Central Australia Chapter





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

www.prostate.org.au

February 2016

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

Volume 9: Number 1

The valuable Subway connection continues

PCFA will once again be the receipient of donations from Subway Restaurants in 2016 – the continuation of fabulous and prosperous partnership that began in 2014.

These valuable funds comprise small change from Subway Restaurants customers, collected in Subway-badged moneyboxes (shaped like baseball caps and coloured in bold PCFA blue) that are stationed at cash registers in Subway Restaurants across South Australia, Western Australia and metropolitan Victoria.

Customers have already been very generous, contributing a deluge of coins and notes that totalled more than \$200,000 – and the amount that Subway provides to PCFA keeps growing.

The Subway team and PCFA volunteers have worked together to ensure money has been collected and banked in a timely fashion.

Heartfelt thanks goes out to the hardworking volunteer crew that collected the



The relationship between Subway **Restaurants** and PCFA that has been so strong since 2014, will now continue into 2016. PCFA national chairman Jim **Hughes AM** is pictured left, proudly showing off a donation cheque for \$200,000.

money, the World Police and Fire Games Club in Victoria, and Subway Restaurant management and staff.

PCFA now looks forward to continuing this partnership in 2016, so that awareness and support for prostate cancer can reach further into the community.



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

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Prostate Cancer Action Group

Many helpers arrived to answer our call to action

The Prostate Cancer Action Group has a committment to promote greater prostate awareness throughout the community during 2016, as David Merry reports.

HE Prostate Cancer Action Group is poised for another busy and rewarding year as it continues promoting greater awareness of prostate cancer to people throughout the South Australian community.

The group plans to conduct activities in both country and metropolitan areas, and is always keen to welcome new members to the group meetings, and to assist with its promotions.

The South Australian prostate cancer community also needs to be aware of the valuable work proceeding with the South Australian Prostate Cancer Clinical Outcomes Collaborative Steering and Research Committees (SA-PCCOCC) – a unit that is currently based at the Repatriation General Hospital, Daw Park.

The state's world-class prostate cancer registry is unique in Australia, and the database administered by the unit recently achieved the milestone of having registered 10,000 local men.

Dr Michael O'Callaghan directs this impressive unit and will be presenting an article in the next issue of the Prostate Supporter newsletter, describing the achievements of work within the unit.

During 2016, the Action Group and the Central Australia Chapter Council will be

supporting Dr O'Callaghan and the unit by presenting a public meeting, which will provide full insight into the activities of this valuable South Australian institution, and to better recognise its research contribution into prostate cancer treatment.

Meanwhile, the Action Group begins its monthly meetings for 2016 on Tuesday February 9 at 5.30pm. The group meets at the boardroom of the PCFA office, 124 South Tce, Adelaide, with entry from the rear door. Visitors and new members are always welcome. For more details, contact David Merry (djmerry@adam. com.au or 8270 2227) or phone the PCFA office in Adelaide (8231 6339).

The first Action Group activity for 2016 is a new venture – The Giant Baseball Day, co-ordinated by the Glenelg Baseball Club at the Glenelg Baseball Ground, Anderson Ave, Glenelg North, on Saturday February 13.

The Action Group will present a prostate cancer information tent at the Giant Baseball Day, while PCFA will help by presenting a raffle and an auction, while the ABC Sports team will be present to promote the event.

The Action Group is also running an information stall at the South East Field Days at Lucindale, Friday March 18 and

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.

• For more information, please visit the Action Group's website at www. pcagsa.org.au or phone David Merry on 8270 2227, or email djmerry@adam. com.au

Saturday March 19. The Kapunda Farm Fair is being held on Friday April 8 and Saturday April 9, and the Action Group will be assisting the Barossa Support Group to present a prostate cancer information outlet.

A public prostate cancer awareness presentation will be held in Bordertown during March or April. More details will be provided once we have a confirmed date from the urologist guest speaker.

Adelaide Hills Prostate Cancer Support Group

• The Adelaide Hills Prostate Cancer Support Group meets at 10am on the third Friday of each month, from February to November, at the Adelaide Hills Community Health Service on Wellington Rd at Mount Barker.

• For more details about the Adelaide Hills support group and its activities, please contact group leaders Sue Tulloch or Emlyn Lewis by phoning 8393 1833.

