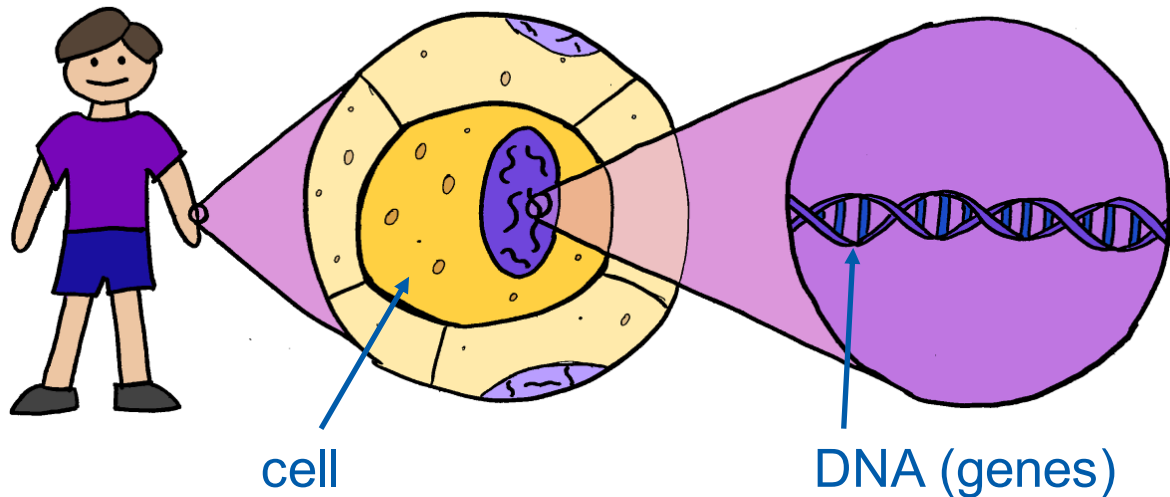




# My Gene Story

A picture book for children with  
Wiedemann-Steiner syndrome  
(WSS)

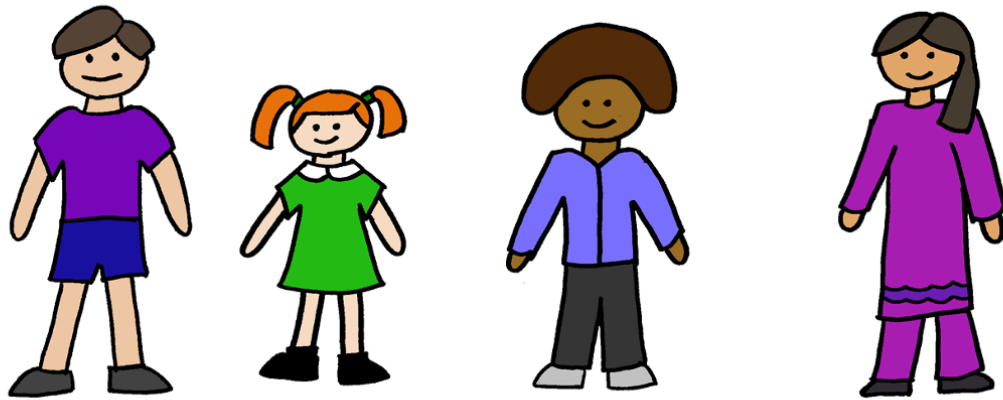


Your body is built from tiny building blocks called **cells**.

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.

