

What's Inside:

Lifeline Mailbox *Page 2*

Tube Talk *Page 3*

Support Oley While
You Shop On-Line! *Page 3*

Medicare 'Back-to-
Work' Web Site *Page 3*

Need Help with
Insurance Issues? *Page 4*

Equipment Exchange *Page 4*

Coping with the
Holidays *Page 5*

Ostomy News *Page 6*

Video Tape Library
Form *Page 7 & 8*

Travel Packet:
Suggested Cover Letter *Page 9*

Travel Packet: Form
for All Consumers *Page 10*

Travel Packet: Form
for HPN Consumers *Page 11*

Travel Packet: Form
for HEN Consumers *Page 12*

In Memory of John
Richards *Page 13*

HMO Humor *Page 13*

Contributor News *Page 14 & 15*

Call a Lifeline —
Free of Charge! *Page 16*

LifelineLetter

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

Packet for Travel and Hospital Admissions

During this year's Oley Conference, several consumers and clinicians put their heads together to brainstorm a document that would be helpful for consumers when they travel or are admitted into the hospital. The resulting packet is meant to help consumers communicate their medical needs and history to hospital personnel, and can be especially important for emergency admissions at an unfamiliar institution. We recommend that all consumers **first copy**, then fill out the relevant parts of the packet and carry it with them whenever they leave home. Consumers may need help from their physician and/or home care company to complete certain sections.

The packet includes

1. a suggested cover letter (choose which points/bulleted statements you wish to convey) **PAGE 9**
2. a general overview of personal information/medical history **PAGE 10**
3. a page for HPN specific information **PAGE 11**
4. a page for HEN specific information **PAGE 12**

Recognizing that many consumers may want to personalize their document, and that all will need to update it regularly, we are offering the Travel/Hospital Admissions Packet in several different formats:

- For multiple paper copies send a self-addressed, stamped envelope to Travel Packet, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208.
- E-mail Roslyn Dahl at DahlR@mail.amc.edu for a Microsoft Word document that can be edited on your computer. Please specify whether you prefer the PC or MacIntosh version.
- Download this packet from our webpage at: <http://www.wizvax.net/oleyfdn/99-027.html>

Any questions? Call Roslyn Dahl at (800) 776-OLEY. We thank everyone who helped put this together, especially Marcia Wise, RN, Barbara Lorenzen, RN, and Irmagail Gordon.

Travel Packet cont., pg. 9 ➤

Oley Publishes HEN Complication Chart

Help spread the word: the Oley Foundation has recently published a complication chart for consumers of home enteral nutrition. The chart is designed to help consumers determine a possible cause for HEN-related symptoms they may be experiencing, and suggests actions they might take to alleviate symptoms and prevent them from reoccurring.

Users are strongly advised to review the entire chart with their physician, noting any differences in protocols and/or procedures, prior to taking any actions recommended by the chart.

A copy of the chart is included in this issue of the newsletter if you have indicated on an Oley membership form that you are an EN consumer or professional. If you are interested in the chart and did not receive a copy, or would like additional copies to distribute to patients, contact Cathy Harrington at (800) 776-OLEY (518-262-5079 outside the U.S.), or HarrinC@mail.amc.edu.

A warm thank you to the authors, Kerry Stone, MS, RD, CNSD, and Pat Brown, RN, CNSN, OCN, and the many professionals and consumers who reviewed drafts of the chart for us. ☺

New Additions at Oley

Good news, the Oley Family is growing. We've recently hired a new part-time staff member at the Oley office and have signed up a new Regional Coordinator in Pennsylvania. Please join us in welcoming them aboard.

Ellie Wilson, RD National Outreach Coordinator

As Oley's new outreach coordinator, Ellie's primary responsibilities are to help Oley expand its membership and improve its outreach services. She will help organize regional Oley gatherings, strengthen our ties to other organizations/resources, and provide much-needed support to our Regional Coordinators. Ellie has a varied past, which gives her



Ellie Wilson, RD, with her friends Emily and Maxwell.

New Additions cont., pg. 6 ➤

✉ ✉ **Lifeline Mailbox: Dietitian Responds to IOM Report** ✉ ✉

Following is a letter reflecting a dietitian's perspective on "The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population"—an Institute of Medicine Report discussed in the "Medicare PEN Issues 2000" article published in the July/August 2000 *LifelineLetter*. The report evaluated the costs and benefits of providing comprehensive nutrition services (including PEN) for Medicare recipients, in in-patient, home and other non-hospital settings.

The recent recommendations of the Institute of Medicine (IOM) come at a time when the delivery of health care is rapidly changing.

Advances in medical technologies, increased longevity, early hospital discharge and patient satisfaction all contribute to a rising number of individuals receiving home and community-based care, including PEN. Recognizing the changes in the delivery of health care combined with the increasing evidence of the benefits of nutrition therapy, the IOM made four key recommendations summarized here: (1) nutrition therapy, upon referral from a physician, should be reimbursed by Medicare; (2) the Registered Dietitian (RD) is currently the health care professional with the standardized education, clinical training, continuing education and national credentials necessary to be directly reimbursed as a provider of nutrition therapy; (3) reimbursement for PEN in in-patient settings should continue and be provided by a multi-disciplinary team that includes a physician, a nurse, a pharmacist and a dietitian; and (4) HCFA should reevaluate their reimbursement systems in all care settings to evaluate the adequacy of care.

