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Prostate Cancer Foundation of Australia

THE WALNUT

September 2023

Newsletter of the Prostate Cancer Support Group–ACT Region

Postal address: C/- SHOUT, Building 1, Collett Place, Pearce ACT 2607

https://pcsg-act.org.au

Coming meetings

Monthly Group Meeting and Annual General Meeting

6:30 pm for 7:00 pm Wednesday 20 September 2023

Our next monthly Group meeting will be at our usual location, the Pearce Community Centre, Collett Place, Pearce.

Refreshments (pizzas etc) will be provided prior to the start of the meeting at 7 pm. This will be a good opportunity to get to know other members, so we hope to see you there.

We will have a short annual general meeting from 7 pm (see separate notice on page).

This will be followed by our normal monthly meeting, which will begin with a presentation from medical oncologist, Prof Paul Craft.

Prof Craft's presentations are always really informative and there will be plenty of opportunities to ask questions.

Coffee morning, 10:00 am Tuesday 12 September 2023

Our next coffee morning is at the Canberra Southern Cross Club, Woden.

From the President

Hi All,

I trust this month's edition of *The Walnut* finds you well and healthy.

With the start of spring and hopefully warmer weather on the horizon, we can start to get a little more active.

I think I should have been a bear as I certainly like to hibernate in winter.

Due to an upcoming relocation to the Gold Coast, our treasurer, Adrian Rumsey, has advised that he will be vacating his position with us as of the AGM in September. Our accounts are not particularly complicated, so if you would like an opportunity to join the committee and take on the role, please contact either John McWilliam or myself.

September 1 sees the start of the Long Run, an annual fundraiser for PCFA. It's not too late to either join the 'Beat Prostate Cancer ACT' team or show your support to the team by donating. You can do by going to our website (https://pcsg-act.org.au) and following the links on the home page.

Donations over $2 are tax deductible.

Let's get behind an organisation that does much to try and improve the support and outcomes for us all.

I hope to see many of you at the AGM on Wednesday 20 September.

We will be supplying some finger food as an enticement.

Greg McRoberts
President

Our August meeting

Our August meeting was moved from 16 August to 23 August because of the Matildas game. We apologise to any members who didn't receive the email about this change. It's a pity that the Matildas didn't win their semi-final game on 16th but they certainly did the nation proud!

Our primary speaker at our meeting was Professor Catherine Paterson, Clinical Chair in Nursing, Faculty of Health, University of Canberra & Canberra Health Services. Sadly for us, but tremendous for her, Catherine will be taking up a new appointment in September with Flinders University and Royal Adelaide Hospital . We wish Catherine well in her new appointment and were pleased that she has offered to join us by teleconference for future presentations, including an update on the research on prehabilitation that she has been conducting in Canberra.

We also had a short presentation from a PhD research student on research she is doing on the effect of physical and cognitive training on brain health in men who have had prostate cancer and who are on ADT therapy. Details of this study and the request for study participants are at page 7 of this newsletter.

Professor Paterson's presentation was on optimising person-centred supported self-management in prostate cancer survivorship. This has been an area of research for Catherine for many years, including during her time in Scotland. Research that Catherine referenced in her presentation included:

- C Paterson et al, *Identifying the unmet supportive care needs of men living with and beyond prostate cancer: A systematic review*, European Journal of Oncology Nursing, August 2015. This research This identified that men can experience a range of unmet supportive care needs with the most frequently reported being needs related to intimacy, informational, physical and psychological needs [Read research article].

- C Paterson et al, *Unmet Supportive Care Needs of Men With Locally Advanced and Metastatic Prostate Cancer on Hormonal Treatment: A Mixed Methods Study*, Cancer Nursing, Nov/Dec 2017. In this study, men articulated that current healthcare delivery is failing to provide a holistic person-centred model of care. Examples of patients' comments were:

  "I was not offered to speak things over with the nurse, to soften the blow so to speak, or to understand what I was just told". (No. 3, 76 years)

  "Nobody has told me prognosis or anything, you know, because what got me was that they told me it was stage IV, and it was aggressive, how long have I got, you know? Nobody told me or what is going to happen next." (No. 5, 67 years)

