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# LifelineLetter

Living with home parenteral and/or enteral nutrition (HPEN)

## Impressions of the Oley Conference

### Shawna Forester Smith's Experience

The past two years I have required parenteral (PN) and/or enteral (EN) nutrition to survive. I live in Winnipeg, Manitoba, Canada. While there are many people on PN or EN in the hospital, there are few who are on it in the community where I live.

My uncle always used to say that it isn't easy being green. Well, it isn't easy being hooked up to a pump twenty hours a day, not being able to eat. People stare. People ask questions. People go on and on about "how horrible it must be to not be able to eat."

When I found out in June that I had won an Oley Foundation Travel Scholarship to attend the Annual Consumer/Clinician Conference, I was ecstatic. Finally, I would be somewhere where there would be people with tubes and pumps who can't eat, like me. In July, my husband, Brent, and I made the eight-hour journey from Winnipeg to Bloomington, Minnesota.

### Sharing

The networking started in the elevator when we met Jodee Reid and her daughter Matisse. We started chatting about my tube feeds and Jodee told us her



*Shawna & Brent at the 2011 Oley conference.*

daughter's story. Immediately I was humbled to see someone so young coping so wonderfully with living with a transplant and tube feeding.

Our first night we went to the welcome ceremony in the courtyard of the hotel. We had a wonderful time meeting others on home PN and EN (HPEN). It was reassuring to see people who have been living a good quality of life on HPEN for 10, 20, and 30+

**Conference Impressions, cont. pg. 12** ➤

## Despicable Diarrhea

### Darlene Kelly, MD, PhD

Just as Gru is one of the most despicable movie characters of 2010, diarrhea is one of the most despicable problems faced by consumers of home parenteral and enteral nutrition (HPEN). This was found in a quality of life study done by Marion Winkler, PhD, a member of the Oley Foundation Board of Trustees. Dr. Winkler conducted extensive interviews with HPEN consumers, who described diarrhea as "disastrous," "degrading," "restrictive," and "immobilizing."<sup>1</sup>

It is important to know that the causes of diarrhea are variable and depend largely on the structure and function of an individual's intestine. In order for the person who has this despicable problem to overcome it, it is critical that he or she knows and understands what may be the underlying cause of it. Anyone who has undergone surgery to remove a segment(s) of intestine should

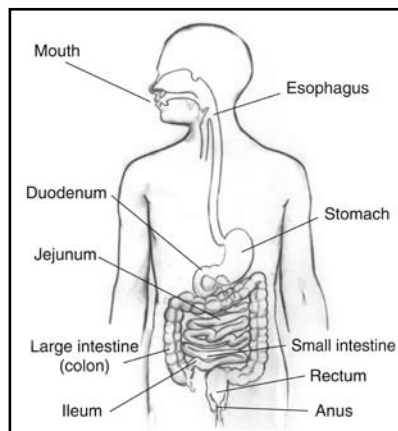
be aware of what has been removed and how much of the intestine remains in place. Each part of the intestine (the duodenum, jejunum, ileum, and colon) has a specialized role. For those who have dysfunction of the intestine, an understanding of the type of problem is helpful in understanding what can be done to effectively treat resulting diarrhea.

### Short Bowel Syndrome

Short bowel, as defined by Medicare, is a residual small bowel length of 5 feet or less. However, the traditional dogma is that a small bowel length of less than 100 centimeters (39.37 inches—remember that meter stick in your classroom?) requires parenteral

nutrition (PN). This assumes that the structure and function of the remaining intestine is normal. When

**Diarrhea, cont. pg. 2** ➤



*Courtesy of National Institute of Diabetes and Digestive and Kidney Diseases, NIH*

### Diarrhea, from pg. 1

the large intestine is preserved, an even shorter segment of small bowel may be sufficient to avoid PN or to taper off PN. If the large intestine is not preserved, and/or the remaining small bowel is not healthy, more than 100 centimeters may be necessary to avoid PN.

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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

Within a few months after a large segment of small intestine is removed, the remaining intestine begins to undergo “intestinal adaptation.” This means that the intestine increases in diameter and length, and the cells of the intestine get much more efficient at absorbing nutrients and fluid. Adaptation occurs over the first year or two after surgery. Consequently, as long as a good oral diet is consumed, the degree of diarrhea that is observed immediately post-operatively will decrease. This fact can hold promise to you, as you may initially feel you can never stray far from a bathroom.

But you can do something besides just waiting for adaptation to be complete. The principle involved is osmosis. We all studied osmosis, sometime between fourth grade and eighth grade. Osmosis means water will travel from a low-density solution across a semi-permeable membrane—such as the wall of the intestine—to a higher-density solution, in order to equalize the density of the two.

Basically, in food terms this means if you eat lots of sugars or extremely high-salt foods, water will move from the bloodstream into the small intestine in order to dilute out the effect of the sugar and salt. If you have an intact small and large intestine, the effect is very minimal, but for those with short bowel the diarrheal effect is huge. Consequently, those who drink sweet beverages (not the diet type) will lose more fluid from the blood (risking dehydration) and have very fluidy stools. By contrast, other carbohydrates (starch in the form of pastas, potatoes, rice, and breads) are digested more slowly and will cause less diarrhea and much thicker consistency stools.

Drinking large amounts of water can also cause excessive losses of fluids from the short bowel, especially when the colon (a major fluid absorber) has been removed. In fact, the volume that is lost can exceed the amount of water that was drunk. The absence of sodium (part of salt) in water causes sodium to move from the blood into the intestine, and where sodium goes, water follows. For this reason, people with short bowel who drink gallons of water will rapidly become dehydrated while spending huge amounts of time in the bathroom. Diet beverages have the same effect as water. If you have a short small intestine and a colon in place, the effect of “free water” is less severe.

### The Fat Story

In order to appreciate the effects of the pres-

ence of colon and distal ileum with short bowel syndrome, some understanding of normal fat absorption is necessary. Fat has different characteristics than water-soluble nutrients. If you look at a bottle of oil and water-based salad dressing, this difference can be seen: fat floats on top of the water-based solution. The same would be true in your intestine if special mechanisms for digestion and absorption were not involved.

When fat leaves the stomach and enters the small intestine, the pancreas releases fat-digesting enzymes (lipase and co-lipase) and the liver provides bile (which has multiple components, the most important of which are the bile salts). The bile salts are critical in making the fats in the oral diet soluble so they can be digested by the enzymes. The fats are absorbed in the jejunum and the bile salts are absorbed in the last part of the ileum. Mother Nature was the original recycler, as these bile salts are used again. The total amount of bile salts is critical, as it determines whether fats are absorbed normally. Consequently, the amount of ileum that has been removed is very important.

