

P.S.A. NEWSLETTER

Proudly affiliated with the
PROSTATE CANCER
FOUNDATION of AUSTRALIA



PROSTATE(CANCER) SUPPORT
AWARENESS
ADELAIDE GROUP

www.psaadelaide.org

over 1030 hits since Nov 03

A Member of the Association of Prostate Cancer
Support Groups (SA) Inc.

Mailing Address:-
PSA Prostate Cancer
Support Group
39 Greenfield Rd
Seaview Downs, SA 5049
Reg at (08) 8298-8040

Report on the September Meetings.

Held at the Burnside Hospital on 13th September '04

Thank you to our sponsors: Abbott Australasia Ltd., City of West Torrens
Council and the Burnside Memorial Hospital for use of their Lecture Room.

The next meeting will be held on Monday 18th October, commencing at 7.00 pm, when Ms. Ann Bressington,
Counsellor on Drug Rehabilitation, will give a talk on "An Insight into the Problems".

Chair: Barry Oakley.

Members present 48

Apologies: Gerry & Cynthia, Trevor & Coralie, Ken, Kerry, John, Roger & Ann, Lyn and Harry & Alma.

Gerry says he is feeling a little better now and is doing a few short walks. We are also pleased to see Eric Francis at our meeting after his hip replacement operations. Goodonya guys!

Visitors from Darwin: John & Nina joined us from the Darwin P/C Support Group. Their President, Keith Williams and all members of the group send their greetings. John is in Adelaide for 7 weeks, undergoing radiotherapy treatment and gave us a run-down as to how he was progressing. He said if it doesn't work, - bad luck! Well, good luck John!

New Members: Welcome to new members John & Jenny and Bob & Sylvia.

Correspondence:

Newsletters have been received from the following Groups:- Onkaparinga, North East, Barossa Valley, Bundaberg, "The Queensland Prostate Cancer News", the Prostate Cancer Action Group (SA) Inc., Cobram, the Cancer Council S.A. "Mosaic" Newsletter, Andrology Australia, the Prostate News from the P.C.F.A., and the Us Too "Hot Sheet". Members can access the Us Too "Hot Sheet" on the internet by clicking <http://www.ustoo.org>

Letter from the **Australian Cancer Research Foundation**, Sydney, thanking us for supporting and giving a few ideas to Ms. Simone Caruana, for her recent fund raising Dinner Dance when she raised \$13,000 for the Research Foundation. Great work!

Letter from **Ms. Vini Ciccarello, MP for Norwood**, suggesting that we might like to apply for a **State Government Grant, through the Volunteers Support Fund**. Reg Mayes & Gary Bowes, Chairman of the Association of Prostate Support Groups, S.A. (Inc), have had a look at this and dashed off an application seeking funds for all the 5 different S.A. P/C Support Groups. So, here's hoping! We thought we might start off by asking for a small grant of, say, **\$1,000,000**. Just joking!

Prostate Cancer Call-In for 2004: Pamphlet received from the Cancer Council, S.A., reminding everyone about the "Prostate Cancer Call-In" conducted from 6.00pm to 9.00pm on Thursday 23rd September. As this newsletter will be received after that date, you can instead "Ask Andy" on the internet by clicking onto the Lions Club Australian Prostate Cancer web site and then click onto "Ask Andy" and submit your question. You will usually receive an answer by the following Tuesday. Their site is <http://www.prostatehealth.org.au>

Other Business:

Volunteer Small Equipment Grants for 2004:

Our PSA Adelaide Group has now received a cheque for **\$1863** as a grant from **the Federal Government's Volunteer Small Equipment Program for 2004**. This has enabled us to purchase a new computer and a scanner, complete with Windows XP, Office 2003 and Norton Antivirus from Cherry Computers Ltd. Our Webmaster, Ian Fisk, set up and installed the computer and transferred all our records from the old computer to the new one. Many thanks, Ian. The grant only covered the purchase of a computer and scanner and cannot be used for other purposes such as newsletter and brochure production or postage costs. This means that we still have to dig deep into our pockets for these expenses. Sorry folks! We greatly appreciate the grant from the Federal Government's Volunteer

PSA Adelaide Report on September 2004 Meeting

Small Equipment Program. We hope it will save Reg from pulling his hair out over the 9 year old computer he was using.

