The Walnut

NEWSLETTER OF THE PROSTATE CANCER ASSOCIATION OTTAWA DECEMBER 2006
P.O. BOX 23122, OTTAWA, ON. K2A 4E2 • (613) 828-0762 • pca@ncf.ca

Message from the Chair

Throughout the year, appeals are made for members to come forward to assist in the work of the Association. This month, I wish to thank each of you who has made a contribution. In doing so, I realize there has been a very creditable turnout of members, beginning with the ORCF Telethon in January through to the last public awareness display. In between, there are those who help to set up and dismantle our meeting room each month..

The team which meets monthly with newly-diagnosed patients deserves special credit for its most immediate and helpful contributions.

The many men – and their spouses – who have volunteered to staff the awareness displays throughout the year or to make presentations to groups are also doing excellent work on the Association's behalf. Many of you turn out for the Do It for Dad Run and Family Walk as volunteers, runners, or donors. Others are in the Motorcycle Ride for Dad. You can take pride that both these events have become major funding sources for the Ottawa Regional Cancer Foundation.

The fellows who deserve hearty commendations are those on the Steering Committee who perform many unsung tasks that ensure the continuation of the Association. The duties range from coordinating volunteers to events, to arranging the programs of monthly meetings, maintaining financial and official records, representing us with other organizations or just providing advice or a helping hand where needed. They are doing this in the knowledge they can be saving lives through their efforts to make more men aware of the threat of prostate cancer and the benefit of early diagnosis and treatment.

In 2007, the Association will celebrate its fifteenth year of existence. Hundreds upon hundreds of men have benefited from meeting with survivors like us. They have been empowered to choose their treatments and go on to continued, useful and loving lives. I hope that, in the coming year, we will continue to have many members participating in small and large ways in activities of the Association.

To close off this year, on behalf of all my colleagues on the Steering Committee, I am pleased to wish you a Merry Christmas, a Happy Hanukah, or however else you may celebrate this season. May you all enjoy a Happy, Healthy and Prosperous New Year.

Ted Johnston

Thursday, December 21, 2006

6:00 P.M. **Orientation for new patients and spouses**

6:30 P.M. **Social time and exchange of information - coffee and biscuits**

7:00 P.M. **Meeting called to order - Association Business**

7:20 P.M. **"Waging War Against Prostate Cancer"** will be the theme for retired **General PAUL MANSON,** former Chief of the Defense Staff. It's Christmas, so we will have special cookies and treats for everyone to enjoy.

We meet 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 Steet on the left, parking is at the rear of the church.

PLEASE REMEMBER YOUR CONTRIBUTION FOR ST. STEPHEN'S FOOD BANK.

PCAO PROSTATE CANCER ASSOCIATION OTTAWA

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The PCAO is a volunteer organization of prostate cancer survivors and caregivers. Our purpose is to support newly- diagnosed, current and continuing 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

Do it for Dad makes a difference

The Ottawa Regional Cancer Foundation released its annual report last month. It includes an article with the heading *Donors Driving Discovery in Prostate Cancer Research.*

The article noted, "Designated donations have been driving research interests in the area of prostate cancer in Ottawa, showing the work of our donors really makes a significant difference. Events such as The Motorcycle Ride for Dad, Do It for Dad Run and Family Walk and Brockville Highlands Golf Tournament have raised a combined total of $1.14 million since 2002. This has ensured that prostate cancer remains an active, on-going and well-funded research priority in Ottawa. The Ottawa Regional Cancer Foundation is honoured to partner with such dedicated fundraisers."

Money raised in the fiscal year 2005-06 was recently allocated by the Foundation; six projects are directly related to prostate cancer. PCAO Chairman Ted Johnston participated in the allocation review committee, which was provided with lists of proposals from research and clinical/patient care sides of the ORCC.

Prostate research projects recommended to the Board of Directors were:

Improved Diagnosis of Prostate Cancer based on molecular Detection of Novel Gene Fusion (Dr. Douglas Gray) $25,000.

