Supporting Mom
Marcia Martin

Last June at the Oley Conference, I gave a brief talk on the role of the support person. At that time, I was brand new to that role. My mother, who is 81, had just finished a 3-week hospital stay due to infection. She had also been switched to enteral support after 20 years of parenteral nutrition. I realized that, upon discharge, she would not be able to return to her home and live totally independently as she had for the last 3 years. Previously my father had been her support person.

At a minimum, she would need time to get her strength back and have to learn the routine of the enteral set-up as well as she knew the parenteral routine. I live three hours away from my mother, so just daily checking in would not work; Mom and her cat, Sam, came to stay with my husband, Joe, and me, and our four dogs.

A New Routine
During that initial period we all learned the mechanics of mixing Mom’s solution and hooking up. Joe labeled two containers with brightly colored lines at the 1000 and 1500 ml levels. He wrote out clear directions in large print and had them laminated. We all learned to recognize the machine’s beep in the middle of the night, how to add fluid to the enteral bag when half asleep and the special quirks of each pump.

Don’t Miss the Oley Conference this Summer!

Join us at the 21st Annual Oley Conference in Salt Lake City, UT, this June. The program is packed with ideas for better daily management of nutrition support at home. In addition, special attention will focus on achieving the best possible quality of life. A registration packet that describes the events and details should have arrived two weeks prior to this newsletter.

If this is your first conference, know that Oley and the conference committee have worked hard to ensure your trip is safe and easy — in addition to fun and educational! To start, we can put you in contact with consumers who have travel experience. Once you arrive, we have two home care companies (Coram Healthcare and Infusion Innovations) to help if you have any problems with broken or missing supplies. Finally, in case of any medical emergency we have LDS Hospital in Salt Lake City that can provide for the specialized needs of HPEN’ers.

Rick Davis, Conference Co-Chair, reports that many reservations have already been made at the Sheraton City Centre Hotel. “Strong, early room reservations are a good sign that we will have excellent attendance,” says Rick. “And the room rate of $116, including a full breakfast, is a great bargain for this full-service hotel.” Reservations can be made by calling the hotel directly, 801/401-2000, or toll-free, 888/625-5144. Be sure to tell them you are attending the Oley Conference to get the special low rate and, if needed, reserve a small in-room refrigerator. For a full description of the hotel visit their website at www.saltlakesheraton.com.

Special Attractions
Many Oley members have contacted Rick (rickdavis320@comcast.net) to plan a visit to nearby national parks. Favorites for a three or four day pre-conference vacation are Zions, Canyonlands and Arches. Others plan to visit Yellowstone, one day’s drive to the north, or the Grand Canyon, a day’s drive south. Rick also suggests...
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to snap together those Tupperware™-type connections on an ostomy bag and how to get my mother’s mail order prescriptions. Sam the cat learned to live with four dogs.

My mother insisted that we not do everything for her. She was concerned that she might forget how, so we observed as she mixed and hooked up. The more she did it, the better she got. By the end of the summer, she was mixing her solution and hooking up quite well. Mom also pitched in to do dishes, vacuum and change the kitty litter. She raved about Joe’s cooking. From April until September, my mother and I took walks every day. We planted and watered boxes of petunias and impatiens. We sat out on the porch and marveled at how close the hummingbirds came to us when they fed at our feeder. As my mother got stronger and into the routine of doing her own enteral support, she longed to return to her own home. She has many friends in her hometown, as well as three brothers and their wives, whom she sees a lot.

Balancing Independence, Safety

Balancing my mother’s desire for independence with keeping her safe and healthy is a major challenge. My sister, brother and I felt that returning to live alone in her home was not the best idea, but we did agree to look at the various senior living options. We looked at some in my town as well as several in my mother’s hometown. We found that there is no perfect solution and all are expensive. It would have been much easier if my mother and her three children all lived in the same town. My mother chose an independent living facility in her hometown. They provide one meal a day as well as light housekeeping and an emergency call bell. She has a lovely apartment and there is a wide array of activities available. If she ever needs it, they have assisted living and a nursing home on the grounds.

