

LifelineLetter

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

What's Inside:

Tube Talk: Medication
Clogging Tubes

Page 3

In Memoriam

Page 4

Hats Off to Cathy

Page 5

Say Cheese!

Page 5

Equipment-Supply
Exchange

Page 5

Nutrition and You

Page 6

Good to the Last Drop

Page 7

Appeal Letter

Page 9

Volunteer Listing

Page 10

Swimming Tips

Page 11

Speaking Up for
Better Care

Page 12

New CDC Guidelines
for Catheter Care

Page 13

Call a Peer, Toll-Free

Page 13

Donor Profile

Page 14

Other Ways to Give

Page 14

Contributor News

Pages 14–15

From the Executive
Director

Page 15

Conference Update

Page 16

The Importance of Food in Our Lives: Finding Balance Even When We Cannot Eat

Marion Winkler, PhD, RD, LDN, CNSC

Eating can be defined as the consumption of food and liquid to sustain life and to meet our body's basic needs for growth, development, and function. Every cell in the body depends on a continuous supply of calories and nutrients, whether obtained through food, IV nutrients, or tube feedings. Eating and food, however, also have symbolic meanings associated with love, sensuality, comfort, stress reduction, security, reward, and power. All of us have turned to food at one time or another for comfort, to help us cope with stressful experiences, and to satisfy desires. Food choices, while influenced by taste and nutritional value, are also typically influenced by past experiences, many of which are social in nature.



Food and eating behaviors often begin during childhood and are closely tied to family and culture. There is a strong relationship between memory and food; for example, the taste, smell, and texture of food can trigger memories of earlier food-related events and activities in our lives. For me, hot chicken soup on a cold and rainy day triggers memories of my own mother taking care of me as a child.

Throughout our lives we may associate certain foods or meals with a holiday, past event, or specific memory. These associations may even provide comfort during times of sadness or sorrow. There is no question that food plays a major role in life. This role does not lessen even if the ability to swallow, chew, digest, or absorb food is lost.

Importance of Food, cont. pg. 2



Cynthia and Ronnie enjoyed meeting others who understand their challenges, and learning different viewpoints.

The Oley Conference The Benefits of Meeting Others

Cynthia Merriam

I have a partner who has been on parenteral nutrition (PN) for sixteen years. He has never had the opportunity to meet anyone, or share what his life is like, living on PN. He had never heard of the Oley Foundation or even considered sharing his experience with anyone or asking any questions other than to his medical providers.

Conference, cont. pg. 11

HPN Awareness Week August 7–13, 2011

Parenteral nutrition, or “IV feeding,” isn't just for patients in the hospital. We know that. And it isn't as uncommon as it once was. So set aside August 7–13 for Home Parenteral Nutrition (or HPN) Awareness Week, and help spread the word that people can survive, and live a full life, on HPN.

We were encouraged in this effort by the success of Feeding Tube Awareness Week, held in February and organized on a grassroots level by Traci Nagy. We'd like to piggyback on that momentum to further expand people's understanding of nutrition therapy.

The week's success will be largely up to you! You are the heart of the effort, and your experiences are the key to creating understanding and hope in others. Contact your local media, post on Facebook, upload a YouTube video, or blog about your story—share these with us, and we'll post them too. If you have Facebook, Twitter, etc., please share this message with fellow HPNers. Create excitement for the week of August 8!

Contact the Oley office or visit www.oley.org for help and ideas.

Importance of food, from pg. 1

Grief Is Common

Eating is something people often take for granted until faced with a situation in which they are unable to eat. The loss of the ability to eat is similar to any loss we may experience in our lives. It is common to mourn this loss or to

have an extended period of grief or sadness.

Being unable to participate socially in mealtimes may leave some people feeling disconnected and isolated from those whom they love. It is important to identify and recognize these very normal feelings. If you would like help dealing with these emotions, you may want to discuss them with your health care professionals so you can be directed to appropriate counseling and resources.

Researchers have found that feelings about food vary depending on a person's illness, their ability to tolerate food, or the need to avoid or restrict certain foods. Those who need to relearn how to eat after surgery or a stroke may struggle or feel challenged; those who are not able to eat at all report dreaming of ethnic foods or exotic meals, or longing for the way they used to eat

in the past. People who have to avoid certain foods may find it difficult to resist the temptation to eat these foods, and are bothered by the many food commercials on TV.

Knowing Why Helps

Medically imposed food restrictions may be difficult to accept or embrace, especially when you receive mixed messages regarding foods to include in your diet and foods to avoid. If you are told to avoid or restrict a specific food, your clinician should explain what the expected goal or outcome of this instruction is. For example, changing the texture or form of the food may make it easier for you to swallow or digest it, or prevent gastrointestinal (GI) obstruction or blockage. Dietary restrictions may be suggested to prevent or minimize unpleasant symptoms, such as bloating, reflux, diarrhea, dumping, constipation, or pain. Bowel rest may be important to decrease GI fluids, lessen GI irritation and inflammation, or promote healing.

Ask your doctor or health care practitioner to discuss the purpose and the intended outcome and goal of the "diet," restriction, or food recommendation. Oftentimes, simply understanding the rationale and purpose of the recommendation makes it more tolerable.

Relearning, Redefining

Depending on your specific situation, surgery, or medical condition, you may need to

relearn how to eat. You may also need to define what "normal eating" is for you now. As much as you may long to "eat the way you always used to," the reality is that eating may become an entirely new experience. For some, the amount they eat must be much smaller. For others, small frequent snacks and sips throughout the day may become the new "norm." Chewing for taste and pleasure then subtly spitting the food out may be required.

Relearning to eat for pleasure, taste, comfort, or health may be a difficult experience; for sure it will require patience and determination.

Being unable to participate socially in mealtimes may leave some people feeling disconnected and isolated from those whom they love.

Guidance may be available from dietitians, occupational therapists, speech therapists, psychologists, or behavioral and mind-body programs. Assume personal responsibility for seeking, finding, and trying foods that you can tolerate. Use trial

and error to determine what you can and cannot eat. A food diary may be very useful to help you monitor food tolerance. Consider the ability to taste and swallow one bite of food a major victory.

Strategies

Home enteral and parenteral nutrition (HPEN) consumers have described many strategies for coping with new limits on what and how much they can eat. Some strategies for restaurant eating include: eating a little bit from the plate of your spouse or friend; selecting an appetizer instead of an entrée; ordering a child's portion; asking for a "to-go" box or "doggie" bag; or planning in advance to eat half of the meal and bring the remainder home for the next day.

An HPN consumer once told me that she just deals with the consequences of eating. She explained, "I still go to a restaurant, sit down and eat, and then excuse myself, go to the bathroom and upchuck."

