THE WALNUT

MAY 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 on **Wednesday 16 May 2018**.

Our speaker on 16 May is Dr Irmina Nahon, Assistant Professor, Clinical Education Coordination at the University of Canberra. Irmina also works as a pelvic floor physiotherapist with ACT Health. She is an active member of the Continence Foundation of Australia and the Australian Physiotherapy Association's Continence and Women's Health group. Irmina is very passionate about continence promotion, as well as research into the assessment and management of incontinence.

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.

President's Message

We are pleased to welcome back Dr Irmina Nahon as our speaker at this month's meeting. Irmina has been a wonderful supporter over the Group over many years and her presentations are always highly informative, with plenty of room for discussion of topics of interest to members.

We did not have a speaker at our April meeting, but there was a really useful discussion among members of their differing treatment experiences.

This month we will be giving a presentation to members of staff of the Federal Department of Human Services. We are always willing to provide presentations to interested groups, so if you know of any group that would like us to come along and speak to them about prostate health, do encourage them to contact us.

Don't forget that our coffee mornings are also an opportunity to share experiences with other members and for you to catch up with or to get to know other members. Our next coffee morning is at 10:00 am on Tuesday, 8 May at the Canberra Southern Cross Club in Woden.

John McWilliam
President

Appreciation

The Group recognises and expresses its appreciation for the support provided by: the PCFA, SHOUT staff, 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

Next coffee mornings

10:00 am, Tuesday, 8 May, Canberra Southern Cross Club, Woden.

10:00 am, Tuesday, 12 June, Canberra Southern Cross Club, Jamison.

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.

SHOUT stalls at shopping centres

SHOUT is planning to stage four stalls at shopping centres each year to promote its members' issues, including those of the PCSG. If you are willing to help out at these events, please email Carol at admin@shourt.org.au or let us know by replying to this email and we will give Carol your details. The next event will be held in June.

Our April Meeting

Our April meeting was an informal one, with discussion of the treatments that many members are receiving and discussion of issues of interest to members.

One member advised that he had had a prostatectomy in 2013 and for the next four years his PSA rose slowly to 8, but then rose rapidly to 460. He was put on ADT (Zoladex) regimen which lowered the PSA to 310. He is currently on Xtandi (Enzalutamide) and Xgeva (to reduce bone fractures) and has been accepted into a trial at the Peter McCallum Cancer Centre (Melbourne). He is also being treated with Ra223-dichloride which irradiates cancer cells within the bone matrix.

Some members spoke about the high cost of their radical prostatectomies in the private system. There also appear to be significant variations in the cost of treatment, even for an open-cut prostatectomy, where a person opts not to use the public system.

Members thought that there would be merit in undertaking a study of the cost of treatment of prostate cancer. They asked that a suggestion for such a study be provided to the Prostate Cancer Foundation of Australia (PCFA). This suggestion has now been provided to the PCFA.

Note was also taken of an announcement by UK Prime Minister, Theresa May, of an additional £75m in funding for 'earlier and faster' diagnosis and treatment of prostate cancer, which kills more than 10 000 men each year in the UK. The funding will enable 40 000 men to be enrolled in trials for new treatments of the cancer. One focus will be higher risk groups, including black men, those aged 50 or over, and those with a family history of prostate cancer.

May Executive Committee Meeting

The Executive Committee met on 2 May. The Committee, among other things:

- discussed arrangements for speakers for the May, June and July 2018 meetings (these arrangements have now been confirmed);
- discussed possible speakers for later meetings and, in this context, agreed to ask Canberra's six-time Paralympics gold medallist, Michael Milton, who was recently involved in promoting awareness of prostate cancer testing in the community, whether he would be prepared to speak at one of our meetings;
- agreed to follow up on an informal offer from John and Leslie Macdonald to assist with arranging speakers for our meetings (John has now agreed to do this);
- agreed to send out a separate email to remind members about the next coffee morning;
- finalised arrangements for the outreach presentation to staff of the Federal Department of Human Services on Tuesday, 22 May;
- noted action that is being taken to follow up on our application to the Australian Taxation Office to update the Group's ABN;
- noted that the Capital Urology Centre will be including copies of the Group's pamphlets in the packs that they give prostate cancer patients. This will help to ensure that their patients can also contact us for support, if they wish. (Dr Mohammad Kahloon from the Capital Urology Centre will be speaking at our July meeting);
- agreed to submit an application for a grant to the Canberra Southern Cross Club, which has provided valuable assistance for the past two years;
- noted a regular monthly report from the Treasurer on the Group's financial position; and
- noted that a booking has been made for the Group's participation again in Seniors Week in March 2019.

