



Below the Belt!

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

While compiling the excerpt from Lance Armstrong's book "It's Not About The Bike" I got to thinking about my own 'cancer journey'.

Like everyone I was stunned when I heard the words "Sorry mate, but you have cancer". You immediately think the worst, why me, what have I done to deserve this, my life is finished, will I see my Grandkids grow up. All of these thoughts are rushing through your head, little wonder that you remember little of what the specialist had said. (*A very good reason to have your partner with you!*) (The 'why me' was easily answered – why **not** me, I was an ordinary Australian bloke in my mid to late fifties so that put me right in the frame for prostate cancer!)

This is when you start to feel alone and confused, trying to take in the myriad of treatment options available. As you chase information you begin to meet other people who are in the same situation as you. You join a support group (such as The Nepean / Blue Mountains Prostate Cancer Support Group) and make a lot of new friends. You become involved in activities with that group such as the Relay for Life and meet more people (more friends!). You help out at events like the Hawkesbury Canoe Classic and meet more friends. Through your involvement with cancer you start Dragon Boating and meet yet more friends.

You have become, as Lance Armstrong puts it '*part of the Cancer Community*'

Recently at a 'Biggest Morning Tea' put on by the Penrith Dragon Boat Club 'Dragons Abreast' Ladies, Jan, a breast cancer survivor summed it up perfectly. She said, in part, '*None of us can be sure that the cancer won't return, we don't know how much time we have left. But by god, we're going to have a damned good time while we're here!*'

Last week Jan was paddling a Dragon Boat down the Thames in London as part of the Queen's Diamond Jubilee Pageant. Now that's what I call 'Having a good time'.

What have I got from my 'Cancer Journey'? A lot of new friends, A different slant on life. I often think that I have gained more positives than negatives.

Hopefully that will continue. (After all, I've got six grandkids to spoil!)

Alan Howard

What's to Come

Group Meeting – Monday June 18th

Mark Mulock - Solicitor

Legal Matters

Group Meeting – Monday July 16th

Open Forum

Topics of Interest Raised by Members

Group Meeting – Monday August 20th

Prof. Mohamed Kahdra - Urologist

Report from the recent Urological Conference in the USA

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

Lance Armstrong – “It’s Not About The Bike”

We are all aware of the story of champion cyclist, Lance Armstrong.

In October 1996, Armstrong was diagnosed with testicular cancer with a tumour that had metastasized to his brain and lungs. His treatment required rigorous chemotherapy and surgery. He was declared cancer free in January 1998 and started back on his career as a professional cyclist. He wrote a biography of his struggle to return to fitness titled:

“It’s Not About the Bike: My Journey Back to Life” (2000)

Armstrong went on to win the prestigious ‘Tour de France’ no less than 7 times from 1999 to 2005.

These days, Armstrong is a tireless advocate for Cancer charities.

Following is an excerpt from his book that should be read by all of us affected by cancer.

“What other choice is there but to hope? We have two options, medically and emotionally: give up, or fight like hell.

After I was well again, I asked Dr. Nichols what my chances really were. “You were in bad shape,” he said. He told me I was one of the worst cases he had seen. I asked, “How bad was I? Worst fifty percent?” He shook his head. “Worst twenty percent?” He shook his head again. “Worst ten?” He still shook his head.

When I got to three percent, he started nodding.

Anything’s possible. You can be told you have a 90-percent chance or a 50-percent chance or 1 percent chance, but you have to believe, and you have to fight. By fight I mean arm yourself with all the available information, get second opinions, third opinions, and fourth opinions.

Understand what has invaded your body, and what the possible cures are. It’s another fact of cancer that the more informed and empowered patient has a better chance of long term survival. What if I had lost? What if I relapsed and the cancer came back?

I still believe I would have gained something in the struggle, because in what time I had left I would have been a more complete, compassionate, and intelligent man, and therefore more alive. The one thing the illness has convinced me of beyond all doubt - more than any experience I’ve had as an athlete - is that we are much better than we know. We have unrealized capacities that sometimes only emerge in crisis.

So if there is a purpose to the suffering that is cancer, I think it must be this: it’s meant to improve us.

I am very firm in my belief that cancer is not a form of death. I choose to redefine it: it is a part of life.

One afternoon when I was in remission and sitting around waiting to find out if the cancer would come back, I made an acronym out of the word:

Courage, Attitude, Never give up, Curability, Enlightenment, and Remembrance of my fellow patients.

In one of our talks, I asked Dr. Nichols why he chose oncology, a field so difficult and heartbreaking. “Maybe for some of the same reasons you do what you do,” he said. In a way, he suggested, cancer is the Tour de France of illnesses.

