Getting Grounded (In a Good Sense)

Jameson Atkinson

I've had short bowel syndrome for almost eight years now. It started with a malrotation when I was a month from finishing up my junior year of high school. I missed the end of that school year and the first bit of the next. Although it was a very tough time, in a way I'm glad it happened. It changed my whole outlook, and in a sense gave me a spark to get out and do more with my life.

When I was well enough, I went back to school as a senior. I started with half days. I went one day in the morning and the next day in the afternoon until I had enough strength and stamina to go a full day again. It was a challenge at first, but I managed, then I graduated. Next up was a bigger hurdle: college.

College Decisions

I had a lot to think about when it came to college. Most people do have a lot to worry about when getting ready for college, but for me it was different. I had a complicated medical therapy to manage, and it was still pretty new to me. I had only had short bowel syndrome and been on HPN for a year. But I was ready for college. Or so I thought.

I decided on a school in St. Petersburg, Florida—five hundred miles away from home. Before I finalized my plans to go to school there though, I traveled down to St. Petersburg to tour the campus. One of the first things my parents and I checked out was the health center. I had an implanted device (commonly

Venous Thrombosis Associated with VADs

Vijaya M. Dasari, MD, Abdullah Shatnawei, MD, and Ezra Steiger, MD

One of the most common non-infectious complications associated with the use of central venous catheters—more properly known as central vascular access devices (VADs), but often just called “lines”—is catheter occlusion. A line is occluded when it is difficult to infuse into the line or withdraw blood through it. Occlusion can be due to mechanical obstructions, calcium phosphate or drug precipitates, and lipid emulsions. However, most VAD occlusions are caused by a blood clot.

Catheter-related thrombotic occlusions are distinguished as either intraluminal, with clots occurring inside the lumen of the catheter, or extraluminal, with clots outside of the catheter and within the blood vessel. A clot inside the catheter can happen when blood backs up into the catheter, or when blood is drawn and not followed by an adequate flush.

Reserve Your Room Now!

Join us at the Trade Winds Island Resort in St. Petersburg, Florida, for Oley's Annual Consumer/Clinician Conference, June 29–July 2. You'll gather a wealth of information—from faculty, exhibitors, and other homePEN consumers—and you'll love the relaxed atmosphere of this Gulf Coast resort. You'll have a chance to enjoy the white sandy beach, curl up in a cabana to "wind down," and/or enjoy the many restaurants, swimming pools, walking paths and activities that the resort alone offers.

The program and activities we have planned are geared to help you explore ways to keep

Thrombosis, cont. pg. 4
The Dorm Experience

While we were there, my parents and I also toured the dorm rooms. Ugh, dorm rooms. I don’t think there are a whole lot of great things you can say about dorm rooms: they’re small, dirty, and you have to share a room the size of a broom closet with a stranger.

It was suggested that I might be better off in a handicap suite. These suites were equipped with their own private bathroom that included a tub/shower. Also, I would have the room to myself, so I could arrange all my medical supplies however I wanted to. As nice as that sounded to my parents, I didn’t want any part of it.

I was going to college. I wanted the college experience. I just didn’t feel like a medical room was what I needed. I was only hooked up to my HPN at night, so I reasoned I didn’t need all that extra room. I decided on a regular room.

One thing I did do was to call my future roommate. I didn’t think he would appreciate it if I showed up on move-in day and said, “Hey, I’m Jameson. Make room for all my meds!” So I called him about a month before we moved in to give him a heads up.

I explained to him my condition. I told him that yes, there would be medical supplies in the room; yes, he would have to see me hook myself up at night; and yes, it may be strange at first. Lucky for me, he didn’t mind. He was very open-minded about it.

After we moved in, my roommate was curious about everything I had to do, and I was more than happy to explain all of it to him. As for the other people I met that year, it was pretty much the same. I went about my business as usual. I didn’t want any part of it. Medical supplies however were a different story.

The Oley Board of Trustees:

Rick Davis, President; Michael Medwar, Secretary; Jane Balint, MD; Ann DeBarbarie; Jane Golden; Kibore Iyer, MBBS, FRCS, FACS; Jim Lacy, RN, BSN, CRNI; Laura Materese, PhD, RD, LDN, FADA, CNSD; Mary Patnode; Gail Santisvero, MS, ANP; Doug Snider, MD, FAGC, CNSP; Rex Sproothas, RPh, CDE, BCNSP; Cheryl Thompson, PhD, RD, CNSD; Marion Winder, PhD, RD, CNSC

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

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

---

**Guidelines for EN Established**

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) has released “The Enteral Nutrition Practice Recommendations.” The document contains valuable evidence-based recommendations that you may want to share with your physician.

Two years ago an A.S.P.E.N. task force was formed to examine literature related to the ordering, preparation, delivery, and monitoring of enteral nutrition (EN), and to gather expert opinion based on current knowledge and best practices. These recommendations are the result.

**Why Are They Important?**

A.S.P.E.N. states: “The complexities of modern healthcare, compounded with decreased staff both at the bedside and at the nutrition support level, have led to the potential for an increase in risks related to EN. Complications can occur throughout the process of ordering, administering, and monitoring nutrition, compromising a patient’s safety. Serious harm—and even death—can result from improper EN.”

Adverse events include misconnections, feeding tube misplacement/displacements, metabolic abnormalities, tube complications, aspiration, formula contamination, and harmful drug/nutrient interactions. “In order for complications in EN to decrease, areas for possible human error, as well as administrative and organizational conditions which can lead to mistakes, have to be clearly identified,” said Kelly Tappenden, A.S.P.E.N. president.

**Available to Consumers**

“Enteral Nutrition Practice Recommendations” can be downloaded as a PDF or purchased (for $19.95) at www.nutritioncare.org/safety.

---

**Equipment/Supply Exchange**

Turn to Oley’s Equipment/Supply Exchange to look for something you need or donate something you don’t—from formula to tubing to feeding bags and more.

A description of how the program works and a complete list of available items is posted on the Oley Web site at www.oley.org/equipexchange.html. If you don’t have access to the Internet, Cathy Harrington at the Oley office can assist you. You can reach Cathy 9 a.m. to 4 p.m. EST at (800) 776-OLEY.
Medical Update

Thrombosis, from pg. 1

A clot within the vein, but outside the catheter, is called a mural or vein wall thrombosis. If left untreated, such a clot can cause complete occlusion of the blood vessel. It is this type of occlusion, venous thrombosis, that we will focus on here.

