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Weathering the Storm: The Drug Shortage Crisis

Marty Kochevar, MS, RPh, BCNSP, Clinical Practice Consultant, A.S.P.E.N.

In October of 2010, the Institute for Safe Medication Practices (ISMP) published an article discussing the drug shortage crisis in the United States. They noted, "All healthcare organizations have disaster plans in place that they practice and refine in preparation for an unexpected crisis. These plans are not developed 'on the fly' because healthcare providers recognize the value of planning for the unexpected and the necessity of minimizing potentially life-saving interruptions in care. The ongoing problem with drug shortages in our nation is rising to the level of 'disaster' status. Drug shortages continue to take an enormous toll on healthcare providers who must deal with the problem on a daily basis, and on patients who are on the receiving end of the shortages."

Drug Shortages Summit

In November of 2010, the ISMP along with the American Society of Health-System Pharmacists (ASHP) and two other professional organizations co-convened a Drug Shortages Summit. The American Society for Parenteral and Enteral Nutrition

(A.S.P.E.N.) sent representatives to this summit. Other summit participants included representatives from health professional organizations, drug manufacturers, and supply chain entities. Representatives of the Food and Drug Administration (FDA) and the Centers for Disease Control and Prevention also attended portions of the meeting as observers.

The summit noted that new drug shortages have increased every year from 58 per year in 2004, to 129 per year in 2007, to 168 in 2010. The reasons for the drug shortages are quite variable. They include:

- Mergers in the drug industry
- Raw materials supply
- Supply chain (drug distribution) issues
- Manufacturing / regulatory issues
- Changes in clinical practice
- Business decisions
- Unknown (most frequent reason!)

Proposed Legislation

The Drug Shortages Summit published a number of **Drug Shortage**, cont. pg. 2



Terry & Ann Edwards, Rick Davis and Laurie McBride representing Oley at Clinical Nutrition Week

Oley in Vancouver

In late January, the Oley Foundation hosted a one-day conference in Vancouver, British Columbia. Over sixty people on home IV and tube feeding from throughout the region—primarily northwestern Canada and the US—gathered to hear nutrition support experts speak on their specialties, and to share with one another their experiences as nutrition support consumers and caregivers.

Oley regional conferences, like the more comprehensive annual conference, provide unique opportunities

Vancouver, cont. pg. 7

At Home at the Annual Oley Conference

A Parent's Perspective

Jennifer Rath

Last year was our first Oley conference. The decision to attend the conference was not necessarily an easy one. I LOVED the idea of meeting other families with kids who were HPN and G-tube dependent; of learning about the latest research and information about how to maximize my son's health; and of meeting some of the people in person who had educated, supported,

Conference, cont. pg. 9

Conference Registration Inside!

Check out the Oley conference registration packet inserted in this newsletter. It includes a schedule of planned events, details about the hotel, and a registration form. You'll also find information about travel grants.

For answers to your questions and updates visit www.oley.org or call (800) 776-OLEY.

Drug Shortage, from pg. 1

recommendations in its Summary Report. One of these included, "Improve communication to, among, and from product manufacturers and FDA, including detailed information on reason and anticipated duration of shortage. Also enhance communication to supply chain

LifelineLetter

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Subscriptions:

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically.

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

entities and health care providers (e.g., Dear Provider letters)."

This recommendation and others have been formulated into U.S. Senate bill S. 296, the Preserving Access to Life-Saving Medications Act, by Senators Amy Klobuchar (D-MN) and Robert Casey (D-PA). This legislation directs the FDA to address drug shortages by requiring manufacturers to notify the FDA about manufacturing problems or when a drug is to be discontinued. The bill also requires that the FDA maintain an online list of drugs in shortage situations, and revises the agency's definition of "medically necessary."

Advocacy Efforts

A.S.P.E.N. leaders and several Oley members participated in the Digestive Diseases National Coalition (DDNC) Public Policy Forum (also called Capitol Hill Day) on March 6-7, where attendees made Congressional visits. This forum allows the attendees to encourage legislators to sign on to legislation like U.S. Senate bill S. 296.

Health professionals and consumers are urged to write their senators in support of this bill. A.S.P.E.N. has created a Support Letter template that will help you. It can be found at <http://www.nutritioncare.org/WorkArea/showcontent.aspx?id=6132>.

For further information on bill S. 296, review the ASHP Legislative Summary at www.ashp.org (search for S. 296). Or read the full

bill on the Thomas Legislative Information Web site, <http://thomas.loc.gov/> (type in "S. 296"). To find your Senator and his or her contact information, visit www.congress.org.

HPEN Shortages

While drug shortages involving home parenteral nutrition (HPN) are a small part of the overall drug shortage situation, it certainly affects us significantly. In the past we have experienced shortages of IV multivitamins, IV fat emulsions (i.e., lipids), and IV amino acids. Currently, we are experiencing shortages of IV electrolytes, minerals, and trace elements that are necessary for the compounding of HPN formulations. These include: sodium chloride (NaCl, salt), potassium chloride (KCl), calcium gluconate, and zinc chloride, among others. For the most comprehensive listing of drug shortages, see the ASHP Drug Shortage Resource Center at www.ashp.org/ shortages.

A.S.P.E.N. has been and is proactive regarding HPN drug shortages for our members and their patients. We actively monitor the situation and publish news articles including PN drug shortage recommendations (e.g., IV multivitamins, IV fat emulsions, and IV amino acids). We are currently actively engaged in the IV electrolyte and mineral drug shortages. With everyone's input and cooperation, we are hopeful we will "weather this storm" and hopefully avert future ones. ¶

The Gastroparesis Gourmet Cookbook

Members and friends of G-PACT (Gastroparesis Patient Association for Cures and Treatments) have contributed recipes for a cookbook, *The Gastroparesis Gourmet*. According to the introduction, this cookbook is "designed to [help] patients find recipes they can tolerate" and "guide patients in making smart food choices."

