

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



NBMPCSG CHRISTMAS PARTY



MONDAY 21st December,2020 6pm till 8pm Weir Reserve, Bruce Neale Drive, Penrith.

Past Nepean Rowing Club. Plenty of parking.

BYO



Come join fellow members and friends. Bring your partner, bring your chair, Bring your food, bring your drink. Think Covid -19 safe. Questions? 1300 13 38 78



What's to Come

Group Meeting – Monday January 18th
This Meeting will not be held

"ZOOM" Group Meeting – Monday February 15th
Details Not Yet Available
"ZOOM" Group Meeting – Monday March 15th
Details Not yet Available
How to "ZOOM – See page 5



Our Web Site <u>"www.prostatesupport.org.au"</u> is now sponsored by the Members of Emu Plains Lions Club

NEPEAN BLUE MOUNTAINS PROSTATE CANCER SUPPORT GROUP INC PRESIDENT'S REPORT TO THE 2020 AGM for Delivery at the 2021 AGM

Greetings members and wider network.

Notwithstanding the year that we have had it is with great pleasure and pride that I present this report, my seventh as President, for the 2020 AGM.

Once again our Support Group started the 2019/20 year very successfully with good attendances at November to February meetings but then the Virus hit!

Our Christmas Party saw the new PCFA CEO Professor Jeff Dunn and his wife Professor Suzanne Chanbers join us and both had a great time. Also present was Shelley from Cancer Wellness Support and both organisations received donations from our Group.

Our February meeting featured our newly appointed Prostate Cancer Specialist Nurse Liz McKervey and it was very pleasing to welcome Liz (a long time member) in her new role.

But then Governments had started with rules about meetings and we had a very shortened meeting in March and were not allowed to share a cuppa . It was therefore decided that meetings be suspended until this virus had passed.

In April we started virtual meetings by Zoom and for the members and visitors who joined those meetings they have been presented with some wonderful speakers who we would not have had in person. For examle we had Karen from Tena in Perth speaking about Incontinence Solutions, Dr David Dandgerfield, a Melbourne Urologist speaking about Penile Rehabilitation, Brendon an Exercise Physiologist and speakers from PCFA from Sydney, Melbourne and Brisbane. Although Zoom has limitatiuions it certainly has some great advantages as well.

We intend to use Zoom from time to time at our face to face meetings so that we can access speakers some distance from us or even from abroad.

Apart from our work at The Hawkesbury Canoe Classic in October 2019 our community activities were also cancelled but it was great to be invited by Leonay Golf Club to again participate in their Charity Day for our Group in September when matters with the virus had eased a little.

Our Group has received some wonderful donations this year from Glenbrook Panthers Bowling Cub, Gaels Irish Club, Leonay Golf Club and Emu Plains Lions who now sponsor our website.

A dissappointment this year was the lack of support from members for the PCFA's fundraiser The Long Run. Altough our Group entered a team and had wonderful coverage in both the Western Weekender and the Blue Mountains Gazette support was very minimal and our goals were not met.

I know that I repeat this each year, but I believe that it is important to understand that although we have a number of new members join each year, and it is important for any group to have new members, ours membership grows through reluctant membership as all, or most of the men here, have been diagnosed with prostate cancer. We are the reluctant brotherhood. I trust that all men and their partners visiting us for the first time have found us welcoming and are encouraged by knowing that they are not alone.

The Board has decided that donations will be made this year to Cancer Wellness Support thus keeping our gold sponsorship with them and to the PCFA for research.

These donations will be in the sum of \$6,000 which is a substantial figure for a relatively small support group particularly in a year when our own fundraising activities were cancelled.

My thanks to each of my colleagues on the Board who work selflessly for the betterment of our Support Group and who, in the absence of an AGM, have agreed to serve until the 2021 AGM. Their efforts with website, awareness, publicity, money matters, library,newsletters etc certainly make our Support Group what it is and their enthusiasm and humour for its continuing success together with respectful attitudes at all meetings have made them a pleasure to chair.

