



# THE WALNUT

AUGUST 2021

Newsletter of the Prostate Cancer Support Group—ACT Region

Affiliated with the Prostate Cancer Foundation of Australia (PCFA)

Postal address: SHOUT, Building 1, Collett Pl, Pearce ACT 2607

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



## Monthly meetings

Our regular meetings are held on the third Wednesday of the month (except in December) in Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607 ([see map](#)).

Our next monthly meeting will be held at **7:00 pm on Wednesday, 8 September**, which will also be our **Annual General Meeting**. We'll run the AGM in-person and online on Skype, so it will still be able to run if the lockdown is still going. Our COVID Safety Plan remains in place so please check in on the app when you arrive.

## Next coffee morning

Our 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, the 7th of September** at the **Woden Southern Cross Club**.

All are welcome to attend our meetings and coffee mornings,

## Ken Behrens! How are you going?

Well, we're back in lockdown again and trying to keep each other safe, but remember that although we can't get together at the moment, you're not alone.

Mental health for anyone dealing with a lockdown is hard enough but for those of us dealing with or supporting someone with prostate cancer, well, we have another level of challenges to deal with.

So how can we look after ourselves and help each other?

- Get out for that one hour walk - time in nature is always good for the soul.
- Give a friend a call. Maybe Skype or Facetime?
- Keep up with your medical appointments and PSA tests. There was a [significant drop in PSA tests](#) earlier in the pandemic, so let's not let this happen again.
- Look after your diet. Watch out for comfort eating.

The ACT Government has some good guidance about dealing with mental health and wellbeing during COVID-19 [here](#), as does PCFA [here](#). Check it out!

Please remember that we still have each other, so don't be afraid to put your hand up and seek help if you want it.

Above all, stay safe and stay strong, Ken Behrens.





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## What is the Long Run?

As we all know too closely, nearly 17,000 Australian men are diagnosed with prostate cancer every year, over 3,000 men die of it and numbers are set to increase by 60% in future.

In addition to helping and being helped by your mates in our support group here in the ACT, you can now make an extra difference for others by getting active and joining the Long Run. The Long Run is an awareness and fundraising event by PCFA inspiring you to run, walk or wheel 72km to raise awareness and funds for Australian men and families impacted by prostate cancer.

It doesn't matter what your level of fitness is because you decide how, where and when you want to complete your personal challenge. You can cover the distance during September anyway and anywhere you like.

## Why 72km?

Prostate cancer is the most common cancer diagnosed in Australian men. Sadly, 1 in 5 men will develop anxiety or depression as a result of their diagnosis, yet 72% of us will not seek help.

## Goals

Our goal with PCFA is to help raise awareness and funds for prostate cancer research, support, advocacy, and outreach. We hope you'll be one of over 1650 Australians taking part so far.

*So who will you run for?*

## How do I join in?

1. Sign up for the challenge at [www.thelongrun.org.au](http://www.thelongrun.org.au).
2. When you register, you'll be automatically set up with a personal fundraising page.
3. Download resources from the website to help with your fundraising.
4. Share your story and track your training distance 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.

## What if I'd like to sponsor someone instead?

Some of our members have already signed up and here are the links to their sponsorship pages:

- [Greg McRoberts](#)
- [David Ault](#)
- [David Newman](#)

[www.thelongrun.org.au](http://www.thelongrun.org.au) [thelongrun@pcfa.org.au](mailto:thelongrun@pcfa.org.au) Phone [1800 22 00 99](tel:1800220099)

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## Current Activities

**Annual General Meeting.** Despite the ACT's current lockdown, [our Annual General Meeting \(AGM\) is still planned for Wednesday, the 8th of September](#), and we'll be sending out the agenda, proxy forms and supporting notes to Full members in the next week. We'll be running the AGM from our regular room in Pearce if the lockdown is over; otherwise we'll rely on Skype. This year, you'll also be able to vote by proxy beforehand if you can't join in the meeting.

The AGM is a legislated requirement and, as per our updated Constitution, we will need a minimum of 18 Full members present in person, on Skype or represented by proxy to achieve a quorum. This is very important because if we can't achieve a quorum, we'll have to stop the meeting and try to run it again the following month. If you can't attend in-person or on Skype, please ensure that you send your completed proxy form to the President before the meeting.

At the AGM, we'll be:

- confirming the Minutes of last year's AGM and our Special General Meetings earlier this year;
- presented with reports from the President and Treasurer, including an audited statement of the Group's accounts;
- electing our Committee for the next year;
- appointing our auditor for the next year and determining their remuneration;
- approving our annual budget for the next year;
- reviewing a list of members who we have lost contact with and approving that their memberships be considered as lapsed; and
- considering other items of business raised by members in accordance with the Constitution.

As you would know from previous Walnuts, we currently have a couple of committee members who will be retiring at the AGM and will need to be replaced. The Committee has three legislated positions (ie. the President, Secretary and Treasurer) and two ex-officio positions. If you'd like a chance to join the Committee and help with the future direction of your support group, please [email the President](#) and advise if there is a particular role that you'd like to help with. We'd love to have you on the team and help support all of us in our Group!

We've made some great advances this year, including updating the Group's Constitution, developing and implementing our strategic plan, remediating our membership database and increasing awareness in the local community. This has built upon the work done by our previous Committee, led by John McWilliam, and resulted in us now having a really solid baseline from which to progress, so the AGM will also provide the opportunity to look back and celebrate.

**Internet update strategy.** As discussed in recent Walnuts, we're currently updating our internet presence, thanks to a lot of hard work by Mark Jardine and Greg McRoberts, so you'll shortly hear of our new web address and email addresses. Standby! We're nearly there!

