Intestinal Care Centers: Who, What, When, Where
Laura E. Matarese, PhD, RD, LDN, FADA, CNSD

Intestinal failure refers to the loss of absorptive capacity of the small bowel secondary to severe gastrointestinal (GI) disease or surgically induced short bowel syndrome (SBS). The presenting features include chronic diarrhea, dehydration, electrolyte abnormalities, and malnutrition. Individuals with intestinal failure are often supported with specialized nutrition, including parenteral and enteral nutrition (PN and EN, respectively), and specialized oral diets and formulas.

Intestinal Care Centers: Mission and Goals
Intestinal care centers are specialized centers devoted to the care of individuals diagnosed with intestinal failure or GI dysfunction. At their best, these centers provide a comprehensive range of services, including evaluation, nutrition support, nutritional rehabilitation, medical management, restorative surgery, and intestinal transplantation. Their goal should be to restore nutritional status through the safest, most physiologic techniques compatible with the patient’s lifestyle and wishes.

You can think of an intestinal care center as being like a three-legged stool (see figure 1). The seat represents the intestinal care center and the legs that support it are the services the center provides: parenteral and enteral nutrition, intestinal rehabilitation (such as diet modification, oral rehydration solutions, soluble fiber, medications, growth factors, and surgical reconstruction), and intestinal transplantation.

Intestinal care centers can provide “one-stop shopping” for those with GI dysfunction or intestinal failure. The services provided should be interrelated.

A Matter of Trust
Laura Bailey, RN, BSN

I am the mother to a medically fragile four-year-old boy, Tyler, who suffers from short bowel syndrome. As a result of the short bowel syndrome, Tyler has a central venous catheter for the administration of parenteral nutrition (PN). Though I am a registered nurse and am now capable of providing all of Tyler’s home care, this care was never taught in nursing school at the level I need to know—and Tyler didn’t come with instructions. I had to learn on my own how to best administer PN at home (HPN) and proper line care.

It has taken me a decent amount of time to learn everything. I have spent the past four years educating myself about Tyler, how to best care for him, and how to care for his central lines. As I’ve learned, I’ve become more and more diligent.
with each step of the process. I have worked so much with Tyler that it has become difficult for me to hand over any of his specialized care to anyone else. This leaves me with a lot of work, but there are a number of plusses to not sharing the nursing side of Tyler’s line care.

Infections
Of course line infections scare me. They are life-threatening events and should be prevented as best as possible. Tyler has had several line infections, with most of them occurring the first year of his life. Those infections were all managed pretty easily with antibiotics and occasionally a night or two in the hospital. Fortunately, it is unusual now for Tyler to end up with a line infection.

I realize there is no guarantee Tyler will remain infection-free if I am the only one accessing his central line, which at present is a PICC (peripherally inserted central catheter). However, I have significantly more experience working with Tyler in this regard than anyone else does, and with only me accessing Tyler’s line, I am confident that everything possible has been done to help prevent any sort of infection. There’s no question in my mind regarding his central line care.

I know without doubt everything that happens related to Tyler’s PICC line care because I’m the only one involved in assessing and caring for it. This allows for consistency of care. Being that I change Tyler’s dressings, I know what’s normal for him and what’s not from week to week. I am able to evaluate his site and note any changes, like line placement and signs and symptoms of infection. There’s no question about what the site looked like previously or how long something has been the way it is.

It would be difficult to monitor the site if I had to depend on others to maintain it. For these reasons and others, I do not mind the extra work associated with being the only one to care for Tyler’s PICC line. I have peace of mind and that’s worth a lot to me.

Mom’s Touch
At this point, I know when Tyler is brewing something before he even spikes a fever. I can tell just by looking at him. I watch my son closely, monitoring for signs and symptoms of illness, noting what his unique cues are when he is sick. Perhaps it’s motherly instinct or maybe it’s from my experience with him, but I know when something’s wrong.

I know how to hold him in a way that’s nonthreatening to him, yet keeps his hands securely out of the way while I’m connecting his HPN. I have earned his confidence with dressing changes. He will hold his arm out for me without a struggle as I complete the procedure with sterile technique.

I have come to learn the best way to wrap his arm to keep his line clean and protected. I have learned how to make the line secure under the weight of the large HPN bag and HPN pump Tyler drags along when he crawls faster than I am able to follow, acting as his IV pole.

Tyler allows me “all access” to himself and his central line because he has learned to trust me. All I do is in an effort to keep Tyler infection-free and to keep his central line in good working order.

Dad’s Role
My husband, Mike, does help with Tyler’s care. He takes Tyler for long walks, changes his clothing if Tyler needs it, prepares his favorite snacks, watches him while I go to the grocery store, and plays with him. He does all of the typical things dads do. He also helps me put some medical supplies away and takes turns with me chasing Tyler around the house with his HPN and pump. I appreciate and want Mike’s help.

Mike is also willing to help with connecting and disconnecting Tyler’s HPN. However, I keep this task for myself. I feel asking Mike to jump in now and try to learn what has taken me four years to master would be unfair of me. There are just too many fine details that I do without even thinking about it for him to learn right off the bat. But Mike does know how to do it if he absolutely needs to.

If I could go back in time, I would have included Mike while I administered Tyler’s HPN and learned everything else that goes along with central line care. It was my mistake not to involve him more in the beginning, when we were first faced with life with a central line. Apparently, I forgot the “team” in “teamwork,” leaving myself with a lot of work. As they say, hindsight is 20/20. But as mentioned above, there are a lot of plusses to managing Tyler’s line myself.

