

P.S.A. NEWSLETTER

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PROSTATE CANCER
FOUNDATION of AUSTRALIA

PROSTATE(CANCER) SUPPORT
AWARENESS



ADELAIDE GROUP
Providing support for men with Prostate
Cancer
and their families

www.psaadelaide.org

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**Report on March 2004 Meeting
Held at Burnside Hospital on Monday 8th March at 7pm**

Thank you to our sponsors: Abbott Australasia, City of West Torrens Council and to the BURNSIDE HOSPITAL for the use of their lecture room.

Chair: Gerry McCreanor

60+ members present!

Special Guests: Welcome to **Max Gardner**, Chairman of the Prostate Cancer Foundation of Australia. & Chairman of the Support & Advocacy Committee. Also welcome to **Don Baumber**, President of the Gold Coast Prostate Cancer Support Group & a member of the Foundation's Support & Advocacy Committee.

Apologies: Jim and Elaine, Hugh, Kathriye, Barry, Chris, Sharon, Tony, Warren, & Maralyn

New Members : Welcome John, Daryl, Noel and Paul

Max & Gerry

SPECIAL GUEST - Max Gardner

- Max is in Adelaide attending a meeting about the development of **Clinical Practice Guidelines for the Management of Advanced Prostate Cancer**.
- Max has been recently appointed Chairman of the Prostate Cancer Foundation of Australia. He will be looking to continue the fund raising work of the PCFA, and also to focus on support and advocacy. **He hopes to raise awareness about prostate cancer**. There is the possibility of setting up another advertising campaign after the work last year fell through. Need to get a message that is agreed upon by everyone.
- **Let's make prostate cancer an election issue**. There are at least 2 MP's in support of further funding for research – Wayne Swan, and Jim Lloyd.
- Max continues to Chair the Support and Advocacy Committee (originally named the Association of Prostate Cancer Support Groups). The SAC currently has **53 groups** involved and has become an important lobbying group.
- The PCFA now has 3 branches, in NSW, WA and Vic. Their web site is www.prostate.org.au.
- The SAC has followed from the work of the Prostate Cancer Action Group here in SA and are beginning to set up prostate cancer awareness evenings for men and their families in country areas.
- There is a new booklet available & written by Dr Stricker and Dr Kerry Phelps for GP's about PSA Testing.



SPECIAL GUEST – Don Baumber

- Don is also in Adelaide attending a meeting about the development of Clinical Practice Guidelines for the Management of Advanced Prostate Cancer.
- Don set up the Gold Coast support group about 7 years ago, the group had 8-10 members. **There are now 350 members !**
- He is involved not only with prostate cancer support groups, and the SAC, but also with the Cancer Alliance Network, and the Cochrane Collaboration.
- **We need to advocate strongly at the political level.**

Melissa and Don



After Max & Don addressed the meeting giving members information about the P.C.F.A., other Support Groups & the Brisbane & Gold Coast Support Groups, Barry Oakley our Vice President, presented both Max & Don with suitably autographed copies of his two books, **“There’s Some Good Years Left Yet”**, and **“Life’s in the Pink”**, as little mementos from Adelaide.

OTHER SPECIAL GUESTS:

Representatives from all other **Association of Prostate Cancer Support Groups (SA) Inc.**, attended. These included representatives from the Barossa Valley (Alan Hall), the North East Group (Ian Mattiske & Bob Hutchins), the Onkaparinga Group (John & Phyllis Shields , Brian & Rhonda Foreman), & Gary Bowes (Chairman). Gary distributed some copies of the Association’s new pamphlet. Further copies are expected shortly. Trevor & Corallie Hunt , & Jeff & Theban Roberts from the Prostate Cancer Action Group (SA) Inc, also attended the meeting. Most are also members of the Adelaide Group. We would like to thank Barry Oakley & Gary Bowes for going to the airport to meet Max & Don, also for Barry taking them to their motel & to our meeting. A big thanks also to one of our members (sorry his name has slipped from our memory, but that’s not unusual) for taking our guests back to their motel after the meeting.

