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LifelineLetter

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

Tips from the Plumber's Helper: Liquid Medications

Mark Klang, MS, RPh, BCNSP, PhD

Medication delivery is always an issue for people on feeding tubes and their caregivers. Little guidance is available and often conflicting information will be delivered from well-intentioned advisors—people you would think actually have knowledge of these problems. One big issue is the lack of solid evidence of what will work and what will not.

Liquid Formulations

A common question with tube feeding is, “What formulation should we use for drug administration through a feeding tube?” The most common reply is, “Use the liquid formulation.” However, just because it’s in a liquid form doesn’t mean it is ideal for a feeding tube.

The liquid formulations of most medications are thick, sweet, and have low drug concentration. This is because most drugs taste bad, and the formulation was likely developed for kids.

Syrups and suspensions have thickeners to help those with swallowing difficulties; sweeteners to mask the taste of bitter medications; and cellulose to maintain a uniform suspension. Most of the suspending agents are acidic to help make the weak base drugs being delivered dissolve more easily. These thickeners, sweeteners, and suspending agents are called “excipients.” For the feeding-tube patient, none of these excipients are needed, and in some cases they contribute to adverse effects.



Liquid medications aren't necessarily the best choice.

Understanding Osmolarity

Osmolarity is the amount of stuff in a liquid. The more small molecules (“stuff”), like sugars and alcohols, in a liquid, the higher the osmolarity. Most manufactured and pharmacy-compounded liquid formulations have very high osmolarity. The osmolarity

Medications, cont. pg. 14 ◀

Oley Coordinates Global ENFit Summit

The Oley Foundation informs and advocates for home parenteral and enteral nutrition consumers. The safety and well-being of all nutrition support consumers is in the forefront of all that we do.

We are aware of several issues and concerns surrounding ISO 80369-3 and ENFit and remain committed to facilitating an open dialogue between consumers, members of industry, the FDA and the clinical community, and to work towards seeing these issues resolved.

Global ENFit Summit

On December 11, the Oley Foundation is coordinating a Global ENFit Summit in Atlanta, Georgia, to bring consumers together with manufacturers and members of the home enteral nutrition clinical community to showcase these issues and concerns of the end-users and to brainstorm possible solutions moving forward. The meeting will be available to view at www.oley.org, live on December 11 and on demand after the meeting.

Visit www.oley.org for more information, or contact the Oley Foundation at bishopj@mail.amc.edu, (518) 262-5079/(800) 776-6539.



The holidays can bring double the stress load.

Reduce Holiday Stress by Educating Others

Toni Bernhard, JD

Chronic health problems can take a toll on relationships any time of the year. Most people have to experience unrelenting pain or illness themselves before they understand how debilitating it is, physically and mentally. Loved-ones (by whom I mean family and close friends) may be in some form of denial about what’s happened to you, or they may be scared and worried about the future. Bottom line, suffering

Holiday Stress, cont. pg. 2 ◀

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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.

Holiday Stress, from pg. 1

from a chronic condition can be an ongoing crisis—for you and for those you're close to.

That crisis can come to a head during the holidays when people's expectations of one another are high and when stress levels for everyone are likely to be off the charts for any number of reasons—health, financial, relationship issues. If you're like me, during the rest of the year, you carefully limit interactions with others in order to manage your symptoms; on a typical day, your most complex decision may be to choose between showering and shopping! But when the holidays arrive, you're suddenly thrust into the middle of a lively and chaotic social scene where you're expected to participate in a range of activities, often for days in a row. A bit of advance warning to loved-ones can go a long way toward minimizing stress levels over unrealistic expectations.

I know that this piece won't apply to everyone. One of the heartbreaking consequences of living with chronic pain and illness is that some people are unable to be with loved-ones at all during the holidays, either because people are too disabled by their pain or illness to be able to gather with others, or because family and close friends have drifted out of their lives. I know the pain of that isolation; I've written about it.

For those of you who are able to gather with others, the holidays can be a recipe for double disaster—the increase in activity exacerbates your *physical* symptoms, while coping with sadness, frustration, and maybe even guilt about your physical limitations gives rise to *emotional* pain. No wonder many people with health problems dread the approaching holidays.

If you're one of the many people with chronic health problems who don't *look* sick, the initiative is with you to *make your condition visible*. Here are some suggestions for helping loved-ones understand what your life is like and for giving them a heads-up on what to expect from you during the holidays. (This piece focuses on the winter holidays but applies equally to other times of the year when loved-ones gather together.)

Share Information with Loved-Ones

Often the best way to educate loved-ones about chronic pain and illness is to use a neutral source because it takes the emotional impact out of the communication. A quick web search will yield a host of organizations devoted to

every conceivable medical problem. Print out select pages or forward a few links to family and close friends. Alternatively, if you have a book about your condition, photocopy the pages that cover what you'd like them to know about you. In your accompanying note, keep it "light"—you could joke that "there won't be a test." But also make it clear that this favor you're asking is important to you.

Find an Ally and Enlist His or Her Help

If you have just one close friend or family member who understands what you're going through, enlist his or her help in explaining your condition and your limitations. Before the holidays start, you could ask your ally to talk to loved-ones on your behalf or to be present when you talk to them. Ask your ally to be supportive if you have to excuse yourself in the middle of a gathering, or even to let you know if you're wilting (as we call it in my household). It's so helpful for me to be "prompted" by my ally because, when I start to overdo things, adrenaline kicks in which fools me into thinking I'm doing fine. But using adrenaline to get by just sets me up for a bad crash later on.

Your ally may be a close friend or family member who's just waiting for you to enlist his or her help. Think long and hard before you decide there's no such person in your life.

Others May Not Accept Your Limitations

Some family and close friends may refuse to accept that you're disabled by pain or illness. I know this from personal experience and it hurts. Try to recognize that this inability is about them, not you. *Don't let their doubt make you doubt yourself.* Your medical condition may trigger their own fears about illness and mortality, or they may be so caught up in problems in their own lives that they're not able to see their way clear to empathize with you.

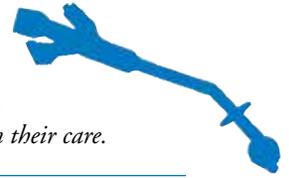
Just as you can't force people to love you, you can't force people to accept you. But getting angry at them just exacerbates your own symptoms. That's why it's important to protect yourself from allowing their lack of understanding to continually upset you. Think of it as protecting yourself from another chronic condition: chronic anger.

