

A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

SEPTEMBER/OCTOBER
2020

MISSION ACCOMPLISHED!

WHAT'S YOUR PLAN?

TOOTING OUR HORN

CARE for the CAREgiver

1 YEAR
SEIZURE
FREE!
😊



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**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

September/October 2020

ON THE COVER:

DC Albert celebrates being seizure free for 1 year on July 18, 2020.

What's Inside . . .



Mission Accomplished!

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Double YOUR Donation

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Port Wine Birthmarks (PWB) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck. Sturge-Weber syndrome (SWS) is a rare congenital condition usually consisting of a facial port wine birthmark, glaucoma, and seizures, (although not all of these symptoms may be exhibited).

SWF POLICY STATEMENT:

In implementing the purpose of The Sturge-Weber Foundation to improve the quality of life for individuals

with SWS and their families, the Foundation will act as a clearinghouse of information, provide emotional support and facilitate research on PWB and SWS.

The Foundation will seek information regarding management and treatment techniques and suggestions concerning education and emotional support and will facilitate the dissemination of appropriate information.

If, in facilitating research on PWB, SWS and KT, the Foundation provides financial or other support to a particular research project, the Foundation will base its decision upon need, the Foundation's financial resources and medical advice.





The Victim or the Victor?

Choice. It's all about choice and discipline with a sprinkle of nurture. We've all read about people and even know people that have overcome insurmountable odds in life that could have made the individual a failure. I've always been curious about the impact one kind word or word of encouragement can have on an individual's life course. My wise old dad, MOO (Mighty Omnipotent One), always said if you didn't get a child by the time they were six the die is cast.

I'm realizing now that he meant knowing right from wrong. One can always gain more education and obtain new skill sets to improve your lot in life. One can seek out mentors to guide us in building worthy impactful lives and which remind us of our worth. Without a good moral compass though, an individual may miss out on many opportunities! I taught school before I had Kaelin. I always tried to instill in my kids that they were unique and worthy and no one else was like them. Some of their parents were extremely strict, some extremely lax and of course those in the middle but having an outside validation of their worth was always wanted and needed.

When you're dealing with a progressive rare disease, there are days, ok many days, when one can feel like a victim with no energy to get up and continue on because life is just too hard and too expensive and just plain unfair! The whole circle of comparison between your child is higher functioning than mine or your child walks and mine doesn't or your child's birthmark is less than mine is a spiral that has no good resolution nor does it imbibe confidence in your child that they can be victorious! One must be vigilant against staying a victim. It takes discipline but I believe our children with SWS deserve the very best of us and they deserve nothing less than as much victory as we can provide and imbibe!

With Faith, Hope and Love,

Karen Ball



CONNECT WITH KAREN

Founder | CEO

Every test in our life makes us bitter or better. Every problem comes to break us or make us. The choice is ours whether we become the Victim or Victor.





SINCE THE LAST BRANCHING OUT

SWF Began
It's 2020-2021
Fiscal Year on
July 1st

Myla's Mission
July 25, 2020

SWF Family
Game Nights in
July & August

SWF Clinical
Care Networks
Updates

What's Your
Plan Program
Began in August

SWF Research
Grant Program
Application
Process Began
in July

New Official
SWF Aware-
ness Facebook
Page Created in
August

Welcome Emily
Varga to Team
SWF!

A Message from the SWF Board of Directors Board Chair, Curt Stanton

The Board of Directors meeting on July 7, 2020 was held via teleconference with all Directors in attendance. The Board approved the 2020-2021 Annual Budget of \$572,600.



This budget reflects a modest increase in light of current economic conditions. I am thankful for each of you who have shared your donations with the Foundation to support vital programs and critical research grants. It is a very exciting time in our organization's history as we anticipate new clinical trials and further research with zebrafish and a SWS mouse model.

