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LifelineLetter

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

Bacterial Overgrowth

Jon A. Vanderhoof, MD, Pediatric Gastroenterologist; Rosemary J. Young, MS, BSN, Pediatric Gastroenterology Clinical Nurse Specialist; University of Nebraska Medical Center, Creighton University

Dr. Vanderhoof covered the topic of bacterial overgrowth, as well as other issues related to managing consumers with intestinal failure, in his talk at the Oley Conference in Milwaukee this past summer. To view his presentation, request the videotape from the 2001 Oley Conference: Plenary Session Day 2 on the order form on page 9.

A variety of bacteria normally resides in the intestinal tract. Species vary from the small to large bowel and increasing numbers occur over the length of the bowel, with about 1000 bacteria per milliliter of intestinal contents being present in the upper bowel to almost 1 billion per milliliter in the colon (See Figure 1, page 12)^[1]. There is a lower number of bacteria in the small bowel as compared to the large bowel because of the forward peristalsis of the intestinal tract, bacteriocidal action of gastric acid and bile, reduction by enzymatic digestion and mucus entrapment, low exposure from the environment, and presence of an ileocecal valve^[2].

Bacterial overgrowth in the small bowel is often associated with gastrointestinal anomalies such as those that result in short bowel syndrome. The causes of small bowel bacterial overgrowth include:

- Anatomical abnormalities occurring due to congenital (birth) defects and traumatic alterations (injury/surgery),
- Abnormalities of intestinal peristalsis (motility) such as intestinal pseudo-obstruction,
- Defects of intestinal mucosal surface and immune defense mechanisms (see Table 1, page 11).

Symptoms of small bowel bacterial overgrowth vary depending on the cause of the overgrowth, as well as the location of the excess bacteria, and type of bacteria present^[3]. Most often, symptoms include combinations of abdominal pain and cramping, diarrhea (which can sometimes be bloody), dyspepsia, gas, and weight loss.

Bacterial Overgrowth cont., pg. 11 ←

The Days Are Long, But the Years Are Short!

Stephanie Harlow, HEN Consumer, 2001 *LifelineLetter* Award Winner

*During the awards ceremony at the 16th Annual Oley Consumer/Clinician Conference, the 2001 *LifelineLetter* Award Winner, Stephanie Harlow shared some of the particular challenges and triumphs of her household (see videotape order form page 9. Stephanie and three of her sons are on HEN; a fourth son is on HPN.*

No matter how difficult getting through any one day can be, it is important to remember how precious each day is. I have the choice to have an optimistic perspective, or not. My children, like yours, are learning how to respond to the challenges they face by how I respond to my own challenges. We each have unique opportunities to teach the eating world how to interact with us. We all have the ability to put together a support system, a safety net to hold us up through the hard times. Throughout these tough times, I try to keep in mind that the days may be long, but the years are short.

After many trying years leading up to our diagnosis, we were faced within just a few months with me coming off TPN and going on tube feeds, Kody going on TPN and three other boys becoming tube fed. The psychological impact of seeing four of my boys being tube-fed was difficult to adjust to.

One of the most important things I have learned about being a parent of several tube-fed and one TPN dependent child, is that my kids use me as a mirror. In other words, their perception of themselves, of their health and especially their self-image, is based on what they see reflected in MY eyes! If I look at them with pity, sorrow — project the impression that I am overwhelmed and feel our lives are awful — well, they feel pitiful, full of sorrow, overwhelmed and that their lives are awful.

We strive to project a matter-of-fact attitude about the whole thing. Yes, we have tubes and are fed by formula but that's okay, we feel great, *so let's get on with it*. It



Stephanie Harlow at the Oley Picnic in Milwaukee

Long Days cont., pg. 2 ←

Long Days, from pg. 1

helps for my children to see an adult dealing with it from a social aspect too. I do not ever deny that this is an unfortunate thing that has happened to us, but we can handle it — together — and we will be just fine.

Getting the Routine Down

For the enteral-fed in our household, the first year or so was punctuated by learning the individual needs of each person. Everyone had different motility needs, different amounts and different rates. Some could tolerate bolus feeds better than pump feeds. There was a lot of vomiting in those days. Some days it was

hard to keep up with WHO was vomiting WHAT, and WHEN and HOW much.

It was quite a management feat just to stay on top of all the different supply needs for the household, much less keep on top of who was getting how much of what. We also had on-going food trials from time to time trying to determine who could tolerate which food protein. Every time any food was introduced we all would have delayed symptoms which would disappear with the removal of the food and re-appear with introduction of a new food. I had an anaphylactic reaction to the formula one evening, which put me perilously on the

TPN fence again, but a switch to Elecare (a brand-new formula at that time) and resumption of steroids, along with switching to a G-J tube kept me on tube feeds.

Overcoming the Social Hurdles

We also had to grapple with the social aspects of our non-eating state. I think we were able to manage all of this so well, because we are our own support system. In our house, tube-feeding is the norm. Everyone gets “g-tube milk” as one of the younger boy’s named it years ago.

We’ve had to work hard at having a few accommodations put in place at the schools, but finally, after years of struggle, after learning the American Disabilities Act and the Individuals with Disabilities Education Act, we have managed to get an individualized plan in place for each of the boy’s unique needs. They play sports, go to parties and have birthdays like everybody else.

