Awareness

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

Dr. Rajiv K. Singal: Twenty years of caring for men with prostate cancer.

t could have been anyone's trip down memory lane, but this was Dr. Singal's trip, and he showed us how treating men with prostate cancer (PCa) has changed over the years.



And he was doing it under some duress, as he was still trying to get his voice back after losing it for several days!

Instead of speaking from the podium on our stage, he chose to talk more casually from the floor which made his talk a bit more intimate with the audience.

He outlined some of the topics he would cover, such as: the Natural History of Prostate Cancer, plus some personal observations covering Trends in Treatment, the PCa Journey, Life changes for men and their spouses /partners, and the Role of Advocacy.

He talked about "how common prostate cancer" is and how it is found in so many men.

He acknowledged that, "We haven't won the battle with PCa yet, but we're doing much better than before."

He went over the diagnosis itself,

using clinical awareness, the PSA (prostate specific antigen) blood test, the DRE (digital rectal examination, and the biopsy.

The current treatment options were discussed briefly: AS (active surveillance), RP (surgery or radical prostatectomy), several types of radiation (External Beam Radiation Therapy, Brachytherapy), Hormone Therapy, and Chemotherapy. He added that "we can kick the can further down the road now" as we have other treatments available to us now.

Dr. Singal said that, generally speaking, patients are much better informed about their disease today because they educate themselves, and he often learns things from them. He cautioned though that, with so many options, nothing is "perfect" and "there is no totally right answer" for everyone. Decisions vary by life experiences, as well as personal and family motivation.

He touched on so many things, at one point saying, "you have to understand what's right for you and what's right for your spouse/partner."

You can watch Dr. Singal's entire presentation on our website - **pccntoronto.ca/videos** - it is listed in the right column.

Our sincere thanks go out to **Dr. Rajiv Singal** for another inspiring talk about prostate cancer.

2016



JULY

PCCN-Toronto Prostate Cancer Support Group

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"Raising prostate cancer awareness" - pccntoronto.ca

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Justin Lorentz: Who is genetically predisposed?

ur immediate past chairman, Ron Benson, first introduced Dr. Danny Vesprini, who would later participate in the Q&A portion of our evening. Then Dr. Vesprini introduced us to his friend and colleague, and our guest speaker Justin Lorentz, a genetic counsellor at the Sunnybrook Odette Cancer Centre.



Dr. Danny Vesprini and guest speaker Justin Lorentz

His talk centered on who is at increased risk of developing prostate cancer (PCa).

He listed and discussed in detail three groups: 1) men of West African or Caribbean ancestry; 2) men with a family history of prostate cancer; and 3) men who have inherited a prostate cancer-associated gene mutation.

Other slides that he presented were entitled: Cancer 101; Genetics 101, where he explained that "all cancer is genetic" and also talked about Hereditary Gene Mutations; and Cancer Genetics 101, where he talked about the differences between sporadic cancer, familial cancer and hereditary cancer.

Also included in his talk was genetic testing, genetic testing criteria and screening for BRCA1, BRCA2, and Lynch Syndrome.

As you can obviously tell, this was not your average discussion about PCa. This was a highly detailed and complex talk about the scientific aspect of PCa.

That's why we record these presentations; because they can't easily be written about in one column. Thank you doctors for another terrific evening.

Watch the presentation at **pccntoronto.ca/videos**

JIM MORAN 1942-2016

e always had that "ruddy" look about him. His smile rarely left his face. He was a long-time prostate cancer survivor, a "mainstay" of our support group,

and a former member of our board.

He loved volunteering for Man to Man and/or PCCN-Toronto at The Princess Margaret



Cancer Centre, and the medical staff there loved him back.

But, suddenly on April 10th, we all lost him, as he passed away courageously surrounded by his family. He hadn't been 100% for a while, but no one really knew his situation because his main goal was always to take care of Lise - his wife of 47 years—who will forever miss him. He will also be lovingly remembered by his daughter Julie (Gabor) and son Derrick (Susan).

Of course, he will also be greatly missed by countless members of our support group, many of whom knew him for several years. He always had some funny lines to add to our PSG meetings and, for years, was the host at our awareness meetings.

Rest in peace old friend. Adieu.

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PCCN-Toronto & Side by Side

invite you to attend our

Awareness Night Meeting

at the

Toronto Botanical Garden In The Garden Hall

777 Lawrence Ave. East at Leslie Street

on

Wednesday July 27, 2016 at 7:30 p.m.

our guest speaker

Dr. Masoom Haider

MD, FRCPC

Sunnybrook Health Sciences Centre

topic:

MRI of the prostate: A revolution in diagnosis and treatment.

