



A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

MARCH/APRIL 2018



#Who

**GROWING GOLDEN:
SWS ADULT SERIES #2**

**MONTH OF AWARENESS:
CARE FOR THE CAREGIVER**
POSTER INSIDE THIS ISSUE

REUNION OF CHAMPIONS 2018

The Sturge-Weber Foundation
MAGAZINE

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Branching Out

March/April 2018

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Month of Awareness!

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).

Klippel-Trenaunay syndrome, or KT, occurs as the result of a congenital vascular malformation in an extremity, such as an arm, leg or foot.

The SWF is a clearinghouse of information for Port Wine Birthmarks, Sturge-Weber syndrome and Klippel-Trenaunay syndrome.

THE 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, SWS and KT.

As a clearinghouse of information, 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 Coalition of Skin Diseases (CSD), and the Association for Research in Vision and Ophthalmology (ARVO).

CONNECTING WITH KAREN



The national weather has lately been like life with a Sturge-Weber, Klippel-Trenaunay or a Port Wine Birthmark coming at us from all directions and in unexpected ways! The best way to manage any storm in life is with effective and timely communication and a solid action plan. The SWF gives it our best effort and sometimes we fall short but we continually strive to ensure you get the latest information so you can make informed decisions for all your needs with your healthcare providers.

The social media world has been a true blessing for many who want or need immediate support from (as our SWF member Larry Gelfund says) “the been there, done that club”. It’s a catch 22 though as what’s best for one family and individual case of SWS isn’t always the best fit for another and when you are new to our world you don’t know who to believe or which end is up! After 31 years, I’ve found it best to gather solid facts, personal experiences and share medical advice.

We are always striving to make life easier for you and the quality of your care better and easier to access. The SWF is launching a fantastic new platform that will have the ability to archive your questions and do it with anonymity if one chooses than other social media platforms. Should a new medical or quality of life issue arise you can have all the “words of wisdom” and resources at your fingertips for a reason, a season or a lifetime!

Take a look in this issue at the latest news from the American Glaucoma Society annual conference and share the fun from the annual Reunion of Champions event. Look in your inbox in the coming months for a few key surveys we REALLY need your input on so we can keep the momentum going!

Gearing up on this end for an amazing Spring filled with fun and educational events both online and in person. Best wishes to keep bucking those headwinds whether in life or in the life of a SWS, KT or PWB diagnosis...together is better!

With Faith, Hope and Love,

Karen

SPECIAL SERIES - PART 2: MENTAL HEALTH

Growing GOLDEN WITH SWS

This issue brings to the forefront the issue of Mental Health in many of its aspects and ramifications. It is not just an adult concern, because parents of children and teens with SWS share the need to anticipate and prepare for whatever is down the road.

The proverbial “Elephant in the Living Room” has been losing weight in the past generation. It is no longer impolite to speak of mental health issues. And not all mental health issues are pathological. Some are characteristics people see in themselves and resolve to get a handle on. But families no longer need to be trapped in silence.

The topics presented in this issue cover concerns of parents for their children who need support, to dealing with death and debilitating mental health disorders, to suggestions on how to find help. We welcome your comments. To reach the Foundation, email us at swf@sturge-weber.org.

Acknowledging the Unthinkable

As difficult as it is, we often have to recognize unpleasant and tragic happenings in our lives.

The death of a person who has lived and coped with Sturge-Weber syndrome is an occasion for sorrow and grief. Even while we celebrate the courage and gifts they have brought to our lives, we are still faced with the reality. Families facing this death need our support, long distance or nearby. They need to know they are not unrecognized or ignored, that someone knows of their sorrow. So much more is the need to acknowledge the unthinkable - a death that is intentional and self-inflicted.

Our immediate response should be to reach out to the survivors, usually parents and siblings. Counselors tell survivors that they share no direct responsibility; persons with an intent to die will find a way no matter what. Those left behind need to know they will not be ignored in their grief.

Parents and loved ones hearing the dreadful news often think "What if..." in their concern for their own family member. Prevention counselors tell families and loved ones that there are subtle signs like withdrawal from activities previously liked, a certain calmness that covers up any turmoil inside, giving away personal possessions, what the psychologists call "suicidal ideation" – talking about ideas of suicide.

