THE WALNUT

NOVEMBER 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 November (12:30pm): Instead of a normal Wednesday evening meeting, our next meeting will be held as a BBQ/ Pizza social function on **Saturday 21st November,** in the BBQ area at the northern end of SHOUT's building at Pearce. More details are provided later in the Walnut, so if you'd like to come, 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.

We've already had our November coffee so our next coffee morning will be held at **10:00 am, Tuesday, 8 December** at the **Jamison Southern Cross Club.**

October Monthly Meeting

We held our October monthly meeting on the 21st and were joined by 14 members in person, with another two joining by Zoom. Once again, our hybrid approach of using in-person and Zoom attendance worked well, other than a minor sound problem caused by us relying on the laptop's microphone. We're looking at getting a desktop microphone setup to improve this for future meetings, so will report back to you on that soon.

We were joined at the meeting by Ms Emma Awizen from the Advanced Care Planning Team at The Canberra Hospital, who explained how Enduring Powers of Attorney (EPOA), Advanced Care Plans and Health Directions work. Importantly, she highlighted that EPOAs are very important documents to have in place in the ACT before they are needed because **Next of Kin cannot automatically be authorised to make end-of-life and other decisions.** The Team is a government-funded service that is open to all people aged 18 and over who live in the Territory. More information can be found here.

We also discussed improved communications strategies (eg. Facebook), impending review of our Constitution and improvements to our membership database, all of which will help improve support to you, our members.

Extra Prostate Cancer Nurses!

At our October meeting, we also discussed TCH getting its second prostate cancer support nurse in the near future. Alison Turner has since advised that Ms Mingxia Wang has started at TCH and is undergoing induction training. We look forward to working closely with her as we jointly support those diagnosed with prostate cancer.

Strategic Planning - let's map out our way-ahead.

As you would have seen from recent emails, we conducted a Strategic Planning session on the 5th of November at our meeting rooms in Pearce that was:

- facilitated by Carol Mead, CEO of SHOUT; and
- attended by Greg McRoberts, Peter Baker, U.N. Bhati, Neil Walker, John McWilliam and David Newman.

The intent of the Strategic Planning session was to help us examine our raison d'être and help identify our strengths and weaknesses. This will help us develop a clearer way ahead into the future in order to improve our support to all of our members and supporters.

We firstly conducted a SWOT analysis to help us identify some of our **Strengths**, **Weaknesses**, **Opportunities** and **Threats.** The sorts of things we came up with included the following:

- ☑ **Strengths.** We all identify as people who have been diagnosed with prostate cancer or as their supporters (eg. family, friends and carers), and we have a common lived experience. We have a defined organisation with a supporting committee structure, constitution and support from SHOUT. Community awareness of prostate cancer has increased in recent years, with us using our website and brochures to increase this in the ACT.
- ☑ **Weaknesses.** Prostate cancer is seen by many as 'an old man's disease', which risks younger men not seeking diagnosis or feeling that our group is not for them. Our membership database has entry errors and omissions, which risks us losing contact with some of our members. Our constitution needs to be updated to better support how we need to operate and keep in contact with our members and supporters.
- ☑ **Opportunities**. We can look at better advertising (eg. banners, specific brochures for doctors, etc) to appeal to a wider audience of potential members and supporters. We can improve our web presence (e.g. improving our website) and create a Facebook presence.
- ☑ **Threats**. COVID continues to impact our support to members and potential fundraising. Men diagnosed with prostate cancer may not be referred by local doctors and specialists.

We then looked at how we could improve our website and general communications:

- Do we need to add '*questions to ask your specialist*' for the newly-diagnosed, and other links, to our website?
- What do we need to do to get our website to show up better in Google searches?
- Do we need to simplify our domain name? Is ***https://prostate-cancer-support-act.net*** too much of a mouthful and difficult to type without error?

The final part was when we developed a draft **Vision** for our group and supporting **Mission**. We'll refine these over the next few weeks and hopefully present them to you for your consideration at our January meeting.

Overall, it was a very useful activity that will help us develop a solid strategic plan in the near future and help us improve how we support you and those who follow in the future.

Current Activities

Membership database update. As you may have seen in recent emails, we're auditing our membership database to ensure that we have current contact details for our members and supporters. Would you believe that we have over 400 people on the books? Phew!

Our database is a legislative requirement and has grown over the years, where some of our entries now have errors where people have changed their email addresses, phone numbers, etc so it's time for a cleanup. At the same time, our database picks up our support network and also those who have subscribed to the Walnut but don't want to be members. Because of this, we're linking the database update with our Constitution review, where we're looking at better defining who is a Full member (and thus has voting rights) vs others, who may be part of our support network, have left or are just interested in getting a copy of the Walnut. We're also looking at creating a formal 'Inactive' membership category, where you may want to temporarily disengage from the Group because you're traveling OK at the moment but want to keep the option to become an active member again. Rest assured that your privacy is assured throughout.

