

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

Editor: Helen Reynolds 02 6259 7737
helenrey@creationcorporation.com.au
Contact: Helen Cotter 02 6281 2988
lung.life1@hotmail.com

Next Meeting	Thursday 8 May 2014 10.15 am – 12 noon The Burns Club, 8 Kett Street, Kambah ACT 2902
Guest Speaker	A representative of the ACT Fire Department will remind us of all the things we should know to keep our home safe.

Dates for your diary

Thursday 22 May 2014 Helen Cotter and Helen Reynolds to speak to the Senior's group at Kippax.
Thursday 12 June 2014 Canberra Lung Life Support Group Meeting.

April Meeting Helen Cotter, Chris Moyle

Worthwhile discussions were held during the business segment of the meeting:

- Helen Reynolds talked about the recent C-PAG Skype conference with the Lung Foundation Australia and reps from around Australia. She talked about one member having had a double lung transplant who is organising an anniversary party to celebrate; and another member who is trialing the use of a hand held fan to the face. More about this technique later.
- Another trial being held in New Zealand with nasal humidified oxygen therapy (HOTER) was discussed. PamG was introduced to the therapy in an Emergency Department in New Zealand during a cruise around that country's two islands.
- Peta's prototype of tear off slips look really good and were accepted as an excellent way to get the message out into the wider community regarding the Canberra Lung Life Support Group.
- Maureen talked about her chronic cough treatment. Look out for that later in the newsletter.

Having finished with General Matters the meeting turned its attention to the social/community activities in which our membership is engaged. The heaviest areas of involvement are:

- family commitments
- maintaining friendships
- doctors' visits
- Lung Life Support Group meetings and organised activities.

Any activity that grabs our attentions has a combination of the three main areas of personal interest:

1. Physical

- i. walking alone or with friends
- ii. attending the YMCA gym at Chifley, the gym at the CIT in Bruce
- iii. Lungs in Action at Bruce.

2. Mental/Social Activities go hand in hand

- i. bingo
- ii. the Woden and Belconnen Seniors Clubs
- iii. Canberra Spinners and Weavers
- iv. video club
- v. University of the Third Age
- vi. caravanning
- vii. gardening groups such as the African violet club and Friends of the Botanic Gardens
- viii. church activities
- ix. volunteering.

Ideas from the discussion for expanding your social horizons:

- Goodwin Homes has a Day Club, open to all, with social outings, interesting activities at a cost, of course. Phone 02 6162 0296.
- COTA has a new service for older people wanting to get out and about more, but who don't know where to start. They will help with transport. Phone 02 6282 3777.
- The latest edition of Canberra's Community Service Directory *Contact 2014*, is now available. It features updated details for around 2,500 organisations that support the social, recreational and community service needs of Canberrans. \$16.50 a copy. Available at CONTACT Canberra Info Shop, Griffin Centre, 20 George Street, Canberra ACT or visit www.contactcanberra.org.au.

We must all remember that physical and social activities in general help to sharpen our minds. So, after all the mental activity of General Business, Helen Cotter led us in a two minute easy exercise session to finish. This should become a regular event. As we all know the young and the mature can't sit quietly for any extended period.

Why I Like Retirement!

Q: How many days in a week?

A: 6 Saturdays, 1 Sunday.

Q: When is a retiree's bedtime?

A: Two hours after he falls asleep on the couch.

Q: How many retirees to change a light bulb?

A: Only one, but it might take all day.

Q: What's the biggest gripe of retirees?

A: There is not enough time to get everything done.

Q: Why don't retirees mind being called Seniors?

A: The term comes with a 10% discount.

Q: Why do retirees count pennies?

A: They are the only ones who have the time.

Seniors Expo

Helen Cotter

The Seniors Expo was again held in the Budawang Pavilion at the Exhibition Centre. The place was abuzz with community, government and private organisations all promoting their wares while competing for the attention of the general public.

