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

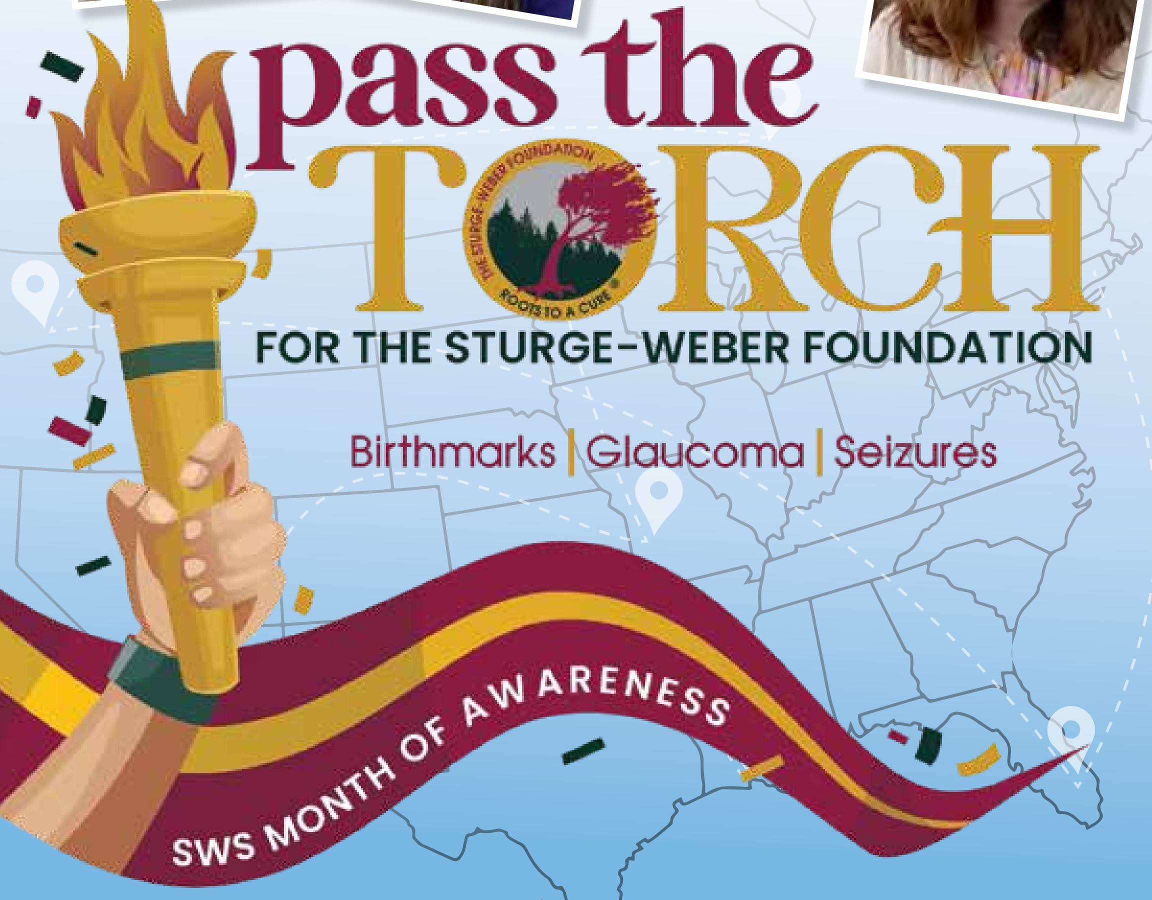
Branching Out

SPRING 2024

pass the TORCH

FOR THE STURGE-WEBER FOUNDATION

Birthmarks | Glaucoma | Seizures



FREE pull-out sws month of awareness poster inside!

The Sturge-Weber Foundation
MAGAZINE

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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).

Branching Out

SPRING 2024

The Spring Issue...

COVER STORY

Pictured: Camryn, Carley, Donny, and Morgan

pass the TORCH
FOR THE STURGE-WEBER FOUNDATION

Everything you need to know about SWS Month of Awareness!
Page 6-7

***Branching Out* Sponsorship Available:**
Contact Julia, jterrell@sturge-weber.org for more information.

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

> *I've been reflecting on the many gems I've met along this journey with Sturge-Weber and how rare and unique each of you are in my life!*

We are all Rare Gems Searching for the Perfect Golden Setting!

