

Lifeline Letter

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

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Learning Together, Sharing Good Times — 17th Annual Conference Was a Huge Success

The 17th Annual Oley Consumer/Clinician Conference, held June 20 to 22 in Buena Park, California, was hugely successful by all counts. Flooded with new and returning families, Oley was pleased to offer several special programs for homePEN children and their siblings: including trips to Disneyland, Knott's Berry Farm and a local fire station; a pajama party and a sharing session just for teens. The adults had plenty of fun as well — from a soiree for the Regional Coordinators, to a comedian at the welcome reception,



Kids lining up for the trip to Disneyland.

from free admission to Knott's Berry Farm, Heather and Andrew Abbott with Snoopy to a shopping extravaganza at the auction. Attendees told us even the information sessions like Oley's "Who Wants to Be a Millionaire" were a fun way to learn more about tube feeding tips and caring for their catheter. Both new and old attendees left the conference better educated about their therapies and how to live fully with them. Highlights included discussions on such topics as gastric pacing, interventional radiology and pain management. Some of the main sessions will be covered in this and future issues of the newsletters; all of the main sessions will also be available on videotape this fall. Stay tuned for more photos and information! ☺



Heather and Andrew Abbott with Snoopy

Just so you know...

The Oley Foundation has a strict policy of not sharing its membership list with anyone: patients, healthcare professionals, Oley Regional Coordinators, research institutions, homecare companies, other non-profit organizations, etc. We are very protective of our members' right to privacy.

Rest assured that no one has access to the names, addresses or phone numbers of our members **BUT when a member chooses to share contacting information by responding to a mailing, advertisement, entering a contest, etc. the landscape changes and members should be aware of that.** The door is then opened for solicitation!

Oley will share a consumer's name and contacting information with another consumer for networking and outreach purposes, but only after getting permission from the consumer first.

If you have any questions, concerns or would like to discuss this policy further, please contact Joan Bishop, by phone (800) 776-6539/(518) 262-5079; or email BishopJ@mail.amc.edu. ☺

Try Your Hand at the HPEN Millionaire Quiz

Back by popular demand, a fun spin-off of the TV show was enacted at the 2002 Oley Consumer/Clinician Conference in Buena Park, CA. Highlights from the program are printed below in quiz format. Answers to the questions begin on page 12. A warm thank you to all of the contestants for being such good sports, and to Regis aka Rex Speerhas, RPh, BCNSP, of the Cleveland Clinic.



Contestant #1:
Suzanne La Vere Herbst,
RN, MA; Vascular Access
Device Consultant

\$100 Question: When was the first tunneled catheter inserted for long term use?

- A. 1944
- B. 1957

- C. 1969
- D. 1975

Millionaire cont., pg. 2 ☺

Millionaire, from pg. 1

\$500 Question: Which of the following is typically NOT a long term Vascular Access Device (VAD)?

- A. Tunneled catheter
- B. Implanted port
- C. Triple lumen non-tunneled catheter
- D. Peripherally inserted central catheter

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The Oley Foundation
For Home Parenteral and Enteral Nutrition
214 Hun Memorial, A-28
Albany Medical Center
Albany, NY 12208
1-800-776-OLEY, or (518) 262-5079
Fax: (518) 262-5528

E-mail: BishopJ@mail.amc.edu
DahlR@mail.amc.edu
WilsonE@mail.amc.edu
HarrinC@mail.amc.edu
Web page: www.oley.org

Executive Director:

Joan Bishop

Director of Publications & Information:

Roslyn Scheib Dahl

Outreach Coordinator:

Eleanor Wilson, RD

Administrative Assistant:

Cathy Harrington

Lifeline Advisory Group:

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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.

\$1,000 Question: The most common complications associated with VADs are:

- A. Nausea and vomiting
- B. Ringing in the ears and dry mouth
- C. Occlusions and infections
- D. Inadvertent removal of the catheter by the patient

\$3,000 Question: Approximately what percent of VAD occlusions are non-thrombotic and what percent are thrombotic?

- A. 20% non-thrombotic / 80% thrombotic
- B. 30% non-thrombotic / 70% thrombotic
- C. 40% non-thrombotic / 60% thrombotic
- D. 50% non-thrombotic / 50% thrombotic

\$6,000 Question: Which of the following is the most common sign of a VAD occlusion?

- A. Pain on infusion
- B. Fever
- C. Swelling in the neck, face or arm
- D. Sluggish flow or poor blood return through the catheter

\$15,000 Question: Which of the following is a reason for treating VAD occlusions?

- A. Ensuring continued ability to infuse and withdraw
- B. Lowering the risk of subsequent complications, including infection, venous thrombosis, and pulmonary embolism
- C. Preventing a small thrombosis from growing larger and more difficult to treat
- D. All of the above

\$32,000 Question: You are experiencing a VAD occlusion. After ruling out obvious medical problems, a first choice of treatment is often:

- A. Device removal and placement of a new VAD
- B. Referral to interventional radiology
- C. Intraluminal instillation of a thrombolytic agent
- D. Ignore it and try the device later

\$64,000 Question: The only drug currently approved by the Food and Drug Administration (FDA) for clearing suspected thrombotic catheter occlusions is:

- A. Urokinase
- B. Streptokinase
- C. Alteplase
- D. Heparin

\$125,000 Question: A person with venous thrombosis could display which of the following signs and symptoms?

- A. Swelling in the face, neck, or arm
- B. Superficial collateral veins
- C. Numbness or tingling in extremity
- D. All the above

\$250,000 Question: Signs and symptoms of VAD related infection include:

- A. Fever and chills
- B. Muscle aches and fatigue
- C. Weakness and hypotension
- D. All of the above

\$500,000 Question: Treatment options for VAD related infection include:

- A. Removal and replacement of device
- B. Administration of antibiotics
- C. Administration of antibiotics and thrombolytics
- D. All of the above

\$1,000,000 Question: What is Snoopy's favorite ice cream flavor?

- A. Schroeder strawberry
- B. Charlie Brown chocolate
- C. Peppermint Patty
- D. Pigpen peanut butter



**Contestant #2:
Sheila Messina, RN, MA;
Experienced HPN
Consumer**

\$100 Question: You are a new HPN consumer. You have lots of questions but don't know who to ask. What can you do?

- A. Call your doctor
- B. Go to your local pharmacy and ask the pharmacist
- C. Go on-line and hope to find a helpful website
- D. Call your home care provider

\$500 Question: Your spouse is on HPN. The noise of the pump drives you nuts. You can't sleep at night and your work is suffering. What can you do?

- A. Talk to your spouse
- B. Call your spouse's physician
- C. Sleep in another room
- D. Grin and bear it

Millionaire cont., pg. 6

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.

