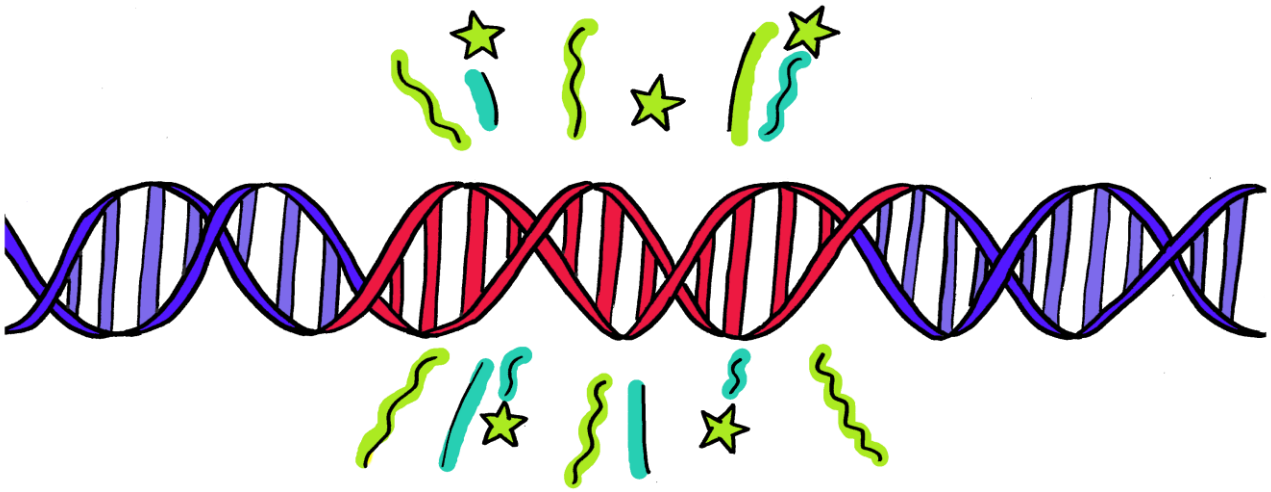
UNIQUE

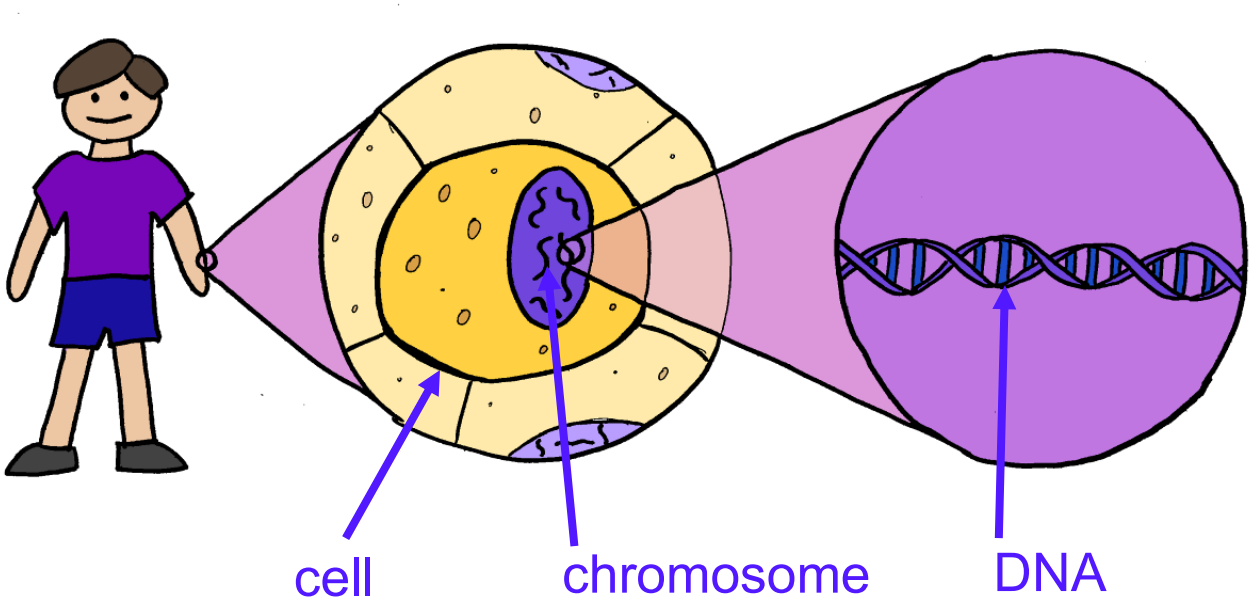
UNDERSTANDING GENES
& CHROMOSOMES



My Chromosome Story

A picture book for children with
a chromosome 5q14.3 microdeletion
including the MEF2C gene

