



## Spotlight: Betty Gray

By Robin Lang

Each time I attend an Oley conference, I meet new people. This year, I met Betty Gray, a first-time conference-goer and fortunate travel scholarship recipient.

Betty and I hit it off immediately. We felt we'd known each other for years, which is ironic because we met only minutes before she left the conference. We talked about living in different planting zones and gardening - HPEN never came up. In our brief conversation, I learned a lot from this spunky, 61 year-old lady. I commented on her ageless looks, she replied, "Usually I tell people I'm 10 year older than I am; that really gets them," she said, "They look at me with amazement and say, "Wow, you look terrific." Without a doubt, this is a whimsical lady.

Betty is petite in stature, with a modest demeanor, but her excitement and enthusiasm for living life is anything but that. I was instantly impressed. Betty is fairly new to TPN, a consumer for a mere two years, yet she possesses the survival skills of a long-term consumer.

Her friend, Nancy O'Hara says, "Betty has faced her situation with courage, grace and inner strength. She makes it easy for others to forget her challenges. Betty nurtures the child within, never losing her common sense in a situation."

In Dec. '01, Betty's surgery left her with short bowel syndrome. Even though she lay critically ill for 3 months, she provided Nancy with moral support because she too, was experiencing a serious life change. Betty comforted and inspired Nancy while she battled her post-surgical trials. "I'm privileged to have her friendship," says Nancy.

I've spoken with Betty since the conference; she's so pleased she had the opportunity to attend. She learned a lot and she was delighted to meet other HPENers. She no longer feels isolated. Betty is wise, entertaining and very funny. I continue to laugh at her wistful comments long after I put down the phone.

I asked her what her secret is. Her reply, "There's a whole lot of life out there, go out and live it. Not surviving isn't an option; we might as well make the best of what we have. You can't quit! Count the things you have, and enjoy every minute God gives you."

Betty credits her 2 daughters, Julie and Robin, son-in-law, John and grand daughter, Hannah, for the happy times in her life. Most recently, they spent a week together camping at "The Lake of the Woods" in southern Oregon. "Camping with TPN is doable; we all had a wonderful time, everyone should try it." She said.

The tedious daily realities of living with short bowel syndrome and TPN do not deter Betty, her mission is to live life to the fullest. She has an applaudable attitude to be sure. All I can say is, "Go, Betty, Go!" ©



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At least that's what Jerry Fickle believes. He's been on Home TPN more than 20 years. In that time he's been on an Alaskan cruise, to wherever Purdue University plays in a bowl game, to Florida, and on bus trips with seniors groups. He plays golf and rides a jet ski when he can find time. Jerry doesn't see why he can't do what he wants. And Coram encourages him, and works with him to make it all possible. Contact us at 972.394.9974 and visit us on the Web at [www.coramhc.com](http://www.coramhc.com).

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resection does not increase the rate of intestinal transit, ileal resection significantly accelerates intestinal transit<sup>8,11</sup>. In this situation the colon aids in slowing intestinal transit. In patients with a short bowel without a colon, a marker fed by mouth is completely excreted in a few hours.

**Absorption of fluid and electrolytes**

The effect of intestinal resection depends upon the extent and site of resection. Proximal resection results in no bowel disturbance because the ileum and colon absorb the increased fluid and electrolyte load efficiently. The remaining ileum continues to absorb bile salts and thus there is little reaching the colon to impede salt and water resorption. In contrast, when the ileum is resected, the colon receives a much larger load of fluid and electrolytes and also receives bile salts which reduce its ability to absorb salt and water, resulting in diarrhea. In addition, if the colon is resected, the ability to maintain fluid and electrolyte homeostasis is severely impaired.

**Absorption of Nutrients**

Absorption of nutrients occurs throughout the small bowel and the removal of the jejunum alone results in the ileum taking over most of the lost function. In this situation there is no malabsorption. In contrast, even a loss of a 100 cm. of ileum causes steatorrhea. The degree of malabsorption increases with the length of resection and the variety of nutrients malabsorbed increases<sup>16,17</sup>. Balance studies of energy absorption showed that the absorption of fat and carbohydrate were equally reduced to between 50% and 75% of intake. Nitrogen absorption was reduced to a lesser extent, namely to 81% of intake. In patients with a short bowel, Ladefoged et al<sup>15</sup> found that the degree of calcium, magnesium, zinc and phosphorus absorption were reduced but did not correlate with the remaining length of bowel and they recommended that in these patients, parenteral supplementation be mandatory. Our studies showed similar reduction in absorption but only half required parenteral replacement. The data taken as a whole suggest that it is easier to meet needs for energy and nitrogen by increasing oral intake than the needs for electrolytes and divalent ions. A review of the literature prior to the availability of parenteral nutrition shows that resections up to 33% result in no malnutrition and those up to 50% could be tolerated without special aids but those in excess of 75% require nutrition support to avoid severe malnutrition.