Diamonds, as we know, start rough and dull, in need of lots of refinement, and select cutting by experts before they reach their peak brilliance. Lately, I've been reflecting on the many gems I've met along this journey with Sturge-Weber and how rare and unique each of you are in my life! It takes a lot of personal work and loving hands to ensure we each become a brilliant gem reflecting the light of joy and resilience amidst life's opportunities. SWF provides the perfect place to polish our skills, refine how we shine in the world, and decide which setting is the perfect one for each of us to be a beacon of inspiration to others.

I don't know about you, but I know this 'little light of mine. I'm gonna let it shine' is a testament to the relentless pursuit of personal growth, the school of hard knocks of knowledge, and as an homage to all those who have contributed to the gem I've become. Yes, we are all gems!

Of course, just like those diamonds and rare gems, sometimes the process of accepting our own worth and brilliance takes a lot of refining, polishing, and making the cuts we need along the way. We may try different settings, such as people, places, and things that will help us try a new path. However, ultimately, we finally decide on the perfect setting that feels the best for our future.

We are speaking of Golden! We are going for the GOLD during the SWS Month of Awareness this year! We are looking for rare gems to participate with us to raise awareness and donations, uplift lives, and ignite research! Come join in the Olympics theme and events in our "Pass The Torch" event as we share unique and powerful stories on this journey. And, you know we have way more fun together!

We also appreciate the terrific turnout and response to the San Diego Reunion of Champions this year! Rox Anderson's sweet tribute to honorees Dr. Fernanda Sakamoto and Dr. Matt Avram was the perfect one to honor Dr. Gary Lask, the quintessential gentleman and lady; I am so blessed to know them all!

I can't wait for the SWF Int'l Family Conference in July! Come hang out with us this summer. In the meantime, I'm lacing up my tennis shoes and hitting the trail to get in shape for Myla's Mission, Pass the Torch for SWF, and all the little events along the way. I hope you will join me!

With love, hope, and faith,

Karen L Ball

Karen Ball
CEO and Founder

Clinical Care Network Update – BVMC in the Homestretch!

JEFF LOEB, MD, PHD
The SWF's Chief Scientific Strategist

Well, we are in the homestretch! While we have recruited over 100 patients with Sturge-Weber into our **BVMC (Brain Vascular Malformation Consortium) study**, we are only half way there and only one year to go.

The data pouring in from all of you and your care providers is absolutely inspiring. We are learning about the natural history of the disease. Natural history is important to help us tell you what to expect next as those with Sturge-Weber progress from infancy, to childhood, to teenagers, and to young and even older adults.

> " We want to make this dream a reality and are currently in the planning and fundraising stage to make it happen."

We built a really cool dashboard to display all of this information for each patient on a digital dashboard. We are learning what the best treatments may be for neurological (seizures, headaches, stroke-like episodes), port wine birthmarks, and glaucoma. We are also learning how these clinical symptoms relate to changes in the brain from MRI studies of the vascular malformation. This project combines support from the **National Institute of Health (NIH)** working hand-in-Hand with the Foundation.

How to Get Involved:

Joining the study I really simple and safe. We collect your medical records and MRI studies digitally. For those willing, we also collect a blood samples. We protect your privacy by de-identifying all of the data. For more information and where to enroll at one of our eight (8) sites across the country (or remotely) please contact either Julia Terrell at jterrell@sturge-weber.org or Luz Rosales at luzr@UIC.EDU via email.

So what happens after the NIH grant ends in one year?

We in the Foundation are committed to transform this project into something that will continue and expand. This information is too valuable to lose — both for our research efforts to discover new treatments, but also to improve quality of life.

Wouldn't it be great for you and your family to have access to your own personal dashboard of everything (including imaging) related to Sturge-Weber that you could share with your doctors? We want to make this dream a reality and are currently in the planning and fundraising stage to make it happen.

Please join us in Philadelphia!

For those of you attending our family meeting in July 2024, I look forward to seeing you there and giving you more updates on BVMC and other advancements from the clinical care network. Even though Sturge-Weber is rare, we need to stand together for those we love as well as the next generation of those who will get the disease.

Remember, we are stronger when we are united.

sws month of awareness

Why ‘Pass the Torch’?

Why did we choose **Pass the Torch** as our theme for this year’s **SWS Month of Awareness**? Imagine for a moment that you stumble upon a committee of four (4) people from across the country sitting at a table brainstorming for our next adventure. You will hear ideas all across around the table, thinking about motivating others to believe in a dream that these four people have to share. You would have heard ideas about batons, light sabers, steps, miles, shoes, and passing knowledge. Then, one person says the word leading to a great idea. *Torch.* Yes, the torch became our one word.

