

AWARENESS

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

Please note that Dr. Sidney Radomski's Awareness Night Presentation takes place on Wednesday November 14th.

2018



OCTOBER

PCCN-Toronto Prostate Cancer Support Group

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Dr. Mark Moyad wows 'em again!

Mark Moyad was back at the microphone in Toronto. He was in front of another Awareness Night audience, and he certainly didn't disappoint anyone!

His presentation actually "went into overtime"! Some said that this wasn't entirely "**Breaking News**", as his previous talks have also gone later than scheduled. The "*newsy*" part was that very few people left!

In an email from him two days later, he said, "I answered my last question in the parking lot around 11:30 p.m."

He began by telling everyone how happy he was to be back in Toronto at another of PCCN-Toronto's important "awareness" meetings!

He showed pictures of his dog Chauncey, saying that "If you show pictures of animals or pets before you start a talk, *people like you!*"

Dr. Moyad talked about so many different subjects, it's almost impossible to mention/highlight them all in this newsletter article.

He did want you to know that "I don't work for any of the companies that I'll mention tonight!"

Radiation patients are sometimes given Ginger. **Curcumin** is an active compound in ginger that has terrific anti-inflammatory capabilities. It also turns things yellow; mustard was not yellow until they made it yellow by adding curcumin!

As part of his "probability speech" he discussed the #1 killer for over 100 years in a row - cardiovascular disease. He said that "anything that

is healthy for the heart is healthy *for anything else!*" So a heart-healthy **diet** is also an excellent prostate-healthy diet!

A common theme throughout his talk was not to overdo whatever it is that you are taking. He kept emphasizing that "*too much of a good thing is not a good thing!*"

When discussing **Calcium**, he mentioned that before taking calcium supplements, you should find out how much natural calcium you are getting in your everyday food. Otherwise, you could end up taking much more calcium than your recommended daily amount.

Potassium, he said, will be the hottest ingredient in the next three years! It also contains fiber and magnesium, and lowers the risk of kidney stones, hypertension and strokes! "The most heart-healthy foods contain potassium!"

Dr. Moyad talked about how real the "mind/body effect" truly can be. He gave the example of **Viagra** when it was first introduced in 1998, and a study was done where men got the real thing while others were given a "sugar-pill" or placebo. Between one-third to one-half of those using the placebo reported having positive results with erections!

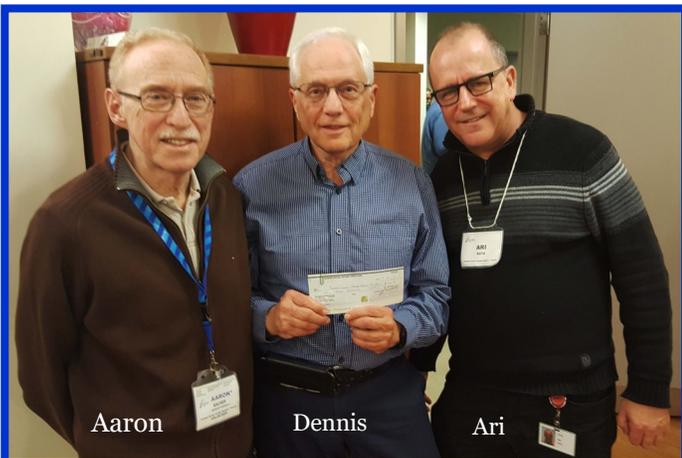
Propecia is used to treat baldness in men with mild to moderate hair loss. A similar study as the Viagra was done, again using placebos, and 20-30% of men claimed to have new hair growth!

... continued on page 7

B'nai B'rith Lodge makes a donation.

Dennis Tolson, a member of the Leonard Mayzel Ontario Lodge #1800, made a donation to PCCN-Toronto recently.

He presented a cheque to Board Director Ari Katz and Past-Chairman Aaron Bacher at the peer



support group meeting at Valleyview Residence on Tuesday October 16, 2018.

