



Awareness

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



2016

Prostate Cancer
Canada Network
Toronto

Dr. Andrew Matthew discusses sexual health and prostate cancer.

He's an old friend of our PCCN-Toronto support group and has spoken at previous Awareness Night meetings. This time **Dr. Andrew Matthew** was back with us to talk about

"Sexual health and prostate cancer".



He began with statistics about prostate cancer in Canada in 2016: Estimated: Life-time risk - 1 in 8; Incidence -

21,600 new cases; Deaths - 4,000; and 5-year survival rate - 95%.

When he started his career, no one knew about "survivorship", and now there are 250,000 survivors in Canada.

Dr. Matthew quickly got into his main topic by discussing "Distress specific to sexual dysfunction post-radical prostatectomy." He noted that 60% of patients report moderate to severe distress with sexual dysfunction, and that it is especially elevated in younger men!

One of his slides said that "sex is part of a quality life" because sexuality is life long, as reported in the following statistics:

- Age 57-64 yrs - 73% sexually active
- Age 65-74 yrs - 53 % sexually active
- Age 75-85 yrs - 26% sexually active
- * half of the oldest group reported a frequency of 2-3 times per month!

Dr. Matthew said that he made sure to show this particular slide to his wife, but it didn't really help much!

He also discussed the various pro-erectile agents/devices, which were

effective anywhere from 30% of the time to 85%, such as:

- * oral medications (Viagra, Cialis)
- * intracavernous injections
- * micro-suppositories
- * vacuum device
- * penile implant

Patients have told Dr. Matthew: *"I've been working on myself in other ways to compensate for the fact that I don't have that same feeling of manhood ... it's like there's something lost, there's something gone, there's something missing!"*

A woman said: "I didn't think it would matter to me...but it matters...I was quite sad that our sex life had changed...That's what I felt, it was like a mourning..."

Dr. Matthew covered other topics that we can't go into detail here because of space limitations. For example, he told us about the *Prostate Cancer Rehabilitation Clinic* and what's involved there for the patients and partners.

He also mentioned *The TrueNTH* ("True North") Sexual Health and Rehabilitation e-Clinic - *the SHAReClinic* - a free, online sexual health clinic focused on dealing with and healing from the effects of prostate cancer, which will launch in *January 2017*.

Following our refreshment break, our speaker answered many written questions from our large and very interested audience about this *delicate* topic.

To watch Dr. Matthew's entire address, please go to: pccntoronto.ca/videos

We sincerely thank Dr. Andrew Matthew for his time and for once again delivering another one of his very informative presentations. HAPPY HOLIDAYS!

DECEMBER

PCCN-Toronto Prostate Cancer Support Group

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"Raising prostate cancer awareness" - pccntoronto.ca

Meet Our New Chairman Philip Segal

My prostate cancer journey started about 10 years ago, when I received the news from my urologist that 2 of the 10 cores taken on my biopsy showed cancerous involvement. To be honest, up until that time I really had never been concerned with prostate cancer and probably, like most men, really didn't understand the disease. My initial reaction wasn't really shock but probably more of a numbness, since there wasn't a lot of cancer involvement and my Gleason score was 3+3.



However, I began to call friends and through them talked to many people who had been through the PCa journey and gradually began

to learn more and more. I also was referred to the "Man to Man" support group (PCCN-Toronto's former name) and went to my first meeting on Holly Street. Suffice to say, I was greeted warm heartedly and made to feel comfortable relating my story. More importantly it really lifted a load off my shoulders, meeting all the guys who had been through it and survived. It wasn't just me alone. Others had gone through the same exercise and seemed just fine.

After meetings with various docs, I decided along with my wife that active surveillance seemed the best option, given my diagnosis, and that was the start of my journey.

I have been a regular attendee at the PSG meetings ever since. Part of being involved makes living with the disease doable. I've learned and continue to learn more each time about the disease and how men cope with it in their different ways. This has certainly helped me in my journey. I joined the Board as treasurer about 5 years ago because I wanted to support PCCN-Toronto's existence and continuance. I accepted the chairmanship for much the same reasons. My immediate predecessor Winston Klass has done a terrific job moving the organization forward in the 3 years he was at the helm. I am also fortunate that the two previous chairs, Ron Benson and Aaron Bacher, continue to play a strong role on the Board, which makes it a lot easier to take over the responsibilities of the Chair.

I look forward to continuing to be part of the terrific work PCCN-Toronto does, and encourage all of our supporters to maintain and increase their volunteerism wherever possible.

The important role of our Side by Side support group.

