

Central Australia Chapter



PROSTATE SUPPORTER

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

www.prostate.org.au

**OCTOBER
2013**

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

**Volume 6:
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PCFA awareness aided by generous ABC assistance

ABC radio broadcasts in SA during September and October are placing an invaluable focus on prostate cancer.

ACROSS South Australia, the prostate cancer awareness message has received a giant boost from 891 ABC Adelaide radio broadcasts. International Prostate Cancer awareness month was introduced with an outside broadcast of 891 ABC Adelaide's Mornings with Ian Henschke at the Metropolitan Fire Service headquarters in Wakefield St, Adelaide – with more than two hours devoted to discussion about prostate cancer. For details about the broadcast, see the story on Page 12 of this newsletter.

The value of this is substantial, with commercial radio sources estimating that the cost of a two-hour outside broadcast would carry about \$10,000 in commercial value (mindful that commercial radio charges \$200 per 30 second advertisement), plus \$3000 in pre-promotion, and a minimum set-up cost of

\$5000. It equates to exposure for PCFA that would have cost at least \$18,000 on a commercial radio station.

Now, the broadcasting boost from 891 ABC Adelaide is about to happen again, because ABC Gardeners' Market on October 12 – one of the twice-yearly community markets promoted by radio station 891 ABC Adelaide – has chosen PCFA as its charity of choice.

To make the most of this opportunity, we need maximum volunteer input to make sure we benefit most from this one-off promotional opportunity. PCFA state manager Karyn Foster needs 40 people to help at the ABC Studios, 85 North East Rd, Collinswood, working in shifts from 6am to 1pm on Saturday October 12.



Dr Peter Sutherland talks about prostate cancer on the air with 891 ABC Adelaide announcer Ian Henschke.



It's the largest number of helpers Karyn has ever asked for - so please spread the net wider to get your family and friends involved.

Please register your help by contacting Janie Green at PCFA's SA/NT office in Adelaide (email janie.green@pcfa.org.au)

• **CONTRIBUTIONS** from all Support Group members to the monthly Prostate Supporter newsletters are most welcome; please email items and images to Karyn Foster: karyn.foster@pcfa.org.au

Prostate Cancer Foundation of Australia freecall hotline is 1800 22 00 99
or visit the website www.prostate.org.au

Prostate Cancer Action Group

Global Action Plan shows cohesive Movember aims

Prostate cancer research being supported by the Movember organisation continues to impress, as David Merry from the Prostate Cancer Action Group reports.

MOVEMBER has found that prostate cancer researchers often work in isolation on similar projects, unaware of, or unable to work with researchers in other countries. This has ultimately slowed down scientific advancement that would otherwise benefit men with prostate cancer.

Movember has taken action to change this, to close the gap that exists between researchers and to accelerate breakthroughs.

The organisation has launched its Global Action Plan that brings researchers from across the globe to work together and collaborate on specific projects.

One of the most significant issues with prostate cancer is the inability to determine whether men have an aggressive or a low-risk type of prostate cancer.

To provide personalised and more effective treatments, this problem needs to be addressed.

Movember has assembled a team of 150 expert researchers from across 15 countries that is working together to examine biomarkers from blood, urine and tissue, to develop better tests to measure the severity of the disease within individual patients.

COMING EVENTS

NOVEMBER MEETING: The Prostate Cancer Action Group SA holds its meetings in the upstairs meeting room at the Cancer Council SA building, 202 Greenhill Rd, Eastwood. The next meeting starts at 5.30pm on Tuesday, November 12. Entry is via the rear stairway.

• **PLEASE NOTE:** There is no meeting of the Action Group in October.

• For more information, visit the Action Group's dedicated website, with detailed archives containing newsletters, at www.pcagsa.org.au or make contact by phoning David Merry on 8270 2227, or email djmerry@adam.com.au

DR BROOK OFFERS HELP

We are fortunate to have Dr Nicholas Brook as lead speaker at the Semaphore Awareness Evening on Tuesday October 8.

Dr Brook will be supported by two survivor speakers, Ray Power and Bryan Hearn, and physiotherapist Louise Fowler from Life Care Active.

