Tissue-engineered Small Intestine: A Proposed Future Treatment for Short Bowel Syndrome

Kathleen Holodya, MD, and Tracy C. Grikscheit, MD

Short bowel syndrome (SBS) results from the removal of a significant proportion of a patient’s bowel, or from the loss of function of the bowel that is present. The condition is fairly rare. It affects approximately twenty-two children for every one thousand admitted to the neonatal intensive care unit at birth. How many adults are affected is more difficult to determine. It is estimated, based upon data describing patients requiring long-term home parenteral nutrition (HPN), that in the United States between ten and twenty thousand adults with SBS are receiving HPN therapy.

The most common reason children develop SBS is the removal of a large portion of bowel due to necrotizing enterocolitis. In some premature infants, necrotizing enterocolitis causes so much inflammation that the bowel does not function well, or even perforates, and needs to be removed. In adults, removal of bowel is most commonly due to damage from inflammatory bowel disease, such as Crohn’s disease and radiation enteritis; short bowel infarction; or after there has been trauma to the bowel. In adults and children, the condition can lead to malnutrition and dehydration. Therapy for SBS is designed to manage these issues.

Inside the Small Bowel

The small bowel is where food is digested and nutrients are absorbed. When a large amount of the bowel is lost, the small bowel tries to compensate by dilating and developing a thicker wall. The cells that line the inside of the small bowel, called enterocytes, reproduce more rapidly in this environment.

Our goal is to grow small intestine from the tissue of the patient.

Meet the Oley Trustee Executive Committee

The Oley Foundation is very excited to welcome several new board members. Over the next several issues of the newsletter, we will introduce each of them. We’d like to begin by introducing our Executive Committee. We’d also like to thank outgoing board members for their dedicated service: Gail Egan, MS, ANP; Laura Ellis, PhD, RD; Doug Seidner, MD, FACG, CNSP; and Cheryl Thompson, PhD, RD, CNSC, CD.

Harlan Johnson, President, has been an Oley Foundation supporter since 1991. Harlan’s wife, Mary Patnode, was serving as Oley President when she passed away last spring. This was a great loss to our community, and we were pleased and honored when Harlan accepted the board’s invitation for him to complete Mary’s term. Harlan says, “I am the first non-consumer president, but I do bring both

Oley Trustees, cont. pg. 10
Coping Skills

Ten Things I’ve Learned, from pg. 1

husband and I adopted our sixth child. Manny is five and very medically complex; he spends a lot of time inpatient. Because of that, I’ve discovered a few things.

My List

Here are ten things I’ve learned in the hospital.

1. Be organized

Why? The moment I hear the words “admitted to the hospital,” my brain goes into overload. I’ve come to accept that about myself. Knowing I have everything I need to know organized and recorded on paper helps me cope.

How? I started by capturing everything I could about my child’s medical condition. At first this seemed an impossible task. But I started with the current information and worked backwards. Everything went on a table within categories (see sample form on page 9). This was a huge undertaking to start, but once it was down it became easy to update it periodically, like when a medication was added. I keep a copy of the most current version with me. I also e-mail it to myself so I can access it at all times.

2. Understand the admission plan

Why? Each admission is different. Each time, the goals will be slightly different, as will the plan of care and the discharge plan. If I am not clear on any of these, I ask for clarification. Some clinicians offer this information up front, with something such as, “We plan to keep you here another day or two until your pain is under control.” But others forget to keep us in the loop.

How? Ask. “What is the goal of this admission?” or “What is the discharge plan?” or “What is the general plan of care for this admission?” Sometimes we think we know but when we hear it, it is slightly different than we expected. And by asking, we also help the clinician think it through and clarify it for him- or herself as well.

3. Stay on guard

Why? I keep a copy of the most current version with me. We must know what is “typical” for the patient so “NOT typical” can be identified. How? Mental status, emotional level, weight, vitals, etc. can be so variable from one person to the next. If we have a good handle on baseline, we can better advocate for the patient. Once when my son was non-responsive in ICU, the doctor asked if this was his baseline. I was able to show her a video of him playing, talking, and interacting, and this helped her know something was very wrong with my son. She knew we had a long way to go to get back to baseline.

4. Know baseline

Why? We must know what is “typical” for the patient so “NOT typical” can be identified. How? Mental status, emotional level, weight, vitals, etc. can be so variable from one person to the next. If we have a good handle on baseline, we can better advocate for the patient. Once when my son was non-responsive in ICU, the doctor asked if this was his baseline. I was able to show her a video of him playing, talking, and interacting, and this helped her know something was very wrong with my son. She knew we had a long way to go to get back to baseline.

5. Be focused on the big picture and patterns

Why? Details. Details. Everywhere. It is easy to get lost in the details and not see the big picture. How? Notice patterns and trends helps us know what is in and out of range for the patient.

Ten Things I’ve Learned, cont. pg. 8
Tube Talk
Send your tips, questions, and thoughts about tube feeding to metzgel@mail.amc.edu. Information shared in this column represents the experience of the individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.

Enteral Connectors Update

Enteral nutrition feeding/administration sets with the new ENFit connectors are scheduled to be released in the U.S., Canada, and Puerto Rico in early 2015, along with transition sets that will allow you to use these feeding sets with your current feeding tube (see illustration below, from www.stayconnected2015.org). Syringes with ENFit connectors should be available in the spring of 2015, and feeding tubes with ENFit connectors should be available in the summer.

Don’t let this new connector catch you off guard. Be ready with questions for the company that provides your supplies, ask them to show you how the new connector works, then use up your old supplies and make room for the new. Note that any new product using the ENFit connector will have a new product reference or code number. If you are used to ordering by reference numbers, record the new reference numbers to ensure you get the correct product the next time you order.

