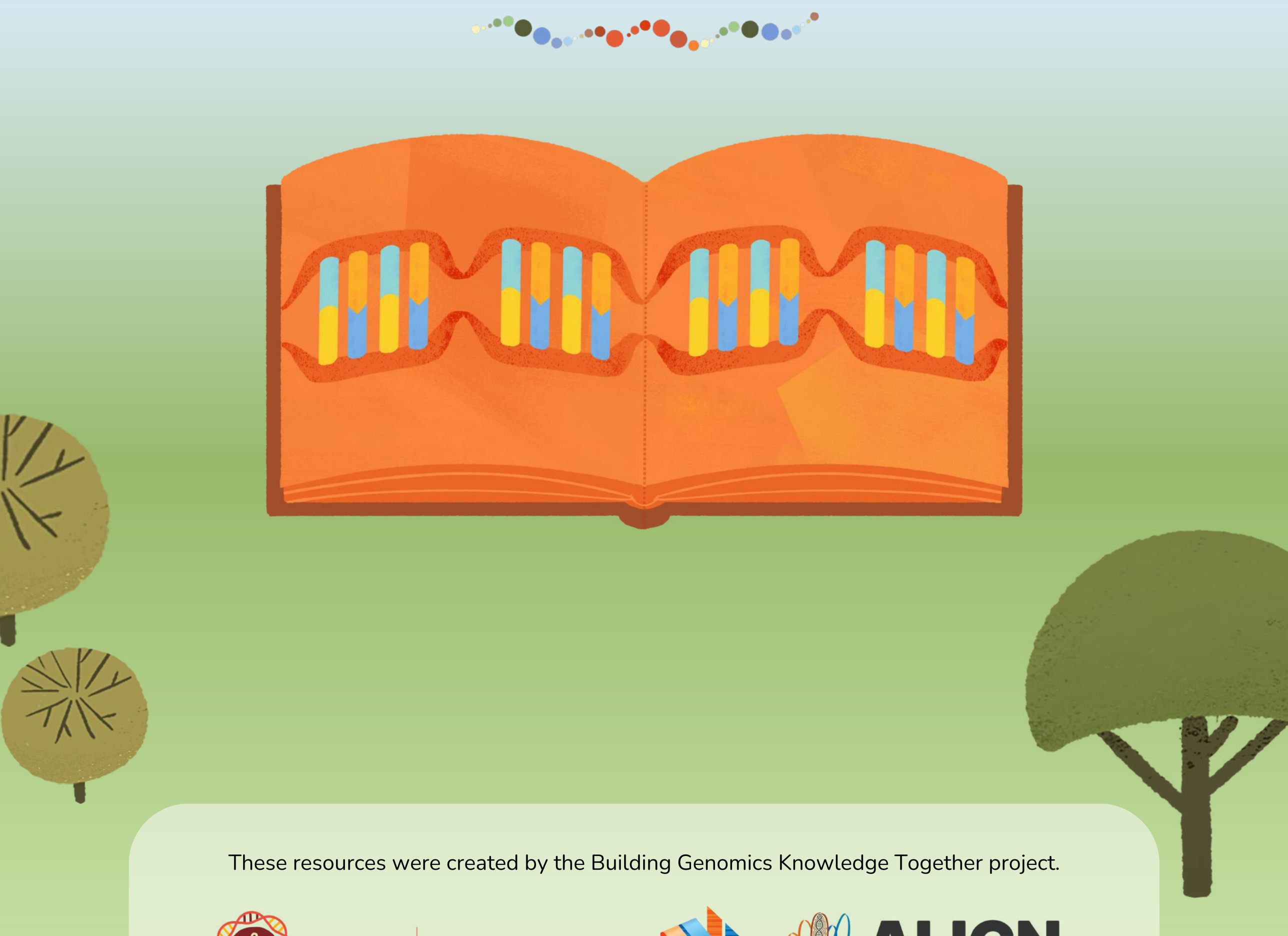
Talking about genes and our health: Frequently Asked Questions

Answering questions you might have about genetics and genetic testing



These resources were created by the Building Genomics Knowledge Together project.

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DNA, Chromosomes, and Genes

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What is DNA?

DNA is a set of instructions that tells your body how to grow, work, and look.

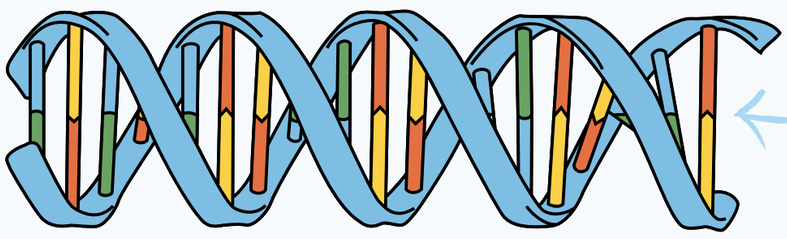
Its full name is **D**eoxyribo**n**ucleic **A**cid, or DNA for short.

DNA is found in all living things - humans, animals, plants, and even the tiniest bacteria! It carries information that helps living things survive and pass on their bloodline and **traits** to their children.

Traits are your characteristics or features.

They can be physical - like hair or eye colour, or things you can't see - like your blood type.

If you look at pictures of DNA, you'll see it looks like a twisted ladder. Scientists call this shape a **double helix**.



