

Seizure Action Plans

Due to the unpredictable nature of DS, school staff may have to respond to a seizure without any warning. It is important for the staff, school nurse, and local emergency medical personnel to understand that the treatment for seizures in a child with DS may vary from typical seizure first-aid protocol. Some rescue medications are contraindicated for use in DS and may prolong the length of the seizure. The individualized Seizure Action Plan (SAP) developed by the patient's neurologist should be easily accessible at all times to guide appropriate intervention during a seizure.

If there is a question about the SAP once it has been received by the school, it should be discussed immediately with the neurologist. The time to question a protocol is not during a seizure. It is not uncommon for a child with DS to experience multiple and/or prolonged seizure events, so each seizure must be treated with urgency according to the protocol laid out in the SAP.

You can learn more about Seizure Action Plans at www.seizureactionplans.org.



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These guidelines have been
reviewed and approved by the
Dravet Syndrome Foundation's
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Patient Safety and Accommodations in Educational Settings

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What is Dravet Syndrome?

Dravet syndrome (DS) is a rare form of medication-resistant epilepsy that begins in infancy and proceeds with accumulating severity of symptoms that significantly impacts patients throughout their lifetime. Initial seizures are most often prolonged events (status epilepticus) and in the second year of life other seizure types emerge.

Individuals with Dravet syndrome face a higher incidence of SUDEP (Sudden Unexpected Death in Epilepsy) and have associated health conditions, which also need to be properly managed. Patients with Dravet syndrome do not outgrow this condition and it affects every aspect of their daily lives.

Can Seizures be Prevented?

Along with finding the medications that are most effective for the patient, it is important to recognize seizure triggers and avoid them when possible. These triggers will vary from patient to patient, but may include:

- Quick changes in environmental temperature (both hot or cold)
- Overexertion
- Overexcitement
- Overheating
- Stress
- Pattern sensitivity
- Light sensitivity
- Loud noises

Educational Challenges

There can be many challenges in teaching a child with DS. Along with developmental delays, it is not uncommon for a patient to miss multiple days of school due to seizures, illness, or medical appointments. A teacher who can adapt to the child's needs with a flexible teaching plan is the best option.

Due to seizure activity or medications, behavior and demeanor may change frequently. The child may tire more easily and have a difficult time staying on task. Prior to a seizure, a child may be more aggressive or defiant. As the staff becomes familiar with the child, they can establish what is unusual behavior and can develop a plan around the child's needs.



How is Dravet Syndrome Different from Other Forms of Epilepsy?

Many people living with epilepsy are able to control their seizures with medication and are able to live a relatively typical life. For those with DS current treatment options are limited, and patients often continue to have frequent seizures even though they take multiple medications.

Patients require constant care to assure their safety due to the unpredictability of seizures, as well as their inability to recognize real danger and the tendency to elope.

What are the Comorbidities Associated with Dravet Syndrome?

- Developmental delays
- Behavior difficulties
- Deficits in social and learning skills
- Movement and balance issues
- Growth and nutrition issues
- Sleeping difficulties
- Chronic upper respiratory infections
- Sensory integration disorders
- Disruptions of the autonomic nervous system (which regulates things such as body temperature, sweating, and toileting)

Providing the Safest Educational Environment

It is important to remember that each child is an individual, not a diagnosis. A strong line of communication and support between parents and educators is the best way to assure that a child with DS has a school environment with appropriate adaptations to keep them safe.

Speak with parents/guardians to learn more about their child and determine seizure triggers that should be avoided. The majority of children with DS require a one-on-one aide in the classroom to assure their safety.