A torch is a light that leads to the Olympics, which leads to honoring all the warriors of your country and, eventually, the world. You still may be scratching your head and ask what it all means. Let me explain.

As you know, 2024 is a leap year and also an Olympic year. In the Olympics, it all starts with a committee (presumably more than four). You have an Olympic village, a team (a literal team or a country “team”), a trainer, long hours in the gym, highs and lows, wins and losses. In the Olympics, you have a sport that you learn, practice, train hard, have tenacity and a drive to win. You live for the praise and are sponsored by many. When it all is over, you LIVE with a remembrance of your success.

As with Sturge-Weber syndrome, too, it all begins with a committee. One you never want to meet—we call this committee *doctors.* Gradually, you start to built your village made up of a team of doctors, neurologists, dermatologists, and therapists. Your family and friends also become a valuable part of your village, as well as The Sturge-Weber Foundation. You learn your journey will follow a new path and you accept it while training and discovering all the knowledge you can with the help of your village. You have wins and losses on your journey, big and small. But then you get to the point where you realize it doesn’t look as scary as the beginning. You can do this! We call this *mastering your journey.* You get to stand tall on the podium of life wearing the SWS medal proudly but still running the race.

JULIA TERRELL
The SWF’s Patient Coordinator

Then, one day you run into a family that is just starting their journey, and you find yourself saying…“Are you ready for the biggest fight of your life?” “You got this!” “You can do this!” “Look for that smile, and it will be okay.”

Some of the best advice I ever received was...*Remember to breathe.* Your journey is the most rewarding fight *and* win of your life. You will win. I promise it will just look different than you ever imagined, and you will be humbled by your SWS Warrior.

We ask you again, *why a torch?* Because all journeys begin with one step taken towards a goal. One step that can light the way on your journey. To our warriors, we want you to say, *“I am a winner every day.”*

From one SWS Warrior family to another, today is your day to “Pass the Torch” of a lifetime to another SWS Warrior family. I know we are all busy, but we don’t just *want* you but *NEED* you to be part of our SWF Team, village, and journey and support the **SWF Torchbearers.** We never want our SWF Team to feel alone in their race.

Let’s go, **TEAM SWF.** Let’s show all of our village, and the world, just how strong and tenacious we are today! We may look like the underdogs like Rocky Balboa but, you are a champion. One that, like Rocky, will win with heart and determination, Let’s meet at the Philadelphia to pass that very last torch, and celebrate each and every one of us as winners! Can we count on you to be a part of Team SWF?

We've Walked a Million Miles in Your Shoes–Now we are **Passing the Torch to YOU, Our Members**

We're shaking things up this year for **SWS Month of Awareness (MOA).** In past years we have kicked off MOA with the Million Miles Walk but this year we are creating our own Olympic torch relay with **Pass The Torch for SWF.** While the walk has always been a big part of our May fundraising, we're ready to think even bigger!

Since the early days, when The Sturge-Weber Foundation was operating from Karen's basement, we have been incredibly fortunate to have amazing supporters who have tirelessly advocated for our mission to fund research, assist families, and spread awareness about this rare condition. With every supporter, another has stepped up to continue the momentum, effectively *passing the torch.*

A million miles are paved with our stories. –now we are *passing the torch* to YOU, our members.

We've reached out to 53 amazing SWF Champions to **Pass The Torch for SWF** and pave the way for the next generation. They will share inspiring stories of dedication, perseverance, and overcoming challenges.

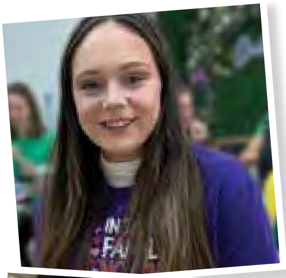
Each has a unique and powerful journey to share, and we can't wait for you to hear their wisdom and insight. The ultimate goal during **SWS Month of Awareness** (which is actually more than a month) is to raise awareness of SWS, KT, and PWB and raise money for continuing initiatives.

It all starts on May 1, 2024, and will continue for more than a month until July 13, 2024.

Warriors, we need your help to make the SWF Olympics a gold place winner!

How does it work?

So glad you asked! We're starting in Louisiana, where **Camyrn**, Miss Slidell Teen (right bottom), will kick things off with her sister **Carley** (right top), a SWF Warrior as our first **SWF Torchbearer.** Camryn will share why she supports The SWF on social media and a call for donations.



