



THE WALNUT

March 2015

Newsletter of the Prostate Cancer Support Group - ACT Region Inc.

Affiliated with the Prostate Cancer Foundation of Australia



What's in this issue

- From the editor – p1
- President's report - pp 2,3
- Secretary's report – pp 3,4
- Articles and reports of interest – p 4
- Disclaimer – p 4

Monthly meetings

All men and women are welcome to attend our regular monthly meetings. No notice is required - simply come along and introduce yourself, or contact one of the people listed later in this newsletter.

When

Meetings of our support group are held on every 3rd Wednesday of the month except in December.

Usual Location and Time

Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. See our web site here for details and map showing the location: <http://tinyurl.com/bjoyczu>. 6:30 for 7:00 pm

Next monthly meeting

PLEASE NOTE! Our next monthly meeting will be at 7 pm on Wednesday 18 March 2015 at the John Curtin School of Medical Research, Building 131 Garran Rd, Acton. All welcome: Check out our website for the latest news on this meeting.

From the editor

This edition provides information about our last meeting, some events of interest, and information about recent articles and reports that may be of interest. If you know of sites, services or events that may be of interest to members of the group I'd be happy to be informed of them. If you have received this newsletter indirectly and would like to be emailed a copy directly please send me (amore6306@gmail.com) an email through the form here: <http://tinyurl.com/2bdbbnk>

Contact us

Postal address

Prostate Cancer Support Group - ACT Region Inc.
PO Box 717, Mawson, ACT 2607

Personal support

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

President: Chris Hansen
Phone: 02 6161 4135
Email: chriskayehansen@gmail.com

Treasurer:
John Lucas
Phone: 02 6293 2532
Email: jandklucas@bigpond.com

Web site

Our web site provides details about the activities of the group, meetings, meeting location map, contact persons and lots of other useful information:



prostate-cancer-support-act.net

President's Report

Recent Events

As has been reported previously, we are in the process of apportioning Mike Boesen's work on the Walnut and our website, due to Mike's ongoing health issues. It is only now, when we look at the volume and depth of work that Mike has been doing that it becomes clear what a big job it will be to take over from him. Aidan Moore will take on the Walnut editing and webmaster tasks, while Alan Jackson has volunteered to undertake the medical literature research. Max Murray on the South Coast has also offered to assist in the webmaster role and we will be able to draw on help from the John Curtin School of Medical Research (JCSMR) to help with the medical literature.

Thank you Mike for the work you have done in getting things moving in this important area.

Graham Erickson and I gave a presentation to the Tuggeranong Men's Shed earlier this month which was well received; we have been asked to return on a periodic basis.

Several of us attended the Canberra Cancer Centre for World Cancer Day at the beginning of the month. While the idea was well intentioned, we had only very minimal interaction with the clientele as most of them were already suffering cancer in varying degrees and hence had little interest in learning more about it. The Centre management have been made aware that there may be better ways of publicizing information on cancer.

The John Curtin School is seeking people to help on their consumer panel. I attended one of these meeting last week. The intent is to provide non-medical feedback on the direction of research and, more practically, to help word the summaries of their intended research more simply. Anyone who is interested in helping with this work (which involves

one afternoon per quarter and includes a light lunch) please let me know.

New Members

One new member, Mike N discussed his circumstances tonight. Mike was recently diagnosed by a local urologist; PSA testing proved unreliable, with no obvious trend, however the elevated count did warrant a biopsy. The biopsy returned one positive sample with an inferred Gleeson score of 8 which in the doctor's opinion may be a 7. Currently Mike is considering various treatments with brachytherapy one of the options.

At our recent Executive Group meeting we had a detailed discussion about the role of our group. While our primary job is to support men and their families going through prostate cancer, perhaps we have not had sufficient publicity. U N Bhati has drafted an advertisement to go into the Chronicle and George Kayaba is looking at the option of free advertising on the Prime television morning show. We have also been offered a slot on 1Way FM radio to outline our role.

