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Prostate Cancer Foundation of Australia

THE WALNUT

July 2023

Newsletter of the Prostate Cancer Support Group–ACT Region

Postal address: C/- SHOUT, Building 1, Collett Place, Pearce ACT 2607

https://pcsg-act.org.au

Coming meetings

'Christmas in July', 6:30 pm Tuesday 18 July

Instead of our usual Group meeting on Wednesday 19 July, we we will be having a 'Christmas in July' function in the Community Room on the ground floor of the Canberra Southern Cross Club, Woden. This will be held on Tuesday 18 July, not our usual Wednesday.

This will be an opportunity to catch up with other members in a relaxed social environment.

You can also bring along family and friends.

To help with table bookings, please advise by Sunday 16 July if you will be attending and the number of attendees to: secretary@pcsg-act.org.au

However, if you forget to do this, please do still come along. We would still like to see you there.

Coffee morning, 10:00 am Tuesday 11 June 2023

Our next coffee morning is at the Canberra Southern Cross Club, Woden.

From the President

Hi All,

I hope this issue finds you all well and managing to stay warm through some of the rather chilly days we have endured in June.

My apologies for not being able to attend our monthly meeting in June but I only arrived back from my trip to the USA on the Wednesday afternoon so need an early night. The joys of getting older. LOL

My trip to the USA presented me with an opportunity to do something which was unexpected but highly motivating so I thought I would share it with you.

My primary reason for visiting the USA was a catch up with daughter Kylie who lives in San Francisco. She had organised a road trip which took us on an 11-day trip through 5 states, travelling over 6000 kms.

I got to travel through, and do some hiking in, some amazing national parks and monuments It wasn't all hard work There were a couple of wineries and distilleries thrown in!

The highlight for me was the second hike I did into the Grand Canyon. Yep, you heard right, second.

I had done an early morning 6.5 km hike starting at 4 am to view the most amazing sunrise at a place called Ooh Aah Point.

My second hike in the same day was called the Indian Gardens Hike. Essentially it was a 4.5 hour 14 km round trip, descending and ascending through 3000 feet.

The hiking journey was about being mentally and physically (which I probably wasn't) prepared, and as my daughter mentioned at the top of the trail before proceeding down, "Dad going down is optional coming back up isn't".

My daughter has done several rim-to-rim hikes through this amazing canyon so in this case she was

my guiding expert.

As with my prostate cancer journey, I realised that I need to listen to the advice, follow directions, doing the right things at the right time and ultimately, I would conquer my journey.

The hike down was amazing and, with every turn in the winding razor back trail, the scenery changed and was mind blowing.

It was the hike out and back up the ever-winding trail gaining 3000 feet in altitude that made me realise how my 19-year prostate cancer journey had prepared me for this moment.

As I ascended the canyon, I spent much time reflecting. I came to the realisation that, while at times my prostate cancer journey had been challenging, and at times difficult without knowing what may be just around the corner and what the outcomes might be, by listening to advice, making timely decisions and pressing ahead I had achieved the best possible outcomes. My hike would be a reflection of these basics. It was these collective fundamentals that drove me to continue on, even during the last 2 kms of the hike where I really started to feel the challenge. Apparently, they call this the 'trudge zone'.

Standing at the top of the rim again, I overlooked the enormity and grandeur of the Grand Canyon. Breathing deeply and taking in the realisation of the challenge I had conquered, I felt overwhelmed with a sense of achievement.

I can say with confidence that I am grateful for what my prostate cancer journey has given me, the person I have become, and that I am prepared to let go of those things which it may have taken away without letting it define me.

I focus on what I can do rather what I can't, what I have to offer rather what I don't, and no matter how small I try to make a difference every day of my life.

The moral here is, stay strong, never give up, allow all that is behind you to keep motivating you to move forward.

We all have something to give.

I wish you, all the best in your journeys.

Greg McRoberts
President

John McWilliam and Dr Don Bradfield with NAVITAS and Women's Health Service members

NAVITAS presentations

This month John McWilliam and Dr Don Bradfield gave three presentations to men from non-English speaking backgrounds on prostate cancer awareness.

Most of the men were newly arrived migrants.

The presentations were arranged through NAVITAS Skilled Futures and the ACT Government's Women's Health Service. NAVITAS assists migrants and refugees in their journey to building better futures, by improving their literacy, numeracy, and digital skills.