The physical suffering that accompanies chronic pain and illness is hard enough to endure without adding emotional suffering to

Holiday Stress, cont. pg. 14 ➤

Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@mail.amc.edu. Information shared in this column represents the experience of the individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



Taping Techniques

Shown below are different methods to give your skin a rest from having tape on it at the same place every day, or even for a few days. Applying tape at different places every day using methods 1–12 will give your skin almost two weeks to recover from having tape on it. Moreover, if you use methods 13–16, there is never tape on your skin. Not all of these methods may work for you, but most should. If the same number appears twice in the drawings, it means two pieces of tape are suggested.

If in method 6a there is not enough tape to adhere well to both gauze and skin, consider method 6b, where a strip of tape has been applied just to the gauze, then the tape above it is applied partially on it and partially on the skin.

A technique for not placing tape next to the main gauze is shown in methods 10 through 12. In methods 10 and 11, small, extra pieces of gauze are placed next to the full-sized gauze and tape ties them all together. The smaller pieces of gauze protect the skin next to the full-sized gauze. This technique can also be used with most of the other methods. You can cut a single piece of gauze into several smaller pieces, thus getting several days' worth of extensions from it.

For method 12, with the adhesive side up, lay out a long strip of tape, as shown in the drawing. Then apply two shorter pieces of tape to it so the adhesive sides face each other. When you lay the longer strip across the gauze, the shorter pieces will provide a gap next to the gauze with no (or very little) adhesive on the abdomen next to the gauze. It works. Of course, you can use this spacing technique with most of the other tape methods. However, it can be challenging.

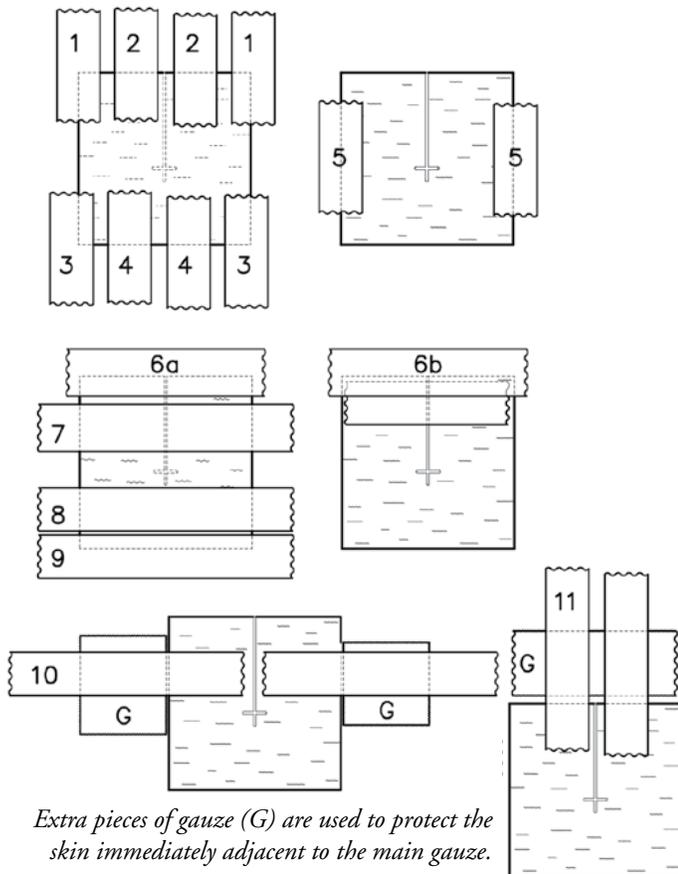
In methods 13 and 14, the two “legs” of the gauze are crossed. Where they cross, there will be two layers of gauze, making the absorption even better. Incidentally, there is not a compelling reason for the slot of the gauze to be at the top.

If methods 13, 14, 15, and 16 work for you, then there is never tape on the skin! The gauze can't fall off, but it can rotate.

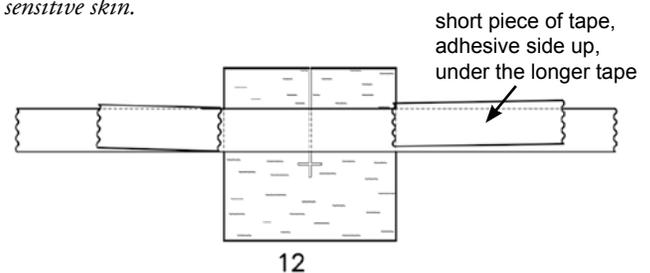
I avoid having tape immediately under the slot of the gauze because I assume it would retard drying. I figure air drying is best. If you have not tried paper tape, it may be worth a try. It works for me.

—Richard Reynolds, rgreynolds11@gmail.com

Editor's note: See pages 4–5 for some suggestions of tape (and alternatives) for sensitive skin.

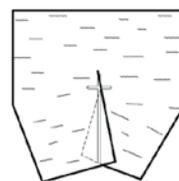


Extra pieces of gauze (G) are used to protect the skin immediately adjacent to the main gauze.

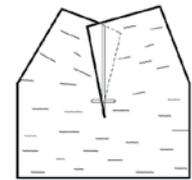


This method puts a short piece of tape, adhesive side up, under a longer piece of tape to protect the skin immediately adjacent to the gauze.

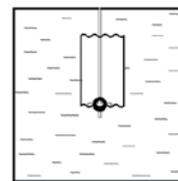
Tape never touches the skin for these methods, though the gauze may rotate. Note: tape is not shown on 13–14 for clarity. In method 15, you apply the tape along an inch of tubing or on the bolster, and overlap the tape on the gauze.



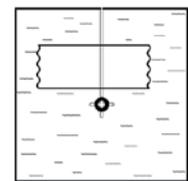
13



14



15



16

Tape for Sensitive Skin

A question to the Oley offices prompted us to turn to the Oley Facebook page and Oley-Inspire forum for feedback from members. To help the member who had called, we asked how people with sensitive skin secured tubes or catheters. The response was overwhelming. The following list is based on these suggestions. We've included a few of the comments, too, where we thought they might be helpful.

Thank you to everyone who contributed to these discussions on our Facebook and forum pages—and for those who answer others' questions daily through these platforms!

3M™ Products

For more information on the following 3M products, contact 3M Health Care Customer Helpline, (800) 228-3957, or visit www.3m.com.

- **3M™ Cavilon™ No Sting Barrier Film:** Alcohol-free hypoallergenic film forms a breathable protective coating on the skin that helps prevent medical adhesive-related injury. Available in wands, wipes, and spray.
- **3M™ Coban™ Self-Adherent Wrap:** A thin, breathable wrap that can be used to support or secure dressings or tubing. Sticks to itself without pins or adhesive. Latex-free version is available.
- **3M™ Durapore™ Surgical Tape:** Hypoallergenic, durable, non-stretch cloth tape for securing tubing and devices. Not made with natural rubber latex. Available in different widths.
- **3M™ Kind Removal Tape:** Hypoallergenic, water-resistant, silicone tape with gentle removal. Tape is light blue and comes in 1" and 2" widths.
- **3M™ Medipore™ H Soft Cloth Surgical Tape:** Hypoallergenic, water-resistant, soft, and breathable cloth tape, helps maintain skin integrity. Not made with natural rubber latex. Available in different widths.
- **3M™ Micropore™ Surgical Tape:** Hypoallergenic, breathable

paper tape for sensitive skin. Not made with natural rubber latex. Available in white and tan.