Group	Title	Voting?	Walnut?	Example
Members	Full	✓	Yes	Normal members
	Associate		Yes or No	Health professionals, Govt officials,
	Honorary		No	Visitors (ie. non-ongoing members)
	Inactive		No	ex-Full or ex-Associate members
	Lost		No	e.g. people we're still looking for!
Ex-Members	Resigned		No	
	Deceased		No	
	Dismissed		No	As per Constitution processes
Other	Walnut		Yes	e.g. people from outside our region
	Unknown		No	This is only a temporary category

Your help is very much appreciated, and we'll be contacting you soon to reconfirm your data.

Constitution update. We've recently set up a working group of six of our members to help update the Group's Constitution so that it can better support our activities and ensure that it complies with recent changes to the overarching ACT Government legislation. The working group will be meeting in early December to consider some of the areas identified for improvement so-far and brainstorm extra changes. We'll then draft a proposed update and rework this in January before presenting the finalised draft to our members at a Special General Meeting, which will be timed with a normal Monthly Meeting (hopefully in February). We also have capacity to slide the vote to the right (ie. into March) if the update needs more work. As you can imagine, it's more important for us to get it right than just get it done quickly.

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.

Adjuvant vs Early Salvage Radiotherapy in Localised Prostate Cancer After Prostatectomy

Adjuvant radiotherapy is radiotherapy treatment initiated at about the time of radical prostatectomy (usually because of some form of unsatisfactory margin on histology) whereas **salvage radiotherapy** is initiated AFTER the PSA begins to rise following surgery, implying that there are still cancerous cells in the body.

The authors of this randomised phase III trial compared adjuvant radiotherapy with salvage radiotherapy at the time of biochemical relapse in 424 patients with localised prostate adenocarcinoma managed with radical prostatectomy and 6 months of hormonal therapy.

The 5-year event-free survival rate was similar between groups, although adjuvant radiotherapy was associated with an increased risk of genitourinary toxicity and erectile dysfunction compared with salvage radiotherapy. A salvage radiotherapy approach may also prevent overtreatment of this patient population.

Basically, the study showed no difference in the two groups of patients in regard to 5 year event free survival. *Read more here*

Bone Mineral Density Testing

A recent Canadian study found that the rate of bone mineral density (BMD) testing is low among men with prostate cancer initiating androgen deprivation therapy (ADT).

Jason Hu, from McGill University in Montreal, and colleagues examined the proportion of BMD testing in the period from six months before through 12 months after initiation of ADT. A total of 22,033 patients initiating ADT from 2000 to 2015 for over 12 months were included in the analyses. Variables associated with ADT testing were examined.

The researchers found that only 17.8% of the cohort taking ADT underwent BMD testing. From 2000 to 2015, there was an increase in the rates of BMD testing from 4.1 to 23.4 percent. History of osteoporosis, rheumatoid arthritis, use of bisphosphonates, and long-term corticosteroid use were associated with increased odds of BMD testing.

The authors concluded that "only a minority of the patients initiating long-term ADT received a BMD test. Although the rates did increase from earlier years, they remain low even in more contemporaneous years." *Read more here*

From our Dr Don Bradfield.

"ADT drastically increases the risk of developing osteoporosis and should be measured prior to commencement of therapy and at subsequent intervals of at least every two years, (possibly one year after commencement).

BMD is Medicare subsidised for ALL patients over the age of 70 and ANY patient with a previous fracture due to minimal trauma or at risk of osteoporosis due to a medical condition (which would include ADT therapy). Hip fractures can be prevented by early treatment of osteoporosis. Ask for a test if appropriate or if you are over 70."

Prostate Cancer Foundation of Australia

Mindfulness for managing the effects of prostate cancer

Dr Natalie Heynsbergh, Prof Trish Livingston and Dr Jacqueline Schmitt have posted a fascinating article on **Mindfulness**.

"Receiving a diagnosis of prostate cancer is a major life stress for most men and their loved ones. Suddenly, the things that matter most seem threatened and it is very normal to experience a wide range of feelings and emotions. Sometimes you may feel more distressed than at other times. Your feelings might be more intense while waiting for test results, making treatment decisions or just before commencing treatment. Side effects from treatment may also cause stress and upset. After treatment, you may worry about the cancer returning. There is growing evidence that mindfulness is one strategy that can be used to reduce symptoms of anxiety and depression associated with prostate cancer. Read more here

PCFA Webinar: Focal Therapy for Prostate Cancer - is it right for me?

Epworth and Icon are collaborating to lead the way in prostate cancer patient-centred care with a new precision target-based treatment - Focal Brachytherapy. This uses the same technique as traditional Brachytherapy, however is a highly targeted technique that places the radioactive source into only the tumour itself instead of the whole prostate, preserving the rest of the prostate gland.

The presentation is now available for you to access at: PCFA Webinar link

Cancer Council ACT

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.

Webinar: Overcoming fatigue: How to get your energy back after cancer

Duration: 60 minutes

Fatigue is when you feel very tired, weak, drained and worn out. Research shows that most people experience fatigue after their cancer diagnosis. Cancer-related fatigue is different to normal tiredness because it doesn't always go away with rest or sleep. Some people describe it as mental and physical exhaustion.

In this webinar, we look at ways you can manage your fatigue and get your energy back. We will also explore some useful services that can support you.

*** This Webinar was conducted in October 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.