



Below the Belt!

Vol. 17 No. 1

December 2017– February, 2018

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



**The December Group Meeting
Monday, December 18th
is**

Venue:

Church Hall
Rear of St Stephen's Church
High St, Penrith.

(Our usual Meeting Place)
Commencing 6.30 - 7.00

Food, Soft Drinks and Music
Provided

(Please Note:
Because of Church Policy No Alcohol is
permitted)

**Christmas
Party Time!**



What's to Come

Group Meeting – Monday December 18th

Group Christmas Party
(But you already knew that!)

Group Meeting – Monday January 15th

Open Forum
Topics of Interest to Members

Group Meeting – Monday February 19th

Kath Edwards – Therapist with Cancer Wellness Support
Relaxation and Meditation

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

Why do we become involved with Support Groups?

(A 'Rant' by the Editor!)

When we are first diagnosed with a potentially life threatening disease such as Prostate Cancer we are immediately thrust into a strange and confusing space.

Why me? What does this mean to me, my Family, my friends? What are my treatment options, Will I get through this? We immediately start searching for answers, these days we usually consult 'Dr. Google' (I know I did! - this can be both a help and a hindrance.) You become overwhelmed with information.

You need help and support!

Then you find out that there is a Support Group in your area. So you make contact. Can't hurt can it? (and it might be of some benefit.) So you attend a meeting. There you find men (and their partners) who have been through (or are going through) what you are experiencing. The members have usually had a range of different treatments, one of which you may be contemplating. They can give you details of their experiences. Your Specialist can tell you the 'nuts and bolts' of the treatment but these men have been there and done it, they can tell you from the patients point of view. There may have been a guest speaker at the meeting from whom you were able to gain some more valuable information. Armed with information and the realisation that your diagnosis and likely treatment although serious and may not be without potential problems, but it does not mean the end of the world. So you make your decision and have your treatment.

What then? Did it go well? We are all different, so how we heal and recover is all different. You may be having some problems. Continence is one area where men experience a range of results. So you attend a few more meetings and discuss with other men how they overcame similar problems to yours.

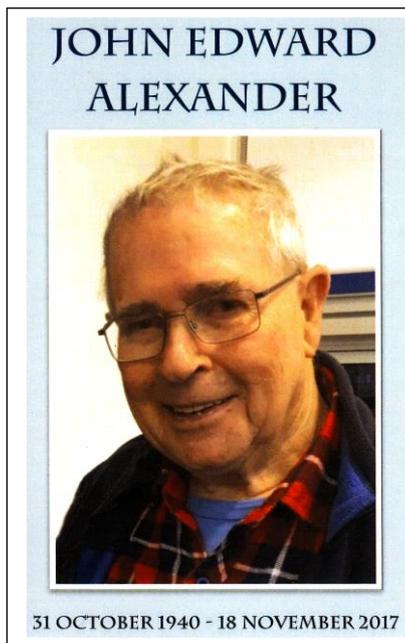
So let's assume that you've recovered and things are back to 'normal' (Mind you 'normal' is probably a bit different to what it used to be!) But you're basically feeling 'OK' Do you just drift off back to your life. You don't need the Support Group anymore. *(Gee I wish they would stop pestering me with emails about meetings or awareness events or the new and latest treatments. They don't interest me, I'm OK!)*

Or do you realise that this Group was there to offer support to you when you needed it so you continue to 'support' the Support Group. They're a pretty good bunch of people and good company, so you decide to continue to attend meetings. At the next awareness event you decide to help out even if only for a few hours. You enjoy the involvement, (you may not have even realised that you could cook a 'Bunnings' sausage sandwich!) At the next meeting they are asking for committee members, Why not? You can help keep the Group running so that newly diagnosed men (Just like you were at the start of this 'journey') can have the Support that you enjoyed.

Which group do you fit into?

Alan Howard
Newsletter Editor

Vale John Alexander



We were all shocked at the recent passing of our friend and fellow Group Member, John Alexander.

John was born in Parramatta being one in a family of four. The family moved to Bungendore and later to Campbelltown and then Fairfield where his father ran the bakery in these places. The family then moved on to Plumpton where they took on the running of a piggery.

John worked hard at the pig farm, and as a 15 year old would often drive a truck into the city collecting food scraps from the restaurants to feed the pigs.

John married and he and his wife Carolyn had six children (5 girls and 1 boy) John and his family then moved to the Central Coast where they bought a milk run. This milk run was sold and the family moved back to Sydney's Western Suburbs where they acquired another milk run. John later became a bus driver working in this industry for 30 years driving for various well known local companies.

