Parenteral Nutrition–Associated Liver Disease and the Role of Lipid Emulsions: An Update

Kathleen M. Gura, PharmD, and Mark Puder, MD, PhD, Children’s Hospital, Boston

Updates on liver disease and Omegaven were presented by Drs. Puder and Gura at the Oley Consumer/Clinician Conference in Cape Cod in June 2007. The presentation is available on DVD (Main Session II); see order form on pages 9 and 10.

Patients suffering from severe short bowel syndrome require life-saving parenteral nutrition (PN). One of the major complications of this essential therapy is PN-associated liver disease (PNALD). This liver injury particularly affects infants on long-term PN and may progress to liver failure, liver transplantation, or ultimately death. Many theories have been brought forward as to the cause(s) of this complication.

One such theory involves the role of currently used IV fat emulsions made from plant oils. The use of an alternative product derived from fish oils, Omegaven, to treat PNALD was discussed in detail in the September/October 2006 issue of Lifeline Letter (available at www.oley.org or call 800-776-OLEY). Since that article was published, the process for obtaining Omegaven has been revised. That new information and other updates are provided in this issue.

Obtaining Omegaven

Neither Omegaven nor any similar product is currently available in the United States for routine use.

Clonidine Reduces Diarrhea, Sodium Loss

Alan Buchman, MD, MSPH, FACN, FACE, FACG, AGAF


For patients with short bowel syndrome, fluid management is a significant problem. It is possibly even more of a problem than absorption of adequate calories and protein. Fluid management is especially difficult for patients with minimal remaining intestine. In a study, investigators found they could decrease the amount of diarrhea and sodium loss in the stool of these patients by approximately 10 percent using a clonidine skin patch. While this is a modest decrease, taken from the perspective of patients who have maximized other therapies.

Holiday Hurdles

Rick Davis

When you cannot eat, cannot drink, and are too depressed to be happy or merry, it would be easy to say, “Bah, humbug!” when someone greets you with, “Happy holidays!” During the holidays, especially, it is easy for those of us who are home enteral or parenteral (HPEN) consumers to be depressed.

For many people, HPEN or otherwise, the holidays are stressful because of the holiday parties, the decorating,
Clonidine, from pg. 1

antidiarrheal therapies, and if used in conjunction with other antidiarrheal therapies, it is clinically significant.

Just like old buildings, some old drugs may have new uses. Clonidine is a medication traditionally used to treat high blood pressure. It has also been used effectively in treating diarrhea in patients with diabetes, and in animal and human studies it has been shown to have significant antimotility effects and to prolong intestinal transit time. A prolonged transit time allows the absorptive surface of the intestine to have increased contact time with nutrients and fluids, which may allow for greater absorption. Further, in a previous study of patients with cholera, clonidine decreased fecal sodium and potassium losses.

The Study

This study was undertaken to see if clonidine could increase fluid absorption for PN-dependent patients who had very little intestine that ended in a proximal jejunostomy. Maintaining adequate hydration is especially difficult for these patients. The study was also designed to measure fecal sodium and potassium losses.

For this controlled, unblinded study, eight PN-dependent subjects received clonidine transdermally, in the form of the skin patch Catapres. All of the patients received their usual medication. The transdermal route also ensures continuous delivery. The clinical practice of the investigators is to encourage multiple meals and snacks in this patient population, and some foods may interfere with the absorption of certain medications.

Clonidine was administered transdermally because, in addition to malabsorption of nutrients and fluids, patients with short bowel syndrome often have difficulty absorbing medication. The transdermal route also ensures continuous delivery. The clinical practice of the investigators is to encourage multiple meals and snacks in this patient population, although some foods may interfere with the absorption of certain medications.

Results

The study results showed a 9 percent decrease in fecal wet weight, as well as a decrease in fecal sodium loss. The decrease in fluid losses with clonidine reduced losses 3.0 L/week and growth hormone 2.1 L/week, once decreases related to dietary intervention are subtracted. The observations of a 9 percent reduction per day were in patients without residual colon, in whom fluid management is much more difficult and dietary adjustments have little to no effect.

The reason for the decrease in fecal fluid loss is not entirely clear, and in this pilot study, no attempt was made to wean PN fluid volume. However, PN fluid volume can be reduced if a daily urine volume of >1200 mL is sustained.

Although with clonidine therapy investigators observed a significant decline in fecal sodium loss along with fecal fluid loss, no relationship was found between residual bowel length and fecal sodium loss. There was no effect on fecal potassium loss. Despite the decrease in fecal sodium loss, all end jejunostomy patients had a sodium excretion substantially greater than dietary sodium intake. Thus, such patients always require significant parenteral sodium infusion.

It is unclear from the results whether the decrease in loss was a result of increased jejunal sodium absorption or a decrease in sodium secretion. Experimental studies with animals have shown clonidine enhances sodium absorption. Sodium is actively absorbed in the jejunum, and a strong correlation has been observed between sodium absorption and water absorption.

Further Study

Given the role of the colon in sodium absorption in patients with short bowel syndrome, it is possible clonidine would be even more effective in patients with some in-continuity colon. Further, the lower dose of transdermal clonidine was selected (0.3 mg./week) for the study because this was the first study and the investigators were concerned about the potential of patients developing low blood pressure (none did). Quite possibly a larger dose, such as 0.6 mg./week, might exhibit greater efficacy.

