



Before my genetic appointment



**Social stories about genetic appointments
For young people with intellectual disability**



What is a genetic appointment?

This social story is to support me to understand what happens at a genetic appointment.

It tells what a genetic test is and what genes are.

Someone I trust can read it to me or with me if I want.



What happens at a genetic appointment?

At a genetic appointment, we talk about our genes.

Genes are instructions in our body.

They tell our body how to grow, work and learn.

I may be able to learn more about my genes from a genetic test.



What is a genetic test?

Our genes make us who we are.

I cannot see them as they are so tiny.

Scientists know how to see if they are working properly.

They can do a genetic test to check them.



Everyone's genes are different.

No one has the exact same genes.

This means that no people are exactly the same.

We all look different because of our genes.

Some of us have different colour eyes.

Some of us have different colour hair



We all have different strengths.

We all learn in different ways.

Some of us are great at reading.

Some of us are great at remembering things.

I can decide if I want to know more about my genes.



Genes can affect our health and how we learn.

Some health conditions and learning differences are caused by changes in how genes work.

These are called genetic conditions.

Sometimes a genetic test can tell if someone has a genetic condition.

I can learn more about genetic tests.



What are genetic tests?

Genetic tests look for changes in genes that cause genetic conditions.

Most genetic tests can be done from my spit.

Some genetic tests can only be done after I have a blood test.

I can learn more about genetic conditions and genetic tests at my appointment.



Genes and family.

We all share some of our gene instructions with our families.

In some families, only one person may have a genetic condition.

In other families, two or more people may have the same genetic condition.

Having a genetic condition is nobody's fault.



What causes a genetic condition?

A genetic condition just happens by chance.

We all have changes in our genes.

Some changes do not affect us.

Some changes can cause a genetic condition.



Having a genetic test is my and my parent's choice.

Not everyone wants to know if they have a genetic condition.

I can think about it first.

I can ask my doctor questions about it.

I can also talk about how I feel about having a genetic test.

It is my and my parent's decision to have a genetic test or not.



How can a genetic test help me

If I know my genetic condition, I may understand myself better.

I may be able to find out if there are other people with the same condition.

It can be helpful to meet people with the same genetic condition.

I can decide if I want to do that.



Meeting people with the same condition.

People with the same condition as me may be my age or older or younger.

They may live in Australia or another country.

I can meet people online, or I can meet them in person.

This can help me feel more supported and connected.



Knowing about my genetic condition can support my health care.

A genetic test can help my family, my doctors and I know the name of my condition.

This can help doctors give me the right health care.

It can help my therapists give me the right support.

I can learn more about my condition if I know its name.



Knowing about my genetic condition can support my learning.

It can help my teachers to know the name of the condition.

They may then understand better how I learn.

I can understand how I learn best.

This can help me get the right learning support at school.

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 Inc.
Speaking for Ourselves



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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