



January 2020 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 13th February 2020
10:15 am – 12 noon
Weston Creek Labor Club
Teesdale Close
Stirling ACT 2611

Dates for your diary

- **Thursday 13 February 2020** February Meeting, Labor Club Stirling.
- **Thursday 12 March 2020** CLLSG's 22 Year Anniversary Celebration and Lunch, full details page 6. Please pay at the February meeting.

January Meeting

Helen Cotter

About 15 people attended the first meeting of the year. This was a lower attendance than usual, possibly as a result of the smoke in the air over Canberra and some members being away.

- Geoff Cox was due to speak about his lung transplant in 2019, but he was unable to attend owing to the bushfire smoke.
- A discussion was held on how the plans for the 22 Year celebration, to be held in March, were progressing (see the invitation on page 6).
 - As a planning group had already met, and the organising for the day begun, the meeting group discussed the decisions that they had made.
- From 11:00 am to 12:00 pm there will be a presentation to look back at Lung Life's 22 years (this will include a visual presentation), and this will be followed by a buffet lunch and a cake.

- Margaret Geaghan who had been near Moruya with her family when the bushfires hit, talked about her experience and just how frightening it was.
- John and Chris had their P2 masks with them, leading to a general discussion about the masks, as well as air purifiers.
 - The group learnt that masks need to be secure around the face, and they only last about eight hours before losing their benefit.
 - A good air purifier needs to contain a medical grade HEPA filter and/or a carbon filter to filter out the fine toxic particles.
- The meeting concluded with a game of Bingo and then lunch.

December Meeting Helen Cotter and Chris Moyle

Owing to club requiring the regular meeting room for Christmas functions our group met for coffee in the lounge, this was followed by lunch.



- We were able to mark a special event for Helen Reynolds, as Helen was unable to attend our Christmas lunch.
- The December edition of the newsletter was Helen's last as editor after many years of dedicated service.
- Helen has resigned from the position, primarily as a result of eye sight problems.
- She was thanked for developing the newsletter to its present format, with its wide variety of interesting articles, photos, jokes and cartoons.
- For those who were unable to attend, the photos sum up the occasion.

An emotional Helen is opening her presents, which included a calendar of young male firefighters, while some lovely words written by Carmel Jarvis are read to her.



Meet Your New Editor, Geoff Cox

- Grew up in Sydney in the 1960s and 70s.
- Attended Macquarie University in North Ryde, graduating with a BA Dip Ed.
- Lived and worked in various places, including Bathurst for eight years.
- Moved to Canberra in 1998.
- Worked at Canberra Girls' Grammar School Junior School.
- Has also worked as a swimming coach in Canberra.
- Married with three grown up children.
- Had a double lung transplant in May 2019.

- Medical conditions include alpha 1 anti-trypsin deficiency (a genetic condition potentially leading to lung and/or liver problems) and diabetes (as a result of medications taken daily).
- Interests – exercise, sport, travel and geography.
- Favourite bands – Cold Chisel, Midnight Oil, The Angels and The Rolling Stones.
- Favourite artists – Billy Joel, Eric Clapton, Rodriguez and Joe Cocker.
- Supports – the Brumbies and the Canberra Raiders.



Geoff indulging in his passion for travel.

London in 2016, outside the Rolling Stones Exhibition. He is a proud Canberran, wearing his Brumbies supporter's cap.

With the 22 year Celebration fast approaching in March, Chris Moyle continues the series, 'remembering our beginnings'.

At My Table

At the 1999 Christmas lunch I sat opposite Susan and Margaret. Susan (turning to face the camera) attended a few functions while Margaret, in the red hat, was a regular attendee.



Margaret Fead lived an interesting life, gaining a BA and B. Commerce before working in London, Rome and then Canberra with the Bureau of Agricultural Economics. After retiring she developed an interest in creative writing and had several articles and short stories published. She loved the theatre and was a Life Member of Canberra Repertory. In 1992 Margaret was diagnosed with emphysema which changed her active lifestyle; however, with the help of her friends, a computer, and the support of the Lung Life Support Group she managed to continue enjoying life.

Sitting on my right was Theresa Finn. Theresa married young and had six children before her 27th birthday. The family then moved from Brisbane to Canberra and Theresa worked as a stenographer in the Public Service. Unfortunately, her life-long habit of smoking later resulted in a diagnosis of emphysema and she was attached to an oxygen tank for the last eight years of her life. She also found friendship and support with our group. Theresa regularly attended the gym to be as fit as possible whilst waiting for a lung transplant. Sadly, this transplant didn't eventuate. Both Margaret and Theresa later passed away.