Incidence of Venous Thrombosis

The incidence of symptomatic catheter-related thrombosis varies from 0.3 percent to 28.3 percent. In a study of 50,470 patients on home infusion care, it was found that catheter dysfunction like kinking, breakage, falling out, infiltration, and symptomatic thrombosis occurred 0.83 times per 1000 catheter days. Nonthrombotic causes for the dysfunction accounted for 0.6 and thrombotic 0.23 times per 1000 catheter days.

In this group, rates of complications like local or systemic infections and thrombosis were found to be higher for midline catheters, followed by peripherally inserted central catheter (PICC) lines, non-tunneled catheters, tunneled catheters, and chest ports. The time of occurrence of thrombosis from different types of central VADs was also reported to be shorter for midline catheters followed by PICC lines, non-tunneled catheters, tunneled catheters, and chest ports. A report by Verso et al noted that tunneled catheters like Hickman catheters and chest ports have less venous thrombotic complications compared to PICC or midline catheters.

**Table 1. Types of Catheters**

<table>
<thead>
<tr>
<th>Type of catheter</th>
<th>Insertion site</th>
<th>Catheter tip position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tunneled (e.g. Hickman)</td>
<td>Jugular or subclavian vein</td>
<td>SVC-RA*</td>
</tr>
<tr>
<td>Port</td>
<td>Chest wall</td>
<td>SVC-RA*</td>
</tr>
<tr>
<td>PICC</td>
<td>Upper arm vein</td>
<td>SVC-RA*</td>
</tr>
</tbody>
</table>

*SVC: Superior vena cava, a large vein draining blood into the right atrium (RA) of the heart.

**Table 2. Signs and Symptoms of Venous Thrombosis**

<table>
<thead>
<tr>
<th>Thrombus location</th>
<th>Internal jugular vein</th>
<th>Subclavian vein</th>
<th>Superior vena cava</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>Pain and swelling at the jaw angle</td>
<td>Swelling of hand and fingers</td>
<td>Face and neck swelling</td>
</tr>
<tr>
<td></td>
<td>Neck pain and swelling</td>
<td>Swelling and discoloration of the arm</td>
<td>Swelling around the eyes</td>
</tr>
<tr>
<td></td>
<td>Headache</td>
<td>Dilatation of subcutaneous collateral veins over the upper arm and chest on the side of the catheter</td>
<td>Blurred vision</td>
</tr>
<tr>
<td></td>
<td>Vision changes</td>
<td>Facial cyanosis or discoloration</td>
<td>Tearing eyes</td>
</tr>
<tr>
<td></td>
<td>Altered mental status</td>
<td>Runny eyes</td>
<td>Sore throat</td>
</tr>
</tbody>
</table>

Risk Factors

Risk factors for venous thrombosis include catheter tip position, catheter material and type, site of VAD insertion, infusate like chemotherapy and PN, underlying illness like cancer and congestive heart failure, duration of catheter in place, traumatic catheter insertion, malposition, immobility, dehydration, and hypercoagulability. Large-gauge VADs with multiple lumens are also associated with a higher risk of thrombosis. Femoral catheters carry a higher risk of thrombosis than internal jugular or subclavian catheters. Silicone and polyurethane catheters are less likely to form clots compared to those made of stiffer plastics.

In several studies it was noted that optimal tip position to prevent venous thrombosis is in the lower third of the superior vena cava (SVC) and above or within the upper chamber of the heart (right atrium). This position allows for the rapid dilution of the concentrated parenteral nutrition solution. Vein wall trauma can lead to thrombosis, and this position is also less likely to traumatize the wall of the SVC.

Pathophysiological Factors

The three pathophysiological factors that lead to clot formation are injury to the inner lining (endothelium) of the vein, circulatory stasis (sluggish circulation), and hypercoagulability. Endothelial injury may be due to surgery, trauma, or intravascular devices. Central VADs may damage the lining of the vessel, causing platelet aggregation and clot formation. Damage may occur during catheter placement, especially if the catheter is stiff, or secondary to malposition of the tip of the catheter.

Circulatory stasis is secondary to general immobility, inadequate hydration, or congestive heart failure. Hypercoagulability may lead to clots occurring in patients with malignancies, pregnancies, infections, diabetes, high blood pressure, inherited coagulation disorders, and inflammatory bowel diseases (such as Crohn’s disease).

Prevention

Steps to avoid venous thrombosis should begin at day one of catheterization. Catheter insertion should be done by an experienced clinician using technical assistance, such as ultrasound, to accurately locate the vein and other imaging support for proper VAD tip positioning. Interventional radiologists usually prefer right-side internal jugular catheters as the catheter can be shorter, and can lie parallel to the vein, and there is a straight line down from the right internal jugular vein to the lower third of the superior vena cava.

Vascular access devices need proper maintenance after insertion. Appropriate flushing regimens and site dressing are some key points to consider in possibly preventing venous thrombosis. Other strategies for thrombosis prevention include early mobilization, limb exercise, and adequate hydration. Use of prophylactic anticoagulation with heparin or coumadin remains controversial. However, patients who have had catheter-associated venous thrombosis in the past should discuss long-term anticoagulation with their physicians (Duerksen).
Signs and Symptoms

Early signs of VAD venous thrombosis include persistent pump alarms, inability to infuse or withdraw, and visible clots in the catheter hub. Symptoms of VAD-related thrombosis can include swelling of the neck, face and arm; appearance of superficial collateral veins on the chest wall (figure 1); swelling and discoloration of the arm (figure 2); swelling around the eyes; rapid heart rate; shortness of breath; armpit tenderness; shoulder or jaw pain; headache; tearing of the eyes; runny nose; and sore throat. Symptoms vary based on the location of the thrombus. (See table 2.)

Diagnosis

A good physical examination is very important in the diagnosis of venous thrombosis. Color Doppler (ultrasound) is now the investigation of choice. It has 95 percent accuracy for clots in the internal jugular and subclavian veins. However, it has less than 50 percent accuracy for clots in the superior vena cava because you can’t see through the sternum. Ultrasound is non-invasive and can be easily done as an outpatient. Venograms are the gold standard, can be done easily as an outpatient, require very little contrast (less than 50 ml), and are quite specific. However, they are expensive and the intravenous contrast may be harmful to the kidneys.
Kyle R. Noble Memorial Scholarship

To further the educational goals of individuals relying on HPN or HEN for their primary nutritional needs.

