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# LifelineLetter

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

## Managing Complications in HPN Consumers (II)

Lyn Howard, MB, FRCP, FACP, Albany Medical Center

*The following overview of HPN complications is excerpted from Gastroenterology, Volume 124, "Management of Complications..." by Howard, et. al., pages 1651-1661, © 2003 with permission from the American Gastroenterological Association. Last issue we covered the infectious and mechanical complications; this issue we will conclude with metabolic complications. The original article contains additional background information as well as sections on psycho-social issues and referral to an intestinal failure center, and is available from [www2.gastrojournal.org](http://www2.gastrojournal.org).*

### Metabolic Complications

**Fluid and Electrolytes.** This is a critical issue for short bowel patients. Many patients after a period of adaptation can absorb enough oral calories and protein to maintain their weight, often by eating four to six thousand calories/day. But using the gut can induce large enteric (bowel fluid) losses especially in the individual with a high jejunostomy. Such a patient may lose 4 L/day compared to a stool loss of 100 ml/day in

a healthy person. Large enteric fluid losses can be exacerbated by a number of factors (Table 2, page 2), and sipping oral rehydration solutions may help address some of these losses, but usually parenteral hydration is required. This hydration fluid should be enough to produce a urine output of > 1 litre/day.

A number of reports have pointed to slow deterioration of renal (kidney) function in long term HPN patients. This may reflect the impact of nephrocalcinosis (kidney stones) from excessive oxalate absorption in patients with an incontinuity (surgically connected) colon or the intermittent use of antibiotics that are toxic to the kidneys, however chronic dehydration may well be an important common denominator. Excessive oxalate absorption in the colon and hyperoxalouria (excessive oxalate in urine) are a consequence of severe steatorrhea (loss of unabsorbed fat in stool). Recent studies show that conjugated bovine bile salts improve fat absorption

HPN Complications cont., pg. 2



## Join Us Next July in San Francisco

Mark your calendar and plan to join Oley as we host our 19th Annual Consumer/Clinician Conference June 30 - July 2, 2004 in scenic San Francisco, CA. The conference offers a unique opportunity to meet others who face the same challenges and learn about maximizing your quality of life on homePEN. In addition to conference events, participants can enjoy the breathtaking, beautiful city; from cable cars, one-of-a-kind shopping and exotic food, to Chinatown, Union Square and Fisherman's wharf — San Francisco offers something for everyone. Plan to bring your family too. The surrounding area offers a variety of vacation options, including sightseeing along historic Route 1, hiking through the Redwoods at Big Basin State Park and wine tasting in Napa Valley. Watch for more details in upcoming newsletters and at [www.oley.org](http://www.oley.org).

## Spotlight: Don Freeman

by Don Freeman

*Don is a long time Oley member and volunteer. He served on Oley's board of trustees and has been a Canadian regional representative for many years; his photographs of Oley conferences and travel tips have graced the pages of dozens of LifelineLetters. We thank Don for his dedication and are pleased to share his story.*

At age 15 I was diagnosed with Crohn's disease. Over the next eight years, I had numerous surgeries and resections leading to an ileostomy at 23; after which I had a 15 year remission. The reactivation in 1979 of my Crohn's and a year of unsuccessful treatment lead to further surgery and short bowel syndrome.

For five months after this last bowel resection my life was hell — no more than sleeping and weakly lying about the house with continuous weight loss. Finally, realizing that my condition was only worsening given



Don Freeman

Spotlight cont., pg. 6

## HPN Complications, from pg. 1

and reduce urinary oxalate, but at the cost of more diarrhea. Cholylsarcosine, a synthetic bile salt analogue not broken down by bowel bacteria, has a more modest effect on fat and oxalate absorption but causes less stool output. In addition to renal problems, chronic dehydration causes fatigue and even low grade fever, late in the day before the cycled infusion is restarted.

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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.

To help short bowel HPN patients understand the precariousness of their fluid balance, it is useful to start out with the patient keeping careful input/output records. This is also important when the patient is starting to wean off HPN. Providing extra hydration fluids at home is useful so patients can boost their parenteral fluid intake on a hot day or after a dietary indiscretion. Hydration fluid can provide not only sodium, potassium, chloride and bicarbonate equivalents (actate/lactate) but also divalent cations, vitamins and trace elements for the patient who has weaned off full parenteral nutrition.

Several **micronutrient deficiencies** were described in the early years of long term parenteral nutrition patients, notably essential fatty acid, vitamin A, vitamin E, thiamin, biotin, zinc, copper, chromium, selenium and molybdenum. Over the past 30 years the commercial parenteral lipid, multivitamin and trace element preparations have added or increased these micronutrients so deficiency syndromes of these micronutrients are now rare. If they do occur, it is when patients are weaned off HPN to full dependence on oral

nutrition. Iron deficiency may occur because it is not routinely added to parenteral solutions and many patients have ongoing disease-related enteric blood loss or frequent blood test monitoring. Routine blood testing should be limited in stable long term patients to perhaps 3 or 4 times/year.

