



Osteoporosis Canada

Ostéoporose Canada

COPING
**The E-newsletter of the
Canadian Osteoporosis Patient Network (COPN)
September 2005**

COPN – Dedicated to representing people with osteoporosis on all issues related to the disease.

COPN Steering Committee Welcomes New Chair

At its August meeting, Priscilla Cole announced that she was stepping down as chair of the steering committee, and that her position would be filled by Marg MacDonell, as of the October meeting. COPN is very pleased to welcome Marg MacDonell as chair of the steering committee. At the June AGM, Marg was elected for a second term to the Osteoporosis Canada national Board of Directors. She is a person with osteoporosis and will speak on behalf of COPN on the Board. Marg has worked as a paediatric nurse; she has a certificate in management for non-profits; and worked for 5 years as Director of Development (largely in a fundraising capacity) for MS. She is also on the Board of the Manitoba Chapter.

The steering committee expresses its profound thanks to Priscilla for the extraordinary work that she has done in leading COPN over the past few years. She has been a driving force behind the growth of COPN, the establishment of our web pages, newsletter, and advocacy efforts. We are delighted that Priscilla will continue to sit on the committee and be involved in various committees such as the Knowledge Exchange Task Force and Canadian Institute of Health Research.

Priscilla Cole Honoured with Eleanor Mills Inspiration Award

The following is the introduction given by Linda Salb, Director, Chapter Operations, at the Osteoporosis Canada Annual General Meeting, June 2005, in presenting the inaugural Eleanor Mills Inspiration Award to Priscilla Cole:

Like all individuals who are learning to live with a chronic and debilitating illness, Eleanor Mills was faced with choices when diagnosed with osteoporosis: She could give in to the disease and accept its limitations or she could struggle against her adversity to live an active life. Eleanor chose to embrace an active life and yet, she took it one step further. She chose to become a role model for all individuals who live with osteoporosis and a champion of the cause to prevent younger women from developing this disease.

Eleanor Mills has been a source of inspiration and hope to millions of Canadians since she first walked with the Boney Express across Canada in 1993. During the summer of 1993 and 1994 her team visited 129 communities from Victoria to St John's. In these communities, Eleanor - at age 80 - led walkers through the streets (using her famous walker for support),

walking at a pace that challenged women even half her age. In every community Eleanor gave a powerful message to individuals with osteoporosis -Never Give Up!

Eleanor's legacy to OC is twofold. First, her Boney Express campaign saw dramatic and encouraging results. A national survey in 1993 showed that in provinces visited by the Boney Express, doctor's visits resulting in osteoporosis treatment were up by 52% over the previous year. These statistics demonstrate that she was able to galvanize the country under the Walk banner.

And secondly - but no less important - she was instrumental in bringing the Osteoporosis Walk Foundation and Osteoporosis Canada together in 1995 - a step that has further strengthened the voice of osteoporosis in Canada.

The Eleanor Mills Inspiration Award honours those special OC volunteers who, like our late Patron, Eleanor, have embraced their own osteoporosis, and by doing so have inspired others with their determination, perseverance and optimism, and have given of themselves to champion the osteoporosis cause. Further, this volunteer is seen as an inspiring positive role model who leads by example, providing hope, encouragement and support to all.

We think this inaugural award winner *is* all that, *does* all that, and more. With over a decade of volunteer service under her belt, most recently as the strong self-described "empowered patient" on the National Board, this lady's passionate crusade for increased bone health is well known throughout our organization.

Call her a firebrand, call her a champion for the underdog, call her a force to be reckoned with ... She is most undeniably an outspoken advocate for patients with osteoporosis.

It is this passion that led her, along with a small group of like-minded women, to create the Canadian Osteoporosis Patient Network, or COPN for short, about 2 years ago. Their vision for COPN was to be the voice of people with osteoporosis on all issues related to the disease.

Those who meet her are inspired by her infectious smile, her ready laugh and her "never give up" attitude, so very much like her friend Eleanor's. Just spend five minutes in her presence and see if you don't agree. Fun-loving and ever energetic, even at 78 years of age, this woman can often be found leading an exercise class at the AGM or volunteering at the zoo.

She believes that getting people involved is the key to success and that every adversity can be mastered. She is truly a testament to the power of positive thinking. A childhood polio survivor, she has never let age or disability stop her from being "out there," in the public eye, educating others. She can always be counted upon to look at the bright side of things, and she is always prepared to take on the next challenge (or as she likes to call them, "adventures").

A strong and vocal patient advocate, she tells governments "like it is" for someone living with osteoporosis and provides a glimpse into the effects of the disease and the very real impact it has on people's lives, in order to focus their attention on the help people require in terms of prevention and education.

