



The Sturge-Weber Foundation
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 **believe**
you. us. progress.



A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

MARCH/APRIL 2020



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The Sturge-Weber Foundation
MAGAZINE

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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

March/April

On the Cover: Rebecca Wolfe Szorcik with her husband Scott and two children, Aaron and Eden.

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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.

SWF COMMUNITY



Race for 7: 7000 Rare Diseases | 7000 Meters

Cubbon Park, India - Geetha and Vinayak Narayanaswamy participated in the Race for 7 Marathon. Geetha is instrumental in managing an SWS group in India.

Vinayak was very excited and was joined by his mother and older brother Chandrasekhar Ramanujan.

Cubbon Park was overflowing with 3,000 plus people of all ages who had come to show their support for rare diseases.

All the patients representing their rare disease were enthusiastic, cheerful and entergetic. Their positive "vibes" was an encouragement to all of us. It was quite an overwhelming experience!





DREAM B-I-G!

Karen L. Ball
Founder and CEO



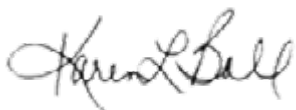
Woke up this morning with that saying, "Dream Big" resonating in my mind! I'm preparing the final manuscript on a book I'm writing and a few of my cherished Warrior Mama's came to mind. Ever since the SWF was founded back in 1987, there have been courageous moms and dedicated researchers who uplifted me when my spirits were down (as my dreams for Kaelin and each one living with SWS were not fulfilled as fast as I'd like). They were my biggest cheerleaders, fundraisers and investigators and always reminded me to stay the course and Dream B I G!

Looking back over 32 years of living with Sturge-Weber and all that it entails, the truth is as parents we all want the same thing for our children whether they are typically developing or have special needs. We want them to have a fulfilled life and be happy. Sharon G. was the first mama who led by example. Though her son, Geoff, became blind due to the glaucoma and learned at a different rate, Sharon never put limits on what Geoff wanted to do but researched and worked to adapt and make his life soar! Today, Geoff is married and lives a life full of travel and a variety of interests.

Nina W. was another mom who had no road map on how to raise a child with SWS but with the right identified support systems and family help has made Cynthia's life fulfilling and complete with a cherished friend who also has SWS. In reflection, it is the friends we meet along the way who nourish our weary souls and who share the smallest of triumphs as HUGE celebrations. Some of these friends we meet because of our shared SWS diagnoses and some through everyday life activities.

Many of the dreams I've had for Kaelin have blessedly come true! The dream I had to find out what caused SWS has been realized and anybody who knows me knows that's not BIG enough! I want models to test treatments and new medications. I want improved lasers to shorten treatment times. I want a whole new generation of your little ones to have more resources to improve their quality of life and care. As always, I want more funding to give to interested researchers to keep the momentum going!

Please join me and Dream B I G! Every pair of hands we have doing our unique part in our little corner of the world gets us improved quality of life and care that much sooner...trust me, 32 years goes by in the blink of an eye!!
TIME'S A WASTIN'!!





RIDE FOR RESEARCH

benefitting groundbreaking research for
Sturge-Weber Syndrome and Port-Wine Birthmarks



Let's Ride Together for Research!

Location: University of Pennsylvania, Philadelphia

Date: June 13, 2020

What is the Million Dollar Bike Ride for Research?

The Million Dollar Bike Ride brings over 750 cyclists and volunteers to Penn's campus to ride either 13, 34, or 72 miles starting in the city, and ranging across the Greater Philadelphia region. In six years, the MDBR's 30+ teams have raised over \$10 million to fund research grants.

What can I do?

Be a participant and ride! Fundraise with us! Commit to cheering riders on to the finish along the side lines!

What do I do as a fundraiser?

There are two ways you may fundraise with us – as a "Virtual" Rider or an "Actual" Rider.

For full details go to the SWF Website - Participate Tab, then UPENN Ride for Research.

If you decide to ride and register, please let Susan Finnell know you have registered and if you will need to rent a bicycle.

QUESTIONS? Contact Susan Finnell at sfinnell@sturge-weber.org.