The SWF Clinical Care Network (CCN) is expanding to even more states enabling access closer to home with healthcare providers dedicated to treating patients with SWS, KT and Birthmarks. As you will see in the upcoming ROOT to RESEARCH supplement in December, many of the CCN sites are participating in the Brain Vascular Malformation Network (BVMC) which will revolutionize the pairing of clinical data and technology to create a comprehensive patient profile and natural history. The SWF International Research Network (SWFIRN) investigators have utilized the seed grant funding provided by your donations to garner more robust funding from the National Institute of Health (NIH). Dr. Nathan Lawson and Dr. Joyce Bischoff are now collaborating with the NIH grant after first meeting at the SWFIRN meeting in Delaware.

The Board looks forward to seeing you again in brighter and healthier times. Be well and I welcome your feedback and input on the SWF and the vital programs we deliver.





MISSION ACCOMPLISHED!

After having to completely reorganize the annual Myla's Mission for Sturge-Weber Awareness, the Speer Family once again pulled off an amazing fundraiser!



The event usually takes place in May during SWF's Month of Awareness. As you know, the nation was in paralysis from COVID-19. The event wasn't canceled but pushed back to July 25th and offered as a virtual walk and silent auction.



This opened up the registration to everyone involved with SWF - not just in the Speer's home state of Indiana.



A total of \$10,500 in donations and sponsorships was received from across the country!

HIGHLIGHTS:

- 135 Virtual Walkers
- 15-20 Physical Walkers
- \$1919 from Silent Auction
- 39 Sponsors



Through the hard work of the Speer Family and volunteers, SWF will be able to continue funding future research and programs for patients and caregivers.

The Foundation **thanks** the Speer Family, the volunteers, community and state of Indiana and donors for your individual support.





VIRTUAL SUMMER FUN!

Exactly, where did Summer go? Was it just us, or did Summer just morph out of Spring into one big long 6 month season?

This Summer became an opportunity for all of us to slow down a bit, be at home, not travel and try something new.

At that particular point in time, SWF's Family Game Night was created. A pilot program was launched to provide a carefree, come as you are, activity for members to participate in from one living room to the next.

Family Game Night was held once a month during June, July and August with free registration. Here's a summary of the outcome!

In June, we began with Bingo Night. Printable Bingo cards were emailed to participants and beans, buttons, even peanuts were used as markers. Our "Biggest Winner" was the Rasmussen Family and Karen Ball ended up being our "Biggest Loser".

July was Pictionary Night. There were 15 participants from Washington state to New Jersey. For a full hour families competed against each other to try and guess first what was being drawn on a computer screen!

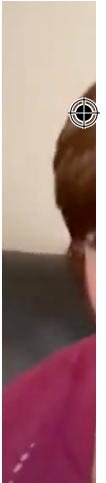


Maya Zidarich was the winner and Brian Fisher was the loser (sorry Brian).

Finally, Game Night in August was Word Scramble. Very much like Boggle, participants were given 2 minutes to come up with as many words possible with specific letters provided. Carola Smail was the winner. Olivia and Crystal Smail tied as our "losers", but they weren't really losers since they came up with some amazing words the rest of us never thought of!

Our winners and losers each received a \$25 Amazon gift card.

Stay tuned for more opportunities to gather together. Plans are forming for Game Night to make a come back in January! If you have ideas, please send them to our general email box at: swf@sturge-weber.org. We love hearing from you and sharing ideas.

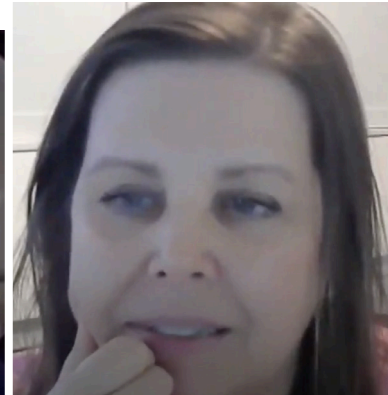
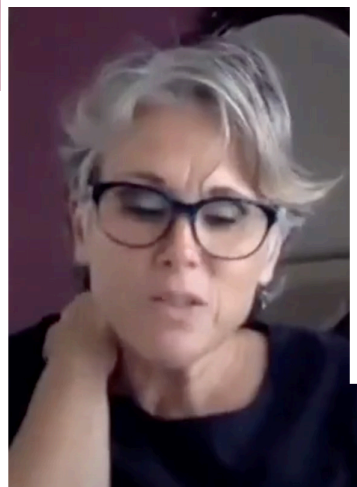
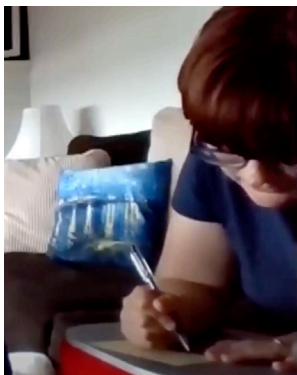




