

Central Australia Chapter



PROSTATE SUPPORTER

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

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www.pcagsa.org.au/pages/supporter.html

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Diligent test analysis thrust into spotlight

THE importance and accuracy of testing for prostate cancer is once again in the news headlines.

The need for all men to be vigilant with prostate cancer testing has been reinforced with the controversial news reports in April about SA Pathology covering up errors in prostate specific antigen (PSA) testing results.

The sensational expose by *The Sunday Mail* newspaper was brought to light by oncologist (and PCFA-SA board member) Dr Peter Sutherland and one of his patients, who uncovered alarming errors in public health procedure.

This issue heightens the importance of PCFA's crucial work to provide health professionals with access to evidence-based recommendations for use of PSA blood tests.

The publication in January of these new clinical practice guidelines – a first for Australia – were developed through a partnership of PCFA and Cancer Council



ABOVE: The strong relationship between Jason Dansie of The Good Guys at Hectorville and PCFA-SA continues to produce fantastic outcomes. Jason recently conducted another VIP night for his customers, with proceeds from the evening being donated to PCFA – and PCFA-SA's Karyn Foster is pictured above thanking Jason for his continued contributions and support of the organisation.

Australia, and have been approved by the National Health and Medical Research Council. Full details of this were revealed in the February 2016 edition of the *Prostate Supporter* newsletter – but can also be downloaded from 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 our most efficient distribution of the newsletter, so please let us know your preference. Send your replies to Janie Green in the PCFA office by email (janie.green@pafc.org.au) or phone 8231 6339.

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

Prostate Cancer Action Group

Exciting SANFL footy match promotional opportunity

Are you a footy fan? Then perhaps you can help the Action Group fulfil a great new awareness and promotional activity this footy season, as David Merry reports.

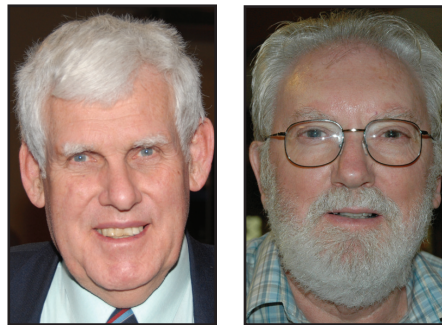
THE Prostate Cancer Action Group's small contingent of 10 members has been given the challenge of manning our Prostate Cancer Information Marquee at nine matches during the 2016 SANFL season, and will receive great support from most of the league football clubs. However, to achieve the best results and make the most of this great opportunity, we now need your help.

If you have experienced prostate cancer or are as passionate as we are about spreading the awareness message – and enjoy Australian Rules Football – please make contact with the Action Group. By assisting us at our stall before the assigned matches, you will be rewarded with free entry to those games.

This activity presents a terrific opportunity to spread the prostate cancer awareness message, and all volunteers will be joined at each event by Action Group members. Our simple role is to man the tent near the main oval entrance before the main game, while members of MFS and SA Police will also be raising funds around the ground.

We look forward to hearing from all footy fans who can assist us on match days throughout this winter. Please contact David Merry (phone 8270 2227 or email djmerry@adam.com.au) or John Thornton (phone 0409 863 235 or email johnjan4@gmail.com).

In other recent activities, the Action Group's stall at the two-day South East Field Days in Lucindale during March was particularly well received and well supported by members from support groups in Naracoorte and Mt Gambier. Our thanks go to the Lucindale Lions Club for presenting this well organised event, and to participating support group members for their assistance, particularly Richard Harry and Graham Hinze.



The Action Group thanks its long-serving retiring members Ray Power (left) and Rob Kitto (right).

The information stall at the Kapunda Farm Fair on April 9 and 10 was also very successful, thanks to the presence of Don Piro and fellow members of the Barossa Support Group. Additional thanks go to Lynton Carle of the Gawler Group and Bob Wood from the Action Group for their participation at this event.

The Action Group has a busy month during June, with Men's Health Week from June 13 to 17 featuring special Prostate Cancer Awareness meetings at Keith and at the Life Care Active Centre, Payneham Rd, Payneham.

