Parenteral Nutrition, Liver Disease, and N-acetyl Cysteine in Infants and Children

Diana Mager, PhD, RD

Editor’s note: There are many people working on the issue of liver complications associated with parenteral nutrition, particularly in children. This article discusses one approach that is experimental, but that appears to offer benefit.

Severe bowel dysfunction can be treated with parenteral nutrition (PN). However, one of the serious complications of this therapy is parenteral nutrition associated liver disease (PNALD). This is more common in children than adults. Estimates of mortality from liver failure are highly dependent on the group of children studied. In France, in a large cohort of children on homePN for digestive diseases (230 children), ages 0.8 to 16 years, the mortality from liver failure was 2 percent.1 In a more vulnerable population of children, in a neonatal intensive care unit in Canada, the mortality from liver failure was 37.5 percent.2

PNALD typically results in changes in liver function that range from mild to moderate changes in liver biochemistries and fatty infiltrate of the liver to inflammation, fibrosis, and cirrhosis with or without pronounced jaundice. In some patients (particularly young infants), disease progression can be rapid, with cirrhosis developing within a few months.3, 4 This can result in end-stage liver failure, necessitating short bowel transplantation, with or without liver transplantation.

The current article will address some of the factors provoking PNALD in infants and children, with an emphasis on how changes in nutritional composition of PN (the amino acid composition) may alleviate this condition. Specifically we will describe how the use of N-acetyl cysteine (Mucomyst®) provided novel...
Catheter-related bloodstream infections lead to bacterial growth and proliferation, which in turn leads to bacterial production of endotoxins and oxidative damage within the liver. The use of sterile techniques can reduce the risk of catheter-related bloodstream infections, thereby protecting the liver.

Stimulation of the gastrointestinal (GI) tract by nutrients present in food is necessary to ensure that cells in the gut maintain their health and function. Lack of enteral stimulation in the gut results in an increased risk for bacterial overgrowth within the GI tract. Bacterial overgrowth in the proximal gut can interfere with the digestion process and gut motility, leading to nutrient malabsorption and other difficulties with weaning from PN. The introduction of food in the gut can reduce abnormal bacterial overgrowth within the upper GI tract. In children dependent on PN, however, the introduction of food should only be done when the physician deems it safe.

At present, it is not completely understood how the nutrient composition of PN solutions may contribute to an increased risk for PNALD in infants and children. This is central to our discussion, however, and will be considered in more detail in the following sections.

**Nutritional Issues and PNALD**

While there is no one single nutritional treatment for PNALD, typically the goal is to encourage food intake by mouth, or if this is not tolerated, through an enteral tube, in an effort to wean children off PN or at least minimize the amount of PN used to meet nutritional requirements for growth. These efforts ensure that the toxic effects of PN are minimized and that luminal nutrients stimulate gut cell growth and motility, which in turn reduces bacterial overgrowth.

It is known that it is important NOT to provide an excess of energy (calories) in the PN as this may lead to metabolic and hormonal changes that stress the liver and contribute to an increased risk for PNALD. However, it is essential to avoid feeding suboptimal amounts of nutrition to the child dependent on PN. Like excessive feeding, nutritional deficiency can contribute to an increased risk for liver disease in children and adults dependent upon PN. Hence, it is important to provide the right balance of nutrients to avoid the development of PNALD and to promote growth and development in infants and children.

**Nutritional Composition of PN**

There is some evidence that the amino acid composition of PN solutions might contribute to the toxic damage to the liver (hepatotoxicity) by PN solutions. Of particular concern are the sulfur-containing amino acids: methionine (MET), S-adenosyl methionine (SAM), and cysteine (CYS). Figure 1 shows how these amino acids are interconnected and how CYS is a precursor for the main intracellular (cytosolic) antioxidant glutathione. Glutathione, in turn, appears to stabilize the enzymes responsible for the MET → SAM → CYS conversion. PN solutions contain little or no CYS because it is highly insoluble, and no SAM because it is highly insoluble. It is known that it is important to provide CYS as this may lead to metabolic and hormonal changes that stress the liver and contribute to an increased risk for PNALD. However, it is essential to avoid feeding suboptimal amounts of nutrition to the child dependent on PN. Like excessive feeding, nutritional deficiency can contribute to an increased risk for liver disease in children and adults dependent upon PN. Hence, it is important to provide the right balance of nutrients to avoid the development of PNALD and to promote growth and development in infants and children.

**Liver Disease, cont. pg. 9**
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 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.

