

November 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 9th January 2025
10:15 am – 12:00 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

The January meeting will be relatively informal (see page 4 for details).



What we did in 2024 – Helen Cotter

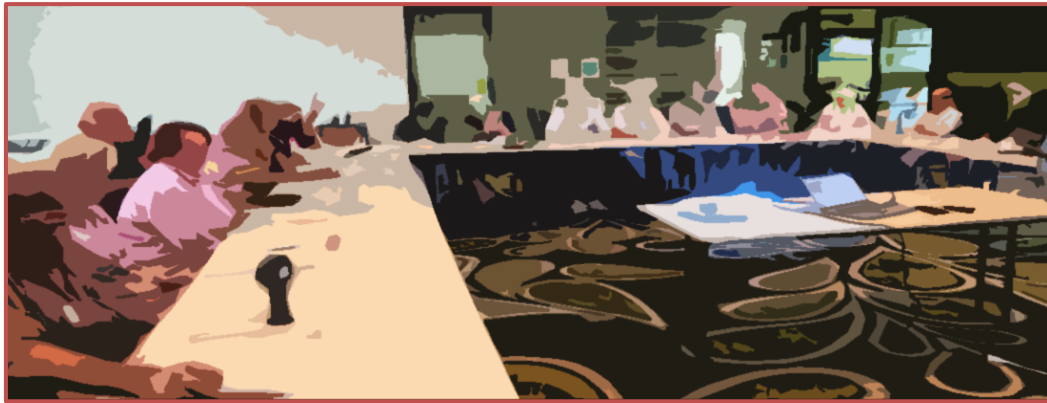
This is the last newsletter for the year. The next one is at the end of January. So, we're taking the opportunity to remind you of all the things that we have done this past year. It's so easy to forget. I'm absolutely amazed at all that we did do. Here's what we did.

Meetings: Marina Siemionow (pictured), our Coordinator, has beautifully chaired our monthly meetings at the Labor Club (thanks to the Club for providing the venue). Occasionally Marina was away and Chris Gray ably chaired the meetings. We had speakers at some meetings; other meetings have been information sessions providing times for discussions and engagement – sometimes these have been quite vigorous.

About 20 to 25 members attend the meetings – probably fewer in winter – but the monthly newsletter goes to many others. Some members have lung conditions and others are wonderful supporters. A large group is able to keep up with what we're doing.



Speakers: Our speakers this year included **Raj, the COPD nurse** at the Canberra Hospital, talking about managing COPD; **Zoe from Lung Foundation Australia (LFA)** telling us about LFA and the information we can access; **Sonia and friends exploring singing and breathing;** **Hasnain and Lincoln** from Erindale Pharmacy informing us about how **pharmacists** can help you.



An artist's impression of a monthly meeting – a lively affair

Lunches: We had lovely monthly lunches at places like Oaks Brasserie, George Harcourt Inn, the Raiders Club, the Mawson Club, the Irish Club, Gary's Kitchen in Erindale, Snapper and Space Kitchen. As well, we had a mid-winter Christmas at the Irish Club and will have a Christmas lunch in December.

Special events: Our special events for the year included the **COTA Expo** which was successfully held in the Kingston Markets area in September; a stand at the **Government House March Open Day** (pictured); and a visit to the **Physio students** at UC.



Publicity: Pam Harris and Val Siemionow were interviewed by Channel 9 about the effects of smoking. Marina and Pam were interviewed by City News about the Lung Life Support Group.



Deaths: We sadly had the deaths of four of our members - Lyn Morley, our past Coordinator; Jan Hunt; Val Reid; and Pam Harris.



Val Siemionow and Chris Gray (above)



Pictures of those no longer with us. Pam, Lyn, Val, and Jan (overleaf).

Newsletter: We've had our regular monthly newsletter, edited admirably by Geoff or Helen. They have been aided by Chris Moyle, Caroline Polak Scowcroft, Marilyn Doak, Marina Siemionow and Don Neal. Val Siemionow has photographed events for us so the newsletter is always colourfully presented with delightful images.