I must also acknowledge my wife Jan who has assisted me tremendously in the background and I thank her for that. I also acknowledge and thank all the Board's wives for their support of our Group.

In conclusion, I look forward to a post virus revitalisation of our Support Group over the next 12 months.

With my best wishes for continuing good health and a reminder of our motto "you are not alone"

David Wilkinson

PRESIDENT

NEPEAN/BLUE MOUNTAINS PROSTATE CANCER SUPPORT GROUP INC

December 2020

From the NBMPCSG Secretary

What a dreadful year. I have no doubt we all have stories to tell about our experiences. All I'll say is that it was probably the worst year of my life!

The issue which for me dominated the year was our inability to hold member meetings; and the highlight was some very successful member's meetings on Zoom where we had some very good speakers and learned that we could source speakers from anyway – nationally and potentially internationally. It is such a pity the Zoom meetings were poorly attended but we can only do our best for our members.

Returning to face to face member's meetings

As a user of the Anglican Church Hall we are required to follow the rules and guidelines set out by the Church Wardens. I've had a number of discussions with the Church administration and we have submitted a COVID-19 Safety Plan for their agreement. The Wardens have indicated they are allowing church groups to use the hall as matters such as attendees, and cleaning arrangements are under the church control. They are nervous about third parties such as us using the hall as, although we can provide attendee details, matters such as cleaning quality are not within their control. They are therefore taking a conservative approach. Many similar hall owners are taking the same approach. At this stage I don't have a date when we might return to the hall. The Board is considering daytime meetings in a park and will assess the success of the upcoming Christmas Party before deciding on park member's meetings.

AGM Delay

We applied for an extension of time for our AGM which under our Constitution is required to be held by 31 Dec each year. We asked for an extension until June 2021 when we hoped this madness would be behind us. The Australian Charities and Not-for-profits Commission (ACNC) who administer the rules for AGMs advised that we were able to delay our AGM until the 2021 meeting (due by 31 Dec 2021) and are required to include financials for both the 2019/20 and 2020/21 at that meeting. The Board has followed this advice.

All Board members indicated they would continue until the 2021 AGM.

Board Meetings

A total of six Board Meetings were held which was the maximum number required under our Constitution. They were held by Zoom which worked well for us. We have plans to return to the Gaels Club, Penrith for our February 2021 meeting.

Wishing you all the best for the festive season.

Stay safe and well

Wayne Singleton

8 REASONS YOUR DOCTOR SHOULD REFER YOU TO AN EXERCISE PHYSIOLOGIST

During our troubled "Covid" times we have been unable to hold our 'Face to Face' monthly Meetings, but, we have been able (courtesy of ZOOM) to call on some experts who may not have otherwise been available. One such person was Brendan Cummins an

Accredited Exercise Physiologist. Brendan spoke to us at our May Meeting and is a member of ESSA (Exercise & Sports Science Australia) the peak body for Exercise and Sports Science in Australia. Here is a recent article from ESSA setting out the health benefits of exercise.

The science is clear – exercise is medicine. But many doctors aren't even asking their patients about their activity levels, much less prescribing exercise. If you want to start moving more, then it might be time for your doctor to refer you to an exercise physiologist.

SO, WHAT EXACTLY IS AN EXERCISE PHYSIOLOGIST?

<u>Accredited Exercise Physiologists</u> are university-qualified allied health professionals. They specialise in designing and delivering safe and effective exercise interventions for people with chronic medical conditions, injuries or disabilities. Services delivered by an AEP are also claimable under compensable schemes such as Medicare and covered by most private health insurers. When it comes to the prescription of exercise, they are the most qualified professionals in Australia.

Here are 8 reasons your doctor might refer you to an exercise physiologist:

1. TO IMPROVE YOUR MENTAL HEALTH

There's plenty of research that demonstrates how valuable exercise is for both improving mental health and helping to protect against mental illnesses like depression. People living with mental illness often experience additional barriers to being active. An exercise physiologists understands these challenges and is specially trained to help you overcome them. They also have the skills and knowledge to deliver safe and individualised exercise prescription for those living with conditions like depression, anxiety and PTSD.

