

**unique**

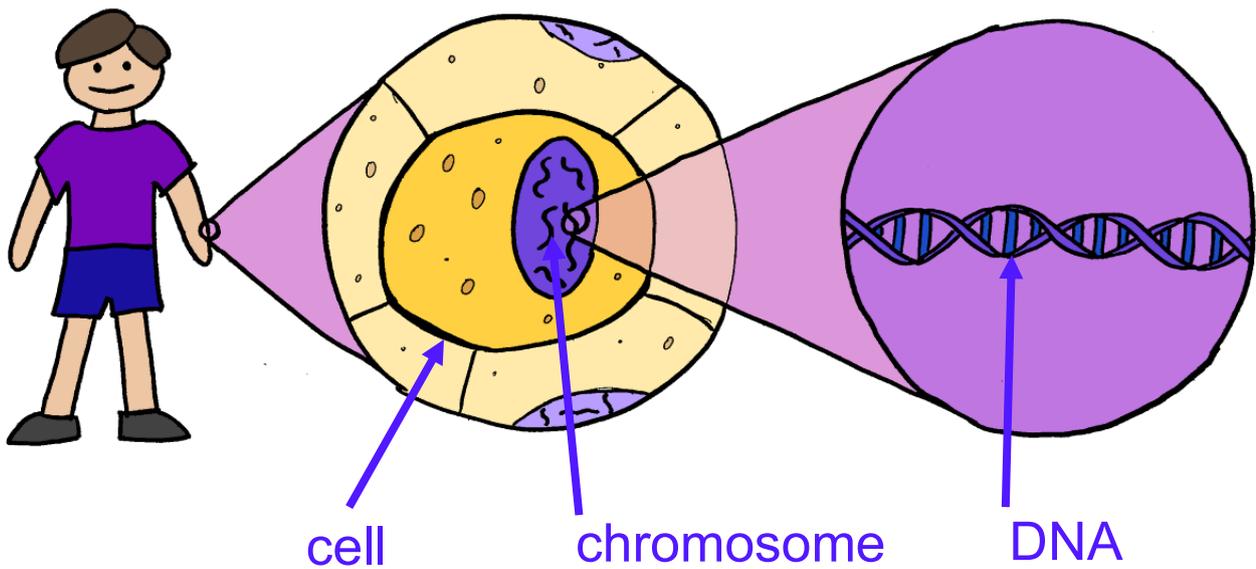
UNDERSTANDING GENES  
& CHROMOSOMES



# My Chromosome Story

A picture book for children with  
a chromosome 22q13 deletion  
also known as  
**Phelan-McDermid syndrome**

[rarechromo.org](http://rarechromo.org)

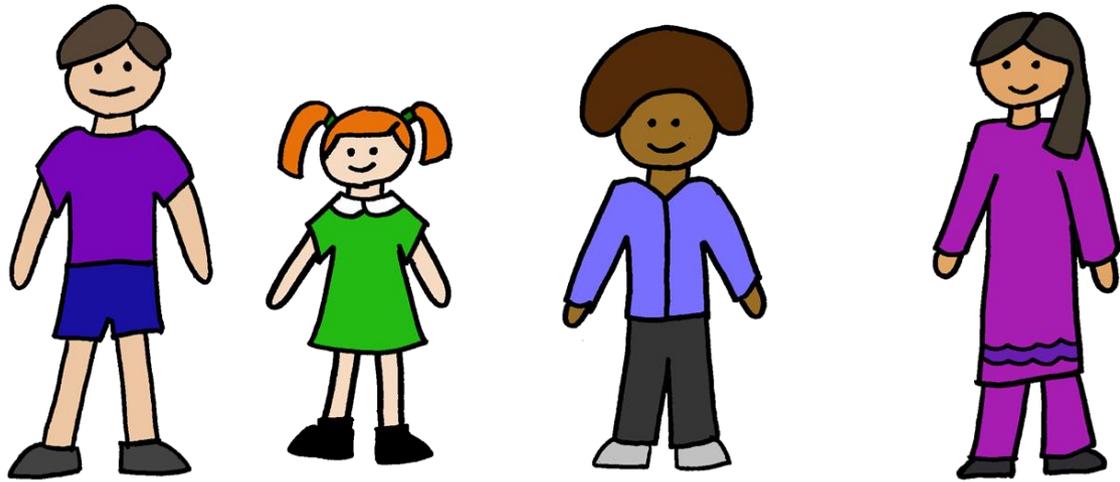


Your body is built from tiny building blocks called **cells**.