- **Nexcare™ Sensitive Skin Tape:** Hypoallergenic, water-resistant, long-term adhesive for those with fragile or sensitive skin. A mom notes, "It almost feels wet when you take it off the roll, but leaves no residue when taking off [your skin] and removes gently."
- **3M™ Tegaderm™ Transparent Film Dressing:** Dressing provides secure, waterproof, sterile barrier. Made with hypoallergenic latex-free adhesive. Available in several sizes and shapes, and in a non-sterile roll.

ConvaTec Product

For more information on the following ConvaTec product, contact ConvaTec customer service at (800) 422-8811, e-mail cic@convatec.com or visit www.convatec.com.

- **DuoDERM® dressings:** Thin, flexible **hydrocolloid*** dressings designed to reduce skin breakdown due to friction. Available in different sizes and styles. One mom suggested DuoDERM or HYPAFIX (see below) as a "long-term" or base layer for taping: "I...put down a layer of 'long term' tape then put my son's 'daily change' on top of that.... That way the tape that's coming off daily is coming off of another layer vs. his skin. When the bottom layer loosens on its own, then I remove and change. Can get about a week out of one area that way."

Smith & Nephew Products

For more information on the following Smith & Nephew products, visit www.smith-nephew.com.

- **HYPAFIX Dressing Retention Rolls:** Soft non-woven fabric with non-irritating adhesive used to secure dressings, tubes, and catheters. One mom wrote, "HYPAFIX is soft and has flexibility and works on sensitive skin." Another wrote, "HYPAFIX is a lifesaver for my daughter's skin. I use adhesive remover when changing the tape or removing. Then I wash with mild soap and rinse well with water. Next I use alcohol wipes on the skin. And allow to dry. Then I reapply the HYPAFIX. Also skin prep is great for helping irritated skin to heal."
- **IV 3000:** Transparent, low-allergy adhesive film dressing designed for easy application and removal. Available in different sizes and styles.
- **SKIN-PREP:** A liquid dressing that forms a protective film on the skin to prepare the area for adhesives and to help reduce friction during tape removal. Available in a pump spray bottle or protective barrier wipes.

Mölnlycke Healthcare Products

For more information about the following Mölnlycke products, contact customer service at (800) 882-4582 or visit www.molnlycke.com.

- **Mepitac®:** Designed for patients with fragile skin or for those who suffer from allergic reactions to traditional tapes/adhesives. Waterproof. One mom wrote, "Mepitac tape is the only one our little man can use, he's allergic to other tapes."
- **Mepore®:** Breathable, gentle, water-based self-adhesive dressing.

***hydrocolloid:** the substances in hydrocolloid dressings form a gel when they get wet (as from drainage from a wound).

Other Products

- **Comfeel® Plus Transparent Dressing:** Flexible and transparent **hydrocolloid*** dressings. For more information, contact Coloplast US Headquarters at (800) 533-0464 or visit www.coloplast.com. Coloplast also makes an adhesive removal spray; free samples available through their website.

- **Hy-Tape:** Latex-free and waterproof zinc oxide-based adhesive for delicate skin. For more information, contact customer service at (800) 248-0101 or visit www.hytape.com. One contributor wrote, "I love Hy-Tape. It has a layer of zinc oxide in the adhesive."

- **NeoBond: Hydrocolloid*** adhesive strips, developed for long-term use on sensitive skin. Not made with natural rubber latex. Available as strips and as a roll. For more information, contact Neotech Products, Inc., at (800) 966-0500 or visit www.neotechhomehealth.com.

- **Press'n Seal™:** As an alternative to tape, cut Press'n Seal to size and press onto desired area to create a secure seal. Available for purchase at most grocery stores. For more information, contact customer service at (800) 835-4523 or visit www.glad.com.

General Tips

One contributor noted that it is less expensive to buy the tape they like (Micropore paper tape) from the local medical supplier than from the pharmacy or Walmart, and there are more widths available. Another person suggested drugstore.com as offering good prices on another brand/type of tape.

Another contributor suggested, "Try using skin prep before tape. Comes in spray or pads. Make sure it dries completely before applying tape. Puts a layer between skin and tape."

A suggestion on adhesive removal sprays: "Lift a tiny corner of the tape and spray it under the tape as you peel the tape off and it eases the tape off without breaking or hurting the skin. Using Cavilon barrier wipes under tape may be an option."

And a good, final tip: "Bottom line, try all the tapes you can lay your hands on economically...and write to suppliers if it's hard to find one locally. They will often send you a free roll to try." Several of the manufacturers above offer free samples through their websites. ♣



Join Oley at A.S.P.E.N.

Oley staff will be in Austin, Texas, January 16–19 to attend Clinical Nutrition Week (CNW16), coordinated by the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.). This is a gathering of some of the most prominent clinical nutrition professionals and an important meeting for anyone in the field.

A.S.P.E.N. is offering a special rate of \$200 for Oley's consumer and caregiver members who are interested in attending. Visit www.nutritioncare.org/cnw to learn more, then contact A.S.P.E.N. at info@nutritioncare.org or (301) 587-6315 to register. If you go, be sure to come see us at the Oley booth in the exhibit hall!



#WithCoramCan

Help our son live a happy life!

Our 2 year old son, Thomas Kevin, nicknamed TKO (Technical Knock Out) for his strength, has received nutrition services from Coram since he was four months old.

TKO was born with a very rare disease, Microvillus Inclusion Disease. The night we brought him home we were overcome with worry. The Coram nurse that met us at our home provided reassurance. With Coram's services and amazing nurses at our side, we are able to help our son live a happy life.



We have met another family living with this disease through an article in Coram's consumer magazine, *Celebrate Life*, which has led to even more connections. Together we will stop at nothing to help our children.

Two parents with a happy son,
Tom & Melissa

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Feeding Tube Awareness Week, February 7–13, 2016

The Oley Foundation is once again joining Feeding Tube Awareness Foundation to celebrate Feeding Tube Awareness Week.

Why?

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

How?