Read more: Exercising with depression

2. TO HELP YOU MANAGE A CHRONIC CONDITION OR INJURY

Unlike other exercise professionals, exercise physiologists focus on clinical exercise prescription. Unlike, say, a personal trainer, who is trained to work with healthy populations, exercise physiologists specialise in working with those living with illness or injury. They understand the challenges and complexities associated with a range of conditions and will work alongside your healthcare team to deliver safe and effective exercise interventions.

3. TO HELP YOU TO INCREASE YOUR PHYSICAL ACTIVITY LEVELS

Exercise physiologists specialise in behaviour change. If you've ever tried (and failed) to start a "health kick" or a new exercise routine, then you know how tough it can be! An exercise physiologist can help you to make long-term lifestyle changes that you'll actually stick to.

4. TO OVERCOME PERSISTING PAIN CAUSED BY INJURY OR OVERUSE

Persistent pain (also called chronic pain) affects over <u>3 million Australians</u>. Many people living with pain avoid exercise for fear that it will make it worse. In fact, research suggests that exercise may be one of the most effective pain management techniques. But – and it's a big but – it must be prescribed by an expert! If you're living with chronic pain, seeing an exercise physiologist can often help you to get more out of life.

Read more: Five yoga poses for back pain

5. TO IMPROVE YOUR HEART HEALTH

Cardiovascular disease kills one Australian every 12 minutes and is one of the nation's biggest health issues. Research has repeatedly shown that living an active lifestyle can reduce your risk of developing

cardiovascular disease. If you have an increased risk of heart disease, either through lifestyle factors or family history, you should see an exercise physiologist to help you keep your heart healthy.

6. TO REHABILITATE FOLLOWING A CARDIAC EVENT

Many people who have experienced a cardiac event are afraid of exercising. Although exercise is beneficial, it's exceptionally important that exercise prescription is administered by an expert who is able to monitor you and ensure you're exercise safely.

7. TO CONTROL YOUR DIABETES OR PREDIABETES

Exercise helps to regulate insulin levels, which helps with management of diabetes. It can also help control weight and reduce your risk of developing comorbidities, like heart disease, that are often associated with diabetes. An exercise physiologist understands the complex relationship between exercise and insulin and will work with you and your GP to help manage your condition.

Read more: 7 facts you should know about diabetes

8. TO IMPROVE YOUR RECOVERY DURING AND AFTER CANCER TREATMENT

Every four minutes an Australian is diagnosed with cancer. Slowly, the way we approach cancer care is changing. An extensive and growing body of scientific research has established that exercise is a particularly potent medicine for the management of cancer. One recent study found that women who began exercising after a breast cancer diagnosis halved their risk of dying compared to those who remained inactive.

Exercise physiologists who specialise in oncology can help to get patients moving sooner, which helps to manage fatigue and other side effects following both chemotherapy and surgery.

Learn more: Download our free Exercise & Cancer eBook

FINDING AN EXERCISE PHYSIOLOGIST

Moving more reduces your risk of virtually all chronic conditions, improves your mood and helps you to get more out of life. Yet, less than half of all Australians get enough exercise. We get it... It can be tough! It's important to remember that there's absolutely no shame in asking for help.

If you want to get healthier and live a more active life, ask your doctor to refer you to your local exercise physiologist. <u>Alternatively, you can use this search function to find an Accredited Exercise Physiologist near you</u>.

