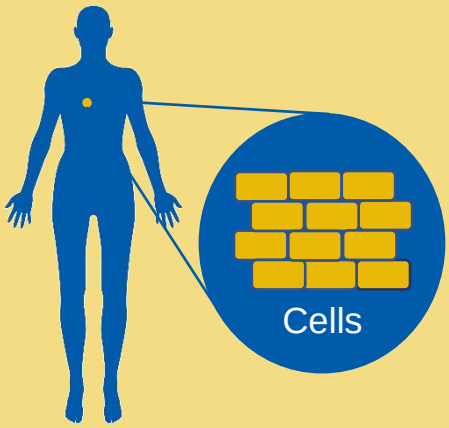
Easy Read Guide for people with 21q22.13 deletions

rarechromo.org

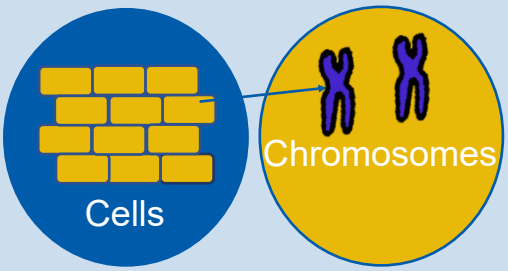
This leaflet is for people with a

21q22.13 deletion

Before we learn about 21q22.13 deletions, first let us learn a little bit about our bodies.



Our bodies are built from millions and millions of tiny building blocks called cells.

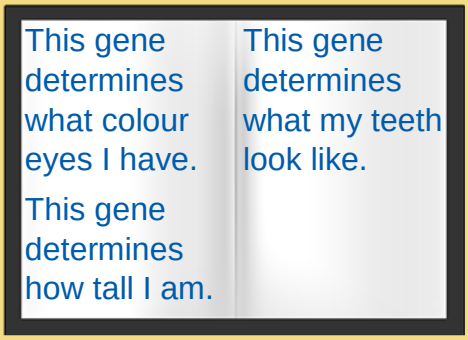


Our cells contain chromosomes.

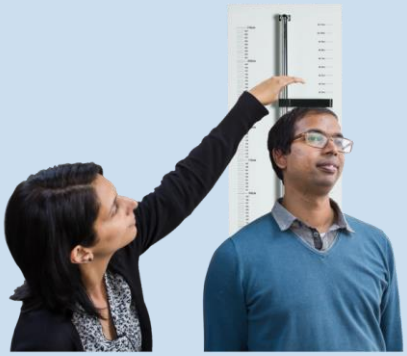
Chromosomes are full of instructions that tell our bodies how to work.

These instructions are called genes.

It might help to imagine that each chromosome is like a chapter in a book.

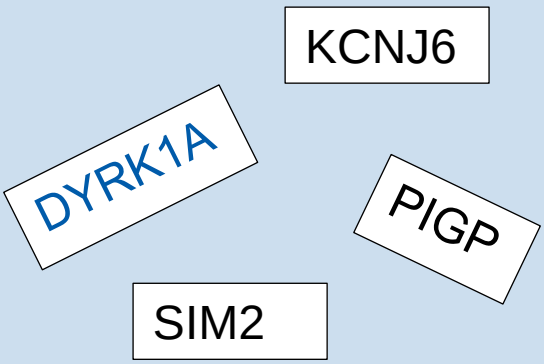


And that each gene is like a different sentence in the book.

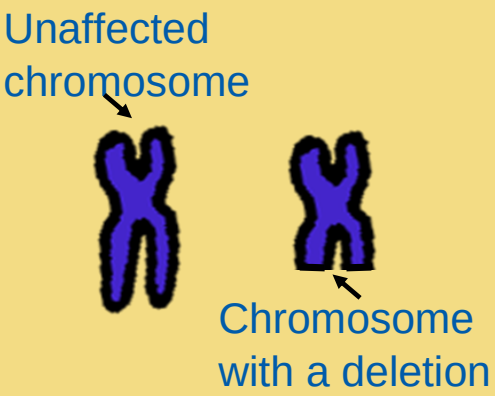


Our genes help to determine lots of things about us, like how tall we are.

And what colour hair we have.



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



When we have a deletion, a piece of chromosome is missing and genes are lost.

We all have two copies of most chromosomes.

So if we have a deletion, we usually have a second copy of the chromosome that has not changed.

Some people with a chromosome deletion have a genetic condition.

What is a genetic condition?

A genetic condition is something that can happen when a chromosome has a change to it.

If you have a genetic condition, it means that your health or development might be affected.

DYRK1A syndrome

People with a 21q22.13 deletion have a genetic condition.

Some people with a 21q22.13 deletion have DYRK1A syndrome.

Just like people who don’t have a deletion, people with a 21q22.13 deletion are all different from each other.

Some people with a 21q22.13 deletion find some things harder to do than other people with the deletion.

Some people find it difficult to learn how to read.

Some people find it difficult to learn how to speak.

Some people need a bit more help to understand things.

Some people find it difficult to make friends.

Some people feel a bit sad or worry a lot.

People with a 21q22.13 deletion might also have other difficulties as well as strengths.

Why do I have a 21q22.13 deletion?

Some people have a deletion because their mum or dad have it.

Some people are the first person in their family to have it.

If you had a child, they could have the same deletion too.

How do I know I have a 21q22.13 deletion?

You can only find out by having a genetic test.

It is good to know about your deletion so you can get extra help if you need it.

We all need help sometimes!

Can the deletion be replaced?

When a piece of chromosome is missing it cannot be replaced.

Knowing you have a deletion is important because it might help doctors and other professionals to find ways to help you.

If you would like to know more about your 21q22.13 deletion, you can talk to someone who knows about genetics or a charity like Unique.

Inform Network Support

Rare Chromosome Disorder Support Group
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Station Rd West,
Oxted,
Surrey.
RH8 9EE.
UK.
Telephone : +44(0)1883 723356
Email : info@rarechromo.org
Website : www.rarechromo.org

Join Unique to meet other families and get 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: www.rarechromo.org/donate Please help us to help you!

Websites that you might find helpful:

DYRK1A.org

https://www.learningdisabilities.org.uk/

https://www.turning-point.co.uk

https://www.unitedresponse.org.uk

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