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LifelineLetter

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

Specialized Nutrition: The Patient's Perspective

By Elizabeth V. Tucker and Darlene G. Kelly

The following article is the first of a three-part series featuring a dialogue between Elizabeth (Liz) Tucker, an experienced home parenteral nutrition (HPN) consumer, and Darlene G. Kelly, a gastroenterologist and medical director of a large HPN program. Although it refers specifically to HPN, most of the issues are also relevant to the home enteral nutrition (HEN) consumer. Occasionally, we mention HPEN, which refers collectively to home parenteral and enteral nutrition, or the HPNer, another name for HPN consumer. The next issue of the LifelineLetter will discuss complications, the role of the Oley Foundation and psychosocial issues.

Introduction to Home HPN Before the Fact

EVT: My introduction to HPN happened approximately five years before parenteral nutrition became a part of my life. A young woman who also had Crohn's disease, a gastroenterologist, a colon and rectal surgeon, and I were on a Public Broadcasting System (PBS) program about Crohn's. The young woman didn't look particularly healthy and most of the things she had to say about being on HPN were fairly negative. My thoughts were that I was very glad I wasn't on the therapy and hoped that I would never need it.

Three years later, after yet another surgery, my

doctor brought up the subject of HPN. I was having a great deal of difficulty keeping my weight up and he thought that the time had come to be evaluated. As anyone with a chronic illness can tell you, keeping a sense of control is very important. After learning about HPN, it became the experience that would represent Crohn's disease finally winning the battle to live a "normal" life. I said absolutely and positively "NO."

During the next two years I tried everything I could think of to keep my weight up. I ate at least 4,000 calories a day and drank high-caloric fluids to try to quench my insatiable thirst, but I still ended up going into the hospital for rehydration and nutrition supplementation more and more frequently. Rehydration solutions were not yet being used for people with short bowel and no one told me that all the high-caloric, high-osmolar drinks (mostly sodas) I was drinking were only making the problem worse. When the hospitalizations for rehydration and nutrition began happening every two to three weeks, I finally said "uncle" and let my doctor know I was willing to be evaluated. I was mentally and physically ready for a change.

My feeling is that the process would be much

Nutrition, Con't. Page 2 ←

Celebrating 20 Years of Winning!

Join us in Saratoga Springs, NY this year for the 20th Annual Oley Consumer/Clinician's Conference!

In upstate New York, Saratoga Springs is known as "The Summer Place to Be". It's a lovely town rich in history with a myriad of exciting things to do. Most exciting this summer however, is the 20th Annual Oley Consumer/Clinician Conference to be held this June 28th - July 1st at the Holiday Inn Hotel and Conference Center.

The conference is an excellent opportunity for home nutrition support consumers, family members, caregivers, clinicians and members of the infusion industry to come together and learn about the latest advances in homePEN therapy, discover the newest developments in products and services, and share coping strategies. It is a serious educational program complemented with youth activities, plenty of social time for networking and child care, all provided free of charge for consumers and their families.

The Holiday Inn Hotel and Conference Center is located on Broadway, the main street of Saratoga, and there are many opportunities for sight-seeing, hiking, dining, shopping and of course, trying your luck at the harness track or the Racino. Check out the following websites to learn what Saratoga has to offer: www.discoversaratoga.org, www.saratoga.org and www.saratoga.com. You can also call the hotel at (518) 584-4550 to get more information about accommodations or visit their website at www.spa-hi.com.

So mark you calendars for June 28th through July 1st for this important event. We'll see you there! ©



Nutrition, Con't, from page 1

different if I hadn't know what TPN was ahead of time, made the decision myself and not had it suddenly made while I was hospitalized for something else, i.e., surgery, disease. Enteral nutrition was never brought up as an option because I had already lost too much small bowel surface (thus severe malabsorption) so it was felt that enteral feedings would not do any good.

DGK: My introduction to home HPN as

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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.

a clinician came a few years after Liz started her HPN. I was newly appointed to the medical staff, and it became apparent that a large portion of my time would involve managing our HPN program. The science of PN was introduced during my residency, but the patient or consumer's point of view was something I had to learn through experience. Much of what I now know came from individual contact, such as my interactions with Elizabeth (a.k.a. Liz) and others over the past 13 years. Additionally, my interaction with the Oley Foundation (to be discussed later) has been a tremendous learning activity. The art of HPN is clearly something that must be acquired by the clinician. This can be greatly facilitated by developing the attitude that you will learn from your patients who have a much better vantage point than you, the clinician, do!

How the Clinical Decision is Made and Presented

EVT: After my 12th or 13th surgery I let my gastroenterologist request that the HPN team come and talk to me about going on the therapy. They also did a number of tests to determine whether PN was really necessary - they said it was. I still wasn't convinced, so they let me go home and try again.

After two weeks of recuperation I flew to San Francisco and spent a week in the Big Sur. I sunned by the pool, drove to Carmel, hiked through Point Lobos, and rested a great deal. However, by the time I got back to Minnesota, it was apparent even to me that I was very weak and dehydrated. The only sensible thing to do was call the TPN physician and say "okay, you were right" - so I did.

The next day I was back in the hospital being nourished and rehydrated. A day or two after that I had my first Hickman catheter placed. Fortunately the surgeon who placed it had a good sense of female priorities. I enjoy wearing low-cut tops and the placement allowed me to continue to wear the things I like. I also have an ileostomy and the catheter wasn't too long. I would be grateful for his expertise when I got home.

