alpha-1 ORGANISATION AUSTRALIA INC

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

Issue 2 Summer 2020

From the President's Pen

The Management Committee has been working hard behind the scenes, advocating on behalf of individuals with alpha-1 antitrypsin deficiency (alpha-1 or A1AD) and their families, and raising awareness about alpha-1. We have been busy producing additional alpha-1 written resources and forming important relationships with key stakeholder groups. I have included a snapshot of some our work over the last six months, which you can read below.

If you would like to discuss any of our activities, you are welcome to contact me by email (president@a1oa.org.au) or phone (0422174590). Meanwhile stay safe and I hope that you can catch up with friends and family during the Christmas / New Year period.

All the best
Gaynor

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Gaynor Heading PhD
President
Alpha-1 Organisation Australia inc

New Initiative! Peer support meetings

The new alpha-1 lung national support group is being trialed during November. It is being established to support lung-affected A1OA members, with video technical support from the Lung Foundation. Members will be able to register and participate in "face-to-face", ie online, support meetings, where a variety of issues affecting members will be discussed.

You can join the group by joining the Lung Foundation first, then registering.

We have 10 members already!

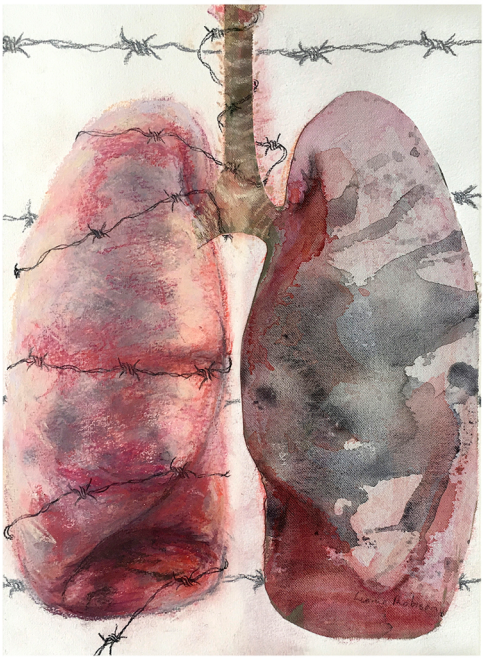
For more information email Jean at comm2.a1oa@gmail.com

Or contactus.a1oa@gmail.com

November is Alpha-1 Awareness month

Here is one of A1OA's posters, designed by one of our members to help raise awareness

IS THIS HOW YOUR LUNGS FEEL?



Feeling breathless? Have asthma, emphysema, lung problems?

Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, leading to lung damage. This is a common genetic disorder but very few are diagnosed.

If this sounds like you or someone you know, visit our website, www.a1oa.org.au, or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at contactus.a1oa@gmail.com.

Alpha-1 Antitrypsin Deficiency Awareness Month

alpha-1
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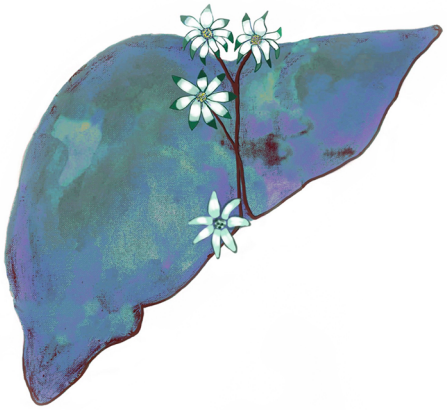
Advocacy, Support and Awareness Snapshot

A1OA registered in June 2020 with the Australian Charities and Not-for-profits Commission (ACNC).
First position paper written and released on the A1OA's website.
Many fact sheets relating to alpha-1 added to our website.
Meeting with the UK Vice President for Patient and Community Engagement from Vertex Pharmaceuticals to encourage Vertex to bring their alpha-1 clinical trials to Australia.
First A1OA newsletter – the Spring edition - was published.
Submission made to Government supporting genotyping for alpha-1 antitrypsin deficiency.
Submission made to the Parliamentary Inquiry into the approval processes for new drugs and novel medical technologies in Australia. This inquiry is very timely, given potential genetic treatment breakthroughs and the need for patients' access to new lifesaving treatments.
The A1OA has written to key groups to share information about alpha-1 and to explore collaborative opportunities; the Lung Foundation Australia, the Thoracic Society of Australia and New Zealand, Rare Voices, the Asthma Australia, and the Alpha-1 Foundation in North America. We had our first meeting with the Lung Foundation CEO and have agreed to explore potential collaborative opportunities.
After a successful presentation on alpha-1, Hornsby District Rotary Club has decided to promote alpha-1 awareness.
A1OA has provided information to be included in a local newspaper, which will be written by a rotary member.
To promote alpha-1 awareness, volunteers published and distributed 12 November awareness-month posters, each covering a different aspect of alpha-1.
These posters depict catchy slogans and original artwork by alpha-1 patients. They are available on the A1OA website for distribution to health professionals or other interested parties, for posting on social media, and for printing.

November is Alpha-1 Awareness month

SEVERE JAUNDICE? LIVER DAMAGE?