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
- √ 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

Il of our 2016 Awareness Night meetings at The Toronto
Botanical Garden and our PCCNToronto 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

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Another glorious, sunny day at this year's Father's Day Walk Run

t was sunny, it was hot, and it all got started very early on Father's Day morning on Sunday June 19, 2016.

It was once again time for our "Do it for Dads" Walk Run, organized by Prostate Cancer Canada and Allison O'Mara and her fabulous committee.

Allison once again had arranged for a booth to be available for our support group, and several members of our "team" used that booth as our central meeting place when they arrived at Ashbridges Bay Park that morning. It was also used often just to get out of the sun and sit in some shade, which felt quite a bit

cooler! Thanks very much Allison.

Rocco Rossi, President and CEO of Prostate Cancer Canada, came by to say hello, wish us all good luck on our Walk, and thank us for the money that PCCN-Toronto had raised again this year for prostate cancer research.

Many of our team members had their

children and, in several cases, their grandchildren with them at the Walk. There were many things available for the younger children, such as facepainting, "tattoos", and several types of games.

What made this year's Walk Run extra special for

our team was the fact that we were dedicating it to a longtime volunteer/survivor of Man to Man/PCCN-Toronto who passed away just a few months ago—**JIM MORAN**.

(Please refer to page 2)

We were especially pleased to have Jim's son and daughter with us - **Derrick Moran** (Susan) and **Julie Moran-Illes** (Gabor) - as well as Julie's daughter Rachelle Potter.

Also, *everyone* on our team wore special blue ribbons which read **WALK FOR JIM** to commemorate this very special day!



"The Walk"

Then it was 10:30 a.m., and time for the Walk Run to actually begin - and off they went!

It was announced later that the first "runners" were back in just under 18 minutes! Of course, the "walkers" took a little longer to finish.

Then the lineups started for lunch: veggie burgers and pizza!

As noon approached, many people started to leave the park, heading off to other "Father's Day" family celebrations.

To all members of our

PCCN-Toronto team: thank you for the dollars that you raised and for joining us again at this year's Walk Run!

Aaron & Stan

"I tried to catch some fog, but I mist!"

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

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GREAT MEMORIES FROM OUR "DO IT FOR DADS" SPECIAL "WALK FOR JIM" FATHER'S DAY WALK RUN



PCCN-Toronto is supported by:

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

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ASK THE DOCTOR

This time the column would be more accurately titled "Ask the Doctor<u>S</u>" because what follows is a collaborative effort on the part of Drs. Danny Vesprini, Sharon Sharir, and Rob Hamilton, in response to two submissions by a member of our Man to Man PCCN-Toronto Tuesday evening prostate cancer support group.

For men on Active Surveillance routine biopsies are a must. Could the newest MRI imaging substitute for a biopsy on an intermittent basis?

Currently, biopsies continue to be part of all Active Surveillance protocols. There is much research ongoing to determine whether use of prostate MRIs can help decrease the need for repeated biopsy. However, there is not enough evidence to date to be able to safely rely on MRI alone. Even with the advances in this imaging modality, there are still 'false negative' scans - meaning that even when the MRI looks 'normal' there can be high grade cancer present. Until this false negative rate is near zero, routine and repeated biopsies will be required.

I am on Hormones and I don't seem to have much energy.

Unfortunately, some of the most common side effects of androgen deprivation therapy ("Hormones") are generalized fatigue (just feeling tired) and muscle fatigue (not being able to exert yourself for as long as previously without taking a break). These side effects are predominantly because 'hormone therapy' is actually 'anti-hormone therapy', as the medications result in your body not making male hormones like testosterone. Because hormones such as testosterone are involved in many processes in the body, the fatigue that is

felt is due to multiple changes that occur, including atrophy (muscle loss), anemia (low red blood cells), loss of libido (decreased interest in sex/intimacy), and weight gain.

Multiple studies have shown that remaining active and following a 'healthy heart diet' can decrease the fatigue that hormonal therapy causes.

"Board News"

by Winston Klass, Chairman

lease join me in welcoming **Ari Katz** to the PCCN-Toronto board. Ari's passion for our cause and his many connections within the business community will be a definite asset.

A document is being prepared describing requirements for volunteering at each of our three hospital partners; this information will be distributed to all volunteers.

Volunteers who work weekdays can now "shadow" existing volunteers at Toronto General Hospital on Saturday mornings, thereby providing some exposure to the hospital volunteer experience. To qualify, you will need to satisfy the requirements in place for hospital volunteers. Ari Katz, Keith Braganza and Tom Flannery have already expressed interest.

An information meeting is scheduled for **Tuesday September 27th**. The agenda will include feedback from the September conference in Vancouver on prostate cancer support programs.

A special "thank you" on behalf of the PCCN-Toronto board to all who contributed to our **Father's Day "Do It For Dads" Walk Run**.

