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# LifelineLetter

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

## Pain: Advocating for Yourself in a Maze of Discomfort

**Betsy Rothley, RN, MSN, FNP, BC**

Pain can be all encompassing and possessive; stealing our emotions, good moods, sexual desire, and invading our capabilities for a good night's sleep. Those who suffer pain know that it literally changes the world that we live in day to day.

Pain has two major components that we focus on: the physical and the emotional. We understand that when we experience pain, the sensation is delivered to our brain and can affect our emotions. We also often see emotional stress/difficulties show themselves as physical ailments. Modern medicine is focused on improving the care options offered to pain patients in two ways: pharmaceutical companies are developing new medications to aid the physical control of pain, and pain centers are now offering emotional support to help patients develop skills for coping with the effects of pain in every day life. Although this article describes the physical management of pain, both components need to be recognized and addressed aggressively and appropriately to achieve a better quality of life.

### Types of Pain

As science has shown us, 'Pain' is a disease process that if untreated, can turn into an out-of-control beast that modern medicine has difficulty controlling.

To better manage pain, we must understand and recognize the type of pain that is being suffered.

**Nociceptive pain** is defined as pain that originates from tissue damage in the somatic or visceral structures (Cherny, 1998). This kind of pain can be caused by inflammation of skin or tissue, or simply straining a muscle. Visceral pain refers to discomfort in your organs, such as: lung, heart, stomach, small bowel, colon, gallbladder, pancreas, uterus, spleen, and liver. The pain from visceral or somatic damage is often described as: "aching, constant, cramping, gnawing, and throbbing."

Pain cont., pg. 2



*Pain changes the way we live.*

## Don't Miss Your Chance!

Consumers and caregivers won't want to miss this unique opportunity to learn the latest advances in homePEN and connect with the extended Oley community at this summer's meeting. Aptly named, "Keeping on Par," the 18th Annual Oley Consumer/Clinician Conference will be held June 19 to 21, 2003, at the World Golf Village Renaissance Resort, in St. Augustine, Florida (the closest city/airport is Jacksonville).

We promise a balanced program of renowned clinician speakers and experienced consumers, and plenty of opportunities to exchange ideas and have fun. Bring your whole family for a rewarding and educational vacation you'll remember for years to come.

For more information call us 800.776.OLEY or visit our website @ [www.oley.org](http://www.oley.org).



## Supporting the Oley Foundation

We have always enjoyed generous support from the home infusion industry: the home care providers, catheter and pump manufacturers, enteral formula companies, etc. For the past 20 years we have been consistent in our message to existing and potential sponsors: **"Oley can make a difference in the lives of the recipients of your products and/or services. Oley members survive by using your products and services and giving back is simply the right thing to do."**

Enticing new donors has brought some success, as the Unrestricted Corporate Donor List reflects, but surviving as a financially healthy organization remains on the shoulders of the select few devoted corporate friends and, of course, our individual contributors.

Recently over 350 copies of an extremely compelling letter (drafted by Oley Trustee, Heidi Andolina) soliciting corporate support was mailed out with the 2003 Corporate Appeal packet and a copy of the

Support cont., pg. 13

### Pain, from pg. 1

Treatment options for nociceptive pain include: non-opioids, such as acetaminophen, aspirin, and ibuprofen; opioid management; and adjuvant or adjunctive medications, such as muscle relaxants and anti-anxiety medications.

**Neuropathic pain or deafferentation** is defined as “an excitatory nerve state” that is

a result of injury or irritation of the peripheral or central neural structures, (Cherny, 1998). A common example is pain that is felt when a patient herniates a disk in their back and pain goes down from the site of injury into their legs and feet. Neuropathic pain is often described in electrifying terms, such as “burning, prickling, tingling, shooting, radiating, and stabbing.”

Treatment options for neuropathic pain include: anticonvulsant therapy, tricyclic antidepressants, and other adjuvant or adjunctive medications. Opioids are used, but not thought of as first line treatment.

### Pain Management Barriers

The management of chronic pain with opioids is still under debate among caregivers. This ongoing battle results in more and more patients with unrelieved pain, (Gladjchen, 2001). Patient issues, such as attitude, lack of communication skills, and psychosocial barriers, are other reasons that many patients' pain is not fully relieved or well managed, (Gladjchen, 2001).

Addiction to pain medication is much more rare than most people think. Addiction means that someone loses control and becomes preoccupied with their pain medications, despite the fact that they are receiving good pain relief. It also means that the person continues to use these drugs, in spite of adverse consequences, (Savage, 1999). What is far more common an issue, but not well understood, is the phenomenon of ‘pseudoaddiction.’ Clinicians sometimes misunderstand the patient's request for opioids as drug-seeking behavior, rather than a true need for good pain control, (Savage, 1999). The difference between pseudoaddiction and addiction is, those who are pseudoaddicted stop seeking additional medication when their pain is well controlled and stop the manipulative behavior that they might have used before.

