

Prostate Cancer Support Group - Northern Beaches

Affiliated with the Prostate Cancer Foundation of Australia

Proudly sponsored by Hammond Care, Health and Hospitals Limited

*A program of support serving men of all ages, their families, carers and friends
before, during and after diagnosis*

Newsletter No. 153 - February 2016

Our next meeting will be held on

Tuesday, 1 March

Our guest speaker will be Dr Raji Kooner, Consultant Urologist

The Prostate Centre, St Vincent's hospital

Everyone is welcome, bring your partners along

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Monthly meetings

All people are welcome to attend our regular monthly meetings. No notice is required - simply come along and introduce yourself, or contact us via the website.

When:

Meetings of our support group are held on the 1st Tuesday of the month except in January.

Usual Location:

The Cottage, Mona Vale Hospital, Coronation Street, Mona Vale.

Time: 6:30pm till 8:30pm

March

Our speaker for March, Dr Raji Kooner, performed the first robot assisted radical prostatectomy in New South Wales. Dr Kooner also pioneered a lot of the techniques with the retrograde nerve sphere, pelvic floor reconstruction that have improved patient outcomes. We look forward to his presentation.

February Meeting Report

Unfortunately Pam Noble, our advertised speaker, was unable to be our guest as she was taken ill the night before our meeting but has agreed to speak later in the year. Instead we had an open forum on the treatment that our members had received for their Prostate Cancer. Denise Taylor very ably led the discussion and began by asking for a show of hands on the time since each of our members had been diagnosed with PC.

Some men had been recently diagnosed and in the 2 year time frame there were 7 members; 2 to 5 years there were 2 men; 5 to 10 years we had 4 men; and over 10 years we had 3 members at the meeting.

The discussion then went on to the type of treatment each person was currently on or had been in the past and how they felt about their treatment options.

Only one of our members was on Watchful Waiting and he expressed the stress and pressure he was under waiting each time before he saw his Urologist.

For the Radical Prostatectomy group the members were asked whether they had chosen Open Surgery or the Robotic system. The number was equally spread over the two types of surgery and the men had differing experiences

and thoughts as to whether they had chosen the right choice for them. Cost was a factor in some cases, the problem of incontinence seemed to be equal in both cases and erectile dysfunction better by the robotic system. Quite a few men said they wished they had waited to weigh up their options and not rushed in to having surgery. All said it would have helped them greatly had they known about our Support Group and had the chance to speak with others diagnosed with PC before they made a decision. Three of our members' treatment had included Radiation, either on its own or as a further course after a Radical. None of our members had gone down the path of HIFU treatment. One member had travelled to Germany for Chemotherapy treatment, but because of the short time he was there had the required dosage in a quick time frame and felt ill for some time afterwards. He was then prescribed Zolidex, which he took for 5 years and is now seeking other treatment options. None of our members had participated in any Trials.

This forum gave the men and their partners a chance to voice their thoughts and opinions and was a successful evening. We had trouble wrapping up the discussions and no doubt the men continued speaking with each other as we enjoyed our usual delicious supper prepared by Jo-Ann and Eleanor.

Big Aussie BBQ 2016 - It's on again!

Planning is under way for our big fundraising and awareness event – the Big Aussie BBQ and Family Fun Day to be held on 18 September 2016.

We have had a preliminary meeting to plan this event and there have been many suggestions on how we can improve on our 2014 success.

Many of our previous participants have agreed to support us again, but there will be new activities to attract to public as we spread the word about early diagnosis of prostate cancer and the need for more funds directed towards research.

One of our initiatives is to hold a major raffle for which we are looking for attractive prizes. Can anyone help there?

We will still welcome anyone who would like to help with the planning and/or assistance on the day. Let's get together and make this a great success.

Please phone me on 0409 909 356 or talk to me at the next meeting.

Mary Jones

PSA Testing Guideline Recommendations Approved by NHMRC

**Associate Professor Anthony Lowe
Chief Executive Officer,**

In partnership with Cancer Council Australia and a multi-disciplinary expert advisory panel comprising urologists, medical oncologists, radiation oncologists, pathologists, general practitioners, epidemiologists, allied health professionals and consumers, Prostate Cancer Foundation of Australia has developed national evidence-based clinical practice guidelines on PSA testing and early management of test-detected prostate cancer.

