## PROSTATE CANCER ACTION GROUP (S.A.) INC

Affiliated with
Prostate Cancer Foundation of
Australia



ABN 26 499 349 142

The views expressed in this newsletter are not necessarily those of the Group. This newsletter is produced for the benefit of members of this Group, for general information, and articles are not intended as professional advice. This Group does not provide professional advice, nor does it endorse any particular product or service. It is recommended that any person needing advice on any health matter should consult their health professional without delay.

Website - www.pcagsa.org.au

# **SEPTEMBER 2005**

## Chairman's Report – September 2005

## **September - Prostate Cancer Month**

September is prostate cancer month with efforts being made to increase public awareness of prostate cancer.

The Association of Prostate Cancer Support Groups (SA) have sent a media release to outlets throughout the State and it is hoped this achieves success.

The National Call-In plus an Awareness Evening to be held at The Cancer Council SA on the 14<sup>th</sup> of the month have ensured increased publicity and this momentum needs to be maintained for the remainder of the month.

#### **BE-A-MAN Adelaide Launch**

The Adelaide Launch of the National Awareness Campaign BE-A MAN may now take place within the next 2 months. We are waiting on further details to be supplied by the PCFA.

## **Awareness Evenings**

#### Kadina

The Action Group's visit to Kadina on the 19<sup>th</sup> August resulted in one of our most successful presentations with a capacity attendance of 128 at the Farm Shed Museum & Tourism Centre. This proved to be an excellent venue with first class facilities

The key speaker was the visiting urologist to the area, Dr Zenon Herzberg who gave an excellent presentation. Both speakers from our Group, Ray Power and Ian Fisk were well received.

At the close of the Evening there was positive feed back from members of the audience. A check of the 59 evaluation forms completed showed 42 regarded the presentation as very helpful and 7 somewhat helpful. The question was not answered on the remaining 10.

In conducting the Evening our Group received great support from the Northern Yorke Peninsula Health Service at Wallaroo (in particular Tim Garfield) and the Bute Lions Club (David Copley). Through the initiative of the Lions Club a Grant of \$500 was received from the Northern Yorke Peninsula Health Service YP – Spoke (located at Wallaroo.) Our Group was also supported by a Grant from the PCFA.

## Adelaide Metropolitan Area

We are hopeful of a good attendance at the Awareness Evening to be held on the 14<sup>th</sup> September at The Cancer Council SA function room – 202 Greenhill Road Eastwood, 7.00p.m.-9.30p.m. Excellent speakers have been arranged. Prof. Villis Marshall will give an overview of prostate cancer, Dr Elizabeth Isenring (Flinders University) will speak on nutrition and Dr Linda Foreman (Cancer Council SA) will outline a GP Education Program. Two members of the Action Group will speak and a panel discussion will complete the Evening. All are welcome to this free Evening. No further awareness evenings are planned in 2005.

## **Prostate Cancer Call-In**

The results of the Prostate Cancer Call-In were as follows:

Monday 5<sup>th</sup> – Thursday 8<sup>th</sup> afternoon 80 calls

Thursday 8<sup>th</sup> Evening 179

Some calls were still being received on the following day

The overall total was in excess of 260 which was considered a good result.

Some radio advertising included interviews with John Francis who is a member of the Mitcham and Adelaide Support Groups.

Several members of the Action Group assisted on the Evening of the Call-In namely Gordon Frith, Dean Wall, Trevor Hunt, Ian Fisk and myself.

## Vietnam Veteran's Day/Men's Health Expo

The Men's Health Expo held on the Torrens Parade Ground on the 21<sup>st</sup> August proved a successful Day. Our Group was one of over 30 organisations who had displays and we had some interesting discussions while handing out a variety of pamphlets. One of the most worthwhile aspects of these Events is the establishing and reinforcing of contacts with other organisations.

I estimated the attendance at approximately 2000 and a steady number came to our tent. There was excellent entertainment during the afternoon although a little loud at times.

I completed an evaluation form sent to me and indicated we would be interested in being involved again next year.

## **Mitcham Prostate Cancer Support Group**

There was an attendance of 21 at the August Meeting including 5 people new to the Group.

The Meeting approved an application be lodged to become affiliated with the PCFA.

The Group has received further favourable publicity through articles in the Mitcham Community News and the Eastern Courier.

The guest speaker for the Evening was Barry Oakley who gave a very interesting talk on his prostate cancer experiences including comments on the emotional side of diagnosis. His talk was well received and several members purchased his books on prostate cancer following the talk.

The next Meeting will be held on Thursday 22<sup>nd</sup> September at the Colonel Light Gardens RSL Club at 7.15p.m. Anyone is welcome to attend and tea/coffee will be provided. The guest speaker will be Barry Ferris, a member of both the Mitcham Group and the Prostate Cancer Action Group, who will speak on his prostate cancer experience.

For more information phone Jeff Roberts on 8277 3424 or check our website on www.pcagsa.org.au

#### **SAC Annual Conference**

The Annual Conference of the PCFA Support and Advocacy Committee will be held in Sydney on the  $19th - 20^{th}$  September. This will be followed by the AGM of the APCC on the  $21^{st} - 22^{nd}$  September.

Trevor Hunt will be attending as will Gary Bowes from the Association of Prostate Cancer Support Groups (S.A.).

## **Effective Public Health Advocacy Conference**

I attended an Advocacy Conference in Sydney on the  $29^{th} - 30^{th}$  August by courtesy of sponsorship from The Cancer Council SA. This was a very interesting and well presented Conference and I gained a lot of worthwhile information. My thanks to The Cancer Council for giving me the opportunity to attend.

.Jeff Roberts

## MOUNT COMPASS FIELD DAY - 2006

Notification has been received that due to the current adverse seasonal conditions and a number of other factors, the Mount Compass Field Day will be in recess for 2006. The committee will be meeting again early next year to reassess the situation and determine the viability of a 2007 event, and will be in contact with an update on the Field Day situation, following further deliberations.

With this event dropping out of our opportunities for the promotion of further awareness of prostate cancer, it allows us to concentrate on other opportunities. Our experience at the 2005 Field Day was successful enough to show that we can conduct effective awareness campaigns at this type of event.

## CANCER SCREENING – IS IT WORTH IT?

Cancer screening tests can find cancer early, but are they always a good idea?

Cancer is a very scary thing. All of us have known someone whose life has been affected by cancer. Particularly in the past, cancer was a terrifying and life-threatening diagnosis.

Then along came screening tests and the notion that cancer could be found early and treated more effectively. Pap smears were introduced to prevent cervical cancer, and large-scale trials showed screening for breast and bowel cancer could reduce the chances of dying of these cancers.

Since then, there's been no looking back. Screening for these and many other cancers - lung, prostate, ovarian, and skin cancer for example - has been proposed and tried.

Now our cancer tests are so good we can find very small, very early Cancers, and maybe finding them is doing more harm than good!

As our medical tests get better and better and we can 'see' into our bodies in ever increasing detail, we can pick up more and more' abnormalities', or, perhaps it's better to call them 'variations' than anyone ever realised existed.

For example, if we look hard for it, we can find prostate cancer in well over half of older men, but for most of these men their prostate cancer will never bother them. About a third of adults have thyroid cancer, and up to 40 per cent of middle-aged women have low-grade breast 'cancer' (ductal carcinoma in situ) if you look hard enough for it.

