**Prostate Cancer Support Group**
**Jacaranda Lodge**
185 Fox Valley Road, Wahroonga NSW 2076

**JULY/AUGUST 2012 NEWSLETTER**

## Remaining meeting dates and speakers for 2012

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<td>PCFA National Director &amp; Chairman Education Subcommittee</td>
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<td><strong>Robotic assisted radical prostatectomy</strong></td>
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<td>Prof. Ian Davis, Medical Oncologist &amp; Cancer Immunologist; Chair of ANZUP (Australia &amp; New Zealand Urogenital &amp; Prostate Cancer Trials Group)</td>
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<td><strong>The work of ANZUP / clinical trials</strong></td>
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<td><strong>Update on clinical trials at Sydney Adventist Hospital</strong></td>
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<td>Greg Millan, Men’s Health Consultant</td>
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Support Group discussion meetings are held at 2.30pm for 3pm on the second Monday of the month.

Our evening education meetings start at 7pm on the fourth Monday night of the month. Partners and families are welcome. Refreshments are provided and meetings are free. Parking is $4.

**Parking update**

Unfortunately, finding adequate parking around Jacaranda Lodge will remain a challenge for the foreseeable future due to construction of the Integrated Cancer Centre. We can only suggest that you remain calm, leave plenty of time to find a parking space and enjoy the walk from the main car park to Jacaranda Lodge. Or try your luck in the area on the left of the drive up to Jacaranda Lodge. Some parking is available behind the Beattie Complex and Store/Dispatch Facility next door. (Follow the signs to Jacaranda Lodge). This area may be more accessible for those members attending the evening presentations.

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Help us raise awareness at our local Bunnings Warehouse during the annual SAH PCSG Sausage Sizzle!

We’d love your help on **Thursday 30th August** to help cook and serve sausages to the hungry hordes at Bunnings Warehouse, Thornleigh. Funds raised go directly to our support group. We also have stacks of information to hand out on prostate cancer awareness and SAH PCSG.

If you can help out between 3pm and 7.30pm on Thursday 30th August, please contact Pam on (02) 9983 0877 or email her at pam.sandoe@gmail.com. See you there!
Highlights of the ANZUP Annual Scientific Meeting
Sydney, July 2012

Report by Pam Sandoe

ANZUP is the Australia and New Zealand Urogenital and Prostate Cancer Trials Group. It conducts clinical trial research to improve treatment of bladder, kidney, testicular and prostate cancers.

From 15 - 17 July, ANZUP conducted its first stand-alone meeting in Sydney. Representatives from PCFA and consumers attended as ANZUP included its first Community Engagement Forum in their program.

The Forum provided information on the latest cancer treatment and research for people whose lives have been affected by cancers of the prostate, testicles, kidney and bladder. Consumers and clinical leaders discussed the importance of clinical trials; better listing and participation in trials in order to improve outcomes for those that needed the newest drugs the most and overall improve the outcomes for those affected by cancer.

A Consumer Advisory Panel is now part of ANZUP to better understand the consumer’s perspective on issues about clinical trials research. This helps ANZUP understand what the community needs and to ensure the results of research are communicated clearly and often to all parties.

Presenters included Pam Sandoe who spoke on her role as a carer; John Stubbs, (Chair, ANZUP Consumer Advisory Panel and consumer) on the cost of cancer to consumers/families; Matthew Carr spoke on his testicular cancer journey; Leonie Young shared sexuality post cancer and the impact it has on patient, carer, lover, partner.

The consumer advisory group also workshopped clinical trial submissions and processes which was very enlightening and beneficial.

The meeting started with a forum tailored for about 80 trainees who were exposed to some of the most challenging cases in Uro-Oncology. Low risk disease and metastatic disease and its best management approach were two of the main subjects discussed. The panel of experts included medical professionals Andrew Kneebone, Jeremy Grummet, Paul de Souza, James Kench and Senan Nagaratnam, together with PCFA National Chairman, David Sandoe, who represented consumers.

