

Prostate Heidelberg

cancer support group

Information, Education and Support for men and their families

Newsletter No. 176

Next Meeting Tuesday 21st August 2018

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 listen.

Respect confidentiality.

UPCOMING SPEAKER **Tuesday, 21st August 2018**

Gina Akers



13 Survivorship studies, what are we learning?

Gina Akers, is currently working at the Department of Health and Human Services in the Cancer Strategy and Development unit. She is responsible for the Victorian Cancer Survivorship Program, which funds organisations to pilot and implement models of care for survivorship, Her background is cancer nursing, having worked in a number of roles in clinical areas, management, research and patient support over the past 30 years.

New Australian drug puts cancer cells permanently to 'sleep'

Scientists in Melbourne say they have discovered a new type of anti-cancer drug without the usual side effects of conventional cancer treatments.

Research so far has shown progress in delaying cancer relapse as well as treating some types of cancers.

The research, published in the journal Nature, shows the new class of anti-cancer drugs, in effect, put cancer cells permanently to sleep. The process of stopping the growth of tumours occurs without damaging any cell's DNA, which occurs in conventional treatments such as chemotherapy and radiotherapy.

The development of the drugs has been a combined effort between the Walter and Eliza Hall Institute of Medical Research, Monash University, Cancer Therapeutics CRC, The University of Melbourne, Peter MacCallum Cancer Centre and the CSIRO.

One of the research leaders, Associate Professor Tim Thomas, from the Walter and Eliza Hall Institute, said it's an exciting development. "So what I think the future of cancer therapy will be is to have directed and targeted treatments which will work on specific patient groups. What we hope we have developed here is a new type of approach to cancer therapy which is stopping cancer cells from growing but leaving the normal cells relatively unaffected and that's by harnessing the body's normal defences against unrestricted growth."

Professor Thomas said the development of the drug is at a pre-clinical stage. The research shows that by targeting certain proteins known to play a major role in the development of cancer, doctors can essentially stop the disease.

2018 SUBSCRIPTIONS \$10

The 2018 annual subscriptions are due from 1st January 2018. The rate is **\$10 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).

Continued from P1

These proteins are known as KAT6A and KAT6B and they are proteins that affect certain genes most commonly found in cancers.

Jonathan Baell, Professor of Medicinal Chemistry at the Monash Institute of Pharmaceutical Science has also been involved in the research.

"The disease-causing protein that has been targeted has really not been able to be targeted before with a small-molecule potential drug. And in fact for many years people were increasingly thinking this sort of disease protein in certain cancers maybe could not be targeted and we had to look for other things to modify their activity.

Advanced Prostate Cancer Patient Value Mapping Study

Lead investigator

Dr Simon Fifer, from Community and Patient Preference Research Pty Ltd, Sydney, NSW, and Dr Wendy Winnall, Prostate Cancer Foundation of Australia.

Summary of project

Community and Patient Preference Research (CaPPRe) is working with Prostate Cancer Foundation of Australia to conduct research with men who have metastatic prostate cancer. This study is sponsored by CaPPRe with funding support from Janssen-Cilag Australia Pty Ltd. Janssen will not participate in, or influence the outcomes of, this study.

We invite you to participate in the research, which will involve a 20-minute online survey.

Your participation will be valuable in improving the understanding of what is important to you in the care of your prostate cancer and helping make better treatments available in Australia for prostate cancer patients. We also intend to publish the results so that others can learn from them.

Who is this study for?

You may be eligible for this study if you are:

- Have been diagnosed with metastatic prostate cancer, and
- Have access to the internet

There is no obligation for you to be involved in this research. If you decide to participate in the research you may withdraw at any time.

If you are interested in participating in the 20-minute online survey, please click on the link below:

www.bit.do/PC-research

If you have a specific question about the research or require any additional information: Please email your query to info@cappre.com.au and enter "query about prostate cancer research" in the email subject heading. You can also contact CaPPRe on 02 8315 2148 or **PCFA at wendy.winnall@pcfa.org.au or on 03 9948 2073.**

University of California San Francisco

NUTRITION & PROSTATE CANCER

A healthy diet may reduce the risk of developing prostate cancer and possibly prevent or delay prostate cancer progression. Good nutrition also reduces the risk of developing other major chronic diseases, such as diabetes, obesity, hypertension and heart disease. It is estimated that one-third of cancer deaths in the United States can be attributed to adult diet and physical activity, including their role in obesity.

Scientific evidence suggests that differences in diet and other lifestyle behaviors, such as exercise and smoking, may account for much of the variability in the rates of major chronic diseases across countries, including many cancers.

