

Prostate Heidelberg

cancer support group

Information, Education and Support for men and their families

Newsletter No. 182

Next Meeting Tuesday 19th March 2019

Prostate Heidelberg provides information, education and support for those affected by prostate cancer.

At the meetings, we:

*Show respect to Members, Speakers, and Guests.
Allow people to speak and the other attendees to listen.
Respect confidentiality.*

Our Guest Speaker on Tues 19th February was Michelle Wells, ACP Education Project Officer, Advance Care Planning Australia

Michelle's talk was very informative addressing the issue of "why should I think about advance care planning?"

To make medical decisions, you must have decision-making capacity.

If illness or serious injury (temporary or permanent) prevents you from making decisions about your health care, advance care planning makes sure that your values, beliefs and preferences for treatment and care are understood and respected. Completed and accessible Advance Care Directive documentation allows you to be heard and is important to your treating team and others.

For further information go to <https://www.advancecareplanning.org.au>

2019 SUBSCRIPTIONS \$20

The 2019 annual subscriptions are due from 1st January 2019. The rate is **\$20 per individual, couple or family**. Pay at your next meeting, by mail or directly into the Prostate Heidelberg bank account: BSB 083-256; Account 583244292 (include your name in the details).

This is our only source of income so if you have not already paid please do so now

CALENDAR 2019

Meetings: **10:00am -12:30pm**

3rd Tuesday each month except January

April 16th A/Professor Miranda Xhilagha



The Research Advisory Committee is coordinated by Miranda Xhilaga, Director, Research programs at PCFA since 2009. In addition, she has a honorary adjunct associate professor position at the School of Health and Social Development, Deakin University. Miranda holds an MBBS from Tirana University and a PhD in molecular biology from Monash University. She has an interest in global health and knowledge translation (KT) and has trained as KT Specialist at the University of Toronto. As Director, Research Programs at PCFA, she is responsible for the implementation and development of strategies that increase coordinated prostate cancer research activities nationwide, research evaluation and knowledge transfer.

Miranda will be speaking on "Current research that is exciting me"

June 16th Associate Professor Nik Zeps
Group Director of Research and Development, Epworth Hospital

"Negotiating your way through the medical system and life for cancer patients"

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Why be part of a support group?

As I was putting this edition of our newsletter together I asked myself "What does a support group have to offer".

The most important aspect is being in an environment where you can make informed decisions on the management of your cancer through education , speaking to others who have been in the same situation as yourself, and realising that you are not alone in this journey.

Whilst researching this question I came across some quotations from an American support group and have included them below. Try them on for size, if they fit keep them, if not discard, but just empower yourself.

- *You're at the beginning of a journey, time to become a warrior! Prepare to battle with as much information and support you can get.*
- *Learn as much as you can about your own personal situation and never ever be afraid to ask questions of anything is bothering u as knowledge is power*
- *Investigate all possibilities. Don't panic. Meet with urologists, oncologists and personal physicians. That will allow you time to make an informed decision based on your lifestyle.*
- *Educate yourself on possible side effects from whatever therapy you choose*
- *Don't take the diagnosis of the C monster as a death sentence. The stages are used to help the physicians determine a specific line of treatment(s). The information you read about when you do your research will show prognosis for different stages. The prognosis given is a general prognosis-determined by stats. That's all. Each c monster diagnosis is unique-not a "One size fits all." Do not panic. Educate yourselves using reputable web sites, others who have traveled a similar journey, and having questions to ask your oncologist. Research your oncologist before agreeing to see them-so you can feel a good, trusting relationship to their suggestions. Having the information so you can make an informed decision about your treatment and care is of the utmost importance-notice I said YOU make the decisions, NOT your doctor. Stay positive.*
- *Take time to make informed decisions based on research, multiple discussions with your doctors, and always asking 'why?' when you get advice or opinion."*
- *Trust your Doctors and never give in, it can be beat.*
- *Take a deep breath, research every option, ask questions, don't be shy about 2nd or even 3rd opinions & come to realize everyone's battle is their own, for there are no 2 Exactly alike...AND yet fight this evil disease with everything you got!!!*
- *Make certain to take someone to your appointments because you won't hear it All or remember it all.*

- Live your life – puts everything else in perspective

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novel machine-learning framework that distinguishes between low and high-risk prostate cancer with more precision than ever before.

The framework is intended to help physicians in particular, and radiologists to more accurately identify treatment options for prostate cancer patients, thereby lessening the chance of unnecessary clinical intervention.

The team of researchers from Icahn School of Medicine at Mount Sinai and Keck School of Medicine, University of Southern California (USC) who made the discovery stated in their report that prostate cancer was one of the leading causes of cancer deaths, second only to lung cancer.

While recent advances in prostate cancer research have saved many lives, objective prediction tools have, until now, remained an unmet need.