ROOTS TO RESEARCH: 100TH MEETING OF NIAMS



Karen Ball Attends 100th Meeting of NIAMS

As a member of the NIAMS Advisory Council, Karen Ball attended the 100th meeting of the National Institute of Arthritis and Musculoskeletal and Skin (NIAMS) Advisory Council on February 4, 2020 in Bethesda, MD to participate in the meeting's very full agenda!

Dr. Susan Gregurick presented the NIH's Strategic Vision for Data Science: Enabling a FAIR-Data Ecosystem. **This presentation underscored that Dr. Jeffrey Loeb's planned direction for the Project 2 SWS part of the Brain Vascular Malformation Consortium (BVMC) was a smart choice to implement more data to speed discovery in SWS and birthmark investigations to improve quality of life.**

There were also presentations from Dr. Charles Helmick on CDC activities and potential partnerships. The NIAMS Collaborations with the

National Cancer Institutes Cancer Moonshot program was also presented. Work in Cancer especially surrounding angiogenesis and therapies for treatment have direct impact on SWS and vascular overgrowth.

Dr. Gayle Lester, Director of Division of Extramural Research moderated a session which updated the Advisory Council from each of the respective section leaders and recommendations for awarding grant funding for reviewed projects was also presented.

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases; the training of basic and clinical scientists to carry out this research; and the dissemination of information on research progress in these diseases.

The NIAMS has selected Robert Colbert, M.D., Ph.D., as the Director of the NIAMS Clinical Research Program and Gayle Lester, Ph.D., as the Director of the Division of Extramural Research. Dr. Colbert assumed his role on February 16, while Dr. Lester will take her post starting March 1.





Month of Awareness 2020: The Many Faces of Sturge-Weber Syndrome

These are the many faces of Sturge-Weber Syndrome.

1 out of 20,000-50,000 babies are born each year world-wide with Sturge-Weber Syndrome, a rare disease that causes:

- Port-Wine Birthmarks
- Seizures
- Glaucoma

Currently there is no cure.

With your support we can change the face of Sturge-Weber Syndrome.

www.sturge-weber.org

The SWF Month of Awareness, May, is less than two months away. This is our opportunity to educate and spread awareness.

Even though it's the 21st century with so much advanced technology and vehicles for communication, SWS is still unknown to so many. Education and awareness eliminates fear and stigmas.

Did you know that your own personal story is the best advertisement for our cause? May is **your** month to share **your** story in **your** community, through social media, holding a fundraiser or simply hanging the SWF Month of Awareness poster for the public to see. We can change the face of SWS, together.

In the center of this Branching Out issue is our Month of Awareness

poster. This year, we have given you the opportunity to personalize it by adding a photo of your family! Simply tape or glue a photo in the designated area of the poster.

Ask your community coffee shop, school or grocery store if you can hang the poster at their location. Additional posters can be downloaded from the SWF website.

Additionally, SWF is holding several Patient Engagement Days for Awareness across the country! Not only is it an opportunity to spend time together, it makes a big impact on others we come in contact with!

Check out what's happening in your area and considering joining us! **Ya'll come on out and join the fun!**



Let's Make An Impact Together!

The Sturge-Weber Foundation Month of Awareness
Night at the Ball Park!
Saturday, May 23, 2020 | Atlanta, GA

If you love baseball and live in the Atlanta area, save this date!

Join us at Truist Park as the Atlanta Braves take on the New York Mets!

Let's impact SWS public awareness together!

Save the Date: Night at the Ball Park - Atlanta, GA

Saturday, May 23, 2020 | 3:00 PM

Truist Park | Atlanta Braves vs. New York Mets

Contact Julia Terrell for questions or to register: jterrell@sturge-weber.org

The Sturge-Weber Foundation
PATIENT ENGAGEMENT DAY

Let's Make an Impact Together!

SAVE THE DATE
MAY 17, 2020

Calling all families in or near Slidell, Louisiana - please join us for a family style bar-b-que and celebrate SWS Month of Awareness together!

Details coming soon.