Transdermal clonidine is pharmacologically available and can now be considered a potential therapy in patients with short bowel syndrome and high fluid losses. However, long-term data will be needed to determine whether the effects are sustained over long time periods.
Making Your Own Food for Tube Feeding

Roslyn Dahl

Over the years we’ve had several members ask about making their own food for tube feeding. The idea is to put a home-cooked meal through the blender, strain it, and then ingest it through the tube. There are advantages to “blenderized” food, but also some serious disadvantages, so be sure to speak with your physician and a dietitian before going down this road. Most nutritionists agree that if you are going to try this option, it is safest to get most of your calories by commercial formula to ensure proper nutrition, and then supplement with blenderized food.

The Pros

Blenderized food will likely be much cheaper than formula—unless you are purchasing special nutrition mixes, vitamins, and so on. Consumers and caregivers report that blenderized food is more appealing than commercial formula. Consumers say they can taste real food again through smelling (and burping). This ‘tasting’ is especially beneficial if you are planning to introduce table food to a child that has never eaten before. Last, but not least, blenderized food allows you the joy of cooking your own food again.

The Cons

Blenderized food may not provide all the vitamins, minerals, fiber, hydration, and calories you need. It is difficult to formulate a well-rounded, calorie-dense diet that can get through your tube. Of equal concern, blended diet may clog your tube. This is serious business and may result in the premature need to change a tube. Further, making your own food can be inconvenient, and longer feeding schedules may be required to get the same amount of calories in, because blended food is unlikely to be as calorie-dense as commercial formula.

Some Tips

You are more likely to tolerate blended food if your intestines aren’t compromised. In other words, if you are on tube feeding because of an upper GI issue (like inability to swallow), you are more likely to be successful with blended food if someone who has an intestinal motility disorder or malabsorption issue. Another important factor is the diameter of your tube: some g-tubes and most j-tubes are too narrow to be practical for blended food feedings. Straining the food first can help with this problem.

If you decide to make food for yourself, you need to choose ingredients carefully to ensure nutritional balance and smooth passage through the tube. Do not mix medications into blended food, and be sure to flush well when you are finished putting food through the tube. A consultation with your dietitian/physician is a must, and a discussion with an experienced consumer will likely be helpful (see list).

Two industrial-strength blenders recommended by consumers for making blended food are:

1. The Vita-Mix 5000 made by the Vita-Mix Corporation (www.vitamix.com / 800-848-2649 / household@vitamix.com). A new model costs $399 and has a seven-year warranty. The company has a special purchase plan ($275 plus tax) if you are using the blender for medical reasons; contact householdsales@vitamix.com or ask for household sales when you call. The Web site has a section in Español for those who need it.

2. The Blendtec HP3 blender or the Total Blender by Blendtec (www.blendtec.com / 800-253-6383). Both models cost $399.95, have with a more powerful motor than the Vita-Mix and programmable mix cycles, and come with a 3-year warranty.

Experienced Oley members you can contact:

Flute Snyder | fluteduo@aol.com | 612-229-6630
Lesley Marino | ninabean@tampabay.rr.com | 727-644-1683
Sonia Blue | soniablue@sbcglobal.net | 831-277-8507

Lesley mentioned that one way to communicate with professionals and families who are learning about blended diet via a feeding tube is to subscribe to the Blended Diet Yahoo Group by e-mailing Blenderized-Diet-subscribe@yahoogroups.com.

How To Blend

Long in the works, the Homemade Blended Formula Handbook, by Marsha Dunn Klein MEd., OTR/L, and Suzanne Evans Morris, PhD, CCC-SLP, is now available. The book is designed as a reference and how-to for parents and professionals interested in learning about a homemade blended diet for tube feeding. The book includes 35 reproducible chapters and 16 food reference charts. In addition to the authors, contributors include several parents of children who are fed by tube; Sanford Newmark, MD; Ellen Duperret, RD; and Jude Trautlein, RD.


Thank you to everyone who sent material for the “Tube Talk” column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail 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.
A New Regional Coordinator

Please join us in welcoming Oley’s newest Regional Coordinator volunteer, Joan Medwar! Joan lives in Sharon, Massachusetts, and if you are familiar with the name, it may be because her son Michael is the Secretary on the Board of Trustees. With experience as both a parent and a patient, Joan has a tremendous amount to offer Oley.

Michael was diagnosed with Crohn’s disease at age nine, two years before his mother was diagnosed with the same disease. Michael’s brother, Greg, is profoundly mentally challenged and requires full-time care. Due to dysphagia, Greg requires a pureed-food diet. During the early years, Joan had to deal with the hospitalizations of both her sons, her own treatments, and outside help, including home health aides and therapists. In addition to Crohn’s disease, which left Joan with an ileostomy, she also has celiac disease.

Presently, both Joan and Michael are off homePEN and are doing well. Though Joan has a nursing background, she credits her personal experiences with helping her understand how chronic illness impacts one’s life—emotionally, physically, and financially. She realizes how important it is to develop interests in hobbies and to seek aid through support groups, government services, and psychological counseling. With all of her experiences, Joan hopes to provide insight and emotional support to people with chronic illness. Call Joan at 781-784-3341.

