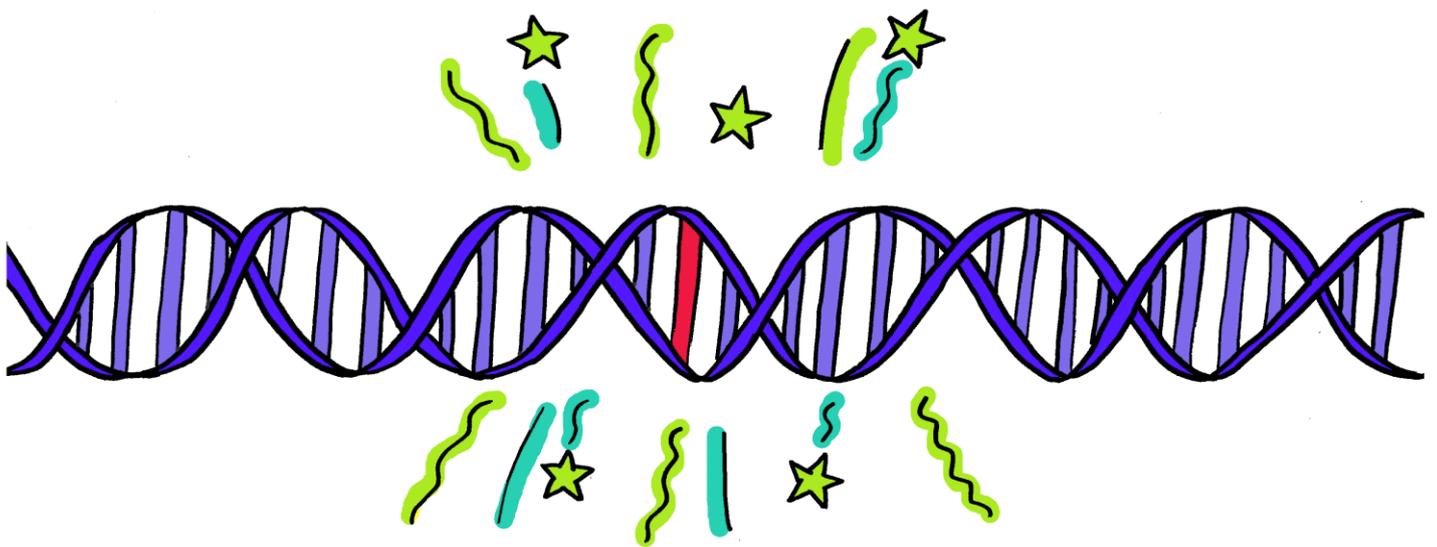


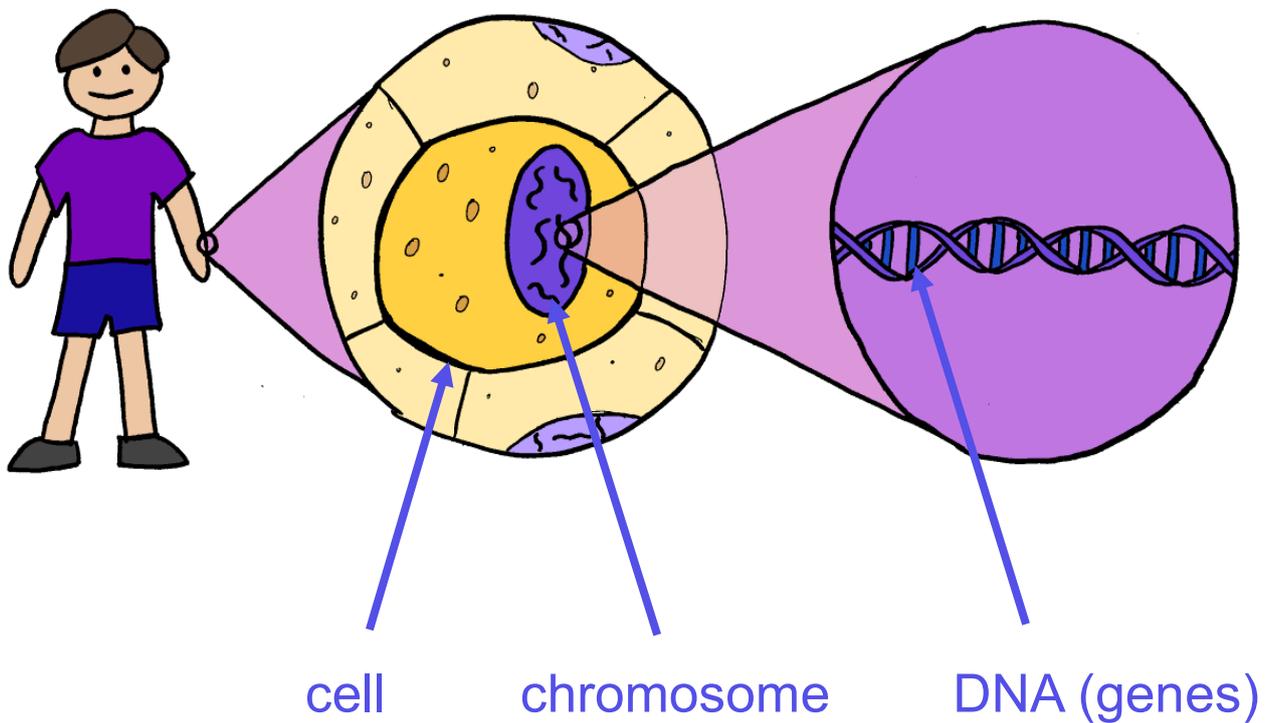
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UNDERSTANDING GENES
& CHROMOSOMES



