



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

www.prostate.org.au

JUNE - JULY 2009

National chain helps to raise PC awareness

Prostate cancer awareness will be the focus of national attention in September – and Bunnings stores will play a major part, reports PCFA's Paul Redman.

B UNNINGS stores across Australia have announced a significant partnership with the Prostate Cancer Foundation of Australia for Blue September – the official prostate cancer awareness month.

Bunnings stores are offering to run simultaneous events in all stores to benefit awareness of Prostate Cancer and to help raise funds for the PCFA. All proceeds from these endeavours will go to each local support group that works with the local Bunnings store – or even several stores in some cases.

The object is for support groups and their local stores to coordinate an activity of their choice in the weeks leading up to Fathers Day on September 7, 2009.

This is the first time this process has occurred involving the 84 prostate cancer support groups across Australia and local communities.

Details of this partnership have been forwarded to all support groups in two detailed documents: the eight-page brochure *Lend a Hand With Bunnings To Help* Raise Awareness and Funds for Your Prostate Cancer Support Group (pictured at right), and the supporting 13-page document Fun Ways to Fundraise, outlining different ways that support groups and stores can work together to achieve fundraising objectives.

The benefit of having PCFA support groups participating with Bunnings at a local level will ensure that fundraising initiatives have a local purpose, with funds being dispersed directly into the local communities and benefitting local service and support activities.

It is also hoped that the individual fundraising initiatives will engage with media at a community level to highlight the support from Bunnings stores across Australia – and spread the crucial message about prostate cancer awareness.

This partnership is a significant development on the relationship between Bunnings and the PCFA that started in 2008, when the hardware store chain participated in raising valuable funds for prostate cancer research.

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

Prostate Cancer Foundation of Australia

LEND A HAND WITH BUNNINGS TO HELP RAISE AVVARENESS AND FUNDS FOR YOUR PROSTATE CANCER SUPPORT GROUP

in brief...

WE MOURN the passing of exceptional prostate cancer campaigner and supporter Trevor Hunt, who died on June 21. A detailed obituary is featured on Page 12, and a summary of his pioneer work with the Action Group is on Page 2 of this edition.

CONTRIBUTIONS of stories and images from all Support Group members to the Prostate Supporter newsletters are welcome; contact Foster Hill PR and Marketing by phoning (08) 8231 3555 or email items and images to **prostate-news@fosterhill.com.au**

www.pcagsa.org.au

Prostate Cancer Action Group

COMING EVENTS

AUGUST 11 **MEETING:**

The Action Group will next meet in the upstairs meeting room of the Cancer Council SA building, 202 Greenhill Rd. Eastwood at 5.30pm on Tuesday August 11. At present, entry is through the front door on Greenhill Road.

• For more information about the Action Group and its activities, visit the South Australian Prostate Cancer Action Group's dedicated website, with detailed archives containing its newsletters. at http:// www.pcagsa.org.au

Trevor's legacy at Action Group core

While Trevor Hunt is acknowledged in an extensive obituary in this newsletter, his achievements with the Action Group are worth special mention, as Dean Wall reports.

REVOR Hunt was until quite recently a very active and crucial member of the Prostate Cancer Action Group, until his deteriorating health forced him to step back.

He was among the group's first chairmen and it was under his leadership that the PCAG became an incorporated body, with Trevor playing a leading part in formulating our constitution and strategic objectives.

the Action Group, Trevor undertook hundreds of hours seeking out scientific research articles relevant to prostate issues, and for several years he edited and circulated the Action Group's newsletter, until the advent of the *Prostate* Supporter.

He was also involved Statewide in the organisation and presentation of prostate cancer awareness events, speaking as a survivor at many of them.

He was a foundation member

of the PCFA Support and Advocacy Committee (SAC), and represented SA on that body for an entire term. His work was recognised with the receipt of the Max Gardiner award at the National conference last November.

Unfortunately, at that time his health had degenerated to the point that he could not attend to receive the award personally, but it was received on his behalf by Jeff Roberts, and presented to him locally.

Throughout his time with

Port Pirie Prostate Cancer Support Group

COMING **EVENTS**

AUGUST 4 MEETING:

The Port Pirie Prostate Cancer Action Group meets on the first Tuesday of each month.

On August 4, the group will be meeting at the BHAS Bowling Club, Halley St, Port Pirie, from 7.30pm.

Guest speaker Alison Carhart will be making a presentation on the Patient Assistance Transport Scheme.

Strong interest in men's health update

SA Health's Port Pirie cancer support coordinator Nicola Champion reports on the Port Pirie group's recent activities.

MEN S Health Update A presented by urologist Dr Richard Wells at the BHAS bowling club in Port Pirie during June attracted a very receptive audience of 25 community members. This event was an initiative of the Port Pirie Prostate Cancer Support Group and took the place of one of the group s regular monthly meetings.

Previous guest speakers that have addressed the support group this year included a Mental Health Nurse from community health to speak about the affects and

treatments for depression, and a presentation by the local funeral director to speak about funerals.

Sadly the group lost two valued members in as many months, and our condolences are extended to their families and friends.

Beyond the regular meetings, support group members and their partners recently enjoyed a social outing to the Pacific Hydro wind farm open day at Clements Gap, stopping for lunch at Port Broughton.

