



Washington State Prostate Cancer Coalition

www.prostatewashington.org

Providing a unified voice for
Prostate Cancer advocacy and
awareness in Washington
State.

November/December 2016, Issue #2

Monthly Support Group Newsletter

Message from the Chairman:

The holidays are in full swing and all of our support groups and coalition partners continue to reach out to local communities in an effort to “make prostate cancer a key public health priority for the people of Washington”. Support group leaders continue to conduct monthly meetings for those individuals and families recently diagnosed or continuing to manage prostate cancer. Coalition partners continue to conduct research and provide education to both healthcare providers and the public.

The Washington State Prostate Cancer Coalition could not continue our important work and support of the coalition partners without donations from individuals and organizations wanting to help the primary WSPCC objective categories of Prevention, Detection, Treatment and Survivorship. We have just launched a new donation page to our website to assist in reaching our 2017 goal of \$50,000. Your donations will go to support; 1) work of the prostate cancer support groups around the state, 2) local prostate cancer and survivorship research, 3) expenses related to community outreach and educational activities, and 4) medical community evidence based education.

The first donation campaign was the 2016 Beard Fest Campaign coordinated by Bev Davidson of the Yakima Support Group through the end of December. This campaign was followed by the annual # Giving Tuesday on November 29, 2016. Currently, End-of-Year-giving campaign and can be accessed by clicking below:

<https://prostatewashington.networkforgood.com/projects/22203-end-of-year-giving>

A daily donation of even a quarter a day will help our efforts. Please share the donation button on our website with your friends and family.

This past year, money raised for the support groups went to provide the following services:

- 1) Annual support group leadership workshop including travel assistance and hotel accommodations for leaders located outside the Greater Seattle area.
- 2) Support Group promotional brochures
- 3) Creation of templates for business cards, flyers, etc
- 4) Monthly newsletters specific to support groups to increase communication throughout the state
- 5) Marketing assistance with local fundraising efforts
- 6) Assistance in identifying and securing speakers for support group meeting

We look forward to continuing the services started this past year and expanding our activities as we hear your needs in the coming months. Contact your administrative assistant, Jessica Watson, with additional needs you have in running your support groups or engaging in activities within your local communities. Jessica@prostatewashington.org.

May you all continue to have a wonderful holiday season and into the New Year!

Debi Johnson
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Washington State Prostate Cancer Coalition
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Press Box:

This past year there has been a lot of publications related to BRACA1 and BRACA 2 genetic mutations and the link between prostate cancer and breast cancer. We have known that in some cases prostate cancer is hereditary and other times it is due to genetic mutations. How does someone know if they are at risk for an inherited cancer versus non-inherited cancer to develop in their lifetime? How do they know if they should go in for genetic counseling, or what kind of conversations someone should have with their physician? So many questions and in many cases, it is the elephant in the room, because no one wants to face the diagnosis or what it does emotionally to an individual or their family.

As support group leaders or someone who has been affected by prostate cancer, having these conversations with your physician is very important. It is even more important that people feel comfortable communicating with their physicians about their family history and then going through the shared and informed decision making process about their health care.

As support group leaders, you often come into contact with people who may not know the facts. The WSPCC would like to highlight some talking points that could help encourage people in our communities to talk with their physicians. Information presented comes from the National Cancer Institute website states the following statistic and statements regarding the BRACA1 and BRACA2 genetic link to prostate cancer:

What is BRACA1 and BRACA2? “*BRCA1* and *BRCA2* are human genes that produce tumor suppressor proteins. These proteins help repair damaged DNA and, therefore, play a role in ensuring the stability of the cell’s genetic material. When either of these genes is mutated, or altered, such that its protein product either is not made or does not function correctly, DNA damage may not be repaired properly. As a result, cells are more likely to develop additional genetic alterations that can lead to cancer”.

Now that we know what BRACA1 and BRACA2 genes are, what are some statistics or statements that could be discussed in a conversation that could get someone thinking about their family history and start talking with their physician?

- “Nearly 12% of men with advanced prostate cancer have inherited mutations in genes that play a role in repairing damaged DNA-associated with an increased risk of several other cancers, including breast, ovarian, and pancreatic cancer.”
- “8% of men with metastatic prostate cancer had inherited a mutation in a DNA-repair gene.”
- “The risk of prostate cancer may also increase in men who have a family history of breast cancer.”
- “Men with a family history of both prostate and breast/ovarian cancer were also at increased risk of prostate cancer.”
- “Analyses showed that breast cancer risk was associated with a family history of both breast and prostate cancers; the risk was higher in black women than in white women”.
- “A family history of prostate cancer also increases the risk of breast cancer among female relatives.”
- “The association between prostate cancer and breast cancer in the same family may be explained, in part, by the increased risk of prostate cancer among men with *BRCA1/BRCA2* pathogenic variants in the setting of hereditary breast/ovarian cancer or early-onset prostate cancer.”

