

# LifelineLetter

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

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## Alycia's Journey

Michael Levy

*"It's fun to have fun, but you have to know how."*  
— Dr. Seuss

We are the Levy's from Silver Spring, MD. We have a beautiful, happy 4-1/2-year-old daughter named Alycia who is, to say the least, a piece of work. Alycia has an older sister named Emily who is even cooler than she thinks she is, and two parents who are decidedly not as cool as we think we are! (Well, to tell the truth, her mom Stefanie was, and is, pretty cool, while I still laugh at Gilligan's Island re-runs). And let's not forget Rocky the Cat.

Alycia goes to nursery school every day and has lots of friends, except, she says, for a boy named Josh, because as she told me today, "...Daddy, he just doesn't cooperate." She went to Disney World when she was two and almost pulled Pinocchio's nose clean off, and she went with us to Las Vegas this past December where she pulled the handle on a slot machine after finding a quarter on the floor. I do not know who was more upset in the two events: Pinocchio or the two



*Alycia Levy shares her sunny disposition.*

casino security guards who rushed over to Alycia, (and yes, to her not-so-cool Dad who thought it was hysterical), and kicked her out. Either way, Alycia thought both instances were terribly funny because she has a wonderful, and sometimes mischievous, sense of humor. Oh, and by the way, Alycia has Chronic Intestinal Pseudo Obstruction, a Broviac, a G-tube, and is soon to be listed for an intestinal transplant due to eminent liver failure.

**Alycia cont., pg. 2** ←

## HomePEN at the End of Life

**Lyn Howard, MB, FRCP, FACP, Medical & Research Director, The Oley Foundation**

*Editorial Comment: From time to time we receive requests for our thoughts on the subject of death, dying and the termination of nutritional support. In response to one such request, we asked Dr. Lyn Howard, who has spent a long and distinguished career caring for patients on nutritional support, to write about her experience with this issue. We at Oley have avoided publishing information on this most difficult topic for obvious reasons. Even people in good health avoid it, and we in the HomePEN community who expend extraordinary effort to survive have more reason for not wanting to dwell on death and its particulars. Recognizing this is a difficult and controversial issue, we sent this article to a number of longterm consumers for review and comment before going to press. We thank everyone involved for sharing their opinions freely. Oley does not intend to take a position on this subject, but will remain a neutral conduit for the exchange of information. If this exchange is to produce meaningful results we must hear from you, our readers, on our handling of this topic as well as comments on the paper itself. We hope you find the article helpful.*

Recently Joan Bishop, executive director of the Oley Foundation, asked me to share some thoughts about dying while on home parenteral and enteral nutrition

(HPEN). I think Joan saw that I'm getting close to the end of my long career supporting persons and families on HPEN and felt I should tackle this difficult topic before I topple over! It's not an easy topic since we traditionally spend our days defeating death and promoting a full and active life. But it's true all of us die at some point and I think there are special issues for persons on HPEN to consider.

### HPEN Not a Likely Cause of Death

First a few facts; who dies on HPEN and what is death due to? The chief factor determining mortality is the underlying diagnosis. HPEN is not so much a disease treatment as a treatment of a disease complication — intestinal failure. The disease itself may stabilize, as in many individuals with short bowel due to Crohn's disease, or it may progress, as in unresectable cancer. Table 1 lists the primary diagnoses where HPN is commonly used. Table 2 gives percent survival at 1, 3 and 5 years for persons who stay on parenteral therapy. Because table 2 largely reflects adult outcome, I have been given permission to share figure 1, the unpublished outcome data in 302 children treated in France on PN.

**End of Life cont., pg. 7** ←

### Alycia, from pg. 1

Not to sound cavalier, but this is the attitude with which we have tried to treat the journey that started when Alycia was 24 hours old and we realized there might be a problem. We simply do not think of her as a sick child, despite the challenges that come when your little girl or boy has medical issues. Life can be like a roller coaster, and you have got to

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\* \* \* \* \*

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.

recognize and appreciate the ups to help you get through the twists, the turns, and the downs. As my cousin told me when Alycia was about 10 days old, "Michael, you know why you are going to deal with this? Because it is there to be dealt with. Simple as that." And so we have.

