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Gastroparesis

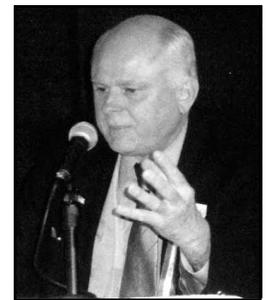
Richard W. McCallum, MD and Sabu J. George, MD, Division of Gastroenterology and Hepatology, University of Kansas Medical Center

The following article overlaps much of Dr. McCallum's presentation at the 17th Annual Oley Consumer/Clinician Conference held this summer in Buena Park, CA. A videotape of his full presentation is now available from Oley's Videotape Library; simply complete the form inserted in this issue. Many thanks to Dr. McCallum for speaking at the conference and authoring this article. For more information on this topic, internet fans may want to visit some websites dedicated to gastroparesis patients; links to these and other helpful sites can be found on Oley's website at www.oley.org/links.

Gastroparesis is a syndrome characterized by the impaired transit of food from the stomach to the duodenum in the absence of mechanical obstruction. Although several conditions can contribute to impaired gastric motility, diabetes mellitus is the most common cause of gastroparesis. Patients may also have idiopathic gastroparesis with no clearly identifiable cause; up to one-third of these patients have viral-induced gastroparesis. Patients who undergo gastric surgery may develop gastroparesis, especially those who have had preoperative gastric outlet obstruction

as a complication of peptic ulcer disease. Other GI surgeries, rheumatologic disorders and neurological disorders, can all contribute to delayed gastric emptying, as can abdominal malignancies. Patients with pseudo-obstruction often have delayed gastric emptying as well.

Symptoms of gastroparesis may include chronic or intermittent nausea, vomiting, early satiety, abdominal distention after eating, and abdominal pain, which also often follows meals. Acute flares can result in severe vomiting. Morning nausea is an important indicator of gastroparesis. Vomiting may not be a dominant complaint, as the patient may have adjusted his/her diet to include only small amounts of food at a time.



Richard McCallum, MD

Gastroparesis cont., pg. 2 ➤

Join Us in June!

Excitement is mounting as plans get underway for the 18th Annual Oley Consumer/Clinician Conference to be held June 19-21, 2003, at the World Golf Village Renaissance Resort, in St. Augustine, Florida. Don't miss this unique opportunity to talk about homePEN with experienced clinicians and consumers from around the country, in a relaxed setting that offers world-class golfing, family recreation, great food, and shopping in a quaint, historic town.

The annual conference is a great time to discover more about homePEN: both the medical updates and coping strategies you need to know. It also offers the unique opportunity to meet people who face similar struggles and move beyond them to lead active and fulfilling lives. Bring your whole family for a rewarding and educational experience you'll remember for years to come.

If you have any ideas for speakers, topics, or social events — contact Joan Bishop at 800.776.OLEY or bishopj@mail.amc.edu. ☺

Catheter Alert

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) reviews serious events in hospitals that adversely affect patient outcomes. One type of event that seems to be occurring with increasing frequency and has resulted in patient deaths, is the inadvertent infusion of tube feedings or other non-IV fluids into Hickman catheters in hospital.

Naturally, we at the Oley Foundation are concerned and are looking into what steps we as an organization can take to prevent these mistakes. Another threat that consumers continue to relay to us, is the increased risk of line infection when hospital personnel access their lines. For now, we are recommending a few preventive steps you can take, should you go to the hospital for testing or are admitted for a procedure and/or emergency health care:

1. Be Vigilant

Ask hospital staff what they are using your line for before they access it. Be vigilant about their septic

Catheter cont., pg. 5 ➤

Gastroparesis, from pg. 1

Diagnosis

A patient's medical history may help clarify the cause of gastroparesis. A history of prior ulcer disease or gastric surgery is obviously significant. The patient's history might also emphasize other medical illnesses and reasons for which the patient may be on medications that contribute to nausea or delayed gastric emptying. These

patients are often on numerous medications, and having a physician carefully review the side effects of these drugs can be rewarding.

The details of the nature of the symptoms, particularly the character of the vomitus, associated complaints, the relations to abdominal pain, and the relation to meals, are important. Gastroparesis typically involves vomiting one to three hours after eating, and "old food" from previous meals can even be seen the next morning. The presence of freshly ingested food is suggestive of a mechanical problem, such as a gastric outlet obstruction. Abdominal pain is common in "idiopathic" gastroparesis, and unusual in diabetics.

Patients with viral gastroparesis typically have an abrupt onset of their disease preceded by an acute gastroenteritis-like illness. These patients have a good prognosis, with shorter recovery periods and better quality of life. Patients may be diagnosed with viral gastroparesis when they: are healthy subjects who experienced the acute onset of symptoms typical of a "viral-like" illness; experience persistent symptoms (nausea, vomiting, early satiety, weight loss) for longer than three months; and have no obstruction, metabolic disease, systemic illness, surgery, or use of antimotility medication. Viral serology, can be used too, if it is available.

Treatment Strategies

Management of gastroparesis centers on hydration, dietary manipulation, nutritional supplementation, and pharmacologic therapy after gastroduodenal disease, systemic disease and offending drugs have been excluded. Nutritional support in gastroparesis begins with encouraging smaller-volume, low-fat, low-fiber meals, and if necessary, liquid caloric supplements. Patients are encouraged to drink at least 1 liter of fluids per day in the form of water, fruit juices, or other low-fat drinks. During periods of acute decompensation, intravenous hydration may be necessary. Jejunal feeding tubes may be used at night to supplement daytime feedings and ensure that medications are fully absorbed. These tubes should be placed either by laparoscopy or mini-laparotomy. There is no role for percutaneous endoscopic gastrostomy (PEG) decompression in gastroparesis unless it is accompanied by dilation of the small bowel. Placement of a percutaneous endoscopic jejunostomy (PEJ) is discouraged because in a patient who is frequently vomiting, the PEJ component is consistently regurgitated back into the stomach. Parenteral nutrition should be used only briefly during hospitalization and not encouraged or sustained on an outpatient diagnosed only with gastroparesis, because of the serious complications associated with its use.

