

PCAO - NOW IN ITS SECOND DECADE OF SUPPORT TO MEN

CS COOP DO IT FOR DAD – FIVE YEARS OLD

PROSTATE CANCER ASSOCIATION OTTAWA



MAY 2003 NEWSLETTER



WE MEET AS USUAL ON THE THIRD THURSDAY OF THE 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 STREET ON THE LEFT.

Parking is available at the rear of the church.

There is no admission fee, but contributions are welcomed for the St. Stephen's food bank.

Please Note: St. Stephen's has asked that we observe the scent-free environment that it has adopted for its parishioners.

THURSDAY, MAY 15

6:30 P.M. REGISTRATION AND ORIENTATION FOR NEW MEMBERS

7:00 P.M. ASSOCIATION BUSINESS;

7:15 P.M.: DR. MICHAEL McBURNEY, Chief of

Research, ORCC: OBJECTIVES AND ACHIEVEMENTS OF CANCER RESEARCH IN OTTAWA

THURSDAY, JUNE 19

ST. STEPHEN'S CHURCH

TOPIC: LOOKING AHEAD -

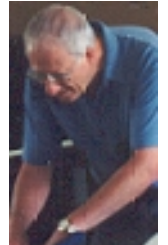
PALLIATIVE CARE; SPEAKER: TO BE CONFIRMED

MESSAGE FROM THE CHAIR

I was in the process of putting together my usual monthly message for this Newsletter when a telephone call changed my whole attitude. It was a call I had been expecting for some time but one, when it finally does come, still hard to accept. The kind of call from which you envisage all kinds of issues that may result and how a part of your life will change. Mottie Feldman, our Association Secretary, was calling as he has done quite often over the five years that we have been associated. After a few words covering a number of PCAO topics, he gave me the news that I did not want to hear: he and his wife would be leaving Ottawa to be closer to their daughter and new grandchild in the Toronto area.

Mottie was the first member I met at my first meeting. I was very impressed with his interest in my concerns and me, personally. I have since witnessed his same sincere interest in others who have come to PCAO for support in their time of crisis.

His personal commitment to the direction and management of our Association over many years of voluntary service has been perhaps the most significant factor in the strength of our organization. Quiet, thoughtful, articulate and caring are but a few of the adjectives that might be applied to him (*ed note: he also avoided the camera*). As a steering



committee member said to me: "His non-stop efforts on behalf of PCAO have been felt by every member of the Association. His deft touch at dealing with, at times, very sensitive issues with members and supporters alike have kept the Association in very high praise from the community it serves."

The timing of his call has been ironic for it came during National Volunteer Week. Mottie met and set the high standards of a volunteer that others should and will aspire to. We will miss his direct involvement in the affairs of our Association but there is comfort that he will remain a member and continue to influence our continuing development.

Mottie, you and your wife, will be deeply missed by all whom you have touched. Good luck, health and satisfaction in your future and in knowing you have left a job well done.

Most sincerely
John

JOHN DUGAN

**PROSTATE CANCER
ASSOCIATION, OTTAWA**

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

Chair John Dugan
Vice Chair Vacant
Vice Chair (DIFD) Randy Dudding
Treasurer Jim Bloomfield
Secretary Mottie Feldman
Past Chair Richard Cathcart

Committee Chairs

Member Services Peter Cooney
Program David Brittain
Church Liaison Bob McInnis
Orientation Herman van den
Bergen

Bill Dey, Harvey Nuelle, Peter Cooney

Hand-in-Hand Vacant
Publicity and Awareness Ted Johnston
Prostate Awareness Week Vacant
Newsletter Editor Ted Johnston
Newsletter Distribution Phil O'Hara
Members at Large

Ken McClymont Jacques Mousseau
John Trant John Webster
Kenn McCuaig Fred Hostetter

The Prostate Cancer Association of Ottawa does not assume responsibility or liability for the contents or opinions expressed in this newsletter. The views or opinions expressed are solely for the information of our members and are not intended for self-diagnosis or as an alternative to medical advice and care.

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

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.

