The Oley Foundation

LifelineLetter

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

MAY/JUNE 2007

What's Inside:

Restoring GI Autonomy to Intestinal Failure Patients

Kishore Iyer, MBBS, FRCS, FACS
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This is an adaptation of a talk given by Dr. Iyer at Albany Medical Center on April 19, 2007.

The current algorithm for managing intestinal failure due to short bowel seems to follow a predictable pattern. The patient has a catastrophic gastro-intestinal (GI) event leading to major intestinal resection. Hopefully the patient recovers and early on in this process parenteral nutrition (PN) is initiated. If the patient does well, then he or she goes home to continue on PN at home (i.e., HPN). If the patient does not do well and develops complications related to PN, either immediately or at some future point, he or she is likely to be referred to a transplant center.


Kishore Iyer, MBBS

There are several disadvantages in this approach. First, there is no early recognition of patients at high risk for developing PN complications. Second, nationally, the majority of these PN-dependent patients are managed by a physician who has neither the time nor the expertise to administer an adequate level of care or take the steps to gradually wean the patient from PN. An effort to wean is a necessary, but not easy process.

Intestinal Rehabilitation

I have for some time embraced a somewhat different approach. Instead of consigning the PN-dependent patient to benign indifference or neglect and then transplant, I prefer adopting a more formal approach to intestinal rehabilitation. This approach incorporates all of the available therapies—nutrition, medical, and in some cases, specialized surgical procedures—in an attempt to wean a patient off PN if possible. Where weaning is not possible, the goal then becomes prevention of PN complications. The hope is that only a very, very small minority—

Transplant cont., pg. 2 ☛

On the Road with Terry Edwards

Terry Edwards

Terry Edwards lives outside of Vancouver, BC, with his wife, Anne, and their two sons. He works for an international packaging company and is responsible for operations in the United States coast to coast. His position also takes him across Canada, China, Japan, and Europe. He has been on enteral feeding for several years, and faces some unique challenges due to the extensive travel his job requires. We asked Terry how he manages with so much traveling, and he shares some of his ideas and experiences with us here.

I was introduced to enteral feeding in the summer of 2005, after having a tumor removed from the base of my brain on the right side. I figured I was looking at a few days in the hospital and six to eight weeks of down time; I had had a similar surgery six years prior without any serious complications. Unfortunately, this time the tumor had enveloped some key cranial nerves—those that control my speech, swallowing, tongue, and esophagus.

While we waited for the trauma of the surgery to subside and the nerves to kick back in, I was TPN-fed. After about three months in the hospital, however, it became obvious the recovery was going to be slow. A J-tube was placed and I was discharged.


Terry in China, hooked up and ready to see the sights.

The mechanics of swallowing are one of those mysterious engineering feats that we never consider until we have to. I went home with a portable suction machine, in addition to the J-tube, as I was unable to manage

On the Road cont., pg. 10 ☛

Late Breaking News!

We're just back from the Oley Annual Conference in Hyannis, Cape Cod. The company was fabulous, the information exchange was stimulating, and the Cape was beautiful. And though we've barely unpacked, through the wonders of technology we have some photos to share on pages 8 and 9. Look for more photos and conference news in the July/August issue of *LifelineLetter*.

Transplant, from pg. 1

perhaps less than 1 percent of all patients in whom PN is initiated—will ultimately require intestinal transplantation.

There is outcome data available from large national databases both in North America and Europe that allows us to think about which type of patient may come to intestinal transplantation. This is more likely in adults who have less than 50 cm of small bowel, or children with less than 30 cm, especially if they have no ileum, iliocecal valve, or colon. The HPEN registry and European data show, for patients with non-malignant diagnoses on long-term HPN, one- and four-year survival rates on the order of 95 percent and 80 percent respectively can be accomplished. The results from smaller, single-center series, UCLA, Alabama, Omaha, Denver, and Paris, are similar. It is important to note that this data indicates survival that is accomplished in patients managed by experts in the field working at the best centers; this may not, therefore, be the survival that all patients are enjoying. Nevertheless, it is clear that excellent survival outcomes are possible in the majority of patients on PN. It is because of these data that the standard of care today for the patient with irreversible intestinal failure remains PN and indications for intestinal transplantation have become the presence of irreversible intestinal failure along with the onset of life-threatening complications of PN.

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The Course of Evaluation

My own approach to the patient with intestinal failure is to ask myself, is this failure permanent? To answer this, I look at etiology, residual bowel length, residual anatomy, residual motility, and a history of enteral tolerance.

If the intestinal failure does not appear to be permanent but the patient is still on PN, I would emphasize enteral nutrition (EN) via diet, or via tube if need be, in the hope of speeding intestinal adaptation, and follow up with close monitoring and good nutritional and medical care. If adaptation occurs, and the patient weans from PN, well and good; if not, I go back and ask again, is this intestinal failure permanent?

