



# THE WALNUT

April 2017

## Newsletter of the Prostate Cancer Support Group - ACT Region Inc.

Affiliated with the Prostate Cancer Foundation of Australia



Postal address  
C/- SHOUT  
PO Box 717, Mawson, ACT 2607

Website: <http://prostate-cancer-support-act.net>

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### Next monthly meeting

Our next monthly meeting will be on **Wednesday, 19 April** at our usual location and time (see below). Our guest speaker will be urologist Dr Simon McCredie. The talk will be about treatment of prostate cancer.

All are welcome to attend our regular monthly meetings, including partners and carers. No notice is required — simply come along and introduce yourself, or contact one of the people listed later in this newsletter.

Meetings of our support group are held on every **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 our website here for details and map showing the location: <http://tinyurl.com/8qkhysb>.

There will be plenty of time available at the meeting for current and new members to exchange information and to discuss matters of interest or concern.

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### Next coffee morning

**10:00 am, Tuesday, 9 May**, Canberra Southern Cross Club, Jamison.

All are welcome to attend including partners and carers. No notice is required — simply come along and introduce yourself.

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### 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 from the Group to contact you. If you would like immediate advice, support or assistance, please contact any of the following people:

**President:** John McWilliam  
Phone: 0416 008 299  
Email: [president@prostate-cancer-support-act.net](mailto:president@prostate-cancer-support-act.net)

**Secretary:** David Hennessy  
Phone: (02) 6154 4274  
Email: [secretary@prostate-cancer-support-act.net](mailto:secretary@prostate-cancer-support-act.net)

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### Appreciation

*The Group recognises and expresses its appreciation for the support provided over the past year by:*

- SHOUT staff
- the Canberra Southern Cross Club
- Holy Family School, Gowrie
- the Burra Patchwork and Quilters Group
- the Naval Association of Australia
- many individuals in its fund-raising activities.

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## President's report

It has now been a year since I took over as President of the Group. The time has flown, and I have learnt a lot. It has been good meeting so many new people.

One of the most gratifying aspects of being a part of our support group is speaking to people who are being treated for prostate cancer and to provide reassurance during their journey. This can be in sharing experiences in the recovery from prostate cancer treatment or in helping them work out what questions they need to ask their doctor. While we all have our individual experiences, it is reassuring to know that others have had similar experiences and that we are not alone in these journeys.

Over the next few months we will be having some interesting presentations from Canberra urologists on recent development with the treatment of prostate cancer in Canberra and revisiting how to regain continence following surgery and maintain it after that.

In this newsletter, there is a progress report on the situation with SHOUT, which provides support to the Group. It is pleasing that progress is being made in resolving the future of SHOUT.

John McWilliam  
**President**

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## Previous meetings

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### March 2017 General Meeting

Fifteen members attended our March meeting. This included one new member.

Our guest speaker was Dr Kate Hannan, Research Fellow in the Australian Cancer Research Foundation, Department of Cancer Biology and Therapeutics at the John Curtin School of Medical Research, Australian National University. Kate discussed the current focus of her lab – 'ribosome biogenesis' – the process of making the machinery that can synthesise our cellular proteins, and how this is regulated in the cell. She described the way in which this basic research identified a new target for cancer therapy, RNA polymerase I. This resulted in

the development of a first-in-class drug, CX-5461, which showed success in haematological malignancy models and led to a clinical trial. She indicated that the lab has also demonstrated efficacy in combination to treat a prostate cancer model, and gave an overview of where the lab will go next with these promising projects.

A copy of the notes of Dr Hannan's presentation is available on our website [see 15 March 2017 meeting at: <http://tinyurl.com/6fy5psg>].



Dr Kate Hannan addressing the March meeting of the Group



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### April 2017 Executive Committee Meeting

At its April meeting, the Executive Committee, among other things discussed:

- the impact of the continuing uncertainty on the long-term future of SHOUT on the operation of the Group;
- engaging administrative support for the Group;
- speakers at future meetings in 2017;
- a new pamphlet for the Group;
- the Treasurer's report;
- applications for community grants to the Group; and
- opportunities for increasing community awareness of Group activities.

The next meeting of the committee will be held on Wednesday, 3 May.

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### Future of SHOUT

In our last newsletter, we reported on the precarious financial position facing SHOUT (Self-help Organisations United Together). Like many other self-help groups in Canberra, the Prostate Cancer Support Group uses the services of SHOUT to help provide our activities. We rent rooms at the Pearce Community Centre for our general and executive committee meetings as well as storage of Group materials; and SHOUT provides administrative support, such as handling our mail, telephone calls and distribution of our mail to other organisations.