Almost all of your cells contain **DNA**, which is full of instructions on how to make you.

The instructions are quite long and complicated and so they are split into different parts called **chromosomes**.

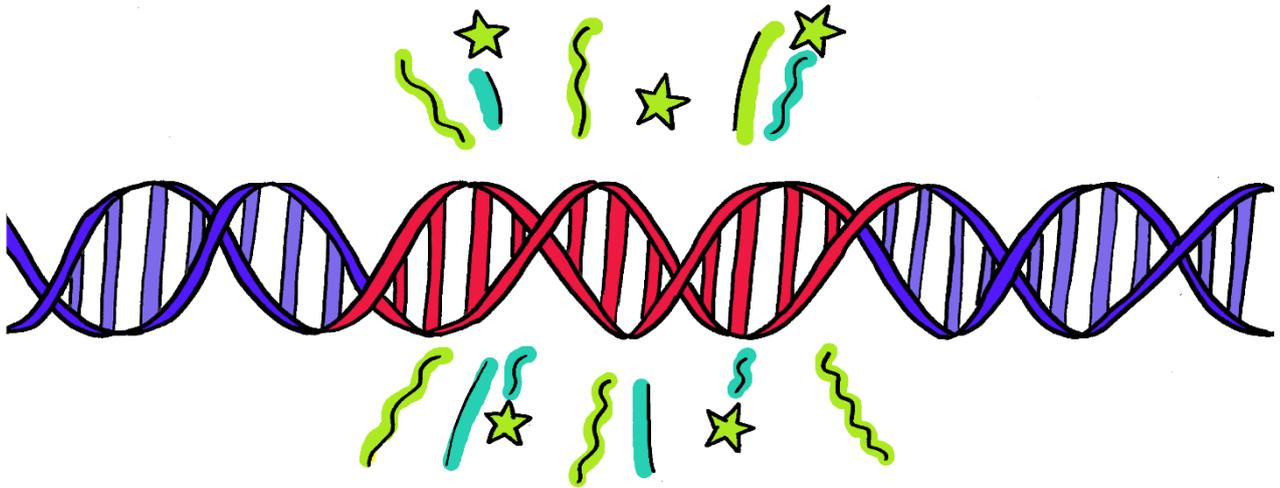
It might help to imagine these instructions are like a big book, and each chromosome is a different chapter.



DNA helps to determine how tall you are, what colour hair you have, and lots of other things about you.

But DNA doesn't determine everything.

Things that happen in your life make a difference as well. If you listen to lots of music you might know more songs. If you don't get enough sleep you might feel tired.



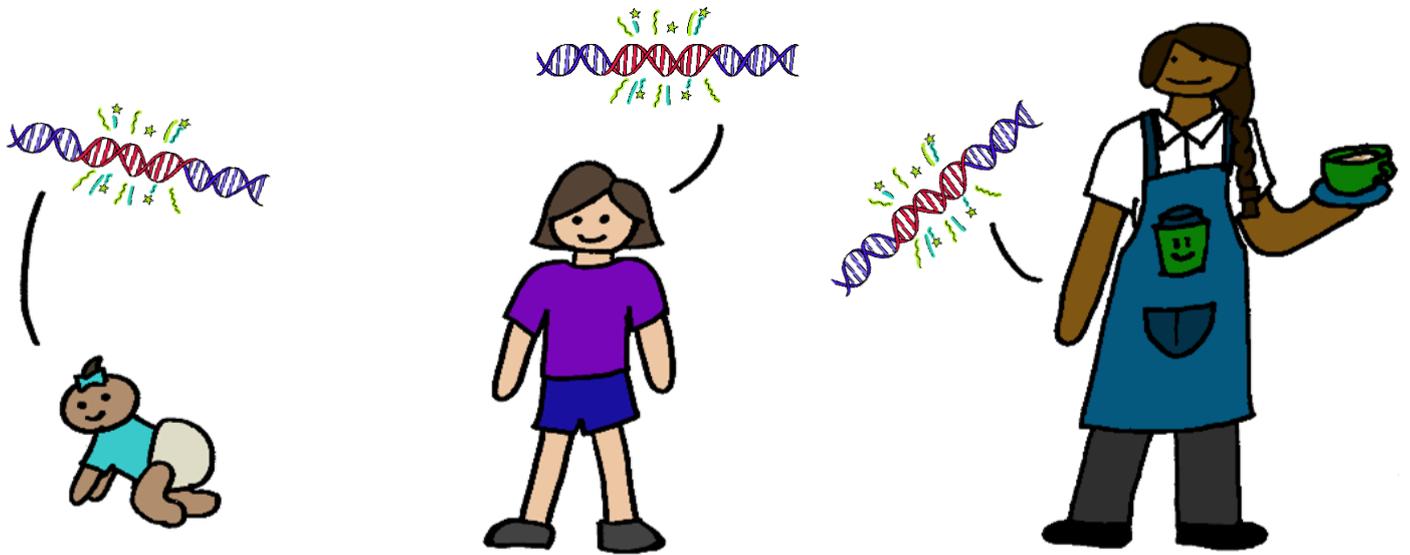
Everyone's DNA is different: some people have extra bits and some people have missing bits.

