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LifelineLetter

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

Salt Lake City — A Great Time!

Elizabeth Tucker

Timely information, humor and fun activities, were all on the agenda at the 21st Oley Consumer/Clinician Conference held this past June in Salt Lake City. We heard from experts like Khursheed Jeejeebhoy, MD, who sent one of the first patients home on TPN. We greeted old friends and made new acquaintances. Most importantly we shared our experiences and learned from one another. (I've been to more than a dozen conferences, and can honestly say that I always learn at least one new meaningful tip.)

Highlights include being entertained at the Silent Auction by HPN Consumer Roy George's piano playing and pharmacist Mike Hester's accompaniment on drum. And if the laughter and noise level were any indication, JamminJammies cheered many younger consumers and their siblings.

Participating in the 5K Walk-A-Thon for the first time I was impressed with the number of walkers and volunteers involved, and appreciated the interesting



Frances Culp, HPN Consumer, her mother, Barbara Gatlin and Anne Brettschneider in the Exhibit Hall.

route and cooling water stops along the way. The picnic at the Salt Palace offered delicious food and a great place for the kids to play games. I believe I speak for everyone when I say it was another very successful conference. I hope we see you next year!

Meet Kate Swensen

If you haven't had the pleasure already, meet Kate Swensen, Oley's new Outreach Coordinator. She is 21 years old and beginning her senior year at SUNY Albany, where she is majoring in Biological Sciences. In her new position Kate provides support to Oley Regional Coordinators. She also keeps busy planning Regional Conferences (see page 5 for details on the next meeting in Indianapolis, Indiana). Her interests include reading Dostoyevsky, Tolstoy and Solzenhitsyn. She loves spending time with her animals and visiting friends too.

Kate's older brother Matt has been a TPN consumer since 1987. He lost all of his small intestine and half of his large intestine to a midgut volvulus when he was five. Kate believes the impact of growing up in a TPN household, and the difficulty in leaving it, has brought her home to work at the Oley Foundation. We are very excited to have her on staff, and ask members to join us in welcoming her aboard!



Kate Swensen

Be All You Can Be

Elizabeth Tucker

The following article is a synopsis of the Friday morning main session at the 2006 Oley Conference in Salt Lake City, UT. Cheryl Thompson, PhD, RD, CNSD, was the moderator and there were five HPEN consumers on the panel: Rick Davis; Flute Snyder, PhD; Shawn Boulette, RN, BSN; Carol Pelissier and Roy George. Videos/DVDs of this and other sessions will be available to borrow from the Oley Foundation Library some time in the fall.

Cheryl Thompson, PhD, RD, CNSD recently completed her doctoral research entitled *Fostering Coping Skills and Resilience in HEN Consumers*. She began the session with a presentation highlighting examples of the coping tips her research uncovered. A summary of her favorite "top ten tips" are as follows:

10. Don't dwell on it. Recognize the difference between dwelling on a problem and contemplating a solution. When you find yourself dwelling on an unsolvable situation, try to short circuit your thinking.

Be All You Can Be cont., pg. 2



Cheryl Thompson

Be All You Can Be, from pg. 1

Find a distraction (e.g. take a walk), put your feelings into writing, or try to look at the situation more objectively.

9. Turn a problem into a challenge. Changing how you view a situation can turn a defeatist attitude into a motivational force. Look at a problem as a challenge and you will find renewed enthusiasm to overcome it.

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

Executive Director:

Joan Bishop
BishopJ@mail.amc.edu

Director of Communications & Development:

Roslyn Dahl
DahlR@mail.amc.edu

Editor:

Elizabeth Tucker
evtucker@charter.net

Outreach Coordinator

Kate Swensen
SwenseK@mail.amc.edu

Administrative Assistant:

Cathy Harrington
HarrinC@mail.amc.edu

Lifeline Advisory Group:

Felice Austin; Patricia Brown, RN, CNSN; Ben Hawkins;
Alicia Hoelle; Robin Lang; Jerry Mayer; Rex Speerhas,
RPh; Stephen Swensen; Ann Weaver

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health care provider prior to actual use. Correspondence
can be sent to the Director of Communications &
Development at the address above.

8. Change it – accept it – or, deal with it.

Problem-focused coping strategies are actions taken to solve the problem or change the stressful situation. Emotion-focused coping strategies are aimed at reducing the negative impact a problem has on you by changing the way you think or feel about the stressful situation. To cope successfully with HPEN, it is essential to use constructive methods of both problem-focused and emotion-focused coping strategies.

7. HPEN is like a team sport. Your team has a quarterback – you. Becoming a skilled quarterback takes effort and perseverance. Your family members, friends, support groups and clinicians also function as part of your “team.” To succeed, you will repeatedly need to pick yourself up and get back in the “game;” and surround yourself with supportive teammates.

6. See one, do one, teach one. Improper or inadequate training causes stress and can lead to serious complications. Many times consumers are educated by being given a pamphlet or instructions (a “See one”). Actually, “doing one” is even more important to demonstrate your knowledge; and teaching someone else will reinforce the new skill and help you to master the new technique.

5. Ask yourself, “What was I thinking?” Whether you are aware of it or not, your mind engages in a constant stream of thoughts, which is sometimes called “self-talk.” Many times that self-talk can be negative. Because we tend to believe our own self-talk, we need to be aware of any negative thoughts we may be having and work to change them into more objective or positive thoughts. To learn more about a technique to change limited-thinking patterns, Cheryl suggested reading literature by Dr. Aaron Beck.

4. Seek and Accept Support. Asking for and then accepting help can be difficult. We need to understand that both are okay. Remember that helping can be rewarding, so pass it on. In addition, nurture those who help you. Start by remembering to say “thank you” as one simple way to show your appreciation.

3. Make every second count. Make the most of the time you spend with your health-care provider. One study found that patients spoke for an average of 18 seconds before their health care provider interrupted them. To maximize your medical appointments: be prepared (e.g. bring your list of questions and topics to discuss), be concise and to the point.

