



# Below the Belt!

Vol. 22 No. 3

May – July, 2023

Newsletter of The Nepean / Blue Mountains Prostate Cancer Support Group Inc.  
(ABN No. 35 871 442 176)

## Life Membership – David and Jan Wilkinson



At the March Group Members Meeting we awarded our President, David Wilkinson and his wife Jan, Honorary Life Membership to the Group. (Page 2)

## What's to Come

**Group Meeting – Monday June 19<sup>th</sup>**

Paul O'Loughlin

An evening of Gentle Yoga (Page 2)

**Group Meeting – Monday July 17<sup>th</sup>**

To Be Advised

**Group Meeting – Monday August 21<sup>st</sup>**

To Be Advised

**Meetings are now held at the Emu Sports Club (Home of Leonay Golf Club)**

Gather at 6-30pm for a 7-00pm start.



Our Web Site "[www.prostatesupport.org.au](http://www.prostatesupport.org.au)" is now sponsored  
by the Members of Emu Plains Lions Club

## **Life Membership – David and Jan Wilkinson**

At the March Group Members Meeting we were proud to award our President, David Wilkinson and his wife Jan, Honorary Life Membership to the Group.

*This award was finally able to take place at our March Group meeting.*

*I say 'finally' for a couple of reasons.*

*We originally planned to present this award at the Group Christmas Party in December, however the day before the party both David and Jan tested 'positive' to the dreaded 'covid' and as we did not hold a January meeting February became the next option. Problem number 2. David and Jan were off 'A' vaning in February!*

*So Vice President Graeme, was 'finally' able to make the presentation in March!*

David was introduced to the Group when he was diagnosed with Prostate Cancer in 2011. He took over the Presidency of the Group when Group founding member, Alan Moran, stepped down.

David's 'Prostate Journey' has not been straight forward. He underwent a Radical Prostatectomy followed by 32 sessions of radiation and is currently on Hormone treatment.

David and Jan were married in 1974 and have two daughters who, in turn also have two daughters giving David and Jan 4 grandchildren.

During his working life, David obtained qualifications in both Accountancy and Health Administration.

He worked in the Department of Education before, in 1976, joining the Health Commission of NSW. When he retired in 2008, David held the position of Manager, Insurance and Risk, NSW Health.

This administrative experience and involvement in the Health sector has contributed to David being an ideal President of our Group.

We all know David is an avid traveller. He and Jan have logged many kilometres in all states of Australia in their trusty 'A' van. David is also a past President of the Australian 'A' Van club. This club boasts 1800 members.

Another of David's interests is Orchid growing. He is also a past President of the local Orchid group.

We have all witnessed first hand Jan's involvement in the running of the Group. As well as providing full support to David, Jan offers support to the partners of Group Members. Jan was, for a time, an 'honorary' Board Member taking the Minutes of meetings. She, in previous times, also organised the supper for our regular Members meetings.

In May of 2022, David and Jan were recognised as 'Legends of The Nepean' and featured in an article in the 'Nepean News'

Here is a link to that article. <https://nepeannews.com.au/issuu/nepean-news-13-may-2022/>



## **June Group Meeting – Monday, 19<sup>th</sup> June – 2023**

Guest Speaker at this meeting will be Paul O'Loughlin. Paul comes to us via the Cancer Wellness Centre. Paul has an affinity with the benefits of Yoga for the older population and people with a disability and accordingly teaches gentle Yoga and chair Yoga which is accessible to all.

# **PSA levels after treatment: All you need to know**

**By Bernard Riley**

**Head of Telenursing and Supportive Care Programs**

“Why are my PSA levels rising again, even though I’ve had my prostate removed? Does the speed at which my PSA is rising mean anything? How can I manage PSA anxiety?” These are all questions PCFA’s Telenursing Service frequently receive from men after treatment for prostate cancer.

PSA, or Prostate Specific Antigen, is a protein produced by both normal and cancerous prostate cells. Its primary role prevents semen from clotting so that sperm can “swim” freely. PSA can move from the cells into the blood stream where it can be detected using the PSA blood test.

