



PROSTATE CANCER FOUNDATION OF AUSTRALIA CENTRAL AUSTRALIA CHAPTER

Inaugural Conference - 16th & 17th October 2009 Mt Lofty House, Crafers, South Australia

Present: 35 members including guests – registrations attached in Appendix 1

Opening at 9.00am

Chairman Malcolm ELLIS welcomed all present to the inaugural conference of the PCFA Central Australia Chapter. He thanked everybody for their commitment and input to the CA Chapter during its first year. He went on to comment on the achievements of the Chapter during this first year of operation and made particular mention of the success of visits by Council to various support group locations for Council meetings.

Apologies: Phil DAVIS (Payneham) and Jeff ROBERTS (Action Group) The Hon Mr John Hill, Minister for Health; The Hon Christopher Pyne, MHR; Mr Graeme Johnson, National Chairman, PCFA; Mr Andrew Giles, CEO, PCFA, Mr Peter Gebert, Chairman of Support and Advocacy Committee of PCFA.

Conference opening

Paul REDMAN, Support Group Services Manager of PCFA then officially opened the conference on behalf of PCFA. He noted that all support groups in South Australia and the Northern Territory were represented at the conference and thanked everybody for making the effort to be present. Paul illustrated how PCFA represents prostate cancer sufferers both Nationally and Internationally. He presented details of the organisations strategic goals as set for 2008 – 2011. Members were informed that PCFA has a current annual income of about 10 million dollars and currently had over 9000 support group members.

PCFA research projects are funded for up to a four year period to provide for stability and continuity. Paul mentioned a number of research projects including a potential ability to more clearly identify causes of death and thus more readily identify mortality rates from prostate cancer.

Paul spoke on the success of the Movember campaign and PCFA Awareness campaigns and how they had led to many more men undertaking annual testing. Members were provided with details of the membership of the National Board of PCFA and explained how the Board interacted with other groups. The presentation is attached as Appendix 2.

Radiation Therapy Services at RAH for Prostate Cancer Patients

Members were provided with an extremely interesting presentation on this topic by Dr Raghu GOWDA, Senior Radiation Oncologist from RAH.

Dr Gowda commented on how important it is for clinicians to acquire an in depth knowledge of their patients and used “The Good, The Bad and The Ugly” to illustrate this fact. He stated that patients fall within risk groups of either *low, intermediate or high* and what investigations were undertaken to ascertain which group was relevant to each patient. Once the relevant patient group had been identified than treatment options had to be considered against the various risks involved. One of the objectives of treatment is “*prize v price paid.*”

Radiation is not a new concept with it first being considered in 1896. It is now used to treat a whole variety of cancer problems. Dr Gowda went on to explain how each type of radiation treatment worked. This included a brief look at the “journey” of a radiation patient.

Brachytherapy treatment was first postulated in 1903 by Graham Alexander BELL. Dr Gowda then explained the steps taken in modern brachytherapy treatment. He used an extremely informative power point presentation to illustrate this procedure.

He concluded his presentation with some discussion on the various side effects that might be experienced by radiation patients. These were obviously dependent on the type of radiation received and the type of cancer being treated.

An in depth Question and Answer session followed following which Dr Gowda was thanked by acclamation and presented with a small gift on behalf of the PCFA CA Chapter.

Molecular Biology and Prostate Cancer

After a short break Paul Redman then introduced Dr Grant Buchanan from the Molecular Ageing Laboratory at the University of Adelaide. This is a PCFA 4 year research project.

Dr Buchanan provided details of the research team members along with statistics of prostate cancer in relation to diagnoses, new cases identified and deaths from prostate cancer.

He described what a prostate gland does in a healthy male body and went on to illustrate the various clinical states of a prostate gland.

By way of a power point presentation he took members inside an actual cell of a prostate gland and demonstrated the effects of testosterone on a prostate gland cell and the resultant effect on a patients DNA at anyone of 250,000 different sites.

Grant went on to explain what happened if the availability of testosterone was limited or suppressed totally. He displayed the results of some of his team’s research into the reaction of proteins with each other and explained how they were working towards the development of a synthetic protein to mimic various results which they had identified.

Researchers were hoping to reprogram the activity of proteins in a prostate gland in an attempt to treat prostate cancer. He commented also that there was a lot of activity by researchers to develop a vaccine to treat prostate cancer.