TREASURER’S REPORT

The full report as been deferred until next meeting, but Reg assured us that the group is still solvent! We received \$250 worth of donations as a result of the mail out asking for donations from members who receive our newsletters but do not attend meetings. **Thank you to all who sent in donations!**

CORRESPONDENCE

- Reg has been at it again! This time he wrote to the SA Health Minister, Ms. Lea Stevens M.P., about funding for prostate cancer research. He also wrote to. Neil Andrews M.P., the Member for Wakefield and Speaker of the House, asking him would he support a motion about research and awareness for prostate cancer. Neil Andrews responded saying that he would definitely support such a motion. The S.A. Minister for Health replied to Reg’s letter, in part, as follows:-
- “The majority of funding for medical research in Australia is provided through the National Health and Medical Research Council (NHMRC). The NHMRC funding for research is rising from \$165 million in 1998/99 to over \$350 million in 2004/05. **The South Australian Department of Human Services (DHS) does not directly commission or fund medical research, although staff within our public teaching hospitals and universities are supported and encouraged in seeking NHMRC and other research grants.**”
- Reg then asked Max was there any possibility of the P.C.F.A. approaching the NHMRC for a special grant (a large one) for research into prostate cancer. Max smiled and gently nodded, so can we take this as being a **“YES”** Max?

PROSTATE CANCER AWARENESS EVENING – WOODVILLE

The next Prostate Cancer Awareness evening organised by the action group will be held on **Tuesday 30th March** in the Murree Smith Memorial Hall, Kemp St, Woodville. The meeting will commence at 7pm & finish about 9.30pm. The key-note speaker will be Dr. Kim Pese, Urologist. Coffee, tea and biscuits will be provided. Jeff & Trevor said that everyone is more than welcome to attend.

GUEST SPEAKER – PROFESSOR VILLIS MARSHALL

Notes by Melissa.

“Prostate Cancer: What is happening in Adelaide? What is happening elsewhere?”

The Robots are Coming?

- The DaVinci machine may be arriving in Adelaide. This machine performs Radical Prostatectomies using laparoscopic techniques that will enable faster recovery. 7000 Radical Prostatectomies have already been performed using this machine.
- Patients who have had surgery using the DaVinci machine report 10-20% impotence rates, and less than 1% incontinence rates.
- The machine costs \$2.5 - \$3 million to purchase, and \$150,000-\$200,000 a year to run. The cost of purchasing the machine for Adelaide is likely to be covered by a wealthy businessman living here.



The Seeds are Coming (Brachytherapy).

- Calvary Hospital and the Royal Adelaide Hospital are currently in the process of tendering for the equipment. Brachytherapy machines should be up and running by the middle of this year

Chemotherapy Trials in the wings.

- We are entering into a new era with chemotherapy. There is a major study coming out in June that is likely to show very good results. The study shows improved survival times, and quality of life using chemotherapy for men with hormone resistant cancers. Clinical Trial programs should be starting up around Australia soon.

Research into Hormone Resistant Cancer.

- 80-90% of men have a good response to hormone therapies at first.
- There are four stages in the process – the androgen receptor: 1. expresses, 2. matures, 3. activates and 4. transactivates.
- There is currently research at the Royal Adelaide Hospital and other sites looking at step 3. the activation step, and trying to produce inactive variants of androgen which block the receptors and stop the development of hormone resistance.
- We can also attack step 2, the maturation step. There are trials of a drug called 17AAG (based on an anti-biotic called Geldanamycin) which is producing very promising results.
- There are a number of alternate androgen pathways in addition to testosterone, & researchers are now looking at these pathways. There is a drug called Gantegrel which works to block another of these pathways.

PSA Testing.

- Results from the CaPSURE study in the US show that since the widespread use of PSA testing, the number of T3 and T4 tumours has dropped from 11.8% in 1989-1990 to 3.5% in 2001-2. Tumours are smaller, and are being discovered earlier.
- In 2001-2 most men were being diagnosed with prostate cancer with PSA levels between 4 and 10, as compared to higher PSA levels 10 years earlier.
- We still don't know all the effects of PSA testing. The results we have now are based on a time when there was no PSA screening in the US. It will take 10 years before we know the full effects.
- There is a notion of a "window for cure". A screening program found that PSA testing led to cancers being picked up 12.3 years earlier on average than they would have been detected clinically.

