

Lifeline Letter

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

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Making Friends with Fear

Sheila Messina, RN, MA, Education and Training Specialist, HomePN Consumer

Most patients on specialized nutrition have had their share of traumatic medical and/or surgical procedures. One would think that repeated exposure to this experience would result in a sense of familiarity and fearlessness, but often the opposite appears to be true: while repeated exposure may bring a sense of the known, it usually brings a greater level of fear.

What happens to you when you are told that you will need another surgery or complicated procedure? If you are like me, your whole body tenses up and you want to run. What's happening? For me, I fear a loss of control. I am afraid my independence will be compromised. I believe I will experience unmanage-

able pain, and if general anesthesia is involved, I am afraid I will not wake up.

I share this from my own experience, but in talking with others, I find this happens to them as well. Over the past 30+ years I have had more than 12 major surgeries. I remember very vividly in 1974 being on the gurney in the hallway outside the OR, trembling and telling the nurse how afraid I was. At that time I did not know why I was afraid. I did not have any skills to deal with this fear and it was apparent that the nurse didn't either as she was unable to comfort me. I went through that surgery extremely tense with a sense of "impending doom" and I believe this contributed to a very difficult recovery.

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Help Secure Oley's Future

Finding yourself or your loved one dependent on homePEN, being required to "hook-up" night after night — and trying to keep a life on track despite the enormous associated hassles — is mind-boggling. But people help, especially people who have walked the same road. Education helps, especially when the technology is new and evolving. The Oley Foundation is chiefly about connecting homePEN people to each other and providing a constant update on these therapies.

Oley has a great number of strengths, including heroic consumers and caregivers, a dedicated staff and

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Don't Let This Happen to You

Tim Joyce

I am writing to tell of a recent loss. More than that, though, the story of this tragic event should serve as a warning to us all.

We of the Chicago Pumpers support group lost a longtime member and friend. Bob Kwiatkowski was a terrific guy. Those of you outside of the Chicago area wouldn't know him. He never attended the Oley Conferences. We, however, will feel the loss for a long time.

Outwardly, Bob had wispy, blond hair topping a prednisone-chubby head and huge, red blotches covering his hands and arms. Inwardly, he suffered from a congenital immunodeficiency that affected his gut. More than that I can't really say, as he rarely talked about his problems.

Over the last few years, Bob had struggled with a virus in his intestines. He would go to the hospital where they'd pump him full of antibiotics until he felt well enough to go home. Then he'd last at home as long as he could before returning for another round. It

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Since that time, with many more ensuing surgeries and procedures, I came to recognize just how fearful I became as I approached these encounters and realized that I must develop some skills for modifying the fear. I have found that I cannot erase it entirely — that would take a major case of denial — but

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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.

I can certainly make it more manageable and not become paralyzed by it.

Recognize the Fear

When a procedure or surgery is scheduled, I acknowledge that I am frightened and need to talk to someone about it. I do this with friends, since talking about it with my family tends to make them as frightened as I am. In fact, many times they look to me to make them feel better. (Maybe that's because I am a nurse and they expect me to know and understand everything.) When I talk about the fear with friends, I find that it gets outside of me and becomes diluted. I am not necessarily looking for answers; I just want others to know what is going on with me.

If you are a family member or caregiver, you also need to recognize your own fear. Find someone to talk to — other than the patient. This can be a health care provider, a good friend, or other family members, as long as they are supportive and trustworthy.

Recognizing that emotions and attitudes can affect a patient's outcome, clinicians too have a role in reducing their patient's fear. Questions like "Do you have any fear about the surgery and/or procedure?" and "Do you have any questions for me?" can invite the patient to express their concerns and give you an opportunity to lessen them. Knowing what to expect, and being aware of the patient's concerns can alleviate the patient's stress, help avoid complications and contribute to a speedier, smoother recovery.

Visit the Recovery Unit

Ever since I had a less than optimal experience in the surgical ICU in 1992, I make certain that whenever possible, I go and visit the hospital unit where I will be recovering — before the surgery. I introduce myself to the staff and try to get acquainted with the personnel and surroundings. A key here is to dress your best when you make the visit. Remember, the hospital gown can hide who you truly are. You want the staff to see you as a whole person with a life, not just as a patient. I want to be known as Sheila Messina: someone with an identity other than "the patient in Room 322."