The Official SWF Awareness Page on Facebook

SWF now has its own **OFFICIAL AWARENESS PAGE!** It is directly connected to The Sturge-Weber Foundation's Facebook Page. This Group page is a public place created to share your questions, stories, pictures and videos. Any questions that are frequently asked will be added to our INSPIRE platform, swf.inspire.com, so the answers are available for future reference.

To register, simply answer the questions provided and access will then be provided. We can't wait to hear from you and continue to share as a community.



L-R: Carola, Olivia and Crystal Smail; Karen Ball; July Game Night Event; Susan Finnell; Debbie Lonergan





WHAT'S YOUR PLAN?

We are all experiencing an unpredictable season of life, now more than ever. Not only is there the existing condition of Sturge-Weber syndrome to handle, but now, everyday life is in question with the ever changing recommendations and mandates concerning COVID-19

What is school going to look like?

What is work going to look like?

What do I need to have in place to protect by child and family?

**So exactly,
What is YOUR Plan?**

During the month of August, SWF hosted conference calls for patients and caregivers to discuss the how, what and why having a plan is so important.

We heard some great ideas, thanks to Julie Terrell, Deborah Brewbaker and Annette Coutu. We also fielded many questions on “where do I even start”, to just connecting on our genuine concern as a rare disease community on being safe and vigilant.

Our response to your questions and concerns voiced during the August called has culminated into the “What’s Your Plan?” program. Throughout the year we will provide information and resources to guide you in creating your personalized plan for:

- Medical Team
- COVID-19
- School (elementary and beyond)
- Estate
- Work
- Special Needs
- Insurance
- and much more

Having plans in place will help not only you, but keep everyone else informed on expectations and emergency situations.

To follow is an article for *eParent* submitted for publication about this new program.





I want to tell you a story. Imagine for a moment you just had a new baby and you're told that your new baby has a rare disease called Sturge Weber syndrome with which only 1 in 50,000 babies are born. The news is unbearable and you try to wrap your hands around the diagnosis and what could it mean. It is very overwhelming and your mind is so stuck on what could go wrong. This little baby has no idea of what is or what will happen but as a parent you have so much to think about. You begin to research, you begin to hire the right people and without you knowing it a plan is born.

Fast forward to today. How many times have you read or heard the words "In these unprecedented times..." recently? No one could have predicted this would happen. But here we are, living through a worldwide pandemic and all of the challenges it presents for everyone. The social distancing is starting to feel like social isolation, and everyone is wishing they could go back to life as usual. No group of people feels that more poignantly than those of us who live with, care for, have special needs or are already medically fragile. This five-month long interruption (with no crystal-clear end in sight at the moment) is taking its toll and affecting the health and wellbeing of an estimated 15% of the population. And when you add in the people who care for them, that adds up to a lot of people feeling the stress of a quarantine and an anything-but-routine schedule.



In addition to dealing with the interruption in services that we've all experienced over the last five months, a lot of us are now finding ourselves in the position of having to create back-to-school plans. Or one could even say back-to-life plans. Special Needs communities, whether a rare disease like the Sturge-Weber, or a more well-known communities like autism and MS, you know that there are so many moving parts. From the day our children and adults were diagnosed we knew our lives would be different and we learned quickly that we have to do more than other parents and caretakers. We have to plan, educate ourselves, and as I often say "become a specialist or advocate" for our family member. What does that look like? It can look very different in each of our worlds but here is what we have in common: We are all resourceful. We look outside the box, and when one door closes we often ask "if we can't do that, what can we do instead?" Funny enough, if you think about it, the rest of the world is now being forced to do what we have been doing every day. They would do well to look to us to learn about patience, and how to depend on themselves





rather than on others, and honestly realize every day there are necessary risks to live, and how to avoid the **unnecessary risks**. That is where this article began because this climate is what we are good at doing and we should all be proud to say we can do this.

