

Awareness

The "PCCN-Toronto" and "Side by Side" Prostate Cancer Walk/Run

**"WALK FOR SOL"
PLEASE SEE PAGE 6**

PCCN-Toronto Participating in Prostate Cancer Canada's Father's Day Walk/Run

Father's Day 2011 takes place on Sunday June 19th. Join us at **Ashbridges Bay Park** at 9:00 a.m. that morning to walk with our PCCN-Toronto support group, as we celebrate Prostate Cancer Canada's (PCC) Father's Day Walk/Run for prostate cancer.

their families with information about this disease.

Some of the best people to raise this awareness and/or provide this information to newly-diagnosed men are the volunteers/survivors in support groups such as ours. For this reason, PCC donates 50% of the funds that we raise back to us so that we can



MAY 2011

PCCN-TORONTO

Prostate Cancer Support Group

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We have two "teams" registered: PCCN-Toronto 1 (captain Aaron Bacher) and PCCN-Toronto 2 (captain Stan Mednick), whose members



have been asking their friends, family members and peers to sponsor them by making a donation on their personal pages. To join either of these teams and start raising funds on behalf of our group, please click on:

It is therefore crucial that we raise as much money as we can for this year's Walk/Run! **Please help us do just that.**

Remember, each year it becomes more challenging for us to sustain ourselves, so receiving this money from PCC allows us to "control our own destiny" financially.

Let's all meet and walk together on Sunday morning June 19th. If you have any questions please call Aaron Bacher at 416-414-4961.

Tentative schedule:

- 8:00 - 9:30am - Registration
- 9:30 - 9:45am - Opening Ceremonies
- 9:45 - 9:50am - Warm-up
- 9:50 - 10:00am - All to Start/Finish line
- 10:00 - 11:00am - Walk/Run
- 11:00 - 12:30pm - Lunch & Closing Ceremonies

**Bring your children and grandchildren!
Just let us know who is coming with you.**

*This year will feature: a **BBQ** hosted by South Street Burger and Iced Tea's from Miller and Bean; a **Kid's Zone**, with carnival games, a bouncy obstacle course, clowns, and face painting; artists will be available to customize t-shirts. We will also have a live DJ and an acrobatic/break dance show.*

to join Aaron's team, or

<http://tinyurl.com/3om7rs7>

<http://tinyurl.com/4vhtspe>

to join Stan's team.

Once there: from our Team Page, click on the "Join My Team" button to register, click on "Toronto", accept the waiver, click on "adult" and then on "I will fund-raise \$150 or more", set up your own personal page, invite your family and friends to sponsor you and begin fundraising. It's as simple as that!

Then you'll be all set to get sponsors to help you raise these much-needed dollars.

It is very important to remember that funds raised by PCC are not only directed toward research; they are also used for raising awareness and providing men and

"Raising prostate cancer awareness" - <http://pccntoronto.ca>

Dr. Roger Buckley March Awareness Night

At our March Scotiabank Awareness Night meeting, we featured three specialists from North York General Hospital (NYGH), who came to talk about: "The Prostate Journey: to the biopsy and beyond".



The three North York General Hospital specialists: Dr. Denis MacDonald (Chief Pathologist), Director: Department of Laboratory Medicine; Dr. Roger Buckley, Chief of Urology; and Dr. Irving Jacobs, Radiologist.

Dr. Roger Buckley, Chief of Urology at NYGH, brought with him a pathologist and a radiologist. Each doctor spoke in detail about the important role that they play with each prostate biopsy that is done at their hospital.

It involves first determining if there is a need for the biopsy, taking the actual samples (cores) and reading those samples, and following up with the patient, depending on what is found.

This was an insightful discussion on the definitive test that determines whether or not prostate cancer is present, and also whether it has started to spread (metastasize).

These very interesting presentations can be seen in their entirety on our website - <http://pccntoronto.ca> - under **RECENT POSTS** on our home page.

We sincerely thank these three specialists for coming to speak to us about this very important topic.

Dr. Rob Bristow January Awareness Night

Our guest speaker at January's Awareness Night meeting was Dr. Rob Bristow, a radiation oncologist from Princess Margaret Hospital.



