



Branching Out **DIGITAL**



FOUNDER AND CEO - KAREN BALL

Blazing A Trail... for A Reason, A Season or a Lifetime!

We are all trailblazers! Each of you have the capacity to go out each day and forge new paths or sustain and maintain the path you are on already. I love the idea that we can all impact the life of another by being good stewards of the path we have chosen in life or been called to lead in life. I just happened to be called to start the Sturge-Weber Foundation when my daughter, Kaelin, was born in 1986. Little did I know the lasting impact that decision would make all these years later!

Brian Bilbow met Marissa Terrell when she was just a baby, and he was growing into manhood. The Bilbow family have been with us on this journey from the time Brian was little. It was so very heartening to learn the two families recently reconnected as Marissa is now emerging into a beautiful young woman! Our lives are so much richer when we care and share. Let's face it the world of Sturge-Weber and Port Wine Birthmarks wasn't even on our radar when we dreamed of holding our child in our arms. I'm so happy though that we have connected and been on this journey together for a reason, a season, or a lifetime.

I was recently asked by a new acquaintance if I would be having grandchildren anytime soon. I used to have bittersweet emotions when asked

about being a grandparent but now truthfully, I feel so blessed. I get the opportunity to watch some of y'all get married and have children of your own. I truly feel like I'm a grandma by proxy! It is so much fun to have watched you grow up and now your babies too.

The May Month of Awareness provides the perfect platform for you to join in the fun and awareness of life with SWS. The impact we all have when we join in the fight and blaze new trails or illuminate the path of another when we pass along the hope and knowledge gained is truly priceless. Y'all come out of your shell and do even one thing to create awareness starting in May and throughout the whole year. Legacies are made when we begin and don't give up!

Wishing you all a wonderful Spring. Thank you for your donations, for volunteering, and for your support of the SWF mission. Warriors United can overcome any foe from within or without...hang tough and hopefully I will see y'all soon on the trails filled with tales!

With faith, hope, and love,

Karen Ball



May is SWS Month of Awareness!

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!



Megan Butler

INDIANA

Megan, Blazing Warriors Coordinator:

Meet Megan Butler—a proud Warrior Mama from Indiana juggling life with her husband, four kids (including triplets!), and two dogs. Her oldest daughter was born with Sturge Weber, inspiring Megan's passion for helping others on a similar path. Though life is busy, her heart is wide open. Now, as the new coordinator of the Blazing Warrior program, she's eager to connect with families, share strength, and remind everyone: you're never alone on this journey.



Isaiah Baker

Isaiah, Social Media Intern:

Hi! I'm Isaiah Baker, a marketing student at Bloomsburg University with a passion for making a difference. I've been building skills in content creation, analytics, and brand storytelling—and I'm excited to put them into action. I'm eager to join the Blazing Warriors team, contribute to the Foundation's growth, and learn from a group committed to creating positive change.

[READ MORE](#)

Events Calendar

Join us to spread awareness!

May 1: MOA Kick-off event with Karen (Virtual)

May 7: Tag, You're It! Watch on Social Media and join in the fun!

May 11: Mother's Day

May 14: Share your SWS Story Day on Social Media

May 15: Mental Health Day and Patient Chat

May 17: Myla's Mission for SWS

May 17: Mini Summit at Boston Children's

May 20: Animal Modeling with Kristen Kelly and Lisa Arken

May 21: Meet the Volunteers Near You

May 24: Rare Revolution Magazine Social Media Take-Over Day

May 28: The SWF Day of Giving

May 29: Mental Health Day and Caregiver Chat



THE STURGE-WEBER FOUNDATION

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THE STURGE-WEBER FOUNDATION PASS THE TORCH FOR SWS

LIGHTING THE WAY FOR THE FUTURE



SWS Month of Awareness Resources:



DOWNLOAD NOW

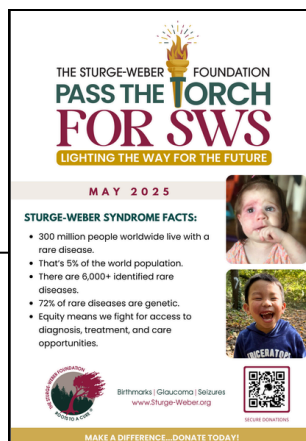


COLORING SHEETS

ENGLISH, SPANISH, AND FRENCH ALL ON ONE FILE. Let's spread awareness with these adorable Webster Bear coloring sheets! Perfect for engaging young minds in meaningful conversations of acceptance. Teachers, let's empower our students to share stories of facial differences.

MONTH OF AWARENESS POSTER

Download from the website and post at schools, doctor offices, rec centers, at the office, and more to spread awareness.



Need a logo for a fundraising event? We've got 'em!

Our community is encouraged to use our MOA logos on banners, t-shirts, bandanas and more for the purpose of raising money for The SWF. Contact Julia for more information.



Social Media Profile Graphic

Social Media Graphics



Myla's Mission for Sturge-Weber Awareness



Hi! 🙋
I'm Myla Jane...

Hi everyone! I'm Myla Jane Speer, and I'm 8 years old! I am a girly girl and I love to sing, I am totally obsessed with Frozen, all things mermaids, and I love hanging out with my little brother and sister, Everett and Aspyn. I'm also a super busy girl! I'm in gymnastics and dance, I'm a Pirate cheerleader, and I even play basketball and softball.

I'm also a superhero – well, kind of! I have something called Sturge-Weber Syndrome, which sometimes makes things a little tricky. It can affect my learning, my eyes, and sometimes I have seizures. But guess what? I don't let it stop me! I'm a fighter, and I'm learning and growing every day. I might need a little extra help sometimes, but I'm strong and I'm brave. So, that's me! Thanks for cheering me and others who have Sturge-Weber on!



May 17, 2025 @ 8:00 AM
Lake Santee, Greensburg, IN

**Join
Us!**

Register: <https://www.mylasmissionsws.com/>

5k, UTV/Jeep ride, silent auction. All proceeds directly benefit
The Sturge-Weber Foundation.