Our mealtimes are a bit different than most of the world. Our kitchen no longer has a table, but has a couch so three kids and IV poles with feeding bags can sit together. There are two bar stools at the island for the two eaters in the house. Our counter tops sport charging stations for those of us that use feeding pumps and my pantry is filled only with formula, TPN, tube supplies, and feeding bags. We have to plan a little differently to leave the house.

Our tube-feeding requirements are now a part of our daily life. I am grateful for the extra time I have not spent planning meals,

shopping in grocery stores, cooking over a stove, cleaning up afterward. The most important aspect for us, however, is *how much better we feel*. After the years of problems, just to finally know what was wrong with me and my boys was a tremendous relief.

Managing the Medical Needs

We have had to figure out what our needs are from our physicians, our TPN supplier and our enteral supplier, as well as our insurance case manager.

Once we determined those needs, it was our responsibility to adequately communicate those needs. Occasionally, a little coercing is needed to pull everyone back in line. The Harlow family is defini-

nitely a team effort and when any one member of that team isn’t pulling their weight, it puts an extra load on everyone else.

The medical management of something this complex is very dynamic, constantly changing and requires the ability of everyone to “think on their feet” and be pro-active. We have chosen the individuals on our “team” based on their ability to be a supportive participant. This took some work, some adjustments and unfortunately, several replacements. We now have had a team in place that works very well together. We try to keep everyone in communication with everyone else at all times, another very important aspect in complex situations such as ours. Thank God for Email.

All of these things were a matter of making adjustments, identifying the problem and working at it until a solution was found. We approached every challenge this way, took each one individually and gradually solved the problems one by one. We are constantly doing this because as the boys grow and change, adjustments are necessary.

Finding Support

In addition to all the things Keith and I do in the house to manage our unique way of life and manage our family in this world, we learned early on to surround ourselves with supportive friends and family and a medical support system that works for us. That was difficult in the beginning. There was a lot of pity, a lot of questions and people just did not know how to act around us.

Long Days cont., pg. 8

We learned early on to surround ourselves with supportive friends and family and a medical support system that works for us.

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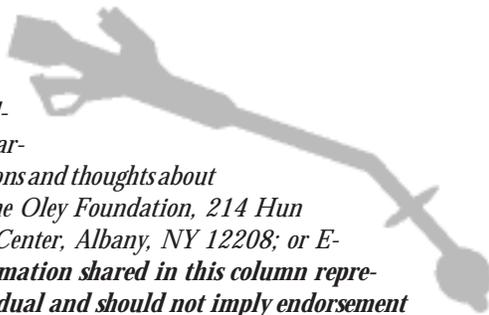
The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

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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.

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.**



No Pain with J-tube Placement

For those of you with surgically placed J-tubes, I have two golden nuggets of advice, compliments of some radiological procedures I underwent recently with Dr. Elvira Lang, Director Cardiovascular/Interventional Radiology, Beth Israel Deaconess Medical Center, Boston, MA. Dr. Lang recently wrote an article on access for the *LifelineLetter*, and spoke on this topic at the 2000 Oley conference.

Prior to meeting Dr. Lang, I had experienced two horrendous procedures to replace and/or reposition my J-tube. I had a standard J-tube which kept falling out of the tract, and spasming in my intestines often caused the tip of the J-tube to end up in places it should not have been. Each of the replacements/repositionings took over two hours without any anesthesia. You could hear my screams of pain from the procedures, two blocks away. Scar tissue in the tract will cause the procedures to be painful, and unfortunately this pain can't be topically anaesthetized with Novocain injections.

My most recent procedure was my first with Dr. Lang. When interviewed prior to the procedure, I was assured that all would be done to minimize discomfort. I listened with great skepticism. Dr. Lang offered me a mild anesthetic intravenously to relax me and mitigate the discomfort. Next she pulled the old tube out for a short distance, sprayed it heavily with an anesthetic called Hurricane Spray (Hurricane Spray* Topical anesthetic, Benzocaine 20%, Beutlich Pharmaceuticals, Waukegan, IL), and slowly pushed it back into the tract. The spray anesthetized the tract from the inside as the tube was pushed back in. Dr. Lang gave the Hurricane Spray a few minutes to work internally and then pulled out the old tube without so much as an, "Ouch." She sprayed the new tube and the guide wire as well. Again, as they were inserted and positioned, I never felt a twinge. The whole procedure was over in 55 minutes without screams, drama, or trauma.

New Tube Stays in Place

The second lesson to be learned from this story is about pain prevention. Dr. Lang chose a different kind of tube for me; one with a pigtail retention which would be far less likely to fall out or need repositioning (Wills Oglesby G-tube, Cook Inc., Bloomington, IN). There is also another model with a mushroom retention to accomplish the same end. When I asked why these tubes are not universally used, Dr. Lang explained that it was because both the pigtail and mushroom tubes are called G-tubes, not J-tubes. Although they are G-tubes, they work well as J-tubes without interrupting the transport of food in the gastrointestinal tract.

