

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



# Branching Out

Summer 2022

**FOR 35 YEARS WE'VE  
BEEN HERE FOR YOU!**

*A reason, a season, or a lifetime.*

STRONGER BECAUSE WE ARE

# UN<sup>IT</sup>ED

THE STURGE-WEBER FOUNDATION



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- 35 YEARS UNITED
- RECAP: INT'L FAMILY CONFERENCE
- NEW BOARD MEMBERS ELECTED

- BACK TO SCHOOL
- BVMC: WHY IT'S IMPORTANT
- ZEBRAFISH RESEARCH



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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).

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**ON THE COVER:**

Group shot at the 2022 SWF International Family Conference in Grapevine, Texas. Photo by KarenImages

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.



Founder | CEO

Connect with Karen

## 35 Years United—We Are Stronger and Making an Impact

### No News Is Good News, as “They” Say!

In most cases, that trite saying is true, and we are sooo happy for you when it is good news for you and yours! This past conference in Grapevine was a memorable and cherished gathering of old and new SWS friends and their families! There is just something about gathering in person that uplifts each one of us and unites us to be a major force for change and answers to all our questions on SWS and birthmarks.

If you are reading this and have been in the “no news is good news” camp, have been enjoying your life without us being with one another—we urge you to make the effort to attend the educational summits, in-person meetings, and engage outside of online social media platforms. The hugs, the smiles, the laughter, the tears, and tales...golden and irreplaceable! We miss you...come again!

We are more than excited about all the terrific events and happenings ahead and we don't want you to miss any of them! As you know, the SWF was hit hard by the pandemic and revenue has decreased over the last two year. I'll admit it was QUITE the ride! We are climbing our way out with strategic diversity of funding options and more of you so thoughtfully stepping up to enroll in monthly donations, stock donations, and participating in the wide variety of ways to join in the “FUN”draising events! Thank you, I am grateful, and it gives us so much fuel to keep the engine running and give it to clinicians, researchers, and families in need.

*Branching Out*

Dog days of summer are upon us, and I wish all of y'all fun memories made as you slide back into school, work and life. The motto SWF has of “a reason, a season, or a lifetime” resonates so deeply with me—especially after 35 years! I spoke to Patrick, a new dad, and it hurtled me back to Kaelin's first seizure. It was sheer chaos those first months. I'm able to handle changes better now and I know y'all can too. There are so many reasons why we exist.

- We exist to help the journey of another a little easier than we had it.
- We exist to bond together united to defeat our common enemy SWS and birthmarks.
- We exist to uplift and learn with each other.
- We exist to honor those living their lives impacted by SWS.
- We exist to do all in our power to give the researchers what they need to increase our quality of life and care.
- We exist because we care about you and yours EVERYDAY in EVERY WAY whether it is good news, and you're radio silent – or it is not good news and you need your warriors *united* to help you fight on.

Whatever the case may be, we are here for YOU! You are our WHY.

With Faith, Hope and Love,

Karen Ball

*A Message from the  
Chairman, SWF Board of Directors*

## Curt Stanton



As we begin a new fiscal year, I am heartened that the Texas conference united you all to bring all you can bear on our war on SWS. We are a community and family based on SWS but maintain the connection because we care. My daughter-in-law, Veronica, has jumped right in to work with the BVMC and had a very successful recruitment at the Conference. We need more of you to join in that effort too! I am never ceased to be amazed at how fortunate we are to have the dedicated scientists and corporations supporting the SWF and our strategic plans.

The Board of Directors is pleased to

bring aboard two new members and to thank Woody Crouch for all his years of dedication. I believe we all do our part to support and fund the SWF to the best of our abilities but on occasion we need to be reminded of the value SWF has in our lives “for a reason, a season, or a lifetime”. Reminded that *united* we can and *WILL* do so much more and at a faster pace. I look forward to moving our plans into action and to working with all of you as we enter our 35th year of service and support.