#### In the Beginning

When big sister Emily was born, she did not "poop" for 56 hours. (Parents with kids that do not have GI issues just don't know how great a word "poop" is, do they?) We started hearing phrases like "motility disorder" and "Hirschsprung's Disease". Well, right there on the Radiologist's table that situation, shall we say, rectified itself, and home we went. Two years later when Stefanie was giving birth to Alycia, there was evidence of meconium in the amniotic fluid, and so a Neonatologist was present at the delivery. No problem, we thought, at least we don't have any GI issues to worry about like we did when Emily was born. This kid just can't wait to make a bowel movement!

Alycia was transferred to Children's National Medical Center in Washington, D.C. when she was three days old. She had surgery, but they found nothing wrong. "Don't worry Mom and Dad, she will be fine in a few days." A week later things were still not fine, and so we went to the Internet. We searched "Pediatric" and "Gastroenterology" and "Disorders". Geeze, who knew there were so many. Finally we came to Chronic Intestinal Pseudo Obstruction and it seemed to fit everything that was happening to Alycia. Now, G-d knows I have an ego and am certain I'm always right, (want to take a guess how many arguments I win in my house living with 3 females? Yeah, that's right, not too many!), but it was like a slap in the face when the Director of Pediatric Gastroenterology at Children's told us a few days later that they had concluded Alycia has CIP. In went the Broviac, in went the G-Tube, and after a total of eight weeks in the hospital, she finally came home. We went back to the Internet and found out about great organizations such as the Oley Foundation and the American Pseudo-obstruction and Hirschsprung Disease Society.

The Home Health Care agency nurse came by, laid out the supplies and started teaching us how to take care of our daughter, who was to be on TPN 18 hours a day. And I thought Algebra was hard! Tubes and flushes and

alcohol pads and Mickey extenders and injection caps. Lipids and Op-Sites and gloves-OH MY! We have it all on videotape, except for the looks on our faces that would have shown two parents in a semi-state of shock. And then cousin Judy's words came back... "You are going to deal with it, because it is there to be dealt with." Stefanie shared such great words with our family and friends during a Naming Ceremony we had, also celebrating Alycia's 1<sup>st</sup> birthday. She thanked G-d that if a little girl was going to be born with such problems, then it was good that she was born into a family that was able to handle it.

#### Getting on with Life

Alycia has had lots of problems, but so many more events in her life have been triumphs. She's on her 4<sup>th</sup> Broviac and has been admitted into the hospital no less than 25 times in 4-1/2 years. She's had over a dozen line infections, and almost broke the Maryland fever record when her temperature hit 106.6°F during one such event (not like we're bragging or anything). When she was 14 months old she had an infection that sent her into septic shock, where she spent five days in critical condition on a ventilator in the PICU. And yet, less than 36 hours after having the breathing tube removed, we have pictures of her jumping up and down in her crib at the hospital. She had this huge smile on her face, and was happy as can be. We are sure she was wondering where Mommy and Daddy have been all week, and why they had all that gray hair so suddenly.

Alycia is happy, strong-willed, and despite things, does not think of herself as being "different" because we have tried not to treat her that way. During several trips to Ocean City, MD, Alycia used to sit in her stroller and watch her big sister go on the kiddie rides. During the summer of 2001, when she was not yet two, we put her onto one of those little cars that goes round and round in a small circle. The only thing brighter than the lights in the amusement park was the smile on Alycia's face. And her smile also conveyed a message to us that we do occasionally need to be reminded of. "Mommy, Daddy, it's not like I'm gonna BREAK!" You should see the way Alycia and her big sister wrestle with each other now. Emily is careful in regards to her Broviac, but Alycia can certainly hold her own.

