



THE WALNUT

June 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, 19 June 2013 at the [usual time and location](#). The guest speakers will be ACT chiropractors Dr Shona Hutchinson and Dr Andrew Norwood. They will tell us about the relationship of the brain, the nervous system and the spine.

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

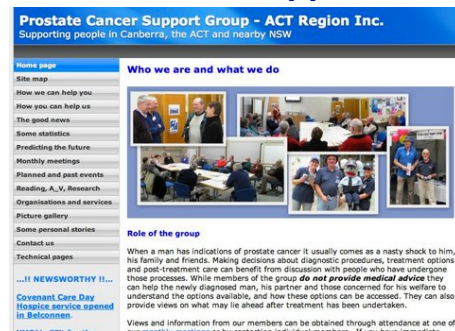
Phone: 02 6254 3493

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, and research and reports that could be of interest.

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/42fyrd>

Mike Boesen
Editor

President's report

My sincere thanks to Jim Clough for chairing the 15 May 2013 meeting. I understand that there was a large gathering there to hear Dr Hodo Haxhimolla speak about his recent trip to the USA to follow up on new developments.

The reason that Patricia and I were absent from the meeting was because we were obliged to represent our Group at the PCFA Training Conference held in Melbourne. Some 260 delegates from all over Australia attended this Conference which started on Sunday, 12 and concluded on Tuesday 14 May. On the afternoon of Tuesday, the NSW/ACT Support Groups Chapter Council held its AGM. It was a fairly hectic few days – the idea of the gathering was to instruct, through a series of interactive Workshops, those Convenors who were setting up new Support Groups. This was a project undertaken by PCFA with financial assistance from Cancer Australia, a Federal Government body, to increase the number of support groups around the country. The Workshops covered the legal and practical requirements, general governance matters, how to attract newly diagnosed members and how to advertise the Group's existence. Sitting through these Workshops, we were pleasantly satisfied that most, if not all, of the matters raised by the speakers had been in place within our Group for many years. The Conference was a great opportunity

to meet many other Support Group leaders from all over the country. There were a number of plenary sessions where we listened to speakers on pelvic floor muscles, psychological issues confronting men and their families on diagnosis, social issues felt by gay and bisexual men diagnosed with Prostate Cancer and Erectile Dysfunction. At the Gala Dinner the Guest Speaker was Andrew Wilkie, the Federal Member for Denison. Andrew was instrumental, some time back, in arranging for Cancer Australia to provide the funding to PCFA to assist with new support groups. I had an opportunity to chat with him and to thank him for his support.



In Canberra on Wednesday, 22 May 2012, Patricia and I represented our Group at a Membership Dinner hosted by SHOUT staff and management. (SHOUT = Self-help Organisations United Together). SHOUT provides our meeting room and storage room facilities in the Pearce Community Center at no cost to us. The dinner was designed to let member groups become aware of the existence of and workings of other members. We were obliged to present a small treatise on who we were, what we did and what our prime objects were. It was an interesting evening and provided an opportunity to meet and speak to leaders of other groups and learn about how and why they operated. At the conclusion of the evening we were asked to consider advertising, through our respective mediums, the existence of the SHOUT organisation and what it provides for its members.

At our next meeting, our Guest Speakers will be Dr Shona Hutchinson, a Chiropractor who practices in Woden, and her colleague Dr Andrew Norwood. I first heard Shona speak at a Movember function last year and I found her talk on the relationship of the brain, the nervous system and the spine to be inspiring. I urge members to come along and listen to her – you will be surprised!

Keep well,

Peter Daley

Report on the 15 May 2013 meeting

There were 32 members who attended the meeting, including two new members.

Discussion amongst members

As our guest speaker, Dr. Haxhimolla could not be present at the commencement of the meeting we proceeded to have new and existing members discuss their involvement with prostate cancer. One new member described his work with veterans and his continuing advocacy on their behalf. There was considerable discussion of the issues he raised and those raised by other members.

