Oley Conference Fosters Community
Lisa Crosby Metzger

The Cape Codder Resort was hopping this June as over three hundred Oley members joined there for the 22nd annual Oley Consumer/Clinician Conference. Titled “Safe and Sound on HomePEN,” the conference was marked by a high level of attendance and by active participation by the attendees. A strong sense of community prevailed, and those new to Oley gatherings (as I was) were quickly made to feel welcome. And there was plenty to keep everyone busy.

Many Regional Coordinators came to the conference early to meet and discuss ideas about how to serve the Oley community. Faye Clements, RN, discussed listening skills with them. Don’t hesitate to call the RCs, and let them try out the new techniques they learned.

Wednesday night saw a bittersweet tribute to Dr. Lyn Howard, who has officially retired from clinical practice after more than thirty years at Albany Medical Center’s nutrition program. Numerous personal stories confirmed how much Dr. Howard has contributed, and how much she will be missed. Dr. Howard will continue on as Oley’s Research and Medical Director.

Thursday and Friday were packed with informative sessions on homePEN issues, with a trip to the tidal pools and miniature golf for the younger attendees. Session topics ranged from probiotics to reducing complications to managing pain. As usual, an afternoon-long enteral workshop was held on Friday.

Each afternoon the exhibit hall was crowded with conference-goers talking to exhibitors about the latest equipment or getting questions answered, and on Wednesday night saw a bittersweet tribute to Dr. Lyn Howard, who has officially retired from clinical practice after more than thirty years at Albany Medical Center’s nutrition program. Numerous personal stories confirmed how much Dr. Howard has contributed, and how much she will be missed. Dr. Howard will continue on as Oley’s Research and Medical Director.

Getting Through the Darker Days
Ann Hill DeBarbieri

The physical aspects of HPEN are often the subject of presentations at Oley conferences or articles in the LifelineLetter. The emotional or psychological aspects are less frequently discussed, but are often just as significant. At this summer’s Oley conference in Cape Cod, I was asked to make a presentation at a session entitled “The Dark Side of Successful Therapies.” I spoke about my personal experiences as I adjusted during various stages of my life on HPEN. This article is a summary of that presentation.

In 1987, just following the surgery that eventually led to my dependence on parenteral nutrition (PN), I experienced some serious problems that were attributed to my psychological state. Prior to my surgery, which was for removal of an intestinal tumor, I had been sick for the better part of a year and had experienced periodic hospitalizations and recurring infections. After surgery, my surgeon felt I should be on the road to recovery. However, I couldn’t sleep, I couldn’t eat, and I felt lethargic and anxious at the same time.

Board Bids Farewell, Offers Welcome

This past June, the Oley Foundation Board of Trustees thanked Darlene Kelly, MD, PhD, FACP, for her many years of dedicated service, and welcomed four new members: Ann Hill DeBarbieri; Gail Egan Sansivero, MS, ANP; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, MS, RD, LDN, CNSD. Dr. Kelly has served as a trustee since 1998, much of the time as the Foundation’s vice president. For the past few years she has chaired the research committee and will continue in this role, organizing Oley efforts for a homePN quality of life study.

Ann Hill DeBarbieri is a long-time homePEN consumer, having been on parenteral or enteral nutrition and/or hydration since 1987. Ann was an attorney
Coping Skills

Getting Through, from pg. 1

My surgical team called in a psychiatrist for a consult. I couldn't relate to this particular psychiatrist, but he did perform a great service for me: He reviewed my chart and came to the conclusion that my problems stemmed largely from my being overmedicated. The medication I had been given for pain caused nausea, so I was given medication for the nausea; this medication caused anxiety. I was given another medication for the anxiety, and so on. After the psychiatrist discussed this with me, we agreed I would be taken off all medications. In less than a day, my appetite returned and I gained energy, and I slept that night for the first time in almost a week.

Following my recovery from this surgery, it became obvious that I needed PN. Although I initially found the mechanics of mixing my solution and “hooking up” somewhat overwhelming, I actually felt very positive about being on PN. I was extremely underweight and so depleted that I looked forward to the relief that PN offered me.

A Long Six Weeks

Over the next couple of years, my remaining small bowel adjusted, but I remained I.V. dependent, primarily for hydration. I went five years with no infections. Then, unfortunately, I developed a series of persistent infections. My physician, Dr. Lyn Howard, began to seek alternative means of keeping me in fluid balance. She suggested we try infusing I.V. fluids slowly through the night into a gastric button, and to determine if my system would absorb enough fluid this way, Dr. Howard asked me to pass a nasogastric (NG) tube on a nightly basis for a trial period. Initially, the fluids would be infused through the NG tube. If my digestive system could absorb enough fluids this way, I would be weaned off PN and start enteral fluids through a gastric button. When Dr. Howard first suggested the NG tube, however, I freaked out. I have lived through a number of obstructions and have a strong gag reflex, and subsequently I have a love-hate relationship with NG tubes—about 5 percent love and 95 percent hate. Dr. Howard convinced me to try the NG tube by offering to train me herself. She proceeded to demonstrate how I should pass the NG tube by using herself as a live model. As Dr. Howard passed the NG tube herself, exemplifying her great dedication, it was hard for me to say no. For six weeks or so I had to pass the tube nightly, and it was difficult each time. I hated sitting down to do it every night, but I knew it was a short-term situation, which made it easier to cope. In the end, I was able to absorb supplemental fluids this way and I went on to get the gastric button.

