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# LifelineLetter

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

## A Doctor's Perspective on Pain Management

**Dr. Richard Patt**

*A growing group of long term HPEN consumers (nearly one-third) have pseudo-obstruction; they have what appears to be a normal bowel in the sense that there is no mechanical interruption, but the musculature or the neurological innervation of the bowel does not work, so it behaves like constant obstruction. It's a very tough diagnosis to make. Often the patient goes through a lot of frustration before they get a diagnosis. The person with pseudo-obstruction also endures a great deal of pain. Because most serious pain medications impair the motility of the bowel, these consumers are caught between a rock and a hard place. And the issues of addiction further complicate their ability to get any relief from their pain. The following are comments from Dr. Richard Patt's presentation on pain management given at the 19th Annual Oley Conference, held in San Francisco, CA in June, 2004.*

### Where We Are and Where We're Going

We are paradoxically in the midst of a rebound phase and pain management, regrettably, is at a low ebb just now. The 1950s and 60s were an era during which



*Dr. Patt delivering his talk on pain management.*

patients with cancer and those at the end of life commonly suffered unremitting pain, despite readily available and inexpensive remedies. Then there were some successful initiatives that arose from several sectors — physicians, nursing associates, patient advocacy groups, and the pharmaceutical industry — with great results in treating pain at the end of life.

**Pain cont., pg. 2** ➤

## Join Oley in Dallas this February!

The Oley Foundation will host a one-day Regional Workshop for patients, families and clinicians on February 11th, 2006, in Dallas, TX. Supported by the American Society for Parenteral and Enteral Nutrition as part of Nutrition Week, our program is free of charge and offers a unique educational and social opportunity for attendees.

The program will run from 9am to 4:30 pm, and features speakers Alan Buchman, MD, of the Intestinal Rehabilitation Program at Northwestern University and Kishore Iyer, MD, of Children's Memorial Hospital, in Chicago. The third member of the panel is Rick Davis, an Oley member and enteral nutrition consumer. Topics will include a short review of current therapy for short bowel, hormone therapies for the gut, surgical therapies for short bowel, and coping with chronic health issues and nutritional support.

Attendees can also choose from a series of small group discussions on a variety of topics, including: enteral feeding led by John Fang, MD; insurance and Medicare led by Alyce Newton, MS, RD, CNSD; catheter care and access led by Ezra Steiger, MD; fluid and electrolyte issues led by Reid Nishikawa, PharmD;



pediatrics led by Mark Corkins, MD; IBD led by Doug Seidner, MD; liver disease led by Dr. Buchman; and surgery and transplant led by Dr. Iyer.

Volunteers are needed to staff the Oley booth in the Nutrition Week Exhibit Hall, Sunday to Tuesday, February 12-14, 2006.

For more information on the regional conference or Nutrition Week visit the Oley website at [www.oley.org](http://www.oley.org) or contact the Oley office at 800-776-6539, [Harrinc@mail.amc.edu](mailto:Harrinc@mail.amc.edu), or 518-262-5528 (fax).

## Pain, from pg. 1

Next we asked, "In this country of sophisticated medical care, do we really have to be dying to get comfort and relief from pain?" So we began the next part of the job, the harder part, which was to deal with patients with chronic, painful medical disorders who are not near the end of life. In this setting, we need to be thinking about functional status

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(performance status) and not just for six days, but for six weeks, six months and even six years — and this raises a lot of issues. Fortunately, to do a better job of controlling pain, it's not a question of finding a new molecule or a new scientific breakthrough. We have simple tools that work today and have worked for the last 100 years. A lot of so called "new developments" are old drugs in a new package, like Duragesic patches, transdermal Fentanyl and M.S. Contin, an old-time morphine pill in a slow-release preparation. Instead the issues are addiction — real or perceived — and building better physician/patient relationships.

Recently the Joint Commission for Hospital Accreditation (JACHO) insisted that hospitals ask about and respond to people's pain, but there is no true mandate or accountability. The health care delivery system is broken and we don't have sufficient time to ask about, or treat, pain.

Professionals are clueless about making the distinction between pain management and drug abuse. We all watch TV and see "Just Say No to Drugs" but it doesn't say "unless your physician prescribes your medications for a legitimate medical reason." There is a picture of Nancy Reagan and Ronald Reagan on his hospital balcony and he is waving at people on the day of his surgery, but nobody explained he had a spinal morphine catheter in. What about the Rush Limbaugh debacle? While I don't know all the details, it appeared that this individual was taking mega doses of strong opioids but none the less he appeared to be pretty functional. This is not consistent with the media depiction of a drug addict living a shady existence from fix to fix.

I'm not sure why, but there was a strong negative reaction to the Limbaugh event. The manufacturer of Oxycontin no longer made available the 160 mg dose. The media spread the word, by every possible means, about how any kid could abuse prescription drugs by subverting the system, chewing, breaking up or injecting time-release drugs. So if the kids didn't know about it, they came to find out about it. Doctors ran in hiding, as there was a great deal of fear of regulatory reprisal. Physi-

cians have been jailed; have been given murder sentences, with an obviously chilling effect on their willingness to adequately care for patients in pain.

#### Pain: An Invisible Tormentor

There is no blood test or X-ray that determines whether or how much pain you have. My assistant used to say, "If pain was a rash, this would be a no-brainer - everyone could see it." In some ways, cancer patients' pain is overt in that at least you can see a tumor. Medical oncologists became our nation's pain specialists by default. They didn't apply for the job, they weren't trained for it and, up until recently, there were no pain management questions on their board exams even though 70 to 90 percent of their patients had pain.

