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# LifelineLetter

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

## Nutrition Week: Once in a Lifetime Experience

The Oley Foundation had a strong showing at Nutrition Week held February 8 to 12, 2004, at Caesars Palace in Las Vegas, Nevada. In addition to a well attended booth, Oley hosted a panel discussion for consumers and caregivers to share with clinicians what their life is really like with home tube and IV feedings. Many thanks to our volunteers on the panel and in the exhibit hall: Mariah Abercrombie, Felice Austin, Deon Balli, Rick & Dianne Davis, Linda & Megan Gravenstein, Charlene and John Henry Key, Robbyn Kindle, Judy Peterson and Erik Schten.

Held at the front end of Nutrition Week, one of the more fascinating and impressive educational experiences was the Intestinal Failure workshop. It was packed with outstanding presenters and a lively participating audience from 15 countries and 35 states. The workshop covered a wealth of information and will help shape future research and clinical management of intestinal failure patients. Below we've covered highlights of the meeting that should be of interest to consumers. To read the full proceedings of



Megan Gravenstein (left), Joan Bishop, and Rick Davis working the Oley booth at Nutrition Week.

the workshop, look for a supplement in an upcoming issue of *Gastroenterology*. Kudos to the meeting's organizers Alan Langnas, MD, and Kelly Tappenden, PhD, RD, and many thanks to all who participated.

### Big Picture is Hopeful

The prognosis for patients with intestinal failure is hopeful. Adults with 100 cm of remaining bowel and

**Nutrition Week** cont., pg. 2

## Register Now!

Now is the time to register for Oley's 19th Annual Consumer/Clinician Conference to be held June 29 to July 2, 2004, at the Marines' Memorial Club and Hotel in San Francisco, California.

Highlights of this year's gathering include plenary sessions tailored for HEN and HPN consumers, more opportunities for casual social interaction, and a revamped schedule to accommodate those who need a later start to their day.

Those who are able are encouraged to join us for one or both pre-conference day hikes, to be held Monday and Tuesday, June 28 & 29. It's a great way to bond with consumers and clinicians while enjoying the beauty of northern California.

A limited number of travel scholarships are available for first time conference attendees and Regional Coordinators. Details on the scholarships and conference are in the registration packet mailed two weeks prior to this newsletter. Information is also posted at [www.oley.org](http://www.oley.org). Bring the whole family for a fun learning experience you'll remember for years to come!



## Labeling of Aluminum Content in HPN

The following article is based on information presented by Philip Schneider, MS, FASHP, John Welsey, MD, Jay Mirtallo, MS, RPh, BCNSP, FASHP, and Marc Stranz, PharmD, at a Nutrition Week workshop sponsored jointly by Baxter Healthcare, a manufacturer of IV multivitamins, and Coram Healthcare, a home infusion company.

There has been a long standing concern regarding aluminum contamination in parenteral nutrition formulas, particularly when protein hydrolysates, which are heavily contaminated with aluminum, were used in HPN solutions. Since the industry moved to using synthetic amino acid solutions in the 1970's, the level of aluminum in HPN solutions and related complications have been substantially reduced, though there has still been pressure on the FDA to further reduce the aluminum content.

Phosphates, acetates and calcium gluconate are the primary sources of aluminum in HPN.

**Aluminum** cont., pg. 8

### Nutrition Week, from pg. 1

a working colon or ileocecal valve should be off TPN within 2 years. Similarly, pediatric patients with 40 cm or more small bowel with an ileocecal valve and working colon are likely to come off TPN; although according to Olivier Goulet, MD, the dependency is often longer (about 48 months) because of children's high growth demands.

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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.

As Lyn Howard, MD, described, the quality of life for those left dependent on homePEN is challenging, but remains good. Depending on their diagnosis 60 to 70 percent of patients reach nearly full rehabilitation and many are able to resume normal, age-appropriate activities such as attending school, raising families, working and/or participating in their community. Research by Carol Smith, PhD, has shown that involvement with a national support organization improves patients' quality of life; decreasing episodes of sepsis and depression. More work is needed to help patients and caregivers cope with the emotional and financial stress of long term homePEN therapy.

Even the patients who develop liver failure have a better prognosis, as the outcome of patients with small bowel transplants continues to improve. Three year survival for patients with isolated small bowel transplant is now at 90%. Some of the steps that have improved outcomes include better antirejection medications (FK506, ALP, Rapamycin), more accurate diagnosis of infected versus rejected transplanted organs, and better techniques for sizing donor organs to fit recipients (most of whom are small children).