Un-buttoning

The greatest challenges I faced in adjusting to HPEN came after additional small bowel surgery in 2001 left me with very little small bowel. (My colon had been removed many years before.) Prior to this surgery, I had anticipated I would lose only a short portion of my small bowel and was optimistic (in denial perhaps?) that I could continue to rely on supplementation through a gastric button. That hope was dashed when my surgeon explained to me what the operation had entailed. I reacted immediately with both terror and despair. It wasn’t the idea of PN-dependence itself that caused that reaction—it was my fear of infection.

During the recovery period in the hospital, I had difficulty sleeping and couldn’t stop crying. I felt very quickly that I needed immediate help in order to cope. Fortunately, my surgeon was receptive and connected me

Seven Steps to Help Smooth the Road

Don Young

A longtime Oley member, Don has been on HPN for thirty-two years due to Crohn’s disease. This has provided him many opportunities to act on his own advice. Don shared these tips as part of a presentation he made at the Oley conference.

1. Be informed, educated.
2. Take control of your therapy and plan ahead as much as possible.
3. Make the lifestyle changes necessary to protect your health. Be a little selfish when necessary to meet your own needs. Know yourself, and don’t get caught up in other people’s adventures and their successes. You can do only what you can do.
4. Be aware of the cost of supplements; comparison shopping can be worth the time.
5. A hospital stay can be a very vulnerable time for a patient. Write things down and be as well prepared as possible.
6. Work well with your homecare company; it can be a great resource.
7. Have faith, from whatever source. Do what you need to do to find the strength to support yourself when push comes to shove.
Remembering Joyce Hydorn

Joyce Hydorn, a quiet but strong and steady supporter of the Oley Foundation, passed away this July. Joyce had Crohn’s disease and had been on HPN and/or hydration since 1992. She was active in her local Oley support group, visited many new HPN patients in hospital, and volunteered at the Oley office and conferences.

Joyce always brought homemade treats for the Oley staff and other volunteers when she visited. She also brought stories, smiles, wit, and wisdom. She was a joy to be around. She and her husband, Bob, made everyone feel welcome at Oley events. Joyce loved her family and she loved to cook. She was an avid hockey fan and a great mother.

It is never easy saying good-bye to friends, and this case is no exception. We miss her very much.

Mark Your Calendar

A workshop titled “Tube Feeding with Love” will be held October 25–26 at Cincinnati Children’s Hospital Medical Center. Presented by Marsha Dunn Klein, MEd, OTR/L, the workshop will challenge the participant to consider the family, mealtime, and interactional aspects of tube feeding. Contact Mealtime Notions at (520) 323-3348 or www.mealtimenotions.com for details.

Lifeline Mailbox

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I order floral cotton covers, which are very pretty, easy to wash, and, best of all, comfortable, since the material absorbs perspiration. The plastic pouches against the skin do not afford the same comfort. Also, I use a transparent pouch so I can check my stoma easily, and I do not like having to view its contents all the time. Having a cover provides a pleasant barrier for me. The ostomy cover also provides some protection in the event of leakage by absorbing fluid and keeping it from going through my clothes.

I have used many pouch covers over the years, and have found Yentl’s pouch covers to be very affordable and easy to maintain. I love them. I order them through the mail. To receive the brochure, call 1-800-749-3685 or visit www.yentlssecrets.com.

—Joan Medwar, Sharon, MA

Garment Provides Access

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The shirts can be worn by men or women and are available in children’s and adult sizes. For further information on the garment, call (815) 941-4894; e-mail mary@medicaldignityclothingcorp.com; or go to www.medicaldignity.com.

Equipment Exchange

For formula, pumps, tubing, or miscellaneous items, try the Equipment Exchange!

• A full listing of items available for exchange is posted on the Oley Web site, www.oley.org. The listing is updated every two weeks, so check frequently. This list includes everything from tubing and bags, to formula, to all kinds of durable items.

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Congratulations 2007 Oley Award/Scholarship Winners!

**LifelineLetter Annual Award**
*In honor of Nutrishare, Inc., Platinum Partner Barbara Klingler, Valkaria, Florida*

This year the *LifelineLetter* Annual Award went to Barbara Klingler. In November 2006, Barb marked twenty years on HPN. She commemorated the anniversary by planting two trees in her front yard. It was, she says, a celebration of life.

Typical of Barb's generosity in helping others, she recently flew over a thousand miles to assist a friend and fellow-consumer recover from a difficult illness. As an HPN consumer herself, during her visit Barb saw needs others could not anticipate. As well as helping to cook, clean, and care for pets, Barb helped organize her friend's medical supplies and locate community resources.

Barb is very involved with her church. She leads the CD/DVD duplication department and the couples' ministry. Since 1999 she has coached the church Bible quiz team. The team has won the state championships for five years.

Barb and her husband, Lee, have been married for twenty-four years. Barb notes that they are best friends. Embracing life and pursuing the things they enjoy, together Barb and Lee have visited forty-eight states.

Barb routinely exhibits the qualities this award sets out to recognize: courage, perseverance, a positive attitude, and exceptional generosity. We are grateful to have her in our midst.

**Nominees:** Pam Belmonte, Jim Cowan, Roberta Gelle, Malisa Matheny, Lisa Miller, Liz Tucker, Jim Wittmann, The Woods Family

**Oley Foundation Child of the Year**
*Gypsy Rose Blancharde, Aurora, Missouri*

Gypsy Rose Blancharde is twelve years old, yet one of her friends says she has wisdom and compassion beyond her years. Multiple health issues don't stop Gypsy from encouraging and uplifting others. Before Hurricane Katrina caused Gypsy and her mother to relocate, Gypsy would talk at a university in New Orleans on why we should help and love one another.

