



## Research into speech & language skills in individuals with Schnitzel Giedion Syndrome (*SETBP1* gain of function variants): 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 Schinzel Giedion Syndrome. By improving our understanding of speech & language abilities in these children, we hope to improve prognoses, better identify individuals in need of speech therapy and develop more targeted therapies.

### We are looking for individuals:

- confirmed to have Schinzel Giedion by a genetic test
- Older than 6 months
- who are verbal or non-verbal
- who speak English, French, Dutch, Italian, German, Portugese, Spanish

### What is involved?

- Emailing us to express interest at: [angela.morgan@mcri.edu.au](mailto:angela.morgan@mcri.edu.au)
- Completing an online survey of speech & language skills, survey of health & medical history, provision of an online speech sample, or video examples of communication, where individuals are able.



## 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 Angela ([angela.morgan@mcri.edu.au](mailto:angela.morgan@mcri.edu.au))