HPN-Associated Liver Disease in Infants

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

Patients suffering from short bowel syndrome require life-saving parenteral nutrition (PN). One of the major complications of this essential therapy is PN-associated liver disease (PNALD), especially in infants and children. This liver injury affects the majority of 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. Here we will discuss the role of lipids and the success we’ve had in treating PNALD in infants.

PNALD Defined

Patients diagnosed with PNALD typically have elevations in their serum aminotransferases, bilirubin, and alkaline phosphatase. Histologic alterations include steatosis (fatty liver), steatohepatitis (inflammatory response), cholestasis (plugged bile ducts), and in some cases, progression to fibrosis and cirrhosis. Risk factors for PNALD include young age, premature birth, low birth weight, long-term use of PN, absence of enteral nutrition, gastrointestinal mucosal disease, bacterial sepsis, and multiple operative procedures.

A number of causes of PNALD have been proposed including nutrient deficiencies (taurine, choline, vitamin E, zinc and essential fatty acids) and excesses (energy, carbohydrates, amino acids, and fats). Intravenous fat emulsions may predispose patients to PNALD due to their phytosterol content. Phytosterols, such as those contained in soybean oils, are thought to damage the liver.

A Holiday Tale

Flute Snyder

Shortly after chemotherapy and radiation treatments for cancer in my left tonsil left me unable to eat, my wife and I moved to the Twin Cities of Minnesota to be near her large family. I was faced with the problem of dealing with relatives aged two through eighty. How should I present myself at parties, dinners, and church gatherings? “Oh, I can’t eat, so just don’t set a place for me.” Or, “You’ll just have to get used to seeing me sit in front of you while I pump my dinner from a horse-sized syringe.”

At large dinner parties in relative’s homes, I often felt like a bump on a log sitting at a table with 22 people, but not eating. So, I became a self-appointed table waiter. Sometimes I serve, fill water glasses, recirculate food items from the kitchen, and then remove the dinnerware to the kitchen. All the while, I can be washing pots and pans, and generally staying out of the way. If I’m careful...
Liver Disease, from pg. 1

PNALD Prevention/Treatment
Care of PN-dependent children is focused on increasing enteral nutrition while the residual bowel increases in size and function so that PN may be discontinued. However, liver injury frequently occurs before bowel adaptation and growth is complete, and irreversible liver damage can pose a serious threat to patient survival. It is often a race between bowel adaptation and growth, and the development of end stage liver disease. Thus, it is essential to prevent, or at least slow, the progression of liver injury for patient survival. In severe cases of refractory hepatic failure, liver transplantation with or without accompanying small bowel transplantation remains the only treatment option.

Treatment for liver disease in children is extremely limited. Often times patients are given ursodeoxycholic acid, hepatotoxic trace elements (manganese, copper) are removed from their PN and/or their PN is supplemented with choline or molybdenum. Some practitioners advocate discontinuing the lipid infusion totally when patients develop signs of PNALD. This practice can be detrimental in infants who are already at risk of developing essential fatty acid deficiency due to their limited fat stores, and need fatty acids for growth and brain development. The most effective treatment is to discontinue PN and begin full enteral feeds. Mortality rates as high as 100 percent have been reported in infants diagnosed with PNALD who are unable to come off of PN within 1 year of diagnosis.

Fatty Acids and their Role in PNALD
Essential fatty acids (EFA) are termed such because they cannot be synthesized by the human body and thus must be derived from the diet. There are two EFA groups: omega-6 and omega-3. They are both characterized as poly-unsaturated fatty acids (PUFA).

Patients need a balance of the products made by both omega 6 and omega 3 fatty acids. Omega 6 (typically given in PN solutions as linoleic acid) breaks down into arachidonic acid, which is essential for bilipid membranes but also produces pro-inflammatory, immuno inhibiting cytokines (see Figure 1). Omega 3 (typically given as α-linolenic acid in PN solutions) breaks down into eicosapentaenoic acid, docosapentaenoic acid and docosahexaenoic acid — which are anti-inflammatory, less immuno inhibiting products. Patients with too much omega 6 product are at risk of developing PNALD, patients with too much omega 3 products are at risk of bleeding disorders.

Liver Disease cont., pg. 13

Figure 1: Biosynthesis of Fatty Acids

**Omega 3**
- Anti-inflammatory/less immuno-inhibitor
- α-linolenic acid in Intralipid
- Octadecatetraenoic acid
- Eicosatetraenoic acid
- Eicosapentaenoic acid in Omegaven
- Docosapentaenoic acid in Omegaven
- Docosahexaenoic acid

**Omega 6**
- Pro-inflammatory/immuno-inhibitor
- Linoleic acid in Intralipid
- γ-linolenic acid
- Dihomo-γ-linolenic acid
- Arachidonic acid in Omegaven

Fatty acids are given in Intralipid in the forms represented by the ovals. These are broken down in the patient's body to the critical metabolic products represented by the rectangles. Infants and children are inefficient at breaking down the omega 3 fatty acids into usable forms and consequently are at high risk of developing PNALD. Researchers have reversed this trend by giving infants/children parenteral fat made from fish oil (Omegaven).
Tube Talk

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 DahlR@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

Tube Feeding Manual Available

Would you, or someone you know, like to cope better with home enteral nutrition (tube feeding)? A self-help manual is now available entitled Coping Well with Home Enteral Nutrition. Resilient HEN consumers who participated in a research study provided the majority of the information and strategies. These adults offered suggestions and insights based on their personal experiences. Although a single coping strategy or technique will not work for everyone, try one or more of the twenty-nine coping strategies offered in this manual and begin coping better today. Consumers and clinicians are encouraged to download and print free copies for personal use or to provide to clients by going to www.copingwell.com.