One would think a rheumatologist would be a pain specialist. In my community, an out-of-state relative complained to our medical board about a local rheumatologist's treatment of a patient. The board is charged with

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The health care delivery system is broken and we don't have sufficient time to ask about, or treat, pain.

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protecting public safety and must respond to every consumer complaint. However, since the board is anxious to get additional funding to pay for its investigations, once they begin one, it's likely that they will have positive findings. This doctor became very frightened and ultimately took his triplicate prescription books and mailed them to Austin for the investigation. One and a half years later, it's still in the very first phase of negotiation. Basically, they didn't understand why a rheumatologist would be prescribing opiates. Unfortunately, because he was a good pain manager, (being the exception and not the rule) and because statistically rheumatologists don't prescribe a lot of scheduled substances, he was punished for doing a good job. So the pendulum has swung back in the wrong direction and will probably overcorrect in the future. There is no question that we need to be alert to concerns regarding the potential for drug abuse. There are patients who have both a substance abuse and a pain problem. They require special management approaches.

#### Finding the Sweet Spot

I'd say 80 to 90 percent of my practice consists of regular patients like you and me

Pain cont., pg. 7

## We Have a Winner!

Congratulations to Julia Lynch of Salem, Massachusetts! Julia turned in her Oley membership form by the October 30<sup>th</sup> deadline and was the lucky winner of the drawing for a \$50 Target gift card.

Thank you to everyone who completed his or her membership form. Having updated information helps Oley staff to better connect members to other members and resources. If you haven't turned yours in, it's not too late! Alternatively, you can call in your information to Cathy Harrington in the Oley office toll-free at (800) 776-OLEY, or email her at [Harrinc@mail.amc.edu](mailto:Harrinc@mail.amc.edu). Thank you!



## Equipment Exchange

The following supplies/equipment are offered free of charge:

### Enteral Formula:

- 2 cases Resource Diabetic, expires 1/06
- 1 case Ultracal, expires 2/06
- 4 cases Fibersource
- 3 cases Jevity 1.2, expires 2/06
- 9.5 cases Ultracal w/fiber, expires 10/06
- 3 cases Optimal, expires 4/06
- 12 cases Neutren 1.0, expires 6/06
- 6 cases Fibersource HN, expires 9/06
- 4 cases Peptamen 1.5, expires 2-9/06, 2-11/06
- 9 cases Neutren Jr., expires 3-3/06, 2-4/06, 4-5/06
- 3 cases Replete, expires 3/06

### Tubes/Bags:

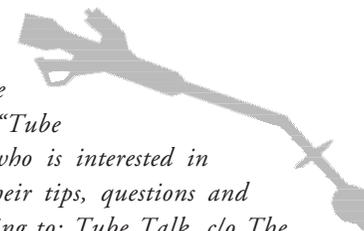
- 23 Kangaroo 500 ml pumpsets, #702005
- 7 Ross EZ Feed bags with pre-attached gravity set, 1000ml, #56
- 9 B. Braun IV Administration sets (79") 15 drop ml, #V1402
- 9 Baxter Solution Sets (97") 2.5ml)2 inj. site w/male luer lock adapter, #2C5439S
- 3 Deltec CADD TPN Administration sets w/1.2 filter, #21-7071

MORE SUPPLIES are available! This is a partial listing of the products that are currently available through this program and outlines supplies that have become available in the last month. If you have a need for any items listed above, would like to view the complete listing of the tubes, formula, etc. or have items to donate; visit our website at [www.oley.org/EquipmentExchange.html](http://www.oley.org/EquipmentExchange.html), or contact Liz Tucker at [evtucker@charter.net](mailto:evtucker@charter.net) or toll free at (866) 454-7351. You should also know that items become available on a daily basis, so check periodically.

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 such as enteral formula or infusion pumps, offer to pay the shipping costs.

## 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 [DahlR@mail.amc.edu](mailto:DahlR@mail.amc.edu). Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.



## G-Tube Splitting

I'd like to correspond with someone who's experienced problems with his or her G-tube splitting and pulling away from the end where you hook up. It seems the covers are so delicate that they wear out quickly and that's when the leaking occurs. I also have a problem with the hub near the skin. It's breaking, and if it goes all the way, there is no way to adjust it to make it fit securely. It seems like there has to be a better system to reduce these problems. Please email me if you have experienced similar problems.

— Carol Pelissier  
[capuniqu@comcast.net](mailto:capuniqu@comcast.net)

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## Profile: Oley Foundation Regional Coordinator Volunteers

Our Regional Coordinator network continues to grow! We are very pleased to welcome LeeAnne Bye, a new volunteer to our network ranks. We'd also like to re-introduce Laura Keser (formerly Laura Mucha), Judi Martucelli, and Judy Peterson. We intend to profile all of our volunteers, a few at a time, in an effort to help you connect locally, and also to offer insight into the different people who make up our network. Maybe they have a similar history to you or someone you know, and maybe you will find you would like to volunteer as well! Please contact the Oley Foundation if you would like to learn more. Thank you LeeAnne, Laura, Judi and Judy!

**LeeAnne Bye – Northfield, NJ:** LeeAnne is an RN and Mom to four children, including her daughter Samantha, who has been on both enteral and parenteral therapies due to chronic pseudo-obstruction. LeeAnne and her family are familiar faces at Oley Conferences. She feels her experiences as a parent and advocate will benefit others struggling with similar issues. She would really like to start a local support group and we will help her with that effort! Contact LeeAnne at (609) 641-9087 or allenleeannebye@aol.com if you are interested in joining the group.



