

**What's Inside:**

**Welcome:**

**Regional Coordinators**  
Page 3

**Equipment Exchange**  
Page 4

**Spotlight:**  
**June Bodden**  
Page 8

**Contributor News**  
Page 10 - 11

**Toll-free Networking**  
Page 12

# LifelineLetter

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

## Specialized Nutrition: The Patient Perspective

By Elizabeth V. Tucker and Darlene G. Kelly, M.D.

*Part I of this article addressed issues of transitioning from patient to consumer and adapting to using nutrition support therapy at home. Part II will focus on complications, the role of the Oley Foundation and psychosocial issues. Part III will appear in the next issue of the LifelineLetter and will discuss travel, children on HPEN, the long-term outlook and other issues such as ostomies, depression and the impact on families.*

### Complications

EVT: I was very fortunate to have only one complication in the first three and 1/2 years. Because of my Crohn's, I had become anemic. The doctor decided I should have an iron dextran infusion. The home care company sent out a bag and I was to infuse it using gravity. While it was running in I inadvertently fell asleep. When the telephone rang, I jumped out of bed to get it, forgetting that I was hooked up, and pulled the catheter out four or five inches. I called a friend who is a nurse, and she told me to get to an emergency room *immediately*. Once there I had a

chest x-ray and lay in a room waiting to see a doctor. Both he and the nurse touched the catheter and the skin around it without putting on sterile gloves or scrubbing their hands thoroughly. I hadn't learned yet that I had to speak up and not let them do it. The catheter hadn't pulled out of the major vein so they sent me home. Over several hours it actually contracted back into my chest. The miracle was that I didn't get an infection. The lesson I learned was that all medical personnel were not familiar with catheters and I needed to take charge in situation like that one.

My first catheter infection evolved very slowly. I felt a little out of sorts, had a cough, and was running a fever. I actually didn't think much about it until my fever was 102 (my normal is 95). I was having chills and sweats consistently, and I could hardly move out of bed.

I have had sepsis several times, tract infections, and even a mechanical malfunction that Dr. Kelly

Nutrition, Con't. Page 2

## Trends in Ambulatory Infusion Pumps

By Jack Saladow

*Reprinted with permission of the National Home Infusion Association (www.nhianet.org). This article originally appeared in the July/Aug 2004 issue of Infusion (vol.10 No.4).*

In the 1980s, as the home infusion therapy market grew exponentially, manufacturers of ambulatory infusion devices introduced a variety of pumps capable of delivering complex therapies outside of the acute care setting to ambulatory patients. Their response to the evolving needs of a fledgling provider community resulted in product improvements, specialization, and introduction of innovative advances in technology.

By the 1990s, as payers began ratcheting down reimbursement, providers faced considerable pressure to remain profitable and the market underwent a significant consolidation. These financial challenges dissuaded providers from

investing in new device technology, and as a result, sales of pumps—and thus the creation of newer models by the manufacturing industry—flattened.

Today, home infusion providers are faced with a variety of challenges—growing patient populations, ongoing reimbursement issues, and national nurse and pharmacist shortages to name a few. However, in the near future they may be more likely to adopt—and invest in—new delivery device technology for a number of reasons.

### The Fittest Survived and are Looking Up

First and foremost the providers who survived the fiscal and regulatory challenges of the recent past have a significantly better understanding of their companies than ever before—these are the

Trends, Con't. Page 6

☛ **Nutrition, Con't. from Page 1**  
wrote up for JPEN. 4 While reading about complications is helpful, experience seems to be my best teacher. I become dehydrated very easily and have had to add extra hydration as part of my daily routine on numerous occasions.

**DGK:** It is essential that time be spent teaching the new HPN consumer about

complications at the beginning. Not only does the individual need to know what they are and the possible consequences, but also the steps to be taken to intervene are a critical part of the initial education.

We also find that trying to readmit patients on TPN to a specific area of the hospital allows us to train the nursing staff in the exact techniques that our consumers have been taught. This avoids inevitable conflicts between patients and their caregivers. I certainly agree with Liz's comments about learning to advocate for herself. Frequently an impressed nurse tells me that a consumer has been very vocal about his or her catheter care. Often the nurse is made aware that this catheter is not just another IV line, but the consumer's lifeline!