There have been recent reports of **excess manganese** accumulating in the brain of HPN patients, presenting with Parkinsonian – like symptoms. Manganese, like copper, is excreted in bile, but can accumulate, especially in the presence of liver disease. Following reduction of manganese intake, abnormal MRI signals slowly disappear over a 3 year period. **Parenteral vitamin D** in doses originally supplied in the multivitamin formulation (400 IU/day) appear to increase bone resorption rather than support bone formation. Parenteral formulations now provide decreased vitamin D (200 IU/day).

**Liver dysfunction:** Mildly abnormal liver function tests (elevated alkaline phosphatase, transaminases >1.5 time normal upper limits) are common in HPN patients. This may  
**HPN Complications** cont., pg. 8

**Table 2: Managing excessive enteric loss in short bowel patients**

Factor	Management
Constant thirst, excessive drinking of water, despite objective evidence of adequate hydration	Possible thirst mechanism is dry mouth from anticholinergics (such as lomitol and imodium) or rapid upper bowel decompression so baroreceptors in duodenum do not signal adequate hydration. Patient has to learn to resist stimulus to drink excessively and to sip oral rehydration solutions so fluid and electrolyte losses are less critical.
Hyperosmolar food and fluid sources	Patient should limit foods or drink with high sugar content (such as soda) or nonabsorbable sweeteners (xylitol, sorbitol).
High gastrin levels as patient adjusts to HPN, usually first 6 months but may be longer if ostomy output remains acid	Treatment is parenteral H <sub>2</sub> blockers. This blocks acid production while permitting the stimulus gastrin provides the proximal small bowel.
Dysmotile segment, bacterial overgrowth, worsening of absorption and aggravation of gall stones	Trial of antibiotics to suppress growth of abnormal flora and probiotics to promote growth of normal flora. A longitudinal intestinal lengthening and tapering procedure should be considered.
Stricture of bowel or at ostomy, proximal dilation and stimulated secretion	Radiologic confirmation. Endoscopy and biopsy to establish cause. Balloon dilatation, stricturoplasty or surgical revision as needed.

## Don't Miss the Intestinal Failure Meeting!

Nutrition Week will host its first-ever World Congress on Intestinal Failure....and Oley members are invited! Nutrition Week will be held this year in Las Vegas, NV, from February 9 to February 12. Just prior to the kickoff of Nutrition Week, there will be a two-day world congress meeting where experts from around the world will determine the future directions of research related to intestinal failure.

Oley Foundation consumers can participate as audience members of this working research meeting. Oley's Medical & Research Director, Lyn Howard, MD, and Board Member Alan Buchman, MD, are members of the expert panel. The programs will run from 8 a.m. to 5 p.m. on both Saturday, February 7 and Sunday, February 8. There is a \$50 charge to attend the meeting which is paid to the sponsors, National Institutes of Health. Dr. Howard emphasized, "This is an opportunity Oley's consumers cannot afford to miss."

The Oley Foundation initiated a regional meeting last year in conjunction with Nutrition Week. It was a great success. We intended to duplicate that this year, but we feel this meeting takes precedence. The difference will be that audience members are not allowed to ask questions or interrupt the meeting — any questions will be given to Oley staff, who will report the researchers' answers at a later time.

The Oley Foundation will hold a reception on Saturday night, and we are researching hotels now for a group rate. We may be able to offer the opportunity of a day pass to the exhibit hall on Monday — a chance to meet with the manufacturers of nutrition support equipment and formulas, and see the newest products. We are also looking for volunteers to assist us with staffing the Oley Foundation Exhibit booth. Watch the website for new information and details as we put things into place. *Viva Las Vegas!* ☺

## Cyber Support Makes Giving Easier

Can't find your annual appeal envelope? No problem. Visit your favorite website, [www.oley.org](http://www.oley.org) and discover how easy giving can be. Simply clicking on the "Donate



Now" button brings you to a secure page that features several different giving options: single donations, or quarterly or monthly contributions can be automatically sent and billed to your MasterCard or Visa.

A separate opportunity allows a direct bank transfer from your checking account — similar to how some people pay their student loans or mortgages. To start this type of donation, you would need to send a check for the first contribution, along with the form (available on-line); subsequent donations would be automatically donated from your account each month or quarter.

The quarterly and monthly donation opportunities are new for Oley, and we hope folks will take advantage of the chance to donate small amounts over the year, and help us reach out to more consumers. The need is great! We appreciate all of your assistance with those efforts, and thank you for helping us continue our important work. ☺

## 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 [DahlR@mail.amc.edu](mailto: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.*

### Bags Help Child with Motility/Pressure Issues

My son currently has a G-tube and separate J-tube. Before he received his J-tube, the Farrell bag was used with G-tube feeds (24 hours continuous) and it was a blessing! Now that he is on J-tube feeds only, the Farrell bag is used solely with the G-tube (without feeds) as a method of continuous ventilation. It has saved him from a tracheostomy; gastric bloating from his dysphagia compresses his lungs. I highly recommend the bags, especially for children who have severe motility/pressure issues like my son. He has herniated his gastrostomy twice and required surgical repair. My son cannot function without them.

