



THE WALNUT

SEPTEMBER 2020

Newsletter of the Prostate Cancer Support Group—ACT Region

Affiliated with the Prostate Cancer Foundation of Australia (PCFA)

Postal address: PO Box 650, Mawson ACT 2607

<https://prostate-cancer-support-act.net>



AUGUST MEETING

On 19 August, we held our first in-person meeting since the onset of COVID-19 Coronavirus restrictions. Eleven of our members joined us in person and an additional three members joined via Zoom. This worked well so we are looking to continue to offer Zoom in the future for those of you who would like to use it, at least until social distancing restrictions are further eased.

Our guest speaker for August was Dr Kieran Hart, who has spoken to us before and provided another fascinating look into how prostate cancer is treated here in the ACT, especially during the pandemic.

At the meeting, Dr Hart discussed his experience with conducting robotic assisted prostatectomies, including the response and recovery of 50 patients who had undergone this

treatment through his Canberra practice. He also discussed post-operative oncological and functional outcomes, including incontinence and erectile dysfunction.

Dr Hart then spoke about prostate cancer treatment and testing during the pandemic, noting that there had been a decline in diagnoses due to fewer in-person GP visits, a reduction in PSA tests and rectal examinations not being done because of COVID-related protections. He said that he expected a resurgence of patients being found to have prostate cancer post-COVID-19, but also suggested that increased use of MRIs will allow investigations of these cases to be less intrusive.

Coming Group monthly meetings

Meetings are held on the third Wednesday of the month (except in December) at 6:30 pm for 7:00 pm. Our usual location is Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607 ([see map](#)).

16 September (7 pm): This meeting will have a presentation by Neil Walker and be followed by our Annual General Meeting (AGM).

Neil's talk will be based on his Master's thesis and will discuss the range of radiological treatment methods available to us today in layman's terms.

At the AGM, there will be reports from the President and Treasurer and the election of office holders for 2020–21.

With COVID-19 restrictions, we are limited to 15 people in our meeting room, but members will be able to attend by Zoom. If you haven't used Zoom before, it is very easy and persons wishing to join the meeting on Zoom will be given instructions on how to do so.

To join the meeting in person or on Zoom, please **REGISTER HERE BY EMAIL**. Priority for in-person attendance within the 15-person limit will be given to those who have registered to attend.

21 October (7 pm): This will be our second-last meeting for the year and we are hoping to be joined by Dr Kellie Toohey, Exercise Physiologist at the University of Canberra.

Next coffee morning

Coffee mornings are normally held at 10:00 am on the second Tuesday of each month and alternate between the Woden and Jamison venues of the Canberra Southern Cross Club.

Our next coffee morning will be held at **10:00 am, Tuesday, 8 September** at the **Woden Southern Cross Club**. If you would like join us, please **REGISTER BY EMAIL** so we can book a table.

All are welcome to attend our Group meetings and coffee mornings, and we'd love to see you there. Just come along and you will be most welcome.

PRESIDENT'S MESSAGE

It was really pleasing to have been able to resume our monthly meetings in August, with the partial relaxation of COVID-19 Coronavirus restrictions.

Our speaker, urologist Dr Kieran Hart, gave a most interesting presentation on his experience with the response and recovery of the first 50 patients at his practice who had undergone a robotic assisted prostatectomy and how this compared with patients who have open-cut prostatectomies. It was an excellent start to the resumption of our meetings.

With COVID-19 restrictions, we are limited to 15 people in our meeting room at Pearce. So, we trialled the use of people attending by *Zoom*. While only three people attended by *Zoom* on this occasion, it worked well. All attendees, including those who attended by *Zoom*, were able to participate and ask questions.

Obviously, in-person attendance has many advantages, in particular, the opportunity to interact with other attendees. However, it was also clear that some people are unable to attend meetings in-person, but welcome the opportunity to attend remotely. So this option may be something that we can continue to provide post-COVID. We will certainly be looking at this, having regard to our experience with further use of this approach.

You will also have noticed that our coffee mornings have recommenced. It has been good to catch up with other members once again in this informal setting. Our next coffee mornings is next Tuesday, 8 September, at the Canberra Southern Cross Club in Woden.

To ensure that we comply with COVID-19 restrictions, please register for our meetings and coffee mornings (details on page 2).

Our next meeting will also be our AGM. As mentioned in my message with the August edition of *The Walnut*, David Hennessy I will be stepping down this month after four years as Secretary and President of the Group respectively. I would like to thank all who have helped me during my time as President, and David Hennessy in particular has been a tower of strength over this period. I have also welcomed and appreciated the support of other members of the executive committee over this time, and the support provided by other Group members, including at our various outreach events.