It is also entirely acceptable to sit at the table and not eat at all. Simply tell the waiter that you are planning to enjoy the company at the table rather than food, and that you do not plan to order anything to eat or drink. You could also give the waiter an Oley "restaurant card," which explains you have a digestive disorder that limits your ability to eat and

Importance of Food, cont. pg. 8 ➤

LifelineLetter

May/June 2011 • Volume XXXII, No. 3

Publisher:

The Oley Foundation
For Home Parenteral and Enteral Nutrition
214 Hun Memorial, MC-28
Albany Medical Center
Albany, NY 12208
1-800-776-OLEY or (518) 262-5079
Fax: (518) 262-5528
www.oley.org

Executive Director:

Joan Bishop
BishopJ@mail.amc.edu

Editor:

Lisa Crosby Metzger
MetzgeL@mail.amc.edu

Director of Communications & Development:

Roslyn Dahl
DahlR@mail.amc.edu

RC Program Director:

Felice Austin
fleecey@aol.com

Outreach Coordinator:

Kate Swensen
kswensen18@gmail.com

Administrative Assistant:

Cathy Harrington
HarrinC@mail.amc.edu

Lifeline Advisory Group:

Patricia Brown, RN, CNSN; Alicia Hoelle; Jerry Mayer; Stephen Swensen; Ann Weaver

Oley Board of Trustees:

Rick Davis, *President*; Mary Patnode, *Vice President*; Laura Ellis, PhD, RD, *Treasurer*; Jane Balint, MD; Kishore Iyer, MBBS, FRCS, FACS; Jim Lacy, RN, BSN, CRNI; Laura Matarese, PhD, RD, LDN, FADA, CNSD; Gail Sansivero, MS, ANP; Doug Seidner, MD, FACC, CNSP; Rex Speerhas, RPh, CDE, BCNSP; Cheryl Thompson, PhD, RD, CNSD; Marion Winkler, PhD, RD, CNSC

Subscriptions:

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically.

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.

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. 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.



Medication Clogging Tubes

According to an FDA Safety Alert issued April 15, the FDA has received reports that lansoprazole delayed-release orally disintegrating tablets (ODT) by Teva Pharmaceuticals “have clogged and blocked oral syringes and feeding tubes, including both gastric and jejunostomy types, when the drug is administered as a suspension through these devices.” Lansoprazole is a proton pump inhibitor (PPI) medication that is manufactured by several companies, and sold as a generic or as Prevacid®.

The Teva ODT tablets, the alert continues, “may not fully disintegrate when water is added to them and/or they may disintegrate but later form clumps. These clumps can adhere to the inside walls of... feeding tubes. In some cases, patients have had to seek emergency medical assistance and their feeding tubes have had to be unclogged or removed and replaced.”

If you have this product, you are advised not to administer it through a feeding tube. Teva Pharmaceuticals has voluntarily withdrawn its lansoprazole delayed-release ODT.

A Personal Experience

One Oley member, responding to an e-mail we sent out about this issue, explains her experience with lansoprazole:

Thanks for sharing the FDA notices with us. As the prime caregiver for my husband who has a feeding tube and Alzheimer's disease, I encountered the lansoprazole delayed-release tablet problem last fall when the pharmacy said that the generic lansoprazole would be substituted for the Prevacid® delayed-release tablet that we had been using for over six months.


When another caregiver and I experienced the problems described in the FDA article, I contacted the pharmacist, who insisted that it was the same as Prevacid. In order for the pharmacist to reissue the Prevacid, I would need to get a special request form completed by our physician. I talked to the physician and insisted that the chemical composition of the two may be the same, but perhaps a different manufacturing process was used. Fortunately, he listened to me and did all the essential paperwork to make the change.

As a result of our prompt actions, we avoided having to replace the feeding tube and having other problems. I will share the article with our physician as it affirms our earlier concerns.

*Thank you,
Valerie S.*

The FDA urges health care professionals and consumers to report adverse events or side effects related to the use of medications or






Tube Talk, cont. pg. 14 ◀



THERAPEUTIC NUTRITION

For the changing needs
of your pediatric patients.

Abbott Nutrition
Pediatric
Therapeutic
Nutrition


HYDROLYZED PROTEIN	
AGE: BIRTH TO 12 MONTHS	
	
AMINO ACID	
AGE: BIRTH TO 12 MONTHS	AGE: 1 YEAR AND UP
	
PEPTIDE	
AGE: 1-13	
	
POLYMERIC (INTACT PROTEIN)	
AGE: 1-13	
	

Complete nutrition for
your patient's unique needs.

Trust the Abbott portfolio of nutritional products to help maximize each patient's potential. As they grow and experience new challenges, there's a formula that can help support their nutritional needs.

USE UNDER MEDICAL SUPERVISION.

EleCare®, EleCare® Jr, PediaSure®, and Similac® Expert Care® Alimentum® are trademarks of Abbott Laboratories.
©2011 Abbott Laboratories Inc. 79489



In Memoriam: June Bodden and Diane Wagner

Meg Cass Garcia and Cheryl Futrell

The Tampa Bay Oley Support Group suffered two great losses in March with the passing of June Bodden, March 11, and Diane Wagner, March 3.

June Bodden was the Oley Regional Coordinator of the Tampa Bay Group for almost twenty years. The group met bimonthly for over twenty years, and has met quarterly for the last two. June was always there for the meetings and insured that the meetings were informative.

In March 2008, the Tampa Bay group celebrated its twenty-year anniversary. Friends, family, and members of the home health community met to share their personal histories, and June and the group received the Celebration of Life award from Coram Specialty Infusion Services. June helped organize this wonderful celebration of the support, encouragement, and friendships that had grown over the years.

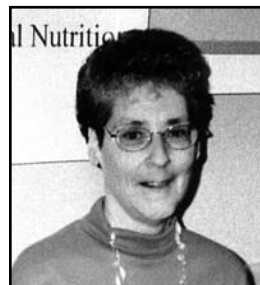
When the meetings went to quarterly, June kept in touch with the members. She was always there for the Oley group.

June was also heavily involved with the wider Oley community. She was often the one at the other end of the phone for Oley's toll-free peer-to-peer support line, and in 2009 she was the co-coordinator for Oley's annual conference in Clearwater, Florida. June was the one with the sunshine smile on her face in spite of the persistent bad weather that week. In 2008, June received the Oley *LifelineLetter* Award.

Cheryl Futrell writes, "June Bodden was always a ray of sunshine. She was a true example of a loving and caring Christian. Always the first one to volunteer and put her foot forward no matter what the task was, she gave of herself with no malice or selfishness. She always kept the Oley members up-to-date on issues involving other members and shared kind words of encouragement to all. June spent the majority of her life battling a multitude of complications associated with Crohn's, but she never complained of the daily struggles she encountered. She truly was mentor to many and will be missed by all who had the privilege to know her."

"The beauty of June's efforts," adds Joan Bishop, Oley Executive Director, "centers on the fact that she never expected anything in return. Her reward was a sense of helping others."

The Tampa Bay Oley Support Group, and all of Oley, send our deepest condolences to Alice, June's mother. June and Alice went to many of the annual Oley meetings together and were often mistaken for sisters.



Diane Wagner

Diane Wagner was also a Crohn's patient who had many complications. She was not a current home PN patient, but she came to the meetings for the encouragement, support, and friendship. Diane always had a smile on her face, and although she was shy, she faced the issues of living with Crohn's with courage and hope. She too will be missed by all, and we send our condolences to her family as well.



June Bodden

The lives of these two women should be an example to those of us who deal with the same issues. Life is truly what you make it, and they both lived their lives as fully as they could. Their faith, family, friends, and loved ones helped carry them through many years of trials and tribulations. Their spirits will live forever in our hearts.

