#### Central Australia Chapter





Newsletter of the Prostate Cancer Support Groups of South Australia and Northern Territory

#### www.prostate.org.au

#### August 2016

Newsletters can also be read online at www.pcagsa.org.au/pages/supporter.html

Volume 9: Number 3

# The long lunch returns

THE Friday Long Lunch will return at noon on Friday August 5, in the Adelaide Oval's Magarey Room – to raise awareness and funds for prostate cancer.

Last year's event attracted a capacity crowd of 550 people and raised nearly \$70,000 for PCFA, which has encouraged us to stage the Long Lunch once again.

Hosted by Channel 7's John Riddell, the event on August 5 will feature entertaining talks from football legends David Parkin OAM (also a very prominent prostate cancer ambassador) and Rick Davies, as well as live entertainment and major auctions.

The Long Lunch is proudly supported by Saint Andrews Hospital, Adelaide Radiotherapy, Channel 7, Clinpath Laboratories, Device Technologies, and Dr Jones & Partners.

Other sponsors include Aramis Vineyards, Battle of Bosworth and Spring Seed Wines, Gemtree Wines, Hardy's Wine, Kangarilla Road Winery, Longview Vineyard, Majella Wines, O'Leary Walker Wines, Peter Lehmann Wines, Pol Roger, Yalumba, Schweppes and Heineken Brewery.



ABOVE: The Magarey Room at Adelaide Oval was packed to capacity for the inaugural Long Lunch last year, and tickets for this year's event at \$145 a person can be booked from the website www. trybooking.com/201376 or queries can be made via SA's PCFA office be emailing janie.green@pcfa.org.au.

• HOW do you want to receive your copy of the Prostate Supporter newsletter? Read it online, or have a hard copy posted? We are trying to streamline eficient distribution of the newsletter, so let us know your preference by emailing Janie Green in the PCFA office (janie.green@pafc.org. au) or phone 8231 6339.

# August

Last year's lunch booked out early. Don't miss out this year! Reserve a table now by return email. Queries to Janie.Green@ pcfa.org.au

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#### **Prostate Cancer Action Group**

# Footy fans spread the word

The Action Group enjoyed great success through having volunteers help take the prostate cancer awareness message to the football stadiums, as Ian Fisk reports.

ADLY, the Prostate Action Group's chairman, David Merry, had a serious accident in early May. While cleaning gutters, he fell from a ladder head first onto concrete. As of mid-July, he is slowly recovering at home, having broken 14 bones, including two skull fractures and seven cracked ribs. He was in intensive care for three weeks and in an induced coma for a week, and later spent time in the Rehabilitation Unit at Daw Park Repatriation Hospital. He is counting his blessings that he is still alive.

Thankfully, Bob Wood has been acting chairman since David has been unavailable. The group has been carrying on with its meetings and activities. For any details or more information about Action Group activities, phone Bob on 0448 454 314.

As described in the previous Prostate Supporter newsletter in May, the Action Group and several volunteers have attended local football games to spread the word about Prostate Cancer. Some have attended pre-game lunches in the company of a South Terrace urologist and others to present talks about prostate cancer. Prostate cancer awareness and PCFA details have been promoted on large screens and with spoken words at the football stadiums. Some members have been handing out prostate cancer brochures at entrance gates. Several South Australian Metropolitan Fire Service members also generously gave their time rattling PCFA donation tins at entrance gates. Considerable funds have been collected so far and Bob Woods has done a great job organising this program.

In other Action Group activities, the anticipated awareness meeting at the Life Care Active Centre at Payneham did not happen in June, but will hopefully take place in August or November.

The group intends to attend the Kingston Show on October 2, and the Penola Show on October 29. Members of local support





The Action Group attracted a great number of volunteers – male and female, young and old – to the Adelaide Oval to rattle the tins and spread the word on prostate cancer.



groups hopefully will assist the Action Group in presenting information stalls at these shows.

The Action Group's Annual General Meeting will be included in our August 9 meeting. More people are very welcome

#### **COMING EVENTS**

• The Prostate Cancer Action Group SA holds its meetings at 5.30pm on the second Tuesday of each month – in the PCFA office at 144 South Tce, Adelaide. Entrance is from the rear door off the driveway.

- The next meeting of the Action Group is on Tuesday August 9.
- For more information, please visit the Action Group's website at www.pcagsa.org. au or phone acting chairman Bob Wood on 0448 454 314

to attend and help the group continue its valuable work. All positions will be up for election.