We realize this could be a big change for you. There may be unanticipated problems and unexpected bonuses. Please share your questions and experiences with us. We will seek answers for you, and we will communicate your concerns to the Global Enteral Device Supplier Association (GEDSA), a group of manufacturers, distributors, and suppliers working to introduce international standards in medical tubing connectors.

Farrell Bags Update

Corpak Medsystems has announced that, pending FDA clearance, they plan to release a new Farrell Valve System in the spring of 2015. In the meantime, current Farrell products will be compatible with new feeding sets using the transition connector. They note that it will be necessary to use new feeding sets with the new valve system.

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We agree.

Dehydration contributes to the incidence of pressure ulcers, CAUTIs, SSIs, DVTs and falls.*

Kangaroo™ enteral feeding pumps with programmable hydration.

Water is vital for the body. Enteral nutrition and medication flushes alone may not meet your hydration needs. Clinical documentation shows hydration status and fluid management are critical contributors to quality care and positive patient outcomes. As the leader in enteral feeding pumps, Kangaroo pumps offer programmable flushing, proper hydration and help to keep your feeding tubes unclogged.

Contact us at:
www.covidien.com/kangaroo

* Zwiebelhafer, Debbie. RD, LD.
Dietary Manager
October 2007: 18-21

www.Covidien.com

The Oley Foundation
2014 Corporate Partner

Covidien

Photo credits: Thinkstock

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Nominate Someone Who Inspires You!

The six awards Oley presents this year recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone by March 18 at www.surveymonkey.com/s/oleyawards2015, or send the information from the form below.

Awards will be presented at the 2015 Oley Consumer/Clinician Conference, to be held June 29–July 3 at the Gideon Putnam Resort in Saratoga Springs, New York, and the awardees will be spotlighted in the LifelineLetter. Recognition is given to all nominees.

The Awards and Criteria

Innovator/Advocator Award
In honor of BioScrip, Inc., Platinum Partner
★ HPEN consumer or caregiver
★ Any age
★ Sets an example by promoting innovation in nutrition therapy, or by advocating for themselves or someone in their care
★ Winner receives a partial travel grant to the Oley annual conference

LifelineLetter Award, HPN
Sponsored by Nutrishare, Inc., Silver Circle Partner
★ Home parenteral (HPN) consumer or caregiver for 5 years or longer
★ 19 years of age or older
★ Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HPN
★ Winner receives a partial travel grant to the Oley annual conference

LifelineLetter Award, HEN
★ Home enteral (HEN) consumer or caregiver for 5 years or longer
★ 19 years of age or older
★ Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with HEN
★ Winner receives a partial travel grant to the Oley annual conference

Child of the Year Award
In honor of ThriveRx, Gold Medallion Partner
★ HPEN consumer for 1 year or longer
★ 18 years of age or younger
★ Shows a positive attitude in dealing with illness and therapy which encourages and inspires others
★ Winner receives a partial travel grant to the Oley annual conference

Celebration of Life Award
In honor of Coram CVS/specialty infusion services, Gold Medallion Partner
★ HPEN consumer for 3 years or longer
★ Any age
★ Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.
★ Winner receives a partial travel grant to the Oley annual conference

Nan Couts Award for the Ultimate Volunteer
Inspired by Judy Peterson, RN, MS
★ Clinician (physician, nurse, dietitian, etc.) practicing in the field of HPEN or related field (psychology, interventional radiology, pain management, etc.)
★ Demonstrates a willingness to give of themselves, above and beyond their regular work hours, to educate, empower, and improve the quality of life for HPEN consumers
★ Winner receives a partial travel grant to the Oley annual conference

2015 Oley Award Nomination

1. Provide the following information:
I am pleased to nominate the following individual for the 2015:
- ☐ Innovator/Advocator Award
- ☐ LifelineLetter Award, HPN
- ☐ LifelineLetter Award, HEN
- ☐ Child of the Year Award
- ☐ Celebration of Life Award
- ☐ Nan Couts Award for the Ultimate Volunteer

Nominee’s name: ___________________________________
Address: __________________________________________
________________________________________
Age: ______    Daytime Phone: ( ______ ) ______ - ________
E-mail: __________________ @ _______________________
Diagnosis: _____________________  Years on HPEN ______

Your name: ________________________________________
Daytime Phone: ( ______ ) _______ - _________
E-mail: ___________________ @ ______________________

2. Tell us why you are nominating this person.
Cite specific examples of how the nominee meets the award criteria. Please limit length to one page (attach).

3. Submit nomination by March 18 to:
The Oley Foundation
43 New Scotland Ave., MC-28
Albany Medical Center
Albany, NY 12208
Fax: (518) 262-5528
E-mail: harrinc@mail.amc.edu
Web: www.surveymonkey.com/s/oleyawards2015

Questions? Call (800) 776-OLEY

January/February 2015
Oley Members Gather in RI

Close to eighty homePEN consumers and professionals met in Warwick, Rhode Island, in late October for a one-day Oley regional conference. Speakers discussed topics ranging from current treatment options for short bowel syndrome to navigating family dynamics with chronic illness. Later, smaller groups exchanged ideas on diet, hydration, controlling diarrhea, minimizing infection, skin care issues, and more.

The goal of this program and other regional conferences being planned (see calendar, back page) is to help you learn what’s new with homePEN, reduce therapy complications, integrate homePEN into your everyday life, communicate your healthcare and emotional needs with greater self-assurance, and recognize that you’re not alone. We hope you will join us in 2015!

Phone a Peer, Toll-Free

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley’s peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

• (888) 610-3008 will be devoted to HPN (intravenously infused nutrition).
• (888) 650-3290 will be devoted to HEN (tube feeding).
• (877) 479-9666 will be devoted to parents of HPEN consumers.

