

A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching

APRIL/MAY 2021

Out

STURGE-WEBER FOUNDATION
LION MILES
for Sturge-Weber Syndrome
Birthmark | Seizures | Glaucoma



**RUN | WALK | RIDE | WHEEL
MILLION MILES FOR
STURGE-WEBER SYNDROME**

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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.

The SWF is a member of:
The Brain Vascular Malformation Consortium (BVMC)
American Brain Coalition (ABC)
The Association for Research in Vision and Ophthalmology (ARVO)
Alliance for a Stronger FDA

POINT ME IN THE RIGHT DIRECTION

CONNECTING WITH KAREN



Many times throughout life I've used the phrase, "point me in the right direction"! I'm also told that phrase even more so now I'm getting more years under my belt.

What do you do when you feel you are off course? Do you rely on your parents or family? Co-workers or friends? In turbulent times, we must come together to stay on course at whatever we are trying to accomplish in life. It's easy to get distracted, tired and frustrated especially when dealing with Sturge-Weber and all the unknowns.

I've been very blessed to have my daddy 'ole M.O.O. (Mighty Omnipotent One) keeping me on course and motivated for 63 of his 91 years. He was a Boy Scout when they still used a compass to get their bearings! When



you're out in the wilderness, a compass is a must to get you where you are going or if you need to backtrack. Today of course we

have a variety of options and aren't we lucky to have them!

In the picture, my dad's compass is pointing North. Why North? My family roots are in Montana and for generations all the direction I ever needed in life came from the North. The photo reminds me to cherish the wisdom of those around me and to share the wisdom I've gained with other people too. It doesn't mean I know all the answers to your questions but I sure can point you in the right direction! The Sturge-Weber Foundation has built a vast reservoir of knowledge throughout the years with our Clinical Care Network and a global network of people who have walked the walk and can talk the talk when you need direction or hope.

Speaking of direction and walking the walk... I'm so excited for what's ahead! Get your compasses or phone navigation devices ready to go in the right direction as you care for the caregiver and go the extra mile for SWS! Together we are going to continue to make great strides and keep the momentum going!

Faith, Hope and Love,


Karen Ball

IN THE NEWS

► Meet SWF's New Board Members

Please welcome two new board members as of January 2021!

Steve Emmons joins us as Board treasurer. Steve is a graduate of the University of Northern Colorado. He has over a 30 year commitment to the banking industry in Colorado and service to several not-for-profit organizations in the Metro area. He also contributes his acumen with several trade associations and Chambers of Commerce.



Molly Speer joins us as well as a Board member. Molly is currently an Administrative Associate with Cummins. She is also a graduate of Marion University. She brings a commitment of service that will be highly beneficial.

Molly's daughter, Myla, was diagnosed with SWS at 8 months old. Myla has been an inspiration to the entire community (Greensborough, IN) and is honored each year with a special event, Myla's Mission, to raise funding for research and Support. This year's Myla's Mission will take place in person and virtually on May 15, 2021.



VERY SPECIAL THANKS . . .

SWF would like to thank **Steve Peltier**, for his service on the Board as treasurer for 3 years. Steve has been a huge supporter of SWF financially, as well as in service. Steve has provided the Foundation with opportunity, financial experience and true commitment through his Board service and beyond.

Thank you Steve for all that you have provided the SWF and the global community!

► ADVOCACY AT WORK

March 4, 2021 | American Brain Coalition - Many thanks to the 82 professional and patient advocacy organizations (including The Sturge-Weber Foundation) who signed on to the American Brain Coalition's letters to Congress regarding the creation of a Neuroscience Center of Excellence (NCE) at the Food and Drug Administration (FDA). Our advocacy efforts have just begun. We encourage you to visit the ABC's NCE Resource Page for information and tools to help you advocate within your own organizations. Look for more communication from the ABC in the coming months as we continue our advocacy efforts.