Anger is often at the root of the act. Anger at the lifelong situation, anger at the people around who can't do anything. Often a milestone event, like school graduation or a family wedding, can be the trigger. There is a feeling of desperation because there seem to be no other options. And for young persons with SWS, the angrier they get, the more seizures they can have.

Usually the underlying depression or emotional distress can be treated. But even though we are not medical doctors or psychiatrists or social workers, it still falls to the families and friends (including an organization like the SWF) to be the support of patients in turmoil.

MENTAL HEALTH: Where to Go When You All Need Help

Sometimes a mental health issue appears suddenly as the result of a trauma, stroke or other medical event. We are caught off-guard, but we know that it needs medical attention.

But when an emotional or mental health challenge emerges slowly, especially if the family member is an adult child, sibling or relative, we tend to think, "oh well, they have always been that way, that is their temperament." Or you make the excuse that the person has SWS and that must be the reason.

(A SWF consultant told us at one point "Don't blame everything on SWS. You have to treat what is presented to you")

Think of "how to boil a frog" – if you drop it in boiling water, it will jump out. So, you put it in a pot of cool water, and slowly, slowly turn up the heat until it is boiling. By the time the poor frog needs to jump out, it is unable to. Same thing with a lot of mental illnesses. The person tends to accept them as the usual, the normal. Depression often presents that way, the inability to get off the couch, the feeling of lethargy, lack of interest in things that used to be important, lack of emotional energy.

Depression often has another side – the manic activity that uses lots of energy and can swing back and forth between activity and passivity

Other psychiatric conditions manifest themselves as oppositional defiance or as obsessive and compulsive behaviors.

Caregivers and other family members try to be helpful but are often argumentative, which leads to more problems. But the bottom line is **You need help.**



Acknowledging the Unthinkable (continued)

Caregivers need to be supported in their efforts to get the patient into treatment, whether medications, hospitalizations, behavioral and emotional therapy. Very often the person in turmoil will not comply with treatment plans or medications. And the parent coping with a physically fit 185 lb teenage son is truly in a difficult place.

Parents and families who have been through these issues can offer, not just hopeful empathy, but some solid ideas. One young man was able to deal with these angry impulses with the help of a biofeedback therapist who led him to writing. Through his writing, he was able to share his grief, and through the sharing, he realized everyone has their battles to fight in life. Those who read his struggles also found peace with their own struggles.

One legal mechanism that can be done well in advance is to obtain a Medical Power of Attorney which would allow the parent to make decisions about medications and treatment. This usually has to be done before the child turns 14, since young persons older than that are asked, in a mental health setting, if they agree with the treatment. They can always refuse. Each state has its own rules and regulations, but the Special Education department or social service office in the resident school district can advise.

Even if it is never used, the MPOA can reassure parents that they are not helpless. Since human development is progressive, the docile child at age 9 may develop into the oppositional young adult at age 19.



Where Do You Go When You All Need Help (continued)

When you decide that it is time to seek help as a family or caregiver, where do you go? First place might be an online search for the resources in your area, but learn to distinguish between private for-profit practices, and public mental health agencies.

In all states there are Mental Health Associations – usually listed by county or area. And each state has a Health and Human Services Department that will list appropriate agencies for you to search.

Your primary doctor will be able to refer you to the appropriate specialist, and the result may be a course of medication that will take the edge off the symptoms. Untreated depression is one of the biggest areas of concern.

Often churches and community organizations have social service arms that provide local assistance.

This is homework and you could enlist the assistance of the physician who knows the patient best. And this is just the beginning. Your chosen therapist needs to be acceptable to your insurance (sad fact of modern life) and have some experience with developmental or medical disorders. The family needs supportive therapy and encouragement just as much as the patient. There are questions of cost, cognitive status (is the patient truly independent, or does the caregiver need to make decisions), and compliance with treatment. This is a long term endeavor and requires commitment all around.

**"YOUR FEELINGS ARE VALID. YOU HAVE THE RIGHT TO FEEL
WHATEVER YOU FEEL. YOU AREN'T EXAGGERATING. YOU
AREN'T BEING TOO SENSITIVE. YOU AREN'T BEING
DRAMATIC. YOU'RE HURTING, AND THAT'S OKAY."**

Remembering Loved Ones

Louann Carver of Colorado, a former SWF Board Member, passed away on December 10, 2017. Louann was a SWF member since 1997 when her daughter Kayla was one year old. She was on the Board and served as Chair in 2006. CEO Karen Ball remembers that when she last spoke with Louann in 2012, she had the same upbeat personality she shared with all.