Despite these recommendations, the recent change (October 1, 2000) in Medicare reimbursement to a prospective payment system (where the number, type and duration of home care visits are strictly limited) does not cover the services of RDs or other nutrition professionals in home and community settings. The lack of reimbursement for professional nutrition services combined with the lack of mention of a nutrition professional in the Code of Federal Regulations and in JCAHO standards for home health agencies means that only a small number of RDs work in home and community settings, and that PEN consumers suffer impaired quality of care.

In a survey by Schiller in 1998, home health administrators recognized the substantial need for RDs in home health but the number one deterrent was the lack of Medicare reimbursement. The survey of 328 *LifelineLetter* subscribers conducted by Ellis demonstrated how poorly the needs of EN consumers are being

met: the EN consumers reported low quality of care and inadequate interaction with professionals knowledgeable of medical, health and nutrition infusion issues. In addition, a patient satisfaction survey of 172 home health clients conducted in 1995 by Costello found that patients were dissatisfied with the continuity of nutrition care they received from the in-patient to the home setting. In a descriptive study of PEN consumers by this author, it was found that 88 percent had no interaction with a RD, there was a lack of understanding and compliance for the nutrition prescription, and that there were multiple gastrointestinal complications, hospital readmissions and bowel surgeries

— many of which may have been preventable. Another consequence of the changes in health care delivery is that many home health agencies are no longer providing service to EN patients and in some hospitals patients who would benefit from EN are being discharged on TPN because of somewhat better reimbursement and visitation coverage. This gap in professional services increases the risk for PEN consumers to experience adverse health outcomes, hospital readmissions, impaired function and lesser quality of life.

The IOM recognized the need for change in health care policy, and as Alan Parver stated in the July/August, 2000 issue of *LifelineLetter*, "there is an opportunity for consumers to play a role." When you communicate with policy makers (Senators and Representatives) let them know about the IOM's recommendations and be sure to mention the need for skilled, trained nutrition professionals in health care delivery. It is not possible to have quality of care without qualified care providers. You can read the IOM report online at <http://www.nap.edu/catalog/9741.html> or order it from the National Academy Press.

— Heidi J. Silver, MS, RD, CNSD
 Doctoral Candidate
 Department of Dietetics and Nutrition
 Florida International University, Miami
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This gap in professional services increases the risk for PEN consumers to experience adverse health outcomes, hospital readmissions, impaired function and lesser quality of life.

LifelineLetter

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The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

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

Tube Talk

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

Flexible Tube Holder

For those of us who are uncomfortable using stiff tube anchor devices, there is a new product from Convetec called "Flexi-Trak Tapes." They hold a tube in place with a BandAid-like tape. (The tape is hypoallergenic, but if you have sensitive skin, try applying a skin prep powder to the area before using the tape.) The tube lays between two clear adhesive tabs that can be opened and closed to allow the tube freedom for flushing etc. They can be opened 10-12 times before they need to be changed (usually three to four days). They are Medicare approved and come in two sizes: 1" and 2" wide tabs. I have showered and swam with these and they stayed in place. Ask your healthcare supplier for some samples to try.

— Barbara Witt • Sparta, WI
(608) 269-2173
luckybucky@centurytel.net

How Do You Handle Leaks and Odors?

Unfortunate as they may be, leaky tubes, leaky ostomies and incontinence 'accidents,' are a common occurrence for people with chronic gastrointestinal disorders and those on tube feedings. Even without an actual leak, many consumers find they emit strong odors at times which can be uncomfortable for the consumer and the people around them. How do you get over these incidents graciously, minimizing your embarrassment, and hopefully avoiding a 'scene?' Please send your comments to the Lifeline editor, Roslyn Dahl (contact information is in the box on page 2).

— Kathleen McInnes
Chicago, Illinois

Need to Take in More Calories?

One active homePEN consumer recommends trying MegaGains mix. He says the mix is not bad, and provides 1800 calories in one quick gulp! The consumer found the mix at www.danielchapterone.com. As with trying any new products, be sure to check with your physician first.

Support Oley While You Shop On-line @ iGive.com

You, your friends and family can help support the Oley Foundation when you shop at favorite on-line stores like Amazon.com, the Gap and Toy'R'Us at the iGive.com mall. There's no cost, obligation, fees, hassles or phone calls. This is how it works:

First: Become a member

Go to: www.iGive.com

Enter your e-mail address and click "Join Now"

As you fill in your information, be sure to select "The Oley Foundation" as your desired cause. (Type in "Oley" as your "keyword" and select "New York" as the "territory.")

Currently, there are three options for donating your money. We recommend you select the top option: "I want to take a tax-deduction for my shopping donations."

Second: Shop On-line

Buy brand-name items from more than 200 top on-line merchants (like Amazon, the Gap and others) through iGive.com's mall and up to 15 percent of each purchase goes towards the Oley Foundation. (For a complete listing of stores, go to iGive.com.) Occasionally, through special promotions, even larger donations are possible.

Third: Forward Your Order Confirmation

After you've shopped, forward the order confirmation e-mail to orders@iGive.com so they can credit Oley for your purchase.