Update Your RC List

In addition to Joan, we’ve gained and lost several Regional Coordinators (RCs) this year, with the result that your RC list is likely outdated. Please check the Oley Web site at www.oley.org for the most up-to-date contact information or call 800-776-OLEY to obtain a newly revised list. The Oley RCs are waiting for your calls!

California, Here We Come!

We’re getting serious about San Diego, California, for next year’s annual Oley conference. We hope to have a contract signed soon. Save the dates—from June 25 to June 29, 2008—and plan to join us at the 23rd Annual Oley Consumer/Clinician Conference! Stay tuned to www.oley.org for updated information or call the Oley Foundation office (800-776-6539) anytime!

On the Web

- Check out www.oley.org! The Web site itself isn’t new, but the information on the home page changes frequently. If you want the latest on Omegaven, the Quiznos advertisement, or the 2008 Oley conference, go to www.oley.org.
- Check out www.fda.gov/medwatch/index.html to access FDA alerts (like the one announced on page 4) as they are posted and to review other interesting FDA information.

Equipment/Supply Exchange

Formula, tubing, and all sorts of miscellaneous items are listed in the Oley Foundation Equipment Exchange. If you need something or if you have something useful that someone else may need, the Exchange is there to serve you. The formula and supplies available change daily, but as of late October, the following formulas (and others) are available: 2 Cal HN, Peptamen, Peptinex, Fibersource HN, Jevity 1.2, Nutren 1.0 & 2.0, Isosource, Viconex Adult, and Portagen.

Full details about the program and an up-to-date listing of items available can be viewed at www.oley.org. Or contact the Oley Equipment Exchange Coordinator, Ben Hawkins, at benhawkins@fuse.net or 866-454-7351 (toll free). Please call Ben between 9 a.m. and 9 p.m. EST.

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Join Oley in Chicago

If you live in the Chicago area, or like to travel, we hope you’ll join Oley for a regional conference at the Hyatt Regency Chicago on Saturday, February 9, 2008. From 9:00 a.m. to 4:00 p.m., Oley folks will gather in the Water Tower Room to listen to prominent speakers and participate in breakout sessions. Program highlights are listed below. At midday a buffet-style lunch will be served, and attendees can browse through the Oley exhibit area.

This centrally located meeting is sure to attract a large audience and present rewarding networking opportunities. (Midwestern members keep an eye out for your registration brochure in the mail.) Stay tuned to www.oley.org for details about speakers and program updates.

The meeting is being held in conjunction with A.S.P.E.N.’s Clinical Nutrition Week, a conference for clinicians who care for patients on tube and IV feeding. Oley will host an educational seminar, “You Prescribe It, But Can You Live With It?” on Sunday, February 10, and provide outreach in the exhibit hall February 10 to 12. For more information about Oley’s regional conference and activities at Nutrition Week call 800-776-6539.

Program Highlights:

8:00–8:45 a.m. Registration
9:00–12:00 p.m.
Welcome, Darlene Kelly, MD, PhD, FACP
Hot Topics: Liver Failure and Trace Elements,
Lyn Howard, MB, FRCP, FACP
Making Tube-feeding Work for You,
Laura Matarese, PhD, RD, LDN, FADA, CNSD
Topic TBA, Doug Seidner, MD, FACG, CNSP
12:00–1:30 p.m. Lunch and Exhibits
1:30–4:00 p.m. Roundtable Sessions
Reducing HomePN Dependency,
Alan Buchman, MD, MSPH, FACN, FACP, AGAF
When to Be Evaluated for Intestinal Transplant,
Jon Fryer, MD
Practical Solutions for Tube-feeding Problems,
Laura Matarese, PhD, RD, LDN, FADA, CNSD
More roundtable topics coming soon!

Oley Exhibit at Nutrition Week:

Want to see the latest products on display in the exhibit hall at Clinical Nutrition Week? We’re looking for volunteers to staff Oley’s exhibit booth February 10, 11 and 12 from 9:30 a.m.–11:15 a.m.; 12:15 p.m.–1:45 p.m.; and 3:00 p.m.–4:15 p.m. Please call 800-776-6539 or e-mail swensek@mail.amc.edu if you can help out!
Order Your Oley Wear Now!

We have a selection of great shirts available to purchase.

**Long-sleeve Denim Shirts:** $20
- Women’s: S, M, L, XL, 2XL
- Men’s: XL

**Polo Shirts:** $15
- Women’s: S, M, L, XL in tan & yellow
- Men’s: S, M, L, XL, 2XL in tan & mocha; navy (S, M, L only)

Sample shirts are shown on right. Visit www.oley.org to view colors.

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**FDA Alert:**

**Interaction with Rocephin and Calcium-containing Parenteral Nutrition**

In October the FDA issued an alert regarding Rocephin. The alert states that Roche Laboratories informed health care professionals about revisions made to the prescribing information for Rocephin (ceftriaxone sodium) to clarify the potential risk associated with concomitant use of Rocephin with calcium or calcium-containing solutions or products.

