

Lifeline Letter

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

What's Inside:

Tube Talk
Page 3

Equipment Exchange
Page 3

Oley Clothing For
Sale
Page 4

Travel Update
Page 4

Thank You For
Supporting Our
Conference
Page 5

2001 Oley Award
Winners
Page 6

In Memory of...
Page 7

RC Update
Page 8

Contributor News
Page 10 & 11

Call a Lifeliner —
Free of Charge!
Page 10

Oleic Acid: A Novel Nutrient-Based Treatment for Improving Absorption

Gregg W. Van Citters, MS and Henry C. Lin, MD
GI Motility Program and Section of Nutrition, Cedars-Sinai Medical Center, Los Angeles, CA

Weaning from total parenteral nutrition (TPN) is the ultimate, although often elusive, goal for both clinicians and patients. A major obstacle for patients with short bowel syndrome (SBS) to overcome is chronic diarrhea with massive loss of water and nutrients. Some strategies clinicians have tried to wean SBS patients off TPN include: enteral feedings along with dietary counseling; growth hormone, glutamine or GLP-2, to promote gut adaptation and absorption; surgical procedures to lengthen bowel or slow transit time; anti-diarrheal drugs to slow transit time; and intestinal transplantation. This article explores a new, nutrient-based treatment that slows intestinal transit time and thus provides more time for patients to digest and absorb nutrients taken orally. While significant positive results have been achieved using this therapy, it is still in the early stages of research and development.

TPN can dramatically improve the outcome of a wide variety of diseases, and if transition to enteral nutrition (EN) is not possible, may be necessary for survival. Unfortunately, long-term use of TPN is associated with the risks of sepsis, altered metabolism, bone disease and liver dysfunction or failure.

Most of these complications can be avoided by enteral delivery of nutrients, therefore an important therapeutic goal is to wean the patient from dependence on TPN whenever possible. The small intestine, the site of digestion and absorption of food and drugs, is capable of adapting to severe insults such as extensive surgical resection. However, this adaptive process is slow, and successful adaptation may take months or years so prolonged TPN support may be required before EN can be fully tolerated.

Oleic Acid cont., pg. 2



Congratulations June!

June Bodden, an HPN consumer and Regional Coordinator from Clearwater, FL, is the lucky winner of the Oley Foundation's \$250 Membership Raffle. Everyone who submitted a completed membership form this spring was entered into the drawing. Shown above is Lauren Huss of Arvada, CO, picking the winning form at the Oley Conference in Milwaukee.

Ever wonder...

"What would happen if funding for the Oley programs were to disappear?"

In 1995, Oley staff and Trustees faced serious financial issues. With managed care creating havoc within the homePEN industry, financial support for the Foundation was critically reduced. Survival measures were taken: expenses were cut, staff was reduced, the national patient registry was dissolved. Oley members faced reality — the organization that connected so many to information and each other might be closing its doors forever.

Since then we have been comforted with successful fund-raising campaigns, both corporate and individual. We've witnessed a shift in financial responsibility from principally corporate to a much better balance between industry and the general membership. Although we've been on solid ground since 1998 and have even managed to replenish our modest reserves, the harsh reality is that in a quick 12 months the atmosphere could change and the services could once again be at risk.

In an effort to ensure that Oley programs and services continue for a very long time, it is necessary

Planned Giving cont., pg. 9

Oleic Acid, from pg. 1

Factors Affecting Nutrient Absorption
Length and Type of Remaining Bowel

The site and extent of intestinal resection are important factors in determining whether the small intestine will adapt sufficiently to support oral or enteral feedings. Loss of the lower or distal portion of the small intestine (the ileum) may allow adaptation, but leave the patient with chronic fat, fat soluble vitamins (vitamin A, D, E and K) and divalent cations (calcium, magnesium, zinc and copper) malabsorption. Loss of the upper portion of the small intestine (the jejunum) may add

to the devastating effect. A massive intestinal resection may lead to lifetime dependence on TPN due to inadequate length of gut available for nutrient assimilation. The length of the small intestine and the presence of the ileocecal valve, have long been viewed as the critical factors for successful adaptation.