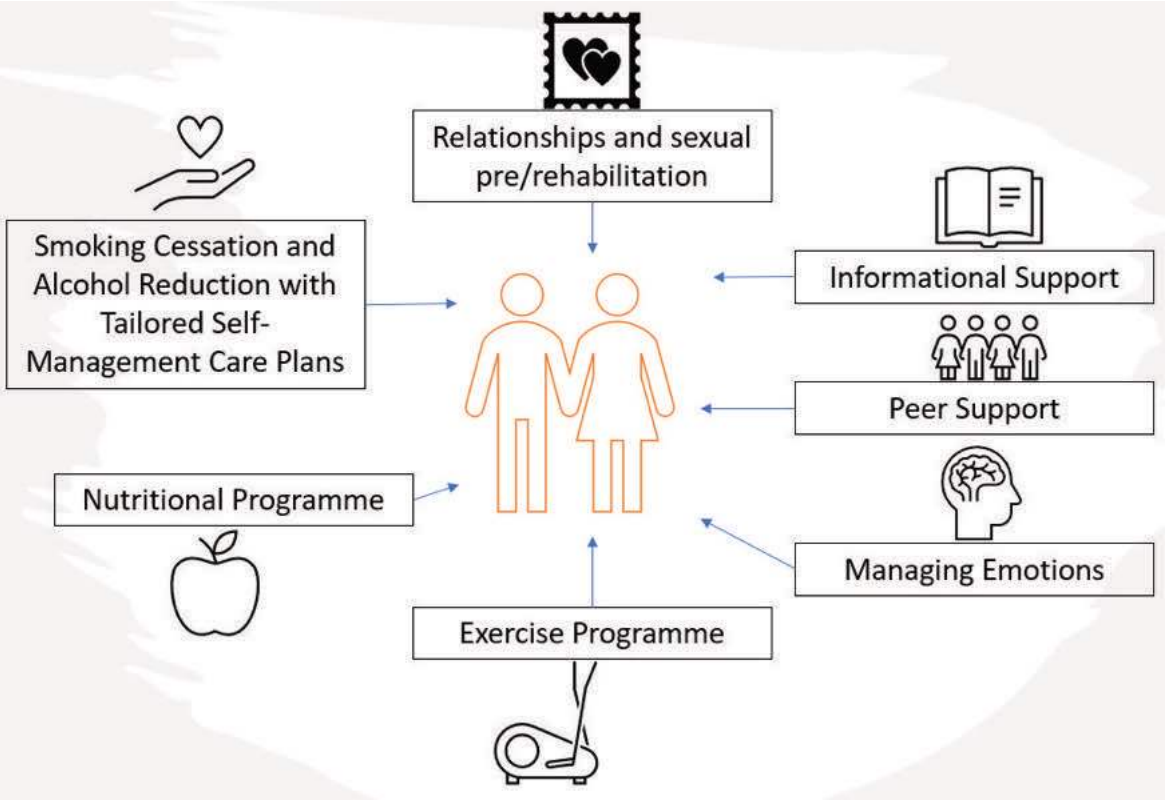
- C Paterson et al, *Management and treatment of men affected by metastatic prostate cancer: evidence-based recommendations for practice*, International Journal of Urological Nursing, Vol 10, Issue 1, March 2016. Clinical guidance is crucial for nurses involved in the care delivery for men with advanced prostate cancer and for their families to maximise their quality and quantity of life. It concluded that nurses involved in the care delivery for this patient group need to be aware of the complex physical and psychological supportive care needs, and evidence-based management care plans to ensure a personalised and

tailored support to optimise quality of life.

- C Primeau, C Paterson et al, *A Qualitative Study Exploring Models of Supportive Care in Men and Their Partners/Caregivers Affected by Metastatic Prostate Cancer*, November 2017. Building on previous research, this study explored the experiences of patients with metastatic prostate cancer and their partners/caregivers, as well as an inter-professional team, with a nurse-led multimodality supportive care intervention. An information booklet "A Prostate Cancer Guide to Thrivership: Men it is time to Thrive" covered the following general topics: how to self-care, managing side-effects of hormone therapy, nutrition and exercise, relationships and sexual well-being, healthy lifestyle approaches and community-based support resources. The findings of Thrivercare were that, while there was no statistical significant difference in the prevalence of unmet supportive care needs between the intervention group and usual supportive care group at baseline, there was a statistically significant difference was observed at 3 months, indicating that the prevalence of unmet supportive care needs were less in the intervention group.

