A Novel Therapy for Short Bowel Syndrome:
Bowel Lengthening Device
Farokh R. Demehri, MD, and Daniel H. Teitelbaum, MD

Short bowel syndrome (SBS) is a challenging disease that can have a life-long impact on patient health and quality of life. There is a high rate of mortality associated with SBS. Patients with SBS often require parenteral nutrition (PN) to maintain their nutritional status, and while PN can be life-saving, many infants as well as adults suffer from a number of PN-related complications. For patients who are unable to wean from PN, current treatment strategies include surgical lengthening of the small bowel, administration of growth hormones, and small bowel transplantation—all with widely variable results.

Mechanotransduction, or the conversion of mechanical forces into cellular signals, is an emerging area of research that may provide a novel treatment for SBS. With mechanotransduction, tissue growth is induced by applying mechanical force to tissues. These forces drive chemical cellular signals that stimulate the growth of cells and whole tissues. This principle has been described for well over a century. It has been applied in using a mechanical ratcheting device to help a shorter leg grow longer. “Distraction-induced enterogenesis” is a term we use to describe the process by which the intestine lengthens with application of intraluminal linear forces (mechanical force applied lengthwise within the intestine). Through this process, the bowel not only lengthens, but demonstrates normal function as well. This has now been demonstrated in a number of studies.

Home Tube Feeding with Blenderized Foods
Theresa A. Fessler, MS, RDN, CNSC

Think about the wide variety of foods most people eat every day. Now imagine “eating” these same foods using your feeding tube. With today’s high-performance blenders this is possible, and many home enteral nutrition (HEN) consumers and caregivers are using blenderized foods instead of, or as a supplement to, standard canned enteral nutrition (EN) products.

Blenderized tube feeding, while not commonplace, is a growing trend among HEN consumers throughout the United States and in other parts of the world. By review of Internet sites, it is more common for children who use HEN, yet adults are doing this as well.

New Camp Scholarships Honor Tim Weaver

At the Oley annual conference earlier this year, Fresenius Kabi announced its plans to provide summer camp scholarships to the Oley Foundation. The scholarships, offered in honor of Oley member Tim Weaver, will be to camps in the United States that are designed for children with chronic health issues and serious illnesses. Most of these camps do not charge a fee; the goal of the scholarships is to help offset the costs of getting to and from camp.
Blenderized Foods, from pg. 1

Why Blenderize Food?

Lisa Epp, RD, LD, CNSC, is the home nutrition support coordinator at Mayo Clinic in Rochester, Minnesota. Epp has been working with HEN consumers for more than eleven years; for the past seven years, she has been working with those who use blenderized tube feeding, the popularity of which, she notes, has been growing since 2011. Epp states that in their program they see about 650 adults and 150 children per year who are just starting on tube feeding, and findings from a preliminary Institutional Review Board (IRB) approved study show that about 50 percent of them use blenderized foods at least some of the time.

There are several reasons some HEN consumers use blenderized foods. Some have allergy or intolerance to certain ingredients that are present in most standard EN products, such as corn, cow’s milk, or soy proteins. Others desire more variety, and/or healthy, unprocessed natural foods for a diet lower in sugar and with phytonutrients and fibers. Most conventional EN formulas contain corn syrup, maltodextrins, sugar, soy, corn oils, and casein and soy proteins. While they provide all the known essential vitamins, minerals, and protein, they do not provide the wide variety of phytonutrients and fibers present in natural foods (see sidebar page 8). [Editor’s note: It is unknown whether this variety provides any health advantage in people on tube feeding.]

Homemade blenderized foods can be less expensive than commercial products, which is an important factor for people whose insurance does not cover EN formulas. Some who are concerned about the environment like blended foods because there are fewer cans and cartons to throw out. Many HEN consumers enjoy sharing meals with their families and experiencing the sight and smell of foods while they prepare and use blended meals. Epp recalls one of the HEN consumers she has worked with saying, “Blending real food has brought the joy of cooking and eating back into my life.” Epp also mentions that people report improved bowel regularity.

Reports written by consumers found on the Internet and shared by word of mouth indicate that tube-fed children tolerate blended foods better than standard EN formulas. According to an article published in the Journal of Parenteral and Enteral Nutrition (2011), clinician researchers in Cincinnati studied thirty-three children who had fundoplication surgery and who had gagging and retching with gastric (G-) tube feedings using standard EN formula. As reported by the children’s parents, seventy-three percent of the children had at least a fifty percent decrease—and fifty-two percent had a seventy-six to one hundred percent decrease—in gagging and retching after switching to pureed foods in their G-tubes.

Choosing and Preparing Food

Blenderizing foods is easier than you might think and many foods can be used. High-speed and commercial-quality blenders such as Vitamix® or Blendtec™ work best for more complete liquification of foods. Foods should be cut into chunks and placed in a blender along with enough liquid to allow blending to a smooth consistency. You may need to strain the blend to remove small chunks or seeds.

Foods that are popular for blending include sweet potatoes, bananas, quinoa, avocado, oats, nut and seed butters, chicken, yogurt, kefir, various grains, and milk (cow’s, soy, almond, coconut, etc.). Other liquids include water, broths, and juices. Some foods have more potential to clog tubes, such as string beans, blueberries, and flaxseeds. Eggs can become lumpy if not thoroughly cooked prior to blending. Epp states that brown rice, fruits, vegetables, lentils, toasted breads, and crackers work well for blending, and that olives, white pasta, white rice, breads, muffins, and bagels tend to gum up in the blender.

General food safety principles are very important, especially if the person using tube feeding has compromised immune function. As with any food preparation, hand washing is essential, and fresh vegetables and fruits and dried legumes should be carefully cleaned to remove any soil, microorganisms, and other contaminants. Dried legumes should be detected for small pebbles prior to cooking.