DGK: The story of each consumer's start on home nutrition support is different. For some it will be a matter of going from a normal diet and good health to a catastrophic event that makes HEN or HPN an absolute necessity. For others it will have been a progressive course that eventually has led to weight loss and chronic dehydration. When

severe malabsorption has been clearly demonstrated and use of less expensive and risky alternatives to HEN and HPN are no longer possible, the steps toward considering these therapies should be begun. Whatever the story it is important that the patient be integral to the decision that specialized nutrition is required. A clear explanation of what HPN/HEN is, what care becomes necessary, how this will change the person's life, what possibilities are for doing "normal" activities, what the risks of the therapy are, and how the medical system will need to be involved is necessary.

Introduction of the HPN Team

EVT: While I had already met the HPN doctor, nurse coordinator, pharmacist, dietitian, and social worker, the most important member of the team after I got my catheter was the nurse who did the training. She was great. After I had the catheter placed, she came in and said we started my training that very day. She went through the process of hooking up that evening and unhooking the next morning; then she said it was my turn. After all the emphasis on sterility, I was really scared, but with her encouragement I did just fine. By the next evening I was doing it on my own.

Every day the TPN doctor and his entourage would come to see me. Little did I know at the time how important they would be as my years on HPN have rolled by - all 18 years.

DGK: Our HPN team consists of multiple health-care professionals who work closely together to ensure safety of the HPN consumer. The center of the team is the consumer him- or herself. Others involved in this team are the medical director(s) of the team, nurse coordinator, pharmacist, nurse educator, social worker, dietitian, surgeon or interventional radiologist who places the central venous access, primary care provider, and the home care company clinicians and reimbursement specialist. Each has a unique and critical part in the consumer's success and future.

Training

EVT: While I do know consumers who are trained either as outpatients or at home, I believe I was fortunate to be trained while still in the hospital. I was given a very large notebook covering all aspects of HPN from

Nutrition, Cont. on page 10 ➤

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.

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.

Carol Kirkland is the mother of 13 year-old Nathan Chin. Nathan has been on a feeding tube for about 12 years. He is in the process of working on eating enough to get his tube taken out. Carol contacted Oley wondering how others fare when venting access is removed. She also wonders if physicians just allow the site to heal and leave the stomach attached to the skin at the insertion point.

In response to this query, Dr. Howard writes, "The surgically created tract may or may not spontaneously heal after a long period with a G tube. If it doesn't heal in three to four weeks, we usually close it surgically. This is a minor procedure. The stomach is always left attached to the anterior abdominal wall."

Members Reach Out...

My 38 year-old daughter has Crohn's disease and has been on and off TPN for 25 years. She now has severe vascular problems. She has stints running from her groin to her heart and recently had vascular bypass surgery. She is trying to sustain herself with eating. She has had two bowel resections resulting in short bowel plus once a ruptured bowel. I was told that a central line would no longer be possible. Has any other TPN long term user have any of these problems?

-Mrs. Pfeiffer, dsedar1@comcast.net

We are a family in Denmark and we have a four year-old child, Camilla, who, because of extensive Hirschsprung's Disease, is 100% dependent on TPN. Camilla is so far the only child in Denmark who lives on TPN at home and therefore we are looking for similar cases elsewhere. I just read the newsletter article about a girl named Alicia Hoelle whose medical situation looks similar to Camilla's. We'd like to communicate with the Hoelle family and maybe you know of other families like ours with children of a younger age with whom we can communicate. I hope you'll be able to help.

-Rikke Tindal (Mother), Rikke.Tindal@carglass.dk

I would like to hear from anyone who is using or has used the Ross Companion Pump. Please contact me at (978) 681-0515 or e-mail me at stamkis@verizon.net. Thank you.

- Alexandra Golden

What's Your Bag?

As Oley members know, recipients of artificial nutrition support therapies lead productive and fulfilling lives complete with families, careers, hobbies, volunteer work and physical activities. The Oley Foundation is proud to feature profiles about our members and their activities in the *LifelineLetter*.

Recently, the Oley Office received a letter from the mother of a little boy in Ohio who is tube-fed. This boy's goal is to one day become a fireman. The Oley Foundation would like to put this young man in contact with one of our members who is tube-fed like him, but also serves as a fire fighter in his or her community. The goal of this union would be to provide the child with a role model who can answer questions and offer guidance about a career in fire fighting.

If you are a member of a fire company, professional or volunteer, and you'd like to share your experiences with a little boy who would love to hear from you, please let us know. We'd also love to hear from other members about their hobbies and activities, from the sports junkies to the computer nuts as we are compiling a database to open up communication between our adult members and young people. This is a great way to provide hope and motivation to consumers and their families. Your information will be used for this purpose only. Please call the Oley office at (518) 262-5079 to share your valuable experiences with someone else. ☺

Oley's First Annual Walk-A-Thon

It'll be a walk in the park!

You are warmly invited to join us for Oley's '05 conference in Saratoga Springs, NY. We are planning many events to celebrate our 20th conference anniversary. This year, we're very excited about kicking off our first Walk-A-Thon. Saratoga Spa State Park is the venue for our walk; it boasts beautiful and easy trails for all to enjoy.

On Friday morning, July 1st, many folks will meet up for our 5K (3.5 miles) Walk-A-Thon. Everyone can participate, even if you can not attend the conference or do not wish to walk, you can still gather sponsors for this event and we will designate a walker for you. We can all make a difference. The average walker can walk this 5K in under an hour.

If everyone gathers at least ten sponsors at one dollar a kilometer, this event could become a very successful fund-raiser for the Oley Foundation. Tell your friends, family, neighbors about the important work Oley does and ask for their support. After our walk, we'll take a rest and then we'll climb aboard the Oley bus and head to our annual picnic where we can relax and have fun with old and new friends. From start to finish, this will be a great day for you and Oley. Thanks in advance for your efforts and support.