What makes this cookbook unique? Colleen Beener, who serves as G-PACT's volunteer coordinator and who helped put the cookbook together, explains that after they collected recipes from G-PACT followers, they "had two dietitians (G-PACT volunteers) evaluate each recipe for nutritional information and fat and fiber content (since fat and fiber amounts are important for gastroparesis patients)."

Calories, fat, fiber, protein, sugars, etc. are listed at the end of each recipe. "The dietitians also evaluated sugar content to identify any recipes that could be problematic for diabetic patients," Colleen adds. The dietitians developed substitution lists for fat and fiber as well.

"Not every recipe will work for every patient," Colleen stresses, but with 140 recipes, from appetizers through desserts, there are a lot of options.

To order, send \$15 per cookbook to G-PACT Cookbook, 39-31 A 201 St., Bayside, NY 11361. To order online, send \$15 through PayPal to G-PACT at accounting@g-pact.org. Proceeds from the sale of the cookbook will benefit G-PACT programs.

Tube Talk

Send your 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 metzgel@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.



Helpful Products: Backpacks for Kids, Tube Wraps, and Button Covers

Last year Cassandra Lepper's little boy Justin (then 18 months old) had feeding difficulties that resulted in the need for a G-tube. The situation was overwhelming for her, and she found it difficult to get out and about with the large backpack the medical supply company had provided for her son. She also had problems with leaky connections, which caused large stains on her son's shirts. There had to be a better way of doing this, she thought.

Cassandra had a meeting with two of her friends, Laura Strait, RN, and me, a fellow "tubie" mom. Laura and I are both seamstresses. Together we came up with products to help meet the needs Cassandra identified. The following products are the result, and available from Cassandra's newly founded company, Feeding Essentials.

Backpacks, etc.

The Kiwi is a super slim, lightweight backpack designed for the Zevex Infinity Enteralite feeding pump. **The Wallaby** is a streamlined bag for the Kangaroo Joey feeding pump. Both feature windows that allow easy access to the pump controls, feeding bag compartments that also accommodate an ice pack, and an extra pocket for medical supplies. A chest strap keeps the Kiwi and Wallaby securely on the back. Made of sturdy canvas, they are available in a variety of patterns and machine washable.



Kiwi Backpack

Strap Pals are an accessory to the Kiwi and Wallaby backpacks that cushion the straps and protect the neck without significant bulk. They are made of soft flannel, are available in a variety of styles, and are machine washable.

The **Line Tamer** is a soft fabric tube that wraps around medical lines, tubes, and/or cords to secure them together. It helps protect ports from dirt, absorbs small leaks, and makes maneuvering easier—all without giving up quick and easy access to ports and connections.

Button Cuddlers are cloth feeding tube pads with a protective, stabilizing, absorbent, and decorative front cover. They absorb moisture and wick it away from the skin and extension connections, and help avoid shirt stains. Extensions are less likely to become unhooked or collect outside dirt, and children love the variety of patterns available. "Button Cuddlers" provide an alternative to medical gauze.

For more information, go to the Feeding Essentials Web site, www.feedingessentials.com, or contact Cassandra Lepper at (616) 558-0528 or feedingessentials@gmail.com.

—Nina Van Harn, feedingessentials@gmail.com



Button Cuddlers

A Pediatric Core Curriculum You Can Trust



The A.S.P.E.N. PEDIATRIC NUTRITION SUPPORT CORE CURRICULUM

EDITED BY
Mark R. Cookson, MD, CNSE, SPL, FAAP
ADDITIONAL EDITORS
Joan Rubin, MD, & Elizabeth Rubin, MS, RD, LDN, CNSD
New England Medical Center • Johns Hopkins University, MD, USA

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The first pediatric specific nutrition curriculum of its kind. A valuable certification study tool.

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American Society for Parenteral
and Enteral Nutrition

Feeding Tube Awareness Week

Traci Nagy

Feeding Tube Awareness Week—February 6–12, 2011—was a grassroots, viral campaign. Each day was focused on a new topic, including the medical reasons for, the benefits of, and encouraging friends and family to ask about, tube feeding. The week closed with a focus on turning negative experiences into positive ones. Many parents in the United States and Canada contacted their local media and were featured on TV news programs or in their local newspaper.

In October 2010, I had posted the idea of an awareness week on Facebook; I was surprised that a lot of other “tubie” parents thought it was a good idea. So I started building a Web site (www.feedingtubeawareness.com), started a Facebook page, and started reaching out to organizations like the Oley Foundation, which graciously offered their support. The Web site serves as a portal for information on daily life with a tube-fed child, as well as a vehicle to raise awareness and educate. Parents have submitted biographies of their children and content to the Web site.



I Heart a Tubie

We chose February 6–12 for Feeding Tube Awareness Week because of the proximity to Valentine’s Day. I felt very strongly about the message, “I heart a tubie.” There is so much negativity around tube feeding. I wanted the tubie to be embraced. I wanted to share how this medical device saved my child’s life and keeps him alive every day. He is an active toddler who is thriving because he gets the nutrition and hydration he needs. I very much love a tubie!

Nearly 1,500 people confirmed their attendance to Feeding Tube Awareness Week online, and thousands more were exposed to status posts, blogs, and tweets. A video on the medical reasons for tube feeding, featuring more than seventy children, has been viewed thousands of times on Facebook and YouTube. The “Let’s Get a Tube Fed Child on Sesame Street!” cause (on Facebook) now has more than 5,200 supporters.

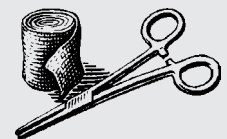
This will be an annual event. I plan on launching a campaign to get Feeding Tube Awareness Week officially recognized for coming years. Our first week was a resounding success and next year will be even better. I hope you’ll join us!

Watch for news about Feeding Tube Awareness Week in the Oley newsletter and on the Oley Web site.

Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? Contact Oley volunteers Tammi and Rob Stillion at Oleyequipment@aol.com, or call toll-free, (866) 454-7351 between 9 a.m. and 4 p.m. EST.



