



Branching Out **DIGITAL**

ISSUE #04, VOLUME 3

December 2025

Year-In-Review

With Gratitude and Awe...

by Founder and CEO - Karen Ball

Dear SWF Family,

As the year draws to a close, I find myself filled with gratitude and awe at what we have accomplished as a community in 2025. Your unwavering support, selfless volunteerism, and heartfelt encouragement have been at the core of everything we've achieved together—and what a year it has been!

This time of year is centered on giving thanks and giving where we can with what we have to give. The SWF has truly been blessed by the many wonderful volunteers who have stepped forward to fill critical roles, steering our programs and initiatives through generous donations and heartfelt care.

Because of you, we've continued to grow, connect, and blaze forward in life-changing ways.

This year, we hosted incredible Mini Summits in Wisconsin and Boston, offering families, caregivers, and clinicians the chance to learn, connect, and feel seen and supported. We also held a vibrant Virtual Summit in Irvine, California, allowing many more in our community to participate no matter their location.

Thanks to your support, we deepened our commitment to research, funding vital work in animal modeling (with Chris Hughes, PhD, Anne Comi, MD, Kristen Kelly, MD and Lisa Arkin, MD) designed to better understand and one day eliminate the impacts of Sturge-Weber syndrome. Our conversations around specific health topics grew as well, including through our Women's Health Mini Summits, which gave space to powerful, meaningful dialogue surrounding women's unique challenges.

One of the most exciting moments came with the launch of Blazing Warriors, a bold initiative to celebrate the courage, strength, and resilience of those living with SWS and related conditions. This inspiring new program is already fueling connections and hope around the world through our dedicated volunteers.

Throughout the year, from Adult SWS Chats to Caregiver Chat, Faith Nights, and Karen and Julia even traveled to conferences to bring back even more up to date information with American Academy of Dermatology, ASLMS, PEDRA, AES and more, plus coordinated tissue donation to clinical education, every program was guided by the belief that no one should face this journey alone—and you proved that belief again and again.



I thank you very much for your continued support and participation in making the SWF a welcome port out of the storms we weather in life. We hope you have a cherished holiday season and a healthy new year too. Hug your loved ones a little longer and linger too. Sending long-distance hugs and much love to all who have touched my heart personally and inspired me and the SWF staff to keep giving it our all.

You are the gift that keeps on giving—and together we are richer for the gifts we share.

To the special "Santa's little helper" who called just to check on me—you uplifted me more than you'll ever know. Thank you.

As we look ahead to our 40th anniversary in 2026, please consider giving a year-end gift to help us continue building on this progress. Your donation, no matter the amount, will allow us to fund more research, expand more programs, and be there for even more families who need our help.

With faith, hope, and love,

Karen Ball

THE COINCIDENTAL MEETING OF TWO FAMILIES ... NOTHING IS COINCIDENCE!

by Wendy Roffers and Brittany Dobry

Every soul you meet is written in your destiny to teach you, to heal you, or to love you!

Hello, we are the Roffers' Family located in Sobieski, Wisconsin, and my name is Wendy. It was March 2, 2024, and our family saw a Facebook communication of an upcoming fundraiser for a Sobieski infant named Angelica. My son Jason and I immediately looked at each other and said — "we have to go and introduce ourselves!"

Why you ask? What was so important about this event? Allow me to share some history of the events that led to this coincidental meeting.

- 45 years ago my husband Mark and I celebrated the birth of our first son Jason. We didn't know what the birthmark on the left side of his face was, nor was anything shared with us in the delivery room. We went through the first three months learning how to care for a child as new parents. It was December of 1980 while I was decorating the Christmas tree that we noticed Jason was shaking uncontrollably in his child seat. After spending 3 hours in the emergency room and crying while Jason continued to seizure, we learned Jason was born with a rare disease called Sturge-Weber Syndrome (SWS). Although there was only a paragraph in the medical journals of this disease at the time, we learned the disease consisted of abnormal blood vessels in the brain, eyes, and skin causing seizures, paralysis, strokes, learning disabilities, vision loss, and other health issues — Jason had all of it!
- In 1987 rose the birth of the Sturge-Weber Foundation (and the internet). Imagine how we felt to know that we were not alone as the organization was formed for patients, parents, and professionals. We took Jason to his first conference and listened intently at other parents' stories of their experiences with this rare disease.
- 25 years ago, Mark started to take Jason to visit a fish farm located behind our house in the rural town of Sobieski. Jason was very interested and eager to learn. While there, Jason would say hi to the grandfather's grandsons James and Wyatt while they were milking the cows and caring for the horses.

