

# Lifeliner

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

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## Affiliation with Oley Foundation Improves Patient Outcomes

Over the past 30 years, home parenteral nutrition (HPN) has become an established therapy for patients with severe chronic small bowel dysfunction. Patients usually have partial or complete return to normal activity, such as work or school. However, this is an expensive home therapy, especially if the patient has recurrent complications that require hospitalization. For example, hospitalization for a single episode of sepsis is estimated to cost \$10,000 to \$50,000. In addition, there are costs to the family in

terms of stress and forfeiture of earnings. (A family member may lose time from work or even give up a job to care for an HPN patient.) Thus, any intervention that can improve the patient's quality of life and ability to manage at home — and reduce expensive complications — offers significant benefit to patients, payers and health care professionals.

A review of literature indicates a consistent strong positive relationship between patient outcomes and participation in peer support services for chronic disease. Participation in such a group decreases depression, anxiety, and hospitalizations, and increases self-care and better management decisions with the supporting health care professionals. Studies have also shown that contact with others who have managed a similar condition enhances patients' self-esteem and sense of well-being.

The following study was undertaken by Carol Smith, RN, PhD, to  
**Oley Affiliation** cont., pg. 2

**Table 1. Percent of affiliated patients reporting use of Oley services**

	Read newsletter	Contacted other HPN patients	Attended national meeting
Group 1-affil. pts	70%	10%	50%
Group 2-affil. pts.	68.4%	14.3%	47.4%

HPN, home parenteral nutrition

## Mark Your Calendar!

The 18th Annual Oley Consumer/Clinician Conference will be held June 19-21, 2003, at the World Golf Village Renaissance Resort, in St. Augustine, Florida. In addition to golf, the resort offers a beautiful relaxed setting for consumers to learn and socialize.

The annual conference is a great time to discover more about homePEN: the medical updates and coping strategies you need to know. It also offers the unique, unbeatable opportunity to mingle with people who walk the same walk as you and your family. Plan to join Oley as we celebrate 20 years of providing information and psycho-social support to homePEN consumers across the nation and the world.

### Volunteers Needed!

Conference Coordinator, Joan Bishop, is busy planning the program and would like your input. If you have any ideas for speaker topics, breakout sessions, social events, or anything else conference related — please contact Joan today at 800.776.OLEY or bishopj@mail.amc.edu.

## Exploring Sexual Matters

**Audrey Kron, MA, CGP**

Dear Audrey,

I'm planning on getting married soon, and I'm concerned that my condition might affect my sexual life. Can someone with a chronic illness have a normal sex life? What kinds of sexual problems might I encounter? —B.L.

Dear B.L.,

Congratulations on your upcoming marriage. I'm glad that you asked about the sexual implications of chronic illness. People find this is a difficult area to talk about, and there is often needless misunderstanding because of the lack of communication.

The simple answer to your question is that, usually, chronic illness does not prevent us from having a very satisfactory sex life. But, there are possible problem areas that could cause you or others some concern in the future:

**Ask Audrey** cont., pg. 6

**Oley Affiliation**, from pg. 1

determine the association between affiliation with an education and peer support organization (the Oley Foundation) and HPN patient outcomes, and is published in the May-June 2002 issue of the *Journal of Parenteral and Enteral Nutrition*. The effect of affiliation with a national education and peer support organization was evaluated in two separate

groups of patients receiving HPN. Group 1 data were collected from programs at large academic medical centers. Group 2 data were collected from small programs to identify whether affiliation with Oley had an effect on outcome regardless of HPN program size and experience with HPN.

In both groups, patients who had an affiliation with Oley were matched with those who had a similar diagnosis, duration on HPN, gender and age — but no affiliation with Oley. When pairing patients, most weight was given to matching their diagnosis since earlier studies have demonstrated that diagnosis is the most predictive factor in HPN outcome. The second most important variable for matching patients was duration on

therapy. It was used to control for the patients' level of experience in avoiding complications. Gender controls were used because there is a greater likelihood of women to join support groups; and age because it has a modest influence on outcomes in patients with stable diagnoses.

The study compared the affiliated and non-affiliated patients' quality of life, emotional well-being, and rate of catheter-related bloodstream infection (CRBSI). To obtain the data, patients completed the Quality of Life Index, and the reactive depression questionnaire.

They were also interviewed by telephone regarding their participation in support groups, contact with other HPN patients, newsletter reading habits, attendance at HPN-related conferences — and whether the services they used were from Oley or other organizations. The occurrence of a catheter-related bloodstream infection (CRBSI) was identified by review of the managing physician's record and review of blood culture results.

