MESSAGE FROM THE CHAIR

There is something wrong with the picture and perhaps the set needs radical adjustment. Prostate cancer is a threat to all men in our society and yet less money is spent on research and treatment than almost any other cancer.

It has become quite clear that the PSA test is the best available marker for this cancer yet it remains 'off the list' for OHIP coverage as a diagnostic tool. The continuing decline in early death rates for prostate cancer patients is largely credited to PSA testing. The big finger, the Digital Rectal Exam, is valid and cheap but it does not provide early warning about the possibility of cancer. The Ontario Legislature has a bill at second reading that would add the screening test to OHIP coverage. Members should take the time to let MPPs know the importance of the PSA test to their own diagnosis.

That's not the only fuzziness on the screen. This past summer saw considerable media attention paid to some select breast cancer cases that led to a sudden decision by the province to fund an expensive drug, Herceptin. At the same time, little noticed, the government approved the use of Taxotere for metastatic hormone resistant prostate cancer. But, at both the provincial and federal level, one has to ask where is the money for research into better diagnostic tools, better less invasive treatments, better support for prostate cancer patients generally? We see enormous amounts of public money being dispensed to more risky ventures but prostate cancer, the silent killer of men, is virtually ignored in Canadian health care. The Canadian government is spending nothing; in fact it refused to fund the second phase of the very successful Prostate Cancer Research Initiative, effectively destroying a developing, fragile research structure. Ironically, the US Department of Defense funds prostate cancer research, even in Canada.

The squeaky wheel does indeed get the grease. Well, it's more than timely that we men become more active in seeking a proper share of funds for the diseases that affect us. We prostate cancer survivors have a duty and responsibility to put the case before the public. This ought to be a daily commitment on our part and, in September, we have a prime opportunity to do so with Prostate Cancer Awareness Week.

PCAO's primary roles are to provide support for the newly-diagnosed and to create greater awareness in the community of the threat of prostate cancer and the ease and benefit of early diagnosis. Members – and all survivors - should become very squeaky wheels on behalf of themselves, their families, friends and their future. Spread the message of awareness and especially awareness of funding needs to bring this cancer to heel.

TED JOHNSTON

THURSDAY, SEPTEMBER 15

6:15 P.M. ORIENTATION FOR NEW PATIENTS
7:15 P.M. DR. SEAN MALONE, ORCC ONCOLOGIST, WILL ELABORATE ON TOMOTHERAPY AND OTHER ASPECTS OF RADIATION TREATMENT.

Members are reminded that contributions to the St. Stephen’s food bank are welcomed and appreciated. Please bring one or more items of non-perishable food to the next meeting you attend as a contribution to our host body. You'll be glad you did.

WE MEET ON 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 STREET ON THE LEFT. PARKING IS AT THE REAR OF THE CHURCH.
ASSOCIATION BUSINESS

The Steering Committee met at the Canadian Cancer Society on July 28 and August 25 under the chairmanship of Ted Johnston. Present were David Brittain, John Dugan, Stewart Given, Murray Gordon, Duane Hess (July only), Ron Marsland, Bill McColm, Eric Meek, Phil O’Hara, and Ludwick Papaurelis.

Financial: Bill McColm reported in July that the financial records had been sent to the auditor and in August that the auditor had completed his work. A report will be submitted to the September monthly meeting. The Association’s finances are all in positive balance. Membership donations for 2005-06 continue to be received and, as of 25 August, the membership stands at approximately 300 new and renewed members; this is consistent with past years. The membership database has been updated by Mr. O’Hara and directories of members distributed to designated steering committee members. It was agreed that these lists should only be used for communication with members and are to be treated as personal information not to be shared outside the Association. It was noted that “Today’s Colonial Furniture” has designated PCAO as the beneficiary of its 29th annual charity golf tournament to be held in September.

The Financial Subcommittee has been directed to develop guidelines for expense claims by Association members.

