

February 2025 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 13th March 2025

<mark>10:15 am – 12:00 noon</mark> Weston Creek Labor Club

Teesdale Close, Stirling ACT 2611

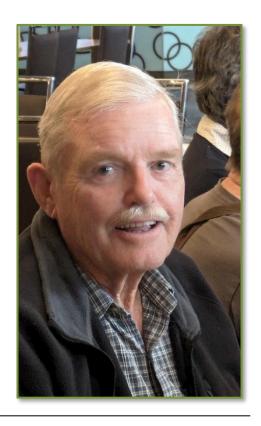
Dylan Grubb is our speaker at the meeting. See page 3 for details.

Vale George Watts – Helen Cotter and Marina Siemionow

George was a welcome regular for many years at Lung Life meetings and events. For a few winter months, he'd disappear; then pop up again during Spring. During his annual winter travels around Australia, he'd keep in contact via lovely photos and information on where he'd been. We'll miss those delightful additions to the newsletter.

George was a Vietnam Veteran and had spent twenty years in the engineering corps of the army. On his discharge in 1988 George set up his own automotive wrecking business here in Canberra which led to an interest in dirt racing. After selling his business and retiring in 2011 George developed a passion for model trains as a very active member of the Canberra Model Railway Club.

As well as a lung condition and diabetes George had other internal conditions which gradually got the better of him. He was in and out of hospital since early January, finally dying on the 28 January. He was 76.



Always bright and cheerful, he'll be missed by all, especially his wife Maureen (50 years married), his children, Stuart and Vicki, and his grandchildren and his great grandson. We will also miss his sense of humour and cheery presence at our meeting and lunches.

The funeral at Weston Creek Uniting Church was packed with mourners, including quite a few Lung Life members. It was a grand send-off for George. He would be pleased.

Ed: These photos were taken by George in Barcaldine, Queensland, on one of his trips exploring the outback.

Farewell Travellin' Man.





February Meeting – Helen Cotter

About 16 members rolled up for the second meeting of the year, including a few new ones – always good to see. After introductions, Marina, our Coordinator, explained that today we were going to talk about how we are going, what we've achieved, and what we might like to do in the future.

Marina first gave us some information about lung conditions in Australia:

- One in three people have a lung condition
- 45 Australians die from a lung condition every day
- Lung conditions are the second leading cause of death in Australia.

She then went on to remind us that our group was started in 1998 by eight people and their carers **as a forum for sharing ideas, experience and information about their lung conditions.** 27 years later we are still going. Lung Life was the first peer support group in Australia – now there are 44 across the country. We have 72 members with 15-20 turning up for each meeting. The majority are women and all are seniors.

Many of our members assist to make Lung Life work including: the Coordinator, the treasurer, newsletter editor and sub-editors, and social secretary. Other tasks include organising stalls, cards and gifts. Our activities include: meetings, speakers, social events, lunches, stalls, visits to UC to assist the Physiotherapy students and such like.

We are loosely organised under the umbrella of Lung Foundation Australia, but Lung Life is only as good as its members make it. We rely on members contributing and supporting each other and the organisation. In January, members at the meeting filled out a survey on their attitudes toward Lung Life. The results showed that:

- Most of us were satisfied (4 very satisfied)
- In order of satisfaction, we liked speakers, social interactions, lunches, the newsletter and advocacy.

In summary, we wanted:

- A safe environment to be heard and understood
- Opportunities to share stories and information
- Advocacy across the health services in ACT
- Education on sustaining quality of life
- Having fun among friends.

To remain sustainable in the future, we need to revitalise. Most of the 'old guard' have left and their places need to be filled. As a first step, we set up an advisory group to take it from here.

Marina's presentation provided a good overview of the situation that Lung Life faces. We look forward to positive effects from now on.

Briefly, at the end of the meeting, Marina told us that the Physio students at UC were hoping to see as many members as possible for two upcoming sessions:

- Either Thursday 6 March and 13 March or
- Friday 7 March and 14 March

The students enjoy having hands on experience with 'real life people' who have a lung condition.

Marina also reminded us of the next lunch at the Oaks Brasserie, Yarralumla Nursery, on Friday 28 February at 11:45 am.

