THE WALNUT

May 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, 17 May** at our usual location and time (see below). Our guest speaker will be urologist Dr Simon McCredie. The talk will be about treatment of prostate cancer. There will also be plenty of time available at the meeting for current and new members to exchange information and to discuss matters of interest or concern.

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, 9 May, Canberra Southern Cross Club, Jamison.

10:00 am, Tuesday, 13 June, Canberra Southern Cross Club, Woden.

All are welcome 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 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.*

President's report

We are very grateful to Dr Irmina Nahon for bringing forward her talk on incontinence from May to April when Dr Simon McCredie had to cancel at the last minute. We are also pleased that Dr McCredie has been able to reschedule his presentation to this month.

There was clearly a lot of interest in Dr Nahon's presentation, judging by the large turnout for her talk and the many questions that were asked. Dr Nahon has been an active supporter of the Group and we hope that she can speak to us again in the not-too-distant future.

While we have urologists speaking at our next two meetings, they will be covering somewhat different topics, and we are planning to have a medical oncologist speak at our meeting in July.

I hope that you can join us for these meetings. I also encourage you to join us for our coffee mornings.

We are planning in the near future to get administrative support for some of our activities, recognising that we are currently heavily reliant on the voluntary contribution of skills and time of a small number of members.

Nonetheless, we are still seeking members who may be prepared to help with the production of our newsletters and with planning of speakers at our meetings and other events. We will, of course, provide support to people who take on these roles. If you are willing to volunteer to take on one of these roles, please email me at: mcwilja@gmail.com. If you are not yet able to commit to a role on the committee, you may be interested in attending committee meetings and contributing to discussions on the operation of the Group. We meet on the first Wednesday of each month at 7 pm at the Pearce Community Centre.

John McWilliam
President

Previous meetings

April 2017 General Meeting

Our speaker in April was Irmina Nahon Ph.D, Physiotherapy Specialist, Department of Physiotherapy, University of Canberra, and practising through Hawker Plaza Physiotherapy.

Dr Nahon said that about one in three mature women and one in eight mature men suffer from some form of incontinence and, for men who have had a prostatectomy, the ratio is also 1 in 3.

Dr Nahon also noted that there are three components of continence: the bladder; the urethra-prostate; and pelvic floor muscles. Pelvic floor muscles are very thin and easily damaged during surgery or radiation but become vital for men after a prostatectomy when the urethra-prostate junction is removed. It is sound advice for men to 'train' pelvic floor muscles well before surgery. Only 5 per cent of men are 'dry' after surgery, whereas 12 months after surgery 80 per cent are categorised as 'dry'; the remainder have problems.

It is also important that men continue to exercise their pelvic floor muscles long after surgery. Dr Nahon demonstrated this. A simple exercise is to concentrate on contracting the muscles from the backbone to the penis area. This can be done sitting in a chair or standing while keeping the abdomen and lateral muscles relaxed.

Dr Nahon with John McWilliam

Some of the participants at our meeting

For the 10 to 15 per cent of men who are unable to maintain continence by using pelvic floor muscles, Dr Nahon discussed the bladder sphincter or sling, for which surgery is needed.

Dr Nahon also said that radiation can affect micro blood vessels in the rectum and up to 5 years post radiation 'leakage' may occur from the rectum and become a particular annoyance. Help from physiotherapists specialising in male continence problems associated with poor pelvic muscle action should be sought when problems occur. In Canberra, these specialists include: Maureen Bailey (Private), Tanya Maselli (Public), Irmina Nahon (Private, at Hawker). Dual specialists (i.e male and female) are Marita O'Shea and Donna Hanlon.

May 2017 Executive Committee Meeting

At its May meeting, the Executive Committee, among other things:

- agreed on the text of a revised pamphlet for the Group and to arrangements for its printing;
- agreed to specifications for the provision of administrative support for the Group and to inviting proposals for the provision of this support from three potential suppliers;
- discussed arrangements for future meetings, including the possibility of a significant event on lifestyle and cancer prevention and recovery; and
- noted reports from the Secretary and Treasurer, including that: given continuing uncertainty about the long-term future of SHOUT, the Group now has obtained its own post office box and will be acquiring its own telephone contact number; and the Group has submitted an application for a community grant from the Canberra Southern Cross Club.

The next meeting of the committee will be held on Wednesday, 7 June.

