

# Newsletter January 2010

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## Next meeting: Thursday 14 January 10.30am

### Weston Club

This is a Welcome Back meeting. We will plan our speakers and activities for the next few months so come with your ideas.

### **Christmas Lunch**

Thirty one (31) of us had a most enjoyable Christmas lunch at the Weston Club on Tuesday 8 December. Many people brought presents for children which we donated to the Salvation Army. Esther ran a noisy auction to raise money for our group and we raised \$201, a useful addition to our coffers. The lunch was a lovely ending to 2009.

The Weston Club has been a good venue for us. It has bright and cheerful surroundings and good food. We appreciate the support they give us during the year as they are always very helpful.

## Extract from LungNet Southern Highlands November Newsletter

**CountryLink:** We have received a response to our requests made to RailCorp about the discrimination practised by CountryLink. It will no longer be a requirement for passengers requiring medical oxygen to produce a medical certificate before purchasing a ticket nor to carry the certificate throughout the journey.

CountryLink will provide an additional seat at no charge in order for the oxygen cylinder to be secured to the seat provided an approved carry bag is used. Passengers using a battery operated oxygen concentrator will be permitted to recharge the battery at manned railway stations.

#### Pam's trial

An article in The Senior, Nov 2009, p54 talks about the Woolcock Institute of Medical Research conducting clinical trials to determine the safety and efficacy of a new drug in the search for better

treatments for COPD - also known as chronic bronchitis, emphysema or smoking related lung disease.

#### Air pollution, chemical fumes, and/or dust can contribute to COPD development but smoking is the cause on 80-90% of cases. COPD is the third most troublesome disease for Australians, and fourth most common cause of death. There is no cure once damage has occurred but it can be treated.

*Pam Harris is currently taking part in a trial for a new type of puffer. Here, she tells us about the trial:* I'm one of four people in Canberra taking part in this world wide trial, testing a new puffer that functions like Ventolin. It's to be used once a day in conjunction with Spiriva. We started the trial in November and finish this January – a three month trial.

I had to go off my medication two weeks before the trial started and rely on one preventer and ventolin. During the trial, I'm on Spiriva and the trial drug, plus Ventolin if I need it. I take the trial drug every morning and fill out an electronic diary twice a day. The diary has questions programmed into it – like, on a scale of 5, rate your cough; rate your breathlessness etc.

Once a month, I go to the hospital for a short visit where they give me a spirometry test before and after medication; and they download my electronic diary. Later in the month, I go for a long full day. On these days, I take my trial drug at the hospital instead of at home. Then I have spirometry tests at the beginning and end of the day. Every half hour, I have a blood test, and a ECG, both before and after medication, with spirometry tests every half hour for two hours.

I'm quite happy to be involved in trials like this when it doesn't cause any major problems. In saying that, I don't feel quite as well as I usually do and will be pleased to see the end of it. I'm still pleased to be able to participate as this is the way we get new drugs that are beneficial to us all.

## Productivity Commission Inquiry into a National Disability Long-term Care and Support Scheme

In November, 2009, the Government announced that it was holding an inquiry into 'developing a National Disability Strategy to enhance the quality of life and increase economic and social participation for people with disability and their carers.

There is significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers, increasing over the coming decades. The Government wants to find the best solutions to improve care and support services, looking at alternative approaches to funding and a focus on early intervention and long-term care as part of the National Disability Strategy.

The Commission is to seek public submissions and to consult as necessary, producing a final report by 31 July 2011. For further information, go to:

### http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/tor.aspx

## Extract from LungNet Southern Highlands September Newsletter

Our guest speaker was **Caroline Scowcroft** from Canberra. Caroline is the wife of the late Bill Scowcroft who was a member of the National Council of the Australian Lung Foundation. Caroline spoke about the importance of having a positive attitude, empowerment and making a difference - in the context of the mission of the ALF. She said that in Canberra the Lungnet support group for the ACT have members who volunteer to assist the medical profession in a variety of ways including being 'patients' for medical students undertaking exams.

Caroline encouraged interaction between members of different support groups in areas of common interest such as with hobbies and welcomed LungNet Southern Highland members to visit the Canberra group at their meetings and to participate in their activities.

Caroline, who with Hazel Mellor, is a member of the patient Task Force, mentioned that goals of the Task Force include having air pollution warnings included in weather forecasts encouraging GP's to include spirometry testing in standard medical checks of patients aged over 35 years.

## Photos from Walk for World COPD Day, Wed 18 November 2009



Caroline Scowcroft starting us off. We were also walking in memory of our members (photos in the frame) who died during the year.



Some of the participants in the Walk for World COPD Day



Ray Fitton holding grandson's teddy. Note the green COPD t shirt on teddy. Grandson also wore a green COPD t shirt as did daughter, all adjusted to size by Esther.



Peter Foy with bike and oxygen. Peter rode 25ks for World COPD Day



Caroline Scowcroft still talking



Noreen Bird, Pam Harris and Helen Cotter

### Reading Matter For Loan: contact Helen ph:6281 2988 or cotterhe@hotmail.com

- ACT Community Recovery Plan; A functional Plan of the ACT Emergency Plan.
- Lost in Space and Time a story of stroke recovery by Arthur McComb

• Health Voices: Consumer voices on depression, anxiety and chronic conditions

### Equipment available or wanted

Lung life Support Group has some equipment, which, at the moment, has been let out. If you no longer use it, could you please let us know.

We have left a wheel chair at the Weston Club for use by members when they need it.

Various members have **nebulisers** they no longer need. If you want one, contact the owner: Reuben 6296 2021; Shirley 6281 3066; Chris 6288 8463

Laurelle has a wheely walker 6288 3127

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