Dr. Rob Bristow

His topic that night was "Prostate Cancer Genes and Personalized Medicine", a highly technical topic indeed. But Dr. Bristow is one of the most respected scientists in Canada and very involved in this research.

His talk was extremely interesting and he answered many questions from the sizable audience that night. To see and hear his entire presentation, please go to our website - <http://pccntoronto.ca> - under **RECENT POSTS** on our home page.

Thank you very much Dr. Bristow for your time and expertise.

May Awareness Night to feature Survivor Forum IV

Come hear how other men faced their diagnosis of prostate cancer, and what made them decide on their choice of treatment.

On Wednesday May 25th survivors from PCCN-Toronto will talk about the following topics: robotic-assisted laparoscopic surgery, advanced prostate cancer, recurrence of the disease, Brachytherapy, and heat therapy followed by hormone therapy.

If you have recently been diagnosed with this disease, come learn from other men how they arrived at their informed decisions. See further details on page 3 (opposite page).

If you would rather receive this newsletter electronically, please email info@pccntoronto.ca and we'll remove you from our regular mailing list and add your name to our email list. Thank you.

PCCN-Toronto & Side by Side
(Prostate Cancer Support Groups)

invite you to attend a
Scotiabank Awareness Night
at the
Toronto Botanical Garden
in the Floral Hall
777 Lawrence Ave. East at Leslie Street

on
Wednesday
May 25, 2011

at 7:30 p.m.

guest speakers

PCCN-Toronto
Survivors

topic

"SURVIVOR FORUM IV"

A Question Period will follow

*All family members, partners & friends
are most welcome!*

FREE parking!

If you have any questions, please call us at
416-932-8820

Doors open at 7 p.m.

**2011 Meetings to Benefit
North York Harvest Food Bank**

When you attend one of our Scotiabank Awareness Night Meetings at The Toronto Botanical Garden, please bring some non-perishable food with you, which PCCN-Toronto will donate to the *North York Harvest Food Bank*.

Below you will find a list of their much-needed items. Please note that all expiration dates must be valid and canned goods cannot be damaged (dented).

- √ **Canned fish & meat**
- √ **Canned vegetables**
- √ **Canned fruit**
- √ **Cooking oil**
- √ **Sugar substitute (Equal)**
- √ **Flour**
- √ **Brown pasta**
- √ **Powdered milk**
- √ **Dried beans**
- √ **Brown rice**



www.northyorkharvestfoodbank.com

We thank you for your continued support.



We are very happy to announce that all of our 2011 Awareness Night meetings at the Toronto Botanical Garden and our Man to Man peer support meetings at Valleyview Residence are being sponsored by Scotiabank.

Therefore, this year we are calling our meetings at the Garden the Scotiabank Awareness Night meetings.

We sincerely thank them for their very generous financial support.

8th Annual Prostate Cancer Canada Leaders Conference at the Halifax Marriott Harbourfront Hotel - Oct. 12-15, 2011

Prostate Cancer Canada (PCC) is dedicated to the elimination of prostate cancer through research, education, support services, advocacy and awareness. Through its network of support groups across Canada, the organization helps men with prostate cancer and their families improve their understanding of the disease by providing up-to-date information in order to assist them in making informed decisions, and provide peer to peer support. PCC promotes the importance of early detection through public education, awareness and special event campaigns.



Peggy's Cove, Nova Scotia

The 2011 conference will offer more than three days of inspiration, information sharing, awareness building, education and mutual support, as conference delegates will discuss everything from survivor-group leadership and capacity building to the latest medical advances in the fight against prostate cancer.

With an expected 130 delegates and spouses from support groups across Canada, this conference is central to building a sense of community and mobilization around critical issues affecting prostate cancer survivors and their families. The conference is also an opportunity to display the unity of purpose necessary to raise public awareness.

Sessions/Workshop and discussion topics will include:

Advocacy 101 / Building capacity and sustainability / Express feelings through Art / Health and Nutrition / Humour – Best Medicine / Medical Updates / Team Building / Train the Trainer – Program Launch and Training / Volunteer Development / Women and Prostate Cancer and much more!