**What the Oley Foundation can do for the consumer**

**EVT:** I was introduced to the Oley Foundation in 1989 by several corporate members of the home care company that took care of me. I had started a business helping people cope with chronic illness and providing stress management in the workplace. They felt I would learn a great deal from Oley and that I had talents Oley could benefit from as well. I flew to Albany, NY and then drove to Saratoga Springs for the meeting. I was so impressed with the information I got from the speakers and the connections I made with other HPN and enteral consumers. I met another HPN consumer from my area, which meant we could support each other. I was hooked!

The executive director and other members of the office maintain a web site, listen and try to direct callers with problems to a solution, work with medical professionals to provide information, and in their extra time, try to solicit funds to keep this unique organization going. With this very small but dedicated staff, Oley provides a yearly conference for consumers, their families, and medical professionals. It is held in a different part of the country every year so more people have access to it without having to travel far. There is a bi-

monthly newsletter, the *LifelineLetter*, which has wonderful articles and provides a list of three consumers with explanations of their expertise (parent of a child on HPN, consumer on enteral, HPNer with experience in insurance, etc.) These people can be reached using a toll-free number (800) 776-OLEY (6539) so there is no expense to the caller. The Oley Foundation has a web site (<http://www.oley.org>) with extensive information, including past *LifelineLetters*.

Every region of the country has a group of regional coordinators – consumers or parents of consumers – to set up small area meetings, to help those with questions, or to just be a sympathetic listener.

**DGK:** The Oley Foundation is an organization started in 1985 to support consumers and their families, to provide information on home parenteral and enteral nutrition, to analyze data regarding outcomes of these therapies, and to encourage networking among consumers and clinicians. In my opinion, every consumer of either home TPN or tube feeds is expected to require these therapies for more than a few months should be made aware of the Oley Foundation. Those who are able to attend the annual consumers' and clinicians' conference almost universally come away with new friendships (someone who understands their therapy and its challenges and is a willing listener), new information based on current scientific data that apply to their situation, and often reassurance that they are not alone. For those who cannot attend the Oley conference, the organization maintains a video library of many of the presentations from the meeting.

A recent publication (5) studied outcomes of HPNers who were members of the Oley Foundation compared to others who were not. This actually identified a lower incidence of infections and of depression among those who were active in the Oley Foundation.

**Nutrition, Con't. Page 5** ☛

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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.

## Welcome Regional Coordinator Volunteers

Spring is blooming, and so is our Regional Coordinator program! We are very pleased to welcome three volunteers to our network ranks, and we will introduce them here. We intend to profile all of our volunteers, a few at a time, in an effort to help you connect locally, and also to offer insight into the different people who make up our network. Maybe they have a similar history to you or someone you know, and maybe you will find you would like to volunteer as well! Please contact Ellie Wilson at the Oley Foundation if you would like to learn more. Welcome, to Sheila DeKold, Rick Davis and Sue Koprucki!

**Sheila DeKold** of Floyds Knobs, Indiana raised her hand and volunteered last year. She is Mom to son David and daughter Olivia, who has pseudo-obstruction and uses both tpn and enteral therapy. Sheila wanted to be available to others in her community and state, and hopes to offer an understanding ear to those in similar situations. She also believes there is strength in numbers, and welcomes the chance to connect to other families and individuals. She can be reached at 812-941-8145, email SheDeKold@aol.com.

**Rick Davis** of Salt Lake City, Utah is reaching out in many ways. Rick uses enteral nutrition exclusively after a bulls-eye stroke destroyed his ability to swallow anything. He struggled for

some time, and then was connected to the Oley Foundation, where he found a wealth of information and folks willing to share their experiences with him. He used that information to effect an excellent recovery. Rick now travels, skis, and hikes, and reaches out to stroke victims and Oley members in an effort to give back some of the assistance and inspiration he found. He can be reached at 801-232-8787, email rickdavis320@comcast.net.

**Sue Koprucki** lives in East Amherst, NY, a suburb of Buffalo, and describes a very frightening, isolating and frustrating time when her daughter Emily was diagnosed with short bowel and pseudo-obstruction and started on nutrition support. She feels it was the families she finally connected with who were in similar situations that helped her find the things she needed to make life work for her whole family, including her sense of humor!

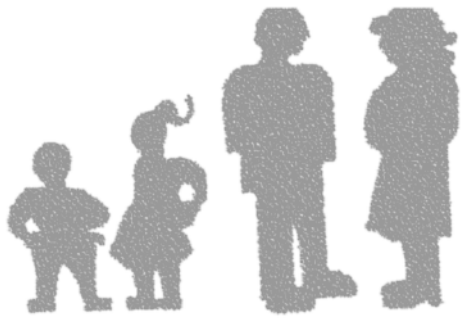
She hopes to make her presence known to regional medical personnel working with PEN, and help bring practical support and connection to people in northwestern New York State. Sue can be reached at 716-308-9517, email ma2mje@yahoo.com.