Member Services: Mr. Brittain reported on attendance and activity at the July and August meetings which were ‘open fora’, allowing members to discuss a variety of topics. Dr. Sean Malone, radiation oncologist at the ORCC, will be the speaker in September on the topic of Tomotherapy. Dr. Susan Robertson, Ottawa Hospital pathologist, is expected to speak in either October or November and Mr. Brittain is pursuing other options through to the end of December. It was agreed that Jim Watson, Minister of Health Promotion, should be invited to address the Association.

Mentoring: Mr. Given reported that the summer meetings saw a dozen new patients, some with spouses, seeking guidance on dealing with their diagnoses. He assured the committee that these mentoring sessions are conducted in confidence both to protect the privacy of participants and to encourage them to speak openly of their concerns. He is undertaking a revision of the new member registration sheet.

Website Management: A report by Wilf Gilchrist on the operation of the website was tabled at the July meeting and is to be discussed in September. The Chair noted there is a continuing need for a content editor.

Volunteers: Murray Gordon has a list of over 40 members who are prepared to take on duties for the Association and he is continuing to contact people to further develop the list.

Publicity and Awareness: Responsibility for editing The Walnut is being transferred to Elie Moussalli and Duane Hess. Mr. Papaurelis has offered to assist on design and graphics. Deadline for future issues is September 2, October 7, November 4 and December 2.

Outreach: Mr. Dugan has taken charge of Prostate Cancer Awareness Week preparations and has had a preliminary meeting with the Canadian Cancer Society, and urologists and oncologists, as key sources for information.

The next Steering Committee meeting will be held on Thursday September 29, 2005 at 9:30 a.m. at St. Stephen’s Church. Attendance is open to all members to come and learn of the opportunities to contribute.
HERE’S HIGHLY IMPORTANT ADVICE FOR THE NEWLY DIAGNOSED

The second annual Canadian Prostate Cancer Network (CPCN) Conference was held in Toronto August 7 – 9. For Bill McColm and Elie Moussalli, the two delegates of the PCAO, it was time well spent. Elie, who has been through treatment for prostate cancer, took his laptop and pencil and papers to capture much of the information dispensed by the medical experts. Wally, our mascot, felt this was important to reproduce in as full a report as Elie could muster, so here is what he calls “one rookie correspondent’s report” for The Walnut.

THE KEYNOTE: KNOW THE ENEMY
Dr. Gerald Chodak, Director of the Midwest Prostate & Urology Health Centre in Chicago and a founder of the US support group Us Too was the keynote speaker and focussed on the impact of the PSA test. He noted that before it had become widely used in the early eighties, prostate cancer used to be diagnosed at a higher stage with uniformly bad outcomes. Certainly things have changed since those days. The take home lesson from him was that patients should educate themselves enough to be able to put the hard questions to their doctor. This was a fitting talk for the line up of speakers.

IS HIFU 4U?
Dr. Edward Wood, from the Scarborough General hospital led off the weekend of speakers elaborating on High Intensity Focused Ultrasound (HIFU). This is a relatively new-to-the New World treatment procedure wherein the temperature of the prostate is raised to 85 degrees Celsius by focusing an ultrasound beam of high intensity in successive tiny volumes of the prostate gland. This procedure is not a replacement, but a complement – or perhaps an alternative – to current treatment procedures. This non-invasive (no surgical instruments are used), non-radio active technology was developed in France and Germany (Chaussy and Wieland are the two researchers) and has been in use on the Continent for over a decade. So far thousands of patients have been treated as the procedure gains acceptance.

HIFU is precise and definitive, has minimal side effects and does not preclude other treatments afterwards; it is not a therapeutic impasse. It is repeatable and adaptable. The movements of the beam can be controlled by one tenth of a millimetre and the wall of the rectum is saved. Parts of the seminal vesicles, the closest to the prostate gland, are reachable by this procedure.