Transit Time

Digestion and absorption of a meal can take several hours, depending on the nutrient composition of the meal. Since digestion and absorption are time-demanding events, the movement of a meal through the digestive tract must be tightly controlled to ensure adequate time for assimilation. Motility of the small intestine determines the duration of time that the contents of a meal is in contact with the digestive enzymes and absorptive mucosal layer of the small intestine. Gastrointestinal motility is normally controlled by transit control mechanisms located in the digestive tract which act to ensure adequate digestion and absorption of the meal. In a normal healthy bowel, this takes place in the proximal and distal small intestine and is known as the 'jejunal brake' and the 'ileal brake,' respectively. These controls are activated when the end-products of nutrient digestion are available to the nutrient sensors of

the small intestine. Fatty acid, an end product of fat digestion, is a very potent trigger of these transit control mechanisms (see Figure 1a). For example, when a person with an intact, healthy digestive tract consumes a fatty meal (e.g., a pizza), the end products of fat digestion from that meal trigger the transit control mechanisms of the small intestine to slow down the movement of the meal in order to optimize digestion and absorption of the meal's nutrients. This feedback also contributes to the feeling of fullness after such a meal.

While diarrhea may be caused by a variety of factors (unabsorbed fats, bile acids, etc.), the effects of the accelerated transit of a meal through the gastrointestinal tract are poorly appreciated. Inflammation or resection of the small intestine can drastically alter gastrointestinal motility and transit, causing diarrhea (watery stool) and steatorrhea (fatty stool). In this setting intestinal transit may become uncontrolled and rapid. A meal is then poorly digested and absorbed, simply because it moves too quickly through the digestive system; there is insufficient contact with the digestive enzymes and absorptive surface (Figure 1b). The result of this rapid gastrointestinal transit is protein and calorie malnutrition as well as

Oleic Acid cont., pg. 8

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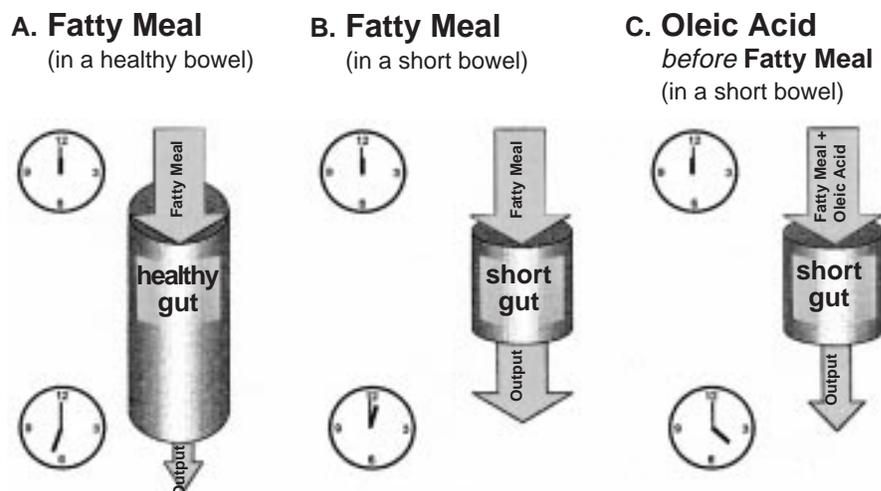
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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Director of Publications & Information at the address above.

Figure 1: Transit Response to Fatty Meal, Oleic Acid

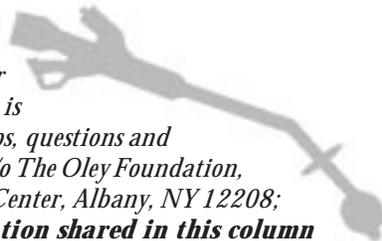


Results:

- a.) Normal slowing in response to ingested nutrients (up to 7 hour oro-cecal transit time). Normal digestion and absorption.
- b.) Little or no slowing of transit by a fat-containing meal in the injured or resected intestine (may be <1 hour oro-cecal transit time). Maldigestion and malabsorption of a meal causing diarrhea.
- c.) Improved slowing of transit by oleic acid before a meal (up to 4 hour oro-cecal transit time). Digestion and absorption of the meal is improved, reducing diarrhea.

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.**



Mortar and Pestle Great for Crushing Meds

Dear Lifeline Readers,

I have been on HomePEN (G and J tubes of various sorts) on and off for 4 years now, and just wanted to share one of the biggest "finds" that I have made over the years. I started out using commercial pill crushers to prepare medications to be put through my tube, and one day in the kitchen store of an IKEA outlet happened to pick up a small ceramic mortar and pestle. That mortar and pestle have made my day 110% easier ever since. The commercial pill crushers broke easily and often, and were hard on the hands, but the mortar and pestle allow me to crush pills easily. On top of that, I can mix them with water in the bowl and fill it to do a water flush afterwards. I realize it's a small thing, but it has made my life so much easier and no one mentioned the idea anywhere along the way; I just got lucky and wanted to share the idea for anyone else who is struggling every day to crush pills.

