Probiotics: Nature Becomes Therapy
Mark R. Corkins, M.D., C.N.S.P., S.P.R., Co-director of Nutrition Support, Riley Hospital for Children, Indiana University School of Medicine, Indianapolis, Indiana

We live our lives surrounded by bacteria. Most of us think of bacteria as causing infection and as bad organisms. Actually, nothing could be further from the truth; we have many bacteria in our lives that are helpful. Without bacteria there would be no cheese or yogurt. We also utilize bacteria that live in our bodies to improve our health. Our lower gastrointestinal (GI) tract is full of bacteria; in fact, more than 500 bacterial species have been cultured from the large bowel.

The idea that bacteria were actually helpful started in 1908, when Metchnikoff reported that Bulgarian peasants who consumed large quantities of sour milk containing the bacteria Lactobacillus bulgaricus lived longer. He coined the term “probiotics,” meaning “for life” and postulated that the bacteria had health-promoting effects.

At birth our GI tract is bacteria-free, but it is quickly filled with bacteria during the birthing process and altered by what we are fed in the first one to two years of life. This collection of bacteria is referred to as our “flora.” Also known as “microbiota,” it most closely resembles that of our mothers, but it is unique to each individual. Why is this important?

The GI tract is one of the most exposed parts of our body. The skin is a major barrier to exterior elements, but the GI tract is constantly exposed to and absorbing things from outside the body. In fact, after bone marrow, the GI tract is the second largest immune organ. The GI lining is full of white blood cells. A balance between bacterial flora and gut-associated lymphoid tissue (GALT) causes a steady state of low-grade inflammation to be

Hyannis in June — Momentum is Building!

With the 2007 Oley Conference program still in the planning process it was a huge surprise to find that rooms at the conference headquarters, the Cape Codder Resort and Spa, were filled up and a waiting list was being formed. If you are planning to attend, we encourage you to consider booking your rooms, and to get on the Cape Codder’s waiting list.

For your convenience we have secured overflow rooms at the following hotels in Hyannis: Holiday Inn, 1127 Iyannough Road, 508-775-1153 (directly across the road from Cape Codder); and Radisson Resort, 287 Iyannough Road, 508-771-1700 (approximately 1.65 miles from the Cape Codder).

Positively Purrfect Pets
Robin Lang

I began HPN 27 years ago and was advised not to own pets. Doctors said, “They carry too many germs. They’re a lot of work. It’s risky business.” HPN was a new therapy then; doctors had reason for concern. My HPN training was excellent and I practice it everyday. I’ve also owned dogs all my life and have never had problems associated with them.

Presently I have Zoë, a black lab, and Doodle, a Jack Russell terrier (JRT). They give me a workout yet it doesn’t feel like work. Zoë weighs 90 pounds and thinks she’s a lap dog. Doodle weighs 25 pounds and has confidence the size of an elephant, yet he believes he can be a mouse and live in my pocket. They’re true friends. Our relationship is one of equal respect and love for each other.
In this era, we are also seeing increasing numbers of autoimmune diseases and infections with unusual organisms. This has led to a “hygiene hypothesis”: decreased exposure to bacteria normally seen in the flora reduces the normal low-grade GI tract inflammation. In other words, the gut’s immune system isn’t busy enough and then ends up making antibodies against its own tissues or substances it should ignore. Also, decreased exposure to bacteria often means there aren’t enough “good” bacteria in the flora to suppress the growth of disease-causing bacteria that can enter our GI tract.

General Principles

In the last few years we’ve seen an explosion of interest in biotics. **Probiotics** are living bacteria (dead bacteria don’t do anything). Different bacteria have been shown to do different things and therefore they are not directly interchangeable. For example, studies that use different bacteria can’t be compared with one another because the body responds differently to each bacterium, which makes understanding the total picture very difficult. Some of the commercial probiotic preparations are actually mixtures of several bacteria. To be a probiotic, the bacteria must not cause disease and must result in a health benefit.

**Prebiotics** are compounds that foster the growth of particular types of bacteria. Studies show that the use of prebiotics results in a shift in the population numbers of bacteria in the GI tract. Prebiotics are usually fibers that we cannot digest, but that the bacteria believed to be beneficial can digest, and use for energy. An example of a prebiotics is fructose oligosaccharide. There is a lot of interest in these agents since they don’t involve living bacteria, and therefore avoid the problem of creating a safe formula that includes living bacteria. There are currently several commercially available enteral formulas that have added prebiotics.

**Synbiotics** are combinations of living bacteria and prebiotic substances to sustain the bacteria’s growth. The studies with these agents are still very sketchy, although the logic of the combination approach is appealing.

**The Implications**

Developments with probiotics, prebiotics, and synbiotics may have important implications for people on nutrition support for several reasons. First, there is a growing realization that many of the infections patients with gastrointestinal problems suffer come from the GI tract itself. Sometimes it appears the balance of the flora is upset, resulting in an overgrowth of bacterial species that in high numbers cause symptoms, such as diarrhea and/or gas. Second, patients with gastrointestinal diseases may have infections in areas outside the GI tract from bacteria normally seen in the GI tract. The term used to describe this is “translocation,” which means bacteria or their toxins present in the GI tract escape and travel through the body via the blood stream.