Now our environment is changing. Sure, it will be quite different from previous years due to masks, social distancing, class size, lack of in-person services, and many other factors that we may not even be

aware of yet. Now is the time that we continue to plan and evolve as the climate changes.

So how do we prepare for the unknown? Well, it's a bit of work, but the peace of mind it will bring you is well worth the effort. A plan has many moving parts. When you make a plan you want to make a plan that is easy, understandable and to be used over and over again.

Let's get started: What do you need to accomplish?

Step 1: Define the situation you need to overcome. You can create a plan for anything - included but not limited to school virtual v in person is on everyone's minds right now. The plan could be for a medical plan or getting a job, going to college and more.



Step 2: Make a checklist of what you need.

When my daughter had a seizure and I began to panic I remembered that, thanks to my doctors, we had a plan in place. It all began with a list in my head of all the things that happened when I called 911 that day. A checklist is so important for many reasons: It will keep you on track, you can add and subtract steps as needed, and you have something tangible that allows you to go on

autopilot if you need to. The checklist should be kept readily available for when it is needed.

Step 3: Once the checklist is complete, make a list of who needs to be involved in your plan.

Step 4: Talk to the new team and set up a time to train them and make sure they understand the importance of their role and where they fit in.

Step 5: Make sure you have all the pertinent information and items in one spot like a binder, on the refrigerator, somewhere where everyone knows where it is. You may need several copies as well depending what your plan is for and who is involved. For example, my daughter has her health plan





in a bag with her medicine that she carries with her when she is at school, a copy in the nurse's office and in the principal's office.

Step 6: Implement your plan and make sure everyone is bought in and understands what is asked of them.

Step 7: Check in on your plan periodically throughout the year to make sure it still makes sense and update the plan where needed.

Step 8: Yearly check in with your medical team or any team that you work with to keep the plan up to date and make necessary changes.

Step 9: Retrain and refresh the team each year. In the example of a health plan it is important to train the new teachers, and any time the team changes so everyone is on board with the plan and understands the expectations.

Step 10: Always thank everyone involved for taking the time to be a part of your team.

This plan can be used for any situation you will encounter. One more part of the plan that we haven't talked about is YOU! Remember that no matter what happens it is ok to be overwhelmed, scared, mad and upset. Just remember the 3 day rule: first day to wallow and have a pity-party if need be, 2nd day to reach out for support, resources, and to get a plan or update your plan, and the last day to implement the comprehensive plan to once again right your world and the loved ones you uplift! Take time to enjoy your family and yourself and take care of you too. We will all get through this pandemic, we have to.

That reminds me, when I am talking to a new family I always say, "Congratulations on that new bundle of joy! I need you to take a deep breath and know it will be ok. Now let's get you a plan in place so you can feel better!"

So remember when you start to feel the uneasiness of this pandemic or any situation that seems so hard to overcome, remember take a deep breath and ask yourself "What's Your Plan?" This will all be ok.

Julia Terrell, Community Relations Director
jterrell@sturge-weber.org





TOOTING OUR HORN!



Thanks to our donors and the hard work of members, volunteers and staff, SWF continues to make improvements to better serve our community!

GuideStar Platinum Level - SWF achieved the Platinum Seal of Transparency on **GuideStar**, an information service that reports information on non-profit organizations. This means we get 2 times more views than other profiles, impacting awareness, and helping the non-profit sector shift from a destructive focus on overhead ratios to a focus on making progress and getting results.



New Staff Member to TEAMSWF

Hi Everyone! My name is Emily Varga and I am the newest member of The Sturge-Weber Foundation. I have recently graduated from Rowan University with a Public Relations and Advertising degree. I have been working with the Foundation since the start of my internship in January. I am glad to be working with the team and ready to start my new role as the Social Media and Development Associate. This Foundation has taught me so much already and I'm excited for what's ahead!

