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

Tube Feeding Associated Diarrhea

Hamish D Duncan, MD, MRCP, Gastroenterologist, Queen Alexandra Hospital, Portsmouth, UK; and David B. A. Silk, MD, FRCS, Gastroenterologist, Central Middlesex Hospital, London, UK

We are grateful to the authors, and Greenwich Medical Media Limited, for allowing us to reprint this condensed version of a chapter that appears in Intestinal Failure ©2001, edited by Jeremy Nightingale, MD.

Please note much of the data used in the article is based on in-hospital studies completed in Europe, thus some sections may not match the US homeEN consumer's experience.

The most commonly reported complication of enteral tube feeding (EN) is diarrhea, which occurs in up to 30% of patients on general medical and surgical wards and up to 68% of patients on intensive care units. Diarrhea is distressing for patients and their relatives, time consuming for nursing staff and can add to potential problems such as infected pressure sores and altered fluid and electrolyte balance. Diarrhea, defined as an increase in bowel frequency and/or fluid content of the stool, can result in nutrient and electrolyte loss in patients being tube fed. The complication of diarrhea may also delay patient discharge and increase hospital



costs. If diarrhea is severe, it may be necessary to stop enteral feeding and institute parenteral nutrition (PN) with its associated risks and costs.

There is considerable variability in the reported incidence of tube feeding related diarrhea (from as low as 2.3% to as much as 68%), which is due in part to differences in the definition of diarrhea used by investigators, and the ability to collect and measure every stool sample, which is often not a feasible proposition. Diarrhea has been defined

empirically as an increase in the frequency and/or volume of stool, or a decrease in the consistency of stool and quantitatively as an increase in stool weight of more than 200 gm per 24 hours, or as an increase in stool water of more than 500 ml per 24 hours, or has simply been a function of the investigator or patients' subjective assessment. These definitions are further confounded because they do not take into account the patient's usual bowel habit and stool consistency.

Diarrhea cont., pg. 2

Golf Tournament Kicks-Off Oley Conference

The 18th Annual Oley Consumer/Clinician Conference will kick off with a Masters Golf Tournament, Wednesday, June 18, at 2:00 p.m. at the World Golf Village Slammer Squire course in St. Augustine, FL. HomePEN consumers golf for free; others pay a \$100 tournament fee. All proceeds from the event support Oley programs. An evening of fun and socializing for all

conference attendees will follow the tournament, before the learning starts in earnest Thursday morning. Aply named, "Keeping on Par," the conference will continue through June 21 at the World Golf Village Renaissance Resort. Consumers and caregivers won't want to miss this unique opportunity to learn the latest advances in home parenteral and enteral nutrition and connect with the extended Oley community.

Conference cont., pg. 7

How It All Began

Lee & Marshall Koonin, Founders of the Lifeline Foundation

You know those thin sponges you can buy that expand when you put them in water? Well, that is what Lee looked like after her first bottle (it was a bottle then) of TPN.

Prior to that happening was a history that probably seems familiar to many of you reading this. Lee had Crohn's disease for more than 20 years. It was active during the earliest stages when all they knew to do was take out the diseased tissue — whatever it was. Some called it ulcerative colitis, but at the time it was not a well known disease, so there was a question of how to treat it. After more than thirty surgeries, Lee had become so malnourished that she weighed 66 pounds and was dying of starvation. Our physician at the time suggested that I buy a plot. My response was to find a new doctor: one who knew enough about medicine to not give up.

A phone call to the physician who had operated on

Koonins cont., pg. 6

Diarrhea, from pg. 1

Diarrhea usually occurs when the capacity of the colon to absorb fluid is exceeded or altered for whatever reason.

Diarrhea may result from a variety of causes including bacterial or viral infection, use of hyper-osmolar formula, lactose intolerance, antibiotic treatment, magnesium containing antacids, drug side-effects (e.g. digoxin and

propranolol) and so called inert fillers of drugs which can include magnesium stearate, docusate sodium and sorbitol. In patients with a short bowel and no colon, additional factors contribute to the development of diarrhea, including loss of the daily intestinal secretions produced in response to food, and rapid gastric emptying and small bowel transit. A lack of peptide YY, which is known to delay gastric emptying and small intestinal motility, and is found in the highest concentration in the colon, may be responsible for this.

jejunostomy do not need to reduce their fat intake, but if the colon remains in continuity with the shortened small bowel, then steatorrhea may develop. Using a formula with a lower fat content (and thus lower energy density) may alleviate diarrhea due to fat malabsorption in patients with a short bowel and retained colon.

