

EXTRA! EXTRA! EXTRA!

The "PCSToronto" and "Side by Side" Prostate Cancer Support Groups

We hope that you and your family are all well and staying safe!

We were just about finalizing this newsletter back in March of 2020 when the coronavirus - COVID-19 - hit everyone, and changed all our lives ever since, including this edition of our newsletter.

For example, we have not been able to host our twice-monthly Peer Support Group meetings at Valleyview Residence or our Awareness Night Meetings at the Toronto Botanical Garden since then.

However, we did discover something new that most of us had never heard about before - *Zoom Video Conferencing* - which many of us have now been using to "visit" with our families and friends, and also to host virtual meetings for our support group!

During the past several months, we have hosted virtual Tuesday night meetings and Awareness Night Meetings online.

Is it the same as "in-person" meetings? No, but it has allowed us to continue "meeting", keeping in touch with our "regulars" and sharing our experiences with newly-diagnosed men and their families. So, despite COVID-19, we've continued to do what we have been doing very successfully for over 26 years in the Toronto area - share information about prostate cancer!

Volunteering at our three hospital clinics also came to a halt, but we are still providing counselling to those who contact us online or by phone.

Our volunteers and other members of our group are all willing to help you in any way we can, as men are unfortunately still being diagnosed with prostate cancer every day.

We recently had to change our support group's name, logo, website and email addresses.

We hope that you approve of the name Prostate Cancer Support Toronto, as it fully explains to people not familiar with our support group exactly what we do - we support men (and their families) in The Greater Toronto Area who have been diagnosed with prostate cancer!

Please note that our support line - 416-932-8820 - is still active and is being monitored by volunteers from our PCSToronto support group.

Please continue to call this number and leave a detailed message as to the type of information that you are looking for, including your name and phone number so that we can return your call promptly.

Our website also contains meaningful information which will help you navigate your way through your diagnosis as well as provide you with other meaningful information.

Please check it out at www.pcstoronto.ca.

Thank you and good luck.

2021



JANUARY

**PCSToronto
Prostate Cancer
Support Group**

**541 Finch Avenue West
Toronto, Ont. M2R 3Y3
Phone: 416-932-8820
Fax: 416-291-3025**

**Email:
info@pcstoronto.ca**

CONTENTS

PCC/CCS amalgamation	2
Apology to Bill Mandel	3
Phil Segal steps down	3
Dr. Urban Emmenegger	4
North York Harvest Food Bank	4
Thank You to sponsors	4
Support group update	5
Awareness Newsletter celebrating 20 years	5
Ask the health care team - Dr. Dean Elterman	6
Ask the health care team (continued)	7
Message from Co-chairs	7
Our on-going projects for 2021	8
Board of Directors	8

"Raising prostate cancer awareness" - pcstoronto.ca

AWARENESS

The "PCSToronto" and "Side by Side" Prostate Cancer Support Groups

Prostate Cancer Canada and the Canadian Cancer Society Amalgamate.

February 3, 2020

On the eve of World Cancer Day, the Canadian Cancer Society (CCS) and Prostate Cancer Canada (PCC) have finalized their amalgamation. This transformational partnership is a bold and critically needed step forward within the cancer charity sector in Canada. The newly amalgamated organization will be led by **Andrea Seale**, CEO of CCS.

"With more than 300 cancer charities in Canada, donors expect us to reduce duplication and work together so that donations go further in helping people facing cancer," explains Seale. "Through this amalgamation, we are bringing together the strengths of two organizations that share many common goals: preventing cancer, funding life saving cancer research, and ensuring no one faces cancer alone. By partnering, we will be more efficient while also amplifying impact for people facing prostate cancer, expanding awareness and activity around important issues like early detection and survivor support."

The amalgamation between PCC and CCS builds upon the momentum created by CCS's unprecedented 2017 merger with the Canadian Breast Cancer Foundation. That remarkable consolidation resulted in a 28% year-over-year reduction in fundraising expenses and increased funding for research, programs and services.

