

Introducing a new clinical research study for Angelman Syndrome

This flyer provides more information about a new clinical research study called The Angelman Syndrome Cerebrospinal Fluid Study (also known as the AS CSF Study) for people with Angelman syndrome or dup15q syndrome.

About the AS CSF Study

As you may know, there are currently no disease modifying treatments approved for AS. Improving the understanding of AS is a very important step in the future drug development process, and AS families are at the center of our efforts. The AS CSF Study is designed to help learn more about AS and to help find potential biomarkers for use in AS clinical trials in the future. Biomarkers are substances, for example proteins, occurring in the body that can change as a result of disease or treatments and can be found in your blood, spinal fluid, and tissue. The AS CSF Study aims to find potential biomarkers that can be measured in the cerebrospinal fluid (CSF), which is the fluid surrounding the brain and spinal cord. Measurement of such biomarkers in AS patients may help guide future disease modifying drug development. Participants in this study will not receive an investigational drug.

What will happen during the study?

During the study, the trained study team professionals will collect CSF (through a procedure called a lumbar puncture) in addition to blood samples from the study participant while they are sedated for an already planned medical procedure.

Study participants will be in the study for up to approximately 33 days and take part in the following activities:

- Screening visit (1 day conducted up to 30 days prior to the sampling visit)
- Sampling visit to collect CSF and blood (1 day)
- Follow-up contact (72 hours after Sampling Visit)

As safety is our highest priority, study participants will be assessed and monitored at the study site and during the follow-up contact.

What else should I know?

If you choose to allow the person you care for to take part in this study, all study-related assessments will be provided at no cost. You may be eligible to receive a stipend for certain study visits on behalf of the person you represent for the time and effort associated with his or her participation in this study including travel expenses related to the study visits. However, please remember that participation is voluntary, and you will be able to withdraw the person you represent from the study at any point without penalty.

If you think you might be interested in the AS CSF study, or would like more information, please call us for an initial no-obligation consultation.

[Study Investigator's Name]

[Contact Details]

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