The support group hopes to



At the most recent Port **Pirie support group** meeting were (from left) Daryl Martin, Dr Richard Wells and Ricky Connor.

further raise prostate cancer awareness in Port Pirie by running a Father's Day raffle, and has submitted an application to PCFA for approval.

Prostate Cancer Support and Awareness: ADELAIDE GROUP

COMING EVENTS

JULY 20 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. Guest speaker will be Morgan Atkinson, to whom a Churchill **Fellowship** was awarded in 2008. to explore exercise rehabilitation interventions for cancer patients.

AUGUST 20:

A light-hearted, humorous meeting with some bush poetry from Jill Wherry and, hopefully, Gordon Weston (who is yet to be confirmed).

• For more information about coming activities, visit the Adelaide Support Group's dedicated website at www. psaadelaide.org or contact lan Fisk by phoning 8296 3350, or send email to ian@ianfisk.org

Highlighting how to counter incontinence

The delicate subject of incontinence problems affects more Australians than we would expect, as Ian Fisk reports.

NCONTINENCE is а widespread problem in Australia, with a report several years ago stating that 3.8 million people have various levels of continence issues. For this reason, Rosalie Donhardt, continence nurse adviser with Disability SA (also an SA committee member of the Continence Foundation of Australia), spoke to the Adelaide support group's June meeting about continence issues for men and women.

The SA Continence Resource Centre – a continence information and advisory service located at Disability SA's Independent Living Centre – is affiliated with the Continence Foundation of Australia, the national peak body for continence management promotion and advocacy, and funded by the Department for Families and Communities.

Rosalie spoke about the Continence Resource Centre providing a free, unbiased information service about continence management, research information, project support, continence literature and providing highly qualified speakers giving educational talks and lectures on every aspect of continence problems.

About 300 products are displayed at their offices in Gilles Plains, and can also be viewed on the Independent Living Centre website (through the state department for families and communities, at www.dfc. sa.gov.au), with information



Rosalie Donhardt

about where the products are available.

Continence Awareness Week is held each August – with a continence education day at Berri planned for Friday August 7 this year.

Two years ago at a similar event in Mt Gambier, an Adelaide man spoke on his issues with continence after his radical prostatectomy, and that he eventually had an artificial urinary sphincter fitted. The audience of surgeons, urologists and other health professionals were fascinated by his presentation.

Good bladder and bowel habits were discussed, along with healthy eating – especially a diet including plenty of fibre and fluid. Limiting caffeine and alcohol intake also can help problems. The urine colour chart was also mentioned: strawcoloured urine is recommended. If possible, wait until the bladder is full before going to the toilet.

Putting off emptying the bowel is not recommended as this may

lead to constipation. And be sure to take time with both functions.

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The need to have strong pelvic floor muscles was discussed. It is very important to have them well toned and regular exercises are recommended. Diagrams were shown as part of the PowerPoint presentation, though it is advisable to see a health professional for exercise guidance.

Rosalie displayed a great variety of products and explained their suitable uses: disposable and reusable pads of various sizes and capacities, uridomes and urinary drainage bags, bedding protectors and car seat protection.

Several different funding schemes exist for people with ongoing continence problems, including the Department of Veterans' Affairs - Rehabilitation Appliance Program (RAP), Continence Aids Assistance Scheme (CAAS) and the Department of Families and Communities (DFC) Equipment Program. Check their websites for more information.

The mission of the Continence Foundation of Australia is to improve the quality of life for people with bladder and bowl problems. They have a free national help line on 1800 33 00 66 that provides a confidential service from trained continence nurses to about 20,000 callers each year. Other resources provided include the National Public Toilet Map (an internet website) plus 17 fact sheets.

City of Onkaparinga Prostate Cancer Support Group

COMING EVENTS

JULY 1 MEETING:

The Support Group met at 6.30pm on July 1 in the boardroom at Noarlunga Community Hospital, Alexander Kelly Drive, Noarlunga. PCFA Support Group Services Manager Paul Redman attended to give a presentation about the PCFA.

AUGUST MEETING:

The Support Group will meet at 6.30pm on August 5 in the boardroom at Noarlunga Community Hospital, Alexander Kelly Drive, Noarlunga to condust a general discussion on health and cancer issues in a Roud Robin format.

• For more information about coming events and archives cataloguing previous events and local group newsletters, visit the City of Onkaparinga Support Group's dedicated website at www.pcsog.org

• Special thanks are extended to the City of Onkaparinga Support Group sponsors:Southern Primary Health Woodcroft, Port Noarlunga-Christies Beach RSL Sub Branch, toneraction Christies Beach, The Original Open Market and to the City of Onkaparinga Council.

Social barbecue adds warmth to winter

The Onkaparinga group's mid-year barbecue yet again proved successful for group members, reports John Shields.

THE City of Onkaparinga

Prostate Cancer Support Group s successful mid-year barbecue was recounted to a large group of visitors at the group s June meeting, including City of Onkaparinga Mayor Lorraine Rosenberg, MP Amanda Rishworth, local Lions Club President Mick and Phyllis Allison and Past President Wolf and Merle Hirsch, Rhona Stanley, Ruth Dohnt, Chene` Kiley and Brian and Rhonda`s daughter and their grandson Jasper.