► LET YOUR VOICE BE HEARD

The Sturge-Weber Foundation is your collective voice on issues that may have a beneficial impact on you. To follow are two acts being submitted that seek to address issues we have heard from many over the years. We encourage you to make your voice heard with ours!

S. 2546 SAFE STEP ACT OF 2021

Purpose: Improve step therapy protocols and ensure patients are able to safely and efficiently access the best treatment for them.

The Safe Step Act amends the Employee Retirement Income Security Act (ERISA) to require a group health plan provide an exception process for any medication step therapy protocol.

S. 2730 Ensuring Lasting Smiles Act

Purpose: to provide health insurance benefits for outpatient and inpatient items and services related to the diagnosis and treatment of a congenital anomaly or birth defect.

In General: A group health plan, and a health insurance issuer offering group or individual health insurance coverage, shall provide coverage for outpatient and inpatient services related to the diagnosis and treatment of a congenital anomaly or birth defect.

Requirements: Coverage shall include any service to functionally improve, repair, or restore any physical need that is medically necessary to achieve normal body functioning or appearance, as determined by the treating physician. Any coverage provided under such may be subject to coverage limits, such as pre-authorization or pre-certification, as required by the plan or issuer that are no more restrictive than the predominant treatment limitations applied to substantially all medical and surgical benefits covered by the plan (or coverage).

TELL THE WORLD YOUR STORY WITH SWF MERCH!

<https://the-official-swf-store.creator-spring.com>

Visit the SWF ONLINE STORE, new merch added monthly. A portion of your purchase goes directly to helping newly diagnosed patients. Share the link on Facebook or Instagram!



SWF IN ACTION



2021 SWF EDUCATION DAY MINI SUMMIT | FEBRUARY 6TH

The SWF had its first Education Day Mini Summit! Additionally, we are excited to announce our new partnership with UCB at this Mini Summit. UCB is a sponsor of SWF Education Days, and joined us on the conference call.

Thirty-five families registered for the Mini Summit from all over the USA as well as Brazil, Nigeria, India, Israel, England, and Puerto Rico. We were fortunate to gather together with 20+ families.

Speakers from 5 of our Clinical Care Networks participated. Dr. Kristen Kelly began the Summit (University of California Irvine) in Dermatology. Next was a very informative talk about glaucoma and how the eye works from Dr. Peter Chang (Bascom Palmer, Miami). Dr. Anna Pinto (Boston Children's Hospital) discussed neurology and finally the talks were rounded out with Dr. Ann Friedman about "mindfulness".

After the speakers provided their talks, there was an excellent opportunity for Q&A. Dr. Jeffrey Loeb (UIC) explained a new project coming from the Brain Vascular Malformation Consortium which the Foundation participates in (Project 2). It was a very productive day and very informative. A special shout out to Veronica Green for her help making this event such a success!

If you missed this past event, we still have 5 more Education Day Mini Summits scheduled. Dates for 2021 Education Days are:

- **April 3 (registration now open @ <https://sturge-weber.org/participate/swf-education-days.html>)**
- June 5
- August 7
- October 2
- December 4
-

If you have any questions or concerns, please contact Julia Terrell, jterrell@sturge-weber.org.



2021 SWF CLINICAL CARE NETWORK CONFERENCE THE MEETING OF SWF'S SUPER HEROES

The 2021 SWF Clinical Care Network Conference was held February 25-27, with a happy hour opening on February 24. There were 35+ attendees from over 15 CCN locations.

Thank you to our partners UCB, Qlaris and Ship Bottom Brewery for helping to make this meeting a huge success. Each member of the CCN that attended the happy hour received a box of goodies to celebrate before the real work began. It was a great opportunity to network and get to know one another on a more personal level. Each one of our CCN professionals is a superhero, utilizing their "super power" of knowledge and expertise to help us along the SWS journey.

Dr. Henrik Klitgaard, a researcher and scientist from our partner UCB, along with Lara Falcon, opened the

meeting with a presentation and discussion on the drug Keppra and the science behind seizure medications.

