

AWARENESS

Prostate Cancer Support Toronto

A MESSAGE FROM THE CO-CHAIRS

It has been six months since Ari Katz and I took over as co-chairs of PCS Toronto from John Roth and Keith Braganza.

What have we accomplished? We are proud that our support group has secured a location for a monthly, in-person, support group session at Lansing United Church in North York, as well as continuing to hold a monthly Zoom meeting. We may be the only Ontario prostate cancer support group to sustain this.

We have continued to reach out to some of the Toronto hospitals where we do not currently have volunteers to peer navigate men and their families. We have disseminated information so that men can reach out to us.



Denis Farbstein

Our support group is now linked with the Ottawa-based Canadian Cancer Survivor Network so that men and their families are able to reach beyond their own communities to our support group, where we can peer navigate.

In this issue:

A message from the
Co-Chairs

UHN News -
True North Article

PCS Toronto Father's Day
Walk-Run

Volunteers at hospitals

Prostate Cancer
Foundation BC
Officially becomes
Prostate Cancer
Foundation Canada

PCS Toronto Father's Day
Walk - Run

Toronto's Light Up in Blue
Kick Off - Sept 1

PCS Toronto Support Line:
(416) 932 - 8820

For more information, go to:

<https://pcstoronto.ca>

or, contact us at:
info@pcstoronto.ca

A MESSAGE FROM THE CO-CHAIRS

Continued from Page 1

And there is much more work to be done! Along with continuing the initiatives mentioned above, we're hoping to explore the use of social media tools to effectively increase our prostate cancer support audience. We are trying to reach out to those men whose support groups have unfortunately folded in recent years or who could benefit from our knowledgeable and experienced attendees.

Both Ari and I were honoured and humbled when we were asked to serve as co-chairs of PCS Toronto. I believe that our varied experiences will complement each other to provide strong leadership.

Ari joined what was then PCCN Toronto in 2013 and initially got involved with helping to organize our awareness nights. He continues to co-ordinate the annual effort to decide on our slate of awareness nights for each calendar year. Since COVID, he has also been handling our Zoom peer support meeting registrations and Zoom awareness night registrations.

For my part, I have dedicated 10 years volunteering at both Sunnybrook and North York General hospitals. It has been more than nine years since I was asked to be a board member and 15 years since my radical prostatectomy. I have also facilitated many in-person and Zoom meetings.

Participating in the Do It for Dads Father's Day Run-Walk over the years and setting up booths and helping to spread awareness in events such as the Canadian Open Tennis Tournament at York University and the Toronto Sportsman Show has allowed me to speak to many people.

Denis Farbstein and Ari Katz.



Ari Katz

TRUE NORTH PROGRAM SUPPORTS PROSTATE CANCER PATIENTS ACROSS CANADA

True North peer navigation program aims to support cancer patients nationwide

(This article, which includes PCS Toronto board member Keith Braganza, is reprinted from a July 2023 article in UHN News, the online newsletter of Toronto's University Health Network.)

Dr. Jackie Bender believes in the power of human connection and digital communication.

This passion led Jackie, a scientist in the Cancer Rehabilitation and Survivorship Program, Department of Supportive Care, Princess Margaret Cancer Centre, to launch the digital True North Peer Navigation Program, a virtual initiative that uses a digital app to match patients and caregivers with a trained volunteer navigator who assesses needs and barriers to care and provides necessary support.

It has provided personalized navigation support to nearly 200 prostate cancer patients and their family members since it was launched in 2016.

Now, Dr. Bender is using it as a research tool to determine the impact of digital peer navigation on patient outcomes and to evaluate the cost-effectiveness, implementation and sustainability of the concept in oncology settings.

Ultimately, she hopes it's something that can be expanded across Canada and extended to patients with different types of cancer.

"Patients and caregivers want to be matched with someone who has had a similar treatment experience and is at a similar life stage," says Dr. Bender.

"They want to feel understood and to learn from their navigator's lived experience."

TRUE NORTH PROGRAM SUPPORTS PROSTATE CANCER PATIENTS ACROSS CANADA (continued)

Dr. Bender was inspired to launch this initiative after research revealed that the impact of prostate cancer on the lives of patients and their families is significant, and the burden of unmet needs is high.

She discovered that patients face considerable anxiety and a lack of support when deciding on treatment and dealing with side effects, and would value support from a trained peer who has been through prostate cancer. Research also revealed the benefit of having a peer navigation program specifically for caregivers.

"A lot of people feel lost when they get this diagnosis," says Keith Braganza, who went through prostate cancer treatment in 2015 and has been participating in the program as a navigator since 2016. "Prostate cancer is a unique illness in that it affects patients in a very personal way, and there are important decisions to be made.

"Patients often have to choose their treatment method, putting stress on those who are afraid of making the wrong choice. It can be easier to talk to a stranger who has gone through what you are about to go through to give their insights on how to deal with the process."

