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

SUMMER 2023

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

Branching Out

FOR 35 YEARS WE'VE BEEN HERE FOR YOU!

A reason, a season, or a lifetime.

What does *Diversity* look like in the Rare World?

Save the Date

2024 INT'L FAMILY CONFERENCE

See Page 9...

TEAR OUT POSTER INSIDE! HELP US SPREAD AWARENESS.

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

SUMMER 2023

The Summer Issue...

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

"...We are united in our love and concern for those with SWS, birthmarks, and KT but that does not keep us from transcending into other commonalities of life we all share."

Connect with Karen

Karen's 2 Cents

The one thing we can be sure of is that change is coming and it IS gonna happen! I suppose because as a young child (we moved almost once a year due to my dad's job) I've always known that to be true and got pretty adept at coping with change. I'm not saying I always liked it but it is easier to plan and prepare as best we can and then execute as best we can too. Upon entry into a new school, job, relationship, there's the honeymoon phase and the excitement of new possibilities ahead.

When it comes to Sturge-Weber Syndrome, there is not always excitement of new possibilities that may bring bad news, bad advice, or medical provider substitutions. Let's face it, there is a comfort in the known and tried and true! I've found that getting outside our comfort zone brings new life and possibilities (yes sometimes not so great ;)) which help us to better understand our strengths and teach us to lean on others when we're not feeling strong.

Today's world seems to want to entice us to engage in fast paced technological advances and communication. Heaven forbid if we don't. I say each one of us is unique and has diverse learning styles, cultural norms, and coping skills. Let's respect the wonderful mix of diversity we bring to our community, literally and figuratively. It's always so fun to participate in the Educational Summits and catching up with old friends and meeting new ones from around the world. We are united in our love and concern for those with SWS, birthmarks, and KT but that does not keep us from transcending into other commonalities of life we all share. Celebrating birthdays, our love of all things chocolate, new milestone achievements, the death of a loved one, and much more is the bread of life and tempers the scary aspects of the unknown that SWS imparts in our world. The further we reach out, the closer we become! I look forward to meeting more of you online and in person especially at The SWF International Family Conference next summer!

Each day is a blessing for me. Especially now my mama has passed on there is a yearning to make each day TRULY matter and to be good to myself…don't give all that emotional support and outreach to the detriment of my own health. Wish I'd told my younger self that 36 years ago! The world's problems will still be there tomorrow so before the sun sets take a moment and savor the smiles, the chats and the wonderful gifts given to you!

I'm so excited for what lies ahead for the SWF! I know some of y'all are thinking, "She always says that!" but it IS true!

Continued on page 15 **>>>**

The SWF's Diversity & Inclusion Plan

At the Sturge-Weber Foundation (SWF) we have a diverse patient and family group as our disease state is rare and affects 1 in 50,000 people without preference to age, income, sex, race, or national origin. As such, we strive to make sure that our Foundation's families, Clinical Care Networks (CCN) and their clinicians, and SWF International Research Network (SWFIRN) and their researchers, scientists, and volunteers represent a diverse cross-section of racial and socio-economic backgrounds.

The Foundation takes steps to ensure diversity in our outreach and research in these areas:

- Identify regions of the country that are underrepresented where The SWF will need to further engage where there is not a Clinical Care Network or Research Lab today: i.e. recruiting Clinical Care Networks, and Hospital systems in cities like Philadelphia, Miami, Los Angeles, Memphis, and St Louis.
- Identify universities and colleges that serve historically underrepresented populations. The SWF together with our clinicians and scientists will send out the call for abstracts and promote and advertise our conference in those areas.
- Announce our professional groups and advertise and promote our meeting and a call for abstracts.
- The key subject matter experts of Sturge-Weber Syndrome will recognize and are encouraged to nominate junior associates or under-represented minorities to be a participant at our meeting.
- The SWF will provide accommodations as needed i.e. dietary, lactating rooms, childcare, etc.

In the future year, the Foundation will be launching The SWF Warrior University where we will also recruit, and educate professionals in Sturge-Weber Syndrome. This will have the ability to earn credits and further education for anyone. This will also further the ability to encourage those in underrepresented areas to learn more about Sturge-Weber Syndrome and encourage involvement in our Syndrome. The opportunity will be advertised and promoted as stated above to get involved in creating the material for the University.

The Sturge-Weber Foundation prides itself to include everyone in learning all we can about Sturge-Weber Syndrome and furthering the science around Sturge-Weber Syndrome. Diversity is critical and a priority for the foundation governed by our team.

