

WHAT'S YOUR PLAN?



THE STURGE-WEBER FOUNDATION



MISSION ACCOMPLISHED!

Congratulations to Molly, Thomas and Myla Speers for another successful Myla's Mission Walk for SWS Awareness held on Saturday, July 25th. Through participation "virtually", **\$10,500 donations and sponsorships** were provided from across the country including bidders at the online Silent Auction. The Speer's family and volunteer's hard work has provided funding for future research and educational programs for patients and families.

Below are just a few highlights from the event:

- A total of 135 Virtual Walkers
- A total of 15-20 walkers walked physically with the Speers
- Silent Auction - \$1919.00 received
- A total of 39 sponsors! Thank you Indiana!

Thank you to the Speers, volunteers and ALL participants for making this year's event successful. Way to Go!



Oh, What A Summer!

We cannot believe that summer has almost come and gone already. It was challenging to find things to do this summer by not traveling and continuing to keep social distance! SWF Game Nights was definitely an improvement on another evening of TV or video games.

In June, we began our "virtual game night" adventure with Bingo. Bingo cards were emailed to all participants that were printed out. Prizes for the Biggest Winner and Biggest Loser were given to the Rasmussen Family as the Biggest Winner and Karen Ball, the Biggest Loser.

In July, we had Pictionary Game Night with 30 participants! Talk about crazy and fun! For a full hour, families tried to guess words and phrases while watching pictures being drawn on a computer screen or smart phone. Yes, it was different, but doable! Maya Zidarich was the Biggest Winner and Brian Fisher was the Biggest Loser!

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



Let Your Company Double or Triple Your Impact!

Many employers sponsor matching gift programs to match charitable contributions made by their employees. Gifts from employees' spouses, retirees, even friends, may also qualify for a match. **Check to see** if your employer offers a matching gift program. If they do, you can automatically apply for your donation to make a bigger impact online!

QUESTIONS? Contact Maristel Aguilar, maguilar@sturge-weber.org



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

Stay tuned for more opportunities to gather together and have some fun. Plans are forming for Game Night to make a come back in January! If you have some ideas, send them to swf@sturge-weber.org. We love hearing from you!

Have a great back to school season, however that may look for you. Be safe and stay healthy!

Neurology Task Force

Dr. Dave Shahani
Cook's Children's Hospital

We thank these professionals for being an integral part of the SWF team and look forward to we can accomplish as a team!



SWF Clinical Care Network Updates

SWF continues to update its online Clinical Care Network information!

Please check out the updates made in July on the [CCN section](#) for patients on our website. The latest updates are:

The University of Utah School of Medicine, Salt Lake City, UT

[Bascom Palmer Eye Institute, Miami, FL](#)

[Cincinnati Children's Hospital Medical Center, Cincinnati, OH](#)

[Rady Children's Hospital, San Diego, CA](#)

[University of CA - Irvine, Irvine, CA](#)

[University of CA - San Francisco, San Francisco, CA](#)

[UNC Children's Hospital Chappell Hill, Chappell Hill, NC](#)

All centers are being updated, so keep coming back as we continue to increase our information and keep you more informed. As always, if you need to discuss a special situation or have questions, please contact our Community Relations Director, Julia Terrell, jterrell@sturge-weber.org.

We've come a long way - **check it out!**

We are in an unpredictable season of life, now more than ever. Not only is there the existing conditions of Sturge-Weber syndrome to handle, but now, lifestyle changes that are changing daily to combat the spread of 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 my child and family?

So many questions. So, what's your plan?

Join the Sturge-Weber Foundation for What's Your Plan Conference Calls. Ask questions, share your experiences, or simply listen as we share information on ways to prepare and plan ahead.

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 THE STURGE-WEBER FOUNDATION

Tuesday, August 18th, 7:00 PM (CST)

What's Your Plan - Back To School Shopping|What Does That Look Like?

To join us - follow the link below using desktop/laptop computer or iPad/iPhone:

Join from PC, Mac, Linux, iOS or Android: **CLICK HERE**
For the best audio experience, please use computer audio.



SWF FACEBOOK UPDATES!

THE NEW OFFICIAL STURGE-WEBER AWARENESS PAGE!!

The Sturge Weber Foundation now has its own **Awareness Page Group!** It's a public place created to share your questions, stories, pictures and videos. The SWF is always here to assist you when you need us. Any questions that are commonly asked questions will be added to our other platform swf.inspire.com so the questions can be stored for future reference. Now it is your turn to share - we hope to hear from you soon.

THE STURGE-WEBER FOUNDATION FUNDRAISING BUTTON

The Sturge-Weber Foundation Facebook page now has a fundraising button. You can now create a fundraiser from our page as well as your personal page. This will increase coverage for your fundraiser to all the SWF followers! **Check it out** and give it a try!



NEW SWF ONLINE STORE!



AUGUST SPOTLIGHT

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.

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

The Sturge-Weber Foundation is working hard on an all new **SWF Online Store** with products from t-shirts, coffee mugs, to caps or leggings! You get to pick from a variety of merchandise and logo to create your style! More details to come. Check for emails and our website for our grand opening!

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!



REGISTER FOR PeDRA VIRTUAL CONFERENCE

The Pediatric Dermatology Research Alliance (PeDRA) will be holding it's Annual Conference virtually, October 22-23, 2020.

Registration is free to patients and families. PeDRA is working on new patient-focused activities this year, including a mini-Camp Wonder for the kids and guided poster tour for the adults. With the virtual format we also expect to improve our inclusion of patient representatives in research-focused breakout sessions.

We encourage you to register for this annual conference. It is a great opportunity to see the latest in research and treatments in pediatric dermatology, as well as connect with other patients, families and professionals.

REGISTER



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Help us keep you informed - stay connected!

If you have any changes in email or primary mailing address, let us know via email:
swf@sturge-weber.org