THE WALNUT

AUGUST 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

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

Next monthly meeting

Our next monthly meeting will be held on **Wednesday 15 August 2018**.

Our guest speaker is Allison Turner, who is the prostate cancer nurse at The Canberra Hospital. Allison will discuss her role at the hospital and provide practical advice on steps men can take in relation to their prostate health and on treatment 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.

Next coffee morning

10:00 am, Tuesday 14 August, 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.

President's Message

Our guest speaker at this month's meeting on 15 August is Allison Turner, the prostate cancer nurse at The Canberra Hospital. This should be a very instructive session, and I am sure that you will also find it very enjoyable.

Those who attended our July meeting were treated again to a very informative meeting, when we were addressed by urologist, Dr Mohammad Kahloon of the Capital Urology Centre. This was the first time that Dr Kahloon has addressed the Group and we hope that he will be able to do so again in the future.

We are participating in Father's Day awareness raising and funding raising events on Friday 31 August (see page 2). If you can help out at these events, please let me know.

On 19 September we will have our annual general meeting, at which the executive committee for the coming year will be appointed. Being on the committee is not a particularly onerous task and I encourage members to consider nominating for a position on the committee, including non-executive positions. Non-executive positions enable members to gain experience on the committee with a view to taking on such positions in the future.

If any member is interested and would like more information, please contact David Hennessy or me. Our contact details are on page 2 of the newsletter.

Those interested can download a nomination form and send it to David Hennessy or bring it to the AGM on 19 September.

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.

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

Volunteers needed

If you are able to assist with the Group's awareness and fund raising events on Friday, 31 August at the Bunnings' 'Tradies Health Awareness BBQ Breakfast' (8 am to 12 pm) and Holy Family School Father's Day BBQ (from 3 pm), please contact John McWilliam on president@prostate-cancer-support-act.net.

Our July meeting

There were three new members at the July meeting. The Secretary reported to members on the request by the ANU Medical School (Canberra Hospital) for volunteers to attend a panel discussion with medical graduates on 'Living with a cancer diagnosis' on 7 August. A separate notice was sent to members following the meeting.

Our speaker in July was Dr Muhammad Kahloon, FRACS, urological surgeon, specialising in robotic/laparoscopic surgery from the Canberra Urology Centre.

Dr Kahloon focused first on lower urinary tract problems and then on prostate cancer.

Dr Mohammad Kahloon (L) with John McWilliam (R)

Lower urinary tract problems

Dr Kahloon described the prostate gland as having two zones — a 'transition' zone around the urethra and the peripheral zone below the transition zone. 80% of prostate cancer is in the 'transition' zone.

Lower urinary tract symptoms can be caused by many factors, resulting in different types of urinary tract symptoms:

- Voiding (obstructive) — resulting in hesitancy, slow/weak stream, intermittency, straining, terminal dribble and splitting or spraying;
- Storage (irritative) — resulting in frequency (daytime), nocturia (waking in the night to pass urine), urgency, urinary incontinence and bladder pain; and
- Post-micturition (after-dribble) — resulting in a feeling of incomplete emptying and post-void dribbling.

One of the most common symptoms that men get as they age is enlargement of the prostate, which can lead to benign prostate hyperplasia (BPH) and obstructive urinary tract symptoms. This results in partial blockage of the urethra and lower urinary tract symptoms.

Lifestyle adjustments can help to moderate some of these symptoms. These include:

- reducing fluid intake but ensuring urine remains colourless;
- moderate caffeine/alcohol intakes, especially no intake in the last 2 hours before retiring;
- relaxing approach to voiding; and
- urethral stripping at voiding (i.e. massaging below the urethra from the anal area forward to the scrotum. Bladder re-training to increase capacity (voiding shouldn't be more frequent than each 3 hours).

Prostate cancer

Prostate cancer is the second most common cancer in men and the second leading cause of cancer deaths in Australia and the USA. In 2012 an estimated 1.1 million men were diagnosed with prostate cancer worldwide.

One in seven men over 60 yrs (15.3%) are diagnosed with prostate cancer in Australia and 1:38 die from it (2.6%). Advanced prostate cancer is a miserable disease but treatment success in Australia is improving. In 1988, only 60 per cent men diagnosed with prostate cancer survived for 5 or more years, now 92 per cent survive for at least 5 years.

The risk factors for prostate cancer are:

- age (1:7 for over 75 years, 1:5 for 85+ years);
- ethnic variation (African/American especially vulnerable; and
- genetic effects (if father + brother diagnosed, the risk is 9 times greater).

