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Lifeliner

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

Tips for Traveling with HomePEN

A little preparation can go a long way when you're traveling far from home with HomePEN. Keeping this in mind, we've compiled some tips from previous articles, conference sessions, conversation and correspondence, to make your next trip safer and more enjoyable. Thank you to everyone who has contributed to these tips and to those who volunteer to share their traveling experience.

1. Consult Your Physician

Ask your physician whether travel is appropriate and what problems might be anticipated. Find out whether your doctor or an associate will be available by phone during your trip. (If possible get their pager number, since the emergency may happen after hours.) In the event of a problem, you and the attending staff at the unfamiliar hospital will want to be able to reach a doctor who is familiar with you and your medical history.

The physician's phone number, your medical history and other vital information should be filled in your "Travel/Hospitalization Packet" and carried with you. (A copy of the Travel/Hospitalization

Packet is available on Oley's website at <http://www.oley.org>. You can also email us at

DahlR@mail.amc.edu for an electronic copy of the packet that you can customize to fit your needs; or call us at 800-776-OLEY/518-262-5079 and we'll mail you a copy.)

Ask your physician to write a letter explaining your need for the 'supplies' you are bringing with you — especially if you are traveling out of the country and/or with pain medications. (Note: for the purpose of this article, 'supplies' refers to everything you need for HPEN, from tubing and syringes, to

Travel cont., pg. 2



"The Best Conference Ever"

The jury is in, and the vote is unanimous, the 16th Annual Oley Consumer/Clinician Conference was one of the best ever. Milwaukee and Chicago-area members gave generously of their time and talents, and it showed! Even the weather was accommodating, allowing us to enjoy a sunny picnic on the shores of Lake Michigan.

In the coming issues we will be sharing the wisdom of plenary speakers, news about this year's award winners, and photos of people who participated. (A sneak preview is provided on page 7.)

Next year's conference will be held June 20 to 22, 2002, at the Radisson Resort Knott's Berry Farm in Buena Park, CA (near Anaheim/LA). Knott's Berry Farm is home to a multifaceted theme park and is a short shuttle from Disneyland — so save the dates and plan to bring the family along for a fun vacation.

In Memory of Woody Freese

Woodrow "Woody" Freese, a longtime Oley friend, Trustee and Regional Coordinator passed away on April 25, 2001. Woody battled Crohn's disease for more than 40 years and had been on TPN for 20 years and EN for three. Woody, his wife Jane and their daughter Lenora volunteered for Oley in many capacities and were visible characters at almost every Oley activity since the Foundation began in 1984. Their inexhaustible technique for gathering friends and acquaintances and sharing memorable times is unmatched.

Woody was a fighter and a firm believer in living life to its fullest. Nothing deterred him from taking on new challenges and helping others out. Laughing

Freese cont., pg. 7



Travel, from pg. 1

HPN solution/HEN formula, to medications and vitamins.) Pack a copy of the letter in each box of supplies, and carry one on your person to share with customs and other travel officials.

2. Prepare for Emergencies

Have a plan of action in case of an emergency. Locate the nearest medical center or community hospital in the area you are traveling to. Ask your physician if he or she knows a physician familiar with homePEN in the area you will be staying. (A second

resource for finding a clinician trained in nutrition support is the National Board of Nutrition Support Certification available at <http://www.nutritioncertify.org>, or call them through ASPEN at 800-727-4567 or 301-587-6315.) The phone number of a local pharmacy is also helpful to find out ahead of time, in case you need a prescription phoned in.

Discuss with your physician what steps to take should you become ill or experience a difficulties with your homePEN. For your convenience and peace of mind, Oley produces a complication chart for HEN and HPN consumers, that covers the symptoms and steps to take for common problems related to these therapies. It is a good tool to use when speaking with your physician prior to leaving, and to

pack with you for the trip. (Copies of the charts are available by calling the Foundation at 800-776-OLEY/518-262-5079.)

3. Research Your Supply Needs

Prepare a list of supplies well ahead of time. This will help you avoid overlooking any items. Pack a few extras in case of loss or damage. Talk to your physician/nurse and/or home care company about a back up plan (extra pump or battery, or how to gravity feed), in case you have trouble with your pump when you are on the road.

