

What's Inside:

Tube Talk: Mechanical Pump, No Batteries Required

Page 3

Drug Shortages: Up Close and Personal

Page 4

Slow Dance: A Poem

Page 4

In Memoriam

Page 5

Equipment-Supply Exchange

Page 5

HPN Awareness Week

Page 6

Bright Ideas: Hand Cream, Rolling Cooler

Page 6

Center of Experience

Page 7

Toll-Free Lines

Page 7

Nutrition and You: Be Prepared

Page 8

Donor Profile

Page 9

Review of Jacob Ryan: Patriot, Medical Miracle, Spy

Page 10

United Way

Page 13

Contributor News

Pages 14–15

Mailbox: Member Finds Support on Forum

Page 16

LifelineLetter

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

Art (as) Therapy

Eric Meythaler

All of us who have joined the Oley Foundation have many worldly cares as a patient, caregiver, or friend. Much is written about the need of breaks for caregivers. And patients would certainly love to escape the pains of disease and treatment. But where do we go if no one can spell us, or we are confined by a body that betrays us? This sounds like a job for art or a craft, or maybe formal art therapy.

Children and adults alike often enjoy being alone while surrounded by family, home, and familiar activity. We may want complete mental involvement while leaving behind homework and chores, and a way to retreat from the cares of the world while outwardly expressing ourselves. Again, arts or crafts can be the answer.

Focus on Process, Not Product

Many of you will remember Robin Lang, a very active, long-time Oley member. During her life, Robin was a watercolor artist who used her creative energy as her own personal art therapy. She was working on an article about art therapy for this newsletter when she died [see

sidebar page 12]. I am privileged to be able to pick up from where Robin left off writing.

Like Robin, I, too, am an artist. My medium is 16-count canvas on which I create landscapes, bird and flower studies, even portraits, using a needle and wool

yarn. This process is called longstitch. It's a form of needlepoint popular in England.

Robin says she sometimes didn't like what she'd painted. I can relate to that. I had four rather nice



Artist Gaile Lyn Beizavi shares the therapeutic effect of art by offering free lessons to "the younger generation," the elderly, and people with terminal illnesses.

Art Therapy, cont. pg. 2 ◀

Drug Administration through a Feeding Tube

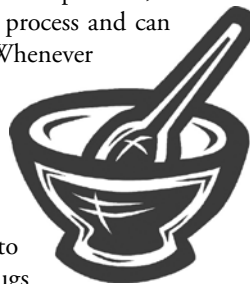
J. Boullata, PharmD, RPh, BCNSP

Administering medications through a feeding tube is more than just a daily task to perform; it is part of the entire drug-use process and can influence health outcome. Whenever possible, the methods and techniques used should be best practice as based on evidence.

According to many surveys, the techniques used to prepare and administer drugs through feeding tubes are often inappropriate. Some of the most common inappropriate techniques identified are listed in Table 1 (page 11). These increase the risk of rendering a drug less effective, or conversely more toxic, or promote clogging of the feeding tube.

Understanding Oral Medications

Oral medications, whether prescribed or purchased



Drug Administration, cont. pg. 11 ◀



A.S.P.E.N. in Orlando, January 22–23

Come help Oley at the American Society for Parenteral and Enteral Nutrition's Clinical Nutrition Week! While distributing Oley materials at our exhibit booth, you'll meet health care professionals from around the world. You'll also learn about the newest products and services available in the field of clinical nutrition as you visit other exhibitors.

We're looking for volunteers for January 22–23. Please join us! Contact Oley for details or to volunteer: (800) 776-6539 or bishopj@mail.amc.edu.

Art Therapy, from pg. 1

pieces in a local gallery's fabric art show. Even as people oohed and aahed, I would comment on all the mistakes of tautness or line. You know, it's okay to criticize your own products. But what is important is the process—dive in and just DO something creative. Enjoy the

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warm feel of clay or the delight of making bead ornaments to give away.

Try It

Robin would even take her supplies along for extended hospital stays. My yarns and tools are light. They don't take up much space and travel well, which is an advantage.

Robin's powerful statement about using art to deal with her poor physical condition rings a bell with all of us. I know when I'm working away I am concentrating so much that for a couple of hours I forget I hurt. I get to use both sides of my brain—the creative side for the picture and use of colors, and the mathematical side counting squares on both the graph paper and canvas (and hoping against hope that east will meet west when I'm done).

The absolutely hardest part, like with many adventures, is taking that first step. We're tired and just don't want to do anything. One of the recent discussions on Oley's online forum was about the connection between fatigue and autoimmune diseases. Half a dozen people chimed in that fatigue was a major component of just about all of the ailments that necessitate getting food through a tube or via IV. Many days it's hard enough for me to just get my legs shuffling across the floor and open a couple of cans of formula.

I can hear people saying, "It's not just fatigue that stops me. I don't have an artistic bone in my body." I thought the same thing for years. During thirty years as an elementary teacher, words and science were my forte. I borrowed craft ideas from colleagues and had parents in to oversee the projects.

Surprisingly, the dam was broken during an outdoor education class for teachers. We learned not to draw a leaf or flower per se, but to draw the lines and shadows and shapes we saw. When we were done, our efforts looked remarkably like what we were trying to draw. Try it. From there, it is a short step to seeing pictures in your mind and creating those. If your fingers are still frozen, though, many hobby stores and catalogues have marvelous projects and kits to put together or draw.

Liking It

So how is all of this therapeutic? What is "art therapy" anyway? For Robin and me, it means distracting the mind and getting so deeply involved—even lost—in what we are creating that the real world of pain, disability, disease, and depression disappears for a pleas-

ant stretch of time. It gives me something to look forward to even on those days when nausea and pain infuse every joint.

One of the tricks is to always have a couple different things going, so if your hands say, "No clay play today!" (I have very poetic knuckles), you can pull out a paint-by-number, or the cute felt teddy bear you are putting together for a grandchild. And guys—no excuses—you can do this just as well. A majority of famous artists have been men. Remember the fierce football lineman Rosey Grier? He was a knitter.