In the case where a large segment of ileum is removed, bile salts are absorbed poorly. This causes the body's pool of bile to become depleted, making it difficult for the intestine to absorb fats. The malabsorbed fats enter the colon, where they are acted upon by the bacteria in the colon to form a product analogous to castor oil. The result is a very oily diarrhea. For those with colon in place, a low-fat diet will decrease this tendency.

By contrast, when a small segment of ileum has been removed, the bile salt pool is maintained at normal levels by increased production in the liver. But in this case, some of the bile is poorly absorbed in the remainder of the small intestine, and the bile that enters the colon will have a secretory effect on the colon, causing watery diarrhea. In this case, some binding of bile may be helpful with respect to diarrhea, but this is not without complication since it will also decrease fat absorption. Your physician will need to assess the effects of bile-binding or other medications to determine what treatment is best for you.

### The Role of Bacteria

Normally bacteria are present in small numbers in the duodenum. There are less than 100,000 bacteria per 1/5 teaspoon. As

Diarrhea, cont. pg. 13

## Tube Talk

Send your tips, questions, and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or e-mail [metzgel@mail.amc.edu](mailto: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.



### Continuous Feeding an Infant or Toddler Overnight

Many parents struggle with overnight feedings because they fear their child will strangle him- or herself. We always keep the IV pole a few inches from the foot of the crib. If the child tangles, the line should pull the pole into the crib making a noise we (the parents) will hear.

With an NG (nasogastric) tube, most parents will tape the feeding set tubing down the child's back and leg. With a G- or GJ-tube (gastrostomy or gastrostomy-jejunostomy), parents usually secure the extension set either with tape on the tummy or by creating a tape tab that can be pinned to the child's pajamas. The extension set is run down the leg of the pajamas.

Those with more active children have used a section of hollowed out pool noodle or an empty paper towel roll to corral the excess tubing and prevent tangling.

*Editor's note:* If your concerns are too overwhelming, consider discussing with your clinician whether you can tube feed during the day.

—Traci Nagy, [supertubiemomma@gmail.com](mailto:supertubiemomma@gmail.com)

### Versatile Tube Protector

There has been a lot of discussion about G-tube protectors. The company Benik was making them for a hospital in Virginia, and the mom of one of their patients posted something about them online. Now, because of the influx of calls from other parents, Benik will be distributing them more widely.

—Traci Nagy, [supertubiemomma@gmail.com](mailto:supertubiemomma@gmail.com)

*Editor's note:* The tube protectors are available in a range of colors and sizes (pediatric and adult) and Benik says they can be used with G-, J-, GJ- and PEG tubes. Made of neoprene, they



Tube protector, flap closed

go around your waist and have an access hole that you'd position over your low-profile access device ("button"). A neoprene flap covers the hole when you want to protect your access device and can be removed entirely when you want to access your tube. Learn more at [www.benik.com/peds/wrap/g-tube](http://www.benik.com/peds/wrap/g-tube) or by calling Benik at (800) 442-8910.



Tube protector, flap open

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## Congratulations to the 2011 Oley Foundation Award Winners

### Samantha Bye & Matisse Reid, Oley Foundation Child of the Year

*In Honor of ThriveRx, Oley Gold Medallion Partner*

This year, we were pleased to present the Child of the Year Award to both Samantha (Sammi) Bye and Matisse Reid. Sammi and Matisse have each faced extraordinary challenges, particularly in the past year, and yet they continue to inspire others.

#### Samantha Bye

Sammi, 14, is known for her sense of humor. “No matter how bad my day has been,” her friend Emily Koprucki writes, “she always makes me feel better. I can be venting away and all of a sudden she has me laughing! Samantha... seems to find something fun or good in every situation, no matter what.”

While Sammi’s health issues have led to more restrictions over the last few years, she keeps in touch with friends through phone calls and texting, and enjoys helping cook family dinners. “Although Sam cannot take in nutrition orally,” says Emily, “she loves to cook for her family.... To me that takes amazing courage—I would be too tempted to taste things! But that’s just Sam. Nothing gets in her way.”

Emily’s mom, Sue, adds, “I vividly recall when...Emily had to go on gut rest for a few weeks. Sammi...was incredibly supportive, even from hundreds of miles away. She gave Em all sorts of ideas on how to make it through that time emotionally. Her sense of humor and practical attitude really helped Em get through those tough weeks that turned into months.”

Sammi “demonstrates many fine qualities as a student, but her tremendous courage and strength as a teenage girl amazes me the most,” says Sammi’s tutor, Courtney Watson. “She has daily obstacles that she overcomes and she does so with an upbeat and positive attitude without complaints.... I know that Sammi has taught me more about life over this past year than I could ever teach her.”



Samantha Bye

#### Matisse Reid

Matisse, 10, is from New Zealand. She and her family moved to the Pittsburgh area several years ago to be closer to a center with experience in HPEN management and intestinal transplantation—surgery that could not be done in New Zealand. In December 2010, Matisse underwent an intestinal transplant. She is now experiencing life without parenteral nutrition for the first time, although she is still on enteral nutrition and sometimes requires IV hydration.

Those who’ve been to an Oley conference recently will easily recognize Matisse’s smile. She is quick to make friends and, with her mom, Jodee, serves as an “ambassador” for both Oley and the New Zealand



Matisse Reid

group Parenteral Nutrition–Down Under (PN-DU). Jodee is an Oley Regional Coordinator, as well as a member of PN-DU.

Brenda Dunn (see below), one of the founding members of PN-DU, says, “Matisse has been a great ambassador, putting up with pain to attend a function so that fundraising—be it for a transplant support group or personal support—can occur. Prior to her transplant she visited other children on PN, happily explaining her extra ‘blings’ and tubings to teach the community what life is really about.”

Matisse is active in her school and once took on a project to collect extra Halloween candy to distribute to other children. She has always liked cooking, even when she couldn’t eat anything. Now she is cooking up a storm (visit her blog at [matissekitchen.blogspot.com](http://matissekitchen.blogspot.com)). She recently made one hundred cupcakes to help raise funds for the Izzie’s Gifts of Hope Foundation!

