PROSTAIDCALGARY

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Wives, Partners & Caregivers Volunteer Facilitator Needed

Newly Diagnosed Volunteer Facilitator Needed

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PROSTAID Calgary is self-funded. <u>Click here to help us to</u> <u>continue our good work by</u> <u>donating on-line</u>

Proud member of the Prostate Cancer Canada Network of support groups PCCN Calgary



Hello PROSTAID Calgary members and friends.

On Friday March 15, more than forty five sponsors, donors and community supporters gathered for

PROSTAID Calgary's Annual Spolumbo's Luncheon. The celebration was hosted at the at the Inglewood Lawn Bowling Club; catering was sponsored by Spolumbo's Fine Foods and Deli; and libations came courtesy of our partners at Village Brewery. Thank you to everyone for coming out to show your support, and for your continued service and commitment to PROSTAID Calgary.

*Special thanks go out to the Calgary Stampeders and Justin Renfrow for being part of this very special day.

The Spolumbo's Luncheon brought us together to break bread with our friends and longtime community partners Tailgate for Charity and Calgary Football Officials Association (CFOA). A cheque presentation was hosted during the event and we are truly humbled by their generosity and community spirit. This year, Tailgate for Charity donated \$4200 to PROSTAID Calgary and CFOA donated \$1800. Thank you sincerely.

PROSTAID Calgary AGM

I want to remind everyone that PROSTAID Calgary will host our Annual General Meeting (AGM) during the May 14 General Meeting at the Kerby Centre. An election for board members will be held at the meeting so if you're interested in serving as an officer on the Board of Directors, you do not want miss this meeting. More information is included on page 4.

Alternatively, we encourage members to become more involved by serving as PROSTAID Calgary volunteers. For more information about volunteer opportunities please contact me at 403-455-1916.

PROSTAID Calgary is supported by the community and exists for the community. <u>Click here to reach</u> <u>our On Line Donation Page on Canada Helps.</u>

If a donation is meaningful to you, it's meaningful to us.

Warm wishes,

Kelly Fedorowich

Executive Director, 403-455-1916



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April 2019

Number 235

Meeting Schedule Tuesday April 9, 2019

Monthly meetings are hosted at The Kerby Centre, 1133 7th Ave SW.

7:30- General Meeting (GM) 9:00PM Lounge (2nd Floor)

> Guest Speaker: Dr. Linda Watson Presentation Topic: PRO's Integrating Patient Reported Outcomes (PRO's) into Ambulatory Care Processes in Cancer Care Alberta (CCA): Making it meaningful



Support Group Meetings

Warriors Advanced & Recurrent Disease Facilitator: Frank Altin Room 208 (2nd Floor)
Wives, Partners & Caregivers Room 313 (Third Floor) No facilitator this month. Drop in for a cuppa tea.
Newly Diagnosed Room 311 (Third Floor) No facilitator this month. Drop in.

The Kerby Centre is located at 1133 7th Ave SW. Parking is FREE in lots on both sides of 7th Ave. The WEST LRT conveniently stops at the front doors of the Kerby Centre.

General Meetings are open to the public and free to attend. A light snack and refreshments are served. Ladies, family members, and caregivers are always welcome!

Our meetings feature Healthcare, Medicine and Health & Wellness Presentations

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GM Guest Presenter: Dr. Linda Watson

Dr. Linda Watson has been an oncology nurse in Calgary for over 25 years. She has held a variety of nursing and inter-professional leadership roles within the CancerControl Alberta (CCA) provincial program and is currently the Scientific Director for Applied Research and Patient Experience within Alberta's provincial cancer care program.

Dr. Watson holds an adjunct professor position with the Faculty of Nursing at the University of Calgary, but her passion for improving the patient experience has kept her committed to her full time position as a transformational leader within the Alberta cancer system. Over the last decade she has worked closely with the Canadian Partnership Against Cancer (CPAC) and the Alberta Cancer Foundation (ACF) to develop new processes, systems, and programs to enhance clinical capacity to deliver tailored, individualized care to cancer patients in the ambulatory cancer setting. These include using Patient Reported Outcomes (PROs) to improve patient experience, the implementation and evaluation of a provincial cancer patient navigation program to improve the rural cancer patient's access to cancer care, and a provincial posttreatment transitions program that aims to improve the transition between the cancer program and primary care.

