

May 2017 Newsletter

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

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Next Meeting: Thursday 11 May 2017

10:15 am - 12 noon

Weston Creek Labor Club

Teesdale Close Stirling ACT 2611

Guest Speakers: This month's meeting will be dedicated to discussion and activities.

Dates for your diary

Wednesday 3 May 2017 Lung Foundation Australia Education Day Thursday 8 June 2017 10:15 am - 12 noon CLLSG Meeting

April Meeting Helen Cotter

The meeting began as usual with Esther calling the roll and checking on the welfare of members not at the meeting. If no one has been in contact there is always someone willing to take on the responsibility of contacting non attendees to make sure everything is OK with them and to enquire if the Group's support is needed.

Matters discussed:

- Kaye talked about the day she and Helen Cotter had at Parliament House, testing the lungs of politicians and parliamentary workers. Details later in the newsletter.
- Helen Cotter reminded people of Lung Foundation Australia Education Day on 3 May 2017 and finalised the list of members attending to send to LFA. More information later in the newsletter.
- Lyn Morley let us know that SHOUT now has ongoing funding from the ACT Government so it can continue



Lyn is looking comfortable in her role as Coordinator of the Canberra Lung Life Support Group.

- its good work. We are affiliated with SHOUT and forward on emails from them about meetings and other activities their member groups are holding.
- Carmel told us about a session she and David attended, organised by the Pain Support Group (and forwarded by SHOUT) on the Feldenkrais exercise method which they found very beneficial.
- Lyn told us about the bus outings organised by the Belconnen Community Centre. The Centre organises outings once a month to different places of interest and once a month to cafes for lunch. They will pick up from anywhere in Canberra. More detail at next month's meeting.
- Next month's meeting will be devoted to general discussion and activities.
- Chris asked for suggestions for future meetings:
 - ♦ Do we want the Minister for Health to talk to us?
 - ♦ What do we want to know?
 - What people do as a hobby or interest?
 - ♦ Follow up on relationships
 - ♦ Other ideas welcome. Give this some thought and bring them to the next meeting.

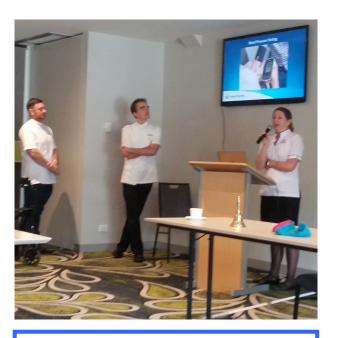
Then it was over to our speakers.

The Role of the Chemist in Our Community Chris Moyle

Our speaker this month was Louise McLean, a managing partner at Capital Chemist Southlands Mawson accompanied by Tim, a junior chemist and Harry from Capital Chemist, Hughes.

The topic was "Things that chemists do", at Southlands in particular.

- **Anaemia screening** if haemoglobin is outside the normal range you are referred on to a GP.
- **Blood Pressure** There is a charge of \$3.00 for a single test and a discount for multiple testing. The reading is recorded and can be printed out.
- National Diabetes Services Scheme (NDSS).
- Diabetes education, blood glucose and Hb A1C testing which measures the average blood glucose level over 120 days (cost \$25.00).
- **Dose administration aids** Webster Packs which are for home use only and not acceptable in hospital.
- MedAdvisor helps you manage your medication, organises home delivery and reminders.
- Medicine review in a pharmacy is a free service subsidised by Medicare. You are entitled to one review every twelve months. Tim mentioned that he finds one or more recommendations for change in every review he performs so it is worthwhile to do this once a year.
- **Home medication review** needs a GP's referral and GP receives the pharmacist's recommendations.
- Pharmaceutical Benefits Scheme (PBS) Safety Net Medicare also has a Safety Net related to number of GP visits.
- **Unwanted Medicines** return to the pharmacist, never flush down the toilet or throw out with the rubbish.
- Vaccinations administered by pharmacist. A change applies.
- **Prescriptions kept on file** particularly useful if you need delivery.



From left: Harry, Tim and Louise filling in the gaps in our knowledge of exactly what is the role of the chemist in our community. • **Sleep Apnoea** - Harry at the Hughes Capital Chemist will check machines and masks and undertake repairs. No appointment necessary.

