



Understanding Chromosome & Gene Disorders

### Rare Chromosome Disorder Support Group

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Join UniqUe for family links, information and support.

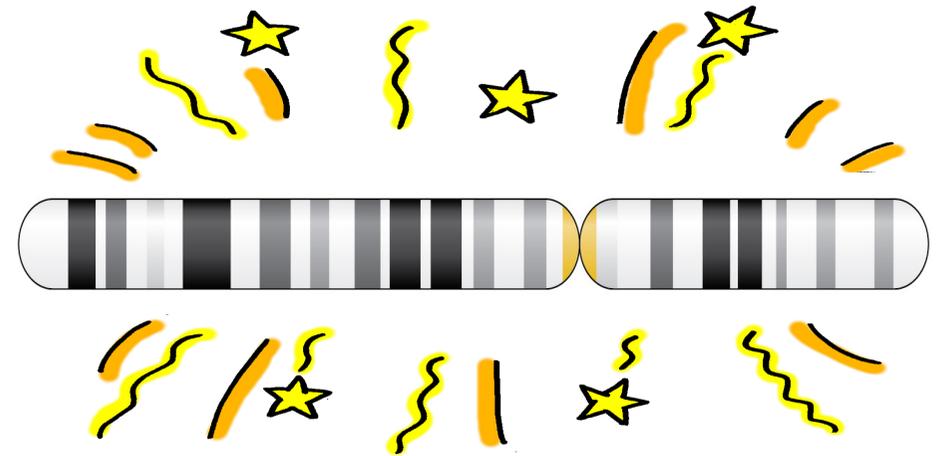
UniqUe is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at <http://www.rarechromo.org/donate> Please help us to help you!

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

This guide was compiled by *UniqUe* using a guide written by Dr. Seonaid Beaumont, Psychiatry Doctor, Sheffield, UK. The original work is licensed under a Creative Commons Attribution-ShareAlike 4.0 International License.

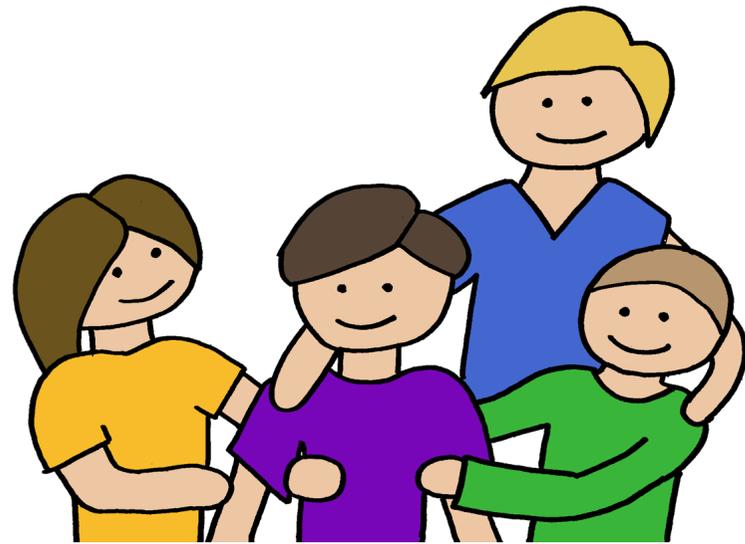
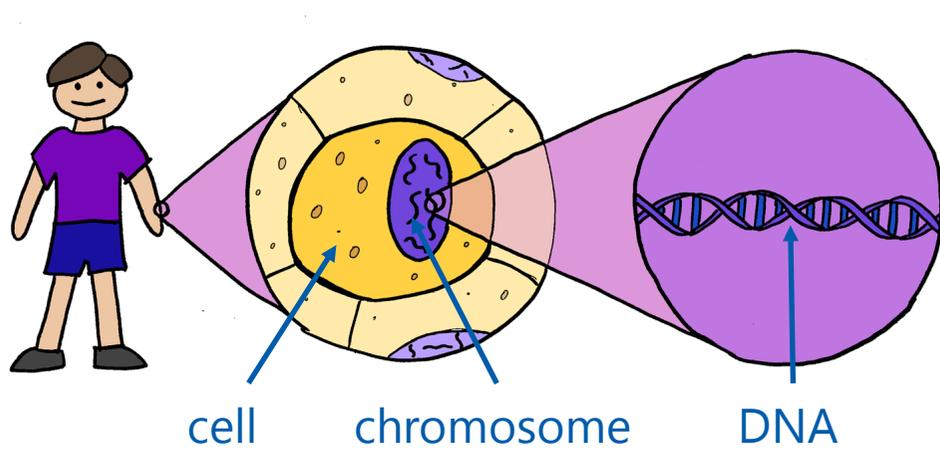


2020 Version 1 (AP)



# My Chromosome Story

A picture book for 49,XXXXY syndrome



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

Almost all of your cells contain **DNA**, which is full of instructions on how to make you. The instructions are quite long and complicated and so they are split into different parts called **chromosomes**.