Fast forward to our introduction to the Dobry Family at Angelica's Fundraiser on March 2nd, 2024!

- Hello, we are the Dobry family located in Sobieski, Wisconsin, and my name is Brittany. On April 16, 2023, James and I welcomed our second baby girl into the world and named her Angelica. As this was our second child, we were at least a little more prepared for her arrival. When Angelica was born, we noticed some different coloring of the left side of her face and arm but didn't think anything as it was originally believed to just be some bruising. After she was cleaned up and we were settling into our room, the pediatrician came into the room to do her exam. She told us the different color skin was not bruising but a port wine stain birthmark that can sometimes align with a rare disease called Sturge-Weber Syndrome (SWS). At that time she mentioned to us that we should take her in to a specialist and have an MRI done to confirm if Angelica had this disease.



- We started our journey with numerous doctor visits and eventually it was confirmed that she does have Sturge-Weber Syndrome (SWS). She was started on Keppra and baby Aspirin right away at 2 months old and she had her first focal seizure at 3 months old.
- We were extremely scared by this diagnosis and tried to stay positive. That was until August 19, 2023 when our lives changed forever. Angelica began a series of seizures that couldn't be controlled with medication. We were down at Children's Hospital in Milwaukee for a total of 6 days. This hospitalization required her to go on a versed drip to completely stop her brain from seizing and then we had to go from one seizure medication to three just to maintain control. After this, we returned home with a new type of lifestyle for our family and Angelica.

CONTINUED TO PAGE 7...

Seen on YouTube:

Explore our YouTube video library to stay informed and inspired with The Sturge-Weber Foundation's latest resources. We've added brand-new 2025 videos alongside recorded mini summits featuring expert insights, research updates, and practical guidance for patients, families, and professionals. Whether you're catching up on past events or discovering new content, our video library is an easy way to connect, learn, and stay engaged with the Sturge-Weber community.

 [YouTube : @thesturgegeweberfoundation](https://www.youtube.com/@thesturgegeweberfoundation)



The Ripple Effect
featuring Karen Ball.



In this video, Kendra shares her Girl Scout Gold Award project focused on raising awareness about Sturge-Weber syndrome, a rare disease she lives with herself. Kendra opens up about what Sturge-

Weber syndrome, a rare disease she lives with herself. Kendra opens up about what Sturge-Weber is, the challenges she faces, and why education and understanding are so important. As part of her project, she helps Marissa create a personalized photobook designed to help siblings, families, friends, and the wider community better understand Sturge-Weber syndrome.



Join us as we look at Sturge-Weber syndrome through the ages. Featuring the Coutu family and Erik Bruun. Thank you to Travis Hatch for producing this video for The Sturge-Weber Foundation.

SUPPORT OUR MISSION TODAY!



THE STURGE-WEBER FOUNDATION
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Sturge-Weber.org



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



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 Jazz Pharmaceuticals

NEW PARTNER ORGANIZATION:

 RARE→READY
A GENETIC CONDITION COALITION

2025

THANK YOU FOR MAKING A DIFFERENCE!

Small Acts of Kindness, Big Impact

Thank you to our generous donors for making Giving Tuesday a huge success! Your support helps The Sturge-Weber Foundation provide vital resources to families living with Sturge-Weber Syndrome (SWS), Port-Wine Birthmarks (PWB), and Klippel-Trenaunay Syndrome (KTS). But we're not done yet. The need is ongoing, and your continued financial support is more important than ever. Every donation helps fund research, support services, and awareness efforts. If you haven't given yet — or would like to give again — please consider making a gift today. Your generosity keeps hope alive for so many.

Keeping it in The Family



My name is Adrian and I'm 39 years old. I have a vascular birthmark, port wine stain on my left cheek and left temple. Throughout my life I have never met someone like me in person. Who has a vascular birthmark. That all changed when I went on social media and discovered our birthmark community. I attended the VBF super clinic in October of 2022 and this was the first time I met others like me in person. It was an extremely emotional day to say the least.

