To Do the Difficult: White Water Rafting on HPEN

Jenn Wright

Accomplishments are personal things. What constitutes achievement differs from person to person and by degrees. It matters less what a person does than what it takes for them to do it. As Eleanor Roosevelt challenged all of humanity, “You must do the thing you think you cannot do.”

Last year I spent six days at the bottom of the Grand Canyon, rafting the Colorado River in the heat and turgidity of monsoon season. For those six days, 18 passengers and two boatmen shared a J-Rig (a motorized pontoon raft) traversing over 120 miles of the most breathtaking, unique, and perilous water in the world. We bathed in 50-degree silt-filled water. We slept on cots with only a tarp to pull over us in case of monsoons (of which we experienced four). The restrooms were divided into upstream and downstream (women’s and men’s, respectively). We ate, drank, slept in, bathed in, walked in, sat in, and breathed sand, finding it in every orifice, skin fold, and body cranny imaginable.

And we loved it.

Not for the Timid

At times, the heat was nearly unbearable; the monsoons traversing the rim of the canyon created a thermodynamic effect that resembled a colossal hair dryer blasting over the water, and the storm clouds kept the humidity well above 90 percent. At other times, a succession of rapids would leave us doused and shivering, silently worrying that we’d never get warm again. It was a battle of extremes: heat and cold; wet and dry; sand and silt; calm and turbulent; hot and cold air; updrafts and downdrafts; and even a full moon and the stars.

Not for the Timid

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You Talk, We’ll Listen

The better we know you, the better we can tailor Oley programs, conference topics, and newsletter articles to your needs. You talk, we’ll listen.

With this in mind, we hope you’ll take the time to fill out the membership survey on the last two pages of the newsletter, and return it in the envelope enclosed in this issue.

A few minutes of your time can help us tremendously. Lisa, new to Oley and the LifelineLetter, adds an earnest plea for your input on the newsletter!

All completed surveys will be entered into a drawing for a $50 gift card. The drawing will be held at the annual conference.

Conference cont., pg. 2 ➔
and dry; dirty and, well, dirtier; placid and perilous; breathtakingly beautiful and breathtakingly severe.

Those six days on the river were an accomplishment for everyone. It took strength of body and of will to hold on. It meant staring down fear, and then charging through it. This trip is not for everyone.

But for my husband, Greg, and me, the trip meant more. For just over three years, I have managed a severe form of gastroparesis, caused by a nonspecific progressive autonomic nervous system failure. In February 2006, I began tube feeding through a j-tube, and that seemed to be working. I gained some weight back, and it was infinitely easier and safer than the previous year of HPN.

So for us, rafting the Grand Canyon, would mean a little more planning, a few more supplies, a few more body parts and appliances to worry about keeping clean and dry. But we were ready, and felt more than a bit of pride at our unwillingness to be limited by my condition.

Rethinking, Repacking

Two months prior to our trip, I started experiencing some difficulty tolerating my tube feeding—and two weeks before the trip I learned that I had acquired an intestinal infection that would require 30 days of antibiotic therapy. Meanwhile, I wasn’t tolerating tube feeding, so I was hospitalized for an HPN start a mere ten days before our trip was to begin. The plan was to keep trying tube feeding, gradually increasing it while decreasing my reliance on HPN as the infection cleared (hopefully within two to three weeks) and I was fully tube feeding once again. (While the infection did clear, ultimately I could not tolerate tube feeding at all.)

But it looked like our trip was out of the question. Tube feeding is relatively easy: sterility really isn’t an issue, infections around tube feeding are ultimately responsible for HPN set-up from the hospital, we worked with my home health care agency to arrange supply ship-

Always remember that you are ultimately responsible for your health and safety.
The Fungus Among Us: Tips for Fighting a Fungal Skin Infection
by Kathy Dahn, RN, Riverside HealthCare

My patients frequently tell me how good it feels when I bathe the skin around the stoma with warm soapy water. A bit of itchiness at that point is normal. What is not normal is to have severe itching under your tube, dressing, or ostomy appliance while you are still wearing it. There can be several reasons for this, but one of the most common is a fungal infection. This is not a cause for panic!

