

THE WALNUT

March 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, 20 March 2013 at the usual time and location. Members will be notified by email about who will be the guest speaker at the meeting.

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 some articles 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/42fyrxd

Mike Boesen Editor

President's report

At our meeting on 20 February 2013 we had a bumper attendance - for which I am extremely grateful. The night was slightly different in that rather than having an expert guest speaker, three of our members spoke to us in detail about various aspects of their treatment, followed by a question and answer session. There was an extensive discussion about aspects of each person's treatment and experiences and a very useful exchange of information between those attending. Comments made at supper time indicated that the presentations and consequential discussion were informative and interesting and that similar sessions should be conducted in the future from time to time.

There was not a great deal of general business to be attended to. I thanked all those members who assisted at our awareness table at the Canberra Multicultural Festival on 10 February 2013. I also expressed our gratitude to John and Marcia Stiebel for attending the Survivors' Carers Walk at Seiffert Oval in Queanbeyan on 16 February. Despite their less than perfect mobility, they actually walked 5 laps of the oval. They were impressed with the evening concert which followed. Congratulations to two of our senior members!

The Combined Prostate Cancer Support Groups of NSW have produced a small booklet on Erectile

Dysfunction – we had some copies available at the meeting. If anyone desires a copy, please let me know and I will order additional copies.

Bunnings Warehouse at Fyshwick are organising a Community Open Day at their store on Saturday 9 March 2013 and we have been invited to run an awareness table. By the time you receive this newsletter this date will have passed but we have sufficient members to staff the table for the 3 hours (11am – 2pm) of the Open Day. Bunnnings are great supporters of our cause and we are always grateful for the opportunity they provide to us to chat with the general public and get the prostate cancer awareness message across.

Help! We still desperately need a couple of guys or gals to take on these tasks:

- organising a roster of Guest Speakers for our meetings and liaising with them
- making up a list of community groups to which our 2-page flyer about our awareness presentations could be sent, and making appointments for such presentations (this task would not require you to present or to attend presentations that would be undertaken by one of our members who have had training in that task).

Neither is a difficult task and I would ask that you give consideration to taking on one of them. The executive committee will provide advice, ideas, suggestions and whatever other help you may require. Please call me on 6293 2532 if you can help.

Our next meeting is on Wednesday, 20 March 2013. As guest speaker I hope we can have one of the Prostate Care Nurses to whom we provided financial support to undertake special training, to tell us about the training and its implications for treatment and rehabilitation of prostate cancer patients.

Keep well,

Peter Daley President

Secretary's report for the 20 February 2013 monthly meeting

There were about 40 members in attendance including five new members.

Speakers

Three of our members gave presentations to the group detailing their history with prostate cancer and treatment thereof:

Terry Bibo

Terry informed the group about incontinence that persisted for 18 months after a radical prostatectomy. He then had a sling inserted and that worked very well for four years, but then failed. A cystoscopy indicated that the sling had eroded and collapsed and was not remediable. It was removed. After recovery from that operation he had a urethral sphincter installed. It was "activated" after 6 weeks. Since then it has functioned satisfactorily, with nil incontinence.



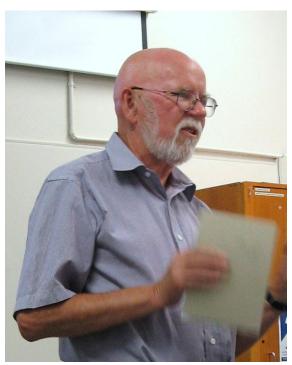
Terry Bibo presenting

Terry indicated that given a choice between a sling (if it performs properly and does not deteriorate) and an artificial sphincter, he would choose the sling. (A copy of the slides used by Terry are on this page of our web site: http://tinyurl.com/auujqum Ed.)

Roger Allnutt

Roger told the group about his situation prior to 2009 at which time he undertook treatment: a rising PSA that at the time he had a biopsy reached 40. The biopsy indicated prostate cancer with a Gleason score of 9 and scans that did not preclude the possibility of extra-capsular spread. After consultations with a number of medicos - including a urologist, radiation oncologist and others - he opted for radiation and hormone therapy. That was undertaken in 2009. Since then after detecting rising levels of PSA he had repeat hormone therapy treatments. Bone scans have not indicated spread. He indicated that he has experienced side effects such as episodes of tiredness and hot flushes. He also reported loss of sexual function. Recently he has suffered a heart attack and he noted that a brochure given to him by Vivienne Van

Dissel suggested that hormone treatment can have consequences for raised risk of heart attack, Type 2 diabetes and also heightened 'bad' cholesterol which he said - is "exactly what I have had". (Roger's full story can be read on this page of our web site: http://tinyurl.com/avcvjvn Ed.)



