



THE WALNUT

May 2013

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

Affiliated with the Prostate Cancer Foundation of Australia



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Monthly meetings

All people 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 below.

When

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

Usual Location

Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. See our web site for details and map showing the location.

Time

6:30 for 7:00

Next meeting

The next meeting will be on Wednesday, 15 May 2013 at the [usual time and location](#). The guest speaker will be urologist Dr Hodo Haxhimolla. He will tell us about new developments in the diagnosis and treatment of prostate cancer, following a study tour he is undertaking in the USA.

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: Peter Daley
Phone: 02 6291 0612
Email: monashmm@bigpond.net.au

Committee member:

John Lucas

Phone: 02 6293 2532

Email: jandklucas@bigpond.com

Committee member, newsletter editor and web site manager:

Mike Boesen

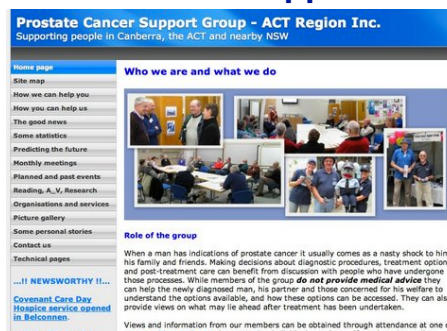
Phone: 02 6254 3493

Email: mboesen2@gmail.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



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.

From the editor

This edition provides information about our last meeting, past and future events of interest, information about the PCFA fund-raising event - The Long Ride (to cairns), some information about focal therapy and a picture of a \$44,000 cheque made out to the PCFA

If you are aware of news, products, publications, web 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 an email. I'm happy to also add any of your friends to the email list. Past issues of *The Walnut* can be downloaded from this page of our web site: <http://tinyurl.com/42fyxrd>

Mike Boesen
Editor

President's report

We were unable to get our Guest Speakers organised for our April meeting, so the meeting was devoted to a few administrative matters and a lot of informative discussion amongst members.

One of the administrative matters raised at the meeting was the invitation to have an Awareness table at the Hall Bushrangers' Rugby Carnival that was to be held on Saturday, 20 April. Patricia and I were involved in another activity that weekend and I wish to thank John Hayhoe for stepping into the breach and setting up and managing our appearance at that event. I also want to thank those members who turned up to assist – I was particularly grateful for this support as the event had to be organised at very short notice. We received, again this year, separate donations from the Hall Bushrangers' Rugby Club and the ACT Rugby Veterans' Club following our appearance.

I indicated we have been invited to set up an Awareness table at the very large display of Holden vehicles at the Queanbeyan Showground on Sunday, 12 May. I am extremely pleased at the response from members who signed on to the sheet at the meeting – we will have sufficient volunteers to cover the day.

Again, Patricia and I are unable to attend because we will be representing the Group at the PCFA Conference and NSW/ACT Chapter Council AGM in Melbourne on that weekend. However, ever helpful John Lucas has offered to manage the event. If you can help at this event please contact John on 6293 2532. In particular, he is seeking a volunteer bring home our gear as he has to leave by 12 noon.

After we addressed that and other administrative matters, members were invited to brief us on their status. An informative discussion ensued and that was extended over supper. Members took the opportunity to use this as a means of getting together to discuss matters of interest as we almost had to suggest to a couple of groups that it was time to go home. In fact, after locking up, one group was still involved in great discussions outside the front door of the building.

Our Guest Speaker for the May Meeting is a great supporter of our Group – urologist Dr Hodo Haxhimolla. He is undertaking a study tour in the USA. At the meeting he will inform us about the latest diagnosis and treatment developments over there, I am sure his talk will be most informative.

We have also scheduled a most interesting speaker for our meeting on 19 June 2013. I had the pleasure of listening to Dr Shona Hutchinson, a Canberra Chiropractor, at a Movember function last year. I was very taken with her talk on the interaction of the brain, the nervous system and the spine – you will, I am sure, find it absorbing, as I did last year. Don't miss it!