Dr. Watson is also currently the President of the Canadian Association of Nurses in Oncology (CANO), providing national leadership to the specialty area of oncology nursing across Canada.

Life After Prostate Cancer Diagnosis Patient Reported Outcomes Study

The Life After Prostate Cancer Diagnosis study funded by the Movember Foundation in partnership with Prostate Cancer UK is the country's largest ever patient-reported outcomes (PRO's) study for the disease.

What are the biggest issues for men living with prostate cancer?

The research revealed that more than 4 in 5 men with prostate cancer struggle with poor sexual function following treatment for the disease regardless of the stage of their disease, their treatment, or their age. Despite this, just over half reported they were not offered help with sexual function, such as medications, devices, or specialist services.

What other issues do these men face?

Men with prostate cancer also reported problems with pain/discomfort, taking part in their usual activities, mobility and anxiety/depression, with just over 60% of men reporting at least one problem in any of these areas.

Men also reported social distress, problems with self-care, maintaining relationships and money matters, although to a lesser degree.

Significantly, men treated with hormones report more problems in all areas.

Men who are not the 'typical' patient with prostate cancer – those who are under 65, single, and/or gay, have specific needs for support and information. They can feel marginalized and lonely, and struggle to accept the impact on their sexual relationships, identities and work life.

Younger couples and parents also struggled to manage the impact of their disease on the family and access the support needed.

What support should General Practitioner's (GP's) be offering?

In line with <u>NICE guidelines</u>, health professionals should proactively initiate discussions about side effects, including sexual problems, and should signpost men to the appropriate support and information.

Men should have access to specialist erectile dysfunction services should they need them, and may be offered a daily low-dose PDE5 inhibitor tablet (Example: Cialis, Viagra, Levitra) to improve their chance of getting erections alongside a range of PDE5 inhibitor tablets to take as and when they want to get an erection.

If this is unsuccessful, or can't be taken because of other health reasons, men should be offered vacuum devices, topical drugs, or penile prostheses as an alternative.

Health professionals also need to consider providing men with tailored information and support that is relevant to their treatment type, symptoms, age, stage in life, marital status and sexuality.

Summary

It's clear from the findings that the side effects from prostate cancer treatments can have a big impact on men's lives. Some of these side effects can be life changing, challenging and long-lasting or even permanent, so it's vital that men get support to help them deal with these changes.

Our meetings are hosted on the second Tuesday of every month at the Kerby Centre Digital Examiner Page 3

With the right support and information, men can find out about treatments or counselling that could help them manage, or come to terms with, sexual problems and other difficulties caused by their cancer experience.

Problems experienced by men with prostate cancer Percentage of men who experienced poor sexual function, by treatment type:

- Active Surveillance 51%
- Watchful waiting 58%
- Brachytherapy 63%
- Surgery 84%
- Surgery + radiotherapy / ADT 92%
- Radiotherapy 79%
- Radiotherapy + ADT 88%
- ADT 94%
- Systemic therapy (ie chemotherapy, abiraterone or enzalutamide) + ADT – 98%
- Systemic therapy (ie chemotherapy, abiraterone or enzalutamide) + radiotherapy +/- ADT 95%

Percentage of men who experienced poor sexual function, by age:

- Under 55 years 54%
- 55-64 years 66%
- 65-74 years 79%
- 75-84 years 88%
- 85+ years 95%

Other problems

Men most commonly reported problems with:

- Pain/discomfort 42%
- Taking part in their usual activities 37.7%
- Mobility 36.1%
- Anxiety/depression 33.6%

They were least likely to report problems with:

• Self-care – 14.3%

Just over 60% of men reported at least one problem on any of these five domains (62%). Men treated with hormones report more problems in all areas. By Dr. Anna Gavin, GP Online.com Article has been abridged. Click here to read in its entirety

CheckMate 650 Trial Phase 2 Results

Unlike many early-stage prostate cancers that need normal levels of testosterone to grow, castration-resistant prostate cancer (CRPC) continues to grow even when the amount of testosterone in the body is reduced to castrate levels. Treatment of this kind of prostate cancer has been rather difficult and a significant amount of research is directed towards finding agents that can successfully counter CRPC.

