

Privacy Statement

Our privacy commitment

The Alpha-1 Organisation Australia (A1OA) is committed to protecting your privacy and personal information in accordance with legislation, the Australian Privacy Principles and our Privacy Policy.

This statement covers how we collect and treat your personal information.

If you have any queries relating to the A1OA's privacy policy or the manner in which we handle your personal information please contact us by email – contactus.a1oa@gmail.com.

What is personal information?

Personal information means information about someone who is reasonably identifiable, or an opinion, or an image of an identifiable individual. Personal information is a broad category which includes for example, individuals' names, addresses, contact details (e.g. phone or email address), date of birth, gender, photographs, videos, opinions - regardless of whether they are true or not. Personal information excludes de-identified and aggregated information. We will never use your personal information without your consent.

Whose personal information does the Alpha-1 Organisation Australia collect?

We collect personal information when individuals or organisations apply to be a member of A1OA, use our social media platforms, purchase merchandise, wish to volunteer, collaborate or partner with us, or provide funding or grants to assist our charitable purpose. We keep a register of members specifying the name and postal, residential or email address of each person who is a member of the association together with the date on which the person became a member.

A1OA collects personal information from people connected to its operations and activities including volunteers, members, donors / sponsors, research registers / research study participants, recipients of support services, participants in advocacy campaigns or health promotion projects, health professionals, suppliers and service providers.

If we hold your personal information, we do not use that information for a purpose other than that for which it was collected unless you have consented to use the information for that other purpose.

If purchasing merchandise using a credit card, we do not store your details.

How does the Alpha-1 Organisation Australia collect your personal information?

Where possible, A1OA will collect your personal information directly from you and you will be advised about the purpose for which the information is being collected. This may be when you apply to be a member of A1OA, request support by telephone or by email, sign-up or attend an event or video conference, purchase a retail product online, or if you answer a

research questionnaire.

When joining A1OA as a member, using our social media sites (e.g. Facebook, Instagram) or providing personal information via our website - when making a purchase for example, you are consenting to have personal information collected.

If we are involved in A1OA research projects, it will involve an ethics approval from an Australian Human Research Ethics Committee (HREC) which has additional obligations associated with it including written consent to collect and hold your personal information in secure locked databases with restricted access.

We may collect your personal information - with consent - for a patient research registry. You can only join a patient research registry with written consent. At the time of joining a patient research registry, you will have the option of limiting your data to Australian use or enable international use. Strict data storage and restricted access applies to patient research registry data. Your information will be used to invite you to join research studies.

If we undertake surveys related to service delivery (e.g. potential new services) or service evaluation, we may collect personal information, however, you will be advised when data collection is not de-identified.

We also obtain information from third parties such as contractors (e.g. assisting with fundraising). If we collect information about you from a third party and it is unclear whether you have given consent, you will be contacted to ensure that you are aware that we have your personal information.

Where is your personal information stored?

Personal information is held in password protected secure databases with restricted access. The A1OA may collect your personal information for a number of purposes including:

- Member support services
- Advocacy work
- Volunteering support to enable you to assist us with advocacy, projects, committees, working groups, fundraising and other activities where we seek community help
- Health promotion activities
- Education activities
- Research to support diagnosis, treatment, management and a cure
- Marketing to communicate with you about our services, products, donations, causes, campaigns, events and impact
- Other issues such as evaluating our support and services or to verify your identity, or to comply with relevant laws.

A1OA will securely delete your information from the Register of Members if you cancel your membership.

The A1OA will use your email address to send our newsletter and information about services. We will not 'spam' you email address.

Health information and sensitive information

As part of administering the A1OA we may collect health information (e.g. diagnosis or treatment) or other sensitive information (e.g. your views). If we do collect health or sensitive information, we will only collect it with your specific consent and if it is necessary for

research or service provision purposes. Data of this nature will be held in password protected, secure databases with restricted access.

We will never disclose your personal, sensitive or health information to any groups within Australia or overseas unless you have consented to be part of a patient research registry or research project. If publications result from any research, you will always be de-identified in line with research ethics.

You are free to provide any information you choose. However, if you do not provide some personal and contact information, your membership may not be possible under the A1OA constitution, you may not be able to receive some services and you may not be able to participate in research related activities.

Website usage and cookies

The A1OA website uses "cookies" to help you personalise your online experience. A cookie is a text file that is placed on your hard disk by a webpage server. Cookies cannot be used to run programs or deliver viruses to your computer. Cookies are uniquely assigned to you, and can only be read by a web server in the domain that issued the cookie to you.

One of the primary purposes of cookies is to provide a convenience feature to save you time. The purpose of a cookie is to tell the web server that you have returned to a specific page. For example, if you personalise A1OA pages, or register with the A1OA site or services, a cookie helps A1OA to recall your specific information on subsequent visits. This simplifies the process of recording your personal information, such as billing addresses, shipping addresses, and so on. When you return to the same A1OA website, the information you previously provided can be retrieved, so you can easily use the A1OA features that you customized.

You have the ability to accept or decline cookies. Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer. If you choose to decline cookies, you may not be able to fully experience the interactive features of the A1OA services or websites you visit.

Please see our [Website Terms of Use](#) for additional information.

Security of your personal information

A1OA secures your online and offline personal and donor information from unauthorized access, use or disclosure. A1OA secures the personally identifiable information you provide in a controlled, secure environment, protected from unauthorized access, use or disclosure.

Access to your data

A1OA members have a right of access to, and correction of, the information contained in the Register of Members which is open for inspection, free of charge. Any member of the organisation can obtain a copy of any part of the register on payment of a small fee (\$1 per page).

If you request that your personal information in the Register of Members should not be available for inspection, all personal information apart from your name will not be available for inspection by members. Members must not use information about a person obtained from the Register of Members to contact or send material to the person, other than for: a) the

purposes of sending the person a newsletter, a notice in respect of a meeting or other event relating to A1OA or other material relating to A1OA.

Members can make appropriate amendments to their personal information held by A1OA by contacting the secretary by email: secr.a1oa@gmail.com.

Disclosing information

The A1OA does not sell, rent or lease its customer or donor lists to third parties. The A1OA may, from time to time, contact you on behalf of external business partners about a particular offering that may be of interest to you. In those cases, your unique personally identifiable information (email, name, address, telephone number) is not transferred to the third party.

When using A1OA social media sites your username will be seen by other users. Please keep in mind that if you publicly disclose personally identifiable information or personally sensitive data through A1OA public message boards, it could be collected and used by others but will not be collected by the A1OA.

We may use de-identified, group information (i.e. no personally identifiable information) at times, for example, when reporting to regulators or to support funding / grant applications.

Contact information

You are welcome to contact us via email - secr.a1oa@gmail.com, to review the personal information we have collected and provide any corrections. The A1OA welcomes your comments regarding this privacy statement. If you believe that A1OA has not adhered to its privacy policy, please email us at contactus.a1oa@gmail.com. We will use reasonable efforts to promptly determine and remedy the problem.