

A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

JUNE/JULY 2020

“I’m on the hunt for who
I’ve yet to become.”

Be Worthy!

2020 Graduate Tribute

New Clinical Trial

Canadian
Connection

SWF Summer
Game Nights



973.895.4445 | www.sturge-weber.org | swf@sturge-weber.org



The Sturge-Weber Foundation
MAGAZINE

CONTACT INFORMATION

12345 Jones Road, Suite 125
Houston, TX 77070
973-895-4445
swf@sturge-weber.org
www.sturge-weber.org

DESIGN/EDITOR
Susan Finnell

EDITORIAL CONTRIBUTIONS

Karen L. Ball, SWF CEO
Anne Howard, SWF Writer
Susan Finnell, Marketing/Communications
Julia Terrell, Patient/Community Director

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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

June/July 2020

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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.

CONNECTING WITH KAREN



BE WORTHY!

Karen L. Ball
Founder and CEO



It was a subdued Memorial Day weekend. For several years, I have been going to the Monarch Pass Memorial event with our dear friends Jim and Cathy Story. Jim received a Bronze Star in Vietnam and his sacrifices then and today, as he counsels suicidal vets, is the persona of "Be Worthy". This phrase has really started to resonate with me as I reflect on our veterans and those we've lost in the SWS fight. Veterans who have survived unspeakable times use this phrase to remember those gone and focus on living a life to honor them.

Am I worthy of the sacrifices they've made? Am I worthy and do I honor those on the early frontlines with SWS who have passed on or do I just give lip service? Aaron Novak. Chad Layman. Danny Keffer. Noel Gelfund. Karen Sebastian. Christian Sarver. Michal Crouch. Nicole Meurin. So many more! So many SWS warriors who bravely fought against the ravaging seizures that took their lives too soon and without the critical funding to find out why.

Am I worthy of supporting our own SWS and birthmark frontline doctors and researchers who give of their time and talents? They leave their families to share time they never get back with them to enrich our loved ones lives and thereby ours. I am forever grateful!

Love. Honor. Sacrifice. Humility.

Thank you to generous donors and long-time dedicated supporters of the Sturge-Weber Foundation. They have led the way in finding the gene mutation that causes SWS, engaging key researchers, developing clinical guidelines, and bringing families together for comfort and care. More can and should be done to honor the fallen and the living who still have far too many days in hospitals, struggle to walk, lose vision, and require special education.

Be Worthy. They need you. I need you.

It's the commitment of time, talent and treasure. Some days are better than others, some years are better than others and there is no money. It's the dedicated commitment to service and honor that's the key. Together we have come a long way in almost 33 years. Together we will continue to assist those living with SWS and birthmarks every day in every way.

Be Worthy.

June/July 2020

A flashBack of SWF Month of Awareness 2020.



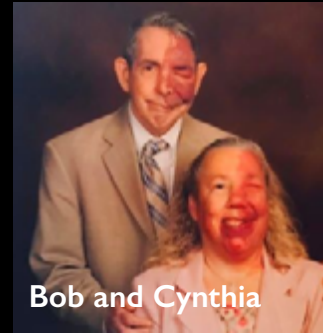
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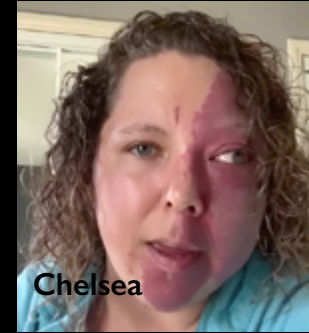
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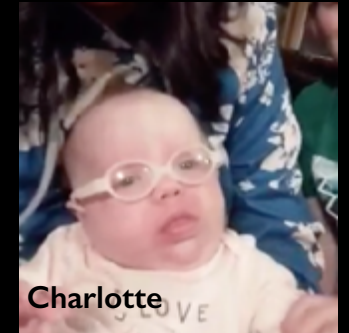
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Bob and Cynthia



