

Awareness

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

Mark Cullen and Dr. Ryan Groll: A Patient and his Surgeon



For the first time in the twenty-one year history of our support group, our September Awareness Night speakers consisted of a prostate cancer survivor **AND** his surgeon!

Mark Cullen, expert gardener, author, broadcaster, and Canada's Gardening Guru and Order of Canada recipient, was the survivor.

And **Dr. Ryan Groll**, a urologist from the Michael Garron Hospital, was the surgeon.

Immediate past chairman Ron Benson handled the introductions of both speakers.

Since all journeys start with that initial consultation, which Dr. Groll referred to as a "blind date", one he said that could lead to: a) a one-night stand, b) a second date, or c) taking it to the "next level". He began the evening by discussing prostate cancer screening, expectations after a radical prostatectomy, and the importance of the doctor-patient relationship along the way.

Mark described that "first date" as awkward, especially when Dr. Groll felt some "firmness" which "didn't sound good" to Mark.

As with many, if not most of the men who are diagnosed with PCa, Mark had no symptoms and was in decent shape through exercise when he was diagnosed. When his Gleason Score

came back as a 7, which Mark called "not so bad, not so good", Dr. Groll took the time to explain his treatment options to him. That included talking a bit about robotic surgery versus open surgery, which he said were almost the same as far as the outcomes were concerned, except for maybe in the short term.



Mark was very comfortable with that information, chose to have robotic surgery, and did not seek a second opinion, even though Dr. Groll encouraged him to do so.

Mark did admit, however, to doing a bit of research on Dr. Groll through some contacts.

His recovery took about six weeks, and the support he got from friends and associates meant a lot to him and was most important!

He added a resounding "YES" in answer to his own question: "Knowing what we know now, did we make the right decision?"

We thank Mark Cullen and Dr. Groll for coming and giving of their time to speak to us. They both answered several written questions from the audience and donations were made to the charities of their choice.

For more information, please go to pccntoronto.ca/videos.



OCTOBER

PCCN-Toronto Prostate Cancer Support Group

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"Raising prostate cancer awareness" - pccntoronto.ca

Dr. Masoom Haider: the important role of the MRI.

At the same time as many people were driving to the Botanical Garden to hear Dr. Masoom Haider, it was raining cats and dogs! Some who arrived early couldn't get out of their cars as it started to **hail!**



But it did stop, and the people did show up. It was the first time that our meeting was held in the Garden Hall, and, between 7:15 and 7:30, the room filled up almost completely!

Winston Klass, our chairman, introduced our speaker, and Dr. Haider started talking to us about how important the use of MRIs (magnetic resonance imaging) have become, and how surgeries/radiation treatments are being modified based on those MRI results!

He did say that one problem with this increased usage is that waiting times are getting longer and, some MRIs are currently being booked into early 2017!

He also touched on Focal Therapy, where a probe is inserted into the urethra, and then they can actually burn part of the prostate which contains the tumor. Then the probe is removed.

This was a technical presentation delivered in a "non-technical" manner which was understood by the large audience who attended.

Dr. Haider was inundated with questions during our refreshment break, all through our scheduled Q&A portion of the evening, and long after he had been thanked and the evening had been brought to a close!

His entire presentation can be seen at: pccntoronto.ca/videos.

Thank you Dr. Haider for your excellent talk.

Meet the newest member of our board: Ari Katz

Most men who choose surgery as their treatment have one primary surgeon doing the surgery.

But not Ari! His decision to have surgery occurred around the same time that Toronto East General Hospital (now called the Michael Garron Hospital) was entering into a partnership with



Sunnybrook Health Sciences Centre about the use of their daVinci machine, used for robotic surgery. His surgeon, Dr. Sender Herschorn, told him that Dr. Rajiv Singal (head of robotics at MGH and a good friend of our support group) agreed to take part

in his surgery. So, on October 9, 2012, both surgeons participated, with Dr. Singal performing the delicate portion of preserving the nerve bundles.