PCCN-Toronto offers a unique mix of programs which require ongoing financial support.

"Don't worry about 'old age': it doesn't last!"

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Meet a new member of our board: Jerry Garshon

e became a regular with our support group when we were still called Man to Man. He attends our Peer Support and Awareness Night meetings (along with his wife Linda) on a consistent basis.



He often facilitates our PSG meetings or acts as the "spotter", a role he created to make sure that men can get their questions asked of the newly-diagnosed men in attendance.

He's been counselling newlydiagnosed men at the Odette Cancer

Centre and he has been visiting patients who have had radical prostatectomies at Sunnybrook and Toronto General Hospital (on Saturday mornings).

And now, most recently, he accepted an invitation to join our Board of Directors to help us continue moving in a positive direction.

Jerry is a seventeen-year prostate cancer survivor, who chose to have surgery in March 1999 at Sunnybrook Hospital. He is a retired engineer who has been married to Linda for 54 years, and looks forward to celebrating their 55th anniversary on December 29, 2016.

Please welcome Jerry to our board; we know that he will be a significant addition to what already is a great group of men!

PCCN-Toronto participates in Health Fair at Celestica

n Tuesday April 12, 2016, **PCCN-Toronto** took part in a truly effective Health Fair, organized by **Sandra Narducci**, Canadian HR Benefits Manager at **Celestica**.

She invited PCCN-Toronto to attend (we were the first men's health organization to be invited to participate in their annual health fair), and it allowed us to speak to approximately 300 or more of their employees who attended the fair and hand out our brochures and other informational pieces from **PCC**.

We plan to follow up this terrific event by giving a Lunch and Learn presentation at Celestica in the future.

PCCN-Toronto takes part in Odette meeting for newly-diagnosed men.

The Odette Cancer Centre hosted an evening for newly-diagnosed men on Thursday April 14, 2016, entitled "Sexual Functioning and Quality of Life Issues".

Seventy patients and their caregivers attended and enjoyed listening to the evening's five speakers: **Aaron Bacher**, past chair of PCCN-Toronto, who talked about our support group and told about his own personal journey; **Kathy Carothers**, an Advanced Practice Nurse, who spoke about Symptom Management - Fatigue; **Dr. Danny Vesprini** and **Angela Turner**, a radiation therapist who spoke about Sexual Health & Radiation Treatment; and **Dr. Andrew Loblaw**, who discussed the Future of Treatment.

Thanks to **Jason Oliver** and **Shannon Gesualdo** of the Odette for organizing this very successful evening, and for inviting our support group to participate.

PCCN-Toronto takes part in Health Fair at Rogers

n Wednesday May 4, 2016 **Aaron Bacher** and **Ari Katz** represented **PCCN-Toronto** at the **Rogers' Health Fair**, held at their head office at One Mount Pleasant Road.

Once again, we provided literature that contained information on prostate cancer, such as: our own PCCN-Toronto brochures and copies of the past two editions of our newsletter "Awareness"; Prostate Cancer Canada's popular A, B, C brochures entitled: A - Answering your questions on prostate cancer, B - Basics on treatment for prostate cancer, and C - Care and Support Post-treatment for prostate cancer, as well as their postcard-size information pieces, such as PSA: Know Your Number, and 1 in 8 men will be diagnosed with the disease.

Many men approached our table and were encouraged to speak to their family doctors about having a PSA blood test if they had never had one previously. The Rogers' medical plan covers the cost of the PSA blood test, so the men were told that there was absolutely no reason for them **not** to be screened!

We were very well received at this health fair and we should look for other similar opportunities.

Are you interested in becoming a PCCN Toronto volunteer?

Please call our support line - 416-932-8820

or email us at info@pccntoronto.ca

"Awareness" newsletter - written and edited by Aaron Bacher unless otherwise noted.

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Our on-going projects for 2016

AWARENESS NIGHT MEETINGS

hese meetings are held at the **Toronto Botanical Garden (in the <u>F</u>loral or <u>G</u>arden 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)

DATE		<u>RM</u>	<u>SPEAKER</u>	<u>TOPIC</u>	
Jul	27	$oldsymbol{G}$	Dr. Masoom Haider Sunnybrook Health Sciences Centre	MRI of the prostate: A revolution in diagnosis and treatment	
Sep	21	F	Mark Cullen & Dr. Ryan Groll Michael Garron Hospital	Gardening expert and prostate cancer survivor. & Mark Cullen's surgeon.	
Nov	30	$oldsymbol{F}$	Dr. Andrew Matthew Princess Margaret Cancer Centre	Family emotions.	

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).

We need a sponsor for our newsletters.

Can you and/or your company help us?

Email Aaron at: aaronbacher@rogers.com Thanks.

PCCN - Toronto Board of Directors

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