Dr Brook also spoke to the Central Australia Chapter Council on Wednesday September 4 about the impressive program that has been introduced at the urology department of the Royal Adelaide Hospital.

COUNTRY SHOW SUPPORT

ACTION GROUP member Jeff Roberts has coordinated a team of 18 volunteers to cover the three days of the Yorke Peninsular Field Days, with the welcome assistance of people from the Barossa, Gawler, Murray Bridge and Port Pirie support groups.

The Action Group's Information Stall is always well supported by the management and visitors and those assisting are kept busy. Arrangements are also in hand for prostate cancer information stalls to be present at the Murray Bridge, Strathalbyn and Jamestown rural shows.

Whyalla Prostate Cancer Support Group

- **THE Whyalla Prostate Cancer Support Group** meets at 7.30pm on the first Tuesday of each month, in the new temporary location at 6 Zeven Street, Whyalla – until we find a new home.
- **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.

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Prostate Cancer Action Group

Physiotherapy staff making the right moves for PC help

The Life Care Active Centre in Payneham has physiotherapy staff that are providing great help to local support groups and prostate cancer awareness evenings.

ON August 8, the new Life Care Active Centre for men and women aged 55 and over was launched at 230 Payneham Rd, Payneham – and David Merry attended as the PCFA Central Australia Chapter representative.

This centre reflects Life Care’s philosophy to “live every day” by keeping active and offers a range of specialist allied health services, complemented by personal training and general exercise classes for older generations.

The centre aims to offer a better class of life for men who have been affected by prostate cancer. It recognises that linking the impact of muscle loss and the benefits of exercise for prostate cancer patients paves the way towards a better quality of life.

Physiotherapist Judith Lowe at Life Care Active can provide more information



Staff at the new Life Care Active Centre in Payneham, which has a particular aim to help restore fitness and muscle development for men with prostate cancer.

about the centre’s services, by phoning 8168 7600 or email judth.lowe@lifecare.org.au

Judith’s colleague Louise Fowler, who is also a physiotherapist at Life Care Active, is addressing the Prostate Cancer Awareness Evening at Semaphore on October 8.

The concept of promoting regular exercise for prostate cancer patients has been embraced by Sue Tulloch, a physiotherapist with the

Adelaide Hills Community Health Service at Mount Barker. Sue has established a class from which the Adelaide Hills Prostate Cancer Support Group was formed.

Sue spoke with brilliance on this topic at the Henley/Fulham Awareness Evening in July, which inspired everyone to start exercising in the aisles.

Professor Daniel Galvao of Edith Cowan University, Perth, is currently

pioneering research on this topic, through the PCFA research program generously funded by the Movember Foundation, and a report on his findings is eagerly awaited.

If you check the Movember website, you can find information about many exciting initiatives that this organisation has supported – on a global scale.

For this coming November, support the Movember cause by registering early for this global fundraising cause. The organisation needs our support to sustain its funding of these research programs.

BARBECUE SUCCESS

THE ACTION Group also extends many thanks to those who assisted at the Bunnings Modbury barbecues held over the Father’s Day weekend, from which more than \$2000 was raised.

Barossa Prostate Cancer Support Group

COMING EVENTS - OCTOBER MEETING

- The Barossa Prostate Cancer Support Group has scheduled its 2013 meetings for the third Tuesday of each month, from 2pm to 4pm at various support group members’ homes. The next meeting will be held on Tuesday October 15. The group also has a few of its members not travelling too well at present, so we wish them a speedy recovery.

- For further information, please phone Don Piro, co-ordinator of the Barossa support group, on 8562 3359 or email don@dppcs.com.au

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Prostate Cancer Awareness Events

Firefighters keen to speak frankly on prostate cancer

The launch of International Prostate Cancer Awareness Month saw several Adelaide firefighters speak out about their personal ordeals with prostate cancer.

WHEN Metropolitan Fire Service Station Officer Neil Mangelsdorf organised a special open day at the Adelaide fire station to serve as a launch for International Prostate Cancer Awareness Month, complete with a live radio broadcast and firefighter emergency demonstrations, he did so with the benefit of hindsight.

