HAPPY NEW YEAR!









January 2022: Issue 3 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



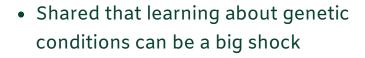
- 12 people have been interviewed by Iva and Julie
- We want to talk to 8 more people



We had an Advisory Workshop in November.



People in the workshop:





 Thought it was important that counselling to talk about feelings is available



 Mentioned some problems with NDIS



 Said doctors and genetic counsellors need to know how to check in with people



 Suggested that people need help to prepare for seeing a genetic doctor



 Agreed that genetic research is important

We will have another Advisory Workshop in February.



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

"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."