Longing to Longstitch

I started doing longstitch when I was recovering from cancer and radiation. (The cancer is gone, but the radiation damage is here to stay.) One can only do so many jigsaw puzzles and read so many books. I needed another low-energy but involving activity. My fabulous advocate and caregiver (also known as Gwen, my wife) brought home a kit to stitch a picture of one of our favorite sites, the San Xavier del Bac mission in Tucson.

The kit came complete with yarn and picture preprinted on canvas. I absolutely loved it and wanted more. But this form of stitchery is not big in the U.S. There are no books or magazines devoted to the hobby and precious few kits can be found in any store or U.S. Web site.

My electronic searching took me to England, where longstitch is very popular. I bought and worked some pieces from there, but with taxes and shipping, \$30 kits were costing well over \$100. Again my advocate saved the day. "Why don't you just create your own pictures?" she asked. After indulging in all the excuses I mention above, I buckled down and discovered a surprisingly good artistic ability. It's more cartoon style than trained artist, but pretty good nonetheless.

I have created landscapes, mountain scenes, a dozen different butterflies, and a series of pictures where I have hidden in the stitchery animals and plants relative to the main picture. For example, my saguaro at sunset has a roadrunner, scorpion, and other desert life hidden as part of the background stitching.

The longstitch process involves drawing a picture and deciding on colors; graphing the work onto paper with the same size squares as the canvas I will use (smaller holes equal more detail); and the actual needlework. A typical piece will consume around a hundred

Art Therapy, cont. pg. 12 ➤

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.

This edition of “Tube Talk” highlights the ingenuity of Oley member Robert “Flute” Snyder. Flute demonstrated how this pump works in the Tube Feeding Workshop at the 2011 Oley conference; it was so well received by other consumers at the workshop, we wanted to share it here. While Flute’s pump might be one of a kind, it shows how resourceful he was, and how you, too, can problem solve. (We recommend you discuss your creative solutions with your health care team before you put them to use.) We are sorry that we were unable to publish this before Flute’s untimely death. He was a frequent contributor to this column, and we’ll miss him tremendously (please see the tribute to Flute on page 5).

A Mechanical Pump: No Batteries Required

I finally photographed my pump system for the *LifelineLetter*. Starting at the far left, you see the G-tube extending from my stomach zone (arrow #1). Next comes the “Y” connector that’s standard on my type of G-tube (arrow #2). Next we see the stopcock that my wife (Ann)’s son Joel fabricated for me (arrow #3). I tried to find a 1/4” ID (internal diameter) stopcock with 1/4” double male barbed ends, but failed. They all had tiny IDs that wouldn’t work with real food. [“Double male barbed ends” refers to ends on either side of the stopcock that fit into and grip the inside of the tubing.]

Next we see a standard off-the-shelf fitting that locks and unlocks with a simple mechanism that has remained totally faithful for over three years now (arrow #4). At five to ten snappings per day, that makes a host of connections.

Next you see the black cap Joel fabricated out of aircraft-quality plastic that’s guaranteed for ten thousand years (arrow #5). I had to change from the standard cap that comes with refrigerator jars because they’d split after four thousand tightenings and loosening. This cap is forever!

As you can see, I’ve ingested most of the 34 ounces of puree and am about to shut off the stopcock, loosen the cap on the jar, squeeze the jar, form a vacuum, seal the cap again, then open the connector. The vacuum then sucks excess puree back into the jar rather than spitting it onto my slacks. After I remove the jar to the kitchen, I put 3 or 4 ounces of water in the jar, shake it around to remove the puree sticking to the jar, and ingest the thin solution through my G-tube. Then I rinse out the jar, put it aside until the next use, put a felt sock on my G-tube apparatus, tuck it into my shirt, and go on with my life.



Flute’s ingenious homemade tube feeding pump.

Oh yes, you’ll notice the blood pressure bulb at the far right, which serves as the pressure-enhancing mechanism driven by my battery-free hand (arrow #6). For your information, after squeezing the bulb several hundred times a day for almost ten years, I’ve got a grip that’ll stop a macho dude teenager in his tracks every time. [Editor’s note: By pumping the bulb, Flute injected air into the jar, which caused the puree to be pushed into the tubing and then his G-tube. He controlled the speed of the flow by injecting more or less air—with more or fewer pumps—as needed.]

You may notice, also, the tiny little white zip-ties that grip three of the connectors (arrow #7). For some reason, when the cat walks on my tubing, the connections come loose and I spray puree all over the place.

Oh yes, the tubing is 1/4” ID fuel line designed for small engines. On the package it states, “Not for medicinal use.” I figure if it’s designed for gasoline, it’ll handle a few beans, a can of tuna, and whatever else Ann tosses into my jar from the leftover shelf in the fridge.

— Robert “Flute” Snyder



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Drug Shortages: Up Close and Personal

Drug shortages and parenteral nutrition (PN) safety were in the spotlight when leaders from several organizations and home parenteral and enteral nutrition (HPEN) consumer representatives (including Oley) gathered at two major meetings in the Washington, D.C., area. The first-ever PN Safety Summit, hosted by the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) on September 23, and the public workshop on drug shortages hosted by the Food and Drug Administration (FDA) on September 26, brought clinicians, consumers, advocates, FDA and industry representatives, and legislators together to address issues of critical importance to HPEN consumers.

Safety Summit

“A.S.P.E.N.’s goal with the PN Safety Summit is to bring together all of the important stakeholders to develop recommendations to make PN the safest therapy that it can be, in order to improve patient outcomes,” said Peggi Guenter, PhD, RN, A.S.P.E.N.’s Director of Clinical Practice, Advocacy, and Research Affairs. This summit focused on recommendations in the areas of PN order prescribing, order review and verification, and compounding. We hope to summarize the

recommendations in this newsletter once they’ve been published.

Also addressed at the summit was the ongoing shortage of vitamins, electrolytes, and other IV nutrition ingredients that has critically impacted HPN consumers nationwide. There are now nineteen PN components on the American Society of Health System Pharmacists’s shortages list.

