

# **PROSTATE CANCER ASSOCIATION -**

### **OTTAWA**

MEMBER OF THE CANADIAN PROSTATE CANCER NETWORK

# **DECEMBER 2002 NEWSLETTER**



WE MEET UNUSUALLY ON THE SECOND THURSDAY OF DECEMBER AT ST.
STEPHEN'S ANGLICAN CHURCH\*, 930
WATSON STREET. FOLLOW THE
QUEENSWAY TO THE PINECREST EXIT,
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.

\*NOTE: The February 2002 meeting will be at Emmanuel United Church on Smyth Road.

# THURSDAY, DECEMBER 12, 2002

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

**7:00 P.M.** Traditionally, our December meeting is a social occasion at which awards are handed out and members have the opportunity to engage in free discussion. You are welcome to bring cookies or other light refreshments to share.

THE JANUARY, 2003
MEETING MARKS THE
BEGINNING OF OUR SECOND
DECADE. DR. JOANIS BORMANIS,
HAEMATOLOGIST, OTTAWA
HOSPITAL, WILL START THE NEW
YEAR FOR US ON JANUARY 16.

### **MESSAGE FROM THE CHAIR**

With the arrival of snow, I look back happily on a most successful year for our Association. We have had excellent presentations on issues of keen interest; attendance at our meetings has grown. We now enjoy a more assured level of financial support from our membership fee. This and other sources of revenues allow us to extend the activities and services required to continue our emphasis on awareness of prostate cancer and the continuing need for research funds to protect the quality of life for men. The merits of this work become most apparent when you witness first hand the anguish and need for support of the newly diagnosed members at our monthly meetings. As well, the Prostate Cancer Association has become better known throughout our community and is seen as a leader in advancing concern for men's health care. Achievements like these and other moments make the whole adventure well worthwhile. And it is a continuing saga. There are encouraging signs for the future; for example, the long awaited Prostate Assessment Centre is closer to reality. We have learned from our monthly guests, new or improved treatments and medications are being introduced. More importantly, we have learned of the dedication of a hard-pressed medical profession that persists in trying to deliver quality health care in a timely fashion.

To forestall our hopes and dreams becoming merely illusions, I encourage each PCAO member to speak out, to take whatever action is needed to ensure treatment of prostate cancer is seen as a priority for our society. We have voices that can speak knowledgeably to the issues that affect us and our fellow men. Eradication of prostate cancer would be a wonderful Christmas gift for all of mankind. Then all the snow, the carols, and the sparking lights would be all the brighter. An extra note: Churchill said: "Never was so much owed by so many to so few". The same sentiment applies to those comparatively few members who, through both dedication and determination, have made our Association what it is over this past year and decade. My sincere thanks for a job well done; my wish is to see your numbers grow in 2003.

A very merry Christmas and a happy, healthy and prosperous New Year. **JOHN DUGAN** 

### **PROSTATE CANCER ASSOCIATON, OTTAWA**

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Chair John Dugan Vice Chair Vacant Vice Chair (DIFD) Randy Dudding Treasurer Jim Bloomfield Mottie Feldman Secretary **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 John Trant John Webster

Jacques Mousseau Kenn McCuaig Fred Hofstetter

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 Nov. 28, for its monthly deliberations with eight members in attendance. This is not to forget that many committee members are busy most days with the ongoing business of running the Association.

Treasurer Jim Bloomfield reported that membership registrations and fee payments continue to come in gradually, along with additional donations. He has now issued receipts for all fees and donations received so far, - about 250 paid-up members. Another 40 applications are now being processed, bringing the total to almost 300. Mr. Bloomfield and Peter Cooney continue to work on applying software that best suits the membership database requirements. The Committee agreed that the Treasurer should have primary responsibility for the database, as processing the money is the first priority.

The Association has obtained a liability insurance policy to cover untoward incidents at general meetings or when members are performing Association business.

The Committee reviewed the policy and guidelines for awards. including the Dried Prostate, and assessed candidates nominated so far. Traditionally, awards are presented at the December meeting but the Steering Committee may make awards at any time during the year.