Device allows feeding tube to go through an ostomy bag without leakage.

This tip is applicable to a small, very specialized portion of our tube-feeding readers and should be discussed with your physician before trying.

Most physicians see important advantages to a patient using their gastrointestinal tract, even if accessing it is somewhat complicated. For example, tube feeding is sometimes done through a small bowel ostomy that is also the site of some secretions, and thus requires an ostomy bag for collection. This might happen if the patient has a pull-through small bowel ostomy and feeding into the more distal bowel is desirable, or if the patient has a Roux-en-Y feeding jejunostomy.

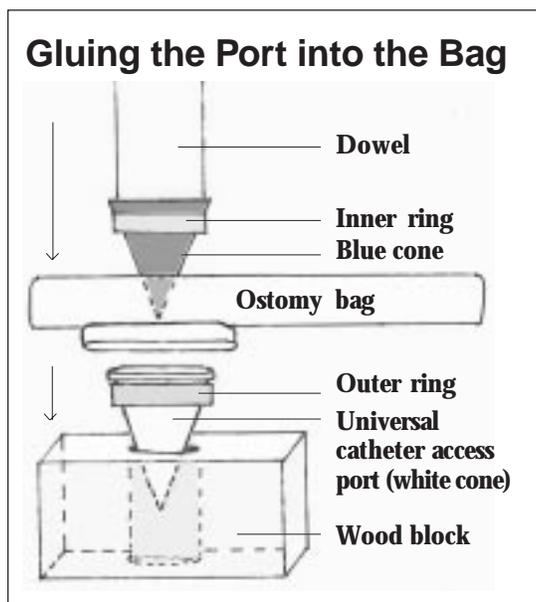
The challenge is to insert the feeding tube through the ostomy bag and avoid any leakage onto the skin. This can be achieved by gluing a "universal catheter access port" (a soft white cone) into the ostomy bag. A consumer in upstate New York developed a simple technique for this process which is described and illustrated below. Using the port allowed him to insert his tube for overnight feeding and remove it during the day, without compromising the functionality of his ostomy bag which only needed to be changed every five to seven days.

Equipment Needed:

- universal catheter access port (Hollister, #HOL 9779) that includes:
 - the port itself (a soft white cone)
 - hard plastic blue cone for inserting the port
 - plastic rings, inner and outer, to help hold the port in place
- approximately 4" long block of 2" x 4" wood, with a hole the diameter of the port's outer ring drilled through it
- wooden dowel, or end of a broom handle
- super glue
- ostomy bag

Gluing the Port into the Ostomy Bag

1. Put the outer ring on the port (soft white cone) and place them tip down into the hole in the wooden block. (The block is used to hold the port and outer ring in place while gluing.)



2. Next, place the ostomy bag face (hole-side) down, on top of the port on the block, centering the bag's hole over the port.

3. Place the inside ring on the hard blue cone, then carefully apply a small amount of super glue to the exposed surface of the inside ring.

4. Using the wooden dowel for pressure, poke the blue cone (tip side down) through the back side of the ostomy bag and into the white cone. This action will make a hole in the ostomy bag, and leave the port sandwiched between the inner and outer rings.

5. Hold in place until the glue sets (about 1 to 2 minutes). Remove the blue cone.

6. Snip the tip of the port carefully, to make a hole just large enough to fit the feeding tube through.

To change the ostomy bag and/or prepare for a feeding, attach the ostomy bag to your body. Then insert the feeding tube through the hole in

the back of the ostomy bag, through the port, and into the distal bowel until it reaches the length indicated by your physician.®

Equipment Exchange

The following HPEN supplies are offered free of charge:

- IMED TPN pump (for use with IV pole)
- CADD TPN pump (portable) †
- 2 Provider One TPN pumps (portable) †
- Provider One backpack, battery pack (no pump)
- 2 Extension tubes 24" #8-2422, for Ross or Mic-Key †
- 3 extension tubes 24" #54971, Y-port for Ross Hide-a-port †
- 5+ cases Perative formula
- 1 case Peptamin, Jr. w/ 24 flavor packets
- Companion Flexiflo bags: 40 - 1000 ml, 12 - 500 ml
- 5 Hollister drain/tube attachment devices

†FREE shipping offered.

For more information, call (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated 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.

Study Recommends Chlorhexidine for CVC Site Care

Chlorhexidine gluconate used for central venous catheter (CVC) site cleansing can reduce the risk of bloodstream infections by 49% compared with povidone-iodine, according to the results of a meta-analysis reported in the June 4 issue of the *Annals of Internal Medicine* [Ann Intern Med. 2002;136(11):792-801.]

Eight in-hospital, randomized control studies involving a total of 4143 catheters of various types were included in the analysis. Most of the catheters (36%) were central venous catheters. In patients whose catheter sites were disinfected with chlorhexidine gluconate, about 1% developed bloodstream infections, as opposed to 2% for those whose catheters were disinfected with povidone-iodine.

From this data the authors conclude that chlorhexidine gluconate solution is significantly more effective than povidone-iodine solution for preventing vascular catheter-related infections. They estimate that for every 1000 catheter sites disinfected with chlorhexidine gluconate rather than povidone-iodine, 71 episodes of catheter colonization and 11 episodes of catheter-related blood stream infection (CRBSI) would be prevented.

Why Chlorhexidine May Be Better

The authors postulate that chlorhexidine gluconate may be superior for catheter site care for several reasons. First, blood, serum, and other protein-rich biomaterials can deactivate the microbicidal effect of povidone-iodine but not chlorhexidine gluconate. Second, chlorhexidine gluconate has a much longer active antimicrobial suppression than povidone-iodine. Third, chlorhexidine gluconate has been proven better than povidone-iodine at reducing colony counts of coagulase-negative staphylococci.

The Final Word

Readers should be cautioned against generalizing the results to their own experience, since the studies looked at *in-hospital* catheter use, and the catheter was in place *only 1 to 10 days*, on average.

Despite the limitations the implications of this research are substantial in reducing costly, life-threatening infections. Ironically, cost may be one reason why chlorhexidine gluconate is not more widely used; the author's report chlorhexidine gluconate costs approximately \$0.92 for a quantity sufficient to prepare an insertion site for a CVC, versus \$0.41 for a similar quantity of povidone-iodine. They are hopeful that a cost-savings maybe found with further analysis that adjusts for the cost of treating a CRBSI. ©

In Memory of Shawn Seiz

Shawn Seiz, a 15 year old consumer from Ocean City, Maryland, died August 3, 2002. The son of Regional Coordinator, Ellen Seiz, he had been on both HEN and HPN since birth due to a mitochondrial dysfunction, motility disorder, and neuronal intestinal dysplasia. Shawn enjoyed his first summer camp experience with fellow teen consumers in 1997, and returned to the Double "H" Hole-in-the-Woods camp in Lake George, NY every year after, until this year. He had a beautiful way of looking beyond his condition and braved his pain with smile. We will remember him fondly.

