Branching Out DIGITAL

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Victim or Victor... The Loads We Carry!

FOUNDER AND CEO - KAREN BALL

I've been honored to lead the SWF these past 38 years and have learned so much from our community. You share such heartfelt challenges and joys with us which truly inspires! It never ceases to amaze me the different loads each family carries in their SWS journey. The Friedlander's, the Leonard's, the single moms, the Ellier's, those who have had brain surgeries and so many more fabulous warriors you KNOW the loads that you carry for a reason, a season, or a lifetime. From the outside looking in on your life, you handle it with such grace. Rarely do we glimpse the fallout on loads you are too tired to carry anymore and the impact on your family. Come ON it is AOK to admit you aren't perfect and forgiveness begins with yourself ;)

A SWS diagnosis brings many loads to carry over a lifetime of battling it. The early years bring the fears for treatment and the future. The middle years bring the challenges of building a life while facing the challenges and joys with renewed hope. The later years one has mostly settled in and accepted what life with SWS has offered in the journey. The peaks and valleys come just like in any family, but it seems our peaks and valleys are higher and lower. You know it DOES take SUCH emotional energy to live as a victor and when the valleys hit as they will do those valleys can be dark places and sometimes harder to climb out of than other times. I encourage you to reach out to us and those friends you've met through the SWF and do not hold back.

It is so easy to wahoo on social media about the celebrations where life is always presented as awesome! Got this! We Rock! You know what I'm talking about ;) I encourage you to share the days you've dropped the load and help the younger ones learn from the not so pretty side of this lifelong journey. The victors have a hard time doing that and I know I surely do!

Recently, I had to take my own advice and lean heavily on some SWF friends and admit I am worn out and am dropping the loads, I've been carrying for 38 years. Very hard time to be so vulnerable and imperfect but what a gift to have their support and understanding which uplifted me to carry on and pick up the loads once again. We have the usual medical issues which we can relate to as the SWS community and then the nuanced layers that impact each family to different degrees. We are so blessed to have each other! There is no judgement for being human and fallible because only you know the cost you've born to love, support and encourage yourself and your loved one with SWS.

May you feel the love from this side of the world to your lil corner. It's ok to drop a load or two and give yourself the love and self-care too. I'm off to take a load off yes pun intended and take a lil bubble bath! Be well and live in joy!

With faith, hope, and love,

Karen Ball

WARRIOR strong

Many of you may say, “YES!”

KENDRA'S GOLD STAR PROJECT

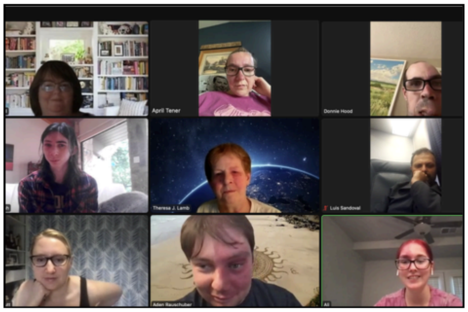
Meet Kendra from New Jersey—a bold, inspiring force to be reckoned with. Kendra is living with Sturge-Weber Syndrome, but let’s be clear: SWS doesn’t define her. She’s a proud Girl Scout with a mission to make waves, and she’s aiming for the Gold Award—the highest honor in Girl Scouting. The Gold Award isn’t just a badge; it’s a call to action: Change the world, change your life. And that’s exactly what Kendra plans to do.

Kendra approached us with an incredible idea—to shape her Gold Award project around raising awareness for Sturge-Weber Syndrome. How could we say no? Together, Kendra and The Sturge-Weber Foundation are helping her create a project that will leave a lasting impact, spreading awareness far and wide, creating sustainable change, and benefiting countless lives. This is just the beginning of her unstoppable journey. Stay tuned—big things are coming!

And to all the dreamers, doers, and go-getters out there: if you’re looking for a meaningful way to make a difference or need a project that matters, we want YOU. Come join us, roll up your sleeves, and let’s create something extraordinary together. Let’s get to work!

Wedding Bells

Michael Carrier and April Tener were married November 9, 2024. April is the daughter of Chuck and Laurie Tener of Albion, Indiana.



Make a Resolution to Join us for our Virtual Chats and Education Events

Visit our Events Page here to see the schedule and register. Stay tuned for new and exciting events coming your way later this year!

Last chance to make a difference in research

Join Brain Vascular Malformation Consortium today! We have until June 30th to register patients. Today we had 140+ already and need to get to 180 patients.