Udderly Practical

We recently had this e-mail from an Oley member regarding a bad smell at her stoma site:

My doctor says it’s a low-grade infection and nothing to worry about. I tried a round of antibiotics and triple antibiotic cream, which did not help at all. I have had a feeding tube for two and a half years with no problem until five months ago.

I tried several different things to get rid of it. This is what worked: I put a layer of Udderly Smooth udder balm on first and then a folded square of toilet paper around the site. In a couple of days the smell was gone. The itching stopped immediately.

I’ve had a little bit of odor back, but it is still a remarkable difference for the better. I have had a BIG improvement since I started the Udderly Smooth.

I would welcome any correspondence through e-mail.

Coleen Neeley
Birdwatcher404@yahoo.com

One of our clinician advisors also made this suggestion:

What some of our patients do—if they are using a dressing—is get oil of peppermint/wintergreen from a pharmacy and put a drop on the dressing, which should help with masking smell.

Exceptional Deal from Exceptional Parent

Exceptional Parent magazine is offering Oley members a sweet deal: name the Oley Foundation as your charity of choice and they’ll take 31 percent off your twelve-month subscription to the magazine (you’ll pay only $34.95). Plus they’ll donate $10 to the Foundation.

Exceptional Parent offers information and inspirational stories for parents of children with disabilities. For more information about the magazine, visit www.eparent.com. To order a subscription with the Oley Foundation discount go to www.kable.com/pub/epar/spdonations.asp, and select the Oley Foundation as your “Preferred Organization to Receive EP’s $10 Donation.”
Information Exchange at Clinical Nutrition Week

Lisa Crosby Metzger

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is to clinicians what Oley is to consumers: a source of information and support regarding IV and tube feeding. At Clinical Nutrition Week (CNW), A.S.P.E.N.’s big annual meeting, the focus is on sharing the newest and best research and techniques and bringing together professionals from many specialties.

Oley staff, board members, and volunteers were at CNW in February. There we gathered information that we hope will benefit consumers, and we disseminated information that we hope will benefit clinicians and, hence, their consumers. By the end of the conference, we’d like to think most everyone had heard of the Oley Foundation (thanks in no small part to Dr. Lyn Howard and Bettemarie Bond, as you’ll see below).

Micronutrients in HPN

Research is featured prominently at CNW, and a research workshop traditionally precedes the actual conference. This year, Oley founder Lyn Howard, MB, FRCP, and former Oley board member Alan Buchman, MD, MSPH, FACCP, FACG, organized and chaired an exciting two-day workshop on micronutrients in home parenteral nutrition (HPN).

In 1979, and again in the mid-1980s, the American Medical Association established guidelines regarding micronutrients in PN. Concerned that these guidelines and the resulting Federal Drug Administration recommendations are outdated, Dr. Howard and Dr. Buchman located funding for the workshop and invited specialists from around the world to present the most up-to-date research on several micronutrients where new data or controversy exists.

“We hope,” said Dr. Howard, “this research workshop will lead to an FDA multi-trace element reformulation and the availability of safer commercial products. In fact, a highly desirable outcome would be parenteral micronutrient formulas that meet international acceptance.”

The research proceedings will be published in an upcoming issue of Gastroenterology. We hope to bring you pertinent information from some of these specialists in the LifelineLetter as well. We’ll keep you posted on the conclusions.

Giving Voice to the Consumer

CNW offers a great opportunity for consumers to present their perspective to clinicians. This year, Oley members Sheila Messina and Bettemarie Bond addressed an audience about cultivating an effective consumer/clinician relationship. Between them, Sheila and Bettemarie have many years of homePEN experience. Using examples from their own lives, they helped clinicians get a glimpse of life on the other end of the tubing.

Sheila Messina also had a poster accepted for presentation at the conference. In the poster, Sheila detailed how, with the continuous infusion of medicine to control her blood pressure, she has been able to maintain a desirable blood pressure while also maintaining her independence and minimizing the number of times her central line has to be accessed. We hope to post this information on the Oley Web site.

Advocacy Award

This year, A.S.P.E.N. inaugurated the Lyn Howard Nutrition Support Consumer Advocacy Award. When Dr. Howard introduced the award, she made the following remarks: “An experience that we nutritional professionals share is the transforming effect of nutrition support therapy. We watch depleted and depressed individuals who realize their gut is no longer dependable slowly regain their strength and slowly their belief in the future.

“Sometimes, because the gut insufficiency persists, this recovery is much tougher, as this complex nutritional therapy must continue indefinitely and be incorporated into a life plan. As watching professionals, we are not sure we ourselves could do this.

