

What's Inside:

Tube Talk
Page 3

Volunteers Needed
Page 3

Research Trials
Page 3

Region II Picnic,
October 5
Page 4

Lifeline Mailbox
Page 5

Medicare Denial
Stories Wanted
Page 5

2003 Oley Awards
Pages 6 & 7

Sharing Information
Page 8

Win the Fabulous Oley
Quilt
Page 8

Equipment Exchange
Page 8

Thanks for a Great
Conference!
Page 9

Contributor News
Pages 10 & 11

Toll-free Networking
Page 12

LifelineLetter

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

2003 Conference Better Than Par!

A great time was had by all at the 18th Annual Oley Consumer/Clinician Conference, "Keep on Par," June 18-21, 2003, at the World Golf Village Renaissance Resort, in St. Augustine, Florida. Turnout was terrific, and we couldn't have asked for a more gorgeous setting, gracious hotel staff, knowledgeable faculty and generous group of volunteers.

Participants learned the latest news about improving absorption, preventing catheter infections and a host of other topics from experienced nutrition support clinicians from around the country. They also shared parenting tips, coping strategies and advice on living more fully.

As if this weren't enough, the conference was packed with fun social events. A huge thanks to our sponsors and volunteers for making these events possible which offer a special time for consumers and families to relax together. The adults enjoyed golf, the silent auction, the welcome reception and the delicious meals; and the kids had a great time bowling, touring Ripley's museum, viewing IMAX movies and playing games at Jammin' Jammies.

We'd like to thank everyone who came. It was a pleasure to meet the numerous first-time attendees — especially some consumers we've been corresponding with for years! — and of course, to greet our old friends. We had a wonderful time and hope you will join us next summer. ☺



June Borden on the green.



Malisa Matheny (left), Colyn Woods, Kyle Noble and Becky Streetman

Managing Complications in HPN Consumers

Lyn Howard, MB, FRCP, FACP, Albany Medical Center

The following overview of HPN complications is excerpted from *Gastroenterology*, Volume 124, "Management of Complications..." by Howard, et. al., pages 1651-1661, © 2003 with permission from the American Gastroenterological Association. Below we will cover the infectious and mechanical complications; next issue we will conclude with metabolic complications. The original article contains additional background information as well as sections on psycho-social issues and referral to an intestinal failure center, and is available from www2.gastrojournal.org.

While HPN is a life-sustaining therapy for patients with severe digestive disorders, it brings with it a host of potential complications. Because home parenteral nutrition (HPN) patients are living at home, management of acute complications is initiated by the patient and their caregiver. This underscores the need for good initial training. To enhance this training, a patient-oriented HPN complication chart is available free to all HPN consumers and their clinicians from the Oley Foundation (www.oley.org or 800/776-OLEY). The frequency of the different HPN complications is shown in Table 1 on right.

Infectious Complications

HPN patients can have fever from many causes, but if no symptoms and signs point to other causes, the chief concern becomes *catheter related sepsis*. As shown in Table 1, adults have an episode of catheter sepsis on average once every 2 to 3 years. In children the frequency is 50% higher. Catheter sepsis rates are decreased in very long term HPN survivors.

HPN Complications cont., pg. 2 ➔

Table 1: Frequency of HPN Complications

Complication	Episodes/catheter yr
Catheter sepsis	0.34
Catheter occlusion	0.071
Central vein thrombosis	0.027
Liver/biliary problems	
Severe	0.024
Mild	0.42
Metabolic bone disease	0.05
Fluid/electrolyte problems	0.12-0.61

Modified from DM Richards et al

HPN Complications, from pg. 1

Although septic events are rarely fatal, they are the most common type of catheter related infection (>80%) and the most frequent reason for hospital readmission so prevention is an important issue.

Factors which reduce catheter sepsis include the HPN training by an experienced nurse. This is best provided in a dedicated teaching

center away from the distractions of the busy ward. Catheter disinfection with 2% chlorhexidine in alcohol is superior to 10% povidone iodine. Recurrent infection with staphylococcal organisms justifies the use of an antibiotic prevention lock (2 ml of 25 ug/ml vancomycin mixed with 2 ml of sodium heparin 10 units/ml). Most patients cover the catheter exit site with a permeable transparent dressing which helps to stabilize the line. It is not known if the dressing is truly essential for patients with a tunneled line and subcutaneous dacron cuff, once the exit site is healed. A formal randomized study would need several hundred HPN patients since HPN sepsis is a relatively infrequent event. This would require a large multicenter study. Most catheter infections occur through contamination of the catheter hub, seeding the proteinaceous biofilm that accumulates on the internal surface of the

catheter. Interval use of fibrinolytic agents to remove this biofilm has been shown to reduce catheter sepsis and thrombosis (blood clot). Current studies are evaluating 2% taurolidine as an antimicrobial lock and an endoluminal brush for diagnosing catheter infection and clearing the biofilm.

Catheter sepsis classically presents with symptoms of fever, chills and lethargy which flare when the cycled infusion restarts. All HPN patients with suspected line sepsis need urgent clinical evaluation, a blood count and blood cultures from the line and a peripheral vein. If the patient appears sick and has leukocytosis and bandemia, hospital admission is appropriate. In 10-20% of septic patients, the white count is depressed. Sick patients and children are started immediately on antibiotics which are adjusted once the culture and