Alycia cont., pg. 10 ➤

## Equipment Exchange

The following supplies are offered free of charge to readers:

### EN Formula

- 4 cans Promod Formula powder, exp. 2/05
- 2 boxes Tolorex packets, exp. 8/05
- 5 cases Fibersource HN, exp. 9/05
- 3 cases Peptamin 1.5 unflavored, exp. 1/05
- 16 cans Probalance formula Vanilla, exp. 1/05
- 8 cases of Jevity, exp. 8/04
- 3 cases Impact w/ fiber, exp. 7/04
- 1.5 cases Osmolite 1 Cal (formerly Osmolite HN)†

### EN Bags/Sets

- 24 Kangaroo gravity bags, 1000 ml
- 20+ Kangaroo bags, 500 ml, 1000 ml
- 6 Ross 1000 ml feeding bags, #52048
- 8 Zevex Enterlite bags, 1200 ml
- 14 Polar EN bags with pump set., 1200 ml
- 1/2 box Embrace Ambulatory EN Bags w/ pump set, 500 ml, #55355†

### Other

- 6 BD 60 ml syringes
- 10+ 60 ml syringes
- 1 sharps container

† will pay for shipping

MORE SUPPLIES are available! For a complete listing, visit our website at [www.oley.org](http://www.oley.org) or contact Cathy at [HarrinC@mail.amc.edu](mailto:HarrinC@mail.amc.edu), (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, especially heavy items like enteral formula or infusion pumps, offer to pay for shipping.

## Scholarships for HPN Consumers

Nutrishare, Inc. is sponsoring three \$500 scholarships for TPN consumers toward the Fall 2004 semester. Interested TPN consumers should write a few paragraphs describing their studies and what they plan to use their education for. Applications should be submitted to the Oley Scholarship Committee who will choose the winners based on potential and need.

Applications should be typed or word-processed and must include the candidate's name, number of years on TPN, address, daytime phone number, and photo. (Email a tif or jpeg file, or send a real "print" on Kodak paper; we can't reproduce photocopies or computer printouts in the newsletter).

The application materials should be mailed to Joan Bishop at the Oley Foundation: [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu) or 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208 and **post-marked by August 30, 2004**. The scholarship money will be distributed at the end of the fall semester when the winner submits a copy of his/her grades to the Oley Foundation. ©



## 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 [PiekarC@mail.amc.edu](mailto:PiekarC@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.*



## Triamcinolone Acetonide Cream for Granulation Tissue

For the last six months, I have been in pain with raised tissue around my J-tube. Every week it was being burned off with Silver Nitrate. Triple Antibiotic held in moisture and made it inflame and bleed. Colloidal Silver was too wet and compromised the healthy skin. Finally, my Stoma nurse prescribed Triamcinolone Acetonide Cream. Within one hour of applying to tissue, the inflammation reduced. The next morning the raised tissue disappeared. Finally, after six months of radiating pain on my whole left side due to the nerves in the raised tissue, last night I slept on my left side!

I hope this helps someone else.

— Melissa Chaney  
Otsego, MN  
[ladybug\\_chaney@hotmail.com](mailto:ladybug_chaney@hotmail.com)

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## Volunteers Needed for Upcoming Meetings

Several exciting conferences are being planned that offer an opportunity to learn more about homePEN techniques and products. They are also a great place to help spread the word about the Oley Foundation. If you are interested in helping out at Oley's booth, please contact Joan Bishop at BishopJ@mail.amc.edu or (800) 776-OLEY for more information. More information about the conferences is available from the sponsoring organizations' websites.

- **Association of Vascular Access (AVA, formerly NAVAN)**

18th Annual Conference  
September 18-21, 2004  
Vancouver, British Columbia  
www.avainfo.org or (888) 576-2826

- **American Society for Parenteral & Enteral Nutrition (ASPEN)**

Nutrition Week 2005  
January 30 to February 2, 2005  
Orlando, Florida  
www.nutritionweek.org

- **National Home Infusion Association (NHIA)**

NHIA 14th Annual Conference & Exposition  
February 10-13, 2005  
New Orleans, Louisiana  
www.nhianet.org

## Oley Welcomes a New Editor

After 10 years as Oley's Director of Publications & Information, I will be passing the torch to Cory Piekarski this July. Cory has a bachelor's degree in English and a master's degree in educational psychology, and has been managing educational programs for New York State employees. She is enthusiastic about taking on the *LifelineLetter* and looks forward to working with homePEN consumers and clinicians. Please give her a warm welcome.



