

Central Australia Chapter



Prostate Cancer Foundation of Australia

PROSTATE SUPPORTER

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

www.prostate.org.au

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An exciting new era for PCFA action

With new administration and a juggling of head office staff, the Prostate Cancer Foundation of Australia is entering an energetic phase, as Graeme Higgs reports.

THE national support group network of Prostate Cancer Foundation of Australia has in rapid succession held annual conferences for the Support and Advocacy Committee, the NSW/ACT Chapter and Queensland Chapter, in Adelaide, Canberra and Brisbane respectively.

At the SAC conference in Adelaide, chair David Gregory said the past year had seen significant change for the support group network – and more was coming.

Part of this change is being driven by SAC, as the committee recognises that its advocacy role has been largely neglected.

As a result, there is now a move towards advocating rigorously by using the PCFA Lobbyist Organisation, along with advocating issues on behalf of advanced prostate

cancer patients in the year ahead.

“SAC is taking steps to join with other organisations in our support and advocacy efforts, and is building representation and collaboration with fellow cancer travellers,” says David Gregory.

“These include Cancer Australia, Cancer Voices, Cancer Councils around the country, the National Rural Health Alliance, Consumers Health Forum, Self-Funded Retirees Association and Seniors Australia.”

Issues to be addressed include Patient Assisted Travel Schemes, MBS and PBS Funding for prostate cancer treatments and procedures, increased awareness of prostate cancer and its impact on the community at all levels, and the lack of government funding available to this crucial area of men’s health.

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



ABOVE: PCFA’S Graeme Higgs (left) at The Rumble Ride, a national biker-based fundraising event, with PCFA champions Jen, Tex and Bundy the dog.

in brief...

- A lavish cocktail party promoting a gala Titanic anniversary dinner is being held in Adelaide Arcade from 6pm on Tuesday May 31, and the PCFA has been invited to present its promotional stand – but Karyn Foster needs volunteers to man the stand. For full details of this event, please see the report published on Page 12 of this newsletter.
- CONTRIBUTIONS from all Support Group members to the monthly Prostate Supporter newsletters are most welcome; please email items and images to Karyn Foster: karynfoster@adam.com.au

The SAC conference also welcomed PCFA Queensland Manager, Graeme Higgs, as the new SAC National Manager, which he will perform in addition to his state duties.

In this part-time appointment until 30 June 2011, Graeme will assist the support groups, chapter councils and SAC, thereby filling a void left by the departure last year of Paul Redman from the PCFA.

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

Prostate Cancer Action Group

Linking arms with service clubs

COMING EVENTS

JUNE 14 MEETING: The next meeting of the Prostate Cancer Action Group SA will be held in the upstairs meeting room at the Cancer Council SA, 202 Greenhill Rd, Eastwood, commencing at 5.30pm on Tuesday, June 14. Entry is via the rear stairway.

• For more information, visit the Action Group's dedicated website, with detailed archives containing newsletters, at <http://www.pcagsa.org.au>

Staging successful Awareness Evenings relies on the support of service clubs, as Action Group convenor David Merry reports.

OBTAINING the help and cooperation of local Service clubs is the most effective means of presenting a successful Prostate Cancer Awareness Night in our communities.

On March 28, the Berri Lions Club's Alan Dand proved this and paved the way for an excellent evening attended by 160 participants – the second equal highest attendance for any Action Group awareness evening.

Among the guest speakers on the night, Dr James Aspinall gave a particularly informative input from the urologist's point

of view about treating prostate cancer.

As both Lions Australia and Rotary International are community partners in the PCFA Speaker program, these organisations are in a key position to assist the Action Group presentations.

Indeed, we already have service clubs working with the Action Group in planning awareness meetings in Port Lincoln, Central Yorke Peninsula, Woodville – and possibly also in Kangaroo Island, Woodside and Lucindale later in the year.

Attendance has also been

arranged for the Action Group to again have a presence during the three-day Yorke Peninsula Field Days event in September.

The Action Group and Central Australia Chapter are currently involved in the planning for a fundraising concert that has been offered by the Adelaide Male Voice Choir for October.

This will be a major event, presenting a grand opportunity for both promotional and fundraising possibilities, so look out for details and be sure to enlist the support of your friends to guarantee its success.

City of Onkaparinga Prostate Cancer Support Group

Finding relevant information

IT'S heartening to know that good prostate cancer information is readily available to those who need it. Onkaparinga support group member Ken presented the group with an information kit he recently received from the Cancer Council of South Australia, containing all the relevant information helpful to Ken at this stage of his prostate cancer journey.

For people seeking immediate assistance with their cancer and treatment options, a call to the Cancer Council Helpline will connect them to a nurse, who will ask about their diagnosis and current situation, then put together the available information that relates to that caller, together with treatment

options that are available in Adelaide. The Cancer Council Helpline is 13 1120.

NEW DVDs

WE ARE pleased to have received three new DVDs from the PCFA – *Mens' Health Seminar: Men's Health Revealed*, ABC's *Life Matters: Sex after Prostate Cancer*, and *Rural Health*. We hope to screen these soon at support group meetings.