In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a $2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered. Applicants are asked to write a one to three page essay describing how he or she has overcome obstacles/challenges posed by HEN and/or HPN and inspired others to live life to the fullest. An educational reference (letter from an advisor or teacher supporting educational pursuits) and a medical reference (from someone on the applicant’s health care team — physician, nurse, dietitian — verifying the medical situation) are required. The scholarship will be distributed at the end of the school year after a copy of the recipient’s transcript of his/her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference in St. Petersburg, FL. Applications for the June 2009 scholarship must be received by April 24, 2009. Complete details posted on www.oley.org.

Prize Encourages PN Research

The Oley Foundation will award $2,500 to each of the top three clinical studies dedicated to improving the quality of life for home parenteral (IV-fed) consumers. Underwritten by Nutrishare, Inc., the HomePN Research Prize was initiated to encourage more research in this area of critical concern to long-term consumers of home intravenous feedings.

Papers must have been accepted for poster/standup presentation or publication by a respected, relevant professional association such as ASPEN, ESPEN, INS, or AGA between July 2007 and March 2009. A portion ($1,000) of each prize will be dedicated towards travel expenses to bring the winners to the 2009 Oley conference in St. Petersburg, FL, to present their research. The deadline for submissions is April 1. Further details and an application are available online at www.oley.org.

Conference, from pg. 1

complications at bay and to make the best of your life dependent upon tube feedings or infused nutrition.

Reservations

Make your hotel reservations by calling the resort at (727) 363-2215. Be sure to mention that you will be attending the Oley Annual Conference. The conference rate is $139/night (which includes the resort fee of $15/night per room).

To register for the conference or for more information, call the Oley offices or visit www.oley.org. We hope to see you in June!
Recognize Someone Who Inspires You!

Oley Award Nominations
The Oley awards give us each a chance to acknowledge someone in our life who has inspired us by their courage, perseverance, or willingness to help others. Nominate someone who has earned your respect because of what they have overcome or inspired you by how they live.

The significance of being nominated is great by itself, as each nominee will be recognized at the Oley conference in St. Petersburg, FL. Combine this with the potential of a travel grant (see award descriptions), and this is awesome!

Ring your own bell!
Don’t resist nominating yourself. Tell your story, and/or share examples of how you have helped others along the way. At the very least, it will motivate others.

It’s FREE and easy!
A simple form (on back side) with three, quick questions is all you need to complete. Technophiles can find it on our Web site: www.oley.org or request a form from Cathy Harrington at harrinc@mail.amc.edu. Just type in your answers — fax it, mail it or click “submit” — and you’re done. Send as many forms as you’d like.

Questions?
Call (800) 776-OLEY.

Award Criteria

The awards will be presented June 30 at the 2009 Oley Conference in St. Petersburg, FL. Nominations will be reviewed by a committee comprised of previous award winners, trustees, and consumers. Oley awardees receive a keepsake, are honored at the conference awards program, and will be spotlighted in the Lifeline Letter. Most awardees will have some of their travel expenses underwritten. Recognition is given to all nominees!

Lifeline Letter Annual Award
In honor of Nutrishare Inc., Oley Platinum Partner
★ 19 years of age or older
★ HomePEN consumer or caregiver
★ Consumer has been on homePEN for at least five years
★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
★ Winner will receive a partial travel grant to the Oley Conference in St. Petersburg, FL, June 29 to July 2

Child of the Year Award
In honor of NutriThrive, Oley Golden Medallion Partner
★ 18 years of age or under
★ HomePEN consumer
★ On homePEN for at least one year
★ Shows a positive attitude in dealing with their illness and therapy which encourages and inspires others
★ Winner will receive a partial travel grant to the Oley Conference in St. Petersburg, FL, June 29 to July 2

Celebration of Life Award
In honor of Apria Healthcare/Coram Inc. Specialty Infusion Services, Oley Platinum Partner
★ Enteral or parenteral consumer, any age
★ On homePEN for at least 3 years
★ Lives life to the fullest—traveling, fishing, gardening, volunteering, performing in local theater, spending time with children and grandchildren, etc.
★ Winner will receive a partial travel grant to the Oley Conference in St. Petersburg, FL, June 29 to July 2

Lenore Heaphey Award for Grassroots Education
★ Oley Foundation Regional Coordinator
★ Organized an outstanding information and/or education program in the past year
★ Winner will receive a nominal cash award to foster educational/support activities in his or her local area

Nan Couts Award for the Ultimate Volunteer
★ Clinician (physician, nurse, dietitian, etc.) must practice in the field of homePEN or a related field, i.e. psychology, interventional radiology, pain management, etc.
★ Has demonstrated a willingness to give of themselves — beyond their regular work hours — to educate, empower and improve the quality of life for homePEN consumers. For example: a nurse who facilitates an Oley support group on his/her day off.
★ Winner will be honored at the Oley Conference in St. Petersburg, FL, June 29 to July 2

Each and every Oley member contributes to the success of those who walk beside them or follow in their footsteps.

Nominations must be submitted by April 24, 2009
Oley Foundation Award Nomination

Deadline for Nominations: April 24, 2009

The Oley Foundation • 214 Hun Memorial, MC-28 • Albany Medical Center
Albany, NY 12208 • Fax: (518) 262-5528 • e-mail: harrinc@mail.ama.edu

1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2009 (please check one):

- LifelineLetter Award
- Child of the Year Award
- Lenore Heaphey Award for Grassroots Education
- Nan Couts Award for the Ultimate Volunteer
- Celebration of Life Award

Nominee’s name: ____________________________ Age: ________
Address: ________________________________________________
City: _____________________________ State: _____ Zip: ______
Phone: ( ____ ) _____ - ______ home,  ( ____ ) ____ - ______ work
E-mail: ______________________ @ _________________________
Primary diagnosis: _________________ No. years on HPEN _____

2 Fill in your name and contact information.

Your name: ______________________________________________
Relationship to nominee: _________________________________
Company (if any): _______________________________________
Address: ________________________________________________
City: _____________________________ State: _____ Zip: ______
Phone: ( ____ ) _____ - ______ home,  ( ____ ) ____ - ______ work
E-mail: ______________________ @ _________________________

Tell how the nominee meets the criteria for his or her award (see other side), describing specific examples: i.e. how this person has demonstrated a positive attitude in dealing with his/her illness; lived a full life; organized an excellent educational program; brought information and compassion to homePEN consumers; or generally has helped others live with HPEN. Attach one additional page if needed.
Basic Terminology: What We Mean When We Say...