Royal Adelaide Hospital Public Health Seminar:

This was held on 2nd Sept. when over 90 people attended. We received notice about the Seminar too late to include it in our last Newsletter. However, Reg and Ian went along to hear talks by **Professor Villis Marshall, Dr. Rosie King, Ray Grigg, Tim Noonan, James Smith, Lynette Miller, Dr. Rod Pearce, and Matthew Primus**. Professor Marshall told Reg that he was happy to give our group a lecture sometime during 2005. **The talks, some with PowerPoint presentations, proved to be very interesting.** Next year we will hop in early and make sure we have a good supply of our brochures available to distribute at the meeting. A number of our brochures have since been delivered to RAH Health Promotions (Main Foyer left of escalators). Reg and Ian didn't come away empty handed as they each received a \$6.40 all day bus/train ticket, 20 or so health pamphlets, a bottle of mineral water, a container of Dick Smith's bush breakfast cereal, a Frisbee, 3 free videos about impotence and stress in men, and a condom. Hell, what would we do with a condom? **Anyhow, well done R.A.H. for an excellent well run presentation.** We did our bit by advertising the seminar on our web site <http://www.psaadelaide.org> for 3 weeks before the evening. During question time, Reg was able to get a message across to the audience asking them to click onto our web site for further prostate cancer information. We hope to include extracts from Professor Villis Marshall and Dr. Rosie King's talks in our next Newsletter.



Helen Nikolas, Dr Rosie King, Tim Noonan, Ray Grigg (Chair, Central Northern Adelaide Health Service), Lynette Miller, James Smith and Dr Villis Marshall. "Source: RAH Health Promotion Photographer Sam Noonan Copyright 2004"

Royal Adelaide Hospital Men's Health Initiative, Tool Box Meeting

The last meeting for the year is on **6th October on Skin Cancer & Men** by Anne Melberg - Clinical Nurse RAH Dermatology Day Care Centre on Wednesday between 12.00 and 1.00pm in the Robson Lecture Theatre. Free lunch and 2 for 1 Movie Passes for every attendee. For further Information Call Health Promotion on 8222 5193

Library News:

John Mayes, our Librarian, has donated a book called "**Cancer Myths**" to our library. We also bought a \$30 book titled "**When the Body Says No**", by Dr. Gabor Mate. John spoke briefly on the merits of the two books and has recommended them as good reading to our members. Thanks John.

The Annual Support and Advocacy Committee Conference held at Brisbane on 19th & 20th August '04.

Gary Bowes, Chairman of the Association of Prostate Cancer Support Groups, SA (Inc), and Trevor Hunt, Retiring Chairman of the Prostate Cancer Action Group SA (Inc), both attended this important conference. Gary said that an **overview of the conference** will be sent, through the PCFA, to all of the 60 P/C Support Groups in Australia. We will print extracts from the conference minutes in our next edition of our Newsletter.

The main items discussed were (a) More support for rural men and that the Federal Government should put more emphasis on rural health matters than they do at present. (b) Closer liaison with individual State Cancer Councils. (c) Closer relationship between the Support and Advocacy Committee (the S.A.C.) and the P.C.F.A. which should result in more support and assistance to the 52 P/C Support Groups throughout Australia. (d) Insurance cover matters for the affiliated support groups. (e) How the S.A.C. can facilitate annual conferences in the future. (f) Group workshops with representatives from each State. (g) How should S.A.C. members be nominated and how long should each stay on the S.A.C. (h) Funding of an Australian Wide Awareness Campaign for prostate cancer next year. (i) Linkages/Networking. (j) Education. (k) Prostate Cancer Day/ Month Badging & Publicity. A number of other matters were also discussed. We will keep you posted!

Sarah & Jenny's University of S.A.'s Project

- A Survey on the Public Awareness of Prostate Cancer:

Two very nice lassies turned up for our meeting telling members about a research project they were undertaking for their University studies. Their subject was "the lack of public awareness for prostate cancer." They said that they were bewildered as to why the Government spent \$90 million per year on women's breast cancer research, mammograms etc., but only \$10 million per year was spent on prostate cancer research and awareness, yet both diseases killed about the same number of the sexes each year (**2,600 in Australia alone**). We told the lassies that no one was more bewildered than us! They gave a brief description of their project and handed out specially prepared survey forms which were duly completed by members. The girls were thrilled with the response as they have to get 120 of the forms completed for their project and got at



Jenny & Sarah

Two very nice lassies turned up for our meeting telling members about a research project they were undertaking for their University studies. Their subject was "the lack of public awareness for prostate cancer." They said that they were bewildered as to why the Government spent \$90 million per year on women's breast cancer research, mammograms etc., but only \$10 million per year was spent on prostate cancer research and awareness, yet both diseases killed about the same number of the sexes each year (**2,600 in Australia alone**). We told the lassies that no one was more bewildered than us! They gave a brief description of their project and handed out specially prepared survey forms which were duly completed by members. The girls were thrilled with the response as they have to get 120 of the forms completed for their project and got at

PSA Adelaide Report on September 2004 Meeting

least 35 in one night. Reg handed them copies of our last 4 Newsletters, 3 copies of the "Prostate News" and some information from the Mr. PHIP project, which he thought would be helpful to them. Barry thanked them for their initiative in coming along and addressing the meeting. Many thanks to John and June Field, for bringing the students along to our meeting.