In Memoriam: Charlene Key

Lisa Metzger

Charlene Key, who passed away in February, was an Oley Regional Coordinator volunteer for many years. She signed up to be a Regional Coordinator in 1994, in part because she wanted to share her experiences and "offer a shoulder to cry on" or an ear if someone needed "to vent their frustrations." A support group, she said, could help relieve anxieties and help make homePEN therapy easier and more successful.

Oley staff remember how Charlene faced the many challenges life put in her path with grace and fortitude. "She was always willing to talk to people and to help them adjust to the often intense drama of the unexpected, such as the loss of intestinal function due to trauma," notes Roslyn Dahl, Director of Communication and Development at Oley. "She would take people under her wing at conferences, making them feel welcome and helping them get the most out of the experience."



Charlene Key

Fellow Oley member Linda Gravenstein met Charlene at an Oley event over twenty years ago. "We all make friends," says Linda, "but an Oley friendship is a special bond and a precious gift. I made such a friendship with Charlene Key. Our bond was instant and deep." "When someone was in need," Linda continues, "Charlene was quietly in the background, ready to give. She was always game for an adventure and looked forward to the Oley conference every year."

"Charlene was small, but she was mighty," says Linda. "Thank you, Oley, for giving me such a wonderful friend." Charlene was a great resource for Oley consumers and she will be missed.

More Members Missed

We are very sorry that, shortly before this newsletter went to press, we also lost two members who were very active in the Oley community in the Albany, NY, area: Ann DeBarbieri, who served on the Oley Board of Trustees, and Bob Hoffman, who, with his wife, Blanche, volunteered in the Oley offices. Please watch for more about Ann and Bob in the July/August *LifelineLetter*.

Hats Off to Oley's Administrative Assistant

When you call the Oley offices, you're almost sure to connect with Cathy Harrington, Oley Foundation Administrative Assistant.

Cathy is the friendly voice on the other end of the line. She fields most of your calls, and manages multiple tasks in a very busy office environment.

Cathy has worked with Oley co-founder Lyn Howard, MD, for twenty-five years. She was Dr. Howard's office manager for twelve years before coming to the Oley Foundation in 1998. She is the glue that holds us together.



Cathy Harrington

Happy belated Administrative Assistant Day, Cathy!

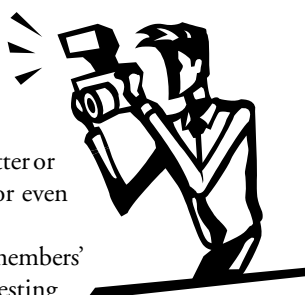
Say Cheese!

Photos taken at Oley gatherings, such as conferences, picnics, exhibit booths, etc., may be used in Oley Foundation materials, like this newsletter or a brochure, on the Oley Web site—or even on the Oley Facebook page.

Generally speaking, we will not put members' full names with photos without requesting permission (exceptions may include members who are already publicly associated with Oley, such as Trustees or Regional Coordinators).

If you do not want your photo used online or in Oley publications, please let us know and we will do our very best to honor your wishes. We can't guarantee that your image won't appear in group shots or on the video filmed at conferences. To "opt out," please e-mail or snail mail your name and an image (so we can identify you) to Lisa Metzger at metzgel@mail.amc.edu or:

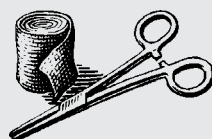
The Oley Foundation
214 Hun Memorial MC-28
Albany Medical Center
Albany, NY 12208



Equipment-Supply Exchange

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

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



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:

Boston
Salt Lake City
Chicago
Washington D.C.
Cincinnati

Date:

June 4, 2011
June 25, 2011
September 10, 2011
October 22, 2011
November 5, 2011



For more information email us at maximizehealth@thrivervx.net or check out our website at www.thrivervx.net.



1-888-6-THRIVE (888-684-7483)
or info@thrivervx.net
www.thrivervx.net

Nutrition and You

Preventing Food-borne Illness

Ever been to a picnic or a party and wondered how long the dip or cold cuts platter has been out? If it isn't on ice and kept cold, don't eat it! Preventing food-borne illness (food safety) may not be on the top of your mind, but it is a serious issue for everyone. Seventy-six million people become sick from food-borne illnesses every year and five thousand people die from them.

Some people have a higher risk of food-borne illness, including those who are already weakened by another disease or treatment for a disease, pregnant women, infants, young children, and older adults. It can take a half-hour to six weeks to become sick from unsafe foods, and not everyone who eats the same food gets sick. Signs and symptoms of food-borne illness include nausea, vomiting, diarrhea, fever, upset stomach, and dehydration. There are four basic principles to avoiding food-borne illness: clean, separate, cook, and chill.

Clean

- Always wash hands with warm water and soap for twenty seconds before and after handling raw meat or poultry (chicken, turkey) and other foods.
- Clean food-contact surfaces, fruits, and vegetables.
- Use a 10 percent bleach solution to clean any cutting boards or surfaces that have been used for raw poultry or meat.

Separate

- Separate raw, cooked, and ready-to-eat foods while shopping, preparing, or storing foods. This prevents bacteria on one food from contaminating another food.
- Use one cutting board for raw meat, poultry and seafood, and a separate one for fresh produce. Replace cutting boards if they become worn or develop grooves. It is harder to clean a board that has grooves where bacteria can hide.
- Never serve foods on a plate that previously held raw meat, poultry, or seafood unless the plate has first been washed in hot, soapy water.

Cook

- Cook foods to a safe temperature to kill microorganisms. The only way to know food has been cooked to a safe internal temperature is to use a food thermometer.
- Scrambled, poached, fried, and hard-cooked eggs are safe when cooked so both yolks and whites are firm, not runny.
- Reheat leftovers until a temperature of 165 degrees F is reached throughout the food.

Chill

- Bacteria multiply rapidly between 40 and 140 degrees F. The recommended temperatures for the freezer and refrigerator are 0 and 40 degrees F.
- Keep refrigerated foods cold. Refrigerate these foods promptly (e.g., milk and milk products, creams, dips, opened fruit juices,

mayonnaise). The total time at room temperature should be less than two hours and only one hour in hot weather (above 90 degrees F).

- Defrost foods properly. The best way to thaw frozen foods is in the refrigerator.
- When cooling foods, use a shallow container.
- Place very hot foods on a rack at room temperature for about twenty minutes before putting them in the refrigerator.
- It's acceptable to refrigerate foods while they're still warm. Just leave container cover slightly cracked until the food has cooled.
- Store raw meat, poultry, and seafood on the bottom shelf of the refrigerator so juices don't drip onto other foods.
- Refrigerated leftovers may become unsafe within three to four days. When in doubt, toss it out.



EN and PN Safety

What about the safety of enteral and parenteral nutrition? These too can become contaminated. It is important to use care in storing, handling, and administering your feedings.