Dr Buchanan then invited questions from members present. Many were forthcoming and one in particular was quite memorable. During his presentation Dr Buchanan had used the nomenclature “SGTA” to identify a particular protein. The questioner asked “What does SGTA stand for?” Without hesitation Dr Buchanan responded “*Small glutamine rich tetratricopeptide repeat domain containing protein alpha.*”

Support Group Highlights

Paul invited a representative from each support present to comment on three highlights and one issue from the past 12 months within their particular support group.

ADELAIDE Ian Fisk - spoke of how close the group came to folding but was glad it was able to continue, he spoke of the excellent speakers the group had heard from and the friendly atmosphere experienced at group meetings. An issue for the group was the need to attract more members and how they felt the need for PCFA to establish the CA Chapter Board and locate its proposed office in Adelaide.

ONKAPARINGA John Shields - donation of \$1000 received from Willunga Lions Club, grant from City of Onkaparinga for a photocopier and the willingness of volunteers who attended at Paskeville. As an issue John identified leadership training.

BAROSSA VALLEY Alan Hall - their opening meeting where 31 visitors plus guests attended and their Cancer Forum which attracted 57 visitors were both highlights. Positive feedback was received from both events. Alan commented that as a group they had succession planning in place. As an issue they hoped that PCFA would continue to support member groups that offered services beyond prostate cancer.

ALICE SPRINGS Murray Neck - group has 48 members and was growing. He was particularly impressed with the Council meeting which coincided with the groups first anniversary dinner. The group is reviewing member’s contribution to administrative matters of the group. They have 2 members of the Ambassadors program but getting guest speakers is a problem. As an issue Murray wanted to get the message out to under 55’s and is currently working on a plan to do so. Paul Redman commented on how successful the dinner was and the wide range of local community members who attended.

MITCHAM Terry Harbour - regular attendance at meetings is in the high 20’s including wives. He informed members of a chap who attended at one meeting by taxi from Pt Adelaide. Terry said as a group they had been able to attract good speakers and not all spoke on prostate cancer or health matters. He also spoke of how their group could be located via Google Earth. The issue he mentioned was making sure that member’s needs are being met and to ensure this occurred, a group survey had recently been undertaken.

KATHERINE Don Lockley - a relatively new group with a very small membership. Don expressed his thanks to Keith Williams from Darwin for his assistance in setting up the group. The group caters for sufferers of various cancers and receives a lot of support from the local Philippine Association. His issue was to increase membership.

MURRAY BRIDGE Ron Lehman - his group was also a relatively new group having been founded in May 2009. They had had a good inaugural speaker and thanked PCFA for their support in getting the group off the ground. He also thanked the local Freemason group for their help. He recognises the need to undertake more PR activities. It is noted that many members were not prostate cancer sufferers, just genuinely interested in the group activities. As an issue Ron explained that many members hoped to see results of research.

PORT PIRIE Alan Manfield - their group has 15 members from a population of about 15,000 so a lot of effort is going into attracting more to join their group. As a group they do not record minutes and have adopted a very casual approach to administration. Social visits are arranged for members to local places of interest, they hold awareness days and a Father's Day raffle. They have arranged an internet connection and have had some very interesting guest speakers including a representative from a local funeral home. The group has received support from local TV and radio station. The major issue is a lack of regular good guest speakers and they would welcome the acquisition of a photocopier.

Advanced Prostate Cancer

Paul introduced Dr Carole PINNOCK AM, Ph. D, Principal Research Scientist, Daw Park Repatriation General Hospital, Adelaide. She informed members of the work being undertaken in the preparation of the new publication "*Advanced Prostate Cancer – a guide for men and their families.*"

Dr Pinnock spoke of how well received the previous book entitled Localised Prostate Cancer had been amongst consumers. This book had first been published in 2001 and its 5th reprint was due in the very near future. Nearly 11,500 copies had been distributed.

A need had been identified for a guide to advanced prostate cancer for doctors and the work had been commenced in 2004. A lengthy development process had been undertaken and currently a draft publication should be available in the very near future. A consumer's version would also soon be available.

This had come about after identifying from various sources what it was felt men and their families required. The purpose of the guide was expressed in the term "I believe we can handle it if we know what's going on." This new guide will have 12 chapters and Dr Pinnock went on to list their contents. Some diagrams were also presented to members.