Questions?
Contact Julia Terrell
jterrell@sturge-weber.org

Save the Date: Family Bar-B-Que - Slidell, LA

Sunday, May 17, 2020
Time: TBD

Contact Julia Terrell for questions or to register: jterrell@sturge-weber.org



Growing Golden: SWS, Pregnancy & Childbirth

by Anne Howard

Growing Golden isn't just for SWF members already there – it is hopefully an informal guide for members in their 20s and onward, and for parents who wonder what the future might hold for their children.

Several months ago, we began to develop a survey that would give some answers and produce some advice for our young women with SWS and PWB who are ready to have a child and wonder how having SWS or PWB would impact pregnancy and childbirth.

We sent out the survey via our monthly eNews and had only a slight idea of what the response might be. It was not a formal research survey and women of all ages who have had successful pregnancy and childbirth experiences were invited to respond anonymously.

The following report is still a work in progress because we have also asked any woman with SWS or PWB to now share her experiences with us.

There is also a profile of a mom who has SWS/PWB and two young children, and a short essay by another mom of 5 that illustrates the fact that every case of SWS/PWB is different and every mom has a different story.

Pregnancy and Childbirth Survey

Many thanks to the women who responded to our online survey so we can share the encouraging news. Our thanks also to **Stephanie Tikkanen** who was a professor of Communications at Ohio University. She is the aunt of a child with SWS and has been a good friend and consultant to the SWF.



She has recently moved to California with her family, including her second child just born in December. Stephanie made many suggestions on the wording of the survey, did the technical work that installed the survey on-line and gathered the data.

The Stats

There were **45** respondents. That is more than we anticipated.

26 women report having a diagnosis of SWS/PWB and **6** with PWB only. But the remaining **13** did not answer the question about their diagnosis. Puzzling, but it could be that the question was interpreted very strictly – many adults do not have a documented diagnosis of SWS, one that insurance companies, researchers and other medical offices require. But they have always been aware of and assumed to have SWS/PWB because of their medical histories.

13 women report a history of seizures, **30** do not have that history. The seizure drugs taken during pregnancy were Dilantin and Carbamazepine, as well as Phenobarbital. Most were considered high risk. This is important because the side effects of seizures and the medications seem to be the most problematic in dealing with pregnancy.

(One thought a member shared was that she had no break-through seizures with her first child but did with her second. Because we now have the option of ultrasound technology to learn the gender of the baby, among other things, she knew that she was carrying a girl. Her doctor suggested that her estrogen level combined with the baby's estrogen level was probably a seizure trigger. Therefore, medication could be adjusted. Women with SWS who gave birth in previous years – before ultrasound was routine – would not have had this information.)

On average, there were **2** successful pregnancies per respondent with a high of four children, this for a mom who has PWB only.

The **majority** of moms gave birth via C-section but some gave birth via normal delivery. This is also hard to pinpoint, since some moms who gave birth vaginally the first time had a planned C-section the next times. Moms who have glaucoma are routinely advised to have a C-section to avoid the increased pressure on the eye that labor contractions and pushing bring on.



We know that several moms have reported an increase in swollen gums and dental problems on the birthmark side of their mouth. All these seem to go away after delivery.

The age of the mothers at birth ranged from 19 years to 45 years – (this was a happy finding for “older” moms). Still to wonder about is what influenced or aided the childbirth experience. Did moms who gave birth in the 1970s or 1980s have fewer procedures and options available to them than moms now? For instance, no widespread use of ultra-sounds or epidural anesthesia. Or the choice of unmedicated delivery or birthing centers with midwives.

This is where we hope moms who have SWS or PWB will share their stories with us. Because this was an anonymous survey, we do not know who answered what question, so we cannot follow up and ask for details. You can email Anne Howard at ahoward@sturge-weber.org to help us develop a more complete story.

It would be interesting to know what young women in previous

years were advised about becoming pregnant and how they dealt with that. Also, what kinds of support was helpful from their families. Thank you for taking time in your busy day to help.