— Cheryl W. Thompson, PhD, RD, CNSD
Salt Lake City, UT

Website Features Tube Talk and More

This and all past tips published in the Tube Talk column are available 24 hours a day, every day of the year, on Oley’s website, www.oley.org. You’ll also find the HEN complication chart, laminated cards to assist you in ordering less or not at all in restaurants, and a host of other resources. So check out www.oley.org today!

Tube Feeding Workshop

A series of workshops designed to teach professionals and parents about the medical and social aspects of tube feeding will be held in several cities in 2007: January 20-21 in San Diego, California; March 9-10 in Birmingham, Alabama; and October 25-26 in Cincinnati, Ohio.

Entitled “Tube Feeding with Love,” the workshops feature Marsha Dunn Klein, MEd, OTR/L, a pediatric occupational therapist who specializes in feeding infants and young children. Workshop attendance costs $350 for professionals and $200 family members. CEUs are available for occupational therapists and dietitians. For more information call (520) 323-3348 or visit www.mealtimenotions.com.
Board Elects New President

The Oley Board of Trustees elected a slate of officers at its annual meeting in July, including a new President, Rick Davis. Rick has been fed by tube since a stroke paralyzed his ability to swallow in December 2000. He brings many talents to the board in the areas of marketing, fundraising and meeting planning. We all got a taste of this at the Oley conference in Salt Lake City this summer. We enjoy working with Rick and look forward to the new energy he brings to the Foundation at the leadership level.

Rick replaces Steve Swensen, who stepped down from the board after many years of service. The trustees and staff recognized the contributions Steve made during his eight years as Oley president (term limits were instated during his tenure). In particular, we thank him for his encouragement of the research program, his representation of Oley at many gatherings and support of the staff. We will miss his wit and wisdom.

We thank Michael Medwar for taking on the challenge of becoming Oley’s secretary. His excellent communication skills will come in handy for sure. We also thank Darlene Kelly, MD, PhD, and Laura Ellis, PhD, RD, for their continued service as vice president and treasurer, respectively. For a listing of the whole board, and a description of each member, visit the Oley website at www.oley.org.

Oley’s board is comprised of HPEN consumers, HPEN clinicians, members of industry as well as business professionals. Trustees are limited to two, consecutive terms of three years, and are voted in by current members of the board. Officers are nominated by the board and elected each year at the annual meeting. Board members meet three or four times a year and assist in fundraising, policy making, overseeing staff and other projects as needed. Anyone interested in being considered for a position on the board should contact Oley’s Executive Director, Joan Bishop (bishopj@mail.amc.edu / 800-776-OLEY).

Be an HPN Trend Setter

Twenty years ago, HPN consumers hooked up to gigantic, immobile pumps, where they would remain, infusing from a variety of glass bottles. HPN has come a long way since then, thanks to advances in technology and with the onset of the 21st century, there are no signs of stopping! You can be a part of the HPN of the future by joining the Oley Foundation and Carol Smith, RN, PhD as we investigate the use of technology to assess HPN complications and issues.

Participants will have access to “tele-health” devices including camera-telephones, internet, and computers, as needed. All opinions gathered will be kept completely confidential and a summary of all participants’ (anonymous) responses will be reported. Each participant will receive a small fee. HPN consumers and caregivers are invited to complete a form online at www.oley.org, email bishopj@mail.amc.edu, or call (800) 766-OLEY to learn more.
A Tale of Two Sisters
Mallory Cyr

Mallory and Maisy Cyr are two sisters from the small town of Sabattus, Maine. Since they have both been on TPN the majority of their lives; their stories and accomplishments are anything but small.

Rare Disease Leads to TPN
Mallory is the eldest of the two girls and just recently turned 21. This is miraculous because when she was an infant, doctors did not expect her to live past the age of two. Mallory was diagnosed with a very rare digestive disorder. It is called microvillous inclusion disease; which means that the microvilli are ingrown and the step of absorption in digestion is omitted. Because of this, Mallory had a central line placed and has been on TPN for twenty years of her life.

It took a little over a year for Mallory to be diagnosed because the only symptoms are diarrhea and vomiting. To this day, the only other people diagnosed with this condition in the U.S. are two boys in California. They have since had small bowel transplants and are no longer on TPN. There have also been a few cases in the UK. Because of the rarity of this disease, treatment when Mallory was a child was still quite experimental. She was deprived of certain essential nutrients and only grew to a height of 3'9”.

