

Alpha Times

Newsletter of Alpha-1 Organisation Australia inc

Issue 1 Spring 2020

From the President's Pen

It is such an exciting time to be able to launch a new Australian proactive charity and newsletter for alpha-1 antitrypsin deficiency. Our dedicated team of volunteers has been working hard during the last few months to establish Alpha-1 Organisation Australia Inc (A1OA), a not-for-profit charity supporting individuals and families affected by the genetic disorder, alpha-1 antitrypsin deficiency (A1AD). The launch of our website is very exciting. The website will be a great adjunct to information exchanged via our public and member only Facebook pages, and works in harmony with the information and support provided to members by our state coordinators.

We provide opportunities to learn about alpha-1 antitrypsin deficiency including website publications for the public, resources for members, Facebook discussions, Instagram information and Twitter messages.

In addition to supporting alphas, we are focused on raising our profile, strengthening our network and stakeholder connections, to leverage opportunities to improve the health and well-being of alphas. Reflecting one of our key aims, A1OA participated in its first piece of advocacy work last month making a submission to Government in support of Medicare funded genetic testing of A1AD. Other advocacy work will follow, including treatment advocacy.

Please consider the benefits of becoming a member through our website, www.a1oa.org.au. I look forward to chatting and learning about your needs and ensuring the A1OA is responsive and relevant.

All the best
Gaynor

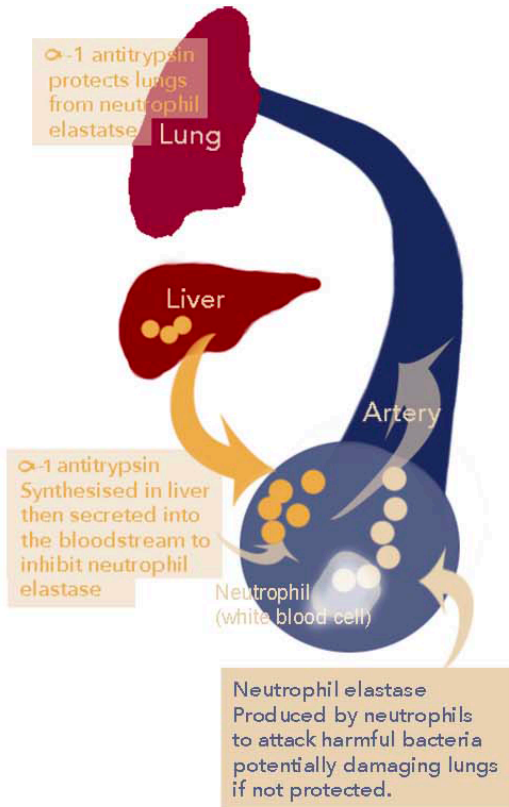
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Gaynor Heading PhD
President
Alpha-1 Organisation Australia inc

ALPHA-1
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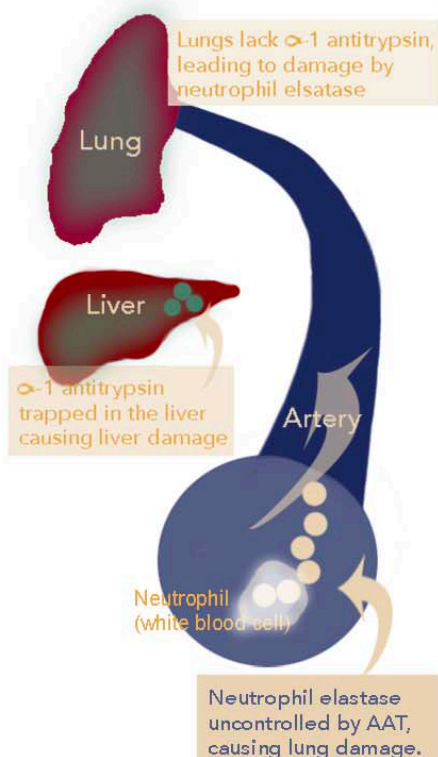


Alpha-1 antitrypsin in normal and deficient individuals

NORMAL AAT LEVEL



DEFICIENT AAT LEVEL



Staying Healthy

There is no way to prevent A1AD as it is inherited, however, while we wait for a cure, we need to protect our liver and lungs, minimize risk and try to delay liver and lung disease. Here are some tips for good health care:

- Have regular health checkups and tests as recommended by your doctor
- Avoid alcohol and smoking cigarettes and vaping
- Check your living and work environments for things that may irritate your lungs
- Avoid lung irritants such as dust, fumes, toxins, air pollution, second hand smoke, household chemicals and cleaners, allergens, pollen, wood-burning stoves, paint fumes
- Have the recommended vaccinations including flu, pneumococcal disease, hepatitis A and B
- Avoid “fatty liver” and keep a healthy weight
- Exercise regularly
- Manage stress
- Avoid sick people e.g. with colds and the flu
- Quickly treat lung infections with antibiotics to limit lung damage

Aunty Alpha

Q: Is alpha-1 antitrypsin a rare or common condition? I've heard it referred to as both.

A: Dear Ian, thanks for your question. This question often comes up amongst those of us with Alpha-1 as well as in the wider community. It can be considered as both rare and common, depending on the specific gene combination of a person.

To illustrate this, it is believed that the incidence of people with two Z genes (ZZ) in Australia is around 1 in 6,000, which would be classified as rare, while the incidence of people with one Z gene and one M ('normal') gene is estimated to be around 1 in 28, which would be classified as common. The picture is further complicated when other genetic combinations are included (150 known, e.g. SZ). Taking these into consideration there are over two and a half million Australians affected.

People with one deficient gene can be symptomatic so it is easy to understand how confusion arises!

Alpha-1 bodies around the world are beginning to use the phrase 'common, but rarely diagnosed' when referring to Alpha-1, and this perhaps best reflects its status here in Australia. It is highly likely that everyone knows someone with at least one deficient gene; but many GPs would say that they don't have a patient with it. So it's important to raise awareness of Alpha-1 across the community, and why the A1OA advocates for testing to ensure people get the most appropriate treatment as early as possible.

Have a question about Alpha-1 Antitrypsin deficiency?

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

An Alpha Story

Sandra Baxendell had been diagnosed with asthma and was on preventative puffers for over a decade but found her symptoms were getting progressively worse and she struggled with a persistent cough and croaky voice.

She saw a number of doctors and underwent various tests but was only diagnosed with alpha-1 antitrypsin deficiency after her sister was found to be an alpha.

Sandra's is a common story. Many alphas take years to be properly diagnosed and many are never diagnosed.



Did you Know

Alpha-1 antitrypsin deficiency (A1AD) is most often associated with chronic lung disease (e.g. early onset emphysema, bronchiectasis), and liver disease.

Liver disease is usually associated with the misshapen Z gene, from alpha-1 antitrypsin (AAT) becoming trapped in the liver increasing the risk of liver scarring. Trapped antitrypsin can't reach the lungs via the blood, increasing the risk of lung disease.

AAT protects the lungs by inhibiting neutrophil proteinases, but AAT has many other functions including anti-inflammatory and antiviral roles and keeps the body functioning optimally.

Currently there is no cure for A1AD, however, there are several new and emerging treatment options under clinical trial investigation for both lung and liver manifestations. This is very exciting as up until recently there was no talk of a cure, with liver and lung transplant being the only real treatments on offer. The current clinical trials focusing on liver and lungs, may deliver new treatments e.g. simple injections or tablets during the next five to ten years. Such therapies may slow disease progression, patch or correct the damaged genes.

These developments offer hope for everyone.

Member's Corner

Greetings and welcome to all our new members!

As a new charity, we have much to do and we are determined to make membership of Alpha-1 Organisation Australia a valuable experience for everyone. As such we have a dedicated Member Coordinator, currently Ian Saunders, who will work with State Coordinators to provide relevant and timely information for members throughout Australia.

We have Fact Sheets and Brochures, as well as a position paper, on topics associated with A1AD, which we make available for our members. We intend to hold online get-togethers, education sessions and ultimately face to face meetings in areas where numbers of members would make this viable. We have links to Alpha-1 organisations around the world and welcome the flow of information and advice to and from these.

Regular, quarterly newsletters will inform and support all members with news from around the globe regarding research and developments associated with AATD.

If you have any suggestions on how we can better support you, our members, please do not hesitate to get in touch at member.a1oa@gmail.com.