

# Lifeliner

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

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## ANCHOR: A Framework for Coping with Chronic Illness

Nancy Groat, HomePN Consumer

People living with chronic illness experience many ups and downs within their illness. These episodes may involve line changes, exacerbation of basic illness, or even a new diagnosis which is added to what may be a long list of things that have already gone wrong. In my experience, a pattern emerges as these health episodes occur: a series of steps that can help us cope with the changes. Taken altogether, the steps spell "ANCHOR," which is my original way to think of the phases of chronic illness and the processing of changes as they occur.

### A — Awareness:

First you are aware that a new problem exists. Something is wrong, a new symptom emerges, sensations change or there is a feeling that something is not right. You may experience anxiety, fear, disorganization — even denial — as the new symptoms appear or existing symptoms worsen.

### N — New Insights:

New insights develop as you contact your health care professionals, get diagnosed, and search for information. Hope is mixed with fear as you gather more information. There is still disorganization and some denial — even while calling the physician for an appointment or the ambulance for a ride to the hospital.

### C — Challenge:

The challenge of making treatment decisions, receiving the treatment, and dealing with side effects are



Nancy with her dog, Mindy

ANCHOR cont., pg. 2

## My First Oley Conference

Donna Noble, Parent of HomePEN Consumer

Last year's Oley Consumer Conference in Milwaukee was my first ever. It was an experience that I will never forget, and offered more than I had imagined. Early this winter, I made airline reservations for this year's conference at Knott's Berry Farm.

As soon as we heard about Oley last February, we wanted to learn more. Our son, Kyle, had been on TPN for more than a year and a half. While visiting the Oley web site I discovered that the annual conference was scheduled for June in Milwaukee. I immediately made plans to attend. When we found out that our son's GI doctor was going to be speaking, there was nothing that could have stopped us, except, of course, a hospital stay.

We arrived at the conference full of anticipation. Even the 8-hour car drive with our 7-year-old daughter, Kelsey, 2 year old Kyle, and mother-in-law couldn't dampen our spirits. After settling in our rooms, we headed to the opening night event. Kelsey and Kyle had a great time watching the magician.

Kelsey even got on stage. During this event we met lots of people and felt welcome. We were also introduced to curly extension tubing for our son's TPN by another family whose child is on TPN. The family was nice enough to give us several tubes to try out. We were sold on it immediately and wondered how we ever lived without it. I knew after this first event, that Oley was the group for us.

### Our First Full Day

The first morning's continental breakfast was great and provided an opportunity to reconnect with people from the night before and to meet new people. Before the awards ceremony, we took Kelsey and Kyle to the child care room. I must admit

I was a little apprehensive about leaving Kyle. He seldom has anyone watch him besides his nurse or grandmother. Once I met the childcare providers and saw that they were comfortable with Kyle and his tubes, I felt much better. I knew I would be able to relax and enjoy the program.

Conference cont., pg. 8

Join Oley in  
Buena Park, CA  
June 20-22, 2002

Details on page 4

ANCHOR, from pg. 1

all parts of the next phase. During the time of challenge your emotions are on a roller-coaster. One day, hour or even minute is fine, while the next is followed by despair or anger. Pain influences emotions during this time, making feelings ebb and flair. Anger and disappointment surface, and must be addressed.

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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.

#### H — Help:

During this phase you seek help; gather the troops. Friends and family rally together, spiritual encouragement is enlisted and health care professionals are questioned about outcomes. The help phase may last a fairly long time depending on treatment programs. Help and hope are good companions. There are still times of sadness and despair, but listening ears are available. 'Help' may be one of the more difficult phases, because asking for help is so difficult in our society. You may experience feelings of weakness, inadequacy, and unfairness.

#### O — Odyssey:

The odyssey of the recovery process is sometimes a long journey; sometimes it means making life style adjustments, but always it is a journey to get to a functional level. As you journey through this latest episode, you start to reorganize your feelings. You begin new routines and start reaching towards new life styles. Grief is important here as changes are made. Any change can be perceived as a loss and must be acknowledged. Crying is important, and sharing the changes with others helps dissipate the grief.

#### R — Resolution:

Finally, there is resolution. You may integrate the changes, or feel bitterness and self-pity (not to be confused with grieving). You choose whether to continue to work through the feelings of each facet, or to wallow in one or another.

It is difficult to cope with changes in a chronic illness. There are many emotions at work during each facet and there may not be a smooth odyssey, as experience has taught me.