“As the person and their family learns to pick up this burden and walk, our respect grows and we feel very privileged to work with such courageous individuals.

“These people are clearly one of the flagships of A.S.P.E.N.’s professional success. I am delighted A.S.P.E.N. has decided to recognize these individuals and their supporting professionals. I am deeply honored to be linked to this award.”

Bettemarie Bond was the first recipient of this newly established award. “I am honored to receive an award named for Dr. Howard,” Bettemarie said. “Her work has truly bettered my life as well as countless others on PN. I am so grateful to her.”

In 2008, Bettemarie participated in the Digestive Diseases National Coalition Public Policy Forum. One of Bettemarie’s goals was to urge Congress to support the Medicare Home Infusion Act. This act would allow those on nutrition support to work and receive Medicare benefits, which would help them to better manage treatment costs.

After Bettemarie received the award and shared her story, the audience of 1,800 stood and loud applause filled the room. An emergency room nurse later commented that she was very moved by Bettemarie’s story. She, like many clinicians, routinely sees patients in crisis, but seldom meets homePEN consumers in other settings. She found it gratifying to know that people can walk out of the hospital and go on to live their lives with enthusiasm and joy.

Clinicians share research findings at micronutrient workshop.
What’s the Big Idea?

Baxter Healthcare Corporation’s “Making a Difference” campaign gave Oley programs a double lift this February at Clinical Nutrition Week. Baxter representatives introduced Oley programs to professionals who visited their booth, and donated $10 for everyone who had his or her photo taken. Their target goal of raising $2500 for Oley programs was quickly met. Oley Foundation president Rick Davis and executive director Joan Bishop showed their appreciation as they accepted the BIG check from Baxter representatives. Thank you Baxter!

Bettemarie participated in advocacy efforts on Capitol Hill again this year. Her activities help politicians realize that homePEN, although expensive, can lead to very substantial rehabilitation. (See also Joan Bishop’s article on Oley advocacy efforts on page 8.)

Exhibiting

The Oley booth was a hub of activity. We talked to hundreds of people. If you think your clinician would benefit from information about Oley, let us know! We’d be happy to send out a packet.

Our sincerest thanks to the volunteers who helped staff the Oley booth: Oley President Rick Davis; board member Laura Matarese, MS, RD, LDN, FADA, CNSD; and members Terry Edwards, Bettemarie Bond, Bette Bond, and Cynthia Bertrand. We couldn’t have done it without you.

Other Exhibits

Oley was represented at many other meetings this winter and spring as well, including: A.S.P.E.N. chapter meetings in New York/Long Island, Arizona, Virginia, and New Jersey; meetings of the Infusion Nurses Society (INS), Association for Gastric Motility Disorders (AGMD), Tennessee Dietetic Association, and International Foundation for Functional Gastric Disorders (IFFGD); and the American Society on Clinical Oncology (ASCO) Cancers Symposium.

We could really use your help at two upcoming meetings! We need volunteers to staff the Oley booth at a meeting of the Infusion Nurses Society in Nashville, May 16, and at Digestive Disease Week in Chicago, May 31 to June 3. If you are available, please contact Kate Swensen at swensek@mail.amc.edu or call the Oley office at (800) 776-OLEY.

At NutriThrive we understand that our consumers are unique individuals, requiring individual attention. Why should this be about your provider? It should be about you.

Our team of professionals can provide customized products and care, along with up-to-date research and programs specific to each case.

Let NutriThrive help you thrive on your terms.

“As a long-term consumer of HPEN I always know that with NutriThrive I am able to try whatever new supplies, pumps, etc, there are that may help make MY life easier. NutriThrive is very easy to work with and they provide patient-centered care with very compassionate staff that, most important of all, include ME as a member of the treatment team.” - Melissa F.

1-888-N-THRIVE (888-684-7483)
or info@nutrithrive.com
www.nutrithrive.com
The next step was going back on home parenteral nutrition (HPN). After discussions with both speakers and product representatives at the Oley conference, I went home with a new list of suggestions for my doctor. The suggestions resulted in a change and the tables have turned in my favor. The knowledge “collective” of the group is outstanding!

Worth the Effort

For those of you who are considering attending this year for the first time, my advice is simply, “Do not miss it!” Yes, it can be a logistical nightmare traveling with all our HEN or HPN “stuff,” but the hassles are well worth it. With all that is going on in our lives that revolves around dealing with our feeding issues in an “eating world,” it is a true gift to spend time with a group of people who are in the same situation. (See article on page 7 for tips on traveling with HPEN supplies.)