Brooke Pennington, who was 16, passed away December 19, 2017. Her mother, Sarah, has been with the SWF since 2003 when Brooke was a toddler and the family participated in a bike rally in Colorado.

Leaving Us Too Soon

One sad reality of living with SWS, either for yourself, or especially for a child, is the fact that death can occur – for reasons we are unprepared for.

In the life of the SWF, we have received phone calls or emails giving the sad and dreaded news. That a precious child, or a teen, or a young adult, or a mature adult, has died. We try to respond immediately with condolences and ask if we have permission to spread the word. Then other SWF families will respond with heartfelt notes and calls of sympathy, strengthening a bond between families.

And the next question is often “What was the cause?” When we are able to get that information, many things emerge.

Often the person had overwhelming infections that their body – compromised by a history of seizures and medication use – could not overcome. Sometimes, there are intractable seizures which attack the vital areas of the brain and cause a “shutdown”. And persons with SWS are not immune to other diseases like leukemia, diabetes, cancers that have no connection to SWS, but make it harder to juggle the immune systems and general health. And then there are accidents that no one could imagine or prepare for. The daily news tells us of car accidents, plane crashes, train wrecks, all the terrible things our modern world presents to us.

But we also know that many people with SWS live long and productive lives, coping with their diagnosis and keeping a watchful eye on side factors. Is SWS responsible for the fact that some of these people take their medications faithfully, watch their weight, keep up their medical maintenance agenda, live a healthy life style specifically because they know that they might be more vulnerable? If they had not had SWS, would they be so careful?

But it also appears that SWS is partly responsible in some deaths when proper treatment has been employed. Life tells us that we will never find answers to some things.

So it is left for us, those left behind, to take some meaning from a sad happening.

Most grieving parents tell us that they find comfort by keeping their loved one’s memory alive. There are many ways that parents do this, especially when a child has died. Some make a firm resolve to help fight the battle against the disorder that took their child, becoming more active in an organization. Some turn to their religious or spiritual family and friends for comfort. Some become mentors and friendly advisors for families facing the same challenges.

Some parents tell us that with time, they do not forget, it just becomes easier and less sad to remember.

TRANSITIONS ALONG THE ROAD Finding the Right Road Ahead

One thing about Growing Golden, it is not just the persons with SWS who are growing older – the parents are not getting any younger either. As parents deal with their own progression of health and life situations, there can be the added concern of making sure their children, as adults, will become either independent, or in a supportive environment. Decisions that have to be made are often left until they become imminent. But with some reality-facing, parents can plan for the smoothest road ahead.

One thing some parents bring to the discussion is the wasted time and money spent getting their child into the wrong college. This seems to be independent of whether or not the child has SWS. One of our SWF parents shares these observations.



“Finding the “Best School” is quite often a matter of finding the “Right School” for our young men and women. No matter how many premier schools you search, they may be the “Best” in name only. Doing your homework and meeting the Special Services personnel ahead of time can guide you to the Right School.

We have been looking for a small state school and we like two Junior Colleges that we have seen. They have my son’s major and on our first visit to one of them, the head of the Student Services Department spent half an hour with us going over every aspect of Special

Making a Connection

A senior member in New Jersey sent SWF the following and is seeking support and encouragement. If you are interested in contacting Paul Kelly, please contact Keevin Lee at klee@sturge-weber.org.



I registered with the Sturge-Weber Foundation many years ago. I was diagnosed at Jefferson Memorial hospital in Philadelphia, Spring of 2005 after 2 years of a stroke-like condition. It was the third MRI of my brain taken at Jefferson when the radiologist compared the 3 over the 2 year period and recognized the AVM was unchanged.

It was that comparison that led to the recognition and diagnosis of SWS. A final MRI of the brain done with contrast performed by the department head at Jefferson presented me with the determination that there was no fix feasible considering my age.

I was 51 years old then. Here I am 63, and although I've seen great improvement in my ambulatory condition, I often wonder what may be to come as the Doctor explained that I was, "living with a loaded gun that could be triggered at any time".

My complication of being a polio survivor and experiencing post polio symptoms has me pressing on each and every morning with different conditions. I'm hoping to connect with others for support and encouragement.