Chelsea



Charlotte

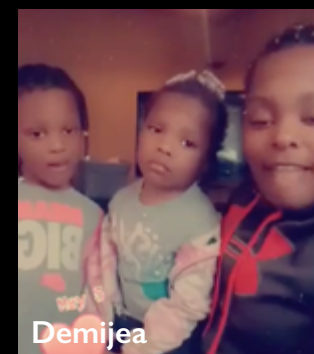
The SWF Bunch



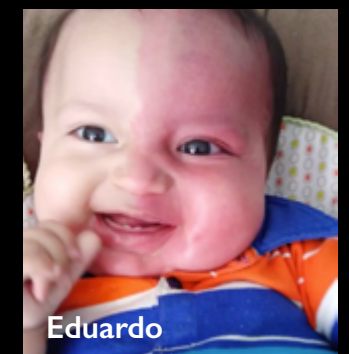
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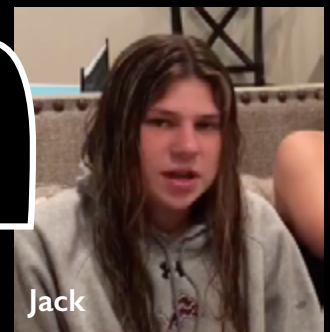
David



Demijea



Eduardo



Jack



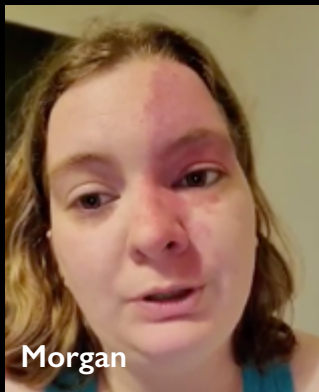
Jackson



Jian Xy-Ris



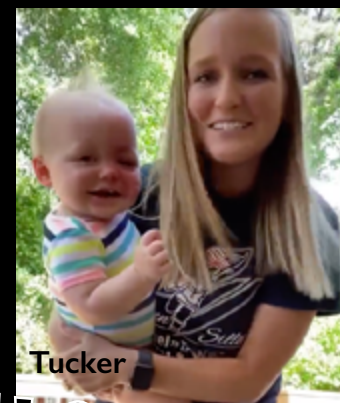
John



Morgan



Trishika



Tucker

Life may have thrown all of us a setback, but as usual SWS families rise to the challenge!

Thank **YOU** for making this year's Month of Awareness possible. With your stories, shared pictures and community support, the general public is more informed about SWS than ever before.

Here is just a glimpse of the past month:

- * Giving Tuesday|NOW on May 5th - \$4870.00 (and we are still receiving generous donations!)
- * Support through giving and participation in the UPENN Virtual Bike Ride (ends June 13th)
- * Daily posts from families providing a portal into their lives and encouragement for all of us from the US, Phillipines, Mexico, Canada, Peru, and more!

Always Better Together

Anjaleek Conner

Graduating Senior from
Rosemont High School, MN

- Captain of Adaptive Soccer Team, State Champions
- Attending Dakota County Technical College for Photography in the Fall of 2021



Shawn Raedy

Graduating Senior from
Scottsdale High School, CA



Congratulations!
GREAT
JOB!

Graduation Tribute 2020

Amanda Hillyard

Graduating Senior from
Estero High School, FL

- Cambridge AICE
- Summa Cum Laude
- Brigh Futures Florida Academic Scholar

Attending FGCU in the Fall 2020



Lizzie Click

Graduating High School Senior





Written by: Julia Terrell
Community Relations Director

Like most of us, Covid-19 came into my world and life as we saw everything begin to shut down. I remember saying to the school nurse "Is this going to happen? Will they close school?" Secretly thinking, "No way, they would never," but no one knew.

Thankfully, my daughter goes to a school that put a plan into place early, chrome books came home a Friday and the following Monday, NJ was shut down and school began that day at home. I couldn't believe it, I just couldn't believe it. My dining room table became a desk filled with books, computers and ipads.

Marissa and I started our mornings at 9:00 am with Zoom classes for Marissa with subject work and I go to work in between questions, and take conference calls outside on the deck of our home. Does this sound familiar? The week of May 15th, we were told no more in-school classes but to continue with projects, tests, computer work, gym, art, coding, Spanish and everything in between.

We have a few more weeks of this new routine and then the unknown all over again.

I wish I could say there is an end in sight, but camps will most likely be cancelled and now I am hearing on Dr. Fauci said, "Can we re-open in September?" My first impression - "Wait, what?"

I took a minute the other day and thought about everything and in some ways it was similar to finding out about Sturge-Weber Syndrome and the revolving door of doctors and realizing life just would not be the same. I went through many days of rushing to get it all done and my mind spinning. Yes, Covid-19 feels exactly like that.