Knowledge is a wonderful thing! Helen Reynolds

A positive outcome to this talk as far as I'm concerned was my visit to Harry at the Capital Chemist at Hughes. He sorted out my problems with my CPAP mask, advised me on the best way to clean my humidifier and checked my technique with a spacer.

I left Harry feeling very much relieved. My CPAP machine is now working perfectly and the cost was not astronomical.

A Community Advocacy Award - Congratulations Caroline! Helen Cotter

Last month, as the guest of Caroline Scowcroft, I attended, along with Caroline's daughter Jane, a dinner at the Annual Conference of the ANZ Thoracic Society.

Lung Foundation Australia (LFA) hosted the dinner at Old Parliament House for those at the conference who were connected with the LFA. About 180 attended.

At the dinner, Dr Christine Jenkins of LFA presented Caroline with a **Lifetime Achievement Award** for her community advocacy over the years and also, in recent years, for her involvement in rural, remote, indigenous and chronic diseases health. It was an enjoyable evening made even more so by the recognition given to Caroline for all the work she has done in our field.

Long term Canberra Lung Life Support Group (CLLSG) members will remember Caroline and her husband Bill who was in a late stage of COPD when they arrived back in Canberra from Canada in about 2007. They joined CLLSG where Bill



Almost didn't recognise Caroline without her green COPD T-shirt.

soon became Coordinator, with Caroline a more-than- able supporter. The couple were responsible for starting many of the activities that are now part of CLLSG's regular activities:

- Education Day
- Seniors Expo
- World COPD Day (remember the walks along the edge of the Lake and the picnic that followed)
- physio and medical students visits
- as well as lobbying for oxygen concentrators for all oxygen users.

On Bill's death, Caroline became Coordinator continuing the work: liaising with politicians, Government departments, and relevant community groups; working with LFA; being a member of LFA's teleconference group, CPAG; appearing everywhere with her green LFA T-shirt, always promoting LFA, CLLSG, lung awareness and information about lung conditions.

In 2012 Caroline left us and moved her base to Cairns where her daughter Sarah is living. Having completed her nurses' qualifications she now continues with her community advocacy concentrating on raising awareness of lung conditions in rural and remote areas, while still very involved with LFA.

Free Lung Testing at Parliament House Helen Cotter

Late March, Kaye Powell and I spent from 10:00 am to 1:00 pm in Parliament House assisting in the free lung testing of any politician, politician's staff or Parliament House worker who was interested in finding out the health of their lungs.

Lung Foundation Australia organised the event, providing doctors and chemists to carry out the testing (including Samantha Kourtis who spoke one year at Education Day and Dean Apollini who spoke at a Lung Life meeting a couple of years ago), and supported by many of the LFA staff, all wearing their green T-shirts.



Helen and Kaye are organised and ready to go to work.



The LFA

workers had set up a room where the tests were to be carried out and it was to this room Kaye and I were escorted. Kaye and I registered the participants who were then taken to a separate section where the breathing tests were performed. If the results weren't too good, they talked to a doctor who advised them of their next step.

It was great to see the number of politicians, their staff and political workers - busy as they all were - who took the opportunity to have their lung health checked. And good to see that most walked out with a satisfactory test result - maybe the benefit of all that walking along the vast corridors of Parliament House. All of this helps to spread awareness of chronic lung conditions and how it can affect people.

You can tell who isn't with LFA. He's a politician and isn't wearing a green T-shirt. It's John Alexander, Member of the Australian Parliament.

It was also rewarding to work with the LFA people, a lovely group who do a great job and were a delight to be with. Kaye and I are now able to put faces to people we only knew by email or phone.

Lung Foundation Australia's Education Day

Wednesday 3 May 2017
The Orion Room, Southern Cross Club, Woden
9:45 am - 2:00 pm
\$15 with lunch included (discounted entry for members of LFA)

Talks on:

- Living Well with Lung Disease and the importance of being proactive in your care Claire Mulvihill, lung cancer nurse
- The importance of good nutrition and weight maintenance for lung health Julie Priestly, dietician and clinical educator
- Exacerbations and your lung disease Mark Hurwitz, respiratory specialist.

To secure your place, call Lung Foundation Australia on 1800 654 301. Please let them know if you have any dietary requirements.