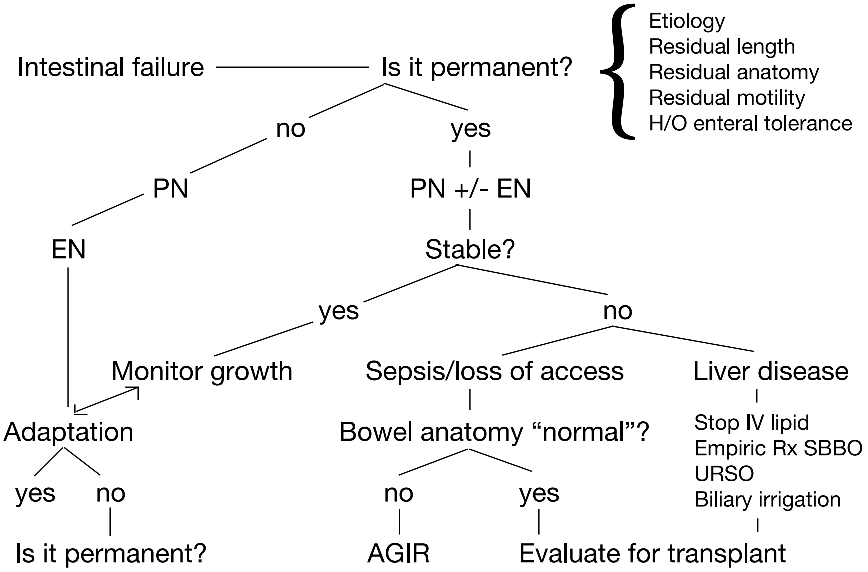
If "permanent" intestinal failure appears likely, I would still optimize PN and aggressively pursue EN. If such a patient is stable, not a lot more needs to be done as long as stability is maintained. In children, growth is an issue and must be monitored. Many of these patients, particularly children, will eventually undergo intestinal adaptation.

If the patient is not stable on PN, the cause of his or her instability needs to be pinpointed. Complications of PN leading to instability should lead to a reassessment of the bowel anatomy. Many patients with short bowel syndrome have markedly dilated bowel. The reasons are not always completely clear; it may be a compensatory mechanism for the loss of length or it may be a function of poor vascularity. Also they may have areas of narrowing and disturbed motility. In these circumstances, overgrowth with abnormal bacteria may be occurring, worsening the absorptive function. Probiotics and cycled antibiotics often help, but eventually a surgical modification of the bowel may be needed. I would resort to one of the series of procedures that we call autologous gastrointestinal reconstruction (AGIR). These include:

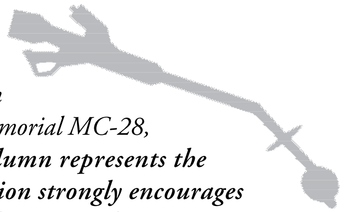
- the Bianchi procedure, described by Adrian Bianchi as a longitudinal intestinal lengthening

Transplant cont., pg. 6 ☛

Figure 1: Transplant Decision-Making Flow Chart



Tube Talk



Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. ***Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.***

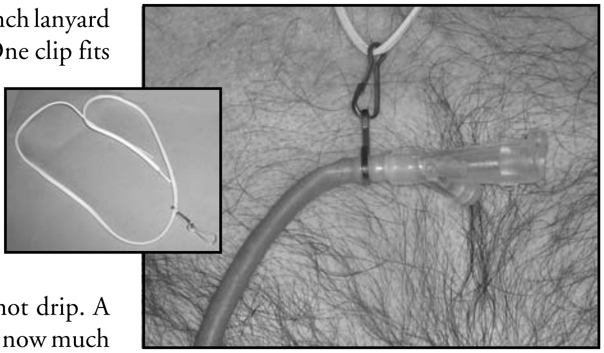
Clip Helps Avoid Drips

I have had a problem with the tube pressure causing top dripping or the tube to open and spill out my stomach contents. I tried one of the Velcro pouches with a strap but found it to be one of the most uncomfortable things I have ever worn; also, it did not stop drips.

So I came up with a solution that works for me, using gravity. I use a pair of 1-inch lanyard clips and an elasticized shoelace. One clip fits perfectly around the tube just below the opening and the other goes on the shoestring, which I wear as a necklace. Then I clip the two clips together. This holds the tube higher, near my shirt neckline, and since the top is higher than my stomach, it does not drip. A secondary benefit is that the tube is now much easier to reach for my five feedings a day.

Besides the comfort, I really appreciate the low cost and convenience. You can find the parts you need for this almost anywhere.

—Floyd T. Greenman
Chatsworth, CA
fgreenman@socal.rr.com



Floyd uses lanyard clips and an elastic shoelace to keep his tube accessible and drip free. The insert shows another view with the entire holder.

Calendula Cream for Granulation Tissue

We have a fifteen-month-old daughter on HEN who has very sensitive skin. We've had multiple problems with inflammation and granulation tissue around her button, and we finally found that calendula cream works like a charm. We periodically apply it as a preventative measure, as well as at the first sign of any redness, and the redness clears up the same day. We get ours from California Baby (www.californiababy.com) but local health food stores also usually carry it.

—Dawn Detweiler
Goshen, IN
dawndetweiler@hotmail.com

Dressing / Site Care Ideas

We have heard from some consumers that they've been using Biopatch™, from Johnson & Johnson, with good results. Biopatch is an antimicrobial dressing with chlorhexidine gluconate.

Oley Foundation's medical and research director, Dr. Howard, generally suggests for her patients a less snug G-tube (i.e., the G-tube standing up 1 cm when the patient is lying down) and Bag Balm® to keep the exit site as comfortable as possible.

Oley at DDW 2007

Janet Platt

Recently I had the opportunity to represent the Oley Foundation at the annual Digestive Diseases Week Conference which was held in Washington, D.C. It was an interesting and unusual experience. What other conference has "live" demonstrations of colonoscopies? And where else could you meet people dressed up as an *H. pylori* bacterium?