Many people worry that having a fungal infection indicates they are not clean, but this is simply not the case. Fungus thrives where it is warm, dark, and moist—which is a great description of the environment under a tube, dressing or an ostomy appliance. The peristomal skin (the skin around the stoma) will usually appear hot pink or strawberry red when a fungal infection is present. The skin may be intact or there may be places where the top layer of skin is missing, leaving an open wound that is red and moist (and tender).

Treatment Options
A fungal infection can be treated in different ways, with the main difference being the use of a powder versus a cream product. Note that whether you use a powder or a cream, tape or an ostomy appliance will probably not adhere for as long a period of time as you are used to, so beware! (As my sixth-grade teacher used to say, “Forewarned is forearmed.”)

Nystatin powder (such as Mycostatin®) will combat a fungal infection. Powder is especially helpful when there are many areas that are open and moist. To use the powder, clean and dry the peristomal skin well, then apply a light dusting of the powder to the affected areas. You can place an ostomy appliance directly over the powder or you can apply a skin prep over the powder to help achieve a tighter seal.

Another method (which I frequently use) is to apply Lotrisone® to the entire reddened area. Lotrisone is a combination product, with clotrimazole to fight the fungus and betamethasone (steroid) to decrease the itching. By the time patients come to see their health care providers with a fungal infection, they are frequently so miserable with the constant itching that we elect to use the Lotrisone to give relief.

Note for ostomates: because Lotrisone is a cream, the appliance will probably slip right off. To help achieve a tighter seal, we cover the Lotrisone with a “second skin”: DuoDERM® Extra Thin. DuoDERM Extra Thin is just what it says it is: it is very thin and it adheres to the skin when the body heat softens the DuoDERM. Skin prep can be applied over the DuoDERM to increase adhesion, then the ostomy appliance can be placed in the usual fashion. The edges of the DuoDERM can be secured with tape as needed. One little hint about using the DuoDERM Extra Thin: if you are cutting a hole in the center to accommodate your stoma, cut the hole smaller as the DuoDERM tends to stretch somewhat when you remove the paper backing.

Fungal skin infection at tube site. Photo courtesy of Kimberly-Clark.
Risk Reduction

With summer around the corner, it’s time to pay greater attention to protecting yourself from skin cancer. Preventive skin care is a good health measure for everyone, and is particularly important to those who are on immunosuppressive medications. By using effective skin protection methods, knowing how to recognize possible skin cancers, and seeking prompt treatment, you can reduce your risk of skin cancer significantly.

**Daily sun protection:**
- Make sunscreen application a part of your everyday routine—brush, shower, and apply sunscreen.
- Apply sunscreen to all exposed skin, especially the face, neck, back of hands, and forearms.
- Wear protective clothing—long-sleeved shirts, pants, wide-brimmed hats, and sunglasses.

**Regular skin examinations:**
- Examine your skin once a month for early signs of skin cancer.
- Have your skin examined regularly by a dermatologist for signs of skin cancer. Low-risk patients should have this done once a year, high-risk patients more often.
- Don’t delay in seeing your doctor if you find a suspicious skin growth. Early diagnosis makes the difference.

To see what skin cancer looks like and for more tips, visit the AT-RISC (After Transplantation-Reduce Incidence of Skin Cancer) Alliance Web site at www.AT-RISC.org. Many thanks to AT-RISC for providing material for this article.

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**Effortless Fund-raising**

Make your next Internet search a Good Search. GoodSearch.com is a new search engine that donates half its revenue, about a penny per search, to the charities its users designate. You use it just as you would any search engine. It’s powered by Yahoo!, so you get good results. Just go to www.goodsearch.com and enter Oley as the charity you want to support. Just five hundred of us searching four times a day will raise about $7300 in a year without anyone spending a dime!

**Lobby for Formula Coverage**

The Children’s Milk Allergy and Gastrointestinal Coalition (MAGIC) was formed to promote reimbursement for amino acid–based elemental formulas (such as Neocate® and EleCare™) for children who are unable to consume normal foods due to allergies, disease, or other conditions. The coalition is lobbying states to mandate coverage for elemental formulas regardless of delivery method, and for use in testing when required by a medical professional. This includes requiring private insurance companies to provide reimbursement for formulas when they are needed for proper nutrition and recommended by a doctor.

