

HAPPY HOLIDAYS!

Thank you for your interest and contribution over the past year!



December 2021: Issue 2 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 Ministry of Health
- Doctors
- Researchers
- Advocates and self-advocates with intellectual disabilities





- 9 people have been interviewed by Iva and Julie
- We want to talk to 11 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.
- Genetic testing information should be shared directly to people.



WHO can join GeneEQUAL?



People who:

- have learning and intellectual disabilities
- live in NSW
- had a genetic test or talked to a genetics team recently
- had a genetic test or talked to a genetics team 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!
- Email: 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.”

SEE YOU IN THE
NEW YEAR!