Oley Executive Director Joan Bishop represented consumer interests at the summit meeting, and came away with the sense that **there is no end to the shortages in sight**. Oley is working closely with A.S.P.E.N. to help share HPEN consumer stories with the FDA and legislators to impress upon them the seriousness of the situation, and stands behind the recommendations A.S.P.E.N. has developed to address the shortages (see below).

FDA Meeting

Critical drug shortages, of course, extend beyond PN ingredients to include other medications HPEN consumers take, such as chemotherapy drugs, antibiotics, and blood pressure medications. A recent study by the American Hospital Association found that drug shortages within a six-month period led to 69 percent of patients receiving a less effective drug and 35 percent experiencing an adverse outcome.

Oley member Davi Cohen was among the many speakers presenting information at the FDA meeting. Davi did an outstanding job sharing her own experiences with HPN product shortages, as well as stories collected from other Oley members. Individually and collectively, the impact of your personal experiences is great. Please continue to forward your experiences to Oley.

More and more frequently, patient experiences are making it into the popular press. A recent story on National Public Radio (NPR), for example, led off with the story of a teenaged HPN consumer who was affected by the shortage of calcium gluconate. As the problem becomes more well-recognized, pressure will mount for the FDA to take action.

Some of the steps A.S.P.E.N. is taking include:

- Asking the FDA to provide safe alternatives and parameters for monitoring the alternatives.
- Recommending that the FDA approve importation from global markets, including Europe and Canada, and other drug manufacturers/suppliers that meet FDA requirements.
- Facilitating communication between leaders and A.S.P.E.N. members concerning patient care-related issues.
- Developing recommendations on how to manage product shortages, and quickly get them approved and disseminated.
- Supporting current congressional legislation.
- Working with the Institute for Safe Medication Practices (ISMP) regarding safety issues and/or patient harm due to shortages.
- Encouraging A.S.P.E.N. members to report shortages.

In addition to sharing your stories with Oley, please advocate for yourselves by sharing your experiences with your representatives. We can help with sample letters. Please contact Joan Bishop at (800) 776-6539 or bishopj@mail.amc.edu.

The impact of your personal experiences is great. Please continue to forward your experiences to Oley.

Slow Dance

David L. Weatherford

Have you ever watched kids on a merry-go-round,
or listened to rain slapping the ground?
Ever followed a butterfly’s erratic flight,
or gazed at the sun fading into the night?
You better slow down, don’t dance so fast,
time is short, the music won’t last.
Do you run through each day on the fly,
when you ask “How are you?,” do you hear the reply?
When the day is done, do you lie in your bed,
with the next hundred chores running through your head?
You better slow down, don’t dance so fast,
time is short, the music won’t last.
Ever told your child, we’ll do it tomorrow,
and in your haste, not see his sorrow?
Ever lost touch, let a friendship die,
'cause you never had time to call and say hi?
You better slow down, don’t dance so fast,
time is short, the music won’t last.
When you run so fast to get somewhere,
you miss half the fun of getting there.
When you worry and hurry through your day,
it’s like an unopened gift thrown away.
Life isn’t a race, so take it slower,
hear the music before your song is over.

Our thanks to Rick Davis, past president, for suggesting we reprint this poem. Reprinted with permission of Charlie Weatherford, from www.davidweatherford.com.

In Memoriam: Robert “Flute” Snyder

Robert Snyder—known to most people as Flute, for his love of and talent with the instrument—died this August. He was a frequent contributor to the *LifelineLetter*, and was known to many Oley members for the time he spent answering tube-feeding questions on the phone or by e-mail. “He had to have been one of the best networkers in the tube-feeding community,” writes his friend and fellow Oley member Dorothy Swann.

Flute was a retired music professor who ran a small engine repair business. He was well-known for his patience and wisdom. “I had great admiration for how he conducted his life,” Dorothy writes. “Flute was a compassionate and complicated man.”

Dorothy notes, too, that Flute was very inventive. In “Tube Talk” on page 3, Flute describes the pump he used for tube feeding. We are fortunate that Flute had shared this with us previously, along with other tidbits that we will publish in future issues of the newsletter with his family’s permission. We will miss his regular contributions to the newsletter and his presence, be it on the phone, by e-mail, or at a conference.

Jane Bent, another of Flute’s friends and also an Oley member, writes, “I met Flute a little over three years ago when I read in an article in ‘Tube Talk’ that he blended his own real food. I had been blending my own real food for my G-tube for five years and had never run into another tuber doing the same thing. I e-mailed him and we became fast friends. Flute was a person who, once you met him, it seemed like you knew him for a lifetime.”

Flute’s son, Bock, notes that his father “took great pride in the relationships he assembled through the Oley Foundation. He survived, or rather flourished, ten years beyond the doctors’ expectations greatly due to his desire to help others, whether through Oley or on a daily basis through his mower repair service.”

“In all of our interactions,” says Dottie, “I see a man with endless curiosity, inventiveness, compassion, adventure, humor. It is an honor to have known him.” Jane speaks for all of us when she concludes, “Flute touched many people’s lives with his kindness, support, and suggestions. He was a man who reached out to people in all walks of life. Flute will be greatly missed by all.”



Robert “Flute” Snyder

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? No Internet access? 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.

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A Look Back at HPN Awareness Week, August 7–13, 2011

There was a flurry of activity during the first annual HPN Awareness Week, August 7–13, 2011. People were e-mailing, posting, tweeting, and “YouTubing”—and we imagine talking, phoning, and writing. Thanks to all who participated.

Each day we asked a new question on the Oley Facebook page. Here are some snippets from those entries.

We asked, “What would you like people to know about IV nutrition?”