The results of the research being undertaken by Catherine and her colleagues emphasise that people with cancer are continually reporting that their needs are not being met across many supportive care domains. It is time for change within the health care system and to full leverage multidisciplinary person-centred models of care to optimise recovery and survivorship experiences.

These needs can be summarised the the following diagram:



Catherine has been undertaking research into prehabilitation models of care in Canberra and the results of this research are currently being analysed. Once the findings are available, she said that she would gladly report back to the Group in a teleconference from Adelaide.

Annual General Meeting

This provides notice that the Group's annual general meeting will take place at 7 pm on Wednesday 20 September 2023 at the Community Centre, Collett Place, Pearce 2607.

This meeting will:

- confirm the minutes of the 2022 AGM;
- receive reports from the President and the Treasurer on the activities and financial statements of the Group in 2022–23;
- elect the members of the Group's executive committee for 2023–24;
- appoint the auditor and determine a remuneration for auditing of the Group's financial statements for 2023–24; and
- transact any other business raised by members.

A minimum of five members must be elected to the committee. Three of these will be the President, Secretary and Treasurer. Our President and Secretary are prepared to be renominated for 2023–24, but our Treasurer is not renominating. So, we need a member who is prepared to take on this role. We would also like to attract other members to the committee, since there can be turnover of committee members during a year and we need to ensure that there is a sound succession plan in place to assure the future of the Group. This also helps to spread the workload of committee members.

There are generally only four or five committee meetings that are held each year, so the workload of committee members is not onerous.

We strongly encourage members to nominate for a position on the committee. This can be done by completing the committee nomination form and returning it to the Secretary. If you require nominators, we can arrange this.

If any member wishes any other matter to be discussed at the AGM, please advise the Secretary of this matter so that it can be added to the meeting agenda.

Note that the AGM will be followed by the Group's normal monthly meeting at which our speaker will be medical oncologist, Professor Paul Craft.

A quorum is required for our AGM. Clause 30(3) of our Constitution states that:

> *A quorum for the transaction of the business of an Annual General or Special General Meeting shall be the greater of 10 percent of the current membership or 15 members present in person, by telephone or internet link, or represented by proxy, being active members entitled under these rules to vote at a General Meeting.*

So, if you are a voting member of the Group and are unable to attend either in person or online, please consider nominating a proxy to represent your interests and advising either Greg McRoberts (president@pcsg-act.org.au) or John McWilliam (secretary@pcsg-act.org.au) of the name of your proxy.

Refreshments (pizzas etc) will be provided prior to the meeting. So, please do come along and join us in person if you can.

PCFA News

Theranostics & You: Learn more about the therapy and diagnostic pipeline

Theranostics have rapidly become established as a new standard of care for men with advanced forms of prostate cancer. The treatment modality combines therapy and diagnostics to improve our understanding of each man's cancer, and how it can be effectively treated, heralding a complete transformation of care. In this latest video for PCFA TV, host Matt Britland is joined by Dr David Cade, Associate Professor Shahneen Sandhu and Will McDonald to explore the topic.

Watch the video.

A millennium of care: 1,000 sessions of counselling for men and their partners

PCFA's Prostate Cancer Counselling Team recently surpassed 1,000 sessions of counselling for men and their partners impacted by prostate cancer, achieving an overall satisfaction score of 99%. The milestone coincided with the first anniversary of the service, which has now supported nearly 400 men and their loved ones. "Counselling results in a statistically significant reduction in self-reported levels of anxiety, trauma and depression in men impacted by prostate cancer," says Bernie Riley, the Head of our Telenursing Service & Supportive Care Programs.

Read more.

Words Woke Me: New work of poetry on the lived experience of prostate cancer

Prostate cancer survivor Steve Jones, pictured with wife Robyn, has captured his journey with the disease in a raw and heartfelt compilation of poetry. "The title of the book, 'Words Woke Me', was born late one night as I was writing a poem and my phone pinged," Steve says. "It was one of my mates in the USA asking why was I not sleeping." Steve replied, "Some words woke me." The anthology of poems describe the different stages of Steve's experience with prostate cancer, from diagnosis to recovery and life beyond. "I hope this book resonates with men going through prostate cancer and that my journey may help them to realise they are not alone." The book is now available on Amazon Kindle and will be available in hard-copy soon.

Check it out.