Speak with the Anesthesiologist

Here, I am trying to achieve three things. First, I want to let the anesthesiologist know about my fear as it can affect my response to the medications being administered. Among other things we tend to become hypertensive when we are fearful which can make recovery more complicated.

Second, I want to know what his/her plans are for anesthesia. Will I be receiving conscious sedation? Is an epidural block being considered? I'm trying to gain more information so I can be mentally and physically prepared for the procedure/surgery.

Third, I want to convey my special concerns. I have major vertebral fractures. The anesthesiologist (and surgeon) needs to know that I cannot lie flat; trying to do so creates major post-op pain problems. Additionally, since I have had so many surgeries the

amount of medication I require will most likely exceed usual expectations. To avoid wasting valuable time and creating confusion with a verbal explanation, I provide the anesthesiologist with an updated list of my relevant medical history.

Practice Your Advocacy Skills

You may believe these skills are too difficult for you to learn — that my training as a nurse gives me an advantage in this area — but it's not true. I had to learn these skills by trial and error. My voice used to tremble when I started "standing up for me" by asking questions. Now I am able to "speak my piece" in a strong, stable voice, most of the time. Like any skill, the more you use it, the stronger it becomes.

You also may believe that your health care providers know all there is to know about you and that you don't need to be an active participant in your care. Again, it's not true. The last time I checked, "mind reading" was not a requirement for the health care professional. And as tighter budgets result in less time for patient care, busy clinicians need to be reminded of your unique situation.

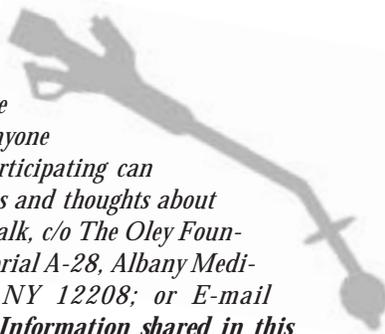
What happens if, despite your best efforts, you find yourself in a situation where everything does not work out as you had

Fear cont., pg. 6

When a procedure is scheduled, I acknowledge that I am frightened and need to talk to someone about it.

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.**



One Piece Clothing for Older Children and Adults

I'm the mother of an-almost 4-year-old who has a g-tube. I have always dressed her in one-piece clothing, especially at night when she is on continuous feeds, as this makes the process easier and creates less worry for us about her pulling on the tube, etc. Shannon is a triplet, and I was afraid of her tube coming open/out/etc. as she and her siblings got more active (and curious). I like the snap-front access for her continuous night feeds because I can thread the tubing out at the best spot to minimize tubing disconnections and entanglements. Snap-front pj's also allow easy access if I need to check the site or connection while Shannon is sleeping; I can usually do this without waking her. In addition, I'm sure it depends on the individual child, but the shorts or pj bottoms that I've tried on occasion haven't "hit" Shannon in a good spot as far as the g-tube, either; they always seemed to rub against the tube and I know that's not good or comfortable for her.

Because Shannon is now a size 4T, it is getting harder and harder to find one-piece clothing, especially pajamas. I found a website (www.ableapparel.com) that carries short-sleeved, v-neck, cotton-knit "onesies" that snap all the way up the front and at the crotch. They carry children's size 4-6, all the way up to adult small. I purchased the smallest ones for my daughter at \$10 a piece. I ordered by calling the toll-free number given on the website (888/688-ABLE), but I believe you can actually order on-line as well. The item is called an EZ-tee. (Just so everyone knows, it says the item is "not intended for use as sleepwear" but I think they have to say that, since by law, clothing labeled as children's sleepwear must be made of fire retardant material — which cotton is not.) I hope this information is helpful!

