

# 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. 203 - August 2020**

Editor: Mary Jones

## All meetings are suspended until further notice

At this stage, there is still no hint of when we will be able to resume normal meetings  
but we will keep you informed.

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### Monthly Meetings – usually!

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 1<sup>st</sup> Tuesday of the month except in January.

#### Usual Location:

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

Time: 6:30pm till 8:30pm

Due to Government restrictions on Covid-19 -  
**THERE WILL BE NO MEETINGS OF  
THE NORTHERN BEACHES  
PROSTATE CANCER SUPPORT  
GROUP UNTIL FURTHER NOTICE**

### No Meetings As Yet - STILL

The situation at The Palliative Care Cottage has not changed and Jo-Ann has again advised us that no meetings are allowed .

Strict hygiene and social distancing rules are in place to protect both staff and patients.

Whilst we are all feeling this distancing immensely, we can only hope that all our members stay safe and well.

Please feel free to reach out to any of our committee if we can help in any way. Our details are on the last page.

*Mary*

### News about Nubeqa

Nubeqa (darolutamide) is a prescription medicine used to treat prostate cancer that has not spread to other parts of your body.

Nubeqa is given after surgery or other treatments did not work or have stopped working.

It is not known if Nubeqa is safe and effective in children or in females.

The \$55,000-a-year treatment has extended the life of men by five years in a clinical trial, but has not been approved by the federal government for subsidy on the PBS.

Despite this the manufacturer, Bayer Australia, has announced it will help nearly 2000 men with high risk, non-metastatic, castration-resistant prostate cancer by making Nubeqa available to them at no cost. Great News!

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## Pathfinder – PCFA’s Research Register

PCFA’s Pathfinder Register engages men and women to take part in research projects to improve our understanding of prostate cancer. It allows men and women to sign up for prostate cancer research projects covering the physical, emotional, psychological, and financial aspects of cancer, beyond just diagnosis and treatment.

As a member of Pathfinder, you can choose to take part in research studies investigating the quality of health care you receive and your choices about follow-up treatment, as well as examining the longer-term effects of your treatment and your post-treatment quality of life and overall well-being. Family members, friends, and caregivers can also register on Pathfinder to take part in these studies. More research is needed to discover ways of improving the quality of life of those affected by prostate cancer, and this is where you can help.

### What is Pathfinder?

Pathfinder is a national online register established as a joint initiative of Prostate Cancer Foundation of Australia and Griffith University for men and women interested in participating in research into improving the health and lives of people post prostate cancer treatment.

Most importantly, Pathfinder will save researchers valuable time recruiting participants for their projects, freeing up more time to spend on vital research. Registration is free and all your personal details are kept completely confidential.

### Who developed and runs Pathfinder?

Pathfinder is a national online register established as a joint initiative of Prostate Cancer Foundation of Australia (PCFA) and Griffith University. Each organisation brings different and complementary expertise to the initiative.

Griffith University is a top 10 Australian research organisation with nationally and internationally recognized expertise in prostate cancer survivorship research.

<https://tinyurl.com/yynvs3k6>

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## Blackmores Running Festival

For all those who have registered to take part in the the Blackmore’s Sydney Running Festival, scheduled for Sunday, 20 September 2020, please be advised that **the event has been postponed to a new date – Sunday 8 October**. More news as it comes to hand.

See July’s newsletter for full details of the event.

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**If you want to think about more exercise you can combine your Blackmore’s run with – The LONG run – organized by PCFA**

**What -** The Long Run is an awareness and fundraising event inspiring you to run, walk or wheel 72km to raise awareness and funds for Australian men and families impacted by prostate cancer. You can cover the distance during the month of September anyway and anywhere you like. On Father’s Day (6 September) you’ll be invited to take part in the 4k Family Fun Challenge.

If 72km is more than you can manage, you can also set your own distance and goals, suited to your fitness level.

**When -** September 2020

Pre-registration opens Monday July 20

**Where -** Anywhere in Australia – Online via your own personal Fundraising Page, on Facebook, Instagram, and Twitter.

**How -**

1. Sign up for the challenge at – [www.thelongrun.org.au](http://www.thelongrun.org.au)
2. When you register, you’ll be automatically set up with a personal fundraising page
3. Download resources from the website to help with your fundraising
4. Share your story and track your training miles on social media
5. Invite others to join the campaign and donate towards your challenge

Along the way, you’ll earn virtual badges for display on your fundraising page, keeping you motivated and inspiring your fundraising.

**Who -** You! The Long Run is open to people of all ages, from diverse backgrounds, and with different fitness levels – whether you’re a beginner or a pro.

**Goals -**

The goal is to raise awareness and funds for prostate cancer research, support, advocacy, and outreach. We hope you’ll be one of 1750 Australians taking part, to reach our fundraising target of \$498,000.