Recently, we have arranged for aide services each evening to insure that my mother mixes and hooks up appropriately. Mom does the actual mixing and hooking up, but the aide can prompt her if necessary. A nurse comes one evening a week. My mother says that this is overkill, and it may be, but I tell her that it puts my mind at ease. The most difficult part of this is coordinating the aides with my mother’s numerous evening activities so that she is present when the aide arrives.

I visit once a week on average, and continue to order my mother’s medications and fill her pillboxes; although, when I visited last week, she had done this task already. I let her medical supply company know what supplies are needed each week, and accompany Mom to doctor’s appointments so two sets of ears are hearing what the doctor says. I call each morning to find out how things are going and what the plan for the day is. I call my current role “long distance support person.” Right now, this is working.

Probably the biggest thing that I’ve learned this past year is that nothing is forever. My tendency is to put a plan in place and make it work, no matter what. In this situation, I’ve learned that flexibility is a must. I have also learned that I am part of a team which includes my husband, my brother and sister and their families, my mother’s doctor and the people at her homecare company.

Editor’s Note: “Mom” is Eleanor Orkis, one of the earliest Regional Coordinators who led a support group in upstate New York for nearly 20 years. She has helped at many Oley conferences and at the Oley office. We admire Eleanor for her fun-loving, warm and generous spirit, as well as her energy and enthusiasm for trying new things. We thank her for her continued dedication to helping others on homePEN and for sharing her wonderful family with us.

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staying over for fabulous 4th of July celebrations. The Mormon Tabernacle choir will perform patriotic songs on Sunday, July 2. Big-name entertainment and fireworks are scheduled for stadium crowds at the University of Utah and Brigham Young University, and the Independence Day parade at nearby Park City is a local favorite. The Olympic Park & Museum, site of many of the 2002 events, is also in Park City.

An enthusiastic local host committee of more than 30 Oley members is planning a memorable picnic, an exciting Walk-A-Thon and spectacular offerings at the Silent Auction. A wide selection of youth activities will also be available. The Gateway Center is just a few blocks from the Sheraton and includes an aquarium, planetarium, children’s museum, movie complex, IMAX, shopping center and scores of restaurants. Volunteers will assist with complimentary local and airport transportation, restaurant and shopping recommendations, child care, nearby hiking and walking, and for general information and assistance. Check out all you can see and do at www.visitsaltlake.com and www.utah!.com.

For more information on the conference call (800) 776-OLEY or visit www.oley.org. Don’t miss this opportunity to learn how you and your family can “Be All You Can Be!”
Tube Talk

Thank you to everyone who sent material for the “Tube Talk” column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

Educating Your Pharmacist

When I started tube feeding, my wife crushed all my pills, one at a time, with a mortar and pestle. Gradually, I became well enough to do it myself. I tried pill crushers, but felt the mortar and pestle were better. At an Oley conference, a pharmacist suggested dissolving my pills would be easier than crushing them, although it might take a little longer. I began dissolving my pills and discovered uncoated pills dissolved faster than coated ones. (And, yes, it was easier than crushing them.) I also learned that some pills could be dissolved together, so that I did not have to draw up separate solutions in my syringe and do separate infusions. (Note: Be sure to check with your pharmacist or physician before combining any medications as they may interact and/or clog your tube.)

Prevacid tablets were the toughest. They took a long time to dissolve. I asked my pharmacist if they came in any other form that would dissolve more easily. He gave me another kind, but the label clearly said, “not for enteral use,” so I took them back and asked him to try again. He said there wasn’t anything else.

So I did my own research. I found Prevacid Solutabs — delayed release orally disintegrating tablets. The label says, “...can be delivered via oral syringe.” When I showed the label to my pharmacist, he said he thought they were only used to dissolve on the tongue and then swallowed. Because I cannot swallow, he did not think I could use them.

Because most pharmacists don’t deal on a day-to-day basis with individuals who have feeding tubes and are on enteral nutrition, this became a learning experience for both of us. My research and advocating for myself helped me find the form of Prevacid that was exactly what I needed. My pharmacist learned more about my special needs, as well as about a form of the medication that could be used in a way he hadn’t even considered.

Now, taking my meds is relatively easy. I do it twice a day — first thing after waking up in the morning and last thing at night before I go to bed. In the morning, I use four Nalgene water bottles. I shake, shake, shake the various medications and my coffee, each in their own bottle. (Note: Nalgene water bottles can be found at sporting goods stores, Target and other retailers.)

