Register Now for the 2001 Oley Conference

Join us at the 16th Annual Oley Consumer/Clinician Conference this summer for a fun and informative gathering. Entitled “Pathways to Positives,” the conference will be held at the Hilton Milwaukee City Center, June 21 to 23, 2001, in Milwaukee, WI. The registration packet, mailed three weeks prior to this newsletter, provides details about the program and how to register.

A few conference updates and highlights follow:

1. A new addition to Friday’s Breakout Session lineup: “Legalese for Lifeliners” will provide an overview of legal documents such as power of attorney, a living will and health care directives, as well as estate planning documents. Thanks to Lenore Heaphey (former Oley Executive Director) for volunteering!

2. A limited number of $250 Travel Grants are available on a “first come, first serve” basis, thanks to corporate support. Call Oley today, if you are interested.

3. We’re also offering one $500 “First-Time Conference Goer” Scholarship. Send a paragraph to Oley by May 9th describing how you would benefit from attending the conference. Allow one week for the committee to make a determination and notify the recipient. This should allow plenty of time for coordinating travel plans. Thank you to the generous consumer who underwrote this special opportunity.

For more details or to register online, visit our website at http://www.wizvax.net/oleyfdn/confer.html. You can also call us (800) 776-OLEY.
Access, from pg. 1

Femoral vein (in the groin) and advance a small catheter to the tip of the tunneled line, snare it with a lasso-device and pull it towards the desired location (see photos below).

Occluded Catheters

Catheters that have become occluded can be treated by injecting a clot-dissolving agent, such as tissue plasminogen activator (t-PA), or can be cleared by mechanical means, such as with a small brush. When a fibrin sheath forms around the tip of the catheter it can adhere to the wall of the superior vena cava, and make it difficult for the consumer to aspirate blood or infusion through the catheter. Traditionally, these fibrin sheaths have been addressed by gaining access from the femoral vein, and stripping the fibrin sheath off with a snare.

We have recently developed a less invasive method to restore patency, which involves placing an “internal lasso” through the hub of the tunneled catheter that breaks the fibrin sheath apart when it exits the catheter. Provided they are not infected, tunneled catheters can also be exchanged for new catheters using a guidewire technique.

Narrowed Blood Vessels

Occasionally, catheters induce intimal hyperplasia at their tips: a build-up of tissue arising from the vessel wall which can lead to some narrowing. Consumers who have had repeat central access, or are on dialysis, are more likely to develop such central stenoses. These stenoses can progress to the point where they occlude the vessels, preventing access, and can also cause swelling of the upper extremities, such as in the neck or face.

Stenoses can be treated by balloon angioplasty. Occasionally it is necessary to place a metallic meshwork (a “stent”) to keep the area of dilated stenosis open. If a clot has developed in the narrowed area, the interventional radiologist can treat it by infusing a clot-dissolving agent. When stenosis or thrombosis persists over an extended time, the occlusion can become very difficult to treat. Commonly, however, we are still able to cross blockages with catheters and guidewires and then proceed with clot-dissolving agents, angioplasty and/or stenting. Even some chronic occlusions may clear up with the infusion of clot-dissolving agents.

An additional “specialty of the house” at the Beth Israel Deaconess Medical Center is sharp recanalization of chronic vein occlusions. In these cases, a special needle system is used to create a new channel through very firm blockages. This is performed when all other traditional means with catheters and guidewires fail in restoring vascular patency. With an assembly of devices invented for this purpose several years ago, we perform the following procedure: The area of occlusion is approached with catheters coming from both ends (typically one upper extremity and one lower extremity approach). After ensuring that both ends are aligned in a straight passageway, a 21g needle is advanced through a protective catheter and very carefully probed under imaged guidance until it enters the adjacent patent vessel. From there on, standard catheter guidewire techniques can be used, and stenting is typically required. This method is particularly beneficial for creating new venous access, when practically all access would be lost otherwise.

When angioplasty or stenting is performed, it is not uncommon for a touch-up to be necessary within one year. In response to these procedures, the vessels may develop some exuberant formation of intimal hyperplasia, which itself can be treated with angioplasty and possibly some additional stenting.

The great advantage of the interventional approach is the availability of multiple devices and experience that can draw from applications in other regions of the body. So, if there is a special problem arising that needs fixing, experienced interventionalists typically can “invent a solution while you wait.”