PSA - Prostate Specific Antigen:

Member, Darrell Mulberry, was particularly intrigued with the pixelated photograph of the naked man that is being used in Andrology Australia's "**What Every Man Needs to Know**" publicity campaign. Darrell says that to get the message across is a talent used by advertisers. An innovative presentation and a picture with a catchy phrase is usually used to catch the attention of a prospective customer. **The message I bring is for men over 50 years to get a blood test for prostate cancer indication.** To demonstrate my point I have here a creative picture and an innovative set of words:-



"I present a **Pixelated Picture** of a **Perplexed Person** **Pondering** on a **Profound Problem** of an **unPleasant Performance**.

On **Sighting** **Such** a **Serious** circumstance of a **Singularly Sad** and **Sourly Stream**, he **Should Seek** **Specialist Support** **So** as to **Speedily** certify a **Subsequent, Suitably Satisfactory, Scenario**.

And, **Abate** his **Anxiety Attack** by **Attending An Appointment** with **An Appropriate Adviser** to **Ascertain Actual Awareness** for his **Abnormality**."

PSA Potentially Serious Ailment Get it? Or PSA Prostate Specific Antigen Get it!

Many thanks Darrell for your great effort. This should get the message across. Men 50yrs and over should get a PSA blood test done as early as possible. We will send "Andrology Australia" a copy of this Newsletter.

Xmas BBQ – Sunday 21st November '04:-

A discussion took place as to whether we have our yearly BBQ Xmas party at Graham Lyons' Chapel Hill property near Echunga, or have a dinner at a hotel or a party in the CFS Hall at the Daw Park Hospital. Members generally agreed that the BBQ is best and Graham has kindly agreed to let up have it on his property where he has a large BBQ set up in a shed. We will print a map in our next Newsletter showing the way to get there. All our members & their friends and members & friends of all the various P/C Support groups are welcome to attend. It's a BYO party commencing at 12 Noon. Thanks Graham. Don't forget, Sunday 21st November. Usually we supply hay rides, trike rides, free raffles, and free Xmas cake. Members supply their own chops, sausages, chickens, salads, and drinks.

Five secrets to a good relationship:



- 1 It is important that a man helps you around the house and has a job.
- 2 It is important that a man makes you laugh.
- 3 It is important to find a man you can count on and doesn't lie to you.
- 4 It is important that a man is good in bed and loves making love to you.
- 5 It is important that these four men don't know each other.

From the Cobram P/C Newsletter, August '04. Thanks chaps.

Treatment: revolutionary treatment for kidney cancer

A revolutionary treatment for kidney cancer has been used for the first time in Canberra to save the life of former federal immigration minister and "King of Canberra", Al Grassby.

Mr Grassby was the first person in Australia to undergo the new procedure known as Radio Frequency Ablation and, according to his doctor, the results were excellent.

Professor of Surgery at Canberra Hospital, Mohamed Khadra said the procedure used three needles to introduce high-frequency radio waves to the kidney and "cook" the cancer tumour without affecting surrounding tissue.

A news item picked up by Kathriye Strassnick, Cancer Council SA, From "*The Canberra Times*" 13/8, p2.

GUMBY gummy: (Aboriginal cancer medicine from Central Qld tree). By Roger Large

Roger gave us an update, and now has 4 candidates for the clinical trial. He is going to Rockhampton to try and ensure very tight supply, to keep the product up to those trialing it here. Roger's contacts in Sydney have been using it very successfully, for a few years.

From the Gold Coast P/C Newsletter, August '04.

(We ought to slip up to Queensland and grab a couple of truck loads of this stuff, fast.)

