THE WALNUT

July 2017

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

Affiliated with the Prostate Cancer Foundation of Australia

Postal address
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In this issue

Next monthly meeting

Our next monthly meeting will be on **Wednesday, 19 July** at our usual location and time (see below). Our guest speaker will be **Associate Professor Paul Craft** (Clinical Director, Canberra Region Cancer Centre, Senior Staff Specialist in Medical Oncology and Associate Professor, ANU Medical School) will speak about recent developments in the treatment of prostate cancer and the main questions that men who have been diagnosed with prostate cancer need to consider in their treatment decisions.

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/8gkhysb.

Next coffee mornings

10:00 am, Tuesday, 11 July 2017:
Canberra Southern Cross Club at Jamison

10:00 am, Tuesday, 8 August 2017:
Canberra Southern Cross Club at Woden.

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

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

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

Appreciation

The Group recognises and expresses its appreciation for the support provided over the past year or so 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.*

From the President

We were very fortunate to again have Dr Hodo Haxhimolla speak at our July meeting. Dr Haxhimolla is always very generous with his time and he provided great insight into the latest developments in the diagnosis and treatment of prostate cancer.

I am also pleased that Dr Paul Craft, Clinical Director at the Canberra Region Cancer Centre, has agreed to address our July meeting. This should be highly informative, so I hope that you are able to attend.

I recently met with the Cancer Council of the ACT (Sandra Turner, CEO, and Kate Aigner, Cancer Information Consultant). The Cancer Council produces an excellent information booklet on 'Understanding Prostate Cancer', which I encourage people who have been diagnosed with prostate cancer to read. There is scope for us to work together more closely in the future to better support men with prostate cancer, and we will explore opportunities to do this. Sandra Turner has also indicated that she would be happy to speak at one of our meetings.

Our annual general meeting in September is fast approaching. This is a good time to start thinking about joining the committee and playing a part. You don't necessarily have to take on a formal responsibility, although we are keen to have a volunteer to manage our speakers for our meetings.

At our meeting in September, we are planning on having members share their experience of their prostate cancer treatment and recovery journey. We would like to have some volunteers for this meeting. People who have had radical prostatectomies (with and without incontinence side effects, and using different methods), radiotherapy and hormone therapy could give brief accounts of their experiences. If you are willing to share your experience at this meeting, plaese email me at my email address on page 1.

We remain concerned about the potential impact on our Group should SHOUT no longer be able to operate. Further information about this is provided on page 4 of this newsletter.

Finally, Mike Boesen has announced that he will be stepping down from the executive committee for health reasons, although he will continue to support our website. I would like to thank Mike for the immense contribution that he has made over many years and the support that he has given me as President.

John McWilliam
President

Previous meetings

June 2017 General Meeting

Our speaker in April was Dr Hodo Haxhimolla, who spoke about recent developments in the treatment of prostate cancer and answered many questions.

- The availability of robotic assisted prostate surgery in Canberra has helped men who want this form of surgery and who previously had to travel to other capital cities. The main advantage of robotic assisted surgery is that there is a shorter recovery time (on average 2-3 days in hospital). This, in turn, has reduced the demand for brachytherapy, because short recovery time is an important factor in the selection of that form of treatment. However, in the long-term, outcomes from the various surgical methods (open surgery, keyhole or laparoscopic surgery and robotic-assisted surgery) are similar. There is little difference between robotic-assisted and keyhole surgery. The main criterion for a person in choosing a surgeon should be the skill level of the surgeon in the method they use. That is a function of their general skills as a surgeon, their training, and the number of times they have used the surgical technique — and that generally means how often they perform that type of surgery. Currently,

he and one other surgeon perform robotic assisted surgery in Canberra, although this number will increase in the future. He has performed over 50 robotic assisted surgeries in Canberra this year following the arrival of the machine. He has undertaken many more robotically-assisted operations in other cities.