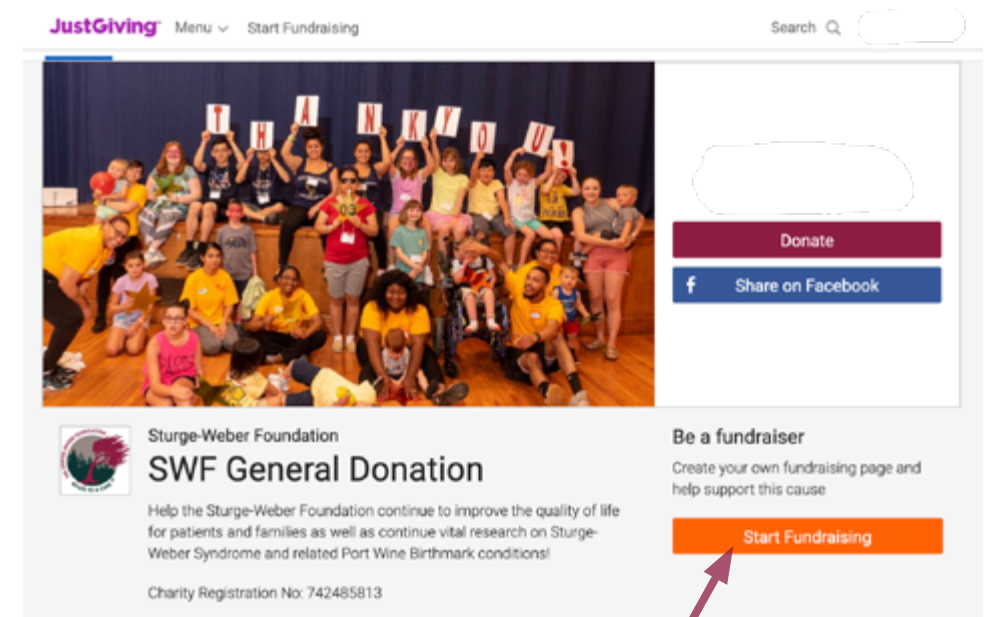
Recommendations & Suggestions

- Inform all your doctors and dentists about your pregnancy and request their input.
- If a high-risk specialist is recommended, use that doctor as the “quarterback” for your care.
- Do not skimp on good nutrition and sleep.
- Keep a positive outlook especially with relatives and friends who may be apt to question your wisdom in being pregnant. Old theories and old tales die hard.
- Have a care plan in place for any post-partum occurrence like seizure recurrence, changes in birthmarks or spike in eye pressure.



JustGiving | SWF's New Peer-to-Peer Fundraising Platform

Check it out! As of January, 2020, SWF has a new peer-to-peer fundraising platform - **JustGiving**. This new platform is much more robust, integrates directly with SWF's donation database (no more manual entry), saving time and money and allows the fundraiser to personalize their own page, push out to social media platforms, or copy and paste links in emails, and invite others to fundraise with you.



It's very simple to use, with step by step instructions. You have your own personal fundraising account page that you can update and use over and over again for different fundraising events.

To start - got to <https://www.justgiving.com/campaign/BELIEVE> and click on the orange “Start Fundraising” button.

The best advantage to this new platform is, SWF is provided with the names of donors so we may acknowledge their support. Facebook fundraising is great, unfortunately, we cannot capture donor information for acknowledgements on their Network for Good platform.

We encourage you to try **JustGiving**, then push your personal fundraising page to your Facebook page. Whatever method you use, we appreciate everything you do. What you do, however you do it, touches the lives of others experiencing similar life journeys. **We are grateful to be a part of it with you.**



2020 Reunion of Champions - Playing it Safe

The 2020 Reunion of Champions, which follows the American Academy of Dermatology's Annual Meeting, was postponed for the first time in 18 years as a preventative measure to avoid the spread of COVID-19.

2020 Reunion of Champions Honorees

**Dr. Henry Chan
Hong Kong**

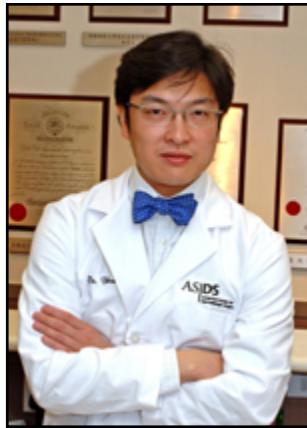
**Dr. Jill Waibel
Miami, FL**

**Thank You to Our
2020 Partners**

Dr. Henry Chan
Dr. Jill Waibel

Alastin
Allergan
Dr. Lisa Arkin
Candela
Craig Drill Capital
Cynosure
Dr. Roy Geronemus
HydraFacial
Dr. Kristen Kelly
MiraDry
R2 Technologies
Softwave
Sciton

The Reunion of Champions offers SWF the opportunity to share our mission and vision with the Dermatology and Laser industry. Each year we honor professionals who have



supported the Foundation's cause and been instrumental in the care and treatment of patients with SWS and PWB across the world.

