



# Below the Belt!

Vol. 20 No. 4

September – November, 2021

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

## August Group Meeting

At our August meeting (via 'ZOOM'), our guest speaker was Vivienne Maitland. Vivien is a psychologist from Cancer Wellness Support based in Penrith and Leura.

Vivien is a long time supporter of our Group having spoken to us on a couple of occasions at our 'Face to Face' meetings (pre Covid)

Vivien spoke on tips for coping with the current lockdown etc., and had some ideas regarding the importance of keeping in touch via phone / facetime/ emails etc with family and friends, trying to maintain a routine and looking forward each day to those routines while adopting self-awareness, recognising feelings and thoughts and dealing with them.

Cancer Wellness Support is a charitable organisation that is committed to helping cancer clients and their families. Our Group is proud to be a 'Gold' sponsor of this organisation.

## What's to Come

**Group "ZOOM" Meeting – Monday September 19<sup>th</sup>**

Dr Natalie Winter,

from Deakin University, Talk about clinical trial called "Mindonline" (Refer Page 2)

**Group "ZOOM" Meeting – Monday October 17<sup>th</sup>**

Group A.G.M.

Refer Pages 7 & 8

**Group "ZOOM" Meeting – Monday Month 00<sup>th</sup>**

To Be Advised

**Due to Covid Restrictions all Meetings will be on ZOOM until further notice**  
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

## **Upcoming Awareness Events**

That title is a bit of a joke isn't it?

Here's a list of the Awareness Events that our hard working Promotions Officer, John Kemp, had organised for us to attend.

But, due to you know what, they have all been cancelled for this year!

### **Shannon's Classic**

Planned to be held at Sydney Motorsport Park (Eastern Creek Raceway)

### **Hawkesbury Machinery Show.**

Was to be held at Hawkesbury Show Ground

### **Bunnings 'Fathers Day' BBQ**

This should have been on the Saturday before Fathers day (September 4<sup>th</sup>). This was doubly disappointing as it is not only a very good awareness event it is also a very good fund raiser.

### **Hawkesbury Canoe Classic**

One of our special annual events, this should have been held on Saturday October 30<sup>th</sup>.

### **Leonay Golf Club 'Prostate Cancer Awareness Golf Tournament.**

Another of our good fund raising days.

Also, at our June Group Meeting at the Emu Plains Sports Club (one of our rare 'face to face' meetings.) I spoke of trying to get our Dragon Boat Team into the Penrith 'REAL; Festival. You guessed it! That's been cancelled too!



### **Zoom Meeting Monday 20 September 2021**

At our group Zoom meeting on Monday, we will be joined by Dr Natalie Winter, from Deakin University, to talk about her trial called Mindonline, a 9-week, mindful on-line study for prostate cancer, breast, and colon cancer. Natalie will explain what is involved with the study and answer any questions you may have. Natalie's presentation should be no longer than 20 – 30 minutes with time for questions.

Importantly, this is one that you undertake at home, therefore it is not invasive and requires no travel.

It is important that we volunteer for clinical trials to aid research into this insidious disease as it will not only help ourselves but will also help men who may be diagnosed down the track. All too often men do not undertake clinical trials until their survival is on the line.

Prior to Natalie's presentation there will be time for chatting/questions etc and time will be available after the presentation as required.

The link to join the presentation

is: <https://us02web.zoom.us/j/82903993060?pwd=Z2R6dVhZ3hYVE05QkhYbUVHRzlpZz09>

Those who have attended Zoom meetings before will also receive a reminder invite on the night.

## **A bit of personal information..**

*I commenced my Prostate Cancer "Journey" 20 years ago. The options for treatment for me at that time were Radical Prostatectomy Surgery, External Beam Radiation or Brachytherapy.*

*(Brachytherapy (at that time) was not funded in any way and was quite expensive so I ruled that out.)*

*After many sleepless nights mulling over my options (something I am sure all Members can relate to) I chose surgery. This was before Laparoscopic Surgery and long before Robotic Surgery so it was 'Open Cut'*

*I have never regretted that decision. (Would have liked to not have to make it! But....)*

*I was very fortunate in that incontinence has not been a problem for me. E.D? A different story. (Fond memories and a vivid imagination!)*