Prostate Cancer Research and Therapies

New therapies on trial



Professor Pamela Russell, the decorated Queensland cancer expert who has made a significant contribution to international oncology research, provides this valuable summary of current imaging and therapy developments for prostate cancer.

ROFESSOR Pamela Russell, head of biomedical imaging and prostate cancer models at the Australian Prostate Cancer Research Centre in the Queensland University of Technology, recently gave the Brisbane Prostate Cancer Support Group an interesting talk about current drug treatments either in use or being considered in Australia.

She initially explained that prostate tumour cells require the male hormone androgen (testosterone) to grow and function. Treatments causing a reduction in androgen levels (through hormone or androgen deprivation therapies) can be successful in halting or slowing tumour growth, but in some cases the cancer can recur and possibly spread. These are referred to as castrate-resistant prostate cancers (CRPC).

Studies by Professor Colleen Nelson at the Prostate Cancer Research Institute (Oueensland) have shown that these cancers are capable of producing their own androgens, which occur from hypersensitivity to androgenresistant gene amplification, and mutations that permit activation by other androgens/ steroid hormones to increase tumour growth and survival.

This mechanism has been the target for new CRPC treatments. Only a decade ago, chemotherapy (docetaxel) was a man's last line of defence if his advanced prostate cancer became castrate resistant. If chemotherapy failed, palliative care was the next option.

There are now more options if chemotherapy is unsuccessful or unable to be used – with some being approved and others still in clinical trials.

• **Docetaxel** is an FDAapproved chemotherapy agent which shows an overall survival benefit and palliation of cancer-associated symptoms. It is approved for use in Australia for CRPC.

• **Cabazitaxel**, also a chemo agent, is FDA approved for use after the failure of docetaxel, with similar outcomes.

• Sipuleucel-T (Provenge) is an immunotherapy drug used to enhance a man's immune system, so it can recognise and induce cytotoxic response against prostate cancer cells. It is FDA approved, but not approved in Australia.

• Abiraterone Acetate is FDA approved and approved for use in Australia. It produces an irreversible inhibition of a tumour's ability to synthesise androgen.

• MDV3100 (enzalutamide) is FDA approved for postdocetaxel use. It is an AR antagonist preventing nuclear translocation and binding to chromatin. It is available in Australia but PBS Authority is required.

• BAZ235 is in Phase I/II

clinical trials in the US, in combination with abiraterone acetate, to inhibit P13K. Results are pending (it is not available in Australia).

• **RAD001 (everolimus)** is in Phase II clinical trials in the US, in combination with bicalutamide, as an inhibitor of mTOR. PBS Authority is required in Australia.

• Alpharadin (Radium 223) is an alpha emitter that selectively targets bone metastases. Phase III clinical trials are being conducted in the UK and Australia for men not eligible to receive, or declined, docetaxel.

• Dovitinib (TK1258) is an inhibitor of FGFR, currently in Phase II trials in the US for men after the failure of docetaxel chemotherapy. It is not approved for Australian use.

• Cabozantinib (XL184) is an inhibitor of c-MET, currently in Phase II/III clinical trials in New York and Australia, for men with CRPC and who have been previously treated with chemo, abiraterone acetate or MDV3100.

Details of ongoing clinical trials can be obtained by visiting www.australianclinicaltrials. gov.au

Along with new and emerging therapies, a new imaging method with improved tumour specificity and sensitivity is needed to give a more accurate diagnosis and better assessment of possible response to therapy.

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At present. Transrectal Ultrasound Guided Prostate Biopsy (TRUS Biopsy) has limited sensitivity. While transperineal biopsies may show a slight improvement over TRUS, both can miss and cancer foci anterior tumours. Following a radical prostatectomy, men with insignificant prostate cancer at biopsy can often show a worse disease.

Multiparametric Magnetic Resonance Imaging (mpMRI) can improve diagnosis and define areas where biopsies should be taken, including anterior tumours, but still have low tumour specificity and sensitivity.

The newly developed biocompatible iron oxide magnetic nanoparticles (MNPs), together with J591 (an antibody to an extracellular epitope of Prostate Specific Membrane Antigen), are being investigated at Queensland University of Technology to enhance MRI of preclinical prostate cancer.