There’s a common misconception that once you’ve had your prostate removed, or undergone other treatment, PSA won’t be detectable anymore. But this isn’t always the case. We answer the most commonly asked questions to help you understand more about PSA levels after treatment.

## **What happens to my PSA after prostate cancer treatment?**

You can expect different effects on PSA results with different treatments.

**After surgery**, the main source of PSA, the prostate, is removed and within 4-6 weeks the PSA is expected to fall to very low levels (less than 0.1) and often to an undetectable level.

**After radiation therapy**, PSA levels will drop steadily and may take 18 months or more to reach the lowest level (the nadir). Radiation therapy does not kill cancer cells right away. It may take a number of days or weeks of treatment before DNA is damaged enough for cancer cells to die. Then, cancer cells keep dying for weeks or months after radiation therapy ends. If you had hormone therapy at the same time as radiation therapy, the PSA level will drop much faster, approaching very low levels by 6 months.

Less commonly, men who have focal therapies, like laser treatments, HIFU, Nanoknife or IRE- PSA, may not be a reliable indicator of the effectiveness of treatment and may result in further investigations such as MRI and biopsy to determine efficacy.

## **What does it mean if my PSA starts to rise again after surgery or radiation?**

In some cases, **after surgery**, your PSA may rise months or years later. We’re often asked where the PSA is coming from if the prostate has been removed. The most common reason is the PSA is being produced by prostate cancer cells somewhere else in the body. These cells may have been dormant for a period of time before beginning to produce a level of PSA detectable on a blood test. Less commonly, at very low levels there may be a protein misread by the testing technology as the PSA protein giving a false result or it may be caused by benign tissue at the edge of the tissue removed producing PSA.

After **radiotherapy and brachytherapy**, there can be a ‘PSA bounce’ in the first few years after treatment, where the PSA temporarily rises and then subsequently falls. This does not mean that the cancer has recurred and does not increase the risk of the cancer returning in the future.

If the PSA does continue to rise (e.g. 2.0ng/ml above nadir), this usually indicates that you still have prostate cancer cells in the body. Not all men who have a rising PSA will develop prostate cancer that affects their health, and further monitoring may be recommended.

### **Can my PSA results differ depending on what pathology lab I visit?**

It can be beneficial to have your PSA testing done through the same pathology provider, lab or centre. While variations in PSA results can be small between pathology reports when these are used to change treatments or initiate further investigations it is important to consider if the PSA test was done using the same technology.

Different laboratories use testing technology produced by different companies. There can be advantages of using different testing kits and machines. Some detect PSA more accurately at very low levels but may not do so at very high levels.

### **Does the speed of the rise in my PSA indicate anything?**

Yes, the speed at which the PSA rises is important. A PSA doubling time (PSA-DT) is a measure of consecutive PSA results which gives an indication of the activity of the prostate cancer cells. The more rapidly a PSA is doubling the more likely you are to need further treatment especially if your PSA reaches or approaches the threshold to commence further treatment. Your specialist will calculate your PSA-DT and there are various [online calculators](#) to do this.

If your PSA is taking longer than a year to grow it is an indication that at this time the growth is slow. If however, your PSA-DT is less than 3 months this may indicate more active cancer cells and warrant further investigation and or treatment

### **If my PSA rises after treatment, what's next?**

For those who have had surgery a PSA or biochemical recurrence (BCR) is defined as a PSA of greater than or equal to 0.2ng/ml. For those who have had radiotherapy a PSA recurrence is defined as 2ng/ml above the nadir (the post treatment lowest PSA level) or 3 consecutive rises in PSA.

However, if your PSA has risen above the detectable limit and rises on consecutive tests then your specialist may look to investigate this with a PSMA- PET scan which may be able to detect deposits of prostate cancer at low levels. As the PSA rises however the sensitivity and accuracy of this scan becomes more reliable.

For men who have had surgery, if the PSMA PET scan shows an area of activity then it may be recommended to have a course of radiotherapy to treat this area when the PSA rises to around 0.2ng/ml. For men who have had radiotherapy, there may be options to give further radiation if the cancer recurs outside the existing radiation area, commence hormone therapies to slow the growth or less commonly surgery to remove the prostate.