*Cory Piekarski with her terriers, Delilah and Ren*

Before I leave Oley, I wish to thank everyone who has helped me. I have learned a great deal during my tenure, witnessing the strength of the human spirit and the joy that comes from living each day to its fullest. I value everyone's contributions

to the newsletter, and treasure the many warm friendships I have made. There are too many people to thank individually, but I would like to acknowledge a few friends for helping me to better understand HomePEN and the courageous people who live with it: Lyn Howard, Don Young, Woody Freese, Robin Lang, Malisa Matheny, Liz Tucker, Pat Brown and the Oley staff. I have enjoyed my time at the Foundation, wish Cory the best of luck and will miss you all.

— Roslyn Scheib Dahl

## Web Site Offers Information About Free Prescriptions

### Cory Piekarski

NeedyMeds.com (www.needymeds.com) is a website designed to provide information about patient assistance programs (PAPs) which provide no-cost prescription medications to eligible participants. The site also offers information about discount prescription card programs, state programs and Medicaid sites. NeedyMeds does not offer programs itself, nor does it supply medications or financial assistance; and they don't have information about over-the-counter medications and supplies.

The first step is to determine whether or not your medication is included in one of these PAPs. If you are unable to locate your medication on the generic or name-brand list on the website, it is probably not available through a PAP. If you do find your medication listed, click on it to see what, if any, guidelines are listed to apply for a PAP than follow the directions specified. Some companies are listed on the site that do not offer a program. These companies are included so you don't waste your time contacting them. Visit the Frequently Asked Questions page on the website for more information.

Please note: The information provided on NeedyMeds.com is designed to support, not replace, the relationship between patient/site visitor and his/her existing physician. ©

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*Lakisha Judge*  
Nutrishare Consumer

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

## Join in the Fun this September

The Mighty Medical Miracles (M<sup>3</sup>) Oley support group in central Ohio is gearing up for its third annual Oley fundraiser to be held September 12, 2004, at the Tall Timbers banquet facility in Reynoldsburg. The event will feature an extensive dinner buffet, a silent auction, and a variety of entertainment for people of all ages, including DJ music, bingo, puppeteer and magician performances, and outdoor inflatable activities. For information about attending or volunteering for this event, contact Richard and Donna Noble (614) 871-8464 / donnanoble2001@yahoo.com or the Oley office (800) 776-OLEY / wilson@mail.amc.edu. Thank you for all your hard work M<sup>3</sup>!



## Ongoing Research Trials

### • Research on Swallowing Problems

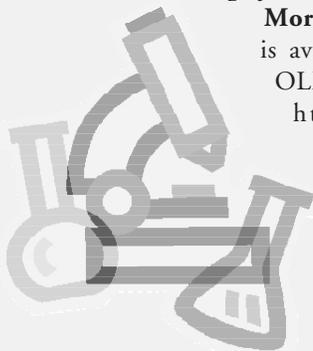
Researchers at the National Institutes of Neurological Disorders and Stroke, NIH, are studying Swallowing Disorders. The purpose of these experimental studies is to develop a new method for helping individuals with life-threatening swallowing problems and to determine if muscle stimulation can reduce choking in individuals with swallowing problems. For more information, please call (301) 496-9367 or (800) 411-1222.

### • Short Gut TPN Patients Wanted

Dr. Thomas Ziegler is researching the effects of modifications in oral diet, with and without treatment with synthetically-derived human growth hormone, on intestinal nutrient absorption and clinical outcomes in TPN-dependent SBS patients. For more details, contact Dr. Ziegler at 404-727-7351 or tzieg01@emory.edu.

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

**More information** on these studies is available by calling (800) 776-OLEY or visiting our web page at <http://www.oley.org/news/researchbox.html>. If you are interested in having your research study listed, complete the form listed on Oley's web page OR fax the same information to (518) 262-5528.



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## Your Catheter and You: A Survey

In the spirit of "helping people" Oley has been invited to participate at the Association for Vascular Access (AVA) Annual Meeting being held in Vancouver, B.C. from September 18-20, 2004. This is a gathering of clinicians and members of industry who have a strong focus on vascular access. We are coordinating a session, *Device Selection from the Consumers Perspective*, focusing on the importance of educating and outlining all options for the patients who are depending upon these vascular devices for survival.