Please email us at contact@sturge-weber.org so the Sturge-Weber Foundation can connect you with one of the centers. To learn more about the study here.

Meet our Honorees

Reunion of Champions

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Dr. Denise Metry, the 2025 Reunion of Champions Honoree, is a leading pediatric dermatologist with a deep commitment to caring for children with vascular birthmarks. After 23 years at Texas Children's Hospital, she joined Driscoll Children's Hospital in 2024 to serve South Texas' underserved communities. A pioneer in her field, she co-founded the Hemangioma Investigator Group, developed diagnostic criteria for PHACE and LUMBAR syndromes, and authored over 130 publications. Dr. Metry has held prestigious leadership roles and now chairs the Vascular Birthmarks Research Consortium for PeDRA, driving advancements in care and laser research. Beyond her groundbreaking work, she is a dedicated mentor and advocate, passionate about improving lives through medicine.

LEGACY LEADERS

planting seeds for a fruitful tomorrow

Jay Bhawalkar Ph.D., the 2025 Legacy Leader Honoree, is a leading innovator in photonics and non-linear optics, transforming medical technology with groundbreaking advancements. After earning his Ph.D. in Physics from the University of Texas at Dallas, he began his career as an Assistant Professor at the University at Buffalo, where his work in multiphoton microscopy and two-photon photodynamic therapy set new benchmarks. As VP of R&D at Candela Corporation (2003–2017), he spearheaded revolutionary products. Now, as CTO of AVAVA, Inc., he's developing cutting-edge energy-delivery technology for safer, more effective skin treatments. With 40+ publications, 15+ patents, and prestigious honors like the Dr. Horace Furumoto Innovations Award, Dr. Bhawalkar is shaping the future of medical innovation.

Can't attend the event? You can still help us ignite SWS research, education, and support. Give today!

The Reunion of Champions takes place March 7 in Orlando, FL at the world-famous ICEBAR.
To read our honorees' full bio and learn more about this event, click here.

THANK YOU TO OUR GENEROUS PARTNERS WHO HELPED MAKE THIS NIGHT POSSIBLE:

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LASER & SKIN SURGERY CENTER OF NEW YORK

HAPPY Retirement!

Please join us to celebrate the retirement of Carolyn Kiolbasa.

Carolyn Kiolbasa, RN was instrumental with our **Clinical Care Network at Robert H. Lurie Children's Hospital.**

She took great care of our patients and always helped them to find all the specialists needed to help our Sturge-Weber patients there in Chicago. She will be missed!

PARTNER NEWS

Empowering Dreams Through Scholarships

UCB supports individuals living with epilepsy, their family members, and caregivers by offering educational scholarships to help them achieve their academic and personal goals.

Since 2005, UCB has awarded over $3 million in scholarships to more than 600 recipients, enabling them to pursue undergraduate and graduate education.

Scholarship Details:

- 30 Scholarships:
  - Up to $5,000 each.
  - Awarded to applicants demonstrating academic and personal achievement.
- **Epilepsy Leader Scholarships:**
  - 2 scholarships of up to $10,000 each.
  - Honors the late Sandra Helmers, MD, MPH, and John M. Pellock, MD—leaders in the epilepsy community.
- **Joe D'Souza Memorial Scholarship:**
  - 1 scholarship of up to $10,000.
  - Established in memory of UCB's global medical director, Joe D'Souza, in 2019.

Eligibility:

- Recipients of the Epilepsy Leader and Joe D'Souza Memorial Scholarships must display:
  - Academic and personal achievement.
  - Advocacy for others and contribution to the epilepsy community.
  - A persevering spirit.

Important Date:

- Applications for the 2025 program are due Saturday, **March 15, 2025.**

LEARN MORE AND APPLY

THE SWF IS PROUD TO

ANNOUNCE

Free Laser Treatment Opportunity for Port-Wine Birthmarks.

The Sturge-Weber Foundation and Sciton, Inc. are thrilled to announce a new partnership with Sciton Cares!

This collaboration brings more opportunities for patients to access treatments—closer to home.

Here's the details:
Sciton Cares Providers are opening their doors to offer treatments to a limited number of patients in need at their clinics all over the world.

This is your chance to qualify for care right in your community!

LEARN MORE AND APPLY

ADVOCACY

Support for Epilepsy Legislation

The Sturge-Weber Foundation is proud to join other organizations in support for the National Plan for Epilepsy Act (H.R. 1189/S. 494).

