver
 5 – 8 years = learning the processes required
 9 – 11 years = taking over the process, with varying degrees of help
 12+ years = total independence can be strongly encouraged

Words of Wisdom from Consumers: Counseling May Help

While not every HPENer will need a professional psychologist, one woman suggested that the emotional impact of HPEN should be addressed. Her medical doctor told her that every relationship she has will go through a transformative process when she begins HPEN. Some relationships won't survive, some will be stressful and some can even improve. Although she didn't feel she needed counseling, her medical doctor insisted she meet with a psychologist that specializes in critical care to help with relationship transitions and other issues that may arise. This consumer was grateful that her physician recognized the emotional impact of this therapy on the individual and all those around her, and insisted she seek preventive help. In her sessions she was able to freely express her emotions and learned to ask herself “what is really causing the emotion?” Then she could evaluate what in her life could and/or should be changed to alleviate the underlying cause.

This consumer also discussed that many women find it difficult to express anger. Dr. Appel said that it can be harmful to suppress negative emotions that fester if left unresolved. A person may also find it frustrating if they are no longer able to participate in their previous roles as a woman/man, mother/father, etc. The issues of how a person's sexual identity changes were also mentioned, as HPEN impacts all aspects of a individual's life — physical, psychological, sexual and spiritual.

Take Charge

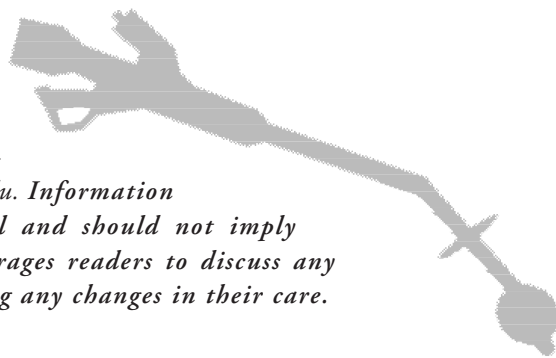
One individual felt she learned to cope by taking charge of her own life, specifically issues related to her health care. When she meets a new health care provider, she establishes a collaborative relationship. She explains to them, “I am the captain of the team”. Her primary care physician is the co-captain, who helps to coordinate the medical care. His advice is very important but she will ultimately make the decision on her own, which may or may not be in total agreement with him.

Not everyone will find it easy to go from a passive to an active voice. She believes that it is difficult to succeed in the current health care system if you are passive about your own health care. Coming from a business background gave her the ability to put the con-

Make It Positive cont., pg. 13

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 DahlR@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.



To Dress or Not to Dress: Securing Enteral Sites While Swimming

The ocean is my natural habitat. I am of Irish decent, and, like my forebearers who came here from an island nation, my life is circumscribed by the ocean. I live on Cape Cod, just five minutes from the ocean. Yet since 1999, I have not been able to go for an ocean swim because of the surgical placement of a J-Tube, in addition to a surgically placed G-Tube. You see, I have two tubes.

The protocol at the hospital where I am treated mandates the securing of all exit sites with a Tegaderm® while swimming. I have followed those instructions since 1999. I would go to the beach and watch others swim, complicated by a life of watching others eat. "Enough of the deprivation!" was my mantra. The concern of the physicians, especially early on during the AIDs epidemic, was that the exposed exit site would come in contact with water that had been contaminated. The Tegaderm would provide a shield over the site, protecting it from exposure to bacteria that might breach the site.

Taping up two sites

If you only have one tube, securing the site with Tegaderm might not be a problem. If it is, ask your physician/radiologist to help eliminate the bulk by replacing it with a smaller tube or surface level device (sometimes called a "button") which can be covered for swimming. The proliferation of new tubes out there is amazing. Today, there are all kinds of options, but you have to ask and do the research.

However, two tubes make for a complicated the situation. It was impossible for me to secure two exit sites, side by side, covering more than half of my abdomen. There was too much area and too much bulk. Even a number of Tegaderms did not work. I tried every combination. How did I know the Tegaderms had been breached? When I removed them, the area underneath was wet. Wearing a wet dressing for hours under a Tegaderm was deemed more serious than not wearing a dressing at all. The water held close to the site, with the site warm because of summer heat, seemed a set up for bacteria to thrive. I made the decision not to swim any more.

Imagine my glee when years later I networked at a couple of Oley Annual Conventions to find "tubers" who had what I had, and swam without a Tegaderm. Imagine swimming bare bellied!!!!

Researching Options

It was time for me to uncover the why and the how. I went to work pumping the super stars of every ilk in this area, and in every discipline. Needless to say, I learned a tremendous amount of information. The purpose of this article is to share with you the information I found so you will be empowered to make an informed decision.

Let me start by stating the obvious; no two tube-patients are alike. You might be able to take all or part of my advice, depending on your diagnosis, the condition of your immune system, and the advice of your physicians. This is not a carte blanche situation.

The first blanket statement that I would make, that every expert would agree to, is that there is some risk in swimming without a Tegaderm. In their collective opinion, the risk is minimized under certain circumstances.

The second blanket statement I would make is that swimming without a dressing is not possible until the area around the exit site is what the docs call "mature." Mature means well-healed and covered with scar tissue. This usually takes three to six months. So, swimming for a period of time after your surgery, is out of the question. Your physician should be able to tell you how much time needs to pass to achieve a mature site. Also, care needs to be taken to cover broken, bleeding exit sites.

Given a mature site, swimming without a dressing is the safest in salt water, or ocean water. Salt water, by its very nature, is a cleansing, self-healing saline bath. We all do a saline cleansing when changing dressings. The ocean is one, huge saline bathtub. The constant ebb and flow of the ocean helps eliminate contaminants. It is a self-cleansing environment: waves come in and go out in seconds. The chance of



Diane swimming in the ocean just off Cape Cod.

