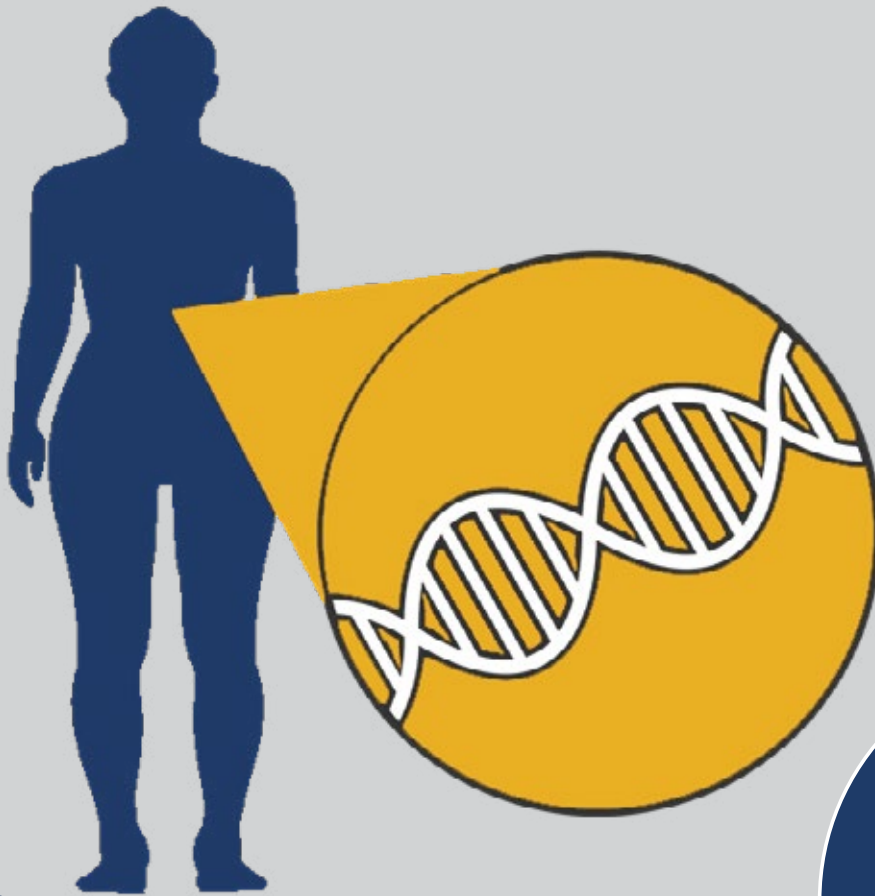




**UNSW**  
SYDNEY

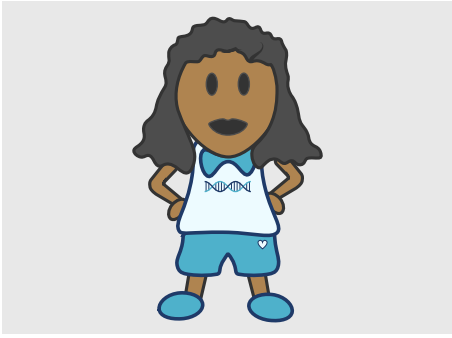


# Tips about genetic health care



**Easy Read**

[www.geneequal.com](http://www.geneequal.com)



This is Gene.

Gene is on all of our booklets and our website.



When you see Gene you know this is information about genetic health care.



We made 5 booklets to help you learn about genetic health care.

1. About genetic health care
2. Genes and genetic conditions
3. How to make a genetic appointment
4. Get ready to go to the genetic clinic
5. Tips about genetic health care



Some things in the booklets might

- Be hard to understand
- Make you feel sad.

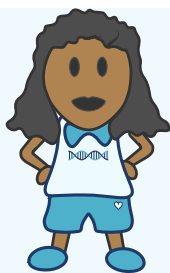


You can read them with someone you trust.