As a newly amalgamated organization, CCS remains committed to improving the cancer experience for people facing all types of cancer, including prostate cancer – the most commonly diagnosed cancer in Canadian men.

"The reality is 1 in 9 Canadian men is expected to develop prostate cancer in his lifetime," says **Peter Coleridge**, former President and CEO of PCC. CCS's national reach, extensive community presence and deep history of public engagement allows us to invest in research and programs that will ultimately make an even bigger difference for Canadians affected by prostate cancer. I am committed to helping with a smooth transition to unify two reputable charities and am confident we can accomplish much more together than we ever could separately."

"CCS is proud to be entrusted with the opportunity to continue the mission of Prostate Cancer Canada. This amalgamation is an example of two great organizations combining for efficiency and increased impact. Together we will do more than we could have separately. More of our donors' dollars will go for mission and less for administration," says **Robert Lawrie**, Chair of CCS' Board of Directors. "Both PCC and CCS have sector leading governance, which will also become even stronger as **Christopher Wein**, the former PCC Chair and **David Woolcombe**, one of its former Vice Chairs, join the CCS Board."

"While PCC has contributed to cutting the prostate cancer mortality rate in half over the last 25 years, we still lose 11 men every day. This amalgamation bolsters our ability to continue our critically important work for Canadian families," says Stephen Pike, former PCC Board of Directors Chair.

About the Canadian Cancer Society:

The Canadian Cancer Society (CCS) is the only national charity that supports Canadians with all cancers in communities across the country.

No other organization does what we do; we are the voice for Canadians who care about cancer.

We fund groundbreaking research, provide a support system for all those affected by cancer and shape health policies to prevent cancer and support those living with the disease.

This was the press release issued jointly on February 3rd, 2020 by PCC and CCS on their amalgamation. Our group subsequently has had to change our name and our logo.

2021



JANUARY

PCSToronto Prostate Cancer Support Group

541 Finch Avenue West
Toronto, Ont. M2R 3Y3
Phone: 416-932-8820
Fax: 416-291-3025

Email:
info@pcstoronto.ca

CONTENTS

**BE
WELL
AND
STAY
SAFE!**

"Raising prostate cancer awareness" - pcstoronto.ca

PCSToronto/Man to Man apology to Bill Mandel

When we published our September 2019 newsletter, the front page included many of the men who have been an integral part of our support group over the first 25 years, including our founding members.

We knew that once you start listing names covering so many years, you're opening up the possibility of overlooking someone important.

And that's exactly what we did, though obviously, not on purpose.

Bill Mandel is one of those important men who, in the very early days of Man to Man, was instrumental in working with Dr. John Trachtenberg and the other founding members, helping to get our support group started at the Princess Margaret Cancer Centre.

Since then, we've come a long way and have been volunteering at three major Toronto Hospitals now for years.

Some of our current members and volunteers might not be familiar with Bill's name, or the names and faces of others who preceded them and the important roles they all played in our group's development during our first 25 years.

I, along with a handful of some of our now "senior" members, did get to know Bill and saw for ourselves how involved he was with our support group.

As editor of our newsletter, and on behalf of our entire Board of Directors, I want to apologize to Bill for omitting his name from the list of men mentioned on that front page back in September 2019.

Our support group would never have achieved the success that we have if not for the efforts of men like **Bill Mandel**, who was there with us when we first started in 1994.

*Aaron Bacher
Editor*

Phil Segal steps down after three years of being chairman!

Phil Segal successfully completed his three-year term as Chairman of PCCN-Toronto on December 31, 2019.



Phil

Keith

On Tuesday, December 17th, 2019, our final peer support group (PSG) meeting of the year, Keith Braganza, incoming co-chair for 2020 (along with John Roth), and representing PCCN-Toronto, presented Phil with a gift as a token of our appreciation.

The men who volunteer to be on our Board of Directors all make a personal commitment to give of their time to make our support group better.