rarechromo.org

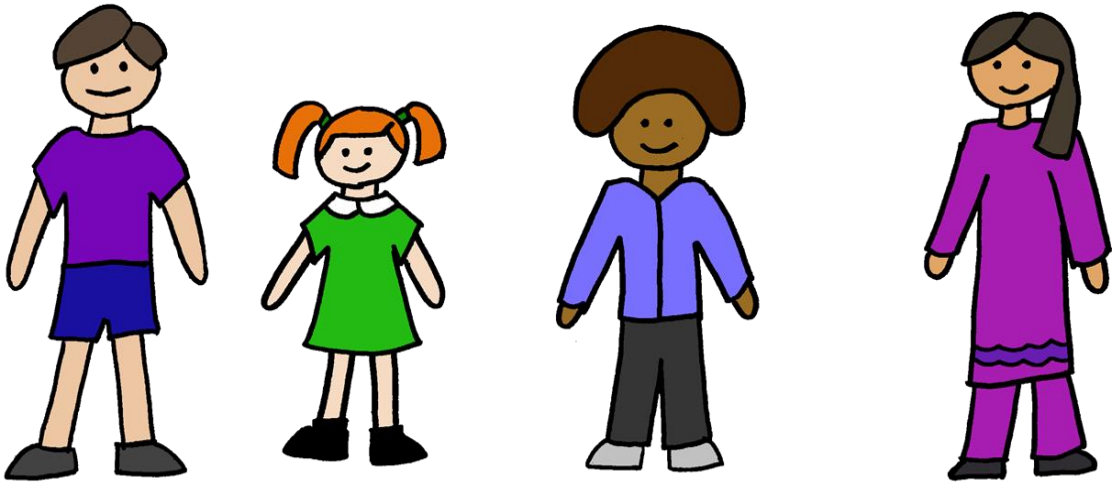


Your body is built from tiny building blocks called cells.

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.

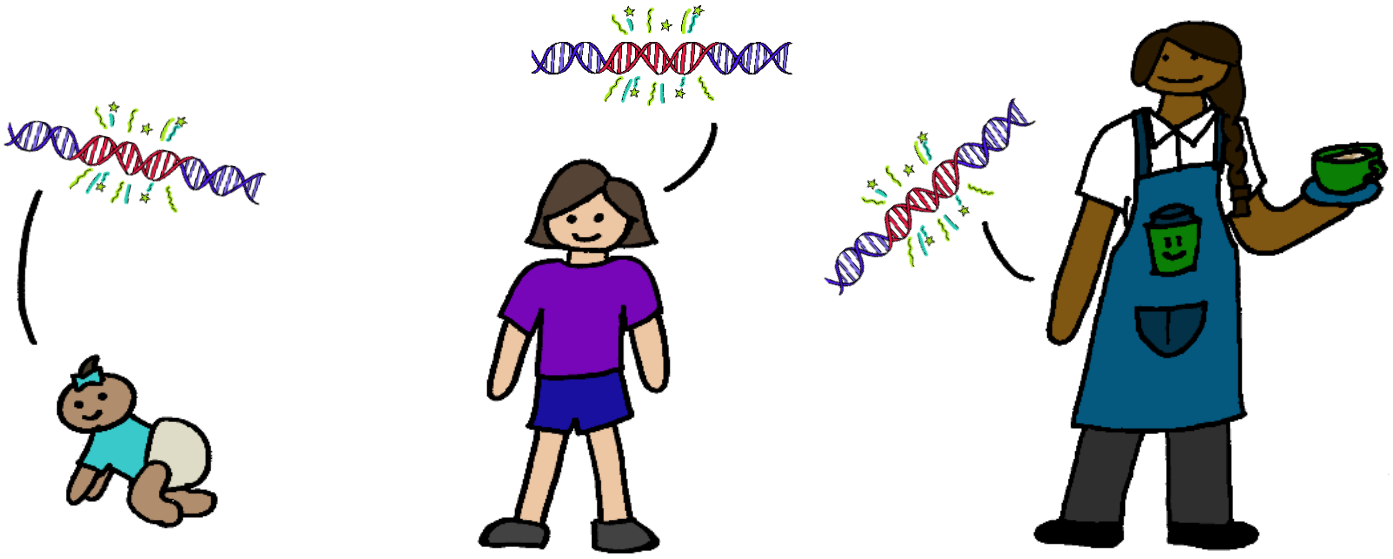
Things that happen in your life make a difference as well.
If you listen to lots of music you might know more songs.
If you don’t get enough sleep you might feel tired.

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 5th chapter of your 'instruction book': chromosome 5.

Your missing piece of DNA is called a microdeletion. Micro means a very little piece, and deletion means a copy is missing.

You also have another copy of chromosome 5 that has not been changed.



There are lots of other children who have the missing bit of chromosome 5 like you. They live all over the world.

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

Most people with this deletion have an important gene missing, it's called MEF2C.

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 5 have more trouble learning to walk, and may need to use a frame or wheelchair.

Some learn how to make friends without talking, and use other ways to communicate instead.

Some have seizures, which are like little fireworks going off in your brain.

And some need more help and time to learn new things.

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 I rarechromo.org

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

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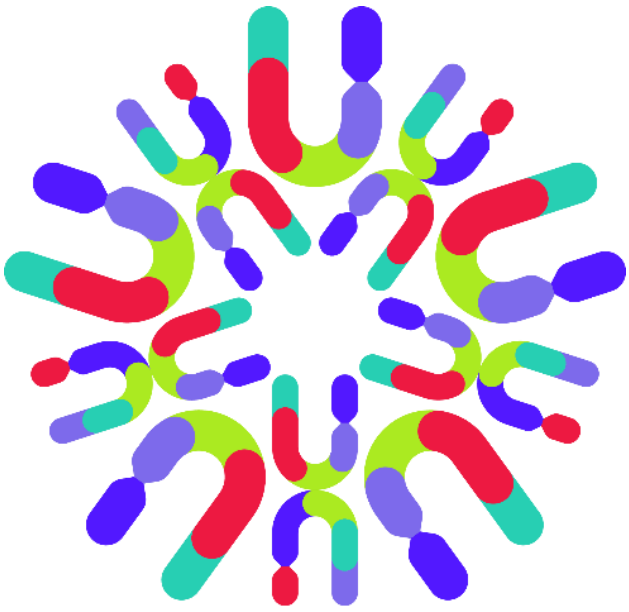
Families should consult a medically qualified clinician in all matters relating to genetic diagnosis, management and health.

This children's booklet was compiled by Unique, Amir Bashiri, McGill undergraduate student in Physiology and member of McGill Rare and Aliya Karsan, McGill undergraduate student in Biochemistry 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.

2026 Version 1 (AP)



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