**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. 210 for May & June 2021**

 Editor: Mary Jones

**Our speaker will Jill Marcham**

**Our next meeting for 2021 is on Tuesday, 6 July**

**WE WILL BE CELEBRATING**

**CHRISTMAS IN JULY**

**AT THE DEE WHY RSL**

**See below for details**

**What’s in this issue**

* May Speaker Report
* June Speaker Report
* Dry July
* Darolutamide - Nubeqa
* Norma’s Quiz
* Meetings for 2021
* Contact Information

**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.
	+ THE BAPTIST CHURCH,
	+ 13 GRENFELL STREET
	+ NORTH NARRABEEN
	+ Time: 6:30pm till 8:30pm
* **July Meeting**
* **Christmas in July at the Dee Why RSL**
* **Arrive Dee Why RSL 6.00pm for dinner**.
* ***You will need to choose and pay for your dinner yourself. You must advise us if you are going -***

**Please ring Norma on 9918 4929 if you wish to join us so that she can organise a table for us all.**

**May Meeting Report**

Sally Sara, Director, Nursing Programmes for PCFA, has been a registered nurse for over 30 years and in 2014 she established the Prostate Cancer Specialist Nursing Service in the Southern Adelaide Health Care Network and has a passion for ensuring quality care and support is provided for men living with prostate cancer and their families.

Her commitment to her chosen profession was evident as she spoke without notes and with a passion for position she so obviously enjoys. Sally was appointed the Director, Nursing Programmes in July 2018.

Sally explained the role of the Prostate Cancer Specialist Nurses:

A Prostate Cancer Specialist Nurse is an experienced registered nurse who has received additional training to make them an expert nurse

in prostate cancer care.

The pilot programme of the Specialist Prostate Cancer Nurses began in 2012 and by 2015 there were 12 nurses. This year, 2021, there will be 15 new nurses starting, in 2022 an extra 25 nurses

and by the end of 2022 there will be 90 nurses in the programme. 43% of these nurses are based in Regional areas.

Only 36% of Aussie men are diagnosed at Stage 1 when PC is easier to beat and survival is higher

*What do the nurses do ?*

* Support and supply information on diagnosis
* Support with treatment decisions at all stages of the disease
* Can put you in contact with other services
* Be there as a point of contact during treatment and beyond
* Help with side effect and long-term
* management at all stages
* Help you access a Support Group

In Australia, there are now over 230,00 men living with a diagnosis of prostate cancer.

Prostate cancer survivorship care encompasses the health and wellbeing of men from the point of diagnosis and is essential to cancer care.

Survivorship recognises the physical, spiritual psychosocial and economic impacts of cancer, which can be long-lasting, and addresses these so that the patient can achieve optimal quality of life.

Not all hospitals have a Prostate Cancer Specialist Nurse and it would be impracticable for that to be the case. Locally we have Prostate Cancer Specialist Nurses appointed to the Macquarie University Hospital, Royal North Shore Hospital and the Sydney Adventist Hospital.

The Prostate Cancer Specialist Nursing Service has been made possible thanks to funding from the Federal Government, the Biggest Ever Blokes Lunch, Dry July, generous local and community supporters and some hospitals fund their own Specialist Nurses.

*Sally touched on six issues for Prostate Cancer* Survivors reclaiming quality of life:

* Acknowledgement of unmet needs
* Side effect and symptom management
* Access to expert advice and information
* Connection to peer support and psychosocial care
* Practical assistance and access to affordable
* Support with navigating the health system
* Nurse led follow up care
* Promotion of awareness and education to other health care professionals and the community
* Research

***The Telenursing Service was launched April 2021* Phone 1800 22 00 99**

After twelve month’s work this programme is up and running to answer questions such as is there a local nurse for me? a local Support Group?

An Electronic Resource Guide has been devised so that everyone gets the same evidence-based response

They can give guidance navigating the health system, support with survivorship issues – local support GP, locally based nurses.

This is a free service. It is available on weekdays during normal office hours - please note that some of our Prostate Cancer Specialist Nurses work part time and may not be available on specific days of the week. It is not an emergency service and you should contact your nearest emergency service for urgent issues.

We felt very privileged to have Sally at our meeting and appreciate her travelling from Adelaide to talk to us.

**June Meeting Report**

Dr Phillip Katelaris first trained as a general and abdominal surgeon and then sub-specialised in the field of urological surgery. Postgraduate surgical training was undertaken in Germany.

He has conducted research in the field of [prostate cancer](https://www.katelarisurology.com.au/prostate-cancer-treatment/), particularly with respect to the application of magnetic resonance imaging technology to an early and accurate diagnosis.

A major clinical innovation was the establishment of the Prostate Cancer Rehabilitation Centre for the purposes of rehabilitating bladder and sexual function after surgery.

Dr Katelaris discussed the different kinds of incontinence which can occur after treatment for prostate cancer– stress incontinence, urge incontinence and overflow incontinence. There are many treatment options for these conditions which include the male sling and artificial urinary sphincter.

Whilst nerve-sparing radical prostatectomy is the goal of all surgeons the problem of erectile disfunction can occur. Dr Katelaris says that erections should be stimulated early in the post-operative period, generally within 2-3 weeks of the catheter removal. Nerve damage can take 2 – 3 years to recover and erections need to be stimulated for this period. Penile injection therapy is favoured in the early post-operative period when nerve dysfunction is most acute.

