

AN ANNUAL REVIEW

At the July meeting we reviewed the operations of our Support Group. We are very grateful to Amanda Pomery, the PCFA Support Group and Outreach Coordinator (Vic/Tas) for attending and helping us to conduct this review.

The immediate leadership issues caused by the health problems experienced by Max Shub and Patrick Woodlock have been resolved for the moment. Now that Max is out of hospital, he is keen to resume an active leadership role. If Max is unable to attend a meeting, then Christopher Ellis will act as the convenor of

the meeting in his place. Paul Hobson has taken over editing the newsletter from Patrick Woodlock. Spiros Haldas will continue as the Group's Librarian. The Steering Committee will work further on succession planning.

Amanda outlined the results of research that she had done on all types of health support groups, including breast cancer groups, not just prostate cancer support groups. She said that the issues confronting Prostate Heidelberg were by no means unique.

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Our Next Meeting

Date: **Wednesday 13 August 2014.**
Time: **10:00 am to 12.30 pm,**
Place: **Ivanhoe Uniting Church, Seddon Street, Ivanhoe** (Melways 31 F8)
Free car parking available at rear.

- Meetings are open to anyone interested in getting support or information on a prostate cancer journey.
- Partners or carers are welcome to all meetings
- **There is no charge for attending.**

Guest Speakers Dr Steve Fraser and Patrick Owen **Exercise and Nutrition Programs that assist Prostate Cancer Survivors**

The foods we eat and our physical activity habits are fundamental to our health and well being.

Deakin University's Centre for Physical Activity and Nutrition Research is a multi-disciplinary research centre recognised internationally for its expertise in nutrition and physical activity.

Dr Steve Fraser and Pat Owen, a PhD Candidate at Deakin University's Centre for Physical Activity and Nutrition Research will speak about Exercise and Nutrition Programs that can assist Prostate Cancer Survivors.

At present Steve and Pat are working on a clinical trial that is investigating whether exercise and nutritional supplementation can reduce the side effects of androgen deprivation (hormone) therapy.

More information about this trial can be found at
<https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=364420>



An Annual Review (contd from pg 1)

Research showed that many men do not want to join support groups. Many men come along to a few meetings and then cease to attend after they have obtained the information that they were seeking. This was to be expected and was a part of the Group meeting the needs of men diagnosed with prostate cancer.

Although numbers of men attending meetings had declined over the last 18 months, Amanda pointed out that bigger is not necessarily better. Studies showed that the most effective meeting size for a support group was between 6 to 12 people.

Even though members were not attending every meeting, the work of Patrick in producing a high quality newsletter meant that members were being provided with excellent information about prostate cancer.

Amanda pointed out that one of the alternatives open to the members on this review was to discontinue the group. The meeting considered that Prostate Heidelberg was still providing important support and information and should not be discontinued.

There was then a discussion about ways of recruiting new members. The Group was not getting many referrals from local urologists. Amanda said that the lack of referrals from urologists was a common problem being faced by all prostate cancer support groups. A comment was made that the appointment of PCFA funded specialist prostate cancer nurses had resulted in these nurses referring patients to hospital support groups, rather than community based support groups.

It was suggested that the group should combine with a hospital support group or operate from one of the local hospitals. The meeting felt that it was important for support to be provided in a community, rather than a hospital, setting. Prostate cancer support groups run by hospitals tended to become "medicalised" and treatment-based and

lacked the emotional support which is found in a community peer support group. It was felt that community peer support groups produced a greater degree of involvement and empowerment of patients.

Little has done in recent times to publicise the Group's services. Advertisements in the local paper were considered not to be cost-effective. It was agreed to publicise the Group's services by placing racks of the newly developed PCFA brochures (stamped with details of Prostate Heidelberg) in local RSL and Bowling Clubs. Max will also speak to a number of urologists at the ANZUP meeting about placing brochures in their rooms.

World Cancer Congress Melbourne 3 - 6 December 2014

Held every two years, the World Cancer Congress is the leading international conference on the latest implementation of cancer control. There will be over 2,500 participants coming from 150 countries bringing together the whole spectrum of cancer control experts - including researchers, clinicians, consumer experts, advocates and other influential players, providing a unique mix of expertise.

In 2014 the Congress is being held in Melbourne at the World Congress Centre ("Jeff's Shed")

The 2014 Congress theme *Joining Forces - Accelerating Progress* will emphasise the impact that can be realised by consistently and energetically applying what we know, rather than waiting for possible future "breakthroughs" to change the landscape.

The final day of the Congress, Saturday 6 December, has been set aside as a Consumer Day. The program for this is still being finalised.

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Are you interested in going to the Consumer Day at the World Cancer Congress?

The Prostate Cancer Foundation of Australia is calling for expressions of interest from members of PCFA Support Groups wishing to attend the Consumer Day. Depending on the numbers who express interest, it may not be possible for everyone interested to attend (PCFA will fund the cost of registration for the Consumer Day for any member chosen to attend).

If you are interested in attending the Consumer Day, please let us know at the monthly meeting or by emailing prostateheidelberg@gmail.com saying that you are interested in attending.