Please reach out to me anytime to learn more or get involved. Thank you!

---

## New Board Members

The SWF Board of Directors elected two new Directors at their annual meeting.

The SWF has also been grateful for the many years of service and support from outgoing Board member Woody Crouch. Woody’s business expertise was vital during organizational changes and growth. The Board approved the annual budget for FY2022-23.



**Don Willard**  
Illinois  
Board of  
Director



**Robert “Rob”  
Zarko**  
New Jersey  
Board of  
Director and  
*Running with  
the Sharks* event  
sponsor



**Crystal Elliers**  
Louisiana  
Re-elected Board  
of Director



**Witney Arch**  
Louisiana  
Re-elected Board  
of Director



**Molly Speer**  
Indiana  
Elected as Vice-  
Chair Secretary

# STRONGER BECAUSE WE ARE

# UNITED

## THE STURGE-WEBER FOUNDATION

by Julia Terrell

This year the whole world learned the importance of being *United*. United is even in the name of our home country. At The Sturge-Weber Foundation we are lucky enough to work with knowledgeable doctors, clinicians, researchers, scientists, industry, patients, caregivers, and all the support people to make our world of SWS a village.

This year the SWF chose our theme to be **UNITED**. Why?

1. Together, when we UNITE we have a bigger voice.
2. Together, when we UNITE our work load gets lighter.
3. Together, when we UNITE we learn more and achieve greater results.
4. The most important why is...

**We are stronger because we are UNITED!**

## NEW 35th Anniversary & United Gear in the [SWF Shop](#)

*Proceeds from each purchase helps support the SWF's programs.*



**Save 10% with Code: 35UNITED**

# Cha-cha-changes...



*Introducing the Foundation's new Task Force  
Leader for Mental Health*

## Luis Sandoval, PhD

Dr. Sandoval is a senior clinician in the ambulatory department of psychiatry and a clinical researcher in the department of Public Psychiatry at Beth Israel Deaconess Medical Center and at Harvard Medical School. His clinical specialization is the treatment of individuals with neurocognitive disorders due to medical or psychiatric conditions, including Sturge-Weber syndrome, and the diagnosis and treatment of adolescents and adults with severe mental illness, including psychotic and mood disorders. Dr. Sandoval has nearly 20 years of clinical experience working in Mexico, Central America, and the U.S.

His clinical and research interests include cognitive remediation in psychiatric disorders, neurodevelopmental disorders, and cross-cultural diagnoses. Over the past twelve

years, Dr. Sandoval has served as Principal and Co-Investigator in multiple studies involving integrating technology in mental health care. His current work focuses on designing and evaluating new technologies to improve psychiatric symptoms and cognitive functioning in individuals with cognitive decline due to medical and/or psychiatric illness. Additionally, he is researching how bilingualism can play an important role in protecting the brain from cognitive decline in psychiatric and medical conditions.

His collaborations include NASA, Harvard University, Yale, Hartford Hospital, Maine Medical, The American University, Dartmouth College, and The University of Texas-Austin.



*Introducing the Foundation's new Task Force  
Leader for Transition*

## Amy Davis, RN

Amy Davis is a Registered Nurse and the Epilepsy Coordinator at Cook Children's Medical Center in Fort Worth, Texas. She has over 20 years of pediatric nursing experience, 10 years of which are pediatric neurology. Amy

enjoys educating families and collaborating with other specialties to help create positive outcomes for patients and their families.



Clinical Care Network

# The Genius Research of Zebrafish and Eyeballs

by Kaelin Ball

For those of you who do not know, the Foundation will be turning 35 this coming September. Mom, a.k.a. Karen Ball, hates taking credit for the work she has done because she did not do it alone. Yes, it was her in our basement, unpaid, for years. In the age of typewriters, actual phone calls, and her lioness courage to take the chance in failing. I genuinely wish I had followed that last part sooner and more often.