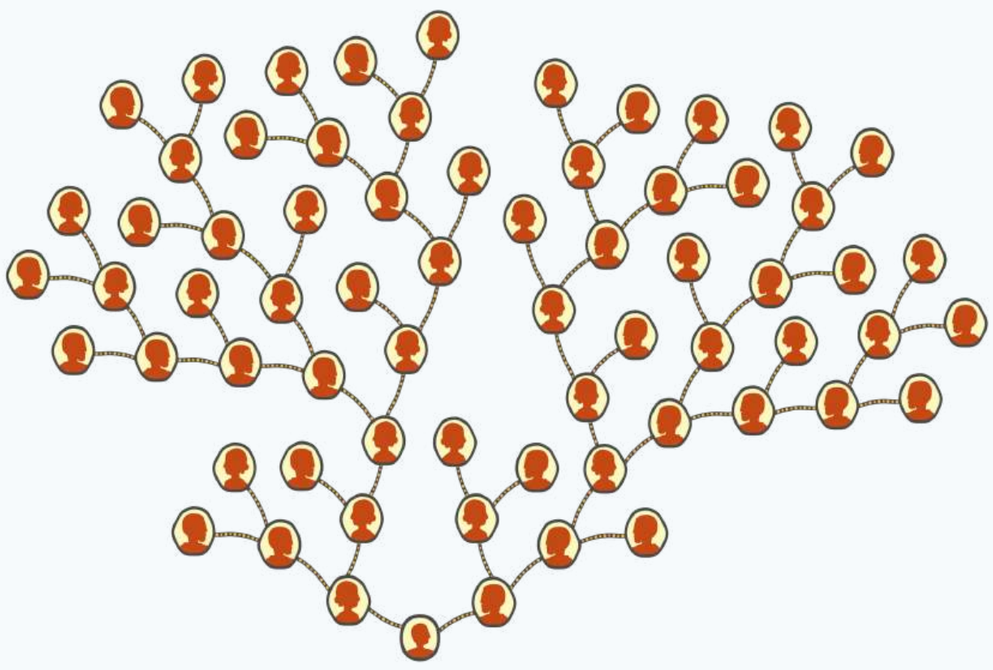
The "steps" of the ladder are made of special chemicals that act like a code to build and run your body. These special chemicals are explained later in this document.

Where does DNA come from?

DNA is passed down the bloodline from parents to children.

Half of your DNA comes from one parent and half comes from the other. This is why you might have your dad's eye colour or your mum's curly hair.

Even though your brothers and sisters get their DNA from the same parents, they don't get exactly the same mix. That's why you and your brothers or sisters might look similar but not identical.



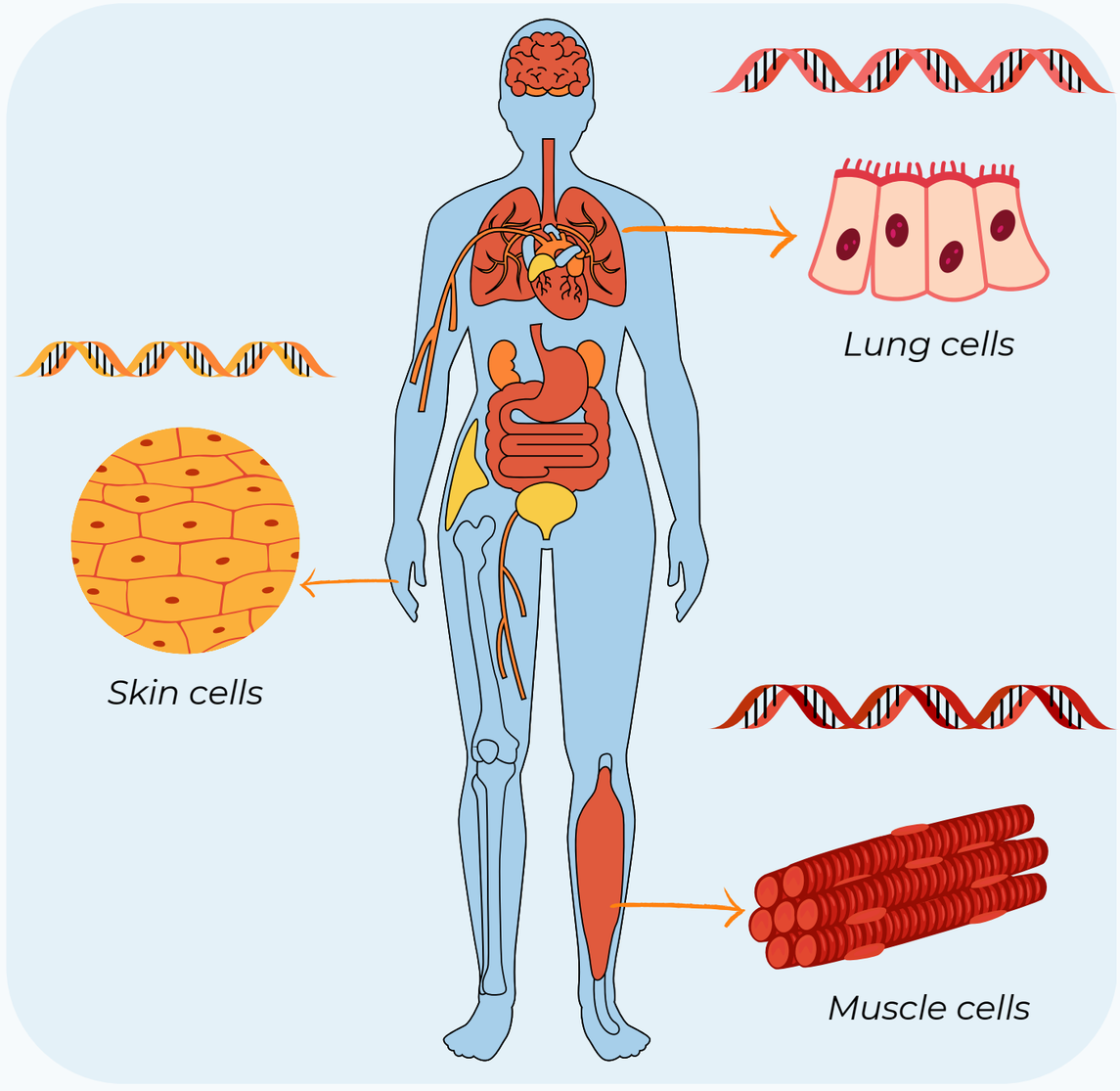
Your parents got their DNA from their parents, and their parents got it from theirs. This means your DNA connects you to your ancestors, going back thousands of years.

