



# Branching Out

## DIGITAL



## To the Families and Communities of Texas,

With deepest sympathy and heartfelt concern, I write to express my sorrow for the devastation and loss caused by the recent flood that struck your community. The images and stories that have emerged are both heartbreaking and humbling, and I want you to know that you are not alone during this time of hardship.

In moments like these, words often feel inadequate—but please know that many across Texas and the nation are holding you in our hearts. We are mourning with those who have lost loved ones, praying for those still unaccounted for, and standing in solidarity with the families whose homes, businesses, and sense of security have been upended.

As a displaced Texan, we are known for our resilience, strength, and unity—and even in the face of such overwhelming challenges, I have no

doubt that your community will draw on that spirit to begin healing and rebuilding. The road ahead may be long, but you will not walk it alone.

If there is any way I or The Sturge-Weber Foundation can assist or support you in any way, please do not hesitate to reach out. Together, we can help bring comfort, aid, and hope to those who need it most.

With faith, hope and love always,

Karen Ball

SWF CEO/Founder and The Warrior Mama

### THE STURGE-WEBER FOUNDATION

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[Sturge-Weber.org](http://Sturge-Weber.org)





## Meet new Blazing Warriors

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

The Sturge-Weber Foundation's Blazing Warriors are the heart and soul of this year's Month of Awareness! These passionate volunteers from across the USA are sparking hope and paving the way for future breakthroughs in SWS patient care, caregiver support, and research awareness. Together, their efforts will fuel our mission to reach an ambitious \$150,000 goal. Let's light the way together! [READ MORE](#)



Lindsay Wright



Jessica O'Reilly



Kimberly Kin



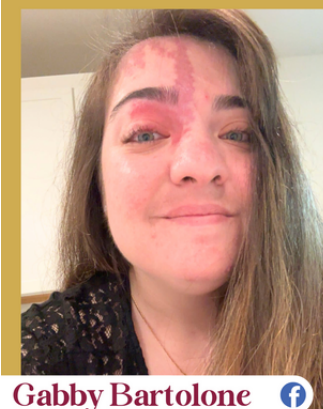
Rebecca McDonald



Ansley Barrett



Rodolfo Reyes



Gabby Bartolone



Brittany Covington

### UPCOMING EVENTS

Join us online!

**August 13:** Adult Patient Chat (21+) (Virtual)

**August 14:** Caregiver/Parent Chat (Virtual)

[Register Here](#)



**In case you missed it:** Watch "Hope. Be the Torch. Be the Light." on YouTube.

Our first faith night hosted by SWS Warriors **Donald and Ansley.**

[Watch Now](#)



## BACK TO SCHOOL RESOURCES



Seizure Action Plan



Educational Resources



Medical Forms



What's Your Plan?



Facebook Support Groups



Books about SWS



IEP Binder Resources



Encouraging Stuff



Be Back-to-School ready with Sturge-Weber Foundation!

# Then and Now—Rooted in Grace, Growing in Strength

By Melinda  
Sturge-Weber Warrior • Glaucoma Fighter • Proud Grandma

I was born with Sturge-Weber Syndrome in 1958. My parents were told I had a 50% chance of dying in infancy. And if I did survive, the prognosis was grim—they were warned I would likely be “mentally retarded,” a term that was clinical at the time but deeply inaccurate and damaging. The truth is, I was bright. I did well in school and loved to learn. I also spent a great deal of time in doctors’ offices and hospitals. I had numerous surgeries, and missed many days of school—but I still excelled academically.

SWS was never a secret in our home. My mother explained the condition to me, and I always knew what it was called.

What was harder to explain, even before that moment, were the stares, the awkward silences, and the rejection I felt from other children and even their parents. My facial differences only affected the right side of my face, but they seemed to define how others saw me—while erasing who I truly was.

My mom deeply loved me. But when it came time for photos, she always positioned me so that only my left side—the “good side”—was visible. For years, I wondered if she was protecting me... or herself.

That question stayed with me into adulthood. Now, as a mother and grandmother myself, I see the tenderness behind her choices. She was doing the best she could in a time when there was no public awareness, no Facebook groups, and no Sturge-Weber Foundation to offer community and hope.

But I had never met anyone else with SWS. Never seen another face like mine.

That changed in graduate school, when I was given an assignment to explore my cultural heritage. I considered focusing on my Irish-Scottish-English ancestry. But something inside me shifted. Instead, I decided to research the experience of growing up with a visible facial difference. That’s when I discovered The Sturge-

Weber Foundation for the very first time.

I remember seeing photos of children—some with birthmarks, some who looked just like me—and I burst into tears.

It was the first time I realized I wasn’t alone.

I went on to earn two master’s degrees and a doctorate in psychology. I spent over 30 years as a public school educator and completed more than 3,000 hours as a registered psychological intern in a separate setting. Today, I offer spiritually grounded life coaching for women and families in seasons of transition.

I was also diagnosed in my 60s with glaucoma in the eye I can still see from. That news was frightening. But instead of giving in to fear, I chose to slow down.

And in slowing down, I began to see. Not just with my eyes, but with my heart.

## **To parents of children with SWS:**

Your child doesn’t need to be fixed. They need to be loved and delighted in—exactly as they are. Even when you’re scared, your presence, your voice, and your belief in them are powerful.

## **To teens and young adults with SWS:**

You are not a mistake. You are not a burden. You are not a problem to be solved. You are a sacred story still unfolding—with courage, with softness, and with strength.

## **These days, I pause often to remember:**

“Be still, and know that I am God.” (Psalm 46:10)  
Sometimes that’s all we can do. And sometimes, it’s more than enough.

With gentleness and hope,