Again, we welcome you all, and thank you for your willingness to reach out to others! ❤️

### Keeping It Simple

We've implemented a policy to include a donor envelope in each issue of the LifelineLetter... simply to make it easy for you to consider supporting Oley Programs.

Thank you so much!



## Is Your Child Being Fed By Tube?

Would you be interested in participating in a study to help better understand what it is like to care for a child who is fed enterally?

I am conducting interviews with mothers of children who are currently being tube fed to see what kinds of stress and coping resources are involved with the day-to-day care of a child who is fed by tube.

Do you have an extra 2 hours that you could spare to help increase the understanding of what it is like to care for your child?

Contact: Deb Steward, RN, PhD, Principal Investigator  
Cathryn Baack, RN, PhDc, Co-Investigator  
The Ohio State University  
College of Nursing  
614-688-3645

## Equipment Exchange

The following supplies are offered free of charge to readers:

### Enteral Formula

- 3.5 cases Promote w/fiber – vanilla, exp. 8/05
- 4 cases Nutren 1.0 w/fiber – vanilla, exp. 3/06
- 8 cases Promote w/fiber , exp. 11/05
- 4 cases Ultracal 1.0 w/fiber, exp. 1/06
- 6 – 1 liter bottles of Choice DM, exp. 1/06
- 1 liter bags of Probalance 1.2 cal w/fiber, exp. 2/06
- 2 cans 9.7 oz. Promod powder
- 16 cases Ultracal HN plus, 7 exp. 9/05, 1 exp. 6/05, 5 exp. 10/05, 3 exp. 8/05
- 9 cases Comply, 6 exp. 6/06, 3 exp. 5/05
- 6 cases Vivonex 10, exp. 10/05
- 6 cases Isosource, exp. 5/06
- 2 cases Fibersource HN, exp. 2/06
- 16 cans Neocate, exp. 8/05
- 9 cases Ultracal w/fiber, exp. 1/06
- 3.5 cases Probalance, exp. 9/05
- 9.5 cases Neutren unfavored 1.0, exp. 1/06
- 11 cases Jevity 1 cal, exp 8/05
- 15 bottles Boost
- 66 cans Osmolite
- 3.5 cases Jevity 1 cal
- 9 cases Jevity 1.2 cal, exp. 7/05
- 1/2 case Boost pudding – vanilla
- 1 case Ultracal, exp. 1/06
- 6 cases Glytrol, exp. 1/06
- 4+ cases Fibersource HN, exp. 9/05
- 1.5 cases Osmolite 1.2 cal
- 9 cases Glucerna, exp. 12/05
- 4 cases TwoCal HN, exp. 1/06
- 3cases Probalance, exp. 1/06
- 4 cases IsoSource 1.5, exp. 10/05
- 4 cases Subdue, exp. 10/05
- 6 cases Neutren 1.5, exp. 2/06
- 4 cans Perative
- 4 cases IsoSource 1.5, exp. 0/05
- 5.5 cases Glucerna, exp. 2/06
- 7 – 1 lb. Cans Portagen, exp. 9/06 and 11/06
- 8 cases Jevity, exp. 11/06
- 2 cases plus 22 cans Isocal, exp. 10/05
- 4 cases Subdue formula, exp. 10/05
- 4 boxes Neocate formula (4 cans to a box), exp. 8/05
- 4 cases Neutren 1.0 w/fiber – vanilla, exp. 12/05
- 6 cans Nestle Good Start/ powder
- 27 cases Resource Diabetic Enteral Formula – French Vanilla, exp. 12/05
- 13 cans Enfamil Lactose Free, exp. 8/05
- 7 cases Suplena, exp. 2/06
- 1 case Isocal, exp. 11/05
- 1 case Isocal, exp. 9/05
- 7 cases Two Cal HN, exp. 3/06

### Miscellaneous:

- 1 Medikmark dressing change tray, exp. 6/07, DC1595
- 1 Centurion dressing change tray, exp. 6/06, DT8560
- 38 BD 20 gauge, 1” precision glide needle, 305175
- 18 pins Braun micropin, 415019
- 5 pins Lifeshield convertible adapter pin, 3 in., 11075
- 4 sterile water for irrigation, 1000 ml