Candidates for this procedure are those recommended for surgery, radiation therapy or cryotherapy; in other words, for localized T1 or T2 stage cancers with prostate size smaller than 50 cc. A five-year follow-up study of a large cohort in multiple centres in Europe has been published in 2004. This period is still a little too short. HIFU is typically preceded by a TURP procedure. Whereas this procedure is a promising primary treatment, it has not been used widely in other settings such as patients who have failed radiation therapy. The best place for that is in France (Lyon). HIFU is appropriate for patients recommended for radical prostatectomy, but for whom surgery is not option for other reasons.

Health Canada declared the procedure “safe and effective” in 2003. The first, and so far only, machine in the hemisphere is in Toronto at a state-of-the-art private hospital in Don Mills where two doctors offer the treatment procedure. Training in this procedure has a sharp learning curve and is undertaken in Germany. And the cost? About $18,000!

Patients considering this treatment option may log onto the website www.hifu.ca to communicate with a doctor to find out more about the procedure.

CPCN EXPECTS TO PUT THE FULL CONFERENCE BOTH ON ITS WEBSITE (www.cpcn.org) AND ON DVD FOR DISTRIBUTION TO SUPPORT GROUPS ACROSS THE COUNTRY.

NO ANTS IN THESE PANTS
Dr. Juanita Crook of the Princess Margaret Hospital addressed brachytherapy, a treatment option that has seen an increasing use over the past decade. It is appropriate for all three risk categories. It is often used in combination with External Beam Ratio-Therapy (EBRT), in a so-called “brachy boost”. This combination
confers survival rates, according to Dr. Crook’s research, that are similar to those of normal males over seventy years of age. No other modality of treatment can deliver a higher dose as safely.

The radio-isotopes used are $^{125}$I (Iodine 125) and $^{103}$Pd (Palladium 103) delivered as seeds that are left in situ for the duration of the treatment. Brachytherapy has some notable advantages in quality of life issues: it has the lowest rates of incontinence when compared to other treatment modalities and sexual function is the least impaired. The insertion of the radioactive seeds is done with the guidance of MRI and CT imagery. While the seeds are in place lead lined underwear will cut out radiation completely.

The post treatment trajectory of PSA shows a bounce after an initial decline; sometimes there is a double bounce in the PSA level before it declines to the desired undetectable level. About 15% of patients need catheterization and about 1% suffer urethral stricture. Proctitis is typically mild. Sexual function is impaired wherein the ejaculate is reduced in 70% of the patients, or lost completely. Phosphodiesterase inhibitors, such a Viagra, Cialis and Levitra may be used prophylactically to increase blood flow.

GOLD SEEDS IN THE GLAND

Dr. Gerard Morton of the Sunnybrook Regional Cancer Centre who talked about Intensity Modulated Radio Therapy (IMRT) and High Dose Rate (HRD) Brachytherapy. With the very accessible metaphor of the family van and a formula one car he distinguished between the multi-purpose and relatively easily self-repaired normal cells and the built-for-speed cancer cells that are susceptible to DNA damage and that do not have the capacity for self repair. Radiation energy is delivered as X-rays by a linear accelerator. Five to 10% of patients suffer rectal bleeding, some degree of bladder scaring and impotence.

Along the continuum of Conventional, 3Dimensional Conformal Radiation Therapy (3DCRT) and IMRT, progressively more advanced targeting of the radiation beam is utilised. Gold seed implants and a CT scan allow for improved targeting and planning of the delivery in 3DCRT in six fields using multi-leaf collimators. In IMRT the shape as well as the intensity of each of the beams can be changed as it rotates around the targeted area. This fine-tuning is made possible by advances in computing technology. IMRT thus provides better means for escalating the dose while reducing the effect on adjacent tissues and side effects than 3DCRT.

Gold seeds inserted in the prostate help visualise the target in three dimensions. This is particularly relevant as the daily minute shifts in the absolute position of the prostate gland can be influenced by such things as breathing, presence of gas in the rectum etc. The fusing of ultrasound with CT scanning affords good targeting that can track the daily shifts in the position of the prostate, minute as they may be.

HDR+EBR=CURE?