Men are diagnosed with prostate cancer every day. However, that diagnosis very often affects more than just the man who received it.

Many of these men have partners who also have a vested interest in the type of news that doctors have given them. And women often deal with their "man's" diagnosis differently.

For years, our Side by Side ladies' support group has been there to offer partners of newly-diagnosed men an opportunity to meet women who have already gone through this same journey with *their* partners.

They have years of experience that they are willing to share with these new women, whose partners are just starting out on their own personal prostate cancer journey.

Side by Side women are willing to give of their time to meet/talk with you.

If you call our support line - **416-932-8820** - you can easily arrange to speak to one of our "ladies" in person on the first or third Tuesday night of each month at Valleyview Residence or, if more convenient, your conversation can take place on the telephone.

Either way, it is important for this vital information to be shared with newly-diagnosed families, so that they can best deal with their potential treatment options. One of the best ways to do that is to speak to someone who can guide you to make an "informed" decision, as this is a very important "first step" on the long journey toward a full recovery.

So please call our support line and meet a women who will definitely help you!

Support line: **416-932-8820**

Valleyview Residence:
541 Finch Ave. W. (West of Bathurst)

PCCN-Toronto & Side by Side

invite you to attend our first 2017

Awareness Night Meeting

at the

**Toronto Botanical Garden
In The Garden Hall**

777 Lawrence Ave. East at Leslie Street

on

**Wednesday
January 25, 2017**

at 7:30 p.m.

our guest speaker

Dr. Raj Satkunasivam

Sunnybrook Odette Centre

Topic:

"The future of PSA-based prostate cancer screening: screening smarter and Individualized Risk Assessment".

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 have been sponsored by

Scotiabank.

We sincerely thank Janet Slasor and all the people at Scotiabank for their very generous financial support.

The Board of PCCN-Toronto



The Rock the Road Raffle is back with more muscle than ever!

Order your tickets now for a chance to **WIN** this custom **2017 DODGE CHALLENGER SRT® Hellcat** and other great prizes in support of **Prostate Cancer Canada** - only 20,000 tickets are being sold so your odds of winning are great!

\$25 a ticket or **3** for **\$60**

To order, call: 1-855-441-1267

For more information please visit:

www.rocktheroadraffle.ca

This one-of-a-kind Hellcat is valued at over \$113,000 including custom upgrades that will take the performance and style to another level! With 707 horsepower and powered by a 6.2L Supercharged HEMI Hellcat V8 engine, it is the most powerful and fastest grand prize ever offered!

The 2017 Hellcat is being donated by TADA (Trillium Automobile Dealers Association) and so 100% of all ticket proceeds will be directed towards prostate cancer research.

Are you going to be in Florida in January 2017?

The 9th W. B. Ingalls Memorial Prostate Health & Cancer Symposium is taking place on

Saturday January 28, 2017

at the

Florida Atlantic University (FAU) in Boca Raton, Florida



A full-day event featuring leading prostate cancer physicians and researchers sharing the latest advancements and results in diagnostic and treatment protocols.

Early registration before December 21, 2016

\$125 per person or \$175 per couple

After December 21, 2016

\$145 per person or \$195 per couple

(Includes refreshments and lunch)

All costs are in U.S. funds.

To register:

Online at www.myhir.org

Click on **SEMINARS**, then **9th Seminar**, then **Register now**



Or call 1-888-694-4755

For more information about the Scientific Presentations and to see the entire Agenda of Speakers, please go to:

www.myhir.org

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.

Meet the newest member of our board - Darryl Radstake

Darryl's prostate cancer journey began almost 20 years ago, when his father was diagnosed with PCa. Knowing the familial risk factor, Darryl started early with screening tests. As feared, just before his 45th birthday, he heard those three dreaded words "you have cancer". A routine blood test came back with an elevated PSA, leading to further tests with a urologist. Biopsy results confirmed cancer was spread throughout the prostate. While a Gleason of 6 is usually considered low risk, the extent of the cancer and his young age indicated treatment was strongly recommended.



Not knowing much about this disease and dealing with the initial shock of diagnosis, he first sought emotional support from family members. Toronto Man-to-Man (now PCCN-Toronto) became the invaluable source of disease information and real experiences in his cancer journey. With second opinions from a surgeon and a radiation oncologist, PCCN-Toronto helped Darryl with treatment selection.

