



The Sturge-Weber Foundation
12345 Jones Road, Suite 125
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believe
you. us. progress.



A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

JUNE | JULY 2019



PROGRESS:

Marrisa Terrell and Congressman Norcross, NJ
Patient Drug Pricing Roundtable



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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

June | July 2019

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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.

(continued from page 3 - Connecting with Karen)

short term and long term goals which all need a variety of volunteer and financial resources to accomplish our goals. The impact of Angiogenesis, cluster seizures, migraines, glaucoma, psychosocial issues, and the discovery of the GNAQ gene mutation and so much more have been answered or illuminated because the SWF fostered collaborations and in many cases funded basic research to get you the answers! YOU. US. PROGRESS.

Lest you think I'm all work and no play (and if you do don't tell) . . . I can't wait to see you all at the SWF International Family Conference in just a few short weeks! We will learn, walk, dance, cry, laugh and strengthen bonds of friendship, new and old! I'm particularly excited to have a complimentary mani and pedi and massage as part of the very generous anonymous donor's contribution to the weekend! Sign up before the appointment slots are all gone . . . you deserve a little pampering! Guys, you don't worry, we didn't forget you either. Enjoy a round of golf and the beautiful nature of Delaware!

Lastly, I hope all the dads had a wonderful Father's Day! I know I wouldn't be where I am today without my daddy!

With faith, hope and love,

UPCOMING EVENTS AT A GLANCE

- Karen Ball will be in **Puerto Rico** for the Brain Vascular Malformation Consortium Meeting, June 12th-14th
- Karen Ball will be in **Houston, TX** at the SWF Coffee Lovers Brunch, June 23rd
- The SWF Staff will be at the 2019 International Family Conference and SWF International Research Network Conference in **Wilmington, DE**, July 18th-20th
- Brian Fisher will be in **Falmouth, MA** at the 10th SWF Falmouth Road Race, August 16th-19th



For a list of the Sturge-Weber Foundation's Clinical Care Network Centers across the country, please visit our website at:
<https://sturge-weber.org/for-patients/>



CALLING ALL TROOPS!

Karen L. Ball
Founder and CEO

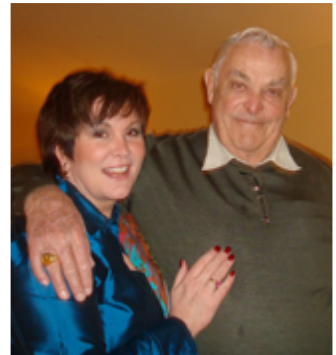


My dad used to always tell me, "Kar, plan your work and work your plan!" Being a dutiful daughter, I have always given it my best shot. Honestly, it was work ethic and tenacity which have guided me all these years and of which the Sturge-Weber Foundation has been a blessed recipient of his wisdom.

When the SWF began in 1987, we started with a plan and have been working the plan and revising it as resources were abundant or scarce (as in 2008) over the years. Today, I'm calling all my troops to join me in taking the SWF and you to new unexplored front lines! It's an exciting time and here's just a few reasons why:



We have many new online social media and relationship building sites at our fingertips. It's second nature when a question arises around SWS, K-T or Birthmarks to flip on the phone and ask our Facebook peeps. I'm calling on you to join the already almost 1,000 other people diagnosed with SWS to share, archive your medical and quality of life issues in the SWS International Registry (<https://swsregistry.patientcrossroads.org/>) so we can continue to amass collective data which serves as a clinical guide for treatment and for research into new genetic information and treatment.



A HUGE celebratory shout out to Dr. Helen Kim, the Brain Vascular Malformation Consortium (BVMC) Lead Principal Investigator, and the respective Project Leaders for a successful 5 year renewal of the BVMC grant! Anne Comi, MD did a yeoman's job the first 2 rounds and Jeffrey Loeb, MD, PhD will take the helm of SWS Project 2 to new heights with all our help! We need you now more than ever for this very important study which is just one of many in the works ... without YOU there is no PROGRESS!

The SWF has been able tirelessly facilitate and foster research in the eye, brain and skin by interacting with clinicians and researchers at medical meetings and in person SWF sponsored meetings. The Foundation we laid in 1987 when we planned our work to one day find the answers to many questions surrounding a SWS diagnosis and birthmark has been made possible because all the troops have been pulling in the same direction supporting and funding the plan! The plan has

(continued on inside back cover)



Nemours / Alfred I. duPont Hospital for Children
July 18 - 20, 2019 | Wilmington, DE



It is hard to **believe** that the 2019 SWF International Family Conference is next month! The staff is excited and looking forward to seeing friends and families again. If you are still considering attending, you're in luck, you can still register!