We will ask **Louisiana Families** to show their support by donating to her page and spreading the word on social media to get even more people involved.

Once Camyrn and Carley *'passes the torch'* to

Continued on next page >>>

Pass the Torch...

the next state, we'll ask families there to do the same—support your state's torchbearer.

We hope you will join in the fun supporting your SWF Torchbearer in your state but sharing on social media too! Be sure to tag us so we can help share your posts.

Your job is to inspire the SWF community to share their own story and to help raise donations for your state torchbearer. Which state will get the gold? Don't know how you can fundraise for The SWF? Check out the side bar at the right for some creative and easy ideas.

Don't forget to cheer on your fellow torchbearers from other states, too!

We're stronger when we are united.

The final torch will be delivered to Philadelphia, PA at the **SWF Int'l Family Conference** in July! *Seriously, you want to be there!*

Get ready to be inspired and motivated by these incredible individuals who have made a difference in the SWF community, no matter your challenges!

Together, we can leave a legacy of light and hope for future generations.

We are truly grateful for the ongoing support and dedication from our community and are inspired by the impact we have made together. Thank you for being a part of our journey and helping us make a difference.

Now, Warriors, let's go for the gold!

Share Your Story

Now it's your turn to tell us your story. Submit your story and photos on our website here: https://sturge-weber.org/for-patients/patient-story.html

Not sure what or how to write your story? On the website, you will find tips and techniques to perfectly convey your story of hope.

Easy and Creative Ways to Start Fundraising for The SWF

There are many reasons to fundraise for The Sturge-Weber Foundation!

By supporting their efforts, you can help provide research travel grants for the "Learn on the Go: Next Gen Warriors" program, support Warrior University, and aid in the Webster Bear Program and Care for the Caregiver initiatives.

We encourage Warriors that have not participated in MOA to make 2024 your year by getting creative and having fun, too! Be a part of a community who is making a difference in the lives of SWS families.

FACEBOOK FUNDRAISER

Probably the easiest way to ask friends and family to donate to your cause is by tapping into your followers. You can follow the instructions here: www.facebook.com/help/990087377765844

KRISPY KREME DONUTS

Raise some dough with these delicious treats. The best part, 50% of the sales is donated to the Foundation! Learn more here: www.krispykreme.com/fundraising

GO LOCAL

Ask local businesses how you can host a fundraiser at their establishment. A local brewery, ice cream shop, coffee shop, or taco restaurant for a portion of proceeds on one day's sales for SWF. Do your part to promote the event to make it a success.

USED STUFF SALE

Ask friends and family to donate used books or other items for a book/garage sale with the proceeds going to SWF.

Need more help?
Email us at swf@sturge-weber.org.
We are here for you!

Continued on page 12 >>>

Batter Up for Reunion of Champions

Our **SWF Reunion of Champions** on March 8th was a great success. **Dr. Fernanda Sakamoto**, MVP of the night, and **Dr. Gary Lask**, our first Legacy Leader, hit it out of the park. The night began at the sold-out Fernanda Sakamoto Stadium in San Diego, CA. There was not a seat in the house!

Karen Ball, SWF CEO and founder, began the evening with a massive "*Thank You*" to all our sponsors in the house, whose sponsorship banner flags could be seen far and wide.

First on deck was last year's honoree and dedicated all-star to dermatology, **Dr. Mathew Avram**. You may have seen him on social media–he is an fantastic fan of **Team SWF.** Commanding the crowd, he gave a great introduction to Dr. Gary Lask.

Not to be out done, Dr. Lask throw a curve ball, bringing in pitch hitter **John Rauschbauer**, a SWF board member, and dad to Aden. John spoke of his caregiver journey and meeting Dr. Lask back in the day when Aden was first diagnosed with SWS. The crowd laughed when he told of the very "chill Californian doctor" telling him "everything will be okay."

Next up to bat was our very own All-Star, **Aden Rauschbauer.** He knocked it right out into left field with his SWS story. The crowd sat on the edge of their seats, and there may

Continued on next page >>>

Pictured (l to r): Julia, Suzanne, Pablo, and Karen

SWS Guests (l to r): Lina and son Pablo with Aden and his parents Shelly and John

Thank you to our sponsors:

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CLUB LEVEL Kristen Kelly, MD

TEAM SWF Legacy Leaders

Pictured: (left to right) Fernanda H. Sakamoto, MD., PhD; R. Rox Anderson, MD; Matthew Avram, MD, JD; .?, Gary Lask, MD; ...

have even been a tear or two as he explained his personal SWS journey and what it all meant to him. *Way to go, Aden!*

Then it was our Legacy Leader, **Dr. Gary Lask**'s turn to come up to the plate. He swung for the fences with his wonderful talk about the importance of dermatology and its relationship with the SWF.