Future events

June meeting: The guest speaker will be urologist Dr Hodo Haxhimolla. He will inform us about the following leading edge technologies as they relate to prostate cancer diagnosis and treatment: 3-Tesla MRI scanning which can be undertaken at the National Capital Private Hospital or through facilities of The Canberra Imaging Group, use of the Da Vinci robotic surgical system now available at the National Capital Private Hospital, and the Ga-68 prostate specific membrane antigen PET/CT scanning procedure that is also now available in Canberra.

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.

In this month's PCFA *Community Digest*, there are articles on:

- prostate cancer in 2017—developments on the treatment of prostate cancer which were reported at the recent European Urology Congress;
- Should we do away with the systematic prostate biopsy?
- Clinical guidelines for PSA testing: how and why?
- The first CAR-T immunotherapy for prostate cancer is ready for clinical trials.

Read more at: http://tinyurl.com/l3x7af7 .

Love Your Sister

Have you heard about 'Love Your Sister' or the Big Heart Project - 5c challenge?

Canberra woman Connie Johnson (whose brother Samuel played Molly Meldrum and just won the Gold Logie) is attempting to break a world record for the longest line of 5c coins. All money raised will be passed onto the Garvan Research Foundation.

This event is being promoted across the country and is happening right here in Canberra at the Lyneham netball courts on **Wednesday 10th May, 8am – 8pm**.

What can you do?

- Start collecting 5c pieces:
  - You can drop your 5c pieces into the Bosom Buddies or SHOUT office by Tuesday 9th May
  - You can 'buy a meter' if you can't make the event online at: http://tinyurl.com/ktnco6d
- Donate at your local Bendigo Bank
- Come along on Wednesday 10th May and hand out shower tags
- Spread the word to your family, friends and work colleagues.

Virtual clinic trial — iCanADAPT

Do you have advanced or recurrent cancer and emotional health difficulties? Are you an advanced-stage cancer patient with ongoing worries or low mood? iCanADAPT is a new online program designed to help cancer patients with depression and/or anxiety. It is operated by St Vincent's Hospital in Sydney.

The program is to be evaluated and the hospital is seeking participants in the trial. Persons admitted to the trial will be given access to an online 12 week program based on cognitive behaviour therapy principles to help them manage their depression and/or anxiety.

If you are interested in taking part in this research trial and would like more information, contact Dr Michael Murphy on (02) 8382 1400 or research@thiswayupclinic.org. You can also find more information on the trial and how to participate in it at www.icanadapt.org.au.

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.

PSA doubling time

A report form Cedars Lebanon Hospital [http://tinyurl.com/k9orehw] shows that, among patients with castration-resistant prostate cancer (CRPC), the PSA doubling time (that is, the time it takes for your PSA to double, e.g. from 0.2 to 0.4 or from 3.2 to 6.4) strongly predicts their risk for metastatic disease and all-cause and cancer-specific mortality.

The study found that a PSA doubling time of less than 3 months was associated with a nearly 9-times increased risk of metastases and prostate cancer specific mortality and a 4.7 times increased risk for all causes mortality, compared with a PSA doubling time of 15 months or more,

The authors concluded that PSA doubling time cut-points of less than 3, 3–8, 9–14.9, and 15 months or more are reasonable for risk stratification of patients with non-metastatic CRPC.

[Editor: A calculator of YOUR doubling time can be found here: http://tinyurl.com/m2goy8m.

To use this calculator, you need copies of your PSA going back to the time of definitive intervention (usually surgery or radiotherapy). If you ask your GP for back-dated copies, you

can enter the figures (note that most of the pathology companies print the last four readings on each printout page, so you only need every fourth sheet, backdated). This chart just requires you to enter the date and PSA for each reading and then 'Calculate' prints out a chart for you. Some other charts, such as the Sloan-Kettering calculators, start with a minimum PSA level of 0.2, which is not useful with the higher sensitivity readings which are now performed.

It is preferable that all your PSA measurements were from the same laboratory.

Keeping this information, as your tests proceed will assist in preparing a doubling time chart to present to your oncologist / radiation specialist or urologist to help in decision making.]

Regular use of aspirin associated with lower risk of cancer mortality

According to study reported in *Renal & Urology News* [http://tinyurl.com/knklvbh] and reported at the annual meeting of the American Association for Cancer Research in Washington in April, regular use of aspirin (0.5 to 1.5 standard aspirin tabs over one week for minimum of six years) is associated with a lower risk of cancer mortality, especially colorectal, breast, prostate and lung cancer.

[Editor: Note that aspirin also has mortality benefits in vascular disease such as coronary heart disease.]