Keith's wife also participates in the program as a caregiver navigator, offering support to people whose spouses or loved ones have prostate cancer.

Caregivers are also profoundly affected by the disease but are often so focused on the patient they don't prioritize their own care, so connecting with someone with a similar experience helps them acknowledge their own needs as well.

"There is no manual for caregivers in such an emotional time, so this program gives them the opportunity to get advice on how to support their loved ones and themselves at the same time," Keith says.

TRUE NORTH PROGRAM SUPPORTS PROSTATE CANCER PATIENTS ACROSS CANADA (continued)

Patients are matched online, like a dating app, by answering questions that enable the program to match them with navigators. Then, the system shows them navigators who match their criteria and the patient has the final say, giving them the autonomy to scroll through selected navigators and choose the best fit.

The program is available through a website and an app, allowing patients, caregivers and navigators to communicate through instant messaging or a video conferencing feature.

Breaking down barriers to access

The program also considers the diverse backgrounds and needs of its patients. "Peer navigation acts as a means to address disparities in access to care and support faced by underserved groups," says Dr. Bender, who is also Equity, Diversity and Inclusion Co-Lead in UHN's Department of Supportive Care.

According to researchers, prostate cancer has a significant impact on relationships and sexual functioning, and patients are often seeking tailored support for these important issues. Additionally, with a higher rate of prostate cancer in Black individuals, Dr. Bender recognizes the importance of ensuring the program meets the needs of Black African and Caribbean patients and their loved ones.

The peer navigation app collects information about race, ethnicity and sexual orientation on a voluntary basis and gives patients the option to prioritize a match with someone with a similar background and life experience.

Navigators' eight-week training program highlights anti-oppressive approaches and understanding diversity to ensure the program takes into account systemic and structural barriers that exist.

Continued in Page 6

TRUE NORTH PROGRAM SUPPORTS PROSTATE CANCER PATIENTS ACROSS CANADA (continued)

Expanding access to patients across Canada

For Dr. Bender, the ultimate goal is to scale and expand the peer navigation program so people across Canada have access to support navigating the health system from someone who has been through it.

Through research funding from the Canadian Institutes of Health Research, she is expanding the prostate cancer peer navigation program to reach patients in British Columbia and Nova Scotia.

She is also developing a similar peer navigation initiative for adolescents and young adults with cancer through funding from the Canadian Cancer Society. And, thanks to a generous gift to the Head and Neck Cancer Survivorship Program, she will adapt the service to support patients with head and neck cancers.



Keith Braganza has participated in the digital True North Peer Navigation Program since 2016 as a navigator for more than 30 patients with prostate cancer. (Photo: Courtesy Keith Braganza)

Keith joined the peer navigation program when it was a pilot project. Since then, he has helped more than 30 patients through prostate cancer treatment.

"I think every patient should have the opportunity to be a part of this program," he says. "I am glad that I'm in such a unique position to be able to support them through this process."

VOLUNTEERS AT HOSPITALS

Most in-person hospital programs have resumed

Supporting prostate cancer patients in Toronto hospitals has always been one of PCS Toronto's core missions. All hospitals suspended in-person volunteer activities during the COVID-19 pandemic but, thankfully, things are gradually returning to normal.

Volunteering at the GU Clinic of Princess Margaret Cancer Centre has not yet restarted, as the UHN volunteer program is still being reassessed.

Our volunteers returned to the Odette Cancer Centre at Sunnybrook in the fall of 2022. The staff there have been very welcoming and we have more or less returned to the role we had pre-pandemic. We have a volunteer in the Thursday clinics to talk with patients and their immediate supporters, if they wish, as they wait for their appointments. We tell them about our group and what we can offer as support. We also visit patients in the short-stay unit who have had procedures on Wednesday.

The Consumers Road site of the North York General Hospital has also allowed volunteers to return. Volunteers peer navigate every Tuesday afternoon, meeting with men and their families.

At hospitals where we do not yet have a presence, we are trying to distribute our brochures. For example, as a result of Dr. Olivier Heimrath's awareness night presentation in November 2022, PCS Toronto has brochures being distributed to patients at Humber River Hospital.

Dr. Andrew Evans's awareness night talk in January 2023 helped our support group connect with Dr. Michael Kogon, a urologic oncologist at Mackenzie Health Hospital in Richmond Hill. Dr. Kogon has distributed our brochures to his colleagues to give to their prostate cancer patients at Mackenzie Health and the Cortellucci Vaughan Hospitals so that they may seek further support.

VOLUNTEERS AT HOSPITALS - Continued

For 15 years, Valleyview Residence in North York opened its doors to Man2Man, PCCN Toronto and PCS Toronto meetings on the first and third Tuesdays of each month, as well as our board meetings on the second Tuesday evening of each month.

