



Susan Finnell <sfinnell@sturge-weber.org>

## 2020 SWF May eNews

1 message

The Sturge-Weber Foundation <swf@sturge-weber.org> Tue, May 19, 2020 at 8:00 AM  
Reply-To: kball@sturge-weber.org  
To: Susan Finnell <sfinnell@sturge-weber.org>



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## UPDATES & EVENTS



### AMAZING IMPACT. SPEECHLESS GRATITUDE.

GivingTuesday | NOW was held on Tuesday, May 5th, to help non-profit organizations across the country, remain viable during COVID-19. Donations received will be matched by the organizers of the event - Non-Profit Hub, Do More Good, Firespring and of course, GivingTuesday.

**Through your generous giving, SWF raised \$4,870.00!**

**Here's the breakdown:**

- 9 donors provided scholarships for children to attend the 2021 International Family Conference



**\$4,870**

- 11 donors provided for 1 hour of research and lab supplies
- 9 donors provided for resources and counseling for newly diagnosed families
- 5 donors provided for Webster to go home with a child patient undergoing surgery or treatments

Thank you so much for your support. Let us not forget those of you who also forwarded our fundraiser to your friends and families. Without ALL OF YOU, getting the word out, making others aware, providing support, WE can not continue our mission.

**Amazing EVERYONE!**

## MONTH OF AWARENESS. STILL GOING STRONG!

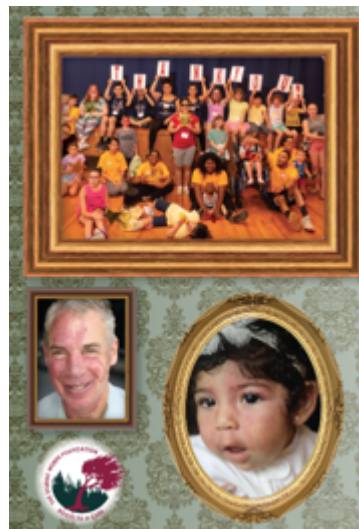
We are over half way through the month of May already! So far you have met 19 SWS families and heard their amazing stories. This community has such a great story to tell . It is through YOUR stories the "general" public learns more about SWS, realizes its impact on so many lives and how easy it is to make a difference whether through sharing stories with others or actually getting involved and becoming a part of the process through funding research and patient assistance.

***By the end of May, we will have 31 stories! Thank you Witney Arch and Julia Terrell for your work in providing a way for families to tell their story and getting it out there!***

**Don't forget, we still have the SWF UPENN Virtual Bike Ride through June 13th. It's still not too late to participate. For details, click the link to the right - "Let's Ride". UPENN has weekly challenges for those participating and there will be a virtual ride party on June 13th.**

Every effort made by each of us truly makes a difference. This is YOUR month. Although we all are at different stages within the COVID-19 situation, there IS a captive audience out there, so get out there and capture it!

**WE appreciate YOU!**



### Let's Ride



### RDCRN COVID-19 SURVEY OPPORTUNITY

Research survey for rare disease patients and their families about impacts of COVID-19

Rare disease patients or their caregivers are invited to complete a 20-minute online

### **UPDATE: NEW JERSEY DEVILS GAME DAY**

Although all SWF Patient Engagement Days had to be cancelled due to COVID-19, we have good news! The New Jersey Devil's are honoring our event tickets and we will be able to reschedule it during the 2021 season. Additionally, they will be providing us with a New Jersey Devil's hockey puck as a give away for those who sign up for the event. Stay tuned!

In the meantime, check out this great downloadable activity booklet for kids!

### **Fun Activities!**

survey from home about the ways the novel coronavirus pandemic is impacting people with rare diseases and their families.

Impacts can be related to physical health, emotional health, availability of supplies, access to care, or other problems. Your responses may help researchers understand the impacts of COVID-19 on the rare disease community.

The [Rare Diseases Clinical Research Network](#) (RDCRN) is conducting this study. The network is funded by the National Institutes of Health. It includes 23 research teams working to advance diagnosis and treatment of groups of rare diseases.

To complete the survey or learn more, [visit the study page here](#). Questions? Email the study team at [rd.covid19@cchmc.org](mailto:rd.covid19@cchmc.org).



### **CCN UPDATES**

SWF is in the process up updating SWF Clinical Care Network Center information on the website. Currently we have updated information on the following centers - photos of physicians and brief bios, contact phone number, email and physical address. The following centers are currently updated and more are on the way!

Detroit Children's Hospital - Michigan

Boston Children's Hospital - Massachusetts

Cooks Children's Medical Center - Texas

### **SWF CCN**



## Father's Day is Coming - Sunday, June 21st!

Send us your "Dad" jokes, good or bad!

For Father's Day, SWF is compiling a montage of father's and their "Dad" jokes. Please send photos or videos with your dad telling his favorite jokes!

Submit jokes to [swf@sturge-weber.org](mailto:swf@sturge-weber.org) by Friday, June 12th.

Questions? Contact [sfinnell@sturge-weber.org](mailto:sfinnell@sturge-weber.org)



## GRADUATION TRIBUTE 2020

Calling all pre-schoolers, kindergarteners, 5th graders, 8th graders, Seniors and college grads! Send us your photo/video and where you are graduating from!