Absorbing science that helps keep kids on the go.

New Vital jr.® Unflavored

Help your child absorb the nutrients they need with peptide-based Vital jr. Ideal for tube feeding or in flavors they’ll love, Vital jr. provides complete, balanced nutrition that gives them a big return in every serving.

USE UNDER MEDICAL SUPERVISION.

Abbott Nutrition, Abbott Laboratories, Columbus, OH 43219-3034 USA © 2010 Abbott Laboratories Inc. 74115/MARCH 2010

Auction Items Needed

The silent auction we hold at the annual conference has raised thousands of dollars for Oley, helping to keep our programs free for you! We need your help in gathering items for the auction. Items donated in recent years include things created by Oley members (quilts, photos, paintings, scarves, afghans); electronics (MP3 players, Wii systems, laptops); gift certificates and baskets; certificates for travel opportunities (time-share units, vacation packages, airfare); tickets to sporting events, concerts, and tourist attractions; DVDs and CDs, games, etc. The possibilities are endless!

If you need help appealing to local businesses, friends, or family for donations, we have an excellent letter available that describes Oley and the auction. Call us and we'll send you copies, or download them at www.oley.org. If you're coming to the conference, you can bring items to the Oley registration desk at the conference. If you're not coming, or if it's more convenient, you can send items addressed to:



Joan Bishop, Guest
 Hold for Arrival on 7/4/11
 c/o Sheraton Bloomington Hotel, Minneapolis South
 7800 Normandale Blvd.
 Minneapolis, MN 55439
 RE: Oley Conference 7/5/11-7/9/11

Items should arrive before July 5th. (Note: July 4th there is no shipping due to the holiday.)

Please keep in mind that many conference attendees will be traveling by plane, and may have limited space in their luggage. Small items, electronics, and gift certificates are always big hits!

Call a Peer, Toll-Free!

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley's peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

- (888) 610-3008 will be devoted to **HPN (intravenously infused nutrition)**.
- (888) 650-3290 will be devoted to **HEN (tube feeding)**.
- (877) 479-9666 will be devoted to **parents of HPEN consumers**.

We hope you'll use this opportunity to improve your quality of life.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.



Thriving on Home Nutrition Support

"ThriveRx is efficient and keeps up with the constant changes to my care and, they are compassionate – and that makes all the difference." - Shelley W.



1-888-6-THRIVE (888-684-7483)
 or info@thrivervx.net
www.thrivervx.net

Oley Toledo Support Group

Rosaline and Bill Wu, and Marcia Grandsko, RD, LD

The idea for starting an Oley Support Group in the Toledo area began about seven years ago, when Marcia Grandsko, RD, LD, attended a national meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). At this meeting, Rick Davis described his procedure for feeding himself and administering his tube feedings. Standing in front of the audience, he demonstrated his daily routine while describing the support he received from the Oley Foundation.

Upon returning to Toledo, Marcia began looking into creating a local Oley Support Group. Two years later, Marcia met Norman Benway, who was on tube feedings. The two of them worked persistently on creating this support group. Norman then applied



Back row: Denis Hojnacki, Jim & Jackie Bain, Bill & Rosaline Wu, and Rob & Tammi Stillion. Front row: Rodney & Linda Stroshine.

for and became an Oley Regional Coordinator (RC) for the Toledo area. Later, Linda Stroshine (enteral consumer), Tammi Stillion (parenteral consumer), Denis Hojnacki (enteral consumer), and Rosaline Wu (parenteral consumer) all joined the group. Rosaline, Linda, and Tammi are RCs as well. We are so fortunate to have this powerful trio, who have resolved to live life to its fullest with tube feedings and parenteral nutrition. Collectively, they encourage any and all who attend our support group.

When and Where

The Toledo Oley Support Group meetings are held at the Hickman Cancer Center on the Flower Hospital Campus, which is part of the ProMedica Cancer Institute. Currently, five meetings have been scheduled for 2011 at the Flower Hospital. The group meets on Tuesdays, 7:00–8:30 p.m. The remaining dates for 2011 are May 10, September 13, and November 8. The address is 5200 Harroun Road, Sylvania, Ohio 43560. All are invited to attend!

Back row: Norman Benway, Tammi Stillion, Denis Hojnacki, Sandy Ruehle, and Marcia Grandsko, RD, LD. Front row: Rosaline Wu and Tom Ruehle.

If anyone needs personal support or information, they can contact Marcia Grandsko, RD, LD, at (419) 824-1952 or marcia.grandsko@promedica.org; Rosaline Wu, (734) 464-2709 or rosalinewu@att.net; Linda Stroshine, (419) 728-2833 or lindamoonglow@buckeye-express.com; or Tammi Stillion, Oleyequipment@aol.com.

FDA Alerts Can Save Lives

U.S. Food & Drug Administration (FDA) recalls are often very significant. For example, FDA announced a recall in January of alcohol prep pads manufactured by Triad (and marketed under several brand names) due to potential microbial contamination. Several lawsuits are pending, and other products manufactured by Triad and H&P Industries are under investigation.

Be proactive. Have safety alerts and news of recalls delivered directly to your inbox by visiting the FDA Web site and signing up to receive their recalls and alerts. Go to www.FDA.gov and click on “Recalls and Safety Alerts” (on the right, toward the bottom). You can sign up to receive product recalls on your mobile phone, as well! On the “Recalls and Safety Alerts” page, click on “Product Recalls Mobile Phone App.”

