The Role of Teduglutide in the Treatment of SBS

Palle Bekker Jeppesen, MD, PhD

Note: because this topic is so complex, we’ve italicized some terms and defined them in a glossary on page 6.

Recently, the U.S. Food and Drug Administration (FDA) and the European Medicines Agency (EMA) approved the glucagon-like peptide 2 (GLP 2) analog teduglutide for the treatment of adults with short bowel syndrome (SBS). In the U.S., teduglutide is marketed as Gattex® (NPS Pharmaceuticals, Bedminster, N.J.).

SBS results from surgical resection, congenital defects, or disease-associated loss of intestinal absorption. The symptoms of SBS vary based on the amount of remaining small bowel, the health of the remaining bowel, and the specific part of the small bowel that has been removed. Many SBS patients with intestinal insufficiency are able to compensate for their malabsorption by changing their diet and increasing oral intake. SBS patients with intestinal failure (SBS-IF), however, need parenteral nutrition (PN) and/or fluids (IV) to maintain nutrient, fluid, electrolyte, trace element, and/or vitamin balances.

Although typically life-saving in SBS-IF patients, PN/IV has been associated with potentially life-threatening complications, including catheter-related bloodstream infection, central venous thrombosis, and embolism. In addition, some components of PN and chronic dehydration may contribute to progressive SBS Treatment, cont. pg. 6 ☛

Meet Your Elected Representatives

We urge you to join us at the 23rd Annual Public Policy Forum, March 3–4 in Washington, D.C. Sponsored by the Digestive Disease National Coalition (DDNC), this effort brings together patients, health care providers, industry representatives, and lawmakers and their staff. You’ll learn about federal health care legislation and policy, then meet with members of Congress from your district to discuss issues of concern to the digestive disease community.

This is an excellent opportunity to help put a face to digestive diseases and showcase the real and often serious issues you are facing. As health care is being reformed, this is more important than ever!

The agenda and hotel information are posted at www.ddnc.org, along with information about applying for one of a limited number of travel stipends. If you have any questions about participating, contact Terrell Baptiste at (202) 544-7497 or tbaptiste@hmcw.org.

Note: You must register with DDNC to participate. Also, please let us know if you plan to attend so we can look for you (800-776-6539 or bishopj@mail.amc.edu). Hope to see you there!
Support Groups, from pg. 1

The Oley Foundation was invited to write the chapter and has obtained permission to reprint it. The first part of the chapter follows. We’d appreciate your feedback, and hope you will share it with your health care provider.

Reprinted with permission from Clinical Management of Intestinal Failure, edited by Kathleen Gura, PharmD, BCNSP, FASHIP; Christopher P. Duggan, MD, MPH, and Tom Jakusic, MD, PhD (Taylor & Francis Group, 2012).

Part One

Individuals coalesce into a support group because of life-altering circumstances, such as chronic illness, dependency, or grief. For those who come to the Oley Foundation, the circumstance is severe bowel or digestive tract dysfunction that has led to the need for home parenteral and/or enteral nutrition (HPEN). For many of them, HPEN has been life saving. However, they are aware that potentially life-threatening complications come hand in hand with HPEN’s life-saving properties, and that both HPEN and the illnesses that lead to HPEN can come with psychosocial side effects. The HPEN consumer or caregiver has his or her hands full with care issues, and then often faces grieving, depression, and feelings of isolation and bewilderment as well. Financial stress, too, often accompanies chronic illness and expensive therapies such as HPEN.

...The Oley Foundation offers HPEN consumers learning opportunities to make day-to-day living safer, more manageable, and more satisfying; and networking and social opportunities to combat the isolation and provide consumers with hope. In addition, the Oley Foundation gives HPEN consumers an opportunity to be heard, both by other consumers and by a larger audience. In this way Oley can help bridge the gap between the consumer’s medical and personal worlds.

The Oley Foundation, and other support groups, can help HPEN consumers live life to the fullest, as independently as possible—and complement the goals of the medical professionals on whom the consumers rely. An Oley member who is fed enterally says, “One of the first things you learn when you have to live with being tube fed or living with other complications dealing with your health is that the more you learn about your condition, the better you can cope with it.” Further, the more the consumer knows about HPEN, from how to reduce episodes of sepsis to how to incorporate it into their lives, the safer, healthier, and happier he or she will be.

Role of a Support Group

There are thousands of support groups in the United States that focus on health issues, from the large and well-known (e.g., the American Cancer Society), to the smaller, more obscure (e.g., the Organic Acidemia Association). They may be local or national, and moderated by a professional or peer-to-peer based; they may meet weekly, monthly, irregularly, or be organized around the Internet or the telephone; and they may combine any or all of these elements. Different support groups have different goals, and they can be successful on a variety of levels.

Support groups offer people opportunities to talk to others who share a common experience; give and receive emotional support; share problems, concerns, and coping skills; and gather information and learn. They can also represent their members in the public arena, giving an organized voice to members’ concerns (consider lobbying efforts by the American Lung Association or the public awareness campaigns by the March of Dimes). Support groups generate understanding and compassion by sharing members’ stories (e.g., in 2009 the Jerry Lewis Muscular Dystrophy Association telethon, in its forty-fourth year, spotlighted seven families). Such understanding can help reduce any stigma that may be attached to illness or “otherness.” These groups also often fund or otherwise support research on their particular health problem.

Benefit of Participation

The relationship between better patient outcomes and better quality of life (QoL), and support group participation, has been demonstrated by numerous studies in a wide range of chronic health disorders. Cancer support groups are perhaps the most widely studied. Pertinent to our concerns—whether participation in a support group is beneficial to people…on HPEN—are the studies by Dr. Carol Smith and her team at the School of Nursing, University of Kansas Medical Center.