— Michelle White
mlwhite@sas.upenn.edu
267-872-1052 or 215-417-7563

Editor's Note: A ceramic mortar and pestle might also be available in a kitchen supply store, such as Lechters, William - Sonoma, Crate & Barrel, etc.

Swim Suit Hides Tubes, Dressings

Dear Lifeline Readers

For the first time in 9 years I have found a swim suit that is suitable for someone with a G-tube and/or J-tube, that doesn't make me look like my grandmother. For the past many years I have been wearing loose shorts with underwear, and a tank top with my bra, to the beach and swimming in them. I'm often mortified because I look like a bag lady who can't afford a swim suit. I have to have a two-piece suit so I can access both tubes for meds, water (if I'm there for the day I can't drink enough to keep hydrated), and some kind of sugar juice, in case my sugar drops dramatically. With a two-piece suit, I can access the tubes discreetly with a 60cc syringe by placing a towel on my lap.

What makes my new suit so marvelous is the cut, design and color, which are fashionable and functional. Mine is navy and white nylon, fully lined and two-piece. The bottom is a full-cut boxer short, and the top is a matching, fully-lined tank top with bra that comes below the waist line of the shorts. Even when I raise my arms, no tubes or dressings show. And when the tubes are placed inside the waistband of the shorts, the boxers are loose enough to not show any bulging.

I ordered the suit from the television shopping channel, QVC. They got it from the company It Figures. You can reach them by email: RLarissa@ItFigures.net, or visit their website ItFigures.net. The suits may be displayed on QVC again too.

— Diane Owens
Marion, MA

Equipment Exchange

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

EN Formula:

- 8 cans Peptamen, exp. 1/02
- Glucerna w/Fiber, exp. 5/02
- Ultracal, exp. 11/01
- Isocal HN Plus, exp. 2/02
- Osmolite HN Plus Ready to Hang, exp. 10/01
- Ultracal, exp. 11/01
- 14 cans Optimal, exp 3/02

EN Supplies:

- 25 Zevex EN Bags (1200 ml, no drip chamber, reorder # EL1200)
- 21 Zevex EN Bags (500 ml, w/ drip chamber, reorder # S0500)
- 3 Kangaroo EN Bags (1000 ml, w/ drip chamber, reorder # 8884-773600)
- Kangaroo pump sets, 500 and 1000 ml.
- Flexiflo Companion Pump Sets
- Spikers
- Nestle Pump Sets

TPN Supplies:

- Abbott Aim portable pump with battery and backpack

Syringes

- 300 cases, bulk packed 60 cc syringes (125 syringes per case)
- 100 cases, individually wrapped 60 cc syringes (30 per case)
- Thumb ring piston EN syringes
- BD 10ml syringe
- EN irrigation kit w/ piston syringes

Wanted:

- Viokase Powder tube feeding formula
- Zevex bags, reorder # Z-12228 (500 ml)

For more information, call (800) 776-OLEY/(518) 262-5079; or send an E-mail to: DahlR@mail.amc.edu. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition.

In the spirit of Oley, we ask that those receiving goods through this column please offer to pay for shipping, especially for heavy items such as formula.

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*Left: Oley Sweatshirt
Model: Donna Noble*



*Right: Oley T-shirt
Model: Larry McInnes*

Oley Shirts, Hats for Sale

Thanks to the efforts of Patty and Darrell Woods, Oley was able to offer top-quality t-shirts, sweatshirts, denim shirts and baseball hats, embroidered with the Oley logo and people, at the conference in Milwaukee. A limited amount of this highly fashionable, and truly functional wear is still available for very reasonable prices. (I wish we could show you the fabulous quality and color! I was so impressed I left with a denim shirt and hat, and am considering a sweatshirt too.) Special orders can also be made. Call the office (800) 776-OLEY for sizes, colors and other details. Prices are as follows:

| | | | |
|-------------|-----------|---------------|------|
| T-shirts | \$10 | Denim shirts | \$20 |
| Sweatshirts | \$15/\$20 | Baseball hats | \$10 |

Please add \$3.50 for postage and handling. All proceeds benefit Oley Foundation Programs.

More Travel Advisors:

After reading the article on traveling with homePEN in the last *LifelineLetter*, the following individuals volunteered to add their names to the list of experts to call for advice:

- **Liz Tucker** of Bloomington, MN, evt8888@aol.com, (952) 435-0013 has travelled domestically and internationally with HPN.

- **Linda Gravenstein** of Tomball, TX, goob19@juno.com, (281) 376-9468 has travelled domestically and internationally with HPN, including cruises. She recommends carrying a copy of your prescriptions on your person at all times when traveling abroad, in case you are questioned about your meds.

