

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. 196 - January 2020

Our next meeting will be Tuesday 4 February

Our speaker will be Dr Megan Crumbaker

Medical Oncologist at

The Kinghorn Cancer Centre

PhD Candidate/Garvan Institute

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

Tuesday 4 February

As our first speaker for 2020 we welcome Dr Megan Crumbaker, Medical Oncologist at the Kinghorn Cancer Centre at the Garvan Institute. Dr Crumbaker will speak to us about the latest treatments for Prostate Cancer. We look forward to her visit.

Christmas Meeting Report

Norma sent in a brief report of our Christmas Celebrations –
Good turnout
Good humour
Good food
Good value
Good music and singing from Alan
See you next time.

PCFA Social Impact Statement 2018 - 2019

Thanks to you, we are supporting more Australians living with prostate cancer. Together we raised over \$12 million

RESEARCH

\$5.28 million for ongoing projects
\$2.15 million investment for two ongoing research projects
48 new research blog posts published

AWARENESS

12,000+ information packs sent
5,000 volunteer hours
4,500 Online Community members

SUPPORT

8,000 new patients supported by Prostate Cancer Specialist Nurses
 51 nurses in 46 locations across Australia
 150+ Support Groups met regularly

Thank you for supporting life-saving research, and transforming the lives of Australians living with prostate cancer.

To read the full statement go to –

<https://tinyurl.com/yf9awlwm>

From Professor Jeff Dunn AO

Tue, Jan 21

Colleagues and Friends,

World Cancer Day on Tuesday February 4 is fast approaching and our latest research is in the news today highlighting the outstanding work of Prostate Cancer Support Groups.

The article takes an honest look at the significant challenges many of you have faced, based on interviews with 50 support group leaders across both urban and regional Australia. Thank you to those support group leaders who took the time to participate in this work, we do appreciate it and I assure you that the effort was worthwhile.

Quite simply – we asked for your advice, and now we are taking action.

Next week we'll launch a new nationwide eNewsletter, *Blue Sky Horizons*, and the following week we'll mark the 20th Anniversary of World Cancer Day by kick-starting a campaign on family history of prostate cancer.

Please share the attached story with your networks and stay posted for more news on how you can get involved in helping us change the game for future generations.

We cannot thank you enough for your tireless service.

With best wishes,

Jeff Dunn

Prostate cancer survivors flex their muscles

The Australian Financial Review

Tuesday, January 21, 2020

Jill Margo Health Editor

Fed-up with the poor level of care, Australian men with prostate cancer want a say in reshaping the way this cancer is managed across the country.

Contrary to the traditional view that men are passive about health, new research shows these men are clear about the challenges they face and what is needed to address them.



Men are banding together to do something about this issue and we are working with them, says Professor Dunn.

Prostate cancer is the most commonly diagnosed male cancer in Australia and currently 210,000 men are living with or beyond a diagnosis of it.

Because Australia has the world's highest survival rates for this cancer - 96 per cent at five years - this population of survivors is growing rapidly.

It's also growing more experienced, more active and more determined. Now the survivors want a role in policy making to improve post-diagnosis care.

When the first blood test for this cancer became available in the 90s, men were thrown into confusion.

Grassroots force

This PSA test, which measures for a protein called prostate specific antigen, is not always accurate. While it led to high survival rates, at the time it also led to a frenzy of testing which culminated in overdiagnosis and overtreatment.

While some men retreated hurt, some began gathering in support groups to try and make sense of what was happening.

These groups are now a grass roots force with around 15,000 members on their books.

There are 150 groups spread through cities and regional areas, with some designated for young men, for those with advanced cancer and for gay and bisexual men.

They are endorsed by the Prostate Cancer Foundation of Australia, which supports them and wants their active participation.

"When you talk to the blokes in these groups, it's sobering," says Professor Jeff Dunn, CEO of the Prostate Cancer Foundation of Australia and Chair of Behavioural and Social Sciences, University of Southern Queensland, USQ.