The SAProstate Cancer Clinical Outcomes Collaborative (SA-PECOC), established in 1998, is an ongoing collaborative venture of Flinders University, Repatriation General Hospital, Royal Adelaide Hospital, The Queen Elizabeth Hospital, the University of Adelaide and the University of South Australia. Its database follows men with prostate cancer treated at the three major metropolitan hospitals (The Royal Adelaide Hospital, The Queen Elizabeth Hospital, Flinders Medical Centre/Repatriation General Hospital) and collaborating private institutions.

To learn more about this issue, an interview with Dr Michael O'Callaghan from SA-PECOC recorded by one of our group members, John Thornton, will be aired on local radio station 5RPH (1197AM) on Tuesday August 2 at 7.30pm in the Rotary Club News program.

**Central Australia Chapter Council Farewell** 

# **Council's final message**

PCFA Central Australia Chapter Council Chairman Joan Manfield explains the organisational restructuring that has seen the end of the chapter councils.

S many will now be aware, recent restructuring of the Prostate Cancer Foundation of Australia means that the Chapter Councils have been made redundant, and therefore this will be my last column.

The Central Australia Chapter Council had its final luncheon/meeting on June 15, and I would like to thank all fellow councillors for their involvement and support, especially over the past 18 months. My time at the helm of the council has been rewarding and helped me grow in confidence to handle anything that comes my way.

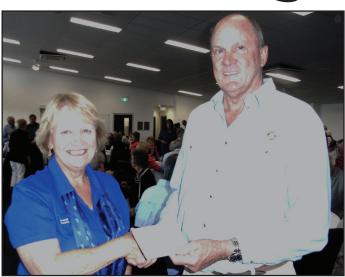
I am sure we will continue to see each other at PCFA events, such as the Community Conversations Forum that will be held on August 12.

To all others who have served on the Central Australia Chapter Council over its eight years, I thank you for your work and efforts to support and inform support groups in South Australia and the Northern Territory.

I wish all members of support groups the best for the future, and hope they continue to receive and give support to men and their families on their prostate cancer journey. Many support groups have members who have not had prostate cancer, and I hope these people continue to attend meetings and show their support.

#### SUCCESSFUL EVENT HELD IN MAITLAND

ONE of my final duties as chapter chairman was to attend a fundraiser organised by the Rotary Club of Maitland on April 17. A luncheon was held at the Maitland Football Club, with a silent auction conducted



ABOVE: Joan Manfield received a \$5000 cheque for PCFA from Maitland Rotary Club president Paul Davey at the Maitland fundraising luncheon held during April.

during the afternoon. There were many great items for auction and a good deal of money was raised. Throughout the afternoon, Kaylene Graham entertained us with great singing, and comedian Rod Gregory (the Old Fella) created great laughter in the hall.

Everyone enjoyed a great day, marked by good food and good company. Members of the Yorke Peninsula Prostate Cancer Support Group attended, and it was good to catch up with some of these members.

The fundraiser beneficiaries from this event were PCFA and Ovarian Cancer. A cheque for \$5000 from the Maitland Rotary Club was presented at the event to Joan Manfield by Rotary Club president Paul Davey.

#### **Barossa Valley Prostate Cancer Support Group**

• The Barossa Valley Prostate Cancer Support Group meets on the third Tuesday of each month, from 2pm to 4pm, at the Vine Inn Hotel, Nuriootpa. The next meeting will be on Tuesday, August 16. For more information, phone Don Piro on 8562 3359 or email don@dppcs.com.au

#### Westside Prostate Cancer Support Group

• Westside Prostate Cancer Support Group meets at 7.30pm on the last Wednesday of each month, at the Temple Uniting Worship Centre, 214 Military Rd, Henley Beach. We note that the group has recently attracted a few extra members at several meetings, and so it is fulfilling its role nicely.

• For more information, contact Andrew Luciani (phone 8356 0887 or 0422 639 828; email andandcl@adam. com.au) or John Cox (phone 8356 8650 or 0419 955 606; email candjcox@adam.com.au)

### Adelaide-Mitcham Prostate Cancer Support Group

# **Radiation therapy explained**

#### A welcome returning speaker gave the Adelaide-Mitcham group key information updates, as Jeff Roberts reports.

HAIRMAN Ralph Walker welcomed radiation oncologist Dr Phuong Tran in April, who previously spoke to our group in 2014. This time, she spoke about Updates in Radiation Therapy for Prostate Cancer, providing an overview of decision making in the management of prostate cancer, treatment processes involved for radiotherapy treatment of prostate cancer, and potential treatmentrelated side effects.