“The burden of cancer is enormous, but what greater challenge can you ask” he said. “There’s no question it’s disheartening and sad, but even when you don’t cure people you’re always helping them. If you’re not able to treat them successfully, at least you can help them manage the illness. You connect with people. There are more human moments in oncology than any other field I could imagine. You never get used to it, but you come to appreciate how people deal with it—how

Incontinence Issues

We were recently contacted by a Continence Nurse Advisor from The Continence Foundation of Australia in NSW. This lady conducts the "Outreach Program" in the Penrith, Hawkesbury and Blue Mountain's area.

The Outreach Program is a clinical service funded by Home and Community Care (HACC). This funds the outreach service for a continence nurse advisor (CNA). A CNA can visit persons who meet the HACC criteria, within their own home who are experiencing bladder or bowel problems. The visit involves chatting with persons and carers or significant others if required, completing assessments, helping identify strategies that may aid the management of continence and assist in organizing trial of aids. We can also provide assistance in applying for both NSW and Federal government continence assistance schemes (Enablensw and CAPS) which are mentioned on our website. A clinic is also provided once per week within the Hawkesbury Community Health Centre.

The Continence Nurse Advisor is a Health Promotion officer, who can also provide information sessions and attend events providing resources to promote bladder and bowel health. It is important to assist and inform people within our community on where they can access help for continence issues if needed.

Contact Details for this program are:-

Health Promotion Officer
Continence Nurse Advisor - NSW Outreach Program
NSW Continence Promotion Centre
Continence Foundation of Australia in NSW Inc
Address: 6 Holker Street, Newington
Postal: P.O. Box 6083, Silverwater 1811
Phone: 02 8741 5699
Facs: 02 8741 5690
Email: clinicfansw@optusnet.com.au
Website: www.continence.org.au
NATIONAL CONTINENCE HELPLINE 1800 33 00 66

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Radiotherapy Survey

Have you or someone you have looked after had radiotherapy or chosen not to have radiotherapy? We would like to invite people who have been diagnosed with cancer and who have either been treated with radiotherapy or have chosen not to have radiotherapy to discuss the practical issues regarding accessing and having radiotherapy. People who have cared for someone in this situation are also invited.

What is involved?

There are 2 ways to share your views.

You can take part in a phone interview (scheduled at a time that suits you) or you can complete an online questionnaire by going to the web site: <https://www.surveymonkey.com/s/Q3RHB5Q>

To register your interest in a phone interview please call Andrea Smith on 0405 622 525 (or email andrea.smith@zest.com.au).

This study is funded by Cancer Institute NSW and is carried out by researchers from The University of Sydney and Sydney Cancer Centre, Royal Prince Alfred Hospital.

It has been approved by the Ethics Review Committee, Royal Prince Alfred Hospital.

Recent Involvements of the Group



Our group was once again invited to man an information and awareness stand at this event. This was the third time that we have attended.

As a follow up to our attendance at this event President Alan Moran asked the members that attended to give some feedback as to how our message was accepted.

Generally it was found that more men are becoming aware of the need for testing with many men admitting that they had been tested. Many men also stated that they had a friend or relative who has had the disease.

Few men were prepared to ask more detailed questions about the disease and its various treatments. The "Little Prick" information leaflets were a real hit and were readily accepted by nearly all men they were offered to. These leaflets are also popular with wives and girlfriends.

All in all it would seem that we are starting to make inroads with the male population but we all realise there is still a long, long way to go!

www

Glenbrook Panthers Bowling Club.



Members of the board of our Group were once again invited to attend the end of season celebrations of the Glenbrook Panthers Bowling Club.

At the function, President Alan Moran, was presented with a cheque for \$1000.00. This money is raised throughout the year by the bowlers making 'contributions' to the fines tin whenever they send down a bowl on the wrong bias. Over the last few years donations from the club members has totalled well over \$3,000.00.

Many thanks to the Bowling Members of Glenbrook Panthers!

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Cambridge Park Lions Club Trivia Night.

The Cambridge Lions Club recently held a fund raiser trivia night which we were invited to attend. Our Group was the beneficiary of the night. The three 'Al(I)ans' (together with Gabrielle, Jean and Coral) attended. We had a great evening, managed to finish equal 2nd in the trivia and picked up a couple of raffle prizes!

We were recently advised that \$750.00 dollars was raised on the night.

Many thanks to Cambridge Park Lions!

www

Where do these funds go?

Our Group uses funds raised by ourselves (and the many Organisations that support us) to purchase much needed equipment required by organisations providing support and assistance to members of the local community.

Our current project is the provision of Self Administering Pain Relief Pumps for the Palliative Care unit of the Mount Druitt hospital.