A new case for wheat – a role in beating prostate cancer:

Our member **Graham Lyons**, who is also an Adelaide University researcher studying the effects of selenium on prostate cancer and the levels of selenium in Australian wheat, gave details of a forthcoming clinical trial. **The trial will commence next February** and is designed to test the various bio-marker effects of high and low based selenium laced biscuits on men. Sorry ladies, only men for this trial at the moment. A balanced diet of vegetables, fruit,

PSA Adelaide Report on September 2004 Meeting

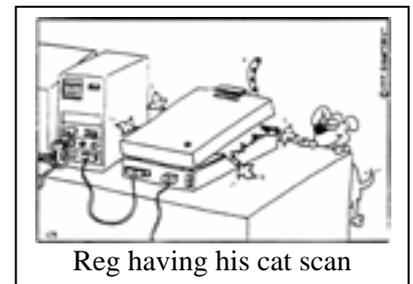
legumes, wholegrain, a bit of meat, fish and a bit of dairy food, just about covers everything in what is considered to be a good diet. But there are several nutrients, such as **follic acid, selenium, vitamin E and iodine** – which in the opinion of some scientists (including Graham), are not delivered at optimum levels, even in a so-called balanced diet.

The anti-oxidant effect of selenium reduces free radical damage to cells and DNA. If you can do something about it early, you should not progress to disease, said Graham. He recommends a daily intake of 220 mgs of selenium. The 6 month trial, eating specially baked biscuits from flour made by the Laucke Flour Mills, is being carried out by the University of Adelaide and the CSIRO Health Sciences and Nutrition Division. Men interested in this trial should ring CSIRO on phone 8303 8882 during working hours. The criteria are for men to be aged between 40 and 70 years of age and who are not undergoing radiotherapy, brachytherapy or hormone treatment at the moment. The volunteers will also have to give blood samples 4 times during the 6 month trial period. Of course, you will have to eat a certain number of biscuits supplied by the CSIRO. You never know, this research could benefit prostate cancer sufferers in years to come. Be in it! The video we screened also gave members details of the research. You can also have a talk with Graham about selenium by phoning his work number on **8303 6533** during working hours if you wish.



Videos and two new machines:

Reg & Ian screened 3 short videos dealing with Testosterone for women, Selenium in flour & wheat and the new “Da Vinci” robotic surgical system being at present installed at the R.A.H. The video dealing with Dr. Holt’s controversial radio-wave heat treatment for cancer has been held over until the next meeting due to shortness of time. It is mentioned that the new robotic machine should be in operation by the end of this year. The machines cost about \$3 million each and the purchase was made possible by a donation from property developer and philanthropist Gordon Pickard, together with businessmen Michael Brock, Rob Gerard and Glen Cooper. Three cheers for these four guys! The State Government will pick up recurrent annual costs of \$500,000 for running the machine at the R.A.H. Head of Urology at the R.A.H., Mr. Peter Sutherland said the technology was a “marvellous international innovation and a major move in this State.” The video gave members an insight as to how the machine operates. Incidentally, Adelaide is the first city in Australia to have one of these machines installed in a Public Hospital.



Talking about new machines, a \$1 million new conformal X-ray machine commenced operating at the Flinders Private Hospital on 13.9.04 and will be mainly used on prostate cancer patients. Reg is going to try it out on 28th Sept. Barry said that Reg already has a tattoo on his belly to mark the spot, but declined to show members the exact location. Shy, isn’t he? The new conformal type x-ray machines are much more accurate than the old broad-beam type machines and have less side-effects. Reg said he hopes they’re right!

Hi Intensity Focused Ultrasound Machines, or HIFU:

In last month’s Newsletter we mentioned the lady who asked us about the HIFU machines as a treatment for prostate cancer. We didn’t know too much about it. The latest is, a clinic in the **Dominican Republic in the Carriibbean** carries out this treatment and say they have about a 90% success rate. Her husband flew to the Dominican Republic last week to undertake the treatment and has promised to give us a run down about it on his return. He will be the first Australian to be treated at the clinic. We might be able to get him to come along to one of our meetings and give us a talk about it. It should be very interesting. It is known as the **Ablatherm treatment** and involves the burning of cancer cells in the prostate gland by using a probe and high intensity focused ultrasound waves.

Lecture by Ray Nicholson - Mantle Cell Lymphoma:

We were very fortunate to have Ray come along and give us a very interesting talk about Meditation, Complementary Medicines, the **Cancer Care Centre** located at 76-78 Edmund Terrace, Unley, and **the story of his own battle with Mantle Cell Lymphoma**. We have printed Ray’s amazing story (page 7) about a miss-diagnosis of the rare disease Mantle Cell Lymphoma, so we will not repeat ourselves here. Ray said that his saviour in battling the disease came from a lady who gave him a copy of **Dr. Ian Gawler’s book “You Can Conquer Cancer”**, a copy of which is in our library. After changing his diet by juicing carrots and other vegetables and fruits he contacted the Cancer Care Centre and practiced meditation and attended a **“Living through Cancer Course”** which he found to be of considerable benefit. He eventually became a volunteer at the centre. Ray pointed out that if you have cancer, **don’t neglect your general health** because one can quite often catch other diseases or wogs that have nothing to do with cancer and these can be easily overlooked with disastrous



PSA Adelaide Report on September 2004 Meeting

consequences. People tend to think that all their aches and pains etc. are caused by the cancer they have and sometimes this is not the case.