Rocephin and calcium-containing solutions, including continuous calcium-containing infusions such as parenteral nutrition, should not be mixed or co-administered to any patient irrespective of age, even via different infusion lines at different sites. Rocephin and IV calcium-containing solutions should not be administered within 48 hours of each other in any patient. No data are available on the potential interaction between ceftriaxone and oral calcium-containing products or interaction between intramuscular ceftriaxone and calcium-containing products (IV or oral).


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**Bright Idea**

Have you ever had the card or package you sent someone in the hospital returned to you as undeliverable? Once a patient is discharged, their mail is usually “returned to sender” and ends up back in your mailbox. To get mail delivered to her friends and family even if they are discharged while the mail is en route, Oley Regional Coordinator Rose Hoelle uses this trick: She addresses the mail to the patient with the hospital address as usual, but then she puts the patient’s name and home address in the space for the return address. If the patient is discharged before the card or package arrives, it will end up in his or her home mailbox—instead of Rose’s.

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**Research News**

In the May/June Lifeline Letter we announced that a study on swallowing disorders was being conducted at the Clinical Center at the National Institutes of Health (NIH) in Bethesda, Maryland. The research is ongoing, but the phone number that ran in that announcement was incorrect. To obtain additional information about the study, contact Katie Burns at 301-594-5193 or dietrichburnsk@ninds.nih.gov.

The Nutrishare HomeTPN Research Prize, which will be awarded for the first time at the 2008 Oley Annual Conference, was recently established to encourage clinical studies focused on improving the quality of life for homePN consumers. To obtain additional information about the research prize, contact the Oley Foundation at 518-262-5079 or visit www.oley.org.
In Memory of Bill Hickey

Carol Ireton-Jones, PhD, RD, CNSD

With the death of Bill Hickey, a tree has fallen. I’m not sure where that line comes from, but it certainly explains how I feel about the loss of Bill. Bill passed away, at home, on August 10, 2007. He was 63 years old.

Bill lived a long life on homePN. In the nutrition world, this gave him a claim to fame. However, Bill considered himself a regular guy who was on homePN to stay alive.

Dr. Stan Dudrick was one of Bill’s heroes. I believe it was Dr. Dudrick who started Bill on PN in the VA hospital in Houston in approximately 1978. Bill had Gardner’s syndrome and had an extensive small bowel resection. He received his PN in the VA hospital for almost a year before they decided he could go home and manage his PN himself. Of course, that meant creating his own pharmacy at home. Bill did it because it meant he could get back to driving trucks and riding horses. It wasn’t easy, but as he always said, “I don’t complain—it’s my lifeline.”

Bill was a great helper to many people who were just getting started in the early days of homePN. He would call, be a friend, and lend support. He knew what they were feeling. Bill testified in Congress about the needs of people on homePN. He also trained a lot of doctors, nurses, dietitians, and pharmacists regarding homePN.

I met Bill in 1991 when he had been on PN for a “short” thirteen years. We spoke together at the American Society for Parenteral and Enteral Nutrition’s twenty-fifth meeting in Washington, D.C. Bill pulled no punches; he told it like it was.

In 2006, Bill was awarded the Celebration of Life Award from the Oley Foundation. I am certain that this was a very rewarding moment for him. It took us awhile to get him up to the stage—he didn’t like the limelight—but once we got him going, he did have a few words to say.

Bill lived the last few years of his life in Cheyenne, Wyoming—a fitting place for an old cowboy! I was in Cheyenne this May and we went out to dinner together. Yes, he relied on homePN for his nutrition, but he always loved to eat and he finished everything on his plate.

I am going to miss Bill Hickey. He will live on in my heart and in the hearts of many others. His words were simple but he meant them: “HomePN is my lifeline and I don’t complain about it—I do it so I can live.” He was an inspiration to me and can be to all of you.
Coping Skills

Holidays, from pg. 1

the visiting relatives, the presents, etc. For HPEN consumers—already hard-pressed to keep up—our lives are tough enough without the extra stress. Our health is precarious, our feeding therapy is time consuming, we are always on guard to avoid infections, we have GI distress on a regular basis.

How do we get over the holiday hurdles?

The easy way out is to shut the door and make the world go away. Or we can try to stick to our daily routine and ignore the holidays. Or we can suffer silently. Unfortunately, many of us do some variation of all the above. We do not have the will power or the energy to cope with the holiday hurdles.

When I first started tube feeding, I was hospitalized four days before Christmas and did not go home until mid-January. For six years, I have been unable to eat; unable to drink; even unable to swallow my own saliva. I have feeding-tube issues, weakness on my right side and balance problems because of a stroke, reflux, dumping syndrome, diarrhea, and all the psychosocial issues most HEN consumers experience. I have good days and bad days. But, mostly, I have good days. Mostly, I enjoy the holidays.

Each of us is unique. What works for one person may not work as well for someone else and vice versa. I want to share some of my coping strategies and make some suggestions that may help you. Some of my strategies may work for you; something may give you an idea. I hope you can have some happy days during the holidays.