The Huttons and Jan Gambino at DDW

I was surprised to find that homePEN is basically not an option in most countries. I spoke with a doctor from Lithuania who practically had tears in his eyes when he learned that we have widespread home-self-care. Likewise, doctors from the Middle East were flabbergasted and had questions about sterility and preventing infection from feeding at home. All of us Oley volunteers did our best to educate attendees about Oley, and how full and active a life tube-feeders can have. We were able to reach many people in a short time.

A huge thanks from Oley to everyone who volunteered at the booth, including Gisela Barnadas, Davi and Steve Cohen, Jan Gambino, Portia and Wally Hutton, Jack Leibee, and Janet Platt.

Swallowing Research

The Clinical Center at the NIH in Bethesda, MD, is conducting a study on swallowing disorders. The purpose of these experimental studies is to compare two new ways of helping individuals with severe dysphagia (swallowing disorders), specifically to determine if surgical implantation of an intramuscular stimulation device, and/or if sensory stimulation, can improve control of and safety during swallowing.

The NIH will pay all study-related expenses. To qualify for a screening visit, a letter of referral and medical history information will need to be sent. Persons admitted to the study will have their expenses for travel to the NIH covered on future visits.

Individuals may qualify if they are 18–90 years of age, have chronic pharyngeal dysphagia (post six months), have been instructed not to take food by mouth or are on a restricted diet, and have functional cognitive skills.

Individuals may not qualify if their neurological disorder is unstable; they have chronic obstructive pulmonary disorder (COPD); they are HIV positive or immune compromised; they are on a regular diet without difficulties; they have dementia, excessive somnolence, or agitation; or they have metal parts in the body, such as prostheses, implants, or shrapnel.

For more information, please contact Katie Burns at (310) 594-5193 or e-mail dietrichburnsk@ninds.nih.gov.

The research study listed above has been deemed appropriate for homePEN consumers by the Oley Research Committee; however, ***we strongly encourage anyone considering participating in medical research to discuss the issue with their managing physician before signing up.*** More information on these studies is available by calling (800) 776-OLEY or visiting our web page at www.oley.org.

In April, former Regional Coordinator Eleanor Orkis hosted her annual support group meeting in Schenectady, NY. The meeting was well attended, with members traveling from as far away as Buffalo. Oley's Medical Director, Lyn Howard, shared a Power Point presentation of her personal journey to Mongolia and led a discussion about homePEN outcomes and the future. Attendees heard traditional Mongolian chanting and learned about a culture based largely around horses, as well as shared in some of Dr. Howard's expectations for the future of homePEN. Pictured from left are: Lisa Metzger, Marcia Martin, Eleanor Orkis, Dr. Howard, Mary Kunz, and Gail and Chuck Brenenstuhl.

HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight the institutions around the country that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org.

Intestinal Rehabilitation and Liver/GI Transplant Division University of Miami, Miller School of Medicine

The Program for Intestinal Rehabilitation and Liver-GI Transplantation was started in 1994, when Dr. Andreas Tzakis joined the University of Miami as director of the program.

A combined effort between the Department of Surgery, Division of Pediatric Surgery and Division of Liver-GI Transplant, plus the Department of Pediatric Gastroenterology allows a multidisciplinary approach to parenteral nutrition patients, resulting in multimodal therapeutic strategies.

Patients with intestinal dysfunction are evaluated and offered medical therapies with intestinal adaptation protocols (with enteral and parenteral nutrition), in collaboration with a team of dietitians and gastroenterologists. Surgical techniques of bowel lengthening (including STEP procedure) and reconstruction are available to complement medical management.

In addition, the center offers alternative surgical techniques such as intestinal auto-transplantation. Finally, intestinal and multivisceral transplantation is offered for those patients with irreversible intestinal failure. This center performs over half of the multivisceral transplants in the nation.

The adult liver/GI transplant associate director is Seigo Nishida, M.D., and the pediatric liver/GI transplant associate director is Tomoaki Kato, M.D. More information about the program can be found at their Web site at surgery.med.miami.edu/livergi/index.asp or by phone at (305) 355-5000.

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and tapering procedure; this can be an effective way to lengthen a dilated bowel and improve its absorptive and functional capacity;

- stapled transverse enteroplasty or STEP, which involves creating a series of longitudinal staple lines in a dilated loop of bowel; the result is a series of "baffle valves" that may slow transit and increase the bowel's absorptive capacity;
- in rare cases, particularly in the setting of diarrhea and rapid transit, without bowel dilation, a surgeon may create a reversed segment of bowel, an anti-peristaltic segment, in the hope of reducing stoma losses; experience with this procedure is limited to a small series of patients.

If the short bowel shows no surgically correctable abnormalities, we are left with a possible indication for an isolated intestinal transplant for irreversible intestinal failure and life-threatening complications of PN. At this point, we would hope to perform an isolated intestinal transplant before the onset of liver disease.

The burning question facing intestinal transplant today is: Should intestinal failure patients with PN complications get preemptive, isolated intestinal transplant before end-stage liver disease, or should we wait until advanced liver disease mandates combined liver-intestinal transplant?

If instability is caused by liver disease in the setting of irreversible PN-dependence, we would implement an aggressive protocol for the management of PN-associated liver disease while simultaneously evaluating the patient for transplant, again in the hope of performing an isolated intestinal transplant. There is increasing support for the idea that PN-associated liver disease may have a multi-factorial origin. Attention to the many risk factors may allow reversal of PN-associated liver disease in some patients, as we have previously reported.