ADVANCED CANCER

CHAPTER Chair Malcolm Ellis is keen to see more emphasis placed on providing information and presentations on advanced prostate cancer. We have focussed a lot on the diagnosis, treatment and all other aspects of the early

stages of prostate cancer, including acknowledging the "prostate cancer journey". However, many who attend support group meetings are more interested in advanced prostate cancer and the various treatment options, which we will now strive to emphasise.

STORAGE UNIT

THE Central Australia Chapter has hired a storage unit at Tonsley Park to store PCFA pamphlets, surplus stock and equipment (such as computers and printers) that may be utilised by support groups, especially when a new group is formed. The key holders are Malcolm Ellis, Jeff Roberts, John Baulderstone and John Shields.

JUNE MEETING: The next City of Onkaparinga Prostate Cancer Support Group gathering will be a barbecue at the Willunga Lions Saleyards on June 5. This will replace the usual monthly meeting at Noarlunga Community Hospital.

• For more information, visit the City of Onkaparinga Support Group's website at www.pcsog.org

• Special thanks to our sponsors: **Southern Primary Health Morphett Vale, Port Noarlunga-Christies Beach RSL Sub Branch, Cartridges Now Christies Beach, The Original Open Market and The City of Onkaparinga Council.**

McLaren Districts Prostate Cancer Support Group

Pondering whether to downsize your house

After the family has flown – and with medical concerns foremost in their thinking – many members consider selling their homes, as McLaren group president Bryan Hearn reports.

THE McLaren Districts Support Group's April meeting featured a very interesting and informative presentation on the benefits and pitfalls of downsizing your home. Deb Tucker, representing McLaren Vale Real Estate agent Raine and Horne, gave attendees a well prepared fact sheet on the subject, then explained that many vendors who she had represented have gone down the route of downsizing from a larger property to a smaller one. In many instances this involved some agony, though none have regretted making this move.

Deb explained that some people had been able to make the decision to sell their homes quite quickly, while others had taken up to three years to resolve this quite emotive issue.

One of the major issues was overcoming the fear of how to go about making the change. This involved a lot of talking with partners, family, friends and others who had made a similar change, or who had decided against such a change.

Selecting a new location also caused some problems. Many people decided to move out of an area and start fresh somewhere new, though this also brings about many problems such as identifying new services, making new friends, finding your way around and registering with health services.

Moving house but remaining in the same suburb is always an option but finding a suitable property may take some time.

There were many pros and cons listed in the real estate company's fact sheet. Pros included a reduction in such work as garden and house maintenance, and many saw the sale of the lawnmower as a big step forward. Other matters

COMING EVENT THURSDAY MAY 26

- The McLaren Districts group will next meet on **Thursday May 26** with a 7pm meeting in the administration building at the rear of the McLaren Vale & Districts War Memorial Hospital, Aldersey St, McLaren Vale. The guest speaker will be Bruce Hale from Retireinvest, who will speak about the latest federal budget, investments in general and the workings of the Stock Exchange.

included less cleaning, a cheaper lifestyle that will hopefully provide more cash for travelling and lifestyle treats, the stimulation of meeting new neighbours, and the opportunity to move into a more modern, lighter, brighter home.

Feng Shui proponents always recommend a good de-cluttering of one's life. An opportunity is provided to move closer to available medical facilities. However, if the move involves building a new property this itself can induce extra stress.

Cons that weigh against moving house included having to adjust to a new location, re-establishing local contacts, having to decide which items of furniture may have to go when there is insufficient room in the new home. Sometimes items can be placed in storage rather than sold, but there may not be room to store big items such as a caravan or boat or even toys necessary for babysitting duties.

One item that was considered as both a Pro and a Con was being able to entertain less guests at any one time, with the pro advocates claiming that stress levels could be reduced as a consequence of this shift. It could even mean a shift in which family hosts Christmas dinner, forcing somebody else in the family to take on this responsibility.

Deb provided a lot of information on the costs involved in making such a move.

Using a base figure of \$400,000 being paid for the new property, this requires payment of \$16,330 in stamp duty, \$2064 in registration of the title with the Lands Title Office, about \$700 for conveyancing plus any adjustments to rates and taxes. Removalist costs also have to be added to the list of expenses.

With regard to selling an existing property, this can involve between 2.5 per cent and 3.5 per cent of the selling price paid to the real estate agent, plus advertising and other costs. It is estimated that at least \$50,000 should be allowed to cover the full cost of moving house.

Several of these costs can be avoided if people move into a retirement village. Several group members live in one of the local retirement villages, and added their views to the discussion.

Deb asked potential sellers to ask "what if" questions, and provided a comprehensive list of Frequently Asked Questions and relevant websites compiled by Keyinvest, which manages the local IOOF Retirement Village.

Members were advised to be particular when selecting an agent, making sure they obtain more than one valuation and appraisal of their property. These appraisals should be professionally done and presented, and not simply a figure written on the rear of a business card.