Presently, the standard methods used to assess prostate cancer risk are multiparametric magnetic resonance imaging (mpMRI), which detects prostate lesions, and the Prostate Imaging Reporting and Data System, version 2 (PI-RADS v2), a five-point scoring system that classifies lesions found on the mpMRI.

Together, these tools are intended to soundly predict the likelihood of clinically significant prostate cancer. However, PI-RADS v2 scoring is subjective and does not distinguish clearly between intermediate and malignant cancer levels (scores 3, 4, and 5), often leading to differing interpretations among clinicians.

Assistant Professor of Genetics and Genomic Sciences at the School, Gaurav Pandey, said by rigorously and systematically combining machine learning with radiomics, their goal is to provide radiologists and clinical personnel with a sound prediction tool that can eventually translate to more effective and personalised patient care.

STEERING COMMITTEE

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Website

Membership

Facilitator

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Lutetium-177 PSMA
This is the work that our own Barry Elderfield has been working on with the team at Peter Mac

Most prostate cancer cell have a molecule on their surface called prostate cancer specific membrane antigen (PS MA). PSMA can be targeted with Lutetium-177 PSMA (Lu-PSMA), is a radioactive drug that kills prostate cancer cells anywhere In the body. The radiation from this drug only travels around 1mm which means that It can kill cancer cells without damaging normal tissues. We recently did a study that showed a great response when we used this drug In men with advanced prostate cancers. Treatment had very few side effects and men felt a lot better and had reduced pain. We think this treatment may be even more effective

If used earlier as a first line rather than a 'last line of therapy. In this research, we will run two world-first trials of Lu-PSMA. We will give Lu-PSMA to men with newly diagnosed prostate cancer that has already spread outside the prostate as an 'up-front treatment followed by standard chemotherapy treatment. In a second Trial we will give Lu-PSMA to men with aggressive prostate cancer that has not showed signs of spreading prior to surgery or radiotherapy, to see if this approach can be considered safe and possibly effective.

Lu-PSMA is a highly personalized treatment and we only give it to men after performing a scan to check that the cancer has the PSMA target. In advanced disease, around 25% of patents do not have this target . We recently identified a protein called Lewis-Y to be common on the surface of these cancers that don't show PSMA. We will use a special immune therapy called CAR T cells to target Lewls -Y protein in PSMA-negative cancers.

Together, these cutting-edge studies have the potential to impact treatment of prostate cancer globally, bringing sophisticated new treatments Into the clinic and leading to longer survival and better quality of life for men with prostate cancer sumval and better quality of lfe for men with prostate cancer.

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Use of the internet is to find your questions to ask your specialist. **It should not be trusted to find answers for your personal case.** The web is general. Your specialist specifically knows you. The following are web sites members have found useful:

| Organisation | Details | Website |
|--|---|--|
| Prostate Cancer Foundation of Australia | <i>For guides and help.</i> | www.PCFA.org.au |
| Prostate Cancer Foundation (USA) | <i>Guide for men newly diagnosed with prostate</i> | www.pcf.org/guide/ |
| Us TOO International PC Education | <i>USA Prostate Cancer support groups and information</i> | www.UsToo.org/Read-Educational-Materials |
| Cancer Council Victoria | <i>For general help and to understand services supporting men with cancer.</i> | www.CancerVic.org.au |
| Ex MED Cancer program | <i>A best-practice exercise medicine program for people with cancer.</i> | www.EXMedCancer.org.au/ |
| Prostmate | <i>The companion for those impacted by Prostate Cancer</i> | www.ProstMate.org.au |
| Beyond Blue | <i>For help with depression or anxiety. HELPLINE – 1300 22 4636</i> | www.BeyondBlue.org.au |
| Continence Foundation of Australia | <i>For assistance with incontinence and for aids (such as pads). HELPLINE – 1800 33 0066</i> | www.Continence.org.au/ |
| Australian Advanced Prostate Cancer Support Group | <i>For men diagnosed with advanced metastatic prostate cancer.</i> | www.JimJimJimJim.com |
| Commonwealth site for palliative care | <i>Government information on palliative care.</i> | www.Health.gov.au/PalliativeCare |
| Banksia Palliative Care | <i>Specialist home based community palliative care service for people living in the north east suburbs of Melbourne</i> | www.BanksiaPalliative.com.au |
| University California San Francisco | <i>One of the leading Prostate Cancer Research centres</i> | www.urology.ucsf.edu/patient-care/cancer/prostate-cancer |

Useful Newsletters

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| PAACT Newsletter | www.paact.help/newsletter/ |
| PCRI Prostate Digest | www.pcri.org/insights-blog/2018/04/prostate-digest-volume21-issue1 |
| US TOO Hotsheet | www.ustoo.org/Read-the-HotSheet-Newsletter |

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