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

- Early chemotherapy for men with metastatic prostate cancer is worth it in the long run;
- Surgeons use radioactivity to spot lymph nodes harbouring prostate cancer cells;
- A potential new drug for advanced prostate cancer discovered in plants; and
- Are biopsies necessary during active surveillance?

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

2017 Max Gardner Award recipients

On Friday, 20 April, Jim Hughes, AM, National Chairman of the PCFA made the following announcement of recipients of the 2017 Max Gardner Award.

The Support and Community Outreach Network reaches out to thousands of people across Australia every year, selflessly volunteering countless hours to help those who have been adversely impacted by prostate cancer. I would like to take this opportunity to thank each and

every one of you for your dedication and commitment.

Prostate Cancer Foundation of Australia received many Max Gardner Award nominations from across the country for Affiliated Support Group Leaders and Ambassadors. I am extremely proud of the exemplary accomplishments made by all those nominated and the collective, positive impact being made by the whole Network.

It is with great pleasure I announce that the Max Gardner Award recipients for 2017 are David Abrahams, Malcolm Ellis and Terry Grano.

David, Malcolm and Terry have made an outstanding and significant contribution to reducing the impact of prostate cancer on the Australian community. Each of these individuals have altruistically served our community, and genuinely encompass our core values of integrity, optimism, compassion, respect and commitment.

Further information on David, Malcolm and Terry is available on our website at (https://tinyurl.com/ybvk6b2z).

On behalf of the National Board, staff and our community, I would like to thank and commend David, Malcolm and Terry for their ongoing commitment to the cause and valuable work.

Please join me in congratulating each of them on receiving this prestigious award.

Yours sincerely

Jim Hughes AM
National Chairman

Volunteers needed for research project: What is my day-to-day experience of caring for someone with prostate cancer?

Partners of men with prostate cancer are invited to participate in a survey study. The aim of this study is to gather information on the quality of life and coping of partners of men living with early stage prostate cancer. The results will help make recommendations to develop new or revise existing support services.

This study is for people who are:

- a partner of a man with early stage prostate cancer (early stage is defined as not metastatic);
- over the age of 18; and
- able to understand English.

Participation in the study is voluntary, and your information will remain anonymous.

The study is led by Prof Mei Krishnasamy from The University of Melbourne. Ethics approval has been granted by the University of Melbourne's Human Research Ethics Committee.

For more information about this study, please contact: Mei Krishnasamy, Chair in Cancer Nursing at the University of Melbourne, 03 8559 7043 or email meik@unimelb.edu.au.

To participate in the study, click this link.

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.

Prostatic biomarkers and PSA testing

Recently clinicians from all over the world gathered in Copenhagen for the 33rd European Congress of Urology. This report is taken from the following blog by A/Prof Miranda Xhilaga, Director - Research Programs, PCFA about the latest news from EAU about prostate biopsy, biomarkers and PSA testing: http://tinyurl.com/yddzg322

Updated PSA testing guidelines in the US

Many discussions at the conference focused on the growing field of biomarker research, patient biopsy preparation, biopsy procedure, management of biopsy complications, the roles of transrectal ultrasound (TRUS) and magnetic resonance imaging (MRI) guided biopsies, as well as TRUS-MRI fusion biopsy.

Prostate biopsy is one of the most commonly performed procedures in urology in the world. The last decades have seen a dramatic increase in prostate cancer incidence due to widespread PSA testing, increased male life expectancy, and an increase in the total number of men undergoing prostate biopsy.

Prostate biopsy after a positive PSA test and/or digital rectal examination (DRE) carries the risk of false-negative findings. These biopsies also risk over-diagnosis, where clinically indolent (very low-risk) prostate cancers are diagnosed. A positive PSA test means an approximate 25-40% of men being diagnosed with prostate cancer. Of the men who have a biopsy after a PSA reading of 4-10ng/ml, 65-70% will have no sign of cancer in the biopsy.

In recent times, there has been a focus on improving the specificity of diagnosis, to better discover the aggressive, high-grade prostate cancers, rather than detecting all cancers including the very low-risk ones.