- Always wash your hands before handling tube feeding or parenteral nutrition.
- For enteral (EN) formulas, the hang time is based on the source of preparation. If you are using a sterile formula in an open system at home, it can hang for 12 hours. If it is a sterile formula in a closed system, it can hang for 24 to 48 hours, as long as the system is not violated.
- Parenteral nutrition (PN) solutions must be kept refrigerated. Take out and leave at room temperature for 1 to 2 hours prior to infusion. Never put your PN bag in a microwave or hot water bath. The PN bag can hang for 24 hours. If lipids are administered separately, the hang time for the lipid bag should not exceed 12 hours. If the lipids are admixed directly to the PN to form a total nutrient admixture (TNA or 3-in-1, where the lipids, amino acids, and dextrose are mixed together), the final PN formulation can be infused over a 24-hour period, since it provides a safe vehicle with respect to infectious risks.

Keeping your home PN or tube feeding safe by making sure you are careful with refrigeration and preparation is probably always on your mind. Take care of your "other" food, too, to keep you and your family safe. It is even more important to remember these rules when eating at outdoor events, buffets, and picnics. Have fun, be safe, and save us a bite!

For further information: www.cdc.gov/ncidod/dbmd/diseaseinfo/foodborneinfections_g.htm

This column has been compiled and reviewed by Laura Matarese, PhD, RD, LD, FADA, CNSC; Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN; Cheryl Thompson, PhD, RD, CNSD; and Marion Winkler, PhD, RD, CNSC.

Good to the Last Drop

The lighter side of HPN

Laurie McBride

Did you ever operate a roadside stand as a youngster? Do you yearn for the “extra” funds that the day’s end divvy would yield? Here is a suggestion for “adding to the pot” and profiting from your current circumstances.

Have you ever experimented with home parenteral nutrition (HPN) solutions and household plants? Well, let me tell you that three drops in a litre of water will make your plants spring to life! Five drops, and they’ll wilt. That should give you some indication of the power available to you in that 60 ml of unused HPN solution.

What does that represent in savings in lawn fertilizer? Say you would normally use two bags of 12-8-6 on your lawn, three times a year. At, say, \$10 per bag, that’s a savings of \$60 per year in garden fertilizer—on your yard alone. Think of how you could market that to the neighborhood. Consider a partnership with the local elementary school, with them earning a commission for every home signed up for three times a year “fertilizing.”

Now think bigger. The local golf course is probably 150 acres or better. Their consumption is more likely ten bags of fertilizer per acre, every four weeks. As for pricing, they are probably spending in the order of \$5 per bag times 1,500 bags—say \$7,500 every four weeks for product, not to mention the costs of application. Since you have a product available to them that can be applied by their sprinkler system, sign them up at \$7,500 per month for the June through September period, and \$2,500 per month for the April, May, and October shoulder season.



You can fertilize large areas with industrial sprinklers.

And that is but one golf course. Do a little driving, and it’s not hard to have four or five clients within a reasonable commuting distance.

As for product availability, you’ll soon begin to need that two-bag-a-month breakage that those of us who’ve been around a while have convinced our home care companies is quite the norm. With the odd “night off” contribution, you should be quite capable of meeting the demands of all but the most entrepreneurial of operations.

See, it’s not hard to contemplate a \$100,000 per year plus in (dis)ability income!

Our thanks to Laurie McBride, an Oley Regional Coordinator from Victoria, British Columbia, for his enduring sense of humor.

*The well-being of our consumers
will always be our mission*

We invite you to learn more

1-800 Home TPN
www.nutrishare.com

20 YEARS
Nutrishare®
1991-2011 20th Anniversary of Home TPN Care



*Nutrishare is a proud partner of
The Oley Foundation*

Importance of Food, from pg. 2

requests that they allow you to order a smaller or child's portion, or share a plate. (Call 800-776-OLEY to request a free card.)

If you are unable to eat, family members, relatives, or friends may feel uncomfortable at mealtimes. Tell your family and friends you are happy to have their support, their conversation, and company. It is important to enjoy the social aspect of being with others even if you are unable to eat. Remember that a meal is not only about food. Meals are also about the human relationships and interactions that go on around food.

To simply enjoy the conversation and socialization is an important reason to attend a party or a food-related event. Wander around the room, mingle, chat, even hold a glass or beverage or a small plate, whether or not you plan to drink or eat. Better yet, ask the hostess if you can help serve the food. A long-term HPN consumer once told me, *"It's part of the ambiance of being together, the social part of it, not just the food per se but the whole social part of it."*

Cooking can also be a strategy to tie food and socialization together, even when you cannot eat. Learning to cook may bring joy to some people who no longer obtain pleasure from eating food. Some of the enjoyment comes from the smell of food, which may help to satisfy you during the cooking experience. Planting a garden and growing



Holding a glass or plate, even if you can't drink, can help you feel more comfortable at a social gathering.

food also keeps some people connected to food. I'll never forget the day a patient brought me a big brown bag of vegetables from her garden and told me she hoped I'd enjoy what she had grown, since she was unable to eat them herself.

Another long-term HPN consumer summed it up well when she told me, *"I enjoy making people happy with food. I feel like this is my expression of love to make these really special things for people, and seeing...them enjoy it. If I participate, I participate, and if I don't, I don't."*

Children and Food

Whether they are able to eat or not, children should also interact with food! Foods may provide oral stimulation and non-nutritive sucking, and promote chewing skills. Expose your child to different textures, tastes, and colors. Develop food-related games to increase his or her familiarity with foods and mealtimes.

Handling food and playing with food and utensils encourages oral-motor skill development. Setting the table for the rest of the family is an important and necessary social skill. Children may also set the table for their dolls or stuffed animals and play-feed them, too. Older children can participate in shopping, food preparation, and cooking. Mealtimes should be maintained for socialization and to allow children to watch others eat. Most importantly, create a supportive eating environment for the entire family.

Quality of Life

The ability to eat and the enjoyment of eating are important aspects of good quality of life. In other words, *"being able to eat what I want, when I want"* makes us feel good. Factors interfering with eating or the enjoyment of eating typically include physical complaints, such as pain or severe or uncontrolled diarrhea; physician orders not to eat (having to stay NPO); restricted diets; a perception of wasting money when food is not digested or absorbed; and general ill feelings associated with poor health. If you've made dietary changes and continue to experience these symptoms or complaints, ask your clinician to help you resolve them. If dietary changes do not improve GI symptoms, balance the benefits and risks of continuing the food restriction.

Relearn to eat for pleasure or comfort when HPN or tube feeding is providing the majority of your nutritional needs. A small bite, taste, or the chew-and-subtly-spit technique may be important for your quality of life. Being able to join a spouse, family, or friends "normally" during a meal is strongly tied to improved quality of life. Try to achieve pleasure from tasting small amounts of food, enjoy dining in restaurants, or obtain satisfaction from participating in social occasions. Community and a sense of belonging and taking part in social gatherings are important, whether you are eating food or not. ¶



Matisse finds great joy in cooking.

NutreStore™
[L-glutamine powder for oral solution]

ZORBTIVE®
[somatropin (rDNA origin) for injection]

Marketed Exclusively by:
EMMAUS MEDICAL, INC.

Dedicated to improving the lives of people with rare diseases
Call 1-877-420-6493 for more information

www.emmausmedical.com
www.nutrestore.com
www.zorbitive.com

Zorbitive® and NutreStore™ are marketed in the U.S. by Emmaus Medical, Inc. © 2009 Emmaus Medical, Inc. SMM-010-01 0907



Joan Bishop, Executive Director
214 Hun Memorial
Albany Medical Center, MC-28
Albany, NY 12208
(518) 262-5079, FAX (518) 262-5528
bishopj@mail.amc.edu / www.oley.org

Dear Friend of Oley,

On behalf of the 11,000 members we support, we encourage you to make a gift to the Oley Foundation, and thank you if you've already responded to our annual appeal.

