

The Sturge-Weber Foundation July 2020 eNew



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TOOTING OUR HORN!

The Sturge-Weber Foundation achieved the 2020 Platinum Seal of Transparency on GuideStar, an information service that reports information on non-profit organizations!

What's Special About Getting to Platinum?

- Nonprofit Profiles with a Platinum Seal get 2x more views than other profiles - impacting awareness!
- We help the sector shift from a destructive focus on overhead ratios to a focus on making progress and getting results





Good News On Brain Research Bills

On Monday, July 14th and Tuesday, July 15th the House of Appropriations Committee passed two bills with funding for the research of brain disorders.

LHHS: Monday, the Committee pass the Labor, Health and Human Services, Education and Related Agencies appropriations bill, including \$100 million for the BRAIN Initiative. The BRAIN Initiative is

A Message from Curt Stanton, SWF Board Chair



The Board of Directors meeting on July 7, 2020 was held via teleconference with all Directors in attendance. The Board approved the FY2020-21 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.

Initiative. The BRAIN Initiative is intended to revolutionize the understanding of the human brain, helping researchers understand more about brain disorders and accelerate the development and application of innovative technologies to treat, cure and prevent brain disorders. The bill also included \$2.5 billion in funding for NINDS and \$2.1 billion for NIMH. Additionally, the bill included \$5 billion in emergency funding to support biomedical research, including support for current grantees to cover the shutdown costs, startup costs, and costs related to delays in research in 2020 due to the COVID-19 pandemic.

CJS: Tuesday, the Committee passed the Commerce, Justice, Science and Related Agencies appropriations bill, including \$8.5 billion in funding for the National Science Foundation, representing a \$270 million increase over FY2020 appropriation. Of the \$8.5 billion, nearly \$7 billion is allocated for research and related activities - a \$230 million increase.

The full House of Representatives is expected to vote on the LHHS and CJS appropriations bills within the next two weeks.

The SWF Clinical Care Network (CCN) is expanding to even more states enabling you to have access closer to home with healthcare providers dedicated to treating patients with SWS, KT and Birthmarks. As you will see in the upcoming Roots to A Cure research supplement, 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 Institutes of Health (NIH). Dr. Nathan Lawson and Dr. Joyce Bischoff are now collaborating with the NIH grant after first meeting at the last SWFIRN meeting in Delaware!

The Board looks forward to seeing you again in brighter and healthier times as the staff plans the next International Conference in Texas in the summer of 2021. Be well and I welcome your feedback and input on the SWF and the vital programs we deliver.

P.S.

This fiscal year, the SWF will adopt a donor acknowledgement program (similar to a church) which will provide donor tax receipt letters at the end of the year. This will make it easier for you to file taxes and optimizes every dollar the foundation receives. We will also be sending periodic handwritten notes throughout the year to our donors, because we want you to know how very special you are to us.



SWF Clinical Care Network Updates

There is nothing more important than having a resource you can rely on when seeking a medical center or specialist. SWF is continuously gathering information on its Clinical Care Network centers and specialists in an effort to provide you the most up to date information.

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

[Boston Children's Hospital, Boston, MA](#)

[Detroit Children's Hospital, Detroit, MI](#)

[Dell Children's Medical Center, Austin, TX](#)

[Mayo Clinic - Minnesota, Rochester, MN](#)

[Nationwide Children's Hospital, Columbus, OH](#)

[Nemours DuPont Hospital for Children, Wilmington, DE](#)

[Seattle Children's Hospital, Seattle, WA](#)

[Texas Children's Hospital, Houston, TX](#)

[Wills Eye Hospital | Thomas Jefferson University Hospital, Philadelphia, PA](#)



SWF FAMILY GAME NIGHTS

Family game nights are 6-7 PM Central (Eastern - 7-8 PM; Mountain - 5-6 PM; Pacific - 4-5 PM)

ONE NIGHT LEFT - IN AUGUST!

August 12th - World Scramble Night

Prizes for the biggest winner and loser!

Please register by following the link below!

Once registered, we will send you the RingCentral connection information (you will be prompted to install the RingCentral app upon connection), along with any materials you will need to play the game.

Let's Play!



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.



MEET JULY'S 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.

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.



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!**

Join us, July 25, 2020

Myla's Mission VIRTUAL SILENT AUCTION!

All proceeds go to the Sturge-Weber Foundation



Founded by Thomas and Molly Speers,
for their daughter, Myla Speers.



Join us for Myla's 1st Virtual Silent Auction!
Great items to bid on!

When: Saturday, July 25, 2020
Time: ALL DAY
Register: <https://event.gives/mylasmission>

Once you have registered you may view auction items as they are added. Actual bidding starts on July 25th.

QUESTIONS? Send them to mylasmissionsws@gmail.com



IN JULY, DID YOU KNOW . . .

National Sunglasses Day

<https://www.thevisioncouncil.org/members/national-sunglasses-day>



National Hydration Day 2020

<https://nationaltoday.com/national-hydration-day/>

1. Set Reminders
2. Tell someone to be hydrated too
3. Make Tasty infused water

<https://www.mayoclinic.org/diseases-conditions/dehydration/symptoms-causes/syc-20354086>
