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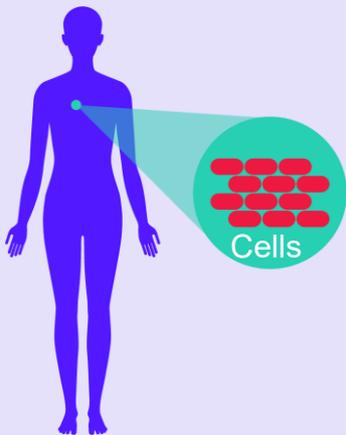
UNDERSTANDING GENES
& CHROMOSOMES

Easy Read Guide for People with RAC1-Related Neurodevelopmental Disorders

rarechromo.org



Before we learn about RAC1-related neurodevelopmental disorders, first let us learn a little bit about our bodies.

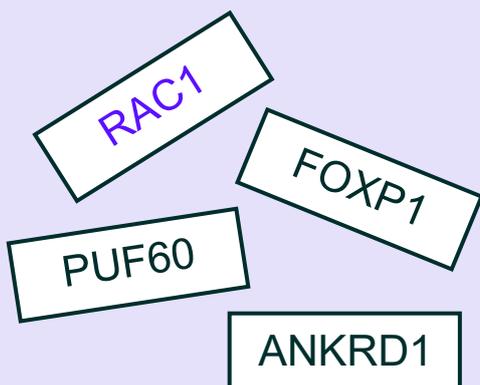


Our bodies are built from millions of tiny building blocks called cells.



Our cells contain genes.

Genes are the instructions that tell our bodies how to grow and work.



We all have thousands of genes.

Each gene has its own special name and function.



Sometimes we have a change in a gene.

The change can affect how the gene works.

RAC1

A change in a gene called RAC1 causes RAC1-related neurodevelopmental disorder, or RAC1-NDD for short.



What is RAC1-NDD?

RAC1-NDD is a genetic condition.



People with RAC1-NDD live all over the world and they all have a change in the RAC1 gene.



Some people with RAC1-NDD find some things harder to do than other people with RAC1-NDD.



Some people find it difficult to learn how to read.



Some people find it difficult to learn how to speak.



Some people need help to understand things.



Some people do not sleep very well.



Some people feel a bit sad or worry a lot.

There is help for people who are sad and worry a lot.



You might also need to visit a doctor, dentist or therapist a bit more often than other people.



Most people with RAC1-NDD are happy and enjoy meeting other people.



Why do I have RAC1-NDD?

RAC1-NDD happens by chance.

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



We all have gene changes.

We only have a genetic condition when important genes are changed.



If you have a child, they could have RAC1-NDD too.



How do I know I have RAC1-NDD?

You can only find out by having a genetic test.



It is good to know that you have RAC1-NDD so you can get extra help if you need it.

We all need help sometimes!



Can the gene change be removed?

The gene change cannot be removed or replaced.

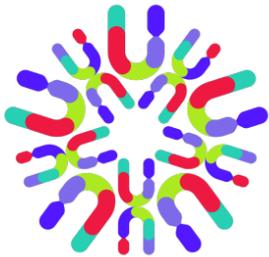


Knowing you have RAC1-NDD is important because it might help doctors and other professionals to find ways to help you.



If you would like to know more about RAC1-NDD, you can talk to someone who knows about genetics or a RAC1-NDD support group or a charity like Unique.

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 to meet other families and get information and support.

[Become a member](#)

Websites that you might find helpful

learningdisabilities.org.uk

turning-point.co.uk

unitedresponse.org.uk

Unique is a charity without government funding, existing entirely on donations and grants. If you can please [make a donation](#). Please help us to help you!

This guide was written by Unique and Ruby Allen, PhD student, University of Manchester, UK with images from Photosymbols.

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