The coalition’s mission is to support current reimbursement lobbying efforts where they exist and to create opportunities for coverage in new states. For more information on MAGIC, or to get involved, visit the coalition’s Web site, www.childrensmagic.org, or contact Jason S. Eberstein at jebenstein@childrensmagic.org.

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**The Coram Care Partner Program**

The Coram Care Partner Program is dedicated to making your experience with Home Parenteral and Enteral Nutrition (HPEN) a positive and rewarding one. Those in the Partner Program have faced the challenges of long-term HPEN consumers, either as a consumer or a caregiver, and will help you and your family overcome these challenges.

**What the Coram Partner Program provides:**

- **Travel Help.** Our Partner Program provides you with tips on how to pack your bags, how to get through security, what to bring and how Coram can decrease your travel stress.
- **Coping.** Those in our Partner Program have seen it all. If your Coram Partner hasn’t experienced it, she almost certainly knows someone who has.
- **Patient Advocacy.** Your Coram Partner can help you with issues related to your insurance company, payor case manager, physician, branch, family and friends, and just about anyone else you may need help with.
- **Education.** Coram’s Partner Program provides you with numerous educational tools, toll-free audio-teleconferences with nutrition experts and resources designed specifically by the Coram HPEN team. Coram’s dietitians and clinicians are widely recognized as leaders in their field and whose published findings have been featured at A.S.P.E.N.’s Clinical Nutrition Week and other national events.

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


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**Lifeline Letter**

March/April 2007
Walk with Oley

If you’re planning to attend this year’s annual conference, you won’t want to miss the third annual walk-a-thon. We will enjoy a stroll through downtown Hyannis, as well as along the paved Walkway to the Sea. This is an excellent opportunity to be a part of one of Oley’s biggest awareness- and fund-raising events! The two-mile walk will conclude with an Oley-style picnic at the Hyannis Village Green. Join us to support Oley and have a great time doing so! For more information about the walk-a-thon and a pledge sheet, visit our Web site, www.oley.org, or call (800) 776-OLEY.

Equipment Exchange

Newly available items offered free of charge include:

**Formula**
- 2 1-lb. cans Alimentum Advance with iron, exp. 3/08
- 13 bottles Ensure high protein, exp. 11/07
- 2–3 cases Glucerna, exp. 8/07
- 1+ case Glytrol, exp. 1/08
- 10 cases Neocate Jr., exp. 11/07
- 9 cases Osmolite 1.2, Osmolite 1.0, exp. 11/07
- 6+ cases Optimental, exp. 6/07 & 9/07
- 8 cases Peptamen with prebio1, exp. 2/08
- 3 cases Peptamen, exp. 6/07
- 10 cases Peptinex DT
- approx. 1 case Resurgent Plus powder

**Tubes/Bags**
- 20 EasyFeed bags, 1000 ml
- 3 boxes Enterlyte bags, EL1200
- 106 Enterlyte bags, 500 ml, ELO500
- 20 Ross EasyFeed gravity feeding sets, 56
- 11 Ross Companion Top-Fill bags, 1000 ml

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

Meet your tube-feeding needs with Jevity 1.2 Cal and Embrace™.

With Jevity 1.2 Cal and the Embrace Pump from Ross, you can be assured you are receiving complete, balanced nutrition.

Jevity 1.2 Cal meets or exceeds 100% RDI for 24 essential vitamins and minerals in 1200 calories. Concentrated calories and protein help you gain and maintain a healthy weight.

The Embrace Pump offers safe, simple operation and the flexibility of ambulatory use.

Contact your home medical equipment supplier or visit Ross.com for more information.
Regional News

There is no special period of time over which you need to use the antifungal products. They can be discontinued once the peristomal skin looks and feels completely normal.

Facts of Life

If you have never had a fungal infection before, you may wonder, why now? One reason is that our immune system becomes less efficient as we age. In addition, increased use of antibiotics not only kills the “bad germs” but wipes out our normal flora—the “good germs” that normally live in our body. Our normal flora help to keep the “bad germs” in check, so when the normal flora is decreased, the fungus can take over. It’s sort of a “when the cat is away, the mice will play” scenario. And, of course, in the summer, heat can cause moisture under the tube dressing/appliance through perspiration.