Raw foods can be used, but foods that normally require cooking (such as meats, brown rice, potatoes) should be cooked just as they would if they were being eaten by mouth. Blenders and syringes need to be thoroughly cleaned right after each use. Unused blends should be promptly covered and refrigerated for up to twenty-four hours.

Feeding the Blenderized Formula

Blenderized foods can be administered the same ways as regular canned formula—by
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.

The following tube displacement tip has been extracted from the Oley Foundation “Tube Feeding Troubleshooting Guide.” Other sections of the guide include tips on what to do about, and what may be causing, nausea and vomiting, diarrhea, tube obstruction, site irritation, and more. You can download the guide at www.oley.org or call (518) 262-5079/(800) 776-6539 for a copy.

Tube Displacement

DESCRIPTION:
Tube has come out of body or has moved out of place. (When your device is placed, mark the feeding tube 1 inch from where it enters the body with a permanent marker. Check the tube before each feeding.)

You may experience choking, difficulty breathing, nausea/vomiting, abdominal pain, and/or diarrhea.

IMMEDIATE ACTION:
• Discontinue feeding.
  • If you have an NG or NJ tube, and the tube is curled in the back of your throat, pull it completely out.
  • If you have a G, J, or G-J tube, and it has moved, do not remove the tube in your abdomen. Call your doctor.
  • If you have a G, J, or G-J tube, and the tube has fallen out, call your doctor or go to the emergency room to have the tube replaced as soon as possible. Depending on the type of tube, you may be able to replace it yourself, but this needs to be discussed with your doctor ahead of time.

CAUSES AND PREVENTION:
Symptoms can be caused by several things.

The tube is not adequately secured.
Accidental or excessive pulling of the tube.
Your stomach may “see” your tube as a piece of food. It may act to pull the tube inside your stomach or intestine.
  • Use a tube attachment device such as a tube holder.
  • Carefully tape the tube to your abdomen, nose, or cheek. Take a piece of tape about 7 inches long. Fold the ends (about 1½” worth on either end) back on themselves. Wrap the tape around the tube; the non-sticky ends should extend out about 1½ inches. Pin the ends to your clothing, making sure you allow for adequate movement.
  • See www.oley.org for undergarments and other products/tips to help secure tubes.

Frequent vomiting.
• See tips on preventing Nausea and Vomiting on page 3 of the Tube Feeding Troubleshooting Guide, online at www.oley.org or call (518) 262-5079/(800) 776-OLEY.

Balloon deflates or bursts.
• Be sure the balloon under your skin is intact. You can check by using a syringe to draw out a few cc’s of water. (Replace the water in the balloon after checking.) Also, the tube will be easy to pull out if the balloon has burst.
  • If the balloon has burst, use tape to keep the tube in place. Call your doctor or go to the emergency room to get a new tube. Depending on the type of tube, you may be able to replace it yourself, but this needs to be discussed with your doctor ahead of time.

Me and My Button

I am in my seventies and I have to travel sixty-five miles to get to the hospital to get a new button [low-profile G-tube] put in. I have become very comfortable with the button. We have been trying to get as much wear out of a button as possible so I don’t have to go to the hospital as many times. For me, a span of four and a half months is the maximum length of time before the button has to be replaced.

I know how the button works and I am familiar with taking the water in and out of the balloon. I have, on occasion, replaced my own tube when it has come out.*

I have to take some medicines that are difficult to administer through a tube. When the medicine is in pill form, you (or your caregiver) should crush it very fine** and mix it with water of the proper temperature. If you have trouble getting it through your tube, try backing it out with the syringe and putting it through again. If this doesn’t work, disconnect and see where the problem is. Usually it is near or at the point of insertion into the button. Try to dislodge the obstruction and try again.

A mortar and pestle works well for crushing the pills into powder form. These come in various sizes, from small to very large. I would recommend one that is big enough to do the job, but not too big for the work at hand. You may have to look, but they are out there.

—Michael Brady

Editor’s notes:
*Whether you can replace your own tube depends in part on the kind of tube you have. You should discuss this with your clinician. Also, if you have been trained to replace your tube, you can ask for an extra replacement tube to have on hand should the need arise.

**There are some medications that should not be crushed. Please discuss with your clinician. Additional information on giving medications by tube is available at www.oley.org/documents/Drug_Administration_through_Feeding_Tubes.pdf or call (518) 262-5079/(800) 776-OLEY and request the article “Drug Administration through Feeding Tubes.”
Meet the Newest Oley Ambassadors

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit www.oley.org or call (518) 262-5079/(800) 776-OLEY. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice.

Judi and Jim Ervin

Judi Ervin first learned of the Oley Foundation a few years ago, following radical emergency surgery that requires her to now be on home parenteral nutrition (HPN). Judi has experience in the counseling/nursing field where she has been employed for many years, along with being involved in raising her three daughters. She has a master’s degree in nursing.

Jim Ervin taught mathematics at the high school and college level. He is now retired.

Jim and Judi have led many meetings for the Commonwealth of Massachusetts on the importance of the role of calcium in patients with osteoporosis. They both continue to remain on the cutting edge of medical knowledge regarding ileitis and other, similar diseases.

Judi and Jim live in Pittsfield, Massachusetts. They can be reached at (413) 499-9928 or jameservin35@verizon.net.