Tube Talk cont., pg. 12 ➔

Congratulations 2005 Award Winners!

LifelineLetter Annual Award Winner

Bettemarie Bond
Levittown, PA

Bettemarie Bond has been an Oley Foundation Regional Coordinator (RC) since October of 1992. Her goals in becoming an RC included helping people on HEN and HPN understand they can live their lives on these therapies. She has guided Oley members in such matters as living successfully in a campus dorm while on HPEN, drawing from her experience in going to college to become a pediatric occupational therapist. Her positive perspective, kindness, generosity, and caring are the qualities that have been cited as what makes her unique and special. She reaches out to others in similar situations, offering her “can do” attitude as an example of what can be achieved while on therapy. She helped set up a program for teens and young adults with special health care needs at The Children’s Hospital of Pennsylvania, where she works hooked up to her HPN — always leading by example. We are very proud and pleased that Bettemarie was selected as the 2005 Lifeline Letter Award!



Bettemarie Bond

Nominees: Nader El Samaloty, Jim Wittmann

Oley Foundation Young Adult of the Year Winner

Sponsored by Pediatric Services of America

Zachary Juhlmann • Waukesha, WI

Zachary Juhlmann is an exceptionally sunny, optimistic 13 year old boy, who smiles often and thinks positively despite a multitude of health issues and some hard knocks no one should have to deal with.



Zachary & Sammy Juhlmann

His road became rocky at 5 weeks old, and eventually mitochondrial cytopathy was determined to be the cause of his challenges. He has gradually lost the ability to eat, then to be fed by J-tube, so now he is wholly dependent on TPN. Additionally, he requires a continuous cardiac drip and two other infusions. His biggest loss, though, has been his younger brother Sam, who succumbed to the same diagnosis this past year. Zachary was a wonderful model to Sammy, who was also completely dependent on TPN for most of his 7 years and 9 months. Zachary taught Sam in word and action that being on TPN

was just the way it was and that did not mean life should not be lived. They were “best brothers,” shared a room, and did everything together. Zachary is fiercely independent, and determined when he started TPN full time that “I am never going to get better, and never going to get off TPN, so I better learn how to give myself my meds and TPN; because I don’t want you to come to college with me, and I am definitely growing up and going to college.” To know you will never get better at the age of 13 is quite a burden to carry. Zachary carries this burden with grace, while doing his homework, going to robotics club, playing piano, and playing with friends. When his class studies nutrition, Zachary shares how his therapies work, helping his classmates understand nutrition support. Zachary’s mom Anne states, “His hope, despite the incredible reality he lives with, and his love of life, are inspirational and humbling to those around him. He is the most courageous, resilient person I know.” We are proud and honored to award Zachary Juhlmann with the Young Adult of the Year Award.

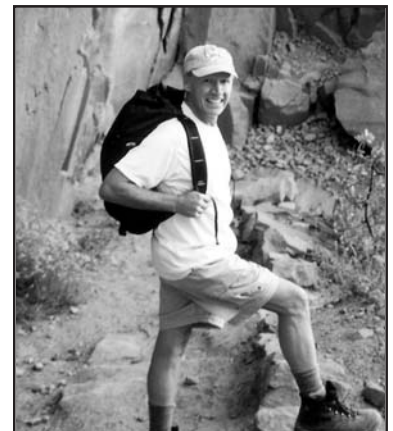
Nominees: Alyssa Douglas, Natalie Eacrett, Adam LaVoie, Kyle Noble, Sean Rawlings, Marrison Vanalsteine

Celebration of Life Award Winner

in honor of Coram Healthcare

Rick Davis • Salt Lake City UT

Over 1 million vertical feet of skiing, a 23.4 miles hike across the Grand Canyon in one day, a trip to New Zealand and another around the country, and walking 25 kilometers at the first Oley Foundation walk-a-thon — is how Rick Davis celebrates life. He has found it to be very precious, surviving a serious stroke that deprived him of swallowing anything, including his own saliva, in December of 2000. Rick was the CEO of Salt Lake City Convention and Visitors Bureau for 16 years; then one year before the Olympic Games he had worked so hard to bring there, Rick found himself sidelined, at first unable to walk, talk, or eat. He set to work and began the long journey to recovery — first walking a hall, then a block, then a mile.



Rick Davis hiking in the Grand Canyon. He hooks up on the trail for hydration and fuel breaks.

Through perseverance Rick worked to regain all his abilities in just this fashion. What was not to be recovered was his ability to eat, so he put his energies into making his feeding therapy work for him, and found the resources to make that happen through the Oley Foundation. He now works to bring hope to others similarly challenged, reaching out through newsletters like ours, city magazine articles, and professional meetings — wherever he feels his story will touch and benefit someone. True to form, he is working to bring Oley’s annual conference next year to Salt Lake City — once a salesman! But

what he sells now is hope, perseverance and inspiration — and we will be the ones to benefit. It is a great honor to award Rick Davis the Celebration of Life Award.

Nominees: Shannon Bullied-Curran, Rebecca Carnes, Nina Marie Marino, Diane Rhodes, Jacqueline Swann, Jennifer Thiesse

Lenore Heaphey Grassroots Education Award Winner

Donna Noble and the Mighty Medical Miracles Columbus, OH

Donna Noble is a great advocate for children using nutrition support therapies. She has worked hard to bring support group meetings, as well as fun programs and fundraisers to the families in their Mighty Medical Miracles (M³) group. Over the last year, the bonds of this group were tested



Donna Noble of M³ with her son, Kyle.

when Donna's son Kyle suffered a major sepsis incident, and the daughter of Michelle Christenson, another founding M³ Regional Coordinator, underwent a multivisceral transplant. This group continues to reach out to people in their own area and beyond. Given the very challenging times Donna and Michelle have had this year, the nomination is actually made for the entire M³ group, as other members like Mitzi Goldsmith and Jennifer Welday have shouldered many responsibilities in an effort to help their friends and sustain their community. These families are a wonderful example of how strength can be found in numbers, and shared joys are that much more precious. We are very proud to award the Mighty Medical Miracles the 2005 Lenore Heaphey Award for Grassroots Education.

