

Remember: You can live well with osteoporosis!

Involving Patients in the Osteoporosis Care Gap and the Research Agenda: The Canadian Osteoporosis Patient Network

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Did you miss the Virtual Education Forum titled *Bone Up with Physical Activity* by Dr. Lora Giangregorio?

[Click here](#) to view the archived presentation.

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Event Calendar

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Patients are playing a more important role in the development and delivery of healthcare policies in many areas of medicine. The Canadian Osteoporosis Patient Network (COPN) of Osteoporosis Canada is a virtual network created by patients whose goals include education and advocacy. COPN is very well suited to the task of spreading patients' ideas and opinions about osteoporosis and about the development of future research programs.

You may remember that a survey was conducted in the spring of 2009 to find out more about you, how you lived with osteoporosis, how much you knew about this disease and where you felt Canadian research should focus. A team of researchers, members in the Scientific Advisory Council (SAC) (including Drs Angela Cheung, Jacques Brown, Alexandra Papaioannou and Suzanne Morin), conducted this survey in collaboration with members of the executive committee of COPN and Dr Famida Jiwa and her staff from OC.

The purpose of the survey was to gain insight from COPN members in preparation for the November 2009 Bone Health Research Consensus Conference. The results of this survey were also formally presented in 2010 (along with the launch of Osteoporosis Canada's new 2010 Clinical Practice Guidelines) at the scientific meeting of the American Society of Bone and Mineral Research (ASBMR) in Toronto. The presentation of the survey showcased the successes and the strengths of COPN to the rest of the bone community. The researchers are very pleased to share this information with us.

In April 2009, 1,851 questionnaires (French and English) were distributed electronically and by regular mail. 563 completed surveys were received at the end of the study period. **Table 1** shows the information that was collected about the COPN members who agreed to participate in the survey. The survey revealed that many COPN members admitted to being restricted by osteoporosis in their daily life. Of those who said they already had experienced a fragility fracture, 78% were afraid of a recurrent fracture and 16% claimed that their daily activities were greatly limited because of osteoporosis.

Table 1

Total number of respondents	563
Average age	67 years
Number of women participating	491 (87%)
Geographical distribution:	
- Ontario and Manitoba	318 (56%)
- British Columbia, Alberta, Saskatchewan	147 (26%)
- Quebec and the Atlantic provinces	54 (10%)
Respondents who said they have osteoporosis	416 (47%)
Respondents who said they have osteopenia (low bone mass)	83 (15%)
Respondents who suffered a fragility fracture after the age of 40	242 (43%)
Respondents who were using a prescribed medication for osteoporosis at the time of the survey	444 (79%)
Respondents who took their medication as recommended:	
-Always	376 (67%)
-Most of the time	34 (6%)
-Occasionally	31 (6%)

A 12-point questionnaire on knowledge about osteoporosis was also part of this survey. Respondents scored an average of 78% on this mini-test. The questions and answers (in brackets) are shown in **Table 2**. COPN members were also asked where they got most of their information about osteoporosis. It was found that the top sources of information were (in order): the COPN newsletter, the family physician, the media (other than the internet), the Osteoporosis Canada website and finally, the bone specialist.

Table 2

Are the following statement True, False , or are you Unsure about the statement? (The correct answer is shown in brackets after the statement)	Correct answers Numbers, (%)
Physical activity helps osteoporosis. (T)	516 (92)
If there is an adequate intake of calcium, one still requires good vitamin D intake.(T)	515 (92)
Osteoporosis is a disease of bone density, causing bones to become brittle and fracture easily.(T)	514 (91)
Vitamin D is important for the health of bones and muscles. (T)	508 (90)
People with osteoporosis can be free of symptoms and unaware of the diagnosis.(T)	506 (90)
There are effective treatments to slow and prevent bone loss and fractures.(T)	491 (87)
Calcium is only found in dairy products.(F)	484 (86)
Cigarette smoking and alcohol drinking are risk factors for osteoporosis.(T)	482 (86)