This week I started to go over what we are going to do this summer. Another hurdle I thought about. Then Marissa, as always, reminded me that it is going to be OK.

It is better than OK. Actually here's why ... several things have changed.

- We are home now and eating dinner together
- We talk more than ever before
- We have slowed down and that was REALLY needed
- I have learned how Marissa learns and working on ideas to help her be a better student
- I have caught up with friends and now have a standing time to catch up and unwind
- Technology is our friend and

Marissa is catching up with friends all over the world with apps like Zoom and Whatsap

- My Girl Scout Troop completed their bronze star pin on Spring break
- We may re-design camps at home

I think the bottom line is, we need to believe in ourselves and know it will be OK. We need to remember to breathe and take each thing one step at a time.

Keeping ourselves safe is the first priority, right? But we can still make contributions from home for one another.

Over the next few months we need to learn from each other as we have done in the past. With you, and the SWF, we can continue to be a huge resource for others.

If you have special skills as a teacher, social worker, anything that you feel that may help someone else get through each day, reach out to SWF. We would love to talk and add your contribution to social media and our Webster's World series. We want you to be a part of our world as you are apart of ours.

Thank you for all you do and much Love From NJ. Marissa, Scott and I wish all of you are safe and healthy.
jterrell@sturge-weber.org



written by Susan Finnell

Summer is here! Wow, already? Does anyone else feel like they have just experienced a time warp? We have all been standing still, but the calendar hasn't.

Summer will definitely be different this year, but it doesn't have to be met with apprehension. There are still plenty of things to do with the family as we embrace longer daylight hours and warmer temperatures.

Below are some reminders to keep you and those you love safe and healthy.

1. **Social Distancing** - this will be with us indefinitely. Plan activities around smaller groups and outside if possible. Try to avoid being in crowded enclosed areas. **AND WASH YOUR HANDS and THEN WASH THEM AGAIN!**

2. **Masks** - this is a personal choice, you either like them or hate them. Of course, some public venues will require them, so it's good to have them close by if traveling. **Think of wearing a mask like this - you are protecting others that may be just as vulnerable as you. It will also keep you from touching your face with hands that have been in contact with public surfaces.**

3. **Heat** - this is nothing new, it's going to get hot folks! The worst time of the day for being outdoors is from 12 - 3 PM. Temperatures are at their warmest. Keep cool water close by and stay hydrated, even if you don't feel thirsty. Take breaks and find shaded areas to rest.



4. **Keeping a Schedule** - Let's face it, life has been really stressful lately and everyone is ready for a break. It's easy, especially for kids, to get lax in routine during summer. If traveling, this is another disruption in routine which includes medication management and other medical priorities. Make sure you continue to keep medication schedules uninterrupted. This will help and hopefully keep medical issues at bay resulting in potential emergencies. Always make sure you have prescriptions filled before travel, medical and insurance documents up to date and on hand. Being overly prepared is not a bad thing!

5. **Water Safety** - Always important! Know your swimming environment, and the swimming abilities of your children. Drownings can happen in an instant. Be consistently watchful over your children and others. Private swimming lessons or small group lessons are great for young children to learn water safety.

6. **Feeling Well** - As much as we all don't want to miss a minute of fun, there may be some days where we just aren't at our best. That's ok. If you are feeling a little under the weather, then take a day of rest and recovery. Feeling under the weather could be a sign of exhaustion (too much fun!) or something else. Either case could lead to unwanted medical emergencies. Summer can be restful, so listen to your body and be observant of how your children are feeling.

7. **Sunburn** - where I come from (Texas Gulf Coast), this is a bad word. Did you know that fair complected people can get sun burned in 3 minutes 43 seconds (I should know!)? Regardless of what skin type you are, use sunscreen! There are so many types to choose from. The best is 30 spf or more and waterproof. Reapply as the product recommends. It may be waterproof, but still wears off.

Please be safe and stay healthy this summer. The SWF staff and board of directors hope you all have a wonderful summer. Treasure those precious moments with family whether you travel or have a campout in the backyard! We're here for you if the need should arise!
Stay Calm and Shine On!