Meet the people within the family of Support Groups

Prepared to work hard to tell more about prostate cancer

Forever busy within the prostate cancer support network – as convenor of the McLaren and Districts group and secretary of the Central Australia Chapter council – Bryan Hearn wants to ensure men can access more information about the disease.

ON THE face of it, my prostate cancer story is not much different to many others – except that I took things just a little further. Like many men of my age I undertook annual checks with my local doctor, though in September 2006 I received a call about 10 days after the check, from my doctor who informed me that my PSA level was a little elevated. His advice was to do nothing but “watch and wait”, though this didn’t sit well with me, as I felt if something was not quite right I needed to know what and why.

I visited an oncologist for examination, who confirmed the early diagnosis and arranged for me to have a biopsy in November 2006. Results showed that I had early signs of prostate cancer, and my wife Kay and I were quite stunned by this.

Being a pragmatic person, having worked in the SA Police Force in positions from the fraud squad to hostage negotiator through a 28-year career, I accepted the situation and started seeking information, though my wife didn’t really stop crying for a week.

Unknown to me, she confided the news with a close friend who also had cancer problems, and between them



Bryan Hearn (far right) and wife Kay (centre), with the full contingent of their children and grandchildren.

they came to grips with the situation.

The information I sought out confused me more than ever. There was such a plethora of information available but none was specific; there were always options and a range of considerations to be borne in mind.

Initially I opted for a radical prostatectomy but later changed to brachytherapy treatment, which was administered as day surgery at the Royal Adelaide Hospital in early August 2007. This proved very successful and my PSA reading is now less than 1 and continues to reduce.

During my recovery, I became aware of prostate cancer support groups, though the nearest to me at McLaren Vale was in Noarlunga. I

attended once to see how the group operated and with the help of their organisers and other various cancer groups, launched a new prostate cancer support group in McLaren Vale in September 2007. It’s an extension of other health interests I have in the area, being the current Chairman of the McLaren Vale & Districts War Memorial Hospital Management Board.

Kay and I are also members of the McLaren Districts Lions Club and I currently serve on the management committee of the McLaren Vale/Willunga Districts Probus Club, the Regional Christmas Carols Association and the local Neighbourhood Watch group in McLaren Vale.

It certainly keeps us busy, in addition to enjoying time with

three granddaughters from our daughter Tracey and her husband Craig Boxer, who run a farm and other small businesses on Kangaroo Island, and a grandson and granddaughter from our son Steven and his wife Donna, who live at Tatachilla.

The McLaren Vale area’s prostate cancer support group continues to run very successfully, meeting on a monthly basis and enjoying presentations from a wide variety of speakers covering many and varied topics, ranging from acupuncture to funerals, chiropractors to nutritionists and almost every thing in between.

New members are always welcome to join the group and should phone me on 8323 7924 if they are interested in attending meetings or having a chat about prostate cancer.

As a result of my experience with this fine group, I have also become involved with the Fleurieu Cancer Network at a local level, and the Prostate Cancer Foundation of Australia both at a local, State and National level.

I now know there is plenty of help and support available in the community for prostate cancer sufferers – and nobody needs face this journey on their own.

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

Prostate Cancer Support and Awareness: ADELAIDE GROUP

Ray shares his inspiring story

The Adelaide support group learned of a man's unlikely survival after cancer – and the organisation that has greatly helped him, as Ian Fisk reports.

RAY Nicholson was at the Adelaide support group's April meeting, discussing his personal experiences with cancer and his role at the Cancer Care Centre, where he is currently president and chairman of the board.

In December 1997, Ray was diagnosed with mantle cell lymphoma (one of the non Hodgkin lymphomas) and he retired to move from the corporate world to the cancer world. The disease was at stage 4 with no known medical treatments available and no hope for the future could be given.

Along with monthly medical monitoring, Ray joined the Cancer Care Centre in Unley, which offers complementary care. Embarking on a regime of meditation, affirmations, visualisation, an organic-based diet of mainly vegetables and fruit with no processed food, setting short term goals to live to achieve, educating himself through the Internet to become informed more on cancers, and attending support groups and seminars on cancer, Ray eked out a survival existence for the next two years.

Early in 2000, the oncologist advised the tumour had spread throughout his bone marrow and a new medical protocol of intensive chemotherapy was embarked upon. Most of the year was spent in and out of hospital.

When the intensity of the drugs was such that some could not be continued, his spleen, which was grossly

enlarged with tumour, was removed, followed by a stem cell peripheral blood bone marrow transplant, and then a mabthera (monoclonal antibody) course of treatment.

During this time, Ray kept visiting the Cancer Care Centre, maintaining his complementary care support, particularly meditation, diet, education and goal setting, along with supporting others with cancer.

By 2001/02, he was on a roller coaster ride, with some gradual health improvement, though in 2003 he was declared in partial remission. In 2005, full remission was attained, with his oncologist saying, "I don't know what you are doing but whatever it is, keep doing it".

At the end of 2000, Ray trained as a volunteer at Cancer Care Centre and has maintained a role there ever since, becoming president and chairman of the board in September 2009.