Roy George

Roy says he’s thrilled to be starting a new adventure as an Oley Ambassador. Along with his enthusiasm, Roy brings to this role a great sense of humor and a lifetime of experience with nutrition support. He has short bowel syndrome, but says he “has managed to do anything and everything he’s dreamed of and wished for” and notes that Oley has played a huge role in his life, along with the friends he’s maintained throughout the years. Some of the friends and people Roy has admired through the years have gone before him, and he feels being an Ambassador will give him the opportunity to continue and carry the banner. “Although I have my bad days,” he says, “I’m ready to raise awareness and hopefully bring some new people to the Oley Foundation.”

Roy says he enjoys “everything any ‘normal person’ would enjoy.” Although he lives in the Virginia Beach area and is surrounded by water, he says, “Thankfully for my doctors, parents, and myself, I do not like swimming with things I may be able to eat.” (Roy is on parenteral nutrition and has a central venous catheter.) Roy attends college; he majors in American Sign Language and Music Education, with a concentration in piano and voice. He performs regularly in New York City, and has an extensive career in his home town in upstate New York, as well as in his new location in Chesapeake, Virginia.

One of his goals as an Ambassador is to raise awareness about parenteral and enteral nutrition, and “get doctors, nurses, and caregivers to understand the life of consumers and our struggles.” He is also hoping he can bring more young adults and teenagers to Oley and help them to share their story and not feel “different” or at a loss. “I am thankful,” he says, “to my family for treating me like any normal sibling would be treated and not allowing me to use my ‘sickness’ as an excuse. They’ve helped me to build character. Truthfully,” he concludes, “it’s time to give back. I’m excited to make a difference.”

Reach Roy at Roysamuelgeorge@gmail.com or (315) 481-9290.

Oley Welcomes Meshal

We are happy to welcome Meshal Samadzada to the Oley staff. Meshal joined Oley as Administrative Support Specialist earlier this year. She works part-time in the office, and attends Russell Sage College. Meshal will graduate in December with a Bachelor of Science in Nutrition. Her next step will be to apply for a dietetic internship, which she must complete in order to reach her goal of becoming a registered dietitian.

Meshal has been a tremendous asset as we seek to meet our project goals and serve our members. She has been heavily involved in preparing material for our new Web site, as well as creating a glossary for consumers and caregivers to help them better understand terms associated with home parenteral and enteral nutrition (HPEN). Welcome Meshal!
Volume XXXV, No. 6

Oley News

PN Drug Shortages

Beverly Holcombe, PharmD, BCNSP, FASHP

Shortages of parenteral nutrition (PN) components continue. The latest product to be in short supply is dextrose 70% water (D70W), but the shortages are revolving constantly. What is in adequate supply today may be unavailable tomorrow. As such, the consumer’s home PN may constantly change.

Consumers should stay informed and vigilant, and continue to have conversations about the shortages with their PN prescriber and their home PN team, including the home care dietitian and home infusion pharmacist. It’s important that they discuss the shortages, how shortages are affecting their PN prescription, if shortages have been communicated to their prescriber, etc. These and other questions consumers should ask are listed in the article on shortages published in the July/August 2014 issue of the Lifeline Letter (www.oley.org/newsletters/JulyAugust2014.pdf or call Oley offices for a copy).

These shortages have been ongoing since 2009 and, although things are improving, shortages continue.

Beverly Holcombe, PharmD, BCNSP, FASHP is a clinical practice specialist at the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.).

Oley Vancouver, Victoria Picnic

Laurie McBride, Oley Ambassador

About thirty people attended this September event, including home parenteral and enteral (HPEN) consumers from greater Vancouver, the Fraser Valley, and Victoria, as well as professional and support staff from our provincial program hospital, St. Pauls, and our service provider, Calea. We were delighted to have Dr. Scott Whittaker join us and introduce Dr. Ko, one of two new gastroenterologists about to join the program and share the load.

The term “picnic” was a bit of a misnomer. After all, how logical is a picnic for a group where eating is often a long forgotten occasion? More appropriately perhaps it should have been labeled a “meet and greet.” In spite of this, we had an excellent turn out and we all had an opportunity to meet other like individuals and share experiences. Many consumers had never met Calea’s customer service staff, in spite of years of telephone conversations.

There are semi-annual or quarterly support group meetings in Greater Victoria and Greater Vancouver. For additional information, or with suggestions for future events/speakers, call the Oley office (518) 262-5079/(800) 776-6539 or write me (Laurie) at Lmcbride@telus.net.

Oley members share experiences in western Canada.
Novel SBS Therapy, from pg. 1

of animal models, including rats, mice, and pigs. A number of studies demonstrate that the lengthened intestine absorbs nutrients and performs peristalsis (to aid the passage of contents through the intestine) normally.

Our laboratory has spent the last decade developing a series of novel devices that can lead to such intestinal growth. This short article describes some of the goals for this process, and the challenges that must be addressed before it can be successful on a clinical basis.

Goals

Our laboratory has shown that patients with less than 10 percent of their normal intestinal length have a very poor chance of weaning from PN. We consider these patients good candidates for enterogenesis. Ideally, in addition to successfully creating enterogenesis in the patient, the device we develop will be implantable with minimal surgical intervention (e.g., endoscopic placement); safely attach to the intestine (couple to the inner lumen of the bowel); and uncouple from the bowel wall for easy removal.

We have used a young adult pig model for most of the work we’ve done in our laboratory. This model has allowed us to scale the size of the devices we’ve developed to the size that would be used in children or adults. Figure 1 shows the concept of one device implanted in a pig. Using a hydraulic device that we had implanted in the pig’s small bowel, we were able to achieve a 2- to 2.7-fold increase in intestinal length over a two-week period.

How does this hydraulic device work? We inject saline into the device through a tube brought outside of the pig. This fluid drives the hydraulic device to expand—much like the opening up of a telescope that has multiple tubes. We have been successful in elongating the bowel with this device. However, to date the work has typically involved at least two surgical procedures: one to implant the device and another to remove it. It is our goal to minimize surgery, as additional surgeries increase risk of surgical adhesions and infection.