2. Focus on the positive. Dr. Martin Seligman teaches “learned optimism” and his books may be useful to many HPEN consumers. Foster an attitude of gratitude for the good things in your life. Start by writing down three things you are thankful for – every day. Instead of comparing your life to the “rich and famous,” rate it against those who have less fame and fortune. You can see your own situation in a more positive light if you compare yourself to someone in a similar situation or recognize there are people with worse problems than your own.

1. Take charge: Develop an attitude of personal responsibility and acknowledge that you have a choice in how you perceive and deal with the challenges in your life.

The Panelists’ Experiences

The first panel member, **Rick Davis**, believes in setting goals and being the best you can be. He had a stroke that paralyzed his



Rick Davis

esophagus and he used goal setting, first to walk – two floor tiles, then four floor tiles, until he had crossed the Grand Canyon. Next, he felt he would eventually learn to swallow. When he learned his muscles wouldn’t allow that, he decided he would become the best tube feeder he could be. He learned how to deal with not eating at social events or in restaurants. Then he worked on spending less time feeding; going from 10 hours a day to five minutes, three times a day.

Rick feels that coming to his first Oley Conference four years ago was one of the best things that happened to him since he had his stroke. Meeting others facing similar challenges and learning from the medical professionals have greatly improved his quality of life.

Surgery for cancer left **Flute Snyder** dependent on tube feeding. To help him cope with the frustrations, he writes humorous essays that let his friends know what he is experiencing. At the conference he shared some of his stories, including one about his tube falling out when he was working in a hardware mower repair shop.

“As I straightened up after lifting a mower, I felt a warm sensation running down my leg.

Be All You Can Be cont., pg. 7

Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their 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 DahlR@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.

Tube Cleaning Tip

I am the foster mom of a 10 month old with severe reflux and complete oral aversions. She is fed by G-J tube only. I wanted to share my tube cleaning tip. While running hot water through her feeding set, I put the tube between two prongs of a fork, then bend the tube and put it between the next two prongs. Next slide the fork from top to bottom in the same direction the water is flowing. Repeat if needed. I have installed two hooks above my kitchen sink to hang the bag on while doing this and to hang the extra tube on to dry between uses.

— Amy Schaubel, Niagara Falls, Ontario, Canada
aschaubel@cogeco.ca

Press'n Seal® Keeps Port Closed

The G-port on my G-J tube kept popping open and spilling stomach contents all over the place. The pressure would build up in my stomach and the next thing I knew the G-port was open. I found that GLAD Press'n Seal® worked to keep it shut. Cut a small strip and wrap it around the G-port just below the J-port; the balloon's port will be covered as well. Then press it so it will seal. You will need to change the wrap 3-4 times a day due to the smell.


I have also used Press'n Seal to keep my PICC line dry during showering. Just wrap it around your arm, seal it and add tape around the top and bottom.

— Franccen Lamarca, Marysville, WA
Bunelover59@yahoo.com

Suggestion for Irritated Skin

I have a G-tube opening that developed red and raw raised tissue around it. It was extremely painful at the slightest touch, and oozed small amounts of seepage and occasionally small amounts of blood. This lasted several months until (with no thought of my G-tube problem), I bought a bottle of Oil of Olay Total Body Wash with vitamins and Shea Butter for Extra Dry Skin (yellow cap). Amazingly, within two days the raised tissue had disappeared, with no more pain or seepage. I have used it ever since and have been just fine. I know it sounds almost too simple, but I hope this tip will help others.

— C. Becker, Saint Louis, MO
Cassa4921-med@yahoo.com



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ROSS NUTRITION

Congratulations 2006 Award

LifelineLetter Annual Award Winner

In Honor of Nutrishare, Inc., Platinum Partner

Sheila Messina, RN, MA • San Jose, California

Sheila Messina is a TPN veteran. She has magnificently embraced the lifestyle that Gardner's Syndrome has presented to her by exploring every possible outlet for positive feedback. Sheila has spoken about patient advocacy at Oley Foundation gatherings, and been a presence at both Nutrition Week and Nutrishare conferences. She is no stranger to A.S.P.E.N. and AVA conferences either.



Sheila & Al Messina

Sheila's commitment to being active ensures that she is always up to date in her information. A great source for information and support, Sheila can and will talk to anyone from the perspective of both an RN and a consumer. Countless

consumers and their families have found their need for a compassionate ear and a shoulder to lean on in Sheila. It is for her unfaltering contribution to the Oley community that we honor her.

Nominees:

Betty Ann Bond, Levittown, PA
Rose Hoelle, Gibbstown, NJ

Robert Stillion, Jr., Toledo, OH

Lenore Heaphey Grassroots Education Award

Rick Davis • Salt Lake City, Utah

This year's Lenore Heaphey award goes to Rick Davis, a name well known. The very fact that you are probably already acquainted with Rick underscores why he is such an appropriate choice for this honor. Rick is an educator. He has a unique ability to speak to people from all walks of life, ranging from consumers to clinicians. Rick is able to use his life altering stroke as a vehicle for supporting, encouraging and educating so many people with obstacles of their own to overcome.

Rick has been remarkably active this past year, organizing this conference, speaking at A.S.P.E.N.'s Clinical Nutrition Week and contributing to a textbook from the consumer's perspective. Rick was also a presence at the Utah Dietetic Association's annual meeting, helping to promote the consumer's point of view. Recognizing Rick in his hometown seems a most appropriate way to say "Thank you" for all he does.



Rick Davis

Nominees:

Betty Ann Bond, Levittown, PA

Sue Koprucki, Rochester, NY

Oley Foundation Child of the Year

Sean Forney • Meridian, Idaho

The 2006 Oley Foundation award for Child of the Year goes to Sean Forney. Sean is just nine years old and had spent his entire life on TPN, until recently switching to a 100% tube-fed diet. This is only one of many challenges faced by Sean, who was born with a rare birth defect known as Congenital Diaphragmatic Hernia. In addition to short bowel syndrome, the defect left Sean with severe scoliosis and a restrictive lung disease that makes him oxygen-dependent. He has endured over 30 surgeries and procedures, spent months at a time in a reclining position while his spine healed. Sean spent many years wearing a full body brace as well.



