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# Lifeline Letter

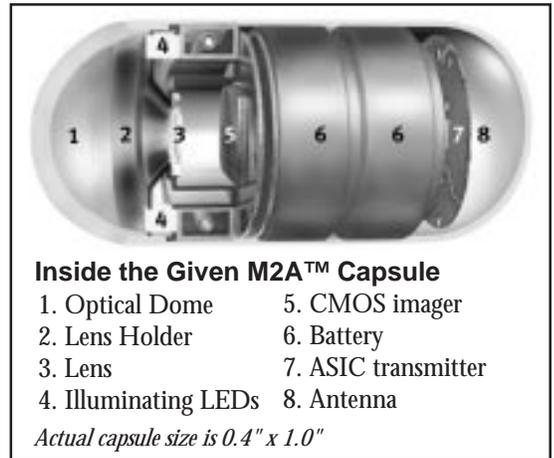
Living with home parenteral and/or enteral nutrition (HPEN)

## FDA Approves New Endoscopic Tool

Alan L. Buchman, MD, MSPH, Northwestern University, Chicago, IL

*Even in the best circumstances, undergoing an endoscopy is something most people would rather avoid. The following article describes a new tool for this procedure, which offers a less painful and intrusive alternative to the conventional scope. Three of the major drawbacks currently, are its limited: availability, use in the colon, and use in patients who have undergone major bowel surgery.*

A revolutionary new endoscopic tool was approved by the Food and Drug Administration in August, 2001. The Given M2A™ capsule video endoscope allows the gastroenterologist to see much of the small intestine as never before visualized. The capsule is like a cruise balloon that is propelled through the intestinal tract by peristalsis, or contractions of the intestines. While the scenery is not like that of an exotic jungle cruise, the Given video capsule endoscope does take the gastroenterologist on a fantastic voyage in a far away land that has previously not been well explored.



**Inside the Given M2A™ Capsule**

- |                      |                     |
|----------------------|---------------------|
| 1. Optical Dome      | 5. CMOS imager      |
| 2. Lens Holder       | 6. Battery          |
| 3. Lens              | 7. ASIC transmitter |
| 4. Illuminating LEDs | 8. Antenna          |

*Actual capsule size is 0.4" x 1.0"*

The capsule spends its first 30 to 60 minutes in the stomach before passing through the pylorus into the duodenum, or first part of the small intestine. With its 240° viewing area, the capsule can allow relatively

Camera cont., pg. 2 ←

## Join Oley this June in Buena Park, California

Excitement is mounting as planning for the Oley Foundation's annual summer conference moves into high gear. The program will be held June 20 to 22, 2002 at the Radisson Resort Knott's Berry Farm, in Buena Park, California. Don't miss this unique opportunity to talk about home parenteral and enteral nutrition with experienced clinicians and consumers from all over the country.

The Oley conference is a place to meet people who face similar struggles and move beyond them to lead active and fulfilling lives. It's a place to learn more about your therapy and optimizing your health. It's also a place to renew yourself and find the answers and support you need.

If you've never been to an Oley conference before, take past attendees' advice: "BY ALL MEANS, GO! It's an unforgettable experience that can literally change your life....I've learned more about homePEN in the last three days (at the conference), than in the five years I've been on this therapy." Or speak with Oley's toll-free hotline volunteers; they all have Oley conference experience, and some of them have been to several (see page 16)!

This year's location at Knott's Berry Farm, a vacation wonderland with six theme parks on-site, make it



the perfect place for you and your family to get away. We are just down the street from Disneyland and convenient to the Anaheim airport. In sunny southern California we'll also have access to top-notch talent, including clinicians from the Medical Centers at UC-Davis, Loma Linda and UCLA.

Plan a family vacation that includes a rewarding and educational experience you'll remember for years to come. For more information call (800) 776-OLEY or visit our web site @ [www.oley.org/knotts.html](http://www.oley.org/knotts.html) ☺

### Camera, from pg. 1

complete viewing of the small intestine. It also magnifies the actual intestine (about eight times) so that villi can be seen. Along the way, the wireless capsule snaps photographs at a rate of two per second. These 50,000 to 60,000 images are transmitted via high frequency radio waves to a data

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\* \* \* \* \*

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 Director of Publications & Information at the address above.

recorder worn on a belt. The images are then downloaded to a computer after the capsule's amazing two to six hour voyage through the small intestine, and are viewed by the gastroenterologist as a video. Currently, we are unable to take biopsies with the capsule, but it is anticipated that next generation devices may permit this function within a few years.

#### How it Compares to Conventional Tools

Visualizing the small intestine to diagnose Crohn's disease, rare tumors and sources of bleeding when endoscopy and colonoscopy were unrevealing, has always been a challenge for gastroenterologists. We are studying how well the capsule endoscope compares to the traditional small bowel study, using barium, for diagnosing Crohn's disease, finding the origin of bleeding, and determining whether a patient's body has rejected a transplanted small intestine. Using the "camera-in-a-capsule," we have diagnosed patients with Crohn's disease who had virtually no symptoms of the disease, only microscopic amounts of blood in their stool.