Prostate cancer diagnosis in Australia increased from 100 per 100,000 men to 250 from 1985 to 1995 when PSA testing became widespread. In 2010 the rate had dropped to 175 per 100,000 men. The death rate from prostate cancer is 30 per 100,000 deaths compared with 20 for breast cancer in women.

While the death rate from prostate cancer in men is still far too high, there as been a decline in mortality because of:

- early detection and stage migration from PSA screening;
- increased utilisation and effectiveness of curative treatments;
- changes in the attribution of cause of death – there is an increased risk of death from secondary causes; and
- improvements in therapy for advanced disease.

The management options for prostate cancer outlined by Dr Kahloon following diagnosis were:

- active surveillance;
- radiation based therapies;
- surgery based therapies; and
- androgen deprivation therapy (ADT) and chemotherapy.

Dr Kahloon highlighted changes in the USA with the advent of da Vinci robotic assisted surgery. In 1999 almost all prostatectomies were laparoscopic/keyhole; now close to 100% are robotic, using the da Vinci protocol. He envisaged that the same trend will occur in Australia.

Dr Kahloon said that, to become competent using robotic assisted surgery, he did a minimum of 60 procedures under supervision.

The main reasons that robotic assisted is so expensive in Australia are the high cost (around $4 million) of the chip used in the surgery, which needs replacing after 10 uses and the fact that da Vinci is currently the only machine that is available (although this is expected to change in the future).

Dr Kahloon also explained that the reason that robotic surgery is not generally possible following radiotherapy is that the tissue around the prostate is damaged by radiation, making surgery and healing difficult. Very few surgeons attempt post-radiation surgery and he added that radiation has accumulative effects which can precipitate bladder and anal cancer.

August Executive Committee meeting

The Executive Committee met on 1 August. The Committee, among other things:

- noted that three new members attended the July meeting;
- noted that we will be participating in a Father's Day breakfast barbecue at Bunnings Belconnen from 8 am to 12 pm on Friday 31 August and that we may also be attending another Father's Day awareness and fund raising event that afternoon (since confirmed at Holy Family School, Gowrie);
- noted that Allison Turner, prostate cancer nurse at The Canberra Hospital had been confirmed as our speaker for the August meeting and planned arrangements for the rest of 2018;
- agreed to again invite nominations for the executive committee, noting that the new committee will be appointed at the annual general meeting in September and there is a need for new members to become available to take over responsibility for some positions, if not in 2018 then certainly in 2019;
- agreed to take out a Dropbox subscription, as there is a large amount of records, including photographs, that need to be archived and available to future committees; and
- agreed to trial the use of Skype for the next committee meeting on Wednesday 5 September.

Men have pelvic floors too

Men's health physiotherapist, Jo Milios, tells us how men can keep their pelvic floor muscles healthy.

How do you instruct a man on how to his pelvic floor and ensure he is switching on his pelvic floor muscles correctly?

Awareness is the most important initial factor in teaching a man about pelvic floor training as very few men know they even have one!

The conversation I routinely start with involves the use of diagrams of male anatomy, pelvic floor location, role of the anal and urinary sphincters, location of the prostate and nerves that supply all of these areas. My language is typically very basic initially, as most men are very unfamiliar with talking about their 'private parts' and I want trust and rapport to develop immediately. From here, I provide a trans-abdominal assessment of the pelvic floor, the least invasive assessment approach, which also provides visual feedback. Instructions to relax the 'belly and buttocks' is the first command, followed by 'a squeeze of the urethral sphincter/stop the flow of urine', followed by a 'lifting of the base of the penis and testes'. As one succinct command, I'll often advise the man to think of lifting their 'nuts to guts' as this brings all components together.

For confidence building, I encourage men to stand in front of the mirror at home and to practise the technique, ensuring minimal movement from the abdominals and buttocks, but rather a slight elevation of the testicles and retraction of the penis. Most men find this works extremely well—with visual feedback being a favourite learning tool!

How often should a man do pelvic floor exercises, and for how long?

Currently, there are no evidence-based protocols for the correct number and duration of pelvic floor muscle exercises and, depending on diagnosis, this should be tailored to each individual, hence the critical role of physiotherapists. For example, a man with pelvic pain will need to learn to relax his pelvic floor and this may involve as few as three contractions for three seconds at 50% effort, with a 10 second rest period x three sets a day.