This year's conference is directed towards PCCN affiliated support group leaders, their spouses, PCC board members, PCC staff and volunteers.

1. Two Support Group **survivor delegates** - designated by each **affiliated support group** executive/board will receive free of charge: registration (all meals) / three nights hotel accommodation / two economy airfares (or mileage)

*We ask that support groups nominate their **two survivor delegates**, and provide PCC with their names by contacting: Ada Jeffrey - ada.jeffrey@prostatecancer.ca*

2. All non-designated representatives from **affiliated support groups**, are required to pay a registration fee of \$100 which will cover three meals a day for the duration of the conference, as well as make their own travel and hotel accommodation arrangements.

3. All spouses are expected to pay a registration fee of \$100 which will cover three meals a day for the duration of the conference, as well as make their own travel arrangements.

The conference will officially begin on October 12th, and will be kicked off with a gala dinner.

PCC has made a commitment to establishing regional organizational presence in the country. Two months ago, PCC launched it's Atlantic Region office in Halifax and the office is now in full operation. It is PCC's hope that a tour of the facility will be scheduled for all conference delegates. The facility houses the regional office staff as well as a Survivors Resource Centre for men and their families seeking information about prostate cancer. The conference will come to an official close on Saturday October 15th, following PCC's Stick it to Prostate Cancer Road Hockey tournament - to which all delegates are invited to attend.

For further information phone Ada Jeffrey at 416-441-2131.

*written by Helene Vassos,
Executive Vice-President, Prostate Cancer Canada*



PCCN-Toronto is supported by:

**AstraZeneca / Harmony Printing / Macgregors Meat & Seafood Ltd.
Prostate Cancer Canada / Scotiabank**

Our Affiliation with Prostate Cancer Canada: One Year Later

an update by Aaron Bacher

As we look back on our first year of being affiliated with Prostate Cancer Canada (PCC), it surely has been just like any other new relationship: a kind of "feeling-out" process, just trying to get comfortable with one another.

Friday April 1, 2011 marked the end of that first year, and it has been a highly successful beginning to what we all hope will be a long and productive association.

PCC promised us opportunities to meet men (and their families) where we previously hadn't had access, so that we could increase their awareness about prostate cancer and provide information to them about this disease.

They met that obligation by inviting us to participate at four major events in the Greater Toronto Area (GTA) in 2010: Tennis Canada's Rogers Cup, the Sportsmen's Show, the International Boat Show, and the Golf and Travel Show. This allowed us to fulfill our promise to them as well, by providing volunteers/survivors to man their booths at these shows. We went even further by involving several other prostate cancer support groups from around the GTA, whose volunteers joined us at these events.

Therefore we were able to tell even more men about the need to have a PSA blood test and a digital rectal examination (DRE), and also talk to them about the importance of an early diagnosis.

Raising awareness and providing information to more men about prostate cancer is, to a great degree, what our affiliation with PCC is all about.

We have also benefited financially from this new relationship. Because our group raised money for PCC's 2010 Father's Day Walk/Run, they returned to us \$7000 to help us continue all of our important programs. We are currently raising funds again for this year's Walk/Run, which takes place on Father's Day. (*Please see page 1*) We hope that more of our survivors/volunteers will join our efforts to raise money, not only for PCC, but to help us sustain our own support group.

As of this week, 60 prostate cancer support groups, representing every province in Canada, have affiliated with PCC, and each one of them is working hard to further develop their relationship.

Prostate Cancer Canada Network - Toronto's first year of affiliation with PCC has proven to be everything that we had hoped for, and more. Both sides have followed through on promises that were made; many more men and their families are now not only aware of our support group, but they have also heard our messages of hope; and we are all looking forward to a long and successful relationship with other PCCN-affiliated support groups across Canada and Prostate Cancer Canada.

Please visit: <http://prostatecancer.ca>



COME "WALK FOR SOL"

Sol Dennis joined our support group just after it was founded in 1994. He served as Vice-Chair on our Board of Directors and volunteered for our group at Princess Margaret Hospital for many, many years.

Unfortunately we all lost Sol quite suddenly when he passed away on December 2, 2010.