Finding the Right Road Ahead *(continued)*

Needs and the accommodations at the school - What these are, how to ensure we get them, weekly check-ins, as well as meeting the entire staff.

I am looking for the Right School for my son, the one where he has the best chance to be successful. I believe it will be a small school where he isn't a number, where he is himself and known to everyone.

We have a lot of time to prepare for our children's future, although it seems to go by so fast. But prepare we must, to give our kids the best chance to succeed in life. It racks my soul when he mentions suicide or tells me he is lonely. I know he is out of place in the world. I work hard to get him to try to see the world as we do. In the end, it is he who has to see the world differently and be able to live in it. He is the one who has to adapt.

In addition to the "in the moment" teaching we do every day, I am focusing on him actively participating in his daily routines, education and social interactions. "Nothing worthwhile is ever easy" I tell him all the time. "If it were easy, it wouldn't be worthwhile".

My favorite example to give him is: Raising good kids isn't easy, but it is the best. If it wasn't the best, every child would be an only child.

I wish I were more of an expert on how to help him and thus all of our kids. I would write a book and go on tour. Hopefully, we will succeed, and he will get a good job,

My favorite example to give him is: Raising good kids isn't easy, but it is the best. If it wasn't the best, every child would be an only child.

I wish I were more of an expert on how to help him and thus all of our kids. I would write a book and go on tour. Hopefully, we will succeed, and he will get a good job, meet a nice girl, live in a nice house and have a family of his own. This is my wish."

One road of assistance the SWF can share is a page on our SWF website. www.sturge-weber.org In the **For Patients** section under **Educational Resources**, is a list of **Higher Education Resources**.

The Center for Schools, Colleges, and Career Resources has several links to various articles and organizations concerned with Vocational Training for Students with Disabilities, Graduate Programs for Students with Disabilities, Resources for Colleges, Financial Assistance, and How to Plan for College for a student with disabilities. This is part of your homework as a parent. It is also a good way to engage your student in the search for options for their young adult life.

Two publications that the SWF has always suggested for parents are **Exceptional Parent** and **Neurology Now** magazines, both have on line formats as well as print.

The following article is a conversation from two mothers in different parts of the globe, but connected by the same feelings and circumstances they experience with SWS.

**From Mandy Lonergan,
Australia**

Since having Sophia, we have never felt more isolated. To feel loved yet so very, very lonely is a strange suggestion. We have never asked for anyone's pity. Nor will we. We know that people who aren't in our situation will never ever truly understand the feelings, emotions and day to day living with a disabled child, and why should you? You don't have to live it, and we wouldn't want that for anyone; ever!

So, to our family and friends who may think we don't want to be a part of your lives; You are so very wrong. We want you to invite us to your events. Even if we can't come. We want you to understand that we can't always do everything anymore, even though we want too. We want you to tell us about all your children's achievements and not feel guilty about that. We truly feel blessed that you want to share such things with us.

Please know too that some days Sophia is happier than others. This might mean missing one event somewhere but the next day she might be coping better. We don't get to choose her feelings. We don't even get to hear her beautiful voice telling us those feelings. We do get to see the meltdown that occurs when she can't, though.

We want you to know you're always welcome here, whether we ask you over or not. Our



Where Do We Fit?

home has always been the best place for Sophia and so that is why I spend most of our days in these four walls. Where she is happiest. Please don't think you need an invitation to come over. That has never been us and never will be.

In my loneliest days I have also realized my strengths. Being isolated by people (deliberate or otherwise) is one thing but being isolated by people to such an unstimulating environment is even harder. Day after day telling yourself to push. It's so hard. I think part of being a parent is the good outweighs the bad. In our case we don't get that feedback. We rarely get the good with Sophia. She is AMAZING. Do not mistake that. I mean the feedback. The smiles, the interaction, the cuddles, the I love you's. We simply don't get that. Not because she doesn't want too but because she simply cannot. So, riding the 'hard' waves day after day is hard, and doing it on our own. Even harder.

Ryan has been my strength through every single day since Sophia has been born. Only a small handful of people come close to his presence and if it wasn't for him, well I'm not even sure I would be here to write this. I just need everyone to know although I am a Mum first and foremost always, I am also a person. The same person I have always been. I love hard, but I feel just as

hard. I know I am a uniquely weird person and I am ok with that. I would hope those closest to me cherish that about me and again know that with everything I ever do or say, it ALWAYS comes from a good place.

