



Osteoporosis Canada

Ostéoporose Canada

COPING
The E-newsletter of the
Canadian Osteoporosis Patient Network (COPN)
January 2006

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

HAPPY NEW YEAR

The first issue of *COPING* (we didn't have a name then) was published in November 2004. With your support, we have grown tremendously in the months since then. Our subscribers have more than doubled, and the list continues to grow every month. Thank you all very much.

We want to be sure we are meeting your needs. Please drop us an email copn@osteoporosis.ca or phone toll-free 1-800-463-6842 (416-696-2663 in Toronto), ext. 229, and give us your answers to the following:

1. Have you enjoyed receiving the newsletter?
2. What have you enjoyed the most?
3. What have you liked the least?
4. What areas of interest to people with osteoporosis would you like us to add to the newsletter?
5. Any other comments?

We look forward to hearing from you.

The Common Drug Review

The Common Drug Review (CDR) is a federally sponsored process for assessing the suitability of a drug for listing in a provincial drug benefit formulary after a Notice of Compliance (NOC) has been issued by Health Canada. The Common Drug Review is intended to provide a mechanism for the review of a drug according to common standards with country-wide validity, thereby reducing duplication of effort, review time and review cost to the advantage of all provincial formularies. What initiates and drives the inclusion of a drug in the Common Drug Review process are submissions from the sponsoring drug companies and requests from doctors or other medical interest groups.

Housed and supported by the Canadian Coordinating Office for Technical Advancement (CCOTA), the CDR process is expected to establish whether the drug

- meets requirements for safety and efficacy in appropriate patient populations
- offers therapeutic advantages relative to current accepted therapy
- meets requirements for cost-effectiveness relative to current accepted therapy

Essentially, the CDR effort is made up of two parts:

- An in-house group of scientific reviewers, supported at times by specialist contractors.
- The Canadian Expert Drug Advisory Committee (CEDAC) composed of experts from across the country.

Frequent briefs are passed to members of CEDAC in preparation for their monthly meetings at which decisions are made as to whether the drug should be *recommended* for listing in formularies or not. In 2005, up to Dec. 1, this panel examined 17 drugs, of which four were recommended for listing. A “list” recommendation from CEDAC does not guarantee the listing of the drug under any provincial formulary and much depends on the review process undertaken by individual provincial governments. These provincial reviews may produce further delays or even a local decision to not permit listing of the drug.

On the other hand, a “do not list” recommendation from CEDAC does not permanently condemn the drug. In fact, a manufacturer is entitled to apply to CCOTA for reconsideration and, if this fails, to re-submit the application at a later date for review at this federal level.

The design and management of the CDR process allows for public forums at which special interest groups may be kept informed as to which drugs are being reviewed and the current stage of the review. As reviews progress, CCOTA issues summaries of the drugs for which CEDAC has issued “*list*” or “*do not list*” recommendations.

On November 14, 2005, the CDR public forum in Toronto was attended by a variety of groups, including The Arthritis Society, The Multiple Sclerosis Society, The Canadian Neuropathy Association and Osteoporosis Canada. Subject material fell essentially into two classes:

1. Informative presentations by government groups associated with, or allied to, the new drug approval and monitoring process.

In this category, the representatives from Health Canada explained the primary drug evaluation process for safety and efficacy data submitted for a drug by its sponsor and the concept of the “Notice of Compliance” (NOC). It also was evident that the CDR process was federally driven and provided only *recommendations* to the provinces and that the final decision to “list” a drug on a provincial formulary rested with the province. Once on the market, the performance of every drug still is of great interest to Health Canada and is monitored by the Division for Marketed Products, as well as by the Canadian Optimal Medication Prescribing and Utilization Service (COMPUS), which seeks to monitor and prevent inappropriate prescription or misuse of medications.

2. Questions and concerns from representatives of special interest groups.

There did not seem to be general recognition or understanding of the CDR process or of the fact that a “list” recommendation from federally sponsored CEDAC did not necessarily guarantee the prompt inclusion of a new drug on the formulary. Indeed, despite all positive recommendations from CEDAC, some potentially valuable drugs might move very slowly towards ministerial approval because of provincial budgetary constraints or other political pressures. Thus it was interesting to note the frequently recurring mention of the need for enhanced “transparency” and “accountability” in the review process.

There was considerable anxiety expressed about the impact that internet pharmacy sales of drugs from Canada to the U.S. would have on the willingness of manufacturers of new “wonder drugs” to seek NOCs in Canada because of the perceived reduction of profit through reduction of sales at the higher prices usually charged for pharmaceuticals in the U.S. There was very distinct fear that such drugs might take a very long time to reach the Canadian market and even longer to find a place on a provincial formulary.

The plight of some patients was evident in reports of high prices preventing access to essential drugs not yet on the provincial formularies. In one case, the speaker indicated that he *could expect to die very soon* without access to a very expensive drug for treatment of Hepatitis C. The question arises: Would it not be more appropriate for individuals and groups to lobby intensively at the provincial level, where the final decision has to be made whether “to list” or “not to list” a drug.

Many thanks to Derek Ilse for attending the Common Drug Review meeting in Toronto in November 2005 and providing the above report.

Advocacy: A Way to Be Proactive

Sometimes things have a way of working out in a serendipitous way, as when the author of the following personal story gave us permission to reproduce it in this newsletter at exactly the time that COPN is planning to be involved in advocacy events across the country. When you read June’s story, you will see that it is a clarion call to action, for, as June says, “There is a long way to go in meeting the needs of those who...are unable to take advantage of more effective medications and other services.” Advocacy events give us the opportunity to influence decision-makers in healthcare policy at the local and provincial level. We can speak to elected officials and civil servants and tell them what issues are of concern, whether it’s access to the most effective medications or more sites for bone mineral density testing. We can provide feedback, information and real solutions to the issues we raise.

We will be contacting many of you in parts of the country where Osteoporosis Canada Chapters are planning an advocacy event. Keep in mind that you can make a difference – sign up to participate in one of these events when you have the chance. You can only gain from any changes to healthcare policy and services that might result!

Knowledge is Power: A Bit of My Story

I had been experiencing frequent upper back pain and my suspicion of having osteoporosis was confirmed several years ago. I enrolled in a clinical trial for one of the later bisphosphonates. Because of my low bone density, I chose to drop out of the trial and begin an approved medication. To further my knowledge of the condition and to help myself keep abreast of new treatments (and to stay active after retirement from a nursing career) I became a volunteer with the Osteoporosis Society of British Columbia (OSTOP), now the BC Division of Osteoporosis Canada. My role was to respond to the frequent inquiries from the public about osteoporosis.

I fully agree that we must be proactive in order to avail ourselves of the best available options for preventing, arresting and treating the condition. The medical field and the public are now much more aware than they were 10 years ago - progress is being made. There is, however, a long way to go in meeting the needs of those who are severely disabled and often physically and/or financially unable to take advantage of more effective medications and other services designed for people with osteoporosis. I have now left that volunteer position, but would encourage everyone with the condition to "Get Involved" in some way for your physical and psychological wellbeing. Knowledge is Power!

June D., BC

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.

What's Happening in Your Area?

Would you like to be the eyes and ears of COPN in your region? COPN wants to know what is going on in your area that would be of interest to people living with osteoporosis in other parts of Canada. Gather the information and 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* and provide content for our web pages

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. 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. Any information contained in *COPING* is not intended to replace medical advice. Readers are advised to discuss their individual circumstances with their physician.