#### Septicemia, Again

Last spring I identified the facets of ANCHOR as they occurred to me. I live with a chronic illness caused by intestinal lymphangectasia, a rare GI disease causing an abnormal abdominal lymph system. This prevents absorption of fat, protein and the elements essential to life.

Having a history of basal cell cancer on my face, I became suspicious of several unusual looking freckles on my arms. Thinking they would clear up with treatment as the ones on my face had done, I had no qualms about having them removed. Little did I expect the hailstorm that followed: the removal of two basal cell cancers from my arms led to a systemic infection by *Candida parasilosis*.

#### Awareness

Within 24 hours of having two lesions removed from my arms, I developed sudden shaking chills. My temperature was 100°F. Because I have a central venous line (CVL) for total parenteral nutrition (TPN) any indication of infection requires attention. I wanted desperately to deny the possibility of a septicemia, thinking that my hypersensitive body was responding to the excisions of the previous day. My anxiety level peaked as my temperature reached 103°F.

#### New insights

I gathered what strength I could muster to call the appropriate doctors. First was the dermatologist, who said the procedure had been superficial and in no way the cause of the fever. The surgeon who deals with my CVL and TPN was next. Because it was Friday afternoon, I wanted to catch him while he was still in the office. Blood cultures and complete blood count were ordered from the local hospital that afternoon. I also called my internist in case it was something unrelated to any of the above. He concurred with the blood cultures.

The results of the blood cultures were called to my surgeon's partner who was on call for the weekend. I wasn't feeling much better, but had kept the fever controlled with medication. About 3:30 Saturday afternoon, the doctor called to say yeast was growing in the blood cultures and I was to go directly to the hospital. My sister helped me pack, got my dog settled, and drove me to the hospital (about an hour away).

Hospitalizations are not new to me, but I still dread the regimentation and need to ask for medications that I take on my own at home. In order to be most comfortable, I requested to be admitted to the oncology unit. I have been on the unit previously and they were acquainted with my situation. I was also more comfortable here, because I had worked on oncology units as a nurse for twelve years. They were very accepting of me, many remembering me from my previous stay three years ago. The Infectious Disease doctors assumed the care of the candidemia I had developed as an opportunistic infection; it had invaded through the excision sites of the basal cell cancers, as well as the cellulitis that had developed around both sites.

ANCHOR cont., pg. 9

## Thank You for Your Support!

The Oley staff and board extend a warm thank you to everyone for their generous contributions to this year's annual appeal. When others told us, "Beware, donations will drop because of the outpouring for victims of September 11," we knew they were wrong; the Oley family would not let us down. We count our blessings for the many gifts, small and large, that enable us to continue our work on behalf of homePEN consumers everywhere. Thanks to the support of individual and corporate members, this past year Oley:

- increased and improved its presence on the world wide web
- published an updated complication chart for HPN patients
- added 9 new Regional Coordinators, and 1800 new members, and
- held three regional workshops in Seattle, Memphis, and Charleston

We extend an especially warm thanks to **Peggy Waldon** and **Richard & Faith Dillon** for the generous contributions they continue to make, every month, year after year. We are inspired by their steadfast support of the Oley family.

Finally, we want to thank the individuals who are helping Oley to build a stronger, future thinking Foundation by joining our Horizon Society. If you, or anyone you know, is interested in helping Oley secure its future with a planned gift, please call Joan Bishop now at (800) 776-OLEY. Oley plans to kick-off the new program and honor the founding members at the annual conference, June 19, 2002 in Buena Park, California. ☺

## 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.*



## PEJ Tubes Are Being Used More Frequently

Those who tube-feed directly into the jejunum are increasingly being offered a new option, the percutaneous J-tube (PEJ), in addition to the standard G/J-tube and surgically placed J-tube. With the proper training, a gastroenterologist can percutaneously place a PEJ directly into the jejunum using a procedure that is similar to placing a PEG into the stomach. The PEJ has a bumper on the inside of the jejunum and the outside of the abdomen which helps hold it firmly in place, and thereby reduces the discomfort and irritation from a tube that rubs at the site because of a loose fit.

When the option is available, the PEJ is more advantageous than the G/J-tube because the diameter of the PEJ tube can be larger than the diameter of the J-tube portion of the G/J-tube, and thus shouldn't get clogged as often. Using a PEJ also eliminates the possibility of the uncomfortable complication where the J-tube on G/J-tube flips back into the stomach.

In addition to eliminating the need for surgery, consumers may find the bumper-secured PEJ more desirable than the surgically placed J-tube because the latter usually requires a suture and has a tendency to fall out more easily.

For more information about the PEJ, and whether it is an option for you, speak with your gastroenterologist.