Last year’s program hosted speakers on research, coping, care giving, and “special issues.” If you had told me four years ago that I would be at a seminar on diarrhea, I would have told you were nuts. But now such topics are of special interest to me. No where will you have the opportunity to surround yourself and your family with this level of expertise and support—and have a really great holiday at the same time.

For those of you with children, either as consumers or part of a consumer’s family, the experience has got to be a priority. I think being around fellow attendees would help children realize that there are ways to lead a very normal life and to perhaps make some new friends. There are special events for the kids, and judging by the stories and smiling faces last year, they had a blast!

And Worth Returning

For those who have attended before, I am sure you will move mountains to be there. The fellowship and tips are invaluable, and as we know, working through a life that involves tube or IV feeding is a continual learning experience. There is no better forum to soak up some sun and support at the same time.

Last year at the conference my G-tube cracked just below the fitting and I sprung a leak! I was making plans to get to the hospital when someone recommended just applying some Krazy Glue® over the hole as a patch. That got me from San Diego to Vancouver without a problem. Now I carry a tube in my briefcase!

Chance to Soak It Up

The program is always a great collection of information, but it is the “chat time” and dinner table talk that allow us all to compare war stories and just be among fellow “consumers.” There is something for each and every one at these conferences. I urge you to surround yourselves and your families with a week of sun, fun, and a chance to learn something all in one. I look forward to seeing you there!

---

Terry chatting with Dr. Howard at the conference.
Planning a Trip?

Before you leave home, be sure to check out the “Travel Tips” page on Oley’s Web site (www.oley.org/traveltips.html). The page offers many resources and great information on how to plan a safe trip with home IV or tube feeding, including:

- a travel packet — so you are prepared for emergency health care needs
- a sample physician letter — to explain your supplies to airport/custom officials
- advice on packing/shipping supplies
- a listing of medical air transport options

Equally important, the travel tips page includes a list of experienced travelers who you can contact with your questions. Don’t miss this excellent opportunity to get advice from the pros.

Finally, Oley staff are here to help, too. If we can’t answer your questions, we’ll find someone who can. Call us at (800) 776-OLEY or e-mail bishopj@mail.amc.edu.

Web Site Offers Rebates

We haven’t tried this Web site’s service, but it looks like it could be worthwhile—if you don’t mind the paperwork. Caregivers Marketplace offers rebates on specific brand name items, including nutritional supplements (very few), topical creams, diapers, and personal hygiene and incontinence products. Only certain products are eligible and you need to submit copies of cash register receipts to get a rebate. Go to www.caregiversmarketplace.com to see a list of eligible items and learn how to participate or call Caregivers Marketplace at (800) 888-0889.

Send Us Your Feedback

If you try the service, please let us know how it went. Did the experience meet your expectations? Was it helpful? E-mail your comments to metzgel@mail.amc.edu.

Oley Member Wins Essay Contest

On Your Behalf

Many advocacy groups schedule visits to state and federal legislators in late winter. It’s a time when legislators are available in their offices. Oley executive director Joan Bishop was in Washington, D.C., and Albany, New York, this winter, helping legislators understand what it is like to suffer from digestive diseases and be dependent on nutritional therapies like enteral and parenteral nutrition, and why they should support legislation aimed at helping these constituents.

Hannah’s Law

In Albany, Joan joined the Devane family and several other Oley members whose children suffer from severe food allergies for a state Legislative Lobby Day hosted by Assemblyman Greg Ball. Assemblyman Ball has drafted, introduced, and has bipartisan support for Hannah’s Law, which will ensure that all insurance plans in New York State will cover the cost of elemental formula, regardless of whether it is taken orally or through a tube.

Many children, including Hannah Devane, drink an elemental formula that is manufactured to be fed through a tube. Children in Hannah’s situation do not have tubes in place, and this interferes with reimbursement for very costly formula that is necessary to sustain the children.

Capitol Hill

In March, Joan met several Oley members in Washington, D.C. They came together with clinicians and representatives from home-care companies and digestive disease organizations (including Crohn’s & Colitis Foundation of America, United Ostomy Associations of America, and Celiac Disease Foundation) to put a “face” to diseases and related therapies. Our representatives on Capitol Hill often have limited knowledge about “living” with complicated diseases and therapies—and these are the folks who are making decisions, and introducing, sponsoring, and voting on legislation that can affect you (for example, increasing or decreasing the budget for NIH research and/or for restructuring and strengthening the FDA).

We are grateful for the support of those who were able to join us for these efforts. Perhaps you will consider participating next year.