Sean Forney

Sean's struggles have evolved into a means for him to reach out to others. Sean is open about showing his scars and tubes to people facing medical procedures of their own. By talking openly with his peers, he brings peace of mind to kids before surgeries and during the healing process. Sean is even credited with easing his own grandmother into a tube-fed lifestyle. As if that isn't impressive enough, Sean allowed himself to be interviewed for a radiothon, benefiting St. Luke's Children's Hospital, on the very same day he was scheduled to undergo a medical procedure. Sean is brave and creative, finding unexpected outlets to share his courage with anyone in need. Congratulations, Sean!

Nominees:

Michael Bramhall, II, Papillion, NE
Kyle Noble, Grove City, OH

Emily Koprucki, Williamsville, NY
Sean Rawlins, Glendale, CA

Nan Coutts Award for the Ultimate Volunteer

Coordinated by Judy Peterson, RN, MS

Carol Ireton-Jones, PhD, RD • Dallas, Texas

Dr. Carol Ireton-Jones is rightfully given this year's Nan Coutts award, as she has shown herself to be the ultimate volunteer. Promoting Oley's services is always high on Carol's list of priorities, and for no other reason than her desire to ease her patients' discomfort. So, while voluntarily spreading the Oley Foundation's message, Carol is also helping consumers and their families connect and find support.

Carol began her altruistic journey by accompanying a doctor on a clinic visit to an HPN patient, simply to see the home-PEN experience herself. She has gone on to contribute such useful



Carol Ireton-Jones, PhD, RD

More Than Just Cars

resources as the “Celebration of Life Circle,” the “Ireton-Jones Equation” for calculating metabolic rates, and a book for clinicians on Home Nutrition Support with a chapter written by HPEN consumers to be published in late 2007.

Not only a strong emotional pillar, Carol makes her presence all the more beneficial by offering informed guidance to those making difficult decisions. Weekends and evenings are of no consequence to Carol, who is happy to be of service for anyone in need at any time. The Oley Foundation would like to thank Carol for helping patients and consumers find stability and comfort in their most tumultuous times.

Nominees:

Terry Clemmer, MD, Salt Lake City, UT
 Craig Petersen, Elk Grove, CA

Celebration of Life Award

In Honor of Coram Healthcare, Golden Medallion Partners

Bill Hickey • Cheyenne, Wyoming

Bill Hickey has been awarded this year’s Celebration of Life Award. No doubt, Bill has received this award because he is always able to keep sight of what’s important. Bill has acted as an expert witness to the US Congress, he has spoken from the consumer perspective before many clinicians, and he relates to those in need of a friend. Bill is so devoted to the needs of others that he once delayed a hospitalization until he found adequate care for his cats.



Bill Hickey

Not only has Bill been an HPN consumer for half of his life (and as he puts it “why wouldn’t I want TPN? It saves my life everyday!”), but he is also a cancer survivor. Bill has been able to celebrate his own life, and in doing so, celebrates the lives of so many of his peers. This is why we want to say thank you, Bill, and your accomplishments have not gone unnoticed.

Nominees:

Wesley Banse, Scotland Neck, NC
 Dianne Bendernagel, Babylon, NY
 Melinda Bear, Cabot, AR
 Sonia Blue, Carmel, CA
 Shannon Curran, Barrie, Ontario
 Rommel Degracia, Lynnwood, WA
 Robin Lang, York, ME
 Bethan Matthews, Bristol, IK

Beverly Mello, Salem, MA
 Sheila Messina, San Jose, CA
 Kyle Noble, Grove City, OH
 Sharon Rose, Nashville, TN
 Sanford Schimel, Bronx, NY
 Reesalee Shutt, Farmington, UT
 May Tallman, Bountiful, UT

Know of someone special in your homePEN circle? Nominate them for a 2007 Oley Award. Look for details in the LifelineLetter or at www.oley.org next January.

On September 9, 2006, the Oley Foundation is hosting a Consumer/Clinician Regional Conference at the Indiana Convention Center in Indianapolis, IN. This one-day event runs from 10:00 a.m. to 4:00 p.m. and covers topics that are of interest to you. Discuss enteral issues, catheter care, coping with HomePEN and more! Enjoy networking opportunities, engage in breakout sessions, and listen to renowned clinicians in the home nutrition support arena.

If this jam-packed program isn’t enough for you, stay on a few extra days because there are even more educational opportunities available! We’re developing this conference in conjunction with the Association for Vascular Access. From September 9 – 12, AVA will be hosting their 20th Annual Clinician Conference in the same place. After participating in the September 9th Oley workshops, you have been invited to audit AVA’s Clinician Conference. Because AVA’s conference focuses on clinicians, we invite you to bring a notebook and record any questions. Later, we can direct you to the proper educational resources. Make the most of this dual opportunity. For more information or to learn about volunteer opportunities, contact Katie Swensen at (518) 262-5079 or email Swensek@mail.amc.edu.

Faster than the US Mail

Because we get a special postal rate as a nonprofit, we also are one of the last items the post office thinks about delivering; it can take up to three weeks from the time Oley mails out your copy of the *LifelineLetter* until the you receive it. Would you like to have it as soon as it is published? Just call or write Cathy (800-776-OLEY / Harrinc@amc.edu) and let her know you would like to have your *LifelineLetter* sent to your “electronic” mailbox. You will get it “hot off the presses.”

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Check Out Oley's New Website!

The Oley Foundation has a brand new website posted at www.oley.org. The new design makes it easier to find the information you need: catch up on the latest news on the homepage; try the pull-down menus to see who's got the toll-free lines this month; or search the index for articles on tube feeding.

You can also download or order Oley publications on-line, like the travel packet. The amount of information available at your finger tips is simply astounding! Questions or comments about the website can be sent to Roslyn Dahl (Dahlr@mail.amc.edu; 800-776-OLEY).

