



Prostate Cancer
Canada Network

Durham Region

Durham

Region

Examiner

MESSAGE FROM THE CHAIR

In March, Dr. Mathur, a local urologist, pictured right alongside Meeting Facilitator Barry Bahm, came to our Support Group meeting and spoke candidly about his role as a urologist and surgeon. He has been very generous by coming to speak to our group a number of times over the years. We are happy to congratulate Dr. Mathur on recently performing his 1,000th radical prostatectomy. We are very fortunate to have such experience right here in Durham Region. Not to mention, Dr. Mathur is a really nice guy too!

Jacqueline Cahill, Executive Director of The Canadian Continence Foundation spoke about some of the issues concerning urinary incontinence at our meeting in April. Many prostate cancer patients suffer this as a side effect from treatment. She was able to provide a few tips about managing this condition and provided some sources for more information. Having some issues with leaking may cause embarrassment and thus alter your lifestyle. It may be a difficult subject to talk about even to your doctor.

Don't forget that at PCCN – Durham Region we know someone who has had the same experience or we've gone through it ourselves. Call if you want to be connected to someone to talk to.

At the May support group meeting, three guys spoke about their prostate cancer journey. Barry told us that 3 years post-surgery, his PSA is going up and he is considering further treatment. John participated in a trial using focal laser ablation as his treatment and has since had a radical prostatectomy. *See HENNING Page 4*



Important Notice

**There will be no support group meetings in July and August.
The new season kicks off on Wednesday, September 4th.**

ONE MAN'S JOURNEY BY PETER PENAK

Before Advanced Prostate Cancer: After my physical exam in 2002 (which included a PSA test) I felt happy to know that I was healthy and I would enjoy my upcoming retirement. Since I no longer worked in the city of Toronto I began looking for a physician closer to home (my General Practitioner was located in Toronto and was planning to move to the west end).

I found it very difficult to find a physician that I liked and would take me on. I depended on the emergency clinics in Oshawa. There were a few times when I felt dizzy and at times not well, but the doctors in the clinic did not find anything wrong and suggested I see my GP.

Finally I gave up my search for a new doctor and got a physical in February of 2005. My PSA test was very high and the doctor suggested I see a specialist. He did tell me not to worry and it may just be a simple anomaly.

My Thoughts: *I was frustrated by my inability to find a physician close to home. I was concerned that something could be happening and the few incidents that made me feel out of sorts should have been looked at closer. After my exam in 2005, I took his advice and did not worry too much while I waited for the referral to a specialist.*

Diagnosis of Advanced Prostate Cancer: When I finally came to see my Urologist some time in March, he seemed very impressed with my PSA score. He pointed out that it was 8 times the normal level.

He sent me for a CT scan and biopsy and in our next meeting confirmed to me that I had cancer showing in the prostate and in lymph nodes near by. I asked if that meant it had metastasized. He confirmed that it had spread and was advanced. He recommended injections every three months of an anti-androgen drug (lupon depot) and prescribed Casodex to be taken orally.

Of course I was not happy to get this news and thought it might be a good idea to get a second opinion. I saw a specialist in Toronto and he told me that he had spoken with one of the top doctors in the field and they both agreed that I was getting the right advice from my urologist. He further confirmed that my specialist was well regarded in this area.

My Thoughts: *I had asked my urologist how long I had to live and he was reluctant to give me any estimate. I went away feeling that this could be my last summer. I went to Hearth Place to get support and joined the Metastatic Support Group. I found it very helpful to join in group discussions with the other participants, but as time went on individual members died off and I was attending more funerals than I had ever done. These events were very upsetting and I needed a positive outlook to deal with this cancer. I joined another group at Hearth Place called the Healing Journey. It is a program that was designed by Alistair Cunningham of the Princess Margaret Hospital in Toronto. The aim of this group was to look at the spiritual side of life and develop a more positive way of dealing with the cancer journey.*

In addition I joined a separate prostate support group called US TOO. This group meets once a month and includes all people who have had prostate cancer. There were only a few members that have the advanced version. Most members had the operation and were 'cured' so I felt quite envious. If I had regular annual checkups in the previous three years I might easily have been one of these people.

I very much wanted to be around to see my grandson grow up.

See ADVANCED PROSTATE CANCER Page 3

Advanced Prostate Cancer

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Learning About Advanced Prostate Cancer:

I learned a lot about progress and new practices through my monthly meeting at US TOO, and from the participants of the Metastatic Support Group at Hearth Place. The support group has had a number of well-informed participants. Currently there just happens to be two nurses who have advanced cancer who were oncology nurses who were working with cancer patients.