Reprinted with permission from the Ostomy Association of Southwestern Indiana’s Re-Route. This free monthly newsletter provides many useful tips for people with ostomies (and usually has a very funny cartoon, too). Oley members can subscribe to the online newsletter at www.ostomy.evansville.net/signup.htm.

Paying Tribute

At the kickoff for this year’s Oley conference in Cape Cod, we will pay tribute to Oley co-founder and Medical and Research Director, Lyn Howard, MD, as she prepares to retire. Please send us your stories and photos. We will include them in the conference program and compile them into a memory book for Dr. Howard. Send to: The Oley Foundation, 214 Hum Memorial, MC-28, Albany Medical Center, Albany, NY 12208, or bishopj@mail.amc.edu.

Tube Talk, from pg. 3

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Facts of Life

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HPN Centers of Experience

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

University of Nebraska Medical Center

The Intestinal Rehabilitation Program at the University of Nebraska Medical Center became formally organized and incorporated the former Nutrition Restart Center (Boston) protocols and patient follow-up in 2000. Prior to that, the surgeons, gastroenterologists, nurses, and dieticians in the program had worked together informally on the care of patients with short bowel syndrome (SBS) and intestinal disorders. Program staff include Dr. Debra Sudan, Dr. Jon Thompson, and Dr. Richard Gilroy, who are international leaders in the treatment of patients with intestinal failure.

The primary focus of the program is weaning patients from TPN. Through in-patient and outpatient programs, the team teaches dietary modifications and monitors patients to safely wean them. For patients who are not candidates for weaning, they provide ongoing medical support and management. Patients can also participate in research.

The center has extensive experience in surgical therapy for patients with SBS. More than 60 percent of patients who have undergone surgical intestinal lengthening procedures have been able to discontinue TPN. It is now twenty-four years since their longest survivor underwent such a procedure.

Through these close associations, the program can be aggressive in medical and surgical interventions, resulting in the reversal of liver disease and clearing of jaundice in patients who would otherwise have required transplantation. However, the university has one of the oldest and most experienced intestinal transplant programs as well. High-risk patients are closely monitored during their weaning process; if the complications are not reversing, they may be placed on a waiting list and undergo intestinal transplantation when appropriate.

The program includes both adult and pediatric facets, with dedicated dieticians and nurse coordinators. The program can be reached by calling (800) 548-3701 or by visiting their Web site, www.nebraskamed.com/services/intestinal.

Book Sales Fund Research

Stories from Her Journey is a book of short stories written by Liz Maxwell. Liz was a liver transplant recipient. When she passed away in 2005, her writing group decided to publish a book of her essays in her memory. The essays cover a range of topics, including her transplant experience. Proceeds from the sale of the book will go to help fund liver transplant research at the University Health Network, Toronto General & Western Hospital Foundation. The book is $20 plus shipping and handling. To order or for more information, visit the Semi-detached Press Web site at www.semidetachedpress.com.
Coping Skills

Rafting, from pg. 2

115 degrees, so even refrigerating tube feeding formula is a good idea. A couple of my cans curdled in the heat.)

Don’t go it alone. While you may be able to handle it, there may also be times when you’re just too whipped to take the best care of yourself, which is crucial at the bottom of the Grand Canyon. At the end of eight hours of rafting, I was very tired, and relied heavily on my husband and two very close friends to help me set up my mini-infirmary each night when we reached camp. I needed those people, and having them meant that the guides were free to take care of the rest of the group without having to deal with all of my stuff.

Know your limits, and those of your partners. Maybe it has always been your dream to do something like this, but if you don’t have at least one (strong!) primary care partner and two or three backups who can take a hefty chunk of the responsibility for your care, reconsider!

Take twice the precautions you normally would with sterilization, cleanliness, safety, and so on. Remember, an emergency medical rescue not only interrupts your vacation, but everyone else’s as well, and a rescue constitutes a hazard for others in and of itself. Don’t be remembered as the one who took a risk and ended up costing the entire group part (or all) of their expedition. Also remember that endangering yourself can endanger everyone with you.