For more information about the Walk-A-Thon, please call Robin Lang at (207) 363-7880 or visit the Oley website at www.oley.org. ☺

Equipment Exchange

The following supplies are offered free of charge to readers:

Enteral Formula

- 18 cases Jevity, 13 exp. 11/05, 5 exp. 1/06
- 6 cases Jevity 1.5 cal, exp. 2/06
- 1 1/2 cases Portagen, exp. 6/05
- 2 cans 9.7 Promod formula, powder
- 8 cases Twocal HN, 2 exp. 9/05 - 11/05
- 3 1/2 cases Ensure Vanilla, exp. 2/06
- 1 case Vivonex-Ten, exp. 10/05
- 5 cases Ultracal, exp. 2/06
- 4 cases Ultracal with fiber
- 4 vcases Ultracal w/fiber, 1.0 cal, exp. 1/06
- 10+ cases Neutren formula, 5 exp. 7/05 - 9/05
- 4 cases Neutren 1.0 w/fiber, vanilla, exp. 3/06
- 63 cans Osmolite, exp. 10/05
- 8 cases Promote w/fiber, exp. 11/05
- 3 1/2 cases Promote w/fiber, vanilla, exp. 8/05
- 9 cans Pregestimil, powder infant formula
- 20 cases Peptamen VHP unflavored, exp 6/05 - 9/05
- 2 cases Peptamen Jr., exp. 2/06
- 6 cases Peptinex vanilla, exp. 7/05
- 4 cans Duocal powder, exp. 2/07
- 6 1 liter bottles Chice DM diabetic formula, exp. 2/06
- 8 1 liter bags Probalance 1.2 cal w/fiber, exp. 1/06

Tubes/Administration Sets

- 50 Kangaroo 1000 ml pump sets
- 52 Kangaroo 1000 ml bags
- 6 cases Ross Companion Enteral feeding bags 500 ml and 1000 ml
- 1 Kendall Mono-Flo Drainage bag
- 35 Zevex 1200 ml bags
- Many Zevex Enteralite 500 ml bags
- 6 Ross 500 ml bags
- 10 Kangaroo 1000 ml pump sets
- 36 Embrace bags 500 ml
- 3 Bifuse 2 to 1 administration set
- 3 enteral feeding tube (w/stylet) 6 fr., length 36"
- 4 Ross Embrace 1000 ml top-fill pump sets
- 60 Embrace 500 ml bags
- 4 36" NG tubes
- 5 Kimberly Clark Mic-Key low-profile gastronomy feeding tube
- Angel Wing blood transfer device, tube holder w/female adapter

Miscellaneous

- 1 Kangaroo 324 enteral pump with battery
- 1 Zevex irrigation syringe with piston (#2L8060)
- 1 Pole with wheels
- 25 Mediport precut dressing covers
- 12 Drain sponges
- 1 box (150) Sterile cotton-tip applicators
- 4 Deltec CADD Prizm adm. set w/spike, 1.2 air eliminating filter clamp, injection site male
- 50 B. Braun rate flow regulator extension sets y site and spin lock connector (#V5200)
- 2 dressing kits for Picc Line
- 4 cases Tegaderm, large and small

- 14 BD Saf-T-PRN 0.14 ml
- 21 sterile 4X4 sponges
- 8 boxes Convatec flanges w/wafers, 1 3/4 size
- 1 BD 10 ml G1 Latex-free syringes/precision glide needle
- 7 Baxter Solution Set 112" vol 7.9 ml for use w/6060 pump
- 25 BD 3ml G1 Latex-free syringes/precision glide needle
- 4 BD 2 oz. syringes
- 3 Baxter vented spike adapter
- 2 B. Braun 15 drips/ml lv administration sets 67"
- 22 Bard irrigation syringes #750379
- 14 60 ml syringes
- 7 sets - 1 flow medi-sis 60 ml/60 min. admin. set #M600600
- 5 pins - Lifeshield convertible adapter pins, 3" #11075
- 14 pr. - Medline powder-free latex exam gloves
- 6 sets - CADD admin. set #21-7022 Deltec
- 2 sets - Baxter extension sets w/control-a-flo regulator #2C7591
- 18 pins - Braun micropin #MP-1000, ref. 415019
- 4 sets - Braun smallbore Y-type extension set #ET103
- 15 sets - CADD Prizm high-volume admin. sets #21-7057
- 27 sets - Y-extension sets ET08YL#471980, exp. 11/08
- 38 pieces - BD20G1 precision glide needles #305175
- 15 pieces - Terumo syringes 1ccml #CE197 w/needle
- 8 pieces - Terumo syringes 10ccml #CE197 w/needle
- 1 tray - Centurion dressing change tray DT8560, exp. 6/06
- 1 tray - Medicmark dressing change tray DC-1595, exp. 6/07

MORE SUPPLIES are available! For a complete listing, visit our website at www.oley.org or contact Cathy at 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.



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or visit www.zevex.com/infinity.

ZEVEX
THERAPEUTICS

In Loving Memory: Nader El Samaloty

By Joan Bishop

Paying tribute to Nader, a wonderful man who spent the past 11 years filling the Oley community with love, laughter, and wisdom, is easy. Everyone who knew him admired him for his quick smile and genuine zest for life. These qualities made Nader many friends whom he cared for deeply.