A more detailed account of Professor Russell's presentation is published in the February 2016 edition of Queensland Prostate Cancer News. A video of Professor Russell's talk and full slide show presentation can also be viewed at www.jimjimjimjim. com/video---research-reportdec-2015.html

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Naracoorte Men's Cancer Support Group

Xmas leads to new year cheer

HE Naracoorte Men's Cancer Support Group continues to meet regularly on the fourth Wednesday of each month, and it looks forward to a very fruitful 2016 – especially after the group members enjoyed such a fine end-ofyear luncheon at the Naracoorte Hotel on Tuesday November 24. It was especially good that the event attracted visitors from the Limestone Coast support group in Mount Gambier, from Kingston SE, and Central Australia Chapter representative Ron Lehmann with several Murray Bridge support group colleagues.

The Naracoorte group recommenced its meetings at the Naracoorte Hotel on January 27, and it was good to see everyone again for the start of a promising year.

COMING EVENT

• The Naracoorte Men's Cancer Support Group usually conducts its meetings on the fourth Wednesday of the month at 10am in the Naracoorte Hotel. The hotel has generously provided free tea and coffee for the meetings.

• Further information about the Naracoorte group can be obtained by phoning Martin (8762 1430), or Graham Hinze (8737 2779, or 0408 803 793).

PCFA 2015 Christmas Fundraising Success

Christmas health message resonates with the public

PCFA achieved a fantastic result from its 2015 Christmas fundraising campaign, gaining valuable research dollars and amplifying the importance of health checks.

THE annual PCFA Christmas fundraising campaign enjoyed special success in 2015, raising significantly more than the projected target amount. The main message for this year's campaign – issued in the form of a letter titled "You Can Give Men The Gift Of A Healthy Future", penned by Darwin's Katie Woolf in memory of her late father Rod who died of prostate cancer – helped make this the organisation's most successful Christmas appeal yet.

The promotional campaign for the appeal smartly pointed to how the fundraising dollars equate to specific research benefits - that a donation of \$75 can fund one hour of prostate caner research, while a donation of \$3000 can fund one week of research work, and a donation of \$12,500 will ensure a month of research work.

It drove home the message of just how much is required to ensure the vital prostate cancer research work being done in Australia forges ahead – and the public responded to this call with outstanding generosity.

The second part of the fundraising campagin had PCFA reinforcing its recommendation that all men get an annual health check.

Using the slogan "There's Nothing Better Than A Meaningful Christmas Gift", the Christmas campaign urged participants to not only give donations, but to also book health checks for the men in their lives.

The campagin asked men to make December the month for an annual check up. It underlined that early detection of prostate cancer may just save a man's life.

Therefore, people were encouraged to give a most unusual Christmas gift: an appointment to get a health check. PCFA is delighted to report that this challenge was eagerly accepted across Australia.

Gay Prostate Support Adelaide

• Gay Prostate Support Adelaide is a support group that meets from 6.30pm to 8pm on the fourth Wednesday of each month (except December) at the Relationships Australia offices, 49A Ormond St, Hindmarsh. For more details, please contact group organiser Ivan Wooller by phone (0429 673 712) or email igwooller@gmail.com

Barossa Valley Prostate Cancer Support Group

Plans to provide more support for women

Recognising the importance of women and the difficulties they face with partners along the prostate cancer journey will become an important focus for the Barossa Valley support group, as group coordinator Don Piro reports.

THE members of the Barossa Valley Prostate Cancer Support Group and their partners enjoyed a lovely Christmas lunch at the Monkey Nut Cafe, housed within Kies Winery at the historic township of Lyndoch. It was a terrific event, and underlines for us all that it is always great to celebrate being together and enjoying some fellowship.

One of the plans hatched for 2016 that came out of discussions during the Christmas lunch was to recognise the importance of our partners' involvement and support they provide for those travelling with cancer.

With this in mind, a small group may get

together and plan an event that involves just the women attached to the support group, allowing them to come and share their stories about how they are affected.

For the group's meeting in March, Kevin O'Shaugnessy will be attending, to discuss his research on this issue – about how a couple's relationship is impacted when prostate cancer occurs.

We may use this presentation as a prelude to planning something further that involves our partners.

The support group also plans to soon have a fundraising barbecue at our local Mitre 10 store, as well as being involved in the Kapunda Farm Fair in April.

COMING EVENTS

- The Barossa Valley Prostate Cancer Support Group meets from 2-4pm on the third Tuesday of each month at the Vine Inn Hotel, Nuriootpa.
- The group's first meeting for 2016 is on Tuesday February 16.
- Please contact group coordinator Don Piro by phoning 8562 3359 for any further information.

