

November 2023 Newsletter

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

Editor: Geoff Cox
lung.life1@hotmail.com

Coordinator: Marina Siemionow 042 962 9180
lung.life1@hotmail.com

NEXT MEETING: Thursday 8 February 2024
10:15 am – 12:00 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

Find out about other planned events in this edition of the newsletter.



From the Editor

Your editor is back from Tasmania just in time to put the Christmas edition of the newsletter together. This will be the last edition for 2023.

Thank you to everyone who has been involved with the production of the newsletter this year, especially the sub-editors, Chris Moyle, Helen Cotter, and Don Neal.



It looks a bit like Christmas came early for these three amigos (Joe, George, and Val) who are obviously enjoying themselves at the October Lunch.

Val Siemionow has been our photographer, as well as sometime Notetaker, along with the other Notetakers, Karen, Helen, and Marina. And thanks everyone else who has contributed to the newsletter in 2023.

November Meeting: 9 November 2023 – Val Siemionow

Our meeting commenced at 10:30 am, with fourteen members attending. Apologies were received from George, Caroline, and Jenny. We were pleased to welcome two new members, Sandra and Les, who came across the Lung Life group through Pam at our stand at Seniors' Expo.

Sandra and Les introduced themselves and explained why our group had interested them. Sandra has emphysema while her partner Les helps with her care. To make them feel welcome the group then introduced themselves around the table.



New members Les and Sandra at November meeting

We collected members' donations towards the Xmas hampers, and then the following points were discussed.

- Our involvement in **World COPD Day**. The theme for this year is focusing on early intervention, *Breathing is life – Act Earlier* (see report on page 4).
- Kaye advised that she would be involved in the COPD presentation by the Lung Foundation to interested members of parliament. Marina asked whether the video used as part of that presentation could be made available for our group to access and view. Kaye agreed to send a link to Marina and provide photos of the occasion.
- **Our Christmas Lunch on 14 December at the Hellenic Club in Woden.**
 - We decided to have an **11:30 am** start so that members had a better chance of getting a car park within a reasonable walking distance of the club. It was also decided not to go for a set menu, and everyone will choose, order, and pay for their own meals. Xmas hampers will be raffled during the afternoon.
- **Handing over some formal roles - the Treasurer, Assistant Treasurer, and Notetaker**
 - After long periods in the roles Chris Moyle (Treasurer) and Helen Cotter (Assistant Treasurer) have handed over the reins to Karen Anable (new Treasurer) and Marina Siemionow (new Assistant Treasurer).
 - It was agreed that Chris, Helen, Karen, and Marina would meet later to discuss how they would undertake the formal transfer with the bank before our next meeting in February. It was reaffirmed that a financial report would be made to the group on a quarterly basis to help the group determine how it would like to allocate funds.

- Val Siemionow agreed to take on the **Notetaker** role from Karen on an ongoing basis commencing immediately.
- The **ABIS project** that Marina and Pam have been involved with over the past year or so, is seeking more participants for its current pilot of a home support service to help people with breathlessness better self-manage their condition (see page 5 for more information).
- A new federally funded project, called **BREATH**, that Marina is involved in (along with the Lung Foundation and the University of Technology Sydney), is reviewing the effectiveness of the myriad of COPD Action Plans. These various plans are currently in use across Australia, New Zealand, and other English speaking countries. The purpose of the project is to create an ultimate Action Plan which is easy to access and use (see page 6 for more information).
- The need to **update our registration system** and form. Pam advised the group that much of the information we hold on our registration forms is no longer current. We need to update the register of members' names, current contact numbers and other relevant details. Marina will send out the registration forms to members to update and return.
- **Members' use of technology.** A number of members raised the issue of technology specifically with respect to people's ability/inability to use mobile phones, tablets, computers etc. as their hardware and software is continually changing and evolving. It was noted that COTA provides a free service to assist and coach people to use their smart phones and computers and that this could help our members who are not confident with their technology. Marina is organising COTA to talk at one of our meetings early in the new year.



- There will **no meeting in December** as this will be the day of our Christmas Lunch (see above).
- There will be no formal **Lung Life Support Group meeting in January 2024**, however, we will have an **informal coffee** and/or **lunch** catch-up from **11:00 am** (Thursday 11 January at the Weston Labor Club).
- Formal meetings will resume on the 8 February 2024.
- A program of speakers and events for 2024 will be developed and sent out to members.

Trivia and Puzzles – sent in by Chris Moyle (Answers on page 6)

1. Trivia Question

The oldest person to have lived was Jeanne Calment, from Arles in France. She died in August 1997 at the grand old age of _____? (Hint: She turned 100 in the same year as *the Dismissal*).

- a. 118 years, 289 days
- b. 120 years, 52 days
- c. 112 years, 65 days
- d. 122 years, 164 days

2. Letter Word

Can you rearrange the letters to figure out what word this is?

K W L N O E G E D

3. Missing Words

Fill in the blank space to make two compound words or phrases:

coffee plant

bread over

coconut shake

4. Incremental

Change the first word to the last by **altering one letter at each stage** to make a new word each time.

S H I R T ; _ _ _ _ _ ; _ _ _ _ _ ; _ _ _ _ _ ; _ _ _ _ _ ; A T O N E

World COPD Day

15 November 2023

Our stand at Cooleman Court

Our stand was set up in the centre for the busy middle of the day period from 10:00 am to 2:00 pm.

Thanks to all those involved in the day. Chris Gray and Collette kindly volunteered to run the stand, however, unfortunately Collette was unwell. Our ever-present coordinator, Marina, stepped in for the first half of the session while husband, Val, helped out in the second half. Val Dempsey also came to lend her assistance.