Inside your DNA there is a bit missing, one little piece of DNA has been lost so you have one less copy than most people. It is in the 22<sup>nd</sup> chapter of your 'instruction book': [chromosome 22](#).

Your missing piece of DNA is called a [deletion](#).

You also have another copy of [chromosome 22](#) that has not been changed.

When you have this deletion, you have a condition called [Phelan-McDermid syndrome](#).



There are lots of other children who have the missing bit of **chromosome 22** like you. They live all over the world.

Just like people without this chromosome change you are all different from each other.

Some people with the missing bit of DNA find some things harder to do than people who are not missing this piece of DNA, but this is different for each person.



Some children with this missing piece of **chromosome 22** take longer to learn how to walk.

Some need more help to understand things, so they learn at their own pace.

Some children have trouble eating when they are very little and others need a bit longer to learn how to pick up or hold their fork or spoon.

Some children take longer to learn how to speak, and some children use other ways to communicate.

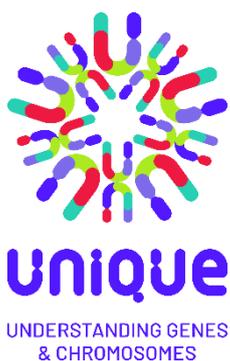
Lots of children don't feel pain very much, or it takes longer to realise when they've hurt themselves.

It is good to know about the change in your chromosome, because now if you find some things difficult to do, your family, friends, carers and teachers might be able to help you even more than before.



Remember that we are all different in different ways, and we all need help sometimes. It's good that you are exactly the way you are, because your family loves you very much just for being you.

# Inform Network Support



Rare Chromosome Disorder Support Group  
The Stables, Station Road West, Oxted, Surrey, RH8 9EE, UK  
Tel: +44(0)1883 723356  
[help@rarechromo.org](mailto:help@rarechromo.org) | [rarechromo.org](http://rarechromo.org)

Join Unique for family links, information and support:

[Become a member](#)

**Please help us to help you!**

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation:

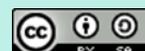
[Donate via our website](#)

Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health.

This children's booklet was compiled by Unique and Ilyas Alam, McGill undergraduate student in Physiology and member of McGill Rare, based on an original work written by Dr. Seonaid Beaumont, Sheffield, UK which is licensed under a Creative Commons Attribution-ShareAlike 4.0 International License.

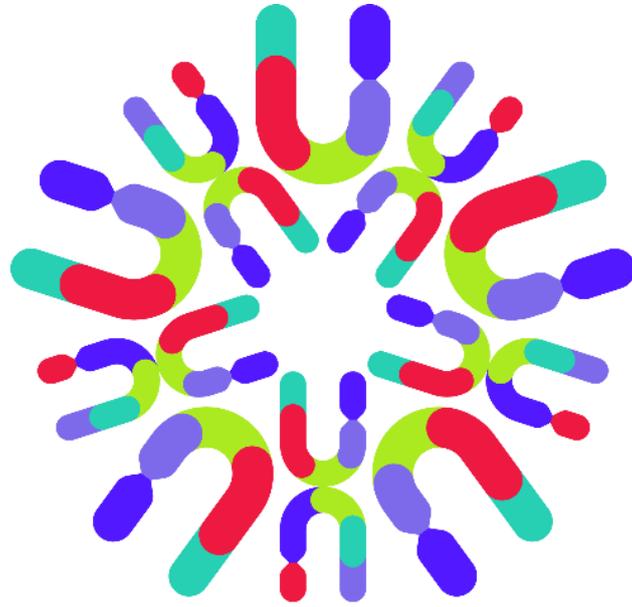
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