John was also a keen Rugby League referee. These activities were curtailed in 1985 when John needed heart surgery to have a heart valve fitted.

30 years ago John met his second wife, Rhonda. With Rhonda's two boys. John's family now numbered 8 children. These children went on to present him with 19 Grandchildren! After retirement, John and Rhonda took to travelling and went on a number of overseas trips and cruises.

John also became more involved with his church and the Retired Men's Club and Probis. He and Rhonda were also heavily involved with the St John's Ambulance organisation.

Of course it was through their involvement with the Support Group that we all came to know John and Rhonda.

I have fond memories of the Group Meeting when John and Rhonda gave a talk on First Aid. Rhonda was the main speaker with comments from the 'sideline' from John, usually witty and funny but always on topic.

John joined the Board of the Support Group becoming our Membership Coordinator. John also took on the task of Liaison Officer, John would contact members who were usually regular attendees of our meetings but who had not attended for a time, just to check that they were 'OK'

John often participated in our Awareness activities. He manned (on his own!) the information desk at our recent Bunnings BBQ event.

John was also an appointed 'Ambassador' for the Prostate Cancer Foundation.

John was an extremely popular member of our Group. His amusing (and usually loud!) greetings when he arrived at Group Meetings will be sadly missed.



Vale Jim Anderson

While we were coming to terms with the loss of John Alexander we learnt that another popular and well liked member of the Group had passed away. Jim Anderson died on the 29th of November. Jim, together with his wife Sheryl, have been active members of our Group since the beginning.

I will include a full tribute to Jim in our next issue.

NEPEAN BLUE MOUNTAINS PROSTATE CANCER SUPPORT GROUP INC PRESIDENTS REPORT TO THE 2017 AGM

It is with great pleasure and pride that I present this report to our members at the 2017 AGM.

In my report at the 2016 AGM I noted that after unanimous agreement by the Board Mr Tony Sonneveld OAM, a member of our Support Group and tireless worker for PCFA until deteriorating health forced his retirement, was asked to accept the honour of being our first Patron. Tony did so but unfortunately his health deteriorated and Tony passed in November 2016. Our Group lost a great man and I personally lost a mentor who became a good friend.

One of our founding and life members was later asked to accept the role of Patron and the Board was very pleased that Mr Alan Moran OAM accepted that invitation with his usual enthusiasm with all things prostate. Congratulations Alan and we look forward to Alan's wise counsel and vast experience over the years ahead.

After many years in the same meeting room our comfort was disrupted during 2016 when we changed meeting rooms to the Theatre on Level 3 Nepean Hospital. This room allowed easy access for those not as mobile as others and we were grateful to Nepean Hospital for providing this room to us.

However, in late 2016 we were advised that with the Nepean redevelopment our last meeting in that room would be in December 2016 and that there would be nothing really suitable for us at Nepean Hospital during the time of the redevelopment.

The Board began looking at alternative sites and thanks to the Nepean Men's' Shed we were offered their shed and held our first meeting there in January 2016. However, it became apparent that without suitable heating and cooling the venue was not suitable for us and so the venue seeking process was on again.

Secretary Ross recommended that the hall at the rear of St Stephen's Anglican Church in High Street Penrith would be most suitable and after a site visit the Board agreed and a 12 month contract was entered into with the Church. This venue is most suitable for our needs being on level ground with easy parking and all facilities required by us. Its only drawback was that for the first time in our Support Group's history we had to pay a rental fee for the use of the room. PCFA offered to meet that cost for us and we thank them for their assistance in that regard.

Once again our Support Group has had a very successful year as demonstrated by the attendances at our meetings, the quality speakers we have had, the community activities that we have been involved with, the donations that we have received and the fund raising that we have done. My thanks to all our members and their friends who helped at any of our community days.

Our website has also grown and is a great resource for our members and wider networks. Thank you to our webmaster Peter for his continuing commitment to making this website work. While it is not used by the members to the level that we would like, the Board considers that if the website saves just one man a year then it is worth the money that is spent on it.

We have had a number of new members join this year and while it is important for any group to have new members, ours grows through reluctant membership as all, or most of the men here, have been diagnosed with PCa. 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.