— Susan McLane
Susan_McLane@cch.com

School Daze

Many parents find working with their school system to be very challenging — developing education plans, health plans, educating school staff on enteral and TPN issues, dealing with time issues for chronically ill children — the ups and downs are endless. Some experienced parents are working with us to develop resources for other parents who are struggling with this, or are unsure how to anticipate their child's needs. We have found that school district staff members often have no idea how to start working with these parents and children. Can you assist us? We are looking for information on school districts that are getting it right, in hopes of tapping them for "best practice" information. If your school district has done anything to "smooth the way" for you and your child, please let us know. Contact information for the relevant person at the school district would be helpful. **Please do not send or call with information on schools that are not meeting your needs**, we are very aware of them, and this is what we are hoping to correct. Please call or email Ellie Wilson at 800-776-6539, wilsonE@mail.amc.edu.

Pediatric Meeting in Pittsburgh

Come learn more about short bowel syndrome and help spread the word about the Oley 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.

Thursday's session (September 12) is specially designed with the family in mind, to enhance the parent/caretaker's understanding of intestinal function. Parents/caretakers are also invited to stay for the general session for an additional fee, although they are reminded of the graphic and intense nature of the scientific portion.

For more information about the conference, contact Sue Haunty at 412/692-7396 (email: susan.haunty@chp.edu); or Jane Anne Yaworski, MSN, RN, 412/692-5217 (email: janeanne.yaworski@chp.edu).

For more information about staffing the booth contact Ellie Wilson, RD at (800) 776-OLEY (email: WilsonE@mail.amc.edu).

Scholarships Offered



Nutrishare is offering three \$500 scholarships for TPN consumers towards the Fall 2002 semester. Interested 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. ☺

Bright Ideas from Our Readers

We have received a barrage of tips from our readers lately. With the hope they make your life easier or more affordable, we are sharing them with you on these pages. Please note the Oley Foundation has not tested any of these products and is in no way endorsing them. As always, check with your physician before making any changes in your health care.

Homemade Mini IV Stand Convenient to Use

I began on HPN about three years ago, infusing overnight using a standard IV pole to hold the formula and the pump. The pole had the advantage of hanging the formula bag upright so any air bubbles in the bag would rise rather than entering the pump. It also had the advantage of making the bag and the pump visible. If the pump sounded during the night, it was easy to reach over and remedy the problem. The disadvantage of the IV pole was that it was noisy on our wood floors when I had to get up in the night to use the bathroom, and carrying the IV pole up and down stairs with the formula bag attached was a cumbersome task.

When I changed health care companies, my new company provided me with an ingenious backpack that could be carried by a single handle like a brief case. The formula bag fit inside along with the pump, and the line extended out of the case through a small hole. This was much more convenient to carry with me, but I had to carefully bleed the formula bag of any bubbles, and if the pump went off in the night, it meant opening the bag and fishing the pump out of its clever Velcro pocket. I also could not see at a glance how much formula remained in the bag. It was awkward plugging and unplugging the AC adapter into the pump, so I started using batteries and I soon found I was amassing dozens of half spent 9 volt batteries.

It seemed to me I could have the best of both worlds, and I ended up making what is essentially a small IV stand. (see photo). My wife calls it "Standly." I made my first Standly from some scrap one-half inch copper pipe and fittings left over from a previous plumbing job. I cut the pipe with a tube cutter, and soldered it together with a propane torch. Because I wanted to pack Standly in a suitcase, I did not solder the two joints that connect the top to the base. Instead I used a bolt and nut on each side so I could take Standly apart.

The top part of Standly is 10 inches wide and about 19 inches high. (The dimensions are not crucial.) The base is 6 inches by 9 inches. It requires 8 copper right angle elbows and 2 tees. The price of the materials would be under \$10.

The pumps I have used (Sabretek & Verifuse) have both had threaded holes in the back. I found a bolt that would screw into that hole (probably metric—your hardware store could help you). I took two pieces of Velcro, punched a hole in the end of both pieces with a paper punch, and put the bolt through the Velcro holes and attached

it to the pump. Now I could wrap the Velcro strips around Standly's copper pipe to hold the pump. To keep the pump where I want it, I fastened a radiator hose clamp on the pipe, and rest the Velcro on top of the clamp. (It is really simpler than it sounds.) I drilled a hole in the top of the frame, and put in a threaded hook with a nut on which to hang the formula bag. To carry Standly, I cut a 7 inch piece of old belt and used a bolt and nut on either side to affix the handle to the frame.