Neil has had prostate cancer surgery and, as vice president of the United Firefighters Union of South Australia, he knows how important it is for his organisation's members to be aware of men's health issues. Neil insists that talking openly about prostate cancer is needed to break down stigmas among some men about this subject.

He was a very forthright speaker on the 891 ABC Adelaide radio broadcast. "It immediately makes you think about what's ahead. I have a wife and family – a seven-year-old daughter and 11-year-old son – and I really needed to get back to work for their sake. I wanted my health to get better, primarily for their sake."

He was ably supported by MFS Chief Officer Grant Lupton, who made the



interesting analogy of fighting prostate cancer being like fighting fires – that it is more prudent and beneficial to prevent, rather than trying to minimise the damage once the problem has become ablaze.

ABOVE: MFS Chief Officer Grant Lupton gave a telling speech during the ABC radio broadcast to promote International Prostate Cancer Awareness month.

LEFT: MFS's Neil Mangelsdorf.

• Photos by Tony Lewis, Nicole Ely and David Sly.



Kym Searle, aged 55 (pictured above), has been an Adelaide firefighter for 36 years and comes from a family of firefighters – his father Ken served as a firefighter for 36 years, while his brother Peter also served for 24 years. Unfortunately, Kym's family also has a history of prostate cancer, which is why he started having blood tests several years ago to check his PSA levels. However, it wasn't until he also suggested a Digital Rectal Examination last year that he learned he had a serious problem to deal with. "The blood test on its own didn't show any alarming movement in my PSA numbers; however, the DRE caused immediate concern and I had biopsies that showed cancer in seven of the 10 samples taken. The prostate was found to be 75 per cent cancerous once it was removed."

Kym is now recovering after surgery, and has found it extremely helpful that other firefighters have also gone through prostate surgery and are happy to talk about their situations. Kym believes that such discussions among workmates are especially beneficial. "I'm really keen to be proactive about this, especially promoting men to have a DRE in addition to a blood test for checking their prostate health," he says. "Ultimately that is what saved me; I want to make sure it can help other men too."

Prostate Cancer Support and Awareness: ADELAIDE GROUP

Learning about everything required of an organ donor

The need for organ donors is acute but it's easy for most people to register in this vital program, as Adelaide Prostate Cancer Support Group's Ian Fisk reports.

THE August meeting of the Adelaide support group featured a fascinating presentation by Nigel Palk, the Organ Donation Co-ordinator with Donatelife. He started his talk explaining the history of organ transplantation – from the reconstruction of noses and earlobes using cheek flaps in India at about 400BC, to diseased organs being removed and replaced with healthy ones in China (200AD), to pharmacologic immunosuppression being invented in 1962.

Age guidelines for organ donation changes among the different organs – from kidneys being anything less than 80 years, to a pancreas being only between 10 and 50 years of age. Tissue donation ages range from bones being from 16-to-65-year-olds, to eyes being donated by anyone aged greater than five year, to skin from anyone less than 70.

The only condition that prevents donation is HIV, but other conditions may influence the suitability; for instance, some cultural and religious groups are opposed to organ donation.

A diagram was displayed showing that in Australia, during 2011, there were more than 1000 transplant recipients but only 337 actual donors. On



Nigel Palk at the Adelaide group's August meeting.

a per capital basis, Australia is 14th in the world donor ranking, with Spain being the highest ranked donor.

Just over 50 per cent of organs are donated by victims of strokes, while road trauma victims contribute 13 per cent.

What is death was discussed in depth. According to the Death Definition Act 1983 (SA), a person has died when either of the following has occurred: "Irreversible cessation of all function of the brain of the person", or "irreversible cessation of circulation of blood in the body of the person".

The Glasgow Coma Scale (GCS) was also talked about. It gives a reliable, objective way of recording the conscious state of a person.

There are many tests done to determine that death has taken place before organ donation can take place. The

organ donation process was explained in detail, from family meetings, the referral process, allocation, surgical retrieval and transportation to the recipient. Different organs and tissues have varying times of survival before being used, from four hours for a heart, to months for heart valves.