— Penny Crittenden  
Bryantown, MD  
[penny@olg.com](mailto:penny@olg.com)

### Pain Around G-tube Site

I have been experiencing pain around my G-tube site. I have tried many, many suggestions but have gotten very little relief. Most recently my GI physician recommended applying a thin layer of Triple Antibiotic Plus Cream, and then a very small amount of Lidocaine Viscous Topical 2% Solution.

It's been wonderful. The pain is gone and so is all the soreness, redness and skin breakdown. After applying these creams I put on a gauze pad or folded-up Kleenex.

— Sue McKallor  
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[Editor's Note: It would be wise to check for granulation tissue around the site as well.]

## Scenes from the 2003 Oley Conference, St. Augustine, FL



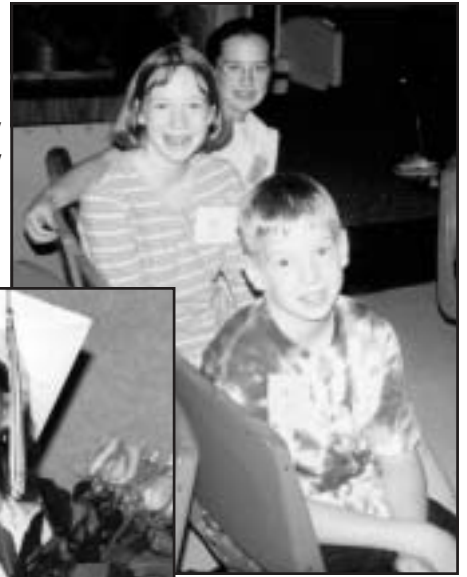
*Regional Coordinator Eleanor Orkis with Blanche and Bob Hoffman.*



*Above: Kory and Killian Harlow  
Right: Martin Bell*



*Alicia Hoelle  
graduating from  
highschool at the Oley  
conference*



*From Back: Rose  
Zimmerman, and  
Lauren and  
Owen Huss.*



*Left: Darrell and  
Patty Woods  
Below: Kaitlyn  
Goldsmith*



*Oley's former executive director, Laura  
Ellis, and her husband Max Lifschitz.*



*Left: David Young and  
his fiancé Sheryl Creyts*



## Tips for Parents: How to make the most of doctor visits

I keep a running list of all the questions that I want to ask the doctor. I have a calendar that has plenty of room to write about my son's health (reaction to medicines, etc.). When I go to the doctor, I take the list of questions and the calendar — it saves time and missed answers.

— JK from Pennsylvania

Our (almost) 3-year-old son causes a lot of commotion during appointments. So, before each appointment I try to jot down a list of current medications and dosage frequency as well as any questions I come up with between appointments. I take the list with me to the appointment and if it's a long list, I sometimes fax it to the doctor ahead of time so he's prepared when we get there.

— AC from Pennsylvania

I have found the most effective way to communicate is to have a timeline jotted down on a piece of paper. I note any changes in my son's condition [like weight or output] when we have a change in medication [or formula]. My son's doctor keeps my notes in his file, so that we can refer back to them and look for trends.

— Adapted from the idea of TJ from California

I make a list of questions before I visit the doctor and I ask about the doctor's knowledge of any research I've read. I want the information, but I also want to know if he is keeping current. Our doctor always completes a written plan of treatment that includes medications and doses at the end of each visit.

— PC from Indiana

I follow up with my doctor by e-mail whenever I need clarification or if something she recommended doesn't seem to be working. I keep my questions concise (both e-mail and at the office visits) because I know her time is precious.

— CK from Hawaii

You really need to educate yourself. Knowledge is power, and you, as parents or patients, need to know about your diagnosis. With this



knowledge you can ask questions. You need to find a physician that is willing to listen to and answer your concerns. Don't give up — we went from GP to pediatrician to specialist. Learn more about your condition, evaluate the care, and go from there.

— AH from Nebraska

At doctor appointments, my son is always included in the conversation and expected to answer the questions first or with me — no matter what his age. If the doctor keeps his level where a child can understand it, so can I! This helps my child be a part of his own plan.

— MB from Oklahoma

I write down any meds that we may be low on ahead of time, so that I can request a new prescription slip. I take notes at the doctor's office about everything that I discuss, and I have them on record in case I need to refer to them at a later date.

— HG from California

I'm often feeling stressed when my son or I am ill, so I make sure I repeat back to the doctor any directions given to me. This reinforces them in my mind. When the doctor is hurried and rapidly firing off directions, this technique also forces him or her to slow down.

— JB from New Hampshire

My husband and I usually both attend doctor appointments. That way what one misses, the other usually has written in notes.