Hypoalbuminaemia: The role that hypoalbuminaemia (low albumin level) may play in causing enteral feeding related diarrhea is so far inconclusive. Hypoalbuminaemia is more likely to be a marker of disease severity and degree of undernutrition rather than a direct cause of enteral feeding associated diarrhea, with changes in bowel structure and function due to starvation contributing to the risk of developing tube feeding associated diarrhea.

Drugs and antibiotics, Major Contributors: Diarrhea is a common complication associated with drugs and antibiotics. Many drugs contain so called 'inert carriers' for the active compound, however they are osmotically active and the inert carrier may cause diarrhea. For example, some drugs such as acetaminophen (Tylenol®) contains sorbitol, and others such as antacids contain magnesium or docusate sodium. Sorbitol, magnesium and docusate sodium can all cause diarrhea in their own right. Other drugs may cause diarrhea as a result of recognized side effects, such as H₂ blockers, anti-arrhythmics, anti-hypertensives, and non-steroidal drug, or because they are designed to encourage bowel movements, such as laxatives.

The incidence of diarrhea associated with antibiotics varies (clindamycin, 7 to 26% and ampicillin, 5 to 10%), depending on how diarrhea is defined. Diarrhea can result from primary structural or functional damage to the small or large intestine. However if this was the only reason, then the incidence of diarrhea in EN patients on antibiotics should be similar to that of patients on antibiotics who are eating normally, which is not the case. Thus there appears to be a synergistic effect of tube feeding and antibiotic usage, resulting in the high incidence of diarrhea in tube fed patients.

The reasons why antibiotics may cause diarrhea are not entirely clear, although it is thought that antibiotics alter the normal intestinal flora, allowing bacterial overgrowth of pathogenic (so called "bad") bacteria such as Klebsiella, Proteus and E. coli. Antibiotic

Diarrhea cont., pg. 8

LifelineLetter

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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.

Etiology of EN Related Diarrhea

Several mechanisms have been proposed as contributing towards the development of enteral tube feeding associated diarrhea, which are discussed below.

Temperature of liquid EN diet: There is little conclusive evidence that either refrigeration or warming of the liquid feed have clinically important effects on gastrointestinal complications including diarrhea or abdominal cramps.

Enteral diet osmolality: Likewise, there is little conclusive evidence that diet osmolality (neither diluted formula nor formula infused at a slow rate) plays any significant role in enteral feeding related diarrhea, when the diet is instilled directly into the stomach.

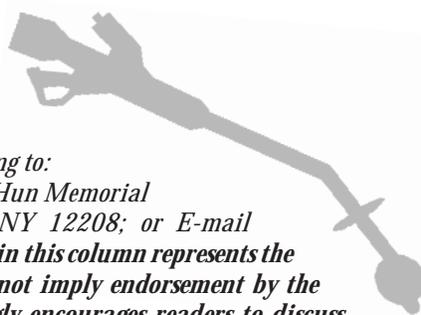
Lactase: Most commercially prepared enteral diets are now clinically lactose free, and thus this potential problem has been removed. However if a patient with diarrhea is taking some oral food, it is important to check that they are not consuming too much milk or milk products. Keep in mind that relative lactase deficiency may develop due to reduced absorptive area (SBS patients) and/or to reduced transit time, resulting in diarrhea when the patient is fed milk or milk-based foods.

Fat malabsorption: Problems with fat absorption can cause diarrhea in tube fed patients. Patients with severe pancreatic disease may have a deficiency of lipase necessary to hydrolyze triglycerides, and gastric surgery may prevent adequate mixing of lipase with luminal contents. Patients with biliary obstruction, ileectomy or ileitis, may have insufficient bile salts for adequate fat absorption, resulting in diarrhea and abdominal discomfort. Medium chain triglycerides can also cause diarrhea, flatulence and abdominal pain in patients intolerant to them. Patients with a

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 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.



Recipe for Surviving a Social Gathering When You Can't Eat

Attitude is everything, so you might as well have a Good One, is my motto. I am unable to eat or drink regular food without becoming ill, so social situations such as parties, weddings, picnics, or just about any place that food is served always presents a challenge for me. I thought I would share some things that have worked for me.

1.) I usually check with the hostess before the occasion to find out what is being served and see if there is anything I can eat or if there is an easy way to modify the menu to my needs. This of course is done as early as possible, without making extra work for the hostess.