The Sturge-Weber Foundation's New Professional Task Forces

We are excited to announce the formation of Professional Task Forces within our Clinical Care Network that will lead efforts in accomplishing goals set annually. Please welcome the following leadership for each Task Force!

- ***Transition Task Force*** - Carol Roethke-Greene, RN, Nemours Hospital for Children
- ***Ophthalmology Task Force*** - Dr. Lauren Blieden, Texas Children's Hospital
- ***Dermatology Task Force*** - Dr. Esteban Fernandez, Nationwide Children's Hospital
- ***Neurology Task Force*** - Dr. Dave Shahani, Cook Children's Hospital



We thank these professionals for being an integral part of the SWF team, and volunteering their time to help us accomplish great things!





Coming Soon: The NEW SWF Online Store!

The SWF is currently working on a new online store for all sorts of great products you may purchase to spread awareness. From t-shirts and water bottles, to caps and Webster Bear! You will have the freedom to pick and choose your own personal style from many products and SWF promotional images. More to come on the GRAND OPENING!



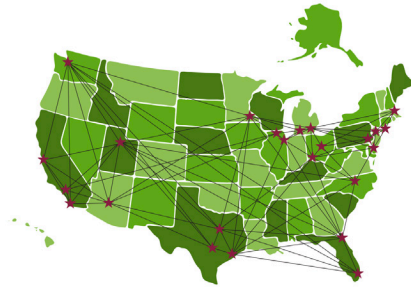
Doubling YOUR Donation

Many employers sponsor matching gift programs to match charitable contributions made by their employees. Gifts from employees', spouses, retirees, even friends, may qualify for a match. The SWF now has an automated program on its Matching Gifts Page that will search for your employer and provide the steps to have your donation matched. Now your donation can have an even bigger impact! Questions? Please contact Maristel Aguilar, maguilar@sturge-weber.org



The SWF Clinical Care Network Updates

The SWF continues to update its on-line Clinical Care Network information to better serve our community. We have also added new centers to the network which will hopefully provide easier access for patients and caregivers. Please visit our CCN PAGE and click on the US map to follow links to the latest information on centers and professionals at your service!



DON'T FORGET! New Peer-to-Peer Fundraising Platform

This year, we introduce our new Peer-to-Peer Fundraising Platform, *JustGiving*. If you are planning a fundraiser and need a platform to take donations and also have team members join your fundraiser, *JustGiving* is easy to use and can be personalized with personal photos and messaging. It is also tied to our merchant account for easy and secure transactions. Check it out here by watching this quick TUTORIAL.





CARE

connect. accept. respect. engage.



This is the year of C.A.R.E. Through C.A.R.E. we connect, accept, respect and engage within our community and the general public. CARE is far reaching and the benefits are infinite when we all do our part. It goes beyond the medical CARE of the patient and includes caregivers, professionals who help both patient and caregiver, neighbors, friends, even the new person you meet tomorrow.

This year we will take a closer look at CARE and take action to make sure we ALL provide and receive the care we ALL need.

CARE for the CAREgiver

“Tonight was so, so hard. Poor Allana, even sleeping is hard for her.” Allana is affected by a myriad of issues related to Sturge-Weber syndrome. Clearly tired, she just could not fall asleep. As soon as she doses off to sleep she is abruptly awakened by who knows what and is irritable and pulling at her trach. Eventually, with a second dose of Seroquel, Allana settles down in a decent deep sleep. Her mother, finally gets 4 hours of sleep after being up for 48 hours straight.





ACCEPT.

Caregivers – mothers, fathers, siblings, grandparents, friend and neighbors, they ALL accept the challenge of caring for those with SWS. They accept willingly the sacrifice of a good night's sleep, a thriving career to stay home to ensure the best care is provided. They continuously seek out new information and better treatments to provide a better quality of life for their loved one.

RESPECT.

Too many times, caregivers find themselves alone, fighting a battle that others cannot understand or feel overwhelmed by. There is a deep need caregivers have to know there is someone they can depend on and place their trust in to go the distance. SWF fills that void for caregivers by providing a network of professionals who specialize in the treatment and research of SWS. They understand the complexity and the obstacles for both patient and caregiver. For many, they have made this specialty their life's work.