- **Barbara Witt** of Port St. Lucie, FL, cell phone: 608-217-7164, has travelled with HEN and HPN. (Barb was in the process of moving at press time. Call 800-776-OLEY for her new home phone and email address.)

Thank You for Supporting the 16th Annual Oley Conference

Special Program Sponsorships

Medical Support:
Coram Healthcare

Picnic Entertainment:
SIMS Deltec

Picnic Transportation:
Ross Products

Grants for Speakers
AstraZeneca, 3M

Thursday's Lunch Buffet:
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Welcome Reception
AstraZeneca

Conference Videotaping Services:
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AstraZeneca, Cynthia Hood, Joyce Hydorn, Robin Lang, Sheila Messina, Nutrishare, Richard Rivett, Ross Products Division, James Vaughn

Conference Registration Bags:
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Awards:
Jan & David Holder; Mead Johnson Nutritionals

Child Care:
Nutrishare, Inc.; Ross Products Division

Photographs:
Pat Brown, RN; Don Freeman

Regional Coordinator's Workshop:
AstraZeneca

Thursday's Youth Activity "Transitioning to Independence":
Nutrishare, Inc.

Travel Grant Scholarships:
Coram Healthcare; Nutrishare, Inc.; Ross Products; Nutritional Restart Center

Bratwurst for the Oley Picnic:
Courtesy of Bruno Sadowski, who loved sausage and picnics.

Exhibitors:
ABBOTT Laboratories AIS; Apria Healthcare; Association of Gastrointestinal Motility Disorders, Inc. (AGMD); Baxter Healthcare Corporation; BD Medical Surgical; Coram Healthcare; Corpak MedSystems; Crohn's and Colitis Foundation of America — Wisconsin Chapter; Curlin Medical; Health Care Solutions; Infusion Care Systems; International Foundation for Functional Gastrointestinal Disorders; Kendall; Milwaukee Ileostomy and Colostomy Assn. (MICA); Nestlé Clinical Nutrition; Northwestern University Affiliated Transplant Center's Intestinal Rehabilitation Center; Nutrishare, Inc; Ross Products Division; SIMS Deltec; Zevex Inc



Barb Witt, Conference Co-Chair, with her grandson, Joshua, and son, Peter.

Volunteers

Conference Co-Chairs

Kathleen McInnes, HEN Consumer; Lynn R. Patton, RPh; and Barbara Witt, HEN Consumer

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Other Volunteers

Mary & Jim Burmesch; International Clown Hall of Fame; Tim Joyce; Joan O'Neil; Marlene & Jerry O'Neil; Stephen O'Neil; Michelle & Peter Witt, Jr.

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Congratulations to the 2001 Oley Award Winners!

LifelineLetter Annual Award

Stephanie Harlow • Fredericksburg, VA

Stephanie has been unable to eat and HPEN dependent since 1996. For 33 years she was without a diagnosis, and underwent a constant barrage of procedures and tests. Rather than wallow in self pity, she fit her medical needs into the family's busy routine and continued the job of raising five boys and building a business. In 1997, she and all five boys were diagnosed with Eosinophilic Gastroenteritis (EE). Now fed via G-J tube, Stephanie has tackled the physical, emotional and management challenges of her own battle with EE while guiding her sons through their challenges. Her courageous attitude has enabled her to keep on top of five different tube fed consumers, formulas, feeding schedules, pumps, doctors appointments etc.

As if this weren't enough, in March of 2000 Stephanie started a non-profit organization, the National Eosinophilic Enteritis Disease Foundation (NEED), where she provides support and education to hundreds of families afflicted with eosinophilic GI diseases and assists with research efforts. She also advocates on behalf of homePEN and NEED families with policy makers and health care providers. For her non-stop, can-do attitude, despite an overwhelmingly challenging load, we are honored to present Stephanie with the 2001 Oley *LifelineLetter* Award.

Look for a story on Stephanie's triumphs and challenges in the next issue of the LifelineLetter.

Nominees: Jim Cowan, Cleveland Heights, OH; Madeline Cravotta, Oakland, CA; Gladys Flowers, Ridgeville, SC; Don Freeman, Ottawa, ON; Malisa Matheny, Doylestown, PA; Eleanor Orkis, Schenectady, NY; Brian Sessions, Fennville, MI; Mark Thimsen, Plymouth, MN



Stephanie Harlow

Oley Foundation Young Adult of the Year

Alicia Hoelle • Gibbstown, NJ

Diagnosed with Hypoganglionosis, Alicia has been on HPN, and sometimes HEN, since birth. Like most consumers, Alicia has had numerous medical problems and hospitalizations, yet she is always positive about life and helpful to other lifeliners. A recent second diagnosis of SMA Syndrome, and the associated pain and fatigue, meant Alicia missed most of her freshman and sophomore year of high school, but she continues to make the honor roll and has been inducted in the National Honor Society. After school, she volunteers her time for a number of organizations, including Oley, SADD, and the Youth Advisory Council at Children's Hospital in Philadelphia.

