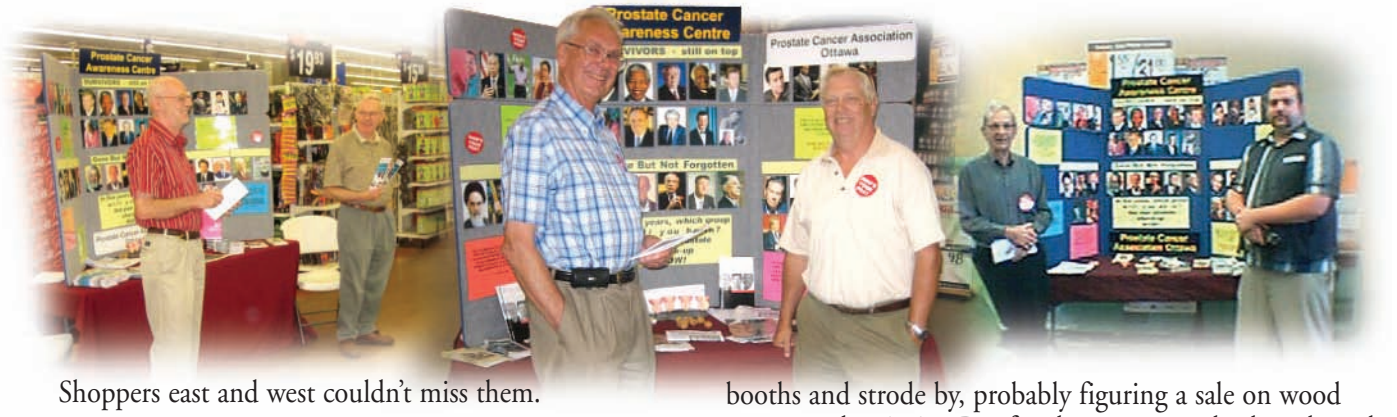
The Walnut

NEWSLETTER OF THE PROSTATE CANCER ASSOCIATION OTTAWA — OCTOBER 2007

P.O. BOX 23122, OTTAWA, ON. K2A 4E2 • (613) 828-0762 • pca@ncf.ca

Volunteers "man" the booths To get the word out during PC Week

By Drake Gifford *Foreign Correspondent - The Walnut*



Shoppers east and west couldn't miss them.

There was only one way to get to the discounted floor tiles, Halloween costumes or cases of soft drinks. That was to run the Prostate Cancer gauntlet.

During last month's Prostate Cancer Awareness Week, a number of men volunteered their time to help the spread the word about early screening and detection of the disease. Booths were set up at various big box stores around town. As well, another group spent the early and late morning hours with the Canadian Cancer Society at OC Transpo on St. Laurent Boulevard handing out information to hundreds of employees.

It may not have been the most exciting way to spend a couple of hours. But it would be hard to find a more important one.

Backed by the striking photo display of who is still with us and who has departed this mortal coil, PCAO members greeted customers and worked their magic to educate. Indeed, some shoppers chose to ignore the booths and strode by, probably figuring a sale on wood screws took priority. But for the most part, both male and female shoppers "of a certain age" responded positively to the effort.

Some were forthright about their experiences or checkups. Others elected to sneak in sidebar tales about what they'd gone through. One compelling story was from a man who described spending two years with a catheter before a different treatment was devised for his post-radiation incontinence.

Thanks to cooperation from the stores, a special CPCN supplement in the Globe and Mail, Citizen columnist Tony Coté's revelation about his own impending surgery, and a Citizen column by PCAO member Richard Bercuson exhorting survivors to spread the word, the event was a tremendous success.

The PCAO acknowledges the hours spent by so many volunteers that weekend. A special debt of gratitude goes to Ron Marsland who organized it all.

Cracking open this Walnut:

Page 1 PC in the stores
Page 2 The Chairman says…
Page 3 A landmark study
Page 4 Bright future for treatment
Page 5 More men need testing
Page 6 Drake Gifford: Now what?