Prokinetics

Medical therapy has changed in this field because of the withdrawal of cisapride from the US market. With the loss of this agent, metoclopramide has again become the prokinetic of choice. It can coordinate antral duodenal and pyloric muscle function and be a powerful, centrally-acting antiemetic. Approximately 70 percent of patients have no side effects and can tolerate this agent, but its antidopaminergic properties (it may cause Parkinson-like symptoms) remain the major obstacle to its more widespread use. Parenteral, oral and rectal preparations are available; a less appreciated, but very important route of administration, is subcutaneous, to allow for continued absorption despite vomiting, which would lead to unpredictable blood levels if taken orally. Even the most severely symptomatic patients can be stabilized by using a subcutaneous injection of 2 ml, two to four

Gastroparesis cont., pg. 9

LifelineLetter

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The Oley Foundation
For Home Parenteral and Enteral Nutrition
214 Hun Memorial, A-28
Albany Medical Center
Albany, NY 12208
1-800-776-OLEY, or (518) 262-5079
Fax: (518) 262-5528
E-mail: BishopJ@mail.amc.edu
DahlR@mail.amc.edu
WilsonE@mail.amc.edu
HarrinC@mail.amc.edu
Web page: www.oley.org

Executive Director:

Joan Bishop

Director of Publications & Information:

Roslyn Scheib Dahl

Outreach Coordinator:

Eleanor Wilson, RD

Administrative Assistant:

Cathy Harrington

Lifeline Advisory Group:

Felice Austin; June Bodden; John W. Broviac, MD; Donald Freeman; Bruce Grefrath; Ben Hawkins; Jere Lifshitz, RN; Jerry Mayer; Anne McCormick, LCSW; Lynn R. Patton, RPh; Elizabeth Tucker.

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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.

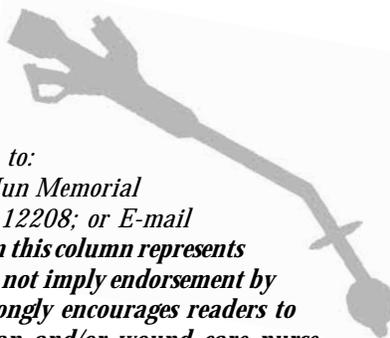
Gastric Emptying Assessment

Gastric scintigraphy is the best method for diagnosing delayed gastric emptying. A 4-hour test which has the patient eat low-fat egg meals (egg substitute) is standard. Normal ranges for gastric emptying in healthy subjects at 1 hour, 2 hours and 4 hours is 90, 60 and 10 percent, respectively. Gastric retention of greater than 10 percent at 4 hours is indicative of delayed gastric emptying. Unfortunately, many centers use only a 2-hour study to save costs. In a soon-to-be-published multicenter study, we compared 2-hour and 4-hour results in patients suspected of having gastroparesis and showed that limiting the gastric emptying time to 2 hours would have missed 44 percent of patients studied who went on to have delayed gastric emptying at 4 hours (See graph on page 9). Thus, while an abnormal result at 2 hours is fairly reliable, and the test may be stopped at that point for patients with abnormal results, the study should be continued for patients with normal results for the full 4 hours.

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.



Parents Comment on Farrell (Pressure Relief) Bags

We have used Farrell bags for my three-year-old son, Gary. They can be helpful, as they create a gastric release valve. As formula is going in, air bubbles can still come out. Any formula pushed up into the bag refeeds into the tube. We use them particularly when he is sick and having trouble with his feeds. What they do not do, is provide any suction; so if you, like us, deal with air bubbles trapped in thick, mucousy stomach contents, the bags may not provide relief for this.

— Angela Gilbert
Spring Branch, Texas.
babygary@gvtc.com

We have a three-year-old son who is bothered by reflux to the point where he wretches and gags on the smallest amount of feeding. You have tears in your eyes watching him while he is connected to his feeding pump. Austin has a G-tube with the Nissan fundaplication, but still has severe reflux issues. Austin is on continuous feedings, because he is volume sensitive and bolus feedings will not accommodate him. We had tried the normal Farrell bags, but the tubing would not handle the amount of pressure Austin had during a reflux fit. The tubing diameter was the problem.

It was a great idea, but it didn't work for him until we got the Super Farrell bags. These bags relieve the pressure and the fits of reflux. For us, the bags are worth their weight in gold. Who could believe a device so simple could help our boy in such a huge way. Austin has no more terrible reflux fits and can now be comfortable while being fed. I hope that this helps other families that have children with similar reflux problems.

— Kimberly D. Cichy
CICH13@aol.com

The Farrell Valve Enteral Gastric Pressure Relief System has been around for quite a few years, around 10, if I remember correctly. I came across it several years ago and it was not well known at that time either. Our daughter was a toddler when we had our brief and unsuccessful trial. I would certainly encourage anyone who thinks it may be helpful to give it a try as it is uncomplicated and non-invasive. I have three sealed sets with an expiration date of 6/2004. I would be happy to mail them to anyone interested. Unfortunately, I no longer have the relevant literature, but any home care company could likely provide that. There are instructions in each package, but they are quite brief and I found the additional information to be helpful. If anyone is interested they can e-mail me their name and address.