In 2002, Dr. Smith and colleagues published the results of a study focused specifically on the relationship between affiliation with a national support group (the Oley Foundation) and home parenteral nutrition (HPN) patient outcomes. The study looked at two groups of HPN patients: group 1 was comprised of 52 patients from large academic center medical programs and group 2 was comprised of 43 patients who were supervised by a physician in private practice. Patients were separated out in this way because many of those in group 1 had access to a nutrition support team through the center that provided their care, and this...
**Tube Talk**

Send your 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 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.

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**Bracelet Holds Medical Information**

I recently got an MD Alert bracelet. It’s pretty clever, as well as high quality, inexpensive, and very unobtrusive. It plugs into a USB port on any computer and has my complete medical life history in it, available to any EMS or MD should someone “find my bones” someplace…laugh…

Nikki [my caregiver] has been inputting my doctors, contacts, medications, existing conditions, allergies, prior treatments, “Do Not Resuscitate” order, living will, power of attorney, etc. It could easily save your life or that of a loved one when seconds count. It’ll be with you when it’s needed.

Mine cost $19.95 at www.buyfromtv.com (search for “MD Alert”).
—Paul Roser, paul@paulroser.com

**Notch Prevents Spills**

Here are a couple of pictures of the syringe I use for tube feeding. I use a big 140cc “sheep syringe,” coupled with various cheapie lightweight “pitchers” (measuring cups) from Wal-Mart. I use large ones for formula (I don’t try to pour direct from can) and small ones for meds. They are $2 to $3 each, much easier to use than heavy glass ones, and there’s less chance for slipping (and a mess). The notch in the syringe makes it easy to pour into—again, no accidents.
—Paul Roser, paul@paulroser.com

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**Lamp–IV Pole Combo**

To kill two birds with one stone, I took a floor lamp and deleted one of the metal sections from the stand. Now it’s a tall lamp on my nightstand. I attached my Zevex EnteraLite Infinity pump to it, and eliminated the IV pole.
—Sanford Schimel, sanfordschimel@gmail.com

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*Medical Bracelet*

At my local Coram office, I am able to reach my nurses at any time. I’ve recommended my Coram “family” to friends, and will continue to do so. I could not be happier with this company. I’ve been on TPN since 1982, and I would never consider changing companies.
—TPN Consumer, Hayward, CA

We have been very pleased with Coram’s services — your nurses and dietitians are not only very knowledgeable in their field, but compassionate people as well.
—TPN Consumer, Marietta, GA

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*Left:* syringe with a notch cut into it.
*Top:* Paul puts the pitcher spout into the notch to keep it steady while he pours.

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*Right:* Lamppost doubling as an IV pole.
Nutrition and You

Tips for Living with a Low-profile G-tube

Low-profile gastrostomy tubes (G-tubes) are a great option for an active lifestyle. Our guest author, Janelle Flaherty, RD, provides some insights for home enteral (HEN) consumers.

Low-profile G-tubes are alternative to standard G-tubes. They have seen increased usage in recent years in both the pediatric and adult populations. Key benefits of low-profile tubes are they are less bulky; they lie discreetly under clothing; and some (depending on the internal bolster) can be changed in the home setting by patients or caregivers with the proper training.

Low-profile tubes are available with balloon and non-balloon internal bolster; they are initially inserted by a physician. Balloon-style tubes are held in place by a balloon that is filled with water; non-balloon devices are held in place by a soft plastic bolster on the end.

Know Your Brand and Size

There are many different brands of low-profile G-tubes available, and it’s important to be familiar with the specifics of the one you have in case you need a replacement. Most low-profile devices are designed to work with specific extension sets, so it’s also important to know what brand you use so you can get the correct supplies from your HEN provider.

In addition to knowing the brand you use, it’s important to know the size. Two measurements determine the size of a low-profile tube: the French size (FR), which reflects the tube diameter; and the centimeter length (CM), which is the length between the inside of the stomach wall and the outside of the stomach. Most low-profile devices range from 12 to 24 FR and 0.8 to 5.0 CM. It’s important for your HEN provider to know both measurements.

The size and reorder number for the low-profile G-tube can be found on the box it came in. Don’t have the box anymore? Both the FR and CM can also be found directly on the device. Typically, they can be found on the device’s closure flap or on the portion of the device that lies on the skin.

If you are unsure what type you have, contact your doctor’s office for this information. Also, your HEN provider is likely to be familiar with the different types of low-profile devices out there, and may be able to determine which one you use from a description or picture.

Size Can Change

The size you need may change over time. Often, as a child grows or a patient gains or loses weight, he or she needs a new size. Having the appropriate size is important. If the CM is too long, there can be excessive leakage from the stoma site, which can be painful and can lead to skin breakdown. Skin breakdown and pain can also be issues if the CM is too short, and the device is too tight against the skin.

The general rule of thumb is that you should have a space the thickness of a dime between the low-profile device and the skin. Your doctor can measure the appropriate CM with a stoma-measuring device.

Expect the Unexpected

A low-profile balloon-style device typically can be in place about ninety days before it needs to be replaced; however, situations may arise when a device needs to be replaced sooner than that. With the balloon type, sometimes the balloon on the device is defective or springs a leak, causing the device to fall out. Sometimes an inquisitive child pulls at the device, causing it to come out. For these situations, it’s important to have a backup low-profile G-tube on hand. Check with your HEN provider to see if they can provide a backup, or to see if a prescription for a backup is needed.

What happens if your device falls out and you don’t have a backup? Don’t panic. The gastrointestinal tract is not a sterile environment, so in most situations the device can be thoroughly rinsed off, put back into the stoma, and held in place with tape until a new tube can be placed. The stoma site can close very quickly, so it’s important to replace the device right away.

Most insurance companies will only cover the cost of a new low-profile device every ninety days. If you find you are going through them more often than this, check with your insurance provider to see what your coverage is. You may also want to contact the device manufacturer or your HEN provider to see if they can help troubleshooting what the issue might be. Or you could consider a different style or brand to see if it works better for you. For example, if you have a child with a balloon-style button and your child keeps pulling it out, a change to a non-balloon–bolster type may be appropriate, as this type is harder to remove.