**IMPLICATIONS FOR MANAGEMENT OF SHORT BOWEL SYNDROME****Control of diarrhea**

Diarrhea is due to a combination of increased secretions, increased motility and osmotic stimulation of water secretion due to malabsorption of luminal contents. Initially, diarrhea is controlled by keeping the patient NPO to reduce any osmotic component. Gastric hypersecretion can be controlled by the continuous infusion of appropriate doses of intravenous H<sub>2</sub> blockers or proton pump inhibitors. In addition, loperamide can be used to slow gastric and intestinal transit. If loperamide does not work, then codeine, phenoxyate or deodorized tincture of opium may be tried.

**Intravenous fluids**

In the immediate postoperative period all patients will require intravenous fluids and electrolytes to replace losses. Sodium and potassium chloride as well as magnesium are the most important ions to be replaced and plasma levels of these ions should be monitored frequently. Fluid is infused according to measured losses and to

maintain an adequate urine output. The infusion is tapered as oral intake and absorption improves.

**Oral Feeding**

The next consideration is to determine the best oral diet. In patients who have more than 100 cm of remaining jejunum as the only small bowel remaining, refeeding should be progressive with a view ultimately to feeding a normal oral diet. In patients with less than 100 cm of jejunum, dietary intake and fluids cause increased fluid loss. In patients who have very little small bowel left, the initial target should be small volume isotonic feeds containing a glucose-electrolyte content similar to the oral rehydration solution. The composition of this solution should be glucose 100 mmol/L, sodium chloride 60 mmol/L and sodium citrate 60 mmol/L. It has been shown that fluid absorption improves as sodium concentration increases. To provide sufficient sodium to absorb dietary carbohydrate, it is necessary to ingest 10-15 g of sodium chloride as tablets daily with meals. Such a regimen avoids osmotic stimulation of secretion, yet stimulates the bowel to absorb, thus promoting adaptation. Progressive feeding should be attempted with the following plan. The same carbohydrate-electrolyte feeds as above should be started. This high-salt intake has been shown to be well absorbed by patients with massive resection who have previously been dependent on intravenous fluids. The diet should be lactose-free since lactase levels in short bowel patients are reduced. Vitamin B<sub>12</sub> absorption should be measured and if subnormal injections of 250 micrograms per month should be started.

Early observations suggested that low-fat diets are beneficial. The theory behind this concept was that malabsorbed long-chain triglycerides (LCT) cause colonic water secretion. However, soluble carbohydrates are also malabsorbed in short bowel syndrome. Using a controlled crossover design in two studies<sup>12,18</sup>, we showed that a high-fat diet was comparable to a high-carbohydrate diet in regard to total fluid, energy, nitrogen, sodium, potassium and divalent ion absorption. We therefore recommend a low-lactose diet containing high calories from both fat and carbohydrate and a high nitrogen intake. In adults who require about 30 kcals/kg/day, we aim to increase intake gradually to about 60 kcals/kg/day to provide sufficient absorbed calories despite malabsorption. The rationale for this approach is discussed by Woolf et al<sup>12</sup>. Supplements of potassium, magnesium and zinc are given while monitoring serum levels. In particular, potassium as gluconate may be added at a concentration of 12 mmol/L in the carbohydrate-electrolyte fluid. In addition, we have found that magnesium heptogluconate is especially useful as a supplement to correct hypomagnesemia without causing diarrhea. It is possible to add 30 mmol of magnesium per liter of glucose-electrolyte mixture and sipped over the day.

**Parenteral Nutrition**

In patients with less than 100 cm of remaining jejunum and in those with a combined small bowel and colon resection, parenteral nutrition is lifesaving. It is started in such patients within a few days of the resection and initially 32 kcals/kg of a mixed energy substrate and 1 g/kg amino acids is infused with sodium 150-200 mM, potassium 60-100 mM, calcium 9-11 mM, magnesium 7-15 mM and zinc 70-100 micromoles per day. Among trace elements, zinc is the most important as we have found large losses in patients with a high endogenous output of intestinal fluids. Oral feeds are simultaneously started and attempts are made to reduce parenteral feeding as oral feeds are increased. It will

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become apparent whether the patients need parenteral feeding on a long-term basis. In this case, the patient should be started on a program of home parenteral nutrition (HPN). We have found that as the bowel adapts over months and even years, the patient requires less parenteral feeding and ultimately about 30% of our patients initially requiring HPN can be weaned off HPN by using up to 2 liters of oral rehydration solution, high calorie diet and supplements of potassium, magnesium, calcium, fat-soluble vitamins and zinc. They are monitored regularly until the weight is stable and they are in electrolyte balance. Hypomagnesemia is a particularly serious problem in these patients. Ingestion of magnesium salts orally enhances diarrhea and it often becomes difficult to use magnesium supplements orally. The author has successfully used Magnesium heptogluconate for this purpose. This preparation is available as a palatable liquid which is added to the gastrolyte supplement in quantities of 30 mM per day. If this approach is not successful, then magnesium sulfate is infused through an indwelling catheter in doses of 12 mM one to three times a week to supplement the oral intake. Normally, specific supplementation with Vitamin K is not necessary for patients not on Parenteral Nutrition. The prothrombin time (INR) is monitored with clinic visits and if raised then supplementation is necessary. However, in the author's experience it was necessary in only one patient over the years.