John Dugan accepted a cheque in November for \$1,000 from the **Ottawa Firefighters**, proceeds from the Battle of the Badges hockey game. PCAO received a donation of \$500 for the second year from the Stardome Bar and Grill in Manotick. The money represents the proceeds of a 50/50 draw at the bar. (When in Manotick, drop in to express thanks.)

**Ted Johnston** noted deadlines for the December and January newsletters and asked that items be submitted as early as possible. He reported on the planning of a Men's Health Conference, to be held in Ottawa in May 2003. This is an initiative of the South East Ottawa Community Centre, using the City of Ottawa's Bodyworx/Exprès program to bring together caregivers and support groups dealing with depression, diabetes, heart and stroke testicular, colorectal and prostate cancer to assess health care delivery in Ottawa.

Randy Dudding reported that the planning and organizing of **Do It For Dad 2003** is proceeding. This year, the Coordinator has been given greater authority to make plans and decisions and to use the subcommittees as working groups. The Chair was tasked with setting up a meeting with Dr. Hartley Stern, CEO of the ORCC, for a briefing on how funds raised in recent years specifically for prostate cancer have been applied.

With regret, the Committee accepted a letter from **John Trant** resigning from the Steering Committee. The Committee accepted his offer to continue to assist the Treasurer in day-to-day financial administration.

**IN MEMORIAM**: We note the passing of members Larry Forest of Gloucester and John Reeves of Stittsville.

### **November Meeting**

# LIFT THAT WEIGHT OFF YOUR MIND - LITERALLY



Exercise is good for the minds and bodies of prostate cancer patients under treatment. That sums up the presentation of **Dr. Roanne Segal**, at November's general meeting. The ORCC oncologist can back that up now with the results of a clinical study pioneered in Ottawa and conducted in both Ottawa and Edmonton. This study is about to be published and Dr. Segal gave a preview of the outcomes. (When published, copies of the study will be available through the Association or the Ninon Bourque Library at the ORCC/Smyth Road).

It has been recognized that, whether treatment is by surgery, chemotherapy or radiation, patients commonly become fatigued. Ordinarily, the advice was to rest, but clinicians observed that this led to muscle loss and heightened the loss of independence experienced through the course of their treatment. This led to development of the clinical study using resistance-training exercise to as a means to potentially improve quality of life, strength and endurance, and body composition in men receiving Androgen Deprivation Therapy (ADT).

"The primary outcome of this study, was to evaluate Quality of Life and Fatigue, as well as other symptoms for 155 men receiving ADT". Over a 12-week period the men were offered an exercise program while receiving their planned therapy. "The results of the research demonstrated a beneficial impact of **p**rogressive **re**sistance exercise (PRET) on fatigue, muscular fitness, cardio-respiratory fitness and health related quality of life in men with prostate cancer receiving androgen deprivation therapy," she explained.

Dr. Segal announced that a new study is now getting underway at ORCC under the title of **PREVeNT** – **P**rostate Cancer **R**adiotherapy and **E**xercise **Versus** Normal **T**reatment. The trial will be seeking to recruit 210 men with prostate cancer, being treated with curative intent and scheduled to receive radiation therapy at the ORCC. When selected, each man will complete an intervention assessment before and after the 24-week program. In the pre-test phase participants will complete the Fatigue Scale (FS), and Health-Related Quality of Life (HRQL) questionnaires.

Physical or anthropometrical measurements (height, weight, waist circumference and sagital abdominal diameter) will be taken and serum free testosterone and PSA levels will be measured. Other tests will be involved before the individual is assigned to one of two strata, depending on the scheduled length of time on ADT. Patients will then be randomly assigned to one of three groups: aerobic exercise, progressive resistance exercise, or a wait list control.

"We are inviting prostate cancer patients now awaiting treatment who are interested in being part of the study to contact us through the ORCC Fitness Centre," said Dr. Segal.

**Chris Scott**, who manages the fitness and research programs for prostate cancer patients at the ORCC, followed Dr. Segal with a practical lecture on exercises that can be done at home. A PCAO member assisted the demonstrations. Information sheets on exercises and the PREVeNT study were distributed at the meeting.