Mallory just completed her junior year of college at the University of Maine at Farmington. She is a full-time creative writing major living on campus. She has been involved in almost every extra curricular activity available through her years at school; not to mention her very active social life. When living with a chronic illness of any kind, it is important to never take anything for granted and to live every day to the fullest. Even though Mallory is a firm believer in living the “no day but today” life, it can’t hurt to look to the future. After completing school, Mallory hopes to live in an urban setting doing freelance work or writing her autobiography. She is willing to go wherever the world takes her.

Walking in Familiar Footsteps
Maisy is going to be thirteen this summer and she could not be closer to being a perfect, beautiful, active adolescent — except for the fact that she is on TPN and has been since she was about two years old. Maisy’s MID onset was later than Mallory’s and less of a problem because the doctors knew what they were looking for. They were also much more advanced when they began the TPN. Because of Anna’s watchful eye (Mal and Maisy’s mother), Maisy got all of her nutrients from day one and she is of average height.

Maisy is also a performer and loves dancing, singing and acting on stage; all of which she excels at doing. She is an excellent student and spends her weekends going to the movies and dances with her friends, but her true passion is at the farm. Maisy spends the majority of her free time at a horse farm, riding, working and doing anything that needs to be done. She has participated in many horse shows and taken home nine blue ribbons; even competing in some classes which were all adults.

The Cyr girls undoubtedly have had their fair share of challenges; but between their endless determination, love of life and amazing support from their parents, Anna and Mike, it is no doubt that they have become, and will continue to be, successful, ambitious young ladies. In such a wonderful, busy world, with so much to offer, TPN is merely an essential accessory!
Scenes From the Oley Conference in Salt Lake City

Reid Nishikawa, PharmD, addresses conference attendees.

We had beautiful weather and a great turnout for the walk-a-thon through downtown Salt Lake City!

From top left: Brittany, Alicia, Kate, Kyle, Brandon, Nina, Colyn, Roy and Caleb at Jammin' Jammies

Michael Antonucci and John Henry Key sharing stories in the lobby.

Richard Noble enjoying a quiet moment between events.
Marjorie, Patty, Samuel, Rose and Jordan at Hogle Zoo

Ellen and Roy catch up over lunch.

The Bayley family checking out products in the exhibit hall.

Brittany finds a new friend, Rachel.

Award winners:
Bill Hickey, and
Carol Ireton-Jones,
PhD, RD

June 28 to
July 1, 2006
Tube Hell and Back Again
Sanford Schimel

June 1, 2005 my first enteral tube was inserted. If I had known then what I know now, I would have had a much easier year. Hindsight is amazing. Back then I had no idea what anyone was talking about, and hadn’t learned about different brands and models of tubes. I took my surgeon’s word for everything.

That first tube was a disaster. Without a cap attached, I had to use Christmas trees from my Kangaroo bags and a knot to close the tube off. Every time I moved, the Christmas tree popped out. It leaked all over every piece of clothing I owned. Once, the Christmas tree popped out onto the subway floor and I couldn’t find it. Not that it would have been too smart to reinset it, but it would have been better than riding 10 blocks on the train, and another 10 blocks in a cab, with my finger over the opening, trying to get home. My sister, who has been my primary support person, called the manufacturer. Turns out that tube was made for people who are bedridden and remain attached to a drainage bag 24/7.

I complained until the tube was replaced. By now, I knew enough to ask for a tube that would allow for mobility. The surgeon, the interventional radiologist (IR), and my Nutritionist all consulted with me Thursday night, and Friday morning the new tube was put in. When I came to, I realized it was a completely different arrangement than we had agreed upon. This new tube, like the previous one, was a J-G tube, but the ports weren’t molded as one piece. It looked like it was built out of Legos. The inner tube, the J portion, initially worked fine; however, about 3 hours after I started feeding, the Christmas tree popped out and would not reattach. I ended up pulling the J-port out of the G-port to un-kink the J-tube, but then stomach fluid started leaking from the G-port. When I complained to IR, they said I should put a dish under the tube to catch the drips while I was feeding.

Saturday morning I checked myself out of that hospital and into one ranked seventh in the country for GI problems. On Monday a new tube was inserted. I immediately noticed that something was drastically wrong. The tube’s ports were right up against the stoma, sticking straight out. They started feeding me anyway, and I threw up four times. An x-ray revealed that the tube hadn’t been inserted deeply enough; the J portion was in my stomach, which is paralyzed with gastroparesis, and all the formula was going there.

A Ray of Hope in the Gloom

The next day the tube was repositioned. Now placed properly, it worked perfectly. I could drain through the G-tube and feed through the J-tube without leaking. More importantly, after ten weeks, I could go back to work. Three months later, the tube’s balloon dissolved and the whole contraption slid out at work. I calmly told my boss, “Uh, I need an ambulance. Disinfect. Don’t touch.” I wanted to go back to the hospital that installed it, but I work in the Bronx and the ambulance wouldn’t go to Manhattan. The staff at the local hospital seemed incapable of helping me. They inserted a Foley catheter to keep the stoma open, and sent me on to the hospital in Manhattan.