Equipment Exchange

The following supplies/equipment are offered free of charge:

Enteral Formula:

- 12+ cases Crucial, exp. 2/07
- 3.5 cases Fibersource HN, exp. 1/7 & 4/07
- 2.5 cases Isocal, exp. 1/07
- Isosource 1.5, 1 case exp. 12/06, 12 cases exp. 2/07 (multiple donors)
- 5 cases Isosource HN, exp. 2/07
- Jevity 1.0, 40+ cases exp. 11/06, 10+ cases exp. 12/06 (multiple donors)
- 5 cases Jevity 1.2, exp. 04/07
- 3+ cases Jevity 1.5, exp. 4/07
- 1+ cases Nutren 1.0
- 3 cases Nutren Pulmonary, exp. 2/07
- 1 case Pediasure, vanilla, exp. 12/06
- 12 cases Pediasure with fiber, exp. 1/7
- 5 cases Peptamen, exp. 04/07
- 1 case Replete, exp. 1/07

- 3 cases Replete with fiber, exp. 2/07
- 6 cases Traumacare, exp. 1/07

Tubes/Bags:

- 5 Kendall Kangaroo Y-site ext. sets
- 16 boxes Kendall Argyle tubes, 8 Fr. 16"
- 31 Ross Companion top-fill 500ml bags
- 67 Ross Companion 500ml bags
- 68 Ross Companion top-fill 1000ml bags
- 22 Ross Companion pumps sets
- 25 Zevex Enteralite 1200ml bags
- 15 Zevex Enterlite Infinity bags, 500ml
- 10 cases Zevex 1200ml pump sets
- 10 cases Zevex 500ml pump sets
- 11 EN ext. set, 60", luer lock female
- 28 Kangaroo Gravity Sets #8884702500
- 28 Ross Top Fill 1000 ml Nutri Bags
- 75 Ross Enteral Gravity Sets #56

MORE SUPPLIES are available! Visit www.oley.org, or contact our volunteer, **Ben Hawkins** (benhawkins@fuse.net; toll free 866-454-7351). This number reaches Ben's home, so **PLEASE, CALL BEFORE 9 P.M. EST!**

Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. We ask that those receiving goods offer to pay the shipping costs.

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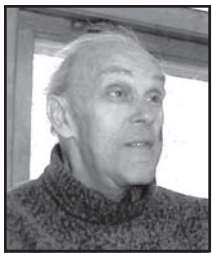
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Be All You Can Be, from pg. 2

I looked down to see my G tube on the dirty, greasy shop floor. My first thought was, 'The hole in my stomach will close up very soon if I don't do something quick.' My second was whether I should clean off the dirty tube before reinserting it. The next question was how to hold the tube in place while driving ten miles to the hospital. So I looked around for some duct tape. 'You know how hard it is to handle with two hands?

**Flute Snyder**

Try holding in your G tube and the roll of tape with one hand, and tearing off a piece with your other!' Eventually I taped the tube to my stomach skin, excused myself, and drove to the hospital.

The fiasco continued there when, after a considerable wait, the nurse informed me that the G-tubes had been packed for a move to the new hospital location. Then inside the operating room, the doctor asked, 'What's the best way to do this?' It was clear he hadn't done the procedure before. I suggested I lay on my back to keep the fluids from spewing out all over the place. 'Good idea.' So, he took the duct tape off, removed the old tube and inserted the temporary replacement: a urinary catheter that was four times as long as my G tube. Keeping my wits, I quipped, 'It looks like it is designed to fit Wilt Chamberlain!'"

Shawn Boulette, RN, BSN, was thirteen when he first went on TPN 27 years ago. He discussed how teens can successfully transition to independence. Get the child involved in their own care; give them an active role. He feels that "the less you expect from the consumer, the less they will expect from themselves." Getting the child involved also gives them a sense of control. Set goals like going to college and moving out of their parent's home. He doesn't believe in setting time frames because the consumer may be discouraged if there are setbacks. Shawn feels that if you change your perception, you can change your reality. Have a positive attitude and turn negatives into positives. He also feels it is important to have a very good home care provider. A good home care company can help give the consumer a sense of control on a day-to-day basis, as well as when they travel.

Carol Pelissier had endometriosis at age nine and later developed a motility disorder that led to a total colectomy at age 37. She is on tube feeding and morphine, and had to stop working as a medical assistant. She believes in shifting your thinking from yourself to other things. "Focus on the things you can do," she advises, "not the things you can't."

Roy George-Thiemann is 17 and has short gut secondary to Hirschsprung's disease. He spoke about the challenges of being a teenager on TPN. He feels his mother's terrific parenting skills were a big part of the reason he has dealt so well with his challenges. Roy has been on TPN since birth. When he first began school his mother educated the children and teachers about his medical condition and need for TPN. He played sports, (soccer and track) and is very involved in musical theatre. His mother, Madeline George-Thiemann shared how Roy likes to teach others and loves to play the piano and sing. Roy echoed that consumers need to find an outlet for their feelings.

**Roy George-Thiemann****Take My Advice**

By **Robin Lang**

Many people hop in their car and think, "Well, I'm only going down the street. I don't need my seat belt." Inevitably that's when an accident happens. Recently I decided to take a spin on my roller blades. I only had a few minutes for this activity so I didn't take time to put on my wrist guards. Yes, you guessed it. I fell backwards and fractured my wrist. How does a person hook up to TPN without the use of one of their hands – especially their dominant hand?

Fortunately for me, I had faced and solved this same problem last fall. I was scheduled to have tendon release surgery on my right thumb. Two weeks prior to surgery I pretended I could only use one hand. I did pretty well with one major exception; I couldn't spike the TPN bags. I spoke with other consumers, doctors, nurses and friends. Their only suggestion was a visiting nurse. I have been on TPN for 26 years and have only had six or eight nursing visits. I have two very excitable dogs and was not looking forward to the commotion which two nursing visits a day would cause.

One day while discussing my quandary with a staff member at Oley, she remembered hearing about a woman with a hand problem whose homecare company pre-spiked her bags for her. Voila! TPN and independence. She solved my problem, albeit with the cooperation of my homecare company. Pre-spiked bags only last one week, so I had to sacrifice my monthly delivery for a short time but it was a small price to pay.

My advice is if you are ever faced with a problem with your hand or arm, check with your homecare company. They, too, may pre-spike your bags until you can resume your regular TPN needs for yourself. Keep challenging yourself. Keep enjoying life. And if you hit a roadblock, ask for help. Chances are someone at Oley has the answer for you or they know someone who does.