Alicia is an upbeat, outgoing young woman, who wears a warm, friendly smile, day in and day out. She strives to lead as normal a life as possible, and until she became famous on the front of the Oley brochure, many conference participants didn't realize she was a homePEN consumer. As a new Regional Coordinator, Alicia networks with other Oley youth and has started a web site where they can post information. She is buzzing with ideas and hoping to implement more of them as the SMA Syndrome resolves. Alicia is a real asset to the Oley family, and we are happy to recognize her with this award.



Alicia Hoelle

Nominees: Paul Butzin, Graytown, OH; Corey Hald, Kakabeka Falls, ON; Caroline Krajicek, Spartan, NJ; Angela Mitchell, Bryan, OH; Colyn Woods, Hemet, CA



Mead Johnson Enteral Award

Kathleen McInnes • Chicago, IL

Kathleen's battle with multiple sclerosis led to motility problems and enteral feeds seven years ago. A desire to help others in a similar situation prompted Kathleen to join Oley's Regional Coordinator network. As an RC and volunteer for the Oley toll-free line, she offers reassurance, information, resources and tips on problem-solving to consumers who call on her. She also runs a support group with Tim Joyce, and shares her experience with lifeliners through the Tube Talk column.

Multiple health problems, including mobility and visual impairments, don't slow her down. Quick to volunteer whenever there is work to do, Kathleen is always willing to learn and willing to share what she has learned. And on those occasions when she doesn't know the answer to a caller's question, she researches the issue or finds them another resource. As one of her nominators said, "There is always kindness in her voice and a smile on her face, no matter what her own circumstances are, which is comforting for the families that call on her in their time of need or frustration. She's been a real inspiration to me, and an unwavering source of support."

Nominees:

Catherine Tokarz, Bloomingdale, IL

Awards cont., pg. 8

The Oley Family Fondly Remembers...



(Front row) Dick & Vi Schultz at the 2000 Oley Conference in Boston, with Greg Tongol, Elsie Roesch, and Mary Jo Walch.

Dick Schultz

by Chris Bauer

Willis "Dick" Schultz, a member of the Oley Foundation since 1986, passed away on June 6, 2001. Dick was first diagnosed with Crohn's disease in 1969 and used TPN as a means for his nutritional support for 18 years.

Dick and his wife, Violet, enjoyed working as Regional Coordinators and attending many of the Oley Foundation conferences. The many friends they made, and the support Dick derived from those friends, helped him to grow as an individual and cope with his illness. Dick was inspired by the articles he read in the Oley newsletter, including those in the "Travels by Nancy" column. These encouraged him and Vi to travel to Canada, Europe and throughout the United States.

Dick was a quiet, yet strong man who always placed family and friends before himself. He will be greatly missed.

Sherril Miller

Sherril Miller, a HPN consumer and Oley Regional Coordinator, passed away May 9, 2001. Sherril had been on HPN since 1989 because of severe gastric dysmotility. She and her husband Ray were regular participants in Oley conferences, and helped to coordinate the 1999 Oley conference in their hometown, Salt Lake City, Utah.

Until recently, Sherril was a case manager for the state. This experience allowed her to help many consumers with their reimbursement issues. We will miss her radiant smile at Oley gatherings.



Sherril Miller

Dori Quiroco

Dorothy (Dori) Quiroco died July 17, 2001, just four days short of her 6th birthday. Dori had been a homePEN consumer for most of her life, under the care of her foster parents, David and Donna Miller.

Dori was a bright and bubbly child who wormed her way into everyone's heart she came in contact with. It is not surprising that dozens of the physicians and nurses who had cared for her traveled long distances to attend her memorial service. She will be remembered by all those who knew her, for her incessant curiosity and love of life.



Dori Quiroco

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Oleic Acid, from pg. 2

insufficient absorption of water, minerals, and micronutrients such as vitamins. The time available for digestion and absorption then becomes the determining factor in the patient's ability to maintain nutritional status without TPN. Thus, in a patient with chronic diarrhea due to short bowel syndrome, a strategy based on providing *more time* rather than more bowel may be effective in reducing dependence on, or weaning from, TPN.