Our protocol checks for other factors that may cause hepatic dysfunction, including viruses, medications, alcohol, or gall bladder disease. We check for unrecognized sepsis and for anatomical dysfunction that may cause bacterial overgrowth (labeled SBBO, for small bowel bacterial overgrowth, on figure 1). We make every effort to feed via the gut to the limit of tolerance and back down PN as much as possible, lowering or completely withdrawing parenteral lipids. There is evidence that plant-derived fat (soy bean oil) and possibly plant-derived cholesterol (sitosterol) given intravenously cause liver inflammation. There seems to be a beneficial effect from the use of intravenous fish oil emulsion. **This data must still be viewed as preliminary and the parenteral fish oil emulsion is not currently approved in the United States by the FDA for clinical use.** (See "HPN-Associated Liver Disease in Infants" article at www.oley.org for details.)

Benefits of Early Referral

Since the vast majority of patients with intestinal failure on long-term PN are managed by physicians who do not have the time or the expertise to closely look after them, it is surprising that more patients are not ultimately labeled as having PN failure and referred to a transplant center.

Unfortunately, from a transplant center's point of view, referrals that are made to transplant centers are often very, very late. Last year, based on national data, over 68 percent of short bowel patients who were listed for intestinal transplant were also listed for liver replacement. There is no other transplant area (i.e., kidney, heart, liver, lungs) managed by a single organ transplant in which the physician waits for a second organ to fail before considering transplant referral. Conversely, from the primary physician's point of view there is concern—legitimate in some instances—that earlier referrals are sometimes transplanted prematurely and possibly inappropriately.

The burning question facing intestinal transplant today is: Should intestinal failure patients with PN complications get preemptive, isolated intestinal transplant before end-stage liver disease, or should we wait until advanced liver disease mandates combined liver-intestinal transplant?

There is a growing body of data that can inform this discussion. Data from the Paris group of Bernhard Messing suggests that most patients who have at least 100 cm of functioning small bowel will be able to come off PN. In contrast, adult patients who have less than 50 cm of small bowel and have been on PN for five years are very unlikely to come off PN. If such a patient is starting to develop significant liver problems, then perhaps referral should be made sooner rather than later. The question really is what is meant by "significant" liver problems. Most patients on long-term PN develop some biochemical evidence of liver dysfunction [alkaline phosphatase and transaminase enzymes twice normal value] but the development of severe liver failure is comparatively rare (perhaps 5 percent of all adults on very long-term PN, although more frequent in children). Perhaps the move to refer should be made when liver function tests start to worsen (increased bilirubin and prolonged clotting time).

Why are these issues important? Jonathan Fryer and colleagues have studied data on the mortality of patients on the waiting list for intestinal and liver transplants compiled from the Scientific Registry of

Transplant Recipients (SRTR). The mortality rate for those awaiting combined liver-intestinal transplant is much higher than for those awaiting isolated intestinal transplant. These studies show that between 30 and 50 percent of patients awaiting combined liver-intestinal transplants will not make it to the transplant. Furthermore, in most centers that contribute to the international registry, survival appears to be better after isolated intestinal transplant compared to combined liver-intestinal transplant.

Advanced liver disease is still the most common indication for intestinal transplant. However, early referrals in patients with liver disease can often allow for reversal of liver disease, and avoid the need for combined liver–small bowel transplant.

The Future

Transplant centers are expanding their therapeutic horizons beyond transplant; there is growing recognition of the need to provide a high level of expertise in all aspects of intestinal failure management—HPN and reconstruction surgery, as well as transplant. Such centers need robust infrastructures with adequate levels of support in order to care for these complex patients properly.

There is a wide range in the percentage of patients who are seen at the different transplant centers who end up receiving an intestinal transplant. Some centers are transplanting a small percentage of all patients they see, others are transplanting 90 percent of the patients they see. This disparity needs to be explained. Perhaps the explanation is as simple as a given center having an interest only in transplantation, as opposed to another center that offers and explores the entire spectrum of therapies for a given patient.

Clearly intestinal transplant still has a long way to go. But we are learning, and getting better. More recent data shows that close to 90 percent of patients survive to the one-year post-transplant mark, and survival at five years is approaching 50 to 60 percent. From a transplant surgeon's perspective, the hope is that earlier referral of patients will lead to improvement in these outcomes.

The goal is to provide the right transplant to the right patient at the right time. To use a cliché, in caring for a patient with intestinal failure, we have many tools in a box, with transplant being the proverbial sledge hammer. It is true that we don't need the sledge hammer for every task. However, to wait too long for referral to an intestinal failure center is to risk reaching a point where no tool, not even the hammer, can fix the problem. ¶

Better Safe than Sorry

Now is the time to order your Keep Me Safe poster and bracelet from the Oley Foundation. Proper line care is essential to your safety. The Keep Me Safe campaign can help you become your own advocate. Call (800) 776-6539 or visit www.oley.org/keepmesafe.html to get your free bracelet and poster today!

Equipment Exchange

It has come to our attention that frequently the items listed in the newsletter version of Equipment Exchange are no longer available by the time readers get their newsletters. Sometimes consumers scoop up items they've seen listed on the Oley Web site or call the exchange coordinator before the newsletter even comes off the press, or before the USPS can get it in mailboxes.

We're hoping to implement a few changes to make the program more useful and more efficient—and to lessen your frustration. Rather than listing specific, potentially outdated information in the newsletter (such as what's available in tubing, bags, and formula at press time), we hope we can facilitate exchanges in the following ways:

For those of you who have Internet access, a full listing of the items available for exchange is posted on the Oley Web site, www.oley.org. The listing will be updated every couple of weeks, so check it frequently. This list includes everything, from tubing and bags to formula to all kinds of durable items. If you don't have Internet access, you can call the Oley office or Ben, the exchange coordinator, and we'll see if what you are looking for is in the exchange database.