Next to Theresa, at the end of the table, accompanied by her portable oxygen concentrator, was a newcomer, Helen. I didn't have the opportunity to converse with Helen, only noticing that she looked young and had the bluest (unpainted) fingernails I'd ever seen. That should have prepared me for what was to come, as a week or two later we heard she'd succumbed to her illness and died. We were all shocked to hear this news and learnt that Helen had been suffering from the genetic disease cystic fibrosis.

The take-aways from this story are: don't smoke, be an organ donor, practise a healthy, preventative lifestyle, find a good GP and lung specialist and join a support group.

Cystic Fibrosis

Chris Moyle

Cystic fibrosis is an inherited disease, which affects the secretory glands of the body, especially the glands that produce mucus and sweat. Symptoms of this disorder include salty sweat, poor growth, excess mucus production, frequent chest infections, incessant cough, breathing trouble, impotence and poor digestion. Those affected with cystic fibrosis produce a sticky mucus that causes a blockage of the ducts and passages of the lungs and other organs, like the pancreas, leading to infections and organ failure.

Cystic fibrosis was identified and recognised as a special medical condition during the 1930s. The sweat test developed during the 1960s proved to be very helpful in diagnosing this disease. With such advances in the methods of diagnosis and treatment, the survival rates of cystic fibrosis patients improved greatly. In 1989 the gene which is responsible for causing the condition was discovered and this discovery became the milestone upon which further advancements in treatment were made.

Nowadays, newborn screening programs in many countries include tests for cystic fibrosis, so that treatment can be started at the earliest time. Even prenatal tests can be conducted to rule out the possibility of this disease. Genetic tests can be conducted on the family members of a person who has been diagnosed with cystic fibrosis. This is done to find out whether they carry the gene responsible for this disease. All these diagnostic methods help in early detection, which enables early treatment and a longer life expectancy. At present, there is no cure for this disease, but proper treatment is available, which will help manage the symptoms in a better way.

As the symptoms tend to worsen during early adulthood, proper treatment during this stage may increase the life expectancy. Though oxygen therapy is believed to improve the health condition as well as the lifespan, studies regarding the same are still underway. It has also been observed that most of the patients, who have opted for lung transplantation are doing well and are said to have an improved life expectancy.

During the early years of the twentieth century, the average age of survival for children with cystic fibrosis was six months. Now the average survival age is 35 to 40 years, with many patients living much longer than expected.

Ref: <https://healthhearty.com/cystic-fibrosis-life-expectancy>

Kaye Powell attended the Governor General's Christmas Party



The Governor General David Hurley and his wife Linda are patrons of the Lung Foundation, Australia. Our active member Kaye was invited to their Christmas party in December.

New year's Mottos

Chris Moyle

"I allow myself to fail and I'm not afraid of my flaws." (Lady Gaga)

"It's important to travel and move and have a continual set of experiences." (Cate Blanchett)

"By overcoming difficulties, we gain strength and maturity." (Angelina Jolie)

"It is very important to know who you are; to make decisions to show who you are." (Malala Yousafzai)

"I've never wanted to be a lady who lunches...I've always wanted to be a woman who works." (Meghan Markle)

"I live every day to its fullest extent, and I don't sweat the small stuff." (Olivia Newton-John)

"You don't learn from successes and awards... you learn from mistakes and failures." (Jane Fonda)

"Success provides you with the ability to make a difference, not only in your own life but in other people's lives." (Oprah Winfrey)



We Are Celebrating

22 years of Support, Education and Friendship for those in the community with chronic lung conditions

PLEASE JOIN US FOR LUNCH

Current and past members will be there along with some special guests. We will start our celebrations with a short formal segment covering our story and achievements to date. This will be followed by lunch (at your own expense, \$45.00 per person). We would love to see you there.

WHEN: Thursday, 12th March 2020

WHERE: The Weston Creek Labor Club, Teesdale Close, Stirling, ACT

TIME: 11:00 am – 2:00pm

RSVP by 29th February 2020 either email lung.life1@hotmail.com or phone Pam on 02 62882053

SimplyGo POC – Too good to miss

We have been donated a SimplyGo portable oxygen concentrator which we'd like to pass on to another user. The SimplyGo provides continuous oxygen as well as pulse.

It was only used for a short while and is in good condition. It has a trolley, a manual, a power cord (charger) and a car power cord.

A new SimplyGo with only one or two batteries costs about \$4500 - \$5000. This one has 4 beautiful batteries. They each cost about \$500 new.

We ask for a donation to Lung Life. Contact Helen Cotter on 02 6281 2988 or cotterhe@hotmail.com.