Support Research That Affects You

Marion Winkler PhD, RD, LDN

Named in honor of Dr. Jonathan E. Rhoads for his pivotal role in the development and application of parenteral nutrition (PN), the A.S.P.E.N. Rhoads Research Foundation supports the personal and professional development of nutrition support researchers. Since 1994 the foundation has awarded over \$800,000 to investigators to conduct research involving nutrition and metabolic support. Many funded projects have great relevance to Oley members, including such topics as:

- Drug compatibility and stability in enteral nutrition (EN)
- Energy expenditure
- Glucagon-like peptide 2 analogue to improve intestinal function in short bowel syndrome
- Glutamine
- Lipids and PN-associated liver disease
- Nutrient recommendations for wound healing
- Parenteral zinc supplementation
- Probiotics and short chain fatty acids and prevention of antibiotic associated diarrhea
- Adaptation of the small intestine
- Treatment of catheter sepsis

Advancements in EN, PN, and nutritional care depend upon the discoveries made by researchers. Help support the scientific and clinical breakthroughs of tomorrow. Please consider making a tax-deductible contribution to the A.S.P.E.N. Rhoads Research Foundation. Donations can be made via A.S.P.E.N.'s Web site by clicking on “Foundation” at www.nutritioncare.org or by sending a check to 8630 Fenton Street, Suite 412, Silver Spring, MD 20910. Please visit the Web site or call (301) 587-6315 to learn more about the foundation.

Dr. Winkler serves as Secretary of the A.S.P.E.N. Rhoads Research Foundation and is a member of the Board of Trustees of the Oley Foundation.



Alive, Well, & Even Better



**26th Annual
Consumer/Clinician Conference**

July 5–9, 2011

Sheraton Bloomington • Bloomington, MN



Registration Packet

Where to Call for Information

To learn more about the conference, call the Oley Foundation at (518) 262-5079 or (800) 776-OLEY; email bishopj@mail.amc.edu; or check www.oley.org.

Registration—Free for Consumers/Families

Register online at www.oley.org or complete the form on the next page. All registrants are responsible for their own hotel and transportation arrangements. Please allow 7 business days before confirming your registration.

Learning Opportunities Abound!

Main sessions in the morning feature formal presentations with opportunities to ask questions. Afternoon breakout sessions are smaller, informal discussion groups, which are typically more interactive. Social events such as mealtimes and receptions allow attendees to get acquainted with each other. The exchange of experiences and practical information can be life altering.

Main Sessions

Enjoy presentations coordinated to boost your understanding of home IV and tube feeding (homePEN) and increase your odds of minimizing complications.

Wednesday: Alive, Well, and More Informed!

A morning devoted to exploring interventional radiology and advanced techniques for vascular access placement and troubleshooting; emerging therapies for treating intestinal failure; and “hot topics” in home parenteral nutrition research.

Thursday: Minimizing Complications: Living Better

A plethora of information designed to help you reduce complications and navigate quality of life issues. Topics covered include metabolic bone disease and diarrhea, with a special appearance by Germ City.

Tube Feeding Workshop

Learn more about options for tubes and sites, troubleshooting complications, skin/wound care, and clogging causes and resolutions! Plenty of time is allowed for interaction with faculty.

Child Care/Youth Activities/Jammin' Jammies

Complimentary child care will be available at the hotel, Wednesday and Thursday during the educational sessions. For children ages 7+ we offer chaperoned activities in the afternoon and a pajama party on Thursday night.

Transitioning to Independence

Learn what needs to be put in place for young adults to assume responsibility for their medical care, head off to college, live independently, etc. This program will be split into multiple sessions: one just for parents, one just for youth, and another that combines both groups.

Walk-A-Thon Raises Funds, Awareness

Join us for a short walk. Forms to gather sponsors for this event and help raise awareness are available at www.oley.org or call (800) 776-OLEY.

“Whether it was ways to reduce line infections or learning about portable pumps to improve our quality of life, Oley provided us hope.”

Conference Headquarters & Housing

Sheraton Bloomington, Minneapolis South
(866) 837-4278 or www.starwoodmeeting.com/Book/oley

Reserve your room today! The rate of \$99/night for single/double or \$109 for triple/quad is in effect through June 12. Note: to secure this rate, use the direct Internet link provided above, or mention you are with the Oley conference if you call.

Shipping HomePEN Supplies

When shipping your supplies, separate items that need refrigeration from those that do not. Clearly indicate on the outside of the box(es) if supplies need to be refrigerated. Remember to take the July 4th holiday into account. Package(s) should be labeled as shown below.

Your Name _____, Guest
Hold for Arrival on 7/___/11
c/o Sheraton Bloomington Hotel, Minneapolis South
7800 Normandale Blvd.
Minneapolis, MN 55439
RE: Oley Conference 7/5/11-7/9/11

Medical Support—Keeping You Safe!

Medical facilities will be alerted and prepared to handle any medical emergencies that arise. The Mendota Heights branch of Coram Inc., Specialty Infusion Services will provide emergency infusion support (should you forget something, have a bag break, etc.) along with telephonic nursing/pharmacy support during the conference.

“A whole new world opened up to me when I attended my first Oley conference.”

Why Should I Attend?

- Understand more about the therapy that sustains you or your family member.
- Discover how to better deal with day-to-day life.
- Learn to communicate your health care and emotional needs with more self-assurance.
 - Meet others on home tube and/or IV feeding.
 - Clinicians learn and become better resources

Plus! Oley Smooths the Way

- Local emergency room information has been identified.
- Nursing/pharmacy backup support has been arranged.
- Hotel is aware of your supplies and shipping needs.
 - Room refrigerators are available for patients.

“As an HPN clinician, I learn more at the Oley conference than I do at nearly any other clinical meeting I attend.”

