

About clinical research studies

Clinical studies like this one help researchers learn more about medical conditions and develop new ways to treat them.

There is no individual benefit expected for you or the participant from taking part in this study.

Joining this study is a choice to be made by you and the participant. You can change your mind and leave the study at any time.

Find out more

Please contact us to learn more about our study.

A doctor or nurse will answer questions and tell you what comes next if you want to join.

Thank you for your interest.

((site contact information to appear here))

Study BP40654

Angelman Syndrome Endpoint Study

The experiences of individuals with Angelman Syndrome (AS), their parents and caregivers can help guide future research.

Please consider joining our non-drug study.

Who can take part?


We are looking for 40 children and 10 adults with Angelman Syndrome (AS) and 20 typically developing children to participate in this clinical research study. The parent or caregiver must be willing to have an active role in the study by providing information, attending appointments, and completing activities at home.




Reason for the study

This non-drug study will help to prepare for future drug trials in AS. We want to find ways to measure the impact of this syndrome in the home and clinic (endpoints) and to use new technologies to learn about it.

Roche, as a sponsor of this study, collaborated with families, patient organizations, physicians and the Angelman Syndrome Biomarker and Outcome Measure Consortium (ABOM) to identify areas in which parents or caregivers would like to see improvement. In this study, we will measure these areas:

 Expressive communication

 Independence and self-care

 Maladaptive behaviors

 Sleep

 Fine & gross motor skills

 Seizures

 Cognition

What to expect of you join

The study will include 2 clinic visits. It will last about 12 months and will include measurements, questionnaires and mainly non-invasive tests. Some of the questionnaires can be completed at home to reduce clinic time.

There will be 3 home visits during the study to set up an electroencephalogram (EEG) and camera to monitor the participant's sleep and brain activity overnight.

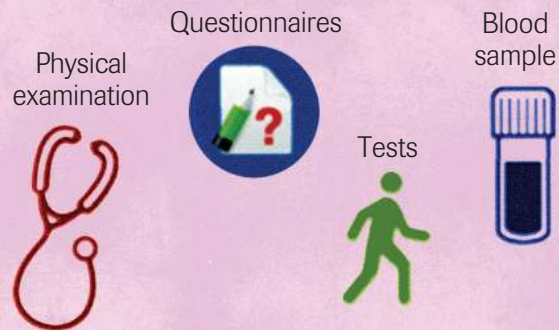
You will be reimbursed for your travel expenses.

All study-related assessments will be provided at no cost.

Study Visits and Activities

approximately 12 months

Start of Study Clinic Visit



Study Procedures at Home Daily



End of Study Clinic Visit