The guideline recommendations have now been approved by the CEO of the National Health and Medical Research Council, Australia's leading expert body for developing health advice for the Australian community, health professionals and governments.

We developed the guidelines in order to resolve the controversy surrounding PSA testing for both men and their doctors. The guidelines do not recommend a population screening program for prostate cancer (a program that offers testing to all men of a certain age group) as evidence does not support such a program. For men who decide to be tested it contains guidance on matters such as what age to start testing; how frequently to be tested; when to stop testing; the PSA level which should prompt further investigation; family history; and the role of the digital rectal examination.

The main recommendations contained in the guidelines are as follows:

- Men who are considering having a PSA test should be offered evidence-based decision support, including the opportunity to discuss the benefits and harms of PSA testing, before making the decision to be tested. Note that we are currently working on a PSA testing decision aid for use by men and their doctors.
- Men who are at average risk of prostate cancer who have been informed of the benefits and harms of testing, and who decide to undergo regular testing for prostate cancer, should be offered PSA testing every 2 years from age 50 to 69. Further investigation should be offered if the total PSA concentration is greater than 3ng/mL.
- Men aged 70 years or older who have been informed of the benefits and harms of testing, and who wish to start or continue regular testing, should be advised that the harms of testing may be greater than the benefits for men of their age.
- Men who have a father or one brother who has been diagnosed with prostate cancer have 2.5 to

3 times higher than average risk of developing the disease. Such men who have been informed of the benefits and harms of testing, and who decide to undergo regular testing for prostate cancer, should be offered PSA testing every 2 years from age 45 to 69.

- Men who have a father and two or more brothers who have been diagnosed with prostate cancer have at least 9 to 10 times higher than average risk of developing the disease. Such men who have been informed of the benefits and harms of testing, and who decide to undergo regular testing for prostate cancer, should be offered PSA testing every 2 years from age 40 to 69.

- Digital rectal examination is not recommended as a routine addition to PSA testing in the primary care setting. Note, however, that on referral to a urologist or other specialist, digital rectal examination remains an important assessment procedure prior to biopsy.

- Since any mortality benefit from early diagnosis of prostate cancer due to PSA testing is not seen within less than 6 to 7 years from testing, PSA testing is not recommended for men who are unlikely to live another 7 years.

Other recommendations contained in the guideline cover further investigations if the PSA concentration is above 3ng/mL; prostate biopsy and multiparametric MRI; active surveillance; and watchful waiting. The full text of the guideline can be found at www.pcfa.org.au/psa-testing-guidelines

Prostate Cancer Foundation of Australia will be actively promoting the guideline recommendations in the coming months. Our goal is to ensure that all Australian men are fully informed about prostate cancer and are in a position to make an informed decision about PSA testing based on the latest available evidence on the benefits and potential harms of testing and treatment for prostate cancer.

PCFA acknowledges The Male Bag Ride as the major fundraising partner of the guidelines.

Take home messages -

- The PSA testing guideline recommendations are approved by NHMRC
- Men should be offered the opportunity to discuss the benefits and harms of PSA testing before making the decision to be tested
- Men at average risk of prostate cancer who decide to be tested should be offered PSA testing every 2 years from age 50 to 69
- The harms of PSA testing may outweigh the benefits for men aged 70 and older

- Men with a family history of prostate cancer who decide to be tested should be offered PSA testing every 2 years from age 40/ 45 to 69 with the starting age depending on the strength of their family history
- Digital rectal examination is not recommended in addition to PSA testing in the primary care setting

Movember Foundation Report

The Movember Foundation, our major research funding partner, has been operating since 2003 and has funded a staggering number of projects in the prostate cancer field in a bid to reduce and/or end the suffering of our men from prostate and testicular cancer as well as depression. The Foundation is committed to changing the face of men's health globally and continues to raise awareness, advocate and fundraise to enable researchers to reach this goal via funding the best projects and teams worldwide.

Late last year, with the help of some of the world's best experts in the field, The Movember Foundation conducted a synthesis of the impact the investment made in research in the last 10 years. The end product was the generation of the attached Impact Report that is written in a way that is understood by our entire community.