We recently had a reader point out that the Oley newsletters are full of terms and abbreviations that are new and unfamiliar to him—and he’s certainly not the first one to ask for clarification. Here, then, with thanks for this reader’s feedback, are some of the basic terms we use and a little bit about each:

**Parenteral nutrition** (or PN) is delivered into the bloodstream through a **central venous catheter** (CVC), which is also sometimes referred to as a **central line** or, as you’ll see in the article on thrombosis on the cover, a **central vascular access device** (VAD). When this nutrition therapy is administered in the home, we call it **homePN**, or HPN for short.

Parenteral means “outside the intestine.” Patients who use this therapy are fed a specially formulated solution through their central lines. The solutions contain nutrients that are already broken down into very simple or elemental parts that can be used by cells in the body. We sometimes use the terms **intravenous feeding** or **IV feeding** to denote parenteral nutrition.

**Enteral nutrition** (or EN) is delivered through a **gastrostomy tube** (G-tube) or a **nasogastric tube** (NG-tube) into the stomach (gastric = stomach), or through a **jejunostomy** (J-tube) into the intestine (jejum = part of the intestine). G- and J-tubes enter into the stomach or intestine through a surgically formed opening, called a stoma. An NG-tube goes through the nose and down the esophagus into the stomach. Sometimes we call enteral nutrition **tube feeding**. Most people use special formulas for tube feeding, though some people create their own formulas/recipes with food and a blender. Note that PN solutions and EN solutions are very different from one another and are in no way interchangeable.

For those on home enteral feeding, we use the term **homeEN**, or HEN for short. Sometimes you’ll see the term **homePEN** (or HPEN)—that’s for those who use both PN and EN, or when we want to include both therapies in the discussion.

And lastly, why do we so often use the term “consumers” instead of “patients” in the newsletter and in our discussions? Oley members have told us that, once they have mastered the “ins and outs” of the therapy they receive they would rather not be considered patients. As health care consumers, they prefer the term “consumers” and, as time passes, they insist on becoming “partners” with their health care providers.

**Glossary**

Some terms are also explained at www.oley.org/generalquestions.html, and we’re looking to create a glossary. Your questions will help us make it as inclusive as possible! Please send any suggestions to Lisa Metzger at the Oley offices or at metzgel@mail.amc.edu, or call her at (800) 776-OLEY.
You’ve Got Mail!

Now, more than ever, the Oley Foundation is using e-mail. We use this mechanism to share breaking news, to invite you to timely events, and to share your perspective to benefit others. For example, we use e-mail to share FDA alerts and product recalls, and to recruit participants for focus groups and online surveys that capture the end-user’s perspective. This valuable insight will help company representatives who are developing and improving products and services that will affect “our” community.

It’s worth mentioning that Oley generates income by coordinating these types of activities and that participants (you!) are also compensated for participating. And the true beneficiaries are the consumers that will use the new and improved products in the future. It’s win/win/win for everyone.

Don’t delay. Send or update your e-mail address to Cathy Harrington at harrince@mail.amc.edu. Indicate whether or not you’d like to receive a link to the LifelineLetter (a much more timely and cost effective way of delivery) or if you’re just interested in receiving bulletins and invitations.

As always, we promise to respect your privacy and not to clog your box with unnecessary mail. Thanks a million!

Getting Grounded, from pg. 2

getting too sick to even get out of bed and go to a class that started after lunch? I decided to do something about it.

I finished up my five-year run of college with a bachelor’s degree in psychology. (I couldn’t get a teaching degree because I was too far along in my major to switch.) And I decided to suck it up and do what I knew I needed to do: move eight hundred miles to live with my parents again. I knew if I stayed where I was, I wouldn’t be able to get out of the rut I was in.

Good Move

Even though it wasn’t exactly what I had in mind when I graduated from college, moving back in with my parents was one of the best things I could have done. I started graduate school the next fall, and I’m set to graduate this May with my master’s degree in elementary education.

It isn’t always easy living in my parents’ home after five years of being on my own. But the move has allowed me to focus on school and, most importantly, on my health. I’m healthier now than I think I’ve ever been in my whole life, and I’m moving toward achieving my goal of being an elementary school teacher. This summer I’m planning on moving back to Georgia, getting a job as a teacher, and living life to its fullest. I don’t know what the future yet holds for me, but I think I’m pretty capable of taking whatever it throws at me.

Lessons from the Teacher-to-Be

I’ve learned a few things from going to college with short bowel. Probably the most important thing I learned is how critical it is to take care of yourself. Make sure you don’t wear yourself too thin. There are a lot of new things to do when you’re in college, but that doesn’t mean you have to do them all. Slow down if you’re tired. You can do other things after you’ve attended to your medical needs. You cannot do them, however, if you’re stuck in the hospital.

Know your limits—on everything. If you don’t think you can handle eighteen hours’ worth of classes, take fewer classes. If you don’t think you can stay out until two in the morning with your friends, don’t. Go home and get some rest. Your friends won’t think any less of you for wanting to watch after your health (and if they do, you need some new friends).

College is a time for new experiences. Try something new; you might like it. Talk to your neighbors; they may end up becoming your new best friends.

Don’t use medical problems as an excuse to not do something. I’ve gone scuba diving, traveled more than Lewis and Clarke, and have made enough memories to last a lifetime.

And lastly, find something you love. In my case, it’s teaching. Once you find that one thing, there won’t be anything to hold you back. ¶
Thrombosis, from pg. 5

Treatment

Treatment options are primarily anticoagulation (or thinning of the blood) or thrombolysis (dissolving the clot). Anticoagulation is either with unfractionated heparin, low molecular weight heparin, warfarin, or direct thrombin inhibitors like ximelagatran. In thrombolysis, thrombolytic agents like Alteplase are usually infused through the catheter to dissolve clots that form within the catheter (intraluminal clots). Most of the time, these treatments are all that are necessary. In some cases, a VAD may need to be removed when substantial clot is present and swelling and pain are severe.

Thrombus is a great medium for bacterial growth. Management of a septic central vein thrombosis includes removal of the catheter, intravenous heparin, and antibiotics for four to eight weeks. If central venous access is essential for care of the patient and no other access is available, the catheter may be left in place and anticoagulation with heparin must be initiated with conversion to coumadin for at least three to six months, or for as long as the catheter is needed.

Some patients can develop a stricture or marked narrowing at the site of a previous clot, rendering the vein unsuitable for further catheter insertions. Interventional radiologists can sometimes dilate up these strictures and restore patency of the vein by inserting a stent device.

