



Awareness

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

Dr. Dean Elterman delivers a powerful talk about Incontinence & Erectile Dysfunction.

This was the night - our November Scotiabank Awareness Night meeting - when men came to The Toronto Botanical Garden, to hear something positive and encouraging about two of their most anxious topics - incontinence & erectile dysfunction (ED)!



What they got from guest speaker **Dr. Dean Elterman** was a lot of information about what causes these two conditions, and ways of correcting them.

Although we've hosted many talks on these same two subjects over the years, we must have set a record on the use of two words - penis and erection! Many adjectives were used with "penis": flaccid penis, erect penis, "rock hard" penis, bent penis, and there was even a reference to penile length due to a shortening of the urethra after having a radical prostatectomy, which could remind one of an old Seinfeld episode which referred to "shrinkage"!

When discussing incontinence, Dr. Elterman defined it, talked about the causes after having a radical prostatectomy (RP), and how to manage it. Therapy ranges from "lifestyle modification" (limiting fluid intake, avoiding bladder irritants like caffeine), Kegel exercises, and medications to correct urgency incontinence (nothing works for stress incontinence). He even discussed various surgical procedures he performs involving a variety of male slings, which lift the bladder and correct incontinence problems.

As for erectile dysfunction, that was only one of seven conditions associated with Post-RP Sexual Dysfunction. Dr. Elterman defined ED as: "consistent or recurrent inability of a man to attain and/or maintain a penile erection sufficient for sexual performance." He discussed how men with ED often feel a loss of their manhood, and have feelings of inadequacy. He said that erectile function is measured at one-year post-op, but erections may return as early as 1-3 months after surgery. PDE5 inhibitors, such as Viagra, Cialis, and Levitra can help in achieving penile function, but Dr. Elterman said, **"you can't take a pill while watching the nightly news, and then say that nothing happened!"** There is definitely a need for sexual stimulation!

While discussing Penile Rehab, he mentioned MUSE (Medicated Urethral System for Erection), Vacuum Erection Devices, Intracavernosal Injections, and the Penile Prosthesis, as ways of attaining an erection.

Following his fantastic talk, and our refreshment break, Dr. Elterman spent almost another entire hour answering questions from our very interested and enthusiastic audience. We sincerely thanked him for giving us so much of his precious time, and, to further show our appreciation to him, a donation was made in his name.

Obviously Dr. Elterman covered much more detailed information than we can describe here. And, because we record our Scotiabank Awareness Night presentations, you all now have the opportunity to see and hear his entire talk at your convenience, as soon as it is posted to our website. (see below)

We look forward to seeing you all again on January 27, 2016.

"Raising prostate cancer awareness" - pccntoronto.ca



DECEMBER 2015

**PCCN-TORONTO
Prostate Cancer
Support Group**

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YOU
AND
YOUR FAMILY
THE BEST
OF THE
HOLIDAY SEASON
AND
A VERY HAPPY,
HEALTHY, AND
PROSPEROUS
NEW
YEAR!** 

Dr. John Bartlett: "We need to know more: PRONTO!"

Our September guest speaker was Dr. John Bartlett, Director of the Ontario Cancer Institute of Research's (OCIR) Transformative Pathology Platform.

He and his collaborators received the \$5 Million 2014 Movember Team Grant (funded by Movember Canada).

Dr. Bartlett said that, for men, "prostate cancer (PCa) is the most common cancer, but often it is not fatal!" Also, "There is no such thing as simple PCa! There are many different kinds of PCa, and we have to start thinking about them in that way and treating them in that way."

The **PRONTO** part of his talk was defined as: **P**ersonalized **R**isk stratification for patients with **pr**ostate cancer. "Our goal over the next four years is to try and identify a translatable and deliverable diagnostic test allowing us to stratify men by their risk and give them the information."

He discussed the controversial topic of PSA screening. When talking about prostate cancer, he said that the big question is whether it is aggressive or not, and for that you need the diagnostic test. He added that between 1985 and 2000, seven million PSA tests were done, with 40% of prostate cancer cases being detected by screening.

When discussing Active Surveillance, he said that about one-third of men on that regimen die after ten years, but almost all of them die from various other "old-age" diseases *and not* from prostate cancer!

We were told how "cancer", which was once referred to as "the big C" has undergone changes over the years: 50's - 70's: cancer was looked at as one disease; 70's - 80's: site specific - "one size fits all"; 90's - 2000: cancer subtypes; to the point that now prostate and breast cancer are each thought to have 20-30 kinds.