#### Congratulations to Sammi and Matisse, and to the Nominees:

Andrew Bodnar; Fahreen Mapara; Aleah Smith

#### Brenda Dunn, LifelineLetter Annual Award

*In Honor of Nutrishare, Inc., Oley Gold Medallion Partner*

Matamata, New Zealand

The *LifelineLetter* annual award is given to an HPEN consumer or caregiver, aged nineteen or older, who has demonstrated courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with HPEN. Brenda Dunn is a wonderful example of these qualities.

Brenda lives in New Zealand, but her influence extends to HPEN consumers in the United States and elsewhere through the wonders of the Internet. Brenda is a real presence in online support groups (such as Yahoo groups) and on the fairly new Parenteral Nutrition–Down Under (PN-DU) Web site. Brenda is an Oley Regional Coordinator (a foreign affiliate) and one of the founders of PN-DU—a group Dr. Gil Hardy, Professor in Pharmaceutical Nutrition at the University of Auckland, calls “Oley’s ‘little sister’ support group.”

“She gives of her time and limited resources in a completely selfless way,” says Dr. Hardy, who is also active with PN-DU. Karen Winterbourn, who has known Brenda since 2009, says, “I have been amazed at Brenda’s passion and energy to bring about best practice and equality for all of us on HPN. Setting up PN-DU has been a great step forward in this endeavor...and she has been tireless in sharing regular and relevant research/medical information with us, pursuing system/government changes for our benefit, designing and creating practical aids for other consumers, and sometimes simply giving us a good therapeutic laugh or some great encouragement.”

Somehow, Brenda also finds time to tend to the many animals on her farm, and, until recently, to work as a nurse.

**Congratulations Brenda, and to the Nominees:** Fran Freeman; Kay Oldenburg; Jennifer Thiesse



Brenda Dunn

## and Nominees

### James Rucks, Celebration of Life Award

*In Honor of Apria Healthcare / Coram Specialty Infusion Services, Oley Gold Medallion Partner*

The Celebration of Life Award recognizes an HPEN consumer who lives life to the fullest. This year, we were pleased to present the award to Jim Rucks. Jim and his wife, Jackie, enjoy touring across the countryside on their Harley Davidson motorcycle. They tow behind them a trailer that carries a cooler full of Jim's HPN supplies. When they are at home, Jim and Jackie run a home daycare center, where they care for four of their grandsons, as well as other children.

Jim and his wife had two small children at home when, in 1985, surgery for a mesenteric infarction led to HPN therapy. Since 1985, Jim has worked as a limousine driver and a property manager, and flown civil air patrol search and rescue missions with the National Air Force Auxiliary. For the latter, Jim had to maintain his pilot's license, which he acquired when he was in college, and comply with strict FAA regulations.

Soon after Jim's initial surgery, he and Jackie packed up the kids for a road trip to California and the Grand Canyon. Since then, he and Jackie have been to Mexico several times and to Alaska. They have ridden their Harley to Yellowstone National Park and Wyoming, and enjoy weekend or day trips around northern Minnesota.

One of the dietitians who works with Jim, Jeanne Moe, RD, says, "He and his wife, Jackie, are remarkable. They take meticulous care, keep abreast of current medical knowledge, and consistently maintain a positive, forthright attitude....Jim is to be congratulated for his amazing perseverance, persistence, and upbeat attitude."

**Congratulations to Jim, and to the Nominees:** Mariah Abercrombie; Marie Latta; Jennifer Thiesse

### Sheila DeKold, Lenore Heaphey Award for Grassroots Education

*Sponsored by Kimberly-Clark, Oley Benefactor Level Partner*

Lenore Heaphey was hired when the Oley Foundation was founded in 1983. She recognized the importance of our Regional Coordinator (RC) volunteers as the "face of Oley" in different areas. When Lenore left Oley to pursue a law degree, this award—which recognizes an RC who has organized an outstanding information and/or education program in the past year—was named in her honor.

This year the award was presented to Sheila DeKold, who has been an RC since 2003. Sheila is mother to David and Olivia. Olivia is on HPEN due to pseudo-obstruction. Fellow RC Patty Woods says, "Sheila is constantly reaching out to others who are new to HPEN throughout her community, either geographically or online....She has



**Jim Rucks**



**Sheila DeKold**

a way of encouraging new parents to continue living despite a new diagnosis or therapy."

This spring, through Sheila's efforts, several HPEN families—including the DeKolds—spent a weekend at the Center for Courageous Kids in Scottsville, KY. Patty notes, "This weekend gave families an opportunity to leave medical worries behind and just be a family, in a safe, camp setting with medical support available 'just in case.' Relationships were strengthened, friendships were formed, and support was fostered. Everyone came away with memories to last forever."

Sheila also staffed an Oley exhibit at the annual meeting of the Society of Gastroenterology Nurses and Associates in Indianapolis in May. Oley representation at professional meetings is important, and staffing an Oley exhibit booth allows HPEN consumers/caregivers the opportunity to share their perspective with professionals in the HPEN field.

### Congratulations and thanks to Sheila, and to the Nominees:

Kathleen McInnes; Tammi Stillion; Linda Stroshine; Aliza Chana Zaleon

### Laurie Reyen, RN, Nan Coutts Award for the Ultimate Volunteer

*Coordinated by Judy Peterson, RN, MS*

Nan Coutts volunteered throughout her life and founded Grossmount Hospital in San Diego. She taught her granddaughter Judy Peterson the meaning of volunteerism, beginning with having Judy help at a senior home when she was ten, which sparked Judy's interest in nursing. We are proud to honor clinicians in the HPEN or related field, who give of themselves, with an award in Nan's name.

This year, the award was presented to Laurie Reyen, RN. Laurie has been working with HPEN consumers for over twenty-five years. She has always been an active supporter of the Oley Foundation, speaking at Oley conferences and sharing Oley with her patients and colleagues. Laurie goes above and beyond in connecting UCLA patients to the Oley Foundation. In October 2010, Laurie was instrumental in organizing an Oley regional conference at the UCLA Medical Center—which was a great success—and in February 2011 spoke at the Oley regional conference in Vancouver, British Columbia.

Mariah Abercrombie, an HPN consumer who helped coordinate the conference at UCLA, says, "Laurie believes in the message that Oley shares. She believes that an educated patient is a happier, healthier patient. She understands the importance of one patient or parent meeting another who is experiencing the same life challenges they have."

In addition to working with Oley, Laurie is active with the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and the National Home Infusion Association (NHIA), as well as other professional organizations. She also helps provide medical care at the Painted Turtle Camp for children on HPEN.