- Many multi-dose vial access spike, CS-50
- 6 – 2oz. syringes Monojet
- 25 BD 60ml syringes w/surelock tip
- 10 dressing change trays with chloridine, exp. 8/06, 5070STKC
- Many Universal vial access spikes w/needleless connector, KS300
- 19 BD 60ml syringes w/catheter lock tip
- 2 Prep tray Chloraprep, exp. 8/05, 8180-3CP
- 6 Infant size breathing treatment nasal cannula, RED1601
- 1 Flexiflo Y-port connector, 836
- 1 box gloves
- Many Universal vial access spikes w/needleless connector, KS300
- 2 Prep tray with Chloraprep, exp. 8/07,ANS81803CP
- 10 Dressing change trays w/Chlorhexidine, exp. 8/06, DC507OSDKC
- Many multi-dose vial access spikes CS-50
- 8 kits Kendal suction kit, 36010

### Tubes/Bags

- 12 Ross Companion 1000ml
- 4 boxes Protol Bagez feed 1000ml
- 15 Compat Enteral 1000ml
- 4 – 36” NG tubes
- 40 Kangaroo 1000ml bags
- 60 Ross Embrace 500ml bags
- 15 Cadd Prizm high vol, admin. sets, 21-7057
- 27 Y extension sets, ETO8YL, 471980
- 4 sets small bore Y extension sets – Braun, ET-103
- 2 Baxter extension sets w/ control a flo regulator,2C7591
- 6 CADD admin. sets, Deltec
- 7 sets Iflow Medi-sis 60ml/60 min. adm. Sets, M600600
- 3 boxes Bard infant feeding tubes 8 Fr 3/32 (2.7mm) 15 in., 0036410
- 3 Bard premature infant feeding tubes, 5 feet, 0036430
- 1 box (10) Corflo w/Hralite HG tubes 8 Fr.
- 1 Kendall feeding tube 8 Fr., 42 in., 155721
- 5 Kendal feeding tubes 5 Fr., 35 in., 155721
- ? Feeding bags
- 20 Kangaroo 1000ml feeding bags
- 30 Ross EZ fill bags 1000ml
- 30+ Kangaroo bags 1000ml
- 9 Kangaroo bags 1000ml
- 5 Kangaroo extension sets, 4 ft., 700207
- 3 sets oxygen supply tubing 7’, 1115
- 1 Argyle feeding tube 8 Fr.,8888-260406
- 33 Flexiflo feeding bags 800ml
- 30 Kangaroo bags 1000ml
- 1 doz. Ross Patrol 1000ml bags
- 15 Ross Patrol 1200ml bags
- 3 Bard premature feeding tubes 5 Fr., 0036430
- 1 Kendall feeding tube 8 Fr 42 in.
- 5 Kendal feeding tubes 5 Fr 36in., 155721
- 1 box Corflo Hralite NG tubes 8 Fr (10 per box)
- 50+ bags Ross Clearstar 500ml feeding bags, 507
- 27 bags Welcon 1000cc ultraflow bags



## ☛ Nutrition, Con't. from Page 2 Psychosocial Issues

EVT: From my perspective, while the physical aspects of taking care of a catheter or J-tube, etc. and being on HPEN are obviously very important, the psychosocial issues and how they are handled are equally important.

Grief and grieving, while a normal part of life, can be a challenge for a person on HPEN. Why? Because while everyone experiences losses in their life and deals with grief, those of us dealing with a chronic illness and complicated medical therapy can experience many more losses which still must be dealt with. Failure to get my Crohn's under control can mean pain, physical challenges, and the side effects of medications. Surgery can mean the additional loss of physical parts of me. Being on HPN means adjustments to my lifestyle. All of these things can have an impact on my ability to work.

Dealing effectively with the grieving process that occurs with these ongoing losses can have a tremendous impact on my quality of life. While we tend to think of grieving as a linear process – denial, anger, sadness, then acceptance – my own experience has shown me that it is really a spiral. In that spiral you can go through any of the emotions once, twice or even more times. Hopefully, they become less intense as I deal with them. What I don't want to do is get stuck in the denial, anger, or sadness and not move on. I have met and known any number of parents who seem to be stuck in the anger stage because this very unfair thing has happened to their child and

changed their life as well. For several HPENers I know it is either the anger or sadness stages that they can't seem to get through – why me, my life will never be “normal,” resentment of those not on the therapy. Not dealing effectively can lead to my next point, isolation versus interaction.