### **How can I manage the worry and anxiety I get before each PSA test?**

Anxiety is a common and normal response to a diagnosis of prostate cancer. It usually occurs when we feel a lack of control over a stressful situation, and cancer is well known to be one of the most stressful experiences we can have in life. Throughout a cancer experience, anxiety also tends to peak at certain time points – at diagnosis, the commencement of treatment, again at the conclusion of treatment, and particularly around the time for follow up scans or with regular PSA testing.

It is normal to experience a range of emotions such as fear and worry, increased irritability, difficulty sleeping, and difficulty with recurring intrusive thoughts. Whilst you can never completely get rid of these feelings when a scan or PSA result date is approaching, there are some strategies you can adopt that are known to be helpful.

Talk things through with your treating team, a [Prostate Cancer Specialist Nurse](#), speak to other men who've been through a similar experience through a support group or [PCFA's MatesCONNECT program](#). Call [PCFA's Telenursing service](#) who can help you understand your result and help you through these difficult moments. Our [Prostate Cancer Counselling](#) team also have a range of strategies to help you manage these stressful moments. It may also be helpful to:

- **Try to maintain your normal routine.**
- **Keep your focus on the things that ARE under your control** e.g. taking care of tasks around the home, and practical activities that keep you occupied.
- **Limit alcohol intake and aim to eat healthily.** Reducing unhealthy foods such as refined carbohydrates and processed foods, and increasing your fruit, vegetable, wholegrains, and healthy fats intake, keeps your blood sugar stable and lowers the likelihood of mood swings and slumps in energy.
- **Increase your exercise if you can.** When we exercise, we release pent up adrenaline and cortisol (our stress chemicals), and activate our endorphins (our natural painkillers and mood elevators).
- **Practice relaxation techniques.** Our counselling team can help you with these.
- **Use distraction to good effect:** Spend time with friends and family, get out into nature, clean out the garage, volunteer to help a friend, listen to talk back radio or your favourite music, do some gardening, play cards, read a good book, watch a good movie, or tackle a project.

Whatever your situation and questions, we are here to help. Please reach out with any questions either via phone or email.

**Call the PCFA Telenursing team today on 1800 22 00 99 to get individual advice or email [telenurse@pcfa.org.au](mailto:telenurse@pcfa.org.au) for more information.**



This item and the item following (You, Your Genes and your Genomics) are reprints of articles published by the PCFA.

There are many more interesting and informative articles available on the PCFA web site online community page. <https://onlinecommunity.pcfa.org.au>

## You, Your Genes and your Genomics

### **Genes, mutations, and your family tree: The hereditary and genetic factors that can influence prostate cancer outcomes.**

The connection between a man's genes and his risk of developing prostate cancer is well established, but not well understood. Around 5-10% of all Australian prostate cancer cases are caused by an inherited genetic risk, and around 10-12% of men with metastatic castration-resistant prostate cancer carry inherited BRCA1/2 mutations. In other cases, acquired genetic mutations can increase a man's risk of developing the disease and influence how aggressive it becomes.

Fact: If your father or brothers have ever been diagnosed with prostate cancer, you have **twice the average** risk of developing the disease.

If you have two or more close male relatives who have been diagnosed, your lifetime risk of developing prostate cancer increases five-fold.

And your risk also increases **if you have a strong family history of breast or ovarian cancer**, especially if a BRCA1 or 2 gene mutation was involved.

However, making a connection between your family history and the genes responsible for prostate cancer is an area of ongoing research, with much to reveal about how we can treat the disease in future.

Here's what we know:

- All of us have Breast Cancer 1 (BRCA1) and Breast Cancer 2 (BRCA2) genes. They are tumour suppressor genes that function to repair cell damage which help to prevent certain cancers from developing. When your BRCA1 and 2 genes have mutations, your risks of related cancers increases.
- About 1 in 500 Australians carry a BRCA1 mutation and 1 in 225 have a BRCA2 mutation.
- Men who have the BRCA1 mutation have a 9% risk of developing prostate cancer, compared to the population average risk of just 5%. These men also have a 1% risk of developing breast cancer.
- Men who have the BRCA2 mutation have a 15% risk of developing prostate cancer compared to the population average, and a 7% risk of developing breast cancer, compared to the population average of much less than 1%.

