

**NEW  
WEBSITE  
COMING  
SOON**

# Canadian Prostate Cancer NETWORK

June 2006

The Voice of Prostate Cancer in Canada™

NEWS

Look forward to a new, improved and, most importantly, easier-to-navigate CPCN website in the coming months. Our web team is currently working to give the site a fresh look, add lots of new content and reorganize the existing material. In the past year, it became apparent that the CPCN website was in need of an overhaul. Originally it was designed as a communication tool and clearing house for support groups, but many people now come to cpcn.org looking for comprehensive material about prostate cancer. The current site has lots of information, but there are some gaps, and the content that is there is not as easy to find as it could be. Visitors to the revised site will find a new section called Understanding Prostate Cancer, which will provide in-depth, up-to-date, information about the disease, its diagnosis and



treatment, along with articles devoted to other prostate problems such as benign prostatic hyperplasia (enlarged prostate).

Much of the existing content will remain, such as the support group listings, news items and archived material. However, everything will be organized by subject, and the site will have an internal search engine, which will make it much easier for users to find the information they need quickly. Another new feature will be downloadable PowerPoint presentations which support groups can use for meetings or community awareness activities.

The result will be substantially more and better material and a lot less clicking and scrolling to find it. A firm launch date has not yet been determined, but the new site is expected to be up and running sometime this summer or early fall.

## Winning the war against Prostate Cancer

### National Conference – Calgary

It's time to finalize your plans to attend the third annual CPCN National Conference, which takes place Sunday, July 30 to August 1 at Calgary's Palliser Hotel.

This year's happening will be unlike any other you have attended. Past events have focussed on the medical side of things -- the latest in diagnosis, treatment and research. Our third conference will provide some of that input but it will also take a significant shift in both theme and approach as exemplified by the theme "Winning the War against Prostate Cancer." That's because the prostate cancer community really is waging a war on many fronts. First, each man who is diagnosed with prostate cancer must fight his own private campaign against the disease with the support of his family and medical caregivers. Then there's the ongoing offensive to find better ways to detect and treat the most common cancer to affect men and to find the money to support that important work. But another part of the war is equally significant and requires a new strategy. That's the ongoing battle for public attention and awareness. Let's face it. Some people think that prostate cancer is just an old man's disease. Others say things like, "Widespread screening for prostate cancer is not justified by scientific evidence," "The PSA is not a good test," and, of course, the old saw, "You're more likely to die with it than of it." As a result, prostate cancer doesn't get the public awareness and funding given to some other health conditions.

But support group members know that prostate cancer kills more men than any other cancer except respiratory and colorectal cancers. We know that those lives matter as do the lives of prostate cancer survivors and all the men currently fighting the disease. That's why we will devote a significant part of this year's conference to developing



new strategies to win this war.

The military theme will pervade all aspects of the event. For example, when delegates arrive, they won't register, they'll visit the recruiting desk and be issued dog tags along with the rest of their conference package.

One of our keynote speakers is General (Ret'd) Paul Manson, who will give an address on strategy and tactics and how they can be applied in the war on prostate cancer. We will also welcome back Dr. Stephen Strum, who spoke so eloquently and passionately at our first

conference in 2004. Dr. Strum, a prostate cancer specialist from Ashland, Oregon, will talk about the medical tactics prostate cancer patients can use to fight their own battles.

On Monday afternoon, delegates will attend small group workshops where they will work with professional facilitators to create new strategies to use in the war on prostate cancer. The hope is that each attendee will leave with fresh ideas to help revitalize the awareness and advocacy work of his support group.

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# PSA test under attack again

In April, the Canadian news media carried a number of stories that, once again, seemed to undermine the message the prostate cancer community is trying to convey about the importance of early detection. The coverage, prompted by a new report from the Canadian Cancer Society, was peppered with dismissive statements about PSA testing, such as the lead sentence from a *Globe and Mail* article of April 11: "Three times as many men are being screened for prostate cancer as for colorectal cancer -- even though the test for prostate cancer is of dubious value and testing for colorectal cancer has demonstrable benefits."