Conventional endoscopy into the small intestine, when possible, can visualize only about 20% of the intestine at most. In the 1980's the Sonde endoscope was developed. This procedure required a long tube to be inserted into the intestinal tract over 6 to 8 hours. The patient lay on a table until x-rays showed the end of the tube to have passed through the small intestine; sometimes it never did. The gastroenterologist could then slowly pull the tube back, observing the intestine during withdrawal. Unfortunately, even under the most optimal conditions, only 50-80% of the intestine could be seen.

Barium x-ray studies of the small intestine do not show pictures of the intestine, but offer an outline of the intestine. Thus they are often successful in identifying an ulcer because an ulcer is similar to an incomplete hole in the mucosa, or lining of the digestive tract, and barium fills in the hole. However, flat lesions, (like vascular ectasias that may cause bleeding,) ulcers from Crohn's

disease, some strictures or blockages of the intestine, and tumors, might be missed.

Although the capsule often passes into the colon while the videotaping continues, its battery runs out before the journey through the colon is complete. Passage through the colon is generally much slower than through the intestine because the contractions in the colon are slower. Therefore, the capsule does not replace traditional colonoscopy for colon cancer screening or other purposes.

#### How it Works

It takes about 20 minutes for a patient to be wired up for the procedure. Several wires are attached to the abdomen like ECG leads. These wires pick up the radio signal from the capsule as it travels through the intestine. The wires are connected to a lightweight data recorder worn on a belt about the size a loading dock worker might wear. The capsule itself measures only 0.4 x 1.0 inches. Inside this miniature 'Voyager' are a color camera, four light sources, a radio transmitter and batteries. The capsule is swallowed along with a small amount of simethicone, which helps prevent air bubbles in the small intestine and makes viewing of the video easier for the gastroenterologist.

We have found that patients tolerate the capsule better than traditional scoping methods, and they can return to work, home or shopping while undergoing the endoscopy.

Camera cont., pg. 13

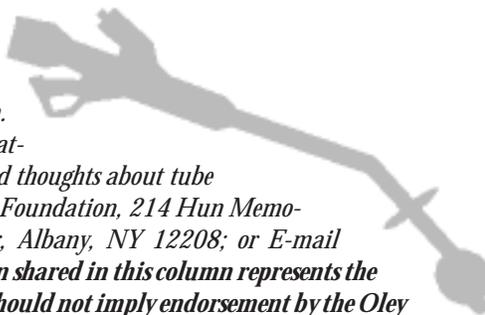


*The inch-long camera-in-a-capsule is swallowed, then travels through the digestive tract, taking 50,000+ photos of the patient's small intestine. Computer software translates the images into a video, allowing gastroenterologists to see the entire length of the small intestine and making it easier for them to diagnose abnormalities such as Crohn's disease.*

## 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 A-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@mail.amc.edu. **Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.**



Special thanks to Laura Matarese, MS, RD, CNSD, Director, Nutrition Intestinal Rehabilitation, Cleveland Clinic Foundation, for answering these questions.

### Black Mickey

1) My daughter has a mickey. The last couple she has had have turned black (visible on the outside part, in the water chamber area). She has had mickeys since April of 2000, and this never happened until this fall. Her doctor says it's just stomach acid, but we just sent the one we took out to the lab for analysis. Has anyone else encounter this?

*The mickey turning black is very common, and okay. You can have it cultured if you are concerned, but more than likely it will be nothing.*

### How Often Should You Change a Mickey?

2) How often do most people change out their mickeys?

*Most institutions/physicians do not recommend changing a mickey until there is a problem. So unless there is an issue like leaking, it is best to leave the mickey alone.*

### Cleaning vs. Changing Extension Tubing

3) How long do people use g-tube extension tubing, and how do you clean it?

*This varies from institution to institution and from doctor to doctor. Many people care for the extension tubing as they would a "plate." In other words, when you finish your dinner, you don't throw the plate out, you clean it. Some institutions/physicians would recommend cleaning with water only; but most, including ours, would recommend daily cleaning with soap and water. A small bottle brush can also be used to gently scrub the inside of the tubing. When you can no longer keep the extension tubing clean, replace it with new tubing.*

### Elevating Nighttime Feedings

4) Does anyone have any specific recommendations on positioning devices/chairs/etc. for a 3-year-old who must sleep semi-upright due to reflux and all-night pump feedings?

*The head of the bed/crib should be elevated. To accomplish this, you can put blocks under the bed frame, so the entire end of the bed is elevated. Do not try to elevate the mattress only, because you could create a situation where the child is bent over, which can lead to more problems with reflux. You will also want to make sure the child can't jump out of the bed/crib.*

Susan McLane

Largo, Florida

Mom to Bryan, Bonnie and Shannon, born 8/6/98 at 28 weeks

S2McLane@aol.com

## Equipment Exchange

The following homePEN supplies and equipment are offered free of charge to Lifeline readers:

### Enteral Formula

- 2+ cases of Subdue, exp. 10/02
- 2 boxes of Alitraq, exp. 12/02
- 1 box of Vivonex Plus, exp. 5/02
- 6 cases Isosource 1.5; 2 exp. 7/02, 4 exp. 9/02
- 10 cases Jevity Plus; 6 exp. 7/02, 2 exp. 11/02, 2 exp. 1/03
- Osmolite HN Plus, Exp 04/02
- Glucerna, Exp 05/02
- Fibersource, Exp 04/02
- Isosource, Exp 04/02
- Deliver 2.0, Exp 07/02
- Isocal HN, Exp 10/02
- Boost Plus, Exp 09/02
- Alitraq Powder, Exp 04/03
- Peptamin, Exp 05/02