There are transplant units in Perth, Adelaide, Melbourne, Sydney and Brisbane, although in Adelaide only the liver and kidneys are transplanted, while Melbourne does the lot!

Nigel encouraged questions during his presentation, and many were asked. He especially asked that people please consider registering as an organ donor. Forms are available at Department of Human Services Offices, Medicare Offices, on the internet at www.donatelife.gov.au, or call 1800 777 203 to

COMING EVENTS

OCTOBER MEETING:

- The Adelaide Prostate Cancer Support Group meets on the third Monday of each month in the Community Room of the Fullarton Park Centre, 411 Fullarton Rd, Fullarton, starting at 7pm.

- The meeting on October 21 will feature a talk from Dr Luke Selth of the Dame Roma Mitchell Cancer Research Laboratories at the University of Adelaide, speaking about the latest developments in prostate cancer research.

- For more information and a detailed archive, visit the Adelaide Support Group's dedicated website at www.psaadelaide.org or phone Ian Fisk on 8296 3350, or send email to info@psaadelaide.org

register on the phone and ask for a registration form to be posted. There is also an option to register when renewing your driver's licence.

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Community support for prostate cancer awareness

Fundraising concert strikes the right note with audience

The decision by a popular municipal band to lend support for prostate cancer has put out the prostate cancer awareness message to a new audience.

MARION City Band presented a charity concert in support of PCFA on September 28 at the Marion Cultural Centre, Oaklands Park.

Proudly supported by the City of Marion, the band can be heard performing in both metropolitan and country areas throughout the year.

As a regular attendee at major competitive brass band events, the members can be found playing under the banners of Marion City Band and/or Warriparinga Brass. With band numbers increasing in recent times it is with great excitement that Marion City Band now supports the growth and development of two competition and playing bands – and sometimes a third Youth Band.

The concert featured



The Marion City Band in concert performance at the Blue Lake Festival in Mount Gambier early this year.

the Marion City Band performing with guest artists Charmaine Jones and Mike Bevan (an outstanding jazz-Brazilian guitar and vocal duo) and the Swing Dance Team called Sausage Sizzle.

The evening was compered by Roy Garreffa from Adelaide's Coast FM,

who has had a prostate experience and spoke about his situation with the audience.

Importantly, the event was also able to sell PCFA merchandise as a valuable fundraising activity, and passed on information leaflets about prostate cancer to the audience.

Darwin 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.

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. Currently, the Gawler group is finding it hard to attract members to its meetings. This seems to be a common problem throughout the past year, but at least the main aim of having a local contact from the support group to telephone in times of need is still in place. Despite the difficulties, we urge the Gawler group to keep going.

• **ANYONE** 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. The next meeting is on **NOVEMBER 5**. More information about the Gawler support group can be obtained from Lynton Carle (phone 8524 4086) or Kylie Fotheringham (phone 8521 2080).

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Port Pirie Prostate Cancer Support Group

Learning about the busy days in local chemotherapy clinic

The Port Pirie Prostate Cancer Support Group was interested to hear about the detailed services and huge number of patients being cared for within the Chemotherapy Unit at Port Pirie Hospital, as Joan Manfield reports.

JOANNE Vermeeren, a clinical nurse from the Port Pirie Regional Health Service's Chemotherapy Unit, spoke to Port Pirie support group members at the September 3 meeting. Joanne is a registered nurse and has worked as a theatre nurse, a palliative care nurse and, since 2006, in the Chemotherapy Unit, situated beside the day surgery unit (it's also close to the theatre, with easy access to specialists and GPs, should they be needed). The room has a great view of The Terrace, making patients' stay more pleasant.

The Port Pirie Chemotherapy Unit is a medium risk unit, which means it can handle most treatments given in a day; the only restriction is with drugs that won't survive the overnight transportation from Adelaide, or drugs that are classified as high risk.