Where is DNA found?

DNA is found inside your **cells**, which are the tiny building blocks that make up your body.

Cells work together to form your skin, muscles, bones, and organs. Each type of cell has a special job. For example, muscle cells help you move; lung cells help you breathe; and skin cells protect your body.

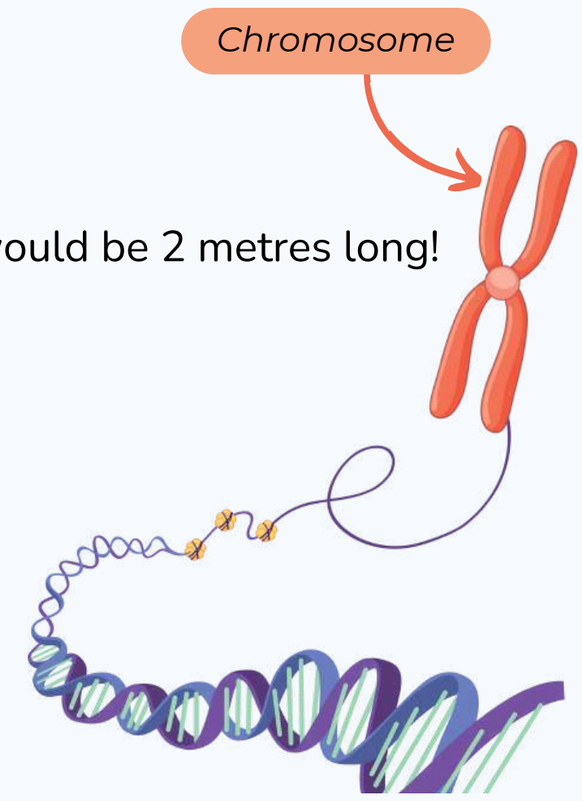
Different cells use different instructions from your DNA to do their jobs.



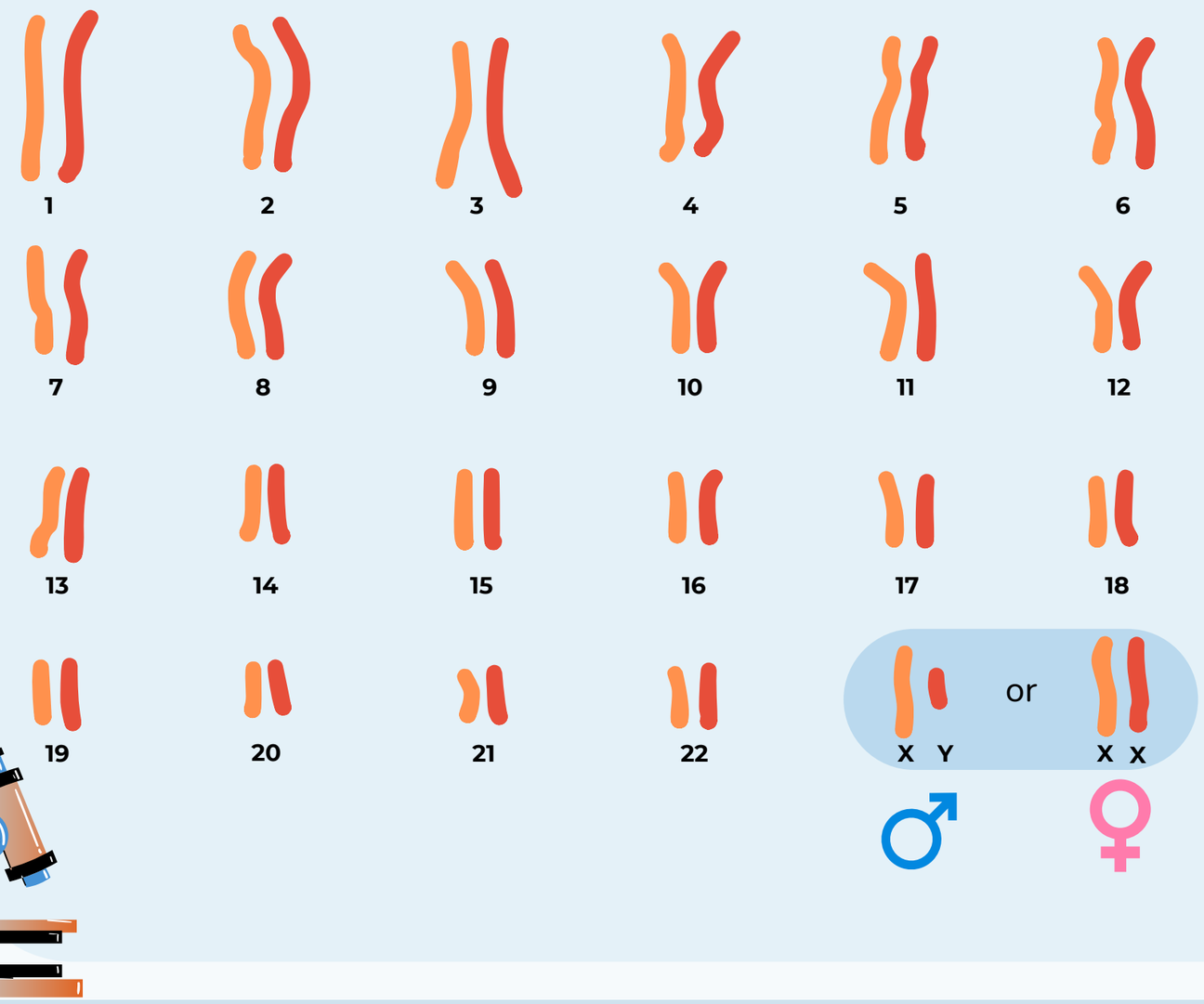
What is a chromosome?

