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LifelineLetter

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

Helping Kids Cope with Illness and Hospitalization

Courtney Hillyard, BS, CCLS

Having a child who is frequently in and out of the hospital is extremely stressful—not only for the patient, but for the entire family. As a child life specialist, I work in the hospital setting to help reduce this stress and provide families with more positive ways of coping with their emotionally intense circumstances. I partner with patients, families, and hospital staff to advocate for the sick child, helping to serve his or her best interests through play, education, and support.

I recognize, too, that even when patients and families are not in the hospital there are challenges at home related to the child's specialized care, such as medications, tube feedings, catheter care, and other complex tasks. Listed below are developmental considerations for different age groups, as well as some distraction and relaxation strategies you may find helpful when your child is hospitalized or not feeling well.

Infants/Toddlers (0-3 years)

Developmental Considerations

- Try to maintain the child's normal routine as much as possible.



With permission of Albany Medical Center

- Provide tactile and other sensory stimulation. Examples include rocking, holding, speaking and singing to, and playing with the child.
- Have only one toy or activity available at a time to prevent overstimulation.
- Infants like to put objects in their mouths, so make sure toys are safe and clean.
- Human contact is most important. Toys can be a secondary source of stimulation.

Helping Kids Cope, cont. pg. 2

You Can't Beat the Experience!

Don't miss the 26th Annual Oley Consumer/Clinician Conference, to be held July 5-9, 2011, in Bloomington, MN. You'll learn from clinicians and consumers who have 20+, 30+ even 40+ years experience with HPEN!



As one former attendee attests, "Talking face to face with other families and health care specialists at these meetings has proven invaluable. We learned tips that made an immediate and lasting difference in my health and quality of life."

Fun for the Whole Family!

Join us next summer, and discover the difference an Oley conference can make in your life.



Clouds and Their Silver Linings

Norman Benway

Several years ago I had been diagnosed with an esophageal motility disorder where I could not eat or swallow. A PEG tube was placed and that became my source of nutrition.

At that time, and at 92 pounds, I met Marcia, a dietitian, who taught me how to use the PEG tube to become healthy and strong again. After two years, my weight increased to 117 pounds. But I began having bleeding problems that would not stop. I could no longer tolerate tube feedings. I went from eight plus cans of formula a day to maybe one. My weight dropped.

A Hospital Visit

One day at work I had several episodes of bleeding and I called my GI doctor. The doctor tried to



Norman Benway

Silver Linings, cont. pg. 14

Helping Kids Cope, from pg. 1

- Designate space for treatments and medications—somewhere other than the child's bed or play space, so that those areas remain "safe."

LifelineLetter

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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.

Distraction/Relaxation Strategies

- Swaddle infant in a blanket.
- Use soothing touch or infant massage.
- Utilize a comfort item, such as pacifier, stuffed animal, or blanket.
- Play soothing music or sing quietly.
- Look at pop-up books together.
- Use rattles or teethingers.

Preschoolers (3–5 years)

Developmental Considerations

- It is difficult for children at this age to differentiate between reality and fantasy. The child may blame herself for becoming sick or may think being in the hospital is punishment for bad behavior. The child may also blame family members for causing the illness or injury.
- Child may exhibit behavior changes or regress to earlier childhood behaviors, such as sucking thumb, clinging, tantrums, withdrawal, wetting the bed, or requesting a pacifier.
- Try to maintain a normal routine as much as possible.
- Provide activities and games that will use fine motor skills as well as gross motor skills.
- Provide constant verbal support and encouragement to show the child you are there for her.
- A sticker chart or reward system may help increase compliance with medications with this age group.
- Play medical kits are beneficial to help the child better understand the equipment she will commonly see at home, a doctor's office, and/or during hospitalization.

Distraction/Relaxation Strategies

- Utilize comfort item, such as a stuffed animal or blanket.
- Use soothing touch or massage.
- If child must be restrained, do so in a comforting way, i.e. hug hold.
- Watching cartoons or a movie.
- Listening to music, singing.
- Bubbles.
- I Spy, lift-the-flap, or push-button books.
- Kaleidoscope, glitter wand, etc.

School-Age (6–11 years)

Developmental Considerations

- At this age, a child may resent the loss of control, autonomy, and competence that come with hospitalization or illness.

- May interpret medical procedures as punishment for past mistakes or bad deeds.
- Loss of contact with peer group will be difficult. This may result in feelings of anger, frustration, or resentment, or sadness, or feeling left out.
- Important school routines may be interrupted.
- Prepare and educate child regarding diagnosis and/or treatment plan to reduce feelings associated with the fear of the unknown.
- Provide choices and control when possible.

Distraction/Relaxation Strategies

- Use soothing touch or massage.
- Use comfort positioning versus restraining.
- Bubbles, books, interactive toys.
- Stress ball, play dough, clay to squeeze.
- Music, movie, video game.
- Deep breathing (have child pretend he is blowing out candles on a birthday cake).
- Guided imagery—have the child imagine a place he would rather be.

Adolescents (12 years and up)

Developmental Considerations

- Self-esteem, independence, and body image may be negatively impacted.
- Loss of control and privacy are hard for this age group.
- Adolescents struggle with dependence vs. independence issues.
- Hospitalization or illness may require an adjustment to separation from peer group and lack of emotional support.
- Very aware of physical changes due to illness or injury. The adolescent is frequently self-conscious about her tubes, an ostomy, and/or surgery scars.
- Changes in behavior may occur. Withdrawal, isolation, anger, aggression, low frustration/tolerance threshold, lethargy, and difficulty with authority are common.
- Encourage teens to ask questions and be involved in their care.
- Educate them about noncompliance and the negative impact it can have on their future.

Distraction/Relaxation Strategies

- Use soothing touch or massage.
- Music, movie, video game.
- Deep breathing (have child breathe in through her nose and out through her mouth).

Helping Kids Cope, cont. pg. 13 ➤

Tube Talk

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



The Tube Feeding Emergency Kit

Susan Agrawal

Imagine having fifteen minutes to evacuate before a natural disaster strikes. Or imagine rushing your bleeding child to the Emergency Department of a local community hospital completely unfamiliar with tube-feeding. Having an emergency kit full of tube-feeding supplies can make these situations much easier and less stressful for you and your child.

We actually have two emergency kits. One is the day-to-day kit that we take along with us wherever we go. It simply contains a 60 mL Monoject™ syringe (that fits into a MicKey button), an extension set, and a roll of tape. You can handle most basic emergencies with this kit.

The larger emergency kit sits atop a cabinet right next to the front door. It is packed and ready to go whenever we need it. We bring it on long trips and hospital visits. Fortunately, we have never had to evacuate!

