PCAO - NOW IN ITS SECOND DECADE OF SUPPORT TO MEN
DO IT FOR DAD – FIVE YEARS OLD

PROSTATE CANCER ASSOCIATION OTTAWA

FEBRUARY 2003 NEWSLETTER

A CHANGE IS AS GOOD AS A REST

WEDNESDAY, FEBRUARY 19

THE FEBRUARY MEETING WILL BE ON A NEW NIGHT AT A NEW LOCATION. WE WILL GATHER AT ***EMMANUEL UNITED CHURCH***, SMYTH ROAD AT BOTSFORD, EAST OF THE OTTAWA GENERAL HOSPITAL, ON ***WEDNESDAY, FEBRUARY 19***.
Parking is available at the rear of the church.
There is no admission fee.

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

7:00 P.M. ASSOCIATION BUSINESS;
GUEST SPEAKER: DR. GAD PERRY, ORCC ONCOLOGIST WILL PROVIDE AN UPDATE ON BRACHYTHERAPY

THURSDAY, MARCH 20
WE RETURN TO ST. STEPHEN'S CHURCH

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

MESSAGE FROM THE CHAIR

You Never Walk Alone is the song that Jerry Lewis closes out his Telethon every year. It's a useful reminder for all of us when faced with a diagnosis such as prostate cancer. In the difficult and anxious drama that follows diagnosis it is not uncommon to forget the one person who has dedicated her life to you and your family: that individual who has been your partner and pictured growing old with you as a life-companion. The person may be your wife, your fiancée, a friend who will now be involved in the long process of your cancer evaluation, treatment, recovery and the life that follows. That person is always there on the sidelines living with the results of your decision. Often sitting quietly and waiting, trying to stay calm to support you while an almost overwhelming fear of the unknown silently torments her.

Women are known to handle crisis very well, to be the stable pillar for the family during illnesses. Think of this for a minute and take the time to include your partner in the decisions facing you. What does she think? What sounds good? What frightens *her*? Include her in your discussions with your doctor, during preoperative consultations and testing or, while on the phone when your doctor calls. Give her the opportunity to listen, to ask questions and, most importantly, *you* listen to what she says. In times like these, women tend to have more common sense and the ability to step back and look at the total picture.

Yes, prostate cancer is a very personal disease and, ultimately, your course of action is your decision. Take the time to include your wife in the decisions that will impact both your lives. Share your feelings with her. Put all of your fears and concerns out in the open, talk to her about them. If it's a concern on how the outcome may affect sexual relations discuss it now. Communicating means to impart and share through the power of honest and open discussion. When faced with the diagnosis of prostate cancer, few are strong enough to walk alone.

JOHN DUGAN

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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 twice in January because the December meeting was deferred to January 9th. We were pleased to have a PCAO member sit in to observe proceedings. If he decides to join our committee, we will be able to reveal his identity. You could observe our meetings too, drop in - the *Steering Committee* always needs more members.

Some of our time was spent planning for the change in location for the February General Meeting (see details on page1). This will be an opportunity to evaluate a different site, in case of some future need, and to see what advantage it holds for our members living in the eastern, southern and central neighborhoods. Let us know how the Emmanuel United Church location helped or hindered your participation.

Dr. Chris Morash has been a frequent, valued contributor to our programs, and at the January General Meeting, we were able to give something back to him. First, we presented Dr. Morash with the **Dried Prostate Award**, PCAO's most prestigious award recognizing outstanding support for PCAO and the prostate cancer cause. Second, we presented our cheque in the amount of **$18,150** to cover a portion of the cost of hiring a research assistant to help Dr. Morash develop data on treatment of early prostate cancer. This donation was the PCAO share of the 2001 DIFD revenue.

As part of being good community citizens, PCAO contributed a telephone answering team to the ORCCF Cancer Telethon on the New RO, January 12th. The team stood out in the yellow DIFD volunteer t-shirts, helping to raise the $1,637,379 achieved for the Cancer Centre. PCAO also got good coverage on CJOH-TV with a news clip interviewing *Ted Johnston* while showing both the PCAO team at the Telethon and the 2002 DIFD run in the rain. The item served to demonstrate that raising funds for cancer goes on all year. *Phil O'Hara* was also shown working the pledge phones.

