

## FEBRUARY 2013 NEWSLETTER

### Meeting program for 2013

You, your partner and family are welcome at any of our meetings, which are held at Jacaranda Lodge, Sydney Adventist Hospital. Refreshments are provided.

|                 |           |     |   |
|-----------------|-----------|-----|---|
| <b>February</b> | <b>11</b> | 3pm | Jenny Rex RN<br><b>Constipation, faecal incontinence and benign issues like obstructive defaecation, haemorrhoids, anal fissure and pruritus ani</b>  |
|                 | <b>25</b> | 7pm | Dr Yvonne McMaster, retired Palliative Care Specialist<br><b>Palliative care: facts, figures and quality care</b>   |
| <b>March</b>    | <b>11</b> | 3pm | Prof. Suzanne Chambers, Psycho-oncologist, Griffith University. <b>Launch of her book: <i>Facing the Tiger: A Guide for Men with Prostate Cancer and the People Who Love Them</i></b> (see review on page 5). |
|                 | <b>25</b> | 7pm | Dr David Smith, Cancer Council NSW<br><b>Improving the quality of life of men with prostate cancer; current research at Cancer Council NSW</b>  |
| <b>April</b>    | <b>8</b>  | 3pm | Assoc. Prof. Pauline Chiarelli, Physiotherapist<br><b>Continence rehabilitation</b>   |
|                 | <b>22</b> | 7pm | Dr Phillip Katelaris, Urologist with Dr Michael Gillman, men's health GP, patient & carer David & Pam Sandoe<br><b>Rehabilitation: erectile function and continence</b>                                       |
| <b>May</b>      | <b>13</b> |     | <i>Due to a national support group leader training conference there will be no meeting on this date.</i>  |
|                 | <b>20</b> | 3pm | <b>Group facilitated discussion</b>   |
|                 | <b>27</b> | 7pm | Associate Professor Henry Woo, Urologist<br><b>Localised prostate cancer &amp; American Urological Association update; robotically assisted radical prostatectomy</b>   |
| <b>June</b>     | <b>24</b> | 7pm | Dr Michael Izard, Radiation Oncologist<br><b>Brachytherapy</b>  |

See back page for remaining meeting dates for 2013. Due to ongoing construction at the hospital, please allow extra time for parking. Parking is \$4. Meetings begin on time.

## Meet our presenters

*Our thanks to these speakers for volunteering their time and sharing their expertise with us*



**Jenny Rex RN** is a Clinical Nurse Consultant and Stomal Nurse Therapist, Continence Manager and Health Counsellor from Royal Prince Alfred Hospital Anorectal Diagnostic Facility and NSW BioFeedback and Continence Centre.

With more than 25 years' experience of bowel education Jenny's talks are always engaging, down-to-earth and very informative. Come and hear from Jenny at our meeting on 11 February.



**Dr Yvonne McMaster**, retired palliative care specialist, campaigned tirelessly during 2011 to re-establish full funding to palliative care units on Sydney's north shore. In 2012 she instigated another highly successful petition to

the NSW Government to urge restoration and improved palliative care facilities across the state. We are always delighted to welcome Yvonne to our meetings as she helps us to better understand pain management and what happens with late stage prostate cancer. Importantly for carers and family, we can then understand what happens as a loved one is dying. Yvonne joins us on 25 February.



**Professor Suzanne Chambers** has been instrumental in working with cancer support groups over many years. Suzanne worked for the Cancer Council Queensland and over time has developed a broad range of cancer

support services and led research into breast, gynaecological and prostate cancer, cancer nursing and physician education, peer support in cancer, supportive care interventions, patient decision-making and patient education. Suzanne is now with Griffith University in Preventative Health.

Her new book, *Facing the Tiger: A Guide for Men with Prostate Cancer and the People Who Love Them*, will be launched in Brisbane on 6 March. Our meeting on 11 March is our opportunity to help launch the book in Sydney.



**Associate Professor David Smith** from Cancer Council NSW has experience in epidemiology, public health and health services research. Since 1990 he has occupied positions with the NSW

Central Cancer Registry, Royal Australian College of General Practitioners, BreastScreen NSW and the research division of CCNSW. David has a major interest in prostate cancer, specifically in the epidemiology of the disease, the effect of PSA testing on the population trends and in the patterns and outcomes of care for prostate cancer. He also has an interest in descriptive epidemiology, particularly in small area analysis of cancer patterns and trends.