But not all of these cancers matter. Some of them grow so slowly they never cause any problems, or we die of something else first anyway, or some of them may even go away (dealt with by genetic repair mechanisms or our immune systems).

## Better safe than sorry, or maybe not

So what's the problem with finding cancer early? The main problem is we can't tell the bad cancers apart from the innocuous cancers and so we have to treat everyone. Thus cancer screening brings with it real risks of over-diagnosis and over-treatment.

Having a cancer diagnosis is a very serious psychological burden for anyone. And of course it doesn't stop there: cancer therapies (surgery, radiation and chemotherapy) have important risks and side effects. So while you would want cancer therapy if you had a cancer that was going to get worse without treatment, you wouldn't want it if all you had was an indolent cancer that was never going to make you sick. In fact if you had one of those cancers, it won't make you sick, but the treatment will.

There are other harms of cancer screening too. Sometimes the tests are wrong. So you can get an abnormal test result even though you don't have cancer. While doctors sort this out, you may have to go through a whole series of increasingly invasive tests. This can be a very stressful time - some people describe it as the scariest time of their lives.

Or the follow-up tests themselves might hurt you. For example, if you get an abnormal result on your faecal occult blood test for bowel cancer, you will be referred for a colonoscopy exam of your bowel. Apart from not being fun, US data from good clinical centres shows this exam can cause major complications, even death. The risks are not well documented for colonoscopy as part of an FOBT screening program, but data suggest the major complications (such as bleeding and bowel tears) may occur in 1 to 3 people per 1,000 having a colonoscopy, and may kill around 4 or 5 per 100,000 people having a colonoscopy (see Screening for colorectal <http://www.ahcpr.gov/clinic/uspstf/uspscolo.htm>, Systematic evidence review, Preventive Services Task Force).

In the case of bowel cancer screening, at least we know it works - it reduces the chances of getting, and of dying of bowel cancer in the future. So you might be willing to trade the risk of harm now against the chance of future benefit. But with other types of cancer

screening, for example screening for prostate, lung or ovarian cancer, there isn't yet any good evidence of benefit.

#### Should I be tested?

Cancer screening is a close call. There is no single right answer to the question 'Should I be tested for cancer?' Some people will say, 'No thank-you. I want no part of this. I want to focus on being healthy now and not worry about getting tests unless I become sick'. Others will say, 'Yes I want to be screened, I realise there are downsides but there are benefits too and I want a chance to be one of the few people who will benefit'. Either choice is rational. If you choose to be screened, the chance that you will benefit is small, and the chance that you will be badly harmed is small. Most people will neither benefit nor lose from screening because all cancers are rare in well people who have no symptoms. (By the way, that's what cancer screening is - having tests for cancer when you're well. If you have symptoms, such as a breast lump, a breast change, or abnormal bleeding from the bowel or vagina you should see a doctor. All doctors agree that finding and treating cancer that is already causing symptoms is important.)

And people may choose differently for different cancers - men may choose, for example, to screen for bowel cancer but not for prostate, or vice versa, or both or neither. We need to resist pressure to push people to get tested because 'that's the responsible thing to do' and give them balanced information so they can choose what they want.

© 2005 ABC <a href="http://www.abc.net.au/common/copyrigh.htm">http://www.abc.net.au/> Radio http://www.abc.net.au/radio/

\*The Pulse Home\* </health/thepulse/default.htm> by Alex Barratt </health/bio/barratt\_a.htm> Published 18/08/2005

## EARLY PROSTATE SCREENING MAY SAVE LIVES

(HealthDay News) -- Early prostate specific antigen (PSA) screening may reduce men's risk of aggressive, metastatic prostate cancer by as much as 35 percent, University of Toronto researchers report.

This type of early blood testing has been "quite controversial. There are many arguments both for and against the efficacy of this form of early screening," Vivek Goel, one of the study's senior authors and professor of public health sciences and health policy management and evaluation, said in a prepared statement.

Reporting in the August issue of the /Journal of Urology/, the research team pored over medical records, comparing the PSA testing histories of 236 men with advanced metastatic prostate cancer with those of 462 randomly selected control patients.

They found early PSA testing associated with a more than one-third decline (35 percent) in metastatic prostate cancer risk.

"Our study shows a fairly significant benefit, and this benefit is demonstrated even among men who were not screened regularly as part of a screening program. There may be greater benefit from an organized screening program," Goel said.

Goel and fellow researcher Jacek Kopec, both public health epidemiologists, said they were surprised by the level of protective effect provided by early PSA screening.

"What usually happens with tests like these is that clinicians tend to be very supportive while public health people tend to be more cautious," Kopec said in a prepared statement.

"The clinical members of our study team feel that these findings are confirming what they had believed all along; we were a bit more surprised," he said. "A 35 percent difference is quite a large amount so from our perspective it is quite a significant link in the chain supporting that early prostate screening has a positive effect."

SOURCE: University of Toronto, news release, July 8, 2005

Copyright © 2005 ScoutNews LLC <a href="http://www.healthday.com/">http://www.healthday.com/">http://www.healthday.com/</a>>. © 2005 Prostate Cancer Foundation.

## Minutes of the Teleconference Meeting of the PCFA – SAC – National Meeting

Held on Thursday 16th June 2005 At PCFA offices at Lane Cove commencing at 3.00 pm

Attended by: Pam Sandoe (NSW), Andrew Giles and Ann Smith (PCFA)

Via Conference Call: David Sandoe (Chair), Keith Williams (NT), Gary Bowes and Trevor Hunt(SA), Jennifer Lyall (Tas) and Bob Wilson (Vic)

**Apologies:** Bill McHugh and Don Baumber (Qld), Con Casey and Graham Nicholls (NSW), John Dowsett (Tas), Karen Rendell and Malcolm Sears (WA) and Ean McArthur (Vic)

## 1. Welcome and confirmation of Minutes of 21st April 2005

David Sandoe welcomed all attendees. Moved by Keith Williams and seconded by Gary Bowes that the minutes of the meeting of 21<sup>st</sup> April 2005 be confirmed.

## 2. Business Arising - Nil

## 3. CEO Update

## Financial Year ending 30 June 2005

Andrew reported that the PCFA had a mixed year. \$1.6m was the budget for this year and so far we have raised \$1.55m. Peeball is \$90,000 behind in expected sales. We have had limited success in being granted CDSE (Community Development Support Expenditure) funding. We are behind by \$60,000 as budgeted. The Foundation has received good corporate and donor support and all four newsletters sent during the year now contain an appeal for funds. During the current newsletter campaign we have received \$15,000 - \$20,000 more than in previous years. The "Be a Man" campaign has had a flow on effect from people seeking information and later donating. The budget for 2005-2006 year has been set at \$2m.

Fellowships/Grants – Research fellowships, Travel Grants and Nurses Scholarships will all continue

## **Corporate Fundraising**

Don Argus from BHP Billiton has sent a letter on our behalf to corporate Australia and to date \$70,000 has been received from major corporations. Don Argus will host some Board Room style lunches.

## **Government Fundraising**

Three applications have been made for Support Group projects. One application on behalf of the Queensland PCSG's was successful to the value of \$60,000 which equates to \$12,000 pa for 5 years. The other successful application was made by the groups in South Australia, who applied for funding under the Federal Government's "Building Cancer Support Network" initiative. The groups received \$26,760. The other application was not successful.