DNA is like a long piece of string. If you stretched out all the DNA in one of your cells, it would be 2 metres long!

To keep it from getting damaged and twisted, our cells pack all our DNA into little packages. These packages are called "**chromosomes**". Each chromosome holds a different part of your DNA.



A "photo" of all your chromosomes might look something like this:



Humans usually have 46 chromosomes. 23 come from **one parent**, and 23 come from the **other parent**.

Chromosomes are given numbers based roughly on how big they are. Each parent gives you one copy of every chromosome number.

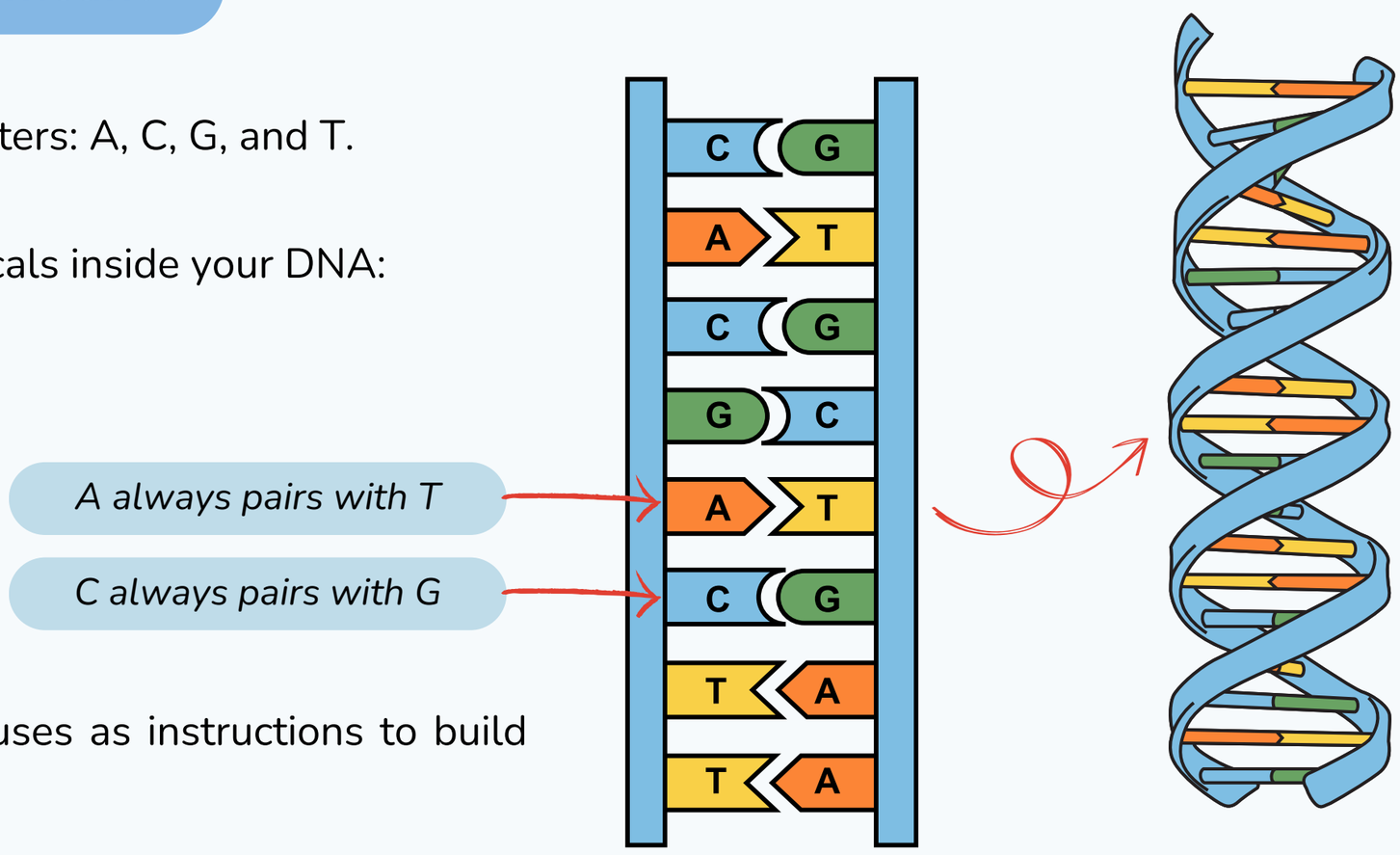
The chromosomes named "X" and "Y" are special. They're called the "sex chromosomes" because they determine your sex - whether you're born a boy or girl.