Last, I remind you of the contents of a message sent by Mike Boesen in the last week or so advising members of the participation of Les Briggs - son-in-law of one of our members - in PCFA's **The Long Ride**. This event is sponsored annually by PCFA. This year the participating bikers are traveling from Sydney to Cairns. I encourage you to make a donation in support for Les and the PCFA.

Keep well,

Peter Daley

Secretary's report

There were 22 members who attended the meeting.

We were unable to secure the attendance of any guest speakers unfortunately.

Peter Daley spoke about a number of administrative matters including an awareness table at the Hall Bushrangers' Rugby carnival on 20 April, and a

planned awareness table at the display of Holden vehicles at the Queanbeyan Showground on Sunday, 12 May. He requested members to volunteer for those activities.

Peter indicated that we were obtaining some additional booklets prepared by the Combined Prostate Cancer Support Groups of Rural NSW, which they state is designed "to help those coping with erectile dysfunction". At the March meeting six members indicated an interest in obtaining a copy.

Mike Boesen indicated that the contents of the PCFA's "Localised Prostate Cancer Information Pack" could be downloaded from a page on the PCFA web site (<http://tinyurl.com/c42pkwg>) .

Members provided briefings on the status of their planned and recent treatment and rehabilitation. This discussion was carried over in an extended supper.

One of our members sought support for Les Briggs who was participating in the ADF team in "The Long Ride" - an event organised by the PCFA. (*See details later in this newsletter - Ed.*)

Next Meeting

Our next regular monthly meeting will be on Wednesday 15 May 2013 at the usual time and location (see: <http://tinyurl.com/bjoyczu>). The guest speaker will be urologist Dr Hodo Haxhimolla. Details about the guest speaker are on page 1 of this newsletter.

George Kayaba

Support Les Briggs on "The Long Ride" to Cairns

Once again this year the PCFA is organising a major fundraising event - **The Long Ride** - starting on 4 May 2013. The event involves teams of riders traveling all the way to Cairns by motorbike, raising money for the PCFA through donations from "sponsors". This page on the PCFA web site provides details:

<http://pcfafundraising.org.au/event/thelongride2013>

One of the participating teams is from the ADF. A member of that team is Les Briggs who is a son-in-law of one of our members. Les is seeking sponsors and if you would like to contribute to the great work of the PCFA through a donation, you can do that by going to this web page and clicking on the "Donate Now" button. Go Les! <http://pcfafundraising.org.au/adf>

Mike Boesen

Advocacy campaign to have Abiraterone placed on the PBS

Abiraterone acetate is a drug that has proven to be effective in the treatment for men who have metastatic castrate-resistant prostate cancer. A number of recent research studies and reviews have reported on its effectiveness, including ones referred to on this page of our web site: <http://tinyurl.com/5wxjojy>

On 4 February 2013 the CEO of the PCFA wrote to the Federal Minister for Health and Ageing in support of the recommendation made by the PBS Advisory Committee that it be listed on the PBS. A copy of the text of that letter can be accessed via this page on our web site: <http://tinyurl.com/dyy4s4c> In letters to support groups, the CEO requested support in the advocacy campaign - the text of that letter is on that page of our web site.

On behalf of the PCFA, Margaret Bennett has sent to our President an email which includes this content:

PCFA is still involved in an advocacy campaign to have Abiraterone (Zytiga) listed on PBS. While several steps in the approvals process have been taken final access is still in negotiations. We are hopeful this can happen before the Federal election.

Many people and their family members have already written to the Federal Minister and I thank those who have done so. It has been important to have letters from family members as well. ...

While we do not have a pro forma letter ... the attached information can assist with any letter individuals, family members or groups wish to send to the Federal Minister for Health. It is important too that any letters sent are copied to me as this assists with assessing the outcome of this approach to PCFA advocacy work.

If we can have as many letters forwarded to Federal Minister for Health from now till end of May, 2013 that would be fabulous.

