

## April 2024 Newsletter

Our mission is to provide a supportive and informative environment for people with lung conditions and their carers.

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**NEXT MEETING:** Thursday 9 May 2024  
10:15 am – 12:00 noon  
Weston Creek Labor Club  
Teesdale Close, Stirling ACT 2611

Note: Our email address (see above) is once again our means of communication.

### Stall at Government House – Marina Siemionow (photos by Val Siemionow)

Last month we had a brief article on the stall we set up on 16 March at the Governor General's Residence. *Here is a more detailed summary of the day, and a photo with the Governor General.*

We were acting as representatives of Lung Foundation Australia (LFA) as well as advertising ourselves to the general public. On the day we joined thirty or so other community organisations on the lawns to 'spread the word'.

We arrived at 7:30 am to set up and decorate the provided gazebo. We found ourselves conveniently located just around the corner from the coffee cart.

With my daughter's expert help we put up easels, green corflutes, posters, ivy fairy lights, small green plants and leaves, along with our normal banners.



We also had brochures, pamphlets and advertising materials on hand. Throughout the day we were congratulated on our stand by other stall holders, staff, and visitors alike.



At this event we had a much larger audience than we were used to; 3,500 people entered the gates that day, representing a broad cross section of our society. We found ourselves talking to children who were really only after free stuff, but we ensured that they were wearing the rubber bracelets and pins before they left our stand and gave them our brochures to pass on to their parents as many were concerned about their parents' smoking and vaping habits.

We had some interesting conversations with a number of travellers from other countries who were very curious about the work of LFA, and they left with the QR code stickers to follow up in their own time.

Given the distances and inclines visitors had to walk to get from the car park to Government House we met no one with a lung condition, although we did capture a number of visitors who were close to someone who had a lung condition and they left with our brochure, to pass on. Hopefully this will lead to a few more new members.

Overall we had a great day. The weather was perfect for such an event. We chatted with the Governor General who enjoyed our lollies especially the mint leaves. I received a couple of invites to speak at other community groups' meetings (which I accepted) and we met an array of interesting people.

## April meeting – Helen Cotter

Despite some of our members being away at the UC Physiotherapy Department (being guinea pigs for their students) we had a good turnout with a few new members. Caroline Polak Scowcroft talked about the Lung Life working party she's on with Val Dempsey and Colette Mommer. They have been contacting the media with the result that there's been a couple of articles about Lung Life and about the closure of the Chifley Gym. There has also been a TV interview about living with breathing difficulties.

Marina let us know that we're hoping our old Hotmail address may be working soon. It was hacked and has been out of use for a couple of months. (*Note: It is working now*). She also handed out a program of Lung Life dates and events for the year – a very useful document to have. Two upcoming events are listed below.

## Dates to Remember

Thursday 9 May: Speaker - Raj, Respiratory nurse from ACT Health.

Friday 31 May: Lunch at the Burns Club

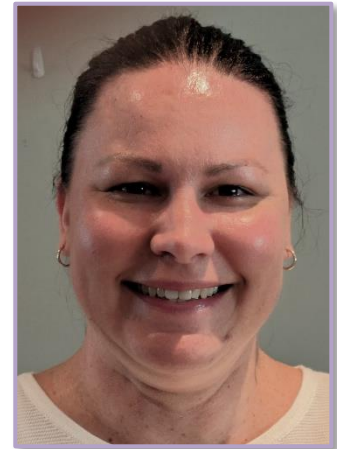
Geoff, our newsletter editor, has advised us that in the future he will not be doing the newsletter every month (he will do roughly every second month). Marina asked for a volunteer to do the other months. (*May, July and October are the month's we require assistance*). Alison Torr agreed to have a trial run – thanks Alison.

Marina told us about the ACT Health Services program called the **Virtual Care Program** which has been focusing on COPD and other respiratory diseases. This program is a **telehealth service** that provides short term support to patients after they have left hospital.

Then it was over to our speaker, Catherine Adcock (pictured) from COTA (Council on the Ageing).