In our ongoing effort to bring prostate cancer to the fore front in making it a key public health priority in Washington State, we want to continue discussing what is being discovered through research. Educating our communities and getting them to talk with their physicians about prostate cancer makes a difference in many lives. In today’s healthcare system we need to empower men and their family’s to discuss their family history and current healthcare status with their physicians. Thank you for being advocates for families

in your communities. Although we may never see the outcome of your efforts in your community, your time, passion, and care for those you talk to can make a huge difference in someone's life.

Let us know if you run across an article you are finding informative for your support groups and we will share with the other support group leaders. Additionally, we will be sharing resources and articles that are shared among the newly created advisory council.

Events:

Bearded Fest 2016



On November 26, 2016 from 6-10 pm Russillo's Pizza and Gelato put on a fundraiser to help bring awareness for Men's Health. The miracle in this story is that someone in the community gave the manager Beverly's name. Beverly is the Yakima Prostate Cancer Warriors support group leader. She met with the manager and assisted in advertising this event in town. Russillo's partnered with other local



businesses and provided raffles and prizes, dinner specials, and 50 cents a beer when the train goes by for all ready consuming folks. Money raised during this event



was donated to the Washington State Prostate Cancer Coalition.

A special thank you to Russillo's for all their hard work in putting on this event.

UsToo International Phone Conferences

UsToo International has started monthly phone calls, support group leaders have two opportunities to participate in these calls. I have had the pleasure of sitting in on them for the month of November and have found that the issues of finding committed leaders to help run support groups is a frequent problem across our nation. It is also another way to gather and share ideas about how to solve problems that we may be facing with running a group.

The calls will always be on the below days, with the same number:

- Pick up the phone and participate in a conference call
 - o Two regularly scheduled calls each month; join one or both
 - o Second Tuesday of every month (except on holidays) one-hour call beginning at 10:00 am Central Time / 11:00 am Eastern Time (8:00am PST)
 - o Third Thursday of every month (except on holidays) one-hour call beginning at 3:00 pm Central Time / 4:00 pm Eastern Time (1:00pm PST)

Call: 866-906-0123 | Participant Code: 936-8258#

Shelton Prostate Support Group

The WSPCC recognizes what a huge volunteer job all support leaders take on. In October Bill Praskta stepped down as a leader for the Shelton group and two member stepped up to co-lead the Group. We would like to introduce them to you all if you have not met them. Jim Reese and Dick Parrett are the new co-leaders of the Shelton Prostate Support

Group. They are very much invested in the continuation of support men and their family's through their journey of being diagnosed with prostate cancer. Below is both Jim and Dick's bios. Please join the WSPCC in welcoming our new leaders. Thank you for your heart, willingness to serve and you take care of your community.



Jim Reese: "Hi, I am Jim Reece, trying to be a co-leader of the Shelton UsTOO chapter. I am 77 years old and in November of 2009 my PSA went to 6.5 during my annual physical after being 2 for many years. One week later the PSA was 7.0 as the doctor could not believe a one year jump from 2 to 6.5. The prostate biopsy came back with a Gleason of 8. Robotic prostatectomy followed in January of 2010 and the Gleason was 9 in the pathology report. By June of 2010 the PSA was back to .47 with unacceptable doubling rates. Salvage radiation covered 33 daily sessions and ended in August 2010. The PSA kept climbing and doubling until August 2011 it was 5.6. Hormone therapy started in September 2011 and the PSA dropped to undetectable in December 2011. It has remained undetectable. December 2016 is the next PSA test as it is now tested every 6 months. My objective is to spread the word on how important it is to know and track your PSA, so that corrections can be made early before the cancer advances. You just need to talk up the subject with every one you meet. For example, I just had a meaningful conversation with a popcorn vendor at a craft show (never had met him before) and he is going to take action concerning his PSA and colonoscopy."



Dick Parrett: "In October of 1993 I had a complete physical examination from my GP for my 60th birthday. He discovered a lump with his "finger wave" exam and referred me to Dr. Gary Miller, an Oncologist in Olympia. After a PSA test result of

18.5 Dr. Miller did a biopsy and found 8 out of 10 samples tested positive. This was over 20 years ago, and a lot of procedures available today were not available at that time.