High Dose Rate (HDR) radiation brachytherapy is a newer form of brachytherapy. Image guided radioactive seeds are inserted in the prostate for a short period of time and then they are taken out. This therapy procedure is usually combined with some form of external beam therapy. One seed of $^{192}$Iridium is inserted and moved throughout the tumour. Each dwell position may be varied and thus a 3-dimensional field may be created to conform to just about any shape. The advantage of this treatment option is that it is the most precise way to deliver radiation. Also the delivery of the dose is very quick, about 1000 faster than permanent seeds. It has lower side effects and is quite effective against rapidly growing cancers.

On the down side, it does have to be combined with external beam radiation; the data to evaluate its efficacy are not long enough. It is appropriate for cancer stage 1 or 2, Gleason score 7 and a PSA between 10 and 20. High Dose Rate Brachytherapy has not been yet after failure of External Beam Radio Therapy or hormonal therapy. The side effects of the procedure are typically mild. Risk of rectal bleeding, for example, is low.

UNBLOCKING BPH

Dr. Allan Toguri, Senior Consultant and Chief of Urology at Scarborough General Hospital, and the Executive Director of the Society of Urologic Surgeons of Ontario took as his topic Benign Prostatic Hyperplasia. BPH is the most common benign tumour in men. It usually has no symptoms and causes no complaints. However, it can cause urethral obstruction and lower urinary tract infection (LUTS). PSA tests, especially the percent free PSA that is the ratio of free PSA over total PSA (i.e. bound and unbound) are part of the management of BPH.

Alpha reductase inhibitors, such as Proscar (Finestaride), given over four years have been shown to be safe and have reduced BPH as well as prevented it. The newest member of this family of drugs is
Dutestartide. Urethral constriction may also be surgically removed by a Trans Urethral Resection of the Prostate (TURP). The sobering statistic that Dr. Toguri showed was that 7% of BPH patients have prostate cancer.

**LAPROSCOPY FOR LUNCH**

Dr. Antonio Finelli, the last speaker, just before the farewell brunch, showed a video of Laproscopic radical prostatectomy. With only four tiny holes in the abdomen, procedure is minimally invasive. Like all other state of the art procedures presented, it does not do much for those of us who failed their primary treatment.

"Prostate cancer is not just a man’s disease!"

We heard a remarkable personal experience with prostate cancer recounted by Ms. Irene Lange-Menchen, a registered Medical Radiation Therapist who treats prostate cancer patients. She was also the sole palliative caregiver to her husband Rainer, the former president of Mercedes-Benz Canada, who lost his battle with prostate cancer in 2000. She is a passionate advocate for prostate cancer research and gave the following comparison in expenditures on research: for HIV/AIDS research Canada spent (I did not the catch the time frame) $54M, for breast cancer $39M and for prostate cancer a mere $2M!

Ms. Lange-Menchen discovered that advocacy was part of her healing process and argued that only political action of the most astute and organised kind will redress this imbalance, even a march on Parliament Hill! She has a website, [Ask Irene](#), (linked from the CPCN site through which she communicates with many people. She shared the importance of having a living will, or an Advanced Medical Directive in her own personal experience. A thirty page explanation of such a directive may be found at the website of the Department of Bioethics at University of Toronto. If you have any question about anything related to prostate cancer, she will answer you.

**ASSOCIATION BUSINESS Continued from page 2...**

**Outreach:** Mr. Dugan has taken charge of Prostate Cancer Awareness Week preparations and has had a preliminary meeting with the Canadian Cancer Society. Displays manned by PCAO volunteers and media attention are being organized. Mr. Marsland confirmed that brief messages about PCAO will be included in e-mail and postal mail notices of Ottawa Public Health to a variety of health care addressees in Ottawa in September. There was discussion of the need for a year-round coordinator for Prostate Awareness Week and the possibility of developing a regional conference on prostate cancer issues.

Mr. Gordon updated discussions with an art gallery in Pakenham for an event on September 19. Mr. Johnston reported on attending the Greely Lions Golf tournament which raised $5,000 towards the new Ottawa Hospital Prostate Assessment Centre.