The story went on to indicate that the CCS was calling for more screening for colorectal cancer, but that current scientific evidence did not justify population-based screening for prostate cancer. Heather Logan, director of cancer-control policy at the Canadian Cancer Society, was quoted as saying, "There is not enough strong scientific evidence to support screening for PSA."

It's no secret that the PSA test is controversial. Expert opinion ranges from Oregon urologist Dr. Stephen Strum's assertion that the PSA test is the best biomarker in medicine, to that of Stanford University's Dr. Thomas Stamey, who was paraphrased in *Reader's Digest* as saying that the PSA test is so inaccurate that you may as well biopsy men because of the colour of their eyes.

Controversy is common in the field of medicine. It is important for those who believe in the value of the PSA test to understand where organizations like the Canadian Cancer Society are coming from.

CPCN News called Ms. Logan to ask her further questions to clarify her comments about the PSA test. She explained that the recent statements about the relative value of screening for colorectal and prostate cancer arose from a section of the recently released report called Canadian Cancer Statistics 2006. This report looked the number of Canadians who are being screened for certain cancers and also the evidence about the efficacy of organized screening programs.

"Organized screening programs" is a key phrase here. A crucial factor in the PSA discussion is the difference between decisions made with regard to the health of any given individual and what policymakers consider to be evidence-based public health policy. Ms. Logan says that when it comes to cancer screening as prevention policy -- that is, organized, widespread, well-promoted programs designed to screen a high proportion of a given population (e.g., all men over 50) -- two key criteria must be met. "One is that screening must be shown to reduce death rates," she says. This has not yet been demonstrated in prostate cancer, she says, although two large-scale studies that are currently underway should answer that question more definitively in about

two years. "The other criteria is that if the screening leads to more cancers being identified at an earlier stage, there must be a proven, effective way to treat the cancer," Ms. Logan explains. "With ovarian and lung cancers, for example, lack of effective treatment means that the value of early detection on a widespread basis is questionable. It doesn't help to identify cancer early if you can't do anything about it."

With early stage prostate cancer, there are effective treatments. The problem, Ms. Logan says, is that some treatments are invasive, carry significant long-term side effects and may be unnecessary in some cases.

Perhaps, but it's clear that the 4000 Canadian men who lose their lives to prostate cancer each year are not dying of over treatment. Dr. Laurence Klotz, head of the Prostate Cancer Group at Toronto's Sunnybrook Health Science's Centre worries that in the absence of screening, more prostate cancers will not be detected until they have progressed to a stage where the disease is harder to treat. "To stop PSA testing will result in the majority of men with potentially curable disease being diagnosed too late," he wrote in a *Toronto Star* opinion piece in September of 2004. American data supports his assertion. According to the St. Louis-based Urological Research Foundation, in 1991, around the time when PSA testing was just starting to become common, 20 percent of American prostate cancers were already metastatic at the time of diagnosis. By 2002, that number had been reduced to five percent. Surely early detection is better than late?

"It's not a straightforward issue," Ms. Logan admits. "It's fraught with grey areas. That's why we support the idea that men should be informed about prostate cancer and all the facts about screening and treatment." She also noted that CCS has not changed its message about screening for prostate cancer, a position adopted after the National Prostate Cancer Forum in 1997.

That position is, essentially, that men over 50 or younger men with particular risk factors should be made aware of the risks and benefits of screening for prostate cancer via the PSA test and digital rectal exams, so they can make an informed decision about whether or not to get the test. That is similar to the position taken by the Canadian Urological Association.

The question is, can men truly make an informed decision if the main media message they get about the PSA test is that it is of dubious value? Clearly, the work of CPCN and prostate cancer support groups is necessary, because it is directed at individual men and helps to balance out the ongoing negative public sound bites, and simplistic information about the PSA test. As Dr. Strum notes: "The 'problem' with PSA screening rests not with the PSA test and not even with making the diagnosis of prostate cancer. It rests with what we do

with that information with respect to advice the physician gives the patient upon establishing the diagnosis of PC. In the absence of screening, we are asking men to live in a state of ignorance about their prostate health. We are also depriving them of the opportunity to become educated so they can institute measures that improve prostate health along with other aspects of their health that will protect them from prostate cancer."