The type of content that Margaret suggests being included in any letter is outlined in a document that can be accessed via a link on this page of our web site: <http://tinyurl.com/dyy4s4c>

The Group's Executive encourages you to write to the Minister as an individual. If you are able to do that, please send a copy of the letter to Margaret Bennett as she requested.

Mike Boesen

Focal therapy for prostate cancer

In April 2013 the ABC broadcast a news item about a "new" treatment of prostate cancer - "focal therapy". The news item is documented as this web page:

Author: Sophie Scott of ABC News

Date: 14 April 2013

Title: New pain-free treatment for prostate cancer

Web link: <http://tinyurl.com/c9l64rg>

In the article, Sophie states:

"There is now a low-risk and relatively painless treatment available for the thousands of Australian now, those men with low-risk prostate cancer have another option, called focal therapy....It is an umbrella term for a number of non-invasive techniques for killing small tumours inside the prostate. Some focal therapies use either heat or cold to destroy tumours and another option, called the Nanoknife, uses electrical currents to kill the tumours."

Sophie interviewed Professor Phillip Stricker from Sydney's St Vincent's Hospital who is reported as trialling focal therapy using the Nanoknife. She also interviewed Professor Mark Frydenberg from Monash University stating that he says the use of focal therapy is very much still at the trial stage for some of his patients.

A very readable and informative description of the merits and the various forms of focal therapy is on this web page of the Memorial Sloan-Kettering Cancer Center's site: <http://tinyurl.com/cpqkn6f> There is also a link on that page to a short video that is worth watching.

Mike Boesen

\$44,000 cheque - dam big!

In the March issue of *The Walnut* newsletter I informed members about our awareness-raising presentations at the Cotter Dam Project in 2012 and the great work that Project Engineer Brandon Perrin had instigated, culminating in a donation of \$44,000 being made to the PCFA. Rachel Clarke of ACTEW Water sent me the following nice write up about the fund-raising activity and a picture of the cheque.

Peter Daley

Beards shaved off for dam good cause

A bearded mate may not generally be fruit for female fantasies, but in this case surplus facial hair certainly

reaped rewards for others. Recently a team of bearded workers at the Cotter Dam site raised \$44,000 for the Prostate Cancer Foundation of Australia.

The Dam Good Beard fundraiser, which ran for nearly six months, was initiated by Project Engineer Brandon Perrin after a few long days at work.

"I worked eight days straight and I didn't have a chance to shave, so I thought it might be a good way to keep the beard and have a bit of fun."

While admitting that his girlfriend wasn't much of a fan, other workers at the Cotter Dam work site certainly were, with Brandon and the five other hirsute workers raising \$10,000 on the site alone. This amount was then matched by Bulk Water Alliance Partners ACTEW Water, Abigroup and John Holland, with GHD chipping in an extra \$4,000.

"We started off just wanting to raise \$5,000, but by the end of the first week we had \$2,500 already, so ten seemed very achievable. It made a difference having the Alliance partners say they would match it – the guys knew that for every \$10 they were putting in it was going to be \$40, so it was a good incentive."

The official presentation of the cheque was held last Friday at the enlarged Cotter Dam with Peter Daley receiving the donation on behalf of the PCFA. Peter was thrilled with the effort by the bearded dam workers saying, "It has been a marvellous project and I can't believe the amount of the donation. It was a great idea of Brandon and his colleagues to kick it off."

Peter also praised the organisers for facilitating information sessions by foundation members who came to the construction site to talk to the workers.

To Brandon it was a critical part of the project and said, "We had a prostate cancer awareness session with someone from the Foundation as well, they talked about the symptoms and health checks and so on, which was good. Most guys don't like to talk about it or even think about it, so it was really good to get so many guys along to the presentation."

The participants in the fundraiser shaved off their beards when the roller compacted concrete on the 80 metre-high main dam was completed in December last year. The project is due for completion later this year.

Rachel Clarke

(See picture on next page Ed.)



The cheque! Peter Daley second from left.

Brandon Perrin second from right.