If you are traveling abroad, you will likely need to plan ahead how you will overcome the issue of running your pump on an electrical system that is different from your home country's. The simplest and most reliable option is to run your pump on regular 9V batteries, which many pumps allow, such as the Baxter/Sabratek 6060 and Provider One. Regular alkaline batteries typically last for two or three infusions, where lithium batteries may get you through five infusions. While you are still at home, run your infusion with 9V batteries for a few days to test how long they last for your pump, and pack accordingly. You can also buy 9V batter-

ies in most countries, though for the small amount of weight and space, you may as well bring them from home.

Another idea is to purchase an adapter made expressly for your pump/battery charger, if the company offers one for the country/region you are traveling to. For example, one consumer was able to purchase a 'European CADD adapter' for his CADD pump/battery recharger through his supplier which he was able to plug directly into different European outlets (without using a generic travel converter,

transformer or plug adapter). This same consumer cautions against using a generic travel adapter/converter/transformer (that you might use for a hairdryer) with your pump/battery charger, since he 'fried' his battery

charger when using one on a previous trip abroad.

A third option for getting around this issue, is to infuse by gravity which you would need to discuss with your physician before implementing.

4. Work with Your Home Care Company

Your home care company may have an office or affiliate in the area you are traveling to that can deliver solutions/formula, and possibly supplies, directly to you at your destination. Many consumers have taken advantage of this opportunity - even on trips to Europe. This avoids the fatigue of carrying the supplies yourself, and reduces the worry about shipping delays and the hassle of dealing with customs officials (when traveling abroad). Just in case of a delay, it is advisable to pack at least one night's worth of supplies with you.

A second option is to have your home care provider ship your supplies for you. If your supplies will be shipped to a hotel, you'll need to explain to a hotel representative (likely the manager of the receiving or security department,) how to handle the supplies properly, especially if any of it requires refrigeration. It is best to do this when you

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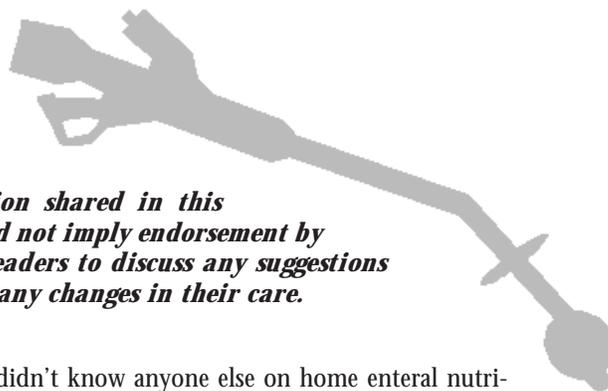
The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

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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.

Tube Talk

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



Insurance Legislation for Enteral Formula

As a 501(c)(3) non-profit organization, the Oley Foundation is strictly limited in the amount of resources we can devote to lobbying. We have not had the opportunity to review the legislation discussed in the article below, and cannot comment on it specifically, but we support the efforts of consumers and families like the Fazzaro's struggling to get fair coverage for homePEN therapy. If you are involved in any similar types of advocacy, or lobbying issues, please keep Oley informed. We will do our best to support your efforts. Readers may also be interested to know that a new bill that aims to ensure insurance coverage of EN formula was introduced in Ohio as well. To read the actual bill, go to <http://www.legislature.state.oh.us>, type in Bill #318, and click on "House." You can also email Sandy Bulcher at Dbulcher@aol.com for more information.

Our son Jon who was diagnosed with Crohn's disease at age 13 has been on Vivonex enteral feedings via a PEG since 1992. This has been a crucial element of his treatment which enabled him to achieve normal growth and development, and which still helps him maintain his active and productive life. Maintaining insurance coverage for this part of his therapy has been problematic for us, and we are concerned about his continued access to this aspect of his care as he transitions into independence.

When he was first started on NG feedings his primary insurance coverage was an HMO through his father's employment. According to every document we had ever received from this HMO, any and all care that any of us might require would be provided as long as we had complied with their rules for arranging care through the primary care physician, obtaining appropriate referrals, etc. So we were shocked when the HMO adamantly denied coverage for either the Vivonex formula or any of the supplies associated with its infusion, stating flatly that this was "not a covered service". Nowhere in their plan description had they hinted that *any* necessary services were simply "not covered".