Dr Hodo Haxhimolla speaking to the Group

- One of the main improvements in the diagnosis of prostate cancer has been due to better screening techniques. The availability of MRI (magnetic resonance imaging)-guided biopsies, in conjunction with ultrasound technology (what are termed 'MRI-guided fusion biopsies'), has greatly improved the accuracy in locating prostate cancer lesions with biopsies. This is because of the superior imaging ability over ultrasound alone. The MRIs produce 3-D images of the prostate. Because fusion images may have some distortion (due to factors such as patient movement or imprecise segmentation mapping of the gland outline), Dr Haxhimolla has found that having the radiologist 'mark the spot' and tracing an outline of the prostate on the ultrasound helps to relate the two images. Fusion biopsies are now being used a lot in Australia, more so than in the United States, where it is often one of the last techniques to be employed. This may be because this is the way urologists have operated in the past. A member suggested that it may also be due to health insurance requirements in the United States.

- PSMA-PET scans are another useful tool, particularly in the diagnosis of cancers that have metastasised outside the prostate. A positron emission tomography (PET) scan is an imaging procedure showing the chemical function of an organ or tissue, rather than its structure. PET scans, with a PET radiotracer, [68Ga] Gallium labelled prostate-specific membrane antigen ligand (68Ga-PSMA), can detect prostate cancer relapses and metastases. These can be graded using a five-point scale called PIRADS (Prostate Imaging — Reporting and Data System (PIRADS)). A PIRADS 1 score would be very low (clinically significant cancer is highly unlikely to be present) and a PIRADS 5 score would be very high (clinically significant cancer is highly likely to be present). The location of metastases can also be identified. While PSMA-PET scans are mainly used to look for cancer after initial treatment of it, in some cases they can be used before treatment, and can assist in the determining the most suitable method of treatment, including watchful waiting.

- The risk of infection associated with the traditional transrectal biopsy procedure is greater than the newer transperineal biopsy procedure. However, the fusion imaging that can be undertaken with a transrectal biopsy is not available for the transperineal biopsy, and that is a significant limitation.

July 2017 Executive Committee Meeting

At its meeting on 5 July and an earlier special meeting on 3 July, the Executive Committee, among other things:

- considered its response to a survey on the services we receive from SHOUT and the expected impact, if these were to cease or we were asked to pay for some or all of these services;

- agreed that we would need to defer a request for casual administrative support

until we have greater clarity on the future of SHOUT and what services, if any, we continue to receive from them (this request had already been sent out, but has now been withdrawn);

- considered options should SHOUT cease operations;
- considered speakers for future meetings;
- discussed possible participation in the 'Big Boys Toys' expo at Exhibition Park in August in light of organiser interest in having more participatory exhibits and other possible outreach activities to increase community awareness of prostate health and raise funds for the Group;
- considered a financial report from the Treasurer. The design and purchase of a new banner for outreach activities was approved by the committee out-of-session prior to the meeting and a progress report was provided on action being taken to obtain recognition of the Group's charitable status for tax purposes; and
- agreed to make some changes to the Group's website, consistent with the wording shown in the Group's new pamphlet.

The next meeting of the committee will be held on Wednesday, 2 August.

Future Group events

16 August: Monthly meeting. Our speaker will be Kellie Toohey, Clinical Assistant Professor (Exercise Physiology), Sport and Exercise Science, Faculty of Health, University of Canberra. Kellie's address will on the role of exercise in rehabilitation after treatment and in helping to prevent cancer and promoting good health in general. We will also hear about a project that the university is running with men on prostate cancer. Kellie is an Accredited Exercise Physiologist and completed her Masters' degree in Clinical Exercise Physiology. She is currently completing her PhD while working as a Lecturer and Clinical Education Co-ordinator (Exercise Physiology).

20 September: Annual general meeting and round-table discussion on member experiences in prostate cancer treatment and recovery.

Future of SHOUT

We attended a meeting convened by SHOUT on Thursday, 6 July to provide feedback on the services we currently provide and the part played by SHOUT in the provision of these services. This meeting was also attended by consultants from PricewaterhouseCoopers (PwC), who are conducting a review of the way SHOUT's services are delivered and how they might change in the future. SHOUT has been funded by the ACT Government to undertake this review. The expectation is that the Government will not continue to fund SHOUT, as it has done in the past.

All of the NGOs present indicated that SHOUT played an important role in the delivery of their services. Some groups indicated that it was unlikely that they could continue without the type of support provided by SHOUT.

In the past year SHOUT received about $126,000 from the Government. This is a small amount to pay to support the many services that are provided by the non-government sector on a voluntary basis. If many of these organisations were to cease operations, the valuable support that they provide would no longer be available. It is likely also that there would be higher cost impacts on the health system.