When is observation appropriate?

- Watchful Waiting, or expectant management, involves identification and observation. If there is no progression of the cancer, then regular follow-up is all that is required. If the cancer progresses then we can look at a curative treatment of either surgery or radiotherapy.
- The median PSA doubling time is 6.8 years.
- The challenge is to convince men about Watchful Waiting as an option. The numbers of men opting for this treatment are dropping.

Biopsies.

- Clinicians used to perform a 'sextant biopsy' i.e. They took 6 core samples of the prostate. Now clinicians use a '5 region biopsy protocol'. A recent study showed that 35% of the cancers detected by this new protocol would have been missed if a sextant biopsy method had been used.
- Clinicians now take about 12 biopsies. (ranging from 7 to 15).
- There is no reason not to have a local anaesthetic when having a biopsy. Your Dr should offer it to you, and if they don't, ask why not! In a study looking at using a local anaesthetic Lidocaine, 93% of men reported less pain from their biopsy with no serious side effects.
- In the USA it has been known to take up to 34 biopsies to detect a cancer! (called "saturation biopsy")
- As a result of PSA screening, tumours are getting smaller and smaller at biopsy. The challenge will be to be able to detect smaller tumours. One response is to use contrast enhanced colour Doppler techniques to enable more targeted biopsies.
- There is a lot happening but there is still a lot to do!

At the conclusion of Professor Marshall's PowerPoint assisted lecture, Gerry, our President, thanked him on behalf of everyone present and presented him with a bottle of the very best of Wolf Blass' red.

NEXT MEETING: Our next meeting is in 5 1/2 weeks time (Not 4 weeks) commencing at 7.00pm on Thursday 15th April, when John Mayes will give us an interesting talk on Diet for Cancer and Recipes. Roll up! Roll up!

Getting the word out on prostate cancer

ONE of every eight men will develop prostate cancer. Similar in incidence and mortality rates to breast cancer in women, it is the most common men's cancer in Australia, with 2600 men dying of the disease each year. And yet, despite these worrying statistics, only one in 10 men are undertaking the routine blood test that, in conjunction with a digital rectal examination, can detect prostate cancer, compared with seven in 10 women undergoing screening for breast cancer.

Why is the number of men taking the test so low? For a start, problems "down south" are not something that Australian men, noted for their reticence, are particularly comfortable discussing. As reported in *The Weekend Australian*, for many men there is still shame and stigma attached to prostate cancer, treatment of which can lead to urinary incontinence and erectile dysfunction. But as Max Gardner, chairman of the Prostate Cancer Foundation's support and advocacy committee, told *The Weekend Australian*, more men need to understand that "you can't have sex in a coffin". Also, new and better treatments are now making the cure/side-effect trade-off militate even more for screening and intervention.

Only government education programs can gel the message out properly. Medicare reimburses men for the cost of tests, but governments have been much slower about getting out information than they were in the case of breast cancer. Men's health simply does not have the vigorous advocacy that the women's movement has provided for women's health issues. While there is quite legitimate disagreement within the medical fraternity on the wisdom of early surgical intervention - given that many prostate cancers will not cause symptoms until late in life - that does not mean that it is better for men to remain ignorant about whether they already have the condition that will one day kill them. With the right information and support, they will make the right choices. For far too long, and at the cost of far too many lives, this has been the cancer that dared not speak its name.

Incontinence .. a common problem at all ages

Every bladder or bowel control problem - no matter how small - deserves expert attention.

You are not alone. Incontinence is a very common condition. There are many health professionals qualified to assist you with bladder and bowel control problems. With a proper assessment, incontinence can be treated or more effectively managed and frequently cured.

Incontinence is not a simple condition. There are many different causes and many different treatments. Incontinence is not only concerned with poor control -urgency and frequency are also problems.

Poor bladder or bowel control affects all age groups, from childhood and adolescent bed-wetting through to aged care.

Incontinence is commonly experienced by older people, especially women. It can occur with pregnancy and childbirth, surgery, in neurological and many other disorders, can be menopause- or prostate-related, or as a side effect of medications - even diet.