I have offered to remain on the committee for the next year in an *ex-officio* capacity to provide some continuity, but know that the future of the Group will be in good hands.

I have gained a lot of satisfaction from meeting so many men on their prostate cancer treatment journeys and their partners. I encourage others – both men and women – to consider joining the executive committee. While our constitution only requires five members, three of whom are the President, Secretary and Treasurer, we welcome other members as a way of spreading the work and encouraging a greater range of views to be heard. It also helps to ensure the future viability of the Group.

I look forward to catching up with as many of you as possible as COVID-19 restrictions are eased further. Stay well.

John McWilliam

Executive Committee Meeting

The Executive Committee met on Wednesday 2 September, and discussed a range of issues following our first in-person group meeting for many months and in the lead-up to September's Group meeting, including our AGM.

September Group Meeting

We discussed arrangements for our next Group meeting, which will combine a talk by one of our members, Neil Walker, with our AGM.

The committee agreed that the meeting would commence with Neil's talk and be followed by the AGM.

Our AGM is a constitutional requirement and will provide you with the opportunity to elect your Committee for the next year. As discussed in *The Walnut* last month, we need a good attendance to elect the Committee. If you would like to nominate for a Committee position, please complete the **NOMINATION FORM** (we can help with sponsors if required). We're always on the lookout for more help and skills, so please **EMAIL HERE** if you would like to help us, but not necessarily be on the committee.

October and November Group Meetings

Plans are still underway for our last two meetings for the year. We've arranged a speaker for our meeting in October and we are looking to run our November meeting as

a more social occasion to wrap-up what has been a very difficult year.

Financials

Peter Baker presented the Group's financial statements, which have been independently audited. It shows that the Group remains in a healthy financial position, which will allow us to continue to support our activities for now and into the future.

You will be briefed on our financial position at the AGM. We are then required to lodge the audited financial statements with the ACT Government and advise of office holders for the coming year.

Facebook

The Committee discussed widening our communications for next year, with this potentially including a closed Facebook group for you, our members. Work on the Facebook page is well advanced.

Other matters

The Group is now represented on:

- the ACT Prostate Cancer Outcomes Registry Steering Committee (a presentation on the operations and results to date was held on 12 August, but the Steering Committee has yet to meet for the first time); and
- the Cancer Consumer Reference Group.

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@prostate-cancer-support-act.net



What is the Long Run?

The Long Run is an awareness and fundraising event inspiring you to run, walk or wheel 72km to raise awareness and funds for Australian men and families impacted by prostate cancer. You can cover the distance during the month of September anyway and anywhere you like. On Father's Day you'll be invited to take part in our 4k Family Fun Challenge.

If 72km is more than you can manage, you can also set your own distance and goals, suited to your fitness level.

When is it?

September 2020, but Pre-registration opened Monday July 20

Where is it?

Anywhere in Australia – Online via your own personal Fundraising Page, on Facebook, Instagram, and Twitter.

How do I sign up?

1. Sign up for the challenge at www.thelongrun.org.au
2. When you register, you'll be automatically set up with a personal fundraising.
3. Download resources from the website to help with your fundraising
4. Share your story and track your training miles on social media
5. Invite others to join the campaign and donate towards your challenge

Along the way, you'll earn virtual badges for display on your fundraising page, keeping you motivated and inspiring your fundraising.

Goals

Our goal is to raise awareness and funds for prostate cancer research, support, advocacy, and outreach. We hope you'll be one of 1750 Australians taking part, to reach our fundraising target of \$498,000.

www.thelongrun.org.au

thelongrun@pcfa.org.au

Phone 1800 22 00 99



Prostate Cancer Foundation of Australia

Prostate Cancer Awareness Month

September is Prostate Cancer Awareness Month, where PCFA hopes that every step we take will get us closer to their vision of a future where no man dies of prostate cancer and Australian men and their families get the support they need.

So far this year, PCFA has achieved some great things along this course, helping to redefine the landscape for prostate cancer services and care.

They have announced the expansion of their Prostate Cancer Specialist Nursing Service, raised over \$500k towards Australia's first Prostate Cancer Telenursing Service, proven the efficacy and superiority of Pro-PSMA therapy, and released the initial findings of the ground-breaking TheraP clinical trial, funded by PCFA.

PCFA has also published Australia's first Prostate Cancer Survivorship Essentials Framework as well as identifying seven priority actions to significantly improve outcomes for you and other Australian men and families affected by this disease.

Webinar

On 14 August, PCFA ran a Webinar on the updated National Health and Medical Research Council PSA testing guidelines, presented by Dr Tom Shannon.