We've learned it's important to refer patients early to a transplant center, before the liver disease has progressed. Far too many patients are dying while waiting for an organ to be donated. Also, as one would expect, survival rates and other measures of outcome are better for patients who were at home and in better health before the transplant.

### Progress Made

After leading the audience through an impressively thorough review of the literature, David Alpers, MD, showed that glutamine does not offer any measurable benefit to HPN patients and therefore should not be considered part of their standard protocol. Similarly, Jim Scolapio, MD, argued that published research does not substantiate the use of growth hormone or a combination of growth hormone, glutamine and diet to reduce long term dependency on HPN in short bowel patients.

Other studies are showing more promising progress towards the goal of reducing HPN dependency. The first is research on rats by Brad Warner, MD, which is helping to pinpoint factors that affect gut adaptation, including the timing and types of growth factors introduced after a bowel resection.

The second set of clinical trials, presented by Palle Jepperson, MD, PhD, showed the success of GLP-2 and another GLP-2 analogue in reducing patients' dependency on HPN. As published in an article in a previous issue of the *LifelineLetter*, GLP-2 helps improve patients' ability to absorb fluid and a modest amount of calories, making it possible for patients who are borderline dependent on HPN and/or hydration to get off therapy, and others to reduce the amount of HPN/hydration needed. An opportunity to participate in GLP-2 clinical trials will soon be available for HPN patients in the US, watch for more details in the "Ongoing Research" section of the newsletter later this year.

Drawing upon years of patient and clinician experience, some patients have been able to reduce their dependency on HPN simply by absorbing more calories taken orally. Some nutrition support programs have also had success in reducing patients' diarrhea and lowering their need for IV hydration using oral rehydration solutions (ORS) and/or a combination of other fluids and salt tablets that mimic an ORS. This topic will be covered more fully in a later issue of the *LifelineLetter* in an article by the presenter, Khursheed Jeejeebhoy, MD.

### Other Gains

Venous access is another area that has seen significant improvement. Over time, access has become less of an issue as interventional radiology techniques to reuse thrombosed, or otherwise compromised veins, are tried and improved. Radiologists and surgeons are also gaining more experience with new areas of access, such as using translumbar veins, when the more common routes of access are no longer available. Newer, more effective products to restore catheter patency are available too, including t-PA for thrombolytic occlusions, and the endoluminal brush, for thrombolytic and other types of occlusions.

Finally, there was a wonderful presentation on advances in the treatment of patients with motility disorders. We are hoping to have an in-depth article on this topic later this year by the presenter, Carol Di Lorenzo, MD.

### Challenges Ahead

Looking to the future, some of the challenges include the familiar complications of HPN: sepsis, and liver and bone disease.

**Nutrition Week** cont., pg. 6

## 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 DabLR@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.*



### Strap Holds G-Tubes

Dear Readers,

I am a recovering cancer patient. About 3 years ago my doctor inserted a feeding tube into my stomach. The radiation and chemotherapy I was undergoing made my mouth extremely sore and I was unable to eat.

After the feeding tube was inserted, I did not like it just hanging down. The doctor said to tape it to the abdominal area. I tried that for a couple of weeks, however, my skin started to break out from the tape.

I had an idea to make a strap and use Velcro to hold the actual tube. It worked out very well. While undergoing radiation, I met other patients with similar problems and began giving straps away. During the past 2 years we have given away approximately 100 of the straps and now are selling them at just over cost.

The feeding tube straps are sold in a package of two (2). This allows the patient to wear one strap while the other is being washed. The straps are machine washable, and hang dry. The price is 2 for \$20.00 + \$3.75 shipping. They are available on eBay (go to "Health & Beauty Aids" and enter "Feeding Tube" in the Search area) or directly from me. I accept checks, money orders or Pay-Pal.

— Bob Emms  
bobemms@comcast.net  
503-245-3908



*Above:  
Strap in use.*



*Right:  
Strap as ordered.*

## Join M<sup>3</sup> at Fall Fundraiser

The Mighty Medical Miracles (M<sup>3</sup>) Oley support group in central Ohio is gearing up for its third annual Oley Foundation fundraiser to be held September 12, 2004, at the Tall Timbers banquet facility in Reynoldsburg. The event will feature an extensive dinner buffet, a silent auction, and a variety of entertainment for people of ages, including DJ music, bingo, puppeteer and magician performances, and outdoor inflatable activities. For information about volunteering or attending this event, contact Richard and Donna Noble (614) 871-8464 / donnanoble2001@yahoo.com or the Oley office (800 776-OLEY / wilsone@mail.amc.edu. Thank you for all your hard work M<sup>3</sup>!



