

## Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

*Issue 6 Spring 2021 ∞ Special Edition ∞ Alpha-1 Awareness Month*

### From the President's Pen

#### Welcome to November Alpha-1 Antitrypsin Deficiency Awareness Month.

At Alpha-1 Organisation Australia (our charity) we have an important message for the general public – get tested.

A simple blood test (the Alpha-1 Antitrypsin Deficiency blood test) could explain why someone has been having trouble breathing, why they have a misdiagnosis of adult asthma or why their liver blood tests unexpectedly show high enzyme levels. Positive test results allow individuals to take protective measures (such as avoiding lung and liver irritants) as there is currently no affordable treatment in Australia or a cure for Alpha-1 antitrypsin deficiency.

In Australia it is common to have inherited a faulty Alpha-1 gene, with approximately 1 in 9 people affected but not aware. The risk starts in the liver where a mutated Alpha-1 gene does not make enough protective Alpha-1 protein, or the protein is the wrong shape and gets stuck in the liver so it can't travel via the blood to control inflammation or protect the lungs from damaging enzymes called proteases.

A key goal of our organisation is to raise awareness about Alpha-1 risk among the public, health professionals, politicians and with health officials. We have also raised concerns about Alpha-1 COVID-19 vulnerability with State / Territory and Federal Ministers for Health.

Let's look after our  
livers and lungs!



Stay away from smoke and fires.  
Eat and drink in moderation.

**November is Alpha-1 Awareness Month. Let's Spread  
the Word!**

Well, in case you hadn't realised, November is Alpha-1 Awareness month.

I know, almost every day/ week/ month seems to have a "theme" these days and they all compete for our time, money, and focus.

November is the month we can all contribute in our own small way to lifting the profile of Alpha-1, which in turn will lead to improvements in care, treatment, research and ultimately to a cure.

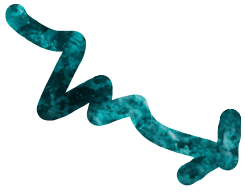
Here are seven small things you can do this month to help raise awareness. Try printing this list, sticking it on your fridge and crossing off the ones you do. If you do all seven in November, let us know and we'll draw a winner at the end of the month who will be sent one of our unique Alpha-1 tote bags.

1. Write a post on your social media page about Alpha-1 and the impact it has on you and your family
2. Invite all your friends to like our Facebook page [Alpha-1 Organisation Australia Inc](#)
3. Write a post in our Facebook group [Alpha-1 Organisation Australia Inc](#) This could be about anything relevant to the Alpha-1 community, a question you may have about Alpha-1, or even just a good joke to make people smile.
4. Print off one of the posters from the Resources section of our website [Alpha-1 Organisation Australia - Resources](#) and put it up in your GP's waiting room or at your local shopping centre.
5. Print copies of our fact sheets from our Resources page and place in your GP's surgery with their permission [Alpha-1 Organisation Australia - Resources](#)
6. Have a conversation with your friends and work colleagues about Alpha-1. Explain that it's genetic, that it can affect anyone, and that it causes lung and liver problems in most sufferers.
7. Have the same conversation with a stranger or your medical professional- someone you meet on the bus, train, the coffee shop, or doctor's waiting room. Go on! Be brave!

That's it!

Just seven easy things in thirty days! Good luck.

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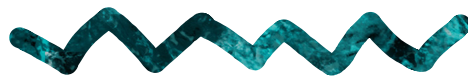


Alpha-1 Awareness month was an initiative of the US organisation, The Alpha-1 Foundation. The aim was to increase awareness of Alpha-1 Antitrypsin Deficiency and to hopefully raise funds to find a cure and improve the lives of those affected by this disease. The idea took off and we, The Alpha-1 Organisation Australia are right behind it.