Pam, Robyn and Barry set up the Lung Life stand and held the fort for most of the day, relieved for a while by Esther and Marilyn. 'It was a worthwhile day,' Pam said. 'We had many enquiries. People stopped to ask us about various lung conditions and to find out more about our support group'.



What would we do without her?

Our thanks once again go to Pam, Robyn, Barry, Esther and Marilyn for the effort they put in on behalf of our group.

The A-Z of Preventative Medicine - G

Chris Moyle

Genetically modified (GM) foods

Genetically modified (GM) foods are foods derived from genetically modified organisms (GMOs). Genetically modified crops have had specific changes introduced into their DNA by genetic engineering techniques, usually to make them more resistant to disease. Typical GM plant products are soybean, corn, canola and cottonseed. Some foods we eat today contain genetically modified ingredients.

Supporters of this technology maintain GM foods ensure and sustain food security globally.

The reason that genetically engineered food *could* be dangerous is because there has been no adequate testing to ensure that extracting genes that perform an apparently useful function as part of that plant or animal is going to have the same effects if inserted into a totally unrelated species

It may be that in the long term, genetically modified foods could provide us with benefits and be a safe alternative, but we cannot know that at this time due to the lack of safety testing.

If you wish to avoid GM foods look for those labelled “No GMO”.

Glycemic index (GI) foods

Low GI foods will be digested slowly, leaving you feeling full for a longer period of time. It is a useful aid for diabetics and anyone who wishes to control their blood glucose levels.

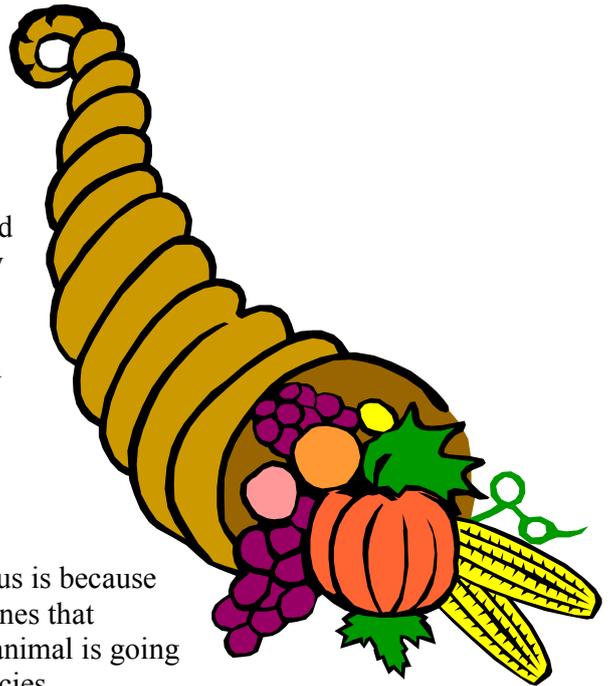
Classification GI range

Low GI 55 or less: beans (white, black, pink, kidney, lentil, soy, almond, peanut, walnut, chickpea); small seeds (sunflower, flax, pumpkin, poppy, sesame); most whole intact grains (durum/spelt/kamut wheat, millet, oat, rye, rice, barley); most vegetables, most sweet fruits (peaches, strawberries, mangos); tagatose; fructose

Medium GI 56–69: not intact whole wheat or enriched wheat, pita bread, basmati rice, unpeeled boiled potato, grape juice, raisins, prunes, pumpernickel bread, cranberry juice, regular ice cream, sucrose, banana

High GI 70 and above: white bread (only wheat endosperm), most white rice (only rice endosperm), corn flakes, extruded breakfast cereals, glucose, maltose, maltodextrins, potato, pretzels, bagels

Source: Wikipedia



Visit to Physiotherapy Students at the University of Canberra

Pam, Chris and Helen R

Ten volunteers with respiratory conditions visited the physiotherapy students at the University of Canberra. Pam, Maddie, Judy, Val and Jan attended the morning session while Pam G, Brian, Win and Helen R attended in the afternoon. Students met us in the car park and escorted us upstairs. One of them even parked Pam's car so she wouldn't have to walk so far!