- Plant-based diet.
 - o Rich in fruits and vegetables.
 - o High fiber – beans/legumes, nuts, seeds, whole grains.
- Include lean protein with every meal – aim to include plant protein daily.
 - o Plant proteins: beans/legumes, soy products (e.g., edamame, tofu, tempeh).
 - o Lean animal proteins: fish, skinless poultry.
- Choose healthy fats when cooking/baking, on salads, or at the table, such as extra-virgin olive oil, nut oils (e.g., macadamia nut oil, almond oil), avocados, and nuts/seeds.
- Choose whole grains such as quinoa, wild rice, brown rice, oatmeal, amaranth, and teff, over processed and refined grains.

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.

- Limit added sugars.
 - Drink a sufficient amount of water (~ 8 cups/day).
 - Do not drink sugar-sweetened beverages.
 - If you choose to drink alcohol, limit to 2 drinks per day or fewer for men (one drink or fewer per day for women).
 - Be physically active. Build up to 150 minutes/week or more of aerobic exercise and 2-3 sessions/week of resistance exercise, balance training, and flexibility exercises.
 - Achieve and/or maintain a healthy weight.
- nutrition & Prostate cancer
For the full report go to
<https://urology.ucsf.edu/lifestyle-studies>

Robotic vs Open Surgery for Prostatectomy: Which Wins?

At 24 months' follow-up, the only phase 3 randomized clinical trial to directly compare functional and oncologic outcomes between robot-assisted laparoscopic prostatectomy and open radical retropubic prostatectomy shows no evidence for a clear advantage of one approach over the other, say researchers.

The international study was led by Robert "Frank" Gardiner, MD, from the University of Queensland Center for Clinical Research at Royal Brisbane and Women's Hospital, Australia.

The new results at 24 months' follow-up were published online July 12 in the *Lancet Oncology*.

The current study shows that functional and sexual outcomes for both approaches have remained comparable at 6, 12, and 24 months' follow-up. However, the oncologic outcomes "require ongoing follow-up and further investigation," the authors say.

The study also showed that 1 of 5 patients continued to experience high levels of psychological distress, regardless of surgical approach.

"Robot-assisted laparoscopic prostatectomy has been widely adopted as the preferred surgical technique for radical prostatectomy without previous validation of improved outcomes," Franklin and colleagues write. "Our study showed that this technique can obtain equivalent functional outcomes to open surgery, with a decreased risk of biochemical recurrence during 24-month follow-up."

Is Aspirin the New (Old) Immunotherapy?

David J. Kerr, CBE, MD, DSc, FRCP, FMedSci

Hello. I'm David Kerr, professor of cancer medicine from the University of Oxford.

For those of you who follow me on Medscape and WebMD, you know that I don't like aspirin: I love it. I think it's a wonderful drug. There's a lot of work going on just now looking at its molecular pharmacology.

There's a great recent paper published by Dr Tsuyoshi Hamada and colleagues[1] looking at the role of aspirin as an immune checkpoint blockade inhibitor. It's a lovely study. Using part of a retrospective sample collection, they were able to look at the impact of post-primary treatment use of aspirin in patients with resectable colorectal cancer.

They hypothesized that patients who had tumors with low expression of programmed cell death ligand 1 (PD-L1) would be more sensitive to the beneficial effects of aspirin. They looked at just over 600 patients. [The study used] a beautiful statistical analysis that stratified [findings] and accounted for all of the other contributory factors that might be tied up with aspirin's use: PIK3CA mutations, [CDX2 expression], and even tumor-infiltrating lymphocytes. It's what you would expect from a research group of this quality. The analysis was done very carefully indeed.

At the end of the study, they showed that their hypothesis was correct. Patients with tumors with relatively low expression of PD-L1 (also known as CB274) did better than those patients who had tumors that expressed high levels of PD-L1, for which aspirin seemed to have no benefits at all.

This all fits in with the link-up between the prostaglandin E2 pathway and immune suppression. It suggests that aspirin may be yet another potential partner drug that may enhance the activity of the huge excitement around the drugs which block the PD-L1, PD-1, the whole immune checkpoint pathway just now.

It was a really nice, very carefully conducted study. The results were quite compelling in terms of the survival benefits accrued to postsurgical use of aspirin in patients with low levels of PD-L1 expression. It again shows the importance of the microenvironment in determining the outcome of tumor behavior.

continued on P4

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.

Optimal Care Pathways

Cancer Council Victoria and the Victorian State Government have created a set of “what to expect” guides, which is part of an initiative called the Optimal Care Pathways.

These guides can help you understand what to expect during all stages of your cancer care, from diagnosis to treatment and living with cancer. They will help you with what questions to ask your health professionals to make sure you receive the best care at every step. Carers, family and friends may also find them helpful. The prostate cancer guide is available in English, Chinese, Vietnamese, Arabic, Greek, Italian, Hindi and Tagalog. These guides have now also been endorsed at a national level by the National Cancer Expert Review Group (NCERG), Cancer Australia, Cancer Council Australia, and the Australian Health Ministers Advisory Council (AHMAC) and are being implemented nationally.