Slowing GI Transit

Building on this idea, we postulated there may be a way to slow transit time by stimulating the 'jejunal brake' in the proximal (or upper) small intestine in patients with short bowel syndrome. The strategy was to manage diarrhea caused by accelerated transit of nutrients through the digestive tract by triggering the patient's natural transit control mechanisms with a small amount of fatty acid *before* they consumed a meal. Recently we described this novel approach in *Digestive Diseases and Sciences* (Lin et al. "Slowing of Gastrointestinal Transit by Oleic Acid: A Preliminary Report of a Novel, Nutrient Based Treatment in Humans," *Dig. Dis. Sci.* 2001;46:223-229).

We found when we administered 1.6 ml and 3.2 ml oleic acid mixed with 50 ml Ensure enteral formula (Ross Laboratories) to patients with chronic diarrhea 15 minutes before a meal, gastrointestinal transit was slowed significantly, with the higher dose producing a greater slowing effect. This increased the time available for completing digestion and absorption of the meal. As a result of having more time for nutrient assimilation, nutrition improved and the amount of diarrhea decreased (see Figure 1c, on page 2).

Transit time in normal, healthy participants averaged about 102.4 minutes. Transit times in patients was shorter at 29.3 minutes with a 0 ml dose, but almost doubled (57.2 minutes) with a 1.6 ml dose and close to tripled (83.3 minutes) with the 3.2 ml dose. Frequency of bowel movements decreased from an average 6.9/24 hrs. to 5.4/24 hrs., as did stool volume which decreased from 1829.0 to 1322.5 ml/24 hrs. with treatment.

To better illustrate the effects of oleic acid therapy, following are some highlights of the clinical response of two patients. The first patient was a 57-year-old woman with a his-

tory of subtotal gastrectomy and gastrojejunostomy for peptic ulcer and gastric cancer. Her symptoms — nausea, cramping, pain, light-headedness, bloating, and explosive diarrhea — were consistent with severe dumping syndrome and occurred after every meal. These symptoms persisted despite aggressive medical therapy, including the use of tincture of opium and anticholinergics. Her transit times with 0, 1.6, and 3.2 ml oleic acid were 16, 99, and 109 min., respectively. On oleic acid, she had only rare episodes of dumping symptoms (about once per month). Her weight increased from 118 to 130 lbs., and bowel movements decreased from four to five

liquid, to two to three formed bowel movements per day. This patient took oleic acid for over five years without loss of efficacy.

The second patient was a 34-year-old man with a 30-year history of Crohn's disease. Five intestinal resections resulted in a remainder of about 100 cm of small intestine and descending colon. He weighed 93 lbs. at presentation and had severe difficulties with oral intake. He was given a central line and expected to be on TPN indefinitely. He had more than 20 bowel movements per day and experienced pain, bloating and nausea with each meal. His transit times with 0, 1.6, and 3.2 ml oleic acid were 8, 16 and 133 minutes, respectively.

Awards, from pg. 6

Lenore Heaphey Grassroots Education Award Malisa Matheny • Doylestown, PA

Malisa has been on HPN and sometimes HEN for more than nine years because of pseudo-obstruction. Despite serious medical setbacks, Malisa participated fully in her demanding nursing program, and graduated on time this May. Even more impressive is the time and energy Malisa has dedicated to supporting homePEN consumers locally, nationally and even internationally. She spends countless hours on phone calls, e-mails and visits, and always takes the extra step to connect consumers to other consumers who have been through a similar situation.

Malisa has organized numerous outings for teenagers and young adults who depend on HPEN, and was instrumental in getting HPEN kids to summer camp, where they built confidence, made friends, and gained independence. Malisa has also run sessions at the Oley Conference for children, teens and young adults where they could speak openly and frankly about their experiences on HPEN. She is a powerful and positive role model for consumers of any age, and more than deserving of this year's Lenore Heaphey Grassroots Education Award.



Malisa Matheny

Nominees:

Barbara Klingler, Malabar, FL; Carol Pelissier, Manchester, NH; Patty Woods, Hemet, CA

Attention Regional Coordinators!

The Regional Coordinator Email Network is now up and running. It's a great place to connect with other Regional Coordinators, see what they are doing, share experiences, ask questions, etc. The catch is, we need your email address. Believe it or not, we have email addresses for only about half you and some of them may be outdated. So please, send your email address to Ellie Wilson at WilsonE@mail.amc.edu. If you don't have email, please call Ellie at (800) 776-OLEY, to find out how you can participate in the network too.