In the students' room we were greeted by a spread of homemade goodies – brownies, delicious muffins, homemade hot cross buns, banana bread and melting moments (just like Mum made!). We were waited on, hand and foot and then launched into the reason for our attendance.

The educational side of the encounter meant:

- numerous questions relating to our lung conditions - asked and answers recorded
- Stethoscopes came out and our lungs performed on cue, some more noisily than others. Some of us had our lungs tested with a spirometer
- blood pressure was taken before and after exercise
- oxygen saturation levels were measured and of course there was
- time for just socialising.



Win is enjoying himself; you can tell by his big smile.



It's important to have your blood pressure taken just so you can keep an eye on it.

Then it was out into the corridor for a six minute walk, our exercise for the day. Not all of us managed this but we tried because there was no pressure to perform.

Feedback from the students lets us know how pleased they are that we come. They see for themselves, how the chronic condition limits us and how the limitations are different in each person. The Physio students realise this knowledge is so valuable for their later work. They showed their appreciation by presenting the participants with a huge tin of chocolates. This in turn was most appreciated.

Thanks to Pam for once again organising this worthwhile activity. The students report that it's very helpful for them to interact with patients, each with their individual problems and at different points in their condition. As well as the day being a most enjoyable and satisfying experience we're able to help these professionals of the future.

Keep this in mind! Next year more "patients" will be needed as the University is expecting a larger group requiring our assistance. Let's plan to do our bit for the physios of the future.



It's always good to know exactly what you have to do.

The A-Z of Lung Disease – I

Interstitial Lung Diseases

Interstitial Lung Diseases (ILD) are a group of rare lung conditions that cause chronic chest problems or breathlessness. The problem usually develops over the age of 50 years, and can affect both men and women, and also children.

Whilst there is some overlap with adult disease, ILD in children often has a very different clinical picture. The causes of ILDs are unknown and are very rarely inherited.

Symptoms

In adults

- Breathlessness on exertion – generally constant from one day to the next, and if it deteriorates, does so over a period of months to years
- Dry cough (occasionally) – this can be the most distressing aspect of ILD and is often made worse by viral infections or exercise

The vast majority of ILDs occur as a result of spontaneous disorder of the body's inflammation and repair mechanisms. Sometimes this disorder only affects the lung; common diseases of this variety include:

- Idiopathic interstitial pneumonias, i.e. Idiopathic pulmonary fibrosis

Other forms of ILD occur as part of a more widespread disorder that can affect other parts of the body as well including:

- Sarcoidosis, rheumatoid arthritis and scleroderma.

Symptoms

In children

- Fast breathing
- Low oxygen concentrations
- Failure to thrive
- Chronic cough
- Persistent noises in the chest known as crackles or wheezes (when listening with a stethoscope).

One of the most striking features is marked breathlessness with exercise.

Idiopathic Pulmonary Fibrosis (IPF)

