



THE WALNUT

JULY 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>



Group monthly meetings

July: No monthly meeting

19 August (7 pm): Speaker is urologist, Dr Kieran Hart.

16 September (7 pm): Speaker to be announced. Annual general meeting.

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

Next coffee morning

10:00 am, Tuesday, 14 July at the Canberra Southern Cross Club, **Woden**.

Coffee mornings are 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.

All are welcome to attend our Group meetings and coffee mornings. Just come along and you will be welcomed.

President's Message

We are hopeful that our monthly meetings will resume in August. This will happen unless there is a 'second wave' of Coronavirus cases in Canberra. Hopefully, the Canberra community will continue to heed the warnings by government and medical advisers to take all necessary precautions to prevent a 'second wave'.

We have also decided to resume our coffee mornings from this month. This will be held on Tuesday 14 July at 10 am.

I am pleased to say that urologist, Dr Kieran Hart, has agreed to speak at our August meeting. We also plan to have a speaker for our September meeting, which will also begin with our annual general meeting — usually a relatively short affair.

I recognise that many of you will be reticent about attending public meetings because of continuing concerns about the Coronavirus. However, provided the risk of contracting the virus in Canberra remains low, and provided we take the recommended social distancing and other precautions, we have decided that it is important that we recommence our meetings. This will make it easier for us to resume the vital support that we provide to men with prostate cancer or an interest in prostate cancer and their families.

Please do not attend our meetings if you are feeling unwell.

Best wishes

John McWilliam

Additional Prostate Cancer Specialist Nurse for the Canberra Region

Following a lengthy Expression of Interest process, the Federal Government and the Prostate Cancer Foundation of Australia (PCFA) have announced 39 new sites for expansion of our Prostate Cancer Specialist Nursing Service around Australia. Pleasingly, one of these new sites is the Canberra Health Service, which supports patients across not just Canberra, but also a large part of southern NSW.

The Commonwealth Government has provided co-funding support for the program since 2013, funding 29 nurses located in hospital and health services nationwide, with additional nurses employed thanks to community donations. Encouragingly, the 2019–20 Federal Budget included funding for continuation and expansion of the program over the three-year period from July 2020 to June 2023, providing support for up to 34 full-time equivalent new prostate cancer nurses from July this year. Notably, more than 34 new nurses will be employed under the expansion, with some of the positions to be hired under part-time arrangements.

Specialist Nurses play a vital role in coordinating the care of men with prostate cancer from the point of diagnosis across the continuum of care, including the

management of side-effects and symptoms of treatment throughout survivorship and recovery. Working with hospitals and health services, the PCFA assists in all aspects of the recruitment, training, and professional development of nurses employed under the program, as well as producing consumer resources to support the program and managing program-specific data collection and independent program evaluation.

Thousands of Australian men with prostate cancer and their families will benefit from the expansion of this service, with about 40 new facilities involved in this expansion over the next three years.

Current estimates suggest by 2040 there will be about 372,000 men in Australia living with or beyond prostate cancer, representing a 76 per cent increase from 211,000 today and the greatest number of men or women diagnosed with any single cancer. Of concern to PCFA, about 13,000 Australian men and families currently lack access to specialist prostate cancer nursing support, a number set to grow without investment in new nurses and telenursing services to reach those in need.

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.

Executive Committee Meeting

The Executive Committee met for the first time in person in several months on 1 July. Previous meetings during the COVID-19 pandemic have been by videoconference. It was good to meet up again in person.

The committee among other things:

- discussed the results of the survey of members who had attended meetings and coffee mornings in the past two years on preferences for the resumption of meetings. These results, limited as they were (26 responses to 65 invitations), indicated that, while some members would be cautious about attending gatherings at this time, there was a significant level of interest in resuming meetings soon;
- agreed that we should provide the opportunity for men and their families to meet, provided that there is no change in the advice from the government about gatherings in Canberra at this time and provided that social distancing and other COVID-19 recommendations are met;
- agreed to resume in-person coffee mornings at the Canberra Southern Cross Club from July, subject to confirmation from the club on arrangements for this;
- agreed to resume Group monthly meetings at Pearce from August, and to invite a urologist to speak at the meeting (Dr Kieran Hart has since agreed to speak at our meeting);
- agreed on possible speakers for our September and October meetings (the annual general meeting (AGM) will take place after the presentation at the meeting);
- discussed arrangements for the AGM, including which committee members were willing to continue to serve on the committee and positions for which they were willing to be nominated. Invitations will also be sent to all members in August inviting nominations to the committee;
- noted that the Treasurer has spoken to the auditor about arrangements for auditing the Group's 2019–20 financial statements;
- discussed other financial support that the Group could provide in 2020–21;
- discussed progress with the establishment of a *Facebook* page for the Group; and
- noted the outcome of contacts with several members about how they are going at this time and that most had indicated they appreciated receiving *The Walnut*, but did not require other support.

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

Please also let U.N. know if there are publications we can usefully add to the Library.



Stay up-to-date by joining the PCFA Online Community

The PCFA Online Community is open to anyone who has been impacted by prostate cancer to share their experiences and connect with others. Through the Research Blog, PCFA Online Community members can also learn more about the latest prostate cancer research developments and findings.