After the patient began taking oleic acid three times a day, his stool volume decreased during the first 24-hour period from 3400 ml to 1400 ml. Over the course of two months, he gained 30 lbs. without TPN and was able to enjoy an unrestricted diet without symptoms. This patient continues to take oleic acid and has reported no adverse effects in five years of daily use.

In addition to slowing transit time, participants in the study reported other positive benefits of the oleic acid therapy. First, the beneficial effect of the treatment was immediate. There was a dramatic reduction in symptoms and diarrhea after the first

dose of oleic acid. Second, the therapy was effective, yet had none of the side effects of established anti-diarrheal drugs such as constipation from opiates. Third, the approach improved their nutrition. Two of the patients studied had severe short bowel syndrome and without this novel approach would have required TPN to maintain their nutritional status. This suggests that oleic acid therapy may be useful in weaning short bowel patients from, or preventing their dependence on, TPN.

In conclusion, the significant factors affecting a patient's ability to maintain their nutritional status without TPN include quantity

and quality of remaining bowel and duration of intestinal transit time. Using an experimental, non-invasive approach that involves administering oleic acid before meals, we were able to slow intestinal transit time and thereby increase nutrient and calorie absorption. The success of this trial suggests that oleic acid therapy may help patients wean from, or avoid dependence on, TPN. This approach is particularly advantageous when it is not possible to increase the length of small intestine or improve its assimilation capacity. *Parts of this article were excerpted with permission from Kluwer Academic Publishers, publishers of Digestive Diseases and Sciences.* ©

Planned Giving, from pg. 1

for us to ask you, your spouse and/or adult children to think about coordinating a "planned gift." Planned gifts are donations other than outright cash gifts, usually from your estate, such as bequests, life insurance policies or stock. Small or large, these gifts, when pooled with other charitable gifts help to create a more secure, healthier organization.

The following information is provided as "food for thought" ... to help you better understand the "ins and outs" of planned giving.

Why is it important for Oley members to consider planned giving?

It is difficult for those who do not deal with the challenges of home nutrition support to truly understand the impact these therapies can have on a person/family's life and the benefits of the services provided through the Oley Foundation. We need to help ourselves and those who will follow in our path!

How can you, a friend or family member can make a difference with a planned gift?

Make a Bequest — specify distribution of your assets through your will. Your attorney could work with you to draft or change your will to include Oley. You might consider stating a dollar amount or a specific property or asset. The gift could be immediate or contingent upon non-survival of preferred beneficiaries (such as a spouse). A bequest could be directed to be used for general needs, an endowment fund or a specific program of interest.

Donate Gift Appreciated Assets (typically equities or stocks) — this type of gift is attractive as it can provide a significant tax advantage. These gifts typically provide an income tax deduction equal to the current value of the asset, a higher value than your original cost. If classified as long term capital gains property, these gifts could also spare you capital gains taxes on the growth of the asset. For example: if you gift stock purchased for \$3,000 that has appreciated to a value of \$10,000, \$7,000 of appreciation could be subject to capital gains taxes. The Oley Foundation is not subject to capital gains taxes and would benefit from the full \$10,000 value.

Am I limited to the methods of giving listed above?

No. There are many more options and methods for making a bequest. We have resources available to help you plan.

Whatever method of giving you use, and whatever amount you choose to give, we appreciate your willingness to join our community of support. For a list of the Founding Members to date, see page 10. We welcome any questions and would be more than happy to entertain any ideas that will contribute to the success of this program. Feel free to contact us at anytime at (800) 776-OLEY/(518) 262-5079 or bishopj@mail.amc.edu. ©

Join the Oley Bequest Society

Plans are underway to formalize the *Oley Bequest Society*.

- It's easy to get involved. You can do so by committing as little as \$500 from your estate.
- It's important to get involved. It ensures the permanence of "your" organization

We are available to assist you on a personal level. Call Joan Bishop at (800) 776-6539/(518) 262-5079, email bishopj@mail.amc.edu, or indicate your wishes below ...

- I've already included Oley in my planned giving! Please list me as a founding member of the bequest society.
- I am interested in joining the Bequest Society. Please contact me.
- I cannot participate at this time, but I am interested in helping to get this program underway. Please contact me.

Name: _____

Daytime Telephone: (_____) _____ - _____

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Send to: Oley Foundation, 214 Hun Memorial A-28, Albany Medical Center, Albany, NY 12208.... **Thank You!**

Individual Contributors: Your Support Makes Oley Stronger!