### Pain in Gastrointestinal Diseases

Unfortunately pain seems to be common with gastrointestinal (GI) diseases, and often complicated, because both nociceptive and neuropathic pain are contributing. Visceral pain happens when we have stretching and contraction of our GI organs. This can feel like bloating or cramping associated with irritable bowel syndrome (IBS) and Crohn's disease, or the contraction of the gallbladder when we eat

too many fatty foods. Mostly our bodies can control the pain/discomfort we feel, but sometimes we have to supplement our bodies with drugs such as opioids to compensate.

Neuropathic pain is common in those patients who have continued inflammation and tissue damage. The damage causes a “remodeling” of our central nervous system and pain signals are continually sent to our brain, not only from the areas where the damage occurred, but areas other than those involved with our disease process, (Marcus, 2000).

When treating pain in GI diseases, one must also understand how absorption can affect the type of medication that a patient is receiving. For example, a medication that is supposed to release itself over 8 to 12 hours can be very appropriate for maintaining a consistent blood level of the drug in a ‘normal patient’, but when the patient experiences absorption or dumping issues, they aren't likely to receive the full effect of the medication. Discussions with your prescribing physician/provider will help to clarify these issues and determine the best type of medication (long-acting vs. short-acting) and the best way to deliver it (i.e. patch, IV, pill, liquid analogs, or oral lozenges).

### How to Advocate for Yourself

When discussing your pain with your physician or nurse, it is best to communicate directly about how the pain feels and how it affects you and your daily activities. Your clinician will typically ask you to rate your pain on a scale from zero to ten, with zero being no pain and ten being the worst pain you can ever imagine. When this question is asked, be specific to describe *where* the pain is. The average person with chronic pain issues has three to four sites of pain. You need to identify where it actually hurts and also *how it feels*. For example, “tingling, burning, shooting, stabbing, radiating” are important descriptors that identify neuropathic pain and will help steer your doctor to proper medication for management.

It is also very important to describe *when* the pain is at its worst and *what, if anything, helps to relieve it*. Describe what activities are you able to do, and what you have given up, because of the pain. Keeping a “pain diary” helps to show your physician what time of the day is worst and hopefully reveals a pattern for better treatment options. Take the diary with

**Pain** cont., pg. 13

## LifelineLetter

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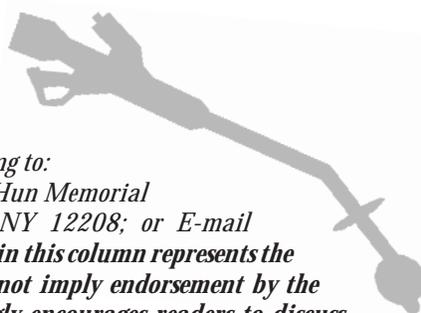
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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed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

## Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to:

Tube Talk, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@mail.amc.edu. **Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.**



### Excilon® Drain Sponges Hold Up Better

I am a first time visitor to Tube Talk and I stumbled on a posting about the softwick drain sponge. I have used them too, but find that they can fray and leave strings/lint pieces in the wound area. May I suggest the Kendall Excilon® split drain sponge. They are a similar product: a 4" x 4" pre-cut drain sponge that will fit nicely around a g-tube, but they hold up better and don't fall apart. They are excellent for tracheostomy care as well-one place where you surely don't want excess lint!

— Susan Mitchell  
Quakertown, PA  
ROBNSUE123@aol.com

### Low-Cost Alternative to Drain Sponge Dressings

One of the great expenses for those with g-tubes and/or j-tubes, is the cost of drain sponge dressings. These dressings are often not covered by insurance. A box of 4" x 4" drain sponges, costs about \$16, and you'll get 35 or 50 depending on the brand you buy.

Recently I was at the hospital for tests. My dressing was soiled and the site terribly irritated and aggravating. I requested the nurse to find me a gauze pad which I would adapt to a drain sponge by cutting a slit in it.

The nurse asked me if I had ever tried using female sanitary napkins as dressings. She expounded on their benefits:

- layers of absorbent material to wick away the drainage from the exit site, lessening the skin irritation at the site,
- a plastic outer layer to protect the clothing from soiled drain sponges, and
- their cost effectiveness compared to using drain sponges.

The nurse prepared a dressing by cutting a sanitary napkin in half. Half is all that is needed for a dressing. She then cut a slit horizontally so it would fit around the tube. It was taped to keep it in place. As you might guess, it worked perfectly.

Here is the financial breakdown: A large package of generic maxi-pads (48 pads) cost me \$4.89. You could probably get an even better price at a discount store like BJ's or Costco. Each maxi-pad, when cut, provides two dressings. That gave me 96 dressings for \$4.89, which works out to be 1/6th or less the cost of regular sponges. For people like me who must change dressings frequently, the savings are phenomenal. Once again the nursing team has provided a practical, inexpensive solution to our everyday, often annoyingly distressful dilemmas.