But with respiratory outbreaks and the onset of COVID at Valleyview, our support group can no longer meet in person at this long-term care facility due to provincial restrictions. A temporary site, Lansing United Church in North York, has been secured.

PROSTATE CANCER FOUNDATION BC OFFICIALLY BECOMES PROSTATE CANCER FOUNDATION CANADA

In a decision in July, Prostate Cancer Foundation BC (PCFBC) voted to change its name to Prostate Cancer Foundation Canada (PCFC), formalizing its evolution into a national organization and filling the void left by Prostate Cancer Canada, which amalgamated with the Canadian Cancer Society in February 2020.

During the onset of the COVID-19 pandemic three years ago, the foundation launched Prostate Cancer Support Canada (PCS Canada), stepping in to help more than 55 local prostate cancer support groups across Canada that had been part of the Prostate Cancer Canada Network (PCCN). The formation of online support groups necessitated by the pandemic has revolutionized the way patients and families connect, providing specialized assistance and fostering a sense of community nationwide.

PROSTATE CANCER FOUNDATION BC OFFICIALLY BECOMES PROSTATE CANCER FOUNDATION CANADA - Continued

To help make PCS Canada a truly national organization, prostate cancer support group leaders, working with PCFBC, have established a national council. Now, under the banner of Prostate Cancer Foundation Canada, the foundation will continue to provide support to local groups, including fundraising events, and will throw its weight behind nationwide initiatives like September's Light Up in Blue campaign, which is geared to raising prostate cancer awareness across Canada.

"As Prostate Cancer Foundation BC officially embraces its new identity as Prostate Cancer Foundation Canada and moves into a new era of leadership in the prostate cancer community," the organization said in a news release, "the foundation will continue its unwavering commitment to innovation, raising awareness, providing support and funding groundbreaking research in the fight against the number one cancer in men."

PCS TORONTO FATHER'S DAY WALK-RUN RAISES MORE THAN \$8,000 FOR SUPPORT GROUPS

The Do It For Dads Father's Day Walk Run, a PCS Toronto tradition, was held virtually again this year to respect pandemic precautions – but some small groups gathered in person on June 18 to take part in the annual fundraiser.

PCS TORONTO FATHER'S DAY WALK-RUN RAISES MORE THAN \$8,000 FOR SUPPORT GROUPS - Continued

One of these neighbourhood, in-person events brought together 35 family members and friends of former PCS Toronto chair Aaron Bacher. Together, they walked a two-kilometre route in Aaron's memory and, afterwards, celebrated all of their dads past and present (see photos).

"It was a nice to gather for such an important cause and to raise money for the PCS Toronto team," Aaron's son Shelly said in an email. "As of today, we've received over \$2,800 in donations."



Continued in Page 11

PCS TORONTO FATHER'S DAY WALK-RUN RAISES MORE THAN \$8,000 FOR SUPPORT GROUPS - Continued

In total, this year's PCS Toronto event raised \$8,338. Fifty per cent of the funds will be used for PCS Toronto activities, with the other half going to Prostate Cancer Support Canada to help support the more than 55 prostate cancer support groups across Canada that are part of the PCS Canada network. Tax receipts were issued for any donations of \$20 or more.

The Father's Day Walk Run has been organized under the auspices of PCS Canada since 2021. In the past, it was one of the main, annual fundraising initiatives for the now defunct Prostate Cancer Canada.

"PCS Toronto is not a fundraising organization, nor do we charge for any of the support sessions, webinars or events that we offer," said former PCS Toronto co-chair John Roth. "More of these will now be offered in-person again. But these things do cost money and the Father's Day Walk Run is our opportunity to raise the funds that we need to run our organization. Any amount donated is greatly appreciated!"

Last year, some of the participants actually walked the traditional Ashbridge's Bay route for the walk-run.

JOIN US ON SEPTEMBER 1 AT TORONTO'S LIGHT UP IN BLUE KICK-OFF

The city may seem a tiny bit brighter in September when it illuminates the Toronto sign at Nathan Phillips Square in blue to help publicize Prostate Cancer Awareness Month.

The City of Toronto has agreed to join the Light Up in Blue campaign along with more than 100 landmarks across Canada, including the CN Tower.

The lighting ceremony at Nathan Phillips Square is scheduled for Friday, Sept. 1, at 11 a.m. and everyone is welcome to attend. The event will also include a formal raising of the PCS Toronto flag – which was created especially for the event. Special guests at the ceremony may include Mayor Olivia Chow and Councillor James Pasternak.



In recent months, PCS groups throughout Canada have been reaching out to authorities at city halls, bridges, arenas, museums and other landmarks asking them to join the Light Up in Blue campaign to help spread awareness of the most commonly diagnosed cancer among Canadian men.

Check out this map showing all Light Up in Blue landmarks so far:

bit.ly/lightupinblue2023.