Role Playing

First of all, you have to decide to make the most of it. Do the best you can. Decide to take charge and be positive. Challenge yourself to make the holidays as enjoyable for you as they are for everyone around you. Fake it, if you have to. Play a role, if it helps. Seek someone to stick with you and help you get the most out of the holidays. Set a goal and stay focused on it. Laugh and relax, even if it does not come naturally. Laugh and relax, even when you do not want to. Laugh and others will laugh and relax with you.

What works for me is to set a goal. For example, my wife and I go to every holiday party we can. I cannot eat or drink, but my wife does, and she enjoys it very much. I’m happy when she is happy, and I enjoy good company and good conversation. The goal I then set is to help everyone else enjoy the party, especially the hosts. I help serve the food and pour drinks. I clear empty glasses and plates. I keep busy helping the hosts and it gets me around the room and makes it easy to visit with everyone there. It distracts me from the fact that I cannot enjoy food and distracts others from the fact that I am not eating or drinking. In many ways, it puts me at ease and puts others at ease. It especially helps the hosts and lets me give them something special for the holidays.

Thinking of Others

We all have “down” days. Because of our chronic conditions, it is easy for us to feel sorry for ourselves. Especially during the holidays, I look for opportunities to help others who are in greater need. I sign up to help make sandwiches for the Salvation Army and then distribute them at a homeless shelter. I join the choir singing carols at nursing homes. I shop for children’s gifts and drop them off at the Marine Corps Toys for Tots collection box. I realize that many people have problems and I feel better because I can help them. I am grateful for all the good things in my life.

During the holidays, I make a special effort to thank the people who support me. Friends and family help me cope and the best way to thank them is by showing them how well I am coping with my condition. Telling them I love them and appreciate all they do for me makes me feel good and makes them feel good. Making a special effort, during the holidays, to appreciate the people around me and to appreciate the good things about my life helps make the holidays better for me and better for the people I am around. The holidays are a good time to “step up” my positive attitude.

Giving Gifts

For several months after I started tube feeding, I felt alone. I did not know anyone else with my condition. I felt isolated and depressed. Through the Oley Foundation, I discovered others who faced the same things I was facing, but who actively improved the quality of their lives. Knowing they could do it made it easier for me to do it. Now, because I make a very deliberate effort to improve the quality of my life, I am a thousand times better than I was five years ago. It did not happen overnight. It was a gradual process and I need to keep working at it. The holidays give me extra motivation.

My suggestion is to recommend that “giving is better than receiving” to everyone you know. Do it by example. Give others the gift of seeing you at your best. Encourage others to give to those who could use some help. This holiday season, I am going to encourage my friends and family to give a donation to the Oley Foundation. I do not know any other organization that does so much with so little money. Every contribution makes a difference. Giving to the Oley Foundation during the holiday season will make all of us feel better. Happy holidays!”

Rick Davis has been the president of the Oley Foundation since 2006.
The Oley Foundation Video / DVD Library Order Form

The Oley Foundation’s video/dvd collection has grown again! Filming of the latest set of dvds — those covering the 2007 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 videos/dvds in Oley’s library at no charge. Simply complete and return the order form. Tapes/dvds are available on a first-ordered, first-served basis, and must be returned within one week of receipt. Tapes/dvds produced by Oley may be copied for repeat viewing. A copy of the order form and summaries of the tapes/dvds are posted at www.oley.org.

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Information About The Oley Foundation
• Support for Life: The Oley Foundation __VHS __DVD
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  • A Day in the Life of a Child __VHS __DVD
  • Tube Feeding (1997, MSKCC) __VHS only
  • Life with Mic-Key Low Profile G-Tube __VHS __DVD
  • Tube Feedings are Mealtimes, Too! __VHS __DVD
  • Tube Feeding: A Guide to Daily Care __VHS __DVD
  • Taking Tube Feedings to School __VHS __DVD
  • Journey from Tube Feedings to Oral Feedings __VHS __DVD
  • The “Get Permission” Approach to Mealtimes and Oral Motor Treatment __VHS __DVD
  • Tube Feeding Your Child at Home (Part 1: Adjusting to Tube Feeding, Part 2: How Tube Feeding Works) __VHS __DVD
  • Stoma Site and Feeding Tube Care and Maintenance __DVD only

Miscellaneous
• Choices In Nutrition: Understanding HPEN Therapy Options __VHS only
• Assn. of Vascular Access 2004 Conference __DVD only
• Product Education: Clinical Evaluation of a Positive Pressure Device to Prevent Central Venous Catheter Occlusion — Results of a Pilot Study __VHS only
• Oley Regional Conference, Phoenix, 1/27/07
  Probiotics; GLP-2; My Life, My Line __DVD only
  • 2007 Oley Conference
  • Main Session 1: Fishing for Solutions. Features the health care team, bowel transplant issues, and living with HPEN __DVD only
  • Main Session 2: The Dark Side of Successful Therapies. Features IV fish oil (Omegaven) for treatment of PN-associated liver disease, preventing sepsis, and complications and psychosocial issues of HPEN ___DVD only
  • Breakout Session: Have the Guts to Transition to Enteral? __DVD only
  • Breakout Session: Pediatric Issues __DVD only
  • Breakout Session: Catheters, Bacteria, and Infection —What You May Not Know __DVD only

updated 10/22/07
2006 Oley Conference
• Main Session 1: What Is Rational Management? Features best practices in managing home IV and tube fed patients, Plus Awards Ceremony __DVD only
• Main Session 2: Being All That You Can Be, Features tips on how to live more fully with home IV or tube feedings, Plus In Loving Memory Service __DVD only
• Breakout Sessions: Reducing HPN Dependency / What Are Probiotics? __DVD only
• Breakout Session: MicroNutrients, Plus Opening Remarks: History and Future of HPN __DVD only