General business

I informed the group that the stall at the EJ-EH Holden Show at the Queanbeyan Show Ground had been a great success. I thanked those who had manned the stall. A total of \$940.25 had been raised by the organising club - EJ-EH Holden Club ACT Inc - through bucket donations, and the club very generously gave it all to our Group. We will be sending the Club a certificate of appreciation



Some of the guys at the Holden Show: From left: Geoff Schmidt and John Lucas from our group, with Club members David Fordyce and Ray Fitzpatrick - photo by Ben Coffison of our group

I indicated that the erectile dysfunction booklet produced by the the Combined Prostate Cancer Support Groups of Rural NSW was now back in print. Copies will be available at our next meeting.

There had been no further progress on the issue of providing CD players for use in the Radiation Oncology unit at TCH. This possibility will be evaluated in discussions with staff at TCH.

Members were advised of two meetings, one organised by the Cancer Council about legal and financial matters, to be held on Saturday 18 May, and a networking dinner hosted by SHOUT to be held on Wednesday 22 May.

Address by our guest speaker

Dr. Hodo Haxhimolla was the guest speaker. He spoke about several issues of importance to men with prostate cancer and their families and answered questions.

The first issue concerned biopsies, while the second dealt with erectile dysfunction.

He spoke about MRI-assisted biopsies which provide useful additional information to the traditional TRUS biopsy. He indicated that if the MRI biopsy is negative then a TRUS biopsy is still required. The MRI biopsy can only take a single sample, whereas he uses a 24-core sample TRUS biopsy. He stated that even with a 24-core sample there is a 20% chance of missing a cancer.

Dr Haxhimolla indicated that after using High Intensity Focussed Ultrasound (HIFU) he was unconvinced of its efficacy as a first line treatment for prostate cancer, but that it might be useful for salvage treatment.

He also noted that 40% of men who opted for watchful waiting developed more aggressive cancer and that at that stage they face a worse outcome than those opting for earlier more aggressive treatment.

Dr. Haxhimolla expressed the view that urologists should be able provide solutions to the problems created by cancer treatment - Erectile Dysfunction being one of those. He stated that it is essential to maintain the blood supply to the penis, and to this end advocated the use of a vacuum pump soon after the operation and Caverject approximately 6 weeks later. If functionality has not been reached after 12 to 18 months then the insertion of a penile implant could be considered. Dr. Haxhimolla explained what the operation involved and how the implant operated. He passed around a sample implant device so that members could better appreciate its construction and how it was operated.



Dr Haxhimolla with penile implant device

In answer to a question, he advised that medical oncologists were better able to manage chemotherapy than urologists.

Dr Haxhimolla fielded a lot of questions posed by members, after which he was thanked for his very informative presentation.



Jim Clough thanks Dr Haxhimolla for his address

Next Meeting

Our next regular monthly meeting will be on Wednesday 19 June 2013 at the usual time and location (see: <http://tinyurl.com/bjoyczu>). Details about the guest speakers are on page 1 of this newsletter.

Jim Clough

Book review - "Beyond Hormone therapy"

The following book review is reproduced with the kind permission of the Sydney Adventist Hospital Prostate Cancer Support Group. The review was written by Nigel Cook - a member of that Group.

Book review: "Beyond Hormone Therapy" by Mark A. Moyad (1st. ed.)

Mark A. Moyad, MD is a primary author of over 100 medical articles and numerous books which help men dealing with prostate cancer. He has maintained a consulting practice on complementary medicine in the USA for the past 15 years at the University

Overall, I found this book very informative and well-written from a layman's perspective (in other words, I could understand it!)

Of course, any book dealing with this sort of area is going to get out of date relatively quickly (the sooner the better, some of us may think, as then we would have a potential cure). However, possibly as it is written and published in the

USA and they have more treatments available to them than we have as yet, it will have a few more years of potency.

Whilst I found the book informative and easy to digest, I would not recommend it for general reading. It would be far better to read it if (and probably as soon as) one's cancer becomes 'resistant' to hormone therapy. It will then arm you with a very good background to enter into discussions with your oncologist over the best treatment for your situation.

I also would not advocate starting at page one and reading every page to the end, although the first section should be at least skimmed through as there is more than likely some new information there you may not be aware of. After that you can just read up on the particular treatment or other information you are interested in.

The book is divided into three sections, and each of these into several chapters. The first section, A Quick and Necessary Review, details the specifics of hormone resistance and prostate cancer in general, as well as all the hormone therapies currently available.