The growth of appropriate flora can keep disease-causing bacteria in check. It is unclear whether this works by competition (stealing the nutrients or occupying receptors) or if some bacteria actually produce substances that suppress the growth of other bacteria. There is evidence that it could be both mechanisms. Also, as stated earlier, the various bacteria affect the GI immune system. There is new research showing that some of the probiotics actually affect the inflammatory hormones produced by the white blood cells normally located in the GI tract lining. Thus the flora affects how well the GI tract works as a barrier to prevent translocation.

Since each bacterial species is unique, each one produces its own substances and the immune system has an individualized response to each species. It is also apparent that every person responds differently to the same bacteria. Thus every probiotic agent is unique; the response to one does not predict the response to another, and a study using one species cannot be compared with a study using another. This makes research in this area difficult to interpret for clinical use. There are a variety of studies scattered throughout the literature using these agents for a variety of maladies. For this review I chose to focus on literature that has the potential to be helpful to the Oley membership.

**Specifics**

The more common families of probiotics are the *lactobacilli* and *bifidobacteria*. Each of these is subdivided into multiple species. These bacteria are not disease causing and produce lactic acid as a by-product of their fermentation of materials. Some members of these species have been used in food production to ferment milk and grains to cheese, yogurt,
**Tube Talk**

Thank you to everyone who sent material for the “Tube Talk” column. Anyone 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 MetzgerL@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.

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**Cruising for Adventure**

Good news for Oley members who enjoy cruising but who may have doubts. In 2006, my husband Dennis (HEN consumer) and I took our first HEN cruise with Royal Caribbean International, which seems to be one of the few cruise lines able to provide supplies for IV or tube feeding. After a simple toll-free phone call to RCI’s medical/special needs department, their “can do” agents arranged for whatever we needed to appear in our shipboard cabin. Our canned nutrition was free of charge.

They apparently can provide for TPN folks, too, as a refrigerator and IV pole appeared in our cabin. We did not need the extra equipment, but were kindly surprised that so much was provided. Call RCI for specific needs and details.

Other cruise lines use a company called CareVacation, available on the Web and via phone. They charge according to what you need, and you can either work with them directly or through the cruise lines.

We love cruising, and there are so many pleasurable activities for everybody on a ship besides eating. If you can still eat orally, the buffets let you nibble or snack without feeling that you are wasting food, and you can have food delivered to your cabin or take it with you to pleasure feed. We had a marvelous time, and so can you!

— Andrea Peterson
Quechee, VT

**Contacts:**
CareVacation, www.carevacations.com or (877) 478-7827
Royal Caribbean International, www.royalcaribbean.com or (800) 722-5472 (Ext. 34492 for special needs department)

We received a note from Andrea, shortly after she shared this travel tip with us, saying that Dennis died on January 4, “after a very long battle with multiple health problems.” “I am glad we did it [the trip],” she says, “as it was the last happy week we had in Dennis’ life.” Please see her letter to Oley in the Mailbox on page 5.

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**Home TPN to go.**

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

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

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

Richard Noble

As Kyle’s orthopedic surgeon Dr. Klingle put it, “He is a very special boy.” This is how so many other people continue to describe Kyle Richard Noble. Kyle passed away to eternity in heaven, December 29, 2006. He was eight years old.

Kyle’s short life was so full of living. Kyle was a brave young man who would not let any obstacles stand in his way. If you had the pleasure of getting to know Kyle… or just seeing him at an Oley Conference you understand that statement. He missed only one conference since his parents first were introduced to the Oley Foundation in 2001; this was when he was in the ICU in 2004.

As soon as you met Kyle you were hooked on his charming personality and contagious smile. Even when he wasn’t feeling well with all his tubes, Kyle always found a way to make others smile and feel better — especially those with other illnesses or challenges in their lives. Words alone cannot describe enough how Kyle’s life challenges, strength of personality, witty humor, and determination to be just a normal kid, touched so many people during his short, but full life. Kyle’s life was so truly enhanced through lifelong friendships made throughout the years. We, the Noble family, are so blessed for the numerous friends, acquaintances, and experiences we have made as a result of being involved with the Oley Foundation.

Kyle Richard Noble

Nov. 10, 1998 to Dec. 29, 2006

Understanding the Grieving Process So You Can Help Others

Joan Bishop

Most of us have no training in or knowledge of what to do to help people who have lost loved ones. I didn’t, but I do know. From my own experience, the conversations with and postings I’ve read from the Nobles, and what I’ve gleaned from the several articles in front of me, I’ve gained knowledge. I hope I can provide you with practical information to help you understand the journey.

Helping people grieve is a long process. Attending the memorial service is an obvious first step, but there is a marathon ahead. First and foremost, consider what you might do to keep a memory alive. The grieving are always concerned that their loved one not be forgotten. Mention the person’s name, share a story, plant a tree, or frame a photo and pass it along. For me, hearing my daughter Julie’s name is a precious gift. Five years after her death, sharing an experience, the conversations with and postings I’ve read from the Nobles, and what I’ve gleaned from the several articles in front of me, I’ve gained knowledge. I hope I can provide you with practical information to help you understand the journey.

