

# **PROSTATE CANCER ASSOCIATION OTTAWA**



## **JANUARY 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.

### **THURSDAY, JANUARY 16, 2003**

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

**7:00 P.M.** ASSOCIATION BUSINESS;  
**GUEST SPEAKER: DR. JOANIS BORMANIS**, PROFESSOR OF MEDICINE AND MEMBER OF THE OTTAWA HOSPITAL HAEMATOLOGY DIVISION EXPLAINS THE BLOOD LINKS TO CANCER.

### **THURSDAY, FEBRUARY 20** **WE WILL MEET AT EMMANUEL UNITED CHURCH ON SMYTH ROAD.**

**GUEST SPEAKER: PEGGY GRAHAM**, Urology Specialist Nurse at the Ottawa Hospital (Civic) will discuss the impact of prostate treatments on men's and women's lives. Is there sex after treatment?

### **MESSAGE FROM THE CHAIR**

In 1996, my PSA count was elevated over what it had been previously. I was advised to have an ultra sound and biopsy. The first test was negative; still, my PSA was increasing. The second and third time... the same result. After the fourth attempt I received the news I thought I had prepared myself for: I had prostate cancer. I was not prepared. I felt hopeless and lost.

Thankfully, my urologist suggested I get in touch with the Prostate Cancer Association. At the first meeting, where I met a number of men and their families in the same situation, I sensed a feeling of comfort and acceptance. I particularly remember the feeling of not being alone. The speaker that first night gave an illuminating overview of the disease, the therapy choices available and the success rates for cure. That, coupled with my more knowledge-based questions for my urologist, gave me a positive attitude that I could fight this and win. I will never forget those early days and the need I had to prepare myself better to understand and accept the path I would choose to take.

But why am I telling you this? Well, my brother rang me late one evening before Christmas. He had just learned, after having gone through three biopsy procedures, he too has prostate cancer. The tone of his voice, the self-pity and the inevitable question as to whether or not the test was correct was like a theme from my own past. I had warned him on a number of occasions that prostate cancer is in our family, that he should be prepared for such an eventuality. I sent him some of the information we make available to members as well as a book recommended by my urologist. We have had several fruitful telephone discussions and he is now far more comfortable with his situation. From my experience, I am able to provide the support he needs to move forward with a positive frame of mind and I think he is much better prepared than I was for my first visit.

I hope this personal scenario will cause each of our members to increase the level of awareness of prostate cancer in and outside their families, that you are the living proof that prostate cancer can be beaten.

**JOHN DUGAN**

**PROSTATE CANCER  
ASSOCIATION, OTTAWA**

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**Vice Chair (DIFD)** Randy Dudding  
**Treasurer** Jim Bloomfield  
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Member Services Peter Cooney  
Program Vacant  
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  
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*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*

*My report this time looks back at PCAO, 2002, taking the opportunity to provide a personal commentary, rather than the usual objective facts that you can find in back issues of the PCAO newsletter. My viewpoint comes from being a member of the PCAO and the Steering Committee for about half of its first decade of support.*

I see a stable, reliable and competent **management of PCAO business**. The Steering Committee membership continued to evolve in 2002, we kept a good mix of more senior members guarding our traditions, and new members with great skills and new approaches. *John Dugan*, in the second year of his elected term, contributes excellent leadership skills along with a clear view of the issues. *Ted Johnston* applies his talents in many activities, but in particular you can see how well he has developed our newsletter. *Jim Bloomfield* energetically and accurately handles our financial affairs. *Peter Cooney* joined us and took up a number of responsibilities. Due to illness and other reasons, veteran contributors such as John Webster, Bill Campbell, Pat Kyte, John Trant, and Gordon Seabrook, had to reduce or withdraw from their duties, or resigned their positions.

Almost all of our Steering Committee, and other key volunteers, now have e-mail. This greatly speeds distribution of meeting agendas and minutes, and especially enables getting work done between meetings. That is how we multiply our efforts to cope with the very many business activities and a growing number of members, and how we keep focussed on our two business areas – support, and awareness.

