STUDY OPPORTUNITY

MED13L Syndrome

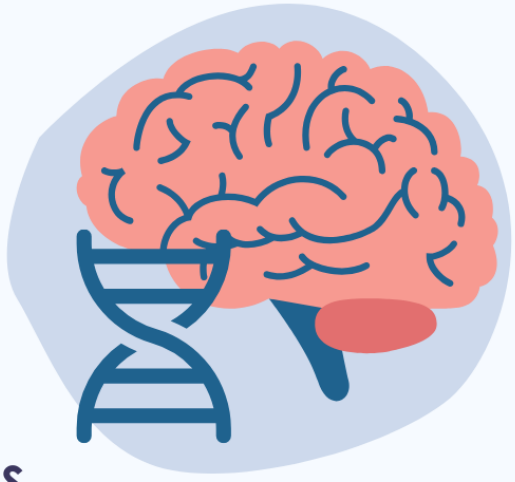
THE MED13L FOUNDATION

ROSAMUND STONE ZANDER TRANSLATIONAL NEUROSCIENCE CENTER

Boston Children's Hospital

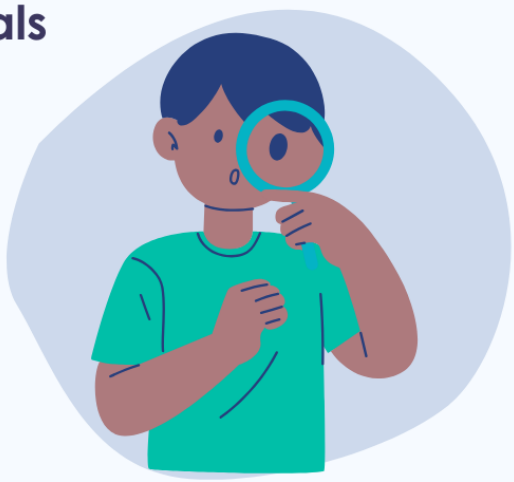
HARVARD MEDICAL SCHOOL TEACHING HOSPITAL

NATURAL HISTORY STUDY
OF INDIVIDUALS WITH MED13L Syndrome



GOALS

- Better understand NDDs
  - Symptoms
  - Specific genetic changes
- Identify ways to measure success of future treatment trials



There is no direct benefit to participating in this research study

ELIGIBILITY

- Individuals of all ages
- Individuals with a gene change in the *MED13L* gene

WHAT'S INVOLVED

- 3 annual visits with the study team (in-person, at 2025 MED13L Family Meetup, or virtual)
- Questionnaires
- Sharing medical records
- Neurobehavioral assessments

This research is being conducted by
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To learn more or participate, please contact **Abigail Sveden, MS, CGC**
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