



THE WALNUT

August 2014

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

Affiliated with the Prostate Cancer Foundation of Australia



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Monthly meetings

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

When

Meetings of our support group are held on every 3rd Wednesday of the month except in December.

Usual Location

Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. See our web site here for details and map showing the location: <http://tinyurl.com/bjoyczu>

Time

6:30 for 7:00

Next monthly meeting

Our next monthly meeting will be on Wednesday 20 August 2014 at our usual location and time (see details here: <http://tinyurl.com/ley8gr1>). One of our members - Aiden Moore - will be telling us about his experiences during treatment for prostate cancer. There will be lots of time available for members to exchange information and to discuss things of interest. All welcome: blokes, carers, partners, members, non-members. There will be time for an in-depth question/answer/information discussion amongst members.

Contact us

Postal address

Prostate Cancer Support Group - ACT Region Inc.
PO Box 717, Mawson, ACT 2607

Personal support

If you would like immediate support, advice or assistance contact any of the following people:

President: Chris Hansen
Phone: 02 6161 4135
Email: chriskayehansen@gmail.com

Treasurer:
John Lucas
Phone: 02 6293 2532
Email: jandklucas@bigpond.com

Web site

Our web site provides details about the activities of the group, meetings, meeting location map, contact persons and lots of other useful information:



prostate-cancer-support-act.net

From the editor

This edition provides information about our last meeting, some events of interest, and information about recent articles and reports that may be of interest.

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 be happy to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy directly please send me an email through the form here:

<http://tinyurl.com/2bdbbnk>

I'm happy to add any of your friends and carers to the email list for the newsletter. Past issues of *The Walnut* can be downloaded from this page of our web site:

<http://tinyurl.com/42fyrxd>

Mike Boesen
Editor

President's report

Annual General Meeting - this is fast approaching and will be held in conjunction with the September monthly meeting.

Help needed

Like most voluntary groups, we have a small group of people who do most of the work. Can you please give some thought to taking a more active role in running the group? While it involves some work there are certainly benefits; here are some:

- the opportunity to provide counsel and support to men newly diagnosed with prostate cancer;
- you can influence the nature of the policies, activities and direction of the Group;
- there is the opportunity meet influential people such as the Chief Minister and attend gatherings with various bigwigs; and
- most importantly, you can bring your real world knowledge and experience and new blood to bear on the way we do stuff.

I encourage all members to think about standing for a position on the Executive Group. The group meets once a month between monthly meetings to consider administrative and procedural matters that would otherwise take up too much time at the regular monthly meetings. Our meetings are generally over within an hour. There is some consequential homework.

Recent Events

"The Long Ride" folk from the Department of Defence ran an information stall in Cooma on 2 August. Although we were not directly represented, our pamphlets were handed with our contact details.

I met with Bronwyn Inch, our Chapter Council Member from the PCFA on Saturday. PCFA has a hierarchical structure beginning with local support groups organized into chapters – we are part of the Southern NSW chapter – which in turn report up to PCFA HQ in Sydney. We discussed several issues mainly to do with co-ordination between our local support group and the PCFA. One significant issue was handling of donations. For people who want a receipt for tax

purposes, we can either direct them to the PCFA website where they have the option of a general donation for research or specifically donate to the prostate cancer nursing project, however there doesn't seem to be the option to direct the donation back to the local area.

The new Canberra Region Cancer Centre held an Open Day on 9 August. Over 600 people attended. I was there with Roger Allnutt and Michael Fullam-Stone. We fielded quite a number of queries from members of the public.

Upcoming Events

- 3 September - **Self-Help and Wellbeing Expo.** This will be held at the Canberra Hellenic Club in Woden. The objective is to raise awareness of Self-Help organisations. It runs from 10am to 3pm on the day.
- 17 September - **Annual General Meeting.** This is the meeting where we report on the past year and formally elect office-holders for the upcoming year. We will also vote on an amendment to the constitution to limit the period of time office-holders can remain in office. Please give some thought to putting your name forward for one of the positions.
- 18-19 October - **Murrumbateman Field Days.** As in previous years we would like to have a strong presence at this event. It provides access to many men who should be made aware about prostate cancer, its detection and treatment, and their partners.

Secretary's report in the meeting on 18 June 2014

Attendance - including one new member - was 14. Signatures in the attendance book have improved lately but are still not always obvious. Please print, rather than sign to make decryption easier.