What do the letters A, C, G, and T mean?

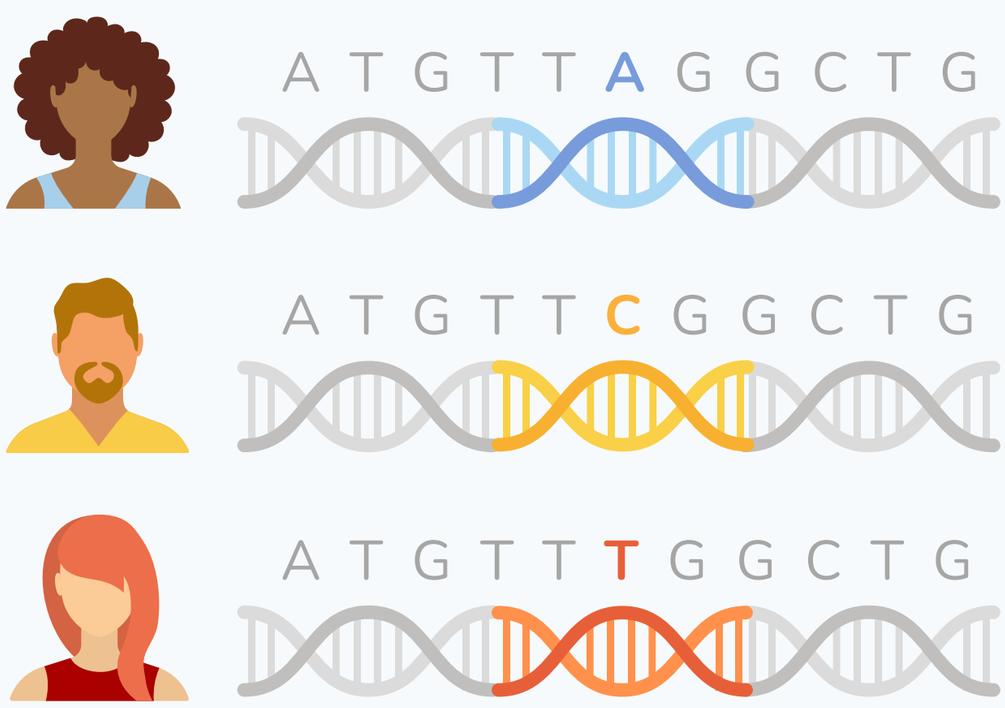
DNA has a special code made up of four letters: A, C, G, and T.

These letters stand for the names of chemicals inside your DNA:

- **A** = adenine
- **C** = cytosine
- **G** = guanine
- **T** = thymine



These letters form words that your body uses as instructions to build itself and function.



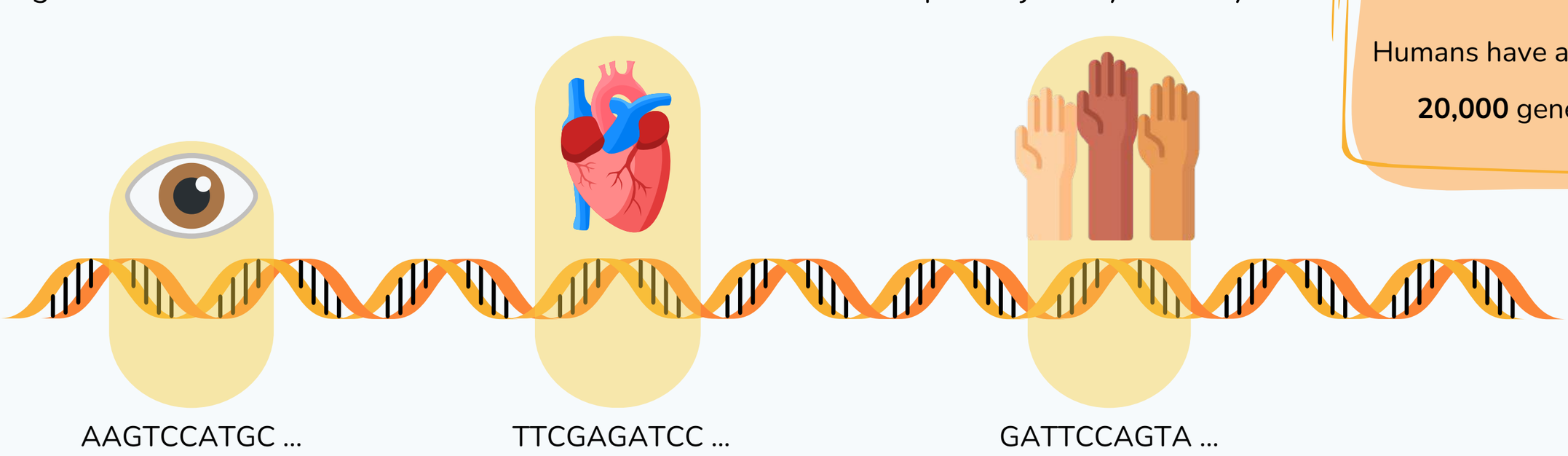
Even though all humans have very similar DNA, small changes in the spelling of our instructions make each person unique.