Roger Allnutt presenting

Peter Daley

Our President - Peter Daley - informed members about the diagnosis of prostate cancer in late 2005 when a biopsy indicated a Gleason score of 9. In early 2006 he had a radical prostatectomy. However, analysis of excised material indicated traces of cancer in the margins and in the seminal vesicles. In



December 2006 he commenced EBRT (External Beam Radiation Therapy) - 32 sessions over 7 weeks. Peter provided informative details about EBRT. Rising levels of PSA soon after his EBRT led to ADT (Androgen Deprivation Therapy) in August 2007 and he has had repeat ADT about every 12 months subsequently. Peter indicated that it is common for there to be side effects from EBRT, one of which he experiences - fatigue. (A copy of the slides used by Peter are on this page of our web site: http://tinyurl.com/cmajwx8 Ed.)

There was considerable discussion between members and the presenters during and after the presentations and this appeared to be of considerable value to those present.

General Business

The President mentioned a number of matters:

- Thanks to those members who flew the flag at the Canberra Multicultural Festival on Sunday, 10 February 2013
- Thanks to John and Marcia Stiebel for representing the Group at the Survivors' Carers Walk at Queanbeyan on Saturday 16 February;
- No response from the Monaro Group regarding the possible operation of an awareness table at the 2013 Wellbeing Expo at Cooma on Saturday 16 March.
- The NSW/ACT Chapter Council AGM to be held in Melbourne in May – in view of the absence of any indications of interest, Peter and Patricia Daley have agreed to represent our Group.
- The Chapter Council are seeking nominations for Councillors for the coming year as 6 of the 9 councillors are retiring. The President asked members to consider nominating as we had not been represented on the Council since Dennis Armstrong moved to Melbourne almost 2 years ago.
- A note from Heather McGowan from the Health Care Consumers' Association about a walk to Mt Kosciusko.
- The Combined Prostate Cancer Support Groups of NSW have produced a small booklet about Erectile Dysfunction. Some copies are available and if further copies are required, these can be obtained from our librarian.
- An invitation from Bunnings Store at Fyshwick for our Group to participate in a Community Open Day on Saturday 9 March from 11am to 2pm. Volunteers were sought.
- The Group is still seeking a member to arrange for Guest Speakers and another to arrange for our Prostate Cancer presentations.

New Members welcomed

Five new members were introduced to the meeting. Each spoke about their present situation.

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 March 2013 at the usual time and location.

George Kayaba

Secretary

Major awareness-raising and fund-raising event concluded at Cotter Dam

In September 2012 members of the Group's executive gave four prostate cancer awareness presentations at the Cotter Dam site. In total, about 200 workers attended these presentations. The idea of the presentations was that of Brandon Perrin - Project Engineer at the site. It was due to his efforts that we were able to inform so many workers about prostate health.



One of the groups that attended an awareness presentation





Brandon (with beard!) after one of the presentations

In addition to being impressed by Brandon's success in getting so many workers along to the presentations we were also impressed with the fact that he had set up an arrangement with the workers and administrative staff to raise funds for the PCFA. This involved the workers in growing beards for which small monthly prizes were awarded. He also persuaded the contracting companies within the Bulk Water Alliance - the John Holland Group, Abi Group, GHD and the ACTEW Corporation - to each match what funds the workers might raise.

As construction of the dam wall is nearing completion, the fund-raising scheme was brought to a conclusion in February 2013. On 2 March 2013 I was invited to a lunch-time gathering at which I was presented with a cheque for \$44,000 for the PCFA. On behalf of the PCFA I presented certificates of appreciation to Brandon and his assistants for their work in managing the fund-raising scheme and to the Bulk Water Alliance.

The activities of Brandon and his co-workers and the co-operation and generosity of the Bulk Water Alliance have been quite outstanding and all those involved are to be applauded. The outcomes have been a significant increase in awareness about prostate health and a large donation that will be support the invaluable work of the PCFA. Well done all those involved!

Peter Daley

Recent articles and reports that might be of interest

The following articles that have appeared recently in various web publications 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.

"The changing landscape in the treatment of metastatic castration-resistant prostate cancer"

In the author's words, "This review describes the clinical trials that brought about the drug approvals of various agents and offers some insights regarding a rational approach to optimal treatment sequencing for these drugs since national guidelines are currently lacking."

