

May 2021 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 13 May 2021
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611

This will be a meeting with no guest speaker, so we have more time for discussion.

May Meeting Helen Cotter

Numbers were down a bit for this meeting, but we did have 15 people attend. The meeting opened with a request from **Fiona Wheatland** (pictured right) from **HCCA** for possible participants in a COPD project. Fiona wants to hear about your experiences in your treatment and care through the COPD services in the ACT. This is open to all who have breathing issues – not only those with COPD.

Fiona would like to know what works well; what doesn't work well; and what suggestions you may have for improving the service. This report is due at the end of June. So we organised a coffee morning at the Labor Club in Stirling for interested people to come and talk to Fiona.



If you are interested in having your say, you can contact Fiona on 0412 172 876 or fionatowheatland@gmail.com.

Business

- Our Coordinator, Lyn Morley, noted the passing of David Morgan, one of our Lung Life members. As is our tradition, Chris Moyle, our Treasurer, donated \$50 to LFA (Lung Foundation Australia) who will send a condolence card to the family. Pam Gaston also sent a condolence card - as is our tradition.
- Esther checked on our members – their absences and wellbeing – as she does at every meeting. A member will contact those whom we have no report for.
- Geoff Cox, our newsletter editor, asked for some general photos to add to the newsletter – travel, coffee with friends, sunsets etc. He also asked if anyone was unhappy with their photo being taken, please let him know. We discussed adding ‘Mission’ to the statement of what Lung Life does at the beginning of the newsletter. This will be discussed further at the next meeting.
- **The Seniors Expo** - which was cancelled last year because of Covid - is on again - this time on Thursday 16 September 2021. We will give you more details later. Pam Harris has previously coordinated our setting up and supervising the Lung Life stand and is looking for assistance in managing it all.
- Lyn reminded us all to take **Lung Life pamphlets** to places we go to – like hospitals, doctors’ surgeries, community centres – anywhere you think appropriate. It all helps to spread the word that we exist and what we do. There are also handy handouts at the meeting from previous speakers for people to look at or take.

Guest Speaker – Darren from LEEF

It was a most interesting talk from our speaker, Darren (pictured right), from LEEF. Previously known as Mobility Matters, LEEF is the reverse spelling of FEEL and the company’s motto is ‘Reverse how you feel’, which they aim to do through provision of services, products, and innovative designs.

Darren spoke about the aims of LEEF and brought various pieces of equipment for us to look at. LEEF is all about trying to find a solution to clients’ issues. They sell standard equipment, but they also specialise in customising rehabilitation equipment. Darren will often go out to a client with the occupational therapist to work out the most suitable item for the client – and LEEF will adapt items to suit the client’s need. Clients may have equipment on loan to see if it is suitable for their needs.

We looked at examples of **bottle and can openers**; a **handy bar** for getting in and out of cars; a **grabber** for picking up items from the floor; a carbon fibre (therefore light) rollator (**wheelie walker - pictured**) which weighs only 5 kilos – and costs \$595; and a **tipping kettle** which tips from its heating base and you don’t have to lift it up – cost about \$55-60. Darren told us about the **ORCAM** which you can clip onto your glasses and it will read what you are looking at – cost about \$1500. He mentioned **shoes** (Homipeds), **cutlery**, **mattress covers**, **calming ‘pets’** – ‘cat’ or ‘dog’ that interacts with you as you pass – and many other items. He told us you can have repairs or buy spare parts. Their shop has about 2000 items on the floor and about 5000 in the warehouse. No need to make an appointment unless you have some special requests.

LEEF 21-23 Townsville St, Fyshwick. Phone 02 6280 7244 www.leef.com.au.



The Researchers that solved the mystery of Acrodynia (Pink Disease)

Chris Moyle

In early childhood I contracted **acrodynia (pink disease)** which led to the diagnosis of **bronchiectasis** a few years later. The *Collins Dictionary of Medicine – Robert M. Youngson 2004, 2005* defines pink disease as a now rare, severe childhood illness formerly caused by mercury poisoning from teething powders. Acrodynia features pink, itching extremities, sweating, floppiness, loss of appetite, insomnia, and low blood pressure. The disease was also caused by local applications of mercury-containing medication.



An Adelaide newspaper published this article – circa 1949.

S.A. MEDICAL DISCOVERY

Simple Cure For 'Pink' Disease

A cure for the hitherto mysterious 'Pink' disease in babies and children, discovered by 25-year-old Dr. Donald Cheek and Professor Sir Stanton Hicks, both of Adelaide, was announced yesterday. The cure, which involves the use of common table salt, is expected to bring immediate relief in thousands of cases throughout the world and to save many lives. The discovery is announced in papers published in the 'Medical Journal of Australia.' 'Pink' disease had baffled the medical world for 140 years. In the past four months, the simple new treatment has affected, within a short time, 100 % cures of 20 stricken SA children, including a seemingly dying baby. About 80 cases of the disease have been occurring in SA annually. The death rate from it in the Adelaide Children's Hospital has been 10 %. Ensuring that babies receive adequate salt in milk during the early months of life is now expected to prevent the disease.