The slide on left shows a snare that has been brought up from the groin vein and encircles the catheter just where it rides up into the internal jugular vein. After pulling the catheter down it can be seen (on right) to be well positioned again with its tip in the superior vena cava.
Tube Talk

Thanks to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@mail.amc.edu.

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

Tip for Parents

If you have no insurance for your school age child, you may be able to get your school to pay for any EN formula and/or TPN your child infuses during school hours through the school lunch program. I stumbled onto this fact when we had a two week lapse in insurance coverage for my daughter Stacy. We applied for the school lunch program, paid our portion of the "lunch" bill ($1.40/day), and were able to get the school to pay the rest of the bill for the nutrition she infused at school. Needless to say, it was well worth the effort.

— Karen Nelson
Nel86@aol.com
(919) 499-2623

New Consumer Seeks Consumers Experienced with Drainage Tube

In October of 2000, I had all but a couple inches of my small intestine removed. I now have a duodenal drainage tube that drains the fluid from my stomach, pancreas and liver. (I can only take in fluids orally, and rely on TPN.) I would love to find someone with a similar type of drainage tube that has more experience living with it.

— Jane Christy
janechristy@hotmail.com
(717) 755-9510

Advertisements not available
Pending Changes in Adult Parenteral Multivitamins

By Todd Canada, PharmD, BCNSP

The importance of parenteral multivitamins for consumers who are unable to adequately absorb oral multivitamins has been emphasized in the last 15 years by the multiple national shortages of parenteral adult and pediatric multivitamins. Several cases of refractory lactic acidosis due to thiamin deficiency occurred in home parenteral nutrition (HPN) consumers and resulted in significant morbidity and mortality. Now that the latest shortage of both forms of parenteral multivitamins has been resolved, the US Food and Drug Administration (FDA) has notified manufacturers of the adult products to reformulate to “new” FDA specifications.

Why Change Now?

Notably, the new specifications (see Table next page) are not from recently derived data, but rather from a public workshop that was held in August 1985 and sponsored by the FDA’s Division of Metabolic and Endocrine Drug Products and the American Medical Association’s Division of Personal and Public Health Policy. Evidently, the clinical testing of the 1975 AMA multivitamin formulation prompted the new recommendations to increase the dosage of vitamins B1, B6, C, and folic acid and to add vitamin K to the available adult products. It is unclear why it has taken 15 years for these recommendations to be implemented, and why the FDA is implementing them without reviewing and incorporating research conducted since the 1985 meeting. Astra-Zeneca and Baxter have responded to the new FDA changes and do not expect to have updated products on the market for another 18 months unofficially.

Clinical Considerations

Vitamin K

Many health care practitioners have expressed concerns over the addition of vitamin K to the new adult multivitamin formulation. These concerns are related to the long-term complications associated with vascular access in HPN consumers. HPN consumers often use oral anticoagulants, such as warfarin (brand name Coumadin), to maintain catheter patency. Since low doses (0.5-2.0 mg) of vitamin K can fully reverse the anticoagulant effects of warfarin, the dosage increase (from 0 to 0.15 mg) in the new multivitamin formulation has many clinicians worried that loss of adequate anticoagulation may result in consumer morbidity and further malnutrition, possibly, after loss of venous access. It is often difficult to provide oral anticoagulation to consumers with significant gastrointestinal resections or malabsorptive syndromes, including short bowel syndrome, because of their erratic absorption of warfarin.

Consumers receiving home parenteral nutrition who are not on anticoagulants, will likely find it more convenient having vitamin K added to the multivitamins, as they will no longer be required to add it to their solutions. Theoretically, they may also benefit from the addition of Vitamin K since the vitamin K-dependent protein, osteocalcin, is one of the most abundant noncollagenous proteins in bone. Thus adding Vitamin K could impede or retard the development of metabolic bone disease in long-term HPN consumers.

Vitamin C

The higher dose of vitamin C presents risks since it may lead to the development of hyperoxaluria (increased oxalate in the urine). In conditions such as short bowel syndrome with an intact/partial colon, there is increased absorption of oxalate from the oral diet (the
Parenteral Vitamin Recommendations for Adults (Age 11+ yrs)

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<th>Proposed New Formulation**</th>
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<td><strong>Fat-soluble Vitamins</strong></td>
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<td>3300 IU</td>
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<td>Vitamin D</td>
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<tr>
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<tr>
<td>Folic acid</td>
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* Proposed by the AMA in 1975
** Proposed by the US FDA's Division of Metabolic and Endocrine Drug Products and the AMA's Division of Personal and Public Health Policy in 1985

Looking for Propulsid®?