— Diane Owens  
9 Oak Street  
Marion, MA 02738

*Editor's Note: We recommend avoiding "deodorant" maxi-pads.*

## Order a Cookbook!

A collection of wonderful recipes, highlighted with snapshots and information about Oley, are now available! The cost is \$10.00 each, plus \$2.50 shipping and handling. Order copies today for yourself, your family, even a favorite clinician! To order, send a check and completed order form to Oley.



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# Cookbooks	Each	Total Amt.
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## Equipment Exchange

The following supplies are offered free of charge:

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- 1 case Jevity w/ Fiber, exp. 11/03
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- 2 cases Osmolite HN, exp. 1/04
- 7 cases Osmolite HN Plus
- 8 cases Perative
- 3+ cases Nestle Probalance, Van. exp. 3/03
- 7 cases Twocal HN, unflvd, exp. 8/03
- 8 cases Ultracal, 5 cases Ultracal HN
- 1000 ml WelcomUltraflow EN bags
- 1 box 1000 cc Flexiflo Easy-Feed EN bags w/ preattached Patrol Pump Set\*

\* postage to be paid by recipient

For more information, call (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods please offer to pay for shipping. ☺

## Making the 21st Century Work for Oley

The new year, 2003, brings us new challenges and new opportunities — and a very special reason to celebrate — The Oley Foundation marks its 20th anniversary in February! As we reflected on what we have accomplished, and look forward to what we still need to do, we realized some parts of how we operate required some fine-tuning. In particular, our financial support structure needed a little attention.

Part of the Foundation's mission is to ensure that all homePEN consumers and their caregivers have access to our support and services free of charge. We are determined to maintain that part of our mission, and have typically relied on corporate support to ensure that we can fulfill that. With the recent economic downturn, and with our own nutrition support industry struggling with cost containment and mergers, we have seen a substantial reduction in our corporate support. Our individual donors, meaning yourselves, have always been an integral part of our financial structure, so we are introducing a new giving opportunity that can make donating easier for you, and help buffer Oley from the ups and downs of the economic cycle.

### Giving a Little at a Time

Many of you have expressed a desire to do more for the Foundation, but find giving a larger amount, all at once, too burdensome. Some folks have been giving by credit card, but it can be costly to Oley. To solve these problems, Oley has partnered with Caring Habits, Inc., which offers some new, 21st Century style giving options to our members. We invite you to consider these new options, and the advantages they offer.

**Automatic Bank Transfer.** This monthly giving program is the most cost and time efficient way to give to Oley. Once a month (either the 5th or 20th day, your choice), your bank would automatically transfer funds from your account to Oley's. Oley pays the 55-cent transaction fee. This enables you to give as little as \$10 per month, while helping us connect ten new people to Oley who need our services. Automatic bank transfer is the same type of secure system with which many people pay their student loans or mortgages. Your bank statement serves as your receipt, and a summary receipt is sent from Oley at the end of the year to assist with tax preparation. You may cancel the gift transfer anytime by calling or writing us, at least 10 days before the next transfer is due.

**Automatic Credit Card Charge.** This works exactly the same way as an automatic bank transfer, except it is billed to your credit card instead of your checking account. This option costs Oley slightly more to process, but is just as convenient for you and Oley. Your credit card statement is your receipt, and a summary receipt is sent at the end of the year for your tax purposes. Again, to cancel,

notify us by phone or in writing 10 days before the next transfer is due.

Both of these giving options offer some great benefits. For individual donors, these include:

- You can give the amount you want to give, without being overburdened at any one time during the year.
- Your gift is maximized; processing costs and time requirements are minimized, freeing up staff time to better serve your information and support needs.
- You spend less time writing checks, obtaining stamps, and mailing your gifts.

For the Oley Foundation, the benefits of a guaranteed monthly income are tremendous:

- We can better plan our information, support and outreach services to meet the needs of our growing membership and reach the homePEN consumers we haven't connected with yet.
- We can budget for new programs or existing program expansions, like research, regional conferences, and computer upgrades.

We are hoping at least 250 of our 6,000 members will take advantage of these new options. Please consider being one of them! ☺



## Sign Up for Summer Camp

Summer camp is a wonderful growing experience that can be safely enjoyed by all children — even those on home nutrition support. Oley homePEN youth speak glowingly about their adventures at Double "H" Hole in the Woods Camp in Lake Luzerne, New York. The camp makes special arrangements so they can safely accommodate children on homePEN during their summer sessions.

The camp is free of charge, but campers are responsible for providing for their own transportation. **Oley recommends that homePEN children planning to attend camp have at least a basic understanding of their therapy and "hooking up" process.**

With help from the Oley Foundation, camp slots are available for homePEN kids at Double "H" Hole in the Woods Camp for the summer of 2003. If you're interested, call promptly and register your child to attend. Be sure to mention your child is on HPEN when you register. Any questions or concerns? Parents can speak with camp officials, previous campers, camper's parents or Oley camp volunteers.