You answered:

- “People hear IVs and then assume that you are lying flat and not living life to the fullest. [HPN, however,] does not run your life, but gives you life.”
- “That preparing TPN is a non-negotiable part of my day. I will refuse phone calls, be late or leave early, leave cleaning undone, turn down invitations and otherwise put things aside to make sure that this is done. I don’t do it to be rude.”
- “That those on HPN are super heroes—365 days of the year, with no time off for good behavior. Every daily plan has to take into account hook-up and un-hook—yet we constantly see smiling faces who make this work for them. They are not slowed down or deterred and continue life which most take for granted.”
- “I would like the world to know...Please invite us to your event. Please don’t assume that we can’t do something because of the vascular access. We can decide, for ourselves, whether or not we are going to eat, drink, swim, climb trees, etc. Please do not decide for us. It is hurtful to hear there was a party and you were not invited because people thought the event would be hard for you.”
- “That consumers have been able to thrive for many years on HPN and how beneficial it is to get connected with other consumers.”
- “That it’s time for nurses and docs to [realize] that the life span of being on PN is not 2 yrs., that getting a CLABSI [a bloodstream infection] is not routine...and just cuz I don’t eat proper food, drink alcohol, or smoke, doesn’t mean I am not capable of thought, feelings, work, and having fun.”
- “I resisted my dr’s discussion of TPN for a long time. When it became an undeniable fact that I needed nutritional support due to intestinal failure I ‘gave’ in. In my mind TPN was an ‘end-of-life’ therapy, not the ‘life saving’ therapy it really is. I gained 40 lbs. in the first two months...and felt better than I had in years. I will always need this amazing therapy and don’t feel hard done by this. I’m just thankful for a new lease on life.”

We asked, “Can you describe a positive experience you have had because of HPN?”

You answered:

- “My daughter has so much more energy when she is receiving TPN...her skin is brighter, she is happier, she has gained some weight, she isn’t dehydrated. Has made a big difference for us!”



- “Met some really amazing, compassionate people through this journey.”

- “I was able to have my son. He is now 12 years old. Thankful every day.”

- “We learned...what is most important in life and to not fret the small stuff. But overall the best thing is to have met friends and caring doctors that otherwise we would not have ever known. We have formed friendships that will last forever but also our kids have made friends. And who better to know the ups and downs we go through than those who walk the same journey.”

- “I have much more energy...I try to do things right away.”

- “Our son is alive and thriving—through Oley we have friends (family) whose lives would never have touched ours had it not been for TPN.”

Mark your calendars and put on your thinking caps for HPN Awareness Week 2012, August 5–11!

Bright Ideas

Oley consumers and caregivers often share tips at the conference that others find very helpful. These two caught our attention.

Gentle on Hands

During the Q&A portion of the presentation on hand washing, Michelle B. said that Extreme Hand Repair, by BeautiControl, has really worked well for her—no matter how many times she washes her hands each day. We found it online for \$15.00 (3.4 oz.) or call (800) 232-8841.

Rolling Cooler Makes Travel Easier

At the breakout session on traveling with HPEN, Linda G. talked about a “rolling cooler.” At 17”, this cooler can hold six 3-liter bags of parenteral nutrition or hydration—plus ice packs—and will fit in the overhead compartment of most airplanes. Six bags fit, Linda says, “like a pair of too-small jeans, and it has to”—snug means less chances of a bag breaking. About it fitting in the compartment, Linda adds, “Not the baby jets. But it is OK to gate check it on this type of aircraft since they are for short flights and not high altitudes.” (We recommend you confirm with the airline both the size allowed for carryons, and whether your solutions will be safe if checked.) Linda notes that there is a sturdy rolling cooler available at walmart.com for \$35.00.



Center of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our readers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org or call (800) 776-OLEY.

University of Virginia, Digestive Health Center of Excellence Charlottesville, Virginia

In the GI Nutrition clinic at the Digestive Health Center of Excellence at the University of Virginia Health System, registered dietitians work with referring physicians to provide specialized nutrition therapy and education for patients. The GI nutritionists specialize in evaluating and developing nutrition care plans for patients with the following conditions: malabsorption (might include persistent diarrhea, continued unintentional weight loss, or inability to gain weight, or be associated with altered anatomy from GI surgeries, such as gastrectomy, Whipple procedure, roux-en-y, gastrojejunostomy); pancreatic insufficiency; short bowel syndrome; unmanageable ostomy or stool output; and gastroparesis with severe weight loss. The GI Nutrition clinic also evaluates and develops nutrition care plans for those with supplemental or total dependence on enteral (EN) or parenteral (PN) feedings who desire a reevaluation of overall nutrition status and potential improvement on their existing plan, or a desire to wean off of tube feeding or PN.

Since the GI Nutrition clinic's inception ten years ago, the team has provided consultation to over 2000 patients with these conditions. The GI nutrition experts at the clinic are Carol Rees Parrish, MS, RD, and Nora Decher, MS, RD, CNSC. For more information about the clinic, contact Robert Fitzgerald, administrative assistant, at (434) 243-4749 or rf7r@virginia.edu, or visit their Web site, www.ginutrition.virginia.edu.

Call a Peer, Toll-Free!

Discuss your situation, explore options, and enjoy the fellowship of someone who can relate to your situation. All of this is available, free of charge, through Oley's peer-to-peer phone lines program.

The following lines will be staffed by seasoned consumers or caregivers, willing to share their experiences.

- (888) 610-3008 will be devoted to **HPN (intravenously infused nutrition)**.
- (888) 650-3290 will be devoted to **HEN (tube feeding)**.
- (877) 479-9666 will be devoted to **parents of HPEN consumers**.

We hope you'll 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.



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– Michelle Burris, Nutrition Consumer

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Nutrition and You

Be Prepared

One of the best mottos for a home parenteral or enteral nutrition (HPEN) consumer is “Be Prepared.” HPEN consumers, especially, need to be prepared for weather-related emergencies and natural disasters. Special planning in advance of an emergency will ensure your unique needs are met and you can continue your therapy uninterrupted.

What do you need to do to be prepared? Here are three easy steps completely focused around your nutrition: (1) have a plan; (2) gather emergency supplies; (3) don't panic! If you're ready with the first two steps, number three will be easy.