What better way to begin shaping this session than going directly to the Oley membership? We've kept it short and sincerely hope that you will find a few minutes to answer the following questions and respond to Joan Bishop via email ([bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu)); phone (800-776-OLEY / 518-262-5079) or U.S. mail with your membership form (214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208).

1. Were you able to choose which type of device was placed? (Yes or no, please explain.)

2. Were you able to influence where the device was placed (taking into account your need to care for the site, your appearance, your comfort, etc.)?

3. a) Who trained you to use the device?

b) Do you feel that the training was thorough? If no, why not?

4. Please outline any pitfalls you encountered with catheter selection and/or training.

5. Describe the help you obtained in dealing with pitfalls.

6. Do you or people close to you have any issues related to device selection worth mentioning (i.e. port-a-cath vs. external catheter), etc.?

7. Do you have any ideas for improving access devices?

Thank you for your assistance!



**End of Life**, from pg. 1

The majority of HEN users have a swallowing disorder, commonly associated with a stroke or cancer in adults, and cerebral palsy in children. Seven percent of HEN users have an intestinal absorption disorder. Most of these individuals started out on HPN and progress to HEN, their survival at 1 year is 99%.

Table 2 survival percentages do not include persons who graduate off HPN recovering full intestinal autonomy. As shown in table 3, a large percentage of persons starting HPN and HEN do indeed recover and resume oral nutrition. This is true for 75% of HPN short bowel (<150 cms.) patients with non-malignant diagnoses. Recovery, if it occurs, is almost always in the first two years of therapy in adults, but in children recovery may take much longer — probably because children have much higher energy requirements (60 - 80 kcals/kg/d compared to 25-35 kcals/kg/d for adults). As children develop they continue to grow their bowel and eventually reach nutritional autonomy once their high growth demands subside. “Permanent” HPEN dependence is about one in eight persons who starts therapy in the USA, currently about 4000-6000 persons. These individuals are the backbone of the Oley Family.

Short-term users of HPEN rarely die of an HPEN therapy complication (1%). Death, if it occurs, is almost always due to the primary disease, occasionally to some other medical illness.

**Sepsis Rarely Fatal**

Long-term HPN users, after many years on therapy, may die from an HPN complication. Over several decades this adds up to 15-20% of all deaths in HPN subjects. Even in this setting, 80-85% of deaths are due to the primary disease or another medical illness. If an HPN-related death does occur, it is most frequently due to sepsis, occasionally to liver failure, venous thrombosis or some other metabolic disorder. It should be emphasized that while sepsis is the cause of 70% of deaths due to HPN, overall sepsis is rarely fatal. In the first few years on HPN, the average adult has a septic event once every 2 years, and the average child has a septic event once a year. Studies show that septic complications are less common in long-term survivors, suggesting a learning curve during which veteran HPN users get better at handling their catheters in a consistent aseptic manner.

HEN therapy results in fewer therapy complications, leading to only one-third of the HPN re-hospitalization rate. Mortality over decades has not been studied in this population. These statistics point to the fact that overall HPEN is a remarkably safe therapy.

Small bowel transplantation is not considered in HEN users at this point. It is potentially life saving for only a small percentage of long-term HPN users.

**Planning Ahead**

If death is approaching and cannot be checked, certain issues arise with HPEN that are best planned for early on. Artificial nutrition, like artificial respiration, may thwart an untimely death, but can prolong a natural death. Most of us, in my experience, want to die peacefully and without undue suffering when our time has come; we rarely want to prolong the dying process or worst still, survive when we are permanently unable to relate to our family and friends. In New York State, and many other states, only an advanced directive, written and signed by the patient allows us to retain some control over our dying process. Only if we have

**End of Life** cont., pg. 8

**Table 1. Chief Diagnoses Where HPN Is Used**

Diagnosis	United States (85-92)	Europe (97)
Cancer	42	39
Crohn's disease	11	19
Ischemic bowel	6	15
Motility disorder	6	ND
AIDS	5	2
Congenital bowel	4	ND
Radiation enteritis	3	7
Other	23	18