**The Results**

The investigators found that the primary connection between patients and the Oley Foundation was through the newsletter (approximately 70%), followed by attending a conference and networking with other members (see Table 1 on page 1). Nonaffiliated patients

reported no involvement or activities with other HPN patients across the 18 months. As shown in Table II below, group 1 and group 2 affiliated and non-affiliated patients had similar underlying medical diagnoses. Patients receiving HPN long-term have a high incidence of Crohn's disease, and this was true of patients in this study; the remaining patients had mesenteric ischemia, radiation enteritis, or a motility disorder. The duration that patients had received HPN was somewhat longer for patients in group 1, but all patients

**Oley Affiliation** cont., pg. 7

The recurrence of catheter related blood stream infections was significantly lower for patients affiliated with Oley.

**LifelineLetter**

Sep/Oct 2002 • Volume XXIII, No. 5

**Publisher:**

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**Subscriptions:**

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Director of Publications & Information at the address above.

**Table II. Variables matched for patients in groups 1 and 2 affiliated or nonaffiliated with Oley \***

Group 1	Underlying medical diagnoses	Years receiving HPN	Gender	Age years
Affiliated (N = 24)	71% Crohn's	10.5 ± 4.4	75% Female	50.0 ± 13.9
Nonaffiliated (N = 28)	75% Crohn's	9.9 ± 7.0	65% Female	47.8 ± 14.4
Group 2	Underlying medical diagnoses	Years receiving HPN	Gender	Age years
Affiliated (N = 21)	70% Crohn's	5.6 ± 2.6	55% Female	46.6 ± 13.2
Nonaffiliated (N = 22)	72% Crohn's	7.4 ± 3.1	65% Female	53.7 ± 15.1

\*All values are means ± SD.  
HPN, home parenteral nutrition

## 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 A-28, Albany Medical Center, Albany, NY 12208; or E-mail [DahlR@mail.amc.edu](mailto: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.

### EN Bag Relieves Pressure While Feeding

The Oley Foundation has recently come across an enteral feeding bag (FARRELL® Valve and Super FARRELL Valve Enteral Gastric Pressure Relief System by CORPAK MedSystems, Wheeling, IL) that is designed to relieve gastric pressure as the consumer is feeding. The company states that it can be used with any feeding and with gravity, pump or bolus administration. We are wondering if any of our readers have used this type of bag, and what their experiences were. Please send your feedback to "Tube Talk" at the address listed above. ©

## Dietitian Conference Planned

Dietitians in Nutrition Support (DNS) are planning their 25<sup>th</sup> Anniversary Celebration. Entitled, "Sharpening Your Skills as a Nutrition Support Dietitian," the conference will be held May 15 - 17, 2003 at the Astor Crowne Plaza Hotel, in New Orleans, LA. Topics include Professional Issues, Neonatal & Pediatric Nutrition Support, Parenteral/Enteral Nutrition, Adult & Pediatric Nutrition Assessment, Home Care Skills, Metabolic Support, and GI Nutrition. For more information email Carolyn Aeby at [carolynaeb@yahoo.com](mailto:carolynaeb@yahoo.com). ©

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Brian Sessions - Fennville, Michigan



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## Howling About Nutrition Week!

Nutrition Week 2003 is looking like Texas — Really Big! To properly celebrate The Oley Foundation's 20 years of bringing consumers and clinicians the highest quality in education, we are presenting a consumer/clinician program on Saturday, January 18<sup>th</sup>, 2003 at Nutrition Week. We are honored to welcome our volunteer faculty — top researchers and clinicians in nutrition support — joining us from all over the country:



Jane Balint, MD, Peds GI, Children's Hospital, Columbus, OH  
Alan Buchman, MD, GI, Northwestern University, Chicago, IL  
Lyn Howard, MB, GI/Nutrition, Albany Medical Ctr., Albany, NY  
Kishore Iyer, MD, Transplant Surgery, Nebraska Med. Ctr., Omaha, NE  
Khurshed Jeejeebhoy, MB, Nutrition, St. Michaels Hospital, Toronto, Canada  
Carol Ireton-Jones, PhD, RD, Nutrition Svcs., Coram Health Care, Carrollton, TX  
Darlene Kelly, MD, GI/Nutrition, Mayo Clinic, Rochester, MN  
Jarol Knowles, MD, MPH, GI, Duke University Med. Ctr., Durham, NC  
Reid Nishikawa, PharmD, Pharmacy/Clinical Svcs., Nutrishare, Elk Grove, CA  
Ezra Steiger, MD, GI Surgery, Cleveland Clinic, Cleveland, OH  
Josie Stone, RN, CPNP, Customer Support, BD Medical Systems, Sandy, UT

