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Prostate Cancer Foundation of Australia

THE WALNUT

May 2023

Newsletter of the Prostate Cancer Support Group–ACT Region

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https://pcsg-act.org.au

From the President

PCFA Community Grants Scheme

I want to let you know that the application we submitted for the Community Grants Scheme has been approved.

Other groups with successful applications were Geelong, Warrnambool, Albany, Southsiders, Bathurst District, Kalamunda, Box Hill, Latrobe Valley, Limestone Coast, Griffith, Parkes, and Fremantle.

Our Group's application was for a sum of $5000, with funding also by our Group, to enable us to undertake a radio advertising campaign in Canberra for three months from August to October.

This will enable to us to increase awareness on the need for men over 40 with high risk factors to have PSA tests and to rally the support of Canberrans for PCFA's major Fundraiser in September, *The Long Run*.

The benefits of this program will be awareness in the Canberra region of early detection, awareness of our support group and supporting PCFA in its fundraising.

Could I ask those of you who are involved with cycling, running or walking groups to have conversations about signing up to the 'Beat Prostate Cancer ACT' team in August ready for The Long Run in September.

Many thanks

Greg McRoberts

Monthly Group Meeting, 6:30pm for 7 pm, Wednesday 17 May

This meeting will be held at our usual location at the Pearce Community Centre, Building 2, Collett Street, Pearce.

The speaker for this meeting will be Michael Irvine from Southside Physio, who will speak about options for dealing with erectile dysfunction following prostate cancer treatment.

Coffee morning, 10:00 am Tuesday 9 May 2023

Our next coffee morning is at the Canberra Southern Cross Club, Woden.

MatesConnect

If you've recently been diagnosed with prostate cancer, you can speak to a member of our Group for advice and support. See page 4 for contact details.

PCFA's MatesCONNECT service can also connect you to a trained volunteer who understands what you're going through. All volunteers have been through prostate cancer.

You can get practical advice on surgery and treatment, and the side effects of treatment, such as incontinence, erectile dysfunction, and coping with Androgen Deprivation Therapy.

Simply call 1800 22 00 99 to be connected with a MatesConnect volunteer.

While MatesConnect volunteers can't give you medical advice, they can provide you with an understanding of what to expect and give you an insight into living with prostate cancer.

For questions about the service, email PCFA at enquiries@pcfa.org.au.

April Meeting

There were 16 at our April meeting (including two on Zoom).

Our speakers at this meeting were Allison Turner and Andrea Lanagan , Prostate Cancer Specialist Nurses at The Canberra Hospital (TCH).

To date Allison has focused on patients undergoing medical and radiation oncology. Andrea, who joined the service in January this year, has focused on surgical patients.

The service provides a liaison and advisory service for public patients who have been diagnosed with prostate cancer. Allison and Angela can nominate themselves to be part of a patient's care team. This enables them to attend appointments with patients. This enhances their understanding of patients' circumstances, and their ability to advise and support the patient.

Allison and Angela noted that, while the service is focused on public patients using TCH, private patients are also welcome to seek support and guidance, although the service would not have access to these patients' records.

The service is transitioning to a model where Allison will focus on patients with metastatic cancer, and Andrea will focus on patients with localised cancer. However, there is no hard boundary between these two groups and Allison and Andrea work together as a team. The support and advice service is provided to the patient 'as long as needed'. ie there is no 'cut off' when, for instance, a course of treatment is completed. Andrea noted that, being funded by PCFA, she complies with a structured follow-up protocol mandated by PCFA with check-ins at specified intervals post treatment. The service has a major emphasis on 'survivorship' and treatment of the whole person, not just treating the illness.

In line with this model the service is available to family members of the patient and can be extended to include other services, such as dietary advice and exercise physiology, particularly pelvic floor exercises, both pre and post treatment.

The transition to the new model has been delayed by the introduction of the Digital Health Record (DHR) at TCH. The service has also been adversely impacted by the theatre fire at Calvary Hospital, which significantly reduced surgical capacity across the ACT, causing major delays for procedures such as biopsies. These issues are being addressed and waiting and surgical access times are improving.

President, Greg McRoberts, thanked Allison and Angela for their presentation, and spoke to the issue of survivorship, and the importance of a support network, both formal or informal. He noted that support needs to be provided by people or organisations that are relatable and have clinical backing.

Greg also noted that the Group will be conducting radio advertising campaigns for Men's Health Week in June and The Long Run in September. He also noted his initiative at the Big Barbecue at Parliament House, seeking bi-partisan support from Government for a national campaign, along the lines of:

- Male?
- Over 40?
- Do you know your PC risk?

A form letter will be circulated to all members seeking support from Government for this initiative. All members are encouraged to send a version of this letter to their local members, and Health Ministers, both federal and state/territory.

Articles and Reports of Interest

The following articles which have appeared recently on web sites or other sources may be of interest to members. Any opinions or conclusions expressed are those of the authors. See Disclaimer below.

Long-term outcomes after monitoring, surgery, or radiotherapy for prostate cancer

The *New England Journal of Medicine* (1 March 2023) reports on the results of a prospective trial to assess the effectiveness of different prostate cancer treatments with a 15-year follow-up.

The trial involved a follow-up of 1643 men between 50 and 69 years of age who had been diagnosed with localised prostate cancer between 1999 and 2009 in the United Kingdom. 545 men were randomly assigned to receive active monitoring, 553 to undergo prostatectomy, and 545 to undergo radiotherapy.

The results showed a high percentage of long-term survival in patients with prostate-specific antigen–detected localised prostate cancer (2.7% rate of prostate cancer–specific death and 21.7% rate of death from any cause), regardless of the treatment modality the patients received.

Radical treatments (prostatectomy or radiotherapy) reduced the incidence of local progression and metastasis as well as the initiation of long-term androgen deprivation therapy by half compared with active monitoring. However, these reductions did not decrease the mortality rate at 15 years.

The study concluded that treatment decision–making should weigh the trade-offs between the benefits and harms associated with therapies for localised prostate cancer, given the low mortality rate at 15 years regardless of the treatment. Longer follow-up of 20 years and more would shed more light on the possible different effects of various treatments.

Novel immunotherapy agent safe, shows promise against high-risk prostate cancers

A new drug, a monoclonal antibody known as enoblituzumab, is safe in men with aggressive prostate cancer and may induce clinical activity against cancer throughout the body, according to a phase 2 study led by investigators at the Johns Hopkins Kimmel Cancer Center and its Bloomberg~Kimmel Institute for Cancer Immunotherapy. If confirmed in additional studies, enoblituzumab could become the first promising antibody-based immunotherapy agent against prostate cancer.

Read the article in Science New

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@pcsg-act.org.au

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: Greg McRoberts, president@pcsg-act.org.au 0413 480 864
Secretary: John McWilliam,secretary@pcsg-act.org.au 0416 008 299

Appreciation

Thanks to all those supporting the Group's fund raising activities, in particular, Harness Racing ACT, the Canberra Southern Cross Club, ACT Masters Hockey, Chartertech ACT, Paddywack Promotional Products and SAC Tyrepower, Belconnen.

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 an email to:
secretary@pcsg-act.org.au

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.