Cancer genes

According to study reported in *Renal & Urology News* [http://tinyurl.com/leq2utv], germline mutations in the BRCA2 gene are linked to development of prostate cancer and suggests BRCA1/2 and ATM mutation carrier status may help distinguish lethal from indolent prostate cancer.

The study found that the combined carrier rate for the inherited mutations was higher in patients with aggressive versus localised prostate cancer: 6.07% vs 1.44%.

The study authors stated that the results have an important translational impact because they clearly demonstrate germline mutations in these three well-established genes can be used to predict the risk for lethal prostate cancer and time to death.

Guidelines recommend clinicians inquire about a family history of BRCA1/2 mutations. The researchers recommend that clinicians also ask patients whether a family member died of prostate cancer before age 75.

BRCA2 gene changes have previously been linked to familial breast cancer.

Under-treatment of prostate cancer in England?

In an *Medscape Urology* article dated 27 March 2017 (see http://tinyurl.com/m7l3oyy) entitled *Prostate Cancer 'Undertreated' in 4 of 10 Men in England*, the author makes a number of interesting observations about a paper presented at the European Association of Urology (EAU) 2017 Congress.

The article observed that, while overtreatment of prostate cancer is a big concern in the United States, the other side of the Atlantic has the opposite problem — the latest data suggest that 4 in 10 men with locally advanced prostate cancer in England may be undertreated.

The article quotes lead author, Arun Sujenthiran, MBBS, MD, from the Royal College of Surgeons, England, as saying that:

> "… Our work shows that up to 40 per cent of patients diagnosed with high risk or locally advanced prostate cancer may not be receiving the best available treatments in combination with hormonal therapy."

Other points made in the article were that:

- Locally advanced prostate cancer is treated in several ways, and long term studies have shown that radical treatments that aim to destroy all cancer tissues (and include radiotherapy and surgery) can improve survival compared with the use of hormonal treatment on its own. Hormonal treatment, such as androgen deprivation therapy, helps to slow the growth of the cancer but doesn't

usually result in complete eradication of the prostate cancer.

- The new figures are the first to come from linking the recently established National Prostate Cancer Audit (NPCA) to other major UK databases, including the National Cancer Data Repository, the National Radiotherapy Dataset, and the Hospital Episodes Statistics database, and so give the most robust estimate of treatment rates.
- The study analysed data come from the 2014–2015 records of the NPCA and included details on 11,957 men with locally advanced prostate cancer.
- Of those who received radical therapy in addition to their hormone therapy: 42% were treated with external beam radiotherapy; 18% were treated with surgery (radical prostatectomy); 1% were treated with brachytherapy (radioactive pellets implanted in the prostate); and less than 1% were treated with high intensity focal ultrasound. The remainder of the group (39%) received hormonal treatment alone.
- In attempting to analyse why patients are not receiving radical treatment, age and comorbidities were risk factors for under-treatment. Patients older than age 75 years and those with two or more comorbidities were significantly less likely to receive radical treatment. So, it may be that some of the men who were described as 'under-treated' may have been too frail or infirm to undergo surgery or radiotherapy.

Survival rates for men who have had their primary tumour eradicated

Radical prostatectomy and radiation therapy are associated with improved survival in men with metastatic prostate cancer, according to a new study, reported in *European Urology online* (April 3) and in *Medscape*. http://tinyurl.com/kny3ewz (free registration required).

This study compared survival using local therapy to the prostate, (including radical prostatectomy (RP) and radiotherapy (RT)), versus no local therapy *(*i.e. hormone treatment or chemotherapy only*)* in more than 13,000 men diagnosed with metastatic prostate cancer between 2004 and 2013.

According to the researchers, cancer specific mortality rates were 6 per cent lower after radical prostatectomy and 52 per cent lower after radiotherapy compared with no local therapy (both $p<0.001$.

In the article, the lead researcher is quoted as saying that:

> *"During the last decade, a marked shift in prostate cancer treatment occurred. Low-risk patients undergo active surveillance regimes or focal treatment approaches. On the other hand, more advanced disease is increasingly treated by radical prostatectomy in the setting of multimodal therapy approaches, e.g., radical prostatectomy followed by radiotherapy and/or androgen deprivation. Similarly, hormone-naive, non-castration-resistant, metastatic-prostate-cancer patients are increasingly treated with docetaxel-based chemotherapy."*

IsoPSA testing

An article in *Medscape* (25 April 2017, http://tinyurl.com/mjr7ffm , free registration required) discusses a new version of PSA testing which concentrates on identifying PSA isomers which come from prostate cancer cells rather than total PSA. This is reported to result in a more sensitive blood test for prostate cancer, so possibly reducing the need for unnecessary biopsies.