This might be

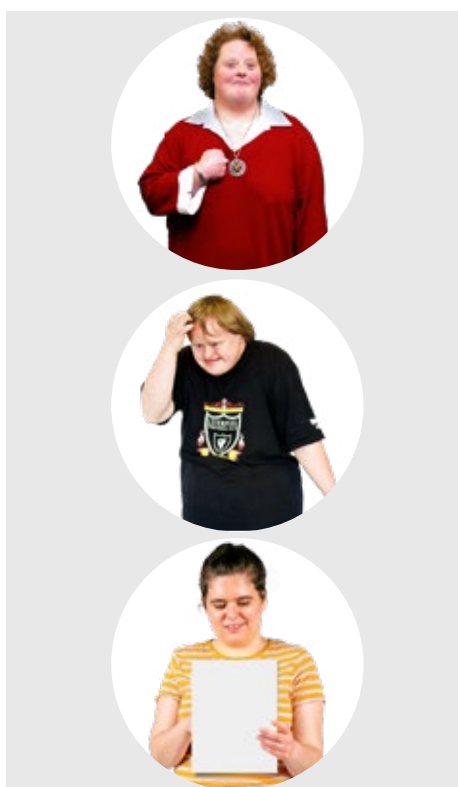
- Someone from your family
- A friend
- Your support worker.



## About this booklet

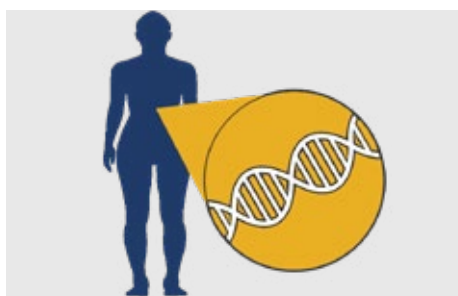


This booklet has tips about **genetic health care** for you and your family.



**Genetic health care** is health care for people who

- Have a **genetic condition**
- Might have a genetic condition
- Want to know more about genetic conditions.



A **genetic condition** is a health or learning issue.



Genetic conditions come from a change in your **genes**.



**Genes** are small things in your body that make you who you are.



Genetic health care can help you

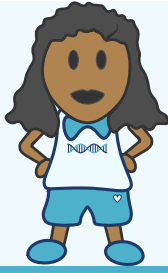
- Look after yourself well



- Make a plan for the future



- Get the right support.



## Where can you find a genetic clinic

A **genetic clinic** is where you can

- Try and find out if you have a genetic condition
- Learn more about genes and genetic conditions.



Genetic clinics can be in hospitals or community centres.



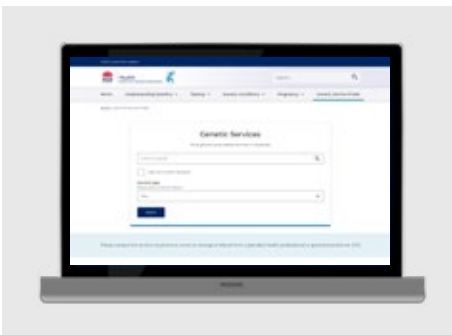
You can also use video calls to speak with someone from a genetic clinic.



You need a **referral** from your doctor to go to a genetic clinic.



A **referral** is a letter from your doctor that asks for you to be seen in a genetic clinic.



You can use a map of genetic clinics to find one near you.

Go to

**[www.genetics.edu.au/SitePages/Genetic-Services.aspx](http://www.genetics.edu.au/SitePages/Genetic-Services.aspx)**



You can also go to the Genetics of Learning Disability Clinic.

They are called **GOLD** for short.



You can go to GOLD if 2 or more people in your family have an intellectual disability.



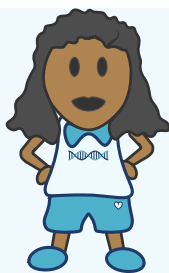
To contact GOLD you can

- Call them on **02 4985 3100**

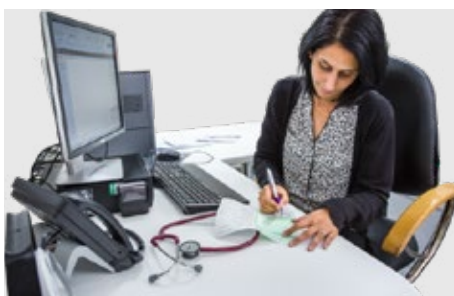
or

- Email them on  
**[hnelhd-gold@health.nsw.gov.au](mailto:hnelhd-gold@health.nsw.gov.au)**

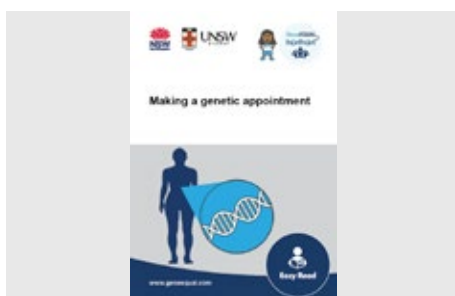




## How do you get a referral



You can ask your doctor for a referral.