## Where Wishes Come True

Do you know what the face of magic looks like? It is the smile on the face of a child who learns that his or her dearest, most heartfelt wish is about to come true. If you know a child with a life-threatening medical condition, consider referring them to the Make-A-Wish Foundation.

Children between the ages of 2-1/2 and 18, who are living with life-threatening medical conditions, are potentially eligible for a wish. Several Oley members have had their wishes granted, for things like family vacations and play ground equipment.

Making a referral is simple. Visit [www.wish.org](http://www.wish.org) and click on "wish referral." You can also call (800) 722-9474. For special children, like ours on homePEN, there is nothing like the power of a wish. Make a difference in a child's life by helping to make their wish come true! ☺



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## Spotlight: My Friend, Linda Gold

By Robin Lang

Sometimes being a long term user of TPN is tiring. Sometimes I get the blues, but then I think of my friend, Linda Gold, and I have to smile. She's an inspiration to me and to many others.

Linda has hollow visceral myopathy, a motility disorder that has left her dependent on homePEN, sometimes TPN, sometimes tube feeding, for many years. She's endured major challenges in her life, yet smiles and charges forward anyway. No one advocates for herself the way she does. She has a way of ferreting out the information she seeks. She doesn't take, "NO" for an answer. Instead, she challenges the world to come up with something better.

### Getting Through Difficult Times

In 1989 Linda went to University of Southern California for major surgery, with her husband, Alex, by her side. While there, Alex suffered a fatal heart attack, leaving Linda widowed at 40 with two adopted children: Dan, age 10, and Emily, age 3. Alex's death was a terrible blow, but Linda didn't falter. She's been a wonderful single mother ever since.

Five years later, in 1994, Linda's father died. After helping with the funeral, Linda invited her elderly mother to come live with her. Sarah Gold is very proud of her daughter, remarking, "Linda takes care of all of us. She is a very loving person and deeply cares for people."

Linda's son Dan (now 25) thinks the world of her as well, saying, "My mom can find her way from the bottom to the top; even if it takes longer than what she wants, she continues to find a way to get there." Emily adds, "Even given the circumstances of adopting two kids and struggling with health problems, she still puts others ahead of herself. She's an amazing person. She is the number one person in my life." To

help explain, Emily continued, "Helping others is medicine to my mom; it's the thing she likes to do the most." Linda is a survivor to be sure.

### Reaching Out

I met Linda in 1997 via the Oley toll-free line. We talked as though we'd been friends forever. At the time Linda hadn't attended an Oley conference yet; she wondered if we might travel together. During a plenary session Linda described her experience with enteral nutrition. She'd only been using it for a few months, yet she spoke like a 'seasoned' consumer. Linda has made numerous friends through Oley since then, and has supported even more TPN and EN consumers as an Oley Regional Coordinator.



Linda Gold with Kathleen McInnes at the 2000 Oley Conference.

Linda and I are now TPN buddies. After having problems with her J-tube, she stopped enteral feeds and is doing well on TPN. She also has a G-tube for drainage, which allows her to eat small amounts for pleasure.

Linda worked as a public health nurse for the Hingham health department (just south of Boston, MA) for 20 years before she retired in July, 2003. She's taught nursing classes and

continues to stay abreast of news regarding all aspects of health care.

She loves to travel, most recently returning from a trip with her mom to visit her aunt in California. She's described as a 'people person,' but Linda's an animal lover too. She has a big, cuddly black lab, Hercules, and a beautiful Carolina dog, Zena. She walks them faithfully and plays with them in the park across from her home.

Along with the trials handed to us in life, we also receive nice gifts; having Linda Gold for a friend is one of them. ©

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## Scholarships Offered to HPN Consumers



Nutrishare, Inc is sponsoring three \$500 scholarships for TPN consumers towards the Fall 2004 semester. Interested TPN consumers should write a few paragraphs describing their studies and what they plan to use their education for. Applications should be submitted to the Oley Scholarship Committee who will choose the winners based on potential and need.

Applications should be typed or word-processed and must include the candidate's name, number of years on TPN, address, daytime phone number, and photo. (Email a tif or jpeg file, or send a real "print" on Kodak paper; we can't reproduce photocopies or computer printouts in the newsletter).