Joan’s Observations

“I repeatedly witnessed representatives or aides,” said Joan, “become speechless as families candidly described their circumstances, medical challenges, strategies for survival, and so on.”

“The plan of attack to educate the legislators,” she continued, “always included a bit about how ‘normal’ the rest of the consumer’s life was—attending school, working, volunteering, and being one of their constituents who votes. The emphasis was that they simply ‘eat’ in a unique way that is complicated and which classifies them as medically fragile.”

Consumers were allowed to present their situations to individual legislators and/or their staff, in small, private groups. “Words cannot describe the interest and amazement legislators expressed as the consumers’ situations unfolded. This reinforces the need to make more visits and introductions to keep the ‘face’ of homePEN therapy in the forefront,” Joan added.

Most elected officials—at all levels—host town hall meetings. These offer an excellent opportunity for you to introduce yourself as a constituent who receives intravenous and/or tube feeding to sustain yourself. It’s a worthwhile experience. Please don’t hesitate to contact Joan for more information at bishopj@mail.amc.edu.

Support for Mito Patients

The Mitochondrial Disease Action Committee, better known as MitoAction, offers monthly support groups by toll-free teleconference. All are welcome! Call (866) 414-2828 to participate; the participant code is 017921#. Calls can also be made free from a computer using Skype. The topics vary, but the groups “meet” following this general schedule:

- 1st Friday of each month, 12:00 p.m. (EST): MITO meeting with topic and guest speaker
- 2nd Tuesday of each month, 12:30 p.m. (EST): Autism and Mitochondrial Disease Support Group and Task Force
- 2nd Friday of each month, 12:00 p.m. (EST): Newly Diagnosed and Suspected Mito Support Group
- 3rd Friday of each month, 12:00 p.m. (EST): Parents Support Group
- 4th Friday of each month, 12:00 p.m. (EST): Adult Patient and Caregiver/Spouse Support Group

MitoAction is a great resource. Learn more by visiting their Web site, www.mitoaction.org, or by calling (888) 648-6228.
Liver Disease, from pg. 2

not commercially available. The PN solution contains as much MET as can be safely added. At high levels MET is toxic to the nervous system. PNALD appears to coincide with disruption of these transsulfuration pathways.7 Low glutathione levels block the MET → SAM → CYS conversion and this becomes a vicious cycle, since low CYS reduces the production of glutathione. When the cells’ antioxidant capacity dwindles, many cellular functions fail, such as the liver’s excretion of bile.

Our approach was to find a way to deliver CYS to patients with PNALD, in a soluable form.

Nutritional Treatment of PNALD: The Sulfur Amino Acid Perspective

We have recently studied the addition of N-acetyl cysteine (NAC) into the IV regimen of three children with PNALD.5 NAC supplementation resulted in significant improvements in liver function tests in these children. NAC is a compound that is very similar in biochemical structure (biological availability and function) to CYS.6,7,8 It is also soluble in PN solutions, which makes it easy to add to PN. NAC has been around for a long time. It is approved by the Food and Drug Administration (FDA) for treatment of acute liver failure in both adults and children.11 It has been particularly useful in the treatment of liver toxicity due to acetaminophen (Tylenol®) overdose. NAC is a powerful antioxidant. The safety of NAC has been well documented in the literature. It may only be used under the direct supervision of a physician.

Although research is limited in regard to the direct impact of NAC on liver function in humans, there is evidence that supplementation in children results in up-regulation of red blood cell glutathione synthesis.8,10 This certainly appeared to be the case in the one child who had red blood cell glutathione measured in our case series. Whether or not this was the reason why all three children experienced improvements in their liver function tests needs further study.

The preferred route of administration of NAC is intravenously, due to the higher bioavailability of NAC to liver tissues when delivered by IV. Delivery of NAC enterally is possible, but the slower gut absorption of NAC and increased utilization of NAC within the gut may mean that less NAC is available to promote liver glutathione synthesis.11 NAC is compatible with a variety of IV hydration solutions and can be run simultaneously with PN in a variety of IV solutions (e.g., IV dextrose).1 Consultation with the nutrition support pharmacist will assist caregivers in determining the best method of NAC delivery.

Summary

The key approach to treatment of PNALD is to minimize the risk of infection and to avoid over/underfeeding of PN in the child or infant dependent on long-term PN. This requires the intervention of a multidisciplinary team that works closely with the child and family.

The addition of IV NAC (at lower doses than those used for treatment of acute liver failure) to infants and children with documented PNALD was associated with improvements in red blood cell glutathione content and reductions in serum ferritin and liver biochemistries.5 This suggests that NAC supplementation could be helpful in the treatment of PNALD. Of course, this does not eliminate the need to pursue, evaluate, and implement other approaches.

