How to Create a Winning Sturge-Weber Awareness Display

Define Your Purpose

Decide if your display is meant to raise awareness about Sturge-Weber Syndrome (SWS), raise funds for research or support, or both. Keep this purpose in mind as you design every part of your display.

Gather Your Materials

Pick up a tri-fold poster board from your local craft or office supply store. Choose a color that is consistent with the SWF branding (burgundy, dark green, and gold). Collect scissors, glue or tape, markers, and any other creative supplies.

Visit the Official SWF Website

Go to www.Sturge-Weber.org and download your FREE display printables. These include facts, statistics, and visual elements to help tell the SWS story.

Choose Your Display Style

Decide whether your display will focus on a personal story (like your own or a loved one's journey with SWS) or be more informational and educational. Consider adding personal photos or artwork to create an emotional connection with your audience.

Print and Organize Your Content

Print the pages you want to use and arrange them in a way that flows naturally on the board. Make sure key facts and visuals are easy to read and well-placed. Use captions and labels to make your message clear.

Tell a Captivating Story

Whether sharing a personal journey or educating the public, aim to draw people in with a strong beginning, meaningful middle, and inspiring end. Use a combination of text and images to keep viewers engaged.

Add Finishing Touches

- Include eye-catching headlines, maybe some fun facts, or even conversation starters to encourage questions.
- Consider adding QR codes or links to direct viewers to more information or donation pages.
- Let your creativity shine and enjoy the process. Your passion for raising awareness about SWS will help others connect with the cause.
- Take photos of your finished display and share it on social media to reach even more people.
- AND, send photos of you and your display to us!

Examples:

Sturge-Weber Syndrome

What is Sturge-Weber syndrome?

\ ‘sterj - ‘web-er- \ (SWS) - Is defined by the National Institute of Health as a rare, neurological disorder present at birth and characterized by a port-wine stain birthmark on the forehead and upper eyelid on one side of the face. Sturge-Weber syndrome (SWS) has three major features: a red or pink birthmark called a port-wine birthmark, a brain abnormality called a leptomeningeal angioma, and increased pressure in the eye (glaucoma). These features can vary in severity and not all individuals with Sturge-Weber syndrome have all three features.

What is the Cause of SWS?

Today, we know the cause of SWS is the somatic mutation in GNAQ somatic mutation on chromosome 9q21. In 2013, the GNAQ gene mutation was researched and discovered by our CSO, Matthew Shirley, PhD working in Jonathan Pevsner’s, PhD lab. The SWF supports their work to understand how these mutations cause both SWS and Port Wine birthmarks in order to identify potential treatments.

Why Support The Sturge-Weber Foundation?

When you support The Sturge-Weber Foundation (The SWF) you are making a difference to continue supporting families and patients while investing in important research and awareness efforts.

Help us light the way for future generations!
DONATE TODAY.

Birthmarks | Glaucoma | Seizures
www.Sturge-Weber.org

SECURE DONATIONS

I AM MORE THAN A BIRTHMARK

SHARE YOUR PERSONAL STORY ON THIS PANEL

It doesn’t seem like a lot unless it’s your child.

In the USA, SWS affects approximately

ONE IN
20,000 - 50,000
(and 1 in 400,000 globally)

SEIZURE FACTS:

72%-80%
SWS patients with unilateral brain lesions

93%
SWS patients with bihemispheric involvement

GLAUCOMA:
30% to 71% of patients

BIRTHMARKS:
3 of 1000 newborns are born with a birthmark, but not all birthmarks are SWS.

THE STURGE-WEBER FOUNDATION
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973-895-4445 • contact@Sturge-Weber.org
Sturge-Weber.org

The Sturge-Weber Foundation is a 501 (c) (3) non-profit organization. Tax ID 74-2485813

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What is Klippel-Trenaunay syndrome?

Klippel-Trenaunay (KT) is characterized by a triad of symptoms: Port Wine Birthmark (capillary malformation) covering one or more limbs, congenital vascular anomalies, usually venous varicosities, absence or duplication of a venous structure, malformation and hypertrophy (enlargement of the limb) or atrophy (withering or smaller limb). KTS involves the lower limbs in approximately 90% of the cases.

Port-Wine Birthmark Treatment

Vascular-specific laser treatment may lighten the color and decrease the size of port wine birthmarks, but complete resolution is possible in only a minority of cases at this time. Treatment can be started as early as one week of age, depending on doctor recommendations & parents' preferences. The earlier a child begins laser treatments, the more effective they will be. Treatments can be done every 6 to 8 weeks, however, the number of treatments needed or the percentage of clearing depends on the stain itself and varies greatly. The type of anesthesia used (topical or general) will be based on the preference of the family and physician.

Why Support Our Mission?

When you support The Sturge-Weber Foundation (The SWF) you are making a difference to continue supporting families and patients while investing in important research and awareness efforts.