Decisions on the most appropriate treatment for a patient's prostate cancer are individualised, taking into consideration:

• The PSA, Gleason Score and Stage/Extent of disease enable a prostate cancer to be stratified into risk categories that guide treatment decisions. Staging or determining the extent of a patient's prostate cancer is done using a number of tests including: Multi-parametric MRI scans, Whole body bone scans, CT (CAT) scans and PSMA-PET scans

• Patient factors, such as their age, other health problems and pre-existing urinary/bowel/sexual functioning, along with individual social circumstances and priorities with regards to potential side-effects are also important in deciding which treatment is acceptable to a patient.

• All treatment options have certain requirements or conditions that may make a patient not suitable for a particular treatment. All treatment options for prostate cancer have potential side effects that need to be weighed up with what is important to a patient.

An overview was provided of the steps involved in prostate cancer treatment using External Beam Radiotherapy (EBRT) vs Brachytherapy (low dose rate or high dose rate). EBRT is used for definitive treatment, or following surgery, or for palliation. Preparation for curative treatment may involve the use of Gold Fiducial markers, to Seed improve accuracy of treatment (Image guided radiotherapy), SpaceOar, to reduce and potential rectal side effects. CT Simulation/Planning is used to design an individualised radiation treatment course using advanced radiotherapy techniques (IMRT or VMAT), which maximises tumour control and minimises doses to adjacent organs, therefore reducing potential side effects. Brachytherapy patients generally need to meet more stringent criteria, including no previous/recent TURP, medical fitness for General Anaesthetic, and a satisfactory urinary flow is required to minimise risk of complications. Low-dose rate brachytherapy is only suitable for low-intermediate risk disease. High-dose rate brachytherapy is given for high-risk disease, usually in combination with external radiotherapy. Volume study is required to ensure the prostate volume/size is suitable and that the bony pubic arch will not block access.

The majority of side effects from radiation treatment for prostate cancer are temporary and only a very small number of patients experience longterm effects. Issues can include



Guest speaker Dr Phuong Tran.

Photo: lan Fisk

#### **COMING EVENTS**

• The Adelaide-Mitcham support group's next meeting will be on Thursday August 25 at the Colonel Light Gardens RSL Club, 4 Prince George Parade, Colonel Light Gardens, from 7pm to 8.45pm. The speaker will be urologist Dr Kym Horsell, talking about the Prostate Cancer Patient Data Base (SA-PCCOC) at the Repatriation General Hospital. • The September 22 meeting will be a discussion evening. October 27 will feature Henry McGregor, a musculoskeletal and sports physiotherapist from Adelaide Men's Health Physio. November 24 is the likely date for our end-of-year dinner.

• For more information, visit the Adelaide-Mitcham website at www.adelaide-mitchampcsg. org or phone Jeff Roberts on 8277 3424 or Ian Fisk on 8296 3350.

tiredness, localised skin reaction, bowel problems of enteritis and proctitis, urinary issues (cystourethritis, retention, strictures, incontinence) or sexual issues (impaired erectile function, altered/reduced ejaculate).

Prostate Cancer commonly spreads to bones, and bone metastases/secondaries are the most common form of cancerrelated pain. Radiotherapy is one of the most effective treatments to relieve or reduce cancer-related pain from bone metastases/ secondaries. It can also delay or prevent skeletal complications, such as fractures, and improve functioning and quality of life. Radiotherapy has an integral role in the management of all stages of prostate cancer, and modern techniques make it an effective and well-tolerated treatment.

#### **PSA testing in the news**

### Make contact if you have PSA queries

#### • Submitted by IAN FISK

MUCH has been written in the press this year about Prostate Specific Antigen (PSA) results, and this interesting article from the SA Pathology website (posted on April 11, 2016) is worth noting:

"SA Health has announced an independent review into Prostate Specific Antigen testing. SA Pathology welcomes the review and apologises for the concern, inconvenience or confusion that may have been caused to patients or their doctors. SA Pathology remains committed to providing the highest quality pathology services for our patients and our population. Our laboratories are accredited by the National Association of Testing Authorities for diagnostic testing against the National Pathology Accreditation Advisory Committee standards. Anyone with questions or concerns should contact their referring doctor or SA Pathology on 8222 3000."

SA Pathology Newsletter from June 4, 2016 devotes page 12 to an article titled "What is PSA?". The section on "laboratory differences" concerns some issues raised when a laboratory switches testing methods (such as using different manufacturer's test kits). Results at the lower limits of sensitivity have been different between the kits that are used, causing some readings to be of concern to many men when the results appeared to change from undetectable to detectable levels of PSA.

Clinicians and their patients that have been tested by SA Pathology are being contacted to explain the situation. If those who tested at other laboratories are concerned about their recent readings, they should discuss the issue with their General Practitioners and/or Specialists.