I am, fortunately, a very social person but there have still been any number of opportunities for me to pull into myself and lessen or stop my interactions with others. Keeping myself engaged in the world, particularly by doing volunteer work and helping others, is very important to me. Because I have a chronic illness and am on HPN, the opportunity to focus too much on *me* is always an option. Interaction with others by doing volunteer work allows me to see that there are many people in the world with problems and to feel good about helping someone else. I highly recommend it.

My last thought in this area has to do with the positives and negatives of having a pet. Actually, I have three – a cocker spaniel and two rescued cats. The positives are many. They give me tons of unconditional love. They are totally accepting of me just as I am – HPN and all. They give me a reason to get up in the morning and to interact with the world – I have to feed them and take the dog for walks, which also gets me moving. Those are just a few of the reasons I feel my pets are so beneficial for me. The only negative I can think of is that I must be that much more careful about sterility when I am changing my dressing, getting my PN ready, or storing my supplies. This is a small price to pay for the positives. 🐾

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**☛ Trends, Con't. from Page 1**

successful providers operating healthy businesses. Collectively, providers have scored some major victories that should allow them to remain a profitable sector of the health care industry, such as the successful adoption of electronic claiming and specialized coding and the creation of a standardized definition of per diem for use in contracting and billing.

Another potentially promising development is the creation of a Medicare prescription drug benefit under the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (MMA). Along with coverage for traditional retail medications, the Part D provisions of the MMA also broaden coverage for home infusion drugs effective January 2006. This could lead to a significant expansion in the patient population for cost-effective home and alternate site infusion therapies. Because this new coverage is not linked to the usage of specific types of durable medical equipment (as it is now under Medicare Part B for the few infusion drugs currently covered in the home) providers may have more freedom to make use of higher-tech delivery devices when indicated, based on the clinical needs of patients as well as cost-effectiveness.

As written, however, the legislation does not specifically discuss the coverage of the professional services, supplies, and equipment needed to make this new infusion drug coverage safe, meaningful, and consistent with professional standards of practice. The per diem reimbursement model used by cost-sensitive managed care plans addresses these issues and provides an ideal model for Medicare coverage that would also help the industry make further strides in streamlining operations. The National Home Infusion Association is actively working with the Centers for Medicare and Medicaid Services to shape this important new benefit in this way.

**Focus on Patient Safety**

The health care industry's ongoing focus on patient safety and reducing medication errors is also contributing to a renewed interest in high-tech delivery devices. While the research and development activities of pump manufacturers has always focused on reducing the cost of care and improving patient outcomes, they are now focusing on the development of new features that anticipate patient safety regulations set forth by the U.S. Food and Drug Administration (FDA), accrediting bodies, and the like. As is typical, such changes are appearing in the acute care sector now but will soon begin trickling into the alternate care settings.

As part of its ongoing efforts to encourage health care providers to use information technology to promote higher quality of care, in February 2004, the FDA issued a final rule requiring bar codes on the labels of thousands of human drugs and biological products. The agency estimates that the use of such technology in hospitals can reduce medication error rates by as much as 85 percent.

Pump manufacturers are already selling "smart" devices to hospitals. These pumps incorporate new enhanced medication delivery safety software that includes drug libraries, pre-programmable dosage levels, drug and concentration selections, bar code scanners, new reporting capabilities, and interfaces with the

hospital's pharmacy software system that support error-avoidance and process improvement.

One such example is the Medley™ Medication Safety System by Alaris® Medical Systems. The Medley is a modular point-of-care computer that integrates infusion, patient monitoring, and clinical best practice guidelines in one platform. Currently, a pump module, a syringe module, and two pulse oximetry modules are available. In addition, the pump uses Guardrails® Safety Software to protect against medication errors. In another example, the Colleague® series of pumps, manufactured by Baxter Healthcare Corporation, offer basic programming as well as dose calculation modes, label library, and programmable personalities, which allow for storage of up to eight user-defined parameters.

B.Braun Medical, Inc. also offers a "smart" pump called the Outlook™ Safety Infusion System. Outlook™ is equipped with DoseScan™ and DoseGuard™ technologies, which allow a qualified clinician to automate the programming of the device and notify the clinician when institution-defined dose limits are exceeded. And, Hospira (a spin-off division of Abbott Laboratories) offers the OmniFlow 4000® Plus Medication Management System™, which features dose calculator, programming up to 24 hours in advance, clinician call-back, and history reports.