Nominees: June Bodden and the Oley/Tampa Support Group; Jim Cowan/Roberta Gelle—NEO Oley Support Group; Kathleen McInnes/Ann Weaver - The Chicago Pumpers

Nan Coutts Award for the Ultimate Volunteer

Sponsored by Judy Peterson, RN, MS

Jane Balint, MD • Columbus, OH

We are proud and very pleased to announce that Jane Balint, MD, a Pediatric Gastroenterologist at Children's Hospital in Columbus, Ohio, has been selected to receive the Nan Coutts Ultimate Volunteer Award. This award is for a nutrition support clinician that goes above and beyond to bring the best of information and care to their patients. The nominations for this award contained numerous examples of why Dr. Balint should receive it. Included in this list were: connecting

patients and families to the Oley Foundation and the local M³ family group; attending local meetings, leading other clinicians to volunteer by her example; purchasing tickets for their local events and giving them to homePEN families who could not afford to pay for them; and participation in developing a weekend camp for homePEN kids.



Jane Balint, MD

Dr. Balint works to locate new research and therapy information for her patients, and ensures each child gets to be a child first, a patient second. A retired nurse familiar with Dr. Balint's work offers that she "exemplifies the very best in medicine – cutting edge clinician, and eloquent advocate." Additionally, our national homePEN community benefits from Dr. Balint's service on the Oley Foundation Board. Please join us in congratulating Dr. Balint!

Nominees: Lyn Howard, MB, FRCP, FACP, Albany, NY; Darlene Kelly, MD, PhD, Rochester, MN

Be All That You Can Be

The Oley Foundation

21st Annual Consumer/Clinician Conference

Sheraton City Centre
Salt Lake City, Utah
June 28 - July 1, 2006

Thanks for Your Support — We Couldn't Do It Without You

Many thanks to the following companies and individuals for contributing to the success of our conference events.

Medical Support:

Coram Healthcare – Guilderland Branch

Conference Videotaping Services:

Creative Networks – Joel Resnick

Audio Visual Equipment:

Stephanie Pelham

Welcome Reception

Roy George

Conference Registration Bags:

Nutrishare, Inc.

Speaker Support:

Apria Healthcare; Association for Vascular Access (AVA); Coram Healthcare; Critical Care Systems; Intravenous Nurses Society (INS); Nutrishare, Inc.; NPS Pharmaceuticals; Option Care

Child Care

Pediatric Services of America
Volunteers: Ted Burton, Kim Butler, Stephanie & Emily Gulbrandsen, Robert Harrington, Kate Letzelter, Jackie Miller,

Stephanie & Jacqueline Pelham, Maureen Rizzuto, Marjorie Quinn

Lunch in Exhibit Hall

Coram Healthcare; Novartis Nutrition

Registration

Jane Freese, Bobbie Groeber, Jeff Hoelle, Stephanie Pelham, Darrel Woods

Jammin' Jammies

Ross Laboratories; Coordinators: Patty Woods & Rose Hoelle

Youth Activity

Capital Communication Cares Foundation, Ross Laboratories; Volunteers: Ted Burton, Kim Butler, Valerie Gyrko, Robert Harrington, Maureen Rizzuto, Daryl Woods

Picnic

Albany Medical Center Food Service Dept., Fox Distributors, Golub Foundation, Stephanie & Emily Gulbrandsen, Joyce Hydorn, Stephanie &

Jacqueline Pelham, Sam's Club, Stewarts, Walmart's, Don Young & Kyle Woods.

Special note of thanks to the cook's: Rick Lavigne and Fred Stuto!

Picnic Entertainment

Al & Kathy Bain; Apria Healthcare

General Conference Support

Pat Brown, RN, CNSN; Jim Cowan; Rick Davis; Ann DeBarbieri; Mary Friel; Linda Gulden; Darlene Kelly, MD; Robin Lang; Jane Lindsay; Joan & Eli Medwar; Sheila Messina; Lynda Yeabower

Focus Group

Kimberly-Clark

Silent Auction

A huge thank you to everyone who generated donations, purchased items, etc. A special nod to Robin Lang for spearheading the effort this year and to the volunteer crew for their tireless effort in soliciting items and/or getting us organized for the event: Pam Belmonte, Ted Burton,

Less PN... More Freedom

Learn how to manage Short Bowel Syndrome through diet and therapy by visiting www.manageSBS.com. You'll find valuable information and answers to questions you may have about living with SBS.



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Ann DeBarbieri, Bobbie Groeber, Blanche & Bob Hoffman, Joyce & Bob Hydorn, Barbara Ives, Stephanie & Emily Gulbrandsen, Mary & Charlie Kunz, Robin Lang, Nancy Linsley, Stephanie & Jacqueline Pelham, Janet Platt, Marjorie Quinn, Jeannie Snyder-Domino and Ralph Valenti.

Walk-a-thon

Rick Davis, Ann DeBarbieri, Bobbie Groeber, Jeff Hoelle, Robin Lang, Phyllis Russell, Darrel & Kyle Woods, Coram Healthcare and— everyone who walked!