Robert Shiell of Calgary has written to support groups across Canada, introducing himself as the new President of the Canadian Prostate Cancer Network (**CPCN**), the National umbrella organization for prostate cancer support groups. Mr. Shiell talks about their new nation-wide Living Proof program publicizing "poster boys" "whose early detection of prostate cancer has saved their lives". Meanwhile, CPCN sent us a cheque in the amount of $5.00, our share of donations they garnered from our area. Included was a set of stringent reporting responsibilities far out of proportion to the amount of money. The *Steering Committee* decided to return the cheque to CPCN. What do you think our relationship should be with CPCN? Tell us your opinion.

IN MEMORIAM: We note the passing of members John E. Reeves of Stittsville and John Robinson of Ottawa.

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.

This month, Wilf Gilchrist sets a challenge for members both as individuals and as members of the Association.

We all know that exercise is good for us but not all of us get around to doing it.

In April 2001, I was diagnosed with prostate cancer and started hormone (antiandrogen) therapy. In September I had a radical prostatectomy. In November, eight weeks after the operation, I decided to start running. I started walking at a slow pace, every other day, for twenty minutes. Over the following weeks I gradually increased my pace. By December I had increased the time to thirty minutes a day, and by the end of the month I was running. In November my initial goal had been to try to run a marathon in May.

In December I found out that I had a significant PSA level. In January the level was up by 30 percent. I was scheduled for radiation and put back on hormone therapy, which I am still on. By the time my radiation started in March I was running fifty minutes daily. The radiation took away a lot of energy. I had to cut back but I still was able to run every other day. My radiation ended on May 9. On Sunday May 12, I ran in the National Capital Weekend run. The most important thing to me was being able to run for 5 km. I was delighted not to be last in my age group.

` So, now I have started **Prostate Guys Running** – **Prostate GuRus** - a support group to help encourage guys to get started, develop, and maintain a regular exercise routine. Each member will develop his own training routine, time schedule, and place to train. Everyone will come together occasionally to discuss progress, training tips, and select events to run in.

Finding a place to run may be difficult for some. I took the easy way out and bought a treadmill. I do weight training in the Fitness Center at Ottawa Regional Cancer Center to which my oncologist referred me. As a cancer patient you should be able to get a referral from your doctor. The training staff will guide you on use of their full complement of weight machines, treadmills, and such. It is also a good place for meeting other prostate guys.

If you have any concerns about any health related problems that could limit your exercising, then it would be a good idea to check with your family doctor.

To become a Prostate GuRu call me, Wilf Gilchrist, at (613) 731-9722 for more information.

Wilf's tips to develop a personal running program

1. Decide to *start.*
2. Do a *self-assessment* by walking at a brisk pace for 10 to 15 minutes.
3. *Set a goal* for a distance or time you think you can work up to.
4. Start to walk or run on a *regular basis* every other day. The slower the pace that you begin with, the easier it is to make improvements.
5. Once you become comfortable at the initial pace, *pick up the pace* a little or extend the time. Do not increase too quickly; allow you body to get used to the routine.
6. *Gradually increase* your pace and distance to build towards the goal. *Reset* the goal if needed.

Dr. Chris Morash, M.D. FRCSC, has been presented with the Association's Dried Prostate Award for 2003. In making the presentation at January's meeting, PCAO Chair John Dugan said:

"Dr. Morash has often served as a speaker for our general meetings, and made special collaborative contributions such as with Prostate Cancer Awareness Week activities. We believe that Dr. Morash is a leading authority on prostate cancer, through his excellent knowledge of the disease, its diagnosis and treatment. He willingly donates his time and expertise for educational and awareness events, despite a very busy medical practice. His time and expertise are a valuable support for the PCAO."

The Dried Prostate Award is given annually to a person or organization for notable support provided to the PCAO. It was designed and first awarded in 1993-94.

FROM A LITTLE BIT OF BLOOD – A CRITICAL DIAGNOSIS

It wasn't quote a magical mystery tour, but it was a tour that helped clear away mystery. **Dr. Joanis Bormanis**, haematologist at the Ottawa General Hospital, led members on an exploration of blood analysis related to prostate cancer. He explained the various methods of drawing blood, then went through the steps that analysts follow to determine the level of prostate specific antigen in the blood.

