

# LifelineLetter

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

## What's Inside:

Going the Distance  
Page 3

Equipment Exchange  
Page 3

Tube Talk  
Page 3

Preparing Your Child for a Procedure  
Page 4

In Memory of Katherine Cotter  
Page 5

Ongoing Research Trials  
Page 5

Spotlight on Sheila Messina  
Page 6

Coming Soon...All New Oley Website  
Page 6

HPN Consumers & Caregivers Needed for Research Study  
Pages 7 & 8

HPN Centers of Experience  
Page 9

Parents Needed  
Page 9

Contributor News  
Page 11

Toll-free Networking  
Page 12

## The Role of Growth Factors and Glutamine in Enhancing Gut Adaptation

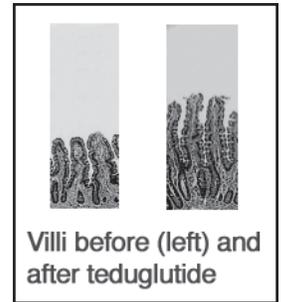
Alan L. Buchman, MD, MSPH

*Over the past 15 years several growth factors and amino acids have been researched to see whether they can enhance bowel adaptability and therefore reduce parenteral nutrition (PN) dependency in patients with short bowel syndrome (SBS). Some of these therapies have shown modest improvements, which has led to the Federal Drug Administration's (FDA) approval of growth hormone in the treatment of SBS; however most therapies are still in the research stages. This article will cover the factors that influence bowel adaptation and lower PN dependence; as well as some of the therapies being researched to enhance these efforts.*

The potential for decreasing or eliminating the need for parenteral nutrition (PN) in a patient who has a shortened bowel depends on several variables. These include the length as well as the absorptive capacity of the remaining intestine, age, the absence of continuing disease in the remaining bowel (such as Crohn's), the presence of the ileocecal valve (this joins the small bowel to the colon and acts as a break for fluid and

nutrients), and the degree to which the small intestine adapts following a resection.

Adaptation is the process during which the intestine "grows." It may become slightly longer, but more importantly, it increases in diameter; total surface area increases and absorption improves. Animal studies, and limited studies in humans, suggest this occurs when the villi (frond-like projections from the lining of the intestine) increase in size and number, and the crypts (where absorption occurs) increase in number and depth. This process occurs naturally, is thought to be most active in the first six months following resection, and is generally considered to be completed by one or two years.



Villi before (left) and after teduglutide  
Courtesy of NPS Pharmaceuticals

**Growth Factors** cont., pg. 2

## My First Oley Conference

Thoughts by Jane Lindsay

My first impression of an Oley Conference was of an atmosphere of friendship that filled the room. Newcomers were warmly welcomed and deftly guided through the conference day.

Valuable, relevant information and insights were conveyed in many ways:

- Presentations by qualified, dedicated medical teams.
- Contributions in group discussions by those who have digestive disorders, as well as their caregivers and family members.
- Suggestions from exhibitors who truly care about conference attendees, as well as about the quality of their products and services.
- Conversations with all who come by and mingle during the wonderful meals, picnic, silent auction, reception and bus rides.

Such a spirit of fun meshes with education and new understandings. I left with a whole new definition of heroes and look forward to renewing friendships in Salt Lake City. I sincerely hope you'll join us too.



Jane (center) enjoying the 2004 Oley Conference.

## See You in Salt Lake City...

"Be All You Can Be" at the 2006 Oley Conference in Salt Lake City, UT, June 28 to July 1. The program is packed with ideas for better daily management of homePEN and achieving the best possible quality of life. Don't miss this chance to learn from the experts and share stories with fellow homePEN consumers and families. Plans are in place to meet any medical mishap, large or small. For more information call (800) 776-OLEY or visit [www.oley.org](http://www.oley.org).

### Growth Factors, from pg. 1

One of the most important factors necessary to enhance this adaptive process is to eat. Eating helps release an intestinal growth factor from the salivary glands called epidermal growth factor (EGF). EGF is useful in simulating the intestinal cells to multiply and grow thereby increasing absorptive capacity. Other hormones produced in the

intestine such as cholecystokinin, secretin and glucagon-like peptide, may also play a significant role in the adaptive process. Having adequate blood flow to the remaining intestine is important as well.