We provided three presentations. The first was at NAVITAS' Civic office, the second in Gungahlin, and the third was an online presentation.

The main thrust of the presentations was to increase awareness of prostate cancer and the need to be proactive in getting PSA tests if in high risk groups, as set out in the PSA testing guidelines.

The presentations appeared to be well received.

We are likely to provide presentations for other migrant groups in the future.

June Group Meeting

Fourteen members attended our June meeting in person and other members attended online. This was a pleasing turnout for a cold Canberra winter's night when the State of Origin match was also being broadcast.

Attendees were treated to an excellent presentation from Dr Irmina Nahon. Irmina is a long-time supporter of our group and it was wonderful to have her present to us again.

It was timely for Irmina to speak to us about male incontinence in World Continence Week.

Irmina noted that support for male incontinence in Canberra has grown over the past 20 years. Whereas 20 years ago there were no clinics dealing with male incontinence, now there are four physiotherapy clinics specialising in continence and around 12 more physiotherapists with a strong interest in this area.

Irmina provided a reminder about the prostate organ, including that it keeps growing and enlarging from puberty and throughout life. This explains why many men have benign prostatic hypertrophy (BPH), a non-cancerous (benign) enlargement of the prostate gland.

The prostate, in addition to its main function in producing the major fluids that make up semen, has muscular tissue that aids in continence in men and helps to keep balance in the bladder. After a prostatectomy, men need to rely on their pelvic floor to regain continence. There is greater movement of the bladder possible when the prostate has been removed.

Aside from BPH and prostate cancer, men may have prostatitis, which often causes painful or difficult urination, as well as pain in the groin, pelvic area or genitals. It is important that men speak to their GP if they have any continence or painful symptoms while urinating.

In treating prostate cancer, two important goals are to:

- find *clinically significant* cancer at a point where a cure is possible; and
- avoid excessively aggressive treatment in *clinically insignificant* disease.

Irmina summarised the options for treating localised prostate cancer in Australia:

- active surveillance;
- surgery;
- radiation; and
- high-intensity focused ultrasound.

She also outlined some of the treatments for advanced prostate cancer.

With radiation, incontinence is generally not too problematic during the first five years. However, incontinence seems to increase over time. Around 33 per cent of patients who have radiation treatment experience some urinary and faecal incontinence once a month after five years.

The male pelvic floor muscles support the abdominal contents, are active during breathing, maintain urinary and faecal continence, increase local blood supply and are active during sexual intercourse.

The male pelvic floor muscles differ from the female pelvic floor muscles. The female pelvic floor muscles are bowl shaped, while the male muscles are like two horseshoes in shape. In males, they lift the base of the penis and play a role in continence (at the end of urination). They also are breathing muscles and make sure that blood is flowing to the area. They are posture muscles.

To regain continence after surgery, it is important that men train the pelvic floor muscles correctly and then do this in everyday activities so that 'this 'knack' is applied unconsciously (much like not having to think about how to ride a bike each time). Ideally, this training of the pelvic floor should start a few months before surgery. The 'knack' is then subconsciously applied in everyday activities, such as standing up and climbing stairs.

Irmina took us through how to use the pelvic floor correctly in regaining continence. A pelvic health continence physiotherapist can assist men to correctly train the pelvic floor and to develop a suitable pelvic floor program.

Around 80 per cent of men will successfully regain continence after surgery. However, for some men, incontinence may persist and there are some surgical options that can be considered.

PCFA News

Max Gardner Award recipients

Three prostate cancer survivors have been awarded a prestigious national award for their community service, dedicating a combined estimated total of nearly 20,000 hours of their time to supporting men and families affected by the disease over many decades.

The award has been presented by Prostate Cancer Foundation of Australia and is named in honour of the late Max Gardner, who helped establish a support group network that now comprises over 120 local groups around the country.

PCFA Chairman, Adjunct A/Prof Steve Callister, announced the recipients on Wednesday 7 June 2023.

"The award recognises the outstanding contribution these gentlemen have made to our mission and their remarkable dedication to supporting other men and families impacted by prostate cancer," he said.

"Over many years they have each gone above and beyond to champion our work, making a profound contribution to each of the three pillars of our service, these being research, awareness, and support.

