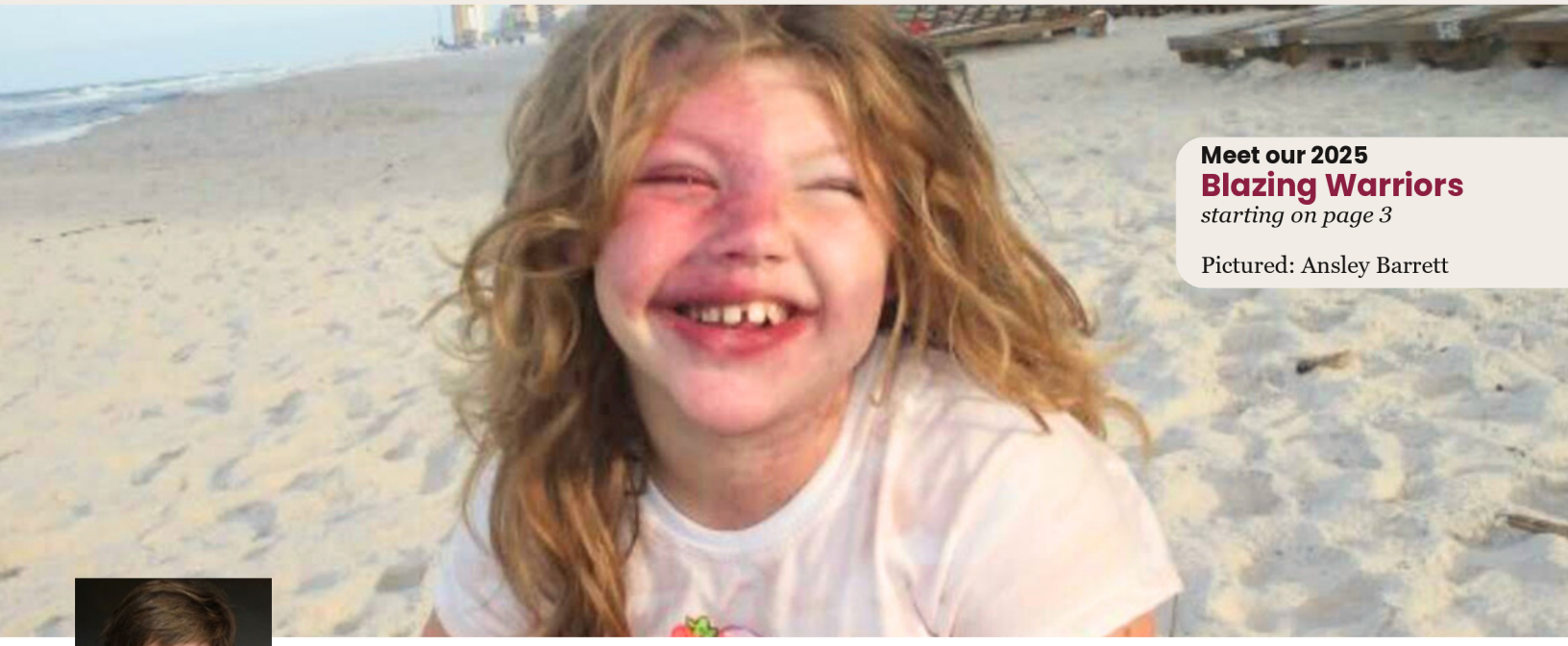
THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

Branching Out

ISSUE #01, VOLUME 1
SUMMER 2025

DEDICATED TO THE LIFE AND CARE FOR PEOPLE WITH STURGE-WEBER SYNDROME AND PORT-WINE BIRTHMARK CONDITIONS



Meet our 2025
Blazing Warriors
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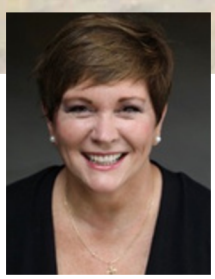
Pictured: Ansley Barrett



Honoring Sacrifice and Hope

FOUNDER AND CEO - KAREN BALL

Memorial Day always brings a moment of reflection and gratitude for those who've made the ultimate sacrifice. This year, after meeting Roger and Candy Krohn—who lost their daughter to Sturge-Weber—I was reminded that many in our community have also experienced deep loss. It was a touching and heartfelt meeting, made even more meaningful with Kaelin there too.

Being part of this journey with families who have lost loved ones is a privilege.

As the Foundation looks ahead, we must remember why we're here: to bring hope, drive change, and support one another through community, fundraising, and groundbreaking research.

