murdoch children's research institute

geneticsofspeech.org.au

Translational Centre for Speech Disorders
Centre of Research Excellence

Speech Tracker: Research into speech, language, and non-verbal communication development over time in individuals with *SETBP1* variants

This study builds on our previous research showing that speech and language is a core developmental challenge for children with *SETBP1* haploinsuffiency disorder (or having a *SETBP1* loss of function variant) (Morgan et al., 2021 European Journal of Human Genetics).

In this new study, we are studying communication development **over time**. This data will help us better understand prognosis and will help us develop more targeted speech therapies.

We are looking for individuals:

- Confirmed to have a *SETBP1* loss of function variant or *SETBP1* haploinsufficiency disorder by a genetic test
- Aged 6 months to adulthood
- Who are verbal or non-verbal
- who speak English, German, Dutch, Italian, French, Portuguese, Spanish

What is involved?

- Enrol using the QR code → or email us at: speechtracker@mcri.edu.au
- Completing brief online surveys of language skills once a year
- Completing quick 15 minute speech tasks from home 2 times a year

About us

The Translational Centre of Research Excellence for Speech Disorders examines speech and language in individuals with rare genetic conditions.

We are trying to better understand the strengths and difficulties of communication in children with rare genetic syndromes. Our longer-term aim is to help develop better targeted therapies.

GET IN TOUCH!

If you or someone you know may be interested in helping with this research, we would love to hear from you. Contact us at:

speechtracker@mcri.edu.au

Translational Centre for Speech Disorders
Murdoch Children's Research Institute
50 Flemington Road, Parkville VIC 3052
geneticsofspeech@mcri.edu.au

This project has been approved by the Royal Children's Hospital Human Research Ethics Committee (RCH HREC Reference Number 37353)