For leaflets and more information about bladder or bowel problems and products and local continence services, please call the continence advisors on the

NATIONAL CONTINENCE HELPLINE A free and confidential service

Phone 1800 33 00 66

6 am to 8 pm Monday to Friday

BRACHYTHERAPY in Adelaide

From the Advertiser 9 3 04 by Jill Pengelley

Adelaide Radiotherapy Centre began performing brachytherapy on Thursday. The first patient was from country SA and the second was Martin Lauritsen, 62, of Hawthorndene. Under a general anaesthetic, Mr Lauritsen had about 83, 3mm implants of radioactive material injected into his cancerous prostate. Yesterday, while the seeds were killing off cells, he was back on the golf course. "I didn't really want to take seven weeks out of my life if I could avoid it," he said. "This seemed a more efficient way of approaching it."

Mr Lauritsen is one of more than 1000 South Australian men who will be diagnosed with prostate cancer this year. Until now, brachytherapy has only been available to those prepared to travel interstate. Mr Lauritsen had been considering going to Melbourne for the procedure before learning he could have it here. Adelaide Radiotherapy Centre director Chris Dibden said it was a costly treatment that was yet to be offered in the public health system in SA. For private patients, the out-of-pocket expense was about \$4000, compared with \$1000 for the seven-week course of external-beam radiotherapy.

Dr Dibden said brachytherapy offered the most convenient therapy and a continuous dose of radiation. It meant country patients did not have to spend seven weeks in the city and the radiation only targeted the affected area. "I think it gives a very real alternative to radical prostatectomy," Dr Dibden said. "A radical prostatectomy is a horrendous procedure, even in the very best hands." He said about 86 per cent of men who had their prostate removed were permanently impotent and less than 15 per cent of them responded to Viagra. Each year, they are about 250 deaths from prostate cancer, which had also spread to other organs.

Cancer link to Agent Orange The Advertiser 24.1.04

WASHINGTON: A study has found an increased risk of prostate cancer and melanoma among US Air Force veterans of the Vietnam War who sprayed the chemical defoliant Agent Orange, the Air Force says.

The cancer incidence was found to be 1.46 to 2.33 times higher than among the national population. An analysis of the study is to be published in next month's edition of the *Journal of Occupational and Environmental Medicine*.

The air force released a synopsis of the article written by members of an air force group that has been studying the Agent Orange matter for more than 20 years.

An air force spokeswoman said it did not plan to release the study or the article before the edition was published.

ERECTILE DYSFUNCTION CAMPAIGN From the Prostate Cancer Action Group(SA) Inc., Mar 04 Newsletter.

Noticed that actor, Gary Sweet, is to head a new campaign about erectile dysfunction in Australia (Performance Pack Information campaign). It is designed to break down barriers about the topic, and give men an easier conversation starter at their next consultation with their GP.

However, with the negative publicity being distributed by certain authorities about prostate cancer testing, and its association with erectile dysfunction, it will probably take much more than this campaign to get men to visit their GP. A balanced campaign to encourage men to talk to their doctor about prostate cancer testing would, quite possibly, find many more men visiting their GP for a check-up. However, the public furore about PSA testing 12 months ago is more likely to have discouraged men from a medical check-up. In fact, I have heard this from some men. The other side of this situation is that I also know of men who have gone to their doctor for a PSA test, and subsequently discovered that they already had a far more serious health problem, not previously diagnosed, or suspected. If authorities continue to criticize men for not seeking health check-ups, they should also look to the messages they communicate about PSA testing and prostate cancer.

The campaign about erectile dysfunction is a good idea, as men are not renowned for seeking advice in this area. However, the campaign is one which could be adapted as a model for a message about prostate cancer awareness. But, in the ED case, the name of the chosen public relations firm was a little unfortunate – Cox Inall Communications.

HRT patches for prostate cancer The Gold Coast Support Group Newsletter April 03

The news that hormone replacement therapy patches could be used to treat advanced prostate cancer was reported by five UK newspapers on the 10 April 2003 (1-5). Whilst the results of this pilot study are encouraging, randomised control trials are needed to confirm these preliminary findings.

Five newspaper articles (1-5) reported that hormone replacement patches normally worn by women to relieve menopausal symptoms could help men with advanced prostate cancer.