The SA Health PSA Steering committee will provide an update when its work and the Australian Commission on Safety and Quality in Health Care (ACSQHC) external review is finalised.

### **Adelaide-Mitcham Prostate Cancer Support Group**

# **Explaining products that help**

R OSALIE Donhardt, a continence nurse at the SA Continence Resource Centre, spoke at the Adelaide-Mitcham Support Group's May meeting, providing an update on continence products. Rosalie explained the SA Continence Resource Centre, Community Continence Services, Continence Foundation of Australia and resources, healthy bladder and bowel habits, continence products and Continence Funding Schemes.

The SA Continence Resource Centre at 11 Blacks Rd, Gilles Plains, has more than 400 products on display, and although it doesn't sell these products it can provide samples and printed information about where they can be purchased. The centre can be contacted by phone on 1300 885 886.

Rosalie showed many of the products available for men with incontinence issues. There is a solution for all situations, so with the array of products available, and with good knowledge of toilet locations



**Rosalie Donhardt** 

Photo: lan Fisk

and planning, there is no need for anyone with continence difficulties to feel they have to stay at home.

Help is also available from Royal District Nursing Service (GP referral required), Repatriation General Hospital-Continence and Urology Service, and Resthaven Day Therapy Services at Marion, Elizabeth and Paradise (book via My Aged Care ph: 1800 200 422). The Continence Foundation of Australia also offer assistance via a free call number 1800 330 066. A National Public Toilet map is also available; its website only requires the entry of a location and nearby toilets will be identified.

Rosalie also mentioned the My Aged Care website, established by the Australian Government to help you navigate the aged care system. My Aged Care is part of the Australian Government's changes to the aged care system, designed to give people more choice, more control and easier access to a full range of aged care services via its website. They can also be contacted by phoning 1800 200 422.

A small number of support group members braved wintery weather to attend the June meeting. After a discussion among members and visitors, a video was shown of the recent PCFA webcast – *Prostate Cancer: Diet, Supplements and Lifestyle*. After a number of members had updated news of their prostate situation, the video provided excellent information from a range of speakers, which was appreciated by those in attendance. www.prostate.org.au

### **New PCFA information services**

# Smart physiotherapy guide

N conjunction with Australian Physiotherapy Association (APA) and Continence Foundation, PCFA has produced a detailed physiotherapy guide to assist men with pelvic floor exercises, both before and after surgery.

It explains that urinary incontinence, or leakage, is to be expected after prostate surgery.

It may be a mild problem, needing pads to manage it for only a few weeks, or more severe and requiring protective pads for up to a year.

The pelvic floor muscles control the bladder and flow of urine. Exercising them effectively will help men regain bladder control earlier. Ideally, the exercises are started before surgery, but they can also help bladder control if started after surgery.

It starts by explaining how to find the pelvic floor muscles. Sit on your hands and find the sitting bones in the middle of each buttock. The pelvic floor muscles stretch between them. Now stand up and find the pubic bone, at the base of the penis, and the coccyx (tailbone), at the bottom of the spine.

The pelvic floor muscles extend from front to back and from side to side between these bones, forming a supportive layer. When tightened, the muscles lift the bladder and bowel inside the pelvis; they shorten the penis and close the anus. When urinating, contracting the pelvic floor muscles should stop the flow of urine.

Exercises are explained in three sections – focusing on technique, how to control flow stop, doing daily workouts, and explaining how to put the pelvic floor into action.

The eight-pager colour brochure was released in June – with the APA released the guide to its members in conjunction with their quarterly magazine, and PCFA providing the following link via its website to download the content of the guide.

http://prostate.org.au/media/743467/ physiotherapy-before-and-afterprostate-cancer-surgery.pdf

#### Adelaide Hills Prostate Cancer Support Group

• The Adelaide Hills Prostate Cancer Support Group meets on the third Thursday of each month, from February to November, at the Adelaide Hills Community Health Service, Wellington Rd, Mt Barker.

• During August, a site visit is planned to the Basil Hetzel Research Institute in Woodville, with a laboratory tour and presentation by research scientist Dr Irene Zinonos. A mini bus is to be organised for transport to the venue, and lunch will be enjoyed afterwards at the Woodville Hotel.

• The Adelaide Hills support group is also investigating a meditation course for those who are interested in joining with the local cancer support group. If there is sufficient interest, the course will be held over a four-week period by meditation practitioner India Wallace.

• For further information, please contact Sue Tulloch or Emlyn Lewis on 8393 1833.