Every day, in all her activities, she manages to incorporate osteoporosis into conversations to better inform people. Here is but a sampling of her osteoporosis activities:

- ❑ Health fair volunteer
- ❑ TV appearance spokesperson

- ❑ Public speaker
- ❑ COPN steering committee chairperson

She is able to balance “wisdom and wit, love and laughter, and compassion and caring” in one bundle of energy.

Writes one of her nominators, Gail Lemieux, a founding member of COPN, “My wish for myself is to have her energy, love, laughter, wisdom and determination when I reach her age ... she is my role model.” And I think Gail’s wish is one we all secretly share.

It is now my great honour to invite Priscilla Cole forward to accept the inaugural *Eleanor Mills Inspiration Award*.

My Story of Living with Osteoporosis and How I Was Encouraged by Eleanor Mills

By Martha Irvine

I was born in Toronto in 1934 and moved with my family to a northern Ontario farm at the age of three. In my early teens I began to experience, and complain of, hip pain. My mother took me to a doctor who said I was having growing pains and to pay no attention to it. The pain in my hip continued on and off, especially after running or other vigorous exercise.

My mother took me to another doctor because I had developed a slight limp. He told her to buy me a pair of sturdy lace-up oxfords. The shoes didn’t help with the pain. The limp continued to be a problem for me, but I learned to live with it. Another doctor said that the cause of my pain was that I had one leg slightly longer than the other, and that I might have osteochondritis (a form of inflammation of bone and cartilage).

I married young and gave birth to three sons. After my third pregnancy, the pain in my hip returned, stronger and more frequently. In 1989 I was sent to a hospital in Toronto for hip surgery that required three months of bed rest, then walking with crutches, before I was finally walking normally again. The hip was scraped of calcium deposits and generally cleaned up. For a time, this surgery was a success!

The repair was successful until 1995, when the pain came back again and another hip surgery was done. Again it was a success, but I was told I had osteoporosis. I sought help from Eleanor Mills, a woman of 80 whom I had met on her walk across Canada to raise awareness about osteoporosis. She sent me letters and called me on the phone to encourage me through this very rough time. Her support and caring helped me to carry on while recovering from fractures in my spine and ankle.

Dr. Tim Murray of Toronto encouraged me to sign up for research testing of a new medication that had been developed. For three years I went once a month to clinics in Toronto for medication and check-ups. It was a great learning experience, and I met many people with the same problems.

Since then, I have been taking 35mgs of Actonel® once a week, since it became available. It was the drug I had helped to test. I am now 71, and survived quadruple by-pass heart surgery 18 months ago. My life has changed for the better, but the pain comes back occasionally. I can live with that for now. I can now live an active lifestyle, but I do hire people to do my heavy work like vacuuming and lifting. I tell people about osteoporosis whenever I can – I want them to know how very often it is overlooked.

Tell Us Your Story of Living with Osteoporosis, Stories that Might Help Others

Here are some topics that you may wish to consider. Email us at COPN@osteoporosis.ca. Please note that stories you submit may be published in subsequent newsletters or on the COPN web site.

- How you have managed to increase your bone mineral density.
- How you are working (or not) with weight-bearing exercises.
- How you are managing to get enough calcium, especially if you are intolerant to dairy products.
- How you deal with the pain of osteoporotic fractures.
- What are your family's experiences with osteoporosis; how are you managing? How has your family been affected by osteoporosis?
- How are you helping your children to be aware of the osteoporosis in your family?
- Your struggle to be diagnosed with osteoporosis.
- Your surprise at the diagnosis of osteoporosis/osteopenia: what was your immediate reaction?
- Did you have problems getting an effective osteoporosis drug? What happened?
- Being a caregiver to someone with osteoporosis.
- Any other aspect of being a person with osteoporosis – tell us your story.

Calcium Absorption and Bone Health

By Ina Ilse

I am one of a number of volunteers at Osteoporosis Canada answering questions on the 1-800 information line about bone health. Many of the questions we deal with on the phones are related to diet, and in particular calcium: what foods are rich in calcium and how much of it is absorbed? For example, spinach is rich in calcium, but the calcium is not well absorbed. Also, can one type of food interfere with the absorption of the calcium in another food (e.g., protein from red meat)? To clarify some of these questions, and to satisfy my own desire for specific answers, I decided to look up a number of research publications. Below are some of the answers I found.

As we all have come to realize, bone is a living part of our body and, as such, needs constant nourishment.

