

PCDH19 Epilepsy at School

What is PCDH19 Epilepsy?

PCDH19 is a genetic epilepsy caused by a mutation of the PCDH19 gene on the X chromosome. Its is a disease with a wide spectrum of severity in seizures, cognitive delays and other symptoms. As this gene was not isolated until 2008, researchers are still working tirelessly to understand the connection between the gene and the wide spectrum of symptoms for which PCDH19 epilepsy is known.

What co-morbidities are associated with PCDH19 Epilepsy?

- ▽ Autism spectrum disorder or autistic features
- ▽ Behavioral problems
- ▽ Aggression
- ▽ ADD/ADHD
- ▽ Anxiety
- ▽ Intellectual disability of varying degrees, ranging from mild to severe
- ▽ Obsessions (OCD)
- ▽ Trouble falling and/or staying asleep
- ▽ Hypotonia (low muscle tone)
- ▽ Fine and Gross motor deficits
- ▽ Language delays or non-verbal
- ▽ Sensory integration issues

Is there a cure?

Unfortunately, at this time there is no cure for PCDH19 epilepsy. Individuals will not grow out of this type of epilepsy, but there is hope for some sense of seizure control through various medications & treatments.

How does a school support someone with PCDH19 Epilepsy?

Due to the diversity of needs within the PCDH19 community, it is crucial that schools take an individualized approach toward meeting the needs of the specific child while at school. For some, an IEP will be most appropriate to support the child's learning or behavioral support needs. For others, a 504 Plan or Health Care Action Plan may be sufficient. Like with any child, it is important to look at that child and determine if/how their learning is being impacted by PCDH19 Epilepsy.

Possible Eligibility Categories that students with PCDH19 Epilepsy may qualify under include:

- ▽ Autism
- ▽ Intellectual Disability
- ▽ Other Health Impairment
- ▽ Speech or Language Impairment
- ▽ Multiple Disabilities

Though diverse, possible needs include:

- ▽ Specialized academic support/instruction
- ▽ Special service supports, such as those provided by an occupational therapist, speech-language pathologist, psychologist or physical therapist
- ▽ Behavior Intervention Plan
- ▽ Emergency medical protocol
- ▽ Flexibility with seating arrangements to avoid seizure triggers
- ▽ Sensory breaks

What else should I know about PCDH19 Epilepsy?

- ▽ Seizures are often drug resistant and difficult to control
- ▽ Due to seizure activity or medications, a child's behavior and demeanor may change frequently. For instance, during a medication change, a child may tire more easily and have a more difficult time concentrating on a task; prior to a seizure, behavior may change and a child may be more aggressive or argumentative. As the teacher and school staff learns more about the child as an individual they will learn what is typical and what is unusual behavior for the child and can establish a plan around the child's specific needs.