Dennis said that he was helped by the discussions and questions that he was asked and those that he asked of others at the meetings that he attended.

We thank him and everyone at his Lodge for thinking of us and supporting our efforts.

Quotes from the past!

"There are more old wine drinkers than old doctors!"

"M.D. shouldn't mean 'Medical Deity', it should mean 'Medical Detective'!"

"Single men are at a lower risk for getting prostate cancer, while married men have better survival rates.

Therefore, men should stay single as long as possible until they get prostate cancer, and then get married very quickly!"

"Cryosurgery is a cool idea!"

Our 2018 newsletters sponsor!



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PCCN-Toronto & Side by Side

invite you to attend our final 2018

**Awareness
Night Meeting**

at the

**Toronto Botanical Garden
In The Garden Hall**

777 Lawrence Ave. East at Leslie Street

on **Wednesday**

November 14, 2018

at 7:30 p.m.

featuring

Dr. Sidney Radomski

Toronto Western Hospital

topic:

**"Erectile Dysfunction and
Incontinence after prostate
cancer 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.

**2018 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 six 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.

Survivor Forum 6 proves to be very successful evening for our appreciative and enthusiastic audience.

On a beautiful summer evening at the Toronto Botanical Garden on Wednesday July 25th, people arrived to hear five prostate cancer survivors talk about their personal journeys.

These men were all from the Prostate Cancer Canada Network - Toronto (PCCN-Toronto) prostate cancer support group.

Our evening began with our host, chairman Phil Segal, welcoming everyone and then introducing each speaker to tell their stories.

Aside from the usual parts of their stories, about being diagnosed with prostate cancer and all the emotions that entails, their own personal "back-stories" added greatly to what we learned about these men.

This year's speakers featured a relatively new "Beek" or beekeeper, who started two years ago keeping bees as a hobby at his house in the country. He (John) found these creatures to be fascinating, industrious, and an excellent and timely distraction from the health issues that he has been going through.

Then we listened to a mineral exploration geological consultant, who for decades worked in the far north of Canada and internationally. He (Bill) told us how he was intimately familiar with black flies, mosquitoes, and deer/moose flies from our pristine northern wilderness, and with the rocks and swamps therein. His work was always about the geology and the rocks, and brought him to such exotic locales as Tanzania, Guatemala, Honduras, Mexico, Ecuador, Venezuela, and Guyana.

A fellow-retiree from Kodak Canada was next, telling us how he (Glen) recently became a part-owner of a craft beer, called "Caribru". He told us how although the initiative is in its early days, things are progressing very well.

We then listened to a man, who is also a member of our Toronto Warriors' Group, and his personal journey with prostate cancer has not only been a

long and difficult one, but very inspiring and encouraging at the same time.

To try and give something back to all the medical people who he has become involved with, he (Darryl) has combined his love of cycling with some major fundraising events which has raised several thousand dollars for medical research.

And finally we met a civil engineer by profession,

whose true passion has always been aviation, as he was a private pilot. He's still flying today, but not for "real" as he has a sophisticated flight simulator at home. He (Roberto) is also an avid aviation photographer, who builds model airplanes, and tries very hard to make sure that his six grandchildren grow up loving airplanes as much as he did as a child.

The personal stories

of these five very interesting men couldn't be more diverse, but the common thread that binds them all together is the fact that they were all diagnosed with prostate cancer.

Here they all share the shock when they were initially diagnosed with this disease, and all the emotions and various steps along the way that followed. Researching which treatment options were available and following up with the different specialists - urologists and radiation oncologists - who helped them reach that important decision.

And then going through the treatment itself and everything that brings with it. That's why we refer to this as a "journey" which can last a long time. These men told us about their journeys so that it can help others, and we thank them very much for doing so.

They also answered several questions from our audience.

To see and hear these five stories in greater detail, please visit our website at:

www.pccntoronto.ca/videos



Speakers: John Van Rhee, Darryl Levenberg, Bill Barclay, Glen Williams, and Roberto Stopnicki.