Statins as Novel Chemopreventative Agents in Prostate Cancer (Dr. Jim Dimitroulakos) $46,000

Clinical Outcome Assessment Companion Study in Prostate Cancer (Dr. Shawn Malone) $40,000

Role of EphB4 receptor in Prostate Cancer Tumorigenesis (Dr. Chrstina Addison) $44,885

Image Guided Radiation Therapy Research Initiative (Dr. Robert MacRae) $30,000

Targetting cullin 4a and the COP9 signalosome in cancer (Dr. Bruce McKay) $30,000

Patient Care allocations were limited by the amount of money available ($40,000). The committee simply agreed to three priorities for funding from the 15 applications. None of these is prostate cancer specific but may benefit such patients.

STEERING COMMITTEE

The Steering Committee met on November 30 but production of the minutes has been delayed. The next meeting of the Committee will be on Thursday, January 4, 2007 (rather than the normally scheduled December 28). Members are always welcome to attend these meetings to learn what makes the Association tick and how they can make their contribution. The meeting begins at 9:30 a.m. in the Shalom Room at St. Stephen's Church and usually runs to 12 o'clock.

Losing The Walnut/Saving a life

Let me begin at the beginning. About 23 years ago my dad was diagnosed with prostate cancer. This was before PSA tests were the norm and sadly, even with one of the best doctors one could ever hope to meet, it was too late to conquer this horrible disease.

From that time on I made a conscious effort to keep an eye on the walnut. It began with an annual PSA test, which were acceptably low for a number of years.

About eighteen months ago, it was the rate of the PSA score increase and the subsequent enlargement of my prostate that raised eyebrows. In these circumstances, the urologist suggested a biopsy, which came back negative.

A year ago, my PSA numbers jumped up again and another biopsy was prescribed which came back negative, even though my prostate was even larger. He was sure something was occurring, but could not yet explain it.

Six months ago, the PSA score and prostate size jumped yet again and prostate cancer was discovered during the third biopsy.

The urologist sat my wife and I down and explained my predicament .The bad news was that I had 1mm of cancer in one site, pre cancer possibilities in one or two other sites.

The good new was that it was a slow growing cancer and the prospect of catching it early was very promising. He offered two options given the size of my prostate: radiation or a radical prostadectomy. He referred me to a younger colleague, who had trained at the Sloan Ketterine Institute, and had the nerve sparing skills for this most delicate operation.

We scheduled a date right away because we did not want the cancer to fester too long or escape the walnut. ALL THE TIME, I felt no pain and looked great. It was incredulous to think that I had a silent disease. Then I remembered my dad!

But my search did not stop there. We had talked to a radiologist who was initially confident that my type of cancer could be treated with radiation. As the discussion progressed, he thought that the risk/rewards were not there in my case.

Actually I was looking for an even easier way out with brachyl therapy. I found out that was verboten in Ontario if your PSA was over 10 and your prostate size was over 40 cc.

Why not cryosurgery? I called the University of Western Ontario and was informed that it was being offered as salvage cryotheraphy and not as primary treatment. Besides which, my prostate was too large for this procedure. So I emailed a doctor in New York City who replied back that I was a good candidate. But there were all kinds of follow up required monitoring if the procedure was successful and no mention of the enlarged prostate. Hmmm, that got me wondering about the chances of success.

Also, John Hopkins offered laproscopic techniques that were really cool. But in reading the literature and talking to my urologist, the results regarding leakage and restoration of sexual function were not dissimilar.

Finally Hamlet had to decide “to operate or not to operate”. Having exercised due diligence and exhausted existing but not experimental treatment, I came back to the “Gold Standard”.