We are pleased that SHOUT has now been given a breathing space to help develop a more sustainable way of operating. It has advised member organisations that it has been told by the ACT Minister for Community Services and Social Inclusion, Rachel Stephen-Smith, MLA, that:

- there will be a transitional period of 6 months that SHOUT is funded for in the first instance. During this time SHOUT will engage in a review of services, business models etc;

- the Minister's Office will work with SHOUT directly as it travels through this process to establish what it needs into the future in terms of funding; and
- the Minister is committed to the future of the Pearce hub and the back-office operations of SHOUT. Furthermore, the Minister acknowledged that these sorts of operations will always need a certain level of Government funding.

As a group using SHOUT services, the Minister also wrote to us advising that the Government is committed to working with SHOUT and member groups, including us, to develop new sustainable support arrangements for SHOUT.

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### Message from Cancer Voices NSW on treatment options

Cancer Voices NSW has written to the Group asking us to bring members' attention to a prostate cancer treatment options sheet that they have prepared for men who have been diagnosed with prostate cancer. This options sheet is accessible through this page on our website: <http://tinyurl.com/lyjbsqf>. It emphasises the need to seek opinions from a radiation oncologist as well as urologists and provides questions that can be asked of your specialists.

According to Cancer Voices NSW the treatment options sheet was prepared because some studies have suggested that the outcomes from patients who have had surgery and radiation oncology were both effective in treating prostate cancer and that sexual and urinary side effects were better long-term with radiation than with surgery.

The position taken by our Group is that selection of the most appropriate treatment for prostate cancer depends on several factors, such as age, stage, aggressiveness, presence of co-morbidities and prior treatments undertaken. Our Group does not recommend one treatment option over another, but supports seeking a range of expert opinions. We also agree with Cancer Voices NSW that there is time to investigate the available information from experts before deciding on the most appropriate treatment. You can ask your GP or urologist to provide a referral to a radiation oncologist. We would

add that the opinion of a medical oncologist should also be considered.

For information about radiation therapy see: <https://www.targetingcancer.com.au/>. Information about medical oncology can be accessed through this website: <http://tinyurl.com/mrmpwon>.

Other good sources of information about prostate cancer treatment options can be found at these web sites:

PCFA: <http://tinyurl.com/jj9e23d>

Cancer Council: <http://tinyurl.com/jvpe7uh> (especially the booklet Understanding Prostate Cancer, which can be downloaded from our website here: <http://tinyurl.com/lqof972>).

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### Future events

**May meeting:** Dr Irmina Nahon, Assistant Professor, Clinical Education Coordinator, University of Canberra will speak about continence rehabilitation, an issue that is relevant to men who undergo radical prostatectomies. Dr Nahon is an active member of the Continence Foundation of Australia and the Australian Physiotherapy Association's Continence and Women's Health group. She is passionate about continence promotion, as well as research into the assessment and management of incontinence.

**June meeting:** The guest speaker will be urologist Dr Hodo Haxhimolla. He will inform us about the following leading edge technologies as they relate to prostate cancer diagnosis and treatment: 3-Tesla MRI scanning which can be undertaken at the National Capital Private Hospital or through facilities of The Canberra Imaging Group, use of the Da Vinci robotic surgical system now available at the National Capital Private Hospital, and the Ga-68 prostate specific membrane antigen PET/CT scanning procedure that is also now available in Canberra.

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### Stay up-to-date

Stay up-to-date by joining the PCFA Online Community. The PCFA Online Community is open to everyone 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.

It is free and easy to become a member of the PCFA Online Community. You can sign up at: <http://onlinecommunity.pcfa.org.au>.

The April edition of the PCFA *Online Community Digest* [see <http://tinyurl.com/kvelepz>] includes articles on:

- supplements and counterfeit drugs to treat erection problems can be dangerous;
- how people cope with advanced cancer;
- how emotional distress after a prostate cancer diagnosis can affect treatment decisions; and
- patient voices: side effects reported by patients can help men with localised prostate cancer choose between treatments.

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### Research study—National survey of cancer survivors—request for survey respondents

In the Walnut of June 2016, we mentioned that researchers at the University of New South Wales are seeking volunteers who have received neurotoxic chemotherapy (i.e. chemotherapy that can cause damage to the nerves) as a treatment for cancer to complete an online survey. Through this survey, the researchers hope to better understand the impact of side effects of chemotherapy on the lives of Australian cancer survivors. The survey is still running and the researchers are still asking people who have had such treatment to respond to the survey.

The survey is anonymous, and takes around thirty minutes to complete. If you are willing to participate in the study please go to the following website:

<http://www.infocusstudy.org.au/survey>

Or for more information please email: [in\\_focus@unsw.edu.au](mailto:in_focus@unsw.edu.au)

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### **Borrowing items from the Library**

Don't forget that 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 (such as the new *Cancer Recovery Guide* book that we have acquired) or finding out more about our collection can contact U.N. Bhati, email: [unbhati@gmail.com](mailto:unbhati@gmail.com).

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### **Articles and reports of interest**

The following articles that have appeared recently on web sites or other sources may be of interest to some members. The Group's Executive has not attempted to evaluate the articles' findings and conclusions or the credentials of the authors. Any opinions or conclusions expressed are those of the authors. Other medical practitioners or other practitioners may have other views. The articles are simply being drawn to your attention so that you can read them in full for yourself and make your own evaluation.

