

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

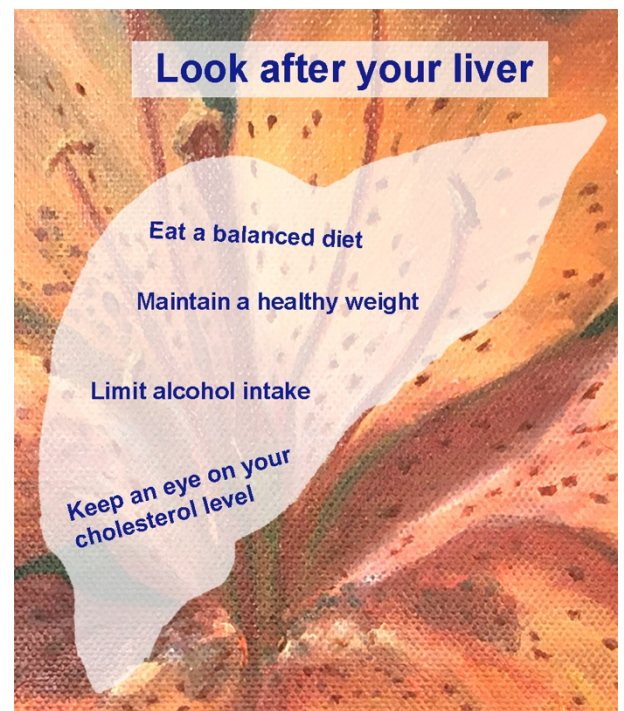
Issue 11 Summer 2022-23

From the President's Pen

Hi everyone
Welcome to our Summer Edition,

After our successful Spring/Summer awareness raising campaign about Alpha-1, we have another year filled with opportunities to raise awareness and to encourage testing if people are displaying related symptoms or are at risk. You may have viewed our new patient videos, where three lung-affected individuals with ZZ phenotype tell their stories. Unfortunately, similar themes emerge across the videos related to the length of time it took them to be diagnosed; the importance of early testing and disease awareness; and the importance of lifestyle change (e.g., not smoking) to preserve lungs as much as possible, as no lung-related life-saving treatments are subsidised in Australia. The interviews show how Alpha-1 impacts every aspect of daily life and why patients dream of and desperately need affordable treatment access. While a few promising clinical trials are underway for both Alpha-1 liver and lungs, it is probably many years until new treatments are available due to the length of time it takes for clinical trials to reveal treatment evidence followed by the necessary government approvals and funding allocation. In the meanwhile, our charity's message remains firm – early testing for Alpha-1 is so important in order to minimize potential liver and lung harm. Our website contains a wealth of free evidence-based information for people diagnosed with Alpha-1.

Wishing you all the best,
Gaynor Heading
President A1OA



A-1 Awareness Month

Every year in November we focus on raising awareness of Alpha-1.

2022 was no exception with a number of different activities and new resources presented.

We now have a large number of supporter T-shirt designs available to download from our website for you to have printed by your favourite print-on-demand online printer.

<https://www.a1oa.org.au/resources/>

We would love to see a photo of you in your new T-shirt.

Drop us a photo of yourself wearing it!

Email the photo to Contactus.a1oa@gmail.com

Let us know if you are happy to appear in our next newsletter or on our Facebook page.

We also had an exercise challenge- The Alpha-1 in 9 Challenge, set up by A1OA board member, Mark Lloyd, which helped raise much needed funds to produce Awareness resources, such as our videos focussing on the stories of individual Alpha-1 sufferers.

<https://www.gofundme.com/f/the-alpha-trail-s2-the-alpha1-in-9-challenge?qid=1842100a2833fdc31e04c3eb6ec2ae74>



Meeting the challenge

Alpha-1 in 9 Challenge

In October 2022, Mark took part in his second fundraiser of the year, completing the Three Bridges Marathon in Western Sydney. The focus for this event was to raise awareness that 1 in 9 Australians has a faulty Alpha-1 gene, a statistic that is alarming when you think Alpha-1 is considered a rare disease.

Between this event and the cycle from Sydney to Melbourne earlier in the year, Mark raised just shy of \$15000. This funding has allowed us to expand our marketing efforts with the recent release of the Alpha-1 Unwrapped video series and more planned activity moving into 2023.

Well done Mark! A great effort!

Our new video resources

Alpha-1 Unwrapped

In August of last year, we kicked off Alpha-1 Unwrapped, a 3-part series where we interviewed 3 Sydneysiders about their Alpha-1 condition.

Craig, who has the ZZ genotype and 46% lung capacity, took part in interview number 1. He dived into his Alpha-1 story including the everyday challenges he faces and his long journey to being diagnosed with the condition.

Craig: <https://youtu.be/ZOUb02CUjFw>

Lara joined us for our next Alpha-1 Unwrapped episode. She spoke about how the condition impacted her both physically and mentally, and the concern she had for her future. She also talked about the long journey to being diagnosed, and how an earlier diagnosis would have helped her make more informed decisions about her life choices.

Lara: <https://youtu.be/dIMnaUYLpsM>

In the last of the series, we interviewed Andrew. He was first diagnosed with asthma, and then COPD which went on for over 10 years. In 2021, Andrew was finally tested for Alpha-1 and the results came back positive.

Andrew: <https://youtu.be/EbhWmnWrelo>

All videos are available on our [a1oa blog](#) and [YouTube channel](#).

Our new T-shirt designs

Different colours and styles to suit everybody.

www.a1oa.org.au/resources

Lungs or liver making you feel blue?
Ask your doctor about
Alpha-1 Antitrypsin Deficiency
www.a1oa.org.au

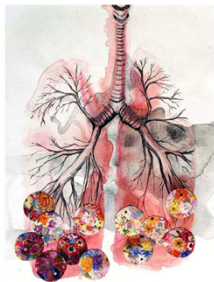


Alpha-1 Antitrypsin Deficiency
Help solve the puzzle
Lung or liver symptoms?
Get tested for Alpha-1
Info @ www.a1oa.org.au



1 in 9 Australians has
Alpha-1 Antitrypsin
Deficiency
www.a1oa.org.au

This is a white design that can be printed on a coloured T-shirt



Emphysema but never smoked?
You may have
Alpha-1 Antitrypsin Deficiency
info @ www.a1oa.org.au



1 in 9 Australians has
Alpha-1 Antitrypsin
Deficiency
Find out more
www.a1oa.org.au



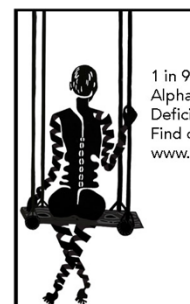
Alpha-1 Antitrypsin Deficiency
Avoid lung damage
Keep smoke out of you lungs
www.a1oa.org.au



1 in 9 Australians has
Alpha-1 Antitrypsin
Deficiency
Find out more here
www.a1oa.org.au



A genetic disorder causing lung and liver disease, skin problems (panniculitis), and inflammation of the blood vessels (vasculitis)



1 in 9 Australians has
Alpha-1 Antitrypsin
Deficiency
Find out more here
www.a1oa.org.au



Aunty Alpha is on holidays at the moment, but she'll be back next issue!

If you have a question about any of the issues raised

write to Aunty Alpha, who is always happy to answer your questions, or contact the A1OA through contactus.a1oa@gmail.com

Mental Health First Aid

Alpha-1 Organisation Australia has an accredited Mental Health First Aider who is ready to help if you are not coping after a diagnosis of A1AD for yourself or a family member. A new diagnosis can cause mental distress, anxiety, or depression. Please reach out to mentalhealth.a1oa@gmail.com

