

## September 2024 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](mailto:lung.life1@hotmail.com)  
**Coordinator:** Marina Siemionow 0429 629 180  
[lung.life1@hotmail.com](mailto:lung.life1@hotmail.com)

**NEXT MEETING:** Thursday 10<sup>th</sup> October 2024  
10:15 am – 12:00 noon  
Weston Creek Labor Club  
Teesdale Close, Stirling ACT 2611

October Lunch: Friday 25 October at Snapper in Yarralumla – see page 5

### Vale Pam Harris (1948 - 2024): *letter to Pam* – Written by Helen Cotter

Dear Pam,

We will miss you. We went to your funeral last month where your family talked about how friendly and caring you were. You loved people and socialising – and we also know that.

They told us you were born in Wollongong in 1948 and had hip problems needing hospitalisation. So when your parents moved to Bungendore (father owned the garage), you stayed for many years with your grandparents in Wollongong for ongoing treatment. Your parents visited you there every weekend.

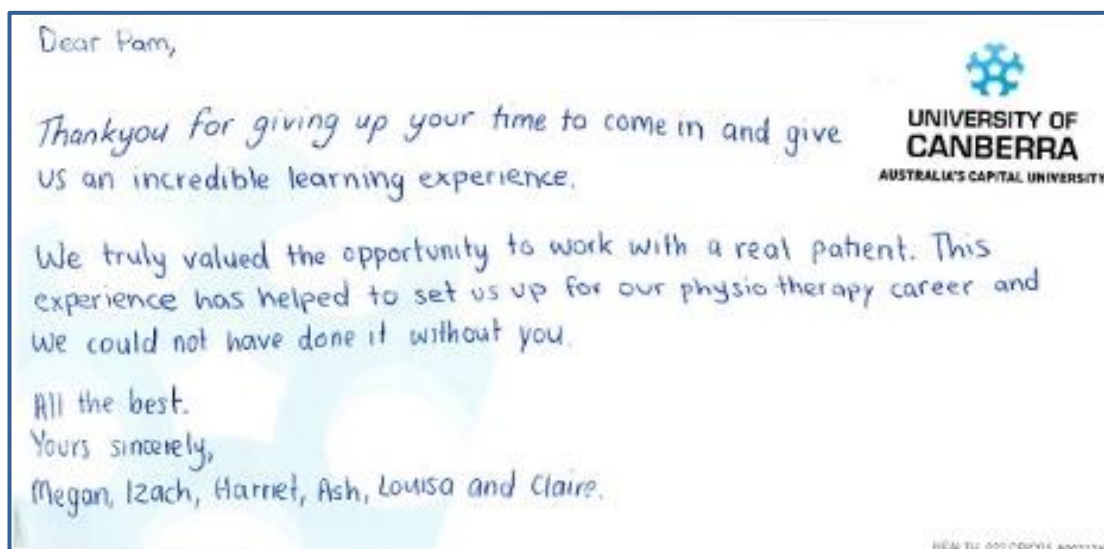


We learnt how you made it to Canberra, attending school here and moving on to working as an aide in a pre-school, a telephonist at PMG, and finally at the ANU. Then you met your husband Brian *dec.* (Brian and Pam are pictured above at the Christmas lunch in 2017).

You met at the Jungle Bar in town and had two lovely sons, Marc and Dean. You adored them and supported them fully. You also doted on their children and grandchildren – your grandchildren and great grandchildren. We remember how proud you were of all of them.

Your family spoke so lovingly of you at the funeral. You would have been really chuffed.

They mentioned your involvement with Lung Life over 20 years, almost from the beginning of Lung Life. But what they didn't have time to go into was how involved you were and how central you were to Lung Life. We know that for many years you were responsible for organising our visits to the physio students (see below) at UC and to the trainee doctors at Canberra Hospital. You organised our Expo and World COPD Day stands, liaising with the management, getting things going and volunteering at the stands all day. And in your unflappable way, you organised many Lung Lifers to willingly help you with these events.



And do you remember those Christmas lunches you organised with Maddie, Pat, Esther and others? The decorated tables, the dot prizes under the chairs, the raffles, the hampers. Such fun.

After all those years, with your increasing breathlessness, you had to pass on these activities to others in Lung Life. But still you were busy – you were a consumer rep on different interstate projects to do with breathlessness and you featured in articles in the Canberra Weekly, the RiotAct and the Canberra Times. Your media articles publicised Lung Life and the closure of the Chifley Gym (you'll be pleased to know that it's reopening although sadly you won't be returning).

