THE WALNUT

February 2013

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

Affiliated with the Prostate Cancer Foundation of Australia

What's in this issue

- President's report - p 2
- Secretary's report - p 3
- Members' briefings at our next meeting - p 4
- Cancer Council ACT's program: "Living well after cancer" - p5
- Recent research and reports of interest - p 5

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, 20 February 2013 at the usual time and location. The speakers will be members who will brief us on their experiences. Details are provided later in this newsletter.

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, a "living well after cancer" program being offered by the Cancer Council ACT, newly reported research and articles of interest, and information about briefings that some of our members will give at the next meeting.

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/42fyrxd

Mike Boesen
Editor

President's report

I was extremely pleased with our first monthly meeting for 2013 with 36 members in attendance, including four new members. I cannot recall having such a large group and I thank all those who made the effort to come along.

The Guest Speaker was Vivienne van Dissel, Prostate Cancer Specialist Nurse at The Canberra Hospital (TCH).

Vivienne has been a staunch supporter of our Group for many years and we have had continual contact with her over the years and assistance from her on many occasions. She was previously the Urology Coordinator at TCH prior to her appointment as Specialist Nurse last year. Vivienne spoke to us about her activities as the Specialist Nurse over the past 12 months and addressed a number of questions on these specialised activities. She also informed us that she had visited Support Groups in Goulburn and Cooma and attended the National Urology Conference in Melbourne. Vivienne was asked about the success rate of brachytherapy. Her response was that the TCH now had a brachytherapy unit within the Radiation Oncology Department and the use of brachytherapy as a treatment was dependant on funding because of the cost of the radioactive elements used. Her view was that this type of treatment at TCH was comparable with the best in the world. On a question about a comparison of traditional laparoscopic and robotic surgery, Vivienne advised that there is an absence of long term data/results and currently it is not possible to determine which procedure was better. After the formal part of the meeting Vivienne was able to discuss specific matters of interest to individual members.

In the formal segment of the meeting I indicated that the Executive Committee felt that there was value in having the guest speakers at some of our meetings comprise members of our group who are able to brief us about experiences that would be of interest to our membership. Mike Boesen indicated that this type of activity is consistent with the suggestions made in the recent electronic survey that members could gain more insights from other members who have "been there, done that" and are willing to provide details, and that more meeting time should be given to discussion based on members' experiences. So at our coming February meeting we are arranging for two or three of our own members to speak to us about their experiences with different forms of treatment. It is something different in terms of guest speakers but I am sure members will find it to be an interesting evening. *(Currently two members have volunteered to*

give a briefing at the next meeting. Details about the content of the two member's briefings are provided later in this newsletter. We are keen to get a third member to give a briefing. If you think that your experiences would be of interest to members, please contact me on 6254 3493. Ed.)

I sought volunteers who could contribute a couple of hours to either of the following events:

- The Canberra Multicultural Festival in Civic on Sunday 10 February. I am pleased to say that it would appear that we now have sufficient volunteers to cover the day
- the Survivors' / Carers' Walk for Life at Seiffert Oval, Queanbeyan on Saturday16 February. We had some members attend this event last year and it would be appropriate if we were represented again this year. If you can spare an hour or so on that day, please let me know (phone 6291 0612).

Members may not be aware but our Executive Committee spends a lot of time and effort in meeting the objectives of the Group, which are extensive and most may not be well known to some members. At the AGM last year we lost the services of three hard-working members who felt that they needed a rest after years of great service. Whilst these people have been replaced, I indicated at the meeting that we urgently need members to assist us in the following activities:

- Meeting/greeting new members; introducing them to members of the Executive; making them feel welcome; telling them a bit about what will happen at the meeting. Arranging name tags.
- Managing a Guest Speaker schedule. This involves: contacting potential guest speakers to invite them to speak; informing them of our requirements (length of talk, focus of the talk, etc); asking them what audio-visual gear will be required (*which I will secure and set up on the night - Ed.*); providing details about our meeting location and parking; meeting and greeting them on arrival. The Executive would be able to identify persons and organisations that should be contacted, so pre-knowledge about who would be of interest as speakers is not a problem.
- Generating a list of target organisations, clubs, work groups and agencies that would benefit from an awareness presentation being given to their members. This could be done by searching for such targets using Google. We have a 2 page blurb about our awareness presentations that can then be sent to interested targets audiences *(see details about that later in this newsletter - Ed.)*. The presentations themselves would be given by one of our executive members or other members that are experienced in giving presentations.
- Organising an occasional (say, quarterly) women-only get together for women who are partners or carers of men who have been diagnosed with or treated for prostate cancer.