Vitamin supplementation needs comment. These patients can absorb water-soluble vitamins but have difficulty absorbing fat-soluble vitamins. They require large doses of vitamin A, D and E to maintain normal levels. Also pills often pass out whole in these patients, hence liquid preparations have to be used. The author recommends the measurement of these vitamin levels and supplementation with aqueous preparations of vitamin A and E (Aqasol A and E) and 1,25 dihydroxy-vitamin D in doses which normalize the plasma levels. Normalization may not be possible with oral vitamins in some individuals, especially vitamin E levels.

In some patients an oral diet will maintain weight and body composition but intravenous fluids and electrolytes are needed to maintain hydration and normal levels of electrolytes, especially magnesium. Patients with a very short bowel may not be able to maintain normal weight and body composition with only intravenous fluids and electrolytes for hydration. These patients need full parenteral nutrition containing protein, energy, electrolytes, vitamins and trace elements.

**Jejunal resection with intact ileum and colon**

Patients in this category can be fed orally immediately and rarely have any problems. The conventional approach is to give clear fluids, then a liquid diet with nutrients followed by a soft and then regular diet. There is no evidence this graduated approach is beneficial. Patients can often take fluids and solids in small quantities as soon as they can pass gas and feel hungry. The process of refeeding after resection is given in detail in the next section.

**Ileal resection of less than 100 cm with colon largely intact**

Patients in this category have so-called bile salt-induced diarrhea and are best helped by the administration of 4 g of cholestyramine three times a day to bind bile salts left unabsorbed by the resected ileum. Vitamin B<sub>12</sub> absorption should be measured and if low B<sub>12</sub> (to be consistent) should be injected intramuscularly in doses of 250 ug per month.

**Ileal resection of more than 100 to 200 cm with colon largely intact:**

This group of patients has little difficulty in maintaining nutrition with an oral diet but has fatty acid diarrhea. For such a patient, fat restriction is mandatory. With the larger resection, the bile salt pool is depleted and cholestyramine is contraindicated because it binds and further decreases bile salts. Parenteral vitamin B<sub>12</sub> replacement is required.

**Resection in excess of 200 cm of ileum or lesser resection with associated colectomy:**

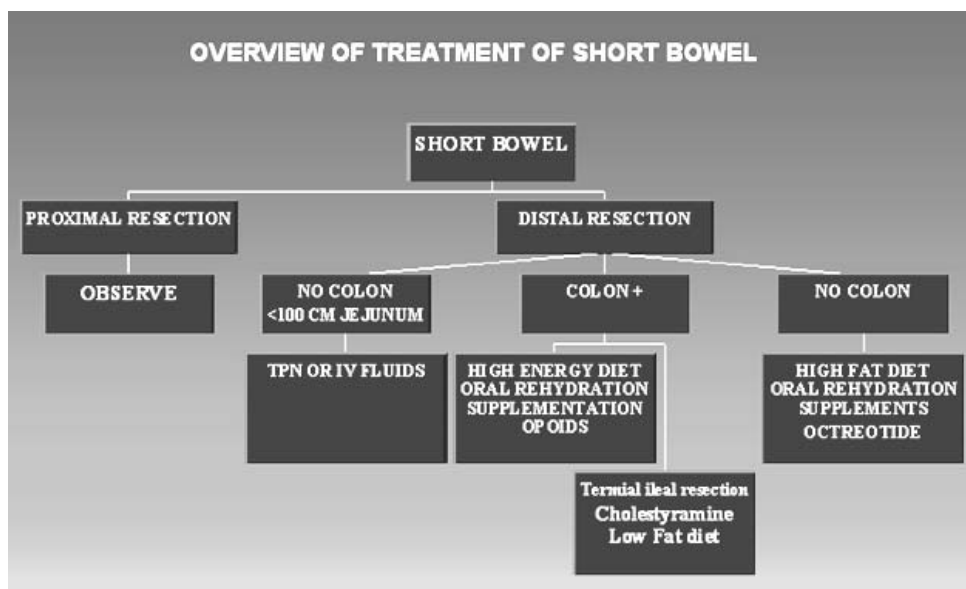
Patients of this class require the graduated parenteral adaptation program indicated previously.

**Resection leaving less than 60 cm small bowel or only duodenum - Massive bowel resection:**

Patients in this category need HPN indefinitely. However, many patients even in this category may show a surprising degree of adaptation and require less parenteral nutrition over time. The indication to reduce parenteral nutrition is weight gain beyond the desired limit and the fact that reduced infusion does not cause electrolyte imbalance and dehydration.