Caution Warranted
Unfortunately, I have found that when Tyler has been hospitalized, some of the nurses have not been nearly as careful as I am with sterile technique. As a result, it has become
Equipment/Supply Exchange

Check out Oley’s Equipment/Supply Exchange whenever you need or would like to donate homePEN supplies or equipment—from formula to tubing to feeding bags and more.

A description of how the program works and a complete list of available items is posted on the Oley Web site at www.oley.org/equipexchange.html. The list is updated weekly. So check often.

New!
The site is easier to use than ever! Go to the list, click on an item, and you’ll be ready to send an e-mail request directly to Cathy at the Oley office. Or call the office from 9 a.m. to 4 p.m. EST, (800) 776-OLEY.

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 Metzgel@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.

Declogging a Tube

In response to a question on the Oley online chat forum (www.inspire.com/groups/oley-foundation) about what to do with a clogged tube, one mother contributed the following tip.

My daughter was prescribed a combination of one capsule of pancrealipase combined with 1 tablet of sodium bicarb dissolved in 10cc of water and instilled into the tube. You draw back whatever you can and put in as much of the enzyme/bicarb solution as you can and let it sit. Flush with as much water as you will tolerate before your next feed, and it should clear. This is particularly effective for unclogging GJ-tubes.

My daughter is 3 1/2 and this combination has prevented a G-tube change at least four times in the last year.

—Regbrigidmom
aka Allison Kidd
allison_m_kidd@yahoo.ca


flourishment

NEW Peptamen Junior® 1.5 formula. All the proven power of Peptamen Junior now packed with greater caloric density.
Give a Thoughtful Gift: A Message from Oley’s President
Rick Davis

Gift giving and gift receiving are parts of many occasions, and we like to give and receive something thoughtful. For many of us, the Oley Foundation has been a gift that has profoundly affected our lives. Oley staff and volunteers give us the gifts of their time and talent every day. All of us—clinicians, caregivers, corporate partners, and consumers—value the work of the Oley Foundation and the positive difference it has made in the lives of thousands of people. What can be more thoughtful than remembering the gift of Oley by making a gift to Oley as part of our final bequest?

It always seemed like a good idea to me to make this kind of a gift, but up until recently, I had never gotten around to it. I think many of us are like that—we have good intentions, but just haven’t acted on them yet. Besides, we are more inclined to think about living and less inclined to think about dying and what we should do before it happens. But we all know we are going to die, right?

Have we thought about what we will leave for our loved ones? Have we thought about what we can do for those people and organizations that have had importance in our lives and, especially, those that will continue to be important to others after we are gone?

My Motivation

This is Joan Bishop’s twenty-fifth year with the Oley Foundation! Now Oley’s executive director, Joan has been with the foundation almost since day one, and has given generously of herself to support and nourish it through its early—and sometimes lean—years. What better way to celebrate this anniversary than to give a gift that will help ensure the Oley Foundation’s future? Marking the occasion was the push I needed. I am pleased to say I am now one of the newest members of the foundation’s Horizon Society, and I encourage you to mark Joan’s anniversary with a similar commitment.

A planned gift to Oley, in your will or otherwise, will not cost you anything in your lifetime. Making a bequest is simple. It is a good thing to do. It is thoughtful. Planned giving can also be a stimulus to get you to do the right thing for your family, to plan for their future. If you do not have a will, you should get one. And if your will is outdated, you should update it and keep it up-to-date. Your family deserves it. You know you should do it.

Options

There are many ways to make a planned gift to the Oley Foundation, in addition to including the foundation in your will. Several types of planned giving are described on the Oley Web site, www.oley.org. Click on Donate, then Planned Gifts. On this page you’ll find an outline of the options available, the simplest of which is the bequest. You’ll also find a link to a story of how and why Oley co-founder Lyn Howard, MD, chose to name the Oley Foundation as a beneficiary of a life insurance policy. For more information and the details of planned giving, please contact Joan at (800) 776-6539 or bishopj@mail.amc.edu.
I just saw my lawyer and updated my will. I left a gift to the Oley Foundation and I made other changes that will be updated from time to time. It was a good thing to do for many reasons. And I feel good I followed through on that good intention. I hope you will do the same. The Oley Foundation is a gift. Give a thoughtful gift back.

Oley 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 contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
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Jim Cowan
★ NEW! Rick Davis ★
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Valerie Gyurko, RN
Alfred Haas
Shirley Heller
Alicia Hoelle
Jeff & Rose Hoelle
Lyn Howard, MD
William Hoyt
Darlene Kelly, MD
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Robin Lang
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★ NEW! Michael Medwar ★
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Nancy Nicholson
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Kay Oldenburg
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Bright Ideas

Information shared in this column represents the experience of the individual and does 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 More Tangles

The Beata Clasp® is billed as a "solution to tangled hospital tubing and tubing misconnections," but you can also use it at home for the same purposes. It is a soft, latex-free foam device that separates lines. This makes it easy to distinguish one from another, to keep them tangle free, and to follow each line back to its source. It struck us as a great idea for people who have multiple lines.

While one side of the product is clamped to a bedrail, IV pole, or other surface (it worked on our desk tops and the arm of our office chairs), the grooves on the other side separate your tubes. The product literature claims, “Medical tubing, lines, and drains fit securely into the product’s bank of circular grooves without occlusion or restriction.” The clasp comes in two sizes (with three or four grooves) and in three colors. The clasps are $5.50 each, plus shipping and handling. For more information or to order, contact the company at (800) 796-5840; info@beataclasp.com; or www.beataclasp.com.