Calcium has multiple functions in the body. Primary is its contribution to skeletal strength and integrity. Calcium is also involved in muscle contraction, nerve impulse conduction, and the regulation of many metabolic processes occurring within the cells. Because the body requires calcium for so many of its activities, large concentrations of calcium are required in the blood plasma and the cells for ready use. How are the levels of calcium in the blood regulated?

Vitamin D plays a very important role here; it regulates the calcium levels in the blood stream. But Vitamin D is not the only hormone working on behalf of bone health; parathyroid hormones, which are secreted by the parathyroid -two small oval-shaped glands located next to the thyroid glands in the neck, are the prime regulators of extra-cellular calcium. How does it work?

The parathyroid hormones (PTH) maintain calcium levels at all times and in all parts of body. If the parathyroid finds that there is not enough calcium to fulfill all the body's needs, it will remove calcium from our bones in order to maintain the proper levels of calcium overall. (Vitamin D does not exercise this control mechanism). So, if we do not bring in calcium

through our diet, calcium will be removed from the bone, but will not be replaced. When the calcium is removed from our bones, it is called resorption, the result of osteoclast activity.

Osteoclasts are cells that “chew up” or resorb old bone, including the removal of calcium from the bone structure; and osteoblasts work by laying down new bone by secreting collagen and minerals and replacing any calcium that has been removed by the osteoclasts. Unfortunately, as one ages, there are more active osteoclasts in one’s system than active osteoblasts, which results in more calcium being removed from the bone than being replaced. Thus, one ends up losing bone mineral density.

Calcium is absorbed by the intestines and moved into the blood stream for ready use. Typical calcium absorption from meals ranges from 25 – 35% in adults. The amount that will be absorbed is determined by many factors:

1. Quantity and form of calcium ingested.
2. The composition of the diet, in other words, what type of food is eaten.
3. The calcium and Vitamin D status of the consuming individual.
4. The age, stomach acid secretion and intestinal transit time of the individual. (Transit time means the length of time it takes for the food to move through the gut.)

How do we know if we are getting enough calcium? How is calcium absorption measured? Because there is always a certain amount of circulating calcium in the blood, it is difficult to measure the amount of calcium absorbed from foods only. So to get accurate absorption data from ingested calcium, scientists used food that had been labelled with a specific type of marker. The individuals who participated in the study consumed this food and then, for a period of time (from 4 hours after the meal to about 48 hours after the meal), all feces and urine were collected by the participants. Because it was known how much labelled calcium was ingested by the individuals, all the labelled calcium excreted or put out in the urine was measured. The investigators would then do a simple calculation by which they could then show how much calcium had been absorbed.

There are many good food sources of calcium: dairy products (the most abundant), leafy green vegetables, legumes, fish, e.g., salmon and sardines with the bones also consumed, calcium-fortified tofu, almonds, dried figs and even oranges, plus a variety of grain products.

Because many people have become concerned about the number of calories they consume, getting enough calcium in their diet has become quite a challenge. Dairy products are abundant and contain high levels of readily absorbable calcium. From one cup of skim milk, one gets 300mg of calcium and the caloric value is low.

Because of the high calcium content of dairy products, manufacturers in food processing plants use dairy calcium to fortify non-calcium-rich foods and beverages (e.g., tofu and orange juice).

Green leafy vegetables, for the most part, are rich in calcium; however, not all the calcium in these plant foods is available for absorption in the intestinal tract. Spinach is very rich in calcium, but spinach contains high levels of oxalic acid, which forms very strong bonds with the calcium and so it will not yield much of its calcium content (only 5%). Kale, however, also a leafy green vegetable, has very low quantities of oxalic acid; thus, calcium absorption from kale can be as much as 41%. When calcium is bound to large molecules such as proteins and carbohydrates, calcium absorption in the intestines will be slowed down, but digestion reduces these molecules to absorbable sizes and, depending on how fast the food moves through the system, some will be absorbed.

Another very interesting discovery was the fact that, even though the spinach does not give up its calcium very readily, in combination with a dairy product, it will yield up to 14% of its calcium. At the same time, some of the calcium in the dairy products was slightly inhibited. This finding led the authors to believe that in the presence of certain substances, spinach will yield some of its calcium without much compromise to the calcium from the other substances. In other words, there will not be a negative calcium effect due to the spinach or other high oxalic-acid-containing foods when taken in combination with other foods. Now, despite the inhibitory effects of many dietary components such as phytates, fibre, phosphates and fats, the bioavailability of calcium from these foods is remarkably uniform in most healthy individuals.