The contents of the kit include:

- 1 extension set
- 1 extra G button (a used one is fine as long as the balloon is intact)
- Stoma care supplies: gauze, Q-tips®, tape, and some triamcinolone cream
- An NG tube or foley catheter to hold the stoma open if the button falls out
- A day's worth of medications...the ones in pill form, at least
- 1 60 mL Monoject syringe for feeding or venting
- 2 smaller Monoject syringes that fit into the button for button problems or medications
- 1 pump feeding bag
- 2 cans of formula
- 1 bottle with cap for mixing and storing extra formula
- 2 single-serving packages of baby cereal for on-the-go feeding
- 1 washcloth
- 1 change of clothing
- 4 diapers
- A package of travel wipes
- Personal care supplies like a toothbrush, hairbrush, ponytail holder, etc.
- Basic care instructions, including a list of medications, feeding schedule, phone numbers for doctors and other medical professionals, emergency medical forms, and any other pertinent information
- A list of items to grab that cannot be kept in the bag...ours includes refrigerated and liquid medications, the feeding pump, and a favorite stuffed animal

All of these items fit in a small diaper bag that can be thrown over the shoulder as you are running out the door. Your items may be different, of course, but this list should get you started on creating your own kit. Give yourself peace of mind by packing yours today!

Reprinted with permission from Complex Child E-Magazine (www.complexchild.org)

Editor's note: Those who know Susan may realize Susan's daughters' health needs have changed since this article was written. When I requested permission to use the article, Susan replied, "Of course!... Though our Go Bag has just about quadrupled in size, because now we have enteral, infusion, urological, and respiratory stuff in there." Susan's experience is a reminder to update your emergency kit periodically, or as needed. To help you in this effort you might try Oley's Travel and Hospitalization Packet online at www.oley.org.

Custom Enteral Backpack

Portable enteral and infusion pumps are a blessing for home parenteral and enteral nutrition (HPEN) patients. They allow us to participate in normal activities while infusing. But as an active twenty-three year old on continuous J-tube feedings, I was frustrated with the lack of options and high cost of backpacks from the pump manufacturers. I wanted to find something more fashionable for daily use.

I went on the popular Web site etsy.com and contacted the seller "Retrofied," who makes cloth bags. Though she was previously unaware of portable pumps and tube feed-



Photos by Retrofied



ings, she and I worked together to design a small backpack that is both stylish and functional.

There is a hook sewn in the top of the backpack to hang the bag of formula and loop of excess tubing, the pump rests on the bottom of the bag, and there are two additional pockets sewn inside that I use for other supplies, as well as personal items like my wallet, keys, etc. A small opening

was also sewn into the lower side of the bag for the tubing to exit. I can then connect it discreetly under my shirt to my J-tube.

I ultimately purchased two bags in different fabrics of my choice. I receive complements on them daily from people unaware they are bags used for tube feeding.

—Emily Convery
emmers42@gmail.com

Oley Southwest Regional Conference

Felice Austin

On a sunny Southern California day, about eighty Oley Foundation members met in the beautiful new Ronald Reagan Medical Center at UCLA for a day of friendship, information gathering, crafting, and fun. Laurie Reyen, RN, MN, served as the moderator and major facilitator for the meeting.

In the A.M.

The first speaker of the morning, Marvin Ament, MD, from UCLA, discussed where we started, where we have been, and where we are going with parenteral nutrition (PN). Doug Farmer, MD, also from UCLA, followed with a discussion of intestinal failure centers and transplants. Khiet Ngo, DO, from Sacred Heart Children's Hospital, discussed quality of life for parenteral and enteral consumers, which coordinates and corresponds with the PN quality of life survey that Oley has posted on the Web site.

During the morning session, the twenty children who attended were entertained by volunteers from the Painted Turtle Camp. As soon as you saw the colorful quilts that represent the welcoming spirit of Painted Turtle, you knew the children would be well cared for. They were entertained with games, arts, crafts, and stories. During the day, they made stuffed animals, and at lunch they were entertained by Pun the magician.

In the P.M.

Everyone stopped at noon for a fleeting respite and delicious boxed lunches. Many people made new friends. For some, it was their first time at an Oley conference and their delight at finally meeting other people who lived lives similar to theirs was emotional to witness. Before you could catch your breath the afternoon sessions began.

In the afternoon, conference attendees selected different round table discussions. Some listened to questions and answers about medical insurance from Jody Strain, a home healthcare reimbursement specialist. It was a very pertinent topic in this day of changing healthcare. Jorge Vargas, MD, addressed a large crowd during his session on enteral feeding, while Marianne Opilla, RN, CNSC, gave an inspired set of sessions on catheter care and introduced some new products (see "Bright Ideas: Keep Caps Clean" on right). Lily Wu, RD, CNSD, presented sessions on diet and short bowel syndrome. Lorraine Shimahara, PharmD, answered the questions everyone wanted to ask a pharmacist, and the UCLA social worker, Kanela Artavia, MSW, presented sessions for young adults on transitioning to independence and later a session for caregivers and parents. People were reluctant to leave these round table sessions because they were getting so much information.

Many Thanks for the Support

The support from the UCLA staff and hospital was invaluable. The group felt like it would be a great benefit if this mini conference could be held annually.

Our thanks to the conference sponsors: Abbott Nutrition, trick or treat bags; Big Dog Impressions, childcare activities; BioScrip Infusion Services, childcare/transition session for young adults and speaker support; Brooks Healthcare, breakfast buffet;

Coram Specialty Infusion Services, speaker support; CSL Behring, LLD, general conference support; Emmaus Medical, boxed lunches; Johnny's Animal, childcare activities; Nutrishare, gift cards and speaker support; The Painted Turtle, childcare activities; Ronald Reagan UCLA Medical Center, speaker support; and Sacred Heart Children's Hospital, speaker support.

Our thanks, too, to the many volunteers who helped make this program successful.



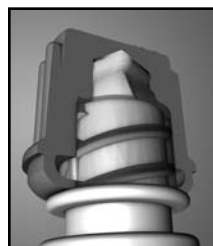
Kids enjoyed the conference too!

Bright Ideas: Keep Caps Clean

"I use SwabCap™ and I LOVE them! They protect the hub of my daughter's catheter from ostomy leaks, G-J tube leaks, and the general yuckiness that may occur from being a kid. I still scrub the end of the line with alcohol as per my usual standards, however it is comforting to know that the hub has been sitting in alcohol if someone else has to access the line."