The meeting at Keith is planned for Wednesday June 15, featuring Dr John Miller as lead speaker, and advertising for the Keith meeting will extend to the surrounding towns. The Payneham meeting on Thursday June 16 will feature a presentation by Dr Nick Brook.

At the Action Group's February meeting, Ray Power announced his need to step down from the group after 16 years of very active participation. During that time, Ray has held most committee positions, including the past six years as secretary. Ray was one of the founding members of the group and his active and wise contribution will certainly be missed.

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 May 10.

- 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

Everyone in the group extends a huge thank you to Ray and his wife Helen for their leadership and guidance.

At this meeting, Rob Kitto also announced his need to retire from the group for health reasons. Rob has been an active member for 12 years, serving as treasurer for six years, and has always been a willing supporter at events including sausage sizzle fundraisers. The Support Group thanks Rob for his contribution, especially for capably looking after the books.

PCFA National Office has acknowledged the committed support of both Ray and Rob with certificates of recognition, and we look forward to an opportunity when these can be presented at an appropriate event. In the wake of these events, John Thornton and Gordon Frith stepped up immediately, offering their services as secretary and treasurer respectively.

Central Australia Chapter Council

Preparing for a busy year



PCFA Central Australia Chapter Council Chairman Joan Manfield offers this update on chapter priorities and support group initiatives planned for the coming year.

MOST support groups are settling into their normal routines and meetings for 2016, and are hopefully helping men and their families through their prostate cancer journeys.

Small groups that only have intermittent meetings can still help men or their families who may be struggling to come to terms with their diagnosis. While it can be very hard for small groups to meet regularly and have guest speakers, catching up with local people for a morning or evening to talk can be most beneficial,

especially for newly diagnosed men.

Some support groups have very interesting speakers – which is reported in Prostate Supporter – and these events can give other groups ideas of guest speakers for their own meetings.

Three significant items were raised at the most recent Central Australia Chapter Council meeting in March:

- The Max Gardner Awards: Because the presentation of last year's awards were not until February this year, there will be no further awards

issued during 2016, although calls for nominations will be made in August, with the successful candidates announced in January 2017.

- PCFA is in the process of evaluating its structure and therefore will not conduct AGMs for Chapter Councils until this has been finalised.

- At the end of our meeting, we had a short session on mentoring groups. We will hopefully be better equipped to converse with support group leaders.

I would like to thank people who responded to my call for

help at the recent Kapunda Farm Fair, and to all who replied to my email asking for someone with prostate cancer who had been on active surveillance for at least two years to speak to a member of the community who had contacted me with his prostate cancer concerns.

Men's Health Week will be held from June 13 to 19 this year, and support groups may be interested in hosting a prostate cancer awareness stall in their community during this week, or may even conduct a promotional barbecue. If so, you need to start organising these events now.

If you are planning an outdoor event, always have a backup plan in case of unpleasant weather.

Most of the state's community awareness events that focus on prostate cancer are conducted by the Action Group, which is unique to South Australia and the Northern Territory, and does a great job. This allows the support groups to do what they do best, which is to provide support for the group members. If anyone is interested in helping the Action Group at any time, please contact David Merry, whose contact details are within the Action Group report on page 2 of this magazine.

To check whether all your group's current contact details are correct, visit the website pcfa.org.au and if there is any change needed in your support group's primary and secondary contacts, please notify Daniel Moore at PCFA by emailing daniel.moore@pcfa.org.au

August

Save the date for our Friday Long Lunch

Adelaide Oval

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

Prostate Cancer Foundation of Australia

Adelaide-Mitcham Prostate Cancer Support Group

Cancer fatigue research news

Adelaide-Mitcham Prostate Cancer Support Group has enjoyed learning of valuable research updates, as Jeff Roberts reports.

THE Adelaide-Mitcham Prostate Cancer Support Group held its initial meeting for 2016 - including the AGM - in February. Office bearers were obtained for all positions other than chairman and we are hopeful this position can be resolved soon.