IMPORTANT: Fill Out Our Diversity Plan Survey!

Diversity means, *"the practice or quality of including or involving people from a range of different social and ethnic backgrounds and of different genders, sexual orientations, etc."*

Although we are already a very diverse group coming from all walks of life and coming together with the commonality of Sturge-Weber Syndrome, yet, when we meet find that once we meet and get to know each other we have many things in common!

Federal and State requirements now need us to define the diversity of those we serve. This is imperative when applying for research or educational grants that will further our mission. **We will be asking you to fill out our survey from the patient perspective only,** which is coming to your email box soon. Please help us by updating and inputting the patient's information and meet government requirements.

Note: We do not use this information for financial gain and will not share your information outside grant applications or to support The Foundation initiatives.

PATIENTS & CAREGIVERS TAKE THE SURVEY:
https://qrco.de/bdx0Xm or scan the QR code

Then vs Now

JULIA TERRELL
SWF Patient Coordinator

I am sitting on a train, listening to music, typing on my computer and enjoying a sunset all at the same time. My family is all around me, listening to their music or maybe they are surfing social media, watching a movie, reading emails or working like I am. No one can hear my music. I can even make it so that no one can see my computer screen. I can work anywhere, I can be a Mom, be all in, and still sometimes not have an idea of what is happening at the same time. WOW, does that sound confusing when you think about what was back in the "old days".

The word transformation comes to my mind. You may ask yourself if that is good or bad? I personally think "Neither" is the right answer. It just is how things are and transformation must happen. We have seen it in everything. Think about lasers we use for port wine birthmarks and that they are only about 30 years old. When my dad was growing he used to have a doctor who came to your home and now we can use teledoc.

> "...the one thing that has not changed over the years, and will never change, is that we have always been here for YOU. You were our "why" in the beginning and will continue to by our focus no matter what changes in the world."

The Sturge-Weber Foundation is no different. When the SWF began, we had to go to libraries, write letters, and hope that you found the right doctors, the right information, and did the right things. You did not have the ability to confirm opinions and in the rare community. Finding information was even more challenging.

When Karen Ball founded this foundation at a desk in here basement, she would say, "You will need to smile and dial." Dialing was probably on a rotary phone. Many won't even know what that means. The phone aside, here are some key differences from then and now…

Then: Telephone was connected to wall
Now: Cellphone is completely portable

Then: Computer was big box on your desk
Now: Your cellphone is your computer and your laptop/iPad can go anywhere

Then: Call people only when in the office
Now: Call/Text/Email from anywhere, at any time of the day

Then: Conference calls on landlines
Now: Conferences are now held in person or via Zoom or both with Hybrid meetings

The SWF Foundation has transformed in all the areas you see before you. Technology continues to evolve but the one thing that has not changed over the years, and will never change, is that we have always been here for YOU. You were our "why" in the beginning and will continue to by our focus.

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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. Things 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 can answer yes to any of these you are not alone.

Here are some shortcuts for you so that your child can have a successful year…

- Talk to your kids, find out what works and what doesn't and change accordingly.
- Pack the 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.
- Medicines and Rescue Meds and doctor notes ready and keep a list for your self.
- Emergency Room guide is helpful to give to the nurse too and keep a copy: https://sturge-weber.org/for-patients/resources/educational-documents.html
- 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 we are not perfect. So be good to yourself and let yourself off the hook as perfection is not in the cards. As with anything, celebrate all the 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.

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.*

Color Me Different

Color Me The Same

A publication of The Sturge-Weber Foundation

Illustrated by Gina Going-Raney

Written by Carol Buck

FREE DOWNLOAD

Download our educational resources including this Coloring Book to share with your school.

www.sturge-weber.org/for-patients/resources/swf-brochures.html

Back-to-School!

Visit the Official SWF Shop for back to school gear:
www.Sturge-Weber.org

SAVE 10% ON YOUR ORDER!

We Are Your SWS Concierge

First and foremost, we are here for you!

The first time you hear the words *"Sturge-Weber Syndrome"* your head spins, the unknown sets in and the journey begins. The Sturge-Weber Foundation was created so **you are not alone on this journey** and together we are all united. From diagnosis, to seizures, to glaucoma, to laser treatments there is so much to learn in so little time. There is no wrong feeling and there is no way you can do it all yourself.

