



Awareness



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

2017

Prostate Cancer
Canada Network
Toronto

DECEMBER

**PCCN-Toronto
Prostate Cancer
Support Group**

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Leah Jamnicky leads terrific discussion on caregivers, partners, and sexual health.

Leah Jamnicky was already at the Princess Margaret Hospital in 1994, when the Toronto Man to Man Prostate Cancer Support Group was founded!

So, she knew the original Man to Man group of men who were the first support group volunteers in her hospital. And she is still connected to PCCN-Toronto today.



She spoke at our final Awareness Night meeting of

2017, talking about the role that partners and caregivers play for men diagnosed with prostate cancer.

She also talked at length about sexuality and the sexual health of these men, especially following a radical prostatectomy.

Leah admitted that you can sometimes be caught up in the moment of talking about sexual function, to the point of sometimes not knowing everyone in your audience! Such was the case once, when she talked for 40 minutes and then asked if anyone had a question, and a man raised his hand and said, "Thank you, but I'm a priest!"



When some nurses tell her that they can't discuss something as personal as "erections" with their patients, she asks them, "Why is it easier for you to ask them how many bowel movements they had! Isn't that just as personal? We need to talk to them about both!"

When men are facing surgery, 10% are worried about recurrence, while 40% are worried about sexual function.

Leah told us that sexual health has to do with what couples were doing **before** the surgery!



One spouse told her husband, "I'd rather have you alive with me than have sex for the rest of my life!"

Leah said, "I want to pull my hair out, every time I hear someone refer to erectile dysfunction as *impotence*." That's because many men can achieve erections and orgasm, after having a radical prostatectomy, even if some need *help* with medications, etc.

Leah has the ability to explain, in very simple terms, how things work. An example was when she was talking about getting blood to the penis in order for an erection to take place, and that, sometimes, "a jack-knifed truck is blocking the highway, and no 'cars' are getting through!" Then, after some 'help', she added, "One, or two lanes, are opened up!" Like I said, she has the knack (and experience) to get her point across.

Leah mentioned something that most of us who have been through this journey already knew; that this cancer diagnosis can be devastating news for many men. Understanding the emotions attached to it can sometimes be very difficult, because men are usually stoic, or, try to be. But, men have to understand that denial and confusion can cause emotional pain to those they love the most!

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"Raising prostate cancer awareness" - pccntoronto.ca

Come volunteer with us!

You get a special feeling, when you know that you are helping someone else! You can see it in their body language, as they start to get a better understanding about what's really going on with them. They also begin to realize that they truly are **not alone**, as they've thought since the day they were first diagnosed. If you are a long-time survivor, they look at you, and start to believe that this could be them somewhere down the road!

You don't only answer their questions, you give them hope, maybe for the first time, that they're going to get through this "cancer" diagnosis, and get on with their lives again!

One way you can do this, and feel very good about what you're doing, is to volunteer with us, the men at PCCN-Toronto. If you were once helped by someone from our group, you will get that same feeling by helping another man who now finds himself in the same boat!

Speak to one of us at a meeting, or call our support line - 416-932-8820 - and leave a message that you want to volunteer with us.

We can definitely use your help! Join us.



Mike Savatovich Retiring as Administrator at Valleyview

Friday March 9, 2018. That will be **Mike Savatovich's** last day on the job, after *twelve years and three days* as the Administrator at Valleyview Residence, but who's counting?

This is where we have held our twice-monthly peer support meetings for almost ten years! The actual tenth anniversary will occur on Tuesday February 6th, 2018, almost exactly the date of our first meeting there, back on February 5, 2008!

We were referred to Mike in late 2007, when we needed a new location to host our meetings. He was very helpful to our support group from day one, and has been extremely supportive ever since. He's always had a soft spot for us, as his late father unfortunately passed away from prostate cancer at 78 in 2001.

He is very much looking forward to retired life, as is his wife of 42 years Janelle, and his three daughters and two granddaughters.