Stores that participated in Prostate Cancer Awareness Week:

West:
Rona Home and Garden
Costco
Walmart

East:
Rona Home and Garden (Innes Rd.)
Walmart

The PCAO thanks both the Canadian Cancer Society for its continuing cooperation and support and OC Transpo for its cooperation on behalf of its employees.

Message from the Chair

The PSA test doesn't save lives - nor does a mammogram, an FOBT, or any other test or examination for deadly disease. But that doesn't make them any less valuable to the welfare of both the individual and society. So I'm pleased that the Ontario Liberals made the pledge to include diagnostic PSA testing under OHIP. That doesn't mean you have to vote for them but they deserve credit for ignoring the bureaucratic caution that has relied on the argument that the test doesn't save lives.

I am so bold as to suggest, despite the best medicines and practitioners, nothing saves lives. We are all going to die some day, some how. In the case of the PSA test, it does provide a reliable indicator of a problem for men that, if not treated in some form, can lead to death earlier and more painfully than if it had been treated. That treatment, be it watchful waiting or the more aggressive methods, does ensure extending a person's life that has greater quality to it. This is a contribution to that person's personal life and, in many cases, to the continued productive input/output to the community in which he lives and works.

Ironically, although I was PSA- and DRE-tested annually after turning fifty, it was the latter test that raised the probability I was about to become a statistic. But my experience since then has only served to strengthen my belief that PSA testing for the mature male population is beneficial and worthwhile to the individual and to society.

Now, even if the coverage is assured by the next Ontario government, the tricks will be to persuade men to have the test, to persuade doctors to issue the requisition and that both doctor and patient understand one PSA test is insufficient for an accurate "read" of the threat. I don't ignore the false-positive argument (particularly with a reading under 10) but is up to the medical community to ensure accurate interpretation of test results to prevent unnecessary or inappropriate treatment based on a single reading. The patient also must do his part by educating himself about prostate cancer.

As survivors, we have played a significant role to increase awareness about this cancer. As our Page 1 story indicates, thousands of Ottawa men and their families were met during Prostate Cancer Awareness Week by our members as they entered major stores. Throughout the year, the Association responds to requests for information and speakers and our regular monthly meetings are open to all as is our website and newsletter. Even when the diagnostic PSA test is paid for, we will still have our work to do to ensure its use and proper interpretation and to provide men with the knowledge that life will still go on whatever the result.

Ted Johnston

Thursday, October 18, 2007

6:00 -7:15 P.M. Orientation for new patients and spouses. The presentation is timed to allow patients to hear the main speaker but everyone is welcome to continue this consultative discussion for as long as they find it useful.

6:30 P.M. Members are welcome to socialize and share experiences over coffee, tea and biscuits.

7:00 P.M. Meeting called to order - Association Business

7:20 p.m. At the moment of deadline, we were awaiting confirmation that a Public Health representative will give advice on maintaining good health in the winter months, how to prepare for a possible pandemic, and protective measures for people with lowered immune systems. Check the website, **www.ncf.ca/pca**, for updated information or read the Sunday Citizen "Our Town" page on October 14.

We meet the third Thursday of each month at St. Stephen's Anglican Church, 930 Watson Street. Follow the Queensway to the Pinecrest exit and proceed north, past the traffic lights, to St. Stephen's Steet on the left. Parking is at the rear of the church.

PLEASE REMEMBER YOUR CONTRIBUTION FOR ST. STEPHEN'S FOOD BANK.

New study will compare PC treatments; Some comment it will take too long

The Canadian Cancer Society announced in September a study to assess which patients will benefit from aggressive treatment at the time of diagnosis. Joining with the National Cancer Institute of Canada Clinical Trials Group, this will be an international study extending over 15 years.

Called START (Surveillance Therapy Against Radical Treatment), the study is designed to compare standard treatment for prostate cancer – either surgery or radiation – with active surveillance. Some 2130 newly diagnosed patients in Canada, USA, England and European countries with low-risk cancer will be enrolled and followed over the course of years. Half will be randomly selected for treatment and the other half are to be closely monitored during regular physical visits.