**Support activities** include daily monitoring of voice and e-mail services, to respond to people suddenly needing prostate cancer information, and receiving a first introduction to PCAO. The new members session has become a mainstay of our monthly general meetings, usually with 5 to 10 new members each time, many with their partners, benefiting from first hand discussion of treatment choices and a myriad of questions. *Herman van den Bergen*, also a leader of our volunteer mentors, is in charge of the sessions, assisted by *Pat Kyte*, *Bill Dey* and *Harvey Nuelle*.

**Support for members** centers around the monthly meeting, where we had a variety of programs. Medical topics are the favorite, and our speakers included Diane Manii, Drs. Joanis Bormanis, Roanne Segal, and Chris Morash. The talk by Dr. Morash was featured as our 10<sup>th</sup> anniversary presentation; he gave an excellent review of prostate cancer, the last decade and what's ahead. Other topics included the Ottawa Regional Cancer Centre (Dr. Hartley Stern), prostate cancer research (PCAO member *David Brittain*), and the Ottawa unit of the Canadian Cancer Society (Richard Loomes). **Learning from fellow members** was important too: Peter Cooney did a splendid solo and the April, July, August, and December member discussion meetings showed the value of sharing. Break times at all the meetings allow informal discussion, time to read the bulletin board, and a look at our materials set out by *Doug Payette*, for the average of around 100 attendees, sometimes only 50, and as many as 150 for some programs. Tying it all together for you, whether or not you can attend the meetings, is the **monthly newsletter** and the **PCAO web site**. *Continued on page 5*

**IN MEMORIAM:** We note the passing of member Pat Barbaro of Ottawa.

## The PCAO: Questions For Our Second Decade

*Fred Hostetter likes what the Association has accomplished but now poses some thoughts as to what we might do in the coming years. The complete answers rest with members and the solutions will depend on people stepping forward to make them work.*

**2002** marked the 10<sup>th</sup> anniversary of the Prostate Cancer Association of Ottawa. While much has been achieved, we need to consider where we should go with our association in the next decade. Our achievements in the first decade include:

- Informing and supporting men newly diagnosed and waiting for treatment,
- Building public understanding of prostate cancer and the importance of early diagnosis,
- Raising money for prostate cancer research, and;
- Building partnerships with other organizations.

These results happened because members and friends of the PCAO worked together towards common goals. We are all benefiting from those achievements. Members of the PCAO now have a “capital” opportunity to steer and propel the association along a course for our second decade. To do this we need answers to some key questions.

**Should we focus more on supporting the newly diagnosed and those awaiting and undergoing treatment?** In my view, the answer is definitely, “yes”. Why else does the PCAO exist if not to directly help its members?

**Should our fundraising continue to be directed primarily at support for research?** I think it should focus squarely on support to members, public outreach, and public awareness, especially with respect to First Nations peoples, new Canadians, and other marginalized groups whose needs may be greatest. What do you think?.

**Should we be having a lot more fun in trying to do the kinds of things I have sketched?** I say “yes”. What about trips, picnics, bowlathons, auctions, all of which can be fundraisers, too.

**How can our association create the capacity to achieve what we want it to do?** A suggestion: ask a member of the steering committee how your special talents can be put to use.

**How can our monthly meetings better address the needs of members?** If you want input to the planning of these events, share your concerns and ideas.

**The PCAO is our organization. Make your voice and your presence known.**

### Here's an Interesting Opportunity

You can make a contribution to civic government, assist men's health and represent the Association. The City of Ottawa has an Awards Program to assist various endeavours in the City, including contributions to men's health. Applications have been received for grants and the City is looking for volunteers to act as judges or referees on the proposals. The panels will meet in late January and early February, and again later in February. If you are interested, call **Hadat Berhane** at 724-4122 ext 2-4322

“The trouble with much creativity today, in my observation, is that many of the people with the ideas have the peculiar notion that their jobs are finished once the ideas have been suggested. They believe that it is up to somebody else to work out the dirty details and then implement the proposals. Typically, the more creative the man, the less responsibility he takes for action. ...Ideas are useless unless used. The proof of their value is their implementation. Until then, they are in limbo.”

**Theodore Levitt**, Harvard Business Review (Aug 2002)

## 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. With this issue, we are opening the newsletter to members' stories.***

### ***Surgery, then Radiation– Sharing My Experience***

As we know, everyone is different when we talk about treatment of prostate cancer. When an individual has surgery, he may not need radiation or hormone therapy but, in my case, both treatments have been required.