Fortunately, I was also employed and Jon had secondary coverage through my employment at a hospital. One provision of this hospital's benefit contract was 80 percent reimbursement for employee purchases from the hospital's own pharmacy. So for a number of years I continued to order the Vivonex where I worked. However, the fact that our HMO could get away with flatly refusing to cover something so obviously medically necessary as Jon's enteral feedings continued to rankle. And, as it became increasingly obvious that Jon would continue to require these feedings indefinitely, we had to worry about what would happen when he was no longer eligible as my dependent for my employer's insurance with its own peculiar loophole.

I didn't know anyone else on home enteral nutrition. I put out a feeler through the Mutual Help Network column of the Crohn's & Colitis Foundation magazine. I received only a few scattered responses from other patients, but their insurance experiences, like ours had been pretty negative. I felt more and more strongly that if insurance companies were not willing to voluntarily cover enteral feedings, there must be regulation or legislation from the appropriate government entity to protect these patients from what amounted to blatantly discriminatory treatment of their particular medical need. But where to begin such a process seemed a very daunting task without more patients or families to join in the petition.

The process received a shove at the end of 2000 when my employer announced a new benefits program which would eliminate the provision under which Jon's Vivonex had been covered. This was a particularly inconvenient time for such an announcement as it coincided with Jon's reaching the age where he would have to transition into COBRA, adding the cost of his own insurance premiums to the usual expenses for a college student. With or without more support, it was apparently time to do something.

One of the parents who had answered my initial inquiry was able to connect me with one additional family in New Jersey. Together we wrote to our representatives in the New Jersey state assembly and senate, and to all of the members of the insurance and commerce committees. Though much of the response from these legislators was discouraging in tone, we have succeeded in having a bill (A-3317) introduced in the New Jersey State Assembly which would mandate insurance coverage for non-prescription enteral formulae. This bill has now gone to the Assembly Health Committee for consideration. How it fares in this committee, and whether it is ever enacted is likely to depend on whether or not we are now able to rally additional supporters to make it a visible issue.

I am so happy that I stumbled onto Oley Foundation on the internet. I hope that this is finally a place where I can connect with others who have similar issues. I would be very happy to hear from HEN consumers anywhere, but especially anybody in New Jersey who can help us support A-3317 and see that this bill is enacted into law.

— Elaine Fazzaro
27 Sycamore Ave.
Bridgewater, N.J. 08807
joyelaine@hotmail.com

Lifeline Mailbox

Nutrition Support Specialty Certification and Your Pharmacist

Dear Lifeline Readers,

An article in a recent *LifelineLetter* described a certification process for physicians, nurses, and dietitians. The process of specialty certification in Nutrition Support for pharmacists is administered through the Board of Pharmaceutical Specialties (BPS). More than 25 years ago, the American Pharmaceutical Association established BPS to provide the public and the pharmacy profession with an objective and independent process for board certification at the specialist level.

Today, BPS is the certifying organization for five internationally recognized specialties in pharmacy, including Nutrition Support. There are more than 3250 BPS-certified pharmacists worldwide. These individuals have met stringent eligibility requirements in terms of training and experience and passed a rigorous written examination. Board certified Nutrition Support pharmacists are required to complete specialized annual continuing education and must be recertified every seven years.

Many BPS-certified Nutrition Support specialists utilize their expertise on a daily basis to provide excellent clinical care to consumer members of the Oley Foundation. These pharmacists are an integral part of your health care team and work closely with you, your physician, and other health care professionals.

For additional information on the BPS specialty certification process for pharmacists, please visit their web site at www.bpsweb.org or call 202-429-7591.

— Reid Nishikawa, PharmD
Nutrishare, Inc.
Elk Grove, CA

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Update on Transplant Patient

Dear Lifeline Readers:

After reading an article in the *LifelineLetter* about intestinal transplantation, I wanted to share the story of my daughter who underwent a small bowel transplant in April 2000 to offer some encouragement for others who might be needing this same transplant.

My daughter Jenna was born three months premature. After a month of doing very well, she then became very sick and was diagnosed with an intestinal disease called necrotizing enterocolitis. This ended with the removal of almost all of her small and large bowel, and meant dependency on TPN for life. Jenna did fine on TPN for seven years, and then started showing signs of liver failure. We knew this was a possibility, but had hoped it would never happen.