Guest speaker

Our guest speaker was Glen Pidgeon who is a locally-based registered nurse. He is going to undertake the Prostate Nursing Care postgraduate diploma level course provided by La Trobe University. Our group is funding his course costs.

Glen is one of a small number of male nurses in the health system in Canberra. He has been in the healthcare business since the 1970's including some time running his own medical supplies business. At present Glen's work involves general nursing at the Tuggeranong Health Centre. Glen has had some experience with prostate cancer patients, most usually following surgery. He indicated that catheters and associated bags are problems for male patients needing ongoing management.

One area that he feels needs more attention is the initial advice provided by medical specialists. His view is that patients are normally referred to a specialist by their GP, usually with no knowledge of the reputation or ability of the specialist. The advice and consequent

action taken is biased towards the specialist's area of expertise. (It is clear this is an area where our group could be of assistance if we contact prospective patients early enough - Sec.)



Glen Pidgeon talks to the group (thanks for the pic U.N.)

Glen's opinion is that there is not enough information available about prostate cancer. His view is that many men are either unaware that they have a prostate gland, or do not know its function. He thinks that breast cancer is more publicized than prostate cancer, perhaps because of the location of the prostate in the body and the fact that women tend to be more open about their problems.

Unfortunately Glenn will be unable to undertake the course in 2014 due to work pressures but hopes to do the course in Semester 1, 2015. He committed to contact us further regarding the course.

General matters

The president noted that he would not be at the September meeting, which will comprise both the Annual General Meeting, and also a Special General Meeting to consider a change to the constitution to limit office-holders length of service. The immediate past president, Peter Daley has agreed to chair this meeting.

Next Meeting

The next meeting will be at usual place and time on 20 August 2014 - see details on page 1 of this newsletter.

George Kayaba
Secretary

Help required - redesign our banner



At meetings and awareness events we have a portable roll-up banner that we use to draw attention to the existence of the Group.

We would like to redesign it to increase its appeal and relevance to the Group and its functions. So if any of you have graphic design skills and could develop a new design for us, please contact me (details are on page 1).

Chris Hansen
President

Prostate cancer treatment breakthrough

You might have noted a very recent news item about impressive results from a 5-year trial of a new treatment regime for aggressive localised prostate cancer. The Director of the trials group is Prof. Jim Denham of the University of Newcastle. We will get details and post them in the next issue of The Walnut. Meanwhile, you might note the content of this ABC online article [here](#) or here: <http://tinyurl.com/owrs2wp>

Professor Denham is quoted as saying: "We've seen something like a 40 per cent reduction in the spread of the cancers and that in a few years time is going to lead to survival improvements, let alone huge reductions in suffering."

Mike Boesen
Editor

Recent articles and reports that might be 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. The articles are simply being drawn to your attention so that you can make your own evaluations. If you cannot access any of the articles, contact me and I'll help.

Enzalutamide decreases risk of progression of metastatic prostate cancer

This is a single double-blind phase 3 study by Tomasz Beer *et al* [reported here](#) or here: <http://tinyurl.com/nkpw6o8> Reported online in the New England

Journal of Medicine, 31 July 2014. Their conclusion: "Enzalutamide significantly decreased the risk of radiographic progression and death and delayed the initiation of chemotherapy in men with metastatic prostate cancer."

Chemotherapy (docetaxel) and ADT therapy combined increases survival time for patients with metastatic prostate cancer

This is a single research study reported by Christopher J Sweeney and is summarised in a web article [reported here](#) or here: <http://tinyurl.com/qcl2zmd> by Jody A Charnow who writes: "Starting chemotherapy (Docetaxel) along with androgen deprivation therapy in patients newly diagnosed with metastatic prostate cancer improved median overall survival by more than 13 months...". Reported online in the Renal & urology News, 2 June 2014

Metformin use decreases risk of prostate cancer diagnosis

This is a large retrospective study by Mark A Preston *et al* and is summarised in a web article reported [here](#) or here: <http://tinyurl.com/ldewhww> by Jody A Charnow who writes: "In a study of 12,226 men diagnosed with PCa and 122,260 population controls, Mark A. Preston, MD, of Massachusetts General Hospital in Boston, and colleagues found that men who used metformin had a significant 16% decreased risk of a PCa diagnosis in adjusted analyses compared with non-users. Among men who had undergone PSA testing in the previous year, metformin use was associated with a significant 34% decreased risk of a PCa diagnosis." Reported online in the Renal & urology News, 12 June 2014

