

# Prostate Heidelberg

cancer support group

Information, Education and Support for men and their families

Newsletter **June 2018** - Issue 174

Next Meeting: **Tuesday 19<sup>th</sup> JUNE 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, 19<sup>th</sup> June 2018**

### A Scientist's Look at PC Drugs



**Dr David J. Owen** BSc (Hons) Ph.D. is the Vice President, Research of Starpharma Ltd. He has experience in medicinal chemistry and biochemistry, and in managing commercially directed drug discovery. Dr Owen has worked

across therapeutic areas, including Starpharma's improved dendrimer-docetaxel chemotherapy formulation.

class of prostate cancers defined by mutations in epigenetic modifiers (genes and proteins that regulate the expression of genes).

Because the samples include a large number of advanced cases, the findings could lead to biomarkers predicting which patients with localized prostate cancer are at high risk for developing metastatic cancer, according to the study, led by researchers from Dana-Farber Cancer Institute, the Broad Institute of MIT and Harvard, and Memorial Sloan-Kettering Cancer Center.

A report was published on line by Nature Genetics and will appear in a print issue of the journal.

Previous studies have identified a number of genes that are frequently found to be mutated in prostate cancer, including genes involved in hormone signalling and DNA repair and in turning on multiple genes in prostate cancer cells.

In the current project, the scientists cast a wider net, analysing 1,013 prostate tumour samples - the large number of samples giving the study the power to detect genes not previously identified in prostate cancer that might be implicated in only a few percent of all cases. In statistical terms, this is known as a "long-tail" distribution.

## SCIENTISTS UNCOVER "LONG TAIL" OF NEARLY 100 GENES MUTATED IN PROSTATE CANCER

2<sup>nd</sup> APRIL 2018

Issued by Dana-Farber Cancer Institute.

By sequencing DNA in more than 1,000 patient samples, researchers have identified a total of 97 genes significantly mutated in prostate cancer, including 70 not previously implicated in the disease. The large-scale study identified a new

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“While many of the significantly altered genes and pathways are mutated at low frequencies, given the incidence of prostate cancer these alterations still impact large patient populations,” say the authors. Corresponding authors are Eliezer M Van Allen, MD, of Dana-Farber Cancer Institute and the Broad Institute, and Nikolaus Schultz, PhD, of Memorial Sloan Kettering.

The scientists analysed whole-exome sequencing data from 680 primary and 333 metastatic prostate tumours. As was expected from previous findings, there was a higher rate of mutations in metastatic tumours than in primary tumours, and there were more extra copies of genes in the metastatic tumours. In all, the researchers identified 97 genes that were mutated and considered likely to be “drivers” of the prostate cancers’ growth.

The majority of these mutated genes were found in less than 5 percent of the 1,013 cases - the “long tail” distribution. Van Allen said this pattern is a “humbling observation about the genetic heterogeneity of prostate cancer,” in that the disease’s genetic causes are highly complex.

The analysis revealed that 20 percent of the prostate cancer samples had mutations in epigenetic modifiers or chromatin remodelling genes. The latter are genes that code for a mechanism by which the cell reads the DNA scripts to turn other genes on or off.

“Overall, our analysis demonstrates the utility of uniform genomic analysis in a single cancer type at a larger scale than previously reported, thereby redefining the molecular landscape of prostate cancer,” the authors said.

The research was supported by the Stand-Up to Cancer - Prostate Cancer Foundation Prostate Cancer International Dream Team, Prostate Cancer Foundation-V Foundation Challenge Award,

and National Institutes of Health grants K08CA188615, P50CA097186, and P50-CA92629 SPOREs in Prostate Cancer, amongst others.

## FROM LUCAS HEIGHTS TO PETERMAC, NEW PROSTATE THERAPY IS A GAME CHANGER



*The Age Monday 9<sup>th</sup> May 2018*

*Barry Elderfield is Prostate Heidelberg’s Secretary and Treasurer*

Barry Elderfield was out of options and almost dead. Prostate cancer had wormed its way into the 76-year old’s bones, sprouting ugly tumours from his skeleton.

He had exhausted all conventional treatments but one. An experimental treatment, ignored by big pharma companies, was being trialled at Melbourne’s Peter MacCallum Cancer Centre. It would involve material hot out of a nuclear reactor being shot straight into his veins. Barry was a dead man anyway. He put his hand up.