Unfortunately, like many others, Ari's PCa journey didn't end after his surgery! His PSA remained undetectable, but then started climbing in 2015 and continued this year. "The PSA is very stressful", Ari says, "especially when it is rising! But I have come to terms with the fact that I will likely need further treatment."

Ari has a long family history with prostate cancer. His dad and two of his uncles had radical prostatectomies, while his grandfather and two other uncles, who were also diagnosed with PCa, passed away without ever being treated for the disease. Ari is also the father of three boys.

He believes strongly in the importance of a support network while one undergoes their prostate cancer treatment. "I was lucky, as I was not only receiving support from my family, but I also had a partner who did not run away from me as a result of my PCa diagnosis, but actually asked that I marry her! So, shortly after my surgery, I married my partner Sherri."

Ari strongly believes in the issues of prostate cancer awareness and the importance of a support group in ones prostate cancer journey, and that is why he is happy to assist PCCN-Toronto in any fashion that he can. He has been attending PCCN meetings regularly since 2013 and was approached to join the board at the beginning of this year.

Ari is a professional accountant with over twenty-nine years of accounting and auditing experience.

We all welcome him to our Board of Directors and look forward to working with him on a variety of programs.

PCCN-Toronto & Side by Side

invite you to attend our final 2016

Awareness Night Meeting

at the

Toronto Botanical Garden

In The Garden Hall

777 Lawrence Ave. East at Leslie Street

on

Wednesday

November 30, 2016

at 7:30 p.m.

our guest speaker

Dr. Andrew Matthew

Princess Margaret Cancer Centre

Topic:

**"Sexual Health and Prostate Cancer:
The "SHAReCLINIC" – an online
sexual health clinic".**

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

THIS JUST IN!

Report on the recent BC Support Group Conference: Friday September 23rd to Sunday September 25th.

Some top of mind impressions after attending this conference:

The easy camaraderie among the leaders of chapters across BC - Prostate Cancer Foundation BC has a relatively long history, the two ladies on staff act as cheer leaders and get things done, and leaders apparently stay in touch with each other. There were as many partners as survivors at the conference. The partnership with UBC - the piggy-backing on the Pacific North West Conference (appropriate technology was used to make this happen). Most of the research-oriented presentations were from the Pacific NW component of the conference (which lasted all of Saturday). The low turnout of chapter leaders from outside BC was surprising, given the aggressive promotion of this conference. I was hoping to benefit from meeting chapter leaders from all across Canada. This did not happen.

The main purpose of my visit was to obtain feedback on maintaining and growing support groups; and the information obtained was somewhat below expectations. Most of the support issues discussed were specific to smaller chapters in small communities; though "succession planning" problems were as prevalent in BC groups as here in Toronto. In addition, because of the reduced presence of attendees outside BC, the breadth of the pool of experiences and ideas was limited.

Presentations covered recent news on topical issues: management of recurrence, hormone resistant cancer, robotic prostatectomy, radiation treatment of localized cancer, hormone therapy and cardiovascular risk, and the genomics of prostate cancer. The presentations were somewhat technical, but it was still possible to get some sense of the nature and value of findings. Some highlights were: Young research scientists at UBC presented on efforts to take the decision-making for recurrence beyond the "doubling in six months" rule. Hormone resistant prostate cancer is now being attacked on three fronts; treatments of proven success at the back end of treatment regimens (for example chemotherapy) are now being tested for effectiveness

closer to the front end ; increasing research is carried out on understanding and frustrating the mechanism by which testosterone enters prostate cancer cells; and treatments are now being tailored to the genetic composition of the prostate cancer (as obtained through blood fluid tests). We should be able to obtain the videos from these presentations.

Feedback from the BC support group sessions: Dr Kuhl, a medical doctor/psychiatrist presented on the application of PTSD therapy to cancer (in particular prostate cancer) survivors. His underlying assumption is that a cancer diagnosis is associated with a sense of loss (in self identity - not being able to do things that you used to be able to do), and he adopts an approach gleaned from grief therapy. Attendees were divided into small groups (roughly equal numbers of men and women) and individuals requested to answer (pencil and paper) a sequence of simple questions about their lives in general and about the impact of a prostate cancer diagnosis. Answers were shared first in pairs and then within groups. This exercise led to a "surprising" lowering of defences and eventually to some self-discovery.