An update on ongoing clinical trials as well as collaborative research projects was given by some of the best Australian faculty in the field such as Clinical Assoc. Prof. Andrew Kneebone, Prof. Suzanne Chambers, Prof. Madeleine King and Dr David Malouf. The highlight of the session was the presentation of the approach and to-date results by Prof. Chambers on an intervention study that is looking at ways to reduce psychological stress in men with advanced prostate cancer and improve their quality of life. This is a telephone-based study that targets mindfulness in 190 men and is being conducted in collaboration with PCFA, ANZUP, Cancer Council QLD and Griffith University.

Clinical Assoc. Prof. Andrew Kneebone reported on results of the RAVES trial. RAVES stands for Radiotherapy - Adjuvant Versus Early Salvage: a trial that aims to answer an important question: What is the optimal timing of radiotherapy post prostatectomy? Is active surveillance with early salvage radiotherapy a better approach compared to adjuvant radiotherapy? As of April 2012, the study has recruited 200 patients across 26 centres around Australia. The target is 470 patients.

The Research Showcase consisted of talks presented by five renowned prostate cancer scientists on topics covering Adaptive Radiotherapy Techniques; Innovations in Intra-vesical Chemotherapy; Surgical Outcome in Bladder Cancer; New Systemic treatment for Prostate Cancer - novel anti-androgens, bone agents and chemotherapy and finally, the Role of MRI for Active Surveillance in Prostate Cancer.

The consumer’s perspective was delivered by Belinda Jago, mother of Jess, a beautiful teenager who fought renal cancer from the age of 14. Her journey was one of determination, resilience and zest for life. Sadly, Jess lost her battle with cancer shortly after she celebrated her 19th birthday. Her story highlighted the need for better coordination and criteria of participation into clinical trials as cancer patients progress into advanced disease. This was a most moving talk.
The ANZUP Concept Development Session revealed new concepts for clinical research in prostate and other urogenital malignancies. It opened up discussion of submitted concepts that have the potential for further development into ANZUP studies, and provided investigators with relevant feedback to improve and develop their concepts. The highlight was a prostate cancer concept from Dr Jeremy Grummet considering the substitution of known analgesics during biopsy of the prostate in order to lessen patient’s pain, or combining existing substances with other analgesics to achieve better results.

A session on Frontiers of Prostate Cancer Management was delivered by Dr Howard Gurney who gave an overview of the latest new therapeutics that either have been or are on the way to being introduced as part of primary care for the treatment of prostate cancer. Over the last three years, five new agents have shown a survival advantage: one immunotherapy (sipuleucel-T), one radioisotope (Radium 223); one chemotherapy drug (Cabazitaxel) and two antiandrogen agents (abiraterone now called Zytiga andMDV3100 - now called Enzalutamide).

The first three agents have reduced the risk of dying from castrate resistant prostate cancer (CRPC) by about 30% and the hormonal agents both reduce the risk by about 35%. It is expected that the dividing ‘wall’ of docetaxel will be broken down by further clinical studies with the likelihood that the antiandrogens will move earlier in the treatment schema before chemotherapy.

Other drugs in the pipeline include an oral TK1 inhibitor of MET/FGF (cabozatinib), and immunotherapies such as ipilimumab (anti-CTLA4) and the PD1 inhibitors. Improvement in bone health and inhibition of skeletal complications has also been achieved with zoledronic acid and the rank ligand antibody, denosumab. The advent of these new therapies has the potential to double the survival of patient with CRPC and when taken in conjunction with the relatively long responses from initial androgen inhibition. It can now be expected that most men with advanced prostate cancer will enjoy many years of good quality life. (Information from “ANZUP - Invited presentations and oral abstracts 037”, H Gurney, Westmead Hospital, Sydney.)

A debate between by Prof. Michel Bolla and Prof. Shahrokh Shariat around treatment choices for the clinician (surgery vs external beam radiation combined with androgen deprivation), highlighted the need for optimal management of high risk prostate cancer patients in clinical practice. Professor Bolla reminded us all in his inimitable French fashion that, “Ze life of ze patient does not belong to ze surgeon!”

New DVDs now available
Our SAH Prostate Cancer Support Group has a fantastic library of resources at Jacaranda Lodge, which you are welcome to browse through and borrow at any time.

