



## Newsletter September 2010

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### Next Meeting

Thursday 9 September

10.30am - noon

The Weston Club,  
1 Liardet St  
Weston

**Speaker: Jan Ironside and Chris Hyland from the Chronic Care Team**

### August Meeting by Chris Moyle

Pharmacist Gareth Wheeldon spoke about generic medications. He told us it can cost up to \$800 million to bring out a new medication. After the patent expires, generic versions, which are cheaper, are able to come onto the market. This generic version contains the active ingredient as well as a 'filler', ie the ingredients that make up the rest of the medication.

Are generic medications inferior? No definitely not as the active ingredient remains the same or bio-equivalent. In Australia the TGA (Therapeutic Goods Administration) stringently tests new medications, sometimes for up to 3 years, to make sure they work properly.

Why use generics? Generics make it cheaper for everyone. Savings can be rather large for the consumer over time. The PBS (Pharmaceutical Benefits Scheme) does a cost benefit analysis and chooses which medications can be subsidised by the Government.

Fillers in generic medications In some cases the fillers are exactly the same and in other cases it is not. It depends on the company.

Any adverse reactions? Some of the colouring agents used can cause allergies for some people. Your Pharmacist has a medication list of all the ingredients, even the colouring. Such information helps to make sure this medicine won't cause you any problems. GPs can state "no brand substitution".

Some herbals can interact with medications. You need to check with your GP or Pharmacist. Many pharmacists will come to your home and do a review of all your medications plus vitamin and herbal remedies, to identify any adverse interactions. Your pharmacist can send this information to your GP.



For more information, see [www.lungfoundation.com.au](http://www.lungfoundation.com.au)  
More information on European *Year of the Lung* activities, see: <http://www.ersnet.org/yearofthelung>  
More information on worldwide *Year of the Lung* activities, see: [www.2010yearofthelung.org](http://www.2010yearofthelung.org)

## **Sleep Laboratory at Canberra Hospital**

Canberra Hospital's new \$750,000 Sleep Laboratory has been opened. It will reduce waiting times for patients suffering from sleep disorders and those who require urgent assessment for respiratory failure.

This laboratory is equipped with digital video monitoring for diagnosis of certain types of sleep disorders, a lifter for immobile patients and both beds in the laboratory are suitable for overweight patients. The lab will allow for overnight sleep studies in the hospital, as well as studies where a patient spends the night at home with diagnostic equipment attached to their body, returning to the laboratory next morning for the data to be downloaded and assessed.

As the population ages and rates of obesity increase, sleeping disorders and breathing problems will become more common. Approximately 10% of Australians suffer from some sort of sleep disorder, the most common being insomnia, with breathing problems during sleep present in 4% of the population.

The unit is staffed by a mix of full and part-time respiratory and sleep physicians, sleep scientists, nurses and other support staff specialising in sleep science.

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## **Woodsmoke up date**

- The government is conducting a survey of people with wood heaters to ascertain why they have and use woodheaters; and whether they would change to a different form of heating if possible.
- The government review into woodsmoke policy is due at the end of September
- The Tuggeranong Community Council has broadened its concerns about air quality in the Tuggeranong to deal not only with woodsmoke but with all issues that affect air quality in the valley – such as the installation of gas turbines at Hume; the planned crematorium, vehicle emissions. The Council is currently developing its policy which they expect will be introduced early next year.

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## **Ginseng Update** by Chris Moyle

**300mg ginseng:** The ginseng study mentioned in last newsletter used a 300mg of standardized extract of Korean (Panax) ginseng (not Siberian or other varieties of ginseng). I have checked in a health food shop and can't find any Korean ginseng tablets with anything close to 300mg of standardized ginseng. The highest dose available is approx. 41mg, so it would require a lot of these tablets to make up 300mg.

It therefore appears that it is not a simple matter to undertake this treatment in Australia, which is a pity as it increased maximum oxygen consumption in the COPD patients by 37.5%. It could possibly be available from an American dispensary - Standardized Korean (Panax) Ginseng (60) capsules for US\$24.25 plus shipping US\$8.95 (total US\$33.20) with discounts available for larger quantities. The dosage is not stated. I am willing to contact the dispensary about the dosage if anyone is interested.

