



### October 2021: Issue 1

## **The Monthly Newsletter**

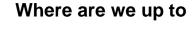
# **GeneEQUAL**



GeneEQUAL will make genetic health care better for people with learning and intellectual disabilities.



We want to hear from you!





 The study has ethics approval to start across NSW.



- A committee was formed with:
- Our team,
- NSW Department of Health
- Doctors
- Researchers
- Advocates and self-advocates with intellectual disabilities



- 5 people have been interviewed by Iva and Julie
- We want to talk to 15 more people









#### What we are learning together

- People want to connect with other people with the same condition.
- People want more help getting support through the NDIS.
- · Genetic testing can be difficult.
- It needs to be explained carefully.
- Lots of support is needed so people feel safe and happy.

### WHO Can join GeneEQUAL?

- Adults (aged 18 years or older) who:
- Have learning and intellectual disabilities
- Live in NSW
- And ever had a genetic test or talked to a genetics team.
- It is ok if the genetic test was a long time ago, like when they were a child.







Want to have your voice heard?

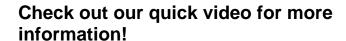
Please contact Iva and Julie and they can tell you more!



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"You need to have a group where we can all sit down and talk, and we work out our own problems.

Not have someone else work our problems out, because I can tell you now, we don't listen to what people think.

It's what we know, what we're going through, and how we can deal with."