#### Fluid Losses

Normally the small intestine absorbs about 6 to 9 liters of fluid daily. The colon absorbs about 1 to 2 liters daily. These organs have the capacity to increase absorption to up to 12 liters and 4 to 5 liters daily, respectively. In patients with a jejunostomy from whom all of the ileum has been removed, and perhaps even part of the jejunum, a state exists where the secretion from the intestine is greater than the amount of fluid consumed by mouth. In other words, these patients are losing more fluid from their bowels each day than they are drinking.

In addition, the stomach secretes a lot of fluid during the first six months following a massive resection of the small intestine. The reason for this is unclear, but may relate to the loss of some hormonal block. This may result in further fat malabsorption because the stomach acid breaks down the enzyme lipase, which is necessary to digest fat, and may also break down bile salts which are necessary for fat absorption. Typically, for the first six months or so, this gastric hypersecretion is treated with intravenous or high dose oral proton pump inhibitors such as Nexium®, omeprazole, Protonix®, or Prevacid®. Older medications such as H<sub>2</sub> blockers (Tagamet®, Pepcid®, etc.) may also be useful if used in sufficiently high doses. Somatostatin (octreotide) is rarely used because some experimental evidence in animals suggests its use may decrease the adaptation process.

Fluid losses should be replaced by drinking oral rehydration solutions. Such solutions were designed knowing that when the intestine absorbs salt, it absorbs sugar, and vice versa. When either salt or sugar is absorbed, water is absorbed as well. When the concentration of salt in a solution taken by mouth is too low (lower than the concentration in blood, for example), the intestine secretes salt in order to bring the concentration of the ingested solution up to that of blood. That results in the secretion of salt and water. Therefore, drinking water may be worse than drinking nothing at all, as it may worsen dehydration. Similarly drinking fluids with high sugar, but no salt, like soda and juice

can actually make the patient more dehydrated. Ideally the amount of salt in the solution should be at least 90mg/liter. Solutions such as the World Health Organization rehydration solution, CeraLyte®, or Pedalyte® (with an extra teaspoon of salt added per liter) can be used.

The World Health Organization formula is available in prepackaged form from Jianas Brother Packaging Co. (2533 Southwest Blvd., Kansas City, MO 64108; 816-421-2880). If you choose to make the rehydration fluid yourself, the recipe is as follows: 1 liter water, 3/4 tsp. table salt, 1/2 tsp. baking soda, 1 cup orange juice, and 4 tbs. table sugar. Flavoring may be added by using sugar-free Kool-aid® or Crystal Light®. CeraLyte is available either on their website, [www.ceraproductsinc.com](http://www.ceraproductsinc.com) or by contacting the company (9017 Mendenhall Court, Columbia, MD 21045; 888-ceralyte). Indicate that you are an Oley member to receive a 15% discount.

#### Nutrient Absorption

The length and absorptive capacity of the remaining bowel is critical in determining a patient's level of PN dependency. To some degree, what's left of the intestine, jejunum (proximal) or ileum (distal), can pick up the slack left from where the other has been removed. The exceptions are that vitamin B<sub>12</sub> and bile salts are absorbed only by specialized cells in the terminal or end part of the ileum. When the bile salts cannot be reabsorbed, they pass into the colon. In the colon they can cause the secretion of fluid, which results in increased diarrhea. In addition, bile salt deficiency may develop and the malabsorption of fat and fat-soluble vitamins A, D and E may worsen.

The colon also plays an important role. It is critical to make use of whatever portion of the colon is available to digest certain nutrients including carbohydrates, fatty acids, electrolytes and some amino acids. Complex carbohydrates that are not absorbed by the small intestine pass into the colon. Bacteria normally present in the colon ferment these carbohydrates and soluble fibers to short chain fatty acids. These fatty acids (butyrate, acetate, propionate) are fuel for cells of the colon and their absorption by the colon's cells results in net energy absorption. Thus it is important to have the colon connected to the remaining small intestine whenever possible.

**Growth Factors** cont., pg. 10

## LifelineLetter

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

## Going the Distance

My nephew, Justin Jett Ohlmeyer, has a rare medical condition that leaves him dependent on homePEN. When I found out about his situation, I wanted to help. My sister-in-law told me about the Oley Foundation and said it had been a great resource for her and my brother. I decided I would run the National Marathon in Washington, D.C., to raise money and awareness for the Foundation.