We decided to dedicate this year's Father's Day Walk/Run to Sol's memory.

When this idea was proposed to Sol's wife Rita, she said that "Sol would be honoured" knowing that this was being done for him and she was very happy to hear about our plan. She said that she hopes to join us for the walk along with other members of her family.

So, why don't you join us too, and we'll all wear our special "WALK FOR SOL" ribbons as well as our PCCN-Toronto ribbons on Father's Day June 19th?

See page 1 for the full story on this year's Walk/Run and how you can click on one of the links to either *join* our team or *sponsor* our team.

You can also donate to our cause by mailing a cheque, payable to PROSTATE CANCER CANADA, to 27 Lynch Road, North York Ontario M2J 2V6.

Official tax receipts will be issued by PCC.

W
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*We'll see you all on
FATHER'S DAY!*



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First Advanced Prostate Cancer Meeting by Winston Klass

Just over a year ago six members of the Newmarket, Brampton, and Toronto support groups met to discuss the feasibility of a special support group for advanced prostate cancer survivors. Feedback from advanced as well as regular prostate cancer survivors had indicated that regular support meetings may not be fully catering to emotional and other needs of advanced prostate cancer survivors. At the end of this meeting the decision was made to launch a joint experimental online support group, with the understanding that at some point this group may progress to a full-fledged support group tailored to advanced prostate cancer survivors. The definition of an advanced prostate cancer survivor was left open, with the decision to join our group left to individual assessments of relevance.

At this early stage our group activities follow relatively simple routines. Any newcomer circulates a profile of his prostate cancer journey (decision points, treatments, drugs, etc.) and members are invited to respond with advice by email or telephone under the guidance of a moderator. The moderator also circulates relevant information periodically from research papers and other sources.

The Calgary Warriors, a pioneer support group for advanced prostate cancer survivors, has provided strong leadership and encouragement...access to their regular newsletters and Ken Dreger (a leader of this group) monitors our email traffic and helps us to refine group procedures. Our support group has grown to approximately 20 members and, with the Calgary Warriors size of 50 approximately, there is potential for significant growth of our membership.

Our first face to face meeting on Wednesday March 15th provided the opportunity for direct sharing of information and comparison of journeys. This went over very well and it was decided that the group will meet quarterly. Our next meeting is at 6:30 p.m. on Tuesday June 21st at Valleyview Residence, 541 Finch Avenue West. In time, our support group will likely become the local chapter of a national online support network, thereby benefitting from advice and support from survivors all across Canada.

Anyone who would like to benefit from the type of support that we provide may contact us at PCCN-Toronto, via email info@pccntoronto.ca or by calling our hotline number - 416-932-8820.

A Heart-warming Story

by Bill Lifchus

Bill Lifchus is my name: I am a pharmacist, a prostate cancer survivor, and a board member of PCCN-Toronto.

In the summer of 2010 I needed a favour from a Canadian pharmaceutical company about a prostate related drug. The first question they asked me was "who are you with?" I answered, "Toronto Man-to-Man", to which they replied, "Oh, a local group. We will call you back." That call was never returned.

In late January 2011, I received two urgent calls from urologists at the Ottawa Civic Hospital and the Hamilton Health Science Center, saying that they were short of a drug which was urgently required for men who were suffering from Peyronie's disease.

This is a progressive disease where plaque forms under the skin of the penis, causing a curvature of the penis. If unchecked, delicate surgery is required. The company which manufactured this drug had decided to discontinue making it, leaving these men in a very precarious situation. That is when I got the call asking, "Can you please help us?"

I then called the largest Canadian drug company, spoke to a top executive and relayed the story, saying that the drug was urgently needed. The first questions asked were, "Who are you?" and "Who are you with?"

I told them, "we're part of the Prostate Cancer Canada Network." "Oh, you are a **NATIONAL ORGANIZATION!**" was their reply. "I saw your group when you had a booth at the tennis championship at York University, where I had my PSA levels done. How can we help you?" asked the executive. I told him about the urgency of the situation.