The Cancer Care Centre started as a support group in 1985, facilitated by Dr Ian Gawler and oncologist Dr Alistair Robertson, to provide choices of complementary care and support of the medical model.

As a not-for-profit volunteer organisation, the centre offers complementary care in a supportive environment for people affected by all cancer types, along with their carers.

Through its Pathways program, the centre aims to create the environment that empowers people to play



Ray Nicholson

an active role in managing their health and recognising the importance of their own contribution to the outcome of medical treatments. Focusing on the benefits of good nutrition, stress management, positive thinking, self-help, fostering support groups and providing access to educational facilities, the centre provides use of its library, quarterly Healthy Living newsletter, courses, seminars, qualified therapists and counsellors.

Some programs include the popular Empower Yourself to Heal course, Juicing for Health, massage and therapeutic touch therapies, men's and women's groups, circle of friends, meditation classes, Tai Chi and yoga, plant-based cooking seminars, art therapies, Sounder Sleep System, meditation and stress management workshops.

In 2010, Ray was diagnosed with prostate cancer. After considering all the available options, he chose radical NS (nerve sparing) prostatectomy.

After surgery, he encountered the not-so-unusual incontinence and sexual functions issues, though his PSA is now .002 (undetectable).

COMING EVENTS

MAY 17 MEETING:
The Adelaide Prostate Cancer Support Group meets on the third Monday of each month in the Park View Room of the Fullarton Park Centre, 411 Fullarton Rd, Fullarton, starting at 7pm. The May 17 meeting will feature a general discussion,

- The Adelaide group's June 20 meeting will feature Kevin O'Shaughnessy speaking on supportive care for men and their partners.

- For more information, visit the Adelaide Support Group's dedicated website at www.psaadelaide.org or contact Ian Fisk by phoning 8296 3350, or send email to info@psaadelaide.org

The Cancer Care Centre, situated at 76 Edmund Ave, Unley, is open on weekdays from 10am to 4pm (excepting public holidays). Visitors are always welcome, including anyone who has been affected by cancer as well as people going through treatment.

Appointments are not required but to have specific requests looked after, phone a client service volunteer on 8272 2411.

Research and news items from around the world

Seeds of hope painted for prostate cancer battlers

The benefits of brachytherapy for low risk prostate cancers are being clearly illustrated in a comprehensive new comparative study from Canada.

THE largest comparative study in the world shows that seed therapy – also called low dose brachytherapy – appears to be the most effective treatment for a long-term cure of prostate cancer.

The Comparative Effectiveness of Prostate Cancer Study, overseen by an international panel of 27 experts, has analysed more than 18,000 articles from 2000 to 2010, showing that in men with low-risk cancers, seeds offer a cure rate of around 90 per cent, compared with 80 per cent for surgery or traditional radiation.

Tom Pickles, professor and radiation oncologist at the British Columbia Cancer Agency, Canada, says this comparative study, which is still in progress, shows seed therapy to be the most durable of all treatments.

It has prompted the president of the Urological Society, David Malouf, to declare there is a lack of awareness that seed therapy offers a good treatment option for localised cancer.

Dr Pickles explained the two ways of doing brachytherapy. “The low dose rate is done as a day case procedure; the patient is usually anaesthetised and through the skin of the perineum (underneath the scrotum) about 25 needles preloaded with radioactive seeds are inserted directly into the prostate gland, so it doesn’t go through the rectum like a biopsy. It means the infection rate is very, very low.

“High dose treatment is usually used for

high-risk prostate cancer in combination with regular external beam radiation therapy and the radioactive seeds are not left there permanently. It typically involves one to three bouts of treatment.

“The main treatment dilemma for men is that either they’re not offered alternatives or it’s really confusing to decide which treatment they might have.

“It has always struck me as being very unreasonable for a patient who firstly is told that he’s got cancer and then sometimes,

Dr Pickles’ assessment of 848 treatment studies showed that within low risk prostate cancers, brachytherapy has a 90-95 per cent cure rate out to nine or 10 years.

even at the same visit or even in the same sentence, is offered a treatment – and the surgeon obviously wants to put a good spin on it – so sometimes the patient will sign up without having duly considered their options.”

Dr Pickles’ assessment of 848 treatment studies showed that within low risk prostate cancers, brachytherapy has a 90-95 per cent cure rate out to nine or 10 years, using PSA as a measure of the success of the treatment.

By comparison, radical prostatectomy in these studies showed an 80 to 85 per cent rate – up to 15 per cent less than brachytherapy.

“For a man with a PSA between 10 and 20 and a Gleason score of 7, and not in an advanced stage clinically, we’re seeing about 85 per cent to 90 per cent cure rates with brachytherapy and around about 70 per cent with the surgery.

“The difference between the two is slightly widening and we see that more with the high-risk cancers.”

His advice in the wake of this research discovery is for prostate cancer patients to examine and consider their treatment options more carefully.

“A man should realise that this is not an urgent situation,” says Dr Pickles.

“Prostate cancer typically grows relatively slowly and even with high-risk prostate cancers, you have the luxury of taking weeks, if not months to make an informed decision.