**PCFA's Support Network Conference Dubbo - 22-24 October - Cancelled.**

Unluckily, the Dubbo conference has had to be cancelled because of the ongoing pandemic. This is really disappointing after all the effort put in by Elizabeth Allen and her team. Thanks for everything that you've done, Elizabeth! Hopefully, we can all meet next year in better times.

## Articles and Reports of Interest

The following article 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.

### Comparing Darolutamide, Apalutamide and Enzalutamide for Nonmetastatic Castration-Resistant Prostate Cancer

Although there are no head-to-head trials comparing **darolutamide**, **apalutamide** and **enzalutamide** for nonmetastatic castrate-resistant prostate cancer, the authors of this study matched patients from placebo-controlled trials (ARAMIS, SPARTAN, PROSPER) to compare oncologic outcomes and risk of adverse events. They found that:

- metastasis-free survival was similar across all three therapies, but
- adverse events were significantly lower with darolutamide compared with both apalutamide and enzalutamide

Read more [here](#).

### Electrical pudendal nerve stimulation vs pelvic floor muscle training plus transanal electrical stimulation for post-prostatectomy urinary continence

This was a randomised controlled trial to evaluate the efficacy of electrical pudendal nerve stimulation (EPNS) compared with pelvic floor muscle training (PFMT) plus transanal electrical stimulation (TES) for post-prostatectomy urinary continence. Post-treatment efficacy was assessed. The study found that:

- the patients in the EPNS group had significantly more improvements in all factors, including quality of life; and

- EPNS was more effective than PFMT and TES for post-prostatectomy incontinence at 8 weeks

Read more [here](#).

### MRI and targeted biopsies could halve the overdiagnosis of prostate cancer

The results of this STHLM3MRI study indicate that **overdiagnoses can be halved by substituting traditional prostate biopsies with MRI and targeted biopsies**. The number of unnecessary biopsies and identification of minor low-risk tumours is reduced, and the new method can detect just as many clinically significant tumours.

Organised screening has been shown to lead to earlier detection, reducing mortality. However, current screening methods can lead to unnecessary biopsy, and detection of numerous, minor low-risk tumours.

*"Our results show that modern methods for prostate cancer screening maintain the benefits of screening while decreasing the harms substantially. This addresses the greatest barrier to the introduction of nationwide screening,"* asserted Tobias Nordström, MD, of Danderyd Hospital at Karolinska Institutet, Stockholm, Sweden. He also said that *"the future of prostate cancer diagnostics probably includes both improved blood tests and MRI."*

This was explained by co-investigator Martin Eklund, MD who said that *"refined screening methods are required to reduce overdiagnosis and overtreatment of low-risk tumors, and prevent unnecessary biopsies and biopsy-related side effects."*

Read more [here](#).



### PCFA Online Community

PCFA runs Australia's largest online group dedicated to connecting Australian men and families who have been impacted by prostate cancer. By joining the conversation in their Community Forum, you can learn more about medical and other scientific breakthroughs. You can access the Community [here](#).

### MatesCONNECT

MatesCONNECT is a telephone-based peer support service for men affected by prostate cancer, and can connect you to a trained volunteer who understands what you're going through. You can get practical advice on surgery and treatment, and the potential side effects of treatment, such as incontinence, erectile dysfunction, and coping with hormone therapy. Simply call PCFA on [1800 22 00 99](tel:1800220099) to be connected with a volunteer.

And if you'd like to become a volunteer yourself, [read this](#) and then [email PCFA here](#).

### PBS listing of Nubeqa®

Australia's Pharmaceutical Benefits Advisory Committee has just recommended PBS listing of Nubeqa® for men with non-metastatic castration resistant prostate cancer.

This is a major victory for PCFA and for Australian men and families impacted by prostate cancer - if we clear the final hurdle to listing of Nubeqa® it will be the first time in 7 years (!!!!) that a new medicine has been subsidised by the Australian government for men with prostate cancer.

[Download your July 21 Blue Sky News 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.

### Daffodil Day

Daffodil Day is Cancer Council's most iconic and much-loved fundraising campaign..

For many Canberrans, Daffodil Day means passing by their local community stall and purchasing a bunch of Daffodils. Sadly, the COVID-19 outbreak this year is preventing the stalls from being held and Cancer Council is unfortunately left without a major source of funding for the second year in a row.

Here are some ways you can [help](#).

### Publication: Nutrition and Cancer

This booklet has been prepared to help you understand more about nutrition and how to eat well **before, during and after cancer treatment**. It covers the general guidelines for healthy eating and some of the common eating problems caused by cancer or its treatment. There are tips for managing these issues, as well as some simple recipes to make at home. Very handy in lockdown!

[Download the publication here](#)

## Appreciation

Thank you to PCFA, the ACT Government, SHOUT, Southern Cross Club, ACT Masters Hockey, Paddywack Promotional Products, Harness Racing ACT, and everyone supporting our fund-raising and other activities.

## Social Media

Facebook has a range of Open and Private groups that may be of interest to you:

- [Prostate Cancer Foundation of Australia](#) (Open)
- [Prostate Cancer Foundation of Australia Support Groups](#) (Private)
- [Prostate Cancer Support Australia](#) (Private)

## Borrowing items from the Library

You can borrow items from the Group's library, which has a wide range of books and videos. Those who are interested in borrowing items or have suggestions for additions to our library can contact U.N. Bhati by email: [librarian@prostate-cancer-support-act.net](mailto:librarian@prostate-cancer-support-act.net)

## 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:

**President:** Greg McRoberts

Phone: 0413 480 864

Email: [president@pcsg-act.org.au](mailto:president@pcsg-act.org.au)

**Secretary:** David Newman

Phone: 0412 812 875

Email: [secretary@prostate-cancer-support-act.net](mailto: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: [secretary@prostate-cancer-support-act.net](mailto:secretary@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.