"In alphabetical order, but equal esteem, they are: Mr Alan Barlee of our Geelong Prostate Cancer Support Group (VIC), Mr John Daven of our Central Coast Prostate Cancer Support Group (NSW), and Mr Alan White of our Bayside-Kingston Prostate Cancer Support Group (VIC)."

"Our work is only made possible by the support of outstanding individuals like these, who give of their own time to ensure that men and their partners do not have to walk alone when prostate cancer strikes," Ms Savage said.

"They play a vital role in providing men and their loved ones with information, comfort, and support, calling on their own personal experiences to make a difference in the lives of others."

'Shine a Light' webinar – Understanding what supportive care means

The first Webinar of PCFA's 2023 Series is now available on its YouTube Channel.

To watch the 'Shine a Light' webinar, please click HERE.

DRY JULY FOUNDATION

Join Dry July for PCFA

Dry July is a fundraiser that encourages you to go alcohol-free in July to raise funds for people affected by cancer.

The funds you raise as part of your Dry July will provide invaluable services for cancer patients, their families and carers – whether it's a lift to a life-saving appointment, guidance from a specialist nurse, connection to an informative voice, access to therapy programs or a bed close to treatment.

Having a month off alcohol also has great health benefits, such as sleeping better, having more energy and of course, no hangovers! So you're not only helping others, you're helping yourself. It's a win-win!

Sign up to Dry July to support PCFA

Articles and Reports of Interest

The following articles which have appeared recently on web sites or other sources may be of interest to members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

US-based guidelines for the early detection of prostate cancer

The July 2023 edition of the American Urological Association's *Journal of Urology* has articles in two parts on recommendations on the early detection of prostate cancer. It also provides a framework to facilitate clinical decision-making in the implementation of prostate cancer screening, biopsy, and follow-up.

Part I focuses on prostate cancer screening and Part II on initial and repeat biopsies as well as the biopsy technique.

Prostate-specific antigen (PSA)-based prostate cancer screening in combination with shared decision-making (SDM) is recommended for screening. For biopsies, a number of recommendations were made based on results relating to the detection of clinically significant prostate cancer.

The systematic review utilised to inform this guideline was conducted by an independent methodological consultant. It was based on searches in Ovid MEDLINE and Embase and Cochrane Database of Systematic Reviews (January 1, 2000–November 21, 2022). Searches were supplemented by reviewing reference lists of relevant articles.

In all there are 36 recommendations.

The PCFA is currently undertaking a review of the current guidelines that apply in Australia. These US-based recommendations should help inform the Australian review of the guidelines.

Read the articles.

PARP inhibitors explained

PARP inhibitors are a type of cancer drug. PARP stands for poly adenosine diphosphate-ribose polymerase, a type of enzyme that helps repair DNA damage in cells.

PARP inhibitors work by preventing cancer cells from repairing, allowing them to die.

These drugs are a type of targeted therapy. They target cancer cells and mostly avoid affecting healthy cells.

Read this article in *Medical News Today* for a useful explanation of PARP inhibitors. A *YouTube* video that explains how PARP inhibitors work in more detail is available HERE.

FDA approves Talzenna for metastatic, castration-resistant prostate cancer

HealthDay (26 June 2023) has reported that the US Food and Drug Administration has approved Talzenna (talazoparib) with enzalutamide for homologous recombination repair (HRR) gene-mutated metastatic castration-resistant prostate cancer (mCRPC). The Talzenna approval was given to Pfizer.

The approval was based on a trial which showed statistically significant improvement in radiographic progression-free survival (rPFS) for Talzenna with enzalutamide versus placebo.

Talazoparib is an inhibitor of PARP enzymes (see explanation above), including PARP1 and PARP2, which play a role in DNA repair. The pharmacology studies support the use of talazoparib to treat tumours with a mutated BRCA background. Talaziparib has been approved for use in Australia in association with BRAC breast cancers.

This research article describes the use of talazoparib – a PARP inhibitor – in association with enzalutamide – a novel ADT agent), to be used – in association with a gonadotropin-releasing hormone analogue.

This article It is mainly relevant to those with a BRAC gene mutation .

The combination refers to American research trials and this combination is not

available in Australia for prostate cancer at present. Enzalutamide is available under two separate indications to be used in conjunction with ADT.