We hope you’ll take advantage of this opportunity.

As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

Equipment-Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Check out the Oley Foundation’s Equipment-Supply Exchange at www.oley.org! The list of items available is updated every Monday.

Questions? No Internet access? Email Oleyequipment@aol.com, or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.
Nutrition and You

**Pass the Carbs, Please!**

Modular products can be used to supplement “complete nutrition.” They can be an appropriate option for those looking to add extra carbohydrates to boost calories or perhaps to make special solutions such as oral rehydration solutions. They are not designed to fully support consumers’ nutritional needs because they do not provide a complete source of vitamins and minerals. Instead, most modular products consist of one or two of the major nutrients (protein, carbohydrate, or fat).

Carbohydrate modular products are used in a variety of circumstances. They can be used to supply additional calories from carbohydrate, especially when it is important to limit fat or protein intake, as in kidney or heart disease. They can be used in the care of patients with inborn errors of metabolism. Carbohydrate modulars are also used when a home parenteral and/or enteral (HPEN) consumer’s medical status prevents adequate intake of calories, for example when gastrointestinal volume is restricted. They can be used when the renal solute load (the amount of nitrogenous waste and minerals that must be excreted by the kidney) is limited, and to increase the energy density of foods. They come in powder and liquid forms, and can be sprinkled onto or mixed into food, mixed into beverages, or diluted into enteral formula or water and flushed through feeding tubes.

### Modular Carbohydrate Products

Since Abbott Nutrition discontinued Polycose in late 2013, consumers looking for commercial carbohydrate modulars have had limited choices. There are now, however, several products available. Specialty high-carbohydrate products designed for inborn errors of metabolism are sometimes used, but their costs can be prohibitive.

Nutricia recently re-released Polycal, a pure carbohydrate modular made from maltodextrin. Maltodextrin, also referred to as a glucose polymer, is derived from corn and is absorbed more slowly than glucose but more quickly than starch. SolCarb by Solace Nutrition is a similar carbohydrate modular made from maltodextrin. These may be used when a rapid source of glucose is required, such as in situations with inborn errors of metabolism, as well as for patients with inborn errors of metabolism; when a HPEN consumer’s medical status prevents adequate intake of calories; when a patient’s renal solute load is limited; or to increase the energy density of foods. Duocal by Nutricia is a high-calorie modular composed of two energy nutrients (59% carbohydrate and 41% fat). Duocal’s blend of nutrients is designed to add calories without milk protein to lessen the risk of GI distress.

### Not for Everyone

There are a few cautions about carbohydrate modular additives. First, carbohydrate quantity and type significantly affect enteral formula osmolality (the number of particles in solution), and high osmolality may lead to gastrointestinal distress. Consumers with fragile digestive tracts should seek medical guidance before adding any product to their feeding program (oral or enteral).

Enteral formula viscosity should be considered, and powder should be well dissolved to avoid tube or pump occlusions. When modulars are providing significant calories, vitamin and mineral intake from other sources should be evaluated to ensure nutritional adequacy. The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) recommends that formulas with additives should hang for no longer than four hours. Finally, modular enteral formulas usually have the billing code B4155, and some insurance companies require clinical justification before they will cover them.

As always, check with your physician and dietitian before making any changes to your current regimen to be sure it is appropriate for your condition.

Written by Sarah Carter, RD, LDN, CDE, CNSC. Reviewed by Carol Ireton-Jones, PhD, RD, LD, CNSC, and Laura Mattaroe, PhD, RD, CNSC, FASPEN.

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**Carbohydrate modulars**

<table>
<thead>
<tr>
<th>Manufacturer</th>
<th>Food source</th>
<th>Calories per tbsp.</th>
<th>Other nutrients</th>
<th>Calories per package</th>
</tr>
</thead>
<tbody>
<tr>
<td>SolCarb</td>
<td>Maltodextrin</td>
<td>23</td>
<td>-</td>
<td>851/227g (8oz) can</td>
</tr>
<tr>
<td>Duocal (41% fat)</td>
<td>Cornstarch, vegetable oils</td>
<td>42</td>
<td>1.87g fat/tbsp.</td>
<td>1968/400g can</td>
</tr>
<tr>
<td>Polycal</td>
<td>Maltodextrin</td>
<td>29</td>
<td>-</td>
<td>1536/400g can</td>
</tr>
<tr>
<td>SOS</td>
<td>Glucose syrup</td>
<td>120, 160, or 190 calories per pkt.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**A Flexible Therapy Choice**

**A Trusted Option**

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From the Desk of Joan Bishop, Executive Director

“Life is good,” and we are thankful for member support throughout 2014. Financially we find ourselves on solid ground again this year. It has been exciting to see the changes that are taking place throughout our community and to be planning for 2015 with enthusiasm. We couldn’t do it without your support, for which we give thanks each day.

Outreach

HPN and Feeding Tube Awareness Weeks were huge successes. If you haven’t seen the videos demonstrating “living” on home parenteral and enteral nutrition (homePEN), please do so at www.youtube.com/TheOleyFoundation. Feeding Tube Awareness Week will be on our doorstep in no time and we hope you will participate. Choose a favorite photo demonstrating “living” with your tube (or, thinking ahead, with your HPN) and send it to us for inclusion in the 2015 video!

The Oley Ambassador program welcomed nine new volunteers in 2014, with three of them representing Canada. In September, representatives from Oley and organizations from Poland, Czechoslovakia, United Kingdom, Italy, and New Zealand and Australia gathered in Geneva, Switzerland, putting us one step closer to creating a formal alliance that will benefit homePEN consumers globally. Watch for details to unfold in 2015.