I found that the formula bag would swing precipitously when I carried Standly, so I took the rest of the old belt, and stapled (using a heavy duty stapler) a piece of Velcro to each end of the belt. Now I wrap the belt around the frame and bag to hold the hanging formula bag in place. I took some more strips of Velcro and wrapped them around the copper pipe to use as line guides to keep the tubing from getting snagged.

After using Standly nightly for a couple of months, I think I can pronounce it perfect—at least for me. It cost under \$10; it is light and portable; I don't have to worry about air bubbles; and both the bag and

pump are readily visible and accessible. In addition, it is easy to plug and unplug the AC adapter when getting up in the night. Standly travels readily, is easy to store during the day, and is completely stable with my four-liter bag of formula hanging from it.

Pleased with the results, I made a second Standly, this time using one-half inch plastic plumbing pipe and glue. The pipe is easily cut with a hacksaw, and it takes no skill to apply the glue. I found that assembling this Standly was a little tricky because, in gluing only one joint at a time, it is difficult to get everything square. However working in plastic is easier for someone without skills or tools. I found the end result was perhaps not quite as sturdy for my four-liter bag, but perfectly satisfactory in use.

I can truthfully say that it has taken me longer to write this account of putting Standly together than it actually took me to do the job. If you have questions, you can write to me at the address below.

— Donald Empson
1206 N. Second Street
Stillwater, MN 55082
empson@usfamily.net



"Standly" the Mini-IV Stand

Parent Likes Catheter/Tube Holder

My daughter, Stacey has been TPN-dependent since age five due to chronic intestinal pseudo-obstruction. She is now 20 years old. Over the years we have had many problems with her line getting pulled, and she would end up with site infections. We tried taping, of course, but the tape irritated her and her skin. We tried tape, rolled gauze, and even taping the line to the inside of the shirt. Then a friend told me about Baboo's patches and I decided to give them a try.

We have used the Baboo's Patch for several months. They are easy to use and great protection for the consumer's line and skin. The patches come in packages of three. They iron onto the inside of the consumer's shirt. Each patch has a velcro area for attaching the consumer's central line and IV tubing; or if used for a G- or J-tube, attaching those tubes. None of the velcro touches the consumer, it is protected by a soft fabric. There are two areas of velcro on each patch allowing for the multiple lines. My daughter likes to attach her CVC on one side and the IV tubing down the other side. We have been able to attach a double lumen line with multiple infusions into this one patch. The tubing does not slip. Using these patches has protected her skin because we no longer have to tape the line or tubing to her chest.

The patches aren't movable from shirt to shirt. We solved that though by attaching them to a light t-shirt and her favorite

shirts. If Stacey wants to wear a shirt without a patch, she just wears the t-shirt underneath.

Valerie, the mother of "Baboo" and inventor/owner of the patch, is very open to suggestions and ways to improve the lives of "our" children. When she first modified the patch to include velcro, my daughter had a problem with the design. We emailed Valerie with the problem. She immediately responded, accepting our input graciously and modifying the patch. This newly-modified patch is now available.

Using the patches has made our life much easier and the line is protected from pulling, hanging, etc.

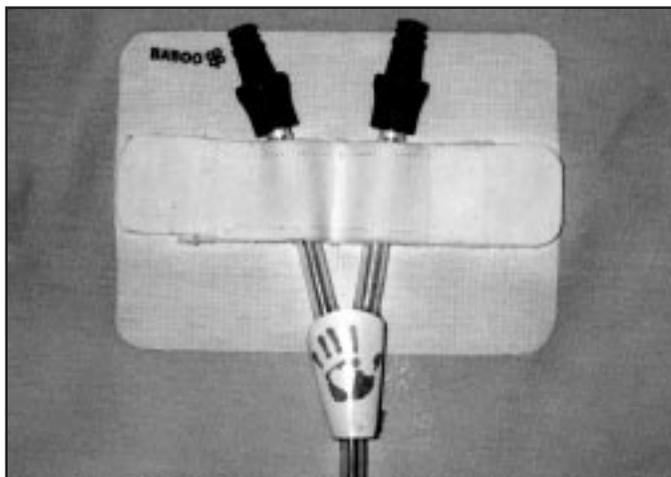
— Karen Nelson

86 Fox Wood Dr

Sanford, NC 27332

KMNelson86@aol.com

919-499-2623



Designed by the parent of a former HPEN-dependent child, Baboo's Patch can be used for IV and G/J-tubes.