Outcomes

Pulmonary embolism associated with upper extremity venous thrombosis (clots located only in patients’ upper extremities) is estimated at about 12 percent of patients with symptomatic catheter-related thrombosis, and is likely between 15 and 25 percent in cancer patients with symptomatic catheter-related thrombosis. If the patient experiences signs of venous thrombosis mentioned previously and/or sudden onset of rapid heart rate, shortness of breath, and chest pain, he or she should seek medical help immediately.

Although it is controversial, thrombosis might predispose the patient to catheter-related blood stream infections. Multiple major venous thromboses may limit venous access for continued parenteral nutrition and is a relative indication for considering intestinal transplantation according to Medicare criteria.

Conclusion

Preventing, diagnosing, and treating VAD dysfunction and thrombosis are critical for maintaining consumer health and comfort and can prolong the life of the VAD for consumers in need of home PN. A skilled vascular access clinician should be consulted for VAD placement to correctly position the catheter tip, minimize complications associated with infection, and effectively prevent and treat complications. Consumers must learn how to recognize the signs and symptoms of venous thrombosis, and report any of these signs and symptoms in a timely manner to their clinicians.

References


Thank You for Your Support in 2008!

The following list represents everyone who generously contributed toward Oley's efforts in 2008. We also want to thank all of those who are

Linda Scholl
Joan & Frank Scheib
Anna Nowobilski-Vasilios
Ron & Lisa Metzger
Laurie McBride
Laura Matarese*, PhD, RD,
Mann Wireless, Ltd.
Sarah Higgins
Stuart & Beth Kay
Mann Wireless, Ltd.
Laura Matarese*, PhD, RD,
LDN, FADA, CNSD
Laurie McBride
Ron & Lisa Metzger***
Frank W. Morgan, MD
Anna Nowobilski-Vasilios
Carol Rees Parrish
Joan & Frank Scheib
Susan & Jeffrey Scheck
Linda Scholl
Mary & Doug Seidner*, MD
Stewart's Shops Corp.
Steve & Edith Swensen
John Wesley, MD
Sheryl Young
Patrons ($100–$249)
Sharon Alger-Mayer
Dominigo T. Alvear
Atlantic Coast Alarm, Inc.
Felice Austin
Gerardo Balli, Jr.
Matthew & Jennifer Banderman
Gisela Barnaud
Carmen & Gertrude Barone
Mary Barron
Anthony & Lorraine Bartalo
Dianne Benda
gel
Sally Bowers
Bruce & On Brady**
Gail Brodiehoft
Gail & Chuck Brennustuhl
Martha Brogan
Paul & Elizabeth Bryant
Charlotte S. Buchanan
Christine Burke
Delmar Burket
S. A. Chaney
Victor Chaney
Nia Cholakis
Steve & Davia Cohen**
Irene Coleman
Charlene Compere, PhD
Tracy & Caroline Cox
Jerry & Lodgie Cronwell
Matt Davis
Ann* & Paul DeBarbieri
Marie DeBarbieri
Dale C. Delano
James & Suzanne Douglas
Lavern Dover
Rebecca Edwards
Herb Emich
Gary & Pam Essary
Randall & Daphne Falck
Sandra Ferrer
Mr. & Mrs. W. Fitzpatrick, Sr.
Roslynne Freese
Todd Friedman
Mary Frey
Abbott & Alice Gavin
Mary Geoffrey
Linda Gold
James M. Goll, MD
Nancy Goodick
Stuart Gordon
Julie Graham
Sharon Gran
The Gravenstein Family
Elizabeth & Joseph Greenberg
Deirdre Herrington
Jeff Hoole
Robert Hyldon
Barbara Kapucinska
Duane & Susan Knauer
Jack Kordash
Nancy Kramer, RN
Robin Lang
Gerald Levin
Jaye Lindsay
Mark Lopez
Charles & Jo Ann MacMullan
Joyce Madden
Barnard & Jane Manderville
David & Theresa Mathiasmeier
May Bea May
Paul & Linda May
Kathleen** & Larry McNees
Joan** & Eli Medware
Sheila Messina, MA, RN
Lois Moran
Laura Mulcahy
Martha Oates
Lou & Martha Pacilio
Pathology & Clinical Labs
Lynn Paton, RPh
David Pempis
Ellen Pierce & Chris Erickson
Helen Pizzuti
James Portock
Dr. & Mrs. Douglas Prince
Beverly Promislaw
Charles Reed
Laurie Reay
Ruth Rosenblatt
Louis & Gail Sansivos*, MS, ANP
Anna Sarkisova
Pet & Val* & Schreiner
Elsmie & William Schwieter
Amy Shearor
Josie Stone, RN, CPNP
Winda Sun
Charlene Teague & Friends
Robert & Karyn Thomas
Joseph Tozi
Carla Truman***
Denise Sutton & Norman Trussell
Randall & Amy Valentine
Mary Jo Walsh
Robert & Patricia Warrington
Dean & Margaret Wieber
Bobbie Jo Winfrey
Rosalinne** & Bill Wu
Donald Young
Supporters ($50–$99)
Mr. & Mrs. Robert Adamo
David & Tabitha Aldrich
U. Spencer Allen
Mary Barton
Anne Beaman
Gerald Bennett
Sheila Banton
The Bond Family
Bettermie Bond***
Chuck Breasat, Jr.
Mary Burke
Dale & Bernice Carpenter
Ann Celik
Coryn Commarre
Sharon Contrill
Christine & Arthur Dahl
James & Cooper Davidson
Davie County Hospital
Crydal Deolouch
Terry Edwards
Robert & Anastasia Fenton
Janelle & Delbert Fortin
Joe Foster
Charlie Freeny
Julie Freier
S. M. Gallivan, LLC
Guadalupe & Virginia Garcia
Debbie Garner
Mr. & Mrs. James Gehringer,
Ruby Thorpe, & Ruby Breder
Daniel Greenleaf
Dr. & Mrs. C. P. Hadtke
Brenda Hansen
Richard Hermansen
Christine Hunt
R. J. Hydorn
Ellen & Daniel lead & Quinn
& Dylan Biter
Igve.com
Barbara & Ron Ives
Charles & Alma Jones
The Juda Family
Lisa Judah
Peggy & Bob Kelley
Karen Kindle
Barbara** & Lee Klingler
Dr. & Mrs. Kramer
Christophor & Larissan Lang
Marie Latta
Claire Lupton
Sarah Mabardy
Sarah MacDonald
Marcia McColl
Stephen & Jeanie McKeone
Medical Records and Lab Staff,
Stokes-Reynolds Memorial
Hospital
Melissa Miller
Ali Mirian
Dan Muennek
Margaret Mulabare
Adolph Neuber
Janet Nunec
Mrs. Linda O’Donnell
Eleanor Orkis
James & Susan Penner
Paul & Donna Peot
Gregory & Christine Pomper
Norma & Craig Courtiport Porter
Chris & Jean Prefet
Mary Probus
Jim Quadracci
Marjorie Quinn
Jim & Sarah Rausch
Sally Roscoe & Scott Hummer
Angelye Schauer
Mark Schenker
Ronald & Lisa Seagraves
Alan Segal
Elaine Shaft
Charlotte Shore
D. Luan Simpson
Thomas & Alison Siragusa
Bob & Mary Smithers
Karen & Rex Speerhaus*, RPh
Stokes-Reynolds Memorial
Hospital
Joseph & Kelli Szom
Clara Taylor
Jeanne Taylor
Mary Tall
Michelle Trunnick-Beben
Carmen Talli
Jenne Valente
Paula Weiss
Carrie & Brian Windham
Marion Winkler**, MS, RD,
LDN, CNSD
Anne Winters-Bilms
Peter Witt
Women's Committee of the
Prince George's Chapter of
the National Symphony
Orchestra
Marcia Woods
Eugene Worek
Jeri Wright
Donna Yarshick
Allan Yeler
Charles & Rochelle Ziegler
Contributors ($30–$49)
Linda Abbott
Anonymous
Susanne & David Appel
Rosemarie Boshroyd
Joan Bowling
Connie Brewer, RPh, BCNSD
Kailee Brown
Mr. & Mrs. G. Camp
Ralph CampANELA
John Cardwell
Clarence Chabak
Valerie Collins
RALPH & Roseann Crafts
Linda Deane
Gretchen DeKalb
Mr. & Mrs. Edwin Delong
Dale Dennard
Tori Dool
The Victor F. Douch Family
Norma & Alan Drou
Barry & Jann Engleman
Elaine Fazzaro
Aimee Fien
Marilyn Flaim
Carole & Melvin Friedland
Good Search
Sophia Gutherz
Margaret Hannah
Robert & Joseph Harrington
Stephen Harris