Crucial implications for biopsy and biomarker development

Over-diagnosis and over-treatment as a result of the low specificity of the PSA test for the diagnosis of prostate cancer has led to a myriad of research approaches to develop tools to predict which patients are at high risk or not. In particular, these approaches aim to better guide the decision to undertake biopsy. The ultimate aim is to identify and treat men with aggressive disease, while sparing from the biopsy those men who will not die from the disease.

To increase the specificity of prostate cancer biopsy when diagnosing prostate cancer, the urologist will need the help of other novel tools such as molecular and genetic biomarkers. In addition, multi-parametric prostate magnetic resonance imaging (mpMRI) is of major help in identifying risk and in targeting the disease in patients in the high-risk group. Indeed, the field is moving towards the use of biomarkers and mpMRI as a guide in a pre-biopsy setting. To avoid the pitfalls of PSA testing, the urologists will need liquid-biopsy biomarkers and risk stratification tools, to assess the risk of cancer without invasive tests.

What's new and relevant in prostate cancer biomarkers?

The best studied blood-based biomarkers are the 4K Score test and the Prostate Health Index.

The 4K Score Test combines four prostate-specific biomarkers with clinical information to provide men with a personalised measure of their risk for aggressive prostate cancer. The 4Kscore can be used prior to biopsy, or after a negative biopsy, and can predict the likelihood of cancer spreading to other parts of the body in the next 20 years. There is evidence that the 4K score can predict biopsy outcome more accurately than PSA and age alone.

The prostate health index (PHI) is a mathematical formula that combines three different measures of the PSA protein in the blood (total PSA, free PSA and [-2] proPSA). Many studies have shown

that PHI outperforms tests for its three individual components for the prediction of overall and high-grade prostate cancer on biopsy. It is also used to predict the likelihood of progression during active surveillance.

The past year has seen the publication of a large meta-analysis which has shown evidence that the 4K Score is superior to the PHI. This review examined 12 previous clinical validation studies comprising of a total of 11,134 men having these tests. 11 of the 12 studies found that the 4K score was more accurate than PHI. Another multi-centre trial demonstrated validity in a population with a large proportion of African-American men, bringing the total number of men involved in the 4K Score validation to nearly 22 000 (reported and summarised by Dr Stefan Czarnietcki at EAU2018).

Prostate Cancer Gene 3 (PCA3) is a prostate cancer biomarker designed for use after a high PSA reading, to determine how likely it is that prostate cancer is present. It is recommended by the EAU guidelines. This test is performed also in Australia, though not by all laboratories and not in all states. Having a PCA3 test done in addition to a PSA test and digital rectal examination is thought to more accurately assess the need for a biopsy. Generally, the test is given if the patient has elevated PSA levels but a biopsy found no cancer. Findings for this test are contradictory but one study has found the PCA3 test to have prognostic value, as higher PCA3 score values were associated to a greater tumour aggressiveness.

A test for 3 gene variants (for the genes called HOXC6, DLX1, TDRD1) was developed at the same Nijmegen (NL) laboratory as PCA3. These tests form the basis of SelectMDx, which also includes clinical data, and can be used to identify patients with clinically significant prostate cancer.

A recent study aimed to compare SelectMDx to PCA3, for predicting multiparametric MRI and biopsy results for prostate cancer detection. This study showed that SelectMDx was a promising predictor of MRI and biopsy results, out-performing PCA3.

STHLM3 Model (Stockholm 3 model) is an evolving prostate cancer biomarker. The Stockholm3 test is a blood-based prostate cancer test that predicts the risk for aggressive prostate cancer at biopsy by analysing five protein markers, more than 100 genetic markers and clinical data.

ExoDx Prostate (Intelliscore) is unique in that it has opened a new category of urine-based biomarker tests, which need not be preceded by a digital rectal exam (as do PCA3 and SelectMDx). It is an exosome-based test – which means that the testing is performed on the protein and RNA that is secreted from cells into fluids such as, in this case, urine.

As they come into common use, prostate cancer biomarkers, imaging, and risk assessment tools will continue to transform the way the urologists deal with prostate cancer detection.

Long-term prostate cancer risk of Finasteride

Joseph M Unger et al, *Using Medicare Claims to Examine Long-term Prostate Cancer Risk of Finasteride in the Prostate Cancer Prevention Trial*, 9 March 2018, https://tinyurl.com/y8pwde7x. Also reported in *Practice Update*, http://tinyurl.com/y96hkccn.