—Jodee Reid, jodee1@zoominternet.net

Marianne Opilla, RN, CNSC, discussed the benefits of the SwabCap and two other products—Curos® Port Protector and Site-Scrub™—at the Oley Southwest Regional Conference. Excelsior Medical describes the SwabCap as "a simple twist-on device that disinfects swab-able luer access valves prior to catheter line access. The FDA-cleared device passively disinfects the valve top and threads while providing a physical barrier to contamination for up to 96 hours" (www.excelsiormedical.com; 800-487-4276).



SwabCap™

The Curos Port Protector is similar to the SwabCap. It is described by the manufacturer (Ivera Medical Corp.) as "a simple... disposable medical device that guards against infection by keeping luer-activated access ports always protected and clean....Simply peel off the seal and twist Curos® Port Protector disinfection cap over the top of a luer-activated access port. Inside this...port protector is a 70% IPA (isopropyl alcohol) saturated sponge-like foam" (www.iveramed.com, 888-861-8228).

The third product, Site-Scrub, is described by Bard Access as an "IPA device...designed to clean the intraluminal (female luers) and extraluminal surfaces of catheter hubs, injection ports, caps and stopcocks through a patent-pending friction scrub design" (www.bardaccess.com, 800-545-0890).



Site-Scrub™

Creating New Boundaries

Sheila Messina

No more boundaries.

No need to eat at five P.M.
Or be there to answer
Whether this soup needs cheese.

No more boundaries.

No need to only sleep on the left side of the bed
Or explain why I got home late.

No more boundaries.

No need to do laundry on Tuesdays and Saturdays
Or park my car in the driveway.

No more boundaries.

The awareness comes that boundaries
Permit structure
Create expectations.
That boundaries develop without permission
And that boundaries can be broken without permission.

Now the boundaries are gone.

Time to look at creating new boundaries.
What will the new boundaries look like?
Will they appear or do I create them?
Will I recognize them?
Will I like them?

I would like to think they are of my choosing
But I did not choose to lose them.
So can I choose to create them?
I believe I can
Create the boundaries that work for me.

Boundaries which expand my horizon
Boundaries which are open to change
Boundaries which are flexible and life affirming
Boundaries which help me be the person I wish to be.

Helping TPN consumers live independently

I'm stubborn and my husband says I'm a pain in the butt.

We've been married 29 years and are more in love than the day we married. I love my friends, enjoy gardening, traveling and partying. Right now I am into redecorating everything.

Message to others on TPN

You have to breath, you have to sleep, you have to do TPN. It's just another thing you do. Get over it, get it done and move on to the fun stuff. Every moment is a gift.

About Nutrishare

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Susan

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SUSAN O'BERSKI

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Nutrition and You

Benefits of Keeping a Nutrition Journal

You've probably heard the adage "you are what you eat." So, what are *you* made of? If your life is hectic, you might find yourself going about your day without paying much attention to what you've eaten. However, if you depend on what you eat to make a difference in how you feel, taking a closer look may help—and surprise—you.

The easiest way to really know what you eat and how it makes you feel is by keeping a nutrition journal. This simple tool can give you a better understanding of what, when, and/or why you eat.

Getting Started

Find a convenient, easy method to record the information you choose to track, such as a notebook or an online document. Several Web sites offer free software to record and analyze your diet.

What you record can be as simple as a tally of the number of fruit and vegetable servings you eat a day (e.g., if you strive to reach the national nutrition goal of five to nine servings a day). Or you could list specific types and/or amounts of food; when and/or why you eat; or how hungry you feel on a scale of 0 to 10 each time you are about to eat. For most HPEN consumers, a nutrition diary will be most useful when you are trying to decide which foods "work" for you and which foods cause "problems" (i.e., more output, pain, GI symptoms).

What to Record

The information you track will depend on your nutrition goals. Here are a few examples:

- Keeping a list of what you eat along with gastrointestinal symptoms or signs can help to reveal food intolerances or allergies.
- Writing down serving sizes and amounts can show that you are increasing your oral intake and can help guide the decision to decrease dependence on parenteral or enteral nutrition.
- Keeping a daily log of your intake and output can help you and your clinician determine if changes in your regimen are needed.
- A nutrition journal can be a confidential way to express your emotions about food—even if you are unable to eat the foods you love. You may also discover emotional "triggers" if you find yourself eating when you aren't really hungry.

• Taking a moment to write down what you ate (or are about to eat) can increase awareness of "mindless eating." You can also uncover how much junk food sneaks into your diet.

• Activity—this journal is a perfect place to record what activities you participate in, from a jog in the park to an intense game of checkers. Activity is a very important part of your overall health, too!

Gaining Insights

The process of keeping a nutrition journal can make you more aware of your overall nutrition and how food and emotions are related. Reviewing your journal entries can help you identify eating habits or trends. You can also compare your intake to a calorie goal or nutrition guidelines (such as a food pyramid, or the calorie guidelines discussed in this column in the Sept/Oct *LifelineLetter*).

Having a written record gives you (and your clinician) an objective summary of what you ate and identifies areas for improvement and progress toward goals. Don't just look for times when your diet wasn't perfect—congratulate yourself for your healthy choices!

Also, don't be hard on yourself if you miss a day or two with the diary. Often, keeping a diary for a "typical" weekday and both weekend days is more realistic. You may want to pick a week or a month to keep the journal.

Holiday Stressors

The holiday season is the perfect time to be more aware of food stresses and emotional eating. Keeping a nutrition journal could also be the perfect New Year's resolution.

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



Patient Education Materials: Where to Find Them

The October issue of *Nutrition in Clinical Practice* is devoted to the topic of nutrition education, with several articles focused specifically on home enteral and/or parenteral nutrition (HPEN). One article we are particularly excited about is the directory of home nutrition support patient education materials compiled by Oley staff member Lisa Metzger, "Education Materials for Home Nutrition Support Consumers."

"Patient education plays a pivotal role in promoting positive patient outcomes and ensuring patient safety within the healthcare environment," say Heather Gifford, BS, RD, CDN, CNSD, Mark DeLegge, MD, and Lou Anne Epperson, RN, MSN. "As the complexity of home care increases and more is demanded of patients with regards to their healthcare needs, the role of patient education becomes ever more important," they continue (NCP, Oct 2010, 443).

A directory of HPEN patient education materials was published in the 1990s, but it hadn't been updated in years. This new directory, compiled with the help of many consumers and clinicians who responded to a request for material, consists of eight tables. Resources are listed in tables that give the name and type of material (for example, handout, booklet, or DVD), the reading level, and how the material can be obtained. There are separate tables for adult PN, pediatric PN, adult EN, and pediatric EN, as well as a table of resources available in Spanish and one for general HPEN resources (for ex., a booklet on coping issues).