During this year our membership has continued to serve its communities through various awareness and/or fund raising events such as Bunning's Sausage Sizzles, The Cancer Wellness Support (formerly The Nepean Valley/Blue Mountains Cancer Help) Sunshine Day, the Hawkesbury Canoe Classic, Dragons Abreast (and we thank PCFA For their support of this activity), the Cancer Council Penrith Relay for Life, Australia Day Celebrations at Glenbrook Park and the Health Tent at Hawkesbury Relay for Life. We also represented the PCFA at the inaugural Diesel Dirt and Turf Expo with PCFA's new partner New Holland. My thanks to all members who chose to give some time at any of those activities. Your assistance, even if only for one hour,

means that someone else can have a break, and without sufficient volunteers we would have to cancel our participation in events such as we reluctantly did with the Barry Sheen Festival of Speed. At our monthly meetings we have had some outstanding speakers who have covered many topics of interest such as radiation oncology, the author of the book An ABC of Prostate Cancer Today (Second Edition), a lawyer speaking on recession planning, wills etc., an exercise physiologist, and a talk and demonstration of Qi Gong. As well as the guest speakers there were three open forums where the men and ladies met separately so that each could pursue their own secret business. At our July forum we had a stress less coach and she has been invited back next year as a guest speaker.

We have received a number of donations this year and these are used within our local community and also for administrative costs associated with printing and postage, website, 1300 number and D and O insurance. Donations were received from the Glenmore Heritage Valley Veteran Golfers, the Hawkesbury Canoe Classic, the Gaels Club, the Glenbrook Panthers Bowling Club, PCFA with our meeting venue costs, and personal donations from L Simpson, Michael Boyle, Mrs Ruth Dowthwaite, Alan Howard and Eric Kent.

The Board has decided that donations will be made this year to Nepean Valley/Blue Mountains Cancer Help thus keeping our gold sponsorship with them, to Palliative Care Hawkesbury Hospital and to the PCFA for research. These donations will be around \$10,000 but final figures will not be known until invoices are received from the palliative care donation.

My thanks to each of my colleagues on the Board who work selflessly for the betterment of our Support Group. Their efforts with website, awareness, publicity, money matters, 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.

Special thanks to retiring Vice President Tom Walsh who has very competently stepped up during my travels this year. Tom has been of great support to me and the Support Group as Vice President and I thank him for his service over the last three years.

I must say that I am disappointed that Tom is not continuing but I respect his decision and wish him well with his new photographic ventures. Thanks also to John Alexander, who will not renominate this year, for his dedication to the Board over several years.

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 wives for their support of our Group and also the members who assist with supper at monthly meetings.

In conclusion, I look forward to continuing success with our Support Group over the next 12 months and beyond and subject to your consideration, and acceptance of my absence during planned travels in 2018, I offer myself for re-election as your President.

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
16 October 2017



2017 Annual General Meeting

Our recent October Group Meeting was once again our Group Annual General Meeting. At the meeting all Board positions were declared vacant and a new Board elected. While the meeting was successful it was disappointing in the fact that we were not able to fill all Board positions. The vacant positions are Vice President, Membership Coordinator and Publicity Officer. All other positions were filled by the present incumbents. (See Page 10 for the full list) In accordance with our Group constitution these vacant positions can be filled at any time. Are **YOU** Interested???

Surgery isn't the only option for prostate cancer yet many men aren't offered others



At our September Group Meeting, we were privileged to have Assoc. Professor Sandra Turner as our Guest Speaker. Assoc. Professor Turner is a Senior Radiation Oncologist, Crown Princess Mary Cancer Centre at Westmead Hospital and an Associate Professor, University of Sydney.

She spoke to us about the many recent advances in Radiation Treatment for Prostate Cancer.

A/Prof Turner recently published an article on alternative treatment for Prostate Cancer. That article is included below:

Australian men with a recent diagnosis of prostate cancer that require active treatment, as opposed to careful monitoring, are often not given all the options available to them. This means not all men are getting the necessary information and support to make a decision on what treatment is best. A growing body of evidence and treatment guidelines support the fact that less invasive radiation therapy is equally effective in curing or controlling cancer as surgical removal of the prostate, known as radical prostatectomy.

While all patients see a urologist - the specialist surgeon who does the biopsies and gives the diagnosis - they only see a radiation oncologist if the urologist or GP refers the man on. In this way, the urologist is the gatekeeper to men receiving optimal (or sub-optimal) care. The fear of cancer and a natural emotional response to get it out may lead to a less than fully-informed decision for surgery, and to possible regret of this decision later on.

Bias in medicine is a reality, and it is not surprising doctors favour familiar treatments. But it is problematic when bias creates a hurdle to men getting accurate, balanced information. There is plenty of evidence men aren't getting the chance to hear about their radiation therapy options. A recent US study found that men seeing both a radiation oncologist and urologist were six times more likely to choose radiation therapy compared with men seeing only a urologist.