## Volunteer and Learn at Pediatric Meeting

Oley needs your help spreading the word about the Foundation at the Third International Pediatric Intestinal Failure and Rehabilitation Symposium, September 12-14, 2002 at the Omni William Penn Hotel in Pittsburgh, PA. The conference is designed for parents and clinicians who care for children with short bowel syndrome (SBS) or small bowel intestinal transplants, and will focus on new developments regarding SBS etiology, pathophysiology, surgical and nonsurgical therapies, and research. For more information about staffing the booth or attending the conference, contact Ellie Wilson, RD at (800) 776-OLEY or WilsonE@mail.amc.edu; or visit our website at <http://www.oley.org/news.html>. ☺

## RC List Update:

Oley has new e-mail addresses for:

**June Bodden:** [holycow4@webtv.net](mailto:holycow4@webtv.net)

**Ruthann Engle:** [ruthannengle@cs.com](mailto:ruthannengle@cs.com)

**Bert Gelle:** [bgelle1@aol.com](mailto:bgelle1@aol.com)

**Robin Lang:** [ivtpn@maine.rr.com](mailto:ivtpn@maine.rr.com), and

**Ellen Seiz:** [moomer@earthlink.net](mailto:moomer@earthlink.net)

We are also saddened to report that Nan Day, a long term HPN consumer and RC, has passed away. She will be missed. ☺

## Drug Warning

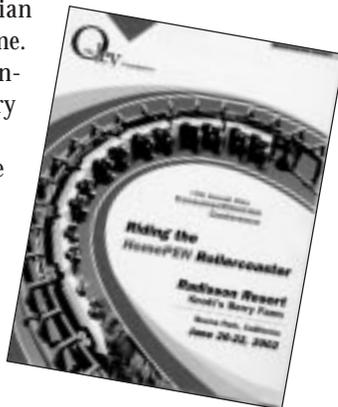
An important drug warning from the Bristol-Myers Squibb Company regarding the small but real potential for life-threatening hepatic failure in patients treated with the anti-depressant SERZONE® (nefazodone hydrochloride) is a good reminder for all of us in the homePEN community to be sure to check all possible drug interactions and side effects before starting a new medication. In an ideal world, your physician or pharmacist should check into this for you; however, given the time constraints of the health care industry and the complexity of most consumer's medical history, it is a good idea to double check everything yourself. (For more information on the drug warning for SERZONE® call your pharmacist or the Oley office.) ☺

## Register Now for the 2002 Conference

Join us at the 17th Annual Oley Consumer/Clinician Conference this summer for a fun and informative time. Entitled "Riding the HomePEN Rollercoaster," the conference will be held at the Radisson Resort Knott's Berry Farm in Buena Park, CA, June 20-22.

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 support you need.

The registration packet, mailed three weeks prior to this newsletter, provides details about the program and how to register. Once again, Oley is pleased to be able to offer some travel grants to the annual conference. Details follow:



1. A limited number of **\$250 Travel Grants** are available on a "first come, first serve" basis, thanks to corporate support. Call Oley today, if you are interested.
2. We're also offering one **\$500 "First-Time Conference Goer" Scholarship**. Send a paragraph to Oley by **May 16th** describing how you would benefit from attending the conference. Allow one week for the committee to make a determination and notify the recipient. This should allow plenty of time for coordinating travel plans. Thank you to the generous consumer who underwrote this special opportunity.

This year's location at Knott's Berry Farm, a vacation wonderland with six theme parks on-site, makes 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 experience you'll remember for years to come. For more information call (800) 776-OLEY or visit our web site <http://www.oley.org/knotts.html>

## Earn Money for You and Oley!

**Here is an opportunity for you to earn \$100.00 for Oley, as well as \$20.00 for yourself.** This opportunity is open to all **short bowel consumers** of home parenteral nutrition (HPN) or IV hydration.

The makers of a product that might help patients with short bowel syndrome are seeking input about you and your condition. They are conducting a short survey that asks your opinions of a new treatment for Short Bowel Syndrome. The product under review may improve symptoms associated with short bowel syndrome and the company that makes it wishes to understand how interested you are in it.

The Oley Foundation Research Committee thinks it is appropriate for you to participate in this survey if you are interested. Please be aware, that it will be at least several years before this product will be commercially available. This is not a sales effort of any kind, nor is it an invitation to take part in clinical trials.

To participate in the survey, all you need to do is contact Oley by phone (800) 776-OLEY, email: [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu), or via good old-fashioned snail mail (see address on page 2). We will send you the questionnaire. It takes about 15 minutes to fill out. For all properly completed responses, the research organization will provide us with \$20 to give you for your time and effort, and in addition they will also donate \$100 to Oley!