We enjoyed exhibit opportunities at many professional conferences, distributing Oley materials and attracting support and volunteers. Our current membership is 14,494, representing an increase of 1,455 since last year. The Oley-Inspire forum has reached a membership of 4,714 and Facebook fans number over 2,500—and the counts grow daily!

Education

In June, we gathered in Orlando, Florida, for another successful annual conference. DVDs of the main sessions and some breakout sessions will be available soon. As always, you can borrow them without charge.

The www.oley.org overhaul is well under way, with plans to launch early this year. People will be able to join the Foundation electronically, update their Oley profile, join groups, include a photo, and navigate (and search!) the site more efficiently. It will also position Oley staff to serve you better! As always, your information will be protected in compliance with Oley’s privacy policy.

If you can spare an hour or two to share your thoughts regarding Web site content, please e-mail Andrea at andreaguidi.oley@gmail.com about joining a discussion group, or send her your comments.

Advocacy

The Foundation continues to represent your voice at meetings with agencies such as the Government Accountability Office, Food and Drug Administration, and Transportation Security Administration, and in joint efforts with organizations such as the American Society for Parenteral and Enteral Nutrition and the Digestive Disease National Coalition. Efforts include improving consumer experiences travelling; understanding enteral competitive bidding issues and the HPN drug shortages situation; and keeping you up-to-date with the new enteral tubing connectors.

Oley staff serve on the National Board of Nutrition Support Certification and on the Education Committee for the Association for Vascular Access, and Oley is a member of the National Institute of Diabetes and Digestive and Kidney Diseases.

Opportunities to participate in homePEN-related market research are ongoing. These allow you to provide input on products and services that are important to you. Please be sure we’ve got your current e-mail address so we can send you invitations we think might interest you.

Support

Support from everyone, individuals and corporate partners, has been extremely encouraging and keeps the Oley Foundation—YOUR organization—healthy and stable. Thank you for keeping us on your list of organizations worthy of support. We have much to be grateful for and your confidence in our efforts keeps us forward thinking.

Hats off to Coram CVS/specialty infusion services, our first major donor for our 2015 campaign! We are also appreciative that many of our Corporate Partners have renewed their pledges for another year, including Baxter Healthcare, BioScrip, Inc., Fresenius Kabi USA, NPS Pharma, Nutrishare, Inc., and ThriveRx. Please join me in showing your appreciation throughout the year.

I would be remiss if I didn’t mention the dedicated Oley staff, Trustees, and volunteers who work tirelessly throughout the year. We look forward to Harlan Johnson’s leadership as President (see article page 1) and working with his team of Trustees, many of whom are just beginning their terms.

The Future

Goals for 2015 include launching and reaping the benefits of the “new and improved” www.oley.org, publishing a revised HPN complication chart, and planning several one-day conferences. Stay tuned for the dates and locations. Details for the 2015 Annual Conference (our thirtieth!) are being confirmed (tentative dates June 29–July 3).

On behalf of everyone at Oley headquarters, I send warm wishes for health and happiness in the new year. See the best in 2015! ¶
Ten Things I’ve Learned, from pg. 2

be a pattern developing. I personally keep a daily log of events and I log by “exception,” meaning that I only record things that are deviations from baseline.

6. Sequence and timing matters

**Why?** We need to handle the steps right in front of us. We can be planning for future steps, but it might not be time to share all our cards just yet.

**How?** Discuss the current situation and the next few steps, not fifteen steps down the line. For example, if Manny has just been admitted to the hospital, I don’t start asking about when we will be discharged. I was talking to a fellow mom of a complex child. She was very opposed to the treatment she thought the doctors were going to propose and wanted to immediately tell them that she would not do it and why. I suggested another approach. How about ask what their thoughts were for treatment? Ask them to explain the options and the one they felt was best. Ask when they need to know your decision. Go home and regroup. She did this, and the doctors made several suggestions that were actually workable. Rather than being confrontational for no reason, this mom was able to be collaborative. There was no need to pounce on them and tell them “the way it would be.”

7. Be mindful of the chain of command

**Why?** Everyone at the hospital has a specific set of skills. They have been hired to do specific tasks. Some job descriptions overlap and some people will help even when it is not their job. However, many are working at or beyond their capacity. If we ask a nurse to do the job someone else should be doing, we will be taking time away from his or her other patients. For example, one day my son was in severe respiratory distress. I pushed the call button but no one was available for quite some time. Why? Our nurse was delivering coffee to the family of the patient next door. It was sweet of her to do that, but it should not have interfered with patient safety. Or how about arguing with the nurse about a prescription when we really need to be addressing that with the doctor?

**How?** Hospitals may use different titles for positions, but every hospital has a similar hierarchy. Take the time to learn who does what. If you need an extra pillow or to know where the coffee pot is, an aide might be your best resource. If you are having issues with your nurse, you might need to ask for the “charge nurse” or the “nurse of the day.” I have spent a great deal of time asking personnel what job they do and what their primary roles and duties are. We just never know when we will need help.

8. Understand “Hospital Time”

**Why?** If we are stuck to certain times and routines in our lives, the hospital might be a difficult place to be. For example, if I usually eat breakfast at 8:00 AM but my tray doesn’t arrive until 8:30, does that really disrupt my day? The staff is working to stick to schedules best they can, but a lot of unexpected issues arise. One time, my husband went with me and Manny for a procedure that was supposed to start at 9:00 AM. By 9:15 AM he was antsy and I realized I had never explained “hospital time” to him. “They will get to us when they can. The schedule is based on priorities. They know he is here. We just have to go with the flow.” Turns out the kid ahead of us had “coded” during a procedure so they were busy saving his life. And here we were sitting comfortably in pre-op.

