



Branching Out

DIGITAL

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Did You Know...

FOUNDER AND CEO - KAREN BALL

Did you know the Sturge-Weber Foundation's research program began with a \$2,500 stipend after Karen and Kirk Ball received the **Betty Ford Award** in 1990?

From there, the research fund grew little by little as dedicated individuals raised both vital awareness and critical funding. Their efforts helped SWF identify and support vetted clinical and basic research worthy of the community's hard work.

Over the years, the fund has supported clinicians, early-career investigators, and basic scientists exploring the unanswered questions surrounding Sturge-Weber syndrome and port-wine birthmarks.

We have been fortunate to benefit from exceptional **volunteer leadership from scientists and clinicians** who have helped shape strategic plans and research goals. Their collaboration with committed people within and beyond the SWS community contributed to the discovery of the SWS gene mutation.

Today, our network of committed researchers, and the fundraising events supporting them, continues to grow. This expanded support is accelerating discoveries and advancing projects designed to improve quality of life and care for individuals and families living with SWS.

The SWF leadership is also preparing for new directions in research, patient support, and family resources. Bringing diverse stakeholders together is essential to ensuring research efforts are connected, purposeful, and focused on shared long-term goals.

Dr. Matt Shirley has been instrumental in his role as Chief Scientific Officer, helping drive research forward and identify new frontiers for closing knowledge gaps. We are deeply grateful for his leadership and look forward to continuing our work together as his tenure concludes.

We are equally excited to welcome **Dr. Sana Nasim** as the next Chief Scientific Officer. She brings a unique and diverse background as we enter a new era of research. You will be hearing more from her very soon!

Please continue to support, participate, and donate so we can keep this momentum going. Every person has something valuable to contribute, whether on the front lines or in a behind the scenes supporting role.

Thank you for caring, sharing, and giving of yourselves. Together, we make the load lighter and move faster toward our shared goal.

With faith, hope, and love,

Karen Ball



A Big Year for Sturge-Weber Syndrome Research and Care

Jeff Loeb, SWF Chief Clinical Strategist

What an incredible year. We held a fantastic family meeting in San Antonio and an outstanding combined research and clinical care meeting in Madison, Wisconsin. Even more importantly, we've completed our Brain Vascular Malformation Consortium (BVMC) natural history study, and the results will be published very soon.

We now understand far more about the natural history of Sturge-Weber Syndrome, from infancy through adulthood, and we can finally connect symptoms like seizures, headaches, and stroke-like episodes to the changes happening in the brain.

Here are two major takeaways:

- 1. Sturge-Weber Syndrome appears to unfold in two phases.** Early seizures usually begin in the first year of life. Our results suggest that early, aggressive treatment may help prevent later complications.
- 2. Brain calcifications happen later and are linked to stroke-like episodes, headaches, and hemiparesis.** This raises an exciting possibility: treating calcification may become a powerful new disease-modifying strategy that could help prevent future flare-ups.

And, there is much more to come!

On another front, our families have given us tremendous support as we build a personalized electronic health record for SWS.

The BVMC has made one thing very clear: having all medical records in one place is incredibly valuable for patients and families, for physicians, and for researchers, the Foundation, and industry partners.

We are now reaching out to BVMC participants to ask them to consent to transfer their data into a Foundation-managed database. This will allow patients to access their full records, share information with their doctors and experts, and help drive future research and clinical trials.

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We are on the cusp of developing new recommendations and having clinical trials for new treatments to 'change the face' of SWS into a truly treatable disorder.

The future of SWS is changing. And, that is exciting!

Continued to next page...

[READ MORE](#) 

Read published articles from our researchers:

- Glaucoma Management in Sturge-Weber Syndrome Using the Delphi Process
- Common and distinct circulating microRNAs in four neurovascular disorders
- Absence of Deep and Basal Veins is Common and Clinically Relevant in Sturge-Weber Syndrome

Thank you!

Through your dedication, generosity, and unwavering commitment to our patients, you have helped grow a series of small, independent efforts into one of the world's largest and most influential rare disease research networks.