The preliminary work of the case series described suggests, but does not prove, that NAC might be a helpful supportive therapy in PNALD in children and infants dependent on long-term PN. Clearly, more work needs to be done to examine the efficacy of NAC supplementation in children with PNALD. ¶

References

8. Hong L, Wu J, Cai W. Glutathione decreased parenteral nutrition-induced hepa
Join Us in Thanking Our Corporate Supporters

Abbott Nutrition

Abbott Nutrition is a longtime leader in the U.S. nutritional marketplace, and strives “to be the worldwide leader in providing superior nutritional products that advance the quality of life for people of all ages.” Abbott Nutrition manufactures and distributes therapeutic nutritional products such as: PediaSure® Enteral Formulas, designed to provide a source of Complete, Balanced Nutrition® for children ages one to thirteen; Vital jr.®, a semi-elemental formula for the nutritional needs of children ages one to thirteen years; EleCare, an elemental formula for infants and children who need an amino acid based medical food, and Jevity® 1.2 Cal, an isotonic, fiber-fortified tube-feeding product with the prebiotic NutraFlora® scFOS®.

Nestlé HealthCare Nutrition

Nestlé HealthCare Nutrition’s enteral product solutions help optimize the nutritional intake of consumers and patients while supporting prescribed medical treatments. Whether a patient needs to combat disease, recover more quickly, or maintain their health, Nestlé HealthCare Nutrition provides quality nutrition products to those with special needs, in every stage of life. Nestlé’s heritage and global leadership in the food and beverage market has given it the ability to touch the lives of consumers in every continent on the globe. Nestlé HealthCare Nutrition is the second-largest health care company in the world.

Chemique Pharmaceuticals, Inc.

Based in Whittier, California, Chemique Pharmaceuticals, Inc. has more than twenty-three years experience providing intravenous infusion therapy to patients in southern California. It also provides custom enteral nutrition and is ACHC accredited. The company states, “Our helpful, knowledgeable and supportive staff provide simple to complex infusion regimes safely and effectively in the comfort of your home.” Chemique specializes in portable and compact mobile delivery infusion systems. The company’s professionals are ready to work with you and your physician’s team on a treatment plan to help you regain your independence and personal freedom.

Baxter Healthcare Corporation

Baxter Healthcare Corporation has more than seventy-five years experience in developing parenteral nutrition solutions that work together to improve patient outcomes. According to the company, “Baxter offers clinicians and patients the broadest portfolio of parenteral nutrition in the industry that includes CLINIMIX Injections, an innovative commercially manufactured multi-chamber bag of parenteral nutrition formulations.” Baxter also offers INFUVITE multiple vitamins for infusion (Sandoz Canada Inc.); lipid emulsions for infusion; AUTOMIX 3+3 and MICROMIX automated compounding equipment; and LOGIX compounding software. Parenteral nutrition solutions from Baxter efficiently help professionals meet the nutritional goals of patients.
### Individual Donors

The following list represents everyone who contributed between January 14 and March 27, 2009. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

**Ambassadors ($2,000+)**
- Jarol Boan, MD

**President’s Circle ($1,000–$1,999)**

**Benefactors ($500–$999)**
- Access IV
- Judy Mutty, in memory of Bruce Grefraith

**Sponsors ($250–$499)**
- George Blackburn, MD, through United Way
- Naga Devi Kanumuri, in honor of Manisha
- Anna Nowobilski-Vasilios, PharmD

**Patrons ($100–$249)**
- Milton Abercrombie
- Mr. & Mrs. Richard Dillon
- Herb & Joan Emich
- Beverly Engle, in memory of Donald Engle
- Mr. & Mrs. W. W. Fitzpatrick, Sr.
- Seymour Goldfarb, in memory of Madalyn Goldfarb
- Ilene Hathaway, in memory of Sarah Joyce and in honor of Sarah’s son, Tim Joyce
- Lenore Heathey
- Mindy Reibstein, in memory of Libby Levin
- Joan & Frank Scheib
- James Vaughan

**Supporters ($50–$99)**
- Cynda Arsenault
- Matthew & Jennifer Banderman, in honor of Matthew’s 10 years on TPN
- Judy S.K. Brown
- Lavern Dover
- Guadalupe & Virginia Garcia, in honor of Sean May’s 10th birthday
- Charlene Key, in memory of Bernice Elizabeth Schaller & in honor of Linda Gravenstein
- Merck Partnership for Giving, matching gift of Allan Yelner
- Angelyn Schauer, to thank Dr. Ellen Pierce for all her moral & physical support the past few months
- Drew Wendt
- Marguerite Zeller