Topics to be discussed will include motility issues and gastric pacing, transplant/intestinal failure, access issues, pediatric nutrition support, history of parenteral nutrition, current topics in liver disease, enteral challenges, interpreting labs, and looking into the future of nutrition support research — a terrific, dynamic program! We are also special guests in the Exhibit Hall on Sunday, January 19<sup>th</sup>. Maintaining our tradition, consumers may attend both days at no charge.

Watch the Oley website — [www.oley.org](http://www.oley.org) — for more information and registration opportunities. Oley members who live in Texas will have registration flyers mailed to them. We have arranged a group rate, \$91 for a suite, at the Best Western Sunset Station, 10 minutes from the San Antonio Convention Center. To reserve a room, call 210-223-4400 and mention you are with the Oley Foundation.

Join us, and help Oley celebrate 20 years of serving the HomePEN community!

## Equipment Exchange

The following HPEN supplies are offered free of charge:

- 20 Hollister Drain/Tube Attachment Devices
- 60 Kangaroo Bags 1000 ml (#8884-773-600)
- Kangaroo Pet Pump (portable EN)†
- 2 Mic-Key G feedings tubes 14 fr., exp. 1/04
- 23 Ross Easy-feed EN bags
- 9+ cases Osmolite
- 6 cases Jevity Plus, exp 5/03

†FREE shipping offered.

For more information, call (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods please offer to pay for shipping.

## 2002 Oley Conference: Full of Fun, Fellowship and Learning



*Left: Mariah Abercrombie and Malisa Matheny glad to have a few days together*

*Below: Tim Weaver playing at Jammin' Jammies*



*Above: Susan and Todd Friedman at the picnic*



*Above: Alicia Hoelle and Colin Woods share a smile*



*Above: Kathleen & Larry McInnes all dolled up for the RC soirée*



*Left: Jeff & Rosie Hoelle enjoy a moment's rest from volunteering*



*Above: Kyle Noble enjoying the auction*



*Above: Michael Medwar poses with his mom, Joan, at the picnic*



*Left: Robbyn Kindel, Tim Joyce, Linda Wyatt, and Judy Peterson swap stories at the RC soiree*



*Above: Samantha Bye hugs her new friend at Jammin' Jammies*



*Left: Linda Gold-Pitegoff, Cathy Tokarz and Kathleen McInnes keeping cool at the picnic*

## Coping Skills

Ask Audrey, from pg. 1

### The general symptoms of your illness:

Pain, fatigue, nausea, dizziness, poor motor control, diarrhea, incontinence, etc., can impede your sex life. However, often there are ways to get around these symptoms. First, talk to your doctor. Sometimes relieving symptoms may be as easy as changing medicines.

Then, communicate with your spouse or partner and together, find ways to modify your sexual activities to accommodate your illness. You may have to find different positions or different times. It might work out better if you could plan to use the time of the day when you are feeling best. Paul Pearsall in his book *Super Marital Sex* gives this practical advice, "If it hurts, check out why. If it can't be helped, try something else." As a last resort you might check with your doctor to see if you can take a pain pill or other medication that will enable you to participate more comfortably in sexual activities.

With good communication and some advance planning, many problems can be overcome. Some find that sex can divert attention away from the symptoms, but the way you handle these symptoms is also very important. Love, caring, and sexuality can be expressed in many ways besides intercourse. You know how. Sometimes, you just forget.

### The psychological impact of the illness:

This can include depression, altered sense of identity, body image changes, loss of job, and role changes within the family and society. Certainly sexual relations are strained when you feel depressed or concerned about your body image, your role in the family, or your work. What happens in these areas will have impact in the bedroom. It's important to involve your partner with your concerns because he or she, too, will have feelings about what's going on.

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With good communication  
and some advance  
planning, many problems  
can be overcome.

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Spouses may be concerned that they are going to cause you to be sicker, or that they may harm you in some way. Others feel selfish that they have needs as well. Communication, again, is the key word. How you look, how you speak, how you act, and, most of all, how you care, can contribute to your sexual attractiveness.