Therefore, prostate cancer support groups can provide a great service to Canadian men by continuing to engage them in conversations about prostate cancer and making sure they know the whole truth about PSA testing. Here are several facts that all Canadian men should know.

Mortality from prostate cancer has declined steadily since the introduction of the PSA, from a peak of 31.2 deaths per 100,000 in 1991 to 25.5 in 2005. (Source: Canadian Cancer Society)

The five-year relative survival ratio for men diagnosed with prostate cancer in 1985-87 was

73%.\* For men diagnosed between 1992 - 94, after the PSA test had been introduced, the ratio was 89 percent. (Source: Statistics Canada) Some of this is possibly due to more diagnoses in younger men, but it's still an improvement. Media reports about PSA tests seldom mention that monitoring PSA levels over time is much more useful than the result of a single test. In October 2005, a Harvard University study reported that men with prostate cancer who had been getting yearly PSA tests before their diagnosis were three times less likely to die within ten years than patients who had not been undergoing annual screening. (Source: Study presented at the American Society for Therapeutic Radiology and Oncology's 47th Annual Meeting in Denver, Oct. 9, 2005)

**Canadian men need all the facts. Our job is to see they get them.**

*\*That means men diagnosed with prostate cancer were 73% as likely to live for five years as men without prostate cancer.*

## Cycling cross Canada for Prostate Cancer

John Wagontall, a firefighter from Lethbridge, Alberta, is cycling across Canada for prostate cancer this spring and summer. Diagnosed with advanced prostate cancer in December 2004 at the age of 46, John has gone through radiation treatment and hormone deprivation therapy. He decided to pedal across the country to raise awareness about prostate cancer, so other men don't have to experience what he's going through.

Wagontall set out from Mile Zero in Victoria on Monday, May 15, and hopes to end up in Prince Edward Island in late July.

On his Cycle for Life, he plans to give talks along the way and to do everything he can to encourage men, even young men, to get tested regularly. "It's not just an old man's disease," Wagontall says. "We need to take care of ourselves so that we can do our jobs and take care of our families." CPCN was pleased to supply John with materials to assist

his efforts. Along the way, he will collect donations for the Canadian Cancer Society, the Lance Armstrong Foundation and prostate centres across Canada.

Wagontall is an experienced cyclist who rode his bike to work every day for 20 years, even in -45° C weather, and who sometimes undertook longer trips as well. While radiation treatment knocked his energy levels down a bit, he has been training regularly and is confident about his ability to complete the trip.

Wagontall and regional organizers such as the Prostate Centre in Victoria are contacting each fire hall on the route and trying to get them to co-ordinate group talks and media coverage. CPCN members and support groups who wish to support Wagontall or perhaps greet him as he passes through their area can follow his journey by reading his blog at [www.cycleforlife.ca](http://www.cycleforlife.ca)

## Our Voice says thanks



Mairi MacKinnon, managing editor of *Our Voice* magazine, wishes to thank the many CPCN News readers

who sent in stories, questions and requests for subscriptions in recent months. *Our Voice*, a magazine for men with prostate cancer, is published four times a year by Parkhurst Publishing thanks to an unrestricted educational grant from AstraZeneca Canada Inc. Among

other things, *Our Voice* regularly prints a selection of questions and personal stories sent in by readers. Ms. MacKinnon reports that the e-mail address for sending stories and questions has changed. To e-mail a question, story or to request a free one-year subscription to *Our Voice* please use this address: [ourvoice@parkpub.com](mailto:ourvoice@parkpub.com)

Regular mail can continue to be sent to:

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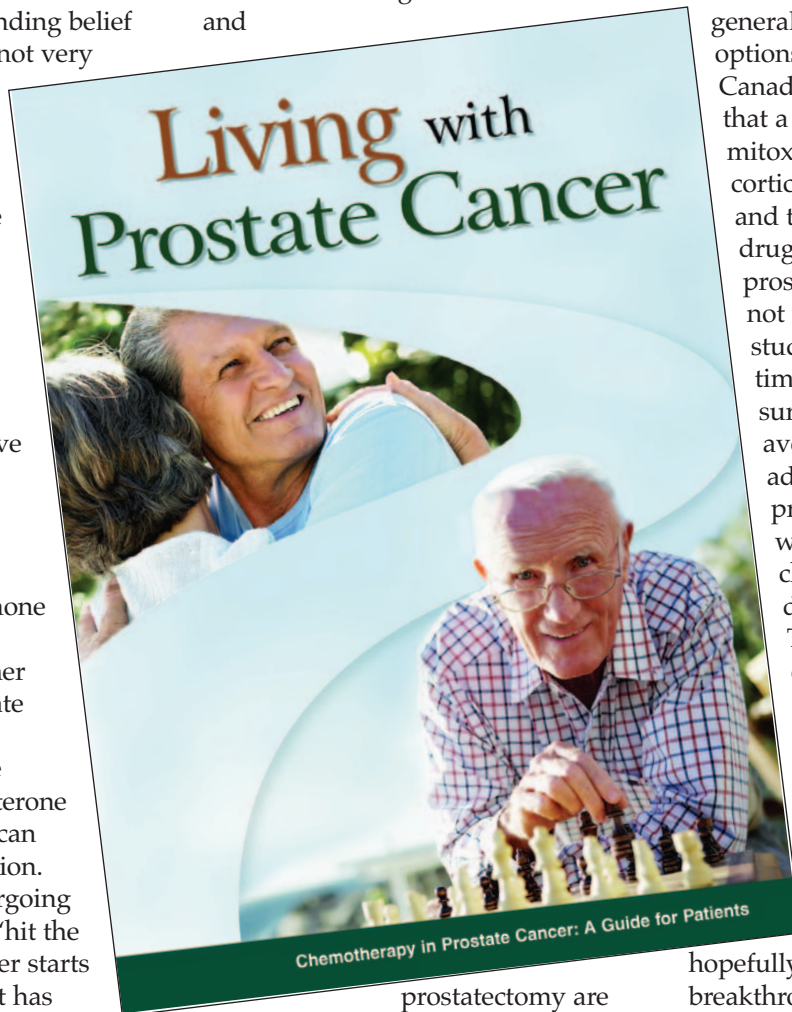
# New booklet on chemotherapy and PCa

Most people think of cancer and chemotherapy as going hand in hand, except with prostate cancer. This is due to a long-standing belief that chemotherapy was not very effective in prostate cancer management and because chemotherapy has not been considered a viable option for older men, who often have other health problems in addition to prostate cancer.

In recent years, however, researchers have been looking into chemotherapy as a treatment for advanced prostate cancer that no longer responds to hormone treatment. Patients with metastatic (spread to other parts of the body) prostate cancer take hormone treatments, which starve cancer cells of the testosterone they need to grow. This can lead to long-term remission. However, patients undergoing hormone therapy often "hit the wall." That is, their cancer starts growing again because it has become resistant to the anti-androgen treatment. This is known as hormone refractory (aka. androgen independent) prostate cancer.

Although earlier detection has led to a complete cure for many men with prostate cancer, a significant minority still reach the hormone

refractory stage. This includes men whose tumors are not detected until the advanced stage when radiation and



prostatectomy are no longer viable treatment options. But even when cancer is detected at an early stage, research indicates that conventional treatment with radiation or radical prostatectomy has a 15 percent failure rate, which means the cancer recurs. Some of these men with aggressive forms of prostate cancer will ultimately reach

the metastatic hormone refractory stage as well.

Men in this situation were generally considered to be out of options. Then, in the mid 1990s a Canadian research group showed that a chemotherapy drug called mitoxanthrone, combined with a corticosteroid, could reduce pain and the need for pain killing drugs in patients with advanced prostate cancer. However it did not prolong life. In 2004 new studies showed, for the first time, small improvements in survival times (2.4 months on average) of men with advanced hormone refractory prostate cancer when they were treated with a chemotherapy drug called docetaxel (trade name Taxotere) combined with the corticosteroid prednisone.