Unfortunately, I couldn’t be admitted on a Friday night, so I went home with the Foley shut with a metal clamp. Back at work on Monday morning, both the tube and the stoma sprang a leak and acid started spewing. I took yet another cab back to the Manhattan hospital (I could buy a car for what I’ve spent on cabs). As I waited in the ER, the leaking stomach acid began to burn my skin. Every time I moved, more acid came out. The gauze was always soaked, and the nurses weren’t quick to change it. I still have scars from those burns in the shape of the gauze.

When the GI doctor came in that night he didn’t want to give me the tube I had asked for; he said the balloons dissolve too quickly and what I really needed was a bumper. Then, without any anesthesia or anesthetic, he jammed a new tube into my injured stoma. Echoes of that scream are all the way to Saturn by now.

Back home the next morning, when I hooked up, the J-port came off. I hadn’t even had it for 24 hours! I looked closely and found more Legos; each port was a separate piece. I went to his office, and his response was to crazy glue it back together. This lasted a week before falling apart. I stopped tube feeding at that point. I couldn’t deal with the aggravation.

Hard Work Pays Off

My nutritionist and I agreed that I needed a tube like the one I had before. I began my research in earnest. I checked every medical supplier on the internet until I found a tube that looked right. The problem then became obtaining one. The company wouldn’t sell to me directly. My homecare company didn’t want to pay for it. Insurance
Join Oley in Phoenix

Start the new year out right by joining Oley on January 27, 2007 in Phoenix, Arizona! This one-day regional conference will show you what’s new in homePEN therapy for 2007. Topics include the emergent therapies, Pre/Probiotics, as discussed by Kelly Tappenden, RD, PhD and Growth Factors: GLP2 and Teduglutide, covered by Palle Jeppesen, MD, as well as Complications Associated with Vascular Access, by Sheila Messina, RN. Roundtable sessions will be hosted by Jane Balint, MD, Doug Seidner, MD, and Sheila Messina, RN, on Pediatric Issues, Avoiding Complications, and Sharing from the Consumer Perspective, respectively. Registration begins at 9:00 a.m. and the program will run from 10:00-4:30 p.m. Walk-ins are welcome. Stay tuned to www.oley.org for the exact location of the conference and for program updates.

Oley’s conference has been developed in conjunction with the annual meeting of the American Society for Enteral and Parenteral Nutrition (A.S.P.E.N.). A.S.P.E.N.’s “Clinical Nutrition Week” runs from January 28-31 at the Phoenix Civic Plaza. We invite you to join us there too by volunteering at Oley’s booth in A.S.P.E.N.’s exhibit hall. Don’t miss this rare opportunity to be among hundreds of exhibitors showcasing their newest products. Volunteers are needed January 28, 29 and 30 to work one or more shifts at the Oley booth from 9:30 a.m. to 11:15 a.m., 12:15 p.m. to 1:45 p.m. and/or 3:00 p.m. to 4:15 p.m. each day. For more information or to volunteer, contact Kate Swensen at (800) 776-OLEY or email Swensek@mail.amc.edu.

Highlights from Indianapolis

The Oley Foundation had an excellent turnout at the regional conference in Indianapolis on September 9, 2006. Many thanks to our guest speakers Jane Balint, MD, Alan Buchman, MD, Jerry Mayer, and Nancy Mitchell, MD.

The afternoon was kicked off with a buffet lunch sponsored in part by Coram Healthcare, Nutrishare, Inc, and Option Care. A host of exhibitor’s kept our attendees busy during lunch, talking about their newest products and services. Afterwards, Oley members enjoyed one-on-one time with clinical nutrition professionals. We are very thankful to Jane Balint, MD, Alan Buchman, MD, Nancy Mitchell, MD, Reid Nishikawa, PharmD, and Sharon Kay Woods, MD for hosting those roundtable sessions!

After the Oley program was complete, many of our attendees helped at Oley’s exhibit booth at the Association for Vascular Access (AVA) conference. This gave our members the unique opportunity to experience the AVA exhibit hall, which was packed with over 100 vendors. We’d like to recognize members Bette Bond, Sheila and Olivia DeKold, Linda and Megan Gravenstein, Timothy Sentongo, Karen Smollen and all those who volunteered with Oley during the AVA meeting. Thank you to everyone who made the day run so smoothly!

Corporate Program Update

We are ever grateful for the generous support of our corporate partners. Please join us in thanking these recent donors to the Oley Foundation.

Novartis Nutrition — Silver Circle Partner

Headquartered in Minneapolis, Minnesota, Novartis Medical Nutrition is the second largest manufacturer of enteral formulas and delivery systems in the United States and an industry leader in oral supplements, tube feeding products and fortified foods used in the institutional and home settings. The company is focused on providing the highest quality nutritional products and services that maintain and improve human health and well-being.