At eight years old, Gypsy took the allowance she had been saving for a trip to Disney and used it instead to buy food and blankets for those in need. When she and her mom ended up in need themselves, Gypsy's mom says she never complained. Instead she would say things are getting better and point out a beautiful flower, saying, “We didn't see that yesterday; how lucky that we can see it today.”

Just ten hours before Hurricane Katrina struck Louisiana, Gypsy and her mother were evacuated to a special needs camp in a safer part of Louisiana. Gypsy named their shelter Camp Bright Beginnings, and arranged for the evacuees to gather for stories, songs, and games. Thank you, Gypsy Rose, for sharing your smile and big heart with the Oley community!

**Nominees:** Ana Maria Bennett, Colyn Woods

**Celebration of Life Award**
*In honor of Coram, Inc., Golden Donor Colyn Woods, Hemet, California*

Colyn Woods, age eleven, has faced many challenges in his life, yet is seldom heard complaining. Though he confronts a lack of energy and pain, he has set a goal to not let either slow him down or keep him from doing things that are important to him. Colyn is quoted as recently saying, “This backpack [with my IV pumps] is a part of me. It doesn't stop me from doing things. If there is something I'm told I can't do, I figure out how I can do it instead of accepting that I can't do it.”

Colyn has taken responsibility for his health care and learned how to handle his PN, fluids, nebulizers, and medications. He has recognized the importance of understanding his health issues and has made it a priority. He is also an active participant in such things as the Oley conference, where he is a friend to so many. Colyn is known to greet everyone, visit the exhibits and talk to the exhibitors, and raise money at the walk-a-thon.

Colyn is noted for his smile, his sweetness, and his compassion, as well as his zeal for life.

**Nominees:** Rommel DeGracia, Alicia Hoelle, Barbara Klingler, Kyle Noble, Mark Reedy, Christopher Tournier, Jennifer Wright, Don Young
Lenore Heaphey Grassroots Education Award

Ben Hawkins, Cincinnati, Ohio

Ben Hawkins has been an Oley Regional Coordinator in the Cincinnati, Ohio, area for over fifteen years. Despite a relatively small turnout at first, Ben and his mother persevered in organizing the outreach meetings. One of Ben’s friends likens him to an early union organizer, “standing on a cold and damp street corner handing out leaflets to people who had never heard of something called Oley. It was hard and often discouraging work.”

As a regional coordinator, Ben takes his message about Oley to others, in the hospital or at home. In a recent article in the Cincinnati Enquirer Ben is quoted as saying, “Oley took me from feeling totally alone to having a network of people I can talk to, and people I can help. Because of my condition, I have great compassion for others.”

More recently Ben took on the volunteer position at Oley as coordinator of the equipment exchange program, which enables Ben to reach out nationally. As coordinator, Ben keeps a spreadsheet record of all the supplies anyone offers to donate—from durable goods to tubes and bags to formula—and looks for a match when someone contacts him with a need. Don’t hesitate to call him. He is very capable at his job, and it makes him happy to make a match. Thank you, Ben!

Nominees: Robbyn Kindle

Nan Couts Award for the Ultimate Volunteer

Coordinated by Judy Peterson, RN, MS
Marcia Boatwright, RN, CRNI, Minneapolis, Minnesota

This year the Nan Couts Award for the Ultimate Volunteer goes to Marcia Boatwright. As a nurse, Marcia is very involved in patient care and goes out of her way to attend to the things HPEN consumers will or may need. Marcia has been active at several Oley conferences, both regional and national. She has actively contributed to making the conferences better and more efficient, and helps consumers in need quickly and appropriately. Marcia is very knowledgeable and is eager to share what she knows with others, both consumers and clinicians. She is dedicated to sharing information that will help each individual consumer and spends much of her time at the conferences talking to consumers about their health issues.

We are very pleased to present this award in recognition of Marcia’s willingness to give of herself in educating homePEN consumers, thereby empowering them and improving their quality of life. Marcia, thank you for going above and beyond in serving others.

Nominees: Alyce Newton, RD

First Kyle R. Noble Scholarship Awarded

In early 2007, the Noble family established the Kyle R. Noble Scholarship in memory of their son. The first scholarship was awarded this June at the Oley conference to Alicia Hoelle, who embodies many of the qualities for which Kyle will be remembered. Alicia has overcome a number of challenges posed by a reliance on HPN and inspires others to live life to the fullest.

Alicia completed her associate’s degree in December 2007 and plans on transferring to a four-year college to work on a bachelor’s degree. She’d like to major in psychology and be a child life specialist when she finishes her education. She’d like to use her education and her experience—twenty-two years on HPN and confrontations with a number of health-related obstacles—to help other children face the difficulties presented by long-term illnesses.

Alicia is very active in her community. Since she was sixteen she has served as a regional coordinator for Oley. She is also a leader with REACH, which, in Alicia’s words, “is an organization founded by teens and young adults with chronic illnesses for teens and young adults with chronic illnesses. [REACH has] monthly meetings on topics like relationships, college, wellness, and transitioning.”

Alicia has also been a member of the Youth Advisory Council at the Children’s Hospital of Philadelphia for eight years, and has served as its president for the past two years.

Congratulations, Alicia! We look forward to hearing what your future brings.

