



#### Participants needed for:

# ASH1L Natural History Study

## What is this study about?

We want to learn more about children and adults diagnosed with ASH1L Deficiency Disorder and their medical, neurological, and behavioral symptoms. We want to see how these symptoms change or progress over time.

### What does participation involve?

We will get the participant's medical, family, and developmental history through a series of interviews. We will ask permission to obtain previous medical records and to collect a small amount of blood. We will conduct a neurological exam and an EEG. A neuropsychologist will also ask the participant to complete some assessments. Lastly, our team will follow up annually to discuss any changes for up to five years.

#### Who do I contact?

Please contact the Principal Investigator, Judy Liu, MD, PhD and the research team at ASH1Lstudy@Lifespan.org or at (401)432-1608.

# What are the costs of participating?

Travel and accommodation costs will be paid for by the study sponsor.