HPN Complications cont., pg. 4

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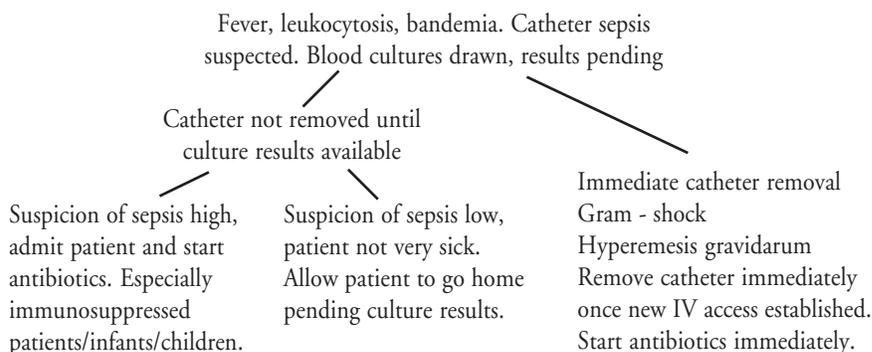
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* * * * *
 The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be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

Figure 1: Catheter Removal vs. Sterilization in Catheter-Related Sepsis



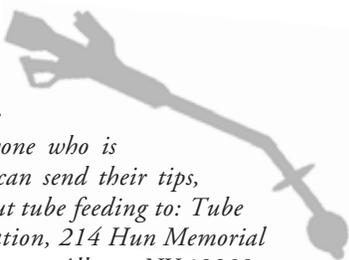
If blood culture results are positive, the decision to attempt line sterilization while the catheter is still in the patient depends on the organism.

Organism	Frequency	Attempt line sterilization +	Success rate of line sterilization
Staph.coag.neg	30-40%	Yes	>85%
Staph. coag. pos	15-20%	Rarely	50% but risks acute endocarditis
Gram neg. bact.	30-40%	Yes	50%
Fungi	6-9%	No	Risks metastatic spread Rarely cleared
Polymicrobial	12%	No	Rarely cleared

+ Attempted line sterilization involves systemic antibiotics down catheter. Catheter antibiotic treatment lock for several hours/day (1mg/ml of vancomycin). Removal of biofilm from internal surface of catheter with a fibrinolytic agent (alteplase 1-2 mg). Parenteral nutrition resumed once blood cultures negative x 48 hrs. Cultures repeated 1 week off antibiotics.

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.



Lopez Valve Helpful

I wanted to tell others who feed by tube or like me, care for someone who does, about the Lopez Valve. At the end of my husband's tube we have a Lopez Valve: a dial with the little arrows that allows us to easily open and close access to his tube.

It is so convenient and leaves less mess to clean up — especially when administering medications. In the morning I flush his tube with 50cc water, switch the valve off while I fill the syringe with the first medicine, insert the syringe, turn the switch back on. When that is done, I turn it off again and do another 50cc water, the next meds, and finish with more water, before reconnecting him to the feeding tube.

— Herta Tompkins
ht838@earthlink.net

Volunteers Needed

If you are interested in volunteering at any of these events, please call the Oley office at (800) 776-OLEY.

NAVAN Conference

September 13 - 16, 2003 • Atlanta, GA

Conference for venous access nurses. Great source of information on the latest in IV access, infection, treatments etc. We need volunteers to help at the Oley booth.

American Motility Society Symposium

January 30 - February 1, 2004 • Nashville, TN

Conference for motility clinicians, with special symposium for patients February 1 from 2:30-4:30 p.m. Volunteers needed to help at the Oley booth. For more information on registering for the patient's symposium call Kim Sanders directly at (913) 588-4480, or call toll-free (877) 404-5823 and ask to be transferred to Kim.

Nutrition Week

February 8 - 11, 2004 • Las Vegas, NV

Conference for parenteral and enteral nutrition (PEN) clinicians. Great source of information on all aspects of PEN. We need consumers and caregivers to speak at an educational session for clinicians "HomePEN from the Patient's Perspective" and to help at the Oley booth. ©

Ongoing Research Trials

• Short Gut TPN Patients Wanted

An NIH-funded study is being conducted by Dr. Thomas Ziegler at Emory University in Atlanta, GA, on the effects of modifications in oral diet, with and without treatment with synthetically-derived human growth hormone, on intestinal nutrient absorption and clinical outcomes in patients with short bowel syndrome who need two or more days of TPN or intravenous hydration per week. The study involves a total of six visits to Atlanta for inpatient or outpatient admissions to Emory University Hospital. There is no cost for participating in the study and all transportation costs to and from Atlanta are covered by Dr. Ziegler's grant. For more details, contact Dr. Ziegler at 404-727-7351 or tzieg01@emory.edu. Time is running out for the study, so call by September 30, 2003 if you are interested.

All of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee, however, *The Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.*

More information on these studies is available by calling (800) 776-OLEY or visiting our web page at <http://www.oley.org/news/researchbox.html>

If you are interested in having your study listed, complete the form listed on our web page at : <http://www.oley.org/news/researchbox/form.html> OR fax the same information to (518) 262-5528. ©

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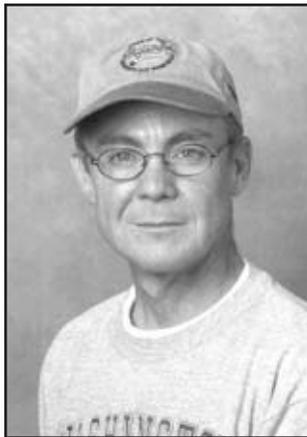
HPN Complications, from pg. 2

sensitivity results are available. Catheters are not routinely removed because in long term HPN patients using up IV access sites becomes a serious issue. Figure 1 (on page 2) suggests a series of steps for the management of catheter sepsis. Sterilization of a catheter without removing it from the patient is usually attempted with staphylococcus coagulase negative and gram negative bacilli, but not with other organisms or polymicrobial infections because the risk of complications is too high. On rare occasions catheter sepsis has presented as endocarditis, an infected right atrial thrombus, renal failure, and osteomyelitis.