The second section deals with the treatments currently available (in the USA) for hormone-resistant prostate cancer. This section is very detailed on each drug, of which only some are

currently available here, including how they work, likely side-effects, and when they are best used. As even the drugs which are not available here very soon will be, this is necessary reading for anyone at this stage.

The last section, and perhaps one of the most interesting, deals with treatments in the pipeline (many of which are in early stages), how to deal with any side-effects, as well as diets, supplements and alternative medicine. In fact, the section on side-effects is over 130 pages long and is probably well worth a browse for almost anyone - including those not suffering from this disease - as some of the conditions are common to many people. Fortunately, all the side-effects dealt with are listed at the front of this chapter in alphabetical order, so it's easy to skip to the side-effects relevant to you.

Note: the book reviewed was the 1st edition. We have ordered a copy of the 2nd edition of the book for our library but it will not be available until September 2013. It is not in the catalogue of the ACT Library system; next time you are at the library you might care to recommend its acquisition.

Mike Boesen

Advanced prostate cancer support group

At the PCFA Training Conference held in Melbourne on 12 to 14 May I met some members of the *Advanced Prostate Cancer Support Group*. I was provided with the following details about the group and you may wish to contact one of the members if you have an interest. It would be good if you could let me know later as to whether or not you would recommend that group to other members of our group .

Advanced prostate cancer disease is simply prostate cancer that has escaped the gland. This can include PSA recurrence, locally advanced disease and confirmed metastatic cancer. We run a support group much like other support groups, with a few key differences:

- * *We cater for men with advanced disease and their partners*
- * *We provide a national monthly phone-in forum from home for the cost of a local call*
- * *We have a website which gives information about current and emerging treatments*
- * *Our website also has an on-line forum for exchanging questions and experiences*
- * *Men who phone in can simply be present as a listener, or as an active participant*

- * *This growing group attracts men from all over Australia, all of whom are on the same journey, and a number of whom have become quite informed about their disease.*

Phone contacts for more information:

Jim Marshall – 07 3878 4567
Neville Black – 07 4637 4018
Tony Maxwell – 02 9651 6682
David Abrahams – 07 4613 6974
Euan Perry – 07 3103 5135
Alan Barlee – 03 5750 1880

Our web address is jimjimjimjim.com

The group runs an active web forum - see here: <http://forums.jimjimjimjim.com>

Peter Daley

Recent articles and reports that might be of interest

The following articles that have appeared recently on web sites or other sources may be of interest to some members. The group's Executive has not attempted to evaluate the articles' findings and conclusions or the credentials of the authors. The articles are simply being drawn to your attention so that you can make your own evaluations.

Mike Boesen

American Urological Association's new guidelines on "Early detection of Prostate cancer"

At its Annual Meeting in May 2013 The American Urological Association (AUA) released new guidelines relating to the early detection of prostate cancer. A good summary of the guidelines and background and related events is in this Medscape Urology News article: <http://tinyurl.com/c98rctu> Other reportage exists, including this article in the New York Times: <http://tinyurl.com/d6f9983>

The full guidelines and the detailed analysis that led to their development can be read here:

<http://tinyurl.com/cc67nt6> The guidelines reflect a more constrained approach to early testing than is recommended by the PCFA or the Urological Society of Australia and New Zealand (USANZ).

In comparison, the testing and diagnosis policy of the PCFA is much more proactive: "Early detection is the key to enabling better outcomes and potential cure of prostate cancer. Accordingly, PCFA recommends that men at 50 with no family history of prostate cancer, and men at 40 with a family history, should talk to their doctor about being tested for prostate cancer in the

form of a Prostate Specific Antigen (PSA) blood test and Digital Rectal Examination (DRE) physical examination as part of their annual health check-up." (see <http://tinyurl.com/96rh19c> and <http://tinyurl.com/98skhpq>)

The Urological Society of Australia and New Zealand's policy is also more proactive. It recommends that men aged 40 or older should undergo an initial PSA test and their risk category determined in consultation between the patient and GP; those identified as being at higher risk should undergo regular tests; those at low risk should consider less frequent testing. (see <http://tinyurl.com/n76wv7m>)

Fish oil study suggests no benefit for patients with a high cardiovascular disease risk

While the study referred to below did not examine the relationship between fish oil and risk of prostate cancer occurrence, recurrence or morbidity, I thought that it may be of interest to those of you who may be taking supplements directed at reducing CVD risk.