It’s important to say something to those who are grieving. Even if you begin by saying that you don’t know what to say, say something and allow them to take the conversation further. People may laugh or cry — and it’s important to realize that if they cry, it isn’t because you have hurt them. Death is the source of the tears. Sharing their grief is a sign of friendship and it is much appreciated. Don’t be afraid.

How You Can Help

In the beginning, you will probably notice that things need to be done. Ask when you can help as opposed to how you can help. People who are grieving are exhausted, confused, unorganized.

Applicants are asked to write a one to three page essay describing how he or she has overcome obstacles/challenges posed by HEN and/or HPN and inspired others to live life to the fullest. An educational reference (letter from an advisor or teacher supporting educational pursuits) and a medical reference (from someone on the applicant’s health care team — physician, nurse, dietitian — verifying the medical situation) are required.

The scholarship will be distributed at the end of the school year after a copy of the recipient’s transcript of his/her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference. Applications for the June 2007 scholarship must be received by May 4, 2007. Complete details posted on www.oley.org.

Kyle R. Noble Memorial Scholarship

To further the educational goals of individuals relying on HPN or HEN for their primary nutritional needs.

The Noble family has established the Kyle R. Noble Scholarship. Each academic year, a $1,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered. Applicants are asked to write a one to three page essay describing how he or she has overcome obstacles/challenges posed by HEN and/or HPN and inspired others to live life to the fullest. An educational reference (letter from an advisor or teacher supporting educational pursuits) and a medical reference (from someone on the applicant’s health care team — physician, nurse, dietitian — verifying the medical situation) are required.

The scholarship will be distributed at the end of the school year after a copy of the recipient’s transcript of his/her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference. Applications for the June 2007 scholarship must be received by May 4, 2007. Complete details posted on www.oley.org.
New Editor for *LifelineLetter*

We are pleased to welcome Lisa Crosby Metzger as editor with this issue of the *LifelineLetter*. Lisa has worked in book and magazine publishing for a number of years and is pleased to apply her skills at “such a worthwhile organization.” Lisa has experienced two short bouts on HPN, which sustained her through difficult pregnancies. As a result, she’s been a member of Oley for almost 15 years. She’s heard such good things about the Oley membership over the years that she’s eager to meet many of you at our annual conference.

In case you’re wondering, Lisa isn’t replacing anyone. Having her join our staff will allow Roslyn Dahl, and our volunteer editor Liz Tucker, to turn their attentions to other Oley projects. Many thanks to Liz for all of her help with *LifelineLetter*!

![Lisa Crosby Metzger](image)

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**Equipment Exchange**

Newly available items offered free of charge include:

**Formula:**
- 8 cans Bright Beginnings Soy Pediatric Drink (Pediasure w/o milk)
- 1 case packets Ceralyte, unflavored
- 5+ cases Glucerna, exp. 6/07
- 24 cans Isosource 1.5
- 4 cans Jevity 1.0
- 4+ cases Novasource Pulmonary, exp. 6/07
- 4+ cases Osmolite 1.2 Cal, exp. 7/07
- 16 cases Perative, exp. 6/07
- 29 bags Vivonex Pediatric, 1.7 oz

**Tubes/Bags:**
- 19 Curlin admin sets, #340-4128V
- 4 Dosaflow ext sets with regulator, #2590250
- 41 ICU Medical 0.18 ml small bore ext set
- Kangaroo spike sets for Ultrapack, #704605
- 20 LifeShield Primary IV pump set, #16453
- 5 Patrol Easy Feed pump sets/bags, #52048
- 15 Patrol Easy Feed pump sets/bags, 1000 ml, #52048
- 15 Ross Companion 1000 ml bags
- 1/2 case Ross Embrace, mixture of 500 & 1000 ml
- 41 Ross EZ feed bags, 1000 ml
- 8+ Ross EZ Feed Patrol 1000 ml
- 4 Ross IV admin sets, #V1402

**MORE SUPPLIES** are available! Visit [www.oley.org](http://www.oley.org), or contact our volunteer, Ben Hawkins (benhawkins@fuse.net; toll-free 866-454-7351). This number reaches Ben’s home, so **please call before 9 p.m. EST**. ALSO, please let Ben know if you have not taken the items referred to you, so he can make them available to other members. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. We ask that those receiving goods offer to pay the shipping costs.

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**Lifeline Mailbox**

Dear Oley,

Andrea (Andi) Johnson and I met through the Oley newsletter seventeen years ago. We never had the opportunity to meet. We kept in touch by mail, e-mail, and phone calls. We shared about our lives, children, and grandchildren, and swapped many photos.

We went through bad and good times with our health, and supported each other with words of encouragement. Andi never complained. We had many laughs, especially when I was learning to use a computer. She taught me a lot for someone who lived thousands of miles away. What she didn’t know, she found out and passed along to me. This got me out of a lot of jams.