**Congratulations to Laurie, and to the Nominees:** Faye Clements, RN, BS; Marcia Grandsko, RD; Jeffrey Randolph, MD; Ezra Steiger, MD; Marion Winkler, PhD, RD, CNSC



**Laurie Reyen, RN**

**Awards, cont. pg. 6** ◀

Awards, from pg. 5

### Winners of the 2011 Oley Foundation HomePN Research Prize

*Sponsored by Nutrishare, Inc., Oley Gold Medallion Partner*

The Oley Foundation HomePN Research Prize, sponsored by Nutrishare, Inc., was established in 2007 to encourage clinical studies focused on improving the quality of life for home PN consumers. At the annual conference, we were pleased to present this year's awards to the following three researchers.

### Parenteral Nutrition (PN) Outcomes of Patients with Short Bowel Syndrome after Discontinuing an Intestinal Growth Factor, Teduglutide

*Charlene Compher, PhD, RD, FADA, LDN*

*University of Pennsylvania School of Nursing, Philadelphia, PA*

An intestinal growth factor, teduglutide, was tested in patients with PN-dependent short bowel syndrome in a phase III clinical trial for efficacy to reduce weekly PN volume. The study concludes that some patients may maintain or further decrease their PN after stopping teduglutide. Patients who sustained PN volume reductions at one year characteristically had longer colon length and colon in continuity, and experienced no significant reduction in BMI. It has not been evaluated if this response would be maintained for a longer time period, or in the context of a challenging clinical situation.

### Central Vascular Access Device (CVAD) Infection Rates for Home Parenteral Nutrition (HPN) Patients

*Melissa Leone, RN, BSN*

*Coram Specialty Infusion Services, Denver, CO*

After collecting CVAD infection rates from several offices of a national home care infusion company, Leone found HPN patients experience higher CVAD infection rates than their non-PN counterparts (those with CVADs for therapies other than PN). This higher infection rate may support the additional expense of a more detailed catheter care protocol for these higher risk catheters. Leone also concluded that dwell times did not play a significant role in the rate of CVAD infection, but the number of CVAD lumens may play a role.

### Relationship between Catheter Related Bloodstream Infection and Bathing Practices in Home Parenteral Nutrition (HPN) Population

*Marianne Opilla, RN, CNSC*

*Nutrishare, Inc., Midlothian, VA*

A survey of bathing practices was conducted in a group of HPN consumers with a tunneled CVAD. A correlation was drawn between these practices and catheter-related bloodstream infection (CRBSI) rates. In this survey, 78 HPN patients confirmed they showered or tub bathed on a regular basis with a tunneled CVAD. The majority did not apply a protective covering to the CVAD during either type of bathing. The study concludes that both groups maintained acceptable CRBSI rates with either type of bathing practice. Adding a protective covering to the CVAD did not significantly impact CRBSI rates.

*For more details on these studies, the prize and an application form, please visit [www.oley.org/HomePN\\_Research.html](http://www.oley.org/HomePN_Research.html).*



*Nathan receiving the scholarship from Executive Director, Joan Bishop.*

### Nathan Natale, Kyle R. Noble Scholarship

*Coordinated by Richard & Donna Noble*

Kyle R. Noble's enthusiasm for life affected many positively, and he is remembered widely with affection. Kyle passed away in 2006 at the age of eight. In 2007, the Noble family established the Kyle R. Noble Scholarship to recognize others who share the admirable qualities for which he will be remembered. This year's recipient, announced at the Oley conference in Minneapolis, is Nathan Natale.

Nathan, who graduated from high school in June, is described by a teacher as "one of the least intimidating and most approachable people in the school." Nathan participated in chorus and student body government, while taking—and doing well in—a battery of challenging honors classes. Nathan is described as "extremely polite," "encouraging to those around him," and "quick in assisting a fellow student struggling with a concept."

Nathan's achievements are impressive, but they are made more remarkable by the challenges he has had to overcome—like missing fifty-two weeks of school when he was 15, after appendicitis and a subsequent blood clot in his mesenteric artery led to a jejunostomy (or J-tube), parenteral nutrition (PN), and dialysis (due to kidney failure).

Nathan, who is still on tube feedings, PN, and dialysis, will be attending Siena College in upstate New York. He is planning to major in biochemistry. "My ultimate goal has always been to become a veterinarian," Nathan says. "I do not feel that my dreams have changed because of my appendicitis and subsequent surgery." After all, he adds, "I already can understand quite a bit of the treatments veterinarians prescribe and how they work." ¶

## Equipment-Supply Exchange

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

Questions? Contact Oley volunteers Tammi and Rob Stillion at [Oleyequipment@aol.com](mailto:Oleyequipment@aol.com), or call toll-free, (866) 454-7351, between 9 a.m. and 4 p.m. EST.

## In Memoriam: Robert Hoffman and Ann DeBarbieri

The Oley Foundation lost two members from the Albany, New York, area in early May of this year. Robert (Bob) Hoffman and Ann DeBarbieri were both long-time Oley Foundation members. They were both very active in the local home nutrition support community—beyond Oley—and they are sorely missed.

### Bob Hoffman

Bob Hoffman started on enteral nutrition in 1995 and became reliant on parenteral nutrition around 2004 after a resection. He was introduced to the Oley Foundation early on by Oley co-founder, Dr. Lyn Howard and, sometimes at her request, would visit other enteral or parenteral patients in the hospital. Bob would answer questions and, in his friendly, understanding way, help new patients become more comfortable with their therapy.

Bob and his wife, Blanche, regularly attended local Oley meetings, and they always brought cheer and camaraderie with them. Blanche was also a frequent volunteer in the Oley offices.

In addition to volunteering with Oley, Bob was active with the Knights of Columbus and, for twenty-five years, owned and operated a successful manufacturers' representative agency.

Bob was positive about everything he did, and although he faced multiple illnesses, he always had a smile on his face. He was kind, warm, and giving. "He was a wonderful man," says Blanche. "He enjoyed life and succeeded at whatever he tried to do." Bob and Blanche spent over sixty years together, and enjoyed everything from golfing to being with their children to watching their grandchildren play sports.



Bob Hoffman

### Ann DeBarbieri

Ann DeBarbieri had been on home parenteral and/or enteral nutrition (HPEN) since 1987 and willingly shared her story to help others. She spoke at Oley conferences, contributed to the Oley newsletter, visited or talked by phone with other HPEN consumers, and helped create a DVD for new clinicians to help them understand the patient's perspective.



