

Prostatitis

The "Man to Man" and "Side by Side" Prostrate Cancer Support Groups

DO IT FOR MOMS WALK/RUN MOTHER'S DAY - SUNDAY MAY 8, 2016

In a very unusual twist to this year's Walk Run, the event will now take place on **Mother's Day** for the first time ever! Also, in another development, this very important fundraising event will be changing its location. It is moving from Ashbridges Bay Park and will now be held at **The Roger's Centre**, where all of the participants will be allowed to "walk - not run" - around the bases!



APRIL

MAN TO MAN Prostrate Cancer Support Group

20 Holly Street
Toronto, Ont. M4S 3B1
Phone: 416-932-8820
Fax: 416-291-3025

Email:
info@mantoman.ca

SUPPORT GROUP RETURNS TO ORIGINAL NAME

For the first time since January 2010, our support group will once again be known as the **Toronto Man to Man *Prostrate Cancer Support Group!**

This decision was made recently after a very close vote. The final numbers were:

FOR	2
AGAINST	1
ABSTENTIONS	7

This change will take place immediately!

* **NOTE:** We are going to use the word "**prostrate**", since most of the men already say it that way! We realize that's wrong - but it's really what they say!

PSA = Prostrate-Specific Antigen
Otherwise known as:
"Pomegranate-Specific Alcohol"

Men from the Toronto gay community have offered us, at no cost, the use of a large room in their social hall at 519 Church Street, to hold our Tuesday night peer support meetings. There is **NO FREE PARKING** available at this location.

We are currently considering it.

DRE = Digital Rectal Examination
Otherwise known as:
Diabolically Revolting Experience

ENOUGH ALREADY!

Because so many of you have decided to help us out by offering to volunteer, we now find ourselves in the position of having **too many volunteers!**

So please **stop** offering, **OK?**

PLEASE READ

SIX MEMBERS OF THE BOARD ASKED TO STEP DOWN!

In a special, late-night meeting of the Board of Directors of our support group, six members were asked to resign immediately due to lack of energy.

More details to follow shortly!

SPECIAL NOTE!

*This front page
should have
been printed on
April 1, 2016,*

or

**"April
Fools'
Day!"**

"Trying to raise money - again!" - mantoman.ca

A w a r e n e s s

THIS IS OUR REAL FRONT PAGE!

The "PCCN-Toronto" and "Side by Side" Prostate Cancer Support Groups

DO IT FOR DADS WALK/RUN FATHER'S DAY - SUNDAY JUNE 19, 2016

Yes, it is almost that time again! Time to look for those running shoes which will carry you along the boardwalk at **Ashbridges Bay Park** this **Father's Day**.

Time for you to start thinking about the Father's Day Walk Run organized by Prostate Cancer Canada, who ask us to help them raise funds which they then allocate to prostate cancer research.

And time as well for as many of you as possible to join our Walk Run team, help us raise our share of the money going to research, and then join us at the Walk itself on Father's Day, down on the Toronto waterfront.

Our team has already been registered; what we need now are team members - **that's you** - who will help us raise the money.

So let's start at the very beginning by having you (and your family) register with our PCCN-Toronto team.

Enter www.doitfordads.com

Scroll down to:

FIND A PARTICIPANT TEAM

Click on **Team Search**.

Under "**Team Name**", type in **PCCN-Toronto**.

Click below on **PCCN-Toronto**.

Click on **JOIN THE TEAM**.

Log in with your previous **USERNAME** and **PASSWORD** or click on **Create New Account**.

Click on **Toronto**.

Accept the waiver.

Click on **Adult (19)**.

Then - **I will fundraise \$125.00**.



Continue with the registration. When you get to the page marked **Ready to Register**, click on **Register me**.

Once registered, you can write a note to send to your friends, relatives and co-workers, asking them to go to your page via a link that you can include in your emails. That link will take them directly to your personal page where all they have to do is click on **DONATE NOW**. It's that simple!

