

## What's Inside:

### Tube Talk

Page 3

### Equipment/Supply Exchange

Page 3

### Oley Board Member Receives National Award

Page 6

### Kyle R. Noble Memorial Scholarship

Page 6

### Prize Encourages PN Research

Page 6

### 2009 Oley Awards Nomination Form

Pages 7 & 8

### Basic HomePEN Terminology

Page 9

### You've Got Mail

Page 10

### Contributor News

Pages 12-15

### Free Magazine for Ostomates

Page 15

### Motility Disorders Support Group

Page 15

### Toll-free Networking

Page 16

### Annual Appeal Update

Page 16

# LifelineLetter

Living with home parenteral and/or enteral nutrition (HPEN)

## 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.



Jameson, celebrating the Christmas spirit with his mom.

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

**Getting Grounded**, cont. pg. 2

## 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.

**Thrombosis**, cont. pg. 4

## 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

**Conference**, cont. pg. 6

### Getting Grounded, from pg. 1

referred to as a “port”) at the time and needed someone to change the needle out for me. (I’m a wimp. There was no way I was going to stick myself!)

We met the nurse at the school health center and explained my situation to her. Luckily, she was very capable and could take care of me. She was also extremely nice and accommodating, which was important to me.

## LifelineLetter

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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/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

### 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 I normally would. If there were people in our room and I needed to start my HPN, I would just tell them I had to start it, explain to them what I was about to do, and invite them to watch if they wanted to.

### Living Off-Campus

I only went to that college for a year. I discovered it just wasn’t for me. So I transferred to Georgia, which was where I went to high school and where my family was—for a short time, at least.

My family moved a few weeks before the

new school year started. I had to find an apartment. I also had to start making new friends, since most of my friends from high school had gone off to other colleges.

I got an apartment in town, right down the road from the University of Georgia, my new school. Needless to say, I had a lot more room than I had had in the dorm room. So you would think that I would’ve had an easier time, right? But then you must not know me too well.

Before, in Florida, I was far away from my family, but I had the nurse I saw every week, or whenever I needed to. I had meals through the meal plan, and I was a quick stroll away from all my classes. It was totally different now.

Now, I lived off-campus. I had to find food for myself and I had to schedule a home-healthcare nurse to come change my dressing

every week. For once, I had to actually take care of myself like an adult. And let me tell you, I wasn’t too great at it.

I went to a party school, and all my friends partied. So what did I do? I partied. In and of itself this isn’t necessarily a bad thing to do, but when you’re on PN and have medical problems, you need to know when to stop and how to take care of yourself. I didn’t know how to do either, and I paid for it. I was sick a lot and in and out of the hospital with line infections. And as for school, let’s just say I wasn’t on the honor roll.

Did I have fun? You bet. Did I have too much fun? Definitely. Did I learn from all of it? Eventually.

### Stuck in a Rut

Part of my problem was I had no direction. Before I got sick in high school, I didn’t even want to go to college. Then it took me until my fourth year of college to find what it was I wanted to do with my life: I wanted to teach. That’s when things started to finally click.

I realized I would never reach my goals if I didn’t start taking better care of myself. How could I get up in the morning to teach a class full of kids if I was constantly

Getting Grounded, cont. pg. 10



*Making the most of a rock concert, despite the rain.*

## 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](http://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](http://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.

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**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.

**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).

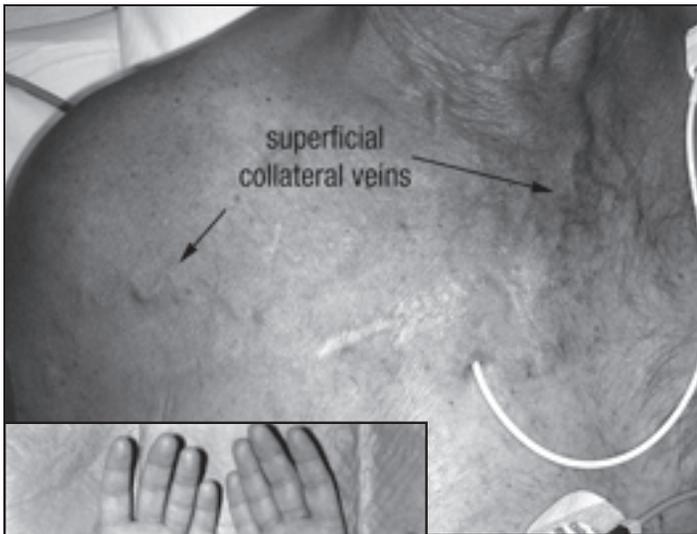
**Table 1. Types of Catheters**

Type of catheter	Insertion site	Catheter tip position
Tunneled (e.g. Hickman)	Jugular or subclavian vein	SVC-RA*
Port	Chest wall	SVC-RA*
PICC	Upper arm vein	SVC-RA*

\*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**

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



**Symptoms of VAD-Related Thrombosis**

**Figure 1 (above).**  
*Dilatation of superficial collateral veins on the chest wall*

**Figure 2 (left).**  
*Discoloration and swelling of right arm*

*Note: to see a clearer, color version of these photos, visit [www.oley.org](http://www.oley.org).*

**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 (figure1); 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 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 50ml), and are quite specific. However, they are expensive and the intravenous contrast may be harmful to the kidneys.