**Summary:**

Appreciation of the function of the different segments of the gastrointestinal tract in promoting absorption and motility helps clarify the effects of intestinal resection and disease. On the basis of this information, a rational plan of management can be formulated to maximize absorption of nutrients including fluid and electrolytes, and to understand the need for supplements as given in the accompanying algorithm (see figure at right).<sup>©</sup>





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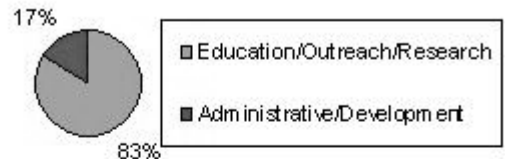


## Where Does It All Go?

Oley's fiscal resources fall into two categories and are distributed as follows: 83% Education/Outreach/Research and 17% Administration/Development. Administrative resources fund the following staff members whose duties are listed below:

Joan Bishop, executive director, is in charge of balancing Oley's budget, organizing the fundraising program and overseeing the organization's long-term vision. Joan also coordinates the annual Oley conference. Cathy Harrington, MA, administrative assistant, is responsible for the equipment exchange program, maintaining the Oley database and updating the Oley web page. She also provides an enormous amount of much-needed program support and handles many of the hundreds of calls Oley receives each month. Cory Piekarski, MEd., director of publicity and information, is responsible for producing the *LifelineLetter*, brochures and other Oley publications, including selling the advertising which helps pay for Oley's publicity. Ellie Wilson, MS, RD, national outreach coordinator, organizes regional Oley gatherings, strengthens our ties to other organizations/resources, and provides much-needed support to our Regional Coordinators. ☺

Allocation of Annual Support



## Give Oley a Sound Future

Help provide a secure financial future for Oley by joining the Foundation's Horizon Society. It's as simple as including a gift to the Foundation — large or small — in your will, and can have tax benefits! For more information on ways you can give, contact Oley's Executive Director, Joan Bishop at (800) 776-OLEY or [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu).

## Short Bowel Patients Needed for Research Study

The purpose of this study conducted by NPS Pharmaceuticals is to evaluate the efficacy, safety, tolerability and pharmacokinetics (PK) of teduglutide compared with placebo in subjects with Parenteral nutrition (PN) - dependent short bowel syndrome (SBS).

Teduglutide is an analog of glucagon-like peptide 2 (GLP-2), a naturally occurring hormone that regulates the growth, proliferation, and maintenance of cells lining the gastrointestinal tract. Teduglutide has been shown in animal studies and previous human clinical trials to increase the number of these cells, thereby increasing the absorptive surface area of the intestines.

This trial will randomly assign approximately 80 patients to received daily subcutaneous injections of .05 milligrams or .10 milligrams of teduglutide per kilogram of body weight, or placebo. Dosing will continue for a period of six months. The primary endpoint in the study is a reduction in the use of intravenous feeding, which is often required to sustain life in patients with SBS.

To participate, you must be 18 or older, have SBS as a result of major intestinal resection resulting in at least 12 months of intravenous feeding, weigh less than 90 kg., and you must require PN treatment to meet your calorie or electrolyte needs due to ongoing malabsorption at least three times weekly and you must be on a stable PN regimen for four weeks before dosing. Your body mass index must be 18 to 27 kg/m<sup>2</sup> and you must have adequate hepatic and renal function.

Reasons for study exclusion include, but are not limited to: a history of cancer or significant lymphoproliferative disease within the last five years; drug or alcohol abuse; participation in other clinical studies; laboratory abnormalities; previous use of teduglutide or GLP-2; recent hospital admission; pregnancy or lactation; and surgery within study time parameters.

This study is taking place at multiple locations in the U.S., Canada and Europe. For more information or to find the study site closest to you, please contact Dominique Adkins at (801) 415-9222 or by e-mail at [dadkins@npsp.com](mailto:dadkins@npsp.com).

## Tube-Fed Patients Sought for Research Study

Do you feel you have successfully overcome challenges associated with home tube feeding? If so, a research team from the University of Utah would like you to share your thoughts so that others might learn from them. The purpose of the study is to understand how individuals cope and overcome the challenges associated with home tube feeding. Participants will be asked to discuss the burdens and challenges they have faced as a result of home tube feeding and the methods they used to successfully cope and overcome them. The information will be used to develop an educational manual to help other individuals learn knowledge and skills to manage and overcome similar challenges associated with home tube feeding.

All participants must be adults (18 years of age or older), currently require home tube feeding, live in a home setting, and perceive themselves as having successfully coped with and/or "bounced back" from challenges associated with home tube feeding.