Abiraterone acetate plus prednisolone with or without enzalutamide for patients with metastatic prostate cancer starting ADT

A study reported in *The Lancet* (18 May 2023) indicates that combining enzalutamide and abiraterone with prednisolone offers no improvement in overall survival compared with abiraterone with prednisolone alone in patients with metastatic prostate cancer who are starting ADT. The authors argue that this should not be recommended, given the increased toxicity observed with the combination.

The authors analysed data from two phase III trials that evaluated the addition of abiraterone acetate plus prednisolone (AP) with or without enzalutamide to standard-of-care (SoC) androgen deprivation therapy (ADT) in patients with metastatic prostate adenocarcinoma. In both trials, additional treatment with either AP or AP plus enzalutamide was associated with longer overall survival than SoC alone (76.6 vs 45.7 months and 73.1 vs 51.8 months, respectively). However, no significant difference in treatment effect was observed with the addition of enzalutamide to abiraterone acetate plus prednisolone .

Read *The Lancet* article.

Study finds weight gain early in life increases risk of prostate cancer death

The Guardian (27 May 2023) has reported on the early results of a decades-long study involving over 250,000 Swedish men that indicated there was a strong link between men gaining weight across their healthiest years and developing prostate cancer.

The analysis, which was presented at the European Congress on Obesity, suggests those who gained at least half a kilogram a year (1.1 lbs) from 17 to 60 had a 10% greater risk of aggressive prostate cancer and a 29% greater risk of fatal prostate cancer. The risks are higher if the weight gain is rapid.

Volunteers Needed

Some of our committee members will step down over the coming year and we want to ensure that there is a succession plan in place.

We are looking for members who would be prepared to join our executive committee.

This is not an onerous task.

The committee only meets about four times a year.

Please contact President Greg McRoberts or Secretary John McWilliam for more information.

Greg: president@pcsg-act.org.au

John: secretary@pcsg-act.org.au

Australian National University

The Co-Creating Safe Spaces Project

Are you passionate about health, well-being, and suicide prevention in Australia?

We invite you to participate in our survey

- Contribute to important research about Safe Spaces for people experiencing emotional distress and/or suicidal crisis
- Fill in our anonymous online community survey to share your insights on new services and support-seeking preferences

Open to anyone aged **16 years** or over

Whether you have personal experience, have supported someone in distress, or simply wish to contribute, we welcome your input!

Access the survey using the QR Code or via this link:

http://quicklink.anu.edu.au/eepr

All questions are optional, the survey will take around 10-30 minutes depending on your choices.

For more information, contact:

Dr Scott Fitzpatrick
Centre for Mental Health Research
The Australian National University
0431 395 389
safespaces@anu.edu.au

The Co-Creating Safe Spaces project is led by a team at The Australian National University and has been funded by **Suicide Prevention Australia**.

The ethical aspects of this study have been approved by the ACT Health Human Research Ethics Committee (Protocol 2022.ETH.00043).

Borrowing Items from the Library

You can borrow items from the Group's library. There is a wide range of materials, from books to videos. Those who are interested in borrowing items from the library or finding out more about our collection can contact U.N. Bhati, email:
librarian@pcsg-act.org.au

Personal Support

For general information, please call SHOUT (Self Help Organisations United Together) during normal office hours on (02) 6290 1984, and their staff will arrange for someone to contact you.

If you would like immediate advice, support or assistance, please contact one of the following two people:

President: Greg McRoberts, president@pcsg-act.org.au 0413 480 864
Secretary: John McWilliam,secretary@pcsg-act.org.au 0416 008 299

Appreciation

Thanks to all those supporting the Group's fund raising activities, in particular, Harness Racing ACT, the Canberra Southern Cross Club, ACT Masters Hockey, Chartertech ACT, Paddywack Promotional Products and SAC Tyrepower, Belconnen.

From the editor

If you are aware of news, products, publications, web sites, services or events that may be of interest to members of the group, we would like to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy direct, or if you would like to add any of your friends or carers to our distribution list, or if you no longer wish to receive copies of the newsletter, please send an email to:
secretary@pcsg-act.org.au

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, audiovisual products, presentations and other interesting materials. However, the group does not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the group.

Any recommendations made in such materials may not be applicable in your case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the group is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.