Held on the Sunday of the Queen's Birthday weekend in June, the mid-year barbecue was a very pleasant gathering – even if the weather was particularly wintry.

This still did not stop us from having another very pleasing get together and enjoying each other s company, along with some very nice food.

However, many of us found that getting to and from this excellent venue at the Willunga Lions sale yard was especially difficult due to the Sea & Vines Festival being held through the region on the same day.

We therefore learned some valuable lessons this year: In future, we will make sure that we do not have our barbecue on a long weekend, or when there are wine festivities planned in McLaren Vale and the roads are congested with visitors to the region as a consequence.

UNFORTUNATE END TO SUPPORT

WE are disappointed to report that the tremendous work done by Dolph Young with the Cancer Support Network Onkaparinga is coming to an end. Dolph has done a great job, and his smiling face will be greatly missed – especially as he has given 100 per cent in his efforts to achieve the best results for Cancer Support in the City of Onkaparinga.

Congratulations must also go to Ann Young, Juli Ferguson and all who have worked so tirelessly with Dolph to ensure that every member of our community affected by cancer has enjoyed the opportunity to attend a local Support Group and talk with others who are in a similar situation to themselves. This is such a very important part of everyone's cancer journey – and why this wonderful, necessary service to our community cannot be continued is hard to understand.

INFORMATION DAYS

AN INFORMATION DAY will be held at Woodcroft Shopping Centre later this year, possibly in September, and the support group will have a look possibly also having a presence at Aldinga and The Hub Shopping Centre at Aberfoyle Park, to help spread the word on prostate cancer awareness.

TELECONFERENCE

THE NEXT Central Australia Chapter Council Executive Teleconference is on July 2 at 10.30am. If you have anything relating to Prostate Cancer Support that you believe needs to be discussed, please contact either John on 8382 6671 (jshields@aandr.com. au) or Malcolm on 8326 5588 (malell@iinet.net.au). The next Central Australia Chapter Council meeting is being held in Alice Springs on Thursday July 16 and some items on the agenda are: Listing loan DVD's available from the PCFA, Central Australia Chapter logo, proposed new PCFA guidelines, template for group reports, Paskeville Awareness Days arrangements.

AN APPLE A DAY

NOTICEABLE on the Internet recently has been a big advertisement telling us about the importance of eating an apple a day to help safeguard us from certain cancers. How many of us actually do eat an apple a day?

Mitcham Prostate Cancer Support Group

Raising a voice for those with cancer

Inspirational support group Cancer Voices SA is encouraging patients and supporters to speak out, as Jeff Roberts reports.

A SHLEIGH Moore, chair of Cancer Voices SA, is a cancer survivor and a committed consumer advocate who addressed the Mitcham group's June meeting.

With a wide ranging professionalbackgroundwhich included a five-year term at Safework SA handling the state's Occupational Health & Safety and Industrial relations, Ashleigh was diagnosed with stage 4 head and neck cancer in 2005. With a wife and two-year-old daughter and limited assistance, Ashleigh coordinated his own care.

His treatments included surgery, radiation and chemotherapy. At one stage he lost 20kg in weight. A keen bike rider, on one occasion after finishing a day of treatment, he went home and rode himself to state of exhaustion. He also tried various types of complementary therapy but not alternative methods.

Ashleigh told of the affect that his cancer had on family relationships and how this can often be a problem – particularly to younger patients.

Following treatment, Ashleigh's commitment to represent the interests, needs and rights of consumers led to his appointment as the chair of Cancer Voices SA, a body launched on November 13, 2007, that works through Cancer Voices Australia to provide a national network of Cancer Voices. He also holds advisory positions on a range of groups, including the SA Safety & Quality in Health Care Council, Health Connect SA, Cancer Voices Australia, Cancer Australia and the Statewide Cancer Network.

Ashleigh drew attention to a brochure detailing the function of Cancer Voices SA, an independent advocacy group that represent the views of South Australians whose lives have been affected by cancer. Its aims are to:

• Better represent the views of those affected by cancer.

• Promote these perspectives to health professionals, government and the public.

• Ensure patients and supporters are receiving the best possible information, treatment and care.

• Work to increase funding for prevention, detection, research and improved treatments.

Key objectives are:

• Encouraging those with experience of cancer to contribute to all levels of decision making about the disease.

• Ensuring cancer patients, carers and supporters receive the best possible information and world's best practice treatment, care and support. • Ensuring cancer patients, their carers and supporters are well represented to health professionals, government and the public.

• Ensuring those affected by cancer are treated equally regardless of their geographical location, social or economic status, age, ethnicity, gender, stage or type of cancer.

Cancer Voices SA has been able to develop quite a high profile and attract media attention on various health issues. Ashleigh showed a slide of newspaper cuttings on some "health bungles" which Cancer Voices SA has been able to pursue. One significant example was the 2008 radiotherapy under-dosing incident at the Royal Adelaide Hospital. Ashleigh was one patient that was under-dosed.

He also showed a DVD on the 2009 Tour Down Under and Cancer Voices' involvement with champion rider and cancer advocate Lance Armstrong (despite him being very difficult to get close to).