Andi died this past November. She had a big, loving heart. I will miss her dearly. I want to thank Oley for bringing us together.

— Beverly Promisel
Leominster, MA

Dear Oley,

My husband, Dennis, died January 4, 2007, after a very long battle with multiple health problems. He had an extra six months thanks to the support of the Oley family, and I want to thank those in the Oley Foundation who gave of their time on the phone to encourage us and help us along with tube and HPN feeding knowledge.

Without Oley, we would not have had the last special six months of life, imperfect though they were, and would not have known what to do with the new mysteries of tube feeding at a very discouraging time. Special thanks to the people in the Northeast region who were available by phone and offered such encouragement and support to Dennis and me.

— Mrs. Andrea K. Peterson
Quechee, VT

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**You Can Rely on Apria**

![Apria Healthcare](image)

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(800) 776-OLEY • *LifelineLetter* — 5

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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 the institutions around the country 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.

University of Pittsburgh Intestinal Rehabilitation and Transplantation Center

The Intestinal Rehabilitation and Transplantation Center at the University of Pittsburgh’s Thomas E. Starzl Transplantation Institute provides care for adults and children with intestinal failure. The program was established by Kareem M. Abu-Elmagd, MD, PhD, FACS, in 1990, and provides enteral and parenteral nutrition, intestinal rehabilitation, and when needed, intestinal and multivisceral transplantation. The program offers a full multidisciplinary team approach for both the pediatric and adult components; the team may include transplant surgeons, gastroenterologists, clinical fellows, nutritionists, pharmacists, physician assistants, nurse coordinators, case managers, social workers, research coordinators, and other support staff. These professionals have extensive experience in managing clients who are unable to maintain their nutritional status through an oral diet as a result of severe malabsorption or intestinal obstruction. The pediatric crew, under the leadership of George Mazariegos, MD, is expanding its experience to include neonates and premature babies with congenital and acquired intestinal failure who need prompt comprehensive medical and surgical therapy.

The team approaches every individual case with the hope to discontinue parenteral nutrition and resume full enteral support. Some patients may be candidates for intestinal rehabilitation without the need for transplantation. Different regimens, including diet modification, medical supplements, growth factors, and reconstructive surgery, may be used in an attempt to maximize nutrient absorption and minimize or eliminate the need for parenteral nutrition. When intestinal rehabilitation is not an option or the patient fails to respond to these therapeutic attempts, intestinal and multivisceral transplantation is offered. The center has the largest series of intestinal and multivisceral transplants in the world with the longest survivors. For more information about our programs visit www.transplant.upmc.com or call toll-free 877-640-6747.

Resources Galore at www.oley.org

Did you know the “Resources” section of www.oley.org has links to literally hundreds of great resources for homePEN consumers and family members? Topics range from disease-specific websites to information on legal issues. New this month is a link passed on by Carla Truman for a website (www.schwablearning.org) that helps families understand tax credits for dependents with disabilities — even for learning disabilities issues — and includes conference expenses related to your child’s condition. In other words, it’s another way to make traveling to the Oley conference more affordable. Check it out at www.oley.org!

E-mail Updates

Send us your e-mail address, and we can send you news updates, the latest conference information, and the Lifeline-Letter long before it would hit your mailbox. Your e-mail addresses will also allow us to better connect you to other members, and e-mail is a great alternative for those who can’t afford long distance phone calls. Our e-mail list is private and will not be shared. Contact Cathy at (800) 776-OLEY or harrinc@mail.amc.edu to share your e-mail address.
Recognize the Quiet Hero in Your Life!

Oley Award Nominations
Each and every Oley member contributes to the success of those who walk beside them and follow in their footsteps. The Oley awards give us each a chance to acknowledge someone in our own lives who has inspired us by their courage, perseverance, or willingness to help others. Nominate someone in your life who has earned your respect because of what they have overcome or inspired you by how they live.

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

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

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

Questions?
Call (800) 776-OLEY.

Nominations must be submitted by May 4, 2007

Award Criteria

The awards will be given June 28 at the 2007 Oley Conference in Hyannis, MA. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a keepsake, are honored at the conference awards program and will be spotlighted in the LifelineLetter. Most awardees will have some of their travel expenses underwritten. Recognition is given to all nominees!

LifelineLetter Annual Award
In honor of Nutrishare Inc.,
Oley Platinum Partner
★ 19 years of age or older
★ HomePEN consumer or caregiver
★ Consumer has been on homePEN for at least five years
★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
➤ Winner will receive a partial travel grant to the Oley Conference in Hyannis, MA, June 27 to July 1

Oley Foundation Child of The Year Award
★ 18 years of age and under
★ HomePEN consumer
★ On homePEN for at least three years
★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
➤ Winner will receive a partial travel grant to the Oley Conference in Hyannis, MA, June 27 to July 1

Celebration of Life Award
In honor of Coram Healthcare,
Oley Golden Donor
★ Enteral or parenteral consumer, any age
★ On homePEN for at least 3 years
★ Lives life to the fullest — traveling, fishing, gardening, volunteering, performing in local theater, spending time with children and grandchildren, etc.
➤ Winner will receive a partial travel grant to the Oley Conference in Hyannis, MA, June 27 to July 1