Adelaide-Mitcham Prostate Cancer Support Group

Smart speakers for new year

HE Adelaide-Mitcham Prostate Cancer Support Group had an enjoyable finale to 2015 by hosting a successful annual group dinner at The Southern, South Road, St Marys, on November 26. A gathering of 37 members enjoyed the event.

The group's meeting on March 24 will feature guest speaker Daniella Albanese, a physiotherapist at the Memorial Hospital Day Rehab Centre.

The meeting on April 28 will feature guest speaker Dr Phuong Tran, oncologist at Adelaide Radiotherapy Centre.

The May 26 meeting will feature guest speaker Rosalie Donhardt, a continence nurse at the Continence Resource Centre.

COMING EVENTS

• The Adelaide-Mitcham support group will hold its first meeting for 2016 on Thursday February 25 at the Colonel Light Gardens RSL Club, 4 Prince George Parade, Colonel Light Gardens, from 7pm to 8.45pm. The format for the evening will be the AGM, plus a discussion on prostate cancer issues among members and visitors. Light refreshments are provided and car parking is available within the RSL grounds.

• For more information, visit the Adelaide-Mitcham website at www.adelaide-mitchampcsg.org or phone Cyril Harrison on 8298 6384, Jeff Roberts on 8277 3424 or lan Fisk on 8296 3350. For archived information of the former Adelaide and Mitcham Support Groups go to www.psaadelaide.org or www. psamitcham.org

Alice Springs Prostate Cancer Support Group

Successful annual dinner points to promising 2016



The Range View Restaurant in the Alice Springs Golf Club is proving an ideal venue for support group events.

A good and versatile meeting venue is helping to ensure strong numbers for the Alice Spings support group, as group secretary Grant Butler reports.

HE December meeting of the Alice Springs Prostate Cancer Support Group included the annual members' dinner at the Alice Springs Golf Club.

This was a very successful event, with approximately 40 people turning up to help celebrate the achievements of the past year.

Support group convenor Russell North gave an overview of the group's many

activities between courses, and it was commented by many that the food provided by the Range View Restaurant was especially tasty.

A big thank you was extended to Murray Neck and his family for organising the event.

The support group's first meeting for 2016 is on Thursday February 4, and will be held at the Alice Springs Golf Club, starting at 6pm.

COMING EVENT

• 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

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.

Dinner ushers in bright new year

HE Murray Bridge Prostate Cancer Support Group enjoyed a terrific 2015 breakup dinner on November 18 to conclude and reflect on a very successful year.

Once again, the annual dinner was held at the Murray Bridge Golf Club and the food excellent, much to the delight of the 32 people who attended.

Central Australia Chapter councillor Ian Wagner was invited to the function and he gave a short talk about the Central Chapter, which the audience found most interesting. As the dinner was held on the night before Doris Klenke's birthday, which added to the celebratory atmosphere. Her husband Max (support group secretary) coyly announced that Doris was two years younger than him – and he is 81.

Sadly, the support group had one member pass away during the year, and a few have now moved to a nursing home.

The first group meeting for this year, on February 17, will include its Annual General Meeting and map out programming plans for the group during 2016.

Port Pirie Prostate Cancer Support Group

Exploring urinary issues

Urinary issues are a significant concern for some men after prostate cancer surgery – and the Port Pirie support group gained valuable news on the subject, as Richard Kruger reports.

J ENNI Edwards, a continence nurse from Port Pirie, recently addressed the Port Pirie prostate cancer support group to explain how urinary catheters work.

It is not uncommon for patients after prostate surgery to suffer various degrees of urinary incontinence. Mild cases can be helped with absorbent pads, and a range of different types is available. But for cases of significant leakage, an artificial urinary sphincter gives excellent results. For this procedure, a cuff is placed around the urethra and connected to a reservoir of sterile fluid (a little smaller than a golf ball), with a small bulb placed in the scrotum. When urination is desired, the bulb is pressed and the cuff is released temporarily so that urine can flow. Sometimes a second press of the bulb is required to empty the bladder. This type of sphincter can be fitted to males and females.