Prostate cancer progression linked to obesity

This is a large retrospective study by Bimal Bhindi *et al* and is summarised in a web article [reported here](#) or here: <http://tinyurl.com/l6cy9ts> by Jody A Charnow who writes: " Obesity may increase the long-term risk of disease progression in men on active surveillance for low-risk prostate cancer (PCa), according to study findings presented at the Canadian Urological Association annual meeting in St. John's, Newfoundland." Reported online in the Renal & urology News, 30 June 2014

Advanced prostate cancer linked to low melatonin

This is a single prospective study undertaken in Iceland study by Sarah C Markt *et al* and is summarised in a web article [reported here](#) or here: <http://tinyurl.com/ks73uyh> by Jody A Charnow who writes: "Low urinary levels of melatonin are associated with an increased risk of advanced prostate cancer (PCa), new findings suggest." He goes on to say that the study's authors state that: "The study adds to accumulating epidemiological data investigating associations between circadian

disruption or sleep loss and PCa, and provides a potential mechanism and framework for understanding prior results". Reported online in the Renal & urology News, 11 August 2014.

ADT-only treatment for localised prostate cancer may not improve overall or disease-specific survival rate

A population-based cohort study of 66,717 medicare patients in the USA was undertaken by Grace L Lu-Yao *et al* and is reported in a JAMA Internal Medicine online article dated 14 July 2014 that can be [read here](#) or here: <http://tinyurl.com/lxvv7yf> The authors conclude: "Primary ADT is not associated with improved long-term overall or disease-specific survival for men with localized (T1/T2) prostate cancer. Primary ADT should be used only to palliate symptoms of disease or prevent imminent symptoms associated with disease progression." An online Medscape Urology article by Roxanne Nelson dated 14 July 2014, provides supplementary information and puts the study in context. She states: "Previous research has shown that ADT is appropriate for use in high-risk patients and in combination with other treatments, but ADT alone, especially in an older population, should be carefully considered." She goes on to indicate that Dr. Lu-Yao said in a statement: "Because of the potential side effects of osteoporosis, diabetes, and decreased muscle tone, clinicians must carefully consider the rationale behind ADT treatment if used as the primary therapy for older patients". The Nelson article can be [read here](#) or here: <http://tinyurl.com/q7n3c9q>

Try sitting if you have an enlarged prostate and LUTS

Men with urination problems as a result of enlarged prostate may be better off sitting rather than standing to urinate, according to a recent systematic review and meta-analysis. In a 25 July 2014 article in Renal & Urology News, Jody Charnow states: "Ype de Jong, MD, and colleagues at Leiden University Medical Center in Leiden, The Netherlands, analyzed data from 11 studies that included healthy men and those with lower urinary tract symptoms (LUTS). Among men with LUTS, a sitting position during urination was associated with a significantly lower post-void residual volume (PVR) compared with standing, the researchers reported..." [Read the article here](#) or here: <http://tinyurl.com/mpot7xv>

Erectile dysfunction drugs used improperly

While this study is a small single study in Spain, its conclusions may be interesting and instructive. In the 2 June 2014 online version of Renal & Urology News, Adam Kaplan and Jaime Landman state:

"A new Spanish study has demonstrated that many patients who fail treatment of erectile dysfunction (ED) with phosphodiesterase-5 inhibitors (PDE5is) are using the medications improperly... Frequent errors included failure to try the medication at least 6 different

days, failure to reach maximum dose, failure to try at least 2 medications, and failure to take the medication on an empty stomach (if required).”

The drugs referred to include Viagra, Cialis and Levitra. The article can be [read here](#) or here: <http://tinyurl.com/n6c8jgm>

Transperineal biopsy may have temporary erectile dysfunction

This is also a report on a single small study, written by Jody Charnow, reported in the 19 May 2014 online version of Renal & Urology news. Charnow states:

“Transperineal prostate biopsy is associated with significant short-term erectile dysfunction (ED), according to study findings presented at the American Urological Association 2014 annual meeting. Erectile function recovers fully by 6 months post-biopsy...The potential impact of transperineal biopsy on erectile function should be emphasized during the informed consent process, the authors concluded.”

The article can be [read here](#) or here: <http://tinyurl.com/kkpt39x>

Mike Boesen
Editor

Interesting radiological image



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 particular 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.