



Branching Out

ISSUE #04, VOLUME 4

SUMMER 2026

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



Together, We Make Life Better!

FOUNDER AND CEO - KAREN BALL

Dear SWS Family,

Thank you so much to everyone who attended the family reunion in San Antonio. It was truly a joy to spend that time together. To those who couldn't make it this year—you were genuinely missed, and we're already looking forward to seeing you at the next reunion.

I left this year's gathering with a full heart, reminded just how true the statement "together, we make life better" really is. Each and every one of you adds something meaningful to my life. Because of you, I feel richer, more supported, and deeply blessed. Knowing we can lean on one another makes life's challenges a little lighter, and I truly hope you feel that same care and support reflected back to you as well.

I'm also excited to share that the Board of Directors has approved the annual budget, which includes funding for two research projects. The next step is

bringing in a few willing volunteers to roll up their sleeves and help us get things moving...*hint, hint!* We'd love your support and involvement.

Enjoy the rest of your summer, and please keep sharing your photos from every corner of the world, we absolutely love seeing them!

With faith, hope, and love,

Karen Ball



Karen, Julia, & Liana



The Sturge-Weber Foundation MAGAZINE

CONTACT INFORMATION

6105 S. Main Street, #200
Aurora, CO 80016
973-895-4445
swf@sturge-weber.org
www.sturge-weber.org

GRAPHIC DESIGN

Jeri Stunkard, Have Faith Studio

EDITORIAL CONTRIBUTIONS

Karen L. Ball, Founder | CEO
Julia Terrell, Community Relations

BOARD OF DIRECTORS

Curt Stanton, Chair
Lake Forest, IL
Shad Elliers, Secretary, Slidell, LA
Dan Schmidt, Treasurer
Colorado Springs, CO
Witney Arch, Mandeville, LA
Molly Speers, Greensburg, IN
Don Willard, Bloomington, IL
Rob Zarko, Wallingford, PA
Annette Coutu, Coventry, RI
Karen L. Ball, President/CEO
Aurora, CO

HONORARY BOARD MEMBERS

Linda Larach Cohen, New York, NY
Stan M. Fisher, Big Fork, MT
Joseph Morelli, MD, Aurora, CO
Gerard E. Puorro, Wayland, MA
Melanie Wood, Bellaire, TX

MEDICAL ADVISORY BOARD

Matthew Shirley, MD, PhD
Chief Scientific Officer
Jeffrey Loeb, MD
Chief Clinical Strategist
Thuy Phung, MD, PhD
Chief Clinical Pathologist
Tina Alster, MD
Craig Burkhart, MD
Roy Geronemus, MD
Carol Greene-Roethke, RN
Mustafa Sahin, MD



SWFIRN ADVISORY COUNCIL

Kristin Kelly, MD
Jeffery Loeb, MD
Doug Marchuk, MD
Anna Pinto, MD
Jonathan Pevsner, MD, PhD
Thuy Phung, MD, PhD
CONSULTANTS
Jack Arbiser, MD, PhD
Jerome Garden, MD
Joseph Morelli, MD
Robert Ritch, MD
Oon Tian Tan, MD

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).



Your Gift Matters.

- ☐ **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: _____

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



SECURE DONATIONS

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.

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

Pivot! A Weekend That Turned Out Just Right

by Julia Terrell, Director of Community Relations

Every conference has a theme. Although it wasn't printed anywhere in the program, this year's unofficial theme became simply:

Pivot!

If you're a *Friends* fan, you probably heard Ross Geller's voice in your head the moment you read that one word.

The truth is, no matter how much we plan, organize, prepare, and double-check every detail, something unexpected always happens. Speakers have emergencies. Technology has a mind of its own. Schedules change.

Sound familiar?

For families living with Sturge-Weber syndrome, that's everyday life. We learn early that sometimes the best-laid plans need to change. We adapt and somehow discover that what first felt like a setback often becomes one of the most meaningful parts of this crazy thing we call life.

For one special weekend every two years, our Sturge-Weber Foundation family gathers from across the world. It's not just a chance to learn about the latest research and treatments, or talk to specialists, but to reconnect, make new friends, find strength in one another, and remember that no one walks this SWS journey alone.