#### **Riverland Prostate Cancer Support Group**

• The Riverland Prostate Cancer Support Group conducts its meetings on the second Tuesday of alternate months at the Combined Services Club Rooms, Kealy St, Berri, from 7pm. The next support group meeting will be held on Tuesday, September 13. For more information about the Riverland support group, please phone Riverland support group convenor Allan Dand on 08 8582 1651, 0488 994 803, or email alglen@iprimus.net.au

#### Murray Bridge Prostate Cancer Support Group

• The Murray Bridge Prostate Cancer Support Group conducts its monthly meetings on the third Wednesday of every month, at 7.30pm in Our Wellbeing Place, 108 Swanport Rd, Murray Bridge. For more information about the group, phone Murray Bridge support group secretary Max Klenke on 8532 1936.

### Port Pirie Prostate Cancer Support Group

# **Regular exercise is vital**

The importance of maintaining a continuing exercise program – especially to help combat prostate cancer – was spelled out to the Port Pirie support group, as Ray Walters reports.

PHYSIOTHERAPIST Clive Munzberg was guest speaker at the May meeting of the Port Pirie Prostate Cancer Support Group. Clive started his career in Salisbury after studying at the University of Adelaide, then moved to Port Pirie in 1989, married a local lass, and started his clinical practice.

Clive talked about keeping active for life and, with help from a PowerPoint presentation, explained statistics and research showing how cancer is impacted by increased levels of physical activity. A recent study showed a 49 per cent reduction in deaths from prostate cancer for those men undertaking three hours or more of vigorous exercise each week.

Clive suggested that maintaining a steady normal body weight, controlling stress and anxiety, paying proper attention to diet and undertaking three or more hours of vigorous physical activity weekly optimises the function of a person's immune system and can lead to reduction chances of dving of prostate cancer.

Any exercise activity (such as walking, running, swimming or cycling) which raises a person's heart rate to 60 per cent of their maximum heart rate (220 minus your age), performed 30 to 60 minutes daily, from three to five times



ABOVE: Port Pirie physiotherapist Clive Munzberg, guest speaker at the support group's recent meeting.

each week (or reaching a total of at least 150 minutes per week) will help prevent developing major diseases and developing or dying from prostate cancer.

Clive suggested that it helps to do some form of resistance exercise, weight bearing or using resistance bands, to boost muscle strength and strengthen bones to prevent osteoporosis. Clive quoted some alarming statistics about falls; one in three people aged 65 and over will suffer a fall, one in 20 of those will break a hip, and one in two of those suffering a fracture would most likely die within the following six months.

To improve your wellbeing, Clive introduced the concept of making a contract with yourself to set aside time each day for exercise that will benefit your health. He suggested starting small and building up to the necessary 150 minutes each week. Any movement, including repeated standing up and sitting down would be of benefit.

"Remote controls are killing us," Clive added with a chuckle. "When we were youngsters, we had to get up to change channels on the TV. With new technology, the remote control has taken away the necessity and incentive to even get up and move.

"Start by parking the car at the supermarket a good distance from the doorway and walking that little bit further. Sitting is the new smoking – and any chance to stand rather than sit, such as when we are watching sport at a sports ground, would be of benefit."

Clive introduced some simple exercises that can be done at home, such as using a chair or table for support to do some lunges. Next came

#### **COMING EVENTS**

• The Port Pirie Prostate Cancer Support Group conducts monthly meetings (from February to November) at 7.30pm on the first Tuesday of the month at BHAS Bowling Club, Halley St, Port Pirie.

• There is usually an excellent guest speaker, and late supper is provided for the 30-to-40 ladies and gentlemen attending each meeting.

• For further details about the group and its activities, please phone the Port Pirie support group coordinator Allan Manfield on 08 8632 1324.

the suggested use of resistance bands in various ways to exercise a variety of muscle groups. Simply using bottles of water as weights for lifting can strengthen the arms and provide great benefit.

He explained that exercise groups for seniors, yoga classes, 24-hour gyms, tai chi classes and walking clubs are very good supportive organisations to keep you motivated with your exercising.

Clive invited questions and gave good qualified answers and explanations to the queries, concluding an informative and interesting session.

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Limestone Coast Prostate Cancer Support Group

# Information aplenty on cancers and continence

The lessons, advice and information that guest speakers are providing to the Limestone Coast support group about broader health issues are resonating clearly for those continuing on their prostate cancer journey, as Richard Harry reports.

OCAL GP Dr Mike Bruorton has a strong interest in skin cancers and melanoma, which he explained in detail during his talk to the Limestone Coast Prostate Cancer Support Group meeting in May.