Let's start from the beginning – no matter the age of the warrior it is so frightening to hear, *"You have Sturge-Weber Syndrome."* We live in a world that we plan for everything and we hate the unknown. We want you to be in the know on your journey. It all starts with a call, email, a post from you…

- ✦ We are here for the crisis call.
- ✦ When you have that seizure, glaucoma flare or laser – call us we are here.
- ✦ If something changes we are definitely here for you?
- ✦ Transition to ___________, we are here too.
- ✦ We Celebrate You: Did you graduate, get married, or hit a milestone, or are seizure-free? We are here to celebrate with you .
- ✦ Get your first job…We are here to celebrate with you and we are here to help if you need help advocating for yourself too.

Patient Engagement

- ✦ Patient Engagement can mean many things. We do many things and we evolve to what you need so that we can get the answers you need when you need them.

Educate

- ✦ Educational Mini-Summits with the subject matter experts.
- ✦ Family conferences where we have specialists tell us about the latest science and what to expect.
- ✦ Assist with referrals in your area to get the right team.
- ✦ Social media posts and email news.

Research

- ✦ Bring Clinical Care Networks and Research Network together to see how they can meet unmet needs while having patients explain their needs.
- ✦ Clinical Care Networks work together with patients to build protocols.
- ✦ Clinical Science and Basic Science come together to learn from each other.

Networking

- ✦ Social Media we want you to meet others and feel part of a family.
- ✦ Confidence that what you find on our pages comes from sources and we believe that your team of doctors know best and we will never give you medical advice.
- ✦ Call us, email us when you need us, and we are able to get you in touch with

Continued on page 9 >>>

JOIN THE SWF BIRTHDAY CLUB!

We love to celebrate here at the Foundation! **Theresa Lamb** has a great talent of remembering birthdays and anniversaries. She has agreed to help us celebrate you, our WARRIORS (patients). If you tell us on the survey *(coming soon to your email box)* your birthday and click the box to join the "SWF Birthday Club" we will highlight you on social media and/or send you a card. We can't wait to celebrate YOU!

More Than a Foundation...

WE WANT TO HEAR FROM YOU:

Is there something missing or a service you think we need to offer? Let us know at contact@sturge-weber.org

We do more than you could imagine. We have a lot of tools in the toolbox to help you.

- We help international families find treatment and doctors in the USA.
- We support the whole body and mind with resources for mental health issues.
- We are here for emotional support when families don't know where else to turn for help.
- We provide a support system of newly diagnosed to those with aging SWS-related issues.

We do more than you could imagine. We are more than a foundation. We are united to meet Sturge-Weber Syndrome-related needs, for a reason, a season, or a lifetime.

Continued from page 5

Then vs Now

We love what we do. After a call with our Adult/Teen Patient Chat with Dr. Luis Sandoval recently, we agreed to call ourselves "warriors" and even "heroes."

No matter the crisis, the question, the need we vow to be here for you. We may not be good at advertising or bragging how many people we help, or what crisis was adverted due to our referrals, or how many people got better care because we were able to consult with specialists. We try in every situation to be like a concierge to you. No crisis is too big or too small that will can't help you solve or encourage you through the storm.

I can tell you our community is better for having partners in the Foundation. Please don't ever be afraid to reach out or hold back with feedback or what you may need. We will always be here to help where we can, the way you need it, and if we can't, we will learn with you to find a solution.

Karen's First Office in the Basement

We have always said, "We are a family you never wanted to join but you are always welcome to come home." The SWF Foundation is home. It's a soft place to land. You will never be alone. Come back for a visit soon we would love to hear your story to come.

THE SWF INTERNATIONAL FAMILY CONFERENCE

WE'RE GOING TO Philadelphia!

SUMMER 2024

Continued from page 7

SWS Concierge...

specialists and help you through what information you need.

Awareness and FUNdraising

- ✦ Month of Awareness activities in May.
- ✦ The SWF Million Miles Walk.
- ✦ **Donnie Hood** does a great job with his ride through Mallorca, Spain.

Extra Fun

- ✦ Webster has been out on the road and **Webster's World** has landed in Sweden, Australia, Italy, Ireland, Turkey, USA, and Canada.
- ✦ Our board member **Rob Zarko** does an event every year in Beach Haven – if you are in the area join us in October.
- ✦ **Coming Soon Birthday Club** and **Warrior-to-Warrior Mentors** – stay tuned for more information.

You are never alone. No matter what you need we are just a phone call, an email, a DM, or a PM away. So please tell us what you need and We ARE here to help you for a reason, a season *AND* a Lifetime!