Finally, our speaker at the next meeting is **Dylan Grubb** from **EQUIPD Allied Health** (the old Chifley Gym) to talk to us about exercise and health.

Then it was time for lunch.

International Rare Diseases Day: 28 February - Val Dempsey

I recently spoke about rare diseases on the **Sunday Roast with Ian** as well as attending Parliament House to represent the **Myositis Association of Australia at the Rare Voices Forum.**

The 28 February is declared **Rare Diseases Day.** It's an international event to raise awareness for people living with rare diseases. As many as 5 in 10,000 people – or approximately **8% of Australians** – are living with a rare disease. That's approximately **two million Aussies**.

Rare Voices Australia has been working with Government to put forward the National Strategic Plan for Rare Diseases through the Department of Health and Government bodies.

There are 7,000 known rare diseases and new ones are discovered regularly, 80% of which are genetic. Non genetic rare diseases include some cancers, infectious diseases, rare poisoning and rare immune diseases, idiopathic or undetermined disease. Some may be rare in one part of the world but not seen as rare in other parts of the world.

Most people living with a rare disease are in a chronic condition perhaps from birth or developing the condition later in life. They face many challenges and difficulties in their daily life. It is crucial that accurate diagnosis is achieved early as early treatment options can often improve better outcomes for the rare disease

patient. Many patients have suffered delays in diagnosis, sometimes even as long as five years. Rare diseases can often be serious and progressive and can have a high level of complex symptoms that can cause ongoing health and psycho-social issues.

It's reported that 5% have less than effective treatment. Improvement in quality of life and extended life expectancies rely on appropriate treatment and care. This is documented through the web pages for Rare Voices and in the National Strategic Action Plan for Rare Diseases and through the Australian Bureau of Statistics in 2024.

Please call me if you would like any more information: 040 996 6923.

International Rare Diseases Day – Lung Foundation Australia (LFA) Information supplied by Helen Cotter

As part of International Rare Diseases Day on 28 February, Lung Foundation Australia is turning the spotlight on rare lung disease in children, Idiopathic Pulmonary Fibrosis (IPF) and Pulmonary Arterial Hypertension (PAH).

Rare lung disease in children

In Australia there is currently very limited, if any, information, support, treatment and research for rare lung diseases in children, often leaving parents feeling isolated, helpless and with heightened uncertainty and despair for the future. LFA is working towards improving the situation with their **Young Lungs Program** throughout Australia and New Zealand.

Idiopathic Pulmonary Fibrosis

Idiopathic Pulmonary Fibrosis (IPF) is a debilitating and life-limiting disease that causes irreversible scarring of the tissue deep in your lungs. The scarring continues to worsen over time, making it difficult to breathe. The biggest challenge is accurately diagnosing IPF, because many of its symptoms are similar to other lung diseases. Lung Foundation Australia has developed a new resource to support awareness of the signs, symptoms and support available for IPF. Download IPF fact sheet.

Pulmonary Arterial Hypertension

Pulmonary Arterial Hypertension (PAH) is a rare and progressive disease caused by narrowing of the arteries in the lungs. This causes high blood pressure in the lungs known as pulmonary hypertension. Our PAH infographic provides a quick and easy guide to identify the signs, symptoms and support available for this debilitating disease. **Download PAH infographic.**

Lung Foundation Australia: <u>1800 654 301</u> Email: <u>enquiries@lungfoundation.com.au</u>

At the Nursing Home – sourced by Chris Moyle

John Farnham visits a retirement home to entertain the residents and host a singalong - but nobody seems to recognise him. Puzzled, he takes an elderly lady aside and says, 'Excuse me - but do you know who I am?'

'Sorry dear,' says the lady, 'I don't....but if you ask one of the nurses, I'm sure they'll be able to tell you.'

City News, October 31-November 6, 2024. It's from Clive Williams 'Whimsy' column - regarding ageing. See page 6 for another joke about ageing.

Drinking water and your health – sourced by Helen Cotter

It's been a hot summer. And when it's hot, we need to make sure we keep up our fluids. Here's why it's a

good idea.

Water is an essential part of life. Over half of the human body is made up of water. We need water to:

- digest food and to absorb nutrients
- move our bodies well
- get rid of waste products
- keep our body at the right temperature.