ZTTK syndrome

A picture book about
ZTTK syndrome (SON-related syndrome)

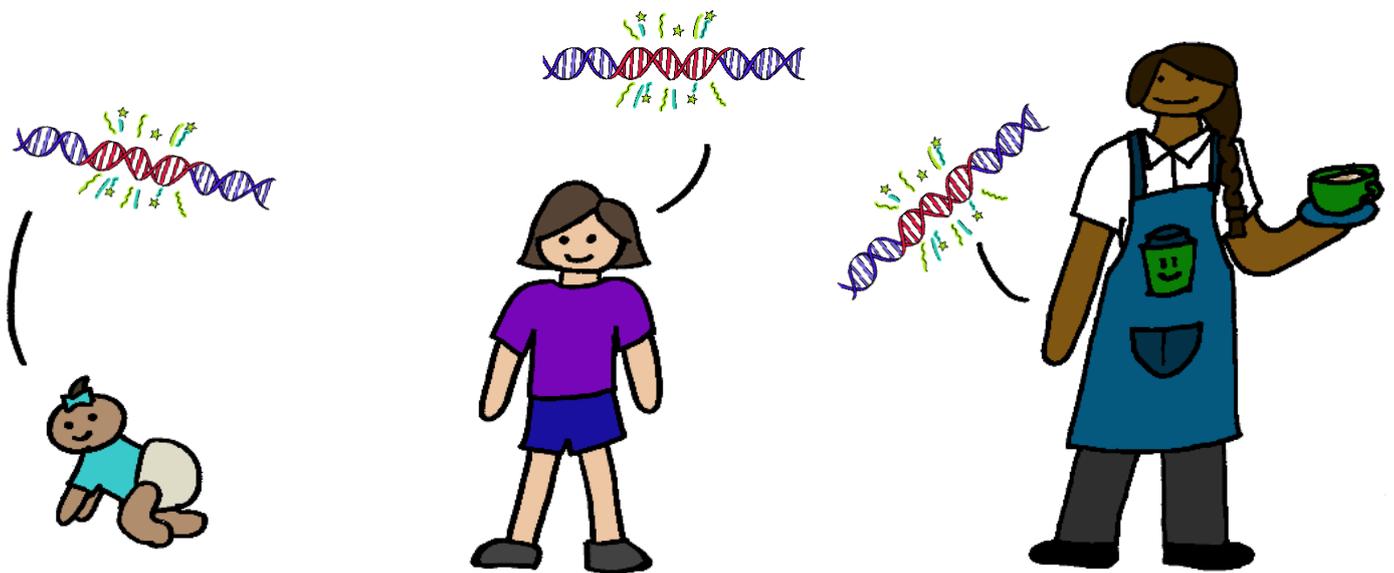


Our bodies are built from tiny building blocks called **cells**.