Our celebration was unfortunately cut short this year as we, like the rest of the nation, take preventative measures to reduce the spread of COVID-19.



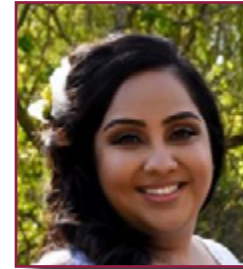
We will celebrate this year's honorees through a virtual presentation, so stay tuned, details to come!



The Sturge-Weber Foundation



Meet Our Newest Staff Member!



Please join us in welcoming Maristel Aguilar to the SWF staff. Maristel began working part-time with SWF in January. She provides much needed office assistance in accounting and administrative duties. Maristel has a true heart for the non-profit sector and is passionate about helping others. Outside of work, she has started a business venture with her sister-in-law and is very active with her church, including singing during worship services. We are grateful to have Maristel on Team SWF!

SWF Clinical Care Center for March: Children's Hospital of Michigan

Congratulations to Children's Hospital of Michigan as our Clinical Care Network for the month of March. We would like you to meet the following team:

Aimee Laut, MD, Pediatric Neurology is an Associate Professor of Pediatrics and Neurology at Wayne State University and is a board-certified pediatric neurologist and epileptologist at Children's Hospital of Michigan. Her clinical and research interest includes epilepsies associated with TSC, Sturge-Weber syndrome and Lennox-Gastaut Syndrome.

Michael Behen, PhD, Neuropsychologist, is a clinical psychologist/neuroscientist in the Translational Imaging Center at Children's Hospital of Michigan. Dr. Behen's research and clinical interests include the neurocognitive, behavioral, and imaging correlates of early social deprivation, Tourette Syndrome, and developmental and psychiatric disorders.

Marla Jahnke, MD, Derm Clinical Director, specializes in Botox and Facial Fillers, Pediatric Dermatology, Skin Repair and Care

John Roarty, MD, Pediatric Ophthalmology, is Chief of Ophthalmology at Children's Hospital of Michigan. He is an Associate Professor of Ophthalmology at Wayne State University School of Medicine and the Kresge Eye Institute

Leigh Flore, MD, Pediatric Genetics, is a clinical geneticist in Detroit, Michigan and is affiliated with multiple hospitals in the area, including DMC Harper University Hospital and Children's Hospital of Michigan.

Sandeep Sood, MD, Neurosurgeon, is a Pediatric Neurosurgeon and an Assistant Professor at Wayne State University School of Medicine.

Csaba Juhász, M.D., Ph.D. Vascular Clinical Director and a Professor of Pediatrics, Neurology, and Neurosurgery at Wayne State University School of Medicine. Dr. Juhász's research interests are in functional and structural neuroimaging of epilepsy, brain tumors, and developmental brain disorders, with a particular interest in the pathophysiology and progression of Sturge-Weber syndrome.



BETTER TOGETHER

Catching Up With the SWF Community

Gloria Andolina is now the mom of 5 school age children. She and her husband Lee live in suburban Rochester NY. She has a port wine birthmark and glaucoma and is a certified health coach. She and her family are ice hockey fans as well as being active recreational players. She emphasizes that this is her story based on her history and her abilities and beliefs.

Straight From Gloria . . .

When we wanted to start a family, I consulted both my ENT (a pediatric ENT who is the only one in our area who provides laser treatment and who took care of my PWS) and my ophthalmologist. Both my birthmark and the eye that was affected by glaucoma were monitored during my first pregnancy and after childbirth, and there were no issues. Things they were looking for were:

- Increase in eye pressure or change in vision due to pushing during labor and hormonal changes
- Increase in size or darkening of PWS due to increased blood volume during pregnancy
- possible onset of seizures
- passing my condition to my children

I had no problems in any of those areas. I did have dental issues - my gums became swollen on the PWS side and I had more bleeding and sensitivity in my gums. But that has since dissipated. I didn't have any special monitoring for the next 4 pregnancies.