We tried to gather materials on all topics that could be useful to the HPEN consumer, from the basic (for ex., how to dispose of sharps) to the specific (for ex., care of an implanted port or a PEG tube). Materials related to coping and psychosocial issues are also listed.

It is our hope that this directory will be used widely to increase HPEN consumers' access to education materials. **You can find a link to the article on our Web site: www.oley.org.**

If you would like a copy of the directory, or you know of any materials that should be added, please contact Lisa Metzger at metzgel@mail.amc.edu or (800) 776-6539. Our thanks to all consumers and clinicians who steered us toward resources.

Book Corner

Toilet Paper Flowers, A Story about Crohn's Disease, by Frank J. Sileo, PhD (Health Press, www.healthpress.com, \$14.95)

Toilet Paper Flowers is a short paperback picture book about Julia, a little girl with Crohn's disease. When Julia's new friend Nikki comes to Julia's for a sleepover, Julia ends up telling her all about Crohn's, what doctors' visits are like, and some of her feelings about Crohn's. They share stories and giggles, and, in the end, a hug. It is a sweet story of friendship, and of a strong little girl who happens to have Crohn's. It could be a great resource to begin a discussion of what it might be like to live with Crohn's.

The book includes an introduction by the author, a licensed psychologist who works with children with Crohn's disease and their families. It also includes a glossary and instructions for making toilet paper flowers. It is, as Dr. Sileo says in the introduction, a story of "a child being hopeful despite adversity."

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Nominate Someone Who Inspires You!

The five awards Oley presents each year recognize those in our community who have earned our respect, inspired us, and taught us. Nominate someone today, following the criteria listed below. We've provided a form you can use as a guideline when submitting your nomination(s). Nominations must be received by April 1, 2011.

Awards will be presented at the 2011 Oley Consumer/Clinician Conference and the awardees will be spotlighted in the LifelineLetter. Several of the awards include a partial travel grant to the conference (to be held July 5-9, in Bloomington, MN). Recognition is given to all nominees.

The Awards and Criteria

LifelineLetter Annual Award

In honor of Nutrishare, Inc., Gold Medallion Partner

- 19 years of age or older
- HomePEN consumer or caregiver for five years or longer
- Demonstrates courage, perseverance, a positive attitude in dealing with illness or caregiving, and exceptional generosity in helping others in their struggle with homePEN
- Winner will receive a partial travel grant to the Oley annual conference

Child of the Year Award

In honor of ThriveRx, Gold Medallion Partner

- 18 years of age or under
- HomePEN consumer for one year or longer
- Shows a positive attitude in dealing with illness and therapy which encourages and inspires others
- Winner will receive a partial travel grant to the Oley annual conference

Celebration of Life Award

In honor of Coram Specialty Infusion Services, Gold Medallion Partner

- Any age
- HomePEN consumer for three years or longer
- Lives life to the fullest: traveling, fishing, gardening, volunteering, attending school, spending time with family, etc.
- Winner will receive a partial travel grant to the Oley annual conference

Lenore Heaphey Award for Grassroots Education

- Oley Foundation Regional Coordinator
- Organized an outstanding information and/or education program in the past year
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area



Nan Coutts Award for the Ultimate Volunteer

- Clinician (physician, nurse, dietitian, etc.) practicing in the field of homePEN or related field (psychology, interventional radiology, pain management, etc.)
- Demonstrates a willingness to give of themselves, above and beyond their regular work hours, to educate, empower, and improve the quality of life for homePEN consumers

2011 Oley Award Nomination

1. Provide the following information:

I am pleased to nominate the following individual for the 2011:

- ☐ LifelineLetter Award
- ☐ Child of the Year Award
- ☐ Celebration of Life Award
- ☐ Lenore Heaphey Award for Grassroots Education
- ☐ Nan Coutts Award for the Ultimate Volunteer

Nominee's name: _____

Age: _____ Daytime Phone: (_____) _____ - _____

E-mail: _____ @ _____

Primary diagnosis: _____

No. years on HPEN _____

Your name: _____

Daytime Phone: (_____) _____ - _____

E-mail: _____ @ _____

2. Tell us why you are nominating this person.

Cite specific examples of how the nominee meets the award criteria. Please limit length to one page (attach).

3. Submit nomination to:

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

Fax (518) 262-5528

E-mail harrinc@mail.amc.edu

Questions? Call (800) 776-OLEY

Save the date!

Oley member Sheila DeKold is organizing a family camp experience for children dependent on home parental and enteral nutrition at the Center for Courageous Kids. Their motto is "We Prescribe Fun!"

April 8–10, 2011

Center for Courageous Kids

1501 Burnley Rd., Scottsville, KY 42164

(270) 618-2900 • www.courageouskids.org

In order to reserve the camp for this group, thirty families need to participate. Please contact Sheila DeKold at sdekold@mac.com.

Equipment-Supply Exchange

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

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

In Memoriam: Tim Joyce

Kathleen McInnes

On August 17, many of us lost a dear friend when Tim Joyce died. Tim died after a valiant battle following the multi-visceral transplant he had had in April.

Tim was diagnosed with Crohn's disease while completing his physical examination for college and spent the next year at the University of Chicago Hospital undergoing surgeries to remove portions of his intestines. He began life on parenteral nutrition (PN) in 1979, when PN was in its infancy.

In spite of all of this, Tim started several businesses, including a car cleaning business and an aquarium business. Tim loved children and he could be seen at conferences teaching them magic tricks and card tricks. Tim was generous to a fault, often buying toys for children and giving of himself.

At Oley conferences, Tim would often do technical things behind the scenes—often in his bare feet! He was known fondly as our "barefoot boy" because of his penchant for running barefoot.

Tim and I shared co-leadership of the Chicago Pumpers. We worked well together, providing outreach and actual meetings for people throughout the Midwest. I miss my good friend, as do the Pumpers and many of you who knew and cared about Tim.

Tim became an Oley Regional Coordinator volunteer in 1999, and, as Kathleen notes, helped lead the Chicago Pumpers, a homePEN support group. He reached out to other HPN consumers, volunteering to give them rides to meetings so they, too, could attend. Tim also published a newsletter, the Picayuna, and advocated for other consumers by encouraging them to learn more about their disease and how to manage their PN; he challenged consumers to play an active role in their health decisions. We appreciate the support Tim provided to fellow consumers.



Tim Joyce

*Wishing You Peace
and Hope for the
Holiday Season
and the New Year*



Start the New Year by Maximizing Your Health!
To register go to www.thriverx.net.

