

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!

Where are we up to



- 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!



i.strnadova@unsw.edu.au

Mobile phone: 0426 959 172



Check out our quick video for more information!



“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.”

