



Privacy Statement

This statement (the “**Privacy Statement**”) sets out the basis on which any personal data we collect from you, or that you provide to us, will be processed by Angelman Syndrome Ireland Limited (“**Angelman Syndrome Ireland**”). By visiting the Angelman Syndrome Ireland website, you are accepting the terms of this Privacy Statement. This website contains external links to other websites and Angelman Syndrome Ireland is not responsible for the privacy policies of these other websites.

Angelman Syndrome Ireland fully respects your right to privacy, and will not collect any personal information about you on this website without your clear permission. Any personal information which you volunteer to Angelman Syndrome Ireland will be treated with the highest standards of security and confidentiality, strictly in accordance with the Data Protection Acts, 1988–2003 (the “**Act**”). For the purpose of the Act, the data controller is Angelman Syndrome Ireland Limited, a company limited by guarantee without a share capital registered in Ireland with company number 506106 and its registered address at Ecka House, Old Road, Tuam, Co. Galway

1. What type of information do we collect?

Angelman Syndrome Ireland may collect and process information and personal data about you when you register on our website, subscribe to our newsletter, fill out a form, make a donation, enter a competition or report a problem with our site. Such personal data may include personal details such as your name, e-mail address, postal address, phone number, as well as details regarding your personal experience of Angelman Syndrome as applicable. Any information which you provide in this way is not made available to any third parties, and is used by Angelman Syndrome Ireland only in line with the purpose for which you provided it, including in anonymised format for research and statistical purposes. Angelman Syndrome Ireland may also collect technical data about your visits to our site from time to time. Angelman Syndrome Ireland will make no attempt to identify individual visitors or to associate any technical details collected with any individual.

2. How do we protect your information?

Angelman Syndrome Ireland will take all reasonable precautions including strict security procedures to prevent the loss, misuse, alteration or unauthorised access to information you give us and will only use the data for the intended purpose. Agents or contractors of Angelman Syndrome Ireland who have access to information you give us in the course of providing services to us are required to keep that information confidential and are not permitted to use it for any purpose other than to carry out the services which they are performing for us. You should note however, that internet transmissions are never completely private or secure. Although we will do our best to protect your personal data, we cannot guarantee the security of your data transmitted to our site and any transmission is at your own risk. You hereby acknowledge and accept that we have no responsibility and shall accept no liability whatsoever for loss, injury or damage occasioned by the interception by third parties of your transmissions, or the disclosure of information including but not limited to credit card numbers by any party with whom you transact (including but not limited to any third party payment processors who may accept donations for the benefit of ASI), nor do we offer any guarantees, warranties or indemnities as to the security or otherwise of any information which you give us.

You acknowledge that the data that we collect from you may be transferred to, stored at and processed at a destination outside the European Economic Area (“EEA”). By submitting your personal data, you agree to this transfer, storing or processing.

3. What do we use your information for?

Angelman Syndrome Ireland may use information held about you in the following ways:

- To ensure that content from our site is presented in the most effective manner for you and for your computer. And to improve our website based on the information and feedback which we receive from you.
- To provide you with information, products or services that you request from us or which we feel may interest you, where you have consented to be contacted for such purposes.
- To carry out our obligations arising from any contracts entered into between you and us, for example to process your registration for an event online and to send you periodic emails relating to our activities.

- To allow you to participate in interactive features of our service, when you choose to do so.
- To notify you about changes to our service.

If at any time you would like to unsubscribe from receiving future emails, please respond to any email with the word “unsubscribe”.

4. Do we disclose any information to outside parties?

We do not disclose information about identifiable individuals, but we may use aggregate anonymised information about our users to advance our objects of raising awareness of Angelman Syndrome Ireland. We do not sell, trade, or otherwise transfer your personally identifiable information to third parties. This does not include trusted third parties who assist us in operating our website, processing transactions, conducting our activities in furtherance of our charitable purposes, or servicing you, so long as those parties agree to keep this information confidential. We may also disclose your personal information to third parties if we are under a duty to disclose or share your personal data in order to comply with any legal obligation. Non-personally identifiable visitor information may be provided to other parties for marketing, advocacy, research or other uses. Our site may, from time to time, contain links to and from the websites of our partner networks and affiliates. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we do not accept any responsibility or liability for these policies. Please check these policies before you submit any personal data to these websites.

5. How can you access information which we hold about you?

If you have given us information about yourself and would like copies of that information, or you would like us to correct any factual inaccuracies in that information, or if you would like that information deleted from our records, then please contact us at Ecka House, Old Road, Tuam, Co. Galway or admin@angelmansyndrome.ie. You should include any personal identifiers which you supplied earlier via the website such as your name, address, phone number, email address etc. We will use reasonable efforts to supply, correct or delete information about you on our files in accordance with law. We are entitled to charge you a fee for supplying you with copies of information which we hold.

6. And if you have any more questions?

If you have any questions regarding this policy or if you are concerned about how personal data is processed via this website, please do not hesitate to bring such concerns to the attention of Angelman Syndrome Ireland at Ecka House, Old Road, Tuam, Co. Galway or by email to admin@angelmansyndrome.ie. Any changes we may make to our privacy policy in the future will be posted on this page.