If you do have a defective low-profile G-tube, don’t throw it away. Contact your HEN provider and let them know. They may be able to return this to the manufacturer and get a replacement at no charge. The manufacturer may send you a box so you can return the defective device so testing can be done for quality improvement.

Low-profile G-tubes can provide a significant improvement in quality of life for people requiring HEN. Making sure you are familiar with your G-tube and you are communicating the relevant information to your HEN provider will help to make life with a G-tube run smoothly.

Guest author Janelle Flaherty, RD, CD, CNSC, Clinical Dietitian, Apria Healthcare. Reviewed by Carol Ireton-Jones, PhD, RD; Laura Matarese, PhD, RD; Cheryl Thompson, PhD, RD; and Douglas Seidner, MD.

New Consumer Autobiography

In the late 1970s, Inalee (Lee) Koonin was one of the first patients to be discharged from the hospital with a central line and a prescription to receive parenteral nutrition at home (HPN). When Lee passed away in 2009—after several decades of HPN—she left behind hundreds of pages about her life, which her family has lovingly compiled into Lee’s autobiography. Tasting Life: A Story of Courage, Strength, Humor and Love is now available as a download from Amazon and Apple ($8.99) or in hardcover ($20). Orders for the hard cover edition should go to tastinglifeynaleekoonin@yahoo.com. Let Lee’s husband, Marshall, know you heard of the book through Oley, and part of the purchase price will be donated to the foundation (Marshall, timber285@yahoo.com). We are looking forward to reading the book ourselves. Watch for a review in an upcoming issue of the newsletter!
Oley, European Organizations Collaborate to Enhance Lives

The Oley Foundation recently joined forces with several European organizations to become an international reference point for health care institutions/organizations and home nutrition support patients and families. Together they want to ensure the exchange of information and advances in the field of home nutrition support and research, and to become the source of guidance and support for patients travelling abroad while dependent upon intravenous and/or tube fed nutrition (home parenteral and/or enteral nutrition, or HPEN).

It all began at an exciting meeting in the small town of Spello, Italy, coordinated by Un Filo per la Vita (A Thread for Life) for the purpose of educating parents of children dependent upon HPN and their extended community. The conference, Paediatric Chronic Benign Intestinal Failure Science, Technology and Psychology: When New Frontiers Meet, brought together representatives from nonprofit organizations from several countries (Germany, Italy, Spain, Sweden, Great Britain and the United States) to learn—from speakers and from one another. These representatives compared missions, shared goals, explored activities, and exchanged ideas on how to further their organizations’ reach and enhance their impact. It was quickly apparent that collaborating to enhance the lives of all members made the most sense. A union was established and an international working group formed. It made national news in Italy!

Center of Experience

This column is meant to highlight institutions that specialize in caring for HPN and HEN consumers. Oley does not endorse any center but brings this to our readers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org or call (800) 776-OLEY.

Home Enteral Nutrition Program, Mayo Clinic, Rochester, Minnesota

The Home Enteral Nutrition Program at Mayo Clinic in Rochester, Minnesota, was founded in 1984 and has evaluated over ten thousand adult and pediatric patients. They evaluate approximately six hundred new patients annually. Their team of nutrition specialists includes home enteral (HEN) dietitians, nutrition physicians, nurses, and pharmacists who follow patients in the outpatient and hospital setting. Team members work closely with patients and caregivers; endoscopists and surgeons placing tubes; primary clinicians; and home medical equipment companies. They develop individual nutrition plans to address the nutrition program, hydration, feeding tube selection and care, medication administration through feeding tubes, and comprehensive individualized education. Their team also arranges HEN supplies and equipment.

HEN dietitian coordinators and nutrition physicians include Adele Pattinson, RD, LD; Lisa Epp, RD, LD; M. Molly McMahon, MD (Practice Chair of Nutrition); and Maria L. Collazo-Clavell, MD (Chair of the Ambulatory Nutrition Physician Group). For more information, call (507) 284-2511 and ask for an HEN coordinator.
SBS Treatment, from pg. 1

IF-associated liver and renal disease. These burdens, combined with the symptoms of malabsorption (e.g., diarrhea, large stomal output, stomal problems, fear of fecal incontinence, flatulence, and abdominal pain), may cause restrictions in the lifestyle of SBS-IF patients and may lead to significant impairment of their quality of life. Therefore, treatments of SBS-IF aim to maximize the absorptive capacity of the remaining intestine; minimize symptoms of malabsorption; and avoid, eliminate, or minimize the need for PN.

Current Approaches to Managing SBS

The fundamental principle of SBS management is to decrease fluid secretion in the upper bowel and to maximize the contact time between the digested nutrients and the intestinal mucosa, thereby increasing absorption of the nutrients. In general, SBS patients are encouraged to compensate for malabsorption by adjusting their diet and by increasing oral intake. Frequent meals and snacks are encouraged.

Historically, treatment strategies have included changes in dietary composition, for example high-carbohydrate, low-fat diets; the use of preferred luminal substrates (e.g., glutamine or medium-chain triglycerides); and even the addition of bile acids in relation to meals. However, the effects of these interventions have not been evaluated in long-term, placebo-controlled studies. Continuous tube feeding has been suggested to improve the absorption of macronutrients, but it may be accompanied by increased fecal fluid and electrolyte losses, which can aggravate abdominal discomfort and diarrhea, and further increase the need for IV fluids and electrolytes.

The extremely salty taste of oral rehydration solutions with a high sodium concentration may keep people from using them over the long term, and their effects on intestinal fluid and adequate electrolyte absorption have yet to be established in studies in SBS patients with more severe IF. Agents such as codeine, loperamide, and tincture of opium slow intestinal motility, but, again, their effect in SBS patients with severe malabsorption has yet to be established. Antisecretory drugs such as H2-receptor antagonists, proton pump inhibitors, or somatostatin analogs have been shown to reduce gastric acid secretions, jejunostomy fluid output, and diarrhea, but no effect on macronutrient absorption has been established. Therefore, there is a high unmet need for medical treatments in SBS-IF patients.