## **National Board**

The Board held its final meeting on 5<sup>th</sup> May and Don Baumber, co-chair of the SAC, attended his first meeting. The members of the PCFA will approve changes to the constitution that will enable the Foundation to alter its structure to establish a truly National Board made up of representatives from each state (as well as the Chairman of the Support and Advocacy committee, the Scientific Research Committee, the Peer Review Committee) and the establishment of state boards. Submissions on the revised structure have been gratefully received from both the Queensland Chapter and some individual groups within both NSW and Victoria. The Foundation's Finance, Audit and Governance Committee will table all submissions. The new board will meet on 4<sup>th</sup> August.

**Be A Man** – will be launched in Queensland on 17<sup>th</sup> June (tomorrow) with both Wayne Swan, Federal Member, and Leigh Matthews, Coach of the Brisbane Lions and some of his team will be the celebrities in attendance. The launch will be held in the Queen Street Mall.

The campaign launch in Perth is set down for 28<sup>th</sup> June. The launch inside the WA Art Gallery, will be attended by Premier Dr Geoff Gallup and Federal Minister Julie Bishop. Planning is also underway for a launch in Adelaide, proposed for October, and Melbourne at Federation Square on 1<sup>st</sup> September. Other launches are planned for Canberra and Newcastle. Trevor and Gary will encourage all support group leaders to be involved in South Australia once a date has been set.

**Speaker's Kit/Leader's Kit** – the complete kit was launched at the NSW Chapter Conference. The kit consists of two folders. The Speaker's kit has presentations on overhead and in PowerPoint, with explanatory notes, and a DVD. The DVD is divided into sections – What is prostate cancer?, the diagnosis and treatments and aftercare. The Leader's kit will contain minutes, Insurance papers, contact details for group leaders, merchandise available from the Foundation. The Foundation has received funding from the Commonwealth Bank for the kits. Andrew reported that the kit will launched to all group leaders in Australia shortly.

**Annual Conference** – planning is underway for the Annual Conference to be held in Sydney on Monday 19<sup>th</sup> and Tuesday 20<sup>th</sup> September in Sydney. The APCC is holding their annual meeting in Sydney on Wednesday 21<sup>st</sup> and Thursday 22<sup>nd</sup> September. Ann Smith will send invitations to all SAC members shortly. David, Don and Andrew will appreciate receiving suggested agenda items.

## 4. State Chapters – key issue reports

**Queensland** – Keith Williams reported that the Chapter Council was working well.

**Northern Territory** – Keith Williams reported that NT lawyer, John George, has metastases and will no longer be continuing to provide support at the level he has in the past. Keith receives a great deal of assistance from John especially on the PCFA Governance issue.

**Western Australia** – no attendees to report.

**Tasmania** – John Dowsett and Jennifer Lyall

John reported that the group now meets in new meeting rooms and there has been a focus on the impact of prostate cancer on families and relationships. Numbers in the group are down at present.

Jennifer reported that numbers in her group are down and she is looking at starting a state newsletter to be issued quarterly to enable interaction to take place between the three groups in Tasmania. David suggested that Jennifer seek copies on some of the bigger groups with excellent newsletters. For example Brisbane, Sydney Adventist Hospital and Nepean were recommended. Jennifer also has an issue with attracting Guest Speakers for meetings. David recommended that the three groups should have a bi-monthly meeting via teleconference and Ann Smith will provide details of how this can be arranged to Jennifer. State meetings are currently held bi-monthly in Queensland and NSW.

#### Victoria – Bob Wilson

Bob reported that Trevor Cottle had retired from Melbourne and Heidelberg groups and both groups have given him life membership. Heidelberg group have had a concert and art exhibition as a fundraiser.

Bob reported that the RSL initiative is going ahead. At this stage three RSL clubs have started support groups and holding meetings at their venues.

## **South Australia** – Gary Bowes and Trevor Hunt

Gary reported that a grant has been received from Adventis for \$5,500. Over fifty people attended a recent meeting at Royal Adelaide with Professor Ian Oliver as speaker. A new group has been established at Mitcham with Jeff Roberts providing assistance. A visit to the Department of Taxation has been arranged for August. Trevor reported that the Action Group will be seeking support from the PCFA for people travelling from country areas. The groups are at present looking at access to trials. Trevor also reported that the Action Group had organised the first of three awareness meetings. A equipment grant has been approved for the purchase of a video projector.

### New South Wales – David Sandoe

Twelve leaders attended the last teleconference on 19<sup>th</sup> May. Sound reports given from all PCSG's with good attendances; ongoing awareness work and plans for Prostate Cancer awareness month/September.

Taxotere – Ron Schmarr submitted paper for consideration. Currently on PBS list for review – no action to be taken until outcome is known.

Interest shown for name badges/T-Shirts and Polo shirts for upcoming APIA launches (Queensland/WA and regional NSW/ACT) and September PCSG Awareness month.

NSW State Chapter Conference – 3<sup>rd</sup> June – CCNSW workshop; well attended and enthusiastically received.

4<sup>th</sup> June: Business session commenced at 8.30 with presentations on remote and rural issues covered by Andrew Giles, John Trollor and Graham Nicholls.

Professional presentations given by Richard New from American Medical Systems; Dr. Phillip Katelaris with an update on the AUA held in San Antonio on 'new advances in Ca.P treatment; bone health by Melanie Griffin Nurse educator from Novartis and a brief introduction to the DVD "Living with prostate cancer".

Dr. Michael Boyer, Clinical Associate Professor, RPA gave an insight into updates on Chemotherapy; Kim Pearce and John Ramsey from CCNSW advised on the various departments that are accessible to PCSG's; the last session gave updates on Leader's/Speaker's Kit; Awareness meetings; Awareness month and general business. A successful and fulfilling agenda, with keen participation by all.

Andrew will meet with Steve Callister (St Vincent's group, Sydney) to discuss what he can arrange for the production of T-shirts. Steve will donate his services.

## 5. Brief Updates on participation in health and cancer organisation meetings - Andrew Giles

Andrew reported that there will be 23 information meetings for GP's sponsored by Mayne Pharma and Novartis. Many GP's are still confused on what to say regarding prostate cancer. At this stage meetings have been arranged in Port Macquarie, Coffs Harbour, Launceston and two in Western Australia. Other meetings are planned for Shepparton and Mornington Peninsula in Victoria and Port Augusta in South Australia.

The Commonwealth Bank will sponsor meetings on prostate cancer awareness for rural men in Victoria and New South Wales. It is proposed that twenty meetings will be held over the next six months.

A "Black Tie" function is currently being planned with the assistance of Max Markson. Raymond Weil Watches are prepared to underwrite a function in both Sydney and Melbourne this year possibly in August. Andrew will advise when further information is available.

On 19<sup>th</sup> October a memorial dinner for Max Gardner will be held in Melbourne which will be hosted by APIA. Cancer Voice, NSW – David reported that Sally Crossing received an AM for her work in establishing Cancer Voices, NSW.

## 6. Other Business

# Update on progress on getting comparative government spending on prostate cancer as breast cancer – Bob Wilson

Andrew reported that no figures are available. Andrew was interviewed by The Age that for every \$10 spent on breast cancer only \$1 is spent on prostate cancer. Jim Lloyd, Federal Member of parliament and survivor and supporter did not agree with Andrew's quoted figures but is not sure where the money is spent. Jim is arranging a meeting in Canberra with members of the PCFA and Health Minister, Tony Abbott.

