

This is *our why*

We first met Cindy and her family when they came to our office in Houston for a visit. Their grandson, Mason, was in the hospital, and they were struggling to navigate a roller coaster of emotions and questions. Our staff and Clinical Care Network experts were able to get them an appointment with Dr. Steve Roach, a leading SWS expert, to set up a comprehensive care plan.

We were so excited to meet them all at the Family Conference a few years later and to know that our intervention made a world of difference in their lives! Mason had the best time meeting others like himself in our kids camp and it was so great to see him laughing and learning!

This is our WHY. We are here for you too!



Mason, SWF Warrior



Karen and Kaelin Ball

KAREN Ball

SWF Founder and CEO

Whether we are connecting in person or online, the SWF family is like an Evergreen tree withstanding cold hard times or bringing renewed hope and inspiring us to always grow and learn from one another. We rely on continued support from our partners to engage patients, researchers, families, and caregivers to improve the quality of life for those we love.

We make a *living* by what we earn, but we make a *life* by what we share and how we care!

Will you help us create a lasting impact for today and tomorrow? Scan the QR code below to become a SWF Partner.

Let's light the way for future generations. *We are stronger because we are united.*

With love, faith, and hope,

Karen L. Ball



STRONGER BECAUSE WE ARE

UNITED

THE STURGE-WEBER FOUNDATION

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



Kids Camp
Photo by Karen Images



For a reason, a season
or a lifetime...
we are here for YOU.

35 YEARS AND COUNTING



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.

Our Programs




The Sturge-Weber Foundation serves patients with Sturge-Weber syndrome (SWS), Klippel-Trenaunay syndrome (KT), Port Wine Birthmarks (PWB), Glaucoma, and seizures.

-  **Advocacy:** Happens in many ways including on state and federal levels, insurance issues, and pressing personal matters.
-  **Clinical Care Networks:** SWF has 25+ centers that provide comprehensive care necessary for treating adults and children with SWS, KT, and PWB.
-  **SWF Million Miles Walk:** Members all gather to walk a million miles for SWF. Held April-June each year.
-  **SWF Month of Awareness:** May is our month! All month we have events and sponsored awareness.
-  **Webster's World:** Our mascot, Webster travels all over the world to give cuddles to children during or after a hospital stay.
-  **Family Conference:** Our International Family Conference is held every two years and provides a chance for patients and caregivers to meet up, make friends, attend educational seminars, and Kids Camp.
-  **SWF Memorial Garden:** This web page is dedicated to those we have lost to SWS. May they never be forgotten.
-  **Reunion of Champions:** This event celebrates one of our professional SWF warriors. Held once a year.
-  **Virtual Events:** Educational Mini-Summits, Caregiver Chats, and Adult & Teen Patient Chats are held throughout the year.




Our Research

The research accomplishments and increase the understanding of SWS biology and pathology of glaucoma, seizures, calcification, growth hormone, migraines and more have been facilitated and in many cases funded by seed grants (\$5000 range) and full basic and clinical research grants and fellowships (\$10,000-\$50,000). **Yes**, it does take money and we support is needed and appreciated! This research is vital to understanding SWS before we can find a cure.

-  **New Research:** Currently, research on zebrafish and mouse models are working to understand SWS biology and discover new treatments.
-  **GNAQ Gene:** In 2013, the GNAQ gene mutation responsible for Sturge-Weber syndrome was researched and discovered by our CSO, Matthew Shirley, PhD working in Jonathan Pevsner's, PhD lab along with Dr. Anne Comi. The SWF supports the ir work to understand how this mutations causes both SWS and Port Wine birthmarks in order to identify potential treatments.
-  **SWS Registry:** With our patient's help, researchers and physicians have access to accurate clinical data to understand how SWS affects patients allowing for improved quality of care.



-  **For Our Professionals:** The SWF SWFIRN and Clinical Care Network is designed to bring basic and clinical science together to increase the pace of discovery and cures.

