

FAQ – Angelman syndrome Online Registry

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Website with all information and material:

<https://www.uniklinikum-leipzig.de/einrichtungen/humangenetik/forschung/angelman-syndrom>

Registry-Link:

<https://redcap.medizin.uni-leipzig.de/redcap/surveys/?s=LFPNK8FPR7>

Why should I join the registry?

The aims of the registration are to establish a registry for children and adults with Angelman Syndrome, to better understand genotype-phenotype correlations and finally to improve patient care.

Who can participate?

This registry is open to parents AND caregivers/clinicians of individuals with a genetically confirmed diagnosis of Angelman Syndrome. There is no age restriction.

How do I register?

Click “Entry Angelman syndrome Online Registry”. Thereafter, please answer a few basic questions on consent and personal information, including your email address.

What questions are being asked in the registry?

Once you have completed the consent section you will be taken through a series of modules on genetic or clinical aspect of the individual’s disorder. A PDF with all questions being asked for in the registry is found on our website (see above). We suggest to have relevant reports at hand.

How much time do I need to go through the registering process?

You will need approximately one hour to complete the questionnaire. However, this time very much depends on how much detail you are able and willing to answer the questions.

You can interrupt this process at any time and continue/correct later on by using the button “Save & Return Later”.

How can I return to my entered data?

You can pause entering your data at any time by using the “Save & Return Later” button. For returning please notice the Return-Code, enter your e-mail address and use the Return-Code and the link sent to your e-mail address. You can change, delete, complete etc. your answers at any time.

What happens if I am unable to answer any of the questions?

We welcome you to fill in the questionnaire as detailed as you can and wish. If, however, you are hesitant in answering particular questions,

- You can always leave this answer blank.
- You can always send us an e-mail and ask (Angelman@medizin.uni-leipzig.de). Feedback is very welcome!
- You can always upload reports, documents, files instead of (or in addition to) answering a question.
- You can always ask the treating physician for help.

Is my information secure?

All information we receive from you will be treated confidentially according to the European General Data Protection Regulation (GDPR) and will be stored on a secured local server. Only pseudonymized data will be processed or published. The study has been approved by the Ethics Committee of the University of Leipzig, Germany (reference number 265/19-ek).

Will I be contacted in case of a suitable clinical trial for Angelman syndrome?

If third parties are approaching the Angelman syndrome Online Registry in order to recruit individuals for a clinical trial, we will inform you in case you have previously agreed to be re-contacted and if your entry matches the respective inclusion criteria. The choice of participation in potential clinical trials will entirely be up to you. We will not forward your contact details to third parties without your explicit consent.

Where can I get additional information about the registry?

Further information is available in the study information on our website. These documents describe the purpose of the study and how data is collected, stored and used. It is important that you read and understand this information before you decide whether or not to participate in the registry. If you have any additional questions, don't hesitate to contact us: Angelman@medizin.uni-leipzig.de.

We would be very thankful for your participation in our research project!