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

March – May, 2024

Are Support Groups Still Relevant?

Vol. 23 No. 2

I would like to stress that these are my personal thoughts and I am definitely not speaking for the Group Board

There are a number of reasons for this question.

Firstly, there is a tremendous amount of good information available on the internet.

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The Prostate Cancer Foundation of Australia web site, in particular, has a huge amount of information. (pcfa.org.au)

The establishment of Prostate Cancer Specialist Nurses in major areas is a fantastic initiative The 'Telenursing' service is a great asset available for all men. (ph 1800 22 00 99)

There is a 'Facebook' page 'Prostate Cancer Support Australia' where men can share their experiences and information with others no matter their location.

So, with all of these services available, why join a Support Group?

A Support Group will give you face to face, human contact!

Rather than sit alone at a keyboard internalising your fears and anxieties, you can speak with other men that, in all probability, may have experienced the stresses you are going through. Friendships are formed. Partners are included, and, as our Group motto says,

You are Not Alone!

So, in answer to my original question

'Are Support Groups still relevant' YES! MOST DEFINITELY!

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What's to Come

Group Meeting – Monday March 18th Liz McKervey Prostate Cancer Specialist Nurse Group Meeting – Monday April 15th To Be Advised

Group Meeting – Monday May 20th 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 <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 2023 AGM

Greetings members and wider network.

Notwithstanding another challenging year that we have had I present this report, my tenth as President, for the 2023 AGM.

My thanks to Emu Sports Club who again allowed us the use of the room that we are in free of charge. Members are very happy with this location as they can enjoy a bistro meal and a drink before or during the meeting. Emu Sports Club Membership is only \$6 per annum and discounts on meals and drinks more than cover that cost.

Unfortunately, neither my wife Jan or I were unable to attend the 2022 AGM and Christmas luncheon as we both had Covid 19 at that time.

I am told that it was a very enjoyable luncheon, a Committee was elected and Chris Kemp received a Life Membership for her support of our Group over many years. Congratulations Christine. Also at that Christmas Luncheon our annual donations were made to Cancer Wellness Support and to PCFA. Appreciation Certificates were given to Terry McCallum representing Masonic Care for their donation to our Group and to the Hon Jim Lloyd who had recently retired from PCFA for his personal support of our Group.

In my absence the Board had also decided to award Life Membership at the AGM to Jan and myself for our support of the Group since our joining in 2011. However, due to Covid we were unable to attend and Vice President Graeme presented us with our Life Membership at the March meeting as we travelling over the February meeting. We are very humbled and grateful for this recognition of our support for this Group.

2023 provided us with some highs and lows.

It was very disappointing that our traditional Bunnings sausage sizzle on the Saturday before Father's Day was cancelled due to a lack of support from the membership. This was to be our major fund raiser and its cancellation has certainly affected our financial position.

Our only fundraising activity this year was the Hawkesbury Canoe Classic and our involvement in the scrutineering saw us receive a donation of \$1,000. My thanks to our members who volunteered on that day and to HCC for inviting our Group to scrutineer once again.

However, Emu Plains Lions Club has continued its sponsorship of our website and we are very grateful to them for that and PCFA reimbursed the Group for the costs of running the 2023 Awareness Night in Prostate Cancer Awareness Month of September.

Highlights were an amazing selection of speakers who presented during the year. These included a Functional Urologist who, I am told, held our members spell bound during her presentation, A Yoga expert who presented on Chair Yoga, four Clinicians who presented at our Prostate Cancer Awareness night in September and a local doctor who presented his invention – The Widdleometer – that measures urine flow.

September was our Premier Meeting for the year being an Awareness Evening that featured a Urologist, Radiation Oncologist, Medical Oncologist (and Director of Nepean Cancer Care Centre) and our own member Liz McKervey our local Prostate Cancer Specialist Nurse.. The Meeting was well attended and finger food, tea and coffee, sponsored by the Prostate Cancer Foundation of Australia was enjoyed after the meeting.

Unfortunately, due to the small numbers of members attending the Group meetings it is rather embarrassing to have a great speaker turn up to a small audience. Consequently, we have had a number of open forums and those new persons or visitors attending get optimism from the experiences of other members particularly survivors of many years. Just a note to new members – if you found our Group meeting gave you some comfort, your story will be of great comfort to newly diagnosed men and their partners who would love to listen to your stories of recent treatment. Please continue to attend our support group meetings when you can.