**Contributors ($30–$49)**
- Susanne & David Appel
- Betty Bailey
- Esther Burch
- Phillip Mabardy
- Karen & Millard Mazer, in honor of Esther Adler for her strength, her amazing progress, & her unbelievable grace under the most difficult conditions. She’s truly an inspiration!
- Lori Siedgas

**Friends (Up to $30)**
- Dorothy Booth, in memory of Raymond Booth
- Kay Carlson, in memory of Bernice Schaller
- S. A. Chaney, via United Way
- Linda Gravenstein, in memory of Bernadette Stuto
- Kara Hibler
- Mary Ann Kovalich, in memory of Sylvester
- Sheryl Longobardi
- Michael Medwar, in memory of Kyle Noble & LaLa
- Laura Mulcahy, via United Way
- Kathryn Shields
- Ray Soto
- Betty Stone
- Joe & Carol Yontz
- Betty Zeller

**In Memory of Dorothy Kelly**
- Lyn Howard, MD, FRCP
- Darlene Kelly, MD, PhD
- Janice Kobayaski
- Stella & Bill Melville, Dean & Mindy Melville, Milley Kay & Bill Baldwin
- Ron & Lisa Metzger*
- Don V. Nelson
- Betty Stone
- Debbie Gaffney, Patty Erehedge, & Carolyn Behrens

* Oley Trustee, ** Oley RC, *** Oley Staff

---

### 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+)
- Apria Healthcare / Coram Inc.
- Specialty Infusion Services Nutrishare, Inc.

**GOLDEN MEDALLION PARTNERS** ($50,000–$69,999)
- NutriThrive

**SILVER CIRCLE PARTNERS** ($30,000–$49,999)
- Emmaus Medical, Inc.

**BRONZE STAR PARTNERS** ($20,000–$29,999)
- Abbott Nutrition
- Nestlé HealthCare Nutrition

**PATRON LEVEL PARTNERS** ($5,000–$9,999)
- Applied Medical Technology, Inc.
- Chemique Pharmaceuticals
- Critical Care Systems, Inc.
- EMD Serono, Inc.
- Hospira, Inc.
- InFuScience, Inc.
- Walgreens-OptionCare

**BLUE RIBBON PARTNERS** ($2,500–$4,999)
- Baxter Healthcare
- B. Braun Medical
- Kimberly-Clark
- Sherwood Clinical

**CONTRIBUTORS** ($1,000–$2,499)
- C.R. Bard, Inc.
- Baxa Corporation
- Zevex, Inc.

---

### 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.

<table>
<thead>
<tr>
<th>Oley Horizon Society Members</th>
<th>Oley Horizon Society Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>John Balint, MD</td>
<td>Valerie Gyurok, RN</td>
</tr>
<tr>
<td>Joan Bishop</td>
<td>Alfred Haas</td>
</tr>
<tr>
<td>Ginger Bolinger</td>
<td>Shirley Helle</td>
</tr>
<tr>
<td>Pat Brown, RN, CNSN</td>
<td>Alicia Hoelle</td>
</tr>
<tr>
<td>Katherine Cotter</td>
<td>Jeff &amp; Rose Hoelle</td>
</tr>
<tr>
<td>Jim Cowan</td>
<td>Lyn Howard, MD</td>
</tr>
<tr>
<td>Ann &amp; Paul De Barbieri</td>
<td>William Hoyt</td>
</tr>
<tr>
<td>Tom Diamantidis, PharmD</td>
<td>Darlene Kelly, MD</td>
</tr>
<tr>
<td>Selma Ehrenpreis</td>
<td>Family of Shirley Klein</td>
</tr>
<tr>
<td>Herb &amp; Joy Emich</td>
<td>Robin Lang</td>
</tr>
<tr>
<td>Don Freeman</td>
<td>Hubert Maiden</td>
</tr>
<tr>
<td>Linda Gold</td>
<td>Kathleen McIveres</td>
</tr>
<tr>
<td>Linda Gravenstein</td>
<td>Meredith Nelson</td>
</tr>
<tr>
<td>The Groheber Family</td>
<td>Nancy Nicholson</td>
</tr>
</tbody>
</table>

---

**Ambassadors ($2,000+)***
- John Diamantidis, PharmD
- Selma Ehrenpreis
- Herb & Joy Emich
- Don Freeman
- Linda Gold
- Linda Gravenstein
- The Groheber Family