Nominees: Robbyn Kindle

Do you know of someone special in your homePEN community? Nominate them for a 2008 Oley award. Look for details this January in the LifelineLetter or at www.oley.org.
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Oley Board, from pg. 1

for the New York State Department of Environmental Conservation from 1988 to 2001, when she retired early due to health issues. Prior to that, Ann worked in private practice in both Clifton Park and Orange County, New York, with a few years in between representing Orange County Social Services in family court proceedings.

Ann was first introduced to Oley through an Oley conference near her home in the late 1980s. Through Oley, Ann has found opportunities to share experiences and information with others who live with homePEN; she considers these opportunities educational, comforting, amusing, and life affirming. She is committed to continued support of the Oley Foundation, as she has seen firsthand the difference Oley can make in the lives of consumers who can otherwise feel a desperate sense of isolation. (See Anne’s article page 1.)

Gail Egan Sansivero, MS, ANP, is a nurse practitioner in interventional radiology at Albany Medical Center in Albany, New York. Gail is responsible for coordinating clinical care for patients requiring vascular access devices and feeding tubes. She works closely with clinical nutrition staff, patients and their families, and home care agencies.

Gail has administrative experience as a national committee chairperson for both the Association for Vascular Access (AVA) and the Oncology Nursing Society. She has also served as president of AVA. She currently (2007) serves on two committees for the Society of Interventional Radiology. Gail has experience with organizational restructuring, educational programming, and strategic planning.

In 2007, Cheryl W. Thompson, PhD, RD, CNSD, is serving as the principal investigator on a National Institutes of Health grant project, the goal of which is to educate clinicians on safe and effective delivery of enteral nutrition. It is her belief that educating both clinicians and consumers about homePEN will help enhance consumers’ lives.

Cheryl has had valuable experience working in elected positions and on committees with several nonprofits, including Dietitians in Nutrition Support and the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). She has a doctorate in Health Promotion and Education, which has enabled her to promote cost-effective educational resources, such as Web-based instruction.

Marion F. Winkler, MS, RD, LDN, CNSD, has over twenty-five years experience in nutrition support, practicing in both acute and home care settings. Since 1985 she has worked as the Surgical Nutrition Specialist in the Department of Surgery and Nutritional...
Support Service at Rhode Island Hospital in Providence. She also serves on the professional advisory committee and as a home care nutrition consultant for Clinical IV Network (CIVN) in Pawtucket, Rhode Island. Part of her professional responsibility at CIVN is to provide nutritional assessment of and monitor individuals receiving homePEN.

Marion also holds the position of Senior Clinical Teaching Associate of Surgery at the Warren Alpert School of Medicine of Brown University and is a PhD candidate at the University of Medicine and Dentistry of New Jersey. Her doctoral dissertation and research interests focus on quality of life for individuals dependent on home parenteral nutrition. She has written numerous journal articles and book chapters on the topic.

Marion is the immediate past president of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and serves on the board of the A.S.P.E.N. Rhoads Research Foundation. She is a former chair of the Dietitians in Nutrition Support practice group of the American Dietetic Association.

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**HPN Research Prize**

The Oley Foundation is pleased to announce the Nutrishare HomeTPN Research Prize. Sponsored by Nutrishare, Inc., the prize has been established to encourage clinical studies focused on improving the quality of life for homePN consumers. Each year at the annual conference, the Oley Foundation will present a $2,500 prize to each of the top three clinical papers dedicated to helping homePN consumers. For details, please call the Oley office at (518) 262-5079 or visit www.oley.org.

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**Conference, from pg. 1**

Thursday evening the silent auction was lively—with “silent” referring only to the bidding. The donation of numerous items for the auction and generous bidding resulted in over $3,700 to go toward Oley programs.

The youth had opportunities to gather at several points during the conference: for the annual Jammin’ Jammies pajama party, for the youth activities, and for a teen roundtable session titled “Teens and Transitioning.” There was a huge turnout of youth this year!

A new addition to the program was a town meeting held Friday night. It was a great way of facilitating dialogue within the Oley community. Attendees made several suggestions that hopefully will take root at Oley as the year progresses. Saturday morning featured a walk through Hyannis—another fund-raising success story—and a picnic at the village green, complete with rock painting (thanks, Sheila!) and a relay race (who was that woman who took our team’s suitcase?).

Overall, the conference was noteworthy for the wonderful sense of camaraderie, and lovely scenes of old friends gathering and new friends meeting, as well as the tremendous wealth of information available from a variety of sources—from presenters to exhibitors to other attendees, both consumers and clinicians. It was my first Oley conference, and having been once, I’ll eagerly await my second.
Walking for Oley

The third annual Oley Walk-a-Thon, held June 30 in Cape Cod, was a great success. Walkers raised over $9,000 to support Oley programs and the group generated a lot of interest in Oley. The walkers had a beautiful day and enjoyed the two-mile route along Hyannis's Main Street, through the village green, and out to the beach.

Thank you to everyone who was a part of the walk-a-thon, whether it was by walking with us in Cape Cod, by gathering sponsorships, or by sponsoring a walker.