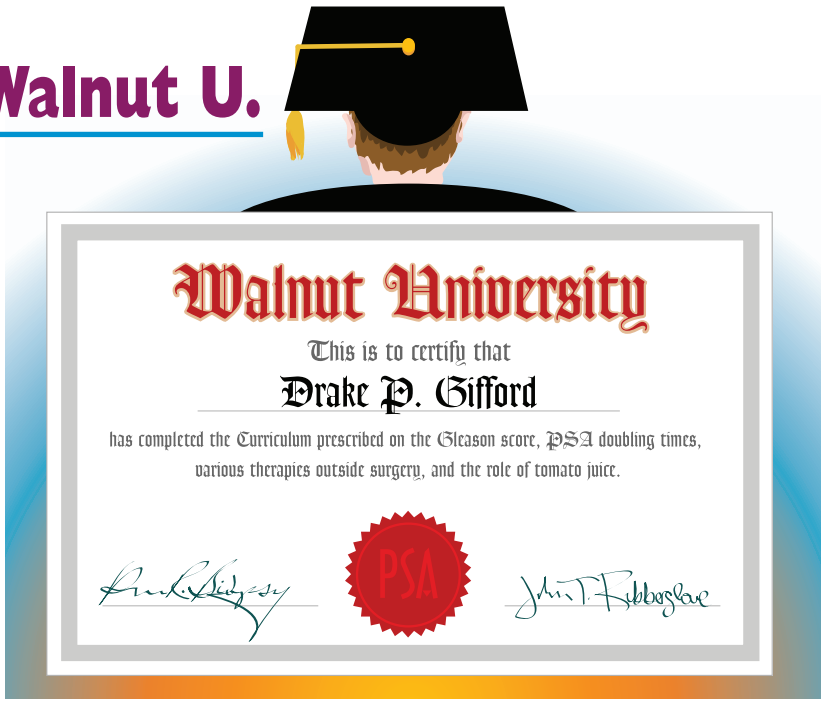
The operation was on a Friday and I was home on Monday. Healing took time, but I was feeling a bit better each day. The young urologist, who I appreciated, not only for his professionalism, but also for his sensitivity, said the results were outstanding and nerve sparing was maximized. I am one of the lucky ones to have caught it early enough to be treated. If it were not for the loving support of my wife, all this would have been impossibly difficult.

The one thing that I did learn in my research is that there is more than one option in treating prostate cancer. The treatment in consultation with professionals will really be determined by the specific nature of the illness.

Submitted by Anonymous

Magna cum laude from Walnut U.

by Drake Gifford



Doctors tend to make quite a fuss about the number of years they spent studying for their degrees. I am living proof this is not always necessary.

I obtained post-graduate degrees in urology, radiation oncology, and plumbing, all within four months. It wasn't easy, and I had to make some sacrifices, but the cause was a good one.

Me.

From the outset, I determined I was the best cause I knew. I'd been advised to take control of my treatment, that I was the one who'd know what I could put up with. Everyone was so enthusiastic about it, I began to wonder if I should do the surgery, too.

To that end (no pun intended), I took charge. Ottawa PC survivors from the local support group gave me the names of books and resources to digest. I visited the Ottawa Regional Cancer Centre's library and left laden with material and a dictionary to trace the Latin and Greek derivations of medical terms.

The word prostate, for instance, comes from the Latin word prostata, which means "tiny icky round thing with lots of wires coming out of it, in the front of the tummy." Those Latins sure knew how to peg something, didn't they?

The reading material was lacklustre. Even as non-fiction, it didn't boast the dramatic moments a good war account might produce. I enjoyed the photos and diagrams though. They lent some credence to the subject and managed to infuse a bit of good ol' gore.

Without much of a science background, I found myself skimming chapters in search of personally relevant content. This turned out to be a frustrating exercise since I was quite new to the prostate cancer experience and couldn't distinguish a relevant chapter from an irrelevant one if my life depended on it. As it were.

The greatest revelations came when I surfed the internet till the wee morning hours. Over the course of my studies, I found web sites where I could actually watch abridged versions of prostate surgeries. Actually, I don't know exactly what they abridged since it seemed most everything was there except the part where they shave the groin area.

I'm not a squeamish guy so I found the videos fascinating. Doctors provided the play-by-play, although their commentary lacked a certain je ne sais quoi.