Novartis Medical Nutrition values the relationship it has with the Oley Foundation, and encourages all of its Partnered Providers to become involved and get to know all HEN consumers whom our products touch every day.

Ross Products Division — Benefactor Level Partner

Abbott’s Ross Products Division is a longtime leader in the U.S. nutritional marketplace, and strives “to be the world-wide leader in providing superior nutritional products that advance the quality of life for people of all ages.” Ross Products manufactures and distributes medical nutritional products such as PediaSure®, and Jeivity®, and enteral feeding devices, such as the Embrace® ambulatory feeding pumps for patients who require nutritional support. PediaSure® Enteral Formula is designed to provide a source of Complete, Balanced Nutrition® for children ages 1-13 who may be undernourished due to illness or inability to eat. Jeivity® is an isotonic, fiber-fortified tube-feeding product, and the Embrace® ambulatory feeding pump is a small, lightweight enteral pump with optional travel accessories for mobile patients. These are only a few examples of the Ross Product family serving your family from infancy through advanced age.

Ross Products supports the Oley Foundation so that they may continue to enhance the lives of home nutrition support patients, their families, and caregivers.

Zevex, Inc. — Contributors

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 website at www.zevex.com/infinity. Zevex is a public company with shares traded on the NASDAQ under the symbol ZVXI.
Ben Hawkins, Equipment Exchange Expert Extrodinnaire

Ben Hawkins is the expert volunteer who handles the Equipment Exchange for the Oley Foundation. Ben lives in Cincinnati, Ohio and has been on HPN since 1980 when, as a high school student, he had a malrotation of the bowel. His own experience includes working with catheters, a port-a-cath and several different models of portable pumps.

Ben wanted to pass along some information about the Equipment Exchange that would help him do a better job for you. Ben lives in the central time zone and, because he is doing this out of his home, he would appreciate it if you would not call before 9:00 a.m. or after 9:00 p.m. CST. Also, he has an answering machine and encourages you to leave him a message, but wants you to know it takes eight rings before the answering machine kicks in.

Ben would like to emphasize how very important it is for you to call back and let him know whether or not you take the item(s) you inquire about. These items become inactive and are not available to anyone else unless he knows you have not taken them.

Last, but not least, Ben wants to thank everyone who calls for the great education he has gotten about enteral formulas and equipment. You are helping him become an expert in this area. And we’d like to thank Ben for doing such a great job in making this program a success!

Newly available items available free of charge include:

**Enteral Formula:**
- 9 cases Fibersource HN with Nutrashield, exp. 9/07
- 18 cans Isocal 1.5, exp. 6/07
- 14+ cases Isosource with Nutrashield, exp. 4/07
- 28 cans Jevity 1.5, exp. 4/07
- 2 cases Neocate powder, exp. 10/07
- 25 packs Novasource 2.0, exp. 4/07
- 7 cases Nutren 1.0, exp. 4/07
- 9 cases Nutren 1.5, exp. 8/07
- 3 cases Nutren Junior, exp. 1/07
- 12 cans Peptamen 1.5, exp. 4/07
- 6 cases Perative by Ross, exp 1/07

**Tubes/Bags:**
- 20 EasyFeed bags
- 13 Kangaroo 1000ml AFF pump sets, #773620
- 30+ Ross Enteral Nutrition sets, #55747
- 6 Ross Gravity feed bags
- 40 Zevex Enterlite Infinity bags, 1200ml (multiple donors)

MORE SUPPLIES are available! Visit www.oley.org, or contact our volunteer, Ben Hawkins (benhawkins@fuse.net; toll free 866-454-7351). This number reaches Ben’s home, so PLEASE, CALL BEFORE 9 P.M. EST! Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. We ask that those receiving goods offer to pay the shipping costs.
The Oley Foundation’s videodvd collection has grown again! Filming of the latest set of dvds — those covering the 2006 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. (We’d be delighted if you could cover the $3 shipping and handling charge per tape/disc.) 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.

**Shipping Information:**
Name:_______________________________________
Address:_____________________________________
City:__________________ State:_____ Zip:________
Daytime Phone:(_____)________-________________

Optional: Enclosed is a check for $_______________
(A donation of $3 per item borrowed will help cover Oley’s shipping charges.)