—Oley Staff
metzgel@mail.amc.edu

Capping CRBSIs

I had difficulty with the first injection cap I was using. The septum of the cap would frequently stick, making it difficult to disinfect; it was also necessary to change the cap frequently, due to flushing or infusion difficulty.

I really like the injection cap I am now using. It is very reliable and easy to use. Further, the InVision-Plus® Neutral® injection cap, manufactured by RyMed Technologies, Inc., is designed to reduce the chances of catheter-related bloodstream infections (CRBSIs), as well as intraluminal thrombotic catheter occlusions.

The surface of this injection cap is tightly sealed and it’s easy to clean it thoroughly with an alcohol swab. There are no crevices for bacteria to hide in. It is also compatible with chlorhexidine, so you have the option of using a Chlorascrub™ Swab for added protection.

The cap is available in a “creamer” type of packaging. You simply peel back the covering and the injection cap is ready to be attached to the end of the catheter without being touched.

With most injection caps, blood enters the catheter when you connect or disconnect syringes or tubing, which increases the chances that the catheter will become blocked. This cap advertises zero fluid displacement, which means that when you connect or disconnect, mechanical blood reflux does not enter the catheter. Because of zero fluid displacement, you do not need to use any specific clamping sequence with this cap; you can use the clamping sequence you are familiar with.

I found this cap felt “tighter” when I connected to it. It has a double microbial barrier system to protect the fluid pathway from contamination. During activation, both barriers must be “pushed in” to access the fluid pathway. This tight connection is easy to get used to, but I would suggest you take a spare flush syringe and spare cap and practice connecting it a few times to get the feel of it.

There is an online demonstration video showing cap changes with the special “creamer” packaging, the “tighter” feel when hooking up syringes, and other tips on RyMed’s Web site, at www.rymedtech.com/ This company also provides educational materials about bloodstream infections on its Web site.

—Tess M. Hopkins
tmhop@yahoo.com

Note: The injection cap idea was submitted by an Oley consumer member who noted that the manufacturer helped write the more technical parts of the article. InVision-Plus® and Neutral® are registered trademarks of RyMed Technologies, Inc. Photos used by permission.
Travel Tip: To and Within the United States

State regulations require that a physician practicing in the state must write any prescription being filled in that state. If you are traveling to the United States from another country, or traveling from state to state within the United States, the easiest way to replace prescription items is to visit a local on-call or urgent-care medical facility, so a doctor there can write a prescription. Have contact information for your local health care team with you; the ability to connect them with the physician in front of you will facilitate the writing of a prescription. A list of supplies, prescription items, etc., signed by your local medical team, can also expedite the process.

Are You Getting Your Mail?

If you've opted to receive e-mails from the Oley Foundation, you'll want to be sure they can make it into your inbox! With spam accounting for so much of today's e-mail, your Internet Service Provider may have implemented filters that block mailings addressed to multiple recipients—like our newsletter mailings. Our e-mails to you may end up in your spam folder or blocked entirely. To avoid this, be sure to add our address, harrinc@mail.amc.edu, to your address book or contact list. We'd hate to miss you!

Ongoing Research

Hirschsprung's Disease Genetics Study

Dr. Aravinda Chakravarti's laboratory at Johns Hopkins University has been investigating the genetics of Hirschsprung's disease (HSCR) for more than fifteen years. The purpose of the study is to continue the search for genes involved in HSCR and to further characterize the known genes and the interactions between them. The study will hopefully lead to a better understanding of the genetics of HSCR and, further down the road, improved diagnosis, treatment, and genetic counseling.

Study volunteers will be asked to complete a medical/family history questionnaire, provide access to some medical records, and submit blood samples from the individual(s) affected with HSCR and his/her parents (if available).

If you are interested, a kit containing all the materials necessary to participate can be sent to you. There will be no cost to you. Individual results are not disclosed but newsletters are distributed with updates about the study’s findings.

For more information please contact the study coordinator, Courtney Nichols, at (410) 502-7541 or hirschsprung@igm.jhmi.edu.

Note: Contact information has been updated from our earlier announce-ments of this study.
Trust, from pg. 2

Increasingly more difficult for me to rely on my own peers (nurses) while Tyler is in the hospital.

There was one incident when Tyler’s tubing came unattached from his PICC and ended up on the floor of his hospital room. When the nurse came in, she nonchalantly picked up the tubing, wiped the end off with a small alcohol pad, and went to reattach it to Tyler’s PICC without any consideration for where that tubing had been and the contaminated T-clave that had been rubbing against my son’s clothing. My jaw hung open in disbelief. All I could say was, “No, no, no!”

This event shook me to my core, as the consequences of that nurse’s actions could have been deadly.

On another occasion, the nurse who was bringing Tyler’s PN to his room to hang it allowed the tubing to drag on the floor all the way down the hallway, as he swung the bag of PN back and forth in merry fashion. Fortunately, I happened to step out and see this, and I insisted on new tubing.

I could cite several examples like these. Now, when Tyler is in the hospital I am leery of anyone who enters his room with the intention of accessing his PICC. In most situations, I insist on being the only one who even touches his line. I often am met with great resistance, but I hold strong. My son’s life is dependent on proper care and I’m not about to take any chances.