SHOUT has been given interim funding until the end of August. However, the consultant's report on options on a future 'more sustainable' operating model will not be available until mid-August. Unless the Government were to agree to a further extension to provide time to consider the findings and recommendations of this review, it seems likely that SHOUT will cease to operate from the end of August. Many organsations would then be placed in a precarious position. We believe that funding for SHOUT should be continued until at least the end of December to provide time for full consideration of the findings and recommendations of the review and to provide time for the organisations that SHOUT

supports to adjust to the decision of the Government.

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.

This month's PCFA *Community Digest* includes articles on:

- Genome sequencing for prostate cancer patients – what is it and how is it helpful?
- Highlights from the American Society for Clinical Oncology Conference.
- Surgical treatments for urinary incontinence.
- Protstate cancer specialist nurses making a difference.

LiveHealthy Canberra

Capital Health Network, the ACT's primary health network, recently launched a new easy to use online directory to connect Canberrans with physical activity programs, nutrition support services and social participation opportunities, to help keep people active and well. The directory was developed with the support of ACT Health as part of the Healthy Weight Initiative.

The *LiveHealthyCanberra* directory is a one stop shop connecting people in the Canberra region with programs and services that aim to improve health and reduce the risk of chronic conditions such as cardiovascular disease, type 2 diabetes and other lifestyle related diseases.

On *LiveHealthyCanberra* you will find information about walking groups, running, cycling and group fitness classes, healthy eating education and programs offered by dietitians on improving your diet. The directory also includes community groups that promote being active, healthy and provide opportunities for social participation.

You can search for programs and services in your local Canberra region by service type, ranging from dietetics/nutrition services and weight management to pain management and physical activity.

Visit *LiveHealthyCanberra* at www.livehealthycbr.com.au and start to move, eat and live healthy in Canberra.

Getting on top of pain

The RSI and Overuse Injury and Association of the ACT and Pain Support ACT have lined up some of Canberra's most knowledgeable speakers for a seminar on pain and pain management.

The keynote speaker is Pain Medicine Specialist Dr Romil Jain, Director of Canberra Hospital's Pain Management Unit, who will tell us about *Chronic Pain: What You and Your Team Can Do***.**

Tom McHugh, a psychologist at Capital Pain and Rehabilitation Clinic, will talk about *Chronic Pain, Depression and Anxiety.*

Randolph Sparks, a clinical psychologist and lecturer at ANU, will draw on his many years of experience treating chronic pain patients to speak on *Getting Your Life Back*.

To end the day, Claudia Creswell from Healthcare Consumers ACT will address these topics: *Getting Medicare to Work for You* and *Building a Great Partnership with Your Healthcare Team*.

The seminar will be held at the Belconnen Labor Club from 10 AM to 3 PM on **Friday, 21 July 2017**. Morning tea will be provided and attendees will be able to buy lunch at the Club or bring their own.

Tickets cost $10 and seats are limited. To book your place you can go to trybooking.com/292462.

Health consumer training

The Health Care Consumers Association (HCCA) runs free training courses to help people navigate the health system, learn about their healthcare rights and how to use their knowledge as a consumer to advocate for themselves and their community. On completion of the training, participants may wish to get more involved in consultation opportunities where they can use their knowledge as a consumer to improve our health services.

The training includes:

- navigating the health system;
- keeping yourself safe in the health system;
- what is consumer participation?
- skills in Consumer participation.

Details of the next course are:

When: Wednesday 19 July and Wednesday 26 July 2017: 10:00am – 3:00pm (both days required to complete course).

Where: HCCA Meeting Room, ACT Sports House, 100 Maitland Street, Hackett, ACT 2602

To register:
Tel: 6230 7800 or
Email: kategorman@hcca.org.au

Morning tea and lunch will be provided.

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.

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. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

With thanks to Don Bradfield for these summaries.

When is it safe to stop PSA monitoring after radical prostatectomy?

Report title: Determining when to stop prostate specific antigen monitoring after radical prostatectomy: the role of ultrasensitive prostate specific antigen
Authors: Matsumoto K et al
Publication: Journal of Urology
Date: March 2017
View at: http://tinyurl.com/yckdq9mp

Japanese researchers have sought to determine when it's reasonably safe to stop PSA monitoring after radical prostatectomy.