Program-At-A-Glance

Tuesday, July 5

- 1:00 pm – 5:00 pm Early Registration
2:00 pm – 5:00 pm Regional Coordinator Workshop
7:00 pm – 9:00 pm Welcome Reception/Awards Ceremony

Wednesday, July 6

- 8:00 am – 4:30 pm Registration/Information
8:30 am – 9:00 am First-Time Attendee Orientation
9:00 am – 12:00 pm Main Session I:
Alive, Well, and More Informed!
12:00 pm – 2:00 pm Grand Opening of the Exhibit Hall
12:00 pm – 4:30 pm Youth Activity
2:15 pm – 4:30 pm Tube Feeding Workshop
2:15 pm – 3:15 pm & 3:30 pm – 4:30 pm
Breakout Sessions I & II (*choose 2*)*
1. Keeping Catheter-Related Complications to a Minimum
2. Navigating Vascular Access Challenges
3. Timing of Referral to Intestinal Failure Center
4. Living with Your Ostomy
5. Understanding Motility Disorders
6. Pain Management Treatment
7. Integration of Care
8. Navigating Reimbursement Challenges
9. Living Longer on HPEN
Session I: Help With Advanced Directives
Session II: Getting Your Financial Planning Under Way
7:30 pm – 9:00 pm Oley Silent Auction

Thursday, July 7

- 8:45 am – 4:30 pm Registration/Information
9:00 am – 11:45 am Main Session II:
Minimizing Complications: Living Better
11:45 am – 12:00 pm In Loving Memory
12:00 pm – 2:00 pm Raffle Day in the Exhibit Hall
12:00 pm – 4:30 pm Transition to Independence
2:15 pm – 3:15 pm & 3:30 pm – 4:30 pm
Breakout Sessions III & IV (*choose 2*)*
1. Metabolic Bone Disease
2. When the Surgeon Joins Your Team
3. Pain Management
4. Communicating with Your Medical Team
5. Functional GI Disorders
6. Food & Supplements: Choices Matter
7. Complementary/Alternative Medicine
8. Identifying Your Advocate
9. Trials and Tribulations of Traveling
10. Preparing for an Emergency
6:00 pm – 10:00 pm Picnic
7:30 pm – 10:00 pm Jammin' Jammies

Friday, July 8

- 11:30 am Oley Walk-A-Thon

Saturday, July 9

- 10:00 am – 12:00 pm Farewell Breakfast

**Additional Breakout Sessions may be offered

2011 Oley Conference Registration

GENERAL INFORMATION

Sign up online! Or complete one form below per adult.

This is my first Oley conference!

Name _____

Address _____

City _____ ST _____ Zip _____

Phone (Day) _____ - _____ - _____

Phone (Evening/Cell) _____ - _____ - _____

E-mail: _____@_____

HomePEN Consumers/Patients:

Primary Diagnosis _____

Began HPEN ____/____/____ (Month/Day/Year)

Catheter/Tube Type _____

Homecare Company _____

Clinicians/Professionals:

Title _____

Organization _____

Specialty _____

AFFILIATIONS

Please check (✓) ALL that apply:

HPN consumer (TPN, IV fed, parenteral or hyperal patient)

HEN consumer (tube fed or enteral patient)

Family member/caregiver: _____

relationship to consumer

Faculty

Physician

Student/Resident

Nurse

Exhibitor

Dietitian

Company Representative

Pharmacist

Other _____

CHILDREN/YOUTH REGISTRATION

Please list children coming to the conference:

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Please indicate how many children will need/participate in:

_____ Child Care _____ Youth Activity (Ages 7 to 15)

_____ Jammin' Jammies (Ages 7+)

Con't on back →

2011 Oley Conference Registration

HELP US PLAN

Help us plan by indicating the number of people in your party who will attend the following events. All events are free unless otherwise marked:

1. Silent Auction (7/6) _____

I'll donate the following item(s): _____

2. Picnic (7/7) _____

3. Walk-A-Thon (7/8) _____

4. Farewell Brunch (7/9, \$13/person) _____

REGISTRATION FEES

Please send registration fees to Oley.

- HPEN consumers, friends, and family FREE
- Oley professional members..... \$50-1 day, \$80-2 days
- Company representatives..... \$100-2 days
(First two reps are free for exhibitors)

➤ Please consider a donation to offset conference expenses.

➤ Make checks payable to "The Oley Foundation."

Amount enclosed \$ _____

MAILING INFORMATION

Sign up online! Or mail or fax this form by June 18.

✉ The Oley Foundation, 214 Hun Memorial, MC-28,
Albany Medical Center, Albany, NY 12208-3478

☎ (518) 262-5079, (800) 776-OLEY

💻 www.oley.org; bishopj@mail.amc.edu

✉ (518) 262-5528 FAX

Please note: photos taken at the conference may be used in Oley Foundation promotional materials, like this brochure, or on the Oley Web site. If you would like to opt out, please sign a form at the Oley desk when you register on-site, or email Joan Bishop at bishopj@mail.amc.edu.

Getting to the Hotel/Mall of America

The hotel is 10 minutes from the Minneapolis/St. Paul International Airport (MSP), and the Mall of America. The hotel offers a free shuttle to both the airport and the mall, and free parking if you bring your car.

Travel Grants for Conference Goers!

Thanks to generous donors who believe the conference is extremely beneficial, there are several partial travel scholarships (worth up to \$500) available this year to homePEN consumers who will be attending the Oley annual conference for the first time.

Applicants should not be receiving any other financial assistance from home-care companies, etc. for travel and/or lodging expenses related to attending the conference.

First-time conference attendees should write two paragraphs describing how they believe attending the conference will affect their life and submit them to us by May 15 (address below). The ideal candidate will also describe their plans to share information learned at the conference with consumers and/or clinicians back home. Travel must be completed and receipts received by Oley before reimbursement can be made.



"I learned things and met people that changed my life."

Compassionate Flights

Air Charity Network and other organizations may provide free air transportation to patients whose financial resources would not otherwise enable them to travel for medical reasons. For a list of these organizations visit www.oley.org/Medical_Air_Transportation.html or call (800) 776-OLEY.

Other Ideas to Cover Travel Costs

- Request a travel scholarship from a church or synagogue; your local United Way; a local Kiwanis, Rotary or Lions club; a disease-specific organization like the March of Dimes, Easter Seals or Muscular Dystrophy Association; or a wish-granting organization (see list posted at www.oley.org/Wish_Granting.html).
- Get a break on your taxes! Because the conference is educational, some conference-related expenses may be tax deductible. Talk to your tax consultant or visit www.schwablearning.org.