How Success Was Achieved?

The story about how young Dr. Cheek, only two years after graduation from the Adelaide University Medical School, and Sir Stanton Hicks achieved their success fills most of the current issue of the 'Medical Journal of Australia.' A revolutionary aspect of the discovery is that 'Pink' disease, which is much more prevalent and disturbing than is commonly realised, had previously been believed due to an infection. But Dr Cheek and Sir Stanton Hicks have shown that leakage of salt from the system to 'Pink' disease is due to faulty functioning of the suprarenal gland. It is stated they overcome this in severe cases by giving, as well as common salt, intramuscular injections of a hormone (synthetic suprarenal cortex extract). They have shown that leakage of salt from the blood moves water by electro-osmotic pressure from the blood into the body's cells, causing painful swelling of tissues. Consequent over-concentration of the blood corpuscles leaves the blood so dense that its slow circulation causes characteristic pinkness and coldness of the palms and soles.

In the early 2000s a Pink Disease Support Group was operational in Australia. A post Pink Disease survey of its members revealed that 53.5% still suffered from headaches/migraines, 69% from unexplained tiredness, 25% from asthma and 26.25% from bronchiectasis. Emotional wellbeing was affecting about half, with

54.25% lacking self-confidence and 57% suffering from nervousness, a common after-effect. It is to be noted that although some sufferers died, and many lived on with varying after-effects, many recovered completely.

The late Professor Donald Cheek is one of the heroes of the Pink Disease Support Group. He was born in South Australia in 1924 and died in 1990.

By the time he was 25 he had received 10,000 letters from grateful mothers around the world. The reason was the medical breakthrough he made in relation to Pink Disease. The disease was affecting young children and the cause was traced to the mercury compounds then being used in teething powders and ointments prescribed for children. The clue to the breakthrough was young patients complaining of constant thirst.

While Pink Disease had been written about, discussed, and theorized about for several generations, Dr Cheek investigated the physiology of the disease a little more thoroughly. He gathered together all the existing information, carried out clinical tests and treatments, and had about a dozen research papers on Pink Disease published. Dr Cheek ran out of patients to investigate (which was a good thing, of course) because once mercury was removed from most baby products, very few babies got Pink Disease. The question still remains as to why only 1 in 500 babies exposed to mercury containing products got Pink Disease. Dr Cheek's theories regarding the immaturity of the adrenal medulla remain the most likely explanation.

He spent 10 years on his thesis regarding adrenal gland involvement in Pink Disease. He continued to have his research papers published up until 1985.

Professor Cheek, who was also a painter who exhibited his works, held appointments at Yale University, the Universities of Toronto, Cincinnati, Texas and Melbourne, the John Hopkins School of Medicine and the University of Adelaide, where he had studied medicine. He was the only non-American to receive the Award for Outstanding Research of the American Academy of Paediatrics.

Reference: [26 Jan 1950 - S.A. MEDICAL DISCOVERY - Trove \(nla.gov.au\)](https://nla.gov.au/nla:gov:1093742)

For further reading about the Pink Disease Support Group see <https://www.pinkdisease.com/heather>.

Chris says: Interesting to note that perhaps I had an immature adrenal medulla. Scans much later in life have revealed I was born with only one kidney (larger than normal), and one ovary – both on the left side. A few parts didn't develop properly or at all.

Excerpts from a book called Disorder in the American Courts

These are things people actually said in court, word for word, taken down and now published by court reporters who had the torment of staying calm while these exchanges were actually taking place:

q: : How far from the accident were you when it happened?

a: : He replied '36 feet, 2 and a quarter inches'

q: : Nonsense how can you be so precise?

a: : Well I knew some bloody fool would ask me so I measured it.

q: : What gear were you in at the moment of the impact?

a: : Gucci sweats and Reeboks.

q : What is your date of birth?

a : July fifteenth.

q : What year?

a : Every year.

q : She had three children, right?

a : Yes.

q : How many were boys?

a : None.

q : Were there any girls?

q : Are you sexually active?

a : No. I just lie there.

q : This myasthenia gravis... Does it affect your memory at all?

a : Yes.

q : And in what ways does it affect your memory?

a : I forget.

q : You forget. Can you give us an example of something that you've forgotten?

q : What was the first thing your husband said to you when he woke up that morning?

a : He said, 'Where am I, Doris?'

q : And why did that upset you?

a : My name is Susan.



Pictured above are former neighbours Marilyn Allen and Esther Fitton enjoying the May Meeting.