When my wife and I were given the news the day before Thanksgiving we were devastated. I went through all of the emotions; anger, denial, fear, and finally resignation. I looked for a support group in Olympia and attended one meeting, but the group at that time was less than empathetic about my problems, they were more interested in talking about their own problems. I had surgery in February of 1994, and at that time was told to expect around a six week recovery time. With exercise and daily walks around Capital Lake with Dolores, I was able to return to work after three weeks.

The following year, with an advancing PSA, I went through a 45day radiation treatment program. Since that time my PSA has remained in the .04-.05 area until September of 2016 it is now 1.2. I will be getting tested more frequently now, but at the age of 83 the Prostate Cancer will probably not catch me until something else does. The moral to this story is, get regular PSA testing and research the many options that are available today."

Seattle UsToo Support Group

November also marked the final Us TOO in Seattle meeting chaired by our founder, John Fogarty. John established the Us TOO in Seattle group more than four and a half years ago, and in that time has secured the meeting space, created informational materials, recruited speakers, facilitated the meetings, and provided individual counsel and support to countless men facing the challenges of all stages of prostate cancer. (While we understand that that pretty much defines the role of an Us TOO chapter leader, we feel that John did it with a great deal of élan!) Although John is retiring, we expect to see him as an engaged participant at our future meetings.

Speaker Spot Light:

Our Speaker Spot Light for this month comes from Seattle UsToo Support Group. Below is a brief summary of their speaker written by Marty Chakioan.

“The Us TOO in Seattle chapter was honored to have Dr. Celestia (Tia) Higano as the featured speaker at our November meeting. Dr. Higano is a Professor in the Departments of Medicine (Division of Oncology) and Urology at the University of Washington and a Member of the Clinical Division at Fred Hutchinson Cancer Research Center. Her research focus has been on new drug development including immunotherapy, the effects of androgen deprivation therapy on the male body and mind, and the development of supportive care/survivorship programs for prostate cancer patients and their partners.

Dr. Higano’s presentation to our group focused on the increased risk of cardiovascular disease among men undergoing androgen deprivation therapy and strategies for reducing that risk. Her efforts have been instrumental in the development of many of the new and more effective treatments for fighting prostate cancer. As a clinician, her focus is on men with the disease and their loved ones. Her deep knowledge, skill, and compassion were recognized and greatly appreciated by our membership.”

Please continue to submit your topics and speakers. Please let me know if it ok to publish their contact information as well. However, if their contact information is not published, feel free to contact Jessica at jessica@prostatewashington.org for specific information.

Advisory Council:



Our Advisory Council is created by a variety of disciplines across the continuum of healthcare. They are not only making a difference in men’s lives around the State of

Washington but also making advances in the following areas of prevention, detection, treatment, and survivorship. With this committed council and the partnership with Washington Prostate Cancer Coalition, a difference is being made in men’s health care as well as helping to further our vision in “Provide the unified voice for prostate cancer advocacy and awareness in Washington State”.

***If you know of an organization or group of individuals that you feel would benefit the coalition, please forward the information to Jessica@prostatewashington.org.**

American Cancer Society (population of health)
Bastyr University (naturopathic medicine)
Desimone Consulting Group (general health policy)
DOH: Healthy Communities (includes Health equity specialist)
Fred Hutch Cancer Research
Healthcare System Cancer Support Services
MaleCare (gay & bisexual community)
MultiCare Regional Cancer Centers
National Association of Chronic Disease Directors
PhRMA: Pharmaceutical Research & Manufacturers
Seattle Cancer Care Alliance
Social Media Consulting
Society of Urologic Nurses
U.W. Urology Oncology Research
UsTOO International
Washington Alliance for Cancer Survivorship
Washington State Academy of Nutrition & Dietetics
Washington State Medical & Radiation Oncology
Washington State Prostate Cancer Support Groups
Washington State Urology Society

Hot Topic for Support Groups:

The month of November is National Family Caregiver Month. As the WSPCC acknowledges the importance of the many different caregivers in our lives, we want to encourage everyone to think about the caregiver in your life and to express your thankfulness for all that

they did for you. What a wonderful way to give thanks during the month of November.

Caregivers play such an important role after being diagnosed with prostate cancer. Suddenly your life takes a turn and your emotional well-being becomes consumed with overwhelming information leading to confusing, frustration, denial, seeking answers, are just a few emotions that one goes through. Our loved ones are also affected. They too go through all the emotions, but also come to the realization that they play an important role in caring for you. The role of caregiver takes on responsibilities that the two of you may have shared in the past, and worked as a team. They move about their day taking care of you as well as the household, finances, and assisting in making medical decisions.