Raj with Chris at Cooleman Court

Raj, a specialist nurse from the respiratory area of The Canberra Hospital, kindly attended to conduct lung function tests for shoppers who were interested.

Lung disease in Australia; some history - Maureen Bell

In light of the current information coming to light regarding silicosis caused by dry grinding of engineered stone kitchen benchtops ('blood money'), you might be interested in three episodes recently broadcast by ABC Radio National in *The History Listen* series -



Maureen at a group lunch

Dusted 01: Gold - the human cost of mining in Australia. It discusses miners' phthisis or silicosis.

Dusted 02: Coal - which discusses black lung disease or pneumoconiosis in the Wollongong area.

Dusted 03: Asbestos - which causes asbestosis or mesothelioma.

The half-hour episodes are available for you to listen to. You can find them on the internet by typing *The History Listen series Radio National* into your search engine. The episodes are then easily found in the *Australian Audio Guide*.

You can also find them on the *ABC Listen app*.

You may also like to read an update on what is happening regarding engineered stone. For those readers reading this on their computer simply click the following link which will take you to the Sydney Morning Herald article. <https://www.smh.com.au/politics/federal/federal-government-under-pressure-to-release-safe-work-s-benchtap-ban-report-20230906-p5e2hz.html> (note this is also the reference for the extract below).

For those who prefer not to, or are unable to read the article in full, here is a brief extract.

Business groups are at loggerheads with unions and health experts, who want a blanket ban on high-concentration crystalline silica slabs – used for fashionable kitchen benchtops but riddling tradies with an incurable disease – after Workplace Relations Minister Tony Burke and his state and territory counterparts gave Safe Work Australia six months to investigate the prospect of a prohibition of the substance.

ACT Breathless Intervention Service (ABIS) Project

At the November meeting Marina and Pam spoke to the group about evaluation findings, to date, for the pilot currently underway for a home support service for people with breathlessness.

So far, the findings are incredibly positive for people who have taken part in the pilot. Participants have all seen a positive change in their approach to their condition. We know of three of our members who have taken part and all three have been very pleased with the results and recommend others take part. As the service is tailored to each participant's personal circumstances the benefits differ between individuals.

Pam Harris, who has lived with COPD for over 20 years, has taken part in the pilot and found that she didn't know everything there was to know about her condition. She really appreciated the holistic support she received, and she encouraged everyone in the group to avail themselves of the service.

More participants are being sought for the pilot which has the added benefits of being a home service and it is free at the moment.

Our Coordinator, Marina, plans to send out a further reminder to all our members together with the appropriate links to enable interested members to take the necessary steps so they can be referred to the service.

BREATH - Joint Lung Foundation Australia and UTS Project

At the November meeting Marina spoke briefly on a new research project that she is involved in. This project is led by the University of Technology Sydney (UTS) and supported by Lung Foundation Australia.

Marina is one of the project members representing carers along with others who are representing people with COPD. The project aims to build the ultimate Action Plan to support people with COPD to better manage themselves through any breathlessness crisis event.

Existing plans across the world are being reviewed and input is coming from a variety of stakeholders including professionals, practitioners (from a wide variety of health services), users and carers. The project is currently collecting Action Plans currently in use and Marina will be forwarding a separate request from the UTS to all our members for any Action Plans they may be using.

At the meeting Kaye raised the issue of a possible duplication/conflict of studies as there was a similar project underway in Melbourne. The situation was noted, and Marina will pass this issue on to the UTS.

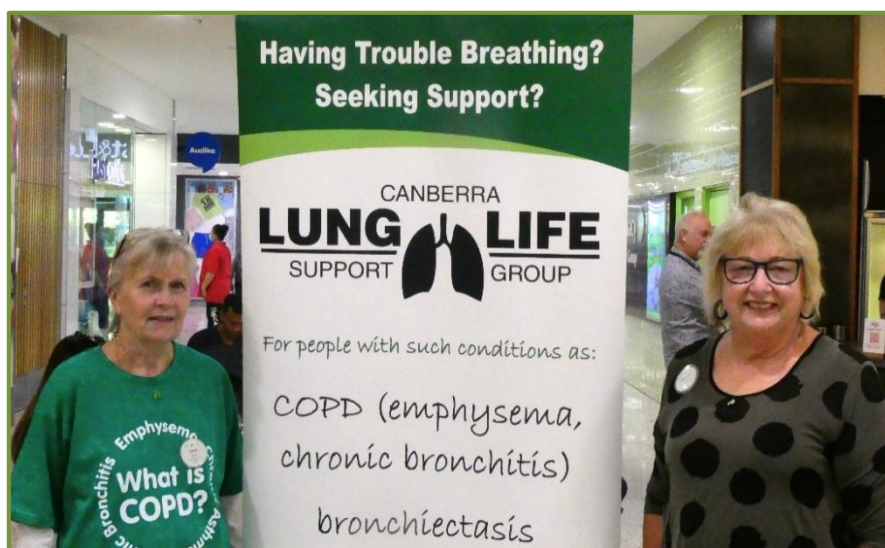
Some members asked whether it would be possible to develop a smart phone app that could verbally guide people through the Action Plan in times of critical events. The suggestion was noted and will be passed on.

The Final Word

And finally here is another photo taken by Val Siemionow on World COPD Day.

The editorial team will be taking a break over Christmas and the next edition of the newsletter is due to come out in late January.

**A Merry Christmas
and Happy New Year
to all our readers.**



Chris and Marina 'holding the fort at Coleman Court'

Answers to Trivia and Puzzles

(1) 122 years, 164 days (2) KNOWLEDGE (3) cup, roll, milk (4) short, shore, store, stone