Research has found that if prostate cancer develops in a man who carries a BRCA1 or BRCA2 mutation, it more likely to be aggressive and to spread beyond the prostate.

**While our current understanding suggests that only 5 to 10% of all prostate cancer cases in Australia are caused by an inherited genetic risk, about 10 to 12% of men with metastatic castration resistant prostate cancer have BRCA mutations.**

**More interesting still, only around half of these are inherited mutations, and about 5% of men with advanced prostate cancer have non-inherited BRCA1 or 2 mutations.**



## **Gene testing and new medicines**

Australian men with advanced prostate cancer now have access to precision medicines that can help stop the spread of tumours linked to genetic variations. In parallel, new research is looking at whether genetic testing should be more widely introduced to help target genetic variants that may be driving some forms of the disease.

In April 2022 the Australian government listed AstraZeneca's **Lynparza®** (olaparib) for eligible men with prostate cancer, responding to a lengthy advocacy campaign by PCFA and others.

Since then, thousands of men have benefitted from no-cost genetic tests and access to the life- extending drug, which has been found to lower men's risk of death by 31% compared to other forms of treatment.

The drug, known as a **PARP** Inhibitor, works by blocking proteins that promulgate cancer growth, but is only effective in men with cancers linked to BRCA gene mutations which cause prostate cancers to become more aggressive.

Evidence shows that men diagnosed with prostate cancer who have mutations in the BRCA1 or BRCA2 genes have higher risks of more aggressive prostate cancers and poorer clinical outcomes.

In particular, men with faults in their BRCA2 gene are five times more likely to be diagnosed with prostate cancer and at a younger age and this high-risk group is twice as likely to have a more serious, potentially life-threatening, form of prostate cancer.

One of the advantages to Lynparza is that it is taken twice daily as a tablet, with a relatively low risk of serious adverse events and side-effects among patients.

In terms of treatment pathways, it's offered to men when their prostate cancer becomes resistant to other forms of treatment, which means **it's important for men with advanced prostate cancer to undergo genetic testing early** so that we can determine whether to target the tumour with Lynparza or other novel medicines.

Identifying BRCA-mutations in mCRPC as early as possible has the potential to change the way we manage advanced prostate cancer, slowing down the spread of the disease and improve overall survival time.

**Call the PCFA Telenursing team today on 1800 22 00 99 to get individual advice or email [telenurse@pcfa.org.au](mailto:telenurse@pcfa.org.au) for more information.**

## **What can you do about family and genetic risks?**

Firstly, know your family history, and talk to your GP about screening for prostate cancer from 40 years old.

Secondly, remember that few men experience any symptoms of prostate cancer at its earliest stages, so don't be fooled by how well you feel.

Thirdly, support research and advocacy in this area. Research has led to breakthroughs in precision medicine that allow us to target BRCA1 and 2 prostate cancers with new drugs.



## **Web Site Update**

Just advising, our web site ([www.prostatesupport.org.au](http://www.prostatesupport.org.au)) is currently being updated and may be out of action for a couple of weeks.

## Penrith “Relay for Life” – May 27<sup>th</sup> - 2023



The Penrith ‘Relay for Life’ was once again held at the Penrith Showground. When we think back to the huge events held in the past at Howell Oval, this year’s event was a relatively tame affair.

After a couple of years of postponements and cancellations due to weather followed by the dreaded ‘Covid’ it has been difficult for organisers to generate interest. This year’s event was not confirmed until very late.