Jenni explained that urinary catheters have been used for about 2000 years. A catheter



ABOVE: Port Pirie continence nurse Jenni Edwards.

is a narrow, hollow, flexible soft tube, inserted into the bladder through the urethra to continually drain urine. A catheter sits at the base of the bladder, and a balloon containing water at the end of the catheter holds it in place.

A catheter should not induce any pain; if there is discomfort, discharge or leakage, you should immediately consult a community nurse or doctor. With a catheter, you do not need to go to a toilet to urinate, and both the catheter and leg bag capturing waste are waterproof.

Catheters can be used so

that patients remain continent (which means voluntarily passing urine in a socially acceptable place) and can ensure urine is expelled (to overcome voiding difficulty and urinary retention).

They are a very valuable post-surgical aid – especially after trans-urethral resection, prostate, penectomy or bladder surgery, or after damage to the urethra or urethral stricture from infection or inflammation.

Catheters are usually used as short-term solutions, but can occasionally be used in the longer term. Sometimes

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.

urethral catheters cannot be used, and instead suprapubic catheters are taken from the bladder through the abdominal wall above the pubic bone.

As a tip for people with bladder concerns, regular doses of Vitamin C, blackcurrant juice and cranberry juice aid good bladder health.

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.

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Limestone Coast Prostate Cancer Support Group

Learning a valuable prostate history lesson

The history of prostate cancer research and treatment developments was explained to a recent meeting of the Limestone Coast support group, as Richard Harry reports.

HE Limestone Coast support group was once again privileged to have urologist Dr Michael Chong as guest speaker in November.

Dr Chong spoke on the history of research and treatment of prostate cancer, focusing on five men he considered responsible for crucial foundation work within this field from the mid-1900s – Andrew Schally, Patrick Walsh, Malcolm Bagshaw, Charles Huggins and Gerald Murphy.

Dr Chong explained the research of these pioneers and their early treatments of prostate cancer, through to detailing the two robots used for prostate surgery at St Andrews and Ashford hospitals in Adelaide, each costing in the vicinity of \$3 million and using consumables of about \$4000 per operation.

The support group's Christmas breakup luncheon at the Umpherston sinkhole on



ABOVE: Dr Michael Chong (left) being presented with a gift from Malcolm Porter after speaking to the Limestone Coast support group in November.

December 6 turned out to be a fire ban day, so the barbecue meal was cooked in the adjacent Country Fire Service shed, alongside their trucks (which were thankfully not required for duty on the day).

It turned out to be a good day under the shady trees, with 34

people attending, and despite the unpleasant weather, many people sat around talking until mid afternoon.

I think this spirit of friendship clearly shows the strength of the support that exists within this group.

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 first meeting for 2016 is on February 4.

• 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

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).

Darwin Prosper Prostate Cancer Support Group

NT support groups enjoy boost through recognition

THE reach and influence of PCFA support groups in the Top End received a considerable lift in 2015 through official vice-regal recognition

An official reception for PCFA representatives hosted for afternoon tea at Government House in Darwin with The Administrator of the Northern Terriory, the Honorable John Hardy OAM, and Mrs Hardy provided significant publicity. The Hon John Hardy was recently announced Patron of PCFA in the Northern Territory. 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 these meetings – especially prostate cancer support group members who are visiting Darwin from other parts of Australia. For more details about the group, please phone Don Lockley on 0401 116 851.



ABOVE: The Honourable John Hardy OAM with NT Rainbow Prostate Cancer Support Group's Peter Kay and Don Lockley of the Darwin Prosper Prostate Cancer Support Group.

NT Rainbow Prostate Cancer Support Group

• The NT Rainbow Prostate Cancer support group is a group of men and their 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.

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, March 8. 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

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.

• To conclude 2015, the group hosted guest speaker Vicki Penglis, a psychologist, at its November meeting. She gave a positive talk on how to cope with difficult daily situations as they occur. The group also came together for a breakfast at Cafe Primo, which was a good finish for the year. We note that the group has attracted a few extra members at several meetings, and the group 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)

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2015 Max Gardner Awards

Rewarding years of service

John Shields - secretary/treasurer of PCFA Central Australia Chapter Council and deputy chairman/secretary of City of Onkaparinga Prostate Cancer Support Group – reflects on what led to his 2015 Max Gardner award.

E were coming home from an Adelaide support group meeting toward the end of 2002, when I told my wife Phyllis that I was thinking about starting a prostate cancer support group in Noarlunga. She immediately encouraged me, so I did.