Extensive advertising of this meeting ensured that several people not involved with prostate cancer were present to hear Mike's presentation, including two representatives from the Mount Gambier Cancer Support Group.

Non-melanoma skin cancers are the most common cancers diagnosed in Australia, with melanoma being the fourth most common cancer overall. In 2005, there were 1272 deaths due to melanoma in Australia. Another interesting fact is that 48 per cent of males had late onset for melanoma while women had 52 per cent early onset.

The main message that Mike promoted was to get your skin checked at least once a year – which is a familiar reminder of how we should monitor our general health.

The support group's June meeting was a social outing – a luncheon at a local tavern – but the July meeting featured Julie Thornley from



ABOVE: Dr Mike Bruorton receives a thank you gift from Limestone Coast support group chair Malcolm Porter. BELOW: July speaker Julie Thornley during her talk with the Limestone Coast group.



Community Health speaking about continence. Although the evening was both cold and wet, a good audience of 18 people braved the conditions to hear Julie's presentation. On show were various continence aids, while Julie explained

their use and when some of these aids are necessary.

She strongly suggested not using female sanitary pads for continence problems, as these are manufactured with different materials, and although they are cheaper,

#### **COMING EVENTS**

• THE Limestone Coast Prostate Cancer Support Group meets on the first Thursday of each month at the District Council of Grant offices, 324 Commercial Street West, Mount Gambier, at 7.30pm.

• The support group's meeting on August 4 will feature a DVD presentation on Brachytherapy.

• For more information about the Limestone Coast support group, phone coordinator Richard Harry on 08 8724 9057 or 0427 978 898, or email richardharry@ bigpond.com

they are also not designed for urinary protection. The Commonwealth Government Continence Aids Payment Scheme was explained, outlining that those people who are eligible can receive a \$506 per annum payment.

### Mount Gambier Gold Cup Carnival Luncheon

## Funds and fun at cup luncheon

HURSDAY May 12 was the first day of the Mount Gambier Gold Cup Carnival – and the racing club sponsored a luncheon with its proceeds donated to Prostate Cancer Foundation of Australia. John Fartch, president of the Mount Gambier Racing Club, was the driving force behind this event, with assistance from the Limestone Coast Prostate Cancer Support Group and PCFA office in Adelaide.

Fantastic support was provided by local businesses that supplied prizes for the silent and open auctions, which helped make this event a great success. Prizes included a deep sea fishing charter, accommodation at Robe and magnums of wine from local wineries.

ABC sports commentator Peter Walsh acted as MC, dressed in eye-catching colours of bright blue and pink. Peter told of his journey with prostate cancer



ABOVE: The crowd enjoys lunch at the Mount Gambier Gold Cup Carnival. RIGHT: Mount Gambier Racing Club President John Fartch with ABC Radio's Peter Walsh and Limestone Coast Support Group Chairman Malcolm Porter.

and why he wants to encourage all men over 40 years old to get a simple PSA blood test. He was also responsible for supplying one of the more interesting auction prizes – a seat in the commentary box during a football match.

The weather, which caused havoc at the race meeting last year, was great for this year's two-day carnival, and about 100

people attended the three-course luncheon on Thursday. Local State MP Troy Bell was part of the gathering.

The Limestone Coast Support Group put in a lot of work and time to make this event successful – and was represented by 14 members at the luncheon. The final outcome was that a very healthy \$10,396 was donated to PCFA.

#### Alice Springs Prostate Cancer Support Group

• The Alice Springs Prostate Cancer Support Group meets at the Alice Springs Golf Club on the first Thursday of each month, from 6pm until 7.30pm. Meals are available at the club immediately after each meeting. For more information about the Alice Springs support group, please phone group secretary Grant Butler on 0417 736 195 or email grantbut@hotmail.com

#### **Darwin Prosper Prostate Cancer Support Group**

• The Prosper Darwin Prostate Cancer Support Group meets on the second Monday of each month at the Harbour Room, Christ Church Cathedral, cnr Smith St and the Esplanade, Darwin, at 7.30pm. All guests and visitors are invited to attend – especially prostate cancer support group members who are visiting Darwin from other parts of Australia. For more details, please phone Don Lockley on 0401 116 851.

#### **NT Rainbow Prostate Cancer Support Group**

• The NT Rainbow Prostate Cancer Support Group is a group of men and partners who have been affected by prostate cancer. They are either dealing with a current diagnosis of cancer or are survivors of cancer. They meet on the last Wednesday of each month at NTAHC in Darwin from 5.30pm to discuss shared experiences, learn more about the disease and how to manage it. Every other month we go to dinner at the Cavanagh Hotel in Darwin. Please contact Peter Moore (0408 845 272) or Peter Kay (0439 778 769) for more details.

