Living with Osteoporosis: A Feature Profile
The Osteoporosis Support Group of Greater Omaha & Nebraska

Ever wonder how other people live with osteoporosis? At the Osteoporosis Support Group, men and women of all ages meet to discuss and learn about ways to manage their osteoporosis. The good news is that there is lots that can be done and more is being learned every day, thanks to the generosity of research subjects such as those in our studies.

The support group was formed in August of 1999 in response to community interest. A generous soul, Virginia Bull, agreed to serve as organizer, with the Osteoporosis Research Center and its staff as resource. The group meets every other month (even numbered) on the second Tuesday of the month here at the Osteoporosis Research Center in our conference room on the 5th floor of St. Joseph's Hospital (room # 5766) at 1 p.m.

Though the group meets at Creighton, it is an independent group affiliated with the National Osteoporosis Foundation. Members come from all over and often car pool to be energy efficient and to help those unable to drive. Though the Osteoporosis Research Center serves as a resource for speakers and location, the group is run by the members who really are the experts in coping and living with osteoporosis. Through discussion and keeping informed all learn about helpful and effective methods to prevent and manage pain, bone loss, and fractures.

Dorothy Norton is co-chair with Virginia and sends out reminder cards to members with notice of the planned speaker or topic for next meeting; she advertises in local papers and public service announcements, and distributes fliers to local clinics and doctors offices. Members take turns bringing a small treat, and the unit provides coffee or tea.

The primary goal of the group is educational: to keep up to date on the latest information on osteoporosis and methods to manage and prevent further loss, pain, or fractures. But there is much sharing and encouragement that helps to improve the quality of living with osteoporosis. The support group helps to deal with the physical and emotional issues that can accompany a diagnosis of osteoporosis. Topics have included exercise, nutrition, new medications and treatments, coping mechanisms and relaxation techniques for pain management, among others. If you are interested, call Virginia at 393-8996, or Dorothy at 493-2493 or luv2bsewing@home.com.
Hip Is as Hip Does

Well, it's football season for all you Husker fans or variants thereof. Our favorite gear at the Osteoporosis Research Center is the hip protector, as you might guess. As we have mentioned in previous issues, this new product has been shown to reduce the risk of hip fractures dramatically, so we are their number one fans, (and no, we don't get a kick-back!) Nonetheless, we are running into a lot of resistance from patients reluctant to wear them. Perhaps this will help you tackle the issue:

FAQ's...

Why should I wear hip protectors?

• More than 350,000 hip fractures are estimated to occur annually in the United States and are estimated to reach 650,000 by 2050
• Hip fractures are costly and painful! (an average cost of $37,000 per patient)
• Only 25-30% of hip fracture patients will make a full recovery; 24-40% will require nursing home care; 50% will need a cane or walker for the rest of their lives; and 20-24% over age 50 will die within 12 months
• A woman's risk of hip fracture is equal to her combined risk of breast, uterine and ovarian cancer. One in eight men over age of 50 will have an osteoporosis-related fracture and this risk is greater than his risk of prostate cancer.
• The rate of hip fractures is two to three times higher in women than men; however the one year mortality following a hip fracture is nearly twice as high for men as for women
• Hip protectors, if worn, would prevent most of these fractures.

How do they work?

Athletes know how important shields can be in preventing injuries. The shield absorbs the major energy of the fall, and diverts the force from the vulnerable spot of the bone and disperses it to less vulnerable areas.

How effective are they?

Reports have shown them to be about 97% effective in prevention of hip fractures. They work the second you put them on. No waiting. No side effects.

Are they comfortable?

They are lightweight, non-restrictive, and can be worn right over underwear. The shield itself is not tight or hard against the skin. I notice no problem sitting, standing or moving around, or lying down. I wear them in clinic, simply to show patients how comfortable, unnoticeable and easy they are. When I have them on I surprise people by knocking on my hips and getting a hard sound-I tell them not to mess with the Bionic Woman! (There is a brand from Canada which is worn on the outside of clothing which appears like a utility belt that a repair person might wear.)

How difficult are they to put on and take off?

I found them to be quite easy to put on and take off. The shields are sewn into the garment, so it is just like putting on any other underwear. The SafeHip protector won the American Society on Aging's 2001 award for outstanding product design, because it is so easy.

Will they make my hips bigger?