Be courteous and grateful. Most people want to be helpful, and usually appreciate a quick explanation about how that is best done. For example, I had a PICC line in my right arm, so a brief lesson on letting me grab them for help, rather than them grabbing me (and risking damage to the line) made people less afraid to help, since they knew how to approach it. They offered their arms, and I grabbed on!

Let your colleagues know your limitations, so that you don’t have to explain every mealtime, for example, why you won’t necessarily be joining in the socializing until after the meal is over. Again, a brief exposition at the very beginning of the trip about your specific condition, your needs, and your basic routine will enlighten others and help them feel more at ease.

Always remember that you are ultimately responsible for your health and safety—not the guides, not your fellow vacationers, but you. While people are often willing to help, the more you and your care partner can take care of yourselves, the happier everyone will be.

For the care partner: Remember to keep energy on reserve. Since you will be responsible for your own maintenance as well as someone else’s, it’s important to make sure you have the mental and physical resources left at the end of the day to help. Bon voyage! ¶

Deliver More Calories in Less Volume

Specifically formulated for children who...

- have increased caloric needs
- are fluid or volume restricted
- may benefit from a reduction in the number of daily feedings

RESOURCE® Just For Kids 1.5 Cal is the first and only calorically dense pediatric formula. For more information, contact your home medical equipment supplier at 1-800-333-3785 or visit www.novartisnutrition.com

Jenn and Greg sharing a quiet moment.
Individual Donors Make A Difference!

The following list represents everyone who generously contributed towards Oley’s efforts between February 9 and March 20, 2007. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

**Ambassadors ($2,000+)**
- Lyn Howard, MD**

**President’s Circle**
($1,000–$1,999)
- George Blackburn, MD

**Benefactors ($500–$999)**
- Jarol Boan, MD
- Joanne Hilferty

**Patrons ($100–249)**
- Casey Barron, c/o Mary Barron
- Richard & Faith Dillon
- James & Suzanne Douglas, in honor of Tanner Shuman, born 11/25/96—off HPN for 3.5 years!
- John Kordash, in honor of Oley’s outstanding work
- Joan & Francis Scheib
- Margaret & Dean Wieber

**Supporters ($50–$99)**
- Matthew & Jennifer Banderman
- Victor Chaney, in memory of Melissa
- Julie Freier, in honor of Darold Hauer
- Kevin & Janet Miller, in honor of Jonathan’s 24 years on HPN
- Doug Seidner, MD*
- Rex & Karen Speerhas

**Contributors ($30–$49)**
- Judy Brown
- Esther Burch
- David Coker
- Coker Design
- The Coker Family
- Pamela Dodman & Kristen Coker
- Alan Segal
- Enrica Thure, in honor of her brother Gregorio Tongol, HPN for 16 yrs.

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- Rex & Karen Speerhas

**Friends (Up to $30)**
- Michelle Juda
- Lavina Kepple, in memory of Gene Bussoletti
- Lisa & Ron Metzger,*** in honor of Dr. Lyn Howard
- Mr. & Mrs. Jack Morgan, in honor of their grandson
- Matthew Morgan
- Michael Raffe & Lauren Signer, in honor of Aidan Raffe, 3 years on G-tube feeds
- Bob & Mary Smithers

**In Memory of Kyle Noble**
- Michael Antonucci
- Jane Balint, MD*
- Eileen Ciricillo
- Steven & Davria Cohen**
- David Gould & Anne Reckline
- Visvalda & Heidi Grabauskas
- Roberta Groeber**

**Goal = $25,000**

Thank You!

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**Conference, from pg. 1**

Outstanding faculty confirmed at press time: Jane Balint, MD, from Columbus Children’s Hospital; Alan Buchman, MD, from Northwestern University; Mark DeLegge, MD, from University of South Carolina; Stanley Dudrick, MD, from St. Mary’s Hospital; Kathleen Gura, PharmD, and Mark Puder, MD, from Boston Children’s Hospital; Mark Korson, MD, from New England Medical Center; Lyn Howard, MD, from Albany Medical Center; Kishore Iyer, MD, from Mt. Sinai Medical Center; Darlene Kelly, MD, from Mayo Clinic; Doug Seidner, MD, and Ezra Steiger, MD, from Cleveland Clinic Foundation. Many outstanding pharmacists, nurses, and dietitians, all of whom are devoted to sharing their expertise and providing you a wealth of information and support, will complement these presenters.