"Dr. Morton is now slicing into…er…dissecting the superior aspect of the urethra…wait a moment…he's taking a drink…yes, he's having his traditional milk shake while at the same time removing the patient's prostate. What a gift. Wait…this was supposed to be an appendectomy…Well, one thing for sure. This fellow will never get prostate cancer now, eh? Ha-ha."

In total, I viewed about a half dozen procedures, including the laparoscopic prostatectomy. This was impressive. Imagine a doctor in Cleveland removing the cancerous gland from a patient in Boston.

As much junk as there is on the internet, there's probably an equal amount of solid research, medical information and valued testimonials. The sum of these after months of reading had me seriously considering med school, with a specialization in big words.

I'd educated myself on the Gleason score, PSA doubling times, various therapies outside surgery, and the role of tomato juice. I now understood what my tumour probably looked like, where it was, and how it would get destroyed or removed.

I'd read about every pre and post-operative complication known to mankind. I could calculate the risks of all possible procedures to the third decimal point.

I was almost certain I didn't need to see another doctor because none could likely give me more info than I'd already read about, seen or heard from PC survivors.

My degree was over. I graduated, giving myself magna cum laude for the intense months of study.

It's about then that my education began.

Next month: *"Looking for Dr. Right."*

Drake Gifford is the pen name for Gary Drake, which is a pseudonym for someone else. All three are PC survivors.

Letter to Drake Gifford

Drake:

You have joined us guys who have had an encounter with the prostate.

Your article brought back memories of my experience. In June 2001, after a biopsy, my urologist advised that my prostate was cancerous. My PSA was 8.8, Gleason score 7. He suggested I could meet with an oncologist to discuss radiation or I could have surgery. As my wife and I left the Civic Hospital I thought it could be a month or so to see the oncologist, another month to see my urologist and, a few months after that, to begin treatment.

As we walked back to my car, I made the decision to have the little guy removed. I did not want foreign matter in my body. In mid-August, 10:00 a.m., I underwent the knife, one night in hospital and home at 6:00 p.m. the following day. I am quite active, so, in a day or so I began walking slowly and in a few weeks was back to normal.

In October 2001, after a few scans, my urologist advised that radiation was the next treatment as some cancer was outside the prostate. Many do not have this problem. In November, I began taking Zoladex, every three months. In February 2002, after a session on a simulator to set the radiation parameter, I underwent 33 treatments: one a day for seven weeks. It was a simple treatment, taking about 10 minutes on the Siemens Accelerator. As I lay on my back, the machine rotated around my body so the cancerous area would receive rays from different angles. My last Zoladex treatment was August 2004. My PSA has been zero for five years. As far as I am concerned, I am cured.

We can beat this disease. Go for it.

Patrick

P.S. *Running 10 km in 51 minutes is excellent. I know you are in good shape so in regard to parking, I suggest you park one block north of Fisher Avenue near Carling (3 hour limit), 10 minutes from the Civic; at the General, you can park within 15 minutes of the site.*

NEWS BITS

A petition was presented to the Ontario Legislature in mid-November by John O'Toole, MPP for Durham from constituents in his riding. The petition describes the double standard that makes men pay for this screening test while women have all routing cancer screening covered by OHIP. "Therefore, declared the petitioners, "we, the undersigned, urge the "McGuinty government" to review its policy on funding PSA testing for men with a view to including this as a service wholly covered by OHIP."

A new website offering current reliable information on prostate conditions and treatment options has been announced: the Johns Hopkins Health Alerts website. It can be found at **http://www.johnshopkinshealthalerts.com/alerts_index/prostate_disorders/25-1.html**. You can sign up to receive a regular newsletter of useful information. Of interest to newly-diagnosed men will be "What to Expect from a Prostate Biopsy"

The Wall Street Journal, in early November, picked up a Johns Hopkins study that screening younger men, i.e. beginning at age 40, can help doctors better interpret screening scores as men age, resulting, they say, in fewer unnecessary procedures. The new study shows that what really matters is the rate at which PSA scores change over time. Trouble is, most men start getting PSA tests at 50, and there's no historical PSA information to help doctors decide if a test score is worrisome or just normal for that particular man.