Ann DeBarbieri

Ann also served as a member of the Oley Board of Trustees. She represented the consumer's voice, and shared her experience as a lawyer who had practiced in the public and private sector. She was a remarkable, articulate woman, whose smile warmed your heart. Her open, kind ways made her a good friend to many.

Paul, Ann's husband of thirty-five years, writes, "Ann loved the practice of law, derived tremendous enjoyment and satisfaction from working as an Oley Trustee, and loved being able to help fellow FAP/short bowel syndrome sufferers. But in spite of her love of the law and Oley, she never defined herself by her profession or her disease. I think she simply wanted to be known as a person who loved God (although she never wore it on her sleeve), life, and her fellow man. Ann was always willing and eager to help someone in need. She was pure strength and goodness."

## A Trusted Provider of Home TPN for Over 30 Years

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## Nutrition and You

### Keeping Young Kids Healthy

Good nutrition for infants and children is one of a parent's greatest concerns. Am I providing the right types of foods? Is my child eating correctly? Can we go to a fast food place? Is she or he gaining enough or too much weight? There are so many things to think about.

When you have a child who relies on home enteral or parenteral nutrition (HPEN), the concerns are not really that much different. Here are a few check points for growth and development so you can know how your kids are doing.

#### Growth

Growth is a key assessment tool for infants and children. At birth, measurements are made of weight, head circumference, and length. Follow-up measurements tell us how well the child is progressing. As the child grows, height and weight are compared to growth charts indicating growth velocity (the rate at which your child grows).

All children have their own natural growth pattern. For example, if a child's parents are both very tall, most likely the child will be tall and also track higher on the weight growth chart. Conversely, if the child's family is shorter, they will likely be closer to the lower percentiles as they grow. The important point is to watch for a sharp upturn or downturn, or for numbers that fly off the chart from either the top or bottom. You can find growth charts online at [www.cdc.gov/growthcharts](http://www.cdc.gov/growthcharts).

Children with special needs, like those receiving HPEN, get a break on having to be measured against the reference "standards." Sometimes we are happy with small increases and sometimes even stability. If your child is receiving HPEN, you probably have a clinician who is charting your child's status, but you can chart it, too.

#### Feeding and Development

Another key point is progress in development. Physical development is tied to the child's ability to eat certain foods. For instance, first foods and cereals are not typically given to infants until they can sit with help or support and can push up on their arms when lying down on the tummy. This is usually around four to six months of age.

By the time your baby is an independent sitter, she has started to master pulling food in and swallowing, and can go on to slightly thicker baby foods—usually called "stage 2." Introduce only one new food every few days to make sure there is no allergic reaction. (If there is a family history of allergies, those foods should not be introduced until around age two.)

Even if your baby is on PN, he should be learning to suck on a pacifier or bottle and have the experience

of different textures and tastes in and around his mouth. Later on, "mouth feel" becomes important. We all know someone who doesn't like a certain food because of the way it feels in his mouth. For example, some kids dislike foods with a slimy or pasty-mouth feel, like certain beans and fruits, while others love them. Depending on the underlying medical condition, it may be good to try some different food items that the child can tolerate to help to prevent food aversions. This is part of the development process.



Around twelve months, infants are graduated to "toddler" status and can typically eat small, cut-up, solid foods. The key is to expose your child to a variety of foods. If your child does not accept a food at first, do not remove that food from the menu. Research shows that a child sometimes needs to be exposed to the same food many times before she accepts that food. If you remove foods right away, this can end up creating a limited variety of foods that your child will eat and prefer. Instead, continue to put foods on her plate and eat those same foods with her so she sees that you like them.

Nutrition for our little ones can be complex. Working with a dietitian, along with your physician, nurse, and others, such as the speech therapist, completes the circle of care.

*This column has been compiled and reviewed by our guest co-editor, Angela Lemond, RD, CSP Pediatric Dietitian; Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN; Laura Matarese, PhD, RD, LD, FADA, CNSC; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC.*



### Thank You Walk / Shop-A-Thon Walkers

The 2011 Oley walk raised over \$1300. Many thanks to everyone who participated in the event: Felice Austin; Alyson & Ondrej Ball; Joan Bishop; Andrew & Kristin Bodnar; Kylie & Vick Brown; Frank Burke; Roslyn Dahl; Kris & Kristin Franklin; Jacqueline Goldman; Ray Gravenstein; Diana Haggerty; Donna Hedlund; Lillian & Daulton Heisey; Rose & Alicia Hoelle; Stephanie Labelle; Marie Latta; Marek Lichota; Rachael Lopez; Michael Medwar; Carlotta Meier-Irving; Wendy, Patrick & Tricia Melland; Lisa & Ron Metzger; Kelsey Noble; Clarice Rossignol; Aleah & Tara Smith; Shawna Forester Smith; Bob & Mary Smithers; Bob & Tammi Stillion; Jennifer Thiesse; Cathy Tokarz; Liz Tucker; Guiliana Valenti; and Jim & Liz Wittman.

## Sharing Good Times at the Oley Conference in Minnesota



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## Thank You for Making the 2011 Oley Conference a Success!

Many thanks to the following companies and individuals for their generous contributions.

### 2011 Oley Awards:

Apria Healthcare / Coram Specialty Infusion Services; Kimberly-Clark; Nutrishare, Inc.; Judy Peterson, RN, MS; ThriveRx

### Audiovisual Equipment Loan:

Apria Healthcare / Coram Specialty Infusion Services; Heartland IV Care; InfuScience

### Breakfast (Wednesday):

ThriveRx

### Child Care:

Emily Abel; Bloomington Police Department canine unit; Natalie Dimond; Sherrie Dimond; Heartland IV Care (supplies); Jessa Justice; Ron Metzger; Quinn Morris; Kelsey Noble; Holland Ringgenberg; Aleah Smith; Dallas Tucker; Savanna Tucker; Guiliana Valenti; Allison Vecellio

### Conference Badges:

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Darlene Kelly, MD, PhD; Mary Patnode, MS Ed, LP; Elizabeth Tucker

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### Faculty:

James Andrews, MD; Jameson Atkinson; Felice Austin; Marcia Boatwright, RN, CRNI; Susan Brand, RN; Alan Buchman MD, MSPH, FACN, FACP, FACG, AGAF; Robert Cima, MD; Charlene Compher, PhD, RD, FADA, CNSC, LDN; Mimi Cook, RN; Rick Davis; Mark H. DeLegge, MD; Marsha Dunn Klein, MEd, OTR/L; Paula Gaida, RN; Deborah Houston, RPh, BCNSP; Lyn Howard, MB, FRCP, FACP; Daniel Hurley, MD; Yi Lisa Hwa, CNP; Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN; Daniel B. Johnson; Jayne Justice, RN; Darlene Kelly, MD, PhD; Nicole Koktavy, MS; Melissa Leone, RN, BSN; Kristyn Maixner, RN; Laura Matarese, PhD, RD, LDN, FADA, CNSC; Sheila Messina, RN, MA, CLNC; Melissa Miller, RN, MSN; David Monson, PharmD; Marianne Opilla, RN, BSN, CNSC; Melinda Parker, MS, RD, CNSC; Mary Patnode, MS Ed, LP; Karen Sexton-Hamilton, MS, RD, LD, CNSC; Joanne Singleton, LCSW; Brian Stahulak, MBA, BSN, RN; Ezra Steiger, MD; Robert Stillion; Kelly Tappenden, PhD, RD; Dave Vermeulen; Ann Weaver; Aliza Chana Zaleon

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*Many thanks to all who helped with the 2011 conference.*

**Silent Auction:**

Jeff Hoelle; Kristen & Kris Franklin; Janet Platt; Bob Smithers; Rose & Bill Wu; and a big "Thank You!" to those who donated and/or purchased items!

**Speaker Support:**

*The following companies and institutions provided funding and/or faculty for this year's program.* Advanced Home Care; American Society for Parenteral and Enteral Nutrition; Cleveland Clinic; Coram Specialty Infusion Services, An Apria Healthcare Company; InFuScience; Kimberly-Clark; Mayo Clinic College of Medicine; Minnesota Department of Health; Nutrishare, Inc.; Thomas E. Starzl Transplantation Institute, University of Pittsburgh; ThriveRx; University of Pennsylvania School of Nursing

**Transitioning to Independence:**

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**Travel Scholarships for Consumers:**

Baxter Healthcare; Jarol Boan, MD; Melissa Chaney Memorial Fund; Critical Care Systems; Friends of Robin Lang Memorial Travel Fund; Bruce Groeber Memorial Fund; Carol Ireton-Jones, PhD, RD, LD, CNSD; NPS Pharmaceuticals; Nutrishare, Inc.; Janet Platt & Christopher Hlatky; ThriveRx

**Videotaping:**

Baxter Healthcare; Joel Resnick

**Youth Activity (Wednesday):**

Pediatric Home Service

**Walk / Shop-A-Thon:**

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### Conference Impressions, from pg. 1

years. Until then, I had worried about quality of life and wondered just how long I could sustain myself on this therapy.

#### Learning

We have been struggling to get me to tolerate tube feeds for almost eight months now, but we have been very frightened for me to go back on HPN because I suffered from septic shock in the fall of 2010 due to a catheter-associated bloodstream infection. My husband and I are less scared of HPN now that we attended the conference because we learned, by talking to others and attending educational sessions, that there are many things we can do to help prevent complications.

Having an opportunity to interact with expert clinicians was paramount to our positive experience at the conference. They deal with people on HPEN on a daily basis. They have seen it all. I was able to discuss my tube feeding intolerance with some specialists as well as representatives from Nestlé Nutrition, the primary EN formula provider in Manitoba.

We came home with a few tricks up our sleeve to discuss with my home nutrition team. I am now on a different formula, which seems to be working a bit better for me. We would have never thought to look at a soy-free formula if it hadn't been for the experts at the conference.

#### Changing

One of the biggest changes that has sprung from going to the conference is that I no longer view myself as a patient; I now look at myself as a consumer. Even though I live in a country where we have little choice when it comes to our health care, I still do have a say in the kind of care I am provided.

Education is a powerful thing. I feel more empowered to stand up for myself and for my health, and to take a greater role in determining what happens to me. Before I attended the conference, I was too scared and passive to advocate for my health.

### Donna Lee's Impressions

I came to the Oley Conference with hope that it would help me and help my husband, Pete, but as much as I wished otherwise, I didn't really believe it would. I had fallen into such despair, despite all of my efforts to maintain a positive attitude, that true belief was beyond me.



Donna Lee

I am thrilled to be able to say, along with so many others who attended, that going to the conference changed everything. My experiences and interactions changed ME, and thus my life.

#### Sharing

My expectation was that I would learn, and hopefully by being around others like me not feel so alone anymore, and these things would lift me up. I had no intention of actually talking about my specific struggles. When I heard Rick Davis speak

about his journey with tube feeding, though, his words resonated deep inside of me. I remember thinking, "Yeah! That sounds like me ... or who I used to be. Now, how do I DO that, like he did?"

Afterward, I managed to gather enough courage to approach Rick and ask if I could talk to him for a few minutes. He readily agreed. A

few minutes turned into an hour and a half, and I was stunned when I heard myself telling him what I was struggling with. He listened with compassion and without judgment, and like I was the only soul on the planet. He shared a bit of his own struggles and offered some ideas, and he shared a tube feeding experience. Prior to the conference I had never been around other tube feeders, except in end-of-life situations. Rick sharing this with me was very powerful, and I will be forever grateful.

#### Learning

Rick later introduced Pete and me to some people he thought could help us, and they did! They gave of their time and expertise freely, with the offer of continued contact and assistance. One of the most remarkable things I noted was that all of the speakers were so focused and passionate. These were all experts, prominent individuals in their fields, who chose to donate their time and services. And they all cared, not just in a general sense, but in a very personal way.

The exhibits were excellent as well. Another life-altering event was a visit to the booth run by my pump manufacturer. The representatives were able to show me why I couldn't get my feeding pump to work in my fanny pack. Now I wear my fanny pack all of the time—even when I sleep!—and it's fantastic.

#### Changing

I left the conference feeling validated, accepted, hopeful for the future, empowered, and better about myself than I've felt in a very long time. I feel part of a community—a real community, not just a virtual one—and no longer so isolated and alone. I experienced fellowship and sharing, but no one was sitting around whining about things. I met people and made friends in a way I never could have otherwise.

I discovered that I did have something to offer, and wasn't useless after all. I was incredibly blessed to be able to attend the conference, because I received one of the travel scholarships offered through Oley, and am so very grateful to my benefactors.