Hyannis will be a great site for the conference and offers a perfect setting for you to learn more about the therapy that sustains you, connect with others who face similar challenges, and have fun. We hope you’ll be joining us!

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**Speed It Up with E-mail!**

Send us your e-mail address, and we can send you news updates, the latest conference information, and the *LifelineLetter* long before it would hit your mailbox. Our e-mail list is private and will not be shared. Contact Cathy at (800) 776-OLEY or harrinc@mail.amc.edu.

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**Keeping an Eye on the 2007 Appeal**

Oley members and trustees have responded generously to our annual appeal—and have pushed the mercury on our thermometer over the top!

If you haven’t made your donation yet, it’s not too late. You can help put us further over the top! Thank you for your generous support.

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**WOW! $25,500**
(as of 3/07)

Goal = $25,000

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**March/April 2007**
Thank You, Thank You
A special thank you to our corporate sponsors who keep Oley and its programs going strong. We appreciate your generous support!

Baxa Corporation
Baxa develops devices and systems for safe and efficient preparation, handling, packaging, and administration of fluid medications. The company’s Exacta-Mix™ and MicroMacro™ Automated Compounders safely mix parenteral nutrition solutions for home and hospital use. Baxa compounders are the only automated systems that accurately deliver both macro and micro ingredients in a single unit, with bar code ingredient verification to eliminate medication errors. These systems represent the state-of-the-art for nutritional support. We thank Baxa for its ongoing support.

Be a Star!
Your face could be the new face of Oley! Send us pictures of YOU doing what you like best: hanging with friends and family; biking, hiking or another activity; with or without your tubes/IV lines showing. You can also shape Oley materials by telling us how Oley has helped you. Let us know what is working and what needs fixing or creating. We want to hear from you! Send your photos and ideas to DahlR@mail.amc.edu, or The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208. Be sure to include your name, daytime phone or e-mail address, permission to print / post them on the web, and your home address if you want prints returned.

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

PLATINUM LEVEL PARTNERS
($70,000+)
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS
($50,000-$69,999)
Coram Healthcare

SILVER CIRCLE PARTNERS
($30,000-$49,999)

BRONZE STAR PARTNERS
($20,000-$29,999)
Apria Healthcare
Serono, Inc.

BENEFACTOR LEVEL PARTNERS
($10,000-$19,999)
Novartis Nutrition
Ross Products Division/
Abbott Laboratories

PATRON LEVEL PARTNERS
($5,000-$9,999)
Critical Care Systems
Option Care, Inc.

BLUE RIBBON PARTNERS
($2,500-$4,999)
Baxter Healthcare
Nestle Nutrition

CONTRIBUTORS ($1,000-$2,499)
Baxa Corporation
Zevex, Inc.

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

John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
Ann & Paul DeBarbieri
Tom Diamantidis, PharmD
Selma Ehrenpreis
Herb & Jay 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
Hubert Maiden
Judi Martuccelli
Kathleen McInnes
Meredith Nelson
Nancy Nicholson
Rodney & Paula Okamoto, RPh
Kay Oldenburg
Judy Peterson, MS, RN
Clemens Pietzner
Beverly Promisel
Abraham Rich
Roslyn & Eric Scheib Dahl
Steve Swensen
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Rosalie Ann & William Wu