The Role of Hormones

In the last two decades, a hormonal treatment plan that focuses on intestinal hyperadaptation by promoting intestinal hyperadaptation has been suggested to minimize the medical consequences of SBS. It has become apparent that, in SBS patients with distal bowel resections, the malabsorption is not only caused by a diminished absorptive area, but also by the disruption of the ileal brake feedback mechanism regulated by hormones such as glucagon-like peptide (GLP) 1 and 2 and PYY. The lack of this meal-stimulated hormonal feedback leads to gastric hypersecretion, rapid gastric and intestinal transit, and poor intestinal adaptation.

The first of these “ileal brake hormones” to be tested in clinical experiments was GLP-2. When food is eaten, GLP-2 is secreted from specialized cells in the distal bowel. Drucker, et al. discovered that GLP-2 induces growth of the absorptive cells (aka the enterocytes) in the intestinal mucosa. Furthermore, GLP-2 inhibits gastric acid secretion and gastric emptying, stimulates intestinal blood flow, and increases intestinal barrier function. It was encouraging to find that GLP-2 indeed decreased diarrhea and increased intestinal wet weight absorption in the first study performed by Jeppesen, et al. in 2001 (Gastroenterology 2001;120[4]:806–15).

The Studies

GLP-2 as produced naturally in the intestinal cells is rapidly degraded by a human enzyme and has a short half-life of only seven minutes. Teduglutide is a GLP-2 analog that has just one single amino acid substitution which extends the half-life to approximately three hours (Marier JF et al, J.Clin.Pharmacol. 2008;48[11]:1289–99; Marier JF et al, J.Clin. Pharmacol. 2010;50[1]:36–49). In a metabolic balance study, seventeen adult patients with SBS were split into five treatment groups using doses of 0.03, 0.10, or 0.15 mg/kg (of patient’s body weight) teduglutide injected under the skin once daily, or 0.05 or 0.75 mg/kg twice daily (Jeppesen PB et al, Gut 2005;54[9]:1224–31). Treatment resulted in structural adaptation as evidenced by increased cell numbers in the intestinal mucosa, and functional adaptation as evidenced by enhanced gastrointestinal fluid absorption.
of approximately 750 mL/day, with improvements in the absorption of macronutrients and electrolytes. The finding of increased urine production as a consequence of enhanced fluid absorption set the basis for the design of a randomized controlled trial.

In two double-blind placebo-controlled, multicenter, multinational studies, the ability to wean patients from PN/IV, based on increases in urine production, was evaluated. In the first teduglutide study, adult patients with SBS were randomly assigned to a dose of 0.05 mg/kg/day (35 patients), 0.10 mg/kg/day (32 patients), or placebo (16 patients) for up to 24 weeks (Jeppesen PB et al, Gut 2011;60[7]:902–14). No statistically significant difference between the group on teduglutide 0.10 mg/kg/day and the placebo group was shown. However, in the group that received the recommended dose of 0.05 mg/kg/day, 46 percent achieved at least a 20 percent reduction of PN/IV at week 20 and 24, while only 6 percent of those receiving the placebo achieved the 20 percent reduction of PN/IV. At week 24, teduglutide treatment resulted in a 2.5 L/week reduction in PN/IV requirements from 9.6 L/week at baseline. In this study, teduglutide also induced growth of the intestinal mucosa.

Sixty-five of the patients who participated in this study opted to enter an open-label, 28-week extension study. In these patients, who received one year of continuous teduglutide treatment (the course of the original study plus the extension study), the average reduction of weekly PN/IV volume was 4.9 L/week, equivalent to a 52 percent reduction from baseline levels.

After the study protocol was modified to allow for earlier (at week 2 vs. week 4) and more aggressive PN/IV weaning (10–30% vs. 10%) a second double-blind placebo-controlled study was performed (Jeppesen PB et al, Gastroenterology 2012;143:1473–81). Forty-three SBS patients were randomized to a 0.05 mg/kg/day dose of teduglutide and forty-three patients received placebo for up to 24 weeks. Findings were significant. Twenty-seven of the patients who received teduglutide achieved a 20 percent to 100 percent reduction of PN/IV at weeks 20 and 24, compared to thirteen of the patients who received a placebo (62.8% versus 30.2%). At week 24, teduglutide treatment resulted in a 4.4 L/week reduction in PN/IV volume from a pre-treatment baseline of 12.9 L/week. Those on placebo had a 2.3 L/week reduction from a pre-treatment baseline of 13.2 L/week. In patients completing the study, twenty-one patients treated with teduglutide (54%) were able to reduce their PN/IV by at least one day, compared to nine of those given a placebo (23%).

The Risks

When using new treatment strategies, it is necessary to evaluate and balance the benefit of the treatment versus the inconveniences, adverse effects, and risks it presents. The studies have revealed that teduglutide treatment may be associated with adverse events, mainly of gastrointestinal origin (abdominal distension, abdominal pain, nausea, and stoma enlargement). However, it was reassuring that only two patients in the teduglutide group and three in the placebo group terminated the final study because of emergent adverse events encountered during treatment. A carefully monitored reduction of the daily dose may be considered for some patients with adverse events.

As a precaution for the development of neoplasia (or tumors), a colonoscopy with removal of polyps should be performed at the start of treatment with teduglutide. Adherence to follow-up guidelines is recommended. In the case of neoplasia of the liver, gall bladder, pancreas, or the gastrointestinal tract, teduglutide treatment should be discontinued. In general, teduglutide should not be prescribed to patients who have had malignancies within the last five years. Cases of cholecystitis, choledochitis, cholelithiasis, and pancreatitis have been reported in the clinical studies; in such cases continued teduglutide treatment should be reassessed. Cases of intestinal obstruction have been described in clinical studies. The cause of obstruction should be evaluated; if it is felt to be attributable to teduglutide, continued treatment should be reassessed. Due to the increased fluid absorption in relation to teduglutide, patients with...
Medical Update

Tube Tips and Bright Ideas

Over the years, Oley members have shared hundreds of tips and ideas for making life with IV and/or tube feeding more manageable. We've published these in the newsletter and have collected them on our Web site. As we update and recategorize those ideas and tips, we'll summarize and list them here. If you'd like more details, check www.oley.org or call the Oley office (800-776-6539).