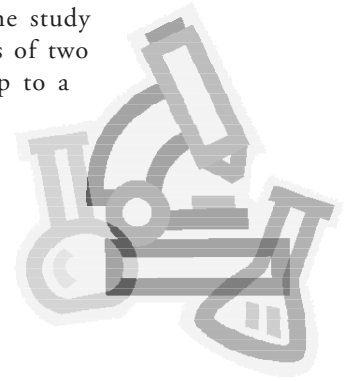
The main requirements of the study include participation in a series of two interviews, which would last up to a total of three hours, filling out a questionnaire, and completing a test to evaluate your "resilience". If you, or someone you know, would like to learn more about this valuable study, please contact:

Cheryl Thompson RD, MEd,  
CNSD

Department of Health Promotion and Education,  
University of Utah

1901 East, South Campus Drive, Annex Room 2140  
Salt Lake City, UT 84112

801-363-3699, 801-674-1199, [cwthompson@hotmail.com](mailto:cwthompson@hotmail.com)



## Participants Needed for Intestinal Pseudo-Obstruction Research Study

Boston University School of Medicine is conducting genetic research aimed at determining the gene(s) that are in some way involved or causally related to Intestinal Pseudo-Obstruction. If you or your child has a diagnosis of this as a primary diagnosis or part of another disease, and you are interested in participating, you can contact:

Mary Ann Whalen, M.S., C.G.C

Boston University School of Medicine, Center for Human Genetics  
715 Albany St., W408

Boston, MA 02118

(617) 638-7170, [maryann@bu.edu](mailto:maryann@bu.edu)

## Investigational Drug Test

The primary objective of this study is to evaluate the efficacy and safety of two dose regimens of r-recombinant human growth hormone (r-hGH) known as Saizen® in subjects with childhood-onset growth hormone deficiency (CAGHD) during the transition phase from childhood to adulthood.

Eligible subjects will receive either the standard starting dose or a higher dose level to evaluate the maximum treatment benefit of this drug. There are 15 test centers for this study. The main eligibility criteria is subjects, ages 13 to 21, with COGHD who have received GH replacement therapy in the past but not within six months of study entry. Replacement of other pituitary hormone deficits is allowed, but subjects must be stable on other hormone replacement therapy. Subjects are excluded with a history of diabetes mellitus, active neoplasia, malignancy, HIV, Hepatitis B or C, contraindication to GH or other clinically significant medical condition that would interfere with study endpoints. For more information, or to participate in this study, contact:

Ami Meyer, Clinical Trial Leader - Serono, Inc.

1 Technology Pl.

Rockland, MA 12370

(781) 681-2314

## A Reader's Response to Dr. Howard's 'End Of Life' Article

First, I want to applaud the decision to deal with this very difficult subject. As noted in the editorial comment, it is not an easy subject to address, especially for HPEN patients who routinely struggle to maintain their good health. Yet, it is a subject worthy of being addressed, since when circumstances force one to address the issue, it is usually the absolute worst time to have to make these types of decisions. The short version of my story is that despite my wife's long history as a TPN patient, we never contemplated what would happen if she became terminally ill. When that happened this Spring, at age 50, my immediate reaction was that it was important to continue TPN, as she had relied on TPN for nutrition for 25 years. I ultimately came to the realization that my first instincts in this difficult situation were probably not the best ones.

I will share with you in more detail my personal experience with this subject in case the article stimulates questions from others contemplating this difficult decision. My wife, Carol, was a Crohn's patient with short bowel syndrome. During those years, she had a number of life threatening infections, including one this past January which resulted in temporary kidney failure. Being the fighter she was (which probably describes a lot of the individuals who manage to make it 25 years on TPN), she made it through each life-threatening episode, including the one this past January. Death, and the decisions which surround it, were the farthest things from our minds. However, this time, while she was still recovering from some of the effects of the infection, she developed symptoms of a bowel obstruction. Even this was not particularly concerning to us, as she had suffered through many such episodes in the past. This time would be different.

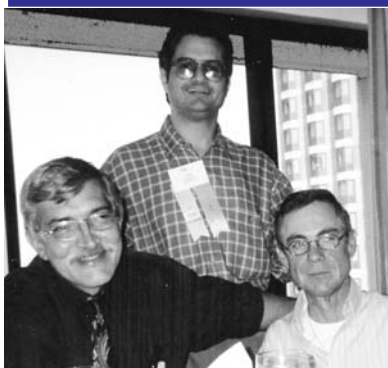
Exploratory surgery uncovered extensive cancer originating in the small intestine. It was determined relatively quickly that no treatment would be recommended, given the type and extent of cancer. Nevertheless, we hoped for a typical post-op recovery with some time afterwards to address questions relating to the cancer. The first week post-op was rather typical, and she was able to walk and converse. While the question of hospice care was discussed, we weren't quite ready for that, and our preference was to find an agency that could assist with some conventional nursing at home, but that later on would be able to provide the hospice care that we would likely need. We had identified such an agency, but before we could transition home, things took a sudden turn for the worse. It was then that we realized that the questions we had preferred to put off, even in the face of the cancer diagnosis, would need to be addressed. By this time, my wife's condition prevented her from being able to fully participate in the decisions that had to be made. TPN was stopped on a temporary basis to address the fluid build up, but the willingness to continue TPN was still high on my list of questions for the hospice organization as I continued to work out logistics for bringing my wife home. I was not ready to face the prospect of giving up the TPN, which for 25 years had truly been her lifeline. The hospice organization worked with me on that, and received approval from its medical director to continue TPN on the theory that it was not introduced because of the cancer, but was her regular source of nutrition.