**Loan Agreement:**
I agree to return the following videodvd(s) to the Oley Foundation within one week of receipt.
Signature:________________________ Date:_______

**Mail Your Order To:**
The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208

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**Information About The Oley Foundation**
- Support for Life: The Oley Foundation ___VHS ___DVD
- Enteral - Tube Feeding
  - 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 only
  - Tube Feedings are Mealtimes, Too! ___VHS only
  - Tube Feeding: A Guide to Daily Care ___VHS only
  - Taking Tube Feedings to School ___VHS only
  - Journey from Tube Feedings to Oral Feedings ___VHS only
  - The “Get Permission” Approach to Mealtimes and Oral Motor Treatment ___VHS only
  - Tube Feeding Your Child at Home (Part 1: Adjusting to Tube Feeding, Part 2: How Tube Feeding Works) ___VHS ___DVD

**Miscellaneous**
- Choices In Nutrition: Understanding HPEN Therapy Options (Free with $5 shipping/handling charge) ___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

**2006 Oley Conference**
- Main Session 1: What Is Rational Management? Features best practises 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: Diseases 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: Multi-Disciplinary 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

2000 Oley Conference
- Plenary Day 1: Awards Ceremony, Catheter & Site Selection, Site Preservation, Catheter/Tube Infections __VHS only
- Plenary Day 2: Insurance Issues, Medicare Legislative Issues, Coming of Age (20s) on HPEN __VHS only
- Breakout: Interpreting Your Lab Values __VHS only
- Breakout: Liver Disease __VHS only
- Breakout: It's Your Line: You're the Boss __VHS only

Videos from the 1999 and earlier Oley Conferences are available, please call (800) 776-OLEY to request them.

Please Return Videos / Discs Promptly!
Liver Disease, from pg. 2

The metabolic pathways for breaking down Omega 3 fat (α-linolenic acid) to its essential products is impaired in infants, and this leads to a relative excess of omega 6 product. To correct this imbalance, we proposed to give infants the omega 3 products already broken down as they are found in fish oil.

Lipid Emulsions

Parenteral lipid emulsions in the United States are soy-based products which are rich in omega-6 fatty acids. Elsewhere in the world, synthesized lipids are available, that provide not only omega 6 but also medium chain triglycerides (similar to MCT oil used in enteral products, such as Pregestimil) and olive oils. Due to regulatory and manufacturing limitations, these products are not available to patients in the U.S. unless their physician petitions the Food and Drug Administration for permission to import them on a compassionate use basis.

There is only one pure fish oil lipid emulsion available for PN use, Omegaven®, and currently it is only approved in Europe, South America and Asia. The manufacturer, Fresenius Kabi, says it is not to be administered as the only lipid product, and when Omegaven is administered with Intralipid®, it is given at a dose of 0.2 mg/kg/day. Thus far it hasn’t been released for use in children and patients with liver disease.

Animal Experiments

We began our studies on liver injury based on a mouse model where animals were allowed to drink PN without lipids. These animals developed fatty livers and elevated liver enzymes. There are at least 2 risk factors for liver injury: a high glucose diet and essential fatty acid deficiency. This, however, would not explain why children develop elevated enzymes in the absence of EFA. We postulated that the route of Intralipid administration may contribute to the problem. We then administered the standard Intralipid emulsion orally, intravenously, and subcutaneously. We found that the group receiving the Intralipid intravenously had severe fatty infiltrates, while the mice receiving the lipid enterally had normal livers.

Based on these findings, we concluded that the PN fat may be a major contributor to PN liver injury. We then repeated the experiments described above, comparing Intralipid to Omegaven head to head. The differences in liver histology were dramatic. Both groups received the lipid solutions intravenously. The Intralipid group had fatty livers while the Omegaven group was normal.

Clinical Experience

It is quite a leap to go from mouse studies to humans. In most cases, it takes up to 10 years before a laboratory discovery is put into clinical practice. In our case, this leap occurred within months of our initial discovery when one of our 5-month-old patients developed severe PN liver injury that included bridging fibrosis. He was listed for a liver transplant. We were asked by our colleague to try our intravenous fish oil protocol on this patient since it worked so well on the mice. Originally, the goal was to help the child survive until organs for transplant became available. After discussing the nonstandard approach with the parents, treatment was started at 0.2 g/kg/day and increased over a 2 week period to a goal dose of 1 g/kg/day. Within 2 months of starting Omegaven the child’s liver function improved and his jaundice resolved. He was removed from the transplant list shortly thereafter. He is still TPN dependent and on Omegaven two years later, but his bilirubin remains low and he is free from jaundice. (See photo on page 1.)

As Omegaven or any similar product is not available in the United States, compassionate approval from our institutional review board (IRB) and from the FDA is required for each patient. We have treated 22 patients with PN liver injury with very good results. Our criteria for treatment include a direct bilirubin of greater than 2 and no other cause for the liver injury. The patient can have any other medical or surgical problem. The exclusion criteria include active bleeding or allergies to fish or eggs.

Theoretical risks of Omegaven alone include bleeding and EFA deficiency. Based on our previous experience of using Omegaven to treat EFA deficiency in a patient with soy allergy, we knew that if Omegaven is dosed at 1 g/kg/day (5 times the manufacturer’s recommended dose) there is sufficient arachidonic acid and linoleic acid that it can be safely used as monotherapy. Other lipid emulsions do not contain arachidonic acid, thus they require considerably more linoleic acid so that the body can produce it. There have been no complications due to hemorrhagic changes; to date, there have not been any active cases of bleeding in our patients. Furthermore, most of our patients undergo 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 who are unable to receive conventional lipid products such as those with a soy allergy or hypertriglyceridemia.