If you have any questions, please call Aaron at 416-414-4961 or email aaronbacher@rogers.com

**WELCOME ABOARD
TEAM "PCCN-TORONTO"**

2016



Prostate Cancer
Canada Network
Toronto

MARCH

**PCCN-Toronto
Prostate Cancer
Support Group**

**541 Finch Avenue West
Toronto, Ont. M2R 3Y3
Phone: 416-932-8820
Fax: 416-291-3025**

**Email:
info@pccntoronto.ca**

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"Raising prostate cancer awareness" - pccntoronto.ca

PCCN-Toronto & Side by Side

invite you to attend our

Scotiabank

Awareness Night Meeting

at the

Toronto Botanical Garden

In The Garden Hall

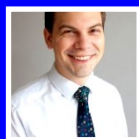
777 Lawrence Ave. East at Leslie Street

on

**Wednesday
March 30, 2016**

at 7:30 p.m.

our guest speaker



Justin Lorentz MSc, CGC

Sunnybrook Odette Cancer Centre

topic:

Genetically Predisposed:

**Who is at increased risk of
developing prostate cancer?**

Joining in the Q&A discussion

Dr. Danny Vesprini MD, MSc, FRCPC

Sunnybrook Odette Cancer Centre

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.

**2016 Meetings Benefit
North York Harvest Food Bank**

Please bring some non-perishable food with you to our Scotiabank Awareness Night Meetings, which PCCN-Toronto will donate to the *North York Harvest Food Bank*.

Here is a list of their much-needed items. Please note that all expiration dates must be valid and canned goods cannot be damaged (dented). Thank you very much.

- | | |
|---|--------------------------|
| √ Canned fish & meat | √ Flour |
| √ Canned vegetables | √ Brown pasta |
| √ Canned fruit | √ Powdered milk |
| √ Cooking oil - canola or olive oil | √ Canned or dried beans |
| √ Cereals - high fibre | √ Rice - white & brown |
| √ Peanut/almond butter | √ Baby formula & diapers |
| √ Cookies (arrowroot, digestive, oatmeal) | √ Baby food & cereals |
| | √ Fruit juice - 100% |



www.northyorkharvestfoodbank.com

All of our 2016 Awareness Night meetings at The Toronto

Botanical Garden and our PCCN-Toronto Man to Man Peer Support Group meetings at Valleyview

Residence are being sponsored by Scotiabank.

We sincerely thank Janet Slasor and all the people at Scotiabank for their very generous on-going financial support.

The Board of PCCN-Toronto

Dr. Shabbir Alibhai discusses ADT (hormone therapy) in great detail.

Overheard before our first Awareness Night meeting: "I'm about to go on Lupron." "The potential side effects concern me, that's why I'm here tonight." "Is two years a normal time to be on hormones?"



Those are only a few of the comments we heard before *Dr. Shabbir Alibhai* took the stage at our first Awareness Night meeting of 2016. But, when he was finished his presentation and the Q & A portion of the evening, we know that those men and many others who attended that night all had their concerns alleviated and their questions answered.

Dr. Alibhai covered many important topics related to Androgen Deprivation Therapy (ADT), also known as Hormone Therapy.

He first discussed *how* ADT is used and *why* it is used. As examples, he mentioned using ADT in combination with radiation or surgery for high-risk disease, if the disease starts spreading (metastatic), for a rising PSA reading after having radiation or surgery, or as a primary therapy in patients being managed conservatively (i.e. not having radiation or surgery).

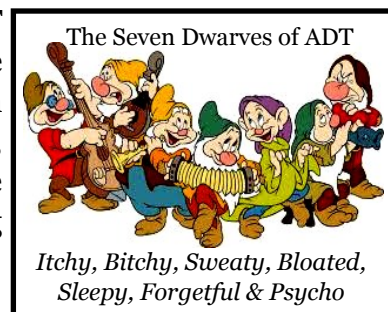
He also mentioned that there was excellent evidence for the use of ADT, such as: many randomized trials demonstrating improvement in quality of life/symptoms, slowing of disease progression, and prolonged survival.

ADT, however, does lead to decreased levels of testosterone, and that can potentially lead to numerous side effects.

One of those side effects is osteoporosis, as ADT can lead to a decline in bone density. One treatment that could prevent this from happening is the daily use of 1,000 to 1,200 mg of Calcium and 1,000 units of Vitamin D.

Another possibility is cardiovascular disease, which is the most controversial major long-term side effect. Others include diabetes, changes in Cholesterol/Lipids numbers, muscle mass goes down, fat mass goes up, weight gain, and breast enlargement.