Ray also mentioned that he is a member of the **Masonic Lodge** and that the charitable arm of Freemasonry in South Australia and the Northern Territory (**The Masonic Foundation**) **has committed \$75,000 to fully fund a doctoral research scholarship into Prostate Cancer over three years in partnership with the Cancer Council SA**. The project is called "**Men's Secret Business**". All donations over \$2 are tax deductible. (*Congratulations to the Masonic Lodge and the Cancer Council SA for undertaking this important fund raising effort. All we want now is for the Federal and State Governments to hop in with some research funding as well. Reg.*)

Incidentally, **Dr. Ian Gawler, OAM**, together with the Cancer Care Centre, will be conducting a **Cancer Workshop** on the 6th & 7th November, '04, at the Unley Civic Centre. For full details telephone **8373 1470** or Visit the Cancer Care Centre. (ph. **8272 2411**) The cost is \$80 per person on each day with a light lunch & morning tea included, or \$150 for the two days.

At the end of Ray's lecture, Barry thanked him on behalf of all members, and handed him a bottle of the very best Wolf Blass Shiraz. **We think Ray needs it after what he has been through!** Don't forget our next meeting on Monday 18th October when Ms. Ann Bressington, Counsellor on Drug Rehabilitation, will give us a talk on the insight into drug problems.

COMBINATION THERAPY FOR PROSTATE CANCER SHOWS PROMISE

Doctors were able to cut the death rate of prostate cancer patients nearly in half and spare them several serious drug side effects by combining radiation therapy with a limited course of hormone therapy, according to a new study.

The finding could have a significant impact on the treatment of men whose cancer is thought to be localized but who are at higher risk because of higher prostate lab test scores. As many as 125,000 men, or about half of all newly diagnosed cases each year, fall into that category, according to lead author Anthony D'Amico, a radiation oncologist at Brigham and Women's Hospital and the Dana-Farber Cancer Institute in Boston.

"This is really the first study to show you can prolong life by adding hormone therapy to local therapy (radiation) ... for men with localized prostate cancer," said D'Amico, also a professor of radiation oncology at Harvard Medical School.

Men getting the combined therapy had an overall five-year survival rate of 88 percent, compared with 78 percent for those who got just radiation.

"That's a huge survival benefit" see the full article in USTOO Sept 2004 HOTSHEET.

Researchers Identify Distinctive Signature for Metastatic Prostate Cancer

September 12, 2004— Howard Hughes Medical Institute researchers have identified a telltale change in cellular machinery that could help clinicians predict whether prostate cancers are likely to spread or remain relatively harmless in the prostate.

The researchers found that a cellular signalling molecule called Hedgehog, which drives normal development and regeneration of prostate tissue, is greatly activated in prostate cancers. This elevated activity distinguishes dangerous metastatic cancers - those that are likely to spread - from those that remain benign and localized to the prostate.

Prostate cancer is the second leading cause of cancer death in men, and an estimated 230,000 cases will be diagnosed this year, according to the American Cancer Society. Treatment for prostate cancer can cause significant side effects, including sexual and urinary dysfunction, yet may not be needed for men whose cancers are unlikely to spread.

The researchers' findings were published September 12, 2004, in an advance online publication in the journal *Nature*. The scientists were led by Howard Hughes Medical Institute (HHMI) investigator Philip A. Beachy and his colleagues at The Johns Hopkins University School of Medicine, Drs. David Berman and Sunil Karhadkar. Additional co-authors included other colleagues at Johns Hopkins and a researcher from the U.S. Department of Agriculture.

"These findings quite unexpectedly extend understanding of the Hedgehog pathway to a role in prostate cancer, which is a major form of cancer," commented molecular oncologist Charles Sawyers, an HHMI Investigator at the Jonsson Comprehensive Cancer Center at UCLA. "The results are incredibly Interesting, because they are among the most promising I've seen to enable distinguishing good-risk cancers from bad-risk cancers - and thus, those that need minimal therapy from those that are lethal."