**How?** Shifting from a “type A” personality isn’t easy but it is necessary. If we are rigid, inflexible, and demanding, we will be emotionally distraught and miserable over things we cannot control. If we have been understanding and then something arises where timing is critical (say a respiratory issue or cardiac symptoms), the staff is more apt to hear us than if we had been demanding all along.

9. Exchange, don’t demand

**Why?** We need to create an atmosphere of collaboration. I know things the staff needs to know. They know things I need to know. We both have pieces of the proverbial puzzle and we need to exchange.

**How?** It is all in the way we word things and the tone we use. Use a lot more questions than statements. “When and how will we know the treatment is successful?” versus, “I’m only going to try this for three days!” Find a way to word most things as questions. Use a tone that conveys genuinely asking, rather than frustration, doubt, or insincerity. I have had to practice this skill. Especially the proper tone.
10. Have emotional power

Why? We do not have the luxury to ever “lose it.” If we do, we lose all credibility. We could be kind one hundred times but if we lose it once, we will forever be remembered that way. Being demanding is the same. The staff might jump now, but what about next time? Those of us with chronic conditions need to consider that we will see this staff member again. We need them for the long haul and cannot burn bridges.

How? Being in the hospital is one of my most stressful times. Typically my child is very ill and I am feeling out of control. I am tired. I am frustrated. I am missing the rest of my family. And in this moment, I am also supposed to be kind and respectful. Even when I believe the wrong judgment is being made, I cannot ever become too aggressive. But at the same time, I cannot be too passive or hand over all say in my son’s care or refuse to speak up when the wrong call is made. Finding the way to be assertive is having emotional power.

We thank Beth for speaking at the Oley conference about advocating for her children and for summarizing her tips here. Please consider sending your experiences to Lisa Metzger, metzgel@mail.amc.edu.

Sample Health History Form

<table>
<thead>
<tr>
<th>Name:</th>
<th>Contact Info:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance and Number:</td>
<td>Pediatrician: (name, number)</td>
</tr>
<tr>
<td>Social Security Number:</td>
<td>Case worker: (name, number)</td>
</tr>
<tr>
<td>Date of Birth:</td>
<td>Home Infusion: (name, number)</td>
</tr>
<tr>
<td>Last Updated:</td>
<td>Pharmacy: (name, number)</td>
</tr>
</tbody>
</table>

Birth History

Born: (where, when)
Gestational age: Delivery: Weight: Height: Birth Complications: Birth Tests: Birth Diagnosis:
Specialists seen:
Released from hospital:
Notes:

Social Situation

Where lives, type of home, who lives with, pets, type of bed, sleeping arrangements, smoking/non, etc.

Current Diagnoses
(list)

Daily Medicines/Treatments/PRN meds

<table>
<thead>
<tr>
<th>Med Type (Started)</th>
<th>Prescribed by</th>
<th>Prescribed for</th>
<th>Amount</th>
<th>Times per day</th>
<th>Last Dose</th>
</tr>
</thead>
</table>

Feeding Schedule

TPN—cycled 21 hours/day (Hospital, stop each day 6 PM, restart 9 PM) Lipids M, W, F

Allergies

1. Drug, reaction

Hospitalizations

<table>
<thead>
<tr>
<th>Dates</th>
<th>Reason</th>
<th>Duration</th>
<th>Hospital</th>
<th>ICU</th>
<th>Diagnosis, tests</th>
</tr>
</thead>
</table>

The full form is available at www.oley.org or by calling (518) 262-5079/(800) 776-OLEY.
the consumer and caregiver perspective to the position. I hope to serve you well.”

Mary was a long-time home parenteral nutrition (HPN) consumer because of short bowel syndrome caused by Crohn’s disease. She had been on HPN for thirty-five years and had had Crohn’s for fifty years. Harlan says, “I was fortunate to be able to help Mary with her daily routine and care. I learned alongside her at the Oley Foundation conferences, and under her direction, I soon was confident enough to be her caregiver when needed.”

Harlan is now retired, after having served as a police chief and later as the Executive Director of the Minnesota Chiefs of Police Association. “In my six years as executive director,” Harlan says, “I learned much about non-profit leadership and responsibilities. I learned about supporting the membership and about advocating for good, ethical practices for the profession. I worked to ensure that all members were represented, and that they received the best, most current information available.”

**Terry Edwards, Vice President**, is currently serving his second term on the Oley board. Terry has been on home enteral nutrition (HEN) since 2005, after having had a tumor removed from the base of his brain.

He has attended several Oley conferences and represents the consumer voice at professional meetings. Terry lives in Vancouver, Canada, and travels frequently in the United States and internationally for work.

After finding himself on tube feeding, Terry writes, “There came a point when I had to decide how I was going to deal with all this. After six months of taking it easy, I needed to get on with it—the charm of hanging around the house was wearing thin. I gradually went back to my Vancouver office and set my sights on making all my feeding and sundry medical supplies as portable and easy to deal with as possible. Lucky for me, I came across the Oley Foundation Web site and learned some of the positive things I could do to make life simpler.” Thus began his involvement with the Foundation.

**Marion Winkler, PhD, RD, LDN, CNSC, Treasurer**, is also a second term Oley board member. Marion is an Associate Professor of Surgery at Brown University School of Medicine and Surgical Nutrition Specialist, Department of Surgery and Nutritional Support Service at Rhode Island Hospital, Providence, Rhode Island. As a member of an interdisciplinary nutritional support team, she provides nutritional assessment and management for PN and EN patients in the hospital and at home. Her current research focuses on quality of life and HPN. Marion is active in the Academy of Nutrition and Dietetics and Dietitians in Nutrition Support and is a Past President of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.).

Marion considers her service on the Board of Trustees and her participation in the Oley Foundation as one of the most rewarding professional activities she does. “Working side by side with HPN consumers, caregivers, and families is a humbling experience,” she says. “So much of what I have learned about the experience of living with HPEN is from people I have met through Oley. This knowledge informs my daily practice and helps me to teach and better prepare the patients with whom I work.”