The topic for this issue is “pill-crushing solutions.” Do you have another approach or product that works for you? Send your ideas to Lisa Metzger at Oley and we will add them (e-mail and mailing addresses are on page 2). We'd love to expand this useful resource.

Note that the information provided here is designed to support, not replace, the relationship between the HPEN consumer and his or her physician. All issues, ideas, suggestions, etc. should be discussed with your health care provider prior to use. Medical information is reviewed by clinicians in a relevant field, but inclusion here does not imply endorsement by the Oley Foundation.

Pill-crushing Solutions

- Small ceramic mortar and pestle: Michelle W. writes, “commercial pill crushers broke easily and often, and were hard on the hands, but the mortar and pestle allow me to crush pills easily. On top of that, I can mix them with water in the bowl and fill it to do a water flush afterwards.” Ceramic mortar and pestle, available in kitchen supply stores (Lechters, William-Sonoma, Crate & Barrel, etc.), for various prices.
- The PillCrusher™ by Welcon: A syringe that allows the user to crush tablet medications, draw up water, and administer the medication—all with one device. The PillCrusher is available through Nurse Assist in Fort Worth, Texas (www.nurseassist.com). Call toll-free (800) 649-6800 and ask for item #3305. The price quoted in January 2013 was $31 for a case of 30 syringes. Please note: As of January 2013, Nurse Assist had a $100 minimum for ordering by phone.

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SBS Treatment, from pg. 7

Because SBS patients vary considerably, it is relevant to ask: Which SBS patients will benefit from teduglutide and how? The only SBS patients who will be able to discontinue PN/IV completely are probably those who are on the borderline between intestinal insufficiency and intestinal failure. It is estimated that these patients may account for 10 to 15 percent of the SBS-IF patients. With teduglutide treatment, these patients may regain intestinal nutritional autonomy. However, in SBS patients with intestinal insufficiency who are “on the edge”—those who are challenged by IF and the potential need for PN/IV—teduglutide may prevent the need for PN/IV.

At the other end of the spectrum, the most severe IF patients may not be able to reduce their PN/IV by a full day. Due to their net-secretory condition and very large fecal fluid and electrolyte losses, these patients would become dehydrated within a day, even with teduglutide treatment, if PN/IV was not provided. The benefits of teduglutide in these patients will relate to the reduction in the burden and inconveniences related to the daily PN/IV infusions and in a reduction in the symptoms of malabsorption. In these patients, who are the most disabled by the condition, a 33 percent reduction of their need for PN/IV (from 6 L/day to 4 L/day) would mean significant time off PN/IV. Patients who require additional daytime IV infusions could avoid these additional infusions. Furthermore, a reduction of stool losses of 2 kg/day could dramatically decrease the symptoms and inconveniences of malabsorption.

In patients with intermediary degrees of IF, the consequences of improved intestinal absorption resulting from teduglutide treatment may vary according to the individual patient. Some may prefer days off PN/IV, even at the risk of becoming slightly dehydrated, whereas others will prefer a larger day-to-day stability, requiring smaller PN/IV volumes and possibly shorter daily infusion times.

Conclusion

The recent approval of teduglutide by the FDA and the EMA bodes well for the clinical use of teduglutide as an adjunct to the limited treatment options for adult SBS patients. However, it should be emphasized that this potent drug should be used only under the guidance and monitoring of skilled caretakers with a substantial knowledge of the pathophysiology of SBS and the management of SBS patients.

Teduglutide treatment has the potential to optimize intestinal absorption, decrease malabsorption and accompanying symptoms, reduce the need, burdens and complications related to PN and IV fluids, and ultimately improve the health-related quality of life in these severely disabled patients. In individual patients with adverse events, adjusted doses may be required depending on tolerability.

Editor’s note: This article is also available, with a full reference list, at www.oley.org.
Tips for Dealing with Drug Shortages

Joseph Nadeau, Pharmacist, Mayo Clinic Home Parenteral Nutrition Program

Shortages continue to be a concern for home parenteral nutrition (HPN) consumers and health care providers. In January 2013, there were 121 drugs listed as being “short” on the FDA Web site (www.fda.gov/drugs/DrugSafety/DrugShortages). Information on shortages is provided voluntarily. As the FDA Web site states, “Manufacturers are not required to report information, such as reasons for shortages or the expected duration of shortages.”

In the past year, virtually every component of a normal HPN solution has been in short supply, except for water. Current drugs listed as short include amino acid solutions, dextrose, and fat emulsion (lipids). While we are out of many things, I will comment specifically only about some of the issues that have been a challenge lately.

Fat Emulsions—Making up the Calories

Several home care companies have begun conserving fat emulsion (lipids), which forces prescribers to examine how calories are delivered and to get creative. There are only three sources of calories in PN: dextrose, protein, and fat. If there is less of one, it may mean more of another. For example, to make up for dropping 50 grams of fat per week (one unit of 20%, 250 ml), it would be necessary to add an extra 20 grams of dextrose per day. It is up to the doctor who prescribes your HPN to determine how to adjust your solution if it is necessary, so it is essential for you to have a good relationship with him or her. You are always urged to discuss issues like this with your physician.

Multivitamins—How You Take Them Matters

Many home care companies continue to conserve IV adult multivitamins. The method of conservation may have a big effect on some consumers. For example, HPN consumers who are taking warfarin (such as Coumadin) for anticoagulation may have noticed widely varying results when they get their INR (a measure of “bleeding time”) checked. Home care providers who are using vitamins three times per week as a conservation measure are adding to this variability, because the dose of vitamin K is now only being provided three times per week, instead of the typical seven times per week, and vitamin K directly affects the INR.