After all the emotional speeches, we needed an intermission, so we took a short break to honor our past and newest honorees. We were so happy to see our **Team SWF Legacy Leaders** model their new baseball hats! The picture will be treasured for years to come as a reminder of the dedication each MVP has given to the field of dermatology, their patients, and to the Foundation.

In the second half, next up to bat was an MVP we can't overlook, **Dr. Rox Anderson**. He so eloquently gave a beautiful speech about the hardworking and dedicated Dr. Fernanda Sakamoto, who just happens to be his beautiful wife. A fantastic couple and their lovely family and friends were in the stands cheering for her. We should all be so lucky to have such an amazing cheerleaders in our lives.

Dr. Frenanda Sakamoto delivered the final pitch, reminding us why she and Dr. Lask deserved to be MVPs. Her *unrehearsed* speech spoke from the heart, and her dedication to the Foundation and her patients is that of a Hall of Fame inductee!

If the night ended there, that would have been enough, but we had one more. Karen came sliding into home base with a donation challenge, and the crowd went wild. MVPs everywhere raised the bat to donate to their SWF Team.

The star of the night with the most significant donation was **Dr. Suzanne Kilmer**, who received a donated bag of gift cards valued at $250 and beautiful art created by our SWF Co-All-Star, **Pablo Leon**. *Great job, Pablo!* We can't forget our outfielders; **Lina Leon** helped the Team add some sparkle to the event by donating the balloon decor. **John and Shelly Rauschbauer** were instrumental in setting up and tearing down the stadium decor. **Teamwork is the best!**

The SWF is truly blessed to have the support of our amazing sponsors, partners, past and present honorees who really hit it out of the park by raising **$85,763** to help The Sturge-Weber Foundation continue to serve our SWS family in a meaningful way.

Just a few of our initiatives include:
- Help SWS families find care when they have nowhere else to turn;
- Support the whole body with mental health programs and talks;
- Advocate on Capitol Hill for patient and family care;
- Provide research grants to continue working on finding a cure and therapies;
- Support aging SWS members;
- Spread awareness of SWS, KT, PWB, glaucoma, and seizures.

REUNION OF

HA

FUNDRAISER KI

Photos by Esteban Roman @secondsfilmeip • To see all the photos, vis

CHAMPIONS

ALL

Fame

CK-OFF EVENT

sit https://sturge-weber.org/for-professionals/reunion-of-champions.html

VIRTUAL CHATS

MAY 2024

SWS MONTH OF AWARENESS

Join us for one or all of our special SWS Month of Awareness virtual chats **every Wednesday during May**. These chats will be led by our SWS Warriors. **Each chat starts at 8 pm EST, except the chat on May 29th.**

05.01.24

Dermatology, Laser Treatments
Special SWS Warrior guests:
Michelle Daoust and Chelsey Peat

05.08.24

Neurology, Hemi Surgery, Migraines, Living with Seizures
Special SWS Warrior guests:
Donnie Hood, Aden Rauschuber, and Annette Coutu

05.15.24

Ophthalmology, Glaucoma, Blindness
Special SWS Warrior guests:
Henry Bartenbach, Jessica O'Reilly, and Marylou Delagarza

05.22.24

The 'Good, Bad, and Ugly' Questions
Anything Goes in this chat. The SWF Staff and Board of Directors will be on hand to answer questions–no matter how good, bad, or ugly (awkward).

05.29.24

Mental Health, Open to Patients and Caregivers @ 7 pm EST
with Luis Sandoval, PhD
We will have two separate rooms for each group

SIGN UP

Sign up on the website at www.Sturge-Weber.org. Click the Events Page, Month of Awareness Page to see all the excitement for this year's event!

2024 MYLA'S mission STURGE-WEBER AWARENESS

Myla's Mission 5k & UTV/Jeep Ride - 2024

Join us for our 7th Myla's Mission for Sturge-Weber Awareness Day on Saturday, May 18 in Greensburg, IN. Mom, Molly is one of The SWF's Board of Directors and has worked tirelessly to spread awareness of this rare disease! Learn more about this event at **www.mylasmissionsws.com**.