The remainder of the meeting was led by our Task Force Leaders on transition protocols to adulthood. **THANK YOU Task Force Leaders!**

- Dr. David Shahani, Neurology, Cook Children's Hospital
- Dr. Esteban Fernandez Faith, Dermatology, Nationwide Children's Hospital
- Dr. Lauren Blieden, Ophthalmology, Texas Children's Hospital
- Carol Roethke-Green, RN, Nemours duPont Pediatrics

The exciting part of these conferences is the collaboration between the 3 different medical teams - neurology, dermatology and ophthalmology. They must work together to obtain the best end results.

The meeting was a success resulting in 10 new goals created for SWS clinical success. Stay tuned as the conversation continues and new insights into SWS are discovered!

OPPORTUNITY ABOUNDS

THE STURGE-WEBER FOUNDATION MILLION MILES

for Sturge-Weber Syndrome

Birthmark | Seizures | Glaucoma



ANNOUNCING SWF'S NEW FUNDRAISING CAMPAIGN

The Sturge-Weber Foundation, is EXCITED to announce the first annual Million Miles for Sturge-Weber Syndrome fundraising campaign!

This is a great opportunity to get in shape or stay in shape while supporting the vital work of the SWF Clinical Care Networks and research.

PURPOSE:

The Million Miles for Sturge-Weber Syndrome is the Sturge-Weber Foundation's 2021 initiative to:

1. Continue in the vision of C.A.R.E. for the patients and families that live daily with this incurable rare disease
2. Raise much needed funding for research, educational advancements and conferences for patients and professionals, global collaboration

3. Make the general public aware SWS exists, how it impacts patients who are diagnosed and their families
4. Provide an avenue for the general public to be a part of the solution in finding a cure.

LET'S REMEMBER - WHAT IS C.A.R.E.?



We **connect** with those who need our help navigating life with SWS.

We **accept** the challenge to forge a better quality of life for those with SWS.

We **respect** those who lead us forward through critical research of SWS.

We **engage** the general public through education and sharing for better understanding of SWS.

SO, HOW CAN YOU HELP?

So glad you asked! There are several ways you can lace up and get into step! Whether you run, walk, cycle or wheel your way, you can help us achieve our goal of one million miles.

1. Join an SWF CCN Million Miles Team

Certain CCNs have created virtual teams. Choose a CCN that is close to you (or you would like to join,) from the list provided, register, create your personal fundraising page and start stepping out!

2. Stepping Out On Your Own

Feel like going it on your own? Great, we like that kind of initiative. You too will need to register and then create a personal fundraising page at the link provided.

3. Post and Push!

So maybe you aren't into this type of fundraising, that's ok! Post the link listed on your personal social media pages and share the opportunity with others!

No matter what you do, DO be a part of this journey! Let's build awareness of SWS by showing others what it's like to walk a mile in someone else's shoes!

REGISTER

<https://sturge-weber.org/participate/>

ON YOUR OWN FUNDRAISING

<https://www.justgiving.com/campaign/SWFMillionMiles>

SWF CCN CONTACTS & FUNDRAISING PAGE

NYU Langone

[justgiving.com/campaign/nyulangone](https://www.justgiving.com/campaign/nyulangone)
Dan Miles, Daniel.Miles@nyulangone.org

Seattle Children's

[justgiving.com/campaign/seattle](https://www.justgiving.com/campaign/seattle)
Catherine Amlie- Lefond
calefond@seattlechildrens.org

University of CA San Francisco

[justgiving.com/campaign/UCSanFrancisco](https://www.justgiving.com/campaign/UCSanFrancisco)
Ilona Frieden, Ilona.Frieden@ucsf.edu

Rady Children's

[justgiving.com/campaign/Rady](https://www.justgiving.com/campaign/Rady)
Lawrence Eichenfeld, leichenfeld@rchsd.org