Dr Pinnock spoke of emerging treatments for prostate cancer and what their side effects might be. She also commented that it was possible that in the future the clinical guidelines might be updated annually in order to avoid having to undertake the large amount of work involved in the current update.

Questions were invited from the floor and the response was quite varied. At the conclusion Paul presented Dr Pinnock with a small gift.

Her presentation is attached as Appendix 3.

Support Group Highlights (continued)

PAYNEHAM Peter Woodrow - theirs was a new group formed late last year but their numbers are good with a regular attendance of 30 – 40 members at each meeting. They are a mixed support group with lots of involvement from wives and partners. The group produces a monthly newsletter and has a heavy involvement in the local community. Regular updates of brochures in doctor's surgery and the Tea Tree Gully library are undertaken. A good response was received from members for involvement in the recent Bunning's promotion and for BBQ's at the local library. Succession planning was an issue for the group.

McLAREN VALE Bruce Driver - the group had started small but was increasing in its membership. As a result of its somewhat isolated location the group had extended its interest beyond prostate cancer to include general men's health issues. Some very good speakers had made presentations and noted that at the groups last meeting the speaker had been a representative of a funeral home. This had been well received by members. No problems had been incurred in getting volunteers for awareness days. Group convenor Bryan Hearn commented that as an issue the group was concerned with the failure of PCFA to honour many of its promises made to support groups and their members.

ACTION GROUP Dean Wall - considered that many people within the group were prepared to act when something was needed and he paid special compliment to Jeff Roberts for his involvement with the recent awareness night at Murray Bridge and information stall at Paskeville. As a group they had been involved in arranging a number of awareness days both in the Country and the Metro area as well as staffing information stalls at various events. An issue for the action group was the lack of support groups being formed around the State and the withdrawal of funding by the State Government for the Man Alive program.

DARWIN Keith Williams - encouraged wives to attend group meetings and urged them to have input into the groups administration. Group had a successful involvement in the recent Relay for Life program held in Darwin and had successfully assisted in the establishment of a support group in Katherine. Succession planning was an issue.

Minutes of previous meeting

Secretary Bryan Hearn spoke to the minutes of meeting held 22nd September 2008 in the Grand Chancellor Hotel, Adelaide. All present had been provided with a copy of these minutes. This meeting identified the suggestion of forming the CA Chapter.

Bryan Hearn moved that these minutes be adopted as a true and correct record of the meeting
2nd by Bev Ellis Carried on a show of hands.

Business Arising

Chairman Malcolm Ellis spoke to the issue of winding up of the previous “Association.” He commented on how much more efficiently the Chapter was operating when compared to the previous Association which will be wound up in the near future. Malcolm commented on how the Chapter had gone from strength to strength and how well the Council had been received at the various locations where Council meetings had been held. He looked forward to continuing with visits to support group areas. Keith Williams spoke on the early formative days of SAC in 2001 and provided a brief history of events from then to current times. He felt that the current Council was an amazing group that worked so well together with so much support from member groups.

A question was asked relative to the attendance of the SAPOL nurse at the previous meeting. Dean Wall responded by informing members that contact had been maintained with the nurse and as a result all SAPOL employees will be subject to an Ambassadors presentation.

Bryan Hearn requested all groups to document the history of their early development and forward to himself as Chapter secretary. He stressed the importance of documenting the Chapter history in this way and undertook to collate all information received from members. Malcolm Ellis commented that this should be extended to include the Association as well along with NT groups who may have had an involvement with Queensland in their early days.

An explanation was provided of the role to be fulfilled by the CA Chapter Board once established. Their role would basically be fundraising and event organising. They will not be in a position to instruct support groups on what they should be doing or how to do it.

Alan Manfield asked about the proposed Chapter logo. Paul responded by stating that he hoped later that day to be able to table 2 alternatives designs from which members might select one for adoption – sadly the designs did not arrive in time for the conference.

Chairman informed members of the monthly Council executive teleconferences and how other Councillors were kept informed where any need was identified. Some discussion was held on the frequency of convening Chapter teleconferences and ultimately it was moved John Baulderstone and seconded by Terry Harbour that Chapter teleconferences be held in the month prior to each Council meeting. This was carried on a show of hands.