### The physical changes from the illness:

Some fear that they will be unattractive or rejected if they gain weight as a result of medication or experience other bodily changes. Others feel less attractive because of a catheter, tube, ostomy or even surgical scar. These fears may in turn accompany a fear of abandonment. Bodily changes need not interfere with sexual activity. I can't repeat enough that a person who loves you won't be bothered by physical changes. Why would you bother with a person who doesn't love you? Other physical changes may make actual intercourse impossible in some cases. Here, again, is where your imagination can help you to find ways to satisfy your sexual needs. There are many parts of our bodies that can give sexual gratification. If you have questions about this, consider some reading. (A list of suggested books is included in Appendix Two of *Meeting the Challenge: Living with Chronic Illness*)

### The specific fears from chronic illness, tubes and ostomies:

Some fear that sexual activity will provoke symptoms, or that one's sex life cannot be resumed. Some fear that sex will make the illness worse, or dislodge their catheter or tube. Some fear pregnancy. In all cases, it is important to get the proper information, and to discuss these concerns with your doctor. Also, consult your doctor about any prescribed medications that could affect your sex drive.

Another less serious, but more embarrassing problem, is the possibility of having a symptom flare up or a tube or ostomy leak

## Celebrating Life!



Donald

Donald Young has been an example to people on TPN since he began receiving it 26 years ago. In his community he helps with snow plowing, chops and sells wood and is involved in local political campaigns. He's even found a creative way to continue working around his farm, having rigged up a bar for his TPN bag on his tractor! Congratulations Don!



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NUTRITION SERVICES



To nominate someone to Coram's Celebration of Life Circle, send the story of a friend or loved one to:  
Coram's Celebration of Life Circle, 1675 Broadway, Suite 900, Denver, CO 80202 or, email: [celebratelife@coramhc.com](mailto:celebratelife@coramhc.com)  
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during intercourse. True, this can be embarrassing, but one has to remember that your partner loves you and will be greatly influenced by your reaction. How you handle the situation makes a great deal of difference. You can get hysterical and hate your body and lower your self-image; or you can look at it as unfortunate, but something that happened. Your doctor may be able to prescribe medication or make some suggestions that can make you feel more secure during intimate times.

#### The specific fears about sex in general:

There are all kinds of concerns about sex, with or without illness. These concerns have to be dealt with as they normally would. You have to work on them, or, if you run into an impasse, you should seek professional help.

In all situations, it's important to focus on the potential, not the limitations. Realize that sex is expressed in many ways. Think of the whole person rather than just the genitals. Flexibility, communication, education, understanding, and humor are all important. Above all, you should try to do what you can to improve any difficulties in your sexual relationship. Never abandon the idea that you can do something to enrich this important aspect of your life. ☺

Ask Audrey columns come from *Ask Audrey: The Author's Personal and Professional Experience with the Day-to-Day Living with Inflammatory Bowel Disease and Meeting the Challenge: Living with Chronic Illness*. Both books feature Audrey's story of living many years with Inflammatory

*Bowel Disease and her expertise as a medical psychotherapist. To order copies of the books, call 248-626-6960, fax 248-626-1379, mail shrinkA@aol.com, or 7466 Pebble Lane, West Bloomfield, MI 48322; or visit www.chronicillness.com. If you mention the Oley Foundation, we will receive a \$2.00 rebate for each book you purchase.*

## Remembering Audrey Kron

We are sad to report that Audrey Kron, M.A., CGP, author, therapist, wife and homePN consumer, passed away September 21, 2002, just before this newsletter was published. Diagnosed with Crohn's disease, Audrey had been on and off TPN and hydration for many years. Her experiences in overcoming the difficulties of living with inflammatory bowel disease inspired her to continue with her education later in life and become a medical psychotherapist.

The combination of her personal and professional viewpoints was evident from the quality advice she offered in her books and "Ask Audrey" columns. Through her work and writing Audrey has inspired many individuals to overcome their personal challenges with chronic illness. As a testimony of her dedication to fellow lifeliners, she has left us some of her writings that we will continue to share. She was a strong, caring person who will be remembered fondly. ☺



**Audrey Kron**

#### Oley Affiliation, from pg. 2

had received therapy for at least 2.9 years. There were more women in both groups and all patients were between 30 and 70 years of age.