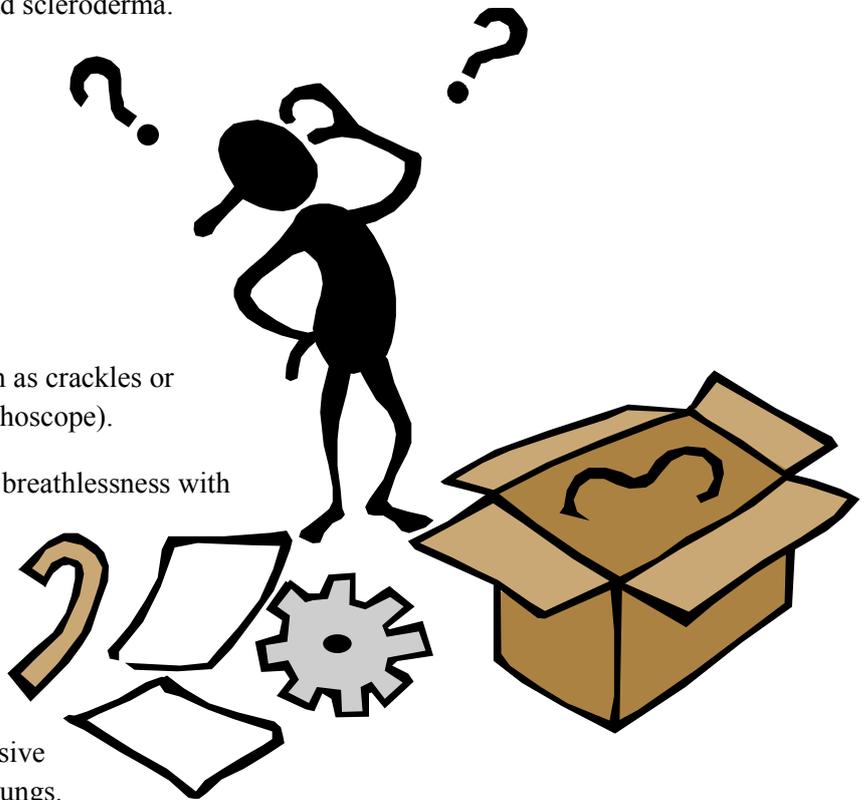
Idiopathic Pulmonary Fibrosis (IPF) is a condition that causes persistent and progressive scarring of the tiny air sacs (alveoli) in the lungs.

The amount of scar tissue irreversibly increases over time. The rate at which the disease progresses is highly variable, with some patients remaining stable for many years while others may rapidly get worse.

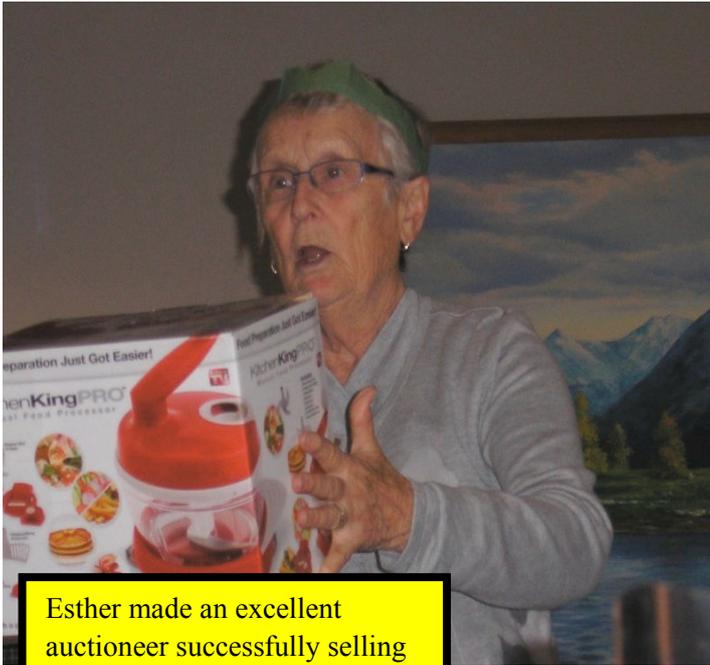
Symptoms

- Shortness of breath on exertion
- Cough (generally dry)
- Fingernails and toenails change to a beak shape, known as clubbing.

At present, it is not known what causes the disease to develop and progress however, it is known that the disease is more common in smokers. 70% of those diagnosed have a history of significant nicotine consumption. IPF has an incidence of approximately 10 per 100,000 of the population per year in Australia.



Members' reasons for coming to Canberra



Esther made an excellent auctioneer successfully selling everything and keeping us all entertained.

Esther Fitton was living with husband Ray and their three children in French's Forest, Sydney. Ray's asthma was slowly getting worse but they noticed that every time they visited a friend in Canberra his breathing improved.

Although their eldest daughter, aged 15 years, wasn't happy and threatened to run back to Sydney and Esther's mother lived in Sydney, the decision was made to sell their French's Forest home and relocate to Canberra.

The family settled into their home in Fisher, where Esther still lives today, 40 years on. Esther's mother later moved to Canberra, living independently, for the latter 20 years of her life.