Memorial contributions, to be used exclusively for G.I. research, may be sent to A.I. Dupont Hospital for Children, PO Box 269, Wilmington, DE 19899 ATTN: Sharon Racine, in memory of Shawn Seiz.



Shawn at Double "H" camp, July, 1998.

Tubes

by Shawn Seiz
*The tubes go in not only the body
 But the soul.
 They can torture the soul
 And tease it,
 But they cannot kill it.*

Health

by Shawn Seiz
*Health is nothing.
 Only the will of God
 And your soul
 Will make you feel better.
 Medicine is a placebo
 For the mind and the body.*

Celebrating Life!



Mary Ann

Mary Ann Jereb, who has been on TPN for nearly 15 years, is a perfect example of someone celebrating life. She likes to write poems and articles, loves to read, is a member of three book clubs and plays bridge often. Mary Ann's husband Joe says she loves people and is very compassionate about those who are less fortunate. Congratulations Mary Ann!



C O R A M
 NUTRITION SERVICES



To nominate someone to Coram's Celebration of Life Circle, send the story of a friend or loved one to: Coram's Celebration of Life Circle, 1675 Broadway, Suite 900, Denver, CO 80202 or, email: celebrate@coramhc.com For information, please call: 972.394.9974

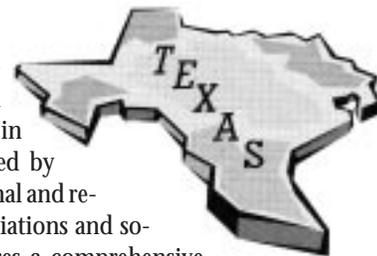
Support Meetings in Idaho

Oley Regional Coordinators Linda Wyatt and Heidi Forney are organizing a support group in the Boise/Southwestern Idaho area. HomePEN consumers, caregivers and family members from anywhere in the state or surrounding states are welcome to participate. Meetings will be held the second Wednesday of every month at 7:00 p.m. in the Cheyenne Room (lower level, use elevators on south side) of St. Luke's Meridan Medical Center, I-84 and Eagle Road, Meridan, Idaho. If you have any questions, concerns or just want to talk, please call either coordinator: Linda Wyatt (208) 922-1797 after 7 p.m. MST, Heidi Forney (208) 584-3708. ☺



Oley to Co-Sponsor Nutrition Week 2003

Olé for Oley! Mark your calendar! Nutrition Week 2003 will take place January 18-22, 2003 in San Antonio, Texas. Developed by non-profit, scientific, educational and research-oriented nutrition associations and societies, Nutrition Week features a comprehensive educational and scientific program focusing on the latest research, clinical practice and technological advances in clinical nutrition.



Always an exciting event, this year the Oley Foundation is a sponsoring organization! We are tapping into the nation's best and brightest in the nutrition support world, and offering an Oley Foundation Regional Nutrition Support Workshop on Saturday, January 18th, in the San Antonio Convention Center from 9 a.m. to 5 p.m. Consumers attending the workshop Saturday will receive special passes to tour the Exhibit Hall on Sunday, seeing the latest in product and technology innovations.

We are also in need of volunteers to staff the Oley booth at various times throughout the week. Booth volunteers will assist us in spreading the word about Oley in the Exhibit hall, and can attend the clinical programs free of charge.

We are currently finalizing faculty and arranging for group hotel rates in San Antonio — watch the Oley and ASPEN websites for updates and registration information. The Oley Program is free, as are the Sunday Exhibit Hall passes, but non-booth volunteers would be required to pay to attend the clinical programs. This is going to be terrific program! For more information about attending or volunteering, contact the Oley Foundation office or email Ellie Wilson, RD, Outreach Director at wilsone@mail.amc.edu. ☺

Join Oley in Spokane

On October 26th, 2002 the Oley Foundation will host a Consumer/Clinician Regional Nutrition Support Workshop in beautiful Spokane, Washington. The program is free to all consumers and their families/caregivers; clinicians are welcome as well.

The one-day event will run from 9:00 a.m. to 4:30 p.m., and will cover a variety of topics, such as enteral issues, catheter care, coping with homePEN, understanding management, lab results, pain included, and others. Lunch is industry representatives will display new technologies and products.



Consumers, come meet folks like yourself! Parents, this is a great way to network with other parents facing the same challenges you are. Clinicians, join us and leave with the resources to offer patients truly holistic care. (Continuing education credits will be available for some disciplines.) For more information on the conference, call (800) 776-6539/(518) 262-5079; visit www.oley.org; or email the conference coordinator, Ellie Wilson, RD, at wilsone@mail.amc.edu. ☺

Realtor Donates Profits to Oley

Susan Noble, a real estate agent with HER Realtors in central Ohio, and aunt to HPN consumer Kyle Noble, has generously offered to donate 5% of her net commissions to the Oley Foundation and The Stefanie Spielman fund for Breast Cancer Research.

Although she is an agent in central Ohio, she can generate donations from home buyers and sellers across the country, through her company's referral network. Here's how it works: if you are looking for a realtor to buy or sell a home anywhere in the U.S., and you call Susan first, she will connect you with her referral department; they, in turn, will put you in touch with some agents in your area to interview. If you choose one of these realtors referred to you, Susan receives a 20% referral fee, 5% of which she would donate to the Oley Foundation. For more information, contact Susan at voice mail: 614-734-7888; home phone: 614-793-9229; cell ph.: 614-619-4245; email: susan.noble@herrealtors.com; or visit her website at: www.herrealtors.com/susan.noble. ☺

"Being part of the Nutrishare family has helped enrich my life on TPN."

Lee & Marshall Koonin - Highland, Maryland



Nutrishare, Inc.
1-800-HOME TPN

Nutrishare scored an unprecedented 100% on its latest ACHC accreditation survey.

Oley Celebrates 2002 Award Winners' Exemplary Attitudes and

LifelineLetter Annual Award

Don Freeman • Nepean, Ontario, Canada

Don is a 21-year HPN veteran and a long time, dedicated Oley volunteer. He has served as an Oley trustee and regional representative for more years than we can count. He founded the Canadian Parenteral and Enteral Nutrition Association which provides information and support to consumers throughout Canada via a newsletter and web site. He's raised a wonderful son, Michael, and volunteered as a coach, ski patroller, scouting leader, curling manager, and more. On top of this, until he retired a few years ago, Don worked full-time for the Canadian government.

