Part 2

At my genetic appointment

Social stories about genetic appointments

For young people with intellectual disability

Visiting the genetic clinic.

A genetic clinic is where people can learn more about their genes, genetic tests and genetic conditions.

The appointment may take about 1 hour.

The doctors and genetic counsellors are great at explaining what genes, genetic tests and genetic conditions are.

I can decide if I want to want to find out about my genes.

Who will come with me?

My parents or someone I trust will come with me to my appointment.

They can support me to remember what we talk about.

I can bring my favourite object with me to help me feel calm.

For example, a sensory object or my iPad.

What will happen at the appointment?

The doctor or genetic counsellor will ask me questions.

My answers will help them to understand me and my health better.

I will answer the questions if I feel comfortable.

It is ok if I do not know all the answers.

Understanding what genetic tests are.

The people working at the clinic will explain what the genetic test is, I can ask them to talk slowly.

I can ask them to tell me what the hard words mean.

I can ask them to show me pictures to support my understanding.

I can ask questions if I am not sure about something.

I can ask questions if I want to know more.

Having the test done is my choice.

The doctor or genetic counsellor will tell me if there is a test that is right for me.

If there is, the doctor or genetic counsellor will ask me if I want the test.

They will tell me if it is a blood test or spit test.

I can talk to my parents to decide if I want the test or not.

I can say yes if I want to have the test.

I can say no if I do not want to have the test.

At the end of the appointment.

If I decide to have the test, the doctor or genetic counsellor will explain what will happen next.

They will tell me when I need to come back.

It is important to ask any questions I may have.

I can also call the doctor or genetic counsellor after the appointment to ask questions.

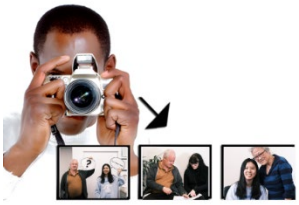
My parents or someone I trust can also call with questions after the appointment.

Who made this story

The **GeneEQUAL** team made this story.

GeneEQUAL is a program to support people with intellectual disability

- get better health care.



GeneEQUAL did not do it alone.

We did a photoshoot with people from **Self Advocacy Sydney.**

Self Advocacy Sydney is a disability advocacy organization.

They support people with intellectual disability to

- speak up
- understand their rights
- make decisions.

These people are in the photos.

1. Shu Hua Chan
2. Amy Nguyen
3. Maaz Abogodah

4. Genevieve Rodriguez
5. Paul Jarnet
6. Roslyn Gear
7. Frankie Guerreiro

8. Skie Sarfaraz
9. Julie Loblinzk Refalo OAM

Julie and Skie are also part of the GeneEQUAL team.

For more information and resources visit:

www.geneequal.com

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