Lenore Heaphe Awar for Grassroots Education
★ Oley Foundation Regional Coordinator
★ Organized an outstanding information and/or education program during 2006
➤ Winner will receive a nominal cash award to foster educational/support activities in his or her local area

Nan Couts Award for the Ultimate Volunteer
★ Clinician (physician, nurse, dietitian, etc.) must practice in the field of homePEN or a related field, i.e. psychology, interventional radiology, pain management, etc.
★ Has demonstrated a willingness to give of themselves — beyond their regular work hours — to educate, empower and improve the quality of life for homePEN consumers. For example: a nurse who facilitates an Oley support group on his/her day off.
➤ Winner will be honored at the Oley Conference in Hyannis, MA, June 27 to July 1
Oley Foundation Award Nomination Form

Deadline for Nominations: May 4, 2007
The Oley Foundation • 214 Hun Memorial, MC-28 • Albany Medical Center
Albany, NY 12208 • Fax: (518) 262-5528 • e-mail: harrinc@mail.amc.edu

1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2007
(please check one):

❏ LifelineLetter Award
❏ Oley Foundation Child of the Year Award
❏ Lenore Heaphey Award for Grassroots Education
❏ Nan Couts Award for the Ultimate Volunteer
❏ Celebration of Life Award

Nominee’s name: ____________________________ Age: ________
Address: ______________________________________________
City: _____________________________ State: _____ Zip: ______
Phone: ( ____ ) _____ - ______ home, ( ____ ) ____ - ______ work
E-mail: ______________________ @ _________________________
Primary diagnosis: _________________ No. years on HPEN _____

2 Fill in your name and contact information.

Your name: ______________________________________________
Relationship to Nominee: _______________________________
Company (if any): _______________________________________
Address: _________________________________________________
City: _________________________ State: ______ Zip: _________
Phone: ( ____ ) _____ - ______ home, ( ____ ) ____ - ______ work
E-mail: ______________________ @ _________________________

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

3 Tell how the nominee meets the criteria for his or her award (see other side), describing specific examples: i.e. how this person has demonstrated a positive attitude in dealing with his/her illness; lived a full life; organized an excellent educational program; brought information and compassion to homePEN consumers; or generally has helped others live with HPEN. Attach one additional page if needed.
Pet owners know the benefits outweigh the risks. The CDC, the National Institutes of Health, and the U.S. Dept. of Health and Human Services all agree that pet ownership can provide benefits, and they have several documents to support the argument. Organizations such as the American Kennel Club, American Veterinarian Medical Association, shelters, hospitals, nursing homes, police and fire departments, and the armed services all report the same: Pets benefit health!

Pets drive us to exercise them, feed and water them. Some days, it may feel like work, but most days it’s a job we do gladly. Care giving is rewarding in so many ways.

**Pet Pals**

Several HPEN consumers, and others associated with HPEN, own all kinds of pets. Oley’s research and medical director, Lyn Howard, MD, enjoys chickens, cats, dogs, horses, and more. They give her, her family, and her friends great pleasure.

Consumer and Oley Regional Coordinator (RC) Barb Klingler says, “Pets have been a huge part of my life.” Her chocolate lab, Sara, can do 25 tricks and has garnered over 11 AKC titles in dog agility. Barb has raised three guide dogs for the blind, all the while running with Sara. Now Barb’s new puppy, Abby, has begun training and Sara can enjoy retirement. “Agility builds my bones and theirs,” Barb comments. When her energy level is low, her dogs inspire her to get involved with people. “Being on TPN doesn’t end things we enjoy,” Barb adds. “My dogs are great cuddlers and companions.” If you’d like to learn more about the fun, challenging activities Barb’s involved in, watch the Animal Planet channel, or contact the AKC or Dogs for the Blind.

The Cyr family of Sebattus, Maine, got Tickles, a JRT puppy, for their 13-year-old daughter Maisy. She’s been an HPEN consumer for 11 years. Maisy loves animals. She recently spent time volunteering on a pony farm, where children learn to ride and conquer fears.

Though many consumers love dogs, others are crazy for cats. Liz Tucker, former editor of Oley’s *LifelineLetter*, owns both. “The companionship is wonderful. They’re a joy to have around,” Liz says. “I’m busy coming and going, yet my pets don’t mind. They’re as happy as I am when I return to relax. While working from home they are always near. They ask little of me, but give so much.”

Oley RC Judy Peterson is passionate about her pals, and her e-mail address reflects that (it’s “catsjp”). Judy has had health problems but knows her cats support her. They cuddle, snuggle, and purr. They sense if she isn’t feeling her best, and they’re there to give her unconditional love. “Being loved by my cats is one of the best kinds of love in the world,” she says.