The effects of ADT on cognition are unclear, but it can cause mood swings, such as feeling more emotional including crying more often.



During the final part of his talk he spoke about a new exercise program aimed at men with prostate cancer on ADT, which is scheduled to open this Spring. Its aim is to determine the most effective and sustainable method of delivering exercise programs to men on ADT for prostate cancer with the goal of improving long-term health and well-being.

In summary: ADT can have many side effects, but most can be prevented or reduced with various approaches. Maintaining physical health, physical activity, being aware and getting educated are all extremely important. For more details, look for Dr. Alibhai's video on our web site very soon.

We thank him very much for coming and sharing his vast knowledge with us. A donation has been made by PCCN-Toronto, in Dr. Alibhai's name, to a charity of his choice.

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.

More on PCC's Walk Run Fundraising Event and how you can definitely help us reach our goals!

Prostate Cancer Canada's (PCC) annual Father's Day Walk Run raises money that goes to research, education, and awareness.

The research dollars are controlled by the experts at PCC, who know the researchers/scientists, and decide which projects deserve support through PCC research grants.

As for "education" and "awareness" dollars, those are given by PCC back to the prostate cancer support groups who participate in the Walk Run. That's because *education* and *awareness* are two important components of what support groups do with/for men (and their families), when they are diagnosed with prostate cancer.

Our particular group utilizes our Tuesday night peer support meetings at Valleyview Residence and our awareness night meetings at the Toronto Botanical Garden to educate everyone about prostate cancer and raise the awareness of this disease.

That is why it is so important for our group to raise as much money as we can for the Walk Run each year. The more we raise, the more PCC can give to research, and the more our group will have to spend on expanding our *education* and *awareness* programs.

That is why we ask YOU for help. Yes, we are a large support group. But the same core of volunteers cannot be expected to participate in all of our events - that is simply not fair.

But each year, for the Walk Run, we have pretty much the same men (and their families) raising the money and then walking with us at Ashbridges Bay Park!

You can help our group by joining our team, raising a few much-needed dollars, and

walking/celebrating with us on Father's Day. You don't need to raise thousands of dollars!

But we know that each of you have family members, friends, and, even business associates who would definitely support you if they knew that you were participating in this major fundraising endeavor.

Whatever amount you are able to raise will obviously be a major help to our PCCN-Toronto "team", and will also benefit numerous newly-diagnosed men throughout this year.

And last but not least. If fundraising is simply "not your thing", there is one more very important option available to you which will still be of great help - **you can make a personal donation to our cause!**

Simply go to doitfordads.com

Scroll down to **DONATE** - click it.

Click **TEAM SEARCH** - then enter PCCN.

Below that you will see PCCN-Toronto - click on our team name.

That will take you to our team page where it says PLEASE SPONSOR **PCCN-TORONTO**. On the right side - click **DONATE NOW**.

Then continue entering personal information and the amount of your donation, including your payment details.

Your generous donation will be directed to our "team" and not to any specific participant but will definitely be reflected in our grand total!

Whether you decide to join our team, raise some funds and walk with us on Father's Day, or choose instead to make a personal donation to our team, **thank you very much** for helping us out in a very big way.

PCCN-Toronto is supported by:
Harmony Printing/Macgregors Meat & Seafood Ltd.
Prostate Cancer Canada/Scotiabank

ASK THE DOCTOR

Dr. Danny Vesprini: Does Prostate Cancer 'Run in the Family'? Who is at increased risk of developing prostate cancer and what are we doing about it?

A common fear many have after being diagnosed with cancer is if their diagnosis means others in their family are at increased risk of developing the disease and, in particular, their children. In those people with a strong



family history (i.e. cancer "runs in the family"), this fear is associated with a term called 'genetic guilt', where people feel guilty for possibly passing on some genetic trait that increases the risk of developing cancer to the next generation in their family. The reality is that

probably no more than 10% of all prostate cancers have a direct inherited cause, as the majority are thought to be random or 'sporadic'. That stated, it is clear that for some men the risk of prostate cancer is passed on from generation to generation, and in these families not only is there an increased risk of the disease, but it tends to be diagnosed at an earlier age and with more aggressive features.