REGISTRATION INFORMATION:

Adult (18 and over): \$300

Child over 3: \$250

Child under 3: \$50

Saturday Night Celebration Cruise (per attendee): \$25

- Hotel accommodations are at the Sheraton Suites in Wilmington, DE (*hotel is not included in the registration fee*)
- Transportation is included

Full details and online registration, go to:

<https://sturge-weber.org/who-we-are/the-2019-swf-international-family-conference/>

Don't forget to sign up for the SWF Route to a Cure walk on the beautiful Nemours Estate. There are great opportunities and events planned the entire conference time! We encourage you to register and join us for this memorable and informative conference. **See you there!**



2019 Clinical Care Network Annual Conference

The poster features a night view of the Chicago skyline with a boat on the water. The Sturge-Weber Foundation logo is in the top left. Text includes: 'THE STURGE-WEBER FOUNDATION', 'CLINICAL CARE NETWORK', '2019 ANNUAL CONFERENCE', 'SEPTEMBER 19-21, 2019', 'UI HEALTH Chicago, IL', 'SAVE THE DATE!', 'Start planning now to attend this conference with other CCN professionals to review 2018-2019 conference initiatives and set goals for 2019-2020.', 'One member from each CCN is required to attend the 2019 conference.', 'DETAILS and REGISTRATION coming soon via email. QUESTIONS? Julia Terrell jterrell@sturge-weber.org', and the UI Health logo in the bottom right. Two small photos of a woman with a child and a young boy are on the right side.

Each year the SWF plans a special conference for the SWF Clinical Care Network Centers. This conference is designed to bring together clinical and research professionals from the SWF centers to discuss progress being made in the dermatological, neurological and ophthalmological areas over the previous year.

Each center sends at least one participant to update other centers and the Foundation on current work being done, patient progress, and new professionals who have joined their team of specialists.

The conference is led by Dr. Jeffrey Loeb, the SWF's Chief Clinical Stategist. With his leadership, the Foundation is hopeful to develop a concrete protocol and guideline for SWS patients which will provide physicians and medical industry with the necessary information to make an accurate diagnosis and guidance in treatment immediately. It will also provide professionals in emergency care with information on specialized treatment of SWS patients.

It is through conferences like this, that cultivates the collaboration of many and the belief that modern medicine can provide answers that keeps progress going!



ON THE ROAD AGAIN WITH SWF

Association for Research in Vision and Ophthalmology (ARVO) Conference - Vancouver, BC

Brian Fisher attended the ARVO Conference in British Columbia, May 1-4, 2019. It was quite an opportunity to expand the SWF reach into the Ophthalmological research world.

Brian met with Dr. Sanjoy Battacharya, Professor at Miami University Bascom Eye Institute. They discussed the need for increasing the eye tissue and the necessary and consistent steps of collection. Dr. Battacharya will be working with the SWF Directory of Pathology, Strategies, Dr. Thuy Phung, in establishing collection standards, targeted next steps in eye research and the quantity of tissues for a meaningful statistical analysis.



Brian Fisher and Holly Swain,
VP of iCare

Brian also met with Holly Swain, VP of iCare, to discuss the next steps in collaboration which they will undertake with the Clinical Care Network, specialists and SWFIRN projects. Holly has been an enormous supporter of the SWF and approached the SWF to develop a caregiver model research project.

This project will be launched at the upcoming 2019 International Family Conference, so stay tuned!



Society for Investigative Dermatology (SID) - Chicago, IL and NIAMS Advisory Council, Washington D.C.



The Society of Investigative Dermatology (SID) is THE place to be to learn about the latest research being conducted in dermatology. Many of the current research abstracts and studies are being done on eczema, alopecia areata, psoriasis, acne, vascular malformations and several other diseases that have GREATLY advanced their knowledge of their respective disease states. The SWF interacts with young investigators and their mentors to learn more about their research and the crossover collaborations that may be beneficial to us both.



