Part 3

After my genetic appointment

Social stories about genetic appointments

For young people with intellectual disability

The results are ready.

The doctor or genetic counsellor will let me know when they have the results.

I will need another appointment with them.

At this appointment they will tell me the test results.

My parents or someone I trust can support me to make another appointment.

Getting the results.

At the appointment, the doctor or genetic counsellor will tell me and my parents the genetic test results.

They will explain what the results mean.

My parents and I can ask them questions about the results.

Going to an appointment to talk about the results.

At my appointment with my doctor or genetic counsellor, we will talk about my genetic test results.

My doctor or genetic counsellor will explain what the results of my genetic test mean.

I can ask them any questions I may have.

The possible results.

There are 4 possible results from my genetic test.

My doctor or genetic counsellor will explain the 4 possible results.

I may have more than 1 result.

Result 1.

There was a reason for my health condition or learning difference.

This means I have a genetic condition.

My doctor or counsellor will explain my genetic condition.

I can ask questions and learn more about my condition.

I can ask if I can connect with other people with the same condition.

Result 2.

My genetic test does not find a reason for my health condition or learning difference.

This means that there may be another reason for it.

We are learning more about genetics all the time.

I can do the test again in 2 years to test if there is new information.

Result 3.

My genetic test results found something, but the doctor or genetic counsellor do not understand it.

As people learn more in the future about genetics, we may understand the results better.

This means I can have another genetic test in a few years' time.

Result 4.

My genetic test finds something that we were not looking for.

For example, it can tell me I have another health condition that I did not know about.

My doctor or genetic counsellor will explain this health condition.

They can help me to find the right doctor for that condition.

My parents or someone I trust, can support me to make an appointment with the right doctor.

Genetic testing takes time.

Having a genetic test and waiting for the results can take a long time.

Altogether, I will have three appointments:

1. Finding out about genetic tests
2. Having the test
3. Getting the results

My parents or someone I trust can support me at the appointments.

If I have a genetic condition, the doctor or genetic counsellor will talk to me about the best ways to stay healthy.

Sharing my results.

The doctor or genetic counsellor will know my test results.

My parents will know my results if I am not an adult yet.

I can decide if I want to share my results or not.

Sharing my results with my school or my friends is my choice.

It is important to remember a genetic test is my and my parent's choice.

It is important to remember that a genetic testing is my and my parent's choice.

I may be able to learn more about my condition if I have a genetic test.

It can help my parents, doctors, teachers and therapists give me the right support.

If I decide not to have a genetic test, my doctor will still give me good health care.

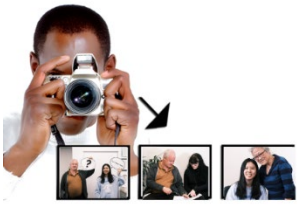
I can decide if I want to have a genetic test to find out more.

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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