On the ambulatory side CME, an Israeali-based company, has recently introduced the Body Guard 323 ambulatory multiple therapy infusion pump. Small and portable, weighing just over 11 ounces without the battery charger, this pump is the first ambulatory device in the U.S. to have the capability to connect to a hand held computer that contains a customizable drug library and allows for a specific a patient identification code that must match in order for the pump to run. The Body Guard 323 also has a bar code reader accessory and a pulse oximeter attachment that can monitor a patient's temperature and heart rate while infusing.

Other manufacturers indicate that the next generation of ambulatory infusion pumps will incorporate similar bar coding software and drug library software, similar to those found in hospital based equipment, to assist in the safer delivery of medications to patients outside the hospital. Several ambulatory pumps on the market today, such as the 4000CMS™ from Curlin Medical, LLC and the CADD® Prism series from Deltec, Inc. (part of the Smiths Medical family of companies), incorporate computerized telecommunications capabilities allowing them to be programmed remotely either over the phone, from an authorized computer, or personal data assistant (PDA). In addition, the Deltec CADD-Sentry™ Medication Delivery Manager allows for the entry of standardized protocols, on a PC, with pump settings and programming limits. The protocols are stored and indexed by patient type, care area, and/or drug for easy reference and selection. Others, such as the GemStar® Infusion System from Hospria, allow for remote data collection via downloadable pump history; the Baxter 6060 downloads history along with a , allow for remote data collection and monitoring function. While these capabilities do not specifically address medication errors, they provide the technological groundwork for such features.

Such developments will be timely considering that the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) may require home care providers to develop a plan for implementing bar code technology for patient identification and for matching patients to their medications or other treatments. The requirement is currently being considered as part of JCAHO's 2005 National Patient Safety Goals; if adopted, providers would need to be compliant by January 1, 2007 as part of their JCAHO accreditation.

**Wider Use of Telecommunications**

Having a computerized ambulatory pump in a patient's home offers several advantages beyond the assurance of safe medication delivery. Providers can benefit from receiving electronic reports from pump data on the administration of therapies or from data, such as height, weight, and blood pressure, entered by the patient or caregiver. This allows clinicians to check compliance and infusion profiles from a distance. The extensive history of events can be used for troubleshooting, electronically sharing with other health care providers, and as part of the documented patient record.

Pumps can be programmed remotely and even make use of digital imaging and messaging technologies for patient training or communication with health care professionals, greatly reducing "windshield time"—an added benefit in light of the current nurse and pharmacist shortage.

Ambulatory infusion pump manufacturers have been incorporating telecommunications capabilities into their devices since the early 1990s, however early technology was not reliable, existed in numerous platforms, and was difficult and expensive to implement. Now many of those hurdles are gone and health care providers use similar technology to a wide extent in their day-to-day business activities.

**Conclusion**

To date, the adoption of new ambulatory electronic infusion technology has been very slow. However, there are clear indications that authorities in the regulatory and accreditation arenas are looking toward computer and telecommunication technology to aid in the significant reduction of medication errors to patients in all health care environments.

For home infusion, widespread adoption of these devices seems inevitable. Yes, initially they may be more cost-intensive and there may not be immediate reimbursement available, but there is no doubt that if regulations are implemented and the technology is available health care providers will respond. One just has to look at the conversion to needleless technology following state and federal mandates to prevent needle stick injuries to see the effect that regulatory authorities have in driving the market and opening the door for the introduction of innovative and new technologies.

*Jack Saladow has more than 30 years of experience in health care sales, marketing, and strategic planning with a specialty in drug delivery systems. As president of Laguna Niguel, California-based, Jack Saladow & Associates (949-495-7097), he provides sales, marketing, strategic planning, and technology assessment consulting services to a wide variety of health care companies throughout the United States, Canada, and Europe.*

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## Spotlight: June Bodden



Although June Bodden originates from Pennsylvania, her father was a salesman so her family moved around a lot when she was growing up. In 1971, she moved to Clearwater, Florida, where she's been ever since. She says the warm sunshine affects her attitude and lifts her spirits.

