# Sturge-Weber syndrome

## What is Sturge-Weber syndrome?

A syndrome is a group of problems that occur together. The most common problem in people with Sturge-Weber syndrome is angiomas (cysts or tumors composed of blood vessels).

Sturge-Weber syndrome (SWS) is rare. It is present at birth in about 1 in every 50,000 babies. However, many people with SWS probably never know they have it, so it may be more common. SWS affects all races and both sexes equally.

## How is it diagnosed?

Sturge-Weber syndrome can be hard to identify. There is no blood test for it, and no list of signs that **must** be present to decide that a person has SWS. For example, most people with SWS have a port-wine stain, but not all people with a port-wine stain have Sturge-Weber syndrome.

An MRI is often done to see if the person has too much blood vessel growth on the brain's surface.

Some combination of these signs will be present:

- port-wine stain (large pink, red, or purple birthmark on the face)
- angiomas
- headaches
- eye problems such as glaucoma (increased pressure in the eye)
- nervous system problems
- problems with other body organs
- seizures
- stroke-like events (part of the face or body is paralyzed for a short while)
- behavior problems, such as attention deficit hyperactivity disorder (ADHD)
- developmental delay or cognitive (thinking) delay

## Does SWS run in families?

No. SWS is not caused by a gene. It is very rare for a family to have more than one person with it.

## What is the treatment?

There is no way to predict what problems a person with SWS will have, or how serious those problems will be.

There is no cure. Treatment depends on the problems the person has, and may include:

| Problem | Treatment |
|---|---|
| ADHD | Medicine and non-medicine therapies |
| developmental delay | special education, rehabilitation |
| glaucoma | eye drops or surgery |
| headache | medicine and non-medicine methods |
| port wine stain | laser treatments |
| seizures | medicine or surgery |
| stroke-like events | medicine to prevent blood clotting |

## How should I care for my child?

In addition to their regular doctor, all people with SWS should be seen yearly by a doctor or nurse practitioner familiar with this condition. Referrals to specialists may be needed.

## When should I call the clinic?

- any new and persistent pain
- concerns about vision or headaches
- learning or behavior concerns

## Questions?

This sheet is not specific to your child, but provides general information. If you have any questions, please call your clinic.

For more reading material about this and other health topics, please call or visit the Family Resource Center library, or visit our website: www.childrensmn.org/A-Z.

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