Through your generosity, the Oley Foundation brings expertise to consumers in need, hope to families in times of trouble, and connection to people in isolation. Ultimately, it means the difference between just surviving and truly living life to its fullest.

As member Jack Leibee affirms, your support has a huge impact:

Six years ago, my life changed dramatically. I was diagnosed with Short Bowel Syndrome (SBS)—my intestines weren't able to absorb sufficient nutrients and fluids to maintain life. I was placed on infusion therapy for twelve hours every night. My wife and I were astounded by the lack of information available to us, and we weren't sure what to do, other than what the gastroenterologist and home care nurse told us: get used to it since you'll live with this for the rest of your life. Unwilling to accept this, we decided we wanted to learn how other people were coping—and if they had found more effective methods of treatment. Fortunately we found out about the Oley Foundation.

Oley provided critical information that has allowed us to make informed decisions about treating my condition. The Foundation put us in contact with individuals and families in similar situations. We attended conferences where we heard experts on the latest treatments and talked directly to our own and other pharmaceutical providers.

Just four months ago I was able to quit the infusion therapy. I am no longer taking any treatment or special medicines for my condition. I was very fortunate that my body adjusted. I know this would not have been possible without the information we learned through Oley and its members with similar problems.

“We urge you to spread the word about the Oley Foundation and to support their important work by making a donation,” adds Jack, and his wife, Carol. “It certainly benefited us, far beyond what we ever expected. It gave us hope and showed us there was a caring community of providers and patients and volunteers who want to help.”

Please consider what Oley means to you and your loved ones, and make a gift today. For your convenience an envelope is enclosed in this newsletter. Or, if you prefer, you may contribute online at www.oley.org.

Gratefully yours,

A handwritten signature in cursive script that reads 'Joan Bishop'.

Joan Bishop
Executive Director

Volunteers: Help Along the Way

Oley Regional Coordinators (RCs) are an integral part of our organization's efforts. They have a wealth of experience between them and a sincere desire to help. Contact them with questions, concerns, or simply for inspiration. Some help organize regular meetings (indicated below with an *). Check with those individuals regarding dates, times, etc.

Volunteers listed below are organized by therapy; within each therapy, they are alphabetical by state. HEN = home enteral nutrition or tube feeding; HPN = home parenteral nutrition or IV feeding; HPEN = enteral and parenteral; TR = transplant; Off = no therapy at this time; and FC = former caregiver. This list, including volunteers' contact information and a short biography, is posted online at www.oley.org and updated regularly.

We must insist that RCs not be contacted for solicitation, marketing, or research purposes.

Contact Joan Bishop at bishopj@mail.amc.edu or (800) 776-6539 to learn more about the rewards attached to serving in this capacity.

HEN - Tube Feeding

Jack Smith (parent)

Southside, AL, (205) 552-6037
bossybaby@charter.net

Eleana Shore (parent)

West Hills, CA, (818) 888-4302
eleanashore@sbcglobal.net

Joanne Platt

The Villages, FL
joanneplatt2006@aol.com

Kathleen McInnes*

Chicago, IL, (773) 763-8791
mckathleen@yahoo.com

Joseph Rogers

New Bedford, MA,
(508) 999-7363
JMR12667@aol.com

Carol Pelissier

Manchester, NH, (603) 625-2362
capuniqué@comcast.net

Sanford Schimel

Bronx, NY, (917) 392-0589
sschimel@hotmail.com

Aliza Chana Zaleon

Chapel Hill, NC, (919) 537-9588
azaleon@gmail.com

Linda Stroschine*

Toledo, OH, (419) 726-2833
lindamoonglow@buckeye-express.com

Jodee Reid (parent), HEN & TR

Gibsonia, PA, (914) 417-5163
jodee1@zoominternet.net

Cherie Dickerson

Richmond, VA, (804) 231-4372

HPN - IV Feeding

Bruce and On Braly (parents)

Davis, CA, (530) 867-2209
b5bru@cs.com

Kristy Poindexter

Concord, CA, (925) 349-4835
krisper29@yahoo.com

Darla Edwards

Fairfield, CA, (707) 437-0241
cookie0241@aol.com

Patty Woods

Hemet, CA, (951) 766-5145
pattywoods@mac.com

Jane Golden

Watertown, CT, (860) 945-6315
janegolden@aol.com

Lynda Yeabower-Heasley

Destin, FL, (850) 654-9667
Lyeabower@aol.com

Barbara Klingler

Valkaria, FL, (321) 724-4566
lbklingler@att.net

Jameson Atkinson

Macon, GA, (706) 340-7261
jatkinson952@gmail.com

Anna Cyr (parent)

Leeds, ME, (207) 933-1051
annahcyr@yahoo.com

Davria & Steve Cohen

Crofton, MD, (410) 721-3399
cohenetnet@verizon.net

Rosaline Ann Wu*

Livonia, MI, (734) 464-2709
rosalinewu@att.net

Elizabeth Tucker

Lakeville, MN, (952) 435-0013
evtucker@charter.net

Mary Patnode

N. Maple Grove, MN,
(763) 420-7052
mpathjohn@aol.com

Felice Austin (parent) & Mariah Abercrombie

Henderson, NV, (702) 435-6007
fleecey@aol.com (mom)
mariah1216@aol.com

Pat McKenney

N. Salem, NY, (914) 277-3275

James Cowan*

Cleveland Hgts, OH,
(216) 932-3512

Roberta Gelle*

Elyria, OH, (440) 365-0908
bgelle1@windstream.net

Tammi & Robert Stillion*

Wauseon, OH, (419) 349-3907
tammis705@aol.com
outdoorsman8888@aol.com

Judi Smith

Drums, PA, (570) 328-5206
Judi@ptd.net

Betty (parent)

& **Bettemarie Bond**
Levittown, PA, (215) 946-0898
eabondrn@aol.com (mom)
bettemarie@aol.com

Robbyn Kindle

N. Richland Hills, TX,
(817) 577-5432
robbynskinder@sbcglobal.net

HPEN - Tube & IV Feeding

Drs. Cindy & Erik Schten

(parents)
Larkspur, CA, (415) 444-0639
ecschten@lvha.net

Melissa Fedell

Rocky Hill, CT, (860) 436-6628
1aprn4kids@att.net

Sheila DeKold (parent)

Floyds Knobs, IN,
(812) 941-8145
SDekold@mac.com

Rose (parent) & Alicia Hoelle

Gibbstown, NJ, (856) 423-4885
Rosiebowah@comcast.net (mom)
suitepixie@yahoo.com

LeeAnne Bye* (parent)

Northfield, NJ, (609) 641-9087
allenleeannebye@aol.com

Sue Koprucki (parent)

Williamsville, NY,
(716) 688-4411
ma2mje@yahoo.com

Malisa Matheny

Philadelphia, PA,
malilibear@aol.com

Emily & Brian Hoopes (parents)