Almost two years later, he’s still kicking. “It’s given me an extension of life I would not have got otherwise, no question,” he says. His voice is croaky from a dry throat - the only side effect so far. “That’s a pretty small price to pay for life.”

Mr Elderfield was part of a group of 30 men with treatment-resistant metastatic prostate cancer the treatment, known as LuPSMA, was trialled on. The proof-of-concept trial, the results of which are published today in *Lancet Oncology*, has been hailed as a game-changer.

The best way to measure prostate cancer is a marker in the blood called PSA. The higher the

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level, the worse the cancer. Of the 30 men, most saw that marker halve. Some reduced it to almost-undetectable levels. Six patients who were on death's door recovered so well treatment was stopped early.

The therapy is not a cure. The cancer will come back. But it is hoped it could significantly extend life. "It's very exciting," says Associate Professor Arun Azad, who heads a prostate cancer therapy lab at Monash University and was not involved in the study.

"If it continues to show the very promising activity it has in this pilot, then it may well become part of the standard treatment options."

LuPSMA is made up of two molecules. Radioactive lutetium-177 is shipped straight from NSW's 20-megawatt Lucas Heights nuclear reactor to Peter Mac, where chemists combine it with a molecule called PSMA-617, which is designed to bind to prostate cancer cells. It is then pumped into the bloodstream, where the PSMA seeks and burrows into tumours. The attached radioactive molecule then poisons the tumour from the inside out. Lutetium only has a tiny active range - about 1 mm - meaning other cells aren't damaged.

The success of the trial makes it all the more remarkable that LuPSMA has spent years sitting on a shelf. The therapy was invented in Germany in 2015, but large-scale trials were never run. Big pharma, which fund most clinical trials, were put off because it uses radiation rather than drugs. "But that's rapidly changing, because big pharma have seen the results."

Professor Hofman, at Peter MacCallum Cancer Centre, is now leading a 200-person national trial that will test the therapy against standard treatments. If it's successful, LuPSMA could be available to patients within two to four years.

## A New Web Site Helping Patients Make Better Choices

Dr Katherine McGrath spoke to Prostate Heidelberg's May meeting. ABC "Four Corners" programme addressed the issue on Monday 28<sup>th</sup> May. Prostate Cancer patients can expect out of pocket surgery costs to be between \$nil and \$20,000. And the issue is the doctors' costs, rather than the health insurance nor hospital charges.

Dr Stephen Clarke and his wife Dr Katherine McGrath are developing a new web site to give patients who think they may have prostate cancer more information about treatment options, and the likely costs of treatment if they choose the private treatment pathway.

The web site when developed will include how to choose a specialist, an outline of treatment options, likely out of pocket costs, and questions to ask their GP and specialist.

They want to prepare the person for their early specialist visits by giving them enough information to understand that there are different options for treatment, and especially about different levels of cost. This will help them ask the right questions of their specialist and make better choices about treatments and where to be treated.

The developers are two retired doctors who want to increase the transparency about health costs and help patients have more control and choice over their treatments. The initial focus of the web site is Prostate Cancer because of the costs confronted by some patients.

They need your help to make sure this web site is

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very easy to use, and very easy for a layman and his family to understand. The site will be free for everyone when it is finished, patient privacy will be fully protected and no doctors' names will be requested.

## Volunteers Needed

They need volunteers to test the site and give them feedback on how well it is working.

If you are willing to help, they will respond to your email expressing interest by sending you a link to the site. You can then complete the questionnaire, and tell them what you think of the site. It won't be ready for testing till mid-June.

Please help them help patients like yourselves.

Contact Katherine or Stephen  
[kmcgrath@westnet.com.au](mailto:kmcgrath@westnet.com.au)  
 K M Health Consulting Pty Ltd  
 Dr Stephen Clarke  
 Dr Katherine McGrath

## 2018 SUBSCRIPTIONS \$10

The 2018 annual subscriptions are due from 1<sup>st</sup> January 2018. The rate is **\$10 per individual, couple or family**. Pay at your next meeting, by mail to the address below, or directly into the Prostate Heidelberg bank account:  
 BSB 083-256; Account 583244292  
 (include your name in the details).

## CORRESPONDENCE

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## BALLARAT

## MEN'S HEALTH NIGHT

### Ballarat Library

178 Doveton Street North, Ballarat, Vic 3353

**Thursday 14<sup>th</sup> June, 6:30 - 8:30 pm**

An exciting evening of discussion featuring a variety of topics, including pain management, fitness, health and well-being. UFS Pharmacies will be providing free blood pressure and diabetes checks. Australian Hearing Care will be providing free hearing tests.