### Parenteral Pumps

- 3 Abbott Provider One Pumps†

### Miscellaneous Supplies

- 300 12cc Monoject Luer Lock syringes†
- 300 cases 60cc irrigation syringes†
- BD 60ML Syringes
- BD 10 ML Syringes (309604)
- Braun Replacement "Blue Caps" BS-1000, (418016)
- Baxter Solution Sets 97" (2.5m) 2 inj. sites (2C5427s)
- Kangaroo 1000ML pump set (8884-773600)
- 14" Ext. Sets
- Lumex IV Pole

### Wanted

- Elecare formula, (Ross) for child
- Kangaroo Pet Pump for child without insurance coverage

†FREE shipping offered.

For more information, call (800) 776-OLEY/(518) 262-5079; or send an E-mail to: DahlR@mail.amc.edu. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods through this column please offer to pay for shipping, especially for heavy items such as formula.

## Consumer Carries the Olympic Torch

Dana Lovorn, an HPN consumer, celebrated her love for the Olympics and life, carrying the torch through Austin, Texas, December 11, 2001 — just five days before her 51st birthday. The day was cold, wet and rainy, but Dana was elated. “The Olympic spirit runs deep in my family. I was proud to be chosen to carry the torch,” she says enthusiastically. Dana had seen some of the Olympics when they were held in Los Angeles in 1984, and enjoyed teaching her students about the games when covering mythology in her English classes. Dana taught 7th grade English and life sciences for 20 years before her condition forced her to retire early.

Since she retired, Dana’s taken to writing and volunteering. “Volunteering is good therapy,” she says, it keeps her upbeat and active. It also led to her nomination to carry the torch. She gives credit to the President of the home owner’s association she belongs to for the first nomination, but she was also nominated by several friends from her Scleroderma support group and the staff at the hospital where she volunteers.

Dana hopes her actions will inspire other disabled persons to reach for their goals. “I’m such an active person, I don’t think people realize how difficult some parts of my day are. Just hooking up is physically demanding with my hands, and I depend on my mother’s help. I can’t spike a bag and have trouble twisting the needleless connectors,” she explains.

Dana was diagnosed with Scleroderma 19 years ago. Unfortunately it is a progressive condition with a variety of manifestations that can severely reduce the functioning capability of individuals living with the disease. Among other body systems, the disease has wrecked havoc on Dana’s digestive tract, causing her to develop pseudo-obstruction with malabsorption, and making her dependent on HPN since August 1996. The damage is severe enough to rule out tube feeding, and she is able to eat very little by mouth. Instead, she hooks up 6 nights a week for about 13 hours. Dana is on her third Groshong catheter. She needs to take extra care with her catheter; Scleroderma has made her skin tight and tough, which makes it very challenging for her surgeon to insert a catheter.

A positive thinker, and outgoing woman, Dana is glad for the HPN. In the years before she was put on the therapy, she had been declining in weight and energy. As she puts it, “The TPN allows me to live, and to live better. It’s what made it possible for me to run with the torch.”

Dana’s been an Oley member since she went on HPN and reads each newsletter cover to cover; although, once she had stabilized her nutrition status, she has been more active in her local Scleroderma support group because of the severe complications brought on by the disease. In addition to the digestive organs and skin, her limbs have also been



*After carrying the torch, Dana was presented with pink roses to symbolize her grace and beauty.*

affected. She has lost parts of three fingers and the use of several others. In fact, she planned the latest surgery on her hands for early in the fall of 2001 so she would have enough time to recover to carry the torch. “I carried the torch with both hands,” says Dana. “Combining the two, I have 4 working fingers and a thumb and a half.” Her can-do attitude inspired at least one individual in her community. When she heard about Dana’s hands, a local weaver knit Dana some special mittens, since she could not wear the gloves supplied by the Olympic organizers. ☺

## Correction on Source for Oleic Acid

In the last issue of the *LifelineLetter* we published, mistakenly, that olive oil can be used instead of oleic acid for those patients who were interested in pursuing the oleic acid therapy described in “Oleic Acid: A Novel Nutrient-Based Treatment for Improving Absorption” by Henry Lin, MD, and published in the July/August newsletter.

Once digested, olive oil is a good source of oleic acid, but according to Dr. Lin, dietary oil does not in itself trigger the desired effects of slowing gut transit and enhanced absorption. Taking olive oil is not likely to work because the beneficial effect depends on the end products of fat digestion and there may not be sufficient time to break down the

dietary oil in short bowel patients with accelerated transit. Note: Olive oil should not create any harmful effects, either, when taken in the small doses mentioned in the previous article (2 to 4 ml).

Obtaining pure, food grade oleic acid, like that used in the research study, is difficult and expensive. In addition, it is important to know that taking oleic acid straight does not work, since there are significant dispersion, formulation and delivery issues to overcome for patients/physicians wishing to replicate the study protocol. One must also address a number of confounding factors that would neutralize the effects of oleic acid, such as exposure to tobacco and the concurrent use of

certain medications that contain an anticholinergic agent such as lomitol. Finally, as an experimental therapy, physicians and patients are best served when this treatment is used under the sanction of an informed, consent-based protocol that is approved by an institutional research board, according to Dr. Lin.