Ashleigh arranged a group from Cancer Voices SA and others to participate in the Mutual Community Challenge Ride. Initially he had five interested riders but by race time this had increased to 123, and he is aiming much higher participation numbers for 2010. He gave examples

COMING EVENTS

JULY 23 MEETING

The next Mitcham Support Group meeting will be held on Thursday July 23, in the Colonel Light **Gardens RSL club** rooms at 4 Prince George Parade, **Colonel Light** Gardens, from 7pm. **Guest speaker will** be PCFA Support **Group Services Manager Paul** Redman, who will give an update on **PCFA** activities of and lead a general discussion on support groups.

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

of the great determination of some riders to compete, despite suffering from various degrees of cancer and other health problems.

During the Tour Down Under Cancer Voices was present when Lance Armstrong launched the Global Cancer Initiative. This cancer initiative is being promoted by the Lance Armstrong Foundation.

Ashleigh said there are currently over 200 members in Cancer Voices SA and many more required. For anyone interested, more information is available from the website at www.cancervoicessa.org.au **Barossa and Gawler Prostate Cancer Support Group**

Bold new plan to combine cancer patient support in the Barossa

Attempts will be made to expand the reach and effectiveness of cancer support networks in the Barossa and Gawler areas, as Alan Hall reports.

HE June meeting of the Barossa/Gawler prostate cancer support group considered a proposal for a joint endeavour with the Barossa Area Fundraisers for Cancer (BAFFC). The primary role of BAFFC has been to raise funds to support cancer survivors, but it also seeks to educate, promote awareness and provide services for anybody with cancer.

We see this as a valuable opportunity to foster support for cancer survivors and enhance their welfare by linking the two groups in a cooperative enterprise.

As a basis for an alliance between the groups, a draft

COMING EVENTS

• As a lot of time and energy is being devoted to the survey and public forum, no arrangements have been made yet for Barossa/Gawler group meetings in either July or August. The next scheduled event is the public forum being planned for September.

"Cancer Needs Survey" has been prepared, with input also from Barossa Health.

It is planned to distribute the survey to as many households as possible in the Barossa and adjacent regions, and to accompany the survey launch with a major publicity campaign through the local media.

The collated survey results

will then be the focus for a public forum early in September, where there will be a guest speaker and a panel comprising GPs, cancer survivors and a representative from Barossa Health to address the information that has been derived from the survey, while also outlining a response to these findings.

It is anticipated that the

publicity generated through media exposure and the subsequent public forum will result in an influx of new members to the prostate cancer support group – some of whom will be prostate cancer survivors but also included will be survivors with other forms of cancer with valuable stories and experiences to share.

Our belief is that there are enough common issues to sustain such an expanded support group, and that the existing prostate cancer support group will be strengthened and energised by opening up its boundaries to include more people.

Research findings and news items from around the world Prostate cancer discovered in men who test negative

UP to 40 per cent of men with prostate cancer may not even know they have it, according to a Prostate Cancer Foundation of Chicago research study (published in *Urology* medical journal) that revealed the standard office biopsy procedure often isn't enough to properly detect prostate cancer.

Researchers used an advanced biopsy technique called stereotactic transperineal prostate biopsy (STPB). This was performed on patients with persistent elevated PSA levels who previously had at least one negative office biopsy. All patients had received transrectal prostate biopsies (TRPB), administered by a urologist. "Men who have negative transrectal biopsies and continue to have elevated PSA levels should consider STPB because 40 per cent will harbor malignancy," says Michelle Braccioforte, director of research and education for the Prostate Cancer Foundation of Chicago. "Our level of confidence is greatly enhanced with regards to the presence or absence of cancer, and more specifically, the exact location of the cancer within the prostate."

STPB is performed by taking a median of 40 samples of the prostate through the perineum while the patient is under general anesthesia. Performed as an outpatient procedure, it allows more comprehensive sampling, compared to the transrectal method, which takes fewer samples through the rectum. In addition, by taking more samples during STPB, the exact location of the cancer can be pinpointed.

Between April 2004 and January 2008, 747 patients with high PSA levels were studied. All patients had been tested using TRPB at least once and all results had been negative. All patients received the STPB. Biopsy results identified the presence of cancer in 291 (39 per cent) of the patients.

• Source: The Prostate Cancer Foundation of Chicago.

McLaren Districts Prostate Cancer Support Group

The raw nutritional value of the foods that we are eating

Trying to achieve balance between a good diet and using supplements is crucial to ensure good health and combat illness, as Bryan Hearn reports.

C ONSULTING dietician Gizelle Wilson presented her second address to the McLaren Districts Prostate Cancer Support Group at its June meeting, offering very interesting information on dietary supplements to a meeting room filled with guests, including McLaren Vale Hospital CEO Maria Duncan and Prostate Cancer PR consultant Karyn Foster.

The first section of Gizelle s presentation focused on the use of supplements. During the 1990s only 15 per cent of the population used supplements, though this has now increased to about 50 per cent.

Anybody eating a good variety of food in moderation should not need to take supplements, however some health conditions can be improved through using supplements.

Much discussion centered on the use of fish oil, which comes in many varieties, including liquid or capsules. If an individual is not eating a diet containing any fish then supplements need to be taken daily. Fish oil contains Omega 3 fats and the required dose would be 6 to 8 capsules per day or 10mls of liquid. Such supplements are good for the heart, blood pressure and arthritis. Daily nutritional requirements could also be met by taking two tablespoons of flaxseed and one piece of salmon.