Some of the services carried out are: oral chemotherapy; blood product transfusion; infusion for arthritis sufferers, multiple sclerosis and bowel disorders; biophosphates for metastatic prostate cancer which strengthens bones and helps prevent fractures.



Fred Pisani, guest speaker Joanne Vermeeren and Vic Pisani at the Port Pirie group's September meeting.

Joanne and her staff work closely with the treating oncologists and urologist, who also refers patients with bladder cancer for chemotherapy, as well as metastatic prostate cancer.

The unit treats patients from as far away as Roxby Downs, Port Augusta, Clare and Yorke Peninsula. Education also comes within her role, dealing with services from Community Health, home nursing and palliative care. Most treatments are in the mornings, with the duration varying, depending on the chemotherapy.

There are three main chemotherapy drugs for treating prostate cancer which are given intravenously; cabazitaxel

(a new drug approved this year), docetaxel and mitoxantrone.

Joanne pointed to the website www.eviq.org.au (prepared by Cancer Institute NSW) as a great place to learn about some of these treatments and drugs. You need to register when you go on to the website but it is free.

Joanne explained that the Port Pirie clinic has five chemotherapy chairs that are extremely comfortable but can't fit any more until more funding can expand their unit.

It serves about 20 chemotherapy patients every month; with other treatments, they treat about 100 people each month,

COMING EVENT

- 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 the BHAS Bowling Club, Halley St, Port Pirie.
- There is usually an excellent guest speaker, and late supper is provided for the 20-to-30 ladies and gentlemen attending each meeting. For further details, please phone group coordinator Allan Manfield on 08 8632 1324.

making it one of the busiest units in the country.

Joanne also had a slide of the new Truss Biopsy machine that is now in use at the hospital thanks to Rotary (an idea proposed by two of our support group members) and the local MP, Geoff Brock, who put a submission to the Country Health Department. One of our new support group members was one of the first to use it.

Limestone Coast Prostate Cancer Support Group

Busy support group work attracts public attention

Training and innovative arrangements with a local library add to expanding prostate cancer awareness in the community, as support group coordinator Richard Harry reports.

ONE way or another, members of the Limestone Coast Prostate Cancer Support Group had a very busy time during August and September. Over the weekend of August 24 and 25, three members of our group attended the Ambassador training seminar in Adelaide.

Garth Wootton, Malcolm Porter and Richard Harry felt that the training they received from Ian Richards and Katie Dundas was not only well presented but also provided important help in presenting factual material prepared by PCFA, while inserting our own personal experiences into a presentation.

The training will soon be put to the test, as we have already had one request (still to be confirmed) to speak to a group in the near future. If this happens, the local Millicent FM radio station has offered to help promote the event.

One important local development is that following discussions with the local public library, it has added a range of books – either supplied or endorsed by PCFA – to its Health section. Some books were purchased by the library, some were public information publications supplied by PCFA. Located alongside these books in the library is a plastic display

stand containing our local support group information fliers with contact details.

On September 1 (Father's Day) a barbecue was held at Mount Gambier's Bunnings store, and although it was a quiet day, we were still able to raise a profit which will cover the support group's gifts for speakers and other costs for the coming months.

A very moving incident occurred during the day when a young woman who was visibly upset came to the stand with \$20 in her hand. She did not want to buy anything but wished to donate the money as it was the first Father's Day since she had lost her dad to prostate cancer.

Noting that September was International Prostate Cancer Awareness Month, local paper The Border Watch ran a feature on September 10 with a lot of information on prostate cancer, together with an interview with Garth Wootton. It certainly helps when the local paper is willing to promote our cause.

The support group meeting on September 5 was possibly our largest yet, with about 30 people attending. Urologist Dr Michael Chong was the drawcard. He spoke about new types of treatment for prostate cancer and covered some areas of health that may increase



ABOVE: Guest speaker Dr Michael Chong was received by a very large audience in Mount Gambier.

COMING EVENTS

OCTOBER MEETING:

The next meeting of the Limestone Coast Prostate Cancer Support Group will be at the District Council of Grant offices, 324 Commercial Street West, Mount Gambier, at 7.30pm on October 3. Guest speaker will be Ian Richards from the PCFA office in Adelaide.