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Planned Gifts for Oley

The Oley Foundation would like to thank the following individuals and families for their planned gifts to the Oley Foundation. We invite anyone else who has made a planned gift or is considering one, to call Joan Bishop at (800) 776-OLEY.

| | |
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| <i>Katherine Cotter</i> | <i>Lyn Howard, MD</i> |
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Coram Healthcare

Coram Healthcare clinicians have provided home parenteral and enteral nutrition support services to consumers throughout the country for more than 20 years. At this year's Oley Conference, Coram Healthcare introduced its "Celebration of Life Circle", which recognizes consumers who face life's challenges with particular courage and success. These consumers are also featured on Coram's website. We thank Coram for their continued support at the Golden Donor Level.

Nutrishare, Inc.

Nutrishare is the only home care pharmacy recognized as specialists in home TPN therapy by the Accreditation Commission for Homecare. Nutrishare focuses exclusively on the long-term home TPN consumer throughout the country. Rod Okamoto and Tom Diamontidis invite TPN consumers to join them at Nutrishare's 10th Anniversary Conference in Orlando in December. We thank Nutrishare for their steadfast support at the Silver Circle level.

ABBOTT Laboratories AIS*

Abbott Laboratories Hospital Products Division develops, manufactures and markets a broad range of health care products for the alternate site market, including the new Gem Star® ambulatory infusion pump. Other key product segments include: pole mounted pumps; total parenteral nutrition solutions; IV administration sets; proprietary and generic injectable drugs; and complete lines of IV solutions. We thank Abbott for its continued support.

Calea Ltd.

Calea Ltd. is a leading Canadian provider of client-focused home healthcare products and services, and pharmaceutical support programs. Together, Calea's two dynamic divisions — Calea HomeCare™ and Calea HealthAccess™ — position the company as the first and only all-encompassing resource of its kind in Canada. Calea HomeCare offers a range of therapies and services including parenteral and enteral nutrition, IV antibiotics and pain management therapies, and clinical consultations. Calea HealthAccess offers product information and disease support programs, reimbursement coordination and patient advocacy, and a host of other services. We welcome Calea as a new Oley Friend.

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Toll Free Numbers Available to Canadian Consumers!

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

Oley circulates two toll-free numbers to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Regional Coordinators with a better grasp of their region's needs.

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

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

| | | |
|-----------------|---|---|
| OCT. '01 | <p>Don Freeman Nepean, Ontario (888) 610-3008 EST</p> | <p>Diagnosed with Crohn's Disease, Don has had an ostomy for 36 years and has been on TPN since 1981. Since then he has raised a son, worked full-time, been active in his community, and has travelled extensively. Don is an Oley Trustee and RC, and the founder of the Canadian Parenteral and Enteral Nutrition Association.</p> |
| | <p>Dava Huss Arvada, CO (888) 650-3290 MST</p> | <p>Dava's son Owen (9 y.o.) has been on TPN and EN feeds for five years after a midgut volvulus resulted in short bowel syndrome. She and her husband, Michael, are interested in the daily struggles and joys of parents with children on TPN or EN, balancing the needs of siblings and keeping the family whole.</p> |
| NOV. '01 | <p>Ann Weaver (parent) Naperville, IL (888) 610-3008 CST</p> | <p>Ann is married and has two sons, ages 14 and 7, the younger of which has short gut syndrome due to Hirschsprungs Disease. He was weaned off HPN at 3-1/2, and is now on HEN with supplemental IV hydration. She has experience in caring for a central line, NG tube, g-tube and ostomy. She looks forward to talking to other parents.</p> |
| | <p>Linda Boutin Chino, CA (888) 650-3290 PST</p> | <p>An Oley RC, Linda has had pseudo-obstruction since 1979 and has lost large portions of her intestines. Despite an ileostomy and gastrostomy, Linda exercises frequently to increase her motility and ability to eat. She also uses resources like prayer and meditation. She looks forward to speaking with others.</p> |
| DEC. '01 | <p>Kathleen McInnes (HEN) Chicago, IL (888) 610-3008 CST</p> | <p>Kathleen is 55 years old and has used enteral nutrition for six years due to a gut motility disorder. She has multiple sclerosis, infuses constantly and uses an ambulatory pump. She believes in leading as active a life as possible, travels and is well-versed in using private insurance.</p> |
| | <p>Laura Krueger (parent) Memphis, TN (888) 650-3290 EST</p> | <p>Laura's son Seth (11 y.o.) was born prematurely, with gastroschisis, and was dependent on TPN until he underwent the Bianchi bowel lengthening procedure in 1993 (see http://expage.com/sethsstory). Laura offers her insights, coping techniques and shortcuts for living with a child on TPN.</p> |

LifelineLetter

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