Much less common (15%) is a **catheter exit site infection**. This presents with redness and exudate, and cultures are usually positive for staphylococcal organisms. It can be cleared 60% of the time with topical antibiotics but catheter removal may be required if the infection keeps returning, especially if it is due to irritation from a partially extruded dacron cuff. Even rarer (2%) is a **catheter tunnel infection**. This presents with fever, redness and swelling along the subcutaneous course of the catheter. This invariably requires catheter removal.

Oley Road Race in Castleton, NY, October 5th

Save the dates! A 5k road race/walk benefitting the Oley Foundation will be held 10 a.m. October 5th at Goold's Orchard in Castleton, NY. Come cheer us on and enjoy the hayrides and other festivities that will follow. A mailing will be sent to those in the immediate area, but EVERYONE is invited. Bring your friends and family. Many thanks to the Miller family for helping to sponsor and organize this event. For details call (800) 776-OLEY or email harrinc@mail.amc.edu. ☺



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**- Matthew Van Brunt
39 years old**

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Mechanical Complications

Catheter occlusion occurs at a rate of 0.071 episodes per year (Table 1, page 1). It often starts as a fibrin sheath that grows around the intravascular portion of the catheter, sometimes acting as a one-way valve preventing withdrawal of blood but permitting infusion of the nutrient solution. Eventually the sheath or a blood clot causes complete catheter occlusion. Occasionally infused fluid, unable to reach the vein lumen, flows back between the sheath and the catheter to the exit site. This situation can only be differentiated from a subcutaneous catheter break by a radioopaque dye study. Catheters partly or completely occluded with fibrin can usually be reopened by a fibrinolytic agent (1-2 mg of alteplase, in 3-5 ml of diluent instilled for a dwell time of 40 minutes). Less commonly, catheters are occluded by waxy deposits from infused lipid, which can be cleared by 3 ml of 70% ethanol solution, or by crystalline deposits, which can be cleared by 3 ml of 0.1N HCL.

Catheters may grow into the vein wall and this presents as chest pain. A dye study demonstrates the lack of free mobility of the catheter tip in the vein. Catheters can also migrate into smaller veins causing phlebitis (inflammation of the blood vessel) and pain.

Catheter tears are most common near the hub. Repair kits are not always available so persons traveling with HPN should take a repair kit with them. The diaphragm of a subcutaneous port is eventually fenestrated (perforated) by multiple needle sticks (>2000) especially if needle placement is over aggressive and the needle tip is burred on the posterior metal surface of the port. **Fenestration** presents as blood when the needle is withdrawn and later with subcutaneous swelling and redness when the infusion starts. This requires port replacement. A small leak is not always evident on a dye study.

Catheter induced central vein thrombosis (blockages in a major vein) **and pulmonary emboli** (small pieces of clots that have broken off and obstruct the blood supply of the lung) are detected clinically with a frequency of 0.027 episodes per catheter year. It may occur in association with catheter sepsis and secondary infection of the thrombus can be a cause of recurrent fever that is difficult to diagnose and which requires long term antibiotic treatment akin to endocarditis.

Central vein thrombosis is more likely in patients with a coagulopathy (history of clotting problems), for example the cancer and mesenteric vein thrombosis patient. Prophylactic use of low dose warfarin (1-2 mg/day, INR rarely prolonged — which implies no serious risk of bleeding) is justified in patients at risk for thrombosis and this should be increased to full therapeutic anticoagulation if central vein thrombosis or pulmonary embolism occurs. Anticoagulation has to be closely monitored in short bowel patients because of their variable absorption of warfarin. Using a parenteral multivitamin containing vitamin K makes anticoagulation therapy extremely difficult.

The addition of regular heparin to the parenteral solution is not recommended because of its effect of increasing bone resorption and because anticoagulation would lapse when the patient cycled off their infusion. In the rare patient who cannot be stabilized on warfarin, a subcutaneous injection of long acting heparin every 12 hours is justified.

We will continue with Metabolic Complications next issue. ☺

Lifeline Mailbox

Boat Race Symbolizes Spirit of Oley

Dear Readers,

The cover story of the May/June 2003 *LifelineLetter*, "My Adventures Raising Luke" had me in tears. How wonderful that you can bring encouragement to people who need it through the newsletter, conference and other programs.

I wanted to share with you some thoughts about "The Amazing Boat Race" at the Oley conference in Florida. Teams had to fashion boats out of supplies provided: cardboard, PVC pipe, a small inner tube, rope, tape, a razor, a flag, and markers. Then each team had to float the boat across the swimming pool with the captain in it. Competition was fierce, as Oley conference attendees cheered and screamed on the edge of the pool.

After the race, Captain Robin Lang modestly credited her teammates for her speed across the pool, "I had an Evinrude on one side of me, and a Mercury on the other side of me." Robin (a consumer) got a boost across the pool in "The Panic Titanic" from Dr. Lyn Howard and home healthcare provider, Ben Maxson, who both jumped into the pool fully clothed.

The parallel to life for Oley consumers struck me. Just as Robin's team crafted the boat and helped push her to the other side, so consumers need the support of their doctor, home healthcare provider, and the cheers of family and friends to encourage them as they sail through the stormy waters of life.

Thanks again to the Oley Foundation staff for putting together a great opportunity to network, learn, and have a great time at the annual conference.

— Susan Staver
Daughter of HPN consumer



Robin Lang and the "Panic Titanic" before the race

Ben Maxson and Lyn Howard, MD, propel Robin forward

Help Wanted for Child with Esophageal Atresia

Dear Readers,

Our daughter was diagnosed with Esophageal Atresia before she was born (fall of 1997). When she reached the age of 19 months she underwent a colon interposition. We are hoping to connect with another family or physician that is familiar with this diagnosis or treatment.