Tips for Travel

Visit www.oley.org or call (800) 776-OLEY for tips on traveling with tube or IV feeding, including sample letters and medical forms to smooth your passage through airports, and a list of experienced consumers to answer your questions.



Many of your meals are covered at the conference!

Including light fare at the Welcome Reception, continental breakfast and lunch Wednesday and Thursday, and a picnic dinner Thursday.

Vancouver, from pg. 1

to learn about home parenteral and enteral nutrition (HPEN) as well as the invaluable experience of making personal connections. Oley organizes regional conferences in different areas of the country—often around another meeting, such as A.S.P.E.N.'s Clinical Nutrition Week, or near an HPEN center of experience—so that as many members as possible can attend.

At the regional conference in Vancouver, Oley President Rick Davis spoke in the morning about strategies he's developed to make tube feeding more manageable, while Oley Regional Coordinator volunteer Laurie McBride spoke about his many years on parenteral nutrition. Following this, healthcare professionals and attendees spoke in large- and small-group settings about communicating effectively with your healthcare provider (Jarol Boan, MD); quality of life issues (Marion Winkler, PhD, RD); Omegaven (Kathleen Gura, PharmD); maximizing the value of the food you eat (Laura Matarese, PhD, RD); tube feeding issues (Mark DeLegge, MD); minimizing HPN complications (Darlene Kelly, MD); micronutrients in HPN (Lyn Howard, MD); and ethanol locks (Rex Speerhas, RPh). In addition, Oley members Terry and Ann Edwards, Rick Davis, and others joined in a roundtable discussion on tube feeding.

Kathie Douglas, who has been on parenteral nutrition since November 2010, was one of the conference attendees. Her impressions of the conference can be found on the next page.

We'd like to thank Laurie McBride for his untiring work and enthusiasm in helping organize this conference. We also thank Calea,

for its generous underwriting of this conference; the speakers who gave their time; and our corporate sponsors and individual donors for their continued support.

Clinical Nutrition Week

As the Oley Regional Conference ended, Oley staff and several conference participants went across the street to the Vancouver convention center for the opening session of Clinical Nutrition Week, the annual meeting of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). Clinical Nutrition Week (CNW) is an important event for professionals involved with tube feeding and IV nutrition; it offers them an opportunity to learn more about PEN, to hear what is new in the field, and to network with peers.

It's an important event for Oley, too. We learn about new research, products, and protocols, and network, network, network. It is our goal to cover as much as possible of the information that is pertinent to members in future issues of the newsletter.

This year, as for the past few years, Oley led a roundtable discussion at CNW. This roundtable allows HPEN professionals to interact with Oley members, helping them to better understand the HPEN consumer's experience.

The other component of CNW that is so important to Oley is the exhibit hall. The Oley exhibit at CNW is usually very busy, with Oley volunteers and staff sharing information about Oley and HPEN, and answering questions.

Members Recognized

At the A.S.P.E.N. awards ceremony, longtime Oley member and
Vancouver, cont. pg. 8 ◀

*Helping TPN Consumers Live Independently***Dear Nutrishare,**

Thank you so much for building a team of professionals who reflect your medical model of being: patient centered, patient friendly and patient safe.

I have been a Nutrishare consumer for a little over a year and have NEVER experienced such a proactive and patient friendly team.

*To be thanked each time I call? ... unheard of!
To encourage us to improve our health? ... WOW!
To get a same day response to calls/concerns?... not until Nutrishare!*

I look forward to meeting you all in August at the Consumer Education conference. Thanks from the bottom of my heart for making my life so much EASIER.

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TRISH POOLEY



Don Young (second from left) with members of the team that has managed his HPN and line care since 1975: Ann Michalek, MD, Lyn Howard, MD, Gail Sansivero, MS, ANP, and John Balint, MD.

Vancouver, from pg. 7

volunteer Don Young was given the Lyn Howard Patient Advocacy Award. Don was unable to attend, and Dr. Howard accepted the award on his behalf. This award was named in honor of Dr. Howard, cofounder of the Oley Foundation, in recognition of her significant contributions to patient-centered care throughout her prestigious career.

Don, who has been on PN for thirty-six years, has served as Oley Foundation president and has been generous in reaching out to others on HPEN. His goal has been to empower home nutrition support consumers by giving them the benefit of his experience and knowledge. "People seem to expect tubes and lines when they come to the hospital, but they don't expect it in the living room," Don has said. He seeks to demystify nutrition support, and to help people understand that "tubes and lines" don't necessarily mean a person has to stop doing what they love to do.

Because Don was unable to attend CNW, he was honored later with a reception at Albany Medical Center, where the Oley Foundation offices are located and where Don has received much of his care over the last thirty-six years. "I can think of nothing I'd like better than to receive this award surrounded by friends," Don said. Congratulations, Don!

Past recipients of this award include Bettemarie Bond and Lee Koonin.

Oley board member Rex Speerhas, RPh, BCNSP, CDE, was also recognized at CNW for his contributions to the HPEN field. Rex received the Stanley Serlick Award, which celebrates a pharmacist who has made significant contributions to improving safe practices for parenteral nutrition through published literature, membership on national committees or task forces and/or presentations at regional and national meetings. Way to go Rex! ♣



Rex Speerhas, RPh, Oley Trustee, receiving the Stanley Serlick Award at CNW.

A Regional Conference Experience

Kathie Douglas

Since I live in Edmonton, Alberta, and my parents live about an hour outside of Vancouver, the one-day Oley conference I read about in the newsletter seemed like an exciting chance to meet people who had the same, or similar, health issues as me and spend some time with my family. I didn't know anyone on parenteral nutrition (PN)! I also knew it would be a great opportunity to meet some of the specialists who were scheduled to talk at the event.

The information presented at the conference was incredible. The patients who've spent years on home tube and IV feeding spoke clearly and enthusiastically about their experiences. They had all gone through some horrific times and conquered in the end. They gave me so much to be thankful for, such a deep understanding of why this new way of life wasn't a curse...but a gift. I was in awe of our speakers.