One member has offered to look after new members attending our meetings and I thank him for his offer. However, we are still looking for assistance with the other things that I have listed above. None of the tasks requires special skills or a lot of work - all that is required is a few phone calls and a bit of administration and for one task some web searching experience. If you can help the Committee in any of the tasks, please let me know (phone 6291 0612).

Let's see if we can have just as large a meeting this month as we did last month. In the meantime, keep well.

Peter Daley
President

Secretary's report on the 16 January 2013 monthly meeting

There were 36 members in attendance including four new members.

Guest Speaker

The Guest Speaker was Vivienne van Dissel, Prostate Cancer Specialist Nurse at The Canberra Hospital (TCH). After the conclusion of the formal part of the meeting Vivienne gave advice and information to a number of members about matters of interest to them.

General Business

President Peter addressed the meeting about the pressing need for more members to contribute time on the Group's activities. He indicated that at the moment the Executive group is hard pressed to undertake the myriad of organisational tasks that are required to meet the group's objectives and some of that load needs to be spread amongst the membership.

Future events

Peter informed members that volunteers are being sought to contribute a little time to the following events at which we have had representation in the past years:

- The Canberra Multicultural Festival in Civic on Sunday 10 February.
- The Survivors' / Carers' Walk for Life at Seiffert Oval, Queanbeyan on Saturday16 February.

New Members welcomed

Four new members were introduced to the meeting. Each spoke about their present situation. One was diagnosed last year with a Gleason Score of 10 and underwent surgery towards the end of June. Another reported on his surgery late last year and indicated that he now had a negligible PSA level but was still suffering from urinary incontinence problems. Another was recently diagnosed as having a Gleason Score of 7 and is about to undergo surgery. The fourth new member had surgery in Sydney last year with what now appears to be good results.

Updates from other members

Other members were invited to report on their status and progress, and a number did so.

Next Meeting

The next regular monthly meeting will be on 20 February 2013 at the usual time and location. There was some discussion about the proposed activities for that meeting. The Executive Committee proposes that two or three members brief the Group about their history and treatments and problems/successes that they experienced. Mike Boesen indicated that this type of activity is consistent with the suggestions made in the recent electronic survey that members could gain more insights from other members who have "been there, done that" and are willing to provided details, and that more meeting time should be given to discussion based on members' experiences.

George Kayaba

Secretary

Briefings by two (or three ?) members to be given at our February meeting

At our next meeting our guest speakers will be group members who will brief us in detail about their experiences and field questions raised by the audience. The two members that we have lined up so far:

Roger Allnutt

Roger will tell us about his experiences with radiation and hormone therapy. His story is on our web site here: http://tinyurl.com/avcvjvn and Roger will elaborate on its contents and bring us up to date.

Terry Bibo

Terry will tell us about his long-term urinary incontinence problem following a prostatectomy by open surgery. Terry then had a sling installed but after some time it failed and had to be removed. Some time later he had an artificial urethral sphincter fitted and that is working well.

Each of the members will talk to the group for about 15 minutes and then field questions and elaborate on any particular matters of interest.

We would like to have a third member present a briefing. If you think that your experiences would be of interest to members, please contact me on 6254 3493.

Mike Boesen

Editor

Cancer Council ACT - "Living well after cancer" program

The Cancer Council ACT has requested that we publicise their "Living well after cancer" program. Their flyer can be viewed here: http://tinyurl.com/agbsr96

It states the following:

> The Living Well After Cancer program is a **free program** for cancer survivors, their family and friends and is run by Cancer Council with trained cancer survivors. If you know someone who has recently finished cancer treatment and may benefit from this program, please feel free to forward this email onto them and their family.
>
> You may find that you see the world differently after cancer. Perhaps you feel that others don't understand your experience and expect you to "get back to normal".
>
> Cancer and its treatment can bring a host of practical challenges, from changes in appearance and body function to managing the emotional and social impacts.
>
> This two and a half hour program includes practical information and open discussion for people who are cancer survivors, carers, family, friends and work colleagues. As a participant, you will learn about the possible changes, challenges and opportunities you may face after completing cancer treatment.
>
> You will also have the opportunity to connect with others on a similar journey, and share tips, ideas and activities to help you live your life well.
>
> Saturday 16 February 2013
> Time: 10am-12.30pm

RSVP: Friday 8 February 2013 (registrations essential)
Call: 1300 200 558 (local call cost)

Mike Boesen
Editor

Recent research articles and reviews that might be of interest

The following articles that have appeared recently in various web publications may be of interest to some members. The members of the Executive have not attempted to evaluate the articles' findings and conclusions and the credentials of the authors. The articles are simply being drawn to your attention so that you can make your own evaluations. Some items are a bit technical and heavy going.

