



# THE WALNUT

APRIL 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, 21 April**, coincident with a Special General Meeting, where we will be joined by Alison Turner. Our COVID Safety Plan is still 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 11th of May** at the **Woden Southern Cross Club**.

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

## The STARGATE Project

As discussed in our last Walnut, the STARGATE Project aims to improve prostate cancer awareness by providing nationwide information on the burden of this disease at a regional level. Four of our members attended the Project's soft launch at Parliament House on Thursday, 18 Feb 21, and our President, Greg McRoberts, followed this up by participating in Stargate's formal launch on 18 Mar 21. The launch was conducted online and the launch's webinar can be accessed [here](#).

You can search the Stargate site [here](#) and find the ACT's results [here](#) - they are very interesting!

## Community Engagement

As you would know, our Group's Vision includes promoting early intervention and raising awareness of prostate cancer in the community. As part of this, we're increasing our engagement with PCFA and peer support groups, and getting out to talk to groups in the local area.

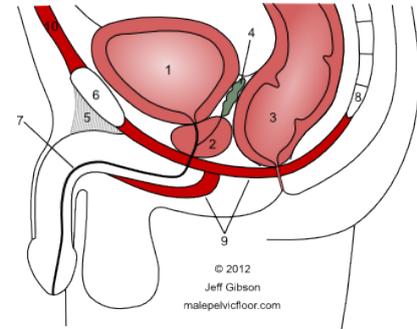
- **Forrest Men's Shed.** On Tuesday, the 6th of April, Greg McRoberts, Don Bradfield and David Newman presented to the Forrest Men's Shed. Two of their members were prostate cancer survivors and there was a lot of interest in what we discussed.
- **Goulburn PCSG.** On Saturday, the 17th of April, David Newman and Neil Walker drove to Goulburn to join the local PCSG at their bimonthly meeting. Our presentation focussed on where we were going with implementing our Strategic Plan and how we had adapted to operating during the early stages of the pandemic and since. The Goulburn group is obviously smaller than ours, but is facing similar challenges in supporting their local community, especially in nearby towns where some are reluctant to discuss their cancer and seek help.

## Management of Incontinence

As many of us have experienced, urinary incontinence is a common side effect in men who have had surgery for prostate cancer, but it can also occur in men who have had radiation therapy. Whether this be temporary or permanent, minor or severe, incontinence can be quite distressing so helping to manage it is a key element of any post-treatment recovery plan.

### Physiology

- The internal urinary sphincter is located at the base of the bladder just above the prostate. It can be damaged or temporarily traumatised during surgery or by radiation.
- The external urinary sphincter is embedded within the pelvic floor muscles just below the prostate.



### Management Techniques

- **Pelvic floor exercises.** Kegel exercises can strengthen the pelvic floor muscles, which support the bladder and bowel, and therefore can help improve bladder control. Guidance on pelvic floor exercises can be found [here](#) (pages 7-8), and you may need the help of a specially trained physiotherapist and/or continence nurse skilled in teaching them. Importantly, pelvic floor exercises should not be performed while a catheter is in place.
- **Continence products.** Pads (also known as shields and guards) are an effective first choice, come in a range of absorbencies and are worn with firm-fitting underwear, not boxer shorts. It is important to change pads regularly and keep your skin clean and dry to avoid irritation. Incontinence pants can be used to manage moderate to heavy incontinence. We currently have a small amount of pads and pants kindly donated by one of our members, so if you would like to have some of these, please email your request to the [Secretary](#).
- **Incontinence pouches.** The pouch is fitted by squeezing the plastic sides to open it, inserting the penis inside and then gently releasing the sides so that the padded closure gently presses down on the urethra to control urinary flow. Any leakage is immediately absorbed by the product.
- **Urinary clamps.** Penis clamps are used to put pressure on the urethra, which runs down the underside of the shaft of the penis, without putting significant pressure on the remainder of the shaft. This is to restrict the uncontrolled flow of urine without significantly restricting blood flow. Clamps should not be used for more than four hours and should preferably be released every two hours to minimise damage to tissue health. They should not be left on at night.
- **Internal slings and artificial sphincters.** A sling is an internally fitted tape that presses on the urethra to keep it closed. An artificial sphincter is a device consisting of a fluid-filled cuff around the urethra, a balloon in front of the bladder and a pump in the scrotum. You can control when you urinate by squeezing the pump. Both systems require surgery.

Further detail can be found in PCFA's ['Understanding urinary and bowel side effects of prostate cancer'](#) publication. Assistance can also be sought from the team at [Men's Health Downunder](#).

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## Current Activities

**Membership database update.** We are finally getting closer to the Finish Line 🏁 in the audit so thank you to everyone for helping us. It's been a long road but this has been a very important activity for us. It has helped us reconnect with a number of you who we'd previously lost contact with because of changes in email addresses and phone numbers. Welcome back!

So what have we found so far? Well, we currently have 432 individual records (🧑) and we've validated nearly 300 of these so only have about 130 to go. Will this never end?

Notwithstanding, a key part of the audit has also been to identify members whose records that appear to be no longer active and that may, under the proposed constitution update, be tagged Inactive. **This is why your response to our membership audit is so important** - we don't want to risk inadvertently reducing our support to you because we can't get in contact with you.

To help us finish the audit, and as we've asked before:

- If you have received an email titled '**PCSG-ACT Membership Audit**' and not responded, **could you please respond to the original email, even if the information is correct?**
- If not, please email Dave Newman at [secretary@prostate-cancer-support-act.net](mailto:secretary@prostate-cancer-support-act.net) so that we can validate your contact and other information.