Mr. Johnston reported on discussions with the Ottawa Regional Cancer Foundation (ORCF) to strengthen our partnership with both the Foundation and the Cancer Centre. He has cosigned a letter with other cancer support groups in support of a funding application by The Ottawa Hospital for a project to improve patient care going through surgical treatment.

**Do It for Dad:** Mr. Johnston noted he and Mr. Dugan had met with the CEO of Alterna Savings who confirmed Alterna’s interest in continuing as title sponsor of this event and of working towards expansion of the run to other cities, notably Toronto.

**Conferences:** The Chair reported that a useful informal meeting had been held in August with members of the West Island (Montreal) support group under the auspices of Mr. Papaurelis, who maintains membership in both groups. Mr. Papaurelis reported on the USA National Conference on Prostate Cancer in Washington D.C. in June and the committee agreed to purchase a complete set of DVD’s containing all presentations at the conference. Mr. McColm said the CPCN Conference in Toronto was an impressive event and more information will be included in the September Walnut and distributed by CPCN in its quarterly newsletter.

**New Publications:** It was noted that *Our Voice* has been revived and free subscriptions are available. Copies of a booklet, *Promoting Wellness during Hormone Therapy for Prostate Cancer*, have been ordered for members. Copies of the *Ottawa Citizen* series on palliative care have been obtained for members. Print versions of Janet Podleski’s April presentation have been received. All these and other items will be available at the September meeting.
INFORMATION FOR MEMBERS

A number of publications and articles appeared over the summer and copies of many of them will be available to members on the Information Table at the September meeting.

The print version of Janet Podleski’s April presentation on diet and nutrition has been received and copied for members to enjoy.

Earlier this year, The Ottawa Citizen ran a series on palliative care. This has now been reproduced in a single reprint, copies of which will be available in September.

If you’re on hormone therapy, you’ll be interested in a new booklet: Promoting Wellness During Hormone Therapy for Prostate Cancer. Written by Dr. A. Moyad of the University of Michigan Medical Centre, Department of Urology, the booklet focuses on General Health Issues and Reducing Side Effects. Dr. Moyad, in his introduction, notes that: “Hormone therapy, or androgen suppression, or LHRH treatment has been around for decades and will probably be around for a long time to come because of its effectiveness. The goal here is to empower you with lifestyle changes to improve your health in general and then to discuss many of the common (and not so common) side effects from LHRH treatment so that you and your doctor or health care professional are better able to prevent or reduce these side effects.” Fifty copies of the booklet, underwritten by Abbott Laboratories, have been ordered for the Association.

Understanding Prostate Cancer is another recent publication from Rogers Media that provides a simplified guide to the disease. Written by Colette Pellerin under the supervision of Drs. Michael McCormack and Fred Saad, urologists at the Centre hospitalier de l’Université de Montréal, it covers the range of topics from diagnosis through initial and recurrent treatments before looking at what may lie ahead in prevention and research. Copies of the book will be available at meetings, courtesy of sanofi-aventis.

Adding to your information about diet, Leslie Beck in the Globe and Mail’s “Food for Thought” column (August 17) reported on two studies suggesting an ultra low-fat vegetarian diet, combined with exercise and relaxation, can stop or even reverse the progression of early stage prostate cancer. The studies are published in The Journal of Urology. Notes Ms. Beck: “These findings add to a growing body of evidence that certain foods and nutrients may lower the risk of developing prostate cancer, reduce the likelihood of its recurrence and slow down the progression of the disease.”

Our Voice, a Canadian periodical dedicated to prostate cancer patients, has been revived, thanks to AstraZeneca. This is a well-written, well-designed publication that uses simple language to address many of the issues facing new and recurrent PCa patients. A free subscription is available for the asking.