And you were busy being a caring friend and member of Lung Life. Your sons, Dean and Marc, were very supportive of Lung Life. For many years, Marc has sponsored - by paying for - the Lung Life flyers. A great help to us.

We were lucky to have known you. We will miss you in so many ways, Pam.

*Helen Cotter on behalf of Lung Life.*

## **Pam Harris and ABIS – Marina Siemionow**

The ABIS (*ACT Breathlessness Intervention Service*) project was commissioned by the Capital Health Network and conducted through the University of Technology Sydney - led by Tim Lucket PhD Associate Professor IMPACT (*Improving Palliative, Aged and Chronic Care through Clinical Translation*).

Pam was on the co-design team for the project and managed to influence the team of health professionals and academics. She had a real impact as the voice for people with COPD and in her very strong, yet gentle and warm way, she provided insights into the lived experiences of people with COPD. These insights influenced the nature of the services that were developed. The ABIS team will be dedicating to Pam the ABIS service (currently being trialled in the ACT) as a free home support service for people with breathlessness.

Through her incredibly positive attitude, warm approach and happy demeanour Pam made a real difference for others with her condition.

*Here are some statements that were sent to Marina by members of the project that Pam and Marina contributed to over the last two years.*

## **Pam's Farewell Statements**

**Ros Kirk, Palliative Care Planning Manager, Capital Health Network - ABIS Project Lead**

'I am grateful for the enthusiastic and valuable contribution that Pam made to the co-design of ABIS. I always smile when I think of Pam identifying 'ironing sheets' as her measure of quality of life. It was such a clear example of the need for patient centred care. Thank you, Pam 🙏

**From fellow ABIS team members at the Capital Health Network, Southside Physio and the University of Technology Sydney**

*"In fond memory of Pam, whose wisdom and warmth have helped so many people through the ACT Breathlessness Intervention Service (ABIS) that she helped design for the people of Canberra. We miss you, Pam!"*

**Associate Professor Jo River, Faculty of Health, University of Technology Sydney**

"I'm grateful for all she gave to the project, and she will be missed."

**Tim Luckett, PhD, Associate Professor**  
IMPACCT – Improving Palliative, Aged and Chronic Care through Clinical Research and Translation

"Despite her age and illness, Pam's spirit continued to shine through as an inspiration to us all. Pam has always made the best of whatever came her way and was a breath of fresh air wherever she happened to be."

**Mirei Churton, Palliative Care Project Officer Capital Health Network - ABIS Project**

I truly appreciate the times we worked together with Pam, and I will remember how she used to speak and smile cheerfully.'

## **September Meeting (Thursday 12 September) – Helen Cotter**

Today, we had a good roll up, including some new members – lovely to see.

Today we first had the talk by **Zoe Wilkinson of Lung Foundation Australia (LFA)** followed by general business. Zoe's talk was via Zoom which needed to be set up (*with a lot of silent swearing and angst*).

Modern technology: good when it works, frustrating when there's a problem. While we waited we introduced ourselves, explained our lung conditions, and our experience of the problem of finding out how to get further information about the services and provisions for people with lung conditions. There was a feeling that the medical profession isn't much help after diagnosis and a feeling of pleasure to have come across Lung Life.

With the Zoom connection up and running Zoe began her talk on the services and products that LFA provides. All the way through her talk, she kept saying that, if you have any problems accessing this information, call the LFA number on **1800 64 301** or email them on [enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au).

Sometimes, there is a place on the webpage where you can click for more information.



*Ruth Schwenson and Libby White at the meeting*

Zoe talked about the following areas of LFA:

- **Information and support:** LFA website contains a lot of information for all different types of lung conditions, including lung cancer. They have a page called **Find a Service** to make it easier to find the right information. They can also give support in navigating their website.
- **Peer support:** LFA enables people to support each other, either face to face or online, in a group or one on one. Use the **Find a Service** to find out about the different groups.
- **Pulmonary Rehabilitation:** this is a six-to-eight-week exercise and education program that teaches you the skills you need to exercise safely and manage your breathlessness. LFA can give you the details of where the program is held (*in Canberra, it's held at the hospital*).
- **Lungs in Action:** Lungs in Action is a community exercise program run by exercise professionals that helps you to maintain the health and wellbeing benefits achieved during pulmonary rehabilitation. Canberra has two sites for Lungs in Action classes: Gungahlin and Woden – details are on the LFA site. You need to have completed a pulmonary rehabilitation course first.
- **Telehealth service:** this is a free service where you can talk to a respiratory care nurse, get lung cancer support or speak to an occupational lung disease social worker. These provide guidance on all aspects of diagnosis, treatment and management of your condition. You need to make an appointment by contacting the Information and Support Centre on free call 1800 654 301 (option 3) or completing the form on the site.
- **COPD learn and education program:** There are online education classes taken by the respiratory care nurse each month via zoom. The program has six modules dealing with all aspects of managing your condition.
- **Resources:** LFA has many booklets, factsheets, flyers, infographics, and webinars that you can access. With the webinars, if you register but can't attend, a recording will be sent to you. One webinar was on exercising safely with a lung condition. You can access the information about this on the website. And if you can't find the information you want, ask the friendly people at LFA.
- **Further involvement:** LFA has consumer advisory committees for a variety of lung conditions; it has a consumer representative group which is composed of consumers from around Australia (*Kaye Powell and Caroline Polak Scowcroft are our representatives*). The organisation also has consumer advocacy which provides consultation on Government services and provision.