Since Propulsid® (Cisapride) was taken off the market last summer, we've received calls from some families who are wondering how they can get this drug for their children with GER or a motility disorder. The only way doctors can obtain cisapride now is through a limited-access program developed by the manufacturer, Janssen Pharmaceutica and the U.S. Food and Drug Administration. This program makes cisapride available only for appropriate patients who suffer from disorders such as gastroparesis, pseudo-obstruction, and severe chronic constipation or severe reflux disease that is not treatable by any other means. Children with other serious gastrointestinal diseases may also be eligible for the program. Patients/parents who are interested in the program should speak to their physician, who would need to enroll in the program. If the physician decides not to participate in the program, but believes the patient is an appropriate candidate, Janssen will provide the physician with the names of other doctors who are enrolled and have agreed to work with new patients. For more information, physicians can call (877) 795-4247.

Resource for Caregivers

Familycare America offers a range of services and products for caregivers, including an e-mail newsletter, support groups and information on caregiving resources. Some of their services are free, for others they charge a fee.

They are open to all kinds of caregivers, and thus the information may be generic or even oriented toward caregiving for an elderly relative; however, they do offer a one-stop-shop for all kinds of basic information caregivers will be interested in on such topics as housing, transportation and legal issues.

One of the organization's new services is to produce a customized “Caregiving Action File.” Interested parties fill out a brief questionnaire on Familycare’s web site, to create a secure profile of their situation. This generates a file of how-to articles, planning forms and resource listings tailored to the caregiver's individual needs. The caregiver can then access these articles, at their leisure, on the web. To find out more information, visit their website at http://www.familycareamerica.com.
Lifeline Mailbox: Resurrecting a Old Pump Power Pack

Dear Lifeline Readers:

If you own a CADD Power Pack, re-order # 21-2365 which rechargeable battery has died (will not hold a charge), you are probably aware that batteries for this power pack are no longer available and the new CADD battery will not work in the 21-2365 power pack. Not only is it necessary to purchase a new battery but also a new power pack at a cost of $1600. [Note: all prices are in Canadian dollars. To convert to US $ subtract 1/3, i.e. $30. = US $20.] Rapid obsolescence is the price we pay for modern technology.

However, do not despair as there is an alternative to purchasing a new power pack. Not only can these old CADD batteries be restored but they can also be reproduced for a reasonable charge.

Due to a similar experience with a lap top computer battery, which would have cost almost $200 to replace, I learned of a local battery manufacturer who could, in most cases, revive dead rechargeable batteries. This company’s process realigns the electrons to restore as much as 80 to 90 percent of the battery’s original capacity. (For example, if the battery’s original full charge was 10 hours it will now be eight to nine hours). The cost was $30. Before processing, the battery is evaluated (at no cost) to determine if it can be restored.

In the case of my pump, three CADD batteries, were evaluated. Two were determined to be restorable but one was totally useless. The best of the two restorable batteries was processed and returned to 85 percent capacity. Believe it or not, I have found this battery actually lasts longer per charge than when it was new.

This company also makes custom batteries and can reproduce the CADD battery for approximately $90 — considerably less than the original battery cost. The only problem is matching the connector wire, but this can be overcome by taking the connector off an old battery. Because of this connector issue, I was advised never to throw out an old battery, even an “unrevivable” one. At this particular company, if I chose to have a new battery made within a month of having my old battery revived, the $30 charge would be credited towards the new battery cost.

I would expect that most cities have a company which can make custom batteries and would advise you to consult them before you replace your 21-2365 power pack and indeed before you purchase any rechargeable battery (pumps, lap tops, etc.). You may find that they can manufacture a new battery at a substantially lower cost than the equipment’s supplier.

If you want further information or cannot find a custom battery manufacturer in your area, please feel free to contact me. The company I used, Alexander Battery, in Ottawa, Canada, can be contacted at (613) 230-7177 or through www.alexanderbattery.com.

