

School Day Precautions

- ◆ Some children need to be shielded from direct sunlight. This is especially important if the child has recently had laser treatments to reduce a port wine birthmark.
- ◆ Some children should not be involved in contact sports.
- ◆ A small cut or bruise to the port wine birthmark could result in profuse bleeding, which may frighten the child and others.
- ◆ School staff should be on the constant look-out for bullying and deal with it immediately and in line with school policy.

Resources

The Sturge-Weber Foundation has many publications for students, families, school staff and medical professionals.

For children:

Color Me Different, Color Me The Same coloring book
A Kids Guide to Sturge-Weber syndrome: illustrated, for elementary & middle school children
Someone Special: Picture book for preschoolers
SWS Guidebook for Teens: ages 13-17

Families:

Emergency Room Guide
Information Brochure
Branching Out Magazine (register for free)
Unlimited resources at www.sturge-weber.org

Nurses: Special packet of materials for nurses on glaucoma, seizures, academic functioning

For medical professionals:

Sturge-Weber Syndrome, 2nd SWS Textbook
Sturge-Weber Syndrome flash drive

The school can be a resource center for parents since many families do not have computer access. The school nurse can be the leader to enlist the assistance of the librarian or information technology staff.

The Web site, www.sturge-weber.org is full of useful information. A good place to start is on the top menu, Learning Center. Under this, Medical Matters will tell you about conditions. Library will have a link for patient resources.

We have an annual **Month of Awareness** to raise funds and awareness, an excellent opportunity for education. Special posters, stickers and program ideas are available. This is a good time to involve the family of a child with SWS. This can be found on the website, top menu, get involved, awareness activities.

The parents of the child with SWS may not know about the Sturge-Weber Foundation or any of the other links to information. Therefore, the **school nurse can be a valuable first-line contact.**

Thank you for your interest on behalf of your students.

You may never have a student who has Sturge-Weber syndrome. But a child might move to your school tomorrow who has SWS or a port wine birthmark. If that happens we hope you will know who to call.



The Sturge-Weber Foundation

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What the
School Nurse
Should Know
About
Sturge-Weber



What is Sturge-Weber Syndrome?

Sturge-Weber Syndrome (SWS) is a rare medical condition characterized by a facial port wine birthmark and neurological abnormalities.

Symptoms can include eye and internal organ irregularities. Each case of SWS is unique, exhibiting the distinctive findings in various ways. It is progressive, with manifestations becoming more vivid as the child grows. In 2013, the GNAQ gene mutation responsible for Sturge-Weber syndrome was discovered. Researchers now understand the cause of both Sturge-Weber syndrome and Port Wine birthmarks, and are investigating the optimal studies for treatment.

Sturge-Weber syndrome was identified over 100 years ago by two physicians in England. Since that time, much has been learned about SWS. But because the incidence is low, less than 200,000 documented cases currently, SWS is classified as a rare disorder or orphan disease.

There is no known cause of SWS at the present time. We know what happens in the brain, but not why. Since it is progressive, children can have seizures which are exacerbated by environmental factors; glaucoma may worsen; a port wine birthmark may thicken and lip enlargement may become evident.

Closely associated with SWS are Klippel-Trenaunay syndrome (KT) and Port Wine birthmark (PWB), a vascular birthmark. KT is characterized by enlargement of an extremity or other body area. A PWB that does not involve the eye or the trigeminal nerve area of the face may not be SWS but will have similar characteristics.

Some children with SWS are cognitively impaired and visually handicapped. Some are typically developing with no cognitive impairment.

With present research leading to advancement in diagnosis and better early treatment, many children have a vastly improved outlook for success in school and in life.

What is the Sturge-Weber Foundation?

The Sturge-Weber Foundation was begun in 1986 by parents who had received a diagnosis of SWS for their baby, but could find no emotional support, education or information for parents.

Today, it is a not-for-profit educational, support and advocacy group with an international membership. It supports selected research into the causes and treatment of Sturge-Weber syndrome, as well as Klippel-Trenaunay syndrome and Port Wine Birthmark conditions.

The SWF is a 501(c)(3) non-profit foundation. Anyone with an interest in Sturge-Weber syndrome or who is affected by this disorder can become a Registered Partner in the Foundation.

Needs of the child with SWS

The biggest need of the school child with SWS is communication between his home and his school nurse.

A child with SWS who has glaucoma needs special care for visual impairment. She may wear eye glasses and need to use eye drops to reduce intraocular pressure. She may have school absences for surgeries and medical appointments. She may need classroom accommodations for her vision.

A child with seizures needs to have his seizure medications monitored. Procedures have to be in place that can coordinate the home, the school nurse, the emergency response crew and the hospital when needed. He may have recurring hospitalizations. Classroom teachers, aides and classmates need to be educated about SWS and seizures.

A child with SWS may have a learning disability. This can arise as a side effect of medications, a visual limitation, or a cognitive disability. The child may have chronic or recurrent headaches. These need to be tracked and reported.

There are many self-esteem issues arising from the child's different facial appearance and therefore there are many avenues of education, both for classmates and school staff. Primarily, other children should be told that SWS is not contagious.

The nurse and teachers need to be alert to the signs of social isolation, obsessive-compulsive behavior and oppositional defiance. Under-achievement in school may be due to an underlying or undetected disability.

As the child gets older, self-care issues take on more importance. A child with SWS should be expected to pay attention to his medication schedules, dietary requirements and safety rules.

Medications and Therapies

Children with seizures will probably be on medications which the school nurse must be cognizant of. Each child's medical folder must be kept up to date with prescribed changes and current clinicians' names and phone numbers. Written permission forms from parents must be kept up to date.

Therapies usually provided to children include **physical therapy** for any degree of paresis; **occupational therapy** for daily living activities and sensory issues; **speech therapy** for articulation and fluency.

Psychological therapy is also required if there is low self-esteem or any sign of depression. Anger management therapy may be warranted.

There should be **periodic neuropsychological assessment** for cognitive and developmental abilities.