SHOUT (Self Help Organisations United Together)

Extract provided by Helen Cotter

The Pearce Centre Collett Place, Pearce 2607 MAWSON ACT 2607 PO Box 717 MAWSON ACT 2607.

Phone: 02 6290 1984. Email: admin@shout.org.au. Web: www.shout.org.au.

Patron: Jon Stanhope

After thirty five years of operation SHOUT was under threat of closure because of changes in funding arrangements as a result of the transition to the NDIS. However, the ACT Government has now come up with some funding so **SHOUT** is able to continue.

SHOUT is a not for profit organisation providing self help and support groups in the ACT with infrastructure, support services, room hire, and high level administrative support. A number of these groups are small community organisations entirely managed by volunteers which provide a lifeline to people with health conditions. They would be unable to stay open without **SHOUT**'s backend support.

Self help is shown to be cost effective. Self help and support groups provide people with:

- information,
- services,
- advocacy and
- an extended social support system essential to the wellbeing of people and their families.
- mutual support,
- resources,
- tools to self manage their health condition and

SHOUT provides a home to ACT Down Syndrome Association, Motor Neurone Disease NSW/ACT, Bosom Buddies ACT (breast cancer support), Friends of Brain Injured Children, People with Disabilities ACT, Brain Tumour Alliance Australia and ACT ME/Chronic Fatigue Syndrome Society. A number of these groups have indicated that they would not be able to continue if SHOUT were to close. The Canberra Lung Life Support Group is an affiliated member of the organisation.

So once again, "Thank you" ACT Government, for providing much needed funding for SHOUT's continuation.

Vehicle Idling and Lung Health Helen Cotter - From The Canberra Times 11 April 2017

Health experts are worried about the damage to lungs caused by idling cars exposing people especially children to high levels of noxious chemicals, including sulphur and diesel particles. They believe that many people do not understand the health risks.

Diesel particles are especially toxic because they are fine enough to go through the skin into the lymph system and through the lungs into the blood stream and central nervous system. One in five cars are now diesel powered and Australia has the lowest fuel quality standards in the developed world, ranking 66th in petrol quality against the other OECD countries.

Experts are calling for anti-idling legislation, starting with schools and then expanding to other public areas such as shopping strips. Anti-idling legislation is already widely used in the US, attracting fines of up to \$25,000 in Virginia and even jail terms in Utah and Denver, Colorado.

It is estimated by the Health Effects Institute that air pollution from light vehicle emissions, including cars, killed 1715 people in Australia in 2015, almost one and a half times more than the national road toll.

Disclaimer: The information in this Newsletter comes from a variety of sources and is intended as a guide only.

COPD Exacerbation Helen Cotter

One of the talks in Education Day this year is about exacerbations, which are periods when your symptoms are much worse than usual. A person undergoing an exacerbation may need to seek medical help at a hospital.

COPD exacerbations can be harmful because they can cause further damage to the lungs. If you've been diagnosed with COPD, preventing an exacerbation from occurring can help you live a healthier life and reduce your risk of death.

Some of the points to look out for in the talk are:

- What are the symptoms? What causes them?
- When do I need to go to hospital?
- Can they cause or affect other conditions?
- How can I avoid them?
- How are they treated?
- How can I prevent them?

The speaker may talk about the importance of having an Action Plan, organised with your doctor, and following the plan that's set out for you.

Good Nutrition and Weight Maintenance

Helen Cotter - extract from The Lung Foundation Website

The second talk on Education Day is about the importance of good nutrition and weight maintenance for lung health. We all know that this is important but here are some issues the speaker may deal with.

What does weight maintenance actually mean?

What effect does your body weight have on your COPD?

What if you are underweight? What can you do about being underweight?

What if you are overweight? What can you do about it?

How can you help yourself maintain good weight?

What are the common issues in lung conditions that affect weight and how can you manage them?

Can you get any assistance in achieving good weight?

Of course, the speaker may not deal with all of these topics but thinking about these questions, especially with your own situation in mind, will help you understand the points the speaker is making.

A big thanks! Helen Reynolds

It is definitely time we recognised the efforts of people who are able to take photos with a camera at our meetings. I'm sure all our members will agree with me that photos not only brighten the printed word, they bring it to life. So to Helen Cotter, Peta, Kaye and all you others who took and contributed photos: **Many thanks**. Please keep up the great work. It is very much appreciated.