

Research into speech & language skills in individuals with a SETBP1 loss of function variant: an international study

Would you be willing to take part in our project?

We are running a project looking at speech & language in individuals with a SETBP1 loss of function variants.

By improving our understanding of speech & language abilities, we hope to improve prognoses, better identify individuals in need of speech therapy and to develop more targeted speech therapies.

We are looking for individuals:

- confirmed to have a SETBP1 loss of function variant 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: angela.morgan@mcri.edu.au
- Completing an online survey of speech & language skills, survey of health & medical history, provision of an online speech sample where individuals are able
- English-speakers will also be assessed via videoconference



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 undersand 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 is interested in helping with other aspects of this research (ie speech & language in other genetic conditions) we would love to hear from you, by writing to:

- Email:
- geneticsofspeech@mcri.edu.au