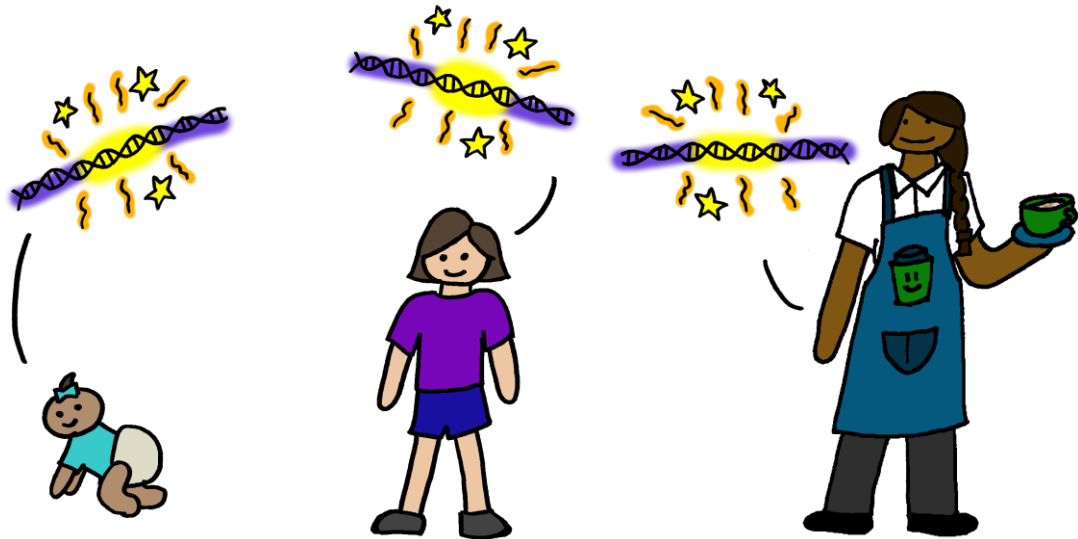


We all have thousands of genes, and each gene has its own special name.

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

One of your genes, called **KMT2A**, has a tiny change so one copy of this gene can't give its usual instructions.

You also have another copy of the KMT2A gene that has not been changed.



There are other children who have a change in their KMT2A gene like you. They all have **Wiedemann-Steiner syndrome**, which is called **WSS** for short.

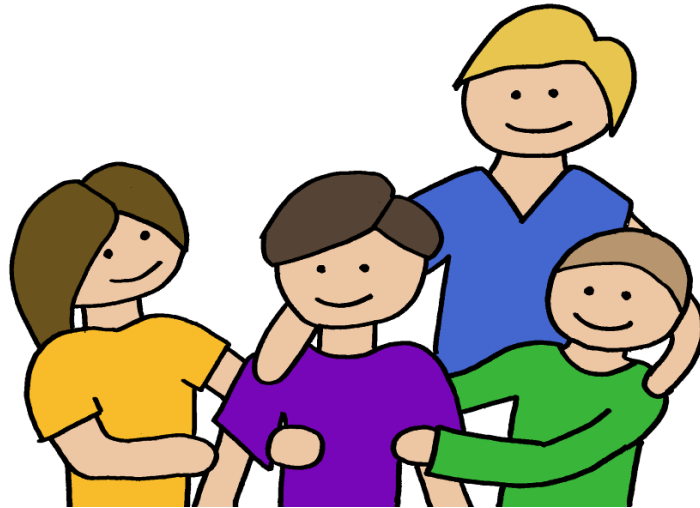
Just like children without this change, you are all different from each other.

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



Some children with WSS take longer to learn how to walk and talk. Some children need more help to understand things. Some children feel a bit fed up when it's difficult to talk or understand what grown-ups are saying.

It is good to know that you have WSS, 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



Understanding Chromosome & Gene Disorders

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

### National Wiedermann-Steiner syndrome (UK)

Website: <https://nwsswarriors.org.uk/>

Facebook: <https://www.facebook.com/NWSSWarriors>

### WSS Foundation (US)

Website: [www.wssfoundation.org](http://www.wssfoundation.org)

Facebook: <https://www.facebook.com/wssfoundation>

Instagram: <https://www.instagram.com/wssfoundation/>

Twitter: <https://x.com/wssfoundation>

### WSS Facebook Support group:

Parent Support Group:

<https://www.facebook.com/groups/667174239987278>

Wiedemann -Steiner Syndrome: Info for Families, Friends, and Professionals

<https://www.facebook.com/groups/339084866256825>

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

This children's guide was compiled by *Unique* using a booklet written by Dr. Seonaid Beaumont, Sheffield, UK. The original work is licensed under a Creative Commons Attribution-ShareAlike 4.0 International License.



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