Ian Fisk advised the group that he had purchased a lapel microphone to assist speakers at our meetings. A portion of Associate Professor Nick Brook's very generous donation from last year will be used for this purchase.

Last year's support group chairman, Cyril Harrison, read the Annual Report, which detailed another successful year for the group in 2015. The average attendance at meetings was 31, which was down slightly on the previous year, but still a satisfactory number. Thanks were expressed to Cyril from the entire group for his contribution as chairman during 2015.

DANIELLA Albanese, a physiotherapist at Memorial Hospital in North Adelaide was guest speaker at the group's March meeting. In August 2015, Daniella set up a Cancer Related Fatigue

Program at the hospital and has been running this program since then.

The following details are contained in an informative brochure on the program:

- Cancer Related Fatigue is a common, debilitating problem for many cancer sufferers. It can continue to impact on a person's life for months to years after treatment has finished.

- The fatigue is thought to be related to aspects of the illness itself, but treatments such as chemotherapy and radiotherapy may also contribute to the symptoms.

Symptoms of cancer-related fatigue include overwhelming tiredness that is not proportional to recent activity, and a weariness that interferes with your ability to maintain a normal lifestyle. It is usually unable to be relieved with rest.

Cancer related fatigue can have a devastating effect on a person's quality of life, ability to work, relationships with others, physical and emotional wellbeing, social and economic status, and can have limited chance of remission or cure.

In the past, it was thought that rest was the best way

COMING EVENTS

- The Adelaide-Mitcham support group's next meeting will be on Thursday May 26 at the Colonel Light Gardens RSL Club, 4 Prince George Parade, Colonel Light Gardens, from 7pm to 8.45pm. The speaker will be Rosalie Donhardt, continence nurse at the Continence Resource Centre, who will provide an update on the range of continence products that are currently available. Light refreshments will be provided and car parking is available within the RSL grounds.

- The meeting on June 23 will be a discussion evening among members and visitors.

- The July 28 meeting will feature guest speaker Prab Takhar, Director of Molecular Imaging and Therapy Research Unit at SAHMRI, North Tce.

- 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. For archived information of the former Adelaide and Mitcham Support Groups go to www.psaadelaide.org or www.psamitcham.org

to manage CRF. However, research has shown that regularly attending supervised, structured exercise programs tailored to the needs of cancer patients can have beneficial effects, including:

- Reduced fatigue levels.
- Improved physical performance.
- Improved vigour/vitality.
- Improved and more consistent moods.
- Reduced anxiety and fear.

According to research, the greatest improvements from exercise for CRF patients are seen when the programs are hospital based, supervised, and involve a variety of different types of exercises.

Daniella's fine presentation was greatly appreciated by group members. For more information on this program, contact The Memorial Hospital - Day Rehabilitation, or visit the website www.thememorialhospital.org.au

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

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Barossa Valley Prostate Cancer Support Group

Group members work together for big event

Efforts of the Barossa Valley support group to provide prostate cancer information at a local event has had a telling effect, as group coordinator Don Piro reports.

THE Barossa Valley support group recently attended the two-day Kapunda Farm Fair, and appreciated the support from the Action Group, which brought resources, its gazebo and banners to the event (special thanks go to David Merry). During the Friday and Saturday, we spoke to more than 120 people and handed out flyers, information and education resources.

It was notable that many women came to ask questions about their fathers or partners, and enquired about information for them. Men who had travelled with prostate cancer came to us and chatted about their journey, although many did not know they could access equipment and help for incontinence. Some gay and bisexual men also came and had a chat, airing a few “what if” concerns and wanting know who they could talk to for more information. Others just came to our information stall and wanted to share their stories.

Our group members who attended the fair said afterwards that it was really valuable for them to be there and speak to individuals who enquired about resources, support groups and needed different information. They agreed that providing such information is something we should always do.



ABOVE: Barossa support group's Don Piro (holding Ollie) and Trevor Miller at the Action Group's information stand during the Kapunda Farm Fair.