---

**Presidents’ Circle ($1,000–$1,999)**
- Access IV
- Judy Mutty, in memory of Bruce Grefraith

**Benefactors ($500–$999)**
- George Blackburn, MD, through United Way
- Naga Devi Kanumuri, in honor of Manisha
- Anna Nowobilski-Vasilios, PharmD

**Sponsors ($250–$499)**
- Milton Abercrombie
- Mr. & Mrs. Richard Dillon
- Herb & Joan Emich
- Beverly Engle, in memory of Donald Engle
- Mr. & Mrs. W. W. Fitzpatrick, Sr.
- Seymour Goldfarb, in memory of Madalyn Goldfarb
- Ilene Hathaway, in memory of Sarah Joyce and in honor of Sarah’s son, Tim Joyce
- Lenore Heathey
- Mindy Reibstein, in memory of Libby Levin
- Joan & Frank Scheib
- James Vaughan

**Supporters ($50–$99)**
- Cynda Arsenault
- Matthew & Jennifer Banderman, in honor of Matthew’s 10 years on TPN
- Judy S.K. Brown
- Lavern Dover
- Guadalupe & Virginia Garcia, in honor of Sean May’s 10th birthday
- Charlene Key, in memory of Bernice Elizabeth Schaller & in honor of Linda Gravenstein
- Merck Partnership for Giving, matching gift of Allan Yelner
- Angelyn Schauer, to thank Dr. Ellen Pierce for all her moral & physical support the past few months
- Drew Wendt
- Marguerite Zeller

**Contributors ($30–$49)**
- Susanne & David Appel
- Betty Bailey
- Esther Burch
- Phillip Mabardy
- Karen & Millard Mazer, in honor of Esther Adler for her strength, her amazing progress, & her unbelievable grace under the most difficult conditions. She’s truly an inspiration!
- Lori Siedgas

**Friends (Up to $30)**
- Dorothy Booth, in memory of Raymond Booth
- Kay Carlson, in memory of Bernice Schaller
- S. A. Chaney, via United Way
- Linda Gravenstein, in memory of Bernadette Stuto
- Kara Hibler
- Mary Ann Kovalich, in memory of Sylvester
- Sheryl Longobardi
- Michael Medwar, in memory of Kyle Noble & LaLa
- Laura Mulcahy, via United Way
- Kathryn Shields
- Ray Soto
- Betty Stone
- Debbie Gaffney, Patty Erehedge, & Carolyn Behrens

* Oley Trustee, ** Oley RC, *** Oley Staff
Chat with Others—Free!

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers. These volunteers are available to talk about day-to-day issues, ideas on coping, etc. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

May 2009
Lesley Marino, mother of Nina, on HEN due to esophageal atresia & VACTERL syndrome
Clearwater, FL—EST    (888) 610-3008
Rose & Alicia Hoelle, Rose, LPN and mother of Alicia, on HPEN for hypoganglionic/NID (both available to talk)
Gibbstown, NJ—EST    (888) 650-3290

June 2009
June Bodden, on HPN for Crohn’s disease
Clearwater, FL—EST    (888) 610-3008
Barbara Klingler, on HPN for short bowel
Valkaria, FL—EST    (888) 650-3290

July 2009
Jack Smith, father of two daughters on HEN
Southside, AL—EST    (888) 610-3008
Felice Austin, mother of Mariah, on HPN for pseudo-obstruction/short bowel
Henderson, NV—CST    (888) 650-3290

Call our May or June volunteers to discuss the Oley conference (June 29–July2)! They can tell you what to expect and share travel tips.

Auction Items Needed

We need your help gathering items for our silent auction. Held at the annual conference, this event has raised thousands of dollars, and helps keep Oley programs free for you!

Need ideas? Items donated in recent years include things created by Oley members (quilts, photos, paintings, scarves, afghans); electronics (MP3 players, radios, televisions, laptops); gift certificates and baskets; certificates for travel opportunities (time-share units, vacation packages, airfare); tickets to sporting events, concerts, and tourist attractions; DVDs and CDs, games, etc. The possibilities are endless! We have an excellent letter available that describes Oley and the auction if you need help appealing to local vendors, businesses, friends, or family for donations. Call us and we’ll send you copies.

Items can be brought to the Oley registration desk at the conference on Tuesday morning or mailed to the Trade Winds Island Resort (Island Grand Beach Resort, 5500 Gulf Blvd., St. Pete Beach, FL 33706), c/o Guest, Joan Bishop, to arrive on June 24 or 25. Please keep in mind that many conference attendees will be traveling by plane, and may have limited space in their luggage.