Agreeing to be chairman for a three-year period is even more of a commitment, as that includes attending board meetings, many PSG and Awareness Night meetings, and being the main contact for all outside companies and organizations. We certainly appreciate the dedication of all our previous chairmen.

Thank you very much Phil for your very important contribution to our success!

PCS-TORONTO IS SUPPORTED BY:

* Astellas Pharma Canada, Inc. * Janssen Pharmaceuticals
* Valleyview Residence

PCSToronto & Side by Side

invite you to attend our first 2021

"Virtual" Awareness Night Meeting

on Wednesday

January 27, 2021

at 7:00 p.m.

featuring

Dr. Urban Emmenegger

Odette Cancer Centre

topic:

**"Metastatic prostate
cancer"**

A question period will follow.

*If you have any questions, please call us at
416-932-8820*

**Join us online
just before 7:00 p.m.**

**Register for the meeting and
receive the necessary link.**

**Check your email for the link to
register for the meeting.**

2020 Meetings Benefit North York Harvest Food Bank

Since you can't bring any non-perishable food with you to our Awareness Night Meetings due to COVID-19, you can still make a donation to the North York Harvest Food Bank.

They need your donation more than ever before.

Go to northyorkharvest.com/donate-today and scroll down to PERSONAL INDIVIDUAL GIFT to make your donation.

Thank you very much.

We hope to start hosting our in-person meetings again sometime in 2021 and then you will be able to resume your donations of much-needed non-perishable food.

Until then, please stay well and safe.



www.northyorkharvest.com

All our PCSToronto Man to Man Peer Support Group meetings and our Awareness Night meetings in 2020 have been hosted virtually on Zoom.

We thank **Stacey Silverberg** and all the people at Janssen, and **Karen Frantzke** and everyone at Astellas for their continued support.

The Board of PCSToronto.



Support group update.

As you read through this newsletter, you will note that the name of our support group is now **Prostate Cancer Support Toronto (PCSToronto)**. Up until very recently, we were known as **Prostate Cancer Canada Network - Toronto**.

This name change was necessitated when Prostate Cancer Canada and the Canadian Cancer Society Amalgamated at the beginning of 2020.

The bottom line is that we are still the same support group, with our twice monthly Tuesday night meetings still taking place, held online on Zoom for now during COVID-19 but hoping to one day get back to hosting these meetings at Valleyview Residence once we are given the green light to do so. The same is true for our Awareness Night Meetings at the Toronto Botanical Garden, which we are also hosting virtually on Zoom until it is safe to go back.

All of our members and volunteers hope that happens very soon!

Awareness newsletter is 20 years old this year!

Our group's first attempt at publishing a newsletter took place in October of 2001 with the printing of this four-page "newsletter". It featured the late Jim Moran thanking Dr. Sidney Radomski and announcing that Dr. Michael Jewett would be our November speaker.

We've come a long way with our newsletter in the past 20 years!

Awareness
The "MAN TO MAN" and "SIDE BY SIDE" Prostate Cancer Support Group Newsletter

October 2001

VOLUNTEERS HONOURED

On Wednesday night August 15, 2001 the Board of Directors of Man to Man honoured many of their volunteers by hosting a complimentary buffet dinner at the Marriott Hotel on Dixon Road. Chairman Moe Wagman and his wife Roz organized the evening, and 40 people attended and had a terrific evening. Those who attended were: Sol and Rita Dennis, Jim and Lise Moran, Bill and Dorothy Hofstetter, Bob and Maria Miller, Leo and Helen Spindel, Jerry and Linda Garshon, Bill and Barbara Gow, Ray St-Sauveur, Aaron and Ronnie Bacher, Bernie and Cyrele Shoub, Des and Terry Halge, Don and Lorna Davis, Earl and Deanna Lagroix, Harry Lockwood, Norm and Pat Roth, Ron and Muriel Nicholson, Dick and Ruth Sprenger, Andrew Matthew and Susan, Clarence Yue and Minnie, Sid and Sonia Traves, and, of course Moe and Roz Wagman. Leo welcomed everyone to our dinner and, later, Aaron thanked Moe and Roz for organizing the evening and all the volunteers for coming. Deanna also said a few words on behalf of Side by Side, thanking Man to Man for inviting the spouses/partners and allowing them to get a chance to meet each other. This was an excellent way to thank our volunteers for all the work they do by visiting surgical patients in the hospital, taking part in or facilitating our bi-monthly Peer Support meetings, and helping out at our Awareness nights at Edward's Gardens. Man to Man's success in helping men cope with Prostate Cancer is due in part to the tremendous amount of work done by our volunteers, and we thank them all again for their effort.