For all of these reasons, Dr. Lin believes that this therapy, while promising, may present a number of practical challenges to patients and their physicians. An alternative, and perhaps less frustrating option would be to enroll in one of Dr. Lin’s studies at Cedars-Sinai Medical Center in Los Angeles, CA. Patients/physicians interested in participating should call Tess Constantino, RN, at (310) 423-6143. ☺

## Missing Mail/Donations

Joan Bishop, Oley Foundation, Executive Director

Several regular contributors noticed recently that their name was not included on the donor listing in the *LifelineLetter* and realized they had not received a "Thank You" note for their latest donation. Through their calls, Oley staff has become aware of missing mail. Fortunately these checks weren't cashed by anyone else! Our best guess is that recent world events have wreaked havoc with the United States postal system.

Keeping this in mind, we ask all of you, that if you have communicated with us for any reason via U. S. Mail and have not heard back from us — call or write again. And if you have responded to our annual appeal and have not been acknowledged with a letter or listed in this issue's donor list (checking the dates located at the top of the list, of course!), may we suggest canceling payment and trying again! Thank you for your patience.

## A HomePEN Prayer

Robin Lang, HPN Consumer

Now I lay me down to sleep

I pray Lord, my pump won't beep.

Most days it's just routine,

Other times I hate this machine.

Occlusions and crimps, make it squeak,

My dreams are shattered when batteries are weak.

A night without it, is sheer bliss,

But my nutrition, I should not miss.

I'm tired, wore out and just plain beat;

So tonight, dear Lord, please let me sleep.



## Motility Meeting April 13-14

University of Kansas Children's Center, Children's Mercy Hospital, and KU Continuing Education are sponsoring a symposium on Pediatric Functional & Gastrointestinal Motility Disorders, April 13 & 14, 2002 at the Doubletree Hotel in Overland Park, Kansas. The symposium is designed for clinicians, but families of children with functional GI or motility disorders, autistic children with GI symptoms or cyclic vomiting syndrome, are welcome. A workshop for parents of children with cyclic vomiting will be held April 13 at 2:00 p.m.; other parent workshops will be held at 2:00 p.m. on April 14th. A \$95 fee for parents and families includes two continental breakfasts, two lunches and refreshments. Clinician fees (\$295 physician, \$125 other) cover credit as well. For more information contact KU continuing education at 877/404-5823 (toll-free) or 785/864-5823.

## Shopping On-line?

Go through [www.iGive.com](http://www.iGive.com)!

For more details visit us at

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or call (800) 776-OLEY.

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## Meet Our New Regional Coordinator Volunteers

*As you can see from the long list of new Regional Coordinators, it's been a busy year for Ellie Wilson, Oley's Outreach Coordinator. Everyone is encouraged to take advantage of the experience and expertise these and all of our wonderful volunteers have to offer. A complete listing of the RCs and their contacting information is on pages 11 and 12, and is always posted on our web site at <http://www.oley.org/regional.htm>. If you have any questions about this program call Ellie at (800) 776-OLEY, or send her an email at [WilsonE@mail.amc.edu](mailto:WilsonE@mail.amc.edu).*

### **Michelle Christenson** Pickerington, OH

Michelle is the mother of two daughters, Madeline and Isabelle. Isabelle was born in 1998 with pseudo-obstruction, Complex III mitochondrial defect, and a suppressed immune system. She has both HPN and HEN therapies, with a high vulnerability to infections. Michelle feels she can assist others with managing the "ins and outs" of HPN and HEN, including communicating with doctors, suppliers, state and federal agencies, and the media.

### **Ruthann Engle** Streetsboro, OH

Ruthann has been on HPN since 1990, due to short bowel syndrome. She has much to offer consumers, and has put a lot of hard work into getting a support group up and running. We welcome her enthusiasm.

### **Heidi Forney** Sweet, ID

Heidi has a degree in psychology, is married and mother to three children. Her son Sean has short bowel syndrome, scoliosis, and a diaphragmatic hernia. Sean is currently on both HPN and HEN. Heidi will be a friendly ear for someone in need. Call her toll-free in May, from 10AM to 8PM (MST!)

### **Roberta (Bert) Gelle** Elyria, OH

Roberta has been on HPN since 1992, secondary to Crohn's disease. She and another new coordinator, Ruthann Engle, are working with

Jim Cowan to "jump start" a support group in their area. She is willing to lend an ear to anyone who needs support, and has lots of enthusiasm Oley plans on tapping into!

### **Laura Mucha** Gilbert, AZ

Laura has been on HPN since 1991, due to short bowel syndrome and D-lactic acidosis. Laura has finally given in to her friend Sandra Sheeley's suggestions that she would be a great coordinator, and we are inclined to agree. She has experience with multiple catheters and a lot of experience with access issues. She has a big, supportive family, and feels she has much to offer other lifeliners. She is also a great believer in hope, and we are happy to have her share that philosophy through Oley!

### **Donna Noble** Grove City, OH

Donna is the mother of Kelsey (7) and Kyle (3). Kyle has been on TPN for 2-1/2 years due to a mitochondrial disorder which causes delayed gastric emptying, chronic diarrhea, and malabsorption. Kyle has a g-tube for drainage, and a j-tube for medications (and hopefully one day feeds). Donna wants to provide support for families dealing with the many issues involved in nutrition support. Call her toll-free in April!