If you identify with any or all of this story, you need to speak to the radiologist prior to your procedure about the pigtail, the mushroom and the Hurricane. Ineffective tube configurations and painful procedures are not necessary, as proven by a knowledgeable, compassionate physician/radiologist.

— Diane V. Owens
Marion, MA

Equipment Exchange

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

- 3 cases Isomil, exp. 12/01
- 3 cases Neocate Plus, pineapple/orange
- few boxes Neocate Plus, unflavored

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.

We've Moved!

The Oley Foundation web site has moved to a new location on the world wide web. Our new site can still be accessed by our domains:

www.oley.org

www.homePEN.org

...but now is much faster, making it easier for you to view and download information.

Please note: specific addresses published in previous issues of the *LifelineLetter* that contain our old "wizvax" address, will eventually no longer work. The information is still available, but you'll need to go through the links on our new home page. If you have any questions about finding information on our web page, don't hesitate to contact Cathy Harrington at HarrinC@mail.amc.edu or (800) 776-OLEY.

We'd like to use this opportunity to remind readers that a wealth of information is available via our webpage, including, but not limited to, articles published in the *LifelineLetter* since 1995.

We are hugely indebted to Stephanie and Keith Harlow, who have donated the new space which we share with NEEDs, an organization that serves patients with Eosinophilic Enteritis (EE) and related diseases. Stephanie and Keith also provided much-needed technical support during the transition.

We also want to thank Harish Charmarthy, who helped us with many technical questions, and along with his wife, has underwritten the Foundation's two domain names. ©

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Participants Needed for Study on Eosinophilic Disorders

Physicians at Children's Hospital Medical Center of Cincinnati need participants for their study of eosinophilic disorders of the gastrointestinal (GI) tract (i.e. the esophagus, stomach, intestines). These disorders are associated with an increased number of eosinophils in the organ affected. Eosinophils are a specific cell type that have been closely linked to allergies.

Eosinophilic disorders are difficult to diagnose and include Eosinophilic Gastroenteritis (EG), which affects the stomach and/or small intestine; Eosinophilic Esophagitis (EE), eosinophilic infiltration confined to the esophagus; and Eosinophilic Colitis (EC), eosinophilic infiltration confined to the large bowel. Symptoms may include feeling full before finishing a meal, swelling, reflux, diarrhea, abdominal cramping or pain, nausea and vomiting, blockages. Patients with these disorders often require enteral, and sometimes parenteral, nutrition.

Currently physicians are trying to expand their limited understanding of the eosinophil-associated disorders of the GI tract by obtaining demographic information via a web-based survey. Full details on the purpose of collecting information, confidentiality issues, the researchers' affiliation, and more can be found at their web site at <http://www.cincinnatichildrens.org/eosinophils>; or by contacting them at (513) 636-7210 or eosinophils@chmcc.org.

A second source of information is Stephanie Harlow, Executive Director of The National Eosinophilic Enteritis Disease Foundation (NEED). NEED is dedicated to increasing the awareness of EE and related diseases; promoting professional research; resolving treatment and quality of life obstacles; and influencing federal, state, and local government policy to benefit EE disease sufferers. To find out more about NEED, visit their web site at <http://c4isr.com/NEED/>; or contact them at (540) 786-4795 or administrator@NEEDsupport.org.

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Conference Session Just For Teens

Malisa Matheny

Teens at this year's Oley Conference had their very own session, entitled "Transitioning to Independence." Led by myself, and two other young adults on HPN, Mariah Abercrombie and Alicia Hoelle, participants had the opportunity to be among their peers and talk about issues that arise when living with TPN or enteral nutrition. This was one breakout session with no adults allowed!

Mixed with conversations about illness, tubes, and coping were lots of fun activities. Alicia started everyone out playing a game that got all of us comfortable and laughing. Then we addressed some of the issues that young people had on their minds and made a poster focusing on issues of independence. Teens also had the opportunity to participate in a contest to guess the number of M & M's in an empty TPN bag. The boy and girl that guessed the closest won a prize of their choice. Prizes included a Blockbuster gift certificate or a Bath and Bodyworks basket full of goodies. Re-



Allison Hillen, Beatrice Weaver and Alicia Hoelle during the teen session.

freshments were served and after everyone had the opportunity to chat, teens made bracelets out of hemp and beads to take home with them. Both parents and young people commented on how much they enjoyed having a session just for this age group. If you missed it this year, hopefully we will see you at the next Oley Conference in Anaheim!

Thanks to Nutrishare for sponsoring this session and to Mariah Abercrombie and Alicia Hoelle for helping to lead it.

Want Your Newsletter Delivered Sooner?

If you have email, and want your copy of the *LifelineLetter* two to three weeks earlier than regular postal delivery, call Oley today! The time savings for people outside the continental United States is even greater.

Rising postal costs and slow overseas and Canadian delivery times instigated a new practice at the Foundation. Dozens of our foreign members now receive the *LifelineLetter* electronically, rather than through the mail. The electronic version is sent as a pdf file which requires Adobe Acrobat Reader™ to open. This free software is available to download at www.adobe.com. Sample *LifelineLetters* in pdf file format are posted on our webpage at <http://c4isr.com/oley/lifeline/artind.html>.