This is, of course, entirely voluntary. As with any research of this kind, your name and address will not be divulged to the company. All responses will be coded so we can reach you if the company needs follow up clarification. All mailings and contact will come to you from the Oley Foundation staff.

## Equipment Exchange

The following HPEN supplies are offered free of charge to readers:

- 1.5 cases Nestle ProBalance (Vanilla)
- 8 cases Vivonex Ped., exp. 11/02, 4/03
- 3+ cases Perative, exp. 10/02
- 1/2 case Comply, exp. 5/02
- 2 Abbott Provider One Pumps†
- 2 cases Companion Pump Bags (500 ml)
- 300 cases 60cc irrigation syringes† (take only some if you want)
- Osmolite HN+, 2 cases exp. 11/02, 4 cases exp. 12/02

**WANTED:** Neocate+ Formula

†FREE shipping offered.

For more information, call (800) 776-OLEY/(518) 262-5079. The Oley Foundation 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.

## Picky Eater or Problem Feeder?

A two-day seminar on children with feeding difficulties will be held June 14-15, 2002 at William Beaumont Hospital in Royal Oak, MI. Entitled, "Assessment and Treatment Using the Sequential, Oral, Sensory Approach to Feeding: The SOS Approach" the seminar will provide an understanding of the SOS theory and approach, general and specific treatment strategies, and details on conducting feeding assessments. The presentation will focus on children ages birth to 10 (but will not focus on eating disorders). Faculty includes Kay Toomey, Ph.D., Pediatric Psychologist, Erin Ross, CCC-SLP, and Melissa Kurtz, ORT. The conference is sponsored by Abilities Center, Inc.; Spaulding for Children; Oakland County Early On; and the William Beaumont Hospital. For details or to register, contact The Abilities Center at (248) 855-0030; Fax: (248) 737-9620; or Email: [otjill@abilitiescenter.com](mailto:otjill@abilitiescenter.com).

## Nutrition Week: A great success!

**Ellie Wilson, RD**

The "First Annual Nutrition Week: A Scientific and Clinical Forum and Exposition" was held in San Diego, CA on February 23-27, 2002. The Oley Foundation attended as an exhibitor, and was the only patient representative at this meeting. This program was the first time the major clinical nutrition societies pooled their resources and efforts to create a single forum for nutrition, and most hailed it a great success. For nutrition support patients familiar with the different clinical programs, this conference replaced the American Society for Parenteral and Enteral Nutrition's (A.S.P.E.N) annual clinical congress.

The Oley Foundation plays a special role at meetings like this. We are working hard to raise our profile, increase our outreach to consumers through the clinicians that care for them, and ensure that members of our industry community know how they can benefit from supporting Oley. We were very pleased and excited to see old friends that have been strong supporters for many years, and to create new relationships with companies that are new to the game, or less familiar with us.

But the best is yet to come. Next January (2003), Nutrition Week will be held in San Antonio, TX. The Oley Foundation will be a sponsoring organization — which is really exciting. In addition, we will be holding a regional conference on the first day of the program, for both consumers and clinicians.

We would like to thank our volunteers who worked the Oley exhibit or participated in the Oley Consumer Panel, a section of the clinical program that allows patients to offer clinicians insight on what it's like to live with home enteral or parenteral nutrition. Those volunteers included Judy Peterson; Patty, Darrell and Colyn Woods; Robbyn Kindle and dad, Ken; Eleana and Harry Shore; Todd Friedman; Matt Van Brunt; and Liz Tucker. We couldn't have done it without you!

Special thanks also to Dr. Mark DeLegge, of the Medical University of South Carolina, for a great consumer program on the past and future of enteral nutrition. He discussed the growth of enteral therapy over the years, reimbursement, and thoughts on the future of this type of nutrition support. A lively and passionate speaker, Dr. DeLegge made the discussion very interactive, and all attendees thought it was terrific. We're looking forward to next year! ☺

## Scholarships Offered to HPN Consumers



Nutrishare is offering three \$500 scholarships for TPN consumers towards the Fall 2002 semester. Interested TPN consumers should write a letter describing their studies and what they plan to use their education for. (A few paragraphs is fine.) A committee set up by Oley will review the applications and choose the winners based on potential and need. The scholarship money will be distributed at the end of the semester when the winner submits a copy of his/her grades to the Oley Foundation. Applications should be typed or word processed, and postmarked by July 30, 2002. Applications should include the candidate's name, photo, number of years on TPN, address and daytime phone number. Send applications to the Oley Foundation (address on page 2). Former applicants are welcome to reapply. ☺

## Oley Workshop: April 27 in Ohio

Get together with fellow homePEN consumers and clinicians — and make things happen! The Oley Foundation is planning a Regional Nutrition Support Workshop to be held April 27, 2002 at the Makoy Center in Columbus, Ohio. The workshop will feature Jane Balint, MD, a Pediatric Gastroenterologist from Children's Hospital in Cincinnati and Robert Hostoffer, MD, a Pediatric Infection Specialist at Case Western Reserve University in South Euclid, as the plenary speakers in the morning.

