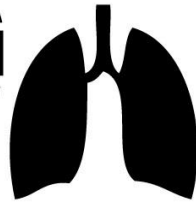




CANBERRA
LUNG LIFE
SUPPORT GROUP



February 2020 Newsletter

Providing a supportive and informative environment for people with a variety of lung conditions and their carers.

Editor: Geoff Cox 0429 901 131
selaca@bigpond.net.au
Coordinator: Lyn Morley 02 6291 0626
lung.life1@hotmail.com

NEXT MEETING: Thursday 9th April 2020
10:15 am - 12 noon
Weston Creek Labor Club
Teesdale Close, Stirling ACT 2611
Please note there will be no monthly meeting in March.

We Are Celebrating

22 years of support, education and friendship for those in the community with chronic lung conditions

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). Current and past members will be there along with some special guests. We would love to see you there too.

WHEN: Thursday, 12th March 2020

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

TIME: 11:00 am – 2:00 pm (please arrive at 10:45 am)

RSVP: By 29th February 2020, either email lunglife1@hotmail.com or phone Pam on 02 6288 2053

PAYMENT: Lung Life Support Group, BSB: 112 908, A/c: 131 363 207
Reference: Your Name

February meeting Helen Cotter

We almost had a full house for this meeting. It was good to see some people who have been away for a while as well as those who couldn't come last month because of the smoky atmosphere.

- Marina ran through her PowerPoint presentation for the Celebration next month. It looked excellent but we were still able to give her some feedback.
- Lyn and John Morley have been on a holiday, only returning the night before the meeting. They had a lovely time catching the Indian Pacific to Perth, then cruising for ten days up the west coast. A cyclone near Broome resulted in a change of destinations for the ship. They visited the ports of Geraldton, Exmouth and Busselton as well as spending time at sea.
- Lyn also talked about having her portable oxygen concentrator (POC) with her, and how easy and convenient it was on the cruise. However, she did have a run around with Qantas who almost refused to let her on the plane for a variety of reasons related to this. Lyn is now wary of travelling with Qantas.
- We brought people up to date on the organisation for the Celebration next month. The working party later had a meeting to finalise some aspects.
- Chris talked about the masks from the chemist and how difficult it was to breathe in them. They were also difficult to use with her glasses. She's pleased it's all over.
- We discussed speakers for later meetings. Geoff Cox is going to talk about his lung transplant at the April meeting, and Kaye is hoping to get a representative from White Lady Funerals to come and talk to us, this could be in May. **We would like suggestions for speakers for later meetings.**
- Geoff, the new editor of our newsletter, told us that **he'd be pleased to receive items for the newsletter** on any topic – not necessarily medical. If he can't get it in the next newsletter, he'll keep it for a later one. His email address is selaca@bigpond.net.au.

Then it was close of meeting and time for lunch.

Remembering the Past - Barry Thom and his mum, Mae Chris Moyle

Barry first came to a Lung Life meeting in 2002 accompanied by his mother, Mae who suffered from emphysema. Barry was her carer and as Mae said, "He's my lifeline."

Barry was soon taken under the wings of Esther and Cecelia, helping them at meetings by looking after name badges and ringing the bell when order needed to be restored. Chairman Gordon had a medical episode after one meeting and Barry stepped in to assist. At the next meeting Gordon gave a formal and grateful 'thank you' speech to Barry and the others who helped him.

When the Raiders Club changed our meeting venue to a downstairs room with steps at its entrance Barry assisted people, with and without wheelie walkers, into and out of the room. After this we soon moved to the Burns Club. Then another change was required, and today we meet at the Stirling Labor Club.



Mae Thom passed away in 2005 at the age of 90 (a good innings) and Barry continues to attend meetings.

At Expos and other public events Barry is there to help set up tables and chairs, as well as our tall Lung Life banner. He willingly fetches coffee and snacks to assist those volunteers with less lung power and energy. It is 'go for this' and 'go for that', which earned him the nickname 'the gopher'.

Barry enjoys keeping in touch with people. He phones those who've been sick, gives lifts to and from meetings and events to people who need them, and visits unwell friends in hospital.



His kindness is well known. He's a friend to many and his friendship is much appreciated.

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.

Do you have an email address?

...and do you receive a paper copy of the Lung Life newsletter?

To assist in making the process of producing the newsletter cheaper, more efficient and environmentally friendly please consider receiving it by email.

Simply email lung.life1@hotmail.com to let us know that you would like to receive your newsletter electronically in the future.

From the Editor

Geoff Cox

Your editor, with his wife Dianne, and his new set of lungs recently spent two days walking in the Snowy Mountains. On the first day they walked down to the Snowy River from Charlotte Pass. On day two they did a longer walk along the Thredbo River and then around Thredbo itself.

Geoff hasn't been able to get out and about like this for years, so he can't thank enough all the wonderful people involved with his transplant.

Geoff at Charlotte Pass



By the Snowy River



The wildlife is best avoided

Gift of Life Walk 2020

Geoff is planning to participate in the Gift of Life Walk at Lake Burley Griffin on **Wednesday 26th February**. This is a free event, open to anyone, to raise awareness for organ donation. There are two distances, a 5km walk which is around Central Basin and a shorter fifteen to twenty minute walk around Commonwealth Park. For either walk meet at Rond Terrace, Anzac Parade at **6:45 am**. See <https://www.giftoflife.asn.au/register-for-gift-of-life-s-donatelife-walk-2020#formanchor> for more details or to enter the event.