The application materials should be mailed to Joan Bishop at the Oley Foundation: bishopj@mail.amc.edu or 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208 and **post-marked by August 30, 2004**. The scholarship money will be distributed at the end of the fall semester when the winner submits a copy of his/her grades to the Oley Foundation. ©

## In Memory of...

### Becky Streetman

#### Contributions from Anne Lanier and Malisa Matheny

Becky Streetman, age 29, passed away February 7, 2004, due to complications from her disease. She had written for the *LifelineLetter*, and corresponded with many Oley members for several years. We were all glad to finally meet and spend time with her at the last Oley conference, in St. Augustine, Florida.

Becky was a sweet, kindhearted person who dealt with much adversity in her life. She struggled with her illnesses and had been on TPN for about 10 years. Although it obviously was difficult, especially for a 29 year old whose social life was restricted, she tried to keep a positive outlook. She sincerely cared for those she met and volunteered her time to help others. She gave numerous talks to students at the high school where her mother teaches, and she "counseled" several people in Vero Beach who were placed on TPN. She made scrapbook pages for many of the families of children on TPN. For the holidays, she sent out boxes of grapefruit for many of these families as presents. She even donated her hair to Locks of Love when she was in college.



Becky Streetman

Becky worked as an account executive for her father's citrus company. Because she had been doing so well, she was contemplating going back to school for her Masters in Social Work. She graduated high school Salutatorian of her class of over 600, and she graduated from Florida Atlantic University Summa Cum Laude. She had scheduled to be trained as a Wish Grantor with the Make-A-Wish Foundation.

Becky was an avid scrapbooker, and she and two of her friends had obtained their license for The Scrappy Cat, a personal scrapbook design service. She was an advisory board member to the Humane Society of Vero Beach. She loved all animals, but cats were special to her. She had three Maine Coons (Alice, Carly, and Simon).

As one of Becky's HPN pen pals shared, "I don't think Becky ever realized the impact she had on others and how much all of us cared about her. She was a good person who had a strong spirit to overcome what life had dealt her." Besides her mother, father and two sisters, Becky's memory will live on in the hearts of her TPN family.

### Suzanne Keating

#### Shirley Heller

I am sorry to report the passing of one of Oley's members, Suzanne Keating, age 81. Suzanne and I met about 9 years ago at a meeting of the West Los Angeles Scleroderma (SD) Support Group. This was a start-up group that was formed from just a small blurb in the Los Angeles Times. We were all floored when 50 people with Scleroderma had come 'out of the closet' to meet one another. Suzanne and I were some of the initial founders, which has since merged with other auxiliary groups serving about 900 people in the LA area.

Since we had fairly small group in the beginning we would discuss complications from SD at our monthly meetings. At one meeting we were discussing GI complications and as always, we were amazed to

find others with GI track involvement. I was having malabsorption problems, stomach distension, and losing too much weight. Initially my doctors recommend that I drink the pre-digested drinks instead of eating food. Suzanne was already on TPN. She is the one who recommended the TPN, not my doctors.

I would have never heard of or considered TPN or tube feeding if it were not for Suzanne. There are a lot of players involved and one has to be prepared to change their lifestyle, be brave, and move-on to survive. TPN/EN, is almost a love/hate situation. Suzanne instructed me about her TPN routine, home health situation and best of all the Oley Foundation. I was lucky to learn from her. She was my mentor and I will miss her very much. ©

## Auction Items Needed

Oley needs your help to make this year's silent auction a success. Whether or not you plan to attend the event, we encourage you to think about what Oley means to you and your family, and how you can help out.

Anyone who quilts, knits, makes jewelry — or any craft — is encouraged to donate items to Oley. You can also be creative in other ways; do you shop somewhere regularly or have connections at a business that might donate a big ticket item like electronic equipment, airfare, an overnight stay at a hotel? Could you spare a few days or a week at your vacation home, time share or condo?

The more funds we can raise, the better we can support Oley's outreach and educational programs, like the *LifelineLetter*, the annual conference, and the toll free hotlines. Every dollar helps!

Raffle and auction items can be sent along with a note detailing who to thank and approximate value, to the Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208. Any questions? Contact Joan Bishop at [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu) or (800) 776-OLEY / (518) 262-5079. We appreciate your support of Oley programs! ©



## 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.



### Nutrition Week, from pg. 2

Though rarely fatal, sepsis is a common, serious complication that erodes patient quality of life, is expensive to the health care system and can lead to lack of venous access. Liver disease remains the most difficult to overcome, especially in infant HPN patients. Bone disease remains a challenge for long term patients, with multiple factors in addition to HPN contributing to the issue, such as malnutrition before HPN, malabsorption syndromes and the use of steroids and other therapies to control the underlying disease.

