

Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Newsletter December 2011

contact: Helen Cotter ph: 6281 2988 lung.life@hotmail.com

This is the last newsletter for 2011. The next newsletter will arrive at the end of January. Have a lovely Christmas and January.

We are creating a hamper to raffle at our Christmas lunch.

If you are bringing a donation, please bring it to this meeting and make it suitable for a hamper.



Next Meeting

Thursday 8 December 10.15am – 12 noon

The Weston Club, 1 Liardet St Weston

final meeting for the year: a relaxed one

A reminder to all: perfume gives many of us breathing difficulties.

Remember not to wear any to meetings, lunches etc.

November Meeting by Chris Moyle

This meeting was a meeting of general discussion, ending with a brainstorming session about various difficulties we come across in our lives and discussing who to access to resolve the issue.

<u>Grumble No. 1</u> was about disabled parking spots. There are fewer of them now that some have been marked with stripes, which is to allow people to unload wheelchairs, walkers etc. There can be problems with the location of some disabled parks and some have posts which are difficult to see in the spots. At Cooleman Court there are 18 spots – not enough – and at weekends it is noticeable that people park illegally in the disabled spaces. Who to contact? Some suggestions included: Cooleman Court management (Mirvac), Simon Corbell (Govt.), GPs, COTA and people with disabilities active in area.

<u>Grumble No. 2</u> Lack of seats inside big Department stores and stores such as Woolies, Coles and Bunnings. Many people find it tiring to walk from one end to the other and need a rest on the way. Helen Reynolds will investigate who to contact for this matter.

<u>Grumble No. 3</u> Uneven pavements. Gutters too high. These make it impossible for people with walkers etc. Suggested contacts included Simon Corbell, TAMS, Community Council.

<u>Grumble No. 4</u> Electric scooters not allowed on buses., yet many buses accept wheelchairs. Suggested contacts included My Way, Action buses, Simon Corbell

<u>Grumble No. 5</u> Jazz in Botanic Gardens: Arboretum. Difficult to access these areas – long way to walk. Who to contact about this?

<u>Grumble No. 6</u> Difficulties in accessing Kambah equipment centre at Village Creek for services, oxygen, wheelchairs etc. It is not near the bus stop, the pavement is uneven and it is dangerous going through the doors. Suggestions included the need to contact occupational health and safety and work cover people.

Ultimately we would like to have a list of the contact details of appropriate people and organisations. If you are interested in following up an area and getting the contact details, send them on to me at lung.life@hotmail.com for further dissemination.

Christmas Lunch @ the Weston Club

Tuesday 13 December 12 noon for 12.30 cost: \$25

bring present for Secret Santa to Value \$10 gift for Child: wrapped with age and sex written on ourside. we'll also hold a raffle of a hamper

rsvp: Pam ph: 6288 2053 or email: bapjh@live.com.au

If you have told Pam you are coming and find that you can't, you must let her know by Thursday 8 December; otherwise, you will need to pay for your meal.

World COPD Day - 16 November 2011

The Canberra Lung Life Support Group held its walk at the Lake's edge at Acton Peninsula from 11am to Noon as we have done the last few years, followed by a combined picnic lunch. About 30 people walked their varying distances in ideal weather. Last year we walked a combined distance of 92Ks; the year before, 110Ks. This year we walked 83 kilometers – a good effort by everyone. We followed the walk with a picnic lunch where we farewelled Caroline Scowcroft who is going travelling for a while and we celebrated a few birthdays. Many thanks to those who supported the



Enjoying ourselves after the walk

Lung life Group in the Walk. We are really pleased to see you with us.



Chris ready to go



The pharmacy Guild and our new banner



Rosa happily walking

Free computer sessions

We are organising some sessions with the PCUsers Group for people in our support group – and their carer/ partner/ spouse if they want to - to help increase their knowledge in what the computer can offer and confidence in using the computer – both Internet and Word. There is so much on the computer that we don't know exists and it's often a light bulb moment when we find out about it.

They will be small group sessions, based at Holder. At the moment, we don't have dates or times – we need numbers first. I am hoping for Thursday morning sessions but it may be Tuesday morning for 2 hours. So if you're interested in improving your knowledge of the computer, let me know on:email: lung.life@hotmail.com or ph: 6281 2988.



Darryl, Judy, Maddie signing forms



The Chronic Care Team: Jody, Beth and Jan

Irish Hereditary Emphysema Rates Found to Be Among Highest in the World

ScienceDaily (Oct. 19, 2011) — Researchers from the Royal College of Surgeons in Ireland (RCSI), Beaumont Hospital, and Trinity College Dublin have conducted a study which has found that Ireland has one of the highest incidence in the world of a genetic condition that causes severe hereditary emphysema. The study raises the possibility that hundreds of people suffering from chronic lung disease could have this genetic condition but have yet to be diagnosed. It is hoped the findings of this study will lead to increased awareness of the disease and earlier diagnosis which can contribute to a better quality of life for people with the condition.