For a man about to have a radical prostatectomy, strengthening needs to be the focus. Five or six sets of both 'fast' (ten seconds once a day) plus 'slow' (up to 10 seconds done 10 times a day) with an equal rest phase in standing, would be my recommendation.

Approximately three sets per day of pelvic floor muscle exercises have been recommended for

men with erectile dysfunction and premature ejaculation, so again, programs specific to diagnosis need addressing.

Generally, two sets of pelvic floor muscle exercises are what I recommend every man to do, forever, following resolution of his dysfunction.

This article was published in "The Bridge' and has been reproduced with permission from the Continence Foundation of Australia. The Continence Foundation of Australia is the national peak body for continence awareness, management, education and advocacy.

Welcome to PCFA CEO Jane Endacott

Jim Hughes, AM, National Chairman of PCFA, recently sent the following message to Support Network members and Ambassadors:

I am delighted to advise that the Prostate Cancer Foundation of Australia (PCFA) has recently appointed Jane Endacott as its Chief Executive Officer.

Jane will bring a professional level of knowledge, experience and passion to the role. She is a motivated and values-based leader with a proven track record of transforming culture, and enhancing people and organisational capabilities.

Jane comes to us with a comprehensive twenty-year leadership career spanning the not-for-profit, commercial and education sectors. Previously, Jane was CEO (Acting) for the Financial Services Institute of Australasia where she revitalised the organisation's value proposition and services to achieve their strategic vision.

I have no doubt that under Jane's leadership, we will continue to progress as a peak body and innovate with partnerships in research excellence and community and outreach services working towards enhanced detection, treatment options, and prolonging the life and wellbeing of men and their families affected by prostate cancer.

Jane is delighted to lead our organisation and is looking forward to working with you and all our stakeholders to create further positive change and advance prostate cancer outcomes for our community.

Jane can be contacted at: Jane.Endacott@pcfa.org.au

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

- Community Conversations 2018, a community forum on prostate cancer;
- clinical trials, which indicate the benefit of stereotactic ablative body radiotherapy (SABR) for men with oligometastatic prostate cancer;
- putting people first: the 2018 ANZUP annual scientific meeting; and
- prostate cancer in Indigenous Australian men.

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

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.

Robotic vs open surgery for prostatectomy: which wins?

Kristin Jenkins, Medscape, 6 August 2016, https://tinyurl.com/yatntahl
[Original study report – Geoffrey D Coughlin et al, 'Robot-assisted laparoscopic prostatectomy versus open radical retropubic prostatectomy: 24-month outcomes from a randomised controlled study', The Lancet, 12 July 2018]

This article reports on a study by researchers in Queensland that followed up patients after 24 months to directly compare functional and oncologic outcomes between robot assisted laparoscopic prostatectomy and open radical retropubic prostatectomy. As with the previous study that was published in 2016 and which followed up patients after 3 months, there were no significant differences in functional and oncologic outcomes between the two approaches.

According to the article, the researchers 'advise caution in interpreting the oncological outcomes of [the] study because of the absence of standardisation in the post operative management between the two trial groups and the use of additional cancer treatments'.

The article's author approached Gerald Chodak, MD, a urologist in Highland Beach, Florida, for comment. His view is that the focus should be on surgical skill, not the surgical approach. He was reported as saying that, 'whether it is an open or robotic assisted approach, radical prostatectomy needs to be performed by someone who does at least 50 procedures a year, and who keeps tab on the oncologic outcomes and post operative urinary and sexual function'. So, patients should be encouraged to ask prospective surgeons how many radical prostatectomies they perform annually to satisfy themselves that the patient is proficient in the procedure they use.

Disease progression and mortality in patients with Gleason score 9–10 prostate cancer

Commentary by Jeffrey Wilsanen, MD in 'Practice Update', http://tinyurl.com/ybqpwey6
Original study report – Amar U. Kishan, MD1; Ryan R. Cook, MSPH2; Jay P. Ciezki, MD3; et al, JAMA, 6 March 2018, http://tinyurl.com/y8fntvoh

In this retrospective cohort study, which included 1809 men with biopsy Gleason score 9–10 prostate cancer, external beam radiotherapy with a brachytherapy boost and androgen-deprivation therapy was associated with significantly better prostate cancer–specific survival and longer time to distant metastasis, compared with external beam radiotherapy and androgen-deprivation therapy (HR, 0.41 and 0.30, respectively) or with radical prostatectomy (HR, 0.38 and 0.27, respectively).