One example of a gene that increases a man's risk of developing prostate cancer lies in the same genes that are known to dramatically increase a woman's risk for breast and ovarian cancer, the BRCA genes (think Angelina Jolie). Men with a mutation in the BRCA2 gene tend to develop prostate cancer at twice the rate that is seen in the general population and unfortunately have a much poorer prognosis. The average man with prostate cancer has a greater than 95% chance of being alive 5 years after diagnosis if he is treated appropriately – whereas some studies have shown that for men with prostate cancer and a BRCA2 mutation the chance of still being alive 5 years after diagnosis is less than 50%! Men with a BRCA mutation are therefore subject to many ongoing studies looking at enhanced screening.

For example, at the Sunnybrook Odette Cancer Centre, we have an ongoing prostate MRI screening study in all men with a BRCA mutation independent of what their PSA is. Thankfully BRCA mutations are rare, with only 2% of all prostate cancers being attributed to these genes.

Other men thought to be at increased risk of developing aggressive prostate cancer are men of Western African/Caribbean ancestry and those with a strong family history. Large population databases have shown that men from African ancestry have nearly twice the rate of prostate cancer and over double the rate of prostate cancer related death compared to non-African men. More specifically, men from Western Africa/Caribbean ancestry following the path of the Trans-Atlantic slave trade see amongst the highest incidence of prostate cancer in the world. Although no specific inherited causes of this have been identified to date, they almost certainly exist.

Regarding family history, men with fathers diagnosed with prostate cancer have approximately double the risk of developing the disease compared to the general population, whereas men with brothers who have been diagnosed have more than triple the risk. This increased risk could be due to multiple factors such as increased awareness (family members are more likely to get prostate cancer), environmental (family members are exposed to the same external risk factors such as diet or other carcinogens), and of course inheritable causes (cancer causing genes). When men have multiple family members or young family members (less than 50 years old) with prostate cancer, the likelihood that there is an inheritable cause of the disease increases and are, therefore, the subject of most research studies.

Though PSA screening in the general population has been challenged in the past several years, screening for the men considered at high risk of the disease as described above should not be controversial and, in fact, likely needs to be improved.

The Male Oncology Research and Education (**MORE**) program at the Sunnybrook Odette Cancer Centre is focusing on this need. In the MORE program, we follow all men who are at high risk of developing prostate cancer. We see these men in our clinic annually for standard prostate screening with a PSA test and physical examination starting at the age of 40. All men have a detailed family history drawn by a genetic counsellor and all non-BRCA mutation carrier patients are given a risk assessment for genetic testing.

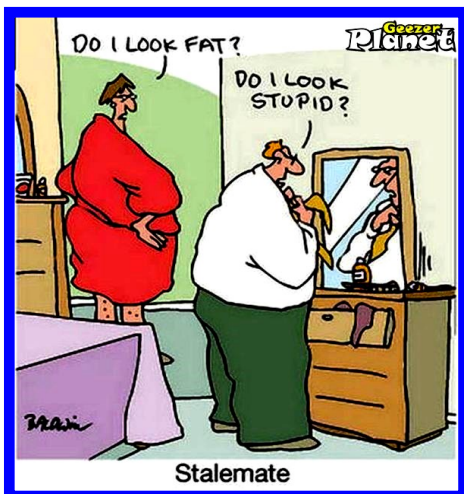
... continued on page 7

Dr. Vesprini . . . continued

All the men are also invited to become involved in our research program, which is attempting to answer, among many things, the following questions: (1) What is the inherited cause of prostate cancer in men with a strong family history? (i.e. We are trying to find new high risk genes); (2) Should men at high risk be screened differently than the general population?; (3) Can diet and/or exercise decrease the risk of prostate cancer in the high risk population? and (4) What are the psychosocial needs of men at high risk?

Clinical and research programs like MORE are of increasing importance as there is more and more pressure to decrease PSA screening for prostate cancer. The identification of inheritable/genetic risk factors will allow us to tailor more enhanced prostate screening protocols, so that disease can be identified prior to being aggressive, and may allow us to tailor prevention or treatment using their genetic makeup. In essence, the more we learn about the factors that make prostate cancer 'run in the family', the less we will need to worry about, and thus get rid of, at least one fear for those who are diagnosed.