Swimwear Covers Tubes Well

More than one female consumer has called the Oley office to rave about the two-piece swimwear offered by Lands' End. According to callers, the mail order company sells a large selection of quality, two-piece (and one piece) swim suits that offer consumers easy access to their tubes, catheters and ostomies, while at the same time making these appliances less visible to others at the pool or beach. If you are interested, and thinking of purchasing the swimwear on-line, please consider going through the iGive.com mall (<http://www.iGive.com>). It costs no more for you, and Oley will receive a donation. ☺

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"Nutrishare doesn't forget about the importance of the opinions and needs of the consumer once they have been on service for awhile."

Elizabeth Tucker - Bloomington, Minnesota



Nutrishare, Inc.
1-800-HOME TPN

Nutrishare is the only organization to have been recognized by the ACHC as specialists in Home TPN care.

NICHCY: A Resource for Families

The National Information Center for Children and Youth with Disabilities (NICHCY) provides information on disabilities and disability-related issues for families with disabled children ages 0 to 22 years. They cover such areas as early intervention, special education and related services, family issues, disability organizations and transition to adult life.

NICHCY's services include: personal responses to families specific questions; publications (fact sheets, newsletters, etc. available in Spanish too); referrals to other organizations and sources of help; information searches of its databases and library.

For more information, contact NICHCY at P.O. Box 1492, Washington, DC 20013; Phone: (800-695-0285); Email: nichcy@aed.org; Web: www.nichcy.org

Fear, from pg. 2

anticipated, and that fear you do not like begins to surface? I had that happen to me recently. I had arrived for elective surgery and found that the anesthesiologist I had requested was not available and the one I would be having was someone who did not "listen to me." I handled it by making certain that everyone in the surgical unit knew my concerns and how I was feeling. It did not change the circumstances of the situation, but it did allow me to "stand up for myself" and let my needs be known.

Facing your fears using skills like those I have described, can only have a positive influence on your recovery, regardless of the pending surgery or procedure. Hopefully they will generate some new ideas that allow you to express yourself in ways that reduce your fear and permit you to have a more positive health care experience. ©

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Equipment Exchange

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

EN supplies/formula

- Calmoseptine Ointment†
- 2 cases Twocal HN exp 11/02 8 oz cans
- 5.5 boxes Vivonex Plus
- 2 Kangaroo 330 Pumps (stationary)
- 15 cases Neocate
- 16 Kangaroo Pump sets 1000 ml (8884-773600)
- 1-1/2 cases Complete Pediatric (exp. 7/02)
- 2+ cases of Tolerex
- 1 Mic-Key G kit, 14Fr/ch 1.2 cm
- Safe-T-Vac suction catheters, 10 Fr, 12 Fr
- 4 Retention Foley Catheters, 12 Fr, 5cc
- 1 Yankauer suction tube
- 5 CPAP filters No. 32226-01
- 2 Mic-Key 12" extension tubes
- 3 Softtouch Suctioning Kits
- 1 Bard universal feeding adaptor #000332
- 1 Corpak NG tube, 6 Fr #20-8366
- 1 Corpak Y-extension set #20-1007
- 2 Rusch foley catheters, #318118, 18 Fr, 5-10 cc
- 11 Sherwood 500ml pump bag/sets, #702005
- 5 right angle feeding set and Y-port, 24"
- 3 bolus feeding sets w/ single port
- 2 Mic-Key extension set, 12", Y-port
- 1 Mic G-tube, 5 cc, 18 Fr.
- miscellaneous EN supplies (syringes, tape, dressings)

†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.

