



Below the Belt!

Vol. 12 No. 2

Mar – May, 2013

Newsletter of The Nepean / Blue Mountains Prostate Cancer Support Group Inc.
(ABN No. 35 871 442 176)



Come and join us on
4th and 5th of May, 2013
and take part in this years
Penrith Rel ay for Life
to help raise much needed
money for
Cancer Research
The Rel ay will be held at
Howel I Oval , Mul goa
Road, Penrith



This is a fun, social weekend that raises
much needed funds for a great cause.
Come along and join one of our teams.
Register direct at 'www.relayforlife.
org.au' and follow the links to either
Prostate Pals 1 or Prostate Pals 2. or
Contact our team Leaders Ian Davis,
John Kemp or Eric Kent to register.

What's to Come

Group Meeting – Monday March 18th

Charles Grech

Testicular Cancer Survivor

Group Meeting – Monday April 15th

To Be Advised (See Local Press)

Your Heart

Group Meeting – Monday May 20th

To Be Advised (See Local Press)

All meetings :- Gather at 6-30pm for a 7-00pm start.

Vale - John Withers

Members of the Group will be saddened to hear of the passing of Group Member, John Withers.

John was a member of the group from our formation in 2001. He was also elected as a Board Member at the Group's 2005 AGM, a position he held for 4 years.

John was often the first point of contact for members when they attended our monthly meetings. He often took it upon himself to welcome members and get them to sign the attendance sheet.

During his working life John was employed by the Sydney Water Board.

In addition to his involvement with our Group, John together with his wife, Margaret, was involved in breeding and showing dogs. They achieved a great deal of enjoyment and success at this undertaking travelling to the various shows and often returning with winners ribbons.

John joined 'Probus' and enjoyed many new experiences through that organisation.

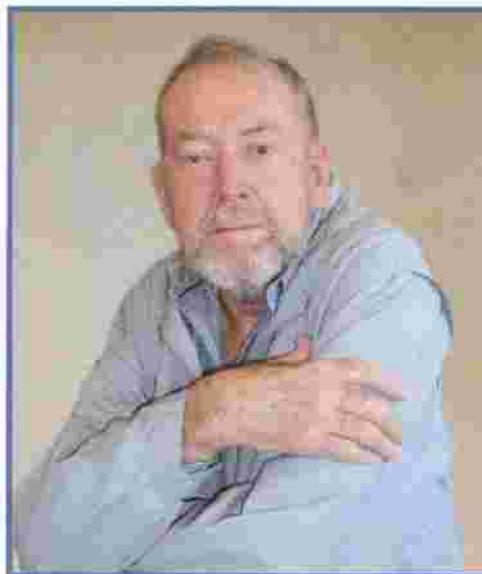
John was also an avid train enthusiast, being a member of the Valley Heights restoration group. John's extensive library of railway books has been donated to this group.

John was late adopter of technology to ensure he could continue his love of jigsaws and card games, and watch cricket on a shiny new 50 inch TV.

John also obtained and mastered the latest technology in the form of an 'I pad'.

John developed severe lung disease and as his health deteriorated this limited his ability to attend our meetings. He did though always make a point of attending our Christmas Party each year.

First and foremost, John was a loving and devoted family man and it is to his wife Margaret, daughter Karen and grand-daughters Laura and Kate, that we extend our deepest sympathy for their loss.



John James Withers

29th March, 1941 ~ 2nd February, 2013

This poem appeared in John's Order of Service.

The Measure of a Man

*Not how did he die
But how did he live
Not what did he gain
But what did he give*

*These are the things
That measure the worth
Of a man, as a man
Regardless of birth.*

*Not what was his church
Not what was his creed
But had he befriended
Those really in need.*

*Was he ever ready
With a word of good cheer
To bring back a smile,
To banish a tear.*

*Not what did the sketch
In the newspaper say
But how many were
Saddened
When John passed away.*

Award for Support Group Members – Alan & Gabrielle Moran and Brett Sowerby

Popular Group Members, President Alan Moran his wife Gabrielle and Brett Sowerby recently received National Volunteer Awards for their involvement in the functioning of our group.

Alan & Gabrielle require little introduction. Alan was the inaugural Secretary when the group was first formed later taking over as Group President, the position he still holds. Gabrielle was the Group Vice president for a number of years and is currently a Board Member of the Group. The success of our Group is due in no small measure to the leadership and drive of this outstanding couple.



Alan & Gabrielle Moran with David Bradbury



Brett Sowerby with (L to R) Alan Moran, Louise Markus, Rosa Sage and Daniel Myles

Brett has been a long serving Board Member and has previously held the position of Treasurer. He has been the driving force behind our involvement in both the Hawkesbury Canoe Classic and Dragon Boating. *(For these efforts I often refer to him as our "Minister for Boating".)*

The awards, a Federal Government initiative, were presented to Alan & Gabrielle at a Function held at the Penrith Cricket Club by local Federal Member David Bradbury (Member for Lindsay) while Louise Markus (Member for Macquarie) presented Brett with his award at a morning tea

held in Springwood. (State MP, Rosa Sage and Blue Mountains Mayor Daniel Myles were also present when Brett received his award.)