Robin Lang remembers, "*Nader was a proud, classy gentleman. He loved people and inspired so many of us with his presence alone. He didn't see the glass half-full or half-empty, he saw the glass overflowing. Nader was always smiling and you couldn't help but smile along. He was a free and happy spirit, and shared it with everyone he encountered. I feel very blessed to have known him and to have the memories of the times we've shared together.*" Ellie Wilson writes, "*My favorite things about Nader were his great sense of fun and his strong sense of what was right. He possessed a quick wit, and an awesomely big heart. He tangibly made life better for friends, family and strangers - he helped them all the same. A rare individual, his sunny demeanor and great big smile are much missed.*" Rose Hoelle reflects, "*Most people did not know Nader's last name, but all knew his smile, and his wonderful kind nature that touched so many. He was always such a positive person who let nothing stop his joy of life and his love of people. We will never forget the energy, the man or that smiling face. Nader, we will miss you more than words can say.*" Dr. Lyn Howard writes, "*Nader was in our kitchen cooking up a storm and we were discussing Islamic fundamentalism. Suddenly there was a squeaky noise coming from the basement. He gave me a questioning look and I explained that we had 25 young women down there in a crate. He looked quite upset, so I asked him if he'd like to meet them. I led him down the stone steps and introduced him to our 25 two week-old chicks. He started laughing heartily and the relief on his face was plain. Good friendships are built from odd ingredients!*"

Nader was truly devoted to his family and his friends. His home was their home; his time was theirs, always. His kindness was overwhelming and his willingness to help others went beyond any expectation. As a member of Oley, he truly exemplified the "power of one". I personally feel extremely privileged to have walked beside him over the past eleven years and particularly more recently as our friendship flourished. Facing the future without him will be most difficult. The void is huge. His smile, his companionship, his playful spirit and his love will be missed.

In the true spirit by which Nader lived, I invite you to follow me down the path that Nader carved for us: Endorse sincerity, embrace a good time and by all means, look after each other as he would want us to!

Nader, you have blessed us with your friendship — now dance, have fun... rest in peace! ☺



Ongoing Research Trials

Tube-feeding Challenges

The University of Utah is conducting a study to better 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

Gut Adaptation and SBS

Dr. Thomas Ziegler of the Emory University School of Medicine announces a new study in adult patients with Short Bowel Syndrome (SBS) funded by the National Institutes of Health. The goal of the study are to determine for the first time how well the remaining small intestine and colon adapt within the first few years after major small intestinal removal (resection) in SBS patients.

Eligible subjects are those who have had surgery with removal of small intestine within the previous two months to two years prior to beginning the study and those with eight feet or less of small intestine, with or without connected large intestine. Subjects are eligible whether or not they require TPN or tube feeding. The study involves two seven-day inpatient admissions to the General Clinical Research Center (GCRC) at one of the four participating medical schools around the country.

Each inpatient admission is spaced six months apart and there is one outpatient visit to the GCRC in the middle of the study about three months after entry. After the initial visit to the GCRC, subjects will be given detailed diet instructions and telephone follow-up to optimize their oral diet on an individual basis. During each of the GCRC admissions, identical tests (including stool collections) to determine intestinal nutrient absorption and other intestinal functions will be performed. During each inpatient GCRC visit, each subject will have a colonoscopy to examine the lining of the intestine. Several small biopsies will be obtained so researchers can examine changes in the intestinal lining that are important for intestinal growth and nutrient absorption.

Support for travel costs and a small honorarium are available for each participant's time. Each study participant will also gain detailed information on the health and function of their intestine over time during the study. If you would like to get more information about this study, please contact Dr. Thomas Ziegler at (404) 727-7351 or tzieg01@emory.edu.

Recognize Someone Who Inspires You! Nominate them for an Oley Award.

Consumers, caregivers, Regional Coordinators, even clinicians love recognition. What a great way to tell them how much you admire their courage, perseverance, and willingness to help others. And who wouldn't appreciate a travel scholarship to the Oley conference in New York this summer? Or extra money for an educational program in their region?

Ring your own bell!

Nominate yourself. If your story is one of inspiration, tell us your tale on this simple nomination form. We want to hear from you!

It's FREE and easy!

A simple form (inserted in this issue) with five, quick questions is all you need to complete. Technophiles can also find it on our website: www.oley.org. Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you like. Need help? Call us!

Questions? See details below or call (800) 776-OLEY.



Your nominee didn't win last year? Nominate him or her again!

Award Criteria

*The awards will be given at the 20th Annual Oley Consumer/Clinician Conference to be held June 28 to July 1, 2005 at the Holiday Inn in Saratoga Springs, NY. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a special keepsake, are honored at the annual conference awards program and will be spotlighted in the *LifelineLetter*. Most awardees will have some of their travel expenses underwritten. Recognition is given to all nominees!*

LifelineLetter Annual Award

- ★ 19 years of age or older
- ★ HomePEN consumer or caregiver
- ★ Consumer has been on homePEN for at least five years
- ★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
- Winner will receive a travel grant to the Oley Conference in Saratoga Springs, NY, June 28 to July 1

Oley Foundation Child of the Year Award

Sponsored by Pediatric Services of America

- ★ 18 years of age and under
- ★ Home parenteral and/or enteral nutrition consumer
- ★ On homePEN for at least three years
- ★ Demonstrates courage, perseverance, a positive attitude in dealing with illness, and exceptional generosity in helping others in their struggle with homePEN
- Winner will receive a travel grant to the Oley Conference in Saratoga Springs, NY, June 28 to July 1

Lenore Heaphey Award for Grassroots Education

- ★ Oley Foundation Regional Coordinator volunteer
- ★ Organized an outstanding information and/or education program during 2004
- Winner will receive a nominal cash award to foster educational/support activities in his or her local area