The article states that, based on decision curve analyses, the use of IsoPSA instead of total PSA would result in a 48 per cent reduction in unneeded biopsies for diagnosing prostate cancer and a 45 per cent reduction in unneeded biopsies for identifying men with high-grade prostate cancer.

[Editor: Some other articles regarding this test imply it may be available in America later this year. However it could take some time after that to acquire Australian approval.]

Genetics and prostate cancer

In a 14 July 2016 *Renal and Urology News* article by Natasha Persaud (see http://tinyurl.com/lcu4ae4) it is stated that 'Swedish researchers have provided new estimates of the hereditary risk of significant

prostate cancers (PCa) that may aid in patient counselling.'

Non-low risk disease was defined as Gleason score 7 or above, prostate-specific antigen (PSA) level 10 ng/mL or above, T3–4, N1, and/or M1. High-risk prostate cancer comprised cases that were Gleason score 8 and above, T3–4, PSA level above 20 ng/mL and above, N1, and/or M1.

The article indicated that:

- The probability of any prostate cancer was 4.8 per cent at age 65 years and 12.9 per cent at age 75 years.
- The chances of non-low-risk prostate cancer were lower: 2.8 per cent at age 65 years and 8.9 per cent at age 75 years.
- For high-risk prostate cancer, the odds were 1.4 per cent at age 65 years and 5.2 per cent at age 75 years.
- If a man had a brother with prostate cancer, the probabilities of any prostate cancer at age 75 were 30.3per cent, non-low-risk prostate cancer, 18.8 per cent, and high-risk prostate cancer, 8.9 per cent.
- At age 65, those risks were 14.9 per cent 7.3 per cent, and 3.0 per cent, respectively.
- Risk increased when a man had more than one sibling with prostate cancer. Men with two affected brothers had a 55.1 per cent, 33.2 per cent, and 13.6 per cent probability of any prostate cancer, non-low-risk prostate cancer, and high-risk prostate cancer at age 75, respectively.
- The risk of aggressive prostate cancer would not be much increased in brothers of men with the indolent form, but it turned out to [be] almost as high as the risk among men with aggressive prostate cancer in the family.

Another study relating to risk factors for cancer heritability amongst twins is reported in *Renal & Urology News*, 13 January 2016 (see https://tinyurl.com/m2x2tzm). That study:

- found that, when one identical twin developed any cancer, the other twin carried a 14 per cent increased cancer risk compared with the general population, and that in comparison, a fraternal twin's cancer risk increased only 5 per cent if their sibling was diagnosed with cancer.
- estimated that about 33 per cent of cancer risk is inherited from genes, but that some specific cancers carried additional genetic risk;
- found that, for testicular cancer, a man's risk of developing this disease was 12 times higher if his fraternal twin developed it, and 28 times higher if his identical twin developed it; and
- found a strong role of genetics in melanoma (58%), prostate cancer (57%), and non-melanoma skin cancer (43%).

Other researchers have studied the risk of prostate cancer and ethnic backgrounds. Of particular interest to Australian men is research reported by the Cancer Council NSW (see https://tinyurl.com/kblrj5o) indicating that Aboriginal men are 50 per cent more likely to die of prostate cancer than other men. The Cancer Council also indicates that the timing of diagnosis, cultural differences, and reduced access to treatment may lead Aboriginal men to have poorer survival than non-Aboriginal men.

Associate Professor, David Smith, Cancer Council NSW, was quoted as saying that: "Prostate cancer is the most commonly diagnosed cancer in Aboriginal men, but there is still a large survival gap that needs to be closed between Aboriginal and non-Aboriginal men."

As reported in *Prostate Cancer News Today* [1 May 2017, http://tinyurl.com/lczaonj], black (African American) men in the United States are known to have a 60 percent higher risk of developing prostate cancer compared to white men — and their chances of dying from this cancer are twice as high. The article reported on a study by researchers at the University of Michigan's Fred Hutchinson Cancer Research Center, and colleagues at Erasmus University in the Netherlands, which was published in the journal Cancer (24 April 2017,

http://tinyurl.com/l3bjjg6). The researchers investigated why black men are particularly susceptible to prostate cancer. They estimated that, by their 85th birthday, 30 to 43 percent of black men develop what is called preclinical prostate cancer (that is, the cancer was starting to develop, but there were no apparent symptoms). For this reason, the researchers recommended earlier screening of black men.

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.