Dietary Management for Short Bowel Syndrome: What You Eat Does Matter

Laura Matarese, PhD, RD, LDN, FADA, CNSD

We eat both for the nutrients food provides and for the pleasure of eating. But if you have short bowel syndrome (SBS), the type of food you eat and the way you consume foods are especially important, as these factors will affect your absorption. This article will review the types of foods you should consume and the way you should consume them if you have SBS.

Short Bowel Syndrome
What exactly is SBS? And what do we mean by “short”? The normal small bowel length in adults ranges from 300 to 800 cm. Loss of two-thirds or more of the small bowel is defined as SBS. However, as many of you know, it is not just the length that matters, but how well the remaining bowel functions. So you may not have much bowel, but what you have works pretty well. Or you may have plenty of bowel, but it is diseased and doesn’t function optimally.

Diet
Dietary modification is the foundation of therapy for someone with SBS. This is one area where you, the home parenteral and/or enteral (homePEN) consumer, have total control. You can decide what you eat, how much, and when. Making small adjustments in your diet will help you manage your ostomy output or bowel movements. This, in turn, may allow you to reduce your dependence on parenteral nutrition (PN).

GI Anatomy
Let’s start with a few basic concepts. Your diet must be based on your own gastrointestinal anatomy. If you have SBS and your colon is in circuit, you will maximize your absorption if you follow a diet that is low in simple carbohydrates and low in fat. If you have SBS and a jejunostomy, there is no need to restrict fat, but limiting the simple carbohydrates will help to decrease the ostomy output.

Carbohydrates
What is a simple carbohydrate and what is a complex carbohydrate? A simple carbohydrate consists of two sugar molecules that are hooked together to form a

Join Oley in Sunny Florida
Mark your calendar for the 2009 Oley Conference, “Finding the Perfect Balance,” June 29-July 2. We’ll be meeting at the Trade Winds Island Resorts in St. Petersburg—an outstanding venue that is offering Oley members the attractive rate of $139/night (this includes the resort fee of $15/night per room).

At the conference you’ll have ample opportunities to learn about nutrition therapies and to meet other consumers. Specialists from across the country will present relevant topics and be available to answer your questions. If there’s a topic you’d like to learn about, give us a call. Suggestions are welcome.

Start planning now! Stay tuned to www.oley.org and the LifelineLetter for updates.

My Life Long Journey on PN

Casey Kellogg

My name is Casey Kellogg. I live in Hornby, New York. I was born on December 25, 1990, at Arnot Ogden Medical Hospital in Elmira, New York. I weighed four pounds, fourteen ounces, and was eighteen inches long. I was born four weeks premature, with a condition called gastroschisis.

Right after I was born, I had to be rushed to surgery to have my small intestine tucked back inside me. During surgery, the doctor needed to remove all of my small intestines except four centimeters. After the surgery, the doctors told my parents they had two options.

The Options
The first option was my parents could try taking me home on an intravenous therapy called parenteral...
felt that this would be the most sensible solution because I would not suffer as long.

The panel of doctors even had a meeting about me. All but one of the doctors agreed that I should not be put on PN. They voiced this opinion to my parents. After careful consideration, my parents decided to bring me home on just the hydration fluids, to let me die a more peaceful death. The doctors gave me three weeks to live.

**Three, Four…**

Three weeks later, I was still here! I had lost some weight, but I was still here! When my parents took me back for a checkup, the doctors were amazed at how well I was doing. Even my electrolytes were still in pretty good shape.

At that moment, my parents just knew I was meant to live. They told the doctors that they wanted me to start PN therapy right away.

**Personal Strengths**

My parents and doctors knew that being on PN would make my life different forever. I have had to overcome many obstacles and I have many goals to achieve. Now, at seventeen, most times I think of myself as living a pretty normal life.

I have a family that helps me through things when I start to struggle. They always say I have great strength and I will have that for the rest of my life. My parents say it is this strength that has gotten me through all of the obstacles.

**Growing Up on PN**

Because the doctors had only given me three weeks to live, members of my family considered me the “miracle baby” on my first birthday. Everyone in my family came to the house that day to celebrate. Although I had made it to my first birthday, I had gone through some pretty tough times to get there.