Nan Coutts Award for the Ultimate Volunteer

Sponsored by Judy Peterson, RN, MS

- ★ Clinician (physician, nurse, dietitian, etc.) must practice in the field of homePEN or a related field, i.e. psychology, interventional radiology, pain management, etc.
- ★ Has demonstrated a willingness to give of themselves — beyond their regular work hours — to educate, empower and improve the quality of life for HPEN consumers. For example: a nurse who facilitates an Oley support group on her day off.
- Winner will receive a travel grant to the Oley Conference in Saratoga Springs, NY, June 28 to July 1

Celebration of Life Award

In honor of Coram Healthcare, Oley Golden Donor

- ★ Enteral or parenteral consumer, any age
- ★ On homePEN for at least three years
- ★ Lives life to the fullest — traveling, fishing, gardening, volunteering, performing in a local theater spending time with children and grandchildren, etc.
- Winner will receive a travel grant to the Oley Conference in Saratoga Springs, NY, June 28 to July 1

Nominations must be submitted by April 29, 2005

Oley Foundation Award Nomination Form

Deadline for nominations: April 29, 2005

1. Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2005
(please check one):

- LifelineLetter Award
- Oley Foundation Child of the Year Award
- Lenore Heaphey Award for Grassroots Education
- Nan Coutts Award for the Ultimate Volunteer
- Celebration of Life Award

Nominee's name: _____ Age _____

Address: _____

City: _____ State: _____

Zip: _____

Phone: (____) ____ - ____ home

(____) ____ - ____ work

Email: _____ @ _____

Primary diagnosis: _____

No. years on HPEN _____

2. Fill in your name and contact information.

Your name: _____

Relationship to Nominee: _____

Company (if any): _____

Address: _____

City: _____ State: _____

Zip: _____

Phone: (____) ____ - ____ home,

(____) ____ - ____ work

Email: _____ @ _____

Please use this form or an accurate reproduction. Be sure to type or print legibly using dark ink, since this form will be photocopied. Include additional pages to provide further information if needed. Feel free to submit more than one nomination.

3. Tell why the nominee qualifies for the award, describing specific examples: i.e. for *LifelineLetter*/Child of the Year Awards, how this person has demonstrated a positive attitude in dealing with his/her illness; for the Celebration of Life Award, lived a full life; for the Lenore Heaphey Award, organized an excellent educational program; or for the Nan Coutts Award, has gone "above and beyond" what could ever be financially compensated for, to bring information, compassion and the Oley Foundation to homePEN consumers.

Continued on back 

4. Describe how this person has been exceptionally generous in helping consumers in their struggle with homePEN.

For example, the nominee may participate in professional educational sessions/research, visit others in the hospital, hold support group meetings, etc. For the Celebration of Life Award, describe further examples of how the nominee lives their life to the fullest.

5. Additional Comments. Please explain anything else that we should know about this person providing as much detail as possible.

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Keeping You S.A.F.E.!

This poster has been developed by Oley, the Association for Vascular Access (AVA) and the Intravenous Nursing Society (INS) in an effort to create a safe atmosphere for you and your catheter in the event you are hospitalized.

Posting a copy at your bedside should prompt your health care providers to take notice of your need for long-term intravenous access and support your plan for the safe delivery of medications and therapy while you are dependent upon them for your care.

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Thank you to Josie Stone, RN, CRNI; Nancy Moreau, BSN, CRNI; and Mary Alexander, RN for their support and enthusiasm in coordinating this effort!



SAFE

KEEP ME

- S**crupulous hand washing between patients and before procedures.
- A**ssess and organize operations separating clean procedures from things like opening packages. Once you apply your gloves don't touch packages or other dirty items, think first.
- F**riktion to the hub! Always scrub access points with alcohol or tincture of iodine prior to injecting medications, flushing solutions or connections.
- E**stablish and maintain sterile to sterile fluid pathway. Only touch sterile pieces to sterile pieces.

KEEP ME FREE OF INFECTION,
I have a lot of living to do!
Patients have been taught these basic principles and deserve this level of care.

Endorsed by:

and

Keeping It Simple
We've implemented a policy to include a donor envelope in each issue of the LifelineLetter...simply to make it easy for you to consider supporting Oley Programs.
Thank you so much!

“He is now living a better life since Coram came into his life.”

That's what David Ray Watkins' 17-year-old daughter said about his Home TPN experience since 1989. His 19-year-old son said he has become a great person and wanted to thank Coram. His oldest son added that his Dad is emotionally the strongest person he knows. They all say his paintings and other art-related projects keep him busy the 18 hours each day he is hooked up to Home TPN. We don't know if we can add anything to that. Coram is proud to help make outcomes like this possible. We got him started. And we'll be there for the long run.

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Nutrition, Con't from page 2

catheter placement to how to work the pump, as well as sterile dressing changes, procedures for hooking up, unhooking, infection and other potential problems. Next, a nurse/trainer showed and explained the procedure to me several times. Only then was I expected to do the various procedures myself.

DGK: In our program, nearly all new patients complete training while they are still hospitalized, or in some cases parts of training may be done in the outpatient setting. In order to do this, it is important that the primary physician is "tuned in" to the needs for this type of nutrition support and initiates the process while there is still a need for hospitalization. In some programs, all of the training is done in the home by the home care company. There are no comparative studies examining the outcomes of these types of training approaches.

While the patient is training, the infusion duration is decreased in a stepwise manner, usually to 12 hours, while labs are monitored closely, especially in the very malnourished who are at risk for refeeding syndrome. This also allows us to be assured that fluid balance is achieved.