Ben has established a request list. Let him know what you need, and he'll contact you if the item becomes available.

As always, items offered through Equipment Exchange are available free of charge. To either offer or claim items, please contact Ben Hawkins, the volunteer coordinator of the Equipment Exchange program, at benhawkins@fuse.net or call (866) 454-7351 (toll-free). This phone number reaches Ben's home phone, so please call between 9 a.m. and 9 p.m. EST.

If Ben matches you with a donor, please let him know whether or not you take the item(s) referred to you. This will help us keep the list current. We also ask that those receiving goods offer to pay the shipping costs. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition.

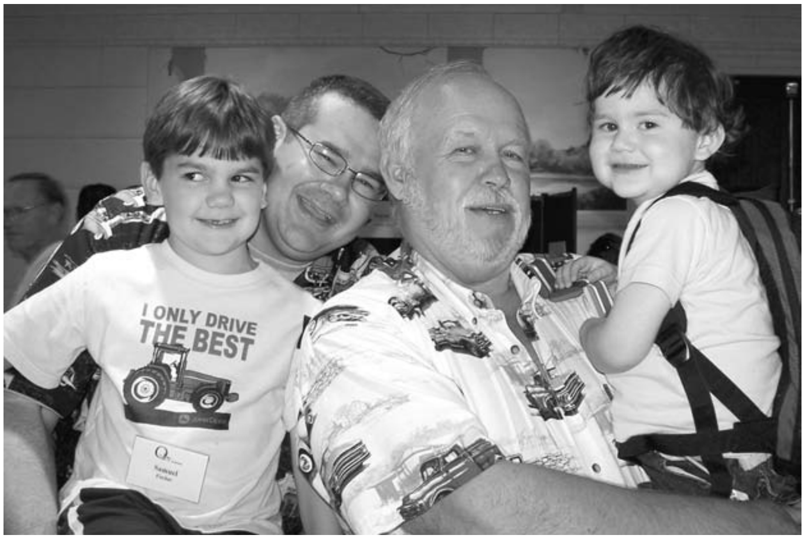
Scenes from the Oley Conference in Hyannis, MA







Held June 27 to July 1, 2007, at the Cape Codder Resort



On the Road, from pg. 1

swallowing my own saliva without choking and possibly aspirating.

At least, I thought, my voice was now workable, if not very strong or clear. But I was in a bit of a tough spot. I made my living by talking and traveling everywhere by air, and now my voice was compromised and my ability to travel was curtailed due to the huge collection of medical supplies I needed each day.

Retiring the Suction Machine

Radiation treatments and other complications had left me weak and sixty-five pounds lighter than when I had started. It took a long time to get the correct combination of feeding products into me to sustain me and build energy to heal. But we managed.

After nearly two years of exercises and therapy, I am still unable to protect my airway from filling with anything I try to swallow, regardless of how I thicken or adjust the texture. The risk of aspiration pneumonia is always there. I have had it three times so far—but who's counting?

Dealing with normal secretions is a problem, but fortunately we have discovered that Botox paralyzes my saliva glands into submission and shuts them down. The treatment lasts for four to five months and works great for me.

Getting Back in the Groove

There came a point when I had to decide how I was going to deal with all this. After six months of taking it easy, I needed to get on with it—the charm of hanging around the house was wearing thin. I gradually went back to my Vancouver office and set my sights on making all my feeding and sundry medical supplies as portable and easy to deal with as possible.

Lucky for me, I came across the Oley Foundation Web site and learned some of the positive things I could do to make life simpler. My biggest victory was learning about other pump systems. I now use a system that is far more lightweight and portable than the system I was using. I find it perfect for my needs.

Beginning to travel again took some adjustments. As left-brained as I am, I have had to force myself into nearly ritualistic adherence to a set of self-devised systems to get by. I have to write lists of things to pack and make myself check the lists. I usually travel alone so I have had to be self-reliant—it requires some discipline to be sure I have everything I need. Even if I am traveling with friends or family, I know I am going to enjoy it more if I am prepared.

New Routine Becomes Second Nature

One of the strange complications of my condition is hypermetabolism and a high heart rate. I had to figure out how to get eight cans (4,000 calories or 2,000ml) of my food into me and still be on the move. Because my tube is placed deep in my jejunum, I can only tolerate a maximum feed rate of around 160ml/hr, which nixes the possibility of fast, bolus feeding sessions. I had also hoped I could arrange a discrete system so as not to call attention to my issues.

Here Terry is hooked up and ready to fly. His feeding tube comes out of a shoulder bag and runs up under his tie. Many people assume it's part of a headphone set.

Through a lot of trial and error, my very patient dietitian at the BC Cancer Agency, Angie Bowman, and I came up with a program that allows me to run five cans during the day at 160 ml/hr and run the other cans slower (for maximum calorie absorption) through the night. By now my friends and associates are all used to the shoulder bag I carry and the tube running up under my shirt, though it took some getting used to—for both me and them. But once I accepted that that was what was necessary to get on with it, it became second nature.

My long feeding schedules make it difficult to avoid being hooked up when I go through airports as I travel for work, but I now always disconnect when going through security. I have learned not to worry about being rushed—it's much harder and time-consuming to be screened with my equipment running and connected.

Once, as I was disconnecting in a Mexican airport, a guard panicked. He rushed over to inspect what I was doing with all the electronic devices and wires and flashing lights hooked up to my stomach. In this day and age, I suppose there is a fine line between being discrete and looking like a suicide bomber.