Surgery was performed by Princess Margaret's Dr. Trachtenberg in 2010. While initial post-surgery lab reports suggested all cancer was successfully removed, the next PSA test was not 'undetectable'. Post-surgery levels stabilized for many months, but the PSA eventually rose a year after surgery. A post-surgery biopsy revealed microscopic disease within small amounts of prostate tissue left after surgery. The need for salvage radiation was clear.

Dr. Padraig Warde planned 35 sessions of external beam radiation treatment. Six months of Androgen Deprivation Therapy (ADT) was added to his treatment regime. When the effects of the injections wore off and testosterone returned to normal levels, the next PSA test result was undetectable! Very welcome news indeed with more than two years since initial diagnosis. Darryl's PSA has remained undetectable for more than three years now, but fears of recurrence will never go away.

PCCN-Toronto is there for Darryl as he navigates this journey, particularly in this evolving landscape of

prostate cancer. Discovery and discussion of different issues means no two peer support sessions are alike.

And so when Darryl saw an opportunity to help PCCN-Toronto, bringing a younger man's perspective, while maintaining a work / life balance, he was pleased to accept the offer to join the Board.

He now looks forward to making a significant contribution to PCCN-Toronto, and to give back to an organization that he says has already given much to him.

We wish him the best of luck in his new position.

To all our special volunteers!

We often ask ourselves : "Where would PCCN-Toronto be without all of our dedicated volunteers?"

It's a very simple question. But the answer is not always that simple.

That's because we wouldn't be able to perform many, if not most, of the activities that we are currently providing without YOU!

Whether you are part of our Speakers' Bureau, or volunteer at some of our Events to promote prostate cancer awareness and early detection, or one of our hospital volunteers, or regularly attend our PSG Tuesday night meetings to support newly-diagnosed men, or our Warriors or E-meetings, you are all extremely important to the success of our support group and greatly appreciated!

So, at this time of year, we sincerely thank you for your support, wish you all a very happy and healthy holiday season, and look forward to working with you again in 2017!

*Aaron Bacher, Past Chairman,
on behalf of The Board of Directors*



PCCN-Toronto is supported by:

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ASK THE DOCTOR

Recently, a landmark research study was completed and results were announced and published: The Prostate testing for cancer and Treatment (**ProtecT**) trial. This trial, based in the United Kingdom, compared treatments for localized prostate cancers detected after PSA screening. In total, 1643 men were randomized to receive "active monitoring", a radical prostatectomy, or external beam radiotherapy with androgen deprivation therapy (often called "hormone therapy").

This paper has received a lot of attention in the press – and rightfully so. To get that many men to agree to leave the choice of treatment of their prostate cancer to chance is an impressive feat. Unfortunately, the interpretation of the study results by the press has been often been overinflated and inaccurate, and we thought it was worth addressing some of this misinformation here.

At face value, the study found there was no difference in the number of patients dying of prostate cancer after 10 years whether they received active monitoring, surgery, or radiation therapy. This confirmed what we already know about prostate cancer – when caught early it has a very long and slow trajectory. It is not surprising that only 17 patients in the entire study died of prostate cancer in the 10-year time frame. This is particularly not surprising when we see that 77% had Gleason 6 disease (so called 'low-grade' or non-aggressive); 76% had T1c (so called 'low-stage'); and the average PSA was only 4.6.

It would be tempting to conclude then, that simply monitoring the PSA is safe and we can do away with surgery and radiation. There are several cautionary notes about this conclusion. First, the study has only followed men for 10 years. Given the long, slow course usually taken by prostate cancer, we will not have meaningful answers until 15 to 20-year data are reported. Interestingly, the group that received active monitoring had early signs of worse outcomes; cancer spread or "metastasis" was seen at more than double the rate when compared to either the surgery or radiation group. At the 15-year horizon this will clearly translate into more prostate deaths in the active monitoring group.

Should we abandon active monitoring then? It's confusing, but the active monitoring in the study involved PSA testing only. This is very different from the Active Surveillance that is commonly practiced in Canada today, where men are monitored closely with repeated prostate biopsies (increasingly with the help of MRI) in addition to PSA and rectal examinations in order to detect disease progression early and offer curative treatment with radiation or surgery.



Moreover, in the ProtecT study, men with "intermediate" or "high" risk features such as Gleason 7-10 disease were included in the active monitoring group (in fact comprising 22% of the active monitoring group). These men have more serious cancers and thus, not surprisingly, are more likely to develop metastases and die of prostate cancer if left untreated.

Allowing these men to be "monitored" is not representative of the current active surveillance practice in Canada. For these reasons, I do not believe we can draw any conclusions about the effectiveness of Canadian active surveillance from this British study.