- Send a photo and/or video clip of yourself to Lisa at Oley (address below—send it today!), along with a sentence or two about what tube feeding means to you, for our Feeding Tube Awareness video. We'll launch the video on You Tube and Facebook February 7!
- Order free Feeding Tube Awareness buttons to wear and share with friends and medical professionals. Request through www.oley.org or by calling or e-mailing us at Oley.
- Share your story in a press release or in your blog. How is tube feeding helping you or your child be active or grow? What do you do if/when you or your child can't eat? How do you cope with the challenges of tube feeding?
- Join us on Facebook or the Oley forum that week for daily discussions.
- Talk to your friends and family, or school or church groups. Have a frank conversation about something you find challenging, or take the opportunity for "show and tell."

We are here to support you! Contact Lisa at metzgel@mail.amc.edu, (518) 262-5079/(800) 776-6539, or The Oley Foundation, 43 New Scotland Ave, MC-28, Albany Medical Center, Albany, NY 12208.

Board Spotlight

Debbie Fox, MS, RD, LD, graduated from college with the intent to attend medical school. However, her health began to deteriorate shortly after graduation, and she began the very long and difficult journey of searching for a cause. After two years of massive weight loss and multiple mis-diagnoses, she eventually learned she had a severe motility disorder, affecting sections throughout her GI tract. Debbie underwent numerous GI surgeries and developed a deep interest in nutrition. She eventually returned to school to become a registered dietitian (RD).

Debbie has worked in the field of dietetics for almost thirty years. For the past twenty years, she has served at the 475-bed tertiary facility of Northwest Texas Healthcare System in Amarillo, Texas, in numerous roles, including critical care/trauma RD, on the nutrition support team, and, currently, in management. She has spoken at local and national conferences for the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.), local and state dietetic conferences and Oley Foundation events, and has presented various patient perspective programs for national and international nutrition providers. She has served as president of a local A.S.P.E.N. affiliate, was a nominee for Oley's Celebration of Life Award,



**Debbie Fox, MS, RD, LD,
on HPN 26 years**

Debbie [has] completed twenty-six years of continuous HPN therapy. "I celebrate every day as a gift," she says.

and currently serves on the Dietetic Internship Advisory Committees for both ARAMARK and Texas Tech.

She has greatly enjoyed the opportunities that having a "dual perspective" as patient and practitioner have afforded, including a

career in the field of nutrition, learning from other consumers/families, and having opportunities to educate other medical caregivers regarding both the challenges and successes of a home parenteral nutrition (HPN) consumer. This past February, Debbie completed twenty-six years of continuous HPN therapy. "I celebrate every day as a gift," she says.

Her areas of interest regarding nutrition support include safety issues with PN formulation/administration in the home and in acute care settings, prevention/amelioration of long-term complications of PN, and improvement in quality of life for home nutrition support patients.

Debbie and her husband will celebrate their fortieth wedding anniversary in January 2016, and although he is an engineer by occupation, her husband has done all her "home nurse care" since she first began PN. They have one son that, in Debbie's words, "keeps them young." In her spare time, she loves playing the piano and spending time with her family.

Debbie has been a supporter of Oley for many years. "I am greatly humbled and honored," she says, "to be chosen to serve on your Board of Directors!"

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The smallest and lightest pump available today.

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www.covidien.com

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Photo credit: Thinkstock ©2015 Covidien

Improved Oley Website!

Check out the new and improved Oley Foundation website at www.oley.org.



The new site will allow you to maintain your own Oley member profile.

Watch your e-mail/mail for more information.

Questions? Contact Oley at (518) 262-5079 or OleyFoundation@gmail.com

HPN Awareness Week 2015

Thank you to all who participated in HPN Awareness Week this past August. You submitted photos for the video; shared buttons and wore t-shirts with the “Alive with HPN” logo; distributed press releases to local media and posted in online media; held fund raisers and gave school presentations. Together we acknowledged the challenges, as well as the successes, of living with home parenteral nutrition (HPN), while focusing also on the normal day-to-day things that bring us all joy and satisfaction—family, friends, work, school, community, hobbies, travel, and more.

Over 1,000 people watched the “Alive with HPN” video. It’s posted at www.youtube.com/watch?v=dN4uNp8zZB8. Watch and share it, and please submit photos for the 2016 video *anytime* to Lisa at metzgel@mail.amc.edu.

Thanks to all who sponsored events and fund raisers during HPN Awareness Week. Both Baxter Healthcare and Fresenius Kabi USA invited Oley Executive Director Joan Bishop to corporate events designed to raise awareness. Joan attended, and an Oley member joined her at each. Baxter noted that its employees “were especially inspired by Elizabeth [the HPN consumer] and her attitude and outlook on life with HPN.”

Mark your calendars for next year’s HPN Awareness Week, August 7–13, 2016, and plan to join in the fun!



Celebrating HPN Awareness Week at the 2015 Oley Conference. “Alive with HPN” t-shirts still available (\$10, call 518-262-5079).



Our mission is to enhance the lives of those we care for each day.

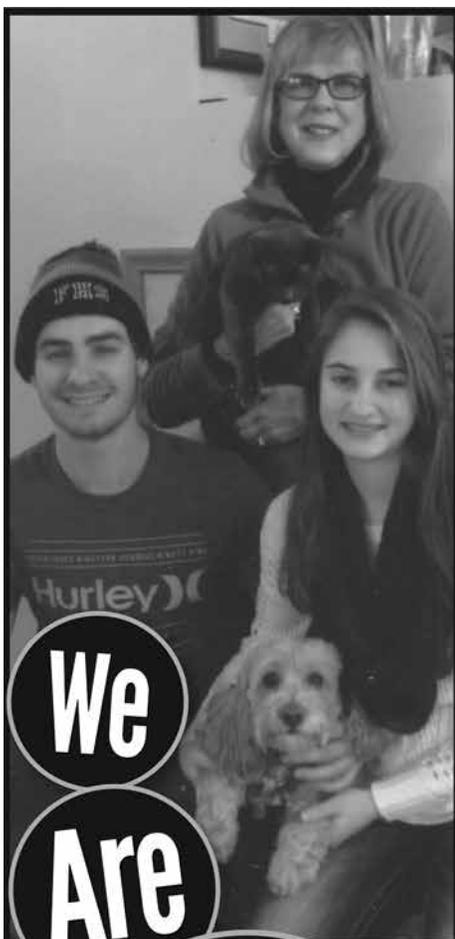
BioScrip’s home parenteral and enteral nutrition program is specially designed to fit your life in the most convenient way possible. For 30 years, we have been delivering clinical excellence in nutrition support for any age and any lifestyle. With over 70 locations nationwide and our extensive payor relationships, we can be there to provide the quality care you deserve so you can focus on living your life.

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Family**

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Nutrition and You

Food is everywhere: on the TV, in magazines, and, of course, with the people around you who eat. If you have very specific nutrition needs, meaning that you have a very specific type and number of foods that you can eat, you probably notice this more than others. If you are an adult, you have probably developed some coping skills to deal with this, and may be using them. But what if you are a kiddo? You may want to be like everyone else and eat like them too. But what if that just isn't good for your system?