During the buffet lunch, attendees will learn the benefits of "community outreach and support" and have an opportunity to exchange information with the various exhibitors of home parenteral and enteral products and services.

Afterwards, several distinguished clinicians will lead the afternoon roundtable discussions on such topics as: transitioning to oral feeds, insurance, catheter care, wound/ostomy care, enteral feedings, motility disorders and interpreting lab values. Participants will have time to attend three different roundtable discussions.

Lunch (and the rest of the workshop) is free for consumers and family members; professionals are asked to pay a \$15 donation. Registered dietitians can get 6 CEU's and we're working on credits for nurses as well.

Registrants are responsible for their own hotel/transportation plans. Oley has arranged for a preferred rate of \$59.00 or \$69.00 at the Wellesley Hotel. These are suite-rooms with full kitchens that can be shared by 4 to 6 people. Contact the hotel directly at 614-760-0245. There is a van for free transport between the Makoy Center and the Wellesley hotel.

For more information or to register, call Ellie Wilson at the Oley office at (800) 776-OLEY. You can also register on-line at <http://www.oley.org/FlyerOH.html> or get further details from the local Oley Regional Coordinator, Donna Noble at (614) 871-8464. ☺

**Advertisement  
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## HomePEN from the Spouse's Perspective

Steven Cohen, Husband of an HPN Consumer

*As part of its outreach and education efforts, the Oley Foundation organizes panel discussions at clinician-based conferences to help health care providers better understand what it's really like to live long term with homePEN. The following article is an excerpt from one panelist's presentation at the National Association of Vascular Access Networks (NAVAN) meeting held this past January in Alexandria, VA.*

As the spouse of a homePEN consumer, it is okay to have a full range of emotions (anger, frustration, depression) concerning YOUR situation as well as your spouse's. Do not feel guilty about having these emotions even though it is your spouse that has the physical problem. You are involved too, and there is frustration at not being able to solve the problem for the person you love.

A big issue for our me (and I think a lot of other men too, although it certainly is NOT restricted to men) was learning that there are times when you just have to listen and be sympathetic, and not try to fix things. Just like the consumer, the spouse may feel a loss too — e.g. life may not be as carefree as before and homePEN may require some changes in lifestyle. There can be many manifestations of this frustration. Some of my own examples are: dreaming about doing TPN on myself; listening for pump sounds while lying in bed (to reassure myself it is working); waking frequently to check that my wife is okay; and having a fear-reaction when I hear the pump alarm.

For me, the single biggest hang-up is not being able to bring myself to participate in the 'hook-up' process for fear that I would be the one who would cause an infection. Given the seriousness of infection and potential loss of a line in a person who has limited venous access, I don't think I am alone in this.

### Positive Aspects

Despite what I said about frustrations, there are very positive things that the spouse can do. If his/her emotional state is appropriate, the spouse can be the 'cool head' of reason and logic in times of crisis, and be able to discern when a problem is minor or serious. The spouse can do research — learning about procedure options, physical conditions, and the like — thus relieving a bit of the stress and time pressure on the TPN consumer. The spouse might be the one to figure out what medical care is needed (e.g. which doctor to call). The spouse may also provide the humor that is necessary to deal with chronic stress. I think humor is a tremendous help.

Finally, a spouse can provide a positive 'push.' I think there is a tendency for people with chronic problems to focus on what they

can't do rather than what they can, and that the spouse can be a positive force to show them how much they can do. In our case, I helped convince Davi, my wife, that she can travel (even overseas). I also encouraged her to finish her degree work at the university, and supported her change in profession.

I also want to add that dealing with chronic problems can bring you very close to your spouse and make you really appreciate the good times and what you have together.