It may be more beneficial to give 5 ml of the vitamins six times per week rather than 10 ml three times per week, in order to provide a consistent level of vitamin K. In the end, the dose of vitamins per week is the same, but the INR levels should become more consistent. If you notice inconsistencies in your INR, you should discuss it with the home care company providing the vitamins as well as with the doctor who prescribes your warfarin and the doctor who prescribes your HPN to arrive at a safe and mutually acceptable solution.

Vitamin levels should be checked regularly and, as always, any concerns should be discussed with your doctor. During this time of IV multivitamin conservation, oral vitamins certainly are being used to help supplement. Depending on your diagnosis, and whether your problem is motility related or if you have short bowel syndrome or another issue, oral vitamin choices can be tailored to the diagnosis to achieve better vitamin levels.

For example, short bowel consumers might benefit from water-soluble forms of the fat-soluble vitamins to provide consistent doses of vitamins A, D, E, and K. This is based on diagnosis and anatomy, where if fat is not getting absorbed properly then also fat-soluble vitamins are not being absorbed properly. The water-soluble trait of these specialized vitamins helps them be absorbed by a different method. AquADEKs® is an example of this type of vitamins.

Consumers with motility problems may not be missing potions of their gut and can use different vitamins to get the desired effect. Chewable vitamins like Flintstones™ Complete may be a perfect choice for them.

In any case, discussion with your local health care provider is the way to get started. Your health care provider should have knowledge of your diagnosis and anatomy and can steer you to the best solution.

Trace Elements—Selenium Is Essential

Trace elements continue to be in short supply. Providers and consumers need to be aware that blood levels of these elements need to be checked regularly and adjusted when needed. Selenium should always be a concern for home care providers. There can be dire consequences, such as cardiac problems, if levels drop too low and go unchecked, yet certain trace element packages do not contain selenium. If IV selenium is not available, you should discuss oral supplementation with your prescribing physician when appropriate.

The Future

At this point, there is no indication that drug shortages related to HPN are resolving. Health care providers have been challenged on a daily basis by these shortages. Consumers are encouraged to discuss any concerns with their doctor as well as with the company providing their HPN.

In addition, you should contact your local political representatives to voice your concerns. Please share your concerns with the Oley Foundation, as well, and any experiences you have had with drug shortages. It is helpful to have those stories available in one place, when legislators or journalists are looking for that type of information.
Support Groups, from pg. 2

support might have reduced what these individuals gained from a national organization.

Twenty-four of the participants in group 1 were affiliated with the Oley Foundation and 28 matched case controls were not; 21 of the participants in group 2 were affiliated with Oley and 22 matched controls were not. The matched case controls had similar primary diagnoses, duration on HPN, sex, and age distribution. All these factors are known to independently influence clinical outcome. Participants each filled out the 35-question Quality of Life Index (QLI) and a 20-question reactive depression questionnaire. “This study,” Dr. Smith writes, “showed that patients affiliated with a national organization have a better outcome, regardless of HPN program size. Specifically, affiliated patients, compared with nonaffiliated case-matched controls, experienced a significantly higher quality of life, less reactive depression, and a lower incidence of catheter-related sepsis” (Smith et al., JPEN 2002;26[3]:162).

Dr. Smith has also reported favorable results in a peer support program initiated at the University of Kansas Medical Center in the late 1990s. In this program, patients who were identified as successfully managing their own HPN underwent training to become preceptors. Their instruction included reinforcement exercises to: (1) develop listening skills; (2) appropriately respond to concerns reported by patients; and (3) avoid providing medical advice (Smith, 11/4/2009, pers. comm.). They were subsequently paired with more recently diagnosed HPN patients. In the results published in 2001, Dr. Smith notes “new patients’ post-preceptor interaction depression scores decreased, whereas confidence to master home HPN increased…. Also, each patient and their peer preceptor rated the interactions as helpful” (Smith et al., Nutrition, 2001;17:176).

Also relevant to our concerns is a study by Dr. Mary Trainor based on the “helper therapy principle.” In this study, 318 members of the United Ostomy Association (UOA) completed a 50-statement scale designed to measure their ostomy acceptance level. Respondents were also asked to provide personal information, including whether they had participated in visitor programs sponsored by local UOA chapters. Fifty-four percent of the participants indicated they had visited other ostomates (“visitors”); the remaining 46% had not visited other ostomates (“nonvisitors”). Dr. Trainor concluded, “visitors had a greater acceptance of their ostomy than nonvisitors….Results support Riessman's theory (1965) that persons benefit from helping others” (Trainor, Nurs Res 1982;31[2]: 105).

Oley Foundation History

The Oley Foundation is a nonprofit, independent organization that provides education, emotional support, and clinical outcome information for HPN consumers, their families, and supporting professionals.

The foundation was initiated in 1983 by Dr. Lyn Howard, then Director of the Clinical Nutrition HPN program, Albany Medical Center, Albany, New York, and her patient, Clarence Oldenburg (nicknamed “Oley”). Dr. Howard strongly believes that HPN consumers benefit from talking to one another, but she recognized that at that time very few had such an opportunity. HPN are complicated therapies. Further, HPN was relatively new in the early 1980s; information about it was difficult to come by and patients were widely dispersed. The Oley Foundation was established to fill this void. It currently [2013] has over [12,500] members across the United States and in Canada, Australia, Europe, and India. Membership is…divided between HPN consumers or caregivers [63% in 2013] and HPN professionals [37% in 2013].