I have wanted to run a marathon for years but have never set aside the time to actually do all the training that it takes to complete one. There were times during the race when I didn't think I was going to finish, let alone make the time goal I had set for myself. When those thoughts crossed my mind, I would think of my nephew and the challenges he is going to face throughout his life, and it would push me up a number of hills that plagued the last 6 miles. My goal was to complete the marathon in under four hours and my time was 3:59:54.

My family and I would like to thank our friends for supporting me throughout this race, and the Oley Foundation for what they are doing to help my nephew and families in similar situations.

— Todd Ohlmeyer



Uncle Todd after the marathon.

## Equipment Exchange

The following supplies/equipment are offered free of charge:

### Enteral Formula

- 3 cases Peptamen 1.5
- 12 cases Osmolite One Cal, exp. 7-10/06, 4-1/07, 1-2/07
- 12 cases Perative, exp. 8/06
- 16 cans Jevity One Cal, exp. 11/06
- 5 cases Impact with Glutamine
- 4 cases Impact with Fiber
- 5 Cases (24 ea) Glytrol, exp. 5/06
- 5 cases + 12 cans Jevity

### Tubes/Bags:

- 1 case Kangaroo 1000 ml gravity bags
- 50 Ross Companion Top Fill 500 cc bags
- 30 Ross Companion Ambulatory 500 cc bags
- 35-40 EnterLite Infinity Feeding Bags
- 55 enteral administration bag/pump sets, 1000 cc
- 3 boxes Nutrition Setups for Jevity
- 2 boxes 1200 cc Zevex Feeding Bags

**MORE SUPPLIES** are available! Visit [www.oley.org](http://www.oley.org), or contact Ben Hawkins ([benhawkins@juno.com](mailto:benhawkins@juno.com); toll free 866-454-7351). 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 offer to pay the shipping costs.

## Tube Talk

*Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail [DahlR@mail.amc.edu](mailto:DahlR@mail.amc.edu). Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.*

### G/J-Tube Helps with Reflux

My son, Abe, has a rare disease called Pelizaeus Merzbacher Disease (PMD). It is a form of leukodystrophy. He had a g-tube placed at the age of 5. He refluxed and ended up having pneumonia five times last winter. By chance they did an x-ray with dye and found he was aspirating every time he was fed.

Because he was so sick, they didn't want to do any surgery. Instead they threaded the tube through his current g-tube site down into his jejunum. He now has a g-port, j-port and balloon port. The g-port is drained into a bag so he can't reflux on anything, and the formula goes into the j-port. He has gained weight for the first time in several years and is very healthy. I wish I had known about this option years ago. I hope someone out there can benefit from his story.

— Carla Schauer

208 773-5115, [carlaschauer@verizon.net](mailto:carlaschauer@verizon.net)

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## Preparing Your Child for a Medical Procedure

When a child undergoes a medical procedure, both the emotional and educational preparations are important. The following guidelines are presented from an integrated interpretation of published guidelines developed by various psychological theorists. Thank you to Linda Bensing, Child Life Specialist at Lutheran General Children's Hospital in Park Ridge, Illinois, for submitting this helpful information.

### Guidelines for preparing the 2 to 4 year old:

- Verbal skills are limited and cognitive skills are not yet developed. Therefore, nonverbal communication is strong. Body language becomes the strongest source of communication for both the nurse and parents. Watch your expressions and what your hands are doing.
- Even though the child is developing a sense of autonomy, the 2 to 4 year old has not yet become independent of his or her parents. Therefore, the child's level of understanding simple preparation is correlated to the parents' level of anxiety.
- Fantasy and reality are closely related. Concrete explanations just prior to the procedure are best. Since the element of time is not well understood, explanation should be done "here and now," not a week before the procedure.
- This age group has a limited amount of previous experience, so try to use words that will be the most familiar to your child (i.e., terms your family uses to name body parts, stool, etc.).
- Stress may result in a regression to more baby like behavior. This should be accepted and supported. Don't allow an I.V. to be started on a thumb-sucking hand, request that your child stay on your lap, etc.
- Transitional objects are extremely important in providing comfort (e.g. security blanket, stuffed animal, binky, etc.).
- Anxiety and fantasy are aroused by each experience a child has. Parents should allow these feelings to be "played out" after the procedure.