In Australia, the proportion of men receiving radiation is much lower than research on effectiveness of radiation therapy would predict if men with prostate cancer were exhibiting truly informed choice. Meanwhile, prostate surgery rates are higher and continue to rise, especially in the case of robotic surgery.

The gold standard of care

The gold standard of care for prostate cancer begins with the patient and his support person talking with the experts – the surgeon (urologist), a radiation oncologist and a specialist nurse. In doing so, the man is provided with the relevant information and impartial advice he needs to make an informed decision about his preferred treatment.

Virtually all specialist doctors who treat cancer profess to be part of a multi-disciplinary team that includes surgeons, medical and radiation oncologists and other experts, and attend meetings where the relevant health professionals discuss patient “cases” to decide on management. These team meetings are valuable, but they are only one aspect of a high quality service. Meetings do not include the patient, the man with prostate cancer, who is integral to the decision-making process.

The multi-disciplinary team model has been successful in the treatment of breast cancer. There is nearly always more than one good treatment option available for men with prostate cancer, sometimes several. For men with low risk cancers, many may not require active

treatment up front (or ever) and are appropriately managed by active surveillance or careful monitoring.

But other men with prostate cancer require active treatment to reduce the chance of dying, or suffering symptoms, from cancer. Alternative treatment pathways are very different for the individuals involved, in terms of patient experience, potential side-effects, the need for additional treatments, and potential out-of-pocket costs. This is why the man with prostate cancer has to be the most important member of the team who decides on the treatment.

Putting the patient at the centre

Only the patient can weigh up the trade-off between the risk of bowel problems (with radiation therapy) and the risk of urinary incontinence (with surgery). Likewise, the choice between attending the cancer centre for radiation treatment every weekday over several weeks versus hospitalisation and time off work for recovery after surgery. There are many other pros and cons that may sway a man to prefer one approach over another.

As already mentioned, the ideal model for decision-making for prostate cancer treatment is that the man has a consultation with a urologist and a radiation oncologist. As the two types of prostate cancer specialists have distinct expertise in different areas, seeing both is the only way men can get complete, up-to-date information.

The man can then consider his options and discuss these with his family and GP if he wishes. The good news is that men can take time to do this, as most prostate cancers are relatively slow-growing.

In the United Kingdom, Canada, and select centres including some in Australia, prostate cancer teams do place the man at the centre of decision-making. But this must become the rule rather than the exception and Australian men should be strongly encouraged and assisted to see all experts.

Ultimately, men need to be empowered in their decision-making through being part of a process that enables and supports them in making fully informed choices. Until then, men who require active prostate cancer treatment need to insist on seeing all the specialists in the area, including a radiation oncologist.

A/Prof Sandra Turner

*Senior Radiation Oncologist, Crown Princess Mary Cancer Centre at Westmead Hospital,
Associate Professor, University of Sydney*



John Kemp – Life Member

At our recent A.G.M. our hard working Promotions Officer, John Kemp was granted a 'Life Membership' of our Group.

John's passion is promoting awareness of Prostate Cancer

John is the man who organises our participation in awareness events such as the Penrith Relay for Life, the Hawkesbury Canoe Classic and the Barry Sheene Festival of Speed.

John also took on the difficult task of getting our brochures placed in Doctors Surgeries throughout our area.

John works tirelessly at these endeavours and is very ably assisted by his wife Chris. Congratulations John, a thoroughly deserved award!

A Successful Day for the Prostate Dragons



Our successful 2017 Team

The Prostate Dragons enjoyed a very successful day at the 2017 Dragons Abreast Regatta at Darling Harbour. We were entered in the 'Social Division' against four other teams. Our Team was once again sponsored by the PCFA. Thanks to Evan Kalopolitis and Daniel Moore for facilitating this. The day's competition consisted of three heats plus a Final. Heat 1 saw us victorious by the narrow margin of 0.07 secs! Heat 2 we won by 0.4 seconds while Heat 3 saw us come home

0.26 seconds ahead of our rivals.

On to the Final!

Here we really 'nailed it' coming home by the margin of 1.63 seconds!

Gold Medallists!

The team that chased us all day "Colly's Crazy Crew" is the team that has won this division for the past 4 years so it was nice to turn the tables on them

This means that we now have a 'Full Set' of trophies. We won the Silver in 2014, the Bronze in 2016 and this year the Gold.

The team consisted of Prostate Survivors (only 3 of us!) our Families and Friends.

Gary paddled with his wife, their 2 sons, plus their daughter in law and 2 cousins – a real family affair. Bob paddled with his son. (My daughter offered to paddle with us but it would have meant shelling out for a return air fare from Scotland!)