For instance, alopecia areata years ago started looking into the role the immune system plays in their disease. SWF staff learned more and then at an eye research meeting found a glaucoma investigator in Germany, Dr. Franz Grus, who was researching the link between immunity and glaucoma. He received a grant which confirmed that SWS has immune suppression. All this thanks to the SID and Coalition of Skin Disease (CSD) sharing and learning together!

You may ask how these diseases also have found their gene(s) and new drugs being developed to address various aspects of their diseases. . . trusted collaborations, skin tissue samples, cell lines, mouse models, and more.

Karen and Kirk Ball Believe!

So, as our beloved Anne Howard likes to say, "What's It Mean to Me?": It means that together we can make the same strides and generate a better future for those who will live with SWS and Birthmarks too! It means many questions you have about laser treatments, seizures, glaucoma etc will have answers!

We need you to BELIEVE the same explosion of research can occur in SWS!

We need you to GIVE tissue samples to Dr Thuy Phung and our Research Network!

We need you to make an IMPACT with donations, special events, corporate contacts and leads which WILL lead to critical funding to ignite HOPE through Research!



BELIEVE IN PROGRESS

Written by Anne Howard

One of the core beliefs of the SWF is Belief in Progress. But Progress does not just happen naturally, like a weed growing by itself. It often takes an idea, sometimes one that comes to many people at the same time – when the time is ripe – when the world around you says “now is the time”. And even then, it takes energy and persistence and courage and faith.

Many families facing SWS or any rare disorder know the experience of facing the heart-wrenching decisions that often must be made. Sometimes it is to face the thought of serious surgery for their child. Often it becomes the decision to have their child live in a safe and nurturing environment when they can no longer provide it in the family home.

This Branching Out issue brings the story of one family who faced these real-life challenges in the 1960's and 70's. Read about them with the knowledge things were not as patient-oriented and family-friendly as they are today. The challenges families face today can be met with so much ammunition that was not around 30 or 40 years ago. These are the stories we need to remember.

While the tools may have improved, the emotional and rational struggles are still present. Using the tools at their disposal, families still must face their own challenges. But small steps toward the goal back then resulted in whatever progress the disability community has made. Something for us to build on. This is a story of one family's role in that progress.

Ann Nehrbaauer of New York shares the journey her family has made from the 1960s until now. Her son Stephen is now 62 years old and they have been with the SWF since 1990.

There are so very many situations to consider when deciding what is best for all the family, not just the person with Sturge-Weber. Because of Stephen's age, now 62, services including school attendance was very different way back then, as were any respite care or help for the ordinary family. Children with disabilities were categorized as either **educable or trainable**.

SWF Growing Golden - Believe in Progress



If your child was deemed **educable** then you might try to fight his way into a classroom. If the child was only **trainable**, good luck. If you could afford it, you might find a program to which you would have to transport him. The education laws came along rather late for Stephen as by the time he was 8, we were expecting another child. Stephen needed almost full-time attention and the four older children needed attention and care too. Our family was given no choice and even advised to institutionalize him.

We took Stephen home for a summer vacation and on the holidays, because we always wanted to make sure he grew up knowing his brothers and sisters. Willowbrook was in a desperate situation, although they did have a school of sorts on weekdays using the education law monies to provide it to the trainable group. There were nearly six thousand people there then, children and adults.

Over those 16 years I cannot count the times I looked back and saw he

That had been advised at age 6 but it took us two rough years to realize it was the only way to preserve the family. Believe me, it was heartbreaking, but God is good, and we made it work the best we could. We visited him often in Staten Island (NY) at Willowbrook State School. We took our other children in turn to visit him.



As we did not have a car then, we used public transportation. It took us a little over two hours to get to Willowbrook from Westchester (NY). If we had one of the other children with us, they thought this was an adventure, (going on a train, subway, ferry boat and bus). We got the NY Central train down to New York City (Manhattan, then a subway down to South Ferry, then the ferry across NY Harbor to Staten island, then a local bus to Willowbrook.

was watching us leave those grounds with tears in our eyes. Only by the grace of God did we endure, but more so Stephen endured those years.

We had approached the public school at age 5, even though there was no law that they had to take him, just for part time. No luck. The Westchester Help of Retarded Children (now the ARC) had a small program but the family had to transport him to and from for a half day and we did not have a car then.

We went to local religious agencies but were turned down as they had no



appropriate programs. As it turns out, I was therefore put in a position of being a witness in federal court to testify to the disaster of Willowbrook and the need to close it and bring our children to their birth community homes with the support services needed to dignify their lives, not have them existing in a ward with 80 or 90 others.