HPN Supplies/Equipment

- 1 Provider One Pump w/ battery, backpack, recharger†
- 1 Abbott Aim Plus w/ battery/2 backpacks/no recharger †
- 1 Pancreatoc Pump w/ battery/backpack/recharger †
- CADD admin sets #21-7042, 21-7032†
- 14 Clinipad dressing changes†
- 10 ml BD syringes w/ interlink syringe cannula†
- Bard repair kit, 1.6 mm lumen Hickman†
- Provider pump sets #13575, 1.2 micron filter

Ostomy Supplies

- Ostomy bags 1.5" and 1.75" †
- 2 boxes of Hollister Ostomy bags #3631, size 2.5
- 3 boxes of Hollister Ostomy bags #3804, size 2.75
- 10 Hollister stomahesive, item #3734, size 2.75
- 3 Hollister premium paste
- 9 Hollister Ostomy bags #3325, size 2.5
- 3 Generic brand one piece ostomy bags.

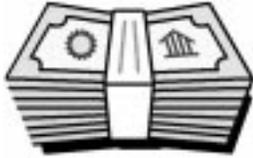
Miscellaneous

- incontinence diapers†
- 3 cases Terumo 60ml syringes, plastic cath tip
- 2 boxes of Latex gloves.
- 2 Cans of Quik Care antimicrobial foam hand rinse.
- IV Pole

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, 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. ©

Horizon, from pg. 1

board, a supportive industry component; however, the Foundation also has its struggles. One of the biggest hurdles that Oley faces each and every year is funding. We are secure enough to survive one year in the red, but we are constantly aware of how vulnerable each program is to the winds of change among our largest supporters.

To put Oley on firm financial footing, to ensure that Oley will continue to be here for consumers in the years to come, we have launched the Oley Horizon Society: a Society of people who have included Oley in their planned giving program (i.e. wills, beneficiary of life insurance policies, etc.).

If Oley was there for you and yours in a substantial way please think about joining the growing number of Oley Horizon Society members. (See page 10 for a complete list of Horizon Society Members.) A simple "yes, plans are underway to include Oley in my will" by December 31, 2002 (an extension of the original deadline) grants you founding member status. This is our best chance of making sure Oley is there for the next consumer and the next.

For more information on making a planned gift to Oley, please contact Joan Bishop, at (800) 776-6539 or BishopJ@mail.amc.edu. She'll be delighted to explain what is needed. ©

Celebrating Life!



James with his wife

The Coram Healthcare staff proudly nominates James Seals to be a member of our Celebration of Life Circle. James has been receiving PN for 11 years. Although he has been unable to work due to intermittent pain, he doesn't let this interfere with his involvement with family and church.

When James' two sons were younger, he volunteered in their classrooms in a program to encourage reading. He now coaches his sons' basketball and football teams. James sings in the church choir, does volunteer work and drives his wife and son to work and school every day.

He has a great, positive attitude, despite occasional setbacks.

Congratulations James.



James was nominated to Coram's Celebration of Life Circle by Coram Healthcare's staff.

To nominate someone, 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: celebratelif@coramhc.com
 For information, please call: 972.394.9974



Don't, from pg. 1

was a vicious cycle and we rarely saw Bob because of it. For us, the worst of it, was that Bob was famous for being out of touch. He rarely returned phone calls and, to our knowledge, never initiated them. We never knew how bad things were for him.

The tragedy of Bob's death is that it was probably preventable. The events surrounding his death could have been so different.

The Last Two Days

Wednesday morning Bob's home care company was attempting to make his delivery. The driver rang the his apartment buzzer and got no answer. This, I'm told, was quite unusual. The driver called the office and someone there phoned the apartment. Still no answer.

The delivery man left to return the next day. He still got no answer. The company attempted to find someone who could tell them what was going on. Unfortunately, Bob's mother was away in Arizona. Eventually they contacted her. She, in turn, called a cousin who lives in the area. The police were notified and they had to bust into the apartment. There they found Bob had passed away.

It was determined that he died sometime during the previous night. There is no telling, I suppose, what might have happened had the home care company made a bigger fuss the day before and gotten into the apartment then. And there is no telling just what Bob might have been going through during the last day(s) of his life that prevented him from reaching the door or the phone. I'll leave that for others to contemplate. But Bob's death can serve as a wake-up call to the rest of us.

I present to you a series of steps that you can take to prevent this sort of tragedy from befalling you or someone you know.