*Samantha and LeeAnne Bye on a Make-a-Wish trip.*

**Laura Keser – Stillwater, OK:** Formerly RC Laura Mucha of Gilbert, AZ, Laura has had a lot of great changes in the last two years. She returned to college at Oklahoma State, majoring in psychology and minoring in sociology. She will graduate in Spring 2006, then return to AZ for graduate work. Her focus is post-traumatic stress. She continues to reach out for Oley in her new city and will do again when she returns to AZ. Laura has been on HPN since 1991, due to short bowel syndrome. She has experience with multiple catheters and a lot of experience with access issues and D-lactic acidosis. Laura is very excited about life these days, enjoying her multiple roles as mother, grandmother, student and social butterfly!



**Laura Keser**

She is a great believer in hope, feels Oley really offered her that when she was first diagnosed, and we are happy to have her share that philosophy through Oley! Contact Laura at (405) 533-1101 or chameleon3@cox.net.

**Judi Smith-Martucelli — Drums, PA:** has rejoined the Regional Coordinator network after a long illness which kept her from performing her RC duties. Judi has over 30 years experience with chronic intestinal pseudo-obstruction, the many peripheral issues

that accompany neuro-muscular disorders, along with the issues all consumers of IV or tube feeding share. As the years have passed, her perspective of viewing life's glass as half-full has grown, as has having faith in the power of God and using creative methods of self-expression. One of the greatest things that she has learned is to view herself as an integral part of her team of health care workers. Oley has been most helpful in this regard. She has been on TPN since 1990, after 16+ years seeking an accurate diagnosis. She can be reached at (570) 788-6333 or judi@intergrafix.net.



**Judy Petersen, RN, MS**

**Judy Peterson – San Diego, CA:** Judy has rejoined the RC network this fall. With a master's degree in pastoral counseling and a background in nursing, she is an excellent resource for consumers and family members. She recognizes the importance of consumers keeping themselves well informed, and is committed to helping consumers realize the positive elements of being on nutrition support. Judy has attended several Oley Conferences and can share what a great experience this can be — especially for new consumers. Contact Judy at (619) 226-2061 or catsjp@cox.net.

## Ongoing Research Trials

### • **Wanted: TPN Patients With Osteoporosis**

The Cleveland Clinic Home Nutrition Support Service is conducting a research study of patients receiving home total parenteral nutrition (TPN) who have osteoporosis. The purpose of the study is to learn about the effects of teriparatide (Forteo®, Eli Lilly Company), a bone forming drug, and its ability to form new bone and reduce the risk of fracture in patients on TPN with osteoporosis. The study is performed over an 18-month period of time and requires 5 visits to the Cleveland Clinic. Participants include men and women between the ages of 25 and 76 years, receiving TPN 4-7 nights per week and who have osteoporosis. Compensation is provided for visits, parking and mileage. If you are interested in participating in this research study, or have questions, please call Cindy Hamilton, RD, at (216) 444-6164, Cleveland Clinic Foundation.

All 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/Researchupdates.html>. Clinicians interested in having their study listed should complete the form listed on Oley's web page at: <http://www.oley.org/form.html> OR fax the same information to (518) 262-5528.

## Kinship, Courage Found at Oley Conference

Gail Brenenstuhl

Two and one-half years ago, the unthinkable happened to me. Twelve hours after being admitted to Glens Falls Hospital in an emergency status, I was rushed into surgery where they removed almost all of my small intestine. Two prior colectomies had already left me with no colon. I now had only 160 centimeters of intestine left. Barely out of the effects of the anesthetic, I was being told I would need home IV therapy called TPN. I was bewildered and didn't really know what they were talking about. The next day I was sent by ambulance to Albany Medical Center and put under the care of Dr. Lee (my former surgeon) and Dr. Howard (a pioneer in HPEN).

I went into a severe sepsis and spent the next two months in the hospital on TPN and numerous IV antibiotic drugs. Fighting the nausea, pain, and confusion was an everyday occurrence with me. Finally, Dr. Lee was forced to operate on me again to clean up the infection. It resulted in a jejunostomy and short bowel syndrome. I had to face coping with HPEN therapy and caring for a stoma for the rest of my life. I was devastated and did not want to believe what had happened to me. I had the support of friends and family, but with the exception of my husband, Chuck, who was my caregiver, no one really understood my situation.

Dr. Howard told me about the Oley Foundation, but I didn't want to listen. I was much too ill to care about what other people had gone through. After I got somewhat better, my husband talked me into going to a local Oley event: Don Young, a former Oley president, was celebrating 30 years on HPN. There I began to meet people like me. Their openness and friendliness encouraged us to attend the Oley Annual Conference in Saratoga Springs this past summer.

At the conference I met so many people willing to talk about their situation and share their experiences, I began to see I was not alone. People who aren't going through this don't really have a clue, but here were people up close and personal who knew, as homePEN consumers and caregivers do, what we are going through.

My husband and I found the breakout sessions very informative. We were even fortunate enough to join a session with Dr. Howard and Dr. Jeppesen from Denmark, who is in charge of the drug study I am participating in. That experience was the highlight of the conference for us.

We, as newcomers, were paired up with an experienced conference goer to help us; and the conference was so well run, we never felt "lost in the shuffle." We thoroughly enjoyed ourselves and are even getting the courage to fly to Utah to join in next year's conference in Salt Lake City. We figure, what better way to test our travel wings with

than with a support group of such experienced people? After all, my own doctor will be with me. And even if she wasn't, there are many of the most experienced HPEN clinicians and homecare companies attending the meeting, staying in the same hotel. What better support can there be than that?