Walkers:

Jameson Atkinson; Leah Atkinson; Bette Marie Bond; Gail & Chuck Brenenstuhl; Anne Brettschreider, RD; Allen & Lauren Bye; Noreen Code; Roselyn Dahl; Rick Davis; Ann DeBarbieri; DeKold Family; Fant Family; Ray Gravenstein; Deborah Groeber & Etzel; Rose Hoelle; Lyn Howard, MB, FRCP; Portia & Wallace Hutton; Randy & Jayne Justice; Melanie & Alex LaVoie; Sue, Abby, & Gwen Lorimier; Eli Medwar; Michael Medwar; Lisa Metzger; Kelsey Noble; Joanne & John Platt; Marjorie Quinn; Charles Rolfe; Bruce Schmitt; Doug & Mary Seidner; Kate Swensen; Team Coram: Carol Ireton-Jones, Krissy Jones, Lauren Jones, Norman Bailey, Dana Thornley; Ginny, Dennis, & Julie Werner; Jim Wittmann

Sponsors:

Anonymous; Steve Atkinson; Barbara Backoff; Edyth Bain; Jane Ballant; MD; Lesley Bennett; Shirley & Verl Benzel; Claudinneea (Dee Dee) & Gypsy Rose Blancharde; Elizabeth Bond; Marilyn Boulaia; Eileen Bowes; Bonnie Braxton; The Brogna Family; Mikayla Brogna; Lorraine Brue; Vincent & Christine Callan; Capewide Enterprise; Chatham Wayside Inn; Deborah Christian; Cinn Corporation; Laura Crimiad; Diane Cumberledge; Patricia Curran; John & Donna Curty; Linda Deane; John & Jean DeBarbieri; Marie DeBarbieri; Kathleen Demontigny; Dr. Joseph & Mary Dieterle; Judy Drabicki; William & Evangeline Dunmire; Milo & Robin Eldridge; Evangeline Ellis; David & Catherine Fant; Susan Feece; Dr. & Mrs. Anthony Ferriola; Cleata Francis; Gary & Jeanette Francis; Robert & Theresa Freeman; Betty & Kenneth Gaylord; Gibson Investments; Isle Gilbert; Robert & Sandra Glazener; James & Mary Good; Julie Graham; Megan Gravenstein; Werner & Gerda Gravenstein; Stuart Green; Bobbie Groeber; Jon & Marilyn Grove; Gregory Guba; Andrea Guidi; Mitchell Haddad; Michael & Roseanne Hardman; Thomas & Paullette Henderson, Jr.; Elizabeth Hill; Peter & Mary Hill; Bob & Blanche Hoffman; Pam Hughes; Alice F. Illian; Cathy Jasignowski; Janis Johnson; Janet Kane; Darlene Kelly, MD, PhD; Karen Kimbaris; Leanne & Kirtland King; Rosemary Kolacia; Jack Kordash; Bill Kubiszne; Pauline Kubiszne; Lena Lambert; LaPerlude France Cafè; Lora Lazaro; Allan Mabardy; Janice Mabardy; Paullette Mabardy; Philip & Anita Mabardy; Sarah Mabardy; Craig & Sharon MacCormack; Sarah MacDonald; Nancy...
HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org.

Cincinnati Children’s Hospital Medical Center
Nutrition and Intestinal Care Center

The Nutrition and Intestinal Care Center at Cincinnati Children’s Hospital Medical Center is a comprehensive center for the management of patients with complex intestinal and liver disease. It combines long-standing expertise in nutritional guidance, medical and surgical intervention, liver transplantation, and recent advances in intestinal transplantation to optimize the care of children with intestinal failure.

The center is led by pediatric gastroenterologist Samuel Kocoshis, MD, and surgeons Maria Alonso, MD, and Frederick Ryckman, MD. Patients are thoughtfully evaluated to ascertain whether intestinal rehabilitation via nutritional and/or pharmacologic methods or non-transplant bowel rehabilitative surgery is feasible, or if the patient will require intestinal transplant. More than 300 liver transplants have been performed at Cincinnati Children’s since 1986, and in 2003, the center performed its first combined liver and intestinal transplant. The center’s small bowel transplant program is the first program in the nine-state Midwest region designated by the United Network for Organ Sharing (UNOS).

The center offers a range of multidisciplinary services, from evaluation and diagnosis to nutritional, medical, and/or surgical care to patient/family education and support groups. The center’s team includes pediatric and transplant surgeons, pediatric gastroenterologists, gastroenterology nurse coordinators, dietitians, social workers, and pastors. Staff home care personnel can tap into local resources in the patient’s area and ensure coordinated care when the patient returns home.

Cincinnati Children’s is also committed to making a safe and effective transfer of research from the laboratory to patient care, and researchers at the center are actively involved in several ongoing research projects. More information is available at www.cincinnatichildrens.org/intestine.

Walkers, from pg. 8

Malinowski; Bernard & Jane Manderville; Danny Marsik; Paul May; Dr. & Mrs. William McCAA; Kay McLaughlin; MCQ Building, Inc.; Suzanne McQuade; Ellen Mead; Joan Medwar; Nora Medwar; Steve Mellor; Mary Messerle; Middleburg Animal Hospital; Patricia Minister; Ali Mirian; Lynn Murphy; Meta Murray; Stacey Myers; Mr. & Mrs. Bob Noble; Derek Noble; Northeast Tool Supply; Diane Owens; Jennifer Paluzzi; Patriot Builders; Peta Pavitt; Dori Pedrol; Janel Pery; James Price; Nancy Rattie; Annmarie Rawlin; Response Custom Publishing; Karl Rodenhausen; Max & Linda Rodriguez; Rolfe Construction; E. Rod & Bette Ross; Robert & Rae Jean Schafer; Bernice Schaller; Mrs. William Schwimm; Sybil Sharf; Devon & Amy Smeal; Thomas & Barbara Squadere; Deborah Sullivan; Helen Taylor; E. Jean Tracy; Carol Valenzono; Joshua & Brooke Wardrop; Chris & Sue White; David Winder; Marion Winkler, MS, RD, CNSD; Donna Wisnaskas; Andrea Wolcott; Don Young; Mary Zeres

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

Conference Photos

Scenes from the Oley Conference in Hyannis, MA

Oley Youth

Gathering information in the exhibit hall

“Doctors” and “patients,” working together

Kids enjoy the conference too!