How many of us have someone in our lives that is not just our loved one, but also whole heartedly took on the role of caregiver? They became your nurse, gave you your medication, made doctor's appointments, they are your sounding board, comforter, and made major decision with you. They supported you during your emotional ups and downs, and continued not only loving you but also caring for you.

The caregivers in our lives are the most giving people we know and this can go unrecognized, especially during the time of new diagnosis, illness during treatment, and adjusting to other life changes. They walk through difficult times without asking questions or complaining. In a majority of situations, it becomes their identity, their needs and desires take a back seat, and they are there to help and support no matter the cost. When was the last time you recognized your caregivers needs without being asked or overhearing a conversation with a friend? How many of us were patients and now becoming a caregiver ourselves or participating in a team to help take care of the one who took care of you?

The caregivers in our lives are very important people. They are loved and cherished, and no matter what we say to express how thankful we are for them, it never seems to be enough, knowing what a difference they

made in your life. When you were going through diagnosis, treatment, recovery, to survivorship and thriving. They continue to be your support and walk along side of you, being your pillar of strength and encouragement. What an awesome reminder of how you did not walk alone, and during this time of thanksgiving be able to express that to our loved ones who became much more.

Nutrition Corner

Nutrition is an important part of everyone's life. How we eat and the life choices that one makes can have various impacts in our life. Below are links to articles that discusses different aspects of nutrition and lifestyle choices. Patty McDonnell, Oncology Nutritionist with the WA State Academy of Nutrition and Dietetics has referred the articles below, feel free to download and share.

The first article is titled, "AICR Guidelines for Cancer Survivors":

<http://www.aicr.org/patients-survivors/aicrs-guidelines-for-cancer.html>

The second article is called, "Prostate cancer progression and mortality: a review of diet and lifestyle factors" by Sam F. Peisch Erin L. Van Blarigan, June M. Chan, Meir J. Stampfer, and Stacey A. Kenfield.

The purpose of this article is to review evidence of diet and lifestyle factors as they relate to the progression of prostate cancer. It is general knowledge that dietary and lifestyle factors impact the progression of prostate cancer. Some of the lifestyle factors are maintaining a healthy weight, regular exercise, and not smoking. Dietary factors that play a role in decreasing the risk of progression related to prostate cancer are coffee, tomato sauce, cruciferous vegetables (broccoli, brussels sprouts, cabbage, cauliflower, collards, kale), and health vegetable fat. Overall, the findings in this article are important enough for researchers to continue

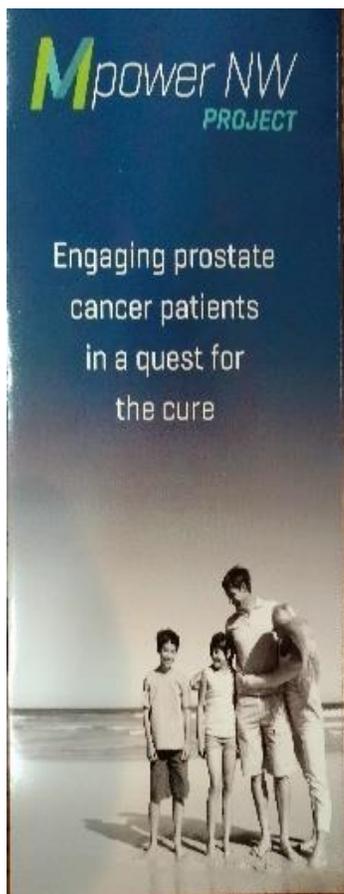
studying their findings to help men and their family navigate positive lifestyle choices and nutrition with prostate cancer. If you would like to read the article, feel free to download load it, the link is below.

<https://rd.springer.com/article/10.1007/s00345-016-1914-3>

If you have any topic regarding nutrition that you would like to have more information on, please feel free to send an e-mail to Jessica Watson, WSPCC Administrative Assistant at jessica@prostatewashington.org

Research Corner:

MPower NW Project Engaging prostate cancer patients in a quest for the cure.



Nola Klemfuss from the Fred Hutch Cancer Research Center joined us during the Leadership Workshop in September and is an active member of the newly formed WSPCC Advisory Council. This was a great time to hear from her how the research project is doing and what is needed.