— SE from Minnesota

I keep a medical logbook where I record all of the medications [changes in diet, formula, etc.]

my daughter is on, what symptoms she has on a daily basis, doctor's instructions, etc. I have a separate book for each year and they are a true diary of her journey. Each doctor that has seen it appreciates it and is thankful for the information that it gives.

— Adapted from the idea of TB from Georgia

When you are well informed, I think doctors tend to treat you more as a partner in care than simply a mom.

I also have made an effort to learn the medical lingo; doctors sit up and take notice when you can speak their language.

I know what kinds of doctors my daughter likes and purposely choose those kinds of doctors for her. My philosophy about doctors is that they are people, just like us. The MD after their name does not grant them special powers. Our doctor knows more about the illness in general than I do (maybe!), but I know more about *Kaitlyn's* disorder than he does.

— Adapted from the idea of KI from Washington

Doctors usually are in a hurry, but I kindly assert myself and ask questions until I understand what it is I need to know. My daughter's health is dependent on it!

— KG from Colorado

When my son was young, I would bring a diaper bag filled with toys, snacks, and drinks to appointments so that while I was talking with the doctor, my son would have something to do. Now that he is older, he brings his Game Boy with him.

— TK from New Jersey

I went through six different doctors before I found the right one for my son. I did not settle for a doctor that rushes me. If I know I am going to have a few extra questions during an appointment, I call ahead to let him know.

— PD from Texas

*This article was adapted with permission from the February 2003 issue of the MA Report Newsletter, published by Allergy & Asthma Network Mothers of Asthmatics. For more information about AANMA call (800) 878-4403. ©*

### Spotlight, from pg. 1

my limited bowel (65 cm.), I was re-hospitalized and put on TPN. My weight had gone from 150 lbs prior to the Crohn's reoccurrence, to 70 lbs in a period of 18 months. Initially the TPN was to rest my bowel, but, after six months, it became evident that TPN would be required for life. This June I marked my 22<sup>nd</sup> anniversary on TPN.

### Lengthy Hospitalization

My first year on TPN was not easy. Being the first person in Ottawa to go home on TPN, there was no hospital protocol — neither for self-administration nor funding. Therefore, I had to remain hospitalized. It took six months to stabilize me. Ultimately, it was 13 months before I was discharged. I may not have been even then, if not for a GI resident determined to discharge me before he moved to Toronto on a post-doctoral fellowship.

That year of hospitalization was difficult as I had a 4-year-old son. Fortunately, by the time I was stabilized in the Fall of 1981, I was allowed to be out of the hospital all day, returning each evening to infuse my TPN. A trying routine, but at least it gave me the full day with my son who was not yet in school. In fact, since I was not discharged until June 1982, I used my day passes, with some adjustment of infusion times to stay out for the evenings and coached my son's T-ball team.

Sometimes positives come out of the worst situations. With the time I was at home before and after my hospitalization, and the day passes out of the hospital, I got to spend almost two years as my son's primary caregiver. This created a good relationship and bond between us — stronger than normal because it was formed under such hardship. However, my year long institutionalization took a toll on my marriage, which ended halfway through my hospitalization. Besides the normal emotions from such an event, it raised issues that added to the problem of getting discharged home on TPN.

While still in hospital, I purchased a home in the same general area as my ex-wife, as we had agreed to raise our son in joint-custody. Now, I went about getting it setup, only to

find that living on my own and being a single parent were strikes against being discharged.

Beyond the funding problem, now arose hospital resistance to discharging a TPN patient who had no backup at home and would be caring for a child. These conditions went against almost all hospitals homePEN protocols — even though I had effectively been on self-care in the hospital for nine months. I did all my solution mixing (you had to mix your own TPN back then), hook up, dressing changes, etc. I was doing everything on my own as I would at home except, in the hospital, where there are nurses on call; although never in nine months had I needed their assistance.

Fortunately, my GI-TPN physician is not one to let tradition get in the way of his patient's welfare. So, with his approval, a resident arranged to discharge me the same day that he was leaving for Toronto to assume his post-doctoral position. A month's supply of TPN solution was ordered from the hospital pharmacy. I was supplied with boxes and instructed to load up everything I would need for several months from the ward supply room. I was warned there could be a problem getting

more supplies once the hospital realized I was no longer an internal patient. Two days later, after having the supplies transported to my new home, I was quietly discharged.

Sure enough, the resident was correct. Two months later, after my second TPN order, questions started to be raised. My doctor told me the hospital was raising concerns about funds to treat me outside the hospital and asked what I would do if he had to bring me back in to cover the therapy costs. My response was I would go to the local media (press, radio, TV) and show how out of the hospital I could lead a normal life, raise my son, work, pay taxes, contribute to my community, etc., while hospitalization would do nothing but tie up a bed others could use. This was at a time when Ontario hospitals were struggling with bed shortages. My doctor stated that he had no intention to re-admit me and just wanted to confirm my intent before he warned the hospital administration that forcing me back in would lead to a negative media campaign. That was 22 years ago and funding has never been brought up again. While during most of that period the hospital never had funding specifically for TPN, they always seemed to find the funds (see "Funding for TPN..."). Right at the start of my home TPN experience I learned the value of being pro-active — knowledgeable, forceful, and prepared to take control of my therapy.