RESEARCH CLINICAL TRIAL



**THE BEST NEWS EVER
IN RESEARCH!**

**More
to come on
how you
may
participate
in this
exciting
opportunity!**

SWF Clinical Care Center, the Children's Hospital of Michigan, and Wayne State University (Detroit) received the 5-year renewal of their R01 grant from NIH entitled "Longitudinal neuroimaging in Sturge-Weber syndrome"! Among others, this grant includes funds for the SWF to help defray costs associated with help in recruitment, identifying and referring potentially eligible patients to go to their facility for imaging, neuro-psychology evaluation with travel costs reimbursed; children and adults alike.

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE

CLINICAL CARE NETWORK

New, NIH-funded imaging and neurocognitive clinical trial at Wayne State University, Children's Hospital of Michigan in Detroit (SWF CCN)
Principal Investigator: Prof. Csaba Juhasz, MD, PhD

In March, 2020, the National Institutes of Health renewed funding for a 5-year clinical trial to study brain vascular and structural changes in patients with Sturge-Weber syndrome (SWS) at Wayne State University (WSU) and the Children's Hospital of Michigan (CHM) in Detroit, a SWF Clinical Care Network Center.

The Principal Investigator of the study is Csaba Juhasz MD, PhD, Professor of Pediatrics and Neurology at WSU/CHM. Clinician co-investigators include Dr. Aimee Luat, MD (pediatric neurologist), Dr. Michael Behen (neuropsychologist) at WSU, as well as Dr. Mai-Lan Ho (pediatric neuroradiologist) at Nationwide Children's Hospital. The study procedures include review of previous brain scans (if available), brain magnetic resonance imaging (MRI) scanning with advanced sequences, and detailed neurology and neuropsychology evaluations. Main goals of the study include the validation of a novel, fast MRI approach to detect SWS brain abnormalities within minutes; this will allow safe MR imaging without sedation and, in many cases, without contrast injection. In addition, mapping of vascular and neuronal connectivity changes in the brain, that may be missed by routine brain MRI, may be able to predict the type and severity of neurocognitive outcome and provide a more accurate guide for future,



targeted treatments. Study results are discussed with the participants and their families, and a copy of the brain images with a report, and neuropsychology report will be provided.

All study tests are free of charge, and travel costs (including transportation and hotel costs if overnight stay is needed for those coming from out of town or state) are reimbursed. All tests can be completed in a single day visit. Eligible participants are both children and adults (up to 30 years of age) with the diagnosis of SWS and those with a facial port-wine birthmark who are at risk for SWS. Participants of previous imaging studies at WSU are also eligible for repeated studies under the new project to evaluate long-term longitudinal changes in the brain. Healthy siblings of SWS patients can also enroll as controls and undergo the same brain MRI.

Those who are interested in study participation can contact directly Dr. Juhasz at csaba.juhasz@wayne.edu (or call his office at 313-966-5136) for further details and scheduling.