On August 14, 2001, I underwent surgery for my cancerous prostate. My PSA had risen to 8.8, Gleason score 7. I came through that pretty well and was back on a regular routine within four weeks, with only some incontinence to deal with.

In October, I was advised that, as cancer had been detected in the surrounding tissue, radiation treatment plus hormone therapy would be necessary. At that point my PSA was .32. In November, I began a three-year program of quarterly injections of Zoladex and was scheduled for radiation in the New Year. In late January 2002, I showed up at the simulator at the General Campus where the radiation specialists made markings below my navel and on each hip to provide target reference points for my treatment.

As I live in the west end, I requested and was okayed for treatment at the Civic Campus, with the first treatment February 5.

It is necessary to have your dosage five days per week, Monday to Friday, for the specified number, in my case 33, which took almost seven weeks. Some patients are treated lying on their backs; others lie on their stomachs. Those lying face down are first fitted with a personal plastic “saddle” which fits over the stomach and hip area for each treatment. They must undress and don a green smock but us “flat-on-our-backers” only have to lower trousers to reveal the markings.

The radiation treatment lasts only about two minutes. If you close your eyes you have no sense of anything except a hum from the accelerator. Following treatment, the radiation therapist (not nurse) returns your appointment card with the next day's time noted.



Many of us have different expectations when we hear the word “radiation”. I found the procedure quite simple. There is no pain or discomfort but you will experience a sense of fatigue during and after treatment. I can't say what the radiation did for the diseased tissue although I am sure it has been zapped. My most recent PSA reading is 0.02. The after effects are increased bowel movements and more night time visits to the washroom indicating what I hope is only temporary incontinence (from both surgery and radiation) but that has been the extent of it on my system.

*Share your experience with members. There is no need to identify yourself nor your doctors, but tell your fellows what you expected, how you have fared, where you are headed. If you would like to contribute, please call Ted Johnston at 748-0346 or e-mail him at [ej407@ncf.ca](mailto:ej407@ncf.ca)*

I know this is silly, but here goes:

Sometimes...when you cry, no one sees your tears. Sometimes...when you are in pain, no one sees your hurt. Sometimes...when you are worried, no one sees your stress. Sometimes...when you are happy, no one sees your smile. But fart just ONE TIME...!

## **WORKING THE WWWEB... with Peter Cooney**



Conversations in Care™ is a resource centre for the improvement of health care through better physician/patient communications. You can find it at:

<http://www.conversationsincare.com/>. The site allows you to explore the many challenges surrounding physician and patient communications in the field of

oncology, and look at ways to build effective partnerships in care. Conversations in Care™ will continue to develop over time. It begins by examining the issues most faced by physicians.

"*Communicating With Family Members*" is a new chapter, authored by Dr. Anthony Back. This chapter addresses the issues that arise and accompany dealing with cancer in the family. Dr. Back is Associate Professor in the Division of Oncology, and Adjunct Associate Professor in the Division of Medical History and Ethics at the University of Washington, Washington State.

*The New York Times* is well known for its health coverage. You can find a comprehensive archive of The Times's health reporting by going to the Topic Searches area of the Health section and simply clicking on the topic that interests you. Get the latest updates on a variety of topics, including cancer, heart disease and diabetes. To learn more, go to:

<http://www.nytimes.com/pages/health/index.html>.



## **Association Business - 2002 in Review**

*Continued from page 2*

With an experienced roster of volunteers, we were involved with many **awareness activities**. We presented displays and talks to different organizations, such as at the Urology Nurses of Canada National Conference, helped with two charity golf tournaments, participated in the ORCC Telethon, and worked with the Canadian Cancer Society on Awareness Week events in September. *Peter Cooney*, and *Mottie Feldman* gave television interviews on CJOH and Rogers respectively. Back by popular demand, *Bill Campbell* along with Dr. Chris Morash appeared on CBC Radio One's Ontario Today, for the second year in a row. Our premier awareness initiative, as well as raising funds for local prostate cancer needs, is our **Do It For Dad** event, more successful than ever this past year, clearing nearly \$80,000, even with the soggiest weather we could imagine. *Randy Dudding* continues as our Vice Chair for DIFD, while *David Brittain*, our first DIFD leader, has stepped down, replaced by Ted Johnston. This year, the ORCC stepped down as partner and the CS CO-OP has stepped up to be our new partner to present the event in aid of prostate cancer awareness, treatment and research.