You can show them our booklet called  
**Making a genetic appointment.**



To look at the booklet go to

**[www.geneequal.com](http://www.geneequal.com)**



If your doctor does not want to give you a referral you can go to another doctor.



## Do you need to pay for the genetic clinic



Most genetic clinics are in **public hospitals**.

**Public hospitals** are owned by government.



This means you do not have to pay money to go to genetic clinics in public hospitals.



Some genetic clinics are in **private hospitals**.

**Private hospitals** are not owned by the government.



You may have to pay some money to go there.



You can choose if you want to go to a genetic clinic in a public or private hospital.



If you go to a private genetic clinic you can ask if they **bulk bill**.

**Bulk bill** means Medicare pays for all of it.



You might also get a rebate for some of the tests they do.

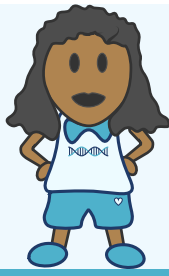


**Rebate** means you get some of the money you paid back later.



It is good to ask before

- How much the tests will cost
- How much money you will get back



## Your rights with genetic health care



Everyone has the right to good health care.



This also means the right to good genetic health care.



The **Australian Charter of Healthcare Rights** says what your rights are.

We will say **charter** for short.



To read the charter go to

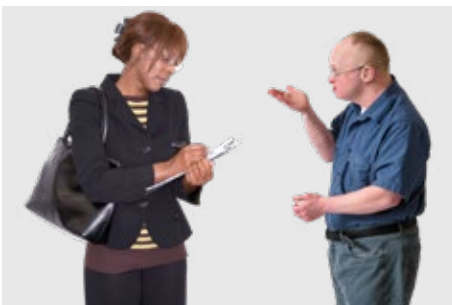
**[www.bit.ly/healthcare-rights-A4](http://www.bit.ly/healthcare-rights-A4)**



## If you are not happy with the genetic clinic



You can ask to see someone else if you are not happy with your genetic health worker.



You can make a **complaint** if you are not happy with the genetic clinic.



**Complaint** means you say what you are not happy about.

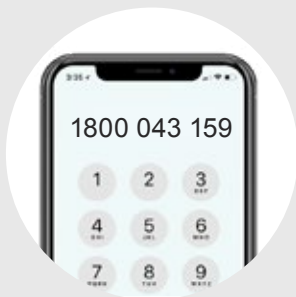


You can make a complaint to the **Health Care Complaints Commission**.



The **Health Care Complaints Commission** looks after complaints about health services in NSW.

To make your complaint you can



- Call them on **1800 043 159**

or

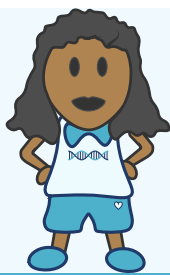


- Go to their website at **[www.hccc.nsw.gov.au](http://www.hccc.nsw.gov.au)**

or



- Send them a letter to  
Health Care Complaints Commission  
PO Box K549  
Haymarket NSW 1240



## Support to make a complaint



There are lots of ways to get support to make a complaint about the genetic clinic.



You can ask someone you trust to help you make a complaint.

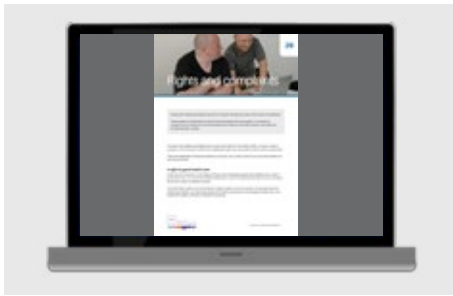


This might be

- Someone from your family
- A friend
- Your support worker.



**Council for Intellectual Disability** has information about how to make complaints.



Go to

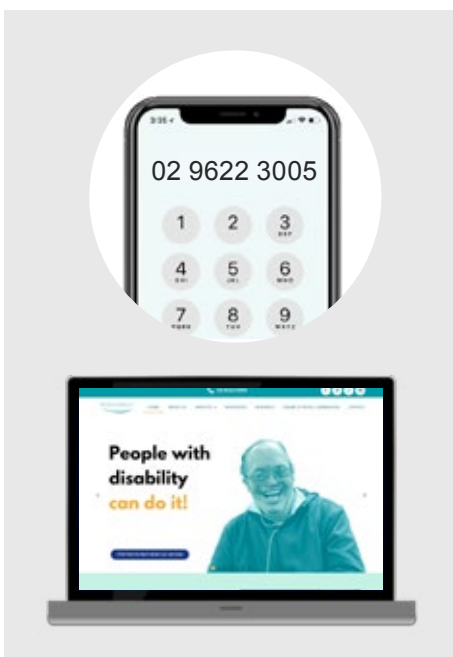
[www.cid.org.au/wp-content/uploads/2019/10/29-Rights-and-complaints.pdf](http://www.cid.org.au/wp-content/uploads/2019/10/29-Rights-and-complaints.pdf)



You can talk to a support group for help with your complaint.