Bidding on silent auction items

Picnic on the Village Green
Held June 27 to July 1, 2007, at the Cape Codder Resort

New friends

Old friends

Rock painting in the shade

Artist and volunteer extraordinaire

Co-chairs: Winkler and Medwar

The future of Oley

Oley RCs, working hard for you
Thank You Sponsors, Volunteers

Many thanks to the following companies and individuals for their generous contributions of time and/or money to the 2007 Oley Conference.

Conference Co-Chairs:
Michael Medwar; Marion Winkler, MS, RD, LDN, CNSD

Medical Support:
Coram, Inc.

Conference Bags:
Nutrishare, Inc.

Conference Program Books:
Hospira Worldwide

Conference Videotaping:
Abbott Laboratories/Creative Networks; Stephanie Pelham, RD

Travel Scholarships for Consumers:
Anonymous; Jarol Boan, MD; Bruce Groeber Memorial Fund; Critical Care Systems; Melissa Chaney Memorial Fund; Nutrishare, Inc.

General Conference Support:
Patricia Brown, RN, CNSN, OCN; Kim Butler; Rick Davis; Marilyn Dolan; Mary Friel; Linda & Colman Gulden; Stephanie Harrison-Bishop; Jeff Hoelle; Portia & Wallace Hutton; Kate Letzelter; Joan & Eli Medwar; Sheila Messina, RN; Andrea Quinn-Guidi; Marjorie Quinn; Charlie & Carol Scoville; Robert & Karyn Thomas

Jammin’ Jammies:
Ross Products; Volunteers: Sheila DeKold, Rose Hoelle, Patty Woods

Child Care:
Critical Care Systems; Option Care, Inc.; Volunteers: Marjorie Quinn, Kim Butler, Stephanie Harrison-Bishop, Andrea Quinn-Guidi, Kate Letzelter, Jennifer Koprucki

Youth Activity:
NutriThrive (both days); Volunteers: Kim Butler, Stephanie Harrison-Bishop, Andrea Quinn-Guidi, Kate Letzelter

Transitioning to Independence:
Darlene Kelly, MD; Jayne Justice, RN

Lunch (Friday):
Coram, Inc.

Flowers for Award Winners:
EMD Serono

Annual Picnic:
Entertainment–Option Care, Inc.; Transportation–Novartis Nutrition; General Picnic–Bobbie Groeber, in memory of Bruce Groeber; Sheila DeKold, Ben & Jerry’s Ice Cream

Silent Auction:
A big “Thank You!” to all who donated, brought and/or purchased items! Volunteers: Pat Brown, Nicole Daddona, Eli & Joan Medwar; Sarah Wittmann

Oley Walk-A-Thon:
Apria; British Beer Company; Critical Care Systems; Coram, Inc.; Kimberly-Clark; BoxLunch; Nutrishare, Inc.; NutriThrive; Spanky’s Clams for their sponsorships. A warm note of gratitude to Holly Brockman Johnson and her family and Anne Brett Schneider from Apria for helping to distribute water and to Blanche Hoffman for assisting with registration. A huge thank you to everyone who walked or otherwise supported the effort (see page 8)!

Thanks for an incredible job coordinating shirt sales, Patty & Darrell!

Oley Shirts/Sweatshirts:
A huge thanks to Patty & Darrell Woods for taking on this great fundraiser again this year. Thanks also to the Nobles for helping them.

Sunscreen:
Fruit of the Earth

Exhibitors:
Applied Medical Technologies (AMT); Apria HealthCare; Association of Gastrointestinal Motility Disorders (AGMD); Bard Access Systems; Cammoseptine, Inc; Coram, Inc; Critical Care Systems (CCS); Critical Homecare Solutions / New England Home Therapies; Crohn’s & Colitis Foundation; EMD Serono, Inc; Hospira Worldwide, Inc; InfuScience; Kimberly-Clark; Mito Action; Nestle Nutrition; Novartis Medical Nutrition; Nutrishare, Inc; NutriThrive; Option Care, Inc; PromptCare Home Infusion; Ross Products Division, Abbott Laboratories; Tyco Healthcare/Kendall; Zeves, Inc

Faculty:
Kimberly C. Aronhalt, RN, BSN; Penny Allen, RD, LD, CNSD; Jane P. Balint, MD; Patricia A. Brown, RN, MSN, CNSN, OCN; Alan L. Buchman, MD, MSPH; David Burns, MD, CNSE; Faye Clements, RN; Rick Davis; Ann Hill DeBarbieri; Mark DeLegge, MD; Marianne Duda, MS, RD, LD, CNSD; Stanley Dudrick, MD, FACS; Kathleen M. Gura, PharmD, BCNSP; Lyn Howard, MB, FRCP, FACP; Yi Lisa Hwa, NP; Carol Ireton-Jones, PhD, RD, LD, CNSD, FACP; Kishore R. Iyer, MBBS, FRCS, FACS; Jayne Justice, RN; Darlene G. Kelly, MD, PhD, FACP; Mark G. Klang, RPh, BCNSP, PhD (Cand); Michael Medwar; Kevin G. Miller, Dc; Reid A. Nishikawa, PharmD, BCNSP, FCSHP; Diane V. Owens; Mark Puder, MD, PhD; Leonel Rodriguez, MD; Douglas L. Seidner, MD; Ezra Steiger, MD, FACS, CNSP; Jody Strain; Marion F. Winkler, MS, RD, LDN, CNSD; Don Young