— Laura Stieve
ls2710@yahoo.com

Equipment Exchange

The following homePEN supplies are offered free of charge to readers:

EN supplies

- 10 Companion EN bags 1000 ml #71†
- 12 Ross Hide-a-port extension tubes #54234†
- 30 Patrol feeding bags #52048
- 1 MicKey low profile G kit 20 Fr./ 3.5 cm
- 1 Ross Hide-a-port low profile G kit 20 Fr./ 3.5 cm
- 18 Kangaroo gravity sets #702500
- 34 Companion Top-fill bags 1000ml #71
- 39 Companion Ambul. bags 500ml #507

EN Formula

- 7 cases Isosource HN, exp. 2/03
- 4 cases Jevity Plus, exp. 6/03
- 7+ cases Jevity Plus, exp. 6/03, 7/03
- 10 cases Perative, exp. 3/03
- 6 cases Resource Diabetic, Vanilla, exp. 7/03
- 4 cases Glytrol, vanilla, exp. 12/02
- 4.75 cases Alitraq, exp. 04/03
- 2.5 cases Ultracal HN Plus, exp. 12/02
- 1 case Nutren 1.5, exp. 4/03
- 1/2 case Nutren 2.0, exp. 1/28/03
- 8 cases Peptamin, 4 exp. 1/03, 4 exp. 2/03 some flavored

IV/Misc. Supplies

- 100 4 x 4 gauze drain sponges†
- 17 Med Stream transfer sets 42 in, univ. spike, dual check valve†
- 28 Admin sets for Baxter/Sabratek 6060 pump (Sabraset #560100, #567100, Baxter #2M9856)†
- 12 Baxter Y-type extension sets #2N1191†
- 8 B. Braun dispensing pins #412022†
- 20 McGaw Trimmed Add-on Filters (0.22u)†
- 20 B. Braun Safsite Valve and Caps #415067†
- McGaw low pressure IV sets #V1712†
- 81 Baxter Interlink Vial Adapters #2N3395†

Latex Free Syringes

- BD 10 ml 20G1-1/2 Precision Guide needle†
- BD 3 ml 22G1-1/2 Precision Guide needle†
- BD 1 ml 25G5/8 Precision Guide needle†

†FREE shipping offered within US.

For more information, call (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 that those receiving goods please offer to pay for shipping. ©

The Peace of Mind is Priceless

Robin Lang, HomePN Consumer

Kudos to Oley for establishing a planned giving program. It ensures our organization will be there in the future for others. I owe my improved quality of life to the services Oley provides. I'm glad to give back, and recently, I discovered just how easy that is to do.

This summer my mother lost a dear friend and neighbor of 50 years. While stricken with grief, we were also stricken with fear. This friend was the executrix of my mother's will. Typically, it's events like these that force us to look at our own mortality and plans. A trustworthy friend recommended an estate attorney, and after a brief meeting, my mother's will was swiftly changed. My mother commented that the original will she and my father had had wasn't as in depth as the new will. That's true because laws change, hence it's a good practice to review your will periodically.

I realized that I should review my will, too. My original was fine 15 years ago, but a lot has changed since then. My son is now an adult, my financial situation has improved, and I've moved twice. The other reason I wanted to review my will, was my travel plans in the near future; the "what ifs" began running through my mind. What if the plane crashes, or if I became deathly ill, who would speak for me if I can't? Who would get my house and possessions? Would my estate be hung up in probate court for months? Should I have a living will? What about organ donation, and charitable giving?

Armed with questions, I returned to the attorney that helped my mom. I live in Maine, my mother lives in Massachusetts; it's interesting how each state handles these issues differently. For example, in Massachusetts doctors aren't forced to abide by a living will. Maine law mandates it. (In fact, Massachusetts is only one of several states that does not require living wills to be honored under law). Also in Maine, if an agent under a power of attorney absconds with someone's assets, they can be held criminally liable and may be prosecuted. In Massachusetts, if someone does the same, the state may suggest a civil suit and not pursue the agent criminally. In effect saying, "You should've picked a more trustworthy person."

General Rules and Wisdom

Here are a few things to consider.

A Will: This tells who you want your property and possessions to pass to. Typically wills must go through probate court, which can take 9 to 18 months. The court's role is to make sure that the will your executor or attorney presents, is in fact the last will; that all the taxes and expenses are paid; and that all of your property is properly distributed to the people/charities it lists. Once all of the property is accounted for and distributed, then the court can close the case.

Wills are changeable; let's say you win the lottery the day after you create a will and you'd like to give more to a person or an organization; with a few stokes on the word

I don't like to think about death...but since I made a new will...etc.; the peace of mind is priceless.

processor, your will can reflect that change. Giving a percentage of your estate is highly recommended because of the example above. Instead of amending your will, you simply state in the beginning that a percentage of the estate, instead of a dollar amount, will pass to those you care for, no need for the word processor. Wills should be reviewed at least every 5 years. (A recent study showed the average time between updates is 19.6 years.) Wills drawn in one state can be carried to another state. Living wills are not recognized by all states.

Power of attorney: this is a person you choose to act for you in regard to money matters if you cannot; i.e. your chosen agent can access your bank account for you or pay your bills. You can choose your spouse, a sibling, a good friend, or anyone you trust. (A side note: most companies are understanding and will waive late fees and interest charges if you provide a doctor's note.) Say you give to Oley every holiday, but you become ill; your agent can continue your gifting schedule for you.

Health care power of attorney. This is a person you choose to speak for you, should you

become unable to yourself. He/she can provide your doctors with your living will and other personal health instructions. This person can be the same person as the agent you chose to have power of attorney. If you haven't chosen someone to speak for you, I strongly suggest you do so. Carry their name and contacting information in your wallet. Two years ago, I had pneumonia and was placed on a respirator. The doctors wanted to pull my TPN catheter, but thankfully my mother intervened; the catheter was saved because the line wasn't the cause of the problem.

Health care directives. Health care directives are not recognized by all states. Check with your primary care physician; if he/she is unwilling to support your wishes, you might consider finding a new primary care physician.

Organ donation: Many consumers think their organs are invalid for transplant consideration. I hear a lot of people say, "No one wants any of my parts." This is a common misconception. Even a small piece of skin or artery can aid another person. If organ donation is not something you've ever considered, I'm not suggesting you change your mind; however, if you like the idea, don't discount your contribution solely on the fact that you've been using HPEN. If it's your intent to be a donor, be sure that the person you've selected as health care agent and your family, understand and will abide by your wishes.

POD and TOD Accounts: Terms meaning Payable on Death, Transfer on Death. Your accounts can be set up with another name attached, similar to a joint account, except the other person listed can only get the money when you die. These accounts do not go through probate. The account passes or transfers in total, or a percentage, to a person, or persons whose name appears on the account. This is the easiest, fastest way to give to your heirs and/or favorite charity.