Switching your subscription from a paper to electronic copy also saves Oley money. The Foundation's postal costs have been rising steadily for the last five years, and are nearly double what we paid in 1995. Electronic subscribers can always switch back to paper copies if they so desire.

To sign up for this free service, or ask questions about how the process works, email Cathy Harrington at HarrinC@mail.amc.edu.

The Oley Family Fondly Remembers

Nancy Harvey

Jim Harvey

Nancy Harvey died July 23, 2001, at age 49, from complications related to pneumonia and kidney failure. She had lived with severe Crohn's disease for nearly 30 years, and had been on HPN since 1980.

An experienced educator, Nancy taught French and English from 1976 to 1999 in public schools in St. James, Vienna and Cuba, Missouri. She loved animals and had become interested in writing in her later years. She was an outspoken opponent of abortion and euthanasia. We will miss her kind and gentle spirit.

*To learn more about Nancy, read her profile in the January/February 2001 issue of the *LifelineLetter*, on-line at <http://www.c4isr.com/oley/lifeline/nancy.html>.*



Nancy Harvey

Julie Bishop

Julie Bishop, a long time Oley volunteer and daughter of Oley's Executive Director, Joan Bishop, died suddenly, September 16, 2001, at age 30. Over the years Julie had provided countless hours of support in the Oley office, at regional picnics and at many annual conferences in Saratoga Springs, NY, and in Memphis, TN. She was also a regular visitor and moral booster for the Oley staff.

Julie had a special warmth and charm that pulled her Oley friends and family closer together. She loved life, fishing, being with friends and family, and most of all, her 3-1/2 year old daughter, Guiliana. We miss her dearly. ☺



Julie Bishop with her daughter, Guiliana.

Good News, Bad News

The bad news is that the photos from pages 5 and 6 make the electronic version of the LLL too large to send via email, and therefore were not included in this file...



The good news is that these photos are available, in full color, on our website at:

<http://c4isr.com/oley/best.html>

Questions? Email DahlR@mail.amc.edu

Long Days, from pg. 2

Our closest circle of support includes those people who were with us during the most difficult times and can understand our perspective now... *that our tube-feeding and TPN give us our life back, they do not take it away.* We have found that surrounding ourselves with people who are upbeat, optimistic and can appreciate the simple joys of life are win-win relationships.

Other than my husband, a few close friends and family members, I find strength and support from organizations like the Oley Foundation and unwavering support from our internet support group filled with the collective experiences and wisdom of parents and patients who have been on TPN in some cases nearly 20 years. It is very reassuring to know if I'm having one of those down-days, or had a frustrating medical encounter, I know there are going to be friends who not only understand what I'm talking about, but understand the consequences and the big picture. I would very much like to take the opportunity to thank them, to point out that this type of support is crucial. They should be recognized and applauded for their support for one another.

Though this lifestyle is extremely difficult at times, I have learned to be grateful for what these challenges have brought to our lives. I am grateful to live in a time where my disease can be accurately diagnosed, and technology can replace food with an amino-acid based formula for myself and three of the boys. For Kody, and on two separate occasions for myself, the advances made in the availability and administration of TPN therapy has kept us alive.

I stop often and watch Kody riding his bike, zipping around the cul-de-sac we live on and try to just soak it all in. How wonderful it is when he is feeling good, and just living and being happy. How wonderful it is when I am feeling good, when **all** the boys are feeling good. I get a level of joy from simple things that most people in our society who do not have these challenges will not appreciate until the autumn of their lives.

Taking Care of Myself

This is not to say, however, that I don't have an occasional poor-me pity party. Another

important thing I have learned is that I have to allow myself some occasional down time. After a significant Kody-crisis, I have learned to give myself a day or so to just cry and be upset — usually beginning with a sappy movie or some sad story that I just completely over-react to. I recognize that as just what it is: an opportunity to vent/project my own frustrations, fears and sorrow, and I allow that to happen. You can't keep it all bottled up inside. A little venting from time to time can prevent big explosions farther down the line. Families like yours and mine who can expect intermittent traumatic medical crises cannot afford to be pressure-cookers. You don't want to have to deal with letting off all that steam in a middle of a crisis which in and of itself is enough to drive anybody over the edge. Take

Though this lifestyle is extremely difficult at times, I have learned to be grateful for what these challenges have brought to our lives.

care of yourself, keep a handle on your own needs and psychological well being so that when you have to face the crisis that will come, you will be able to get through it, then quickly recover after it's over and get back to enjoying life. Remember, the days may be long, but the years are short.

Never has that rang more true than the last two weeks in June in the Harlow household. Attending Kody's kindergarten graduation followed the next day by my oldest son's high school graduation, brought everything quickly back into perspective for us. Friday night, just five days ago, it all came together, quite literally, at the very last minute. Kody had been discharged from the hospital with a fresh central line with very little time to spare, but we managed to make it to our oldest son's high school graduation ceremony. Cameras were charged and ready, tissues were close at hand. The previous couple of weeks beginning with my very inconvenient laceration and resultant repair, formula and tube problems; the difficulties with two separate school education plans; a traumatic change in nursing and pharmacy companies; Kody's broken back and the new finding of osteopenia; the senior pranks (involving a 6

foot shaving cream snowman); Kody's septic episode, resultant line removal and roller-coaster hospitalization, were all behind us. All that mattered is that we were together, we got through it all okay and successfully graduated our first-born child.