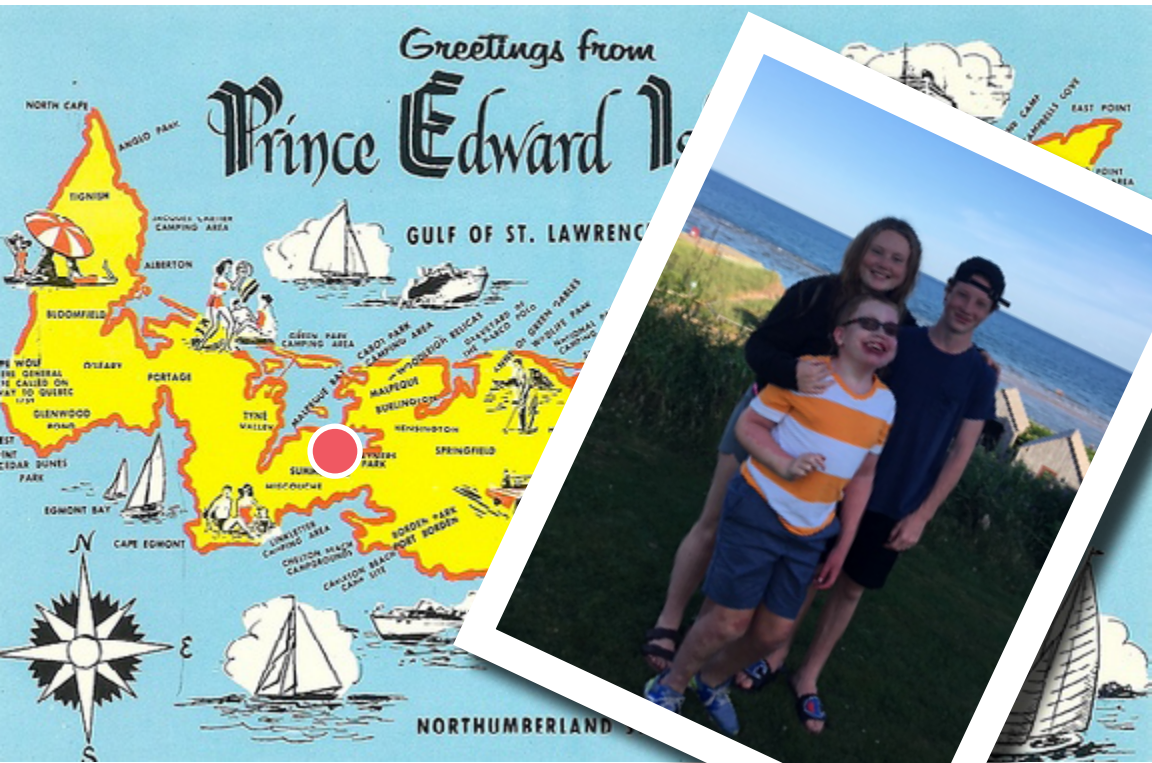
Contact Information Update

In July, be on the look out for an email from SWF about updating contact information and setting preferences for receiving information.

Setting preferences will provide you an opportunity to opt in or out for emails, direct mailings, Branching Out, text messaging, etc. This will help us serve you better.

Be reassured your information is safe and confidential, we do not share it outside of the Foundation.

CANADIAN CONNECTIONS



Written by Anne Howard
(pictured: Sophia, Xavier and Gabriel Dalton)

CANADIAN CONNECTIONS

This current pandemic we are living with makes us realize how connected all our SWF families are.

Sam and Mary Dalton and their kids, Sophia, Xavier and Gabriel, live in Summerside, Prince Edward Island, Canada, on the Atlantic coast. They have been with the SWF since Gabriel was born and have been frequent correspondents to our newsletters and with other families. They often travel to Montreal for laser treatments for Gabriel.

Canada celebrated Victoria Day, which is similar to the U.S.

Memorial Day, on a weekend in May. But other similarities abound. Sam tells us: -

“We are very fortunate here on Prince Edward Island. Being on an island puts us in a unique situation and there are currently no active cases on Prince Edward Island, and they were never any from the community that were spread. All cases previously were from travel and all the people self-isolated, very easy to track.

The kids’ school year was canceled, like many places and Mary has been



home for over a month with pay. This time in isolation has certainly had its benefits, brought us together to spend more time as a family. Mainly, because we replaced the kids’ friends... LOL

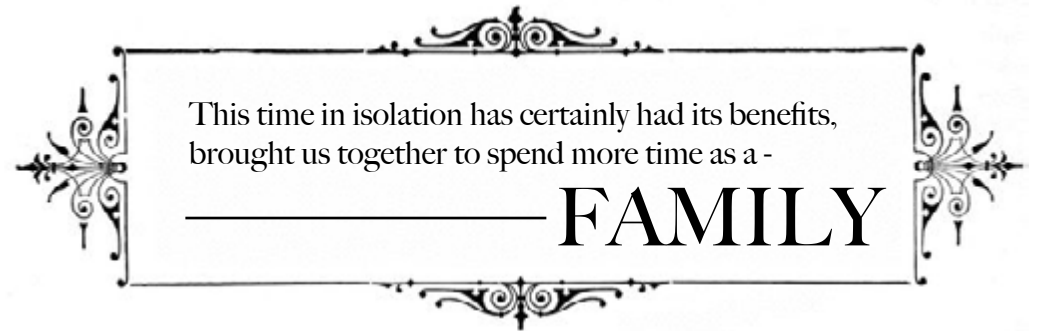
However, things are slowly starting to open back up and it is so nice to be able to see our children playing basketball, going for a bike rides or just hanging with their friends outside.

Only bummer is my daughter is an honour student in Grade 12 and loves school, so we are super disappointed that we cannot see her

receive her diploma from 12 years of dedication.