An order confirmation is the receipt the merchant e-mails you, usually the day you made your purchase. It should contain:

- a confirmation number (also called an invoice or order number)
- the name of the merchant
- the amount and date of purchase
- the e-mail address you used to register at iGive.com

It takes between five and seven days for the information to appear in the stats on your on-line membership page.

Questions?

Try the online help function at iGive.com or call Oley at (800) 776-OLEY.

Thank you for supporting the Oley Foundation!

Social Security Web Site for Consumers Who'd Like to Work

Social Security's Office of Employment Support Programs has designed a new web site called "The Work Site" It is located at <http://www.ssa.gov/work>. The site details information about Social Security's programs, like the Ticket to Work program, and pertinent legislation, like the Work Incentives Improvement Act of 1999. The site also contains links to other web sites on related topics. ☺

PAF Helps with Insurance Issues

Finally, some good news for consumers with insurance issues. Oley has recently discovered a source of information and advocacy help: the Patient Advocate Foundation (PAF). PAF is a non-profit organization based in Newport News, VA, whose mission is to help patients (nation-wide) facing a health-related insurance, employment or debt crisis.

PAF can assist consumers who have been denied coverage, and those who, because of their condition, have been discriminated against at work, and/or are have real financial problems.

PAF deals with all kinds of insurers, from HMOs to Medicare and Medicaid, and can guide consumers through the application and appeals process for Medicare and Medicaid. They are there to help consumers who don't have the know-how or energy to battle with their insurance company or employer alone.

PAF has a staff of full-time case workers, as well as national and state resource networks. Best of all of, their services — except for legal counsel — are offered free of charge. (About one-quarter of PAF cases require legal help; most of these cases are settled out of court. Patients requiring legal help are referred to a lawyer within PAF's network who will review their case and provide an initial consultation free of charge. Consumers are charged for any subsequent legal services they choose to contract for.)

Obviously PAF is not a wonder cure for all insurance and employment issues; but they can help consumers get through the maze of information and bureaucratic hoops to determine:

- what care or insurance coverage they are eligible for
- what rights they have as employees
- what resources are available for them, and
- how to best present their case.

For more information, contact PAF at 753 Thimble Shoals Blvd. Suite B, Newport News, VA 23606; Phone: (800) 532-5274; Email: patient@pinn.net; Internet: www.patientadvocate.org. ©

Equipment Exchange

The following homePEN supplies are offered free of charge:

- CADD administration sets, Reorder #21-7042, #21-7071
- Flexiflo EN feeding bags, reorder #507 (500 ml), #71 (1000 ml)
- 5+ cases of Vivonex EN formula
- 5+ boxes of Vivonex Plus EN formula
- 150+ Kangaroo pump sets 1000ml bags, reorder #8884
- gauze bandages, 2"x2" split, 2"x2" solid
- syringes, 60cc and 12cc
- Ross flexiflo bags
- IMED TPN stand

For more information, call Roslyn Dahl at the Oley Foundation at (800) 776-OLEY/(518) 262-5079. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition.



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Coping with the Holidays

Audrey Kron, MA, CGP

Holidays can be a real source of joy but they can also cause concern for those with a chronic illness. Here are answers to some of the questions I have been asked about coping with the holidays.

Q. How can consumers work with friends and family to minimize the stress of preparing for the holidays?

A. Give yourself more time to prepare. Start long before the holiday actually arrives. Realize that things don't have to be perfect. Consider your expectations. Often we lose sight of the fact that the most important aspect of the holidays is celebrating with loved ones.

Everything doesn't have to resemble *Better Homes and Gardens*. Learn time management techniques such as prioritizing, delegating and most importantly, saying "no" when necessary. Make the meal preparation easier. Order in, use frozen food or have others help with the cooking. Remember it's not what you eat that is important, it's celebrating together.

Q. A person who isn't feeling well may worry that their illness could ruin the holidays for family and friends. If you're going to travel to a big get-together with family or friends and are concerned about having a flare-up, what are the best ways to explain your concerns to the people you're visiting?

A. Communicate ahead of time. They will feel more comfortable if they know your needs. Let them know if you are on a special diet or have special requirements. If your strength is limited at the time, make sure that plans allow adequate time for rest.

Do as much as you can for yourself in advance. Have your doctor give you the name of a doctor and health care company in the city you plan to visit. Make sure you have a letter from him or her, telling about your condition (see travel packet pages 1, 9-12). If you fly, it's also a good idea to carry your nutrition, supplies and medications on the plane and not risk their loss. (Call 800-776-OLEY for travel tips.) The most important items to pack are a sense of humor and a pleasant disposition, so that your host and hostess won't mind any inconveniences that may ensue. Be prepared in case, but go expecting to enjoy yourself.

Q. How do you deal with your own disappointment during the holidays?

A. People tend to expect more on the holidays. Movies, books, TV and advertising always depict the so-called perfect family gathering. Even without an illness, most people have difficulty in accepting reality. Our memories often fail us, and we only remember the good times. For some, just being with family is a cause for anxiety. In that case we're disappointed before anything happens because we feel our family doesn't measure up to the standards that we see in the media.