We're not sure if we had any influence on him, but he has said that we wants to do some volunteering in the Newmarket area where he lives! We strongly urged him to stay away from our meetings, as we don't need him to become another 'survivor'.

Thank you Mike for everything that you have done for PCCN-Toronto, and everyone here wishes you a long and healthy retirement in whatever you choose to do. Merry Christmas to you and your family.

Our 2017 newsletter sponsor!



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PCCN-Toronto & Side by Side

invite you to attend our first 2018

**Janssen Awareness
Night Meeting**

*at the
Toronto Botanical Garden
In The Garden Hall*

777 Lawrence Ave. East at Leslie Street

on Wednesday

January 31, 2018

at 7:30 p.m.

our guest speakers

Dr. Stanley Flax

Dr. Adam Tunis

North York General Hospital

Topic:

**"Perineal biopsies and
the role of imaging."**

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*

**2018 Meetings Benefit
North York Harvest Food Bank**

Please bring some non-perishable food with you to our Janssen 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 cans). 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 2017 Awareness Night meetings at the Toronto Botanical Garden and our PCCN-Toronto Man to Man Peer Support Group meetings at Valleyview Residence have been supported by a grant from Janssen Pharmaceuticals.

We sincerely thank Stacey Silverberg and all the people at Janssen for their very generous financial support.

The Board of PCCN-Toronto.

Branson's Gale and Graham Wright Prostate Centre celebrates its 10th anniversary!

In June 2017, the Gale and Graham Wright Prostate Centre, at the Branson Hospital site of the North York General Hospital, celebrated its 10-year anniversary.

On October 26, 2017, more than 50 people involved in the overall success of the clinic were at the home of Dr. Leslie Spevack and his wife Ann, for cocktails and dinner and to share in the success of this important clinic.

Those in attendance included Tim Rutledge, President and CEO of North York General Hospital, philanthropists Graham and Gale Wright, clinic nurses Bev Persaud and Jana Ailenberg, receptionist Colleen Andersen, urologic oncologists, radiation oncologists, radiologists, OR nurses, technicians, and PCCN-Toronto volunteers.

Dr. Stanley Flax and Dr. Roger Buckley welcomed everyone and gave heartfelt speeches, attributing the clinic's success to teamwork. They mentioned our volunteers and how much we contribute to "their team" effort. It's one thing to be told that privately, but to hear that the services we provide are valued highly by the medical staff, in front of everyone in attendance, is both humbling and very much appreciated. Denis Farbstein represented us there, as Bernie Shoub, Aaron Bacher and Robert Abelson were unable to attend.

Those of us who volunteer at the Branson clinic really enjoy our time there, and look forward to working with their tremendous staff for many years to come.



Leah Jamnicky

. . . . continued from page 1

She even quoted the late Sol Dennis, a long-time member of Man to Man, who would say, "Don't worry about yesterday, it's over! Tomorrow will come, whether you're here or not! So, live for the present - for today!" Remember that your family is your strongest ally, although we often want to shut them out, to protect them. But we really do need their strength!

This was not your normal/everyday prostate cancer presentation. You don't always hear topics/words, like erections, orgasms, penetration, Viagra, Cialis, Levitra, vacuum pumps, etc. But, that's what this evening was all about; discussing things that are very important to men/couples following a radical prostatectomy.

And, as those who were in attendance that night learned, Leah Jamnicky has been dealing with men in these same situations for many years, and her vast experience makes her an expert in this field.

We sincerely thank **Leah** for coming and making this very important presentation, to an audience that she totally owned, after her opening, "Good evening!"

* * * * *



A robust panel discussion, moderated by **Sharon Braganza**, followed our refreshment break. The panelists were: Roberto and Becky Stopnicki, Steve Salkovitch and Joyce Kwart, Keir MacMillan and Keith MacMillan.