Details on the study are available from the Canadian Cancer Society website, **www.cancer.ca**.

At our September meeting, Murray Gordon invited members to comment on the study's approach. Bernard Poirier took up the challenge to make the following observations:

To say that the "START clinical trial will answer . . . whether or not, and when to start aggressive treatment" may be misleading in not stating how it will do so. Simply waiting for up to15 years to determine whether or not the patient's cancer has progressed is no different than what we have now.

At first glance, the question "which patients benefit from aggressive treatment at the time of the diagnosis" could be seen as "loaded" - in that the clinicians, at the time of diagnosis, already can anticipate who are those patients to be treated aggressively. The study outline refers to the "biggest" choice a patient is asked to make—whether the treatment should be *immediate* or to remain on *active surveillance*.

It should be remembered here that we are dealing with what is a *localized and apparently non-aggressive* cancer. It is true that a choice remains but, to the patient who has just been given the diagnosis, the shock is severe. When the cancer has been confirmed, the shock is worse and, as a measure of comfort, that aspect of aggressiveness should be stressed.

This may or may not help but herein enters yet another aspect which is recognized as weak in the clinical element, the psychological effect. Too much is already known by the layman not to be aware of the negative aspects of various functions. This is not to mention the two first elements known as "Denial" and "Anger," which make the third element of "Bargaining" a natural, but something which also puts the medical authority on the spot.

All practitioners involved need to make a psychological evaluation of the patient by closely observing reactions to evaluations. This alone can help tremendously in determining when to broach the matter of aggressive treatment and how. A low key explanation of "possibilities," even when the first PSA is taken, lays the groundwork for any of the changes that may take place thereafter. Determining the patient's dietary and physical habits along with age and general health provide further clues on the method of approaching and evaluating the situation.

Liberals promise to cover PSA test

The Ontario Liberals have promised to cover the PSA test under OHIP as a diagnostic test. Health Promotion Minister Jim Watson held a press conference in late September to bring attention to the pledge, which generally would apply for men 50 years and over.

Ted Johnston, Chairman of PCAO, attended the press conference and expressed the Association's pleasure at the pledge and presented the Minister with a reef knot pin and a supporter's wrist band. He noted that the Association has long advocated early testing to establish the baseline and the need to observe the velocity of change before acting in haste. He also pointed out to the Minister the related problem of a shortage of family doctors in the province.

Neither the Progressive Conservatives nor the NDP are known to have made a similar pledge, although the Green Party indicated its support. Cliff Oldridge, an Ottawa resident still free of prostate cancer, embarked on a campaign this year to have the test covered. He wrote to all the party leaders as well as individual MPPs urging they give this consideration. He joined other individuals and organizations who have similarly called for coverage of the test. At the press conference Oldridge said he was pleased and excited by the announcement.

PCAO THANKS ASTRA ZENECA FOR ITS GENEROUS SUPPORT OF THE WALNUT

PCAO PROSTATE CANCER ASSOCIATION OTTAWA

P.O Box 23122
Ottawa, ON. K2A 4E2
Tel: (613) 828-0762 (Voice Mail)
E-mail: pca@ncf.ca
Website: **www.ncf.ca/pca**

The PCAO is a volunteer organization of prostate cancer survivors and caregivers. Our purpose is to support newly- diagnosed, current and continuing patients and their caregivers.

PCAO is a member of the CANADIAN PROSTATE CANCER NETWORK: www.cpcn.org

PCAO MISSION STATEMENT

We provide information on prostate cancer to those in need, gathered from a variety of sources. We participate in events that provide a venue for promoting awareness of prostate cancer through our informed member interaction at public gatherings or as speakers. Raising funds for prostate cancer research is a continuing challenge. We collaborate with local organizations such as the Ottawa Regional Cancer Centre, Canadian Cancer Society, and urologists and oncologists, as key sources for information

A bright future looms for local PCa treatment: Doiron

There's a brighter future ahead for prostate cancer treatment in the Ottawa Valley, according to Greg Doiron, Director of Clinical Operations at The Ottawa Hospital Regional Cancer Centre. Speaking to the September meeting of PCAO, Mr. Doiron acknowledged that the treatment wait times have been among the worst in the province but that should change as new structures and equipment come on line.