2.) I usually bring along my enteral feeds with me, so that I don't feel quite so hungry during the occasion. An alternative is to eat something you are able to tolerate before the event.

3.) This is probably the most important thing to remember. It is a social event *with* food. Food is just one aspect of the event. Enjoy the conversations with other guests, or if the event is a football game for example, enjoy the game, and your surroundings. You must make up your mind beforehand that food is not everything, and don't dwell on the reason why you can't eat during the occasion. If this is impossible, skip this one event until you are ready to take on this challenge.

4.) Remember that there are other aspects to eating food other than swallowing it. Allow yourself to enjoy the aromas, the colors and the textures of the food. Mingle in the buffet line and comment on how good the food looks to you. Don't be shy during eating time but explain matter of factly why you can't eat, and then let it go.

5.) If you decide to eat something, remember there isn't any "food police" around to haunt you. Decide what you can reasonably tolerate and then just do it. Remember what consequences you'll have to pay, such as being detained in the restroom the entire time, then make your decision for yourself and stick to it.

6.) Bring something along that you can tolerate, such as bottled water, Jell-O or hard candy, and enjoy it while the others are eating the planned menu. Remember how well you are going to feel that night or the next day, if you need any reinforcement to stick to your plan.

— Kathleen McInnes
Regional Coordinator
L.McInnes@attbi.com
(773) 763-8791



Equipment Exchange

The following equipment/supplies are offered free of charge to readers:

EN Formula

- 5 cases Jevity, exp. 12/03
- 7 cases Nepro, exp. 9/03
- 5 cases Jevity, exp. 1/04
- 6.5 cases Jevity, exp. 7/03
- 15 cases Jevity Plus
- 4 cases Neutren 1.5
- 1 case Perative, exp. 7/03

EN Bags/Feeding Sets

- 50 Ross EZ feeding bags, 1000 ml (#56)
- Ross EN gravity feeding set, 1000 ml (#56)
- 12 Ross topfill bags w/ gravity feeding sets (#189)
- Ross Patrol bags, 1000 ml (#520488)
- 70 Enterlite bags 1200ml, #EL1200
- 1 box Corflow cuBBY Rt. angle feeding set, # 31-2621
- 20 boxes Kendal Entristar cont. feeding sets w/ 90° adaptor, # 8884 741821, Exp. 5/06

EN Tubes

- (6) Ross 8 Fr. 45" EN tubes w/ stylet, # 473
- 2 boxes Corflo ultra-pedi NG tubes w/ stylet, 6 Fr. 36", # 20-73366
- 3 boxes Compat G-Tubes 24 Fr., # 087424
- 1 box Compat G-Tubes 22 Fr., # 087422
- 1 box Compat G-Tubes 20 Fr., # 087420
- 1 box Compat G-Tubes 18 Fr., # 087418
- 1 box Compat G-Tubes 16 Fr., # 087416
- 1+ box Compat G-Tubes 14 Fr., # 087414
- 1+ box Compat G-Tubes 12 Fr., # 087412
- 1 box Compat NG Tubes 12 Fr., # 083105
- 1 box Corflo ultra lite NG Tubes 6 Fr., # 20-9366
- 1 box Corflo ultra lite 10 Fr. NG Tubes, # 20-9361
- 8 Panda EN tubes, 8 Fr. w/ stylet, # 02-0845
- 7 Mic G-tubes, 22 Fr., 6 exp. 11/03, 1 exp. 10/03, # 0100-22

Miscellaneous

- 1 box Corflow cuBBY Decompression sets
- 60 ml BD syringes #309654
- 1 box 5 ml syringes
- 1 Bard stoma measuring device

For more information, call (800) 776-OLEY or email DahlR@mail.amc.edu. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods please offer to pay for shipping. ☺

Lifeline Mailbox

Information Sought on CLC2000

Dear Lifeline Readers:

I am a scleroderma patient with major GI complications. I depend strictly on TPN, not being able to eat/digest any food or candy, and not getting much drugs, sex, or rock and roll — but still hanging in there. I would love to hear from other “survivors” with the same complications and share our “food” recipes.

Speaking of which, my home health company has just introduced a new part for my pump’s delivery system protocol (a connector) called the CLC2000. This is to replace my Baxter Interlink. The beauty of this device is that there is a spring action which does not require use of a threaded lock cannula or flushing with heparin, and you are able to flush with a needless saline syringe. That’s an elimination of at least four plastic parts, needles, syringes, cannula and heparin. I have a lot of room in my medicine cabinet now, a lot less plastic waste that never gets recycled, and of course the elimination of heparin from my diet.