Current Work

With the support of the Hartwell Foundation, the National Institutes of Health (NIH), and the Food and Drug Administration (FDA), we
are working to address the shortcomings of our previous work. Figure 2 shows the design of our current bowel-lengthening device. This new design allows for endoscopic or radiologic placement of the device, rather than surgical placement. The two balloons can be inflated. The friction the inflated balloons create provides attachment to the inner lumen of the bowel. The device can then be mechanically extended between the two balloons using a hydraulic concept similar to the one described above. To remove it, the balloons are deflated and the device is pulled out through an intestinal stoma.

While this device offers many improvements compared to our previous generation of devices, we still face several challenges. Our first is the need for a better and safer way to couple the device to the inner surface of the intestine. The second challenge is to improve our ability to measure how much force we are placing on the intestine during the process of enterogenesis. Too little force will fail to drive intestinal growth, while too great of a force will lead to intestinal perforation.

Future Directions and Challenges

Our laboratory is now preparing a next generation device. This device will ideally be ready for a clinical trial in the next few years. However, many internal and external challenges exist. This includes refinement of the present device with improved safety features and modifications for straightforward clinical utility. These refinements appear readily achievable.

External challenges will include clinical testing of this device for efficacy and safety. An even greater external challenge will be an economic one. Bringing such a device to market will not be easy. One of the greatest challenges we face is the fact that SBS is a rare disease. Attracting a company to partner with in the clinical development of this device has been quite challenging.

References upon request.

Figure 2

Above: Fully endoluminal distraction-induced enterogenesis device. In this current model, two balloons are used to anchor the device to the inside of the intestine. This device can be implanted, extended, and removed via a stoma, allowing intestinal growth without additional operations.

Right: The fully endoluminal distraction-induced enterogenesis device implanted in a pig’s intestine.
Phytonutrients

Phytonutrients (also referred to as “phytochemicals”) are naturally occurring substances present in plant foods, including fruits, vegetables, whole grains, teas, legumes (beans), and nuts. The intake of phytonutrients is associated with decreased risk for cancer and chronic diseases.

- “Phytonutrient FAQs,” USDA Agricultural Research Service, ars.usda.gov/Aboutus/docs.htm?docid=4142#what_are
- “Phytonutrients,” www.webmd.com/diet/phytonutrients-faq
- Micronutrient Research for Optimum Health, Oregon State University, Linus Pauling Institute, lpi.oregonstate.edu/infocenter/phytochemicals.html

Dietary Fiber

Dietary fiber is the non-digestible carbohydrate part of plant foods. There are several different types of dietary fiber, soluble and insoluble, found in whole grains, fruits, vegetables, legumes, and nuts. Intake of dietary fiber helps with bowel function and is linked to lower risk for chronic diseases. Note: It is important to discuss with your doctor and dietician whether increasing dietary fiber intake is right for you, depending on your individual medical and surgical history.


Blenderized Foods

Blenderized Foods, from pg. 2

gravity, bolus, or pump. However, most often they are infused into G-tubes (including PEG-tubes and low-profile devices) slowly with a 60 mL syringe, by using gentle pressure on the syringe plunger (called bolus feeding). All methods work well with tubes of 14 French size or larger. Although very uncommon, some people use nasogastric (NG-) tubes in the home setting; using blended food is difficult or not possible with small-bore NG-tubes.

As with any tube feeding, the person being fed should be seated upright or have their upper body elevated at least 30 degrees to help prevent reflux. Tubes need to be flushed with warm water before and after each feeding and whenever medications are administered. Water flushes are critically important to clean out the tube and prevent clogging. If any lumps are seen in the blend, pour it through a strainer. Although it is less common, some people with G- or J- (jejunal) feeding tubes administer their blends with feeding bags and a pump. This will typically only work with thinner blends, which usually requires more fluid be added to the mixture and thus would not be appropriate for those with fluid restrictions or high calorie needs. According to Epp, a blended diet administered by pump via J-tube has been successful for some children with low calorie needs who can use a thinner blend; however, she cautions, for those with higher calorie needs, it’s too difficult to get the goal volume in when using pump feeds. With pump feeding, the blend should be infused within two hours to avoid spoilage. If the blend is left in feeding bags too long, ingredients may separate out in layers, increasing risk for clogging and inconsistent intake of nutrients. Some manufacturers of feeding pumps have specifically stated that their pumps are not to be used with anything but commercial formula.

Some health professionals and consumers are concerned about possible problems using blended formulas with the new EN connector devices that are to be a standard of practice in the next year or so. This past summer, these new “ENFit” connectors were tested using conventional tube feeding formula, applesauce, a very thick EN formula (used in Japan), and a commercial blended formula. Researchers measured the amount of pressure needed to push the formulas (and applesauce) through a 60 mL catheter-tip syringe and a 60 mL syringe fitted with an ENFit connector. They also measured the gravity flow of the formulas after they had been refrigerated. They found no significant differences in either the pressure required or the gravity flow rate using a catheter tip syringe or a syringe with an ENFit connector. More
Creating Healthy, Balanced Meals

One can find many blenderized diet recipes, but consultation with a registered dietitian/nutritionist (RD/RDN) is crucial to ensure that a diet is appropriate for the individual's specific nutrition needs; otherwise, one is at risk of under- or overdosing on various nutrients. RDs will calculate calorie, protein, water, and micronutrient needs based on age, height, weight, and, for children, growth goals. RDs can evaluate food and fluid choices and monitor a person's nutritional progress.