COMING EVENT THURSDAY JULY 23

The McLaren Districts group will next meet in the administration building at the rear of the McLaren Vale & Districts War Memorial Hospital, Aldersey St, McLaren Vale, at 7pm on Thursday, July 23. Guest speaker will be Yvonne Howlett, a local hospital nurse who will speak about the benefits of counseling.

• Contact group president Bryan Hearn on 8323 7924 or 0410 539 274, to confirm your attendance.

Calcium supplements should be taken by both men and women over 55 years of age, to help with bone health. Three serves of dairy produce a day would be sufficient to meet these needs. (one serve = 250mls of milk, or 40g cheese, or 200g yoghurt).

Vitamin D supplements are growing in popularity as a result of people avoiding direct sunlight to help reduce skin cancer dangers. Margarine and eggs are a good source of vitamin D, however consuming more than four eggs daily will increase your cholesterol level.

Gizelle presented a number of grocery products from her usual shopping list, describing their contents and relevant nutritional details:

• Anlene Milk contains no fat, is good for bone health and contains lots of vitamins. It is very concentrated and two glasses each day would satisfy a person s calcium and Vitamin D needs.

• Whole grain pasta contains

three times the amount of fibre than ordinary pasta. One cup each day can provide half the daily fibre requirements. It s very filling food and good for diabetics.

• **Kraft single cheese slices** provide additional calcium and Vitamin D to a diet. One slice equates to 10 per cent of daily needs.

• UP wholemeal bread contains Omega 3 fats (fish oil) and four slices provide half the daily needs. Wholemeal bread is much the same as wholegrain bread and selecting between them is a matter of personal choice.

• Elivae Yoghurt contains three live beneficial bacteria, has lots of nutrients and a small amount of fibre equal to about half an apple. Many standard yoghurts contain same cultures.

A **Red Heart Tick** label on any product is a good indicator of a healthy food, meeting very high standards and subject to regular testing, but it should be noted that many good products exist without the tick. Soft cheeses generally have no added calcium and are higher in fat content, while low fat cheeses are not always very tasty. Many low fat goods have lots of sugar in them in an attempt to improve their taste. Foods that are subject to little or no processing are preferable and can be very beneficial to diabetics.

Gizelle explained the contents of the "Nutrient Information Panel" displayed in three columns on all food products, with information based on a "per serve" basis – though we don t always eat produce in single serve portions and need to adjust accordingly. Energy content and fat content are displayed in these columns and each needs to be considered.

It is suggested that a 70kg male needs 8700 kilojoules each day. Energy equates to calories or kilojoules, so the lower the amount the better. Less than 10 grams of fat per 100 grams of food is a moderate intake, while less than 5g is excellent.

The glysemic index, which measures how long it takes for specific foods to break down within the body, was a topic of particular interest. A high GI indicates that food will break down quickly with a resultant rise in the blood sugar level, while a low GI rating will take much longer to break down and is the preferred option.

Payneham Prostate Cancer Support Group

Exciting new US surgery results

Progress has been made in treating prostate cancer which has advanced outside the prostate capsule, as Phil Davis reported to the Payneham support group in June.

MAYO Clinic in the US has announced dramatic results in an advanced prostate trial. Two patients whose prostate cancer had been considered inoperable are now cancer free, thanks in part to an experimental drug therapy used in combination with standardised hormone treatment and radiation therapy.

The men were participating in a clinical trial of an immunotherapeutic agent called MDX-010 or ipilimumab. In two cases, physicians say the approach initiated the death of a majority of cancer cells and caused aggressive tumours that had grown well beyond the prostate into the abdominal areas to shrink dramatically, allowing surgery.

"The goal of the study was to see if we could modestly improve treatment for advanced prostate cancer," says Mayo Clinic urologist and leader of the clinical trial Dr Eugene Kwon. "However, we were startled to see responses that far exceeded any of our expectations."

The patients first received hormone therapy (androgen ablation), then had a single dose of ipilimumab, which builds on the antitumour action of the hormone and causes a much larger immune response, resulting in massive death of the tumour cells. Both men experienced consistent drops in their PSA counts over the following weeks until

Meeting an inspirational cancer spokesman

ASHLEIGH Moore, the dynamic Chair of Cancer Voices South Australia, addressed the Payneham group's June meeting – and also made a presentation at the Mitcham support group's June meeting, with a full report on Page 5 of this edition of *Prostate Supporter.*

SA Cancer Voices represents South Australians whose lives have been affected by cancer, and now has more than 200 members. It is an independent, incorporated, volunteer consumer organisation and has a list of and evidence-based reliable links on their website www. at cancervoicessa.org.au/ website-links.asp

Cancer Voices have links on their website to help you connect with others at http://www.

both were deemed eligible for surgery. Then during surgery came a greater surprise.

"The tumours had shrunk dramatically," says Mayo urologist Michael Blute, who operated on both men. "I had never seen anything like this before. I had a hard time finding the cancer."



During this year's Tour Down Under, Ashleigh Moore (right) met with Lance Armstrong Foundation CEO Doug Ulman.

cancervoicessa.org.au/ connect-with-others. asp

Voices has Cancer consumer cancer representatives on a committees including the SA Safety and **Quality in Health Care** Council, **Statewide Cancer Clinical Network** Committee Steering (at the state level) and Cancer Australia (at the national level).