This study linked Medicare claims and National Death Index data to clinical trial records from the Prostate Cancer Prevention Trial (PCPT) to characterise the long-term implications of Finasteride treatment with respect to prostate cancer risk. Investigators found that, after a median follow-up of 16 years, treatment with Finasteride reduced the risk of prostate cancer by 21.1%. While the benefit of Finasteride therapy was most pronounced in the first 7.5 years of therapy, these risk reductions were maintained throughout the duration of follow-up. There was no increased risk of prostate cancer or all-cause mortality among Finasteride-treated men.

Taken together, these data suggest that the prostate cancer risk reduction is sustained over a 16-year horizon in men who take Finasteride. Furthermore, there does not appear to be any increased risk of mortality among those treated,

suggesting that the possible increased risk of high-grade cancer is not associated with an increased risk of mortality.

The PCPT was a landmark study that randomised 18 880 men to Finasteride or placebo daily for 7 years to assess Finasteride's role as a chemo-preventative agent. Eligible men were >55 yo, had a normal digital rectal examination, and prostate-specific antigen <3 ng/mL. The trial was closed early due to interim analysis indicating a 25% reduction in the prevalence of prostate cancer in men receiving Finasteride. However, the study also revealed the possibility of an increased rate of detection of high-grade prostate cancer (6.4% vs 5.1%) with Finasteride use.

Over the years, many studies have attempted to explain these findings and different hypotheses have been put forward.

The present study by Unger et al. is a long-term survival analysis of the PCPT cohort. The authors used the PCPT study records and linked patients with Medicare claims to obtain longer term follow-up outside of the study protocol. This unique method of blending trial data with secondary claims data allowed an expansion of the trial beyond the designated study period. The authors found that Finasteride maintained a substantial (21%) reduction in prostate cancer diagnoses through 16 years of follow-up. This was most pronounced during the first 7.5 years (the original study time frame); however, this benefit did not diminish over time. Given the controversy surrounding the original PCPT findings, one major limitation of the present study is the lack of Gleason grading information available in the Medicare claims data.

Comment by Don Bradfield

Finasteride is marketed as Proscar, and has been available for some years for treatment of benign prostatic hypertrophy, with a mode of action of inhibiting dihydrotestosterone production resulting in prostate shrinkage. Due to the original trial there had been a doubt in the minds of prescribers that use of Finasteride may result in the development of higher grade prostate cancers although it also appeared to reduce overall development of prostate cancer.

A second agent use in benign prostatic hypetrophy is Tamulosin marketed as Flomaxtra , which has an action on the smooth muscle of the bladder and hence assists in urination.

Although the two agents are not individually available on the PBS and are therefore significantly expensive (approximately $60 per month each), a combination agent containing both Finasteride and Tamulosin is available and the monthly cost is therefore only about $39 (or much less for those with a health care card or pensioner card).

For some time the combined agent could only be prescribed after consultation with a urologist, however this restriction was eased several years ago. The combined agent is useful for those with symptoms of benign hypertrophy and this present study now also shows benefit in reduction of prostate cancer risk .

Impact of androgen-deprivation therapy on self-reported cognitive function in men with prostate cancer

Marzouk, Shireen et al,Impact of Androgen Deprivation Therapy on Self-Reported Cognitive Function in Men with Prostate Cancer, Journal of Urology, February 2018, http://tinyurl.com/ydfscoo3.

Recent reports have highlighted the morbidity of androgen-deprivation therapy (ADT). However, the extent of association between ADT and declines in cognitive function remains largely unknown. The authors of this prospective study included men with prostate cancer receiving and not receiving ADT, and matched controls, to evaluate the effect on patient-reported cognitive function after 1 year of ADT. They failed to identify any association between 1 year of ADT use and decline in cognitive function.

The study involved three groups of men aged 50 years or older and matched on age and education: PC patients starting continuous ADT

(n=81), PC patients not receiving ADT (PC controls, n=84), and healthy controls (n=85).

Two scales from the Functional Assessment of Cancer Therapy-Cognitive Questionnaire (FACT-Cog) version 3 were used to assess self-reported cognitive function. Changes in cognitive scores over time were analysed using two approaches: multivariable regression and calculation of the proportion of subjects per group with declines of 1-SD or more. Multivariable regression was used to assess predictors of decline in self-reported cognitive function. Relationships between the FACT-Cog and a neuropsychological battery of 15 tests were also examined.

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 us an email through the form here:

http://tinyurl.com/ybkxnlg4.

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.