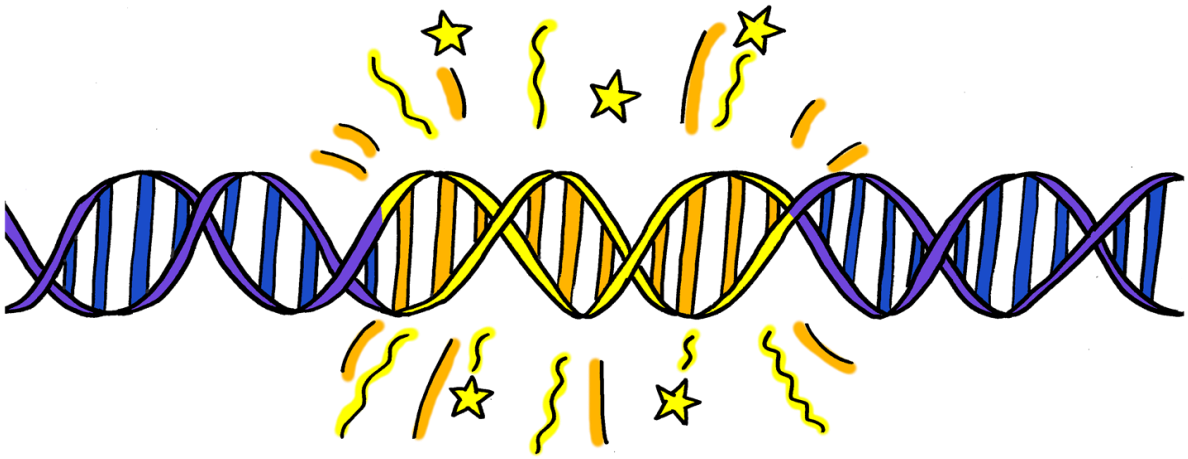
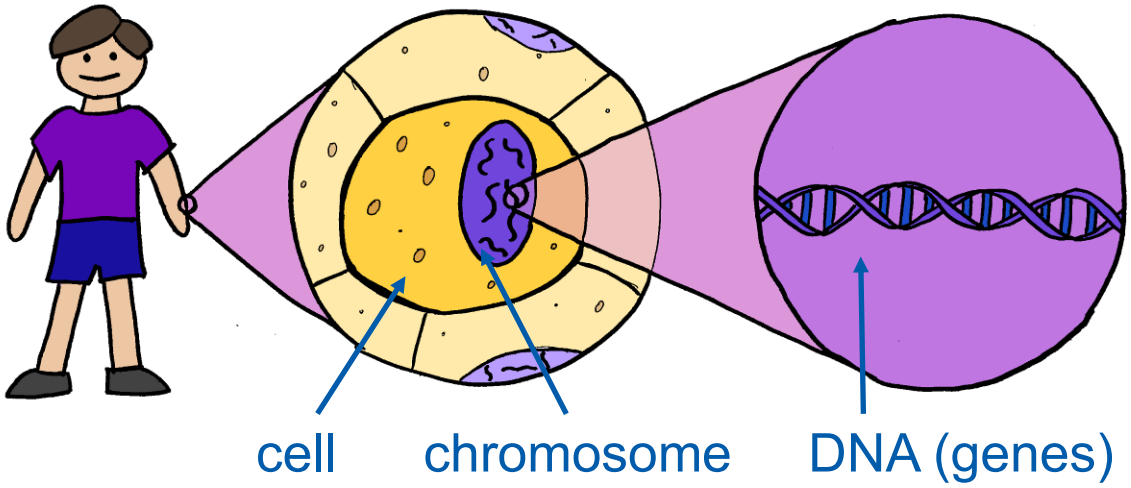


My Gene Story

A picture book for children with
Malan syndrome

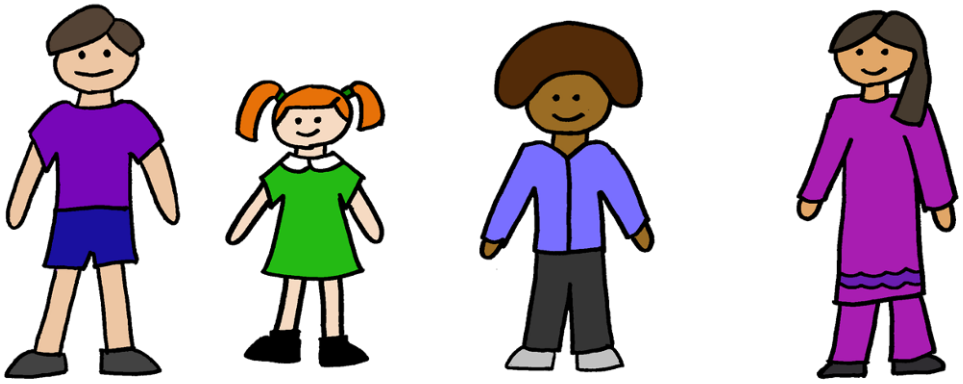


Your body is built from tiny building blocks called cells.

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

These instructions are called genes.