I would like to know if anyone else out there in “TPN Land” is using the new “space station” CLC2000 and for how long. How happy are you with it, any complications? Also are you an active consumer; Swimmer, skier, showerer? I’d love to hear the pros and cons. Meanwhile, as of this writing (March 10) I am giving it a try and will let you know about my experience.

— Shirley Heller
Los Angeles, CA
Shoyleeh@aol.com or 310/203-0183

Experience with Camera-in-a-Capsule

Dear Lifeline Readers,

I recently read the article in the Jan 2002 edition of your newsletter about the camera-in-a-capsule endoscopy. I want to let you know that I had this exam in July 2002. The capsule became stuck at the site of

a twenty five year old anastomosis. About ten days later the capsule was removed surgically, along with about six inches of small intestine that had a small ulcer which clearly showed on the video.

For several months before the capsule endoscopy exam I had non-specific abdominal pains. After the endoscopy I have had no pains. I have also gained about eight pounds since July 2002, receiving 1,700 calories of TPN over ten hours each night starting in July and reducing to 1,600 calories in about November 2002.

This past week my calories were again reduced to 1,500 because I had gained too much. Since going on TPN three years ago I have gained 27 pounds, I now have only three feet of small bowel left. I had my first resection of my small intestine in 1962 when four feet were removed. That was the start of my battle with Crohn’s disease. Since then I have had seven resections of my small bowel, and removal of my colon five years ago.

— James Vaughan
jvaughan@wi.rr.com

Author’s Response

The published “non-natural passage” rate for capsule endoscopy is 0.075%; however, the risk is certainly higher in patients who have had multiple abdominal surgeries and in those with Crohn’s disease. In fact, some strictures associated with Crohn’s disease do not show up on a small bowel x-ray. Patients must be made aware of that. In this case, it sounds as though the capsule not passing was a good thing, since it lead to the diagnosis of a stricture (I assume not found on other imaging studies) and therefore led to surgery and resolution of his pain.

— Alan L. Buchman, M.D., M.S.P.H.
Northwestern University Medical School
Chicago, IL

Mother Donates Part of Bowel to Son

Dear Lifeline Readers,

My 23-month-old son, Carter, became dependent on TPN at birth. He lost all but 19 cms. of small intestine from an antenatal volvulus, secondary to gastroschisis (a birth defect where the intestines grow on the outside of the baby in utero). He was able to come home at five months on HEN and HPN, but became recurrently septic from line infections. No matter how sterile and careful we were, Carter repeatedly became ill from what doctors call “a leaky gut” or bacterial translocation. In fact, there wasn’t a month prior to transplant, that Carter wasn’t admitted to our local Children’s Hospital.

At 13 months old, Carter was listed for a cadaveric small bowel transplant, but an organ just wouldn’t come. Carter became so sick from sepsis on a couple of occasions that we almost lost him. He also has developed recurrent thrombosis (blood clots) in his veins and has very limited central line access left. His liver and kidneys were also beginning to show signs of damage. I wasn’t willing to sit back and watch him go through any more visits to the PICU. I was scared to death that he might not make it through another serious bout of sepsis. So when I first heard about the living related small bowel transplant program at the University of Illinois in Chicago, in December, I jumped at the opportunity!

On January 24th, 2003, Carter became one of the youngest patients ever to undergo a living related small bowel transplant. I donated 5 feet

*“The best thing is that I know everyone personally at Nutrishare; they are my friends and family.”
Kathryn Bundy - Los Angeles, California*



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of my intestine, or about one third. They used the distal part of intestine near the ileum. I have fully recovered with no problems. Carter has also been discharged from the hospital, and is playing, eating and dancing to his videos like normal. My husband and I truly believe the operation saved his life.

Carter is now completely off of TPN, and his liver functions are completely normal again. He keeps a central line for replacement fluids at night, but his doctors are saying they may be able to remove it in a few more weeks. He also remains on enteral feedings at night until his appetite increases a little more.

I think this transplant will become an increasingly popular alternative to cadaveric transplantation. It was so exciting for us to know that we weren't going to have to wait anymore for an organ to become available, and that Carter was going to have a chance at life!

Carter's doctors agree that this operation is a good alternative to what can be a seemingly endless wait. They also point out that having a living related donor greatly increases the chances that more antigens will match between donor and recipient, making post transplant rejection much less likely. Also, damage to the donor organ is significantly reduced because the organ is only outside of the body for a minimal amount of time, and there is no great distance for the organ to travel. So far, the living related small bowel transplant program here has been very

successful for both adult and children recipients. At least one other major transplant center has plans in the works to start up a similar program.

