murdoch children's research institute

Speech Tracker: Research into speech & language development over time in individuals with *SETBP1* variants

Would you be willing to take part in our project?

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

In this new study, we are examining speech & language 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 - adulthood
- who are verbal or non-verbal
- who speak English, German, Dutch, Italian, French, Portugese, Spanish

What is involved?

- Emailing us to express interest at: speechtracker@mcri.edu.au
- Completing brief online surveys of language skills once a year (families who have taken part in our previous research may have already completed some of the required surveys, and these can be reused for this study)
- Completing a quick 15 minute speech task from home 3 times a year

Centre of Research Excellence in Speech and Language

About us

The Centre of Research Excellence in Speech and Language 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, either by writing to Prof Angela Morgan (angela.morgan@mcri.edu.au) or to our general email below!

Email:
speechtracker@mcri.edu.au

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