## Tissue Bank Donor Awareness - Gary Bowes

Professor David Horsfall suggested that a letter be sent to all men who are in hospital for radical prostatectomy to agree to having excess tissue after the prostatectomy and pathology given to the Tissue Bank. Gary Bowes will produce a sample form and will send this to Professor Horsfall and to David Sandoe and Andrew Giles for approval. The logos of PCFA and APCC will appear on the forms.

#### 7. General Business

**Keith Williams** – Keith advised that the Pharmacy leaflet on prostate cancer which he brought to our notice at the last meeting as been recalled as it contained a lot of misinformation. A new leaflet dated August 2004 is now available in Pharmacies, and from other outlets.

Keith also advised that the GP failed to do a DRE on John George and now admits that if a DRE had been done he would have years of life ahead and would not be in the situation he is now facing. This issue should be taken up with Division of GP's. All PCFA information links DRE and PSA together. Andrew reported that Royal Australian College of GP's don't promote PSA and DRE.

Andrew proposed a committee under the Advocacy and Awareness Committee of the Foundation should meet and discuss this matter. Keith is keen to join the committee and Andrew proposes a teleconference meeting to discuss the issue.

**Bob Wilson** –believes that PSA and Free to Total test should be combined.

Urine testing is currently in research phase.

Bob also advised that a show in Melbourne talked about dogs detecting cancer in urine samples – for melanoma, bladder cancer that is used in Germany.

**Gary Bowes** – advised of the promotion of the ginger wine. Ann Smith advised the website address is <a href="http://www.drred.com.au">http://www.drred.com.au</a>

The meeting closed at 4.25pm.

Next meeting – Thursday 18<sup>th</sup> August and the National SAC Conference Monday 19<sup>th</sup> September and Tuesday 20<sup>th</sup> September 2005

## Additional Report by Don Baumber (Queensland)

## Commonwealth cancer support groups grants

The most significant news that SAC members should know is that the Qld Chapter Council (QCC) submitted a successful application for a grant under the commonwealth cancer support groups grants program. Andrew has details. The QCC are planning to meet immediately following the conclusion of the BE A MAN launch activities to discus strategies for implementing the plan submitted for the grant funding in addition to presentations to be made at the COSA annual scientific conference being held in Brisbane this year (starts November 15).

Also some International news of note; The Chair of Europa Uomo, Tom Hudson, Ireland has advised me that at the end of this month he is giving a report at the 6<sup>th</sup> International Consultation in Prostate Cancer and Prostate Disease Conference in Paris, the topic 'Patient's Perspectives in Prostate Disease' and is asking for our contribution/knowledge input towards this presentation. At the last Board meeting of PCFA I raised that Europa Uomo indicated they wanted to form some type of alliance with PCFA even though we were outside the European connection and this was considered favourably, at least in general terms, by the Board.

Europa Uomo are beginning to talk to similar PCa Survivor Groups across the world with the aim that it would be worth while building up an International Collaboration of Prostate Cancer Patient Groups.

QId Cancer Fund (QCF) are also asking for input on names for organising an international forum of prostate cancer support groups to be held in Brisbane early in 2006. Andrew also has some info on this from discussions he had with CEO of QCF. This is related to the Union of International Cancer Councils (UICC) sponsorship similar to the International Reach for Recovery organisation that UICC have for Breast Cancer organisations.

PROnet (formed by AstraZeneca) are also asking for members to decide if they should continue to seek independent funding for their international events/operation.

The NZ Prostate Cancer support group in Wellington that I addressed earlier in the year following the Cancer VOICES NZ conference, are seeking help with information linked to hormone refractory disease and our Australian TGA approval of Taxotere for treating prostate cancer. (A submission has been made for PBS approval by sanofi-aventis). Regards, DON B.

## **CEO Report to National SAC Executive**

## **National Structure**

The members of the PCFA met in Sydney on 21st June to approve changes to the constitution that will enable the Foundation to alter its structure to establish a truly National Board made up of representatives from each state (as well the chairman of the Support and Advocacy Committee, the Scientific Research Committee, the Peer Review Committee) and the establishment of state boards. Submissions on the revised structure have been gratefully received from both the Queensland Chapter and some individual groups within both NSW and Victoria. All submissions will be tabled by the Foundation's Finance, Audit and Governance Committee.

The board of the Prostate Cancer Foundation of Australia (NSW Division) have now met twice, chaired by David Sandoe. This now means the Foundation has active boards in Victoria, Western Australia and New South Wales.

The revised National Board met on 4<sup>th</sup> August in Sydney to review the accounts for the last financial year and to approve the budget for 2005-06. In addition the National Board approved:

- The call for application for the Max Gardner Research fellowship
- The call for applications for the Mazda Research Fellowship
- A project to conduct a national audit of prostate cancer research in Australia
- Funding to assist with the production of guidelines for metastatic prostate cancer by the APCC

## "Be A Man" Campaign

Our "Be A Man Campaign", proudly sponsored by Australian Pensioners Insurance Agency (APIA), was launched in Queensland on 17th June with a successful launch on Brisbane's busy Queen Street Mall. Federal Shadow Treasurer Wayne Swan and his wife Kim, and Brisbane Lions Coach Leigh Matthews were just three of the high profile celebrities who where on hand to join APIA General Manager Kevin Patterson and PCFA Chairman Patricia Watson. It was a wonderful turn out from support group members from across Queensland who travelled from far and wide to take part in this important launch. The PCFA and APIA are now undertaking mini-regional launches with each support group starting with Bundaberg, Maroochydore, Hervey Bay, Toowoomba and Rockhampton.

Two weeks after the Brisbane launch, attention moved to Western Australia and our next launch, this time inside the WA Art Gallery. Premier Dr Geoff Gallup and Federal Minister Julie Bishop joined PCFA Director Jim Freemantle – and other high profile West Australians – for this major launch. A highlight yet again was the show of strength from our newly established support group network from across WA.

Planning is now underway for launches in Melbourne (1st September), Adelaide, Canberra and Newcastle.

## **GP Education Campaign**

Providing information to GPs is a vital part of our "Be A Man" campaign. The Foundation has already provided education to GPs via our national mail-out (undertaken in the first half of 2004) and in the past few month the Foundation and AstraZeneca have undertaken a further distribution of our "Be A Man" packs.

We are now undertaking an extensive range of GP educational seminars across Australia. We are currently delivering two distinct GP seminars:

1) The ProCare Prostate Cancer Testing and Diagnosis Programme

The ProCare Programme is an Active Learning Module, accredited by the RACGP. By taking part, GPs can gain 30 Category 1 points in the Royal Australian College of GPs Program. The Programme has four modules to comply with RACGP requirements. The Foundation is working with Mayne Phama to deliver these vital education sessions.

2) Prostate Cancer and Bone Health Education Seminars

These educational seminars aim to help GPs be better informed about prostate cancer – and in particular maintaining bone health – and treatments available for advanced prostate cancer. General Practitioners will gain an understanding of the importance of maintaining bone health in men receiving treatment for HRPC and will be introduced to a variety of support materials both for patients and health professionals. The Foundation is grateful to Novartis Oncology for providing an education grant to make these seminars possible.

The timetable of the 33 functions is now available on the website.