Faculty

Penny Allen, RD, CNSD; Susanne Appel, MD; Jane Balint, MD; John Balint, MD, FRCP, FACP; Patricia A. Brown, RN; Charlotte Buchanan; Rick Davis; Mark H. DeLegge, MD; Tom Diamantidis, PharmD; Lenora Freese, LMT; Madalyn George-Thiemann, RN, MSN; June Greaves, RD, CD-N; Janet Gregory, MB, ChB.; Lyn Howard, MB, FRCP; Palle Bekker Jeppesen, MD, PhD; Darlene

Kelly, MD, PhD; Mark G. Klang BCNSP, PhD; Lesley Diane Marino; Marcia Martin; Laura E. Matarese, MS, RD, LDN; Reid Nishikawa, PharmD, BCNSP, FCSHP; Susan Poole, RN; Gail Sansivero, MS, ANP; Douglas L. Seidner, MD; Marc Stranz, PharmD; Mary L. Walsh, BS, CRNI; Donald Young

Exhibitors

Baxter; Boston Scientific Oncology; Ceralyte; Coram Healthcare; Critical Care Systems; Crohn's & Colitis Foundation; Hospira; Mayne Pharma; Nestle Nutrition; New England Life Care; Novartis Medical Nutrition; Nutrishare, Inc.; Option Care; Pediatric Services of

America, Inc.; Ross Products Division; Serono; Sigma-Tau; Tyco Healthcare Kendall; United Ostomy Association; Zevex, Inc.



Blanche & Bob Hoffman, Kay Oldenburg and Robin Lang— long time Oley members and dedicated volunteers — at the finish line of the first annual Walk-a-thon.

Conference Photos



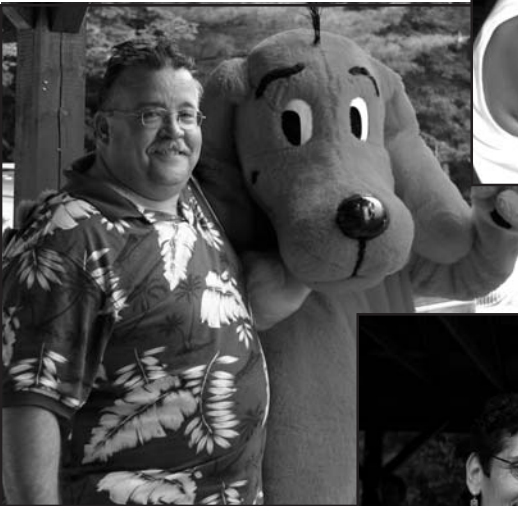
Award winner Bette Bond and Michael Medwar celebrating



Kyle Noble finds a furry friend



Kayla Woods, Jacqueline Pelham and Amanda Yelner bond at Jammin' Jammies



Thanks for all your help at registration and the auction Jeff!



Kelsey Noble, Robin Lang and Colyn Woods at the walk-a-thon



Madalyn George-Thiemann, RN, and Lyn Howard, MD sharing information



Diane Cumberledge acknowledging the cheers as she completes the walk-a-thon.

Thanks for the great music Al & Kathy!

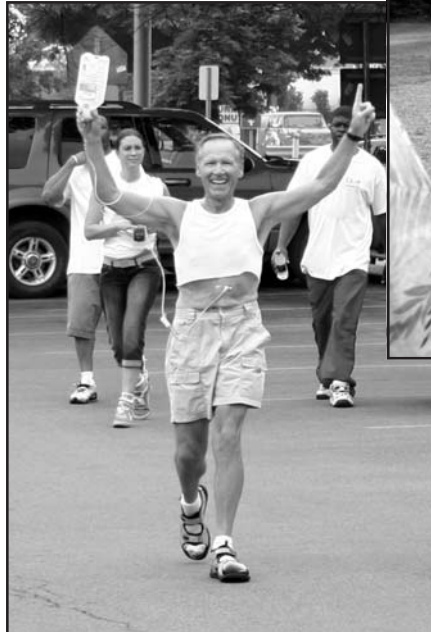
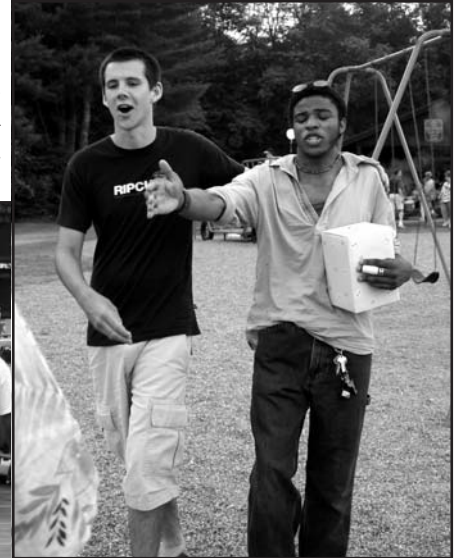


Conference Photos



Don Young, 30-year TPN consumer, shares his warmth and charm with all attendees.

Kyle Woods & Roy George goofing off at the picnic



Rick Davis finishing the Oley walk-a-thon which raised more than \$16,000 for Oley programs.



Nina Marino enjoys the kids activities.

Mary Kunz carrying hydration for a fellow walker.



Ann Weaver & Patty Woods, Regional Coordinators in Chicago and Southern California.



Thanks for grilling for us, Rick and Fred (not shown)!

Joan Bishop with award nominee Adam LaVoie and his mom, Melanie



Equipment Exchange

To make it less frustrating for those donating and receiving items through the equipment exchange we've decided to refine the equipment exchange process.

Donors should contact Liz Tucker, preferably by email evtucker@charter.net, or call toll-free, (866) 454-7351 between 9 a.m. and 5 p.m. CST. Liz needs your contact information as well as a list of the products you are donating; please include all the details requested on the form on right.

Donated items will be listed in the LifelineLetter and on the Oley website for three months (without the donor's name, etc.). We ask donors to hold onto the items for the entire three months, OR until they are requested through the equipment exchange. Donated items will be taken off the list at this time.