Author: Joelle El-Amm et al

Source: Ther Adv Med Oncol. 2013;5(1):25-40

Web link: http://tinyurl.com/c6jtd2a

Extract from author's abstract:

"The past few years have brought increasing advances in the therapeutic management of metastatic castration-resistant prostate cancer with the approval of several agents, including vaccine therapy with sipuleucel-T, second-line chemotherapy with cabazitaxel, the bone-targeted pharmaceutical denosumab, and the novel antiandrogen therapy abiraterone acetate. There are ongoing developments with other agents in the pipeline such as MDV3100 and alpharadin that have shown promising results."

"Chemotherapy for Prostate Cancer - When Should a Urologist Refer a Patient to a Medical Oncologist?

This article by Dr N D Shore of the Carolina Urologic Research Center provides *inter alia* a comprehensive description of chemotherapy agents that may be used in treatment of castrate-resistant prostate cancer. (CRPC).

The author concludes the article with this optimistic statement: "The way of the future in CRPC treatment points to the application of multiple agents, each with a particular efficacy at a particular stage of disease, administered to the same patient at various times with appropriate sequencing."

Author: N D Shore

Source: Prostate Cancer Prostatic Dis. 2013;16(1):

1-6.

Web link: http://tinyurl.com/b9aqbkg

Author's abstract:

"The last few years have seen considerable evolution in treatment options and therapeutic strategies for patients with castrate-resistant prostate cancer (CRPC). One major change was the expansion of chemotherapeutic options with the approval of cabazitaxel, representing the first chemotherapeutic therapy after docetaxel to demonstrate improved survival in patients with CRPC. A number of other noncytotoxic therapies have either recently been approved or are in advanced development for treating this patient population. Offering novel mechanisms of action, these new agents make considerably more expansive and complex the decisions regarding when to treat, which agents to use, and the order in which they are administered. A pivotal decision point for urologists who treat patients with advanced prostate cancer has been timing the patient's referral to an oncologist for chemotherapy. Although clinical guidelines regard chemotherapy as only appropriate for prostate cancer patients with symptomatic metastatic disease, increasing evidence points to the possibility that a subgroup of patients may benefit from an earlier introduction of chemotherapy. At the same time, additional treatment options that may either precede chemotherapy or follow initial chemotherapeutic failure mean that urologists must closely monitor their patients' health status to match specific clinical profiles with specific treatment options. With the increase in number and variety of therapeutic approaches, the role of the urologist has been expanded, in part, owing to the opportunity for urologists to administer treatments previously unavailable, and also owing to the growing importance of working cooperatively with oncologists and as a member of a multidisciplinary team."

"Shorter ADT appears to be best for highrisk prostate cancer"

A Medpage Today article reports a single phase 3 trial undertaken by a team led by Dr Abdenour Nabid, in which they compared the effectiveness of 18 months of adjuvant androgen deprivation therapy (ADT) with 36 months. The team concluded that ADT over 18 months was as effective as that for 36 months.

Reporter: Charles Bankhead

Date: 12 February 2013

Web link: http://tinyurl.com/agif7kg

Extracts from the article:

"Men with node-negative high- risk prostate cancer lived just as long with a 50% shorter duration of androgen deprivation therapy (ADT) compared with standard duration therapy, results of a randomized clinical trial showed.

"After a median follow-up of 6.5 years, 76.2% of patients who were treated with pelvic radiotherapy and androgen blockade remained alive after 18 months of ADT versus 77% of the men whose hormonal treatment continued twice as long, reported Abdenour Nabid, MD, of Sherbrooke University Hospital in Quebec.

"The treatment groups also did not differ with respect to 5- and 10-year overall and disease-specific survival (DSS), said Nabid during a press briefing prior to the Genitourinary Cancers Symposium. 'In localized high-risk prostate cancer treated with radiotherapy and androgen blockade, androgen blockade duration can be safely reduced from 36 to 18 months.' he explained. 'Eighteen months of androgen blockade could represent the threshold effect, with no further benefit for our patients. For these patients, side-effect duration and treatment costs of androgen blockade are significantly reduced.' 'My hope is that the shorter duration can become the standard,' he added.

A summary of the results reported in Nabid's paper are reported in this Prostate Cancer Infolink article: http://tinyurl.com/agkfysd

Note: Making generalisations from the results of a single study would be inappropriate. Bankhead cautions that "This study was published as an abstract and presented at a conference. These data and conclusions should be considered to be preliminary until published in a peer-reviewed journal."