The hedgehog signalling pathway is a well-known regulator of organ development Beachy and his colleagues, as well as researchers at other Institutions, have found that in some cancers, this pathway has escaped the normal control mechanisms and helped spur uncontrolled cell proliferation. These include cancers arising in organs of the gastrointestinal tract, such as the stomach, pancreas, esophagus and biliary tract.

According To Beachy, since all these cancers arise in organs of endodermal origin, it seemed reasonable to test whether activation of the hedgehog pathway might similarly drive the development of prostate cancer, which also arises from endodermal tissues.

PSA Adelaide Report on September 2004 Meeting

In their initial studies, Beachy and his colleagues established that the hedgehog pathway was, indeed, active in cultures of human metastatic prostate cancer cell lines. Blocking Hedgehog signalling with cyclopamine, a drug discovered by Beachy's group that targets another protein in the pathway, *Smoothened*, inhibited growth at these cell lines. Furthermore, they showed that when the tumor cells were introduced into mice, cyclopamine caused a permanent regression of the tumors.

"We Interpreted the finding in mice to mean that we had probably killed tumor stem cells responsible for propagating the cancers," said Beachy. "This finding led us to explore the role that the hedgehog pathway might play in the function of normal progenitor cells."

To study the relationship of the hedgehog pathway to normal prostate stem cells, the researchers performed experiments in mice in which they eliminated the male hormone, androgen, causing regression of the prostate. Normally, restoring androgen causes the prostate to regenerate. However, the scientists were able to block this regeneration by giving the animals cyclopamine or a hedgehog-neutralizing antibody.

In additional studies of cultures of cells that closely resemble these prostate progenitor cells, the researchers found that switching on the Hedgehog pathway caused them to proliferate and form tumors when implanted into mice.

"This was a very striking observation, because it's very tough with manipulation of expression of a single cellular gene - and has never been done before, to my knowledge - to cause a primary human cell to become a cancer," said Beachy. "And that suggests that perhaps we have identified the right prostate target cell and activated the right pathway to trigger cancerous growth."

To relate their findings to the metastatic process, the researchers tested samples of metastatic prostate cancer from men who had died of the disease. They found a uniformly high level of Hedgehog activity in these tissues, compared to benign prostate tissue samples. The researchers also found high levels of Hedgehog pathway activity in rat prostate cancer cells known to be actively metastatic.

In contrast, cells that were not metastatic showed low levels of activity. In particular, said Beachy, their experiments showed that pathway activation in metastatic cancers depended on the expression of *Smoothened* - suggesting that gene may be "a focal point of regulation in tissue regeneration and tumorigenesis."

They also found they could convert low-metastatic cells into highly metastatic tumors by activating the Hedgehog pathway. "We actually found we could interconvert the two kinds of cell lines in mice," said Beachy. "Whereas the high-metastatic lines were normally rapidly lethal in the mice, we could prolong survival essentially indefinitely by giving them cyclopamine. And when we activated Hedgehog in the low-metastatic lines, they became highly lethal," he said.

HHMI investigator Matthew Scott, a developmental biologist who has studied the Hedgehog pathway at Stanford University, noted that Beachy's "study is very thoroughly done and holds great promise in the search for new treatments for human disease. Quite possibly only some of the cells in a tumor - "tumor stem cells" - have the especially dangerous property of unlimited growth, so the search for ways to identify such cells is important," he said.

According to Beachy, both diagnosis and treatment of prostate cancer could benefit from understanding the role of Hedgehog activation in carcinogenesis. "If clinicians could use Hedgehog activation - perhaps measured by detecting some marker in the blood - to distinguish indolent from metastatic disease; they could know to treat the metastatic form and not the indolent form," he said. "If the indolent form, for example, were detected in older men, it might not be as necessary to perform a prostatectomy, since there would be little likelihood of metastasis.

"This finding also suggests that it may be possible to treat the metastatic disease with inhibitors of the Hedgehog pathway" said Beachy. "However, given the broad importance of this pathway, there are questions of unwanted side effects. We have been able to give effective doses of cyclopamine to mice for long periods of time without any obvious detriment. But we have no idea whether there are long-term physiological effects, or whether humans might suffer side effects that we could not detect in animals."

Diagnosis: *Mantle Cell Lymphoma from Cancer Care Centre Inc - Healthy Living June 2003*

Living and working in Melbourne in the four Years leading to my cancer diagnosis, I was travelling extensively overseas for my Company. I contracted a number of illnesses - cholera, shingles, rubella, chronic rhinitis, frequent diarrhoea, bad coughs and so on. Medical treatments were administered for these ills but no one could attribute the reason for me picking up so many complaints. My general health was declining - burning and very red eyes, very dry mouth, night sweats, ears constantly ringing, coughing, shortness of breath, stuffy nose, extremely tired both lacking energy and motivation (I had to push myself all the time), prone to excessive chills where my bones seemed to be frozen, waves of feeling very unwell, headaches, pains in my back.