DON'T KNOW WHY?



Do you have unexplained liver disease?

Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, which can lead to lung damage. This is a common genetic disorder but very few are diagnosed.

If this sounds like you or someone you know, visit our website, www.a1oa.org.au, or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at contactus.a1oa@gmail.com.

Are you creative? An artist? Love painting or just doodling?

Do you make art about alpha-1 or about your health journey?

Consider emailing us a good quality jpeg of your work with your contact details and it might be featured in a future issue of the Alpha Times!

An Alpha Story

Jean Gray

It was 2013. I was studying for my Masters in Child Health Nursing. Procrastinating over an assignment, I decided to do some cleaning. I became breathless very quickly and knew something was not right. I had been told I had asthma but was not responding to treatment. Allergy tests didn't show much. My fitness never seemed to improve, even with a personal trainer. I thought of walking with friends but they would have become frustrated with my slow pace.

After finishing my Master's, I started looking for answers. My first clue came when my sister had pneumonia and was told by her specialist that she didn't have asthma. She also had lymphoma and I remembered reading that this was a risk factor for a genetic disease called alpha-1.

My mother had asthma for as long as I remember and my father had pleurisy. Several relatives had lung problems, including an uncle who died in his 20s from pneumonia. It was looking genetic.

I have also developed syringeo myelia which affects me from T10 to L1 so I can't lift my right foot more than a couple of inches. This has been made worse by my lungs being overinflated.

I asked for an alpha test and it came back 0.2 PiZ. I now had the task of letting my siblings know that they were also at risk.

I never thought for a minute that in 3 years' time I would stop work. Luckily, I was able to get income protection insurance. A conscientious saving of superannuation is no protection. My dreams of travel were dashed on the rocks.

At first I believed the guidelines that said there was no treatment but found that was not true, it is just too expensive. Since then I have talked to and written to politicians, become active with a1oa and try to do what I can.

Sadly, I have a daughter with a chronic mental health condition and unfortunately my husband was diagnosed with multiple myeloma, though luckily he is doing well after a stem cell transplant. To top it off, just before I stopped work my house burnt down because I left my laptop plugged in charging and it overheated.

I currently have some home care and am hoping not to have to go into an aged care facility as I am only 65.

My husband is my rock and I have a gorgeous greyhound, good friends and neighbours. I am still able to sew in my beautiful sewing room.

Aunty Alpha

Dear Aunty Alpha,
I am having trouble with breathlessness and my doctor says it is asthma. It doesn't seem to respond to my reliever puffer though. Could it be alpha-1 antitrypsin deficiency?
Regards, Shane

Dear Shane
You may have alpha-1.
Many people (around 90%) with A1AD have not been diagnosed or have been misdiagnosed with COPD or asthma. Although the cause and disease mechanisms of these are distinct, lung affected individuals with alpha-1 commonly present first with asthma-like symptoms and so receive asthma treatment. Correct diagnosis can be complicated by the overlap of symptoms with other obstructive lung diseases, especially asthma. Additionally, allergy and asthma often coexist with A1AD. Lung function tests should always be carried out when diagnosing lung disease, including responsiveness to bronchodilators, e.g., Ventolin. This can help confirm diagnosis as people with asthma would typically improve after inhaling a bronchodilator. If someone doesn't respond, clinicians should start wondering if it could be A1AD. Having a blood test to determine antitrypsin levels and phenotype is important to confirm or rule out A1AD.

Have a question about Alpha-1 Antitrypsin deficiency?

Write to Aunty Alpha at contactus.a1oa@gmail.com

Newly Diagnosed? Part 1.

If you're newly diagnosed you're probably shocked and bewildered. This is completely normal; apart from any of the associated medical issues, just getting your head around the language can be difficult – Alpha-1 Antitrypsin Deficiency (A1AD), Homozygous, Heterozygous etc. – enough to baffle anyone, and your doctor or specialist also probably told you how rare this is.

As with any medical condition, your best outcome comes with knowledge and understanding, and with this condition there is certainly much to know! So, where do you start?

Initially your wellbeing should be your focus, both mentally and physically. Typically, Alphas (as people diagnosed with A1AD are commonly called) can be 'lung-affected', 'liver-affected' or both, and will have come to a diagnosis of A1AD through the investigation of either a lung or liver problem. Below are a few simple suggestions to get you started on your journey:

- Connect with others affected – there are many Facebook groups associated with A1AD both in Australia and globally, and these are great places to learn from others who have been on the same journey - The Alpha-1 Organisation of Australia has one here - Alpha-1 Organisation Australia Inc Public

- Focus on your immediate health – make sure you have a GP who knows about A1AD (or who is willing to learn), identify lung and/or liver specialists in your area who you can work with, make sure you're not exacerbating your symptoms through your lifestyle (e.g. avoid smoke/pollutants, eat a healthy diet, exercise as much as you can etc)

- Write down any questions that occur to you – answering these on your journey will give you more control and help you make decisions

In Part 2 of this series we'll look at some of the broader implications of your diagnosis, in particular what it means for your children, siblings and wider family.