Instead of looking at your limitations during the holidays, look at what you can do. For instance, you'll feel much better if you focus on what you can eat rather than what you can't. Help someone less fortunate than you are. It's not hard to find someone whose

situation is worse than yours. It might just be a phone call to someone shut in, but it will make you feel better as well.

Make sure your expectations are realistic. Remember everything is "time-limited." Consumers should plan ahead to try and prevent situations that may cause depression. Modify plans to suit your requirements. Above all, do not leave having company around to chance. Make plans to be with someone. If worse comes to worst, at least use the phone to make contact with others. Again, remember others are lonely on holidays when they can't be with their families. If you can't find ways to relieve the depression, don't hesitate to seek professional help. If possible, try to find someone that has some understanding of the special needs of the physically ill patient.

Q. How can consumers cope with being hospitalized during the holiday season?

A. Nobody wants to be in the hospital for a holiday. However, if it's necessary, make the most out of a distressing situation. Decorate your room. Have your family help. Arrange for your family to visit and perhaps share a holiday meal with you. If you're on I.V.'s and can't eat, use your imagination and sense of humor and pretend it's your turkey dinner. It will be something you'll remember long after you will have remembered any particular meal. If you want to exchange gifts, use the phone, mail or lap top computer to buy the gifts and have them delivered. Buy yourself a gift too. It doesn't have to be anything expensive, but it's okay to pamper yourself a little. If celebrating the holiday is very important to you, arrange to have a celebration when you get home. Take control; you decide when and how you want to celebrate. Consider how much more you will appreciate celebrating the holiday next time when you are feeling well. ☺

Audrey Kron, MA, CGP is director of the Center for Coping with Chronic Illness. She has spoken nationally and internationally on various aspects of chronic illness, and is best known for her books, Ask Audrey and Meeting the Challenge: Living with Chronic Illness. In addition to her professional credentials, Ms. Kron has first hand experience with chronic illness, having battled Crohn's disease for most of her life. She has been on TPN since 1985. For information on ordering Ask Audrey or Meeting the Challenge: Living with Chronic Illness, you can contact her at 7466 Pebble Lane, West Bloomfield, MI 48322; E-mail ShrinkA@aol.com; Phone: (248) 626-6960; Fax: (248) 626-1379. If you mention the Oley Foundation when you order, the Foundation will receive \$2.00 for each book sold.



Medicare Improves Ostomy Supply Policy

Good news for consumers with ostomies! The United Ostomy Association (UOA) reports that Medicare's four Durable Medical Equipment Regional Carriers (DMERCs) have adopted recommendations from UOA for improving their Medicare ostomy policy. The DMERCs have increased the number of items ostomates can use per month without the need for additional documentation for medical justification.

Monthly usage guidelines have changed as follows:

- **drainable pouches** have increased from up to 10/mo. to **up to 20/mo.**
- **urinary pouches** have increased from up to 10/mo. to **up to 20/mo.**
- **closed pouches** have increased from up to 31/mo. to **up to 60/mo.**
- **irrigation sleeves** have increased from 1/mo. to **up to 4/mo.**
- **solid skin barriers and skin barriers with flanges** have increased from up to 10/mo. to **up to 20/mo.**
- ostomates can now use **one ostomy belt per month.**

UOA says basic documentation, such as a doctor's order or prescription, continues to be required for the dispensing of supplies. Other important news:

- If you have a colostomy and choose to use closed pouches to manage your ostomy, you do not need to provide any additional medical justification for the use of closed pouches.

- If you need more supplies than the new increased guidelines allow, there is a new, streamlined process for providing the required medical justification. You will simply be required to provide a letter from your doctor explaining the medical reason for needing more supplies than the usual maximum quantities. Your supplier does not need to routinely submit this letter with your claim, but must keep it on file in your records as a copy may be requested at a later date by the DMERC.

The changes took effect on October 1, 2000, across the country. UOA reminds ostomates that they are entitled to obtain 1, 2 or 3 months supply at a time if they live at home, and 1 months supply if they are in a nursing home. If you would like more information, contact the United Ostomy Association at: 19772 MacArthur Blvd., Suite 200, Irvine, CA 92612-2405; (800) 826-0826; www.uoa.org. ©

Coram 2nd Ad

letter emailed to David

New Additions, from pg. 1

a unique combination of skills that will benefit Oley. In addition to being a dietitian, she worked for many years in sales and marketing. She is bright, energetic and enjoys public speaking. Ellie is active with the Arthritis Foundation of America. Additionally, she is involved in a national project funded by the USDA to assess the nutrient content of school lunches. To round out the picture, Ellie is also close to finishing a Master's degree in community health.

Edward Marchewka

Sewickly, PA, Region II Coordinator

Edward has been on TPN since October 1997 due to radiation enteritis. He has a Hickman catheter and uses a CADD pump. He is also familiar with the disability process. His interest lies in developing internet businesses. Edward is joining the Regional Coordinator team because he wants to promote knowledge of TPN and to help others. He can offer hope to new consumers. Edward would like to get connected with other consumers who have radiation enteritis, in particular to discuss what they can and cannot eat. He is 48 years old and married. Readers can contact Edward at PO Box 2, Sewickly, PA 15143-0002; E-mail ed@productivity.com; (412) 741-8623. ©

The Oley Foundation Video Tape Library Order Form

The Oley Foundation's video tape collection has just grown again! Filming of the latest set of tapes — those covering the 2000 Oley Annual Consumer/Clinician Conference — was coordinated and underwritten by Abbott Laboratories. Many thanks for their generosity and support.