Please visit www.cancerpathways.org.au/optimal-care-pathways/prostate-cancer

What to expect - Prostate Cancer

What to expect during each stage of treatment and beyond

Prostate cancer support

For information about prostate cancer or where to go for support call 1800 22 00 99 or visit Prostate Cancer Foundation of Australia www.prostate.org.au

Also, qualified cancer nurses at the Cancer Council can answer your questions about the effects of cancer, explain what will happen during treatment and link you to support groups and other community resources. Call the Cancer Council on 13 11 20.

If you need an interpreter, call TIS (the Translating and Interpreting Service) on 13 14 50. For support and advice for carers, call the Carers Association on 1800 242 636.

Other resources include:
Continence Foundation of Australia www.continence.org.au

1. Initial investigations and referral

If you have a family history of prostate cancer, your GP should discuss the option for annual PSA testing. If you do not have a family history of prostate cancer, you may still wish to consider tests for early detection after discussing the risks and benefits with your GP.

Your general practitioner (GP) will assess your symptoms, conduct a physical examination and arrange blood tests if needed. Your GP should also discuss your needs (including physical, psychological, social and information needs) and recommend sources of reliable information and support.

It can be helpful to bring a family member or friend with you to your appointments.

If prostate cancer is suspected, you will be referred to a specialist (likely to be a urologist) for further testing. Your GP will provide the specialist with information about your medical history, whether there is a history of cancer in your family, and your test results.

Tests you may have:

- Prostate specific antigen (PSA) testing**
The PSA blood test looks for the presence in the blood of a protein that is produced specifically by prostate cells.
- Measurement of PSA free to total ratio:** Most PSA in the blood is attached to proteins but some is free (unattached). Measuring the proportion of free PSA in the blood can assist in identifying the likely causes of an elevated PSA.
- Biopsy**
Small samples are removed from your prostate gland to be examined under a microscope.
- Computed tomography (CT) or bone scan**
Computer technology and x-rays are used to create cross-section views of the body.
- MRI scan**
Magnetic fields and radio waves are used to take pictures of inside the body.
- Digital Rectal Examination (DRE)**
The doctor inserts a gloved finger in the anus and examines the surface of the prostate, looking for irregularities.

2. Diagnosis and staging

The specialist should discuss your test results and options for further testing. This is to find out whether cancer is present, and if it is, its stage of development and if it is confined to the prostate.

Your specialist should also explain the risks and benefits of having a prostate biopsy and give you time to decide if you want to undergo further testing.

It can be helpful to contact prostate cancer peer support groups, carer support groups, and special interest groups.

Further tests you may have:

3. Treatment

To ensure you receive the best care, your specialist will arrange for a team of health professionals to plan your treatment based on your preferences and needs. The team will be made up of health professionals who have experience managing and supporting a person with prostate cancer. Your specialist will tell you when the team will be discussing your case. Your team should discuss the different treatment options with you including the likely outcomes, expected timeframes, possible side effects, and the risks and benefits. Your doctor may also suggest you consider taking part in a clinical trial.

Let your team know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment. You might want to ask for more time before deciding on your treatment, and you should be offered an opportunity for a second opinion by a radiation oncologist and a urologist in order to have a balanced view about the treatment options. There are a number of ways to treat prostate cancer. In some cases, more than one type of treatment could be used to get the best outcome.

Treatment options for early prostate cancer:

- Active Surveillance**
No treatment is given or treatment is postponed but the cancer is closely monitored.
- Watchful waiting**
Less strict monitoring than active surveillance. Often suitable for older patients or patients who have other health issues.

3. Treatment cont'd

Surgery (prostatectomy) Surgery to remove the prostate may benefit those with early prostate cancer. It is important that the surgery is performed by a surgeon who is very experienced in performing prostatectomies and performs several operations every year.

Radiation therapy also called radiotherapy can be given with or without surgery.

Radiation therapy may be external or internal brachytherapy - when radiation is delivered using an implant placed into your body through or near the tumour.

Your doctor should discuss your needs with you during and after treatment including physical, psychological, social and information needs and may refer you to another service or health professional for different aspects of your care.

Treatment options for advanced prostate cancer (i.e. affecting other organs or bones)

- Androgen deprivation therapy (ADT)** is an injection and/or tablet based hormone treatment. Your specialist will discuss possible side effects.
- Chemotherapy and other drug therapy** may be given in conjunction with ADT.