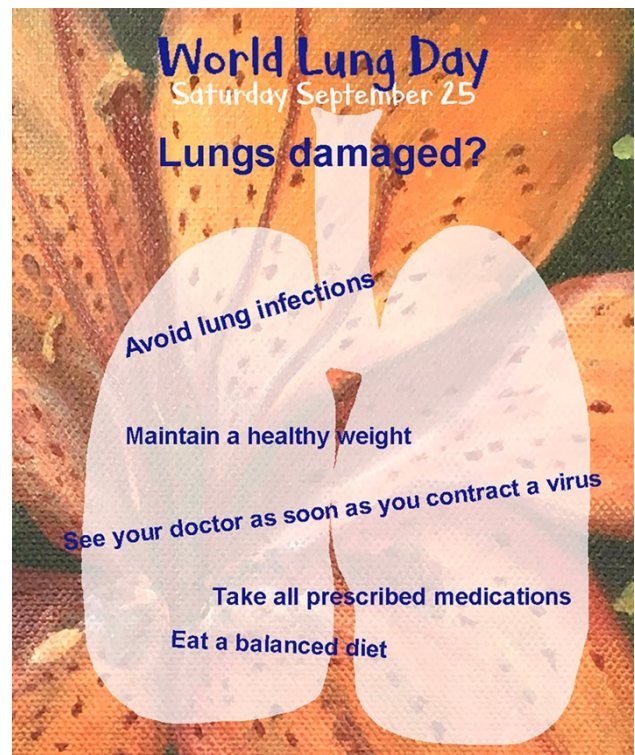
It is great to see television advertisements from the Lung Foundation being played as well.

Television advertising is something AIOA aspires to. We are applying for grants and starting to fundraise to achieve this and other awareness raising ideas.

What else can you do this month to help raise awareness? Encourage any friends with bad asthma or "adult-onset asthma" or unexplained emphysema or liver disease to get tested for Alpha-1.



Recently we celebrated World Lung Day • These are our posters



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## Celebrating Alpha-1 Awareness Month

### Just for Fun

We are running a quiz during November:

#### *Alpha-1 Awareness Month Quiz*

*Download or copy the questions. Answer as many as you can and email to [contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com)*

*Winner announced on Facebook and by email 30 Nov. Virtual trophy awarded to winner. In the event of more than one person with all answers correct, a winner will be drawn from a hat.*

1. What does AATD stand for?
2. What is the difference between AATD and A1AD?
3. Can you be a carrier of alpha-1 antitrypsin deficiency?
4. Is there only one gene that causes alpha-1 antitrypsin deficiency?
5. What bodily organs can be affected by alpha-1 antitrypsin deficiency?
6. Is there any treatment for alpha-1 antitrypsin deficiency?
7. Can children have alpha-1 antitrypsin deficiency?
8. What percentage of the population has alpha-1 antitrypsin deficiency?
9. What is the average length of time it takes to get diagnosed with alpha-1 antitrypsin deficiency?
10. What is the average life span of someone with alpha-1 antitrypsin deficiency?

**Quiz winner will  
be awarded  
this stylish virtual trophy**

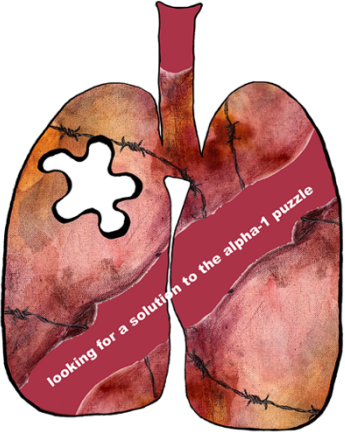


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To help raise awareness and create a focus on lung and liver health, Alpha-1 Organisation Australia has developed a series of posters for November.

**ALPHA-1 AWARENESS MONTH**  
How do your lungs feel?

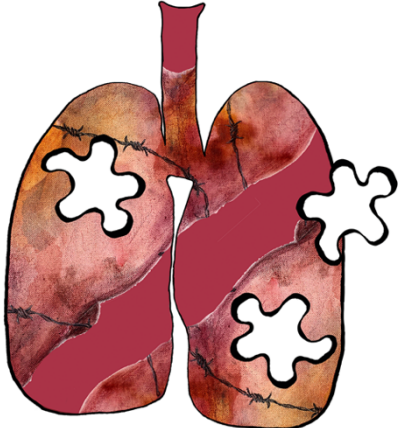


Feeling breathless? Have asthma, emphysema, lung problems?  
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, leading to lung damage. This is a common genetic disorder but very few are diagnosed.  
If this sounds like you or someone you know, visit our website, [www.a1oa.org.au](http://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](mailto:contactus.a1oa@gmail.com).

