From Us to You - THANK YOU!

The SWF Staff and Board of Directors THANK YOU for your continuous support to the SWF cause. Together we are making a daily impact!

WE WISH YOU A HAPPY AND SAFE HOLIDAY SEASON!

ROCK FOR A CURE!

The Saden Family

In the month of November, Kris and Kellie Saden held their annual "Rock for a Cure"Karaoke fundraiser. They raised over $6,000 for SWS! The local newspaper even did a feature story on the event. SWF members who were in attendance included Curt and Pam Stanton, along with Eric Benson, Donna Tilley and their son, Ty.

Because of great community support, the Saden's received a number of donated items which were used in a Silent Auction at the event. Thank you so much Kris and Kellie for your continuous support and wonderful impact!

Let's hear it for the Saden Family . . .

YOU ROCK!

IN REMEMBRANCE - PEARL DAVIDSON

The SWF received a letter from Samantha Davidson, Milford, DE, telling us the sad news that her grandmother Pearl, had passed on October 2nd. just short of her 93rd birthday.

While we mourn the death of Pearl Davidson, we celebrate her life of service, love and humble caring. While being a wife and mother she became the legal guardian in 1966 of her granddaughter Samantha, who was born with SWS at a time when little was known about treating the disorder and little to no support services were available.

Pearl became the whole support of her infant granddaughter. Pearl and Samantha joined the SWF in 1991 and became active and knowledgeable members, attending the International Conference in Hershey in 2005 and the Philadelphia Education Day in 2010. Pearl always sought information and suggestions to help them cope with SWS and was a good teacher and advocate for Samantha. Samantha is an energetic letter-writer, not bashful about writing to Congressmen as well as to the SWF.

They were active and generous members of their local Methodist church and always interested in the activities of the SWF although they had no computer. Pearl leaves 2 adult children, 5 grandchildren and 7 great-grandchildren in addition to many SWF friends who loved her gentle concern.

YEAR END CAMPAIGN UPDATE

Giving Tuesday was a great success and Webster's Wish List is being fulfilled! **SWF has received over $10,500 through year end campaigns.** BUT WAIT, THERE'S MORE! This total doesn't include the generosity of our members who ran Facebook fundraisers, their donations, and the matching donations from Facebook and PayPal! **What an awesome example of working together!**

Stay tuned for a report after the New Year as we receive additional information on Facebook fundraising totals. Thank you all for continuously stepping up for a great cause!

> *"Contacting the Sturge-Weber Foundation made me realize I wasn't alone. I now realize there are others to help me when I need answers and talk about my experiences."*

WE STILL NEED YOUR HELP!

SWF still needs $20K by year end to continue to fund the budget for 2018-2019.
Send in your Year End Donation and make sure it is postmarked December 31, 2018!

Follow us on Facebook and share your story to friends!
Your story is what makes the biggest impact!

YEAR-END GIVING

As this year draws to a close, many choose to make charitable donations during this time of year. Here are just a few reminders about year-end giving:

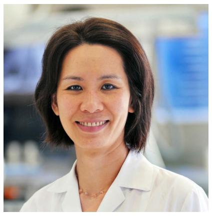
- To receive a 2018 tax-deduction on a charitable contribution, it must be postmarked, or given online by December 31, 2018.
- You may make charitable donations by check to the Sturge-Weber Foundation, or by credit card by **clicking here**
- The Foundation also accepts donations of stock, bonds mutual funds, real estate and automobiles! If you would like to donate any of these, please contact the SWF home office at 973.895.4445 or by emailing Susan Finnell, **sfinnell@sturge-weber.org**.
- If your employer has a charitable gift matching program, make sure you notify them of your donation and double your gift!

Thank you for your continued support. Without donors, we would not be able to continue the invaluable work done to further research and assist others with an SWS diagnosis, PWBs and K-T.

July 18-20, 2019 | Wilmington, DE
Nemours Alfred I. duPont Hospital for Children
Registration Opens January 2019

NEWS IN RESEARCH

The Sturge-Weber Foundation Announces Thuy L. Phung, Ph.D. as New Director of Pathology Strategies (DPS)



This appointment fulfills one of SWF's goals to advance research of Sturge-Weber syndrome (SWS). The primary goal is to establish a tissue bank in which patient tissues are collected and stored for research. SWS patients have the authority to help steer the course of research by participating in this collective effort. Dr. Phung will be the lead in all pathology collection, storage and tissue requests for research. "We are excited to have Dr. Phung accept this new position. This will fortify our efforts to ensure the SWF global team of diverse researchers will create lasting impact", stated Karen Ball, SWF Founder and CEO. SWF Chief Scientific Officer, Dr. Jonathan Pevsner, Ph.D. stated, "We are delighted to welcome Dr. Phung to this new role in the Sturge-Weber Foundation. She brings passion, excellence and a broad range of expertise that will help us make progress toward solving Sturge-Weber syndrome."

READ ENTIRE PRESS RELEASE

Colette Bichsel, PhD Receives $10K One Year Grant From The Sturge-Weber Foundation for New Research Project

Colette Bichsel, PhD, at the Vascular Biology Program at Boston Children's Hospital/Harvard Medical School has been awarded a one year $10K grant from SWF to support the research project, ***"Altered GNAQ Activity in CM and SWS-Affected Endothelial Cells May Lead to An Abnormal Response to Shear Stress".***

The aim of this project is to generate endothelial cells having the mutant GNAQ R183Q gene product, and to expose them to shear stress. This research is intended to discover the consequence of the GNAQ mutation on endothelial cells, possibly explaining how abnormal blood vessels form in Sturge-Weber syndrome.

DID YOU KNOW? SWS AND GLAUCOMA

On Inspire Sturge-Weber Connection, SWF had its second Ask the Expert with Dr. Levin, Pediatric Ophthalmologist at Wills Eye Institute. Here is some important information he provided about glaucoma in SWS patients:

If the port wine mark is touching the upper or lower eyelid, then the child is at risk for glaucoma and should begin seeing an eye doctor (preferably a pediatric ophthalmologist) in the first 2-3 weeks after birth. If they eye looks bigger or cloudy, or there is a lot of tearing or aversion to bright light, then the appointment needs to be made even more quickly or promptly should these signs develop any time during infancy. Monitoring should continue more frequently during infancy and gradually spacing out, if all is well, to perhaps every 6 months once the child is about 2 years old assuming no glaucoma has developed.

Remember that glaucoma in Sturge-Weber can occur anytime during life. There is one variant in infancy that may even be present at birth and then another variant that is more likely from about 4 years old to 14 years old. There is even an increased chance of getting glaucoma as an adult. So, lifelong monitoring is essential. Early diagnosis and early treatment of glaucoma offers the best outcome. Remember also that glaucoma after the first few years of life often has no symptoms at all and if one waits for symptoms it is often too late.

WE ARE BETTER TOGETHER. SUPPORT!

STAY CONNECTED:

SWF CONNECTION by INSPIRE