‘My Face is a Masterpiece’

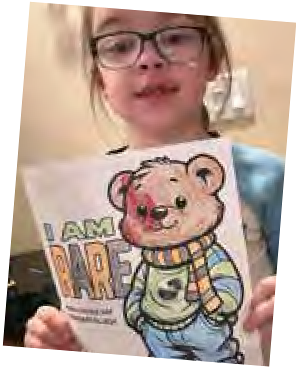
Face Equity Week, May 13–17, comes from our friends across the pond. Art is a universal language. So whether you have a visible difference or not, unleash your creativity as a tool for social change.

Here are some tools to get you started:

- Host an online or in person exhibition or event to support face equality.
- Get your colleagues, friends, or family together for a life-drawing session in support of face equality (don’t worry, no nudes necessary).
- Host an art class (like a Sip and Paint) as an opportunity to discuss visible difference.
- Use **‘My Face is a Masterpiece’** to share your story, or amplify someone else’s, whether you’re an ally or someone living with a facial or visible difference, join the movement. One fun way to do this is to “paint” your birthmark and post your story online. For a little inspiration, check out the amazing @flawless_affect and @_amba_smith_ on Instagram.

FACE EQUALITY INTERNATIONAL

Learn more about Face Equity Week:
https://faceequalityinternational.org/about-fei/international-face-equality-week/

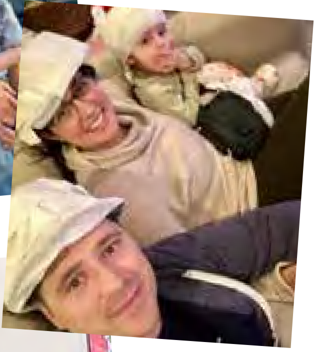


Mackenzie on Rare Day

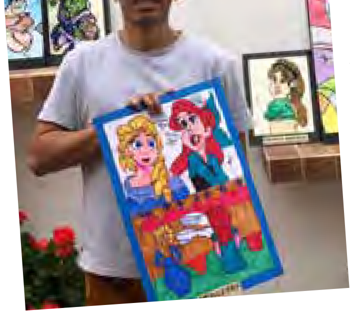
In Case You Missed It...

As seen on social media.

Matthew (L) and Lincoln (R)



Supporting Harper’s EEG with Toilet paper hats



Román shares his artwork

SHIP BOTTOM
Brewing
RACE SERIES
2024 RACE DATES

Swarthmore, PA
MAY THE FOURTH RUN
5.4.24 6 PM
ECTO GHOULER RUN
10.5.24 6 PM

Beach Haven, NJ
RUNNING WITH THE SHARKS
6.9.24 9 AM
ECTO GHOULER RUN
10.5.24 10 AM

4 AWESOME RACES IN 2 AWESOME LOCATIONS

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Join Us In Philadelphia

We know everyone has been "patiently" waiting to know what we have planned for this Family Conference, so let's break it down!

Get ready to kick off an amazing event on **Thursday, July 11!** Registration starts at 1:00 pm, where you'll check in, grab your swag bags, full program of events, and conference t-shirts. Then, meet our fantastic doctors for **Clinic Appointments**. After that, enjoy dinner at the hotel or nearby restaurants on your own. Later, join us for a **Torch Walk to Arden Theatre for an Ice Cream Social** and 'Get to Know You' Bingo. Sponsored by SWF Australia.

Friday, July 12 events start bright and early at 7:00 am with **breakfast** on us in the main room. At 8:00 am children can head to the **KidsCamp** for all day fun activities while parents, caregivers, and SWS Adults attend seminars and workshops. **Karen Ball**, SWF CEO and Founder, and **Stephen Falchek**, MD will open the conference and welcome you to the City of Brotherly Love, Philadelphia! **Jeff Loeb**, MD, PhD and **Matt Shirley**, PhD will give updates on CCN and Research.

Sheldon Lewis, from AccessiBe will join us virtually as our **Keynote Speaker.** Sheldon's story an inspirational story of overcoming obstacles and succeeding despite physical limitations. You will hear from **Lara Falcon, UCB**, our sponosor. Next up is a **Research Study Panel Q & A** with Csaba Juhasz, MD, Aimee Luat, MD, Michael Behen, MD, Jeff Loeb, MD, Anna Pinto, MD, and Luis Sandoval PhD. Then, we have a wonderful lunch planned for you too!

Continued on next page >>>

THANK YOU TO OUR GENEROUS SPONSORS

ucb Inspired by patients. Driven by science.