"INCONTINENCE & IMPOTENCE"

Jim Moran, left, Man to Man Volunteer and Awareness Night Facilitator, with September guest speaker Dr. Sidney Radomski.

Over 200 men and women laughed out loud on several occasions. There were many whispers and nodding of heads in the audience as the speaker made certain points. What were these people enjoying so much? A speech about Incontinence and Impotence, two serious side effects associated with Prostate Cancer. The speaker was Dr. Sid Radomski, who was there to discuss this very important topic, and discuss it he did! He explained more in his 45-minute presentation than most of the men in the room had heard from their own doctors. And he did it by using humour and terminology that everyone understood. After a short break, Dr. Radomski answered many questions posed by audience members. His overall message was simple: that there is lots of hope out there for men suffering from either or both of these serious issues. Medications and procedures are available which will improve these two conditions, resulting in a better quality of life for the men. His message was very well received, if you measure it by all the applause.

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

ASK THE HEALTH CARE TEAM

An Enlarged Prostate and Its Role When Treating Prostate Cancer *by Dr. Dean Elterman*

For most men, dealing with an enlarged prostate is simply a matter of time. Approximately 50% of men aged 50 and older and up to 90% of men by the age of 80 will have benign prostate enlargement. While the condition of Benign Prostatic Hyperplasia (BPH) or enlargement is unrelated to cancer, it can impact a man's quality of life. Symptoms of an enlarged prostate may include:

Frequent and/or urgent need to urinate, day and night.

Difficult or delayed start to urination.

- Weak or slow urinary stream or one that stops and starts.
- A sense that you've not fully emptied your bladder.
- Complete inability to urinate.

Things can get complicated when using a prostate specific antigen (PSA) blood test when monitoring for prostate cancer. Each prostate cell produces PSA and when the prostate enlarges with BPH, the PSA will rise. Prostate cancer cells make more PSA than normal non-cancerous cells; thus the PSA will rise more steeply. The challenge is figuring out what is causing an elevation in PSA – benign or cancerous cells. This is why we often monitor PSA over time to see the velocity of change in PSA. Traditionally, we perform a prostate biopsy to sample the prostate for cancerous cells. This is still the standard way to make a diagnosis of prostate cancer.

Increasingly, we can use Magnetic Resonance Imaging (MRI) of the prostate to look for suspicious areas that are concern for cancer. A suspicious area may then be targeted during a biopsy using the MRI images as a guide. There are even some "liquid biopsies", such as the SelectMDx urine test, which detects prostate cancer, ribonucleic acid (RNA) genetic material and can give a percent probability of having an aggressive cancer. As men get older, we expect their PSA to rise as the prostate enlarges. Thus, we have different ranges of "normal" PSA based loosely on age, which corresponds to having more prostate growth as men age. For a urologist who treats BPH, I'm always thinking in the back of my mind about the possibility of an underlying prostate cancer.

Eventually, most men's symptoms of an enlarged prostate will progress until they (or their partners) are so bothered that they will want some kind of treatment. Medications are available to relax the muscles within the prostate and bladder neck or shrink the prostate over time, but these medications need to be taken daily for life to benefit from their effects. Many men will experience negative side effects from these medications including loss of ejaculation (dry or retrograde),

erectile dysfunction, light-headedness or dizziness, and drops in blood pressure. If these side-effects cannot be tolerated or their symptoms worsen, then surgery is the next step.

