THE WALNUT

JUNE 2018

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
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Next monthly meeting

Our next monthly meeting will be held on **Wednesday 20 June 2018**.

Our guest speaker on 20 June is Alison Turner, who is the prostate cancer nurse at The Canberra Hospital. Alison will discuss her role at the hospital and provide practical advice on steps men can take in relation to their prostate health and if being treated for prostate cancer.

All are welcome to attend our regular monthly meetings and coffee mornings, including partners and carers. No notice is required – simply come along and introduce yourself, or contact one of the people listed on page 2 of this newsletter.

Meetings of our support group are held on the 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/8gkhysb.

Next coffee morning

10:00 am, Tuesday, 10 July, Canberra Southern Cross Club, Woden.

Coffee mornings are 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.

President's Message

On 22 May 2018, we provided an information session on prostate health and prostate cancer to staff at the Department of Human Services (Chief Technology Office). We received feedback that the presentation was well received and we were given a very generous donation of $1,730.70 by the DHS staff. We were overwhelmed by this generosity and express our huge appreciation to the DHS staff for this donation. A report on the event is provided separately in this newsletter.

Dr Irmina Nahon, Assistant Professor, Clinical Education Coordination at the University of Canberra, was the guest speaker at our May meeting. As usual, Irmina gave a most informative and stimulating presentation. We are very appreciative of the support that Irmina has provided to the Group over many years.

I hope to see you at our next meeting when Alison Turner, prostate cancer nurse at The Canberra Hospital, will be speaking to us. This promises again to be a very informative and interesting session.

John McWilliam
President

Appreciation

The Group recognises and expresses its appreciation for the support provided by: the PCFA, SHOUT staff, staff of the Department of Human Services (Chief Technology Office), the Canberra Southern Cross Club, Holy Family School Gowrie, ACT Veterans' Hockey Association Inc, Paddywack Promotional Products, the Naval Association of Australia, German Auto Day and the many individuals who have assisted in our fund-raising activities.

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. After hours, please call 0490 784 151.

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

President: John McWilliam
Phone: 0416 008 299
Email: president@prostate-cancer-support-act.net

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

New PCFA CEO

The Prostate Cancer Foundation of Australia has appointed a new Chief Executive Officer, Jane Endacott. Jane took up her new position on Tuesday 12 June. Read more at:

https://tinyurl.com/ycgy6xe2

Our May Meeting

The guest speaker at our May meeting was Dr Irmina Nahon, Assistant Professor, Clinical Education Coordination at the University of Canberra.

Dr Nahon announced that the National Health and Medical Research Council (NHMRC) is providing a grant of $953,000 to the University of Queensland for a project on 'Targeted pelvic floor muscle training for urinary incontinence after radical prostatectomy: A randomised controlled trial with embedded physiological studies'.

In introducing her topic, Dr Nahon contrasted male and female anatomy with respect to the ureter and urethra. Urine produced in the kidneys passes through the ureters, collects in the bladder and is then excreted through the urethra. In females, the urethra is narrow and about 4 cm long, and extends from the bladder neck to the external urethral orifice in the vestibule of the vagina. In males, the urethra is around 22 cm long and extends from the bladder neck through the prostate to the external urethral orifice at the end of the penis.

Dr Irmina Nahon giving her presentation

In males the part of the urethral sphincter muscle that passes through the prostate is relied on heavily to control continence. The removal of the prostate also removes this sphincter muscle. Following prostatectomies, males, like females, have to rely on pelvic floor muscle contraction to maintain continence. Retraining is required for men to learn to rely on the pelvic floor muscles. Men do this in a slightly different way to females and men are often not instructed on how to perform pelvic floor exercises correctly. The criterion for successful

muscle control is that, when urinating, tightening the muscles should stop the flow in mid-stream. You should not pull in around the back passage.

Dr Nahon said that there is a 3-month waiting list for guidance from pelvic floor practitioners. But it is important to develop control before surgery. The bladder takes 3 months to recover from a prostatectomy and on average 75% of men recover within 12 months. If the 'bladder neck' is damaged, the pelvic floor muscle cannot close completely and often a prosthesis is required.

Dr Nahon emphasised the need for frequent exercising of the pelvic floor muscles. Men who have had a prostatectomy should do this for the rest of their lives, since the muscles become less strong as we age. Practice should be in real world situations. For example, when crossing a street at the lights, raise the muscles until you commence walking. When golfing, raise your pelvic floor muscles tightly before hitting the ball. Remember that coughing/sneezing places a lot of downward pressure on the bladder.