The WSPCC encourages all members of the prostate support groups to enroll and participate in this research project. The research is different than other project in that it is specifically looking at partnering with patients to improve prevention

and treatments of prostate cancer. The goal is to gather statewide trends of prostate cancer patient's experiences with diagnosis, treatment, and quality of life. Your enrollment and willingness to participate in this research study will help future diagnosed patients.

Please log onto: www.mpowernw.org to get involved. "Your opinion will help shape what we know about prostate cancer"

Fundraising Activities:

We are excited to announce we have a partnered with Network For Good to assist with raising funds for the next 12 months. Jessica has been working closely with them to get different campaigns up and running so we can build a donor data base, writing grants, and receive the money raised.

Our Network For Good page is up and running and there is a direct link on our website. We have made changes to the ProstateWashington.org website to make the "Donate" tab more visible to those who visit our site. When you click on this it will connect you the Network For Good to complete the donation.

What can you do to help raise money? Here are some ideas in which you could help raise money for the WSPCC so we can grow in our support.

- Running small events with the goal to raise money.
- Every time you are doing an outreach, have a computer or mobile phone that if someone wishes to make a donation, you can assist them.
- Hand out cards with the WSPCC donate information on it.
- Make short 2 minute videos and send them to jessica so they can be used on the different campaign pages to encourage donations.

All funds raised through WSPCC activities are used to support the four (4) objective categories of prevention, detection, treatment and **survivorship** along with the primary general objectives of the organization:

- 1) Increase public awareness and visibility of prostate cancer
- 2) Advocate for prostate cancer research funding, prevention and intervention
- 3) Increase awareness of and accessibility to clinical trials
- 4) Improve accessibility to early detection, diagnosis and treatment
- 5) Advocate for healthy lifestyle behavior
- 6) Support the medical community evidence based education
- 7) Advocate for shared and informed decision making across the continuum of care.

We are currently working on raising money through a variety of WSPCC led initiatives and events so we can continue our work for the people of Washington including off-setting expenses of the prostate cancer support groups.

Zero 5K Run/Walk:

Mark your Calendars for October 7, 2017 will be the Seattle Zero 5k fun run/walk. Time of event to be announced.

Plan to attend and participate in the celebration of prostate cancer survivorship with the hat ceremony performed for all survivors in attendance. Bring your families to create your own individual teams or plan to establish a team for your support group. This will be the first of many large outreach and awareness Run/Walks that will be conducted in Washington for those who have been diagnosed with prostate cancer and their families.

If you are interested in volunteering at the event or creating a team, please contact Jessica by e-mail at jessica@prostatewashington.org

End of Year Giving

Here are some end of the year giving opportunities, please go to the address below to donate.

Beard Fest 2016 (Campaign open Nov. 26-Dec. 31, 2016)

<https://prostatewashington.networkforgood.com/projects/21030-beard-fest-2016>

Giving Tuesday November 29, 2016 (One day only)

This was only 1 day and it is now closed, but we are not done. Our efforts have now moved into the End of year giving campaign. This campaign can be reached by clicking on the link below or by going to our website and clicking on the donate tab and selecting End of year Giving.

End of Year Giving December 2016 (Dec.1-Dec. 31, 2016)

<https://prostatewashington.networkforgood.com/projects/22203-end-of-year-giving>

To make our donation efforts successful, we need everyone's help. When you receive information in your e-mail box, please forward to friends, family, physicians, clubs, insurance firms, banks, various clubs, and so on. We are fairly new on the donation scene and need all the help we can do to get our name out there and donations coming in.

The Washington State Prostate Cancer Coalition is a nonprofit 501(c)3 organization is tax deductible.

Upcoming Events:

Annual Membership Meeting for the WSPCC:

We would like to thank everyone who participated either by poll or e-mail to help determine a date for our Annual membership meeting. This will be a great time to hear what was accomplished in 2016 and what we are looking forward to in 2017.

Please mark your calendars:

Date: Monday January 9, 2016

Time: 12:00 pm-1:30 pm

Location: Evergreen Healthcare

Green/Conference

Green 1270-1272/Kitchen

Please RSVP your attendance with Jessica at jessica@prostatewashington.org

April: The WSPCC would like to bring together the Support Group Leaders for another day conference. Goal is to prepare for summer and September advocacy and outreach events during June (Men's Health Awareness Month) and September (Prostate Cancer Awareness Month). The date will be announced soon.

NOTE: If you have an event you would like the WSPCC assistance with or would like to make available to the other support group; please contact the WSPCC Administrative Assistant, Jessica Watson jessica@prostatewashington.org so the event can be included in the next newsletter.