Seniors Week 2020

ACT Seniors Week is being held this year during the week beginning Monday 23rd March. The **Seniors Expo** at Exhibition Park is on **Thursday 26th March** from 10:00 am to 3:00 pm. **Lung Life** always has a stand there and volunteers are needed for this (contact **Pam** on 02 6288 2053, if you can help). Many community groups and other organisations (120 altogether) will offer information on lifestyle, retirement, travel, government services and so on. It's a great Expo and well worth a visit, not only to support Lung Life but also to see the other 120 groups there.

Also happening as part of Seniors Week is the **Positive Ageing Awards** at 2:30 pm on 27th March at the Weston Creek Labor Club.

The Chief Minister's Concert will be held on 24th March at 11:00 am, with a second concert at 1:00 pm in the Albert Hall. You need to make a reservation: contact COTA 6282 3777 or email www.concert20.eventbrite.com.au. There is no catering there (but the Hyatt is just across the road). Support and enjoy Seniors Week.

ACT Companion Card Program

https://www.communityservices.act.gov.au/companion_card

The companion card enables people who need an attendant to attend the pictures, theatre or other participating places to go there without the need to buy a second ticket. To be eligible for a Companion Card, you must meet all four of the eligibility criteria:

- **You** must be a permanent resident of Australia, residing in the ACT.
- **You** must demonstrate that you have a significant, permanent disability.
- **You** must demonstrate that, due to the impact of the disability, you would be unable to participate at most community venues or activities without attendant care support.
- **You** must show that the need for this level of attendant care will be lifelong.



To apply for an ACT Companion Card, you (or your representative) must complete and submit an ACT Companion Card Cardholder Application Form. Part A of the form, you fill in; Part B needs to be completed by a health professional: doctor; nurse, physiotherapist etc. You also need to have 2 passport sized photos initialled by the person who completed Part B of your application.

For more details, use the website above or **contact** the ACT Companion Card Program:

Access Canberra

GPO Box 158

CANBERRA ACT 2601

Phone: 02 6205 4333

National Relay Service phone 133 677 then ask for 133 427

Email: companioncard@act.gov.au

What is Alpha 1 Antitrypsin Deficiency (Alpha-1)?

Geoff Cox

Alpha-1 is a genetic condition resulting in serious lung and/or liver damage. The stage of life when this may occur varies from individual to individual.

Alpha-1 antitrypsin is a protein that is produced mostly in the liver. **Its primary function is to protect the lungs** from the enzyme, neutrophil elastase. For most individuals neutrophil elastase is a very useful enzyme, its role in the body is to promote healing by digesting damaged or aging cells and bacteria. If left unchecked; however, it will also attack healthy lung tissue. Alpha-1 antitrypsin will trap and destroy neutrophil elastase before it has a chance to begin damaging the fragile lung tissue. **Consequently, if an individual doesn't have enough alpha-1 antitrypsin, the enzyme is unrestrained and attacks the lung.**

Most people have two normal copies of the alpha-1 antitrypsin gene. Some people may have one normal copy and one damaged copy of the gene; they are considered **Alpha-1 Carriers**. Individuals with two damaged copies of the gene have the deficiency of the alpha 1. They are considered to have 'Alpha-1' and are referred to as '**Alphas**' (your editor is one of these).

Alpha-1 Carriers can generally stay healthy (especially if they don't smoke) and may never know that they carry the defective gene. Individuals with two damaged copies of the gene have a far greater problem. A variety of conditions can result from not producing enough antitrypsin. '**Alphas**' are often diagnosed with **emphysema as their primary disease**. They may also have to also deal with asthma, chronic bronchitis, and/or bronchiectasis. 'Alphas' are also usually quite susceptible to lung infections. In the Alpha-1 patient, any of these conditions can cause further damage if they aren't treated right away.

Cirrhosis of the liver is another disease that some Alpha patients develop. This scarring of healthy liver tissue affects Alpha-1 infants, as well as 12% to 15% of adult Alphas. Unfortunately, there is no cure for cirrhosis of the liver, regardless of its cause. If caught early and protective steps are taken Cirrhosis can be managed as a chronic condition. Still, a liver transplant is currently the only option available for advanced disease.

More rarely, Alphas may also have a disease known as panniculitis. Panniculitis is an inflammation in the fatty tissue under the skin. It can occur in both children and adults.

'Alphas' and physicians regularly speak of a patient's '**primary disease**'. This means the principal way the deficiency is manifested in each patient, whether it is in the lungs, the liver or the skin.

3% of Caucasians are Alpha-1 Carriers and 1 in 2500 have the condition. There is no cure. In Australia a lung and/or liver **transplant** is an option which can improve their quality of life.

Ref: <https://www.alpha1.org.au/index.php/info/what-is-alpha-1>

The Final Word

Don't forget the **22 Year Celebration** on 12th March, we would love to see you there. All the details are on page 1 of this newsletter.