

Newsletter Issue 166

Next Meeting: Tuesday 19th September 2017

OUR SPEAKER for 19th September is Dr NIK ZEPS

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

Nik is a great speaker, in great demand, we are very fortunate that he has agreed to speak to our group.

Dr Nik Zeps has been recently appointed as the



inaugural Group Director of Research for Epworth HealthCare. Prior to that he was the Director of Research at SJG HealthCare from 2012 to 2016

and head of their cancer translational research program.

He is an Adjunct Professor at Monash University Medical School, in the School of Health Sciences at Curtin University, the Centre for Comparative Genomics at Murdoch University and at Notre Dame Medical School. He is an Adjunct Associate Professor in the School of Surgery and the School of Pathology and Laboratory Medicine at the University of Western Australia.

He was a member of the Australian Health Ethics Committee from 2006-2012 and the Research Committee of the National Health and Medical Research Council (NHMRC) of Australia from 2009-2015.

He is the chair of the Cancer Biology Group of the Clinical Oncology Society of Australia (COSA) and a member of the Scientific Advisory Committee of the Australasian Gastro-intestinal Trials Group (AGITG) and of the Primary Care Collaborative Cancer Trials Group (PC4) Advisory and Scientific committees. His is a founding director of the Australian Clinical Trials Alliance (ACTA).

He is the Australian representative on the Ethics and Policy Committee of the International Cancer Genome Consortium (ICGC) and was recently appointed Co-Chair of the Communication Committee of the ICGC-Precision Medicine initiative.

2017 CALENDAR OF SPEAKERS

19 Sept <u>Ass Prof Nik Zeps</u>

Negotiating your way through the medical system and life for cancer

patients.

19 Dec Carla D'Amico

A nurse led Prostate Cancer

survivorship clinic.

UNEXPECTED COSTS of SURGERY

If you think the toxicities of cancer treatment are limited to the physical nausea, fatigue, depression, and blood toxicity, think again.

Financial toxicity is of major concern. And not all the costs are fully covered (some not even partly) by Medicare or private health insurance. The costs include loss of employment, pharmaceutical and pathology, carer's leave, and transport and accommodation; all of these on top of the costs of the treatment, hospital and the surgeon's "out-of-pocket costs".

Prostate cancer patients are forking out as much as \$10,000 for "out-of-pocket" costs for a radical Prostatectomy, as well as \$40,000 for the total cost of surgery and hospital stay.

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Robotic surgery attracts "exorbitant" out-ofpocket costs, despite warnings from the Cancer Council Australia that robotic surgery offered no better cancer or functional outcomes than other forms of radical surgery.

It is also reported that rates of complications for radical prostatectomies ranged from zero to as high as 313 per 1,000 surgeries. "There is no evidence that the fee level charged by individual urologists equates to better surgical outcomes," said Dr Peter Heathcote, President of the Urological Society of Australia and New Zealand.

Before deciding on whether surgery, radiation or active surveillance with a particular oncologist, ask for a quote for the surgery/radiation, hospital, out-of-pockets, anesthetist, scans, pathology, pharmaceuticals, and supporting surgeon costs, all nett of Medicare and your private health insurance refunds. If you get second opinions, ask the costs of them as well. You may find you can reliably get the same result for less cost.

If you qualify for a pension (cancer is a "chronic condition" that may qualify you for a Disability Support Pension), this can mean less outlays usually costs are cheaper and refunds are more.

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RADIATION ONCOLOGY for the TREATMENT of PROSTATE CANCER

ONJCWRC and PCFA on Thursday, 24 August put on a presentation on Radiation Oncology at the Oliver Newton-John Cancer Wellness and Research Centre. A lot of the work was done by Carla D'Amico, ONJCRWC's Prostate Cancer Nurse, with help by the Wellness Centre and the Radiation Department staff. As an attendee, and on behalf of all the other attendees, I wish to express our thanks for informative presentations and a nourishing meal in the casual, enriching and sharing environment.

BOX HILL PROSTATE CANCER SUPPORT GROUP INFORMATION EVENING

Tuesday <u>26th September</u> 7:00-10:30pm Box Hill RSL 26 Nelson Rd Box Hill

Mr Philip Dundee (Urologist):

"Symptoms, Diagnosis and Treatment Options".