— Donald Freeman
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Nepean, Ontario, Canada
donaldfreeman@aol.com
(613) 825-4341

[Editor’s Note: As with all companies, products and services discussed in the Lifeline Letter, the Oley Foundation cannot guarantee or endorse the company, product and services described in the article above.]
Cheer Up a Friend!
Do you know someone in the homePEN circle who is overwhelmed, under the weather or simply tired of the weather and in need of cheering up? Let us know and:

- we will have a card mailed or sent electronically (via e-mail)
- and/or
- coordinate a personal call

Thank you to Robin Lang for spearheading this project in an effort to keep Oley connected to everyone in good times — and in sad. To initiate the greeting process call Cathy Harrington at (800) 776-OLEY or e-mail: HarrinC@mail.amc.edu.

Auction Items Needed
Oley needs your help securing donations for the annual silent auction, to be held Thursday, June 21, 2001 at the Oley Conference in Milwaukee. The event is fun for everyone involved and auction, to be held Thursday, June 21, 2001 at the Oley Conference in Milwaukee. The event is fun for everyone involved and

- stained glass, gift baskets etc. Thank you for your support!

- Homemade crafts and art work are also welcome: such as quilts, letters and tips to help you solicit items from your local merchants. Contact Cathy Harrington at (800) 776-OLEY or send an E-mail to: HarrinC@mail.amc.edu. She can supply you with a

- list of needed items.

- for Special Event:

- 50 Blunt Plastic Cannulas, Reorder #303345
- 50 Interlink lever locks, Reorder # 303370
- 10 H olister draining tube attachment devices
- 10 packages H olister premium powder for Peristomal Skin Protection
- misc. T PN and EN supplies

WANTED: Neocate Formula, EN pump

For more information, call (800) 776-OLEY/(518) 262-5079; or send an E-mail to: D ahIlR@mail.amc.edu. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition.

In Memory of Irma Gail Gordon

Stuart Gordon

Irma Gail Gordon, an active member of the Oley Foundation, passed away on February 26, 2001. Irma Gail had been an HPN consumer for 15 years due to Crohn’s disease. She was a long time Oley Regional Coordinator and helped with last year’s conference in Boston.

Irma Gail was very knowledgeable about Crohn’s, her allergies and homePEN, and would talk to anyone who needed information about them. Up to the end, she held on to the hope that research for her disease would help her and others. She engaged in countless hours of research herself, looking for that little something that might make a difference. Over the years, several of her findings turned into suggestions and articles published in the LifelineLetter. Irma Gail is survived by her mother, father and two brothers. She will be greatly missed.

Scholarships Offered
Nutrishare is offering two $500 scholarships for TPN consumers: one towards the Spring 2001 semester and one for the Fall 2001 semester. Interested TPN consumers should write a letter describing their studies and what they plan to use their education for. (A few paragraphs is fine.) A committee set up by Oley will review the applications and choose the winners based on potential and need. The scholarship money will be distributed at the end of the semester when the winner submits a copy of his/her grades to the Oley Foundation. Applications should be typed or word processed, and postmarked by May 1, 2001 for the Spring scholarship, and October 30, 2001 for the Fall scholarship. Applications should include the candidate’s name, photo, number of years on TPN, and daytime phone number. Send applications to the Oley Foundation (address in box on page 2). Former applicants are welcome to reapply.

Is Your Clinician Certified?

Board of NBNSC

Were you aware that not all nutrition support professionals are certified? The National Board of Nutrition Support Certification (NBNSC) was formed in 1985 as an offshoot of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), A.S.P.E.N. has been the preeminent organization devoted to the study and safe administration of nutrition support in the hospital and at home for 25 years. Now, NBNSC has certified more than 1400 dietitians, 700 nurses, and 250 physicians. Professionals who have passed the NBNSC examinations have met criteria for the safe provision of nutrition support.

Ask your physician, dietitian, or nurse whether they are certified, or have considered becoming certified, to demonstrate their knowledge in the field. And ask your home infusion company whether the pharmacist preparing your parenteral nutrition is nutrition support certified. There is an examination for them, too, through a different organization that works closely with NBNSC. Information about A.S.P.E.N. and the NBNSC can be found at www.nutritioncare.org or by calling A.S.P.E.N. at (800) 727-4567/ (301) 587-6315. NBNSC maintains a list of certified physicians, nurses, and dietitians at http://www.nutritioncertify.org.
Individual Contributors: Your Support Makes Oley Stronger!