Phyllis and I retired on my 65th birthday and the following year, when I had my annual blood test, my GP advised having my PSA level checked. The results showed an elevated PSA level, so my GP referred me to a local urologist. No mention was initially made about prostate cancer, and I didn't even know I had a prostate gland.

The outcome was that I was diagnosed with prostate cancer, and had my prostate gland, together with the cancer, removed at Repatriation General Hospital.

I could have had radiotherapy, but the idea of having radiation to any part of my body did not appeal to me, although many men have had radiotherapy and have had no problems. My urologist told me about five years ago that I was cured.

When I was diagnosed, I wanted to attend a support group and talk to others diagnosed with prostate cancer. I was given the phone number of Reg Mayes, secretary of the Adelaide support group, and Phyllis and I became members. It was of



A proud day as John Shields (left) receives his Max Gardner Award at SA's PCFA office in November.

great support to us.

Before retiring, I had been a personal care worker in the dementia unit at a local aged care facility, and had set up and led two support groups for people whose partners had Alzheimer's disease – one group for their family member still living at home, the other for those in the dementia unit of the aged care facility where Phyllis and I worked.

This experience gave me the confidence to start the Noarlunga group only a month before the operation to have my prostate gland removed.

Our support group website www.pcsog.org (set up by Ian Fisk) contains our monthly newsletters, in which I put as much information as possible.

This was all long before the chapter's Prostate Supporter newsletter, which is a great way to keep everyone in the picture. It's certainly interesting to join Malcolm and Beverley Ellis checking everything our support groups send in and correct any errors before it is printed and distributed.

Soon after starting the support group, I compiled a manual with everything needed to run our support group, together with information about who was who in our national office, the Central Australia Chapter council and the Action Group.

Later on, when new groups were forming, I sent copies to all Central Australia Chapter leaders for verification, and the edited prostate cancer support group leaders' manual was presented at the chapter council meeting in Whyalla on May 20, 2010 – when the new Whyalla support group leader held the manual above his head and called it "my bible".

I then prepared more leaders' manuals and delivered them to other new groups.

I have always needed to do

something useful, so I became treasurer of the Central Australia Chapter Council and enjoyed receiving the finance information from the support groups, collating it and sending a report to our national office in Sydney.

One of my next projects was to produce something for the ladies, who are so important where prostate cancer is concerned. Some ladies do not like to talk openly, or in front of the men, about how prostate cancer is affecting them, so I produced a pamphlet specifically for those ladies.

I also put together some information for female Chapter Council members, and we ensured that ladies on the Chapter Council can be in regular contact with ladies in all of our support groups.

I was support group leader of the City of Onkaparinga support group for 10 years (Malcolm Ellis has taken over the role of leader), and I thank him for his help and friendship over a long period of time.

A support group is not a oneman band, and information days in local shopping centres have been greatly assisted by Mark Milosovic. Our annual fundraising barbecue at the local Bunnings store also gets great help from our members and families.

I would especially like to thank Phyllis for standing beside me from the beginning of my prostate cancer journey.

City of Onkaparinga Prostate Cancer Support Group

Wise Elder continues to provide key information

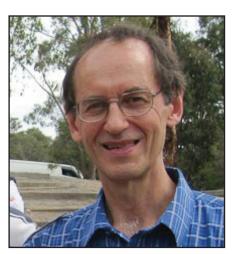
A longstanding relationship with a local urologist provides fantastic information for City of Onkaparinga support group members, as John Shields reports.

HE City of Onkaparinga support group welcomed local urologist Dr David Elder as guest speaker in November, for the final meeting of 2015. It was the latest chapter in a wonderful, long-lasting relationship, as Dr Elder has been a guest speaker every year since our first meeting in October 2003, and we always look forward to his talks – especially the way he interacts with the group members.

Dr Elder gave us an easy-to-understand, illustrated update on prostate cancer, and the various treatment options that are available to us today. He also gave a lot of his time to answer many questions from group members.

There are always new treatments on the horizon and it is good to get the reassurance that we are travelling along the right path on our own prostate cancer journey.

The support group's end of year luncheon was held at the local Aussie Inn on Sunday December 6, and it was very good to catch up with some of our members who are not always able to attend the support group meetings. It reinforces that this is a very good reason for the group members to continue having six-monthly get togethers.