Ultimately, she stabilized enough for me to move her home with the assistance of 24-hour care from the hospice organization. Again, I was focused on whether the TPN or at least some IV hydration should be restarted. A minimal amount of IV hydration was given for a short time, but the TPN was never restarted. Ultimately, I came to understand the basis for making the decision—as well as all of the other decisions related to her care. Although these decisions initially seemed difficult and complex, they were really quite simple. Each decision was based solely on what would make Carol more comfortable. While it seemed hard for me to grasp that not giving fluid and hydration would enhance her comfort, I soon realized that given the details of her condition, that was the case. It may also have had the effect of not prolonging her life. I don't really know that. But even assuming it did, that also was in the end the right decision, due to the suffering involved at the end of her life, when she was no longer able to meaningfully communicate with me or others.

In our case, it was only a month from Carol's diagnosis to her death so with the speed at which things were moving, there was not a lot of time to ponder these decisions. While I wish we had thought about, and talked about, some of these decisions more when she was doing better, I can't honestly say it made a difference in the outcome. But, I think stimulating thought about these choices before they have to be made is absolutely the right thing for your publication to do.

— Steve Davidson

**Editor's Note:** The Oley Foundation is grateful to Mr. Davidson for sharing his story and his feelings on such a delicate subject. We've received a number of calls reflecting the same sentiments - that although painful, readers are in agreement that we did the right thing by addressing this topic.



### Call for Information!

We have a number of members who are approaching or have reached their 30-year anniversary on homePEN. For example, Jim Wittmann, Todd Friedman and Matt VanBrunt, pictured at left, have over 90 years of combined experience with TPN.

We'd like to celebrate those milestones at the summer conference. If you've been on homePEN for 20 years or more, we'd love to hear from you too! Please contact the Oley Foundation at 800-776-OLEY or e-mail us at [piekarc@mail.amc.edu](mailto:piekarc@mail.amc.edu) and tell us about your experience. ©

## Save the Date!

The Oley Foundation's Chicago Patient/Family/Clinician Regional Nutrition Support Workshop will be held on November 13<sup>th</sup> from 9 A.M. to 4:30 P.M. in Chicago, IL. This workshop will take place at the Pritzker Auditorium, Feingold Pavilion, at the Northwestern Memorial Hospital. Supported by our local volunteer group, The Pumpers, our program is free to all consumers (patients) and their families/caregivers. We welcome clinicians as well.

Dr. Alan Buchman will discuss "Dietary Management of Short Bowel Syndrome", Dr. Kishore Iyer will offer some insight on GI surgery options, and Dr. Jonathan Fryer will offer an update on intestinal transplant. Other programming for the day will include a variety of topics, such as enteral issues, catheter care, wound care, coping, understanding labs, and pediatrics. Continental breakfast and lunch are included, and exhibits for home care companies, new technologies and products will be available.

Patients, come meet others like yourself. Parents, this is a great way to network with other parents facing the same challenges you are. Clinicians, get the latest research and practical solutions to patient problems. We are currently finalizing details. Watch for the Oley registration brochure, which will give you those details and information on registering for the program.

For more information on the conference or The Oley Foundation, contact us at 800-776-6539. You may fax us at 518-262-5528. You may also e-mail Ellie Wilson, MS, RD, Outreach Director for the Oley Foundation at [wilson@mail.amc.edu](mailto:wilson@mail.amc.edu).

*Come join us for a day that's all about you!*



## Location Confirmed for 20th Annual Conference

The Oley Foundation's Annual Conference for 2005 will be held at the Holiday Inn in beautiful Saratoga Springs, New York from June 28<sup>th</sup> to July 1<sup>st</sup>. Rooms are available at a conference rate of \$129/night. You can visit the Holiday Inn online at [www.Holiday-Inn.com](http://www.Holiday-Inn.com) or get information by calling (518) 584-4550.

Saratoga offers sight-seeing, shopping, a fine variety of restaurants and delicatessens, concerts, events and art exhibits. Of course, there's also the Saratoga Race Track where you can see some of the finest racehorses in the country as well as a variety of beautiful hats. The track also offers a wonderful people-watching opportunity and you can try your luck on the ponies or in the nearby Racino, which offers video lottery terminals as well. Visit [www.oley.org](http://www.oley.org) for updates.