Each patient is provided with an extensive manual that provides background, step-by-step instructions, troubleshooting instructions, and most importantly, phone numbers for questions and concerns. The patient is encouraged to make phone calls to ask questions rather than wondering what is going on or worrying about it.

Insurance Issues

EVT: Insurance issues can tend to be the last thing HPENers think about once they have been accepted into their therapy, but in my opinion, it is one of the more important issues and should be dealt with on an ongoing basis.

Enteral nutrition does not have the overwhelming cost on a daily basis that HPN can generate, but keeping track of those hospital and home care generated costs is still important. The lifetime maximum insurance coverage can still be a problem, if there are numerous hospitalizations. While enteral nutrition is much less expensive therapy, it is often much more difficult to get insurance companies or HMOs to reimburse for it compared to HPN. One of the reasons that I have been given for this is that insurance companies consider enteral nutrition as just nutrition or food, a replacement for normal diet, but HPN is considered a life-support system. Several people I know on enteral seemed to have less difficulty if the use of a "J" tube or a "G" tube was required, as opposed to a nasogastric tube. What concerns me about this approach is whether there are people placed on HPN because of insurance issues, when HEN is what they really need.

With HPN daily costs, antibiotic costs for infection, any nursing costs or hospitalizations, a lifetime maximum can be consumed quickly. Some companies will raise their maximum if they are self-insured and have a valuable employee, but that doesn't happen often. Some states have high-risk pools that can take up the slack if a person has gone through their lifetime maximum, but not all plans are the same. Many states do not have plans at all and the states that do have a wide variance in cost, what they cover and their lifetime maximums.

Every HPEN consumer should do his or her best to make sure bills are accurate, overpayments do not occur, and to be knowledgeable about the options should another insurance plan be required. You can never be too informed!

DGK: I once attended a panel discussion of several consumers of

HPN and HEN. I was very disappointed to hear these people laughing about how they just threw their bills into the wastebasket. It is important to discuss financial issues with the patient at the outset. This may help the person to realize that he or she has a responsibility to keep close tabs on charges and on the lifetime insurance allotment. In Liz's case her awareness of this proved to be critical to resolve issues related to incorrect billing that could have resulted in reaching her lifetime maximum years before this should have occurred.

Going Home:

Transition From the Patient Role to the Consumer Role

EVT: I remember most of what occurred the day I went home from the hospital as though it were yesterday. A friend picked me up at the hospital and drove me home. I had brought my new pole-mounted pump and pole with me. Two home care nurses were waiting for me with several very large boxes and a small refrigerator. The boxes contained PN and all the ancillary supplies I would need. We talked about the role of the home care company; providing my PN and supplies on a two-week schedule, when I wanted my deliveries and I signed some papers.

After they left I took everything upstairs to my bedroom, put the pump and pole next to my bed, then sat and just looked around the room: the refrigerator in my bedroom, the large box of supplies, and the pump and pole next to my bed. I remember thinking that it had looked so much different in the hospital room and that it didn't look as though it belonged here in my bedroom. I had a nice, long cry, all the time wondering how I was going to manage this alone and why me anyway. Once I was through with my good cry, I put my mind to ways I could make it work. I put the refrigerator in a large closet in my spare bedroom, added shelves in that closet and arranged all the ancillary supplies so they were readily available. Next I brought a drop front desk and put it into my bedroom, cleaned it out and put the things I would use every day in it. That left the pump and pole by my bed, and I knew I would just have to get used to that. I did.

DGK: Having a nurse from an experienced nursing agency at the home when the consumer first arrives can alleviate many of the initial anxieties. This also allows the individual to have professional input into laying out convenient and safe areas for cares to be done.

One of the lessons I learned from Liz is that when she is in the hospital she is a patient, but when she is not, she is a consumer. I feel that Liz's comments about having her supplies out of sight were a very healthy way for her to react to her new therapy. This probably has played a major role in her ability to be a consumer in the home setting, not a patient! Some people want their home to look like a hospital, and this makes it difficult for them to step out of the sick role rather than to be an individual who just happens to be on HPN or HEN.

Integration of HPN Into Everyday Life

EVT: Part of the process I went through when I came home from the hospital was the first part of integrating it into my life. I have known other HPN consumers who leave their ancillary supplies in boxes in their living room and rummage through them when they need something. I couldn't do that. I wanted very much to resume my normal life and while HPN was part of that, I wasn't going to let it be my entire life. Being organized and able to shut the closet door or desk front when I wasn't on HPN was psychologically important to me.

After that I made adjustments as they came along: Learning to get

Nutrition, Con't next page ➤

Nutrition, from previous page

the pump, pole, and me down the stairs to let my dog out, waking up in the night to go to the bathroom and remembering to take the pump and pole with me, clearing air-in-line alarms without really waking up, gaining my strength, and going back to work.

DGK: For individuals such as Liz, adjusting the PN to fit into his or her life is very important. I often tell the patient in the hospital that he or she should “run the PN,” the PN should not “run his or her life.” I feel this is a healthy attitude that is associated with better outcome for the consumer, as well as the consumer’s family. However, it is not uncommon for consumers of HPN to make the therapy the center of their lives. The clinician should be alert to this and try to discourage this approach. Unfortunately, for some consumers that use their health issues for secondary gain, HPN can exacerbate this problem. This often results in unhealthy family interactions.

I also emphasize to the patient that he or she can adjust the timing of the HPN infusion to the activities of the day. It is not unusual for patients to have been told that they absolutely have to run the PN from 7 p.m. to 7 a.m. Anything we can do to make this therapy fit into the consumer’s life will be helpful in encouraging compliance.

