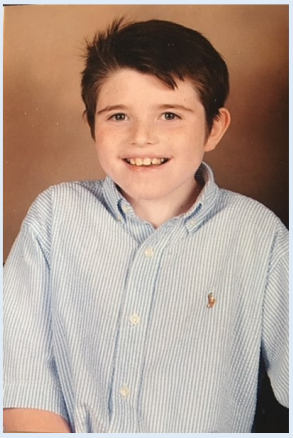
Angelman Syndrome
Natural History Study

Nov. 2020, Vol 1

STUDY NEWSLETTER

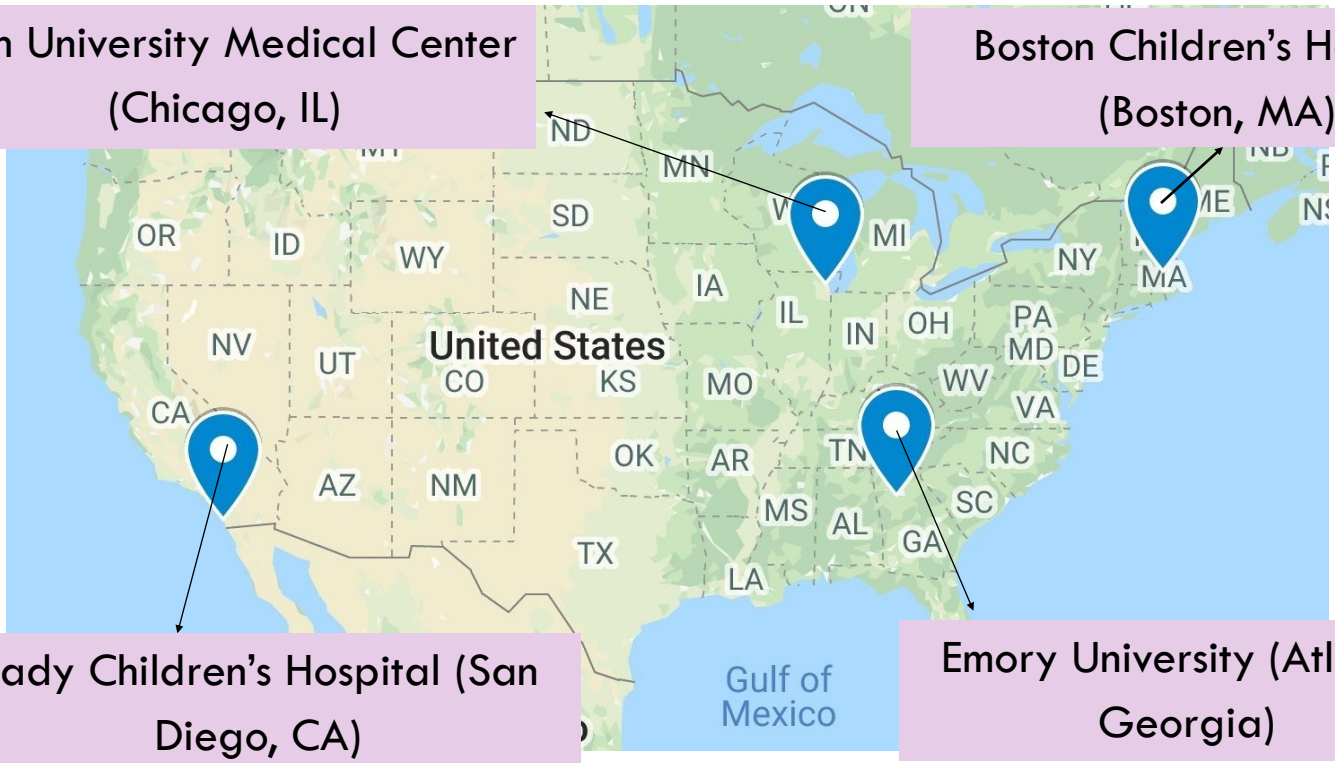




Help improve our understanding of how development, behavior, and communication change in individuals with Angelman syndrome over time. For detailed information about the study, visit https://www.angelman.org/studies/angelman-syndrome-natural-history-study/

Current Study Sites

Rush University Medical Center (Chicago, IL)

Boston Children's Hospital (Boston, MA)



Rady Children's Hospital (San Diego, CA)

Emory University (Atlanta, Georgia)

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Introduction

This is an FDA-funded, multi-site study that collects longitudinal data to understand the natural progression of Angelman syndrome over time. Participation would involve yearly visits to one of our study sites.

We are excited to launch our first study newsletter and hope to provide you with study developments on a regular basis.

Exciting Updates

- As of November 18, 2020 we have 94 participants enrolled across all sites.
- We welcome Emory University to the list of activated sites.
- In light of COVID-19, we have been conducting virtual study visits. We are also happy to report that all current study sites are open and ready to resume in-person visits. We can't wait to see you!
- Please find our contact info below and schedule your visit today.

Study Team Spotlight

Name & Role: Wen-Hann Tan, Principal Investigator

Site: Boston Children's Hospital

What you'd like us to know: I am a clinical investigator who has been actively involved in the Angelman community since 2006, and in addition to my role as the PI on the Natural History study, I am also the site PI of the clinical trials sponsored by Ovid and a co-investigator in the ASO therapy trial sponsored by GeneTx. I am also involved in the Bohring-Opitz syndrome community and co-developed a patient registry for individuals with ASXL disorders.

Contact Us

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