I think it takes less time to actually do my medications than it took for me to type out this story for you on my laptop. A feeding tube should not get in the way of staying well medicated!

— Rick Davis
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Salt Lake City, UT 84103-2819
Phone: 801.232.8787 or 801.521.6070
rickdavis320@comcast.net

Tube Feeding Workshop

A series of workshops designed to teach professionals and parents about the medical and social aspects of tube feeding will be held in several cities in 2006: May 6-7 in Durham, NC; July 28-29 in Albany, NY; September 7-8 in the Detroit, MI area; and October 6-7 in Salt Lake City, UT.

Entitled “Tube Feeding with Love,” the workshops feature Marsha Dunn Klein, MEd, OTR/L, a pediatric occupational therapist who specializes in feeding infants and young children. Workshop attendance costs $350 for professionals and $200 family members. CEUs are available for occupational therapists and dietitians. For more information call (520) 323-3348 or visit www.mealtimenotions.com.

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How to Win Health Insurance Appeals

Jennifer C. Jaff, Esq.

It would be impossible for me to tell you everything I know about how to take a health insurance appeal in 1000 words. But I can give you some pointers that will help you to present your case more effectively.

First, don’t just make a phone call or write a letter, or let your doctor write a brief letter. That is not enough. You need to put together a packaged appeal that addresses the issues in question with the support of objective evidence, i.e., test results, biopsies, labs, etc., as opposed to subjective evidence, i.e., reports of pain and other symptoms unless corroborated by objective evidence.

The Three Critical Steps

Step One: In the letter denying coverage for the treatment your doctors propose, there will be a statement offering to send you a copy of the entire file, including their internal clinical criteria. Take them up on it. Write a letter, quote the language from the denial letter, and ask that they send you the file. If you don’t hear within 30 days, start calling. I find that not all insurance companies really understand that this is a requirement of federal law, that they can’t pick and choose what they send you — it has to be the entire file, and that they have to include their internal criteria. You may have to explain that this is one of the requirements of ERISA, the federal statute governing employee benefits, as well as laws in many states.

Step Two: Gather objective medical evidence. I strongly urge patients to get copies of test results, surgical reports, hospital discharge summaries and so on as you go. It is easier to get your doctor to mail you one lab slip than it is to get a copy of your entire file. What you need for your appeal is evidence that establishes a) your diagnosis; b) your history (how long have you had the illness, what surgeries have you had and when); c) recent attempts to treat your disease (medications, surgeries, other therapies); and (d) the failure of these attempts.

If you are lucky enough to have a doctor willing to help, he or she could write a letter that addresses these points, but I would add test results and other objective proof to the doctor’s letter so that it’s clear that what your doctor says is proven by the medical evidence.

In some cases, in addition to medical records, you need to gather scientific information. For example, if you need Enterra therapy, and your insurance company denies coverage because it is unproven or experimental, you need to produce copies of peer-reviewed medical journal articles showing the effectiveness of the proposed treatment. Pharmaceutical and device manufacturing companies will give you this material upon request.

Step Three: Write the appeal letter. This often surprises people, but if you want to win an insurance appeal, you don’t just send your medical records and hope. You have to make the argument. You’re very sick (citing to objective evidence such as weight loss or blood work showing malabsorption, for example); you’ve tried everything else (also citing to evidence of what you have tried); nothing has worked (again, citing to attached records); and your doctor thinks this treatment is worth a chance for certain logical reasons.

As to this last, most crucial point, start with the clinical criteria that the insurance company sends you. What you have to argue is that the evidence shows that you meet those criteria. Sometimes, going through each item on their criteria, labeling each paragraph accordingly, is an excellent way to organize your appeal.

Federal law also requires that the insurance company provide you with a reason for the denial that is clear enough that you can focus your appeal accordingly. For example, if they say “the treatment is not warranted according to our clinical criteria,” that is not enough — that could be said of every denial. You have a right to a clearer answer.