There's a new generation of brave, smiling children counting on us. Their families and friends are counting on us too—to keep pushing forward, to support, and to discover. Every day is a gift. Every small victory is worth celebrating, and every challenge is a reason to keep going.

Thank you for standing with The Sturge-Weber Foundation. Together, we've made a difference—and we're not stopping now.

With faith, hope, and love,

Karen Ball

PS: Got fun summer photos?
We wanna see 'em! Sun, smiles, splashing around — send them our way!

PSS: Love flipping through Branching Out?
Help keep it in your hands with a $25+ donation. Printing + postage costs are climbing, and we don't want this inspiring publication to disappear!
Let's keep the stories alive — and the presses rolling!

The Sturge-Weber Foundation MAGAZINE

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The SWF is a member of the Brain Vascular Malformation Consortium (BVMC),American Brain Coalition (ABC), The Coalition of Skin Diseases (CSD),and the Association for Research in Vision and Ophthalmology (ARVO).

Branching Out

SUMMER 2025

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Boston Children's Hospital Day: Page 8

Port Wine Birthmarks (PWB) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck.

Sturge-Weber syndrome (SWS) is a rare congenital condition usually consisting of a facial port wine birthmark, glaucoma, and seizures, (although not all of these symptoms may be exhibited).

SWF POLICY STATEMENT:
In implementing the purpose of The Sturge-Weber Foundation to improve the quality of life for individuals with SWS and their families, the Foundation will act as a clearinghouse of information, provide emotional support and facilitate research on PWB and SWS.

The Foundation will seek information regarding management and treatment techniques and suggestions concerning education and emotional support and will facilitate the dissemination of appropriate information.

If, in facilitating research on PWB, SWS and KT, the Foundation provides financial or other support to a particular research project, the Foundation will base its decision upon need, the Foundation's financial Resources and medical advice.

Meet Our 2025 Blazing Warriors

Passing the Torch. Blazing the Trail. Lighting the way for SWS Awareness.

Missed the epic stories of our Blazing Warriors during Month of Awareness? No worries — we've got your back!

Eloise
2 YEARS OLD
MICHIGAN

The Kin Family
When Eloise was diagnosed with Sturge-Weber Syndrome, I was overwhelmed with emotion—sadness, fear, anger, and confusion. I was desperate for answers.

The Sturge-Weber Foundation became a lifeline for us. They helped us connect with other families navigating the same journey, giving us a sense of community and comfort. They also connected us with specialized doctors in our area, which has been incredibly helpful.

The hardest part has been facing so many unknowns. But the diagnosis has given us perspective—it's taught us to appreciate the things we once took for granted and to approach others' differences with empathy and positivity.

Ansley

Ansley Barrett
I was born with Sturge-Weber Syndrome, but for the first twenty-four years of my life, my health was relatively unaffected. My seizures ceased shortly after my parents decided to take me off medication at the age of four. My glaucoma was managed with two surgeries and eye drops, and I received laser treatments until I was ten.

During my elementary years, I was severely bullied for my facial difference and learned to walk with my head down. From a very young age, I knew I had been robbed of normalcy. I learned early on that the world is not always kind to those who look different. I became accustomed to walking into a room and immediately being the center of attention. Receiving glaring looks from children and adults alike, the target of people's stares, pity, comments, questions, and even their unsolicited prayers.

Some interactions came from a good place and often ignorance, not malice, though some were intentionally cruel. Through all of the good and bad experiences, I understood that I would never be someone who simply blended into a crowd. One of my beloved mentors mentioned that I should take the attention already on me, capitalize on it, and use it for good, which was a compliment I was honored to receive. Even now, after twenty-five years of living with this syndrome, there are still days I wish I could go unnoticed in public and not feel the weight of so many eyes on me and constant whispers cannot tell my story without pointing to the hope I've found in God. I hold tightly to the promise that He brings all things together for good (Romans 8:28). I believe that what the enemy intended for harm is what God will use for good. That truth doesn't erase the pain or the reality of living with this syndrome, but it gives my suffering purpose, not just for me but for others, too.

People often compliment me on my confidence. I want to be clear: I'm not brave or confident just because I exist with a facial difference. Any strength you see in me is evidence of God's grace. Yes, I've faced adversity because of how I look. Yes, my experiences have shaped who I am and what I believe. But these challenges have made me more dependent on God. What you see is the fruit of that dependence and trust. I'm not superhuman. If you peel back the layers of the warm smile and welcoming presence, you'll find a woman who still wrestles with the tension of living with a rare syndrome and believing in a good God. Even after becoming a Christian in 2013, I struggled with verses like Psalm 139:14 and Genesis 1:26–27. But it's in that struggle that I've found God's love and grace.