And throughout my journey in our community I felt that there was something missing. So after a lot of reflection and looking internally I soon realized that we don't have anything to call our own. Which sparked the idea of our own unique brand. And that's how Birthmark Society was created. I look forward to meeting you all!

Let's celebrate Adrian @Birthmark_Society_Apparel_co

We're thrilled to announce a new chapter in the SWS merch journey! Starting now, all official Sturge-Weber Foundation apparel will be printed and fulfilled by Adrian, a fellow SWS warrior and port-wine birthmark champion.

What does this mean for you?

- Faster delivery
- Passionate, personalized care
- We're keeping it in the SWS Family

This is more than apparel. It's SWS Family helping SWS Family.

 sturge-weber.org/shop-now



OUR MEMBERS GIVING BACK



THE STURGE-WEBER
FOUNDATION

the Giving Market

The Sturge-Weber Foundation's Giving Market is a place to connect with and support our community by discovering products and services offered by our members. It's not a sales platform; it's a connections marketplace designed to uplift one another and share the stories behind our member-owned offerings.

Each participant is encouraged to donate a portion of their proceeds in exchange for being featured in the market, helping us continue to strengthen the community and support our SWS research efforts. Interested in becoming a SWF Gift Market partner? Learn more [here](#).

SAVE the DATE

2006 INT'L FAMILY CONFERENCE

Respite
and Family
Vacation



 **June 25-27**
 **San Antonio, TX**

HAPPY Retirement!

There are some Board of Director's that roll up their sleeves and never stop working for all of us each and every day in every way! **Crystal Elliers** has been a cherished member and then long time Board member. Tenacious and compassionate her drive is endless. We are extremely grateful for her contributions and willingness to do whatever needed to be done.

We look forward to still having Crystal's participation but in a much deserved less active role. We are excited to welcome **Shad Elliers** to the Board. His business and sales acumen will be an asset as the SWF gears up for our 40th anniversary and new organizational structure.

Gems of Hope and Strength: Volunteer for the 2026 Reunion of Champions in Denver

The Sturge-Weber Foundation is proud to host its annual Reunion of Champions (ROC) on Friday, March 27, 2026, at the Downtown Aquarium in Denver. This inspiring evening marks the official kickoff of the foundation's yearly fundraising efforts to support research, education, awareness, and patient-care services for those affected by Sturge-Weber syndrome—a rare neurological condition.

Celebrating Leaders, Honoring Strength

The ROC is a special night that honors individuals who champion the Sturge-Weber syndrome community through vision, compassion, and commitment. This year's event will recognize:

- Dr. Paul M. Friedman — ROC Honoree and acclaimed leader in dermatology
- Dr. Brian Biesman, FACS — Legacy Leader recognized for his dedication to patient care and advocacy
- Dr. Roy Geronemus — Serving as Master of Ceremonies

Together, they represent the excellence and passion driving progress for patients and caregivers alike.

A Theme of Radiance and Resilience

The 2026 theme, "Gems of Hope and Strength," is a tribute to the rarity and beauty of those supported by the Foundation. Just as rubies—reflected in the port-wine birthmark many patients carry—shine with intensity and value, so do the lives touched by Sturge-Weber syndrome. Set against an elegant underwater and gemstone-inspired backdrop, this year's gala will be a celebration of courage, community, and hope.

Volunteers Needed: Make a Meaningful Impact

We are seeking volunteers from the Denver area to help bring this extraordinary event to life. Volunteer roles include:

- Event setup and cleanup
- Guest check-in and registration
- Silent auction support
- General guest assistance throughout the evening

Whether you're a student, professional, or simply passionate about serving a meaningful cause, your help can make a lasting difference. Contact Julia (jterrell@sturge-weber.org) if you are interested.

To learn more about this event, visit www.Sturge-Weber.org.

2025 Reunion of Champions in Orlando:



The Sturge-Weber Foundation
Kick-Off Fundraising Event

GEMS HOPE & STRENGTH

CELEBRATING RARE BRILLIANCE
& THE POWER OF RESILIENCE



REUNION OF CHAMPIONS
HONOREE
PAUL M. FRIEDMAN, MD



LEGACY LEADER
HONOREE
BRIAN BIESMAN, MD, FACS

WITH MASTER OF CEREMONIES:
ROY GERONEMUS, MD

Downtown Aquarium • Denver
Time: **5:30-8:30 pm**
Friday, **March 27, 2026**

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THE COINCIDENTAL MEETING CONTINUED...