There were many questions following Dr Nahon's presentation.

Presentation to staff of the Federal Department of Human Services

On 22 May, John McWilliam and Dr Don Bradfield gave a presentation to to staff at the Department of Human Services (Chief Technology Office) on prostate health and the treatment of prostate cancer.

We were pleased to have been invited to provide this presentation, and it reminded us of the value of such presentations. There was a good attendance (around 50 people) and there were many questions.

After the presentation, staff of the Department donated $1,730.70 to the Group. This hugely generous donation will help us extend awareness of our activities. We were taken aback by the size of the donation.

We are hopeful of doing many more such presentations in coming months. If you know of any group that would be interested in having a presentation on prostate health, please let us know.

John McWiliam giving the formal part of the presentation

Don Bradfield answering questions

John McWilliam and Don Bradfield answering questions

June Executive Committee Meeting

The Executive Committee met on 6 June. The Committee, among other things:

- discussed arrangements for speakers for the remainder of the year. The program has been largely confirmed for the year. Dr Mohammad Kahloon from the Capital Urology Centre will be speaking at our July meeting and our annual general meeting will be held in September. Canberra's six-time Paralympics gold medallist, Michael Milton, has indicated that he would be agreeable to speak to the Group around October;
- noted that we had received positive feedback from the Department of Human Services on our presentation to them and that DHS staff had provided a generous donation to the Group; and
- discussed possible government departments and community groups which might be approached to see whether they would like to have similar presentations.

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.

The June edition of the *PCFA Online Community Digest* has articles on:

- PSA testing and prostate cancer diagnosis patterns in the United States;
- ADT with early salvage radiotherapy benefits patients with aggressive prostate cancer;
- Finasteride for the prevention of prostate cancer;
- Evolution of prostate cancer cells helps to identify aggressive tumours.

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

RANZCR prostate cancer position statement — informed decision making in the management of localised prostate cancer

The Royal Australian and New Zealand College of Radiologists issued a media release on 12 June 2018 publicising its new prostate cancer position statement, 'Informed Decision Making in the Management of Localised Prostate Cancer'. Copies of the media release and position statement are available at: https://tinyurl.com/y7l8hbul.

Getting what you need from the health system

Pain Support ACT has extended an invitation to a presentation by Claudia Cresswell, Project Officer at the Health Care Consumers' Association, ACT. Claudia has extensive experience in health promotion and community development with state/territory and national agencies.

What: Claudia will talk about: 'How to stretch your health dollar'

- Choosing the right health service at the right time for you
- the best questions for you as an individual to ask yourself and your health professional.

Where: SHOUT Meeting Room, Bldg 1, Pearce Centre, 1 Collett Place Pearce (opp. shops)
When: Tues 26th June 12-2pm
Cost: Small donation to help cover costs.
More Information: 6281 1036

University of Canberra art and dementia study

The University of Canberra is seeking participants for an innovative new research study it is conducting with the National Gallery of Australia and Dementia Australia.

It is seeking people in the greater Canberra and Queanbeyan regions living with dementia and their carers to attend a six-week art and dementia program at the National Gallery of Australia. Participation includes one visit per week to the NGA for six weeks for both the person with dementia and the carer (in separate tour groups, but at the same time), as well as before and after questions, and collection of saliva samples. Including the visits to the NGA, the total time commitment to participate is approximately 18 hours.

The NGA program has been running for ten years, and current participants come from both the community and residential care. The NGA encourages relaxed discussion of works of art in small social groups. Each tour includes 3 - 4 works of art introduced by a qualified art educator. There is no cost to participate in the study. Each visit lasts for up to two hours and includes a visit to the NGA coffee shop at the end of the tour. Previous interest in art is not necessary. The study is planned to commence in mid-July.

This study has the potential to promote future engagement between existing community organisations and people living with dementia and their carers.

Contact: Call Nathan M D'Cunha on 0437 709 355 or email nathan.dcunha@canberra.edu.au

More information about the program can be found at nga.gov.au/artdementia/

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

Articles and reports of interest

The following articles which have appeared recently on web sites or other sources may be of interest to some members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below. With thanks to Don Bradfield and Mike Boesen for their assistance with this segment.

Are active surveillance patients properly monitored?