Another major concern is poor reimbursement for physicians specializing in nutrition support. Few physicians are going into the field, making it more difficult for HPN patients to have access to experienced, qualified clinicians.

#### Hopes for the Future

Beyond the obvious, but elusive goal of "curing" intestinal failure, there were some practical themes that recurred throughout the two days of discussion. Everyone agreed it would be extremely helpful to reinstate a registry of HPEN patients to track outcomes and fuel future research. Ideally it would be an expanded version of the North American HomePEN Patient Registry the Oley Foundation used to run before a funding crisis in 1994. Such a registry would help track HPEN outcomes, fuel research, and make it easier to make a more meaningful comparison between HPEN and small bowel transplantation.

The other much discussed goal is to create a new model of care for intestinal failure patients in the United States. The idea would be to have integrated intestinal failure centers where specialists in nutrition support and small bowel transplantations work together, as they do in countries like France. Ideally, every long term HPEN patient would receive training and care from such a clinic periodically, if not all the time. Research shows that patients under the care of more experienced clinicians have better outcomes, and by working together, it would be easier to identify and successfully treat patients who need small bowel transplants. Geography and insurance issues are obvious obstacles, but are not insurmountable when you consider the trends of growing managed care systems and fewer intestinal failure specialists. ☺



*Regional Coordinators Robbyn Kindle and Charlene Key promote Oley's programs to Nutrition Week attendees.*



*Paul and Jean Bamber (parents) share ideas with Megan Gravenstein (HPEN consumer) during a free moment at Nutrition Week.*

## Equipment Exchange

The following supplies are offered free of charge to readers:

#### Enteral Formula

- 1 case Fibersource HN, exp. 2/05
- 4 cases Two cal, exp. 6/04
- 3 cases Two cal HN, exp. 10/04
- 2 cases Choice, exp. 10/04
- 5.2 cases Osmolite 1.2, exp. 9/04
- 10+ cases Osmolite 1 cal (formally HN), exp. 1/05
- 6 cases Fibersource HN, exp. 11/04
- 6 cases Resource Diabetic, exp. 6/04
- 3 cases RCF formula, exp. 3/05
- 3 cases Glucerna w/ fiber, exp. 3/05
- 25 cases Promote, exp. 6/04-11/04
- 11 cases Ultracal, exp. 10/04
- 2 cases Jevity 1.5, exp. 5/04; 8/04
- 1 case Jevity 1.2, exp. 2/05

#### Tubes/Administration Sets

- Kangaroo 1000 ml pump sets
- 20 Kangaroo 1000 ml bags
- Ross EZ feed 1000 ml bags
- Ross Companion Bags
- 1 case Ross Gravity Bags, 1000 ml
- 21 Baxter ext. sets 16", 0.22 micron filter, # 2C5671
- 2 Baxter ext. sets 21", 1.2 micron filter, # 2C1103
- 1 Baxter ext. sets 8", 0.22 micron filter, # 1C8363
- 6 Baxter Continu-Flo Solution sets, # 2C7595
- 8 Sabratec 6060 sets, .22 micron filter, # 567122-L
- 12 Sabraset Sets with spike/cassette, # 560100

#### Miscellaneous

- 2 TPN Backpacks
- 1 box Bio Dressing (Johnson & Johnson)
- 20+ 4" x 4" Sterile drainage sponges
- 50 Kendall Rayon Tip Applicators
- 12 cases Large pull-up diapers
- 4-2 oz Bolus catheter tip feeding syringes
- 100+ 12 cc syringes
- 2-60 ml syringes
- 6 Clave needle free injection site (luer lock)
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- 1 Gripper Port-a-cath needle 0.7 mm (22G) x 25 mm (1 in)

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## Bright Ideas:

### ORS and Pedialyte Pops for Excessive Thirst at Night



I was on TPN for about 1 year due to short bowel syndrome as a result of radiation enteritis and two operations for obstructions. I've been on hydration since April of 2003. My problem is maintaining my weight. I weigh 120 lbs now, but if I lose 5 lbs. more I'll have to go on TPN again. I find it difficult to deal with thirst — especially in the evenings — and have to drain my colostomy often. Of course I know by drinking I am not helping my body to absorb food. It's a vicious cycle.

I've been to the Leid Transplant Center in Omaha, Nebraska, and was given an oral hydration solution (ORS) which helps me absorb more nutrition from the food I eat. I mix the ORS with diet soda, and it tastes fine. So far, the ORS and the liquid vitamins I take are keeping me off TPN. I also enjoy having frozen Pedialyte pops. (Editor's Note: Pedialyte is a rehydration solution made for children and is available in liquid and 'freeze pop' form in most drug stores. For more information about purchasing oral rehydration solutions, call Oley at 800/776-OLEY.)

