

AWARENESS

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

DO IT FOR DADS WALK RUN FATHER'S DAY - SUNDAY JUNE 16, 2019

by Aaron Bacher

It was Father's Day, and the weather forecast was one that we'd heard several times before: it could rain or it could be sunny!

Now, isn't that a helpful forecast?

Well, for most of the morning, as everyone gathered at Ashbridges Bay Park preparing for the actual Walk Run part of the event, we were blessed with lots of sunshine, although the temperature was a little cool! Then, as the Walk began, the sun disappeared and it became very cloudy with a bit of wind.

But it did not rain!

PCCN-Toronto was well-represented at the event and raised \$24,598.00. **Stan Mednick**, our co-captain, collected \$4,924.00 on his own and was the leading fundraiser on our team.

Of the top 10 fundraisers across Canada, six were members of our support group team!

Of course, **Robyn Feldberg**, head of the Phil's Pals team (honouring her late father **Phil Feldberg**) is in a league of her own! She alone raised \$39,784.00 for her team! Congrats!

Tim Horton's supplied boxes of doughnuts for all the participants, while Pizzaville provided lunch for everyone after they completed their Walk. Needless to say, lunch was a big hit with everyone. People started to leave the park around noon, as they all had Father's Day plans to attend to.

But, earlier in the morning, President and CEO of Prostate Cancer Canada **Peter Coleridge** warmly welcomed everyone to this year's 2019 Walk Run. He gave a brief description about what is done with the funds that are raised, and how prostate cancer research is the major beneficiary!

Then he started talking about various awards that he was about to present to individuals for different reasons.

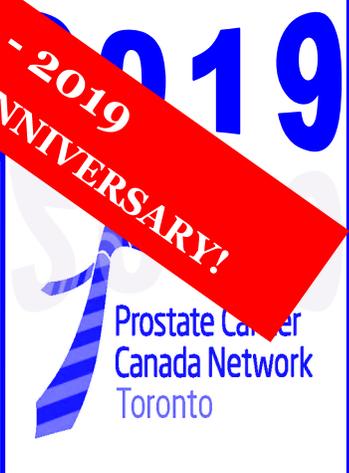
The first award was the 2019 Local Hero Award, and he began talking about the individual, while my wife Ronnie and I were, to be honest, just casually listening. That is, until he announced this year's recipient - **Aaron Bacher** of the PCCN-Toronto team! Ronnie and I immediately looked at each other, uttering the same word, "**What?**"

He then asked me to come to the stage to receive my award, which also included a **MIDO** watch! I made a few comments, thanking PCC and "selling" the importance of being screened early, an early diagnosis, and going to a support group meeting when diagnosed!

Other award winners were Robyn Feldberg, for once again leading the highest fundraising team; and, our own **Denis Farbstein**, who won 50,000 Aeroplan points!

It was another very successful day, a lot of money was raised for prostate cancer research, *and it did not rain!*

JOIN OUR TEAM NEXT YEAR!



JUNE

PCCN-Toronto Prostate Cancer Support Group

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"Raising prostate cancer awareness" - pccntoronto.ca

Our March and May Awareness Night Meetings prove to be very successful evenings.

The people who came to our March Awareness Night Meeting in the Garden Hall at Edwards Gardens were eager to hear



Justin Lorentz and Ari Katz

Justin Lorentz tell them how genetics plays a role in prostate cancer diagnoses. He discussed what is happening in genetics today and where it's going in the future. It was a very technical talk with many slides to make it more understandable.

His presentation was very well received!

Claudia Aronowitz was pleasantly surprised to see all the people arriving early at our May Awareness Meeting to hear her talk about "Living a life that matters".



As a cancer survivor herself, she was able to speak from experience and talked about how important it was to be as positive as you can be, even when diagnosed with a serious medical condition. It was a terrific motivational talk, and, as she said, "Change starts from within!"

Both of these complete presentations can be seen on our website. Simply go to www.pccntoronto.ca/videos



Karen Frantzke from Astellas Pharma Canada, one of the Pharmas currently supporting our group financially, attended our March Awareness Night Meeting and met several members of our board.

Pictured at left are:

Chairman Phil Segal, Karen Frantzke, Ari Katz, and Aaron Bacher, past chairman.

Our 2019 newsletters sponsor!



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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 31, 2019
at 7:30 p.m.

featuring

Dr. Chirag Patel
Sunnybrook Health Science Centre

topic:

**"PET scans, MRIs, CT and
Bone Scans, and Imaging in
general."**

*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.

**2019 Meetings Benefit
North York Harvest Food Bank**

Please bring some non-perishable food with you to our Awareness Night Meetings, which PCCN-Toronto donates 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 fiber | √ Rice - white & brown |
| √ Peanut/almond butter | √ Baby formula & diapers |
| √ Cookies (arrowroot, digestive, oatmeal) | √ Baby food & cereals |
| | √ Fruit juice - 100% |



www.northyorkharvestfoodbank.com

All our *PCCN-Toronto Man to Man Peer Support Group* meetings at Valleyview Residence are being supported by a grant from Janssen Pharmaceuticals.