Other PCFA videocasts

Prostate Cancer Discoveries | New and emerging frontiers in the treatment of prostate cancer

View

Regaining confidence by improving continence | World Continence Week

View

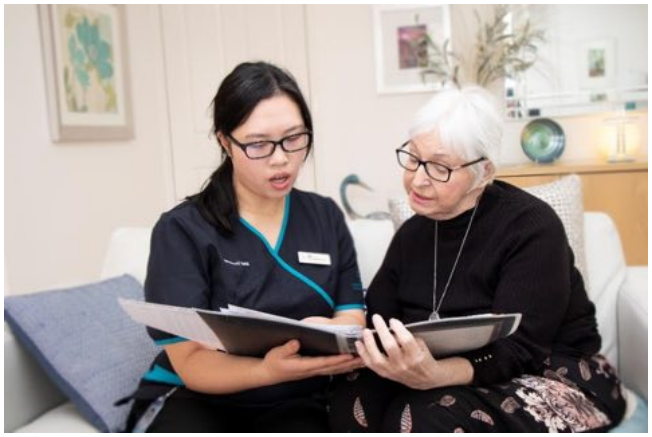
Next generation radiotherapy in Australia

View

CAS Care@Home

ACT Government | Canberra Health Services

Join our pilot program!



We are inviting patients to be a part of our home care pilot program, designed to provide person centred care.

Through the CAS Care@Home program, eligible cancer patients can receive care from the comfort of their own homes.

Care available includes:

- blood collection and tests
- central line care
- surgical dressing care
- some types of chemotherapy (no IV)
- some infusions.

The aim of this service is to make the cancer treatment journey smoother and less stressful, by allowing patients to receive treatment in a familiar and relaxing setting.

For more information and to register your interest in the program, please provide your name (or patients name if emailing on behalf of someone) and best contact number to: **CHS.OutreachHaematology@act.gov.au**

Acknowledgement of Country
Canberra Health Services acknowledges the Ngunnawal people as traditional custodians of the ACT and recognises any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and contribution to the life of this region.

Accessibility
Call (02) 5124 0000 | Call 131 450
canberrahealthservices.act.gov.au/accessibility

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CAS Care@Home would like to include a prostate cancer patient in this trial.

Prostate Cancer Study - World Cancer Research Fund — Men on ADT Therapy Needed

Our study is looking for men with **prostate cancer** to participate in a research project which aims to understand the effect of physical and cognitive training on brain health

Who can participate?

Males over the age of 18, diagnosed with prostate cancer and currently receiving primary Androgen Depravation Therapy (ADT) for either metastatic or non–metastatic hormone-sensitive prostate cancer.

To be included, you must meet the following criteria:

- commenced ADT at least six months prior to enrolment in the study and are expected to receive treatment for another 6 months with life expectancy of >12 months
- no chemotherapy, radiation or novel anti-androgen agents within the last 3 months
- not currently receiving steroids equivalent to >10 mg of prednisolone a day
- no opioid-based medication within the last 28 days

What is involved?

- Eight weeks of fully supervised physical and cognitive training
  - (2x ~1 hour sessions per week each)
- Pre- and post-intervention testing including:
  - Blood test at a pathology clinic
  - Online questionnaire
  - Cognitive and physical fitness assessments

Participants will receive a $360 gift card upon completion of the study

For further information contact Professor Ben Rattray
via Ben.Rattray@canberra.edu.au or prostatebrainhealth@canberra.edu.au I 02 6201 5145
or
Download the information pack

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ACTIVE BRAIN

This project is approved by the University of Canberra Human Research Ethics Committee (approval #11955)
This project is registered as a clinical trial: ACTRN12623000767606.

Participation in Macquarie University Projects

A team of researchers from Macquarie University is exploring how prostate cancer treatments may be impacting men's lives and their families.

They have three projects running that members may be interested in.

1 Online Focus Group (~Sep-Oct 2023)

If you have been diagnosed with prostate cancer, are currently on hormonal treatments (e.g., androgen deprivation therapy) and are having difficulty managing fatigue, memory, concentration and cognition, you are invited to participate in an online focus group (~2hr) helping design an intervention to support men like yourself. You will be reimbursed $150 for your time. For more information: https://redcap.link/FocusGroupPROCOG

2 Online Cognitive Rehabilitation Program (~Jan-Ma 2024)

If you have been diagnosed with prostate cancer, are currently on hormonal treatments (e.g., androgen deprivation therapy) and are having difficulty managing fatigue, memory, concentration and cognition, the team is running four weekly cognitive rehabilitation sessions online. For more information: https://redcap.link/GroupPROCOG