From our experience, we now rapidly advance the use of Omegaven starting at a dose of 0.5 mg/kg/day and increasing to 1 g/kg/day after 48 hours. Laboratory monitoring includes EFA profiles, hepatic enzymes, lipid panels, C-reactive protein, electrolyte, mineral, albumin/prealbumin prior to the initiation of therapy, and weekly until the bilirubin level normalizes. We also check complete blood counts, coagulation parameters, lipid panels and vitamin status. We then test every 2 weeks, and eventually, monthly. Patients may go home on this treatment and be followed as outpatients.

There have been no complications directly related to this new treatment. Our central line infection rate is lower once on the Omegaven, but may be due to improvement in liver function and close attention to indirect markers of sepsis such as C-reactive protein and platelet counts.

Since this continues to be an investigational therapy, costs of therapy must be born by the sponsoring institution and cannot be passed along to the patient or their insurer. At Children’s Hospital, Boston, the surgeons have funded the costs for their patients. At other centers, unrestricted grants have been obtained through donations.

Future Research

Despite these dramatic findings, the research does not end here. Our next step is to determine if using intravenous fish oil at the start of PN nutrition may prevent the development of this often fatal complication. The March of Dimes recently awarded us a grant to investigate this, comparing the use of Omegaven to the currently available commercial products. This 3-year randomized controlled clinical trial will be starting within the next several months and will be conducted at Children’s Hospital, Boston.
and don’t clank the dishes, the host and hostess forget that I’m working in their kitchen and avoiding the dish washing machine. (They like to show off their machine when the relatives come for a visit.)

Entertaining Myself and Guests

At holiday gatherings, I often play background music on the piano, usually Christmas carols. It’s particularly curious when the grandfather of the group, 82-year-old Chuck, relates later, by title, which songs I played. Amazing memory! I get the impression he prefers my music to the conversation right next to him at the table. At any rate, the hostess always remarks how nice it is to hear her piano played, even though it doesn’t get played much anymore. In fact, she found out that the piano needed to be tuned, so she hired me to tune it. Not a bad way to make some money off the rich relatives!

In homes where there’s no piano, I can play my flute in the downstairs family room near the stairway leading up to the eating area. Having been a college professor and professional flute player for thirty years, playing the flute is one of the easier things that I do. When I’m downstairs and out of sight, the audience doesn’t notice that I need to take a sip of water every fifteen minutes or so to keep my mouth wet. Radiation killed my saliva glands, so playing the flute requires some planning. Blow, blow, wet; blow, blow, wet. The moist air passing helps keep my mouth wet. Radiation killed my saliva glands, so playing the flute requires some planning. Blow, blow, wet; blow, blow, wet. The moist air passing helps keep my mouth wet. Radiation killed my saliva glands, so playing the flute requires some planning. Blow, blow, wet; blow, blow, wet. The moist air passing helps keep my mouth wet. Radiation killed my saliva glands, so playing the flute requires some planning. Blow, blow, wet; blow, blow, wet. The moist air passing helps keep my mouth wet. Radiation killed my saliva glands, so playing the flute requires some planning. Blow, blow, wet; blow, blow, wet. The moist air passing helps keep my mouth wet.

Recently, one of the more adventurous male members of the family pressured me to tube feed by syringe at the table with the other twenty-two people in attendance. However, he’s never witnessed the times when something goes wrong, the syringe pops out of the G-tube, the food blows out onto Grandma’s white ceiling, white walls, and oyster-white carpet. No thanks, I prefer to make my booze in private: in the bathroom downstairs where I can easily wipe off the four-foot mirror, the Formica countertop and the imitation Florentine floor tiles.

Coping with social situations when you’re fed by tube becomes a matter of making choices. I choose not to feed in front of any audience, but have found pleasure in serving and entertaining my friends and family.

Tube Hell, from pg. 8

wouldn’t cover it. I finally persuaded my Case Manager from the insurance company to pay for two: one for the present and a spare for when the first one fails.

In the meantime I ran into two major complications. First, over Thanksgiving I started choking on what I thought was a green bean, but turned out to be the interior end of the J-Tube. Though the port had fallen off, the tube was still there. A trip to the hospital removed all the J portions of the tube, but left the G portions intact to hold open the stoma. Second, since I was no longer feeding enterally, I had a PICC line inserted. This became infected with Staph. The Hickman that replaced it became infected with Candida, and I developed C.Difficile from the antibiotics.

Finally, at the end of February, I was well enough to have the coveted tube placed (Kimberly-Clark MIC Jejunal feeding tube). It has worked perfectly ever since. After missing another 10 weeks of work, everything is copasetic with my tube, though I am fully prepared for it to wear out.

I strongly urge everyone, both patients and support people, to educate yourselves on what’s out there and find what works for you. Learn the names of the models and makers. Learn what jargon like “french” means: it’s the diameter of the tube. You have the right to approve equipment that is being installed in your body. If your tube isn’t working properly, or doesn’t feel right, alert your doctor and don’t give up until the issue is resolved. Lastly, if your doctor doesn’t like you asking questions, he’s the wrong choice.