A Plan

A plan starts with thinking: What will you do if the electricity goes out? If clean water is not accessible? If deliveries cannot be made to your home? Also think about how you would respond in different types of emergencies (flood vs. power outage, etc.). Your plan should meet your needs for a variety of emergencies.

A plan also requires action. Develop an emergency contact list (home care provider, physician, etc.). Also, call your electric, gas, and/or water companies and tell them you have a medical condition and need to make sure your services are turned on first when power is restored. If a medical letter is required, contact your physician. A plan should also address evacuations, family communications, insurance and vital record information, medications, and supply inventory needs.

Create a health emergency card. It should include your address and phone number; your emergency contact's address and phone number; doctor's name and phone number; blood type; allergies (food and medication); special equipment needs; medication list (including dose and frequency); home care/pharmacy name and number; and any difficulties you may have related to seeing, hearing, or movement. Keeping a current copy of your nutrition prescription would also be helpful.

After you have thought about these questions and developed a plan, then you can gather emergency supplies.

Emergency Supplies

For enteral nutrition:

- Formula that: is easily accessible; does not need to be refrigerated; and is in small amounts (such as 12 oz cans). These can work with bolus, intermittent, and pump feedings, and with smaller containers you don't need to worry about storing open formula. Have a hand-operated can opener if you need one to open your formula.
- Extra bags or syringes in case you do not have a clean water supply to wash them out.
- Water for flushes: Do you have a supply of “safe” water? Bottled water will be important if the water supply is affected, or if your home has a well and the water pump is affected by a power outage.
- Pump: Keep and maintain batteries for your HEN pump. Check the expiration dates quarterly and use the oldest first.
- Flashlights: Some flashlights only have a three-month life expectancy, so check them often. Or get a good one! The small ones with focused light can be extremely useful. Additionally, battery-operated candles offer good light and ambiance!

For parenteral nutrition:

- PN solution: If you have ready-to-use PN, in a multi-chamber bag, that doesn't need refrigeration, you are set as far as refrigeration and power outages. Most of you, however, have PN that needs to be kept refrigerated. If the power goes out:
 - * Keep the refrigerator closed as much as possible to keep the cold air in.
 - * Put ice and ice packs (that you keep on hand for this and travel) in a cooler to keep your PN cool. Stick a thermometer in the cooler. The temp should be around 40 degrees F. If it starts to climb, you should not use your PN.
 - * Do not put your PN out in the snow to keep it cool. That is too cold!
- Power:
 - * Keep and maintain spare batteries for your HPN pump. Check them at least quarterly.
 - * Flashlights and battery-operated candles (see above, under enteral nutrition).
 - * Make sure you have enough light to read clearly. You don't want to use the wrong drug or syringe.
- Clean hands: Without soap and water, you may use hand sanitizer. Be extra careful with your technique.



Don't Panic

If you lose power in the winter, seek warmth as soon as possible. Don't wait. In the summer, open your windows and create a breeze if possible. If it is too hot, seek shelter where it is cool. Heat may affect your tube-feeding formula. When it is very hot, use only small portions at a time; you don't want open formula to overheat, allowing bacteria to grow.

If you lose electricity often, consider purchasing a generator. You can have it available to power only the essential services, such as your refrigerator, furnace, and certain lights and outlets. A generator can give you peace of mind if a power emergency should occur.

If you make a plan and have supplies on hand, you can be sure there will be no need to panic!

Some great resources can be found on the Internet:

www.bt.cdc.gov/preparedness
www.nahc.org/regulatory/EP_Binder.pdf
www.FEMA.gov/plan
www.ready.gov
www.fsis.usda.gov/factsheets/keeping_food_safe_during_an_emergency/index.asp

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

Donor Profile: David McGee

I have lived on home parenteral nutrition (HPN) seven days a week for almost eight years. I learned about Oley during the first nine months of adjusting, while trying to find ways to improve my quality of life. At first, it was the Oley newsletters that helped me see how others coped with this whole “deal of being hooked-up.”

Just over three years into accepting my “new normal” way of life, I was blessed with a Godly woman who wanted to marry me and live the rest of her days with me, willing to accept the job of “caregiver” added to her many other roles. After a couple of years, we—together—decided to attend the Oley conference in Tampa, Florida. This was overwhelming. We saw people who had lived on HPN for over forty years and just how keenly the Oley Foundation is committed to HPN consumers. Based on the very positive experiences we had, my wife and I decided we couldn't miss the next year's twenty-fifth conference in Saratoga Springs, New York.

Through the open e-mail access such key persons as Joan Bishop allow, I offered a couple of suggestions for breakout sessions related to ostomies. (Since I also am an ostomate and know that many other Oley members are, too, I felt this needed to be offered as part of the conference experience.) And what do you know—when we got to the conference in Saratoga we found they had listened to my suggestions! One of the co-founders of the United Ostomy Associations of America (UOAA) conducted a breakout session and the UOAA had a table of materials onhand.

Again, the resources made available to educate and equip me for managing this major segment of my life (but in a way so that it became not such a big or “defining” part of who I am), meant so much to me. The exhibit hall and the access it offered to all of the companies and organizations who support us as consumers proved to be extremely beneficial to me during this conference.

Oley is a group of people who share many things in common. Often it is simply in talking with others that you can learn tips you had never heard or thought of. Here's an example: I had always found it somewhat of a challenge to spike my HPN bag each night. Turns out, Marion Winkler, PhD, RD, CNSC, a member of the Oley Board of Directors, knew a gentleman in her hometown area who could make a device that would greatly assist in this tedious process. I contacted him and he did, in fact, custom-make the devices for me and two other HPN users I had befriended during the conference. This alone has been a magnificent side-benefit—something Oley was not directly involved in, but did make possible.

Giving Back

It was at some point during the Saratoga conference that I decided I wanted to give back and help support this organization that had done so much for me. I gave a one-time donation before leaving. But, since I do still work (part-time during each year's tax season), I knew the tax-deductible value of a larger donation. I decided I wanted to give, regularly, over the course of the year, through an automatic monthly method.