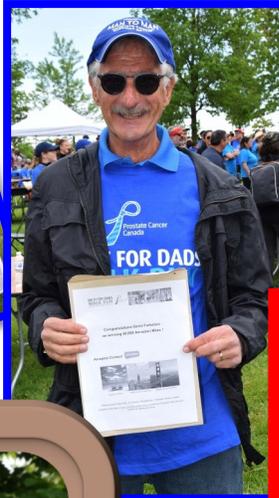
We thank Stacey Silverberg and all the people at Janssen.

Our Awareness Night meetings at Edwards Gardens are sponsored by Astellas Pharma Canada, and we thank Karen Frantzke and everyone at Astellas.



The Board of PCCN-Toronto.

CELEBRATING OUR DO IT FOR DADS WALK RUN



FATHER'S
DAY

JUNE
16
2019



PCCN - TORONTO TEAM - 2019



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.

... AT ASHBRIDGES BAY PARK ON FATHER'S DAY!



2019 Local Hero Award winner Aaron Bacher and CEO & President of PCC Peter Coleridge.



The first rule of cleaning while listening to music: "The toilet brush is never to be used as the microphone - NEVER!"

ASK THE HEALTH CARE TEAM

Ron Benson asked Drs. Sharon Sharir (urologist/surgeon) and Danny Vesprini (radiation oncologist) to respond to questions raised at our Prostate Cancer Canada Network-Toronto (PCCN-Toronto) support group meetings by men who have been recently diagnosed with prostate cancer and are seeking information about surgery and radiation before making a treatment decision.

Here's what they had to say in response:

Q: I've been diagnosed with prostate cancer.

How do I decide what treatment I should have?

Dr. Sharir: Most importantly, you need to understand your particular situation, because options differ depending upon how aggressive or non-aggressive the cancer is, whether the cancer has spread or not, your medical situation, etc. Ask your doctor about these factors and what management options are relevant to your particular case. Then do your homework. Read a pamphlet or book (your doctor will often have some), talk to men who have been in a similar situation (the PCCN – Toronto support group can help with that), and check out reputable sites on the internet.

Q: How do I learn about the pros and cons of each of my options?

Dr. Vesprini: Research, research, research. Use multiple sources but be careful. The internet is a wonderful but also a 'dangerous' place, as it is unregulated so anyone with an agenda or bias can post misinformation – and there is a lot of it when it comes to complicated and quite frankly scary things such as cancer. Get your online information from trusted websites and groups, such as Cancer Care Ontario, the hospital you will be treated at, and of course excellent organizations like the Prostate Cancer Canada Network – Toronto website (pccntoronto.ca). Watch many of the presentations that you can find online about the different treatment options. And of course, ask your doctor. For prostate cancer, it is important to see both a urologist and an oncologist. If you need a second opinion, ask for one. Ultimately the decision as to what treatment you should have is up to you – so make sure you are well informed to make the right and best decision for you.

Q: If I choose a radical prostatectomy, what is the medical follow-up? How am I monitored and for how long?

Dr. Sharir: If you have had surgery, the initial follow-up is related to surgical factors such as making sure the surgical wound is healing well, removing the catheter, etc. At around 6-8 weeks after surgery, the surgeon will do a PSA test to check whether the PSA has dropped to undetectable levels, as would usually be expected. In the medium term, your urologist will be asking you about potential side effects of surgery such as ED or incontinence, and advising possible measures to address these. If things are going well, PSA is usually done every

3 months to start, and then the interval of testing is gradually increased, until eventually you have just yearly PSAs and appointments.

Q: If I choose radiation what is the medical follow-up and for how long?

Dr. Vesprini: If you choose radiation (either with brachytherapy or external beam) follow-up varies somewhat from centre to centre, but in general you are likely to have an appointment with the radiation oncologist within a few months of finishing the initial treatment, every 6 months for the first 2-3 years, and then yearly until 5 years. You will have a PSA prior to each visit, and you may or may not have a physical exam at each visit, depending on how you are doing and what your PSA level is. At 5 years, if your PSA is under control, you may be discharged to have your annual exam and blood test with your family doctor, but your radiation oncologist may choose to continue to follow you beyond 5 years depending on individual factors such as if you experience more side effects than expected or if there are any other concerns that warrant continued visits with a cancer expert.

Q: If things don't work out as hoped for, is there a follow-up treatment after a radical prostatectomy?