Support for Speakers:
Albany Medical Center; Children’s Hospital, Boston; Cleveland Clinic Foundation; Columbus Children’s Hospital; Coram, Inc.; Critical Care Systems; Feinberg School of Medicine, Northwestern University; InfuScience, Inc.; Lahey Clinic; Mayo Clinic, Rochester; Medical University of South Carolina; Memorial Sloan-Kettering Cancer Center; Mount Sinai Medical Center; Nutrishare, Inc.; Option Care, Inc.; Pediatric Motility Center, Massachusetts General Hospital; Rhode Island Hospital; Sloan-Kettering Institute; University of Kansas School of Nursing; Women and Infants Hospital
with a psychiatrist who was familiar with short bowel syndrome, PN, and related issues. The psychiatrist was helpful, but even more helpful in the short term was the antidepressant medication she prescribed. It didn’t take away all my worries, but it did allow me to sleep and lifted me out of the depths so I could function.

Redefining Retirement

A few months later, after my physical recovery from that surgery, I began to face the reality that returning to work was not a viable option. Although I had never thought of myself as defined primarily by my job, I had a difficult time accepting the idea of disability retirement. When I was still working, I had looked forward eagerly to retirement. I saw it as an opportunity to try new things and to devote more time to pursuits I already enjoyed. With that in mind, I couldn’t understand why facing disability retirement left me so depressed. I went back on the antidepressant medication I had taken right after my surgery and went for counseling. Over time, I came to realize that retirement was difficult for a few reasons. First of all, it was not on my terms; it was forced on me due to circumstances beyond my control. I had not anticipated that this would be an outcome of my surgery in June 2001. In addition, my physical limitations wouldn’t allow me to do all the things I had anticipated when I was looking forward to retirement.

With time and effort, I have made a good adjustment to my new lifestyle. This is not to say that I never have a “blue” period. I am especially subject to these in winter. So how do I cope? First, I try to find something to look forward to. It may be something as simple as having lunch with friends. Further, I try to find something I enjoy that gives meaning to my life. After searching, I have found activities that allow for flexibility. I can do them when my physical well-being allows and within the limited time available after managing my PN and hydration. These include visiting a nursing home with one of my dogs. I also do volunteer counseling by phone and the Internet from home for a Medicare rights organization.

I love to garden, and spring through fall offer me the opportunity to be outside and play in the dirt when I am physically able to do so. I have taken up music. I began playing the organ at the ripe age of fifty-one. These things keep me in a fairly positive frame of mind most of the time. However, I have also learned that an occasional pity party is not necessarily a bad thing. For me, this generally means a day when I make no pretense of doing anything productive and allow myself to feel down, rather than trying to fight it. I do my best to ensure that these days do not occur frequently and that I shake off the inertia they produce by at least the next day.

I’ve learned depression can be a normal reaction to the life-altering experience of becoming dependent on HPEN. This is particularly true when that dependency comes about suddenly and is not anticipated. My advice is to seek professional help if depression continues and/or begins to impact your ability to function on a daily basis. Ensure that there is no physical cause of your depression, such as my response to the medications after surgery. Antidepressant medication may be advisable, as may be counseling in some form. As part of your long-term coping strategy, look for a reason to get out of bed each day. Finally, at least for me, faith in God truly can move mountains—even the ones you may feel you are carrying on your back.

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Just For Kids
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Individual Donors—Thank You!

The following list represents everyone who contributed between June 9 and August 8, 2007. We also want to thank all of 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.

Ambassadors ($2000+)
Darlene Kelly, MD

President’s Circle ($1000–$1999)
Ezra Steiger, MD

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CONNSPEN

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Lenore Heaphey, in honor of Joan Bishop’s*** birthday, Dr. Lyn Howard’s*** retirement, and for the Lenore Heaphey Grassroots Education Award

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Richard & Faith Dillon
Rebecca Edwards
Randall & Daphne Falck
Nancy Goodick
Elizabeth Greenberg, in honor of Rachel Schten
Jane Lindsay
Cynthia & Thomas Macko, in memory of Clarence Oldenburg, Oley’s co-founder

Supporters ($50–$99)
Elizabeth & Earl Bond, in memory of Warner Smith

Victor Chaney, in memory of
Melissa
Eleanor Orkis, in honor of Dr.
Lyn Howard’s*** excellent
care & Joan Bishop***
Doug Seidner, MD*

Contributors ($30–$49)
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Anonymous via United Way
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Barbara Laird
Carole Ryan
Mark & Regina Stoker, in memory of Frank Bianco
Hanna Schwarz, in honor of
Sanjay Chepuri
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Richard & Barbara Ost
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Katherine Snow
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The Wagar Family
John & Mary Lou Yetto

In Memory of Kyle Noble
Darlene Kelly, MD*
Beverly Mello
James Wittmann

Thank You, Thank You
Please join us in thanking our corporate sponsors who keep Oley’s programs going strong. We appreciate their generous support!