As a support group coordinator, this response was really heartening, as it can be a struggle to get enough volunteers to cover both days and still give everyone the chance to have a break. We did struggle for numbers on the Saturday, but those who came stayed most of the day and contributed a big effort. Special thanks go to Bob Wood and others of the Barossa group who could come to the fair, and to Lynton Carle from Gawler.

The Barossa Group is in discussion with two speakers to attend coming meetings and deliver presentations;

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. Contact group coordinator Don Piro by phoning 8562 3359 for any further information.

a local continence nurse, and Kevin O'Shaughnessy to discuss his research on the impact of prostate cancer on relationships.

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)

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Adelaide Hills Prostate Cancer Support Group

Benefits from expert advice

The Adelaide Hills support group is enjoying great input from experts, as group member Ian Wagner reports.

THE Adelaide Hills support group's April meeting featured social worker Lesley Norton, who gave an interesting presentation on Wellbeing and Resilience, particularly focused on stress factors, feelings and impact. Various points were discussed and a rigorous group discussion followed. Everyone who was in attendance agreed that the talk and interaction was very beneficial.

Future guest speakers for the support group meetings will be:

- **MAY:** Jill Miller from Cancer Council SA.

- **JUNE:** Dietician Effie Skoumbros, who returns to the group by popular demand.

- **JULY:** A Christmas in July social lunch gathering at Auchendarroch Tavern, Mt Barker.

- **AUGUST:** A site visit 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 prostate cancer support group is also investigating a meditation course for those who are interested in joining with

COMING EVENT

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

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.

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.**

New officers for the new year

A guest speaker delighted the Murray Bridge support group as it organised its new committee during the first meeting of this year, as group secretary Max Klenke reports.

THE first meeting for the Murray Bridge support group in 2016 was held in February and included the group's Annual General Meeting. Reports for 2015 were delivered by the group chairman, treasurer and secretary, and were favourably received by the group members.

Some plans were also made for the coming year, and new officers were elected. Ron Nance, who has been the group's chairman for some time, did not stand for re-election this year. The resulting election saw Malcolm Piggott voted as chairman, Bob Hunter as vice-chairman,

Richard Parsons as treasurer, Max Klenke as secretary and Bronwyn Lehmann as assistant secretary.

At the support group's March meeting, local retired man Bruno Lablack spoke and entertained us with a very enjoyable and interesting talk. He spoke about his work with cotton production in the central and northern areas of NSW, from growing, preparation of soil, harvesting to getting the cotton ready for sale. Many questions were asked of Bruno, and the talk proved a most entertaining addition to the group's usual meeting activities.

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, May 10. 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 alglan@iprimus.net.au**

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Port Pirie Prostate Cancer Support Group

Meeting our new urologist

Having the region's new visiting specialist urologist as a guest speaker at the monthly meeting was a special moment for the Port Pirie support group, as Ray Walters reports.

THE Port Pirie Prostate Cancer Support group's March meeting attracted 39 members to hear a great presentation from special guest speaker Dr Raj Singh-Rai, a visiting specialist urologist from the South Terrace Urology Clinic in Adelaide. Dr Singh-Rai has taken over from Dr Andrew Fuller as visiting specialist urologist to the Port Pirie Hospital.

Dr Singh-Rai was born in Leicester, England, and went to medical school then did his internship in and around London's teaching hospitals, before doing his research degree in Prostatic Cancer and training on England's south coast. Dr Singh-Rai came to Melbourne in 2010 and worked with Professor Mark Frydenburg (who is actively involved with PCFA) for a year before returning to the UK. However, his five and seven-year-old children proved a catalyst for his family's permanent move to Australia after an opportunity to work in Adelaide emerged. He has now been in Australia for three years and joined the South Terrace Urology practice about a year ago.

Dr Singh-Rai gave a very informative talk on lower urinary tract conditions, symptoms and treatments, including a descriptive and enlightening PowerPoint presentation. Points of interest included the physiology of the lower urinary tract components,



ABOVE: Port Pirie support group member Graham Williams discussing an article on treatments for prostate cancer with guest speaker Dr Raj Singh-Rai.

the bladder as a muscle and its action, back pressure because of restriction, prostate enlargement as men age, interference with lifestyle and sexual function and concern about possible complete blockage and catheters, and the worry of possible cancer.