A Miracle in Salt Lake City

It was yet another exciting Oley meeting in Salt Lake City. People gathered together looking for old friends and making new ones. We enjoyed the laughter of the kids and adults and learned a lot. Truly, this conference is a miracle given the many "mountains" everyone must "climb" to come together.

There was a special miracle at this meeting when one of our group needed some help. His old car got him to Salt Lake City, but it wouldn't get him home. He needed more cash than he had to fix it. In the true spirit of caring, an announcement was made and the "hat" was passed. In less than two hours, the money had been raised — from people who scrimped and saved to get to this meeting, from people who didn't know this person, but knew he needed help. Oley members also helped him with the repair process, and to make the most of his extended stay in Salt Lake. He made it back home safe and sound due to everyone's efforts.

These actions demonstrate the true spirit of the Oley Foundation. Oley is about people helping people: consumers helping each other, consumers helping clinicians, and clinicians helping in return. For all of you who participated in this miracle, know that you each made a difference in one man's life and many others.

— *Conference Attendee*

Thank You, Thank You

Many thanks to the following companies and individuals for their generous contributions of time and money to the 2006 Oley Consumer/Clinician Conference.

Conference Co-Chairs:

Rick Davis; Lorraine Linford, RN, CNSN; Cheryl Thompson, PhD, RD, CNSD

Conference Planning Committee:

Salt Lake Convention & Visitors Bureau; Gastronomy, Inc; Mariah Abercrombie; Toni Anderson; Felice Austin; John Bacon; Nathan Bascom; Scott Beck; Sharon Caldwell; Gretchen Davenport, RN; Shawn Fojtik; Lori Fullerton, MS, RD, LD; Tom Guinney; Stacy Hale; Robbi Hogan; Jennifer Hyde, RD, CD, CNSD; George Johnson; Katy Kessinger, MS, RD, CNSD; Robin Lang; Bob Larson; Hau Le, RPH, MS; Mindy Lewburg; Michael Mack; Von Nelson; Bryan Nichols, RPH; Tom Pilger, RPH; Kristy Bemis-Rennemeyer; Julie Rhoads; Reesalee & Dale Shutt; Josie Stone, NP; Jennifer Street; Clinton Wasuita; Gayle White; Jeff Zwick

Preconference Hike/Walk:

Lee Adamson; Rick Davis; Jody Doner

Registration:

Salt Lake Convention & Visitors Bureau; Scott Beck; Myrna Burningham; Tammy Collings; Kristi Despain; Katie Dolar; Annie Harrell; Natalie Hatch; Jeff Hoelle; Sheryl Jones; Nicole Maughan; Kristy Bemis-Rennemeyer; Jed Stowers; Larry Vaughan; Alyson Watt

Child Care:

Option Care; Volunteers coordinated by Infusion Innovations; Deanne Birch; Christy Coe; Julie Devore; Georgia Flanders; Christine Hale; Tara Maynard; Autumn Marie Perea; Kristy Bemis-Rennemeyer; Megan Stover; Tamra Vawdrey

Faculty:

John Bacon; Deanne Birch; Shawn Boulette, RN, BSN; Patricia A. Brown, RN, MSN, CNSN, OCN; Claudia E. Campbell, RN, BSN; Terry Clemmer, MD, FCCM, FCCP; Sharlene Coombs, RD, CD, CSP, CNSD; Gretchen Davenport RN, CRNI; Rick Davis; John K. DiBaise, MD; John C. Fang, MD; Roy George; Cynthia Hafner, RN; Suzette Holt, RD, CNSD; Lyn Howard, MB, FRCP, FACP; Jennifer Hyde, RD, CD, CNSD; Kishore Iyer, MBBS, FRCS, FACS; Khurshed Jeejeebhoy, MB, BSc, PhD, FRCP; Darlene G. Kelly, MD, PhD, FACP; Katy Kessinger, MS, RD; Jim Lacy,

RN; Mindy Lewburg; Lorraine Linford, RN, CNSN; Judi Smith-Martuscelli; Frank A. Murawski; Alyce Newton, MS, RD, CNSD, LDN; Bryan Nichols; Reid A. Nishikawa, Pharm. D., BCNSP, FCSHP; Carol A. Pelissier; Craig Petersen RD, CNSD; Susan Poole, RN; Kristy Bemis-Rennemeyer; Glenn E. Richardson, PhD; Helen Rollins, RN; Douglas L. Seidner, MD; Carol Smith, RN, PhD; Robert "Flute" Snyder, PhD; Josie Stone, RN, CPNP, CRNI; Marc Stranz, PharmD; Stephen Swensen; Cheryl Thompson PhD, RD, CNSD; Clinton Wasuita

Exhibitors:

Apria HealthCare; Bard Access Systems; BD Medical Systems; Boston Scientific Corp; Calmoseptine, Inc; CME Devices; Coram Inc.; Critical Care Systems; Hospira Worldwide, Inc; Infusion Innovations; Intermountain Homecare; Kimberly-Clark; Logan's G-Tube Accessories; Nestlé Nutrition; Novartis Medical Nutrition; Nutrishare, Inc; Octic Medical Devices; Option Care, Inc; Ross Products Division, Abbott Laboratories; Salt Lake Convention & Visitors Bureau; Serono, Inc; Tyco Healthcare/Kendall; Zevex Inc

Youth Activity:

Program — Ross Products; Transportation — Salt Lake Convention and Visitors Bureau; Heidi Falk; Pat Holmes

Silent Auction:

Salt Lake Convention & Visitors Bureau; Mariah Abercrombie; Dusty Allred; Felice Austin; Scott Beck; Myrna Burningham; Michelle Campbell; Susie Collins; Kristi Despain; Michelle Howe; Patricia Isabella; Janet Platt; Sanford Schimel; Kate Schoening; Scott Seager; Tina Stark; Jean Tracy

Lunch (Friday):

Coram Inc.