Our Group was again represented at Relay for Life and in the PCFA's Long Run and although support was very minimal from members and network, we managed to raise some money that the Cancer Council and PCFA would not otherwise have had.

During this year the Group also represented itself or PCFA at the Bathurst 12 Hour Sports Car Race, Shannons Sydney Classic, the Regional Support Groups Conference at Dubbo, Clarendon Classic Machine Truck Toy and Hobby Show Sydney German Autofest (over 600 German cars on display), Penrith Relay for Life and the Hawkesbury Canoe Classic.

Craig Lowndes is the driving force behind PCFA's participation at Bathurst and he is a wonderful Ambassador for PCFA and his car was painted in PCFA colours

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, our 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.

My thanks to each of my five colleagues on the Board who have worked selflessly for the betterment of our Support Group. My thanks to them for also for putting their hands up to serve in 2024. A quorum at our Board Meetings is five and these are held at 4 30pm on our Group meeting night. If two members are absent then a Board Meeting cannot be held and this happened on a number of times in 2023 but our Secretary ensured that the requirements of our constitution were met in respect of numbers of meetings held.

I encourage all members to consider nominating for the Board as our Board Meetings are now held, as mentioned before, prior to the Monthly Group Meeting and last less than an hour. **New nominations are welcome as new faces bring new ideas.**

The Board looks after awareness, publicity, money matters, library, newsletters website, Facebook etc and certainly make our Support Group what it is. Their enthusiasm and humour for its continuing success together with respectful attitudes at all meetings have made them a pleasure to chair.

This year our website was rewritten by a non member, Penny Sheridan who volunteered in discussion with our Web Manager John Parsonage, to rewrite the website for us. Our group is most appreciative of Penny's efforts and thanks her very much. I will call Penny at the end of the meeting to receive a token of our appreciation.

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. Without our ladies and those of our member survivors the Group would be a much lesser entity.

In conclusion, I again look forward to continuing a post virus revitalisation of our Support Group through the continuation of face-to-face meetings over the next 12 months.

With my best wishes for a Merry Christmas, Happy, Prosperous but most importantly a healthy New Year and a reminder of our motto "YOU ARE NOT ALONE"

David Wilkinson **PRESIDENT** NEPEAN/BLUE MOUNTAINS PROSTATE CANCER SUPPORT GROUP INC **18 December 2023**

New Aussie app for men's health

Around 250,000 Australian men impacted by prostate cancer are set to benefit from a new app designed to eliminate confusion about the disease and its treatment.

The online web app has been created by Prostate Cancer Foundation of Australia, giving men and their loved ones access to evidence-based information, advice and expert nursing services.

PCFA Chief Executive Anne Savage says it is hoped the launch of the Survivorship Toolkit will save many lives.

"Men often feel isolated when they are diagnosed with the disease. Until now, the information has been hard to find in one place. Our Survivorship toolkit will change that, becoming the first in Australia to be the single source of expert information to help men navigate their diagnosis and treatment,"

PCFA CEO Anne Savage says.

"With 1 in 5 men likely to be diagnosed with the most common cancer in Australia, the Toolkit marks a new era of support, separating fact from fiction. Designed to address the individual needs of those impacted, the toolkit covers the continuum of cancer care, from diagnosis to life after treatment."

"From testing to diagnosis, what the different stages and the treatment options are, as well as mental health and wellbeing support, including for men with advanced stages of the disease, providing men with access to vital information and resources. We know that awareness levels of prostate cancer in Australia are low, which often makes diagnosis and treatment that much harder," says Ms Savage. "The Survivorship Toolkit puts complex concepts into easy-to-understand terms, making it easier for men and their families to make decisions about their diagnosis and treatment."

The website also covers treatment side effects. "Prostate cancer treatment can result in lifelong side-effects, which means we must support patients and offer specialised care well beyond their initial treatment," she says. "Our Toolkit helps to debunk myths and misconceptions about living with prostate cancer, providing guidance on health and fitness practices that aid in recovery. This new Toolkit is one more weapon in our armoury to defeat prostate cancer."

The Survivorship Toolkit offers specialised support for recurrent or advanced prostate cancer, ensuring that no man faces this terrible journey alone. The website also includes information on supporting health and wellbeing, access to PCFA Nurses, and connection with support groups around Australia.

Here is the link to access the tool kit.

Prostate Cancer Survivorship Toolkit.