**200mg ginseng:** Another study used the ginseng extract in the treatment of chronic respiratory disease in individuals on home oxygen treatment. Patients were given 200 mg twice daily of Panax ginseng and were evaluated every month and a half. The study found increased respiratory strength, improved oxygenation and walking distance increased.

The very reputable Mayo Clinic in America says further research is needed to confirm these results.

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## **Caveat Emptor**

Having recently seen an ad for a new portable concentrator in the LungNet News, Albie Richards emailed the firm, AirSep, for 'specification and cost' of the portable concentrators advertised, including their battery cost. He also asked if they had a local agent in Canberra so he could look at the concentrator.

**The first response** he received was not very inspiring: **The two POC's you mention below are not yet available for purchase. Our plans are go into production and introduce the Focus unit around end of September/October. Currently, the unit is undertaking final agency testing & approvals, etc., before we can produce it in any quantity. The FreeStyle 5 unit will not be ready for production until sometime in the 1st Q of 2011.**



**In a later response,** a representative of Wymedical (South Australia) that said they had stock of the one of the units and were taking orders for the other. But the email contained no reply to his query about costs and specifications.

**Albie replied:** Someone needs to get their act together! AirSep informed me that the Focus 2 lpm pulse flow and Freestyle oxygen concentrators are not yet available for purchase yet you are offering them for sale!

**Another response** appreciates the company's concern at 'our offer of products not quite available as yet.

**However, it will not be long before these products will be available.** We wished to alert potential users of these

products before they committed themselves to another product. Airsep field test all new products for some time before release into the international market. We **need to make sure that this brand new concept of oxygen delivery actually works** and will not give you any problems in the future'.

**The fourth response** said: I believe your enquiry was via email and that we did not have your telephone contact details to discuss the matter with you. We would be interested in discussing how we can assist you and what your actual requirements are.

### **Albie's comment**

None of my original questions on specifications and cost have been answered yet. I am not impressed by being offering a product that is not yet available and by the contradictory responses. However, what has annoyed me is that AirSep and WyMedical (twice) have ignored my original enquiry, as to the cost of the 'New' concentrators and their battery packs. All this shows the problem buying goods unproven at the coalface: caveat emptor!

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## **Improving Health and Wellbeing Knowledge**

*by Chris Moyle - taken from **It goes with the Territory! ACT Women's Views about Health and Wellbeing Information** July 2010 (Most of this information applies to men and women)*

Good quality health and wellbeing information increases knowledge and assists people in making choices about their lifestyle, making decisions about their health, reducing anxiety about health issues and assisting in the health and wellbeing of their families. This information needs to delineate what is available, affordable, accessible and appropriate to their needs.

In Australia there are numerous medically endorsed websites which contain good information such as:

- *the Jean Hailes Foundation website,*
- *Healthinsite,*
- *The Better Health Channel,*
- *the ABC Health and Wellbeing information portal,*
- *Informed Health Online.*

There are also a number of good quality and credible international websites such as:

- *MayoClinic,*
- *the British Medical Journal,*
- *OncoLink,*
- *MEDLINEplus.*

For more urgent advice there are the 24 hour telephone helplines such as:

- *Lifeline*
- *Health Direct.* Health Direct is staffed by trained nurses who can tell you whether or not you need to visit the emergency department. If your condition deteriorates you are welcome to phone again for further advice, even if it's 4 a.m. They are also very good at guiding you through minor problems, and can be contacted on 1800 022 222.
- *Life Goes On.* Their motto is "We don't talk about the disease but what it is doing to the person. We provide a soft place to fall." Phone 1300 364 673.

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## Financial Report

Currently, we have \$5316 in the bank. This is as a result of money collected at meetings, christmas lunches, auctions, raffles etc – and \$3718 from Tommy and Daphne's CRAD group which folded. We spend money on:

- donations to Lung Foundation when a member dies(last donation on behalf of Dianne Proctor)
- members expenses such as  
the cards etc we send to sick members;  
costs involved in organising the christmas lunches;  
computer paper and ink and other 'office' expenses;
- the Chronicle *Caring Community* Ad
- membership of organisations  
HCCA (Health Care Consumers' Association of the ACT)  
SHOUT (Self Help Organisations United Together)
- a one off payment to Caroline Scowcroft of \$500 for the expenses incurred over the last few years and in her future time with CLLSG – see below for details of her activities.

### Caroline's input to CLLSG

In 2007 Caroline with her husband Bill joined CLLSG and were happy to relieve Laurelle of the running of the group.