Routine Communication with the HPN Team

EVT: Shortly after I came home from the hospital, I called the manager of my home care provider and made an appointment to go through the company. It was an excellent experience. I met the persons who would be calling me for my orders, saw how the PN was mixed and met the people who mixed it. I got to know the people in the warehouse, the driver who would bring it out to me, and became friends with the nursing manager and company manager.

The benefits I got from doing this were enormous. I got to meet and see the people and the process. It made it more understandable and clear. They got to put a face and personality with a name. I believe that enhanced our ability to work together for the mutual benefit of both.

My interaction with members of the medical team has been even more important. Working with the physician, the nurse coordinator would call me to check on how things were going, as well as to schedule blood work. The blood tests were initially every week, every two weeks, every month, and finally, when I was very stable, every three months. The pharmacist helps me when I have questions about drugs or components in my PN and, with the team, determines the exact formula of the PN.

These people are the first ones I call if I have any problems or questions. Am I running a high fever or does it spike after I start infusing my PN? Am I feeling a little out of sorts even if I am taking extra fluids? Any unusual occurrence can be brought to them for their expertise. If they haven’t heard from me for a while, I can count on them calling to check up on me!

DGK: We often ask the home care company’s nurse to visit the patient while he or she is still in the hospital. This allows the person to have a link to the company before going home and, I believe, makes the transition to home an easier one. ©

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Spotlight: Matthew Van Brunt

Matt’s looking forward to the Annual Oley

Conference in Saratoga Springs, New York this summer. He’s from Adelanto, California but he’s been to Saratoga before, more than once. Matt’s a horse-minded person, and has been since he was a teenager.

Matt was diagnosed with Crohn’s disease when he was around 10 (he’s not one for anniversary dates), and was relieved to have a diagnosis for the symptoms he’s suffered since the age of seven. Everyone thought the flu was the culprit so having a name for his ailment was a step in the right direction. The next step came when Matt went on TPN in 1975. He spent the first 20 years of his nutritional support experience at UCLA Medical Center and in the early days, contended with obstacles like fragile glass bottles, big, clunky poles and pumps and mixing his own TPN. Matt says, “The emergence of home health care companies was a Godsend.” This, along with technological advancements like needle-less systems and portable pumps, have made things easier for TPN consumers like Matt.

Matt actually admits that things are relatively easy for him, especially after almost 30 years on TPN. He’s a self-professed junk-food junkie and has few food limitations. He eats three meals a day and enjoys parties and social events. Even when it comes to things like sepsis, Matt’s had it pretty good with few infections, none serious. That’s not to say it’s all been a walk in the park - he’s been hospitalized for months at a time but he keeps a positive outlook.

In the earlier days, Matt felt somewhat alone. He and friend Todd Friedman (also an Oley member), spent time in the hospital together and thought they were the only ones with such physical problems. Matt’s home care company, Nutrishare, Inc. told him about the Oley Foundation around nine years ago and since then he says he enjoys seeing other members at the conferences because it gives him a valuable networking opportunity. “The conferences let me see people I haven’t seen in years,” says Matt, “I learn stuff about advancements in medications, surgical procedures and technology. I also listen to others’ experiences with things like catheter infections and I like to network.”

Matt has some valuable advice for TPN ‘newbies’. “Be patient,” he says. “Don’t get uptight, it only makes things worse. Medications, formulas - it takes time to get it right. But it will all come together.” ©

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Don’t forget 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.

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The following generous individuals have donated a gift to the Oley Foundation between December 9th and January 31st, 2005. 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. For a complete listing of everyone who donated in 2004, see page 14.

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Oley needs your help to make this year's silent auction a success. Whether or not you plan to attend the event, we encourage you to think about what Oley means to you and your family, and how you can help out. Anyone who quilts, knits, makes jewelry — or any craft — is encouraged to donate items to Oley. You can also be creative in other ways; do you shop somewhere regularly or have connections at a business that might donate a big ticket item like electronic equipment, airfare, an overnight stay at a hotel? Could you spare a few days or a week at your vacation home, time share or condo?

The more funds we can raise, the better we can support Oley's outreach and educational programs, like the *LifelineLetter*, the annual conference, and the toll free hotlines. Every dollar helps!

Raffle and auction items can be sent along with a note detailing who to thank and approximate value, to the Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208. Any questions? Contact Silent Auction President Robin Lang at 5 Buffalo Lane, York, ME 13909, e-mail ivtpn@maine.rr.com or call (207) 363-7880. We appreciate your support of Oley programs!





From the Desk of Joan Bishop, Executive Director

The past few months have been very busy. Hosting the regional program in Orlando in conjunction with the Nutrition Week (A.S.P.E.N.'s annual meeting) proved to be very rewarding. Topics covered ranged from preventing catheter infections to g-tube maintenance and complications. I just can't emphasize enough the quality of the programs offered on the regional level.

The Oley Session at Nutrition Week this year *"From the Patient's Perspective"* featured Rick Davis, Robin Lang and Barbara Klingler. All of our panelists shared their thoughts and experiences on living with home nutrition support therapies. While it's not always easy to recall painful experiences both old and new, it is helpful for clinicians to learn from the recipients of their care and we really appreciate their participation.

Advocacy efforts include: voicing concerns to the Government Accountability Office (they have been mandated to report to Congress and Senate on reimbursement issues for IBD) on concerns as they relate to homePEN reimbursement; participating at Digestive Disease National Coalition Education Day on Capital Hill this month; and planning to work with National Home Infusion Association in clarifying issues that Medicare Part D may bring to the table.