Some people who have poor digestion or malabsorption will not be able to use blended foods. Others might need to restrict fiber. If you are transitioning from conventional canned EN formula to blended foods, it is recommended you try one new food for several days and monitor tolerance before adding another new food. However, if you were eating a variety of foods just prior to starting EN, this will not be necessary.

Use of blended feeding can range from adding one fruit or vegetable blend daily to a regimen of standard commercial EN formula, to a diet that consists only of blended foods. One way to make a balanced meal is to portion out foods in amounts that would otherwise have been eaten by mouth, add liquid, and blendize. Another way is to blend a specific number of portions each day from the different food groups: carbohydrates (grains and starchy vegetables), protein, vegetable, fruit, dairy (or dairy substitutes), and fats and oils.

According to Epp, they use the USDA MyPlate system at Mayo clinic (visit www.choosemyplate.gov). The SuperTracker program on the MyPlate Web site can help guide healthy choices and serving sizes. For those who wish to create nutritionally complete recipes, or just find general nutrient information, the free USDA National Agricultural Library's Nutrient Data Web site (ndb.nal.usda.gov) or other published nutrient databases can be helpful.

Prepackaged Blenderized Formulas

For convenience and variety, some HEN consumers use prepackaged commercial blended formulas, either alone or in addition to their homemade blended diets or standard HEN formulas. Nestle® Compleat™ and Blenderized Foods, cont. pg. 10

<table>
<thead>
<tr>
<th>Formula</th>
<th>Serving Size</th>
<th>Calories</th>
<th>Protein (grams)</th>
<th>Dietary Fiber (grams)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RealFood Blends Orange Chicken, Carrots, and Barley blend</td>
<td>8 oz.</td>
<td>330</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td>RealFood Blends Salmon, Oats and Squash blend</td>
<td>8 oz.</td>
<td>330</td>
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<td>2</td>
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<tr>
<td>RealFood Blends Quinoa, Kale, and Hemp blend</td>
<td>8 oz.</td>
<td>330</td>
<td>11</td>
<td>4</td>
</tr>
<tr>
<td>Liquid Hope organic whole foods meal replacement</td>
<td>12 oz.</td>
<td>440</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>Compleat</td>
<td>250 mL</td>
<td>265</td>
<td>12</td>
<td>1.5</td>
</tr>
<tr>
<td>Compleat Pediatric</td>
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<td>9.5</td>
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<tr>
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<td>150</td>
<td>7.5</td>
<td>2.5</td>
</tr>
</tbody>
</table>
Compleat™ Pediatric have been available for years. These formulas are similar to conventional EN products in that they contain some maltodextrin, corn syrup, sodium caseinate (milk protein), and canola oil. Compleat, however, also contains chicken, pea, carrot and tomato purees, and Compleat Pediatric contains green pea, green bean, chicken and peach purees, and cranberry juice.

Consumer demand has resulted in some new prepackaged blenderized natural food products. The inventors of RealFood Blends™ and Liquid Hope™ shared information about their formulas at booths at the Oley conference in Orlando, Florida, in June.

RealFood Blends was founded by Julie Bombacino, the mother of a young boy who required tube feeds and who did not tolerate standard EN formulas. Currently there are three RealFood Blends meal varieties: orange chicken, carrots, and barley blend; salmon, oats, and squash blend; and quinoa, kale, and hemp blend. None of these contain corn syrup, dairy, soy, or nuts. Other ingredients include grape, orange, and pomegranate juice concentrates; grapeseed, flaxseed, and extra virgin olive oils; cinnamon, sunflower seeds, and water.

Liquid Hope is an organic, vegan whole foods meal replacement blend produced by Functional Formularies®. Robin Gentry McGee invented this formula while providing care for her father who used HEN. Ingredients include (all organic) garbanzo beans, green peas, carrots, whole grain brown rice, whole grain brown rice protein, flax and borage oils, sprouted quinoa, sweet potato, broccoli, almond butter, kale, garlic, turmeric, rosemary, ginger, wakame (seaweed), and added vitamins. Liquid Hope contains no genetically modified foods (non-GMO), no added sugars, and no dairy, soy, corn, or gluten.

Financial Coverage
Prepackaged blenderized food formulas are more expensive than standard formulas, and the cost will not be covered by Medicare unless the physician documents in the patient’s medical record a medical reason that a standard EN formula is not tolerated. The Medicare term is “blenderized natural foods with intact nutrients” and the billing code is B 4149. Medical reasons for coverage are intolerance, or adverse or allergic reaction to a standard EN product. Examples include corn, soy, or casein allergy; or severe constipation, vomiting, or diarrhea.

For help with the expense of blenders, check out the manufacturers’ Web sites or call the companies (for Vitamix, Blendtec, Oster®, and other brands of blenders); some reduce prices for those using the blenders for medical use. If you are just starting out with blended foods, it is wise to use a regular or less expensive blender at first, to make sure blenderized diets will work for you before purchasing a very expensive one.

Conclusion
The practice of home tube feeding with blenderized foods is not common, but interest is growing and more consumers are choosing this method of nutrition support. It is up to each consumer, along with his or her medical care team, to decide what is best. Consumers and caregivers should discuss options with the HEN user’s health care professionals before changing an HEN regimen. Registered dietitians who specialize in HEN can be helpful in choosing appropriate foods, however not all RDs/RDNs are familiar with blended tube feeding diets. For HEN consumers whose health condition allows, and who desire a variety of fresh healthy foods instead of or as a supplement to their current tube feeding regimen, blenderized foods are an option to consider.