The inherited condition known as Alpha-1 antitrypsin deficiency (Alpha-1), results in the most severe form of hereditary emphysema. The genetic disorder is caused by a deficiency in a naturally occurring protein produced in the body which protects the lungs from the harmful effects of cigarette smoke and bacterial infection. People with the condition develop COPD in their 40s and 50s and can also develop liver disease.

This study has revealed that Alpha-1 is much more common than was expected in Ireland. 1 in 25 Irish individuals were found to be carriers for the gene responsible for the most severe form of Alpha-1, making the condition the most common fatal inherited lung condition in Ireland after cystic fibrosis.

A simple blood test is all that is required to diagnose this condition: over 90% of Alpha-1 individuals remain undiagnosed. The importance of an early diagnosis cannot be overstated as the proper medical follow-up and lifestyle changes can help prevent or at least delay the development of lung and liver disease associated with this condition and greatly increase life expectancy."

The lead author on the study is Dr Tomás Carroll who worked with colleagues from RCSI's Department of Medicine based in the Education and Research Centre at Beaumont Hospital in Dublin and collaborated with researchers at Trinity Biobank, Institute of Molecular Medicine, St. James's Hospital; the Department of General Practice, RCSI; and the School of Medicine and Dentistry, Queens University, Belfast.

The study was recently published in the journal *Respiratory Research*.

Eat your broccoli

Broccoli-Based Compound Beats Drug Resistance in Lung Disease

ScienceDaily (Oct. 17, 2011) — Chronic obstructive pulmonary disease (COPD) is a common lung disease that gets progressively worse over time, making it harder and harder to breathe. It is caused primarily by cigarette smoking, which leads to persistent inflammation in the airways and the subsequent destruction of the lung tissue.

Given the central role of inflammation in COPD, it is surprising that patients derive little benefit from treatment with potent anti-inflammatory drugs known as corticosteroids.

Working with cells from individuals with COPD, a team of researchers led by Shyam Biswal and Rajesh Thimmulappa, at Johns Hopkins University, Baltimore, has identified a candidate therapeutic that could potentially be used to augment the anti-inflammatory effects of corticosteroids in individuals with COPD -- sulforaphane, a compound obtained from cruciferous vegetables such as broccoli, Brussels sprouts, and cabbages.

The research is published in the *Journal of Clinical Investigation*.

Snippet

Allan Foskett has written a new book on "Post-War Canberra Hotels: What Happened to them and What Happened in them". He relates an incident that occurred when former US President, Lyndon B. Johnson, was staying at the Canberra Rex Hotel.

Ron Dillon was the senior police officer who escorted LBJ on an evening out. Unfortunately the President imbibed rather too much alcohol, becoming visibly drunk and staggering about, so the decision was made to drive him back to the hotel, but hidden from view. Ron bundled him into the back seat of his car, covered him with a blanket and drove to the back entrance of the Rex. LBJ was returned safely to his room without being noticed. It would have made quite a story if the Press, waiting out front, had seen him. Ron Dillon was a former member of LungLife and COPD sufferer, and is the late husband of current member, Shirley Dillon. He had many other such stories.

Dates for your diary

Thursday 29 March 2012 Session with Physio students @ UC

Tuesday 14 August 2012 Session with Physio students @ UC







"Living a Healthy Life with Long-Term Conditions" 2012 COURSE SCHEDULE

Do you have diabetes, asthma, heart disease, arthritis, cancer, back pain, obesity or any condition lasting longer than 6 months?

Does it prevent you from living life as you would like?

Cause you stress? Impact on your relationships?

	Arthritis ACT	Belconnen Health	Phillip Health
	- phone 6288 4244	Centre	Centre
February	Friday	Thursday	Thursday
	24	23	23
	12pm - 2.30pm	10am - 12.30pm	10am - 12.30pm
March	Fridays	Thursdays	Thursdays
	2, 9, 16, 23, & 30	1, 8, 15, 22 & 29	1, 8, 15, 22 & 29
	12pm - 2.30pm	10am - 12.30pm	10am - 12.30pm
April			
May		Mondays 7, 14, 21 & 28 2pm - 4.30pm	Thursdays 10, 17, 24, & 31 10am - 12.30pm
June		Mondays 4 & 18 2pm - 4.30pm	Thursdays 7 & 14 10am - 12.30pm

To register for Health Centre courses or discuss course details please phone:

Community Health Intake

Phone 6207 9977 between 8am-5pm Monday-Friday

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<u>lung.life@hotmail.com</u> or return the mailed newsletter