The most widely available surgery for BPH has been the transurethral resection of the prostate (TURP). TURP cuts away tissue using electrocautery with men typically staying in hospital 1-3 nights. While effective, men require 6 or more weeks of recovery with long term expected side effects also including loss of ejaculation in up to 70% of men.

Unlike medications and TURP, new technologies exist that are not covered by OHIP that preserve sexual and ejaculatory function. The procedures are performed outside of the hospital in under 15 minutes without the need for general anesthesia. The recovery is shorter than traditional surgery. The newest treatment, available in Canada for the first time is Rezum, a water vapour treatment where energy stored in heated water is released into the prostate tissue for 9 seconds causing cell death and tissue shrinkage. After 3-7 days with a catheter, men can return to normal activity while the prostate continues to shrink over the subsequent 3 months. The second treatment available is the UroLift system, which uses a few small implants to pull apart the obstructing lobes of the prostate. These new minimally invasive options afford men the choice of a treatment that preserves sexual function, comes with minimal downtime and has a safe and durable outcome.

In the setting of prostate cancer, the size of the prostate can sometimes play a role in treatment options. Generally speaking, the size of the prostate is less important when undergoing a radical prostatectomy surgery or external beam radiation therapy. Men with enlarged prostates can often have bladder issues, such as overactive bladder, which will persist after the prostate is treated. When it comes to brachytherapy (implanted radiation seeds) the size of the prostate and particularly the transition zone, which is the middle part where urine travels, are more important. Men with BPH have overgrowth of the middle part of the prostate called the transition zone. They may also have a large median lobe of the prostate, which grows like a ball into the bladder. When any BPH procedure is performed, we target removing or shrinking the transition zone and median lobe to improve urinary flow.

Men with BPH will often have more negative urinary side effects after brachytherapy or external radiation therapy.

continued on page 7

Dr. Elterman . . . continued

Thus, many radiation oncologists who perform brachytherapy will want to shrink the prostate before implanting the seeds. Methods to shrink the prostate include hormones, TURP or similar surgery, and now with of the new techniques, Rezum or UroLift.

Many men with low risk prostate cancer will be placed on Active Surveillance. This involves close monitoring of the PSA with subsequent MRI and/or biopsies. Many men on active surveillance will also be living with the symptoms of BPH. Hence, the options laid out above (i.e. medication, Rezum, UroLift, surgery) remain an important consideration to maintain an optimum quality of life. This group of men will be living with both prostate cancer and BPH, so carefully selecting a treatment strategy for the BPH that allows continued monitoring of the prostate cancer should be considered.

Urinary function after prostate cancer treatment may vary from man to man. Your pre-treatment urinary symptoms and the presence of an enlarged prostate may play a significant role later on. Understanding your symptoms and discussing them with your doctor will help prepare you for life after treatment.

Dr. Dean Elterman, MD, MSc, FRCSC, a Urologic Surgeon & Assistant Professor in the Division of Urology of the University Health Network and the Department of Surgery at the University of Toronto, is also a Clinician Investigator at the Krembil Research Institute in Toronto.



We welcome Dr. Elterman to our growing team of contributors to this column. We appreciate his interest and his support, and we thank him for so readily accepting our invitation to participate.

*Ron Benson
Past Chairman, PCSToronto*

Year-End Message from our Co-chairs

There is an old curse:

“May you live in interesting times.”

This year has certainly been interesting. The first major event occurred on Feb. 1st when Prostate Cancer Canada (PCC) merged with the Canadian Cancer Society (CCS). CCS does not provide support for groups other than providing training for support group facilitators. So, the Prostate Cancer Canada Network effectively no longer exists. In view of this, we decided to change our name to Prostate Cancer Support Toronto, which is reflected in the banner on this newsletter and our continuing mission. We've also changed our logo since we can no longer use the familiar double blue tie which belongs to PCC/CCS and our website has changed to www.pcstoronto.ca. The Father's Day "Do It For Dads", our major annual fundraiser, did not happen in 2020 and its future is currently on hold.

