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 hairdryer 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; hair and sand. We came out of the river with more sand than hair, and more hair than sand.

Coming Soon... Hyannis in June!

The conference registration brochure is enclosed in this issue and is available online at www.oley.org. If you haven’t already made your plans to attend, do so soon. Rooms at all participating hotels are being reserved at a record pace. To help you decide, some of the topics being covered include: avoiding HPEN complications; the offerings of intestinal rehabilitation centers; coping with HPEN; the role of probiotics in maintaining a healthy gut; the importance of staying hydrated; transitioning to enteral nutrition; managing pain; monitoring medical costs; the history of HPN; tackling tube and catheter complications; and what we know today about mitochondrial disorders.

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.
Rafting, from pg. 1

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 the line require treatment, but I didn’t have to worry about keeping the line sterile. (Note: While I would not recommend this type of feeding supplies to all, I was aware of the advantages of being able to feed myself.)

But we did it. We rafted the Colorado River on HPN and tube feeding with the best of them. And for me and my husband, that was some accomplishment.

Lessons Learned

While I would not recommend this type of vacation for everyone on supplemental nutrition, I did learn quite a bit about what it takes to make such a trip go as smoothly as possible. Here are some tips and things to remember if you choose to undergo a rafting expedition:

As independent as you might like to feel, this is a team effort. You must be able to partner with the expedition company, which means “full disclosure.” While some companies may choose not to engage the risk, others are more than willing to go out of their way to help, provided you do not require them to actively provide your care.

Our guides were extremely helpful—as well as grateful that their largest responsibility was just to hand us our medical supplies when we made camp. Also, make sure they have the storage space for your extras, as well as refrigeration for your nutrition. (Note: Things that usually don’t need refrigeration often need it when the temperature is too high.)

Always remember that you are ultimately responsible for your health and safety.

Rafting cont., pg. 7
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 Metzel@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.

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.

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 $7,300 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 jeberstein@childrensmagic.org.

Contact us toll-free at 866.4.HomePEN (866.446.6373)
www.coramhc.com
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
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- 8 cases Peptamen with prebio1, exp. 2/08
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- 10 cases Peptinex DT
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- 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.

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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.
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!

Jenn and Greg sharing a quiet moment.

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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.

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George Blackburn, MD

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Joanne Hilferty

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Casey Barron, c/o Mary Barron
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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
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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
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Alan Segal
Enrica Thure, in honor of her brother Gregorio Tongol, HPN for 16 yrs.

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Mr. & Mrs. Jack Morgan, in honor of their grandson
Matthew Morgan
Michael Rafe & Lauren Signer, in honor of Aidan Raffe, 3 years on G-tube feeds
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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.

WOW! $25,500 (as of 3/07)
Goal = $25,000

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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**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!

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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.

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**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
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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.

Kevin & Janet Miller
Rumford, RI
(888) 610-3008 EST
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.

Liz Tucker
Lakeville, MN
(888) 650-3290 CST

Diane Owens
Marion, MA
(888) 610-3008 EST

Don Young
Porter Corners, NY
(888) 650-3290 EST

Ann Debarbieri
Gansevoort, NY
(888) 610-3008 EST

Mariah Abercrombie
Henderson, NV
(888) 650-3290 PST

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.

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

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.

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 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 HPN.

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.

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.
### You Talk, We’ll Listen
Complete this survey (both sides) and you could win a $50 gift card from Oley!

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<td>5. Annual Summer Conference</td>
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<td>6. Regional Conferences</td>
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<td>9. Support Group Meetings</td>
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<td>10. Equipment Exchange Program</td>
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<td>11. Tools for Better Living:</td>
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<td>Keep Me Safe poster and bracelet</td>
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Any ideas for future programs or newsletter topics? 

Other comments?

Return this survey in the envelope inserted in this newsletter, or complete it online at www.oley.org.

Thank you for your time and participation! Your name will be entered to win a $50 gift card.
Fast Facts From You

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

Phone (_____) _______ - _________

E-mail ___________________@___________________________

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

Date of birth _____/_____ (month/year)

Sex _____Male _____Female

Diagnosis ______________________________

Began HomePEN therapy _____/_____ (month/year)

What therapy are you on? (Check all that apply.)

_____ HPN (IV fed)   _____ HEN (tube fed)   _____ Hydration   _____ Presently off therapy

Catheter type (IV feeders) _________________________________

Tube type _____G-tube _____ J-tube _____Button _____Other

Please consider enclosing a membership donation when you return this 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.

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