Recently, I got a denial on the ground that a certain medication is not FDA approved. The patient has Crohn’s disease. There are only two drugs that are FDA approved for Crohn’s disease: prednisone and Remicade. Yet all insurance companies pay for a host of other drugs for the treatment of Crohn’s disease despite the fact that they are not FDA approved. (This is called an off-label use). So I called the insurance company, got the person who signed the denial letter on the phone, and said, “I know that this can’t be your real reason because you pay for all of these other drugs that aren’t FDA approved for treating Crohn’s disease, so now tell me your real reason.” I was told that there weren’t enough medical records in their file.

Now, I know how to handle that appeal.

Insurance companies are not used to seeing appeals packaged like this. I recall one recent instance in which I spoke with the insurance company by phone, told them I would be taking an appeal, and they asked if I wanted them to send the file up to their appeals department. They expressed surprise when I said that I would be making a submission to the insurance company that would include evidence and argument. Taking the process more seriously than most people do will make your appeal stand out.

Of course, when we patients have to do this sort of work to get treatment it is most often the time when we feel the sickest. Unfortunately, in our health care system, being sick can be very hard work. However, these issues are a necessity.

So maintain your medical records, read about your medications, treatment, and disease (the internet is an amazing source of everything you ever wanted to know and then some), and make sure you understand the decisions that are being made for your care. If you are an active participant in your health care, writing appeals will be far easier for you.

Finally, when all else fails, you may wish to contact me at patient_advocate@sbcglobal.net. Or you can purchase my book, Know Your Rights: A Handbook for Patients with Chronic Illness, on my website, www.advocacyforpatients.org. The book contains far more information than I can provide in the space allotted here, along with sample appeal letters, including one successful appeal from a denial of coverage of Enterra therapy. These and other tools are things you should be gathering all the time, regardless of whether, at

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New Tube or Catheter?

If you are getting a new tube or catheter placed, ask the surgeon or radiologist to give you the product papers/packaging that come with it. These papers should tell you the exact name of the product, the manufacturer and specifications (like size, material composition, etc.) that may come in handy down the road if you have a problem with the device. Keep the papers with your other medical files for easy future reference.

Similarly, it is a good idea to keep a label from your formula can or cleaned EN/TPN bag, and bring it with you to office visits and hospital admissions. The label has the most up to date information on the composition of your formula/solution. This information may not be readily available otherwise, and is needed by your physician to make adjustments that could be critical to your well being.

Travel Scholarship Honors
Melissa Chaney

Victor R. Chaney

I am the husband of Melissa Chaney, a TPN consumer and Oley contributor. Melissa passed away from natural causes on January 30, 2006. For more than nine years, Melissa battled Pseudo-Obstruction, Polymyocitis, and Mitochondrial Myopathy-Transport Chain Deficiency. Over those years there were many drastic ups-and-downs.

In the summer of 2003, Melissa learned of the Oley Foundation, and the network of support and outreach that they specialize in. At that time Melissa’s healthcare management was less than adequate. Her weight was in a downfall, she was 5’1” and she averaged around 75 lbs. The change in her healthcare and overall quality of life was amazing. We credited the education and contacts she acquired at that first Annual Conference as the turning point in her health.

Melissa’s wishes in life were that any memorial donations given after her passing would be directed to Oley. In keeping with those wishes, we are establishing a travel scholarship to the annual Oley conference in her honor, so that others may have the opportunity she had in attending. For more information on applying for the Melissa Chaney Scholarship, contact Oley (800/776-OLEY; harrinc@mail.amc.edu) or visit the website at www.oley.org.

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that time, you need them. If you do so, when you get your next denial, you will be ready to go forward with your appeal, armed with information and educated about how to present it.

Jennifer C. Jaff is an attorney in Hartford, CT who is the Executive Director of Advocacy for Patients with Chronic Illness, Inc. She has written Know Your Rights: A Handbook for Patients with Chronic Illness, available for purchase at www.advocacyforpatients.org. Reprinted with permission from Association of Gastrointestinal Motility Disorders’ (AGMD) Digestive Motility Forum Volume I, Number Two - November 2005.
Support the Oley Walk-A-Thon

Join us Saturday, July 1, for the second annual Oley Walk-A-Thon in Salt Lake City, Utah. The 5k (3.1 miles) walk is open to the public, will follow a paved route through a scenic area of the city, and should take most adults under an hour to walk at a comfortable pace.