University of Texas

[justgiving.com/campaign/Utexas](https://www.justgiving.com/campaign/Utexas)
Alice Frigerio, Alice.Frigerio@hsc.utah.edu

Dell Children's

[justgiving.com/campaign/dell](https://www.justgiving.com/campaign/dell)
Moise Levy, MLLevy@ascension.org

Texas Children's

[justgiving.com/campaign/texaschildrens](https://www.justgiving.com/campaign/texaschildrens)
Denise Metry, denise.metry@comcast.net
Lauren Blieden, Lauren.Blieden@bcm.edu

Mayo Clinic Minnesota

[justgiving.com/campaign/Minnesota](https://www.justgiving.com/campaign/Minnesota)
Megha Tofellson, tolfelso.megha@mayo.edu

Bascom Palmer

[justgiving.com/campaign/bascompalmer](https://www.justgiving.com/campaign/bascompalmer)
Peter Chang, t.chang@med.miami.edu

UNC/Duke

[justgiving.com/campaign/UNC](https://www.justgiving.com/campaign/UNC)
Julie Blatt, jblat@med.unc.edu

Cincinnati Children's

[justgiving.com/campaign/cincinnati](https://www.justgiving.com/campaign/cincinnati)
Adrienne Hammill, Adrienne.Hammill@cchmc.org
Shannon Thornberry, Shannon.Thornberry@cchmc.org

Nationwide Children's

[justgiving.com/campaign/nationwideteam](https://www.justgiving.com/campaign/nationwideteam)
Warren Lo, warren.lo@nationwidechildrens.org
Esteban Fernandez
Esteban.FernandezFaith@nationwidechildrens.org

Michigan Children's

[justgiving.com/campaign/michigan](https://www.justgiving.com/campaign/michigan)
Csaba Juhasz, csaba.juhasz@wayne.edu
Aimee Luat, ALuat@dmc.org

UIC

[justgiving.com/campaign/UIC](https://www.justgiving.com/campaign/UIC)
Jeffrey Loeb, jaloeb@uic.edu
Veronica Green, vgreen5@uic.edu

Lurie Children's

[justgiving.com/campaign/lurie](https://www.justgiving.com/campaign/lurie)
Carolyn Kiolbasa, CKiolbasa@luriechildrens.org

Nemours

[justgiving.com/campaign/nemours](https://www.justgiving.com/campaign/nemours)
Steve Falchek, Stephen.Falchek@nemours.org

Wills Eye/Jefferson

[justgiving.com/campaign/nemours](https://www.justgiving.com/campaign/nemours)
Jade Price, jprice@willseye.org

Boston Children's

[justgiving.com/campaign/bostonteam](https://www.justgiving.com/campaign/bostonteam)
Anna Pinto, Anna.Pinto@childrens.harvard.edu

Colorado

[justgiving.com/campaign/colorado](https://www.justgiving.com/campaign/colorado)
Karen Ball, kball@sturge-weber.org

Cook's Hospital

[justgiving.com/campaign/cooks](https://www.justgiving.com/campaign/cooks)
Dave Shahani, dave.shahani@cookchildrens.org
Amy Davis, Amy.Davis@cookchildrens.org



THE STURGE-WEBER
FOUNDATION
MONTH OF AWARENESS

PARENTS

NURSES

DOCTORS

SIBLINGS

RELATIVES

DONORS

Caring for Sturge-Weber Syndrome takes more than one.

Sturge-Weber Syndrome (SWS) affects 2 percent of those born with a port-wine birthmark and affects the skin, brain and eyes.

There is not a cure yet.

Those with SWS spend a lifetime with this condition.
SWS caregivers spend a lifetime caring for this condition.

Join us this month as we celebrate SWS caregivers and how they sacrificially give.

www.sturge-weber.org/MOA-CARE

CARE for those who CARE for others.

CARE
connect. accept. respect. engage.

2021 SWF MONTH OF AWARENESS

CARE for those who CARE for others.