3 Online Survey (~end Oct 2023)

If you have been diagnosed with prostate cancer and are on 'Watchful Waiting' or 'Active Surveillance' (i.e., monitoring and not undergoing any active treatment), you are invited to participate in an an online survey investigating men's experiences with prostate cancer treatments and potential side-effects. This involves comparing responses between men on treatments and men who are not on any treatments. The survey should take ~20min. The following link contains more information about the study and the actual survey itself if you choose to proceed: https://redcap.link/PROCOG

For further information, contact Lorna Huang on lorna.huang@hdr.mq.edu.au

Information on travel reimbursement and community travel options

Reimbursement for Isolated Patients – Travelling from NSW to ACT for Medical Treatment

The Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS), provides financial assistance towards travel and accommodation costs when you need to travel more than 100km one way or 200km within a week for specialised medical treatment that is not available locally.

This service requires the patient to pay upfront and then get reimbursed which can be problematic but might be an option for some.

Community Transport & Community Buses

Various community service organisations around Canberra are funded by the ACT Government to provide community transport. These services can be provided via Aged Care Packages, NDIS packages or short-term transport packages through a community assistance funded program. They sometimes require a small co-payment, and all require registration and pre-booking.

More information can be found at these websites:

- Community Transport - Capital Region Community Services (https://crcs.com.au/programs-services/community-transport/)
- Transport - Communities at Work (https://www.commsatwork.org/services/community/transport-services/)
- Community Transport - Northside Community Service (https://www.northside.asn.au/aged-care/community-transport/)
- Community Transport – Get Out and Moving! – Community Services (https://communityservices1.org/community-transport-get-out-and-moving/).

The different operators will all have different availability for their transport and bus options, but this service is partly funded by ACT Health to provide for people who require transport to medical appointments so it's worth pursuing if transport is needed.

COTA Transport Brochure

COTA – provides the following excellent summary of the various transport options available in Canberra:

COTA summary of transport options.

Articles and Reports of Interest

The following articles which have appeared recently on web sites or other sources may be of interest to members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

Optimal timing of salvage radiation therapy on metastasis-free survival in patients with relapsed prostate cancer following prostatectomy

This study in *The Prostate* (31 October 2022) examined the optimal timing of salvage radiation therapy on metastasis-free survival in patients with relapsed prostate cancer following prostatectomy.

The study analysed the impact of prostate specific antigen (PSA) levels at the time of salvage radiotherapy with regard to both biochemical relapse-free (bRFS) as well as metastasis-free survival in 397 patients with biochemically recurrent prostate cancer who received salvage radiation therapy between 1985 and 2016.

The study concluded that Initiation of salvage radiation therapy while PSA levels remain ≤0.5 ng/ml was associated with improved metastasis free survival. It also concluded that consideration for salvage radiation therapy initiation while PSA levels remain low is warranted to minimise the risk of future prostate cancer metastasis.

Read the study abstract. Access to the full article is available for purchase.

Hopes that MRI scans can screen men for prostate cancer

For the Reimagine study, which is published in *BMJ Oncology* (Vol 2, issue 1, 21 August 2023), men aged 50 to 75 in London were invited for screening MRI and PSA tests, which were carried out at University College Hospital.

Of the 303 who had both tests, 48 had a positive MRI that indicated cancer and of these 25 were diagnosed with significant cancer after further tests, including biopsies.

More than half the men whose cancer was picked up on MRI had low PSA test scores below 3ng/ml, which is considered normal, and so would have been falsely reassured they were free of disease.

Prof Caroline Moore, consultant urologist UCLH and chief investigator of the study at University College London, said: "Our results give an early indication that MRI could offer a more reliable method of detecting potentially serious cancers early, with the added benefit that less than 1% of participants were 'over-diagnosed' with low-risk disease."

PSA tests are considered useful but unreliable indicators of prostate cancer. As the trial showed, a low PSA score might miss cancer. And while high levels may indicate cancer, high PSA can also be caused by other things, such as a recent infection or vigorous exercise and sex. Even when there is cancer, PSA alone will not tell you which tumours are the aggressive ones that need treating, rather ones that can be safely left.

Read more.