The following generous donations were received between February 16, 2000 and March 16, 2001. Nearly listed donors (those who gave January 19, 2001 or yet have supported the Foundation in other ways, (i.e. volunteering their time and talents).

**AMBASSADORS ($2,000+)**
- John & Carol Broviac, MD
- John Balint, MD
- Felice Austin
- Robert & Laura Andolina
- Steve & Edithe Swensen*
- John Steiger
- Patricia Searle, in memory of Paul Koessler Foundation
- Thomas Kent
- Darlene Kelly, MD*
- David & Jan Holder
- Michael O’Donnell
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- Jerry Gronske
- Gary Gronske
- Roger Eiler
- Frank Dewey
- James Dawson
- John Carton
- Joe Boures
- Edward Bell
- **DAUNCEY CUP ($500-$999)**
- William Hoyt
- Alfred Haas
- Bob Biener
- Mary Mek</p>
later) have their acknowledgments listed. Thank you for your support...it really does make a difference! We also wish to thank all those who are not listed below.

Gary Strite
Kenneth Storch
James & Sarah Tennessen, in honor of Blake’s transplant and return home 2 yrs ago
UPC Health Network
M ary Jo & Jeff Walch
Eleanor & Mr att Werkheiser
Robert Winters
Steven W olfert
Eugene W orek
Carl Zecher

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FRIENDS ($500-$999)
B axa Corporation
K endall
P harmacy Resources
Reach Out and Talk to a HomePEN Consumer — Toll Free!

To make speaking with fellow lifeliners more affordable, Oley circulates two toll-free numbers to experienced HomePEN consumers on a monthly basis. We strongly encourage you to take advantage of this program which enhances consumer-to-consumer networking and provides Regional Coordinators with a better grasp of their region's needs.

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

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 15 minutes. The exception is **FRIDAYS, WHEN ALL CALLS ARE FREE** — including calls to the Oley office!

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

<table>
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<tr>
<th>Month</th>
<th>Name</th>
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<tr>
<td>MAY '01</td>
<td>Robin Lang</td>
<td>York, ME</td>
<td>(888) 610-3008 EST</td>
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<td>JUNE '01</td>
<td>Elizabeth Tucker</td>
<td>Bloomington, MN</td>
<td>(888) 650-3290 CST</td>
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<td>Hemet, CA</td>
<td>(888) 610-3008 PST</td>
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<td>June Bodden</td>
<td>Clearwater, FL</td>
<td>(888) 650-3290 EST</td>
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<td>JULY '01</td>
<td>Carolee Jones</td>
<td>Muncie, IN</td>
<td>(888) 610-3008 EST</td>
</tr>
<tr>
<td></td>
<td>Bonnie Sjoberg</td>
<td>Milaca, MN</td>
<td>(888) 650-3290 CST</td>
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</table>

A TPN consumer for 21 years, Robin lives with her son and two dogs on 10 acres in Maine. She has traveled a lot (twice abroad) and worked prior to her recent application for Social Security disability. She loves to help others and make new friends. Robin keeps busy as a writer, Regional Coordinator and club volunteer.

Liz has had Crohn's disease since 1965, and been on HPN since 1985. She can discuss her experience with Remicade, a drug that battles Crohn's disease. Liz is very interested in health care and health insurance advocacy. She also has experience with a variety of stress management techniques.

Patty & Darrell live in So. California and have five children, one of whom has been TPN dependent since 1996. They enjoy speaking to others about managing TPN issues and keeping a positive perspective in an active family. They have gone to Oley Conferences and would love to share their experiences!

June has had Crohn's disease since age 15, an ileostomy since age 21, and TPN since age 35 (20+ years). A Regional Coordinator and an active support group member, she believes networking with others is important. A strong faith, volunteer work and help from family and friends keep June upbeat.

Carolee is a retired college professor dependent on TPN since 1994 due to radiation enteritis (from ovarian cancer treatment). She and her husband Ron are a "dynamic duo" who embrace a positive, productive lifestyle. Carolee keeps busy writing, editing, consulting and enjoying the outdoors.

Diagnosed with pseudo-obstruction, Bonnie has been on EN for 1-1/2 years, and before that, TPN for 4+ years. She has had an ileostomy for 15 years. Bonnie can share her experience with Mayo's pain rehabilitation program and weaning from narcotic medication. She has traveled with HPEN and attended Oley conferences.