### Guidelines for preparing the 4 to 7 year old:

- The child's thinking is based on immediate perceptions and experiences. Discuss previous medical experiences and explain how this procedure will be the same or different.
- These children are concrete learners. They focus on what is seen, felt, and heard. They are also very literal, so language choice is very important. For example, if you say, "The nurse is going to start an I.V. in your hand now," your child may picture the nurse trying to stick an ivy plant in his/her hand.
- Fantasy is still closely linked to reality, so a child's perception can be distorted. Be truthful and selective in what is said and seen. Ask your child about a previous "hurt" and correlate it to the amount of discomfort he/she will feel during the procedure. This will also give your child confidence.

- It is common for a child this age to view medical procedures as punishment. Explain what will be done and how you will help your child accomplish this. Refrain from using words that can increase the child's guilt or sense of failure. (e.g., "You're a good girl" If your child is not able to cooperate, it does not mean the child is no longer "good.")

### Guidelines for preparing the 7 to 11 year old:

- The child now has the ability to think and reason logically. He/she still does not have very abstract thinking, so the same concrete details of look, feel, and sound are understood best.
  - Children now have greater attention spans and greater imaginations. Therefore, information should be given ahead of time (clinic, home) including pictures, models, simple anatomy demonstrations, a procedure doll, educational play. Detail is well accepted and understood. Since their imaginations are so vivid, be truthful and complete. Simple analogies help to clarify information (e.g., scopes are used for looking closely at things, like microscopes, telescopes, and endoscopes).
- Again try to relate a similar pain experience to your child.
- A school-age child can be encouraged to write a story or draw pictures. This can reinforce the difficult experience that your child has endured.

### Guidelines for preparing the adolescent:

- The maturity level of adolescents varies widely, especially under a stressful situation in which regression may occur. Be accepting and supportive of all behaviors.
- Again, information should be given ahead of time with as much detail as questioned. Brochures typically given to parents can be helpful.
- Most adolescents are concerned with embarrassment and privacy. Address these issues and explain how you will respect them.

Preparation in all age groups should include truthful information and responses to questions. All children and parents experience increased anxiety when they feel out of control. Therefore children of all ages should be given the opportunity to make a choice whenever possible. Simple choices, such as sitting in mom's lap or on the bed, starting the I.V. in the right or left hand, or putting the oximeter on which finger can all make a big difference in the child's perception of control and will lessen the child's level of anxiety.

*This article is reprinted with permission from EA/TEF Child & Family Support Group, which also offers a brochure entitled "Helping Your Child Cope with Painful Medical Procedures." The brochure outlines specific examples of ways to reduce your child's level of anxiety when undergoing an invasive medical procedure and is available at [www.eatef.org](http://www.eatef.org).*

## In Loving Memory of Katherine Cotter

On March 13, 2006, The Oley Foundation and all the people Katherine Cotter had met along the way, lost a good friend and wonderful supporter. She dealt with many seemingly overwhelming challenges over her life, TPN and cancer among them, but Katherine always worked to be positive and cheerful. She consistently had a good word for everyone and her quick wit kept those around her laughing. Katherine loved to go to Oley Conferences because she wanted to see the people who looked ill and overwhelmed the year before, come back looking healthy, in charge and wanting to help other new consumers and families the way Oley had helped her.



*Katherine Cotter at the 2000 Oley Conference in Boston.*

Katherine became a pen pal to one of Oley's younger consumers and forged a relationship that helped her become the active and beautiful young woman she is today. Being a member of Oley since 1987 brought out the best in Katherine; helping others, but asking for nothing in return. Katherine, you are very loved and will be sorely missed.

*Thoughts for this article came from Joan Bishop, Roslyn Dahl, Robin Lang and Rosaline Wu.*

## Ongoing Research Trials

### •HPN Consumers Needed

HPN consumers are needed to discuss by telephone, what it is like to receive home parenteral nutrition (HPN) and the meaning of food in their life. To be eligible, participants must: 1) receive PN at home; 2) have a diagnosis of intestinal disease, intestinal failure, short bowel syndrome, radiation enteritis, or inflammatory bowel disease; 3) not have major depression; 4) be older than 18 years of age; 5) speak English; and 6) be willing to talk about their experiences during a telephone interview lasting about 60 to 90 minutes.