Other treatments include PDES inhibitor products such as Viagra, Cialis and Levitra. These products are taken on an on-demand basis. Penile prosthetic surgery has been used for 30 years and is a three-part inflatable device for the management of erectile dysfunction.

For men who have suffered erectile dysfunction and urinary incontinence it is possible to concurrently implant a penile prosthesis and a male trans obturator sling, or in severe cases of urinary incontinence, an artificial urinary sphincter. Such intervention can dramatically improve quality of life, self-confidence and social confidence.

Dr Katelaris has specialised in the rehabilitation of men after treatment for cancers of the prostate, bladder and rectum for many years. He is director of the Prostate Cancer Rehabilitation Centre and a consultant urologist at the Sydney Adventist Hospital with a special interest in the clinical applications of MRI technology in the diagnosis and management of prostate cancer.

His presentation was well received by our members and we thank him for taking the time to come to our meeting.

**Drinks That Can Make Incontinence Worse**

While fluids can help to prevent incontinence, there are some drinks that can worsen the problem by irritating the bladder, particularly those that are acidic in nature.

* Caffeinated drinks such as coffee and some soft drinks.
* Alcoholic drinks such as wine, beer, cider, and spirits.
* Carbonated / fizzy soft drinks.
* Citrus juices.

**DRY JULY 2021**

**When: 1 July – 31 July 2021 (Register now!)**

**Where: Everywhere**

Each day in Australia, 45 men will be diagnosed with prostate cancer and 9 men will tragically die from the disease.

You can help save their lives by registering your interest for Dry July 2021 in support of Prostate Cancer Foundation of Australia.

When you do, you'll be helping to fund life-changing nurses, including nurses on the ground and on call via our new nationwide Prostate Cancer Specialist Telenursing Service.

Sign up or donate at <https://www.dryjuly.com/pcf>

*Remember to spread the word and invite family and friends to support your Dry July efforts!*

**Darolutamide - Nubeqa**

It has now been 7 years since the Pharmaceutical Benefits Advisory Committee (PBAC) has approved a new medicine for prostate cancer.

Darolutamide (Nubeqa®) is currently being considered for the third time and PCFA is supporting the application. Evidence suggests around 560 men will progress to metastatic prostate cancer for every year this application is delayed.

PCFA is fully supporting the inclusion of Nubeqa for men with high risk, non-metastatic, castration-resistant prostate cancer

**Farewell**

Our best wishes go to Kim Pearce and Sally Carveth who are leaving the Cancer Council after a combined 56 years of work in the Sydney

Metropolitan office.

Kim especially has been a great support at our monthly meetings and will be greatly missed.

May the future hold many wonderful times for them both.

**New Resources**

The new resource booklets noted in last month’s newsletter have arrived and will be available at the next meeting.

**Norma’s June Quiz**

1. Martin Pellow was lead singer of which group?
2. Which metal becomes liquid at room
3. temperature?
4. 3. What was Alan Borders nick name whilst
5. playing cricket and remained with him for the
6. rest of his career?
7. 4. Alexander Graham Bell invented the telephone
8. but never phoned his Mother or Wife on it, Why[?](http://www.apple.com/au/)
9. 5. Where is the Ufitzi Art Gallery, Florence, Rome

 or Venice?

6. What are fillisters, thumbs and collars?

7. Which word in the English language rhymes

 with Orange?

8. Taronga Zoo is in Milson Road, Chowder Road,

 Bradleys Head Road or Scenic Drive?

9. What is Roquefort Cheese made from?

10. What does Veni Vidi Vici stand for?

**Answers to Norma’s April Quiz**

1. How many Oscars did Walt Disney win up to the time of his death?…..*32,* 22, 12, or 2 - **32**
2. What is the chemical symbol for Tungsten? **W**
3. In cookery what is a Caper? ***Flower bud of Capparis spinosa***
4. Monkeys Eyebrow is a town in the USA. True or false? ***True***
5. What do get if you cross a frog with a calendar? ***A leap year***
6. Who wrote *The Da Vinci Code?* ***Ben Brown***
7. In gardening what does the PH of soil indicate? ***Levels of acidity or alkalinity***
8. In the nursery rhyme what did Jill use to mend Jack’s head? ***Vinegar and brown paper***
9. What do you call a row of hares walking backwards? ***Receding hare line***
10. Why did the ants run fast across the top of a sachet of tea? ***Because it said ‘tear across the dotted line’***

**Meetings in 2021**

Tuesday 3 August Karin Slade - author

 ‘Where there’s a Will there’s a Wake’

Tuesday 7 September Men’s Night

Tuesday 5 October TBA

Tuesday 2 November TBA

Tuesday 7 December End of year event

**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.

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:

[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

Useful websites:

[www.pcfa.org.au](http://www.pcfa.org.au) Telephone: 02 9438 7000

SeePCFA Newsletters online at:

[www.pcfa.org.au/articleLive/pages/PCFA-Newsletters.html](http://www.pcfa.org.au/articleLive/pages/PCFA-Newsletters.html)

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

.