Zoe's talk was most informative about LFA. I expect we all went home and checked out some of the information. If you have any problems finding information on the website, call them on 1800 654 301 or email [enquiries@lungfoundation.com.au](mailto:enquiries@lungfoundation.com.au).

## Meeting Business

Marina reminded people that the next lunch is on **Friday 27 September at the Space Kitchen, Furzer St, Woden**. Meet at **11:30 am**.

The October lunch: 11:30am Friday 25 October at Snapper, Southern Cross Yacht Club, Yarralumla.

And on Wednesday September 25 the **Seniors Expo** at the Kingston Bus Markets was held from 10:00 am onwards. As usual, we had a stand there (organised by Chris Gray, Marina and Val Siemionow). We hope many of you popped out to see the Expo.

We started to think about our Christmas lunch and set up a working party to organise it. Margaret Geaghan and Jacqui Cole are currently the working party but could do with some extra help – so you may like to volunteer.

As part of that, we need donations of items for the hampers: **please bring donations of dry goods items to the next meeting**.

Finally, Marina thanked **Marilyn Allen** (pictured listening to Alison) for being the **Social Secretary** for many years, organising monthly lunches, Christmas lunches, Christmas in July lunches, hampers, raffles and doing all the other jobs that go with it. She has done a really sterling job.

With that, the meeting ended, and it was off to a welcome lunch.



## Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) survey

**Maureen Bell** completed the Centre of Research Excellence in Pulmonary Fibrosis (CRE-PF) survey, and she is on their subscriber list. As a subscriber Maureen will receive a quarterly newsletter, which contains lots of updates about activities going on within the CRE-PF and how to be involved.

Maureen has passed on these links for those amongst us who would like more information on this topic.

[Our Research - Centre for Research Excellence in Pulmonary Fibrosis \(cre-pf.org.au\)](http://cre-pf.org.au)

[Consumer Advisory Group - Centre for Research Excellence in Pulmonary Fibrosis \(cre-pf.org.au\)](http://cre-pf.org.au)

[Support Groups - Centre for Research Excellence in Pulmonary Fibrosis \(cre-pf.org.au\)](http://cre-pf.org.au)

[Consumer Advisory Group - Centre for Research Excellence in Pulmonary Fibrosis \(cre-pf.org.au\).](http://cre-pf.org.au)

And here is a link from the Rare Lung Disease Conference, which Maureen has also sent to us.

<https://lungfoundation.com.au/resources/living-well-with-pulmonary-fibrosis-interstitial-lung-disease-consumer-information-day/>

## **Vale Val Reid – Chris Moyle**

Long-time member, Valerie (Val) Reid, died on 30 July at the grand old age of 95.

I was delighted to meet Val when I first joined Lung Life as she had bronchiectasis, the same lung disease as I have, and she kindly gave me printed information about the illness.

A number of years passed, and Val was no longer able to attend meetings. The last time I saw her, at a lunch, she was on a special diet due to digestive problems. Then I would occasionally hear that she was still sharp and that she was such fun to be with.

I never knew her age and was amazed to learn that she'd made it to 95 while suffering with bronchiectasis. Everyone is different, and I don't expect to reach that age myself, but she certainly is an inspiration.

Val was warm and kind, and we've lost another lovely person.



*Val in 2012*

## **Way out west where the rain don't fall – George Watts**

*Hi. This is a photo of the water pipe that supplies water to Kalgoorlie from Perth. It was badly damaged in 1968 when an earthquake hit the place at 6.9 doing a lot of damage to the pipeline, roads, houses and other infrastructure including the railway line to Adelaide and Sydney. A very impressive monument of the happenings are in the town of Meckering – east of Perth.*