Although great strides have been made over the years to liberalize the diet for short bowel syndrome (SBS), each person tolerates foods differently. It can be tough when you are raising a child with SBS. Jennifer Rath has seen both sides of this challenge, first as a child-life counselor, but now as a mom to a child who has a restrictive diet due to SBS. In the article below, Jennifer discusses food from her perspective: mom. She raises many good points to which many people (parents, but also adults with SBS) will be able to relate.

The article highlights the role of the registered dietitian nutritionist (RDN) and health care team in working with nutrition support consumers. These professionals can help assure that nutrient needs are being met—and be creative—while considering the emotional and social benefits of eating. As Jennifer suggests, maybe the oral rehydration solution (ORS) is frozen so everyone gets an icy cold treat. Or an RD can help provide a list of foods that are good for “cheating.” We should all be cognizant of foods we provide at events, from school functions to family get-togethers, to make sure everyone's needs can be accommodated.

Thanks, Jennifer, for bringing this important topic forward. The suggestions she makes may not fit you, so always remember to bring this back to your individual situation and your clinical team. Do you have questions? Talk to your health care team or send a question to the “Nutrition and You” team by e-mailing or calling the Oley Foundation (Lisa at metzgel@mail.amc.edu or 518-262-5079).



Dietary Restrictions and Kids

Jennifer Rath

Before I had children of my own, I used to work professionally with families who had children with severe dietary restrictions. A core part of my job was to teach families strategies and basic skills to help them make sure their child kept on his or her prescribed diet at home, at school, in the community, and at special events. A lot of families struggled to follow these recommendations. It wasn't until I had my first child that I came to understand how challenging this task is, both logistically and emotionally.

Austin was born at thirty-nine weeks, after a healthy pregnancy. After a week in the neonatal intensive care unit (NICU) he was diagnosed with ultra-long segment Hirschsprung's disease with 26 cm of small intestine (8 percent of his entire intestine) remaining. I could not nurse him. I could not hold him. I had no idea how to do his medical care. I was in shock.

When Austin was about seven days old, I sat alone in a waiting room as he had his first central line placed. I picked up a parenting

magazine and started thumbing through it. It was summer. There were images of children running through sprinklers, articles about sending your child off to sleep away camp, recipes for homemade popsicles and amazing Fourth of July cupcakes. It hit me like a ton of bricks: parenting Austin, with his ostomy, G-tube, central line and parenteral nutrition (PN), was going to be very different than what I had dreamed of when pregnant. It was as if everything I had imaged about being a parent was erased and I had to start from scratch. It was the start of a lot of grieving for me and also the start of some creative problem solving to ensure life was as “normal” as possible despite the medical challenges.

Food Is Everywhere

Parenting a child with short bowel syndrome (SBS) has had a lot of ups and downs. There have been enormous challenges and equally wonderful times too. In the beginning Austin had a very poor appetite and didn't want to eat. That was really hard; I just wanted him to

eat a chicken nugget like every other toddler in America! As he got older, Austin's appetite grew excessively, as did his desire for all the sweets, fruits, and drinks he wasn't allowed to have. The dietary restrictions have been tough, really tough. I now better understand why so many parents struggle to enforce dietary restrictions with their kids.

First, food is everywhere. It's part of our everyday life as well as at the heart of almost every celebration, holiday, and special event. It's woven into most traditions and celebrations across cultures. Second, it's difficult to maintain restricted diets for some members of a family when the rest don't have dietary restrictions. Lastly, food is emotional—it's how we care, love, celebrate, and socialize. Celebrating a birthday without cake, Halloween without candy, or Thanksgiving without apple pie can seem impossible. My biggest struggle was the emotional heartache that food restrictions created. In trying to figure out how to handle each challenge, I always made "quality of life" for Austin our number one priority, and that has really helped when making decisions.

Managing a Restricted Diet

Austin has severe short gut, so he cannot tolerate even small amounts of sugar, sugar substitutes, fruit, or most drinks without dumping, which can cause dehydration and behavioral meltdowns. At nine years old, Austin craves the very drinks and sugary foods that aren't good for him. In addition to Austin, I also have a six-year-old child and three-year-old twins who don't have any dietary issues. A well planned and predictable approach for how we handle food at our house is critical to keep stress and anxiety to a minimum.

While every child and family is different and a dietary plan needs to be created with direction from the medical team, here are some of the tips that have worked for us.

- **Request instructions** from the medical team and develop a plan from there. Is any amount of a restricted food permitted? A physician or dietitian may provide this information.

When in doubt, consult the medical team.

- **Obtain specific and concrete information** from the medical team about what foods are permitted and what foods aren't, using volumes or nutritional guideline information whenever possible. For example, the team might instruct, "Any food that has less than 6 grams of sugar per serving size is OK," or "Trace amounts of dairy are OK, but not a full glass of milk." Request sample food lists or menus of appropriate foods to eat.

- **Create a written "food plan"** of what foods are allowed; volume guidelines (we follow serving sizes); meal instructions (such as have beverages separate from meals); how many meals and snacks per day and at what times; how to handle special events, etc. Review the plan with the child (if appropriate) and all caregivers, including grandparents, babysitters, and nurses.

- **Keep expectations reasonable.** Some children aren't bothered by their dietary restrictions while other children struggle. Their attitudes may change over time. It's important to set your child up for success and modify the environment whenever possible to help them cope with their restrictions. Pushing too much will create stress for the whole family.

- **Be as consistent as possible** in ensuring that your child follows the medical recommendations regarding his or her diet. Making exceptions to the plan once can lead your child to expect that the rules will be broken; this can lead to disappointment, anger, frustration, and behavior issues. If the medical team or family makes changes to the dietary plan, review

them with your child at a neutral time, not at meal time or a special event. Never reward tantrums or negative behavior by giving in as this will only increase the behavior. If needed, ask a spouse to assist, leave an event or meal, or use other strategies to deal with behavior issues, rather than give in. That said, no one is perfect, so expect you're going to make an occasional mistake.



Austin at his second birthday, surprised by a treat that fits within his dietary restrictions.



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Nutrition and You, cont. pg. 10

Nutrition and You, from pg. 9

- **Inquire ahead** about what foods will be at an event whenever possible. The unexpected can create stress for everyone.

- **Have a plan** for when restricted food will be present. For example, if your child can't have sugar and there is a back-to-school ice cream social, decide if you'll skip the event, permit a small amount of ice cream (ask the medical team for direction), bring a substitute food that your child can eat, or substitute a non-food item (extra iPad time, stickers, money, etc.). Review the plan with your child prior to the event, so he or she knows what to expect.

