AWARENESS

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

NEWS UPDATE

We are very sad to report the passing of **WILLIAM THOMAS DEANE**, a regular Tuesday night attendee for years.

Bill usually came to those meetings with his good friend Ivan Samuels.

Bill passed away on Tuesday, September 7, 2021, in his 91st year. Beloved husband of 64 years of the late Mary (2020), and loving father of Howard (Fran) and Susan (Paul).

Bill was the proud Grandpa to Matthew, Thomas, Michael, Jennifer, and Zach, son of the late John and Hester Deane, and is predeceased by brother Robert and sister Hester.

We send our sincere condolences out to his entire family.

He is greatly missed.

A memorial service with immediate family members is planned.

In lieu of flowers, those who so wish may make a memorial donation to the charity of their choice.

Service of Remembrance (Private)

September 27, 2021

Kane Jerrett Funeral Home

6191 Yonge Street
North York, Ontario
M2M 4K4

For everyone, Covid has brought with it a collection of challenges, insights, perceptions, and opinions.

In response to my request that our newsletter **HEALTH TEAM** column contributors recount how these times have affected their medical practices, prostate cancer radiation oncologist Dr. Danny Vesprini (Sunnybrook Odette Cancer Centre) and urologist/surgeon Dr. Sharon Sharir (Humber River Hospital) have offered their reflections.

It is hoped that you, as readers of this column, will gain insight and appreciation for the challenges the medical community has faced during this unique time in our lives.

We are most appreciative that they agreed to share their personal and firsthand experiences and thoughts with us.

Ron Benson

2021

Prostate Cancer Support Toronto

September

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

September

BE WELL

AND

BE SAFE

ASK THE HEALTH CARE TEAM

By Dr. Danny Vesprini

Sunnybrook Odette Cancer Centre

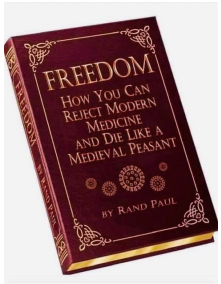
Providing care during the pandemic has been a challenge to us all. Unlike our surgical colleagues, my radiation oncologist colleagues and I saw minimal impact on access to our radiation machines, and other than having to halt several procedures such as brachytherapy or gold seed insertion that we use to treat prostates with a stereotactic approach during the first and second waves of pandemic, we did not have any decrease in ability to treat our patients. In fact, it was the opposite as radiation utilization was only at 70-80% capacity – whereas we were normally over 100%. But this is not for a good reason of course. There has been decreased use of radiation over the past 18+ months because people are not getting diagnosed given the decreased screening in the general population with mammograms and PSA testing. In addition, given the fear people have had coming to the hospital, we know there are patients avoiding or delaying treatment and that reality will eventually need to be dealt with at a more advanced and sometimes incurable stage. We fear that a tsunami of cancer patients, particularly prostate cancer patients, awaits us, which will be a challenge to deal with given our current infrastructure. This has already been seen with our surgical teams, given the enormous backlog of operations that were delayed.

But waitlists aside, and albeit for very good reason, the pandemic has been challenging in providing care given the emphasis that the hospitals have had on switching essentially overnight to virtual care. As one of the busiest clinicians at the Sunnybrook Odette Cancer Centre, this change has been the hardest and most frustrating. Telemedicine is a horrible way to provide care in the majority of situations. It is neither good for the doctor and certainly not good for the patients and their families. I am now piloting doing clinics via a video platform, which certainly is better than a phone call. However, it has its challenges, particularly with my prostate cancer practice, given that many of my patients do have not have access to this technology and ultimately it does not replace seeing someone in person in clinic. Hybrid clinics with some people being seen in person, some via video link, and some by phone calls has increased the administrative burden on everyone at the hospital, including the doctors and nursing teams. This has also had a negative impact on our academic pursuits, e.g. research and teaching, as there are only so many hours in the day.

As well, providing in-person care, which of course we continue in oncology as patients need to come in for their chemotherapy or radiotherapy, has been incredibly challenging given the strict no-visitor policies in place. Having a discussion about treatment or prognosis with a patient without a family member in the room is less than ideal, and in a diverse city like Toronto with a high proportion of our patient population not having English as their first language has added to this complex scenario. However, no-visitor policies were and still are needed. The Odette Cancer Centre is not big enough to allow physical distancing for all our patients, let alone if they have a visitor – but it has resulted in suboptimal care that leaves patients and their families frustrated and overall leads to a decreased quality of life.

All this said, there have been a lot of silver linings in these stormy pandemic clouds. With minimal warning we learned to be nimble and adapt to changes brought upon us. We have learned to work as a team, have compassion for our colleagues, and really understand that we are all in this together. Although telemedicine may not be ideal, other forms of virtual care, e.g. ZOOM appointments, are here to stay and will allow patients to stay connected to their medical teams without having to come into the hospital. This will result in saving time, money, and valuable infrastructure in the hospital itself that was bursting at the seams pre-pandemic. Overall, the pandemic has been a challenge, but I am grateful that I live in Canada with its amazing health care system that has been able to continue to provide the best care possible despite the mess that we are in. After the pandemic is over we will have learned valuable lessons and I believe have a better system given the changes that we have and will make as a result.

