

## Angelman Syndrome- Remote Video Capture Study

Casimir, a clinical research organization specializing in incorporating patient-reported data into clinical trials, Boston Children's Hospital, and Ionis Pharmaceuticals are in the process of developing an at-home assessment for potential use in clinical trials that would capture patients with Angelman syndrome (AS) in their everyday environment. To date, the outcome measures used in clinical trials for AS patients have focused mostly on in-clinic assessments.

Casimir is currently seeking participants for a pilot study that they are running to assess the feasibility of the at-home assessment. The intention of the study is to test the instructions, selected activities, and acceptability of the Angelman Syndrome Video Assessment. **The study does not involve any experimental drugs.**

Patients and their caregivers together may be compensated up to \$100 for their time spent participating in the study.

### Eligible Participants:

- English-speaking
- Patients (of any age) living with AS and their caregivers, who together are willing to record videos of activities of daily-living using a smartphone or Wi-Fi-enabled device.

### What will happen during the study?

- 2 Scheduled Phone Calls:



Phone Call #1- "Screening and Training Call", approximately 1 hour

Phone Call #2- "Exit Interview", approximately 30 minutes to 1 hour

- Video Recordings:



Caregivers will be asked to record videos of their child performing activities of everyday life (i.e. walking, climbing the stairs, getting up from a chair, etc.).

## Interested in participating?

Call or text (800) 699-2704 or email [ASVA@casimirtrials.com](mailto:ASVA@casimirtrials.com). Or ask your health care provider for a referral.