Then there were the roundtable discussions, where I learned more than I could possibly have imagined. I was a little confused about one of the discussions at a roundtable, because people described a procedure that differed from the one I followed. They explained it to me, and when I got home I spoke with my nurses. The next delivery from my home care company came with a note saying that due to changes in protocol, PN patients were to follow the procedure I had learned about in that discussion. What a great thing to learn! I also found the discussions lively and stimulating.



Kathie exchanging ideas at the meeting.

There was happiness in the meeting room and I could see lots of joyful reunions between people who had met at previous conferences. The organizers of the event were warm and welcoming. I can't say enough about how they made me feel. There was also a small "trade show" type display, where I found many items that were intriguing. I'm investigating a few in regards to my own PN.

I want to take this time to thank the Oley Foundation for presenting all of this, including breakfast and lunch at no cost to patients and their family members. It was an unbelievable day for me. I came away excited to go to the next conference. I will go a little better prepared with ideas and questions.

I've made a great friend, found some tremendous information resources, and have come home with a whole new attitude towards my life with PN. As my doctor said to me the first day of PN when I was a little touchy, "It has given you back your life, now you need to put it into perspective." It wasn't until the Oley conference that her words clicked and my attitude changed from pitying myself to being ever so thankful at being given this "second chance" at life.

Conference, from pg. 1

and inspired me after Austin was born with Short Gut. But truthfully, the first thoughts that popped into my head were, “Can I deal with airport security and flying with him? How will I manage getting all his supplies to the conference and trying to do his care while attending a conference? What if he has a medical emergency while we’re out of state? And, can I really trust someone else to watch him in childcare while I attend some of the seminars?” I think I forgot that I would be surrounded by people who have lived in our world, and who could help us get through any challenges.

I knew I had to get Austin’s input on attending the conference to help make the decision. I explained to Austin, who was almost four at the time, that there was a special conference where people who have ostomy bags, G-tubes, and central lines like him all get together to make friends



Austin met Ellie (left) and other friends “with bags and lines” at the meeting.

and learn about how to stay healthy. Did he want to go? He was initially in disbelief. “There will be a lot of people with bags and lines like me?” he asked. He then started shouting, “Yes, I want to go to the ‘Bag, Line, and G-tube Conference!’” And so, in a leap of faith that everything would work out, we made our reservations and started planning. As the conference approached, Austin told me, “Mom, you’re not going to fit in there, but I will.” I realized how important it is, even at this young age, to be surrounded by people who are just like you.



Austin (right) meeting long-time consumer Don Young, at the 2010 Oley conference.

Most everything went smoothly, from flying to shipping our supplies directly to the hotel to the childcare, which Austin loved! There were a few challenges—a middle-of-the-night ostomy explosion and forgetting to have formula shipped—but they were solvable problems. I learned so much and met so many great people that my expectations were exceeded, and I was so thankful we made the trip. For me, the most amazing moment was meeting Don Young (who had been on TPN for thirty-five years!) and getting a picture of Austin and Don together [see photo on left].

Within a week of last year’s conference ending, Austin began asking when we could go to the next ‘Bag, Line, and G-tube Conference.’ We’re planning on going, and we hope to see you in Bloomington, Minnesota! ♣

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Donor Profile: Sarah Higgins

My name is Sarah Higgins. My family members include my husband, Bud, and our twin sixteen-year-old boys, Trevor and Dashiell.

Both boys were born prematurely. Unfortunately, Dash fared poorly as a neonate, resulting in the loss of two-thirds of his small bowel and brain injury. At present, Dash still has a Broviac catheter, G-tube, and colostomy.

One spring afternoon, when the kids were around three, Bud and I took them out on a double-stroller stroll. We were feeling pretty isolated as many of our friends had kids—all “typically developing”—and the banter never strayed far from, “What are your kids doing now? Walking? Solid foods?” We began to avoid these conversations that rendered us crestfallen.

We are New Yorkers, Manhattanites. When living on a tiny island, in such finite space and among infinite humanity of every ethnicity, street conversations, and, okay, occasional arguments, are unavoidable. We found ourselves sometimes more comfortable with strangers—kind strangers. Dash had tubes emanating out of his little jacket and his brain injury caused his eyes to cross, so he got a lot of looks. But countless times those looks were not ones of pity; rather we’d see glances of understanding, potential camaraderie, or empathy. These were the strangers who became our friends.

On this day, we headed towards Broadway on 102nd Street to grocery shop. Shaded by an apartment building awning was a beautiful young mother smiling down at her daughter, who was riding up and down the sidewalk on her Big Wheel trike. Tableaus like this would give us a pinch of pain, as our kids were not yet easily showing their development. Bud and I are only human, however, and this little kid had beguiling, Mediterranean blue eyes. When the sun hit them they were filled with diamonds.

I exclaimed to the mother what a beautiful child she had. She graciously thanked me. Immediately she, the stranger Mom who eventually became the friend Valerie, stooped down to greet our boys. Grace and compliments cascaded from her mouth as she got smiles from Dash and Trevor.

Then the three adults started the classic quick, overlapping conversation. Speaking of intimate topics, I think, also comes fast on our streets. We shared with Valerie about the early birth and Dash’s ensuing problems. She hesitated. Then she asked, “Have you ever heard of the Oley Foundation?”

I truly could not believe other people endured things that we did, [and] knew the terminology.

Strange name, I thought. Is she asking me to join something irrelevant to our often mired lives?

“I have an ileostomy,” she continued. Valerie uttered this with gravity, but she trusted this information into our hands.

She knew we knew what this meant. She explained that the foundation is nonprofit and assists people nationwide who contend with all things tube, catheter, and somehow related to problems with receiving nutrition. She spoke of an equipment exchange, personal stories, and the respect that physicians, nutritionists, nurses, administrative assistants have for their consumers. Oley expected nothing in return. No obligations. If you could, donations were appreciated but this was

not required to receive guidance. She spoke of the boundless help she was given, from tips about appliance care to conversations about the stigma of the appliance. She confided to us it had caused problems in her marriage but she had a larger community, through Oley, that often anchored her.