David completed a PhD in prostate care and outcomes at Sydney University in 2008. David will be presenting his talk on 25 March on improving the quality of life of men with prostate cancer, as well as updating us on current research at CCNSW.

“**Hearing from the experts and being able to ask them questions is very reassuring.**”  
- Nigel Cook, support group member



Tongue-in-cheek physio **Associate Professor Pauline Chiarelli** has been known to say, “We live on a very dry continent with a very wet population! Pelvic floor exercises, before surgery, are advantageous and of course,

necessary to recover bladder control after a radical prostatectomy”.

During her presentation to our support group on 8 April, Pauline will be revealing results from a recent research study: *Symptoms of pelvic floor muscle dysfunction after prostate cancer treatment*. She'll also give us a further overview on lower urinary tract symptoms (LUTS) and bladder training. We'll also be reminded about frequency, urgency, nocturia, hesitancy, intermittent stream, terminal dribble and urinary incontinence. Pauline will also fill us in on the value and importance of bowel and bladder health.



Consultant urologist **Dr Phillip Katelaris** has particular expertise and experience in the diagnosis and management of prostate cancer, especially in the field of erectile dysfunction. He is the Director of the Prostate

Cancer Rehabilitation Centre (PCRC) in Hornsby NSW. He will present with men's health expert Dr Michael Gillman on 22 April.



**Dr Michael Gillman** is a men's health GP based in Brisbane. He is nationally recognized as an expert in male health issues and works closely with other colleagues in the fields of Urology, Cardiology, Endocrinology, Psychiatry and Primary Care.

*David and Pam Sandoe will also be on hand on 22 April to represent patient/carer perspectives.*



**Dr Michael Izard** is a Radiation Oncologist at the Mater Hospital, Crows Nest, NSW. He is also involved in teaching at undergraduate and post-graduate level as a Clinical Senior Lecturer at the University of Sydney Northern Clinical School.

His special interests include prostate cancer and breast cancer, with a particular interest in brachytherapy. He is also active in multidisciplinary meetings in these and other areas.

Michael is well versed in presenting to consumers/carers and families about prostate cancer brachytherapy treatment. He enjoys the challenge of the question and answer sessions and often now asks what we want to know rather than give a prepared presentation. We extend a warm welcome for you to join us on 24 June for what is always an excellent presentation.



**Associate Professor Henry Woo** is a specialist prostate surgeon. His primary clinical and research interests lie with prostate cancer and benign prostatic hyperplasia.

Henry is actively involved in clinical research and regularly presents papers at both Australian and international meetings.

Henry is an experienced surgeon in the Da Vinci Robotic assisted laparoscopic radical prostatectomy. Part of his talk to our support group on 27 May will bring us up-to-date on this procedure, together with updates on anything new from the American Urological Association (AUA) conference in San Diego, California, which Henry will be attending in early May.

**“I'm always happy to share my knowledge with those going through a life-changing event like prostate cancer.”**

*- Suzanne Chambers, one of our expert speakers*

## World Cancer Day

It's World Cancer Day on 4 February and the focus this year is on dispelling myths about cancer.



See [worldcancerday.org](http://worldcancerday.org) for more information and helpful resources.

## NORTH SHORE PROSTATE CANCER SUPPORT GROUP

Missed a meeting at the SAN? Then catch up at the North Shore Prostate Cancer Support Group on Sydney's lower north shore which has a complementary program.

Meetings are held on the third Thursday each month at 4.30pm to 6.30pm (except January and December). Meet in the foyer, 5th floor, Kolling Building on the Royal North Shore Hospital campus. Parking is available at RNS.

Speakers for this year include Dr Phillip Katelaris, Urological Surgeon in February and Professor Warick Delprado, Histopathologist, in March.

There is no charge to attend and it is not a requirement to have had treatment at RNS.