He explained that the small amount of blood drawn from a patient to test for PSA is further reduced through centrifugal treatment to isolate plasma from red blood cells, and to further isolate from the plasma the glycoprotein from epithelial cells. More simply, he said, the prostate gland has cells that are sugar coated. Those cells and that protein are normal products of the prostate and are not a cancer. The quantity of serum PSA, measured in nanograms per milliliter, is an indicator only of a problem in the prostate. It is, he emphasized, a screening test, not one that determines the presence or absence of cancer. "Benign Prostatic Hyperplasia is one cause of elevated PSA," he said, "as is an inflammation of the prostate, or perianal trauma that might be caused by an ill-fitting bicycle seat or the digital rectal examination."

In assessing the PSA reading, doctors must take into consideration factors such as the age of the patient, the racial character (Blacks have a higher risk rate than Hispanics or Caucasians), genetic history, and dietary habits. Generally, he suggested, doctors consider the following PSA ranges as reasonable for their age groups:

Age 40-49: 0-2.5; Age 50-59: 0-3.5; Age 60-69: 0-4.5 Age 70-79: 0-6.5

"Patients must remember that the PSA reading is only an indicator of a problem in the prostate," he said. He noted that some research is now trying to refine these scales to be more precise. A good test he said must be sensitive and precise and, so far, the PSA test doesn't meet that criterion. Other factors influencing interpretation of PSA results are density of the proteins, the velocity of change and levels of free or bound serum. The controversy over PSA testing is essentially for the early stages where readings of less than 10 are found. "Over ten, there is no argument." Nonetheless, he asserted, "When combined with a digital rectal examination, the PSA is the most accurate guide to early detection of cancer."

Dr. Bormanis' talk was interspersed with questions from the audience that brought out interesting points. In itself, he said, prostate cancer has no effect on the blood but the treatments that influence production of testosterone can. As this is a metastatic disease, it can influence the level of hemoglobin, lowering of which leads to anemia and a reduced quality of life. Through treatments that may include blood infusions and drugs, the hemoglobin level can be raised back to near normal levels.

Blood clots are more common in prostate cancer patients, he said, suggesting the risk level is six times that of the normal male population. *(Members may wish to look back at the April 2002 newsletter issue for the report on Dr. Bormanis' presentation in March. See Page 5 for more on PSA testing.)*

TO PSA OR NOT TO PSA – DIFFERING VIEWS

In January, the Canadian Medical Association Journal (CMAJ) reported a retrospective **British Columbia Cancer Agency** study on PSA testing that led to a conclusion that there was "no beneficial effect" of the test on mortality rates. At about the same time, the **U.S. Department of Defense Centre for Prostate Disease Research (CPDR)** reported two findings that support PSA testing: "(PSA testing), which is the current method used by physicians to detect a protein in a patient's blood which might indicate the present of prostate cancer, has improved survival for prostate cancer patients. The second conclusion is that PSA testing has decreased the percentage of patients that present with metastatic disease or disease that has spread from the prostate to other parts of the body or vital organs."

In December, the **US Preventive Services Task Force** dropped its objections to routine prostate cancer screenings for millions of middle-aged and elderly men, saying it is possible the test saves lives. The panel did acknowledge there is insufficient evidence about the long-term benefits and risks of prostate screening.

Our eagle eyed screener of the web, Peter Cooney, came up with the following websites which deliver on each of these stories: CMAJ: http://www.cmaj.ca/cgi/content/abstract/168/1/31
CPDR: http://www.cpdr.org/news/impact.html and commentary of the USPSTF is at http://www.intelihealth.com/IH/ihtIH/WSIHW000/24479/33000/358742 .

The CMAJ report stimulated the following commentaries by PCAO members:

FRED HOFSTETTER: Anyone following media reports on PSA testing is probably confused. In the past, philosophers beat each other up over the number of angels who could dance on the head of a pin. Today, scientists, doctors, drug and insurance companies and governments argue the merits of mass "PSA screening".
The truth is that PSA "screening" does not exist, but PSA "testing" does and is a most valuable and important part of a suite of possible diagnostic techniques.
A positive PSA test obtained as part of a regular prostate health examination for men 50 and over (40 and over for black men and anyone with a family history of prostate cancer) can indicate any of several problems: enlargement of the prostate, benign infection of the prostate, or, possibly, cancer. But there is only one way to identify prostate cancer: a biopsy.
The message is clear. Get a regular prostate examination, including a PSA test. Keep a record of all the test results. Consult your doctor if your PSA results are high for your age, or if they are increasing over time. Keep informed, but don't be distracted by the academic debates or media reporting.