Personal Preferences

I belong to an online group of parents and individuals who are all managing short bowel syndrome. The people in this group have been a tremendous help, both for general information and emotional support. I have found that I am not alone in choosing to be my child’s only central line caregiver, but also that there are some who allow others to help.

Within my group, there are some parents who feel as I do and keep the central line responsibility strictly to themselves. Others share that responsibility with their husbands. Some allow their home health nurses to connect and disconnect their child’s HPN, once the nurse has established his or her competency.

None of the parents, however, simply assume that because someone is in scrubs he or she knows what he or she is doing, and allow free access to their child’s line. It takes time to determine if an individual can be relied upon with our special and precious children. Most of our children are considered “frequent fliers” in hospitals, so some of the parents have come to trust the nurses whom they’ve come to know. However, these parents still “watch the nurses like a hawk and gently encourage them to use [their family’s] protocol” (as one parent in my group put it) because they know their protocol is effective in preventing infection.

Trusting Others

I’ve always found it a little tough to entrust my children to others, but now that one of my children has medical problems it’s a lot harder. I have more to consider than how well I know a person or if that person has good references. For me to feel comfortable, I have to know that anyone caring for my son watches out for the usual childhood hazards, but also knows the many, many other things that pose a threat to him, even if some of those things seem harmless—like getting wet.

It’s almost as if anyone caring for my son must be able to watch him as a typical child and care for his central line as a separate entity. Tyler is a challenge because of his medical issues and I do not leave him with anyone other than my husband or his grand-parents, who all know the drastic ramifications of PICC dislodgement and septicemia.

I remember the day that I left my daughter, Chloe, at a home daycare for the first time. She was two years old and I was in nursing school. I worried that she would be confused and scared,

...but I totally trusted the woman, Christine, who would be caring for her. Christine had worked at my elementary school when I was in the first and second grades, and I clearly remembered her being soft-spoken, kind, and gentle. I had visited her home prior to leaving Chloe for the first time and it was warm, friendly, and filled with art projects that her little kids had created.

It was relatively easy to trust Christine, who had experience and had proven reliable with my daughter’s care. But circumstances have changed for me. It’s not so easy for me to trust others with my son, who requires so much more than my daughter did.

If there were the equivalent to Christine for Tyler, a loving and reliable person who had a strong history of caring for central lines with little infection, maybe I would trust again … maybe. For now, I will continue to be my son’s only nurse and I will continue to do so happily, with pride, peace of mind, and a lot of love. ¶

Tyler’s mom, Laura, keeps a blog about Tyler and their experiences, and invites you to visit it at http://www.freewebs.com/tylersdog
Enter Our Drawing!

Where would Oley be without you, our members? You are our reason for being! Please take a minute now to renew your membership and update your membership information. You can use the envelope enclosed or do it online at www.oley.org. Either way, respond by July 17 and you’ll be entered into a drawing for a $50 gift card.

It is really helpful for us to have up-to-date member information, especially your diagnosis, therapy (PN, EN, or both), phone number (with the correct area code), and e-mail address. In the last several months, hundreds of Oley members have earned money by sharing their experiences in focus groups or interviews. Tight deadlines usually mean we can only invite members we can contact by phone or e-mail. And we’d like to be able to invite you!

Sometimes, too, researchers turn to us to get an idea of how many people are on HPN or HEN, how many people have short bowel syndrome, how many people have motility disorders, etc. We won’t share your personal information and we won’t sell our mailing list, but it is useful to have an overall picture of our membership base.

You can easily update your member information online at www.oley.org. Choose “Join” and fill out the appropriate form. Or enclose a brief update in the envelope enclosed in this issue.

Please consider, too, making a donation to help support Oley’s programs. The suggested donation for consumers and family members is $20, and for professionals, $40. Your dollars make the Annual Conference, Equipment Exchange, LifelineLetter, Forum, MY HPN learning module, toll-free lines, the Regional Coordinator program, and so much more possible.

Oley Exhibits, Help Needed

We are looking for volunteers to help distribute information and answer questions about the Oley Foundation at exhibits at several upcoming conferences. As a volunteer you can usually visit other exhibits and talk to company representatives, and you’ll always meet interesting conference attendees. For exhibit times and other details, please contact Kate Swensen at swensek@mail.amc.edu or call the Oley office at (800) 776-6539.

- Association for Vascular Access (AVA) Annual Scientific Meeting, Riviera Hotel and Casino, Las Vegas, Nevada, September 14–17
- American College of Gastroenterology 2009 Annual Scientific Meeting, San Diego Convention Center, San Diego, California, October 23–28
- Virginia Chapter ASPEN, Crowne Plaza Hotel, Williamsburg, Virginia, November 13–14

A Customized Care Approach

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nutrition support program

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877.WeNourish
(877.936.6874)
Intestinal Rehabilitation, from pg. 1

designed to meet the needs of the individual patient/consumer, and provided by a multidisciplinary team that includes surgeons, physicians, pharmacists, nurses, dietitians, and social workers.

HomePEN

Many intestinal care centers specialize in home parenteral and enteral nutrition (homePEN or HPEN). If you are failing PN (that is, your liver is not tolerating the PN, or you have multiple line infections or vanishing vascular access), it may be worth your while to visit one of these special centers. They may be able to recommend changes in your PN prescription or discuss other issues with your local physician to help you.