The report can also be accessed via the link below:

<https://au.movember.com/uploads/files/Our%20Work/Movember%20Foundation%20Prostate%20Cancer%20Impact%20Report%20-%20web.pdf>

Norma's Quiz for February

1. In 1812 why were the armies of France told to sew brass buttons on the sleeves of their uniforms?
2. Which famous late night TV host does this saying spell out NERD AMID LATE TV?
3. If you suffer from triskaidekaphobia what have you got?
4. In 1938 who was named Man of the Year by Time Magazine?
5. Which Australian tennis legend won The Australian Open, French Open, Wimbledon and US Open all in the same year,(twice in his career?)
6. As a member of Parliament Sir Isaac Newton spoke only once in public did he say "apples are very important to science" OR "science is a critical science and should be taken seriously" Or "Please will someone open a window"?

Answers to Norma's Quiz for January

1. Who shot Jesse James, the outlaw in 1882? William Ford, Henry Ford or Robert Ford? - *Robert Ford*
2. Which town did the cartoon Flintstones live in? - *Bedrock*

3. Fisheye, apochromatic and infrared are all types of what? - *Photographic lenses*
4. Is Pelota a sport, an Italian food dish or a card game? - *A sport*
5. If Steve Smith is Australian 45th Test Cricket Captain who was the 44th? - *Shane Watson*
6. Which two countries that begin with the letter N border with China? - *North Korea and Nepal*
7. Rose is French for which colour? - *Pink*
8. What is the name for the hall for slain warriors in Norse mythology? - *Valhalla*
9. In which part of the body does gout usually strike first? - *The big toe*
10. Time and tide it is said wait for what or who? - *No man*

Meetings for 2016

Tuesday 5 th April	A/Prof Kneebone, Oncologist
Tuesday 3 rd May	Pam Noble
Tuesday 7 th June	Nicola Pelegrini,
Tuesday 5 th July	TBA

Publicity

One of the main aims of the NB Prostate Cancer Support Group is to reach out to men and their families and provide information and emotional support for those diagnosed with Prostate Cancer. PCFA Ambassador Programme we may be able to reach more men's groups and clubs and spread the word about the importance of regular testing for prostate cancer.

This year, we are hoping that with the support of the PCFA Ambassador Programme we may be able to reach more men's groups and clubs and spread the word about the importance of regular testing for prostate cancer.

If you know of any organisations that may benefit from having one of the Ambassador speakers visit them please let a committee member know.

We are always seeking ways to reach the public and articles about our Group have appeared in Pittwater Online News and the 'What's on Pittwater' website provides information about our meetings.

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, 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 particular 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.

Contact Us

Postal address

Northern Beaches Prostate Cancer Support Group
PO Box 324, Mona Vale, NSW 1660

Web site

Our web site provides details about the activities of the group, meetings, contact persons and lots of other useful information:

prostate-cancer-support-nb.net

Personal support

If you would like support, advice or assistance contact any of the committee:

Treasurer - Alan Taylor	Phone: 02 9981 2616
Library - Ron Jones	Phone: 02 9997 2709
Programme Organiser - Denise Taylor	Phone: 02 9981 2616
Catering - Jo-Ann Steeves	Phone: 02 9918 6575
Eleanor Swansbra	Phone: 02 9918 6428
Norma Norman	Phone: 02 9918 4929
Committee member, newsletter editor and web site manager: Mary Jones	Phone: 0409 909 356
Email:	info@prostate-cancer-support-nb.net

Useful websites:

www.pcfa.org.au Telephone: 02 9438 7000

See PCFA Newsletters online at:

www.pcfa.org.au/articleLive/pages/PCFA-Newsletters.html

Other useful links-

www.prostatehealth.org.au

www.cancercouncil.com.au

www.andrologyaustralia.org

www.acf.com.au

www.prostate-cancer-support-act.net

www.prostate-cancer-support-sydneynorth.org

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 be happy to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy directly please send me an email. I'm happy to also add any of your friends to the email list.

Past issues of our newsletters can be viewed on our website: www.prostate-cancer-support-nb.net