Time for active surveillance of intermediate-risk disease?

Author: Hashim U. Ahmed

Source: Nat. Rev. Urol. 10, 6–8 (2013); published online 13 November 2012; doi:10.1038/nrurol.2012.213

Web source: http://tinyurl.com/b3ga2s5

Author's abstract:

> Active surveillance has become increasingly popular as a management option for localized prostate cancer. Although widely viewed as a means to enable men with low-risk prostate cancer to avoid or defer the effects of whole-gland radical therapy, two new studies demonstrate that it might be a safe approach in intermediate-risk disease.

The link between benign prostatic hyperplasia (BPH) and prostate cancer

Authors: David D. Ørsted, Stig E. Bojesen

Source: Nature Reviews Urology 10, 49-54 (January 2013) | doi:10.1038/nrurol.2012.192

Web link: http://tinyurl.com/aar49mp

Author's abstract:

> Benign prostatic hyperplasia (BPH) and prostate cancer are among the most common diseases of the prostate gland and represent significant burdens for patients and health-care systems in many countries. The two diseases share traits such as hormone-dependent growth and response to antiandrogen therapy. Furthermore, risk factors such as prostate inflammation and metabolic disruption have key roles in the development of both diseases. Despite these commonalities, BPH and prostate cancer exhibit important differences in terms of histology and localization. Although large-scale epidemiological studies have shown that men with BPH have an increased risk of prostate cancer and prostate-cancer-related mortality, it remains unclear whether this association reflects a causal link, shared risk factors or pathophysiological mechanisms, or detection bias upon statistical analysis. Establishing BPH as a causal factor for prostate cancer development could improve the accuracy of prognostication and expedite intervention, potentially reducing the number of men who die from prostate cancer.

New Agents for the Management of Castration-Resistant Prostate Cancer

Author: Robert J Cersosimo

Source: The Annals of Pharmacotherapy. 2012;46 (11):1518-1528.

Web link: http://tinyurl.com/bn8hvpg

Author's abstract:

> **Objective:** To review the activity of 3 new agents approved for the management of advanced castration-resistant prostate cancer (CRPC): sipuleucel-T, cabazitaxel, and abiraterone acetate.
>
> **Conclusions:** The advent of new agents for the management of advanced CRPC has increased the choices for patients whose options were limited. Additional experience will determine the optimal sequencing of these agents, their roles in combination therapy, and their activity in patients with earlier disease.

Maximizing Survival in Metastatic Castrate-resistant Prostate Cancer

Author: Alison Birtle

Source: Medscape Urology News: Expert Rev Anticancer Ther. 2013;13(1):89-99.

Web link: http://tinyurl.com/b8g2yt8

Extract from the article:

> Recently, licensed and emerging treatments for metastatic castrate-resistant prostate cancer are transforming the prognosis for men whose disease

has already progressed during or after docetaxel-based chemotherapy. Two agents (cabazitaxel and abiraterone) are already accessible to prescribers, having shown survival benefits versus their comparators in randomized controlled trials, and other agents are showing promising results. A future in which metastatic castrate-resistant prostate cancer can be managed as a 'chronic disease' looks tantalizingly close. The challenge for clinicians will be to use these treatments rationally, in a way that optimizes each individual patient's chances of prolonged survival.

Abiraterone in Metastatic Prostate Cancer without Previous Chemotherapy

Authors: Charles J Ryan *et al*

Source: N Engl J Med 2013; 368:138-148January 10, 2013DOI: 10.1056/NEJMoa1209096

Web link: http://tinyurl.com/avyayp5

Extract from the article:

Background: Abiraterone acetate, an androgen biosynthesis inhibitor, improves overall survival in patients with metastatic castration-resistant prostate cancer after chemotherapy. We evaluated this agent in patients who had not received previous chemotherapy.

Conclusions: Abiraterone improved radiographic progression-free survival, showed a trend toward improved overall survival, and significantly delayed clinical decline and initiation of chemotherapy in patients with metastatic castration-resistant prostate cancer.