Why This Legislation Matters:
The National Plan for Epilepsy Act is modeled after successful plans for Alzheimer's and Parkinson's.

Here's what it will do:

- Create a National Plan for Epilepsy, led by the Secretary of Health and Human Services (HHS).
- Establish an Advisory Council of epilepsy experts, researchers, health care providers, patients, and families.
- Host public meetings, deliver actionable recommendations, and assess progress annually.
- Prioritize the development of better treatments and transformative care models.

Why We Need YOU:
This bill means hope, progress, and a better future for millions of people impacted by epilepsy.

- It will streamline federal coordination to improve outcomes.
- It will fund research to develop targeted, effective therapies.
- It will give families a fighting chance at a better quality of life.

Together, we can make a difference for the epilepsy community. Let's get this done!

Read the full sign-on letter.

Learn how to contact members of Congress here.

ADVOCACY SIGN-ONS:

Speak Up, Spark Change: Advocacy for Sturge-Weber Syndrome

Did you know Members of Congress play a pivotal role in shaping federal programs that drive medical research, foster treatment breakthroughs, and improve access to healthcare? Yet, when it comes to rare conditions like Sturge-Weber syndrome, most lawmakers know little to nothing about the challenges and needs of those affected. Without that knowledge, vital research and public health initiatives may completely bypass our community.

Here's where you come in. Sharing your story can be a powerful tool to educate and inspire change on Capitol Hill. By connecting directly with your elected officials, you can shine a light on the realities of living with Sturge-Weber syndrome and ensure your voice shapes the decisions that matter most.

The good news? Reaching out to Congress is easier than you think—and you're not alone in the process. The Sturge-Weber Foundation is here to guide, support, and empower you every step of the way. Together, we can turn stories into action and advocacy into impact. Contact members of Congress here.

Below are some of our most recent Congress sign-ons. Click the title to read more.

- Feb 14, 2025 | National Plan for Epilepsy Act Support for the National Plan for Epilepsy Act, H.R. 1189/S. 494. Read the full support letter by clicking the title above.
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- October 2024 | Healthy People 2030 objectives The Epilepsy Foundation of America (along with The SWF) asking that an epilepsy objective be included in Healthy People 2030, as it was in Healthy People 2020.

- 21st Century Cures Act 2.0 July 2024 | This legislation's goal was to accelerate medical innovation and improve care by delivering new advances to people with epilepsy and other disorders. In 2019, Representatives DeGette and Upton introduced the 21st Century Cures Act 2.0 (Cures 2.0) to build upon the efforts of the first bill. Since 2019, parts of Cures 2.0 have been enacted through legislation and regulation.

- LaborHHS-Education bill for FY 2025 to provide needed services for the American public while ensuring continued support for NDD programs.

- FY 2025 BRAIN Initiative letter 4/2/24 | We are happy to announce the submission of the Brain Research Through Advancing Innovative Neurotechnologies (BRAIN) Initiative and the Neurology Drug Program (NDP) sign-on letters. The BRAIN Initiative letter was submitted to the House and Senate Subcommittees on Labor, Health, and Human Services and Education Appropriations. The BRAIN Initiative is revolutionizing our understanding of the brain and offering hope for the millions of individuals impacted by brain diseases, disorders, and injuries.

- Neurology Drug Program (NDP) sign-on letter 4/2/24 | We are happy to announce the submission of the Neurology Drug Program (NDP) sign-on letter. the NDP letter was submitted to the House and Senate Subcommittees on Agriculture, Rural Development, and Food and Drug Administration Appropriations. Support for this program will allow the FDA to gain the expertise to develop policies and guidance that keep pace with emerging brain science.

- Epilepsy Leadership Council Digest for Monday March 11, 2024 One in three Americans will have a brain or nervous system disorder sometime in their life, and the cost of treating neurological disorders is nearly $1.5 trillion each year. The BRAIN Initiative is revolutionizing our understanding of the brain and offering hope for the millions of individuals impacted by brain diseases, disorders, and injuries.

- FDA Neurology Drug Program in FY 25 As your subcommittees begin to craft FY 2025 appropriation legislation, we ask that you provide $5 million for this important program, an increase of $3 million. Funding at this level will help advance discoveries in all areas of brain health including neurodevelopmental, neurodegenerative, psychiatric, brain injuries, and more.