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LifelineLetter

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

HPN-Associated Metabolic Bone Disease

Cynthia Hamilton, MS, RD, CNSD

Patients receiving long-term parenteral nutrition (PN) are at risk for developing abnormal bone metabolism or metabolic bone disease (MBD), which can result in osteoporosis or osteomalacia. Patients with MBD may complain of back, bone or joint pain; loss of height; or atraumatic fractures. They also may be asymptomatic. The exact cause of MBD in long-term parenterally fed patients is unknown, although several contributing factors have been identified, including various components of the PN solution and disease states for which PN is prescribed. All patients receiving long-term PN (over 1 year) should be monitored and treated for MBD.

Definition

MBD is associated with various disorders of bone metabolism, the most common of which are osteoporosis and osteomalacia. Osteoporosis is characterized by a normal ratio of bone matrix to bone mineral content, but the total amount of bone is decreased. Osteoma-

lacia is characterized by inadequate calcification of bone matrix that leads to soft bones. Both forms of bone disease lead to increased risk of bone fracture.

Osteoporosis affects more than 20 million women in the United States, with 25 percent to 30 percent of women older than 65 years having symptomatic disease. Women are affected primarily, but men have one seventh of all vertebral fractures and one quarter of all hip fractures. The lesser incidence and prevalence in men are due to a greater peak bone mass, shorter life expectancy, and lack of menopause effect. Primary osteoporosis is further divided into postmenopausal, type I, or age-associated, type II (see Table 1 on page 2). Type I osteoporosis primarily occurs in women and is associated with estrogen deficiency. Although rare, type I osteoporosis also can occur in men due to decreased androgen production. Type II osteoporosis is the normal loss of

Bone Disease cont., pg. 2

Be All You Can Be!

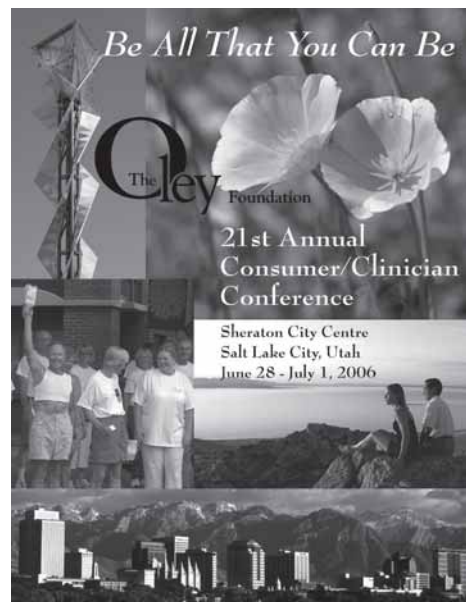
Join us in Salt Lake City for the 21st Annual Oley Conference!

Oley will be going west to the Rockies this year to Salt Lake City, UT for our 21st Annual Consumer/Clinician Conference. It will be held June 28th – July 1st at the Sheraton City Centre. Salt Lake City is a cosmopolitan city rich in history and has a multitude of interesting places to see and things to do.

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 to meet new people and old friends, and child care, all provided free of charge for consumers and their families.

The Sheraton City Centre is located at 150 W 500 South and complimentary transportation is available from the airport. Not far from the hotel you can visit museums, shop, experience fine dining, visit the 2002 Olympic venue or hear the Mormon Tabernacle Choir. Twenty minutes from downtown you can hike, mountain bike, bird watch, or play golf. Check out www.visitsaltlake.com to learn what Salt Lake City has to offer. You can also call the hotel at (801) 401-2000 to get more information about accommodations or visit their website at www.saltlakecitysheraton.com.

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



Bone Disease, from pg. 1

bone mass that occurs after age 25 to 35 years in both genders. The loss of height due to bone loss is approximately 1 cm per decade of life, but it is slower in men than women due to the postmenopausal effect.

A number of secondary factors contribute to MBD, including endocrine disorders, genetic disorders, malignancies, drugs, liver disease,

renal failure, inflammatory bowel disease, immobilization, and nutrition-related factors.

Osteomalacia is characterized by defective mineralization of bone matrix that results in a decline of bone strength. It causes pain and fracture in adults. In children, it affects the bone and cartilage growth plate, resulting in the deformities seen with rickets (bowed legs). The most common cause of osteomalacia is vitamin D deficiency, which may be the result of inadequate dietary intake, inadequate ultraviolet light exposure, fat malabsorption (as seen in short bowel syndrome), jejunoileal bypass, inflammatory bowel disease, liver disease, and renal disease. Certain drugs, including anticonvulsants, fluoride, aluminum, furosemide and etidronate, inhibit bone mineralization and may cause osteomalacia.

Bone Structure

Three types of cells continually interplay in the remodeling of bone. Osteoblasts promote bone formation, osteoclasts promote bone resorption or breakdown, and osteocytes are mature bone cells found within the bony matrix that transfer mineral from interior bone to growth surfaces. Bone also consists of two types of tissue: cortical and trabecular. Cortical bone represents about 80 percent of the total bone mass, is the outer layer

phosphate can alter the calcium/phosphate ratio, especially if calcium intakes are low, resulting in bone resorption.