### **Pam Rector** Mt. Pleasant, SC

Pam was on HEN for 3 years and has been on HPN since 1998. Diagnosed with pseudo-obstruction, gastroparesis and colonic inertia, she has an ileostomy and a gastrostomy tube. She is a great listener and happy to share her experience with both therapies with folks in the Oley family. Pam was formerly a licensed nurse. She made several of her medical decisions with the assistance of Oley members, and wants to ensure that other members have access to our resources when they need them. Call her toll-free in May.

### **Ann Weaver** Naperville, IL

Ann holds a degree in Psychology, and is mom to Tim. Tim was born in 1996, and is on EN and TPN secondary to Hirschsprungs disease. Ann would like to "give back" for all the help and support she has received, and to spread the word about Oley to other parents.

### **Linda Wyatt** Kuna, ID

Linda joins the Oley Regional Coordinator network to give and receive support. Her motility disorder has kept her seesawing between HEN and HPN, so she can offer a lot of perspective on both types of nutrition support. Linda feels that keeping a good attitude and staying active will encourage others to do the same. ©

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## What Makes a Research Study Valid?

Darlene Kelly, MD, PhD; Medical Director HPN Program, Mayo Clinic, Rochester, MN; Vice President, The Oley Foundation

The *LifelineLetter* and other periodicals often report the findings from medical research studies. When deciphering the results, consumers should be attuned to the study design before making any conclusions about whether a therapy is beneficial, better than no treatment at all or better than a previously used therapy. Several factors that go into the design of research can make the results more or less convincing.

### Retro or Not?

Let's say we are looking at a study that tested the effectiveness of drug A versus the standard treatment, drug B, for asthma. Patients that received drug A were considered the "test" group, and those that received drug B, were the "controls." First, there is the issue of whether the study was prospective or retrospective. A prospective study is one that is planned before the data are collected. It offers the advantage of allowing the investigator to organize a study that makes the testing phase and the control phase totally comparable. Using our example, the investigator can be sure that patients who received drug A are comparable to those who received drug B, and that they received the treatment under the same conditions.

By contrast, a retrospective study looks at information that was collected in the past, often from routine clinical laboratory tests. Outcomes based on data collected retrospectively may be inaccurate, because the investigators (and you, the reader) cannot be sure that conditions were equal for the patients being studied. Getting back to our example, if it were a retrospective study, data from the test group who are given drug A today, may have been compared to data collected from the control group who used drug B five years ago. The investigator may have overlooked factors, like air quality, that could have changed significantly during the five year gap in testing. Additionally, patients in the two groups may not have the same type of asthma and the same degree of disease severity.

### Are Subjects Randomized?

Secondly, the issue of randomization comes into play. How have subjects for a study been picked for drug A or drug B? Are the participants assigned to a treatment based on a randomization schedule or is the investigator

looking at each subject and deciding which treatment they should receive? If the latter plan is used, the opportunity for bias is all too obvious. For example, drug A may be given

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Outcomes based on data collected retrospectively may be inaccurate, because you cannot be sure that conditions were equal for the patients being studied.

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only to patients with mild asthma, and drug B to those with more severe symptoms; with these unequal conditions, you couldn't know

whether it was the drug or the milder symptoms that produced better outcomes. In a true, randomized study there is typically a scheme for the randomization, and often someone other than the investigator decides who gets which therapy.

### Is the Study Double Blind?

A third, related issue is whether the research is what we call "double blind." In a double blind study, neither the investigator nor the subject knows which treatment is being provided. This prevents the investigator (and the subjects themselves) from influencing the subject's response to the treatment and also prevents the investigator

Research cont., pg. 13 ←

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## Recognize Someone Who Inspires You!

### Nominate them for an Oley Award.

Consumers, caregivers, Regional Coordinators, even clinicians love recognition. What a great way to tell them how much you admire their courage, perseverance, and willingness to help others in their struggle with homePEN. And who wouldn't appreciate a travel scholarship to the Oley conference in California this summer? Or extra money for an educational program in their region?

### It's FREE and easy!

A simple form (inserted in this issue) with five, quick questions is all you need to complete. Technophiles can also find it on our website @ <http://www.oley.org/nomform.html>. Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you like.

### Questions? See details below or call (800) 776-OLEY.

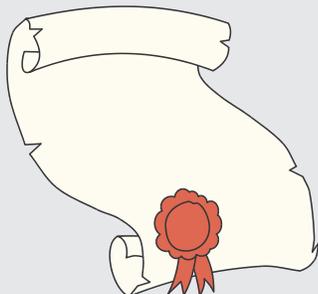


#### **LifelineLetter Annual Award**

- ★ 19 years of age or older
- ★ HomePEN consumer or caregiver
- ★ Consumer has been on homePEN for a minimum of five (5) years
- Winner will receive a travel grant to the Oley Conference in Buena Park, CA, June 20 - 22, 2002

#### **Oley Foundation Child of the Year Award**

- ★ 18 years of age and under
- ★ Home parenteral and/or enteral nutrition consumer
- ★ On homePEN for a minimum of three (3) years
- Winner will receive a travel grant to the Oley Conference in Buena Park, CA, June 20 - 22, 2002