Mark Your Calendars

CCN/SWFIRN Meeting for Professionals

September 14-17, 2023
Renaissance Hotel in Charlotte, NC

Ecto Ghouler Run

Beach Haven, NJ, October 7
https://runsignup.com/Race/NJ/BeachHaven/EctoGhouler5K

Virtual Educational Mini-Summit

@ 6:00-8:40 pm EST, October 13
Doctors will be from UC Irvine led by Dr. Kristen Kelly, Dermatology

Townhall with Karen Ball

December 6, 7:00 pm EST

2024 Reunion of Champions Fundraiser

San Diego, CA, March 8, 2024

SWS Adult/Teen Patient Chats

Monday, October 23, 2023 @ 7:30-8:30 pm EST
December, TBA

SWS Caregivers Chat

Thursday, September 28 @ 7:30-8:30 pm EST
Sunday, November 5 @ 7:30-8:30 pm EST

STRONGER BECAUSE WE ARE

UNITED MILLION MILES WALK

THE STURGE-WEBER FOUNDATION

BIRTHMARKS | GLAUCOMA | SEIZURES

We would like to thank, whole-heartedly, our amazing Million Miles Walkers! For all the sweat and miles, **1,587 miles** to be exact, know that it was worth every step. Every step gets us closer to our goal of stopping SWS in its tracks.