They organised the speakers, ran the meetings, organised a social event for the 4<sup>th</sup> Thursday of the month, organised the COPD Walk in November, liaising with ALF. As well, they moved into an advocacy role, aiming to promote CLLSG and lung issues in the ACT. Bill joined the committee of ALF and Caroline joined the COPD task force, a sub-group of ALF.

Since Bill's death in 2009, the ACT has lost its representative on ALF but Caroline is still a member of the COPD Task Force. This mainly involves her in teleconferences but earlier this year, she attended a meeting in Melbourne for all the Task Force members. ALF pays for the teleconferences and paid some costs for the Melbourne trip.

Caroline is also a member of various organisations in ACT where she advocates to increase the awareness of the government, the health industry, and the community about CLLSG and lung disorders, arguing for better provision and services for people with lung disorders:

- HCCA – Caroline is Vice-President of this organisation
- Domiciliary Oxygen – This group consists of respiratory doctors and health workers with Caroline as the consumer representative.
- ASH – the anti-smoking organisation
- Committee on the Intensive Care Unit at Canberra Hospital – community representative
- committee for the Walk-In Nurses Centre – community representative
- and of course, co-convenor of CLLSG. She feeds CLLSG information into the other groups and feeds information from them to us.

Caroline has attended conferences over the world and given papers at some. She had covered the costs of these herself – the flights, accommodation, conference fees and expenses – although she has tried to combine the flights with a visit to her daughter in Canada.

Our thanks go to Caroline for the time, effort and expense she has put in - and still puts in - that benefits our group.

## Charity Computers

Charity Computers take old IT equipment and, where they can, prepare them for giving to people in Canberra who can demonstrate an appropriate level of need (they can tell you the exact criteria). Very little is charged in such cases. They do charge for accepting TVs and some other items (monitors I think).

Charity Computers also train people on unemployment benefits and have a very good approach to the community. They are closed 12-1pm and the best spot to take heavy things is round the back at the loading dock. If you contact them, they can tell you details:

Charity Computers Australia

46 Lhotsky St Charnwood ACT 2614

ph: 02 6101 6931

<http://www.charitycomputers.com/content/welcome-charity-computers->

[australia](http://www.charitycomputers.com/content/welcome-charity-computers-australia)<http://www.charitycomputers.com/content/welcome-charity-computers-australia>

### Information available from Chris

- a. Advance Care Plan - including
  1. Appointing an Enduring Power of Attorney
  2. Documenting your wishes in the Statement of Choices
  3. Completing a Health Directive under the Medical Treatment Act
- b. Some questions and answers about anaphylaxis (severe allergic reaction)
- c. National Companion Card Scheme - enables disabled people's attendance with a carer at venues and activities without incurring the cost of a second ticket for their carer.

## Snippet

### **Breath by Tim Winton**

Tim Winton's novel **Breath** looks at people who take life to its edges, including taking breathing to its limits, and who get hooked on the adrenalin rush it provides. On p40/41, one of his characters says, *'You never really think about breathing. Until it's all you ever think about...More than once, I've wondered whether the life threatening high jinks..I..got up to in the years of my adolescence were anything more than a rebellion against the monotony of drawing breath.'*

Ever thought about breath and breathing like that?

## ACT Chronic Conditions Alliance

As its name says, this alliance provides support for people with chronic conditions in the ACT. It meets every second Wednesday in the month at Woden Community Service rooms, from 7-8.30pm.

The meetings and speakers are organised each month by a different group. Meetings for the rest of the year are:

<i>date</i>	<i>topic</i>	<i>speakers</i>	<i>organiser</i>
Wed 8 Sept	disability pensions, healthcare cards, Centrelink and CRS	Jacinta Bennet; David Rothschild	RSI
Wed 13 Oct	Alternative approaches to pain and rehabilitation such as acupuncture	Dennis Yu (Capital Rehab)	Epilepsy
Wed 10 Nov	Meditation and relaxation	TBA	Arthritis

## Dates for your diary

**1-8 September** Asthma week

**Wednesday 8 September** National Self Help & Support Group Awareness Day

**Thursday 14 October** World Spirometry Day – part of **2010 Year of the Lung** activities - involving public lung testing in hospitals and clinics around the world

**18-24 October** Carers Week

**November** lung awareness month

**Wednesday 17 November** World COPD Day

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