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## **Zometa helps with bone pain**

by John Hoffman

About a year ago, things were not going well for Terry Bubbs. The 59-year-old from Winnipeg, Manitoba was having various bone problems related to metastatic prostate cancer: pain, lightheadedness, and what he refers to as a general wobbliness. "If sat and watched a movie for a couple of hours, when I'd get up from my chair, I'd often fall because of a sudden weakness in my legs," Terry explains.

His doctor said these symptoms were due to spinal cord compression, a complication experienced by some prostate cancer patients with bone metastases.

At the time Terry Bubbs was experiencing these symptoms, he was taking Aredia, a drug often given to breast cancer patients with bone metastases. However, it was doing very little. So when Terry was offered the chance to attend the annual meetings of the Canadian Urological Association (CUA), he and his wife were eager to go -- to see if they could learn anything that might improve Terry's outlook.



That trip to Halifax was more fruitful than they could have imagined. Not only did it lead to treatment with Zometa (zoledronic acid), a drug that relieved some of his symptoms, it set off a chain of events that would lead to this medication becoming funded and available to Manitoba men with bone metastatic prostate cancer.

Rather than fight the cancer directly, Zometa helps keep bones strong and less vulnerable to the effects of cancer, resulting in less pain and fewer fractures and other skeletal-related events such as spinal cord compression.

While at the CAU meetings, Terry's wife, Anne, happened to sit beside Joe Applebaum, past president of the Montreal West Island Prostate Cancer Support Group who, as people often do at these get togethers, asked what Terry's story was. After Joe heard about Terry's situation, he spoke to Montreal urologist Fred Saad, who said, "He might as well be taking a placebo for all the good it will do him. He should be taking Zometa."

The next morning, Terry and Anne visited the booth of Novartis, the manufacturer of Zometa, looking for more information. That's where they met Eric Lefrancois, a Novartis rep from Montreal. Lefrancois gave them information, but he knew it would not be easy for Terry to get Zometa. "At that time, Zometa was funded for prostate cancer treatment only in Ontario and Quebec," he explains. "However, if patients and physicians really want to use a drug and live in a province where that particular drug is not funded, our company has a program in place to assist them."

Eventually, Novartis was able to arrange for Zometa to be shipped to Terry's local pharmacy, so he could receive it through intravenous infusion at his cancer clinic. "But the nurses at the clinic said they couldn't do the infusion because it wasn't on the formulary (list of approved drugs for treatment of various cancers)," Terry explains. It's easy to imagine how frustrating it would be to have a potentially helpful drug in your hands, but not have a way to get it into your body.

Happily, arrangements were made for Terry to travel to Lake of the Woods Hospital in Kenora, Ontario, where the drug was funded. The effect of treatment was dramatic. "Right away I felt better," Bubbs says. "I had less pain, and less trembles. Even my doctor noticed. He ran his hand up and down my spine and said, 'The lumps and bumps are gone.'"

### **Why would Canadians have to travel to another province to access treatment?**

Each province has its own process for approving cancer drugs. To make a long story short, expert committees scrutinize research evidence about the effectiveness of the new drug and make recommendations as to the clinical circumstances in which this treatment should be approved. The Ministry of Health, or cancer care agency, then makes final decisions.

Apart from budget -- like many new cancer drugs, Zometa is expensive -- three of the main criteria are survival time, disease-free survival time, and quality of life. Lefrancois explains that some of the benefits of Zometa fall in between the cracks. "The data showing the benefits of Zometa were not based on the particular end points used by some of the cancer care agencies," he explains. Although data from a clinical trial showed that men taking Zometa had fewer fractures, less severe pain, and less spinal cord compression than men taking a placebo, these specific outcomes were different from the more general quality of life indicators used by the committees in some provinces.

These niceties of funding criteria are completely lost on men with prostate cancer. All Terry knew was that he felt better than he had in a long time.

Terry's case spurred his local prostate cancer support group to become involved in a campaign to have Zometa added to the Manitoba formulary. "Our group sent a letter to the Minister of Health," says Norm Oman, chair of the Winnipeg Prostate Cancer Support Group. "We also sent a letter to Cancer Care Manitoba, and had several meetings and telephone conversations with individual doctors who were on the committee which approves funding for cancer drugs."

Dr. Darrel Drachenberg, who heads up the geno-urinary division of Cancer Care Manitoba, also made a presentation to the committee. Within months Zometa became available to all Manitoba men in Terry's situation.