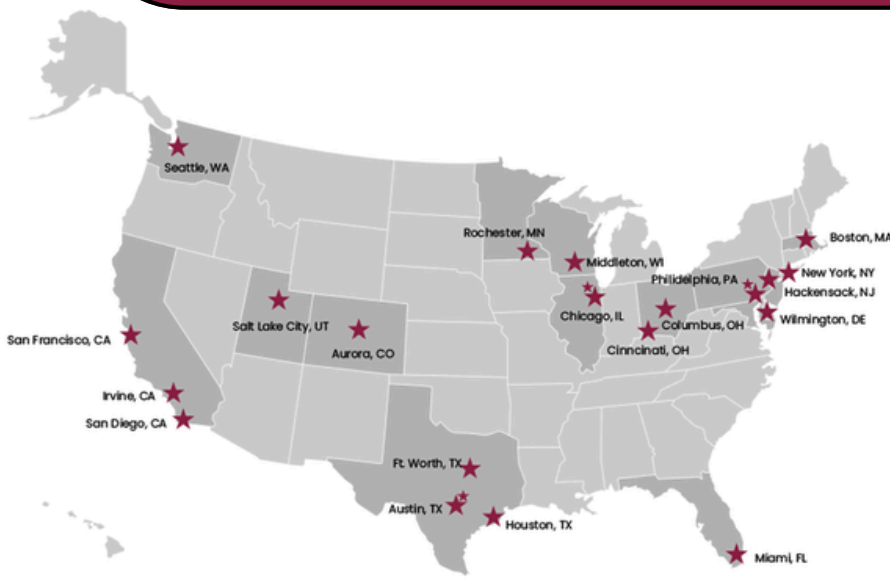
For Patients & Caregivers

In 1987, founder, Karen Ball started The SWF for her daughter, Kaelin, and other families who desperately needed information, resources, and support for their children born with SWS. Over the years we have grown to support adults with SWS, caregivers, and healthcare providers all over the world.

For Research

The SWF is committed to research and science. We financially foster and facilitate research grants and programs throughout the year.

25+ CLINICAL CARE CLINICS



The SWF's Network has over 25+ centers that provide the comprehensive care necessary for treating adults and children who have a port wine (PW) birthmark, Sturge-Weber syndrome (SWS) or Klippel-Trenaunay (KT).

Kids Camp
Photo by Karen Images

How is SWS Diagnosed?

SWS is usually diagnosed with a presence of a PWB on the upper eyelid or the forehead combined with glaucoma, abnormal blood vessels in the brain, or both. SWS can manifest at any time. Children with PWB accompanied by neurological signs/symptoms should receive a neurological evaluation. Additional signs of SWS may include:

• Seizures, early handedness or evidence of a visual preference by age two Neurological symptoms can start in later childhood or even in adulthood.

• Glaucoma can begin at any time; at-risk individuals should be examined by an ophthalmologist every three months for the first few years and at least annually for life.

Help us light the way for future generations!

DONATE TODAY.

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ROOTS TO A CURE®

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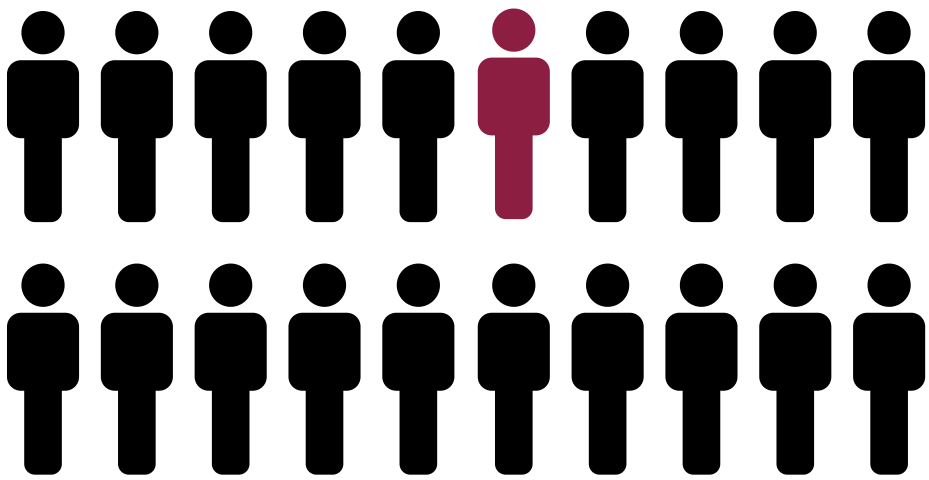

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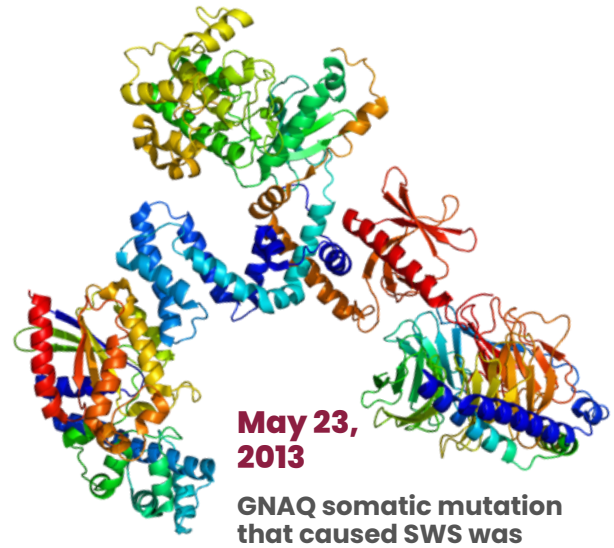
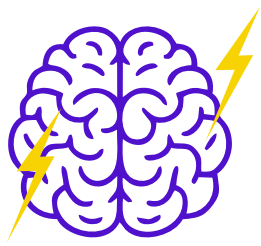
This day in history!



May 23, 2013

GNAQ somatic mutation that caused SWS was discovered by scientist Matt Shirley, PhD!



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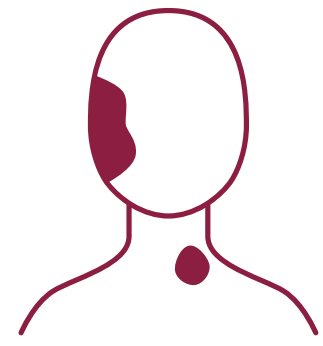

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THE STRONGER THE WIND, THE TOUGHER THE TREES.