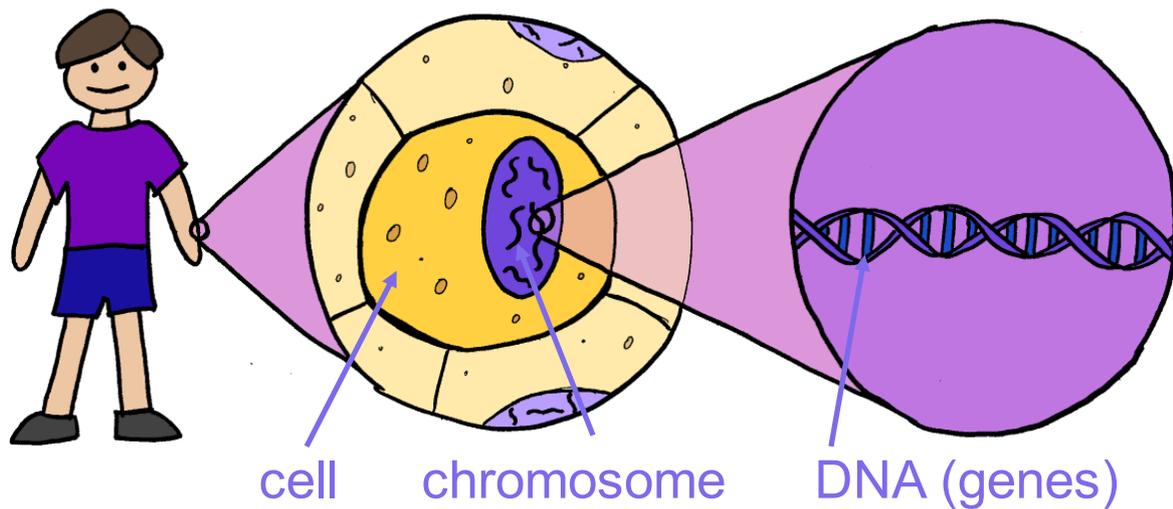


ReNU syndrome

A picture book about
ReNU syndrome and the RNU4-2 gene

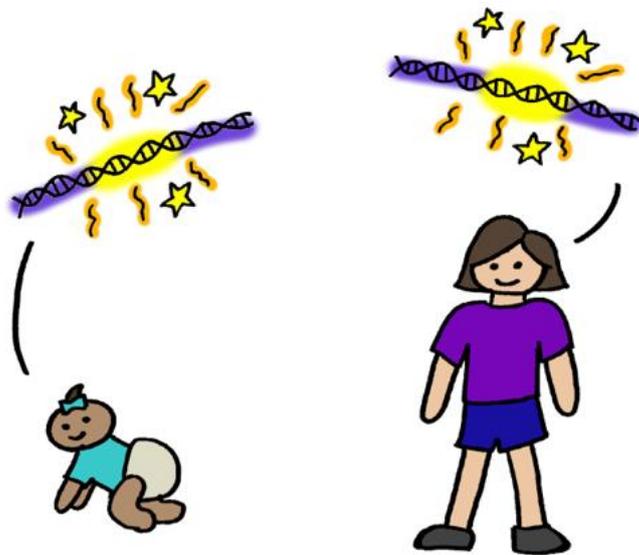


Our bodies are built from tiny building blocks called **cells**.

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.

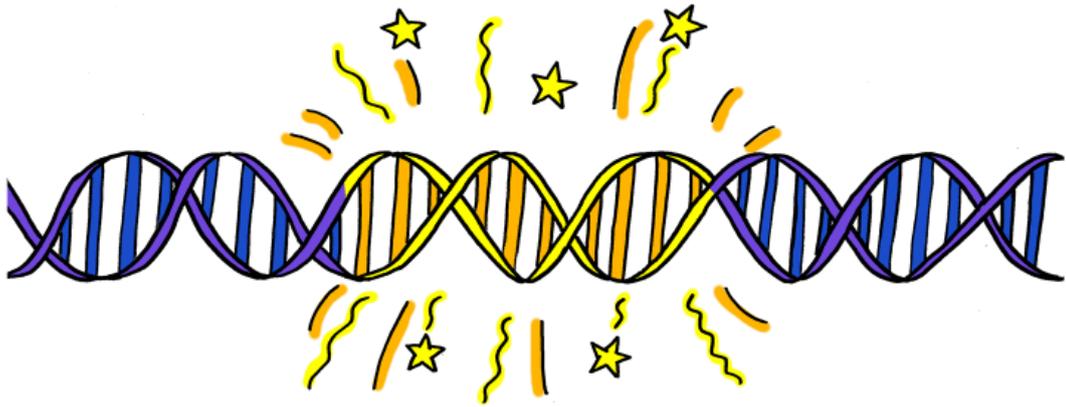


Genes help to determine how tall we are, what colour hair we have, and lots of other things about us.