2005 Oley Conference
• Plenary Day 1: Match Game, Featuring tips on avoiding long term complications, tube feeding, spouse/caregiver issues, hydration, liver disease and bone disease, Plus Awards Ceremony __DVD only
• Plenary Day 2: Oley’s Mixed Bag, Featuring information on trace elements, GLP-2, dietary management of intestinal failure, Plus In Loving Memory Service __DVD only
• Breakout: Coping Well, Thinking Positive __DVD only
• Breakout: Fluid Conservation __DVD only
• Breakout: Enteral Workshop __DVD only

2004 Oley Conference
• Plenary Day 1: Aluminum and Current FDA Labelling Regulations, Signs and Symptoms of HPEN-Related Complications, Pain Management __VHS __DVD
• Plenary Day 2: Vascular Access-Complications/Treatment, Endoluminal Brush, Preserving Access __VHS __DVD
• Breakout: Management of Short Bowel Syndrome __VHS __DVD
• Breakout: Drugs and How They Effect Your Gastrointestinal Tract __VHS __DVD
• Breakout: Parenting Journey: Chaos to Calm __VHS __DVD

2003 Oley Conference
• Plenary Day 1: Awards Ceremony, Effects of Growth Hormone, Glutamine and Diet on Nutrient Absorption __VHS __DVD
• Plenary Day 2: History of HPN/Micronutrients, Tube Feeding, Catheter Infections __VHS __DVD
• Breakout: Small Bowel Transplants __VHS __DVD
• Breakout: Gutsy Issues __VHS __DVD
• Breakout: Catheter Care for Ultimate Success __VHS __DVD

2002 Oley Conference
• Plenary Day 2: Interventional Radiology, Motility Disorders/Gastric Pacing, Tube Feeding Plus: In Loving Memory Service __VHS only
• Breakout: Dealing with Feelings __VHS only
• Breakout: Bone Disease/Bone Building __VHS only

2001 Oley Conference
• Plenary Day 1: Who Wants to Be a Millionaire? Featuring: Infection, Travel, Motility Disorders, Trace Elements __VHS only
• Plenary Day 2: Managing Intestinal Failure: Multidisciplinary Approach, from Diet to Surgical Options Plus: In Loving Memory Service __VHS only
• Breakout: Transplantation __VHS only
• Breakout: Preserving Your Liver __VHS only
• Breakout: Good Grief (Coping With Loss) __VHS only
• 2001 Oley Foundation Awards Ceremony __VHS only

Videos from the 2000 and earlier Oley Conferences are available; please call (800) 776-OLEY to request them.

Please Return Videos / Discs Promptly!
HPN Centers of Experience

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

Center for Advanced Intestinal Rehabilitation
Children's Hospital, Boston

The Center for Advanced Intestinal Rehabilitation (CAIR) at Children's Hospital Boston is a multidisciplinary program that offers coordinated nutritional, medical, and surgical therapy, with the goal of providing the quality care to patients with intestinal failure.

The CAIR program was founded in 1999 and over 150 patients with short bowel syndrome have been treated at CAIR. Survival for these patients has exceeded 90 percent. In the 2006–2007 fiscal year, the CAIR program had 695 outpatient encounters and managed 132 admissions. The CAIR program members include experts in the fields of nutrition, social work, nursing, pharmacy, gastroenterology, surgery, and liver/intestinal transplantation; all program members have a specific interest in the integrated management of intestinal failure.

The team actively participates in research focused on the treatment and understanding of short bowel syndrome and has made major contributions to the field, including the development of a new bowel lengthening procedure (the STEP operation) and the development of a novel, potentially liver-protective, parenteral nutritional formula based on omega-3 fatty acids. (See “Parenteral Nutrition–Associated Liver Disease and the Role of Lipid Emulsions” on the front page.)

CAIR program members include: Tom Jaksic, MD, PhD, Surgical Director; Christopher Duggan, MD, MPH, Medical Director; Sharon Collier, RD, Dietitian; Kathleen Gura, PharmD, BCNSP, Pharmacist; Julie Iglesias, RN, MSN, CPNP, Nurse Practitioner, CAIR Coordinator; Daniel Kamin, MD, Medical Director, Intestinal Transplantation; Heung Bae Kim, MD, Surgical Director, Intestinal Transplantation; Clifford Lo, MD, PhD, Home PN Physician; Mark Puder, MD, Surgeon; and Denise Richardson, RN, Home PN Nurse.

Consultations to the CAIR program can be arranged by phone at 617-355-5275 or by e-mail at gabriela.ardon@childrens.harvard.edu. The CAIR Web site address is www.childrenshospital.org/cair.