BVMC Scholars



Yasir Khan, MD, MPH
Takeda Pharmaceuticals



Takeo Nishida, MD
Osaka City University



Eboni Lance, MD, PhD
Kennedy Krieger Institute



Hélène Choquet, PhD
Kaiser Permanente DOR



Michael Golden, MD
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Xiaowei Zou, PhD
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RARE DISEASES
CLINICAL RESEARCH NETWORK



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Claudia Moy, PhD



RARE DISEASES
CLINICAL RESEARCH NETWORK

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From Genetic Discovery to Better Care: Advancing SWS Research

Matt Shirley, SWF Chief Scientific Officer

Since The Sturge-Weber Foundation was founded in 1987, our understanding of Sturge-Weber syndrome (SWS) has advanced tremendously. When the Foundation began, we did not know what caused the condition. The discovery that changes in the GNAQ gene cause SWS and related port-wine birthmarks gave researchers a starting point for understanding the biology behind this complex disorder.

Since becoming Chief Scientific Officer in 2021, I have been fortunate to witness and contribute to this progress. Researchers are now working to understand how GNAQ mutations affect the brain, eyes, and skin, while searching for biomarkers that could help identify infants with port-wine birthmarks who are at greatest risk for brain involvement. These measurable signs, identified through imaging, EEG, and other tests, could help doctors recognize potential complications earlier and improve care. Although there is still much to learn, we have made significant progress toward understanding SWS and developing better approaches to treatment.

I am particularly proud of how the Foundation continues to bring people together to move research forward. In August, SWF leaders joined scientists, biotechnology companies, and patient advocacy organizations at the RareNet Symposium at MIT's McGovern Institute to discuss ways to help discoveries in rare brain disorders reach families sooner.

Read Patient stories meet scientific innovation at the inaugural Rare Brain Disorders Nexus (RareNet) Symposium.

The meeting highlighted the important role patient foundations play in ensuring research addresses the needs of families. Our New Horizon and Catalyst grants are supporting promising early-career researchers, our Clinical Care Network has grown to 27 validated sites,

and our Brain Vascular Malformation Consortium (BVMC) is building on 15 years of work to develop a patient registry that can support research around the world. These accomplishments would not be possible without the dedication of our researchers, clinicians, families, and supporters.

Serving as Chief Scientific Officer has been a privilege, and I am grateful to everyone who has helped advance this work. I look forward to seeing what we can accomplish together in the years ahead.

on the road again



Karen Ball and Julia Terrell attended the 14th PeDRA Annual Conference on October 15-17, 2026, in Alexandria, VA. This year's theme: *From Intention to Impact: Making Space for Research*, highlights our shared commitment to advancing meaningful research.





Dr. Sana Nasim Joins USF to Advance Cardiovascular Disease Research

Sana Nasim is an Incoming Assistant Professor at the Heart Institute in the Department of Pathology and Cell Biology at the University of South Florida Morsani College of Medicine. She earned her BS and PhD in Biomedical Engineering from New Jersey Institute of Technology and Florida International University, respectively. Her graduate research focused on understanding aortic valve interstitial cells responsible for elastogenesis. As a postdoctoral fellow in the Vascular Biology Program at Boston Children's Hospital and Harvard Medical School, she investigated cellular and molecular mechanisms that drives capillary malformations caused by a somatic activating mutation in GNAQ. She was later promoted to Instructor in Surgery at Harvard Medical School before joining USF in Fall 2026.

Dr. Nasim's lab combines expertise in vascular biology, bioengineering, and developmental biology to build multi-cellular models of the heart and blood vessels. Her research aims to uncover the biomechanical and cell-signaling mechanisms that drive congenital and acquired cardiovascular diseases, identify new therapeutic targets through AI-driven drug discovery, and enable earlier interventions that improve patient outcomes.

Dr. Nasim's research has been funded by NIH K99/R00 Pathways to Independence award, NIH NRSA F32 fellowship, Florida Heart Research Foundation, NSF Bridge to the Doctorate fellowship, and McKnight doctoral fellowship.