As I mentioned earlier, Sturge-Weber didn't significantly affect my physical health for most of my life. But in 2024, that changed. I was in the middle of pursuing my master's degree and working on my mental health when I learned I needed another surgery. I didn't think much of it at first—I assumed it would be similar to the ones I had as a child and teenager.

However, that first surgery led to complications, which required another surgery. Tragically, that second surgery resulted in the loss

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of sight in my right eye. After months of pain and discomfort, my doctors and I decided that a prosthetic eye would be the best next step. In my twenties, Sturge-Weber Syndrome has taken a lot from me. But—spoiler alert—my God is bigger.

There are still hard days ahead. My body and face constantly change due to Sturge-Weber, and I'm still learning to love myself. But I am confident that God will use my story for His glory and my good.

Ezra
7 MONTHS OLD
LOUISIANA

The Gulino Family

When Ezra was first diagnosed with Sturge-Weber, we were scared, overwhelmed, and worried for his future. The Sturge-Weber Foundation has provided a wealth of knowledge and resources to understand SWS and help parents become the best advocates for their children. After all, there are times when we are educating doctors on the ins and outs and possibilities of this disease.

The Foundation has also made us feel less alone as we face the challenges and unknowns of Ezra's diagnosis. It's promising to see the research going on to work towards preventative care and managing symptoms. The biggest struggle for us is the unknown and the constant feeling that something is about to happen, a breakthrough seizure, a bad eye appointment, etc. It is also hard to navigate what is normal baby behavior, what could be side effects of medication, and what could be seizure activity or a developmental delay. After Ezra's diagnosis, we were forced to slow down and evaluate our priorities and what is most important to us.

We now celebrate every small step of progress and are so grateful for our village, our specialists, our SWS community, and everyone who has walked this journey before us.

Ruby
6 YEARS OLD
INDIANA

The Diefenderfer Family

Meet Ruby—our one and only.

From the start, Ruby did things her own way. She arrived via C-section, sunny side up. A red mark on her face was thought to be a bruise, and her feet turned blue in the nursery. She had a sacral dimple, which turned out to be harmless. But once we got home, we noticed more.

Ruby had trouble latching, was often inconsolable, and her limbs looked uneven. Her right eye seemed larger. We were told not to worry —"everyone has some asymmetry." But we pushed for answers. An eye exam at eight weeks revealed dangerously high pressure—46 in her right eye. We were sent straight to Riley Children's. That's where her glaucoma journey began.

She's had four eye surgeries so far, two shunts (one not working), and seven laser treatments for facial capillary malformations. This year alone, she's getting her third set of ear tubes and a sleep study. She sees ophthalmology, hematology, neurology, ENT, orthopedics, and pediatric dentistry. She gets weekly OT outside of school and daily OT in kindergarten.

She's also had a heart echo that found a PDA and atrial septal defect. Luckily, her brain MRI at one year showed involvement but no seizures. Ruby had a leg length difference and left-sided weakness. She wore braces and a shoe lift for a while. She hated them, but they helped. She also struggles with depth perception, especially on stairs.

At school, Ruby wears sunglasses at recess for eye protection. She teaches friends why. She also has to explain her cold intolerance and skin changes due to her syndrome.

We've always been honest with Ruby. She knows about her condition and handles it with surprising grace. She just learned this year that not everyone has glaucoma. Through it all, we've learned to trust our instincts, ask questions, and never accept "no" for an answer. If it weren't for Facebook groups and The Sturge-Weber Foundation, we'd be lost. Connecting with other families—and meeting Karen—has been life-changing.

Ruby is on max eye drops (four kinds, three times a day), but her vision is perfect, so no glasses for now. She loves dance and gymnastics. She's kind, thoughtful, and wise beyond her years.

We wouldn't change a thing. Ruby is here to teach us—and she's doing an amazing job.

**"A sacral dimple is a small, shallow indentation in the skin on the lower back, typically just above or within the crease of the buttocks. It's a congenital condition, meaning most people are born with it. While generally harmless, sacral dimples can sometimes be associated with other spinal conditions."*
- Mayo Clinic

Zaya
9 MONTHS OLD
OREGON

The Bailey Family

When Zaya was diagnosed with Sturge-Weber, I was in shock, but I wasn't. I was relieved to have an answer, but I knew that our lives were going to change for the better. And I was going to be learning something new. I knew so much about autism. But nothing about the rare condition of Sturge-Weber.