(800) 776-OLEY • LifelineLetter — 9
Toll-Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<table>
<thead>
<tr>
<th>MAY ’07</th>
<th>JUNE ’07</th>
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<tbody>
<tr>
<td>Kevin &amp; Janet Miller</td>
<td>Kevin and Janet’s son Jonathan (24 years old) has been on HPN since birth due to short bowel syndrome from gastroschisis. They can speak about the many issues of raising a child on HPN and have attended several Oley conferences in the past. They look forward to sharing their experiences with you.</td>
</tr>
<tr>
<td>Rumford, RI</td>
<td>Diane has been on HEN for 14 years due to myotonic myopathy. She was on TPN prior to enteral and has experience with a variety of tube issues. She is proactive in care issues. Diane lives on Cape Cod and can answer questions regarding the area in which the conference will be held. Please call Diane after 5 p.m. EST.</td>
</tr>
<tr>
<td>(888) 610-3008 EST</td>
<td>Don has been on HPN for 32 years due to SBS and Crohn’s disease. He also has an ostomy. Call him to learn more about CVCs, 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 HPN.</td>
</tr>
<tr>
<td>Liz Tucker</td>
<td>Ann is a retired attorney; she loves gardening and walking in the woods with her husband and dogs. Diagnosed with Gardner’s syndrome, she has years of experience with TPN, tube feeding, traveling, and working, and is familiar with the disability approval process. Call Ann Tuesday to Thursday.</td>
</tr>
<tr>
<td>Lakeville, MN</td>
<td>Mariah is a 25-year-old college student on TPN 22+ years due to pseudo-obstruction and SBS. She also has a G-tube and ileostomy. She enjoys swimming, Jet-Skiing, traveling, scrapbooking, shopping, reading, and cooking. Her mother Felice can talk to parents about raising a chronically ill child. They both have attended many Oley conferences and can discuss the benefits. They can take calls after July 11.</td>
</tr>
<tr>
<td>(888) 650-3290 CST</td>
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Partnering for Success
Enhancing Oley Efforts

The following suggestions may help you brainstorm ways to support the Oley mission to enrich the lives of those dependent upon home nutrition support. Please consider implementing one or more of these ideas.

Enhancing Oley’s Outreach Efforts:

1. Introduce the Oley Foundation to all of your patients/customers.

2. Host an Oley membership campaign within your institution. We can provide sample newsletters with membership forms for you to distribute. Consider offering an incentive.

3. Introduce the Oley Foundation resources to physicians, discharge planners, and case managers, emphasizing that Oley efforts include tools that educate patients and reduce complications/costs.

4. Introduce the Oley Foundation to folks with whom you are connected, i.e. companies you purchase from, and other organizations that you believe would benefit from an affiliation with Oley.

5. Have an Oley member speak at an in-service to describe how becoming affiliated with Oley has impacted his or her life.

6. Contact “your” Regional Coordinator to introduce yourself and your organization. (A list of Regional Coordinators and their contacting information is available at www.oley.org.) Provide a speaker or refreshments when/if they host support group meetings. Note: Our volunteers are encouraged to restrict attendance at these meeting to consumers/family members, but a 20-minute presentation by someone with expertise in the field is encouraged and will enhance the effort. The remainder of the gathering will be restricted for consumer networking purposes.

7. Notify the Oley Foundation of conferences or meetings where its presence as an exhibitor seems appropriate.

8. Include Oley information in teaching materials and on labeling whenever possible.

Thank You! Thank You! Thank You!
You Talk, We’ll Listen

Help us update our membership records by correcting the information on the address label below, if necessary, and answering these few questions.

Phone (day): (____) ________-_________ Phone (eve): (____) ________-_________

E-mail: _____________________

Send me the newsletter via e-mail for faster service.

What is your specialty? ________________________________

What types of patients do you work with? (Check all that apply.)

_____PN  _____EN  _____Outpatient  _____In-patient

Do you need any Oley materials for you or your patients? (indicate quantity)

_____HPN Complication Chart  _____HEN Complication Chart  _____Newsletter

_____Keep Me Safe poster and bracelet  _____Flyer to introduce patients to Oley

What topics would you like to see covered in the newsletter or at conferences?

______________________________________________________________

Your $40 membership donation helps keep Oley services free of charge for HPEN patients.
Please return your donation with the completed survey in the envelope inserted in this issue.

Questions? Contact us at (800) 776-OLEY or (518) 262-5079; bishopj@mail.amc.edu; or www.oley.org.

Nominate Someone Special for an Oley Award!
Visit www.oley.org for details.

LifelineLetter
The Oley Foundation
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Albany, NY 12208