The actual hip protector covers the upper leg and so that area will be a little wider. I have found that the protector is not noticeable at all with clothes that have some room at the buttocks and leg area, like relaxed-fit pants.

How do I know what size to wear?

Each company has different sizing, so you need to contact the makers for specifics. You may want to measure your waistline prior to calling as sizing may be based on that.

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How do you launder them?

The undergarment variety is safe in the machine washer and dryer. (I prefer to dry them on the line as it may be easier on undergarments, but they can get a little stiff, so a low heat "fluffing" may help.)

Are they just for women?

Hip protectors are made in styles for men and women. (Men have hip fractures, too!) Some are available in black or white and a variety of styles as of this printing.

What if I have some incontinence?

Hip protectors are available in incontinence styles, or can be worn over your usual protector. There are also styles which can be changed more easily for the bedridden.

How expensive are they? Does Medicare cover any of the cost?

Prices vary from around $30-90. Medicare does not cover the cost as of this printing, but manufacturers are working on getting approval. Some health care plans do cover them, so check with your provider. (SafeHip offers 50% off your first pair if you tell them you read about them in the Creighton Osteoporosis Newsletter.) Even at 3-4 pairs a year, hip protectors are less expensive than medication therapy. Needless to say it is much less expensive than a hip fracture.

How can I get one of these wonderful products?

They are not available locally. You need to call their toll-free numbers, write them or visit their web sites. (see table on page 5)

Which brand is the best?

Of the six brands that I could locate, I could find only three for which there have been clinical studies. SafeHip is the one with the most extensive testing and peer review. (continued on page 5)
Living With Osteoporosis: A Patient Profile – Isabella Threlkeld

A sketch book is a constant companion of Isabella. An avid artist and owner of an art studio, drawing comes as naturally as breathing. Isabella has brushed up with the famous in her educational pursuits. She was a classmate of Warren Buffett's in grade school; a roommate of Dr. Ruth Strang at Wellesley; knew Albert Einstein as her uncle was head of engineering at Yale when Isabella was at Wellesley; and was able to see Pablo Picasso’s final art show in 1958. She received her Masters in Art in Rome and went on to get a degree in art therapy. She was working at Walter Reed Hospital when she met her husband, who was a commander in the US Navy, later under General MacArthur. Her nephew is a published author and former correspondent for CBS news. Isabella has served the Omaha Community as art teacher at Duchesne, as well as curator at the Joslyn Museum. Since setting up her own studio in 1977, Isabella enjoys doing what she loves: teaching and creating art.

We first met Isabella in 1996 when she came to see if she qualified for a research study. Our screening found five vertebral fractures and a greater than 4 inch loss of height! She realized she was getting shorter, but had no idea she had suffered so many vertebral compression fractures. (As painful as these fractures can be, they can also occur slowly and silently.) At 74, she worked full time running a business and worked out three times a week at a fitness center. In her spare time enjoyed swimming and hiking. She also had a good dietary intake of calcium. Isabella wasn’t really surprised with the diagnosis, however, as she had a strong family history of osteoporosis (both mother and father as well as aunts and grandparents); she also smoked cigarettes, and had noticed having trouble with balance despite taking Tai Chi classes. She also had broken her wrist in 1995, an indicator of bony fragility. Isabella started on a bone building medication plus extra calcium and vitamin D. This treatment increased her bone density substantially and she has been stable except for a fracture in her upper leg in 1999, while recuperating from a hip replacement. Though there is some residual pain in her knee, hip and back associated with this injury, Isabella enthusiastically continues to run her studio, teaching art classes and is a passionate participant in life. A recent showing of her artwork in Fremont, where she grew up, attests to that.

To show her appreciation of life and the healing arts, Isabella has remembered the Creighton Osteoporosis Research Center in her will. Because medical care is expensive, the university and medical center at Creighton rely heavily on goodwill contributions from individuals in the community. Gifts to medicine and research are the key to sustaining critically needed health programs. If you, relatives, or friends are supportive of the Creighton mission or are especially grateful to a specific department or person for your care, please do not hesitate to let us know. If you would like to discuss the Grateful Patient Gift Program, call the School of Medicine at 402-280-5745, visit the website http://medicine.creighton.edu, or send in this card.

"Accuse not Nature, she hath done her part; Do thou but be thine.”

John Milton (Paradise Lost)

How Patients & Friends CAN HELP!

