

THE WALNUT

JANUARY 2019

Newsletter of the Prostate Cancer Support Group—ACT Region

Affiliated with the Prostate Cancer Foundation of Australia (PCFA)
Postal address: PO Box 650, Mawson ACT 2607
Website: http://prostate-cancer-support-act.net



Next monthly meeting

Our next monthly meeting will be held on **Wednesday 16 January 2019**.

Our speaker is Tim Stewart. Tim is a community pharmacist and men's health consultant based out of Cooleman Court Pharmacy in Weston. In the last 3 years, Tim has helped hundreds of men with erectile dysfunction stemming from various causes including prostate surgery. His passion lies in helping men in his community and beyond with finding a solution to their specific health needs. Tim and his team pride themselves in providing ongoing support around a topic that is rarely spoken about.

All are welcome to attend our regular monthly meetings and coffee mornings, including partners and carers. No notice is required simply come along and introduce yourself, or contact one of the people listed on page 2 of this newsletter.

Meetings of our support group are held on the third Wednesday of the month (except in December) at 6:30 pm for 7:00 pm. The usual location is Room 22, Building 1, Pearce Community Centre, Collett Place, Pearce, ACT 2607. See our website here for details and map showing the location.

Next coffee morning

10:00 am, Tuesday 12 February 2019 at the Canberra Southern Cross Club, <u>Woden</u>. Remember to put the date in your diary.

Coffee mornings are held at 10:00 am on the second Tuesday of each month and alternate between the Woden and Jamison venues of the Canberra Southern Cross Club.

President's Message

Happy New Year! I wish you all good health and fortune in 2019.

How wonderful Harness Racing ACT was in making the Prostate Cancer Support Group its nominated charity for its Twilight event in December! Close to \$8,000 was raised at the event — an amazing result.

We are so thankful to Harness Racing ACT — and Genny Weston, in particular — for its very generous support of the Group and men and their families experiencing prostate cancer. The money raised will enable us to help sponsor prostate cancer research through the PCFA. We are also planning to sponsor prostate cancer nursing scholarships in 2019 to help provide better support for men in the ACT Region during their prostate cancer treatment. We will make announcements about this soon.

The Twilight event was also a most enjoyable occasion. About 20 members attended and we all enjoyed each other's company.

We have some interesting speakers arranged for our meetings in coming months. As indicated opposite, Tim Stewart will be speaking on a topic that is often not discussed, but which is a significant concern for many men. We look forward to his presentation.

My thanks to all who have contributed to the activities of the Group in 2018. Your contributions, including your attendance at our meetings and coffee mornings, are greatly appreciated.

John McWilliam

Appreciation

The Group recognises and expresses its appreciation for the support provided by: the PCFA, SHOUT staff, Harness Racing ACT, staff of the Australian Department of Human Services (Chief Technology Office), the Canberra Southern Cross Club, Holy Family School Gowrie, Paddywack Promotional Products, the Naval Association of Australia, German Auto Day and the many individuals who have assisted in our fundraising activities.

Personal support

For general information, please call SHOUT (Self Help Organisations United Together) during normal office hours on (02) 6290 1984, and their staff will arrange for someone to contact you.

If you would like immediate advice, support or assistance, please contact one of the following two people:

President: John McWilliam Phone: 0416 008 299 Email: <u>president@prostate-cancer-support-act.net</u>

Secretary: David Hennessy Phone: (02) 6154 4274 Email: <u>secretary@prostate-cancer-support-act.net</u>



Stay up-to-date by joining the PCFA Online Community

The PCFA Online Community is open to everyone who has been impacted by prostate cancer to share their experiences and connect with others. Through the Research Blog, PCFA Online Community members can also learn more about the latest prostate cancer research developments and findings.

The December 2018 edition of the *PCFA Online Community Digest* has articles on:

- Ductal cancer—a rare form of prostate cancer. Read article;
- Why do men drop out of active surveillance? Read article;
- Radiotherapy for men diagnosed with metastatic prostate cancer. Read article; and
- The US patent for Abiraterone (Zytiga) has been declared invalid, raising the prospect of cheaper versions. Read article.

It is free and easy to become a member of the PCFA Online Community. You can sign up at:

http://onlinecommunity.pcfa.org.au.

Borrowing items from the library

You can borrow items from the Group's library. There is a wide range of materials, from books to videos. Those who are interested in borrowing items from the library or finding out more about our collection can contact U.N. Bhati, email:

librarian@prostate-cancer-support-act.net

Articles and reports of interest

The following articles which have appeared recently on web sites or other sources may be of interest to some members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below. With thanks to Don Bradfield for his assistance with this segment.

Online tool to assist in prostate cancer decision making regarding active surveillance

Patients with early-stage favourable-risk prostate cancer who are deciding on what management to follow can now see what other men in their situation have opted to do via an online tool. Favourable-risk prostate cancer patients are those with early-stage tumours and Gleason Score of 6 or less, as well as select patients with low-volume Gleason Score 3+4=7 cancer. After diagnosis, these men should consider active surveillance as one management option.

The tool has been developed by the Michigan Urological Surgery Improvement Collaborative (MUSIC). The team at MUSIC have tested the tool and found it to be accurate in identifying what men in similar situations have decided to do. To access the tool, click here.

YouTube awash with misinformation on prostate cancer

With over 600,000 videos about prostate cancer on the social media platform, a team led by New York University analysed the top 150 English-speaking videos after searching for prostate cancer screening and treatment.

They found the majority of videos (77%) contained potentially misleading and/or biased information, with more than a quarter of these marked by a high degree of misinformation.

Around a quarter of these dubious videos promoted complementary or alternative medicines, while 35% had a commercial bias.

Worryingly, combined, these videos had reached more than six million viewers, the researchers report in *European Urology*.

Read article.

From the editor

If you are aware of news, products, publications, web sites, services or events that may be of interest to members of the group, we would like to be informed of them.

If you have received this newsletter indirectly and would like to be emailed a copy direct, or if you would like to add any of your friends or carers to our distribution list, or if you no longer wish to receive copies of the newsletter, please send us an email through the form here:

http://tinyurl.com/ybkxnlg4.

John McWilliam

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 does 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 Group. Any recommendations made in such materials may not be applicable in your 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 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.