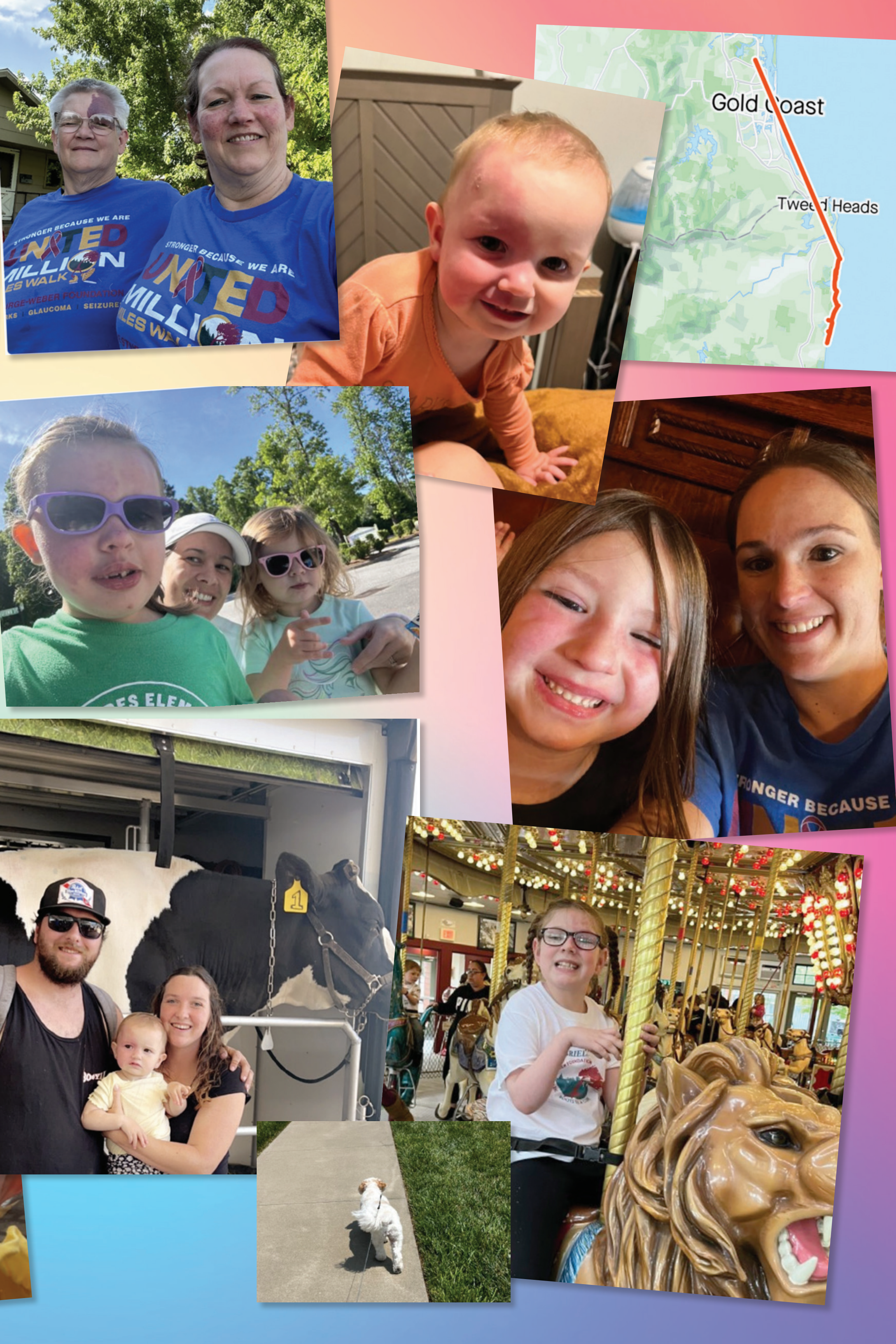
Total Raised: $10,458

Thank you:

Aleksandar & Jelena Ljepoja, Webster Walkers
Annette Blazek, The SWF
Annette Coutu, Team Brielle RI
Bob Lapin, A Lapin
Brielle Coutu, Team Brielle RI
Brooke Atkins, Marissa's World
Caroline Green, Team UCB
Cindy Phillips, Family
Danielle Ebbert, Ruby's Reason
Deborah Zehe, Team UCB
Hannah Whitford, Team Brielle RI
Heather Coutu, Team Brielle RI
Janet Parker, Family
Jennifer Kieninger, Ruby's Reason
Jeri Stunkard, Webster Walkers
Jessica O'Reilly, For Sarah
Joel Coutu, Team Brielle RI
Julia Terrell, Marissa's World
Lara Falcon, Team UCB
Mallory Kilgore, Steps For Scarlett
Taylor Shaw, Steps For Scarlett
Whitney Diefenderfer, Ruby's Reason

OUR SPONSOR:

ucb Inspired by **patients.**
Driven by **science.**


STRONGER BECAUSE WE ARE
UNITED
MILLION MILES WALK
STURGE-WEBER FOUNDATION
GLAUCOMA
SEIZURE
Gold Coast
Tweed Heads
STRONGER BECAUSE
1

The SWF is “In the Know”

The Sturge-Weber Foundation prides itself as being an active participant in the community for all things Sturge-Weber. This includes all levels of organizations including but not limited to:

- **National Institute of Health (NIH)**: The SWF attends meetings around the areas of SWS and has the ability to apply for funding for our meetings and research.
- **National Institute of Arthritis Musculoskeletal and Skin Disorders (NIAMS)**
- **National Eye Institute (NEI)**
- **National Institute of Neurological Disorders and Stroke (NINDS)**
- **Rare Epilepsy Network (REN):** The SWF is a member of a group of rare of epilepsies that meet monthly to talk about what others are doing and how we can learn from each other.
- **Global Genes:** The SWF has been working with Global Genes and partner with residents to learn more about Sturge-Weber Syndrome and what it means to be a patient with a rare disease. **Erik Southard** was our first student from the University of Toledo and will be attending our mini summit in August.
- **Rare Disease Legislative Advocates (RDLA):** The SWF is working with RDLA to advocate on the hill and locally. Stay tuned for more information about the new epilepsy caucus and how you can help further the cause for funding.
- **The Association for Research in Vision and Ophthalmology (ARVO):** The SWF will be working with ARVO to further science in glaucoma by sponsoring a researcher to submit abstracts in glaucoma.
- **Epilepsy Alliance America:** At the end of July we were approved to be partners with the Epilepsy Alliance America. Attend any of the free webinars in the box to the right. Through **Epilepsy Services NJ** and **Paul’s Purple Warriors**, Morgan McDonald and Marissa Terrell, were able to take part in **Seize the Wave in Sea Isle City, NJ**. Children with epilepsy had the opportunity to surf the waves with a professional surfer from Heritage Surf Shops. As the *Press of Atlantic City* stated, “Sea Isle City surf lessons allow kids with epilepsy to ‘Seize the Wave.’” The group did a great job with EMS help present, as well as, two neurologists. The day ended with ice cream on the beach while building sand castles. So much fun was had by all. *(See photos of this event on the back cover.)*

Epilepsy Alliance Back-to-School Webinars:

August 3
Off to College: A Guide for Students with Epilepsy

August 6
Preparing your Child with Epilepsy for the new school year

August 10
Seizure Rescue Therapies, Seizure Action Plans, and Seizure First Aid

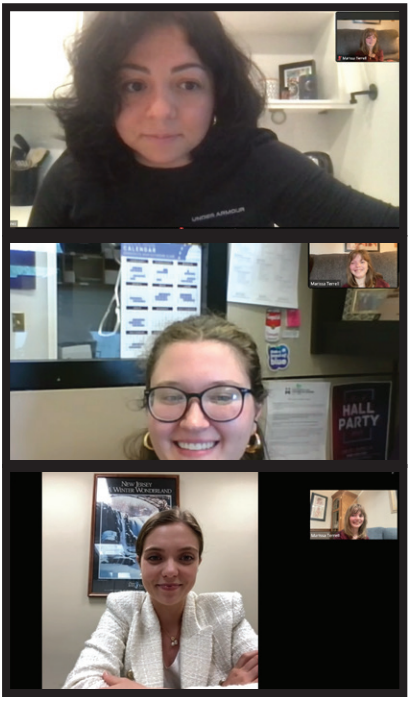
September 27
Seizure Triggers and Precipitating Factors

October 12
Special Considerations for Women with Epilepsy

SIGN UP:
https://qrco.de/beC5KK OR scan the QR Code below:

UPDATE YOUR SEIZURE ACTION PLAN DOWNLOAD:
www.epilepsyallianceamerica.org/seizure-safety/seizure-action-plan

Advocacy: You Can Do It!



In June, Marissa Terrell met with Congressman Donald Norcross's Legislative Aide, Madison Hughes; and Senator Cory Booker's Legislative Aide, Gloria Nunez, today to discuss the Rare Caucus and also to ask for them to co-sponsor the Accelerating Kids' Access to Care Act.

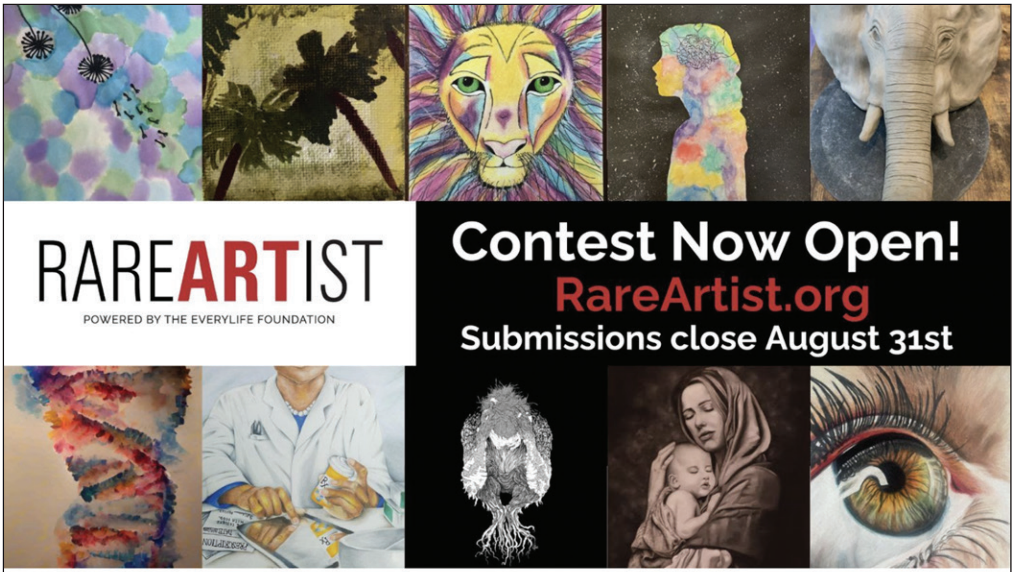
She then met with Senator Bob Menendez's Legislative Correspondent, Jordyn Ramsey in the afternoon.

RDLA did a great job getting the kids ready and Marissa did an amazing job with her "asks" and telling her story.

Do you want to learn how to advocate for rare disease? Contact Julia, jterrell@sturge-weber.org for more information.

In the words of Elle Woods, "What? Like it's hard?"

You can do it and have fun too!



(Participants in USA only)

Rare Artist Contest is now Open for Submissions

Enter July 23rd - August 31st at RareArtist.org

ON THE ROAD AGAIN

World Glaucoma Congress, Rome Italy

The WCG was a fabulous conference bringing together leading glaucoma specialists and ophthalmology practitioners wanting to learn more about glaucoma and glaucoma care. The key nugget for attending these meetings in person, wherever they are held, is the face-to-face conversations. There were several companies that exhibited and had exciting devices, innovation, and supplements which improve the care and lives of those living with glaucoma. The company iCARE had a highlighted session, where SWF was able to tell of our experiences in Houston, by Dr. Benjamin Frankfort using the device for women teenagers with glaucoma assessing hormonal changes. Two companies were approached to assess whether clinical trials in SWS would be possible with their respective implants and supplements. There is an old song that has a line, *"I love to tell the story…"* and we think it is what Karen does best. Tell our story. Find the best and brightest. Engage them to help us help you! Stay tuned and please sign up and participate when new opportunities arise from these targeted and fruitful meetings!