*Over the 20 years I have had regular PSA tests. These started from the 'old' 'Less than 0.1' and into the more accurate readings. 0.01, 0.02, 0.03 etc. It gradually got up to 0.16, 0.18. Then the most recent it jumped to 0.24!*

*Now I'm off for a Bone Scan and a PSMA test.*

*Chapter 2 begins! I'll keep you posted.*

*Wanting to know what a PSMA PET Scan involved, I found this article on the PCFA Web site. I share it for your information.*

## **A ground-breaking new Australian trial funded by PCFA has tested the benefits of PSMA-PET scans used at diagnosis.**

Results show that these scans can replace the current CT and bone scans used by men with high-risk prostate cancer at their time of diagnosis. This week's research blog asks why this trial is ground-breaking and how it could change clinical practice.

### **What is a PSMA-PET scan?**

PSMA-PET scans are the most sensitive scans available for detecting prostate tumours. This means that they are able to see small tumours where other types of scans miss them. Australia is a world-leader in PSMA-PET scans. Unlike most other countries, PSMA-PET scans are commonly used by Australian men with recurrent prostate cancer. These scans can also be used by men who have been diagnosed with high-risk or metastatic prostate cancer.

The long name of this scan is gallium-68 PSMA PET-CT. There are two parts to the scan – an x-ray component (CT) and a PET scan.

*CT scan:* The CT scan uses x-rays taken in different directions to make a 3D image of the body.

*PSMA-PET scan:* PET scans use a radioactive dye to light up specific regions in the body. PSMA-PET scans look for areas of the body where the PSMA protein is found, showing the presence of prostate cancer cells. PSMA stands for prostate specific membrane antigen - a

protein found on the surface of prostate cancer cells. Gallium-68 refers to the radioactive part of the PET scan.

By combining the results from the CT and PET scans into one image, we can see the location of prostate tumours in the body.

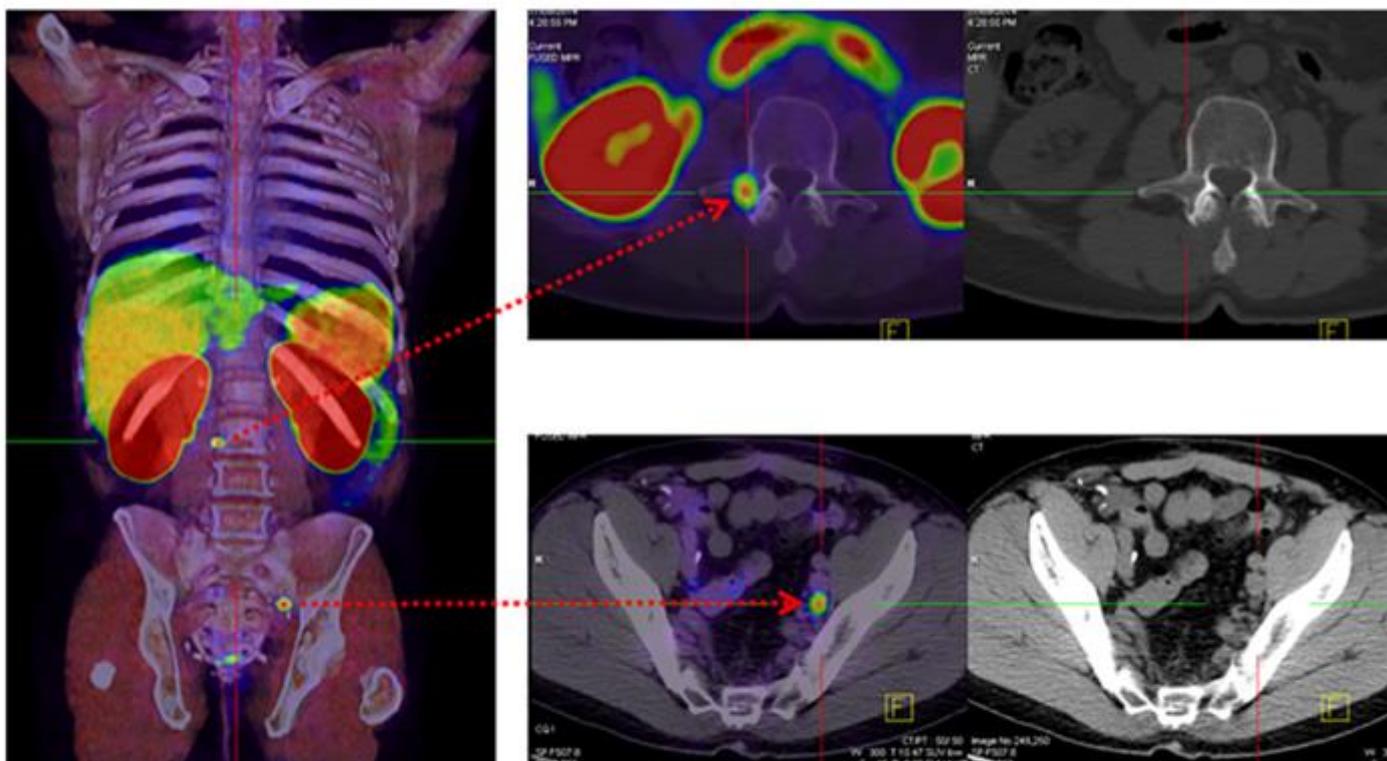
### When are PSMA-PET scans currently used?