Calcium Homeostasis

Approximately 99 percent of the body's calcium is found in the skeletal system, but the small percentage found in blood and extracellular fluids (1 percent) is critical to metabolic and cellular processes. The body maintains blood calcium at a narrow concentration (approximately 8.5 to 10 mg/dL), deriving calcium from the diet and bone fluids and tissue. A negative feedback system involving two antagonistic hormones, calcitonin and parathyroid (PTH), maintains the concentration of calcium in the blood which, in turn, affects the release or retention of calcium in bone. An increase in blood calcium levels induces the thyroid gland to secrete calcitonin, which stimulates calcium deposition in the bones, reduces calcium uptake in the gastrointestinal tract, and increases calcium losses via the kidneys. If blood calcium concentrations are low, PTH is secreted by the parathyroid glands to stimulate calcium release from the bones, increase calcium uptake in the gastrointestinal tract, and increase calcium uptake from the kidneys.

Bone Disease cont., pg. 9

LifelineLetter

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

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

Table 1. Categories of Osteoporosis

Primary

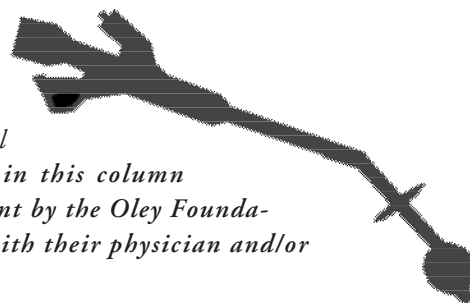
- Type I: Postmenopausal (estrogen deficiency, decreased androgen production in men)
- Type II: Age-associated (normal aging process)

Secondary

- Endocrine (Cushing's disease, pituitary tumor, diabetes mellitus, primary hyperparathyroidism)
- Malignancy (multiple myeloma, leukemia, lymphoma, disseminated carcinomatosis, chemotherapy)
- Drugs (ethanol, heparin, steroids, cigarettes, cyclosporine, methotrexate)
- Immobilization
- Liver disease (primary biliary cirrhosis)
- Renal failure (active form of vitamin D not metabolized)
- Genetic disorders (osteogenesis imperfecta, Ehlers-Danlos syndrome, Marfan syndrome, homocystinuria)
- Inflammatory bowel disease (Crohn's disease, ulcerative colitis, short bowel syndrome)
- Nutrition (inadequate calcium, vitamin D, long-term parenteral nutrition)

Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail 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.



Tube-fed Growing Baby

Our 13-month old son Thomas had heart surgery and now has a severe oral aversion. He has a feeding tube while he is learning to eat by mouth again. Our problem is that Thomas is getting more active and sitting up in bed, etc. We have the tube from the extension taped and tucked under a roll of blanket with just enough room to roll a little bit from one side to the other. How do most parents deal with the extension and tubing in bed? Tape it to the child's leg? Put in his/her pajamas?

— Kevin & Sherrie Fischer
KSTFischer@gmail.com

Our first recommendation would be to contact one or more of the following Regional Coordinators. They have children and should be able to talk to you about their experiences.

- Donna or Richard Noble, parents of 7 y.o. Kyle on TPN and tube feeding; (614) 871-8464, donnanoble2001@yahoo.com
- Ann Weaver, mom of 10 y.o. Tim on tube feeding, was on TPN; (630) 335-2613 amweaver@wowway.com
- Patty Woods, mom of Colin, on both TPN and tube feeding; (951) 766-5145; The7woods@adelphia.net

We also have information at the Oley Foundation about some specialized clothing, belts, straps or clamps that might be helpful. Call Cathy at the Oley Office for further information.

Odor Problem

I recently had a new J-tube placed. It is the kind that is just popped into the opening and held in place by a balloon. It is working just fine for me, but unfortunately it puts off a terrible odor.

Do you have any suggestions as to what I could do to reduce this horrible smell? Some days it seems to be worse than others, not sure why. Maybe it's just that I'm more distracted and just don't notice the scent.

— Sue McKallor
(410) 721-3075 or smc@riva.net

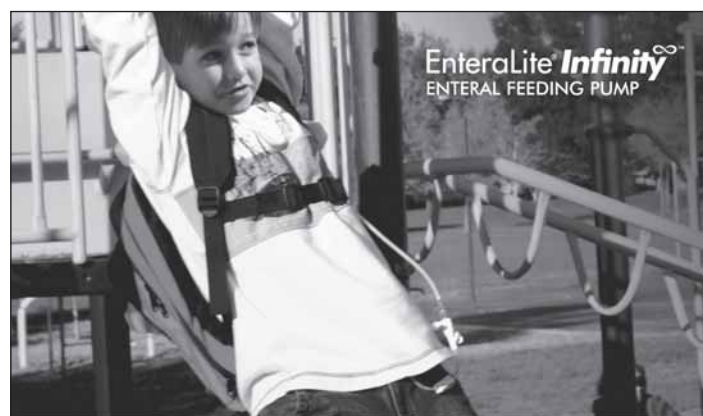
Oley's Medical and Research Director thought the odor is likely stemming from residual formula and/or medications stuck to the inside wall of her tube. We recommend cleaning the residuals out of the tube by squeezing it between two fingers and running them along the length of the tube from the site to the end; disposing of the gunk that comes out, then flushing with water. A similar technique is to place the tube on a table and run a flat, blunt object along the tube to squeeze out the residuals.

Oops!

Our apologies for a typographical error in the September/October "TubeTalk." Diane Owens is of Irish *descent*, in addition to being a *decent* (really great) person.