Dr. Sharir: If surgery does not appear to have "cured" the cancer (the most common scenario would be a continuously rising PSA following surgery), then there are other treatments possible. If it appears that the cancer cells are most likely in the area where the prostate was, then a patient may be sent for "salvage radiation" to try to kill off any remaining cells that remain in the pelvis. However, if it appears that the cancer cells have spread more distantly, then medication (hormonal medication or chemotherapy) would usually be used to control these cells.

Q: How about after radiation?

Dr. Vesprini: For men who have radiation and then experience biochemical failure - i.e. the PSA goes up over 2 - there are several options depending on the clinical scenario. If there is evidence that the cancer has spread to the bones or other organs, then the treatment is 'systemic', meaning it is usually a medication that works everywhere in the body such as androgen deprivation therapy (also known as 'hormonal therapy', or chemotherapy). If there is no evidence that the cancer has spread, and it is thought that the disease is still just localized to the prostate, the options are 1) surgery, 2) radioactive seed therapy – or brachytherapy (this is currently offered as part of a clinical trial) or 3) do nothing and observe, as for many of these men the cancer never leaves the prostate although eventually most of these men will need hormonal therapy.

continued on page 7

Health Care Team

Q. If my primary treatment is surgery then, if necessary, I've heard that I can have radiation as a secondary treatment. Is that true?

Dr. Sharir: That is true; however, when men are choosing their primary therapy, I discourage them from thinking that if they choose surgery they get "two shots" at the cancer (i.e. radiation if the surgery is not curative) rather than generally "one shot" if they choose radiation (as surgery is not usually done after radiation). In most men the success rate for surgery vs. radiation as an initial therapy is likely similar, and so the likelihood that a treatment fails is similar for both. What happens if a treatment fails may differ between the two, but the choice of one treatment vs. the other should be made on its own merits, rather than on what might happen if a treatment doesn't work.

Q: I've heard that if I have radiation as my primary treatment, I can't have a radical prostatectomy as a secondary treatment. Is that true and, is there a secondary treatment if I should need one?

Dr. Vesprini: Although having the prostate removed after radiation ("salvage prostatectomy") can be done, the side effect profile, mainly high risk of being incontinent of urine, is significant enough that most men will decide not to undergo the procedure, and the procedure is usually reserved for young, fit men who want to be ultra-aggressive.

Dr. Sharir: The radiation that is done after surgery (when there is no prostate there) is not the same as radiation that is being done with the prostate in place. You should speak to your specialist about this, so you understand the difference.

Q: Should that be a major consideration when I make my treatment decision?

Dr. Vesprini: If offered the choice between surgery and radiation, your decision should be focused on the side effects of therapy - both physical and psychological and which better suits you in your situation.

Q: I'm concerned about changes in my lifestyle and worried about my emotional well-being both through the treatment process and afterward. How and where can I get support and direction for those components of my journey?

Dr. Vesprini: There are many ways to get support. Professionally, there are experts whose main focus is on cancer-related issues. For example, at cancer centres there are cancer-specific psychologists, psychiatrists, and

Continued

social workers. Cancer is a complicated disease that affects many aspects of a patient's life. Specialized support programs can be an advantage of being seen at a cancer centre, compared to being managed in the community. It's not about the doctors...it's about the support team. Patients who are struggling should also seek help from their family doctor, given that most patients have a long history and strong relationship with their primary doctor. This history and relationship can be of enormous help and support. Most men get support from their family and those who are religious seek spiritual help from their clergy and religious community.

Last but not least, groups like PCCN - Toronto provide incredibly valuable peer support from men and families who have been through the journey and who understand the challenges and issues that can arise.

As they say - 'It takes a community....'

Dr. Sharon Sharir is a urologist/surgeon in the Department of Surgery at Humber River Hospital.

Dr. Danny Vesprini is a radiation oncologist at Sunnybrook Health Sciences Centre.

They are good friends of PCCN-Toronto and both have also been guest speakers at our Awareness Night Meetings at the Toronto Botanical Gardens.

Sometimes, I shock myself with the smart stuff I say and do.

Other times, I try to get out of the car with my seat belt still on!

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 2019

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 27	G	Justin Lorentz, MSc <i>Sunnybrook Health Science Centre</i>	Cancer genetics and its impact on prostate cancer and potential treatments.
May 29	G	Claudia Aronowitz MPH, CPCC, ACC	"Change starts from within: Live a life that matters!"
Jul 31	G	Dr. Chirag Patel <i>Sunnybrook Health Science Centre</i>	PET scans, MRIs, CT and Bone Scans and imaging in general.
Sep 25	F	Dr. Neil Fleshner <i>Princess Margaret Cancer Centre</i>	Prostate cancer and the genes you were born with.
Nov 26	G	Dr. Danny Vesprini <i>Sunnybrook Health Science Centre</i>	Active Surveillance: the decision of when to treat.

*** Please note this meeting will take place on TUESDAY November 26th.**

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 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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My ability to remember song lyrics from the 50's far exceeds my ability to remember why I just walked into the kitchen!