1) Set up a system whereby somebody calls you on a daily basis. Better yet, have them call once in the morning and once in the evening. Alternatively, you can make the call to a friend or family member. Even if you are calling an answering machine, they only have to hear your voice, not hold a conversation. This person should be trusted with a key or be able to contact someone who has one.

My mother tells me of a neighbor of hers in

her youth. Every night this neighbor would place a pennant in her back window and remove it every morning. In this way, the folks in the house behind her could simply look for the flag in that window. No more than 12 hours need go by before someone would know if there was a problem. Similarly, you might signal to your neighbor all is well by opening and closing your curtains/blinds each day.

2) Be sure to act when a situation changes; make new arrangements as soon as needed. I'm told Bob had made such an arrangement with one of his neighbors. Unfortunately,

Leave standing instructions with your home care company — or any other people or companies that make regular stops at your home — about how to react should you not answer when expected.

she had moved away some months before and Bob had yet to find another neighbor to take her place.

3) Leave standing instructions with your home care company about how to react should you not answer when expected. This goes for any other people or companies that make regular stops at your home. This is an unlikely scenario, to be sure, but obviously possible. I might suggest that they continue to try your phone, on the hour, for say, four to six hours. If they don't get an answer, then a neighbor, friend, family member or the police should be notified. Make sure they have those numbers available. And always notify your company if you do not expect to be home for a delivery.

4) The US Postal Service has a program called Carrier Alert. A notice is placed in the mail box to alert the letter carrier. After three days, if the mail has not been picked up, the carrier notifies the Post Office and calls are made. You may have noticed that letter carriers now have cell phones with them to keep in touch with the home office.

5) Remember the lady on television shouting, "I've fallen and I can't get up!" Look into one of those personal medical alarm 'panic button' systems that will automati-

cally place a phone call to an emergency number such as 911 or your doctor. Your hospital may offer such as service or know who does in your community.

6) Consider becoming a member of MedicAlert®, a non-profit membership organization (800/432-5378 or www.medicalert.org). The membership fee (\$35 the first year and \$20 a year thereafter) entitles you to several services, including indentifying you and your medical needs/conditions to emergency responders should you be discovered unconscious. It can also tell ER personnel which family member or friend to notify if you are in trouble.

7) Check with your city or township. They may have another program in place for just this situation.

8) Hire a Wake-up Service. Alarm clocks don't work for some people and there are plenty of firms that are set up to be a substitute. Have them call you twice a day with instructions on what to do if you do not answer. Of course, don't forget to inform

them if you simply go out for the evening, or when you attend the Oley Conference.

9) If you work, ask a coworker to be alert for days when you don't show up. Have them place a call to your home to check on you.

10) If you live with one or more other persons, don't assume you are immune from this situation. Have a plan in place should your family or roommates leave town for a few days. Your arrangements don't have to be continual, but someone should be available to perform this service occasionally. Then be certain to put them in force when you need them.

These suggestions are but a start. If you are doing something that hasn't been covered here or have a story that might interest the rest of us, please contact the *Lifeline-Letter* editor (contact information on page 2). I'm going to miss Bob, but if his tragedy helps to save someone else then his loss will have some meaning. ☺

Unfortunately, this is not the first time such an event has happened to a member of the Oley family, and it can be very painful for the survivors. So please, if you won't take these steps for yourself, take them for the sake of your family, friends and Oley.

Little Brother

by Chelsea Marek

A mother sent in this poem, written by her 11 year old daughter about her brother, to share how siblings are affected by all that homePEN families go through. Part one she wrote when her brother first went through the g-tube surgery/take-away-all-oral-intake drama and part two was when her mom took him to Cleveland for swallowing therapy. The mother writes "I feel very lucky for the love and compassion both of my girls have for all he has been through!!"

Part One

Through the highway we will race,
Down to this horrid place.
To the hospital we go,
Through thunder, lighting, rain, and snow.
I wish I could see him, but I can't,
Like everyone else, my mother and aunt.
It would be great if he was just fine,
But not him, not that brother of mine.
They think it's asthma. No, maybe stomach pain,
On to the next doctor, this is driving me insane.
So when he comes out, I'll say "Hi",
Until then we have to say good-bye.
I want to say bye to that horrid place,
Good-bye to the doctor's puzzled face.
And when he is finally asleep in his bed,
I'll have good thoughts to put in my head.
I wish so much that he was safe and well,
I love him so much, there are no words to tell.
Like any sister, my love for him is deep,
I'll pray for him nightly before I can sleep.