Oley Annual Conference planning is well underway. The official Registration Brochure will be enclosed in the next issue of the *LifelineLetter*. Watch the web for updates, too. We are very excited about saluting the long-term consumers (if you are approaching the 20+ anniversary, please let us know!) the topics being offered, the tentative faculty list and bringing everyone back to the Albany area. Plan to attend!

I cannot emphasize enough the importance of having your medical information organized and on-hand when traveling and/or in the event of an emergency room visit. This documentation is often too complicated to retrieve in an emergency. Please make things easy on yourself and spare a family member from having to piece things together for you. The Oley web site has forms available to help you organize information, or you can call (800) 776.6539 and we'll send them to you.

I remind you that we are always open to new ideas, suggestions for topics to be covered in the *LifelineLetter* and introductions to those in your area with an interest in homePEN therapies. Help us serve you better - share with us!

Now, with my fundraising hat on, I'd like to take this opportunity to thank everyone again for their generous financial support. Your contributions really make a difference. For those who have been putting off the task, we've enclosed an envelope to assist you. Keep us going.

Last but not least, I want to thank all of you for your support. My dear friend Nader lost his battle in December and while this is a very sad time for me, I also feel blessed to have the many wonderful memories. His spirit and enthusiasm for life taught many of us the true meaning of **"living"** whether on homePEN or not. For his influence and impact I am grateful. For your encouragement I am thankful. ☺

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Phyllis Wakefield
Manuela Wenz
Arleita Wiczorek
Dan Wolfe
Patricia Wright

We Really Want to Hear From You!

Did you read about something in the *LifelineLetter* and want to get more information? Do you have important information about a previously printed topic that you want to share? Even if you just want to share your opinion on an article or some other content of our newsletter, we want to hear from you. We value your opinions and views because without you, there would be no us. Please share your thoughts with us by contacting the *LifelineLetter* Editor, Cory Piekarski, at PiekarC@mail.amc.edu.

Just So You Know...

The Oley Foundation has a strict policy of not sharing its membership list with anyone: patients, healthcare professionals, Oley Regional Coordinators, research institutions, homecare companies, other non-profit organizations, etc. We are very protective of our members' right to privacy.

Rest assured that no one has access to the names, addresses, or phone numbers of our members BUT when a member chooses to share contacting information by responding to a mailing, advertisement, entering a contest, etc. the landscape changes and members should be aware of that. The door is then opened for solicitation!

Oley will share a consumer's name and contacting information with another consumer for networking and outreach purposes, but only after getting permission from the consumer first.

If you have any questions, concerns or would like to discuss this policy further, please contact Joan Bishop by phone (800) 776-6539/ (518) 262-5079 or e-mail bishopj@mail.amc.edu.



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.

Oley Foundation Horizon Fund Members

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

...and growing every day!!

The Horizon Fund is a group of members who are securing the future of Oley programs by naming Oley as a beneficiary in their wills.

'Nutrishare knows their stuff. I can ask THEM for answers ... so refreshing!'

Dave and Sheila
Parents of David and Olivia

Nutrishare, Inc.

1-800-Home TPN

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



Toll-Free Numbers Available to US and Canadian Consumers!

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

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

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

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

APRIL '05

Jennifer Welday
Reynoldsburg, OH
(888) 610-3008 EST

Jennifer is the mother of 6 1/2 year-old triplets that were 26-week premies, two of which came home with g-tubes. Caleb continues to receive g-tube feedings as he learns how to overcome his oral-motor hypersensitivity. In spite of his struggles with cerebral palsy, he is a happy and healthy kindergartner, just like his siblings.

Bettemarie Bond
Levittown, PA
(888) 650-3290 EST

Bettemarie is 34 and has Biliary Dyskinesia with smooth muscle disorder. She receives lipid infusions a few nights a week and is connected to a PCA pump around the clock. Bette's worked full-time for the past six years as an occupational therapist and recently purchased a home. She's experienced with TPN and NG feeds and she and her mother both have experience dealing with insurance issues.

MAY '05

Amy Vohsing
Grandville, OH
(888) 610-3008 EST

Amy is the mother of three children. Her oldest son is 17 and has Short Bowel Syndrome. He lost all but ten inches due to a car accident. She would be happy to talk about all issues surrounding this condition (siblings, adolescence, life-changing adjustments, etc.) She has experience with TPN and EN feeds.

Joyce Hydorn
Troy, NY
(888) 650-3290 EST

A terrific Oley office volunteer, Joyce began TPN in January of 1992 as part of her battle with Crohn's disease. She has an ostomy and uses a CADD pump. She looks forward to networking with fellow consumers and sharing her experience in dealing positively with chronic illness.

JUNE '05

Rose/Alicia Hoelle
Gibbstown, NJ
(888) 610-3008 EST

Alicia, 20, has been on HPN since birth due to hypoganglionis/NID and was recently diagnosed with Crohn's Disease. She graduated high school in 2003 and is attending college to become a child life specialist. She has enjoyed camp, sports and other activities. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. They would love to hear from kids, teens or parents. Their favorite topics are advocacy, school accommodation, transiting issues and dealing with long-term HPN.

Ann Debarbieri
Gansevoort, NY
(888) 650-3290 EST

Ann is a retired attorney and loves gardening and walking in the woods with her husband and dogs. Diagnosed with Gardner's Syndrome, she has years of experience with TPN, tube feeding, traveling and working. She is also familiar with the disability approval process. It is best to call in the afternoon or early evening.

LifelineLetter

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