**NEW!**

#### **Nan Coutts Award for Ultimate Volunteerism**

- ★ Clinician 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 HPEN consumers. For example: a nurse who facilitates an Oley support group on her day off.
- Winner will receive a travel grant to the Oley Conference in Buena Park, CA, June 20 - 22, 2002

#### **Mead Johnson Enteral Award**

- ★ Enteral consumer, any age
- ★ On homeEN for a minimum of one (1) year
- ★ Resident of the Greater Los Angeles area (roughly 200 mile radius around the city)
- Winner will receive a travel grant to the Oley Conference in Buena Park, CA, June 20 - 22, 2002

#### **Lenore Heaphey Award for Grassroots Education**

- ★ Oley Foundation Regional Coordinator volunteer
- ★ Organized an outstanding information and/or education program during 2001
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area

In addition to the award-specific criteria listed above, all nominees should demonstrate courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN. The awards will be given at the 17th Annual Oley Consumer/Clinician Conference to be held June 20 to 22, 2002 at the Radisson Resort Knott's Berry Farm in Buena Park, California. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a special keepsake, are honored at the annual conference awards program and will be spotlighted in the *LifelineLetter*. Most awardees will have all or some of their travel expenses underwritten. Recognition is given to all nominees!

**Nominations must be submitted by April 1, 2002**



# Oley Foundation Award Nomination Form

Deadline for nominations: April 1, 2002

## 1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2002  
(please check one):

- LifelineLetter Award
- Oley Foundation Child of the Year Award
- Mead Johnson Enteral Award
- Lenore Heaphey Award for Grassroots Education
- Nan Coutts Award for Ultimate Volunteerism

Nominee's name: \_\_\_\_\_ Age: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (\_\_\_\_) \_\_\_\_ - \_\_\_\_ home, (\_\_\_\_) \_\_\_\_ - \_\_\_\_ work

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

Please use this form or an accurate reproduction. Do not submit additional pages. 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 why the nominee qualifies for the award, describing specific examples of how this person has demonstrated a positive attitude in dealing with his/her illness and shown courage in overcoming illness-related problems. For the Nan Coutts Award, tell how the nominee has gone "above and beyond" what could ever be financially compensated for, to bring information, compassion and the Oley Foundation into the lives of homePEN consumers.

**4** Describe how this person has been exceptionally generous in helping consumers in their struggle with homePEN.

*For example the nominee may participate in professional educational sessions/research, visit others in the hospital, hold support group meetings, etc.*

**5** Additional Comments. Please explain anything else that we should know about this person.

**Return your  
form(s) by April 1 to   
Questions? Call (800) 776 - OLEY**

The Oley Foundation  
214 Hun Memorial, A-28  
Albany Medical Center  
Albany, NY 12208  
Fax: (518) 262-5528

# 2002 Oley Regional Coordinator Listing

updated  
2/5/02

Regional Coordinators are an integral part of the Oley Foundation's outreach efforts. To date, the following patients/caregivers have accepted these volunteer positions. If you need someone to speak with, or are interested in a get-together, contact the volunteer nearest you (even if he or she is not in your region). We encourage you to contact any or all of the others as they have an assortment of knowledge and experience to share. To make speaking with fellow lifeliners more affordable, Oley also circulates two toll-free numbers to experienced HPEN consumers on a monthly basis. A schedule of the toll-free numbers is printed in the LifelineLetter. The toll-free schedule, and updated RC list, are also posted on our web page @ [www.oley.org](http://www.oley.org) or available by calling the Oley office at (800) 776-6539.

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## Coverage Denied for Ostomy Supplies

The United Ostomy Association (UOA) needs your help identifying the extent of a growing threat to ostomates living in the U.S. United Healthcare, a major insurer, has discontinued coverage for ostomy supplies. It appears this is based on their re-definition of these items as “disposable,” and it is being implemented a few states at a time. So far we have heard from affected members in Illinois, Arizona, Colorado, Wisconsin and Florida. Needless to say, UOA wishes to fight this — both to preserve the access of UHC beneficiaries to coverage, and to keep other insurers from duplicating this discriminatory action.

If you have non-Medicare insurance through United Healthcare, please communicate with me at [advocacy@uoa.org](mailto:advocacy@uoa.org). Even if you are

having no trouble getting reimbursement right now, I'd like to start a database to track of the spread of the problem, and periodically update all who might be affected by the situation. This information will be used in aggregate form only, and I will seek your permission if it appears necessary to put people within the same state in touch with each other for strategizing a campaign.

Help us spread the word! If you know of anyone else having trouble getting reimbursement for their ostomy supplies, please ask them to contact me. Many thanks for your assistance.

— Linda Aukett, United Ostomy Assn.  
Tel: 856 854 3737/Fax: 856 854 5637  
[advocacy@uoa.org](mailto:advocacy@uoa.org)

## Camera, from pg. 2

Strenuous exercise is discouraged to avoid pulling off one of the wires. No eating or drinking is permitted for the first two hours of the study, after which liquids can be consumed. A small meal is permitted after four hours. The patient returns to the gastroenterologist after eight hours to have the belt and wires removed. The capsule is excreted naturally in a couple of days and is disposable; most patients never notice it.