Consumers and clinicians are welcome to borrow any of the video tapes in Oley's library at no charge. (We'd be delighted if you could cover the \$3 shipping and handling charge per video.) Simply complete and return the order form. Tapes are available on a first ordered, first served basis, and must be returned within one week of receipt. Tapes produced by Oley may be copied for repeat viewing.

Shipping Information:

Name _____

Address _____

City _____ State _____ Zip _____

Daytime Phone (_____) _____ - _____

Optional: Enclosed is a check for \$ _____
(A donation of \$3 per video borrowed will help cover Oley's shipping charges.)

Video Loan Agreement:

I agree to return the following video(s) to the Oley Foundation within one week of receipt.

Signature _____ Date _____

Mail Your Video Order To:

The Oley Foundation, 214 Hun Memorial, A-28, Albany Medical Center, Albany, New York 12208

Indicate your choice by checking the box. Limit 2 tapes per order.

Information About The Oley Foundation

- Support for Life: The Oley Foundation

Enteral — Tube Feeding

- Tube Feeding (1997, MSKCC)
 Tube Feeding: A Matter of Nutrition

Miscellaneous

- Choices in Nutrition: Understanding HPEN Therapy Options (Free, with \$5 shipping/ handling charge)
 1992 Oley Breakout Session: The Comings & Goings of Crohn's

2000 Oley Conference

- Plenary Session Day 1: Awards Ceremony, Catheter & Site Selection, Site Preservation, Catheter/Tube Infections
 Plenary Session Day 2: Insurance Issues, Medicare Legislative Issues, Coming of Age (20s) on HPEN
 Breakout Session: Interpreting Your Lab Values
 Breakout Session: Liver Disease
 Breakout Session: Using Your Gut
 Breakout Session: Pediatric Issues

1999 Oley Conference

- Plenary Session Day 1: Preserving Venous Access, Independence/Dependence Issues, Physician/Patient Relationship, Defining the Role of the Oley Foundation
 Plenary Session Day 2: Using the Gut, Liver Disease, Bone Disease, Venous Access Management, Health Care Corporate Compliance
 Breakout Session: Using Your Gut
 Breakout Session: Pediatric Issues
 Breakout Session: Keeping Complications to a Minimum

1998 Oley Conference

- Plenary Session Day 1: Thrombotic Catheter Occlusions, Transition from TPN to Oral and Enteral Nutrition
 Plenary Session Day 2: Evaluating and Acquiring New Equipment, Tips for Traveling with HPEN, Living Fully, Decision Making: Who's Involved and How Much?
 Breakout Session: What's Missing in TPN?
 Breakout Session: Complications from TPN
 Breakout Session: Research: What's Being Done?

More Videos Listed on Back 

Indicate your choice by checking the box. Limit 2 tapes per order.

1997 Oley Conference

- Plenary Session Day 1: Switching Physicians/Seeking Second Opinions, Switching Therapies, Reducing Dependency on TPN, and Returning to Work
- Plenary Session Day 2: History of TPN, Current Medical Challenges, Small Bowel Transplantation Update, Reimbursement Issues
- Breakout Session: Update on Inflammatory Bowel Disease
- Breakout Session: Improving Gut Functions
- Breakout Session: Reducing Complications from TPN

1996 Oley Conference

- Has HPEN Met It's Early Expectations?
- Plenary Session Day 1: Catheter Dressing Techniques, The Evolution of Infusion Control Devices, and HPEN Research
- Plenary Session Day 2: Maintaining Control in the Presence of Chronic Pain, Taking Charge of Your Health Care, and Advice on Insurance Issues
- Breakout Session: Minimizing the Risk of Liver Disease
- Breakout Session: Is Enteral Nutrition for Me?
- Breakout Session: Pain Management

1995 Oley Conference

- Plenary Session Day 1: Managed Care from the View of the Provider, Insurer and HPEN Consumer
Plus: The Annual Awards Ceremony, Regional Coordinator Workshop and Help Plan Oley's Future

1994 Oley Conference

- Opening Remarks: How HPEN Began
- Plenary Session Day 1: Alternatives to HPN, Catheter Complications, Pros and Cons of Tube Feeding, and Bowel Lengthening
- Plenary Session Day 2: Forum on Health Care Reform
- Breakout Session Day 1: Medical Management of Pain
Plus: Alternative Pain Management
- Breakout Sessions Day 2: Management of Diarrhea
Plus: Pseudo Obstruction Update

1993 Oley Conference

- Plenary Session Day 1: Small Bowel Transplantation and Dietary Program to Enhance Bowel Function
- Plenary Session Day 2: What You Need to Know About the Business of HomePEN and Why
- Breakout Session: Pain Management
- Breakout Session: Sepsis & Catheters

Please Return Videos Promptly!

Name
Address
City, ST Zip

Date:

Dear Healthcare Provider,

I am a person who requires specialized nutritional support to sustain my life. My physician and I are providing the following information to familiarize you with my special needs.

(Pick which of the following statements you wish to include in your letter.)