The US TOO group has changed to PCCN. In the years I have been there on the executive committee, I have attended two annual conferences and many other seminars where the latest research has been discussed and reviewed.

My Thoughts: *I have read and heard about many discoveries and research which have had great success and treating prostate cancer and many treatments that have increased the life span of T4 patients. I have yet to hear of a 'cure' for T4 patients. I continue to look for something that will give me more years on this planet but at times I feel very discouraged.*

Learning About my current treatment: I have changed treatment many times in my journey. Each time I have a discussion with my oncologist. These discussions seem all too brief and I resort to looking up the latest literature. Last August I was introduced to a new 'miracle' drug that treated the bone as well as the cancer. I was to get monthly injections in addition to the Zytiga I was taking orally. I had heard about this new drug called Denosumab (it has a different name in the US). I looked it up in a book on advanced cancer and saw it mentioned there. Unfortunately I had not paid enough attention to the para-

graph on its side effects. Apparently these class of drugs sometimes cause blockages to occur in the blood system. In September just after my second injection I had a heart attack. I had to be resuscitated, twice. I was fortunate to be in the emergency room of the Bowmanville Hospital when this happened.

The other drug Zytiga I have been taking for the past year funded by the drug company as I understand it is very expensive. My PSA has risen gradually over the past year. I had blood tests every month. The test this month reached 31.9 which is higher than the test I did at the beginning of my journey. My CT and bone scans show significant increases in the spread of cancer throughout my body. My oncologist and I have decided to try something else. He has suggested Docetaxel which I had taken in 2008/2009 winter.

My Thoughts: *I feel I should take greater care in starting any of these new 'wonder drugs'. I nearly lost my life in September. I don't feel too strong about going back to a chemotherapy that I had already taken. I have heard about injections of casodex that show some promise and I feel I should look into that.*

Life Today with Advanced Prostate Cancer: I am much older and wiser on the subject of cancer. I am also much weaker and have to depend on others to do most things like shovelling the snow and handiwork around the house.

My Thoughts: *I feel very fortunate to still be here. There have been many considerate and talented people in the medical profession that kept me going. I often miss the many people who have died from cancer since my journey began. Some were very good friends to know.*

Editor's Note.

The above article is based on notes that Peter Penak prepared for a prostate cancer focus group meeting that he participated in earlier this year. It is a very compelling story of one man's fight with this dreaded disease.

Peter's philosophy is to try to lead as normal a life as he can despite the horrendous challenges he has faced in his battle with advanced prostate cancer. For the past 6 plus years Peter has served on our Executive Committee performing the duties of Treasurer for the group. We very much appreciate Peter's efforts under very difficult circumstances.

Henning

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Henning has just completed his treatment of external beam radiation. Thank you to each of the fellows for being so forthcoming with your stories. It's when we hear others speak about their triumphs, let-downs and concerns that we know that we are not alone.

Bill Holtby from Durham Ride For Dad gave us an update on how the monies raised have been spent on GTA research projects at the Durham Region Cancer Centre and in various Toronto hospitals. This year's event is on Saturday, June 8th.

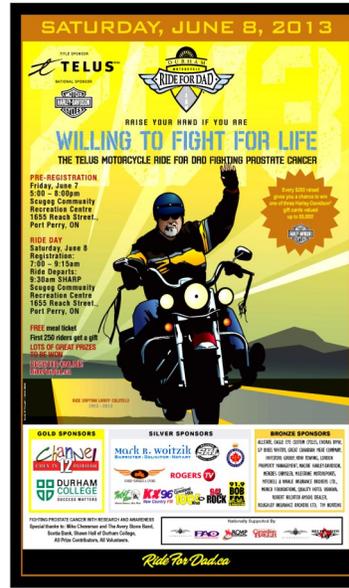
Our upcoming meeting in June will feature an overview of programs and information provided by Prostate Cancer Canada presented by Maureen Rowlands.

Looking further ahead.... We've been busy planning for the upcoming 2013/2014 season. After taking a break for July and August, our next meeting on September 4th will feature Lisa O'Leary. If you could take a pill that reduced pain, increased oxygen, boosted your immune system, helped to increase your physical activity and eliminated negative emotions, would you want to take it? Find out why and how laughter and breathing do exactly that.

The week commencing September 16th has been declared Prostate Cancer Awareness week by the City of Oshawa. There will be a flag raising ceremony on Monday, September 16th at 10:00 AM at City Hall. You're invited to come out and show your support. Be sure to check our web-site for more information as we get closer to the event.