HPN Centers of Experience

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

Northwestern Memorial Hospital

Dr. Robert Craig established one of the first home parenteral nutrition (HPN) programs at Northwestern Memorial Hospital (NMH) in 1972, and continues to direct the nutrition support service. Dr. Alan Buchman, an adult gastroenterologist specialized in intestinal failure and inflammatory bowel disease, directs NMH’s Intestinal Rehabilitation Program. He works in close collaboration with Dr. Valeria Cohran, a pediatric gastroenterologist with special interest in Intestinal Failure and Transplantation, of Children’s Memorial Hospital (CMH). Northwestern also has an Intestinal Transplant program, which is directed by Dr. Jonathan Fryer, and achieved Medicare Certification in 2006. Together the NMH and CMH programs follow more than 200 intestinal failure patients.

Northwestern’s Intestinal Failure management optimizes existing clinical strategies, while developing new approaches through clinical and basic science research. Their multidisciplinary, integrated approach combines medical (including hormonal therapy), surgical (including gut-lengthening procedures) and nutritional strategies to reduce or eliminate PN dependency.

Northwestern has also strived to better define the role and timing of intestinal transplantation in intestinal failure management. High risk patients who remain PN dependent are monitored closely so that intestinal transplantation can be performed before the situation becomes irretrievable due to severe parenteral nutrition associated liver disease or other life-threatening PN-associated complications.

Northwestern’s clinicians are international leaders in the refinement of techniques for dietary, medical, surgical management of patients with intestinal failure, have lectured worldwide and have published their discoveries and recommendations in the leading scientific journals. Visit www.gutfailure.com and www.ibdcenter.org for more information.
Individual Donors Make A Difference!

The following list represents everyone who generously contributed towards Oley’s efforts between July 27th and October 4th, 2006. 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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The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. For their continued interest and strong commitment we remain grateful.

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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 call Joan Bishop or Roslyn Dahl at 800-776-OLEY.
Toll Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the US 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 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 on our web page @ www.oley.org. Comments? Call (800) 776-OLEY.

<table>
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<th>Toll Free Numbers</th>
<th>November '06</th>
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<th>January '07</th>
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<tr>
<td>Lou Pacilio</td>
<td>Leeds, MA</td>
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<td></td>
<td>(888) 610-3008</td>
<td>EST</td>
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<tr>
<td>Portia Hutton</td>
<td>Ft. Myers, FL</td>
<td>(888) 650-3290</td>
<td>EST</td>
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<td></td>
<td></td>
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<tr>
<td>Jim Cowan</td>
<td>Cleveland Heights, OH</td>
<td>(888) 610-3008</td>
<td>EST</td>
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<tr>
<td>Ester Adler</td>
<td>Baltimore, MD</td>
<td>(888) 650-3290</td>
<td>EST</td>
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<tr>
<td>Laura Keser</td>
<td>Mesa, AZ</td>
<td>(888) 610-3008</td>
<td>MST</td>
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<tr>
<td>Matthew Van Brun</td>
<td>Apple Valley, CA</td>
<td>(888) 650-3290</td>
<td>PST</td>
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Diagnosed with sarcoidosis Lou developed a swallowing disorder. He was on TPN briefly, then weaned to J-tube feeding 7-1/2 years ago. He works part-time as a radiologist. He is experienced with changing feeding tubes, caring for ostomy sites and coping with not being able to swallow his own saliva in public.

Portia is 75 years old and has short gut syndrome due to a blood clot in her superior mesenteric artery. She has been HPN dependent since March 1999. She enjoys working during tax season as a CPA. She has been married to her husband Wally for 53 years; they have two grown sons.

A long time consumer, Jim has been on HPN since 1977 due to Crohn’s disease. He supports both the Oley Foundation and the Crohn’s and Colitis Foundation. Jim has experience with many of the issues surrounding home PN and can be a wonderful resource to new and long time consumers.

Esther Ann Adler is 40 y.o., married, and has 4 kids ages 14 to 7. She was born with a defect in the muscles of her digestive system. She has had many surgeries. She has an ileostomy and a g-tube for enteral feeding and drainage. She also has experience with many types of catheters. She lives an active life and has tried alternative therapies like, message, yoga and a hyperbaric chamber.

Laura has been on HPN since 1991 due to short bowel syndrome. She has experience with multiple catheters, dealing with infections and traveling. She has also returned to college at Oklahoma State and graduated in the spring 2006. She looks forward to sharing her experiences with you.

Matt has been on TPN for 20+ years due to Crohn’s disease and short bowel syndrome – so he is experienced with the up’s and down’s of TPN. He likes riding his bike and spending time with friends. He is happy to talk about anything associated with TPN or otherwise.

Searches Made Easy

Looking for information on a specific topic? Your task is now a whole lot easier with the new search function on Oley’s website. One click and you’ll be linked to every part of the site that mentions your topic.

Check it out today!