Oley Fundraiser in Anaheim

An Oley event and fundraiser will be held at the Honda Center in Anaheim, California, on Sunday, February 24, 2008, at 5 p.m., when the Anaheim Ducks take on the Chicago Blackhawks in an NHL hockey game. A box in the club level with twenty seats has been reserved for the event, so any needs can be comfortably accommodated. An auction and other activities during the game are being planned. The event is being sponsored by NathanMed, a new producer of enteral feeding devices. For each seat, a tax-deductible contribution of $200 made directly to Oley is suggested. Please contact Mitchell Price at 949-468-8468 or at mitchprice@cox.net for reservations and information.
Liver Disease, from pg. 1

clinical use. We obtain it under our protocol at Boston Children’s Hospital for compassionate use. Compassionate approval from our institutional review board (IRB) and from the FDA is required for each patient. Practitioners who would like additional information and guidance on starting similar research protocols at their institution can contact us. (See “How Physicians Can Obtain Omegaven,” next page, for contact information; check www.oley.org for updates.)

Until such a product becomes available within the United States, physicians can e-mail the division of Gastroenterology and Blood Products within the FDA to get further information. (Again, please refer to “How Physicians Can Obtain Omegaven” next page, or on www.oley.org.) This process has been simplified over the last several months as requests for the product have increased.

Progress Report

Since September 2004, we have treated 59 patients with PNALD with very good results. Our criteria for treatment include a direct bilirubin of greater than 2 mg/dL, no other cause of liver disease, and the need for continued treatment with PN for at least an additional 30 days. Patients whose liver disease did not reverse (two, to date) had severe liver injury showing evidence of cirrhosis or reversal of portal flow. However, such patients may still benefit from Omegaven as it will help optimize their nutrition prior to their undergoing a liver or liver-intestinal transplant.

The exclusion criteria include active bleeding and allergies to fish or eggs. Patients who are expected to be weaned off PN within 30 days would not be eligible as clinical improvement does not typically occur until after at least 30 days of therapy, with most patients experiencing normalization of their direct bilirubin within 60 days of starting Omegaven. Our clinical experience from our first 18 patients has been submitted for publication.

Theoretical risks of Omegaven include bleeding and essential fatty acid (EFA) deficiency. To date, there have not been any active cases of bleeding in our patients. Furthermore, many of our patients have undergone extensive surgical procedures after starting Omegaven without developing this complication. The EFA profiles are followed weekly and no patients have developed EFA deficiency. In fact, we have used Omegaven to treat EFA deficiency in patients with a soy allergy and are unable to receive conventional lipid products.

Based on our experience, we now start patients on Omegaven at the goal dose of 1 g/kg/day. Laboratory monitoring includes EFA profiles, hepatic enzymes, lipid panels, C-reactive protein, electrolyte, mineral, and albumin/prealbumin prior to the initiation of therapy and weekly until the bilirubin level normalizes. We then test every two weeks and then monthly. Patients may go home on this treatment and be followed as outpatients.

Although we continue to look for complications, we have not seen any directly related to this new treatment. Our central line infection rate is lower for patients on Omegaven, but this may be due to improvement in liver function and close attention to indirect markers of sepsis such as C-reactive protein and platelet counts. Patients such as Charles, who was profiled in the September/October 2006 LifelineLetter article, continue to be on Omegaven as they are gradually transitioned over to enteral feedings. Charles has now been on Omegaven for more than three years. Several other patients have been receiving Omegaven for more than one year without problems. These children are at home leading active lives with their friends and family, and many attend nursery school.

Costs of Investigational Therapy

Since Omegaven continues to be an investigational therapy, physicians must petition the FDA for permission to bill third-party payers once the sixty-day approval period has ended and they have received their emergency IND number. Adhering to this process, however, does not obligate the third-party payer to pay. In fact some third-party plans have contracts with many health care systems that specifically state that they will not pay for any investigational therapy. In such situations, the cost of therapy must be borne by the sponsoring institution.

At Children’s Hospital, Boston, the institution has agreed to fund the unreimbursed costs of Omegaven for their patients. At other centers, unrestricted payment grants have been obtained through donations. To date, we are aware of at least twenty-five other institutions in the United States and Canada that are treating their patients with Omegaven.

Future Research

Despite our dramatic results, the research does not end here. Our next step is to determine if using intravenous fish oil at the start of PN nutrition can prevent the development of the often fatal complication of PNALD. The March of Dimes recently awarded us a grant to investigate this, comparing the use of Omegaven to the currently available commercial products. This three-year randomized controlled clinical trial is now underway.

Several other studies investigating the use of Omegaven in very low birth weight infants and patients awaiting liver transplant will begin within the next several months. These will be coordinated by Children’s Hospital, Boston, in conjunction with other centers around the United States.
How Physicians Can Obtain Omegaven

(Revised September 25, 2007)

Note: Many of these steps will occur concurrently so the prescriber should not wait for a response to proceed to the next step.

1. Obtain permission from FDA: e-mail Cristi Stark, at the FDA to alert her that a request for Omegaven is forthcoming. Send her your contact information (including phone number) and brief information on the patient. It is not necessary to send her any forms at that time. She will contact you and e-mail you the proper documents. Her e-mail is: cristi.stark@fda.hhs.gov. We typically hear back by phone in one to two days.

