

September 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 14 September 2017
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close
Stirling ACT 2611

Guest Speakers: Marg Wade, author of *Canberra's Secrets*

Dates for your diary

September 2017	Pulmonary Fibrosis Awareness Month
Thursday 12 October 2017	CLLSG Meeting
Tuesday 17 October 2017	Flora the Explorer at the National Botanic Gardens
Wednesday 15 November 2017	World COPD Day
Tuesday 5 December 2017	Christmas Luncheon

August Meeting

Lyn Brooks and Chris Moyle

As Lyn Morley was ill, Esther Fitton chaired the meeting. John, Lyn's husband, came along to assist whenever and wherever he was needed. The attendance was lower than usual, with only fifteen people present. Esther welcomed them and called the roll. The agenda was also small (people who were to report on activities were not present), but included the following:

- The Canberra Lung Life Support Group was founded nineteen years ago this Christmas. Esther Fitton and Shirley Dillon are two members who were present at that inaugural meeting. Next year we must celebrate: twenty years is a milestone!
- Helen Reynolds asked whether members were interested in a trip around the Botanic Gardens in Flora the Explorer this year. As members indicated they were interested, a date of Thursday 19 October 2017 was suggested. Helen undertook to make bookings for *Flora the Explorer* and

lunch. Confirmation of attendance will be required at the next meeting. Remember, if you don't want to take the tour of the gardens you can always join the group for lunch and socialisation.

- Pam Harris has made tentative arrangements with the Weston Creek Labor Club for our Christmas Party to be held on **Tuesday 5 December 2017**. Cost for a traditional Christmas dinner is \$35 per head. It had been decided to hold our party earlier in the week this year. Hopefully the Club won't be quite so noisy on that day.

There was time to spare so Peter Olley took on the persona of Elvis Presley and entertained the members with two well known Elvis Presley songs. Well done Peter!

Guest Speaker - Trish Low **Lyn Brooks and Chris Moyle**

Many of us are at that time in our lives when we begin to ask questions of ourselves regarding what we want from life and how to fund those wants. For many our home is our largest asset, consequently we find ourselves pondering the pros and cons of selling the family home and downsizing.

Reasons for moving house

- Wanting a smaller house.
- Downsizing your debt in order to have more disposable income.
- Being closer to family.
- Wanting a change of lifestyle – sea change or tree change.



Trish Low joined the team at COTA, the peak advisory body for seniors based at Hughes. After a background in student accommodation at the ANU Trish now manages the housing advisory service at COTA.

Practicalities

- If your house is too big it is probably a good reason to move.
- Being close to family. Family and friends can move to another area too.
- Can you find a house you want? Competition can be fierce.
- Are you physically capable of moving? Consider who will help and what it will cost.
- How long will you be able to stay in the new property?
- Will there be extra travel costs to see doctors, specialists and friends?
- To release equity – can you afford a house in the area you want?
- Stamp duty costs – there are concessions available under Pensioner Duty Concession Scheme. The rate is variable depending on the cost price.
- Will the money from the sale affect any government support?
- Understand the differences between moving to a retirement village (fully self funded, but you may not own your property; plus entry costs, exit fees and ongoing maintenance costs) – versus apartment or townhouse which you own, but which may have Strata Title (Body Corporate) costs.
- The Home Care Package can help seniors stay in their own home if they don't want to move to an aged care home.
- The Green Shed has a "little green truck" that will transport donated goods. It comes with a driver.

Always get financial advice first

Contact Trish at COTA ACT on 02 6282 3777 for:

- further advice on housing options.

- advice on de-cluttering.
- respite.
- home modifications.
- accessing NDIS arrangements to assist you to stay in your own home.

Trish does not provide financial or legal advice.