The equipment exchange program cannot accept prescription drugs, and no longer accepts smaller, lower cost items that typically go unexchanged such as end caps, sterile fields, gauze, etc. Feel free to contact Liz if the item you would like to donate isn't on the list of accepted products in the form but you feel it is a good item to exchange.

We ask donors to use the common sense approach before listing items: do you have a reasonable quantity to make it worth the expense and effort of listing and mailing the items?

Individuals interested in receiving items listed through the equipment exchange should contact Liz for the donor's name and contact information. It is your responsibility to arrange and pay for shipment of the donated items. Please notify Liz if you do not end up taking the items she has referred you to so she can make them available to other members. Unwanted items may be accepted by your local Humane Society or veterinarian.

Supplies Offered Free of Charge This Issue:

Enteral Formula:

- *7 cases Neutren with fiber
- *3 cases Jevity Plus – exp. 11/05, 2/06
- *5.5 cases Jevity 1.0
- *6 cases Protain XL
- *5 cases Choice DM – exp. 2006
- *12 cases Osmolite
- *3 cases Optimal – exp. 4/06
- *11.5 cases Probalance
- *4 cases Peptinex
- *7 cases Peptamen Jr.
- *1 case 2 Cal HN – exp. 2/06
- *5.5 cases Promote with fiber – exp. 2/06
- *3 cases Isosource 1.5 – exp. 3/06
- *2 cases Subdue Plus
- *47 cans Peptamen Jr. – vanilla – exp. 10/07
- *6 cans Similac Alumentun Advance with iron

Tubes/Bags:

- 23 1200ml Enteralite enteral feeding bags, No. EL1200
- 33 Kangaroo Gravity sets
- 85 Ross Easy Feed enteral bags, No. 56
- 8 Ross Top-Fill enteral bags, No. 71
- 8 Ross Ambulatory enteral bags, No. 507

Equipment Exchange Donations

Donor Name _____
 Phone number (_____) _____ — _____
 City _____ State _____
 Email _____ @ _____
 Will donate shipping costs as well (optional)? ___ yes ___ no

Products Accepted for Donation

Enteral Formula

Mfg. Name _____ # Cases/Cans _____
 Formula type _____ Exp. Date _____

Enteral tubes

Mfg. Name _____ # Tubes _____
 Size & type of tube _____ Re-order # _____

Enteral bags

Mfg. Name _____ # Bags _____
 Size _____ Re-order # _____

Enteral or TPN pump

Mfg. Name _____ Model # _____
 Portable? ___ yes ___ no Battery? ___ yes ___ no
 Recharger? ___ yes ___ no Backpack? ___ yes ___ no

TPN Administration sets

Mfg. Name _____ # Sets _____
 Fits Pump Model _____ Re-order # _____

Syringes

Mfg. Name _____ # Syringes _____
 Size _____ Type/tip _____

Ostomy supplies

Mfg. Name _____ # Sets _____
 Size/type of bags _____ Re-order # _____

MORE SUPPLIES are available! This is a partial listing of the products that are currently available through this program and outlines supplies that have become available in the last month. If you have a need for any items listed above or would like to view the complete listing of the tubes, formula, feeding bags, etc.; visit our website at www.oley.org or contact Liz Tucker at evtucker@charter.net or toll free at (866) 454-7351. You should also know that items become available on a daily basis, so check periodically.

Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods, especially heavy items such as enteral formula or infusion pumps, offer to pay the shipping costs.

Lifeline Mailbox

Dear Readers:

We have an 11-year-old son, Patrick, who has had a G/J tube for several years. This past August it was confirmed that he has no motility in his stomach and a nonfunctioning esophagus which has been requiring frequent dilations. We are facing a surgical procedure to disconnect his esophagus and reroute his GI tract. We would like to connect with a parent who has experienced this procedure with their child. We have traveled a long and complicated journey...with more twists, turns and uncertainties to face, and are looking for support, feedback and a connection for our family and our son. It is heartbreaking to see this little guy choking up anything he dares to taste. We are so very thankful that we have had the ability to nourish him through his J-tube. We wonder what the future will hold for him? We pray that he will have the physical and emotional strength to get through the next set of surgical challenges. Many interventions have been tried to correct his esophagus and none to date have been successful.

We have been told that he will forever remain dependent on his tube feedings — a reality we are working hard to help him cope with in a positive way. If anyone has any insight or advice, please send an e-mail to: ccarman@usadatanet.net. Thanks :-)

— Coleen
Syracuse, NY

Nutrition Week Rescheduled: Oley Regional Meeting Planned

Following the devastation in New Orleans, the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) was forced to move the Nutrition Week program to the Hyatt Regency Dallas in Texas, and to change the dates of the meeting to February 12-15, 2006.

Plans have begun for a full-day Oley Consumer Educational Program in conjunction with this professional gathering to be held on Saturday, February 11. Capitalizing on the nutrition support expertise that will be gathered in Dallas, the Oley program will include presentations from some of the top researchers and clinicians in the country. You're invited to come and learn from pioneers in the field, network with other consumers and perhaps find solutions to issues you've been struggling with.

Oley needs volunteers to staff the exhibit booth during Nutrition Week. This is an excellent opportunity to showcase the value of Oley programs/services to the professionals and visit other vendors to learn more about new products, services, etc. For additional information about Nutrition Week visit www.nutritionweek.org; the Oley Regional conference visit www.oley.org or call (800) 776-6539.