* * * * *

Dr. Jackie Bender, PhD, began the evening, talking about the TRueNTH Peer Navigator Training Program at the Princess Margaret Cancer Centre. This program connects prostate cancer patients or caregivers with trained **peer navigators** who have been through the journey first-hand.



For more information or to volunteer, please contact program coordinator **Mihaela Dirlea** at **416-581-7652**.

Please see Leah Jamnicky's entire presentation, on our website **now** - pccntoronto.ca/videos

Thank you.

OUR PANEL

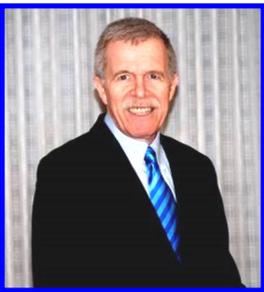
Roberto, Becky, Steve, Joyce, Keir and Keith



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.

CHAIRMAN'S HOLIDAY GREETINGS

As we approach the end of 2017, and find ourselves in the midst of seasonal holiday celebrations, I'd like to take this opportunity to thank all our wonderful volunteers for the work that they do in raising awareness of prostate cancer and providing support to newly-diagnosed men and their families.



December 17th marked the end of my first year as chairman of PCCN-Toronto, and I am continuously amazed at the on-going commitment of our volunteers, who offer their time and energy toward support and awareness, be it in the Peer Support Group meetings, at community events about prostate cancer, such as our awareness nights, and in the hospitals where we volunteer. I know that those receiving our counselling and support are truly appreciative of what we do, as are all of the urologists and prostate cancer specialists who continue to support and offer encouragement for the work we do. I think each of us can take pride in the fact that our volunteers form an important and integral part of our prostate cancer awareness and support.

I am very appreciative of my fellow Board members, and of the help and advice I have received from them throughout the year. It has made the position of chairman infinitely easier. Thanks go out to Valleyview management for allowing us to continue using their facilities for our meetings, and to Janssen Pharmaceutical for their support of our Awareness Night events. Thanks to Joshua Damdar, of Keller Williams Realty, for his support of our quarterly newsletter. I also want to thank Prostate Cancer Canada for their on-going support throughout the year. Finally, thanks to Rocco Rossi, the out-going President and CEO of Prostate Cancer Canada, for all the wonderful work he has done at PCC during his tenure there, and the best of good luck to him in his new position as President and CEO of the Ontario Chamber of Commerce.

To everyone reading our newsletter, a happy and healthy holiday season and best wishes for 2018.

**Happy
Hannukah**

Sincerely,

Phil Segal



**Merry Christmas, Happy Hannukah, Happy Kwanzaa
and a Happy, Healthy and Safe New Year.**

ASK THE DOCTOR

This column has proven to be very popular, and our sincere thanks go out to all our medical contributors.

We are very happy to announce that "ASK THE DOCTOR" will continue in 2018.

Look for our first column early in the new year.

Until then, please watch some of the videos on our website - www.pccnoronto.ca/videos - featuring some terrific speakers making presentations on treatment options and several other topics, all related to prostate cancer. You will definitely increase your overall knowledge about prostate cancer.



Prostate Cancer Canada announces new President & CEO

Rocco Rossi to be succeeded by long-time health executive **Peter Coleridge**.

After five successful years under the leadership and guidance of outgoing President and CEO, Rocco Rossi, Prostate Cancer Canada (PCC) is excited to announce the appointment of a most worthy successor in Peter Coleridge, past national CEO of the Canadian Mental Health Association and current national President and CEO of Big Brothers Big Sisters of Canada. Peter will begin effective February 28, 2018.

"I am honored to be joining the PCC team and advancing a cause that touches us all," Coleridge said. "I am excited to build on Rocco's legacy and work with the PCC team to lead the organization into the future."

"When you've been inspired by so many incredible people along the way, and had the distinct honour of being part of a genuinely smart and dedicated team that has made a measurable difference in the lives of so many, saying goodbye can be an extremely difficult thing to do," explained Rossi.