ROBERT & JOAN DIRCKS FOUNDATION, INC.

SCAN ME

After lunch we will break into two groups: Pediatrics Parents/Caregivers and SWS Adults, which have their own track of seminars and workshops. **Pediatrics Parents/ Caregivers Track** planned seminars include Diagnosis, Glaucoma, Pharmacology, Neuropsychology, Migraine Management, and new this year, Neuro ophthalmology.

For the **SWS Patient Track** we have included seminars on Mental Health, Neurology, Transition of Care, and a fun adventure we are calling "The Sandoval Scavenger Hunt."

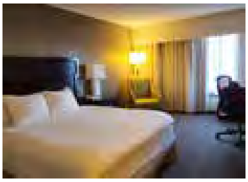
You will pick up your kiddos at KidsCamp and enjoy dinner on your own and a short rest before the evening events. This year we have two options. Option one: jump on our Team SWF bus and join us for a **Phillies Baseball game** where everyone attending will receive a free baseball cap, be featured on the jumbotron, and a chance to meet the Phillie Phanatic! You may also eat dinner on your own at the stadium, if you choose. Option two: enjoy some downtime at your own pace. Take a dip in the **hotel pool** or head out for some sightseeing at **Penns Landing.** The **Liberty Bell** is within walking distance from the hotel!

We wrap it all up on **Saturday, July 13** with breakfast at 7:00 am, followed by KidsCamp, and **Keynote Speaker Elizabeth Laba**, Mom and Patient in PA. The day will be filled with seminars on Special Needs Trust/POAs, breakout rooms on Assistive Technology, Art Therapy, Recreational Therapy, Integrative Medicine, IEP, and an interactive Social Media Video Workshop, and a "More Than" Photoshoot lead by our special SWF Torchbearers. Don't worry, we planned time for **Care for the Caregiver** to just relax and unwind before picking up the kiddos again at KidsCamp.

We end our Conference, as we always do, with a **Warrior's Gala Dinner** and presenting of the SWF Torch. This event is a sports theme dinner, so pack your favorite sports team jersey or t-shirt! There will be a silent auction, raffle for prizes, a photo booth, DJ music, and more! Finally, we say 'Goodbye' with tears and hugs.

It's going to be an amazing Conference! We hope to see you there.

The Hotel



Wyndham Philadelphia Historic District
Wyndham Philadelphia Historic District is just one block off Market Street and within walking distance of popular landmarks like Independence National Park, Liberty Bell Center, Independence Hall, and the Betsy Ross House. Rates start at $189/night USD which includes The SWF discounted rate.

Quick Facts:

Are you aware that the doctors, clinicians, and researchers who speak at the SWF Int'l Family Conference generously volunteer their time? The Foundation doesn't pay for their presentations and they cover their own hotel and travel expenses. Furthermore, besides planning seminars, many of them actively participate in organizing family activities. Their dedication and commitment to supporting families is truly amazing! We're so grateful for their selfless contributions to our community.

The SWF kicked off our very first conference in **Denver, CO** back in 2005.

We have three Clinical Care Networks (CCN) in the Philadelphia area! When choosing a host city for our Conference, one of the key factors we consider is the proximity of a CCN in case of a medical emergency—and have access to wonder doctors and speakers. Having access to medical care near our Conference is a top priority in our event planning. The three CCN's near Philadelphia include Thomas Jefferson University and Jefferson Health, Wills Eye Hospital, and Nemours Children's Health.

Advocacy News

Find all sign-ons here: *https://sturge-weber.org/get-involved/advocacy.html*

Quantification of enlarged deep medullary vein volumes in Sturge-Weber syndrome
Research Paper by: Jeong-Won Jeong, Min-Hee Lee, Aimee F. Luat, Yang Xuan, E. Mark Haacke, **Csaba Juhász**. It is largely an MRI (methodology) paper, providing a new quantitative approach to measure the volume of enlarged deep veins that could serve as an objective imaging marker of deep vein changes in SWS, while using the combination of SWI and high-resolution T1-weighted MR images (and some computation to segment out these veins from the brain). The Foundation is acknowledged at the end of the paper. You can read it here: *https://sturge-weber.org/for-professionals/swf-research.html*