Another concern raised was the need for more one on one support; Greg Amos and Graham Erickson are spearheading this individual support aspect. While the current initiatives such pamphlet distribution at public events , print and radio exposure are of value, we are missing over 90% of men diagnosed. We discussed direct approaches to the five local urologists, which has in the past been less than successful. We are attempting to address these concerns and welcome any suggestions that may assist.

On a positive note, both new members tonight have voluntary mentors who will help them with practical, non-medical issues associated with the disease.

General

Sat 21 February – Queanbeyan Relay for Life. We had a total of six team members in this year's event, which helps to raise the profile of prostate cancer generally. Our effort raised a modest sum but, more importantly, fed into the general community spirit engendered at the event. Next year we will look at setting up an information stall.

Following attendance at the consumer panel at the John Curtin School of Medical Research, we have had an offer from Luke Sartor, an honours student in the School, to assist us with medical and technical issues as well as offering to volunteer at our events. Luke has already provided some helpful feedback on the worth of Saw Palmetto herbal treatment and is currently looking at the current status of PSA testing. We are fortunate to have Luke's help in these areas.

Our March meeting will be held at the JCSMR – check the front page and the details at the bottom of the Secretary's report.

Secretary's Report:

Minutes of the meeting 18/02/15

Meeting was opened 19.03 by the president.

Apologies received were from: Mike Boesen and John Hayhoe.

Attendance was: 15 members including two new members.

It was mentioned already a number of times, that signing the attendance book is quite important for the reporting/existence of the group. As the members of the executive are not mind readers or cryptographers it is also important to sign legibly and preferably print the individual names.

Presentation:

Tonight's presenter sent last minute

apologies, therefore the evening was without an official presentation, instead time was spent on a general agenda of items raised by individual members.

General agenda

Our visit and presentation to the Men's shed did prove very interesting and may include a follow up in a near future.

We were invited to visit John Curtin Medical facilities and also to hold there our next meeting. See the notice (opposite) on this page and on the front page.

Our attendance to the 'cancer day' in the Canberra Cancer Centre was rather disappointing.

U N Bhati, our Librarian, presented his report on a new video report/pack [produced by the Prostate Cancer Foundation of Australia], available in our library, addressing the needs of gay and bisexual PC patients and survivors. [Editor's note: I got some of these also and added them to our library. I endorse UN's finding that these report packs are very handsomely produced and deal clearly with most aspects of Prostate Cancer. You don't have to be gay to read and be informed and helped by them. If you have a gay/bi friend, colleague or relative who has been diagnosed with PC you would do him a favour by getting a pack from our library for him. Ask UN Bhati (Librarian) or Aidan Moore (Editor).]

At some length we discussed the ways we are dealing with the prostate cancer sufferers. Statistically there is one diagnosis made per day of this sickness and we are getting on average only one member a month. This is an indication that we are not penetrating the problem sufficiently and possibly we need to change our approach.

Attendance for this weekend 'walk for life' has been canvassed and change in the venue to the Queanbeyan Showground was

announced for the benefit of members.

Meeting was closed at 20.00

NEXT MEETING:

The next meeting will be held at 7.00pm on Wednesday 18th March 2015 at the John Curtin School of Medical Research, Building 131 Garran Rd, Acton. We have been booked to attend at 6.30 for 7pm and will be welcomed by the Director of the School, Professor Simon Foote.

Articles and Reports of Interest

This will be detailed from next month onwards.

From Aidan Moore

I will share with others the discoveries I have made in my recovery of sexual function after prostatectomy. This process is not widely discussed – men find it hard to reveal what is regarded as a reduction in their masculinity, seen as a weakness. The result is that information is not shared and many men live in silent misery. Women are more open about these things and about mastectomy, the female equivalent operation, which may attack their sense of self-worth as women.

Survivors should not live in misery, we and our partners should enjoy life and love. I have produced a one-page summary of my no-cost organic approach to recovery which I will have with me at the monthly meetings. When I have a website to put it on I shall, and I will list the hyperlink here. Meanwhile I will e-mail it to whoever contacts me at amore6306@gmail.com

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's Executive and the editor of this newsletter do 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 Executive or the editor. Any recommendations made in such materials may not be applicable in your particular 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's Executive 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.