Growth seemed to be normal considering her condition. I guess we're expecting more. She is 6 years old and still only 30 lbs. This June we discovered that scar tissue had formed around the area where the colon is attached to her stomach. The physician said the stricture was not as big as expected and the colon's tissue was considered in good shape except for a slight kink right above where it is attached to her stomach.

Our biggest concern is to find a way to get food down her esophagus faster (it can take 12 hours). Is there anything medication that would help her colon act more like a real esophagus to help food down her stomach? And is the kink in her esophagus (colon) causing more complications?

If anybody can help us, please send us an email.

— Arnel and Jennifer Distor
jennndistor@cox.net

Medicare Denial Stories Wanted

The National Home Infusion Association (NHIA), an association of companies that produce homePN supplies and/or services, is seeking stories of unjustified Medicare homeTPN claim denials and how the denial negatively affected the HPN consumer. NHIA plans to use the stories to advocate for a solution to the longstanding problem of unjustified Medicare home TPM claims denials. The Oley Foundation's only involvement in this process is to let you know this opportunity exists.

Specifically they are seeking stories of Medicare beneficiaries who:

- were denied access to medically necessary homeTPN
- had to assume an excessive financial burden to receive homeTPN because their claims were unjustifiably rejected
- had to be treated in a more expensive setting because it wasn't clear whether homeTPN would be covered
- refused treatment rather than risk the possibility of financial responsibility
- suffered adverse clinical outcomes because of having claims denied
- suffered other harm

When sending a story, the patient's identity should remain anonymous. Email stories to david_franklin@bshsi.com. ©

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2003 Oley Award Winners

The Annual Oley Awards Program recognizes homePEN consumers and family members who exhibit courage and perseverance in

LifelineLetter Annual Award Winners

Carolyn Wheatley • Christchurch, Dorset, Great Britain

On homePN for more than 20 years due to Viscera Myopathy, a motility disorder, Carolyn is a founding member and current chairman of PINNT — Patients on Intravenous and Naso-gastric Nutrition Therapy — an organization similar to Oley located in Great Britain. She shares her time freely with fellow consumers and caregivers, talking about their problems or how to improve their quality of life. She organizes gatherings for PINNT members, has set up a network of regional groups, and visits consumers when they are hospitalized.



Carolyn Wheatley beaming at the awards ceremony

Carolyn is also a member of the British Association for Parenteral and Enteral Nutrition (BAPEN) council where she informs clinicians about the homePEN patients' point of view and advocates for advances to improve patients' quality of life. Through BAPEN Carolyn has helped train hospital nutrition support teams on how to help new homePEN patients adjust to their therapies.

She has written a booklet for PINNT members about traveling with homePEN, authored a chapter on living with homePEN in the reference text "Intestinal Failure" and has spoken at many BAPEN and European Association for Parenteral and Enteral Nutrition (ESPEN) conferences.

Nominees:

June Boddin, Mica Coffin, Jim Cowan, Anna Cyr, Leah Funke, Mitzi Goldsmith, Suzanne Keating, Dana Lovvorn, Sheila Messina, Donna Noble, Tracy Phalen, Diane Pina, Christopher Tournier, Woods Family

Nader El Samaloty • Cocoa Beach, Florida

A kind man with a huge smile, Nader has an amazing ability to maintain an everlasting positive attitude and to inspire others with his caring and wisdom — despite his serious condition. Nader has been on TPN for 11 years after emergency surgery left him with short bowel syndrome.

Rather than wallow in pity, Nader has seized the illness as an opportunity to change people's perspectives and show them the things in life that are truly important: appreciation for each day and everything we have, and loving and caring for others. He shares his joy through conversation, cooking and dance.

We believe this connection with others is his source of energy and compassion. Nader will go to great lengths to assist his Oley companions, and help them cope with their condition. He shares advice and support with many homePENers, and has been known to drive hours just to attend an Oley support group meeting or cheer up a friend. His strength of character and caring attitude are an inspiration to many in our community.



Nader El Samaloty celebrates life and friendship

For their outstanding efforts to support homePEN consumers, we are honored to present this award to Nader and Carolyn.



Regional Coordinator Barb Witt at the 2001 Conference

Mead Johnson Enteral Award

Sponsored by Mead Johnson Nutritionals

Barbara Witt • Port St. Lucie, Florida

Barb has been a Regional Coordinator for the Oley Foundation for many years, providing information and support to people on tube feeding, and those who eat very little or nothing at all. Originally on TPN, Barb has been on HEN since 1993 due to a gut motility disorder.

Barb works hard to bring attention and support to fellow homePEN consumers in many capacities; she has covered the toll-free line, helped plan many conferences, represented Oley at various functions and written for the newsletter. In fact, she was the driving force behind "Tube Talk" — the *LifelineLetter* column for enteral consumers.

What we admire most about Barb is her ability to talk to just about anyone, and share her experiences and empathy freely. She has comforted hundreds of Oley members and is always willing to listen to more. When a consumer is in need, Barb is there to help. As a testimony to her sincerity and dedication, she has made many close friends through her work with Oley.

For her unending support of fellow home enteral consumers, we are proud to recognize Barb with the Mead Johnson Enteral Award.

Nominees:

Bonnie Fischer, Cheryl Furtrell, William Letchworth

overcoming the adversity of illness and are generous in the effort of helping others. Congratulations to all winners and nominees!

Oley Foundation Young Adults of the Year

Sponsored by Pediatric Services of America

Mallory Cyr • Sabattus, ME

Mallory has been on TPN since birth due to microvillus inclusion disease. Growing up with chronic illness, she learned a special way to look at the world, and has taken each challenge and turned it into a positive step that has helped forge her special brand of young adult. She has shared her positive outlook on life with her classmates, friends, teachers and parents of kids with chronic illness. She has also been a positive role model for her younger sister, Maisy, who has the same diagnosis and dependency on homePEN.