Some media and academic commentaries on the ProtecT trial have tried to read between the lines and draw conclusions about the effectiveness of radiation vs. surgery. Some argue radiation is superior to surgery as there was one more prostate cancer death in the surgery group (5) than in the radiation group (4). Others argue that surgery is superior to radiation as there were fewer men clinically progressing (8.9 vs. 9.0 per 1000 person-yrs), or developing metastases (2.4 vs. 3.0 per 1000 person-yrs). The truth is, the numbers are so small and the follow-up is too short to draw any conclusions about radiation vs. surgery at this point in time.

The study also compared quality of life measures between and among the three treatment arms. This taught us nothing particularly new. Radiation and surgery cause bigger declines in quality of life than active monitoring. Surgery causes a larger decline in sexual function and urinary control, while radiation causes more bowel symptoms. This underscores the rationale to using active surveillance when appropriate to avoid or defer the potential declines in quality of life that come with surgery or radiation.

To summarize, the ProtecT trial reminds us that PSA-detected prostate cancers have a very long, slow course with a low risk of prostate cancer death by 10 years. The comparative data on "monitoring" vs. radiation vs. surgery are, unfortunately, too immature to conclude anything. Even once the study matures to have 15-20 year data it may still not be that helpful as the "monitoring" done in the study is not the same as Canadian active surveillance.

Written by Dr. Rob Hamilton

IN MEMORIAM

Over the years, we have lost several dedicated men and women who were long-time supporters and/or volunteers with **M2M/PCCN-Toronto** and **Side by Side**. We honour each of those men and women below. (If we have inadvertently missed anyone, please let us know and we'll recognize him/her in the future!)

PCCN-Toronto

- Maury Budin
- Mark Dailey
- John Dell
- Sol Dennis
- Ron Evason
- David Fine
- Wally Hamilton
- Patrick Hare
- Dick Howe
- Anthony Iozzo
- Harry Lockwood
- Harvey Mandel
- Jim Moran
- Ron Nicholson
- Rudy Phillip
- Doug Phillips
- Stan Sandler
- Christopher Skinner
- Ray St-Sauveur
- Philip Taylor
- Ray Turner
- Patrick Vernon
- Moe Wagman

Side by Side

- Roz Wagman
- Olive St-Sauveur

"Board News"

by Philip Segal, Chairman

This has been a year of more than usual change on the Board. I have replaced Winston as Chairman of PCCN-Toronto, and I think I speak on behalf of the entire Board and all our volunteers in thanking Winston for the tremendous work he has done over the past three years as Chair. It has certainly made PCCN-Toronto stronger and the transition much easier.



During the past year three new members have joined the Board - Gerry Garshon, Ari Katz, and Darryl Radstake. We look forward to their participation and contribution towards helping strengthen the Board in its activities. Sadly, Stan Mednick, a long-serving member of our support group has decided to retire from the Board. All of us at PCCN-Toronto thank Stan for his long involvement with PCCN-Toronto and the Board, and for his leadership in the Speakers Bureau and the annual Do It for Dads event. We all wish him well.



One of my goals next year will be to try and increase volunteer activities amongst the regulars at the Tuesday night peer support group meetings. There are many PCCN-Toronto activities, such as social events, awareness nights, etc. where help is required for a single event. These do not require long-term commitments, so if anyone can help please let me or any of our Board members know.

Lastly I'd like to wish everyone season's greetings, and best wishes for a safe and healthy holiday season.

See you all in the New Year!

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 2017

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 25	G	Dr. Raj Satkunasivam <i>Sunnybrook Odette Centre</i>	The future of PSA-based prostate cancer screening: Screening smarter and Individualized Risk Assessment.
Mar 29	G	Dr. LaBoissiere <i>Sunnybrook Odette Centre</i>	Andrology.
May 31	G	Dr. Appelman & Dr. Menen <i>Menen Centre for Optimum Health and Canadian Integrative Cancer Centre</i>	Alternative approaches to treating prostate cancer.
July 26	G	Dr. Nathan Perlis <i>Princess Margaret Cancer Centre</i>	Focal therapy.
Sep 13	F	Dr. Juanita Crook <i>BCCA Center for the Southern Interior</i>	Brachytherapy for prostate cancer & breast cancer.
Nov 29	G	Leah Jammicky <i>Princess Margaret Cancer Centre</i>	Partner, caregiver, and survivor forum.



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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).

We need a sponsor for our newsletter.

Can you and/or your company help us?

Email Aaron at: aaronbacher@rogers.com. Thanks.