Jammin' Jammies:

Option Care; Sheraton City Centre; Rose Hoelle and Patty Woods

Oley Walk-A-Thon:

BD Medical; CeraLyte; The Church of Jesus Christ of Latter-Day Saints; Coram Inc.; Critical Care Systems; The Delta Center; Farmer's Market; The Gateway; Nutrishare, Inc.; Ross Products Division; Salt Lake City Downtown Alliance; Salt Lake Convention & Visitors Bureau; Salt Palace Con-

vention Center; Utah Jazz; Lee Adamson; Brent Allenbach; Kim Angeli; Scott Beck; Ellen Birrell; Nikki Brice; Myrna Burningham; Sharon Caldwell; Allison Chappell; Susie Collins; Rick & Dianne Davis; Jennifer

Epperson; Robert Farrington; Devon Glenn; Peter Grundfossen; Kate Hanks; Patrice, Adam and Christine Isabella; Amber Ivie; Tracy James; Dan Jones; Sheryl Jones; Katie Kessinger; Mindy Lewberg; Lorraine Linford; Jennifer Miller; Larry Miller; Bryan Nichols; John Pace; Todd Pace; Tom Pilger and family; Peter Poulsen; Joan Proctor; Marjorie Quinn; Amy and Jon Rahl; Marcy Reed; Raylene and Lamar Reed; Aaron Rennemeyer; Kristy Bemis-Rennemeyer; Chip Smith; Bob and Gwen Springmeyer; Cheryl and Greg Thompson; Tamra and Samantha Vawdrey; Clinton Wasuita; Lisa Whitmer; Andrea Wilkinson; Camille Winner...and thank you to everyone who walked or sponsored a walker!

Annual Picnic:

Catering — Nutrishare, Inc.; Transportation — Serono, Inc. Special recognition to Salt Palace Convention Center / Allyson Jackson; Utah Food Services / Robert Sullivan; and our masseuse, Rich Mendoza.

General Conference Support:

Salt Lake Convention & Visitors Bureau; Scott Beck; Pat Brown, RN, CNSN; Allison Chappell; Heidi Falk; Annie Harrell; Natalie Hatch; Jane Lindsay; Michael Mack; Sheila Messina, RN, MA; Marjorie Quinn; Diane Utley

Publicity / Promotion:

Salt Lake Convention & Visitors Bureau; Scott Beck; Karen Boe; Sean Buckley; Curtis Calder; Mark Crosby; Anne Heller; Patrice Isabella; Kate Schoening; Shawn Stinson; Tamme Thompson

Medical Support:

Coram Inc., Infusion Innovations, LDS Hospital with Intermountain Healthcare



Jeff Hoelle helps out at the Oley registration desk.

Conference Media:

Abbott Laboratories/Creative Network; Joel Resnick; Stephanie Pelham

Conference Bags:

Nutrishare, Inc.

Registration Brochures:

Hospira Worldwide

Program Books:

Kimberly-Clark

Transportation:

Salt Lake Convention & Visitors Bureau; Avis Rent-A-Car; Scott Beck; Frank Jones

Travel Scholarships for Consumers:

Anonymous; Bruce Groeber Memorial Fund; Critical Care Systems; Melissa Chaney Memorial Fund; Nutrishare, Inc.; Serono, Inc.; Sunshine Scholarship

Support for Speakers:

Albany Medical Center; BD Medical Systems; Boston Scientific; Children's Memorial Hospital, Chicago; Cleveland Clinic; Coram Inc.; Infusion Innovations; Intermountain Pain Center; LDS Hospital; Mayo Clinic, Rochester; Mayo Clinic, Scottsdale; MD Informatics, LLC; Memorial Sloan-Kettering Cancer Center; Nutrishare, Inc.; Ross Products Division; St. Michael's Hospital; Salt Lake Convention & Visitors Bureau; University of Kansas Medical Center; University of Utah

Educational Materials:

Intermountain Healthcare

Focus Groups:

Kimberly-Clark...and thank you to the participants!

Ongoing Research Trials

HPN Technology & Troubleshooting

HPN consumers and their caregivers are needed to help us gain insight into the use of technology to assess and troubleshoot issues and complications that relate to home nutrition support. With funding from the NIH, the Oley Foundation and Carol Smith, RN, PhD are coordinating the effort.



Caregivers/support persons are defined as anyone who assists the consumer in any of the following ways: accompanying them to physician visits, picking up prescriptions, navigating through insurance issues, trouble shooting complications, organizing and/or inventorying supplies, coordinating health care professionals, etc.

We invite you to help us uncover valuable information that could impact the care of many Oley members. Please note that:



- Opinions will be collected via checklists that are anonymous.
- Checklists/opinions will be mailed to a university research center.
- A summary of all (200+) participants' responses will be reported.
- The required computer, telephone

and Internet connection will be provided, along with training.

- A small fee will be given to each participant.

Anyone interested in learning more can complete the form on-line at www.oley.org; email bishopj@mail.amc.edu; or call (800) 776-OLEY.

HPN and the Meaning of Food

HPN consumers are needed to discuss by telephone, what it is like to receive home parenteral nutrition (HPN) and the meaning of food in their life. To be eligible, participants must: **1)** receive PN at home for less than 10 years; **2)** have a diagnosis of intestinal disease, intestinal failure, short bowel syndrome, radiation enteritis, or inflammatory bowel disease; **3)** not have major depression; **4)** be older than 18 years of age; **5)** speak English; and **6)** be willing to talk about their experiences during a telephone interview lasting about 60 to 90 minutes.

Confidentiality of all information will be maintained. The interviews will be coded and the participants' identity protected. For more information contact Marion Winkler, MS, RD (800-217-6035; winklema@umdnj.edu).

All of the research studies listed have been deemed appropriate for homePEN consumers/caregivers by the Oley Research Committee; however, *The Oley Foundation strongly encourages anyone considering participating in medical research to discuss the issue with their managing physician before signing up.*

More information on these studies is available by calling (800) 776-OLEY or visiting our web page at www.oley.org. Clinicians interested in having their study listed should complete the form listed on Oley's web page or fax the same information to (518) 262-5528.



Who says Home TPN and tractors don't mix?