THRIVER_x

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

From the Desk of Joan Bishop, Executive Director

Giving Thanks

It's the time of year to reflect on the past and give thanks for all that surrounds us. First on my list of the things I am grateful for are the consumers, clinicians, corporate partners, Oley Trustees, staff, family, and friends that make up the Oley "family." My cup runneth over. I continue to be inspired by the positive attitudes that surround Oley.

All that you have done to help one another and to help Oley as an organization has not gone unnoticed. Whether you've supported us financially, reached out on your own or responded to an appeal from us to support someone, staffed an Oley exhibit table, distributed Oley materials to your clinician in an effort to expand our reach, responded to a posting on the Oley forum, or, as a clinician and/or Trustee provided guidance, you have seriously contributed to the "spirit" of Oley—a spirit and attitude that is trusted, contagious, energizing, and extremely powerful. Each and every one of you is responsible for another successful year at Oley.



Joan Bishop

One gift for me personally this year was the strong and determined Oley staff that plugged through what needed to be done during my medical leave. It was comforting to know the Foundation's efforts would/could continue without me.

Highlights of 2010

Membership reached the 10,000 mark in October 2009 and is currently 11,000+. In 1984 we inherited approximately 200 members from Lee and Marshall Koonin, so we're very pleased with the growth.

The annual conference in Saratoga Springs was a smashing success and, again, a huge nod to all who participated. The golf tournament was a nice addition, the educational aspect was outstanding, and the networking incredible. Plans for the 2011 annual meeting in Bloomington, Minnesota, are under way, with details to be outlined soon.

The recent regional meeting held at UCLA was a huge success with attendance reaching one hundred and plenty of interest in a repeat performance. (See article on page 4.) Could this be a site for an annual meeting in the future? Hats off to Felice Austin and Laurie Reyen, RN, and all who participated and helped coordinate.

Our online presence continues to grow. With over 10,000 visits per month, www.oley.org—the MYHPN modules, the Oley forum (with over 1,100 participants), newsletters, bulletins, patient profiles, and more—has become the "go to" place for trusted information and support.

We've coordinated eight focus groups this year, connecting HPEN consumers with company representatives as companies seek input on new products and services. The enthusiasm of those participating made these efforts move forward with ease, especially if we were able to reach you via e-mail. If you're interested in sharing your experiences, please make sure we have up-to-date e-mail and telephone contacting information on file. These are the most efficient and preferred means of sharing information and invitations with you.

Our relationships and collaborations with other organizations (i.e., American Society for Parenteral and Enteral Nutrition [A.S.P.E.N.], Association for Vascular Access [AVA], Intravenous Nursing Society [INS], United Ostomy Associations of America [UOAA], Digestive Disease National Coalition [DDNC], Gastroparesis Patient As-

sociation for Cures & Treatments, Inc. [G-PACT], and Association of Gastrointestinal Motility Disorders [AGMD], to name a few) seriously strengthen our ability to reach new members, showcase your concerns, and advocate on your behalf. We are truly blessed by these partnerships.

Excitement fills the air at Oley headquarters this month as the article "Education Materials for Home Nutrition Support Consumers," authored by our newsletter editor, Lisa Metzger, is published in *Nutrition in Clinical Practice*. This comprehensive directory lists HPEN patient educational materials for clinicians so they can connect patients in their care to resources that will help them understand the therapies that sustain them. This article will undoubtedly keep Oley efforts front and center in the minds of the clinicians who are using it. Read more on page 7.

Come to Vancouver!

The upcoming regional meeting in Vancouver, January 29, is being planned in conjunction with A.S.P.E.N.'s annual meeting, Clinical Nutrition Week (CNW). If you can be in the area, we encourage you to attend (see article on back page). We also look forward to the Oley roundtable sessions at CNW. Titled "The Oley Foundation: Don't Go Home Without It!" this will be a lively, interactive session for clinicians, showcasing the value of connecting consumers to Oley programs.

Happy New Year

Last but not least, as you consider the causes you'll support this holiday season, I hope the Oley Foundation is on your list—and thank you to the many who have already responded to our annual appeal. With your help, we can continue to provide the valued services that make a difference to so many in our community, and continue to provide these services to consumers without charge. We're on a limited budget and it's a lot of hard work, but the resources and assistance you provide make it all possible. We couldn't do it without you—the centerpiece of all we do!

I close with warm wishes for a peaceful holiday season and a happy, healthy New Year from all of us at the Oley Foundation headquarters.

Have Your Questions Answered

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.



Smooth Traveling

Oley is aware of the uncomfortable atmosphere airport security presents to members who want or need to travel via air. We are working with other organizations to try to make airport screening officers more aware and more understanding of your circumstances.

Advocacy

In December, Oley and twenty-three other organizations sent a letter to Transportation Security Administration (TSA) Administrator John Pistole. "We believe," the letter states, "that more information and training about how to be sensitive to travelers' medical conditions is needed. This is especially true because ostomies and other medical conditions and devices that previously had not shown up in security screenings will show up more frequently in full body scans."

We encourage the TSA to:

- develop educational materials for security officers that explain medical issues and the specific TSA procedure for screening travelers with these issues
- develop training to ensure that officers listen with respect to travelers who explain they have medical issues
- include people who live with different medical devices as part of the training sessions
- make the TSA information card for people with medical issues more readily available



"Clearly," the letter concludes, "a one-size-fits-all approach for screening has not worked for people living with ostomies and those who use medical appliances and devices." (The complete letter is posted on our Web site, www.oley.org.)

We encourage you to share your experiences with us—good or bad, and in as much detail as possible. This will help us in our advocacy efforts. Share your stories with your elected officials, too. Most will be familiar with Thomas Sawyer's experience in Detroit (you can read the story at www.freep.com/article/201011201935/NEWS06/101120044). This may be a good starting point for discussing your concerns. We're interested in who you talk to and their response.

Traveling Now

Before you go to the airport, visit the TSA Web site and read the page devoted to traveling with disabilities and medical conditions (www.tsa.gov/travelers/airtravel/specialneeds/index.shtm). Or call the TSA Contact Center at (866) 289-9673 with your questions and concerns.

Note that you do not have to go through a scanner; if you choose not to go through a scanner, you will be subjected to a pat-down. You have the right to be patted down by someone of the same gender. If you are scanned and something is detected, you will be subjected to a pat-down; again, you have the right to be patted down by someone of the same gender. You also have the right to ask for the pat-down to be conducted in a private place and to have someone else present.

The TSA has developed a card for those with medical conditions to use to discreetly communicate their situation to security officers. You can obtain a copy of the card at www.oley.org or by calling Oley at (800) 776-OLEY.

Unfortunately, catheters, tubes, drainage bags, etc. are likely to be foreign to screeners and will need to be investigated. We hope advocacy efforts, such as the letter described above, can increase understanding and help make your traveling go smoothly.