An avid traveler, Don has taken numerous trips on HPN across Canada and the United States, and has been to Europe several times. His actions and advice have inspired many consumers to travel beyond their immediate surroundings. No unforeseen obstacle will deter Don from getting away, as exemplified by his ingenious solution of gravity feeding — hanging his TPN bag from his ski tips — when his pump charger burned out on a trip to Germany.

Of course, his first trip suggestion has always been, "Go to an Oley conference." Don has been to almost every Oley conference himself, and has recorded them, through his fabulous photography, for the benefit of *Lifeline* readers.

Don's willingness to share his expertise in travel and the Canadian health system, as well as his experience with Crohn's disease and positive attitude about HPN with anyone who asks, is what makes him so special. We are honored to share this award with him today.

Nominees:

Jim Cowan, Cleveland Heights, OH
 Anna Cyr, Sabattus, ME
 Todd Friedman, San Pedro, CA
 Jane Golden, Watertown, CT
 Brenda Hawn, Warren, OH
 Barbara Klingler, Malabar, FL



Don receives his award from Oley President Steve Swensen and Executive Director Joan Bishop.

Sonjia Layton, Buccan, Australia
 Nathan Marlow, Muncie, IN
 Jerry Mayer, Indianapolis, IN
 Sheila Messina, San Jose, CA
 Donna Miller, Highland, CA
 Helen Miller, Baltimore, MD
 Laura Mucha, Gilbert, AZ
 Eleanor Orkis, Schenectady, NY
 Don Young, Porter Corners, NY

Lenore Heaphey Grassroots Education Award

Donna Miller, RN • Highland, CA

Donna has opened her heart and her home to more than 100 medically fragile foster infants and small children during the past 21 years, a third of whom are maintained on homePEN. She is "Mom," nurse and more for four-to-six children at a time, providing a caring and loving family and home.

It all began when Donna and her husband applied to be part of a pilot program that would allow foster homes to accept children with stomas. State regulations at that time required these children to be institutionalized (for years, if necessary) until their medical conditions were resolved to the point where they could return to their natural parents or be adopted. Instead of being hospitalized indefinitely, these children are now sent home to Donna (and others like her). When the children are ready to move on, Donna trains their parents on how to meet their remaining specialized nursing care needs. She has pro-

vided this special training to more than 50 parents in the past five years alone.

As if this weren't enough, Donna went back to school and in 1989 obtained her certification as an RN, in order to provide more and better nursing services for the children in her home. She has been a Regional Coordinator for several years, spreading the word about Oley in her area and generously sharing her experiences with other parents over the phone and at conferences. She also helped to organize this year's conference.

Donna has demonstrated exceptional courage, perseverance and commitment towards helping homePEN children regain their health and lead as normal a life as possible. We are in awe of her accomplishments and



Donna teaching a parent how to feed her child.

how gracefully she handles them. Keep up the good work, Donna!

Nominees:

Don Freeman, Nepean, Ontario, Canada
 Donna Noble, Grovescity, OH
 Eleanor Orkis, Schenectady, NY
 Patty Woods, Hemet, CA

Accomplishments — Congratulations!

Mead Johnson Enteral Award Erin Nicole Shore • West Hills, CA

Diagnosed with gastroesophageal reflux (GERD), dysmotility, allergies and an eating disorder, Erin has been fed by tube for five of her six years of life. Like others with these diagnoses, she has undergone multiple surgeries and hospitalizations, and is limited as to what she can and cannot eat. Despite these challenges, Erin is optimistic. She has a wonderful sense of self and self esteem. She also has a great sense of her body image, and proudly wears a two-piece swim suit to the beach or pool.

At school she is known by her teachers as an outgoing friend to her peers. She enjoys helping her fellow classmates and is compassionate to children with or without disabilities, looking only to celebrate the unique person they really are. To be sure her transition to school went smoothly, Erin decided to educate her peers at the beginning of the year about her condition and tube. By letting

them know she is comfortable talking about her medical issues and willing to answer their questions, they became comfortable with her and her situation.

The one thing Erin is not comfortable with, is getting special treatment because of her condition. When her classmates have tried to give her special status, like first in line, Erin graciously refuses — reminding them she is perfectly capable of waiting her turn. This attitude is echoed by the brave, smiling face she assumes at school and in the hospital, despite her pain. She advocates for herself with hospital clinicians and has taught them and her loved ones how to be strong.

Erin is ready and willing to try anything. She enjoys skiing and horse back riding. She loves a new challenge and sets her sights high for the future. We salute her shining, exemplary attitude!



Erin accepts her award at the 2002 Oley conference.

Nominees:

Ashley Rowley, Ontario, CA

Oley Foundation Young Adult of the Year Luke Vohsing • Granville, OH

Luke is an exceptional 14-year-old who lost all but 10 inches of his small bowel when he was in 3rd grade. Eager to educate his peers, Luke went before his class when he returned to school and explained his surgery, what short bowel syndrome is, and all about homePEN. Like other outgoing and active teenagers, Luke participates in school, scouts and sports. What sets him apart, is his ability to handle his struggles with grace, and to continually look on the bright side.

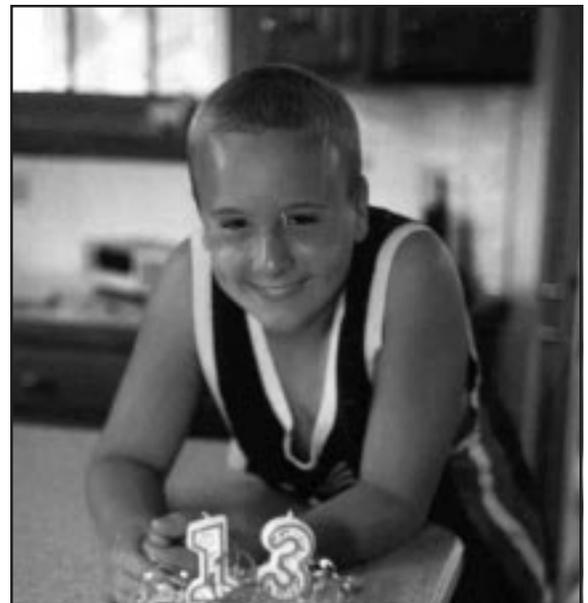
After years of interrupted sleep, Luke invented a device to prevent his feeding line from occluding during the night. He entered this device in a prestigious science fair and won second place. He is working on getting the device patented and produced. The news of his award has also allowed Luke to educate people about SBS and homePEN, via the press coverage it has generated.

Luke puts his energy into living first, and then fits in his medical needs. This philosophy has enabled him to live fully and to give to others. Luke works with parents who have

children on homePEN who are too young to speak for themselves. He explains what it is like to be on therapy, answers questions for them, and most of all gives them hope for their children's future. He also volunteers in a variety of capacities for Columbus Children's Hospital, including educating new staff members on what it's like to be a patient there. We are proud to present him with the Young Adult of the Year Award.