The second big event happened in mid-March when Covid-19 caused a lockdown of all social gatherings. We quickly turned to Zoom meetings for Peer Support and Awareness Nights. After some teething problems, these meetings have generally been successful. On the one hand, people don't have to travel, sometimes in bad weather, and people from as far away as Singapore have attended! On the other hand, we do miss the in-person contact. Moving forward, when we can meet again, we are looking at a hybrid model of the meetings.

We only had to cancel one Awareness Night in March 2020 with Dr. Emmenegger. We are pleased to announce that he has agreed to be our first 2021 speaker, on January 27th. Please see the rest of our 2021 schedule on page 8.

We continue to provide support for prostate cancer patients and their families, friends and caregivers through the support line (416-932-8820) and email (info@pcstoronto.ca). We have not been able to volunteer in the clinics at Princess Margaret, Sunnybrook, and Branson Hospital, or visit surgery patients post-op. We hope this is temporary.

We wish you and yours a Happy and Healthy New Year.

John Roth and Keith Braganza

Are you interested in becoming a PCSToronto volunteer?

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

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

Our on-going projects for 2021

AWARENESS NIGHT "ZOOM" MEETINGS

These meetings are normally 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.**

<u>DATE</u>	<u>SPEAKER</u>	<u>TOPIC</u>
Jan 27	Dr. Urban Emmenegger <i>Odette Cancer Centre</i>	Metastatic prostate cancer.
Mar 31	Dr. Gerard Morton <i>Odette Cancer Centre</i>	Radiation treatments.
May 26	Dr. Andrew Mathew <i>Princess Margaret Cancer Centre</i>	
Jul 28	PCSToronto survivors	Survivor forum.
Sep 29	Dr. Rajiv Singal <i>Michael Garron Hospital</i>	
Nov 24	Christina Dzeduszycki, MSc PT, BA [Kin] <i>Registered Pelvic Floor Physiotherapist</i>	Physiotherapy Approach for Rehabilitation (to address incontinence, ED, and related issues)

Man to Man Peer Support Meetings - 7 p.m.

These meetings take place on the **FIRST** evenings of each month at the **Valleyview Residence** (just west of Bathurst Street on the Bloor Street West side). They provide an opportunity for men to meet and talk about dealing with prostate cancer.

Support Group

This is a support group, where you can share your experiences. Please visit our website for more information.

Personalized Support

Trained staff can provide support in your home, by phone, or in person. For more information, please contact our medical social workers at **Michael Garron Hospital** or **Princess Margaret Hospital**.

Counseling

Our volunteer counselors provide support at the **Princess Margaret Cancer Centre** (on Friday), the **Odette Cancer Centre** (on Tuesday), and the **Graham Wright Prostate Cancer Centre** at North York (on Tuesday afternoon).

PCSToronto Board of Directors

Co-Chairmen
Keith Braganza
John Roth

Treasurer
Philip Segal

Secretary
Darryl Radstake

Directors
Aaron Bacher
Ron Benson
Denis Farbstein
Jerry Garshon
Ari Katz
Winston Klass
Allan Lappin
Bernard Shoub

Immediate Past Chairman
Philip Segal

Past Chairmen
Aaron Bacher
Ron Benson
Winston Klass

**Have a question?
Need some information?
Call our support line: 416-932-8820**

All of our meetings, personal support, and counseling in hospital prostate clinics have had to change in 2020 due to COVID-19. Our meetings have all been successfully hosted on Zoom and we have not been allowed into hospitals to counsel new patients. However, we are still available to you at info@pcstoronto.ca or by calling 416-932-8820 and we will get back to you.