My advice to other families approaching the prospect of a living related small bowel transplant is to have a lot of faith and patience when approaching your insurance company. Coming all the way from Virginia to Chicago, we had a bit of an insurance battle on our hands. I'd suggest laying everything out on the table as to why the procedure could be lifesaving for your loved one. And get medical and legal professionals to back you up in your fight if necessary. We had surgeons from Virginia, Chicago and even Pennsylvania backing us, which I think really helped our case.

I also recommend having the procedure done before the liver becomes too compromised. In the patients at Chicago that have had the procedure so far, recovery has been much quicker and easier for those who didn't have major liver damage.

I'd love to help anyone by answering their questions.

— Nicole Wells
Norfolk, VA
momof3CWs@aol.com

Note: Because outcome data is better for patients on homePEN therapy, small bowel transplants are recommended only when parenteral and enteral nutrition has failed. ☺



Nicole and Carter Wells, donor and recipient of living small bowel transplant.

Regional Coordinator Updates:

Welcome Aboard:

Bruce & On Braly (parents)

1239 E. 8th St.
Davis, CA 95616
(530) 867-2209

bbraly@compuserve.com

The Braly's have recently joined the Regional Coordinator team, hoping to share experiences and support. Their son Matthew, born in 1988, has short bowel and is on homePN. Feeling they have received much support through Oley over the years, they decided they wanted to give some back!

Drs. Cindy & Eric Schten (parents)

617 Claire Ct.
Novato, CA 94949
(415) 885-9626

eschten@ucsd.edu

Eric and Cindy are parents to Rachel,

born in 1997, and dependent on both homePN and homeEN secondary to a short bowel. They have been amazed at the challenges they've encountered, and feel that as medical professionals they have a unique opportunity to help other homePEN parents and consumers who aren't on the "inside track." They have found the Oley Foundation to be a great resource and would like to share their experiences.

New Contact Information:

Donna Noble's correct zip code is 43123, and she has a new email: donnanoble2001@yahoo.com

Elizabeth Tucker has a new email address: evtucker@charter.net

Barbara Witt has a new area code (772) 344-8908

Hey, That's Me on TV!

Are you willing to help Oley and not too shy about your therapy? Oley is looking for members to volunteer their story for a publicity project. The idea is to broaden the general public's awareness of Oley — making it easier and faster for homePEN consumers and families to connect with Oley.



A member of the Oley team would work with you to get publicity for you or your family member in your local media outlets. The "news" could be a graduation, birthday, award, new job, homePEN anniversary — or just plain surviving/thriving on homePEN. This last story angle can be particularly successful if you are NPO, or take very little by mouth. If you are interested, please contact Joan Bishop at BishopJ@mail.amc.edu or call (800) 776-OLEY.

Nutrition Week — A Great Success!

Ellie Wilson, MS, RD

The conference was a terrific educational and networking time for the Oley Foundation, as well as a great place to kick off our celebration of Oley's 20th Anniversary. We had more consumer involvement in this conference than ever before, with presentations on several different topics offered by consumers or parents, as well as our usual Oley Consumer Forum. The primary meeting coordinators, the American Society for Parenteral and Enteral Nutrition, (ASPEN), went above and beyond the call of duty, assisting us with meeting space for the conference, and the meeting's sponsorship by Nestle, Inc., was very much appreciated. ASPEN's staff worked hard to make sure we had many opportunities to bring the Oley Foundation to the 2,000+ nutrition support clinicians that attended the meeting, and we are very grateful for their efforts.

We owe the success of Nutrition Week and

our regional conference to the clinicians, consumers and parents that volunteered their time and resources as faculty and booth staff. Many thanks go out to Tammy Adams; James Andrews, MD; Jane Balint, MD; Alan Buchman, MD; Steve and Davria Cohen; Debbie Fox, RD; Angela Gilbert; Linda Gravenstein; Lyn Howard, MB, FRCP, FACP; Kishore Iyer, MD; Khursheed Jeejeebhoy, MB, BS, PhD, FRCPC; Carol Ireton-Jones, PhD, RD; Darlene Kelly, MD, PhD; Charlene and John Henry Key; Jarol Knowles, MD; Robbyn Kindle, RD; Sheila Messina, RN, MA; Laura Mucha; Reid Nishikawa, PharmD; Ezra Steiger, MD; Josie Stone, RN; and Patty Woods. Unable to make it at the last minute, Patty sent a terrific presentation, and Joan Bishop picked up the ball and ran with it! It was a fine effort, and



Regional Coordinator Laura Mucha (left), speaker Khursheed Jeejeebhoy, MB, and Oley Outreach Coordinator, Ellie Wilson, MS, RD

will hopefully translate into connecting more consumers to our community.