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I was open-minded and excited to learn. The Sturge-Weber Foundation has given me so much information and hope. Our biggest struggle is probably the financial adjustment, but we are overcoming it and taking it one day at a time.

Some days, I have mom-guilt like I should be doing more. Our journey has been an interesting one. There have been a lot of ups and downs, more positive than negative. And we have such an amazing team in Seattle.

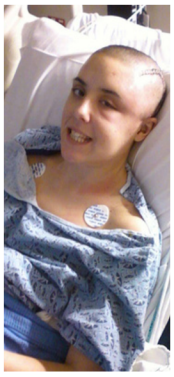
I'm excited to continue her journey and to begin her laser treatment to better her life. I am excited to continue to learn more, understand, and study her birthmark, diagnosis, and her arm growth.

Thank you to everyone who prays, thank you, God, for every day. She has a beautiful life. Thank you to Dustin for working so hard so I can be home with her daily and never worry. I am thankful for my parents who give my son weekly sleepovers and help whenever they can. Thank you to Dustin's family for loving our daughter and spreading awareness. Thank you to my friends, aunts, and uncles who love her.

We are blessed to be her parents. We are blessed to have a rare daughter born in the time of innovative medical treatments. I am thankful we found a team within a couple of hours of driving. I am thankful to everyone who has helped us. I am thankful for everyone who loves Zaya for who she is and is willing to learn about her.

Shelby Jennings

I'm 36 years old and live with Sturge-Weber Syndrome Type 3,* a condition my twin sister doesn't have.
For me, growing up with Sturge-Weber, every time I'd have a new neurologist, it was always questioned if I had Sturge-Weber because I was "too high functioning and I don't have a port-wine stain," but after having MRIs, I was diagnosed with Sturge-Weber.
The doctors first discovered that I had Sturge-Weber when I was nine months old. I had a seizure that lasted for over two hours, which turned into a stroke.



Shelby
36 YEARS OLD
CALIFORNIA

My goal and hope is to one day maybe become seizure-free. I had a part of my left temporal lobe removed back in 2012, and my seizures went down 99%, and a few years without a seizure. The last two years, I have had a few recurrences, and I'm currently in the process of possibly getting round two of brain surgery as they think they didn't get all of the scarring out.

I'd say my biggest struggles with the disorder are overcoming my learning disabilities. I feel a bit of guilt for "not having bad symptoms," and I felt I didn't have the right to complain. I also dealt with all forms of abuse as a child because people believed I wouldn't be able to tell when I'd become an adult.

I have learned you can live a full, independent life even if you have seizures. I've lived on my own since I was 19 years old. My seizures started to become chronic when I was 20 years old. I would have 2-6 seizures a day, but I was still able to start as a patient transporter at the hospital I was working at, and move up positions before having the surgery. I called my seizures "mc twitchels" to help ease people's fears in case I had one in front of co-workers (this was to help ease people's fears.) I could later show them that I was back to my full self. I currently have a career as a radiology assistant.

I am thankful for those who show empathy. One of my biggest goals in life is helping others with disabilities who have been abused, because sadly, it

I am thankful for those who show empathy. One of my biggest goals in life is helping others with disabilities who have been abused, because sadly, it happens often, and unfortunately, I can relate because I am an abuse survivor. The beauty of having my disability is that, over time, I learned how to use my voice and face my past. I can understand people who can't speak, because when I have grand mal seizures, I have stroke-like symptoms and understand the feeling of being trapped within the body. I can make patients laugh during their hard times in the hospital because I know what it is like to be in a hospital bed. I love helping others who struggle because I can relate to them.

**Type 2 SWS: This type of SWS is commonly noted to have a leptomeningeal angioma, with no facial involvement and usually no development of glaucoma. Commonly referred to as forme fruste, this type is identified through brain scans. It can also be confused with other diagnoses prior to a brain scan with a contrasting agent. While social stigma is lessened by the absence of PWB, the unknown natural course of the syndrome is still frustrating for parents and professionals treating the condition. - The Sturge-Weber Foundation*

Esther
73 YEARS OLD
UNITED KINGDOM

Esther Harrold

I was born in 1951 in London, UK. Information about Sturge-Weber Syndrome was very different in the 1950s.

I was treated at the Children's Hospital for only a short time when I was about three or four years old. I found out only five years ago that I was treated with a radiation called Thorium X.* It was painted on my birthmark to try and fade it, but it didn't work. Thorium X was too dangerous to continue as it was withdrawn from use in the 1960s. I read that it was found to cause cancer in some people many years after use, but luckily, I'm okay.