### A New Lease on Life

Within a month of my discharge in June 1982, I made my first trip on TPN, taking my son to Toronto and Canada's MGM Wonderland for a week. My security blanket was the phone number of the resident who had treated me. Since then I have traveled throughout North America and Europe by car, train, and air.

With my last Crohn's remission (22 years and counting) and strength from good HTPN nutrition, I have had a pretty normal life since 1982. Within four months of discharge, I returned to work as a Human Resource's Officer with the Federal Government. However, having seen the value of life, I reduced my workweek to four days. Fridays were for rest and errands to fully enjoy free weekends with my son. During that first year, I took up curling,

### Funding for TPN in Canada

Some explanation of the Canadian Health Care System is required to explain the funding problem my hospital faced in 1981. The Federal government defines the care to which all Canadians are entitled and the provinces, which administer the system, must provide. Provincial governments fund hospitals in several ways — annual capital grants to cover maintenance and, improvements; a set fee for each occupied bed/day; and annual grants for specific high-tech programs such as dialysis, HPEN, etc. The prime factor in all funding is that it is provided for in-hospital or outpatient (i.e. Dialysis) care — not home care.

Outside of the hospital, the Canadian health care system covers doctors' fees, tests, etc. but not prescriptions (like TPN), except for seniors. This was the problem faced by the hospital when it came time to discharging me. As long as I was in the hospital, the TPN could be charged to the government; but once I went home the funding ceased.

My hospital was not the designated HPEN program hospital for my province (Ottawa), but, I insisted in staying with it because I had established a relationship with the HPEN team, and it's closer location made checkups and acquiring supplies far easier. Ultimately, to be discharged, my TPN costs were absorbed within the hospital's regular operating budget. This continued for 15 years until the Ontario government began merging hospitals and the costs for my TPN were merged into the General campus's provincial special program grant.

resumed skiing, including rejoining the Canadian Ski Patrol, and got active in community programs such as scouting and children's sports.

Around 1983 I made the first attempt to establish the Canadian Parenteral and Enteral Nutrition Association (CPENA) and produced some newsletters. Through the aid of Travenol — a predecessor of Calea — the newsletters were distributed across Canada. This activity led to contact with HPEN consumers at Toronto General Hospital and participation in their association, which was a boon since I had not met any other HPEN consumers in Ottawa or elsewhere.

After a hiatus in the newsletter in the late 80s, with the aid of the Toronto HPEN association, *PenLine* was reincarnated. Unfortunately, after many years as a very vibrant group, the Toronto group ceased activities and, shortly after, a downturn in my health (line infections) resulted in another hiatus for the newsletter and CPENA. However, thanks to the support of Calea, in 2000 CPENA and *PenLine* were revitalized, and an expanded and updated website was developed.

In 1985 I learned of the Oley Foundation, and attended their and my first annual conference held in Saratoga Springs, NY. Since then I have attended all but two conferences, and have served as a trustee, a regional coordinator for Canada, a conference co-chair, and on conference and *LifelineLetter* Advisory committees.

My work with Oley has made me aware of the importance of contact with others who share my experiences. This is my motivation for CPENA; particularly, since our medical system presents many needs and concerns which are distinctly different from Oley's mostly-American consumer environment.

#### **Mixed Blessing**

I have been fortunate with my home TPN. It was nine years before my first line infection and change. However, during the next five years, I had five line changes with the last two occurring within a six month period in 1995. Since then I have been on disability leave and find it necessary to infuse (3L+\night) over a longer period with more ups and downs. This fall I was approved for an early medical retirement.

I find, particularly since leaving the work world, it is important to keep active and involved with others for both my physical and mental health. I try to maintain an active regime both to avoid infections and TPN side-effects. Since loss of bone density can be a problem, I do weight training 3 times a week and walk extensively on the off days. While I no longer ski on a weekly basis (only occasionally), I continue to curl and coordinate a large curling league, travel, and keep active in my community and volunteer work. I have discovered that volunteering as a dog walker for the local humane society is an excellent way to ensure about an hour's walk every day, and the unconditional appreciation of a dog is a great pick-me-up even on the most difficult of days.