These small differences help decide things like your height, hair colour, and even whether you like the taste of certain foods!

Sometimes, if there's a spelling mistake in the instructions or a letter is missing, it can cause problems in the body - like making someone sick or stopping things from working as they should.

What is a gene?

A gene is a small section of DNA that contains instructions for a specific job in your body.



Each gene is made up of a unique sequence of A, C, G, T, just like a sentence is made from different letters in the alphabet.

DID YOU KNOW?

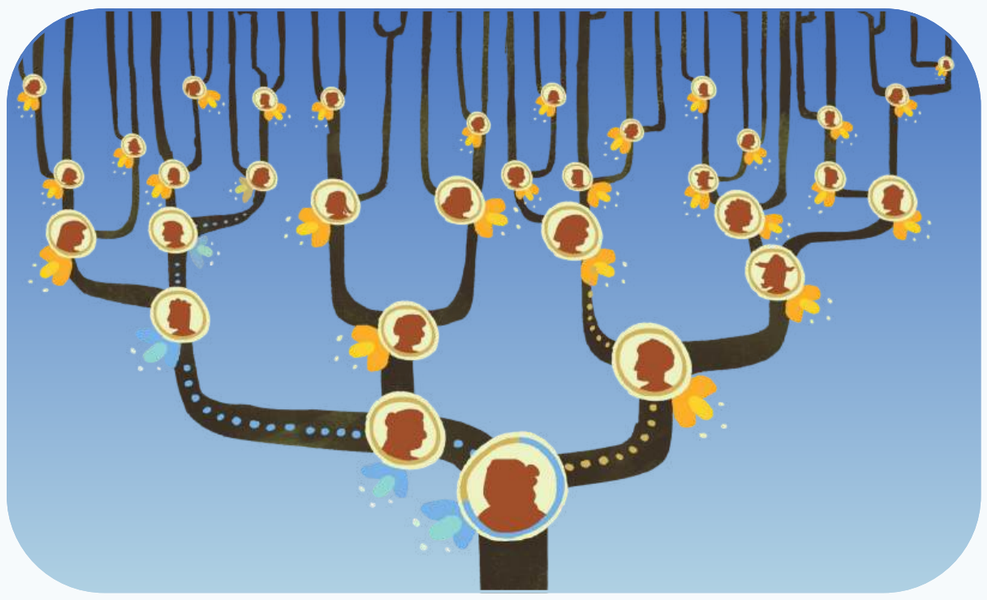
Humans have around **20,000** genes!

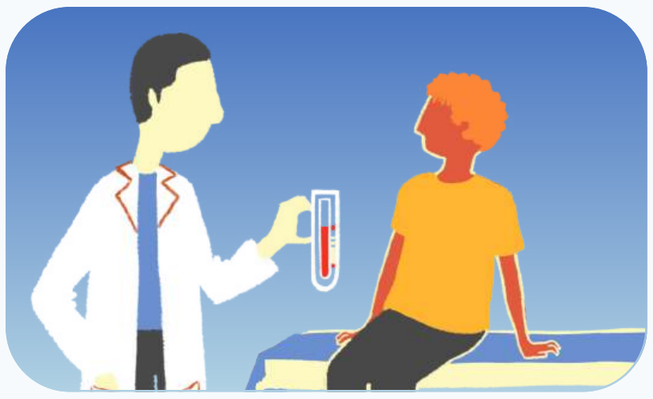
How can genes affect my health?

Most of the time, small changes in DNA don't cause any problems. But sometimes, a change in a gene can stop it from working properly. This can make a person more likely to get certain health conditions.

Some health conditions run in families because they are passed down through DNA.

For example, some types of diabetes and cancer are more common in certain families.





Other times, a gene changes in only one person for the first time in their bloodline.

This is rarer, and doctors might not always know what it means right away.

It's important to remember that no one can control how their genes work. If a gene doesn't work properly,

it's not anyone's fault.

Also, having a gene change doesn't always mean you will get sick—it just means your chances might be a little higher.