To find the ESSA web site follow the link https://exerciseright.com.au/

(A resume of Brendan's talk to our May Group Meeting is available on the Group web site https://www.prostatesupport.org.au/presentation-at-may-monthly-meeting-on-exercise-for-prostate-cancer/

How to:"ZOOM"

- Download "ZOOM" (if you do not already have it on your computer)
 (Open your web browser and type in 'ZOOM' Select one of the available options and 'download' There is no cost involved)
 - (In order to participate, it is essential that your computer has a Camera)
- Send President David an email asking to attend
 <u>president@prostatesupport.org.au</u>
 (David is the 'Host' of the meeting and must issue you an invitation to 'attend' the
- 3. At the scheduled meeting time (6-45pm) Click on the link that David will provide (or enter the meeting code)
- 4. <u>Note:</u> You only have to 'set up' once. When you are on David's list, you will automatically receive an invitation

Harnessing the immune system to control prostate cancer spread to bone

28 April 2020

By Dr Jacqueline Schmitt - Manager, Research Programs for PCFA

In a ground-breaking discovery for men with aggressive prostate cancer, Australian scientists have found a new way to make prostate cancer cells that have spread to bone more visible, so that the immune system can more easily recognise and kill them.

The scientists found that the use of an existing drug could reprogram cancer cells to produce proteins that make the cells identifiable for targeting by immune cells. Impressively, the therapy not only blocked the growth of cancers in the bone, it also established immune memory, serving as greater protection against cancer recurrence. While further research is still needed, this approach may one day be used to make immunotherapy more effective for the treatment of aggressive prostate cancers.

Growth of prostate cancers cells in bone, known as bone metastases, occurs in up to 90% of men whose prostate cancer has become resistant to treatment. Bone metastases can occur many years after a man is first diagnosed and treated and scientists believe that these tumour growths are due to dormant prostate cancer cells or sleeping cancer cells. We have written about dormant cancer cells previously in an article called "Why cancer cells go to sleep".

It is very difficult to detect dormant cancer cells. These tumours are often small and don't produce symptoms, so patients are often unaware of them and conventional diagnostic tools are unable to "see" them. Dormant cancer cells also commonly operate in slow-metabolism mode, so even sophisticated diagnostic techniques, such as PET scans, may not pick up these tumours.

Interestingly, the real challenge lies not just in detecting these dormant cancer cells, but in stopping them from "waking up" and growing into large destructive tumours.

The project was led by scientists at the Peter MacCallum Cancer Centre, in collaboration with LaTrobe University, Garvan Institute of Medical Research and the University of Melbourne. Click here to read more about the project.

The scientists used a mouse model of prostate cancer to study dormant cancer cells in bone. In this model prostate cancer cells called RM1 cells were injected into the mice. These cells move through the blood and settle on the bones where over time they form bone metastases. Animal models like this are very important for scientists to study diseases like cancer. Before being injected into the mice, the RM1 cells were modified with a special dye system that allowed the scientists to "see" the cancer cells in bone using PET scans and differentiate dormant cancer cells from those that were growing.

The scientists were able to locate areas of bone harbouring prostate cancer cells and remove the cells to study the differences between dormant and growing cells. To do this they used a sophisticated state-of-theart single cell sequencing technique that allowed the characteristics of individual cells to be examined. They found important differences between the cells.

Prostate cancer cells that had remained dormant in the mouse bones were found to express genes that made the cells susceptible to being attacked by the mouse's immune system, but in the growing cancer cells, these genes had been switched off. Many of these genes make proteins that are part of the important type I interferon (IFN) pathway. If IFN is inactive, the immune system does not see the cell as a threat so it will ignore it allowing the tumour to continue to grow.

The scientists went on to study prostate cancer bone metastasis samples removed from men being treated for castrate resistant prostate cancer. These men generously agreed to donate samples of their cancer for medical research. The scientists compared the primary tumours removed from the prostate with the bone metastasis tumours and found that genes associated with immune response including those associated with IFN signalling were reduced in the metastasis samples compared to the primary tumour.

'The confirmation that IFN was important for outgrowth of bone metastases in men with prostate cancer prompted us to look for ways to reactivate IFN production in the actively dividing cancers,' says Dr Katie Owen from Peter Mac, who led the study.