As you can see, this was a very detailed, scientific talk, given by one of our top experts in the field. For much more detailed information on Dr. Bartlett's speech, you'll soon be able to go to our website and watch his entire talk (pccntoronto.ca/videos).

We thank him very much for coming to our Awareness Night and giving such an interesting presentation.

To show our appreciation to him, a donation was made to his favourite charity.



PCCN-Toronto hosts successful volunteer dinner and holiday peer support meeting!

On October 27th, our support group hosted our annual Volunteer Dinner, this time at Jerusalem Restaurant on Leslie Street, just south of Finch Avenue.



Close to fifty of our volunteers, many of whom



attended with their partners, had a very enjoyable evening together, with the only "rule" being **not** to talk about prostate cancer!



On Tuesday December 1st, after the first hour of our regular peer support meeting, which was again devoted to men attending

for their first time, we had a special "holiday" refreshment break, which happily included several of our Side by Side ladies who were also attending. Chairman Winston Klass arranged for food to be catered as we all celebrated the onset of the holiday season! Our meeting concluded with everyone together in the same room.



Thank you Winston.



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

invite you to attend our first 2016

Scotiabank

Awareness Night Meeting

at the

Toronto Botanical Garden

In The Garden Room

777 Lawrence Ave. East at Leslie Street

on

Wednesday

January 27, 2016

at 7:30 p.m.

our guest speaker

Dr. Shabbir Alibhai

The Princess Margaret Cancer Centre

topic:

**Understanding, preventing,
and managing side effects of
hormone therapy.**

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.

**2015 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
- √ Canned vegetables
- √ Canned fruit
- √ Cooking oil - canola or olive oil
- √ Cereals - high fibre
- √ Peanut/almond butter
- √ Cookies (arrowroot, digestive, oatmeal)
- √ Flour
- √ Brown pasta
- √ Powdered milk
- √ Canned or dried beans
- √ Rice - white & brown
- √ Baby formula & diapers
- √ Baby food & cereals
- √ Fruit juice - 100%



www.northyorkharvestfoodbank.com



All of our 2015 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 are very proud to continue calling our meetings at the Garden "The Scotiabank Awareness Night" meetings.

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

\$50-million donation to Toronto hospital enshrines memorial for son!

The story about this donation broke on Tuesday December 2, 2015. Dr. Rajiv Kumar Singal, a Urologic Surgeon at Toronto East General Hospital and friend of PCCN-Toronto, wrote the following blog about this historical donation. We are sharing it with you here in our newsletter with his permission.

* * * * *

I cannot begin to tell you what great pleasure it gives me to write today on behalf of the physician staff as well as a member of the foundation board and perhaps most importantly as a friend of Berna and Myron Garron. This morning we announced an historic gift to Toronto East General Hospital. At \$50 million dollars, it is monumental. It is the second largest gift to any hospital in Canadian history.

Our hospital will now be called the **Michael Garron Hospital**. We will also use the opportunity to create a larger Toronto East Health Network that will tie all of this institution's partners across the city and provide a vehicle for further growth.

The Garrons in so many ways define the best of what I think makes being a good citizen. They embody what we all hope to be. Having built their success in this amazing and generous country, their long-standing commitment to give back, in order to support and enhance our most important and valued public institutions is extraordinary. In our rapidly changing, resource challenged healthcare environment, Canadians still expect and deserve the best evidence-based care. Without the collective philanthropic spirit of all of us this would not be possible. In 2010 we combined to give 2.1 billion dollars to various institutions. A quick look through the recent past and one realizes that the Garrons have supported many of Canada's leading healthcare institutions. Over the last five years alone, in addition to today, they have given away \$30 million to Sick Kids, \$10 million to the Princess Margaret Cancer Centre and \$10 million to IWK in Halifax, Nova Scotia. Clearly they care very deeply about the country they live in. That the Garrons now recognize our great hospital with this singularly unprecedented gift is personally very gratifying to me. Over the last three years, as I have come to know the Garrons, they have come to know and believe in TEGH and have expressed that support with a series of progressively larger gifts. It is very fitting that we should celebrate a gift of this magnitude by renaming the hospital in honour of Michael Garron.