The very best outcome of the move to Canberra was that Ray's breathing was near perfect. It was only many years later that he again developed breathing problems.

Chronic Cough: Does It Come From Your Lungs?

Maureen Bell

I have had a chronic cough for more than 20 years, beginning after a severe respiratory infection and exacerbated by whooping cough. It resulted in the abandonment of a teaching career in English as a Second Language, left me with constant sore throat and chest, inability to speak a full sentence, exhaustion, bladder problems and exclusion from attendance at concerts, theatre and movies.

I was thoroughly tested for allergies and asthma. I had a gastroscopy to check whether my reflux disease was affecting the throat area. I searched every reputable internet site for possible treatment including surgery. (Did you know that there is an International Society for the Study of Cough?) I worried that the cough was caused by my interstitial lung disease (cough is commonly caused by ILD) and this would indicate a worsening of the condition. My GP thought I probably had a hypersensitive cough reflex - sometimes called laryngeal sensory neuropathy or laryngopharyngeal mechanosensitivity. I asked if hypnotherapy would help. But before finding a hypnotherapist who might treat me I had my regular checkup at TCH for both ILD and Obstructive Sleep Apnoea.

In discussing my OSA I complained that the CPAP machine gave me a lot of bloating – stomach colic and intestinal wind. I questioned the possibility of a malfunctioning epiglottis, so that air was going not only into my lungs but also down my oesophagus. Dr Rosie Wee (TCH) referred me to a speech pathologist, Margaret Jacobs in Phillip, for evaluation and possible treatment of a voice disorder.

It turns out that Margaret Jacobs is not just a voice specialist but also a specialist in chronic cough. Halleluia! I had a one hour consultation with Margaret who gave me eight or so strategies to prevent a cough triggering a bout of coughing; within 24 hours there was marked improvement.

I now consider myself, like an alcoholic, 'controlled but not cured'. There has been a quantum leap in my quality of life and not only can I attend concerts without distress but was able to join a U3A course for beginners in harmonica playing - great fun and excellent exercise for lungs. Win, win!

This story might not be of a direct help to you but possibly to someone you know. My view is that allied health professionals - and there are many sub-specialities - are not sufficiently recognised by the medical profession.

Have your say about your out-of-pocket costs in your health care!

Eleanor Kerdo Health Care Consumers' Association Inc

Does cost affect your ability to access health care? How does the cost of pharmaceuticals, primary care visits, medical devices or supplies, and dental care affect your everyday life?

HCCA invites you to participate in a community consultation to inform the HCCA submission for the Federal Senate inquiry into out-of-pocket costs in Australian healthcare.

Date: Tuesday 6th of May 2014

Time: 10:00 am - 11:30 am

Venue: HCCA offices, ACT Sports House,
100 Maitland Street, Hackett ACT 2602

RSVP: Please RSVP to Eleanor Kerdo (eleankerdo@hcca.org.au, 02 6230 7800) by Friday May 2nd. Please provide any dietary requirements (light morning tea provided).

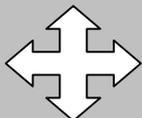
Note: If you are unable to attend and would like to contribute to the submission please contact Eleanor. More information on the terms of reference for this inquiry can be found at:

http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Australian_healthcare

Let Helen Cotter know if you have any thoughts on the matter or want to attend. I'm hoping to go. Helen C

Rusty Woodward

Chris Moyle



A long time member of our Group and an active member of many community organisations, Rusty Woodward died at The Canberra Hospital on April 11, 2014. Rusty had migrated, in 1964, from England to Cobar, NSW, moving to Canberra in 2007. She said she'd NEVER move to Canberra but her daughter, a nurse, said she must move here because she was sick and needed to be closer to her family.

Last year she was a speaker at one of our meetings, discussing with us the danger of falling and how to prevent falls. Care with medications was another string to her bow. She was also involved with the Tuggeranong Community Council in raising awareness regarding the dangers of woodsmoke. In spite of her physical limitations Rusty did much to help the community.