Taylorville, UT, (801) 955-6526
emily.hoopes@gmail.com

TR - Transplant

Carla Truman (parent)

Phoenix, AZ, (602) 547-8952
ctruman6@gmail.com

Sonia Alagna (parent)

Dewitt, MI, (517) 669-5940

Jodee Reid (parent), HEN & TR

Gibsonia, PA, (914) 417-5163
jodee1@zoominternet.net

Off - No Therapy Currently

Tara Smith (parent)

Avondale, AZ, (623) 882-3556
smith.tarasmith@gmail.com

Judith Peterson, MS, RN

San Diego, CA, (619) 226-2061
catsjp@cox.net

Bonnie Sjoberg

Milaca, MN, (320) 983-2138
centuryfarm92@webtv.net

Beverly Buchanan

Bozeman, MT, (406) 624-0350
knitter63@gmail.com

Laura Krueger (parent)

Memphis, TN, (901) 682-3982
sethsmom10@msn.com

FC - Former Caregiver

Patty Woods (parent)

Hemet, CA, (951) 766-5145
pattywoods@mac.com

Joan Medwar

Sharon, MA, (781) 784-3341

Bobbie Groeber (spouse)

Columbus, NJ, (609) 298-1227

Kay Oldenburg (spouse)

Syracuse, NY, (315) 635-9775
KFOldenburg@verizon.net

Chuck Lindley

Burlington, NC, (336) 229-9346
clindley@masonlindleymiraclefoundation.org

Michelle Christenson

Seven Fields, PA, (724) 776-9556
mchrister@zoominternet.net

Valerie Schreiner (parent)

Stratford, WI, (715) 687-4551
schreiner4@hotmail.com

Foreign Affiliates

Shannon Curran, HEN

123 Collier St., Apt #3
Barrie, ON, Canada L4M 1H5
(705) 252-5272
shannoncurran@rogers.com

Don Freeman, HPN

23 Halley St.
Nepean, ON, Canada K2J 3W5
(613) 825-4341
donfreeman@sympatico.ca

Laurie E. McBride, HPEN

837 Sayward Rd.
Victoria, BC, Canada V8Y1R5
(250) 658-2915
lmcbride@telus.net

Brenda Dunn, HPN

PN-Down Under
State Highway 29
Matamata, New Zealand
(647) 888-2955
contactpndu@gmail.com

Carolyn Wheatley, HPN

PINNT
PO Box 3126
Dorset, UK, BH23 2XS
01 202 481625
pinnt@dsl.pipex.com

John R. McDonald, HPN

5281 Valestrandsfossen
Bergen, Norway
johrm@online.no

Swimming Tips

“What do I do about swimming and bathing with a central venous catheter or a feeding tube?” Because we hear this question so frequently, we’ve posted some suggestions and resources on our Web site. Go to www.oley.org/Swimming.html for some tips.

The first tip? Check with your health care provider for his or her advice on how you should approach swimming and bathing.

For those looking to cover a PICC line while swimming or bathing, Dry Pro has offered Oley members a \$3.00 coupon. Mention Oley and this discount when ordering.

If you don’t have Internet access, call us at (800) 776-6539 and we will send you the information.



Nolan enjoys swimming.

Conference, from pg. 1

At the Oley conference in Saratoga last year, he was in awe... sitting and listening to others who live as he does. Listening to the issues that only someone with this alternative nutritional need could understand was almost overwhelming for him. He was very interested in the information that he hoped to share with his providers regarding the new research being done in this area.

I cannot tell you how nice it was to know that when you discussed things like PICC lines, the need for access to bathrooms, and infections, people understood. The networking was wonderful. Ronnie and I met a couple who were also from Canada. I believe any person of any age should experience what Oley has to offer. They need to have the opportunity to attend a conference, to be exposed to different viewpoints.

I found that a couple of the sessions were not appropriate for first timers, due to the amount of information being shared. If you had never been exposed to the material before, it was difficult to relate to it. But the conference was well put together... if that is the correct term... or well done!

The scholarship for first time attendees is an excellent program. It gives a person who might hesitate to go due to the expense of attending a chance to “check it out.” I know Ronnie and I both hope to be able to attend the next conference that is on the East Coast.

Who should attend? In my opinion, the conference can meet the needs of both those new to PN and those who have been on it for a while. I definitely believe the Oley conference would be a great help to someone who is new, just to help with the emotional changes that occur with having to live an alternative nutritional lifestyle. They would be able to establish a network and contacts. But I found it nice to watch the people who come often reconnect with the friends they have made. I think that every year it is helpful for you to “get recharged” and keep up with the changes in the field. So, even Ronnie, on PN for sixteen years, felt that he benefited from it.

We also enjoyed the exhibitors. It is interesting to see the new products and services that are available. ¶

For more information on this year’s conference go to www.oley.org/annualconf.html, or call (800) 776-OLEY.

A Trusted Provider of Home TPN for Over 30 Years

“Coram is not just an infusion services provider but rather a network of caring, educated and devoted people who rally together and who make the impossible, possible.”

– Michelle Burris, Nutrition Consumer

Coram's Nourish Nutrition Support Program™ provides a customized care approach for home TPN and tube feeding patients. We are dedicated to providing high quality clinical care, nutrition expertise and personal support for nutrition consumers in the home.

- Personal Support and Advocacy
- In-home Training and Ongoing Education
- Free, Educational Consumer Teleconferences
- 24/7 Access to Clinicians
- #1 Home TPN Provider in the Country

Nourish[™]
nutrition support program

WeNourish.com
877.WeNourish

A service of

CORAM[®]
specialty infusion services
An Apria Healthcare Company



Speaking Up for Better Care

Ellen Pierce, MD, has been on nightly homePEN for twenty years, after an extensive small bowel resection for Crohn's disease. She has been an Oley Foundation member since 1992 and is the author of several articles on Crohn's disease. (Her articles can be found online at www.pubmed.gov.)

Ellen recently shared the letter below with us, and we, with her permission, are sharing it with you. It is a good example of an appropriate, well-written letter from a patient to a health care provider expressing concern over protocol issues. We hope you will find it useful as you seek to advocate for better care, for yourself and/or your friends and family members.

Other resources to help you feel more comfortable advocating for yourself include Oley's:

- **MY HPN, Module One: Take Charge**—an online, interactive learning module available at www.oley.org. The goal of this module is to teach you, the HPN consumer, how to take a more active role in managing your HPN therapy.
- **Keep Me Safe posters and bracelets**—for use by HPN consumers when hospitalized. Placed near the patient's chart, the poster will help remind health care providers about basic principles that will keep you and your central line "safe." The bracelet is a further reminder. To obtain a *Keep Me Safe* poster and bracelet, call (800) 776-6539, e-mail harrinc@mail.amc.edu, or download the poster at www.oley.org (choose "Resources," "Keep Me Safe").

May 22, 2011

Hello Dr. _____

Thank you so much for squeezing me into your schedule last week to take a look at the thinned segment of my Hickman catheter. I appreciate our thoughtful discussions. I am writing to you today because of an issue that arose during the appointment.