Australia's first living lab to beat deadly prostate cancers

Australian researchers are among the first scientists in the world to establish a living lab to help find new treatments and therapies for deadly forms of prostate cancer.

The ground-breaking project, funded by the Prostate Cancer Foundation of Australia, aims to help end Australian deaths from the disease.

Seed funding has been provided to establish the national consortium, with hopes of raising significantly more from community donations as part of Prostate Cancer Foundation of Australia's annual Christmas appeal.

The lab will expand on the capabilities of the Australian Prostate Cancer BioResource, a national collaboration currently managed by Monash University.

The existing biobank will be enriched by the inclusion of specimens and data from individuals with advanced metastatic disease, and will for the first time include unique collections of patient models of prostate cancer.

These precious resources will then be available for access by prostate cancer researchers around the country.

PCFA's Chief of Mission and Head of Research, Professor Jeff Dunn AO, hailed the project a game changer for men with advanced prostate cancer.

"The living lab will accelerate medical and scientific research and transform our ability to analyse deadly tumours and test new methods for preventing and eliminating prostate cancer."

The lab has been given the acronym ALLURe, short for the Australian Living Lab for Urological Repositories.

"This will be a world-leading biorepository of metastatic prostate cancer and will allow us to closely study and experiment with metastatic prostate tumours to try and unlock new ways of defeating the disease," Professor Dunn said. "Importantly, it will allow us to break down the barriers to survival, providing us with a platform to amass population-wide data to eliminate sampling bias that often arises due to inequities in care. The project is exciting for many reasons, including the fact that the platform will enable tissue samples and test results to be uploaded and shared across the research community, allowing scientists to work together nationally and globally to find solutions for one of the leading causes of cancer death among Australian men. We urgently need donations from individuals and businesses to help mobilise Australia's research community in the fight against prostate cancer," he said.

Around one in five Australian men will be diagnosed with prostate cancer in their lifetime, with 250,000 men alive today after a diagnosis of the disease.

Leading project proponent and world-leading prostate cancer researcher, Professor Lisa Butler, said the lab would spark a revolution in research. "We are confident the lab will accelerate research discoveries and result in new clinical trials that can be made available to patients more rapidly than ever before, extending and saving men's lives," Professor Butler said. "The lab will give researchers access to high-quality living or preserved tissue and blood samples allowing researchers to access and compare hundreds of thousands of pieces of clinical information for the very first time. If we are successful in our fundraising target to build the lab, Australia will stand at the forefront of worldwide research into prostate cancer, powering discoveries around the globe."

It is hoped the project will unlock discoveries that have the power to end deaths from prostate cancer within a decade.

"Until now, Australia has lacked a national repository for metastatic prostate cancer specimens, clinical data and lab-ready models," Professor Butler said. "Thanks to this seed funding, all that will change, putting us on a path to find the answers we need to solve the puzzle of prostate cancer.

"Every researcher in Australia will have the opportunity to access the lab's data and specimens, strengthening our ability to synthesise medical and scientific investigations.

"Our hope is to unlock new precision medicines, allowing the development of therapies that are tailored to each patient, extending and saving lives. "We call it a living lab, and for good reason – its role is to keep men alive," Professor Butler said.

Go to https://www.pcfa.org.au/LivingLab to donate.

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Leonay Golf Club - Charity Golf Day – February 2024



Leonay Golf Club in conjunction with the Emu Sports club held a Charity Golf day for the benefit of our Support Group.

158 members of Leonay Golf Club participated on the day and a raffle was also organised.

Members of our Group (David, Wayne, John K. and Denis –

the 'usual suspects'!) were on hand all day to sell raffle tickets and also 'wave the flag' to promote Prostate Cancer awareness.

Prizes for the raffle were donated by Corey Fletcher from the Stonecutters Ridge Golf Club, Ben Breckenridge Golf Pro at Leonay Golf Club, Corey Fletcher from Emu Sports Club.

Many thanks also to Les Knox from Leonay Golf Club and other members of the organising committee.

Money raised from Members Fees and the raffle totalled \$2500.00

2023 A.G.M. and Christmas Party.

The Group once again decided to hold a combined AGM and Christmas Party

This was held at our regular venue, the Emu Sports Club.

The formalities of the AGM were quickly dealt with. All existing Board Members agreed to step up for re-election. Thank you David, Graeme, Wayne, John P, John K and Alan. We would like to welcome to the Board, Ron Gibbins who stepped up to join the Board. Thank you Ron.