Potluck meals can be challenging because you don't know what dishes will be available or what ingredients are in each dish. Again, a plan is important. You could bring "safe" food from home; plan to select foods with your child (and not accept foods offered by others); or arrive after people have eaten. Well-meaning friends and family may not understand or follow your child's guidelines, so supervision is important.

- **Provide positive reinforcement** in the form of praise, encouragement, and rewards when your child follows his or her diet plan.

- **Discreetly inform** people about your child's food restrictions and request they not offer your child restricted foods. For example, at birthday parties I ask the host to not offer Austin cake or ice cream. Depending on how Austin's feeling, we may leave before cake is served.

- **Develop consistent mealtime habits** to decrease mealtime distress and behavior issues at home. You may establish rules in your home such as "we don't share food," "you may only have the food you are served," or "no seconds," depending on the dietary issues. Consider keeping restricted foods out of sight such as in a bin on top of the fridge or in a locked cabinet if necessary.

- **Make mealtime at home about more than just food** (and the stresses that may be associated with that). Make it a time when the family comes together and shares about their day. Some families turn off the TV and screens, play relaxing or fun music, or play a game. In our home, we play "truth or fiction." Each person shares something about their day that actually happened and something that is made up and the rest of the family tries to guess which is which.

- **Find a balance** between the needs of the child with food restrictions and those of the rest of the family. What works for each family will vary and will change as your child ages. Siblings and family members may initially need to eat restricted foods out of view of the child with the medical condition, with the goal that eventually those foods can be eaten in front of the child. Make a decision about whether or not you will keep restricted foods in your house. Decide when the adults and siblings without food restrictions will have access to food. Austin's siblings get to have special treats such a cupcake or cookie when they are served at school or when Austin isn't present. We don't keep sugar in the house.

A medically ill child can get a lot of extra attention and siblings sometimes make a lot of sacrifices. Try to make special one-on-one time with siblings. We have "date nights" where each child gets to go out alone with a parent for the "date" of their choice, such as breakfast at McDonalds, a movie, or going to the park.

- **At restaurants, inform the hostess or waiter** ahead of time that you have a child with dietary restrictions and request that they not offer your child things they can't have. For example, if your child can't have sugar, ask that the waiter not bring the desert tray to the table. Before going to the restaurant, discuss what foods will be selected so there is a plan in place. This makes the meal more enjoyable for all.

- **Follow the stop light idea.** Younger children may benefit from having lists of foods broken down into "green foods," which they can eat all the time or in large volume; "yellow foods," which are allowed daily, but must be eaten in moderation; and "red foods," which are restricted.

- **Plan an occasional "Red Food" day,** if OK with your child's medical team. Some children can tolerate occasionally having a small amount of a normally restricted food. This must be planned in advance; you must all have very clear expectations of how much of the restricted food will be permitted; and it works best for children that are older and able to understand that it is a special occasion. Review with the medical team any instructions, such as a need for extra hydration.

- **Teach your child to read nutrition labels** to help them determine what foods they can eat and to help them take ownership of their diet.

- **Accommodate dietary restrictions** by experimenting with different foods and getting creative. We make low-sugar popsicles with oral rehydration solution that all my kids enjoy. Since Austin can't have concentrated sugar, we occasionally have a "sundae" made with whipped cream and ice cream cones or mini graham pies, with a few sprinkles on top. It's tasty and surprisingly low in sugar. For birthdays, I've made "cakes" out of corn bread mix and sugar-free vanilla pudding (see photo page 9). Connect with other families to exchange recipes and ideas.

- **Find new, non-food-related traditions** for the holidays. At Christmas, we go to a tree farm and take a tractor ride out to cut down our own Christmas tree. We also make bird feeders for the birds, sing carols, and sponsor a needy family.

- **Modify food-related holiday traditions.** For the first few years, Austin couldn't tolerate Christmas baking without a major meltdown or trying to sneak food. But now that he's older, the kids each bake and decorate one big cookie for Santa. It's a well-established tradition to bake for Santa and Austin is able to participate and enjoy it along with his brothers. We also decorate gingerbread houses but don't eat any candy. I buy candy Austin has said looks "gross" and that he wouldn't want to eat.



Austin, right, enjoying a fun, non-food related holiday tradition.

• **Discuss a plan for lunch at school** based on your child's needs. Can your child eat with other students? Do they need to eat in a separate location? (Try to avoid separating from peers if possible.) Can a reliable adult or nurse monitor the child to ensure the diet plan is followed while they sit next to their peers? Some schools have a closely monitored "allergy table" where all children with allergies sit. Find a balance that works for your child while allowing them to have social time with their classmates.

• **Educate your child's teacher and school nurse** about your child's dietary restrictions and, again, come up with a plan. I send notes home to the other parents about Austin's medical condition and requesting they not, for example, send candy home. Before an event where food may be present, we always come up with a backup plan. For example, the morning of Valentine's Day I review that if someone forgets Austin can't have candy and sends him some with his Valentine, we will exchange the candy for a quarter or extra screen time (Austin's choice). Once your child is school aged, include them, as developmentally appropriate, in planning how to handle these events.

• **Acknowledge there may be a sense of loss** if your child can't eat. Beyond the emotional challenges of raising a medically complex child, parents and children may experience grief over the inability to eat; the grief will evolve as your child ages. Not being able to eat certain foods really upsets Austin. Feeling like the "bad guy" or "food police" takes its toll on me, as his mom, emotionally.

Finding support from others dealing with similar challenges may benefit both parents and children. Support can be found through online TPN and short gut groups, specialty medical camps such as the Serious Fun network of camps for medically ill children (many offer family camp, sibling camp, and GI camp), Oley conferences, Childlife, and counseling. ¶

Reviewed by Carol Ireton-Jones, PhD, RD, LD, CNSC, FASPEN, FAND; Laura Matarese, PhD, RDN, LDN, FADA, FASPEN, CNSC; and Marion Winkler, PhD, RD, LDN, CNSC, FASPEN.



Sixty plus Oley members—nutrition support consumers, caregivers, and professionals—gathered in Kirkland, Washington, in September for an Oley Regional Conference. Many consumers said it was the first time they had ever met anyone else on home IV nutrition and/or tube feeding. One attendee said, "TPN and HEN users are very isolated in this area," then added, "Many, many thanks for putting on this regional/local session." Watch www.oley.org for dates and locations of 2016 regional meetings. Many thanks to Shire whose support makes these meetings possible.



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Welcome Oley's Two Newest Ambassadors!

Would you like to speak with someone who has “been there, done that”? Call an Oley Ambassador. For a complete list of Ambassadors, visit www.oley.org or call (518) 262-5079/(800) 776-6539. Note: Ambassadors volunteer to provide peer support for HPEN patients and family members. They are not medical professionals and do not offer medical advice.