- After this first hospitalization, we returned to Children's Hospital every 6-8 weeks until April of 2024 when we were able to go until December of 2024 without a seizure breakthrough. During this time, we found that Angelica's seizure breakthroughs are linked to illness. Even though she doesn't have seizures every day or regularly, this didn't make it any easier. We also found out that Angelica is considered Bilateral Sturge-Weber Syndrome which means she can have seizures from either side of her brain. Originally, in January of 2024, we were considering doing a hemispherectomy to disconnect the left side of her brain to gain seizure control, but once we had made the decision and were working on getting a date, Angelica decided to have a seizure breakthrough that started on the right side of her brain resulting in the halting of surgery as an option. God has a plan for her and she was not to have surgery. The discussion of surgery and trying to make that decision was one of the hardest things we have ever done in our life. I really didn't want to go through with it, but it seemed to be our best option at the time. Looking back, I truly believe nothing is a coincidence as Angelica had this right-sided seizure breakthrough and then our decision for surgery didn't matter anymore. God must have felt our despair at the time and answered our prayers.
- During all of her breakthroughs, this required me to be off work for extended long periods of time to care for her in the hospital and my husband, James, to be off as well to care for our oldest child, Cassidy. Not only is it hard on the parents but our oldest child, Cassidy, has definitely suffered trauma from this as well with Angleica and myself being gone for long periods of time and in the beginning, it was both my husband and myself which was even more difficult. To this day, if she hears Angelica has a doctor's appointment, we need to explain thoroughly to make sure she understands it is not a bad appointment and that we won't be gone long.

- Due to our inability to make our hours for work, our family decided to hold a benefit for us on March 2nd 2024 to help raise money to support our family during our unexpected time off to care for Angelica in the hospital and at home. On that day, we had the honor of meeting Wendy and Jason Roffers. We found someone who not only has the same condition as Angelica, but they also live down the road from us two minutes away!
- Since the benefit, we have made a close family connection with Jason and his whole family. We are able to use them as a resource and rely on their support as we navigate Angelica's childhood. Angelica is now able to go 5-7 months at a time without a seizure breakthrough and we hope to keep lengthening the time between.

And this is the destiny ...

- How could anyone know ... a path was in place for the intentional meeting of Jason and James!
- How could anyone know ... a path was in place that James and Brittany would celebrate the birth of their second child who was also born with the rare disease of Sturge-Weber Syndrome.
- How could anyone know ... a path was in place for Jason and Wendy to see their fundraising event and attend to introduce themselves to James and Brittany.
- How could anyone know ... that the young teenager Jason met at the fish farm over 25 years ago was James!

How would anyone know ... God knew!

There is a quote we came across that is a good reminder to everyone of life's struggles and unknowns.

Nothing is coincidence ...

Every soul you meet is written in your destiny to teach you, to heal you, or to love you!

Merry Christmas and Happy New Year from the Roffers and Dobry Families!

The Official SWF
**Fundraising
Gift Shop**

POWERED BY
 PledgeIt

Support The SWF by shopping the **Official SWF Fundraising Gift Shop!** Every purchase directly fuels research, family support, and awareness for those affected by Sturge-Weber syndrome. Choose from meaningful items like SWF tree necklaces, children's books, Give-a-Bear-Get-a-Bear sets, Laser Care Kits, and more. Your purchase brings hope, connection, and vital resources to the Sturge-Weber community.

Visit: <https://charity.pledgeit.org/swfgive>



Oh, What a Year...





WEBSTER'S

WORDS OF RESILIENCE

A word search tribute to the warriors, caregivers, and hearts that make our SWS family Sturge-Weber Strong. Every word in this puzzle reflects the strength, love, and unbreakable spirit of our community. Complete the challenge, snap a photo, and share it online with #SWSstrong — let the world see how powerful our words (and people) truly are.



RESILIENT	COMMUNITY	I AM A FIGHTER	ADVOCATE
SWF FAMILY	STRENGTH	TOUGH TREES	I ❤ MY BIRTHMARK
SWS STRONG	SWS WARRIOR	UNBREAKABLE	WEBSTER BEAR
TOUGH TREES	WE ARE FAMILY	OVERCOMER	INSPIRING