In mid-February, Bristol-Myers Squibb announced results from its pivotal trial CheckMate-650, which showed that Nivolumab plus Ipilimumab provided a significant response in patients with metastatic CRPC. Nivolumab is an Anti PD-1 antibody which prevents tumor cells from suppressing T cells. Ipilimumab is an Anti CTLA-4 antibody which allows dendritic cells to fully activate T cells against tumor cells. The combination has shown success against other tumor types and hence was tested in CRPC.

The results showed that among 32 patients whose disease had progressed after second-generation hormone therapy and who had not received chemotherapy, the objective response rate (ORR) was 25%.

In a second cohort of patients, among 30 whose disease progressed after taxane-based chemotherapy, the ORR was 10%.

Across both cohorts, higher response rates were seen in certain patient sub-groups, including patients with high tumour mutational burden, in patients with homologous recombination deficiency and in patients with high levels of PD-L-1 expression.

The clinical results from this study are encouraging and provide the foundation to test the combination strategy in a larger cohort of patients. They also suggest that this kind of treatment may be better done earlier, before chemotherapy. Chemotherapy likely makes the immune system weaker and less responsive to immune based therapies such as this.

Healio.com, Genitourinary Cancers Symposium <u>Article has been edited. Click here to read in its entirety.</u>



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Board Members, Support Group Facilitators & Volunteer Opportunities

The benefits of volunteering are enormous to you, your family, and your community. It can help you reduce stress, find friends, connect with the community, learn new skills, and even advance your career. Giving to others can also help protect your mental and physical health.

Volunteering offers vital help to people in need, worthwhile causes, and the community, but the benefits can be even greater for you, the volunteer. Volunteering and helping others can reduce stress, combat depression, keep you mentally stimulated, and provide a sense of purpose. While it's true that the more you volunteer, the more benefits you'll experience, volunteering doesn't have to involve a long-term commitment or take a huge amount of time out of your busy day. Giving in even simple ways can help those in need and improve your health and happiness.

Volunteers

We hope you'll consider becoming a PROSTAID Calgary volunteer! Please contact <u>Kelly</u> to have your information added to PROSTAID Calgary's Volunteer Database and be notified of Volunteer Opportunities via email.

Facilitator for Wives, Partners, and Caregivers Group

Prostate cancer is a couples disease. We're currently looking for an individual with a sincere interest in helping others through the often difficult journey of prostate cancer.

Meetings are held on the second Tuesday of each month from 6:30 to 7:20PM.

Facilitator for Newly Diagnosed Group

We are currently looking for an individual with a sincere interest in helping others through the often difficult journey of prostate cancer. A level of personal understanding of a prostate cancer diagnosis is valuable but not mandatory.

Meetings are held on the second Tuesday of each month from 6:30 to 7:20PM.

Please contact Kelly for more information 403-455-1916 or info@prostaidcalgary.org

New Board Members Needed

PROSTAID Calgary will be electing several new members to our board in 2019. We're looking for board members who believe in our mission and are willing to be active in their role.

Formed in 1993, PROSTAID Calgary's mission to help men and their families deal with prostate cancer. We do this by: •Providing peer-to-peer mutual support for men and their families on their journey with prostate cancer.

•Educating and informing our members about prostate cancer

•Increasing public awareness of the disease.

•Advocating for a strong provincial voice in matters relating to prostate cancer.

Directors are responsible for overseeing the mission and purpose of the organization. Duties include participation in strategic planning and making policy decisions, then securing the financing of them and the monitoring of their execution. Members must be willing to attend monthly meetings, follow through on commitments, and participate fully in the decision-making process. The board also presents the organization's image to the community and solicits its support in achieving PROSTAID Calgary's goals.

The next several years promise to be exciting ones for PROSTAID Calgary. The organization will continue to have a positive impact on the communities we serve and the Board of Directors will play a central role in this important work.

PROSTAID Calgary Board of Directors meet on the first Thursday of every month at the Danish Canadian Club from 11AM until 12:30PM. Lunch follows.