Although extending life by two and a half months is not a huge improvement, this is the first encouraging news of any kind in an area where there has been little hope up to now. And hopefully there will be more breakthroughs in coming years.

One reason to be hopeful is that finding a solution to hormone resistance has become one of the more intense areas in prostate cancer research. For example, Dr. Marianne Sadar, senior scientist with B.C. Cancer Research Agency, has identified a part of the androgen receptor\* that appears to be responsible for the ability of prostate cancer cells to grow in the absence of testosterone. She is working to identify substances that disable the androgen receptor, so they can be used as the basis for new drug

therapies, specific to hormone refractory prostate cancer.

Dr. Paul Rennie, of the Prostate Centre at Vancouver General Hospital, heads up a team of 16 researchers and doctors working on six related research projects, which among other things, will identify genes involved in prostate cancer's progression to the hormone refractory stage. They will test the possibility of blocking the activity of various proteins thought to be involved in this progression to a more aggressive form of prostate cancer. This could also lead to the development of new drugs.

But for now, the newest treatment for hormone refractory prostate cancer is chemotherapy with Taxotere.

For men who would like to learn more about this treatment, CPCN has produced a booklet called *Chemotherapy for Prostate Cancer: A guide for patients*, co-written by urologists, Dr. Fred Saad, director of Urologic Oncology at the University of Montreal and Dr. Michael McLean of Toronto's Princess Margaret Hospital. The booklet explains the issues around chemotherapy for advanced prostate cancer in detail, including how cancer recurrence is detected and all treatment options (including lifestyle factors) for metastatic hormone-refractory prostate cancer with a particular emphasis on the process of treatment with Taxotere.

A limited number of copies of this booklet have been sent to Canadian support groups. Your health care team may also be able to assist you in obtaining a copy.

*\* a protein on a cell membrane that initiates the cellular response to testosterone*

## Communications error causes confusion in B.C.

Prostate cancer support groups in British Columbia were nonplussed earlier this year when they received a letter from the British Columbia and Yukon division of the Canadian Cancer Society (CCS) about new guidelines for prostate cancer support groups. Among other things, the letter stated that prostate cancer support groups would now be required to have two co-facilitators who had been screened and trained by the CCS and that, when planning their group's activities, they would have to choose topics from standardized content modules. The implication seemed to be that all prostate cancer groups would now be required to be affiliated with the CCS and operate under its rules and standards. It seemed like a pre-emptive take over.

Actually, support groups in BC -- or elsewhere in Canada for that matter -- needn't worry. This was all a mistake, says Linda DuBick, vice-president of programs and regions for the B.C. and Yukon division of the CCS. The biggest error was that the memo should have been sent only to support groups who were already affiliated with the CCS. But instead it went out to all prostate cancer groups, most of whom had no formal affiliation with the CCS. "The letter was deficient," Ms. DuBick acknowledges. "It didn't

provide a rationale for what we were doing, and it created the impression that we were trying to apply our standards to all support groups." This past spring, Ms. DuBick met with Len Gross (Vancouver), Ian Baxter (Burnaby) and Ted Butterfield (B.C. Foundation for Prostate Disease) and apologized for the mistake.

The background to all this is that, in 2004, the B.C./Yukon division of the CCS launched a peer support initiative to improve the consistency and quality of support groups. "We had noticed that referrals to CCS support groups from health care providers were decreasing rapidly," Ms. DuBick explains. "We investigated and found a number of concerns about the quality of peer support, and we also realized that we had not done a good enough job of training and supporting volunteers." The new guidelines were part of the initiative to improve quality and consistency in peer services including support groups (for all cancers, not just prostate). "We know that support groups are doing some wonderful work," says Ms. DuBick. "If any prostate cancer groups would like to inquire about the training, support and other benefits of affiliation with the Cancer Society, we'd be happy to hear from you."