The Joys of Solo Travel

I learned the hard way that it's useful to keep an easy-to-find-and-flash abridged card with your feeding pump information on it—like the one suggested by Oley—to speak for you when you can't. While traveling alone to San Francisco last year I inexplicably became physically sick on the BART (the Bay Area's public transportation system). I got off in a nearly empty station.

Not being able to swallow complicates the simple act of throwing up; as I got sick, my airway became blocked and I aspirated. As I turned blue, the few passersby in the station took me for a drunk and kept their distance. I finally sorted it out before I hit the pavement and managed to get myself together. This caused one of my bouts with aspiration pneumonia, and I gained a new appreciation for traveling alone and being prepared.

With all of the travel I do, being prepared is critical. When I travel I carry enough of my supplies—food, meds, feeding bags, and water—to get me through a day or more. This sounds simple, but it requires some planning. My bags have been delayed or lost twice in one year and I had no need to panic either time. My carry-on bag is always maxed out, so I replaced my attaché case with a wheeled carry-on case and it all works out.

When flying, if I need water to flush, I bring a wide-mouth hard-plastic water bottle. It's always empty when I go through screening—it's easy to get bottled water at the shops on the other side of security. If I ask around a little, I can usually get a bottle at room temperature. With all the different airports and countries I visit, I can't risk tap water.

Once I nearly had my tube pulled out in a crowd when it became hooked on a passerby. I now carry a simple Foley catheter with me and have been trained on how to insert it in case of a "radical extraction" of my Mic-key tube. I figure my radiologist will thank me for keeping my stoma viable.

Things that are easily handled at home become a bigger issue on the road. Clogged tubes happen every once in a while. I have always carried pancrelipase tablets and bicarb to clear the tube. I have thankfully found a new, simple-to-use product called Clog Zapper—preloaded syringes that have twice got me out of trouble far from home. No one likes a trip to a strange emergency ward.

Air Travel

I have to keep my sense of humor when I travel by air, as it presents some unique challenges. Just passing successfully and quickly through security with a bag full of "dreaded liquids" took some refinement. Few of the security staff have ever seen—or thought about—tube feeders. They are trained to focus on the liquids, not the reasons for the liquids.

I have a letter from my doctor at the cancer clinic fully explaining my condition and necessary supplies—by brand name—which I offer at the time of screening, before my bag ends up in the x-ray. I have tried declaring in advance and not declaring in advance, and my best experiences have been when I've offered the information unsolicited. If all else fails and the screeners still do not seem to get the whole idea, I flash them my stoma and explain slowly what enteral feeding is. I have a letter translated into Chinese, and I'm working on copies in French, Spanish, and German.

Hobbies

When I am not traveling for work, I enjoy all the things the outdoor life offers. I had been active in sailboat racing on the West Coast for years before all of this began. I don't have the physical strength yet to do the job I used to do for the crew—lots of winching and pulling lines—but I plan to return to the boat this coming fall as a timer and tactical support person.

Terry out and about in China.

To keep me busy until I can get back to sailing, I purchased a vintage Italian sports car to rebuild with one of my sons.

How do I fit it all in? You'd be surprised how much time you have when you don't have to stand in line at Starbucks or McDonald's!

A Canadian Consumer

My food is not covered on any medical insurance, so I have learned to shop carefully. There's one thing I have found that has helped me and may be of use to some Canadian consumers living close to the boarder: When traveling to the United States, I have my formula shipped to one of my U.S. offices to avoid carrying all but forty-eight hours worth. My enteral formula costs approximately $82 for a case of twenty-four cans in Vancouver. But I've discovered that on the Internet there are many suppliers who will ship to a U.S. destination for a fraction of the cost (about $30 a case).

If you have a U.S. address—a friend, relative, or branch office—you can arrange to have a shipment sent there and you can pick it up and drive it home at a great savings. I save over $5,000 a year. If you are planning a trip, check out sites such as Walgreens; you can have your food shipped to any one of their retail stores for pick up. Why pack two cases to Disneyland when you can pick it up when you get there? ¶

In Memory of Marie Hartwick

April 18, 1947–April 23, 2007

Marie Hartwick was a delightful woman with great strength who would want to be remembered as a loving mother to her children, Tina and Richard, and a devoted grandmother. She was a great listener and a quick learner, and she had a great deal of experience to share.


Marie Hartwick

Marie began her journey on parenteral nutrition in 1981 when there was still much to be learned about bringing this hi-tech therapy home. In 1991 she was presented with the Oley Foundation Annual *LifelineLetter* Award, which recognizes an individual who demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN. Marie quietly and efficiently helped others, never asking or expecting anything in return.

Marie's transition from parenteral to enteral nutrition in 1993 was especially difficult. She checked in with Oley on a weekly basis and we could hardly imagine getting through what she described. But Marie did get through it, and to this day we speak of the challenges Marie faced and how she overcame them in an effort to prepare others for what could be a long road.

As an Oley Regional Coordinator volunteer in Little Rock, Arkansas, Marie coordinated monthly support group meetings and drafted newsletters to keep people informed of the happenings in her area. She used the media to create awareness of Oley Foundation efforts and to call attention to insurance issues.

Marie will be sorely missed by the Oley Foundation community.

We're Still Listening!

Thanks to those of you who completed the membership survey that was included in the March-April *LifelineLetter*. If you still have the survey in your to-do pile, it's not too late to send it in! Completed surveys help us to serve you better—to make appropriate referrals, to tailor articles and programs to your needs, etc.—and it is our goal to serve you well.