Chuck and I would urge all newcomers to HPEN therapy to get involved with Oley and attend the conferences and other events. We can't begin to explain what a help it is to have the support of all these people. You have to find out for yourselves what it means to know you are not alone. Perhaps even I could help as an "experienced" conference attendee, that is after I have mastered the seemingly daunting task of travel with all the homePEN requirements. There too, Oley

— Gail Brenenstuhl

has many "tricks of the trade" to pass on to us and we are certainly going to enlist their expertise.

*For tips on traveling with HPEN, contact the Oley office (800-776-OLEY or Harrinc@mail.amc.edu) and ask for the collection of travel articles and the travel/hospitalization packet you should carry with you whenever you leave home.*



*Be All That You Can Be*

The Oley Foundation

21st Annual  
Consumer/Clinician  
Conference

Sheraton City Centre  
Salt Lake City, Utah  
June 28 - July 1, 2006

## Back-to-Basics Plan Saves Lives in ICU's

Brad Heath

*This excerpt was first published in the Detroit News on October 14, 2005. The staff at Oley felt it contained a very important message for those on HPN. A copy of the complete article can be accessed on the Oley website ([www.oley.org](http://www.oley.org)) or you can contact Cathy at the Oley office for a copy (800-776-OLEY or [HarrinC@mail.amc.edu](mailto:HarrinC@mail.amc.edu)). In conjunction with this article we have included a **Keep Me Safe** flyer in the newsletter for your use when hospitalized. Additional copies are available free of charge from the Oley office (contact information above).*

Steps as simple as ensuring doctors wash their hands have sharply reduced the rates of two potentially fatal complications for intensive care patients in Michigan, researchers said Thursday as they outlined the results of a two-year project to curb medical errors.

The project included the vast majority of Michigan's intensive care units. Since it began in 2003, they were able to lower the rate at which patients suffered infections after receiving "central line" IV's more than 80 percent and cut the rate of pneumonia 45 percent, the researchers said. Both conditions are frequently linked to mistakes by doctors and nurses.

"What we have shown here is the vast majority of those cases are preventable," said Dr. Peter Pronovost of Johns Hopkins University, who was one of the project leaders.

The project was part of a broad effort to lower the toll of medical mistakes nationwide. A study published in May found up to 98,000 Americans are killed by medical errors each year. The rate has scarcely

budged in the five years since a landmark study showed mistakes were the nation's eighth-leading cause of death. The news pushed physicians and the government to focus on improving safety.

Few of the steps the researchers recommended are complicated. To keep intravenous lines from causing infections, they urged doctors to wash their hands and asked nurses to check up on them; they recommended that doctors wear caps and gowns when inserting the line and asked that doctors use a different type of disinfectant before inserting the IV, among other steps.

To keep patients on ventilators from developing pneumonia, researchers urged that their heads be kept elevated – a standard instruction in nursing school.

"It's those back-to-basics that can really impact the patients' quality of care," said Maria Palleschi, a registered nurse who has worked in Harper University Hospital's intensive care unit for 29 years. "When you're in an environment that's high-tech and you have a reduction in nursing hours, when you have so many things that are going on with the patient, the basic things sometimes have a tendency to get away from you."

The project, by Johns Hopkins and the Michigan Health and Hospital Association, included 127 intensive care units at 77 Michigan Hospitals.

It focused only on bloodstream infections linked to "central line" IV's, which let doctors deliver drugs and fluids to a main artery instead of the smaller vessels in patients' arms; and on pneumonia among patients on ventilators. Both complications can prove fatal. It did not include a variety of other safety problems, such as medication errors, because they are more difficult to measure, Pronovost said.

Researchers estimated the changes have prevented 1,500 deaths and saved nearly \$166 million in health-care costs, though they were unable to precisely measure either. Sixty-eight of the ICU's that participated in the project have not had any cases of bloodstream infections or ventilator-associated pneumonia in at least six months.



*Simple steps like handwashing have sharply reduced CVC infection rates in the ICU.*



*"I feel very fortunate to have Nutrishare in my life. I have accomplished amazing things with their help."*

Lakisha Judge  
Nutrishare Consumer

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

## Keep Me Safe - It's Free!!

If you read the article, "Back to Basics," then you already know about the free **Keep Me Safe** flyer that is included in this issue of the *LifelineLetter*. If you or a family member on HPN are hospitalized, use it to start a conversation with the doctors and nurses taking care of you. Make sure they know you expect the guideline to be followed. You can also share information about the Oley Foundation printed on the back of the poster. A colored, laminated version of the **Keep Me Safe** poster can be obtained by contacting the Oley Foundation at 800-776-OLEY or [HarrinC@mail.amc.edu](mailto:HarrinC@mail.amc.edu). You can never be too safe!

Information on the companion program for clinicians, "Save That Line," run by the Association for Vascular Access (AVA), is available at [www.avainfo.org](http://www.avainfo.org). CME's are offered.

**Pain, from pg. 2**

who are *not* near the end of their lives. I have a stable group of patients with whom I work. I put a lot of time into the evaluation phase, probably three or four hours with a new patient. In my experience this makes it much easier to manage the patient further down the road. I also get the family involved, because I'm interested in their observations, even though the patient is the main authority.