Tube Feeding Workshop

A series of workshops designed to teach professionals and parents about the medical and social aspects of tube feeding will be held in several cities in 2006: March 17-18 in Mesa, AZ; May 6-7 in Durham, NC; July 28-29 in Albany, NY; September 7-8 in the Detroit, MI area; and October 6-7 in Salt Lake City, UT. Entitled "Tube Feeding with Love," the workshops feature Marsha Dunn Klein, MEd, OTR/L, a pediatric occupational therapist who specializes in feeding infants and young children. Workshop attendance costs \$350 for professionals and \$200 family members. CEUs are available for occupational therapists and dietitians. For more information visit www.mealtimemotions.com or call (520) 323-3348.



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Recreation Event for Families

Looking for a unique opportunity for your tube fed or TPN dependent child to experience typical camp activities in a safe environment? Join us for the 1st Annual M³ Day Camp!

Columbus, Ohio based Mighty Medical Miracles(M³) is organizing a FREE day camp to be held Saturday October 14, 2006 from 11 a.m. to 8 p.m. The event will be held at Recreation Unlimited, a fully accessible campground in Ashley, Ohio. There will be planned activities for children of all abilities, their siblings and parents. Families will enjoy breakout sessions consisting of crafts, Olympic games and nature activities such as tree climbing, fishing, hiking and more. The day will close with a bonfire. Two meals and snacks will be provided.

Please join us for this one-of-a-kind, fun-filled, all inclusive Day Camp. Limited spaces are available. For more information and to register please visit <http://mightymedicalmiracles.com> or call Donna Noble at (614) 871-8464.

Equipment Exchange

The following supplies/equipment are offered free of charge:

Enteral Formula:

- 27 bags Neocate, exp. 12/06
- 4 cases Jevity 1.5, exp. 7/06
- 5 boxes Neocate powder, expiration unknown
- 9+ cases Comply, exp. 2/06
- 4 cases Isosource HN, 2 exp. 1/06, 2 exp. 3/06
- 5 cases Jevity, exp. 11/06
- 9.5 cases Probalance, expiration unknown
- 6 cases Probalance, expiration unknown
- 5 cases Ultracal w/fiber, exp. 1/07
- 2 cases Jevity, exp. 8/06

EN Pump

- 1 Novartis Compact Enteral Pump

Tubes/Bags

- 20+ Abbott Aim/Aim Plus Pump Kits
- 20 Kangaroo 1000ml bags
- 25 Kangaroo 1000ml bags

Miscellaneous

- 20 – 60 cc syringes
- 10 BD 10ml syringes
- 4 bottles of Benefiber

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, or contact Liz Tucker at evtucker@charter.net or toll free at (866) 454-7351. 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.

Lifeline Mailbox

Dear Lifeline Editor,

Thank you for the chart of Lowest Cost Mail Order Ostomy Supplies printed in the last newsletter. I researched the websites and came up with the following information. I could not reach Northwind Medical.

— Dr. Robert Flute Snyder
Hudson, WI

Lowest Cost Mail Order Ostomy Supplies

Dealer Name	Ph # / Website	Shipping
Express Medical	(800) 633-2139 www.exmed.net	\$6 for orders less than \$95
Parthenon	(800) 453-8898 www.parthenoninc.com	\$4 for orders less than \$150
Medical Care Products	(800) 741-0110 www.ostomymcp.com	\$5 for orders less than \$100
Nat'l Healthcare Warehouse	(800) 847-5715 www.medicalbymail.com	\$5.50 for orders less than \$50
Bruce Medical	(800) 225-8446 www.brucemedical.com	\$6.75 – 13.95

In Memory of Shirley Heller

Last fall Shirley Heller, a member of the Oley community from Southern California, passed away. Shirley was on TPN for several years due to digestive complications from scleroderma. Shirley found the Oley Foundation through her friend and mentor Suzanne Keating, and attended conferences when she was able. Warm and personable, Shirley made friends easily and was very helpful to many Oley members. She gave advice on how to cope when you can no longer eat (including tips on the few foods she found she could “cheat” with) and living with a degenerative disease. Her hobbies included going to museums,



Shirley Heller

working out at the gym, shopping, and playing board games. Her favorite charities included the Oley Foundation, The Amanda Foundation (places pets for adoption), and her temple. Shirley worked as a secretary for many years before her illness worsened. Later her passion for pets led her to be a pet sitter. Shirley also helped fellow consumer, Todd Friedman, with his newsletter the Sweet TPN Times. Shirley will be missed for her many contributions and her charming personality.

Spotlight on Sharon Rose

Robin Lang

Bravery doesn't always take guts! When you think about pioneers, what images come to mind? The pilgrims heading west, astronauts going "where no man has gone before," Louis Pasteur or Madam Curie. When you think about the modern day pioneers names such as Doctors Shils, Bozian, Jeejeebhoy and the like come to mind. Their research led to the invention of home parenteral nutrition.

As inventive as they were, nothing could have been achieved if there hadn't been brave patients willing to try this new therapy. Think about the courage it took to try something so new and unproven. The lucky ones not only survived, but thrived.

One such woman is Sharon Rose from Nashville, Tennessee. She has been on TPN for 35 years but doesn't think of herself as a brave pioneer.

In the Beginning

Sharon's intestines were removed because of a blood clot to an artery supplying blood to her gut. She endured primitive methods of TPN delivery, stints, "cut downs" and long hospitalizations. "During those hard, early years...I survived because of one man, my doctor, Rich-

ard Bozian," she explained. "He was a maverick and we learned together. He fought the medical board to allow me to go home."

