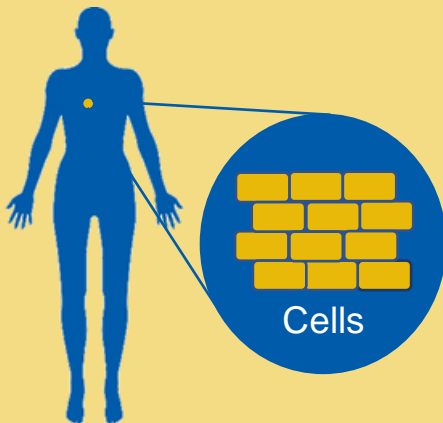


Easy read guide for people with CDK13-related disorder

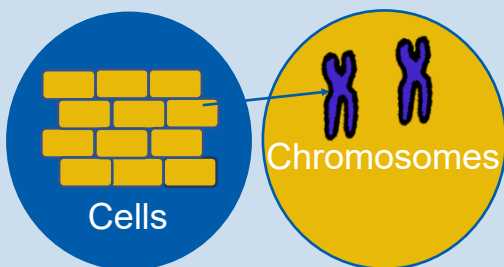
**This leaflet is for people with
CDK13-related disorder.**



Before we learn about what CDK13 is, 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 book and that each gene is like a different sentence in the book.

G A T C

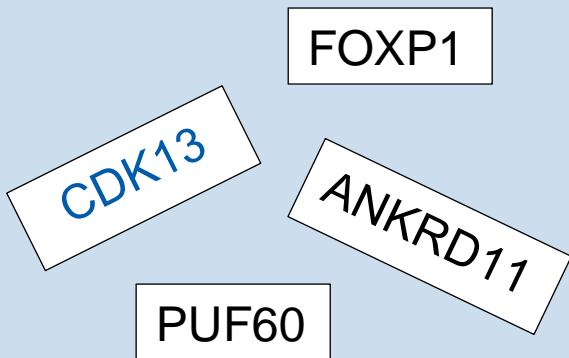
Genes are like really long sentences, but they are made from an alphabet that only has four letters.



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



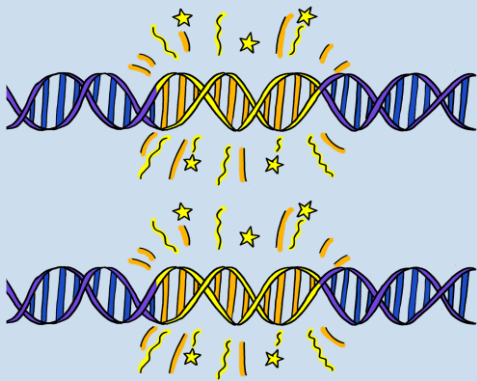
And what colour hair we have.



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

GATTCATGC
↓
GATCCATGC

Sometimes the letters in our genes are changed. This is called a gene variant. The variant can change how the gene works.



We all have two copies of most genes.



So, if we have a change to one gene, we usually have a second copy of the gene that has not been changed.

Genetic Condition

When we have a change in a gene we can have a genetic condition.



What is a genetic condition?

If we have a genetic condition, it means that the change in our gene has affected our health or development.

Disorder

What is a disorder?

When lots of people with a change in the same gene are affected, the genetic condition is sometimes called a disorder.



People with CDK13-related disorder live all over the world.



Just like people who don't have CDK13-related disorder, people with this disorder are all different from each other.



Some people with CDK13-related disorder find some things harder to do than other people with the same disorder.



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 CDK13-related disorder might also have other difficulties and strengths.



Why do I have a CDK13-related disorder?

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



We all have gene changes, but we only notice when important genes are changed.



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



How do I know I have a CDK13 gene change?

You can only find out by having a genetic test.



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

We all need help sometimes!



Can the change be removed?

A gene change cannot be removed or replaced.



Knowing you have a gene change 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 gene change, you can talk to someone who knows about genetics or a charity like Unique.

Inform Network Support



Rare Chromosome Disorder Support Group

Address : The Stables,
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:

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

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

<https://www.unitedresponse.org.uk>

Facebook group: CDK13 – Genetic Disorder

<https://www.facebook.com/groups/121545531684772>

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