Jan Hunt

For those who can't attend monthly meetings the event is always recounted in detail. The guest speaker is reported on, and the general business is all there. The newsletter also contains:

- **Informative articles of all sorts:-** e.g. the **Companion Card**, POC repairs, information about **COTA** and what it does, **vaping**, information about **SHOUT** and the re-opening of **Chifley Gym**.
- Also covered was the new tool for navigating **Canberra's health system**, and a **breathing project** Pam, Marina and Kaye have been involved in; as well as information about Canberra's **ASH Organisation** ([Action on Smoking and Health - ASH](#)).
- **Health articles:-** Including **energy assistance** for chronic health conditions. Information about a common virus, **CMV**, which floored your editor, Geoff. **Pulmonary fibrosis** clinical trials and a related survey. **Silicosis**, **conserving energy** when you have a health condition, and **breathing exercises** were all included.
- **General interest articles:-** George Watts kept us informed of his travels around Australia during winter and provided us with beautiful photos. Marina wrote about her visit to Sydney to see both the Ramses and the Kandinsky exhibitions. Val Dempsey showed us her award from St John's (awarded for her volunteering work). Sub-editor, Chris Moyle, often provides **jokes or cartoons** to lighten the newsletter.



Editors: Geoff, enjoying the great outdoors and a pensive Helen Cotter.

Coming out 11 times a year the newsletter contains both information and lots of photos about our events and lunches. Sadly, it is quite frequently that we have put in a farewell or 'Vale' to one of our members. The newsletter is a very worthwhile record of Lung Life's activities and events. Thanks go to the people who help bring it about every month - with a special thanks to Don whose editing skills bring polish to each edition.

Finally, we must acknowledge and thank all those people who put the extra effort into assisting Lung Life in its various activities – especially Marina for so ably organising speakers and 'running the show' as Coordinator of Lung Life. There are all the others: event organisers and those who assist at events, the lunch planners, the photographer, the newsletter editors, and those who provide items for the newsletter and assist as sub-editors, those who organise publicity, and no doubt others who do that extra bit for Lung Life. Not to forget those who attend the meetings and maybe follow it up with lunch and a chat at the Club.

On the right are two of our involved members Kaye Powell and Marilyn Allen.



November meeting – Helen Cotter

We had a strong roll up for the November meeting. Lovely to see. It was the last formal meeting of the year. Next month, we won't be having a meeting; however, our Christmas lunch is on Friday the 13th! We next meet in January 2025 and we look forward to another great year.

Summary of Upcoming Events

- Friday 29 November at 11:30 am our **end-of-month lunch** at the Belconnen Labor Club, 59 Cameron Ave, Belconnen. There is a car park underneath.
- Friday 13 December at 11:30 am the **Christmas lunch** at the Raiders Club, Weston.
- Thursday 9 January we **catch up with each other** but also spend some time giving feedback on the Breathlessness Action Plan that Marina has been involved in. Note: There'll be no lunch at the end of December, so the meeting in January will be the next time we meet.
- Friday 31 January at 11:30 am **end-of-month lunch** at the Jamison Southern Cross Club.

At that the meeting ended and we moved on to our speaker for the day on The Advance Care Plan.

All you want to know about the Advance Care Plan

Our speaker was **C Moore** (pictured) **from HCCA** (Health Care Consumers Association). HCCA is an organisation that speaks up for people who use health care. C (as she likes to be known as) explained what an Advance Care Plan is, why you should have one, how to get a plan, and who can help you.

An Advance Care Plan is a set of documents that outlines the future health care that you would like – especially if, for some reason, you can't speak up for yourself. The Plan lets others know what you would like, including your family, the hospital, and any other relevant people. For instance, you may not want to have extensive treatment if you won't be able to look after yourself or be able to communicate with others.

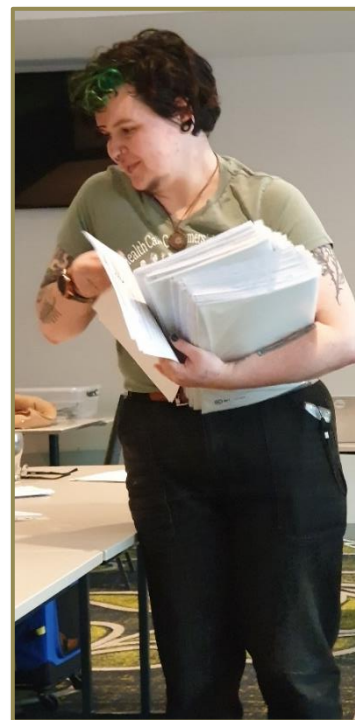
You need to work out what is right for you. It can help if you talk to others about it. There is a website if you want help in sorting out your values:

www.myvalues.org.au.

There are three parts involved: the Enduring Power of Attorney, Statement of Choices (the Plan) and a Health Direction. This last one is optional, but it lets the medical system know the medical treatment you want or don't want.

After you've filled out the forms, you need to give copies to relevant people such as your attorneys (the ones who will look after your wishes – often family members), your family doctor, relevant hospitals, relevant support providers, the ACT Digital Health Record, and My Health Record.