12—LifelineLetter • (800) 776-OLEY
not listed below, yet have supported the Foundation by volunteering their time and talents.

Vicki Hassan
Charles Henrick
John & Nancy Holzermer
Sue Hornig
Dan Hutchinson
Carol Juno-Jones, PhD, RD
Charles Karnack
Don Kendall
Scott & Melba Lightcap
Ainsley Malone, MS, RD, CNSD
Mercedes Manson
Elizabeth Mays
Karen & Millard Mazur
Zera Merani
Meredith Nelson
Melinda Parker
Elizabeth Pembble
Mary & John Petersoric
Karen Pickup
Philip & Alice Santandera
Doug Scarnelli, RD, CNSD, LDN
Edith Schuler
Kathleen Schweitzer
Z. Shihabi
Carol Smith, RN, PhD
Karen Smollen
Donna Stempien
Myrna Stinnente
Dana Thorsley
Enrica Thure
George & Katherine Timmons
Cathy Tokarz
Mary VanderKley
Darlene Vargo
David & Stacey Vermette
James & Susan Wachta
Dolores Weifenback
Marianne Weiss

Friends (Up to $30)
Hannah Abeles
Joseph & Kimberly Ailes
Dorothy Alley
Charles & Lucy Alund, Sr.
Anonymous
Anonymous
Michael Antonucci
Keith Arlington
Therese Arwell
John & Angie Ayre
Joan Barnett
Carl & Julie Bellmyer
Juliana Bennett
Carlota Bentley
Norman Benway**
Bill Berglas
Annette Block
William Bonaiso
Martha Boone
William & Ann Booth
Eileen Bowes
Jacqueline Breckling
Jonathan Brodkin
Kirk, Ruth, Kyle, & Brett Bye
Joseph & Barbara Caro
Frank & Carol Casale
Nicolino & Frances Casale
Macy Chancey, RD
Dorothy Cook
The Cope Family
Laura Crimlidi
Bert Crosby
Barbara Crouse, RD
Lisa Dathon
Ellen Deed
Elizabeth Dieckhoff
Enzo Digennaro
Terry & Robert DiGiulio
Dante DiOrio
Colleen Dixon
Geraldine Dougherty
William & Evangeline Dunmire
Ray Dyer
Andrea Elyuchar
Marion Finch
Jan Franke
Theresa Freeman
Edward Fritz
Alexandra Golden
Gladys Gonzalez
David Grier
Carrie Guerini
Cynthia Haddad
Jean Hammes
LuAnn Harris
Nolan Heiden
Theresa Higgins
Glen & Karen Hillen
Louis Hirdele
Andrea Hirschbrunner, RD
Rose** & Jeff Hoelle
Bob & Blanche Hoffman
Dan Hogan
Lynn Hooker
Penny Hooper
Susan Horn
Noreen Iacobucci
Nicholas & Lisa Iatarola
Lisa Illiano
Henry Johnson
Robert & Cynthia Johnson
Earl & Margie Jones
Rita Joseph
Dorothy Juda
Lawrence & Karen Juda
Marie V. Karatz
Kris Kasen
Tina Kerrigan
R. Kibble
Susan Koetner
Rita Kozushin
Dale & Kevin Kronau
Ronald and Bernice Lamont
Lisa Levy
Richard Lewis
Simon L’Heureux
Peter & Maureen Lovell
Noreen Luzsz
Janice Mabardy & Carol Valenzano
Paulette Mabardy
David, Craig & Shannon MacCormack
Cathie Maglio
Hubert Maiden
Janet Mancini
Peggy Manrodt
Nina Marino
Cindy Marks
Phyllis Martone
Margaret McHugh
Sue McKallor
Michael Medvar
Dolores Metzger
Noel Metzger
David Mineoggi
Patricia Miller
Jim Montgomery
Morris & Donna Mummery
Merrick Murphy
Ann C. Murray
Stacey Myers
Nadine Nakazawa
Howard & La Vonne Nicholson
Roger Niosi
Richard Noble
Mr. & Mrs. James O’Connell
Rita Ohlman
Diane Owens
Barbara Palmer
Susan Parker
Robert Patterson Jr. & Elizabeth Brady
Liz Pazos
Rachel Penney
Dori Pedroti
Ubelat Pianjarlyakul
Ellen Pierce, MD
Mina Porterfield
Becky & Robert Puckett
James Quigley
Richard & Harriett Real
Molly Reich
Rensselaer County Democratic Committee
Francesca Roy
Emily Reynolds
Joseph Reza, RD
Doris Richards
Gary Rieck
Sharon Roker
Vicki Ross, RD
James & Suzanne Rotroti
David Sagransky, MD
Stacey Sanders
Lawrence Schall
Randall & Linda Schuele
Tracy Scott
Patricia & James Shuflet
Lauren Signer & Michael Caff
Patricia Snyder
Mark & Denise Sorrentino
Barry & Ronna Staley