Can’t Make It? You can still help gather support for this event by sponsoring a designated walker, or by walking in your hometown. Call (800) 776-OLEY for details.

More information about the Walk-A-Thon and a pledge sheet were sent in the conference registration packet two weeks prior to this newsletter; they are also available on-line at www.oley.org.

Learning, Sharing in Dallas

Learning and sharing were enjoyed by more than forty attendees at the Oley Foundation’s one-day conference in Dallas this February. The regional conference was held in conjunction with Nutrition Week, an annual educational gathering of clinicians hosted by the American Society for Parenteral and Enteral Nutrition.

Leading clinicians and experienced consumers discussed topics like managing patients with intestinal failure, when should a small bowel transplant be considered, maximizing oral intake to reduce HPN dependency, and how to live well on homePEN. Many thanks to the speakers and breakout session leaders for volunteering their time and sharing their expertise: Alan Buchman, MD; Mark Corkins, MD; Rick Davis; John Fang, MD; Lyn Howard, MB, FRCP; Kishore Iyer, MD; Alyce Newton, RD; Reid Nishikawa, PharmD; Doug Seidner, MD; Ezra Steiger, MD; and Cheryl Thompson, MS, RD, CNSD.

Oley hosted a panel at Nutrition Week where Rick Davis, Valinda Woffert and Esther Burch (all consumers or caregivers) shared their personal experiences with home tube and IV feeding, and the way it impacts their lives. Oley staff and volunteers also coordinated a booth in the exhibit hall to educate clinicians about the services the Foundation offers and to encourage them to refer their homePEN patients. Thank you to Rick Davis, Laura Keser, Robbyn Kindle, RN, Elaine Lightfoot, Chuck Lindsay and Cherrie Simpson for helping at the Oley booth.

Possible Peds Multivitamin Shortage

There is currently a limited supply of intravenous multivitamins for infants and children. This may or may not affect you or your child as the availability of pediatric multivitamins from the manufacturers has been frequently changing. It is hoped that a steady supply will be available soon. In the interim, ASPEN has issued guidelines for how to manage the shortage. Similar guidelines were followed a number of years ago when there was a more widespread shortage of pediatric multivitamins. With use of these guidelines, infants and children were able to continue to receive reasonable amounts of multivitamins safely.

Your physician should be able to answer any questions you have about this issue. For additional information and a copy of the guidelines, you can visit the ASPEN website at: http://www.nutritioncare.org/mvi shortage 3-20-2006.pdf.

Silent Auction Items Needed

Now is the time to be gathering items for this year’s Silent Auction! Your participation can make or break this fun fundraiser held at the annual Oley conference. Proceeds help support Oley programs like the LifelineLetter and conferences, so the more funds we raise, the better!

Big hit items have traditionally been electronic equipment (boom boxes, iPods, games, karoke machines, etc.), handmade quilts and other crafts (stain glass items, jewelry, decorations), airfare, hotel accommodations, and tickets to attractions. Smaller ticket items like clothing, sunglasses, stuffed animals, games and toys are fine too.

Contact Joan Bishop (bishopj@mail.amc.edu; 800-776-OLEY) for ideas or more information. We appreciate your support!!

Faster than the US Mail

Because we get a special postal rate as a nonprofit, we are also one of the last items they think about delivering. It can take up to three weeks from the time Oley mails out your copy of the LifelineLetter until the time you get it. Would you like to have it as soon as it is published? Just call or write Cathy (Harrinc@mail.amc.edu; 800-776-OLEY) for details.

More information about the Walk-A-Thon and a pledge sheet were sent in the conference registration packet two weeks prior to this newsletter; they are also available on-line at www.oley.org.