### Where to Call for More Information

**Double "H" Hole in the Woods Camp**  
Camp Admissions/Nicole Carner (518) 696-5676

**Previous Campers/Volunteers**  
Volunteer/Bette Bond, RN (215) 946-0898  
Camper & Volunteer/  
Malisa Matheny, RN (215) 345-7783  
Camper/Mariah Abercrombie (702) 435-6007  
Camper/Roy George (315) 492-9309

**Parents of Previous Camper's**  
Ruth Matheny (215) 345-7783  
Felice Abercrombie (702) 435-6007  
Madaline George-Thiemann (315) 492-9309



*Oley campers, summer 1998*

## Spotlight: Life in Maine is “Just Peachy”

*The Oley Foundation is made up of thousands of interesting people who are out there meeting the challenge of living with homePEN, or helping those who are. We on the staff are privileged to connect with you all, but as we grow ever larger, we realize the need to share the talents and traits of members with each other. This column, which will run as space permits, is intended to do just that. If you have any one you'd like to see profiled, or would like to write a profile yourself, contact the editor, Roslyn Dahl, at Dahlr@mail.amc.edu or (800) 776-OLEY.*

Some people eat to live; I live to eat. It's rather ironic because I've been a TPN consumer for 23 years due to an infection after a C-section when 95 percent of my intestines were removed. Even though I can't absorb it, I love food and love to cook. I can't even eat all the stuff I make, but it's fun to play with fancy recipes. I can hardly wait get through my Oley cookbook to see what tasty things my friends and others have cooked up.

Oley has been a part of my life for so long, I can't remember when I wasn't involved. I've been a member since the very beginning. You may have seen me as “Peaches” the clown back then. For nearly 20 years I've entertained at parades, children's parties and holiday gatherings. One of my favorite gigs was the Oley picnic. Years ago we had a dunk-the-clown tank. One dollar bought three chances. Everyone got into the act, including Dr. Howard, who was dripping by the end of the day. As you know, even fund-raisers are fun when they are for Oley.

Being a member of Oley has changed me. I've learned to be my own advocate; I've learned about new products that have given me more freedom. The best invention is the portable pump. One morning I was running my TPN late when I discovered I ran out of sweetener for my tea. With my backpack in tow I went off to the store. In the sugar aisle, I couldn't reach the brand I wanted. I asked a store clerk if he could give me a hand; he bent over and threaded his fingers together as if to give me a boost. I smiled and said, “You're so much

taller than me, you might throw me over the aisle.” He patted my backpack and said, “Well you'll be alright, after all, you've wearing your parachute.” I laughed all the way home.

The best thing about being a TPNer is all the friends I have met. Thanks to the many friends who've broken down barriers and blazed trails, we can all live more normal lives.

I'm grateful to friends who've encourage me to “hang in there” in the tough times, and friends who've supported my dreams. One of my dreams was to move to Maine; two years ago I achieved that dream. Up until then I lived on the same block for 43 years. I traded the hustle and bustle of the city for 10 wooded acres in this small peaceful village called York. I hike, kayak, swim and garden in the summer. Much of my time lately has been spent cutting and clearing the old trees from my little forest. My favorite housewarming gift is my chain saw. I share my property with rabbits, owls, wild turkey, deer, loads of birds, and an occasional moose. Every day is an adventure; my dog Zoe and I never know who we might meet on our walks. It's a regular paradise here.

This isn't to say I never get the urge to go other places. I love to travel and love to fly. Last October I traveled to Ireland with my mother and friends. This year I plan to visit my HPN friends in Florida for Oley's annual conference. Just thinking about it almost makes me forget the 3+ feet of snow presently covering the ground.

Happy Healthy New Year everyone. Hope to see you in Florida! ☺



*Above: Robin as “Peaches” the clown*



*Left: Robin with last summer's harvest*

### Celebrating Life!



A long-term home HPN patient, Norma has a generous heart and energetic spirit. After getting comfortable with HPN, she now embraces how “normal” her life can be. Today she hikes and camps with her family, continues her love for photography and supports others who are learning to live with HPN. Congratulations Norma!

Norma

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NUTRITION SERVICES

To nominate someone to Coram's Celebration of Life Circle, send the story of a friend or loved one to:  
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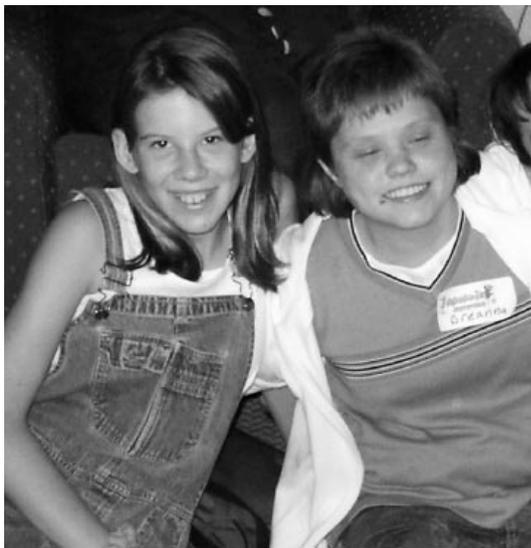
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## Welcome Aboard New Regional Coordinators, Trustees!