More Information
- The Oley Foundation, “Making Your Own Food for Tube Feeding,” www.oley.org/lifeline/TubetalkSO07.html#Making%20your%20own
- “Real Food for Real People, a Blended Diet Resource,” www.foodfortubies.com
- “Blenderized Diet, Unlock the Nutrition,” www.blenderizeddiet.com
- Feeding Tube Awareness Foundation, www.feedingtubeawareness.com
- “Blenderized Tube Feeding and Related Stuff,” youstartwithatube.blogspot.com/searchlabelrecipes
- Functional Formularies, www.functionalformularies.com
- RealFood Blends, www.realfoodblends.com
- Complete Tubefeeding: Everything You Need to Know about Tubefeeding, Tube Nutrition and Blended Diets, by Eric Aadhaar O’Gorman, 2012 (written by an HEN consumer)
- Lisa Epp can be reached at mayohen@mayo.edu; and Theresa Fessler at taf4c@virginia.edu.

Note: This information should not be used in place of the advice and direction of your physician and registered dietitian.
New www.oley.org Offers Help Along the Way

We have been busy this year creating a new Oley Web site, and it is very exciting to be able to share a snapshot of what you will experience when we launch in early 2015.

The Web site will offer several new features. You will be able to access a clinician directory, follow news and Oley events more easily, and register for Oley events more effectively. As always, all of the information pages on our site will be accessible to everyone. Oley members who sign up and create a profile will have special features available to them, such as the ability to save articles to files they create for later reference, join groups, and more.

An important part of the project has been integrating our database with the Web site. This will improve our efficiency and accuracy, and gives us a better understanding of your needs. The database information will be accessible only to Oley staff.

When we launch:

• You will be invited to login and create a user name and password.
• You will be asked to review the accuracy of the information we currently have for you/your family in our database, and to make changes as needed (i.e., maybe you have transitioned from IV to tube feeding, moved, or changed your e-mail address). This small effort on your part will greatly improve our ability to serve you.
• You will be asked to respond to some medical questions. This information will be used to tailor the notices and invitations we send you, and to develop programs that better meet your needs.
• Your privacy remains a top priority. As in the past, we will not share membership information with any outside parties.
• We promise to make the transition as painless as possible. For those who prefer, calling us with updates is always an option!

The new Web site offers us many possibilities and room for growth—perfect for an organization that now serves over 14,500 members! We are excited for you to join us in exploring the new features.

In this season of thankfulness...

The Oley Foundation extends warm wishes to you and your family.

Some people say water is the most powerful force on earth.

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

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

Enteral Connectors Update

This year we’ve been talking a lot about the new design standards for enteral nutrition (EN) tubing connectors. If you’ve been following this, you’ll know the new standard means transitioning to new feeding tubes, administration sets, and EN syringes that use “ENFit” connectors. These new connectors are designed to be incompatible with connectors used for other purposes (such as central venous catheters, or tracheostomies). The goal is to ensure patient safety.

Revised Timeline

The timeline for the release of EN administration sets with ENFit connectors (and with adapters that will allow the new administration sets to connect to your current feeding tube) has been pushed back. Originally manufacturers expected to release these products in the United States, Canada, and Puerto Rico in the fall and early winter of 2014; now they expect to release them in these areas in early 2015. ENFit syringes should be available next spring, and G- and J-tubes with ENFit connectors next summer.

Resources

For the latest news on ENFit connectors, go to the GEDSA site www.stayconnected2015.org. GEDSA is a nonprofit association of manufacturers, distributors, and suppliers who have joined forces to help introduce international standards in medical tubing connectors.

A video on YouTube shows what the new connectors will look like and how they will be used. Search YouTube for “Stay Connected Initiative Overview.”

Premier, Inc. offered a Webinar that will answer many of your questions about ENFit connectors. Slides and audio for the Webinar are at www.premierinc.com/tubingmisconnections.

New PN Products

Kabiven and Perikabiven

In August, Fresenius Kabi announced it had received approval from the U.S. Food and Drug Administration (FDA) for Kabiven® and Perikabiven®, intravenously infused solutions of lipids (Intralipid® 20%), dextrose, amino acids and electrolytes in three-chamber bags, with the flexibility to make additions. Fresenius states, “The unique three-chamber bag simplifies the delivery of parenteral nutrition [PN] by providing a premixed solution that is shelf-stable at room temperature for up to two years until activated for patient use….The design of the three-chamber bag keeps the macronutrients separate and shelf-stable until the bag is activated and the contents mixed together….The formula is intended to meet the daily nutritional requirements of broad patient populations.”

Nutrilipid 20%

Also in August, B. Braun announced that it had received FDA approval for Nutrilipid® 20% (IV fat emulsion) for PN therapy in adult and pediatric patients. Nutrilipid 20% is indicated as a source of calories and essential fatty acids for PN and as a source of essential fatty acids when a deficiency occurs when oral or enteral nutrition is not possible, insufficient, or contraindicated. B. Braun states, “The approval of Nutrilipid 20% will help alleviate the short supply of lipid emulsion products the U.S. has seen over the past two years. It will be available in flexible containers that are not made with DEHP, PVC or natural rubber latex.”
Nutrition and You

FODMAPs

FODMAPs is an acronym for “fermentable oligo-, di- and mono-saccharides and polyols.” FODMAPs are short-chain, small molecular weight carbohydrates that are poorly absorbed in the GI tract. As a result, they are rapidly fermented by normal bacteria in the intestine, causing GI distention, increased gas production, pain, and fluid delivery to the GI tract.

People with irritable bowel syndrome (IBS) and some other GI disorders have used a diet low in FODMAPs to treat symptoms with great success. The diet includes eliminating or limiting certain foods containing fructose, fructo-oligosaccharides (fructans and galacto-oligosaccharides), lactose, and polyols (sugar alcohols). Modification of the diet to limit FODMAPs (less than 4 gm/day) has been shown to be effective in decreasing symptoms in 75 percent or more IBS patients. After four to six weeks, higher FODMAP foods are re-introduced, carefully and systematically, as tolerated.