EnterateLite[®] Infinity[®] Enteral Feeding Pump



Meet your tube-feeding needs with Jevity[®] 1.2 Cal and EnterateLite[®] Infinity[®] Pump

With Jevity 1.2 Cal and the Infinity Pump you can be assured you are receiving Complete, Balanced Nutrition[®].

Jevity 1.2 Cal has a unique fiber blend to promote normal bowel function. Concentrated calories and protein help you gain and maintain a healthy weight.

The Infinity Pump offers safe, simple operation and the flexibility of ambulatory use.

Contact your home medical equipment supplier or visit AbbottNutrition.com for more information.

Important Safety Information

- **THIS PUMP IS FOR ENTERAL USE ONLY - NOT FOR IV USE**
- Pump set and container should be replaced as needed, or at least every 24 hours, to avoid fluid contamination problems.
- See Pump Operating Manual for Complete Safety Information and Instructions for Use



Federal law (USA) restricts these devices to sale by or on the order of a physician, registered dietitian, registered nurse, or other licensed practitioner. Jevity is a medical food for use under medical supervision.

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On the Receiving End: Living with PN

Brenda Dunn, PN-DU Convenor

Our first Parenteral Nutrition—Down Under (PN-DU) symposium for HPN consumers, carers, and health professionals was held at the Gold Coast in Australia, during Australian Gastro Week, as a satellite to the Gastroenterology Society and AusPEN meetings. This allowed delegates and speakers at these meetings to attend all or parts of our symposium and for us to make the most of their availability.

We were especially delighted that our two invited international speakers, who traveled from the US and UK at their own expense specifically to participate in our PN-DU symposium, stayed with us the whole day, networking and engaging in one-to-one conversations with our consumers and carers.



Dr. Hardy and Karen show off Pendoo, the PN-DU mascot.

The day opened with a welcome from Karen, the PN-DU secretary, who read a letter of support and encouragement from Joan Bishop, Executive Director of the Oley Foundation, our American sister organization. Joan acknowledged the contribution Brenda Dunn has made as an Oley member and Regional Coordinator/Foreign Affiliate, adding: *“Whether in the USA, or Down Under, HPN consumers face similar challenges. We are happy to be able to share information, experiences, and member-to-member support with your group. Our members are here to help you if you are ever traveling in the United States, and we are grateful we can refer our more adventurous members to you as they travel, as well. We are glad to know there is support for fellow consumers in your part of the world, and wish you the best with this and future conferences.”*

Frederick (Fritz) Schwenk, MD, from Mayo Clinic USA and Chairman of the ASPEN Rhoades Research Foundation, discussed the management of pediatric intestinal failure with PN. Fritz was later presented with the annual IPaNEMA Award for services to PN, by trustee Patrick Ball.

PN filters, and whether or not they are required, produced a lively debate, as did a presentation on catheter care and our survey on designs and practical experiences with PN bags (to be published later). Managing adult intestinal failure and improving standards (after the NCEPOD report into the care of hospitalized PN patients in the UK was released) were addressed by pharmacist Peter Austin, who had been an advisor reviewing the UK cases discussed in the report. Then a constructive and interactive discussion on how this important report relates to the “Down Under” part of the world was moderated expertly by Mel Davis.

This certainly was not as big as an Oley meeting, but everyone seemed to leave on a positive note, including the treasurer (Gil Hardy, MD) with his successful raffling of our Pendoo® mascots. Many folk left with one tucked under their arm.

[Editor’s note: The NCEPOD report Brenda refers to is titled “Parenteral Nutrition: A Mixed Bag.” You can find this 102-page report online at www.ncepod.org.uk/2010pn.htm.]

Capitol Hill Day 2011

Every year the Digestive Disease National Coalition (DDNC), of which Oley is a member, organizes a two-day public policy forum in Washington, D.C. On Sunday, March 6, 2011, homePEN consumers, caregivers, health care providers, and industry representatives will have the opportunity to meet together to learn about federal health care legislation and policies of concern to the digestive disease community. Monday, March 7, will be Capitol Hill Day, where members of this group will be scheduled to visit members of Congress and/or their staffs to discuss the issues they feel are important to them.



In 2010, approximately 150 people participated, forming seventeen teams that completed over seventy meetings with Congress staff, says Oley member Alan Robinson, who participated in the event. “These meetings were informal and provided an opportunity for Congress to hear from patients who face challenges in trying to make their digestive tracts work well enough for them to survive. The impact was powerful,” Alan wrote in the Mar/April 2010 issue of *LifelineLetter*.

Your participation in Capitol Hill Day will help your legislators know their decisions do affect real people—people who are eager to participate as fully in life as they are able. It will help your legislators put a face to digestive diseases and allow them to make informed decisions when supporting legislation.

DDNC hopes to have some funds available to help with travel, and Oley is compiling a list of hotels that are situated close to public transportation to make travel easier for HPEN consumers. For more information or to register, contact Oley at (800) 776-OLEY or bishopj@mail.amc.edu. The DDNC’s key priorities are listed on their Web site, ddnc.org.

Rare Disease Day February 28, 2011

Visit the Web site rarediseaseday.org to see how you can be involved in Rare Disease Day in 2011. Established in 2008 by the European Rare Disease Organization (EURORDIS) and now co-sponsored by the National Organization for Rare Disorders (NORD), Rare Disease Day is celebrated each year on the last day of February. The goals of the initiative are outlined on



the Web site, along with suggestions for involvement and opportunities to share your stories and videos. Visit the Web site, and set February 28, 2011, aside to help raise awareness about rare diseases.

Helping Kids Cope, from pg. 2

- Progressive muscle relaxation (tighten and release each muscle group in succession).
- Guided imagery—you can purchase cds or go to itunes online for imagery scripts with relaxing music.

Holiday Hospitalization

Having a child admitted to the hospital or sick at home during a holiday can create havoc for families. Remember that most traditions that are celebrated at home can be incorporated into the hospital environment (i.e., bring a Thanksgiving meal to a child's hospital room or decorate his room for the holiday you are celebrating). Even though you may have to modify certain traditions, try to include the sick child in whatever way you can. Provide opportunities he can look forward to.

At Children's Memorial Hospital, we have a playroom space with special activities and regular play programming that occur on a daily basis. These provide unique opportunities patients and their families can look forward to and participate in. If your hospital does not have these resources, pack a special hospital bag for your child with games, activities, and some of her favorite things to make the experience more familiar and positive.

It's a good idea to keep some special toys that your child can only use during procedures or dressing changes. These toys will continue to capture the child's attention, unlike everyday toys he is used to seeing and playing with.