GI Motility Symposium for Patients and Clinicians

The American Motility Society is holding a symposium for patient support groups and health professionals "Getting Help for Patients and Their Families" at 12:30 to 2:30 p.m., February 12, 2006 at the Sheraton San Diego Hotel & Marina in San Diego, CA. Attendees will gather in small groups to encourage the sharing of information, and a box lunch will be served. The symposium follows a course on GI Motility in Clinical Practice held by the same organization February 10-12. For more information call Maria Sutton at (913) 588-4499 or email msutton@kumc.edu.

CVC User Warning

The Federal Drug Administration posted an alert this summer regarding the potential for serious injury when a vascular access device (such as a CVC or PICC line) that has limited pressure and flow rate is used by clinicians for "power injection" of "contrast media" (fluids) for a CT scan or MRI screening. Catheters have ruptured, and in some cases resulted in device fragmentation with embolization or migration that required surgical intervention. To help prevent a catheter rupture, clinicians should check the labeling on your CVC to verify whether its maximum pressure and flow rate can accommodate a power injection.

Serious adverse events like these can be reported to your hospital administration or to FDA's MedWatch voluntary reporting program (800-FDA-1088 or <http://www.fda.gov/medwatch/report.htm>).

Paid Advertisement

ACHC Recognizes Nutrishare, Inc.

It is with pleasure that ACHC announces its first Platinum sponsor, Nutrishare, Inc. of Elk Grove, CA. In the newly updated Sponsorship program, Platinum signifies the highest level of corporate giving of \$100,000 or above. This was achieved by Nutrishare over several years through sponsorship of conference exhibiting, standards development projects, clerical and operations support and two surveyor training events.

In addition to funding, the company provided in-kind expertise with advice on pharmacy standards development and marketing and sales.

Nutrishare is owned by Rod Okamoto and Tom Diamantidis, familiar faces in the pharmacy infusion world. Rod and Tom established the company in 1991, which serves TPN patients nationally, out of offices on the west and east coast. Their company is known for research and development of best clinical practices and for TPN and patient education. Nutrishare pharmacists provide clinical education at NHIA and ASHP.

TubeTalk, from pg. 3

contracting bacterial infections in this environment is minuscule. (Before diving in, use your common sense; some beaches are obviously polluted and should be avoided.)

Swimming at a pool is the next safest. The chemicals put in the water to control bacteria levels make the water pretty safe. It is your job to ask for the bacteria count before swimming. As long as it is within the normal range, you can go for a dip without worrying about dressing the site.

The least safe environment is a lake or a pond because the water is potentially stagnant. On lakes and ponds you have a plethora of bird life: geese, swans, ducks. The fecal material from the birds, floating atop the water, makes swimming without a Tegaderm, a dangerous proposition. Use caution here.

The strongest argument for tube feeders in favor of swimming without the dressing, is the fact that the GI tract is not a sterile environment. Consider the amount of contamination we take into the GI tract when food is eaten. The body has its own way of dealing with GI contaminants. The acids in the GI tract will kill most anything that enters the tract, whether it enters by mouth or through the tube/site. (Note: This is in sharp contrast to TPN patients who need to keep their site sterile. Contact the Oley office toll-free at 800-776-OLEY for information about swimming with a vascular access device.)

Whether you swim with an enteral tube, and whether you do this with or without a dressing, is a personal decision that should be made in conjunction with your medical providers. The bliss I experienced in my first swim, after all those years of deprivation, defies vocabulary. I will let the picture speak for the experience. Friends were on the beach to chronicle and celebrate the launching of the proud leviathan. I wish all of you the same blissful experience.

— Diane Owens, HEN Consumer
Marion, MA



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From the Desk of Executive Director, Joan Bishop

As we conclude another fiscal year (September 30) in the black and in a position to replenish the Oley reserves, I want to take this opportunity to express gratitude to the Oley membership for their continued support. Nothing pleases me more than knowing that we are moving forward financially and a future on solid fiscal ground seems more apparent with each passing year. What once looked like an 80:20 ratio of corporate donor to individual support now resembles a 50:50 ratio – a much healthier balance.



Joan Bishop

Since assuming fundraising responsibilities for the Oley Foundation I have learned more about “clever” and “inspiring” and “enticing” than one can imagine. It’s “sink or swim” in this arena, I’m told. My perspective: It feels more like “Sleepless in Seattle,” but it does help to know that Oley members stand behind their programs. Whether corporate or personal, the gifts are plenty and freely given. When drafting a budget for the upcoming year I found myself retaining all services/programs and even brainstorming ways to make Oley a better resource for our community. To say that I am in a better position than most non-profit Executive Directors is an understatement.

Contributing to my positive frame of mind today is the return of Roslyn Dahl as Director of Communications/Development and the addition of Liz Tucker to the Oley staff. You may recall that Roslyn spent 10 years with Oley as Editor of the *LifelineLetter* and rejoins us after a year of fundraising for another non-profit. Liz Tucker, Regional Coordinator and former Trustee joins Oley “officially” as Editor of the *LifelineLetter* and coordinator of the Equipment Exchange Program. Please join me in welcoming Roslyn dahlr@mail.amc.edu and Liz evtucker@charter.net, and their energy and wisdom. Brace yourself for the good things that are sure to happen this year!

Oley’s Quality of Life Research project is moving forward. As outlined in the last issue of the newsletter we look forward to your participation in developing a resource for consumers, healthcare providers, and payers. Benchmark information is invaluable in helping everyone in the homePEN community further increase the quality of life for homePEN consumers and their families.

Plans for the 2006 conference in Salt Lake City are also moving forward. We encourage you to pass along ideas and suggestions for topics, speakers and activities. Both Rick Davis, conference co-chair, and I are available to answer your questions regarding programming, pre- and post-conference activities and sponsorship opportunities (rickdavis320@comcast.net). We encourage you to get involved: send ideas forward, volunteer on site, help organize the walk-a-thon, walk, solicit items for the silent auction, take photos of events/speakers, etc. At the very least, stay tuned to the website (www.oley.org) and the *LifelineLetter* for updates.