In Australia these scans are used by some men with prostate cancer, despite being expensive. They are useful for men:

-who have been treated for localised prostate cancer but their PSA is rising (recurrent prostate cancer)

-who have metastatic prostate cancer at the time of diagnosis

-who are diagnosed with high-risk prostate cancer that appears localised (no tumours seen in CT or bone scans).



68Ga-PSMA-PET/CT scan (coloured images) compared to conventional imaging (right hand side). The 68Ga-PSMA-PET demonstrated a small lymph node metastasis in the pelvis (bottom middle panel) and bone metastasis (upper middle panel). Image kindly supplied by A/Prof Michael Hofman.

### Men with high-risk localised prostate cancer

Men who are diagnosed with high-risk localised prostate cancer might find these scans useful. They wish to know whether their cancer really is localised to the prostate gland, or whether it has spread to other regions. Many of these men in the private health system will have a PSMA-PET scan in addition to other scans after their biopsy. But this is not the case

for men in the public system. Fewer men in the public system have PSMA-PET scans after diagnosis. It's likely that the high price is a problem for these men.

There are two important reasons why a clinical trial is helpful for men with high-risk localised disease. The first is to ask whether it's worth having this expensive scan. Does it actually change the treatment chosen by these men and their doctors? The second is to provide evidence that these scans are useful, which can be used to pressure the government to reimburse the cost, improving access for men in the public system.

### **ProPSMA, an Australian clinical trial for PSMA-PET scans at diagnosis**

Results from an Australian clinical trial testing the value of PSMA-PET scans were [published last week](#) in a top journal called The Lancet. This trial was led by Prof Michael Hofman from the Peter MacCallum Cancer Centre.

The aim of the ProPSMA trial was to ask whether PSMA-PET scans were more accurate for detecting metastatic tumours than the current CT and bone scans used at diagnosis. The study also tested whether the scans changed treatment decisions and reduced radiation exposure. The trial recruited men diagnosed with high-risk localised disease by biopsy.

302 men joined the study from 10 different treatment centres around Australia. The men joining the study were recently diagnosed with a biopsy showing high-risk prostate cancer. They were considering surgery or radiotherapy to treat their cancer.

Half of the volunteers had PSMA-PET scans and half had the usual CT and bone scans. These scans were used to look for tumours that had spread beyond the prostate gland. Tumours were found either in distant sites or in the pelvic region of some of these men. Information from their scan together with PSA levels, biopsy and other results were used to prepare a treatment plan. These men were followed-up after 6 months to check for the presence of metastatic tumours.

### **Accuracy of PSMA-PET scans**

The main read-out from the ProPSMA trial was the accuracy of the scans. The PSMA-PET scan was 92% accurate in detecting metastatic tumours (or the lack thereof), compared to only 65% accuracy for CT and bone scans.

Accuracy relies on two measures, specificity and sensitivity:

*Specificity* is the ability to correctly identify those **without** metastatic tumours (true negative rate). PSMA-PET identified 98% of men correctly who had no metastatic tumours. This was significantly higher than the 91% for CT and bone scans.