I loved being pregnant each and every time. I loved labor and delivery too. After having the first two in the hospital with no intervention or drugs, we opted to have the last three at home - a water homebirth in a birthing pool in front of our fireplace in the living room. Each pregnancy and



childbirth was beautiful and special. I didn't have any problems and all five children were born healthy and are thriving.

My advice to every woman, with a medical condition or not, is to embrace the experience! Trust in your body and the process of pregnancy and childbirth. Our amazing female bodies are equipped to do amazing things. Modern medicine likes to intervene in this natural experience, making it more of a medical emergency. Taking care of yourself before and while you are pregnant with good clean food, gentle exercise, fresh air, and avoiding unnecessary medications and excess

testing will give you and your baby the best chance of a positive experience.

I had the opportunity to be a doula 3 times the past 2 years for three different women that I love. Helping them give birth the way they wanted and supporting them during their pregnancy is an experience I will hold dear to my heart. I would actually love to become a certified doula in addition to my health coaching and possibly make a career out of it once I'm done homeschooling this crew! My husband has been my "doula" for all five of our births. **We make a great team.**

Rebecca Wolfe Szorcik lives in NJ with her husband Scott and two school age children, Aaron and Eden. She was been with the SWF since her parents found the Foundation in late 1989. Rebecca also worked at the SWF NJ office as a volunteer occasionally in 2009 to help with fund raising events.

Rebecca's Story . . .

I was born in 1979, before there was a Sturge-Weber Foundation. I was born with a port wine stain on my face, eye, scalp, and neck. Luckily, I have never had issues with my eye pressure. I have calcifications on my brain, and I have always needed a lot of sleep - I usually can't function on less than 8 hours of sleep. I experienced my first seizure at the age of 3 but fortunately, after a few seizures, the seizure activity was stable. I started laser treatments for my birthmark with Dr. Roy Geronomous when I was in 5th grade. My parents always let me take the lead in setting goals for myself. I was never told I could not do something due to my Sturge-Weber.

I grew up in New York City, and was lucky enough to attend private schools. Despite my learning disabilities due to Sturge-Weber Syndrome, I graduated high school having been on the honor roll all 4 years and then attended and graduated from Mount Holyoke College. I began my working career on Wall Street before changing fields to teaching. I obtained my master's degree from Columbia University. I live in suburban New Jersey with my husband and my two children. I have always been under the care of a neurologist; however, the frequency of the appointments has changed throughout my life. I was first followed by a pediatric



neurologist, which I continued to see into my 20's. I changed to an adult neurologist in my mid 20's. I took care to find a neurologist who not only was well versed in Sturge-Weber syndrome, but her specialty was also epilepsy and pregnancy. I knew I wanted to have children, so it was important for me to find a neurologist that would be supportive with my decision.

I became pregnant with my first child in 2010. I was under the care of a high-risk doctor, not for the health of my child (since SWS is not hereditary), but for me. I had been with the same gynecologist since I was 15. While she does not do obstetrics, I knew that she would recommend someone who was equipped to handle anything my Sturge-Weber decided to throw at us. I had every pregnancy symptom in the book: morning sickness (for all 9 months), heartburn, leg cramps, fatigue, heightened sensitivity to smell (the smell of laundry detergent was awful), there was increased bleeding from my gums when I would brush my teeth, as well as a few other lovely symptoms. Because my eye pressure was stable, my ophthalmologist did not increase the frequency of my eye pressure checks, electing to keep the checks at yearly intervals even after my pregnancy.

When it came time, my neurologist suggested that we find out the gender of the baby so that we had all the information that was available. Despite my health issues, I gave birth to a healthy baby boy on November 5, 2011 (5 days after my due date) weighing 6 pounds, 6 ounces. I had a

regular vaginal birth accompanied by an epidural.