To begin, my parents had to search for a doctor who had a positive outlook for me. They ended up in Binghamton [about one and a half hours from Hornby]. During my stay in Binghamton, the doctor tried giving me drip feeds through a tube. This made me vomit often.

The doctor referred me to a pediatric surgeon in Syracuse to see if he had any suggestions.

**Toddlerhood**

When I was really young, I had many central line infections. I was in the hospital a lot, just like the early doctors said I would be. I lost line after line. I was running out of places for new ones.

Finally, the only thing Dr. Ratner knew left to do was to open up my chest cavity and place a new line right next to my heart. It was a complete success! I had that catheter for four years. My parents were so grateful.

**Valuable Referral**

Although my catheter worked great for many years, I was not facing so well health wise. I was vomiting up to twelve times a day sometimes. By the time I was two years old, Dr. Ratner thought that it would be wise for us to meet with a doctor from Albany. He referred us to Dr. Lyn Howard [co-founder of the Oley Foundation].

Dr. Howard was my lifesaver. When I met her, I was a bloated mess. She spent a great deal of time listening to my parents talk about the history of my life. She wanted to know every single detail, so she could help me the best she could. She even wanted to hear about my family!

Because I was vomiting so often, she suggested I have surgery to wrap my esophagus. Several months after that surgery, my health began to improve. I became less bloated and a little bit stronger, though my legs didn’t gain enough strength for walking until I was four years old.

**Line Troubles**

Although I wasn’t really strong physically, my immune system proved to be. I was infection free for the entire time I had that central line. Unfortunately, that line became blocked. My
Tube Talk

Thank you to everyone who sent material for the “Tube Talk” column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

From Soup to Nuts

I have always been a lover of good food. All over the world I’ve sought out the finest dining establishments, from five-star restaurants to hole-in-the-wall eateries. When I first survived three occurrences of throat cancer (three surgeries and a full course of radiation) over a three-year period twenty years ago, I was still able to eat and swallow without too much difficulty. Yet over the years many side effects have occurred.

With the first surgery, my epiglottis (the valve that separates the airway from where the food goes down the throat) was removed. As a result, when I ate, food would go into my lungs and cause infections. Several times I ended up with pneumonia and I developed bronchiectasis. Five years ago, I had had at least one infection a month over the previous twelve-month period, all treated with antibiotics.

I’ve had all of the surgeries, treatments, and follow-ups at Mayo Clinic in Rochester, Minnesota. In October 2002, the doctor gave me two options to eliminate the infections: to surgically separate my esophagus from my trachea so food would not be able to get into the lungs; or to surgically put a feeding tube in my stomach. With the first option, they would have to remove my voice box. With the second, no more eating or drinking of any kind. Wow! I though. These are my options! But I knew I had to choose one.

I was not prepared to forever give up my voice, so I chose the feeding tube. I immediately had concerns about using canned formulas. During my first throat cancer surgery they had me on a canned formula during my recovery and I got nauseous while I was on it. I did not want a repeat. In addition, I have always been conscious of healthy food and made efforts to eat healthy. So I hit the books and researched foods that could be blended and put through this lovely tube I now had sticking out of my belly. No formulas for me!

I stumbled upon Barry Sears’s Zone Diet, which balances fat, carbohydrates, and protein in the right proportions [editor’s note: please see comments on page 10]. And then a friend mentioned this great device called Vita-Mix. It’s a high-powered blender that will pulverize anything, and I mean anything.

My very loving wife helped me develop over thirty recipes for soups and a half-dozen different smoothies that all utilize primarily fresh vegetables and fresh fruit as the primary ingredients, with some fish, chicken, nuts, tofu, soy milk, and other foods. Over the course of a month I don’t repeat the same meal twice, so I’m getting a wide spectrum of nutrients. I figure as long as I’m not going to be tasting

Tube Talk, cont. pg. 10
Newman Leaves a Legacy

We join members of the Oley community in grieving the loss of actor, philanthropist Paul Newman. Newman’s Hole in the Wall camps have changed the lives of numerous critically and chronically ill children.