The study retrospectively reviewed data for 582 consecutive patients who underwent open or laparoscopic radical prostatectomy between 1995 and 2004, excluding 4 patients who received adjuvant therapy.

Their work suggests that, if the PSA level, measured by an ultrasensitive assay, remains undetectable 3-5 years after radical prostatectomy, PSA monitoring could reasonably be stopped.

In 187 patients with undetectable prostate specific antigen at 3 years levels (less than 0.01 ng/ml) the 10 and 15-year biochemical recurrence-free survival rates were 99% and 96% respectively.

In 162 patients with undetectable prostate specific antigen levels at 5 years the 10 and 15-year biochemical recurrence-free survival rates were both 100%.

"This long-term review indicates that, if patients have continuously undetectable PSA levels by an ultrasensitive assay for five years,

monitoring can be stopped," the authors concluded.

Surgery seen as superior to radiation therapy in younger men with high-risk prostate cancer

Report title: Survival impact of initial local therapy selection for men under 60 with high risk prostate cancer
Authors: Adeel Kaiser, Soren Bentzen, Minhaj Siddiqui, Michael J Naslund, Young Kwok, Pradip P. Amin, Zeljko Vujaskovic, Mark Vikas Mishra, and Shahed Nicolas Badiyan
Publication: Journal of Clinical Oncology, 35 no 15
Date: May 2017
View at: http://tinyurl.com/y8v8twd6

In this study, which was reported in *Prostate Cancer News Today* (16 June 2017, http://tinyurl.com/yax7wq4g), men under age 60 with high-risk prostate cancer who underwent radical prostatectomy as an initial treatment showed significantly improved overall survival at four years than those given radiation therapy.

The findings were presented at the 2017 American Society of Clinical Oncology Annual Meeting.

The study used the National Cancer Database to analyse 16,944 high-risk prostate cancer patients, age 59 or younger, who had Gleason scores of 8 to 10 with no metastasis or nodal involvement. The study included data collected between 2004 and 2013.

Of the study population, 12,155 men had radical prostatectomy, and 4,789 had external beam radiation therapy (EBRT) — alone or in combination with brachytherapy — as a first therapy. In 82.5 percent of radiation-treated patients, hormone therapy was also used. Post-operative radiation therapy was given 17.2% of those who had a radical prostatectomy.

After a median 50-month follow-up, statistical modeling was used to determine differences in overall survival between the two groups, and found a significant 48 percent improvement in those who underwent surgery. The estimated survival rate at eight years was also higher in this group, 85.1 percent versus 74.9 percent, respectively.

"When a younger man has high-risk prostate cancer, it generally makes sense to choose surgery over radiation," David Samadi, a prostate cancer surgeon and urologic oncologist, said in a press release. "Radical prostatectomy has many advantages over radiation which include shorter recovery times, less pain, and from what this study is showing, the prostate cancer is removed with a higher cancer control and survival rate."

Overview of the clinical management of prostate cancer in Australia and what's on the horizon

Video title: Current clinical management of prostate cancer
Author: Dr Ian Vela, Urologic Oncologist, Princess Alexandra Hospital, Department of Urology
Date: 19 May 2017
View at: http://tinyurl.com/ycd8sskz

Prostate management now consists of a risk stratified approach:

- active surveilllance for low risk cancers;
- radical therapy for intermediate and high risk cancers; and
- watchful waiting for older patients.

Early detection

PSA testing remains the backbone of early detection**.** However, there are modfications of PSA test which assist, as does the 3T mp (multi-parametric) MRI.

The *PHI (Prostate Health Index) test* is a new variation on the PSA test; it is not Medicare rebateable, costs about $100 and assists in assessing the patient with PSA range 4-10, normal digital rectal examination to help distinguish benign from malignant disease.

The *Polaris Cell Cycle (PCC) progression assay test* by Myriad Genetics costs about $3000, with no Medicare rebate and measures a number of genes in the prostate biopsy sample and gives a risk stratification score and percentage chance of 10 year mortality.

The Oncotype DX *Genomic Prostate Score* (GPS) test costs about $4500 and gives a percentage risk of favourable or unfavourable pathology.