Importance of Routine

Remember that children of all ages benefit from a consistent caregiver presence and a familiar routine. Several patients with whom I have worked have benefited from having a visual schedule posted in their bedroom or hospital room so they can anticipate upcoming medical events, when to take medicine and fun activities, as well as activities of daily living, like bathing and teeth brushing. Have the child participate in making this schedule, including items she feels are important, and allow her to decorate it with photos and stickers.

Continue to set limits with your child so his behavior does not get out of control. Again, children need structure and guidance to thrive. They depend on their caregiver(s) to provide clear expectations for them in a caring and loving way.

Provide clear choices when they exist, but be clear that with certain tasks the child's choices are limited. With taking of medication, for example, a choice of whether or not your child takes it does not exist. You can, however, incorporate choices into the taking of medication by allowing her to choose how she wants to take her medication or what she wants to take it with (i.e., spoon or syringe, juice or water). The choice can even be to choose what activity she wants to engage in once she has been cooperative in taking her medicine (i.e., watching a favorite cartoon, doing a project, reading a book).

Expression of Feelings

As caregivers, you should speak honestly and openly with your children. Research has proven that it is better for children to know what is happening versus dealing with feelings associated with fear of the unknown. Some caregiver(s) think it is best to express their own emotions in private. At times, it is good to show kids that adults are only human

too! It gives children permission to more openly share their feelings in front of others instead of keeping them all bottled up inside.

Keep in mind that, depending on the age of your sick child, he may want to express his feelings in other ways besides just talking to a trusted adult. Oftentimes kids I work with will relay that they don't want to share their feelings with their caregiver(s) because they don't want to make them more upset or burden them with their feelings.

Peer support groups are a great outlet, especially for school-agers and adolescents. Through peer support groups they can come to realize they aren't the only ones dealing with a difficult time or a chronic illness—or the only ones with tubes or catheters. Encourage your child to keep a journal where she can write about her feelings or use art, poetry, or music as an expressive outlet.

For younger children, you can read a feelings book with them, which may help them to identify the feelings they are having. It can often be confusing for them to verbalize their feelings. So frequently, because they don't know or understand why they are feeling a certain way, they will act out as a way to gain positive attention. Caregivers may have difficulty pinpointing the root cause of the behaviors and may respond in a negative way, which is not what the child is hoping for. Provide verbal reassurance and let the child know that what he is going through is really hard and that you are there to help him get through it. Lots of hugs and kisses are good, too!

If your child is opting to act out physically, make sure you let her know it is not okay to hurt herself or anyone else. If she wants to punch something because she is very angry, provide a pillow as a punching bag or give her play dough to pound as a more positive way of dealing with aggressive feelings.

Conclusion

In closing, caring for a child with specialized needs can be demanding and draining. Remember to take time for yourself, ask others for help, and seek out support services. ¶

Helpful Web Sites/Resources:

www.kidshealth.org—The Nemours Foundation Web site, devoted to children's health and development.

www.infantmassageusa.org—Learn more about the benefits of infant massage.

www.wish.org—The Make-a-Wish Foundation is a wish-granting organization.

www.familycrafts.about.com—Cute craft ideas.

www.familyfun.go.com—Disney Family Fun Web site, featuring crafts and printable activity pages.

www.childlife.org—Child Life Council is the professional organization for child life specialists.

www.starlight.org—The Starlight Children's Foundation offers "a comprehensive menu of outpatient, hospital-based and Web offerings" for children with chronic and life-threatening illnesses.

Guided Imagery Books:

Healing Images for Children, by Nancy Klein and Roger Klein
Ready, Set, Relax, by Jeffrey Allen and Roger Klein

Feelings Book:

The Way I Feel, by Janan Cain

Silver Linings, from pg. 1

encourage me to keep the appointment I had coming up in a month, but I didn't think I could wait that long. I am a persistent man and he wouldn't listen to my concerns, so I went to the emergency room.

They admitted me, and after some tests diagnosed me with ulcerative colitis. I was put on bowel rest and parenteral nutrition (PN). I was hospitalized for several weeks in order to give my digestive tract a rest and to formulate a plan.

During the hospital stay, it was suggested I have a swallow study to determine my current swallow function. The doctor ordered it.

I was able to watch the procedure on the screen and—miracle of miracles—I PASSED! An oral diet was ordered for me. I started out slowly, for this was the first time in years I was able to swallow. My esophageal motility disorder had prohibited that luxury for over two years.



Norman relaxing with his grandson.

The tearful thrill for my wife and me was unbelievable. We had conversations revolving around what she was going to cook for me when I got out. Thanksgiving and Christmas were coming and I had dreams of what I could eat. Yet I still had bleeding issues.

The doctors wanted me to have surgery to correct the problem but I was advised to try Remicade, an IV infusion that I needed to get every two months.

Trouble Healing

As my weight came back—and my eating improved—the next step was to remove my PEG tube, my dining buddy for greater than two years. I made an appointment and the doctor removed it, but unfortunately the insertion site did not close up as the doctor had stated it would. The acid from my stomach continued to leak and cause redness, burning, and irritation on the surrounding skin. What had started out as a small insertion site for a PEG tube grew into an uncontrollable seeping, painful problem that lasted for weeks.

I continued to contact the GI physician about these complications, however he had no answers for me, no solution. He responded, "That is not my expertise." Now what do I do, I thought.

In an effort to get some help I again went to the emergency room. A surgeon was consulted and Anne, the enterostomal nurse specialist, came into my room. Using an ostomy bag, Anne devised a way to collect the drainage and protect my skin. Surgery was then scheduled in two weeks to surgically close the wound.

Prior to surgery, I saw Anne every day to change my dressing. After surgery, visiting nurses came to the house two times a day to change my dressing for four weeks.

The Good in the Bad

Sometimes when we are tube fed or PN patients we think everything goes wrong. I thought that myself and I seemed to have the experiences to prove it. However, there are wonders and miracles along the way.

My original hospitalization for bleeding cradled the miracle of a swallow study and allowed me to eat again. The PEG tube removal

couched the miracle of allowing me to meet Anne and the enterostomal group, and understand their medical needs and talents.

We must meet our challenges and setbacks with persistence and optimism. We all are who we are because of the way we handle these problems. I continue to remain persistent in my medical care, and I am better for the experiences of the past year [written April 23, 2009].

This is the Norman that I am today. I trust that from my experience I can give you hope and encouragement that miracles can happen for you, too. ¶

Corporate Partner Spotlight

Please join the Oley Foundation in thanking our most recent corporate contributors. To read about other Oley Foundation Corporate Partners, visit www.oley.org/donorinfo.html.