RC Update

Please note that Davi & Steve Cohen, Regional Coordinators from Crofton, Maryland, have a new email address: cohennet@verizon.net.
Equipment Exchange

The following supplies/equipment are offered free of charge:

**Enteral Formula**
- (9) 6-packs Ensure, exp. 1/07
- 16 cases Fibersource HN, exp. 6/06
- 15 cases Glytrol, exp. 8/06
- 6 cases Isosource 1.5, exp. 7/06
- 20 cans Isosource, exp. 10/06
- 4 cases Jevity 1.2, exp. 12/06
- 90 cans Jevity 1.5, exp. 11/06
- 5 cases Jevity 1.5
- 14 cans Moducal Calorie Powder
- 4 boxes Neocate Plus One, exp. 4/07
- 5+ cases Neutren 1.0, exp. 10/06
- 42 cans Neutren, exp. 11/06
- 7.5 cases Neutren 1.5, exp. 10/06, 12/06
- 3 cases Peptamen 1.5
- 7+ cases Probalance, vanilla, exp. 12/06
- 2+ cases Replete w/fiber, exp. 10/06
- 1+ cases Replete, exp. 11/06

**Tubes/Bags:**
- 50 Ross EZ Feed Bags, #52048
- 5 boxes 1000ml Kangaroo Bags without ice pouch
- 4 boxes Kangaroo External Pump Sets Easy Cap Bags w/ice pouch
- 25 Ross 1000ml Companion bags
- 10 Ross 500ml Companion bags

MORE SUPPLIES are available! This is a partial listing of the products that are currently available through this program and outlines supplies that have become available in the last month. If you have a need for any items listed above, would like to view the complete listing of the tubes, formula, etc. or have items to donate; visit our website at www.oley.org/EquipmentExchange.html, or contact Liz Tucker at evtucker@charter.net or toll free at (866) 454-7351. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods, especially heavy items such as enteral formula or infusion pumps, offer to pay the shipping costs.

To Be (a Parent), or Not to Be

Have you had a child, or raised a child while you (the parent) depended on home parenteral or enteral therapy? Please consider sharing your thoughts and experiences with other Oley consumers who are exploring their parenting options. As you might guess these consumers have many questions and concerns that only someone who has “been there, done that” can answer. Parties interested in helping should contact Roslyn Dahl at the Oley office (800/776-OLEY; dahlr@mail.amc.edu).

Carrying a torch for more than the Olympics.

Kenneth Lighthall has used his illness and subsequent Home TPN as a springboard to a different life. Spiritually as well as in his relationships. His kids think he has actually improved. He volunteers all the time and has become very unselfish and giving. He was honored to be able to carry the Olympic torch in 2002. He doesn’t stay put. He’s fishing on the canal or traveling to see his grandkids from Michigan to Florida.

Kenneth is just one of the consumers that Coram is helping get on with life. 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.
Spotlight on Richard Rivett
Robin Lang

So many Oley members view life as a glass half-full, not half empty. Richard Rivett, or “Dick”, as he prefers to be called, is one of those members. Dick is a 15-year consumer on enteral nutrition.

Like many Foundation members, he came to the therapy the hard way. Doctors looked for reasons for his illness, but the usual ‘cause and effect’ diagnosis eluded them. Dick cannot swallow and his disease was finally diagnosed as inclusion body-myocytis (IBM). It has robbed him of the ability to use the internal muscles that help food move forward through his digestive tract. If he eats anything, there’s a high risk he could inhale the food into his lungs, causing life-threatening pneumonia.

Dick was told by his doctors that IBM is a degenerative autoimmune disease with no cure. As the disease progresses, the lower extremities are affected; i.e., loss of balance and the inability to bear his own weight. These are new symptoms Dick deals with gracefully and with dignity. He’s not worried about his future though. “After all,” he says, “Aunt Duffy lived to be 104 years old. I figure I’ve got at least 20 years ahead of me.”

Making the Best of Life

Though he does not eat and has limited mobility, Dick is not a hermit. He gathers quite frequently with 20 neighbors for their morning coffee club. He keeps up with current events; “Leesburg, Virginia,” he says, “is quite a place. There’s a lot of politics and other subjects to ponder and converse about.”

Dick also enjoys social contacts through the Oley Foundation. The first Oley meeting he attended was held in Saratoga Springs, many years ago, and he has attended several more. “I’ve been unable to attend the last 3 or 4 years because of my decreased mobility, but I continue to keep up with friends I’ve met at the Oley conferences.”

Dick also credits his daughter, Tyanna, and her family for giving him the will to carry on. His daughter and son-in-law, John, live close by with their two children. Dick’s grandson is a senior in high school and his granddaughter is a 23-year-old Olympic quality swimmer. He has a lot to be proud of.