Confidentiality of all information will be maintained. The interviews will be coded and the participants' identity protected. For more information contact Marion Winkler, MS, RD (800-217-6035; winklema@umdnj.edu).

All of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee; however, *The Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.*

**More information** on these studies is available by calling (800) 776-OLEY or visiting our web page at <http://www.oley.org/Researchupdates.html>. Clinicians interested in having their study listed should complete the form listed on Oley's web page at: <http://www.oley.org/form.html> OR fax the same information to (518) 262-5528.

## Meet pediatric tube-feeding needs with PediaSure® and Embrace™

Children who are tube fed need nutritional products and a delivery system that meet their special needs and the needs of their caregivers as well. PediaSure® Enteral Formulas and the Embrace™ Enteral Pump from Ross can help meet those needs. PediaSure Enteral Formulas meet the nutritional needs of children 1 to 13 years of age, and Embrace meets the needs of caregivers by offering safe, simple operation and the flexibility of ambulatory use.

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## Spotlight on Sheila Messina, RN, MA

Robin Lang

Allow me to introduce Oley Board Member, Sheila Messina, RN, MA, and share a bit of her TPN journey with you.

Sheila has Gardener's Syndrome, which involves tumors in her intestines. She was on and off TPN for a few years early on; but due to the progression of her disease, went on therapy permanently in 1993.



Sheila Messina, RN, MA

To say Sheila keeps active at the age of 70 is an understatement. She lives in San Jose, CA, but travels extensively to wherever her employer needs her to go. A former nurse for many years, Sheila draws on her professional and personal experience as she educates professionals about TPN, pain management, and new equipment. She also speaks at and attends many conferences, Oley, A.S.P.E.N. and AVA to name a few, to educate herself and to share with others.

Sheila is passionate about patients advocating for themselves. She has spoken on this topic at Oley gatherings and advised dozens of individuals via phone and email. With her help they get results. "Sheila works methodically to solve problems, yet makes it look effortless," says Oley's Executive Director, Joan Bishop. "She's a huge asset to Oley and it's members."

Sheila's knowledge and positive attitude empower many. She's a great listener and consumers, young and old, truly appreciate that

about her. One member touched by Sheila's generous spirit is Ann DeBarbieri. "Sheila is an amazing person," shares Anne. "She's dealt with very significant health issues with tremendous style and grace. Even more, she's used her experiences to teach and support others. She hasn't allowed her health issues to slow her down!"

Quite to the contrary, Sheila credits coping with her illness for her determination and can-do attitude. "Before I got sick, I was a wimp," she says with a grin. Through her work, dealing with illness, etc. she is often faced with new challenges, and notes, "Even when I'm unsure about my abilities, I tell myself to keep on going." Good advice for everyone, whether or not you have a chronic illness.

### Visit Oley's New Website!

The Oley Foundation will be launching a brand new website this July at [www.oley.org](http://www.oley.org). The new design will make it easier to find the information you need: catch up on the latest news on the homepage; try the pull-down menus to see who's got the toll-free lines this month; or search the archives for an article on liver disease. You can also download or order Oley publications on-line, like the HEN Complication Chart. The amount of information available at your finger tips is simply astounding! Questions or comments about the website can be sent to Roslyn Dahl ([Dahlr@mail.amc.edu](mailto:Dahlr@mail.amc.edu); 800-776-OLEY).

## Nutrishare is the Home TPN Specialist Pharmacy

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Sarah (parent of Angel)  
Mitzi (parent of Derick)

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# Your Opinions Are Valuable. Help Oley Help Others!

**Nurses**



**HPN Families**



## **HPN consumers and caregivers are needed!**

HPN consumers and their caregivers are needed to help us gain insight into the use of technology to assess and troubleshoot issues and complications that relate to home nutrition support. With funding from the NIH, the Oley Foundation and Carol Smith, RN, PhD are coordinating the effort.

Caregivers/support persons are defined as anyone who assists the consumer in any of the following ways: accompanying them to physician visits, picking up prescriptions, navigating through insurance issues, trouble shooting complications, organizing and/or inventorying supplies, coordinating health care professionals, etc.

We invite you to help us uncover valuable information that could impact the care of many Oley members.

