



Angelman Syndrome Association Australia - Privacy policy

The Angelman syndrome Association Australia (ASAA) recognises the importance of protecting the privacy and the rights of individuals in relation to their Personal Information. This document is our Privacy Policy, and it explains how we collect and manage your Personal Information.

We respect your rights to privacy under the *Privacy Act 1988 (Cth)* (Act) and we comply with all of the Act's requirements in respect of the collection, management and disclosure of your Personal Information.

What is Personal Information?

When used in this Privacy Policy, the term "Personal Information" has the meaning given to it in the Act. In general terms, it is any information that can be used to personally identify you. This may include your name, address, telephone number, email address and profession or occupation. If the information we collect personally identifies you, or you are reasonably identifiable from it, the information will be considered Personal Information.

What Personal Information do we collect and hold?

We collect information from you when you register for membership. This includes your email address and additional demographic information as provided by you on the registration form.

This may also include information you provide when completing surveys, commenting on discussion forums or on the ASAA social media accounts.

We may also collect some information that is not Personal Information because it does not identify you or anyone else. For example, we may collect anonymous answers to surveys or aggregated information about how users use our website.

How do we use your Personal Information?

The main ways ASAA uses Personal Information are to:

- Advocate for people with Angelman syndrome and any related issues
- Engage directly with our Angelman syndrome community about local, state and national matters, and provide updates through our communication channels
- Provide aggregated non-identifiable data to inform submissions and/or publications on Angelman syndrome related matters
- Answer enquiries and resolve complaints.

When do we disclose Personal Information?

We will generally only disclose information for the primary purpose for which it was collected or a directly related secondary purpose where the individual would reasonably have expected us to use it for those purposes.

For other uses we will obtain consent from the affected person, unless the disclosure is required by law or the need for the disclosure (e.g. health & safety of individuals) outweighs the need for privacy.

Security

While no online service is completely secure, we work very hard to protect information about you against unauthorised access, use, alteration, or destruction, and take all reasonable measures to do so.

We take reasonable steps to ensure your Personal Information is protected from misuse and loss and from unauthorised access, modification, or disclosure. We may hold your information in either electronic or hard copy form. Personal information is destroyed or de-identified when no longer needed.

As our website is linked to the internet, and the internet is inherently insecure, we cannot provide any assurance regarding the security of transmission of information you communicate to us online. We also cannot guarantee that the information you supply will not be intercepted while being transmitted over the internet. Accordingly, any Personal Information or other information which you transmit to us online is transmitted at your own risk.

External links

Our website may contain links to other websites. Those links are provided for convenience and may not remain current or be maintained. We are not responsible for the privacy practices of linked websites, and we suggest you review the privacy policies of those websites before using them.

Requesting access or correcting your Personal Information

Subject to applicable local laws and regulations, you may have some or all of the following rights with respect to your personal data, to:

- Access your personal data and to rectify any inaccuracies within that personal data
- Request for the erasure of your personal data residing with us
- Request your personal data in portable, machine-readable format
- Withdraw your consent to our processing of their personal data.

If you wish to contact us with a request relating to Personal Information we hold about you, please contact us using the contact details set out below including your name and contact details.

We may need to verify your identity before providing you with your Personal Information.

In some cases, we may be unable to provide you with access to all your Personal Information and where this occurs, we will explain why. We will deal with all requests for access to Personal Information within a reasonable timeframe.

Contact us

For further information about our Privacy Policy and related information practices, or to access or correct your Personal Information, or make a complaint, please contact us at info@angelmansyndrome.org

Changes to our Privacy Policy

We may change this Privacy Policy from time to time. Any updated versions of this Privacy Policy will be posted on our website.

This Privacy Policy was last updated in November 2021.