Join Us in Thanking Our Corporate Sponsor

Sherwood Clinical

Sherwood Clinical began as the vision of one man. Seeing a need, Charles Sherwood developed a plan to deliver high-quality infusion care in the comfort and convenience of patients’ homes, and in 1993 Sherwood Clinical was born. Today, more than a decade and one hundred employees later, Sherwood Clinical provides home-infusion care throughout Georgia, the western Carolinas, parts of Tennessee, and Alabama. Sherwood Clinical provides a wide range of services, including antibiotics; EN and PN therapy for adult and pediatric patients; on-site dietitian with clinical enteral and TPN expertise; central line maintenance; IV hydration; IV inotropics; IVIG therapy; pain management; Synagis home injections (for RSV prevention); intermittent therapies; midline catheter placement; skilled nurse visits; and patient and caregiver education. Sherwood Clinical also provides nebulizers through our newest division, Nebs and Meds.
Individual Donors

The following list represents everyone who contributed between November 25, 2008, and January 14, 2009. We also want to thank all Foundation by volunteering their time and talents.

**Ambassadors ($2,000+)**
Geoffrey O. Burney

**President’s Circle ($1,000–$1,999)**
John Balint, MD

Ms. Patricia A. Brown, RN, MSN, CNSN, OCN, in memory of Sallie Simpson, Barbara Laird, & Bruce Grefrath

**Benefactors ($500–$999)**
Robert & Laura Andolina, in honor of Julie Andolina
John & Carol Boviac
Nancy & Peter Kudan
Violett Schultz, in honor of Oley’s 25th anniversary & in memory of Willis (Dick) Schultz

**Sponsors ($250–$499)**
Valerie Gyrurko, in honor of the Oley staff for their tireless dedication to Oley
Nagarani Kanumuri, in honor of her beloved daughter Manisha
Jack Leibee
Laura Matarrese*, PhD, RD, LDN, FADA, CNSD
Krista Middlebrooks, in honor of her son Luke
Lynn & Kurt Patton
Stephen & Edithe Swensen
John Wesley, MD

**Patrons ($100–$249)**
Domingo T. Alvear

**Contributors ($30–$49)**
Helen Lu Anderson, in memory of her mother, Alma Louise Anderson
Felice Austin**, in memory of LaLa, Isabelle Christensen, & Sallie Simpson
Marci Boatwright, RN, CRNI
Sally Bowers
Bruce & On Braf**
Gail & Charles Brenenstuhl
Martha Brogan, in honor of Eleanor Brogan
Mary Caruso, in memory of Joanna Lang
Irene Coleman, in memory of Jennifer Coleman
Charlene Compfer, PhD
Tracy & Caroline Cox
Ann* & Paul DeBarbieri
Marie DeBarbieri, in honor of Ann DeBarbieri*
Dale & Martha Delano
Drs. Dan Dietel & Kathleen Jackson
Mr. & Mrs. Richard Dillon, in memory of Nancy Harvey
James & Suzanne Douglas, in honor of Tanner Shuman off TPN for six years
Rebecca Edwards
Herb & Joan Emich
Gary & Pam Essary
Roselyn Freese, in memory of Woody Freese
Mary Gergely
Linda Gold
Nella & Bernd Gravenstein, in memory of Bernice Elizabeth Schaller
Elizabeth & Joseph Greenberg, in honor of Rachel Schlen

**Supporters ($50–$99)**
Gisela Barnadas
Mary Barron, for Casey Barron
Anthony & Lorraine Bartalo
Mary Burke, in memory of Megan Burke
Davina & Steven Cohen**
Coryn Commare
Cheryl Conlon
Christine & Arthur Dahm
Mr. & Mrs. Richard Dillon
Lavern Dover
Robert & Stacey Fenton
Mary Friel
Leah FUNK
Julie Graham
Christopher & Larissa Lang
Marie Latta
Claire Lupton
Adolph Neuber
James & Susan Penzer
Paul & Donna Post, in honor of Ryan’s 16 years on TPN
James & Donna Quadracci
Marjorie Quinn
Angelyn Schauer, in honor of Dr. Ellen Pierce
Mark Schenker
Alan Segal
Bob & Mary Smithers
Mary Till, in honor of 2 1/2 years on homePN
Michelle Trunick-Sebben, in memory of Kyle Noble

**Sponsors ($250–$499)**
Barbara Kapuscinska
Diane & Susan Knaier
Bernard & Jane Manderville
David & Theresa Mathiasmeier
Kathleen** & Larry McNnes
Sheila Messina, MA, RN
Ron & Lisa*** Metzer, in memory of Kenneth R. Crosby
National Grid, matching donation of Ron & Lisa Metzer – National Grid Nutrition Support Team Mt. Carmel West Hospital, in honor of all PN & EN consumers
Lou & Martha Pacilio
Ellen Pierce & Chris Erickson, in memory of Jeff Dutton, MD, Bob Sweet, & Paula Southwick
Dr. & Mrs. Douglas Prince
Louis & Gail Sansivero**, MS, ANP
Pete & Val** Scheiner, in memory of Becky
Judith Schwarz, in honor of Sandy Schwarz & Ellen Pierce
Josie Stone
Mary Susan Thomas
Robert & Karyn Thomas
Randall & Amy Valentine, in honor of June Bodden**
Margaret Wieber

**Contributors ($30–$49)**
Anonymous, through United Way of the Capital District
Gerald Bennett
Kaelie Brown
RALPH & Mary Campanella, in honor of thanking God we are helping people
Bernice Carpenter
Clarence Chabak
S. A. Chaney, through United Way
Teri Dool
Aimee Fien
Good Search
Sophia Guthert
John & Nancy Holzemer, in memory of Florence Bye
Sue Bauder Hornig
Charles Karnack
James Kellner, in memory of Diane & Gary Kane
Phillip Mihardy
Tom Markert
Karen & Millard Mazer, in honor of Esther Adler for a speedy, safe, & successful transplant
Laura Mulcahy, through United Way
Elizabeth Pemble
Anna Sarkisova
Charlotte Short, in honor of Erin Shores’ birthday
Karen Smollen, in honor of Lia Smollen
Frances Sneider & Beth Cohen, in honor of Peggy Bradberry & her family
Myrna Stinnette
Enrica Trute, in honor of Greg Tongol, 19+ years on HPN
George & Katherine Timmons, in memory of Kyle Noble
Mary VanderKley
David & Stacey Vermette, in memory of Robert Klenke