Free telephone support is also available. Contact support group leader John Goodall for more information. Call (02) 9638 6203, or email [jgoodalldundas@hotmail.com](mailto:jgoodalldundas@hotmail.com)



# Coming to Wahroonga!

When: Saturday 23 February 2013  
 Time: 10 am - 12:30 pm  
 RSVP by: Friday 15 February 2013  
 Call for more details: **1300 200 558** (local call cost)

## Living Well After Cancer

A program for cancer survivors, their family and friends.



### Finished cancer treatment and ready to move on?

You may find that you see the world differently after cancer. Perhaps you feel that others don't understand your experience and expect you to 'get back to normal'.

Cancer and its treatment can bring a host of practical challenges, from changes in appearance and body function to managing the emotional and social impacts.

Living Well After Cancer program is a free community education program and is run by Cancer Council with trained cancer survivors.

This two and a half hour program includes practical information and open discussion for people who are cancer survivors, carers, family, friends and work colleagues. As a participant, you will learn about the possible changes, challenges and opportunities you may face after completing cancer treatment.

You will also have the opportunity to connect with others on a similar journey, and share tips, ideas and activities to help you live your life well.

**// I am so grateful for this program. I felt so lost when I finished treatment ... I just thought everything would go back to normal //**

For more information about the next program in your area, please contact **Cancer Council Helpline 13 11 20**



CAN940 06/11

## Sydney Adventist Hospital palliative care nurse practitioner service



SYDNEY ADVENTIST HOSPITAL

A nurse practitioner is a registered nurse educated and authorized to function autonomously and collaboratively in an advanced and extended clinical role.

The nurse practitioner role includes assessment and management of clients using nursing knowledge and skills. The nurse practitioner works within a defined scope of practice and is authorized to prescribe medications and order diagnostic investigations. The role provides innovative and flexible health care delivery that complements other health care providers.

The role of the nurse practitioner in palliative care is to manage pain and other distressing symptoms such as nausea/vomiting and mobility. The nurse practitioner works

collaboratively with palliative care and specialist doctors, GP's and community care providers.

The service is bulk-billed through Medicare, therefore there is no gap payment.

Contact and monitoring is through:

- Review while a patient at the San
- Telephone follow-up
- Outpatient clinic
- Home visits
- Visits to residential aged care facilities
- Visits in emergency care

Contact Julie Edwards, Nurse Practitioner, Palliative Care at the San for more information.

Phone (02) 9487 9060 or 0400 053 591.

## Preview of Professor Suzanne Chambers' new book

Called *Facing the Tiger: A Guide for Men with Prostate Cancer and the People Who Love Them*, this keenly anticipated book will be launched in March 2013

An introduction from the author, psycho-oncologist Professor Suzanne Chambers:

"Prostate cancer is now the most common male cancer in the western world, excluding non-melanoma skin cancer. In the United States over 2.5 million men are living with a diagnosis of prostate cancer; in the United Kingdom over 250,000 men and in Australia over 120,000 men. For each man who has had prostate cancer, there will be people close who care about them, and love them, who are also deeply affected. This book is for them too. It provides a map to help the reader find a path to regain a sense of ease about the situation in which they have found themselves. It is not a guide book about treatment options and will not give any medical advice. It is structured so that each chapter works on its own so the reader can choose what part seems most relevant right now. Personal stories and insights from men and women offer both comfort and inspiration. Everyone's experience of prostate cancer is their own, and there is no one right or wrong way. However, there is nothing quite like personal experience and the wisdom that comes from this experience."

What other experts have had to say:

*"Suzanne Chambers is one of those rare people who not only sees a problem but immediately starts to think about how to do something about it. So much of the psycho-oncology literature is full of studies about observation and measurement. Suzanne's group is leading the way in devising meaningful interventions based on this knowledge and then testing whether they actually make a difference. Suzanne has taken her practical insights and loaded them into this easy-to-read book, illustrating them with real examples. This book will make a large difference to the lives of people affected by prostate cancer."*

**- Professor Ian Davis, Medical oncologist, Chair, Australian & New Zealand Urogenital and Prostate Cancer Trials Group**

*"An excellent handbook. Suzanne Chambers has had an enduring and innovative commitment to helping to resolve the many difficulties encountered by those involved with prostate cancer for many years. Tracing the many dilemmas faced in what is so often a long journey with this condition, this book proposes*