If you are interested in becoming an Ambassador, contact Lisa Metzger at metzgel@mail.amc.edu or (518) 262-5079/(800) 776-6539.

Meet two of our newest Oley Ambassadors! Mary Wootten and Lynn Wolfson joined the Oley Foundation as Ambassadors this summer. They are among the several volunteers who came on board after attending the annual conference. (We'll be introducing more new Ambassadors in coming issues!)

Mary Wootten

Mary's daughter, Natalie, has had a feeding tube since 2009 due to failure to thrive, slow motility, and visceral hypersensitivity. They have been members of Oley since 2012.

Mary is a stay-at-home mom of three children (Natalie and two boys) and a Reiki Master Teacher. She is owner of Lotus Flower Reiki in Troy, New York. Mary studied psychology and serves as a board member for the SETH Project (“SETH” stands for Supporting Everyone That's Hurting).

Mary says she is very excited to join us as an Ambassador. “One of my goals as an Ambassador,” she writes, “is to help parents transition to life with a child that is tube fed and to bring more awareness to the support that is available. My family felt isolated for the first couple



Mary Wootten

of years that Natalie had her feeding tube, and I want to help others who may feel the same way.”

Mary lives in Troy, New York. She can be reached at (315) 529-5062 or lotusflowerreiki@gmail.com.

Lynn Wolfson

Lynn was born with Hirschsprung's disease, which has severely affected her digestive system. She has had several surgeries since she was four years old. “All of my intestines have been affected,” she writes. At this time (2015), she has an ostomy (her seventh), a gastric tube (for stomach venting), and a jejunal (J-) tube (for feeding, due to severe motility issues, difficulty breaking down foods, and malabsorption of nutrients). In addition, she has a neurogenic bladder and needs to catheterize two to three times a day.



Lynn Wolfson

Lynn was on home parenteral nutrition (HPN) for two years. However, she writes, “after two bouts with sepsis, we decided to try J-tube feedings, which have worked out very well for me.”

Lynn has a service dog named Zev, who has been professionally trained for her specific needs. Lynn writes, “Zev carries my handbag in his backpack, helps me up by bracing if I fall, helps me up and down stairs or curbs, lets me know if my ostomy is leaking, and carries things in his mouth to help me. He even holds my feeding tube backpack in his mouth when I am in a public toilet! He is with me wherever I go.”

“Zev and I do a lot of traveling together,” Lynn continues. “I lobby in Washington, D.C., for more money to be appropriated by Congress for research in digestive diseases; I am an active member of the Broward Ostomy Association and traveled to St. Louis for the national conference; I spoke before the FDA in May; and went to Boston, Massachusetts, for the Hirschsprung's Disease Conference and Saratoga Springs, New York, for the Oley Conference, in June. I also attended the Oley conference in Orlando, Florida, in 2014.”

Lynn and her husband, Eli, have two grown daughters. Lynn has several advanced degrees and has worked as both a corporate executive and as a teacher at the middle and high school levels. Currently, Lynn says she swims three to five times a week; is forming a group for ostomates who like to compete in swimming, biking and/or running; attends adult education classes and runs a book club; knits hats for cancer patients; tutors students; and serves on the board of the Central Agency of Jewish Education of Broward County. Lynn is also a great traveler! She has recently returned from a trip with her family that included Australia and Indonesia.

Lynn says, “My goal is to live my life to the fullest by being a functioning family member and contributing to my community through touching individuals I meet in a positive way so they can appreciate the gifts life has given them and contribute positively to society.”

Lynn lives in Weston, Florida. She can be reached at (954) 562-7417 or lewolf1815@aol.com.

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Representatives of PACIFHAN at ESPEN meeting in Lisbon.

New International Alliance of HPEN Consumer Groups

Joan Bishop, Oley Foundation Executive Director, and Darlene Kelly, Oley's Science and Medicine Advisor, attended a meeting of the European Society for Clinical Nutrition and Metabolism (ESPEN) in Lisbon, Portugal, this fall, where they and representatives from other nutrition support consumer groups hosted an exhibit for PACIFHAN, the newly organized Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition (pacifhan.org). This exciting new alliance will facilitate the international sharing of information and resources to improve the quality of life of home artificial nutrition (HAN, the equivalent of our term "HPEN") consumers.

PACIFHAN had its beginnings in September 2014, when representatives from five organizations (including the Oley Foundation) first met formally in Geneva, Switzerland, also in conjunction with an ESPEN meeting. Currently, the alliance includes the Oley Foundation (representing the U.S.) and groups from Australia/New Zealand (PNDU), the Czech Republic (Život bez streva), Italy (Un Filo per la Vita), Poland (Stowarzyszenie Apetyt na Życie), Sweden (Svenska HPN-Föreningen), and the United Kingdom (PINNT). In the future, it is hoped that other HAN patient organizations will join PACIFHAN, and that members will share ideas on how PACIFHAN can help HPEN consumers and suggest areas that the alliance can investigate or develop with a patient focus. Please share any of your ideas with Joan at bishopj@mail.amc.edu or (518) 262-5079.

PACIFHAN's Goals:

1. To be a trusted international reference on home artificial nutrition (HAN) from the patient's perspective;
2. To encourage the exchange of internationally peer reviewed published medical-scientific information related to HAN;
3. To assist HAN patients who wish to travel/stay abroad to seek guidance through the member association in the destination country affiliated with the international organization;
4. To organize an annual general meeting that will be attended by a representative of each member association;
5. To increase awareness of HAN;
6. To improve the quality of life of HAN patients.

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References: 1. September 2013 - August 2014 patient satisfaction data, survey of 207 EN patients and 205 PN patients.

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Holiday Stress, from pg. 2

it. When I feel let down by family or close friends, the first thing I do is acknowledge how much it hurts. Then I reflect on the many possible reasons for their behavior. Finally, I work on genuinely wishing them well. These three steps immediately lessen my emotional suffering.

As you experiment with these suggestions, treat yourself kindly. Don't blame yourself if one of them doesn't work out. Instead, give yourself credit for having had the courage to try! My heartfelt wish is that your loved-ones come to understand and accept your limitations, but that if they don't, you'll be able to accept them as they are without bitterness. ¶

Toni Bernhard is the author of the award-winning How to Be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers and How to Wake Up: A Buddhist-Inspired Guide to Navigating Joy and Sorrow. Her newest book is called How to Live Well with Chronic Pain and Illness: A Mindful Guide. Before becoming ill, she was a law professor at the University of California—Davis. Her blog, "Turning Straw Into Gold" is hosted by Psychology Today online. Visit her website at www.tonibernhard.com. Reprinted from the author's blog with the author's permission.