Let's just hope this can happen sooner than later as I would really like to see my patients smiling, unmasked faces in person in a clinic with no screen between us!



PCS-TORONTO IS SUPPORTED BY:
* Astellas Pharma Canada, Inc. * Janssen Pharmaceuticals
* Valleyview Residence

PCSToronto & Side by Side

invite you to attend a 2021

"Virtual" Awareness Night Meeting

on Thursday

September 30, 2021

at 7:00 p.m.

featuring

Dr. Rajiv Singal

Michael Garron Hospital

topic:

"Managing prostate cancer in a pandemic."

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.

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.

NORTH YORK HARVEST FOOD BANK

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.

janssen

astellas

Our November Awareness Speaker

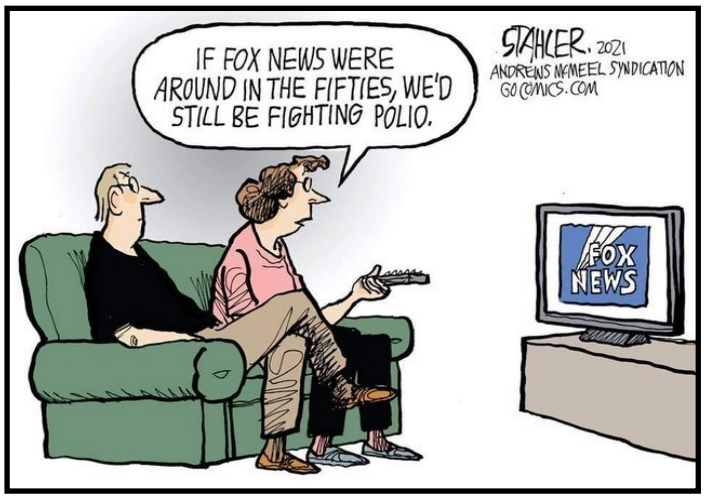
Hi! I'm Christina Dzieduszycki.

I'm a Registered Pelvic Floor Physiotherapist. I treat men, women and children, suffering from Pelvic Pain and Bowel & Bladder dysfunction.

For over 20 years I have worked as an exercise specialist and helped injured military personnel, chronic pain sufferers, patients with neurological impairment spinal cord injuries, and cancer survivors, learn rehabilitative exercise programs that helped improve the quality of their lives.

I am a strong believer in integrating rehabilitative exercise into patient treatment to not just treat existing conditions, but to also prevent new injuries.

I have a Masters in Physiotherapy and a Bachelors degree in Kinesiology. I am currently looking to pursue a PhD in Physiotherapy at McMaster University, looking at the effectiveness of pelvic floor physiotherapy in preventing post operative incontinence in men who have had their prostates removed as a result of prostate cancer.



See below for our September speaker

Looking specifically at which approach is more effective; "PRE-habilitation" or Rehabilitation.

You may have heard me on radio shows like "Ask the Expert" or read about my services in the Hamilton Spectator.

I am a member of the Canadian Physiotherapy Association (CPA) and Women's Health Division.

Christina is the scheduled speaker at our Awareness Night Meeting on Wednesday, November 24th at 7 p.m.

Join us for what will be a very informative evening.

Please check back here in your email for a link for you to REGISTER for this presentation.

See you on the 24th!

This month's Awareness Night Meeting:

THURSDAY, September 30th, 2021

DR. RAJIV SINGAL

Michael Garron Hospital

"Managing prostate cancer in a pandemic."

Check your email or our website for your link to register.

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

By Dr. Sharon Sharir

Humber River Hospital

The arrival of COVID-19 at the start of 2020 resulted in changes to most people's lives. For health care workers and patients, things are also quite different now than they were two years ago.

COVID made a rapid initial impact on how health care was delivered. At the start of the pandemic, in-person appointments suddenly changed to virtual/telephone ones. While we all expected a shift in this direction in the future, COVID caused the future to arrive much faster than anyone could have anticipated.

Some patients welcomed the change. For working people, the convenience of not having to take a half-day off work for a doctor's appointment was a major advantage. Similarly, elderly patients who had difficulty travelling, particularly if it involved longer distances or winter travel, found virtual visits to be an improvement. There were also many people who were afraid to go out of the house, particularly at the start of the pandemic; they appreciated having a virtual option.

However, not everyone was happy with the change. Some people wanted to see their doctor in person. A few worried about the potential for loss of confidentiality if they used the phone or computer rather than an in-person visit. People with communication difficulties, including language barriers or hearing loss, sometimes found that virtual communication exacerbated their difficulties.

Another major way that COVID has impacted health care is in causing delays in procedural treatments. As hospitals filled up with COVID patients during the various waves, scheduled surgeries and radiation treatments were put on hold. By the third wave, the main reason for this was a lack of nurses available to staff the operating rooms; most surgical nurses, and even some surgeons, were forced to bolster staffing in the overflowing ICUs, and were thus unavailable to do surgeries and other procedures.