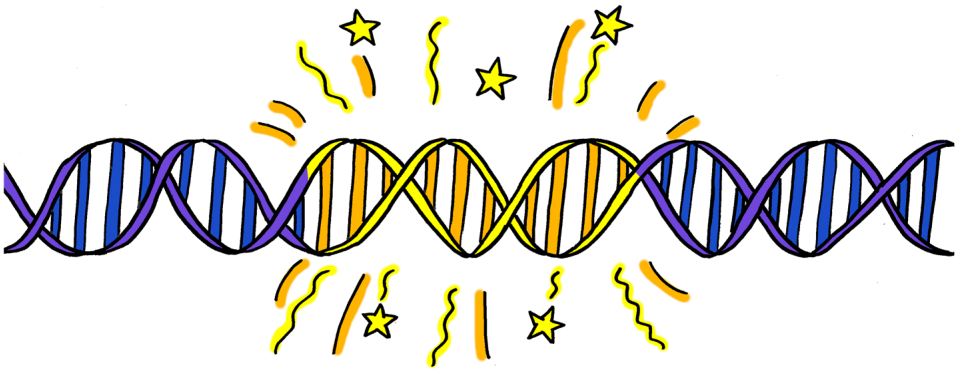
It might help to imagine that your cells contain a big book of instructions and each gene is a different sentence in the book.



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

But genes don’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.

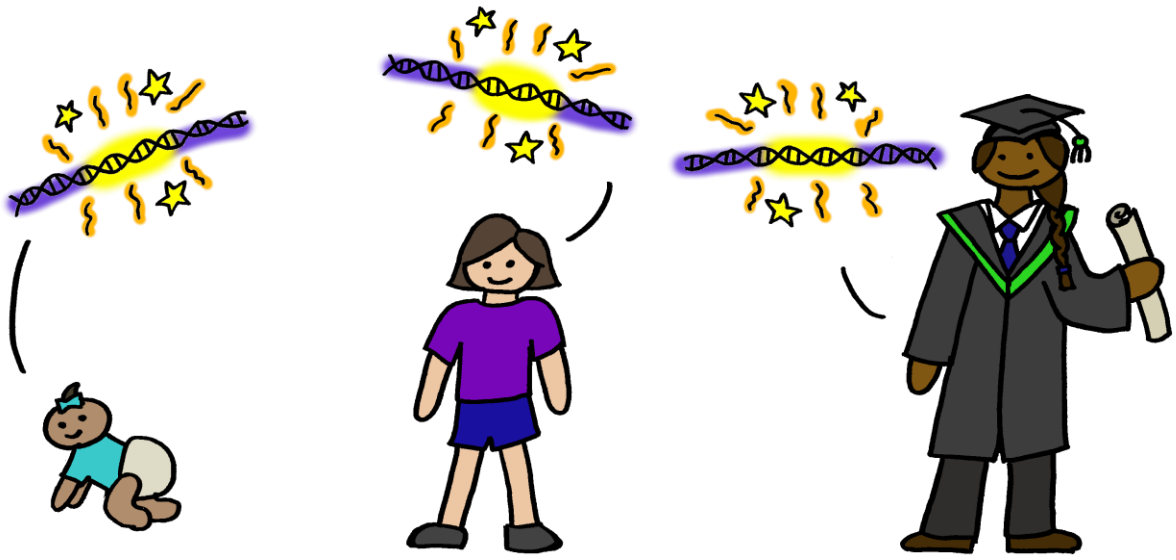


We all have thousands of genes, and each gene has its own special name.

Sometimes one of our genes has a change in it and this can change its instructions.

One of your genes, called NFIX, has a tiny change so one copy of this gene can’t give its usual instructions.

You also have another copy of the NFIX gene that has not been changed.



There are other children who have a tiny change in their NFIX gene like you. They all have Malan syndrome.

Just like children without this change, you are all different from each other.

Some children with this gene change find some things harder to do than children without it, but this is different for each child.

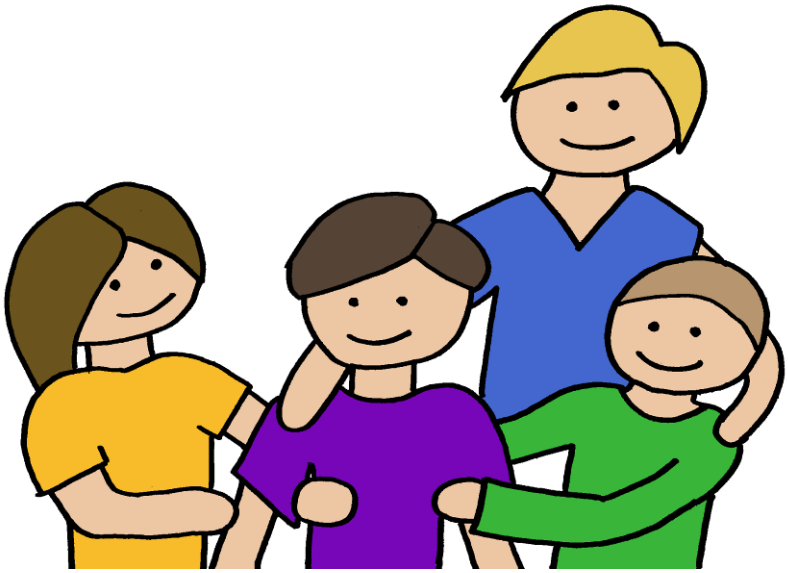
Some children with an NFIX gene change take longer to learn how to walk and talk.

Some need more help to understand things.

Some can’t see very well without glasses.

And some feel a bit fed up when it’s difficult to talk or understand what grown-ups are saying.

It is good to know about the change in your gene, because now if you find some things difficult to do, your family and teachers will 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
info@rarechromo.org I www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at http://www.rarechromo.org/donate Please help us to help you!

Websites and Facebook groups:

Malansyndrome.org - Our mission is to improve the lives of individuals and families affected by Malan syndrome in the global community through support, outreach and research.

www.facebook.com/MalanSyndromeFoundation?mibextid=LQQJ4d

www.instagram.com/malansyndromefoundation_?igsh=MWw3NjFsMHFiZ29iNA%3D%3D&utm_source=qr

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

2024 Version 1 (CA)