## **Things you should know:**

- ◆ Opinions will be collected via checklists that are completely anonymous.
- ◆ Checklists/opinions will be mailed to a university research center.
- ◆ A summary of all participant (200+ participants) responses will be reported.
- ◆ The required computer, telephone and Internet connection will be provided, along with training.
- ◆ A small fee will be given to each participant.

## **Interested in learning more?**

Complete the survey on the back side of this flyer, and return it in the envelope provided in this newsletter. Or go to the Oley website ([www.oley.org](http://www.oley.org)) and complete the form on-line. If you have questions about the survey, email [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu) or call the Oley office at (800) 776-OLEY.

**Thank You!**

# I am interested in learning more about this study. Please contact me!

## 1. Contact Information

Your Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone # (\_\_\_\_\_) \_\_\_\_\_ - \_\_\_\_\_ Best Time to Call \_\_\_\_\_ am/pm

Email Address: \_\_\_\_\_ @ \_\_\_\_\_

## 2. Are you an HPN consumer or caregiver?

HPN Consumer  Caregiver

## 3. What is your gender? (For research randomization purposes.)

Male  Female

## 4. How long have you been on HPN or caring for the HPN consumer? \_\_\_\_\_ Years

*Caregivers/support persons are defined as anyone who assists the consumer in any of the following ways: accompanying them to physician visits, picking up prescriptions, navigating through insurance issues, trouble shooting complications, organizing and/or inventorying supplies, coordinating health care professionals, etc.*

## 5. Is the consumer receiving any special treatment for depression?

Yes  No

## 6. Does the consumer take any preventive action to avoid catheter complications, i.e. antibiotic lock, special catheter hub, anticoagulant treatment, etc.?

Yes  No

## 7. Type of telephone service:

land line  digital (via cable service)

## 8. Equipment available so that the appropriate materials can be mailed:

CD-ROM  DVD player  Videotape  Audio-cassette player  None of the above

## 9. Computer and/or internet connection available to review consumer and caregiver webpage:

computer  internet  access to computer via public library



**Return completed form in the envelope enclosed in this issue of the newsletter**

(For your convenience, this form can also be completed on-line at [www.oley.org](http://www.oley.org) or mailed to:

The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208-3478.)

## HPN Centers of Experience

*Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight the institutions around the country that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any physician or medical institution but brings this to our consumers strictly as an informational tool.*

### Cleveland Clinic – Cleveland, Ohio

The home parenteral nutrition (HPN) program at the Cleveland Clinic is one of the largest programs of its kind in the United States. The Nutrition Support Team was established in 1975 by Ezra Steiger, MD, a general surgeon, who is still an active member of the team. He was joined in 1991 by Douglas Seidner, MD, a gastroenterologist, who is currently the director of the team. They work together to assure that HPN is provided in a safe and effective manner to consumers who require this therapy.

There are presently over one hundred consumers being cared for each day. These efforts are supported by two dietitians, two nurses, and a pharmacist, social worker, case manager and secretary. These individuals have extensive experience in managing individuals who are unable to maintain their nutritional status through an oral diet as a result of severe malabsorption or intestinal obstruction. In addition, the team works closely with interventional radiologists with expertise in catheter placement, infectious disease specialists who help manage catheter infections and surgeons who perform procedures when it is necessary to relieve bowel obstruction, repair fistula, and sometimes put bowel back into circuit with the digestive tract.

While the primary focus of the program is to provide optimal HPN, the team assesses all consumers to see if they are able to discontinue this form of nutrition support. A new Intestinal Rehabilitation Program focuses on diet modification and when appropriate, growth factors, for those individuals who are able to eat in an attempt to maximize nutrient absorption and minimize or eliminate the need for HPN. The team is also involved in clinical research to advance their understanding of short bowel syndrome and of the complications of HPN so they might best serve consumers who need this treatment.

## To Be (a Parent), or Not to Be

Have you birthed, adopted or raised a child, while you (the parent) depended on home parenteral or enteral therapy? Please consider sharing your thoughts and experiences with other Oley consumers who are exploring their parenting options. As you might guess these consumers have many questions



and concerns that only someone who has “been there, done that” can answer. Parties interested in helping should contact Roslyn Dahl at the Oley office (800/776-OLEY; dahlr@mail.amc.edu).