For more information about treatment and treatment side effects see your doctor or visit www.cancer.org.au/about-us/cancer-treatment

4. After treatment

After treatment is completed, your doctor should provide you with a treatment summary which details the care you received, including:

- diagnostic tests performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- support services provided to you

To monitor your health, and make sure the cancer has not returned, you will need regular check-ups. You and your GP should receive a follow-up care plan that tells you about:

- the type of follow-up that is best for you
- care plans for managing any side effects of treatment, should they occur

- how to get specialist medical help quickly if needed
- your doctor should
- discuss your needs with you and refer you to appropriate health professionals and/or community organisations, if support is required
- provide information on the signs and symptoms to look out for that might mean a return of the cancer
- provide information on prevention and healthy living

Treatment for prostate cancer sometimes damages nerves and muscles that help you with pen-ile-ct, to reduce symptoms or to help restore your quality of life. For more information about palliative care see your doctor or visit www.cancer.org.au

The aim is to reduce side effects such as incontinence, erectile dysfunction, fatigue and loss of interest in sex. Fortunately, there are many ways to reduce or manage these, and most men are able to continue to lead active lives after their treatment.

5. If cancer returns

Prostate cancer can come back after treatment.

This is why it is important that you have regular check-ups. Usually this will be detected at your routine follow-up appointments or if you notice symptoms are coming back.

6. Living with cancer

Side effects: Some people experience side effects (for example, incontinence) that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished. For more information about side effects see your doctor or visit www.cancer.org.au/about-us/cancer-treatment/side-effects

Advance care plan: Your doctor may discuss with you the option of developing an advance care plan. An advance care plan is a formal way of letting out your wishes for future medical care. For more information about advance care planning see your doctor or visit www.advancecare.org.au/

Palliative care: The type of treatment could be used at different stages to help you with pen-ile-ct, to reduce symptoms or to help restore your quality of life. For more information about palliative care see your doctor or visit www.cancer.org.au

7. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service, even if you have private health insurance. You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have. If you are experiencing financial difficulties due to your cancer treatment also see contact the social worker at your hospital.

For more information about cost of treatment see your doctor or visit www.cancer.org.au

For more information about accommodation and travel costs see your doctor or visit www.cancer.org.au/about-us/cancer-treatment

Continued from P3

Is Aspirin the New (Old) Immunotherapy?

This gives some potential therapeutic insight into why aspirin might be a very useful companion drug to give in combination with these rather more expensive, more complex immune blockade inhibitors.

Aspirin wins again. There's yet more plausible biological mechanism supporting its use.

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.



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

All your cancer care details in the one place

My Cancer Care Record is a resource that has been designed to support people affected by cancer to:

- store and organise their medical and cancer related information
- aid communication with their healthcare team
- prompt the sorts of questions to ask and useful information to record
- be more informed and in control of their care.

The folder has:

- coloured dividers to help organise information
- questions to ask
- plastic pockets to keep important documents safe
- places to record other useful details

The resource is an initiative of the North Eastern Melbourne Integrated Cancer Service (NEMICS) consumer group.

With NEMICS support, consumers engaged the assistance of oncology clinicians in the region to develop the concept, content and overall design of *My Cancer Care Record*.

A small proof of concept pilot was initially conducted. Following consumer feedback, revisions were made and a second version is now available. The current implementation project has involved the participation of numerous hospitals and cancer services across north eastern Melbourne and the Grampians regions. Patient and family/carer feedback is currently being evaluated.

We are still keen for feedback, so if you think the resource could be of benefit to you or someone you know and you would like to obtain a free folder, please see Max Shub - Prostate Heidelberg Support Group 0413 777 342 or contact Anna Mascitti (NEMICS project officer) on 9496 3322.



Tues 21 Aug'18

Gina Akers

"Survivorship studies, what are we learning?"

Tues 18 Sep'18 General Discussion

Tues 16 Oct'18

Dr Renu Eapen

"ED and Incontinence: do we need to put up with it?"

Dr Renu Eapen is a Consultant Urologist in the Genitourinary Oncology service at the Peter MacCallum Cancer Centre. She also has appointments at the Austin Hospital and Olivia Newton-John Cancer Centre.

Tues 20 Nov'18 General Discussion

Tues 18 Dec'18

A/Prof Nathan Lawrentschuk

"How genetics is impacting therapy now and in the future."

Associate Professor Nathan Lawrentschuk is a urological surgeon and oncologist in the Uro-Oncology Service at the Peter MacCallum Cancer Centre. He also has appointments at The University of Melbourne, Department of Surgery and Olivia Newton-John Institute for Cancer Research at the Austin Hospital, Melbourne

COMMITTEE

Barry Elderfield,	Treasurer
Chris Ellis,	Welcoming
David Bellair,	Website
Janis Kinne,	Membership
Max Shub, Ph. 0413 777 342	Facilitator
Patrick Woodlock,	
Spiros Haldas,	Library,

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.

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

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

DISCLAIMER: Information in this newsletter is not intended to take the place of medical advice. You should obtain advice from your doctor relevant to your specific situation before acting or relying on anything in this newsletter. We have no liability whatsoever to you in connection with this newsletter.