**Friends (Up to $30)**
Hannah Aleshs
Therese Arwell
Joan Barnett
William Bonson
Rosemarie Boothroyd
Joseph & Barbara Caro, in memory of Woody Freese
Mary Caruso, in honor of Robin Lang
George & Margaret Coefer
Gretchen DeKalb, in honor of Mary Kunz
Terry & Robert DiGiulio
Jodean & Edward Fritz
of those who are not listed below, who gave earlier this year or who have supported the

Kathy & Terry Gibson, in memory of Bernice Elizabeth Schaller
Helen Grimes
LuAnn Harris
Raymon & Patricia Hawkins
Bob & Blanche Hoffman
Noreen Iacobucci, in memory of Joyce Hydorn
Henry Johnson
Marie V. Karatz
Sherry Lutz
Sue McKallor, in honor of Dianne Sluder
Patricia Miller
Lois Moran
Morris & Donna Mummery
Merrick Murphy
Ann C. Murray, in memory of Francis J. Murray
Nadine Nakazawa, in honor of Joan Bishop,*** for her tireless advocacy of Oley
Howard & La Vonne Nicholson
Roger Niosi
Diane Owens
Rachel Penney
Mary & John Petrosoric
Mary Probus
James Quigley, in honor of Dr. Lyn Howard***
Jim & Sarah Rausch, in honor of Julie Andolina
Gary Rieck
Joanne Rodgers, in memory of Rudolf Bentlage
Lauren Signer & Michael Raffe, in honor of Aidan Raffe
Barry & Ronna Staley
James & Mary VanKleunen
Amy Wampler
Ann** & Michael Weaver
Joe & Carol Yontz, in honor of Rowan Windham
Jason & Kelly Zamora

In Memory of Libby Levin
Dana Hilton
Gerald Levin
Hila Reichman & Josh Podietz
In Memory of Sallie Simpson
Felice Austin**
Ms. Patricia A. Brown
Joan** & Eli Medwar
Susan Parker
Leonard & Joyce Thompson

* Oley Trustee
** Oley RC
*** Oley Staff

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.

PLATINUM LEVEL PARTNERS
($70,000+)
Apria Healthcare / Coram Inc., Specialty Infusion Services
NutriShire, Inc.

GOLDEN MEDALLION PARTNERS ($50,000–$69,999)
NutriThrive

SILVER CIRCLE PARTNERS ($30,000–$49,999)

BRONZE STAR PARTNERS ($20,000–$29,999)

BENEFACTOR LEVEL PARTNERS
($10,000–$19,999)
Abbott Nutrition
Nestlé Nutrition

PATRON LEVEL PARTNERS ($5,000–$9,999)
Applied Medical Technology, Inc.
Chemique Pharmaceuticals
Critical Care Systems, Inc.
EMD Seronoi, Inc.
Hospira, Inc.
InfuScience, Inc.
Walgreens-OptionCare

CONTRIBUTORS ($1,000–$2,499)
C.R. Bard, Inc.
Baxa Corporation
Zevex, Inc.

Free Magazine for Ostomates
ConTact™, a magazine that will carry practical advice and feature articles on living a healthy and active life after stoma surgery, is available in print and electronic format from Convatec, a producer of various medical technologies. According to Convatec, the “magazine will feature professionally written, in-depth articles on a wide variety of important topics tailored to the unique needs of people who have an ostomy and their families, including nutrition, sport and exercise, travel, intimacy, mental health and skin care.” The magazine will be published three times a year and is currently available in several countries, including the United States and Canada. To sign up for a free subscription, visit www.convatec.co.uk and click on “Ostomy.”

Motility Disorders Support Group
The Association of Gastrointestinal Motility Disorders (AGMD) holds educational/support group meetings each month in Lexington, Massachusetts. The meetings are free and open to the public, but pre-registration is required. Meetings are held from 12:15 to 2:15 p.m. at Cary Memorial Library in the Learning Center, 1874 Massachusetts Avenue, Lexington, MA. Dates for the first part of 2009 are March 28, April 25, May 30, and June 27.
Pre-register by calling AGMD at (781) 275-1300 or e-mailing AGMD at digestive.motility@gmail.com. If the weather is questionable, visit www.agmd-gimotility.org or call AGMD to be sure the meeting will take place as scheduled.
The July meeting will be replaced by the AGMD Digestive Motility Symposium, at the DoubleTree Bedford Glen Hotel, Bedford, MA, July 24-26. Visit the AGMD Web site for more information.
Chat with Others—Free!

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers who are willing and eager to talk and listen. These volunteers are available to discuss your homePEN concerns and answer questions. Call to talk about day-to-day issues, for ideas on coping, to share suggestions, and so on. The volunteers staffing the phone lines change regularly. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

March 2009
Kim Lorimier, mother of Gwen on HPN for mitochondrial disease
Needham, MA—EST  (888) 610-3008
Linda Stokes on HPN for short bowel/Crohn's disease
Dover, FL—EST  (888) 650-3290

April 2009
Portia Hutton, on HPN for short gut syndrome/blood clot
Annapolis, MD—EST  (888) 610-3008
Ann Weaver, mother of Tim on HPEN for short bowel/Hirschsprung's disease
Naperville, IL—CST  (888) 650-3290

May 2009
Lesley Marino, mother of Nina on HEN due to esophageal atresia & VACTERL syndrome
Clearwater, FL—EST  (888) 610-3008
Rose Hoelle, LPN and mother of Alicia Hoelle on HPEN for hypoganglionis/NID (both available to talk)
Gibbstown, NJ—EST  (888) 650-3290

Just a Little More and We’re There

We have had a phenomenal response to our 2009 Annual Appeal. Thank you to the hundreds of members who’ve donated so far.

We are still shy of our goal, but just a little! If you have not returned your envelope, now’s the time. Or you can donate online at www.oley.org.

Among other things, your donation allows us to send this newsletter, free of charge, to thousands of HPEN consumers. Your donation also supports our toll-free hotline, summer conference, online chat forum, online educational modules, research, and more.

Thank you for your generous support!

Rowan Windham, HPEN consumer featured in this year’s appeal

Visit www.oley.org for conference updates