Next year, Nutrition Week will be held in Las Vegas, Nevada! We are hoping to offer similar programs then, such as a Regional Conference, so watch for more information on that conference in the newsletter or on-line! ☺

Koonins, from pg. 2

Lee — a kind and caring doctor, as well as a world renowned surgeon — suggested that we talk to a friend of his right in Boston. What may have had a positive or a negative effect on Lee's health, was the fact that my work required us to move around quite a bit; we were in the habit of looking for the best doctor in the area. We were now living in Boston, Massachusetts.



Lee & Marshall Koonin, Founders of the Lifeline Foundation

TPN was very far from the "routine" therapy it is today. We were still talking about an experimental therapy that was not even allowed in some hospitals. Fortunately, it was okay at the Lahey Clinic and the Deaconess Hospital, and equally fortunate, it was okay with the doctor who carried Lee on toward good health.

That thin sponge expanded with her very first "gulp." But it was not the weight that changed, it was the eyes: they were alive again. I didn't realize

that the light had almost been extinguished until it came back.

Three days later, Lee said that it was fine to have this, but it is an experiment. She felt like a freak, she was the only one doing this stuff. I was determined that the light would not fade again and set out to find others who were doing this therapy, and to let anyone who would listen know that this "stuff" worked and could save lives.

In those days there was no internet to search for information or communicate with anyone through — we are talking about 1978. The personal computer had not yet been developed. So we contacted an attorney to set up a foundation, the art department of Boston University to design a logo, and physicians in Texas, New York and Seattle, to get the ball rolling. But it was an article about Lee in the local suburban newspaper that was the publicity key. That article led us to Evening Magazine — a precursor to the interview shows of today — who wanted to do a TV story on Lee and the Foundation. It turned out to be the program that received the most responses in the show's history. From that show, came a drug company prepared to sponsor a national media tour to help tell the public about parenteral and enteral nutrition. In four short lines we have described three years of hard work; of writing the LifelineLetter, making and answering phone calls, arranging the first Lifeline picnic, and getting the professionals to understand that our purpose was to help the process and provide the new "lifeline" with someone to talk to who understood their situation.

After six years, almost one hundred thousand dollars out of pocket and Marshall's employer telling him that he could not have this second job, we finally ran out of money, time and ability to expand. We needed help to ensure that the work we had started would continue. The Oley Foundation was just established by Clarence "Oley" Oldenburg, and his physician, Lyn Howard, MD, in Albany, NY, and appeared to be funded and organized in a way that would allow our work to continue on indefinitely into the future. After several conversations, the Lifeline Foundation was merged into the Oley Foundation. We congratulate all the parties in that organization — the families, clinicians, volunteers and dedicated employees — for the effort over the years to maintain the Foundation and grow as they have. ☺

Planning a Trip Abroad?

As when travelling anywhere on homePEN, you will want to know about the health care resources available to you when travelling abroad. In many ways it is even more important to do your research when travelling outside your native country because of the potential for insurance issues, language barriers, and differences in customs/procedures. You will likely want to know the nearest hospital that can handle an HPEN patient, where you can obtain home care supplies, or at least the safest way to have them shipped to/brought with you.

One way to get make your research easier is to correspond with a homePEN patient or family living in the country you are travelling to. Oley is happy to try to connect you to such a patient wherever possible, though admittedly, the vast majority of our

members are from the US. The other possibility is to hook up with another homePEN association like the Oley Foundation. Oley is aware of the associations listed in the sidebar below. If you know of others, please send us all relevant details (name of organization, contact person, address, phone, email, etc.).

We also recommend speaking with fellow homePEN consumers from your own country who have travelled abroad. The sidebar includes a list of consumers from North America who are happy to share their experiences and tips.