I am a firm believer in the tenacity of the human spirit. Within every one of us is the ability to persevere, no matter what the obstacle. I think it is simply a matter of personal choice, and at some point during our initial years on parenteral and enteral therapy, we chose optimism. For the Harlow family, we are going to take each new day and find some joy, some happy defining moment and hold on to it.

I believe each of us has a specific purpose on this earth. We each have different strengths and weakness, we each have a very unique individual spirit. I have a personal goal to continue to do all I can to help find a cure for the disease that keeps my family on tube feeds. I believe by working together with others we can support and empower each other toward a common goal. Each family in our network of eosinophilic disease sufferers and each family of the Oley Foundation is at a different place in their journey, but we each have something to contribute and together we can help hold each other up. By continuing to network, we will reach our goal faster, we will find a voice and we will be heard. In fact, we are already making a difference.

For our family, we choose to live our lives with an optimistic perspective. I try to keep in mind that my children's attitudes are a reflection of what they see in me. I want them to have full and happy lives, confident in who they are and confident of their place in our world. I am blessed beyond measure with the support from my internet TPN and Eosinophilic families, organizations like the Oley Foundation, a fairly large and ever-growing supportive team of health care professionals, and a community including friends, family, and a few very special teachers who have been open and willing to learn about our alternative lifestyle. We are all learning together how to make a place at the table for everyone. The days are long but the years are short. Make the most of each day that you have, no matter what, and you can look back with peace, happiness and satisfaction. ☺

The Oley Foundation Video Tape Library Order Form

The Oley Foundation's video tape collection has just grown again! Filming of the latest set of tapes — those covering the 2001 Oley Annual Consumer/Clinician Conference — was coordinated and underwritten by Abbott Laboratories. Many thanks for their generosity and support.

Consumers and clinicians are welcome to borrow any of the video tapes in Oley's library at no charge. (We'd be delighted if you could cover the \$3 shipping and handling charge per video.) Simply complete and return the order form. Tapes are available on a first ordered, first served basis, and must be returned within one week of receipt. Tapes produced by Oley may be copied for repeat viewing.

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Optional: Enclosed is a check for \$ _____
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The Oley Foundation, 214 Hun Memorial, A-28, Albany Medical Center, Albany, New York 12208

Indicate your choice by checking the box. Limit 2 tapes per order.

Information About The Oley Foundation

- Support for Life: The Oley Foundation

Enteral — Tube Feeding

- Tube Feeding (1997, MSKCC)
 Tube Feeding: A Matter of Nutrition

Miscellaneous

- Choices in Nutrition: Understanding HPN Therapy Options (Free, with \$5 shipping/handling charge)
 1992 Breakout Session: The Comings & Goings of Crohn's

2001 Oley Conference

- Plenary Session Day 1: Who Wants to Be a Millionaire?
Featuring: Infection, Travel, Motility Disorders, Trace Elements
 Plenary Session Day 2: Managing Intestinal Failure: Multi-Disciplinary Approach, from Diet to Surgical Options
Plus: 2001 Oley Foundation Memorial Service
 Breakout Session: Transplantation
 Breakout Session: Preserving Your Liver
 Breakout Session: Good Grief (Coping with Loss)
 2001 Oley Foundation Awards Ceremony

2000 Oley Conference

- Plenary Session Day 1: Awards Ceremony, Catheter & Site Selection, Site Preservation, Catheter/Tube Infections
 Plenary Session Day 2: Insurance Issues, Medicare Legislative Issues, Coming of Age (20s) on HPEN
 Breakout Session: Interpreting Your Own Lab Values
 Breakout Session: Liver Disease
 Breakout Session: It's Your Line: You're the Boss

1999 Oley Conference

- Plenary Session Day 1: Preserving Venous Access, Independence/Dependence Issues, Physician/Patient Relationship, Defining the Role of the Oley Foundation
 Plenary Session Day 2: Using the Gut, Liver Disease, Bone Disease, Venous Access Management, Health Care Corporate Compliance
 Breakout Session: Using Your Gut
 Breakout Session: Pediatric Issues
 Breakout Session: Keeping Complications to a Minimum

More Videos Listed on Back 

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1998 Oley Conference

- Plenary Session Day 1: Thrombotic Catheter Occlusions, Transition from TPN to Oral and Enteral Nutrition
- Plenary Session Day 2: Evaluating and Acquiring New Equipment, Tips for Traveling with HPEN, Living Fully, Decision Making: Who's Involved and How Much?
- Breakout Session: What's Missing in TPN?
- Breakout Session: Complications from TPN
- Breakout Session: Research: What's Being Done?