As a consumer-based organization, we are deeply indebted to our many volunteers who share their time and talents with the Oley community. Below we introduce our new Regional Coordinators and board members. A complete list of Regional Coordinators and their contacting information is on pages 11 and 12, and posted on our website at: <http://www.oley.org/region.htm#1>. A list of Oley board members and staff is posted at: <http://www.oley.org/brd%26staf.html>.

### Tammy Adams, Oley RC Liberty Lake, WA • Region X

Although she is Oley's newest Regional Coordinator, Tammy Adams is not new to the Oley Foundation. She and her daughter Breanna Clark have attended many Oley conferences, and 20 year old Breanna won Oley's Child of the Year Award in 1998. Breanna has been TPN dependent since birth, due to pseudo-obstruction. They have been dealing with liver failure issues for about five years, in addition to osteoporosis, arthritis, seizures and deep vein thrombosis. Tammy has two other active daughters, ages 15 and 11, and is happy to share her experience with sibling issues and being a proactive caregiver for 20+ years. Readers in the Spokane area shouldn't miss the opportunity to join Tammy's new support group; she is fun, informative and is pulling together an excellent program. She looks forward to helping others in her new official capacity.



Breanna Clark (right) and Kayla Woods enjoying the teen Jammin' Jammies at the 2002 Oley Conference.

### Linda Gold-Pitegoff, Oley RC Brookline, MA • Region I

Linda is a public health nurse with a diffused motility disorder — Hollow Visceral Myopathy. She has depended on enteral feeds for her nutrition and IV for her hydration for many years, and has experience with TPN as well. Widowed with two adopted children, Linda has an amazingly positive, can-do attitude that contributed to her winning the 2000 Mead Johnson Enteral Award. She is easy to talk to, well informed and a good listener. It is best to call her in the evenings.



Linda, all smiles, receiving the 2000 Mead Johnson Enteral Award

### Eleana Shore, Oley RC West Hills, CA • Region IX

Eleana's daughter Erin (age 7) is fed via G-tube due to multiple diagnoses, including GERD, food allergies and motility issues. She has undergone three Nissen Fundalpliations. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently. A real plus if you know of any consumers who are struggling with language



Eleana and Erin share a quiet moment together.

issues! Eleana and Erin are organized, bright and full of enthusiasm — and are sure to rub off their positive influence when you contact them. In recognition of her shining example, Erin received the Mead Johnson Enteral Award and travel scholarship to the 2002 Oley Conference in Buena Park, California.

### Laura Ellis, PhD, RD, Oley Trustee New York, NY

I'm thrilled to be serving on the Oley Foundation's Board of Trustees. This honor caps a decade-long involvement with the Oley Foundation, and one that I continue to treasure.

My history with Oley began in 1993. Armed with a doctorate in nutrition and experience in research, fund-raising and finance, I joined the Oley Foundation that year as its executive director. The next few years were difficult ones for the home infusion industry, and marked the beginning of a challenging financial period for Oley. With everyone pulling together — from board members and staff, to homePEN consumers and health professionals — we were able to navigate our way through this tough time. What I found most remarkable was everyone's resilience, spirit of conviction, and sheer determination to secure Oley's future.

I now work in fund-raising in a much different environment. Teachers College is the graduate school of education affiliated with Columbia University in New York City. I am currently executive director of development programs in a forty-member Department of Development and External Affairs. I oversee the annual fund, alumni relations, stewardship, special events and computer information services, and



Laura Ellis at a 1996 Oley Meeting

manage a \$3 million-plus budget. Last year, we raised \$25 million, and now are nearing the successful conclusion of a \$140 million capital campaign.

As a board member, I look forward to capitalizing on my experience in fund-raising and my background in nutrition to strengthen the Oley Foundation's funding base and research programs. The result: homePEN consumers in search of information, research findings and psychosocial support will have a strong and vibrant Oley to turn to for years to come.

**Michael Medwar, Oley Trustee  
Attleboro, MA**

In 1979, when I was nine years old, I was diagnosed with Crohn's Disease. I had my first Broviac inserted when I was 14, and began home parental nutrition. After having a bowel resec-



*Michael Medwar at the Oley picnic in Knott's Berry Farm last summer*

tion and trying a stint on home enteral feedings, I had the first of many Port-a-Caths implanted in 1987 and resumed home TPN.