Oley was very flexible in arranging this. I was able to choose whether I wanted it done by debiting my bank account or charging to a credit card. I even got to decide the date for the withdrawal/charge each month—and they never forget, like I might be prone to do.

I highly recommend the monthly, automatic way of contributing to Oley. Once it starts, you will never “miss” that money as it's automatically and unnoticeably given each and every month. Even as little as \$5 per month = \$60 for the year. Coincidentally, this was the amount of my initial donation to Oley. But now, by spreading my smaller donations out over twelve months, I am able to give several times this amount in total. It really becomes completely “painless” and does help Oley continue to be involved in making a positive difference in so many people's lives! Please consider giving to the Oley Foundation.

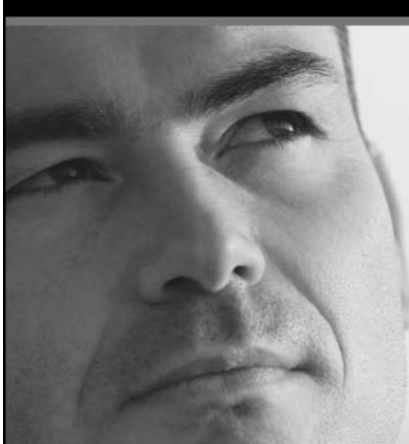
David and his wife Ceil find the monthly, automated withdrawals an easy way to donate to the Oley Foundation.



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My PN Support Program

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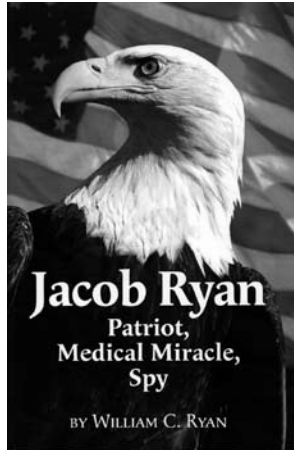
Book Recounts True Story of Tube Feeding Hero

Jacob Ryan: Patriot, Medical Miracle, Spy, by Bill Ryan, is the remarkable true story of Jake's journey from what promised to be a life of high-flying adventure as a navy combat pilot to the secret world of the CIA after spending almost six years in military and veterans hospitals, where he was often described as a gastric cripple. Home nutrition support consumers and their caregivers will be able to identify with Jacob Ryan.

Working with pioneering doctors at the Albany Medical Center, including Oley's co-founder, Dr. Lyn Howard, Jake survives to begin a new career as one of the first tube-fed patients ever to convince the U.S. government to let him serve his country as a senior intelligence officer. Jake's ability to function so well while juggling a rigid tube-feeding regimen at home and while traveling overseas on active duty makes for great reading.

Author Bill Ryan maintains, "This is a story that will make you proud to be an American."

Jacob Ryan: Patriot, Medical Miracle, Spy is available as a paperback through Amazon (238 pages; \$15.95) or as a Kindle e-book (\$9.99).



A Review

Mary Patnode, Oley President

What promises to be a story of catastrophic health problems, medical challenges, survival, and systemic roadblocks turns out to be all that and more. Jacob Ryan (a pseudonym) is truly remarkable in his determination, stamina, and personal strength. He had always brought those qualities to his life goals and he brought those same attributes to his sudden illness. His story is inspiring, intriguing, and hopeful, but never simple or easy.

Even more than the medical challenges, I was impressed with the power of love and support from family and friends that fills each chapter in Jacob's journey. Written by his father, this true story is more than a medical journal. This tribute to Jacob is also the love story of a family and a story of the strength of their faith in the face of sudden and catastrophic illness.

While some of the specifics of Jacob's story may be unique, in the end it is a story of survival, faith, and courage that many readers will find inspiring and with which they will be able to identify.

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Drug Administration, from pg. 1

over-the-counter, are made to be taken by mouth. The physical and chemical properties of each drug are carefully considered and accounted for when the dosage forms (either solid, like tablets and capsules, or liquid, like solutions or suspensions) are designed and evaluated. A specific dosage form is chosen to ensure that the active drug ingredients are absorbed.

The manufacturers and the Food and Drug Administration (FDA) rarely investigate or approve a drug to be administered specifically through a feeding tube. This means any change to the construction of a dosage form (for example, crushing a tablet) or diluting its contents in food or fluids will alter the design as intended by the manufacturer and approved by the FDA. It will affect how the drug is released. Yet in order to administer these oral medications through a feeding tube, it is necessary to alter their form. It is important that you consider how your medications are designed (liquid or solid; immediate-release, modified-release, or extended-release) in order to understand how they can best be administered.

Dosage forms contain the active drug molecules along with several other ingredients that determine how the drug will be absorbed. Solid dosage forms (tablets or capsules) can allow the drug to be released immediately after it dissolves in the stomach (i.e., “immediate-release”) or allow the drug release to be modified (i.e., “delayed-” or “extended-release”). Liquid dosage forms are usually immediate-release.

Modifying Dosage Forms: How, When, and Why

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) recently published *Enteral Nutrition Practice Recommendations*, which includes a section on medication administration. This was followed by a “Medication Safety Alert” issued by the Institute for Safe Medication Practices (ISMP) for preventing errors when administering drugs through a feeding tube. The major recommendations are provided in Table 2 (on right). A brief explanation of the rationale behind the recommendations follows.

Do not add medications to the enteral nutrition formula. A medication should only be added to an enteral nutrition formula if there is adequate data on the compatibility of the mixture and the stability of each component. Such data would assure that the drug (and nutrients) is still absorbed as expected.

Use only immediate-release dosage forms. Enteric-coated tablets or capsule contents are considered a modified-release product. If these are compromised by crushing, the drug will be susceptible to destruction by stomach acid before it has the chance to be absorbed. Also, the enteric coating can get sticky when combined with water, the tablet may not fully disintegrate, or the product may form clumps, all of which can result in tube obstruction.