Alicia Hoelle, an Oley Regional Coordinator and former camper, writes that Newman “created one of the most magical places on earth…. At the camp, I never felt like I couldn’t do something because I was sick…. Most of the time we never spoke about being sick, because we just wanted an escape from feeling sick and a place to ‘be like everybody else.’”

“That first summer changed my life for the better, and I am very grateful that I was able to go for six years. I met Paul Newman my second summer at the camp, and he was such a nice guy. Many of the kids didn’t know who he was; he didn’t act like a movie star. When I got older, I could see the joy in his face every time he was around the kids.”

We are grateful for the many gifts Newman shared. His memory will live on in the hearts of every camper.
Help Oley in New Orleans
February 1–4, 2009

Join Oley staff in telling clinicians what it’s like to live with home IV and tube feedings, and how Oley services can benefit their patients at Clinical Nutrition Week this winter. Hosted by the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), the annual gathering will be held February 1–4, 2009, at the Ernest Morial Convention Center in New Orleans.

We need your help at the Oley booth (February 1–3), covering one or more of the following time slots on each day:
- 9:15 a.m.–11:15 a.m.
- 12:15 p.m.–1:45 p.m.
- 3:00 p.m.–4:15 p.m.

Booth volunteers will interact with conference attendees and have the privilege of exploring the exhibit hall, which is packed with information on the latest parenteral and enteral products.

In addition to exhibiting at this conference, Oley staff will coordinate a session titled “What Is the Most Effective Consumer/Clinician Relationship: The Consumer Perspective,” to be held February 2 from 1:30 to 3:00 p.m. Join us for this lively discussion that’s guaranteed to be an eye-opener for many of the clinicians who attend.

Oley is also one of the sponsors of a pre-convention meeting to establish safe levels for micronutrients in parenteral nutrition solutions entitled, “Micronutrients in Parenteral Nutrition: Too Little or Too Much?” Stay tuned to the LifelineLetter and www.oley.org for updates from that meeting.

Equipment/Supply Exchange

Are you looking for formula, pumps, tubing, or miscellaneous items? Do you have items that you no longer need? Call the Equipment/Supply Exchange! Supplies available change daily.

**How does the Exchange work?**

- A full listing of items available—from tubing and bags to formula to durable items—is posted on the Oley Web site, www.oley.org. This list is updated every Monday, so check frequently. Call or respond online if you see something you need.
- If you don’t have Internet access, call the Oley office and we’ll see if what you are looking for is in the exchange database.
- You can also let us know what you need, and we’ll contact you if the item becomes available.
- Contact Oley by phone or online if you have items available.

Items offered through the Exchange are available free of charge. To offer or claim items, contact Oley at (866) 454-7351 (toll-free) or harrinc@mail.amc.edu. If we refer you to someone offering supplies, please give us a follow-up call—if you don’t take the supplies, we need to know they are still available, and if you do take the supplies, we’ll remove them from the list.

We ask that those receiving goods offer to pay the shipping costs. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition.
Recipe Request

The Association for Gastrointestinal Motility Disorders (AGMD) is gathering recipes, food tips, and eating advice from and for people with motility disorders. All recipes will be evaluated and reviewed by the AGMD recipe team, which is headed by: Marlene Hisaka, RN, BSN; Dorothy Petito, RD, CDN, and AGMD Nutrition Consultant; and Mary-Angela DeGrazia-DiTucci, President/Patient/Founder of AGMD. Recipes will be posted on the AGMD Web site (www.agmd-gimotility.org), appear in the AGMD Digestive Motility Forum publication, and possibly be published as a cookbook. AGMD invites you to e-mail your recipes, tips, eating advice, and a short paragraph about yourself to them at digestive.motility@gmail.com. More details are available on the AGMD Web site.

Essay Contest to Honor Caregivers

Shield Healthcare, a medical supplies provider based in California, has announced an essay contest for caregivers. Entitled “What Makes Caregiving Rewarding?” the contest is designed to recognize the voice of caregivers and home healthcare professionals.

The contest runs through November 25, 2008, in celebration of National Family Caregiver’s Month.