*Sensitivity* is the ability to correctly identify those **with** metastatic tumours (true positive rate). PSMA-PET scans correctly identified 85% of men with metastatic tumours, compared to only 38% for CT and bone scans.

**PSMA-PET scans are therefore more accurate for finding or ruling out metastatic tumours at the time of diagnosis than CT and bone scans, for men with high-risk prostate cancer.**

### **Other findings from the ProPSMA trial**

More good news from this trial includes:

- PSMA-PET scans were more likely to change treatment plans (28% of cases compared to 15% for CT and bone scans).
- Men having PSMA-PET scans had less radiation exposure during their scans than men having CT and bone scans.
- Men having PSMA-PET scans were less likely to have uncertain results from their tests (7% versus 23% uncertain findings from CT and bone scans).

### **What does this mean for Australian men?**

PSMA-PET scans are popular in Australia but they are expensive, costing hundreds of dollars. They are most commonly used by men whose PSA is rising after surgery or radiotherapy treatment for localised prostate cancer. At this stage, PSMA-PET scans are the most sensitive scan to detect new tumours that have spread despite treatment.

PSMA-PET scans are also used by men whose biopsy has shown a high-risk cancer but CT and bone scans don't see any metastatic tumours. These men may be diagnosed with high-risk localised prostate cancer, but wish to know if there are small tumours that have escaped from the prostate gland. This is known as oligometastatic prostate cancer – where a few small tumours have spread. Currently, men with high-risk disease in the private system often get PSMA-PET scans but men in the public system do not. It's likely that the high price is putting them off.

The results from the ProPSMA trial have shown that men with high-risk prostate cancer get more accurate results from PSMA-PET scans at diagnosis. They can forgo the CT and bone scans, reducing their radiation exposure. Having the higher accuracy PSMA-PET scans changed treatment plans in 28% of cases and lead to fewer ambiguous results.

The authors of the study state in their publication that “existing guidelines should be reviewed in light of these findings”. They believe that PSMA-PET scans can replace the CT and bone scans used by men after their biopsy and diagnosis with high-risk prostate cancer – a improvement to current clinical practice. We hope that this evidence can also be used to support government reimbursement for these expensive scans.

PCFA are proud to have funded this ground-breaking trial with help from The Movember Foundation.

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*Follow up:-*

*I was due to have my scans on the 14th & 15<sup>th</sup> of September, however due to cancellations (probably due to Covid) they were brought forward and I was able to have the scans on 18<sup>th</sup> & 19<sup>th</sup> of August.*

*Results? After a few anxious days, All Clear! No prostate cancer cells detected. The bone scan did show up arthritis developing in my spine. Frankly, that didn't really surprise me. Probably the reason for my increasingly creaking bones!*

*The reason for the jump in my PSA? Who knows? My urologist did say he was going to bring it up at the next Nepean Multi Disciplinary Group meeting.*

*I am due for another PSA test in November so we will see what eventuates.*

## Preliminary Notice of Annual General Meeting of the Nepean / Blue Mountains Prostate Cancer Support Group

Dear Members and Network

All members are advised that the Annual General Meeting will be held on Monday 18 October 2021 commencing at 7.00pm. Given the uncertainty of the Covid situation, we propose holding the meeting via Zoom video conferencing.

You may recall we were given dispensation to defer the AGM scheduled for October 2020 for up to one year provided the next AGM includes the Treasurer's Report for 2019/20 and 2020/21.

**This is a preliminary notice.** A formal notice of meeting, Minutes of the last AGM (October 2019), agenda, etc will be distributed at least 28 days prior to the AGM.

**Reminder** – only paid-up members may vote at the AGM. The \$10.00 annual membership fee which covers a member, their carers and/or partner is due by the AGM. Would those who haven't paid the membership fee please pay before the AGM. Details of paying into our bank account directly are:

Bank: Westpac

Account name: Nepean/Blue Mountains Prostate Cancer Support Group

BSB: 032 837 Account No: 206701

Please put your name in the appropriate block before sending to our account.