Even if you are doing well you may benefit from visiting one of these centers once a year for an evaluation. It is like taking your car in for a tune-up: sometimes it is best to do a little preventive maintenance in order to avoid a bigger problem down the road. The advantage here is if the clinicians in the intestinal care center have broader experience with PN or GI failure than your local physician, they can use that experience to shed light on your individual case. It is important that you, your physician, and the center all communicate effectively regarding your care in order to get the most benefit from the recommendations.

Intestinal Rehabilitation

Intestinal rehabilitation includes strategies and therapies designed to make the remnant bowel work better, such as nutrition support, nutritional rehabilitation, medical management, and restorative surgery. Anybody who has had major small bowel resection might benefit from at least learning about rehabilitation strategies. These strategies and therapies are likely to be especially helpful for anyone with short bowel, which in adults is usually defined as 150 cm of small intestine and no in-continuity colon, or 60 to 90 cm of small intestine plus 50 percent or more of colon.

Nutrition Support and Nutritional Rehabilitation—These may include diet modification and/or the use of an oral rehydration solution (ORS) or soluble fiber. Candidates must be able to eat by mouth to benefit from dietary strategies.

Medical Management—Standard medications such as antidiarrheal agents, antisecretory agents, and bile acid sequestrants may be used. In December 2003, the Food and Drug Administration (FDA) approved the use of growth hormone (Zorbtive®) for patients with SBS receiving specialized nutritional support. Zorbtive® should be used in conjunction with optimal management of SBS, which may include dietary modification, PN, EN, and fluid and micronutrients supplementation. Nutritional supplements may be added according to the discretion of the treating physician. All treatments must be adjusted for individual patient requirements and preferences.

Surgical reconstruction—Sometimes the native gastrointestinal tract can be surgically reconstructed to make it more functional. Surgical reconstruction is individualized and requires a consultation with a surgeon. The surgeon may be able to put an isolated loop of small bowel back into circuit or do some other creative surgery, such as a lengthening procedure, to give you more absorptive surface. Surgical reconstruction procedures include longitudinal intestinal lengthening (Bianchi procedure), serial transverse enteroplasty (STEP), and reverse segments (rare).
Intestinal or Multivisceral Transplantation
A patient should be thoroughly and carefully evaluated before the
decision to proceed with intestinal or multivisceral transplantation
is made, and such evaluations are done at intestinal care centers. In
general, you must have irreversible intestinal failure in order to be
considered for this surgery, along with evidence of the onset of comp-
llications associated with PN, such as PN-associated liver disease.

Table 1. Medicare-Approved Intestinal Transplantation
Centers (by state)

<table>
<thead>
<tr>
<th>Name and address</th>
<th>Effective date</th>
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<tbody>
<tr>
<td>University of California, Los Angeles Medical Center</td>
<td>May 23, 2003</td>
</tr>
<tr>
<td>108336 Conte Ave. Los Angeles, CA 90024</td>
<td></td>
</tr>
<tr>
<td>Jackson Memorial Hospital</td>
<td>April 1, 2001</td>
</tr>
<tr>
<td>1801 NW 9th Ave. Miami, FL 33136</td>
<td></td>
</tr>
<tr>
<td>Clarian Health Partners, Inc.</td>
<td>June 7, 2005</td>
</tr>
<tr>
<td>I-65 at 21st Street Indianapolis, IN 46206-1367</td>
<td></td>
</tr>
<tr>
<td>Mount Sinai Medical Center</td>
<td>April 1, 2001</td>
</tr>
<tr>
<td>One Gustave L. Levy Place New York, NY 10029-6574</td>
<td></td>
</tr>
<tr>
<td>Children’s Hospital of Pittsburgh, University of Pittsburgh Medical Center</td>
<td>January 5, 2006</td>
</tr>
<tr>
<td>3705 Fifth Ave. Pittsburgh, PA 15213-2583</td>
<td></td>
</tr>
<tr>
<td>University of Pittsburgh Medical Center – Presbyterian</td>
<td>April 1, 2001</td>
</tr>
<tr>
<td>UMPC Montefiore 7th Floor, Suite N725 3459 Fifth Ave. Pittsburgh, PA 15213-2582</td>
<td></td>
</tr>
<tr>
<td>Georgetown University Hospital</td>
<td>June 24, 2004</td>
</tr>
<tr>
<td>3800 Reservoir Road, NW Washington, D.C. 20007-2113</td>
<td></td>
</tr>
</tbody>
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Notes:
—This reflects all centers listed as of May 28, 2009. See www.cms.hhs.gov/ApprovedTransplantCenters for the most up-to-
date information.
—Other centers provide HPEN and/or intestinal rehabilitation.
They are not listed above because they either don’t do intestinal transplants, or don’t have Medicare approval to do intestinal transplants. It is also possible that your own physician and dietitian may be able to do intestinal rehabilitation for you. (The Oley Foundation is aware of many, but not all, centers with PEN, intestinal care, and/or transplant experience. A list of these centers can be found at www.oley.org/medical_expertise.html.)
repeated life-threatening catheter infections, and/or lack of vascular access. The most common cause for the intestinal failure leading to intestinal transplantation is SBS, but transplants are also performed for dysmotility and malabsorption syndromes.