Beneficiaries There are many beneficiaries on our papers; bank accounts, wills, life insurance policies, 401Ks, IRAs, etc. Another way of planned giving is this: let's say you took

Planning Ahead cont., pg. 5 ←

Howling About Nutrition Week!

Nutrition Week 2003 is looking like Texas — Really Big! To properly celebrate the Foundation's 20 years of bringing consumers and clinicians the highest quality in education, we are presenting a consumer/clinician program on Saturday, January 18th, 2003 at Nutrition Week. We are honored to welcome our volunteer faculty — top researchers and clinicians in nutrition support — joining us from all over the country:



James Andrews MD, Vascular & Interventional Radiology, Mayo Clinic, Rochester, MN

Jane Balint, MD, Peds GI, Children's Hospital, Columbus, OH

Alan Buchman, MD, GI, Northwestern University, Chicago, IL

Lyn Howard, MB, GI/Nutrition, Albany Medical Ctr., Albany, NY

Kishore Iyer, MD, Transplant Surgery, Nebraska Medical Center, Omaha, NE

Khursheed Jeejeebhoy, MB, Nutrition, St. Michaels Hospital, Toronto, Canada

Carol Ireton-Jones, PhD, RD, Nutrition Services, Coram Health Care, Carrollton, TX

Darlene Kelly, MD, GI/Nutrition, Mayo Clinic, Rochester, MN

Jarol Knowles, MD, MPH, GI, Duke University Med. Ctr., Durham, NC

Sheila Messina, RN, MA, Education & Training Specialist, San Jose, CA

Reid Nishikawa, PharmD, Pharmacy/Clinical Svcs., Nutrishare, Elk Grove, CA

Ezra Steiger, MD, GI Surgery, Cleveland Clinic, Cleveland, OH

Josie Stone, RN, CPNP, Customer Support, BD Medical Systems, Sandy, UT

Topics to be discussed will include motility issues and gastric pacing, transplant/intestinal failure, access issues, pediatric nutrition support, history of parenteral nutrition, current topics in liver disease, enteral challenges, interpreting labs, and looking into the future of nutrition support research — a terrific, dynamic program! We are also special guests in the Exhibit Hall on Sunday, January 19th. Maintaining our tradition, consumers may attend both days at no charge.

Watch the Oley website — www.oley.org — for more information and registration opportunities. Oley members who live in Texas will have registration flyers mailed to them. We have arranged a group rate, \$91 for a suite, at the Best Western Sunset Station, 10 minutes from the San Antonio Convention Center. To reserve a room, call 210-223-4400 **no later than January 2nd**, and mention you are with the Oley Foundation.

Planning Ahead, from pg. 4

out a life insurance policy 20 years ago, and your beneficiary was your daughter. She has subsequently grown and is now financially well off. Maybe you'd like to change the beneficiary so that she and your favorite charity now split the insurance. The message here is to review the beneficiaries on your documents. Are they still current? Do you have more children/grandchildren or a charity you'd like to remember? In some cases insurance policies purchased years ago are worth more now as cash than as the payout at death. Cash them in, take it as a windfall and/or give a

percentage to charity and receive a tax break. These changes are simple and easy.

I hate to admit that I am getting older. I don't like to think about death and all this other stuff, but since I made a new will with clear instructions, health care directive, etc.; the peace of mind is priceless. ☺
As Robin noted, each state has different laws, but we have a resource that can get you on the right path. Oley volunteer Stephanie Pelham is a Registered Dietitian and an Agent: Registered Representative of NYLife Securities. She is happy to offer assistance to Oley members. For more information call Stephanie at (888) 773-5426, or Oley at (800) 776-OLEY.

Catheter, from pg. 1

technique as well, before allowing them to touch your line. If possible, have a friend or family member with you before and after procedures when you are not alert enough to protect your access yourself.

2. Communicate with Clinicians

Share your concerns about misuse of your IV line. Ask the head nurse on your floor and/or in the laboratory/examination area, "What steps does your institution take to insure that you do not infuse non-IV fluids into IV catheters?" Ask what steps they take to prevent line infections. Write down your catheter access/dressing change protocol and share it with the hospital personnel caring for you. (It helps to have your physician sign it.) Also, if you and your physician have placed restrictions on your line, such as no blood draws, be sure this is communicated to hospital staff and on your personal protocol sheet.

3. Tape IV Line Above the Waist

Tape your catheter tubing to your chest, arm (wherever most appropriate), above the waist and far away from any other tubes or ostomy appliances. When you are hooked-up to IV fluids, secure the catheter to the outside of your hospital gown to avoid tugging and pulling. If you have a feeding tube in addition to your catheter, keep it taped in place, away from the IV.

4. Label Your Line

Wrap a piece of tape on the soft part of your catheter, at least 1-inch above the hub, such that it sticks out, perpendicular to the line (like a clothing tag), and print "FOR IV USE ONLY" on it in large letters. Show this label to any clinician who wants to access your line. If you have a feeding tube as well, label it in a similar manner "FOR ENTERAL USE ONLY."

5. Be Creative

Brainstorm with family members, clinicians or other consumers and **share your ideas with Oley**; call (800) 776-OLEY or email the *LifelineLetter* Editor at DahlR@mail.amc.edu. ☺



Lifeline Mailbox



Mom Learns Advocacy Skills and More at Oley Conference

Dear Lifeline Readers,

Hello! I am the mother of a former home-PEN patient. My son and I attended the annual conference in Boston a few years ago. Mackenzie and I had such a wonderful experience and networked with so many people. I am very proud to say that because of the contacts we made at the conference, Mackenzie is now no longer receiving enteral feeding or TPN! We went to the Behavioral Feeding Clinic in Cincinnati for two months and he is finally eating well and back on the growth charts! We even pulled the G-tube. Although he has a long road ahead with his development and other medical problems — we are glad he is tube free now. THANK YOU!

One of the important contacts we made was Dr. A. J. Kaul. He was so helpful and discussed my son's case with me in-depth. He suggested that we go to Cincinnati where he could rule out pseudo-obstruction and other conditions such as malabsorption. It seemed as if no one knew what to do with Mackenzie or what was causing his problems. Although we still do not have a real diagnosis, at least finally we had someone who was willing to take the time to focus on the cause of his troubles, instead of treating only the symptoms to just keep him alive.