Mallory Cyr shares her sunny disposition

Mal has been involved in patient education and awareness for years. Her most recent venture is with “YEA ME” — Youth Educators and Advocators of Maine — a group of young people with chronic illnesses whose mission is to educate the public and professionals about the roadblocks they face as they are transitioning into adulthood. Mallory has helped organize statewide conferences, spoken at the meetings and led breakout sessions. She has also been invited to speak at a national conference on children who are medically fragile or technology dependent.

Demetra Nakos • Mays Landing, NJ

Demetra is a 16-year-old sophomore who has been dependent on HEN and HPN since she was nine years old due to short bowel syndrome. From the onset of her illness, she has shown amazing responsibility in taking care of her line and dressing changes herself. She is very involved with her medical care, maturely discussing her illness, concerns and treatment options with her physicians.

She works hard to keep her spirits up, and everyone else’s, by looking at the positive side and using her sense of humor. Instead of hanging out with her friends at the beach, she spent most of last summer in Children’s Hospital. One day a nurse popped in to ask if she needed anything. Demetra responded “Yes, how about some intestines?” making everyone laugh. She shows maturity by ignoring peer pressure and making choices that are in her best interest. Like choosing to laugh and calmly replace her G-tube, rather than get angry or embarrassed when the tube fell out amongst her peers.

Demetra has learned to appreciate life and has made the best of things. She is compassionate, caring and a joy to all who know her. For her family and friends she is an inspiration and role model.

We are proud to honor Mallory and Demetra with this award.

Nominees:

Sean Forney, Roy George, Derek Goldsmith, Owen Huss, Aaron Leppin

Lenore Heaphey Grassroots Education Award

Donna Noble • Grove City, OH

Donna is an exceptional woman, mother and Regional Coordinator. She has a tremendous energy level and willingness to share her talents. She is also a great organizer. So when she gets an idea — no matter how big — she makes it happen.

We first heard of Donna two years ago when she attended the 2001 Oley conference in Milwaukee. Within a few months she and other parents were running regular support group meetings in the Columbus, Ohio region. Later that year they hosted an Oley Regional Conference. After the 2002 national conference, she, her husband Richard, and other friends of Oley, organized one of the most successful Oley benefit dinners ever. We’re holding our breath to see what happens next!



Donna and Kyle taking a break for lunch in the exhibit hall.

Donna became involved with Oley after adopting her second child, Kyle, who is on TPN because of a mitochondrial disorder and other secondary diagnoses. She and Richard do such a good job at keeping life normal and balancing attention for Kyle and his big sister Kelsey, that aside from the ever present drain bag and tubes, you couldn’t tell they are a family living with homePEN.

Donna’s caring nature also shows as she shares her experiences and support with the many families she’s met through Oley. She is always willing to lend an ear to listen or a shoulder to cry on. In addition to all this, Donna works full time with children who have special behavioral needs, volunteers at her church and is active in various committees at Children’s Hospital in Columbus.

For all you do for Oley and others, we salute you, Donna!

Nominees:

Tammy Adams, June Bodden, Ruthann Engle

Awards cont., page 8 ←



Friendly and outgoing, Demetra (left) made many friends at the conference, including Roy George and Emily Gold-Pitegoff.

Making the Most of Shared Information

Oley's goal is help homePEN consumer live as fully as possible. To accomplish this we provide:

- accurate, current information about homePEN and related topics
- opportunities for homePEN consumers and families to share their experiences.

The annual conference is an excellent opportunity for consumers and families to benefit from both of these approaches. However, as with any information published by the Foundation, we strongly urge that medical information or advice shared at the Oley conference (formally or informally) be discussed with your managing physician prior to making any changes in your health care. ©

Winning the Fabulous Oley Quilt, Easy as 1-2-3!

The Oley quilt is complete. It is magnificent and it can be yours!

This lovely 8' x 7-1/4' work of art, currently on display in the Oley office, combines squares prepared by Oley members from across the country. The squares



and reverse side are mostly buff-colored, and the fabrics in-between are solid burgundy, and a burgundy/blue/green floral print. More photos are available, in color, on our web site: www.oley.org.

The quilt was skillfully sewn together by Mildred, Isaac and Beatrice Weaver, and their family and friends from the Menonite Family, Shippensburg PA. A huge thank you to the Weavers for coordinating the project within their community and Madalyn George for coordinating the effort within the Oley community. An enormous thank you to all who contributed a square.

To participate in this raffle, clip and complete the coupon below and send it along with the suggested donation of \$5.00 each (no purchase is necessary). For multiple tickets, send your money (any multiple of \$5) and one completed coupon; we'll do the math and copy it for you.

The lucky ticket will be drawn on October 20, so hurry!



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Make checks payable to "The Oley Foundation."

Send to: The Oley Foundation, 214 Hun Memorial A-28,
Albany Medical Center, Albany, NY 12208

Drawing October 20, 2003 • Suggested Donation \$5/ticket

Oley Awards, from pg. 7

Nan Coutts Award for the Ultimate Volunteer

Sponsored by Judy Peterson, RN, MS

Meg Cass-Garcia, RN, MSN • Tampa, Florida

Meg has been the health care medical advisor for the Tampa Bay Oley Support Group since day one: March 26, 1988. The group meets the first Saturday of every other month. Instead of doing her own thing on her day off, Meg has faithfully attended these meetings, and usually brings homemade muffins.

Meg has been a great encourager, and goes 'above-and-beyond' for the support group. She is a terrific resource: keeping the group informed of medical advancements, explaining medical terms in laymen's language, and answering individual's questions — with follow-up research when necessary.

She connects her patients with the Oley Foundation and the local support group, and has aided Oley members' medical needs while visiting the Tampa area. Because of her extensive involvement in other medical organizations, Meg has acquired exhibit space for Oley, giving local members a voice.