“As well as seeing a urologist, visit another urologist who also does brachytherapy, because not all of them do, and an oncologist who has a different perspective on brachytherapy or external radiation.

“Most patients make a decision based upon the perceived side effects; quality of life tends to outweigh quantity. So patients want to choose somebody who’s good at what they do.”

• Sources: *Cancer In The News*, issued by the Cancer Council, March 2011, and *ABC Radio: The Health Report*, broadcast on 14/3/11.

And now for something completely different ... a touch of humour

A tour bus full of Americans arrives at Runnymede, England. They gather around the tour guide who says, “This is where the barons forced King John to sign the Magna Carta.” A man pushing his way to the front asks, “When did that happen?” 1215, answers the guide. The man looks at his watch and says, “Shoooot! Just missed it by a half hour!”

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or visit the website www.prostate.org.au

Port Pirie Prostate Cancer Support Group

How to help the Red Cross help people in local districts

Red Cross has a range of valuable services that help people in our local communities but our assistance is needed to ensure they can continue, as Richard Kruger reports.

MEMBERS of the Port Pirie Prostate Cancer Support Group were delighted by a presentation at the April meeting on the Red Cross Telecross and Telecross REDi services. Several group members were already aware of the Telecross service, where volunteers phone persons at risk, daily or as otherwise determined, to ensure they are alive and well.

People targeted for this service are those who are isolated and at risk of an accident or illness that may go unnoticed – especially people who have a disability, are frail and aged, are housebound, recovering from an illness or accident, have an ongoing or chronic illness or are carers, whose presence is paramount for the wellbeing of others being cared for.

Pauline Fetherstonhaugh from Australian Red Cross gave a brief outline of the origins of Red Cross organisation, and the other international banners of Red Crescent and Red Crystal that it operates under.

She explained that under the Geneva Convention, Red Cross workers are not supposed to be shot at, and remain impartial without taking sides in conflict zones, being non-political so that it can help patients and victims from any source of trauma, whether that be war,



Margaret Seyfang, Pauline Fetherstonhaugh of the Red Cross Organisation and Lorraine Lang pictured at the Port Pirie support group April meeting.

natural disaster, or calamitous accident. Red Cross also helps families that have been scattered during crises to reconnect.

Pauline then explained who Telecross clients are, and how volunteers are needed to make phone calls between 8am and 9 am to ensure that the clients are all right.

She explained that in the event of no answer, up to two repeat calls are made and then if no reply is received, nominated local contacts are asked to perform a physical check on whether the client is home and well or otherwise.

Telecross improves socially isolated people's quality of life by keeping them connected to the community. Pauline emphasised that while Red Cross receives some government funding, donations are always gratefully received.

She also stressed that without the help of volunteer phone operators, this valuable service could not operate.

Pauline mentioned that the service is totally flexible; if a client will be away and advises the Telecross service, then they will not be called.

Similarly, volunteers only need to work on the dates that they specify, and if they cannot meet their rostered duty a replacement can be arranged.

Pauline then explained Telecross REDi, which was less familiar to the audience. On days when extreme heat is likely to threaten the health of certain clients, Telecross REDi volunteers will call them at various times during the day, to ensure that they are coping and not overly distressed throughout the extreme heat conditions.

Pauline emphasised that

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 the BHAS Bowling Club, Halley St, Port Pirie.

- For further details, contact group coordinator Allan Manfield on 08 8632 1324.

while there is no shortage of clients, volunteers are eagerly sought.

Commitment from volunteers is determined by how much time each individual can supply. If all they can spare is one hour a month to be a Telecross volunteer, then that is all that will be asked of them.

Telecross REDi volunteers are only required during a heat wave.

Port Pirie Telecross volunteers make their calls from the Red Cross office, whereas volunteers in outlying areas make theirs from the local hospital.

Barossa Prostate Cancer Support Group

Supporting each other - when it matters

THE past month has been a very interesting time for the Barossa Valley Prostate Cancer Support Group, with the members quietly supporting each other as a few have received challenging medical test results that are a bit scary. It has been great to see people visiting, ringing and spending time together, helping each other and their partners through these difficult periods, bringing hope and support to each other. Such unity underlines the true value of belonging to a support group, and demonstrates the level of help that we can all provide to each other. Our thanks go to everyone for pitching in through this difficult time.

COMING EVENT

MAY 17 MEETING

- The Barossa Support Group will next be meeting at the home of group member Robert Reimann, at 29 George St, Greenock, from 2pm to 4pm on Tuesday May 17.
- Please contact group coordinator Don Piro for further information on 8562 3359 or 0419 863 124.

Alice Springs Prostate Cancer Support Group

The power of positive thinking

The story of how a young man of 42 coped after being diagnosed with advanced prostate cancer, as Murray Neck reports.

DEREK Hollingsworth attended his first Alice Springs Prostate Cancer Support Group meeting in February, having arrived from Brisbane with wife Vanita and one-year-old daughter. He was half way through a two-year engineering contract, loved the town, was enjoying his new challenge and felt that life was good – until last December, when a Brisbane urologist informed him that he had advanced prostate cancer and his life expectancy was 12 months.