Another person who helped us a great deal was Andrea Anastas from IFFGD. We discussed Mack and all his symptoms; she was full of knowledge! She got Mack and I open-ended plane tickets donated by the airlines. What a tremendous help! She was also a great moral support. The same goes for Becky Till, and her mom Linda, from Canada. Linda had been through a lot of what we were going through, and her energy, positive outlook and input helped me to know that I could make this trip to Cincinnati — and that if we had to go to the ends of the earth, we could.

My mother came with us to the conference, and so we split up for the afternoon sessions and rushed to our room to share what we had learned about eating tools for oral motor stimulation, tube care etc. The psychologist in the support group helped me gain strength. I'm sure I could rattle on for hours.

The conference is where I began to be proactive, and like I said, our lives have taken a huge turn for the better ever since. Before

going to the conference in Boston I hadn't even heard of some of the possible gastrointestinal diseases that we should be looking at. It took my thinking in a whole new direction. It still amazes me that I happened upon Oley and no doctor ever told me there was help or support out there. The Oley Foundation is a great support. I tell all of my son's doctors and our friends with special needs about the support we received, and hope they will share it with other patients who need it.

At the conference I learned that I am my son's best advocate. I have attended other small advocacy groups since then, and was given a great certificate. It's long but worth sharing:

"By this certificate know ye that Renee Legg is a lifetime member in good standing of The Society Of Empowered Parents and is hereby and forever entitled to advocate for her child and family, ask lots of questions, ask for help, be persistent, say yes, say no, speak from her heart, trust herself, enjoy life, enjoy her special child, stop to smell the flowers, have adventures, dream big dreams, laugh and cry for the health of it, express herself relentlessly, see things differently, feel scared, feel sad, feel mad, feel happy, give up worry and guilt and shame, fall down and get up again, take naps, do nothing, daydream, play, find out how

things work, make up new rules, tell her story, save the world, make friends with her neighbors, ask why, ask when, ask anything, ask for everything, question authority, appreciate others, give hugs, get hugs, be totally authentic, just be, and do anything else that brings more love, acceptance, happiness, celebration, relaxation, courage, communication, health, joy, creativity, passion, pleasure, abundance, grace, self-esteem, balance, serenity, beauty, peace and life energy to the above named member and to other humans and beings on this planet.

"FURTHER, the above named member is hereby officially authorized to frequent classrooms, principals offices, school board meetings, senators offices, churches, agencies, and all other places with resources for kids with special needs, and is encouraged to always remember the motto of The Society of Empowered Parents: It Never Hurts To Ask!"

I hope this empowers everyone reading this newsletter as much as it has me! I have found my voice and I am very proud to say that I found it during our conference experience. Knowing we weren't the only ones going through this was the beginning of a new life!

— Renee Legg
Reneelegg@aol.com
Temple, Texas

Ever Traveled to Europe with Tube Feeding?

Dear Lifeline Readers,

I just received my first *LifelineLetter*, and found it very interesting. I have CREST and started out with a PEG tube and then had to go to a J-tube because of GERD. I am running 3 cans of Nutren 1.5 through per night. I have an excellent support system here between my primary care physician, GI physician, wound care nurse and the company who supplies my supplies.

I have, however, a question which I'm sure has come up in the past and maybe someone who gets the *LifelineLetter* could answer. My daughter is graduating from the University of Washington this Spring and wants to go to Europe for several weeks. I know I can take my pump but I don't know how to go about getting the

nutrition supplements over there. I've talked to the company who supplies the products and they said it would be difficult to ship as we would be traveling around. Does someone know if the supplies could be purchased over in Europe? (We're looking at England, Ireland and Scotland.) Any information you can supply would be very helpful.

I am really glad I have this source now in addition to my local help. I don't know anyone else on a pump getting nutrition so I welcome further *LifelineLetters*!

— Margaret Coder
23013 LaPierre Dr.
Mountlake Terrace, WA 98043
(425) 775-5822
E-mail: raftmaggie99@hotmail.com

Successful Meeting in Spokane!

On October 26th, the Oley Foundation held a regional nutrition support workshop at the Deaconess Health and Education Center in Spokane, Washington. We had a good turnout; lots of clinicians, but fewer consumers than we had hoped for. It was a terrific, interactive program, and all attending told us they had learned a lot and were excited to have been there. Best of all, we introduced our brand new Regional Coordinator for Spokane, Tammy Adams, and set a great stage for her to launch a local support group! If you are from that area and missed the program, contact Tammy Adams at 509-255-5966 for information on the support group meetings to be held at The Shriner's Hospital in Spokane. Great thanks to Tammy Adams, Kathy Dirks, RD, and Annie Fredericks, RD, for helping us find a facility and contact many of the area clinicians.

Our faculty are always volunteers, and we could not offer these programs without their generous gifts of time and effort. Thanks to: (again) Kathy Dirks, RD, and Annie Frederick, RD; L. Morgan Pitschka, RN, Michelle Smith, RD, Crystal Johnson, RD, Ruth Seignemartin, RN, Ingrid Carlson, RN and Vanessa Kumpff, PharmD. Our plenary session presenters deserve special thanks, Richard Molitor, R.Ph. discussed pain control, and Henry Lin, MD, discussed new thoughts for motility issues.

A final thanks to our exhibitors, who support these programs and make them possible. They include Evergreen Homecare, Family Home Care, Integrated Health Professionals, Kimberly Clark/Ballard Medical, Lifecare Solutions, Inc., Maxim Healthcare Services, Nutrishare, Inc., and Tyco Healthcare/Kendall.