I hope everyone enjoys the summer and we look forward to seeing you again in September.

Cindy Hammett, Chairperson



All you bikers out there join the Durham Ride For Dad on Saturday, June 8th.

It's part of a cross Canada event that each year raises a lot of money for prostate cancer. For more information visit motorcycleridefordad.org

Instead of the John I call my bathroom the Jim!
That way it sounds better when I say I go to the Jim first thing every morning!!!

COCKROACH ANALOGY

Prostate cancer is similar to finding a cockroach in the middle of your kitchen table. You panic, knowing that where there is one there are probably more and they do multiply. You call several exterminators.

The surgeon recommends removal. He'll use a chain saw and remove the kitchen from the rest of the house and repair the plumbing as best he can with what remains.

The external beam radiation exterminator wants to stand outside the kitchen and blast away with a twelve gauge shot gun hoping he will miss the plumbing.

The seed implant exterminator is really slick. He just wants to drill holes in the wall and toss in grenades.

The cryosurgery exterminator wants to drill holes in the walls and pump in liquid nitrogen, hoping he doesn't freeze the plumbing.

The hormone guys.. well they just want to pump in sleeping gas. Knowing all too well that in a couple of years the cockroaches will wake up pissed off and hungry.

Chemotherapy boys will offer to poison everything in the kitchen and will promise you that if you eat the poison they will give you an antidote which may or may not work.

The alternative medicine people will give you a bit of eye of newt and toe of frog plus a couple of other exotic ingredients and hope to hell that chases the cockroaches away.

And then there are the watchful waiting folks, some of whom are not real sure that there was a cockroach and some of whom think it may have been just an old bachelor 'roach with no kids that they saw.

The active surveillance men are a little different - they set up their equipment color dopplers, infra-red cameras - ready to pounce on those pesky cockroaches if they ever show themselves again.



Now if there is only the one cockroach the odds are good - you can get rid of the infestation. However if the little buggers laid eggs elsewhere or more of his buddies are lurking about in other places... well you get the picture. In any case, life in the kitchen will never be the same. One of these days an exterminator will come along who just swats the cockroach and puts out poison bait for the others!! You'll never know he was there. Until then good luck on your choice of exterminators, and low or non-existent PSA's to you all.

And remember - Don't take life too seriously. You won't get out of it alive anyway!



There seems to be general agreement that laughter, like exercise, is good for us. Both release endorphins, the body's natural feel-good chemicals. These help to fight depression and, it seems, can help the immune system in its work. It was with this in mind that we decided to include a humorous page on the You Are Not Alone (YANA) website. It was named by Mac, a Vietnam Marine vet who said we were all members of The Royal Order of Prostate Cancer (Troop-C). He wrote what is still one of my favourites – the [Cockroach Analogy](#).

For an enlightened view on prostate cancer visit the YANA website at www.yananow.org.

Support Group Meetings

The meetings are held on the first Wednesday of the month at L'Amicale, which is located at 707 Simcoe St. South in Oshawa.

Parking is at the rear of the building.
The meetings run from 7 pm till 9 pm.

Next Meeting - Wednesday, June 5th

**Guest Speaker: Maureen Rowlands, Director,
Prostate Cancer Canada**
Topic: Overview of programs & support services.

Upcoming Meetings

**Please note there are no meetings scheduled
for July and August.**

Sept 4th: Laughter Yoga with Lisa O'Leary

**Prostate Cancer Canada Network - Durham Region
Executive Committee**

- Cindy Hammett, Chair
- Don Hunter, Meeting Room Manager
- Peter Penak, Treasurer
- John Logue
- Frank Dimalta, Hospital Visits
- Barry Bahm, Facilitator
- Graham Lockey, Peer Support & Newsletter
- Clark Weddell, Facilitator
- Georges Corbeil
- Ken Rudolfo, Hospital Visits

Our Patrons

MSB Industries Inc., Pickering

**PCCN - DURHAM
Prostate Cancer
Support Group**

We are a volunteer organization providing prostate cancer information and support to men and their families in the Durham Region in Ontario.

We appreciate any donation to help defray our operating cost. We are, however, unable to provide a charitable tax receipt for donations.

Visit our website at:
www.pccndurham.ca

Or contact us by phone at:
905 571 0055
or by email:
info@pccndurham.ca

**Prostate Cancer
Canada Network**

Our group is affiliated with and receives significant support from Prostate Cancer Canada through the Prostate Cancer Canada Network. For more information visit:

www.prostatecancer.ca