Ann out and about on a beautiful fall day.

Small Ways Oley Helps

Ann LaBotz

Like many with short bowel syndrome, I've experienced the need to get to a toilet immediately. Thank goodness the few times this has happened the establishment owners have realized what a panic state I'm in and have kindly let me use their private facilities. I'm sure at some point I will run into someone who needs a little more proof, so I recently ordered a Bathroom Access Card from Oley. As soon as I got it in the mail I went online and made a contribution. This organization is so important for all of us with severe digestive problems. It's the area of the body the public still can't talk about. Thanks for all you do.

Order your **FREE Bathroom Access Card** at www.oley.org or by calling (518) 262-5079/(800) 776-6539.



Medications, from pg. 1

of most liquid medications is much greater than 1000 mOsm/liter, for example, whereas the osmolarity of stomach fluids is about 280 mOsm/liter.

The presence of high osmolar liquid in the GI tract will cause a shift of fluid from surrounding tissues. The greater the difference in osmolarity, the higher the shift of fluid. This shift will feel like cramping, and the resulting extra fluids in the GI tract will contribute to diarrhea formation. This issue is so common, it is surprising how few compounders and manufacturers are aware of the consequences from the formulations they provide.

Diluting liquid medication isn't always practical. It can take up to three times the volume to dilute it adequately, and the water doesn't eliminate the sugars, such as sorbitol, which often cause diarrhea. It's easier sometimes to just add water to a pill.

Crushing Solid Medications

The next time a drug is available in both a solid and liquid formulation, ask if the solid medication can be crushed, rather than being put into a liquid form. In most cases, solid dosages can be made into suspensions with tablets mixed in water; these have small shifts in osmolarity, so there is less cramping and/or diarrhea.

Tablets are often very hard and require thorough crushing, as undissolved shards can clog small-bore feeding tubes. Crush the tablets in a round-bottom solid bowl. A mortar and pestle is ideal for this purpose. Grind to a fine powder, but avoid making dust as the ingredients in tablets are often irritating if inhaled. Add water (about 3–5 mL) and make a slurry (a semi-liquid mixture). Withdraw the contents into an oral or catheter syringe and rinse the mixing bowl to remove remainder (this should follow the dose through the tube).

For capsules of non-hazardous nature, open the back of the syringe and open the capsule; dump capsule contents into the syringe; close the syringe; and add water to the syringe. Allow a slurry to form and then administer. For hazardous medication, like chemotherapy, add the tablet/capsule intact into the back of the syringe, close the syringe, and add water. Most drugs form a slurry within twenty minutes. These methods do not work well for time-release or sublingual medications.

Rinse the feeding tube with about 5–10 mL water, administer the drug slurry, and follow with 5–10 mL plain water.

Check with your pharmacist on guides for which drugs can be administered by simple crushing and mixing with water. (The Institute for Safe Medicine Practices offers a list called "Oral Dosage Forms That Should Not Be Crushed," online at www.ismp.org/tools/donotcrush.pdf.) ¶

General recommendations on medication administration through a feeding tube can be found on the Oley website, www.oley.org (see "Tube Feeding Troubleshooting Guide" and "Some Practice Recommendations for Medication Administration," by J. Boullata, PharmD, RPh, BCNSP, LifelineLetter, Sept/Oct 2011).

Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. A complete list of the contributions received in 2015 will be published in the March/April 2016 issue. We are grateful for the following gifts received from August 15 through October 16, 2015:

In Memory of: Barbara Clark; Davria Cohen; Isabella Daley; Jeff Dutton; Imagail Gordon; Dr. Maurice Shils; Paula Southwick; Bob Sweet

In Honor of: Todd Friedman, with gratitude; the Oley Foundation

Fundraisers: Amazon Smile; Jeans Day for HPN Awareness Week

Matching Gifts: Allstate Giving Campaign; The GE Foundation

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

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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 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. Learn how you can make a difference at (800) 776-6539.

<i>Felice Austin</i>	<i>The Groeber Family</i>	<i>Rodney Okamoto, RPh,</i>
<i>Jane Balint, MD</i>	<i>Valerie Gyurko, RN</i>	<i>& Paula Okamoto</i>
<i>John Balint, MD</i>	<i>Alfred Haas</i>	<i>Kay Oldenburg</i>
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<i>Jerry Fickle</i>	<i>CNSC, FADA, FASPEN</i>	<i>Eleanor & Walter Wilson</i>
<i>Don Freeman</i>	<i>Kathleen McInnes</i>	<i>Marion & Larry Winkler</i>
<i>Linda Gold</i>	<i>Michael Medwar</i>	<i>James Wittmann</i>
<i>Linda Gravenstein</i>	<i>Meredith Nelson</i>	<i>Patty & Darrell Woods</i>
<i>Deborah Groeber</i>	<i>Nancy Nicholson</i>	<i>Rosaline Ann & William Wu</i>

LifelineLetter

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Albany, NY 12208

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Three Ways to Support Oley's Annual Appeal

- Donate at www.oley.org,
- Use the envelope inserted in this newsletter, or
- Check your mail for the letter that shares Lynda's story.

Thank you!

2015–2016 Oley Calendar

January 16–19, 2016: Oley exhibiting at Clinical Nutrition Week, Austin, TX

February 7–13, 2016: Feeding Tube Awareness Week

March 6–7, 2016: Digestive Disease National Coalition Capitol Hill Day

March 18, 2016: Deadline for Oley award nominations, HomePN Research Prize submissions, and Kyle Noble Scholarship applications

March 21–24, 2016: Oley exhibiting at National Home Infusion Association conference, New Orleans, LA

May 14–19, 2016: Oley exhibiting at Infusion Nurses Society conference, Fort Lauderdale, FL

May 18–20, 2016: Oley exhibiting at Michigan Association for Home Care conference, Acme, MI

July 5–9, 2016: Oley Annual Consumer/Clinician Conference, Newport Beach, CA

August 7–13, 2016: HPN Awareness Week

September 2016 (date TBA): Oley Regional Conference (in conjunction with AVA meeting), Orlando, FL

September 16–19, 2016: Oley exhibit at Association for Vascular Access (AVA) conference, Orlando, FL

For updates on Oley regional conferences or if you are able to help at one of the Oley exhibits listed above, please contact Cathy at harrinc@mail.amc.edu or (518) 262-5079/(800) 776-6539.

Happy Holidays

from the

Oley Foundation

Additional Meetings of Interest

December 5, 2015: National Organization for Rare Disorders SBS Patient Meeting, Atlanta, GA

February 2–7, 2016: Cleveland Clinic Digestive Disease Institute, Boca Raton, FL

May 21–24, 2016: Digestive Disease Week, San Diego, CA