• 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

the risk of prostate cancer, or make it more difficult for it to be diagnosed.

Michael also mentioned the program at Daws Road hospital, where men who have been treated for prostate cancer are being surveyed – one of the largest surveys of its type in Australia. All this was followed with many questions, completing a great and informative evening.

The Commonwealth Bank in Mount Gambier usually has a barbecue during September to support PCFA, with assistance from our support group.

This year the bank has decided to hold a cake stall instead, and our group members were yet again there to promote our group and hand out information on prostate cancer to bank customers.

Businesses giving support for our support groups

These are Good Guys to offer financial assistance

THE Good Guys electrical and appliance stores continue to provide great support for prostate cancer research and awareness by extending its donations to PCFA through The Good Guys Local Giving Program.

This commitment began in 2012, and we have just learned that The Good Guys stores at Edwardstown, Mile End, Noarlunga, Gepps Cross and Hectorville will be continuing its support of PCFA throughout the 2013/2014 financial year.

With the local giving program, The Good Guys



PCFA National Chair David Sandoe OAM thanked The Good Guys team at Mile End early this year.

customers are given a token with every purchase made in-store or online, and from this a percentage is given to local projects. Tokens placed in a PCFA token box located within store will result in a

higher proportion of funds donated to PCFA.

The Good Guys Local Giving Program has raised more than \$5 million dollars since November 2006, providing support for over 150 charitable

organisations. Suzanne Tonks from the national The Good Guys Support Centre hopes that the company will celebrate giving \$6 million in donations later this year, and is delighted that PCFA can be a part of these celebrations.

As per last financial year, donations will be paid to PCFA at the end of each financial quarter, based on the percentage of tokens received in each store's token boxes. We therefore urge support group members and friends to consider purchases and directing their tokens to the PCFA boxes in The Good Guys stores.

Mitcham Prostate Cancer Support Group

COMING EVENTS – OCTOBER MEETING

- The Mitcham Group's October 24 meeting will be at the Colonel Light Gardens RSL Club, 4 Prince George Parade, Colonel Light Gardens, from 7pm to 8.45pm. Tea, coffee and cake are provided for those attending the meeting. Car parking is now available within the RSL grounds. The October meeting will feature our annual Open Discussion Evening.
- The Mitcham support group's November 28 event will be the traditional Annual Dinner, at a venue that will be announced at the October 24 meeting.
- For more information on support group activities, visit the Mitcham Group's website at www.psamitcham.org or phone Roland Harris on 8277 2138.

Murray Bridge Prostate Cancer Support Group

- The Murray Bridge Prostate Cancer Support Group will conduct its next monthly meeting at 7.30pm on WEDNESDAY, OCTOBER 16 at Our Wellbeing Place, 108 Swanport Rd, Murray Bridge.
- The support group is busy with many promotional activities. Members will be working on a prostate cancer information stall at the Strathalbyn Show on Monday October 7, and will be presenting a fundraising barbecue at Bunnings Store in Murray Bridge on December 6.
- For more information about the group, phone Murray Bridge support group president Ron Nance on 08 8532 2873, or group secretary Max Klenke on 08 8532 1936.

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Prostate Cancer Support Groups

Riverland Prostate Cancer Support Group

COMING EVENT

NOVEMBER MEETING:
The Riverland Prostate Cancer Support Group will conduct its final meeting for 2013 at the Combined Services Club Rooms, Kealy St, Berri, from 7pm on Tuesday November 12.

• For more information about the Riverland support group, please phone group convenor Allan Dand on 08 8582 1651 or 0488 994 803, or email alglen@iprimus.net.au

Call for participants in new health care survey

Men with prostate cancer have an opportunity to contribute to an important new health survey – and get paid for their time, as SA/NT Support Group and Outreach Coordinator Ian Richards reports.

THE Australian Bureau of Statistics wants to conduct one-hour surveys in late October with people who have seen a health professional so far this year – and in return you will receive \$50 to cover any costs that you may incur from attending.