In the late '50s, June was diagnosed with ulcerative colitis. Later, they called her ailment regional enteritis and she endured several surgeries to remove parts of her intestine. Then, in 1966 she underwent an ileostomy and when she got out of the hospital, she weighed 76 pounds. A long period of uncertainty followed and then she was diagnosed with Crohn's disease in 1972. Her first experience with TPN was not a good one. A doctor had used a subclavian "stick" instead of a catheter and inadvertently filled her lungs with solution instead of her veins. Understandably, when the issue of TPN came up again, June was a bit apprehensive but was placed on TPN in '82 and '83 but only for a few weeks. However, in 1984 she developed gangrene due to adhesions and once again was placed on TPN. Doctors also tried a feeding tube for a while but by the end of '84, they placed her on TPN with the goal of having her reach 100 pounds. When this was accomplished, it seemed TPN was the solution. It's continued to be June's solution for just over 20 years now.

June's doctor explained that the home health care company would deliver her supplies and train her. Nobody knew if June would be able to eat. "At first, I didn't know what I was going to do," she said. June is an accomplished cook and prefers to read a good cookbook over a novel any day. She had serious concerns about the social issues surrounding eating but her fears were alleviated when she discovered that she could eat moderate amounts of food. She was pleased to have a large group of supportive friends, family and co-workers and managed to continue working. However, because June was an income tax preparer, she experienced high stress levels at her job,

which caused stomach ulcers, so her doctor recommended that she quit. When she worked, she needed to infuse for 22 hours a day to ensure that she got enough nutrients. However when she stopped working, she only needed to hook up for 14 hours a day. She attributes this change to the lack of pressure in her life. Now June enjoys the hobby of stamping and she delivers Meals on Wheels. Her mother lives nearby (and accompanies June to Oley Conferences) and she has a sister and a brother that she visits as well. She's got a very strong faith and is active in her church, attending and conducting Bible studies and on-line prayer requests as well as having served as treasurer.

In 1986, June received a note in her supply delivery from another TPN user named Madelyn Goldfarb who was looking to meet others in her position. They made contact and Madelyn told June about the Oley Foundation. "Just knowing one other person in the world is going through the same thing is wonderful," says June. In 1988, they started a local support group. Since then, she's gotten a wealth of information from Oley about organization and technological advancements, not to mention gaining a few close friends.

June thinks the key lies in knowing one's limits. At first, she took things slow so she could learn what she was capable of doing. She also admits she's fussy about her line care and hygiene. As a result, she's only had three catheters and three infections. June passes on some valuable information she got years ago from other TPN users, "Don't let it overwhelm you. Focus on what you can do and not on what you can't." 🍀

### On-line Shopping?

Don't forget [www.igive.com](http://www.igive.com) will donate a portion of your spending to Oley at no charge to you, and there are hundreds of great stores to choose from!

Call (800) 776-OLEY for details

*Nutrishare's one-on-one personal contact gives me a sense of comfort in knowing that they are doing everything possible for my care.'*

**Allison Hillen**  
Nutrishare Consumer

**Nutrishare**, Inc.  
1-800-Home TPN

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

## Kid Connections

Sarah Vasilakos is a 13 year-old TPN consumer from Annandale, Virginia. Sarah wants to correspond with other TPN users around her age so they can share information and tips and just be friends that have something in common.

If you want to drop Sarah a note, send an e-mail or give her a call, she can be reached at:

3705 Forest Grove Dr.  
Annandale, VA 22003

[djvasil@aol.com](mailto:djvasil@aol.com)

(703) 642-5291

## Build a Bridge!

Trying to keep family and friends up to date about you or your family member's condition can be exhausting. A simple way for everyone involved is through a free service offered through Caringbridge. Caringbridge offers a place to journal latest updates, post pictures and share your favorite websites.

Enjoy a visit to [www.caringbridge.org](http://www.caringbridge.org) and explore the concept of creating a page. 🍷

## Announcement

AGMD Digestive Motility Symposium July 29-31, 2005 at the Renaissance Bedford Hotel in Bedford, Massachusetts.

Sponsored by the Association of Gastrointestinal Motility Disorders, Inc. (AGMD) and The University of Kansas Medical Center Office of Continuing Medical Education.

This symposium will be beneficial to physicians (especially gastroenterologists, endocrinologists, pediatricians, and surgeons), nurses, basic science and clinical researchers, pharmaceutical representatives, home healthcare professionals, nutritionists, patients, and those in the community interested in digestive motility diseases and disorders.


For further information and to register, contact Mary-Angela DeGrazia-DiTucci:


Tel: 781-861-3874


E-mail: [gimotility@msn.com](mailto:gimotility@msn.com)

Web address: [www.agmd-gimotility.org](http://www.agmd-gimotility.org)










## Carrying a torch for more than the Olympics.

Kenneth Lighthall has used his illness and subsequent Home TPN as a springboard to a different life. Spiritually as well as in his relationships. His kids think he has actually improved. He volunteers all the time and has become very unselfish and giving. He was honored to be able to carry the Olympic torch in 2002. He doesn't stay put. He's fishing on the canal or traveling to see his grandkids from Michigan to Florida. Kenneth is just one of the consumers that Coram is helping get on with life. We got him started. And we'll be there for the long run.