Light supper and refreshments provided.

### Guest Speakers:

Steve Sedgwick & yoga demonstrations (fitness and yoga instructor)

Grant McKechnie (pain management)

Gay Corbett (specialist prostate cancer nurse)

**MC:** Steve Martin (ABC presenter).

Bookings required at:

[www.menshealthnight2018.eventbrite.com.au](http://www.menshealthnight2018.eventbrite.com.au).

For more information contact Ballarat Libraries at 03 5338 6850.

## COMMITTEE

Max Shub, Facilitator	0413 777 342
Barry Elderfield, Treasurer	0400 662 114
Patrick Woodlock, Newsletter	0438 380 131
Chris Ellis, Convenor	
Spiros Haldas, Library	
Janis Kinne, Membership	
David Bellair, Web site	

Please contact Patrick Woodlock to redirect or cancel receipt of this Newsletter at [ProstateHeidelberg@gmail.com](mailto:ProstateHeidelberg@gmail.com) or on 0438 380 131.

**CALENDAR****2018** Meetings: 10:00am -12:30pm

- Tues 19 Jun '18 David Owen, Chief Scientist,  
Starpharma Ltd  
*"A scientist's look at Prostate  
Cancer drugs"*
- Tues 17 Jul '18
- Tues 21 Aug '18 Gina Akers  
*"Survivorship studies, what are  
we learning?"*
- Tues 18 Sep '18
- Tues 16 Oct '18 *"ED and Incontinence: do we  
need to put up with it?"*
- Tues 20 Nov '18
- Tues 18 Dec '18 *"How genetics is impacting  
therapy now and in the future"*  
plus Xmas lunch

**2019** Meetings: 10:00am -12:30pm

- Tues 19 Feb '19
- Tues 19 Mar '19
- Tues 16 Apr '19
- Tues 21 May '19
- Tues 18 Jun '19
- Tues 16 Jul '19
- Tues 20 Aug '19
- Tues 17 Sep '19
- Tues 15 Oct '19
- Tues 19 Nov '19
- Tues 17 Dec '19, including Xmas lunch
- Sometime 2019 Nik Zeps, Epworth  
*"Negotiating your way through  
the medical system and life for  
cancer patients"*

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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 **websites** members have found useful:-

**Prostate Cancer Foundation of Australia**  
*For guides and help.*

[www.PCFA.org.au](http://www.PCFA.org.au)

**USA Prostate Cancer Foundation (Guide)**  
*USA PDF guide for men newly diagnosed with prostate cancer.*

[www.PCF.org/guide/](http://www.PCF.org/guide/)

**Us TOO International PC Education/Support Network (USA)** [www.UsToo.org/Read-Educational-Materials](http://www.UsToo.org/Read-Educational-Materials)  
and <http://www.ustoo.org/Read-the-HotSheet-Newsletter>  
*USA Prostate Cancer support groups information and newsletter.*

**Cancer Council Victoria**  
*For general help and to understand services supporting men with cancer.*

[www.CancerVic.org.au](http://www.CancerVic.org.au)

**Ex MED Cancer program**  
*A Melbourne-based best-practice exercise medicine program for people with cancer.*

<http://www.EXMedCancer.org.au/>

**ProstMate (PCFA)**  
*The companion for those impacted by prostate cancer, particularly to record all your results.*

[www.ProstMate.org.au](http://www.ProstMate.org.au)

**Beyond Blue**  
*HELPLINE - 1300 22 4636; for help with depression or anxiety.*

[www.BeyondBlue.org.au](http://www.BeyondBlue.org.au)

**Continence Foundation of Australia**  
*HELPLINE - 1800 33 0066  
For assistance with incontinence and for aids (such as pads).*

[www.Continence.org.au/](http://www.Continence.org.au/)

**Australian Advanced Prostate Cancer Support Group**  
*For men diagnosed with advanced metastatic prostate cancer.*

[www.JimJimJimJim.com](http://www.JimJimJimJim.com)

**PCRI Prostate Digest (USA)** <https://pcri.org/insights/> *"Prostate Publications"*  
*Prostate Cancer Research Institute supports research and disseminates information that educates  
and empowers patients, families, and the medical community.*

**PAACT Newsletter (USA)**  
*Patient Advocates for advanced Cancer Treatments.*

<http://paact.help/newsletter/>

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