The history of the patient – including age, examination of the kidneys, bladder, genitalia, and a digital/rectal examination – is used to establish the current size and condition of the prostate. Dr Singh-Rai explained that a normal prostate should be about the size of a walnut (20 grams), but can range up in size equivalent to a ping pong ball (30g), golf ball (40g), small orange (50g) or tennis ball (150g).

PSA testing can provide a proxy measure of prostate size, with the higher value

signalling the higher likelihood of having an enlarged prostate, which leads in turn to urinary problems. Post void and urine flow testing which indicates the rate of emptying of the bladder and volume of retained urine, with the intent of indicating whether a blockage may occur.

Explanations around whether the bladder itself is the cause of weak urinary flow, the urethra and scar tissue from previous procedures or the enlargement of the prostate causing a restriction.

Treatment options include doing nothing and just monitoring the condition; conservative treatment by changes in lifestyle; drugs, including 5 alpha reductase or alpha blockers (often used in combination) to assist in reducing the prostate size; and surgery to hollow out or rebore

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.

a prostate gland to prevent further complications.

The information presented on the evening was well received and provided many opportunities for group members to ask questions and seek explanations. A good point made during the discussion was that urinary complications affect men and women in different ways, but there are common symptoms and infections.

The group thanked Dr Singh-Rai with a small gift for his presentation and candid replies to questions. He then joined the group for supper afterwards to conclude a terrific evening.

Limestone Coast Prostate Cancer Support Group

Speakers providing key messages to membership

Presenting interesting guest speakers is giving the Limestone Coast support group valuable information about their health and life issues, as Richard Harry reports.

THE meeting in February was the Limestone Coast support group's first for the year, featuring guest speaker David Sanford, a senior estate planner from Australia Executor and Trustee Company. David made it very clear that although he represented a trustee company, his main aim was to give information on estate planning and the importance of having a current will – and to get it reviewed regularly.

A will is a legal document and everyone over 18 years of age should have one. David explained many of the pitfalls when wills had not been changed after changes in marital status or other situations, and suggested having two rather than one executor of the will. This is a serious subject that will have a bearing on us all at some time.

In February, Malcolm Porter and Richard Harry began the meeting by discussing arrangements with John Fartch, president of Mt Gambier Racing Club, for the Prostate Cancer Luncheon during the Gold Cup Meeting



ABOVE: Dr Trevor Hodson explains glaucoma to the Limestone Coast support group in April.

on May 12 and 13. Profits from this luncheon on Thursday May 12 will go to PCFA.

The support group's AGM was held in March, which resulted in no change to our management team. A round robin discussion was then held, with updates on the health of the members present.

On March 6, some of the group members were involved in the opening lap of the Relay For Life, acknowledging survivors and carers, which was a very humbling experience.

The Action Group presented an information stand at the Lucindale Field Days and several of our members

assisted David Merry over the two-day event.

Dr Trevor Hodson, an ophthalmologist from the Mt Gambier Eye Centre, spoke on eye health at our April meeting. He advised that the four main causes of eye problems in people of our age group were macular degeneration, cataracts, diabetic retinopathy and glaucoma.

Dr Hodson explained (with a dash of humour) the causes and affects of all these problems. He strongly advised getting our eyes checked every two years, concluding a very interesting presentation.

On April 22 to 24, the

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.**

- **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**

Limestone group will assist Graham Hinze at The Great Outdoor Expo in Mt Gambier, where a stall promoting the Murray Meander and all cancer groups in Mt Gambier will be providing a wide array of information to the public.

Our meeting on May 5 will involve Dr Mike Bruorton speaking on skin cancer.

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).**

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Naracoorte Men's Cancer Support Group

Discussions lead to shared info

The value of information shared at support group meetings provides many unexpected benefits, as Naracoorte group secretary Graham Hinze reports.