I look forward to the upcoming year and encourage everyone who has questions, comments or a desire to get more involved, to contact me directly (800-776-OLEY or bishopj@mail.amc.edu).

Make It Positive, from pg. 2

sumer/clinician relationship “on the table”; almost like a contract so that each party knows his/her role and responsibilities. She realizes that it can take a shift in perspective. In many cultures men may find it easier to be assertive than women. In addition, male clinicians may, at first, be unaccustomed to having a female patient “in charge”.

Fostering good communication is critical to any relationship between the consumer and clinician. Work to improve your communication skills, and if the relationship is not working, do not hesitate to make a change. For this consumer it is important to be able to call her physician by his/her first name. Although using a doctor’s title is a common courtesy and sign of respect in the hospital culture, she feels that they both must be relaxed and able to speak about emotional topics with openness and not hiding behind a title or position.

Developmental Differences

Developmental aspects of growing up with a chronic condition were discussed in both workshops. Some concerns that parents expressed need to be understood in terms of stages of development, for example:

Disclosure of information can be especially challenging for teenagers. Teenagers who require HPEN face additional challenges. Denial and difficulty accepting the need for the therapy were two challenges that were mentioned. Often the teenager is very self-conscious and embarrassed to let others know about his/her need for HPEN and does not disclose this information. This can be a problem if other family members divulge this information when it might seem to the teenager that the person really didn’t need to know. Other teenagers may hide all of their supplies, not want to dress in front of other kids or skip a day of therapy to keep from seeming different from their peers. The need to be like everyone else also should be understood as developmentally appropriate in early adolescence but usually diminishes in later adolescence; so even though a teenager will be secretive that may change with age. Two mothers also commented that teenagers may increase the rate on the enteral infusion pump to decrease the infusion time.

The group members commented that, although teenagers are terrified of being different, most kids are really more accepting than you would think. Most people will treat you the same or don’t find you “different.” If a friend doesn’t accept it, they may just be a shallow person. This is really a way to separate superficial friendships from individuals who are interested in a deeper friendship. Let the superficial friendship go, they are really doing you a favor by leaving. The family should be aware that the teenager will want to be in control of who is told, when they are told and how much information is shared. They may be afraid that if you told someone about his/her HPEN before, that you are going to tell others as well. Several people commented that although disclosing this information to kids in high school can be difficult, friends in college are at a different level and much more accepting.

Dining in a restaurant

For HPENers of any age, going to a restaurant can be challenging – just because of the interaction with the waitress. The waitress may try to encourage you to eat or drink at every course. [While it wasn’t mentioned in the group, Oley has small cards available which can

Make It Positive cont., pg. 14

**Home TPN to go.**

John Zink, on Home TPN since 1977, designed a back pack that allows him to keep going and doing the things he wants to do. On infusion 15 hours each day, he works in his vegetable garden, mows the lawn and restores old cars. He visits old friends back at the saw mill and attends Zink Zoo reunions. And he follows his son’s basketball teams to all their games. John is getting on with life. And, Coram helps him get there.

We got him started. And we’ll be there for the long run.

Contact us toll-free:
1-866-4-HomePEN (1-866-446-6373) and
visit us on the Web at www.coramhc.com.



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

Welcome, from pg. 1

member of the board allows him other ways to give back to the people and organization that assisted and inspired him when he needed it. We feel inspired by Rick's enthusiasm and ability to reach his goals, and look forward to having these strengths on our board.

Kishore Iyer, MD, trained in England for ten years doing adult, general and pediatric surgery, the latter with Dr. Adrian Bianchi. He also has trained in liver and intestinal transplantation in Chicago, IL, and Omaha, NE; and has recently joined the faculty at Children's Memorial Hospital and Northwestern University in Chicago, IL. His interests are varied and include the surgical management of short bowel syndrome, with an emphasis on non-transplant surgical options; as well as intestinal transplantation. While he has written for the *LifelineLetter*, his first personal introduction to Oley's consumers came at a conference where he and his good friend, Dr. Jon Vanderhof, spoke at a morning session. Not only did they give everyone a great deal of information, they did it in such a way there were people rolling in the aisles. We appreciate having Dr. Iyer's interest and expertise on the board.



Kishore Iyer, MD

Jim Lacy, RN, has more than 25 years experience in nursing, education, training and program development. He is currently employed as Clinical Leader – Western Area for Boston Scientific Corporation, Inc., Oncology Division. His primary professional role is to develop and provide clinical programs for health care professionals on vascular access devices, supporting best practices in infusion therapy. Special interests include community-based education, vascular



Jim Lacy, RN

access, infusion therapy and infection control. He has served as a volunteer and board member for community-based and national organizations, including the Association for Vascular Access. Jim lives near Salt Lake City, Utah and is an avid scuba diver. With his appointment to the Oley Foundation he hopes to contribute his experience and act as a liaison and advocate to health care professionals and organizations. Welcome aboard, Jim!

Doug Seidner, MD, FACP, CNSP is a member of the Department of Gastroenterology and Hepatology at the Cleveland Clinic Foundation. He serves as chairman of the Nutrition Services Committee, program director of the Clinical Nutrition Fellowship and director of the Nutrition Support and Vascular Access Team. He completed a fellowship in Nutrition and Metabolism, and in Gastroenterology. He is also certified by the American Board of

Internal Medicine in both Gastroenterology and Internal Medicine. He is an expert in nutritional therapies, including diet, enteral and parenteral nutrition. He is a long time supporter of the Oley Foundation. He has written a number of articles for the *LifelineLetter*; as well as being a speaker at several Oley Conferences. He accepted a position on the Oley Board because he believes he has much to learn from the consumers involved with Oley. We are glad to have Dr. Seidner's continued support and to welcome him officially on the board of trustees.