## **Government Funding**

It was positive news to be told that two of the Foundation's submissions for funding under the Commonwealth Cancer Support Scheme were successful. The largest was to support the further development of the Queensland Chapter, whilst the South Australian Chapter was also funded. Thanks to everyone who worked so hard to ensure the very high standard of the applications.

## **Rural and Regional Issues**

As part of our commitment to rural and regional areas, we are launching a new campaign to raise the profile in key areas. With the support of the Commonwealth Bank we are assisting some of our rural and regional support groups with holding major information session. The details are: Bathurst – 23<sup>rd</sup> September: Dubbo – 16<sup>th</sup> November: Tamworth – 19<sup>th</sup> November: Similar events will then be arranged in: Illawarra, Port Macquarie, Mornington Peninsula,

Shepparton, Bengdio, Ballarat, and Cobram

As part of the official launch with CBA we are undertaking internal promotions with the 38,000 CBA staff via CBA TV – their internal TV network that is watched three times a week in all 1000 branches — via intranet to the 9,000 head-office staff, and via their newsletter "Which News".

In addition to these rural and regional events we are adding a new section to the website on rural and regional issues as well as a supplement in the December issue of Prostate News, thanks to support from Graincorp and Perpetual Trustees. We are also working on a partnership with the rural press network to provide substantial coverage of our activities.

Through our new relationship with Telstra Country Wide, via Mr Roger Bamber (a friend of David Sandoe's) who is the MD or NSW TCW joining the NSW Board we are able to have a presence at all key rural field days in NSW, as well as opening doors with the NSW Farmer Federation and Country Women's Association.

## **Community Awareness**

The PCFA is working on a range of events throughout September – Prostate Cancer Awareness Month – to raise community awareness. Each of the support groups has been asked to provide details of their planned events and this list with be posted on our website and in the September issue of Prostate News.

## **Support Group Resources**

With the completion of our DVD "Living with Prostate Cancer" and the revised speakers kit, a two volume resource pack for each support group is now under production for distribution as soon as available. The DVD was successfully launched at NSW Parliament House by our local member Mr Anthony Roberts. The DVD was made with the support of Novartis.

## **NSW Community Support and Expenditure Scheme**

After a disappointing result last year, this year we have been fortunate to already have received notification of several donation from poker machine income from clubs across NSW. The funds – from Port Macquarie, Campbelltown, Pittwater, Liverpool, Holroyd and Sawtell – are to assist with local support group needs.

## **Arabic Community**

In a strategy to broaden the Foundation's interactions with men from culturally and linguistically diverse background's I am working with the senior leaders of the Muslim community in Sydney to launch our prostate cancer fact sheet – that has been translated into Arabic – during September.

## **Rotary Research Fellowship**

We have had a positive response to the launch of the Rotary Research Fellowship. I wrote to 1050 clubs across Australia informing them of our links with Rotary and new research fellowship. Despite it being changeover - and most funds already being allocated - we have received \$25,225 from 48 clubs so far. This compares to \$13,000 from 26 clubs who responded to the newsletter in the same period last year. I will feature the new fellowship in the next issue of Prostate News.

In addition I have been appointed the Chairman of the Prostate Cancer Committee for District 9680 and hope to utilise our support group leader in the area (North Sydney to Newcastle) to make presentations at each of the 67 clubs.

## **Upcoming events:**

1<sup>st</sup> September

• Be A Man Launch, Federation Square, Melbourne

5<sup>th</sup> September – 18<sup>th</sup> September

• Adshel promotion – 100 bus shelters across Australia will have "Be A Man" posters

19<sup>th</sup> and 20th September

Meeting of the National Executive of the SAC Committee, Sydney

21<sup>st</sup> and 22<sup>nd</sup> September

Australian Prostate Cancer Collaboration Scientific meeting, Sydney.

23<sup>rd</sup> September

 Wayne Swan fundraising lunch in partnership with Prince of Wales Oncology Research Unit and UNSW at Dockside Cockle Bay.

24<sup>th</sup> September

• Bathurst Information Evening (and launch of CBA Partnership)

13<sup>th</sup> October

• Sail Aid Fundraising Event (Prostate Cancer Foundation of Australia is beneficiary). Hosted by Sir James Hardy and Ian Murray at Doltone House, Sydney.

19<sup>th</sup> October

Concert for Max Gardner, Art Gallery of Victoria. Hosted by APIA.

30<sup>th</sup> October

Movember registration days.

## WOMEN AND PROSTATE CANCER...

QUESTION: Why should women care about prostate cancer when we can't even get it? We already have breast cancer, cervical cancer, uterine cancer, and a whole host of other gynecological cancers to worry about. What on Earth could make us want to get interested in a cancer that we can't have?

ANSWER: Four reasons. First, it is the form of cancer that our husbands, lovers, fathers, grandfathers, sons, and brothers are most likely to contract. Second, if identified sufficiently early it is a curable form of cancer for many patients. Third, if it is *NOT* caught early, it can lead to a long and drawn out clinical decline, and death from prostate cancer can be a painful process for the patient and emotionally harrowing for his family and friends. And finally, we can playa major role in ensuring that the men we care about take some important steps to reduce the impact of prostate cancer on their lives - and ours.

Others have dealt extensively with the incidence and prevalence of prostate cancer. We want only to show women how we can help spread information about this disease and motivate our male family and friends to adopt appropriate health-seeking behavior.

And we speak from experience. We want to help you avoid the trauma we've experienced in -helping the men in our lives deal with prostate cancer, often when it was too late to do anything to cure them.

Men are appallingly lax in their health care behavior. For a significant majority of them, health self management means stopping playing basketball at 50 because it's becoming embarrassing. Men often eat badly; don't exercise well (*if* at all); some men smoke, drink excessively and think that relaxing means falling asleep in front of the television with a plate of nachos on their stomachs. (Anyone out there recognize this individual?)

Is it surprising that they have high blood pressure, high cholesterol levels, lung cancer, and a whole host of other chronic ailments which start to show themselves at their worst sometime after men reach their 40s?

This article isn't about changing the entire male behavior system for the red-blooded American male. Despite all of his flaws, many women still feel these guys are...really kinda cute. HOWEVER, one of the most critical issues today, in my mind, is whether we can persuade those men who are at greatest risk for prostate cancer to *GET* A CHECK UP.

Programs like Prostate Cancer Awareness Week (in September) have successfully persuaded hundreds of thousands (if not millions) of men to get an annual digital rectal examination (DRE) and a prostate specific antigen or PSA test. However, the men who tend to go for these tests MAY *NOT* BE THOSE WHO MOST NEED THEM! It is our suspicion that it is going to take the much greater involvement of wives, partners, mothers, daughters, girl friends and whatever if we are to persuade the average 50-year-old male man to actually go and have his health care needs checked on an annual basis.

Women tend to be more health conscious than men -- who often deny all health problems until they cannot actually move!

Thus, I propose the beginnings of WOMEN FOR MEN'S HEALTH -- a movement that 1 personally believe could do much more for male health in America than anything doctors, employers, the government, or *HMOs* will ever be able to do! This is an entirely imaginary movement at the moment ... but people are welcome to do with it as they wish, and prostate cancer would be a good place to start, although there are many other peculiarly male health problems (e.g., testicular cancer) which need to be addressed, quite apart from the appalling state of men's cardiac care!