A retired engineer from the computer giant, IBM, he sees the irony in life; he worked for IBM, now his disease carries the same acronym. Dick believes that his engineering skills have helped him deal with the many challenges that accompany homePEN.

When asked what he credits his success to, he replies, “My mother gave us a good start with a proper diet and exercise. I’ve also learned to accept my situation, and to be patient.” His advice to others: “Be positive; don’t fight it. Patience and a positive attitude will carry you through.”

As I hung up, I thought how lucky Oley is to have such wonderful members like Dick. He is a true gentleman and a delight to speak with.
Recognize the Quiet Hero in Your Life!

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. And who wouldn’t appreciate a travel scholarship to the Oley conference in Salt Lake City this summer? Or extra money for an educational program in their region?

Ring your own bell!

Nominate yourself. If your story is one of inspiration, tell us your tale on this simple nomination form. We want to hear from you!

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 can now be submitted up to May 5, 2006

Award Criteria

The awards will be given June 29 at the 2006 Oley Conference in Salt Lake City, Utah. 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 Salt Lake City, UT, June 28 to July 1

Oley Foundation Child of The Year Award
★ 18 years of age and under
★ Home parenteral and/or enteral nutrition 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 Salt Lake City, UT, June 28 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 a local theater spending time with children and grandchildren, etc.
Winner will receive a partial travel grant to the Oley Conference in Salt Lake City, UT, June 28 to July 1

Lenore Heaphey Award for Grassroots Education
★ Oley Foundation Regional Coordinator
★ Organized an outstanding information and/or education program during 2005
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 HPEN consumers. For example: a nurse who facilitates an Oley support group on her day off.
Winner will be honored at the Oley Conference in Salt Lake City, UT, June 28 to July 1
Oley Foundation Award Nomination Form

New! Deadline for Nominations: May 5, 2006

The Oley Foundation • 214 Hun Memorial, MC-28 • Albany Medical Center
Albany, NY 12208 • Fax: (518) 262-5528 • email: harrinc@mail.amc.edu

1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2006 
(please check one):

☑ Lifeline Letter 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

Email: ______________________ @ _________________________

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

Email: ______________________ @ _________________________

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.
Thank You! Thank You!

The following list represents everyone who generously contributed towards Oley efforts between February 20 and March 21, 2006. We also want to thank all those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

Ambassadors ($2,000+)

Presidents Circle ($1,000 - $1,999)

Benefactors ($500-$999)

Milton Abercrombie Phillip & Vera Gerhardt

Sponsors ($250 - $499)

Valinda & Steve Woflert, in honor of Will Woflert

Patrons ($100 - $249)

Teresa Byrne Michael Grimes, in honor of Todd Ohlmeay running the National Marathon Mark & Patty Tavill

Supporters ($50 - $99)

Beth Cohen, in honor of Peggy Bredberry Bruce Schmitt, in honor of my team at Coram Frances Sneider, in honor of Peggy Bradberry Michelle Trunick-Sebbin, in honor of Kyle Noble

Contributors ($30 - $49)

Daniel & Kathleen Amaral, in honor of their son, Liam Amaral Richard & Faith Dillon Charlene Key, in memory of Harry Clark Pat Mielle Cherrie & Greg Simpson, in honor of “Our Son” Scott Sullivan on TPN 1 yr, and HEN 12 yrs Joann Wingert

Friends (Up to $30)

Annex Nutrition Services Margaret Coefer Kimberly Morgan Rose & Jeff Hoelle, in honor of Alicia’s 21st Birthday!!! Robin Lang, in honor of and to celebrate the recent union of Anar Shah & Chad

In Honor of Justin Jett Ohlmeay


* Board Members ** Regional Coordinators *** Oley staff

Oley Corporate Partners

PLATINUM LEVEL PARTNERS ($70,000+)

Nutrishare, Inc.

GOLDEN DONORS ($50,000-$69,999)

Coram Healthcare

SILVER CIRCLE MEMBERS ($25,000-$49,999)

Novartis Nutrition

BRONZE STAR PARTNER ($20,000-29,000)

Serono, Inc

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

Ross Products Division/Abbott Laboratories

PATRONS ($5,000-$9,999)

Hospira Worldwide Option Care, Inc.