New on the Web

MitoAction, a nonprofit organization that provides support and education to families living with mitochondrial disease, has launched a new Web site at www.mitoaction.org.

Check out their new look and the Web site's updated resources.

Individual Donors–Thank You!

The following list represents everyone who contributed between March 21 and June 8, 2007. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

Ambassadors ($2000+)
Estate of Shirley Heller

President's Circle ($1000–$1999)
Frona Brown, in honor of Ester Ann Adler
David Winder, supporting Rick Davis*, ** walk

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Gibson Investments, supporting Rick Davis*, ** Walk
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Portia & Wallace Hutton
Robin Lang,** in honor of the Lang family
Sharyn Leaver, in honor of Margaret Leaver
Sheila Messina*
Fred Nading, Jr., in honor of his mom
Nancy Lee Oates
Maria Isabel Pedreira de Freitas Ceribelli
Ellen Pierce & Sandy Schwarz, in honor of their 25 years of friendship
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Chris & Sue White, supporting Rick Davis*, ** Walk
Andrea Wolcott, supporting Rick Davis*, ** Walk
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Don Young, in honor of Bettemarie Bond**

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Brenda Leake
Sarah Mabardy, supporting Michael Medwar* Walk
Mercedes Marson
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Dr. & Mrs. William McCaa, supporting Rick Davis*, ** Walk
Laura M. Mulcahy
National Ability Center, supporting Rick Davis*, ** Walk
Robert & Karyn Thomas

Contributors ($30–49)
Margaret Bald, with grateful thanks for the newsletter!
June Bodden**
Glen & Deanna Clark
Kathleen Demontigny, supporting Rick Davis*, ** Walk
Marilyn Dolan
Elaine Fazzaro
Marilyn Flaig
Frances Hovey
Lisa Kinder
Wendy Russo, in honor of Noreen Code

Friends (Up to $30)
Clauddinnea Blancharde
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Victor Chaney, in memory of Mellisa
Gretchen DeKalb, in honor of Mary Kunz's birthday
Bobbie Groeber,** in memory of Bruce Groeber
Mitchell Haddad, supporting Michael Medwar* Walk
Raymon & Patricia Hawkins
Glen & Karen Hillen, in honor of Allison's 23 years on HPN and liver and small bowel transplant in Jan. Off HPN since 1/22!
Earl & Maggie Jones
Marie Latta
Philip & Anita Mabardy, supporting Michael Medwar* Walk
Roger Niosi
Janiel Perry, supporting Rick Davis*, ** Walk
Joan Phillips, in honor of Betty Moen
Justin Sandoval
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In Memory of Dale H. Vanderhide
Dennis & Rita Dura
Susan Otto
Keith & Sue Partee
Alan & Barbara Pavlus
Charlene Vanderhide

* Oley Trustees
** Oley Regional Coordinators
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Thank You, Thank You

A special thank you to our corporate sponsors who keep Oley's programs going strong. This fiscal year we've seen a tremendous outpouring from long-time friends and some new partners. We appreciate your generous support!

Nutrishare, Inc.

Rod Okamoto and Tom Diamantidis attended their first Oley Conference in 1991, the same year that Nutrishare was founded. The company's cornerstone principle of focusing exclusively on home TPN care and honoring the consumers' rights to choose their health care providers and the products they use were forged during that remarkable conference in Saratoga Springs that summer.

In 2007, Nutrishare, together with the Oley Foundation, is proud to launch the Nutrishare Research Prize, designed to recognize and encourage clinical research that will improve the quality of life for home TPN consumers and their families. The entire Nutrishare family (consumers, caregivers, and employees) share in the honor of pioneering Oley's new Platinum Level of corporate support as a tribute to the Oley Foundation's mission.

Coram, Inc.

Coram provides the highest quality clinical care and personal support for HomePEN consumers through its One-to-One program, consumer advocate (Coram Partner), and toll-free help line. Once again, Coram is proud to be a Golden Medallion partner of the Oley Foundation, helping to fund educational and outreach efforts.

Apria Healthcare

Apria Healthcare Group, Inc., is a leading national provider of home health care products and services, including parenteral and enteral nutrition, antibiotics, and other therapies. With over five hundred branch and thirty-two infusion pharmacy locations nationwide, Apria serves over 1.5 million patients annually through all fifty states.

Apria Nutrition Advantage is a nutrition support program providing a customized care approach to patients' nutritional needs. The program's team of nutrition support dietitians, IV certified nurses, and registered pharmacists provides expert clinical care for patients with nutritional deficiencies. The company's mission is to be the first choice of patients and customers for their home-care needs. The company seeks to accomplish this by exceeding its customers' expectations every day; demonstrating high clinical standards and compassion in patient care; and being responsive and flexible.

Abbott Laboratories / Ross Products Division

Abbott Nutrition is a longtime leader in the U.S. nutritional marketplace, and strives "to be the worldwide leader in providing superior nutritional products that advance the quality of life for people of all ages." Abbott Nutrition manufactures and distributes medical nutritional products such as: PediaSure® Enteral Formulas, designed to provide a source of Complete, Balanced Nutrition® for children ages 1-13; Vital jr®., a semi-elemental formula for the nutritional needs of children ages 1-13 years; Jevity® 1.2 Cal, an isotonic, fiber-fortified tube-feeding product with the prebiotic NutraFlora® scFOS®, and the Embrace® ambulatory feeding pump.