The Board of Directors of PCCN-Toronto is looking forward to working closely with Peter to continue educating men throughout the GTA about the importance of an early diagnosis and of being screened.



"My parents didn't want to move to Florida, but they turned sixty, and that's the law." - Jerry Seinfeld

My personal plea to family doctors everywhere! By Aaron Bacher

There I was recently, volunteering again in another hospital prostate clinic, speaking to men (and their families) who have recently been diagnosed with prostate cancer. These men were also meeting with urologists and radiation oncologists, trying to decide which treatment they would choose to have.

And there, sitting with me, was a 69-year-old man, next to his wife and daughter, whose Gleason score was 8, with 8 positive cores out of 11 samples taken. But, his story was only starting to pique my interest. That's because, when I asked him how long he had been getting PSA blood tests, he told me that he hadn't - this recent one had been his first!



This was another man who was NOT advised to get a PSA test! As we all head into 2018, we (survivors) are very aware of 1) how important it is to be screened, and, 2) receiving an early diagnosis!

Why are family doctors still not advising their male patients properly? Are they trying to save them the \$25 to \$30 cost of the test? If a doctor doesn't personally believe in the accuracy of the PSA test, that's fine; he or she is entitled to their opinion. But, if I'm their patient, I feel strongly that they should put their bias/opinion aside, and give *me* the best possible medical advice. Knowing that there is a screening tool available for prostate cancer, then I should be told about it, and allowed to make my own decision about whether or not to have the blood test - no one should be making that decision for me!

This 69-year-old man is only one of so many men who I have personally met, with Gleason scores of 8, 9, or 10, with almost the same story. They were either never told about the test by their doctor, or they were actually talked out of getting screened altogether. I'm not naïve enough to believe that some of these men wouldn't, in future, be diagnosed with prostate cancer anyway. But, if they had been screened earlier, there'd be a good chance that their Gleason scores would be lower, theoretically giving them more treatment options to consider.



So, please help me! What can we do to get family physicians do a better job of advising men about the benefits of screening for prostate cancer. Please email me - aaronbacher@rogers.com or call 416-414-4961. Let's try to help these men we don't even know yet!

"WE REMEMBER"

Man to Man / PCCN-Toronto

Dick Arai	2017
Maury Budin	2014
John Dell	2014
Sol Dennis	2010
Ron Evason	
Joe Fraga	
Dwight Griffin	2017
Wally Hamilton	
Patrick Hare	2014
Dick Howe	2016
Anthony Iozzo	2014
Harry Lockwood	2014
Harvey Mandel	2015
Jim Moran	2016
Ron Nicholson	
Rudy Phillip	2008
Doug Phillips	2014
Nat Marvin Placey	2017
Stan Sandler	
Chris Skinner	
Dick Sprenger	
Jerry Stevens	2017
Ray St-Sauveur	2014
Philip Taylor	2009
Ray Turner	2009
Patrick Vernon	
Moe Wagman	2014

Side by Side

Olive St-Sauveur
Roz Wagman

Are you interested in becoming a PCCN-Toronto volunteer?

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

PSG Meeting - December 5, 2017



Celebrating the up-coming holidays!

Our on-going projects for 2018

THE JANSSEN 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 31	G	Dr. Stanley Flax Dr. Adam Tunis <i>North York General Hospital</i>	Perineal biopsies and the importance of imaging.
Mar 28	G	Dr. Andrew Loblaw <i>Sunnybrook Odette Centre</i>	The role of clinical trials.
May 30	G	Carrie Poteck, *M.T.	An evening on exercise, diet and well-being.
Jul 25	G	SURVIVOR FORUM	PCCN-Toronto survivors/volunteers share their personal prostate cancer journeys.
Sep 26	F	TBD	
Nov 28	G	Dr. Sidney Radomski <i>Toronto Western Hospital</i>	Erectile dysfunction, incontinence, and sexual "toys"!



* **Masters of Teaching**

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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