Not every hospital performs these types of transplants. Medicare has approved certain centers to perform intestinal transplants (see table 1). From a transplant center’s perspective, many patients who are referred for intestinal transplantation are often referred very late. Approximately two-thirds of patients transplanted in the United States last year for intestinal failure also required liver transplantation (combined liver-intestine) or liver and intestine along with addition organs (multivisceral transplants). The combined liver-intestine transplants and multivisceral transplants are much bigger operations performed on much sicker patients, and may be associated with poorer outcomes than isolated intestine transplants. Patients with irreversible intestinal failure who are being followed, at least peripherally, by an intestinal care center that also offers transplants have the advantage that transplantation, if it becomes inevitable, can be optimally timed to avoid unnecessary liver replacement.

These centers offer a complete assessment of adults and children with short bowel syndrome, intestinal failure, and dependence on parenteral nutrition.

When to Visit a Center
What happens when you visit one of these centers? When should you go? These centers offer a complete assessment of adults and children with SBS, intestinal failure, and dependence on PN. Since intestinal care centers offer a comprehensive approach to the treatment of intestinal failure, they can do a variety of tests to evaluate the extent and severity of the intestinal failure and gastrointestinal dysfunction. A thorough review of the PN prescription is also performed by an experienced team of medical PN specialists.

Making It All Happen
So, now you have decided that you want to visit an intestinal care center for a review. How do you make it happen? You can approach your physician about getting a referral for an evaluation. Gastrointestinal dysfunction requiring PN therapy is complex, and most physicians are pleased to have suggestions on ways to enhance or improve the management. Alternatively, you can refer yourself. However, most of the major intestinal care centers would prefer to work closely with the primary local care-providers.

Intestinal Rehabilitation, cont. pg. 14 ▶

Myth or Fact?

➤ Any physician or medical center can provide PN. Unfortunately, this is a myth. There are many superb clinicians who do PN well. But PN is best done by individuals who have special training, are board certified, and/or have a special interest. Someone who is board certified in nutrition support and has experience with PN will have the following credentials after his or her name: CNSC (certified nutrition support clinician), CNSP (certified nutrition support physician), CNSD (certified nutrition support dietitian), CNSN (certified nutrition support nurse), or BCNSP (board certified nutrition support pharmacist).

➤ PN is dangerous and expensive, and will destroy your liver. It is true there are risks associated with PN, but these are minimized when the therapy is managed by knowledgeable individuals and patients are compliant with all safety protocols. The cost of home PN is approximately $100,000 to $150,000 per year. Parenteral-associated liver failure is a potential complication, particularly in patients with SBS, but not everyone with SBS on home PN develops this complication.

➤ Everyone can be totally rehabilitated. This too is a myth. Many people do quite well with various intestinal rehabilitation programs. Through these programs, you may be able to reduce or totally eliminate the need for PN. Unfortunately, however, not everyone responds to intestinal rehabilitation. But clinicians generally agree that if there is any way they can make the bowel work better, they will try it. And it may be that an intestinal care center can help optimize your PN.

➤ You need to take special growth factors, such as growth hormone, to be in a bowel rehabilitation program. This is not necessarily true. Many patients are able to reduce their requirements for PN with diet modification, or by using ORS, soluble fibers, and standard medications. Others may need hormonal therapy such as Zorbtive® (growth hormone), or GLP-2, which is still investigational.

➤ If you go to a transplant center you will automatically be transplanted. This is a myth. In fact, most transplant centers try NOT to transplant. Patients are transplanted only when it is indicated. If a center can rehabilitate your remaining bowel either through diet modification, medications, or surgical reconstruction, they will try this first. Sometimes the clinicians will just recommend you stay on PN and offer suggestions on improving the PN prescription. The most appropriate therapy is used for each patient. The goal of an intestinal care center is to improve your medical and nutritional status and enhance your quality of life.

➤ Transplantation is a last resort and should be considered experimental. This is another myth. Intestinal transplantation is no longer considered experimental. It is now a Medicare-approved therapy and has saved and improved the quality of life of many patients. The view currently held by many intestinal care centers is it is better to transplant early rather than wait until a patient is so sick that the outcomes might not be as good (see earlier comments comparing isolated intestinal transplant with combined/multivisceral transplants). Whether this applies to you, however, can only be determined by a thorough evaluation.
More Resources on the Web

As we go to press, the FDA has announced it will be updating all of its Web sites. Some of the addresses below may be changed, or may link you to a new address. We will post the new addresses on our own Web site, www.oley.org, under “Other Organizations,” as they become available.

Safety Information
A new Web page created by the FDA’s Center for Drug Evaluation and Research (CDER) has made it easier to access information about prescription medicines, recalls, labeling, clinical trials, and so on. Go to www.fda.gov/cder/drugSafety.htm and click on any of the links.

Pumps and Problems
The FDA Web site www.fda.gov/cdrh/CDRHHHC/brochure-infusion.html provides basic information about infusion pumps. Topics include traveling with a pump, preparing for emergencies, and who does what (an outline of the consumer’s, supplier’s, and homecare company’s responsibilities).

Having a problem with medical equipment or a medicine that you’d like to report? Go to “Your Guide for Reporting Problems to FDA” at www.fda.gov/consumer/updates/reporting_guide061008.html.

Medication Records
It’s important to have a complete and up-to-date list of your medications to take with you should you have an emergency, or just for your next doctor’s visit. There are a number of Web sites that will help you create such a list and then allow you to print it out. Here are two that we’ve found: www.fda.gov/cder/consumerinfo/my_medicine_record.htm and www.azcert.org/consumers/med-record.cfm.