I became pregnant with my second child in 2013 – a girl this time. Again, I had all the lovely pregnancy symptoms that I had with the first one. In May of 2014 at the age of 34, I experienced my first seizure in 29 years. Just like my previous seizures, this one was a focal seizure. I will be forever grateful that my son was sleeping in his crib so did not witness it. When I called both my neurologist and my high-risk obstetrician, they both said the same thing: "Get the baby checked out first to make sure you did not fall, roll, etc. on your stomach!" My mother happened to be at the house that day, so she watched my son so my husband and I could make the trip into New York City.

We know now why I had a seizure and what caused it. When I carried my son, my hormone levels were elevated,



but still in check. When I was carrying my daughter, there was such a surplus of female hormones with no male hormones to balance them; it pushed me over the limit. Luckily, everything was fine. For the first time in decades, I was put on anti-seizure medication, which I am still on to this day. As my doctor says, "You drive with your kids in the car. You are carrying precious cargo; it is not worth the risk." I was induced one week before my due date because she was not growing from the prior week appointment, possibly due to the Keppra I was taking. I had no other seizures during my pregnancy and delivered my healthy baby girl, with a vaginal delivery, on July 29, 2014 weighing 6 pounds, 12 ounces.

your gut. Additionally, my father always would remind me to make sure I take care of myself. It is a hard thing to do as a mother, but he would always remind me, "on an airplane they make you put on your oxygen mask before helping others." When I had one child, it was easy to ensure I got the sleep that my body needed – sleep when they sleep. When you have two children, it takes wonderful grandparents and a great husband willing to help out to make sure that you get the sleep you need. My parents would come once or twice a week so I could take a nap! There have been a few surprises/challenges that I did not expect, which I have had to address with my children as they have gotten older. The first is that I

Don't let anyone tell you that you are a bad mom, listen to your doctors and your gut.

While I exclusively breastfed my son, all my doctors (high risk obstetrician, pediatrician, neurologist) and I agreed that it was not worth the risk to expose her to my Keppra. Some members of the maternity ward did not agree with that decision. Go with your gut and do what you think is best for you and your child! In some ways it was easier because my husband and I took shifts, so I was able to get more sleep than I did when my son was an infant. And since she was bottle-fed, my husband could say, "Now I have the right equipment to help!"

Don't let anyone tell you that you are a bad mom, listen to your doctors and

had to educate them on what a seizure is, so they won't be scared if it happens again and they are unlucky enough to see one. I am now 5 ½ years seizure free. As my neurologist has pointed out, Sturge-Weber is never typical and the next big milestone to watch for in my seizure activity is menopause. Just like puberty and pregnancy, the change in hormones can be an additional trigger. I know they will be scared, but if I can help lay the groundwork that "mom is ok", I think that will help!

The second challenge related to my SWS I have had to deal with relates to laser treatments. I have received treatments for the port-wine stain with

SWF COMMUNITY



Dr. Gerenomous from 5th grade until my mid-20's and decided to take a break. I resumed treatments in 2016 when my oldest was almost 6 and my youngest was a little over 2, since I was developing blebs (thickened nodules like pimples) as my skin aged. My parents come and bring their dog and stay with us for about a week while I recover.

My kids love having their grandparents sleep over for a week and it makes the situation a bit less scary for them. It has become our routine. I always let their teachers know ahead of time, and it is very interesting how differently they react. My son always gives me "extra love and attention" when I come home with my dots. My daughter is usually a bit hesitant to hug me at first, but when Grammy and Pop leave, she becomes much clingier.

What challenges will the future hold in helping my kids deal with the fact that life throws unexpected things at you? Will I ever have a health episode in front of them? Who knows! What I do know is that I was able to have 2 healthy kids and while they have had to experience things that are unique, I think it has made them stronger. They know that toys with flashing lights are not good for mom. They know that mom will have her "polka dots" every few months.

The stronger the wind, the tougher the trees! As a mom, I would have liked my children to have developed their strong branches in a different way, but whatever we face in our journey with Sturge-Weber syndrome, I know with the loving support of my husband and my parents.



Social Media Survey: What Can SWF Do More To Communicate With You?

The SWF would like to hear from you our members. Social media is so important and we want your opinion.

Please take the SWF survey by typing in this link:
<http://alturl.com/7zsxk>

Thank you in advance for your time.