When I was in middle school, mom would take me with her to “boring” lectures and symposiums. Lots of “dull” research terms about neurology and ophthalmology. Mom went to a “boring” meeting for the American Academy of Dermatology while my father, brother, and I went to Epcot and played tourist. It was that same meeting, during an SWF fundraiser, where we lost my brother. If you have ever met Derek, you know what a handful he can be. Thankfully, he was found pushing his racing stroller by an ATM machine.

Memories aside, I avoided those “boring” meetings as much as possible. My view of “the boring meetings” started to change around high school. Cell division was not a GPA booster, but it helped with my understanding of what they were talking about in the “boring” meetings. Seeing a frozen brain section at the Maryland Brain and Tissue Bank made science “real”. Mom watched a live hemispherectomy in the OR, with permission, of course. *Gross...* but also cool. Without the mouse model, we would not have found the GNAQ gene that causes SWS.

The lioness of my mom was asking questions, cold calling doctors in the “basement days”, and giving up time with our family to attend those “boring” meetings.

All that time morphed into finding Jonathan Pevsner’s team and Harry Chugani’s team (among all the other brilliant hard-working minds credited in the published papers on Sturge-Weber syndrome).

Every day when I am allowed, or sometimes not, to eavesdrop on Mom’s work phone calls I am closer to understanding why she is SO freakin’ excited about the zebrafish model, the EVP study, and so much more. Studying zebrafish models is an excellent way to discover and characterize new genes involved in genetic diseases. She was “pumped” for the SWFIRN meeting this past month after the conference. (*Woot, zebrafish!*)

All the year’s Mom has been working with researchers and doctors she had to learn the language of science. She and the researchers do the hard work so we can understand the 140-character Twitter version of what it all means.

The SWFIRN, the CCN (Clinical Care Networks), and BVMC are what help us progress! It’s those “boring” meetings where “the impossible” manifest miracles and answers.

I had two choices the day after the conference ended. “Boring” science meeting or spending half the day alone on my iPad wasting brain cells on

Fishdom. I chose a boring and technical conference, the SWFIRN meeting. It was like the old days. Hesitant to be there “uninvited”, not being “smart enough”, and anticipating I was going to be bored out of my skull.

*It was SO NOT BORING!*

Did you know an eye can “live” for up to 2 weeks when the researchers preserve it correctly? *TWO WEEKS!* I remember the sheep’s eyeball (at some point within my schooling) and being grossed and in awe of how the eye is layered. If my eye can save the vision of a one-year-old child with Sturge-

It was tissue which helped figure out the first part of GNAQ. Without the tissue there would be no mouse model. No mouse model, no answers and no gene.



in  
loving  
memory

TERESA  
ELAINE  
HICKLING

*Sad to inform you that our daughter, Teresa Elaine Hickling passed away June 2, 2022. She had been declining and ill for awhile, but more quickly since January.*

*This photo from her 33rd birthday.*

*We and Teresa were one of the first families who joined the SWF in 1987.*

*Carol and Carl Hickling*

## Zebrafish...

*Continued from page 7...*

Weber syndrome down the road I am SO giving my eyes to research when the time comes to leave this world.

The lioness in my mother asked my plastic surgeon and me to donate the excess tissue from a lip reduction to our current tissue bank. *THAT TISSUE WAS TALKED ABOUT IN THE SWFIRN!* (Hypothetically, since it is illegal to identify individuals in any kind of research.)

Tissue is one of the catalysts to finding answers to the Sturge-Weber questions. It was donated tissue that helped figure out the first part of GNAQ. Without the tissue, there would be no mouse model. No mouse model, no answers, and no gene therapies.

The long-term studies of our MRIs can also help us figure out what exactly happens when we have Sturge-Weber, seizure episodes, and why I have migraines every time it rains, snows, or spent too much time writing term papers without sleep or hydration. (That last one is normal human stuff but normal humans don't get triggered with strokes because I was being a "normal" Sturge-Weber college student.)