Novartis Nutrition
Headquartered in Minneapolis, Minnesota, Novartis Medical Nutrition is the second-largest manufacturer of enteral formulas and delivery systems in the United States and an industry leader in oral supplements, tube feeding products, and fortified foods used in the institutional and home settings. The company is focused on providing the highest quality nutritional products and services that maintain and improve human health and well-being.

Novartis Medical Nutrition values the relationship it has with the Oley Foundation, and encourages all of its Partnered Providers to become involved and get to know all HEN consumers whom their products touch every day.

Sherwood Clinical
Sherwood Clinical began as the vision of one man. Seeing a need, Charles Sherwood developed a plan to deliver high-quality infusion care in the comfort and convenience of patients’ homes, and in 1993 Sherwood Clinical was born.

Today, more than a decade and 100 employees later, Sherwood Clinical provides home-infusion care throughout Georgia, the western Carolinas, parts of Tennessee, and Alabama. Sherwood Clinical provides a wide range of services, including antibiotics; EN and PN therapy; central line maintenance; IV hydration; IV inotropics; IVIG therapy; pain management; Synagis; intermittent therapies; midline catheter placement; skilled nurse visits; and patient and caregiver education. Sherwood Clinical also provides home medical equipment through its partnership with Care Medical, Inc.

Wanted: Your Stories
We are hoping to develop an article for the LifelineLetter about how HPEN consumers should care for their gums and teeth once they have been placed on artificial feedings. Please consider sharing your experiences with gum or teeth issues. Your story may help someone else. Please e-mail your personal stories to Lisa Metzger at metzgel@mail.amc.edu.
Oley Welcomes NutriThrive

With a huge splash, NutriThrive dove into the Oley sponsorship arena in June at the Golden Medallion Level ($50,000–$69,999). This major gift demonstrates a strong vote of confidence in the work of the Foundation as well as provides financial support to sustain Oley programs. Thank you. Thank you.

The folks at NutriThrive, Inc., write:

Consistent with Oley’s mission, NutriThrive is dedicated to improving the lives of those at home on nutrition support. NutriThrive is focused on providing products and clinical services that are customized to specialized nutritional requirements. Our goal is to provide excellent care, minimize therapy needs, and help individuals get on with living life.

As an Oley Partner, NutriThrive has put its mission into action by providing an annual base contribution and additional financial support through the Full Circle program, contributing $1 for every day of parenteral nutrition and $1 for every course of enteral nutrition that our patients require nationwide. We are committed to giving back to improve life for those on homePEN.

Oley Foundation Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

John Balint, MD
Joan Bishop
Ginger Bolinger
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Tom Diamantidis, PharmD
Selma Ehrenpreis
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Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

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Thanks!
**Toll-Free Numbers Available to US and Canadian Consumers!**

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

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

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

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

<table>
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<tr>
<th>SEP. ’07</th>
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<tr>
<td><strong>Barbara Klingler</strong>&lt;br&gt;Valkaria, FL&lt;br&gt;(888) 610-3008 EST</td>
<td>Barbara Klingler has been on TPN since 1986 due to SBS from an infarction. She enjoys traveling. While on TPN, she has been on a cruise, motor-homed Alaska and cross country. She has been scuba diving and enjoys dog agility with her labrador. She has overcome liver failure and kidney stones. She has a strong faith in God.</td>
</tr>
<tr>
<td><strong>Patty &amp; Darrell Woods</strong>&lt;br&gt;Hemet, CA&lt;br&gt;(888) 650-3290 PST</td>
<td>Patty and Darrell have five children, one of whom (Colyn) has been TPN dependent since 1996 due to pseudo obstruction secondary to a mitochondrial disease. They are easy to talk to and enjoy swapping tales about managing TPN issues, keeping a positive perspective, and having a normal, active family life.</td>
</tr>
<tr>
<td><strong>Jerry Fickle</strong>&lt;br&gt;New Haven, IN&lt;br&gt;(888) 610-3008 EST</td>
<td>Jerry has been on HPN since 1981 due to Crohn’s disease and short bowel syndrome. He also has an ostomy. He currently has a Hickman catheter and has had a Gastrohong in the past. Jerry can also discuss the benefits of attending Oley’s annual conference. He looks forward to speaking with others.</td>
</tr>
<tr>
<td><strong>Eleana Shore</strong>&lt;br&gt;West Hills, CA&lt;br&gt;(888) 650-3290 PST</td>
<td>Eleana’s daughter Erin (age 11) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, arthritis, and hypomotility disorder. She has undergone three Nissen fundoplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</td>
</tr>
<tr>
<td><strong>Melanie LaVoie</strong>&lt;br&gt;Tauton, MA&lt;br&gt;(888) 610-3008 EST</td>
<td>Melanie is mom to 6 y.o. Alex and 3 y.o. Adam who is on Mickey G-tube feedings due to gastroparesis. Melanie and her family have attended a few Oley conferences and look forward to speaking with others about the rewards of attending an Oley gathering.</td>
</tr>
<tr>
<td><strong>Karyn Thomas</strong>&lt;br&gt;Midland, MI&lt;br&gt;(888) 650-3290 EST</td>
<td>Karyn has had a total colectomy and ileostomy since 1975 and has been on HPN for 29 years due to strangulation of the bowel (ischemia) leading to SBS. She is a 10-year breast cancer survivor. Karyn has been married to her husband Bob for 48 years; they have 5 grandchildren. Karyn is on the go most of the time. If you call and don’t reach her, please try again. She looks forward to talking to you.</td>
</tr>
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