Earlier this fall, a Canadian-developed urine-based genetic test for prostate cancer was picked up by an American laboratory for offer to its patients. The test, titled uPM3(™), originates with DiagnoCure Inc. of Quebec, which holds worldwide patent rights for the diagnostic and therapeutic application of the PCA3 gene. This is a specific gene that is profusely expressed in the prostate cancer tissue. You can learn more at: **www.diagnocure.com** or **www.bostwicklaboratories.com**

The Ottawa Regional Cancer Foundation Telethon is scheduled for Sunday January 14 aired on the A-Channel, Cable 6 in Ottawa.

UPCOMING MEETINGS

The **December meeting** – as well as featuring General Paul Manson on fighting the war against prostate cancer – will also be a more social affair with special treats. As usual, the doors will be open at 6:00 p.m. to welcome the newly-diagnosed and to allow regular members to enjoy coffee, tea or juice while exchanging information and experiences with each other. The meeting will get underway at 7:00 p.m.

At **January's meeting**, we will award the Dried Prostate to an individual or an institution that has made a significant contribution to the fight against prostate cancer. This award, annually presented by the Association, has previously been awarded to: 2005: Garry Janz, Founder and Co-Chair, Motorcycle Ride for Dad; 2004: Max Keeping, Vice President News, CTV-Ottawa; 2003: Ninon Bourque Patient Resource Centre of The Ottawa Hospital Regional Cancer Centre; 2002: Dr. Chris Morash, Urologist, The Ottawa Hospital; 2001: CS CO-OP; 2000: The Ottawa Citizen; 1999: Sharon Holzman and Kathryn Leroux (Hospitality Management Services); 1998: MDS Nordion; 1997: Elizabeth Wiebe, Astra Zeneca; 1996: Margaret Lehre, ORCC Education; 1995: Nancy Smith, R.N., Founding Contributor; 1994: Diane Duthie, CBC, Founding Contributor; 1993: Dr. John Collins, Urologist and Inspirational Founder of the Association and the Dried Prostate Award.

Plan to attend both these special nights and bring your spouse, a family member or a friend.

Surgeon says breast cancer fight is way ahead.

By John Miner London Free Press, Nov. 9, 2006

Research into prostate cancer, a disease that strikes one out of six men in Ontario, needs to catch up with breast cancer, a London surgeon said yesterday.

Stephen Pautler said the detailed studies that have been done to find the best treatments for breast cancer haven't been done for prostate cancer.

"We are well behind where the breast cancer movement has been, both medically and in fundraising," said Pautler, who spoke at a breakfast sponsored by the Prostate Cancer Research Foundation of Canada and St. Joseph's Health Care Foundation.

For every dollar raised in Canada for prostate cancer research, $10 is raised for breast cancer, he said.

That's despite the fact there is a higher rate of prostate cancer than breast cancer. Current estimates are that about one in eight women will develop breast cancer.

The lack of studies means doctors don't know for certain if minimally invasive robotic surgery to remove the prostate is better than traditional surgery, Pautler said.

Until October, London was the only centre in Canada to use robotic techniques in prostate cancer surgery.

"A lot of people don't realize it, but we are really on the cutting edge here," he said.

Without the use of a robot, minimally invasive prostate cancer surgery is very difficult and many surgeons don't have all the skills required, he said.

"We are working very deep in the male pelvis against the pelvic floor and accuracy is something that is really critical," said Pautler.

Once the cancerous prostate is removed, the surgeon has to rebuild the urinary system, reconnecting the bladder to the urethra.

"That is the tough part of the surgery. The great risk is incontinence and erectile dysfunction," he said.

But while using the robot makes the surgery easier and reduces blood loss and pain, Pautler said he can't say for sure the final outcome is better. "The long-term studies haven't been done. We don't know that," he said.

PCAO THANKS ASTRA ZENECA FOR ITS GENEROUS SUPPORT OF THE WALNUT