

Frequently Asked Questions about Alpha-1 Organisation Australia

Questions About Alpha-1 Organisation Australia (A1OA)

Q. What does the Alpha-1 Organisation Australia (A1OA) charity do?

A. The Alpha-1 Organisation Australia (A1OA) is a not-for-profit charity focused on helping and supporting individuals and their families affected by alpha-1 antitrypsin deficiency (alpha-1). Our strategic plan is available on our website. The Plan outlines the charity's vision, mission, values and our four main aims. Each aim contains a number of projects and activities related to patient support, community awareness raising, advocacy for treatment access and a cure, health professional education and knowledge building. A1OA is committed to improving and extending the lives of all Australian alphas through these activities.

Q. Why was A1OA started?

A. The A1OA charity was registered in June 2020 after the gap in support and advocacy was recognised by patients. The charity was formed by patients diagnosed with alpha-1 in recognition of the need for a well-governed, responsive, proactive charity to support patients and their families and to fight for treatment access and a cure.

Q. Who started A1OA?

A. A1OA was started by seven alpha-1 patients who made up the inaugural management committee (the Board). They recognised that much more needs to be done for alpha-1 patients and made it their mission to help all Australian alpha-1 patients.

Q. What makes A1OA special?

A. The A1OA is dedicated to alpha-1 and is registered with the Australian Charities for Not-for-Profits Commission (ACNC). The A1OA has a sound governance structure, a strategic plan, reporting mechanisms, policies, state coordinators in most states / territories to support members, and is making alpha-1 a household name through awareness raising, education and advocacy work. The A1OA provides scientific based information to ensure that the latest peer review research underpins our work. The management committee welcomes feedback and ideas and is proactive in seeking out suitable partners and grants to help it meet its charitable purpose. The A1OA provides advice to government and other peak groups.

Q. How does A1OA financially support itself?

A. The work of the A1OA is made possible through generous donations, sponsorship, grants, and membership fees. The management committee reviews the budget regularly, which

becomes a guide for the expenditure of funds against strategic priorities. If funds are allocated to a specific project, they are strictly used for that piece of work.

Q. Do you have to have alpha-1 to join?

A. You don't have to have alpha-1 to apply to become a member of A1OA. Anyone interested in alpha-1 antitrypsin deficiency can apply. Members have voting rights and pay a small annual fee of \$20. We have a variety of member categories including patient, family, carer, researcher, health professionals, community member, and organisation.

Q. I want to join the A1OA Charity. How do I join?

A. The easiest way to join is via our website – www.a1oa.org.au. Alternatively, you can make contact via email at contactus.a1oa@gmail.com.

Questions About Donations to A1OA

Q. Are donations tax deductible?

A. Yes, donations to the A1OA over \$2 are tax deductible. The A1OA is endorsed by the Australian Tax Office for: a) Charity Tax Concessions; and, b) Deductible Gift Recipient - DGR.

Q. Can I donate in honour of someone?

A. Yes, you can make a donation in honour of someone – to celebrate a birthday, or another special occasion, or in memory of someone. Such thoughtful gifts will make a difference to our cause.

Q. How can I update my donating details?

A. You can contact us at any time via email – contactus.a1oa@gmail.com.

Q. What does A1OA do with donations received?

A. We are a not-for-profit charity so all donations are used to support our organisation and its goals. We have very low running costs as volunteers work from home. We don't have any paid employees and we don't have paid board members. All donations are used to fund special projects and to run the charity.

Questions About Membership

Q. How much is the membership fee?

A. The annual membership fee is \$20.

Q. Is the membership fee tax deductible?

A. No unfortunately, but donations over \$2 are tax deductible.

Q. Is the membership fee payable annually?

A. Yes, it is an annual fee, renewable each year.

Q. How will I know when my membership is due for renewal?

A. You will receive a reminder from A1OA, sent to the contact details provided when joining.

Q. How can members become involved in A10A?

A. There are several ways to become involved. You can join in conversations on Facebook; or you can apply to volunteer by sending us a message by email - contactus.a1oa@gmail.com, following which we will be in touch to discuss opportunities; or, you can put in an expression of interest (with your resume/CV) against one of our vacancies / volunteer opportunities noted on our website. You can be involved as little or as much as you like, for example, assisting with a small task or a long-term activity or project.

If you apply to become a member you can vote at our AGMs and vote in our management committee. You can participate in other member only activities.

Q. How do I obtain support from a state coordinator?

A. Support from state coordinators is available to members diagnosed with alpha-1. When individuals apply to become a member, if they provide their home address, we will be able to assign a state coordinator. If a home address isn't provided, we will contact you by phone or email to find out about your interest in having contact with a state coordinator. You will be asked about which state/territory you live in. Then individuals will receive a welcome phone call from the state coordinator who will provide advice about activities that are on offer to members.