Almost all our cells contain **DNA**, which is full of instructions on how to make us.

These instructions are called **genes**.

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

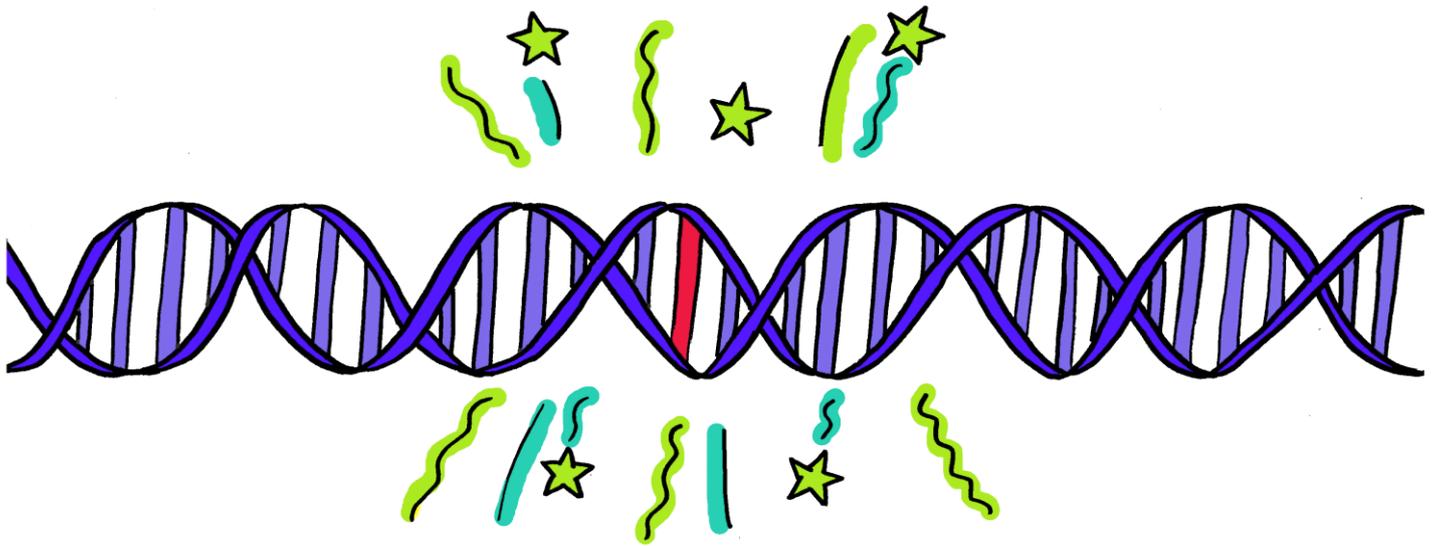


Genes help to determine how tall we are, what colour hair we have, and lots of other things about us.

But genes don't determine everything.

Things that happen in our life make a difference as well.

If we listen to lots of music, we might know more songs. If we don't get enough sleep, we 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.

When a change happens in a gene called **SON**, then the person with the change will have **ZTTK syndrome**.