Nominees:

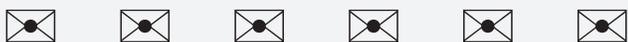
Paul Butzin, Graytown, OH
Maisy Cyr, Sabarrus, ME
Malory Cyr, Sabattus, ME
Rommel Degracia, Lynnwood, WA
Roy George, Syracuse, NY
Owen Huss, Longmont, CO
Katherine Jones, Portland, OR
Lakisha Judge, Kelso, WA
Nina Marie Marino, Clearwater, FL



Luke celebrating his 13th birthday.

Lauren Moore, Nashville, TN
Maggie Neff, Middlebury, IN
Shawn Seiz, Ocean Pines, MD
Chelsey Williamson, Lake Elsinore, CA
Colyn Woods, Hemet, CA

Awards cont., pg. 8 ←



Lifeline Mailbox

Hypnosis Dissipates Fear Before Surgery

Dear Lifeline Editor:

I really enjoyed the article "Making Friends with Fear" in the May/June issue. Ms. Messina is absolutely right that in the case of surgeries, familiarity does not breed fearlessness.

I've had six surgeries, one of which was 15 hours long and included hyperthermic chemotherapy on the operating table. The magnitude of the surgery was terrifying, as I knew I would also lose my spleen, my gallbladder, possibly my stomach, and several feet of intestine.

My surgeon was kind enough to send a very complete description of the entire procedure, starting from the day before surgery, continuing through waking up in ICU, and eventually being transferred to the floor. I took this description to a hypnotist (who was also an MD). He took me through the whole experience under hypnosis, giving me cues such as "when you see the nurse who wheels you into the operating room, you will feel relaxed, and you will know that there's no where else in the world you should be." He gave me similar cues to help me relax with the bright lights and noise in the ICU, etc.

The morning of the surgery, I was so relaxed that I didn't need the pre-surgery medication. I truly felt that I was doing exactly the best thing in life, and I believe that the benefits of hypnosis helped my body to heal.

— Carole Koda
Nevada City, CA

Awards, from pg. 7

Nan Coutts Award for Ultimate Volunteerism Pat Brown, RN, OCN, CNSN • New York, NY

"And now abideth faith, hope, charity, these three; but the greatest of these is charity."

— I Corinthians, 13:13

These words are surely inscribed in Pat Brown's heart. We don't believe that "no" — "I don't have time" — "I'm too tired" — or "I can't" are even in her vocabulary. Pat has served through the Oley Foundation since its early days, has been an Oley trustee for seven years, and has worked at one of the larger and older nutrition support programs since 1977.

She has steadfastly supported Oley on many levels, a few of which include: providing on-the-spot consultations in the middle of the night; co-authoring the HEN and HPN complication charts; providing and tagging auction items; registering conference attendees; and chaperoning youth activities. Her photos of conferences and other gatherings are countless; she can be recognized by her camera.

But that work merely touches the surface of Pat's loving devotion as a volunteer. She accompanies patients to the hospital and follows up on their care. She sits at the bedside of patients who are ill; helps calm their fears and comforts them; sees that medical treatment is provided; counsels with family members. She has even shared her own hotel room so that attending a conference would be affordable for someone who would otherwise not be able to attend.

As a volunteer Pat expects no payment, no trade off, no favors, no acknowledgment; and if she were to ask for anything, it would be, "What needs to be done and how can I help?" She spends countless hours for others and shoulders the expenses herself. The candidate chosen to receive the first annual award for the Ultimate Volunteer will set the standard for those who follow. Pat Brown is a spirit-sustaining individual whose selflessness quietly flows through the lives of so many, giving them hope and ease along the way. Although Pat has earned professional accreditations that indicate what she has **learned** — RN, OCN, CNSN — we would like to add four more letters to indicate what she **is**. They are L. O. V. E.



Pat Brown, RN, OCN, CNSN

Nominees:

Patti Keagley, RN, Westerville, OH
Nancy Stoner, RN, MSN, Philadelphia, PA
Douglas Wilmore, MD, Boston, MA

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Many thanks to the following companies and individuals for their generous contributions of money, time and talent.

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Patty Woods; Laurie Reyen, RN

19th Annual Picnic

Nutrishare, Inc.

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Coram Healthcare

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Abbott Laboratories/Creative Network

Thursday's Lunch Buffet:

Coram Healthcare

Conference Registration Bags:

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Nestlé Clinical Nutrition; Radisson Knott's Berry Farm Resort

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Awards:

Jan & David Holder; Mead Johnson Nutritionals; Judy Peterson, RN, MS

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Youth Activity:

Thursday: Knott's Berry Farm Outing
NeoSan Pharmaceuticals; Woods Family; Director Gary, Liz & Chip Ungriect; Captain Mike Bongorz, Firefighter Dave Hellman; Pala Fire Department Chris Hutch; Ashley Kunz; Chris Nichols; Joe Scoma

Friday: "Transitioning to Independence" and Disneyland Outing

Sims Deltec; Mariah Abercrombie; Alicia Hoelle; Malisa Matheny; Ian Dawes; Richie Berry; Debbie Scott, RN; Wesley Scott; Finesh Child, RN; Chris Child; Mike & Jamie Cartwright; Tammy Adams; Craig Petersen...and special thanks to Joan Gordon, MSW, for doing such a super job with "Transitioning to Independence"

Exhibitors, con't

Nestlé Clinical Nutrition; Novartis Nutrition; Nutrishare, Inc; Ross Products Division of Abbott Labs Inc.; Jack Saladow & Associates; Shield Healthcare, Inc.; SIGMA International; Thomas Crown Publishing; United Ostomy Association; Zevex Inc

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Josie Stone; Joel Resnick; Suzanne Herbst; Michael Rigas; Tim Joyce; Linda Wyatt; Darien Small

Silent Auction

Thank you to everyone who donated items, and to our volunteers, Shirley Heller; Jeff Hoelle; Maryland Mayer; Steve Swensen; David Miller; and Stephanie Pelham

Registration

Huge thanks to Stephanie Pelham; Jeff Hoelle (aka Mr. Oley); Donna & David Miller