But currently, the cross-Canada availability of Zometa for prostate cancer could best be described as a patchwork. In Ontario, Quebec, and Manitoba, Zometa is fully funded for men with hormone refractory prostate cancer. In Alberta, it's not covered by the province, but Zometa is available in certain hospitals where it has been added to the formulary. In British Columbia, it is only available in cases that meet strict criteria for palliative care. In Saskatchewan and the Atlantic provinces, Zometa isn't funded at all.

Support groups can play an important role in keeping tabs on these sorts of inequities in prostate cancer treatment. Urge your local group to become involved in advocacy work to ensure equal access to treatment for all Canadian men with prostate cancer.

### **HIFU: A New Treatment for Prostate Cancer**

Bill Hall and his wife Anne run a lumber business in Renfrew, Ontario. At age 76, Bill is out in the yard all day, heavily involved in the day-to-day activities of the business.

So when Bill's urologist recommended hormone therapy followed by radiation to treat Bill's prostate cancer, the couple were very concerned. "We were going to have to travel to Ottawa, 100 km away, five days a



week for seven weeks,” Bill says. “Plus the radiation wouldn’t start for a few months, so I would be dealing with this for a long time.”

Then Bill heard about HIFU (High Intensity Focused Ultrasound), a non-invasive prostate cancer treatment, and called a private Toronto clinic for more information. “It seemed like it would be different than the radiation,” he said, “and I was so pleased when they told me they could perform the procedure in two weeks, and I’d be home in two days.”

HIFU is a procedure in which a probe placed into the rectum emits a focused sound wave at the prostate, quickly raising the temperature and destroying the cells. This process is repeated until all the prostate tissue is destroyed. The treatment usually takes 1-3 hours, depending on prostate size.

The HIFU treatment has been used in Europe for several years and for two years in Canada, primarily on patients with T1 or T2 cancer localized in the prostate. It is available in countries all over the world, though not in the US. Health Canada has licensed two HIFU systems: Ablatherm® (2003) (<http://www.hifu.ca>), operating in Don Mills, Ontario, and Sonablate® 500 (2005) (<http://www.can-amhifu.com>), operating in downtown Toronto. HIFU is not covered by most insurance companies, and the procedure costs approximately \$20,000 CDN.

Clinical studies show that 85–95% of qualified patients undergoing HIFU therapy, using either system, will not require further treatment for prostate cancer. The studies show a low percentage of incontinence and urethral stenosis (narrowing) following the procedure. Impotence results vary widely, depending on the location of the cancer.

Bill's urologist did not recommend HIFU because Bill's Gleason score was high (8). Bill sought a second opinion from another urologist, who convinced him that HIFU was appropriate in his case, and, in January 2007, Bill travelled to Don Mills with his wife, to undergo treatment at the Ablatherm facility.

The procedure caused “close to zero pain,” and Bill easily managed the train-ride back to Ottawa the next day. Bill says the catheter was a “nuisance” (it stayed in for two weeks), and he experienced slight incontinence for a day or so after the catheter came out. He continues to have difficulty with impotence, but has been told this will clear up in a few months.

Three months after the procedure, Bill's PSA level was slightly higher, which is considered normal. Bill's next PSA, six months after the treatment, will indicate whether the procedure has removed all the cancer.

For now, though, Bill is happy with the HIFU treatment. “I was pleased that my general well-being was unchanged, that the procedure time was short, and that I didn’t have to deal with the side effects of hormones and radiation treatment.”

“If my next PSA tests show the cancer is gone, I would consider this a home run.”

*The HIFU treatment is not appropriate for all prostate cancer patients. For more information about HIFU, including comparisons between Ablatherm® and Sonablate® 500 systems, clinical studies, doctor contact information, and patient stories, visit*

Ablatherm – <http://www.hifu.ca>

Sonablate – <http://www.can-amhifu.com>

Patient forums discussing the Canadian procedures can be found at <http://www.cancercompass.com/message-board/message/all,3457,0.htm>

## CPCN & Support Groups: On your team against PCa

CPCN, with the generous support of sanofi-aventis Canada Inc., is staging a new awareness campaign on the benefits of teamwork in the fight against prostate cancer. Urologists and prostate cancer support groups across Canada will receive display units and rack cards that outline the advantages to men battling prostate cancer of pulling together a team of health care professionals, family and friends, and prostate cancer support group members.