Critical Care Systems

Critical Care Systems is a leading national specialty infusion company that provides comprehensive clinical services to pediatric and adult populations through a national footprint of Joint Commission accredited community-based branches. The company's Specialty Nutrition Support Program is supported by a team of dietitians, nurses, pharmacists, and reimbursement specialists who excel in parenteral nutrition, clinical support, and customer service. Whether their customers require short- or long-term therapy, Critical Care Systems provides flexible, individualized care adapted to the consumer's lifestyle.

It is the company's belief that customized nutrition support, state-of-the-art standards of practice, and a team of TPN experts leads to optimal clinical outcomes. The company's 96 percent satisfaction rate demonstrates their mission that "Patients are the center of all we do." Critical Care Systems is proud to support the Oley Foundation.

EMD Serono, Inc.

EMD Serono, Inc., with headquarters in Rockland, Massachusetts, is an affiliate of Merck, KGaA, in Darmstadt, Germany. EMD Serono is a leader in the U.S. biotechnology arena, integrating cutting-edge science with unparalleled patient support systems to improve people's lives. EMD Serono is committed to discovering and developing innovative products that address unmet medical needs in specialized therapeutic areas, including reproductive health, metabolic endocrinology and neurology, and new therapeutic areas, including oncology and autoimmune diseases.

EMD Serono has seven recombinant products in the United States across three therapeutic areas, including one product for patients with short bowel syndrome. EMD Serono is committed to improving the patient experience, with unique delivery systems for many of its products as well as comprehensive patient educational resources across all of its therapeutic areas, including SeroCareSM. Package inserts for EMD Serono's U.S. marketed products are available at www.emdserono.com or by calling (888) 275-7376. The Oley Foundation thanks EMD Serono for its contribution at the Bronze Level this year.

Speed It Up with E-mail!

Send us your e-mail address, and we can send you news updates, the latest conference information, and the *LifelineLetter* long before it would hit your mailbox. Our e-mail list is private and will not be shared.

To switch over to an electronic subscription, contact Cathy Harrington at the Oley office at (800) 776-OLEY or harrinc@mail.amc.edu.

One Last Gift from an Oley Angel

We owe an enormous nod to the late Shirley Heller. We always recognized and admired Shirley's passion and enthusiasm for Oley efforts. She was a steadfast supporter, both financially and emotionally, and attended several conferences.

While still mourning her passing, we received word from the attorney handling Shirley's estate that she had bequeathed almost $18,000 to the Oley Foundation.

Nothing or no one can replace Shirley, her suggestions and her overall presence. She was one in a million. We sincerely hope that Shirley is resting in peace knowing that her final contribution will go a long way in helping to preserve the programs that she found so precious.

Oley Foundation Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
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Tom Diamantidis, PharmD
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Eleanor & Walter Wilson
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Patty & Darrell Woods
Rosaline Ann & William Wu

Oley Corporate Partners

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

PLATINUM LEVEL PARTNERS
($70,000+)
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS
($50,000-$69,999)
Coram, Inc.

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($30,000-$49,999)

BRONZE STAR PARTNERS ($20,000-$29,999)
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Kimberly-Clark
Nestlé Nutrition
Sherwood Clinical
Sigma International

CONTRIBUTORS ($1,000-$2,499)
Baxa Corporation
Zevex, Inc.

Toll-Free Schedule ☎

Toll-Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the United States 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 Oley's 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 at www.oley.org. Comments? Call (800) 776-OLEY.*

JULY '07	**Ann Debarbieri** Gansevoort, NY (888) 610-3008 EST	Ann is a retired attorney; she loves gardening and walking in the woods with her husband and dogs. Diagnosed with Gardner's syndrome, she has years of experience with TPN, tube feeding, traveling, and working, and is familiar with the disability approval process. Call Ann Tuesday to Thursday.
	Mariah Abercrombie Henderson, NV (888) 650-3290 PST	Mariah is a 25-year-old college student on TPN 22+ years due to pseudo-obstruction and SBS. She also has a G-tube and ileostomy. She enjoys swimming, Jet-Skiing, traveling, scrapbooking, shopping, reading, and cooking. Her mother Felice can talk to parents about raising a chronically ill child. They both have attended many Oley conferences and can discuss the benefits.
AUG. '07	**Angie Mitchell** Bryan, OH (888) 610-3008 EST	Angie was born with chronic intestinal pseudo obstruction in 1984. She was on J-tube feedings, then TPN for 18 years. She did well for most of that time. In 2005 she had a multivisceral transplant (stomach, liver, small bowel, and pancreas) in Pittsburgh. She is very knowledgeable about care of lines, tubes, and transplantation.
	Linda Stokes Dover, FL (888) 650-3290 EST	Linda has been on TPN since 1986. Surgery for Crohn's disease left her with short bowel syndrome and dependent on TPN. Linda uses a Hickman® catheter. She looks forward to connecting with other homePEN consumers and sharing their experiences.
SEP. '07	**Barbara Klingler** Valkaria, FL (888) 610-3008 EST	Barbara Klingler has been on TPN since 1986 due to SBS from an infarction. She enjoys traveling. While on TPN, she has been on a cruise, motor-homed Alaska and cross country. She has been scuba diving and enjoys dog agility with her labrador. She has overcome liver failure and kidney stones. She has a strong faith in God.
	Patty & Darrell Woods Hemet, CA (888) 650-3290 PST	Patty and Darrell have five children, one of whom (Colyn) has been TPN dependent since 1996 due to pseudo obstruction secondary to a mitochondrial disease. They are easy to talk to and enjoy swapping tales about managing TPN issues, keeping a positive perspective, and having a normal, active family life.

LifelineLetter
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