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Blazing Warriors continued...

I must have SWS Type 2,** as luckily I never had any seizures or developmental issues, but looking back, I was quite a sickly child and grew into an adult with several medical issues, though nothing sinister. I don't believe they were SWS-related.

However, I was diagnosed with bilateral glaucoma in my 40s, and only at that time was I told I also had this thing called Sturge-Weber. I didn't know what it was and I wasn't referred to anyone about it, although, of course, I had to go see an eye specialist for the glaucoma. Obviously, the glaucoma in my right eye is caused by the SWS, but my mother also had glaucoma, so I inherited that from her in my other eye. Bad luck, as my specialist said.

Unfortunately, I didn't use the glaucoma drops as they brought side effects, but pretended to the eye doctors that I did. I didn't realise how serious glaucoma could become. About four years ago, I was told I could go blind, so I started the drops again. But I had resumed the drops too late, and now I am registered as Severely Visually Impaired.

The eye specialists did not want to perform glaucoma surgery on my SWS eye because it's too risky with the abnormal blood vessels in my eye. They said they could burst during surgery. But now things are getting worse, and they want to save what sight I have left, and now want to do the surgery. I have agreed, but am very nervous about it.
I don't know if in the 1950s if my parents were told what caused my birthmark. I have never seen a neurologist and have never had an MRI for my SWS condition, although I've had plenty of scans over the years as I have a benign tumour in my pituitary. I know my mother must have felt that it was her fault I was born with such a mark. We never discussed it, but she was a very loving mother, and I wish she were alive to tell her what actually causes SWS and that it wasn't her fault. Over the years, I thought it must have been caused by forceps, as my mother had a 30-hour labour, or a sort of blood flow problem, because my grandmother was dying when my mother was pregnant and died three months before I was born. I thought this great upset to my mother and might have affected me in the womb. We didn't know then what we know now.

My biggest struggle is feeling the need to constantly cover my birthmark with cosmetics because if I didn't, people would always remark on my "red eye". Although I'm now 73, I still feel the need to cover my birthmark on social occasions. I am still extremely aware and embarrassed by it. It has defined my life, and I wish laser treatment had been available for me when I was younger. I did have some in my 50s, but feel it was too late as it made my mature skin too dry after, and makes it more difficult for me to cover my birthmark now. But I'm vain and still like to look good despite my years.

And finally, something good...I was blessed with kind and loving parents. I made my own way in the world from the age of 18. I am very strong-minded. I've been very lucky to have had a loving and strong marriage. I couldn't have children, but I was ok with that. I grew up to be an intelligent, independent, attractive woman. Despite my many health issues over the years, I have always been a very caring person to others and proactive in my community in various ways. I've always had good and interesting jobs. I put my sensitivity to others down to the fact that I've always had to live with a birthmark, which I consider a disfigurement, but ultimately, I never let it hold me back. I never give in and always try and look for the positives in life. I am stronger and more compassionate because of my birthmark. But I am not a SWS warrior, I do not like that word.

Although I think it is wonderful that babies, children, and parents have access to so much more medical help and information these days for SWS, I do think those of us with Type 2 SWS should not be wrapped up in cotton wool by their parents. They should be encouraged to be strong and independent so they can enjoy a normal life. After all, parents aren't here forever to protect their children, so we need to also learn to stand on our own two feet.

**Thorium X: "Thorium X is an ionizing radiation treatment that was commonly used by dermatologists in the 1930s to 1950s to treat a variety of benign dermatoses and vascular lesions, including port-wine stains." -NIH, https://pubmed.ncbi.nlm.nih.gov/19077098/*

***Type 2 SWS: This type involves a facial angioma and the possibility of glaucoma, but no evidence of intracranial disease. There is no specific time frame for the exhibition of symptoms beyond the initial recognition of the facial PWS. Throughout the life of the individual, interrelated symptoms may manifest in glaucoma, cerebral blood flow abnormalities, headaches, and various other complications. Additional research needs to be conducted on this type of SWS to determine the course of the syndrome over its natural progression.*

Lathan

"HAVE FAITH IN GOD. "Mark 11:22, the verse I clung to 18 years ago, and have spoken this verse for the last 18 years over Lathan.

Lathan was diagnosed with Sturge-Weber at 3 months. The seizures, numerous hospital visits, glaucoma, multiple therapies, medications, shots, and all the other stuff didn't slow him down one bit.