His presentation focused on the capital expansion planned for the regional cancer centre. This includes new buildings and radiation bunkers at both the General site of The Ottawa Hospital and the Queensway-Carleton Hospital.

"It has been ground breaking work," said Mr. Doiron, "to develop the first partnership based on regional needs." The agreement with Queensway will see new capability to deal with cancer patients in Ottawa west and the upper Ottawa Valley.

The poor record on wait times is largely for radiation therapy and this is where the big changes can be expected. New bunkers at both the hospitals are to be built ready for patients by 2010. They will be part of new and expanded facilities that will also increase chemotherapy stations and facilitate surgical activity. Construction at both sites is expected to begin by January 2008.

"Prostate cancer has been seen as one of the slower evolving diseases, and this has been used as an excuse for not treating it more aggressively," said Mr. Doiron. "But that is going to change with this expansion and there will be a major impact on the community."

There are now seven radiation machines operating at the General site, and approval has been given for two more. There will be three radiation machines at the Queensway-Carleton in the first phase of development. Planning at both sites will also allow for more machines to be added and refurbishing of present equipment will add to capacity.

"As well, by 2014, we expect to triple our chemotherapy capacity at the two sites," he added. "These will augment chemotherapy stations now in existence at the regional hospitals."

Funding and facilities will also be in place to expand preventative oncology, support care, training, basic science research and strengthening the clinical trials.

Doiron gives PCAO pat on the back

Before he made his presentation, Greg Doiron paid tribute to the work of the Association and its members:

"The work that your team has been doing every year to educate and inform this community about prostate cancer, to get the word out about the kinds of support that are there, are so important.

"I can't tell you how often I am told by my staff and our patients about the impact this group is having. So all of you who had your hands in the air earlier and will have your hands in the air in terms of volunteering on future events, I commend you for the hard work and dedication on this fantastic cause."

More men need testing, foundation says

By André Picard *Public Health Reporter of the* Globe and Mail

Fewer than two in every five Canadian men in the high-risk age group have been tested for prostate cancer in the past year, a new survey shows.

Specifically, only 39 per cent of men over the age of 45 have taken a blood test to measure their prostate specific antigen (PSA) level in the past year, while 33 per cent have undergone a digital rectal examination (DRE), according to a poll commissioned by the Prostate Cancer Research Foundation of Canada.

"I'm sad to say that men aren't taking action," said John Blanchard, the group's CEO, in an interview. "Testing levels just aren't where they should be."

A rectal examination should be an integral part of an annual physical, but Mr. Blanchard said too many men have a "locker-room type reaction" to the test.

The foundation also recommends that all men have their PSA level tested annually, even though universal testing is controversial.

"This test isn't perfect," Mr. Blanchard said. "But if men go every year and keep their own numbers, they will see the 'velocity' of change, and that's what's important."

Dr. Michael Pollack, a medical oncologist at the Jewish General Hospital in Montreal, said "there are a lot of subtleties in the PSA screening debate" that can be confusing to men.

While there is no question that PSA tests will detect more cases of cancer, it is not clear that doing so will mean fewer men will die of prostate cancer. Dr. Pollack also said what is important is that men have frank discussions with their doctors about prostate cancer and take the tests deemed appropriate for them individually.

In the poll, only 64 per cent of men even discussed the issue with a physician.

Even fewer, 49 per cent, did so in the key 45-to-54 age group in which aggressive forms of the cancer are usually detected.

Prostate cancer is the most common cancer in Canadian men. In 2007, an estimated 22,300 men will be diagnosed with prostate cancer and 4,300 will die of the disease, according to the Canadian Cancer Society.

Dr. Pollack said it is important to keep these numbers in perspective: About one in eight men will develop prostate cancer during his lifetime, mostly after age 60; one in 27 men will die of prostate cancer.

"That's not because we cure so many men: It's because so many who are diagnosed have a non-aggressive form of the disease," he said.