As you know, I have been on TPN for 20 years, and have had my current catheter for 13. At my PN provider's conferences and through Oley Foundation newsletter articles, I have heard many horror stories about careless, sloppy handling of central lines by health care providers. I personally know of two PN patients whose deaths were a result of central line infections. I have made it a policy to not let anyone within 5 feet of my catheter without having observed them wash their hands and whatever else will be near the catheter, including stethoscopes and ECG pads! I make it a point to "hook up" to a bag of saline before procedures involving conscious sedation or general anesthesia, so only the injection port in the tubing, rather than the catheter itself, will be touched. When I hook up or unhook at home, I wash my hands at the closest sink. I wash them again with rubbing alcohol from a bottle at the hook up table just after arranging the supplies, and then usually again, depending on what I have accidentally touched on the table. This can sometimes reach comical numbers!

I specifically brought a bottle of rubbing alcohol to the appointment, because I do not touch my catheter without first washing my hands with soap and water or rubbing alcohol. After discussing what was going on with the catheter, you were just about to examine it when I asked you to wash your hands...and you refused, because you "weren't going to touch the catheter." I put some of my rubbing alcohol on my hands and then we looked at the catheter. During our examination you...touched the catheter. I was upset that you refused my request to wash your hands, and my dismay was compounded by your touching the catheter without having washed them.

I know that, now that I have brought my concerns to your attention, I can rest assured that you will follow the Ellen Protocol for Her Hickman Catheter during future appointments. I am enclosing a pamphlet on hand washing. I hope you might consider having a similar pamphlet in patient care areas. I look forward to your continued help with my catheter, Dr. _____!

I am most gratefully and respectfully yours,

Ellen S. Pierce, MD
Spokane Valley, Washington

Wash Your Hands, Please!

Extracts from "Help Us Help You Prevent Infections," reprinted with permission of Washington State Hospital Association. To order copies, call (206) 577-1839 or go to www.wsha.org/page.cfm?ID=bookstore. The brochures are available in English and Spanish.

Make your care safer. Ask your doctor, caregivers, and visitors to wash or sanitize their hands.

How?

Become a partner with your doctor, nurse, all the health care workers that enter your room, and your visitors by asking them, "Did you wash or sanitize your hands?"

When and Where

Ask the question any time your doctor, nurse, or health care worker is about to touch you or touch things that are used in your care.

Isn't It Rude to Ask?

No! ...Health care workers are interested in your care and will expect you to ask them about hand hygiene!

Facts About Hand Hygiene...

- Germs that cause infections can be spread in a number of ways. The most common is through hands.
- Health care workers can get their hands clean in two ways: washing their hands with soap and water, or sanitizing their hands by rubbing them together with alcohol-based gel. [Editor's note: current research shows that soap and water is more effective against *C. diff* than alcohol-based hand sanitizers and wipes.]

New Guidelines for Preventing Catheter-Related Infections

The Centers for Disease Control and Prevention (CDC) “Guidelines for the Prevention of Intravascular Catheter-Related Infections, 2011” is now available online. This document replaces guidelines issued in 2002. It will be a great resource for home parenteral nutrition (homePN) consumers looking for the latest evidence-based recommendations on care and maintenance of their catheters.

Lead author of the guidelines, Naomi O’Grady, MD, of the National Institutes of Health, says, “Previous prevention efforts have focused on central venous catheter placement in intensive care units, due to the frequency and the profound effect of hospital-acquired infections on ICU patients... But now we know that maintaining catheters can be equally associated with risk of infection, not just in the ICU but in outpatients too.”

While directed at health care personnel, the guidelines acknowledge that avoiding catheter-related infections should be a multidisciplinary effort that involves the patient as well as health care professionals. “This guideline,” notes Dr. O’Grady, “will address many issues associated with keeping a catheter in place by emphasizing attention to the details of good catheter care.”

The guidelines address many areas of concern. It would not be practical to list them all here, and many are directed more toward the health care provider than the homePN consumer. There are many issues, however, that will be important to the patient caring for his or her own catheter, or providing care to someone with a catheter at home, including: hand hygiene and aseptic technique; skin preparation during dressing changes; catheter site dressing regimens; patient cleansing; catheter securement devices; antibiotic locks and flushes; anticoagulants; replacement of catheters; replacement of administration sets; and needleless systems.

We are hoping to include a more detailed summary of these guidelines in a future issue of the newsletter. In the meantime, you can access the full document (83 pages) on the CDC Web site: www.cdc.gov/hicpac/BSI/BSI-guidelines-2011.html. If you don’t have computer access but would like information regarding any of the areas of concern mentioned above, contact Lisa at the Oley office (800-776-OLEY) and she will try to send you the relevant section(s) of the guidelines.

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.

Balloon
Breakage?
Granulation Tissue?
Leaky
Buttons?



Try **Mini ONE**[®]
Low Profile Buttons

Comfort • Durability • Confidence



AMT
The Leader in Enteral Device Innovation

Toll-Free: 800-869-7382
www.appliedmedical.net

© 2010 Applied Medical Technology, Inc.
Mini ONE is a registered trademark of Applied Medical Technology, Inc.

Donor Profile: Josie Stone, RN, CPNP, CRNI

On any given day, I am sure to receive numerous solicitations—by mail and phone—to help support many worthy causes. It is almost an emotional challenge to decide how far my “contribution budget” can stretch and which donation will have the most impact. Obviously, depending on our background, job, business, family, past history, etc., some causes will resonate with us more than others. In my life there is one organization that is always at the top of my list: the Oley Foundation. I have no hesitation in offering Oley my support and recommending to others that they do the same.

I am very familiar with the amazing work the Oley Foundation does as a consumer organization for a very specialized population of committed, dedicated, self-disciplined, and remarkable patients. This Foundation provides this population with the very heart of what makes life manageable: education, outreach, networking opportunities, family involvement strategies, medical and clinical resources and updates, and most important, a sense of worthiness and productivity. The management of this organization superbly demonstrates their mission with warmth, patience, and undying support for their members, who quickly become “family.”

As a nurse practitioner and vascular access specialist, I have seen firsthand the complexities that can come with the need for ongoing enteral or intravenous support. Patients and families must learn many new and complex things. They quickly realize that this means of providing essential nutrition is a true “lifeline,” and that the management of it is indeed “in their hands.” It is enormously inspiring to see everyday people take charge; learn the steps of line care; manage their fluids and medications; and, at the same time, know they too deserve to love, laugh, and live a full and happy life. Through the Oley Foundation this is made possible over and over again.

I encourage you to support Oley today. Your donations truly make that “impact” here.



Josie Stone, RN, CPNP, CRNI

Other Ways to Give

Looking for ways to stretch your donation, without writing a bigger check? We remind you to explore alternate giving options, such as:

- employer matching grants (extremely worthwhile!)
- payroll deductions (United Way)
- 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 the future.

Spotlight on Our Corporate Partners

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. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

Baxter Healthcare Corp.

Baxter Healthcare Corporation has more than seventy-five years experience in developing parenteral nutrition solutions that work together to improve patient outcomes. According to the company, “Baxter offers clinicians and patients the broadest portfolio of parenteral nutrition in the industry that includes CLINIMIX Injections, an innovative commercially manufactured multi-chamber bag of parenteral nutrition formulations.”