Our next regional program will be held this January in conjunction with Nutrition Week in San Antonio, Texas (see page 5 for more details). Those interested in bringing a one-day regional program to their area should contact Ellie Wilson at (800) 776-OLEY or wilson@mail.amc.edu. Thank you, Spokane, for a great program! ☺

Bone Health Reminder

Many consumers on nutrition support, particularly TPN, are at risk for bone disease, or osteoporosis. It is not known why TPN patients are so much more vulnerable to bone disease, but there are opportunities for reducing risk. Taking a page from national efforts to reduce osteoporosis in the general population, we encourage you to:

- Discuss your risk level with your health care team,
- Request a DEXA scan if you have not had one,
- Consider weight-bearing exercise to increase bone and muscle strength.

One resource we've come across that can assist with that is the National Osteoporosis Foundation's 30-minute exercise video "Be BoneWise Exercise." This is a balanced, carefully instructed total-body workout for any beginner. It may be ordered from the National Osteoporosis Foundation for \$19.95, at (877) 868-4520. As with any exercise program, please be sure to discuss this with your health care team before ordering. Those consumers with a high risk of fractures may require a more supervised exercise program. ☺

TPN Scholarship Winners

Congratulations to the following winners of Nutrishare's \$500 Higher Education Scholarships. As all of the judges would contend, it was extremely difficult to choose from such a talented bunch of consumers. Many thanks to Nutrishare, Inc. for underwriting this scholarship program for TPN consumers.

Heather Schwenk, Coopersburg, PA

Heather is a graduate student at Thomas Jefferson University in Philadelphia, PA. She hopes to complete an Advanced Masters of Science in Occupational Therapy (OT), with a specialty in pediatric sensory integration and early intervention, by May 2003. Heather is interested in continuing on to an OT doctorate program which will enable her to do research or be a program administrator. She has been on TPN for almost six years due to chronic intestinal pseudo obstruction.



Heather Schwenk

Allison Hillen, Leigh, NE

Allison has been on TPN since birth (18.5 years) due to gastroschisis, which resulted in short bowel syndrome. She is pursuing a major in pre-medicine at the University of Nebraska, and would like to work with children. Her experience in dealing with clinicians sparked her interest and she is eager to help people in need of good care.



Allison Hillen

John Mark Silliker, Surrey, BC, Canada

Mark began TPN therapy in 1997 after a series of surgeries for Crohn's disease left him with short bowel syndrome. In early 2000 he could no longer physically manage the responsibilities of his job and was forced to go on disability. Mark is a single-parent and wants a better life for he and his son, Jeffrey, and thus is working on a two-year degree in Computer Information Systems. He looks forward to re-entering the work force and raising Jeffrey. ☺

Nutrishare has helped play a part in keeping me healthy and fulfilling my dreams.
Christina Gann - Boerne, Texas



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

Oley Cookbooks Have Arrived!

A collection of wonderful recipes, highlighted with a few of our favorite snapshots and information about Oley, are now available! The cost is \$10.00 each, plus \$2.50 shipping and handling. Order copies today for yourself, your family, friends — even a favorite clinician!

We're guessing with the Christmas mail rush that this newsletter will arrive late, BUT just in case it isn't, **Special Delivery** is available for the holidays. Let us ship your books/gifts from here. We'll insert the greeting of your choice and send the book directly to your favorite cook! **For Oley by December 20.** We'll complete the form below and send it with your **Special Delivery, be sure to call** these are posted on our website; be sure to visit **www.oley.org** frequently for the latest news from Oley.) **For all non-rush orders,** complete the form below and send it with your check made out to "The Oley Foundation" A huge thanks to Dava Huss for spending countless hours organizing, categorizing, sorting and stuffing our recipes. We're extremely grateful!



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Based in Mansfield, MA, Kendall is one of the largest manufacturers of disposable health care products in the world. The company's full line of products includes traditional and advanced wound care products, vascular therapy products, urological products, incontinent care, needles/syringes, sharps safety and a complete line of enteral nutrition therapy, which allows it to serve all patient populations. We thank Kendall for their continued support of the Oley Foundation and its equipment exchange program.

Celebrating Life!



Christopher

As Coram dietitian Maryann King simply puts it, Christopher Tournier is "pretty amazing." A home parenteral nutrition consumer for 19 years, 35-year-old Christopher is one of those people who is always upbeat. In spite of his health challenges, he is a great single father to a 7-year old daughter, was a finance major at St. Joseph's College and is just an all-around remarkable person. Congratulations Christopher!



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Gastroparesis, from pg. 2

times a day. This can be supplemented orally, until the desired control is achieved. The subcutaneous approach is particularly helpful as an alternative to emergency room visits for hydration and IV metoclopramide, and gives patients the option of fasting or drinking only liquids while gaining symptomatic control with subcutaneous injections. In the IV form, metoclopramide needs to be given every three hours, based on the fact that there is a rapid peak. It is generally well tolerated for two or three days in gastroparetic patients, where there really is no other recourse to break their vomiting cycle. Diphenhydramine hydrochloride (Benadryl) can be used to control side effects.

Erythromycin is the only other prokinetic currently available in the United States. This drug binds to motilin receptors on gastrointestinal tract smooth-muscle membranes, thereby mimicking motilin's actions. It is more effectively given intravenously than orally, and has decreased efficacy with long-term use. Another potential problem is antimicrobial resistance. Erythromycin is effective in gastroparesis in very low doses of 125-250 mg twice a day, administered in liquid suspension form and can be used in combination with metoclopramide. Reduced

dosing lessens the possibility of drug tolerance while maintaining options to increase the dose during symptom exacerbation. Motilin agonists without antimicrobial properties are currently under investigation.

Domperidone is another option that blocks receptors in the central and peripheral nervous systems. The approval of domperidone is not being pursued in the US, but remains the drug of choice in patients who cannot tolerate metoclopramide, and is uniquely suited for patients with Parkinson's disease who have GI symptoms as a side effect of dopamine-agonist therapy.

Antiemetic Support

Therapy in gastroparesis should be aggressive and extra antiemetic efforts supplied in addition to the prokinetic approach, at least initially, to gain control of symptoms. Nausea is a very severe, debilitating symptom, and antiemetics should be used extensively. Once nausea leads to vomiting, a cycle invariably ensues, resulting in dehydration and hospital admission. Scopolamine patches are often recommended in this situation. Two new drugs, 5-hydroxytryptamine 3 antagonists ondansetron and granisetron, are powerful agents that should be used sparingly because of their cost. The intravenous form is effective when metoclopramide cannot be tolerated.