A/Prof Ken Sikaris (Pathologist):

"The Value of the PSA Test".

Prof H Miles Prince (Haematologist):

"Genomic Mutation Testing in Prostate Cancer".

RSVP by 10th September for catering purposes to <u>frank_blackwell@bigpond.com</u>; M: 0408 366 268; or M: 0407 409 961.

SEPTEMBER IS PROSTATE CANCER AWARENESS MONTH

September is Prostate Cancer Awareness month. Details are available on the web site: http://www.prostate.org.au/get-involved/events/find-an-event/prostate-cancer-awareness-month-2017/. Specifically it's aimed at motivating men to get their prostate checked (the digital and PSA tests) by their local GP if they are not already doing so. Get on the bandwagon!!!

MOVEMBER

Movember (https://au.movember.com/) is nearly upon us. Get yourself ready. Starting locally, it has internationally raised funds for and awareness of prostate cancer. Effecting us, Movember has started the prostate cancer nurse program and much new research. Be ready!!!

MAN JUNK PROJECT

Search the internet for "You Tube Man Junk Project Prostate". The result will give you a series of video presentations on what the prostate is biologically by using spare parts from a hardware store. A very interesting way of learning about the different parts and functions of the man's body "down there".

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NEW PCFA STUDY:"NEEDS of MEN WITH ADVANCED PROSTATE CANCER"

The PCFA Research study is investigating treatment preferences of men with advanced and metastatic prostate cancer. The study aims to develop an understanding of the specific treatment attributes that men with advanced disease value; the relative importance of each of these treatment attributes; and the risk/benefit trade-offs that characterize men's choices around treatment options.

If your cancer is out of the prostate (metastatic), and ordinary hormone therapy (ADT) is not enough to keep your PSA in check (castrate resistant or hormone resistant), Miranda Xhilaga and Wendy Winnall would love to interview you in Phase 1 of their study.

Reply to <u>miranda.xhilaga@pcfa.org.au</u> or <u>wendy.winnall@pcfa.org.au</u> with <u>Name</u>, <u>Address</u>, and <u>phone number</u>. Wendy and Miranda will get in touch. (Address is needed because a variety of men are needed from city, regional and rural locations.)

DEAKIN UNI. IMPACT STUDY

Deakin University (Burwood) is recruiting for the IMPACT Study investigating the effects of exercise and nutrition in men aged 50-85 diagnosed with Prostate Cancer and being treated with Androgen Deprivation Therapy.

If you are interested or would like further information, please contact Professor Robin Daly or Jack Dalla Via, Institute for Physical Activity and Nutrition, Deakin University (Burwood), www.deakin.edu.au/research/ipan/participate-in-our-studies or (03) 9246 8347 for more details or to register your interest.

OUR MEETINGS

Prostate Heidelberg provides information, education and support for those affected by prostate cancer. At the meetings, we

- Show respect to members and speakers;
- Allow people to speak and we listen;
- Respect confidentiality;
- Allow new ideas to be shared.

We meet on the <u>3rd Tuesday</u> of each month (except January) from 10:00am - 12:30pm at the Uniting Church Meeting Room, Seddon St, Ivanhoe (behind the Commonwealth Bank in Upper Heidelberg Rd). Free parking is available in a large public parking area at rear of the church. Ivanhoe railway station and various bus routes are nearby.

Meetings are open to anyone interested in getting support or information on a prostate cancer journey. Partners or carers are welcome to all meetings. There is no charge for attending. After the meeting you are welcome to join us for lunch in a local Thai restaurant (depending on numbers). If you can't attend daytime meetings, the Diamond Valley Prostate Cancer Support Group has evening meetings: http://www.dvpcsg.org.au/

CORRESPONDENCE

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Please contact Patrick Woodlock to redirect or cancel receipt of this Newsletter.

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CALENDAR

2017 Meetings: Tues 19th Sept 10:00am -12:30pm 10:00am -12:30pm 2018 Meetings:

Tues 18th December

Nik Zeps "Survivor Pathways" Tues 20th February Tues 17th Oct Tues 20th March

Tues 21st Nov Tues 17th April Tues 19th Dec Tues 15th May Carla D'Amico & Xmas lunch

Tues 19th June Tues 17th July Tues 21st August Tues 18th September Tues 16th October Tues 20th November

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