## The NHIA to Hold its Annual Conference

The National Home Infusion Association will hold its Annual Conference February 10-13, 2005 at the Ernest N. Morial Convention Center in New Orleans, Louisiana. They offer preconference programs, roundtables, best practice sessions and symposia. For a schedule of activities or more information, visit their website at [www.nhianet.org](http://www.nhianet.org).

## Clinical Nutrition Week 2005

The American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) will hold its Scientific and Clinical Forum and Exposition January 29<sup>th</sup> through February 2<sup>nd</sup>, 2005 in sunny Orlando, Florida. Participating organizations include the American society for Bariatric Surgery (A.S.B.S.), the American Society for Gastrointestinal Endoscopy (A.S.G.E.), Dietitians in Nutrition Support (D.N.S.), (a practice group of the American Dietetic Association, or A.D.A.) and of course, the Oley Foundation.

This year's program includes pre-conference educational opportunities, plenary sessions, symposia, ancillary educational programs, abstract sessions, the exposition, and of course, a party - A.S.P.E.N. After Dark. Continuing Educations Credits are available for physicians, nurses, pharmacists and dietitians.

For more information about this event, visit [www.nutritionweek.org](http://www.nutritionweek.org).

## A Note from the Editor

As many of you know, my predecessor, Roz Dahl, has left Oley after ten years for a position closer to home, leaving some pretty big shoes to fill. As I came on board, Roz and the rest of the staff were working feverishly to organize and prepare for the San Francisco Conference, our biggest annual event. In the process, the July/August edition of the *LifelineLetter* was postponed and eventually fell behind. In an effort to catch up our issues, the staff and I decided a double issue was a great way to combine our efforts and allow us to get back on track. It also provides our readership with a great deal of useful information to absorb and enjoy. I'm sorry to make you all wait so long for this issue, but I certainly hope you enjoy it. I welcome your comments on my first *LifelineLetter*. Feel free to e-mail me at [piekarc@mail.amc.edu](mailto:piekarc@mail.amc.edu).

Thank you!

~ Cory Piekarski



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### Coram Healthcare

For 25 years, Coram Healthcare has provided HomePEN consumers with personalized care and nutrition support teams, through a national network of 77 branch locations throughout the US and in Canada. Coram is proud of their 20-year partnership with Oley and their vast experience in providing Oley members with "care for a lifetime". Coram provides the highest quality clinical and personal support for home parenteral and enteral nutrition consumers, through its One-to-One Program, consumer advocates and consumer contact line: 1-866-4-HomePEN.

### Nutrishare, Inc.

Nutrishare focuses exclusively on caring for long-term TPN consumers throughout the country. Rod Okamoto and Tom Diamantidis invite all Home TPN consumers to visit our website: [www.nutrishare.com](http://www.nutrishare.com) and attend our next Home TPN consumer conference in San Diego, California (August 10 - 14, 2005). Nutrishare is proud to sponsor the TPN consumer scholarship program.

### B. Braun Medical, Inc.

B. Braun is a full-line supplier of innovative healthcare products and programs designed to improve both patient and clinician safety. Our proven line of parenteral nutrition solutions includes FreAmine® (Amino Acid Injections) for standard TPN therapy, TrophAmine® (6% and 10% Amino Acid Injections) for infants and young children, and ProcalAmine® (3% Amino Acids and 3% Glycerin Injection with Electrolytes) for peripheral parenteral nutrition. Call 1-800-227-2862 or visit [www.bbraunusa.com](http://www.bbraunusa.com) for more information. We thank B. Braun for their donation.

Nutrishare scored an unprecedented 100% on its latest ACHC accreditation survey.



*"Nutrishare is kinder and more caring than my previous 2 providers put together. They encourage a family atmosphere. They are true to their 'sharing' name."*

**John Tucker**  
Nutrishare Consumer

**Nutrishare** Inc.  
1-800-Home TPN

## Oley Foundation Horizon Fund Members

<i>John Balint, MD</i>	<i>Darlene Kelly, MD</i>
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<i>Ginger Bolinger</i>	<i>Robin Lang</i>
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<i>Alfred Haas</i>	<i>James Wittmann</i>
<i>Alicia Hoelle</i>	<i>Patty &amp; Darrell Woods</i>
<i>Lyn Howard, MD</i>	<i>...and growing every day!!</i>
<i>William Hoyt</i>	

## Alicia Hoelle Joins Horizon Society



Alicia Hoelle has been on almost total TPN since shortly after her birth. At a month old, she was diagnosed with hypoganglionosis, a form of Hirschsprung's disease. Doctors told her parents, Rose and Jeff Hoelle, they had three choices - "let her go," leave her in a pediatric nursing home or put her on nutrition support therapy. They chose the latter and at three months old, Alicia went home with little expectation she would live out the year.