We are delighted to advise of the release of the following DVD presentations from recent months:

**The Prostate - What Men really need to Know,** a presentation by Dr David Malouf, Urologist, National Director PCFA & Chairman - Awareness & Education Committee PCFA; Immediate Past President of USANZ (Urological Society of Australia & New Zealand).

**Brachytherapy for prostate cancer,** Dr Michael Izard, Radiation Oncologist; PCFA NSW Board Member.

**Heart Health - Primary prevention and risk reduction** with Dr Tommy Wong, Cardiologist.

Each of these talks is well worth viewing. Shortened clips are available on YouTube.

Time to start planning your mo: Movember is on its way
During November each year, Movember is responsible for the sprouting of moustaches on thousands of men’s faces in Australia and around the world. The aim is to raise vital funds and awareness for men’s health, specifically prostate cancer and depression in men.

2012 will be Movember’s ninth year. Big steps have been taken towards changing attitudes and habits relating to men’s health but there is still much to be done to catch up with the women’s health movement. Leading the charge and together with PCFA & beyondblue, Movember aims to fulfill its vision of having an everlasting impact on the face of men’s health by continuing to provoke conversation each year.

So, MoFellas: grow a moustache! MoSistas will support you by seeking sponsorship for your efforts!
Boots and all: a Victorian support group discusses life after prostate cancer
Geelong, VIC, 25 July 2012

Geelong and the Bellarine Prostate Cancer Support Group facilitators Bruce Kinnersley (left) and Roger Northam (right) invited SAH PCSG leaders Pam and David Sandoe (centre) to participate in an information night in Geelong, Victoria.

Pam and David Sandoe were delighted to take part in the information evening put on by the Geelong and the Bellarine PCSG in late July. They presented alongside two local urologists, Dr Greg Neerhut and Dr Paul Kearns, who spoke on regaining sexual function post treatment and urinary continence post radical prostatectomy. In addition, Kate Schofield, Nurse Educator Barwon Health, spoke on a new local cancer survivorship program.

The visit to Geelong had David and Pam testing their arms in the Victorian Blue Gumboot Throwing Championship, a wonderful fundraising initiative (see photograph below).

Local support group facilitators Bruce Kinnersley and Roger Northam put in a huge effort to attract 138 locals to the event, which included securing a number of community-minded businesses who offered advertising for the evening. Supported by Coloplast and combined with notices in local newspapers, community television and radio, support group numbers have been considerably boosted. Congratulations to all involved.

A new study into fertility and cancer: your input requested

Have you been affected by cancer? Are you able to take part in a study about cancer and fertility?

The following organisations are joining forces to research people’s experiences and views about fertility following a cancer diagnosis.

Your input will assist these organisations develop resources to help people affected by cancer address fertility issues.

What is required? You just need to complete one survey asking about fertility in relation to cancer. The information you provide will be confidential.

This study is seeking:

- People who have, or have had, cancer of any age (16 years+)
- Intimate partners (eg wives, husbands, girlfriends, boyfriends) of people who have, or have had, cancer

You don’t have to be in a relationship to take part. You can find out more about the study and complete the survey online at: www.uws.edu.au/cancerandfertility

If you want to fill in a paper version of the survey or would like more information about the study, please contact us on: 1800 192 002 (free call) or cancerandfertility@uws.edu.au.

SAN Cancer Support is participating in the Relay for Life on October 20th at Rofe Park, Hornsby, 9am ‘til late. This outdoor fundraising event celebrates life. Join in!
Melbourne Convention and Exhibition Centre hosted this key event which attracted over 800 local and international guests.

The program was very diverse and included:

- **Prostate Cancer in General Practice** with a debate on “Prostate cancer testing in general practice does more harm than good”, moderated by “Dr Feelgood” GP, Sally Cockburn. The debaters were Assoc. Prof. Declan Murphy, Urologist for the negative and Assoc. Prof. Ian Haines, Medical Oncologist for the affirmative.

- This was followed by a panel discussion on “What to expect after treatment and how to manage the symptoms”, with Mr Dan Moon, Urologist; Dr Pat Bowden, Radiation Oncologist; Dr Addie Wootten, Psychotherapist and Ms Helen Crowe, Nurse Practitioner.