Doug Seidner, MD

Make It Positive, from pg. 13

be handed to the server. It lets them know that there is a medical reason why you are not eating. Call (800) 776-OLEY to request a free dining out card.]

Transitioning Teens to Independence

One family mentioned that it has been difficult to handle the transition of allowing their teenager to be independent with his nutrition care – not knowing when to “be in his face” or when to “back off.” While parents and healthy teenagers may have conflicts about curfews, medical “chores” will probably become the focus when there is a chronic illness. Respecting the teenagers' need to establish autonomy while maintaining adequate medical compliance is a very tricky process.

One young woman discussed how difficult it was for her when her mother tried to make sure she remained in the hospital to receive the care she needed; yet the young girl wanted desperately to go home. At other times she knew her parents were pushing her to be independent and do her self-care – but sometimes when a parent pushes, the child becomes resistant. She also mentioned that conflicts would arise when her TPN nurse told her to do things one way and her family told her to do it another way. It would have been more developmentally appropriate for the TPN nurse to work with the family as a team. As she looks back, she appreciates the things her family did to care for her.

Peer pressure was also a difficult issue for her. She was hospitalized so frequently during high school that some of her friends were afraid that she was contagious. Luckily, she had a boyfriend who helped to change her perspective and appreciate TPN.

One family mentioned that when they couldn't deal with the stress of their child's illness any longer, they started using destructive behavior, tobacco and alcohol. After a period of time they realized that wasn't helping them either so they went back to their faith. This allowed them to stop the destructive behavior and work on positive stress relievers. Avoidance, dissociation and denial are other destructive ways of dealing with stress. Positive stress relievers are faith, using relaxation techniques, meditation, exercise, a sense of humor, support groups, involvement with others, and volunteering, to name a few.

Many thanks to Suzanne Appel for facilitating these groups and Cheryl Thompson for taking such excellent notes on which we based this article.

Thank You! Thank You!!

The following list represents everyone who generously contributed towards Oley efforts between August 10 and September 29, 2005. We also want to thank all those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

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memory of Walter Yaffa

Thomas Lachanski

Kimberly Morgan

Monte Stokes

Bruce and Dawnette Sweet

Conference, from pg. 1

Denmark, Palle B. Jeppessen, MD, PhD, who spoke about his program's experience with GLP-2, a growth hormone. We also heard from Laura Matarese, MS, RD, LDN, FADA, CNSD, about the effects of treating intestinal failure with diet, and Lyn Howard, MB, FRCP about trace elements. During the lunch break many exhibitors raffled off some great items. Once again, adults shared and learned through small group discussion in the afternoon breakout sessions or attended a special enteral nutrition workshop, while the kids went to the Great Escape. That evening the kids enjoyed games and crafts at Jammin' Jammies.

Friday was the picnic. Hamburgers, hot dogs and chicken were expertly cooked on the grill with many of the Albany area consumers and clinicians contributing salads, cakes and cookies, to name just a few. Music was provided by Al & Kathy Bain. There were many games for the kids, and who will ever forget seeing Palle Jeppessen blindfolded and made up as a horse for the flat track races? What a good sport everyone was who participated in this event.

Leaving is always hard; so many wonderful people, fantastic information and a great chance to connect with clinicians and vendors, it is hard to say good-bye. We look forward to seeing you in Salt Lake City, Utah, June 28 to July 1, 2006!

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...thanks for your support!



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 call Joan Bishop or Roslyn Dahl at 800-776-OLEY.

John Balint, MD

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Toll Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the US 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 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 on our web page @ www.oley.org. Comments? Call (800) 776-OLEY.

NOV. '05	Diane Cumberledge St. Albans, WV (888) 610-3008 EST	Diane has vast experience as an HPN consumer. She can address the search for employment and related issues, and has experience maintaining her nutritional status for a period of time without HPEN. Diane is currently working part-time so the best time to call her is early evening.
	Rick Davis Salt Lake City, UT (888) 650-3290 MST	Rick knows about HEN. He is 62, cannot swallow, has been 100% dependent on HEN for 5 years and is very active. (In fact you'll probably reach him at the slopes when you call.) He and his wife travel frequently, enjoy being retired and want to hear from you.
DEC. '05	Mary Friel Framingham, MA (888) 610-3008 EST	Mary has been on TPN for 12 years due to SBS and Crohn's (34 years). Mary is active in community groups, travels with TPN and keeps busy with family and friends. Please call evenings 7-10 pm EST as she works during the day.
	Sue Koprucki East Amherst, NY (888) 650-3290 EST	Sue is mom to Emily, 10.5 years old, who has been on bolus g-feeds for 10+ years. She has been on and off TPN twice, and is currently on IV hydration via a PICC line. Emily has pseudo obstruction, SBS and an ileostomy. Sue has had some wonderful experiences working with teachers and school administrative staff to make her daughter's life easier. She looks forward to talking with you!
JAN. '06	Sheila DeKold Floyd Knob, IN (888) 610-3008 EST	Sheila is the mom to 7-year-old David and 5-1/2 year old Olivia, who was diagnosed with pseudo-obstruction at the age of 2 years. Olivia is TPN dependent and has tolerated enteral feeds in the past. Olivia has a G-tube and a separate J-tube, as well as an ileostomy, and requires catheterization overnight.
	Marilyn Sobiech Brainerd, MN (888) 650-3290 CST	Marilyn has been on TPN since March 1997 due to scleroderma with a lot of GI involvement. She stays very active with her 3 grandchildren. She is currently on disability and has a lot of experience with travel — domestic and international, as well as camping and cruises. Ask Marilyn about attending Oley conferences.

LifelineLetter

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