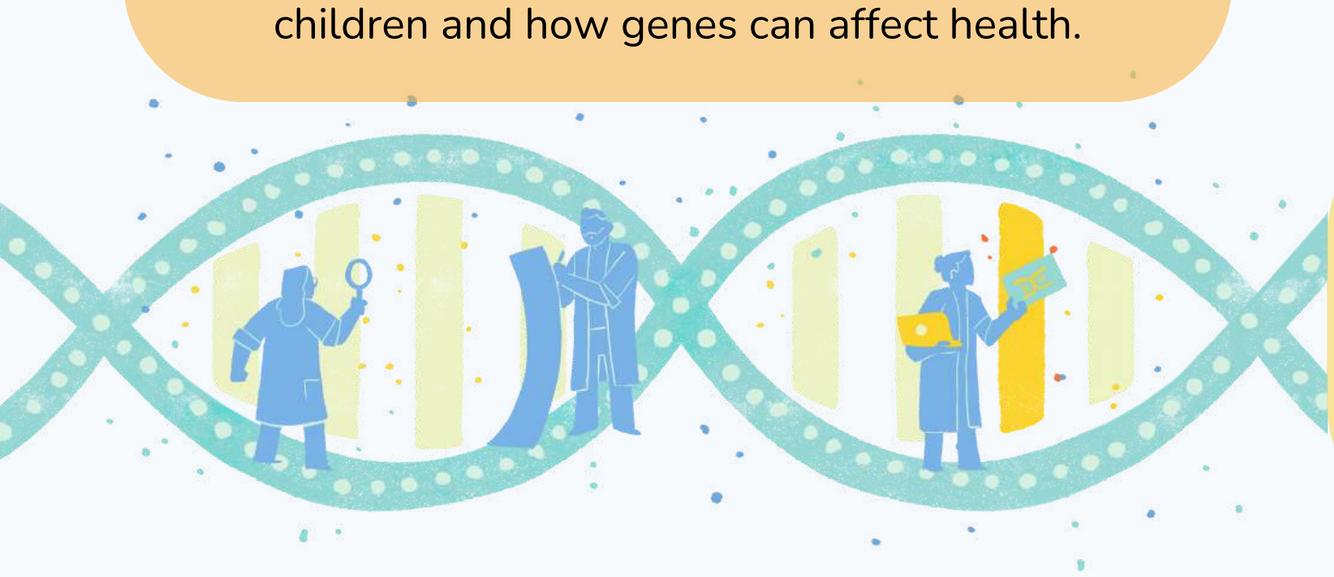
What is the difference between genetics and genomics?

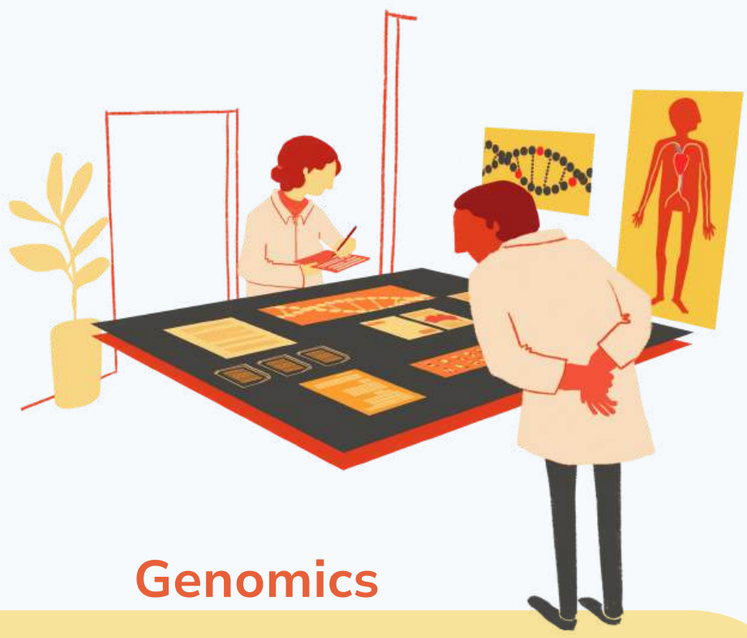
Even though they sound similar, **genetics** and **genomics** are different.

Genetics

is the study of **one or a few genes** at a time.

It looks at how traits are passed from parents to children and how genes can affect health.





Genomics

is the study of **all a person's genes** together.

It looks at how genes work as a whole and how they interact with each other.

Section 2

Genetic Testing Explained

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What is genetic testing?

Genetic testing is a special type of health test that looks at your **DNA.** It helps doctors understand your genes and how they might affect your health. This can help them give you the best care possible.

How can genetic testing help me?

Genetic testing might help in different situations such as:

Finding answers: If you're sick and other health tests haven't explained why, genetic testing might help doctors understand what's happening.

Family history: If certain health conditions run in your family genetic testing can show if you might be at risk.

Choosing the right treatment: Some medicines work better for certain people. Genetic testing can help doctors decide which treatments might work best for you, especially for conditions like cancer.

Planning for a baby: If you're thinking about starting a family, genetic testing can check if there's a chance your child might inherit a condition.

Who do I see when I want to do a genetic test?

If you're thinking about having a genetic test, your first step is to talk to a health professional. This could be your local community health worker, GP, or Aboriginal Health Worker.

They can help you understand whether genetic testing might be useful for you and guide you on what to do next.

Depending on your situation, you might be referred to:

A specialist doctor: This is a doctor with extra training in a particular area of health, such as specalising in genetics, the brain (a neurologist), or the heart (a cardiologist). They may do further tests to help decide whether genetic testing is needed.

A genetic counsellor: Genetic counsellors are specially trained health professionals who explain how genetic testing works, what it can and can't tell you, and what the results might mean for you and your family. They can also provide support before and after testing. **[Click here]** to learn more about genetic counselling.

Other health professionals: Depending on your health concern, you may also see other specialists, such as a paediatrician (for children's health), an oncologist (for cancer-related genetics), or a reproductive specialist (for pregnancy and fertility-related testing).

