A Novel Method to Study Natural History in Angelman Syndrome: Use of Home-Based Video Recordings

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The Angelman Syndrome Natural History Study has been collecting longitudinal developmental data using standard developmental instruments and inquiring about developmental milestones since 2006. However, we have found that participants were not always performing at their best in the hospital environment due to situational anxiety or lack of interest in the tasks required of them in the developmental assessments. Hence, there is a need to develop a different approach to capture developmental skills of children and adults with Angelman Syndrome (AS) that would provide a more accurate representation of their developmental skills in their natural environment.

The overall goal of this observational study is to use home-based video recordings as a method for assessing gross motor, fine motor, and communication skills in individuals with AS. Participants are recruited through the Angelman Syndrome Natural History Study. Once enrolled, caregivers use a HIPAA compliant app on a smartphone or iPad to film the participant engaging in different tasks such as maneuver in their home environment, self-feeding during mealtime, and their typical method of communicating (using AAC devices, signs, gestures, or words). The caregivers film and upload video recordings every three months to track how these behaviors change longitudinally. This will allow us to capture behaviors in individuals with AS as demonstrated in their natural environments and to explore the feasibility of using home-based video recordings as a tool for studying the natural history of AS.

We will present preliminary data on our analysis of the participant’s levels of functioning in their gross motor, fine motor, and communication domains.