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

Baxter Healthcare Critical Care Systems

Daniel F. & Ada L. Rice Foundation

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

BD Medical Systems C.R. Bard Foundation Kimberly Clark Zevex, Inc.

FRIENDS ($500-$999)

Accreditation Commission for Health Care, Inc.

The Oley Foundation Horizon Society

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

John Balint, MD Joan Bishop Ginger Bolinger Pat Brown, RN, CNSN Katherine Cotter Jim Cowan Ann & Paul DeBarbieri Tom Diamantidis, PharmD Selma Ehrenpreis Herb & Joy Emich

Don Freeman Linda Gold Linda Gravenstein The Groeber Family Valerie Gyurko, RN Alfred Haas Alicia Hoelle Jeff & Rose Hoelle Lyn Howard, MD William Hoyt

Darlene Kelly, MD Family of Shirley Klein Robin Lang Judi Martuscelli Kathleen McInnes Meredith Nelson Rodney & Paula Okamoto, RPh Kay Oldenburg Judy Peterson, MS, RN Clemens Pitzner

Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<table>
<thead>
<tr>
<th>MAY '06</th>
<th></th>
<th>JUNE '06</th>
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<tbody>
<tr>
<td>Rose &amp; Alicia Hoelle</td>
<td>Laura Keser</td>
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<tr>
<td>Gibbstown, NJ</td>
<td>Stillwater, OK</td>
<td></td>
</tr>
<tr>
<td>(888) 610-3008 EST</td>
<td>(888) 650-3290 CST</td>
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<tr>
<td>May '06</td>
<td></td>
<td>JUNE '06</td>
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<tr>
<td>Mariah Abercrombie / Felice Austin</td>
<td>Rick Davis</td>
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<tr>
<td>Henderson, NV</td>
<td>Salt Lake City, UT</td>
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<tr>
<td>(888) 610-3008 PST</td>
<td>(888) 650-3290 MST</td>
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<tr>
<td>JULY '06</td>
<td></td>
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<tr>
<td>Don Young</td>
<td>Eleana Shore</td>
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<tr>
<td>Porter Corners, NY</td>
<td>West Hills, CA</td>
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<td>(888) 610-3008 EST</td>
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<thead>
<tr>
<th>Alicia</th>
<th>Laura</th>
<th>Mariah</th>
<th>Rick</th>
<th>Don</th>
<th>Eleana</th>
</tr>
</thead>
<tbody>
<tr>
<td>(21 y.o.) has been on HPN since birth due to hypoganglionis/NID, and was recently diagnosed with Crohn’s disease too. She is attending college to become a child life specialist. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. They’d love to discuss advocacy, school accommodation, transitioning issues and dealing with long term HPN with kids, teens or parents.</td>
<td>has been on HPN since 1991 due to short bowel syndrome. She has experience with multiple catheters, dealing with infections and traveling. She has returned to college at Oklahoma State and will graduate in the spring 2006. She looks forward to sharing her experiences with you.</td>
<td>is a 24 y.o. college student on TPN 21 years due to pseudo-obstruction and short bowel. She has a g-tube and ileostomy. She enjoys swimming, jet-skiing, traveling, etc. Felice is a single mother, a former social worker, and has been active in Oley since the late 1980’s. She can share her experience with patient advocacy, separation, disability, travel etc. Both can speak about the benefits of attending the Oley conference and are familiar with the area near the hotel.</td>
<td>is 62, cannot swallow, has been 100% dependent on HEN for 5 years and is very active hiking, skiing, traveling and volunteering. Rick encourages everyone to attend the Oley conference and can answer your questions on just about everything conference related — from the program to site-seeing.</td>
<td>has been on TPN for 31 years due to SBS and Crohn’s disease. He also has an ostomy. Call him to learn more about CVGs, PICC lines and reimbursement issues (i.e. social security, Medicare, private insurance, etc.) or for a great chat with someone who has a healthy perspective on living with TPN.</td>
<td>’s daughter Erin (age 10) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, Arthritis and Hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</td>
</tr>
</tbody>
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Join Us!

2006 Oley Conference

June 28 — July 1
Salt Lake City, Utah