If you find other sites for recording your medications—or when using the Internet in general—be careful about inadvertently submitting your personal or contact information to the company or organization sponsoring the site. The two sites listed above, for example, do not collect the information you record on the forms; they just provide a tool to make it easy for you to create a complete personal medical record. Other sites might ask for contact information for marketing purposes. This isn’t always bad! Just consider the purpose and make an informed decision before you sign up.

This and That
For a little bit about everything health related, check out CHAIN Online. CHAIN stands for the Clinician-Consumer Health Advisory Information Network, and their Web site has a lot of diverse information. Check them out at www.chainonline.org.

If you are looking for an activity for a rainy or sick day, check out the Story Corps Web site, at www.storycorps.org. Story Corps is an oral history project. The project’s mission “is to honor and celebrate one another’s lives through listening.” You can listen to wonderful personal stories on this site, or, by clicking on “record your story,” you can find a great list of questions on which you can base your own interview. Sometimes it’s hard to know what to talk about when someone is ailing and you are worrying. A list of questions, and the act of recording the answers, can be a rewarding way to fill that empty space.
Most centers will require prior approval from your insurance company before you can be evaluated. The good news is that many of these centers will get that prior approval for you.

**Pediatrics**

It is important to note that this article is specific to intestinal failure in adults. Some of the information is pertinent to infants and children, but as with all circumstances, children are not just little adults. For example, the length of bowel an infant or child requires in order to survive without PN support is generally much less than that necessary for an adult and they can potentially achieve independence from PN with tube feedings.

If your child has intestinal failure, it is important that he or she be cared for by a physician who has experience in this area. Your child may need a referral to a specialized center, but again, this needs to be a center that has pediatric expertise.

**A Real-Life Example**

A thirty-seven-year-old female with a history of superior mesenteric artery (SMA) thrombosis and previous small bowel resection and jejunostomy was referred to the University of Pittsburgh for evaluation for small bowel transplant. Although the patient had short bowel syndrome, it was determined during the evaluation that her bowel had dilated and she may have enough to undergo a bowel lengthening procedure.

The patient was taken to the operating room and a STEP procedure was performed to increase the length of her bowel, and potentially improve the function of the dilated segment. After surgery she was started on an intestinal rehabilitation program that included modified diet and standard medications. She was eventually weaned off PN over the course of several months, thus avoiding transplantation. In this real-life example, the patient was referred to small bowel transplantation but was able to be rehabilitated instead.

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**Tincture of Opium**

If you have a prescription for deodorized tincture of opium but:

- your plan—public or private—has removed it from its formulary;
- you’re in the Medicare “donut hole”;
- you’ve reached the maximum of your private insurance policy; or
- filling the prescription would cause you financial hardship,

there may be a program available to help you afford to get the prescription filled. Marathon Pharmaceuticals, now the sole manufacturer of tincture of opium in the United States, offers patient support/ reimbursement options. Contact Marathon directly at (866) 945-7860, option 6, to see what might be available to you.

The Patient Advocate Foundation (PAF) is also available to talk to you about filing an appeal with Medicare, if that seems like the appropriate course of action. They can be reached at (800) 532-5274. Ask to speak to a Medicare case manager.

Let us know how you make out. It would help us steer others in the right direction.

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**News You Can Use**

**Especially for Ostomates**

“In North America alone, there are approximately 70,000 new ostomy surgeries performed every year.” So begins the “Handbook for New Ostomy Patients,” written and compiled by the Vancouver Chapter of the United Ostomy Association of Canada (2006) and distributed by Evansville Ostomy News. You don’t have to be new to the world of ostomies to benefit from the handbook. It is full of tips and interesting, inspiring stories. It is available online at www.ostomy.evansville.net/ostomyhandbook.htm. While you’re there, you might want to visit the Evansville Ostomy News homepage and sign up for their online newsletter (at www.ostomy.evansville.net).

You can also download an ostomy travel certificate on the site (at www.ostomy.evansville.net/certificate.pdf). The hope is that such a certificate would allow you to travel a little more easily through airport security points with an ostomy.

**For Anyone with IBD**

If you’re willing to share your story for the benefit of others, look into the Great Comebacks® Program, a cooperative effort of ConvaTec, the Crohn’s and Colitis Foundation of America (CCFA), the United Ostomy Associations of America, and the Intestinal Disease Education and Awareness Society (IDEAS).

The Great Comebacks® Web site states, “Through the awards, and the efforts of the recipients, we hope to further de-stigmatize intestinal diseases…and help give people the hope, guidance and the information they need to make their own great comeback.” There are awards for adults, teens/young adults (a $1000 scholarship), and children. For details and application, go to www.greatcomebacks.com or call (858) 259-2092. **Deadline for all awards is July 15.**
Individual Donors

The following list represents everyone who contributed between March 27 and May 19, 2009. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

- Merck Partnership for Giving, to match Mindy Reibstein’s gift in memory of Libby Levin
- Cheryl Thompson*

**President’s Circle ($1000–$1999)****
- Friends (Up to $30)
  - Gretchen DeKalb, in honor of Mary Kunz’s Birthday
  - Kimberly Morgan

**Benefactors ($50–$999)**
- In Memory of Betty Gray
  - Alan & Darlene Amark
  - Maizie Brown
  - Dave & Bonnie Cox
  - Scott, Debi, Bryan, & Amanda Emery
  - Charlene Gray
  - Alvin & Mary Jackson
  - Lucille LaFollert
  - Walter Leja
  - Dan & Sue Skelton
  - Don & Barbara Stracener
  - Friends (Up to $30)
  - Gretchen DeKalb, in honor of Mary Kunz’s Birthday
  - Kimberly Morgan

**Sponsors ($250–$499)**
- Supporters ($50–$99)
  - Brenda Hansen
  - Erik Jacobson, in memory of Kenneth Crosby
  - Jo Ann Preston, in honor of Rowan Windham
  - Laurie Reyen, in memory of Jim Alvarez

**Patrons ($100–$249)**
- Anonymous, via United Way of the Capital Region (Albany NY area)
- Betty Bailey, with God’s help and Oley info, I’ll make it!