1997 Oley Conference

- Plenary Session Day 1: Switching Physicians/Seeking Second Opinions, Switching Therapies, Reducing Dependency on TPN, and Returning to Work
- Plenary Session Day 2: History of TPN, Current Medical Challenges, Small Bowel Transplantation Update, Reimbursement Issues
- Breakout Session: Update on Inflammatory Bowel Disease
- Breakout Session: Improving Gut Functions
- Breakout Session: Reducing Complications from TPN

1996 Oley Conference

- Has HPEN Met It's Early Expectations?
- Plenary Session Day 1: Catheter Dressing Techniques, The Evolution of Infusion Control Devices, and HPEN Research
- Plenary Session Day 2: Maintaining Control in the Presence of Chronic Pain, Taking Charge of Your Health Care, and Advice on Insurance Issues
- Breakout Session: Minimizing the Risk of Liver Disease
- Breakout Session: Is Enteral Nutrition for Me?
- Breakout Session: Pain Management

1995 Oley Conference

- Plenary Session Day 1: Managed Care from the View of the Provider, Insurer and HPEN Consumer
Plus: The Annual Awards Ceremony, Regional Coordinator Workshop and Help Plan Oley's Future

1994 Oley Conference

- Opening Remarks: How HPEN Began
- Plenary Session Day 1: Alternatives to HPN, Catheter Complications, Pros and Cons of Tube Feeding, and Bowel Lengthening
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1993 Oley Conference

- Plenary Session Day 1: Small Bowel Transplantation and Dietary Program to Enhance Bowel Function
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- Breakout Session: Pain Management
- Breakout Session: Sepsis & Catheters

Please Return Videos Promptly!

Bacterial Overgrowth, from pg. 1

Diagnosing Overgrowth

Identifying the cause of small bowel bacterial overgrowth, and even diagnosing it as the cause of the patient's symptoms, is often challenging. Aspirating fluid from the bowel during an upper gastrointestinal endoscopy was once considered the gold standard for diagnosis; however, this method is often not helpful because it may be impossible to aspirate from the area where the overgrowth is occurring and because methods of culturing the fluid are often affected by errors in obtaining and processing the fluid. Glucose breath hydrogen testing is sometimes beneficial in identifying overgrowth. Glucose is used as a substrate for this breath test because it is rapidly metabolized by bacteria in the small bowel (before it can be absorbed) and results in excess hydrogen which is easily detected in the patient's breath^[4]. Other diagnostic tests include quantitative and qualitative evaluation of urine for indicans and detection of an elevated level of serum d-lactic acid, both of which indicate bacterial metabolism^[5-6]. At times, d-lactic acidosis can be so severe as to cause seizures and metabolic acidosis with

coma. Elevated serum folate levels may also be present with bacterial overgrowth. The presence of a dilated bowel segment on upper GI x-ray may identify the location of overgrowth in advanced cases.

Treating Overgrowth

Treatment of small bowel bacterial overgrowth is varied, depending upon the severity of symptoms. Broad spectrum antibiotics have been utilized with fairly good success. Long-standing cases of bacterial overgrowth or the presence of very pathogenic organisms require more aggressive, and often a combination of, treatments^[7].

Diet

The simplest method to treat small bowel bacterial overgrowth is to alter the patient's diet. If chronic low-grade symptoms are present, utilizing a high fat (50-60% of total caloric intake), low carbohydrate diet is beneficial: it reduces the food substrate which most bacteria thrive on, i.e. carbohydrates; and limits bacterial proliferation, which results in symptomatic improvement. If the patient is eating a completely oral diet, achieving a high fat intake is often not difficult; however, reducing concurrent carbohydrate intake is more of a challenge (see

Table 1. Etiological Factors Associated with Small Bowel Bacterial Overgrowth

<i>Anatomic disorders</i>
Diverticula
Surgical loops
Bowel obstruction (complete or partial)
Intestinal resection with dilatation
Loss of ileocecal valve
Enterocolic fistula
<i>Motor disorders</i>
Chronic intestinal pseudo-obstruction
Autonomic neuropathy (diabetic)
<i>Immunologic mechanisms</i>
Immune deficiencies (innate or induced)
Malnutrition
Reduction of gut-associated lymphoid tissue after resections
<i>Non-immune mechanisms</i>
Achlorhydria or hypochlorhydria
Deficiency of exocrine pancreatic secretions

Table 2, page 13). Consultation with a dietitian is helpful in this regard and it is our experience that this diet should be rigidly adhered to on a daily basis. If the **Bacterial Overgrowth** cont., pg. 12

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Bacterial Overgrowth, from pg. 11

person is also receiving enteral formula, modifying the solution by the addition of fat and/or switching to a higher fat formula, such as Pulmocare®, may make a significant difference.

Antibiotics

If the dietary therapy is insufficient to control symptoms, it should be continued with the addition of antibiotics. Broad spectrum antibiotics, such as Bactrim and Flagyl, used continuously, at half the usual antibiotic dose, are often very effective. Trials of different antibiotics may be needed to find the right combination. In addition to Bactrim and Flagyl, we have found Augmentum and Keflex to be beneficial. Our most severe case of small bowel bacterial overgrowth was a child with short bowel syndrome who suffered severe d-lactic acidosis with seizures. He went through several treatment regimes before we identified oral Vancomycin, a potent antibiotic, as an effective measure to control his overgrowth. After the acute overgrowth has been controlled, antibiotic therapy may be required only for a few days out of every month or may be so severe as to require prolonged continuous therapy. If symptoms reappear after a few months, switching antibiotics is often necessary. We have seen no development of antibiotic resistant complications utilizing this therapy over prolonged periods of time, probably because of the low doses utilized.

