

# 6 Sturge-Weber Syndrome

## How can I support a student with Sturge-Weber syndrome?

- ✓ Ask the student and their family directly how you can help. Take this opportunity to listen to their individual needs.
- ✓ Create a relationship and strong communication with the student's parents to best understand the student's needs in the classroom.
- ✓ Provide the opportunity for them to discuss their condition with the class if they wish to do so. They may prefer the teacher provides information to the class. This can allow their peers to ask questions in a productive setting.
- ✓ Immediately address any teasing and bullying. Provide education to any students saying harmful things and offer effective support for the affected student.
- ✓ Recognize their interests and acknowledge their successes in the classroom and in social settings.

## OVERVIEW

Sturge-Weber syndrome is a condition present at birth which is caused by a genetic mutation. The three features of Sturge-Weber are a birthmark on the face (port-wine stain), increased pressure in the eye (glaucoma), and abnormal growth of blood vessels on the surface of the brain (leptomeningeal angioma).

Port-wine stains are a birthmark of dilated blood vessels in the skin, typically on the forehead, nose, cheeks, and chin. Most children with a port-wine stain do not have other medical issues, but a small percentage will have Sturge-Weber syndrome.



# Sturge-Weber Syndrome

**What symptoms does someone with Sturge-Weber syndrome experience?**

The symptoms of Sturge-Weber syndrome vary between affected children. Involvement of the eye and brain has the potential to cause seizures, headaches, developmental delay, weakness, and vision changes or vision loss.

**What special measures might students with Sturge-Weber syndrome need?**

Some students with Sturge-Weber will have several special needs in the classroom, which makes strong communication with the child's parents and the teacher/school nurse very important.

Underlying cognitive impairments, seizures, anti-seizure medication side effects, attention problems, and psychologic stress can all affect the school performance of children with Sturge-Weber.

Children with Sturge-Weber are at risk for seizures which may occur in the classroom. During seizures, remain calm, stay with the student, move away dangerous or sharp objects, do not restrain the student, and talk reassuringly to them after the seizure subsides. After a seizure, it may be helpful to explain to other students what happened –

discuss that the student is safe and that the seizure was a temporary change in their brain activity. If you have a student at risk for seizures, discuss with the student's parents and school nurse regarding your role and when to call an ambulance.

If the student has vision changes, they may need to sit closer to the front of the room. If a student is undergoing laser treatment, they may need to sit in a part of the classroom that does not get direct sunlight.

Some children should not participate in contact sports – the child's parent will be able to tell you if this is the case based on the doctor's recommendations. Avoid overprotection of these students and do not overly limit or eliminate their participation in activities and play unless recommended.

**Is it contagious?**

No, Sturge-Weber syndrome is not contagious. Other students will not get Sturge-Weber through physical contact or play.



## ADDITIONAL RESOURCES

- > **What the School Nurse Should Know About Sturge-Weber**  
The Sturge-Weber Foundation  
<https://sturge-weber.org/for-patients/educational-resources/educational-documents.html>
- > **Information Kit for Elementary Schools**  
The Sturge-Weber Foundation  
<https://sturge-weber.org/for-patients/educational-resources/educational-documents.html>

- > **Information Kit for Daycare**  
The Sturge-Weber Foundation  
<https://sturge-weber.org/for-patients/educational-resources/educational-documents.html>

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