When we parted, I really thought I wouldn’t bother. I was definitely in my blue period, grief-stricken by our enormous responsibilities. I thought it would hurt less to isolate ourselves, as to reach out would remind me of how abnormal we were.

But I no longer was able to push against our reality. I either needed to embrace it, still honoring my sadness, or be crushed beneath the weight. I called Oley.

I spoke first to Cathy Harrington, who is wonderful, helpful, and current. Then the newsletter started arriving. I truly could not believe other people endured things that we did, knew the terminology, and through their writings suggested methods of improving our and our son’s quality of life.

We even trekked to Robin Lang’s house (a former Oley volunteer who lived in Maine). Blessed Robin, whom we lost last year, welcomed our whole family after a three-hour phone conversation. What trust and generosity. She helped enormously, as she was so seasoned in the use of her myriad devices. She is so missed.

Our communal experience with Oley has been virtual and face to face. I have sent copies of the newsletter to countless friends who live lives similar to ours.

My gratitude—our gratitude—to the organization cannot be quantified. It is deep, meaningful, medical, emotional, and loving.

If I were in fifth grade, I would end my assignment with: And that is why I give money to the Oley Foundation. I’m not a fifth grader. I’m a fifty-plus-year-old Mom. And I would like to end this letter of love with: And that is why I give money to the Oley Foundation. ♣



Sarah and her husband, Bud, sharing a happy moment at a birthday celebration.

Go Green, Go Electronic

- Help Oley save printing costs and trees.
- Receive notices, alerts, invitations, and newsletters quickly.
- Preserve your newsletters electronically.

Write harrinc@mail.amc.edu or call (800) 776-6539 to learn more, or to convert to electronic delivery of the *LifelineLetter*.

Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2011 in the Jan/Feb 2012 issue. Between January 21 and March 17, 2011, gifts were received:

In Memory of

Barbara Buonanno, Charlie Eidem, Charlene Key, John Pappas, and Audrey Yadrich

In Honor of

Jameson Atkinson; Mary Ellen Costa; the dedicated Oley staff; Barbara Klingler; and Ann Weaver, for her continued support of pharmacy education at MWU

Matching Gifts were received from National Grid.

We appreciate all gifts and comments we receive throughout the year. Your support continues to be a source of inspiration. Thank you!

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. We are grateful for their continued interest and strong commitment.

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Thank You!

Join the Oley 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.

<i>Felice Austin</i>	<i>Shirley Heller</i>	<i>Kay Oldenburg</i>
<i>Jane Balint, MD</i>	<i>Alicia Hoelle</i>	<i>Harold & Rose Orland</i>
<i>John Balint, MD</i>	<i>Jeff & Rose Hoelle</i>	<i>Judy Peterson, MS, RN</i>
<i>Joan Bishop</i>	<i>Lyn Howard, MD</i>	<i>Clemens Pietzner</i>
<i>Ginger Bolinger</i>	<i>William Hoyt</i>	<i>Beverly Promisel</i>
<i>Pat Brown, RN, CNSN</i>	<i>Portia & Wallace Hutton</i>	<i>Abraham Rich</i>
<i>Katherine Cotter</i>	<i>Kishore Iyer, MD</i>	<i>Gail Egan Sansivero, MS, ANP</i>
<i>Jim Cowan</i>	<i>Doris R. Johnson</i>	<i>Roslyn & Eric Scheib Dahl</i>
<i>Rick Davis</i>	<i>Darlene Kelly, MD</i>	<i>Susan & Jeffrey Schesmol</i>
<i>Ann & Paul DeBarbieri</i>	<i>Family of Shirley Klein</i>	<i>Doug Seidner, MD, FACC, CNSP</i>
<i>David & Sheila DeKold</i>	<i>Jim Lacy, RN, BSN, CRNI</i>	<i>Judi Smith</i>
<i>Tom Diamantidis, PharmD</i>	<i>Robin Lang</i>	<i>Steve Swensen</i>
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<i>Herb & Joy Emich</i>	<i>Laura Matarese, PhD, RD,</i>	<i>& Gregory A. Thompson, MD, MSc</i>
<i>Jerry Fickle</i>	<i>CNSD</i>	<i>Cathy Tokarz</i>
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<i>Alfred Haas</i>	<i>& Paula Okamoto</i>	

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**Conference Information
Inside this Issue!**

Take a Walk for Oley — At the Oley Conference, or in Your Home Town

For those who are able to come to the Oley conference or who live in the Minneapolis area, we hope you'll join us Friday, July 8, for the annual Oley Walk-a-Thon. This event has been a very successful fundraiser, netting over \$4,000 for Oley programs last year! With your help, we can raise even more in 2011.

If you can't make it to Minneapolis, you can still help. You can gather support for this event by sponsoring a designated walker, or organize a walk in your home town. Call (800) 776-OLEY for details.

Setting Goals

We encourage walkers to set a fundraising goal. Newcomers might try for \$50, while experienced participants have raised more than \$10,000! Every contribution helps. Special gifts will be awarded to the top three fundraisers.

Besides raising funds for Oley programs, the event helps raise awareness of the issues home IV and tube-fed consumers face and the services Oley offers. Tell your friends, family, and neighbors about the important work Oley does and ask for their support.

Get Your Company Involved

Companies small and large are encouraged to get involved. Gather a team of walkers from co-workers and family members. Or become a corporate sponsor and get your logo on the back of the official Oley Walk-a-Thon t-shirt.



2010 Oley Conference attendees enjoying the social aspects of the walk as much as the exercise.

We Appreciate Your Support

Thank you in advance for your efforts and support. For more information, or to obtain sponsorship forms, visit www.oley.org or call (800) 776-6539.