Don't be afraid of coming "uninvited" to the next "after party". Researchers and doctors are people. They play in bands, attend their own bachelor parties, get excited about eyeballs, felt more loved like family talking with our SWS families than you will ever realize!

*Woot, zebrafish!*

## Resources

### Facebook Groups

#### **OFFICIAL STURGE-WEBER FOUNDATION AWARENESS PAGE:**

A public place created to share your questions, stories, pictures, and videos. [sturgeweberfoundation](http://sturgeweberfoundation)

#### **SWF ROAD WARRIOR BEAR WEBSTER:**

Webster is our Road Warrior who loves to get his picture taken. [SWFRoadWarriorBearWEBSTER](http://SWFRoadWarriorBearWEBSTER)



#### **STURGE WEBER FOUNDATION WORLD OF CARE AND SHARE NETWORK:**

A place to gather so we as a group have an open forum to ask questions, learn together and brain storm. [WorldofCare](http://WorldofCare)

Let's Connect



## “DONATING TISSUE IS A GIFT.”

Michael Fautsch, PhD stated at the SWFIRN meeting, “Donating tissue is a gift.”

Now is the time, get ready to give a gift of tissue donation for further research. Don't wait for a crisis or accident to happen.

Email Julia Terrell, at [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org). We can help you give the best legacy and gift of all.



# The Conference and SWFIRN by the Numbers

## Family Conference Facts:

- 35 families attended
- With a total of over 150 people in attendance
- Families from Canada and Puerto Rico
- 45 speakers, vendors, scientists, researchers and clinicians
- Clinical Care Networks represented with new applications to process
- Over 5 Virtual speakers
- Respite and free time

## First time ever

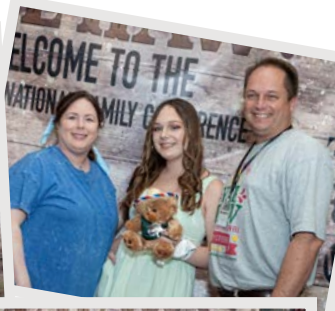
- Silent auction
- Vendor exhibits
- “Have You Ever?” game and raffle prizes
- Million Mile Walk inside
- Make up tutorial
- Music therapy demonstration
- Selfie station
- Meet the Scientists round tables

## SWFIRN Meeting

- Attendee as far away as Austria
- 21 Researchers in person and virtually
- 9 Abstracts submitted
- Established new goals and Virtual Animal Model Meetings



*The Yee-Haw Dinner Party was a huge hit. That evening it didn't matter what you do, why you came, everyone was UNITED and had a great night dancing, taking selfies, and having just plain FUN!*



# YEE HAW





# 2022 SWF International Family Conference

July 17-19, 2022 | The Great Wolf Lodge in Grapevine, Texas USA



# SWFIRN Reception *Highlights*



Thank you to Qlaris Bio ([qlaris.bio](http://qlaris.bio)), Thurein Htoo, Barbara Wirostko, and Mike Fautsch for sponsoring our SWFIRN Reception at the 2022 SWF Int'l Family Conference in July.



Thanks to everyone who braved the Texas heat on the Loose Moose patio at The Great Wolf Lodge, Grapevine! It was a hot one but well worth it to connect with all the amazing doctors and scientists who attended this event.