Jenna Mihalevich

We were then sent to the University of Nebraska Medical Center in Omaha where we met with the transplant team. Jenna went through the evaluation process, and at that time they didn't feel her liver was bad enough to list her for a transplant. The doctors wanted to try some medications and different things, hoping it would help. About six months later, another biopsy showed that her liver was getting worse. This is when they decided it was time to list her for small bowel transplantation before her liver worsened to the point where she would need both a new small bowel and liver.

Jenna was then listed. It was a very emotional time as you can imagine. We were told that the wait would probably be at least six months or better. We got the call four weeks later, the day after Easter. At this time you would think we would be very happy that Jenna didn't have to wait long for her organ; but you see even though Jenna's liver was becoming sick, it was not yet affecting the way she felt. She has just been playing basketball with her dad that day, as if there were nothing wrong with her at all.

When I heard them say we have donor organs for your daughter, I thought my heart would beat out of my chest. I don't think my husband and I had accepted the fact that she needed a transplant yet. Our first instinct was not to go because Jenna was feeling great at that time. After calling the doctors in Omaha, they assured us it was the right thing to do. Jenna's liver was going to do nothing but get worse, and we knew that, but I guess at that time we needed some reassurance.

So we packed our bags and headed for Omaha along with a lot of family members. It was very hard trying to explain to Jenna what was about to happen to her. She was scared to death and so were we. Jenna received her small bowel the next morning. The surgery took about five hours. It seemed like a lifetime. The surgery went very well and 10 months later Jenna is still doing well.

Equipment Exchange

The following homePEN supplies are offered free of charge:

- 2 Abbott Provider One portable TPN pumps, w/ backpacks
- Flexiflo Companion EN portable pump
- 10 cases Jevity, 7 cases Exp. 12/01, 3 cases Exp. 2/02
- IV stand
- 48 cases Criticare, Exp. 9/01, 3/02, 11/01
- 3 cases Peptamen, unflavored

WANTED: Ross-Hide-A-Port Extension Tube with Right Angle Adapter #5423 (by Maise Mead maisiem@philpotts.net) for child with limited health care coverage

For more information, call (800) 776-OLEY/(518) 262-5079; or send an E-mail to: DahlR@mail.amc.edu. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods through this column please offer to pay for shipping, especially for heavy items.

Mothers of Children Dependent on HPN

A research study is being conducted to describe the experience of mothering a child dependent on home parenteral nutrition (HPN). This study is being conducted in order to help the health care community recognize and understand the care that is given by mothers of children dependent on HPN. If you live in California, Arizona or Nevada, please consider sharing your experience with Lorie Judson, a nursing doctoral student at the University of San Diego and a professor at California State University, Los Angeles. Email her at Ljudson397@aol.com or ljudson@calstatela.edu; or call (626) 794-3625 or (323) 343-4719.

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We were in Omaha two months initially and have been back and forth several times. Jenna had an ostomy after surgery for six months, to give easy access for the bowel biopsies they routinely do after transplant, but that is gone now. Yes, there have been some complications: one episode of rejection which was treated with steroids and some complications with her medications, but overall, they tell us she is doing great.

After having a central live her whole life, Jenna is now without one. That was a happy day for her and us too. She still has a g-tube for her enteral feeds, because she has never really eaten and doesn't know how to. We are working on that. She is a wonderful child. We are so very proud of her for being so strong and so brave. Sometimes we think that she has dealt better with all of this than we have.

If you could see Jenna, you wouldn't be able to tell all that she has been through because she looks and feels great. We know that problems can arise, and probably will, but she is doing well now and the transplant team seems to think the future looks brighter for her. We thank God every day for Jenna's health and for the family that donated their child's organs to save our child and a lot of others.

My husband, Jenna and I are happy to share our experiences with any readers who are interested.

— Patti Mihalevich
906 Cherry Lane
Kirksville, MO 63501
(660) 665-5339

Art or Science?

Dear Lifeline Readers,

Recently a physician told me that the practice of medicine is an art. I understand the phrase to refer to how a physician applies what he or she learns through formal training and practical experience to benefit his or her clients.

I would like to share my viewpoint as a consumer of medical services that we must insist on evidence based medicine - which treatments have been proven effective, have given the best outcomes at minimal risk of death, medically induced disability or prolonged suffering and hardship. It is essential to have the most complete, accurate, unbiased information in order to make wise medical decisions.