There was an interesting sidelight to the day, Two American tourists came up and spoke to us, and they were quite impressed with our participation and appearance. They have a friend back in the U.S. who was undergoing treatment for Prostate Cancer and wanted to show him a positive side to this disease. They took a team photo and we were able to give them some of our brochures. (It would be interesting to see how our 'Little Prick' brochure was accepted back in the States!)



Our 'Bling'



Our hardworking Team

Hawkesbury Canoe Classic – 2017

The Group once again carried out the scrutineering of the craft taking part in this year's Hawkesbury Canoe Classic.

This is a race (at night!) along the Hawkesbury River from the Windsor Bridge to the Brooklyn Bridge.

We have been performing this task for many years and even though the number of competitors was down compared to past years, we still 'earned' a donation of \$1,500.00 from the organisers.

This will help us in our support undertakings

A Laugh at Life !

Say Your Prayers

Everyone was seated around the table as the food was being served. When little Johnny received his plate, he started eating straight away.

“Johnny wait until we have said our Prayer” his Mother reminded him.

“I don’t have to” the little boy replied

“Of course you do” his Mother insisted,

“We say a prayer before eating at our house.”

“That’s at our house,” Johnny explained,

“But this Grandma’s house and she knows how to cook!”



Worms.....

A minister decided that a visual demonstration would add emphasis to his Sunday sermon.

Four worms were placed into four separate jars.

The first worm was put into a container of alcohol.

The second worm was put into a container of cigarette smoke.

The third worm was put into a container of chocolate syrup.

The fourth worm was put into a container of good clean soil.

At the conclusion of the sermon, the Minister reported the following results:

The first worm in alcohol - DEAD.

The second worm in cigarette smoke - Dead

Third worm in chocolate syrup - DEAD.

Fourth worm in good clean soil - ALIVE.

So the Minister asked the congregation “What can you learn from this demonstration? “

Maxine was setting in the back, quickly raised her hand and said,

“As long as you drink, smoke and eat chocolate, you won’t have worms!”

That pretty much ended the service...

Take Care...

Please, take care of yourself. A recent joint study conducted by the Department of Health and the Department of Motor Vehicles indicates that 23% of all traffic accidents are alcohol related.

This means that the remaining 77% are caused by idiots who just drink coffee, healthy smoothies, juices, yogurts, and stuff like that.

Therefore, beware of those who do not drink alcohol. They cause three times as many accidents.

This message is published by someone who worries about your wellbeing!



The Talking Clock

Newfie was proudly showing off his new apartment to a couple of his friends late one night.

He led the way to his bedroom where there was a big brass gong and a mallet.

'What's with that big brass gong?' one of the guests asked.

'It's not a gong. It's a talking clock,' the Newfie replied.

'A talking clock? Seriously?' asked his astonished friend.

'Yup' replied the Newfie.

'How's it work?' the friend asked, squinting at it.

'Watch' the Newfie replied. He picked up the mallet, gave the gong an ear-shattering pound, and stepped back.

The three stood looking at one another for a moment.

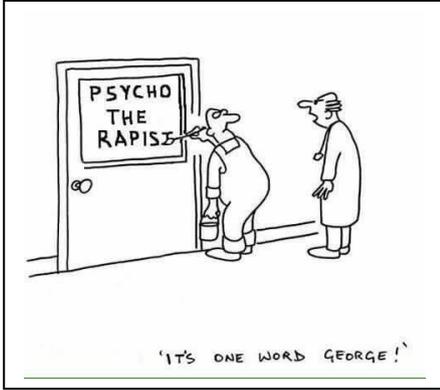
Suddenly, someone on the other side of the wall screamed, 'You donkeyhole! It's three-fifteen in the morning!'



Wonderful English from Around the World :

Dry cleaners in Bangkok:

DROP YOUR TROUSERS HERE FOR THE BEST RESULTS.



**I hate spelling errors...
You mix up two letters and your whole post is urined.**

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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 2015"



**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, Allan Burrow.**

Board Members of the Nepean / Blue Mountains Prostate Cancer Support Group for 2016 are as follows:-

President :-	David Wilkinson
Vice President:-	Vacant
Secretary :-	Ross Baker
Treasurer :-	Allan Burrow
Librarian :-	Bob Wittrien
Newsletter Editor:-	Alan Howard
Web Site Manager :-	Peter Murphy
Promotions Officer :-	John Kemp
Membership Co Ordinator :-	Vacant
Publicity Officer :-	Vacant

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