In 1975 I joined other parents in a lawsuit against the State of New York to close the place and create community group homes.

We advocated at all levels for services in the community and finally with the help of the Civil Liberties Union and Lawyers for the Public Interest, who came with us as a friend of the court. Much public attention at the time came from the newspapers and TV. We did succeed in getting the Willowbrook consent agreement and an injunction that broke the chains of the institution.

Now, thanks to the internet, you can learn all about our struggle by searching Willowbrook State School. (Such a sweet name for a horrid place).

Could we have included Stephen in the choice of moving out of our home? Stephen is in the severe range of functioning but has good speech – often with lack of understanding but he

surprises us at times. When we would bring him home for a vacation and it was time to go back to Willowbrook, he would resolutely repeat “I not go back” at which I would put on my serious voice and say “Oh yes, you will, just like your brothers and sisters go to school. You know we will come and visit you soon”. That was it and into his building he would go.

Would I have done anything differently so long ago? I don't think so. As my husband put it “when the ship is sinking someone has to bail out”. That was Stephen, because we had the responsibility of five other children to care for and no other help.



Now Stephen lives in a home near us with 24-hour staffing and goes to an OT program daily. He has lived there 40 years with seven other people, happily. We visit him, just as we might visit our other adult children. His balance

and mobility are declining with the atrophied left side and has hypertension and some medical problems found in the general population at age 62.

He is now more accepting of disagreeable situations. He cannot read except for known advertising signs of many products. He knows the calendar and marks it for visiting dates or special events. His seizures have been much less frequent than in the early years when we changed medications often.



He cannot dial a phone but loves to answer it or talk when we call him. Usually, children grow up, become independent and self-sufficient and move out of the nest. So it is not too strange that those who will not become so, could move out of the nest too, but to a place that will supply protection, security and a lifestyle to fit their individual needs, medically and in an habilitative environment whether their status is educable, trainable or profound.

It was an Ann Landers newspaper article ages ago that alerted us to the Sturge-Weber Foundation. What a blessing. Over the years I have called the SWF for information and most recently I had Stephen at the Center of Excellence at NYU (now an SWF CCN) concerning a tooth extraction on the area where the roof of his mouth shows the birth-mark. I was advised to have it extracted under anesthesia by the Center. Few people at the Westchester Medical Center in Valhalla knew SWS. The tooth was removed without any excessive bleeding in a short

20 minutes, stitched, and the bleeding was controlled and stopped. He healed well. He has a very high pain tolerance and does not admit to any pain.

My husband and I always had the idea that the other children did not have the responsibility to care for Stephen but of course to always include him as family, visit him when we are gone. My husband George died nine years ago. Stephen thought a lot about it and only asked "Who will take his place?". We assured Stephen his sisters and brothers would come visit him and take him places. That satisfied him. He has always been totally accepted by our immediate and extended family.

It is my firm belief that Stephen came into this world for a reason - a reason that did not appear to be within our expectations or planning. But God is the Divine Planner and author of all good, so Stephen is here. Our family is grateful that through years of trials and smiles, Stephen is settled in a good home, in the community, is given good medical care, has friends (even a lady friend) and is valued. Admittedly, it has been a long road to travel.

**“It is my firm belief that
Stephen came into this
world for a *reason* -
a *reason* that did not appear
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But God is the
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GROWING GOLDEN LEGACY

Written by Anne Howard

Before the progress in diagnosis and treatment of rare disorders like SWS, before the anti-seizure meds, before even the information for parents from medical sources, or the emotional and community support that comes from awareness, a family given a diagnosis of SWS for their loved one (usually a child) had only their own instinctual strength to guide them. So, they called upon their love for their child and persistence in the face of adversity to live with the challenges.

As we mark the passing of many parents and of adults with SWS, we always want to remember and pay tribute to the day to day courage and hard-won wisdom they have passed along.

When Tim Fitzgerald died in April, at age 65, he left a legacy of love and caring that truly branched out to his siblings and extended family. His parents, Herbert and Elaine, had joined the SWF in 1990 to learn what they could for Tim. When they passed in 2013 and 2015, his brother Kevin took the reins as guardian when Tim was in a nearby skilled nursing facility.