To help you complete these forms, there are community sessions available at the hospital. You can contact the Advance Care Planning Team on 5124 9274 or by emailing acp@act.gov.au. COTA at Hughes also can help (phone: 02 6282 3777). If you don't have an Advance Care Plan it's a good idea to follow up on the information above.



October lunch at Snapper – Information and photos by Val Siemionow

Here are a couple of photos I took at the Lung Life lunch which we enjoyed on Friday (25/10) at the Yacht Club. Only eight of us attended so the turnout was only small, however we had a great time. The service was good, the food very tasty, and the company was great.

From the Editor

While most of us see the Yacht Club as a pleasant place to eat and drink it does of course have another purpose – sailing.

The Yacht Club was formed in 1959 in anticipation of the lake being completed in Canberra (at that time golf was the game you could play on the dry land that was eventually flooded – the original Federal Golf course can be found on the lake's floor).

The club has done well over the years producing Olympians and Sydney to Hobart crew members.



M&Ms - Maureen and Marina



The M&Ms are joined by our travellin' man, George, and the 'other Val' (Val Dempsey) in this shot.

Fibroner trial for IPF/PPF – Maureen Bell

I have just finished participating in a 12 month Phase 3 world-wide trial, '**Fibroner**' (by Boehringer Ingelheim). I was one of 3000 patients with **Idiopathic Pulmonary Fibrosis** (Progressive Pulmonary Fibrosis). There were only two participants in Canberra.

The results have been very promising; it will be the first medication which actually **reverses lung damage** and doesn't just slow progression of the disease.

I am now continuing in an ongoing investigational study with the active medication, **Nerandomilast**. I will not know until the results are analysed (expected May 2025) whether I was on active medication, 50% medication, or placebo. But meanwhile I am on Nerandomilast as 'Open Label'.

If the final results are as good as expected, Boehringer Ingelheim will have to gear up for commercial production in Australia. They will require an approval of safety from the Therapeutic Goods Administration and after that submit it to the Pharmaceutical Benefits Scheme for approval. It will unfortunately take a couple of years before it is generally available

Wishing everyone the best possible health,

Maureen (*For those that don't know her, Maureen is pictured above in both of the photos*)

Irish Joke – Chris Moyle

Liam from Kilkenny meets with his doctor who says, ‘Look, Liam. I’ve some bad news and some terrible news for you.’

‘My God, what’s the bad news?’ asks the patient.

‘Well,’ replies the doctor, ‘the diagnosis from Dublin is that you only have three days to live.’

‘You’re joking,’ says the patient, ‘how on earth can there be worse news than that?’

‘Well,’ says the doctor, ‘I’ve been trying to get hold of you for the past two days.’

Reference: Clive Williams, City News August 31-September 6, 2023

<https://citynews.com.au/2023/digital-edition-august-31/>

More from Maureen ‘Of interest to Lung Life members (especially those with IPF or PP)’

Every State in Australia, but not the ACT nor I think the NT, has a Multi-Disciplinary Team (MDT) to treat patients with IPF or PPF. This healthcare team normally includes a respiratory specialist, GP, physio, and Clinical Nurse Consultant (CNC). This CNC acts as a go-between between the patients and other health professionals, giving advice and behind-the-scenes support. They have been called ‘the glue that holds the MDT together’.

The Lung Foundation has a nurse you can phone for information, but it is not as valuable as having someone in Canberra that you can see in person.

Dr Stuart Schembri, specialist respiratory physician at The Canberra Hospital and Kim Bailey, respiratory CNC, are trying to get a specialist nurse at the Canberra Hospital (TCH) for IPF and PPF patients but there is not currently funding to do this. They are planning a study looking into the impact a CNC nurse would have on patients and their wellbeing.

I have been invited to provide consumer input into their application for the research grant and it would be really helpful if members with IPF or PPF could contact me with their views. It does not matter whether you are under a hospital or private physician. Kim Baily from (TCH) <https://cre-pf.org.au/about/our-people/australasian-ild-nurses-alliance/kim-bailey/> will be doing a survey of patients; prior to this she is happy for you to pass on feedback to me of what you feel would be valuable.

Maureen Bell - Email: maureen.bell@gmail.com Phone or text: **0434 877 957**

Finally, guess the year? (*Maybe try this one on your relatives on Christmas Day and see how they go*)

- Cyclone Tracy devastated Darwin
- The ACT and NT were each allocated two senate seats
- The classic Australian album *Living in the Seventies* (Skyhooks) was released

*Note: All three events occurred in the same year. **The answer will be revealed in 2025.***

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