What is really needed, Dr. Pollack said, is a better test, one that can identify men with aggressive prostate cancer.

The new survey was conducted by Innovative Research Group. A total of 1,135 Canadians aged 45 and older were polled; the results are considered accurate within +/- 3.1 per cent, 19 times out of 20.

By the numbers

92

Percentage of Canadian men 45 and older who believe early testing results in more effective treatment.

39

Percentage who were tested for prostate cancer in 2006 via PSA.

33

Percentage who were tested for prostate cancer in 2006 via digital rectal exam.

22

Percentage who can accurately assess their own disease risk.

Source: Prostate Cancer Research Foundation of Canada

NOW WHAT?

by Drake Gifford

For someone who'd never been hospitalized, I quickly concluded this was not a place I'd enjoy for a long visit.

I shared a room with two other men. Still, from almost the time I awakened post-op, I became concerned about privacy. My bed was just inside the door so passers-by were able to see me lying there, all tubed up. My roomies and I were at close quarters, separated only by white drapes and so I could hear conversations or the sounds of tape or machinery. Or bodily functions. There's a lot of that in hospitals.

In a hospital, your privacy is gone. Especially with a prostatectomy where it seemed the focus was on nothing but urination, passing gas, getting an early bowel movement, and care of a catheter.

The man who'd knelt by my bed to empty the catheter bag was Dave, a patient care worker, once known as an orderly. He became an integral part of my recovery, both physically and mentally. While nurses scurried about on rounds, Dave seemed to appear out of nowhere to adjust this or that or see to it I was comfortable. This was immensely important because I hadn't a clue how to go about recovering from cancer surgery. I quickly got the impression the hospital didn't want me around for very long. Barring a setback, I was due to leave on Sunday morning, less than four days later. In fact, after my visitors left and I awaited the meal of my life, I contemplated what had been done in my gut.

A prostatectomy is delicate. It's not just tinkering with soft tissue; it's finger-dancing though the finest of nerves and vessels. The slightest slip could permanently affect a number of bodily functions, all of which I wanted to keep working for a good long time.

The empty feeling in my gut was only partly due to being minus a prostate. Hunger was setting in. I wasn't sure if I was allowed to eat so soon after surgery. Meanwhile, moving in the bed was a chore. The nurse instructed me to hold a pillow to my stomach whenever I felt the need to cough, laugh, or sit up. This didn't leave much. It had something to do with popping the incision. Fortunately, the modern hospital bed is equipped with electronic controls for the patient to play with. For about 15 minutes, I tinkered with it, putting my body in weird positions to test comfort levels.

And right away, they wanted me up and walking. Were they nuts? My stomach was empty and my legs practically limp from a numbing anaesthetic. I was still on pain medication and felt a bit of a buzz. How could I possibly walk, let alone get out of bed? Sleep seemed the better option.

Along came Dave.

He showed me how to lean and twist, the pillow against my stomach. He helped me swing my rubbery legs over the side of the bed and untangle from the tubes. He stood on one side of me while the other was occupied by the IV stand. I couldn't help being embarrassed by the catheter bag, but the feeling was soon overtaken by concentrating on taking a few steps without falling. Nine weeks earlier I'd run a marathon, for crying out loud. How the mighty had fallen.

I managed to walk as far as the next room down the hall, perhaps four metres. Dave told me it was enough for the first day. He got no argument. I returned to my bed exhausted.

Dinner arrived shortly after. There may have been potatoes and carrots and a piece of, I think, pork chop. The food may or may not have been fully cooked or even edible. It didn't matter. It vanished from my plate in a blink. When the tray was removed and Dave happened by again to empty the catheter bag, he told me that the next big thing would be tomorrow. The first post-op bowel movement and how to shower with a catheter.

I could barely contain my excitement.

Last month: *Wake up call*

Next month: *Escape plans*

Drake Gifford is the pseudonym for a PC survivor. This is one of his serialized accounts of his journey through prostate cancer. Previous stories can be found in PCAO newsletters on the association website.