My doctor kept ordering more and more blood tests. He was convinced that there was a serious problem but could not diagnose it. Then one day the blood analysis showed positive for Hepatitis C. Shock horror! This was of great concern. How could I have contracted this disease which is transmitted by bodily fluids? I was sent to a

PSA Adelaide Report on September 2004 Meeting

gastroenterologist who asked some very intimate questions to which he received negative responses so I was sent to another specialist who was conducting research into Hep C and he asked the same questions to which he received similar responses. So a rerun of the blood tests, an ultrasound and HIV/Aids tests concluded that I did not have Hep C after all but had a blood condition that saw me then referred to an haematologist.

It transpired that the laboratory had mixed up blood samples so that was the bad news. The good news was being referred to the haematology oncologist. He immediately ordered a bone marrow biopsy from where the diagnosis was made on 19th December 1977

In sombre terms the doctor advised my wife and me: You have a condition known as mantle cell lymphoma (one of the non hodgins lymphoma's). It is rare, about 5-7% of the lymphoma's, very advanced at stage 4 and is spread through your bone marrow and lymphatic system including tumours in **your** spleen, arm pits and neck. This disease behaves more aggressively than other cancers and it is a malignancy. There is no recorded cure. Treatments from moderate to radical chemotherapy, to a combination of various drugs, may provide temporary relief from your present health condition but will not prolong your life as toxic treatments were not curing anyone with this disease. The Lymphoma in the bone marrow will increase and spread to peripheral blood and other bone marrow cells. As the way forward is not clear medically, we will have a watch and see regime, monitor your progress, and consider action when your position deteriorates further. Wow!

Our wake up call at age 58 could not have been any clearer. With a Medical Certificate for indefinite sick leave from work, we left the hospital in a state of shock, anguish, anxiety, anger, confusion and high emotion. We moved back to Adelaide near our children. My wife had suffered bowel cancer ten years earlier requiring a major operation - the disease had again entered our family and me the invincible one, "who never used to get sick", struck down. Just before leaving work I was given two books - one by a staff member on spiritual living and one from my boss's wife, "You can Conquer Cancer" by Ian Gawler. This book became my guide and reference manual. In response to the question of what I would like as a retirement present from work, my farewell gift could not have been better - a Champion Juicer.

Back in Adelaide my daughter suggested that I visit the Cancer Care Centre Inc to see what they could offer. So I came to the Centre. I set life style goals of- Diet, juicing, organic fruit and vegetables, limited meat, no processed food, exercise, goal setting (life events in the near future), attitude (I really wanted to get well again and having a strong faith) and **de** stressing particularly meditation (the silent healer). At the Cancer Care Centre I attended Meditation Classes, their Living Through Cancer Course and a Support Group. For the next two years life consisted of monthly trips to the QEH Oncology Ward, more tests and examinations with no treatment offered. With the great support received from the Cancer Care Centre I decided to "give something back" and trained as a volunteer.

I was surviving against the odds but concerns were growing regarding the spread of the disease. My blood results were declining, spleen was grossly enlarged and all the rigours of ill health prevailed. By February 2000 my condition was very poor and the doctors recommended immediate intensive chemotherapy treatment called Hyper CVAD. The comment was, "your bone marrow is now chock full of tumour". This required me to enter hospital for each treatment as I was placed on a 24 hour drip prior to the chemo to reduce the effects of toxicity. Complete hair loss of course occurred and Nilstat and Amosan protection fought a losing battle against mouth ulcers and infection. The months wore on. Eleven visits to hospital either for treatments or sometimes due to soaring temperatures, a number of operations, treatments for leg ulcers, abscess' on my rear end resulting in two visits to the operating theatre and isolation in hospital for an e-coli infection. Numerous platelet and blood transfusions kept my blood counts at some sort of level to cope with living. Sickness with chemo was the norm coupled with an inability to eat caused a weight loss of some 20 kilo's.

Every smell churned up an overwhelming desire to be sick. Within our church community we received a lot of prayerful support. Meditation was maintained but sometimes even this was too hard to handle. Tai Chi lessons were undertaken and set a goal to do Tai **Chi** on the Great Wall in China - this was achieved.