The ABS is looking for appropriate people to test an upcoming national survey with the working title of “Health Care Pathways”. This survey is concerned with the experiences of people as they move through the health care system of Australia.

The survey aims to be thorough and as diverse as possible, looking at concepts such as patient experience, continuity of care and identifying possible improvements. The results from the survey will feed into National Health Performance Authority reporting.

The survey organisers are looking for participants aged 18 years and over to participate in a one-hour, electronically recorded, confidential interview.

The survey is interested in people who fit one or more of the following criteria: Have a long term health condition, either physical or mental; Have given birth in the last 12 months; Are over 65 years old; Have seen a medical specialist in the last 12 months.

Please forward this participation invitation on to anyone you know who may be interested in this survey. Some support groups in other states have used such surveys as a fundraising opportunity.

Survey testing consists of a one-hour interview with an ABS staff member about the survey questions from which information is gleaned about how to improve the questions.

Participants in the testing will receive \$50 to cover any costs they may incur to attend the testing, which takes place at the ABS office – Level 9, ANZ House, 11 Waymouth St, Adelaide. To register for participation in the survey, please call Wendy on 8237 7487 by October 18.

Alice Springs Prostate Cancer Support Group

COMING EVENT OCTOBER MEETING:

The Alice Springs Prostate Cancer Support Group will conduct its next meeting at Medicare Local NT, 5 Skinner Street, Alice Springs on Thursday October 10, running from 6pm to 7.30pm. Please note the NEW MEETING TIME. Please note that the proposed mid-year dinner, which was cancelled due to PCFA's Ian Richard not being able to attend, has been re-scheduled for December.

• For more information about the Alice Springs support group, please phone group convenor Ian Wagner on 0409 534 950, or group secretary Grant Butler on 0417 736 195.

McLaren Districts Prostate Cancer Support Group

• The McLaren Districts Prostate Cancer Support Group now conducts its meetings on a quarterly basis. For further information, phone support group president Bryan Hearn on 8323 7924. The meetings start at 7pm and are conducted in the administration building at the rear of the McLaren Vale & Districts War Memorial Hospital, Aldersey St, McLaren Vale.

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City of Onkaparinga Prostate Cancer Support Group

Support group discussion can conquer fear of the unknown

The ability to talk with fellow travellers along the prostate cancer journey can provide a great benefit for many men, as City of Onkaparinga support group chairman John Shields reports.

FOR the September meeting of the City of Onkaparinga Prostate Cancer Support Group, we welcomed Joe before having a round robin discussion to catch up with how we are all progressing on our particular journey through life. While our attendance numbers are down, we continue to provide strong support to each other and it is good to experience the value of face-to-face support, which is the prime purpose of our monthly meetings.

It is pleasing that everyone in attendance is happy to share stories of their prostate cancer journeys, talking about their general health and everyday events that we each experience. It was especially good to hear what Joe had to tell us, and we wish him well for the future.

Malcolm Ellis showed the group the informative DVD Just Take it Day to Day - A Guide to Surviving Life After Cancer. Malcolm gave some good commentary on the content of this DVD and was able to speak from his own experiences as a prostate cancer survivor.

It is always encouraging to hear from people who have experienced other cancers and are now coping very

well after the treatments they had. Fear of the unknown often has a deeper effect on some people than the treatment itself, and watching and listening to so many survivors who have a positive story to tell is an uplifting experience.

BENEFITS FROM LOCAL BARBECUE EVENTS

THE BARBECUE that the support group held at Bunnings Noarlunga Store on Sunday August 25 was very successful, with \$1312 going into our bank account. Many thanks go to Brian, Fred, Joel, Cathy, Robert and Rhett for doing their best to make this fundraising day a success.

For next year, we have asked for this barbecue event to be held on a Saturday instead of Sunday, and this was agreed upon.

Malcolm also suggested having another fundraising barbecue before next winter, and I will keep you posted on the outcomes.