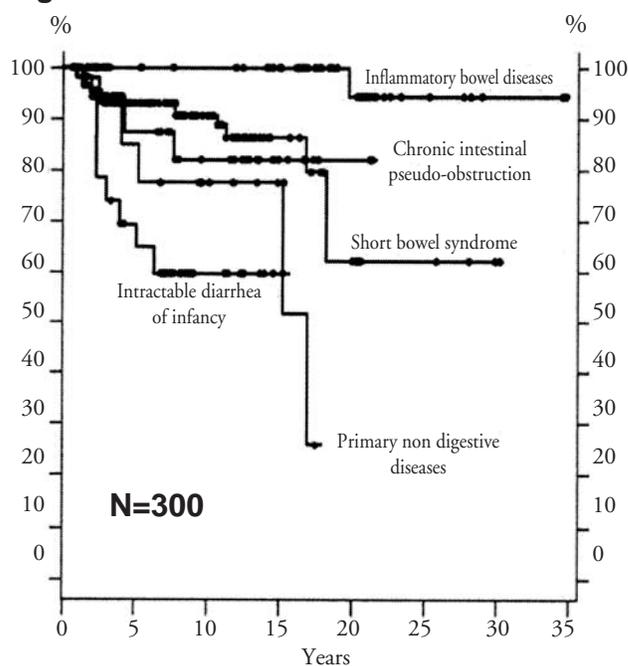
European data refers to adults only.  
US data refers to all age groups. ND - No data

**Table 2. Survival on HPN Therapy**

Diagnosis	% Survival			
	1 Yr.*	3 Yr.*	5 Yr.#	5 Yr.†
Crohn's	96	87	82	92
Ischemia	87	84	56	60
Congenital	94	80	—	—
Motility	87	62	—	48
Radiation	87	58	52	54
Chronic Obst.	83	40	—	—
Cancer	20	—	—	—

\* North American HomePEN Registry, n = 4,350  
# France/Belgium, n = 217 † Mayo Clinic, n = 225

**Figure 1. Pediatric Survival France. Goulet et al.**



Note: These survival curves differ from those in Table 2 because they include children who eventually weaned off HPEN.

## End of Life, from pg. 7

designated a health care proxy can a close friend or family member act on our behalf, keeping our wishes foremost, when we can no longer do it for ourselves. An advanced directive is easily written when one is well and not under stress. A form can be obtained from any hospital or clinic. A copy should be kept with your medical records and by the person who agrees to be your health care proxy. Advance directives are advisable for everybody, but especially for persons on HPEN or other forms of artificial life support.

HPEN seldom benefits persons on the edge of death and can, in fact, create unwanted complications. A terminal patient is defined as a person who will die in three months or less from their debilitating fatal illness. Recognizing the terminal phase is not always easy. Often

it is more recognizable to the dying person than to their clinician. At some point there needs to be a discussion between the person and their close caregivers about steps in the dying process. If the plan is to die at home, is there a circle of friends who can help? When is it best to transfer from artificial nutrition to more simple hydration? There are very few nursing homes who can manage a patient on parenteral nutrition, but tube feeding or simple IV hydration is not usually a problem.

In the last month or two it is often helpful to involve a hospice service. In my experience, hospice nurses are more available than the usual visiting nurses and can make the dying process more comfortable. Hospice nurses are very experienced with managing pain symptoms and take responsibility for indicating to the physician what the home patient needs. In

many situations the hospice organization can only get involved when active treatment, such as HPN, has ceased. At the very end, intravenous fluids need to be scaled back to make breathing more comfortable. Hospice nurses are familiar with this aspect of care.

In my experience, if a person on artificial nutrition understands these end-of-life issues, they will signal when they are ready to stop artificial nutrition to simplify his or her care. The most important element is for the clinician to know the person and their family and stay in close contact. For me, without exception, helping someone I've cared for, for a long time, to have a peaceful dying process, is the end of a long privileged partnership. ☺ *Articles on other end of life issues such as health care proxies and estate planning, are available from the Oley office, call (800) 776-OLEY.*