Myron Garron grew up in Westport Nova Scotia, a small fishing village off the Fundy coast. If you look on a map it is quite remote, one of literally hundreds of unique and tightly-knit communities across this country. His ultimate success was built on that foundation, long a tradition in the Maritimes, of local community and hard work. My wife's entire family has roots in the Maritimes. My kids have spent every summer on Prince Edward Island. I understand this ethos well. As many other Maritimers have done over the years, Myron came to Toronto many years ago to pursue a career. While here, he met Berna while working at the Bank of Nova Scotia and started a family. Michael, their eldest, was born at TEGH. At the age of six, Michael was diagnosed with synovial sarcoma, a rare form of cancer that ultimately claimed his life in 1975 at the age of 13.



Michael's story is both intensely heartbreaking and ultimately inspirational. Before he died his parents made a promise that he would never be forgotten. That promise has entirely informed their history of giving. Today represents the ultimate fulfillment of that pledge. Michael Garron, like so many others a child of the Toronto East community, finally came back home today. His legacy will ultimately be borne out in the great things that this institution will do for many years to come. It will be defined by excellence, compassion, courage and integrity. It will lead by example and with a mandate of inclusivity. In essence we will build on the very things that have brought us from 1929 to this remarkable day.

Watching the reaction of Berna and Myron to the unveiling of the new banner was very emotional for myself and the entire hospital community. Myron spoke with great pride today about his family, his son and their commitment to the Michael Garron Hospital.

This hospital has occupied a unique place in our healthcare system, serving both the needs of this community as well as leading on a provincial and national scale. This has very much been the order of business for 86 years.

To borrow a little from our CEO Sarah Downey, today's extraordinary gift essentially provides a key that opens the door to a whole new adventure. As our healthcare system evolves into the 21st century, this gift will ensure that we have access to leading-edge medical technology in order to provide the best care for our patients. The creation of two research chairs will also provide a platform from which we will be able to innovate and lead. For this we are eternally grateful to the Garrons.

I will close on a personal note. I have been a proud member of the surgical staff at Toronto East General Hospital over the last 20 years. We have accomplished many things and have several well-respected and talented departments. We are an integral part of the University of Toronto. As I look ahead, I will be proud to continue to be a member of the medical staff at the new Michael Garron Hospital. I hope to be able to do so for many years to come.

I am additionally thankful that today's announcement fell after the end of November!

Make sure you continue to follow the jewel at 825 Coxwell, as it heads into a bright future as the Michael Garron Hospital.

Special things happen here. It will always make you proud.

Thank you Berna and Myron for sharing the memory of your son with all of us.

Rajiv

To see the original blog, please click on this link:

<http://www.rajivsingal.com/blogs/view/introducing-the-michael-garron-hospital>

PCCN-TORONTO VOLUNTEERS ARE MORE THAN THAT: THEY ARE TRULY OUR "UNSUNG HEROES"

As another very successful year, 2015, comes to a close for PCCN-Toronto, we must acknowledge the reasons for that success.

We often refer to them as our "volunteers", but they are honestly much more than that! They are our "**unsung heroes**" - involved in all aspects of our support group, who often go about their "business" without much recognition. But our support group really can't exist without them!

Specific heroes return your calls when you leave a message on our **information line (416-932-8820)**. Email inquiries can be sent to: info@pccntoronto.ca



Other heroes "do their thing" at our various meetings: for example, at our Tuesday night **peer support meetings**, one might be facilitating that night; acting as the spotter - noting that someone has a question for the group; or greeting men at our sign-in table. They may also offer advice to first-time attendees based on their experiences.; at our **Scotiabank Awareness Night meetings**, you might be emceeing that night, or manning the front table to personally welcome our guests; at our **Warriors** and **E(motional)** meetings, we have heroes facilitating those meetings as well.

All of our meetings feature refreshment breaks, and our heroes can be seen setting up the cookies on our refreshment tables, or preparing the coffee/tea for everyone. Other heroes actually go out and do the shopping for the cookies, coffee, water, juices, etc. These supplies don't just magically appear on their own!

Some of our heroes over the years have been "heroines", as members of our sister support group **Side by Side**. These women talk and share their experiences with partners/spouses of newly-diagnosed men.

Our **Speakers' Bureau** consists of another group of heroes, who are invited to speak at a variety of companies, churches/synagogues, community centres and other non-profit organizations. Here they discuss: a) their own

personal prostate cancer (PCa) journey; b) the importance of: being screened and an early diagnosis of PCa; and c) our support group.