THE Naracoorte Men's Cancer Support Group continues to meet on the fourth Wednesday each month, with an average attendance of 11 men – and the stories shared among the group members are always interesting and entertaining.

These can vary from recounting a flight with the Flying Doctor Service, to growing up in outback New South Wales, recalling what happened during the building of the local CFS memorial – and even some rather dubious but amusing stories about learning to drive a vehicle 60 or 70 years ago.

On most occasions, the support group is able to help someone with PATS queries or discuss accommodation options for when they need to leave the district for treatment.

Unfortunately, due to the continuing doubt that surrounds the continuation of some specialists in the region, we often discuss where other people have been for treatment, and these suggestions sometime prove very helpful.

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 Gull (0437 299 760) or Graham Hinze (0408 803 793).

Information about new accommodation being made available near the Queen Elizabeth Hospital was discussed at a recent meeting, and will no doubt be used by members in the future.

Several group members assisted at a prostate cancer information stall at the recent Lucindale Field Days, and will also assist at the next Caravan and Camping Expo in Mt Gambier.

The recent election of office bearers for the support group in 2016 saw Martin Gull returned as chairman, Graham Hinze as secretary and Geoff Tanner as vice-president.

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 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.

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SA Prostate Cancer Research Update

Registry provides answers

Michael O'Callaghan provides this update on the crucial research work of the South Australian Prostate Cancer Clinical Outcomes Collaborative.

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.

The likelihood of prostate cancer reoccurring after radiotherapy or surgery is also significantly lower now than 10 to 15 years ago.

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



ABOVE: A recent meeting of people involved in the South Australian Prostate Cancer Clinical Outcomes Collaborative (front row, left to right): Tina Kopsaftis, Leigh Pretty, Kim Moretti and Kerry Beckmann. Back row: Scott Walsh, Michael O'Callaghan, David Merry and Kym Horsell.

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 – not just from a clinical perspective, but also 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

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).**

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Prostate Mates Support Group

New support group aiming for full, frank discussions

A new city group will be aiming to provide an environment where men can feel comfortable talking about the most intimate aspects of their prostate cancer journey.

THE inaugural meeting of Prostate Mates will be held on Tuesday May 31 at 5.30pm in the PCFA SA/NT Chapter Meeting Room at 144 South Tce, Adelaide.

This new group has been initiated by John Sheehan, whose 10-year prostate cancer journey has endured many difficulties, yet is prepared to not shirk any difficult issues as a means of providing essential support.

Prostate Mates stems from a circle of about six friends who had met for several

years, and their raw conversations proved most beneficial to them. John now hopes that Prostate Mates meetings will be equally frank – the place where men can “get down and dirty” with very raw and honest conversations, as John explains.

Prostate Mates presents an opportunity for men to meet with other prostate cancer survivors and talk about their prostate life journey. Discussions will be open and friendly, conducted in a forum that is similar to a group therapy environment.

Talking points could be about incontinence, impotence, or problems in relationships with wives and partners. The only aim is for men to openly talk about their experiences with other men who will understand and support them.

Bookings for this inaugural event are essential, and to register your interest, please phone group leader John Sheehan on 0409 929 933, or assistant Gordon Frith (a male nurse who has worked with Dr Peter Sutherland) on 0424 747 044.

City of Onkaparinga Prostate Cancer Support Group

THE City of Onkaparinga Prostate Cancer Support Group's April meeting had guest speaker Robert Brokenshire MLC explain the SA government's Transforming Health policy. He mentioned that the systems in place now can't be changed and urged members to question local MPs and express our concerns about facilities for prostate health in SA, suggesting that we lobby for Noarlunga Hospital to become a centre for specialist prostate health in the south.

Support group convenor John Shields and his wife Phyllis are both in respite/recuperative care at McLaren & Districts War Memorial Hospital due to cardiac problems. They are both doing well and should be home soon.