FDA approves use of prostate cancer pill (abiraterone) before chemo

Author: Kate Johnson

Source: Medscape Urology News, Dec. 11 2012

Web link: http://tinyurl.com/arvl486

Extract from the article:

The US Food and Drug Administration (FDA) has approved the expanded use of abiraterone acetate (*Zytiga*, Janssen Biotech Inc) to first-line therapy for metastatic castration-resistant prostate cancer (mCRPC). The drug, which decreases testosterone production, was approved in April 2011 as a second-line treatment after docetaxel chemotherapy in the same population. This expanded approval "demonstrates the benefit of evaluating a drug in an earlier disease setting and provides patients and healthcare providers the option of using [abiraterone] earlier in the course of treatment," Richard Pazdur, MD, director of the Office of Oncology Drug Products in the FDA Center for Drug Evaluation and Research, stated in an FDA news release. The expanded use of abiraterone was approved by the FDA's priority review program on the basis of a randomized double-blind study, which was published online December 10 in the *New England Journal of Medicine*. *(That is the Ryan et al study referred to above - Ed.)* It comes on the heels of a recommendation made last month by the Committee for Medicinal Products for Human Use at the European Medicines Agency, which usually means an approval in Europe.

Abiraterone benefit extends to bone-related symptoms

Author: Sarah Payton

Source: *Nature Reviews Urology* **10**, 1 (January 2013) | doi:10.1038/nrurol.2012.232

Web link: http://tinyurl.com/byhjb4k

Extract from the article:

Abiraterone acetate not only improves survival but also provides pain relief and delays the occurrence of skeletal-related events, compared with placebo, in patients with metastatic castration-resistant prostate cancer (CRPC), according to new analysis of the COU-AA-301 trial published in *The Lancet Oncology*.

Postoperative radiotherapy after radical prostatectomy for high-risk prostate cancer: long-term results of a randomised controlled trial (EORTC trial 22911)

Author: Michel Bolla *et al*

Source: The Lancet, Volume 380, Issue 9858, Pages 2018 - 2027, 8 December 2012 doi:10.1016/S0140-6736(12)61253-7

Web link: http://tinyurl.com/bsc5yzz

Extract from the article:

Background: We report the long-term results of a trial of immediate postoperative irradiation versus a wait-and-see policy in patients with prostate cancer extending beyond the prostate, to confirm whether

previously reported progression-free survival was sustained.

Interpretation: Results at median follow-up of 10·6 years show that conventional postoperative irradiation significantly improves biochemical progression-free survival and local control compared with a wait-and-see policy, supporting results at 5 year follow-up; however, improvements in clinical progression-free survival were not maintained. Exploratory analyses suggest that postoperative irradiation might improve clinical progression-free survival in patients younger than 70 years and in those with positive surgical margins, but could have a detrimental effect in patients aged 70 years or older.

Comparison of side effects for treating prostate cancer via radical prostatectomy and IMRT (Intensity-Modulated Radiotherapy)

Author: Fran Lowry

Source: Medscape Urology News, 30 January 2013

Web link: http://tinyurl.com/ccqn4dh

Extract from the article:

Men *(aged 55 to 74 at treatment - Ed.)* with localized prostate cancer who elect to have prostatectomy or radiotherapy will experience problems with urinary, bowel, and sexual function in the long term, according to a new study published today in the *New England Journal of Medicine*.

Data from the Prostate Cancer Outcomes Study (PCOS) show that in the short term, men who have had surgery will have more urinary incontinence and sexual dysfunction, and those who have had radiotherapy will have more bowel dysfunction, but by 15 years, dysfunction in all domains is not significantly different.

"Whatever the reason, it could be aging, it could be the treatment, it could be secondary treatments, but in the long run, there are not a lot of differences between the 2 primary treatments for localized disease, whether they are surgery or radiation," senior author David F. Penson, MD, from Vanderbilt University, Nashville, Tennessee, told *Medscape Medical News*. The results from PCOS should give men with localized prostate cancer pause before they choose a treatment, Dr. Penson said. (*See abstract for that study here: http://tinyurl.com/axqvyrc*

Note: the men in this study were aged between 55 and 74 at treatment and so would have been aged 70 to 89 at the 15-year follow-up date.

Nomogram tool updated for predicting prostate cancer severity

Author: Nick Mulcahy

Source: Medscape Urology News, 9 January 2013

Web link: http://tinyurl.com/afumo2c

Extracts from the article:

An update of the staging nomogram known as the "Partin tables," which predicts the severity of prostate cancer and helps clinicians and patients make treatment decisions, has been published in the January 3 issue of the *British Journal of Urology International*.