- I have a central venous catheter and/or enteral feeding tube. Maintaining access is critical to my ability to receive my nutrition.
- My physician and I have determined an appropriate regimen for the care of my catheter/tube. This protocol may be different than your standard protocol, but I would appreciate your following the recommendations in this form while I am in your institution, if at all possible.
- If I am able, I would prefer to take care of my own catheter.
- The following person has also been trained to care for my catheter and deliver my nutritional support:

Name: _____

Phone: (____) _____ - _____

Please feel free to contact my physician for any questions you may have regarding my care.

Sincerely,

Consumer Signature

Consumer Name _____

Physician Signature

Physician Name: _____

Physician Phone #: (____) _____ - _____

Travel Packet cont., next 3 pages ➡

Coram Ad
new -- email to David

Baxa Ad
emailed directly to david

Travel Packet Page 2: All Consumers

1. Personal Information

Patient Name: _____
 Caregiver Name: _____
 Relationship to patient: _____
 Address: _____
 Phone #: (____) _____-_____
 Insurance Provider: _____
 Policy or ID #: _____
 Group #: _____

Emergency Contacts:

Name: _____
 Phone #: (____) _____-_____
 Name: _____
 Phone #: (____) _____-_____

2. Clinician Contacts

Primary Physician: _____
 Address: _____
 Phone #: (____) _____-_____
 Physician Managing HomePEN: _____
 Address: _____
 Phone #: (____) _____-_____

Other Specialist:

Area of Specialty: _____
 Address: _____
 Phone #: (____) _____-_____

Homecare Agency:

Address: _____
 Phone #: (____) _____-_____
 Homecare RN Name: _____

3. Medical History

(See attached Discharge Summary if available)

Primary Diagnosis: _____
 Other Diagnoses: _____

Type of HomePEN Therapy: ____ PN ____ EN ____ Both *(check one)*

Allergies: _____

Procedures/Surgeries: *(See attached list of Procedures if necessary)*

Date: _____ Procedure: _____
 Date: _____ Procedure: _____

Current Medications: *(See attached list of Medications if necessary)*

Medication	Strength	Dose	Frequency	Route (IV, tube, mouth)

Note: several medications come in different strengths, including heparin which comes in 10 unit, 100 units, and 1000 unit strengths. The strength might be 5mg/5cc or 15mg/ml whereas the dose might be 5.0 cc or 10.0 cc

4. Nutrition Related Information

Infusion Schedule:

I have been on the attached formula since ____/____/____.
(Attach a label from your bag.)
 Infusion Vol.: ____ Rate: ____ Over ____ # hrs.
 I infuse ____ #days/week
 Time: *(check one)*
 ____ Overnight ____ Daytime ____ Around the Clock

Additives: *(i.e. MVI, Iron, and Meds...list may be attached)*

The following substances are added to my HPN:

Additive	Amount	Freq.

I infuse lipids ____ Yes ____ No *(check one)*

If yes, as a: ____ 3-in-1 Solution ____ Separate Sol. *(chk one)*

I infuse extra hydration *(Attach label from bag):*

____ Yes ____ No

If yes: Volume: ____ Rate: ____

I use gloves and mask when hooking up *(Recommended for pts with direct connect lines or ports):*

____ Yes ____ No *(check one)*

Other Pertinent Information:

Recent Lab Values: *(See attached Lab Results)*

Daily Input/Output:

Usual Weight ____ *(may be a range)*

Input Volume: ____ Output Volume: ____

Oral ____ Urine ____

IV ____ Ostomy ____

Tube ____ Other ____

Total ____ Total ____

5. Access Information/Protocols

Central Venous Catheter:

Type: *(check one)*
 ____ Externalized Catheter ____ Port ____ PICC
 Brand Name: ____ Size: ____
 Date Inserted: ____/____/____
 Inserted at Institution: ____
 By: ____ Surgeon ____ Vascular Radiologist
 ____ Nurse ____ Other ____
 Phone #: (____) ____-____
 If multilumen:
 ____ Lumen is for TPN
 ____ Lumen is for ____ *(blood draws, pain meds,)*

Flushing Protocol:

Solution: *(i.e. saline, heparin)* ____
 Amount: ____ Frequency: ____
 I use gloves and mask when flushing *(Recommended for pts with direct connect lines or ports):* ____ Yes ____ No *(check one)*

Dressing Change Protocol:

Frequency: ____
 Dressing Type: ____
 Skin Prep Solution: ____
 Catheter/Securement Method: *(check one)*
 ____ Subcutaneous Cuff ____ Tape
 ____ Sutures ____ None
 I use gloves and mask when changing my dressing *(Recommended for all pts):* ____ Yes ____ No *(check one)*

Cap Change Protocol:

Type: ____
 Frequency: ____
 I use gloves and mask when changing my cap *(Recommended for all pts):* ____ Yes ____ No *(check one)*

6. Pump & Supplies

1. Brand: ____ Mfg: ____
 Used for ____ PN ____ EN ____ Pain Meds *(check one)*
 Pump Tubing Brand & Reorder #: ____

2. Brand: ____ Mfg: ____
 Used for ____ PN ____ EN ____ Pain Meds *(check one)*
 Pump Tubing Brand & Reorder #: ____

Attachment Tubing *(for EN button)* Brand & Reorder #: ____

7. Ostomy (Output) Supplies & Protocol

Type of Ostomy: *(check one)*
 ____ Jejunostomy ____ Ileostomy ____ Colostomy
 Date Created: ____/____/____
 Institution/Surgeon: ____
 Phone #: (____) ____-____