As a person with an underlying diagnosis of Crohn's Disease, TPN has been a therapy with a positive outcome for me; however, there are many with more difficult diagnoses such as pseudo-obstruction, etc. which are not so treatable by surgery or don't have the possibility of lengthy remission like there is with Crohn's. I consider myself to be fortunate that with TPN I have been able to raise my son (now 26 and working as a marketing coordinator), have a rewarding career, and participate fully in my community. ©

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## *Check out our support for long-term consumers!*

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**HPN Complications**, from pg. 2

reflect hepatic (liver) dysfunction due to pre-existing illness, for example Crohn's disease or toxic hepatitis secondary to intra-abdominal infection, or some dysfunction precipitated by parenteral nutrition, developing after a few months on therapy. Liver biopsies usually show pericholangitis (inflammation around the bile ducts) and bile duct plugging. In most patients these abnormalities remain stable but in a few, more serious hepatic dysfunction develops and biopsies show extensive fibrosis with bridging, going on to cirrhosis. A recent study in France reported 22% of deaths in long term HPN patients were due to liver failure. In the US, liver disease accounts for 15% of HPN deaths in long term patients. Liver disease is more common in very short bowel patients (remanent <50 cms) and in children. The French study found a strong association between liver disease and a parenteral lipid intake of > 1 g/kg/day. One possible explanation for a lipid toxic effect is the presence of phytosterols (plant cholesterol) in lipid solutions. Different lipid solutions appear to have different toxicity even when the basic ingredients of soy oil and egg phospholipid are the same.

Many factors other than just parenteral lipid, are thought to contribute to HPN liver disease. Current research is particularly focused on hepatic transsulfuration pathways (shifting of sulphur from one important biological compound to another in the liver). Methionine is the only sulphur containing amino acid in most parenteral formulations, because other sulphur containing amino acids are relatively insoluble and difficult to incorporate. However, methionine delivered systemically (e.g. via HPN), rather than via the normal, physiologic portal route, results in a shortage of critical sulphurated byproducts. HPN patients and animal models have demonstrated depleted choline, lecithin, carnitine, cysteine, glutathione and taurine levels. All these sulphur containing products have important functions in mobilizing fat and synthesizing lipid membranes with receptor and transport functions for the secretion of bile pigment.

Table 3 lists approaches with some evidence of benefit in managing HPN cholestasis. If liver damage continues and biopsies show

bridging or early cirrhosis, the patient should be listed for small bowel/liver transplantation. In patients with fatal outcome the interval between onset of jaundice and death was 10 months.

Overlapping the problem of cholestasis (impaired excretion of bile pigment) is **bile sludge and cholelithiasis** (gallstones). About 25% of short bowel patients develop gall stones and require cholecystectomy (gallbladder removal). Prophylactic cholecystectomy at the time of the initial surgery is probably not warranted if the gall bladder is healthy at that point. Oral intake of some fat and ursodeoxycholate therapy reduces the risk of cholelithiasis.

**Bone disease in HPN**, like liver complications is present in a high percentage of patients in a mild form and presents as a major problem in a few. Cross sectional studies of bone mineral density using dual energy x-ray absorptiometry (DEXA scan) showed a T score below -1 in 84% of 165 HPN patients and T Score below -2.5 in 41%. The lower T scores were associated with bone pain in 35% of patients and with a pathological fracture in 10%. Multiple factors that can contribute to bone disease including malabsorption syndromes, pre-existing liver disease, steroid administration, high levels of cytokines and other factors. Much of the problem relates to the primary disease and its treatment, and predates HPN.

Bone turnover studies in HPN patients show a low rate of bone formation with low serum osteocalcin. In the early years of HPN, aluminum contamination was a serious problem but this largely stopped when

synthetic amino acid solutions replaced hydrolysates. Some batches of parenteral additives, such as calcium gluconate, are still contaminated and the Food and Drug Administration (FDA) is studying ways to eliminate this problem. Removal of vitamin D is recommended if the parathormone and hydroxy vitamin D levels are low. Amino acids result in hypercalcuria (too much calcium in urine), so reducing protein to <1.5g/kg/day is appropriate.

Low magnesium is common in short bowel patients. Magnesium is critical in gut absorption of calcium and magnesium. It is also important in activating parathormone and renal conservation of calcium. Magnesium status is best measured by a 24 hour urine collection. Less than 50 mg of urinary magnesium/day suggests magnesium depletion. An HPN formula for a short bowel patient, with normal renal function, should provide 20-25 meq Mg/day. Oral calcium supplements of 1-2 g/day are probably safer than large doses of calcium in the parenteral formula. There has been a serious problem of calcium phosphate crystals causing microvascular pulmonary emboli, fatal in two patients. This led to an alert by the FDA. Studies subsequently showed the importance during HPN solution preparation of modestly reducing the high pH of the amino acid solutions, adding most of the water early, agitating constantly throughout the mixing process and adding calcium last.