Certainly not Don Young. Whether working his land, attending a concert or visiting his loved ones, Don doesn't let being a Home TPN consumer for 30 years keep him from doing what he wants to do. Coram consumers are like that. We have a long list of consumers like Don. They know life goes on. They face challenges everyday. And Coram is there to help them. The more we get involved with consumers like Don, the more we learn from them. We got him started. And we'll be there for the long run.

Contact us toll-free:
1-866-4-HomePEN (1-866-446-6373) and
visit us on the Web at www.coramhc.com.



Coram consumers. Going places. Doing things. Living life.



Walking to Support Oley Programs

The Second Annual Oley Walk-A-Thon, held July 1 in Salt Lake City, was very successful. More than \$7,000 was raised for Oley programs and additional pledges are expected. Walkers had a beautiful day, and enjoyed the 5k route that wound through several sites of interest like the Farmer's Market, the Delta Center and Temple Square.

Following is a list of people who gathered sponsorships. They participated by walking in Salt Lake City, walking in their hometown or by sponsoring a designated walker. Thank you to everyone who walked or sponsored a walker.

Leah Atkinson	Robin Lang
Mike Battaglia	Mindy Lewberg
Betty Marie Bond	Denise Lind
Betty, Buddy & Jerry Bond	Michael Medwar
Shawn Boulette	Jon Morningstar
Sally & Bill Bowers	Alyce Newton
Chuck & Gail Brenenstuhel	Craig Peterson
Janice Corbin	Tom, Alex & Emily Pilger
Penny Crittenden	Marjorie Quinn
Frances Culp	Aaron Rennemeyer
Roslyn Dahl	Lawrence Scott
Rick & Dianne Davis	Flute & Ann Snyder
Trisha Fuhrman	Tina & Richard Stark
Barbara Gatlin	Barbara Stark
Madalyn & Roy	Josie Stone
George-Thiemann	Kate Swensen
Ray Gravenstein	Liz Tucker
Rose & Alicia Hoelle	Kathleen Tushinski
Lyn Howard	Tamara & Samantha Vawdry
Scott Hummer	Addie Vigil
Carol Ireton Jones	Robert Warrington
Adam & Christine Isabella	The Woods Family
Shai Johnson	The Zimmerman Family

Individual Donors Make A Difference!

The following list represents everyone who generously contributed towards Oley's efforts between May 4th and July 26th, 2006. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

Ambassadors (\$2000+)
 Victor Chaney
 Darlene Kelly, MD*
 Nancy Nicholson Bequest

Alice Gustafson
 Charles Henrich

Presidents Circle (\$1000-\$1999)
 Frona Brown, in honor of Ester Adler

Friends (Up to \$30)
 Michael & Sue Backenmueller
 Dieter & Sharon Bargel
 Jacqueline Anna Breckling
 Mrs. Bernice Carpenter
 Marilyn Dolan
 Mr. & Mrs. Robert H. Ikier
 Steve & Janet Krohmer
 Lisa Marple-Evidon
 Joan & Elias Medwar, in memory of Katherine Cotter**
 Guy & Madeline Pfeiffer, in memory of Disney Pfeiffer

Benefactors (\$500-\$999)
 Anonymous*
 Jane Balint, MD*
 Lyn Howard, MD***
 Marjorie & Frank Miller

Sponsors (\$250-\$499)
 Susanne & David Appel
 CONNSPEN on behalf of Exec Board
 MAVAN
 United Way of Northeastern NY

In Memory of Ashley Russo
 Dana Cunningham
 Michael Busta
 Eileen Franey
 Gregory Kempf, DC
 Frances Shaul

Patrons (\$100-\$249)
 Milton Abercrombie
 Robert & Molly Davis
 Richard & Faith Dillon
 Melanie Fitzpatrick
 Todd Friedman
 Trisha Fuhrman, in honor of Carol Ireton-Jones
 Michael Grimes
 Portia & Wallace Hutton
 Grant Johnson
 Kathy Mayo
 Less & Julie McNamee
 Eugene Worek
 Sheryl Young via Allstate Giving

In Memory of Paul Sawitzki
 Lisa & Scott Brennan
 Alan & Regina Cornelius
 James & Linda Delsavio
 Laura & Frank Falco
 Ted & Lucille Farell
 Christine & Richard Getman
 Gary Gillan
 Louis Gowie
 William Meleski & Melanie Fitzpatrick
 Mohawk Resources
 Tom, Karen & Lou Pasquarelli
 Marie Pietzykowski
 Post 701 Softball Team
 The Richmond Family
 Robert & Lesia Thaisz
 Bruce Van Genderen
 Shirley & Phillip Willette
 Gary & Stephanie Wusterbarth

Supporters (\$50-\$99)
 Felice Austin*
 Pat Brown, RN
 Christina Fleet
 Mary Friel
 The Gravenstein Family, in honor of Carol Ireton-Jones
 Jane Lindsay
 Mercedes Marson
 Todd & LeighAnn Olson

* Oley Trustee
 ** Oley Regional Coordinator
 *** Oley Staff

Contributors (\$30-\$49)
 Susan M. Andrew



Corporate Donor Program Update

Apria Healthcare presented Oley with a very generous contribution at the Corporate Donor Recognition Ceremony held during the annual conference in Salt Lake City. The company now joins Serono, Inc. at the Bronze Star Partner Level. (Our apologies for misprinting Serono's level last issue.)

We also thank Critical Care Systems for their continuing support at the Patron Level. We are very excited to have these companies partnering with us. Their efforts strengthen our circle of support and ensure the continuation of quality programs. Thank you!

Apria Healthcare

Apria Healthcare Group Inc. is a leading national provider of home healthcare products and services, including parenteral and enteral nutrition, antibiotics and other therapies. With over 500 branch and 31 infusion pharmacy locations nationwide, Apria serves over 1.5 million patients annually through all 50 states.

Apria's Nutrition Advantage program's team of nutrition support dietitians, IV certified nurses and registered pharmacists provide expert clinical care for patients with nutritional deficiencies. Apria Nutrition Advantage is a nutrition support program providing customized care approach to patients' nutritional needs. The company's mission is to be

the first choice of patients and customers for their home care needs. The company will accomplish this by exceeding its customers' expectations every day; demonstrating high clinical standards and compassion in patient care; and being responsive and flexible.