**Rex Speerhas, RPh, BCNSP, Secretary**, is serving a second term on the Oley board, too. Rex has recently retired, after working for thirty years at Cleveland Clinic. Rex joined Cleveland Clinic as a staff pharmacist, then became a staff development specialist, and from 1985–2013, served as a Nutrition Support Clinical Specialist. In addition to being a Board Certified Nutrition Support Pharmacist, Rex has also been a Certified Diabetes Educator. Rex’s areas of interest include blood glucose management and trace elements. “I have enjoyed being a member of the Oley Board of Trustees,” Rex says, “and am excited to continue as secretary. I am proud to represent the profession of pharmacy on the board.”

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**Kyle R. Noble Memorial Scholarship**

To further the educational goals of individuals relying on HPEN for their primary nutritional needs.

In 2007, the Noble family established the Kyle R. Noble Scholarship. Each academic year, a $2,000 scholarship will be awarded to an applicant who embodies the qualities for which Kyle will be remembered.

The scholarship will be distributed at the end of the school year after a copy of the recipient’s transcript of his or her grades has been submitted to the Oley Foundation. The award recipient will be announced at the Oley Annual Conference this summer.

**Application Materials**

Applicant must submit the following:

1. Cover letter with name, address, daytime phone, email, age, diagnosis, HPN and/or HEN, and years on therapy.
2. A one- to three-page essay wherein the applicant describes how he or she has overcome obstacles/challenges posed by HPEN and inspired others to live life to the fullest.
3. A letter from an advisor or teacher supporting applicant’s educational pursuits.
4. A letter from a clinician or homecare company reflecting the applicant’s need for HPEN.

**Deadline is March 18, 2015.** Send applications to Kyle R. Noble Memorial Scholarship, c/o The Oley Foundation, 43 New Scotland Ave., MC-28, Albany Medical Center, Albany, NY 12208; andreaguidi.oley@gmail.com; or fax to (518) 262-5528.
Oley Offers New Camp Scholarship—Apply Now!

To provide youth on HPEN the chance to experience summer camp, building self-confidence, independence, courage, and creativity in a safe environment.

Applications are being accepted for the Oley Tim Weaver Camp Scholarship, sponsored by Fresenius Kabi USA. Up to five $1,000 scholarships will be awarded each year, as long as funding is available, to help cover the cost of getting a youth to and from camp (i.e., airfare/mileage, lodging, and food).

Applicants will know early in the year if they have received a scholarship, but the scholarship will be issued as a reimbursement, after travel has been completed. When they return home, campers will be asked to submit receipts as well as a photo or short statement about the experience that Oley can use in its publications or materials promoting the scholarship.

Some of the camps that offer programs appropriate for HPEN consumers are listed at www.oley.org. Plan now for a summer of fun!

Criteria

Applicant must be an HPEN consumer aged 7 to 18, and must qualify for a camp that provides medical support appropriate for an HPEN consumer. Applicants who have not attended camp in the past will be given first consideration.

Application Materials

Applicant must submit the following to the Oley Foundation:

1. Cover letter with name, address, daytime phone, email, age, diagnosis, HPN and/or HEN, and years on therapy.
2. An original essay, video, or song describing why attending summer camp would be a meaningful experience and how it would make a difference in their life.
3. A letter of recommendation from a teacher, family member, or community member detailing how they think the applicant could benefit from the summer camp opportunity.
4. A letter from a clinician or homecare company reflecting the applicant’s need for HPEN.

Deadline is February 18, 2015. Send applications to the Oley Tim Weaver Camp Scholarship, c/o The Oley Foundation, 43 New Scotland Ave., MC 28, Albany Medical Center, Albany, NY 12208; andreaguidi.oley@gmail.com; or fax to (518) 262-5528.
setting. Imagine an individual blade of grass growing in a meadow. As the blade grows quickly in the spring, the soil becomes thicker with tangled roots. The blade of grass can be compared to an enterocyte, and the entire meadow to the epithelium, which lines the inside of the small intestine. As discussed below, the epithelium is made up of several different types of cells in addition to the enterocytes.

The process of increasing the number of enterocytes, increasing the size of the small bowel, and developing a thicker wall is called intestinal adaptation. It occurs mainly in the first two years following loss of the small bowel, and it is controlled by stem cells that live in the wall of the small bowel and which maintain the small bowel’s ability to absorb nutrients. The stem cells live in the crypt, and the crypt lies between villi (plural for “villus”; see figure 1).

Villi are covered with the epithelium of the small intestine, which contains specialized cells called enterocytes, goblet cells, enteroendocrine cells, and Paneth cells. Enterocytes are responsible for the absorption of nutrients. Goblet cells secrete mucus, which protects the intestinal epithelium from mechanical stress. Enteroendocrine cells produce and release hormones into the bloodstream and locally; they have the ability to react to substances within the lumen of the small intestine and aid in digestion and protection. Finally, Paneth cells act as the immune cells of the small intestine by secreting granules that protect the intestine from bacteria. Paneth cells also reside near and help support the intestinal stem cells in the base of the crypts.

There are unique types of small intestine stem cells. As enterocytes get older, one type of stem cell multiplies and replaces them with fresh cells. These are called crypt base columnar cells, or CBCCs. When the small bowel is injured, +4 stem cells, which are normally relatively inactive, respond to this injury and help to replace damaged enterocytes.