I can't precisely date the time when I turned the corner to start feeling less sick and more well. It had been a slow process. In September 2000 the doctor advised that while the tumours had been reduced and my spleen had reduced in size the chemo treatment regime could not continue at the present levels. A Splenectomy was carried out to remove that area of cancer and the decision was made to kill off my bone marrow and transplant my stem cells in an endeavour to re-grow new non cancerous bone marrow. Contracting pneumonia after my spleen was removed slowed progress. However sufficient stem cells for two bone marrow transplants were harvested. On the eve of the Sydney Olympics I entered hospital for six weeks to undergo BEAM chemo to kill my bone marrow and when my blood counts were off the bottom of the scale to transplant my stem cells - I then learned what it was like to be really sick. Whatever was left of my immune system was ruined. Weeks of nausea, ulcers from my lips down into my gullet, no interest in the Olympics (or anything else), and time had no meaning. After about 25 days of purgatory my blood counts started to rise indicating that the bone marrow graft had taken - progress indeed and I was slowly regaining strength.

PSA Adelaide Report on September 2004 Meeting

In October the decision was then made to undergo a treatment of mabthera (a monoclonal antibody especially designed for this lymphoma), to kill off residual cancer cells (I had located this treatment on the internet). In December a bone marrow biopsy revealed some minor "strands" of lymphoma but for the most part it had been eradicated

The year 2001 saw progressive improvements in health and this has vindicated my mantra, "every day and in every way I am getting better and better" which I kept repeating all the way through my journey of coping with cancer. The Cancer Care Centre resumed its place in my life and activities there increased helping where I could to serve the needs of clients and the well running of the operations.

It is now 2 and half years since treatment and 1 am in 'full remission'. One cannot be complacent of course, but it is great to get on with life. What has been learned from this experience? Given the early incorrect diagnosis, I believe one should always seek a second opinion on major health matters. Set about taking control of your cure. Learn as much as you can about your disease (if you are on the internet this is great), attend a Living With Cancer Course.

Keep asking questions of you doctor re treatment options. Take every opportunity to improve your general health including diet, meditation and exercise. Get an interest in life (Cancer Care Centre provided this fillip for me). Join a Support Group. Don't ever give up - medical advances are continually coming along. Have faith. Mental attitude is everything. Life is great, precious but tenuous. The old adage one day at a time is true but look up and plan what you might like to do to enjoy that day. Take an interest in those around you and see where you can help. When you think you are sick then there will be someone who is sicker.

Thanks go to God, family, the many doctors and staff at the hospital and volunteers at the Cancer Care Centre who provided support in my journey with cancer. *Ray Nicholson-*

The Place of Beer	Tax time again!
<p>A professor stood before his philosophy class and filled a large jar with golf balls. The students agreed that the jar was full. He then poured pebbles into the jar, shook it lightly and the pebbles rolled between the golf balls. He then poured sand into the jar and it filled up everything else. Then he poured in two cans of beer.</p> <p>'Now this jar represents your life. The golf balls are the important things - your family, your children, your health, your friends, your favourite passions - things that if everything else was lost and only they remained, your life would still be full. The pebbles are the other things that matter - like your job, your house, your car. The sand is everything else - the small stuff. If you put the sand into the jar first, there is no room left for the pebbles or the golf balls. The same goes for life. Pay attention to the things that are critical to your happiness: play with your children; take time to get medical checkups; take your partner out to dinner; play another 18 holes. Take care of the golf balls first, the things that really matter. The rest is just sand.'</p> <p>A student inquired what the beer represented. 'I'm glad you asked.' replied the professor. ' It just goes to show that no matter how full your life may seem, there's always room for a couple of beers.'</p> <p><i>From the Bundaberg P/C Newsletters, Aug & Sept '04. Thanks guys.</i></p>	<p>Murphy meets Shamus down at the local.</p> <p>"My shout" says Murphy to Shamus.</p> <p>"You seem happy today Murphy" says Shamus.</p> <p>"To be sure, to be sure" says Murphy.</p> <p>"For years now the Tax Dept has been hounding me saying I owe them money.</p> <p>Well, today I received a letter from them saying "FINAL NOTICE."</p> <p>Thank God I won't be hearing from them again."</p> <div style="text-align: right;">  </div>

This Newsletter was compiled and typed by Reg Mayes. Ian Fisk, Jeff Roberts, Paul Ferrett and Reg folded and posted the Newsletter. After re-arranging news items on his computer and supplying the photographs, Ian printed the master copy. 270 copies were distributed. We would like to thank the Cancer Council South Australia for providing their support and particularly Anne Milne for her contribution. The views expressed in this Newsletter do not necessarily represent the views of The Cancer Council SA.