I'm interested in meeting others who struggle with excessive thirst at night, and can be reached via the email address printed below.

— Jeanne Taylor  
jeannetaylor686@hotmail.com

Send your tips for 'Bright Ideas' to the *LifelineLetter* Editor: DahlR@mail.amc.edu or Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208. Ideas will be published in the newsletter and posted on Oley's website ([www.oley.org](http://www.oley.org)) as space permits. Photos or illustrations are welcome. Be sure to include your name, city and state, daytime phone number and what therapy you are on. ☺

## Life on TPN

Irene Scott

I have this machine, it feeds me,  
can't say much for its' menu, though.  
It'll never serve steak and potatoes,  
so I sit there and go with the flow.

Sometimes I even hate the thing,  
and then sometimes I don't.  
I'd like to chuck the blasted thing,  
deep down I know I won't.

Cause it's given me my life again,  
and although it's not pretzels and beer,  
It really is a friend to me,  
without it I wouldn't be here.

*This poem was first published about 20 years ago in a newsletter by Regional Coordinator, Ben Hawkins, of Cincinnati, OH. Thanks for sharing it Ben!*



## I couldn't have made it without Fred.

There is a very poignant story about one of our consumer's graduation from college, having received TPN since 1991. She named her TPN pump "Fred". It became her constant companion throughout her trials and tribulations for the next 12 years.

We who provide home enteral nutrition and home TPN support can learn a lot from her story.

Coram's Advanced Nutrition Management believes in our face-to-face-with-life approach, providing the most appropriate and effective nutrition support and therapy, improving our patients' quality of life. Contact us at 972.394.9974 and visit us on the Web at [www.coramhc.com](http://www.coramhc.com).

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**Aluminum, from pg. 1**

In 2000 the FDA proposed limiting the amount of aluminum in parenteral nutrition to 25 mcg/L, and requiring manufacturers to print the level of aluminum on the label of large and small volume parenterals (LVP and SVP), and pharmacy bulk packages (PBP) of products used to make HPN. The FDA delayed the effective date of the aluminum labeling requirements in 2001, and in 2002 ruled that SVPs and PBPs containing 25 mcg/L or less of aluminum did not have to declare the specific amount on the label; instead, wording such as "Contains no more than 25 mcg/L" would suffice. The labeling requirements are to take effect by July 2004. HPN consumers may not actually see the new labeling (depending on your home care company's policy), but your pharmacist will.

**Effect of Long Term Exposure**

Aluminum is taken into the body through the lungs, skin, GI tract and IV solutions. Intravenous administration increases the potential exposure to aluminum because it bypasses the body's normal barrier systems.

The tissues most sensitive to aluminum include the brain, bones, and liver. Long term exposure to toxic levels of aluminum can present clinically as bone pain, metabolic bone disease (fracturing osteomalacia), encephalopathy, impaired neurologic development and microcytic hypochromic anemia. Signs of aluminum exposure in long-term HPN patients include: a decrease in bone formation; increased aluminum levels in plasma, urine and bone; and accumulation of aluminum in the mineralization front of the bone. One major problem is that bone pain, patchy osteomalacia, and neurotoxicity can have a wide range of causes other than aluminum toxicity. The precise "safe"

level of aluminum in HPN is unknown; more research is necessary and is ongoing.

The most reliable way to monitor aluminum exposure is a bone biopsy stained to show bound aluminum. A plasma analysis may also be taken (in a metal-free, royal blue test tube to eliminate any contamination from the tube); however, plasma levels do not reflect tissue levels, and therefore are not very useful.

Aluminum is normally excreted fairly well in the urine. However, patients with impaired

iron, when the patient is anemic. Long term HPN patients may be at greater risk simply because of their greater exposure to aluminum over time, although aluminum related bone disease is relatively uncommon now.

**Aluminum in HPN**

Unfortunately, aluminum is found in many of the products used to make HPN. Phosphates, acetates and calcium gluconate are the primary sources, and typically account for 80-90% of the aluminum contamination in HPN. All are essential ingredients for

HPN. All are packaged in small glass containers, like other SVPs, that allow aluminum to leach from the silicon in the glass into the product. Thus, the longer the product is stored in these glass containers, the greater the aluminum content.

Minor sources of aluminum contamination include many electrolytes and trace elements, and multivitamins. Other non-HPN potential parenteral sources of aluminum include heparin, albumin and other blood products.

