



THE WALNUT

OCTOBER 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>



Monthly meetings

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

21 October (7 pm): This will be our second-last meeting for the year and we will be discussing ways-ahead for the Group in 20/21. We may still be limited to 15 people in our meeting room so please [register here by email](#).

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, 13 October** at the **Jamison Southern Cross Club**.

All are welcome to attend our meetings and coffee mornings, and we'd love to see you there.

Annual General Meeting

We held our Annual General Meeting (AGM) on the 16th of September, with a total of 17 members joining us in person or via Zoom. Our hybrid attendance method worked well again so we are looking to continue to offer Zoom for those of you who would like to use it.

The AGM was preceded by a presentation by one of our members, Neil Walker, dealing with '*Nuclear treatment options for prostate cancer*'. It was a fascinating talk where Neil drew from research that he's conducted as part of his Masters studies and dealt with everything from EBRT and brachytherapy through to proton beam therapy.

After Neil's talk, we conducted the AGM itself, where our retiring President, John McWilliam, spoke of last year's fundraising and recent donations to help The Canberra Hospital purchase three bladder scanners. He also thanked the retiring Committee and others who had supported the Group's activities during the year. Peter Baker followed with the Treasurer's Report, and advised that our finances are still healthy.

We then elected our new Committee of five members for the year, following the retirement of John and David:

- **President.** Greg McRoberts, replacing John McWilliam
- **Treasurer.** Peter Baker
- **Secretary.** David Newman, replacing David Hennessy
- **Ex-Officio members.** John Richmond and Don Bradfield

As incoming President, Greg said that he was looking forward to working with the members of the Group to continue our activities, and welcomed hearing from the Group's members so we could all learn from each other.

President's Vision for 2020/21

As with 2020 so far, one of the key challenges moving forward will be the unknown of COVID. Having said that, I think that it's important to move forward with a sense of hope and optimism.

As your new President, I am looking forward to leading our Group through whatever challenges may lay before us. After all, we are Prostate Cancer survivors, so we are all familiar with dealing with the unknown and obstacles put before us.

Continuing to build on the incredible work and foundation laid by our predecessors is paramount, and I believe that the areas we should look to focus on during the next term are as follows:

1. **Membership** – Whilst continuing to meet the needs of our current membership base, I believe there is an opportunity for us to look at how we can continue to attract new members to our group. I believe it important to increase the diversity of our cultural and age background so that we can ensure that we have a member base that is truly supportive and can offer the mentoring needed for all recently diagnosed or treated men.
2. **Membership Database** – We need to refine our database so as to ensure that we have a current and accurate list of members. As part of this, we must also ensure that the database is as secure as we can make it, given the sensitive nature of our conditions.
3. **Budgeting** – We need to work with Peter Baker, our Treasurer, to ensure that we have an up to date budget that correctly reflects all our incomings and outgoings. This will enable us to better utilise raised or donated funds to support meeting our Group's objectives.
4. **Communication** – We need to look at opportunities to improve our accessibility by those who seek our support. This may look at using social media, and networking through other groups and organisations associated with SHOUT and PCFA. We can also look at having an increased presence at community events, subject to COVID limitations.
5. **Networking** - We need to look into creating opportunities to meet with GPs and GP groups to set up a more personal relationships and engagement. My vision here is that it would be ideal that when a person is diagnosed with PSA level that requires referral to a specialist, they are told about our group and the benefits we can offer.
6. **Building Relationships.** We need to enhance our relationships with the groups that support us; eg. SHOUT and the PCFA. As part of this, we can look for opportunities to benefit group members through our region's medical and Allied Health network.

Clearly, we need to spend more time with our network and find out **what they can do for us**.

Above all, I am very interested in hearing from you so that we can work together to build the group on the very strong foundations that we already have. If you have any issues, concerns or ideas, please contact me any time - we don't have to wait for our regular meetings.

cheers,

Greg

Recent Activities

Pearce Inclusive Community Garden. For those of you who have joined us at our Pearce meeting room recently, you may have noticed some ground works on the sloping lawn, just

outside our window. Well, the works are now complete - the Pearce Inclusive Community Garden was formally opened on Wednesday, September 16th, by Carol Mead, CEO SHOUT, and Shane Rattenbury, representing the ACT Government, and the garden looks great. Some of the community groups supported by SHOUT, including ours, were invited to attend the opening and set up stands so that we could show what we do. Our stand had a fair bit of interest and was visited by some of the politicians standing for election, so hopefully this helped us get our message across to Government.



PCFA's Long Run. In our last two editions of '*The Walnut*', we've advertised '*The Long Run*', which was PCFA's awareness and fundraising event for September inspiring us to run, walk or wheel 72km to raise awareness and funds for Australian men and families impacted by prostate cancer. Although *The Long Run*'s target was originally about \$500,000, over 3,500 people enrolled and over \$1,500,000 has been raised! This is an amazing result, especially during the pandemic where it's been harder for people to get out and donations to charities have generally been down. Our new President, Greg McRoberts, joined in and raised over \$3650, easily exceeding his target of \$3000. Well done, Greg!