Little Brother Part 2

Here we go on the plane,
This is driving me insane.
Off to Cleveland we will go,
Though it's freezing and ten below.
Rainbow Babies is the name of the place,
It takes two weeks 'cause this isn't a race.
An electric stimulation is what they have to do,
The number of hours it takes is a dreaded 2!
For three weeks I won't see my mom,
Nor my Grandma or my brother, so I'll just have to be strong!
It's hard when you're waiting in anticipation,
While some of your family is across the nation.
I love my brother and I hope he gets well,
Like I said before, there are no words to tell.
It's hard you know him being sick and all,
When you can't buy him a slushy at the Collin Creek Mall.
I guess it's not so bad since he's so cute,
If he gets well his solid-only diet will forever be on mute.
So I'll end this poem whether you like it or not,
I like what I have and I have what I've got.
And, I repeat, to make a long story short- my brother can't drink,
So when they go to Cleveland he'll get well. I think.

Northern California ASPEN Meeting Planned

The Northern California chapter of ASPEN (NoCalspen) is holding a conference Wednesday, September 25, 2002, from 8:30 a.m. to 3:00 p.m. at the Scottish Rite Center in Oakland, California. Entitled, "Navigating to Knowledge" the conference offers wonderful speakers on topics which include: Pain Management and Gastrointestinal Disease, Managing the Enteral Patient, and Vascular Access Update. For additional information please contact Sheila Messina at 408-978-0466 or sheila.messina@gte.net

A Story of Triumph

Last December we let lifeliners know about "On Eagles' Wings," the story of one family's health care experiences written by a long time Oley member and father of an HEN consumer. In the book, the father recounts the painful and ultimately triumphant story of his son's journey through his unexpected total gastrectomy, the long and difficult search for proper nutrition and care, and the inspiring new career he builds for himself serving his country as a disabled person.

Since that time, we've heard from several people how this book has brought them insight into the challenges of homePEN, and have been urged to share the information with readers again. The family is generously donating a significant portion of the proceeds from the book to the Oley Foundation.

Order Form

Thomas Crown Publishing
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Quantity	Description	Each	Total Amt.
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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.

JULY '02	<p>Heidi Andolina Greenfield Ctr, NY (888) 610-3008 EST</p>	<p>An Oley board member, Heidi is the parent of Julie (2-1/2 y.o.) who has been on TPN and intermittent EN since birth due to SBS. Julie had a very difficult first year, but has made great progress since. Call Heidi to talk about living fully while meeting the challenges of raising a child on HPEN.</p>
	<p>Linda Wyatt Kuna, ID (888) 650-3290 MST</p>	<p>Linda is one of Oley's new Regional Coordinators. She is a single mom with two grown children. She was diagnosed with GI dysmotility in 1997 and has experience with both TPN and EN. She has both lines but is currently maintained with TPN. Linda works full time, and enjoys reading, yard work and shopping!</p>
AUG. '02	<p>Sharon Rose Nashville, TN (888) 610-3008 CST</p>	<p>Sharon has been on TPN since October 1968 (on <i>home</i> TPN for 32 years), making her the longest HPN survivor known to Oley. However, TPN is far from the focus of her busy life. She is married, a mother of two teenage boys, and employed as an RN. She currently has a Hickman catheter.</p>
	<p>Robbyn Kindle Bedford, TX (888) 650-3290 CST</p>	<p>Robbyn has been on TPN since 1991 due to a malrotation of the small bowel. She received a small bowel, kidney, pancreas and liver transplant in May 2000 because of TPN induced liver disease. Despite this, she was able to graduate with university honors in the spring of 2000 with a degree in Nutrition & Dietetics.</p>
SEP. '02	<p>Jim Cowan Cleveland Heights, OH (888) 610-3008 EST</p>	<p>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.</p>
	<p>Eleana Shore West Hills, CA (888) 650-3290 PST</p>	<p>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 Fundalplifications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</p>

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