Long-term consumer Marsha Brent has owned cats all her life. She, too, was advised of the risk of germs and infections. Marsha keeps her HPN bags and supplies separate from her cats. She cleans their boxes and practices the principles outlined in Oley’s “Keep Me Safe” poster. Marsha says, “It isn’t hard, it’s common sense. I keep myself clean and my pets clean and I don’t mix the two. It’s a nuisance to wash my hands so much. Living in New England my hands get raw, but I wouldn’t trade my kittens. Products like Germ-X and Purell make it easier for me to stay clean.” Marsha admits feeling low at times, but she’s thankful her cats nudge her forward. “They love me even when I feel lazy, yet they don’t allow me to feel blue for too long. I love them for that and much more.”

Consumer Sharon Riffice may be relatively new to Oley, but she’s a seasoned cat lover. She can’t imagine having less than two cats, and presently has four. Sharon says, “They’re mushy and cover me with hair while they knead my lap.” She adds, “They’re fun and amusing and provide lots of company. They seem to know when I don’t feel well and they hover. My cats keep me happy and grounded. I’d hate to come home without cats waiting at the door.”

Like Sharon, Jeanne Wilson, RN, an expert infusion nurse for over 30 years, says, “Animals intuitively know our needs, whether it’s a laugh, a lick, a snuggle, or a purr.”

RC Ben Hawkins, like Dr. Howard, has a myriad of pets: a bird, two cats, a tank of fish, and a dog named Sasha. Ben says, “Sasha is my protector and makes me exercise. She has lots of energy. I wish I had some of that. Sasha and my cats give affection and make me feel loved. I’m careful not to let my pets near my table where I prepare to ‘hook up.’ My cats sit on my lap and keep me company when I run my hydration. Petting my pets and watching my fish put me a peaceful mood. They lower my blood pressure and I relax. I’m lucky, and healthier with my pets around me.”

Another multi-pet owner is Carol Ireton-Jones, PhD, RD, of Coram, Inc. Carol writes, “After my mom’s death, I cared for her cats. It was difficult at first but they comforted me. My dog Annie is amazing, and she’s always smiling, which makes me smile. I recommend pets because they accept us just the way we are, be it in our jammies with messy hair, happy, sad, or mad. They’re so forgiving of us and adjust to our ways.”

Consumer Charleen Rouleau of Alberta, Canada, writes, “My pet has a huge impact on my life.” Charleen owns a 15-year-old Pomeranian. Her dog is number one in her book. Charleen says, “Owning a pet is like having a child around.” It’s an experience she feels blessed to have.

**Love at Home**

Pets come in all shapes and sizes. My brother Christopher and his wife, Larissa, have owned ferrets for years. Ferrets are not comics. I “pet sat” for many years and can attest to that fact. They snuggle like...
Probiotics, from pg. 2

and other foods. These bacteria have been classified by the FDA as “generally recognized as safe” (GRAS) for human consumption.

Studies have shown that breast-fed infants have increased numbers of *bifidobacteria* in their GI tract. Breast-fed infants also have lower rates of infectious illnesses, particularly diarrheal diseases. Although some of this is attributed to the immune factors in breast milk, some is believed to be a result of better flora in the GI tract. Studies have shown that formula-fed infants given probiotics or prebiotics have a change in their flora. The studies show this is only temporary, however, and the flora reverts back after the agent is stopped. Once the flora is established it is quite resistant to change.

Studies have shown that infants with viral gastroenteritis have a shortened illness course if they are given a probiotic. Most of these studies were with *Lactobacillus GG* (rhamnosus) (see photo page 1). There have also been some studies that indicate that probiotic use may prevent diarrhea from developing.

One of the proposed uses for these agents would be to prevent antibiotic-associated diarrhea. It is assumed that antibiotics change the normal GI flora, which leads to diarrhea. The use of a probiotic to counteract this is logical. There are several small, poorly designed studies in this area. Two meta-analyses suggest that the use of a probiotic with antibiotics could reduce the incidence of diarrhea by up to 60 percent. The best probiotic agents identified in these studies appear to be *Lactobacillus GG* and *Saccharomyces boulardii*. There are small studies using other bacterial species, which do not appear to be effective in preventing diarrhea.

Another malady that can result from antibiotic usage is a *Clostridium difficile* infection (sometimes called *C. diff*). A lot of people who frequent health care facilities are colonized with this bacterium; the normal flora keeps it in check until antibiotic usage allows it to grow to levels that lead to GI symptoms. Again, this would be a logical intervention area for a probiotic. Only a few studies have been conducted in this area, but it appears that *Saccharomyces boulardii* reduces the chance of developing a *C. difficile* infection when taking antibiotics.

Individuals who have had their colon removed and replaced with a surgically created pouch are at risk of developing pouchitis, bacterial overgrowth in the pouch. There are several studies that demonstrate that VSL#3, a cocktail of eight different probiotics, is effective at preventing the recurrence of pouchitis after initial treatment with antibiotics. In fact, this literature is the most convincing of all of the probiotic studies. Interestingly, *Lactobacillus GG* was found not to be helpful in treating pouchitis.

There are also studies looking at the use of probiotics in inflammatory bowel diseases and in gastrointestinal allergies. However, these studies are very mixed in their quality and agents used, and thus I have not reviewed them in this article.