I use the following for my appliance:

Type of Pouch: ____
 Type of Wafer: ____
 Type of Skin Prep: ____
 I change my dressing/pouch every ____ days.
 I use gloves when changing my ostomy dressing:
 ____ Yes ____ No *(check one)*

4. Nutrition Related Information

Feeding Schedule:

I use the following brand of formula: _____
(Attach a label from your can.)
 Method: (check one) _____ Bolus _____ Gravity _____ Pump
 Infusion Vol.: _____ Rate: _____ Over _____ # hrs.
 I have _____ # of feedings/day
 Total Volume fed in 24 hours: _____
 I tube feed _____ #days/week
 Time: (check one) _____
 _____ Overnight _____ Daytime _____ Around the Clock

Additives: (i.e. Iron, and Meds...list may be attached)

The following substances are added to my HPN:

Additive	Amount	Freq.

I infuse extra hydration (Attach label from bag):

_____ Yes _____ No
 If yes: Volume: _____ Rate: _____
 by: _____ Tube _____ IV (check one)

Other Pertinent Information:

Recent Lab Values: (See attached Lab Results)

Daily Input/Output:

Usual Weight _____ (may be a range)
 Input Volume: _____ Output Volume: _____
 Oral _____ Urine _____
 IV _____ Ostomy _____
 Tube _____ Other _____
 Total _____ Total _____

5. Access Information/Protocols

Feeding Tube:

Type: (check one)
 _____ N/G _____ N/J _____ G-Tube
 _____ G-Button _____ J-Tube _____ G/J- Tube
 Brand Name: _____ Size _____
 Date Inserted _____ / _____ / _____
 Inserted at Institution: _____
 By: _____ Surgeon _____ Interventl Radiologist
 _____ Gastroenterologist _____ Other _____
 Phone #: (_____) _____ - _____

Flushing Protocol:

Solution: (i.e. water, saline) _____
 Amount: _____
 Frequency: _____

Dressing Change Protocol:

Frequency: _____
 Dressing Type: _____
 Skin Prep Solution: _____
 EN Tube Securement Method: (check one)
 _____ Attachment Device _____ Tape
 _____ Sutures _____ None
 I use gloves when changing my dressing: (check one)
 _____ Yes _____ No

6. Pump & Supplies

1. Brand: _____ Mfg: _____
 Used for _____ PN _____ EN _____ Pain Meds (check one)
 Pump Tubing Brand & Reorder #: _____
 Attachment Tubing (for EN button) Brand & Reorder #: _____

2. Brand: _____ Mfg: _____
 Used for _____ PN _____ EN _____ Pain Meds (check one)
 Pump Tubing Brand & Reorder #: _____
 Attachment Tubing (for EN button) Brand & Reorder #: _____

7. Ostomy (Output) Supplies & Protocol

Type of Ostomy: (check one)
 _____ Jejunostomy _____ Ileostomy _____ Colostomy
 Date Created: _____ / _____
 Institution/Surgeon: _____
 Phone #: (_____) _____ - _____

I use the following for my appliance:

Type of Pouch: _____
 Type of Wafer: _____
 Type of Skin Prep: _____
 I change my dressing/pouch every _____ days.
 I use gloves when changing my ostomy dressing:
 _____ Yes _____ No (check one)

In Memory of John 'Rooster' Richards

Robin Lang, HPN Consumer, Regional Coordinator

John Pershing 'Rooster' Richards, 82, past away on August 29, 2000. He had been on TPN for 12 years due to a bowel resection from clots and adhesions.

John was a true gentleman. He loved people and his kindness extended to anyone who needed help. This trait elevated John to an extraordinary status twice, when he was instrumental in saving the lives of a neighbor and his grandson.

John had many dear friends in the homePEN community and he enjoyed educating others about TPN. He was very disciplined with his TPN care and used a common sense approach to maintain his health and strength.

Readers may remember John as the man who made beautiful crucifixes and crosses for Oley's Silent Auctions. John was an industrious and skilled craftsman. He loved wood working and had his own shop in Alpena, MI, where he could take any scrap of wood and create special gifts.

John was a supportive friend, and wrote many beautiful letters to his homePEN pen-pals. He had a great sense of humor, as illustrated by the story behind his nickname. He once told me, "My wife called me 'Rooster' because she said I liked to chase hens."

John is survived by his daughter, Joy, son-in-law Tom, six grandchildren and ten great-grandchildren. Joy and Tom lived nearby and took wonderful care of him. They gave him all his independence and sought help from others in the HPEN community when John needed an additional 'shot in the arm;' although it was usually John giving support to others. He frequently asked, "Did you get your hug today?" Then he would dole out hugs to all who needed them.

As a faithful member of St. Mary's church, John loved God deeply, as he did his family and friends. His generous and gentle spirit will be missed.