The pivot-spirit perfectly described our **2026 Sturge-Weber Foundation Family Conference in San Antonio**. Nearly 150 families, clinicians, researchers, volunteers, sponsors, vendors, and friends came together for a weekend filled with learning, laughter, hope, and yes, a few pivots along the way.

Looking back, we wouldn't have changed a thing.

Thursday Was For Reconnecting.

Thursday afternoon marked the beginning of an unforgettable weekend as registration opened at 1:00 p.m. We didn't have to wait long before the hotel lobby was buzzing with hugs, happy reunions, first introductions, and the excitement that comes when your conference family is together again.

At 2:00 p.m., families participated in one of our favorite conference traditions, *Ask the Experts*. This informal session gave families the



opportunity to sit down one-on-one with physicians and specialists to ask questions, discuss concerns, and receive guidance in a relaxed setting. These conversations often become some of the most valuable moments of the weekend.

One of our first schedule changes actually began that afternoon. **Dr. Michael Behen**, one of our *Ask the Experts* physicians, experienced an unexpected emergency. While none of us could have predicted it, we did what this community always does—you guess it, *we pivoted*.

By 7:00 p.m., it was time to trade medical questions for a rodeo-themed ice cream social with games and simply enjoying one another's company.



We were also honored to celebrate **Bruce and Mary Ann Bedell's** 54th wedding anniversary (pictured above). It was a beautiful reminder that while we gather because of Sturge-Weber syndrome, we stay connected because of the friendships and memories we create together.

Continued on next page...





Friday, Our Kick Off.

Friday morning, as we officially welcomed everyone to the conference, I couldn't help but make an observation:

"This has to be the safest place in the country to have a neurological emergency—we have seven neurologists in the building!"

Little did I know that we would soon test that statement!

During the conference, **Dr. Anna Pinto** was called away to assist a family at the hospital. Without hesitation, she jumped into an Uber, leaving the doctor's dinner, without a question. It was another reminder that our physicians don't simply speak at our conferences, they care deeply about our families and are always willing to step in whenever they are needed.

As the weekend unfolded, that number actually grew to eight neurologists, along with representatives from nine Sturge-Weber Foundation **Clinical Care Networks (CCN)**. Seeing so many experts together in one place was truly inspiring.

Pivoting continued on Friday when **Dr. Michael Behen** had to join us virtually because of that aforementioned emergency. Thanks to technology, and his incredible dedication, families were still able to benefit from his expertise. Even more remarkable, he continued calling patients well into the evening, freely sharing his personal cell phone number with families. His willingness to go above and beyond perfectly demonstrated the compassion that defines our physician community.

Continued on next page...



The dedication of our faculty was evident everywhere you looked. **Dr. Steve Roach** shared the history of Sturge-Weber syndrome with both wisdom and heart, reminding us just how far we have come as a community. He reflected on the pioneers who laid the groundwork, the progress made over the years, and the perseverance of families, clinicians, and researchers whose dedication has brought us to where we are today. Several physicians even flew in for only a few hours to ensure important specialties—including neurology and neurosurgery—were represented. Their commitment to our families was extraordinary and greatly appreciated.

After a full day of learning, it was time to trade lecture halls for the beautiful **San Antonio River Walk**. Families boarded buses for an evening boat ride, sharing stories, laughter, and creating memories together.

Saturday, We Looked Ahead.

Saturday morning continued the journey. Following Dr. Roach's inspiring look back, **Dr. Jeffrey Loeb**, Chief Clinical Strategist for the Sturge-Weber Foundation, looked ahead. He shared where the science is going, the Foundation's vision for the future, and the exciting opportunities that lie ahead through research, collaboration, and innovation. He reminded us that every family who participates in research, each new partnership, and hard-fought scientific discovery moves us one step closer to better treatments, improved quality of life, and ultimately a cure.

Together, their presentations perfectly captured the spirit of the weekend: Dr. Steve Roach reminded us how far we've come, and Dr. Jeffrey Loeb showed us where we're going. As a Foundation, we left inspired, not only by our history, but by the possibilities that lie ahead as we continue working together to change the future for everyone affected by Sturge-Weber syndrome.

Saturday also featured our first **Community Resource Exchange**, where families learned about assistive technology, driving, financial planning, special needs legal services, and service dogs. These resources provide practical support long after the conference ends.

The five adorable puppies visiting throughout the day may have stolen the spotlight more than once!