MAY IS SWF'S MONTH OF AWARENESS

Each year, SWF promotes awareness of SWS during the month of May.

Whether a patient or caregiver, this is our opportunity to showcase YOU through the victories and the struggles of living with Sturge-Weber Syndrome every single day.

This year we are focusing on those who care for the SWS patient - parents, siblings, doctors, nurses, relatives, even our faithful donors. We **CELEBRATE** the sacrifices they make to ensure those with SWS have the same opportunities and quality of life as everyone else.

During May be sure to visit SWF's various social media sites as we share stories of many of our members.

We also encourage you to post photos of your own Month of Awareness endeavors on our pages, and personal pages. We'll even have a Month of Awareness selfie frame you can download and use!

Much of the nation public events are limited, but you can still promote awareness with personal online



fundraisers. Consider participating in the SWF's Million Miles for Sturge-Weber Syndrome Campaign (April 1 through June 30). It's easy to register, and can be done on your own by just counting your steps daily and asking others to support your endeavor.

Don't forget to pull out the 2021 Month of Awareness poster (center of Branching Out) and post it at your office, local coffee shop, school bulletin board or window of your home. Anywhere is a great place to share and grow awareness of SWS.

Consider supporting MYLA'S MISSION 5K WALK for STURGE-WEBER AWARENESS!

Once again, Molly Speer and her family will be hosting their annual 5K Walk for Myla and SWS in Decatur County, IN, May 15th. Although you may live else-

where, you can impact the success of this fundraiser right where you are!

For details on how to register, go to <https://mylasmissionsws.com>.

Lastly, check out the **Ann & Robert H. Lurie Children's Hospital of Chicago Children's Wellness and Weight Management Program!** This is another great opportunity to celebrate the Caregiver through self-care for the child patient, event adults and caregivers. It's a perfect program to pair with the Million Miles campaign to educate and involve the entire family! Share it with friends and neighbors, make it a neighborhood awareness project that everyone benefits from.

LINK: <https://www.luriechildrens.org/en/specialties-conditions/pediatric-wellness/>



... AND NOW A MESSAGE FROM OUR SPONSORS

SWF depends on several corporations to provide funding as sponsors for many of the programs and daily support the Foundation provides at little to no cost to members. Sponsors are usually businesses that have a passionate connection to our mission, whether it be a pharmaceutical company that develops seizure medications to protective outerwear from the sun's UV rays. Below are SWF's 2021 sponsors (to date) and a brief summary about what their company offers and their connection to SWF's mission.



Allergan (now Abbvie) has been a long time supporter and sponsor of SWF. The Allergan Foundation has provided funding that has allowed us to continue to provide Branching Out and many other brochures and publications. Allergan is a dermatological pharmaceutical company - allergan.com



Qlaris Bio is a new sponsor of SWF. This company specializes in ocular therapeutics and has been a big supporter of the SWF Education Day Mini Summits and SWF Clinical Care Network Conferences - qlarisbio.com



UCB joined SWF as a sponsor in January 2021. They have provided support for SWF Education Day Mini Summits, SWF CCN Conference and SWF's Million Miles for Sturge-Weber Syndrome Campaign. UCB is a pharmaceutical company that manufactures seizure medications such as Keppra - ucb.com



Axiom Advisory Group joined SWF as a sponsor in January 2021. Curt Stanton, SWF Board Chair is a designated managing broker for Axiom and is key to Axiom's support of SWF. "True humility is not thinking less of yourself; it is thinking of yourself less." quoted by C.S. Lewis, defines the true nature of Curt's and Axiom's sponsorship. Axiom will be one of many sponsors for the SWF Million Miles Campaign - axiom-ag.com

SWF COMMUNITY

NFL REFEREE OFFICIALS CHOOSE SWF AS CHARITY TO BLESS

In January, the NFL REFEREE OFFICIALS provided a generous contribution to SWF. Imagine the surprise when the Foundation found out that Don Willard, father to Sydney Willard who has SWS, is an NFL referee official.