Chapter Reports and Strategic Planning

Those present had been provided with a copy of the proposed discussion paper relative to the formation of a new support group. Given the complexity of the document it was agreed that members would need to read the document thoroughly prior to discussion tomorrow.

Paul spoke of Informed notice boards in GP surgeries and their involvement and commitment to PCFA. He explained how they were preparing a special brochure run for a 3 month period commencing December 2009. Paul also spoke about the 2008 Federal Government grants and what was being applied for in 2009.

It was hoped to provide support groups who received benefits from the 2008 grants with a PA system with speakers and a radio and collar microphones, a screen and a multifunction printer/scanner. New groups will receive the same equipment plus a lap top and digital projector. Members should note that all lap tops and data projectors carry a 3 year "on site" service warranty and guarantee.

General comments were made by several members of the invaluable input into groups by wives and partners and how much this was valued. Paul informed members that in WA they had 2 female Councillors and a female SAC rep.

Expenses and Budgets for Support Groups, Councils and Chapters

Paul delivered a power point presentation on this topic slides of which are attached as Appendix 4.

Support Groups should note that funds received in any particular year should be spent during that same year.

Paul confirmed that each Support Group receives a telephone allowance of \$20 per month and an internet allowance also of \$20 per month. Councillors receive similar allowances at the rate of \$30 per month but if a Councillor should also be a group convenor he will only receive the higher amount, not both.

CA Chapter SAC representatives

Chairman Malcolm Ellis introduced the three current SAC reps being Dean Wall, Keith Williams and Ian Fisk. Each rep is required to serve a 3 year term of office with the possibility of an extension of 12 months in exceptional circumstances.

Ian's term of office concludes in December 2009 and he will therefore need to be replaced as a CA Chapter SAC rep. At this point Malcolm vacated the chair as he was nominating to fill this vacancy. Paul called for nominations to fill the vacancy with Malcolm being the only nominee and consequently appointed to the vacancy. Malcolm resumed as Chairman and thanked Ian for his input over the past 3 years.

Any other Business

Keith Williams raised as an issue a desire to put in place a scheme whereby any sufferer and/or carer attending a major hospital in Adelaide for treatment from a country region could have a contact in the metro area to advise of the visit and to arrange local contact as appropriate.

Following discussion Keith Williams moved, seconded John Shields that a Councillor be appointed as the contact liaison officer for this purpose. Motion carried on a show of hands.

Geoff Kain from Alice Springs volunteered to be the liaison contact point from their end. In general discussion it was noted that, in order to maintain privacy, a patient's authority should be first obtained prior to making any arrangements

Business Plan

All members present had been provided with a copy of the proposed CA Chapter Business Plan. As the author of this document Terry Harbour addressed members as to its contents. He welcomed input from members particularly as to information for the "Accountability" column. Terry requested that any changes, amendments and additional information be emailed to him on harbour@adam.com.au.

He pointed out that many of the roles are not necessarily restricted to Councillors.

Councillor's position

Ian Fisk queried his ongoing role as a Councillor now that he would no longer be a SAC rep. It was noted that Ian was a Councillor on the basis that he was a SAC rep and therefore his role as a Councillor would conclude at the completion of his SAC term – 31st December 2009. He pointed out that this would mean that the Adelaide group would have no representation on Council. The Chairman responded by stating that other groups also have no representative on Council.

During general discussion that followed, it was noted that currently Council consisted of 10 members despite fact that guidelines required only 9. The reason being that John Shields had been co-opted on to fulfil the role of treasurer. Dean Wall moved, seconded Bev Ellis that John Shields appointment as Chapter treasure be ratified by this meeting. Motion carried on a show of hands.

This would mean that as from 31st December 2009 Council would revert back to 9 members. The Chairman explained to members that each Councillor's term of office was for 3 years but that under the Chapter's guidelines, in an attempt to provide sustainability and maintain continuity, only 3 members would be eligible for re-election for each of the next 3 years.

It was noted that no structure existed within the current guidelines to cover the filling of a casual vacancy. This matter to be addressed in the course of business tomorrow.

Moved John Shields, seconded Dean Wall that a Councillors term of office shall commence from 1st January following the date of AGM at which appointed. Motion carried on a show of hands.