Even this **newsletter** has one of our heroes publishing it.

Heroes on our **Events Committee** are periodically invited to participate in health fairs, Prostate Cancer Canada (PCC) events (e.g. auto shows), or to man information booths in major malls.

Many of our heroes are well-known to urologists and radiation oncologists throughout the city, especially at the **Princess Margaret Cancer Centre, The Odette Cancer Centre** (Sunnybrook), and the **Gale and Graham Wright Prostate Centre at Branson Hospital**. That's because while some heroes counsel men in the hospital clinics, others who had a radical prostatectomy visit patients in Toronto General Hospital and Sunnybrook Hospital who also chose to have surgery as their primary treatment.

A few of our heroes manage our group's **website**, which is a major project. Here, pages of information have been created, listing details about all our activities. As well, if you have any questions about PCa, you will find answers here. Our site also features several videos of PCa specialists talking about their specialty. These have proven to be very useful for men looking for information about treatment options. Please visit our website today: pccntoronto.ca

Some of our unsung heroes are fairly new, while others have been with us for many years. We may not say it often enough, but we hope that our **heroes** can see how much their efforts are appreciated by everyone.

*Do you want to become one of our **unsung heroes**? Call us or write to us now (see above).*

HAPPY HOLIDAYS TO ALL!

Last year I joined a support group for procrastinators. We haven't met yet!

PCCN-Toronto is supported by:

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

ASK THE DOCTOR

Dr. Sharon Sharir: What are the risks involved in having a prostate biopsy?

Doctors use various tests to help decide if a man might potentially harbour prostate cancer. These include a digital rectal exam (DRE) and PSA testing.



More recently, there has been increased use of MRI as well. However, these tests cannot make a diagnosis of prostate cancer – they are used to decide if a man appears to be at higher risk for having prostate cancer. If it is determined that he may be at risk, a prostate biopsy is necessary to actually tell whether there is cancer in the prostate or not.

Some people may wonder why, if a prostate biopsy is the only way to definitively diagnose prostate cancer, doctors don't just do that instead of doing a DRE, PSA or MRI. One of the main reasons doctors don't just automatically do prostate biopsies if they are wondering about the possibility of a man having prostate cancer, is that there are risks to doing a biopsy. As with all medical procedures, if there are risks (which there usually are), we have to weigh the risks against the benefits, and proceed with doing a procedure if the likelihood of benefit outweighs the likelihood of harm.

The potential benefit of a prostate biopsy is that it can (and is generally the only way to) diagnose prostate cancer; a diagnosis is necessary to be able to determine what the appropriate management or treatment should be.

But there are also risks, and men need to be aware of these. This is important so they can appreciate why a doctor is suggesting a biopsy – the suspicion of the possibility of cancer needs to be sufficiently high. It is also important to be aware of the risks so men know what to look for after a biopsy and to determine if they need to seek any medical attention. Finally, they need to understand that there are limitations to a biopsy's ability to provide answers.

The first risk of having a prostate biopsy is the risk of discomfort or pain. In my experience, there is a very wide range of men's perception of pain during the procedure. Some men say that they hardly feel a thing. Others feel a very significant amount of pain. Most find that it is not comfortable, but is bearable.

The second risk is the risk of bleeding. There will inevitably be bleeding from the rectum after a biopsy, which will eventually stop on its own. While it may sometimes seem like a lot of bleeding, it is actually very rare that men require medical attention for this. Sometimes blood can also be seen in the urine after the biopsy. It can be present in the semen too – and there it can last many weeks. One thing to note is that if you are on blood thinners, you need to speak to your doctor about stopping the medication or switching to a different one temporarily, and to ask about when you can resume your usual medication.

The third risk of having a prostate biopsy is a risk of having difficulty passing urine after the biopsy. This is not very common, and is more likely in men who have pre-existing problems with urination.

The fourth, and most concerning risk, is that of infection. Around the time of a prostate biopsy, it is standard procedure to have men take antibiotics to prevent infection. However, about 4% of the time men can get infection problems despite using antibiotics. This can occur because some bacteria are not sensitive to the antibiotic that was taken. Having an infection means a trip to the emergency department, and possibly admission to hospital for treatment.