Don Young, who has been on HPN since 1975, has been part of Oley since its inception. “I had eight years’ experience [on HPN] prior to Oley,” he says. “I think we were unique in our area in that we had a physician who drew us all in together. We used to have clinic on the same day and we always planned to get together after our appointments, so we had that support group right from day one. When I started there was only one other patient in the Albany program, and he soon died. It took a year until we got to the grand total of four. But we still were a group, and we did see each other, and we talked to each other on the phone. So we had kind of a mini Oley Foundation going before the foundation actually started.”

In 1978, Marshall and Lee Koonin had begun a patient group in Sharon, Massachusetts. When Lee began HPN in 1977, she remembers that it was considered an experimental therapy “that was not even allowed in some hospitals.” Lee felt very alone and Marshall was determined to find others who were using HPN, both to bring them together...
and to let others know the therapy worked and maybe shouldn’t be considered experimental. The Koonins’ Lifeline Foundation grew to about 600 members. They published a newsletter, organized picnics, and started a network of consumers who were willing to talk to other consumers. It was, however, a huge commitment of the Koonins’ time and money, and after reassuring themselves that the Oley Foundation would continue the work they had begun, in 1984 the Koonins were relieved to hand the Lifeline Foundation over to the newly established Oley Foundation.

Making Connections

It is now over 25 years since the Oley Foundation was founded, but it is often still difficult for HPEN consumers to connect with one another or for new HPEN consumers to learn about the Oley Foundation or other HPEN support groups [for a list of other support groups, contact Oley or visit www.oley.org]. Many health care providers and hospital discharge planners do not know about these groups; and those who do may initially have little success introducing them to new consumers, who are so preoccupied with the medical issues surrounding HPEN—such as maintaining sterile technique or avoiding infection—that they cannot think about future needs.

One HPEN consumer says, “You’re just so busy dealing with the day-to-day in the beginning that you don’t even think about the long term or whether you’re going to be secure in the long term.” On the other hand, the mother of a child born with intestinal dysfunction remembers: “When they gave us a diagnosis, I said, ‘I want a way to figure out how we’re going to get her home, and I need to have support. Find me another child somewhere in this world who has this diagnosis. At the time we were told there wasn’t anybody because it was such a rare disorder.’” She learned of Oley, and did find another child with the same diagnosis, through one of the intensive care nurses, who had read about a child with this diagnosis in an Oley newsletter.

Sometimes patients who receive information about the Oley Foundation while in the hospital read the literature they received much later, when they are able to process that information or when they are looking for answers to specific questions. Consumers or caregivers often turn to the Internet for information on HPEN. The Internet has been a tremendous source of growth for the Oley Foundation, with the Web site (www.oley.org) averaging [9,913 hits per day in 2012]. Sometimes consumers learn about the Oley Foundation through their home care companies; some companies, however, are reluctant to encourage this kind of networking between consumers for fear of losing customers or receiving demands for different/better equipment, supplies, or services that another company offers.

However reluctant people or companies may be to refer HPEN consumers to Oley, patient and family connections are important. Steve Swensen, who served as president of the Oley board of trustees, likens the Oley Foundation to a mosaic: “I feel as though all the ‘catheter people’ I’ve met through the Oley Foundation—those who have them or care for them, who place them or make them or manage them clinically—all of these individuals have a tile or two to add to a larger mosaic that depicts how to live with central lines. You can’t see much by looking at just your own tiles, you have to step back and see what others have added to get the [big] picture.” (J.V.A.D., 2001;6[1]:38).

Full reference list available upon request or at www.oley.org. Watch for Part Two in an upcoming issue of the newsletter.
Thank You for Your Support in 2012!

The following list represents everyone who generously contributed toward Oley’s efforts in 2012. We also want to thank all of those who are:

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Volume XXXIV, No. 1
(800) 776-OLEY • LifelineLetter — 13
From the Desk of Joan Bishop, Executive Director

We are awestruck again by the generosity of Oley members. A steady outpouring of gifts from families tops the list as we count our blessings this year. We’ve had an extremely positive response from our corporate appeal this year, as well, which leads us to believe that we will be happily in the black again in 2013, and in forward-thinking mode! We cannot thank all of you enough. Oley programs and membership continue to grow, and with your support we are able to continue our tradition of offering life-altering information and support free-of-charge to those who need it.

Financial support is not the only thing for which we are grateful. Not a day goes by that we do not rely on the kindness and compassion of Oley members. Whether we’re reaching out for personal assistance to help a fellow consumer, in search of participants for market research projects, or something else, Oley members always respond quickly and favorably! Thank you so very much. It’s worth mentioning that having your current e-mail address and telephone numbers is invaluable, especially when it comes to market research projects and regional programs. Call (800) 776-6539 or write harrinc@mail.amc.edu with any changes.

As you may have noticed, plans are under way for the 28th Annual Oley Consumer/Clinician Conference at the Cape Codder Resort and Spa in Hyannis, Massachusetts. Please mark your calendar and plan to join us from June 26 to 29, 2013. We have plenty of travel grants available for first-time conference attendees (see page 16 for details), a great hotel rate, and a terrific program planned for you and your family. Stay tuned to www.oley.org for updates.

Again, thanks to all of our members and our corporate sponsors for the continued support. And welcome to two new corporate sponsors: Fresenius Kabi USA at the Silver Circle level, and MOOG, Inc., at the Benefactor level!

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Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference by calling (800) 776-OLEY.

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Roadine Ann & William Wu

Summer Camps for Your Kids

Youth who rely on home parenteral and/or enteral nutrition (HPEN) have several options when it comes to summer camps—and now’s the time to apply! We’ve compiled a list of camps that are prepared to meet the needs of children on HPEN, with dates, times, and contact information. Please e-mail harrinc@mail.amc.edu or call (800) 776-6539, and we’ll get it out to you. NeedyMeds.org also maintains a database where you can finds camps organized by diagnosis. Camp offers a safe opportunity for your children to gain some independence and for you to have some respite. Don’t miss it!
Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

**Fresenius Kabi USA**

Fresenius Kabi is dedicated to caring for critically and chronically ill patients by providing intravenously administered drugs, infusion therapies, clinical nutrition, and related medical devices—both in hospitals and in outpatient care settings. “Throughout our long history,” they write, “we have been driven by excellence and innovation, and those ideals continue to inform our work today. As a global healthcare company, we are positioned to meet the needs of our customers and patients worldwide. Each day, more than 23,000 employees affirm our commitment to ‘caring for life’ and dedicate themselves to what we believe matters most in healthcare: improving patients’ quality of life.”