"Exercise" and "Nutrition" seem to be the new buzz words, and this makes sense given the shift (where appropriate of course) to living with and managing one's prostate cancer. Presentations covered the benefits of exercise and group exercise suggestions.

Folders containing paper copies of PowerPoint presentations were made available. I will consider adding my folder to our library.

Other observations: Ron Benson and Aaron Bacher were mentioned in conversations (encounters from previous conferences); it seems that we have some influence out west!

Winston Klass



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.

"Stepping down" by Chairman Winston Klass

My 'three year' stint as chairman of PCCN-Toronto ends at the end of October - and the PCa environment continues on its path of gradual but persistent change; the proliferation of treatment and support options - the increased scope and sophistication of promotions and tools for increasing awareness - the growing need for flexibility when working with the emergent crop of volunteers.



And changes specific to our organization are also evident. Our constitution is being replaced by a simple handbook of guidelines, and we are experimenting with more realistic modes of governance.

In addition, in recognition of the profound impact that a prostate cancer diagnosis could have on partners and caregivers, we are rebuilding our Side by Side program and exploring ways of integrating partners and caregivers into appropriate PCCN-Toronto programs and activities.

There are some immediate internal challenges: increasing the opportunities for seamless interaction between the board and volunteers; consolidating our very unique hospital volunteer program; working towards development of a 'PCCN-Toronto tailored' blend of 'bricks and mortar' and 'social media driven' support.

PCCN-Toronto has evolved in distinct stages, each associated with specific issues. Our leaders have all been energetic and committed but with

contrasting styles and differing (but fundamental) impacts on the trajectory of PCCN-Toronto; and we have done very well.

I perceived myself as a technician - trying to understand the factors driving the maturation of a relatively large support group with a wide range of programs - and doing what was necessary to consolidate this maturation process.

My tenure as chair has been an interesting ride and I thank PCCN-Toronto for providing me with this special opportunity to serve. I treasure the many friendships acquired along the way and, in particular, thank Ron Benson and Bernie Shoub for those informal lunches and their support and encouragement through the ups and downs.

PCCN-Toronto is serving a diverse, world class sophisticated city that appears to lean to the more liberal social ideals; and this reality may need eventually to be factored in the way we operate.

My best wishes to our new team of leaders - Phil Segal, Bernie Shoub and John Roth.

The promise of freshness in vision is heartening and I feel confident that we will be in good hands.

Winston Klass

Chairman - PCCN-Toronto



PCCN-Toronto is supported by:

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ASK THE DOCTOR



Dr. Sharon Sharir: Questions you should ask your doctor.

It is important to make good use of the time you have with your doctor during appointments. It's a good idea to come prepared with questions to ask, and a way to record the answers. It's also a good idea to

bring someone with you who can listen, ask questions, and remember or record information to help you out.

There are some questions that are relevant to everyone, regardless of where you may be in your cancer journey, and others that are specific to particular situations. In terms of general questions that are always relevant, the following are important to ask:

Everyone should ask, if it is not clear, **whether there have been any changes in your situation** compared to when they were last seen. In some people the cancer status is stable, and may remain so for long periods of time or, perhaps, indefinitely. In others, there may be changes that have occurred over time, sometimes even rapidly. It is important to understand whether this is the case because, if so, that should prompt follow-up questions, for example, about prognosis, a change of treatment plan, or the need for new investigations.

Ensure that you have a **clear understanding of the current goal of your cancer plan**. Are you being or have you been treated to try and cure the cancer? Alternatively, is the plan to control the cancer without actually curing it? Is your doctor working on controlling side effects of treatment or medications? Is your doctor trying to control side effects from the cancer itself? Are you working together to extend your life? Or is the plan to preserve your quality of life rather than focusing on the length of time? Be sure you understand the plan, and that you agree with it.