*practical ways to straddle the hurdles that appear in the paths of patients and partners. The book is written from the heart and provides a self-help guide in simple and unambiguous language. A major strength is the inclusion of sections by a number of courageous patients and partners who have openly shared what are so often regarded as private experiences."*

**- Professor RA ('Frank') Gardiner AM, MBBS MD FRACS FRCS, Professor of Urology, University of Qld, Consultant Urologist, Royal Brisbane & Women's Hospital**

*"Once a patient, partner/carer or a family member affected by prostate cancer starts to read this book they will not be able to put it down. It is a wonderful blend of real life stories, practical tips learnt by experience and professional know-how. Quality of life is a theme that resonates, along with confidence building and knowing you are not alone."*

**- David Sandoe OAM, National Chairman PCFA and Co-Leader (with wife Pam) of the Sydney Adventist Hospital Prostate Cancer Support Network**

*"A must-read for anybody coping with a prostate cancer diagnosis. It is equally as useful and important for their partners. I wish it had been around when I was diagnosed."*

**- Peter Dornan AM, Sport Physiotherapist, Author, Sculptor and Convenor of the Brisbane Prostate Cancer Support Network**

*"A must-read for all patients, and their families, who are faced with a diagnosis of prostate cancer and the life after it. The medical community is still in the infancy of incorporating issues of patient distress and the psycho-social elements of therapeutic care into clinical practice. This book helps medical consumers find their internal strength and empowers them to be advocates for their own best quality of life."*

**- Virgil H. Simons, MPA, Founder/ President The Prostate Net, an international non-profit patient education and advocacy organisation for men with prostate cancer**

**Centre Manager** Shirley Lofgren, support@sah.org.au, phone: (02) 9487 9061

**Prostate Cancer Support Network 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 out recently?

*It is regularly updated with fantastic information on resources, events and research news*

www.prostatehealth.org.au www.beyondblue.org.au www.cancercouncil.com.au www.andrologyaustralia.org

**Useful websites USA:** www.ustoo.org www.prostatenet.org www.pcri.org www.malecare.org

PCFA Newsletters online: <http://www.pcfa.org.au/articleLive/pages/PCFA-Newsletter.html>

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

To read previous editions of this newsletter go to [www.sah.org.au/cancer-resources-and-information](http://www.sah.org.au/cancer-resources-and-information)

## Remaining 2013 meeting dates

July 8 and 22  
August 12 and 26  
September 9 and 23  
October 14 and 28  
November 11 and 25  
December 9

Speakers to be confirmed, but if there is any topic you'd particularly like to hear about, contact Pam Sandoe at [pam.sandoe@gmail.com](mailto:pam.sandoe@gmail.com)

## Life story writing course

Life Story Writing is a six-week course from 5th March to 16th April 2013 from 10am - 12 noon. Run by Bridget Brandon, an artist, teacher and life writing skills expert, the sessions will be held at the Cancer Support Centre, Jacaranda Lodge, Sydney Adventist Hospital. There is no charge but a donation would be appreciated.

Life story writing will take you on a journey through the ordinary and extraordinary moments of your life. You will learn to use writing as a tool for tuning into your inner, reflective, self and telling your story. This is particularly helpful during a challenging time, such as when we face cancer. Taking the time to write moments from your life both present and past can be a gift to yourself and your family.

"Bridget's skill in calming our apprehension about our skills and encouraging us gently is fabulous," says a previous participant.

So bring your favourite pen, a journal or lined paper and join the group to explore your own story. Bookings essential, contact (02) 9487 9061 or email [support@sah.org.au](mailto:support@sah.org.au)

## Localised Prostate Cancer Pack

Prostate Cancer Foundation of Australia's Patient Pack is designed for people with a recent diagnosis of prostate cancer.

This pack contains information resources for men, their families and friends.

It is available as a pre-loaded USB.

If you wish to have this posted to you, simply complete the order form on the PCFA website or call **1800 220 099**.



**Disclaimer:** The information in this newsletter is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your qualified medical professional. Whilst the SAH PCSN is proudly affiliated with Prostate Cancer Foundation of Australia (PCFA), content of this newsletter is independently published and does not necessarily reflect the views of PCFA.

**Writers/Editors:** Pam and David Sandoe