The research study which included 12,513 patients was undertaken by Maria Roncaglioni *et al* and is reported in this May 8 2013 Medscape Urology News article by Michael O'Riordan: <http://tinyurl.com/kqg5qw3> The article states that "The supplemental use of n-3 fatty acids does not reduce the risk of cardiovascular morbidity and mortality in patients with multiple cardiovascular-disease risk factors." Supporting views of other researchers is mentioned in the article.

Opinion piece suggesting that more consideration be given to an active surveillance strategy for intermediate-risk prostate cancer patients

This opinion piece by Dr Hashim Ahmed comes to the conclusion that:

"...a growing body of data from randomized controlled trials of treatment versus no treatment as well as data from tissue-preserving strategies such as active surveillance have demonstrated that increasing numbers of men could safely avoid the harms of radical therapy. The uro-oncology research community needs to urgently prioritize studies that can determine whether such strategies should become standard care for intermediate-risk as well as low-risk prostate cancer in a timely manner."

In support of his views, the author cites results from two recent research studies - one by Bul *et al* and the other by Godtman *et al*, and findings of the Prostate Cancer Intervention versus Observation Trial (PIVOT) study.

Source: Nature Reviews Urology 10, 6-8 January 2013

Web link: <http://tinyurl.com/b3ga2s5>

Mike Boesen

Inverse association between Type 2 diabetes and risk of prostate cancer

A meta-analysis of epidemiological studies published between 1970 and 2011 came to the conclusion that Type 2 diabetes is significantly *inversely* associated with the risk of developing prostate cancer. The analysis was undertaken by Dr A Bhansali *et al*.

An abstract of their report is in this article in Prostate Cancer and Prostatic Diseases: <http://tinyurl.com/k9rrgr2>

New American Urological Association guideline for castration-resistant prostate cancer

In May 2013 the American Urological Association issued a "Guideline" relating to treatment of castration-resistant prostate cancer (CRPC). A summary of the guideline is presented in this 9 May 2013 Medscape Medical News article by Nick Mulcahy: <http://tinyurl.com/c4ob354>

The guidelines give consideration to the many drugs used in the treatment of CRPC including the new therapies that were approved for use in the USA since 2010: sipuleucel-T (Provenge, Dendreon), cabazitaxel (Jevtana, sanofi-aventis), abiraterone (Zytiga, Janssen), and enzalutamide (Xtandi, Astellas/Medivation).

The detailed guideline including the rationale for its structure is available from here: <http://tinyurl.com/czh88p7>

Treatment options for older prostate cancer patients

The conclusions reached by a research team led by Dr Timothy Daskivich at the UCLA are summarised in a May 20 2013 press release by Kim Irwin:

Older prostate cancer patients with other underlying health conditions should think twice before committing to surgery or radiation therapy for their cancer, according to a multi-center study led by researchers from the UCLA Department of Urology. The study reports 14-year survival outcomes for (3,183) men diagnosed with prostate cancer

between 1994 and 1995. The results suggest that older patients with low- or intermediate-risk prostate cancer who have at least three underlying health problems, or comorbidities, are much more likely to die of something other than their cancer.

"For men with low-to-intermediate-risk disease, prostate cancer is an indolent disease that doesn't pose a major risk to survival," said the study's first author, Dr. Timothy Daskivich, a UCLA Robert Wood Johnson fellow. "The take-home point from this study is that older men with multiple underlying health problems should carefully consider whether they should treat these tumors aggressively, because that treatment comes with a price."

The full press release is here:
<http://tinyurl.com/mcp3zd3>

Anna Azvolinsky's 28 May 2013 article in CancerNetwork provides a few more details here:
<http://tinyurl.com/qbf97yr>

Risk factors associated with development of prostate cancer

On 6 May 2013 Dr Norman Swan interviewed Lorelei Mucci who is Associate Professor of Epidemiology at the Harvard School of Public Health Boston.

This ABC RN broadcast can be listened to and/or a transcript downloaded from this source:
<http://tinyurl.com/c3mof7c>

The interview ranges over a number of risk factors associated with development of prostate cancer and prediction of its development, including: obesity, overweight, exercise, biological markers (e.g. genes, proteins), and STDs.

It also advocates consumption of coffee! Worth listening to.

Mike Boesen