Neoadjuvant enoblituzumab in localised prostate cancer: a single-arm, phase 2 trial

A new drug, a monoclonal antibody known as enoblituzumab, is safe in men with aggressive prostate cancer and may induce clinical activity against cancer throughout the body, according to a phase 2 study published in *naturemedicine* (3 April 2023). Acoording to the study authors, if confirmed in additional studies, enoblituzumab could become the first promising antibody-based immunotherapy agent against prostate cancer.

In a clinical trial, 32 men with high-risk or very high-risk prostate cancers who were scheduled for prostate cancer surgery were treated with six weekly infusions of enoblituzumab prior to surgery, and were followed for an average of 30 months thereafter. Twenty-one patients, or 66%, had an undetectable prostate-specific antigen (PSA) level 12 months following surgery, suggesting that there was no sign

of residual disease. Additionally, the drug was well-tolerated overall; no patients had any surgical delays or medical complications during or after the operation.

Enoblituzumab works by binding to a protein called B7-H3 that is over-expressed on prostate cancer cells and believed to impede the immune system's ability to attack cancer cells.

One of ther study authors said that, "What this means is if these results can be replicated in a larger, randomised study, it opens the possibility that combining this therapy with local, curative-intent therapies like surgical prostate removal or radiation therapy, would allow this drug to potentially kill micro-metastatic disease hiding elsewhere in the body, and therefore prevent a significant number of men from experiencing recurring disease. That could be a paradigm shift in prostate cancer."

Read the study abstract. Access to the full article is available for purchase.

Radiation Facility Volume and Survival for Men With Very High-Risk Prostate Cancer Treated with Radiation and Androgen Deprivation Therapy

This study published online in JAMA Network Open (8 August 2023) examined whether there was a difference in outcomes between patients with very high-risk prostate cancer who are treated at radiation facilities with high vs low patient volume.

The analysis included 25,219 men identified from the National Cancer Database.

The researchers found that 25.5 percent of men were treated at facilities with high average cumulative volume. During a median of 57.4 months of follow-up, median overall survival was 123.4 months for men treated at high-volume centres versus 109.0 months for those treated at low-volume centres. Further, treatment at a high-volume centre was associated with a lower risk for death (hazard ratio, 0.89). Results remained significant after inverse probability score weight-based adjustment.

"These findings suggest that the expertise and resources that accompany high-volume treatment facilities are associated with improved outcomes for men with very high-risk prostate cancer, but further investigation is needed to identify the specific causes for this association," the authors write.

Read more

Borrowing Items from the Library

You can borrow items from the Group's library. There is a wide range of materials, from books to videos. Those who are interested in borrowing items from the library or finding out more about our collection can contact U.N. Bhati, email:
librarian@pcsg-act.org.au

Personal Support

For general information, please call SHOUT (Self Help Organisations United Together) during normal office hours on (02) 6290 1984, and their staff will arrange for someone to contact you.

If you would like immediate advice, support or assistance, please contact one of the following two people:

President: Greg McRoberts, president@pcsg-act.org.au 0413 480 864
Secretary: John McWilliam,secretary@pcsg-act.org.au 0416 008 299

Appreciation

Thanks to all those supporting the Group's fund raising activities, in particular, Harness Racing ACT, the Canberra Southern Cross Club, ACT Masters Hockey, Chartertech ACT, Paddywack Promotional Products and SAC Tyrepower, Belconnen.

From the editor

If you are aware of news, products, publications, web sites, services or events that may be of interest to members of the group, we would like to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy direct, or if you would like to add any of your friends or carers to our distribution list, or if you no longer wish to receive copies of the newsletter, please send an email to:
secretary@pcsg-act.org.au

Disclaimer

From time to time in our newsletters we provide information about developments in the diagnosis and treatment of prostate cancer, research articles, documents, audiovisual products, presentations and other interesting materials. However, the group does not have the medical expertise required to make an informed evaluation of the conclusions and recommendations presented in such materials, and we have not verified such conclusions and recommendations through appropriately qualified medical professionals. The information presented in this newsletter must not be interpreted as being endorsed or recommended by the group.

Any recommendations made in such materials may not be applicable in your case. Before implementing any recommendations made in the materials that are reported, it is essential that you obtain advice from appropriately qualified medical professionals. The view of the group is that no two prostate cancer cases are alike and that no single treatment option is better than any other in all cases. While the information in this newsletter should be of interest, there is no substitute for getting informed medical advice from your own GP, specialists and other medical professionals.