Like most things we have rules we must follow. In our case the Constitution directs the processes for operating the Group and how an AGM must be conducted. We need a quorum of 15 members for the AGM to proceed. A membership is defined as the member along with their carers and/or families who also able to vote. (Ie, more than one vote per membership). We strongly encourage you to join or renew by paying the membership fee prior to the AGM. The Board has struggled for the past two years with only six directors. A Board quorum is five directors. We would like to have a couple of additional Board members to give the Board some flexibility. The task is not onerous but if you are happy to come onto the Board but don't wish to take a key position that is okay. You will find the meetings interesting, and it is an opportunity give back into what is an important support function for all people in our region who have been diagnosed with prostate cancer or have been or are being treated for prostate cancer.

Board positions which are up for re-election are:

President\*

Vice President/Treasurer\*

Election of Honorary Secretary\*

Newsletter Editor\*

Promotions Officer\*

Librarian\*

Assistant Secretary/Membership Coordinator

Webmaster & Publicity Officer

\*Indicates currently filled positions for which the incumbent is willing to renominate.

The Board welcomes anyone who wishes to attend a meeting to meet the current directors and gain an understanding of what the Board does at its meetings.

If you would like to attend a meeting, they are held bi-monthly. Meetings are normally held at the Penrith Gaels Club if the Covid rules permit. Otherwise Zoom video conferencing is used. Please find attached an application form if you wish to nominate for the Board. If you have any questions, please don't hesitate to call the President on 130013 38 78. A Board member will endorse nominations.



**NEPEAN / BLUE MOUNTAINS**

Prostate Cancer Support Group Inc.

You are not alone.

**NOMINATION FORM For  
ELECTION TO THE 2021/2022 BOARD OF THE  
NEPEAN / BLUE MOUNTAINS PROSTATE CANCER SUPPORT GROUP INC.**

To: The Honorary Secretary  
Nepean/Blue Mountains Prostate Cancer Support Group Inc.,  
PO Box 763  
KINGSWOOD NSW 2747  
Email: [secretary@prostatesupport.org.au](mailto:secretary@prostatesupport.org.au)

I, ..... wish to nominate for election to  
the position of

.....

on the Board of the  
Nepean/Blue Mountains Prostate Cancer Support Group Inc.

Signed..... Date ..... 2021

We endorse this nomination:

Name: ..... Signed: .....

Name: ..... Signed: .....



As you are know, September is Prostate Cancer Awareness Month.  
The Nepean / Blue Mountains Support Group has once again entered a team in the PCFA  
fund raising event "The Long Run" taking place during the month of September.  
The format of the event is participants sign up to walk / run / ride 72 kms during the month  
and get friends and supporters to sponsor them.  
You may not be able to participate yourself but please consider sponsoring one of our team  
members. Here is the link to our team:-

<https://www.thelongrun.org.au/fundraiser/nepeanbluemountainsprostatecancersupportgroupinc>

All donations are tax deductible.  
This is one of PCFA's major fund raising events of the year. Funds contribute to funding the  
ongoing research into Prostate Cancer.  
At the time of writing, donations were well over the \$1,000,000 mark.



### **Contact Us**

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Email [info@prostatesupport.org.au](mailto:info@prostatesupport.org.au)  
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Facebook ['Nepean Blue Mountains Cancer Support Group'](#)  
Postal Address  
Nepean / Blue Mountains  
Prostate Cancer Support  
Group  
P.O. Box 763  
Kingswood, N.S.W. 2747



Never in the history  
of calming down  
has anyone ever  
calmed down  
by being told to  
calm down

womenafter50.com

**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 2021"



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 2021 are as follows:-**

|  |                 |
|--|-----------------|
| <b>President :-</b>                    | David Wilkinson |
| <b>Vice President / Treasurer :-</b>   | Graeme Renshaw  |
| <b>Secretary :-</b>                    | Wayne Singleton |
| <b>Assist. Secretary :-</b>            |                 |
| <b>Librarian :-</b>                    | Bob Wittrien    |
| <b>Newsletter Editor:-</b>             | Alan Howard     |
| <b>Publicity / Web Site Manager :-</b> | Vacant          |
| <b>Promotions Officer :-</b>           | John Kemp       |

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.**

**email: [nbmpcsgnews@gmail.com](mailto:nbmpcsgnews@gmail.com)**

**Nepean / Blue Mountains Prostate Cancer Support Group Web Site [www.prostatesupport.org.au](http://www.prostatesupport.org.au)**