Meg is extremely generous with her time and also volunteers with other groups like Big Sisters. She is a remarkable person, and we are proud to present her with the Nan Coutts Award for the Ultimate Volunteer!

Nominees:

Jane Balint, MD; Bethellen Coughran; Lynn Patton, RPh; Craig Petersen, RD, CNSD ©



Volunteer Meg Cass-Garcia, RN

Equipment Exchange

The following equipment/supplies are offered free of charge:

EN Formula

- 9 cases Complete, exp. 5/04
- 12 cases Jevity, exp. 6/04
- 16 cases Pediasure, exp 2004
- 4 cases Peptamin Jr., exp. 11/03
- 1+ case Peptamin unflvd., ex. 5/04; 1 case w/ prebio, exp. 2/04
- 2 cases Promote, exp. 4/04; 1/2 case Promote w/ fiber, exp. 1/04
- 2 cases Vivonex Pediatric (dry), exp. 4/04

Equipment/Bags/Sets/Tubing/Misc.

- Zevex Enterlite Pump
- 2 cases Ross Patrol feeding bags #52046
- Kangaroo Pump sets 1000 ml #884-7736009

MORE SUPPLIES are available! For more information and a complete listing, visit our website at www.oley.org or contact Cathy Harrington at HarrinC@mail.amc.edu, (800) 776-OLEY. 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 offer to pay for shipping. ©

Thank You for Making the 2003 Conference a Success!

A huge thank you to everyone who volunteered their time and resources so generously.

20th Annual Picnic:

Food & Beverage: BD Medical
Challenge Hole, Mini Master's Tournament:
Coram Healthcare
Fudge Demonstrations: Kilwins
Boat Races: Rose & Jeff Hoelle; Barb & Lee
Klingler; Robin Lang, Patty & Darrell Woods
Sunscreen: Ocean Potion

Medical Support:

Coram Healthcare

Conference Registration Bags:

Nutrishare, Inc.

Oley Masters Golf Tournament:

Coram Healthcare. Organized by Ben Maxson and Debbie Meyer, RN; Volunteers: Carol Ireton-Jones, PhD; Melinda Parker, RD; Brigid Parado, RN; Marjorie Quinn; Lisa Roberts, RD; Jim Tanner

Conference Videotaping Services:

Abbott Laboratories/Creative Network;
Joel Resnick

Lunch Buffet:

Thursday: Nutrishare, Inc.
Friday: Critical Care Systems and Patient Support Services

Travel Scholarships for Consumers:

Ballard Medical-Kimberly Clark; Bruce Groeber Memorial Fund; Coram Healthcare; Nutritional Restart Center; and an anonymous donor

Grants for Speakers:

Cleveland Clinics; Coram Healthcare; Mediflex; Nestlé Clinical Nutrition; Nutrishare, Inc.; Mayo Clinics; Option Care

Awards:

Mead Johnson Nutritionals; Pediatric Services of America; Judy Peterson, RN, MS. Presenters: Pat Brown, RN; Denise Haynes; Melinda Parker, RD; Liz Tucker

General Conference Support:

Patricia Brown, RN; Jim Cowan; Richard Davis; Randall Falck, Barb & Bob Klenke; Robin Lang; Larry & Kathleen McInnes; Sheila Messina, RN; William & Margaret Taber

Child Care:

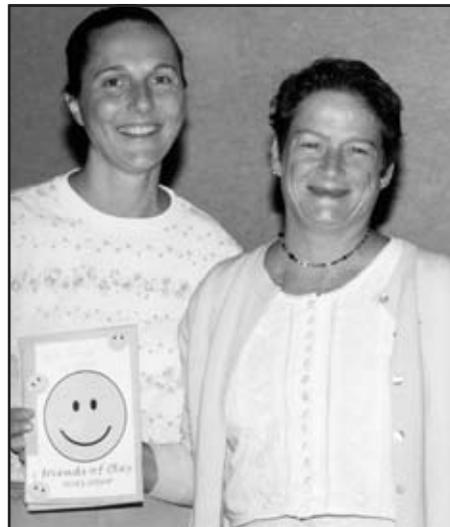
Option Care. Volunteers: Jeff Hoelle; Marjorie Quinn; Mike Stoffels; Darrell & Patty Woods

Jammin' Jammies:

Ross Products. Coordinated by Rose & Alicia Hoelle and Patty Woods. Volunteer: Julie Fisk; Dave Rhoads

Youth Activity:

Bowling Excursion: Coram Healthcare/Jacksonville Branch. Volunteers: Brigid Parado, RN; Lisa Johnson, RD; Ann Yacalavitch; Steve Blanchard, RN; Julie Tanner, RN
Trip to Ripley's: Nutrishare, Inc. Volunteers: Mary Dickerson; Shirley and Will Weitman; Lillian Vantilberg



Barbara Klingler and Robin Lang, organizers of the Sunshine Scholarship Fund

Gifts/Flowers for Award Winners:

Zevex, Inc. Volunteers: Pat Brown, RN; Jeff Hoelle

ORS/Sport Drink:

Cera Products, Inc.

Sharps Containers:

Sharps Compliance, Inc.

Photographs:

Pat Brown, RN; Don Freeman; Malisa Matheny; Ben Maxson; Brigid Parado, RN; Valerie Parmain; Marjorie Quinn; Sue Staver; Patty Woods

Oley T-shirts, Hats, etc.:

Patty & Darrell Woods

Registration:

Jeff Hoelle; Barbara Klingler; Lynda Yeabower

Exhibit Hall Coordination:

Laura Ellis, PhD

Silent Auction:

Nader El Samaloty; Myra & David Heineck; Barbara & Lee Klingler; Robin Lang; Randy Menk; Jen Thiesse; Barbara & Peter Witt; Lynda Yeabower. ...And thank you to everyone who donated items to the Oley Silent Auction — we couldn't do it without your help!