From their observations in the mouse and human studies, the scientists hypothesised that restoring IFN function would stop the cancer cells that were growing in bone. They decided to test drugs from a family of drugs called HDAC inhibitors. HDAC inhibitors have many effects on cancer cells and make them more susceptible to being attacked and killed by the immune system.

Through a series experiments, the research team found that the HDAC inhibitor Entinostat effectively restored IFN function and prevented the growth of prostate cancer cells in bone by increasing immune signals in the cells. In the mice studies, Entinostat was found to reactivate IFN in prostate cancer bone metastases slowing their growth and increasing the survival time of the mice when compared to mice not treated with the drug.

Importantly, Entinostat treatment was seen to trigger the activation of specific T cells that can kill tumours. When the drug was combined with an immune activator bone metastasis was completely eliminated.

'We have now identified how prostate cancer cells persist in bone, by specifically blocking immune proteins that reduce their visibility to the immune system. This opens the doors for new therapeutic approaches aimed at releasing the brakes on these immune pathways to target the cancer cells for immune destruction' says Associate Professor Belinda Parker.

'Future research will confirm whether use of agents that turn on IFN signalling in prostate cancer cells, including HDAC inhibitors, can be harnessed to offer new therapeutic opportunities in men with no current treatment options to combat bone metastasis through immune signalling restoration at the tumour cell level.'

The results from this study provide important information that can be built on to develop new treatments for men with advanced metastatic castrate resistant prostate cancer.

"This is a call to action," says PCFA CEO Professor Jeff Dunn. "Deaths from prostate cancer are avoidable, and we must not slow down the pace of work until Australia's fathers and sons are saved from this disease.

"The breakthrough demonstrates the tremendous value of Australian-based prostate cancer research towards a future free of prostate cancer."

Vale Ruth Dowthwaite



Photo shows Rob and Ruth when Rob stood down from the Group Presidency in 2004

Long standing Members of the Group will be saddened to hear of the recent passing of Ruth Dowthwaite.

Ruth was the widow of Rob Dowthwaite, the inaugural President of the Nepean / Blue Mountains Prostate Cancer Support Group. (We lost Rob in September of 2012)

Rob and Ruth met in Sydney when they were both studying theology at Moore College. They went on to share nearly 53 years of marriage. They were married in Cape Town in 1958 where their three children were born while Rob was in charge of a suburban Church of England Church in that city.

Rob and Ruth are survived by their three children and their families. (including grandchildren and great grandchildren.)

Vale Robyn Yates OAM

Robyn Yates OAM, - Founder Cancer Wellness Support



We were recently all saddened to learn of the passing of founder of the Cancer Wellness Support, Robyn Yates OAM. Robyn passed away on Friday, 27th November 2020.

Robyn founded the organisation in 2005 and has worked tirelessly to achieve major outcomes for cancer wellness in the Blue Mountains and Nepean communities. With a great vision in mind, Robyn leased a space in Katoomba and opened an Op Shop to fund her work. Within days, someone had donated the contents of a late relative's home and the RSPCA gave her a cash register and shelves to sell. The word spread, the shop expanded and a second shop began successfully operating in Penrith in 2009. This community based model today, annually provides over 5,000 subsidised therapies, supporting people who are experiencing cancer, including counselling, lymphoedema management, massage, yoga and art therapy.

In 2015 Robyn's work was recognised with the Order of Australia Medal "for service to community health through support for people with cancer". In an interview with the Blue Mountains Gazette in recognising Robyn's OAM, she said, "The thing that really floats my boat is when I see a person transformed from someone who is anxious and vulnerable when they come in the door. And then, when they start accessing our services or going to groups, they regain control and confidence and can actually see a future for themselves. Blue Mountains Cancer Help tries to offer a sense of hope. It's empowering to discover there are many things you can do to improve your healing capacity."