The Sturge-Weber Foundation is Committed to Advocacy
Did you know that members of Congress have a direct impact on federal programs that advance medical research and improve healthcare? Unfortunately, many lawmakers may not fully understand rare conditions like Sturge-Weber syndrome and the unique needs of those affected. This lack of awareness can lead to our community being overlooked in important medical research and public health activities. The best way to make sure our voices are heard is to personally educate our elected officials about our condition and community. This is why we sign-on to many SWS related initiatives. Here are a few:

Latest Sign Ons
In the last few months, we have joined some new organizations that will allow us, The Sturge-Weber Foundation, to have more of a voice in areas like Rare Disease, Neurology, the NIH, and more. Some groups we engage with are the Rare Epilepsy Network, Epilepsy Alliance America, American Epilepsy Society, Epilepsy Leadership Council, and so much more. We have always been members of many others as well. This is important because when you are small and rare, we need a bigger voice for advocacy to get bills passed on both the national and local levels, too. We have also signed on the following bills as well to support even more efforts:

- S 652/HR 2630, the Safe Step Act
- FY 25 BRAIN Initiative® Funding
- FDA Neurology Drug Program in FY 25

If you want to do your part, here is your chance.

- Ask YOUR Senators and Representatives to join the two NEW bipartisan Epilepsy Caucuses.
- **Step One:** Are your Senators and Representatives on the Caucus? Check here: www.epilepsiescaucus.org/expertise.
- **Step Two:** If they are not, send them a personal message asking them to join.
- **Share your story.**
- **Call to Action.** End your message by asking them to join the bipartisan Epilepsy Caucus.

Look them up YOUR Senate and House of Representatives here: www.senate.gov/senators/senators-contact.htm and www.house.gov/representatives/find-your-representative.

I know we did; can we count on you, too?

JOIN IN RESEARCH

BVMC
BRAIN VASCULAR MALFORMATION CONSORTIUM

https://bvmc.rarediseasesnetwork.org/our-consortium

Mardi Gras for a Cause

Witney Arch reports on her Mardi Gras for a Cause event: "What a great afternoon! I put together a fundraiser for The Sturge-Weber Foundation and we made Mardi Gras Door Hangers! **Beau** [Witney's son with SWS] came as well and wore his pink shirt for his birthmark. **Crystal Kilgore Elliers** and I have served on the Board for The Sturge-Weber Foundation for many years. Her daughter, **Carley**, who also has SWS, is now in college and has defied many odds. SWS a cruel disease and we hold on to every bit of hope that Beau will be okay. So far, he is surpassing what we knew may be in store for him.

Beau was thrilled that all these people came to paint and to support the Foundation! He did very well talking to people, he posed for a ton of pictures, and he actually smiled. I'm feeling like this is a real miracle.

He chose to paint a King Cake and at first, I thought it was going to be a messy piece of art. He picked all these random colors, making sure to include his favorites – pink and teal. He calls it "Sunset King Cake" because it looks like a sunset.

Carley's sister, **Camryn**, Miss Slidell's Teen, uses her platform to spread awareness of Sturge-Weber! I love how passionate she is about bringing awareness to this rare disease. She spoke, and when Carley started crying, it made most of us cry. So thank you to those who came and those who donated! It warms my heart."

Thank you for sharing passion and your hard work for this Foundation. This event raised $1,000 to help support SWF initiatives, such as research, awareness, and advocacy.

Take a cue from SWF Board Member, Witney Arch and son Beau—planning a festive fundraiser doesn't have to be complicated. Focus on having fun and rest will take care of itself!

Rare Disease Day

The first of the year is been off and running! Here is one of our amazing events we attended or hosted.

The Today Show on Rare Disease Day, 2024
The National Organization for Rare Disorders (NORD) hosted Rare Disease Day by taking its mission to create a brighter future for people living with rare diseases to the TODAY Show in New York City.
This was a fun morning for viewers trying to spot our SWF Warriors in the crowd!

Marissa and Julia was joined by Kristen and Kayla, and Linda Cohen in a very cold NYC. Thank you NORD!

MARK YOUR CALENDARS:
THE SWF DAY OF GIVING ON MAY 25TH

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

STRONGER BECAUSE WE ARE
UNITED

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
- ○ Stock Donation
- ○ I have enclosed a check
- ○ Please pay by credit card* ○ VISA ○ MasterCard ○ Amex ○ Discover

Name on Card: ____

Credit Card #: ____

CSV: ________________ Exp. Date: __________

**You may also make a secure donation at 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: ____

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

SAVE THE STAMP!

Use the QR Code to the right to donate securely on-line
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MARK YOUR CALENDARS:
THE SWF DAY OF GIVING
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