Please note: This contact information is expected to change in November. Updated information will be available through Oley at www.oley.org or 800-776-OLEY.

2. Submit a copy of the protocol you plan to follow to your institutional review board.

3. Place an order for Omegaven with International Pharmacy in Hamburg, Germany. Fresenius, the maker of this product, won’t ship small orders; using the Hamburg pharmacy is much easier if only applying for one patient. There are probably other international pharmacies that could also do this, but this is whom we have dealt with. We are not endorsing them, it is just the process we have followed.

If you use International Pharmacy, they will NOT accept U.S. credit cards. Their preferred method of payment is an international bank transfer or wire transfer to their bank account. They will submit the bank details by e-mail directly to the customer. Checks are unreliable as they may be lost or take weeks to arrive and the conversion rate may change in the meantime. Shipping is extra.

Contact them at:

Mrs. Elena Ekrot
Export Sales
Pharmacy International
Hamburg (Germany)
Phone: +49 40 241 241
Fax: +49 40 280 25 18
E-mail: mail@pharmacy-international.de
Web site: http://www.pharmacy-international.de

4. Get it delivered. Once you place the order, they will e-mail you when it is in stock. Then you must call a courier to deliver it or have Pharmacy International ship it at an additional charge. I strongly suggest you use World Courier as they have experience with getting it through the FDA and Customs without a problem. Other hospitals have used DHL or Fedex and their shipments have been held up in Customs and by the FDA for up to two weeks. Using World Courier, you get it within 24 hours of shipping. World Courier’s Web site address is http://www.worldcourier.com.

Any questions, please contact: Kathleen Gura (Kathleen.Gura@childrens.harvard.edu, 617-355-2336) or Mark Puder (Mark.Puder@childrens.harvard.edu, 617-355-1838).
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.

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Designate Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this by designating the Oley Foundation on your United Way campaign pledge card. Questions? Please contact Roslyn Dahl or Joan Bishop at the Oley office, 800-776-OLEY or bishop@mail.amc.edu.

Save a Tree

Send us your e-mail address, and we can send you news updates, the latest conference information, and the LifelineLetter. You’ll save paper and postage, and receive the news well before the postman could deliver it. Our e-mail list is private and will not be shared.

To switch over to an electronic subscription, contact Cathy Harrington at the Oley office at (800) 776-OLEY or harrinc@mail.amc.edu.

Thank You, Thank You

Please join us in thanking our corporate sponsors who keep Oley’s programs going strong. We appreciate their generous support!

B. Braun Medical, Inc.

A recipient of the 2007 Frost & Sullivan Medical Technology Global Excellence Award, B. Braun Medical, Inc., has built a large store of knowledge and expertise in delivering innovative health care products, medical devices, and programs that enhance working processes in hospitals, alternate care settings, and medical practices—increasing safety for patients, doctors, and nurses. The company writes, “Our 34,000 employees worldwide are proud of their commitment to translating customer needs into products with unmatched quality, superior technology, cost-effectiveness, and environmental responsibility.” Today, B. Braun offers a complete line of basic nutrition products for parenteral administration, including 3%, 8.5%, and 10% FreAmine® III (Amino Acid Injections), and Concentrated Dextrose (20%–70% Injections). B. Braun states, “We are more than a reliable supplier of parenteral nutrition products—the company is a partner, too, providing customers with assistance on product decisions, technical support, and more.”

ZEVEX, Inc.

ZEVEX manufactures and markets the EnteraLite® Infinity™ enteral feeding pump. The company writes, “The EnteraLite Infinity is highly portable, +/-5% accurate, easy to program, and rugged—it can be washed under running water without fear of damage!” The Infinity weighs less than 15 ounces, has 24-hour battery life, and can be operated in any orientation due to the elimination of the drip chamber. To learn more about the Infinity, and how to remove the traditional barriers to enteral feeding, visit ZEVEX’s Web site at www.zevex.com/infinity.
Individual Donors—Thank You!
The following list represents everyone who contributed between August 9 and October 22, 2007. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

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Sharon Sakowitz, in honor of Nor-
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pleting her residency program!

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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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Thanks!
Toll-Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<table>
<thead>
<tr>
<th>Toll-Free Schedule</th>
<th>Toll-Free Numbers Available to US and Canadian Consumers!</th>
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<tbody>
<tr>
<td><strong>Melanie LaVoie</strong></td>
<td><strong>Tauton, MA</strong> (888) 610-3008 EST</td>
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<tr>
<td><strong>Karyn Thomas</strong></td>
<td><strong>Midland, MI</strong> (888) 650-3290 EST</td>
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<tr>
<td><strong>Sharon Rose</strong></td>
<td><strong>Nashville, TN</strong> (888) 610-3008 CST</td>
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<tr>
<td><strong>Joseph Rogers</strong></td>
<td><strong>New Bedford, MA</strong> (888) 650-3290 EST</td>
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<tr>
<td><strong>Marilyn Sobiech</strong></td>
<td><strong>Brainerd, MN</strong> (888) 610-3008 CST</td>
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<tr>
<td><strong>Dave Helgeson</strong></td>
<td><strong>Vancouver, WA</strong> (888) 650-3290 PST</td>
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**LifelineLetter**
The Oley Foundation
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