This devastating news brought with it side effects including sleepless nights, mild depression, lethargy and weight loss as he slowly contemplated a bleak future.

Derek was due to return to Brisbane the following week and attended the Alice Springs support group's open forum meeting on the suggestion of a friend.

Other members spoke of their prostate cancer journey and

generally agreed that Derek should seek a second opinion.

Prior to his diagnosis, Derek had visited a local GP for a check-up after suddenly experiencing urinary problems and slight weight loss. This prompted the urologist's referral. Derek had known nothing about the disease and only just learned that his father had been diagnosed with prostate cancer but had kept his condition a secret from family and friends for a considerable time.

At our recent March support group meeting, Derek told us about his return visit to Brisbane, where he had undergone a radical prostatectomy. He said that the encouragement given to him by the support group members had lifted his spirits and prompted him to get a second opinion, from which a very astute female urologist performed more detailed tests.

Derek's PSA reading was 41 and the Gleason score 10.

New scans showed that what the first urologist mistakenly diagnosed as bone tumours – there were five – were old bone fractures. Derek had played both Australian Rules and Gaelic football, and by all accounts, quite vigorously!

The prostatectomy operation was prolonged as the urologist said Derek's prostate had grown abnormally large and he also had two lymph nodes removed.

Derek said his new PSA reading was 3.2 with the possibility that it may keep falling. He praised the guidance given to him by a Brisbane naturopath, whose dietary advice was to exclude red meats, fried foods, takeaways, sugar and alcohol, and to include fruit and vegetables juices and salads.

Derek is adamant that his earlier reading about prostate cancer on the Internet was both confusing, misleading and a curse. His recommendation to support groups is to encourage

COMING EVENTS

MAY MEETING:

The Alice Springs Prostate Cancer Support Group will meet on Thursday May 12 from 6.30pm to 8pm in the conference room of General Practice Network NT, Skinner St, Alice Springs.

the medical profession to refer men with prostate cancer to join a prostate cancer support group.

He now has a new lease on life and feels his recovery is beyond expectation. His grateful thanks go to all who stood by him and contributed to his positive future. We have learned so much from this man and have certainly enjoyed listening to his lilting Irish brogue.

Throughout the whole stressful ordeal, Derek's wife Vanita was a tower of strength. They may have shed many tears together but can now enjoy each other's smiles.

Prosper Darwin Prostate Cancer Support Group

Support group registers a significant first for women

Inviting a woman to chair a prostate cancer support group meeting signifies an important step forward, as Prosper Darwin group secretary Graeme Tierney reports.

ANNETTE Weir, the wife of one of our long time members, chaired the Darwin Prostate Cancer Support Group's monthly meeting in April, and we think this may be a first – having the wife of a member chair a meeting.

We had 12 people at our meeting, which is about normal for Darwin, but this included a visiting couple from Gympie – Graeme (Crikey) and wife Cynthia, who are caravanning around Australia and endeavour to attend many local support group meetings. It was great to chat with them about other support groups they have visited.

WHAT WE DO

IN ADDITION to hosting monthly meetings, the Darwin support group also publishes a local monthly newsletter, printed and posted by one of our local MPs. This newsletter usually includes updates on members, snippets of information, some jokes and the minutes of our last meeting, with a reminder of our next meeting.

Everyone and anyone is invited to come to our meetings. Most who attend are prostate cancer survivors but there are also wives and friends – and we regularly have men attend who have recently been diagnosed with prostate cancer and are looking for information on treatments.



Darwin support group members enjoying good cheer at their April meeting (front row, from left): Ray Weir, Erina Ellis and Albert Goodrich. Back row (from left): Cynthia Bright, Annette Weir, Alan Groves, Peter Ellis, Pat Williams, Allan McEwen, Graeme Tierney and Graeme (Crikey) Bright.

COMING EVENT
The Prosper Darwin support group meets on the second Monday of each month, at the Harbour Room, Christ Church Cathedral, corner of Smith St and the Esplanade, Darwin, at 7.30pm.

Our meetings are very informal, we try to have a guest speaker every second month, maybe an informative video at other times, and always conclude with a cuppa and general discussion on any queries or questions that anyone may have.

RECOGNISING KEITH

KEITH and Pat Williams are on leave this month. Keith formed the Darwin Prostate Support Group in 1998 and has always been our most active member. He remains the group's convenor, chairs meetings, invites and arranges special guest speakers, does



Keith Williams

a monthly talk on local radio and follows up any support queries. We honestly do not know what we would do without him at the helm.

It takes great time and

dedication to be involved in any community group. All too often, it's easy to get overawed and consumed with everyday life and family commitments, so I give great credit to people who manage to fit in a heavy volunteer commitment for groups such as ours. My relatively small role for the group still demands considerable time – and we honestly do not know how Keith has carried this load for all these years.

On behalf of all our members, we truly appreciate Keith's enduring dedication for the promotion of and success of the Darwin support group.