Patients affiliated with the Oley Foundation from large and small programs had significantly higher scores on the quality of life index than those who had no affiliation (see Table III on right). It should be noted that mean scores fell below 22, the normal score for healthy adults. The reactive depression score was significantly less (better) in both groups of patients affiliated with Oley. The normal score for healthy adults is 0 to 15.5, with mild depression scores 16.0 to 20.5, moderate depression 21.0 to 30.5 and severe depression greater than 31. Patients affiliated with Oley showed none or minimal depression, whereas nonaffiliated patients showed moderate depression. Finally, the recurrence of CRBSI in an 18-month period was significantly lower for patients affiliated with Oley (0.1 infections for affiliated patients, versus 0.6 infections for nonaffiliated patients).

In conclusion, the study showed that patients affiliated with the Oley Foundation have a better outcome, regardless of HPN program size. Specifically, when compared with nonaffiliated case-matched controls, affiliated patients experience a significantly higher quality of life, less reactive depression, and a lower incidence of catheter-related sepsis. A limitation of the study's design is that more positive and self-reliant patients may be more likely to join organizations and may exhibit superior outcomes even if such an organization was not available. Further studies are recommended to rule out this possible limitation. ☺

This article is based on the study "Home Parenteral Nutrition: Does Affiliation with a National Support and Educational Organization

**Table III. Group 1 and 2 Outcome Results\***

Group 1	QLI**	Reactive depression scores†	Infection incidence over 18 mos.††
Affiliated (N = 24)	19.8 ± 4.7	10.9 ± 10.4	0.10 ± 0.3
Nonaffiliated (N = 28)	17.6 ± 5.6	20.4 ± 13.6	0.60 ± 0.55
Group 2	QLI§	Reactive depression scores§§	Infection incidence over 18 mos.§
Affiliated (N = 21)	20.4 ± 5.2	12.5 ± 9.64	0.27 ± 0.55
Nonaffiliated (N = 22)	17.3 ± 4.8	18.5 ± 10.8	0.71 ± 0.64

\*All values are means ± SD

\*\*t = -1.96, p = .05

§ t = 2.056, p = .05

† t = 2.86, p = .01

§§ t = 1.87, p = .03

†† t = -2.769, p = .01

‡ t = -2.41, p = .02

QLI, quality-of-life index

CRBSI, catheter-related blood stream infection

*Improve Patient Outcomes?" written by Carol Smith, RN, PhD, ARNP, et. al., published in the May-June 2002 (Vol. 26 No. 3 pp. 159-163) issue of the Journal of Parenteral and Enteral Nutrition (JPEN).*



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  - Patty & Darrell Woods*
- ...and growing every day!!*

**Your Support Makes Oley Stronger!**

The following generous individuals have donated a gift to Oley between July 25 and September 20, 2002. 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 and/or by volunteering their time and talents. A complete listing of everyone who donated this year will be published in the January/February 2003 issue.

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Chick Casillo and Sherril Miller\*\*

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\*\* Oley Regional Coordinator

\*\*\* Oley Staff

**Building a Community**

We would like to salute Donna & Richard Noble, Mitzi Goldberg, Michelle Christensen and friends of the **Mighty Medical Miracles (M<sup>3</sup>)** of Columbus, Ohio. Since joining Oley 1-1/2 years ago these folks have built terrific awareness in their community of homePEN challenges and triumphs. The following contributions are a direct result of these efforts.

Dona & Kevin Allen  
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Coram Healthcare's dietitians, nurses and pharmacists provide home parenteral and enteral nutrition support services to more long-term consumers than any other company. All of their 79 branches throughout the country are ACHC Accredited with Commendation. Through the One-to-One program and the Celebration of Life Circle, Coram focuses on providing consumers the expertise they need and the caring they deserve. We wish to thank Coram for their continued support at the Silver Circle Level.

### Nutrishare, Inc.

Nutrishare focuses exclusively on caring for long-term home TPN consumers throughout the country. Rod Okamoto and Tom Diamantidis invite all Home TPN consumers to attend their next conference to be held May 7-11, 2003 in Sacramento, California.

Nutrishare proudly sponsors the scholarship program for Home TPNers. We thank Nutrishare for their continued support as Silver Circle donors.

### Calea Ltd.

Since the early 1980s, Calea has made it possible for home TPN clients to lead normal lifestyles. Calea's healthcare professionals work in partnership with healthcare teams to provide clients with the training, supplies, and ongoing emotional or technical support necessary to manage their TPN therapy at home. Calea HomeCare supports the home TPN community through its efforts with the Canadian Society of Nutritional Support, the Canadian Parenteral and Enteral Nutrition Association (CPENA), the Oley Foundation, and the American Society of Parenteral and Enteral Nutrition (ASPEN). We thank Calea for supporting Oley at the Friends level.