A limited number of friends and family were also able to attend these functions.

'These awards are a great opportunity to acknowledge the incredible work done by volunteers across our community.'

Volunteers form the social fabric of the community. There are countless individuals whose lives have been made better because of the work and service of a volunteer.'

PCFA Campaign to get Abiraterone (Zytiga) listed on the Pharmaceutical Benefits Scheme (PBS)

The Prostate Cancer Foundation is currently conducting a campaign to get Abiraterone (Zytiga) listed on the Pharmaceutical Benefits Scheme (PBS). They have asked us (ie Support Group Members) to lend our support.

As you may know, abiraterone (Zytiga) is the first new treatment for advanced prostate cancer to become available in Australia in more than a decade. It is the first of a new class of therapies that target the androgen-receptor signalling pathway, the major driver of prostate cancer growth. These therapies offer the prospect of substantially improved survival and quality of life for men with advanced prostate cancer.

Currently abiraterone is approved in Australia for men with metastatic prostate cancer that is resistant to androgen deprivation and who have failed docetaxel chemotherapy. It has the great benefit that it is taken orally and has low toxicity, which provides improved quality of life, particularly in the later stages of the disease. Ultimately, we expect that abiraterone will be proven to be effective in a pre-chemotherapy setting and will fundamentally alter and improve treatment of advanced and metastatic disease.

In November 2012, abiraterone received a recommendation for listing on PBS by the Pharmaceutical Benefits Advisory Committee (PBAC). This means that the Federal Government has the ability to make abiraterone available to men with advanced prostate cancer who have exhausted all other treatment options. However, in recent times listing of new therapies has been delayed by the Federal Government for many months. In the absence of listing, the cost of some \$3,000 per month (\$36,000 per annum) is prohibitive to many men and their families.

Dr. Anthony Lowe, (CEO of the PCFA) in conjunction with John Stubbs of canSpeak has recently written to the Federal Minister for Health and Ageing urging her to confirm listing of abiraterone without delay. As members of a support group we have been asked to assist.

We have been asked to do the following

- § Identify men and their families in our support group living with advanced prostate cancer
- § Request them to write to The Hon Tanya Plibersek MP and their Federal Member of Parliament about their experience
- § Encourage them to ask their family members to write.
- § Identify men and their families in our support group living with advanced prostate cancer. We are requesting them to write to The Hon Tanya Plibersek MP and their Federal Member of Parliament about their experience.
- § Encourage them to ask their family members to write.

The focus of these letters is to inform the Minister about

- § Their experience of living with advanced prostate cancer and having no treatment available to them at all
- § What this new treatment could do for them.

Note that some men may already have started taking abiraterone and they will need to mention the high cost and why PBS listing is so important to them and their family.

The success of this letter writing campaign depends on our support and the support of affected men and their families telling their story.

If any members are interested in speaking to local media about this issue please forward their name and contact details to

Ms Margaret Bennett
National Manager, Education & Awareness
Prostate Cancer Foundation of Australia
PO Box 1332
LANE COVE NSW 1595
Email: margaret.bennett@pcfa.org.au

Palliative Care

Notes taken by Gabrielle Moran at the meeting of the Nepean/Blue Mountains Prostate Cancer Support Group Inc. held on Monday 18th February. 2013.

**Guest Speaker: Trish Dalglish:
Unit Manager / Palliative Care
Mt. Druitt Hospital**

Trish dispelled a number of the myths associated with palliative care, the major one being that it is not just for people at the end of their lives. One of its main goals is also to improve the quality of life for people with life limiting illnesses, and some people can and in fact do receive palliative care for as long as five years.



Group President Alan Moran with Trish Dalglish

A holistic approach is taken not only with the patient, but their family i.e. mind, body and spirit, and having an incurable illness doesn't necessarily mean that you are going to die, today, tomorrow or even next month.

Palliative care does not look at resuscitation, it looks at giving pain relief to make the patient feel better in themselves and of the patients admitted to the Mt. Druitt unit, 30% are able to go home after treatment. Pain relief pumps can also be supplied and a community nurse will come around on a daily basis to replace the ampoules in the pump and check the dosage to see if it needs to be adjusted in any way i.e. increased. Often increasing the dosage of morphine lengthens life because the patient is free of pain, whereas you actually die earlier if you are in intense pain.

If a patient at home cannot take oral medication, medication such as Stemetil can also be used in the pain relief pump.

A hospital bed can be supplied for home use if needed, and after hours nurses are available on call between 11.30pm and 8.30am.

Attached to a palliative care unit there is usually an occupational therapist, a psychologist, psychiatrist and a bereavement counsellor (who can supply you with a very informative bereavement pack to help you and your family deal with your loss).

Most hospitals have palliative care beds available, however If you, or a member of your family is likely to need palliative care at some stage during illness it is better to get your name put down as soon as possible because there is usually a waiting list for beds. You will also need a referral for palliative care from your G.P. or specialist who is treating you.

* * * * *

If you are a man. You know you're getting old when..... You see a scantily clad young woman and you are concerned as to whether she is warm enough!!