ASSOCIATION BUSINESS

By Mottie Feldman, Secretary

The Steering Committee met on April 24, John Dugan in the chair and a quorum present. In the absence of the Secretary, the record was maintained by John Webster. Jim Bloomfield, Treasurer, reported on the healthy status of Trust and Chequing accounts and took note of two cheques received from the Ottawa Firefighters Association and Investors Group (West). The former was for \$1,000 as proceeds from the annual "Battle of the Badges" hockey game (see page 5) and the latter was worth \$3,000 representing proceeds from a 2002 golf tournament. The Treasurer reported that he has established a database for physical assets of the Association

There are now 322 subscribed members out of the 748 names on the mailing list. It was agreed that notices will be sent to the outstanding names and if there is no response, they will be dropped from the mailing list. It was agreed that a category of "Friends of the Association" be created in recognition of their assistance and interest and that fees would be waived; there are currently 37 names in this category. Membership renewal notices for 2003-04 will be included in June, July/August, and September newsletters.

The Awards Committee, under Mottie Feldman, reported on nominations for Supporter Appreciation and Meritorious Service Awards. The Nominations Committee, chaired by Gordon Seabrook, is now seeking names for the elected positions of Chair, Vice-Chair, Secretary and Treasurer. Elections will be held at the June meeting. Nominations for awards or elected positions may be left on the Association voice mail (828-0762) by e-mail to pca@ncf.ca.

Gordon Seabrook reported that the next issue of Challenge magazine will focus on the effects of cancer on family relationships and he will contribute an article relating to prostate cancer. Phil O'Hara attended a forum on colorectal cancer and raised the possibility of cooperation with the fledgling support organization in Ottawa. Mr. Hostetter, appointed by the Chair as liaison with the Canadian Prostate Cancer Network, reported on a recent meeting in Ottawa with the national executive director and the Manitoba coordinator to be briefed on the national programs and share views on closer cooperation at the local level.

Mr. Dugan reported he would be meeting with the President of The Ottawa Hospital Foundation to be updated on the status of the Prostate Assessment Centre. The centre will be under the management of TOH, in collaboration with the ORCC.

Administrative Notes: Fred Hostetter has taken over from Mottie Feldman responsibility for daily monitoring of voice mail. Jim Bloomfield is in the process of becoming Webmaster in place of Herman van den Bergen. Messrs Feldman and van den Bergen have done exceptional service in these duties for which the Steering Committee is grateful.

The next meeting of the Steering Committee will be at 9:30 on Thursday May 29 at St. Stephen's Church. Any PCAO member is welcome to attend.

IN MEMORIAM: We note the passing of member Robert Terrera

THE APRIL MEETING

THE IMPORTANCE OF GROUP MEETINGS TO PROSTATE CANCER PATIENTS AND SURVIVORS

The group discussions in April had interesting exchanges on the various modes of diagnosis, treatment and after care support. To summarize each group's discussions would strip the resources of this newsletter, but Fred Hostetter undertook a survey during the meeting to assess the value of the group exchanges.

The four topic groups –Radiation, Brachytherapy, Hormones, and Surgery - were all agreed that the round table type of discussion is very important. Why? Because it allows for the exchange of experience, to hear other views, and to help focus on individual problems through the shared knowledge. New members in Surgery said they found it extremely worthwhile. How frequently should these meetings be held brought forth an average of twice yearly, although the Surgery patients favoured more frequent sessions.

The summary of views had no response from Radiation or Hormones, but the Brachytherapy members spoke very positively about the process, noting that it avoids the trauma of surgery, targets the cancer and pinpoints the radiation. The single day event as opposed to 35 trips for beam therapy was seen as favourable. Surgery patients supported the groups as useful ways to learn about new techniques and the experience of members with different surgical approaches.

Some consideration to the above results might be given to the numbers in each group: Radiation had 18 participants; Hormones – 12; Surgery 22; and Brachytherapy only 3, reflecting the relative newness of the procedure in the Ottawa Centre.