A final risk is getting an "incorrect" answer from the biopsy – most commonly this is when a biopsy comes back negative when in fact a man does have prostate cancer. In medical terminology, this is called a false negative result. This can occur because the biopsy samples only a tiny proportion of the entire prostate. False negatives can occur up to 25% of the time in a first biopsy. So if a first biopsy comes back negative, but there is high suspicion for prostate cancer (e.g. if the PSA keeps rising), doctors will sometimes recommend second and even third biopsies to improve the likelihood of getting the "correct" result.

While these risks may sound worrisome, one has to keep in mind that there is also a risk to not doing a biopsy. If there is a high enough level of concern that a man could have prostate cancer and a biopsy is not done, the cancer is potentially not being dealt with as it should be.

As with all medical situations, a good discussion with your doctor about the risks vs. benefits of doing a prostate biopsy is the best way to come to the best possible decision about your health.

Board News!

Holiday wishes from our chairman!

Navigator Project:

At our September board meeting Dr. Andrew Matthew, staff psychologist at the Princess Margaret Cancer Centre, briefed us on the Navigator Project. This involves pairing men recently diagnosed with prostate cancer with trained prostate cancer survivors, and it is funded by Movember and Prostate Cancer Canada. The Navigator project has already produced impressive technical aids for choice of treatment at diagnosis; and also for access of personal medical data. It became clear however that human contact was necessary to any effective support program; hence the interest in recruiting PCCN-Toronto volunteers (a natural resource for Navigators). The PCCN-T board is considering a pilot project manned by at most five PCCN-T volunteers. Please contact board members if this interests you; your feedback will inform any PCCN-T decision re participating.



E Meetings:

Our bimonthly E(motional) meeting - third Tuesday of Jan, March, May, July, Sept, & Nov - are a first step towards addressing important 'intangible' consequences of a prostate cancer diagnosis; its impact on lifestyle, relationships, work, etc. Meetings involve primarily the sharing of experiences, in particular reassurances that your experiences are not unique. There is also the opportunity to learn new coping skills. Please invite partners, caregivers and friends. These meetings are incidentally our only mixed gender "person to person" support sessions.

Website Survey:

John Roth has just released the results of the recent website survey. Some of the highlights are:

Forty percent of all respondents visited our website at least once a month.

Of those who visited our website, 90% rated its appearance as good or excellent, and around 80% rated "ease of navigation" as good or excellent.

Over 60% of all respondents rated "peer support" as very useful and over two thirds rated "awareness night" as very useful.

A more detailed report of findings will be made available. If you have any ideas related to the enhancement of our website - for example, an online forum has been mentioned - please let us know.



Approaching your pharmacists:

At a recent meeting of our marketing subcommittee, Stan Mednick provided feedback on a personal initiative; he persuaded some pharmacists to promote our brochures. We are considering asking volunteers to do the same - to connect with their pharmacists and to invite them to promote our brochures. We will keep you posted.

Over the next few weeks there should be many opportunities to celebrate the holiday season.

It is our sincere wish that you will each find the space to make good use of these opportunities (in particular survivors with more challenging conditions). Please take time to reflect on the advice and support you have provided to men with prostate cancer during the year, and the likelihood that you may have helped these men to better enjoy their holidays (and pat yourself on the back).

As I enter my final year as chair of PCCN-Toronto, I am struck by the ongoing changes in the approach to treatment (thanks to efforts of the committed researchers/fundraisers); and, as a consequence, the ongoing challenge to adjust our programs to keep up with corresponding changes in needs.

Thanks for your ideas in this regard and also your commitment and good work throughout this year.

Wishing you all the best for 2016 and looking forward to working, growing and learning with you for another year.

Winston Klass
Chairman
PCCN-Toronto

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 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>
Jan 27	G	Dr. Shabbir Alibhai Princess Margaret Cancer Centre	Understanding, preventing, and managing side effects of hormone therapy.
Mar 30	G	Dr. Justin Lorentz Sunnybrook Health Sciences Centre	Hereditary factors.
May 25	F	Dr. Rajiv Kumar Singal Michael Garron Hospital	"A twenty year personal reflection on the privilege of caring for men with prostate cancer."
Jul 27	G	Dr. Masoom Haider Sunnybrook Health Sciences Centre	Imaging tests.
Sep 21	F	TBD	TBD
Nov 30	F	Dr. Andrew Matthew Princess Margaret Cancer Centre	Family emotions.



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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).

Our 2015 "Awareness" newsletters are being sponsored by an unconditional grant from AstraZeneca.