**Table 3: Summary of Outcome on HPEN**

Diagnosis/therapy	No of Patients	Age [yr (SDI)]	Survival on Therapy [% (observed deaths' expected deaths)] <sup>a</sup>	Therapy status at 1 year [% (SEM)] <sup>b</sup>			Rehabilitation status in first year [% (SEM)] <sup>c</sup>			Complications <sup>d</sup> (per pt. yr)	
				Full oral nutrition	Cont'd on HPEN	Died	Complete	Partial	Minimal	HPEN	Non-HPEN
<b>HPN</b>											
Crohn's disease	562	36	96	70	25	2	60	38	2	0.9	1.1
Ischemic bowel Disease	331	49	87	27	48	19	53	41	6	1.4	1.1
Motility disorder	299	45	87	31	44	21	49	39	12	1.3	1.1
Congenital bowel Defect	172	5	94	42	47	9	63	27	11	2.1	1.0
<b>Hyperemesis</b>											
Gravidarum	112	28	100	100	0	0	83	16	1	1.5	3.5
Chronic pancreatitis	156	42	90	82	10	5	60	38	2	1.2	2.5
Radation enteritis	145	58	87	28	49	22	42	49	9	0.8	1.1
<b>Chronic adhesive</b>											
Obstructions	120	53	83	47	34	13	23	68	10	1.7	1.4
Cystic fibrosis	51	17	50	38	13	36	24	66	16	0.8	3.7
Cancer	2122	44	20	26	8	63	29	57	14	1.1	3.3
AIDS	280	33	10	13	6	73	8	63	29	1.6	3.3
<b>HEN</b>											
Neurological disorders of swallowing	1134	65	55	19	25	48	5	24	71	0.3	0.9
Cancer	1644	61	30	30	6	59	21	59	21	0.4	2.7
Impaired small bowel absorption	329	36	99	45	28	17	43	42	15	0.4	2.7

NA, not applicable because the group was too small

<sup>a</sup>, Survival rates on therapy are values at 1 year calculated by the life table method. This will differ from the percentage listed as died under therapy status because all patients with known end points are considered in this latter measure. The ratio of observed vs. expected deaths is equivalent to a standard mortality ratio.

<sup>b</sup>, Not shown are those patients who were readmitted to the hospital or who had changed the type of therapy by 12 months.

<sup>c</sup>, Rehabilitation is designated complete, partial, or minimal relative to the patient's ability to sustain normal age-related activity.

<sup>d</sup>, Complications refer only to those complications that resulted in rehospitalization.

Data from the North American HPEN Patient Registry <sup>1</sup>

## Your Support Makes Oley Stronger!

The following generous individuals have donated a gift to the Oley Foundation between April 23 and June 9, 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 donates in 2004 will be published in the January/February 2005 issue.

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## Giving a Little at a Time

In previous newsletters, we outlined plans for a new giving option, via a secure server online. The Oley Foundation has connected to the 21<sup>st</sup> century!

If you're looking for an easy, safe way to give to Oley, sign on to our website ([www.oley.org](http://www.oley.org)), and click the blue "Donate Now" bar. You will be linked to a form that allows you to donate a one-time gift, or offer monthly or quarterly donations.

Please consider supporting us, and helping us continue to offer education and outreach to all children and adults using nutrition support therapies. Large or small, any gift is appreciated. Thank you!

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*...and growing every day!!*