The City of Onkaparinga 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. For the May meeting, clinical psychologist Dr Tim Upsdell will speak about psychological aspects of grief and loss, including dealing with cancer diagnosis. The June meeting will be a Sunday lunch at the Aussie Inn in Hackham, and the July meeting will feature a representative from Cancer Council SA. We recently initiated a social daytime get together two weeks after each monthly evening meeting. We meet on the third Thursday of the month, usually at Rito's Continental Café at Christies Beach. 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.

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.

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

PCFA celebrates an important milestone

Mates helping mates



PCFA Chief Executive Officer, Associate Professor Anthony Lowe, reflects on the first 20 years of the national prostate cancer organisation, which began on March 14, 1996.

THE PCFA anniversary is hardly a cause for celebration, as after 20 years of hard work 20,000 Australian men are diagnosed with, and 3300 die of, prostate cancer annually. Equally importantly, some 200,000 Australian men and their families are living with the disease, and in far too many cases living with a psychosocial and quality of life burden that includes heightened psychological distress, an increase risk of suicide, and long term quality of life concerns, especially in the area of sexual well-being.

Still, much has been achieved. In 1996 there were no prostate cancer specific cancer control or support agencies, and information and advice for prostate cancer survivors and their partners about treatment side effects and management strategies was largely non-existent. In response, ordinary men and women affected by the disease formed a grass roots health activist movement to address these issues, founded on the simple principle of mates helping mates.

Australian support groups began to emerge in 1993, first in NSW with the formation of self-help group Prostates Anonymous, then further groups emerged throughout the country. Many were initiated independent of health services while others had informal partnerships with local health professionals who supported meetings by providing venues and occasional guest speakers.

Independent advocates within these groups were important in driving towards a national collective. Prostates Anonymous leader Peter Schade partnered with Us Too International to form Us Too Australia, that later merged as a division

of the Continence Foundation of Australia in 1995 (which became Prostak in 1996, but sadly ended in 1998 when Peter died).

In this period, two organisations emerged in NSW which played a pivotal role in the national movement. In 1994, television personality Roger Climpson OAM, a member of the Rotary Club of Lane Cove, was successfully treated for prostate cancer but was concerned by confusing information available to him and by the apparent lack of research into the disease being carried out in Australia. In 1996, he persuaded fellow club members to form Prostate Cancer Research Foundation, to raise funds for research.

IN 1998, a committee of support group representatives from the greater Sydney and Newcastle area formed the Association of Prostate Cancer Support Groups (APCSG) that hoped to connect support groups nationally.

APCSG, led by Max Gardner AM, moved to affiliate with PCRf – just as NSW-based fundraising group Australian Prostate Cancer Foundation (APCF) emerged. In 1999, the three groups merged and Prostate Cancer Foundation of Australia was chosen to reflect the new organisation's widened agenda.

In 2001, the relationship between the national support group movement and PCFA was clearly and formally established, with 31 support groups across the country.

An inaugural conference of Affiliated Prostate Cancer Support Groups was organised by PCFA, providing the first national forum for support group representatives across Australia, to connect and devise strategies that would

address priority issues for prostate cancer survivors and advance the broader movement. At this conference, the support groups declared PCFA as the peak national body for prostate cancer and the Association of Prostate Cancer Support Groups became the Support and Advocacy Committee (now known as the National Support Groups Committee) within PCFA's governance structure.

Max Gardner, who was a key figure in the movement, died in 2004. Over the next decade, more support groups formed under the umbrella of PCFA and there are now approximately 170 prostate cancer support groups affiliated with PCFA, including groups for partners and carers; gay and bisexual men; men with advanced prostate cancer; men from culturally and linguistically diverse communities; younger men and sport and fitness groups.

PCFa remains a broad based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners and families, recognising the diversity of the Australian community. We do this by:

- Promoting and funding world-leading, innovative research into prostate cancer.
- Implementing awareness campaigns and education programs for the Australian public, health professionals and government.
- Supporting men and their families affected by prostate cancer through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses.

PCFA relies on the generosity of individuals, the community and partnerships to carry out its essential work, and while there is still much to be accomplished, we can now take pause to celebrate the achievements of the pioneers who initiated this very valuable national prostate cancer support movement.