Thank you to the Oley Foundation for being an essential source of much needed information and a forum for sharing of experiences.

— Maria Ternes
Houston, TX

Match Wanted

Dear Lifeline Readers,

I am interested in networking with someone who has chronic intestinal pseudo-obstruction and has experienced having their colon interposition and stomach removed, and then had their small intestine attached to their remaining segment of esophagus. I would like to discuss IV infusions with them, and to find out where they had the surgery.

— Kathy Zessie
St. Clair Shores, MI

Travel, from pg. 2

make your reservation to ensure they can accommodate you, and then to verify the information a SECOND TIME the day you expect the supplies to arrive. Again, because of the possibility of delay, it is advisable to pack at least one night's worth of supplies with you.

To be sure your supplies are there when you need them, you may want to have them shipped such that they arrive a day ahead of you. This way you can verify before you leave home that they have arrived safely. (This may be helpful when going on a cruise.) Unfortunately, some companies will not ship supplies ahead for fear of mishandling or loss.

Having your supplies shipped overseas can be a more risky and time consuming adventure.

If you decide to go this route, one experienced traveler suggests having them shipped 'directly' to you via air cargo. (He cautions against using an international courier such as Fed Ex or UPS, because no one knowledge about the supplies will be there to answer questions if difficulties arise with customs officials.) He advises carrying two days worth of supplies with you (at least one day's worth in the cabin), choosing a direct flight whenever possible, and having the rest of the supplies arrive a day

after you. This gives you time to orient yourself in the foreign city, and to be at the air cargo terminal when your supplies arrive so you can personally assure their safe and timely passage through customs.

No matter how you choose to ship your supplies, planning ahead and coordinating your efforts with your home care company can make this process a lot smoother and is well worth the extra effort. Before you leave, both you and the home care company should know details like how many boxes are being shipped, their contents (clearly labeled) and your travel itinerary (including flight/transportation information, destination addresses and phone numbers).

One consumer whose luggage - including 8 days of TPN and hydration - was lost on a flight to Europe, recommends carrying on all of your supplies when traveling anywhere you cannot be guaranteed overnight delivery by your home care company. This approach can be very fatiguing, of course, and requires extra work with the airlines to avoid a financial charge for the extra baggage.

5. Keep Solutions Cool

Refrigeration can be a nuisance, but there are some tried and true tips that experienced travelers follow. To reduce your load, pack

items that require refrigeration separately, clearly labeling those that need to stay cold.

To be sure your solution/formula stays cool enough, use cooling packs on the bags/cans and cover both with ice. Don't forget to re-cool your cooling packs in a freezer whenever you have the opportunity — especially when traveling by car in hot weather. When making a hotel reservation, be sure they can guarantee a refrigerator or your room, or space in their kitchen's refrigerator that you will have adequate access to. When your hotel doesn't offer refrigeration, but does offer ice, try this method. Using plastic containers or Zip Lock baggies make some ice blocks, each morning, pour off any water that has melted and fill any empty space in the bag/container

with ice cubes. These can last several days, depending on the weather. As the days pass, and your solution gets used, fill any empty space in the cooler with crumbled newspaper, and cover with a heavy bath towel.

Unopened/unmixed HEN formula will require refrigeration only if it will be exposed to very warm temperatures, typically 77°F or higher (check the label on your can or package). Unused formula from an open can or packet that has already been mixed,

should be refrigerated. Thus it is possible you will need refrigeration for your HEN formula only at your hotel, and not for the actual transporting.

On the other hand, HPN solutions almost always require refrigeration. To get around this obstacle, you might consider bringing the components of your solution in separate containers (i.e. fluids, lipids, additives, and vitamins). When they aren't mixed together, they don't need to be refrigerated. Of course this means you will have to mix them yourself before hooking up. Before you plan on taking this route, talk to your physician and home care company to be sure this is a possibility for you. (Eleanor Orkis and Robin Lang have experience with this.)