### INTERESTED AND ELIGIBLE TO PARTICIPATE IN PREVENT?

Call **Chris Scott at 737-7700 ext 5-6812** to arrange an appointment to learn more. You will be asked to complete a referral form to be signed off by your attending oncologist. With that in hand, Chris will begin the pre-trial measuring and, with Dr. Segal, prescribe an appropriate personal exercise regime. The Fitness Centre is in the basement of the ORCC/Smyth Road, accessed by elevator or by the stairs to the left of the elevator bank.

### **MEMBERSHIP - GOING UP!**

The numbers are climbing but there is still some distance to go in confirming membership on the part of all names on the Association mailing list. Just under three hundred have affirmed their membership in the Prostate Cancer Association Ottawa (PCAO) but there are still several hundred who can make the modest commitment of \$25.00 in support of the Association.



As of June of this year, there were 723 names on the Association mailing list. "We can make allowances for some having moved away without asking to be removed from the list or for other good reasons," said John Dugan, PCAO Chair, "but surely we should be able to demonstrate a better showing than this." He emphasized that the fee is in effect a donation to the Association and a tax receipt will be issued for that amount.

In the New Year, the Steering Committee will likely agree to continue mailing the newsletter only to those who are signed up. "Given the nature of our Association," said Mr. Dugan, "we would always welcome anyone to attend our meetings but we cannot in good faith continue to send the newsletter or make other resources freely available to non-members." He noted that the cost of the newsletter for an individual each year is just over \$6.00 "but this does not include the generous donation of MDS Nordion in printing it or the volunteers who help put it together."

Mottie Feldman, longtime Secretary of the Association, pointed out that maintaining an office has certain costs. Ted Johnston, Publicity and Awareness Head, said that the displays used at conferences or public events have basic capital cost and operating costs to update them regularly. "We are fortunate that members volunteer to carry out speaking engagements and that we have a variety of information materials from the Canadian Cancer Society and others to distribute," he said, "but there are even costs associated with that activity."

If you have put off completing your membership application, the November newsletter had a form with it, or you can always get one at the monthly meetings. Or telephone the office and leave a voice mail message requesting a form (828-0762).

#### **HELP FOR SMALL SUPPORT GROUPS**

The monthly meetings provide an opportunity to learn of new developments in medicine or social care and allow members to chat with fellow survivors. Sometimes these chats lead to impromptu smaller support groups where three or four men with spouses come together to have more personal and pointed discussions about their concerns. The Association would be pleased to know of such formations. Sometimes one of our mentors might make a useful addition to the group, or you may want to borrow information materials such as videotapes, books, or pamphlets. If you are in a group and would welcome such assistance, please call the PCAO Voice Mail (828-0762) or send an e-mail to <a href="mailto:pca@ncf.ca">pca@ncf.ca</a> with your request.

A reminder about meetings: The <u>December</u> meeting is one week earlier than usual, on December 12. The <u>January</u> meeting is, as usual, on the third Thursday, January 16, at St. Stephen's Church. Dr. Joanis Bormanis, a haematologist at the Ottawa Hospital will be making a return visit after his well received talk in March, 2002.

In <u>February</u>, the meeting will be at Emmanuel United Church on Smyth Road as a one-time experiment. In <u>March</u>, we will meet again at St. Stephen's Church. Both February and March meetings are on the  $20^{th}$  of the month.

Newsletter Deadlines: January 3 for January; and January 30 for February issue.



## **WORKING THE WWWEB...**

Peter Cooney thinks December is a useful time to do some techy stuff and suggests getting free tools for Microsoft programs. Why?

Most speakers coming to future PCAO meetings will be using PowerPoint presentations – and these can be shared with almost anyone using a computer. However, most of our members probably do not have PowerPoint on their computers. Some may even spit on Microsoft and not have any Microsoft Office products on their computers. This is difficult to believe, but apparently true!



No problemo!! You can download, for free, a PowerPoint viewer from Microsoft. Viewers allow people who don't have Microsoft Office programs to see files in programs like PowerPoint. So, if you miss a presentation, we may be able either to load it onto the website or send you a copy which, with the PowerPoint viewer, you can view to your heart's delight.

