

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:



- Shared that learning about genetic conditions can be a big shock



- 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.”