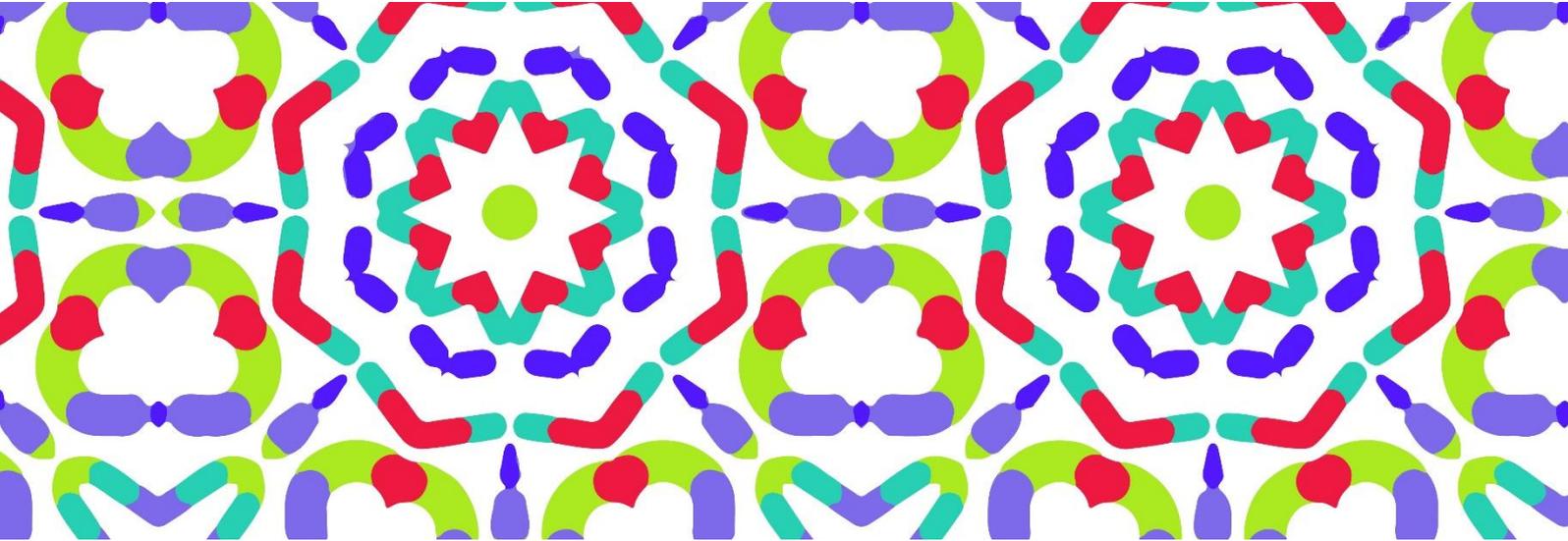


There are lots of children who have **ZTTK syndrome** and they live all over the world.

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

Children with **ZTTK syndrome** like to do lots of things like:

- ... listen to music
- ... watch TV shows and movies
- ... splash in a swimming pool
- ... clap their hands when they are excited
- ... play on the swings
- ... giggle and laugh when they are happy!