In a touching memorial eulogy, Kevin shares:
To grow up with Tim was to see and experience early on that life often isn't simple, or fair, or easy, or pain-free but also to learn through the other-worldly, relentless love and devotion of our mother, and the gritty dedication of our father, that these troubles in life that so often threaten to – and often do – consume is, aren't to be mistaken for life – rather life is given meaning and is sustained by the unyielding power of love. And through that power, one frail, damaged baby that was Tim in 1954 and thought destined to be with us perhaps 6 months or 6 years, left is instead more than 6 ½ decades later at a ripe old age.

Our condolences go to Kevin and Marie Fitzgerald and siblings and especially to aunt Ruth Eagan who sent us a sweet letter and a copy of Kevin's remarks.

**Love and
persistence
is the recipe
for facing
adversity**



And in this same month, we heard of the passing of the father of our SWF member Patricia Hill Grim. William David Hill was a retired State of NJ Supervising Judge. He was a decorated Army veteran of the Korean era. Kathy Hill, Pat's mother, who passed away previously, had often called the SWF office in NJ for information on medical suggestions and contacts. Pat Grim, who now lives in GA, is the mother of two young adults.

Glenn Beechler, age 47, also passed away the end of May. He is survived by his father,, Dale, daughter Alexandra and his sisters Deborah Pilapil and Jessica Passero.

The legacy of these families is shared by every family that learns the lessons of living with SWS. Like the ripples in a pond, once begun, it touches unknown shores.

**Family
legacy is
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PREGNANCY and SWS Survey

We know there are many women who have SWS or PWB who have had successful pregnancies. We are planning a survey to get a picture of the current status. In the past there was always a fear or reluctance to attempt pregnancy because of the medical challenges above and beyond the normal. With current childbirth practices and available medications, that possibility is now a reality.

Many women with SWS have children and can help us develop a survey that will add to the knowledge. Please let us know if we can count on you.

We have a list of survey questions planned, but need to know who can help us on the first step - developing an effective survey that targets the real-life concerns, not only the stats.

Please email Susan Finnell, sfinnell@sturge-weber.org and let her know you are willing to be a "consultant" on this particular topic.





you.
us.
progress.



believe
you. us. progress.

MARVELOUS MONTH OF AWARENESS!

Month of Awareness has come and gone again, BUT what an amazing month it was! The SWS community is strong, thriving and making PROGRESS. So many of you did your part in spreading awareness about SWS, and it truly does make a difference. Here is just some of the impact made in the month of May!

- Pam McIntyre held her annual Fit Revolution fundraiser in North Reading, MA.
- Jessica Melo held a fundraiser at Anytime Fitness in Grafton, MA raising \$837.00.
- Donnie Hood cycled in the Malorca 167 in Spain and raised \$6,087.78.
- Trish Bourne's Dance School raised \$175 combined at their dance recitals - The Super Girls and Steps Too groups.
- The Speer Family held Myla's Mission for SWS 5K Walk in Greensburg, IN and raised over \$16,000. They also held a fundraiser dinner at Arby's.
- The Saden Family held a MOA Open House and Ice Cream fundraiser raising over \$130.00
- The Arena family was honored in having the Berlin NY school district choosing to support SWF at their annual 5K Walk/Run event.
- The SWF Facebook page is now over 5,000 subscribers and had the best social posting month ever
- Special thanks to the following who honored us with their personal "championship" story during MOA: Chloe from Australia; Isaac from Oklahoma; Mallory from Texas; Myla from Indiana; Jeremiah in Washington; Bryon in South Africa; Camilla in Texas; Jason Roffers; Violeta from Michigan; Ryder from Missouri; Kamila from Puerto Rico/Florida; Mackenzie from Iowa; Sara from Sweden; Emma from Oregon; Marco from Arizona; Neeley from Texas; Summer from Tennessee; Robbie from Illinois; Jacklyn Kate from Arkansas; Tammy from Arkansas and so, so many more!

SWF Month of Awareness - RECAP



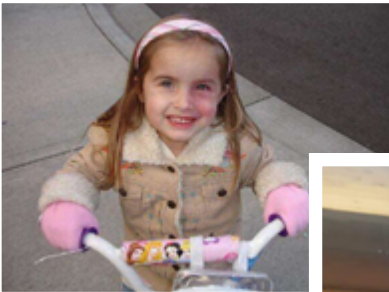
So much of our progress comes from all of us being a caring and sharing community. Across the globe we can be THE ADVOCATE for all those with SWS and be the source of improved quality in their lives! What an amazing TEAM! Please enjoy these photos from 2019 MOA.