**Thrombosis, cont. pg. 11** ➔

# A Customized Care Approach

The Nourish Nutrition Support Program™ provides home parenteral (TPN) and enteral (tube feeding) support to individuals who cannot consume or absorb nutrients through regular food intake. With more than 25 years of nutrition clinical expertise and comprehensive patient care, we are dedicated to providing high quality clinical care and personal support for nutrition consumers.

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## Oley Board Member Receives National Award

Last fall, the Association for Vascular Access (AVA) presented Oley board member Gail Sansivero with the Suzanne LaVere Herbst Award for Excellence in Vascular Access. The award, presented at the association's annual meeting, in Savannah, Georgia, recognizes an individual who has made a substantial contribution to vascular access practice by improving patient outcomes and/or contributing to the science of vascular access.

Gail has over twenty years of experience in oncological and vascular access nursing, has published extensively, and has participated in research. Always concerned with the consumer, Gail recently coordinated a trip for a group to an upstate New York catheter manufacturing plant. The group included several consumers, as well as Oley Executive Director Joan Bishop and Oley board member and consumer Ann DeBarbieri. The group had the opportunity to meet with the company's research and development team, who found their views invaluable.

In announcing the award on their Web site, AVA concludes, "As impressive as her CV may be, it is the impact that she has made on her colleagues and patients, both past and present, that speaks most to Gail's accomplishments." Way to go, Gail!



*Gail Sansivero, right, receiving the award from Suzanne LaVere Herbst.*

## 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](http://www.oley.org).



**Kyle Richard Noble  
11-10-98 to 12-29-06**

## 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](http://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](http://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](http://www.oley.org) or request a form from Cathy Harrington at [harrinc@mail.amc.edu](mailto: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.**

*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**

## 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 LifelineLetter. Most awardees will have some of their travel expenses underwritten. Recognition is given to all nominees!*



### LifelineLetter 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

- ★ 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

### 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

### Nan Coutts 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

### 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



# 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.amc.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 Coutts 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: \_\_\_\_\_ @ \_\_\_\_\_

Please use this form or an accurate reproduction. Attach one additional page if needed. Be sure to type or print legibly using dark ink, since this form will be photocopied. Feel free to submit more than one nomination.

## 3 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.

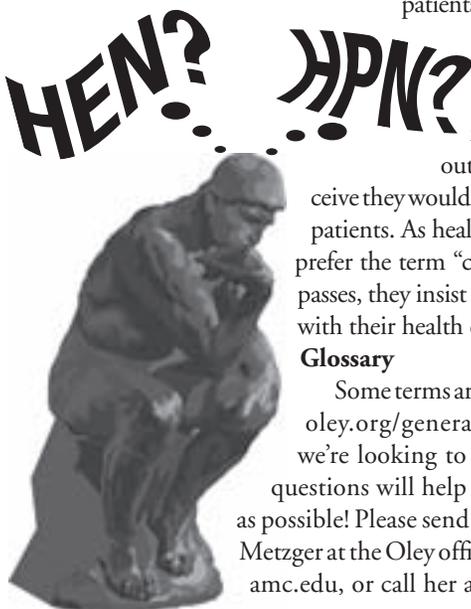
**Enteral nutrition** (or **EN**) is delivered through a **gastrostomy tube** (**G-tube**) or a **nasogastric tube** (**NG-tube**) into the stomach (gastric = stomach), or through a **jejunostomy** (**J-tube**) into the intestine (jejunum = part of the intestine). G- and J-tubes enter into the stomach 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](http://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](mailto:metzgel@mail.amc.edu), or call her at (800) 776-OLEY.



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## 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 harrinc@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. ¶

*Jameson all set for his first student teaching stint.*



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2. A portion (\$1000) of each prize will be dedicated towards travel expenses to bring the recipients to the Oley conference to present their research.
3. Deadline: April 1, 2009.



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**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**

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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  
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## Free Magazine for Ostomates

*ConTact*<sup>TM</sup>, 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](http://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](mailto:digestive.motility@gmail.com). If the weather is questionable, visit [www.agmd-gimotility.org](http://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.



## Oley Corporate Partners

*The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.*

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## 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](http://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



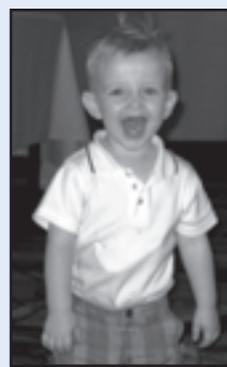
## Just a Little More and We're There

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](http://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*

## LifelineLetter

### The Oley Foundation

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