The Darwin group's mission for 2011 needs the assistance of all members to help Keith reduce his workload. If each member takes on a small task or two, this will make our group more cohesive and give Keith a bit of a breather.

The weather and life in Darwin is now heading for the best part of the year; the rain seems to have finally stopped (we received a record amount in my suburb, with just over three metres for the year to date), the Mindil Beach Markets have commenced, the barramundi are on the bite and, of course, the influx of tourists commences. Darwin and the Northern Territory certainly put their best foot forward for the next six months or so, so we expect to see even more visitors coming our way.

Mitcham Prostate Cancer Support Group

Attracting record numbers

If a support group meets in the mid-year holiday season, can it still expect a big turnout? Mitcham group joint-chairman Roland Harris reports on a most pleasing outcome.

AN extended holiday break over Easter proved no barrier to a record attendance at the Mitcham support group's April meeting – largely due to having a top urologist as guest speaker and his presence being well promoted.

This record number of 55 members is even more amazing because some regulars were absent due to the five-day Easter/Anzac Day break and continuing school holidays.

It was all due to the Power of One – Dr Peter Sutherland, the head urologist and leader of the robotic prostatectomy program based at the Royal Adelaide Hospital, and our guest speaker for the meeting.

General business at the meeting covered correspondence from Graeme to local state MP Martin Hamilton-Smith, who then asked Minister for Health John Hill to fund the purchase



Dr Peter Sutherland

of a new robotic machine for the Royal Adelaide Hospital.

Dr Sutherland told us that the existing 6.5-year-old analogue Da Vinci machine is not worn out, but outdated. The new generation SI digital machines offer superior imagery and control. Alas, it's not fixable with a set-top box!

A brief segment of the classic 1947 Danny Kaye movie *The Secret Life of Walter*

MAY MEETING

The Mitcham support group's next meeting will be held on Thursday May 26. The group meets on the fourth Thursday of each month at the Colonel Light Gardens RSL Club, 4 Prince George Parade, Colonel Light Gardens, from 7pm to 8.45pm. Guest speaker will be a representative from the RAA.

• For more information on events and group activities, visit the Mitcham Group's dedicated website at www.psamitcham.org

Mitty showed heroic surgery performed by Dr Mitty as an introduction to Dr Sutherland. His presentation emphasised that the success of modern surgery, including robotic surgery, depends on teamwork as much as technology.

An excellent account of Dr Sutherland's work can be found in the April edition of *Prostate Supporter*, written by Bryan Hearn of McLaren Districts Group.

Another article titled "Robodoc" in the SA-Weekend section of *The Advertiser* on 22/1/11 gives a patient's perspective.

Dr Sutherland's talk concluded with many good questions and answers. Our joint-chairman Terry thanked him with two bottles of McLaren Vale's finest, and we adjourned for supper to conclude a memorable evening.

Port Augusta Prostate Cancer Support Group

Bid for new support group commences

ON March 31, Port Augusta launched its bid for a new prostate cancer support group – the result of a very successful public meeting held at the Port Augusta Golf Club in December.

Central Australia Councilors Malcolm Ellis and Bryan Hearn attended with their wives for the group's inaugural meeting at

the Flinders Hotel, though sadly only four members of the public attended with local convener Paul Smith. A rather large event was held in Port Augusta that same evening and many people were in attendance there.

Despite the low numbers, the presentation was held and at the conclusion of the evening it was

resolved that a PCFA-affiliated group should be formed, as Paul believes that many people who had been at the initial public meeting are still interested in forming a support group.

A PCFA affiliation form was provided to those hoping to set up the group, but as yet no paperwork had been submitted.

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

Murray Bridge Prostate Cancer Support Group

Discovering readily available help for continence problems

There's more to maintaining and aiding healthy continence than most people would consider, as Murray Bridge group secretary Richard Parsons reports.

IF you suffer from incontinence, you are not alone. This complaint affects no less than 3.8 million Australians across all ages, genders, financial and social standings, according to Rosalie Donhardt of SA Continence Research Centre. She addressed the Murray Bridge support group, talking about incontinence aids at our April meeting.

The importance of this subject was highlighted in the notice of this meeting sent to our members encouraging partners to attend. The response was pleasing, as several new faces appeared at the meeting.

HELP IS AVAILABLE

ROSALIE started her talk by advising that a specialist continence nurse, Amanda Mowbay, is available in the Adelaide Hills Health Centre. Assistance can also be accessed at the SA Continence Resource Centre, 11 Blacks Rd, Gilles Plains (phone 1300 885 886 or 08 8266 5260). This centre provides a free advisory and information service, including details about available products – but it is not a clinical service.

Another free service is provided by Continence Foundation Australia, which operates a helpline on 1800 3300 66 from 8am to 8pm, Monday to Friday. Matters related to bladder and bowel control, and the location of

COMING EVENT

- The Murray Bridge support group conducts monthly meetings at 7.30pm on the third Wednesday of each month, at Our Wellbeing Place, 108 Swanport Rd, Murray Bridge.
- The next group meeting on WEDNESDAY MAY 18 will feature a talk and general discussion. As usual, the evening will finish with tea, coffee, biscuits – and some friendly chat.
- Please note that the Murray Bridge support group now has its own postal address. Please send correspondence to: PO Box 880, MURRAY BRIDGE, SA, 5253.