One patient underwent radiation therapy after surgery and both have resumed their regular lives. Further research is being planned to understand more about the mechanisms of the antibody and how best to use the approach in practice.

• Source: Mayo Clinic Press Release, June 19, 2009.

COMING EVENTS

JULY 21 MEETING: The Payneham Support Group will meet in the Payneham RSL Clubrooms, 360 Payneham Rd, Payneham at 7pm on Tuesday July 21. Guest speaker will be urologist Dr Jehan Titus, talking about erectile dysfunction, treatment options and men's sexual health.

AUGUST 18: Urologist Dr Samantha Pillay will speak about the widespread problem of urinary incontinence.

SEPTEMBER 15: Registered nurse Rosalie Donhardt will speak about good bladder and bowel health, while Colorectal Surgeon Dr Rieger will talk on bowel problems.

OCTOBER 20: Discussion evening facilitated by Kevin O'Shaughnessy.

NOVEMBER 17: Annual general meeting. election of office bearers for 2010, social evening and barbecue.

• For more information, phone Phil Davis (8263 2217 classic100@bigpond. com), Peter Woodrow (8263 5556) or Arthur Seager (8289 4180), or visit the Payneham Support Group's dedicated website at www.psapayneham.org

Murray Bridge Prostate Cancer Support Group

MONTHLY MEETINGS

The new Murray Bridge Prostate Cancer Support Group conducts its mothly meetings at 7.30pm on the first Thursday of each month, at Our Wellbeing Place, 108 Swanport Rd, Murray Bridge. The next meeting is on THURSDAY, AUGUST 6. For further details about the group and its meetings, phone support group chairman Ron Lehmann on (08) 8532 3277.

Light at the end of the tunnel

Responding to a call from Professor Jan Paterson, prostate cancer survivor "Peterdene" anonymously compiled these recollections of his treatment and recovery after prostate surgery.

N June 2004, my PSA was 5.6 so my GP suggested that I see a urologist to check out the problem. I thought nothing of it, as I d never had this brought up before. Dr Peter Sutherland took a blood sample and suggested that the reading of the PSA 5.6 was borderline and asked to check again in six months.

In December, the PSA reading had risen to 7.2 – and Dr Sutherland decided it was time to take action.

He explained all the treatment options and said it was up to me to decide what I wanted to do. I attended meetings and found out the best option was to have radical pinhole surgery under the robot at the RAH.

I thought I had everything in place but didn t realise what was in store for me after the operation, as the road ahead was certainly not easy.

Urologists will tell you about the functions of the operation but the road to recovery is very difficult. Women after breast removal get help from many sources, but I found that men mostly know nothing about such issues as incontinence – though I soon learned.

This is why I put my views together. It s very important to be prepared for the unforeseen – to try meditation, relaxation therapy, learn from a physiotherapist how to exercise the pelvic muscle (exercising before surgery is a must and will help greatly in the days that follow), preventing incontinence, what napkins to use and where to purchase them, and having waterproof bedding for the mattress and a change of night wear during the night.

These are all things that no one informed me about, so now I point them out to others so their life can be a little easier after their operation.

Make sure that your spouse or partner is with you when attending appointments with doctors, so they know first hand what is going on. This is very important as the help you get and understanding from your partner is very satisfying.

Don t try to go it alone – it will be a lonely and very frustrating road to travel.

Find out from your doctor any information on what procedure he is undertaking – via DVDs, books, websites or contacts. Contact Cancer Care for information on meditation and relaxation therapy, as you will need this in times of trouble.

Ensure that you have tight underwear to hold you in place and to use as support (you ll find out what I mean).

Incontinence is the main problem after surgery that will cause embarrassment. Seek out napkins yourself – don t leave it to your partner as if you do have problems, only you can rectify it.

Find a good supplier to hold stock of the product you prefer. At first you will need napkins that hold 350mm of urine, though this will decline over time. Contact a nursing home to see what they use on their clients: nurses are very helpful with such inquiries.

Over time you will need smaller napkins and these can be purchased from a chemist; POISE brand is made for men and women. These will be required over the months after one has started to dry up.

You must accept that you are going back to you childhood and have to start all over again, training yourself in this area, and it will be very frustrating. Discuss these things with your partner, as they do not know what you are going through and tend to laugh.

Exercise is one of the most important things. Walking strengthens the muscles around the bladder, which is a must if you want quick recovery. May I suggest that before surgery, enjoy a good sexual performance, as it will be some months before you can perform with your partner.

Speak openly to nurses and doctors and do not hold anything back as they are trained in this field and can be of great benefit.

You will become very frustrated, so please try to be patient; it will be hard, but use meditation and relaxation methods. Avoid taking the frustration out on your family or partner; explain to them it will be much easier if you to share the ups and downs you come across during recovery.

Last but not least, attend a Prostate Support Group, as people are there just like you with the same problems – and one gets a welcome laugh from time to time.

It is now five years since I undertook the climb up the significant mountain that is prostate cancer surgery, and now I am on the other side, enjoying life as it was before I was diagnosed with prostate cancer.