## Welcome to Holland

Emily Pearl Kingsley

I am often asked to describe the experience of raising a child with a disability; to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this..

When you're going to have a baby, it's like planning a fabulous vacation trip — to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michaelangelo. David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy

place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, go away because the loss of that dream is a very, very significant loss.

But, if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland. ☺



## Survey Raises \$4200

A warm thank you to everyone who participated in the Short Bowel Syndrome (SBS) study earlier this year, and to National Analysts Inc., sponsor of the survey. Together we raised \$4200 for Oley programs, and provided valuable feedback on a potential new product for consumers with SBS. We also wish to thank the individuals who volunteered but were unable to participate in the study. Your dedication is appreciated. Companies interested in consumer feedback on existing products, or those still in the development phases, can contact Oley's Executive Director, Joan Bishop at (800) 776-OLEY for more information on availability, costs and restrictions. ☺

### Unrestricted Corporate Donations

**GOLDEN DONORS (\$50,000+)**

**SILVER CIRCLE MEMBERS (\$25,000-\$49,999)**

Coram Healthcare  
Nutrishare, Inc.

**BENEFACTORS (\$15,000-\$24,999)**

Abbott Laboratories  
(Alternate Site Product Sales/  
Ross Products/Creative Network)

**PATRONS (\$5,000-\$14,999)**

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Daniel F. & Ada L. Rice Foundation

**SUPPORTERS (\$2,500-\$4,999)**

Critical Care/Infusion Care Systems  
Mead Johnson Nutritionals

**CONTRIBUTORS (\$1,000 - \$2,499)**

B. Braun  
Kendall/Tyco Healthcare  
Kimberly Clark/Ballard Medical  
Nestlé Clinical Nutrition  
Patient Support Services  
Zevex, Inc.

**FRIENDS (\$500-\$999)**

Baxa Corporation  
Calea Ltd.  
Nutritional Restart Center

## 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.

NOV. '02	<p><b>Amy Vohsing</b> Granville, OH (888) 610-3008 EST</p> <p><b>Janet Dobbins</b> Harrington, WA (888) 650-3290 PST</p>	<p>Amy is the mother of three children. Her oldest son is 15 and has Short Bowel Syndrome. He lost all but 10 inches of bowel due to a car accident. She would be happy to talk about all issues surrounding this condition (siblings, adolescents, life changing adjustments, etc). She has experience with TPN and EN feeds.</p> <p>Jan has had SBS since 1997, and a colostomy since 2000. Her husband, Myles is a great supporter and caregiver. Jan promotes a take charge attitude and encourages sharing experiences with others. She enjoys playing guitar, writing music, and humor. Jan is not currently on TPN or EN, but still has nutrition/hydration issues.</p>
	<p><b>Charlene Key</b> Boerne, TX (888) 610-3008 CST</p> <p><b>Don Freeman</b> Ontario, Canada (888) 650-3290 EST</p>	<p>Charlene was left with a short gut after a car accident. She has had only one catheter infection in her 17 years on TPN! Charlene has been married for 39 years and has 2 children and 7 grandchildren. She enjoys speaking with other Lifeliners and hopes to see ya'all at Nutrition Week in San Antonio, TX this January (2003).</p> <p>Travel? Canadian eh? Don has traveled widely on his own in North America and Europe. Diagnosed with Crohn's at 15, an ostomate for 37 years, and on TPN since 1981; he has raised a son, worked full-time, and is active in his community. Don, founder of the Canadian PEN Association, is an Oley RC and the 2002 <i>LifelineLetter</i> Award recipient.</p>
JAN. '03	<p><b>Matt Van Brunt</b> Adelanto, CA (888) 610-3008 PST</p> <p><b>Tammy Adams</b> Liberty Lake, WA (888) 650-3290 PST</p>	<p>Matt has been on TPN for 20 + year's due to Crohn's disease and short bowel syndrome — so he is experienced with the up's and down's of TPN. He likes riding his bike, spending time with friend's, and visiting his girlfriend in Florida. He is happy to talk about anything associated with TPN or otherwise.</p> <p>Tammy is the mother of Breanna, a 20 y.o. who has been TPN dependent since birth, due to CIIP (pseudo-obstruction). They have been dealing with liver failure issues for about five years. Tammy also has two other active daughters, ages 15 and 11. She looks forward to sharing her experiences with others.</p>

LifelineLetter

**The Oley Foundation**  
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