Reference: [Disorder in the American Courts](#) by Marcelle Bowen - 2016

What a Fantastic Photo

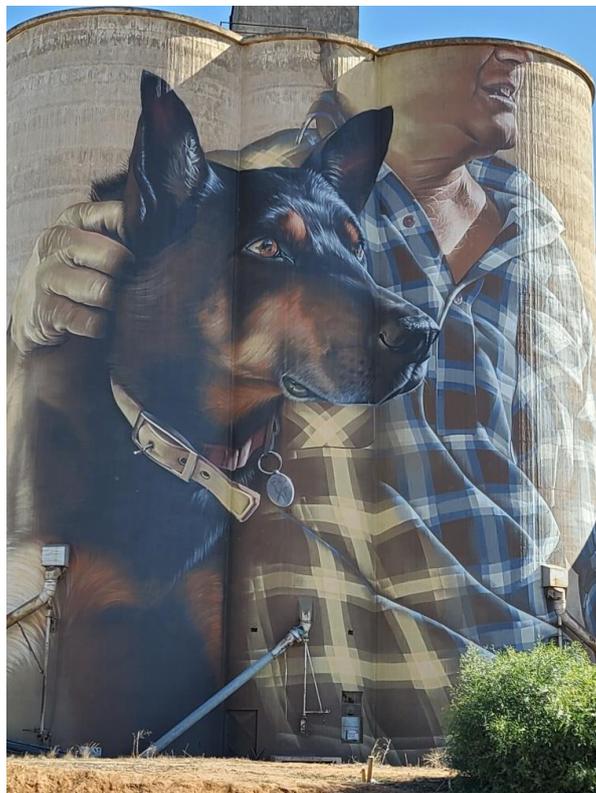
John and Lyn Morley have 'answered the call' for interesting photos to be included in our newsletter.

John and Lyn enjoy travelling to rural areas where Silo Art can be found. This fabulous piece of work is to be found in **Nullawil** – *yes, I had to go to Google maps as well*. This small town on the Calder Highway is about mid-way between Melbourne and Mildura and is part of an art trail that stretches across the Wimmera and Mallee.

This work was completed by Australian born street artist Sam Bates who now resides in Glasgow. He is also known as Smug or Smug One.

Reference - [Silo Art Trail welcomes its newest addition in Nullawil | Bendigo Advertiser | Bendigo, VIC](#) at

<https://www.bendigoadvertiser.com.au/story/6288479/nullawil-the-latest-to-join-the-silo-art-trail/>



Stay Alive by Breathing

Edited from: [American Lung Association Breathing Exercises | American Lung Association](https://www.lung.org/lung-health-diseases/wellness/breathing-exercises)
<https://www.lung.org/lung-health-diseases/wellness/breathing-exercises>

Exercise for as little as 5-10 minutes a day. What could be easier than that to improve your breathing?

Step 1: Relax neck and shoulder muscles

Out with the old, stale air and in with new fresh air. Breathing exercises can make your lungs more efficient. When you have healthy lungs, breathing is natural and easy. You breathe in and out with your diaphragm doing about 80 percent of the work to fill your lungs with a mixture of oxygen and other gases, and then to send the waste gas out. Over time, though, with asthma and especially with COPD, our lungs lose that effectiveness. They don't return to the same level as when you start breathing, and air gets trapped in our lungs.

Stale air builds up, leaving less room for the diaphragm to contract and bring in fresh oxygen. With the diaphragm not working to full capacity, the body starts to use other muscles in the neck, back and chest for breathing. This translates into lower oxygen levels, and less reserve for exercise and activity. If practised regularly, breathing exercises can help rid the lungs of accumulated stale air, increase oxygen levels and get the diaphragm to return to its job of helping you breathe.

Step 2: Pursed Lip Breathing

This exercise reduces the number of breaths you take and keeps your airways open longer. More air is able to flow in and out of your lungs so you can be more physically active. To practise it, simply breathe in through your nose and breathe out at least twice as long through your mouth, with pursed lips.

Step 3: Belly Breathing, aka Diaphragm Breathing

As with pursed lip breathing, start by breathing in through your nose. Pay attention to how your belly fills up with air. You can put your hands lightly on your stomach, or place a tissue box on it, so you can be aware of your belly rising and falling. Breathe out through your mouth at least two to three times as long as your inhale. Be sure to relax your neck and shoulders as you retrain your diaphragm to take on the work of helping to fill and empty your lungs.

These exercises may seem simple, but they take some time to master. Ideally, you should practise both exercises for about 5 to 10 minutes every day.

Newsletter History (with thanks to Helen Cotter for her historical knowledge)

The Lung Life Newsletter was first published in 2009. Initially it was through the efforts of **Deanne Proctor** who unfortunately died before it became a reality. **Helen Cotter** then took over and became the first editor of the then four page newsletter. **Helen Reynolds** was the editor from 2012 to 2019, and gradually the newsletter became more colourful and varied, with jokes and cartoons becoming regular features.

A now permanent fixture on the front of each newsletter is the statement: '**Providing a supportive and informative environment for people with a variety of lung conditions and their carers**'. This statement was first used in May 2011, and to this day it is what the group is about. At the May meeting we discussed the merits of adding '**Mission**' or '**Our Mission**' to this statement, and it will be discussed further at our June meeting. If you would like to have input on this your views would be most welcome.