BERNARD POIRIER: I was thoroughly dismayed and confused by the article in the January 7 issue of The Citizen. … I will challenge anyone to prove to me that the value of PSA testing is questionable. By itself, I agree, it does not say much but it should be considered as the most reliable means of establishing a norm over a period of time. For 25 years my PSA was 1.02 or so. At the same time my annual physical included a DRE. About seven years ago I was told that the prostate was hardening a bit, something natural for my age, but the doctor wisely said we would "watch". The following year, the PSA was just a bit higher and the prostate harder still. The year after that my PSA had doubled—still quite low—but there was a little lump! Notwithstanding that the acceptable range of PSA is between 0 and 4, I was sent to an urologist for a battery of tests. I had cancer. Prostate cancer also has stages and grading to determine size and how aggressive it is—factors to be considered in choosing treatment along with age and general state of health. As a palliative care volunteer I see too many who are not as fortunate as I am mainly because it was not caught in time. PSA is a valid test and, while the patient still has to pay, it's a small price for its role in early detection.

HEALTH NOTES – HERE IS A HELPFUL DOZEN

Enclosed with this issue are 12 Healthy Tips for You, a mini-poster produced by the City of Ottawa Women's and Men's Health Programs.

"We want men and women to be empowered to take charge of their health" said Lyne Gillespie of the Public Health Department. "This poster targets men and women of all ages and we hope that it will increase awareness of our publications: *Bodyworx* for men and the *Women's Passport to Health*." The poster was produced with the help of the Canadian Cancer Society and is being launched across the city during February and March.

"Our Association is pleased to assist in the promotion of this poster," said John Dugan, PCAO Chair, "and trust it will be welcomed and displayed in members' homes. It is pretty simple advice and will be useful to keep this in a place to remind you and your family of healthy lifestyles and living practices, and early detection practices."

Additional copies of the poster will be available at the general meetings.

YOU DO WHAT WITH SOYBEANS??

Soybeans get a high rating when it comes to suggestions of what to eat to improve prostate health - but what comes to mind immediately are menacing looking blocks of white stuff called bean curd along with clever instructions on how to make the stuff tasty. Here's a novel suggestion from **Ariella Hofstetter**: **try edamamization**.

In Japan a glass of beer usually comes with a side order of edamame. Served in the shell these green soy beans are flavoured with salt and sesame oil to make them tangy and bring out the delicate sweet taste of the beans inside. An easy way to prepare this treat is to head for the freezer section in an oriental grocery store. Look for small bags of frozen soybeans. In appearance they're a lot like peas in the pod.

At home, **boil the contents of a 10 oz. bag in four cups of water for 7 to 10 minutes. Drain; in a frying pan warm up a teaspoon of salt, then add the drained cooked soy beans. Heat them through and then pour in about a quarter teaspoon (or more to taste) of toasted sesame oil. Mix and serve hot on a plate.** To eat them use your hands or, if you're nimble, chop sticks. Savour the coating on the bean hull and eat the small bean inside. Keep a bowl handy for the shells. Edamame can also be shelled and used boiled as a side dish or in soups and stews.

DIFD – YEAR FIVE!

CS COOP Do it for Dad!

MEMBER SUPPORT IS FUNDAMENTAL

Form a team, volunteer to do a job, raise pledges, tell your family and friends, or just come and watch. There are many ways that you can support Do It For Dad this year. When you do, you are telling everyone that prostate cancer can be beaten and they can help to do it.

On event day – June 15 – we want to all members and their families and friends at Anniversary Park (Carleton University at Dow's Lake) playing a role that supports the Prostate Cancer Association in this major activity. Call our Voice Mail at 828-0762 or e-mail us at pca@ncf.ca if you would like suggestions on what you can do.

In the meantime, help in another way by wearing the reef knot, the symbol of prostate cancer survivors.

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.