World Orphan Drug Conference (WODC), National Harbor, MD

The WODC brings together a wide range of individuals and companies interested in the rare disease space. It is a great mix of lectures from companies that are developing new indications for treatment or regulators that help them navigate getting a drug to market. The FDA and NIH staff members are readily available to visit with on SWS opportunities and it is a great time to meet new and old friends. We are so pleased to be working with Chris Smith and his staff at Smithsolve this coming year to foster awareness and create public relations outreach. There were a few new biotic companies that we will be continuing to dialogue with that may have exciting potential for us. As always, these meetings generate LOADS of ideas and of course the staff just pulls out the "parking lot list," as we call it, whenever we return from a meeting. We have more to do with less time to do it but we WILL do it all for you and yours!

Mental Health Group Chats

Our online group chats are a great way to connect with others in the SWS community and meet new friends. Luis Sandoval, Ph.D., Task Force Leader for Mental Health leads two groups via Zoom: "Adult/Teen Patients Chat" and "Caregivers of SWS Chat". Each alternate months.

To register, go to www.Sturge-Weber.org, click the "Events" tab. *We hope to see you there!*

- **SWS Adult/Teen Patient Chats**: October 23, and December, TBA
- **SWS Caregivers Chats**: September 28 and November 5

The SWF Official YouTube Channel

Check out the new video "The Making of a Rare Disease Foundation" with Karen Ball on YouTube now!

Be sure to head over to, as they say, "like and Subscribe to our channel" today!

@thesturgeweberfoundation

Continued from page 3

2 Cents

We are working with a FABULOUS Strayer University team of interns on a 'lil project I hope you'll like and use. The CCN and SWFIRN will be meeting again in September to crow about all their leads in clinical care and research progress. A new Strategic Plan for the next three years is in the works and we have some new volunteers coming on-board to ensure that we will be a success! I must have been a GREAT Girl Scout because I DO make new friends, "... but keep the old. One is silver and the other gold" ;)

We realize your world consists of lots more than focusing on SWS and that is how it should be! A robust and happy life is our eternal wish for you and yours. Just like the Girl Scout motto, though you make new friends and keep the old…don't forget your old friend The SWF and those who love you. God willing we will always be here for you as long as time, talent, and funding last. For a reason, a season, or a lifetime…I made that commitment and I intend to keep you it…will you? Please join me in giving up a latte or burger a month to help fund and keep the value you found in us as a new friend and for others until they become a dear old cherished friend! Together we can conquer any enemy and united we WILL overcome and be victorious!

Seek joy and embrace it!

Karen L Ball

Karen L. Ball

UC Irvine Mini-Summit

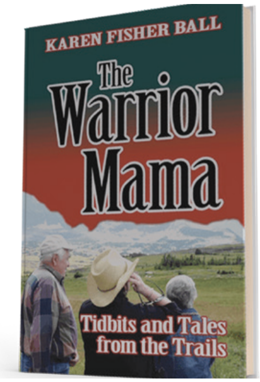
October 13th
Virtual Meeting
3:00-5:40 pm PST

Register at: Sturge-Weber.org
Click the Events tab for
more information

Karen and daughter Kaelin

#TheWarriorMama

The SWF founder and CEO, **Karen Fisher Ball: "The Warrior Mama".**



Inspired by faith and driven by determination, Karen blazed her own trail and created the Sturge-Weber Foundation to battle SWS. She embarked on a fundraising and research journey through the medical community and the pharmaceutical industry that has helped people worldwide.

There is sadness and joy in these stories, and plenty of hope for anyone who feels they are facing an impossible situation with the health of a loved one.

PLUS, 100% OF PROCEEDS BENEFIT RESEARCH AND AWARENESS

Pick up your copy today in print or digital.

Around the World SWF International

Brazil

The day the family painted their face with a birthmark just like João's

Warrior Mama Desireé started the Brazilian Sturge-Weber group because her son, João Gabriel was born with SWS.

"I made this profile to talk about him, what he lived through... and to find more mothers to share experiences with.

When João was born, I felt very alone. Without having other mothers to share. The purpose of this profile is more for that."