I now have a PSA reading of 0.040. It pays to look forward to good health and to focus on the light at the end of the tunnel.

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Prosper Darwin Prostate Cancer Support Groups

Speakers spice up meetings with diverse presentations

The Darwin support group is benefiting from interesting guests at recent group meetings, as Darwin president and Ambassador Keith Williams reports.

THE Prosper Darwin Prostate Cancer Support Group was fortunate to have two guest speakers at its June meeting.

Lynne Ritchie, a peer educator from the Council on the Aging NT, spoke to the group about the appropriate use of medications, and she was followed by Catherine Balfour-Ogilvy, who had previously occupied Lynne s position with COTA and is now with Mental Health Carers NT.

Catherine covered the subject of depression, using material from the Beyond Blue support organisation. A quantity of good resource material on these subjects was made available to the group members.

BARROW PUSHER GOES FURTHER NORTH

DAVID Baird, who has pushed a wheelbarrow from Perth to Sydney and from Alice Springs to Uluru and back to Alice Springs as a means of raising money for prostate and breast cancer, has arrived in Darwin with his wife, Joanne Richardson.

Taking the prostate cancer message to the airwaves

TERRITORY FM radio station in Darwin featured Prosper Darwin Support Group president Keith Williams discussing prostate cancer awareness with host Daryl Manzie on the Territory Talk program, broadcast on June 10.

Keith spoke about the importance of receiving regular tests and discussedanarticleinthe Australian Consumers Association's monthly Choice publication magazine, which recommends that men undertake both blood and digital tests for prostate cancer.

It was mentioned that prostate cancer is just as prevalent in men as breast cancer is in

contacted Keith Williams and were scheduled to attend the support group s July meeting.



Keith Williams

women, though Keith explained that some doctors are still ignorant about prostate cancer, and related his and his brothers' personal experiences.

Keith concluded the interview by saying that people can obtain further education by phoning 8981 4506, or by attending a support group meeting in Darwin.

David s recent barrow pushing exploits were well covered by Murray Neck s

COMING EVENTS

Next support group meeting: MONDAY AUGUST 10.

The Prosper Darwin 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.

report in the May/June issue of Prostate Supporter.

KATHERINE SUPPORT GROUP PROGRESS

DARWIN group members Keith and Pat Williams and Peter and Beth Harvey attended the "Proshelp" Katherine Prostate Cancer Support Group meeting on June 10.

While this new support group is still quite small, it is functioning well and is providing an important service to cancer patients and survivors in Katherine.

This inspiring couple have

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

A STUDENT wants to be a really good proctologist, so he gets a part-time job at the morgue after class so he can practice. He uncovers the first body and there is a cork jammed in his butt. He thinks this is a little strange, so he pulls the cork out and jumps back when music suddenly starts playing: "On the road again, just can't wait to get on the road again..."

The student freaks out. He runs to get the doctor and drags him back to the table. "Look," he says and pulls the cork out, and the music starts again: "On the road again ... "

The doctor is unimpressed. "So what?" he says. The student is aghast. "Isn't that the most amazing thing you've ever seen?"

"Are you kidding?" says the doctor. "Any asshole can sing country music!"

Alice Springs Prostate Cancer Support Group

Preparing to celebrate first anniversary of giving support

The Alice Springs Support Group celebrates its first 12 months of providing valuable service to its local community, as convener Murray Neck reports.

I NAUGURATED in May 2008, the Alice Springs Prostate Cancer Support Group support group is holding a celebratory dinner on Thursday July 16, to mark its first anniversary as a vibrant and active organisation that has made its mark on the Alice Springs community.

Attending the special celebration will be councillors of the Central Australia Chapter and Prostate Cancer Foundation of Australia support group service manager Paul Redman, visiting Alice Springs to attend the chapter s bi-monthly meeting. They will be welcomed to Alice Springs by support group chairman Tony O Brien.

Invitations have been posted to all members and partners of the support group and a large attendance for this very special occasion is anticipated.

The prostate cancer movement in Australia is recognised worldwide as a leader in providing community awareness and support, in addition to valuable help in funding research. Our visitors, who between them have dedicated many years towards the development of this national organisation, will inform us of what progress is being made in both prevention and treatment of prostate cancer, as well as future challenges facing the Prostate Cancer Foundation of Australia. We especially acknowledge the financial support of the PCFA.

The Central Australian Chapter Council meeting will be held in the conference room of Quest Apartments on South Tce, Alice Springs, starting at 2pm on Thursday July 16. All support group members are invited to attend as observers.

NEW AMBASSADORS

THE Alice Springs support group is very proud that two of its members – Geoff Kain and Robert Gates, who attended a men's health ambassador speaker training program in Darwin – have been accepted as ambassadors. Their knowledge and support in speaking of men s health issues to consumer groups and to rural communities in Central Australia will prove to be of great benefit to the wider community.

NATIONAL SENIOR CITIZENS CONFERENCE

WHILE the National Senior Citizens Conference is being held in Alice Springs next month, the Alice Springs PCSG will be manning an information booth in the Town Council s Andy McNeil Room on Tuesday August 18 and Wednesday August 19. This will be an opportune time to support these people whose age makes some of them vulnerable to prostate cancer. Volunteers to work at the information booth are now being sought.