October Committee Meeting. Our new Committee held its first meeting on Wednesday, 7 October, where we completed handover activities and discussed a range of issues on our

planning horizon for the next few months and into next year. We were joined at the meeting by Jim Lloyd, PCFA's National Support Groups Executive, who spoke about how PCFA was using social media and other innovations to increase engagement with support groups, including ours. We then discussed looking at our Constitution, which hasn't been updated since May 2009, in order to ensure that we are still compliant with legislation and to also identify opportunities to improve it and how it supports us. We'll be forming a working group soon to look at possible improvements,

including allowing proxy voting, and will be calling for your ideas and help. We also discussed strategic planning, and will discuss this further at our next general meeting on 21 October.



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.

PSMA PET CT

This retrospective analysis explored the utility of 18Ga-PSMA PET/CT in defining radiation coverage fields, where the most frequently detected metastatic lymph nodes were in the internal iliac (25.2%), external iliac (20.6%), and common iliac (19.5%) stations. The iliac crest is the area where arching bones sit on either side of your pelvis. The iliac crest bones are attached to your oblique muscles. The study concluded that extending the cranial margin of the pelvic field from L5/S1 to L4/L5 increased the accuracy of pelvic field irradiation in approximately 20% of patients and suggested adjustments to pelvic radiation fields to improve accuracy and lymph node coverage. [Read more here](#)

Sequencing DNA Repair Genes

This study was a relatively large-scale analysis of germline DNA repair gene mutation variants in relationship to aggressive versus nonaggressive prostate cancer, and included 5,545 European-ancestry men, including 2,775 non-aggressive and 2,770 aggressive PCa cases, of which 467 cases were metastatic (16.9%). *BRCA2* and *PALB2* were the most frequently noted mutations, with there being an observed tendency toward younger age at diagnosis of aggressive prostate cancer in *BRCA2* carriers in this study. The study was larger than previous studies of its kind and highlighted the need for large-scale genetic testing studies to further clarify the relationships between rarer mutational variants and cancer rates as well as aggressive behaviour. [Read more here](#)

Active Surveillance in Intermediate-Risk Prostate Cancer Carries a Fourfold Higher 15-Year Mortality Risk

*** This study is from 2015 ***

An analysis of data on roughly 945 patients with prostate cancer managed with active surveillance showed differences in outcomes depending on whether the cancer was low or intermediate risk at diagnosis. Compared to patients with low-risk disease, those with intermediate-risk cancer (prostate-specific antigen [PSA] >10 ng/mL or Gleason score 7 or clinical stage T2b/2c) had a nearly fourfold higher chance of dying from prostate cancer within 15 years. The study said that '*Patients on active surveillance undergo physical examinations, digital rectal examinations, PSA measurements, and repeat tumour biopsies but did not mention using MRI.*

The presenter said that this was the first study to examine long-term outcomes of patients with low- vs intermediate-risk prostate cancer managed on active surveillance.

Dr. Loblaw concluded, "For low-risk patients with prostate cancer managed with active surveillance, the risk of dying of prostate cancer is low, validating this approach for this group of patients. More research, however, is needed to better characterise intermediate-risk patients who can safely be monitored in a surveillance program." He urged extreme caution in using active surveillance for intermediate-risk patients. [Read more here](#)

That's it for this month!



Mates connect to cope with prostate cancer

Men newly diagnosed with prostate cancer in Western Australia will now have mates they can turn to for support, thanks to a new program by PCFA. Launched in September, the MatesCONNECT program connects newly diagnosed men with trained volunteers who have been through the disease. PCFA State Board Chair, Bill Munro, said the service will be accessible to more than 2000 WA men who are newly diagnosed each year. "About one in five Western Australian men with prostate cancer will experience long-term anxiety and depression, and men in regional and rural areas of Western Australia have a 24 per cent higher risk of death. Of equally great concern, men with prostate cancer face a 70 per cent increased risk of suicide compared to the general population. MatesCONNECT provides vital support to ensure these men do not suffer alone." [Read more here](#)

PCFA Ask The Experts Webcast: Survivorship Essentials

This is PCFA's final webcast in this series - 'Prostate Cancer Survivorship: The Long Run'

"For the first time, we have brought together experts from New York, Vancouver, Sydney, and Perth to talk about the challenges of prostate cancer survivorship. We're calling it out – **men impacted by prostate cancer face specific challenges that are seldom addressed in mainstream health care delivery.**"

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



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.

Upcoming Webinar: Men in Survivorship; Stuff mates don't say

Duration: 60 minutes

Many more men are more likely to die of preventable cancer than women, and even more unlikely to talk about their disease. It is estimated that over 78,000 men will be diagnosed with cancer in 2019, with an average five-year survival rate of 69%. With so many men being diagnosed and surviving cancer, this webinar explored the physical and psychological effect that cancer can have on many aspects of a man's life. It also explored the impact that a cancer diagnosis, its treatment and post cancer life can have, not only for physical but mental state.

**** This Webinar was conducted in Nov 19 so to watch the recording of it, you need to register so that you can then access the link that they will send you ****

[Register for the Webinar here!](#)

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.

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.

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@prostate-cancer-support-act.net

Secretary: David Newman

Phone: 0412 812 875

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: 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.