I would like to end with this message: You are not alone, and you are needed. Our lives get frustrating and exhausting, to say the least, but Oley offers resources to help us get what we need, and to support each other. Through Oley, my life has changed, and that's something to celebrate. ♣

*Shawna Forester Smith is an HR consultant for the Winnipeg Regional Health Authority, a graduate student of health systems leadership, and a writer. She has a blog at [www.gpandme.org](http://www.gpandme.org). Donna Lee is a freelance editor and graphic artist. She would like to become an advocate for others.*

## Call a Peer, Toll-Free!

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation, through Oley's peer-to-peer toll-free 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 (IV 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 use this opportunity to improve your quality of life.

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

**Diarrhea, from pg. 2**

you move into the jejunum and ileum, the numbers increase relative to the numbers in the duodenum. But beyond the ileocecal valve between the small bowel and colon, the numbers of bacteria skyrocket!

The valve keeps the colonic bacteria and contents of the colon from moving upstream. When the valve is removed, there is a tendency for the bacteria from the colon to enter the small bowel. The bacteria of the small bowel increase in number and become more typical of the bacteria that are normally only found in the colon (i.e., bacteroides). When these bacteria are in the small bowel, they impair digestion and unabsorbed carbohydrate produces gas (causing bloating and gas per rectum or ostomy).

These same bacteria use vitamin B12 from the diet, making it unavailable to your body and causing you to be depleted in the vitamin. The bacteria also interrupt the absorption of fats, which itself causes diarrhea (as discussed above). Finally, the bacteria affect the intestinal wall so that secretion of fluids occurs (diarrhea!). When the normal small intestinal bacteria increase in numbers and abnormal bacteria migrate from the colon into the small bowel, it's called small intestinal bacterial overgrowth.

In intestinal dysmotility, bacterial overgrowth as described above can also occur, but the mechanism causing it is different. In this situation, overgrowth occurs because the flow of the intestinal content is slowed. I often describe this as being like the backwaters of a river, where the stagnant water becomes overgrown with algae. Although algae are not involved in the intestine, certainly bacterial numbers do increase.

**Treatment of Bacterial Overgrowth**

Bacterial overgrowth is often treated by providing rotating antibiotics. This can be done with a number of different antibiotics. I prefer to use two to three different antibiotics, asking patients to take one antibiotic for a week, followed by one to three weeks without medication and then a week of a different antibiotic. We repeat this pattern as needed.

It is quite possible that a specific antibiotic will not be beneficial and may need to be replaced with a different one. In my experience, we cannot predict the effectiveness of a given antibiotic for any individual. The reason for rotating different antibiotics and allowing time off antibiotics is to avoid having bacteria become resistant to an individual antibiotic. The break also allows the body to replace beneficial bacteria. This type of treatment must be monitored by your physician.

Another approach to bacterial overgrowth is to provide "good bacteria" in the form of probiotics or to encourage growth of good bacteria with prebiotics. "Prebiotics" are a type of food that helps to enhance normal intestinal bacteria. "Probiotic" is a dose of these healthy bacteria. This can be accomplished by using a form of good bacteria (especially lactobacillus) that can be found in some medications and in yogurt.

**Anti-diarrheal Medications**

These medications are helpful when taken in adequate amounts and when the timing is appropriate. Specifically, such medications as loperamide (Imodium) or diphenoxylate sodium/atropine (Lomotil) work by slowing movement of the liquid food (also called chyme) through the intestine. The amounts typically recommended on the label of the over-the-counter product are quite low and are intended for persons with

**Diarrhea, cont. pg. 14** ◀

## On the Road with Maximize Health!

### The Basics of Short Bowel Management

- The GI Tract and Intestinal Failure
- Diet Tips for the Short Bowel Consumer
- Consumer Advocacy: Helping Each Other to Thrive

**Location:**

Chicago  
Washington D.C.  
Cincinnati

**Date:**

September 10, 2011  
October 22, 2011  
November 5, 2011



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## Corporate Partner Spotlight— New Silver Circle Member!

Please join the Oley Foundation in thanking our most recent corporate contributors. Without their support Oley could not provide its many programs free of charge to home parenteral and enteral consumers. We are especially grateful to announce another increased gift, this one at the Silver Circle level made by NPS Pharmaceuticals, which helps us keep pace with our fast-growing membership. To read about other Oley Foundation Corporate Partners, visit [www.oley.org/donorinfo.html](http://www.oley.org/donorinfo.html).

### NPS Pharmaceuticals

NPS Pharmaceuticals is developing orphan products for patients with rare gastrointestinal and endocrine disorders. The company is currently preparing a registration dossier for GATTEX® (teduglutide) in adult short bowel syndrome (SBS). NPS is committed to supporting groups like Oley to advance patient care in SBS.

### Critical Care Systems

Critical Care Systems is a leading national specialty infusion company providing comprehensive clinical services to pediatric and adult populations through a national footprint of JCAHO-accredited, community-based branches. Its Specialty Nutrition Support Program is supported by a team of dietitians, nurses, pharmacists, and reimbursement specialists who excel in parenteral nutrition, clinical support, and customer service. Whether the company's customers require shorter or longer term therapy, Critical Care Systems provides flexible, individualized care adapted to the consumer's lifestyle. It is Critical Care System's belief that customized nutrition support, "state of the art" HPN standards, and a team of TPN experts, leads to optimal outcomes. Its 97 percent satisfaction rate in 2010 supports their motto: "Patients are the center of all we do." The company is proud to support the Oley Foundation.

### Diarrhea, from pg. 13

an intact intestine and for use with intermittent diarrhea. The maximal amount for you should be recommended by your physician.