Your GIFT CAN HELP

...and will continue the Creighton Osteoporosis Research Center’s Tradition of Innovation and Service to Humanity.

The cost to fund research, treatment and prevention of osteoporosis is expensive. As a non-profit institution, the Creighton Osteoporosis Research Center exists to serve and improve the plight of humanity. Because of this, the University relies heavily on goodwill contributions from patients and friends. Gifts to medicine and research are the key to sustaining this critically needed health program. Please help the Creighton Osteoporosis Research Center continue to educate and find tomorrow’s cures.

Your support of the Creighton Osteoporosis Research Center can be expressed through a wide spectrum of giving options including:
- Cash
- Gift of appreciated securities or real estate owned for one year
- Bequest (by will or trust)
- Gift with life income for donor and/or spouse
- Gift of income with assets to heirs
- Gift of life insurance
- Gift of personal residence or farm
- Bequest of IRA or qualified retirement plan assets

I am interested in receiving information regarding support of the Creighton University Osteoporosis Research Center.

Name: ___________________________ State: ___________________________ Zip: ___________________________
Address: ___________________________
City: ___________________________ Phone: ___________________________
E-mail: ___________________________

Creighton University School of Medicine, Office of Development 2500 California Plaza • Omaha, NE 68178 Toll Free: 800-561-1649 or 402-280-5745 http://medicine.creighton.edu e-mail: rheid@creighton.edu
**Bone Appétit**

**Viva Las Papas**

**A Tribute to the Tater (or a root for a root)**

**Horseradish Potatoes**

20-22 new potatoes—or 2 lbs. all-purpose potatoes
3 tablespoons margarine
2 tablespoons horseradish
⅓ cup skim milk

Scrub the potatoes, (peel if you like), cut in half, and boil in large pot with lightly salted water til tender. Drain. Mash or beat adding horseradish and margarine. Gradually beat in milk til light and fluffy. Makes 8 servings

Nutrients per serving: calcium 45mg, calories 145, fat 4.42 gm, fiber 2 gm,

**Sweet Potato Casserole**

1 large can sweet potatoes (or about 16 oz)
2 eggs
1 cup milk
1 tsp. cinnamon
⅓ cup sugar
⅓ cup butter

Mix all ingredients and put in baking pan. Add topping and bake at 30-40 minutes.

Topping
⅔ cup crushed cornflakes
⅓ cup brown sugar
⅓ cup butter-melted
⅓ cup chopped nuts

(1 cannot credit original source as I got it from an in-law of an in-law, so don't sue us and make me an out-law—Remember, tuber is human!)

Nutrients per serving: calcium 60 mg, calories 289, fat 14.25, fiber 1.38g

**Potato Soup**

⅓ cup of celery -chopped
⅓ cup of yellow onions-chopped
2 cups peeled potatoes-diced
⅓ tsp salt
2 tbsp flour
2 tbsp butter
2 cups skim milk

Put chopped celery, onion, and potatoes and salt in a saucepan and add just enough water to cover. Bring to boil and simmer for 10 minutes. Set aside. (Do not drain.) In another saucepan melt the butter, stir in the flour, and gradually add the milk. Stir constantly until mixture thickens and comes to a boil. Add the milk mixture to the potato mixture and heat through. Makes 8 servings.

Nutrients per serving: calcium 170 mg, calories 183, fat, fiber 2.11 g

**Mix and Match?**

We are often asked if combinations of different therapeutic medications are helpful in the prevention and treatment of osteoporosis. The answer is, we are looking into it. We currently are studying the use of two commonly used medications in bone health in combination vs. alone.

Another study, for which we are currently recruiting is comparing two commonly used medications (See a different combination of “Opportunities to Participate” on the back of newsletter). We don't know if the two together have any greater effect than one alone, or if the effect is additive or even greater than the sum. Clinically, it is something we consider in some situations, but each situation is unique.

**Forteo, Forteo, Wherefore Art Thou Forteo?**

You may have heard about a new medication that is coming out, called Forteo. It is a preparation of parathyroid hormone, which is a naturally occurring hormone. It has been shown to increase bone density dramatically in the presence of sufficient calcium and vitamin D. It has been tentatively approved by the FDA for treatment of osteoporosis, but we are awaiting production by the pharmaceutical company. It will be administered by self-injection (like insulin) probably for a period of 1-2 years. It is likely to be costly. Insurance coverage will no doubt vary. Whether Forteo will be for you is something to discuss with your health care provider. There are no strict criteria but Forteo will probably be indicated for those with moderate to severe osteoporosis. Other questions regarding whether to continue with current treatments remain uncertain, but to maintain bone after completion of the treatments, a bone active drug is indicated. Release on the market will no doubt be accompanied by press releases, so keep an eye out for Forteo.