CORAM



### Can-do Co-ed!

Twenty-one and a half years ago Megan Gravenstein went on TPN. She was a very sick little girl. Now she is twenty-two. She is in college, dating and enjoying life as a co-ed. Studying hard. Living life.

Coram's Advanced Nutrition Services helps Megan and many others who rely on TPN.

We're proud of Megan. She does what she has to do, and she keeps on going. We're there to support her and help whenever we can.

Coram consumers are often like Megan. They take things as they come. They enjoy doing things and they don't let anything prevent them from doing them. We got her started. And we'll be there for the long run.

Contact us toll-free:  
1-866-4-HomePEN (1-866-446-6373) and  
visit us on the Web at [www.coramhc.com](http://www.coramhc.com).



**Coram consumers. Going places. Doing things. Living life.**

### Growth Factors, from pg. 2

Those individuals with the most remaining colon generally have the least fluid loss and need the least PN.

Finally, age and disease effect nutrient absorption. Younger patients generally do better, but there isn't much one can do about age. However, diseases like Crohn's, recurring in even a small segment of intestine can reduce absorption, and must be aggressively treated.

### Artificial Enhancements

There is a limit to the natural adaptation process. In an attempt to artificially enhance the normal adaptive process, several studies have researched the effects of growth hormone, and/or glutamine.

An early study by Dr. Douglas Wilmore and Theresa Byrne suggested providing growth hormone and glutamine, together with a modified diet, would lead to a decrease in the amount of PN patients required. However, the majority of the patients studied had a colon and could decrease their fluid losses simply by changing their diet. Similarly, the progress made by other patients in the study could be attributed to an increase in their overall food intake and consumption of oral rehydration solutions, rather than the growth hormone or glutamine. In addition, there may have been a placebo effect or biased results since the patients, as well as the investigators, knew the patients were receiving a treatment that was supposed to work. Subsequent studies, where the patients did not know whether they received treatment or a placebo yielded little or no decrease in PN dependence. Since then a study in France of patients given only growth hormone, showed a modest improvement in both fluid and nutrient absorption.

Most recently, a study was undertaken that included 41 patients. This four-week study had three groups of patients: those that received only a specialized oral diet and glutamine, those that received the diet and growth hormone, and those who received the diet, growth hormone and glutamine. PN was able to be decreased

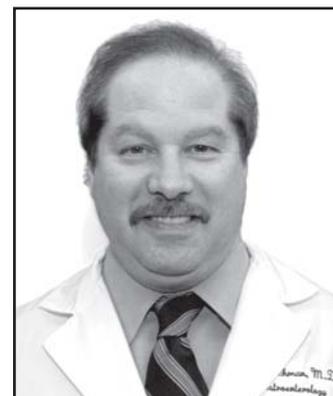
in all patient groups, but more so in those patients that received growth hormone than in those that received the new diet alone. Patients that received growth hormone were able to reduce their PN by an extra day per week. The addition of glutamine had a modest, but not significant, effect on reducing PN requirements. Unfortunately absorption of fluid and nutrients was not measured. This study led to the Food and Drug Administration (FDA) approval of growth hormone for the treatment of short bowel syndrome. Side effects from growth hormone were reported, although these were generally mild. Some patients developed swelling because of the fluid retention induced by the growth hormone, and painful joints (most likely related to fluid accumulation in the joints). The joint pains resolved with growth hormone dose reduction and/or Tylenol®. Other studies have reported the rare development of carpal tunnel syndrome and high blood sugar.

Glucagon-like peptide-2 or GLP-2 is a growth factor that is released in healthy individuals from specialized cells in the distal small intestine and beginning part of the colon in response to eating a meal. Investigators in Denmark found GLP-2 levels did not increase in SBS patients after eating because they were missing the cells that normally produce the hormone. When GLP-2 was administered to SBS patients over a six-week period, fluid absorption improved to a modest degree. The problem is this growth factor is very rapidly metabolized by enzymes in the intestine. Subsequently, Dan Drucker at the University of Toronto, found a way to alter GLP-2 so that it still had the same effects, but lasted longer in the intestines. The resultant teduglutide is currently undergoing investigation across the U.S. and in Europe to determine how it can be used to reduce PN volume and frequency. Initial results have indicated this new growth factor may have some efficacy in decreasing PN.