### Issues for the Clinician

HomePEN can be complex, multifaceted and challenging. Some specific concerns I'd like to share with those who provide care for long term consumers include:

#### • *Who is in charge of catheter maintenance?*

This issue falls in the medical cracks. The patient has primary responsibility on a day-to-day basis, but when a problem develops, the question of who to turn to for help is serious. Many of the medical providers the patient may be working with will lack the training and experience to deal with vascular access issues, particularly mechanical problems. I want to emphasize that there is little in the way of long-range planning. Access problems are typically dealt with in a reactive mode, rather than developing a plan to minimize future problems. This latter point is one of the MOST SERIOUS and INADEQUATELY addressed issues for long-term TPN consumers. Furthermore, consumers are often told that when a problem comes up they should call their doctor. This is not adequate advice given the issues raised in this point and the one below.

#### • *Who is Coordinating 'the team'?*

Davi has five to six doctors as well as nurses and a pharmacist. It is hard to find some who takes charge of the whole patient and who is willing (and able) to coordinate the treatment through all of the other specialists.

#### • *What is the best case scenario when drawing blood?*

I think it is best to avoid blood-draws through the catheter, even though the temptation is there for people whose veins are hard to hit. Sometimes using the catheter is necessary, but it increases the chances of losing a line and as you well know, line-loss, and even worse, loss of a useful vein, is a major concern for long-term TPN users.

#### • *What can be done to improve trips to the E.R.?*

Emergency room personal may not be aware of TPN issues such as infusion reactions and infection issues. In fact, we have been sent home from an ER being told that cultures showed there was no line infection, when in fact that was the problem. Serious, life threatening mistakes like this can happen when an emergency forces you to seek medical care from providers not familiar with the issues and concerns of long term HPEN consumers. ©

*We thank Steve and the rest of the panelists for speaking on behalf of the Oley Foundation and its members.*

## Consumers/Parents Wanted!

Oley needs consumers/parents to staff the Oley exhibit booth at the Infusion Nurses Society (INS) Annual Meeting, May 4-9, 2002, at the Phoenix Civic Plaza in Phoenix Arizona. Spend a few hours distributing Oley materials to attendees and squeeze in a few of the educational seminars (free for exhibitors!). If you have any questions or are interested in additional information, contact Joan Bishop at (800) 776-6539 or bishopj@mail.amc.edu.

## Please Join Oley in Thanking Our Corporate Donors

### Critical Care Systems/Infusion Care Systems

Critical Care Systems/Infusion Care Systems is your choice for excellence in home infusion therapy. CCS/ICS offers a network of branches providing a customer-focused model of care. TPN experts in nutrition, pharmacy, nursing and reimbursement are available — supporting the company's dedication to clinical excellence and quality improvement. CCS/ICS clinicians are chosen for their experience and expertise in home TPN management, which provides you and your physician with the confidence that they will assist in providing an optimal plan of care that meets your needs and keeps you living life to the fullest. We thank CCS/ICS for their support.

### Patient Support Services

Patient Support Services, Inc. (PSSI) distributes a complete and comprehensive line of enteral and oral nutritional products, as well as enteral pumps, pump sets, gastrostomy kits and feeding tubes. The company has been providing in-home delivery as well as distribution to nursing homes and other facilities throughout the U.S. for over 14 years. As a health care partner, PSSI is committed to providing quality and excellence in enteral and oral nutritionals and supplies. Enteral feeding is more than just a business to PSSI. As an expression of the company's pride and commitment to those with special needs, it is prepared to provide nutritionals from all major manufacturers and is dedicated to serving the needs of the individual nutritional consumer. We thank Patient Support Services for their donation.

### Nutritional Restart Center/University of Nebraska Medical Ctr

The Nutritional Restart Center (NRC) and University of Nebraska Medical Center (UNMC) offer a combined intestinal rehabilitation program for individuals with short bowel syndrome and malabsorptive disorders. The program offers non-invasive treatments designed to maximize the absorption of an oral diet in an effort to reduce, eliminate, or prevent the need for TPN and the recognized complications associated with intestinal failure and/or TPN dependency. An inpatient program is offered at UNMC, and an outpatient and home treatment option is available through NRC. We thank NRC/UNMC for their donation.

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## Lifeline Mailbox

### HPN Consumer Struggles with Nursing Home Issues

Dear Lifeline Readers:

I am 88 years old and have been on HPN for ten years. I also have Osteoporosis and in 2000 I fractured my pelvis.

I entered Northcrest Health Center here in Napoleon, and had a very bad experience. They didn't have an RN on duty at night so they insisted on infusing me during the daytime. (I had been on night time feedings.) They used their company's nutrition, did limited flushing, and administered insulin, which I never had before. I developed edema in my right arm, neck and face. Constantly getting worse, I insisted on going home where I soon got back to normal again with outside help.