The top three winners will receive $1000 in American Express Gift Cheques and a one-year subscription to Today’s Caregiver magazine. The two runners-up will receive a one-year magazine subscription and $250 in American Express Gift Cheques. All contest entries must be one-page, typed or hand-written, and postmarked by November 25. Entries should be mailed to Shield Healthcare, Attn: Caring Solutions, 27911 Franklin Pkwy., Valencia, CA 91355 or e-mailed to caring@shieldhealthcare.com. Full contest details are available on Shield’s Web site at www.shieldhealthcare.com.

Standing Shoulder to Shoulder

The Oley Foundation salutes Co-founder Lyn Howard, MD, for her tremendous dedication in supporting home parenteral and enteral patients and their families for more than twenty-five years. In addition to running a prestigious clinical nutrition program, Dr. Howard co-founded the Oley Foundation, served on numerous boards, and continues to bring cutting-edge research into clinical practice. Above all, patients, families, and colleagues treasure how she treats the patient’s whole person, not just their physical health.

Newly Created Howard Award Honors Consumer Advocates

American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) has created a new patient, family, caregiver advocacy award in honor of Oley co-founder Lyn Howard, MB, FRCP. Dr. Howard, a long-time A.S.P.E.N. member, has made substantial contributions to patient-centered care and patient advocacy throughout her career and has leadership status in the nutrition support community.

The Lyn Howard Nutrition Support Consumer Advocacy Award will be given for the first time at the A.S.P.E.N. Clinical Nutrition Week (CNW) meeting in New Orleans in February 2009.

Nominate an Advocate!

Please consider nominating a homePEN consumer, caregiver and/or family member for this award.

Criteria for Award

• Nominee must be a patient (EN or PN consumer), or a family member or caregiver of such a patient.

• Nominee must have demonstrated admirable activities to advocate for him- or herself or others receiving EN or PN.

• Award winner or his/her representative should be able to briefly articulate his or her story at the awards ceremony at the CNW meeting. (Not an absolute requirement.)

For more information and an application, contact Peggi Guenter at A.S.P.E.N. (peggig@aspen.nutr.org), or a member of the Oley staff (www.oley.org /800-776-OLEY).
My Life, from pg. 2

Mom could no longer flush fluids through it. Dr. Ratner was still my surgeon, so we went to see him.

There was nothing he could do to free it. Everything he tried, failed. The only option was to remove that catheter and hope to find a new site. Keep in mind, this was in 1994.

In Dr. Ratner’s first attempt he went through my back muscle. This worked, at first. When my mom hooked me up the first night, I was in severe pain. The line had slipped out and fluid was collecting inside me. The doctor’s last attempt was to go through my liver. That failed as well. It seemed like my parents had to take me home once again to die.

During this time, I lost a lot of weight. I dropped down to just thirty-two pounds. I was getting very weak and my hair was falling out by the handful. I could barely stand up on my own and I was in a wheelchair at school. This was an attempt to make things easier for me.

I also had to have a G-tube at this time. My mom used to mix all kinds of stuff together to keep me going. For nine months I continued on this path. I started to fall behind in school.

Finally, Dr. Howard said she found someone who thought they could help me. My parents took me in right away. The surgeon placed the catheter through my back muscle once again. Thankfully, this time it worked. Within weeks, I was feeling stronger.

School Days

I was back to school without a wheelchair. However, at school it was like starting all over again. I had forgotten everything I had learned.

School has always been difficult for me, especially math. Yet I am still in normal classes because I give it my best and I have always put school first. I will never give up. I was always afraid of getting picked on at school, but now I just put that behind me and forget about it. I am now in tenth grade and I have many friends who accept me for who I am.

When I get home from school, I have a very tight schedule. I get hooked up to my PN five days a week for twelve hours each time. Even with all of this, I am still able to fit in a lot of activities. I like to play baseball, ride a four-wheeler, and go bowling. My future goal is to go horseback riding.

New Obstacles

Just four years ago, when I was thirteen, I had to have my gallbladder removed. I had developed several stones and I was in a lot of pain. With all of the surgeries I have had, I have a scar on my front side that looks like a cross.