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### SA Prostate Cancer Research Update

# **Registry continues to help**

The South Australian Prostate Cancer Clinical Outcomes Collaborative (SA-PCCOC) is based at Repatriation General Hospital and manages the state prostate cancer registry. The registry has been running for over 15 years and is unique, capturing a comprehensive data set about clinical outcomes, survival times and times of cancer recurrence, while also investigating patient reported outcomes, such as symptoms men may experience after treatment.

The registry aims to improve patient outcomes by informing clinicians about their patients' outcomes and helping patients select the best treatment option for their situation. According to SA-PCCOC researchers, five-year survival from prostate cancer has increased from 84 per cent for men diagnosed 15 years ago, to 96 per cent for men diagnosed in the past five years. Better outcomes are likely due to more men being diagnosed at an earlier stage, and capturing data has a big role to play in this.

The registry holds data from more than 10,000 men, with more than 1300 added in the past 12 months. Very few registries in the world have equivalent levels of participation and depth of data.

This gives the South Australian collaborative unparalleled insight into what really happens to men who have

prostate cancer – by hearing from men about how they feel before and after treatment.

SA-PCCOC enables collaboration between prostate cancer researchers, health care providers and patients across the state. Projects that the collaborative has underway include investigating the outcomes and best treatment options for older men with prostate cancer, and noting any differences in survival rates between rural and metropolitan men.

For more details about SA-PCCOC, visit the website **www.sa-pccoc.com** or contact senior researcher and educator Michael O'Callaghan by email to Michael.OCallaghan2@sa.gov.au

#### Whyalla Prostate Cancer Support Group

• The Whyalla Prostate Cancer Support Group meets at 7.30pm on the first Tuesday of each month, from February to December, in Room 72 of the UniSA campus, Nicolson Ave, Whyalla Norrie.

• Contact Terry O'Brien (08 8645 1310) or Stan Oates (08 8644 0591) for more details. Everybody is welcome to attend these meetings – indeed, the wives and partners of group members are an integral part of this group, because any cancer affects the whole family.

#### **The Men's Engagement Network**

• The Men's Engagement Network is a Victor Harbor-based support group that meets fortnightly on Wednesdays between 6pm and 8pm at the Gospel Centre Meeting Room, George Main Rd, Victor Harbor (entry is from the council car park). For more details, contact group leader Lud Allen (0422 459 660, ludcounselling@gmail.com) or group secretary Bill Harris (08 8552 3004, deacbill@dodo.com.au).

#### **Gawler Prostate Cancer Support Group**

• THE Gawler Prostate Cancer Support and Awareness Group has been formed to support men in the Gawler area diagnosed with Prostate Cancer – and their partners and carers – during the stressful and confusing time immediately after diagnosis and after treatment.

• Everyone is welcome to attend the Gawler support group meetings, which are held in the conference room at the Gawler Health Service facility, 21 Hutchinson Rd, Gawler East (phone 8521 2000) at 7pm on the first Tuesday of each month. More information about the Gawler support group can be obtained from coordinator Lynton Carle (phone 8524 4086).

**City of Onkaparinga Prostate Cancer Support Group** 

# Addressing grief linked with the onset of illness

A discussion about grief affecting those diagnosed with serious illness resonated with City of Onkaparinga support group members, as John Shields reports.

HE guest speaker for the City of Onkaparinga Support Group's May meeting was Tim Upsdell, the principal psychologist at Fleurieu Psychology Services, who spoke about dealing with that grief and loss that comes with a diagnosis of serious illness.

Tim has a Masters Degree in psychology (organisational) and a certificate in family therapy from the Dulwich Centre, plus training in cognitive behavioural therapy, solution focussed therapy, narrative therapy, hypnosis and rapid eye movement desensitisation.

Tim gave an interesting interactive talk which encouraged some really good questions from members, and prompted many informative answers.

He spoke about coping, a person's psychological attitude, different types of personality and how complex things can be. Addressing the impact that grief and loss has on the family, led to a discussion about the symptoms associated with Post Traumatic Stress Disorder (PTSD), and the classic stages of grief. Tim explained that this follows a pattern:

(1) The denial stage.

(2) Questioning how to deal with the problem.

(3) Wondering who can be blamed – but explaining that a lot of blame directed towards people will not change anything.(4) Depression.

People in the support group spoke about their own experience with depression, and Tim acknowledged that these stages are quite normal.