Probiotics

Probiotic therapy is another potential treatment for small bowel bacterial overgrowth. Probiotics are live, human-derived microorganisms that benefit the person taking them by improving their intestinal microbial balance. There are many probiotics available, but few have undergone rigorous evaluation in clinical studies. Lactobacillus GG has been well studied and found to be beneficial in some mild cases of

bacterial overgrowth⁸¹. One child that we followed seemed to respond to antibiotic therapy initially, but eventually became symptomatic regardless of the antibiotic protocol utilized. He had experienced severe arthritis due to bacterial by-products from his overgrowth. The addition of Lactobacillus GG, (2 capsules a day,) to Flagyl therapy significantly decreased his arthritic symptoms.

Bowel Flushes

If medication therapy is not effective, or if symptoms are quite severe, daily or weekly bowel flushes may be beneficial. These routines work by mechanically flushing excess bacteria from the bowel. We have found daily use of low dose magnesium citrate or Miralax® (both osmotic laxatives) to be helpful for some of our patients. At times, simply having the patient attempt to pass stool every couple of hours is sufficient to improve their condition. Many patients with short bowel syndrome have learned to avoid stooling in order to control their frequent watery bowel movements, which can be particularly counter-productive when they have bacterial overgrowth.

Avoid Acid Suppression Agents

There have been some reports of bacterial overgrowth being exacerbated by the use of acid suppression agents. These agents are commonly used in patients with short bowel syndrome to help control excess acid production and reduce small bowel fluid losses. Using acid suppression agents can be harmful because they suppress gastric acid which plays a normal role in reducing the bacteria consumed in the diet. Therefore, if possible, these agents should be avoided or reduced in dosage.

Steroids

Inflammation from bacterial overgrowth can be so severe as to result in a colitis situation with bloody stools. In addition to treating excess bacteria through antibiotic therapy and diet, it may be necessary to use sulfasalazine and/or corticosteroids to reduce the inflammation caused

Figure 1. Micro-organisms in the GI Tract

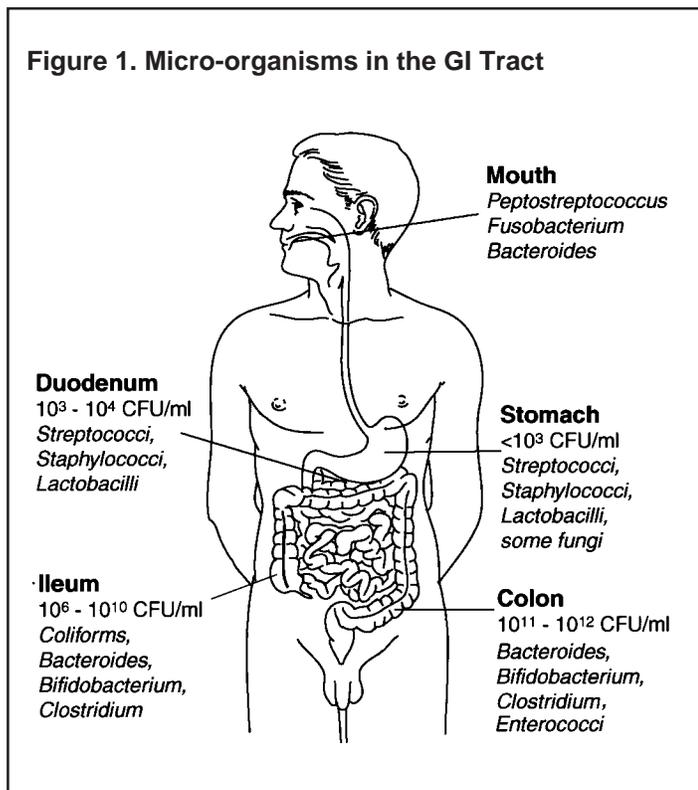
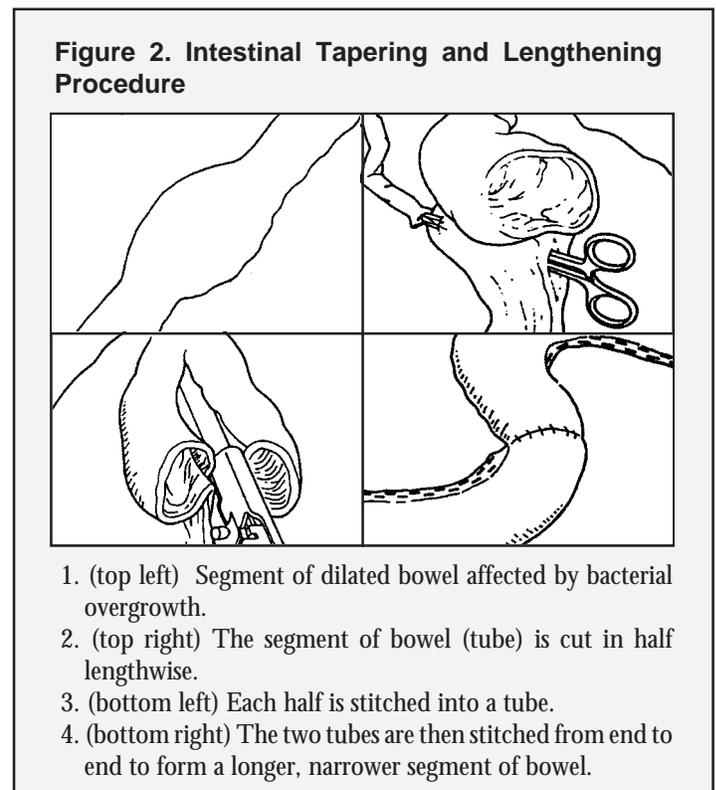