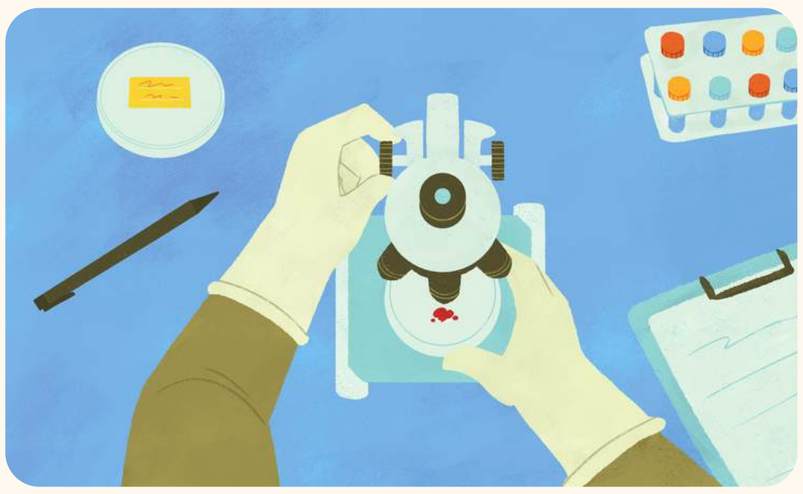
Your doctor or health worker will help connect you with the right people. If you'd like to know more about the different health professionals involved in genetic testing, **[click here].**

How does genetic testing work?

Before you have a genetic test, a health professional - like a doctor or **genetic counsellor** - will talk with you about what the test can and can't tell you. They will explain the process and answer any questions you have. You will only have the test if you decide you want to and give your permission (consent).

Once you agree, you will need to give a small sample. This is usually blood or spit, but sometimes it might be a swab from inside your cheek or a small piece of skin. In some cases, a different type of sample might be needed.

Your sample is then sent to a laboratory, where scientists use special machines to look at your DNA. They will check your genes to see if there are any changes that might explain a health condition, predict future health risks, or help guide treatment options.



Most of the time, only a small part of your DNA is examined—just the sections that are linked to the health issue your doctor is looking into. But in some cases, all of your DNA may need to be analysed, especially if doctors are unsure what might be causing your symptoms.

Because genetics is complex, different types of health professionals may be involved in analysing and interpreting your results. Scientists, genetic specialists, and researchers may also be asked to help make sure the results are as accurate as possible. This process can take some time—sometimes weeks or even months—depending on the type of test being done.

Once your results are ready, your doctor or genetic counsellor will go through them with you. They will explain what the results mean for you and your family and discuss any next steps, including treatment or further testing if needed.

Section 3

Things to Consider Before Genetic Testing

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How can I get the support I need?

Genetic testing can feel overwhelming. There might be a lot of information to take in. Here are some ways to make the process easier.

Take someone with you – A support person or translator can help you feel comfortable and ask important questions.

Find an advocacy group – There are organisations in each state and territory that can support you. (Click here for a map.)

Lean on family and friends – They can provide emotional support, and genetic testing results might be important for them too.

How much will genetic testing cost?

The cost of genetic testing depends on the type of test. Some tests might be covered by **Medicare** or your state/territory government. Your **doctor or genetic counsellor** can explain your options.

Will my genetic test results affect my insurance?

In Australia, there are strong rules to protect you from insurance companies using your genetic testing results unfairly or without your permission. If you're unsure, your doctor or genetic counsellor can give you more details.

Who will have access to my test results?

Your test results are only accessed by your health provider and yourself. If anyone else wants access to your test results, you need to give consent. See the next section to learn more about consent.

Section 4

Consent

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What is consent?

Consent means giving permission for something to happen. Informed consent means you fully understand what you're agreeing to before you say yes. This means that everything has been explained to you in a clear way, and you understand it all, before you say yes.

Before doing a genetic test, some things that your doctor or genetic counsellor should explain are:

- How the test might help you
- What the results might mean for you and your family
- Where your sample and DNA will be sent to and kept
- Who can see your test results

REMEMBER, YOU SHOULD NEVER FEEL PRESSURED TO SAY YES. ONLY SAY YES IF YOU FEEL COMFORTABLE.

How do I give consent?

There are two ways in which you can provide consent:

Written consent – You'll sign a form saying you understand everything and agree to the test.

Verbal consent – Sometimes, you may just need to say yes without signing anything.

Can I change my mind later?

Sometimes you might change your mind after already signing a consent form. What happens after will depend on things like:

- How much of the genetic test has already been done
- What state or territory you live in
- Where your sample and DNA is

The first person you should talk to is your doctor or genetic counsellor. You can find more information **here.**

What is an incidental finding?

An **“incidental finding”** is when a genetic test shows something unexpected about your health. When you give consent, you can choose whether or not you want to know about these findings. Incidental findings don’t happen to everyone, but it’s still important to talk to your doctor or genetic counsellor about it.

Can my genetic data be used for research?

When you send a sample for genetic testing, the people taking care of it must keep it protected. They can’t share it with others.

Your **DNA and genetic test results are protected**. Only the health professionals helping you can access them.

Sometimes, your doctor might ask if you’d like to join a research project. This could help scientists learn more about health conditions or create new medicines.

If you agree, your sample or test results might be shared with researchers, but only with your permission. Make sure to ask questions before deciding and remember that you can always say no if you’re not sure.

What is data sovereignty?

Your genetic data is valuable knowledge.

Data sovereignty means that Indigenous people have the right to own, control, and protect their data. This ensures that communities decide how their genetic information is collected, used, stored, and shared in ways that respect their values, knowledge systems, and governance.

Data sovereignty is especially important in genomics, as it helps safeguard cultural identity, strengthen community decision-making, and ensure research benefits Indigenous peoples.

To learn more, visit the Maiam nayri Wingara website by scanning the QR code.