Both types of stem cells multiply and become intermediate progenitor cells that differentiate into the specialized cells of the epithelium. Progenitor cells are located in the crypt above the stem cell zone. They multiply approximately four to six times before differentiating. As they differentiate, the cells move up towards the tip of the villi, which is exposed to the lumen of the small intestine, to help protect the small intestine and absorb nutrients. The stem cell populations are crucial in maintaining healthy intestine and responding to bowel injuries. They are also an important part of intestinal adaptation in the setting of SBS.

**Current Therapies for SBS**

Current therapies for SBS address the malnutrition, electrolyte disturbances, and dehydration associated with the condition. The many people who may be involved in the care of patients with SBS include a neonatologist or pediatrician, a gastroenterologist, a nutrition specialist, and a surgeon. Each team member contributes a unique aspect of care to support the patient. Therapy often involves the placement of a central line so fluids and/or parenteral nutrition (PN) can be provided directly into the patient’s veins.

Other treatments include anti-motility agents, which are designed to slow the transit of food through the small bowel, allowing for greater contact time with the epithelium, increasing absorption. Novel medical therapies are also being developed, such as teduglutide (Gattex®, NPS Pharma), a GLP-2 analog that is administered subcutaneously and promotes repair and growth of the cells that line the small bowel. Several clinical trials have shown increased absorption and decreased need for PN with the administration of teduglutide.

Surgery can also be a therapeutic option for the treatment of SBS. The procedure with the best outcomes is the serial transverse enteroplasty procedure, or STEP. This procedure effectively lengthens the bowel and can help wean patients from PN. It may be repeated multiple times as the bowel heals. It cannot be performed on all patients with SBS, however. As with any surgical procedure, careful patient selection is very important to increase the likelihood of success.

Small bowel transplantation is another surgical treatment for SBS. This procedure essentially replaces the removed small bowel with a donor patient’s small bowel. However, only thirty-seven of one hundred donated small intestine grafts are still functioning five years following transplantation. Patients must also take immunosuppressive medications for the duration of the transplant, which means the patient is more susceptible to infection.

**Tissue Engineering of Small Intestine**

Many laboratories throughout the world are working to create long-term solutions for SBS patients that do not require daily administration of intravenous fluids or immunosuppression. Our goal is to grow small intestine from the tissue of the patient. This tissue-engineered small intestine, or TESI, would ideally be nearly identical to the patient’s native tissue, thus eliminating the need for immunosuppression. We believe that in the future this may be a suitable treatment for those suffering from SBS.

Our laboratory has successfully grown TESI in several different models. This is possible because of the stem cells present in the epithelium of the small intestine. We take a sample of small intestine and, using enzymes and mechanical means, break the sample into smaller pieces of tissue, or “digested tissue.” This tissue includes the epithelium of the small intestine; the supporting structures of the small intestine, called the mesenchyme; and the small intestine stem cells. This collection of the crucial components is loaded onto a scaffold, a small, semipermeable tube, and given a blood supply. Over a period of four weeks, human TESI develops and grows as a result of the interactions between the intestine stem cells and the other components.
The human TESI produced in the laboratory looks similar to native human small intestine. It contains the basic small intestine lining, including crypts and villi. It also contains the mesenchyme supporting the epithelium that consists of a muscular layer and nervous tissue. The four important cell types of the epithelium—enterocytes, goblet cells, enteroendocrine cells, and Paneth cells, all of which are essential for functional small intestine—are also identified within the human TESI.

At this time, TESI only contains approximately three times the original number of cells that were present in our digested tissue. This is inadequate to replace the small bowel in a patient following removal of a significant proportion of their bowel.

Current work is focused on enhancing the growth of TESI and various factors that encourage growth are under investigation. Testing the function of TESI is another focus. In order for TESI to be a treatment for SBS, it must be able to perform the same function as native small intestine. We are studying the presence of transporters on the luminal side of the TESI bowel and the ability of TESI to absorb fragments of protein and carbohydrates.

The Future

While human TESI has been created, many experiments must be performed before patients may benefit from it. We do know that the maturation of digested tissue into organized TESI is controlled by the stem cells of the intestinal epithelium. However, this is a highly regulated process that is still not clearly understood. By understanding the pathways and factors that enhance TESI growth, scientists hope to overcome these limitations so that in the future, TESI may be used as a therapy for SBS. "

References available at www.oley.org.

NY Requires Ostomy Coverage

New York State Governor Andrew Cuomo has signed into law a bill (S7893, A10140) that requires all commercial major medical insurances to cover the provision of ostomy supplies. The bill takes effect on January 1, 2015.

The United Ostomy Associations of America (UOAA) notes that New York and Connecticut are the only states to have such legislation in place. They also note that New York's Child Health Plus plan does not cover ostomy supplies. Hoping to change that, the UOAA is looking for examples of problems or hardship resulting from non-coverage by this program. If anyone has a child with an ostomy who is covered by Child Health Plus, please contact the UOAA at (800) 826-0826 or visit www.ostomy.org.

Figure 2. The relative size and shape of the scaffold (black arrowhead) and resulting TESI that is produced after 4 weeks. From Sala, et al., “A multicellular approach,” Tissue Eng Part A, 2011, 17:1841-50.
Oley Opens Doors, Broadens Horizons

Laurie McBride

Laurie McBride has been a member of the Oley Foundation since 2000, and on home parenteral nutrition (HPN) since 1990 due to short bowel syndrome secondary to Crohn’s disease. He has written for the newsletter, organized and attended Oley meetings, provided one-on-one support to fellow consumers, and donated financially to the Foundation. Below Laurie explains how he has benefitted from advice and connections he’s made through Oley.

Oley has been at the end of a telephone or an e-mail from the first time I turned to the Foundation for advice. For example, when I was diagnosed with two occluded jugular veins and a blocked superior vena cava, I wanted to see if any other specialists could offer more advice or treatment than was available via my local hospital. Oley staff put me in touch with an interventional radiologist at the Mayo Clinic. While a review of my medical data found that nothing more could be done, I was totally comforted that I had conducted a thorough search before accepting my situation.