The presentation is now available for you to access at: [PCFA Webinar link](#).

The guidelines are [here](#).



Cancer Council NSW Study: the impact of COVID-19

Cancer Council ACT has asked us to promote the following activity by Cancer Council NSW, which is inviting participants to take part in a research study to investigate the impact of COVID-19 and social distancing measures on people affected by cancer. If you are living with a current or previous cancer diagnosis, or if you are a carer or family member of someone affected by cancer, you may be interested in participating in the study and can do so here by completing their survey.

The findings from this research will be used to provide new insights about the psychological and environmental impacts of COVID-19 to ensure that there are appropriate systems and support in place both during and after this evolving health crisis in Australia.

You can find out more information about this research project on the Cancer Council NSW website by clicking [here](#).

Cancer Council 13 11 20

Cancer Council 13 11 20 is a free, confidential telephone information and support service. Their specially trained staff can answer your questions about all aspects of cancer, including prevention, early detection and treatment. They can also assist with practical and emotional support as well as referring you to appropriate services in the area. They are open Monday to Friday, from 9am – 5pm. Outside these hours, you can leave a message and they will call you back.

Articles and Reports of Interest

The following articles may be of interest to members. Any opinions or conclusions expressed are those of the authors. Please see the Disclaimer at the end of this edition of *The Walnut*.

Understanding PSA Results

Medicare data suggests that up to 21% of Australian men aged 45–74 choose to have a Prostate Specific Antigen (PSA) test each year, and about 19% of men aged over 74 also undergo testing. New guidelines regarding testing have recently been released and reinforce the familial links. Have you spoken to your sons and other male relatives that have similar paternal links to you?

[Read more here](#)

Nubeqa

In March this year, Australia's Therapeutic Goods Administration approved darolutamide (Nubeqa) for the treatment of high-risk non-metastatic hormone (castrate) resistant prostate cancer. Clinical trials have shown that Nubeqa can extend the lives of prostate cancer sufferers by up to five years. This is great news for men who have a rising PSA despite hormone therapy, with Nubeqa shown to slow tumour progression, thereby delaying metastases and extending overall survival. However, for many men, the treatment has been unaffordable as the drug normally costs \$55,000 a year. [Read more here from PCFA](#)

Although PCFA has lobbied for Nubeqa to be subsidised under the PBS, the Federal Government declined this request. Notwithstanding, Bayer Australia has advised that nearly 2,000 prostate cancer sufferers will have free access to Nubeqa (darolutamide) by the company making it available to them at no cost.

[Read more here](#)

Prostapedia

Prostapedia is a quarterly digital magazine from the United States and contains a number of articles of interest. The August edition includes articles about chemotherapy, and discusses treatment solely with testosterone suppressing agents, such as LHRH agonists like Lupron (leuprolide), or in combination with Taxotere (docetaxel) or one of the newer androgen antagonists, such as Xtandi (enzalutamide).

It also discussed Nubeqa, which is FDA-approved and in the same drug family as Xtandi and Erleada (apalutamide). The latter two cross the blood-brain barrier (BBB) and can impair brain function and can be associated with seizures. However, Nubeqa does not cross the BBB and is much less likely to cause central nervous system toxicity (CNST).

The article also discusses a second drug, Relumina (relugolix), which is an oral drug that blocks production of testosterone much more effectively than Lupron and has a lower risk of cardiovascular events, but it is not yet approved for the treatment of prostate cancer.

[Read more here from the August 20 edition](#)

First patient enrolled in Australia in prostate cancer trial

The ENZA-p trial, led by the Australian and New Zealand Urogenital and Prostate Cancer Trials Group (ANZUP), has enrolled its first

patient at Austin Health in Melbourne. The new randomised phase 2 study aims to compare the effectiveness of enzalutamide in combination with Lutetium-177 PSMA, versus

enzalutamide alone, for the treatment of prostate cancer.

[Read more here](#)

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: John McWilliam

Phone: 0416 008 299

Email: president@prostate-cancer-support-act.net

Secretary: David Hennessy

Phone: (02) 6154 4274

Email: secretary@prostate-cancer-support-act.net

Appreciation

The Group recognises and expresses its appreciation for the support provided over the past year by: Harness Racing ACT; TAB Corporation; Holy Family School Gowrie; Paddywack Promotional Products; the Residents' Social Clubs at Isabella Gardens, Isabella Plains and The Grove, Ngunnawal; the ACT Masters Hockey Association; the PCFA; SHOUT staff; and the many individuals who have assisted in our fund-raising activities.

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:

president@prostate-cancer-support-act.net.

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.