One of the happiest surprises of the weekend was **Balloon Therapy**. What began as entertainment quickly became one of everyone's favorite experiences as colorful balloon masterpieces appeared throughout the conference—even bringing our beloved Webster Bear to life.

Meanwhile, our youngest attendees were having just as much fun. **Amanda, Maddie, and Lucy** cared for our children with incredible kindness, patience, and energy, making every child feel welcomed and loved. Because of their care, parents could fully participate in the conference knowing their children were having an amazing experience of their own.

Our heartfelt thanks also go to our incredible host families—the **Wright, Young, Walsh, and Marlow/Osborne families**—who made everyone feel right at home. From beautiful decorations and thoughtful Bingo prizes to encouraging everyone to embrace their cowboy and cowgirl names, they created a warm and welcoming atmosphere throughout the weekend. Along with **Annette Coutu**, they also worked tirelessly to organize the wonderful raffle prizes that brought smiles to so many faces.

We were also delighted to welcome **Brittany Stewart**, a student volunteer who attended with her family and shared her beautifully inspired book and journal with attendees.

It Truly Takes a Village.

Events like this simply would not be possible without our generous sponsors. A heartfelt thank you to **UCB, Lundbeck, and Dicks Foundation** for believing in our mission and continuing to invest in our families. Our swag bag was made possible in part by **4Imprint's One by One Grant**, and several families were able to attend the conference thanks to **Kimmi's Sunflower Fund** and **Jayden's Smile Scholarship**. We can't say, "Thank You!" enough for their partnership which allows the Foundation to bring together families for this conference.

Continued on next page...



The service dogs were a hit!



Alamo Assistive Technology



Stromatt Rehabilitation Services



Fireside Chats

The Moment That Said It All.

There was one conversation that perfectly captured the heart of the weekend: A grandmother said she simply needed to say thank you to the whole SWF family because of the overwhelming support she experienced during her granddaughter's medical emergency at the conference.

She reminded us that while we can connect through virtual meetings, webinars, emails, and texts, there's something deeply human about a family conference. It brings us together in ways technology simply can't, with an understanding that only face-to-face moments can create.

Most of us are not part of this community because we *chose* to be. Sturge-Weber syndrome *brought* us together. Somewhere along the way we became family without anyone realizing it.

You could feel it in every hug, conversation, shared tears, laughter, and with each new friendship. For that, this conference felt like coming home.

Listening to our adults living with Sturge-Weber syndrome speak of their shared journeys, I found myself smiling. They reminded us that life rarely follows the plan we carefully map out. Sturge-Weber syndrome has a way of changing directions when we least expect it.

If this community has taught us anything, it's that we know how to pivot. We know how to adapt, learn, dig deep for strength, and we lean on one another.

Somehow things have a way of working out just as they should, despite all the pivoting.

How We Said Goodbye, For This Year.

We closed the conference with a Texas-style celebration complete with lassoing, selfie stations, raffle winners, and plenty of dancing.

Perhaps the greatest gift of all wasn't the decorations, the prizes, or even the incredible educational sessions. It was the laughter.

For one beautiful weekend, we put the worries of Sturge-Weber syndrome aside. We just sat in the moment, and for just a little while, Sturge-Weber syndrome wasn't the center of every conversation. It was about this big, beautiful family spread out all over the world. And it for all of that, it is why we do this.

Finally, if you captured special moments throughout the weekend, we would love to see them! Please send us your favorite conference photos so we can continue sharing the memories of this incredible gathering.

Because if this weekend taught us anything, it's this: Life with Sturge-Weber syndrome is full of pivots. We didn't just pivot because the conference required it. We pivot because that's what families living with Sturge-Weber syndrome do every single day.

Maybe Ross Geller was onto something after all. When life doesn't go the way you planned: *just Pivot.*

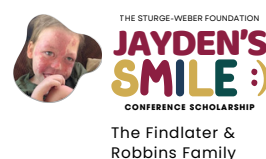
THANK YOU TO OUR SPONSOR(S):



Inspired by patients.
Driven by science.



SCHOLARSHIPS MADE POSSIBLE BY:



SWAG BAG MADE
POSSIBLE BY ONE
BY ONE GRANT:





THE STURGE-WEBER FOUNDATION

6105 S. Main Street, #200 • Aurora, Colorado 80016



**KICKIN' IT WITH
MY★FAMILY**