For men with prostate cancer, these changes had several specific manifestations.

There were men who were initially afraid of any contact and thus refused to see anyone to continue their hormonal treatments. Others would not go get a PSA test, necessary for assessing prostate cancer patients in a variety of circumstances. As the pandemic wore on, most people did eventually restart having treatments and doing tests.

Decreased in-person doctor's visits also meant that sometimes home care was used for things lik hormone injections for some patients. It has also meant a decrease in the use of digital rectal exams. While still necessary in some situations, given that not everyone can be seen as frequently as before, exams have been deferred in some patients whose clinical situation and PSA remained stable.

For patients experiencing delays in their surgical or radiation treatments, this caused anxiety to patients and doctors alike. In some situations, men were given hormonal therapy to control the cancer if there was a prolonged delay. In those who did have their surgeries, there were many new hospital protocols related to pre-operative testing and post-operative visits.

The advent of COVID likely means that virtual care is here to stay, and eventually a good balance will be struck between virtual care and in-person visits. With time, the delays that are currently being experienced should improve.

The most important message to patients is not to ignore other aspects of their health care as we continue to learn how to live with this new virus.

WINSTON KLASS JOINS BOARD OF PROSTATE CANCER FOUNDATION OF BRITISH COLUMBIA

During my first year as Chair of Prostate Cancer Support Toronto, I attended a conference organized by the Prostate Cancer Foundation of British Columbia (PCFPC). It was primarily for its network of support groups; and I was intrigued by the ease with which attendees intermingled - the energy and the camaraderie. This left an impression.

And it was this 'first' impression that sparked my interest in PCFBC's decision to build a national network of support groups. I attended the meetings convened by the PCFBC operating arm, Prostate Cancer Support Canada (PCSC); and my involvement with drafting guidelines for a formal Council provided opportunities to work more closely with PCFBC.

PCFBC subsequently decided that its board should begin to reflect its emergent national presence, and I was invited to join their board - the first member east of BC.

The PCFBC board is composed entirely of volunteers, supported by two passionate and hardworking staff members. PCFBC stages fundraising events throughout the year - to address the needs of its support groups, and also to award modest grants to graduate and post doctoral students involved in prostate cancer research.

Activities and basic components are already in place to maintain and strengthen PCFBC's budding national network. A PCSC website, a directory of Canadian PCa support groups, a Calendar of support group events, regular national newsletters, regular presentations by specialists and national support sessions for AS (active surveillance) survivors and partners of PCa survivors. In addition, PCFBC is already jointly raising funds with support groups across Canada.

Each support group employs a unique blend of creativity, skills and experience to service a unique local (primarily) environment. An active network is in fact a promise - that groups could individually tap into this rich pool of 'prostate cancer support' wisdom. (Alternatively groups evolve in isolation - prone to blind spots, 'group think' and wastage of time and energy reinventing wheels). Moreover, in matters requiring activism, a network potentially provides support groups with a distinct advantage - a single voice.

I perceive my role on the board as familiarizing PCFBC with the support environment in Ontario (in particular), and providing input towards a productive relationship with support groups. The experience has been quite satisfying so far.

I am hopeful that PCFBC will build on its success in BC, and create a strong autonomous national network of prostate cancer support groups.

Winston Klass
Past chair

Are you interested in becoming a PCSToronto volunteer?
Please call our support line - 416-932-8820 - or email us at info@pcstoronto.ca

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.**

DATE		SPEAKER	TOPIC
Jan	27	Dr. Urban Emmenegger *Odette Cancer Centre*	Metastatic prostate cancer.
Mar	31	Dr. Gerard Morton *Odette Cancer Centre*	Radiation treatments.
May	26	Dr. Andrew Mathew *Princess Margaret Cancer Centre*	
Jul	28	PCSToronto survivors	Survivor forum.
Sep	**30**	**Dr. Rajiv Singal** *Michael Garron Hospital*	Managing prostate cancer in a pandemic.
Nov	24	Christina Dzieduszycki, MSc PT, BA [Kin] *Registered Pelvic Floor Physiotherapist*	Physiotherapy Approach for Rehabilitation *(to address incontinence, ED, and related issues)*

Man to Man Peer Support Meetings - 7 p
These meetings take place on the **FIRST** evenings of each month at the **Valleyview Resid** (just west of Bathurst Street on the Br Room. They provide an opport setting about dealing wit

Sid
This ort group, altho se visit our websi

Person
Trained nily in your home, by ical patients at **ybrook Hospital** (

Counseling
Our volunteer cer clinics at the **Princess Mar** gh Friday), the **Odette Cancer Centr & Graham Wright Prostate Centre at Nort ison site (**on Tuesday afternoon).

All of our meetings, personal support, and counseling in hospital prostate clinics have had to change in 2021 due to COVID-19.
Our meetings have all been successfully hosted on Zoom as 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.

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

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