### **COTA: Improving life for Seniors**

COTA ACT has been improving the lives of ACT Seniors since 1973. It identifies gaps in provision and implements programs and services to encourage older people to participate in the community and contribute to their fullest. It has advocacy with the ACT Government and with local MLAs. The organisation also sits on many different reference groups and provides submissions on both Federal and Territory issues.



COTA's other hat is providing programs and services for seniors in the ACT. These include events such as Seniors Week with its Expo Day, a seniors concert with the RMC band, and senior awards which recognise services to/for seniors. There are also meetings, called Midweek Matters, on various topics such as dementia, and heart health.

COTA manages the **Seniors Card** which is connected with MyWay transport cards – and a directory showing which businesses give discounts to seniors. This is reciprocal throughout Australia and some other countries.

News and information are part of their services. This includes a **regular newsletter**, plus an older drivers' handbook, a guide to getting around Canberra and multiple brochures. They also have a facility that connects you to other services such as volunteer schemes, tax help, advance care planning, finance etc.

Education is part of their service. One-on-one sessions are available to help seniors to use mobile phones, tablets, or notebooks. These are often held at libraries.

At Hughes, where COTA is based, you'll find the Community Shed and Garden (available for both men and women) and the Community Centre which is often used by other organisations such as U3A. COTA also provides information on many different topics, often on a one-to-one basis (in person or by phone). Information includes your housing options, My Aged Care and its home care packages or residential care. They will also assist you to navigate the government Aged Care website.



Catherine went on to talk about **My Aged Care**, how you access it and what it can do for you. The first step is registering through Aged Care, then getting assessed. After that you have to find a provider. The My Aged Care website is the best place when searching for options. Providers have to supply up to date information on what they have available.

Catherine gave us more detail about Aged Care packages and costs but it's worthwhile talking to COTA about these issues before you dive in.

**It was great to see Jaqui (pictured left) joining us at the meeting for the first time. Welcome Jaqui.**

Finally, Catherine mentioned that COTA does not get any government grants – and becoming a member will both help them - and enable you to keep up to date on COTA's advocacy, programs and events.

**COTA** Contact details: [www.cotaact.org.au](http://www.cotaact.org.au) ; [contact@cotaact.org.au](mailto:contact@cotaact.org.au) : ph 02 6282 3777.

Hughes Community Centre

Wisdom St Hughes (along from the shopping centre)

**My Aged Care** Contact Details: ph 1800 200 422

**Website:** [Access Australian aged care information and services | My Aged Care](#)

## **From the Editor** - Cytomegalovirus the virus with a name so long we just call it CMV

You may recall from the March edition that your editor spent some time locked up in hospital over parts of the summer. Here is the reason why.

Your editor had CMV which is a very common virus (part of the herpes virus family). Most people get away scot-free when they have it; in fact most people don't even realise they have CMV because it rarely causes problems in healthy people. **Around 1 in 2 people have been infected with CMV by young adulthood**, and once infected, your body retains the virus for life.

If your immune system is weakened (or if you're pregnant) CMV is cause for concern. For people who have a weakened immune system, especially people who have had an organ, stem cell or bone marrow transplant, CMV infection is serious and can even be fatal. Women who develop an active CMV infection during pregnancy can pass the virus to their babies, who might then experience symptoms.

CMV spreads from person to person through body fluids, such as blood, saliva, urine, semen, and breast milk. **For transplant patients the problem is most likely to be the result of a mismatch where the donor was positive and the recipient negative.** As the transplant recipient is dealing with a new virus, they are very vulnerable (and they must take medication as a preventative measure for some time after transplantation).

There is no cure, but there are medications that can help treat the symptoms. Hence your editor's 'summer break' in hospital to receive daily IV treatment.

Your editor also contracted COVID-19 in hospital - no explanation is required to describe that one.

What are the symptoms of CMV?

The symptoms of CMV can vary. For the more vulnerable it could be any of the symptoms below. Your editor had a fever and fatigue.