You can also download other Microsoft Office viewers for programs like Excel, Word, and Access. These software programs are used by some members of the PCAO Steering Committee, and would be of particular interest to members who volunteer to help PCAO.

FREE Tools on the Web: Microsoft Office Viewers <a href="http://office.microsoft.com/Assistance/9798/viewerscvt.aspx">http://office.microsoft.com/Assistance/9798/viewerscvt.aspx</a>

Interested in a free newsletter? The Prostate Cancer Research Foundation of Canada (PCRFC) offers a monthly review of prostate cancer research, treatment and other activities. You can subscribe by e-mail by going to <a href="mailto:news@prostatecancer.ca">news@prostatecancer.ca</a>. Another one is to be found at <a href="mailto:www.questhealthlibrary.com/newsletter\_archive.php">www.questhealthlibrary.com/newsletter\_archive.php</a>; Quest Vitamins issues an interesting general health newsletter and the November 2002 issue is a timely follow up to the presentation of Dr. Segal. It's entitled Maintaining Good Health Through Exercise and Attitude. (Any questions or suggestions for "Working the WWWeb, please send me an e-mail at <a href="mailto:cooneypw@sympatico.ca">cooneypw@sympatico.ca</a>.)



There is always a need for workers with the Prostate Cancer Association. For a start, any member is welcome to attend the monthly Steering Committee meetings (usually the last Thursday of each month, 9:30 a.m. at St. Stephens Church) where you can get a good idea of the range of activities and the need for specific talents. While you think about it, these are some of the areas where we can always use a helping hand: We would like to find a few people who can think in terms of **long-**

term development of the Association. Where we can be headed, what resources we need to get there, and how do we find those resources. Some people with a penchant for writing to assist in preparation of the monthly newsletter – to make sure we have the guest speaker covered; to scan the papers, periodicals, TV, etc. for items of interest to the membership, or to write/edit original pieces. Represent PCAO to other groups and learn where we can be joining forces to help improve health care. The Do It For Dad Committee needs people to assist both in advance and on the actual day. Right now, if you have experience in marketing, publicity, and promotion or in people management or data organization, there is a useful job waiting. What is most important is a readiness to get in and do the job. Give a call to the Voice Mail (828-0762), e-mail us at pca@ncf.ca or come along to

the next steering committee meeting, Thursday January 9.

# WHY THE REEF KNOT?



The reef knot has been adopted as the symbol of prostate cancer survivors and supporters. The knot represents strength and each of the four ends of the rope

signify the survivor, the caregivers, the family and friends, and the broader community of support groups across the country. The knot is in the form of a brass pin and is always available at our general meetings for the modest

sum of \$5.00. Buy one for yourself and for your chief supporter. Incidentally, a membership donation of \$30 or more entitles you to a pin.

A PCAO sweatshirt was created this past summer as a presentation item for special events and as a "thank you" gift for our monthly speakers (*Richard Loomis of the Canadian Cancer Society at right*.) A limited number are available for members to purchase at \$30.00 apiece. The shirts are navy blue and carry the reef knot and "PCAO" in gold on the left breast. While supplies last, they will be on display at monthly meetings. If there is sufficient demand, we can order a larger quantity. You might want to put this on your Christmas list – or buy one for a son, brother or friend who may be entering the age for prostate cancer awareness.



### SMILE — IT DOESN'T COST AND IT DOESN'T HURT...



Most prostate cancer survivors are men of mature years, wisdom, understanding, and a sense of the hereafter – as in I go somewhere to get something and then wonder what I'm here after.

Other thoughts that might help us through the day: *I started out with nothing – and I still have most of it.* I wish the buck stopped here; I sure could use a few. *Now that I have my head together, my body is falling apart.* My wild oats have turned into prunes and All Bran. And to wind it up: *God grant me the senility to forget the people I never liked anyway, the good fortune to run into the ones I do, and the eyesight to tell the difference.* 

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.

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GOOD WISHES FOR THE SEASON TO ALL

# A MERRY CHRISTMAS

AND

THE BEST OF HEALTH AND HAPPINESS IN THE NEW YEAR