After two years in the hospital, Sharon had had enough. She felt she had learned all she needed to know about her care. She juggled glass bottles, needles, syringes, ampoules and additives every night for years prior to the advent of pre-mixed solutions. Thirty years ago there were no flexible catheters, specialized pumps or plastic TPN bags. As the medical professionals worked to perfect this new therapy, Sharon endured numerous trials, procedures and errors along the way. Sharon and the other original patients were the pioneers helping to determine the improvements that were necessary for the safe administration and maintenance of TPN.

Life Goes On

Sharon goes about her life in a quiet, humble manner. Asked her recipe for success; she says, "Don't live your illness. It's all in your outlook; you have to have a positive mindset."

The biggest joy in her life came nineteen years ago when, while managing her home, a job and being on TPN, she gave birth to twin

boys, Adam and Brent. While working full-time as a nurse in the critical care and hemodialysis unit for many years has been difficult, Sharon says it gives her a great deal of satisfaction knowing she is helping others. She also enjoys sewing and gardening. Her strength, endurance and time management skills are impressive. She also credits support from her husband, George, and her children for the good life she has today.

Being a rather private person, Sharon was apprehensive about giving this interview, and is embarrassed to be considered an inspiration, but if it helps someone else she is happy to share her experience. She wants everyone to know that a long life on TPN is possible, and that the ups outweigh the downs.

Sharon is hoping to join us at Oley's 2006 conference in Salt Lake City. Keep an eye out so you can meet this delightful woman.



Sharon Rose, RN

Nutrishare is a Home TPN Specialist Pharmacy



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- TO IMPROVING THE QUALITY OF LIFE OF OUR CONSUMERS AND THEIR FAMILIES
- TO IMPROVE THE CLINICAL OUTCOMES FOR OUR HOME TPN CONSUMERS
- NUTRISHARE CONSUMERS CAN CHOOSE THE PUMPS AND SUPPLIES THEY PREFER

Empowerment

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Norma Blank

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1-800 Home TPN

HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight the institutions around the country that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any physician or medical institution but brings this to our consumers strictly as an informational tool.

Mayo Clinic – Rochester, MN

The home parenteral nutrition (HPN) program at the Mayo Clinic was started in 1972 when the first patient was sent home on PN by Richard Fleming, MD, a gastroenterologist. A second patient was discharged in 1975 and in 1976 four more patients were added to the program. At the present time, Darlene Kelly, MD, PhD is the gastroenterologist and nutritionist overseeing the program in Rochester, MN. Other members of this specialized team include a gastroenterologist who takes over when Dr. Kelly is out of town; and a Nurse Coordinator, who is the link between Dr. Kelly and the patients. There is also a pharmacist, a social worker, a dietitian and the nurse educators who train new patients. Mayo has vascular radiologists and surgeons who specialize in catheter placement and problems, and, last but certainly not least, a secretary. This team of people works with each person from the time they are first diagnosed as needing long term PN.

The program in Minnesota has an average of 85 to 90 consumers at any one time, and Dr. Kelly has calculated that the team has worked with consumers who have a total of 1,480 years of catheter experience.

When asked what the benefits would be of a center of experience, Dr. Kelly felt the following was true. "This is a team of people who have an express interest in HPN and continue to be educated in this area. They network with other centers nationally and internationally and work to keep themselves at the cutting edge of the therapy. They work to be available to their consumers. They act as a resource to other physicians in the field."

Pediatric Meeting in Pittsburgh

Come learn more about short bowel syndrome and help spread the word about the Oley Foundation at the Fourth International Pediatric Intestinal Failure and Rehabilitation Symposium, June 1-3, 2006 at the Sheraton Station Square Hotel in Pittsburgh, PA. The conference is designed for parents and clinicians who care for children with short bowel syndrome (SBS) or small bowel intestinal transplants, and will focus on new developments regarding SBS etiology, pathophysiology, surgical and nonsurgical therapies, and research.

Thursday's session (June 1) is specially designed with the family in mind, to enhance the parent/caretaker's understanding of intestinal function. Parents/caretakers are also invited to stay for the general session for an additional fee, although they are reminded of the graphic and intense nature of the scientific portion.

For more information about the conference, contact Maureen Hewko (412/647-8261; ccehs@upmc.edu); or Jane Anne Yaworski, MSN, RN (412/692-5217; janeanne.yaworski@chp.edu).

For more information about staffing the booth contact Joan Bishop (800/776-OLEY; BishopJ@mail.amc.edu).

Scholarships for HPN Consumers

Nutrishare, Inc is sponsoring two \$500 scholarships for TPN consumers towards the Spring 2006 semester. Interested TPN consumers should write a few paragraphs describing their studies and what they plan to use their education for. Applications should be submitted to the Oley Scholarship Committee who will choose the winners based on potential and need.



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

The application materials should be mailed to Joan Bishop at the Oley Foundation: bishopj@mail.amc.edu or 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208 and **post-marked by April 14, 2006**. The scholarship money will be distributed at the end of the spring semester when the winner submits a copy of his/her grades to the Oley Foundation.

Interesting Web Links:

Have you ever struggled when trying to tell a friend or relative about TPN? The National Home Infusion Association website may be the answer. Go to the "Frequently Asked Questions" section (www.nhianet.org/faqs.htm) and find short answers to: "What is infusion therapy?" "Who provides infusion therapy?" and "Does Medicare cover home infusion therapy?" Their web site also allows you to find out about the NHIA, search for a job in home infusion and look for patient resources.