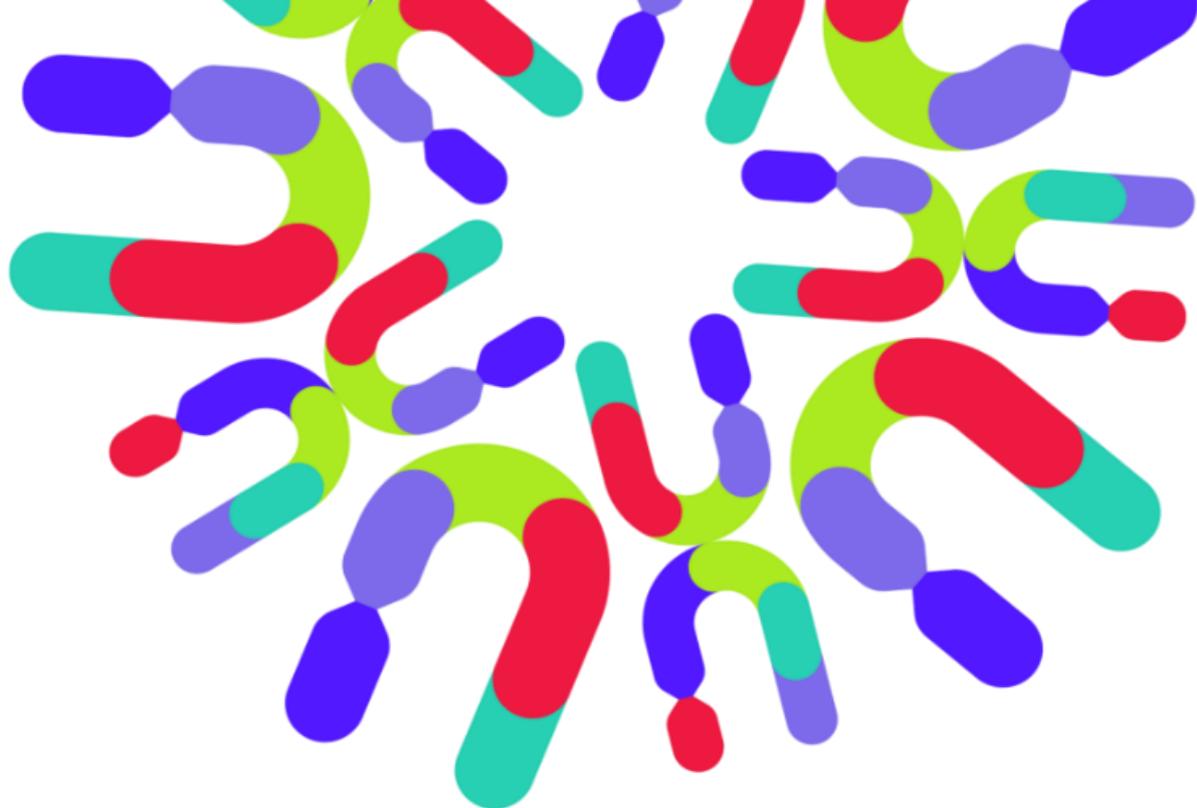


Children with **ZTTK syndrome** may find some things more difficult as well. Some find it harder to:

- ... walk, talk, eat or sleep without help
- ... express how they are feeling,
which might mean they get frustrated
- ... learn or understand things
- ... do activities since their muscles may not
be very strong

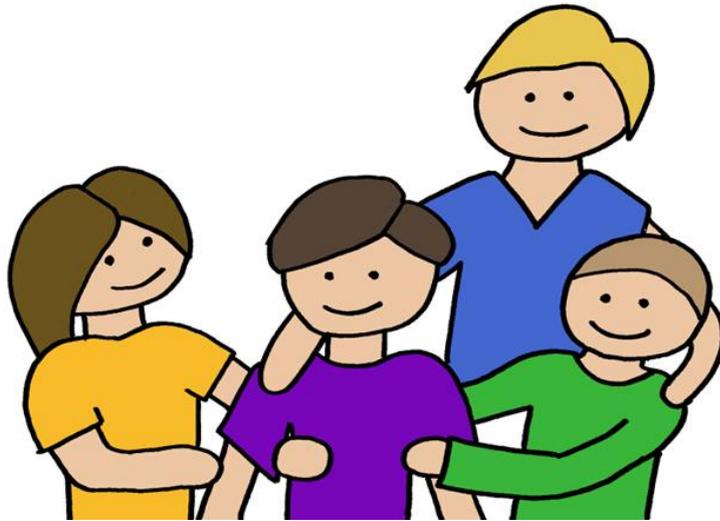
Some children can become overwhelmed by loud noises or certain textures so we should be gentle and calm if we notice they are stressed.

Children with **ZTTK syndrome** may have more doctor and therapy appointments to help them. At school, children may have extra help to allow them to do things that others do.



Sometimes, children with **ZTTK syndrome** have epilepsy which can cause them to have seizures, and this can look scary. If this happens when you are with them, it is important to stay calm, tell a parent or responsible adult and make sure there is nothing near them that could hurt them.

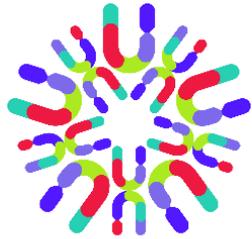
Children with **ZTTK syndrome** can understand much more than they can say and have their own special ways of communicating. Lots of children with **ZTTK syndrome** use sign language or pictures to express themselves ... and they often give great hugs!



It is good to know when someone has **ZTTK syndrome**, because it will help their family, friends and carers understand their needs better.

Children with *and* without **ZTTK syndrome** are all different and we all need help sometimes – so it is important to support each other.

Inform Network Support



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Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey, RH8, 9EE, UK
Tel: +44(0)1883 723356
help@rarechromo.org | rarechromo.org

Join Unique for family links, information and support:

[Become a member](#)

Please help us to help you!

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

[Donate via our website](#)

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 and reviewed Dr Mari Mori (MD), Associate Professor, Human Genetics, Emory University School of Medicine, Atlanta, Georgia, USA. This booklet is 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.

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