ON THE WEB…

It’s perhaps timely to remind members of websites that address prostate cancer issues generally and specifically: www.cpcn.org is the umbrella group for Canadian support groups and addresses many issues and points to other sources of information. New patients in the Ottawa area should benefit from the regional cancer centre’s website for guidance on ‘going through the system’ – http://www.ottawahospital.on.ca/sc/cancer/index-e.asp. Downloadable pdf versions of the Patient Information Guide, other booklets and information sheets and the monthly patient education calendar are available here.

If you have faith in the PSA test and want to support it being included under OHIP as a diagnostic test, visit http://www.epcdo.ca, a website run by an individual who has helped to put the item on the Ontario Legislature agenda.

http://mywebmd.com has news and comment on prostate cancer matters; http://www.prostatecancerfoundation.org covers a range of useful topics; http://www.psa-rising.com will be of interest to those with an advanced cancer. And, if you’re concerned about strange recommendations or potions, you can visit the Canadian Institute of Health Research at www.ehir-irsc.gc.ca or for information on scams or frauds www.quackwatch.com. Or you can always ‘Google’ them.

If you have a favourite website to share with fellow patients, please let us know at pca@ncf.ca
Dr. Chris Morash, urologist at The Ottawa Hospital, has commented on our website (www.ncf.ca/pca) on PSA trials described in articles published the July issue of the Journal of Urology. A limited number of copies of the articles and Dr. Morash’s comments will be on the Information Table.

WALLY reminds us that a walnut closely resembles the size and shape of the prostate gland and that is why the newsletter is called The Walnut! And Wally is proud and happy to be our mascot.

WALLY SAYS: Remember to check the PCAO website (www.ncf.ca/pca) for current information. The Walnut is posted on line at the PCAO website, usually during the first full week of each month. The on-line edition has the bonus of being in colour – and reduces mailing costs for the Association. Twelve back issues of the newsletter are also archived for easy reference. If you would like to be added to the monthly e-mail notification, please send your request to Phil O’Hara at philneri@primus.ca.

EH, WHAT’S UP, DOC, FOR THE PCAO FALL MEETINGS?

In September, radiation oncologist, Dr. Sean Malone, will discuss current and future developments in this form of treatment with particular reference to tomotherapy. The October meeting is being developed with a view to a return visit by Ottawa Hospital pathologist, Dr. Susan Robertson. In November, it could be a presentation on nutrition, incontinence, sexual dysfunction, palliative care, or something we haven’t yet thought of. Suggestions are always welcome.

Members with advanced or metastatic prostate cancer may have missed the summer announcement that Taxotere (docetaxel) has now been approved for use in Ontario. Federal approval came earlier this year. Taxotere slows the growth of cancer cells for symptomatic men who have been diagnosed with Hormone Refractory Prostate Cancer; it is to be used once hormone treatments have stopped working. While approved for use, it has not yet been added to funded drugs in Ontario. The approval for Taxotere was overshadowed by the media coverage of herceptin for breast cancer patients.

Membership renewal

Envelopes with renewal forms and cheques continued to be received over the summer months. At the end of August, there were over 300 new and renewed members of the Association. “I take this as a terrific vote of confidence in the work we are doing,” said Ted Johnston, Association Chairman. “The support we provide newly diagnosed patients may be the most important thing we do, but reaching out to the community to make men more aware of this threat is very much a priority for us.”

If you haven’t renewed your pledge in support of the Association, please take the time to do so now. Don’t forget, each renewal is eligible for a handy pocket knife.
I am pleased to support the continuing work of the Prostate Cancer Association Ottawa with the enclosed donation of $____________.

NAME:
ADDRESS:
CITY: PROVINCE POSTAL CODE
Optional: TELEPHONE NUMBER ( ) E-MAIL ADDRESS

PCAO is a registered charitable organization

PCAO THANKS ASTRAZENECA FOR ITS FINANCIAL SUPPORT FOR THE PRODUCTION OF THE WALNUT AND COMMENDS IT FOR ENSURING THE RETURN OF OUR VOICE, THE MAGAZINE FOR PROSTATE SURVIVORS.