Do you have questions about Medicare or the new Medicare prescription drug coverage? The site for you is www.medicare.gov, where a tremendous amount information about the prescription drug plan can be accessed. Unfortunately, even with information from this web site, there is a great deal of confusion about this benefit that probably isn't going to be cleared up soon. Other information that can be accessed from the home page include Medicare billing and appeals, preventive services, long-term care, enrollment, plan choices, etc.

Auction Items Needed

It's not too early to be planning for this year's Silent Auction. Your participation can make or break this fun fundraiser held at the annual Oley conference. Proceeds help support Oley programs like the *LifelineLetter* and conferences, so the more funds we raise, the better!

Big hit items have traditionally been electronic equipment (boom box, games, karaoke, etc.), hand-made quilts, airfare, hotel accommodations, and jewelry. Smaller ticket items like clothing, games and toys are fine too. Contact Joan Bishop (bishopj@mail.amc.edu; 800-776-OLEY) for ideas or more information. We appreciate your support!!



Recognize the Quiet Hero in Your Life!

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 Salt Lake City this summer? Or extra money for an educational program in their region?

Ring your own bell!

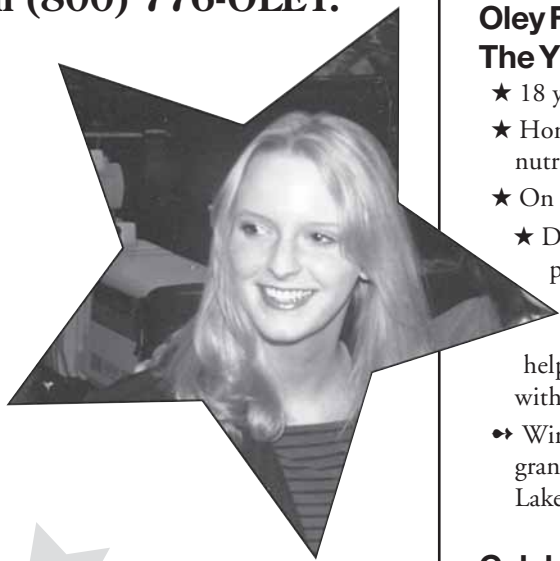
Nominate yourself. If your story is one of inspiration, tell us your tale on this simple nomination form. We want to hear from you!

It's FREE and easy!

A simple form (on back side) with three, quick questions is all you need to complete. Technophiles can find it on our website: www.oley.org or request a form from Cathy Harrington at harrinc@mail.amc.edu. Just type in your answers — fax it, mail it or click "submit" — and you're done. Send as many forms as you like.

Questions?

Call (800) 776-OLEY.



**Nominations must
be submitted by
April 27, 2006**

Award Criteria

The awards will be given June 29 at the 2006 Oley Conference in Salt Lake City, Utah. Nominations will be reviewed by a committee comprised of previous award winners, trustees and consumers. Oley awardees receive a keepsake, are honored at the 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

*In honor of Nutrishare Inc.,
Oley Platinum Partner*

- ★ 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 partial travel grant to the Oley Conference in Salt Lake City, UT, June 28 to July 1

Oley Foundation Child of The Year Award

- ★ 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 partial travel grant to the Oley Conference in Salt Lake City, UT, 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 3 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 partial travel grant to the Oley Conference in Salt Lake City, UT, June 28 to July 1

Lenore Heaphey Award for Grassroots Education

- ★ Oley Foundation Regional Coordinator
- ★ Organized an outstanding information and/or education program during 2005
- 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

- ★ 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 be honored at the Oley Conference in Salt Lake City, UT, June 28 to July 1

Oley Foundation Award Nomination Form

Deadline for Nominations: April 27, 2006

The Oley Foundation • 214 Hun Memorial, MC-28 • Albany Medical Center
Albany, NY 12208 • Fax: (518) 262-5528 • email: harrinc@mail.amc.edu



1 Select the award, identify the nominee.

I am pleased to nominate the following individual for the 2006
(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. Attach **one** additional page if needed. Be sure to type or print legibly using dark ink, since this form will be photocopied. Feel free to submit more than one nomination.

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Bone Disease, from pg. 2

Vitamin D plays an important roll in calcium homeostasis. Vitamin D ingested from the diet or derived from the skin via sunlight activation is metabolized in the liver to 25-hydroxyvitamin D and then in the kidney to its active for, 1,25-dihydroxyvitamin D which, in turn, enhances calcium absorption in the intestines.

Diagnosing MBD

MBD is diagnosed by the radiologic presence of fracture (atraumatic) or by measurement of bone mineral density. Low bone mineral density is an important determinant of susceptibility to osteoporotic fractures. The most common method used to measure bone mineral density is dual energy x-ray absorptiometry (DXA). This technique has low radiation exposure (less than chest radiography), has a short examination time (20 min), is highly accurate (1 percent to 2 percent reproducibility), and relatively low cost. DXA measures bone density of the lumbar spine, femoral neck, and radius. The bone density of an individual is compared with a control group comprised of gender-matched young adults, and deviation from this value is expressed in standard deviations (SD) above or below the mean as a T-score. The T-score is a classification of osteoporosis fracture risk. The World Health Organization has defined a T-score of -1 SD or above as normal, a T-score between -1 and -2.5 as representative of osteopenia (the precursor state to the more serious osteoporosis), and a T-score at or below -2.5 SD as osteoporosis.