If you are having a problem of some sort,

ask about it. Do not assume that the doctor will ask you about the concern you may have. Mention the problem that you are having, and ask what could be done to help the situation. Problems can range from a symptom to having difficulty getting through on the clinic telephone number. All of these can impact your health. So be assertive and ask about it.

At the end of each appointment, everyone should **understand what the plan is and when the next follow-up appointment should be.** Occasionally, people "fall through the cracks" because they are not clear on what the next steps are and when they should expect to hear back regarding a result, a date for an investigative test, or the next appointment.

There are also many questions that are specific to particular points on the prostate cancer journey, or specific to individual cases. These may be related to diagnosing or doing investigative tests; choosing from treatment options; managing side effects of treatment; deciding whether to enter clinical trials; making end-of-life decisions; deciding how to manage cancer symptoms, and so on.

These more specific questions are too numerous to list, but you can access ideas regarding questions to ask on the World Wide Web. There are many organizations that have developed lists of relevant questions to consider. For example, the Canadian Cancer Society has developed a list of questions that can be used in various situations:

<http://www.cancer.ca/en/cancer-information/cancer-journey/your-healthcare-team/questions-to-ask/?region=on>

The American Cancer Society has lists of suggested questions that are specific to prostate cancer:

<http://www.cancer.org/acs/groups/cid/documents/webcontent/003289-pdf.pdf>

Remember that you are at the centre of your health care team. Be an active participant, and ask questions to ensure that you understand your health situation.

2016 Cruisin' For A Cure Canada

Congratulations to all our friends at **PCCN-Brampton** on their 10th anniversary of hosting **Cruisin' For A Cure Canada**.

Not only do you have the opportunity to see classic cars from our past, but men can also take advantage of getting a **FREE** PSA blood test there: **287 men did this year!**



All net proceeds from the day went to **Prostate Cancer Canada**. Tenth anniversary logo was designed by *Fernando Pacheco*, who has done one every year since 2007.



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"Board News"

by *Winston Klass, Chairman*

PCCN-Vancouver has leveraged its proximity to UBC (a centre for research on support groups) to stage an ambitious three-day conference on support groups. A PCCN-Toronto representative was sent to this conference and we hope to get some useful feedback (which will be shared with you).

The procedure for adding members to the PCCN-Toronto board has changed somewhat. Recommendations from volunteers and board members are accumulated over time; and whenever appropriate, prospects are assessed and leading candidates approached for board membership. Over the past year one member of the board (Stan Mednick) has resigned, and two volunteers have accepted the invitation to join us - Ari Katz and Jerry Garshon. Our board now consists of ten members and we are actively seeking one more board member.

We are in the process of rebuilding our Side by Side program and (to this end) a batch of redesigned Side by Side brochures are now in circulation. If your partner/caregiver is interested in sharing and offering advice, please provide us (by email or through the info line) with contact information. A board member or Side by Side volunteer will then make contact.

At the end of October a new team will be leading PCCN-Toronto. This will be the start of an interim 'experimental' period with relatively fluid governance. **Phil Segal** will be the new Chair (a two-year term); **Bernie Shoub** and **John Roth** will be Vice-Chairs.

We regret the cancellation of the 2016 Information Meeting. We may arrange a smaller 'strategic planning' meeting (hopefully in the near future) with the opportunity for interested volunteers to participate.

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>
Nov 30	G	Dr. Andrew Matthew <i>Princess Margaret Cancer Centre</i>	<i>Sexual health and prostate cancer: The "SHAReCLINIC" - an online sexual health clinic.</i>



AWARENESS NIGHTS 2017

Jan 25	G	Dr. Raj Satkunasivam <i>Sunnybrook Odette Centre</i>	<i>Minimally invasive surgery & robotics</i>
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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).

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We still need a sponsor for our newsletter.

Can you and/or your company help us?

Email Aaron at: aaronbacher@rogers.com Thanks.