Typically, it takes a lot of work to find the right medications and the right doses. We work hard in the beginning adjusting the medication to get things just right. Once we do, there often is a short period when the individual gets a little greedy and they say, "This is really good, maybe more is better."

When I'm following up with a patient I ask, "are you better, worse or the same?" They usually assume I mean is their pain better, worse or the same; but in fact, the question is more relevant to the potential adverse effects of drug X, Y and Z, and ultimately, to their functional status. For example, I ask, "Do you have constipation?" You only have to be on the wrong end of a manual disimpaction once to not want to go there again. There may be a phase where the consumer finds that, with the next step upward in pain control, they have more problems with nausea or grogginess than benefit from relief of pain. With work, however, they find the right balance. My patients have taught me most of what I know, and fortunately I've been smart enough to listen. In my experience, once they find that sweet spot where pain is not eliminated, but is tolerable and side effects do not interfere, then the majority of patients will stay at that dosage for months and even years. If there is a need for a sudden dose increase, we look for progression of disease, such as an abscess or obstruction.

If you're going to get a side effect from an opioid, it's almost always going to occur at the initiation of therapy, not after prolonged use. Everyone wants to blame the opioid. I'm intentionally not using the word 'narcotic' because it conjures up back-alley images.

**Addiction**

For someone who's gotten through five decades or more of their life without a problem with alcohol or drug abuse, it's a fallacy to think that simple exposure to opioids will produce an addiction syndrome as if by magic. It's not only wrong, it's demeaning and it doesn't say much about what we think about people, and their values, and the strength of their convictions. It should be pointed out that I *do not* think of these drugs as primarily addictive. I believe people and their coping strategies are potentially addictive in nature. To be fair, you can say it's the interaction between these substances and our lifestyles that leads to addiction. If someone is stressed out or is having a problem, it is not uncommon for them to take a drink, gamble, spend money or choose another poor alternative to an appropriate adult way of managing their stress. These individuals are at greater risk of developing a psychological dependence on opioids. However, as a new behavior this is not common, since the best predictor of future behavior is past behavior.

*Addiction is not tolerance.* Even if the Pope developed pseudo-obstruction and was experiencing pain and needed opioids, he would eventually become accustomed to the medication, and need a higher dose over time. Galloping tolerance is rare. Tolerance is simply the need for adjustment of dose to maintain a given effect over time.

*Addiction is not synonymous with physical dependence.* Anyone exposed

**Pain** cont., pg. 9

CORAM



## I couldn't have made it without Fred.

There is a very poignant story about one of our consumer's graduation from college, having received TPN since 1991. She named her TPN pump "Fred". It became her constant companion throughout her trials and tribulations for the next 12 years. We who provide home enteral nutrition and home TPN support can learn a lot from her story.

Coram's Advanced Nutrition Services believes in our face-to-face-with-life approach, providing the most appropriate and effective nutrition support and therapy, improving our patients' quality of life. We got her started. And we'll be there for the long run.

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visit us on the Web at [www.coramhc.com](http://www.coramhc.com).



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## Who's Who at the Oley Foundation

**Joan Bishop** has been with Oley since 1985 (nearly it's inception) and has served in many capacities. Currently as Executive Director, Joan handles the multitude of tasks it takes to keep Oley running and growing, including budget planning, building relationships, fundraising, board development, and coordinating the annual conference. She is dedicated to fulfilling the Foundation's mission and welcomes your ideas, comments and criticisms. Feel free to pass along any suggestions you may have for the annual conference, or anything that may assist her with ensuring Oley reaches everyone who needs us.

**Roslyn Dahl** has rejoined the Oley staff as Director of Communications and Development. She is responsible for producing the *LifelineLetter*, brochures and other Oley publications. She also manages the wealth of information available through Oley's web page, and information clearing house. She works closely with other staff members and volunteers to raise funds for the Foundation and to promote it's services to an ever-growing audience. Call on her to research your questions, or to share ideas for Oley publications or promotions.



Roslyn Dahl



Cathy Harrington

**Cathy Harrington** has been Oley's Administrative Assistant since 1998, and for 12 years before that the Secretary for Albany Medical Center's Division of Clinical Nutrition. She has experience in patient care, extensive knowledge of the homePEN arena and a strong desire to

support Foundation activities. Cathy manages the member database, answers most of your calls, and meets all of the day to day needs of the Foundation office. She is the glue that holds us together, so be friendly when you call!

**Elizabeth Tucker** is the new Editor of the *LifelineLetter*, though she is anything but new to the Foundation. Liz has been a member and Regional Coordinator since the early 90's and was a Board member for many years. Now on staff, Liz is responsible for soliciting, writing, and proofing the editorial content of the newsletter. She also runs Oley's equipment exchange program. Liz welcomes your input on the *LifelineLetter*.

Lastly, we are sad to report that after five years of dedicated service,

**Ellie Wilson, RD, MS** will be leaving Oley. As Outreach Director, Ellie worked with Regional Coordinators and others to bring the Oley Foundation to consumers and clinicians across the country. We thank her for her diligent efforts, the expertise she brought to her work, and



Liz Tucker with her companions, Peaches and Dolly.

the humor and spark she shared with us all. We will miss her, but know that her soft spot for Oley will keep her in touch with the Foundation and her many Oley friends!

Contact information for Foundation staff, including individual email addresses, is always listed in a box on page 2 of the newsletter. We are just a toll-free call or email away and would love to hear from you!



Ellie Wilson, RD, MS

## From the Desk of Executive Director, Joan Bishop

Christmas came early this year! Nutrishare, Inc. is pioneering the Platinum Partner Level of Oley sponsorship!