Please join me in congratulating Lathan Parker, graduating with honors. His honors are much different than the academic honors. Lathan's honors include walking, talking, riding a bike, being able to identify every type of vehicle make and model on the road, being a sports enthusiast, a person who never meets a stranger, and being able to carry on a great conversation. Has the sweetest heart and always looks out for his family and friends, loves being told he is handsome, loves his cowboy boots and cowboy hat. He has worked hard for his honors.

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Behind the Scenes

May was nothing short of incredible at The Foundation. From powerful conversations and national conferences to boots-on-the-ground awareness events, our team was out in full force, shining a light on what matters most. Here's a BTS (behind-the-scenes) look at what we accomplished **together** last month.

Fireside Chats & New Beginnings

We kicked off the month on **May 1st** with a Fireside Chat, where **nine passionate community members** joined **Karen Ball** to discuss the heart of the Foundation and our exciting future direction. These open conversations are where ideas ignite. We also proudly introduced our **new Blazing Warrior Program** — a powerful initiative designed to spotlight and support the warriors within our community. This will be one of many thrilling new chapters!

Women's Health, Epilepsy & Empowerment

SWS Month of Awareness

On May 4th, our team attended the Empowerment Through Information: **Women's Health and Epilepsy Conference.** Thanks to **Julia, Marissa,** and **Rebecca McDonald,** we were able to collaborate with the **Epilepsy Foundation** and our **Clinical Care Network from Jefferson Health** to advocate for integrated care and shared experiences.

Music, Awareness & Powerful Conversations

- May 6th launched our successful *Tag, You're It!* social media challenge, spreading awareness and deepening community engagement.
- We interviewed the talented Gabby Bartolone about her upcoming album.
- On tour, we connected with Jordan St. Cyr, whose music continues to inspire and uplift our mission.

Real Talk Chats

- May 15th brought our monthly **Patient Chat**, a safe space to share, learn, and grow.
- We held a **Caregiver Chat**, recognizing and supporting the tireless heroes walking alongside our warriors every day.
- For our professionals in the field, **Modeling Call** took place with **Dr. Kristen Kelly, Dr. Lisa Arkin,** and **Dr. Beth Drolet** — leading voices from our Clinical Care Networks — to spotlight *"how you do awareness"* and the power of representation.

Spotlights & Collaborations

- We collaborated with **Rare Revolution** from across the pond on **May 24th**, raising our voices alongside rare disease advocates around the world.
- **May 28th** was a major milestone — **Giving Day** — and we saw incredible generosity. Thank you to everyone who gave, shared, and supported!

Family, Legacy, & Connection

- We collected moving warrior stories from 7–10 amazing families whose voices carry the heartbeat of our mission.
- Honored loved ones on the Memorial Wall for **Sarah Ann Hammett**, a sacred space of remembrance and love.
- The Butterfly Quilt for **Hailey's Hope** projects brought creativity and community together.
- We joined forces with **Adrian at the Birthmark Society** in a local initiative that brought more visibility to our cause.

Coast to Coast: Mini Summits & Marathons

- **Julia Terrell**, **Anna Pinto**, and **Pam McIntyre** hosted an in-person **Mini Summit** at Boston Children's Hospital, deepening connections and creating action plans.
- **Karen Ball** represented us at **BVMC in California** and **ARVO in Salt Lake City**, ensuring our voices were heard on both coasts.
- Hats off to **Molly Speer** and the **Myla's Mission** for a powerful **5K/Jeep Ride** — blending movement, mission, and momentum.

United We Blaze Forward

Each event, each voice, and each step we took in May brought us closer to our vision — a world where awareness, care, and community come together to uplift every warrior and every family.
Stay tuned — June is just heating up.

Want to get involved? Be sure to follow us, share your story, and join our next chat!

Let's blaze a trail. Together.

Boston Children's day of education

Sturge-Weber Syndrome Family Day Brings Community, Knowledge & Hope to Boston

On Saturday, May 17th, families and individuals affected by Sturge-Weber Syndrome (SWS) gathered at Longwood Hall in Boston for a day of connection, learning, and support.

A BOLD STEP FORWARD

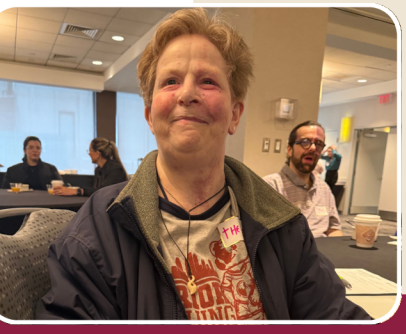
The day was packed with expert talks on mental health, neuroimaging advances, treatment options for port-wine stains, and other topics. Attendees also heard inspiring personal stories from **Ryan McIntyre** and **Erik Bruun**, who shared their experiences living with SWS.