Sunshine Scholarship Fund:

Barbara Klingler and Robin Lang..and everyone at the conference who contributed to this new consumer travel scholarship fund

Audio/Visual Equipment Support:

Abbott Laboratories/Creative Network; Stephanie Pelham; Joel Resnick

Exhibitors:

aaiPharma; Abbott Laboratories; BD Medical Systems; Boston Scientific Corp.; Coram Healthcare; Critical Care Systems; IFFGD ; Kendall Healthcare; National NAVAN; Nestlé Clinical Nutrition; Nutrishare, Inc.; Option Care, Inc.; Patient Support Services, Inc.; Ross Products Division of Abbott Labs Inc.; Sharps Compliance, Inc.; VIASYS MedSystems; Zevex Inc.

Faculty:

Jane Balint, MD; Thomas Baumgartner, PharmD, MEd, FASHP, BCNSP; Marcia Boatwright, RN, CRNI; Peggy Borum, PhD; Patricia Brown, RN, CNSN, OCN; Tom Diamantidis, PharmD; Marianne Duda, MS, RD, CNSD; Margaret Cass-Garcia, RN, MSN; Barry M. Farr, MD, MSc; Don George, MD; Roy George; Alicia Hoelle; Lyn Howard, MB, FRCP, FACP; Kishore Iyer, MD; Paula Johns, RN; Darlene G. Kelly, MD, PhD, FACP; Lee Klingler; Vanessa Kumpf, PharmD, BCNSP; Robin Lang; Malisa Matheny, RN, BSN; Michael Medwar; Sheila Messina, RN, MA; Reid Nishikawa, PharmD, BCNSP, FCSHP; Melinda Parker, MS, RD; Susan Poole, RN; Michelle Romano, RD; Betsy Rothley, RN, MSN, FNP, BC; Maurice E Shils, MD, ScD; James Scolapio, MD; Ray Stokes; Elizabeth Tucker; Andrew Ukleja, MD; Thomas R. Ziegler, MD

Your Support Makes Oley Stronger!

The following generous individuals have donated a gift to the Oley Foundation between May 10 and July 28, 2003. Thank you for your support! We also wish 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. A complete listing of everyone who donated this year will be published in the January/February 2004 issue.

PRESIDENT'S CIRCLE (\$1000 - \$1999)

- Estate of Selma Ehrenpreis
- Richard Rivett
- Thomas R Kent
- "Friends from Daufuskie Cup"
- Joe Boures
- Steve Carlidge
- John Darden
- Roger Eiler
- Rick Goga
- Gary Gronsko
- Jed Hoban
- Robert Merlo
- Robert Tooley
- Ron Trevaloni
- Peggy Waldon, in memory of David Waldon, Sr

BENEFACTORS (\$500 - \$999)

- Linda Gold
- Margaret Taber

SPONSORS (\$250 - \$499)

- Milton Abercrombie
- James Cowan**, in honor of the 18th Annual Oley Conference Award winners and nominees
- Rick Davis
- Bruce & Susan Grefrath**
- Nebraska Health System
- Kathleen Mayo

PATRONS (\$100 - \$249)

- Betty & Bettemarie Bond**
- Richard & Faith Dillon
- Bruce Groeber Memorial Fund
- Rebecca Edwards
- Susan Ellzey
- Randall Falck
- Jerry Fickle
- Todd & Susan Freidman
- Marie Hayden, a grateful recipient of the LifelineLetter
- Stephen Heineck

- Sarah Higgins
- Portia Hutton
- Joyce Madden
- New York Life Insurance for Stephanie Pelham
- Lou Pacilio
- Beverly Promise
- Kay & Roger Tims
- Donald Young

SUPPORTERS (\$50 - \$99)

- Mary Freil
- Robin Lang**
- Sandy Schwarz, in honor of Ellen's Details
- Brian Sessions
- Eugene Worek

CONTRIBUTORS (\$30 - \$49)

- Betty & Bettemarie Bond**, in memory of John Manrodt

- Phyllis Cashbaugh, in honor of my 8 years on TPN
- Michele D'Avello
- Marolyn Ford
- Carolyn Taylor, in honor of Aleah Smith

FRIENDS (UP TO \$30)

- Todd & Susan Freidman, in memory of Ruth Ann Engle's Collie, Lady Shirley Heller, in honor Suzanne Keating, Todd Friedman & Dr. Marvin Ament
 - Glen and Karen Hillen, in honor of Allison Hillen's 19 years on TPN
 - Elias Medwar
 - Benny Smith
 - Donna Noble**, in honor of her son, Kyle Noble
- * Oley Trustee
** Oley Regional Coordinator



Giving, a Little at a Time

In the January/February 2003 newsletter, we outlined plans for a new giving option, via a secure server online. We have finally connected ourselves to the 21st century!

Sign on to the Oley website, and click the blue "Donate Now" bar. You will be linked to a form that allows you to donate a one-time gift, or offer monthly or quarterly donations.

Please consider supporting us, and helping us continue to offer education and outreach to all children and adults using nutrition support therapies. Large or small, any gift is appreciated. Thank you!

We're Getting Closer!

Last issue we explained how our individual contributions exceeded our goal by \$7,000, but our overall financial position is not without challenges. Expenses are on the rise (i.e. insurance premiums have doubled, postage has increased, printing and publication costs have soared — we are serving over 6,000 members now!). The picture is looking better now, with some generous commitments from our corporate supporters.

Help us make the final push. If you have not yet contributed to our efforts, **please consider doing so today.** For those who have been constant supporters, please **consider "giving" again.** We *ARE* making a difference, one consumer at a time, and this makes "asking" a little easier. Thank you and stay tuned for more updates!