Diagnosis of osteoporosis is made after a blood test.(F)	404 (72)
Other than bone density, the most robust risk factors for osteoporosis are age and existent fracture.(F)	362 (64)
Overweight persons are at increased risk for osteoporosis.(F)	263 (47)
Osteoporosis affects men, women, and different ethnicities equally.(F)	221 (39)
	78% (68-88%)
(T)=True, (F)=False	

Finally, COPN members were asked to rank certain research topics according to what they felt should be the order of priority in the Canadian research agenda. These rankings are shown in **Table 3**.

Table 3

Research topic	Ranking
A cure for osteoporosis	493 (88%)
What physicians know about osteoporosis	492 (87%)
What people know about osteoporosis	489 (87%)
How to prevent osteoporosis	485 (86%)
Risk factors for osteoporosis	485 (86%)
How to promote quality of life for people with osteoporosis	484 (86%)
New drugs for osteoporosis	478 (85%)

Then, you were asked to identify top research topics that *you* felt were important. You highlighted the following themes:

- medication side effects
- alternative (non pharmacological) interventions
- new drug interventions
- risk factors for osteoporosis.

The researchers concluded that *“in order to improve the osteoporosis care gap, it is very important that patients be involved in the development of our research agenda and in the dissemination of the knowledge that is learned from that research. This survey confirms that COPN has successfully contributed to both of these areas through its educational and advocacy actions and should be proud of these achievements. It is very important that COPN continue its tremendous work and that many more members join its rank”*.

The Canadian Institutes of Health Research (CIHR) has shown that they, too, have heard the voices of COPN members when, in the spring of 2011, they launched a special competition called "Team Grant: Bone Health" to encourage and stimulate new and established researchers to undertake new, high priority research in the field of bone health.

Now we have scientific proof that COPN members, through their involvement, contribute significantly to the betterment of the bone health of all Canadians. All Canadians deserve to live well with osteoporosis. Is there someone you know who could benefit from being a member of COPN? The more we increase our membership, the closer we will get to closing the osteoporosis care gap, and that many more people who break a bone will have the knowledge and the power to make their FIRST break their LAST.

FUNNY BONE:

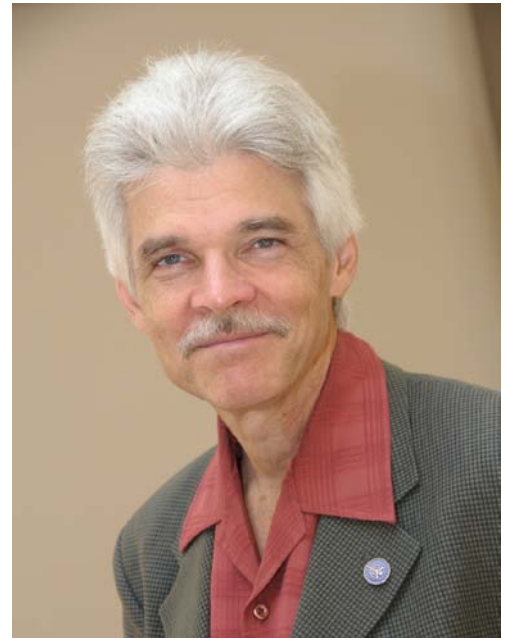
Why didn't the skeleton cross the road? He had no guts.

Upcoming Virtual Education Forum: Thursday, December 1, 2011

New Developments on Fracture Risk Assessment

Presenter: Dr. William Leslie, MD MSc FRCPC

On Thursday, December 1, 2011, Dr. Leslie will be focusing on the topic of fracture risk assessment. He will be guiding us through the various fracture risk assessment tools and explaining how to interpret results. The presentation will include practical tips on what patients need to know before going to their health care provider. There will be opportunity to ask questions! Participate in this event and have your questions answered in real-time.



For more information on virtual education forums [click here.](#)

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