The Online Community Research Blog has recent articles on:

- *Low awareness can be lethal:* Alarming new research has revealed about 70 per cent of Australians don't know the signs and symptoms of prostate cancer, prompting Prostate Cancer Foundation of Australia to call for greater public investment in targeted community awareness activities. [Read more](#); and
- *Not all high-grade prostate cancers are the same:* In a recent study, researchers examined Gleason grade group 5 prostate cancers which are associated with aggressive disease and poor outcome, and found that some cancers of this type were more aggressive than others based on differing patterns of gene expression. This may one day help clinicians decide how best to treat different subgroups of Gleason grade group 5 prostate cancers. [Read more](#).

It is free and easy to become a member of the PCFA Online Community.

You can sign up at:

<http://onlinecommunity.pcfa.org.au>.



Sign up for Dry July

For the third consecutive year, the Prostate Cancer Foundation of Australia (PCFA) has been selected as one of the major beneficiaries of the *Dry July* campaign. Dry July fundraisers have delivered a whopping 20,000 hours of nursing support to men facing prostate cancer and their families.

Please join the team for *Dry July 2020* to help deliver this expert care from one of PCFA's nurses to more men.

Please also encourage family and friends to support a challenge that means much more than giving up alcohol. It provides an opportunity to raise funds to help men affected by prostate cancer.

This year, there are a few new options, and you can choose to have a 'Dry(ish) July' and go dry for 21 or 14 days.

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

By giving up alcohol during July, you'll be making a massive difference for Australian men and families during one of the most challenging times in their lives.

Sign up or donate today to PCFA and invite others to support your efforts! Click the link below:

[Go Dry this July](#)



Cancer Council Supported Research Projects

Cancer Council ACT has asked us to promote the following two studies, which may be of interest to some members.

1. Cancer Council NSW and the impact of COVID-19

Cancer Council NSW is inviting participants to take part in a research study, investigating 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.

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

2. Out with Cancer study

The 'Out with Cancer' study is examining LGBTQI+ (lesbian, gay, bisexual, trans, queer and intersex) people's experiences of cancer from the perspective of cancer survivors, their carers and healthcare professionals.

Funded by an Australian Research Council Linkage grant, the study is based at Western Sydney University, in partnership with the Prostate Cancer Foundation of Australia, Cancer Council NSW, National LGBTI Health Alliance, ACON, Breast Cancer Network Australia, CanTeen, UTS, Melbourne, La Trobe, New South Wales and Monash universities.

If you are LGBTQI+, 15y+ and have ever had cancer or medical intervention for cancer risk the researchers like to hear from you. They would also like to hear from your partners, family members and friends. The survey asks about your experiences of cancer or caring for a person with cancer, your wellbeing, social support, relationships, and experiences with the healthcare system. To take part, and for more information click [here](#).

If you have any questions, please contact the relevant study.

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.

New test delivers improved accuracy in prostate cancer detection

New Australian research has shown that a ground-breaking test can improve the early detection of Prostate Cancer. Research published in the open access journal *Frontiers in Oncology* (and reported in *Oncology News*) has revealed that the ISET®-Circulating Tumour Cells (CTC) Test can markedly improve detection of prostate cancer, compared to the existing Prostate Specific Antigen (PSA) blood test.

Researchers from the National Institute of Integrative Medicine used the cytology-based ISET®-CTC Test plus PSA marker test, to evaluate the risk of developing prostate cancer in a group of Australian men.

The ISET®-CTC Test is used to identify abnormal cells circulating in the blood from any origin. By monitoring the presence of CTC cells it may help with the early detection of cancer. Generally, the higher the CTC count, the higher the risk of cancer.

The research findings suggest that the combination of the ISET®-CTC testing and PSA marker testing has an estimated positive-predictive-value (PPV) of 99% and negative-predictive-value (NPV) of 97%. This means there is a greater certainty about diagnosis than the standard PSA-blood-test, which provides a PPV of approximately 25% and NPV of 15.5%.

[Read more.](#)

Intense form of radiation slows disease progression in some men with prostate cancer

Highly focused, intense doses of radiation called stereotactic ablative radiation (SABR) may slow progression of disease in a subset of men with hormone-sensitive prostate cancers that have spread to a few separate sites in the body. This is according to the results of a phase II clinical trial of the therapy (published in *JAMA Oncology* and reported in *Oncology News*).

The trial, called ORIOLE, has been examining primary outcomes of a Phase II randomised trial of observation versus stereotactic ablative radiation for oligometastatic prostate cancer. It is led by Johns Hopkins Kimmel Cancer Center, USA. In the study researchers compared the effectiveness of SABR versus 'wait and watch' observation in recurrent cases of oligometastatic prostate cancer. Oligometastatic cancers are those that have spread from a primary tumour to one to three sites within the body.

Some men would prefer to delay treatment of metastatic cancer because of the adverse side-effects of the treatment (ADT is the standard form of treatment). The study therefore wanted to see whether stereotactic ablative radiation would help delay treatment.

Among the 54 men enrolled in the trial, the disease progressed within six months in seven out of 36 (19%) of participants treated with

SABR, compared to 11 out of 18 participants (61%) undergoing observation alone.

The risk of new cancers at six months was also lower, occurring in 16% of those receiving SABR compared to 63% of those under observation.

Analysis of immune system white cells in blood drawn from the patients indicated that SABR treatment was associated with an expanded population of T cells, suggesting

that the treatment stimulated a full-body immune system response to their cancers,

The findings suggest SABR might be usefully paired with other immunotherapies to treat recurrent oligometastatic prostate cancers, but any potential benefits of such combined therapy will need to be tested in future clinical trials.

[Read more.](#)

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

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.