On the 11th May 2020, with Robyn in attendance, Cancer Wellness Support celebrated 15 years in operation with the vision being to provide affordable, subsidised therapies to people living with cancer, their carers and families throughout the Blue Mountains and Penrith Valley regions. As a celebration of this milestone, the Leura Centre, was named the Robyn Yates Centre. Cancer Wellness Support recognising the outstanding achievements of Robyn in establishing and expanding this vital community organisation that support people undergoing treatment and living with cancer.

Robyn's funeral was held in early December. Robyn requested no flowers, but you may consider making a donation to the Robyn Yates Memorial Fund <u>here</u>.

(The Nepean / Blue Mountains Prostate Cancer Support Group is a gold sponsor of the Cancer Wellness Support)

A Laugh at Life!

Early Morning Shopping

When we went in to 'Covid' lockdown, many shops created an early morning 'Seniors Only' shopping session.

This started at 8.00am.

Apparently this incident occurred at 7.45 one morning.

People were waiting outside the shop when a young man came from the parking lot and tried to cut in at the front of the queue. A little old lady beat him back into the parking lot with her walking stick The young man returned and tried to cut in again. This time an old man punched him in the gut, kicked him to the ground and rolled him away.

As he approached the line for the third time he shouted out:

"If you don't let me unlock the door, none of you will be able to get in!" ******

The mouths of babes....

A little girl was sitting next to her Grandfather as he read her a bedtime story. From time to time she would take her eyes off the book and reach up and touch his wrinkled cheek. She would touch her own cheek after touching his. After a few moments of thinking she asked "Grandpa, did God make you?" He looked at her and said "Yes sweetheart, God made me a very long time ago." She paused for a few seconds and then asked "Grandpa, did God make me too?" He replied "Yes, indeed pumpkin, God made you just a little while ago." Feeling their respective faces again she whispered "God's getting much better at it isn't he?"

Cake or Bed

A husband is at home watching a football game when his wife interrupts, "Honey, could you fix the light in the hallway? It's been flickering for weeks now."

He looks at her and says angrily, "Fix the lights

Does it look like I have General Electric written on my forehead?

I don't think so."

"Fine," she says

Then the wife asks, "Well then, could you fix the fridge door? It won't close right " To which he replied,

"Fix the fridge door? Does it look like I have Westinghouse written on my forehead? I don't think so."

"Fine," she says

"Then you could at least fix the steps to the front door?

They are about to break."

"I'm not a carpenter and I don't want to fix steps," he says, "Does it look like I have Mitre 10 Hardware written on my forehead?" "I don't think so.

"I've had enough of you. I'm going to the pub!!!!"

So he goes to the pub and drinks for a couple of hours.

He starts to feel guilty about how he treated his wife, and decides to go home.

As he walks up to the house he notices that the steps are already fixed.

As he enters the house, he sees the hall light is working.

As he goes to get a beer, he notices the fridge door is fixed.

"Honey," he asks, "How'd all this get fixed?" She said, "Well, when you left I sat outside and cried. Just then a nice young man asked me what was wrong, and I told him. He offered to do all the repairs, and all I had to do was either go to bed with him or bake a cake."

He said.

"So what kind of cake did you bake?"

She replied,

"Hellooooo..

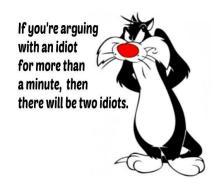
Do you see Sara Lee written on my forehead? a I don't think so!"

A new teacher was trying to make use of her psychology courses, she started her class by saying, "Everyone who thinks they're stupid, stand up!"

After a few seconds, Little Johnny stood up.

The teacher said, "Do you think you're stupid, Little Johnny?"

"No, ma'am, but I hate to see you standing there all by yourself!"



Contact Us

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<u>PAYMENT OF Membership Fees</u>. 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 deductable.

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 2020 are as follows:-

President:- David Wilkinson
Vice President / Treasurer:- Graeme Renshaw
Secretary:- Wayne Singleton

Assist. Secretary :-

Librarian:- Bob Wittrien
Newsletter Editor:- Alan Howard
Publicity / Web Site Manager:- Misel Hader
Promotions Officer:- 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

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

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