Faculty

Mariah Abercrombie; Marvin Ament, MD; James Bartley, M.D., Ph.D., FACMG, FAAP; William Berquist, MD; Patricia Brown, RN, CNSN, OCN; Alan Buchman, MD; Mark H DeLegge, MD; Tom Diamantidis, PharmD; James Dolenga; Joan Gordon, MSW; Suzanne F. Herbst, RN, MA; Alicia Hoelle; Lyn Howard, MB, FRCP, FACP; Carol Ireton-Jones, PhD, RD, LD, CNSD; Lorie Judson, PhD, RN; Darlene G. Kelly, MD, PhD, FACP; Marquelle Klooster, MD; Vanessa Kumpf, PharmD, BCNSP; Jim Lacy, RN, CRNI; Henry C. Lin, MD; Barbara Lorenzen, RN; Malisa Matheny, RN, BSN; Richard W. McCallum, MD, FACP, FAGC; Larry McInnes, MSW; Sheila Messina, RN, MA; Reid Nishikawa, PharmD, BCNSP, FCSHP; Craig Petersen, RD, CNSD; Sally Rajcivich, RN; Laurie Reyen, RN, MN, CNSN; Betsy Rothley, RN, MSN, FNP, BC; Christopher Russell; Paula Sandoval, RD; Gail Egan Sansivero, MS, ANP, AOCN; Rex A. Speerhas, RPh, CDE, BCNSP; Ezra Steiger, MD; Josie Stone, RN, CPNP; Elizabeth Tucker; Jorge H. Vargas, MD; Marcia Wise, RN ☺



Conference Co-Chair Patty Woods, with her husband Darrell (left) and Richard Rivett (center)

Child Care/Trip to Fire Department:

Nutrishare, Inc.; Woods Family; Kay McKnight; Kim Hall; Chief Kevin Brame and family; Captain Mike Morganstern; and the personnel from Orange County Fire Authority

Gifts/Flowers for Award Winners:

FAS Medical; Shirley Heller

Photographs:

Pat Brown, RN; Don Freeman; Tim Joyce; Patty Woods

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Conference Coverage

Millionaire, from pg. 2

\$1,000 Question: I have to infuse so much fluid each day that it is affecting my social life. What are my choices?

- A. Don't infuse on the night you want to stay out late
- B. Increase the rate of the infusion
- C. Talk to your physician about reducing the volume
- D. Don't take all your infusion

\$3,000 Question: We are having a conversation about Fosamax and Aredia. We are talking about:

- A. Medications used to treat osteoporosis
- B. Herbs that promote energy
- C. Seasonings for summer salads
- D. Medications added to TPN

\$6,000 Question: You would like to start an Oley group in your area. How do you get started?

- A. Advertise in your local newspaper
- B. Put a notice up at the local hospital
- C. Call Oley and ask for help starting a group
- D. Talk to your friends

\$15,000 Question: HPN consumers need to have lab work done regularly because:

- A. The doctor wants to know the results
- B. It is important to monitor your body's response to HPN
- C. HPN increases your blood supply and you need to have some removed on a regular basis
- D. Your home care provider told you so

\$32,000 Question: You are very tired of having to explain your medical history each time you see a new health care provider. To avoid this you can:

- A. Make a video and show it to the clinician
- B. Refuse to give any information
- C. Carry an updated medical history with you
- D. Recognize that you may not have a choice

\$64,000 Question: I have been told that I need an ERCP. This is an examination that:

- A. Looks at the rectum using a sigmoidoscope
- B. Visualizes the gallbladder through a laproscope
- C. Examines the pancreatic duct using a special endoscope
- D. None of the above

\$125,000 Question: When I tell my doctor how much pain I have after eating I am told there is nothing wrong and it will go away. What can I do?

- A. Believe your doctor and do nothing
- B. Get a second opinion
- C. Start taking OTC pain medications
- D. Talk to your best friend

\$250,000 Question: If you have a central line and a stoma it is important to care for them separately because:

- A. It can get real messy changing them at the same time
- B. You can contaminate the central line with material from the stoma
- C. No particular reason, it is just done that way
- D. Because the visiting nurse told you

\$500,000 Question: A major reason you want to smile instead of frown is:

- A. It takes more muscles to frown and that can be very tiring
- B. Frowning promotes wrinkles
- C. It just feels better
- D. All of the above

\$1,000,000 Question: What is Snoopy's favorite ice cream flavor?

- A. Schroeder strawberry
- B. Charlie Brown chocolate
- C. Peppermint Patty
- D. Pigpen peanut butter



Contestant #3:
Craig Peterson, RD,
CNSD; HPEN
Educator/Researcher;
UC Davis Medical Ctr

\$100 Question: How many people in the

U.S. receive tube feedings each year?

- A. Over 5,000
- B. Over 10,000
- C. Over 100,000
- D. Over 1,000,000

\$500 Question: When is the optimal time for receiving instruction in tube feeding administration?

- A. In the middle of the night, on the phone with your nurse, dietitian, or pharmacist
- B. At home, a few days after being discharged

- from the hospital on tube feedings
- C. In the hospital, when tube feedings are initiated
- D. No instruction is necessary, the entire process is intuitive

\$1,000 Question: What is the best temperature for administering tube feedings?

- A. Room temperature
- B. Refrigerator temperature
- C. Body temperature
- D. 37°C

\$3,000 Question: What is the proper fluid to use when flushing enteral feeding tubes?

- A. Cola
- B. Cranberry juice
- C. Liquid-Plumr®
- D. Water

\$6,000 Question: How often should a feeding tube be replaced?

- A. When the tube malfunctions
- B. Every month
- C. Every 3 months
- D. Every year

\$15,000 Question: Which is the most common cause of feeding tube occlusion?

- A. Feeding formula
- B. Stomach acid
- C. Medications, and medications interacting with formula
- D. Gremlins

\$32,000 Question: What action should be taken if a gastrostomy tube comes out in the middle of the night?

- A. Panic
- B. Replace with a tube of the same French size immediately
- C. Get a good night's rest and deal with it in the morning
- D. Call your doctor for advice

\$64,000 Question: When traveling by airplane, what should be done with a gastrostomy tube balloon?

- A. Deflate balloon to 50% of usual volume
- B. Deflate balloon entirely
- C. Maintain balloon at usual volume
- D. Inflate balloon to 20 times its usual volume, allowing you to act as your own personal flotation device, in the event of a water landing

\$125,000 Question: At what residual stomach volume should tube feedings be held?

- A. There is no specific volume
- B. 100 ml or higher
- C. Greater than half of the volume of the previous 4 hours of feeding
- D. 200 ml or higher

\$250,000 Question: A feeding formula is termed "isotonic" if the concentration of particles in solution is:

- A. Significantly higher than the concentration of particles in blood
- B. Significantly lower than the concentration of particles in blood
- C. The same concentration of particles as blood contains
- D. The same as that found in fruit juice or soft drinks

\$500,000 Question: Diluting an isotonic feeding formula will:

- A. Improve stomach emptying
- B. Improve tolerance to feedings
- C. Reduce the risk of contaminating formula
- D. Reduce the nutrient content of the formula

\$1,000,000 Question: What is Snoopy's favorite ice cream flavor?