However, even that is supposed to be worked out somehow, just not the usual way... We will see what they come up with. Of course, this also takes away the prom and the money already spent on her \$600 dress.

However, in the big scheme of things we know we’re blessed, and I really can’t complain and no one is hanging their heads or anything like that in this household.”



SNAIL MAIL STILL EXISTS!

We love receiving letters from you, telling us how you are doing! This summer pick up a postcard and send us a line or two. Tell us how you are doing, what you are doing, and maybe even why you are doing it!

We’ll share it in our next issue or post it on our social media pages.



REMEMBERING PAPA

Anji Hill Whelpley sends us this tribute to her recently deceased father. Kaydie will be 16 in August and mom Anji has been with the SWF since she was a baby. They live in Michigan.

“It is with a heavy heart that we say William Y. Daniel, Kaydence Hill’s loving grandfather, lost his battle with NK T-Cell Lymphoma in November 2019.

If you knew him personally you would have called him Billy ...

Billy was an all-American guy, born from immigrant parents. He grew up in a small town, graduated high school with the same life-long friends he went to kindergarten with, and went to work for the local mine. There he trained and became an electrician, making an honest blue collar living for over 35 years. He built his own home from the ground up. Lived and lost through a couple of failed marriages and raised 6 children. Eventually he became “papa” to 11 grandchildren.



He was always the life of a party, the first to arrive and the last to leave. He could amaze you with interesting random facts, or make you laugh with some quick witty comment. Some of his favorite things were sports, rock and roll, roulette, home cooking and everything about the desert.

His loud laugh and big personality will leave a void in our lives that will never be replaced. Our only comfort comes from knowing that he is no longer suffering or in any pain.

Until his arm started to swell before he passed away, he wore his Sturge-Weber bracelet.

He had several as back-ups just in case one would break. During his first treatment he refused to take it off and he would explain why. Between my dad and sister Reymi and PICU RN they have been amazing advocates for Kaydie.

Kaydie and papa shared a special bond that will never be forgotten.”
(Kaydie and Papa pictured together on page 16)



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 by Friday, June 12th.



The Sturge-Weber Foundation invites you to be a part of our virtual world. What does that mean? Stories on both Instagram and Facebook have grown and it's time we learn from each other.

Now it's YOUR time to share what you know and help others at the same time.

Introducing Webster's World, where you, our followers, can further Webster's Adventures! To do this, send pictures, short videos, content and more. Some examples may be an art class, or tips on how to get through speech therapy, or even take a walk outside and we come along. The SWF will post your adventure to our many social media platforms including, but not limited to, Facebook, Instagram, Twitter or even Inspire. Did you know Webster has his own pages too?

This will be a window into a world that communicates and educates others in positive ways. We want to "grow" Webster's World, build community and awareness.

[Find out more by clicking here!](#)



That's right, it's game night with SWF, coming this summer for your Wednesday night entertainment!

Join us on the following dates for an hour of family fun and competition! Come play against the SWF staff! You bring nothing but your game face and winning personalities! We will do the rest!

Family game nights are 6-7 PM Central (Eastern - 7-8 PM; Mountain - 5-6 PM; Pacific - 4-5 PM) Prizes for the biggest winner and biggest loser!

June 17th - Bingo Night

July 15th - Pictionary Night

August 12th - World Scramble Night

Please register for the game nights you wish to attend using 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 (ex: Bingo cards, etc.).

See you on Game Night!

[SWF Family Game Night Registration](#)

Just the Facts Ma'am!

SWF Month of Awareness Outcome



SOCIAL MEDIA

- Facebook reach - 50,537
 - Instastories on Facebook - 574
 - Twitter posts - 12,500 posts
 - Instagram posts - 8,234
- TOTAL SOCIAL MEDIA - 71,845**
+ 50 new followers

MOA EVENTS

- MOA Virtual Dance Party on May 31st
- UPENN Virtual Bike Ride (through June 13th)
- Giving Tuesday | NOW on May 5th
- Ask the Experts on Inspire - May 22-28
- Meeting 25 new families on Social Media



MOA SUPPORT



- GIVING TUESDAY | NOW - \$5,180
- UPENN Virtual Rider Donations - \$1000 to date
- Ship Bottom Brewery Summer Ale Beer Sales (NJ) - \$2,000
- MOA General Donations - \$8,609

Thank YOU
for another successful
Month of Awareness!