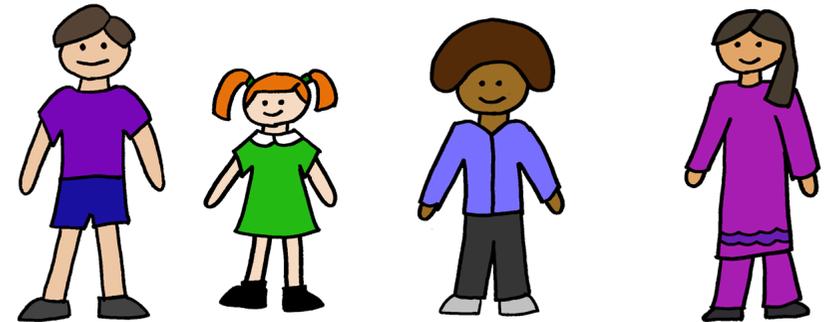
It might help to imagine the instructions are like a big book, and each chromosome is a different chapter.

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.

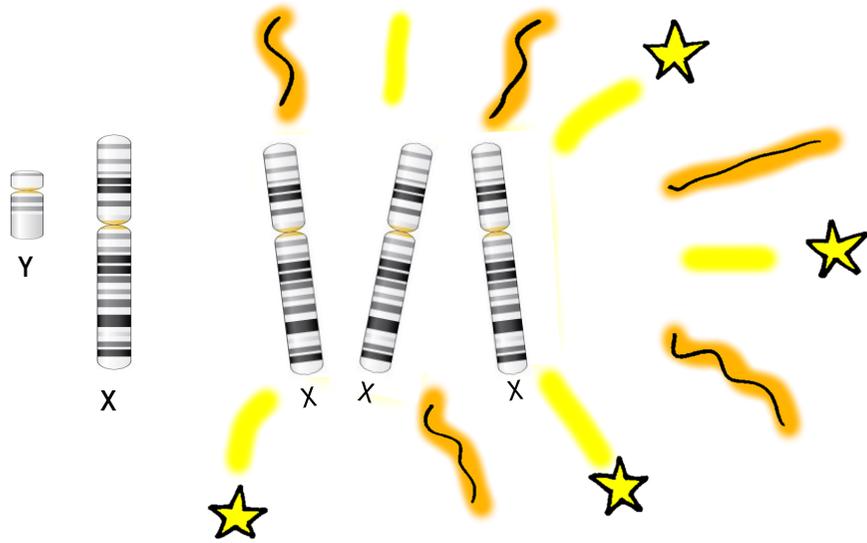


Some people with three extra X chromosomes take a bit longer to learn how to talk and walk when they are little. Some children need a bit more help at school to understand things properly. Some children don't have very strong muscles and have joints that bend a lot and elbows that are difficult to turn.

It is good to know about your extra DNA, because if you find some things difficult to do, your family and teachers will be able to help you even more.



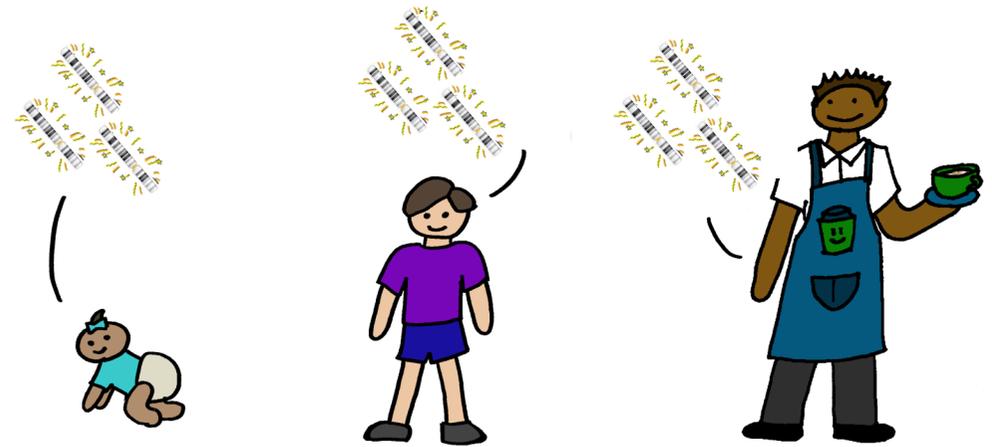
DNA helps to determine how tall you are, what colour hair you have, and lots and lots of other things about you. But DNA doesn't determine everything. Things that happen in your life make a difference as well, like if you live in a sunny place you might get darker skin, or if you do lots of art you might become more creative.



Everyone's DNA is different: some people have extra bits, some people have missing bits and some people have bits that have moved to a different place on a chromosome.

Inside **your DNA** there are **extra bits**. You have more copies of 'chapter X' in your 'instruction book' than most people.

You have three extra copies of your **X chromosome**.



Other people also have three extra copies of their X chromosome like you. Just like people without this extra DNA, you are all different from each other.

Some people with extra X chromosomes find some things harder to do than people who do not have this extra DNA, but this is different for each person.