Finally, we recommend reviewing the articles Oley has published on travel tips. These are available on our website at <http://www.oley.org/lifeline/travindex.html>, or by calling us at (800) 776-OLEY. ☺



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Foreign Organizations for HPEN Consumers

Canadian Parenteral-Enteral Nutrition Association
<http://www.cpena.ca>

LaVie Par Un Fil (French)
<http://perso.wanadoo.fr/lavieparunfil/>
(English Translation available)

PINNT (British)
<http://www.pinnt.com>

The Swedish Society for HPN, Children & Youth
<http://www.dataphone.se/~hpn/index.htm>

Oley Consumers Who've Travelled Abroad

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Corrections:

• Betsy Rothley, RN, MSN, FNP, BC, author of last issue's article on pain management, is the Director of Pain Services for Coram Healthcare. Thank you again for contributing to the newsletter!

• Kasa's web address is <http://www.fvkasa.org>

• Robin Lang is the author (and subject) of last issues' Spotlight "Life in Maine is 'Just Peachy'." We apologize to Robin for overlooking this omission, and to readers for any confusion this may have created. ☺

Conference, from pg. 1

The program includes renowned HPEN clinicians from the Mayo and Cleveland Clinics, as well as experts from the local area.

Information will be offered in a variety of formats, from an entertaining 'talk show' session, to formal speakers and interactive small group discussions. We're also offering a longer "Ask the Experts" panel, as requested by last year's attendees — so come prepared with your questions!

A limited number of travel grants are available, as well as discount fares from Southwest Airlines (see enclosed brochure for details).

In addition to golf, the area boasts beautiful beaches, the picturesque town of St. Augustine, quaint shops and loads of history. Lots of activities are planned for children too, so bring your whole family for a rewarding and educational vacation you'll remember for years to come.

For more information see the enclosed brochure, call us at 800.776.OLEY or visit our website @ www.oley.org. ☺



Celebrating Life!



Mary Ann

Mary Ann Jerab, who has been on TPN for nearly 15 years, is a perfect example of someone celebrating life. She likes to write poems and articles, loves to read, is a member of three book clubs and plays bridge often. Mary Ann's husband Joe says she loves people and is very compassionate about those who are less fortunate. Congratulations Mary Ann!



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To nominate someone to Coram's Celebration of Life Circle, send the story of a friend or loved one to: Coram's Celebration of Life Circle, 1675 Broadway, Suite 900, Denver, CO 80202 or, email: celebrate@coramhc.com For information, please call: 972.534.8974

Diarrhea, from pg. 2

usage is associated with *Clostridium difficile* and its toxin in some patients with diarrhea. *Clostridium difficile* has been found in 20 to 50% of patients with antibiotic related diarrhea and in 95% of cases of pseudomembranous colitis. The presence of *Clostridium difficile* does not necessarily confirm that this organism is the cause of diarrhea, however, since up to 25% of patients receiving antibiotics have tested positive for *Clostridium difficile* toxin but have no diarrhea, and *Clostridium* is found in about 4% of healthy adults. Thus, *Clostridium difficile* is likely to contribute to some cases of EN feeding related diarrhea, but certainly not all.

Antibiotics could also increase the likelihood of diarrhea developing, by reducing the production of colonic short chain fatty acids (which promote the absorption of water and electrolytes in the colon), and increasing the risk of overgrowth of potentially pathogenic bacteria.

Contaminated formula and feeding equipment: EN formula provides an excellent growth medium for a variety of micro-organisms, and once contaminated they will rapidly multiply. Although formulas are sterile, as soon as the bottles or cans are opened, there is a risk of contamination from handling, the delivery system, prolonged hanging time and spread of bacteria up the administration set. Contaminated feeds may cause diarrhea, sepsis, pneumonia and urinary tract infections.

Bacterial contamination of enteral feed can be a major problem, with up to 36% of enteral diet fed by a continuous drip method being contaminated. A drip chamber may prevent the backwards spread of organisms from the patient to the sterile feed chamber, by interrupting continuity in the column of feed. (*Editors note: In the US we are increasingly using a "closed" system which prevents this type of contamination.*) Because of the high incidence of bacterial contamination in the

There appears to be a synergistic effect of tube feeding and antibiotic usage, resulting in the high incidence of diarrhea in tube fed patients.

enteral bag and feeding system found with continuous tube feeding, feeding bags and administration sets should be changed every 24 hours.

Allowing breaks in continuous feedings may also help by allowing the pH of the stomach to fall between feeds. When the stomach is functioning normally and is acidic, most bacteria are killed. Continuous infusion of enteral feed, however, raises gastric pH, (as does H₂ antagonists or other antisecretory drugs) which allows bacterial overgrowth in the stomach.