This might be a service like **Self Advocacy Sydney.**



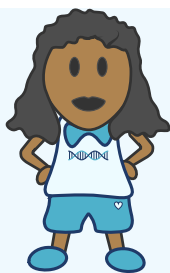
You can

- Call them on **02 9622 3005**

or

- Go to their website at [www.sasinc.com.au](http://www.sasinc.com.au)



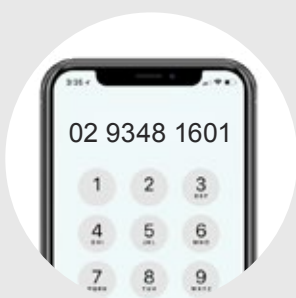


## What if you have more questions



You can contact the GeneEQUAL team if you have more questions.

To contact us you can



- Call Emma from GeneEQUAL on **02 9348 1601**

or

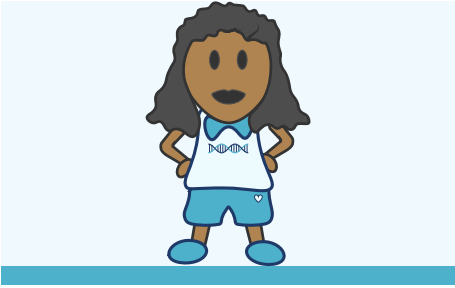


- Send an email to **[geneequal@unsw.edu.au](mailto:geneequal@unsw.edu.au)**

or



- Click on the Contact us button on our website **[www.geneequal.com](http://www.geneequal.com)**

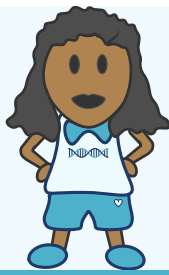


## Notes



You can use this page to write things down.

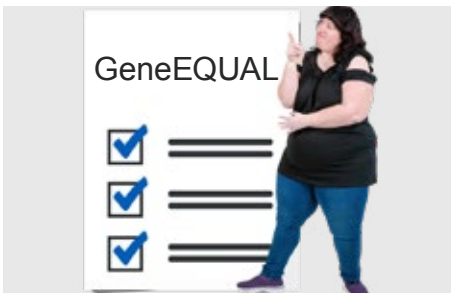
This image shows a blank sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.



## Who made this booklet



The **GeneEQUAL** team made this booklet.



**GeneEQUAL** is a program to help people with intellectual disability get better health care.

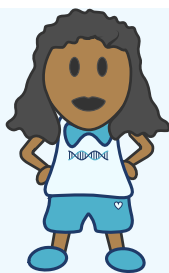


We got money from the **NSW Ministry of Health** to write this booklet.



**NSW Health**

The **NSW Ministry of Health** is the part of government that looks after people's health.



## More information



GeneEQUAL made other booklets about genetic health care.



To get our booklets you can

- Go to our website  
**[www.geneequal.com](http://www.geneequal.com)**

or



- Email the GeneEQUAL team on  
**[geneequal@unsw.edu.au](mailto:geneequal@unsw.edu.au)**

or



- Send us a letter with your address to

GeneEQUAL  
c/o Emma Palmer  
Centre for Clinical Genetics, Sydney  
Children's Hospital, Level 9  
The Bright Alliance Building  
NSW 2052, Australia

You can go to our website for more information



- Go to **[www.geneequal.com](http://www.geneequal.com)**

or

- Scan this QR code with your phone



NSW Council for Intellectual Disability has lots of health information in Easy Read.

To look at them go to

**[www.cid.org.au/resource-tag/easy-read](http://www.cid.org.au/resource-tag/easy-read)**

Council for Intellectual Disability made this document Easy Read. **CID** for short.  
You need to ask CID if you want to use any pictures in this document.  
You can contact CID at **[business@cid.org.au](mailto:business@cid.org.au)**.

GeneEQUAL acknowledges the financial support from the NSW Health 'Transforming healthcare through genomic technologies' initiative, funded by the Australian Government through Stage One of the Health Innovation Fund.