Just please remember to keep involving us. Being a parent of a special needs child is hard work. We've lost a lot of ourselves to this gig we were given. Please don't let us loose anymore.

Julia Terrell in New Jersey adds . . .

Mandy's story touches so many of us. I think the story needs to go further. At least for me it does. I often think we don't have an extreme case since Marissa does talk and walk and run and jump and for the most part everything that Sophia and others like her can't. But the feelings are the same.

See, Marissa does not fit anywhere and I, like Mandy, am not saying that for pity. She doesn't belong in the special needs classroom, she doesn't belong in gifted, and many feel she doesn't belong in the everyday classroom either. Sure, she needs help and every teacher says the same thing - "You know her reading skills aren't up to par." I think, wow, but if you only knew what she was like just a

Where Do We Fit?

(continued)

few years earlier you would sing from the high heavens.

Her teacher said to me just last week "Do you know how busy Marissa is - she is here there and everywhere". She gets pulled out for different things and every teacher says the same thing "Once we get over what she doesn't do well, what a joy she is!" and can't believe that when we least expect it, she gets it. I noticed at basketball practice there were conversations happening about different things that the others were accomplishing and when I could chime in I got "Oh, that is good". Then I go to Special Olympics swimming and the coach said, "You do know she will be the best on the team behaviorally, but we have to get her stronger."

So where does she belong? Right where she is, I know in my heart and soul. I remember in my first SWF conference in NJ a mom said to me "Are you ready for the fight of your life?" I just looked

at her and smiled. Had no idea what that meant.

Today I am researching assistive technology because the teachers say we don't have money or that isn't typically done. I laugh to myself almost like an insane person and think none of the last 8.5 years have been typical so why should I start now. The box we live in is so small and yet we are always thinking of new ways and new things to get out of the box and think differently.

I have been asked by families why Marissa does well, and their child does not. I was told I couldn't possibly understand what they are going through. I know I don't, but that doesn't mean I don't have concerns too.

One last note: I too am one of those people that wouldn't share my story at first with another family. And that mom yelled at me and said "Stop - you have to share your story because it gives moms like me hope."

I think, as Mom and Dad caregivers, no one is walking in your shoes but you. It is easy to get sucked in, especially when there is so much to do and the "village" we all talk about doesn't quite understand and doesn't know what to do. Because you get so overwhelmed that even to ask for help is one more check box that is so cumbersome, it is easier to do it yourself and what happens is simple, you become alone, at least you feel that way. It is vicious cycle that once you are in it, is hard to come out.

When I am working on What is your Plan... one should be "What is your plan for yourself" to socialize and keep you healthy as caregivers

The resources you should have in place will be governed by where you live – in the US, each state has a system of special education based in the patient's school district. One basic "bible" of available resources is published by Exceptional Parent Magazine. Check out eParent.com for their Special Needs Resource Directory and get them on your radar.

A Good Thing Remembered-Outreach Support Volunteers

Jan Branson of Kansas, who has been with the SWF since 2000, responded with her experience, which illustrates very clearly how you can never think your voice will not be heard and remembered when you reach out.

"I just read the email regarding "Outreach Support Volunteer Group"-- Do A Good Thing.

I don't know what I could do to help, but I do know how horrible my childhood was because of Sturge Weber. Of course, each individual case is going to be different, as each of us are different whether we have Sturge-Weber or not.

I do know there is help in listening to someone hurting, sharing encouragement, offering hope, based upon what they say, looking ahead and beyond the current moment for a better future because of all the studies, the changes and outcomes of experiments and testing that are affecting Sturge Weber patients on a daily basis.

Several years ago, someone from SWF called me and wanted to know if I would go visit with a distraught mother who had a Sturge-Weber baby in Wichita, KS, where we both live. I did go visit her and her child.

When we met in their home, we were kind of speechless. The mother couldn't see my birthmark because of my makeup. I couldn't see the child's birthmark, because she is black. We were kind of speechless not knowing what to say, since it seemed to each of us that there was no birthmark to see. I never knew what the outcome of the visit was until several years later.

Many years later after the child (and I) got older, the mother became an employee at a nursing home. I met her in the hall one day at the same nursing home where I was visiting my parents. We both knew we recognized each other, but I wasn't sure why. Then she asked me--remember when you came to my house?