**Constitution update.** The draft update to our Constitution ([you can download it here](#)) was presented at a Special General Meeting (SGM) on Wednesday, 17 Mar 21, so that we could vote for/against it by Special Resolution. Unluckily, we didn't meet the quorum requirements so the vote couldn't take place.

Sub-rule 27(5) of the current Constitution addresses this type of situation and requires that "*the meeting shall stand adjourned to the same day in the same week of the following month at the same time ... at the same place*". If the standard quorum requirements still can't be met, the Constitution allows the second SGM to progress with a reduced quorum under Sub-rule 27(6).

Based on this, we will be presenting the draft update to our Constitution to you a second time for voting for/against, coincident with our next Monthly Meeting at SHOUT on **Wednesday, 21 Apr 21**. This is a critical activity so please attend this meeting if you can.

**Committee membership.** Having a strong and engaged committee is fundamental to keeping our Group going and staying strong. We currently have a couple of committee members who will be retiring at our next Annual General Meeting, which is planned for the third Wednesday in September this year, so we'd like to start looking for their replacements early.

The Committee has three legislated positions (ie. the President, Secretary and Treasurer) and two (soon to be two+) ex-officio positions, so the work can easily be spread across the team and is not onerous. Our Strategic Plan is in place, we'll soon have an updated Constitution and supporting processes to keep the membership database current so we have a clear path ahead.

If you'd like a chance to join the Committee and help with the future direction of your Group, please [email the Secretary](#) and advise if there is a particular role that you'd like to help with.

## 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.

### Ongoing LUTETIUM Trials

In the February Walnut, we ran an interesting article where ANZUP had reported the results of its "TheraP" clinical trial, which had been partially funded by PCFA; [read more here](#).

Since then, trials into the use and efficacy of 177Lu-PSMA-617 in treating prostate cancer have continued and have been the subject of a recent webinar by A/Prof Arun Azad from the Peter MacCallum Cancer Centre and University of Melbourne. A/Prof Arun Azad is also Chair of the ANZUP Cancer Trials Group Translational.

The webinar can be accessed [here](#). In it, he discusses ongoing studies and trials of lutetium-177-PSMA (177Lu-PSMA-617) radionuclide in patients with prostate cancer. These include the:

- **UpFrontPSMA trial** (NCT04343885), a randomized phase 2 study of sequential 177Lu-PSMA617 and docetaxel versus docetaxel alone in patients with metastatic hormone-naïve prostate cancer that is recruiting right now;
- **LuTectomy study** (NCT04430192) looking at 177Lu-PSMA-617 in patients with high-risk localized prostate cancer as presurgical treatment;
- **proof-of-concept phase 1/2 trial** investigating whether patients can receive high doses of radiation to the prostate before surgery;
- **ENZA-p trial** (NCT04419402), which is currently looking at first-line enzalutamide (Xtandi) with or without 177Lu-PSMA-617 in patients with metastatic castration-resistant prostate cancer (CRPC); and

- **International VISION phase 3 trial** looking at second-line 177Lu-PSMA-617 versus docetaxel in those with CRPC who previously progressed on abiraterone (Zytiga) or enzalutamide.

A/Prof Azad says that 177Lu-PSMA-617 has shown efficacy in metastatic CRPC in late-stage disease, and there are more data coming out in that area. The studies discussed above will also show if there is efficacy in the frontline setting with 177Lu-PSMA-617 for these patients.

### Hormone Therapy for Prostate Cancer? A Genetic Test Could Help

A large study in the USA has recently confirmed that a genetic test can correctly predict how likely it is for recurrent prostate cancer to metastasise. Researchers concluded that the test could help people with prostate cancer and their doctors choose the most appropriate treatment.

The standard treatment for recurring prostate cancer is radiation therapy, either alone or with hormone therapy. However, it's currently difficult to determine which patients have aggressive cancer that may require the addition of hormone therapy. The study found that the [genetic biomarker test](#), called Decipher, may have the ability to do just that. Using data from an NCI-sponsored clinical trial, researchers found that people with higher Decipher scores were more likely to have [cancer that spread years later and to die from the cancer](#). The results, published February 11 in JAMA Oncology, also showed that hormone therapy helped people with higher scores live longer but was far less helpful for those with lower scores.

[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. All MatesCONNECT volunteers have been through prostate cancer.

PCFA's MatesCONNECT service is similar to that provided by Cancer Council's peer support program but specialises in prostate cancer. It can also offer you the anonymity that maybe our meetings can't, so is worth considering as an additional option for you.

You can get practical advice on surgery and treatment, and the 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. They'll take your details and find a volunteer who suits your situation. While their volunteers can't give medical advice, they can provide you with an understanding of what to expect and give you an insight into living with prostate cancer.

[Download your Mar 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.

### **'Making Treatment Decisions'**

The thing about cancer is that it can be hard to know if you are making the right decisions about your treatment.

How much choice do you actually have? How do you know you have explored all your options? And once you know the options, how do you decide the best way forward?

In this episode of The Thing About Cancer podcast, Julie sits down with Professor Lyndal Trevena to tackle these questions, and much more.

More information can be found [here](#).

### **Publication: Sexuality, Intimacy and Cancer**

This booklet has been prepared to help you understand the ways cancer and its treatment may affect your sexuality, sex life and relationships. Sexuality and intimacy are an important part of our wellbeing, and are closely linked to how we relate to ourselves and others. [Download the publication here](#)

## Appreciation

Thank you to PCFA, the ACT Government, SHOUT, Paddywack Promotional Products, Harness Racing ACT, and everyone who has assisted in 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@prostate-cancer-support-act.net](mailto:president@prostate-cancer-support-act.net)

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.