A warm and grateful thanks to the folks at Nutrishare, Inc. for sending us into the new year with a giant leap from the Silver

Circle Level! What a wonderful showing of support and confidence... and assurance that Oley programs will continue and remain strong. Rod Okamoto, RPH, President and Tom Diamantidis, Pharm. D., Vice President write: *"From the very beginning, Nutrishare pledged to increase its support of the Oley Foundation as the company grew, given our Home TPN specialty. Pioneering the new PLATINUM level of sponsorship together with the*

*Oley Foundation represents a gratifying milestone for the entire Nutrishare family. We hope other Home TPN providers will join us in support of Oley's important Mission."*

Other gifts that created excitement in the office this month are the "new" computers that have been passed along to Oley from Simmons College in Boston. Simmons has a policy to keep their systems state of the art and this has resulted in a serious upgrade for us. We received two desktop systems and two laptops. We look forward to working more efficiently and utilizing the laptops for outreach efforts when away from the office! A grateful note to Simmons College and to staff member, Claire Chantelle for coordinating this effort!

Plans are finalized for our participation at the Association for Vascular Access (AVA) conference, January 12-15 in Savannah, GA; the Oley Regional Conference in Dallas, TX, on February 11; and Nutrition Week program from Feb 12-15. We look forward to these gatherings each year as they provide opportunities to network and learn from the professionals who strive to improve your quality of life. We hope that you are planning to join us.

Last but not least, on behalf of everyone here at headquarters I send warm wishes for the happiest of holiday seasons. See the best in 2006!!



Joan Bishop

**Pain, from pg. 7**

to opioids on a chronic basis that were then abruptly stopped, would develop a syndrome of withdrawal, with a runny nose and other symptoms seen on TV. This can be avoided simply by gradual withdrawal. Typically, we see that patients get off the drug much faster than we, as clinicians, would like. In fact, I spend more of my time helping patients understand that taking these medications is appropriate than I do trying to get patients to turn them down. But patients are reluctant, especially when it comes to drugs like Methadone. We've rediscovered Methadone and it's become one of our drugs of choice. It's got interesting pain-relieving properties, and it's cheap, but the whole stigma of drug abuse in methadone maintenance programs makes people reluctant to use this medication.

**Honesty in the Physician/Patient Relationship**

I gave up a long time ago trying to determine, as someone walks through the door, whether their pain is authentic and how much they hurt. Even after talking to them for hours, it's hard to know. I choose to believe everything my patient tells me. I've learned that addicts, or people who are trying to scam the doctor, declare themselves very quickly with lost prescriptions, tales of 'the baby threw up on my prescription' and all sorts of behaviors characteristic of people likely to develop a drug problem. We provide a lot of supervision, observation, and rules for the family, and we encourage people to use journals and logs. This is low-tech but important stuff; it's simple but requires a mature approach.

One of the most important things for someone with pain is to cultivate and honor the relationship with his or her physician. It is not a good sign if I find myself thinking, "Is that really true? Can I really rely on them when they're telling me this is the last refill?" Similarly, if the patient finds him or herself thinking, "I hope Dr. Patt believed me. I'm not sure because of the look in his eyes," there is a problem with the physician/patient relationship. It cannot possibly be therapeutic if it continues this way. The physician should say, "I have trouble believing what you're telling me. I like you, I respect you, but help me understand this because it doesn't make sense to me." On the other hand, if the patient is saying, "Dr. Patt, I feel you don't believe me," then it is time to talk it out, deal with it and move forward. If the trusting relationship cannot be reestablished, it's time to find another doctor.

**Keeping it Simple**

We keep it simple whenever we can. We know we can give 30 mg. of oral morphine and get the same effects as 10 mg. of IV morphine, though not as quickly; but when treating chronic pain, we're not interested in a quick fix. In fact, sometimes it's useful to send the message that pain is not an emergency and should be addressed in a fashion least likely to overshoot the need. An exception is a spinal or epidural morphine pump that is implanted surgically and pumps tiny amounts of morphine into the spinal fluids so that the patient gets profound pain relief with little risk of side effects. The spinal system is more expensive and high-tech than most patients need, but some people, particularly elderly or very ill patients who cannot tolerate medication fluctuations, are excellent candidates. There's also the individual with the compromised gut, like Oley members; we don't necessarily rule out using

oral drugs with these patients, but we need to recognize that the absorption of pain medication is going to be affected.

We all bring our own styles to bear in clinical relationships, and I've come to recognize that I can't help everyone. This realization has been difficult for me to accept. It's better from the consumer's point of view to be the turtle, than the hare; it's more important to get there over time, than to remain on a roller coaster. You need to set goals, which need to be functional goals, rather than just relief from pain. No matter how good a job I do, all my patients still have pain every day. They have fewer bad days, the bad days are not as disruptive, and they feel more control; but chronic pain at some level continues. It's a question of bringing it down to an acceptable level for each person, so that even though they still have pain, the pain no longer "has them."

It is important that we work together honestly to accomplish pain control. Addressing this issue through conferences like the Oley annual meeting is helpful. Thank you for inviting me.