Here are some things that WOMEN FOR MEN'S HEALTH could do:

- 1. Form a network of women who could talk to other women's groups about prostate cancer and prostate cancer screening.
- 2. Form a pressure group to regularly hound the managed care community, public health departments, large companies, and the national political establishment about how working men can only work efficiently and productively if they are healthy, and the way to make sure they are healthy is to have their companies INSIST on annual health checkups, using prostate cancer as an example!

3. Teach the next generation of American males that health-seeking behavior is GOOD and does not make one some sort of wimp! (We'll have to start with the 5-year-olds!)

Now there are many men who would be pleased to participate in this type of effort. They include men with prostate cancer, men with AIDS, men with cardiovascular diseases, and healthy men ... even men with MD or RN after their names! But women are more likely to be the motivators because we exhibit this type of self care more easily and with a greater degree of awareness than do men

If you love your guy ... make sure he gets checked!! To protect the health of the current and future American male, we ask American women to add one more thing to the list of accepted male duties as follows:

- 1. Cut the grass
- 2. Take out the trash
- 3. Lower the toilet seat
- 4. Get an annual DRE and PSA test after age 50

This article was written by a committee and suggested by Mike Scott The Prostate Cancer InfoLink, <a href="http://www.comed.com/Prostate">http://www.comed.com/Prostate</a> (from http://www.prostatepointers.orglpacnet/wapca.html)

Obviously, this article was written for an American publication. However, the thoughts expressed are equally applicable to the situation in Australia.

## POST-SURGERY PSA LEVELS PREDICT DEATH

Mortality risk for the one in three men who have a recurrence of PSA after radical prostatectomy can be quantified for the first time, a prostate cancer expert says. Data published in the Journal of the American Medical Association (27<sup>th</sup> July) provided the first clear cut risk stratification for men who experienced PSA recurrence, said Professor Gill Duchesne, Head of radiation oncology at Melbourne's Peter McCallum Cancer Centre.

Three key factors were associated with significantly increased risk of prostate cancer mortality – rapidly increasing PSA levels, PSA recurrence soon after surgery and a high Gleason score – according to the study of 379 men.

Patients with all three risk factors had a median survival of only three years after recurrence compared with more than 16 years for the cohort as a whole. (Australian Doctor, 5/8, p3)

## ANTI-CHOLESTEROL ADDITIVES IN JUICE RAISE HEALTH FEARS

Coca-Cola Amatil has applied to sell fruit juice and drinks with a cholesterol-lowering chemical added. The proposal is to add phytosterols, naturally occurring chemicals found in all fruits, vegetables, nuts and seeds. But the Australian Consumer Association is concerned about the impact of phytosterols on carotenoids, chemicals found in fruit and vegetables and which were thought to cut cancer risks.

Phytosterols are already included in margarines and their use in low-fat milk, yoghurt and breakfast cereals is under consideration by Food Standards Australia New Zealand. Dietician Rosemary Stanton said she is opposed to the additive. "Phytosterols reduce cholesterol by sticking to it and taking it out of the body," she said. "But at the same time it sticks to good things such as carotenoids that lower cancer risk." (Daily Telegraph, 5/8, p3)

# Minutes of the Teleconference Meeting of the PCFA- SAC – National Meeting

Held on Thursday 18 August, 2005, Commencing at 3.00 pm

**Teleconference attendance:** David Sandoe (Chair); Pam Sandoe (Minute Secretary); Andrew Giles (PCFA); Con Casey & Graham Nicholls (NSW/ACT); Keith Williams (Qld/NT); Don Baumber (Qld/NT); Gary Bowes & Trevor Hunt (SA); Karen Rendell (WA); Ean McArthur & Bob Wilson (Vic).

Apologies: Bill McHugh (Qld/NT); Ann Smith (PCFA); Jennifer Lyall (Tas).

**Item 1: Welcome** and confirmation of Minutes of previous meeting – moved Keith Williams, seconded Gary Bowes. (Karen Rendell confirmed she had sent an email updating WA events in lieu of attendance).

## **Item 2: Business Arising**

**Speaker's Kit/Leader's Kit (two volume set)** which is in production and should be couriered by end of month. Advice will precede distribution.

**DRE** – Keith Williams/Andrew Giles/David Sandoe to have further discussion regarding a move away from the AMA line to more general application of procedure undertaken by GP's across Australia as part of every day examination for prostate cancer.

## **Item 3: CEO Update** as per **previously circulated** - 3 page report from Andrew Giles.

Update on National Board meeting held 4 August at which time the figures for the last financial year showed the PCFA on budget. The budget for 2006 is \$2.1million. Graeme Johnson has been appointed Deputy Chair of PCFA. With the vacancy caused by the appointment of Graeme, the Victorian State Board Chair is now David Curtain who will also sit on the National body as will Jim Fremantle, WA and David Sandoe, NSW/ACT.

It was decided to call for two further research fellowships by advertising.

They are to be named: (1) Max Gardner Fellowship (2) Mazda Fellowship.

The PCFA, as the peak body, is concerned and interested in establishing the amount of funding in prostate cancer research. The need is to know whether \$10 in every \$100 is the figure or if it is in comparison to Breast Cancer funding.

An audit, perhaps with the appointment of a retired Senior Professor, will be undertaken to establish Prostate Cancer research across Australia which will include funding (government & private); location and specific facilities involved. The information will be recorded on a data base which can be easily upgraded yearly. This is in pursuit of evidence, not yet made available through the Federal Government, of how and where money is being spent on "Men's Health" and/or specifically on prostate cancer. (We have been advised that \$1.4m has been allocated in this area but no evidence exists as to who has the money). This information was requested some 13 weeks ago. "Face to face" meetings will ensure if individual resources are government based or privately funded. The PCFA will then know if a cohesive program is underway. The PCFA may enlighten the Government if nothing is forthcoming from them in the near future. (Andrew indicated he's received advice that similar audit research in the USA took 6 – 9 months – similarly in the UK). All NHMRC funding is relatively identifiable, however, private funding is not.

BHP-Billiton is, perhaps, a likely source of funding for the audit.

Discussions continue with the APCC about possibility of an ongoing partnership.

The parliamentary dinner, in the ACT, with the Minister for Health, Tony Abbott, may be the forerunner for the APIA "Be a Man" launch in the National Capital.

Date still being pursued.

The way South Australia and Qld/NT PCSG's applied for the recent Commonwealth Grants need to be analysed and discussed at the next National Conference in September for other States to learn from their success. It was advised that Ian Kemp from the Department of Health was defensive of the allocations whilst Gary Bowes indicated he made several phone calls in pursuit of their application process and to push the "boundaries".

Debate ensued regarding APIA launch in Darwin (as a capital city); the media interest and coverage it may promote or whether a lunchtime 'handout' of material would be suitable considering the population base. It was noted that dates have not yet been set for Tasmania or South Australia. Discussion will cover these points at the Melbourne launch on 1<sup>st</sup> September with APIA. It was also noted that video airplay coverage in Queensland/Northern Territory is creating awareness and debate.

With the 10<sup>th</sup> Anniversary ALF Match – EJ Whitten Memorial suggestions were made as to why more is not made of the contact between his son and the PCFA (Ted died from CaP). It was decided that an invitation be made to him for the APIA Launch and discussion cover his confusion between CCVIC and PCFA because the monies raised from the match are given to CCVIC with no flown on to prostate cancer research of which we are aware.