But genes don't determine everything.

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

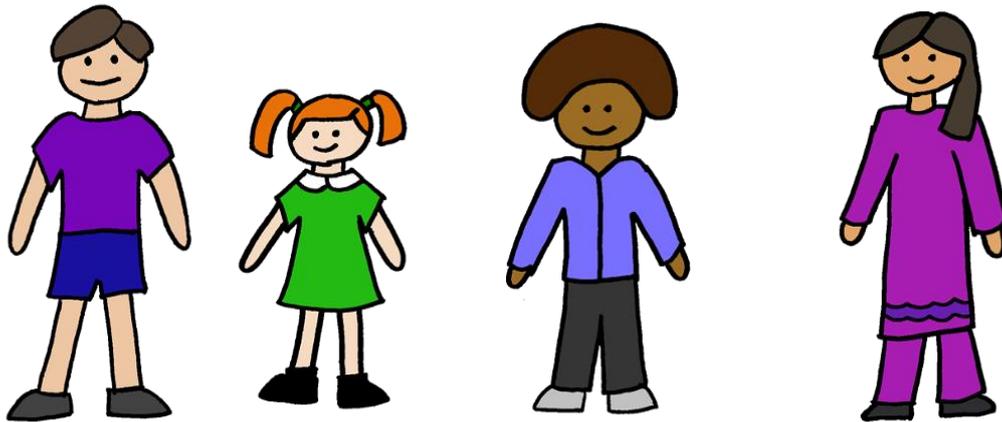
If we listen to lots of music, we might know more songs. If we don't get enough sleep, we might feel tired.



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 **RNU4-2**, then the person with the change will have **ReNU syndrome**.



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

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

Children with ReNU 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!

ReNU syndrome

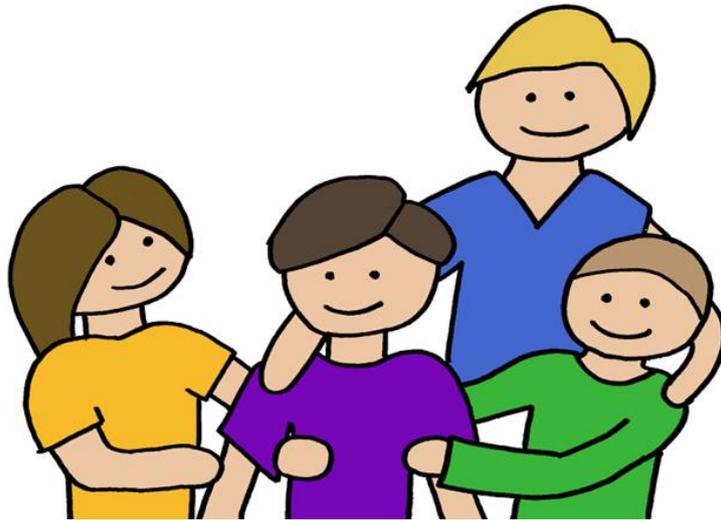


Renewing hope
for the future!

Children with ReNU 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
- ... learn or understand things
- ... do activities since their bones may be fragile or they might not be able to see very well

Children with ReNU syndrome may have more doctor and therapy appointments, may dribble or drool, and might get frustrated easily because of their challenges.

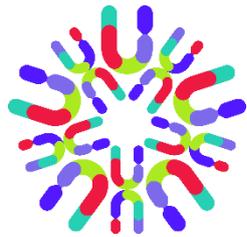


Children with ReNU syndrome can understand much more than they can say and have their own special ways of communicating. Lots of children with ReNU syndrome are known for giving great hugs!

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

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

Inform Network Support



unique

UNDERSTANDING GENES
& CHROMOSOMES

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

Join Unique for family links, information and support.

<https://rarechromo.org/join-us/>

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!

ReNU syndrome Resources:

[Unique ReNU syndrome guide](#)

www.renusyndrome.org

<https://www.facebook.com/groups/rnu4-2>

<https://www.facebook.com/RNU4-2/>

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.

Violet, aged 9, has contributed to and reviewed this Gene Story. Violet has a big brother named Devon who has ReNU syndrome.

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