While I still have a Port-a-Cath, I have had the good fortune of being off TPN since late 2001.

In 1992 I graduated from the University of Rhode Island and now am an editor at the MetroWest Daily News in Framingham, Massachusetts. I enjoy sports, reading and music.

I have been a member of the Oley Foundation for approximately 15 years, and have attended multiple conferences as a child and an adult. I appreciate all of the information and support I have received from the Foundation and its members over the years and am honored to serve on the board. My mother, Joan, who also has Crohn's disease (you may have met her at the 2002 conference in California), and father, Eli, are members of the Oley Foundation too. ☺

## Lessons from a Friend

**Robin Lang**

Sue Anne Dickert lived most of her 52 years in the suburbs of Boston. She married her high school sweetheart, Don, had two kids, Jeff and Amy, then became pregnant again. In her 8-1/2 month of pregnancy the blood supply to her intestines was cut off. She ended up losing her baby and her intestines, and was TPN dependent for the rest of her life.

Sue Anne faced this life-changing condition with her usual good humor. She wasn't a complainer; she met her problems head-on. She raised her children, enjoyed preparing meals for her family, and nurtured the people around her. She taught me and many others how to be independent by her example.

When I first met Sue Anne she was still new to TPN and I'd only had a few years under my belt. We met via the Lifeline Foundation at a small get together put on by the founders, Lee and Marshall Koonan. After the Koonans merged Lifeline with the Oley Foundation, Sue Anne and I worked together running a monthly support group in New England.

I was single and worried about body image then; Sue Anne and Woody Freese presented a breakout session on body image at an Oley conference in Saratoga Springs that turned my anxiety into hope. Back in '92 when Dr. Douglas Wilmore was doing research for his Nutritional Restart pro-

gram, Sue Anne and I stayed in the hospital together for a month. We laughed, we cried, we ate, and we measured in's and out's. Mostly we gave each other moral support. I remember two very important things she taught me then: to keep in shape (I still use the stretching exercises she taught me) and to problem solve creatively (she saved me hours of frustration and time by teaching me to prime by gravity).

Sue Anne loved her home on Cape Cod and often invited me to come and stay. She was so generous to my son and I. I'll never forget the cohogs she made on my last visit. Truly the best I've ever tasted. We sat on the deck, looked over the bay, and watched the sun go down. She knew how to make the most of life.

Sue Anne was always smiling and full of encouragement. Even though she wasn't feeling well, Sue Anne helped plan for the Oley 2000 conference and never let on to anyone the current challenges she was facing. Instead her conversation focused on the current accomplishments of her children and her husband, who she loved so much.

Over the 20 years she was on HPN, Sue Anne faced complications like staph infections, glaucoma, and liver problems. In the end, she died from pancreatitis. Sue Anne had more faith in me than I had for myself, but I've seen better days because of her. We'll miss her very much. ☺

## Web Sites for Youth

<http://depts.washington.edu/healthtr>

Sponsored by the Children with Special Health Care Needs Program at Washington State Dept. of Health, the Adolescent Health Transition Project is designed to help smooth the transition from pediatric to adult health care for adolescents with special health care needs. They are a resource for information, materials, and links to other people with an interest in health transition issues.

<http://hctransitions.ichp.edu>

The Promising Practices in Health Care Transition Project is a research and training activity of the Institute for Child Health Policy at the University of Florida. The focus of their research is to better understand the process of health care transitions by interviewing young adults, family members and providers involved in the process. The project also supports training and information sharing activities.

<http://fvkasa.org>

KASA is a national grassroots network created by youth with special needs, to educate their peers and society about issues such as living with special health care needs, health care transitions issues, education, and employment. KASA believes in supporting self-determination, creating support networks and proactive advocacy for all youth with disabilities. ☺

## Recognize Someone Who Inspires You!

### Nominate them for an Oley Award.

Consumers, caregivers, Regional Coordinators, even clinicians love recognition. What a great way to tell them how much you admire their courage, perseverance, and willingness to help others in their struggle with homePEN. And who wouldn't appreciate a travel scholarship to the Oley conference in Florida this summer? Or extra money for an educational program in their region?

### It's FREE and easy!

A simple form (inserted in this issue) with five, quick questions is all you need to complete. Technophiles can also find it on our website @ <http://www.oley.org/nomform.html>. Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you like.