*Csaba Juhasz, Anna Pinto, Matt Shirley*



*Thomas Speer, Julia Terrell, Molly Speer, Kaelin Ball, Thurein Htoo*



*Michael Fautsch, Matt Shirley, Karen Ball, Sarah Swanson, Kaelin Ball, Thurein Htoo*



*Left: Julia Terrell, Sarah Swanson, Michael Fautsch, Jeri Stunkard, Karen Ball, Thurein Htoo*



**At the SWFIRN Meeting:**

**Back Row:** Thurein Htoo; Francesca Galeffi, MD; Jan Pruszek, MD; Aliece Goodman, PhD; Michael Fautsch, PhD; Sana Nasim, PhD; Csaba Juhasz, MD, PhD; Michael Onken, PhD; and Jeff Loeb, MD, PhD  
**Seated Front Row:** Doug Marchuk, PhD; Anna Pinto, MD, PhD; Joyce Biscoff, PhD; and Matt Shirley, PhD  
**Not Pictured:** Lisa Arkin, MD; Beth Drolet, MD; and Naiem Issa, PhD (Virtual)



**Webster's Travel Log**

**Webster's Trip to the Conference**



Webster on the plane from Denver



Greeted at the airport by Kaelin, Derek (a.k.a. Bucky), & Myla's Mission Bear



Sheriff Webster



Headshot taken as a member of the SWF Staff

EXTENDED THROUGH DECEMBER 2022!

THE STURGE-WEBER FOUNDATION

MILLION MILES WALK

BIRTHMARKS | GLAUCOMA | SEIZURES

Pledge to raise \$100 to receive SWF Swag!

It's not too late to join our Million Miles Walk journey! We have extended this fundraiser out until the end of the year. So, lace up your walking shoes and get out there for SWF.

Bucky and Kirk in Montana

Cool SWF t-shirt

Note: Limited t-shirt sizes are available.

Collectible shoelace charm



REGISTER TODAY:

Pledge It!

Thank you to our sponsors



# Back to School

Back to School is upon us! We all have seen the first day of school pictures on Facebook with all updates to things like what do you want to be when you grow up. There is typically a smile and some are excited and some may just be sleepy. For parents, it is time for the kids to go after summer and you may even be giddy with excitement.

In the world of Sturge-Weber, we put up those same pictures and we smile like everyone else but you probably feel a bit different. We ask question like, will the new teacher know what to do? How will the kids handle being back on schedule? Will there be behavior issues? What does the nurse know? Has everyone seen the Individual Health Plan? All new medicines need to come back to school and what will I need to do? If you have asked any of these questions you are not alone.

## Here are some shortcuts for you so your child can have a successful year...

- Talk to your kids: find out what works and what doesn't and change accordingly
- Pack their backpack together
- Schedules: go over what is to be expected at school and at home and do this often or daily so the family gets used to it.
- Transportation: make sure everyone is in

the know

- Have Medicines and Rescue Meds and doctor notes ready and keep a list for yourself
  - An Emergency Room guide is helpful to give to the nurse too and keep a copy ([download it here](#))
  - Don't assume everyone has the IEP/504/Health Plan/Seizure Action Plan, if applicable, and keep a copy handy
  - Trainings: scheduled for any meds or epilepsy – The epilepsy foundation will come to your school or have a virtual webinar, if requested, for free.
  - Remember hydration and water bottles
  - Sunscreen and hats as needed
- Remember new things can be challenging. New teachers, new schedules, and more is a lot of change and no one is perfect. So be kind to yourself and let yourself off the hook as perfection is not in the cards. As with anything, celebrate all the small wins, know you will get calls, and it will be okay, and it will work out. If you need help or any questions or advice please email the Foundation so we can help too at [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org).

Don't forget to not just send us your back to school pictures, but every win we want to see too! *Welcome back to school.*

## EFEPA's Camp Achieve

Marissa and her friends had a blast at EFEPA's Camp Achieve in PA last week! EFEPA is an epilepsy summer camp.

"The EFEPA believes no child should feel excluded or unsafe because of their epilepsy. We strive to alleviate the stress and fear that many children with epilepsy face by providing access to all the life experiences – including summer camp."

Thank you EFEPA's Camp Achieve for preparing this fun camp!