- fever
- tiredness
- sore throat
- swollen glands
- abdominal (tummy) pain

References: <https://www.healthdirect.gov.au/cytomegalovirus-cmv>  
<https://www.mayoclinic.org/diseases-conditions/cmv/symptoms-causes/syc-20355358>

## Lung Foundation Australia (LFA), Consumer Advisory Committee

By Caroline Polak Scowcroft (who has been involved with our group since 2006)

Lung Foundation Australia (LFA) works tirelessly in the interests of Australians with a range of lung conditions. I am currently the **chair of one of the LFAs Australia Consumer Advisory Committees** (as an individual, not as a position endorsed by our Canberra based group).

- The COPD Consumer Advisory Committee that I chair has a brief of *Priority areas for action 2023/2024*.
- The brief details **five identified areas of expressed need**.
- It includes **activities** and ideas to address these needs.
- And outlines the LFA's actions and activities.

Throughout 2024 I hope to outline each of these five areas of need - and let you know how things are progressing. Comments and feedback are of course always appreciated.

This month, we are looking at '**Awareness-raising**' - the expressed need is for general awareness-raising of LFA's services and patient resources. The **activities** are to use opportunities to host more community level activities such as stalls, events, and presentations. These activities will involve people with lived experience of chronic lung conditions.

Another area of need is **Health Professional (HP) awareness-raising** to improve understanding of COPD and its management among primary care HPs, especially with a focus on early and correct diagnosis.

A further area is finding **opportunities to partner** with universities to increase awareness of LFA among undergraduate medical/nursing/allied health students, so there is an integration of '*lived experience with real people*' into their courses.

### March Lunch at the George Harcourt Inn – Photos by Val Siemionow



**Long-term members Barry and Margaret were there to enjoy the March lunch.**

## An excerpt from the City News Article by Katarina Lloyd Jones, 4 April 2024

Marina and Pam were recently interviewed by Katarina from City News. You can read the full article by clicking on this link: <https://citynews.com.au/2024/group-breathes-hope-into-lung-disease-suffering/> .

*The group was formed in 1998 and is a volunteer-led social network supported by Lung Foundation Australia, says Marina Siemionow, co-ordinator since 2019.*

*“It started with a group of eight people who had lung problems, and it’s just grown since then, we actually have about 70 members now,” says Marina, who discovered the group while walking through the Seniors Expo with her partner Val, who suffers from bronchiectasis and asbestosis.*

## Thoughts and comments on Ageing - Chris Moyle

The average life expectancy in Australia is 81.3 years for males and 85.4 years for females. Women are thought to have stronger immune systems. Out of the top 49 oldest people alive today, only two are men.

‘The older I get, the more clearly I remember things that never happened.’

Writer **Mark Twain**

‘I’m at that age where my back goes out more than I do.’

Comedian **Phyllis Diller**

‘Nice to be here? At my age it’s nice to be anywhere.’

Comedian **George Burns**

‘You spend 90 per cent of your adult life hoping for a long rest and the last 10 per cent trying to convince the Lord that you’re actually not that tired.’

Author **Robert Brault**

‘Old people shouldn’t eat health foods. They need all the preservatives they can get.’ Comedy writer **Robert Orben**

‘It’s paradoxical that the idea of living a long life appeals to everyone, but the idea of getting old doesn’t appeal to anyone.’

Television writer **Andy Rooney**

‘You know you are getting old when everything either dries up or leaks.’

Musician **Joel Plaskett**

‘There are advantages to being 102. There’s no peer pressure.’

Comedian **Dennis Wolfberg**

‘There are three stages of man; he believes in Santa Claus, he does not believe in Santa Claus, he is Santa Claus.’ Journalist **Bob Phillips**

‘Looking fifty is great – if you’re sixty.’

Comedian **Joan Rivers**

Reference: Clive Williams article City News April 13-19, 2023

[https://issuu.com/citynews/docs/230413\\_citynews](https://issuu.com/citynews/docs/230413_citynews)