- Breakfast meetings included Translational Science and Pathology.

- Nurses’ Bone Health Symposium: “It takes more than just milk to maintain bone health in prostate cancer”.

- Nursing and Allied Health meeting with the topic: “Morning Glory: Practical approaches to discussing patient sexuality: why is it so hard?”

- Friday provided an educational update for urologists, nurses and physios on post-prostatectomy incontinence with a master-class on Robotic Assisted Radical Prostatectomy.

There were cutting-edge presentations from leading researchers including topics such as:

- **Genomics** - how to integrate the latest in genomic profiling of cancer patients spanning the latest 'next generation sequencing' (NGS) technologies to large population-based ‘genome wide association studies’ (GWAS) to lead to advances in cancer diagnostics and prognostics. (Genomics relates to the sum of all the chromosomes within each nucleus of any species).

- **Biomarkers** - with a focus on the latest results of screening regulatory microRNAs in biological fluids as biomarkers for disease stratification and treatment response.

- **Imaging** - highlighting presentations on the latest imaging modalities being applied to the clinical problem of prostate cancer diagnosis and staging.

- **Cancer Genomics** - continued the theme from Day 1 on the latest developments in bioinformatics analysis of complex data sets to distil out clinically actionable information.

- **Metabolomics** - will highlight the complex interplay between metabolic processes nutrient and steroid signaling pathways in the emergence of castrate resistance in advanced prostate cancer.

- **Developmental Therapeutics/Targets** - the near horizon for emerging drugs and novel therapeutics for advanced prostate cancer.

The Psycho-Oncology Meeting aimed to bring together clinicians and researchers working in the field of psycho-social care of prostate cancer patients, their partners and families.

The meeting explored the social and emotional impact of prostate care and research and showcased the outstanding work being conducted in Australia and internationally in the field of Psycho-Oncology in prostate cancer.

In conjunction with Nurses and Continence Practitioners two plenary sessions were held to outline highlights to explore and develop multidisciplinary prostate cancer care. Two speakers presented on sex therapy for men and their partners. It highlighted the importance of a reasoned approach to the subjective assessment of men pre and post prostatectomy.

A representative from Calvista, suppliers of sexual aid products across Australia, gave an informative and fun discussion about their products.

**A date for your diaries: next year’s meeting will form part of the Prostate Cancer World Congress, to be held in Melbourne on 7 to 9 August, 2013.**
Centre Manager Shirley Lofgren, support@sah.org.au, phone: (02) 9487 9061

Prostate Cancer Support group leaders:
David Sandoe OAM and Pam Sandoe OAM, pam.sandoe@gmail.com, phone: (02) 9983 0877
Graham and Adele Staggs, gstaggs@accsoft.com.au, phone: (02) 9871 5599
Graeme and Margie Postlethwaite, gpostlet@bigpond.net.au, phone: (02) 9872 2542

Useful websites: www.pcfa.org.au - have you checked this one out recently?
It is regularly updated with fantastic information on resources, events and research news


NEW! You can now view clips from SAH PCSG presentations on YouTube: http://www.youtube.com/user/pcfaweb

Useful websites USA: www.ustoo.org  www.prostatenet.org  www.pcri.org  www.malecare.org
To read previous editions of this newsletter go to www.sah.org.au/cancer-resources-and-information

Host a Big Aussie Barbie for great food and fun for a good cause

Time to get out your tongs: the Barbie is one of the great Aussie icons that celebrates many good things about this country such as the weather, the food and the people.

September is International Prostate Cancer Awareness Month, and PCFA is encouraging us all to host a Big Aussie Barbie to celebrate the Aussie male and help to raise money and awareness for prostate health.

Last year the Big Aussie Barbie helped raise $600,000 for PCFA to help advance research, raise awareness and provide essential peer support to men living with prostate cancer and their families.

Register your best ever Big Aussie Barbie today:
Host a footy Barbie to celebrate your team
Host a spring Barbie to celebrate the new season
Host a Barbie with your friends to celebrate your mates
Host a Barbie around Father’s Day to celebrate your dad, grandad and all the men you love in your life.

Register now at bigaussiebarbie.com.au