Ambassadors

Concern expressed re the lack of co-operation between ambassadors and support groups. The proposition that steps be taken to remedy this situation was discussed. Paul explained that the ambassador program was administered by another body outside of PCFA and therefore any action taken would require input from both bodies.

Suggestion made that all Ambassadors provide their contact details to Chapter secretary who will then be in a position to exchange contact information between all support group convenors and ambassadors.

Nutrition

Malcolm Piggott, Murray Bridge asked Paul if PCFA had any funding directed towards areas covering nutrition, minerals and other alternative medicines. Paul was unsure if PCFA were moving in this direction but agreed to provide Malcolm with contact details of relevant groups who did. In saying so he noted that Complimentary Medicines were included in the customer guidelines that Dr Carole Pinnock had spoken about earlier.

Keith Williams commented that a book by Sir William KEYES entitled “Flowers in Winter” made excellent reading on this topic.

Paul commented on a number of the issues raised by Support groups during the day and noted that many would be addressed during the second day of the Conference. He also commented very appreciatively on the work done by the Action Group during the past 12 months re awareness days and their plans for further such awareness days in the upcoming near future.

4.50pm Day One of Conference completed.

Day 2

17th October 2009

Present: 35 members plus guest speakers

Paul welcomed new members who had not been present yesterday. He then recapped on all presentations delivered on Day 1 and commented on the high quality of each.

Chairman read to the meeting a proposal prepared by Chapter Secretary relative to the Casual Vacancy issued raised yesterday. After general discussion of this proposal the following motion was moved by Trevor Muirhead (Murray Bridge) and seconded Ron Lehman (Murray Bridge) that:-

“Should a vacancy occur on Council for any reason whatsoever it should be declared a “Casual Vacancy”

Such Casual Vacancy shall be filled by Council co-opting another member onto Council in which case that appointment shall be ratified at the next AGM.

Such appointment shall only be for the remaining period of the term of office in which the vacancy occurred at which time the incumbent shall be eligible for re-election as per rule 7.

No Casual Vacancy shall be filled if occurring within 6 months of the completion of the term of office of the outgoing member.”

Motion carried on a show of hands.

Guest Speaker

Paul then introduced to members the Leader of the State Government Opposition and the local member for Hysen, Ms Isobel REDMOND.

Isobel spoke enthusiastically of the Mt Lofty area and her involvement with local organisations. She also informed members of some of the plans of the opposition in the lead up to the next State election and in particular for the Royal Adelaide Hospital.

Questions were asked for from the floor and during this time Pam Fisk suggested that at some time in the future Parliament should be presented with an Ambassador type presentation on Prostate Cancer. Isobel commented that this had already been done on Juvenile Diabetes and saw no reason why this couldn't occur after the election.

At the conclusion of her speech Paul presented her with a small gift and she left to a standing ovation.

Beyond Blue

Paul introduced Adrian BOOTH, clinical psychologist and facilitator for Beyond Blue who delivered a presentation on depression, anxiety and related disorders.

At the conclusion of the presentation handouts were provided covering all topics discussed by Adrian and he was thanked by Paul.

Prostate Supporter

Paul introduced Karen FOSTER of Foster Hill, the producers of The Prostate Supporter.

Succession Planning - Paul REDMAN

This is an issue that is experienced by many groups in numerous organisations throughout Australia. It should be considered as part of Group Leadership and indicates a need to share the jobs around. All members can participate and ways need to be found how all can become involved.

Identifying and sharing the roles to be filled will involve an understanding of the group members. Nobody should be concerned about asking for feedback on their performance and likewise, leaders should be prepared to provide feedback on others.

Potential leaders should be encouraged to act in roles in the short term thus gaining experience. Leaders should be trained before they become leaders.

Managing & Facilitating Groups - Paul REDMAN

This session discussed the differences between managing and facilitating support groups. Skills in facilitation were then explored and one case study was worked through briefly. The notes of this session are attached as Appendix 5.

Closure

Chairman Malcolm Ellis closed the conference by thanking everybody for their attendance and input. He commented on how good the atmosphere had been between members for the duration of the conference. He noted that members had a lot of information to take back to their respective groups.

He particularly thanked Paul for his contribution. This resulted in a standing ovation for Paul.

Malcolm closed the conference by wishing everybody a safe journey home.

3.15pm

Conference closed