Donations of \$1000.00 were made to Cancer Wellness Support and also the PCFA. Appreciation Certificate were also presented to Penny Sheridan for the work she done for us in creating our new web site and to Peter Murphy (Finally !!) for his efforts previously as the group 'Web Master'









In old English pubs, ale was ordered by pints and quarts... So in old England , when customers got unruly, the bartender would yell at them 'Mind your pints and quarts, and settle down.'

It's where we get the phrase 'mind your P's and Q's'

Planned Awareness Events for 2024

We may be in a relative 'quiet time' but John Kemp has been busily working in the background.

John has come up with a preliminary list of awareness events that we will be attending this year.

Here they are:-

Bunnings Father's Day BBQ

Saturday, August 31st, 2024 Bunnings South Penrith. (There may be other events at Bunnings throughout the year that we may be invited to attend. We will keep you 'posted')

Antique Machine Toy and Hobby Show

Saturday 21st and Sunday 22nd September, 2024 Hawkesbury Showground

Warragamba Damfest

Sunday, October 20th, 2024 Warragamba Showground

Hawkesbury Canoe Classic

Saturday, October 26th, 2024 Macquarie Park Windsor

You have possibly noticed that the Penrith Relay for Life is not included on this list. Two reasons. The support for the Relay from Group Members over the last couple of years has been very poor and secondly the Relay this year will be held on October 26th. The same day as the Hawkesbury Canoe Classic!

This is a very early Notice for these events. Start organising your diaries and see if you can assist.

Further information will be made available closer to the dates.

We will need plenty of commitment especially for the Bunnings Day and the Canoe Classic.

There may well be other events coming up. We will keep you up to date!

Q. If you were to spell out numbers, how far would you have to go until you would find the letter 'A'?
A. One thousand !
(Just had a thought, what about One Hundred **A**nd One etc)

A Laugh at Life !

Married Life

Three men were sitting together bragging about how they had given their new wives duties.

Terry had married a woman from Greece

He bragged that he had told his wife she needed to do all the dishes and housework. He said that it took a couple days but on the third day he came home to a clean house and the dishes were all washed and put away.

Jimmie had married a woman from Italy

He bragged that he had given his wife orders that she was to do all the cleaning, dishes, and the cooking. He told them that the first day he didn't see any results, but the next day it was better. By the third day, his house was clean, the dishes were done, and he had a huge dinner on the table.

The third man had married a Australian girl

He boasted that he told her that her duties were to keep the house cleaned, dishes washed, laundry and ironing twice a week, lawns mowed, windows cleaned and hot meals on the table for every meal.

He said the first day he didn't see anything, the second day he didn't see anything, but by the third day most of the swelling had gone down and he could see a little out of his left eye, just enough to fix himself a bite to eat, load the dishwasher, and call a handyman.

"I'm fine thank you"

by Gladys Jessie Farrow

There's nothing the matter with me, I'm as healthy as I can be I have arthritis in both knees And when I talk. I talk with a wheeze My pulse is weak and my blood is thin But I'm awfully well for the shape I'm in.

Arch supports I have for my feet Or I wouldn't be able to be on the street Sleep is denied me night after night But every morning I find I'm alright My memory's failing my heads in a spin But I'm awfully well for the shape I'm in.

The moral is this, as my tale I unfold That for you and me who are growing old It's better to say "I'm fine" with a grin Than to let folks know the shape we are in. How do I know that my youth is all spent? Well my "get up and go" has got up and went.

ON BEING OLD.

'OLD' IS WHEN ... Your friends compliment you on your new alligator shoes and you're barefooted.

'OLD' IS WHEN ... You don't care where your spouse goes, just as long as you don't have to go along.

'OLD' IS WHEN You are cautioned to slow down by the doctor instead of by the police

'OLD' IS WHEN ... 'Getting lucky' means you find your car in the car park.

'OLD' IS WHEN ... An 'all-nighter' means not getting up to use the bathroom.

AND

'OLD' IS WHEN ... 9 You are not sure these are jokes?

God Bless Australian Women



<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 2024"



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 2024 are as follows:-

President :-Vice President / Treasurer :-Secretary :-Newsletter Editor / Publicity:-Web Site Manager :-Promotions Officer :-Board Member David Wilkinson Graeme Renshaw Wayne Singleton Alan Howard John Parsonage John Kemp Ron Gibbins

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

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This newsletter has been compiled by Alan Howard from material culled or provided. email: <u>nbmpcsgnews@gmail.com</u>

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