ABOVE: Dr David Elder, a longtime supporter and guest speaker at City of Onkaparinga support group meetings.

The City of Onkaparinga group's first meeting for 2016 is at 6.30pm on Wednesday February 3, and our guest speaker will be Nina Magaletta from Cancer Council South Australia.

However, please note that the group's March meeting has been moved from its regular date, and will instead be held on Tuesday March 1 at 6.30pm. The guest speaker will be Andrew Wong from Carrig Chemists in Colonnades Shopping Centre, Noarlunga Centre.

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.

- However please note that the group's March meeting has been moved from its regular date, and will be held at 6.30pm on Tuesday March 1. The guest speaker will be Andrew Wong from Carrig Chemists in Colonnades, Noarlunga Centre.
- 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.

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).

Breakthrough PCFA support for health professionals

First approved guidelines on prostate cancer testing

Australia's first evidence-based clinical guidelines for health professionals on prostate cancer testing were launched in January by PCFA and Cancer Council Australia.

C OR the first time in Australia, health professionals have access to evidence-based recommendations for using the prostate specific antigen (PSA) blood test to assess prostate cancer risk and manage test-detected patients, following the publication in January of new clinical practice guidelines.

The guidelines, titled "PSA Testing and Early Management of Test-detected Prostate Cancer: Guidelines for health professionals", were launched in draft form for consultation more than a year ago. The recommendations have now been approved by the National Health and Medical Research Council (NHMRC).

Developed through a partnership of PCFA and Cancer Council Australia, the guidelines provide evidence-based recommendations to health professionals involved in localised prostate cancer risk assessment, surveillance and treatment. The recommendations also cover matters such as retesting, active surveillance, watchful waiting and biopsy.

PCFA and Cancer Council Australia believe the guidelines – aimed to help healthcare professionals navigate the daily professional dilemma of informing men about the risks and benefits of testing – will help prevent scenarios where PSA tests are conducted without patient consent.

PCFA Chief Executive Officer, Associate Professor Anthony Lowe, says that while the PSA test is not suited for population screening, it remains in widespread use, so there is a need for evidence-based guidelines to maximise the benefits of the test and minimise the possible harms.

"Contention about the PSA test has made it difficult for health professionals to take a consistent, evidence-based approach



PCFA Chief Executive Officer, Associate Professor Anthony Lowe.

to the test," says Associate Professor Lowe. "While the debate has played out, thousands of men have continued to take the test, as it's the only available biomarker to assist doctors in assessing a man's prostate cancer risk.

"The guidelines cut through the contention and provide guidance in relation to an individual man's circumstances, and on how to manage a patient if he requests and consents to taking the test.

"The recommendations were developed following a systematic review of the evidence and consensus on its interpretation by a leading team of epidemiologists, urologists, GPs, radiation oncologists, medical oncologists, allied health professionals and consumers."

Cancer Council Australia CEO, Professor Sanchia Aranda, says NHMRC approval is the gold standard in Australia and reflects the rigour applied to the guidelines' development. She says application of the guidelines should result in less over-treatment associated with PSA testing.

"The PSA test is an imprecise test and

has potential harms as well as benefits," says Professor Aranda. "The NHMRC's Information Document for health professionals, which is recommended as a companion document to the guidelines, estimates that for every 1000 men aged 60 with no first degree relatives affected by prostate cancer who take the test annually for ten years, two will avoid a prostate cancer death before the age of 85 as a result. Yet 87 men will receive a false-positive PSA test result and have an invasive biopsy that they didn't require - and 28 will experience side-effects, including impotence and incontinence, as a result of this biopsy, and one will require hospitalisation.

"Use of the guidelines will hopefully reduce the level of over-treatment and guide improved management of men with early-stage prostate cancer – until we have a better biomarker.

"With prostate cancer causing the second most cancer deaths in Australian men after lung cancer, and the numbers of death increasing with population ageing, we urgently need more sophisticated risk assessment and early-detection technology."

PCFA and Cancer Council Australia are currently working together to develop a separate decision aid aimed at assisting GPs and individual men discuss whether the test may be beneficial to them.

"PSA Testing and Early Management of Test-detected Prostate Cancer: A guideline for health professionals" is recommended for use by all professionals involved in PSA testing and early-stage prostate cancer surveillance, treatment and care. It is available for download at www.pcfa.org.au and wiki.cancer.org. au/PSAguidelines