- A. Schroeder strawberry
- B. Charlie Brown chocolate
- C. Peppermint Patty
- D. Pigpen peanut butter

Contestant #4: Marvin Ament, MD, Pediatric HPN Specialist, UCLA Medical Ctr.



\$100 Question: In 1974 the first person to go home on TPN was discharged from the UCLA Medical Center. Who taught her how to care for her Broviac catheter and administer her TPN?

- A. Her nutrition support nurse
- B. Her pharmacist
- C. Her home care nurse
- D. Her doctor

\$500 Question: The nutrition support team at UCLA has been privileged to care for

many children who have been supported by TPN their whole lives. How old is the oldest living person who has been supported by TPN since birth?

- A. 10 years old
- B. 15 years old
- C. 20 years old
- D. 25 years old

\$1,000 Question: Many individuals have maintained their central venous catheters for very long periods of time. At UCLA, how long has the current record holder had his catheter in place?

- A. 6 years
- B. 12 years
- C. 18 years
- D. 24 years

\$3,000 Question: Many very young infants have been discharged home on TPN. At UCLA, how young was the youngest?

- A. 21 days old
- B. 6 weeks old
- C. 3 months old
- D. 6 months old

\$6,000 Question: How was it discovered that aluminum was causing toxic effects to individuals on long term TPN?

- A. By rigorous scientific investigation
- B. By bone biopsy
- C. By kidney biopsy
- D. By accident

\$15,000 Question: The group at UCLA published early reports on Selenium deficiency. How was Selenium deficiency first recognized?

- A. Bone pain
- B. Changes in blood levels
- C. Changes in hair color and texture
- D. Scaling and flaking skin

\$32,000 Question: Over the years we have learned that even individuals with very short segments of small bowel can adapt and be weaned off of TPN? How short is the shortest in the UCLA Medical Center experience?

- A. 5 cm
- B. 10 cm
- C. 15 cm
- D. 20 cm

\$64,000 Question: Is Somatostatin analog recommended in the treatment of short bowel syndrome?

- A. Yes, always
- B. No, never
- C. Sometimes
- D. What the heck is Somatostatin?

\$125,000 Question: In the early years of TPN, fat emulsions like Intralipid were not readily available. What treatment was prescribed to prevent essential fatty acid deficiencies?

- A. Eat 1 small avocado per day
- B. Rub 1 tablespoon of safflower oil onto arms and legs each day
- C. Take 2 Vitamin E capsules per day
- D. Bath in olive oil 3 times per week.

\$250,000 Question: We have seen many important advances over the last 30 years in caring for individuals on long term nutrition support. What is one of the most significant?

- A. Home delivery of solutions and supplies
- B. Portable infusion pumps
- C. Maximizing early enteral feedings
- D. The addition of glutamine to parenteral and enteral formulas

\$500,000 Question: What do we need to know more about in caring for individuals on long term parenteral nutrition?

- A. How to prevent catheter related infections
- B. How to promote more rapid intestinal adaptation
- C. How to prevent liver-related complications
- D. All of the above

\$1,000,000 Question: What is Snoopy's favorite ice cream flavor?

- A. Schroeder strawberry
- B. Charlie Brown chocolate
- C. Peppermint Patty
- D. Pigpen peanut butter

Congratulations!

You've finished the Oley HPEN Millionaire Quiz.

Answers to the Quiz

are on pages 8 and 9.

Answers to the 2002 Millionaire Quiz:

Contestant #1: Suzanne Herbst, RN, MA

\$100 Question:

C. 1969

\$500 Question:

C. *Triple lumen non-tunneled catheter*

\$1,000 Question:

C. *Occlusions and infections*, with inability to withdraw being the biggest problem.

\$3,000 Question:

C. *40% non-thrombotic / 60% thrombotic*

\$6,000 Question:

D. *Sluggish flow or poor blood return through the catheter*, according to a survey by the National Association of Vascular Access Networks (NAVAN).

\$15,000 Question:

D. *All of the above.*

\$32,000 Question:

C. *Intraluminal instillation of a thrombolytic agent*. Many people ignore VAD problems, but they shouldn't. Difficulty withdrawing indicates a problem that should be dealt with. Because removing/replacing catheters destroys vascular pathways, it is advisable keep lines in place whenever possible.

\$64,000 Question:

C. *Alteplase*. Urokinase used to have FDA approval; however, a few years ago it was removed from the market. Streptokinase poses too great a risk of allergic reaction for routine use in patients, and heparin does not break up clots.

\$125,000 Question:

D. *All the above.*

\$250,000 Question:

D. *All of the above.*

\$500,000 Question:

D. *All of the above*, though whenever possible it is best to try to treat the infection without removing the line.

\$1,000,000 Question:

C. *Peppermint Patty* — *Incorrect, better luck next game Suzanne!*

Contestant #2: Sheila Messina, RN, MA

\$100 Question:

D. *Call your home care provider*. You can do any of the things listed, but you'll likely be educating them rather than yourself.

\$500 Question:

A. *Talk to your spouse*. We all know there are no quiet pumps — despite what the manufacturers claim. They seem quiet, until you turn the lights off.

\$1,000 Question:

C. *Talk to your physician about reducing the volume*. If you do not infuse, or take only part of your infusion, you'll feel miserable the next day. Discuss your options with your physician. It's not a black and white situation. There maybe special times when you can decrease the volume.

\$3,000 Question:

A. *Medications used to treat osteoporosis*

\$6,000 Question:

C. *Call Oley and ask for help starting a group*

\$15,000 Question:

B. *It is important to monitor your body's response to HPN*

\$32,000 Question:

C. *Carry an updated medical history with you* — wherever you go. This way your needs can be met without wasting time. It can also save you should you be in a situation where you are unconscious or in too much pain to relate your medical history. (Editor's note: for a FREE copy of Oley's "Travel/Hospital Packet" which can help you record your medical history, visit our website at <http://www.oley.org/pubs.html> or call 800/776-OLEY.)

\$64,000 Question:

C. *Examines the pancreatic duct using a special endoscope*

\$125,000 Question:

B. *Get a second opinion*. There may be another physician with greater or different experience in treating your particular problem. Also, I would not recommend over the counter drugs; they could be very dangerous.

\$250,000 Question:

B. *You can contaminate the central line with material from the stoma.*

\$500,000 Question:

D. *All of the above*. As a nurse I can tell you that smiling uses fewer muscles than frowning, and that smiling really does help prevent wrinkles, but the biggest reason to smile, is it truly makes you feel better.

\$1,000,000 Question:

A. *Schroeder strawberry* — *Incorrect, better luck next game Sheila!*

Contestant #3: Craig Peterson, RD, CNSD

\$100 Question:

D. *Over 1,000,000*. It sounds incredibly high, but it's true!

\$500 Question:

C. *In the hospital, when tube feedings are initiated*. Receiving instruction while in a comfortable setting, without the added pressures of being on your own, is best. This is also a time when you can access available resources and professionals.