Melanie A Evans, Jeremy L Millar, Arul Earnest, Mark Frydenberg, Ian D Davis, Declan G Murphy, Paul Aidan Kearns and Sue M Evans, *Active surveillance of men with low risk prostate cancer: evidence from the Prostate Cancer Outcomes Registry–Victoria*, Medical Journal of Australia, Insight issue 20, 28 May 2018, https://tinyurl.com/yaa7h9xu.

Low risk prostate cancer is increasingly being managed with active surveillance. The objectives of active surveillance are to avoid unnecessary treatment, and to monitor men with low risk cancer according to a protocol that facilitates recognition of progression which justifies deferred radical treatment with curative intent.

While active surveillance has become an accepted management tool, evidence for the optimal frequency of monitoring and the most appropriate triggers for intervention is scarce.

Several active surveillance protocols and guidelines with differing inclusion and follow-up criteria have been published. The recommended frequency for measuring prostate-specific antigen (PSA) levels ranges from every 3 to every

6 months, and the European Association of Urology guidelines acknowledge that the available evidence is inadequate for defining optimal timing.

It is generally accepted, however, that the first follow-up biopsy should be undertaken within 12 months of diagnosis; the recommended timing of subsequent biopsies ranges from annually to once every 5 years.

The Monash study suggests that men assigned to active surveillance may be slipping through the cracks, and in fairly significant numbers. The Monash researchers, led by Associate Professor Sue Evans looked at over 1600 Victorian men diagnosed with prostate cancer between 2008 and 2014 who had been managed with active surveillance for at least 2 years. They found that only 26.5% adhered to an active surveillance protocol, defined as at least one follow-up biopsy and at least three PSA tests in the 2 years after the diagnosis. Nearly 40% of patients did not have a repeat biopsy in the 2 years after the diagnosis.

The odds of adherence were lower for men diagnosed at a public hospital, vs a private hospital, and also lower for those diagnosed with transurethral or transperineal biopsy, compared with transrectal ultrasound biopsy.

While Professor Evans described the results as 'concerning', Brisbane urologist Adjunct Professor Peter Heathcote, who is currently president of the Urological Society of Australia and New Zealand, noted that:

- the authors benchmarked with just one set of protocols, while many different protocols are used;
- urologists are increasingly using magnetic resonance imaging (MRI) instead of biopsies to assess disease and use of MRIs was not captured in the study; and
- from 1 July 2018, there will be a Medicare Benefits Schedule reimbursement for the use of MRI in prostate cancer assessment.

Radionuclide treatment in patients with metastatic castration-resistant prostate cancer

Hofman, Michael S et al, [177Lu]-PSMA-617 radionuclide treatment in patients with metastatic castration-resistant prostate cancer (LuPSMA trial): a single-centre, single-arm, phase 2 study, The Lancet Oncology, Volume 19, Issue 6, 825 - 833, http://tinyurl.com/ya8qq292.

Progressive metastatic castration-resistant prostate cancer is a highly lethal disorder and new effective therapeutic agents that improve patient outcomes are urgently needed.

Lutetium-177 [177Lu]-PSMA-617, a radiolabelled small molecule, binds with high affinity to prostate-specific membrane antigen (PSMA), enabling beta particle therapy targeted to metastatic castration-resistant prostate cancer. This study aimed to investigate the safety, efficacy, and effect on quality of life of [177Lu]-PSMA-617 in men with metastatic castration-resistant prostate cancer who progressed after standard treatments including taxane-based chemotherapy and second-generation anti-androgens.

Patients underwent a screening PSMA and FDG-PET/CT to confirm high PSMA-expression. The primary endpoint was PSA response according to Prostate Cancer Clinical Trial Working Group criteria defined as a greater than 50% PSA decline from baseline and toxicity according to CTCAE. Additional primary endpoints were imaging responses (as measured by bone scan, CT, PSMA, and FDG PET/CT) and quality of life (assessed with the EORTC-Q30 and Brief Pain Inventory-Short Form questionnaires), all measured up to 3 months post completion of treatment.

The authors reported that the study's findings showed that radionuclide treatment with [177Lu]-PSMA-617 has high response rates, low toxic effects, and reduction of pain in men with metastatic castration-resistant prostate cancer who have progressed after conventional treatments. The authors further indicated that this evidence supports the need for randomised

controlled trials to further assess efficacy compared with current standards of care.

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 us an email through the form here:

http://tinyurl.com/ybkxnlg4.

John McWilliam

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.