Today, I still have a central line that travels through my back muscle. I have had many central line replacements; however, I have only had one infection in this site. That occurred during a trip I took to Myrtle Beach with my family.

Dr. Howard was so supportive. My mom called her from the hospital in Myrtle Beach and she told the doctors exactly what to do to help me. I’ve lost the other lines because they became blocked or they slipped out of place. The good thing is that they have always been able to put one back in the same place.

Just Normal

I have never thought of myself as having a disability. For all of the things that I have gone through, I think I have had a great life. Even though I have a catheter, I have made my life as normal as I can, and as normal as it will ever be.
disaccharide. Examples of these are sucrose (table sugar) and lactose (milk sugar). These are found in foods such as candy, cakes, cook-ies, pies, regular soda pop, jelly, jam, syrup, ice cream, sherbet, and sorbet. If you have SBS and you consume large amounts of these simple carbohydrates, you may experience more diarrhea.

Complex carbohydrates are composed of large starch molecules. When consumed, complex carbohydrates generally do not produce a lot of diarrhea. Complex carbohydrates are found in pasta, potatoes, breads, cereals, whole grains, fruits, and vegetables.

It might be tempting to consume foods that are “low carb.” However, these foods often contain sugar alcohols such as sorbitol and manitol instead of sugar. Sugar alcohols are not absorbed by the gastrointestinal tract. They tend to cause diarrhea and foods containing these “sweeteners” should be avoided. You may find these sugar alcohols in sugar-free mints and chewing gum, as well as in diabetic candies and cookies. Read the labels carefully.

Many people ask if they need to restrict milk and milk-containing products because milk contains lactose (the sugar found in milk) naturally. Many people lack the enzyme lactase, which is necessary to digest the lactose. If you cannot digest lactose, you will have gas, diarrhea, and bloating when you consume milk products. However, many people can tolerate small amounts of milk. For example, you may be able to tolerate milk on your cereal, even though you cannot drink a glass of milk.

Fiber

Soluble fibers are very important to someone with SBS, particularly if the colon is connected. Any undigested soluble fibers that reach the colon are metabolized into short chain fatty acids (SCFA). These SCFA are then absorbed through the mucosa of the colon and used as a source of energy. These SCFA also help with sodium and water absorption.

You can get fiber naturally through food (i.e., oatmeal, whole grains, fruits, and vegetables) or get it through various fiber supplements (see table 1). Even if your colon is not connected, you can use fiber to help to thicken up your ostomy output. This may give you a little more control over your output.

### Table 1: Examples of Fiber Supplements

<table>
<thead>
<tr>
<th>Product</th>
<th>Manufacturer</th>
<th>Type of fiber</th>
<th>Amount per serving (g)</th>
<th>Forms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefiber</td>
<td>Novartis</td>
<td>partially hydrolyzed gua gum</td>
<td>3</td>
<td>powder, chewable tablets</td>
</tr>
<tr>
<td>Citrucel</td>
<td>GlaxoSmith Kline</td>
<td>methylcellulose</td>
<td>2</td>
<td>powder, caplets</td>
</tr>
<tr>
<td>Metamucil</td>
<td>Proctor &amp; Gamble</td>
<td>psyllium</td>
<td>3.4</td>
<td>powder, capsules, wafers</td>
</tr>
<tr>
<td>FiberCon</td>
<td>Wyeth</td>
<td>calcium polycarbophil</td>
<td>1</td>
<td>caplets</td>
</tr>
</tbody>
</table>