### Questions? See details below or call (800) 776-OLEY.



#### **LifelineLetter Annual Award**

- ★ 19 years of age or older
- ★ HomePEN consumer or caregiver
- ★ Consumer has been on homePEN for a minimum of five (5) years
- Winner will receive a travel grant to the Oley Conference in St. Augustine, FL, June 19 - 21, 2003

#### **Mead Johnson Enteral Award**

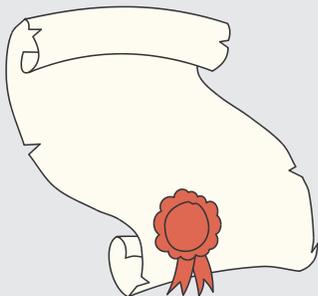
- ★ Enteral consumer, any age
- ★ On homeEN for a minimum of one (1) year
- ★ Resident of the St. Augustine/Jacksonville area (roughly 200 mile radius around the city)
- Winner will receive a travel grant to the Oley Conference in St. Augustine, FL, June 19 - 21, 2003

#### **Oley Foundation Child of the Year Award**

- ★ 18 years of age and under
- ★ Home parenteral and/or enteral nutrition consumer
- ★ On homePEN for a minimum of three (3) years
- Winner will receive a travel grant to the Oley Conference in St. Augustine, FL, June 19 - 21, 2003

#### **Lenore Heaphey Award for Grassroots Education**

- ★ Oley Foundation Regional Coordinator volunteer
- ★ Organized an outstanding information and/or education program during 2002
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area



#### **Nan Coutts Award for the Ultimate Volunteer**

- ★ Clinician (physician, nurse, dietitian, etc.) must practice in the field of homePEN or a related field, i.e. psychology, interventional radiology, pain management, etc.
- ★ Has demonstrated a willingness to give of themselves — beyond their regular work hours — to educate, empower and improve the quality of life for HPEN consumers. For example: a nurse who facilitates an Oley support group on her day off.
- Winner will receive a partial travel grant to the Oley Conference in St. Augustine, Florida, June 19 - 21, 2003

In addition to the award-specific criteria listed above, all nominees should demonstrate courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN. The awards will be given at the 18th Annual Oley Consumer/Clinician Conference to be held June 19 to 21, 2003 at the World Golf Village Renaissance Resort in St. Augustine, Florida. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a special keepsake, are honored at the annual conference awards program and will be spotlighted in the *LifelineLetter*. Most awardees will have all or some of their travel expenses underwritten. Recognition is given to all nominees!

**Nominations must be submitted by April 1, 2003**



# Oley Foundation Award Nomination Form

Deadline for nominations: April 1, 2003

## 1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2003  
(please check one):

- LifelineLetter Award
- Oley Foundation Child of the Year Award
- Mead Johnson Enteral Award
- Lenore Heaphey Award for Grassroots Education
- Nan Coutts Award for the Ultimate Volunteer

Nominee's name: \_\_\_\_\_ Age: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (\_\_\_\_) \_\_\_\_ - \_\_\_\_ home, (\_\_\_\_) \_\_\_\_ - \_\_\_\_ work

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

Please use this form or an accurate reproduction. Do not submit additional pages. 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 why the nominee qualifies for the award, describing specific examples of how this person has demonstrated a positive attitude in dealing with his/her illness and shown courage in overcoming illness-related problems. For the Nan Coutts Award, tell how the nominee has gone "above and beyond" what could ever be financially compensated for, to bring information, compassion and the Oley Foundation into the lives of homePEN consumers.

**4** Describe how this person has been exceptionally generous in helping consumers in their struggle with homePEN.  
*For example the nominee may participate in professional educational sessions/research, visit others in the hospital, hold support group meetings, etc.*

**5** Additional Comments. Please explain anything else that we should know about this person.

**Return your  
form(s) by April 1 to   
Questions? Call (800) 776 - OLEY**

The Oley Foundation  
214 Hun Memorial, MC-28  
Albany Medical Center  
Albany, NY 12208  
Fax: (518) 262-5528

# 2003 Oley Regional Coordinator Listing

updated  
1/2/03

*Regional Coordinators are an integral part of the Oley Foundation's outreach efforts. To date, the following patients/caregivers have accepted these volunteer positions. If you need someone to speak with, or are interested in a get-together, contact the volunteer nearest you (even if he or she is not in your region). We encourage you to contact any or all of the others as they have an assortment of knowledge and experience to share. To make speaking with fellow lifeliners more affordable, Oley also circulates two toll-free numbers to experienced HPEN consumers on a monthly basis. A schedule of the toll-free numbers is printed in the LifelineLetter. The toll-free schedule, and updated RC list, are also posted on our web page @ [www.oley.org](http://www.oley.org) or available by calling the Oley office at (800) 776-6539.*

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**Support, from pg. 1**

**“Home Parenteral Nutrition: Does Affiliation with a National Support and Educational Organization Improve Patient Outcomes?”** This article outlines the findings from the National Institute of Health (NIH) study conducted by Carol Smith, RN, PhD at the University of Kansas and reported in the *Journal of Parenteral of Enteral Nutrition (JPEN)*. Those connected to the Oley Foundation have lower incidence of catheter related sepsis, significantly higher quality of life, and lower incidence of depression. This information empowers me to invite you to examine the Unrestricted Corporate Donor List and:

1. Take note of who the supporters of YOUR organization are.
2. Support these companies, if you have the ability to do so, without compromising your care.
3. Assist us in soliciting the support of the manufacturers and home care providers “missing in action” on the list.