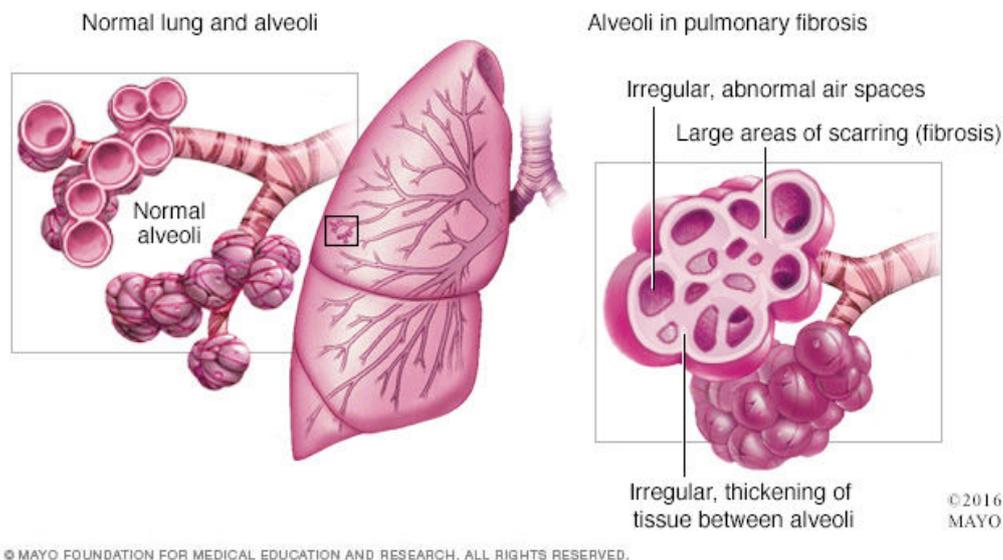
September 2017 is Pulmonary Fibrosis Awareness Month

Helen Reynolds

Pulmonary Fibrosis has a literal translation of "scarring of the lungs", an apt description given the damage it can do to the lungs that interferes with breathing. The term fibrosis refers specifically to the build up of fibrosis connective tissues which causes the walls of lungs to thicken and impacts on their ability to transfer oxygen to the bloodstream. The scarring associated with pulmonary fibrosis can be caused by a multitude of factors. But in most cases, doctors can't pinpoint what's causing the problem. When a cause can't be found, the condition is termed idiopathic pulmonary fibrosis (IPF).

Lung Foundation Australia aims to ensure lung health is a priority for all in Australia and works to promote lung health among the wider community, patients and health care professionals. Lung disease doesn't discriminate – it affects the young, old, male, female, smokers, former-smokers and never smokers. At least one in ten Australians has some form of lung disease however Lung Foundation Australia estimates the number to be significantly higher.

Pulmonary Fibrosis Awareness Month was established to help raise awareness of this disease through education and fundraising to aid research into the condition. Research has helped doctors learn more about IPF. As a result, they can more quickly diagnose the disease now than in the past. Also, researchers are studying several medicines that may slow the progress of IPF. These efforts may improve the lifespan and quality of life for people who have the disease. But it all takes money.



Pulmonary fibrosis scars and thickens the tissue around and between the air sacs (alveoli) in your lungs, as shown on the right. A normal lung with normal alveoli is shown on the left.

Pulmonary Fibrosis is a serious disease that usually affects middle-aged and older adults. In some people fibrosis happens quickly. In others, the process is much slower. In some people, the disease stays the same for years. As yet there is no cure for Pulmonary Fibrosis. The most common cause of death related to it is respiratory failure. Other causes of death include pulmonary hypertension, heart failure, pulmonary embolism, pneumonia and lung cancer.

The lung damage caused by pulmonary fibrosis can't be repaired, but medications and therapies can sometimes help ease symptoms and improve quality of life. For some people, a lung transplant might be appropriate.

Sources: <https://www.nhlbi.nih.gov/health/health-topics/topics/ipf/>
<http://www.lungfoundation.com.au>

LFA Research Interests From LungNet August 2017

Research offers hope and undisputed benefits for improving outcomes in lung diseases. In 2016, Lung Foundation Australia (LFA) funded 29 research projects that studied both respiratory and thoracic oncology conditions and reached a significant funding milestone of \$2.25 million, an increase of 47 percent since 2015.

Lung Foundation Australia has identified four priority areas to help them focus their research strategy into areas where they can make the biggest impact for those living with a lung condition. These include

- Chronic Obstructive Pulmonary Disease (COPD)
- lung cancer
- rare lung diseases such as Idiopathic Pulmonary Fibrosis (IPF)
- bronchiectasis and
- Childhood Interstitial Lung Disease.

LFA fund research that aims to make a difference and every application they receive for funding is peer-reviewed to find the research projects that will have the biggest impact. They have recently opened five respiratory awards for their 2018 funding round, with their oncology awards opening on 1 August this year. Lung Foundation Australia is committed to increase their award funding into lung disease research to \$5 million per year by 2020.

To find out more about their research awards and research platforms visit www.lungfoundation.com.au/research.

Interstitial Lung Disease/Idiopathic Pulmonary Fibrosis Maureen Bell

I attended the Rare Lung Diseases Conference Patient Education Day in Sydney on Saturday 19 August. By accident I found myself in the clinicians' area and picked up a number of trade publications from Ofev (<https://products.boehringer-ingelheim.com/ofev/>). As I am on Esbriet (Pirfenidone) they are not relevant to me but I would be happy to pass them on to anyone who is taking Nintedanib and who might find them useful. Call me on 02 6251 5837 or 0434 877 957.