In another instance, I had heard U.S. homecare companies were researching the use of ethanol lock therapy to protect against central line infections. At Oley’s annual conference I was able to speak with a variety of pharmacists about their research trials and results. When I returned home to Canada, I shared this information with my program coordinator and eventually obtained a similar medication to use as a lock for my central line. This part of my personal protocol provides me great comfort in the protection it offers against further sepsis events. [Note: This type of therapy may not be appropriate for every HPN patient and should be discussed with your health care provider,] Additionally, I now cruise to locations further away from hospitals or airlines confident that I am not accepting undue risk to my life.

The Oley Foundation has opened doors for me, and allowed me to comfortably broaden my travel horizons, which is something I value greatly. If we all pitch in what we are able, Oley will continue to be a great resource for those seeking advice and education, as well as the ability to meet other consumers in a similar situation and professionals who support us.
Support for Conference Travel

Below are some options to help patients and caregivers get to medical conferences. We encourage you to send us your suggestions, too.

Oley Travel Grants
Thanks to generous donors there are several $500 travel grants available for consumers/caregivers who will be attending the Oley annual conference for the first time, and for Oley Ambassadors. Applicants should not be receiving any other financial assistance for travel and/or lodging expenses related to attending the conference. Travel grants are limited to one per family.

Qualified conference attendees should write two paragraphs describing how they believe attending the conference will affect their life and submit them to harrinc@mail.amc.edu. The ideal candidate will also describe their plans to share information learned at the conference with consumers and/or clinicians back home. Travel must be completed and receipts received by Oley before reimbursement can be made.

Local Organizations
Organizations such as United Way, Altrusa International, the Kiwanis, Rotary, or Lions Club, churches or synagogues, and disease-specific and wish-granting organizations may be willing to sponsor your travel. One Oley member, Amanda, got support to bring her to an Oley conference in California (from Massachusetts). She says, “I went to one of the club’s meetings as a guest speaker and presented my disease and complications, said what I thought about Oley and how a conference could help me, and how I could bring it back full circle by helping others when I felt better….This is the type of thing these organizations do: they raise money to help other organizations or individuals. They have money set aside to help.” Let us know if you have any questions for Amanda and we’ll pass them along.

Family Caregiver Scholarship
The Rosalynn Carter Institute for Caregiving offers a scholarship to family caregivers. According to their Web site, the Mattie J. T. Stepanek Caregiving Scholarship provides assistance to caregivers “who are seeking training or education in specific skills, procedures and strategies that lead to more effective care while serving to protect their own health and well-being.” In 2014, the institute offered four $2,500 scholarships. Find details at www.rosalynncarter.org/Mattie%20Stepanek/.

Tax Deductions
IRS Publication 502, Medical and Dental Expenses, states, “You can include in medical expenses amounts paid for admission and transportation to a medical conference if the medical conference concerns the chronic illness of yourself, your spouse, or your dependent. The costs of the medical conference must be primarily for and necessary to the medical care of you, your spouse, or your dependent. The majority of the time spent at the conference must be spent attending sessions on medical information.” Note that the cost of meals and lodging while attending the conference is not deductible as a medical expense.

Notable Gifts from Individuals
Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. A complete list of the contributions received in 2014 will be published in the March/April 2015 issue. We are grateful for the following gifts received from October 11 to December 5, 2014:

In Memory of: Karuna Agrawal and Danielle Peterson
In Honor of: Susan Agrawal; Paulette and Rick Lebowitz; Rachael, Sue, and Eddie Miller; and David Rowland’s birthday and two years on a feeding tube
Fundraiser: GoodShop

Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.
Don’t Miss

Feeding Tube Awareness Week
February 8–14, 2015

Go to www.oley.org for ideas on how you can participate, or contact Lisa at metzgel@mail.amc.edu, (518) 262-5079/(800) 776-OLEY.

Traveling Soon?

Check out the travel tips page on the Oley Web site. There is a wealth of information on everything from what to pack to a list of experienced travellers to contact.

We’ve made a few updates, including an important change related to international flights. Based on the recent experience of an Oley Ambassador, we feel it is advisable that you carry with you in the cabin at least three days worth of medical supplies or drugs you cannot replace. This should allow you adequate time to replace lost items or to book a flight home, if necessary.

Check back often for safe traveling!

Help Oley, Help Others

The Oley Foundation changed Colleen’s life—and the lives of countless others on home IV and tube feeding. Help us continue this important work. Please be as generous as you can in responding to the Foundation’s annual appeal.

An envelope is included in this newsletter. Or, if you prefer, you can donate online through our secure credit card payment system on www.oley.org.

Questions? Call Joan Bishop or Roslyn Dahl at (518) 262-5079/(800) 776-OLEY. Thanks for your support!

Colleen has been on HEN since 2010

2015 Oley Calendar

January 24:
Oley Regional Conference, Chicago, IL

February 8–14:
Feeding Tube Awareness Week

February 14:
Oley Regional Conference, Long Beach, CA

February 14–17:
Oley exhibit at Clinical Nutrition Week, Long Beach, CA

February 18:
The Oley Tim Weaver Camp Scholarship deadline

February 28:
Pediatric Feeding Conference, Phoenix, AZ

March 18:
Oley awards, Kyle Noble Scholarship, and HPN Research Prize deadline

April 20:
Boston Marathon, Team Oley (contact Oley for details)

May 16–21:
Oley exhibit at Infusion Nurses Society (INS), Louisville, KY

June 29–July 3
★★ Oley Annual Conference, Saratoga Springs, NY ★★

August 2–8:
HPN Awareness Week