Guests joined small-group sessions for deeper conversations with:

- **Luis Sandoval, PhD,** discussed mental health and cognitive care
- **Csaba Juhasz, MD,** shared the latest in neuroimaging
- **Joyce Bischoff, MD,** hosted a tour of her vascular biology lab, highlighting new research on SWS

Also lending their expertise were:

- **Mustafe Sahin, MD,** gave a warm welcome to all attendees
- **Matt Shirley, PhD,** discussed genes and disease mechanisms
- **Sara Gallant, MD,** presented ENT-related insights
- **Pierre Grenier, MD,** sharing dermatological perspectives
- **Anna Pinto, MD, PhD,** who contributed her extensive knowledge to the day's discussions



This day was about more than science—it was about support, shared stories, and the strength of the SWS community. Until next time!

BLAZING WARRIORS EVENT

Myla's Mission for Sturge-Weber Awareness

Myla's Mission 5K, UTV/Jeep Ride, and Silent Auction took place on May 17, 2025, in Greensburg, Indiana—and what an incredible day it was! Over 400 people came out to support Sturge-Weber awareness and research.

The day kicked off with our 5K at 9 AM, followed by the UTV/Jeep ride at 12:30 PM, wrapping up around 5:30 PM. The silent auction ran all day with amazing participation.

One of the most meaningful moments was connecting with four other Sturge-Weber families who joined us. Thanks to our amazing community and strong support system, **we raised an incredible $27,000 for the Sturge-Weber Foundation.**

Great weather, even better people, and a cause close to our hearts—thank you to everyone who made it possible!

Hailey's Hope

Quilt Fundraiser for SWF

Butterflies have always held a special meaning for Hailey. Her family chose them as the theme for her nursery before she was born—before they knew about her rare disorder. To them, butterflies represent hope, and from day one, hope has carried them through the journey of raising a child with disabilities.

One verse that's been close to their hearts is Isaiah 40:31: *"...those who hope in the Lord will renew their strength. They will soar on wings like eagles..."*

That message still inspires them today as they work to raise awareness for rare disorders and promote inclusion for all.

Thanks to the generosity of Hailey's Granny who made this beautiful butterfly quilt and to everyone who supported, shared, and bought tickets.

This year's quilt raffle was a big hit — we raised $1,400! That's $145 more than last year.

Research Study Last Call

The NIH-funded clinical research study on brain imaging in patients with Sturge-Weber syndrome has entered its last year.

The study team at Wayne State University in Detroit is still looking for several participants who are willing to undergo a non-invasive brain MRI and neurocognitive evaluation at no charge.

Subjects with known SWS or high-risk port-wine birthmark (age 3 months - 30 years), and their healthy siblings (3-30 years of age) are potentially eligible for the study. Both new patients and those who participated in previous stages of this study could be enrolled.

For further information, please contact Prof. Dr. Csaba Juhasz by email: csaba.juhasz@wayne.edu.

Travel Grant Winner

The SWF is proud to partner with the Association for Research in Vision and Ophthalmology (ARVO) to award a travel grant to promising young investigators advancing research in glaucoma and vision science.

This year's grantee is **Hasti Golchin** of the Oregon Health & Science University Casey Eye Institute, United States. Congratulations to Hasti!

Got a story, achievement, exciting news to share?

Share it here: https://tinyurl.com/your-sws-story

Events Calendar

Join us at one or all our upcoming events!

June

June 12: Virtual Caregiver Chat, 7:30-8:30 PM EST

Spanish Virtual Mini-Summit
June 14: 12:00 pm - 1:00 pm EST, Dr. Esteban Fernandez, Dermatology

June 14: Fathers Day Run in Swarthmore, PA. Ship Bottom's version of The Beer Mile.

June 16: Be the Torch. Be the Light, a faith-based event, 7:30 pm - 8:30 pm EST

June 19: Virtual Patient Chat, 7:30-8:30 PM EST

July

July 17: Virtual Caregiver Chat, 7:30-8:30 PM EST

July 9: Virtual Patient Chat, 7:30-8:30 PM EST

July 22: PROFESSIONAL EVENT, Animal Modeling with Dr. Anne Comi

sturge-weber.org/events

Blazing Warriors continued...

He has had quite a journey in his 18 years and knows without a doubt he will continue to thrive and succeed. Others should be so fortunate as to achieve what Lathan has. Lathan is a reflection of the love, support, and prayers that he has been covered with by those who love him most. Congratulations Lathan! Be proud of everything you've accomplished, rejoice, stand tall, and never stop pushing forward with much love from your warrior mother and your praying granny.