ABC PUTS CANCER DRUGS IN FOCUS

THE cancer story featured on ABC-TV's Four Corners program recently focused on the huge cost of "end of life" drugs and a new Melanoma drug called Yervoy, which cost one patient more

than \$100,000 for a four-session course; this month Yervoy was placed on the Pharmaceutical Benefits Scheme (PBS) and now costs patients \$36.10.

The taxpayer foots the quoted bill of \$380 million over the next four years. There are already 91 cancer treating drugs on the PBS that costs \$1.8 billion. For the full report, go to <http://www.abc.net.au/4corners/stories/2013/08/26/3831617>

CHANGE SUGGESTED FOR OUR MEETINGS

THE City of Onkaparinga Support Group is looking at perhaps changing its meetings from evenings to daytimes, or meeting at one of the local Community Halls.

There is a small cost to the group if we were to meet at a Community Hall, but free parking is more readily available.

The move is tempting, as Christie Downs Community Hall staff have said that a TV will be available for us to watch DVDs.

We have found that guest speakers are not keen to travel to Noarlunga for an evening meeting and are more amenable to speaking at daytime events.

COMING EVENT

OCTOBER 2 MEETING:

The Onkaparinga support group will conduct its next monthly meeting in the boardroom of the Noarlunga Community Hospital (Alexander Kelly Drive, Noarlunga) on Wednesday October 2 at 6.30pm.

• For more information about the group and its activities, visit the City of Onkaparinga Support Group's website at www.pcsog.org, or phone John Shields on 8382 6671, or Malcolm Ellis on 8326 5588.

• 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.**

Some of our members have also asked whether the cost of parking is keeping people from attending support group meetings.

We discussed this and decided to wait until the weather warms before making a decision.

Broadcasting the prostate message across the State

THE Metropolitan Fire Service headquarters in Wakefield St, Adelaide, provided an inspiring site for an outside broadcast of 891 ABC Adelaide's Mornings with Ian Henschke on Friday, August 30. It was an event designed to announce the start of International Prostate Awareness Month and to stimulate more discussion among the community about prostate cancer.

The broadcast featured interviews on prostate cancer from local medical experts including leading Adelaide urologist Dr Peter Sutherland, and prostate cancer survivors including MFS firefighter Neil Mangelsdorf, Barossa winemaker Grant Burge and former SACA curator Les Burdett. This trio spoke frankly and candidly about their personal experiences of being diagnosed and treated for prostate cancer, highlighting their fears and apprehensions, reflections on business and family, and their approach to the future.

It was especially interesting to hear their views and experience on sex after prostate surgery – that imposing elephant in the room that is so often not talked about. They had the courage to speak about sex matters as they are, demystifying an important subject to a vast listening audience.

They also divulged other



LEFT: The broadcast featured (from left) Grant Burge, Neil Mangelsdorf, 891 ABC Adelaide's Ian Henschke and Les Burdett.

BELOW: PCFA's Karyn Foster and Les Burdett enjoyed the drinks and food prepared by Assaggio chef Camillo Crugnale, Pam Tobin and the team from Mushroom Growers Association.



secrets in the process of advancing prostate cancer promotion. Les Burdett said his prostate cancer surgery ultimately prompted his decision to retire from work early. "I had just written eulogies for five close friends – none of them died from prostate cancer – and I realised how I wanted to get more out of life than just working constantly. I never disclosed that earlier on, because I considered it very private – but now I know the more that someone like me

can talk about prostate cancer, and the more open I am, the more it may encourage men to look more closely at the quality of their own health."

We thank the participating organisations: major sponsor Commonwealth Bank, Metropolitan Fire Service, United Firefighters Union of SA, food donors including Barossa Fine Foods, Bakers' Delight, Mushroom Growers Association, Schweppes – and 891 ABC Adelaide.

Interestingly, out of this



event there was also a great willingness and keen interest to create other novel prostate awareness events. Perennial moustache wearer Les Burdett has offered to shave *off* his mo for Movember – as a means of raising more funds and drawing more attention to the campaign. Other famous Aussie moustache wearers will now be approached, from winemaker Geoff Merrill to sports stars Leigh Matthews, Wayne Phillips, Merv Hughes, Dennis Lillee and Robert DiPierdomenico.