*A videotape of Dr. Patt's presentation is available from the Oley Video/DVD Library, and can be borrowed by calling (800) 776-OLEY. For more information about this topic, read "The Complete Guide to Relieving Cancer Pain and Suffering" (current edition) by Dr. Patt and Susan Lang. (Copyright 2004, Oxford University Press).*

**Happy New Years!**

The board and staff of the Oley Foundation wish all of you a happy and healthy New Year! We'd also like to thank everyone who has volunteered for the Oley Foundation, from staffing the toll-free lines to submitting pictures and stories for the newsletter. Your hard work compliments our efforts throughout the year, and makes our jobs easier. The wonderful community we serve and the ways in which you have helped each other are extremely inspiring. We look forward to working together in 2006!



*Photo by Robin Lang*

**Update Your Address**

We want to make sure that our records include your current address, e-mail, and telephone information. If you have changed any or all of the above, there are several ways to update this information: by calling Cathy Harrington at (800) 776-6538, by faxing (518) 262-5528, by emailing Harrinc@mail.amc.edu or by visiting our web site [www.oley.org](http://www.oley.org) (click on "join now" and follow instructions for changing contact information).

This might be a nice time to consider receiving the *LifelineLetter* electronically. It reaches you much quicker than U.S. mail service (bulk mail can be held for up to three weeks at the local level) and saves Oley the printing and postage costs. Why not try it. If you are not satisfied with the results it can be changed.

If, throughout the year, your information changes please notify us quickly. We want to ensure that you receive all of Oley benefits, services and communications in a timely manner.

## News from United Ostomy

United Ostomy Association (UOA) closed September 30, 2005, due to financial difficulties. A group of former UOA volunteers have organized the United Ostomy Associations of America (UOAA) in order to continue national advocacy for ostomates and patient support through affiliated support groups (about 90 of UOA's former chapters have joined to date, and more are anticipated). To learn about their support, advocacy and other services, visit their website at [www.uoaa.org](http://www.uoaa.org). To expedite replies, UOAA prefers questions be sent via email to [info@uoaa.org](mailto:info@uoaa.org); please use the organization's toll-free number (800) 826-0826 if email is not an option.

UOAA reports that patients in need of ostomy supplies, who do not have insurance coverage, may be interested in two manufacturer run programs:

1. ConvaTec has an income-qualified program. Most ostomy nurses have the applications, or consumers can call the company's Customer Service line at (800) 422-8811 and ask about their 'Access' program. Once qualified they are eligible for 3 months, and can reapply quarterly up to a year.
2. Hollister has a similar program, but they send products a month's supply at a time. For more information call (800) 323-4060.

From time to time ostomy supplies are donated through the Oley Foundation's equipment exchange program (complete list posted at <http://www.oley.org/EquipmentExchange.html>) and UOAA chapters/support groups (lists posted at <http://www.uoaa.org/supportgroups.shtml>)

The next option is making the most of a limited budget by shopping where the dollars stretch furthest. In 2001, UOA found the following suppliers to have the best overall retail prices (except for Northwind Medical, which is a recent discovery).

If you have a significant fight with your insurer, email Linda Aukett, UOAA Advocacy Chair at [advocacy@uoaa.org](mailto:advocacy@uoaa.org). She may be able to help troubleshoot the process.

Lowest Cost Mail Order Ostomy Supplies		
Dealer Name	Phone #	Shipping
Express Medical	(800) 633-2139	\$6 for orders less than \$95
Parthenon	(800) 453-8898	\$4 for orders less than \$150
Medical Care Products	(800) 741-0110	\$5 for orders less than \$100
National Healthcare Warehouse	(800) 847-5715	\$5.50 for orders less than \$50
Bruce Medical	(800) 225-8446	\$6.75 – 13.95
North Wind Medical	(866) 866-2444	no information available

## GI Motility Symposium for Patients and Clinicians

The American Motility Society is holding a symposium for patient support groups and health professionals "Getting Help for Patients and Their Families" at 12:30 to 2:30 p.m., February 12, 2006 at the Sheraton San Diego Hotel & Marina in San Diego, CA. Attendees will gather in small groups to encourage the sharing of information, and a box lunch will be served. The symposium follows a course on GI Motility in Clinical Practice held by the same organization February 10-12. For more information call Maria Sutton at (913) 588-4499 or email [msutton@kumc.edu](mailto:msutton@kumc.edu).

### Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. For their continued interest and strong commitment we remain grateful. We have revamped our levels of corporate giving for 2006. Over the next few months you will notice changes. We appreciate your patience while we transition.

#### PLATINUM LEVEL PARTNERS (\$70,000+)

Nutrishare, Inc.

#### GOLDEN DONORS (\$50,000-\$69,999)

Coram Healthcare

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

Novartis Nutrition

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

Ross Products Division/Abbott Laboratories  
Serono, Inc.

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

Hospira Worldwide  
Option Care, Inc.

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

Baxter Healthcare  
Critical Care Systems

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

BD Medical Systems  
C.R. Bard Foundation  
Kimberly Clark  
Zevex, Inc.

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

Accreditation Commission for Health Care Inc.

## Thank You! Thank You!

The following list represents everyone who generously contributed towards Oley efforts between September 1st and November 23rd. We also want 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.