6. Network with Other Travelers

Whether you are planning your first trip on homePEN, or your first trip overseas, it's a good idea to call a consumer who has experience traveling with HPEN. The volunteers listed in the chart below have happily provided helpful tips and stories to Oley members over the years. Feel free to call on them for advice concerning your next trip. Bon Voyage! ☺

Consumers with Significant Travel Experience

| | | |
|---------------------|----------------|-----------------------------|
| Robin Lang* | (207) 363-7880 | ivtpn@earthlink.net |
| Sheila Messina* | (408) 978-0466 | smessina@1connect.com |
| Eleanor Orkis* | (518) 377-0526 | saintemo7@aol.com |
| Elizabeth Tucker | (952) 435-0013 | evt8888@aol.com |
| Felice Austin (mom) | (702) 435-6007 | fleecey@aol.com |
| Judy Peterson* | (619) 226-2061 | catsjp@juno.com |
| Don Freeman* | (613) 825-4321 | donaldfreeman@aol.com |
| Allison Hilf | (303) 393-2619 | ahilf@aol.com |
| Ann DeBarbieri* | (518) 587-0373 | paul-ann-d@worldnet.att.com |

* indicates international travel experience



Scenes from the Picnic:
Above: Emily Pitegoff, Beatrice Weaver, Rochelle Schneider, Greta Huss and Alicia Hoelle enjoy a ride through Veteran's Park.

Left: Kyle Noble watches the 'big' kids with his new friend.

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Freese, from pg. 1

was very important to Woody. He made you laugh, he could be so silly; he made you cry, you could feel his pain (near the end). And sometimes he had you so confused you laughed until you cried. Nonetheless you enjoyed every minute with him.

His contributions to the Oley family were immeasurable. His spirit everlasting. We will miss him greatly as we strive to match his inspiring and endearing qualities.



Woody Freese flipping burgers at the 1984 Oley picnic.

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or later) have their acknowledgments listed. Thank you for your support...it really does make a difference! We also wish to thank all those

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Toll Free Numbers Now Available to Canadian Consumers!

Thanks to a donation by Calea, the Oley Foundation is now able to offer it's toll-free lines to consumers in Canada. The new plan also offers lower rates, but we no longer have free calls on Fridays.

Oley circulates two toll-free numbers 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 15 minutes.

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

| | | |
|-----------------|--|---|
| AUG. '01 | <p>Pam Rector Mt. Pleasant, SC (888) 610-3008 EST</p> | <p>A new Regional Coordinator, Pam was on HEN for 3 years and has been on HPN since 1998. Diagnosed with pseudo-obstruction and gastroparesis, she has an ileostomy and a gastrostomy tube. She is a great listener and happy to share her experience with both therapies with folks in the Oley family.</p> |
| | <p>Laura Mucha Gilbert, AZ (888) 650-3290 MST</p> | <p>Laura is another new Regional Coordinator. She has been on TPN for 10 years due to short bowel syndrome, secondary to a volvulus. She has experience with many types of pumps and catheters, and is interested in learning about new technologies. She looks forwarding to networking with fellow consumers.</p> |
| SEP. '01 | <p>Mary Jo Walch Green Bay, WI (888) 610-3008 CST</p> | <p>Mary Jo has been on TPN since 1990 due to a volvulus during pregnancy. As a wife and mother of a teenage daughter she is very busy and tries not to let her dependency on TPN control her life. She has travelled extensively. As a degreed Medical Technologist, she is very involved in the technical side of her therapy.</p> |
| | <p>Stephanie Harlow Fredericksburg, VA (888) 650-3290 EST</p> | <p>Stephanie and her 5 sons are diagnosed with Eosinophilic Gastroenteritis (EE). They are unable to eat which leaves 5 family members dependent on HEN and one dependent on HPN. Her can-do attitude allows her to manage this and a Foundation for other EE families, while providing a nearly 'normal' life for her family.</p> |
| OCT. '01 | <p>Don Freeman Nepean, Ontario (888) 610-3008 EST</p> | <p>Diagnosed with Crohn's Disease, Don has had an ostomy for 36 years and has been on TPN since 1981. Since then he has raised a son, worked full-time, been active in his community, and has travelled extensively. Don is an Oley Trustee and RC, and the founder of the Canadian Parenteral and Enteral Nutrition Association.</p> |
| | <p>Dava Huss Arvada, CO (888) 650-3290 MST</p> | <p>Dava's son Owen (9 y.o.) has been on TPN and EN feeds for five years after a midgut volvulus resulted in short bowel syndrome. She and her husband, Michael, are interested in the daily struggles and joys of parents with children on TPN or EN, balancing the needs of siblings and keeping the family whole.</p> |

LifelineLetter

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Albany, NY 12208

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