Extremely dose-escalated radiotherapy combined with androgen deprivation was associated with better clinical outcomes.

There were a number of cautions in regard to the data analysis. However, one clear message that has been shown time and time again in other cancer types at high risk of recurrence is that multimodality therapy is superior to monotherapy. This was demonstrated by the superior outcomes of combination

brachytherapy (external beam radiation + brachytherapy) +ADT over radiotherapy, noting that only 9 per cent of radiotherapy patients received adjuvant radiotherapy. These data should reinforce for these very high-risk men that multimodality therapy is warranted, and it would be of interest to understand what the results would be if the majority of the radiotherapy patients received adjuvant radiotherapy +/– ADT.

Importantly, this paper should not be used to infer that combination brachytherapy is a 'better' local therapy than dose-escalated external beam radiotheray or radiotherapy plus adjuvant radiotherapy, but rather that further prospective investigation is warranted to compare and contrast tumour control and quality-of-life outcomes among these different treatment types.

Long-term use of androgen deprivation therapy (ADT) can make prostate cancer lesions difficult or impossible to see on some imaging scans

Iqra Mumal, Prostate Cancer News Today, 26 July 2018, http://tinyurl.com/y8yddn8h
[Original study report – Afshar-Oromieh A et al, 'Impact of long-term androgen deprivation therapy on PSMA ligand PET/CT in patients with castration-sensitive prostate cancer', European Journal of Nuclear Medicine and Molecular Imaging, 7 July 2018, http://tinyurl.com/y8mcgubg

In 2011, researchers developed a technique known as 68Ga-PSMA-11 PET/CT that targeted the prostate-specific membrane antigen (PSMA) — a protein that is over-expressed in most aggressive prostate cancers. That technique allowed physicians to scan for recurrent cancer.

Men with hormone-sensitive prostate cancer often undergo ADT, which led physicians to question how ADT affects PSMA imaging.

Studies have shown that short-term ADT can increase PSMA expression in castration-sensitive prostate cancer cells, leading to greater sensitivity of the imaging technique. But the long-term effects of ADT on PSMA expression and tumour visibility have not been investigated in detail. So researchers did a study to analyse long-term ADT's effect on tumour visibility and detection using PSMA PET/CT scans.

The retrospective study included 1,704 patients who underwent PSMA PET/CT scans to detect prostate cancer. Among this group, 306 were scanned at least twice, but only 10 had started ADT between the two scans and had achieved a clinical response to ADT — meaning their PSA levels were back to normal. Researchers then focused on these 10 patients.

The study did not pinpoint how many lesions that were not showing up on scans remained in patients. Rather, the researchers noted that some lesions were growing, but the amount of radioactive tracer dye they were taking up was decreasing, making them less visible on scans.

The results show that long-term and effective ADT significantly decreases tracer uptake on PSMA PET/CT scans, the researchers said.

They concluded that, "If the objective is visualisation of the maximum possible extent of disease, we recommend referring patients for PSMA PET/CT before starting ADT."

Men with negative prostate MRI may not need standard biopsy

Caroline Moore, European Urology, July 2018, Volume 74, Issue 1, http://tinyurl.com/ybzv7pk3

Can we omit routine standard biopsy for all men with negative MRI (multiparametric magnetic resonance imaging)? Based on this study, it seems that no immediate harm will be done, as none of the men in the study progressed or died of prostate cancer during 4 years of follow-up.

This article reports on a study by Panebianco and colleagues on negative MRI for prostate cancer in the July 2018 issue of *European Urology*. Panebianco et al analysed the missed cancers seen on subsequent radical prostatectomy, and found that one-third of the 36 men who had MRI-negative cancers and subsequent radical prostatectomy had small tumours in the anterior horn, an issue that could in part be addressed by

additional training. Eight of the 36 had cribriform pattern cancer and one had mucinous cancer, both of which are more worrisome findings, although they are rare when looked at the cohort of 1255 men as a whole. Work from New York University suggests that there are distinct histological differences between MRI-visible and MRI-nonvisible prostate cancers, with a postulation that MRI negativity may independently confer a more favourable prognosis.

In some countries, such as the UK and Australia, there is widespread use of prebiopsy MRIs across different settings. In the light of the work by Panebianco et al on intermediate-term outcomes for men with a negative for the significance of a negative MRI, in conjunction with PROMIS and PRECISION, the time has come for urologists to strive to make prebiopsy MRIs available to all men being assessed for prostate cancer.

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.