Fiber in tube feeds: Many commercially produced liquid EN tube feeds are low in fiber (poorly metabolized carbohydrate). The ingestion of fiber has been found to slow intestinal transit time and therefore may produce a more regular bowel habit; However, the addition of fiber to enteral diets has not been uniformly successful in preventing development of enteral tube feeding related diarrhea. The reason for this apparent lack of an effect by fiber on bowel function may lie in the small particle size of soy polysaccharide in enteral formula, which is necessary to help reduce viscosity of the feed.

Reducing particle size reduces the amount of undigested fiber available to hold water and diminishes its ability to bulk the feces. There is thus currently little evidence to suggest that the addition of fiber to enteral diets can overcome the diarrhea associated with tube feeding.

Bolus versus continuous feeds: The method of 'bolus feeding' is frequently reported to be associated with a high incidence of complications such as nausea, bloating and diarrhea, although there has previously been little scientific substantiation of this statement. (*Editor's note: Drip feedings are needed if gastroparesis is a serious issue.*) It has been suggested that continuous intragastric feeding is generally better tolerated than intermittent feedings although this too has been disputed. We have recently shown that there is little evidence that small volume bolus feeding causes diarrhea more frequently than continuous nasogastric tube feeding. Continuous nasogastric enteral tube feeding may, in fact, cause diarrhea because it fails to provoke a normal postprandial response, suppresses distal colonic segmenting motor activity, and causes an abnormal secretory response in the ascending colon.

Summary

Tube feeding related diarrhea is unlikely to be due to the enteral diet itself, and other reasons must be sought — especially the use of antibiotics and other drugs (such as those with sorbitol, magnesium and docusate sodium). Other tips that may be helpful in controlling enteral related diarrhea, although many of them only under specific circumstances, include switching to a lower-fat formula, changing the bags and administration sets every 24 hours, allowing breaks in continuous feeds, using a drip chamber, minimizing the amount of milk and milk products eaten orally, and using bolus feeds. If diarrhea is a problem despite attention to possible causes as discussed, then loperamide (or codeine phosphate) can be instituted to control symptoms and there are anecdotal reports of live yogurt being helpful. Regular monitoring and early involvement of nutrition teams should result in early recognition and treatment of enteral related diarrhea, and thus prevent it from progressing into further complications. ©

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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. Comments? Call (800) 776-OLEY.

MAY '03	<p>Tara & Kevin Smith Pittsboro, IN (888) 610-3008 EST</p> <p>Robin Lang York, ME (888) 650-3290 EST</p>	<p>Tara & Kevin have 3 daughters; Aleah (8 y.o.) their oldest, was born with only 10 inches of small bowel. Aleah went off TPN 2 years ago, and is doing great on EN and oral feeds. They can share how their marriage has survived, and the difficulties of meeting healthy siblings' needs when raising a chronically-ill child.</p> <p>Robin has been on TPN for 23 years. She lives on 10 acres in Maine with Zoë, her 6 y.o. black lab. She has done extensive traveling and worked prior to her recent SSD status. She loves to make new friends. Robin keeps busy as a writer, RC and church volunteer. Feel free to call her anytime; day or night.</p>
	<p>Pilar Basso New York, NY (888) 610-3008 EST</p> <p>Barb Witt Port St. Lucie, FL (888) 650-3290 EST</p>	<p>Pilar (29 y.o.) was diagnosed with Crohn's Disease at 10 years old. She has had nine surgeries for ileostomies, abscesses, and fistulas. She has been on TPN for the last 4 years but tries to remain active and travel whenever she can. She is a native New Yorker and welcomes questions from anyone anywhere.</p> <p>Diagnosed with a motility disorder, Barb has been on and off TPN since 1983, and on HEN since 1993. She is also visually impaired and has an ileostomy. None of this slows her down; however, she loves to travel and has been to many Oley conferences. She can also share her experience with eating very little or nothing at all.</p>
JULY '03	<p>Angela Gilbert Spring Branch, TX (888) 610-3008 CST</p> <p>Sheila Messina San Jose, CA (888) 650-3290 PST</p>	<p>Angela is the mother of Gary, a 3-year-old on enteral feedings due to a reflux-related feeding disorder. She is knowledgeable about some feeding programs and about the struggle to balance oral feedings with enteral feedings. She can also share her experience with using Farrell (pressure relief) bags for EN feeds.</p> <p>An Oley trustee, Sheila has been on TPN for 20 years due to short bowel syndrome. She is an education and training specialist for case managers and has a lot of experience with managed care. She enjoys helping other lifeliners function as independently as possible and participate in their health care decisions.</p>

LifelineLetter

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