Tim then talked about recovery, and the possibility of suffering chronic dysfunction, which is when it is time to see a psychologist. Tim explained that when someone gets into deep stress, it is hard to get out. He said it is good to know the stages, but advised that it is best not to be held hostage to them.

PTSD is an anxiety disorder where a person becomes anxious and angry, and this is one type of emotion that comes out of trauma.

He explained maps to work your way through difficult situations, and said trauma is a major psychological reaction.

He spoke of other traumatic situations, such as having flashbacks, or dreams, and explained that PTSD is an intrusive experience - something that often happens out of the blue.

Sometimes people take pains to avoid possible episodes, sometimes stopping themselves from going outside or making contact with people, however he emphasised that avoidance does not work.

In terms of illness or cancer, Tim said that adopting a certain way of thinking amounts to a form of avoidance: for instance, "If I don't think about the cancer, it's as though I haven't got cancer." Such denial is to be avoided at all costs. Acknowledgement of the problem facing you always comes first.

#### BENEFITS FROM LOCAL BARBECUE EVENTS

THE support group's June gathering at The Aussie Inn in Hackham proved to be a very good outing, and enabled everyone to catch up with some old friends who hadn't been seen in a while. This proved an ideal opportunity to put our cares behind us, and enjoy each other's company.

A planned guest speaker from the Cancer Council did not attend the group's July

#### **COMING EVENTS**

• The City of Onkaparinga Prostate Cancer Support Group conducts its monthly meetings in the boardroom of the Noarlunga Community Hospital (Alexander Kelly Drive, Noarlunga) on the first Wednesday of each month, starting at 6.30pm.

- The next support group meeting is on August 3.
- Special thanks go to our support group's generous sponsors: Southern Primary Health Morphett Vale, Port Noarlunga-Christies Beach RSL Sub Branch, The Original Open Market and The City of Onkaparinga Council.
- For more information, visit the City of Onkaparinga Support Group website at www.pcsog.org, or phone Malcolm Ellis on 8326 5588, or John Shields on 8382 6671.

meeting, so our members made the most of time spent together and talked about a wide range of topics and events that impact on our daily lives.

#### LUNCHEON AT RITO'S

A FORTNIGHT after our usual support group meeting, some of the members meet at noon for a cuppa or stay for lunch over a chat at Rito's Continental Cafe on Beach Rd at Christies Beach. There is no time limit to these informal events; some people stay for only a short while, but others are in no hurry to leave and like to linger for longer conversations. It's proving to be a popular gathering.

### PCFA free public forum for Adelaide in August

# An open conversation

**P**CFA has chosen Adelaide to host the inaugural Community Conversations, an event aiming to connect Australians with leading prostate cancer researchers and share information about their latest findings.

PCFA is encouraging people to attend the free event on Friday, August 12 at the South Australian Health & Medical Research Institute (SAHMRI) on North Terrace, Adelaide. The open, interactive forum will give attendees access to the latest information on prostate cancer and the trends about managing the disease.

This is the first time PCFA has created a platform where researchers specialising in prostate cancer can address an audience impacted by the disease.

PCFA chief executive officer Associate Professor Anthony Lowe says it is important for Australians to have an opportunity to interact with Australian researchers and understand what research projects are supported by PCFA.

"PCFA supports world leading research into prostate cancer and we feel it is important for people in the community who have been affected by the disease to hear the latest news direct from the source," says Associate Professor Lowe.

"When a family is faced with a prostate cancer diagnosis, being exposed to the latest research can help put them in a better position to participate in decisions about treatment.

"The Community Conversations event will bring together researchers, members of the public and PCFA representatives to deliver information about prostate cancer from a range of perspectives."

The Community Conversations event will be hosted by columnist and former ABC Radio presenter Carole Whitelock OAM. Diet and nutrition recommendations will be covered to help manage the ongoing impact of prostate cancer, with Rosa Matto from SA Life sharing simple and nutritious meal ideas for men living with prostate cancer.

Adelaide-based prostate cancer survivor and PCFA National Board member Ian

Wagner says the event will help many who have been impacted by the disease. "Living with prostate cancer is an ongoing journey, and there are challenges we all tackle," says Ian. "For me, meeting others that have faced similar experiences and sharing our stories has been important and I am pleased PCFA is providing an opportunity for us to connect at this Community Conversations forum."

Associate Professor Lowe added, "PCFA is thrilled to host this new event at South

Australia's flagship health and medical research institute, where some of the most promising research for prostate cancer is being undertaken. We look forward to rolling out Community Conversations in other states and territories over the next two years."

Registration to the Community Conversations event is essential. To book your place, visit www.pcfa.org.au/ communityconversations or call 1800 220 099 (free call).