Another option is the Relief band (Woodside Biomedical, Calsbad, CA), an electronic wrist device that noninvasively stimulates the median nerve by sending electrical impulses of up to 35 mA through two electrodes on the back of the device. The wrist location that the device acts on is coincidentally a well-known acupuncture point referred to as Pericardium 6 or Neiguan point. This device can be a useful adjunct to control nausea when other agents aren't working or produce undesirable side effects.

Special vigilance should be paid to situations that can thwart medical therapy and result in breakthrough symptoms. For example, hyperglycemic episodes often accompanied by infections, can undermine nausea control. Migraine headaches can provoke symptoms as well, and should be treated with sumatriptan. Cyclic nausea and vomiting occurring abruptly with intervening normal periods can be addressed with combinations of ondansetron, sumatriptan and amitriptyline too. Gastroparesis shows a strong female predominance, and menstrual cycles are important; in the week before menses, when progesterone levels are high, nausea and vomiting can be exacerbated. If this is a predictable event, inhibition of the hormonal milieu by Lupron (TAP Pharmaceuticals, Deerfield, IL) or other gonadotropin-releasing hormones agonists should be considered.

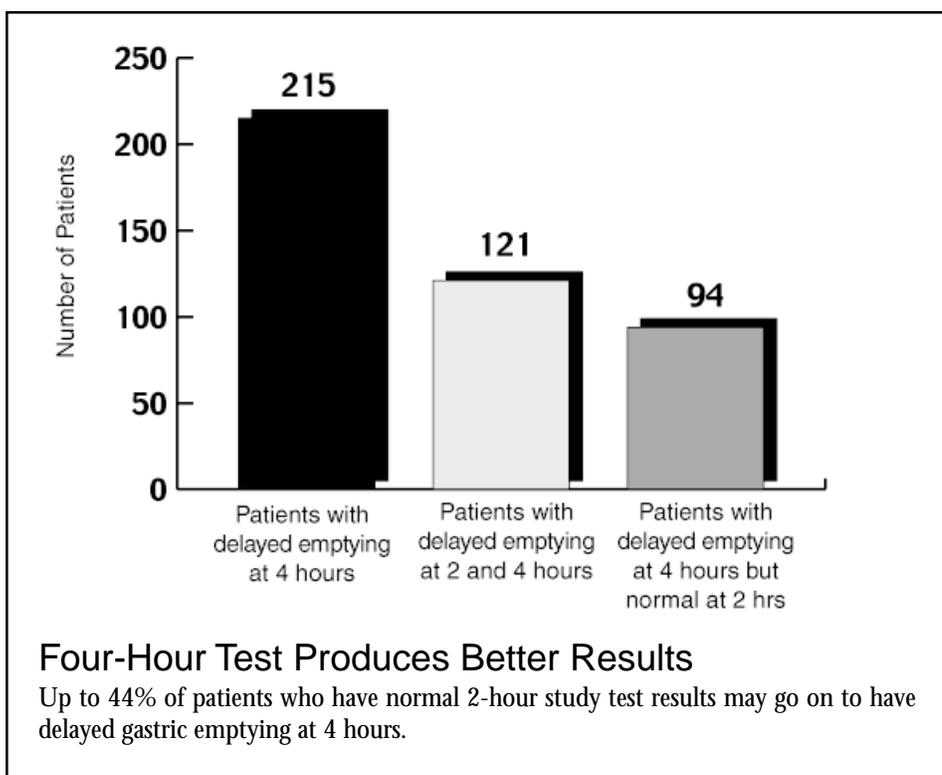
Clinical Outcomes

The only data published indicate that over a 5-year-followup, up to 65 percent of gastroparetics required continuous prokinetics therapy, 15 percent were off all prokinetics, and 15 percent required additional nutritional support.

Surgery

The role of surgery in the treatment of gastroparesis is limited. Surgical jejunostomy tubes can be placed as a definite feeding source past the ligament of Treitz. Total gastrectomy is reserved for intractable weight loss and vomiting in end-stage gastroparesis after all other options have failed. This is usually in the patient who has had a partial gastric resection of either Billroth I or II with or without a Roux-en-Y. Here without an antrum, medical therapies are less successful and bezoar formation is common.

Gastroparesis cont., pg. 10



Gastroparesis, from pg. 9

Gastric Electrical Stimulation

Gastric pacing involves using electrical stimulus to activate contraction of smooth muscle, or nausea and vomiting control mechanisms by either: 1) entraining (pacing) at a rate of the intrinsic slow wave by a low-frequency, high-energy method, or 2) using a high-frequency, low-energy stimulation to achieve symptomatic relief. In a study with dogs, gastric emptying increased with low-frequency, high-energy gastric stimulation. Electrical stimulation was also shown to induce gastric emptying and increase the motility index in dogs, if stimulated at frequencies higher than the basal rate.

High Energy; Low Frequency Method

External gastric stimulation with a low-frequency, high-energy method has yielded both significant improvement in symptoms of gastroparesis and acceleration of gastric emptying times of a solid meal into the normal range in nine patients with refractory diabetic or idiopathic gastroparesis. These devices had 4 pairs of pacing wires that were placed on the outer surface of the stomach, along the bottom edge, at an interval of 4 cm., beginning in the midbody. The nearest electrode was used as the pacing electrode. Using neuromuscular stimulation, the stomach was paced at a rhythm of 3 cycles/min., and gastric dysrhythmias were converted to normal rhythm. The patients wore the external stimulator strapped on a belt around the waist. Eight of the nine patients no longer relied on jejunostomy tube feeding. Unfortunately, the external devices were somewhat cumbersome and obtrusive, and required frequent maintenance. Dislodged electrodes were also a common problem. Because these external devices are impractical for long term use, they are available only through an experimental protocol at Kansas University Medical Center.