**NPS Pharmaceuticals**

NPS Pharmaceuticals is a biopharmaceutical company focused on bringing orphan products to those with rare disorders and few therapeutic options. The company’s lead product, Gattex® (Teduglutide [rDNA origin]) for Injection is FDA approved for the treatment of adult patients with short bowel syndrome (SBS) who are dependent on parenteral support.

**MOOG, Inc.**

MOOG Medical Devices / Curlin Infusion-Zevex Enteral offers a full line of infusion pumps and enteral pump devices, disposable administration sets, and accessories. The company’s pumps combine the convenience of small size ambulatory pumps and the sophistication of hospital devices.

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**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 will share this list of honorees in each issue of the newsletter. In addition, please see pages 12-13 for a complete list of the contributions received in 2012.

Between November 21, 2012, and January 8, 2013, gifts were received:

**In Honor of**

Julie Andolina; Casey Barron, 15 years on strict J-tube feeds and thriving; Michael Christenson; Colorado State Infusion Staff; Mary Ellen Costa's continued courage; Jim Coyle, for being a wonderful and understanding supervisor; Rodyn Dahl; Daniel Dehart, 15 years on HPEN; Bill Fitzpatrick, Jr., 30 years on HPEN; Sam Hofmans-Currie; Lyn Howard, MB, FRCP, FACP, and Oley Foundation Co-Founder; Chelsea Johnson; Darlene Kelly, MD, for her continuing contribution to Oley and to the world of HPN; Emily Koprucki; Mary Kunz; Mike, Jenny, and Katie Lunsford; Ryan Peot's 16 years on TPN; Dr. Ellen Pierce & Chris Ericksen; ValDean Richards; the Erik Schten family; Rachel Schten; J. T. Shearrow; Maurice E. Shils, MD; Tanner J. Shuman (off HPN almost 10 years); Gregorio Tongol, 23 years on HPN; and Michael Yelner's 18th birthday and 13 years on HPN

**In Memory of**

Theresa Ashley; Nancy Backinger; Annette Block; Ann DeBarbieri; Jeff Dutton; Charlie Eidem; Donald Engle; Eileen Ericksen; Lynne Erickson; Woody Freese; Mary T. Friel; Ron Gendrich; Richard M. Harris; Joel Hershey; Vicki Howard; Portia Lyon Hutton; Joyce Hydorn; Tom Jacobs; Diane Kane; Shirley D. Klein; Robin Lang; Pat and Judy Lewis; Mary and Lawrence Mayer; Francis J. Murray; Clarence “Oley” Oldenburg; Beverly Promisel; Nader El Samaloty; Willis “Dick” Schultz; Josh Shapiro; Sallie Simpson; Paula Southwick; Bob Sweet; Bunny Wong; and Audrey Grace Yadrich

We appreciate all gifts and kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration. Thank you!
Nominate/Apply Today for

• Patient/Clinician Awards
• HomePN Research Prize
• College Scholarship

Details at www.oley.org or by calling (800) 776-OLEY.

Forms due March 18!

28th Annual Oley Conference

Where: Cape Codder Resort & Spa, Hyannis, Massachusetts

When: June 26–June 29

General Attendee Rate: $139/night, single or double. Cut-off date is June 5. Reserve now! Rooms will sell out. Call toll-free (888) 297-2200 and mention you are with the Oley Foundation “Attendee Block” to receive this room rate. If navigating stairs present a challenge for you, please request a room on the first floor or in a building with elevator access when making your reservation. Or register at www.capecodderresort.com, and use Oley’s attendee code: TOFAB13. Online room reservations will be automatically assigned to first floor rooms or in a building with elevator access.

Exhibitor Rate: $179/night, single or double, in effect through June 5. Use the code TOFEX13 at www.capecodderresort.com, or call (888) 297-2200 and tell them you are in the Oley Foundation “Exhibitor Block.”

Travel Grants Are Available: If you’ve never been to an Oley annual conference, we encourage you to apply for a first-time attendee travel grant. Submit two paragraphs describing how you believe attending the conference will affect your life, and how you might share information learned at the conference with consumers and/or clinicians back home. The cut-off for travel grant applications is April 2 and determination will be made by April 15, allowing recipients plenty of time to make travel plans. Send to harrinc@mail.amc.edu or The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208. Travel must be completed, and receipts received by Oley, before reimbursement can be made.

Watch for the registration brochure. Updates will be posted on www.oley.org and circulated via e-blasts. Keep us posted with your e-mail address changes!

Paying It Forward

Tammi and Rob Stillion have been managing the Oley Foundation’s Equipment-Supply Exchange since 2009. The Stillions help coordinate hundreds of exchanges each month—helping those who no longer need formula and HPEN-related supplies and equipment get it into the hands of those who do need it. What makes them do it?

Tammi has short bowel syndrome and has been on home parenteral nutrition since 2001. “When we first found out about Oley,” Rob says, “we found out we were not alone. We got so much information at our first conference in 2007. We brought a lot of it back to our doctors, and Tammi is stable now. When we got to the point where we knew what we needed to do, we decided it would be nice to help other people.” And so, when they heard Oley was looking for volunteers to help with the Equipment-Supply Exchange, they stepped forward.

“I was raised in that environment,” Rob continues. “When you get something, you give back. We couldn’t help in other ways, so we decided to take this on and do it.”

Tammi and Rob devote significant amounts of time and energy to the program, and through it, are giving generously to the Oley Foundation and their fellow Oley members. We are grateful for their contribution.