✍

Name _____ Send to:
 Address _____ Oley Foundation *Second Appeal*
 City/St/Zip _____ 214 Hun Memorial MC-28
 Albany Medical Center
 Albany NY 12208-3478

Phone (____) _____

Enclosed is my check for \$ _____. *Make checks payable to "The Oley Foundation."*

Charge my VISA or Mastercard for a **ONE-TIME GIFT** of \$ _____.

Credit card #

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Exp. Date ____/____/____ Signature _____

Join Us in Thanking our Corporate Donors

Nutrishare, Inc.

Nutrishare focuses exclusively on caring for long-term Home TPN consumers throughout the country. Rod Okamoto and Tom Diamantidis invite all Home TPN consumers to attend Nutrishare's next TPN Consumer Conference in Washington D.C. at the Pentagon City Ritz Carlton, from March 10-14, 2004. Nutrishare is proud to sponsor the higher education scholarship program for Home TPNers. A warm thank you to Nutrishare for their generous contribution.

BD Medical Systems

BD Medical Systems is a worldwide leader in the medical supplies, devices and systems industry. Sandy, Utah, is the company's headquarters for the infusion, injection, surgical, anesthesia, and critical care businesses. BD is committed to providing innovative, quality products, educational programs and services. Many thanks to BD for their continued support!

Bard Access Systems, a division of C.R. Bard Inc.

For more than 95 years, C. R. Bard, Inc. has committed its resources to creating innovative products and services that meet the needs of healthcare providers and patients. Bard Access Systems employs

innovation, expertise and education to give the best value in products, programs and outcomes. The company's complete line of products and accessories is designed to support the clinician, in improving patient outcomes. We welcome Bard as a new corporate contributor.

ZEVEX, Inc.

ZEVEX manufactures the EnteraLite® Ambulatory Enteral Feeding Pump. The EnteraLite® delivers enteral nutrition solutions with unprecedented +/-5 percent accuracy, and is suited for ambulatory patients. The pump weighs little more than one pound, has a 24-hour battery and can be operated in any orientation due to the elimination of the drip chamber. The EnteraLite® was developed to improve the quality of life of patients while accurately delivering solution according to prescribed feeding schedules. ZEVEX also manufactures products for cataract surgery, infusion therapy, hemodialysis and open heart surgery. All of these products are designed and manufactured at its headquarters in Salt Lake City, Utah. The company's facilities meet world-class manufacturing standards ISO9001 and EN46001. ZEVEX is a public company, with shares traded on the NASDAQ under the symbol ZVXI. We thank Zevex for their ongoing contribution to Oley programs. ☺



Oley Horizon Fund Founding Members

John Balint, MD

Joan Bishop

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*Ann & Paul DeBarbieri
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...and growing every day!!

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Coram Healthcare

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(\$25,000-\$49,999)

Nutrishare, Inc.

BENEFACTORS (\$15,000-\$24,999)

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(Alternate Site Product Sales/ Ross
Products/Creative Network)

PATRONS (\$5,000-\$14,999)

BD Medical Systems

Daniel F. & Ada L. Rice Foundation

SUPPORTERS (\$2,500-\$4,999)

Critical Care Systems

Mead Johnson Nutritionals

CONTRIBUTORS (\$1,000 - \$2,499)

Bard Access Systems, a div. of C.R. Bard Inc.

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Nestlé Clinical Nutrition

Patient Support Services

Zevex, Inc.

FRIENDS (\$500-\$999)

Calea Ltd.

Nutritional Restart Center



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.

SEP. '03	Ann Weaver Naperville, IL (888) 610-3008 CST	Ann is married and has two sons, ages 16 and 8, the younger of which has SBS due to Hirschsprungs Disease. He has been on HEN since birth in addition to being on HPN for 3 years and IV hydration for 7-1/2 years. She has cared for a central line, NG-tube, g-tube and ostomy. She looks forward to talking to other parents.
	June Bodden Clearwater, FL (888) 650-3290 EST	June has had Crohn's disease since age 15, an ileostomy since age 21, and TPN since age 35 (20+ years). A Regional Coordinator and an active support group member, she believes networking with others is important. A strong faith, volunteer work and help from family and friends keeps June upbeat.
OCT. '03	Davi & Steve Cohen Crofton, MD (888) 610-3008 EST	Davi has been on TPN for 20+ years due to SBS resulting from a car accident. She has experience with port-a-caths in both subclavian and femoral sites. Davi and Steve have been active at recent Oley, NAVAN, and ASPEN meetings and can discuss the medical, logistical, and emotional aspects of long-term IV therapy.
	Bob & Blanche Hoffman Albany, NY (888) 650-3290 EST	Bob has been on tube feeding since 1995 due to Crohn's disease. Though he has recently retired, Bob can share his experiences traveling and working while on therapy, and battling multiple health issues. His wife Blanche is very supportive and both look forward to hearing from other Oley members.
NOV. '03	Nader El Samaloty Cocoa Beach, FL (888) 610-3008 EST	Nader has an amazing positive attitude. He has been on TPN for 11 years after emergency surgery left him with SBS. He enjoys cooking for friends, and networking with other homePEN consumers. He can share his experience with traveling, and attending Oley conferences and support group meetings.
	Patty & Darrell Woods Hemet, CA (888) 650-3290 PST	Patty & Darrell live in So. California and have five children, one of whom (Colyn) has been TPN dependent since 1996 due to pseudo obstruction. They enjoy speaking to others about managing TPN issues, keeping a positive perspective, and having a normal, active family life.

LifelineLetter

The Oley Foundation
 214 Hun Memorial
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 Albany, NY 12208

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 we need to know
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 Please update your membership
 on-line at www.oley.org/join.html
 or call us at (800) 776-OLEY.