Unlike conventional endoscopy, there is no air insufflation during the video capsule procedure, so the patient is less distended and not uncomfortable. The lack of air insufflation does not affect the viewing of the video, but does make it appear a little different to the gastroenterologist than what he/she may be used to during conventional endoscopy. Unlike conventional endoscopy, the capsule can flip over and the view can be much like CircleVision™ at Disney World.

It takes about 2-1/2 hours to load the video onto a computer, so the video is generally not seen by the gastroenterologist until the following day. Special software to help the gastroenterologist pinpoint the location of the intestine that is abnormal will soon be available, most likely in early 2002. Currently, it may be difficult for the gastroenterologist to determine the exact location of an abnormality.

There is a small risk the capsule could become lodged in the intestine. Although

the capsule is quite small, it should be used with caution in patients who have had major abdominal surgery. The capsule should not be used in patients with symptoms of a bowel obstruction, including nausea, vomiting and abdominal distention, unless the patient clearly understands the capsule could cause a complete bowel obstruction that may require hospitalization, and possibly surgery.

Physicians at Northwestern University have used the video capsule procedure on two patients with significant small bowel strictures without a problem, although the capsule did take more time to pass. There have been a couple of cases, at institutions other than Northwestern, in which patients were found to have asymptomatic strictures. These patients required hospitalization for bowel obstruction and were treated with NG tube suction. To the best of my knowledge, no patient has required surgery to remove the unplanned obstruction by a capsule, but it is always a concern.

If you think you may benefit from undergoing testing with the video capsule endoscope, you should first speak with your doctor to determine if this test would be helpful for you and potentially change the way you are treated. For more information on studies with the capsule endoscope in patients with Crohn's disease visit Northwestern's website at [www.ibdcenter.net](http://www.ibdcenter.net)  
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## Research, from pg. 7

from looking harder for subtle changes based on the therapy. Both of these factors make the data collected from a double-blind research study more convincing.

When reading research that evaluates a treatment's effectiveness, you'll also want to know whether the investigator has ruled out the “placebo effect.” This is when a subject perceives a benefit from a treatment just because “something” is being done. If the research compares the outcome from patients given treatment X to those given no treatment at all. The individuals who are to receive no treatment at all should actually be given a placebo (such as a sugar pill) that looks and tastes essentially the same as treatment X. This avoids subjective changes that might occur because “something” is being done.

Well-designed research that addresses the issues mentioned above, is often referred to as “Prospective, Randomized, Double Blind” and offers the most convincing results. Sometimes investigators are not able to use these study methods, and various other designs are reported. The results from these studies should be looked at carefully and with a certain amount of skepticism. Some of the questions that you, as a reader, should consider, include: Were all subjects comparable? If there were opportunities for bias on the part of the investigator, was care taken to avoid this? Was the number of subjects large enough to make the conclusions that were made? Was the paper adequately reviewed? (Journals that require “peer review” — where independent colleagues in the same field determine whether the study results are substantiated by the data — offer a more reliable source of research information than journals that don't.)

Finally, do not hesitate to share research articles with your physician or other health care practitioner. They are valuable resources for helping you evaluate the validity of a study, and equally important, whether the information applies to your personal situation.

*Editor's note: Medical-related information published by the Oley Foundation is reviewed by Oley's Medical and Research Director and/or other clinicians; however, the Foundation strongly urges members to carefully evaluate any information with their own physician, before making any changes in their care.* ☺

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Shirley Heller, in honor of Dr. Marian Goldsmith (Happy Hanukah!) and Suzanne Keating  
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Kevin & Janet Miller, in honor of Jonathan's 18 yrs on TPN  
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Laurie Eyan, RN  
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Stephen Abshire  
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### FRIENDS (UP TO \$30)

Hannah Abeles  
Hans Arnold  
Margaret Bald  
Sue Bauder  
Gerald Bennett, in honor of his years on HPEN  
Rudolf Bentlage, in honor of 3 years on TPN  
Ann Berger  
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City Packing Co.  
Bill & Sandra Clark  
Lee & Joyce Colouris  
Wanda Courtney, in honor of her niece Robin L. and her health and happiness  
Laura Cronin  
Curry Family, in loving memory of our friend Eydie Kirby

November 28, 2001 or later) have their acknowledgments listed. Thank you for your volunteering their time and talents.

Beth Davenport	Suzanne Keating	Toni & William Palmer	Ethel Weissman, in memory
Monica Decoteau	Deborah Kellogg	Rachel Anne Penney	of Shirley Klein
Peggy Digney	Marie Kellogg	Arnold & Gwen	Manuela Wenz
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Arthur Eggleston	my 15 years on TPN	Aimee Sable	Jesse Wise
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Richard & Louise Gabel	Eydie Kirby	Skidmore College	
Linda George	Chris LaPofla	Kathy Simons	
Gessner Family	Paula Lerfeld	Marlene Smith, in honor of	
Joyce & John Gilman, in	Carole Maiwald	my husband	
memory of Woody Freese**,**	Mayville Historical Society	Leona Strother	
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Jean Jacobs	Palenville Fire Dept. Ladies	of 14 years on HPEN	
Earl & Margie Jones	Auxiliary	Weglein-Greene Families	

**IN MEMORY OF  
JULIE BISHOP**  
Marcia Boatwright  
Rose, Jeff & Alicia Hoelle\*\*  
Charlene Key\*\*  
Michael Medwar  
Clemens Pietzner  
Sharon & Gary Sakowitz

**IN HONOR OF  
LYN HOWARD, MD**  
Dr. & Mrs. John Jenks  
Lisa, Ron, Bryan & Sarah Metzger  
Lynn R. Patton, RPh, MS  
Clemens Pietzner

\* Oley Board Trustee  
\*\* Oley Regional Coordinator  
\*\*\* Oley Staff

## Planned Gifts for Oley

The Oley Foundation would like to thank the following individuals and families for their planned gifts to the Oley Foundation. We invite anyone else who has made a planned gift or is considering one, to call Joan Bishop at (800) 776-OLEY.