Figure 2. Intestinal Tapering and Lengthening Procedure



by the excess bacteria. This is only used in extreme cases and on a very short-term basis.

Surgery

Severe situations of small bowel bacterial overgrowth unresponsive to dietary, medical, or mechanical measures may require surgical therapy. Temporary colostomy placement or an intestinal tapering and lengthening (Bianchi) surgical procedure may be beneficial in these cases^[9]. These methods, of course, are not without complications themselves and should only be reserved for the most severe cases (See Figure 2, page 12).

Small bowel bacterial overgrowth is a condition which can occur at any time in many consumers of home parenteral and enteral nutrition. If a previously stable homePEN consumer becomes symptomatic with diarrhea, weight loss, abdominal pain, cramping, and an increase in intestinal gas, this condition should be considered. Numerous measures are available as treatment options. Research into this area is ongoing especially in the areas of probiotic therapy, and new surgical measures. ©

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Table 2. Low carbohydrate, high fat diet

FOOD	ALLOWED	EXCLUDED
Milk and milk products	Whole milk, cheeses, unsweetened yogurt Minimum 4 servings recommended daily (1/2 cup milk or yogurt, 3/4 oz. natural cheese serving size)	Low fat milks, ice cream, ice milk, low fat yogurt
Vegetables	All allowed Minimum 3-5 servings recommended daily (1/4 to 1/2 cup serving size) Add butter, cheese or gravies	Any with sweetened sauces (i.e. candied sweet potatoes)
Fruits	Fresh fruits, unsweetened canned fruits Minimum 2 to 4 servings recommended daily (1/4 to 1/2 cup serving size)	No juices, no sweetened canned fruit (i.e. in heavy syrup)
Meats & Meat Substitutes	All allowed including peanut butter, eggs, dry beans, nuts Minimum 3 to 5 servings recommended daily (1 oz. cooked meat, poultry, fish; 1 egg; 1/2 cup cooked beans serving size)	None
Breads, Cereals, and Starches	Low sugar cereals, breads, crackers, rice and pastas Minimum 6 to 11 servings recommended daily (4 crackers, 1/2 slice bread, 1/4 to 1/2 cup rice or pasta serving size)	Sugar coated and sweetened cereals, frosted or sweetened muffins, rolls, doughnuts.
Fats	All allowed. Butter, margarine, salad oils, cream cheese, salad dressings, bacon, etc.	None
Desserts	Use allowed fruits	All but allowed fruits
Soups	Any	Sweetened dressings and sauces
Beverages	Whole milk, water	All sweetened
REMEMBER:		
1. No pop, juices or sweetened drinks (Koolaid®) allowed!		
2. No desserts, candies, etc.		
3. Snacks should consist of high protein and/or high fat foods - like hard cooked eggs, whole milk, peanut butter, cheeses, cold meats, pizza, etc.		

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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.

DEC. '01

Kathleen McInnes (HEN)
Chicago, IL
(888) 610-3008 CST

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.

Laura Krueger (parent)
Memphis, TN
(888) 650-3290 EST

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.

JAN. '02

Ben Hawkins
Cincinnati, OH
(888) 610-3008 EST

Ben Hawkins has been on HPN since 1980. He had a port-a-cath for the last 10 years, but in September went back to a Hickman catheter. He has used many brands of pumps, both portable and pole mounted, and last year went through the process of qualifying for Social Security Disability.

Barbara Klingler
Malabar, FL
(888) 650-3290 EST

Barb has been on TPN for 15 years due to a volvulus. She is active in her church and raises future guide dog puppies. While on TPN she has camped cross-county and traveled the Caribbean, including a recent cruise. She has also been scuba diving with her Hickman. She looks forward to speaking with other consumers.

FEB. '02

Linda & Angie Mitchell
Bryan, OH
(888) 610-3008 EST

Diagnosed with pseudo obstruction at 11 mos, 17 y.o. Angie has been on TPN for 15 years. She has also been on j-tube and g-tube feedings. Angie has lived much of her life in hospitals far from home. Angie and her parents, Linda and Merrill, would like to speak with fellow teens and parents. Call Angie after 6 pm EST.

Nancy Groat
Grand Haven, MI
(888) 650-3290 EST

Nancy is a single retired nurse with a very supportive family. Diagnosed with Lymphangectasia she has been on TPN for 7 years which has improved her quality of life. She has a support group for people with rare disorders. Nancy is currently on disability and can share her experience with the process.

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