There are various other growth factors that are just starting to be evaluated for potential therapeutic use. These include neurotensin, transforming growth factor, hepatocyte growth factor (which, interestingly, has greater effects on the intestine than on the liver), keratinocyte growth factor and others. They may be useful in decreasing the frequency of intravenous fluid and PN use in those that require a significant amount, such as 5 to 7 nights a week, but will likely be of greatest use in the individual that requires a minimal amount of PN or perhaps only intravenous hydration fluids.

Information regarding these issues is a "work in progress" and more research is continuing. If you are interested in finding out more about growth hormones, or participating in a study of GLP-2 or any other growth hormone, be sure to discuss it with your physician. More information is also available by calling the Oley office (800-776-OLEY).

*Dr. Buchman is an Associate Professor of Medicine and Surgery in the Division of Gastroenterology at the Feinberg School of Medicine, at Northwestern University, in Chicago, Illinois.*



**Alan Buchman, MD, MSPH**

Unmet needs.  
Unmet needs met. That's our focus at Serono.

We're one of the world's leading biotech companies. For a hundred years, the people of Serono have been focusing on significant unmet medical needs. Meeting them. And helping people live more fully. Embracing life. Enhancing life. That is the spirit of Serono.

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## Individual Donors Make a Difference!

The following list represents everyone who generously contributed towards Oley efforts between March 22 and May 3, 2006. We also want to thank all those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

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## The Oley Foundation Horizon Society

*Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference call Joan Bishop or Roslyn Dahl at 800-776-OLEY.*

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*The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. For their continued interest and strong commitment we remain grateful.*

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

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

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

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

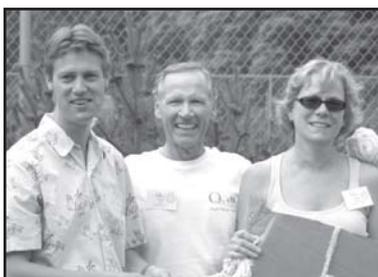
*The schedule of toll-free numbers and volunteer coordinators is updated in each [LifelineLetter](#), and posted on our web page @ [www.oley.org](http://www.oley.org). Comments? Call (800) 776-OLEY.*

<b>JULY '06</b>	<b>Don Young</b> Porter Corners, NY (888) 610-3008 EST	Don has been on TPN for 31 years due to SBS and Crohn's disease. He also has an ostomy. Call him to learn more about CVCs, PICC lines and reimbursement issues (i.e. social security, Medicare, private insurance, etc.) or for a great chat with someone who has a healthy perspective on living with TPN.
	<b>Eleana Shore</b> West Hills, CA (888) 650-3290 PST	Eleana's daughter Erin (age 10) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, Arthritis and Hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.
<b>AUG. '06</b>	<b>Bryan Tims</b> Richmond, VA (888) 610-3008 EST	Bryan has been on TPN since the age of 5 (29 years total) due to a swimming pool accident that left him with SBS. He has completed graduate school, is happily married and works full-time doing molecular testing to track disease outbreaks. He's experienced a short bout of liver abnormality and is receiving pyridrinatate for his osteoporosis. He's traveled within the US and to Mexico.
	<b>Dave Helguson</b> Vancouver, WA (888) 650-3290 PST	Dave is a psychologist and began HEN via a j-tube after losing his esophagus and stomach to Barrette's Disease in 1997. Two years ago he added TPN to his regimen due to problems with malabsorption and chronic weight loss. He is happy to share what he has learned through trial and error to save others from the same pitfalls.
<b>SEP. '06</b>	<b>Jane Golden</b> Watertown, CT (888) 610-3008 EST	Jane has been on TPN since 1993 due to SBS. She has been an RC for many years, has attended several Oley conferences and is an Oley board member. She feels strongly that SBS survivors need other survivors to network with. She worked outside the home until a few years ago and is married.
	<b>Bruce &amp; On Braly</b> Davis, CA (888) 650-3290 PST	The Braly's 17 y.o. son Matthew has been on TPN since the age of 9. He has SBS due to malrotation of the gut and uses a CADD pump. They have traveled abroad with TPN and look forward to sharing their experiences with you.

### LifelineLetter

**The Oley Foundation**  
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**See You Soon!**  
**2006 Oley Conference**  
*June 28 — July 1*  
 Salt Lake City, Utah