Critical Care Systems

Critical Care Systems is a leading national specialty infusion company providing comprehensive clinical services to pediatric and adult populations through a national footprint of JCAHO accredited community-based branches. The company's Specialty Nutrition Support Program is supported by a team of dietitians, nurses, pharmacists and reimbursement specialists who excel in parenteral nutrition, clinical support and customer service. Whether their customers require short or long term therapy, Critical Care Systems provides flexible, individualized care adapted to the consumer's lifestyle. It is the company's belief that customized nutrition support, "state of the art" Standards of Practice, and a team of TPN experts, leads to optimal outcomes. The company's 96% satisfaction rate demonstrates their mission that "Patients are the center of all we do." Critical Care Systems is proud to support the Oley Foundation.

Oley Foundation 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 call Joan Bishop or Roslyn Dahl at 800-776-OLEY.

<i>John Balint, MD</i>	<i>Valerie Gyurko, RN</i>	<i>Rodney & Paula Okamoto, RPh</i>
<i>Joan Bishop</i>	<i>Alfred Haas</i>	<i>Kay Oldenburg</i>
<i>Ginger Bolinger</i>	<i>Alicia Hoelle</i>	<i>Judy Peterson, MS, RN</i>
<i>Pat Brown, RN, CNSN</i>	<i>Jeff & Rose Hoelle</i>	<i>Clemens Pietzner</i>
<i>Katherine Cotter</i>	<i>Lyn Howard, MD</i>	<i>Beverly Promisel</i>
<i>Jim Cowan</i>	<i>William Hoyt</i>	<i>Roslyn & Eric Scheib Dahl</i>
<i>Ann & Paul DeBarbieri</i>	<i>Darlene Kelly, MD</i>	<i>Steve Swensen</i>
<i>Tom Diamantidis, PharmD</i>	<i>Family of Shirley Klein</i>	<i>Cathy Tokarz</i>
<i>Selma Ehrenpreis</i>	<i>Robin Lang</i>	<i>Eleanor & Walter Wilson</i>
<i>Herb & Joy Emich</i>	<i>NEW! Hubert Maiden</i>	<i>James Wittmann</i>
<i>Don Freeman</i>	<i>Judi Martuscelli</i>	<i>Patty & Darrell Woods</i>
<i>Linda Gold</i>	<i>Kathleen McInnes</i>	<i>Rosaline Ann & William Wu</i>
<i>Linda Gravenstein</i>	<i>Meredith Nelson</i>	
<i>The Groeber Family</i>	<i>Nancy Nicholson</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.

For their continued interest and strong commitment we remain grateful.

PLATINUM LEVEL PARTNERS
(\$70,000+)
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS (\$50,000-\$69,999)
Coram Healthcare

SILVER CIRCLE PARTNERS
(\$30,000-\$49,999)
Novartis Nutrition

BRONZE STAR PARTNERS
(\$20,000-\$29,999)
Apria Healthcare
Serono, Inc.

BENEFACTOR LEVEL PARTNERS (\$10,000-\$19,999)
Ross Products Division/
Abbott Laboratories

PATRON LEVEL PARTNERS
(\$5,000-\$9,999)
Critical Care Systems
Hospira Worldwide
Option Care, Inc.

BLUE RIBBON PARTNERS
(\$2,500-\$4,999)
Baxter Healthcare
Daniel F. & Ada L. Rice Foundation
Nestle

CONTRIBUTORS (\$1,000-\$2,499)
BD Medical Systems

FRIENDS (\$500-\$999)
Accreditation Commission for
Health Care, Inc.

Toll Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the US and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Regional Coordinators with a better grasp of their region's needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

The schedule of toll-free numbers and volunteer coordinators is updated in each LifelineLetter, and posted on our web page @ www.oley.org. Comments? Call (800) 776-OLEY.

SEP. '06	<p>Jane Golden Watertown, CT (888) 610-3008 EST</p>	<p>Jane has been on TPN since 1993 due to SBS. She has been an RC for many years, has attended several Oley conferences and is an Oley board member. She feels strongly that SBS survivors need other survivors to network with. She worked outside the home until a few years ago and is married.</p>
	<p>Bruce & On Braly Davis, CA (888) 650-3290 PST</p>	<p>The Braly's 17 y.o. son Matthew has been on TPN since the age of 9. He has short bowel syndrome due to malrotation of the gut and uses a CADD pump. They have traveled abroad with TPN and look forward to sharing their experiences with you.</p>
OCT. '06	<p>Joseph Rogers New Bedford, MA (888) 610-3008 EST</p>	<p>A new Regional Coordinator, Joseph has been on and off tube feeding for the past 6 years due to end stage Achalasia, a rare disease. In 2000 Joseph had his esophagus removed and his stomach stretched and attached. Joseph is an RN and currently has a J-tube. He looks forward to hearing from you.</p>
	<p>Candace Verners Victoria, BC, Canada (888) 650-3290 PST</p>	<p>Candace is 42 years old and has short bowel syndrome due to a Crohn's-related bowel resection. She has been on TPN for the past 10 years. Candace became pregnant while on TPN and now has a very healthy and happy 8 year old son. She has experience with a port-style catheter and Remicade therapy. The best time to call is between 9-5 PST.</p>
NOV. '06	<p>Lou Pacilio Leeds, MA (888) 610-3008 EST</p>	<p>Diagnosed with sarcoidosis Lou developed a swallowing disorder. He was on TPN briefly, then weaned to J-tube feeding 7-1/2 years ago. He works part-time as a radiologist. He is experienced with changing feeding tubes, caring for ostomy sites and coping with not being able to swallow his own saliva in public.</p>
	<p>Portia Hutton Ft. Myers, FL (888) 650-3290 EST</p>	<p>Portia is 75 years old and has short gut syndrome due to a blood clot in her superior mesenteric artery. She has been HPN dependent since March 1999. She enjoys working during tax season as a CPA. She has been married to her husband Wally for 53 years; they have two grown sons.</p>

LifelineLetter

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

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Thanks for a great conference!