Let’s begin NOW by launching a grassroots campaign, drawing attention to the fact that we are making a difference, one consumer at a time. Help us cement existing relationships and to influence new donors:

1. Provide us with testimonials/documentation as to how your life has changed because of your relationship with Oley and other members.
2. Express your gratitude for ongoing corporate support. (Contact us for the names and addresses of the folks responsible for contributions or send your letters to us and we’ll forward them on).
3. Demonstrate disappointment to the businesses who have been reluctant to step up to the plate.

Without further explanation, and in a rather bold move, we are requesting that Oley members support Oley donors whenever it seems reasonable. ☺

**Pain, from pg. 2**

you on your routine visits to help with communication.

Nausea and vomiting can be an issue associated with your disease process and taking a pain medication that increases that symptom can make you less likely to take the medication. This can alter your medication levels and interfere with your pain control. Because some opioids may enhance the feeling of nausea and vomiting, discussing this issue with your caretaker may lead to more appropriate medication choices.

Pain is debilitating and can take over your life very quickly. Increased knowledge and good communication with your doctor or nurse can help with proper identification and management. Set goals with your provider and track your success; with good teamwork you can expect to reduce your pain and increase your functional capability.

Quality of life, as defined by David Roy, is the “experiences that make life meaningful.” Becoming a team member with your provider allows everyone to focus on conditions that provide such experiences.

**References**

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Savage, S.R. (1999). Opioid use in the management of chronic pain. *Medical Clinics of North America, 83(3):* 761-786. ☺

**Nutrishare becomes the first Home Infusion Pharmacy**

to receive a perfect score of 100% in its 2002 ACHC accreditation survey.

100%

**Nutrishare and the Oley Foundation congratulates**

the winners of the fall 2002 ‘Nutrishare Higher Education Scholarships’:

- Allison Hillen  
J Mark Silliker  
Heather Schwenk**



**Mark your calendars for Nutrishare’s 2003 Home TPN**

Conference: May 7-11, 2003 at the Sacramento Hyatt Regency Hotel, in Sacramento, California.



**Nutrishare, Inc.  
1-800-Home TPN**



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*Patty & Darrell Woods*  
*...and growing every day!!*

**Individual Contributors: Your Support Makes**

The following generous individuals have donated a gift to Oley between January 1, 2002 and January 9, those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year

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- Anonymous  
Lyn Howard, MD  
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## Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

*The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted on our web page @ [www.oley.org](http://www.oley.org). Comments? Call (800) 776-OLEY.*

**MAR. '03**

**David Young**  
Plainfield, IL  
(888) 610-3008 CST

David has been on TPN since 1998 due to pseudo obstruction and malabsorption. He is in his early thirties, and can speak to fellow consumers about the issues of juggling work, therapy, college and having a social life. He can also share his experience with Oley conferences and travel. Call him after 6:30 p.m. CST.

**Diane Owens**  
Marion, MA  
(888) 650-3290 EST

Diane has been on enteral nutrition for the past 9-1/2 years due to myotonic myopathy. She was also on TPN prior to enteral. She has experience with a variety of tubes issues. She is very proactive in pushing for and receiving adequate care, and looks forward to sharing her experiences with others.

**APR. '03**

**Hilda Hahn**  
Napoleon, OH  
(888) 610-3008 EST

Hilda, 88 years old, has been on TPN for 10-1/2 years due to bowel obstruction, radiation injury, and bowel resections. She has survived multiple cancers. She loves crocheting, reading, writing and photography. She is interested in genealogy. She corresponds with other HPN consumers and would love to hear from you.

**Rose & Alicia Hoelle**  
Gibbstown, NJ  
(888) 650-3290 EST

Alicia (18 y.o.) has been on HPN since birth due to hypoganglionis/NID. She graduates this June and will attend college in the fall. She has enjoyed camp, sports, and other activities. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. They would love to hear from kids, teens or parents. Their favorite topics are advocacy, school accommodation, transition issues and dealing with long term HPN.

**MAY '03**

**Tara & Kevin Smith**  
Pittsboro, IN  
(888) 610-3008 EST

Tara & Kevin have 3 daughters; Aleah (8 y.o.) their oldest, was born with only 10 inches of small bowel. Aleah went off TPN 2 years ago, and is doing great on EN and oral feeds. They can share how their marriage has survived, and the difficulties of meeting healthy siblings' needs when raising a chronically-ill child.

**Robin Lang**  
York, ME  
(888) 650-3290 EST

Robin has been on TPN for 23 years. She lives on 10 acres in Maine with Zoë, her 6 y.o. black lab. She has done extensive traveling and worked prior to her recent SSD status. She loves to make new friends. Robin keeps busy as a writer, RC and church volunteer. Feel free to call her anytime; day or night.

LifelineLetter

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