Bisphosphonates decrease bone resorption. Given cyclically, intravenous clodronate  
**HPN Complications** cont., pg. 9

**Table 3: Medical Management of HPN Cholestasis**

Some evidence of benefit	Comment
Encourage oral intake, or if necessary start enteral feedings	Stimulates bile output. May provide critical nutrients
Limit parenteral calories glucose/lipid to modest amounts	Excessive intake of all types of parenteral calories aggravates steatosis
Treatment of bacterial overgrowth syndromes with cycled antibiotics/probiotics and prokinetics	May require surgical reconstruction of dilated non-motile segment.
Oral lecithin, oral choline; or parenteral carnitine	Parenteral choline under investigation
Ursodeoxycholic acid 20-30 mg/kg/day	May increase diarrhea

**HPN Complications**, from pg. 8

stabilized but did not increase spinal bone density over a 12 month period in 20 HPN patients. Calcitonin given intravenously for ten days relieved the bone pain in a severely demineralized patient. It is not clear if calcitonin has a long term role in treatment of HPN bone disease.

In summary, much progress had been made in the management of HPN complications since the first patient was sent home on this therapy in the late 1960's. Proper training of HPN patients and caregivers, as well as careful management by experienced clinicians can further minimize the risks from therapy complications. ☺

**Got the Wrong Member Form?**

It has come to our attention that some of you have received the wrong membership form. We apologize for the distribution problem and encourage you to complete the correct form (consumer or professional), on-line at <http://www.oley.org/join.html> or call for a new form at (800) 776-OLEY. Thanks for your patience! ☺

**Ongoing Research Trials**

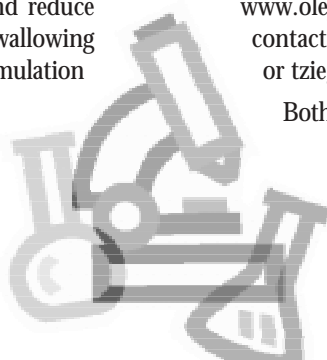
**• Research on Swallowing Problems**

Researchers at the National Institutes of Health (NIH) are conducting experimental studies to develop a new method for helping individuals with life threatening swallowing problems to determine if: (1) muscle stimulation can elevate the larynx and reduce aspiration in persons with swallowing problems, and, (2) muscle stimulation to elevate the larynx will open the esophagus and allow food to enter the stomach in persons with swallowing problems. This outpatient study is located in the Clinical Center at the NIH, Bethesda, MD campus and lasts for a period of 2 days for approximately 3-4 hours each day. The NIH will pay all study-related expenses. To qualify for a screening visit, a letter of referral and medical history information are required. Persons admitted for study will have their expenses for travel to the NIH covered on future visits. For more information, please call Ianessa Humbert at (301) 496-9367 or (800) 411-1222.

**• Short Gut TPN Patients Wanted**

As published in a previous issue of the newsletter, Dr. Thomas Ziegler is researching

the effects of modifications in oral diet, with and without treatment with synthetically-derived human growth hormone, on intestinal nutrient absorption and clinical outcomes in TPN-dependent SBS patients. For more details, visit the oley website at <http://www.oley.org/news/researchbox.html> or contact Dr. Ziegler at 404-727-7351 or [tzieg01@emory.edu](mailto:tzieg01@emory.edu).



Both of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee, however, **The Oley Foundation strongly encourages 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 <http://www.oley.org/news/researchbox.html>

If you are interested in having your research study listed, complete the form listed on Oley's web page at <http://www.oley.org/news/researchbox/form.html> OR fax the same information to (518) 262-5528. ☺

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- 30 cans Polycose, exp. 5/04†
- 3 cases Prosure (cancer pts) exp. 4/04
- 6 cases TwoCal HN exp. 4/04
- 10 cases TwoCal HN exp. 4/04

### Equipment

- 1 Provider One Pump
- 1 Flexiflow Companion pump
- 1 Sugar Monitoring System w/lancets
- 1 IV pole, disposable
- 1 Kangaroo carry case

### Admin Sets/Tubing/Bags

- 2 Allegiance Catheters 16 fr.
- 20 Kangaroo 1000 ml bags
- 40 Ross Flexiflo Companion bags 500 ml
- 5 boxes Ross Companion 1000 ml bags
- Sabrasnet tubing
- 4 boxes Zevex 1200 ml bags
- sample Farrell gas relief EN bags†

### Miscellaneous Supplies

- 4 boxes 2" x 2" gauze dressing
- 1 dozen 2 cc Syringes
- 60 ml BD syringes
- 1 box diapers XX Large

†will pay for shipping

**MORE SUPPLIES are available!** For a complete listing, visit our website at [www.oley.org](http://www.oley.org) or contact Cathy at [HarrinC@mail.amc.edu](mailto:HarrinC@mail.amc.edu), (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask those receiving goods offer to pay for shipping — especially for heavier items such as formula or infusion pumps. ☺

## Reaching Out With Stories

Last spring we put out a call for your stories, to help us reach out to others through the media in an article entitled, "Hey, that's Me on TV!" We'd like to thank the people who have stepped forward. We have launched some stories, and they have been powerful and exciting!