The drug was being manufactured, the executive explained, but would not be ready for at least 4 months, as all drugs have to be tested and approved before they are released to the public. However, since this was a serious situation, the executive transferred me immediately to their *international* vice-president. The V.P. again asked me which organization I was representing, and I reiterated that

I was part of the *Prostate Cancer Canada Network - a national organization*. The response was overwhelming!

He told me that they had a supply of the medication in a warehouse in Amsterdam and a *courier would ship it immediately!* I was overjoyed! The boxes of pentoxyphylline 400mg arrived at my pharmacy the very next day! The top box said, "Invoice enclosed". I quickly opened the invoice, expecting a bill in the thousands of dollars. To my amazement, it read "**NO CHARGE WITH OUR COMPLIMENTS**".

Patients were contacted immediately, and their medications were sent out to them by courier - all **FREE!** When these patients received their drugs, they were astonished! They had previously paid \$200.00 for their prescriptions - the normal fee at the pharmacy.

These men had their lives vastly improved because of the generosity and good will of a Canadian Pharmaceutical company named Apotex. Also, because of the foresight and work of Bob Shiell (Calgary) and the executives at Prostate Cancer Canada in creating and organizing the national Prostate Cancer Canada Network, this situation turned into a positive event for the patients.

To Aaron Bacher, Ron Benson and the men of PCCN-Toronto, thank you for understanding and believing in the benefits of belonging to a national organization. Without the dedication and devotion of these individuals, 60 men would have needed to be hospitalized.

I would also like to thank Apotex Inc. for their generosity. It is heartwarming to know that there are people out there who care, and who made an extreme effort to help.

*Are you interested in becoming
a PCCN-Toronto Volunteer?*

*Please call our hotline - 416-932-8820
or email us at info@pccntoronto.ca*

OUR ON-GOING PROJECTS FOR 2011



These meetings are held at the **Toronto Botanical Garden (Floral Hall)**, at the corner of Lawrence Avenue East and Leslie Street, from 7:30 p.m. to 9:30 p.m. Here, leading medical professionals speak on a range of topics related to prostate cancer and then, following a refreshment break, answer your questions. Family members and friends are welcome to attend. If you are on our mailing list, a notice of each event will be sent to you.

Please bring some non-perishable food with you for the North York Harvest Food Bank. See page 3.

<u>DATE</u>	<u>SPEAKER</u>	<u>TOPIC</u>
May 25	PCCN-Toronto Survivors	SURVIVOR FORUM IV
Jul 27	Dr. Alexandre Zlotta <i>Mount Sinai Hospital</i>	Diet and Nutrition
Sep 21	Dr. Timothy Owen Davies <i>Henderson Hospital - Hamilton Ontario</i>	Incontinence and Erectile Dysfunction
Nov 30	Dr. Andrew Matthew <i>Princess Margaret Hospital</i>	Psychological factors associated with treatment decision-making and prostate cancer treatment (radiation, surgery and active surveillance)

Man to Man Peer Support Meetings - 7 p.m. to 9 p.m.

These meetings take place on the **first** and **third** Tuesday evenings of each month at **Valleyview Residence**, 541 Finch Avenue West (just west of Bathurst Street on the Branson Hospital site) in the All-Purpose Room. They provide an opportunity for men to talk in a safe and comfortable setting about dealing with their diagnosis of prostate cancer.

Side by Side Peer Support Meetings - 7 p.m. to 9 p.m.

The ladies' support group also meets at Valleyview Residence (see above) in The Board Room, but only on the **first** Tuesday of each month. These meetings allow for personal discussion from a female perspective.

Visitation

Trained volunteers, all prostate cancer survivors, will talk to you/your family in your home, by telephone or in the hospital. Each week, our volunteers visit surgical patients at **Toronto General Hospital** (Thu. & Sat.) and **Sunnybrook Hospital** (Thu.), bringing them messages of hope and support.

Counseling

Our volunteers counsel men in prostate cancer clinics at **Princess Margaret Hospital** on Monday, Tuesday, Thursday and Friday, at the **Odette Cancer Centre** on Thursday, and at **The Prostate Centre** at North York General's Branson Site on Tuesday afternoon.

PCCN - Toronto Board of Directors

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Our 2011 "Awareness" Newsletters are being sponsored by an unconditional grant from AstraZeneca.