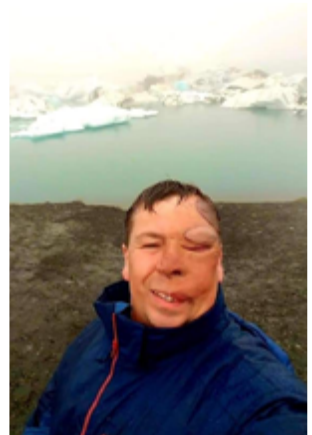
Donnie Hood
at Mallorca
312 in Spain,
April 27th.



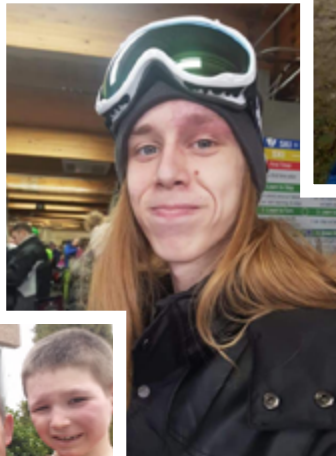
Camilla from Texas



Emma from Oregon



Robbie from Tennessee

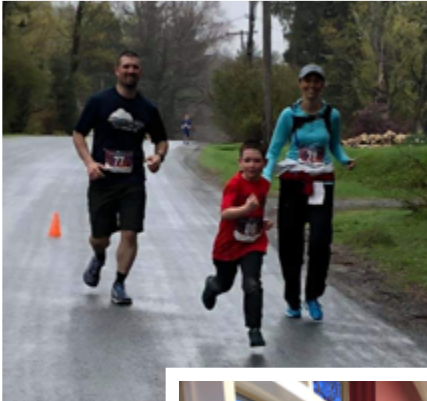


Isaac from Oklahoma



Evan and the Arena Family

SWF Month of Awareness - RECAP



Evan and the Arena Family



Steps Too Class



Silas and ? at Ice Cream fundraiser in Illinois



Super Girls Dance Group



Myla from Indiana



Myla's Mission for SWS 5K Walk in Indiana



BETTER TOGETHER

Catching Up With the
SWF Family



THE COVER STORY

Last year, my family, (Julia, Marissa and Scott Terrell) headed to Washington DC to advocate with the AADA. We had the wonderful opportunity to meet and talk with our Congressman, Donald Norcross. We spoke about pharmaceuticals and how insurance companies may not pay for brand name drugs and what that looks like for a family like ours.

By the time we returned to New Jersey, we had a call from his office. They had been working with insurance companies and others to get to the root of the problem and what needed to happen.

About a month ago I received an email from Congressman Norcross asking if I would be willing to share our story at a round table meeting on pharmaceuticals.

Marissa just happened to be on Spring break and we all agreed this would be a great opportunity to have her accompany me to the meeting. Marissa is learning about government in school. This was a great opportunity for her to see how research and collaborative communication can help make bills, which in turn can become laws.

Marissa got to sit next to the Mayor, and, together with Congressman Norcross, other patients, a pharmacy and a doctor, we discussed the issue in detail. It was a great experience for both of us.

At the end of the meeting, Marissa presented Congressman Norcross an SWF Heart of a Champion lapel pin and explained what it meant to her. She felt it was a good offering to him for all of his help and awareness the Congressman and his office have done for our family and so many others.



Marissa and I received wonderful handwritten thank you notes from the Congressman. In Marissa's thank you note he wrote, "You are a brave and strong girl, wise beyond your years. I have enclosed one of my challenge coins that recognized your special achievements and overcoming challenges and obstacles."

Marissa is truly her own advocate. She took the coin the next day to school to show her class and tell them about her special day. This goes to show that no matter how young or old you are, telling YOUR story is so important and the best way to advocate for yourself and others! It's PRICELESS!

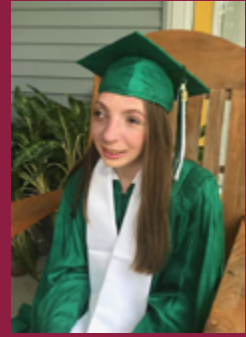
She was so proud and the best part she says is the coin is all about our Congressman. She said, "I am so lucky!"