In July, the Courier-Post newspaper, a regional paper in Philadelphia and southern New Jersey, published an article about Alicia Hoelle, an Oley Regional Coordinator Volunteer who has just graduated high school. Like many of "our" kids, Alicia was not given much opportunity of living beyond the age of one year, but is now attending college to become a child life counselor, and work with chronically ill children to ensure they have all the opportunities they should.

In September, the Noble's, Welday's, Christenson's and Goldsmith's, all families in the Columbus, Ohio, started a media campaign for outreach and to advertise their fall fundraiser. At the time this article was written, they had three articles covering an entire newspaper published in 17 regional newspapers, they've had a television spot on a CBS affiliate and live promotion for their fundraiser, and a 20-minute radio interview! WOW! All that came from a press release written by Ellie Wilson at Oley, and Donna Noble.

Next up: Lillian Horn in South Dakota, and Ben Hawkins and Ronna Staley in Cincinnati, Ohio. Each story is different, and has the opportunity of bringing our community to another person or family using nutrition support therapies. Please consider joining this effort. Call Ellie Wilson at the Oley Foundation, or sign on at <http://www.oley.org/stories.html> and share some details of your story. It's not about your illness or therapy – it's about your resiliency and spirit!

Thanks to all who are in the line up now. We look forward to hearing from YOU next! ☺

## Thanks for Your Support!

### Coram Healthcare — Golden Donor

The Oley Foundation is thankful to Coram Healthcare for its on-going support of member programs and is proud to recognize Coram's donation at the Golden Donor level. Coram's more than 2000 employees nationwide, including dietitians, nurses and pharmacists, are among the most experienced at providing parenteral and enteral nutrition support services to consumers. Through its 72 ACHC accredited branch pharmacies, Coram has nearly 25 years experience in providing nutrition support and recognizes the importance of meeting the unique needs of the nutrition consumer. In the Spring and Fall, Coram sponsors two key consumer initiatives, a parenteral and enteral consumer newsletter and they also host two consumer focused interactive audio teleconference for the Coram family of nutrition consumers twice yearly. Coram is planning some new, informative consumer focused programs for 2004. Thank you again for your continued support of The Oley Foundation.



### Welcome Novartis Nutrition — New Silver Circle Member

A warm welcome to Novartis Nutrition our newest donor at the Silver Circle Level! Headquartered in Minneapolis, Minnesota, Novartis is the second largest manufacturer of enteral formulas and delivery systems in the United States and an industry leader in oral supplements, dysphagia products, and fortified foods used in institutional and home settings. Novartis Nutrition is focused on providing the highest quality nutritional products and services that maintain and improve human health and well-being. One area of special interest is Pediatrics. One-of-a-kind children deserve special treatment. That's why the company created the Novartis family of pediatric products. Designed to help satisfy the highly particular nutritional demands of children ages 1 to 10, each helps promote healthy growth and development in an often-neglected population. We thank Novartis for their generous support.

## Your Support Makes Oley Stronger!

The following generous individuals have donated a gift to the Oley Foundation between July 29 and September 17, 2003. Thank you for your support! We also wish 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. A complete listing of everyone who donated this year will be published in the January/February 2004 issue.

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*...and growing every day!!*

## Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<b>NOV. '03</b>	<p><b>Nader El Samaloty</b> Cocoa Beach, FL (888) 610-3008 EST</p> <p><b>Patty &amp; Darrell Woods</b> Hemet, CA (888) 650-3290 PST</p>	<p>Nader has an amazing positive attitude. He has been on TPN for 11 years after emergency surgery left him with SBS. He enjoys cooking for friends, and networking with other homePEN consumers. He can share his experience with traveling, and attending Oley conferences and support group meetings.</p> <p>Patty &amp; Darrell live in So. California and have five children, one of whom (Colyn) has been TPN dependent since 1996 due to pseudo obstruction. 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.</p>
	<p><b>Betty &amp; Bettemarie Bond</b> Levittown, PA (888) 610-3008 EST</p> <p><b>Linda Stokes</b> Dover, FL (888) 650-3290 EST</p>	<p>Bettemarie has been on and off TPN for 10 years due to Billiary Eyskinsia with smooth muscle disorder. She currently has a Hickman catheter. She and her mom Betty have experience dealing with insurance issues as well as transitioning from school to college. Bettemarie is employed as an occupational therapist.</p> <p>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 is an active member of an Oley support group, and looks forward to connecting with other homePEN consumers and sharing their experiences.</p>
<b>JAN. '04</b>	<p><b>Eleana Shore</b> West Hills, CA (888) 610-3008 PST</p> <p><b>Eleanor Orkis</b> Schenectady, NY (888) 650-3290 EST</p>	<p>Eleana's daughter Erin (age 7-1/2) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, Arthritis and Hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</p> <p>Eleanor has an ostomy and has been on TPN since 1983 due to radiation enteritis. A retired school nurse teacher, she plays golf, enjoys travel and runs an Oley support group. Eleanor mixes the additives into her TPN so she can travel easier. She has attended several Oley Conferences.</p>

### LifelineLetter

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