So how does this affect you as an Oley consumer? If you are receiving tube feeding and you have noticed bloating or diarrhea that you cannot seem to manage and cannot attribute to another cause, it might be too many FODMAPs in your formula. If you are a home parenteral nutrition (HPN) consumer and you get these GI symptoms after eating, it may be because you have consumed too many FODMAP foods.

FODMAP Diet

Managing FODMAPs food intake is a little tricky. You need to work with a registered dietitian who has expertise in this area. While primarily problematic for people with IBS, some of these foods can be troubling for anyone with a compromised GI tract.

For the most part, protein is not a culprit unless the protein is associated with higher lactose content. When supplementing, look for protein with low or zero lactose, like brown rice protein, egg protein, or whey protein isolate. Fat also is not usually a problem—just not too much! Food sources of FODMAPs are more pronounced in “real food” or blenderized formulas, so check the formula label and consider the contents.

Carbohydrates in tube feedings that can cause symptoms are most often associated with the fiber components. Some examples of the high FODMAPs fibers are inulin (chicory root extract), fructo-oligosaccharides (FOS), trans galactooligosaccharides, and raffinose, which is a fiber from legumes. Added fiber may be good for most people, but depending on your GI system you may need to limit these types of fibers. These fibers have been added to enteral (tube feeding) formulas because they have a shorter chain and do not increase the viscosity (thickness) of the formula. However, formulas supplemented with FOS have been associated with increased gas and stool frequency. This will not happen for everyone, but it is something to consider if you aren't tolerating your formula when everything else looks right.

Bottom line: What you eat matters, whether it is administered through a tube or as a supplement to HPN. Keep in close contact with your dietitian, who can assist you in managing GI symptoms.

Carol Ireton-Jones, PhD, RDN, LD, CNSC, FASPEN, reviewed by Laura Matarese, PhD, RDN, LD, CNSC, FASPEN.
Online Shopping Benefits Oley—at no charge to you!

When shopping online, consider these EASY options that can benefit the Oley Foundation without costing you a cent.

**www.iGive.com/oley**

Shop your favorite online stores through iGive.com. Select Oley as your charity of choice, and a portion of your purchase will be donated to the Foundation. If you are new to iGive, when you shop before 1/15/15 they will donate an extra $5 to Oley! You can also make up to $1,000 for Oley by getting your friends to join iGive by this deadline.

**AmazonSmiles (http://smile.amazon.com/ch/13-3194182)**

Shop AmazonSmiles (featuring the same products and service as Amazon.com), select “The Oley Foundation” as your charity of choice, and they will donate 0.5% of your eligible purchases to the foundation.

**www.GoodSearch.com**

Use GoodSearch for all your Internet searching needs. If you select the Oley Foundation as your charity of choice, a penny is donated to Oley for every search you make—whether you are shopping or researching.

**www.GoodShop.com**

Use the GoodShop Web mall for shopping, choose Oley as your favorite charity, and up to 37 percent of your purchase will be donated to the Foundation.

**www.oley.org**

You might also consider making a donation to the Oley Foundation in honor or in memory of someone special.

Thank you for supporting Oley!

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Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors who help keep Oley programs free of charge to home parenteral and enteral consumers. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

**BioScrip, Inc.**

BioScrip nutrition consumers receive personalized, safe and effective infusion and nutritional therapies to improve their quality of life. The company acknowledges and accommodates each individual’s functional, psychosocial and lifestyle needs. Its goal is to recognize, understand and exceed the expectations of each consumer while providing effective and affordable healthcare solutions. BioScrip subsidiaries names you may be more familiar with include: Applied Health Care, BioScrip Infusion Services, Deaconess HomeCare, HomeChoice Partners, Infusion Partners, Infusion Solutions, InfuScience, Infusioncare, New England Home Therapies (NEHT), Option Health, Professional Home Care Services (PHCS) and Wilcox Medical.

**ThriveRx**

ThriveRx is proud to be a Gold Medallion Partner of the Oley Foundation. The company is dedicated to providing customized customer service and clinical care for the home enteral and parenteral nutrition consumer. Its mission is to ensure quality care that fosters independence and empowers patients and their families. Visit www.thriverx.net to learn more about its Short Bowel and iThrive programs.

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Feeding Tube Awareness Week, February 8–14, 2015

**Why?**

- Help others understand what life with feeding tubes and enteral nutrition is all about.
- Increase tolerance and knowledge.
- Create bridges to people who are feeling isolated or struggling with tube feeding.

**How?**

- Send a photo and/or video clip of yourself to Lisa at Oley (address below), along with a sentence or two about what tube feeding means to you, for our Feeding Tube Awareness video. We’ll launch the video on YouTube February 8!
- Share your story in a press release or in your blog. How is tube feeding helping you or your child be active or grow? What do you do if/when you or your child can’t eat? How do you cope with the challenges of tube feeding?
- Join us on Facebook or the Oley forum for daily discussions.
- Talk to your friends and family, or school or church groups. Have a frank conversation about something you find challenging, or take the opportunity for “show and tell.”