Extended- (aka sustained-) release tablets or capsules are intended to deliver a large dose slowly over many hours. Crushing these will make a potentially toxic dose available all at once.

Other drugs can pose a risk to the care provider if crushed in an open vessel. Place these medications inside a syringe

and dissolve prior to administration. Use caution when mixing to avoid breathing the dust and skin exposure.

[Editor’s note: See the “Do Not Crush” list from the Institute for Safe Medication Practices (Web site is listed below) and discuss with pharmacist and/or health care provider as necessary.]

Administer each medication separately. Each drug appropriate for administration through the tube should be administered separately to reduce the chance of tube clogging and drug interaction. There is a greater potential for drugs to interact with each other when pulverized into a powder and/or mixed in a fluid.

Dilute the medication before administration. This is very important, especially if the liquid is a suspension. Diluting powdered or liquid medication with water improves the chances of drug delivery to the end of the tube. Dilution of liquid medication with water can also reduce the risk for gastrointestinal discomfort, particularly for tubes into the duodenum or jejunum. Solubilizers and other ingredients can irritate the gut and cause fluid secretion and/or cramping

Flush the feeding tube before and after each medication. Flushing between medications also limits the potential for interaction and tube clogging. The volume of water should be at least 30 mL unless instructed otherwise.

It is important to administer medications the same way every time and to space the interval from eating consistently to avoid the influence of food on the drug’s absorption.

Use oral/enteral syringes to measure, prepare, and administer medications. Use of syringes and tubing intended for IV injection opens the

Drug Administration, cont. pg. 13

Table 1. Common Errors in Medication Preparation and Administration

- Not flushing the tube before administering the medication
- Administering multiple medications mixed together
- Not flushing the tube between each medication
- Crushing modified-release tablets
- Not diluting liquid medication before administration

Table 2. Some Practice Recommendations for Medication Administration

- Do not add medications to the enteral nutrition formula
- Use only immediate-release dosage forms
- Administer each medication separately
- Dilute the medication before administration
- Flush the feeding tube before and after each medication
- Use oral/enteral syringes to measure/prepare/administer medications
- Consult with a pharmacist

Additional resources:

Oral Dosage Forms That Should Not Be Crushed (“Do Not Crush” list):

www.ismp.org/Tools/DoNotCrush.pdf

A.S.P.E.N.’s Practice Recommendations:

nutritioncare.org/Professional_Resources/Guidelines_and_Standards/Guidelines/2009_ENPR_-_Section_VII_Medication_Administration/

FDA Dissolution Methods:

www.accessdata.fda.gov/scripts/cder/dissolution/dsp_SearchDissolution.cfm?nr=y

Art Therapy, from pg. 2

hours from start to finish. What I do is not fine art, but it is much more than craft. I've had two gallery showings so far, with lots of compliments, but no buyers.

A Release

When I read the journal entries and discussion on the Oley forum or in the newsletter, several things stand out. None of us is a one-ailment/one-problem patient. Stress, family issues, and depression are constant companions. The mental and social aspects of tube or IV feeding are powerful enough, then add on everything else and our lives can be overwhelming.

Oley is and will remain a marvelous source of support and caring, a place to vent and get answers. But how else can we deal with all these feelings? How do we get them out so they don't eat holes in us both mentally

and physically? Arts, crafts, or a more organized formal art therapy can help. As you are creating your work, you get the joy of the tactile and kinesthetic aspect, as well as touching a hidden creative part.

Have you ever gardened? The peace of mind of simply feeling the soil is astounding. Remember the pottery scene in the movie *Ghost*? If that's not a release of feelings, nothing is.

Formal Art Therapy

Kaye Shaddock is an art therapist in the Chicago area who has her master's degree in this form of helping people cope. I was lucky to have her answer my questions about art therapy via an interview through our computers. She is personally a fiber artist who "dabbles in painting." Her training, like all art therapy professionals, includes art therapy theory and practice, counseling and psychotherapy skills, and dealing with the dynamics and varieties of family and cultural issues.

Art therapy uses visual arts—as opposed to music or writing—as a conduit. The American Art Therapy Association has as a primary goal "to improve emotional well-being." A recent newsletter from the Mayo Clinic reports that their art therapy studies have also shown a marked reduction in physical pain for the clients. Although art therapy addresses both physical and mental concerns, however, the main focus is on the thoughts and emotions of the client.

The art itself is not the main thrust of an art therapy program. It is the means to an end. Clients choose their own art form—be it painting, sculpture, or found-item collages. What the client creates is completely up to that individual. Indeed, what you create is generally considered a direct expression of how you are feeling inside. It may be slashes of red and black marker if anger is welling up, or a serene place where you would like to be in your head.

This is where the therapist earns her keep. Her job now is to have you explain and analyze your art and describe the emotions expressed in it. You are taking your inner world and creating a physical outward expression of it. Not only is this cathartic, but it allows you and the therapist to then deal with the emotional issues of your situation. As nutrition support consumers, we have our fair share of those emotions.

When I first had my PEG I was struck by how much of our family and social lives revolve around food. Holiday gatherings, parties, playing cards at a friend's house...they all involve the kitchen or a restaurant. Eating with a plastic plunger or bag and dripline certainly sets us apart. As Kaye so eloquently stated, "People who are tube [or IV] fed can process the loss

Art Therapy

Robin Lang

As a child, do you recall drawing, coloring, and painting as fun activities? Many people do. As we grow older we become involved in other things and leave behind that "kid's stuff." Art therapy is a mental health profession that uses the creative process of art-making to improve the physical, mental, and emotional well-being of people of all ages.

Art therapy dates back to the mid 1940s, and about a decade later it became a recognized profession. Art therapy integrates the fields of visual art, such as drawing, painting and sculpture, and the creative art process with counseling and psychotherapy. Art therapy is helpful to people at any stage of life. It treats anxiety, depression, and other mental or emotional problems. People with social and emotional problems related to disabilities and illness, and those who've suffered trauma and loss, find art therapy to be beneficial. Art therapy programs can be found in many settings—hospitals, clinics, wellness centers, educational institutions, businesses, and private practice.