## Videoconferencing: The wave of the future

The Thunder Bay and Area Prostate Support and Awareness Group continues to make impressive strides in networking with other towns. Anyone who has traveled through northern Ontario knows that its population is spread out over a huge area. Many communities don't have sufficient numbers to sustain a support group, and distances between towns often make regional groups impractical as well. The Thunder Bay group has met that challenge through video conferencing. Last year, we reported that they were providing presentations via video to prostate cancer patient groups in Dryden, Hearst and Kenora. Since then they have added Fort Frances and Nipigon/ Red Rock to the video network. They hope to be able to bring Terrace Bay/Schreiber on board later this year.

"It's gone over quite well," says Bill Vantour, president of the Thunder Bay and area group. "People from the other towns watch our presentations live on a television monitor. They can even

ask questions when the presentation is over. One time recently we had 21 people watching from Hearst and 12 in Dryden."

Vantour says everything is handled from the video conference room at Thunder Bay Regional Hospital, a facility which is used primarily to connect with smaller northern hospitals for medical purposes. "It's pretty well foolproof for us," he says. "There's a video conference operator who handles everything."

So far presentations, which currently take place every other month, have covered standard topics such as prostate cancer treatments and side effects such as incontinence and ED. The sessions are generally attended by between 5 and 25 men in each location. Let's hope this innovative approach to prostate cancer support will soon be routine in more remote communities across Canada.

The video conferencing facilities in Thunder Bay were supplied through a grant from AstraZeneca Canada Inc.

# Private Member's PSA Bill in Ontario

Bill Mauro, the MPP for Thunder Bay-Atikokan in northern Ontario, has re-introduced his private member's bill to make PSA testing free for men in Ontario. Bill #4 proposes to amend Ontario's Health Insurance Act to make screening for prostate cancer using the prostate-specific antigen test an insured service for the purposes of the Act. If his bill passes, Ontario men without diagnosed or suspected prostate cancer will no longer have to pay for their own PSA test. Right now, the province pays for PSA tests only



for men who have been treated for cancer or whose doctors suspect cancer because of the results of a physical examination (including digital rectal exam). Because it did not get passed in the previous session, Mr. Mauro had to re-introduce his bill when the Ontario Legislature re-opened in autumn 2005. Currently, Bill #4 is at the committee stage, where the challenge is navigating the politics required to get on the agenda.

Expressions of support from individuals and support groups in

Ontario will undoubtedly assist Mr. Mauro in getting his legislation passed. The Thunder Bay and Area Prostate Support and Awareness group has sent several mailings to all Ontario MPPs, along with five cabinet ministers and Ontario Premier Dalton McGuinty. To date, they have received 39 replies, 37 of which have indicated support for Mr. Mauro's bill.

Anyone interested in supporting Bill #4 is invited to contact their MPP, Minister of Health George Smitherman or Premier McGuinty. Contact information for your local MPP can be found in the government pages of the telephone directory. The CPCN website ([www.cpcn.org](http://www.cpcn.org)) also has a link that will take you to contact information for all Ontario MPPs.

## CPCN's privacy policy

Personal information is any information that can be used to distinguish, identify or contact a specific individual.

Personal information gathered by CPCN is kept in confidence. Our directors and employees are authorized to access personal information based only on their need to deal with the information for the reason(s) for which it was obtained. Safeguards are in place to ensure that the information is not disclosed or shared more widely than is necessary to achieve the purpose for which it was gathered. We also take measures to ensure that the integrity of this information is maintained and to prevent it being lost or destroyed.

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Email: [cpcn@nexicom.net](mailto:cpcn@nexicom.net)

Mark your letter or email "Please delete my personal information from your mailing list".

# A donation – worth thinking about

When you are thinking about where your charity dollars will go this year, please consider a donation to the Canadian Prostate Cancer Network.