Biochemical tests can also be used to help detect MBD and include blood and urine studies. Blood tests that document decreased amounts of serum calcium, phosphorus, 25-hydroxyvitamin D and osteocalcin (a marker of bone growth) or increased amounts of alkaline phosphatase and PTH may be indicative MBD. Urine tests documenting decreased amounts of calcium and magnesium or increased amounts of n-telopeptide (a collagen marker reflective of bone resorption) can also be predictive of MBD.

Parenteral Nutrition-Associated MBD

MBD associated with long-term PN initially was described in the early 1980's. Among 38 patients who were receiving home total parenteral nutrition (TPN) for more than 3 months, 11 had severe debilitating bone pain and hypercalcuria, and 7 iliac crest bone biopsies documented patchy osteomalacia in patients who had pain. Another early report documented increased bone turnover without calcification (by bone biopsy) within 1 to 4 months of starting PN among 12 of 16 patients, with progression to osteomalacia within 12 to 16 months. Seven of the 16 patients had hypercalcemia, and 10 patients had hypercalcuria. Vitamin D was removed from the PN solution, despite the presence of normal serum levels in the patients, and resulted in decreased urinary calcium excretion and normalization of serum calcium concentrations.

Vitamin D

A number of studies were undertaken after an early report of improvement of MBD when vitamin D was removed from PN solutions, with conflicting results. One study found that early on patients showed improved bone histology when vitamin D was removed from their solutions; but abnormal bone histology was evident at a 6-month follow-up. In a study by Verhage and col-

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leagues, they found that there was improved bone mineral content of the lumber spine among long-term PN patients in which vitamin D was removed for an average of 4.5 years.

Current usual practice is not to remove vitamin D from PN formulas because bone disease is known to be associated with chronic vitamin D deficiency. The recommended parenteral dose of the vitamin is 200 IU/d for adults.

Aluminum

Initial investigations of MBD in long-term PN patients also examined the role of aluminum (Al). Early PN solutions contained protein as casein hydrolysates, which contained significant amounts of Al; 3,400 mcg/3 L of PN versus 33 mcg/3 L of PN solution made with free amino acids. In several studies, patients who received casein hydrolysate solutions had significantly detectable amounts of Al in plasma, urine, and bone compared with patients receiving free amino acid solutions. Discontinuation of the casein hydrolysate solution resulted in reduction of bone pain, reduction of hypercalcuria, improved bone formation, and normal serum concentrations of 1,25-dihydroxyvitamin D.

Casein hydrolysates have not been used in PN solutions for many years, virtually eliminating Al toxicity as a risk factor for the development of MBD. While there may be small amounts of Al in other additive to PN, the amount can vary among manufacturers, the United States Food and Drug Administration made new rules to attempt to regulate the amount of Al in PN solution. Effective July 26, 2004, all large volume parenterals, such as dextrose, saline solutions and crystalline amino acids must contain no more than 25 mcg/L of Al. In addition, small volume additive, including calcium gluconate, phosphate salts, and vitamin and mineral solutions, must have the Al content note on their labels.

Incidence of MBD

The incidence of MBD in long-term PN patients is unknown. One review of several studies reported a 42 percent to 100 percent prevalence of MBD. A recent study documented a prevalence of 84 percent among patients receiving PN for more than 6 months. Although the exact cause of MBD in parenterally fed patients is not known, several factors may contribute to altered bone metabolism, including inadequate provision of calcium and phosphorus, excess amounts of protein and vitamin D, cyclic infusion, and metabolic acidosis.

Conditions for which patients are placed on PN include disorders that may contribute to MBD, such as severe malnutrition, Crohn's disease with malabsorption of calcium and vitamin D, and short bowel syndrome. Cancer may contribute to MBD through decreased intake of calcium and vitamin D from the diet or from surgery and chemotherapy.

The use of glucocorticoids for inflammatory bowel disease can be a major contributor to MBD. Glucocorticoids suppress osteoblast activity, inhibit vitamin D and calcium absorption in the gastrointestinal tract, and increase the activity of osteoblasts that leads to suppressed bone formation. Abitbol and associates evaluated bone disease in 84 patients with Crohn's disease and ulcerative colitis. Patients had no complaints of bone pain and exhibited normal serum levels of calcium, phosphorus, and vitamin D. However, bone mineral density by DXA

showed osteopenia among 43 percent of the patients, 52 percent of whom were receiving glucocorticoid therapy and 7 percent of whom had vertebral fractures. A statistically significant correlation with age and cumulative glucocorticoid doses was also observed. Other medications used to treat inflammatory disorders that can contribute to MBD include methotrexate, cyclosporine, and tacrolimus.

Calcium and Phosphorus

The single most important contributor to bone disease is a negative calcium balance, characterized by decreased intake and increased urinary calcium losses. The kidney filters 10,000 mg of non-protein-bound calcium each day, with greater than 98 percent reabsorbed by the renal tubules. The normal daily excretion of urinary calcium is 100 to 300 mg. Phosphate, also a major component of bone formation, is filtered by the kidneys. Approximately 7,000 mg of phosphate are filtered by the kidneys daily, and 87 percent is reabsorbed by the renal tubules.

Inadequate provision of calcium and phosphorus in PN can lead to nutrition-related MBD. Many of the early studies suggested that hypercalcuria may be the result of abnormal renal tubular function or disruption of PTH regulation, and adaptation appeared to occur with time, resulting in calcium conservation.