Along with all the volunteer resources reflected above, PCAO needs financing too. A look at the **2001-2002 financial report** at the end of our fiscal year in June shows expenditures of over \$20,000. Donations from members and from outside supplied 92% of the needed funds; the rest came from our Nevada Tickets lottery. Among the outside donations, the Police/Fire Fighters "Battle of the Badges" hockey game gave us \$1000, and \$500 came from the Stardome Bar and Grill, Manotick. At the same time, "flow through" donations enabled us to give \$19,000 to local needs.

But a growing mailing list and a high reliance on donations finally precipitated a decision that had been debated many times in the past. PCAO implemented a **membership fee of \$25**, and it is a work in progress. Many of you have returned your registration form and fee donation, but we need to hear from many more. Managing this new membership policy and the new processes involved will continue as significant challenges for the Steering Committee.

I think 2002 has been the busiest and most-accomplished year yet. There are more activities and details but space is limited. PCAO's challenges and opportunities will continue to grow, unfortunately, because prostate cancer is a long way from being vanquished.

**Editor's Note:** *The author, Mottie Feldman, deserves a congratulatory hand for his efforts over the past five years of his membership on the Steering Committee. His influence has been felt on all of the activities he describes in this article.*

## MEET THE NEW LOGO\*



There is a new look for the 2003 Do It For Dad. The hairy leg remains but it now is running with the speed of light in support of prostate cancer fund raising. This year's preparations are proceeding apace and with less than five months to go, old sponsors are returning and some new ones are now on board. John Dugan, chair of PCAO said "We are especially pleased that the CS CO-OP is again the title sponsor, as well as our partner for this, the fifth year." Randy Dudding, PCAO Vice Chair for DIFD, said that discussions with several sponsors are still underway but the Ottawa Police Association is returning as the five kilometer run sponsor and the law firm Nelligan O'Brien Payne is again taking the lead

on the Corporate Challenge.

"The Corporate Challenge showed last year its potential to attract both runners and pledges. This year, André Lagasse and Bill Siekierski have again teamed up to canvass companies and organizations to enter teams into the Challenge," reported Randy. "Last year we had more than 20 teams competing; this year, the expectation is for over 50 teams to be entered."

Mr. Dudding repeated his plea for PCAO members to volunteer for assignments in the lead-up period. "Right now, I am looking for assistants to marshal volunteers for jobs as they arise. At this stage, it is a matter of creating the data base that ensures we link the right talent to the right job." He suggested that if there are one or two members with human resource experience, they could make a useful contribution at this early stage. "In March and April, we will need four or five members with cars to deliver posters and brochures to locations throughout the city," noted Mr. Dudding.

Mr. Dugan called on all PCAO members to plan now on making sure we set a new record in fundraising. "Do It For Dad is 'our' event," he said, "and we should ensure that members are seen as the strongest supporters. You can run or walk, encourage family and friends to join in, but above all gather pledges in this once-a-year campaign on behalf of prostate cancer."

\*The original logo was "borrowed" from the London, Ontario DIFD. This year's refinement, by graphic designers McGill Buckley, now puts a distinctive stamp on the Ottawa event.

There is still room to grow. That's the message from our coordinators of membership registration. Peter Cooney and Jim Bloomfield report there are now more than 325 paid up members of the Association. "In September, our mailing list had over 700 names on it," noted Mr. Bloomfield, "so more than 50 percent of newsletter recipients have not yet responded to the membership drive. Anyone not paying the annual membership fee will be dropped from the mailing list."



Registration forms were attached to the September and November newsletters and are available at monthly meetings. A tax receipt is issued for the \$25.00 fee.

If you have questions about the fee or the Association's finances, please feel free to speak with any Steering Committee member – or come observe a Steering Committee meeting on the last Thursday of each month at 9:30 a.m. at St. Stephen's.

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.