The *mpMRI (multiparametric MRI) test* assists by indicating a PIRADS score from 1-5 (very low 1 to very high risk 5) and assists in reducing the need for some biopsies as well as indicating the area most likely to require a targeted or *fusion biopsy* where the MRI results are merged with the ultrasound during biopsy. There is a false negative rate of 10-15%. There is currently no Medicare rebate (although this is under consideration).

Standard treatment of prostate cancer

Prostate surgery and radiation are BOTH standard care in 2017.

Robotic prostatectomy is now widely used due to increased accuracy with dissection. While long term outcomes for robotic and open procedures are similar, recovery may be faster with robotic surgery.

Radiation treatment has a number of new techniques becoming available, such as image guidance, proton beam and intensity modulation. However, these still need long term data. *Brachytherapy* is declining due to increased active surveillance. High risk disease may need multimodal treatment with both surgery and radiotherapy and patients should preferably discuss management with both a surgeon and a radiation oncologist.

Focal treatment is treating the index lesion and leaving rest of prostate intact. This is still experimental. As prostate cancer is multifocal, focal treatment of the visualised lesion only is fraught with difficulties, including follow up and the fact that a small unseen lesion may be more dangerous than the larger treated lesion. Most data on this form of management has been on low risk patients who may be adequately served by active surveillance.

Molecular imaging PSMA (Prostate Specific Membrane Antigen) testing is a new imaging technique that uses substances, which specifically latch onto the prostate cancer antigens and is much more sensitive than previous scanning techniques. However, best management as a result of finding these lesions is still uncertain.

Treatment of advanced prostate cancer

ADT (Androgen Deprivation Therapy) remains the backbone of treatment of advanced prostate cancer. When that fails Enzalutamide and Abiraterone are second-line treatments that have been shown to increase survival in pre-chemotherapy and post-chemotherapy patients. In Australia these two drugs are only approved in the post-chemo group or if intolerant to chemo.

Chaarted and Stampede trials showed 17 month survival benefit resulting from use of ADT and Docotexal in High volume hormone sensitive disease with 4 or more metastases on standard scanning (ie not PSMA scanning).

Low volume disease requires initial ADT followed by *Abiraterone*, *Enzalutamide* or chemotherapy. (Chemtherapy is much lower cost than *Abiraterone* or *Enzalutamide*, but is also much more toxic). It remains uncertain as to which is the best order to prescribe the drugs.

Evidence is showing that the lower you keep testosterone the better. Different forms of ADT may have different effects.

Oligometastatic disease

Minimal metastatic disease (less than five lesions which may be found on PSMA scanning). Uncertainty as to whether treatment of local metastases (e.g. local stereotactic radiation to bone mets or excision of pelvic lymph node mets) will be of benefit. The lesions seen on PSMA scanning may only be the first lesions in a patient with multiple widespread very small lesions and concentrating on treating these initial local lesions may only delay the introduction of ADT rather than provide a cure. This treatment is still experimental and benefits have yet to be demonstrated in clinical trials.

New treatments and drugs

*Apalutamid*e is a second generation anti-androgen.

Immunotherapy has not yet been very effective in prostate disease. A new vaccine is

very expensive and is not yet available in Australia.

PARP inhibitors Act on DNA repair pathways.

Theranostics refers to radiopharmaceutical or chemotherapy delivered by targeted nanoparticle or molecular targetting through PSMA binding agents. It is currently under trial particularly in men with very advanced disease with previous significant treatment load.

Vega or *Radium 233* has been approved but is not yet funded. It improves survival and is very good for bone pain.

With *precision* medicine tumours are defined on their molecular subtype and the therapy is targeted to the specific subtype eg a patient may be found to have a genetic variant which means he may not respond to antiandrogen therapy and would be better managed with chemotherapy.

Rehabilitation following prostate treatment

Video title: Rehabilitation following prostate cancer treatment
Author: Dr Philip Katelaris
Date: 27 Feb 2017
View at: http://tinyurl.com/ybvq64b6

This video argues that a team approach to rehabilitation is desirable following prostate surgery. It includes discussion of:

- pelvic floor exercises —techniques;
- management of urinary incontinence, including urinary slings urinary sphincters;
- urethral stricture following surgery and radiation —stenting;
- erectile dysfunction following surgery;
- treatment with pills, penile injections and penile prosthetic surgery; and
- relationship issues.

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.

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.