Advice was given that the Speaker of the House of Parliament SA has recently been diagnosed, with prostate cancer, so it will be with great interest to follow whether he becomes an Advocate.

## Item 4: State Chapters -

Minutes for NSW/ACT Teleconference – attached to Agenda QLD/NT Teleconference Notes – attached to Agenda

## **Additional Queensland/Northern Territory report:**

Advice received that public awareness meeting set for next week in Gladstone in conjunction with Rockhampton PCSG.

The Commonwealth Grant funding is, unfortunately, not enough to cover video recording of events at Queensland chapter conferences.

Regional areas undertaking "Be a Man" work with success.

The APIA Launch in Brisbane received very poor media response with the timing of the presence of MP Wayne Swan meaning State Parliamentarians missed out attending. All will be available in Cairns when the launch coincides with a parliamentary conference in that City.

The Sanofi-Aventis group is looking to fund PCSG's.

Keith reported activity is on the increase in Darwin with the MLA Independent recently hosting an awareness evening. (25 attended). A secondary school librarian recently sort Keith out to obtain information for a display on prostate cancer which raised the issue of having readily available resources of material for this purpose. A "Kit" definitely required that is 'dateless' to include pull up banners as posters et al. Andrew Giles considered material for use in Metropolitan bus shelters may be suitable.

## **South Australian Chapter:**

Report of Prostate Cancer Action Group (SA) Inc. see attachment from Trevor Hunt.

Gary Bowes reported that TCCA – Lisa Herron held a meeting August 1 to gain information for her project on establishing a cancer consumer network or advocacy group in South Australia.

The Royal Adelaide Hospital approached Gary, as leader of a consumer group, to offer him a Board position with regard to "Men in Hospital".

The recent Commonwealth Grant is to be paid in three monthly increments and the necessary formalities are required on constraints, records and how the money is allocated amongst the groups.

A visit to the Mitcham group now requires local facilitator(s). They have received a sum of money from their local Council.

### Western Australia

Karen advised receipt of local shire grant of \$500. Numbers increasing for each meeting.

Busselton group successful with another visit planned to distribute information booklets from Abbott Australia. Mandurah group led by lady however, retaining interest with 25 attending last meeting.

In Perth, Malcolm Sears has pulled out as Leader.. September 20 their next meeting to which Karen plans to attend.

Lack of connection with WA Board, Jim Fremantle and Cheryl Mellor.

Invitation for dinner, from WA Parliament, at their annual meeting in Albany on 6 September to which Karen has accepted.

This is an Agenda item for State Chairmen to discuss.

## **Victorian Chapter:**

Formal application received on funding of groups by Secretariat.

Victorian Chapter is stalled with discussion on whether 'face to face' or teleconference approach required first up.

Bob & Ean will make contact and encourage affiliation with those Melbourne based groups not yet affiliated.. Peter Cluff is interested in becoming involved in awareness programs.

Following receipt of a letter from Alistair Harkness, MLA for Frankston and Chelsea Member, Ean reworded document to fall in line with PCFA advocacy on diagnosis and treatment.

Ean not impressed with APCC flyers – GP brochures, which have been endorsed by PCFA, with wording of Page 1 regarding statistics etc. (Inference on (yellow card) page 1 – 'counsel your patient at great length and talk them out of testing'. Pages 2 and 3 ok).

NB: Agenda Item for National conference.

National Board to cover off on professional view and governance.

Advice given that Laurie Henss has disbanded his website and pulled out of work with PCSG; Ean indicated an 'opportunity lost'.

Bob Wilson indicated that Cotham Private Hospital is holding a Men's Health Forum night at Box Hill RSL at which he's speaking as a prostate cancer survivor. Requires further copies of "PSA Booklet for GP's" by Phelps/Stricker as he gave his last one away at the initial information session.

Question asked as to whether the booklet went to every GP?

Answer: It was distributed to all GP's within the "Division of GP's" to which not all GP's are bound!

Bob enquired as to HIFU treatment?

(High Intensity Frequency Ultrasound).

Part reply which is still under review: "Nothing definite presented at last AUA Conference in San Antonio, Texas, April 2005. It's been around for best part of 15 years; used unsuccessfully for small renal cell cancers in past; it remains a non-validated technology but attractive marketing tool for surgeons and companies". Apparently Prof. Tony Costello (Melbourne) already has a unit and Assoc. Prof. Phil Stricker (St. Vincent's) obtaining one. It is approved for use but does not receive government funding rebates.

Query as to the rate of prostate cancer in the Arabic/Australian community and the comparison to incidence overseas with the report that translation of "Be a Man" documents are to be handed out near mosques. (Please note SAH PCSG's member keen to be involved in handout if required.)

Bob suggested that we all be aware of the location of PCFA information in Drs. rooms and move them to a more conducive eye level.

David raised the question as to what involvement had been asked of the PCSG's in Victoria for the Launch? Deb Cutts and Shannon Davies need to phone around with their requirements and to establish liaison with groups for the day. Bob & Ean will also encourage groups to participate.

## Additional information from -

## **NSW/ACT – Graham Nicholls:**

Graham will be attending the Public Health Forum being held at Parramatta on 29/30 August. The invitation was extended through CCACT.

In association with Lions, Graham is visiting Bombala in November to be part of a Men's Health open day.

As previously indicated, when and if, the parliamentary dinner with Mr. Tony Abbott is established the APIA launch will go ahead then.

MOVEMBER interest through young voluntary community worker who is willing to approach RMC for candidates to raise funds in the Canberra area.

Item 5 - Brief Updates/Reports on participation in inter-related national health/cancer organisation meetings

#### Don Baumber

Prof Alan Coates retires in 10 months.

Australian Cancer Screening services – Harry de Koenig, Holland, European trial 7/20 countries (2007-2010) wait for results.

Lead time in relation to CaP is 1 - 13 years – psa test going since 1990. No significant mortality drop because of length of time it's been in full swing (1994) in Australia.

Bruce Armstrong not convinced either and he worked on study with David Smith.

Cancer Network working party in Melbourne 4 – 6 September.

APCC funding from PCFA is allowing continuation of the book on "Advanced Prostate Cancer". Also Dr Carole Pinnock recommends that the "Localised Prostate Cancer" be looked at by a working party for upgrade as they are down to their last 10,000 copies.

**David Sandoe** advised that Dr. Phillip Katelaris is now a Director of IMRR and working closely on Magnetic Resonance Spectroscopy imaging with results 'the best ever seen'. Information will be shared as it comes to hand.

Results of the Foundation Diane Gala Dinner at the new Hilton Hotel were very encouraging with the Governor and Sir Nicholas attending together with medical specialists and dignitaries totalling 432. It is encouraging for all cities to do something similar under the auspices of the PCFA.

As reported, the APCC and PCFA new structure continues to bring both parties closer together with the National conference backing the APCC conference with exciting progress being made.

Cancer Voices in throes of design of new livery and logo.

The APCC and Cancer Voices have well distributed Newsletters with both reporting on PCFA.

**Con Casey** indicated the need to review the Lion's website with input and feedback due by 24 August. Please circulate to other interested support group consumer members for dialogue and feedback direct to Con.

## Item 6: Agenda Items National Conference/APCC Conference:

Reference to ongoing strategy plus discussion on and amended/additional Agenda Items under various headings as noted in Minutes.