The investigators also did some absorption studies on foods such as seeds and nuts that have large quantities of a component called phytic acid to see how it affected calcium absorption. They studied soya beans and some seeds that they knew contained high levels of phytates (a form of phosphorus in the phytic acid), which is an inhibitor of calcium. They found that phytate is not as strong an inhibitor of calcium as oxalic acid.

They first studied soya beans and saw that some variety of soya beans had a higher content of phytate than others. The beans that contained a higher level of phytate had lower calcium absorption than those with lower phytate content. However, it was not very significant. Next they looked at wheat, which is rich in calcium and is also a very important part of the North American diet. They ground the wheat into flour, baked cookies with it to see how much of the calcium would be absorbed and found that absorption was 37%, better than the calcium absorbed from milk at 33%. The investigators then baked some bread with some of the flour and found that the absorption was significantly higher than in the cookies. They reasoned that the yeast contains enzymes that would cleave the calcium away from the phytic acid and therefore more calcium became available for absorption. The absorption was much higher than that from milk, but one would have to eat great amounts of bread (about 15 slices of whole wheat) to get the same amount of calcium as absorbed from an 8 oz. glass of milk.

What is the role of calcium in the development and maintenance of peak bone mass?

- Approximately 60 – 70% of our peak bone mass is determined by genetic factors.
- Lifestyle can promote the development of peak bone mass or hamper it.
- Between ages 30 and 40 we maintain peak bone mass through dietary calcium and lifestyle.
- Calcium-regulating hormones are concerned with maintaining an extra cellular fluid level of calcium for normal functions of the body.
- Exercise is essential.

Dr. Robert Heaney states that optimal calcium intake is the amount of calcium that would supply the body with sufficient calcium, both during the rapid growth period and during adulthood. Osteoporosis Canada recommends the following intake levels of calcium and Vitamin D:

1. Prepubertal (4-8 years) ----- 800mg/day, Vit. D 200IU
2. Adolescents (9-18 years) --- 1300mg/day, Vit. D 200 IU
3. Women and men (19-50 years) --- 1000mg/day, Vit. D 400IU
4. Women and men over 50 --- 1500mg/day, Vit. D 800IU
5. Pregnant or lactating women (≥ 18 years) --- 1000mg/day, Vit. D 400IU

During the peak growth period, one should aim for a positive amount of calcium; in other words, there should be enough calcium for rapid growth and also enough for body functions. Failure to achieve this means that the bones will not be very dense when one reaches adulthood (around ages 20 - 25). Dr. Heaney states that we unfortunately tend to get serious about our skeletal health somewhere in midlife, but he also comments that osteoporosis is a paediatric disease that waits until old age to show itself.

I hope that my research has provided the readers with some answers to their questions regarding the role of calcium in the body.

Rock This Joint 2005

From November 1 – 3, in Ottawa, the Arthritis Society will bring together approximately 250 representatives of the arthritis community for the first-ever Summit on Standards for Arthritis Prevention and Care. COPN steering committee member Sheila Brien has sat on the planning committee for the Summit and will attend as a delegate. The mandate of the Summit is “through consensus involving all stakeholders, (to) set evidence-based national health system standards for arthritis prevention and care, to ensure optimal arthritis care for all Canadians.” Sheila comments that being involved with this Summit has been a terrific learning experience.

US Surgeon General’s Report on Osteoporosis Canada Web Site

In October 2004, the US Surgeon General issued the first-ever report on the nation’s bone health. To read the report, go to www.osteoporosis.ca, click on Programs & Resources, then click on Related Web Sites, and finally click on Bone Health and Osteoporosis: A Report of the (US) Surgeon General (2004).

What’s Happening in Your Area?

COPN would like to know what is going on in your area that would be of interest to people living with osteoporosis. E-mail us at COPN@osteoporosis.ca with your report.

Volunteer with COPN

Is your life in any way affected by osteoporosis?

Are you interested in representing people with osteoporosis?

COPN is a virtual network of people whose mandate is to provide the patient perspective wherever possible. We are a dynamic, growing network and we have many opportunities for you to join us:

- Steering committee members to provide leadership
- Publicists to spread the word
- Writers/editors to help put out the e-newsletter *COPING*
- Web-savvy people to work on our web site

Join our team. E-mail us at copn@osteoporosis.ca.

Newsletter disclaimer: We invite you to contribute to this newsletter. Selection of material is at the discretion of the editor. Opinions expressed in material published in the COPN newsletter do not necessarily reflect the position of the Osteoporosis Society of Canada. Individuals contributing material are solely responsible for the content, accuracy and originality of the material. To contribute to the next edition of the COPN newsletter, contact us at copn@osteoporosis.ca.