“Now they are banding together to do something about this issue and we are working with them.

“Our aim is to develop a framework for survivorship so we can start to advocate for that change.”

In cancer, the convention is that once people have had a diagnosis, regardless of what happens next, they remain survivors until their death.

These survivors now want a role in creating Australia’s first set of survivorship guidelines for prostate cancer and the PCFA is providing them with the opportunity.

Such guidelines are usually devised by medical, allied health and research experts, sometimes with a patient on the panel.

The PCFA wants at least a third of the panel to be survivors because they’ve been through the maze and know where the problems lie.

'Lost within the system'

To lay the ground for guidelines the PCFA co-funded two studies. The first involved prostate cancer nurses who provide long-term survivorship care for men and their partners.

The nurses’ consensus view, published in the Journal of Clinical Nursing, was that the prostate cancer survivorship experience of men was under-resourced, disjointed and distressing.

The second study, called 50 voices, interviewed 50 support group leaders. It is both a *cri de cœur* and a call to action.

The participants painted a dark picture of sustained physical, psychological and social burdens throughout the illness experience.

Men had to manage multiple side effects including incontinence, sexual dysfunction and bowel problems.

Some also had to cope with muscle-wastage, hot flushes, fatigue, weight gain and shrinkage of genitalia.

Many also struggled with depression, distress, cognitive impairment, fear of recurrence, social withdrawal and partner distress.

In addition, there was often financial distress from reducing work hours and expenditure related to their care.

This USQ study highlighted the “loss of identity” and “loss of control” experienced by survivors.

A lack of information about how to manage their problems and a lack of access to services, often left them “lost within the system”.

But the study, published in journal Psycho-Oncology, also recorded a determination to gain

consistency of care and for survivors to regain a sense of dignity and agency.

Australia’s prostate cancer support group movement is proportionally the largest in the world and is beginning to flex its muscle.

For more information, go to www.pcfa.org.au.

Norma’s January Quiz

- 1 Which organ in the body produces bile?
- 2 What is the human body’s largest organ?
- 3 What was the nickname of Julius Marx?
- 4 What word can go after “Machine” and before “Dog”?
- 5 What opens when Ali Baba said “open sesame”?
- 6 What is the only English word that has three consecutive double letters?
- 7 Which significant event occurs this year in the Eastenders TV show?
- 8 Which letter describes a soft lead pencil?
- 9 How many English pounds would you have if you had a monkey a score and a pony?
- 10 Who was the last prisoner to be imprisoned in the Tower of London?.

Answers to Norma’s November Quiz

1. What did the other reindeer not let Rudolf do because of his shiny nose? *Join in any reindeer games*
2. How many ghosts show up in the book ‘A Christmas Carol’? *Four*
3. Where was baby Jesus born? *Bethlehem*
4. What are the other two most popular names for Santa? *Kris Kringle and Saint Nick*
5. Elvis did not have a white Christmas – he had a? *Blue one*
6. In the film ‘The Grinch Stole Christmas’ the Grinch was described in words – what were they? *Stink, stank, stunk*
7. In the song ‘The Twelve Days of Christmas’ what did my true love give to me on the eight day? *Eight maids a milking*
8. Which country started the tradition of the Christmas Tree? *Germany*
9. Which fairy tale inspired the ginger bread house? *Hansel and Gretel*
10. What was the first company to use Santa Claus in its advertising? *Coca Cola*

Meetings 2020

- March 3 - Kim Pearce, Cancer Council
 April 7 - Jo Watson, Deputy Chair PBS
 May 5 - Robert Galsim, Financial Information Services
 June 2 - 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 organisation that may benefit from having one of the Ambassador Speakers visit them please let one of the committee members 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. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified professionals, as 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, specialist and other medical professionals and we have not verified such conclusions and recommendations. 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 professionals, as 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, specialist 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:

www.prostate-cancer-support-nb.org

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.org

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