As the campaign says, support groups provide your team with a "hometown advantage."

*These local survivors of prostate cancer and their families have a wide range of experiences and will give you the confidence to make the decisions that are right for you.*



Many confirm the benefit to men of connecting with others who are facing the challenge of prostate cancer. As Nick Ramage of BC writes, "Cancer survivors -- no matter what type of cancer, no matter what age -- exhibit the will to fight the disease, the spirit to be optimistic, and the humour to laugh when tough times come. The community of survivors can teach us all true lessons in living life to the fullest. " Researchers also suggest that support group membership is linked to improved coping and adjustment, increased knowledge about the disease and its treatment, a better ability to maintain treatment regimes, reduced stress, and even better health and a longer life span. (See the reviews of this literature listed below.)

Local support groups are enthusiastic partners in this campaign. They are recommending various places for the distribution of the rack cards, reporting to CPCN on the numbers needed in each location, and arranging matters on the ground.

And the campaign is already starting to generate excitement. Ray Martheleur reports from Nova Scotia: *At our regular meeting of the Cape Breton prostate cancer support group last evening, the members were very impressed with the cards and holder that I received several weeks ago ... we have to get the word out to the people to listen, ask questions, and keep on living. We feel that this card, made available in pharmacies and other locations, could prompt a call to us.*

## REFERENCES

[Prostate Cancer Canada](#), "[Nick's story](#)."

L. Thaxton, J. G. Emshoff, and O. Guessous, "[Prostate Cancer Support Groups: A literature review](#)." Journal of Psychosocial Oncology 23, no.1 (2005): 25-40.

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## CPCN Welcomes Three New Directors

Heightened public awareness about the benefits of support groups (not to mention the growing prestige of the CPCN) is evident when you are introduced to the three newest members of the CPCN Board of Directors: William Kennedy, Murray Gordon, and David Stanger (pictured opposite). The men also represent the geographic reach of our organization, coming as they do from eastern, central, and western Canada.

William Kennedy has recently retired from the Faculty of Education at Memorial University in St. John's, Newfoundland, but you wouldn't know it from his schedule. He seems to be continuing uninterrupted his more than 25-year career of researching, writing, and teaching in the fields of education and counselling psychology. Kennedy is a published author, and he is currently researching a history of counselling in Newfoundland. As well, he is completing an SSHRC-funded study of the effects of natural resource depletion on the health and education of people in several Newfoundland and Nova Scotia communities. In spite of this busy "retirement," Kennedy remains active in professional and community-based organizations in the province. Two things of particular relevance are his service as vice-chair of the Health and Community Services Board, St. John's Region, and his chairmanship of the Prostate Cancer Division of the Canadian Cancer Society.



Murray Gordon, a prostate cancer survivor, hails from Carp, Ontario. (He is pictured opposite.) Before retiring, he worked for 27 years with Agriculture Canada and the Canadian Food Inspection Agency (CFIA). Prior to that, he worked in private practice. Over his long career in veterinary medicine, Murray has served on numerous national organizations. He was Chief Auditor and Associate Director of Field Services for the National Animal Health Program, and he served on the national executive of the Canadian Veterinary Medical Association for four years. Since "retiring" and managing to spend "a fair bit of time at the curling rink," Gordon has served the prostate cancer community as well. He has been co-chair of the Regional Cancer Program's Community Advocacy Committee and is currently a member of the steering committee of the Prostate Cancer Association of Ottawa.



David Stanger, a Toronto native who now splits his time between offices in Langley and Calgary, is one of Canada's best-known media professionals, having spent more than 30 years in the Canadian advertising industry. Stanger's contributions to the media profession were recognized in 2004, when his colleagues presented him with the "Audrey" award. In 1997, after 15 years with the firm Baker Lovick, Stanger established his own independent media company (DSA). The firm specializes in media research, media planning, and retail marketing. Stanger has a life-long interest in teaching and in media research. He regularly lectures at universities across the country, and he spent 17 years as a marketing and media instructor at the British Columbia Institute of Technology. He also served for three years as chair of ComBase, North America's largest media study and an initiative of the Canadian Community Newspaper Association.

From psychology to veterinary science to advertising, and from east to west, our new directors bring a wide range of experiences and talents to the CPCN Board.