### Table 2: Oral Rehydration Solutions

<table>
<thead>
<tr>
<th></th>
<th>CHO g/L</th>
<th>NA+ mEq/L</th>
<th>K+ mEq/L</th>
<th>HCO3 mEq/L</th>
<th>Osmo mOsm/L</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>World Health Organization ORS</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Standard Formula</td>
<td>20</td>
<td>90</td>
<td>20</td>
<td>30</td>
<td>310</td>
</tr>
<tr>
<td>Reduced-Osmolality Formula</td>
<td>13.5</td>
<td>75</td>
<td>20</td>
<td>30</td>
<td>245</td>
</tr>
<tr>
<td><strong>Rehydration Solutions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CeraLyte 70 (Cera Products)</td>
<td>40</td>
<td>70</td>
<td>20</td>
<td>30</td>
<td>235</td>
</tr>
<tr>
<td>CeraLyte 90 (Cera Products)</td>
<td>40</td>
<td>90</td>
<td>20</td>
<td>30</td>
<td>260</td>
</tr>
<tr>
<td>Equalyte (Ross)</td>
<td>30</td>
<td>78</td>
<td>22</td>
<td>30</td>
<td>305</td>
</tr>
<tr>
<td>Jinas Brothers ORS</td>
<td>20</td>
<td>90</td>
<td>20</td>
<td>10</td>
<td>300</td>
</tr>
<tr>
<td>Liqualyte (Gerber)</td>
<td>25</td>
<td>45</td>
<td>20</td>
<td>30</td>
<td>250</td>
</tr>
<tr>
<td>Pedialyte (Ross)</td>
<td>25</td>
<td>45</td>
<td>20</td>
<td>30</td>
<td>300</td>
</tr>
<tr>
<td>Rehydralyte (Ross)</td>
<td>25</td>
<td>75</td>
<td>20</td>
<td>30</td>
<td>300</td>
</tr>
<tr>
<td><strong>Sports Drink</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gatorade</td>
<td>60</td>
<td>20</td>
<td>3</td>
<td></td>
<td>340</td>
</tr>
</tbody>
</table>
foods you eat, affect absorption. In order to maximize absorption, you should eat five or more small meals a day. These should contain plenty of complex carbohydrates, e.g., bread, pasta, rice, potatoes, and low-sugar cereals. Your diet should also contain about 20 percent protein. You should keep concentrated simple sugars to a minimum.

As you can see from the sample menu in Table 4, the diet for someone with SBS can be very palatable, and there are plenty of foods to choose from! Fiber supplements, along with anti-diarrheal medications, can be used as needed to prolong intestinal transit time.

**Supplements**

Multivitamins with minerals should be taken orally two or three times a day if you are not receiving PN. Monthly vitamin B12 injections are recommended if you have had the terminal ileum resected. Additional oral supplementation of several essential minerals such as calcium, magnesium, and zinc is often necessary to replace excessive losses in patients with SBS. Often, calcium is taken in divided doses two to four times per day, as well as magnesium supplements in the form of lactate or gluconate salts, taken one hour before meals on an empty stomach. Zinc acetate is the most readily absorbed zinc salt.

### Table 3: Recipes for Oral Rehydration Solutions

<table>
<thead>
<tr>
<th>1. Gatorade base</th>
<th>2 cups Gatorade</th>
<th>2 cups water</th>
<th>½ teaspoon salt</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Grape or cranberry juice</td>
<td>½ cup juice</td>
<td>3 ½ cups water</td>
<td>½ teaspoon salt</td>
</tr>
<tr>
<td>3. Apple juice</td>
<td>1 cup juice</td>
<td>3 cups water</td>
<td>½ teaspoon salt</td>
</tr>
<tr>
<td>4. 1 liter (32 ounces) water</td>
<td>1 cup orange juice</td>
<td>8 teaspoons sugar</td>
<td>¾ teaspoon baking soda</td>
</tr>
<tr>
<td>5. 1 liter (32 ounces) water</td>
<td>¾ teaspoon table salt</td>
<td>3 tablespoons sugar (sucrose)</td>
<td>1 teaspoon baking powder (or ½ teaspoon baking soda)</td>
</tr>
</tbody>
</table>

* By prescription
† Concentration: 7-14 mEq potassium per gram; one teaspoon: 5 grams (1/6 oz) = 35-70 mEq potassium

### Is It Okay to Modify the Diet?

Sometimes you just have to have that favorite food even though you know it is going to run right through you. Is this okay? Well, on occasion, it is acceptable to sample that favorite food. But it is best to just “sample” it, and to do it when you are close to a bathroom. If you do this too often, you are likely to lose too much fluid and too many electrolytes.