Equally distressing as the poor care I received at the first facility, was discovering that the facility of my choice refused me entry because they didn't employ an RN around the clock to handle my HPN. They told me this was an Ohio ordinance. I can't understand why it is necessary to have an RN present when my husband and I (non-medical professionals) have administered my HPN, hook up and all, for 10 years.

Has anyone else had or heard of a similar experience? Does this ordinance apply in Ohio only? Do other states have different rules? Is there any place to challenge rules like this that threaten the availability of nursing home care for HPN consumers?

I am concerned that if the need for nursing home care arises, I may not be admitted because of my HPN, and at my age this could easily become a reality.

— Hulda Hahn  
Napoleon, OH

*Please send your comments to the Lifeline Editor (see address on page 2).*

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### Conference, from pg. 1

The awards ceremony was inspirational. I came away with the feeling that I could handle Kyle's care and that I was not alone anymore. During the ceremony I decided that I wanted to become a Regional Coordinator and start a local support group so others did not have to wait as long as I did to discover Oley.

Immediately following the awards ceremony was the plenary session entitled "Who Wants To Be A Millionaire?" The entertaining format was a great way to present a lot of information, while not putting everyone to sleep. I only wish there was time for a question and answer session.

Next Oley provided a box lunch for participants. The tables for eating and socializing were located in the middle of the room.

Along the perimeter were various vendors and associations. Combining the socializing, eating and information gathering, was an excellent idea. By the time lunch was over, I had discovered many new products and companies. The experience opened up a world I didn't know existed. I left with bags of information and lots of samples.

After dropping off our daughter for the Oley youth trip to the Clown Museum, and leaving Kyle with his grandmother to nap, my husband and I went to the breakout sessions. The first session we attended was on Motility Drugs. Even though we had tried most of the drugs they covered, we learned a lot of useful information. The second session on support offered a more informal discussion. Unfortunately, Kyle developed a tube and pump problem, so I left early to resolve the issue. Rich stayed, and said the session was informative and motivating.

After going back to our rooms to relax and try to absorb what we had learned, we

headed to the Oley Silent Auction. This is a time to bid on items, earn money for Oley, and socialize. We had a great time, bought too much loot, and were able to learn a lot from other families.

### Day Two

The next morning we attended the plenary session on intestinal failure. I must

admit I wasn't sure if the session was going to be beneficial to us since Kyle wasn't in intestinal failure, but the information presented related to anyone needing home nutritional support. I found the discussion on bacterial overgrowth especially helpful since it is something we face with Kyle daily. I left with pages of notes to take home to our nurse and discuss with our son's doctor. His GI doctor was sitting in front of us during the session.

Several times we turned to each other and gave the silent look "yes, we will have to look into that or give that a try."

We dropped our daughter off with the other Oley youths going to the Milwaukee Zoo, before heading to the breakout sessions. My husband and I had the honor of introducing our son's special GI doctor, Dr. Jane Balint, in the session "Pediatric Issues." The session was very good and reaffirmed our belief that Kyle has the best GI doctor around. The parents asked many questions and liked the idea that their children are kids FIRST and patients second. Parents were visibly relieved when Dr. Balint said it was okay stray from the strictly prescribed routine occasionally, if it allows the kids to experience life like other children. My husband and I split for the last breakout session. I

attended "Ostomy Care" while he attended "Catheter Care." I learned about skin protectant products to minimize skin breakdown, and Richard learned about new products to clean around Kyle's central line. We were disappointed to learn that the cleaning product is not widely available in the USA.

### Saturday's Picnic

We were all looking forward to Saturday afternoon's farewell picnic. Kelsey was eager to play with her new friends, and Kyle couldn't wait to see the clowns one last time. The location was excellent and allowed for a multitude of activities including flying kites, renting bikes, watching the boats pass, tree climbing, and playing the games planned for the kids. The adults enjoyed socializing one last time, and swapping phone numbers and addresses. The picnic would have been perfect if not for the fact that one of our new friends had to admit their child to the hospital with a fever.