<b>AMBASSADORS (\$2,000+)</b>	Sue Dell Thoman, in honor of Kyle Noble	Hanna Schwarz Phyllis Wakefield
<b>PRESIDENT'S CIRCLE (\$1,000 - \$1,999)</b>	Rodock & Doris Worthington	<b>FRIENDS (UP TO \$30)</b>
Jane Balint, MD	<b>SUPPORTERS (\$50 - \$99)</b>	Florence Bye, in honor of Amanda Bye
<b>BENEFACTORS (\$500 - \$999)</b>	Catherine Brant, RD	Mary & Alicia Corrado, in memory of Walter Yaffa
Lyn Howard, MD	Cera Products	Marc Ehrlich
<b>SPONSORS (\$250 - \$499)</b>	Melissa Chaney	Charles Freeny
<b>PATRONS (\$100-\$249)</b>	James Cocke	Stephen Harris
Gail Brenenstuhel	Richard & Faith Dillon	Roger Niosi
Patricia Brown	Steven Groenwoldt	James & Donna Quadracci
James & Suzanne Douglas, in honor of Tanner Shuman	Tiffany Matthews	Amisha Sheth
Laura Ellis	Mary Bea May	Jennifer & Randy Menk, in memory of Uncle, Leo Messner
Mary Gray	Susan Penzer	<b>IN MEMORY OF</b>
Portia Hutton	Doug Scartelli	<b>JOSH SHAPIRO</b>
Norma Johnson	Thomas & Alison Siragusa, in honor of Don Young	Jean R. Demichelle
Barbara Kapusinska, MD	Lorraine Uthke	Robert & Sena Gillenwater
JoAnn MacMullen	Frederick Weir	Fredric & Palmira Martin
Frank & Marjorie Miller, in memory of Mrs. Raymond Riddick	<b>CONTRIBUTORS (\$30 - \$49)</b>	Gloria C. Sanchez
	Frances Hovey	
	Hubert Maiden	
	Larry & Kathleen McInnes	
	Peggy Roth	

## Thanks for Your Support!

A special thank you to our corporate sponsors who keep Oley and its programs going strong. We appreciate your generous support! Here are some descriptions from the corporate sponsors about their products and services, as well as their commitment to the Oley Foundation.

### Coram Healthcare – Golden Donor Partner

For more than 25 years, Coram has provided HomePEN consumers with personalized care and clinical expertise, through a national network of 70+ locations throughout the US and in Canada. Coram is proud of their 20-year partnership with Oley and their vast experience in providing Oley members with “care for a lifetime”. Coram provides the highest quality clinical and personal support for HomePEN consumers, through its One-to-One Program, consumer advocates – Coram Partners – and consumer contact line: 1-866-4-HomePEN.

### Novartis Nutrition – Silver Circle Partner

Headquartered in Minneapolis, Minnesota, Novartis Medical Nutrition is the second largest manufacturer of enteral formulas and delivery systems in the United States and an industry leader in oral supplements, tube feeding products and fortified foods used in the institutional and home settings. Novartis Nutrition is focused on providing the highest quality nutritional products and services that maintain and improve human health and well-being. Novartis Medical Nutrition truly values the relationship it has with the Oley Foundation, and encourages all of its Partnered Providers to become involved and get to know all HEN consumers whom our products touch every day.



## Oley Horizon Society

*Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference call Joan Bishop or Roslyn Dahl at 800-776-OLEY.*

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

## 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>JAN. '06</b>	<b>Sheila DeKold</b> Floyd Knob, IN (888) 610-3008 EST	Sheila is the mom to 7-year-old David and 5-1/2 year old Olivia, who was diagnosed with pseudo-obstruction at the age of 2 years. Olivia is TPN dependent and has tolerated enteral feeds in the past. Olivia has a G-tube and a separate J-tube, as well as an ileostomy, and requires catheterization overnight.
	<b>Marilyn Sobiech</b> Brainerd, MN (888) 650-3290 CST	Marilyn has been on TPN since March 1997 due to scleroderma with a lot of GI involvement. She stays very active with her 3 grandchildren. She is currently on disability and has a lot of experience with travel — domestic and international, as well as camping and cruises. Ask Marilyn about attending Oley conferences.
<b>FEB. '06</b>	<b>Melanie LaVoie</b> Taunton, MA (888) 610-3008 EST	Melanie is mom to 4-1/2 y.o. Alex and 20 month old Adam who is on Mickey G-tube feedings due to Gastroparesis. Melanie attended her first Oley conference this past June and can share her experiences. She is hoping to speak with other parents of children who have had a Nissen Fundalplication or have Gastroparesis.
	<b>Robin Lang</b> York, ME (888) 650-3290 EST	Robin has a Hickman catheter and has been on TPN for 26 years due to SBS. She lives on 10 acres in Maine with her two dogs, Zoe and Doodle. She has done extensive traveling both in the U.S. and abroad. Robin worked for 20 years prior to her recent SSD status, and raised a son. She loves to make new friends. Robin keeps busy as a writer, RC and gardener. Feel free to call her anytime; day or night.
<b>MAR. '06</b>	<b>Heidi Forney</b> Meridian, ID (888) 610-3008 MST	Heidi is mom to 3 boys, the youngest (Sean) has SBS as well as pulmonary and orthopedic issues, and has been on TPN since 1997. He is tube fed as tolerated. Her mother-in-law lives with them and is tube fed due to cancer. Heidi is an RC and enjoys providing support to others living this different, but normal, lifestyle.
	<b>Davi &amp; Steve Cohen</b> Croton, MD (888) 650-3290 EST	Davi has been on TPN for over 20 years due to SBS resulting from a car accident. She has experience with port-a-caths in both subclavian and femoral sites. Davi and Steve have been active at Oley, NAVAN, and ASPEN meetings and can discuss medical, logistical, and emotional aspects of long-term IV therapy.

### LifelineLetter

**The Oley Foundation**  
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 Albany Medical Center, MC-28  
 Albany, NY 12208

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## Join Us!

### 2006 Oley Conference

June 28 — July 1  
 Salt Lake City, Utah