*Katherine Cotter*      *Lyn Howard, MD*  
*Roslyn & Eric Scheib Dahl*      *William Hoyt*  
*Tom Diamantidis, PharmD*      *Judi Martuscelli*  
*Don Freeman*      *Kathleen McInnes*  
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*Alfred Haas*      *Judy Petersen, MS, RN*

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## Thank You for Your Support!

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Based in Evansville, Indiana, Mead Johnson Nutritionals provides medical nutritional products for infants, children and adults; and specialty formulas for patients with specific medical nutritional needs. The company's product line includes Boost®, Respalor®, Ultracal®, ChoiceDM®, Isocal®, Subdue®, Magnacal® Renal, and other specialty formulas. We thank Mead Johnson for their donation at the Supporter Level.

### Nestlé Clinical Nutrition

In the science of food and nutrition, Nestlé Clinical Nutrition draws on the expertise of Nestlé, one of the world's largest food companies, to bring the resources and commitment to provide health professionals and consumers with the most appropriate clinical nutrition solutions and services. Nestlé Clinical Nutrition provides a comprehensive line of enteral nutrition formulas and delivery systems to the health care community. The company's clinical nutrition family of products for adults and pediatrics include both tube feeding and oral supplements in the form of whole-protein, peptide-based, amino acid and special disease diets. The Peptamen® family of elemental products is well recognized and trusted by clinicians for use in patients with impaired gastrointestinal function. All products are available through the company's HomeLink® home delivery service. We thank Nestlé for their continued support.

### Baxa Corporation

Baxa develops and manufactures innovative systems for the safe and efficient preparation, handling, packaging and administration of liquid medications. Key company products include the Exacta-Mix\* 2400 and 600 Compounders and MicroMacro\* 12- and 23-Station Compounders for mixing custom TPN solutions, the Halobag\* Dual Chamber Bag for storage and shipment of 3-in-1 solutions for home TPN patients, and the Repeater\* Pump for accurate filling of medication syringes and IV bags. We are thankful for the continued, and prompt, support of Baxa.

## Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<b>MAR. '02</b>	<p><b>Carol Pelissier</b> Manchester, NH (888) 610-3008 EST</p>	<p>Diagnosed with endometriosis and pseudo-obstruction, Carol is unable to eat and on EN and TPN. She is also on pain therapy. She can share her experience with operations, an ileostomy and coping with chronic conditions. She has a medical background and until a few years ago worked full time.</p>
	<p><b>Mariah Abercrombie &amp; Felice Austin</b> Henderson, NV (888) 650-3290 PST</p>	<p><b>Mariah</b> is a freshman in college who has been on TPN since 1985 due to pseudo-obstruction. She also has a gastrostomy and ileostomy. Despite these challenges, Mariah travels, swims, jet-skis, dates and has been to summer camp. Her single-mother, <b>Felice</b>, is active in Oley and can speak about a range of parenting challenges, including insurance, advocacy and separation issues.</p>
<b>APR. '02</b>	<p><b>Donna Noble</b> Grove City, OH (888) 610-3008 EST</p>	<p>Donna's son Kyle (3 y.o.) has been on TPN for 2-1/2 years due to a mitochondrial disorder which causes delayed gastric emptying, chronic diarrhea, and malabsorption. Kyle has a g-tube for drainage, and a j-tube for medications. Call her about traveling, coordinating care w/ multiple specialists, and trying new therapies.</p>
	<p><b>Joyce Hydorn</b> Troy, NY (888) 650-3290 EST</p>	<p>A terrific Oley office volunteer, Joyce began TPN in January of 1992 as part of her battle with Crohn's disease. She has an ostomy and uses a CADD pump. She looks forward to networking with fellow consumers and sharing her experience in dealing positively with chronic illness.</p>
<b>MAY '02</b>	<p><b>Heidi Forney</b> Sweet, ID (888) 610-3008 MST</p>	<p>Heidi is the mother of a 5 yr old who has been TPN dependent due to short gut since he was 3 months old. He is also occasionally fed via g-tube, and has a variety of other issues. She looks forward to speaking with others about the many challenges of having a small child on TPN. Call from 10 am to 8 pm MST.</p>
	<p><b>Pam Rector</b> Mt. Pleasant, SC (888) 650-3290 EST</p>	<p>A new Regional Coordinator, Pam was on HEN for 3 years and has been on HPN since 1998. Diagnosed with pseudo-obstruction and gastroparesis, she has an ileostomy and a gastrostomy tube. She is a great listener and happy to share her experience with both therapies with folks in the Oley family.</p>

### LifelineLetter

**The Oley Foundation**  
214 Hun Memorial  
Albany Medical Center, A-28  
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## Save the Dates!

17th Annual  
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