

Baby Talk in TSC study

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Why Early Vocal Development (aka 'Baby Talk')

Language deficits impact many of individuals with TSC, yet little is known about how language develops in this population.

Early diagnosis of TSC presents an opportunity to study language development from the early days of life.

Background

Tuberous sclerosis complex (TSC) is associated with a 50% risk of autism spectrum disorder (ASD).

However, there is no clear way to determine which children will develop ASD despite the high risk.

TSC is also associated with a 90% risk of epilepsy.

Early detection of ASD given these risk factors and the availability of targeted medications is important; however, there are no early indicators for ASD in TSC that are used clinically.



Why is this study being conducted?

The overarching goal is to assess the use of early language as an indicator for the development of Autism Spectrum Disorder ASD and/or speech/language disorders in children with TSC.

Who can participate in the Baby Talk in TSC study?

- Babies ages 0-36 months old
- English-speaking
- Patients can have a TSC diagnosis, at risk for other developmental disorders, and those without any known developmental risk



Where is the study being done?

- Le Bonheur Children's Hospital located in Memphis, TN.
- All study visits are being conducted in-person.



What will study participation involve?

Patients can be enrolled in the study at any age point between 0-36 months old.

In-person TAND clinic evaluations at Baseline, 9, 12, 18, 24, 30, and 36 months of age

Video recordings of speech and language tests

Video recordings of natural parent-child interactions

Neurodevelopmental tests

Parent questionnaires

LENA Home Recordings

LENA Home Recording Device

LENA Home Recordings will be conducted at 9, 12, 18 and 24 months of age.

The recordings are obtained by placing a soft vest containing a small recording device on the child as indicated in the photo.

The patient will wear the LENA device for one full day at each age point.

The recordings are being collected to analyze the baby's speech.



Interested in participating?

Contact the Study coordinators:

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Questions?