Nevertheless, after a lot of hard work by the committee, a successful event was able to be held. The weather ‘Gods’ smiled on us and the day was a glorious warm, sunny autumn day. (Pity about the freezing early morning and evening!) Our team the “Prostate Pals” was once again organised by our hard working Promotions Officer, John Kemp. The team was, unfortunately, again poorly supported by members of our Group. The majority of our team members were John’s friends from his church group. Many thanks to these people for their support. Our team fund raising contribution was over \$1700.00 (10<sup>th</sup> highest team total!) At past relays, John has endeavoured to match his number of completed laps of the course to his age. This year he claimed to have “finally worked out this relay caper”! He handed his lap counter to other people to help out! One of John’s friends, Jarred, an ‘Ultra’ trail runner clocked up the majority of laps for ‘Team Kemp’. The total laps completed were 107. (When you consider that each lap was 475M that’s not a bad effort.



### A Couple of Dates for your Diary

Our Promotions Officer, John Kemp, has organised a few awareness / fund raising events for the Group. These events require help and assistance from ALL Group members. John will be calling for names closer to each of these events. These days not only raise awareness (and in some cases, funds) but are great social get together. Please consider becoming involved.

**Bunnings BBQ** – Saturday, 2<sup>nd</sup> of September 2023 (The day before Fathers Day) Bunnings Penrith South  
(We have also been invited to set up PCa awareness tables at Bunnings Penrith South on other days – more details later)

**The Clarendon Classic Machine, Truck, Toy, Hobby Show** – Saturday 16<sup>th</sup> and Sunday 17<sup>th</sup> of September, 2023.

This is an extremely interesting event (if you like checking out old cars, trucks and machinery!) We will be in the pavilion with the old racing cars etc..

**The Hawkesbury Canoe Classic** -- Saturday 28<sup>th</sup> of October. 2023

The Group has been providing scrutineering assistance at this event for many years and it is always popular day among members. It is a couple of years since this event has been held (due to Covid and Floods!) let’s hope this year’s event goes ahead.





## Contact Us

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**IT'S ALL FUN AND GAMES  
UNTIL THEY START  
PLAYING BANJO MUSIC  
IN THE MIDDLE OF YOUR  
PROSTATE EXAM.**



**PAYMENT OF Membership Fees.** Members can pay their annual Group Membership Fees by direct deposit to our bank account.

Our Westpac Account Name is 'Nepean / Blue Mountains Prostate Cancer Support Group'. BSB is 032-837 and the Account No. is 206701. Current Fees are \$10.00 P.A. per family. Don't forget to advise who you are in the Lodgement Reference i.e. " John Smith Fees 2023"



**Would you like to make a cash donation to our group?  
Do you know any Group or Organisation that would like to make a donation?  
We are a registered charitable organisation and all donations are fully tax deductible.  
All donations help us to support cancer and health related projects in our local area.  
If you are able to assist, contact our Treasurer, Graeme Renshaw.**

### **Board Members of the Nepean / Blue Mountains Prostate Cancer Support Group for 2023 are as follows:-**

<b>President :-</b>	David Wilkinson	'phone 02 4739 1685
<b>Vice President / Treasurer :-</b>	Graeme Renshaw	'phone 04 1827 6422
<b>Secretary :-</b>	Wayne Singleton	'phone 04 1494 5263
<b>Newsletter Editor / Publicity:-</b>	Alan Howard	'phone 02 4739 3320
<b>Web Site Manager :-</b>	John Parsonage	'phone 04 3851 4707
<b>Promotions Officer :-</b>	John Kemp	'phone 02 4739 2852

The Nepean / Blue Mountains Prostate Support Group Inc. is grateful for the support of its members and various local groups. This enables us to produce this newsletter and cover other incidentals in the running of the group.

The Below the Belt 'Zipper' logo (Page 1) is copyrighted to Ms. Caroline Redwood and is used with her kind permission

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**The views expressed in this newsletter are not necessarily the views of the Group.**

**The Group does not offer medical or other professional advice.**

**Articles presented in this or any other issues are presented only as a means of sharing information and opinions with members.**

**It is important that health professionals should be consulted before making any decisions about any treatments.**

**This newsletter has been compiled by Alan Howard from material culled or provided.**

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**Nepean / Blue Mountains Prostate Cancer Support Group Web Site 'www.prostatesupport.org.au**