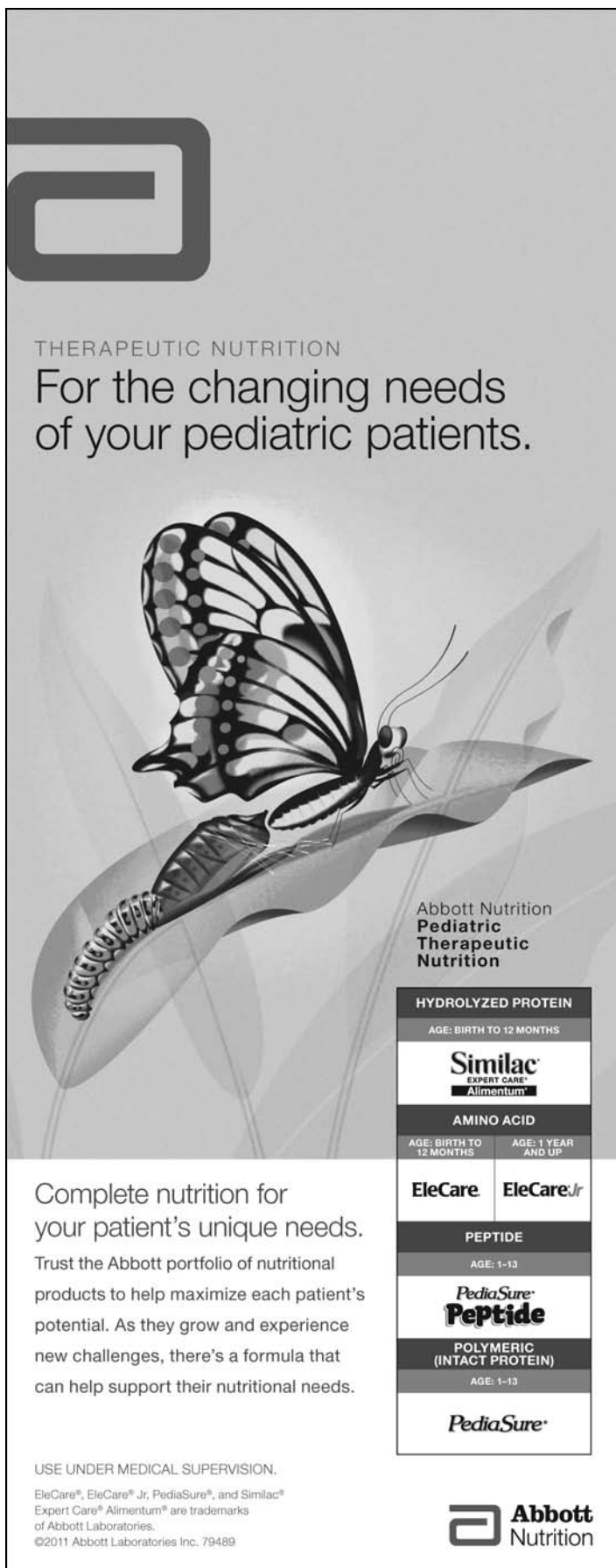
Another important hint to maximize the effect of anti-diarrheals is to open the capsules or crush the tablets, then add the contents/powder to sugar-free applesauce or similar foods (this may improve absorption of the medication). Also, timing is truly everything! These medications should be taken about thirty minutes before eating in order to maximize their effects.

### Conclusion

In summary, controlling despicable diarrhea may require limiting sweets and concentrated (or high osmolality) drinks (or diluting them); avoiding free water, coffee, tea, and diet pop and substituting constant sipping of electrolyte drinks; limiting fats if you have an incontinuity colon; and treating bacterial overgrowth. As you can see, your approach depends on your anatomy and intestinal function. At times everyone, whether they have an intact intestine or not, will experience some diarrhea, but this should not occur continually. ¶

1. Winkler, Hagan, Wetle et al. JPEN 34:395-407, 2010.

Dr. Kelly addressed this topic at Oley's annual conference in July 2011. To see her slide presentation, go to [www.oley.org/Conference\\_Presentations.html](http://www.oley.org/Conference_Presentations.html)



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## Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2011 in the Jan/Feb 2012 issue. Between May 28 and August 5, 2011, gifts were received:

### In Honor of

Joan Bishop; Patricia Brown; Paul Butzin being on HPN for over 22 years; Rick Davis; Karuna Agrawal, 5 years on PN; *The LifelineLetter*; Don Young

### In Memory of

Daniel W. Benninghoff, MD; June Bodden; Ann DeBarbieri; Gweneal Y. Goulet; Andre Hirschler; Robert Hoffman; Joyce Hydorn; Diane Kane; Robin Lang; Eva Marie Souza Williamson

### For:

Kyle R. Noble Scholarship in memory of Tarita Noble; Freihofer's Community Walk fundraiser; Hoelle's Guest-Bartender fundraiser; Silpada fundraiser

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

## 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.*

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*Thank You!*

## 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. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at (800) 776-OLEY.

*Felice Austin*

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ALBANY, N.Y.



### Advocacy Award Nominations Due

Nominate an HPEN patient or caregiver for A.S.P.E.N.'s Lyn Howard Nutrition Support Consumer Advocacy Award by October 15. For more information visit [www.nutritioncare.org/Membership/Awards/Lyn\\_Howard\\_Award/](http://www.nutritioncare.org/Membership/Awards/Lyn_Howard_Award/)

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## Reacting to Drug Shortages—a National Health Care Crisis!

*YOUR story is powerful and needed.*

Your clinicians and home care providers have probably been dealing with shortages of parenteral nutrition components for more than a year now and are trying their best to keep you healthy. Adjustments have been made to ensure that the folks who absolutely need specific items get them. You may have noticed some changes in your supplies, infusion schedules, etc. This needs to be resolved.

Senate bill **S. 296 Preserving Access to Life Saving Medications Act**, along with the companion House of Representative bill **H.R. 2245**, are designed to address drug shortages. These bills are posted on the Thomas Legislative Information Web site, <http://thomas.loc.gov/home/thomas.php>.

Put a face, **YOURS**, to home parenteral nutrition (HPN) therapy and the drug shortage issue. A brief outline of why you require HPN and how this therapy allows you to live your life will help your representatives understand more about HPN and the impact of the shortages. Are you working, enjoying retirement, raising a family? Have you experienced any shortages, changes in your regimen, consequences, etc.? Express your concerns.

Links to legislators, addresses, etc. can be found on [www.congress.org](http://www.congress.org). If your representatives have already signed on in support of these bills, thank them. If they haven't, encourage them to do so now. Send letters to your representatives at both their District and Washington, D.C. offices.

Send copies of the letters to the chairmen of the Senate and House committees that are considering the bills, along with a note that urges them to report (vote) the bill out of their committee and onto the floor for a vote. If the bills are not voted out of committee, they will not be brought to a vote by the full Senate or House! The committee chairs' names and addresses are provided below.

Sample letters and additional information are available at [www.oley.org](http://www.oley.org) or 800-776-OLEY. Please send copies of your correspondence to Oley Executive Director Joan Bishop, at [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu). Thank you for helping bring attention to this critical matter. We will continue to keep you updated.

### Committee Chairs' Addresses

Hon. Tom Harkin, Chairman  
Committee on Health, Education, Labor and Pensions  
731 Hart Senate Office Bldg.  
Washington, D.C. 20510

Hon. Fred Upton, Chairman  
House Energy & Commerce Committee  
2183 Rayburn House Office Bldg.  
Washington, D.C. 20515

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