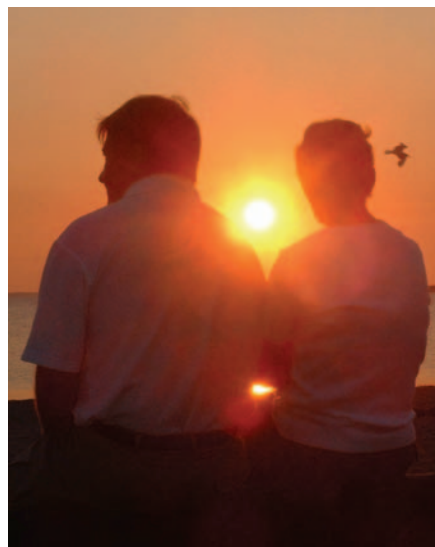
CPCN is a registered charity that depends on private donations to continue its work on behalf of the 20,000 Canadian men who are diagnosed with prostate cancer every year and the many others living with the disease.

Your dollars will help CPCN to

- support individuals and their families by providing information on prostate cancer to newly

diagnosed patients and assisting in the creation and maintenance of prostate cancer support groups in communities across Canada;

- increase awareness of prostate cancer among the general public by producing and distributing print, radio, and television materials; and
- represent the survivor's perspective while working with government, industry and the medical community, advocating for better treatment modalities and increased funding for research into the disease.



# Winning the war *continued from p. 1*

To cap the military theme, the gala banquet on Monday night, will have a MASH 4077th theme.

Attendees will be issued mess hall trays for their supper. Fortunately, for those looking forward to a fine meal, the resemblance to military life ends with the theme. CPCN

president Bob Shiell assures us that the food that night will definitely not be like the fare eaten by Hawkeye Pierce, Radar and Hotlips Houlihan. And don't worry about

having to sleep in a bunkbed or having to bounce a dime on your crisply made bed in the morning. The Fairmont Palliser, the site of our first convention in 2004, is one of Calgary's finest hotels.



Fund. She believes that prostate cancer's time has come. "A window has opened for prostate cancer," Ms. Parry declared in her closing remarks at the Prostate Cancer Charity's national convention, last year. "But you have only got a very limited time in

which you can move that agenda forwards. I really do believe that prostate cancer has moved far enough now for you to be able to go that final mile." She will deal directly with the issue of why breast cancer gets so much attention and why prostate cancer doesn't.

Dr. Larry Goldenberger, director of the Prostate Centre at Vancouver General Hospital, will speak at a special session on advanced prostate cancer, a topic requested by CPCN members. Dr. Goldenberger is also the author of *Prostate Cancer: All you need to know to take an active part in your treatment*, which some people are calling the best prostate cancer book for patients.

To cap it all off, CPCN president Bob Shiell will present the President's Award to an individual who has provided outstanding service in prostate cancer support and awareness. The winner receives

a plaque and a \$1000.00 cheque for awareness activities in his community. Past winners include Bren Witt of Kelowna and Colin Campbell of Owen Sound. There's still time to send in nominations for the President's Award. To nominate a deserving individual, send a one page summary of his or her achievements to CPCN executive director, Wally Seeley, P.O. Box 1253, Lakefield, Ont. K0L 1H0. E-mail [cpcn@nexicom.net](mailto:cpcn@nexicom.net)

All in all, it should be another grand event. Make your arrangements soon.

Registration is \$150.00 per person and covers all activities including meals (but not accommodation).

Accommodation must be reserved separately. To reserve a room at the Fairmont Palliser, call 1-800-441-1414 or 403-260-1230.

WestJet is the official airline of the CPCN National Conference. Delegates who book their flight through WestJet can save 10% off that airline's best available regular fares.

In appreciation for their work in the trenches, CPCN will waive the registration fee for one person from each of the 125 support groups across the country.

To register online, visit [www.cpcn.org](http://www.cpcn.org).

To register by mail: CPCN, Box 1253, Lakefield, Ont. K0L 2H0.

## OTHER HIGHLIGHTS

CPCN is very fortunate to have confirmed the appearance of Vivienne Parry, an acclaimed British writer/broadcaster, whose warmth and wit never fail to capture the hearts and minds of her audiences. Ms. Parry has covered an extraordinary range of scientific topics in her career. She also helped found the Prostate Cancer Charity in the U.K., and was once a trustee of the Princess Diana Memorial



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This newsletter has been produced by the Canadian Prostate Cancer Network. CPCN welcomes comments, contributions of articles or questions.

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