Meeting members' interests at each meeting is an ongoing process and your views are invited. Drop a line or a voice mail to the Association if there are topics or speakers that you think will be helpful and informative on dealing with prostate cancer.

WORKING THE WWWEB... with Peter Cooney

The Web continues to trap helpful information for all cancer patients, not just prostate guys. As always the Canadian and American Cancer Societies are reliable sources and I selected this item from the American Cancer Society on the substantial increases in risk of dying from cancer by being overweight or obese. To read about this study go to:

<http://www.cancer.org/docroot/home/index.asp>. Look for: *Focus: Excess Weight Linked to 90,000 US Cancer Deaths Annually.*

Asking a few simple questions may help you gauge the reliability of information about **complementary and alternative cancer treatments** you find on the Internet, says a report from the psychiatry department at the University of California, San Diego. The researchers found treatments of dubious scientific merit that tout a cancer cure include patient testimonials, and claim to have no side effects, compared to more reputable information. Such reports also tended to be for sale online.

<http://story.news.yahoo.com/news?tmpl=story2&ncid=1285&e=4&u=/hsn/20030322/hl_hsn/sifting_trough_alternative_cancer_therapies&sid=95862980

And from the Pacific Northwest Research Institute come reports of a **new DNA test** to distinguish life-threatening prostate cancers from more slow-growing tumours. There is a caution that more tests will be needed to verify findings, but the study report can be found at www.pnas.org/papbyrecent.shtml. A second study, published in the Proceedings of the national Academy of Science online edition, has findings relating damage of DNA in the prostate to cancer. More on that can be found at <http://www.sciencedaily.com/releases/2003/04/030416085729.htm>.

Remember, most of these articles can be found at the information table at our general meetings. If you don't have access to a computer, try your local public library for assistance or the ORCC's Ninon Bourque Library.

THIS IS MY STORY

One of the key benefits in belonging to the Prostate Cancer Association has been the informal exchange of information among members. We each think that our experience in dealing with prostate cancer is unique but the more we are together, the more we come to realize how much we all have in common. The nights when we sit around the circle – as at the summer or December meetings – are often the most personally illuminating.

Colin Campbell of Owen Sound received External Beam Radiation Therapy (EBRT) for his prostate cancer – but it recurred and he then was treated with Cryosurgery. Here he argues that this method is more cost effective and ought to be the primary method of treatment.

Why must men have to travel, sometimes hundreds of km away from their homes and live in lodges provided by OHIP for up to seven weeks while receiving radiation treatment, which appears to have a high failure rate? The cost of EBRT is high both in dollars and in personal terms. When a therapy option like cryosurgery, which can be done almost on an outpatient basis, is available, not only is the patient happier but also the cost to the health system is also dramatically reduced. Before radiation therapy even began, I had to make a 300 km round trip journey for routine preparation involving the precise location of prostate, tattooing aim points, and designing and constructing a radiation shield. Add to this physician consultation time, technician time, and clinic time. Again, treks to the cancer clinic once treatment began at intervals of five days for seven weeks, making lengthy trips home for weekends. The distance alone was over 2600 km! Two years after EBRT, biopsy showed a Gleason score higher than that found prior to radiation therapy. Not only did EBRT fail to cure my prostate cancer, I was left with a more aggressive and dangerous form of the disease. I underwent salvage cryosurgery therapy, the only minimally invasive treatment option for recurrent prostate cancer. The cryosurgery experience involved the same 300 km round trip though similarities stopped there. I was admitted at 9 am and prepared for the procedure, woke in recovery room at approximately 1 pm, and finally, stayed overnight in hospital and was discharged at 2 pm the next day. A surgical catheter was removed after three weeks necessitating a further 300 km round trip although this could have been done locally. Cryosurgery was a complete success. If it had been available as primary therapy, a great deal of time, trauma, and money could have been saved and additionally, radiation technology would have been reserved for those cancer patients who needed it. If primary cryosurgery failed, it could have been repeated with a minimum of trouble and at minimum cost. Further, cryosurgery has not been observed to aggravate prostate cancer. If it had recurred, I would not have been at greater risk due to a higher Gleason score. Prostate cancer is a grave health concern for Canadian men and I think it makes sense to add cryosurgery to OHIP's roster of covered primary prostate cancer treatments. Radical retro pubic prostatectomy, external beam radiation, and brachytherapy are each appropriate prostate cancer treatments for patients meeting their specific patient selection criteria. But for Ontario men, these remain the only primary treatments covered by OHIP. Cryosurgery is not only effective in treating low-to-high risk tumors—it is effective at treating the most aggressive cancers: those following failed radiation therapy. Yet it has been overlooked as a cost saving, safe, and effective first line treatment for prostate cancer despite the increasing clinical evidence. If this procedure had been available as a Primary Therapy it can readily be seen that a great deal of time, trauma, and money could have been saved and additionally, there would have been space freed up for those cancer patients who must have Radiation! If cryosurgery had failed, then it could have been repeated with a minimum of trouble and at minimum cost.

