HOW WE HELP

SUPPORT & CONNECTION
Helping families find support and connect with others.

EDUCATION & RESOURCES
Providing the latest information to help guide families.

AWARENESS & ADVOCACY
Advocating for CUL3 recognition in medical and research communities.

RESEARCH & COLLABORATION
Supporting scientific research to improve outcomes and understanding of CUL3.

Feb 2025

EVERY CHILD, EVERY FAMILY, EVERY STORY MATTERS.
WHETHER YOU'RE LOOKING FOR SUPPORT, WANT TO HELP SPREAD AWARENESS, OR ARE INTERESTED IN RESEARCH, WE NEED YOU!

WWW.CUL3.ORG

CUL3
support & awareness

CUL3 SUPPORT & AWARENESS

BUILDING COMMUNITY

RAISING AWARENESS

SHAPING THE FUTURE

ABOUT US*

We are a not-for-profit patient advocacy group dedicated to those who are affected by CUL3-related neurodevelopmental disorder.

Our mission is simple:

- Support families by providing education and resources.
- Raise awareness so that healthcare providers and researchers better understand this disorder.
- Advocate for research that leads to improved care and future treatments.

CUL3-related neurodevelopmental disorder* is a rare genetic condition caused by pathogenic variants in the CUL3 gene. This autosomal dominant disorder can lead to a range of neurodevelopmental and health concerns, which vary from person to person.

While there is no cure, early interventions such as therapies (e.g., speech, occupational, physio), specialized education plans, and ongoing medical management can help improve functional skills and overall well-being.

More research is needed to fully understand this condition, and we are committed to supporting that progress.

** Also referred to as CUL3-related syndrome and neurodevelopmental disorder with or without autism or seizures (NEDAUS).*

SIGNS & SYMPTOMS

DEVELOPMENTAL/BEHAVIORAL

- Speech & language delays
- Gross & fine motor delays
- Intellectual disability
- Autism spectrum disorder
- ADHD
- Anxiety

NEUROLOGICAL

- Hypotonia
- Seizures
- Brain changes on MRI
- Dystonia, tremor, spasms

FEEDING & GROWTH

- Fetal growth restriction
- Feeding difficulties
- Growth faltering
- Digestive issues

OTHER

- Congenital heart defects
- Hand & foot abnormalities

It is important to note that this list is not exhaustive, and symptoms and characteristics vary in both presence and severity.