Hypercalcuria generally parallels urinary phosphate excretion. Adequate amounts of both calcium and phosphorus are necessary to promote maximal retention of calcium and phosphorus.

Recommended amounts of daily electrolytes for normal organ function have been suggested by the American Society for Parenteral and Enteral Nutrition, but electrolytes need to be individualized to the patient based on disease state and excess losses. Increasing the amount of phosphate and calcium in the parenteral nutrition formula can be a challenge and must be done cautiously. Excess amounts of phosphate and calcium can form a precipitate that makes TPN unsafe for administration.

Protein

High amino acid concentrations in PN have been shown to cause hypercalcuria. Patients receiving PN often require high doses of amino acids, especially at the initiation of therapy, to promote surgical wound healing and to replace losses, but protein doses should be reduced as serum protein concentrations normalize. Additional calcium should be added to the TPN while the amino acid provision remains high.

Metabolic Acidosis

Metabolic acidosis in patients receiving long-term PN may contribute to MBD. Patients with renal insufficiency and renal failure and those with chronic diarrhea and malabsorption due to short bowel syndrome frequently experience chronic acidosis.

Patients who develop metabolic acidosis require substantial amounts of acetate in their PN to prevent mobilization of calcium carbonate stores from bone to buffer the acid load.

Treatment of MBD

Because of the many factors contributing to the development of MBD in long-term PN patients, treatment can be challenging. Adequate amounts of calcium, vitamin D, magnesium, and phosphorus in the PN solution are the foremost considerations. Supplemental doses may be indicated for severely depleted patients. Underlying conditions or diseases such as those that involve inflammatory responses should be treated because the release of cytokines in stress promotes bone resorption. Glucocorticoids or medications that worsen calcium wasting should be eliminated or reduced substantially.

Exercise is one component of treatment for osteoporosis. Although its effects have not been studied in patients receiving long-term PN therapy, one investigation documented that a low-impact exercise routine for Crohn's patients increased bone mineral density.

Exercise is one component of treatment for osteoporosis. Although its effects have not been studied in patients receiving long-term PN therapy, one investigation documented that a low-impact exercise routine for Crohn's patients increased bone mineral density.

Routine assessment and monitoring for MBD should be a standard of care for patients receiving PN for more than one year.

Pharmacologic Treatments for Osteoporosis

A variety of pharmacologic agents may be helpful for patients who have PN-associated MBD. Treatment options for osteoporosis include vitamin D and calcium supplements, hormone replacement therapy (estrogen for women, testosterone for men), selective estrogen

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Table 2. Suggested Guidelines for Monitoring and Managing PN-associated MBD

1. Evaluate all patients receiving long-term PN (>1 yr) for MBD
2. Monitor for physical signs of MBD: lost of height, bone or back pain.
3. Provide adequate amounts of minerals in the PN solution for bone remodeling, including calcium (-15 mEq), phosphorus (-15 mmol), and magnesium (adjust amount per serum and urine levels).
4. Reduce higher protein doses to 1 g/kg/d once nutritional status is improved and proteins are repleted.
5. Treat metabolic acidosis with adequate amounts of acetate in the PN solution to avoid calcium carbonate mobilization from bone to buffer excess acid.
6. Monitor blood studies (at least monthly) to evaluate calcium, phosphorus, magnesium, and acetate levels. Maintain normal serum levels by adjusting amounts in the PN solution. Specific markers of bone metabolism may be of further diagnostic help.
7. Obtain 24-hour urine collection for calcium and magnesium every 6 to 12 months. Adjust PN to maintain positive balances.
8. Obtain DXA measurement and refer patient to endocrinologist for evaluation and pharmacologic treatment if there is low bone mineral density (T-score below -1). Repeat DXA every 1 to 2 years.
9. Minimize steroid use and all medications known to cause bone resorption.
10. Promote exercise or refer to physical therapist.
11. Encourage cessation of smoking.

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receptor modulators, antiresorptive drugs such as bisphosphonates, calcitonin, and bone-forming drugs.

The most widely used pharmacologic treatment for osteoporosis is the drug class of bisphosphonates (e.g. etidronate, alendronate, risedronate), which inhibit osteoclastic activity and decrease bone resorption. However, these medications can have undesirable gastrointestinal adverse effects and may not be well absorbed in patients with malabsorption or short bowel syndrome. Some of the bisphosphonates are available as weekly doses or in intravenous form. Calcitonin is available as a nasal spray.

To date, only one study has been performed in long-term PN patients using pharmacologic treatment. In a prospective, double-blind, randomized, controlled trial, Haderslev and colleagues compared the effects of clodronate, a bisphosphonate (available in Europe), with those of placebo in patients receiving long-term PN (>1 year) who had evidence of abnormal bone mineral density (DXA T-score, <-1). Biochemical markers of bone resorption were statistically lower in the bisphosphonate group, and there was a significant increase in bone mineral density in the forearm. Bone mineral density was also increased in the spine and hip, but not significantly.

The bone-forming drug recently approved by the FDA for treatment of osteoporosis is teriparatide (Forteo-Eli Lilly, Indianapolis, Ind.) recombinant human parathyroid hormone. This drug increases osteoblast activity and has been shown to increase bone mineral content significantly and reduce the risk of fracture in patients with osteoporosis. Teriparatide has been shown to increase bone mineral content significantly in postmenopausal women, men with idiopathic osteoporosis, and patients with glucocorticoid-induced osteoporosis. It may be effective treatment for long-term PN patients with MBD, and clinical trials in this population are indicated.