Colin Campbell, MSAE MCAI OCE CET, is Chair of the Owen Sound Prostate Cancer Support Group and can be reached at colinc@grey-bruce.net or (519) 371-4779

Suggestions for Practical Implementation

Since major surgery is commonplace in our Regional Health Centres the addition of Cryosurgery should be easily handled since it is minimally invasive and usually only an overnight stay. Surgery training and proctoring (provided by the manufacturer) would be rapid, included in the equipment price, and the Ultrasound Physician's current skills would readily transfer. The cost of the equipment is minimal when compared with the savings all around and the added improvement in provision of Health Care. The freeing up of conventional radiation equipment at major centres would be of great benefit to patients who must have it, as well as reducing waiting time for quickly needed treatments. As mentioned elsewhere the cost of equipping and training and trying out the procedure is relatively modest, even in this day of increasing costs.

THESE BOYS CAN REALLY MOVE IT



The Prostate Gurus: Mike Scott, Wilf Gilchrist, Fred Nadeau, Arland Benn and Don Hampton

The Prostate Gurus hit the road at the end of April and made a commendable showing in the 5 km Physiotherapy Run. "I think we did absolutely marvelous", said Wilf Gilchrist, after the run. "The weather turned out to be really good for running. The temperature was cool and runners didn't have to worry about overheating."

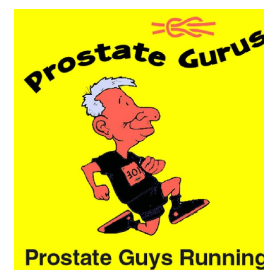
Arland Benn, at seventy-seven years young was the quickest of the GuRus (Guys Running) with a time of 31:30.8. For some of the men, it was the farthest they had run in years.

"It felt really good to be out there as a team", reported Wilf. "I heard a lot of comments about us, both addressed to me directly and overheard of people passing. People knew that we were there. That is a benefit in helping people become aware that there are prostate cancer patients out there and that we are active." Just how active is reflected in Fred Nadeau who had a radical prostatectomy last November and five months later he completed this 5 km race. He had not run for several years before his operation.

In addition to Messrs Benn, Nadeau and Gilchrist, the Prostate Gurus this time included Don Hampton, Mike Scott and a new member, Peter Jones. "We want to welcome more PCAO members into the team," declared Wilf, "so we can make a strong survivors showing in Do It For Dad in June."

Meet the GuRu himself

Wilf Gilchrist, the designer, says: Our runner is representative of the men with prostate cancer. Above him is the reef knot that has been adopted as our symbol for strength, unity, and courage in the fight against prostate cancer. He is slightly older than the average baby boomer and is inclined to enjoy beer more than saunas. He has more hair than most of the guys in the group. Early on, he had his PSA levels measured and is now satisfied that he has done all that he can in follow up. He is aware of both his body and the world around him. He is contented and enjoying life. He is happy to be able to jog along with others.



