Research Interview about Angelman Syndrome

Does your child have Angelman Syndrome?

We invite you to share your experience of caring for your child with AS and help us better understand how Angelman Syndrome affects the daily life of your child by taking part in a research interview.

About the Interviews
Research interviews are being conducted with primary caregivers of children (age 2 and older) and adults with Angelman Syndrome. This is a non-medication research interview study seeking information about symptoms and effects on daily life that children with Angelman Syndrome experience, from the caregiver’s perspective. Information from these interviews will be used to better understand how to assess potential benefits of treatments in upcoming clinical studies of Angelman Syndrome.

All interviews will be conducted by researchers from Evidera. Evidera will contact potential participants to determine eligibility. Eligible participants will be scheduled for a 60-90 minute telephone interview at a time convenient for the participant. Prior to the interview, the participant will receive a packet via FedEx with an informed consent form explaining the purpose of the study, the study procedures and how the findings will be used, as well as a brief sociodemographic questionnaire.

Eligible participants must agree to an audio-recorded interview, for transcription purposes to ensure accurate and thorough data collection. All interviews will be completely confidential, and only summary results will be shared with the study sponsor.

No compensation will be offered to eligible participants.

The study will enroll up to 30 caregivers of people with Angelman Syndrome across approximately three countries (United States, and for example the Netherlands).

If you are interested in participating in this study, please send an email to Evidera at ASinterview@evidera.com. Please do not include any personal medical information in the email, only your contact information, thank you.