## 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>JULY '04</b>	<p><b>Felice Austin &amp; Mariah Abercrombie</b> Henderson, NV (888) 610-3008 PST</p> <p><b>Ben Hawkins</b> Cincinnati, OH (888) 650-3290 EST</p>	<p>Mariah is a 22 y.o. college student, on TPN 19+ years due to pseudo-obstruction and SBS. She also has a g-tube and ileostomy. She enjoys swimming, jet-skiing, traveling, scrapbooking, shopping, reading and cooking. Felice is a single mother and former social worker. She's been an active RC since the late 80's. She is happy to share her experience with parenting, patient advocacy, separation, disability, travel etc.</p> <p>Ben Hawkins, 40, has been on TPN since 1980, when he lost over 90% of his small intestine due to a malrotation. He has experience with midline catheters, port-a-caths and Hickman catheters, and has used a variety of different pumps. He also went through the process of going onto Social Security Disability in 1999.</p>
	<p><b>Malisa Matheny</b> Doylestown, PA (888) 610-3008 EST</p> <p><b>Bruce &amp; On Braly</b> Davis, CA (888) 650-3290 PST</p>	<p>Malisa is 26 y.o. and has been on TPN and a small amount of j-tube feeds for 10 years due to a motility and mitochondrial disorder. She earned her RN, BSN in 2001. She works at Children's Hospital of Philadelphia developing a program for chronically ill teens transitioning into adulthood. She has experienced summer camp, living in the dorms, and managing a job while on TPN.</p> <p>Bruce and On's son Matthew has been on TPN since the age of 9, and is now 15. He has SBS due to malrotation of the gut and uses a CADD pump. They have traveled abroad with TPN and look forward to sharing their experiences with you.</p>
<b>SEP. '04</b>	<p><b>Erik &amp; Cindy Schten</b> Novato, CA (888) 610-3008 PST</p> <p><b>Jim Wittmann</b> Stanford, CT (888) 650-3290 EST</p>	<p>Erik &amp; Cindy are the proud parents of 4 y.o. Rachel, who's had SBS since infancy due to complications of Hirschprung's disease. They have lots of experience dealing with the frustrations of SBS care at all levels. They strive to have her lead the life of a typical 4 y.o. and continue to learn and grow with her.</p> <p>Jim, 54, has had an ileostomy since he was eight. After four bowel resections due to Crohn's, he was put on TPN at age 25. He has had four permanent lines over 29 years, and currently has a Hickman. Jim has two great kids: Elizabeth (21) and Sarah (18). He volunteers for Meals On Wheels and enjoys photography.</p>

### Alycia, from pg. 2

Alycia is on TPN for 11 to 12 hours each night at this point, which accounts for about 95 percent of her calories. She has a big tummy because of the "stuff" that accumulates in her intestinal track that her GI system just can not move down. On average of six nights per week, Alycia will throw up about three to five times a night; but usually in the middle of the night, which keeps us on our toes even when laying down. Obviously, she needs to wear a diaper at night because her infusion is 1900 cc's at this point. But, when she was close to three years old, she decided, on her own, she wanted to wear underpants like her big sister. And so, in less than a week, she was potty trained. BOOM, she just did it. We figured she'd be eight before she got out of diapers, but this kid just decided what she wanted, and to our amazement, did it.

#### So Where Are We Now?

This past September Alycia had her gall bladder removed. During the operation they discovered her liver was being damaged by the otherwise life saving TPN. A followup biopsy December 31<sup>st</sup> showed she is in stage three liver failure. And so, this March Stefanie and Alycia went to Pittsburgh, 200 miles away, to be evaluated for intestinal transplant. A great transplant team from Mt. Sinai in New York has relocated here to D.C., but our insurance company has not recognized them yet and will not make an exception.

We always endeavor to tell our children the truth, and so we explained to Alycia about getting a new intestine, and that it would most likely mean getting off TPN and no more Broviac. She pondered that for a few moments. You could see the wheels spinning in her head about what it would mean to her. Finally, she

looked at me and said, "Daddy, you mean I could get out of bed all by myself in the morning?"

"Yes," I told her.

"Daddy, you mean I won't throw up anymore?"

"That's right," I told her.

"I can eat all the broccoli I want?" (I'm thinking, 'broccoli?')

"Sure Alycia; all the broccoli you want, sweetie. Knock yourself out." Go figure.

Two nights later, we were talking about it again as she got ready to go to Pittsburgh. Four and a half years, all the clinic visits, all the hospitalizations, all the overheard discussions, the TPN, the Broviac, G-tubes, Pseudo Obstruction, motility disorders, IV's, etc, etc, etc. Alycia looked at me and asked, "Daddy?"

"Yes Scooter Pie."

"What's an intestine?" I knew there was something we'd missed! ☹

To learn more about Alycia, her journey with Pseudo Obstruction and getting a transplant, visit her website at [www.caringbridge.org/mlalycia](http://www.caringbridge.org/mlalycia).

### On-Line Shopping?

Don't forget [www.igive.com](http://www.igive.com) will donate a portion of your spending to Oley at no charge to you, and there are hundreds of great stores to choose from! Call (800) 776-OLEY for details.