SWF will be commemorating graduates of all ages during the month of June on social media and in the June/July Branching Out issue.

Send photos/videos to [swf@sturge-weber.org](mailto:swf@sturge-weber.org). Questions? Contact [sfinnell@sturge-weber.org](mailto:sfinnell@sturge-weber.org).



## ASK THE EXPERT on INSPIRE

Join us May 18th-22nd for "Ask the Expert" Caring for Sturge-Weber Patients During COVID-19.

### Guest Experts

Karen Ball  
SWF Founder and CEO  
Crystal Elliers  
SWS Parent, Teacher,  
SWF Board Member  
Dr. Jeffrey Loeb  
SWF Chief Clinical Strategist  
Dr. Jonathan Pevsner  
SWF Chief Scientific Officer

If you have not signed up for the SWF Inspire Community, [click here](#). It's absolutely FREE!

## SWF COMMUNITY NEWS

### A Grandmother's Words

A grandmother in any language holds a special place in our hearts and memories. It can be your Abuela, Nonna, Nana, Oma, Babba, YaiYai or Meme. She was there to be happy for a good report card, encourage you in your music lessons, hang your drawings on the frig, or, out of your sight, to be the support your parents needed in any difficulty. She knew when to step up or when to step back.

Grandparents of children with chronic disorders like SWS, are always "on call" either in person or to just be present in mind and heart.

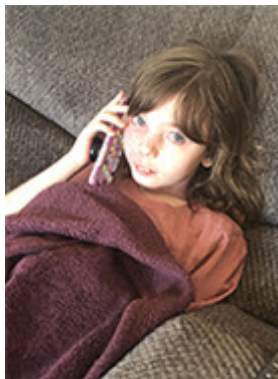
Annette Coutu lives in Rhode Island and has been with the SWF since her granddaughter Brielle was born. Brielle is now 5. She

shares these thoughts during this unusual time of quarantine and uncertainty.

“I wish I had wisdom to share on this whole Covid-19 and quarantine, but I too have never been through anything like this. The only time we were separated from family and friends when I was growing up or raising my children was during severe winter storms, hurricanes or the chicken pox. But I do know how important it is to reach out to family and friends through any means – social media, phone calls, texts, or calling out to neighbors from your front porch or balcony.

I am fortunate that Brielle and her family live here with us, so we are able to see them every day. I do have other grandchildren and I am only seeing them through Amazon Show, Face Time, through windows and over fences from 10 feet away. I have one who wants a hug I cannot give her and another who just looks at me with sad eyes, others struggling with separation they can't understand but just need someone to ease them. I try so hard to make sure they see me and know they are loved and not alone. I try and assure them that it won't be long before we are all back together and I can hug them so tight.

And I am dealing with the isolation from my family and not being able to work, or just go to parks and the mall. I am making sure I eat healthy, try to exercise, do puzzles, read, keep my mind agile because I know that it can be a slippery slope once you ignore the apathy and boredom you can so easily fall into. I would tell anyone dealing with this kind of stress to talk with someone. Don't think it will all just go away or that there is something wrong with you because there is not. These are not normal times we are going through.



## Staying Connected

Jean Schneider of New York City has connected with several SWF families. She has been in touch with Florana Jimenez-Gutierrez of Costa

Rica for many years since they met at a dermatologist appointment she attended for her granddaughter Temima.

Temima met Marissa Terrell when they were both 3 years old. They met a few times later when Temima and her family lived in New York and Marissa was in New Jersey.

Flash forward: both girls are now pre-teens. Temima lives in Israel with her family and Marissa's mom is the SWF Community Relations Director, Julia Terrell. At Jean's suggestions, Julia contacted Jean's son in Israel to see if they could restart the friendship the two girls had enjoyed.

Julia helped make the contacts by phone and the girls have chatted on **Whatsapp**. Both Julia and Jean were delighted to know that they engaged in "girl-talk" for almost an hour. They shared comparisons of their recent holidays of Easter and Passover, talked about what was going on in school that they missed, agreed on their opinions of laser treatments. They will be talking again to be sure.

If any SWF parent thinks this would be a good thing for their son or daughter to get started doing, please let Julia know. It can be on **Zoom**, or **Facetime**, any other virtual conference calling app, or plain email. We can help make the connections to link kids of similar ages, interests, and talents. We are mindful of time zones, both here and internationally. We can work with you and your son or daughter.

The important thing is to help our kids banish the isolation and boredom that preys on everyone. For school kids, this could also be a learning adventure. But first we need a parent's interest and permission. Contact [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org)



***"We need to take care of ourselves because those little ones are waiting***

*to run into our arms calling our names and looking for that awesome hug only a grandma can give. “*



**CRAIG BURKHART @ HIS NEW OFFICE!**

Check out Dr. Craig Burkhardt and Webster at his new office location in North Carolina! Thank you Dr. Burkhardt for all you do and remind Webster to check in with us on what you're up to in NC!



**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](mailto:swf@sturge-weber.org)

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