*If you wish to become involved in the **MORE** program, please ask your doctor to refer you to **Dr. Danny Vesprini** at the **Sunnybrook Odette Cancer Centre**.*



"Board News"

by Winston Klass, Chairman

Bowling: A bowling evening is planned for Spring this year; likely the last Tuesday of April or May. You will be covering your bowling fees and PCCN-Toronto will provide light refreshments. Will keep you posted.

Revision of PCCN-Toronto governance guidelines: Our current constitution is becoming outdated; in particular, demands on the Chair and Vice Chair are unrealistic given the active lifestyle and varied interests of current board members. At the end on my tenure as Chair (October 2016) governance will be relatively fluid for an interim period of one year. A subcommittee comprising of Aaron Bacher, Philip Segal, William Deane and myself met for a couple of hours over coffee to determine the guidelines for interim governance. More appropriate governance guidelines (developed through ongoing board discussions) will be ready for implementation at the end of the interim period.

The Navigator Project: At our last board meeting Dr. Jackie Bender and Dr. Parminder Flora, research scientists at the Princess Margaret Cancer Centre (PMCC), introduced us to the Navigator project. Men newly-diagnosed with prostate cancer will be paired with prostate cancer survivors (buddies) who will help and advise regarding choice of treatment and navigation of health services. PCCN-Toronto was invited to be a partner in this project; to provide buddies, to help in training buddies and to assess the proposed training program. PCCN-Toronto volunteers will be invited to provide feedback on particulars of the training program (a link will be circulated). Please make an effort to open this link and answer the questions...your input will provide valuable information. Dr. Bender and Dr. Flora also advised the board on options for augmenting our current programs with 'social media based' support initiatives.

Hospital counselling: Our Tuesday night peer support meetings provide advice and support within a group setting. Those of you who may be interested in interacting one-on-one with survivors should consider participating in our counselling program for clinics at PMCC, Sunnybrook (the Odette Cancer Centre) and Branson Hospital. To qualify for assignment to such clinics, you will need a TB vaccination; then a brief period of training and shadowing regular PCCN-Toronto volunteers.

Are you interested in becoming a PCCN-Toronto volunteer?

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

Our on-going projects for 2016

AWARENESS NIGHT MEETINGS

These meetings are held at the **Toronto Botanical Garden (in the *Floral* or *Garden Hall*)**, at the corner of Lawrence Avenue East and Leslie Street, from 7:30 - 9:30 p.m. 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 meeting will be sent to you. **PARKING IS FREE.**

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

<u>DATE</u>	<u>RM</u>	<u>SPEAKER</u>	<u>TOPIC</u>
Mar 30	G	Justin Lorentz MSc, CGC <i>Sunnybrook Odette Cancer Centre</i>	<i>Genetically predisposed: Who is at increased risk of developing prostate cancer?</i>
May 25	F	Dr. Rajiv Kumar Singal <i>Michael Garron Hospital</i>	<i>"A twenty year personal reflection on the privilege of caring for men with prostate cancer."</i>
Jul 27	G	Dr. Masoom Haider <i>Sunnybrook Health Sciences Centre</i>	<i>Imaging tests.</i>
Sep 21	F	Mark Cullen & Dr. Ryan Groll <i>Michael Garron Hospital</i>	<i>Gardening expert and prostate cancer survivor.</i> & <i>Mark Cullen's surgeon.</i>
Nov 30	F	Dr. Andrew Matthew <i>Princess Margaret Cancer Centre</i>	<i>Family emotions.</i>

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 the **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

This program has undergone some recent changes. Our ladies' support group, although still very active, now provides advice by appointment only. Please visit our website for more information.

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** (Thursday & Saturday) and **Sunnybrook Hospital** (Thursday), bringing them messages of hope and support.

Counseling

Our volunteers counsel men (and their families) in prostate cancer clinics at the **Princess Margaret Cancer Centre** (Monday through Friday), the **Odette Cancer Centre** (on Thursday), and **The Gale & Graham Wright Prostate Centre at North York General's Branson site** (on Tuesday afternoon).

PCCN - Toronto Board of Directors

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Email Aaron at: aaronbacher@rogers.com Thanks