Guidelines for Monitoring and Managing PN-Associated MBD

Several clinical studies have identified the prevalence of MBD and the contributing factors in long-term PN patients. Routine assessment and monitoring for MBD should be a standard of care for patients receiving long-term PN (>1 yr). Suggested guidelines for monitoring and managing these patients are listed on Table 2 (see page 9).

Routine blood and urine studies can aid in detecting MBD and evaluating the adequacy of minerals supplied in the PN solution, which are critical for bone remodeling. Protein concentration in PN may need to be adjusted and adequate amounts of acetate included to prevent mobilization of calcium carbonate from the bones. DXA should be used to assess bone mineral density, with referral to an endocrinologist, if necessary, for appropriate pharmacologic treatment.

Bone resorption medications should be minimized. Patients can be encouraged to incorporate exercise and cease smoking.

Conclusion

Patients receiving long-term PN are at risk of developing MBD, which can lead to severe bone pain, fracture, loss of height, and debilitation. The cause of MBD in patients receiving PN is not known, but several factors have been identified that contribute to its development. Clinicians who manage long-term PN patients should establish a standard of care for routine assessment and monitoring for MBD. PN solutions should be adjusted for adequate amounts of calcium, phosphorus, magnesium, and acetate, and protein should be limited after

normalization of serum protein concentrations. Routine laboratory evaluation and 24-hour urine measurements of calcium and magnesium can help determine the adequacy of minerals supplied in the PN. DXA, which provides a definitive measure of bone mineral density and risk of fracture, should be obtained every 1 to 2 years. Patients with low bone mineral density should be referred to the endocrinologist for specific treatment. Pharmacologic agents, including bisphosphonates and bone-forming agents, have not been well studied in long-term PN patients, and clinical trials are indicated.

This article was adapted with permission from Support Line, a publication of Dietitians in Nutrition Support Dietetic Practice Group. For a copy of the complete article or references you may contact Jenifer Lefton, Support Line Editor at Jcannon390@aol.com.

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Rod Okamoto and Tom Diamantidis attended their first Oley Conference in 1991, the same year that Nutrishare was founded. The company's cornerstone principles of respecting the consumer's right to choose the pumps and products they use and the company's focus on improving the everyday lives of homeTPN consumers were forged during that remarkable conference in Saratoga Springs that summer. Nutrishare has focused exclusively on homeTPN pharmacy care to consumers located throughout the U.S.

The entire Nutrishare family (consumers, caregivers and employees) "share" in the honor of pioneering Oley's new Platinum Level of Corporate support as a tribute to the Oley Foundation's mission.

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Abbott's Ross Products Division is a longtime leader in the U.S. nutritional marketplace, and strives "to be the worldwide leader in providing superior nutritional products that advance the quality of life for people of all ages." Ross Products manufactures and distributes medical nutritional products such as PediaSure®, and Jevity®, and enteral feeding devices, such as the Embrace® ambulatory feeding pumps for patients who require nutritional support. PediaSure® Enteral Formula is designed to provide a source of Complete, Balanced Nutrition® for children ages 1-13 who may be undernourished due to illness or inability to eat. Jevity® is an isotonic, fiber-fortified tube-feeding product, and the Embrace® ambulatory feeding pump is a small, lightweight enteral pump with optional travel accessories for mobile patients. These are only a few examples of the Ross Product family serving your family from infancy through advanced age.

Ross Products supports the Oley Foundation so that they may continue to enhance the lives of home nutrition support patients, their families, and caregivers.

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Hospira is a global specialty pharmaceutical and medication delivery company dedicated to Advancing Wellness™ by developing, manufacturing and marketing products that help improve productivity, safety and efficacy of patient care. With 70 years of service to the hospital industry, Hospira's portfolio includes generic acute-care injectables, integrated medication management and infusion therapy solutions, and injectable contract manufacturing.

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.

MAR. '06	Heidi Forney 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.
	Davi & Steve Cohen 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.
APR. '06	Ann Weaver Naperville, IL (888) 610-3008 CST	Ann is married and has two sons, ages 18 and 11, the younger of which has SBS due to Hirschsprungs Disease. He has been on HEN since birth and has an ostomy. She has cared for a central line, NG tube, G tube and ostomy. She looks forward to talking to other parents.
	Ben Hawkins Cincinnati, OH (888) 650-3290 EST	Ben Hawkins, 44, has been on TPN since 1980, when he lost over 90% of his small intestine due to a malrotation. He has experience with midline catheters, port-a-caths, and Hickman catheters, and has used a variety of different pumps. He also went through the process of going onto Social Security Disability in 1999.
MAY '06	Rose & Alicia Hoelle Gibbstown, NJ (888) 610-3008 EST	Alicia (21 y.o.) has been on HPN since birth due to hypoganglionis/NID, and was recently diagnosed with Crohn's disease too. She is attending college to become a child life specialist. Her mother, Rose, is an LPN and experienced caregiver with a great sense of humor. They'd love to discuss advocacy, school accommodation, transitioning issues and dealing with long term HPN with kids, teens or parents..
	Laura Keser Stillwater, OK (888) 650-3290 CST	Laura has been on HPN since 1991 due to short bowel syndrome. She has experience with multiple catheters, dealing with infections and traveling. She has also returned to college at Oklahoma State and will graduate in the spring 2006. She looks forward to sharing her experiences with you.

LifelineLetter

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