We were sad to head home. We had accomplished so much in just a few days. We had developed friendships, learned lots of new information, found new products, and most importantly, discovered that we are not alone in this journey. As we drove away, I was filled with enthusiasm about trying out the new ideas and starting a local support group. On the drive home we began planning our trip to California for the next Oley conference. We could hardly wait. ☺



*Kyle Noble with a clown at the Oley picnic.*



*Kelsey Noble (right) and her new friend, Beatrice Weaver, at the Milwaukee Zoo.*

**ANCHOR**, from pg. 2

### **Challenge**

The challenges I encountered involved learning about the yeast infection causing the candidemia and the drugs that would treat it. Intravenous (IV) Diflucan was started first, then IV Caspofungin was added as the sensitivity of the yeast was identified. The oral antibiotic linzolid (Zyvox) was started as the excision sites developed cellulitis with a possible staphylococcus infection. It took several days for the fever to break and even longer for the fever symptoms to stop. I could feel my energy leave my body as the infection was being fought. The immune system had been overwhelmed by the infection with an initial white blood count (WBC) of 2,000. (Normal 5,000 -10,000)

The reality of my situation was hitting me pretty hard. I would no longer be able to attend my niece's graduation and party, nor would I be able to attend the Oley Conference in Milwaukee, WI. For these losses I needed to grieve fully, as well as for the health setback and time it takes to regain the energy I had lost. For every day on bedrest, it takes the body about ten days to recover.

### **Help**

I needed help to make the adjustments necessary to get through the next several weeks. While I was still in the hospital, the RN who worked on discharge planning and the Infectious Disease RNs spent many hours setting up the IV administration of Caspofungin at the local hospital out-patient department so I could go home. I would need to be there at 8:30 every morning for the five days left of my fourteen day course of treatment. They had done their work well as my appearance was anticipated at the clinic, and I couldn't have asked for a better reception. The IV was hung, and the Caspofungin added within fifteen minutes of my arrival.

Other help that made my transition back home easier, was having my parents stay with me for the first week. They brought me to the hospital, fixed meals for me and provided lots of encouragement. My sisters were around as well and helped, each in her own way, to ease my hospital and post-hospital stay. The church was great in having people bring in meals for us, and assured us they would do whatever was needed. Their prayers were welcome as always.

As I gathered my energy together again, my sisters and friends were available to help me cope. Friends from the Oley network called to express their sorrow at my not being able to attend the conference. The home care nurses picked up where we left off, and continued doing my blood work and assess-



*Nancy with her sister, Barbara Groat, at the 2000 Oley Conference in Boston.*

ments. In getting back to my normal health, I continue to use the help of friends, family and health care professionals. Even my dog is helping by behaving much more willingly than before her forced 'vacation.'

### **Odyssey**

The journey of recovery to the pre-episode level of functioning is often a long time. There are many emotions involved, the main one being grief. I grieved the loss of my health status, the loss of my trip, and the loss of the opportunity to meet new friends at the Oley Conference.

It is easy to become discouraged because of the length of time it takes to regain lost energy. The encouragement of family

and friends is important, and can help be a guide to measure progress. The knowledge of having survived another setback reinforces the faith that there is a plan for me in God's world. I don't know what it is, but I am still alive to be available for it.

### **Resolution**

Resolution is a process that occurs every time there is a change in life. One can become bitter and angry, not attempting to integrate changes, or one can integrate the episode into one's life history. I have done this by adding the episode to my list of medical experiences and by taking each day as it comes, making the best of it I can.

The facets of ANCHOR are a useful tool in helping reach resolution following a change in a chronic illness pattern. By defining the process and naming emotions, it was much easier for me to reach resolution and integration. The steps are not always in a consistent order, many emotions overlap into each facet. If there are many changes occurring simultaneously, facets will get intertwined. As a case in point, this yeast infection has lasted almost one year and I have lost four CVL/PICC lines. Each loss had its own progression of emotions overlapping with the larger infection episode. What is important to remember, is that resolution can be reached and a choice made about how to cope with the roller-coaster feelings, as changes occur within a chronic illness. ©

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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.

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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](http://www.oley.org). Comments? Call (800) 776-OLEY.*

<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>
<b>JUN. '02</b>	<p><b>Barbara Ehrenpreis</b> Jericho, NY (888) 610-3008 EST</p>	<p>Barbara is married with two children ages 18 and 20. She has been on HPEN since 1989 due to gastroparesis. She also has multiple sclerosis and is a breast cancer survivor. She has experience with CVCs, ports, g-tubes and j-tubes. She enjoys networking with others. You may also email her at <a href="mailto:ontpn@aol.com">ontpn@aol.com</a>.</p>
	<p><b>Sandra Sheeley</b> Seattle WA (888) 650-3290 PST</p>	<p>Sandra was diagnosed with Crohn's disease in 1967. She has an ostomy and has been at home on TPN since 1981. Prior to that she was hospitalized for her TPN infusions. She has traveled all over the world. TPN has never slowed her down as much as the Crohn's disease. She looks forward to hearing from others.</p>

### LifelineLetter

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