**Summary**

Probiotics are living bacteria that benefit an individual by helping create a GI flora that resists the growth of disease-causing organisms. Different bacteria behave in different ways, and studies with different agents are not readily compared. A probiotic beneficial against one disease may not be so for another. This field is growing rapidly and administering probiotics has become standard clinical practice in many situations.

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**Happy Nu Year!**

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cats, nip like puppies, and are fast friends. Presently Chris and Larissa own Mozart, a tropical lovebird. Recently they discovered Mozart knows when its coffee time. He flies onto their shoulders, marches down their arms, and steals a sip of morning java. Chris and Larissa have stressful, high-power jobs, but at the end of the day Mozart puts everything into perspective. Larissa said, “This is one of the greatest gifts I’ve received from Chris. Love and a lovebird in our home.”

Pets heal us and our hurts. My friend Sharon and her bulldog Bugsy went through a painful divorce. Sharon credits Bugsy for getting them through. They moved in with her mom, Mary, who was afraid of dogs. Mary now says, “Even my friends can’t believe the change in me. I’m young again at 75 years old and Bugsy deserves some credit. He and I are buddies while Sharon works.” Mary continues, “I take him for his daily ‘drag.’ He is slow, but we’re moving forward further each day.”

Problem Solving

Of all of the people I interviewed, I only met two people who have had problems with pets, and they were small and easily remedied. One woman woke to find her kitten chewing on tubing; the kitty didn’t breach the sterility of the line, though. She changed the tubing (just to make sure all was sterile again) and resumed infusion; then she gave her kitty an alternate toy to play with. Distraction is a wonderful tool to use when you own pets.

Another person tripped over his line while avoiding a pet. (This happens to me all the time.) Though he did not fall, it could have been a big problem. Now he loops his tubing much like an electrical cord and stuffs it in his pocket. That way nothing is loose and flying free. I too use this technique.

No pockets? No problem. When moving about the house, I carry a cane or fly swatter and hold it in front of me, or to one side; this makes my “space” larger and the dogs won’t come near me, therefore yielding to my movements. Nudging them with my leg or arms also lets them know where the invisible line is. Most animals gladly yield with voice or body commands. Once I’m hooked up with HPN in a chair or bed, then they’re allowed to enter my space—when the tubing is tucked away and secure.

Many consumers pin their tubing to their clothes. Try wrapping a piece of tape around the tubing about 8-12” away from the body; have the ends of the tape overlap about 1” to create a tab. Then take a safety or diaper pin and pin it through the tab, then through the clothing, and close the pin. In the event the tubing gets pulled by a pet, or caught on a doorknob or other protrusion, the pressure is put on the pin not the tubing. The tugging will warn you before a big problem occurs.

If you’re considering owning a pet, do your research first. You can go online and find many sites with information. Choose a pet that fits your lifestyle. If you’re unable to own a pet, there are volunteer opportunities that will allow you to be near pets; ask at your local shelters, kennels, animal farms, zoos, and wildlife rehab facilities.

Pets are wonderful companions. They help us live longer, happier lives. They give us the will to live, and they’re always ready to give unconditional love.

Not long after Robin submitted this article, her black lab Zoë died of cancer. Robin writes, “She was a great girl. She made friends wherever she went. She was a cream puff, and she hung in with me for almost 11 years.”

---

**Oley/Tampa Group Welcomes New Members**

You are invited to join the Oley/Tampa support group. This group has been meeting since 1988 and is well-versed in the issues that consumers want to discuss. Oley Regional Coordinator June Bodden organizes each meeting as an open forum for sharing concerns, experiences, tips, and support. June often presents DVD coverage of past Oley conferences and refreshments are provided.

The group is overseen by medical advisor Meg Cass Garcia, RN, MSN. Meetings are informal and you’re welcome to bring friends and family. Join the group at the H. Lee Moffitt Cancer Center, University of South Florida (12902 Magnolia Drive, Tampa, Florida), on the following dates:

- **June 2** 10:00 a.m.
- **September 1** 10:00 a.m.
- **December 1** 10:00 a.m.

June Bodden can be reached for details at (727) 784-9659 or holycow4@webtv.net. A map and driving directions to the H. Lee Moffitt Cancer Center are available on www.oley.org in the “Meetings/Support Group” section or by calling (800) 776-6539.

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**Conference, from pg. 1**

These hotels will honor the rate of $129/night during the conference, June 27 to July 1, and three days pre- and post-conference based on availability. When making your reservation, indicate that you are attending the Oley conference to secure this rate, and whether you will need a handicap accessible room and/or a room refrigerator.