Whyalla Support Group

The new Whyalla Support group meets on the first Tuesday of the month. Contact Terry O'Brien (08 8645 1310) or Stan Oates (08 8644 0591) for details.

public toilets throughout Australia are covered. Literature is available on skin care, strengthening pelvic muscles, constipation, diarrhoea and foods that cause flatulence.

INCONTINENCE AIDS

THERE are over 400 types of products displayed at the Independence Centre at Gilles Plains, including disposable pads, pants, absorbent sheets and chair pads. Reusable products are washable but it is important to note that they take a long time to dry. Other items include waterproof mattress protection, toileting

equipment, adapted clothing, odour control products and moistened wipes to counteract the effect on skin of acid from urine and bowel movement.

SOME SERIOUS EFFECTS

ROSALIE pointed out the effects caused by incontinence, including social costs, financial burdens, serious infections and loss of self-esteem. She stressed the need for sufferers to seek help to manage the problems created by their condition.

GOOD HABIT GUIDELINES

SHE set out some guidelines for maintaining a healthy state

of continence by developing good bladder and bowel habits. These include:

- Eat well: Adopt a healthy diet to prevent constipation and diarrhoea.
- Drink well: At least six to eight cups of fluid (1.5 litres water) in summer. Limit intake of caffeine, alcohol and soft drinks. A healthy urine colour is pale straw.
- Exercise regularly.
- Practice good toilet habits. Only urinate when feeling the need to do so – not just in case. Respond promptly to urges to open bowels and take time to complete the job.
- Ensure pelvic floor muscles are strong. Help may be needed from physiotherapy and/or continence nurse.

FUNDING SCHEMES

- Department of Veterans Affairs – Rehabilitation Appliances Program (RAP).
- Continence Aids Payments Scheme (CAPS).

Rosalie had a range of pamphlets for members to pick up, and received a warm round of applause from members for her talk.

She was presented with a posy of flowers and a certificate of appreciation – and in light of her comments about limiting the intake of alcohol, it was fortunate that we didn't give her a bottle of wine.

A MAJOR PROSTATE CANCER AWARENESS OPPORTUNITY IN ADELAIDE

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An extravagant gala cancer fundraiser we have ALL been invited to attend

THE Prostate Cancer Foundation in SA is very busy with fundraisers at the moment, and here is an opportunity for us all to participate.

We are all invited to a unique event – a cocktail party launching a much larger event for 2012, marking the anniversary of the sinking of the Titanic. The cocktail party will be held in the Adelaide Arcade from 6pm on Tuesday May 31, and tickets are available for \$35 from www.1912theevent.com.au or phone 1300 664462, or 08 8232 9102 to make a booking.

Breast cancer is also a beneficiary of this fundraising venture, so it would be good to get as many people along as possible to also wave the prostate cancer flag and bring this disease into the forefront of people's minds.

In addition to the cocktail function, a promotional and fundraising stand promoting the 2012 event will be open in Adelaide Arcade from Monday May 30 to Friday June 5, between 9am and 5pm – and also at the cocktail function on Tuesday May 31, from 6pm to 8pm.

Karyn Foster needs assistance to man this stand, so it is suggested that each local support group take a day and establish a roster with their members.

The breast cancer people will again be present at the promotional and fundraising stand, so it is imperative that PCFA SA also has a strong presence. Can a representative from each group please contact Karyn on karynfoster@adam.com.au to secure their day.

Research findings and news items from around the world

Links found between bone growth and prostate cancer

SIGNIFICANT links have been discovered between a man's bones and his prostate risk by urologist Dr Stacey Loeb at Johns Hopkins University School of Medicine in Baltimore. She probed into studies suggesting that bone density is associated with prostate cancer.

Using the Baltimore Longitudinal Study of Ageing, started in 1958 and one of the world's longest studies of following a group of people into old, Dr Loeb examined the bone density measurement of men in the 1970s and 1980s to observe the incidence of prostate cancer in these men over time.

"We found that bone density

does decline in men with age - yet for men that later developed prostate cancer, they had less of a decline with age," says Dr Loeb.

"It suggests there are some common factors involved with bone growth and maintenance, and with prostate carcinogenesis.

"It could be a sign of a common factor like male hormones, though another interesting recent study shows that men with higher serum calcium levels had a higher risk of fatal prostate cancer, so there could be some involvement of the calcium parathyroid hormone access.

"Local growth factors in the micro environment could allow for the growth of prostate cancer as well as the maintenance of bone.

"It's very provocative that we have demonstrated this link between bone density measurements 20 years prior to diagnosis with prostate cancer, and that high risk prostate cancer had the least decline in bone density with age.

"This study really sets the stage for more work to define the factors that allow for prostate carcinogenesis."

• Source: ABC Health Report, 14/3/11