**Tuber, or not tuber; That is the question...**

Shakespeare, Hamlet, Act III, Scene 1
Hip Is as Hip Does

continued from page 2

On-going randomized clinical studies will help to clarify the issue.

For our patients we suggest you buy SafeHip. If you find it difficult to sleep in them, try HipSaver for sleep. It wouldn’t hurt to have a HipGuard on hand for those quick trips out to get the mail on cold icy winter days.

People who haven’t tried them tell me that wearing hip protectors would make them feel old. Growing old is good! Staying healthy and active while you do it is the important thing. Like anything new, it takes a little getting used to—seat belts, bike helmets, eyeglasses. Pretty soon, it becomes habit and you don’t even notice them. The hardest part is in taking the leap to try the first pair. Once you try them, you will know how easy they are to use. (A hip fracture can really make you feel old!)

So, football fans, get your gear on and get in the game! Don’t be “hip”ocritical!

<table>
<thead>
<tr>
<th>Hip Protector Feature</th>
<th>SafeHip</th>
<th>HipSaver</th>
<th>HipGuard</th>
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<tbody>
<tr>
<td>Proven effective in published clinical study, with peer review</td>
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<td>Easy to put on &amp; take off</td>
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<td>Available for men and women</td>
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<td>unisex</td>
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<td>Available for incontinent</td>
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<td>not applicable</td>
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<td>Least noticeable</td>
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<tr>
<td>Demonstrated patient compliance</td>
<td>3 mo-75%, 2 yr-40%</td>
<td>6 mo-31%</td>
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<tr>
<td>Variety of sizes</td>
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<td>Variety of colors, styles</td>
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<td>Manufacturers suggested retail price</td>
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<tr>
<td>Toll-Free Telephone Number</td>
<td>1-877-728-3447</td>
<td>1-800-358-4477</td>
<td>1-800-299-8892</td>
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</tbody>
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Adapted with permission from Dowd R. Are you hip to hip protectors? [sidebar]. Am J Nurs 2001;102(1). In press.

Legislative News

According to the World Health Organization, osteoporosis is now considered the second largest public health problem for women. Unfortunately due to co-pays, many women are not seeking the early screening test which can lead to early treatment and prevention. The Improved Access to Osteoporosis Testing Act of 2001 proposes to eliminate the Medicare co-pay. Contact your Congressperson if you would like to let them know your thoughts on this legislation.
OPPORTUNITIES TO PARTICIPATE

The Creighton University Osteoporosis Research Center is conducting the following new and exciting studies. If you or someone you know is eligible and interested, or if you would like to be notified of further studies, please call 280-4250, Toll free 1-800-368-5097.

NUCLEAR FAMILY STUDY
- Men and women
- Mom and Dad and one child over 19, or one parent and 3 children over 19
- One time visit
- Bone density measurement at no cost
- Call Burch at 280-4474

SMOKING STUDY
- Men and Women
- Smokers ages 20-30, 45-60 and over 65
- One morning time needed
- Stipend offered
- Contact Susan 280-4647

COMPARISON OF TREATMENTS
- Women 2 or more years past menopause
- Free bone density measurements, mammograms and medications for eligible participants
- Contact Jen at 280-4250

EFFECT OF SURGERY ON BONE
- Healthy men or women, scheduled for surgery
- 50 years of age or older
- Willing to come in prior to surgery and then 4 times in the year following the surgery
- Free Bone Densitometry - (Osteoporosis Screening)
- Home Nurse visits at no cost
- Contact Rachel at 280-4178

PARENTS: If you would like your children to be considered for research participation opportunities in future studies looking at bone health conducted at the Creighton Osteoporosis Research Center, please call Gina Lypaczewski at 280-4174.

Thank you for your continued support and interest!

Editor: Rachel Dowd Graphic Artist: Stacee Milan

This newsletter and the Osteoporosis Support Group has been brought to you in part, through donations from Eli Lilly, Merck and Wyeth-Ayerst Pharmaceutials.