The tool uses commonly available preoperative data - serum prostate-specific antigen (PSA) level, clinical stage, and biopsy Gleason score - to accurately predict pathologic stage, which can only be fully assessed once the prostate is surgically removed.

The update is based on a study of more than 5600 men treated at Johns Hopkins from 2006 to 2011. Earlier versions of the nomogram were also based on patients at the institution; this single-center data pool is a limitation of the tool.

By inputting the PSA, Gleason score, and clinical stage into the updated Partin tables and clicking the Find Results button, an individual can see the percentage chance that the cancer is confined to the prostate, has migrated to the edge of the gland, has invaded the seminal vesicles, or has spread to the lymph nodes.

The nomogram tool can be accessed here: http://tinyurl.com/dme35x The term "clinical stages" is explained on this page of our web site: http://tinyurl.com/a3xkkk2

Mike Boesen

Editor

Our flyer that we distribute to inform people about our awareness presentations

We have a two page flyer which we send to people and organisations that may have an interest in having one of our members provide a prostate cancer awareness. The flyer is available in printed and electronic form. Its content is as follows.

Prostate cancer Support Group - ACT Region Inc.

LET'S HAVE A TALK ABOUT PROSTATE CANCER

If you need to know the basics about prostate cancer and how it could affect you or those dear to you, our Group can provide that information. We have members who can give a powerpoint presentation followed by a question and answer session. The presentation can be tailored to the needs of your group.

Who are we?

The **Prostate Cancer Support Group - ACT Region Inc.** is a voluntary association of men (and partners of men) who have been diagnosed in the past as having prostate cancer. The men have undertaken procedures that are used in detecting and diagnosing prostate cancer, undergone various treatment options and rehabilitation activities. Their ages range from 45 to 90.

We are NOT medical practitioners or medical experts; we are simply people who are able to provide information and suggestions to other people, based on our real-life experiences with prostate cancer and its treatment.

We are affiliated with the Prostate Cancer Foundation of Australia (PCFA).

What are our group's objectives?

The groups objectives are to:

- promote testing that will lead to early detection of prostate cancer
- provide information and sources of information about prostate cancer and the options for detection, diagnosis and treatment
- provide support to those diagnosed with prostate cancer and to their partners
- convince Government of the need to allocate more resources to activities relating to prostate cancer
- provide financial support for training of prostate cancer nurses
- raise funds for PCFA and assist through its consultative processes

How do we achieve those objectives?

We try to achieve those objectives through:

- presentations to workgroups and social groups
- awareness-raising stalls at events
- if needed, one-on-one confidential support
- group discussions at monthly meetings
- organising presentations to be made by medical experts
- our library
- our web site
- our monthly newsletter
- submissions to the Government/s and to PCFA
- funding the training of prostate cancer nurses

What we can cover in a presentation to your group

We can do this in a presentation:

- provide basic information about what prostate cancer is and its prevalence
- describe its symptoms (which can be non-existent)

- indicate risk factors associated with its occurence
- explain how it can be detected and diagnoseddescribe treatment options and their possible side effects
- inform you about how our Group functions and how it can be of assistance
- give you the names of Group members you can contact
- inform you about our library, our web site, newsletter and some excellent other sources of information
- tell you the good news

What's the good news?

- If prostate cancer is detected early, the chances of treatment leading to enduring remission and with minimal or manageable side effects are good
- Prostate cancer is usually slow growing and after treatment, survival rates are high and improving
- Even if not detected early, there are treatments for which side effects are manageable, enabling an enjoyable and useful life for many years

Who would gain from our presentation?

These types of people would benefit from the presentation:

- men aged 40 or more
- partners or friends of such men

What happens in our presentations?

We can tailor a presentation to meet the needs of your group. Our most common form of presentation is:

- about 40 minutes of a powerpoint presentation
- followed by about 15 minutes for questions and answers
- presenter usually a male member of our Group and where possible assisted by a female who would provide a woman's perspective
- informal situation

For more information or for copies of this document:

Contact one of these people:

- Peter Daley (President): Phone 6291 0612 Email: monashmm@bigpond.net.au
- George Kayaba (Secretary): Phone 6286 5254 Email: gakayaba@tpg.com.au

Or go to our web site: prostate-cancer-support-act.net

This document in PDF format can be downloaded from the following source and can be reproduced and distributed without any restrictions: http://tinyurl.com/4nfbfcc