Estimates of aluminum content vary widely, but based on data presented at Nutrition Week by Jay Mirtallo, MS, RPh, BCNSP, FASHP, the aluminum content of a sample adult PN solution could range from 8 to 31 ug/kg/day, depending on the ingredients used to make the individual patient's formulation. It is important to note that the techniques used to estimate the aluminum content are just that: estimates, not precisely measured, that change (usually increase, and sometimes substantially) over the shelf life of the product. The FDA is requiring that the aluminum level shown

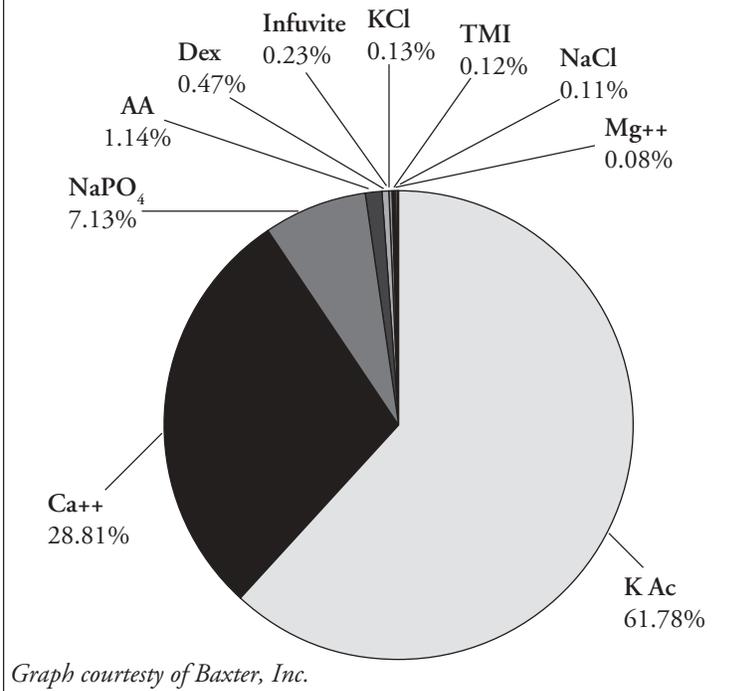
on the label be the maximum amount it could reach by the product's expiration date. Thus the amount actually in the product at the time of consumption could be much less than is shown on the label.

**What is a Safe Level?**

In 1997 Bishop et. al. published a study on "Aluminum neurotoxicity in preterm infants

**Where Does the Aluminum in HPN Come From?**

The amount of aluminum contamination in an HPN solution can vary widely depending on the amount and type of additives it contains, as well as the age of the additives. As seen below in the sample HPN formulation for a 68kg patient, the largest contributors to aluminum contamination are potassium acetate (K Ac), calcium gluconate (Ca<sup>++</sup>), and to a lesser extent, sodium phosphate (NaPO<sub>4</sub>).



renal function (end stage renal disease or neonates with immature renal function), are at greater risk of aluminum toxicity. Patients who are iron deficient, especially preterm infants, also face a greater risk of aluminum toxicity; aluminum shares a similar chemical makeup as iron which allows aluminum to bind to free proteins in the body, instead of

receiving intravenous-feeding solutions” in the New England Journal of Medicine (May 29, 1997;336, 22:1557-61), which showed that premature infants who received standard HPN had lower neurologic development scores than those who received a specially-made aluminum-depleted HPN solution. Based on the Bishop study, the FDA established that up to 4-5 ug/kg/day of aluminum taken parenterally was safe, with no increased amounts found in the patient’s plasma, urine or tissues. Higher levels may be safe for adults, but further research is necessary and is ongoing. The American Society for Clinical Nutrition (ASCN) and American Society for Parenteral and Enteral Nutrition (ASPEN) state that increased amounts of aluminum found in plasma, urine or tissue without overt signs of toxicity, or exposure to 15 to 30 ug/kg/day parenterally, is unsafe; while bone pain and patchy osteomalacia (shown to be due to aluminum) or exposure to 60 ug/kg/day parenterally is toxic.

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The FDA cautions that it is more important to receive the essential nutrients in HPN as prescribed by your physician and compounded by your pharmacist than to omit any ingredient because of possible aluminum toxicity.

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As you can see, the aluminum content of an average HPN solution may be above levels considered “safe” by the FDA, but under the 25 mcg/L recommended limit. The reality of the situation is that, currently, it is not practical to get aluminum (at expiration date) levels below 12-13 ug/kg/day in a normal mix of HPN without removing essential components. The FDA cautions that it is more important to receive the essential nutrients in HPN as prescribed by your physician and compounded by your pharmacist than to omit any ingredient because of possible aluminum toxicity. We still have a lot to learn about the effects of aluminum in HPN solutions. We do know that in patients who have normal kidney functions and who are not iron deficient, aluminum administered intravenously is cleared in the urine within 24 to 48 hours.