InfuScience, Inc.

As one of the "next generation of comprehensive infusion providers," InfuScience is proud to be an Oley partner. Utilizing decades of experience from leaders in the infusion industry, InfuScience excels in the delivery of nutrition services, antibiotic, and other infusion therapies in the home. The InfuScience team is dedicated to exceeding its customers' needs while providing optimal patient care, education, and support. Maintaining high standards in the delivery of infusion therapy allows InfuScience to provide a valuable experience to customers. Visit www.infuscience.com to learn more about the company's commitment to serving patients with integrity, quality, and accountability.

B. Braun

B. Braun is a leading manufacturer of infusion therapy and pain management products with an environmentally friendly focus. Guided by its "Sharing Expertise®" philosophy, B. Braun addresses the critical issues of infection prevention, medication safety, and environmental responsibility by promoting best practices that help reduce medication errors, prevent healthcare-acquired infections (HAIs), and achieve sustainability objectives.

Consistently recognized by Frost & Sullivan and KLAS for its medical technology, B. Braun shares knowledge with colleagues and customers to improve working processes in hospitals and enhance the safety of patients and healthcare professionals. For more information, call (800) 227-2862, e-mail inquiry.us@bbraun.com, or visit www.bbrawna.com.

Drink Your Meals

Drink Your Meals offers blended recipes for tube feeders, people with swallowing problems, dieters, and those looking for healthy drinkable meals. The company was founded by Jesse Jones, a twenty-six-year cancer survivor and tube feeder for eight years, who wanted to be sure he was getting the best nutrition possible.

Jones states, "My partner, Chef Mike O'Connor, and I have developed more than one hundred delicious balanced meals using a wide variety of fresh fruit, veggies, whole grains, whole beans, nuts, good fats, grass-fed poultry, and wild-caught seafood." He adds, "Our philosophy is to provide you with recipes with 100 percent fresh ingredients that have not been processed (or minimally processed)." Jones is offering readers a special Drink Your Meals membership deal: pay \$5.99 for the first month's membership and get an additional three months free by using code OLEY-DYM when joining. For more information visit www.drinkyourmeals.com.

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 the list of honorees in each issue of the newsletter. A complete list of contributions will be published annually in the January/February issue of the *LifelineLetter* and in the Oley Annual Report.

Between October 1 and November 23, 2010, gifts were received:

In Memory of

Claire Berlowitz, Floyd Greenman, and Robin Lang

In Honor of

Jeff Allshouse, Mary Ellen Costa, and Laura Titrud

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



Join the Oley Horizon Society

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

<i>Felice Austin</i>	<i>Alfred Haas</i>	<i>Rodney & Paula Okamoto, RPh</i>
<i>Jane Balint, MD</i>	<i>Shirley Heller</i>	<i>Kay Oldenburg</i>
<i>John Balint, MD</i>	<i>Alicia Hoelle</i>	★ NEW! Harold & Rose Orland ★
<i>Joan Bishop</i>	<i>Jeff & Rose Hoelle</i>	<i>Judy Peterson, MS, RN</i>
<i>Ginger Bolinger</i>	<i>Lyn Howard, MD</i>	<i>Clemens Pietzner</i>
<i>Pat Brown, RN, CNSD</i>	<i>William Hoyt</i>	<i>Beverly Promisel</i>
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<i>Rick Davis</i>	<i>Doris R. Johnson</i>	<i>Roslyn & Eric Scheib Dahl</i>
<i>Ann & Paul DeBarbieri</i>	<i>Darlene Kelly, MD</i>	<i>Susan & Jeffrey Schesnol</i>
<i>David & Sheila DeKold</i>	<i>Family of Shirley Klein</i>	<i>Doug Seidner, MD, FACG, CNSP</i>
<i>Tom Diamantidis, PharmD</i>	<i>Jim Lacy, RN, BSN, CRNI</i>	<i>Judi Smith</i>
<i>Selma Ehrenpreis</i>	<i>Robin Lang</i>	<i>Steve Swensen</i>
<i>Herb & Joy Emich</i>	<i>Hubert Maiden</i>	<i>Cheryl Thompson, PhD, RD, CNSD,</i>
<i>Jerry Fickle</i>	<i>Laura Matarese, PhD, RD,</i>	<i>& Gregory A. Thompson MD, MSc</i>
<i>Don Freeman</i>	<i>CNSD</i>	<i>Cathy Tokarz</i>
<i>Linda Gold</i>	<i>Kathleen McInnes</i>	<i>Eleanor & Walter Wilson</i>
<i>Linda Gravenstein</i>	<i>Michael Medwar</i>	<i>James Wittmann</i>
<i>The Groeber Family</i>	<i>Meredith Nelson</i>	<i>Patty & Darrell Woods</i>
<i>Valerie Gyurko, RN</i>	<i>Nancy Nicholson</i>	<i>Rosaline Ann & William Wu</i>

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

PLATINUM LEVEL PARTNERS (\$70,000+)

GOLD MEDALLION PARTNERS (\$50,000–\$69,999)
Coram Specialty Infusion Services
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A gift that changes lives

Recently you received an appeal to support the work of the Oley Foundation. With your help, Oley can continue to touch the lives of thousands of consumers on home tube and IV feeding. Please give as generously as you are able.

Donor Profile: Richard and Faith Dillon

"We know, because of our daughter, that people who are on TPN feel kind of lonesome sometimes. The Oley Foundation gives them [home nutrition support consumers] someone behind them, encouraging them and sharing anecdotes. We think you have a good program and it's needed. That's why we've given all these years."

—Richard and Faith Dillon

Richard and Faith's daughter, Nancy Harvey (1952–2001), went on HPN in 1980.

"Nancy taught school for twenty years on TPN," says Richard. "Providers had to go all over Missouri and Kansas to get the supplies and ingredients for her PN when she started. It's been interesting watching the technology grow."



Regional Conference in Vancouver, British Columbia

This one-day conference will be held in conjunction with the American Society for Parenteral and Enteral Nutrition's Clinical Nutrition Week (January 30–February 2). With so much homePEN expertise gathering in Vancouver for Clinical Nutrition Week (CNW), we can promise an outstanding educational opportunity.

Stay for CNW and help at the Oley exhibit! Distribute Oley materials and talk to clinicians. Exhibit hours are: Jan. 29, 6–7:30; Jan. 30 and 31, 9:30–11:15 a.m., 12–2 p.m., 3–4:15 p.m.

Watch www.oley.org or call 800-776-6539 for details on the Oley conference and other opportunities at CNW. Registration (and a passport) is required, so don't delay!