ENGAGE.

It's clear, while the SWS patient is in need of care, so is the CAREgiver. Whether it be the immediate family, the surrounding community or even the professional medical team, CAREgivers matter just as much. SWF is focused on every aspect of CARE for everyone that is involved.

This year, join us as we provide CARE for those that give so abundantly. CARE for the CAREgiver is a part of the SWF C.A.R.E. campaign to raise funding for more comprehensive online learning, social media engagement, personal support, and research which drives positive change for patients and caregivers.

Stories like Allana's are too frequently conveyed to us. It is our desire to change outcomes, and provide the assistance needed to have the best quality of life for ALL. Many opportunities are coming soon to show support for the Caregivers in your life or someone you know.

**CARING today will provide CURES tomorrow!
Stay tuned!**





FROM OUR COMMUNITY



POSITIVE INSPIRATION - NATASHA MATT!

I was born in Moscow, Russia on September 25th, 2003 and when I was 15 months old, I was adopted by my American parents. More than likely, the reason I was put up for adoption in the first place was because of my Port Wine Birthmark. In Russia they don't have nearly as much medical technology, resources, and knowledge for treating Port Wine Birthmarks as in the United States.

Therefore, when I was born with a Port Wine Birthmark, my birth mother probably decided to put me up for adoption in hopes that Americans would adopt me and I could get the treatment I needed for my face.

I tend to look at my birthmark in a positive way more so than a negative. Sure, it can be annoying to have it at times, but I might have never been able to come to the US if I didn't have it. I have been receiving laser treatments on my face ever since I was adopted and brought to the US.

Dr. Burton is my doctor at Duke Hospital in my home state, North Carolina.

Over the years, my Port Wine Birthmark has lightened, but still continues to cover almost the entire left side of my face.



I love surfing, swimming, spending time at the beach, dancing, singing, acting, playing soccer, cheering, skiing, gardening, cooking, hiking, playing with my two dogs, and spending time with my friends and family. Even though my Port Wine Birthmark continues to be on my face, even after years of treatment, it hasn't stopped me from being happy and doing all the things that I enjoy.

STRENGTH & COURAGE - DANIELA FERNANDEZ

Daniela Fernandez, Mexico City Hi, my name is Daniela and I am from Mexico City. I am 29 years old and





when I was born, I was diagnosed with Sturge-Weber. Throughout the years it's been difficult for me and my family because of the number of treatments needed for my condition. It has been a real struggle for me personally, maybe because of how society is in Mexico. Many people in my country bully or even despise others who look differently than themselves and believe they are better than you.



I really am. I am working hard to recover the courage, strength and confidence I lost while I was younger.

Recently I received a diagnosis that I have Klippel-Trenaunay, not Sturge-Weber syndrome, which is also a vascular malformation that causes skin tissue overgrowth, a port-wine birthmark and severe pain in the overgrowth areas. My PWB covers the left side of my body, but the overgrowth is in my right leg.

I now look at my disease in a positive way and not allow negativity to control me. Day by day, I try to unlock a "step" that has impeded me to grow as a person. Regardless of my physical situation, I am a whole person with a lot to offer! I thank my family and true friends who have encouraged me to see life differently than before!

Now that I am 29 though, I want people to know the real me, who

In Loving Memory . . .

Lakshmi Menon was probably the oldest SWS individual in India. She passed away on 5th August in Mumbai due to Sepsis. She was 66.

Lakshmi was a voracious reader despite having lost one eye when she was a teenager. She went on to do a masters in library science and worked as a librarian in the Mumbai university college. She was a medical activist and a born fighter.

She flew down from Mumbai to meet my family in Feb, 2017 and to see how we could make the Indian SWS group more active. She was a storehouse of medical info.





BACK TO SCHOOL!



L-R: Kaylee Embrey (7th grade);
Derrian Stormer; Jordyn Taylor





L-R: Evan Cragin; Gavin Credle; Chloe Nadler





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