



# **SETD5 Syndrome and You**

**A Kids' Guide to Understanding  
SETD5 Syndrome**

# Tiny Pieces of You

Your body is made of billions of tiny pieces called cells. They are so small you cannot see them, but they are part of every part of you - from your fingers to your eyes to your heart and brain, and more!

And inside every single one of those tiny cells is something even more amazing.

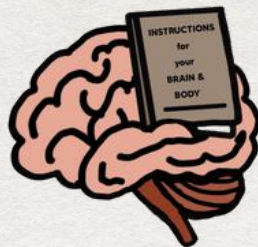


# What Are Genes?

Inside each cell is a set of instructions called genes. You can think of them like an instruction manual for your body. These instructions help make you who you are and help your body grow and develop.

Every person has their own instruction manual, and no two are exactly the same.

They are part of what makes you you.





# The Important SETD5 Gene

Most people have two copies of a gene called SETD5.

SETD5 is special because it does not just do one job by itself. It helps many other genes in your body know how to do their jobs too.

That means it can affect lots of important things, like how your body grows, how you learn, and how you experience the world around you.



# A Name for It

In kids with SETD5 Syndrome, one SETD5 copy is a little different or missing. That can affect how the body and brain grow, learn, and work.

A “syndrome” is just a name doctors use when a group of things often happen together.

That is what SETD5 Syndrome means.



# Everyone's Different

Because that small change in the SETD5 gene affects everyone a little differently, people with SETD5 Syndrome can be very different from one another.

One person may need help with talking.  
Another may need help with learning.

Someone else may be extra sensitive to sounds, textures, or change.



# Uniquely You

But just like no two people with SETD5 have the same challenges, no two have the same strengths either.

One kid might be a great artist. Another might have an amazing memory.

Someone else might be great at putting puzzles together.

No two people with SETD5 Syndrome are exactly the same, and that is part of what makes you uniquely you.

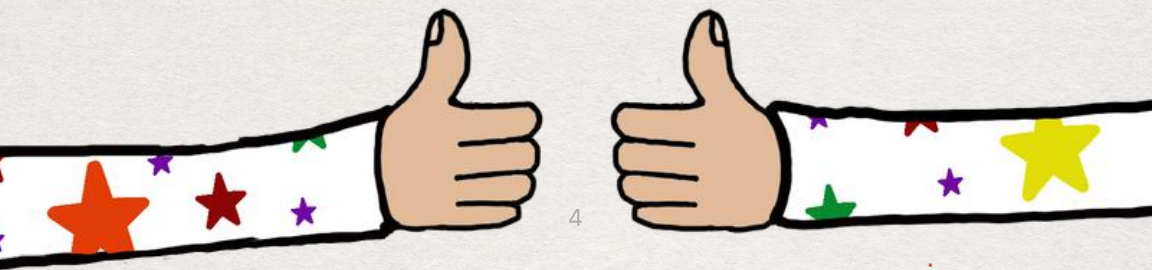


# We're on Your Team

Doctors, scientists, and educators are still learning about SETD5 Syndrome every day.

The more they learn, the better they can help kids and families like yours.

And having a name for it helps the people who care about you understand you better, support you better, and cheer you on as you keep being exactly who you are - one of a kind!



**psssst....You're awesome.**

For grown-ups: This book was created by a parent of a child with SETD5 Syndrome, for fellow SETD5 Syndrome families. You are welcome to download and print this book for personal use. Please do not modify or edit it in any way.

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