### Conclusion

We eat for nutrition as well as for pleasure. If you have SBS, the type of food you eat and the way you consume food will affect your absorption. Small adjustments in the diet can give you more control over your output without you having to sacrifice nutrition or taste.

Dr. Matarese is the Director of Nutrition, Intestinal Rehabilitation and Transplantation Center, Thomas E. Starzl Transplantation Center, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania. This article is based on a presentation Dr. Matarese gave at the Oley Annual Consumer/Practitioner Conference in San Diego in June.
anything, I might as well give my body the highest quality food I can give it—so no caffeine, no sugar, no alcohol (one time I did put some sake through for fun), no pasta, no bread, no desserts, no dairy. Nothing but fresh ingredients, organic when possible.

I’m eating as healthy as one could possibly be eating. I eat four times a day with a volume of 28 oz of food and 12 oz of water with each meal (8 am, noon, 4 pm and 7:30 pm). My blood sugar remains balanced throughout the day and I hardly ever feel hungry as long as I eat on time. My weight has remained steady at about 165 pounds (I’m 6’4”).

After the initial seven months I switched the long tube that had been used to a button; it looks like I have an extended belly button. I attach a short tube to it every time I eat. This gives me great flexibility, which is good as I remain very active at fifty-five years old.

I am happy to share the recipes I use with anyone who would like them. Whether you are able to feed yourself or need someone to do it for you, you might give it a try. One of my favorite things is walking into the kitchen while the soups are cooking and smell the aromas of the day. I am blessed to be able to continue to live a very good life. Aloha.

—Jesse Jones
Honolulu, Hawaii
jj42@aol.com

Editor’s notes:

❖ Many diseases and disorders can lead to a person being tube fed, and neither blended nor food nor the diet suggested here will work for all Oley members. As always, we encourage you to speak to your doctor before changing your routines.

❖ We also asked Laura Matarese, PhD, RD, LDN, FADA, CNSD, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania, for her thoughts on the Zone Diet. She responded:

“The Zone Diet has received mixed reviews from the scientific community. Unfortunately, there is no scientific evidence to support the diet. However, it is not necessarily bad for the patients. It is very high in protein and may be too high if someone has renal insufficiency. The complex carbohydrates from fruits and vegetables may not be tolerated by many Oley consumers.

“On the positive side, the Zone Diet encourages people to eat often throughout the day—at least every five hours. It also eliminates foods many people overeat, such as sweets, chips, certain starchy foods, and, of course, junk food. It concentrates on including a number of healthful foods—low glycemic fruits and grains, vegetables, lean proteins, and monounsaturated and omega-3 fats. The Zone Diet works for weight loss because it is actually a low-calorie diet. For instance, the sample meal plans for an average woman total approximately 1200–1300 calories per day. Most women would lose weight at this level of caloric intake, regardless of the source(s) of these calories.”

❖ You can learn more about the Vita-Mix at www.vitamix.com or by calling 800-848-2649. Inquire about the company’s special purchase plan if you are using the blender for medical reasons (contact householdsales@vitamix.com or ask for household sales when you call).

❖ For other articles about blending food, visit the Oley Web site: www.oley.org/lifeline/TubetalkSO07.html#Making%20your%20own

Individual Donors

The following list represents everyone who contributed between July 17 and September 30, 2008. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

Ambassadors ($2000+)
Laura Mulchahy
Becky & Robert Puckett, in honor of Nathan Puckett
S. A. Chaney
Jeffrey & Susan Schesnol, in loving memory of Lea K. Preis
Bobbie Jo Winfrey

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Jane Lindsay
Linda O’Donnell, in memory of Joan Harper, her mother
Chris & Jean Prefete, in memory of Joan Harper
Jeffrey & Susan Schesnol, with heartfelt thanks and appreciation for Dr. Lyn Howard***

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Danniella Valente
Jennie Valente
Emma Valenti

*Oley Trustee
**Oley Regional Coordinator
***Oley Staff
From the Desk of the Executive Director

Fall has come and brought with it some wonderful news: Emmaus Medical has joined the growing list of Oley corporate partners at the Bronze Star level. Please join us in welcoming them aboard and thanking them for their generous support of Oley programs.