WE THANK DON AND HIS COLLEAGUES FOR THEIR GENEROSITY!

MAKING MUSIC FROM THE STRUGGLE

JORDAN ST. CYR'S COMPELLING STORY IN THE SINGLE "FIRE"

Story authored by Lindsay Williams (KLOVE) January 25, 2021

Manitoba, Canada-based singer, songwriter and worship leader Jordan St. Cyr initially wrote his song, "Fires," about a man named Nathan. A husband and father of three, Nathan worked multiple jobs to provide for his family, but was on the verge of

losing his home. Miraculously, a community of believers stepped in to pay off his house and some additional debt that he owed, inspiring St. Cyr to pen the moving lyrics that comprise the soulful ballad.

In the wake of his own personal fire, years after writing the song with Micah Kuiper and Krissy Nordhoff, the lyrics took on a new meaning altogether. "Looking back now, I realize that God gave me Nathan's story so that I could walk through mine," the father of four shares.



In November 2018, St. Cyr's youngest daughter, Emery, was born with a rare brain disorder, Sturge-Weber syndrome. An MRI revealed that the left side of her brain was not receiving enough blood and was shrinking, resulting in Emery experiencing a series of seizures. The serious condition led to countless doctor appointments and emergency room visits.

Although there's still much that remains uncertain about his daughter's illness more than two years later, St. Cyr says this unexpected trial has refined his faith like nothing else.

"While this journey has not been easy, and we're left with so many more questions than we have answers, we know more than ever now that God is with us and that He always will be. He has made us stronger, and He has grown our faith in ways that we never thought were possible," the singer attests. "He's used the hardest parts of our story to refine our hearts and draw us closer to Him."

To hear this compelling hit single, visit YOUTUBE at <https://www.youtube.com/watch?v=XOrSj9w0Iiw>.



JULIA TERRELL ADVOCATES FOR SWS DURING RARE DISEASE WEEK

Julia Terrell participated in Rare Disease Legislative Advocate in Rare Across America. She was able to meet with Legislative Aides for Congressman Norcross and Senator's Menedez and Booker from New Jersey. She asked each of the senators to become members of the Rare Disease Caucus and also thanked Congressman Norcross for always being an ally.

She discussed extending Telemedicine when it comes up for reapproval and the Start Act, the Start Act and asked them to participate in the Brain Consortium's Neuroscience Center of Excellence. Each year Julia advocates on behalf of all SWF members and says it is always so exciting. In times of uncertainty it is empowering to share the her story and that of the Sturge-Weber community.

If you would like to get involved in advocacy, contact Julia at jterrell@sturge-weber.org, she has a wealth of knowledge and always eager to help!



SWF CONGRATULATES ALAN FANECA FOR HIS INDUCTION TO THE HALL OF FAME

SWF congratulates Alan Faneca for his election into the Class of 2021 as one of the best guards to ever play the game as #66 with the Pittsburgh Steelers.

An unknown fact about Alan Faneca -

Alan Faneca's Foundation provided a generous \$7500 donation for an SWS "twin study", which was one of many, instrumental in the SWF and BVMC finding of the GNAC, the gene directly associated with SWS.

Alan Faneca has definitely made his mark, not only in the Hall of Fame, but also in the lives of so many living with SWS.



Way to go Alan!



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Branching Out and other SWF publications are made possible by these 2021 sponsors.



DOUBLING YOUR DONATION

Many employers sponsor matching gift programs to match charitable contributions made by their employees. Gifts from employees', spouses, retirees, even friends, may qualify for a match. Many families, like the Rasmussen's have been able to double their donations and sustain SWF programs and fund future opportunities!



The SWF now has an automated program on its [Matching Gifts Page](#) that will search for your employer and provide the steps to have your donation matched. Now your donation can have an even bigger impact!

Questions? Please contact Maristel Aguilar,
maguilar@sturge-weber.org