You need to express your interest by Wednesday 10 September 2014 (the date of the September meeting) at the latest. PCFA will tell us in early October who can attend the Consumer Day.

Different Prostate Cancer Support Groups

Not all prostate cancer support groups are the same. Groups can be face to face, on-line or by teleconference. Some groups have a special focus or address particular needs.

One of the sessions at the recent PCFA VIC-TAS Chapter Training Conference was a Roundtable Discussion about Diversity in Support Groups.

This Roundtable Discussion looked at a number of different groups including the following:

- The Australian Advanced Prostate Cancer Support Group
- The Younger Prostate Cancer Support Group
- The Gay Melbourne Prostate Cancer Support Group

The Australian Advanced Prostate Cancer Support Group

There are approximately 22,000 Australian men alive today with advanced prostate cancer. Men with advanced prostate cancer have a very different journey from men with localised prostate cancer. This support group provides information and support for these advanced men.

Members have a monthly meeting by phone conference, usually the last Friday of the month.

Members can also obtain information and participate in online forums at www.JimJimJimJim.com

For further information, visit the website www.JimJimJimJim.com or email paul@JimJimJimJim.com

The Younger Prostate Cancer Support Group

Around 730 Victorian men under the age of 60 years are diagnosed with prostate cancer each year, with some feeling disconnected at times from older support group members due to the variations in experiences and life stages. This new support group is for younger people impacted by prostate cancer to connect and access information.

Meets Last Tuesday of the month 8:30am to 9:30am at Carlton Football Club Royal Parade, Carlton, Mike Fitzpatrick Room

For further information, contact Sam Gebert phone 9444 0039 or sgeb@live.com.au

The Gay Melbourne Prostate Cancer Support Group

Studies show that, compared with heterosexual men, prostate cancer can have a more profound impact on gay men. It can be difficult for them to navigate the heterosexually biased world of prostate cancer treatment. Prostate Cancer treatment has

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side effects that can drastically affect sexual function, both from a physiologic and psychological standpoint. This problem can be particularly difficult for gay men to deal with as many are too afraid or embarrassed to discuss altered sexual function with their doctors and sexual partners.

Meets First Thursday of the month 6.00 pm - 7.30pm at the Victorian AIDS Council- Gay Men's Health Centre, 6 Claremont Street, South Yarra.

For further information, contact Chris Thomas phone 0402 402 106 or email gaymelbpca@hotmail.com

Latest Additions to Our Library

The following books have been added to our library and are available for borrowing. The brief summary of each book is from the publisher.

Making Love Again

by Virginia and Keith Laken

In their timely and medically recognized book, *Making Love Again*, Virginia and Keith Laken give hope to these individuals who, like themselves, want to "feel normal" again.

Virginia tells the story of how she and her husband have dealt with his sexual dysfunction, brought on by a radical prostatectomy at the age of forty-nine. She reveals the solutions that have brought them closer together, and offers further resources and support groups that can be found on both the Internet and through local and national organizations.

Intimacy With Impotence: The Couple's Guide To Better Sex After Prostate Disease

by Ralph and Barbara Alterowitz

Erectile dysfunction is a frequent consequence of prostate cancer and other prostate disease treatments. Though unwelcome and embarrassing, it doesn't have to end a couple's sex life. Written with complete honesty and compassion by a prostate cancer survivor and his wife, this is the essential resource for couples trying to re-establish intimacy and sex in the face of impotence.

Conquer Prostate Cancer: How Medicine, Faith, Love and Sex Can Renew Your Life

by Rabbi Edgar J. Weinsberg, Ed Weinsberg and Robert I. Carey

The author and his wife share the most intimate details of their prostate cancer journey, readers learn how to:

- Become an active member of their medical team
- Reduce pain and stress and renew vitality
- Overcome impotence and incontinence
- Enhance intimate relationships
- Draw strength from faith, family, and friends

Prominent robotic surgeon Dr. Robert Carey discusses medical and patient-care concerns and the author's wife provides a running commentary, sharing her thoughts about how she and her family coped with the disease and its effects.

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Prostate Heidelberg provides information, education and support for those affected by prostate cancer. At the meetings, we

- 1. Show respect to members and speakers;*
- 2. Allow people to speak and we listen;*
- 3. Respect confidentiality;*
- 4. Allow new ideas to be shared.*

COMMITTEE:

Max Shub, Facilitator 0413 777 342
Paul Hobson Secretary 0405 086 869
Chris Ellis
Spiros Haldas
Patrick Woodlock

CORRESPONDENCE

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www.ProstateHeidelberg.info

MEETING VENUE:

Uniting Church Meeting Room
Seddon St, Ivanhoe
(behind the Commonwealth Bank in Upper
Heidelberg Rd).

MEETING CALENDAR 2014

10:00am -12:30pm

Wed 13 August '14
Wed 10 September '14
Wed 8 October '14
Wed 12 November '14
Wed 10 December '14 (Christmas Lunch)

***Annual subscription - \$5 from 1st January
per individual, couple, or family.***

Please contact Paul Hobson to redirect or cancel receipt of this Newsletter.

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