CONGRATULATIONS!

Marlee Little

Carroll, Suzanne Little's granddaughter graduated from Maurepas, LA High School. She was honored with a special cord for being the only senior to receive the Star Student Award presented for growth, courage, determination and spirit. Marlee also participated in the Miss Maurepas Pageant and finished as high as second runner up!



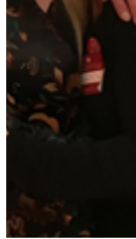
Carley Elliers of Slidell, LA, graduated from Northshore High School and will be attending the University of Southern Mississippi in the Fall to pursue a BFA in Dance Education.

Congratulations to these ladies and ALL of our members celebrating milestones this year!



SWF MOTHER'S DAY TRIBUTE

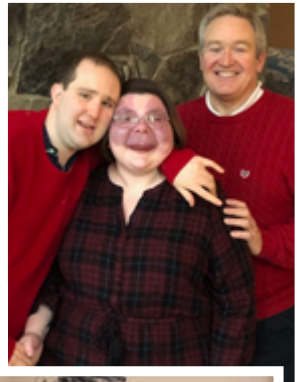
I Love you
mom





HAPPY
FATHER'S
DAY

SWF FATHER'S DAY TRIBUTE





Men Cry Too

written by Celine's Daddy

When a child is born with a disability we hear a lot of the mothers and well we should. In a lot of cases they bear the brunt of their child's disease. Not much is said about the fathers.

True there are those who choose to run, or to just turn their backs and not get involved. I don't consider them men at all. But there are real men who are there constantly and fight for their child every day and this is for them.

When my child was born, though I held it together for my family ... when I was alone, I cried.

As I watched countless doctors prod and poke, then deliver the news, I held my wife tightly as I cried inside.

I watched as other children the same age met milestone after milestone and as mine struggled to get to one, I cried in lonely celebration.

I work with my child with physical and occupational therapists both at home and in clinics trying to get to the next level. When she fails I cry. When she succeeds I cry.

Test after test, poke after poke I see her take it all in stride, for it's what she knows and I cry.

I hear the whispering talk when they see her port wine birthmarks and I hear the "what is wrong with her" comments and I cry.



I see her weakness as she approaches stairs and I try to take her hand, but she boldly says, "I do it", and I cry.

I count the minutes when she enters a seizure praying all the time, it doesn't go over 5 minutes and as I look at her limp body ... I cry

Then, seizures come one after another and I cry as I race her to an emergency room 15 minutes farther for our local hospital because they know nothing about her disease.

As I watch ER techs doing all in their power to stop the seizures, I feel so alone and break down in the arms of a social worker.

I see a little body laying in a hospital bed with tubes and monitors, laying lifeless, from a ball of energy just yesterday, and I cry.

I cry reading words of encouragement from people that have never met her yet love her and follow her journey.

SWF Community News




I see my other child, who don't understand, and feel like their sister is getting special treatment, for he does not understand all these trips to doctors and therapists are NOT trips to Chucky Cheese, I cry.

As fathers of children with disabilities, we try so desperately to hold it together for our families, so we cry alone most of the time.

So do us fathers cry alot. - yeah, we do But, I guarentee you we do not cry for ourselves. We cry for our children, our wives and families. Women like to talk about things and guys just want to fix things.

We cry because we are helpless. We can't fix this and it's hard. We will fight with every ounce of our being until these diseases, syndromes and the like are beaten.



SAVE THE DATE

**THE STURGE-WEBER FOUNDATION
EDUCATION CONFERENCE**

October 5, 2019 | 8:00 AM - 2:00 PM
Ann & Robert H. Lurie
Children's Hospital of Chicago
225 E. Chicago Ave. | Chicago, IL 60611

*To Register: Contact Carolyn Kielbasa RN with questions or to register -
312-227-8521 or email vlc@luriechildrens.org.*

*There will be activities for the children so parents can focus on the information. Our day
will end with lunch together, to provide time to connect with other parents and families.*

Discuss Treatment with Experts from Lurie Children's Hospital
Ask Questions
Connect with Parents and Their Children

Speakers Include:
Dr. Sarah Chamlin, Dermatology
Dr. Hawke Yoon, Ophthalmology
Dr. Miller Shivers, Psychology
Dr. Cynthia Stack, Neurology
Dr. Jeffrey Loeb, SWF Chief Scientific Strategist