The newspaper articles were based on the preliminary findings of a pilot study (6). The study included 20 men with advanced prostate cancer who were treated with transdermal estradiol therapy (hormone replacement therapy patches). The researchers reported that all the men in the study experienced an improvement in quality of life and had biochemical evidence of disease regression and increased bone mineral density.

Gynaecomastia (enlargement of breasts) caused mild to moderate distress in 80% of the men, but none of the men suffered from hot flushes. These findings are not reported in detail in the research paper and the authors state that further information will be published at a later date.

All except one newspaper (5) reported that the study was a small pilot, and the Daily Mail mentioned the likelihood of clinical trials being carried out in the future. None of the newspapers made it clear that the findings were preliminary. Four newspapers (1,2,4,5) quoted the researchers as saying that the treatment caused 'fewer side effects compared to other treatments'. This was not supported by the pilot study as no comparative therapy was used in the study. One newspaper (2) claimed that the treatment shrank the prostate tumours, however no information about tumour size was reported in the research article.

ZOMETA

Since November 1 2003, the Government through the PBS system has approved the prescribing of Zometa for advanced prostate cancer where hormonal treatments have failed.

Prior to this arrangement being in place, some public hospitals, where a patient has high calcium in their blood, and private health insurance funds, for hormone-refractory metastatic prostate cancer, have helped cover the full costs of Zometa. The importance of the November 1 registration of Zometa under section 100 of the PBS system is the significant increase in the number of advanced prostate cancer patients who can now access Zometa and receive PBS reimbursement with its use.

PRAECIS PHARMACEUTICALS INCORPORATED

The Future in Drug Development

Plenaxis™ USA (abarelix for injectable suspension) has been approved for marketing by the United States Food and Drug Administration.

To learn more about Plenaxis™ and for full prescribing information, visit www.plenaxis.com.

Plenaxis™ - European Union

In addition to the approval in the United States, PRAECIS has also initiated the regulatory review process for Plenaxis™ in the European Union with a submission in Germany in June 2003. The Company expects an action by the German regulatory authorities during 2004 and will pursue broader European Union approval under the Mutual Recognition Procedure to market Plenaxis™ for the treatment of hormonally responsive prostate cancer patients.

Androgen Receptor(AR) Antagonist for the Treatment of Hormone -Independent Prostate Cancer

Because testosterone and other hormones are growth factors for prostate cancer cells, hormone-lowering therapy is a safe and effective treatment for patients with hormone-dependent prostate cancer. However, most patients eventually progress to a condition known as hormone-independent prostate cancer, where the prostate cancer cells no longer need testosterone and other hormones to grow and, as a consequence, hormone-lowering therapies are ineffective. Genetic studies in these patients reveal that most of them have accumulated mutations in the gene encoding the Androgen Receptor (AR) allowing it to function in the absence of testosterone. These studies indicate that the AR is central to the growth of prostate cancer cells.

Using our LEAP™ technology, we have discovered and are testing ligands that bind to the AR which could provide the basis for a new class of drugs to treat hormone -independent prostate cancer. If successful, the use of these drugs could be expanded to treat prostate cancer at all stages.

Cancer patients to get taped reminders

Doctors are to begin recording early consultations with patients after Sydney researchers found people diagnosed with cancer remember only a quarter of the information their specialist tells them. The Sydney Cancer Centre at the Royal Prince Alfred Hospital will give specialists recording devices after researchers at The University of Sydney found taping conversation benefited doctors and improved a patient's psychological state.

The trial, involving 1000 patients, showed that people had a greater understanding of their disease and treatment when they replayed the consultation on an audio tape.

Sydney Cancer Centre director Professor Chris O'Brien said many doctors didn't communicate well, often using medical jargon when explaining a condition. Sun-Herald (Sydney), 11/1 p42

If it's about Men's Health, it's about time - too! Always seek a second opinion, just ask your local Prostate Cancer Support Group, they second that too.

An old wag once said that it's hard to make predictions, especially about the future. Nothing could be truer in the case of health policy

Newsletter by Reg, Melissa, Ian & Jeff. Photos by Ian. Printed by the Cancer Council, South Australia.

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