Emmaus Medical, Inc. is a Torrance, California-based, private pharmaceutical company that develops and markets new treatments for rare diseases and conditions. The company launched its first product, NutreStore™ (L-glutamine powder for oral solution), in June 2008, and is currently conducting clinical trials to investigate the safety and efficacy of oral L-glutamine for sickle cell disease.

The company writes, “NutreStore™ is the amino acid L-glutamine, identical to the L-glutamine that the human body naturally produces. NutreStore™ is used together with Zorbrive® (somatropin [rDNA origin] for injection) and a specialized diet tailored to meet a patient’s specific needs as an FDA approved treatment for short bowel syndrome (SBS). NutreStore™ is the first prescription L-glutamine available in the U.S.”

And the bounty doesn’t stop there. We extend a warm and grateful thanks to NutriThrive for continuing their support at the Golden Donor level. NutriThrive’s mission is to optimize the nutritional well-being of the homePEN consumer through advocacy, clinical care, and education. The company writes, “Advocacy is at the forefront of our agenda as reflected in our customized products and services, advisory boards, and Consumer Advocate program. Our goal is to empower consumers and their families to live!”

They continue, “As an Oley Partner, NutriThrive has put its mission into action as a Golden Medallion Sponsor, and contributes additional financial support to Oley through the company’s Full Circle program: $1 for every day of parenteral nutrition and $1 for every course of enteral nutrition that its patients require nationwide. NutriThrive is committed to giving back to improve life for those on HomePEN.”

Generous renewals have allowed Oley to continue popular services like the LifelineLetter and annual conference, and to expand its outreach and education to include programs like the new Oley forum and MY HPN online educational module. I urge you to take a look at Oley’s corporate partner list on right. If the company that makes or provides your supplies is listed, thank them for supporting your organization; if it is not, help us bring them on board. The first step is to contact me or Roslyn Dahl at (800) 776-OLEY. We look forward to hearing from you!

Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

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+)
Apria Healthcare / Coram Inc., Specialty Infusion Services
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS  ($50,000–$69,999)
NutriThrive

SILVER CIRCLE PARTNERS  ($30,000–$49,999)

BRONZE STAR PARTNERS  ($20,000–$29,999)
Emmaus Medical, Inc.

BENEFACCTOR LEVEL PARTNERS  ($10,000–$19,999)
Abbott Nutrition
Nestlé Nutrition

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

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

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

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers (given below) are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers who are willing and eager to talk and listen. These volunteers are available to discuss your homePEN concerns and answer questions. Call to talk about day-to-day issues, for ideas on coping, to share suggestions, and so on. The volunteers staffing the phone lines change regularly. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

November 2008
Don Young on HPN for Short Bowel/Crohn's Disease
Porter Corners, NY – EST (888) 610-3008
Sheila DeKold, Daughter on HPN for Pseudo-obstruction
Floyds Knobs, IN – EST (888) 650-3290

December 2008
Elizabeth Tucker on HPN for Short Bowel/Crohn's Disease
Lakeville, MN – CST (888) 610-3008
Flute Snyder on HEN for No Swallow/Throat Cancer
Hudson, WI – CST (888) 650-3290

January 2009
Jameson Atkinson on HPN for Short Bowel/Volvulus
Yardley, PA – EST (888) 610-3008
Mary Probus on HPN for Short Bowel
Louisville, KY – EST (888) 650-3290

’Tis the Season

As we move into the season of giving we cannot help but worry about the fragility of our economy and how this might effect our 2009 fundraising to support Oley programs. The annual appeal letter will arrive soon and we hope that you will consider gifting generously.

We remind you to explore alternate giving options, such as:
• payroll deductions (United Way)
• employer matching grants (extremely worthwhile!)
• friends and family who might add Oley to the list of organizations they support
• planned gifts (include Oley in your will, transfer stock or arrange another planned gift)
• automated monthly gifts

Your support will ensure that the Oley Foundation remains healthy and strong as we move into our twenty-sixth year.

Thank you.