To learn more, visit:  
[www.efepa.org](http://www.efepa.org)

*Pictured: Rebecca (mom) and Morgan (daughter) with Marissa and Mom Julia as they were leaving Camp Green Lane.*

# United We Can Make a Difference



In 2022, we launched our **Million Miles Warrior Challenge** to get companies engaged in helping spread awareness of Sturge-Weber syndrome and help raise money for the work we do at the Sturge-Weber Foundation. The companies that joined us this summer and all of our amazing individual walkers/teams have helped raise nearly **\$30,000!** Our goal is to hit \$45,000 before the end of the year, so we are launching a **Fall Challenge**.

We are reaching out to our corporate partners to get them signed up, but everyone can help. **We need to raise just \$15,000 more** — every mile walked and every dollar raised makes a difference. Sign-up as an individual or introduce a company to the Walk. Learn more at [charity.pledgeit.org/MillionMiles](http://charity.pledgeit.org/MillionMiles).

Here are just a few small ways you can unite with us to make a difference:

## *Shop with Smile.* Amazon

There are many ways you can support the Sturge-Weber Foundation. When you shop on Amazon – go to [Smile.Amazon.com](https://www.smile.amazon.com) and select the **Sturge-Weber Foundation** as your beneficiary. It's your same Amazon account but every purchase benefits the SWF.

## *Matching Gift Program*

Don't forget many companies have **matching gift programs** — it's a terrific way to double your investment. Check with your company.

## *Participate*

Do you have some spare time? Volunteer service is always welcome and needed. Your support is appreciated in every way you can give it! Thank you! Click [HERE](#) to learn how you can participate.

## WANT MORE INFORMATION ON FUNDRAISING OPPORTUNITIES?

CONTACT: Sarah Swanson at 617.596.4081  
[sswanson@sturge-weber.org](mailto:sswanson@sturge-weber.org)

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## Can You Run with the Sharks?



It's the return of this 5K run through the streets of Beach Haven, NJ! **Race day: September 10, 2022.** Sponsored by Ship Bottom Brewery and presented by Second Capital Running. Join us at the Brewery after the race for the awards ceremony and complimentary beer for runners 21+. Run in-person or virtually.

**SWF friends and family get 50% off your registration fee with code: SWFWARRIORS**

Sign up at: [runsignup.com](https://runsignup.com)





# Why You Should Consider Registering for the BVMC Project

It was great attending the 2022 SWF International Family Conference – thank to all who joined us! It was an honor to tell you about our exciting clinical research programs, especially our Brain Vascular Malformation Consortium (BVMC) project that has the potential to transform our understanding and develop new treatments.

The attendance and gathering by our Sturge-Weber community helps magnify our cause and invigorate our passion for the research we do.

We could not do anything without your support and continued participation in our research efforts. It was exciting to share the progress we have so far with those in attendance. We look forward to our next interaction soon and to be able to bring you more results!

*YEEHAW! - Dr. Loeb (just kidding about this part) :)*



**It's one small thing that can make a big difference!**

If you would like to learn more about ways to get involved with the BVMC Sturge-Weber project please:

**Click on the links to register today at:**  
[Rare Disease Network](#)  
[or Clinical Trials.](#)  
Call us at 312-413-1882

*Mark your calendar*

## Upcoming Events

### **AUGUST 28**

Mini Summit

### **SEPTEMBER 15-17**

CCN Meeting in Boston, Hybrid Event

### **OCTOBER 18**

SWF Modeling Meeting

### **NOVEMBER 3**

Mini Summit

### **DECEMBER 7**

Town Hall with Karen End of Year

### **SEPTEMBER 1**

**Adult Chats** are now scheduled with Dr. Sandoval Adult Member with SWS, 7:00-9:00 pm EST

If you would like to join this call, email [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org)

### **AUGUST 30**

**Caregivers of adult members**

7:00-9:00 pm EST

If you would like to join this call, email [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org)

# #WarriorMama Brooke Atkins

*“As a mother, I felt I had failed my son, like I hadn’t protected him enough inside me.”*



*Recently, Brooke Atkins, who lives in Australia with partner Kewene Wallace, made headlines for fighting Internet trolls. They called her a “Monster” for choosing laser treatment on her baby. Brooke didn’t let it get to her. She fought back. Here is her story.*



Seven months ago, my beautiful son, Kingsley was born with a PWS. Before we could even research it, we had specialist after specialist come in, informing us of the “bad things” in regards to a PWS. As a mother, I felt I had failed my son, like I hadn’t protected him enough inside me.