Currently, the Brazil SWS group counts about 90 mothers as members who share experiences and information. The SWF had the pleasure of meeting Desireé and many other members during their Sturge-Weber awareness day on Instagram last month.

The group also has WhatsApp for communicating.

@sturgeweberbrazil

Welcome new members from:

- Indonesia
- Sweden
- Brazil
- Italy
- Northern Ireland
- Philippines

Italy

The *Associazione Sturge-Weber Italia* was born in 2017, and today can count on 180 members.

The Association has a Scientists Committee, formed by six Doctors from various Children's Hospitals in Italy.

Research:

- Ophthalmology Imaging in SWS with Telethon Foundation (UniversitàLa Sapienza in Rome);
- Multidisciplinary Approach for SSW's patients diagnosis and treatments (Ospedale Pediatrico Bambino Gesù in Rome, Istituto Giannina Gaslini in Genova, and Azienda Ospedaliera Integrata Verona Italy);
- Retina vascular evaluation in SWS patients with OCT-A (Azienda Ospedaliera Integrata Verona Italy);
- Dissecting molecular pathogenesis and identifying new therapeutic targets in Sturge-Weber Syndrome (UCL Great Ormond Street in London, UK)

The Italy association is made up of three committees:

1) The Steering Committee (Antonella Perini, Laura Longaretti, Gianluca Ghiotto, Mameli Biasin, Elisa Bertone)
2) The Scientific and Steering Committees
3) Little patients with SWS

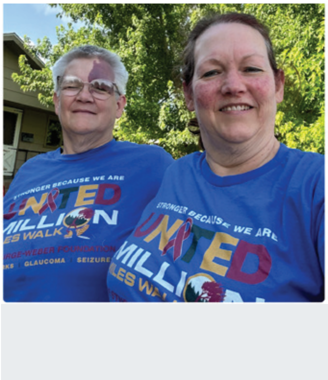
@sturge_weber_it

Special Delivery by Webster's World

One of our programs is to send our mascot, Webster all of the world for cuddles and comfort. We love to see the joy he brings to everyone's face! If you, your child, or someone you know is living with Sturge-Weber Syndrome and receiving any type of treatment and feel they could use the comfort of Webster bear, just let us know!


Bruno (1st trip to Italy)


Carson



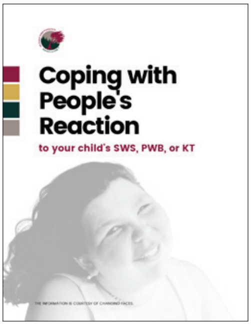
Jade


Nicholas (1st trip to Sweden)


Liam

Chelsey

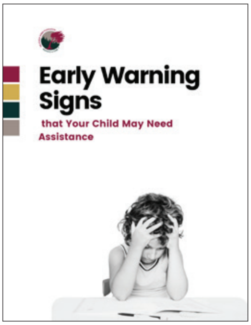
Newly Design Downloads



Coping with People's Reaction

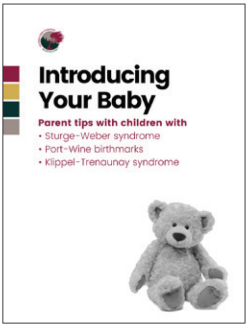
to your child's SWS, PWB, or KT

THE INFORMATION IS COURTESY OF CHANGING FACES



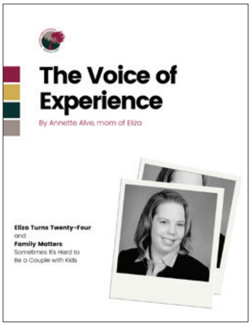
Early Warning Signs

that Your Child May Need Assistance



Introducing Your Baby

Parent tips with children with
- Sturge-Weber syndrome
- Port-Wine birthmarks
- Klippel-Trenaunay syndrome



The Voice of Experience

By Annette Alve, mom of Eliza

Eliza Turns Twenty-Four
and
Family Matters
Sometimes It's Hard to
Be a Couple with Kids

DOWNLOAD THESE FREE DOCUMENTS: *www.Sturge-Weber.org/new-to-swf/*

Tear out this mini poster and display it in a public place →

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Your donation is driving change

- ○ **YES!** I will make a tax deductible donation of $____________.
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- ○ 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.*

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City, State, Zip: ____

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Mobile Phone #: ____

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Let's Connect

Summer

Seize the Wave in Sea Isle City, NJ, Page 14

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