Contact us toll-free:  
1-866-4-HomePEN (1-866-446-6373) and visit us on the Web at [www.coramhc.com](http://www.coramhc.com).



**Coram consumers. Going places. Doing things. Living life.**

# Thank You! Thank You!!

The following list represents everyone who generously contributed towards Oley efforts between February 1 and April 27, 2005. We also want to thank all 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.

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Betty & Morris Tobin  
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Frances Walther  
Ryan & Sheila Ziems



## The Oley Foundation Salutes *Allan and Cheryl Yelner*

For their continued support via payroll deduction and a Corporate Matching Gift!

Allan and Cheryl describe their motivation: *‘Allan’s employer, Merck, has a matching program so whatever we donate through the United Way, they will match. Michael is only 10 years old and has been on TPN for almost 6 years. With only about one inch of small intestines remaining, we know that he will be on therapy for life or a future transplant candidate. We are grateful to have Oley as a source of support and information for our family. I have met a lot of great people like Rose Hoelle, Malisa Matheny, Patty Woods to name a few. They have helped us get adjusted to Michael’s life on TPN. We were so lost and scared in the beginning. It is nice to know that there are others out there who “get it!”* 🐾

## Just So You Know...

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

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

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

If you have any questions, concerns or would like to discuss this policy further, please contact Joan Bishop by phone (800) 776-6539/(518) 262-5079 or e-mail [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu). 🐾

## We Really Want to Hear From You!

Did you read about something in the *LifelineLetter* and want to get more information? Do you have important information about a previously printed topic that you want to share?

Even if you just want to share your opinion on an article or some other content of our newsletter, we want to hear from you. We value your opinions and views because without you, there would be no us. Please share your thoughts with us by contacting the *LifelineLetter* Interim Editor, Elizabeth Tucker.

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## Give Oley a Sound Future

Help provide a secure financial future for Oley by joining the Foundation's Horizon Society. It's as simple as including a gift to the Foundation — large or small — in your will, and can have tax benefits! For more information on ways you can give, contact Oley's Executive Director, Joan Bishop at (800) 776-OLEY or [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu). 🐾



## Toll-Free Numbers Available to U.S. and Canadian Consumers!

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

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

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

*The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter and posted on our web page, [www.oley.org](http://www.oley.org). Comments? Call (800) 776-6539.*

<b>JULY '05</b>	<p><b>Elizabeth Tucker</b> Bloomington, MN (888) 610-3008</p>	<p>Diagnosed with Crohn's disease, Liz has been on TPN for 19 years. She is an experience traveler, loads of fun and well-versed in stress management techniques. She is also very knowledgeable about insurance issues and the various treatments for Crohn's, including the latest developments.</p>
	<p><b>Carol Pelissier</b> Manchester, NH (888) 650-3290</p>	<p>Carol has been on and off TPN for the past 10 years and now has a G-J tube. Carol has undergone 43 operations over the past 23 years. She has had an ileostomy for the past 5 years. She has experience with insurance issues and looks forward to hearing from you.</p>
<b>AUGUST '05</b>	<p><b>Barb Klingler</b> Malabar, FL (888) 610-3008 EST</p>	<p>Barbara Klingler has been on TPN since 1986 due to short bowel syndrome from an infarction. She enjoys traveling. While on TPN, she has been on a cruise, visited many of the Caribbean Islands, motorhomed to Alaska twice, and also traveled cross country via motorhome for 9 weeks. She has been scuba diving and enjoys dog agility with her labrador. She has overcome liver failure and kidney stones through prayer and her faith in God. "TPN has become a part of my life. I don't allow it to change what I want to accomplish."</p>
	<p><b>Marie Hartwick</b> Little Rock, AR (888) 650-3290</p>	<p>Marie began TPN in 1982 due to SBS secondary to Crohn's Disease. After 12 years she ran out of access and transitioned to HEN. She has a g-tube and receives Vivonex via a Patrol pump. She's had an ostomy twice and over 50 surgeries. She is 57 y.o., a single mother and ran a media campaign to get coverage for her HPN.</p>

### LifelineLetter

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