Visit www.oley.org for the latest updates on the program and accommodations. Looking forward to seeing you in Cape Cod!
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We also want to thank all of those who are not listed below, yet have supported the Foundation

Alicia Hoelle**, in honor of
Dominic Cucinotta’s 80th birthday
Blanche & Bob Hoffman
Maryann Jenkins
Henry & Anna Johnson
Brenda Leake
C.A. Leskovansky
Joan & Kenneth Lighthall
Sheryl Longobardi, in honor of
the Oley Foundation and all
their years of support for those,
in need!
Jenny Mayer, in honor of Mr. &
Mrs. Larry Mayer, Ashley & Larry
Ron & Lisa Metzger***
Norma Neapolitano
Roger Niosi
Maryann & James O’Donnell, in
memory of Marion & Robert O’Neil
Diane Owen
Kristie Palmer
Jim & Sarah Rausch, in honor of
Julie Andolina
Gary & Karen Rieck
Peggy Roth
Kelly Schlager RD CNSD
Charlotte Shore, in honor of Erin
Shore’s birthday
Jeanne Taylor
Jennifer Thiese & Randy Menk, in
memory of Jennifer’s Aunt
Laurel Malo and, in recognition
of Jennifer’s 5 years in remission
of leukemia
Janet Thompson, in memory of
Norma Thompson
Ticonderoga Elementary
Sunshine Club, in memory of
Michael Speshock
Jason Timmons
D.E. Vincent

**In Memory of Andrea Johnson**
Rebecca Coleman
Megan Edwards
Lori O’Brien
Dorothy & Patrick Pheny
Beverly Promisel
Helen Santiz
Tayler Prescriptions

**In Memory of Kyle R. Noble**
Felice Austin** & Mariah
Abercrombie
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The ECOT Counseling
Department
Robert & Sherry Fink
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** Oley Regional Coordinator
*** Oley Staff

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**Thank You, Thank You**
A special thank you to our corporate sponsors who keep Oley and its programs going strong. We appreciate your generous support!

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

**Nestle Nutrition — Blue Ribbon Partner**
Nestle Nutrition, part of the world’s largest food company, provides a comprehensive line of enteral nutrition formulas to the health care community. Markets served include hospital, home care and long term care sites. The company’s product offerings satisfy a wide range of demanding clinical nutrition needs with products that include oral supplements and tube feeding formulas in the form of whole-protein, elemental and special diets for both adults and pediatrics.

**Option Care, Inc. — Patron Level Partner**
For more than 25 years, Option Care, Inc. has made patients’ lives easier with a full range of health care services outside the hospital setting, working with more than 400 payor organizations representing more than 75 million Americans. With the largest home infusion and specialty pharmacy footprint in the industry, Option Care offers treatment nationwide to patients in their homes, physician offices or other alternate sites, including ambulatory treatment centers. Services are provided by highly skilled, clinical professionals from 113 pharmacy locations.

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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.

<table>
<thead>
<tr>
<th>MAR. ’07</th>
<th>Toll-Free Numbers Available to US and Canadian Consumers!</th>
</tr>
</thead>
<tbody>
<tr>
<td>Michael Medwar</td>
<td>Franklin, MA</td>
</tr>
<tr>
<td>Sheila DeKold</td>
<td>Floyds Knobs, IN</td>
</tr>
<tr>
<td>June Bodden</td>
<td>Clearwater, FL</td>
</tr>
<tr>
<td>Mary Friel</td>
<td>Framingham, MA</td>
</tr>
<tr>
<td>Kevin &amp; Janet Miller</td>
<td>Rumford, RI</td>
</tr>
<tr>
<td>Liz Tucker</td>
<td>Lakeville, MN</td>
</tr>
</tbody>
</table>

Michael was diagnosed with Crohn’s disease at the age of 9 in 1979. He was mostly HPN dependent from his teen years until late 2001 when he was fortunate enough to get off therapy thanks to good luck, diet and exercise. He has been an editor at a daily newspaper for many years. He is glad to chat with anyone.

Sheila has an 8-year-old son David and a 6-year-old daughter Olivia, who was diagnosed with pseudo-obstruction at the age of 2 years. Olivia is HPN dependent and has tolerated enteral feeds in the past. Olivia has a G-tube and a separate J-tube as well as an ileostomy. She requires catheterization overnight.

June has had Crohn’s disease since age 15, an ileostomy since age 21 and HPN since age 39 (over 20 years). An RC and an active support group member, she believes networking with others is important. A strong faith, volunteer work and help from family and friends keep June upbeat.

Mary has been on HPN for 13.5 years due to short bowel syndrome and Crohn’s disease (35 years). Mary is active in community groups, travels with HPN and keeps busy with family and friends. She has attended four Oley conferences. Please call evenings 7-10 PM EST as she works during the day.

The Miller’s son Jonathan (24 y.o.) has been on HPN since birth due to SBS from gastrochisis. They can speak about raising a child on HPN. They have attended several Oley conferences, and can give tips on traveling to this year’s meeting from the Providence, RI, airport — an easy travel option for those renting a car.

Diagnosed with Crohn’s disease, Liz has been on HPN for 20 years. She is an experienced traveler, loads of fun and well-versed in stress management techniques. She is also very knowledgeable about insurance issues and the latest treatments for Crohn’s. Be sure to ask her about the annual Oley conference.

LifelineLetter
The Oley Foundation
214 Hun Memorial
Albany Medical Center, MC-28
Albany, NY 12208

Nominate Someone Special for an Oley Award!
See pages 7 & 8 for details.