She is passionate about mentoring and training next generation scientist from all backgrounds with aim to promote inclusive excellence.

Mark
YOUR
Calendar

Register for all events at
[Sturge-Weber.org](https://www.sturge-weber.org)

Mental Health Chat for Patients 21+

Wednesdays @7:30 PM EST

Our Mental Health virtual chats allow one to meet other adults (21+) with SWS, KTS, and PWB. Register below, and we will send you the Zoom link on the day of the event. Moderated by Luis Sandoval, PhD, SWF Task Force Leader for Mental Health.

Mental Health Chat for Caregivers and Parents Thursdays @7:30 PM EST

These virtual chats are an opportunity to meet other caregivers and parents of SWS, KTS, and PWB children and adults. Moderated by Luis Sandoval, PhD, SWF Task Force Leader for Mental Health.

Be the Torch, Be the Light Mondays @7:30 PM EST

Join us for a virtual chat, Be the Torch. Be the Light, with Ansley and Donald—a night of hope and inspiring conversations about faith.

Gaming Lounge Tuesdays @7:30 PM EST

Participants are invited to bring their favorite game, whether it's a video game, mobile game, tabletop game, or online activity, and spend time playing, chatting, and hanging out with peers who truly understand their journey.

SUPPORT OUR MISSION TODAY!



THE STURGE-WEBER FOUNDATION

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

TWO NEW PARTNER ORGANIZATIONS JOIN SWF



A DEE is a condition where someone has frequent seizures that are very difficult to control with available medicines and where the abnormal electrical activity in the brain, as well as the underlying cause, makes it more difficult for the brain to develop and function typically.

Developmental Indicates that the underlying cause of the condition directly affects brain development, leading to intellectual disabilities, developmental delays and/or the regression of acquired skills.

Epileptic Refers specifically to epilepsy, a condition where the brain sends abnormal electrical signals that cause seizures which are often very difficult to control with medications.

Encephalopathy Any disturbance that affects the brain's structure or function that means that the brain is unable to function the way it is supposed to. [Learn More about DEEP.](#)



ISSVA

AISSVA is a multidisciplinary international society of physicians, scientists, and health care providers united by an interest in vascular anomalies. The Society aims to promote the highest standards of care for patients with vascular anomalies by advancing clinical and scientific knowledge concerning causes, diagnosis and treatment, and by education of physicians, health care providers, patients and the community. The Society encourages the free flow of information between its members and interested groups, through workshop meetings and teaching programs, and by the dissemination of a classification scheme and pertinent scientific data.

The International Society for the Study of Vascular Anomalies (ISSVA) is the formalization of prior biennial international workshops, which were started in 1976 by Drs. John Mulliken and Anthony Young, of specialists interested in the diagnosis, management and investigation of these disorders. [Learn More about ISSVA.](#)

A NOTE FROM DAVE



Dr. Dave Shahani,
Cook Children's
Healthcare
System

When faced with a rare diagnosis that most people have never heard of, the Sturge-Weber Foundation has been a beacon for my patients and families feeling lost at sea. As a pediatric neurologist, I've been drawn to people living with SWS. As a student about 20 years ago, I met a 3rd grade girl crying in the waiting room while her father spoke with the neurologist. Thinking I knew a little about her condition, I naively felt I knew something about what she must be sad about. I was wrong and forever changed. She was not crying about her seizures, her weak left arm, her medications, or some diagnosis on paper. She was crying about a bully at school who made fun of her birthmark that morning. We spoke, shared stories, and somehow eventually

started laughing about how mean kids can be. That interaction is when I chose to become a neurologist and she will never know how much she changed my life.

Our lives are so much more than a diagnosis. Through the foundation and my practice, I have met with so many beautiful people each facing their own unique life challenges. I am so grateful for the conferences, virtual meet-ups, and frequent opportunities to connect with people around the world that the foundation creates. Each of them has helped me learn, grow, and hopefully be a little more useful to the next child I meet. To the foundation and all of you engaged with us, thank you from the bottom of my heart."