

RESOURCES

KIF1A.ORG

KIF1A.ORG is a global community dedicated to improving the lives of those affected by KAND (KIF1A Associated Neurological Disorder) and accelerating research to find a cure. As a patient-focused foundation spearheaded by parents of children with KAND, we're here to connect and support every family affected by this disorder.

We want to hear from you!

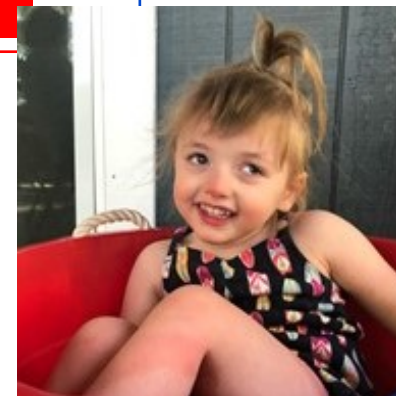
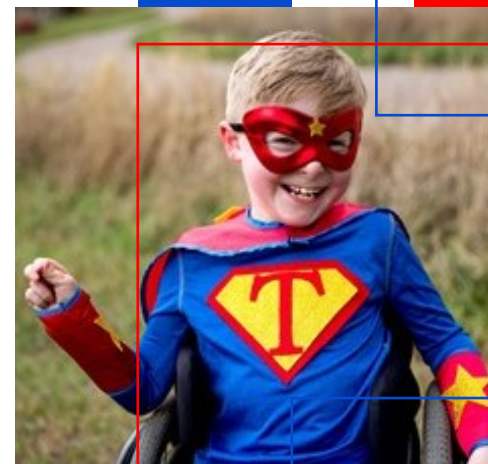
Email us at impact@kif1a.org.



www.kif1a.org

Our goal is clear:
immediately find treatment for
every individual living with
KIF1A Associated Neurological
Disorder.

**We dream of a world with an
easily accessible cure for kids
with KAND.**



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WHAT IS KAND?

KIF1A Associated Neurological Disorder, or KAND, is a neurodegenerative disease caused by mutations in the KIF1A gene.

KIF1A is a protein we all have in our nervous system that keeps our cells healthy. KIF1A acts like a “truck” by transporting “cargo” inside our cells.

In KAND, the gene mutation impairs KIF1A transport. (Think of a truck driving through rush-hour traffic or with a flat tire.) The result of these mutations is harmful to the nervous system, often causing a complex set of life-altering, and sometimes life-threatening, symptoms.

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WHAT DOES IT MEAN?

KAND is a rare disease, but it is drastically underdiagnosed. Today there are over 200 people known to be affected. However, we believe the actual number of people affected to be in the thousands.

Some of the symptoms many of our superheroes share are:

- Spastic Paraplegia
- Hypotonia
- Ataxia
- Intellectual disability
- Epilepsy
- Optic nerve atrophy
- Peripheral neuropathy
- Autism

Due to the overlap in symptoms, KAND is often misdiagnosed as Cerebral Palsy.



“Care Until Cure.”

HOW CAN YOU HELP?

Currently, there is no cure or treatment for KAND. Gene therapy and drug development are within reach, but there are two things preventing us from finding that cure: time and money.

There is no time to wait, we need to find treatment today. Visit kif1a.org/donate to help parents continue to accelerate life-saving research.

Finally, help us spread the word about KAND! Our goal is to not only raise awareness and foster a sense urgency about KAND, but also to help others get the **correct** diagnosis to ensure they receive the best care until we have a cure.

If you know somebody with an undiagnosed disease that may be KAND, please contact us.

KIF1A.ORG thanks Finlay Pilcher & the team at Berger Lab at University of Vermont for contributing to this resource.