Ottawa Professional Fire Fighters and the Ottawa Police Blues took to the ice on Easter Sunday at the Jim Durrell Arena for the Sixth Annual *Battle of The Badges Hockey Game*. This year, the beneficiaries were the Prostate Cancer Association, In Aid of Breast Cancer Action and the Canadian Special Olympics. PCAO Chairman **John Dugan**, for the third year, happily accepted a cheque for \$1000.00 from **Chief Bertrand** of the Ottawa Fire Fighters prior to the game. Over 300 fans of the teams enjoyed the event with **Crazy Claude** and his trumpet adding flair to the event. **Eddy Shack** was the proverbial referee. **Jack Valiquette** formerly with the Toronto Maple Leafs and **Mark Napier** of Montreal Canadien fame demonstrating their skills as celebrity players.

MEMBERSHIP RENEWAL



The time is coming to renew your membership in the Association. “We instituted the \$25.00 membership in September of last year”, said John Dugan, PCAO Chairman “but the Steering Committee had agreed that the term would be consistent with our financial year which ends in June. We also agreed that we would cease mailing the newsletter to those who had not made the commitment.”



Jim Bloomfield, Treasurer, advised the last steering committee that, of the 748 names on our mailing list, only 322 had paid the fee. Committee members were puzzled at the lack of response since many of these were survivors who would have benefited from their experience with the Association. “I am hopeful still, that those who have not paid for the past year will recognize the value in helping to maintain the Association and will join for the new fiscal year,” he said.

The fee helps to cover the administrative costs of the Association, which range from maintenance of the office in St. Stephen’s Church, to postage on the newsletters, to updating our information materials for public presentations, and defraying costs for members undertaking duties on behalf of the Association. “The Steering Committee members provide their services freely but they shouldn’t have to pay costs incurred for that donation of time, explained Mr. Dugan.

The Chairman pointed out “It’s important to remember that monies raised in Do It For Dad or in other charitable activities that donate money to the Association - such as the Battle of the Badges or at golf tournaments - goes to prostate cancer research, treatment or education, not to the Association itself.”

A membership renewal form will be included with the June Newsletter.

WHY BE A MEMBER OF THE PROSTATE CANCER ASSOCIATION OF OTTAWA?

- TO LEARN ABOUT PROSTATE CANCER – ITS DIAGNOSIS, TREATMENT OPTIONS
- TO ENJOY THE SUPPORT AND ENCOURAGEMENT OF SURVIVORS
- TO PROVIDE AWARENESS AND SUPPORT TO OTHERS
- TO ENSURE ADEQUATE FUNDS ARE DIRECTED TO THE RESEARCH AND TREATMENT OF PROSTATE CANCER
- TO CONTRIBUTE TO PUBLIC AWARENESS OF THE BENEFITS OF EARLY DIAGNOSIS AND TREATMENT

LOOKING FOR A WAY TO HELP? Set up or put away chairs at the general meeting, staff the information desk, greet newcomers, become a mentor, volunteer for duties, stand for office by election or appointment, search and assess information about prostate cancer, volunteer for a committee, write articles, take photographs, become a PCAO representative to other health or community groups, write a cheque, share information about prostate cancer diagnosis and treatment with younger men, bring a friend to meetings, pay your membership fee promptly, organize a fund-raiser, be active in your life and participation in the Association. Speak to any member of the Steering Committee (the names are on page 2), leave a message on PCAO Voice Mail (828-0762), or e-mail us at pca@ncf.ca. (It may sound strange but if you don’t want to or can’t help, let us know that, too.)

TAKE PRIDE IN BEING A PROSTATE CANCER SURVIVOR: JOIN THE SURVIVORS VICTORY LAP AT THE RELAY FOR LIFE, NEPEAN SPORTSPLEX, JUNE 6. FOR MORE INFORMATION CALL THE CANADIAN CANCER SOCIETY IN OTTAWA (723-1744) OR GO TO www.cancer.ca/ccs AND FOLLOW THE LINKS TO “RELAY FOR LIFE” AND THE “SURVIVORS VICTORY LAP”.

PCAO thanks **MDS NORDION**, a major supplier of reactor and cyclotron produced isotopes for health care and research applications, for the printing of this newsletter.