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#### **Association noted between prostate cancer and higher grade of male pattern baldness**

Men with a family history of prostate cancer, and of other types of cancer, men of African descent and, to a lesser extent, men who smoke and men who are overweight are known to be at higher risk for prostate cancer. According to two studies reported by the Prostate Cancer Foundation [see <http://tinyurl.com/n4sh4le>], it could be that men with certain types of early baldness could also be at higher risk of prostate cancer.

An association was noted between moderate (but not mild) levels of male pattern baldness (assessed at time of prostate biopsy and retrospective question to baldness at age 35) and higher grades of prostate cancer. The association was noted between frontal with moderate crown baldness and more severe prostate cancer at biopsy.

This should be qualified by the fact that 50-70 per cent of males may develop some degree of baldness and hence the study should probably be regarded as a soft association. One theory mentioned is that this association may be connected with a tumour suppressor gene.

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#### **Active surveillance vs surgery decision is influenced by emotional distress at time of diagnosis**

The February 2017 edition of the Journal of Urology reported on a study of treatment decisions of men with clinically localised prostate cancer, particularly men with low risk disease [see <http://tinyurl.com/ktok5qt>]. The study involved 1,531 participants recruited from two academic and three community facilities. This study analysed the emotional stress at time of diagnosis and treatment decision and found that men who were more emotionally distressed were more likely to choose surgery over radiation or active surveillance, including those patients who had a low risk biopsy.

*Comment:* This finding is not surprising but it does emphasise the need for support to the patient at the time of diagnosis and the need to discuss the treatment options fully. It also emphasises the need for a better multi-disciplinary approach.

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#### **Association between choice of radical prostatectomy, external beam radiotherapy, brachytherapy, or active surveillance and patient-reported quality of life among men with localised prostate cancer**

In a study reported in JAMA (March 2017), active surveillance of low-risk prostate cancer was found to be as good as treating it in many cases, and spared patients such distressing treatment side effects as sexual-functioning problems. The study examined the quality of life impacts of 1,141 men who had been diagnosed with early-stage prostate cancer between January 2011 and June 2013. It found that, after two years, men who had received treatment for their prostate cancer had all experienced various side effects, which had impacted on their quality of life, and that there were similar outcomes at that time for people who pursued active surveillance. This emphasises the need for all treatment options to be explored, particularly for men with low risk prostate cancer.

A good summary of the study can be found in *Prostate Cancer News Today* (5 April 2017) [<http://tinyurl.com/kxy3dqq>].

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## Bipolar androgen therapy

At our last meeting, a member of the Group asked about bipolar androgen therapy (BAT). Bipolar androgen therapy, where the body is alternately flooded with and starved of testosterone in the treatment of metastatic prostate cancer.

At the 28<sup>th</sup> Symposium on Molecular Targets and Cancer Therapeutics in Munich, Germany from 29 November to 2 December 2016, Dr Sam Denmeade, Professor of Oncology at the Johns Hopkins School of Medicine reported on trials of the use of BAT. He has also given a recent lecture on the trials [see <http://tinyurl.com/lbdo47v>]. Dr Denmeade said that, counter intuitive as it is, early trials had shown that large doses of testosterone following hormone therapy or chemotherapy appeared to be effective for some men in reducing PSA. The trials were performed in castrate resistant men (i.e. already treated and resistant to androgen deprivation treatment) in whom monthly spikes of testosterone were given while continuing the hormone deprivation treatment. It acted by the testosterone binding to androgen receptors on the prostate cancer cells, thereby blocking cell division. The benefit may be of greater significance in patients with certain gene markers. Further work is needed.

Testosterone treatment has previously been contraindicated in prostate cancer in Australian prescribing information. The authors in their protocol commented BAT may not be advised in patients with significant pain, possibly due to a flare reaction, but also commented that this could be managed with analgesia.

*It should be noted that the prescribing regulations for testosterone (androgens) are quite strict in NSW and the ACT. Testosterone is NOT available on the PBS for this indication and GPs would have difficulty prescribing it. Urologists may prescribe it on the PBS for testicular failure, but not necessarily for this currently off-market indication.*

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## Researchers working on alternative test for prostate cancer

In an article in *Prostate Cancer News Today* (10 April 2017), details are provided about

research being done to develop a urine test for prostate cancer, to replace the current biopsy test. After establishing that dogs could detect proteins associated with prostate cancer in urine, researchers are seeking to establish which scent molecules the dogs reacted to. You can read the article at: <http://tinyurl.com/kv27y7b>.

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## 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 I'd 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, or if you no longer wish to receive copies of the newsletter, please send me an email through the form here: <http://tinyurl.com/grshy8s>.*

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## 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's Executive and the editor of this newsletter do 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 Executive or the editor. 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's Executive 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.*