#### Conclusion

Sometime soon your HPN or additives’ packaging may contain a new warning regarding the estimated level of aluminum found in that product. The FDA recommends no more than 25 ug/kg/L aluminum in HPN products, and considers 5 ug/kg/day to be a safe level of exposure. Manufacturers continue to work on reducing aluminum content in their products, though it is impractical as yet to get to the desired “safe” levels. Monitoring of long term HPN patients through blood work and bone biopsies may be important, especially in patients with renal insufficiency. Preventing iron deficiency is one of the best defenses against aluminum toxicity, as is maximizing EN intake to minimize dependence on IV products. ©

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### Calea

Calea is a specialized pharmacy that supplies TPN solutions, supplies and the equipment needed for home TPN therapy. For more than 20 years, Calea has partnered with many Canadian hospitals to make home TPN as safe and uncomplicated as possible. The company's goals, simply stated, are to ensure that clients receive solutions and supplies of unsurpassed quality, and service that is responsive, timely and accurate. In addition to Home TPN, Calea offers a broad range of intravenous therapies, nutritional services and medical supplies to meet the needs of clients requiring long term or temporary care. We thank Calea for its contributions to the Foundation.

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## Nutrishare's 12th Anniversary Home TPN Conference Held in Nation's Capital, March 10-14, 2004

We'd like to thank the attendees, faculty and Nutrishare staff for making this year's 12th Anniversary Home TPN Consumer Conference, in Washington DC, an awesome success!

If you measure a conference's success in terms of: education provided, friendships deepened and positive memories made, then this year's meeting scored an A+.

*Tom Diamantidis and Rod Okamoto*

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# Toll Free Numbers Available to US and Canadian Consumers!

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

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

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

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

<b>MAY '04</b>	<p><b>Bryan Tims</b> Richmond, VA (888) 610-3008 EST</p> <p><b>Jane Golden</b> Watertown, CT (888) 650-3290 EST</p>	<p>Bryan has been on TPN since the age of 5 (23 years total) due to a swimming pool accident that left him with SBS. He is on for 9 hours a night, 7 days a week. He has been to college, graduate school, and now is happily married and works for a state lab doing molecular testing to track disease outbreaks.</p> <p>Jane has been on TPN since 1993 due to SBS. She has been an RC for many years, has attended several Oley conferences and is a new Oley board member. She feels strongly that SBS survivors need other survivors to network with. She has worked outside the home until a few years ago and is recently married.</p>
	<p><b>Donna Noble</b> Grove City, OH (888) 610-3008 EST</p> <p><b>Barbara Klingler</b> Malabar, FL (888) 650-3290 EST</p>	<p>Donna's son Kyle (5 y.o.) has been on TPN for 4-1/2 years due to a mitochondrial disorder which causes delayed gastric emptying, chronic diarrhea, and malabsorption. Kyle has a g-tube for drainage, and a j-tube for meds and feeding. Call her about traveling, coordinating care with multiple specialists, and trying new therapies.</p> <p>Barbara has been on TPN since 1986 due to SBS from an infarction. She enjoys traveling and has been on cruise and motorhomed Alaska for 3 weeks with TPN. She has also gone scuba diving and enjoys dog agility with her labrador. Her faith in God has helped her overcome liver failure and kidney stones.</p>
<b>JUNE '04</b>	<p><b>Felice Austin &amp; Mariah Abercrombie</b> Henderson, NV (888) 610-3008 PST</p> <p><b>Ben Hawkins</b> Cincinnati, OH (888) 650-3290 EST</p>	<p>Mariah is a 22 y.o. college student, on TPN 19+ years due to pseudo-obstruction and SBS. She also has a g-tube and ileostomy. She enjoys swimming, jet-skiing, traveling, scrapbooking, shopping, and cooking. Felice is a single mother and former social worker. She's been an active RC since the late 80's. She is happy to share her experience with parenting, patient advocacy, separation, disability, travel etc..</p> <p>Ben Hawkins, 40, has been on TPN since 1980, when he lost over 90% of his small intestine due to a malrotation. He has experience with midline catheters, port-a-caths and Hickman catheters, and has used a variety of different pumps. He also went through the process of going onto Social Security Disability in 1999.</p>
<b>JULY '04</b>		

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