**Contributors ($30–$49)**
- Kathleen** & Larry McIntire

**Join Us in Thanking Our Supporters**

**Applied Medical Technology, Inc.**

Applied Medical Technology, Inc. (AMT) was present at the birth and development of the percutaneous endoscopic gastrostomy (PEG) movement. The company’s founder co-invented the first button low-profile feeding device. “Since then,” the company writes, “AMT has introduced innovative designs and materials to advance PEG tubes by increasing patient comfort while improving patient outcomes. AMT’s Mini ONE® Balloon and Non-Balloon Buttons have unique design features that provide increased patient comfort and long life.” The company’s products are compatible with other manufacturer’s feed sets as well as its own feed sets and accessories.

**Critical Care Systems, Inc.**

Critical Care Systems is a leading national specialty infusion company that provides comprehensive clinical services to pediatric and adult populations through a national footprint of Joint Commission accredited community-based branches. The company’s Specialty Nutrition Support Program is supported by a team of dietitians, nurses, pharmacists, and reimbursement specialists who excel in parenteral nutrition, clinical support, and customer service. Whether their customers require short- or long-term therapy, Critical Care Systems provides flexible, individualized care adapted to the consumer’s lifestyle.

**Walgreens-OptionCare**

Walgreens-OptionCare is a single-source provider of total parenteral nutrition and/or enteral therapy with individualized care based on the patient’s therapy needs. The company’s services provide care to those of any age and at any condition stage. Walgreens-OptionCare proactively manages the consumer’s nutritional requirements with a thorough medical assessment, therapy monitoring, and 24-hour access to healthcare staff.

Walgreens-OptionCare is committed to outstanding clinical programs and quality care. “Our dietitians and home care professionals balance patient needs with those of the healthcare team to achieve successful results” Walgreens-OptionCare offers accredited home infusion, respiratory therapy/oxygen, nutrition support, and home medical equipment in thirty-six states.

Oley Corporate Partners

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

**PLATINUM LEVEL PARTNERS ($70,000+)**
- nutrishare, Inc.

**GOLDEN MEDALLION PARTNERS ($50,000–$69,999)**
- Coram Inc., Specialty Infusion Services
- NutriThrive

**SILVER CIRCLE PARTNERS ($30,000–$49,999)**
- Emmaus Medical, Inc.

**BRONZE STAR PARTNERS ($20,000–$29,999)**
- Abbott Nutrition
- Nestlé HealthCare Nutrition

**PATRON LEVEL PARTNERS ($5,000–$9,999)**
- Applied Medical Technology, Inc.
- Chemique Pharmaceuticals
- Critical Care Systems, Inc.
- EMD Serono, Inc.
- Hospira, Inc.
- InfuScience, Inc.
- Walgreens-OptionCare

**BLUE RIBBON PARTNERS ($2,500–$4,999)**
- Baxter Healthcare
- B. Braun Medical
- Kimberly-Clark
- Sherwood Clinical

**CONTRIBUTORS ($1,000–$2,499)**
- C.R. Bard, Inc.
- Baxa Corporation
- Zevex, Inc.
Chat with Others—Free!

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers. These volunteers are available to talk about day-to-day issues, ideas on coping, etc. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

July 2009
Jack Smith, father of two daughters on HEN
Southside, AL—EST (888) 610-3008

Felice Austin, mother of Mariah, on HPN due to pseudo-obstruction/short bowel
Henderson, NV—CST (888) 650-3290

August 2009
Bettemarie Bond, on HPN due to biliary dyskinesia with smooth muscle disorder
Levittown, PA—EST (888) 610-3008

Dave Helgeson, on HPN due to Barrette’s disease
Vancouver, WA—PST (888) 650-3290

September 2009
Gail Brenenstahl, on HPN due to short bowel syndrome
Queensbury, NY—EST (888) 610-3008

Karyn Thomas, on HPN due to bowel ischemia/short bowel
Midland, MI—EST (888) (888) 650-3290

Just a Few Days Left!

Thanks so much to all of you who have gathered items for the silent auction to be held June 30 at the Oley annual conference. We can feel the momentum and excitement growing!

If you haven’t already done so, you may still have time to ask local vendors, friends, and employers if they’d like to contribute something. If you’re coming to the conference, stick something for the auction in your suitcase! The silent auction is always a fun family event, and the more there is to bid on, the more fun it is…and the more funds we raise to help keep Oley programs free for you.

Items can be brought to the Oley registration desk at the conference on Tuesday, June 30, or mailed to the Trade Winds Resort (Island Grand Beach Resort, 5500 Gulf Blvd., St. Pete Beach, FL 33706), c/o Guest, Joan Bishop, to arrive June 24 through 27. Please keep in mind that many conference attendees will be traveling by plane, and may have limited space in their luggage.

Enter the Oley Drawing!

See page 9 for details.