PCCN-TORONTO ATTENDS PCC WAKE-UP CALL BREAKFAST

The Wake Up Call Breakfast is a unique opportunity to support the 1 in 7 Canadian men who will be diagnosed with prostate cancer in their lifetime. It brings together business leaders in an event tailor-made for them, to raise awareness and funds for the most common cancer affecting Canadian men.

Since its inception in 2001, it has attracted over 50,000 from across the country. Attendees include financial services organizations, community groups, private equity, law, accounting, and consulting firms, in addition to many individuals.

On Thursday October 4, 2018, the Toronto "Breakfast" took place at the Fairmont Royal York Hotel, and board members from PCCN-Toronto **Jerry Garshon** (and his wife **Linda**, who has been active for years with our Side by Side group) and **Keith Braganza** decided to get up very early to be downtown at 7:00 a.m. to register and then enjoy the breakfast and the speakers.



Jerry and Linda Garshon, and Keith Braganza

The Master of Ceremonies was **Alan Carter**, the anchor and Queen's Park Bureau Chief for Global News Toronto.

The Keynote Speaker was **Phillip Crawley**, the Publisher and CEO of the Globe and Mail, Canada's National Newspaper.

The recipient of the John Ferguson Memorial Award was **Roman S. Dubczak**. He is the Managing Director and Head of Global Investment Banking for CIBC Capital Markets.

This was another very successful "Breakfast" and Prostate Cancer Canada raised more funds for prostate cancer research.

Correction from our last newsletter:

In the front-page article with Carrie Poteck, the line, "Mindfulness means paying attention in a **participating** way" should have read "Mindfulness means paying attention in a **particular** way", which is the standardized 'mindfulness' definition used by most researchers and coined by Jon Kabat-Zinn.

We apologize for the error.

PETER COLERIDGE BRINGS GREETINGS FROM PCC

Peter Coleridge, the new President and CEO of Prostate Cancer Canada (PCC), brought greetings to everyone at our September Awareness Night meeting.

"Cancer has affected my family just like it has all of your families, so I am quite honoured to be leading the 'team' at PCC and how we look into the future together.



Two of my early impressions are, a) we've made huge strides in decreasing the mortality rate of PCa by 40% and we want to do more in this area together, and b) how volunteers within the PCa community and support groups such as PCCN-Toronto help raise much-needed funds; e.g. the Do it For Dads Walk Run where Toronto has raised \$215,000 since you first got involved with this great event, the most funds of all the PCCN teams across Canada."

He also talked about how we focus in on raising "awareness" by holding our six Awareness Night Meetings each year featuring specialists talking about prostate cancer.

He mentioned how he wants to develop more of a "family approach", since this disease definitely affects the entire family, and he talked specifically about reaching out to younger men and getting more of them to go get the simple PSA blood test.

He closed by saying that he wants to build on the work that's been done to date by bringing the mortality rate even lower, and hopes to do that by building more partnerships with support groups. *He said that another goal is to have the government pay for all PSA tests.*

He thanked us for inviting him to our meeting and looks forward to many more interactions with our support group and others, "since we are all on the same journey!"

ASK THE HEALTH CARE TEAM

“What’s the deal with PSA after Radical Prostatectomy?”

While there is ample controversy over the utility of PSA as a screening test, there is no debate that PSA is an incredibly sensitive marker of prostate cancer recurrence after surgical removal of the prostate (radical prostatectomy). Thus, PSA monitoring is a cornerstone of follow-up after prostatectomy.

The first PSA should be checked at 6-8 weeks post-operatively. Then at 3 months, 6 months, and every 6 months until 3 years; thereafter it can be checked yearly (NCCN & EAU guidelines). However, your doctor may choose a different schedule depending on the risk of recurrence of your particular cancer.