Apart from his birthmark, he looked perfectly “normal”, healthy weight of 10 pounds, and a happy, calm little boy. All within the first few days, he was taken through to have an MRI, ultrasound, and eye tests. Thankfully, his MRI and ultrasound were clear but his eye test wasn’t so good. He had a whole heap of pressure in his left eye and his eye began to bulge.

Within the first two months, he was put under twice and had a glaucoma drainage implant put into his

eye. It was the scariest thing ever! Because his glaucoma was so bad, they asked for another MRI with contrast—this time around we weren’t so lucky. He was diagnosed with Sturge-Weber syndrome and we were devastated.

Five months old since diagnosis and our son is kicking goals! He can sit up unassisted, dance, has good muscle movement, and no seizures, yet.

He has had 3 laser treatments in total and been all over the world in the news for his treatments. After his videos have gone viral, we had people telling me to “put my son down”, “oh, he was so ugly before”, and “wow you are abusive as a mother”. We received a lot of negative comments from random people but we also received a lot of positive comments too.

At the start, I would get so upset and cry but as time went on I realized these comments came from uneducated people and that I need to try to educate them!

Now we are worldwide educating the best we can and couldn’t be more thankful to have the opportunity to share awareness!

Instagram icons followed by @b.co.a and @kingsley\_colvin

[Read the Internet story here.](#)



## Got a Minute?

SWF is turning 35 next month — **we need to clean the house and update our database.**

**WHY IT’S IMPORTANT:** We want to be sure to communicate with you how and where you want. This will keep you up-to-date on events, research news, and inspirational stories. Please take a minute to let us know by filling out our form online [HERE](#). Thank you!



STRONGER BECAUSE WE ARE  
**UNITED**  
THE STURGE-WEBER FOUNDATION

## Your donation is driving change

- YES!** I will make a tax deductible donation of \$\_\_\_\_\_.
- YES!** I want to make an ongoing monthly pledge of \$\_\_\_\_\_.
- In **MEMORY** of: \_\_\_\_\_
- In **HONOR** of: \_\_\_\_\_
- Endowment Donation
- I have enclosed a check
- Please pay by credit card\*  VISA  MasterCard  Amex  Discover
- I have stock I'd like to donate, please contact me.

Name on Card: \_\_\_\_\_

Credit Card #: \_\_\_\_\_

CSV: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

*\*You may also make a secure donation at [www.sturge-weber.com/donate](http://www.sturge-weber.com/donate) or scan the QR Code below.*

*Please provide your contact information in the area above for credit card donations.*

*\*\*You may also **donate gifts of stock or real estate** to the Sturge-Weber Foundation.*

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Email: \_\_\_\_\_

Mobile Phone #: \_\_\_\_\_

*By providing your email and mobile number, we are able to send you news updates immediately!*

### SAVE THE STAMP!

Use the link to the right to donate  
securely on-line or print and mail this  
form to:

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

SECURE DONATIONS

[sturge-weber.org/participate/  
donate-today.html](http://sturge-weber.org/participate/donate-today.html)

## Kids Camp at The Conference



This Virtual Edition of Branching Out is Sponsored By:

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### OUR MISSION

The Sturge-Weber Foundation (The SWF) global mission is to improve the quality of life and care for people with Sturge-Weber syndrome and associated Port-Wine Birthmark conditions through tenacious collaboration with clinical partners and pioneers, education, advocacy, research and friendly support.



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