Baxter also offers INFUVITE multiple vitamins for infusion (Sandoz Canada Inc.); lipid emulsions for infusion; AUTOMIX 3+3 and MICROMIX automated compounding equipment; and LOGIX compounding software. Parenteral nutrition solutions from Baxter efficiently help professionals meet the nutritional goals of patients. More information about multi-chamber bag PN is available at www.clinimix.com.

Kimberly-Clark

Kimberly-Clark develops, manufactures and markets the comprehensive line of MIC* and MIC-KEY* Feeding Tubes, including the Kimberly-Clark* MIC*, MIC-KEY* Introducer Kit and components providing physicians with an innovative solution to facilitate the initial placement of balloon-retained enteral feeding tubes making patients’ lives better and physicians’ lives easier.

Applied Medical Technology, Inc.

Applied Medical Technology, Inc. (AMT) was present at the birth and development of the percutaneous endoscopic gastrostomy (PEG) movement. The company’s founder co-invented the first button low-profile feeding device. “Since then,” the company writes, “AMT has introduced innovative designs and materials to advance PEG tubes by increasing patient comfort while improving patient outcomes. AMT’s Mini ONE® Balloon and Non-Balloon Buttons have unique design features that provide increased patient comfort and long life.” The company’s products are compatible with other manufacturer’s feed sets as well as its own feed sets and accessories.

Tube Talk, from pg. 3

medical devices to the FDA’s MedWatch Safety Information and Adverse Event Reporting Program. You can obtain a form online at www.fda.gov/MedWatch/report.htm or by calling (800) 332-1088.

Updates from Oley

If you’d like to receive occasional, important updates from us, be sure we’ve got your e-mail address! Drop Cathy an e-mail at harrinc@mail.amc.edu with your e-mail address and other contact information. Please indicate whether or not you’d also like us to switch your newsletter subscription to electronic delivery—you’ll get the newsletter faster! ♣

From the Desk of Joan Bishop, Executive Director

The annual conference is an exciting time for Oley staff. As we plan, we look forward to the information we'll learn, the old friends we'll see, and the new friends we'll meet. We enjoy the energy and enthusiasm that surrounds this gathering—and it won't be long before it's here!

We hope you will be able to join us, but if you cannot, look for photos on Facebook. We will do our best to post daily. Many sessions will be recorded again this year, thanks to a generous grant from Baxter. You'll have an opportunity to borrow the DVDs later this summer.

Communication

As you know, drug shortages remain a huge concern, especially for HPN consumers. We're keeping www.oley.org updated and will link to other sites for information as appropriate. We are also circulating many updates and timely information—on the shortages and other topics—to our members via e-mail blasts.

If you haven't supplied us with a current e-mail address, please do so now. It's an efficient way to get these alerts/messages, invitations, and more, especially if there is a need for you to respond.

Our Partners

There isn't a thing we do at Oley that doesn't remind us of the value of our corporate partners...our helping hands. We just wouldn't be able to do all that we do without their support!

I'd like to acknowledge two longtime corporate partners who significantly increased their annual gifts this year. Baxter Healthcare soared from the Patron Level to the Bronze Star Level. Baxter also designated Oley as the recipient of their Make a Difference Campaign at Nutrition Week earlier this year, netting another \$5,000! Kimberly-Clark has leapt to the Benefactor Level! This gift reflects their long-standing confidence in the value of Oley programs. These commitments help to keep us in forward-thinking mode.

Thank You, Our Members

I'm extremely pleased to report that the response to our annual appeal was overwhelming again this year. We exceeded our goal, with donations totaling \$19,000+. We were prepared for the worst in these challenging economic times, but we can count our blessings—each of you who stand behind us. Thank you for recognizing the impact we have on members and for supporting Oley. We simply couldn't do it without you!



Joan Bishop

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 March 18 and May 27, 2011, gifts were received:

In Honor of

Mariah Abercrombie's graduation; Bettmarie Bond; Mary Kunz's birthday; and Marcia Denenholz

For

Kyle R. Noble Scholarship Fund, Kelly Keefe's Senior Project Fundraiser, Guiliana Valenti's Villa Valenti Fundraiser, and the Freihofer's/Community Walk Fundraiser

In Memory of

Erin Arsenaault, June Bodden, Ann Hill DeBarbieri, Jeff Dutton, Robert Hoffman, Charlene Key, Angie Mitchell, Sheila Alice Shelley, Paula Southwick, Bob Sweet, Hildegard Voelker, Diane Wagner, and Audrey Grace Yadrach

Matching Gift

Bank of America Charitable Foundation

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.

GOLD MEDALLION PARTNERS

(\$50,000–\$69,999)

Coram Specialty Infusion Services
Nutrishare, Inc.
ThriveRx

BRONZE STAR PARTNERS

(\$20,000–\$29,999)

Baxter Healthcare
Emmaus Medical, Inc.
NPS Pharmaceuticals

BENEFACTOR LEVEL PARTNERS

(\$10,000–\$19,999)

Abbott Nutrition
InfuScience, Inc.
Kimberly-Clark
Nestlé HealthCare Nutrition

PATRON LEVEL PARTNERS

(\$5,000–\$9,999)

Applied Medical Technology, Inc.
Critical Care Systems, Inc.
Walgreens

CONTRIBUTORS

(\$1,000–\$2,499)

B. Braun Medical
Drink Your Meals

Thank You!

LifelineLetter

The Oley Foundation

214 Hun Memorial
Albany Medical Center, MC-28
Albany, NY 12208

NON-PROFIT ORG.
U.S. POSTAGE
PAID
PERMIT NO. 687
ALBANY, N.Y.

Google™

Thanks to Google, Inc. for their
in-kind donation of advertising.

Coming Soon! The Oley Annual Conference

See It Live in Minnesota, or Borrow the DVD, to Be Released This Fall!

26th Annual Consumer/Clinician Conference: Alive, Well, and More Informed!
Bloomington, Minnesota, July 5–9

featuring...

Keynote Addresses:

“Vascular Access Issues”

Jim Andrews, MD

“Emerging Therapies for Treating Intestinal Failure”

Kelly Tappenden, PhD, RD

“Despicable Diarrhea”

Darlene Kelly, MD, PhD

“Battling Metabolic Bone Disease”

Dan Hurley, MD

Transitioning to Independence:

“Mapping the Route,” “Letting Go,” and “Taking Charge”

Speakers TBA

Hot Topics in Home Parenteral Nutrition:

Presentations by winners of the Oley HomePN Research Prize, sponsored by Nutrishare, Inc.

“Parenteral Nutrition Outcomes of Patients with SBS after Discontinuing an Intestinal Growth Factor, Teduglutide”
Charlene Compher, PhD, RD, FADA, CNSC, LDN

“Central Vascular Access Device

Infection Rates for Home

Parenteral Nutrition Patients”

Melissa Leone, RN, BSN

“Relationship between Catheter-Related

Bloodstream Infection and Bathing Practices in HPN Population”

Marianne Opilla, RN, BSN, CNSC

Tube-Feeding Workshop:

“Exploring Complications,” “Blenderized Diet,” “Reimbursement Issues” and more

Speakers TBA

Social Activities:

Jammin’ Jammies Pajama Party for Youth

Poolside Picnic

Silent Auction

Walk-a-thon

Youth Activities at the Mall of America!