Go to [www.thelongrun.org.au](http://www.thelongrun.org.au)

thelongrun@pcfa.org.au

or phone 1800 22 00 99

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## The Prostate Zone - From Alan White

### Incontinent after 12 months? What next?

For many men, the incontinence issue has been overcome 12 months after treatment. For others, “leaky plumbing” can be an ongoing battle – often not spoken about except within the confines of a support group setting.

Over the years of giving presentations about the NAVIGATE trial and prostate cancer, I still meet men who are having bladder or bowel problems years after their treatment. For one reason or another, many of these blokes are not aware that there are treatments, services and products available that can help them.

*Where do I start?*

The <https://www.continence.org.au/> is the best place to start. Their website is full of information and resources. They also have a confidential helpline – 1800 33 00 66.

After you've checked out the Continence Foundation, some men will find the next step is to talk with a urologist regarding treatment.

In Alan's support group, a couple of men have had the sling done, and they are very happy with the outcome.

Please note that the following links should not be seen as an endorsement for any specific clinic or urologist. The information on these sites simply provides a starting point to obtain information about what to do next.

General information about the male urinary sling can be found at

<https://tinyurl.com/y3oszquf>

The next treatment possibility is the artificial urinary sphincter (AUS). Our colleague, Victoria Cullen, recently posted a story on her website from a physiotherapist who had his ongoing incontinence resolved with an AUS. For further general information about the AUS, go to:

<https://tinyurl.com/y6za7qkp>

There are also urologists who focus on treating issues that arise after prostate cancer treatment.

Throughout Australia, there are many urologists who perform these procedures.

Talking to other men who have had their continence resolved by any of these procedures, will give you an idea of what you might expect.

Always do your research, ask around, and get a second (or third) opinion. There are solutions available in most cases, so don't suffer needlessly. So, there is no need to put up with leaky plumbing after the initial treatment and recovery period.

If those pelvic floor exercises are not cutting the mustard, then it's time to move to Plan B.

Don't let COVID-19 stop you.

With the whole COVID-19 impact, remind your friends that this is no time to drop the ball. They need to get checked – doctors have warned that tests for PSA and follow-ups are dropping. Remember, prostate cancer doesn't go into hibernation just because of the pandemic.

Take care, stay safe, healthy and strong. You only have one body in this lifetime, so make sure you look after it. <https://tinyurl.com/y56nrmef>

Alan White – The Prostate Zone 25 August, 2020

## August Quiz

1. Which French phrase means "already seen"?
2. Who wrote the novel *Lady Chatterley's Lover*?
3. Which 1960s singer got a number one song singing about a dustman?
4. What term describes a triangle with 2 equal sides?
5. What does an Anthropophobic fear?
6. What is the lightest element?  
Caesium, Hydrogen or Carbon?
7. What taste is detected by taste buds at the back of the tongue, bitter, salty, sweet?
8. Which bane of high school maths students did John Napier devise in 1614?  
The slide rule, Decimals or Logarithms?
9. What part of the eye continues to grow through a person's life? Retina, Iris or Lens?
10. What is the most versatile piece on the Chessboard?
11. Paper celebrates which wedding anniversary?
12. Which Steve starred in the film 'Papillion'?
13. Which capital city stands on the Potomac River?
14. Which New York TV cop ate lollipops?
15. In Greek mythology who was God of the Sun?

## Answers to Norma's July Quiz

1. Which country boasts the most dams than any other country in the world?  
USA, Russia, Netherlands? *USA*
2. What nationality was the thriller writer Edgar Allan Poe? British, American, Irish? *American*
3. Which Senior Office ends on the 20 January?  
The Pope, Secretary of the United Nations or President of the USA? *President of USA*
4. What word describing composers such as Vivaldi, was taken from a Portuguese word meaning misshapen pearl?  
Rococo, Baroque or Byzantine? *Baroque*
5. What title is bestowed on the ruler of Venice?  
Capo, Duce or Doge? *Doge*
6. Who founded Bolshevism? Marx, Lenin or Trotsky? *Lenin*
7. What is the name of Israel's parliament?  
Dail, Knesset or Douma? *Knesset*
8. Who was artist Vanessa Bell's famous sister, who apparently made some people afraid?  
Margot Asquith, Dorothy Parker or Virginia Woolf? *Virginia Woolf*

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9. Which country cans three quarters of the worlds canned pineapples?  
Hawaii, Thailand or South Africa? *Hawaii*
10. How many claws has a Manx cat?  
16, 18 or 20? *18*
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### 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.

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### 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 articles 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.

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### 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](http://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](mailto:info@prostate-cancer-support-nb.org)

Past issues of our newsletters can be viewed on our website: [www.prostate-cancer-support-nb.org](http://www.prostate-cancer-support-nb.org)