Alicia recently turned 18 and the Oley Foundation has been an important part of her life for most of those years. That's why, when she was taking care of some legal issues, she decided to name Oley in her will. "I wanted to give back to the organizations that have helped me throughout the years and Oley is one of the very few," she says. Alicia and her family have enjoyed the annual conferences so much that they make it a point to attend every year. Alicia's parents support her decision and said, "We will be adding Oley to both our wills since we have gained so much from this wonderful foundation."

The Oley Foundation would like to thank Alicia for her generosity and enthusiastically welcomes her into the Horizon Society. ©

## Your Support Makes Oley Stronger!

The following generous individuals have donated a gift to the Oley Foundation between June 9 and September 13, 2004. Thank you for your support! We also wish to thank all 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. A complete listing of everyone who donated in 2004 will be published in the January/February 2005 issue.

### Ambassadors (\$2,000+)

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(\$1,000 - \$1999)

Anonymous

Louise Gabel, in memory of

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Manuela Wenz

Arleita Wieczorek, in memory of

Elsie Roesch

\*Oley Trustee

\*\*Oley Regional Coordinator

## Calling All Helpers!

### (But shhhh...this is a silent auction!)

It's that time again when Oley begins its search for silent auction items for our annual fundraiser. Our '04 auction doubled last year's funds and our goal for '05 is to double the funds again.

You all know Oley is a great cause so let's get out there and get those special, sought-after items such as quilts, autographed sports memorabilia, jewelry, hand crafts, childrens' toys, electronics, airline tickets, restaurant and hotel gift certificates, or possibly someone is willing to donate a week of their time share or summer home. Remember, big-ticket items help out Oley a lot!

Ask family, friends, neighbors, home-care companies and local merchants and invite them to join in our fundraiser. Check with employers - possibly they have a service or product they'd like to offer and promote. Tell them about Oley and our mission and inquire if they'd like to support this worthy cause. After all, any donation is gratefully received.

Many Oley members think, "Others do so much, how can I help?" Oley's silent auction is just the place for your talents. This fundraiser is very important as funds raised support valuable Oley programs. Even if you're unable to attend the auction, your efforts will be very much appreciated.

Oley is celebrating its 20th conference anniversary in '05 so climb aboard this fun, fundraising movement and we'll commemorate our 20-year success with the best auction ever! For more information or to donate, contact Silent Auction President Robin Lang at 5 Buffalo Lane, York, ME 13909, e-mail [ivtpn@maine.rr.com](mailto:ivtpn@maine.rr.com) or call (207) 363-7880.



## Unrestricted Corporate Donations

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Shield Healthcare Centers

# 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](http://www.oley.org). Comments? Call (800) 776-OLEY.*

<b>OCT. '04</b>	<p><b>Eleana Shore</b> West Hills, CA (888) 610-3008 PST</p> <p><b>Don Young</b> Porter Corners, NY (888) 650-3290 EST</p>	<p>Eleana's daughter Erin (age 8) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, arthritis and hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and she speaks both English and Spanish fluently.</p> <p>Don has been on TPN for almost 30 years due to short bowel syndrome and Crohns disease. He also has an ostomy. Call him to learn more about HICKMAN® catheters, PICC lines and reimbursement issues (social security, Medicare, private insurance, etc.).</p>
	<p><b>Robin Lang</b> York, ME (888) 610-3008 EST</p> <p><b>Rick Davis</b> Salt Lake City, UT (888) 650-3290 MST</p>	<p>Robin has been on TPN for over 24 years due to SBS and has a HICKMAN® catheter. She lives on ten acres in Maine with Zoe, her black lab and Doodle, her Jack Russell terrier. She has done extensive traveling both home and abroad. Robin worked for 20 years prior to her recent SSD status. She loves to make new friends. Robin keeps busy as a writer, Regional Coordinator and gardener. Feel free to call her anytime - day or night.</p> <p>Rick knows about HEN. He wants you to call. He is 61, cannot swallow, has been 100% dependent on HEN for four years and he is very active. When you call, you will probably reach him skiing where Olympic athletes skied in 2002. He and his wife travel frequently, enjoy being retired and he looks forward to hearing from you.</p>
<b>NOV. '04</b>	<p><b>Ann Weaver</b> Naperville, IL (888) 610-3008 CST</p> <p><b>June Bodden</b> Clearwater, FL (888) 650-3290 EST</p>	<p>Ann is married and has two sons, ages 16 and 8, the younger of which has SBS due to Hirschsprungs Disease. He has been on HEN since birth in addition to being on HPN for three years and IV hydration for seven years. She has cared for a central line, NG tube, G tube and ostomy. She looks forward to talking to other parents.</p> <p>June has had Crohn's disease since age 15, an ileostomy since age 21, and has been on TPN since age 30 (20 years). A Regional Coordinator and an active support group member, she believes networking with others is important. A strong faith, volunteer work and help from family and friends keeps June upbeat.</p>

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## LifelineLetter

**The Oley Foundation**  
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