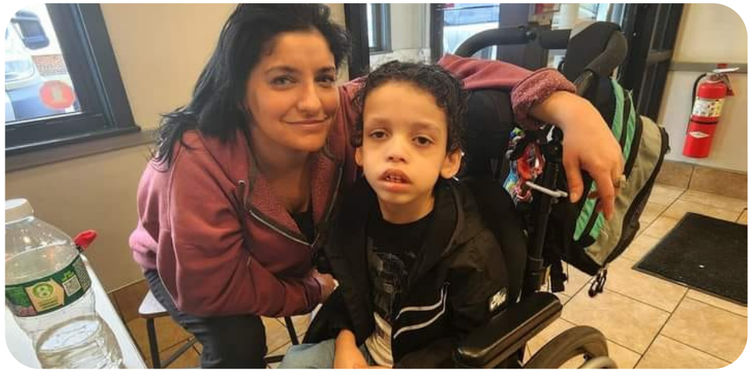
OUR MISSION

The SPATA Foundation's Mission is to advocate, educate, and drive research for SPATA5 and SPATA5L1 Related Disorders. Our hope is that our efforts will help us better understand the function of the genes & lead to treatment for disorders related to these genes.

The SPATA Foundation was created by a family affected by SPATA5L1, for everyone affected by SPATA5 and SPATA5L1 Disorders.

Our #1 priority is our children affected and the SPATA Families. Everything we do is for the betterment of the lives of those affected.



AMPLIFYING AWARENESS.
FUNDRAISING FOR HOPE.

SCAN TO DONATE

CONTACT US

Mariah George, President & Founder

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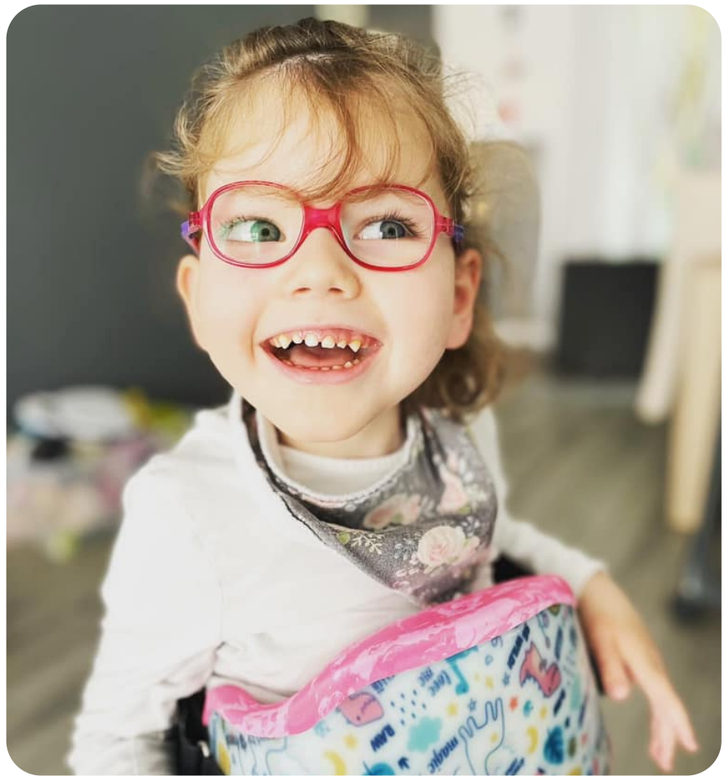
www.SPATAfoundation.org

THE SPATA FOUNDATION



AMPLIFYING AWARENESS.
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SPATAfoundation.org

WHAT IS SPATA5 AND SPATA5L1?

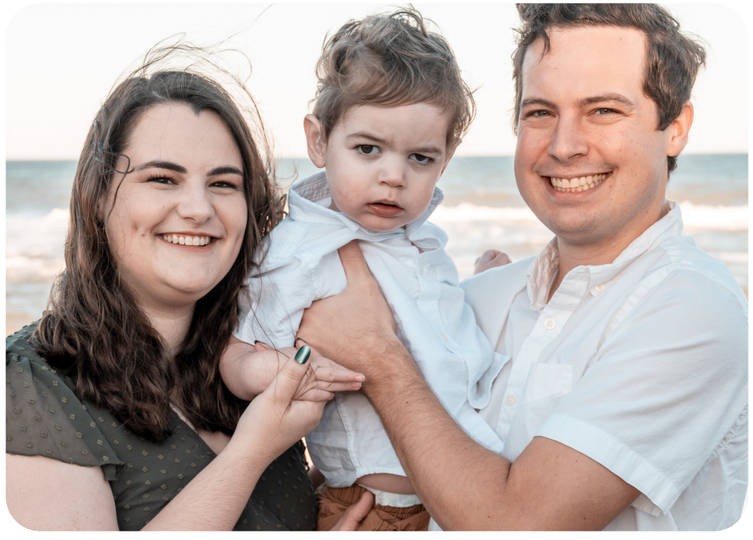
SPATA5 and SPATA5L1 are the names of the genes affected in these disorders. They are separate genes with a common ancestry and similar structure and function. Think of them like cousins. They are sometimes referred to as AFG2A(SPATA5) and AFG2B(SPATA5L1).

The function of these genes is not fully understood.

Because these genes are so closely related, disorders related to SPATA5 and SPATA5L1 result in hearing loss, epilepsy, developmental delay, movement disorders, and more.

Although we don't have an official number, we know there are somewhere between 100-150 diagnosed cases of these disorders world-wide.

DONATE TODAY AT
WWW.SPATAFOUNDATION.ORG



WE NEED YOUR HELP

We live in a world of rapidly advancing science. New medications are beind discovered daily and gene therapy is actively being used as treatment in multiple genetic disorders.

The science exists to find a cure for our children. Two things stand in our way: time and money.

YOU can help with one of those. We depend on donations to help us reach our goal of a cure.

ABOUT US

The SPATA Foundation is a non-profit organization founded by Mariah and Nicholas George. Their son, Luca, was diagnosed with SPATA5L1 Disorder in 2023.

The SPATA Foundation is the only patient organization dedicated to both SPATA5 and SPATA5L1 Disorders.

We are on a mission to treat and cure these ultra-rare diseases.

Launched in October 2023, The SPATA Foundation is running full-force towards every research avenue possible.

Rare diseases are often overlooked due to the small patient population, but these are our children. Our children deserve research and a cure.

Can you help us fund important research for a cure?