Attendees at the conference include all National SAC members (12) to discuss policy and directional issues. Additional SAC NSW people are being issued invitations however, consideration is *due on voting requirements for National SAC members* from each state (3 each from NSW/ACT and Qld/NT; 2 each from other states). **Chapters to nominate as per voting rights.** 

Funding requirements for APCC conference attendance.

Ann to organise teleconference between Andrew Giles/Don Baumber/Con Casey/David Sandoe after next week (Andrew away all week) for clear direction/comment/agreement of agenda and include comments as above.

Include review of affiliation rules by Graeme Johnson.

## Item 7: NSW Board Update.

Two meetings have been held to date. Acknowledged services of two medical specialists Drs. Izard and Katelaris on Board. Bryan Lowe, from the Board, was instrumental and persistent in organising the 60 Minute programme.

Through the Managing Director of Telstra Countrywide, Roger Bamber, we have the beginnings of an incredible association and access to rural/remote NSW men. This association also gives access to the Surf Life Saving Association, the NSW Farmer's Federation and the Country Women's Association, which should have a flow on effect to other States through referral from Roger Bamber. Interest generated through Field Days and other community partnerships, including Queensland Rail contacts.

A meeting of State PCFA Chairmen will assist in the moulding and progression of other state boards.

Fund raising for PCFA.

## Item 8: Other Business:

Review of affiliation rules by lawyer, Graeme Johnson, Deputy Chair PCFA, and presentation in 'user friendly' form for edit in draft form.

Big response to 60 Minutes program through website and phone calls. Although the PCFA was not named referral to the 60 Minute website showed 1800 phone number and the Foundation's website address. Some detail missed but no control available from PCFA or through Bryan Lowe to cover off certain issues. If the video is available through Channel 9 all showed keen interest in obtaining multiple copies for distribution.

The Cancer Council of Australia's position statement on prostate cancer is dubious especially in relation to the statement regarding 'high priority on testing'! Perhaps they can give a list of research bodies that are specifically working in CaP field especially with the audit mooted.

Perhaps the approach should be to TCCA on detection of fatal cancers from their list as PCFA is doing an audit. Suzanne Steginga defended their policy.

The need is to politely ask, be non confrontational, as they made the statement.

Poor choice of words: testing screening/monitoring, examination?

Don Baumber will produce a paper with his thoughts and the influence of the position statement that should be better than TCCA.

Question of reduction in age for base line of level of PSA/DRE?

Non-reliance on Urological Society and position statement from the PCFA a necessary requirement.

The PCFA Exceptional Services Awards under consideration for those who need rewarding / recognition with a practical approach. Questioned raised as to whether this was for work with PCFA or CaP in general? Andrew suggested acknowledgement of Lane Cove Rotary long term Directors who have provided exceptional service to PCFA and/or the community with regard to Prostate Cancer. Guidelines definitely needed.

There are now 61 affiliated support groups across Australia. The PCFA website is out of date and Con is willing to assist in moving it forward; needs to include Queensland prostate.org.au.

Business cards are required also for all support group facilitators.

Meeting closed at 5pm.

Next meeting will be the National Conference in Sydney in September.

**NOTE:** Should any item require clarification or amendment please contact the writer.

Pam Sandoe 24 August 2005.

# Melbourne Launch of "Be A Man" Campaign Federation Square 1<sup>st</sup> September 2005

The 'Be A Man- talk to your doctor about prostate cancer' campaign had the Melbourne launch at Federation Square on Thursday 1<sup>st</sup> September. The weather was fine and sunny and there was a great array of high-profile celebrities including football greats Robert Flower and Luke Darcy, Federal Shadow Treasurer Wayne Swan, comedians Brian Dawes, Shane Bourne, Chairman of BHP, Secretary of the AWU, Chairman of the PCFA Patrice Watson, Professor Tony Costello, Angry Anderson and his band, Graeme Johnston PCFA board member, Australian Pensioners Insurance Agency General Manager Kevin Patterson and many more. Also present were Andrew Giles CEO of PCFA, David and Pam Sandoe SAC, many staff from The Cancer Council Victoria.

The compere was Tony Jones of Channel Ten Sport and the opening stand-up comic was Dave Grant- this guy was simply terrific! Then there were the Victorian Support Group members helping and handing out show-bags while wearing their 'Be a Man' white T-shirts, as did all the participants.

The basic message from the speakers was that either they had been diagnosed with prostate cancer or had a father or partner diagnosed, sometimes too late. All agreed on the vital importance of early testing, indeed we were astonished when Professor Costello advocated PSA and DRE testing of men from the age of 35 as a routine part of their annual medical check-up. All in all, it was a great launch, with great injections of humour. One sample was Dave Grant's opening quip that he had not been aware that he had a prostate until told about it on a plane trip. He was so intrigued that he wrote it down on his airline ticket (big shot at Tony Jones and the umpires, of course). Look, it was a great enjoyable day. Attendees from our group were Bob, Kevin and Ean. We enjoyed a few drinks and eats afterwards at the Bok Choy courtesy of the very generous sponsors APIA who are contributing two million dollars over three years to the Prostate Cancer Foundation of Australia.

One of our number pronounced the smoked salmon to be excellent. (Submitted by Ean McArthur)

## **National Prostate Cancer Awareness Month 2005 Proclamation**

http://www.whitehouse.gov/news/releases/2005/08/print/20050829-8.html

For Immediate Release Office of the Press Secretary August 29, 2005

## **National Prostate Cancer Awareness Month, 2005**

A Proclamation by the President of the United States of America

Prostate cancer is the second leading cause of cancer-related deaths among American men. This year, thousands of men will be diagnosed with prostate cancer, and thousands will die from the disease. While great strides have been made in the battle against prostate cancer, we have more work to do. **During National Prostate Cancer Awareness Month**, we renew our commitment to fight prostate cancer by finding better ways to prevent, detect, and treat this deadly disease.

My Administration is committed to funding research for prevention and better treatments for prostate cancer. This year, the National Institutes of Health will invest an estimated \$381 million in prostate cancer research, including \$310 million at the National Cancer Institute. The Department of Defense's Prostate Cancer Research Program will spend an estimated \$85 million, and the Centers for Disease Control and Prevention will devote an estimated \$14 million toward prostate cancer research. Scientists are examining risk factors to identify ways to prevent prostate cancer, and they are finding ways to detect this disease earlier, when it is easier to treat. In addition, newer treatments are helping to slow or stop the spread of prostate cancer in men with advanced stages of the disease. This progress offers hope to men who are living with prostate cancer and those who are at risk.

As we observe National Prostate Cancer Awareness Month, I encourage **all men**, especially those over the age of 50, **to talk with their doctors about the risk of prostate cancer** and the appropriate screenings. I commend those who fight this disease, and I applaud the dedication of researchers, health care providers, and all who are working to increase our knowledge of prostate cancer. **By raising awareness and supporting research, we can save lives.** 

NOW, THEREFORE, I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim September 2005 as National Prostate Cancer Awareness Month. I call upon government officials, businesses, communities, health care professionals, educators, volunteers, and all people of the United States to reaffirm our Nation's strong and continuing commitment to treat and prevent prostate cancer.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty ninth day of August, in the year of our Lord two thousand five, and of the Independence of the United States of America the two hundred and thirtieth.

GEORGE W. BUSH

Newsletter compiled by Trevor Hunt