We are here to support you! Contact Lisa at metzgel@mail.amc.edu, (518) 262-5079/(800) 776-OLEY, or The Oley Foundation, 43 New Scotland Ave, MC-28, Albany Medical Center, Albany, NY 12208.
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 August 16 to October 10, 2014:

In Honor of
Daniel Dehart; Richard & Donna Noble & their efforts to help others; Ian & Donna Oxford; Steve Russell and keeping donations of liquid nutrition free for those in need

In Memory of
Wendy Agar; Patricia Brown; Michelle Dehart; Gerald Hashbrouck, Sr.; Tom McManus; Charannie Miller; Clarence “Oley” Oldenburg; Eleanor Orkis; Danielle Peterson

Fundraisers
Baxter Healthcare HPN Awareness Week Jean’s day; Emma Tillman’s San Francisco Marathon; Ice Bucket Challenge; Lisa Metzger’s San Francisco Half-Marathon; Morris Plains Branch, BioScrip, monthly fundraiser; NPS Pharma HPN Awareness Week event

Matching Gift
FM Global Foundation

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.

Join the Oley Horizon Society

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 at (800) 776-OLEY.

Felicie Austin
Jane Balint, MD
John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Faye Clements, RN, BS
Katherine Catter
Jim Cawain
Rick Davis
Ann & Paul DeBarkieier
David & Sheila DeKidd
Dale & Martha Delano
Tom Diamantidis, PharmD
Gail Egan, MS, ANP
Selma Ehrenpreis
Herb & Joy Emich
Jerry Fickle
Don Freeman
Linda Gold
Linda Gravenstein
Deborah Groeber

The Groeber Family
Valerie Grywko, RN
Alfred Haas
Shirley Helle
Alicia Hoelde
Jeff & Rose Hoele
Lyn Howard, MD
William Hoyt
Portia & Wallace Hutton
Kishore Iyer, MD
Doris R. Johnson
Darlene Kelly, MD, PhD, FACP
Family of Shirley Klein
Jim Lacy, RN, BSN, CRNI
Robin Lang
Hubert Maiden
Laura Maatme, PhD, RD, LDN,
CNSC, FADA, FASPEN
Kathleen McNees
Michael Medwar
Meredith Nelson
Nancy Nicholson
Rodney Okamoto, RPh,
& Paula Okamoto
Kay Oldenburg
Harold & Rose Orland
Judy Peterson, MS, RN
Clements Pietzner
Beverly Promisel
Abraham Rich
Wendy Rivner
Ruth & Eric Scheib Dahl
Suan & Jeffrey Schenol
Doug Seidner, MD, FACC, CNSP
Judi Smith
Steve Svensen
Cheryl Thompson, PhD, RD, CNSC,
& Gregory A. Thompson, MD, MS
Cathy Tokarz
Eleanor & Walter Wilson
Marion & Larry Winkler
James Wittmann
Patty & Darrell Woods
Routine Ann & William Wu

Oley Corporate Partners

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

PLATINUM LEVEL PARTNERS
($70,000)
BioScrip, Inc.

GOLD MEDALLION PARTNERS
($50,000)
Coram CVS/specialty infusion services
Covidien
ThriveRx

SILVER CIRCLE PARTNERS
($30,000)
Boston Scientific
NPS Pharma
Nutrishare, Inc.

BRONZE STAR PARTNERS
($20,000)
Baxter Healthcare
Fresenius Kabi USA

BENEFACTOR LEVEL PARTNERS
($10,000)
Abbott Nutrition
Kimberly-Clark
Nestlē Health Science
Walgreens Infusion Services

PATRON LEVEL PARTNERS
($5,000)
Applied Medical Technology, Inc.
Nutrishare Canada

Thank You!
Give the Gift that Changes Lives!

Soon you will receive an appeal to support Oley programs. Please give generously. By pooling our resources and talents, together we can improve the lives of consumers and their families.

Oley Joins A.S.P.E.N. in CA

Members of Oley staff will be in Long Beach, California, to attend Clinical Nutrition Week (CNW15), coordinated by the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), February 14–17, 2015. This is a gathering of some of the most prominent clinicians practicing in the field of clinical nutrition and a “must attend” meeting for those of us who wish to stay informed.

We are recruiting help to distribute Oley materials at our exhibit booth and hope you will come from near and far to join us. You will meet health care professionals from around the world and learn about the newest products and services while visiting with other exhibitors, and learn of new advances in the field by networking with attendees and faculty and viewing the posters on display in the exhibit hall.

More information can be found at www.nutritioncare.org, including a list of the exhibitors and faculty. It is definitely worth a glance!

Regional Meetings

While we are town for CNW, Oley will host a regional conference on Saturday, February 14. Plan to spend part of your Valentine’s Day learning more about the therapy that sustains you! It’s a great opportunity to share your experience with fellow consumers as well.

Oley will also be planning one-day regional conferences in Chicago, Illinois, and Atlanta, Georgia, in the very near future. Invitations will be e-mailed to everyone (be sure we have your address!) and sent by the US Postal Service to those in the surrounding areas.

If you live outside of these areas and would like to receive an invitation, write to Joan Bishop at bishop@mail.amc.edu or call (518) 262-OLEY/(800) 776-6539.

Oley Calendar

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<tr>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>November 14–16, 2014</td>
<td>Oley exhibit at Infusion Nurses Society (INS), Atlanta, GA</td>
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<tr>
<td>February 8–14, 2015</td>
<td>Feeding Tube Awareness Week</td>
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<tr>
<td>February 14, 2015</td>
<td>Oley Regional Conference, Long Beach, CA</td>
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<tr>
<td>February 28, 2015</td>
<td>Pediatric Feeding Conference, Phoenix, AZ</td>
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<td>March 18, 2015</td>
<td>Deadline for Oley awards, Kyle Noble Scholarship, and HPN Research Prize</td>
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<tr>
<td>May 16-21, 2015</td>
<td>Oley exhibit at Infusion Nurses Society (INS), Louisville, KY</td>
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<tr>
<td>April 20, 2015</td>
<td>Boston Marathon, Team Oley</td>
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<tr>
<td>August 2–8, 2015</td>
<td>HPN Awareness Week</td>
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