After a prostatectomy the PSA should be “undetectable” - meaning below the lower limit of detection of the laboratory where the test was done. The problem is, one lab may have a lower limit of “<0.05”, while another may have a lower limit of “<0.008”. As long as that “less than” sign is in front of it, then everything is good. There are times when the PSA will be reported out as detectable but incredibly low (e.g. 0.010). Do not panic if you see this - this doesn’t mean that the cancer has recurred - speak with your doctor but likely, you just need to follow the PSA and make sure it doesn’t climb upwards. Usually prostate cancer recurrence is not declared until the PSA climbs above 0.2 ng/mL.

How long to follow, and with whom to follow (urologist vs. family doctor) an undetectable PSA after surgery is debatable. Most guidelines agree that 5 years is a minimum. After 5 years it is up to your physician how to follow your PSA but follow-up to at least 10 years is recommended. Follow-up beyond 10 years depends again on the risk of your prostate cancer, and your doctor can guide you on whether you should continue to have your PSA checked.

Dr. Robert Hamilton
Princess Margaret Cancer Centre

“Will I be radioactive?”

A common question that radiation oncologists are asked while men are trying to decide what treatment they will choose for their prostate cancer is “If I choose radiation, will I be radioactive?”, or variations of the question e.g. “Do I have to avoid being around children?”; “Will my partner and I have to sleep in different beds?” “Will I gain superpowers?” The answer to these questions is thankfully “**NO**”, with one small exception as described below.

When a person undergoes external beam radiotherapy (e.g. IMRT, VMAT, SBRT/SABR) the radiation is similar

to that which is used in diagnostic x-rays that you get through your family doctor or dentist, albeit at a much higher energy. It is a beam of radiation that goes through the body, and energy is deposited where the beam is aimed which then causes damage to the cancer cells which leads to their death. **No** radiation is left in the body, just like no radiation is in your body after a dental x-ray. I often joke that if there was radiation left in my patients after external radiation I would either be dead or glowing. The two other most common types of radiation are High Dose Rate (HDR, or temporary seed) brachytherapy and Low Dose Rate (LDR, or permanent seed radiotherapy). Given the radioactive seed we use for HDR is only temporarily put into the prostate during the procedure, much like external radiation there is no radioactivity left over afterwards. For LDR brachytherapy, the radioactive seeds are permanently implanted in the prostate and are clinically active for several months. Given the risk of getting a radiation induced cancer (what we call a ‘secondary cancer’) is not increased in the person that has the LDR radioactive seeds inside of them, the risk to others around those that have had LDR brachytherapy is negligible. That stated, radiation therapy follows the ALARA (As Low As Reasonably Achievable) principle for radiation exposure. Although the risk to others is thought to be almost zero we do recommend a few things to minimize any exposure to others such as avoiding close or long periods of contact with children during the first 2 months (for example: child sleeping on your lap), although normal day to day contact including hugging is perfectly fine. We also advise not sleeping with a woman who is pregnant, and if sexually active to wear a condom for the first 2 months just in case one of the seeds is passed in the semen (a very rare but reported event). Finally, for the first few months, it is possible that the radiation detectors in airports or at border crossings can be triggered, so documentation of the procedure is advised to be carried just in case.

So to summarize . . . For the vast majority of patients receiving prostate radiation, there is no concern about being ‘radioactive’. For men who receive LDR brachytherapy, it is advised that for a few months after the procedure that they be a bit careful just to be ultra-safe, though the risk to others is negligible. Unfortunately, the superpowers will remain in the domain of comic book or movie characters...for now.

Dr. Danny Vesprini
Radiation Oncologist
Sunnybrook Health Centre

If you get an email entitled, "Nude Photo of Nancy Pelosi," don't open it.
It actually contains a nude photo of Nancy Pelosi!



Dr. Mark Moyad continued

So, as these two studies showed, our minds can definitely have an impact on our bodies!

Using the examples of "**placebos**" and "**nocebos**", he told us that it is always better to associate yourself with people who lift you up and not bring you down!

At one point, he asked the audience if they were getting tired as he had gone on for a while and still had a ways to go. He blamed it on our first speaker (PCC's Peter Coleridge, who only spoke for five minutes!) That got a big laugh! He was kidding!