You might be aware the Australian Lung Foundation is setting up a Peer Support project for ILD patients, to be launched soon. Contact them if you wish to participate. Sharon Gavioli is the organiser and can be contacted at sharon@lungfoundation.com.au.

The A-Z of Preventative Health Care Chris Moyle

Stroke Symptoms include difficulty finding words, numbness or paralysis on one side of the body, being unable to smile normally, and being unable to raise both arms. Dial 000. If you get to hospital within 3 hours you may save a life.

F = face (smile) A = arms S = speech T = time (act fast).

Prevention

- Don't smoke
- Exercise
- Have a low salt and low alcohol diet
- Avoid high blood pressure
- BP should be under 140/90 LDL
- Cholesterol should be over 100. HDL cholesterol should be under 50
- Blood sugar should be between 5.6 and 6.5
- Waist size should be less than half your height
- Avoid processed meats and fats
- Eat leafy green vegetables and fruit

Source: *Dr Oz*

Flora Explorer Helen Reynolds



We take the hassle out of a visit to the Australian National Botanic Gardens for a group of older people with lung conditions and turn it into a truly enjoyable event.

How you might ask?

We catch Flora the Explorer, the Gardens' 12-seater electric shuttle bus. In it we relax and are driven around the Gardens while listening to a running commentary on all the sights.

Where:	Visitor's Centre ANBG
When:	Tuesday 17 October 2017
Time:	11:00 am
Cost:	\$5.00

We are then finally delivered to the door of the restaurant where we meet up with others joining us for a meal.

Love Your Lungs. LFA's membership group

From: LungNet News August 2017

One of our members is written about in this article

Tania has chronic bronchitis, which falls under the Chronic Obstructive Pulmonary Disease (COPD) umbrella and was diagnosed in 2015. Tania looks forward to receiving her copy of LungNet News each quarter and most enjoys reading about medical updates, the CEO report and the diary dates. She takes a copy of LungNet News to her local Cancer Support Coffee Club each month and says there is always something within the news that is of benefit to someone. "Just to know there is support out there can be of great comfort to a lot of people whether they access it or not. Thank you for the wonderful work you do and the services you provide."

Our second member would like to remain anonymous; however she is a patient who was diagnosed with bronchiectasis at about 10 years old. In her forties, she developed asthma and takes a preventive puffer to help. She has been a member of Lung Foundation Australia for about 10 years and first heard of us at a support group meeting. She enjoys attending this monthly meeting as it provides access to guest speakers and useful information as well as friendships. She is now in her 70s and takes very good care of herself. She shared some insights into her daily tips for managing her lung disease.

“Clearing my lungs of secretions daily with various physiotherapy methods which although not always easy, is becoming increasingly important, as is daily exercise and a healthy diet which means no junk food.”

To join **Love Your Lungs** call Lung Foundation Australia freecall 1800 654 301 or email enquiries@lungfoundation.com.au.

POC for Loan

We have an InogenOne G2 POC for loan.

If you are on oxygen cylinders and thinking of buying a POC, you may like to borrow this one for trial.

If you are on oxygen cylinders and need, for instance, to travel to another city for a break or to visit a doctor, this may help.

The Inogen is about a year old and has all its attachments.

We ask for a donation to Lung Life for its use.

Contact Helen on cotterhe@hotmail.com or ph: 02 6281 2988

NXTBUS

From Consumer Bites, Issue 12, 2017

NXTBUS is the real time passenger information system for ACTION buses. NXTBUS tracks the location of your bus so you can find out when the next bus departs, wherever you are. NXTBUS can tell you if your bus has a bike rack, if it is 'easy access' and if a service has been delayed. NXTBUS looks 90 minutes ahead with real time information updated every 30 seconds.

To use NXTBUS visit www.nxtbus.act.gov.au. Use the search bar to look up departure times by bus stop ID, route or location. Results will be provided for the next 90 minutes. Live times are shown in minutes, counting down until the bus departs. It will tell you if your bus is easy access and/or has a bike rack.

NXTBUS real time information is accessible via desktop computer, laptop, tablet or smartphone.

<http://www.nxtbus.act.gov.au/>

RECEIVING THIS NEWSLETTER

Please be aware that if you receive this Newsletter by post and you have an email address and would like to receive it instead by email you may send your request to Helen Reynolds at helenrey@creationcorporation.com.au.