Drinking water also keeps your **teeth and mouth healthy**. Water is also needed for the body to make saliva which washes food away from your teeth.

In most parts of Australia, the tap water contains fluoride. This helps to protect against tooth decay.

Click to view the image opposite in full size: Water and your health.

How much water should I drink?

People who don't drink

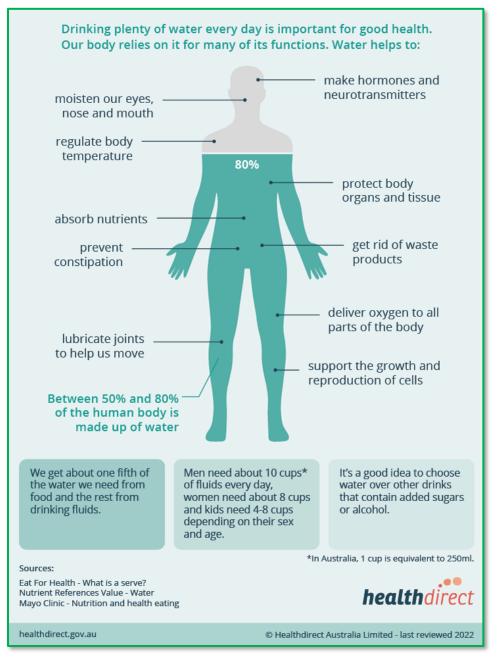
enough water every day are at greater risk of problems such as **kidney stones**, **constipation**, **urinary tract infections**, **and headaches**. As a general rule:

- males need about 10 cups (2.6 litres or 2600mL) of fluids every day
- females need about 8 cups (2.1 litres or 2100mL) of fluids a day.

We get about one fifth of the water we need from food, the rest comes from liquids that we drink. **You can get water from any fluids** — including tea and coffee, fruit juice, milk, soup and soft drinks. You should be careful how much fruit juice, cordial and soft drinks you drink as they can make you put on weight and damage your teeth.

What happens when you don't drink enough water?

Older people are at greater risk of dehydration because they naturally feel less thirsty. Their kidneys may also not work as well. Memory problems and not being very mobile can make it harder to stay hydrated.



Certain types of medicines such as diuretics and laxatives can also lead to dehydration. For older people, not drinking enough water over a long period of time can lead to problems such as **constipation and confusion**. Signs that you are dehydrated and need to drink more water include:

- feeling thirsty
- dark coloured urine
- headaches
- dry skin, tongue and mouth
- tiredness
- irritability
- light headedness or fainting.

What if I don't enjoy drinking water?

You can vary the taste of plain tap water by adding some berries or lemon slices or other fruit. You could also try sparkling water (not soft drink) or herbal teas. You could look also for some recipes for iced tea but avoid iced tea with added sugar as a regular drink.

https://www.healthdirect.gov.au/drinking-water-and-your-health#how-much

Opportunity too good to miss: Portable Oxygen Concentrator



John Morley has available for sale the small InogenOne oxygen concentrator pictured here. It has hardly been used and, as you can see in the photo, it has:

- two batteries
- the two cords for recharging the batteries
- the cord for use in the car
- a carry case
- the manual.

New, they cost \$4 - 5 thousand. John is asking a reduced price for a machine that is almost brand new. It was used only once.

You can find out more about it by phoning him on **0400 112 473**; or emailing on: jmorley126@gmail.com.

Another joke from Clive Williams at City News – sourced by Chris Moyle

Ageing widower Tom and widow Juliet have been close friends for years. Finally, Tom realises that it would make sense for them to get married and spend their remaining time together.

So Tom takes her out to dinner and eventually pops the question, 'Will you marry me?' Juliet is pleased that he has finally asked, and says, 'Yes, of course'.

At the end of the evening, they part company and return to their respective homes.

The next morning Tom can't remember whether he asked Juliet to marry him or not. Tom eventually plucks up the courage to phone Juliet and asks, 'Did I ask you to marry me last night?'

'Yes,' said Juliet 'and I said yes - and meant it with all my heart.'

She continues, 'I'm so glad you called because I couldn't remember who'd asked me.'