The audience's interest seemed to pique when he brought up the subject of **Cannabis /Marijuana!** Although he did mention a couple of things that we know for sure about it - that it seems to work for patients with epilepsy and that it increases appetite, there's still a lot we don't know about the drug as far as benefits vs risk factors. For example, we know that it can interact with many of the current approved drugs on the market today - "**but we don't now which ones!**"

The use of **Aspirin** was discussed as the best over-the-counter product which helps reduce the risk of heart attacks and strokes. However, it can sometimes be toxic and cause major bleeding!

Dr. Moyad brought up the proper way of having your **blood pressure** taken by your GP. Always have your arm at the same level as your heart. Raising or lowering your arm will raise or lower your blood pressure. He added that your feet should be firmly planted on the floor, and you have to be quiet and relaxed, and your bladder must be empty! "*You should visit the bathroom even if you don't think that you have to go!*" He emphasized that "in 2018, blood pressure is really a big deal."

Diets were discussed at length, and he talked about passing the "Moyad 5B test diet": if a diet passes the 5B test, he endorses that diet. They are: **B**lood cholesterol, **B**lood pressure, **B**lood sugar, **B**MI (**B**ody mass index), and **B**rain health.

The (**DRE**) Digital Rectal Exam was talked about, in both serious and humorous ways. The serious part was having Dr. Moyad reiterate how important this test is to possibly detect prostate cancer, and the fact that several medical groups/panels want to eliminate the test altogether! He had some fun with this serious topic when he gave his three top quotes said during this test: 3) "Have you found Jimmy

Hoffa yet?"; 2) "Now you know how a muppet feels!"; and number 1) "Can you please write a note to my wife that my head *is not* up here!"

Of course, he began his DRE topic by quoting a doctor as saying, "*I'm sorry that I'm late for your DRE test, but I just slammed my finger in the car door!*"

Other topics covered were: **Sugar**, and all the products that contain, in some cases, massive amounts, which is definitely not good for you at the best of times; **Alcohol**, which also features "liquid sugar", and portion sizes and calories are always being increased; **Exercise**, which should be done for your *mental* as well as your *physical* health, and in shorter times such as 20 minutes per day; **Ginseng**, can give you an energy boost and help fight fatigue; **Hippocampus**, which is located in the memory centre of the brain, and can prevent dementia. He touched briefly on the importance of lowering your **Cholesterol** levels, not necessarily taking massive doses of **Vitamin D**, and the dangers of **tobacco smoke/second-hand smoke** which can cause prostate cancer or recurrences of the disease.

When you invite Dr. Mark Moyad to come to Toronto to make a presentation, you quickly realize that he doesn't only cover one subject. He includes many different topics all aimed at our overall health and his wealth of knowledge is very hard to describe in simple terms.

Just getting him to come here is a coup in itself, as he is always in tremendous demand around the world, and having him able to fit our support group into that very busy schedule of his is constantly a challenge.

Following his extensive, information-filled presentation, he then answered many, many questions from our audience. As noted earlier, he answered his final question very late in the evening. We found out that he got to bed around 2 a.m. and was up at 6 a.m. to drive back to Michigan the next morning.

We cannot thank him enough for being here again with us, and for sharing so much of his expertise.

*With that, there's really only one more thing left to say: **GO BLUE***

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 2018

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 | Dr. Mark Moyad <i>University of Michigan</i> | "Fad diets, dietary supplements and Rx from A to Z: What works and what is worthless (2018 update)." |
| Nov *14 | G | Dr. Sidney Radomski <i>Toronto Western Hospital</i> | Erectile dysfunction and incontinence following prostate cancer treatment. |

*** Please note change of date!**

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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**Someone asked an old man: "Even after 70 years, you still call your wife 'darling, honey, or luv'. What's your secret?"
Old man replies: "I forgot her name a while ago, and I'm afraid to ask her!"**