\$1,000 Question:

B. *Refrigerator temperature* allows for the greatest rate of formula absorption and the most rapid stomach emptying. Lower initial formula temperature also retards the potential growth of any bacteria in the formula.

\$3,000 Question:

D. *Water*. There are several studies which clearly indicate that water is the best liquid for flushing feeding tubes. Other liquids, such as cranberry juice or cola offer no additional benefits and since they are high in sugar, leave a coating of sugar on the wall of the tube.

\$6,000 Question:

A. *When the tube malfunctions*. To minimize potential complications, don't fix something that isn't broken.

\$15,000 Question:

C. *Medications* that aren't crushed enough, and medications that interact with proteins in the formula, are the most common causes of

problems. This is a good reason for flushing well with water after each infusion.

\$32,000 Question:

B. *Replace with a tube of the same French size immediately.* Be sure you always have an alternate tube on hand to maintain the tract and preserve your enteral access.

\$64,000 Question:

C. *Maintain balloon at usual volume.* There shouldn't be a problem because the cabin is pressurized, and even if it weren't, there wouldn't be a significant expansion of the water in the balloon.

\$125,000 Question:

A. *There is no specific volume;* tolerance is the best guide.

\$250,000 Question:

C. *The same concentration of particles as blood contains.* Isotonic stems from the Latin root word "iso" meaning "the same as."

\$500,000 Question:

D. *Reduce the nutrient content of the formula.* Diluting isotonic solutions actually reduces stomach emptying and tolerance. Formulas are designed to be isotonic for increased tolerance and absorption.

\$1,000,000 Question:

B. *Charlie Brown chocolate — Incorrect, better luck next game Craig!*

Contestant #4: Marvin Ament, MD

\$100 Question:

D. *Her doctor.* There was no TPN nurse, home TPN pharmacist or home care nurse knowledgeable in HomePEN. The doctor was the only resource.

\$500 Question:

D. *25 years old.* She graduated from UCR and is currently a school teacher.

\$1,000 Question:

D. *24 years* and in all that time he hasn't had a line infection with this catheter!

\$3,000 Question:

A. *21 days old.* This patient had gastroschisis

with no other problems. With motivated parents and medical team this was a very successful discharge.

\$6,000 Question:

D. *By accident.* Aluminum was a contaminant from different additives used in TPN. These accidental findings prompted several changes in the production of Total Parenteral Nutrition.

\$15,000 Question:

C. *Changes in hair color and texture.* Since this discovery, Selenium levels are monitored more closely.

\$32,000 Question:

B. *10 cm.* The patient had an otherwise healthy gut, and consistent feedings from birth that ultimately prompted her gut to adapt. She is currently eating by mouth and has been thriving for more than 12 years.

\$64,000 Question:

C. *Sometimes.* Somatostatin has been helpful for some, but doesn't have a purpose for every SBS patient. The most benefits have been seen in patients with high ostomy output.

\$125,000 Question:

B. *Rub 1 tablespoon of safflower oil onto arms and legs each day.* Essential fatty acids are required for only 2 percent of your daily calories.

\$250,000 Question:

C. *Maximizing early enteral feedings.* Early use of the gut brings us closer to the goal of getting individuals off TPN.

\$500,000 Question:

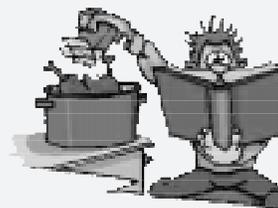
D. *All of the above.*

\$1,000,000 Question:

D. *Pigpen peanut butter — Congratulations!*

Help Oley Prepare a Cookbook to Recognize 20 Years of Service!!

A successful cookbook can be an excellent fundraiser as well as a great public relations tool. As one could assume, a key element to its success is the collection of great recipes. We appeal to you to send along a few of your favorites... from soup to nuts!!! It would be helpful to have them in our hands by **September 27th**.



Send your recipes via:

- Email: bishopj@mail.amc.edu
- Oley's website: <http://www.oley.org/cookbook.html>
- Surface mail:

Great Recipes
c/o The Oley Foundation
214 Hun Memorial, MC 28
Albany Medical College
Albany, NY 12208

The books will be available in plenty of time for the holidays. They make terrific hostess or birthday gifts, stocking stuffers, etc.

If you'd like to be a part of Oley's official "unofficial" sales force reserve a supply of books by calling (800) 776-6539 or email bishopj@mail.amc.edu.

As always... we are appreciative of all of your efforts and continued support.

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contributed since the previous issue.

A complete listing of everyone who
donated this year will be published in
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Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

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

SEP. '02	Jim Cowan Cleveland Heights, OH (888) 610-3008 EST	A long time consumer, Jim has been on HPN since 1977 due to Crohn's disease. He supports both the Oley Foundation and the Crohn's and Colitis Foundation. Jim has experience with many of the issues surrounding homePN and can be a wonderful resource to new and long time consumers.
	Eleana Shore West Hills, CA (888) 650-3290 PST	Eleana's daughter Erin (age 6) is fed via G-tube due to multiple diagnoses, including GERD, food allergies and motility issues. She has undergone three Nissen Fundalplactions. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.
OCT. '02	Bonnie Sjoberg Milaca, MN (888) 610-3008 CST	Diagnosed with pseudo-obstruction, Bonnie was on TPN for 4 1/2 years, then enteral for 1-1/2 years, and was off everything for 8 months. She has recently resumed enteral feeds. She can also share her experience with an ileostomy (16+ years), traveling, and weaning off pain meds at Mayo's pain rehabilitation clinic.
	Kay & Roger Tims Roanoke, VA (888) 650-3290 EST	Kay and Roger are the parents of Bryan (26 y.o.) on HPN since he was 4 y.o. due to a swimming pool accident. They are happy to share their experiences raising a TPN-dependent son from childhood through his college years. Brian has been independent for 8.5 years, has graduated and is married now.
NOV. '02	Amy Vohsing Granville, OH (888) 610-3008 EST	Amy is the mother of three children. Her oldest son is 15 and has Short Bowel Syndrome. He lost all but 10 inches due to a car accident. She would be happy to talk about all issues surrounding this condition (siblings, adolescents, life changing adjustments, etc). She has experience with TPN and EN feeds.
	Janet Dobbins Harrington, WA (888) 650-3290 PST	Jan has had SBS since 1997, and a colostomy since 2000. Her husband, Myles is a great supporter and caregiver. Jan promotes a take charge attitude and encourages sharing experiences with others. She enjoys playing guitar, writing music, and humor. Jan is not currently on TPN or EN, but still has nutrition/hydration issues.

LifelineLetter

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