Alpha-1 Antitrypsin Deficiency Awareness Month

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**ALPHA-1 AWARENESS MONTH**  
Chest tight? Trouble breathing?

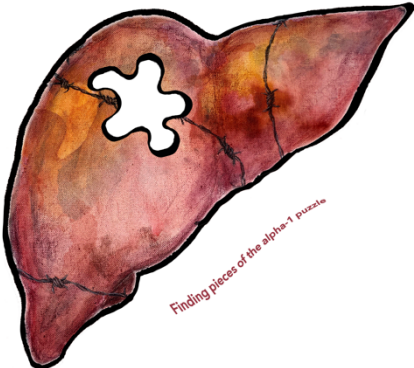


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If this sounds like you or someone you know, visit our website, [www.a1oa.org.au](http://www.a1oa.org.au), or our Facebook page or follow us on Instagram or Twitter, or contact the Alpha-1 Organisation Australia at [contactus.a1oa@gmail.com](mailto:contactus.a1oa@gmail.com).

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**ALPHA-1 AWARENESS MONTH**  
Is your liver okay?

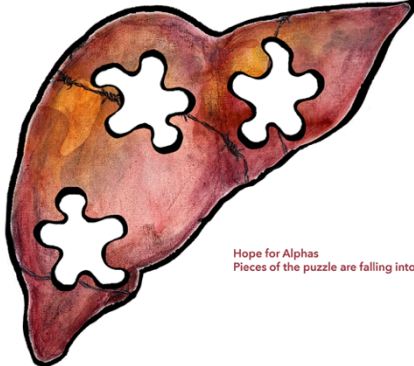


Do you or someone in your family have unexplained liver disease?  
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, which can lead to liver damage. This is a common genetic disorder but very few are diagnosed.  
If this sounds like you or someone you know, visit our website, [www.a1oa.org.au](http://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](mailto:contactus.a1oa@gmail.com).

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**ALPHA-1 AWARENESS MONTH**  
Unexplained nausea, itchiness, bloating?



Do you or someone in your family have unexplained liver disease?  
Over two million Australians are deficient in a protective protein called alpha-1 antitrypsin, which can lead to liver 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](http://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](mailto:contactus.a1oa@gmail.com).

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## **COVID-19 and Alpha-1 Antitrypsin Deficiency – Understanding the Risk**

Much has been speculated about the interaction between the Covid-19 virus and the potential implications for Alpha-1 patients. Our organisation has been reviewing international COVID-19 publications and conference presentations on the subject including: the theoretical risk of worse outcomes for Alpha-1 patients (7 papers); Alpha-1 studies (8 studies); genetic studies and risk (11 papers); and papers exploring the potential role of antitrypsin in COVID-19 recovery (12 studies).

Please note the summary below should not be taken as medical advice, and if you have any specific questions or concerns, your GP should always be your first point of contact.

The analysis presents this picture:

1. Lung conditions such as COPD/emphysema have been reported to contribute to more serious COVID-19 outcomes (e.g., hospitalisation / mortality), as do other issues including older age, and comorbidities like heart disease and diabetes.
2. Study designs and small PiZZ numbers don't support clear conclusions and more research is needed. Some COVID-19 studies suggest a greater susceptibility, higher rates of hospitalisation and higher death rate while other studies have not been able to prove an increase in susceptibility or mortality compared to the general population.
3. There are unproven hypotheses that vaccines for COVID-19 may be less effective in Alpha-1 patients, however the overwhelming advice is that Alpha-1 patients should be vaccinated unless specifically advised otherwise by their medical professionals. The COVID-19 Vaccine Taskforce has advised that at this stage it is not aware of any evidence to prove a lack of vaccine efficacy among individuals with Alpha-1.
4. Alpha-1 patients should continue to take all possible practical measures to avoid contracting covid 19, such as social distancing (particularly indoors), mask wearing where distancing is not possible (especially indoors), thorough handwashing with soap and water or an alcohol-based solution after external contact and remember to cover your nose and mouth with your bent elbow or a tissue when you cough or sneeze and stay home/get tested if you feel unwell.

We will continue to monitor research and share findings.

If you would like a printable copy of any of our posters for yourself or to display in your neighbourhood or doctor's surgery, see our Resources page on our website [Alpha-1 Organisation Australia - Resources](#) and download a copy.

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