Three ways your gift makes an impact:



$50 WEBSTER BEAR FOR CARE

Your donation will send a Webster Bear to two kids while in the hospital recovering from treatments.

$100 LASER CARE KITS

Your donation will provide a laser care kit for three children recovering from laser treatments.

$250, $500, $1000+ LEGACY LEADER

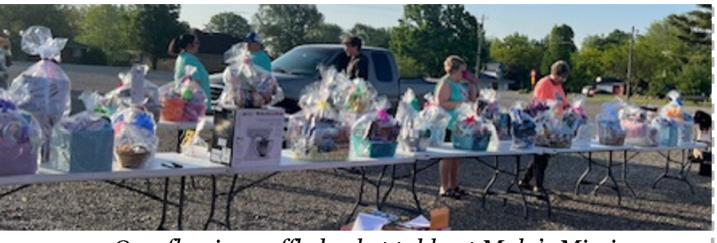
By planting seeds (acorns) for a more fruitful tomorrow, you are contributing to the growth of a robust and resilient community, where challenges only make us stronger, like trees standing tall against powerful winds.

Do you like receiving Branching Out in the mail?

If you enjoy reading and receiving news from *Branching Out* in the mail, we kindly ask for your support with a minimum annual donation of $25. Due to rising printing and mailing costs, we're no longer able to offer complimentary copies, but your contribution helps keep the publication going strong!

The SWF can now accept Bitcoin & DAF!

Wow! How times have changed! You can now support us through a Donor-Advised Fund (DAF) or with Bitcoin.



Overflowing raffle basket table at Myla's Mission

Your Gift Matters.

STRONGER BECAUSE WE ARE UNITED
THE STURGE-WEBER FOUNDATION

- ☐ **YES!** I will make a tax-deductible donation of $ _____
- ☐ **YES!** I will make an ongoing monthly pledge of $ _____
- ☐ In **MEMORY** of: _____
- ☐ In **HONOR** of: _____
- ☐ Endowment Donation
- ☐ Stock Donation or Real Estate Donation*
- ☐ I have enclosed a check #_____
- ☐ Credit card* (circle one) Visa MC Amex Discover

Name on Card: _____

Credit Card #: _____

CSV: _____ Exp. Date: _____

**See "ways to give" at the left, for online donations, text-to-donate, and mailing address. You may also donate stock or real estate to The Sturge-Weber Foundation. Please contact us for more information.*

Name: _____

Address: _____

City, State, Zip: _____

Email: _____

- ☐ **YES!** Sign me up for email newsletters.

Mobile Phone: _____

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

WAYS TO GIVE:

SAVE THE STAMP!

Use the QR Code to the right to donate securely on-line or fill out this form and mail to:

The Sturge-Weber Foundation
6105 S. Main Street, #200
Aurora, CO 80016

TEXT-TO-DONATE

TEXT IGNITE2024 TO 53-555

SECURE DONATIONS

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

THE STURGE-WEBER FOUNDATION
6105 S. Main Street, #200 • Aurora, Colorado 80016

Shop for a Cause 2 Ways!

SHOP NOW

The Official SWF Merch:
Teespring

Webster Club Gift Shop:
Zazzle

The Sturge-Weber Foundation (SWF): On a Mission to Make Lives Better!

We're here to improve life for those living with Sturge-Weber syndrome and Port-Wine Birthmark conditions by teaming up with brilliant clinical partners, trailblazing researchers, and passionate advocates.

Together, we're driving:
- Groundbreaking education
- Life-changing support
- Vital awareness

At SWF, it's all about collaboration and compassion. We're building a stronger, brighter future—one person, one breakthrough at a time. Learn more at www.Sturge-Weber.org

The stronger the wind, the tougher the trees.

Thank you to our sponsor and partners....

sofwave™

ucb Inspired by patients. Driven by science.

The Sturge-Weber Foundation prides itself as being an active participant in the community for all things Sturge-Weber. This includes all levels of organizations including but not limited to:

epilepsy ALLIANCE AMERICA

REN Rare Epilepsy Network Proud Member

ARVO The Association for Research in Vision and Ophthalmology

Global Genes® Allies in Rare Disease

National Eye Institute NATIONAL INSTITUTES OF HEALTH

NIH National Institute of Mental Health

NIH National Institute of Neurological Disorders and Stroke

NIAMS

patientworthy® RARE PATIENT NEWS. WELL DONE.

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