HMO Humor

David Lubar

Q. What does HMO stand for?

A. This is actually a variation of the phrase, "Hey, Moe!" Its roots go back to a concept pioneered by Doctor Moe Smith, who discovered that a patient could be made to forget about the pain in his foot if he was poked hard enough in the eyes. Modern practice replaces the physical finger poke with hi-tech equivalents such as voice mail and referral slips, but the result remains the same.

Q. Do all diagnostic procedures require pre-certification?

A. No. Only those you need.

Q. I just joined a new HMO. How difficult will it be to choose the doctor I want?

A. Just slightly more difficult than choosing your parents. Your insurer will provide you with a book listing all the doctors who were participating in the plan at the time the information was gathered. These doctors basically fall into two categories—those who are no longer accepting new patients, and those who will see you but are no longer part of the plan.

HMO Humor cont., pg. 15 ←

Nutrishare Ad
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Call (800) 776-OLEY.*

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HMO Humor, from pg. 13

But don't worry—the remaining doctor who is still in the plan and accepting new patients has an office just a half day's drive away!

Q. What are pre-existing conditions?

A. This is a phrase used by the grammatically challenged when they want to talk about existing conditions. Unfortunately, we appear to be pre-stuck with it.

Q. Well, can I get coverage for my pre-existing conditions?

A. Certainly, as long as they don't require any treatment.

Q. What happens if I want to try alternative forms of medicine?

A. You'll need to find alternative forms of payment.

Q. My pharmacy plan only covers generic drugs, but I need the name brand. I tried the generic medication, but it gave me a stomach ache. What should I do?

A. Poke yourself in the eye.

Q. What if I get sick while traveling?

A. Try sitting in a different part of the bus.

Q. No, I mean what if I'm away from home and get sick?

A. You really shouldn't do that. You'll have a hard time seeing your primary care physician. It's best to wait until you return, and then get sick.

Thanks to Merrill Mitchell, parent of HPEN consumer, Angie Mitchell, for sharing this joke.

Liberty Medical Supply

Liberty, a division of Polymedica Corporation located in Stuart, Florida, is a national leader in direct-to-consumer diabetic, respiratory and enteral supplies. The company has built a reputation for providing the highest quality of customer care in the industry.

Liberty's enteral products division delivers nutritional formulas, portable and stationary pumps, and other enteral supplies to tube feeding customers in the comfort and convenience of their home. Liberty provides free home delivery of supplies with no up front, out of pocket expenses. There are no forms to fill out and Liberty bills your insurance company directly. Liberty provides products for all individuals that have medicare, medicaid or private insurance coverage. A Liberty Registered Dietitian will work with you and your physician to insure that your tube feeding regimen is the best fit for you and your life-style. The Oley Foundation thanks Liberty Medical Supply for coming on board at the Benefactor Level.

Reach Out and Talk to a HomePEN Consumer — Toll Free!

To make speaking with fellow lifeliners more affordable, Oley circulates two toll-free numbers to experienced HomePEN consumers on a monthly basis. We strongly encourage you to take advantage of this program which enhances consumer-to-consumer networking and provides 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 15 minutes. The exception is **FRIDAYS, WHEN ALL CALLS ARE FREE** — including calls to the Oley office!

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.

NOV. '00	<p>Nancy Groat Grand Haven, MI (888) 610-3008 EST</p>	<p>Nancy is a single retired nurse with a very supportive family. Diagnosed with Lymphangectasia she has been on TPN for 7 years which has improved her quality of life. She has a support group for people with rare disorders. Nancy is currently on disability and can share her experience with the process.</p>
	<p>Willis & Vi Schultz Mayville, WI (888) 650-3290 CST</p>	<p>Willis (Dick) has been on TPN for 17 years. He has SBS due to Crohn's disease. He leads an active life, travels, loves to garden and takes pride in his lawn. The friendships he has made through Oley have been most rewarding. His wife Violet (Vi) is bright, friendly, and happy to speak to anyone about caregiving issues.</p>
DEC. '00	<p>Sonia Alagna Dewitt, MI (888) 610-3008 EST</p>	<p>Sonia is the mother of 11 y.o. Jessica, who received an intestinal transplant six years ago. Before that Jessica was on both HPN and HEN. Sonia is experienced with issues dealing with learning to eat, stoma care, potty training, school and SSI. She is interested in sharing information with others.</p>
	<p>Marie Hartwick Little Rock, AR (888) 650-3290 CST</p>	<p>Marie has been on EN for 6 years and was on TPN for 12 years prior to that, due to short bowel syndrome. She is well versed on the potentially difficult transition from TPN to EN. She has used media publicity to attain insurance coverage, is a single mom and has some ostomy experience.</p>
JAN. '01	<p>Diane Kane Lecanto, FL (888) 610-3008 EST</p>	<p>Diane is married with two children. She has idiopathic pseudo obstruction and experience with both enteral and parenteral nutrition. She can also speak to callers about pain management issues. Diane is active in providing support to homePEN consumers living in the central Florida area.</p>
	<p>Alicia & Rose Hoelle Gibbstown, PA (888) 650-3290 EST</p>	<p>Alicia is 15 y.o. and has been on TPN (and sometimes EN) since birth due to hypoganglionis. She lives a very normal life. She goes to camp, plays sports, etc. She would love to hear from kids, teens or parents. Her mother, Rose, is an LPN and experienced caregiver. She looks forward to hearing from other parents.</p>

LifelineLetter

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