Low Energy; High Frequency Method

Since then a different type of stimulator has been developed (Enterra, Medtronic, Minneapolis, MN) and is now approved by the US Food and Drug Administration under a Humanitarian Device Exemption. The new gastric neurostimulators are permanently implanted in the patient, and use

high-frequency (12 cycles/min.), low energy parameters. The Enterra devices are placed surgically via laparotomy or laparoscopy. The electrodes are placed 9.5 and 10.5 cm from the pylorus on the greater curvature of the antrum of the stomach. The leads connect to the neurostimulator, which is placed in a small pocket incision in the abdominal wall. An upper endoscopy is performed in the operating room to confirm proper lead placement and rule out perforation. In addition, endoscopic ultrasound can be used to confirm placement more accurately. A programmer who communicates with the device via telemetry turns it on just before the patient is discharged from the hospital.

The multicenter Worldwide Anti-Vomiting Electrical Stimulation Study (WAVESS) trial has successfully inserted internal gastric stimulators in 33 patients. The initial design of the WAVESS study was a double-blind crossover (1 month of stimulation and sham) followed by 12 months open label. In the double-blind section of the study, the WAVESS study group showed a significant reduction in vomiting and a clear patient preference for having the device turned on. During the next 12 months, the WAVESS study group reported a greater than 50 percent improvement in vomiting and quality of life. In the majority of these patients, gastric emptying was improved, but still had not returned to normal by one year. Unlike the high-energy, lower frequency method, the Enterra device does not pace or entrain the stomach, nor does it normalize dysrhythmias.

Improvement in patients' symptoms when using the Enterra device may be explained by a number of theories involving neurostimulation: 1) activation of a central mechanism for nausea and vomiting control related to the constant high-frequency stimulation of the stomach wall, 2) augmentation of the amplitude of the gastric slow wave after eating, 3) enhanced relaxation of the proximal stomach and hence better accommodation, or 4) a modest improvement in gastric emptying.

WAVESS analysis of long-term hospitalization outcomes and economic impact of long-term gastric electrical stimulation indicates a 75 percent reduction in hospital use in the first year after implant for these

patients with challenging problems. Average savings in the first year were approximately \$65,000 per patient. Analysis of nutritional outcome has shown a significant increase in the body mass index (BMI) and an average 12 to 15 pound weight gain. In addition, 90 percent of patients who required jejunal feedings, had the tubes removed within six months and were eating. Most important to remember is that these are young patients, the majority of whom are women in the prime of their life who can now be restored to a functional life at home, school or work.

Current inclusion criteria for Enterra therapy at our institution are the following: symptoms for more than one year despite standard medical management, over seven episodes of vomiting per week, and abnormal gastric retention (at 2 hours over 60% or at 4 hours over 10%). Exclusion criteria include any patient with an organic obstruction or pseudo-obstruction, a primary eating or swallowing disorder, chemical dependency, or current pregnancy. Surgical complications related to placement of these devices have consisted of lead impedance out of range; infections; and device erosion, migration and stomach wall perforation. Three patients required surgery and device removal.

Conclusion

In the future, multipoint electrical stimulation will integrate stimulation from electrodes in a number of sites, beginning in the stomach and extending into the small bowel and even the colon. Optimally, this technique should be performed with an electrical frequency that is close to the body's natural frequency and high-energy stimulus, and will help promote and coordinate the signal throughout the upper gastrointestinal tract, thus accelerating gastric emptying and small bowel transit. Patient populations for electrical stimulation are now extending into those who are postvagotomy or post-gastric surgery and those with nausea and vomiting not responding to standard therapy without delayed gastric emptying, small bowel dysmotility, recurrent small bowel bacterial overgrowth, and intestinal pseudo-obstruction. ©

This article was based on "Gastroparesis" published in the May/June 2001 issue of Clinical Perspectives in Gastroenterology.



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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. Comments? Call (800) 776-OLEY.

JAN. '03	<p>Matt Van Brunt Adelanto, CA (888) 610-3008 PST</p>	<p>Matt has been on TPN for 20 + year's due to Crohn's disease and short bowel syndrome — so he is experienced with the up's and down's of TPN. He likes riding his bike, spending time with friend's, and visiting his girlfriend in Florida. He is happy to talk about anything associated with TPN or otherwise.</p>
	<p>Tammy Adams Liberty Lake, WA (888) 650-3290 PST</p>	<p>Tammy is the mother of Breanna, a 20 y.o. who has been TPN dependent since birth, due to CIIP (pseudo-obstruction). They have been dealing with liver failure issues for about five years. Tammy also has two other active daughters, ages 15 and 11. She looks forward to sharing her experiences with others.</p>
FEB. '03	<p>Ann DeBarbieri Gansvoort, NY (888) 610-3008 EST</p>	<p>Ann is a recently retired attorney, outdoor enthusiast and new Oley Board member. Diagnosed with Gardener's Syndrome, she has years of experience with TPN, tube feeding, traveling, and working. She is also familiar with the disability approval process. It is best to call Ann in the afternoon or early evening.</p>
	<p>Heather Abbott Alexandria, VA (888) 650-3290 EST</p>	<p>Heather is the mother of Andrew who is 1-1/2 y.o. Andrew was on TPN for the first 15 months of his life due to short bowel syndrome. He is currently on continuous G-tube feeds and has an ileostomy. Heather was also a Pediatric ICU nurse before having Andrew, and attended her first Oley conference this summer.</p>
MAR. '03	<p>David Young Plainfield, IL (888) 610-3008 CST</p>	<p>David has been on TPN since 1998 due to pseudo obstruction and malabsorption. He is in his early thirties, and can speak to fellow consumers about the issues of juggling work, therapy, college and having a social life. He can also share his experience with Oley conferences and travel. Call him after 6:30 p.m. CST.</p>
	<p>Diane Owens Marion, MA (888) 650-3290 EST</p>	<p>Diane has been on Enteral nutrition for the past 9-1/2 years due to myotonic myopathy. She was also on TPN prior to enteral. She has experience with a variety of tubes issues. She is very proactive in pushing for and receiving adequate care, and looks forward to sharing her experiences with others.</p>

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