Me and Art

"Beauty is in the eyes of the beholder." I know this to be true, however, as a watercolor artist, oftentimes I do not like what I behold. It takes great concentration to enjoy the experience of painting and turn the critic's voice "off" in my head.

Sometimes I'm too tired to do house chores, but I am able to paint. When I've been hospitalized for long periods, I've asked my sister to bring art supplies from home. She brought them and a new tablet of paper from my nephew. I painted away anger, frustration, loneliness, and scary things that kept me awake at night. I gave paintings to other patients. They liked them, which made me feel good. I feel peaceful after painting—no longer like a caged animal. It's great therapy.

Get Involved

Whether you're painting or you choose another medium, try something creative. The benefits are immeasurable. For more information about getting involved with arts, crafts, classes, and the like, check with your adult education centers, after-school programs, and local library. Many offer very reasonable classes on all kinds of activities.



This watercolor of pears was photographed during an exhibit of Robin's works (the bit of glare on the left side is from light reflected off the glass).

that they experience by no longer eating by mouth...they can learn to reframe their situation, through art, gathering a deeper understanding of the feelings that are behind this loss. Like any emotion, gaining greater insight is so helpful in understanding and moving forward.”

Art therapists are most commonly found in private practice or in hospital and clinic settings. Sessions are invariably less expensive than the classic fifty-minute hour spent with a psychologist. What's better is that art therapy is a lot more fun.

As much as my longstitch is therapeutic to me, it is not true art therapy. I might idly think about my art and why I do the pictures I do, but I don't have a guide, a person trained to help me sort out how the art and associated emotions relate to my diseases and having a PEG tube. Like Kaye says, if you “are looking for more insight/help from an outside party,” you need a trained art therapist. But whatever direction you choose, a creative outlet is another possible and important way to deal with our lot in life. ♣

Drug Administration, from pg. 11

possibility that a feeding-tube drug or nutrition be given by mistake as an injection.

Consult with a pharmacist. Your pharmacist should be able to tell you of possible drug interactions.

As with all guidelines, there are exceptions. Proton pump inhibitors (PPIs), for example, are enteric-coated, but are sometimes administered through feeding tubes (this should be done with extreme caution in preparation and administration). Some dissolve better than others. (In April, the FDA issued a notice that they had received reports of clogged tubes with the use of delayed-release oral lansoprazole tablets manufactured by Teva Pharmaceuticals.) In some cases, the guidelines are issued because of the potential for problems. There are some medications, for example, that can be safely combined, such as immediate-release multi-vitamin products.

The preparation and administration of medications through a feeding tube using these recommendations, however, will help assure appropriate drug use and limit the chances of unwanted outcomes. ♣

Designate Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this by designating the Oley Foundation on your United Way campaign pledge card.

Questions? Please contact Roslyn Dahl or Joan Bishop at the Oley office by calling 800-776-OLEY, or emailing dahlr@mail.amc.edu or bishopj@mail.amc.edu.

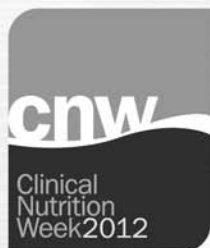


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American Society for Parenteral
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Notable Gifts from Individuals

Among the many contributions from individuals received at any given time, there are always several dedicated to those who have inspired the donor. We will share this list of honorees in each issue of the newsletter. In addition, we will include a complete list of the contributions received in 2011 in the Jan/Feb 2012 issue. Between August 6 and September 27, 2011, gifts were received:

In Honor of

Rick Davis's five years as Oley President

In Memory of

Ann DeBarbieri, Irmagail Gordon, and Matt VanBrunt

For:

Conference Travel Grant

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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!

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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 continued interest and strong commitment.

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

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LifelineLetter

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Lifeline Mailbox

Oley Member Grateful for Support from Online Forum

There should be a quota for bad breaks in life, a variation on spreading the wealth. But only in dime-novels and Sunday morning cartoons from the 1950s will you find life presented as a fair deal, where the good guys always win in the end. Real life is sloppy, unfair, filled with hard knocks, and it takes a lot of chutzpah to keep dancing.

The slap in the face is that just because your life has been woefully complicated by an often debilitating, chronic state of ill-health, it doesn't mean that you are suddenly exempt from developing other equally difficult, interlacing ailments, like wheels within wheels. Fair has nothing to do with it. Those of us with short bowel syndrome, or any of its many prodigies, are more familiar with diarrhea, dehydration, nausea, and the challenges of nutritional compromises than anyone has a right to be.

In many ways, I have been tested as I could never have anticipated over the past few years, with a myriad of life-altering circumstances that rocked my world for quite a while. I was at an all-time low, buried beneath the weight of sorrow-upon-sorrow. No doubt some of you could echo those words with accounts of your own. Feeling not up to the fight, you have met your Goliath...your Cyclops, and you haven't the grit or strength of purpose to fight one more round.

When sorrow and the weight of being overwhelmed takes up residency in your life, it is our kneejerk response to want to crawl under the covers and never come out, or worse. Living alone, without

the support of family or friends to speak of, magnifies difficulties exponentially. Mounting health and personal problems can take on a life of their own.

So what are we to do when we are besieged with problems that sweep over us with the force of a nor'easter—beyond hunkering into a fetal position and rocking back and forth or shaking an angry fist at God? The [Oley] Inspire Web site was my Moirai, where people pulled up alongside me, bathed me with kindness and empathy, then armed me with tools to shake off the dust, dry the tears, and become a strong advocate. It was when action displaced fear that I found the five smooth stones to combat my Goliath. Sure, it's hard, but the fog dissipates and clarity is restored and, by the grace of God and the help of others, we are given the opportunity to pass it forward.

There are those who I would like to thank personally for their tremendous help and friendship, but in doing so I would undoubtedly omit someone. So, instead, I trust you will each accept my heartfelt gratitude for your investment in my life. I couldn't have done it without you.

—Judi Smith, Regional Coordinator
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