AN INSPIRATIONAL MAN

THE Alice Springs support group mourns the passing of

COMING EVENTS

JULY 16 MEETING The anniversary dinner on Thursday 16th July will replace the support group's usual monthly meeting.

In other months, the Alice Springs support group meets on the second Thursday of each month, from 6.30pm to 8pm in the conference room of the General Practise Network, Skinner St, Alice Springs.

Trevor Hunt and extend our deepest sympathy to his wife Coralie and family. We never had the pleasure to meet Trevor but learned much about him through the *Prostate Supporter* newsletter. A remarkable man who dedicated so much of his life to the support and health of others. He leaves us with a legacy and a challenge to carry on his good work.

Recognising medical excellence: Dr Carole Pinnock AM Queens Birthday list honours prostate cancer expert

W E Congratulate Dr Carole Pinnock, a Principal Research Scientist in the urology unit at the Repatriation Hospital at Daw Park, who received an AM (Member in the General Division) for service to medicine, particularly

urological research and to men's health through the development of support programs for people with prostate cancer. Dr Pinnock, also part of the Australian Prostate Cancer Coalition, is principal author of the consumer guidelines for advanced prostate cancer and is obtaining input from a working party that represents a broad range of health care and Prostate Cancer Foundation of Australia consumer involvement, in different aspects of the prostate cancer journey.



Dr Carole Pinnock

www.pcagsa.org.au

IN MEMORIUM – TREVOR HUNT

A champion for promoting prostate cancer awareness

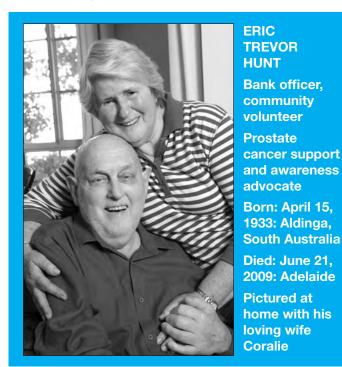
The dedicated rigour of Trevor Hunt's service contributions to the community stand as a worthy monument of his life, as his friend Jeff Roberts writes in this obituary.

T is with great sadness that we acknowledge the recent passing of Trevor Hunt – one of South Australia s great advocates and organisers of prostate cancer support groups, a determined promoter of prostate cancer awareness, an energetic contributor to support group activities and the Prostate Supporter newsletter, and a great friend to all within the nation s prostate cancer fraternity.

Born in Aldinga, Trevor grew up at McLaren Vale and attended McLaren Vale Primary School before receiving a scholarship to attend Kings College in Adelaide. Trevor initially worked on his family s vineyard for two years before joining the Savings Bank of SA at McLaren Vale in 1951, and remained a bank officer throughout his working life – at Bordertown, Kadina, Adelaide (where he married Coralie Bond in 1958) and Whyalla, where the couple lived for nine years and raised their three children, then to Eudunda where he became manager in 1968, McLaren Vale, Mt Barker from 1978 and Clovelly Park from 1987.

Through this time, Trevor s community involvement took off – with Whyalla Jaycees (as president, and editor of an award-winning magazine), Mt Barker Lions, various school councils, football and bowling club committees, the National Trust and Friendship Force.

When Trevor retired after 40



years service with the bank, he served as president and secretary of the Noarlunga/ Morphett Vale Lions Club, and took cabinet positions before being awarded the Melvin Jones Award and James D Richardson Certificate Award of Lions.

In January 1999, Trevor was diagnosed with prostate cancer and the following month he and Coralie attended their first support group meeting at the Adelaide Group. By early 2000, Trevor and Coralie had joined the Prostate Cancer Action Group, which led to speaking engagements and advocacy work.

In 2001 the group became incorporated and Trevor took a leading role in wording the

constitution, then was initial chairman for three years. Together with Jeff Roberts and Ray Power, Trevor formed a small committee to plan new directions for the group and this led to the public awareness presentations which are still continuing very successfully to this day. He also produced a wonderful newsletter that received acclaim from groups throughout Australia. His contribution to the Action Group was phenomenal.

Trevor was greatly involved with the Prostate Cancer Foundation of Australia, being the initial SA representative on the Support & Advocacy Committee in 2001. Trevor s commitment to the PCFA was recognised when he was honoured with the prestigious Max Gardner Award at the first National Conference in November last year. Unfortunately he was not well enough to attend.

Trevor was associated with the Cancer Council SA as a volunteer for about nine years before resigning in 2008, and involved in many committees on prostate cancer issues, recently as a consumer representative on a committee preparing a book, Consumer Guidelines for Advanced Prostate Cancer, which should be available late this year.

In May, a few support group people and partners visited Trevor and Coralie at their home to present Trevor with the Premier's Certificate of Appreciation Award for outstanding volunteer service – recognition that Trevor was very pleased to receive.

Trevor and Coralie had a wonderful relationship and celebrated their 50th wedding anniversary in 2008. Trevor always deeply appreciated the love, care and support that Coralie readily gave him.

He showed great courage and determination in battling his disease but died in hospital on June 21. An estimated 200 people attended a funeral service for Trevor in the Heysen Chapel at Centennial Park on June 26. He is survived by his wife Coralie, children Brian, Neil and Alison, six grandchildren and three greatgrandchildren.