By this time, the child was a teenager doing well in high school. What all had taken place over the years, I really don't know, but it was a special unexpected meeting for both of us. We connected and found joy in sharing the positive outcomes for her daughter and myself.

Care^{for the} Caregiver



During the Month of May, SWF will be recognizing Caregivers for Month of Awareness!
Spread awareness, connect others, give back to those who give so careFULLY!

What Can You Do During Month of Awareness?

- Fundraising Event
- Classroom Education Program as your child's school
- DressDown Day at your place of business (tickets to dress down for a donation)
- Hang the Month of Awareness Poster (included) in a public place you frequently visit
- Include information in your church newsletter or bulletin about SWF Month of Awareness
- Have a Bake Sale

OR whatever you believe will spread awareness and connect others to our cause and the importance of both patient AND caregiver.

If you need assistance with obtaining materials for an event, classroom education day or any other information, contact Susan Finnell at sfinnell@sturge-weber.org. We are ready and able to provide what you need to make an impact!

But Wait, There's More!

During the Month of Awareness, SWF will hold a special "Step Up for Caregivers" Fundraising Opportunity that you, family, friends and co-workers can participate in and practice one of the many benefits of "self-care" - EXERCISE!

Date: Saturday, May 5th, 7 AM - 7 PM

What: Step Up for Caregivers

How: Count the number of steps taken on May 5th and pledge or have donors pledge to donate for each step you take (1 cent, 5 cents, 25 cents or more!) Use one of the following FREE phone apps (Stepz or Accupede) or any other pedometer (FitBit) you may have to track steps.

Register At:

<https://app.mobilecause.com/vf/STEPUP4>

Set up your registration to participate by going to the link above. You will click on Be a Fundraiser. If you prefer to make a donation only, click on Make a Donation. Share this with your friends and family! Make it a family project. Get out there, step up, give back and take care of yourself too!

Care^{for the} Caregiver

As we prepare for Month of Awareness and emphasize “Care for the Caregiver”, take the time to review the following “self-care” tips that will destress and rejuvenate you. Your care is as important as the care you give!



- **Stop Over-thinking.** You don't have to have all the answers to life's riddles. Over-thinking can cause you to miss out on the actual journey.
- **Accept What Is. Stop Pushing.** Give yourself a break. Stop trying to wade upstream at high tide. Sometimes you have to go where the current is taking you.
- **Be Still.** We all live in a rushed, over-stimulated society. Find somewhere beautiful and just sit still.
- **Stop Comparing Yourself and Family to Others.** Envy robs you of appreciation for the little things. Everyone has their own journey and your's is just as special.
- **Create Joy.** Create simple easy to do rituals that ground your day and provides a sense of joy.
- **Cherish Your Friends.** Surround yourself with true friends, those who have seen you at your best and worst.
- **Know Your Strengths.** Our weaknesses are always shouting out for our attention. Identify your strengths and focus on them daily.
- **Eat a Healthy Diet.** You are what you eat they say. Fill up on healthy vegetables, fruits and other natural products. You will be surprised how delicious food really is and how good it will make you feel!
- **Exercise Regularly.** Exercise transforms you you think, how much you can accomplish, and how much energy you will have. One hours of exercise equals for extra hours of productivity and better sleep!
- **Don't Let People Walk Over You.** Be nice, but not a doormat. Be strong in who you are and know your boundaries.
- **Forgive Yourself. Forgive Others.** There's nothing worse than the burden of unforgiveness. Anger, grudges, and resentment only hurts the person holding onto it.
- **Stay Away From Negative People.** Nothing can pull you down faster than negativity. You can control this by just staying away from it and whoever creates it.
- **Don't Be Negative.** Easier said than done, especially when you get bad news. When negativity starts to take control, remind yourself of what you are thankful for, even if it's just one thing.

- **Don't Live on Facebook.** Facebook is fun, but not exactly a reality to live in. Reading too much from Facebook can cause “Facebook depression”. Too much of anything isn't good.
- **Allow Yourself To Feel What You Are Feeling.** Don't fight the feelings you have. It's better to feel it and get it out than to suppress the feeling.
- **Breathe Deeply.** Enough said.
- **Read More.** Pick up a good fiction novel and expand your imagination. Reading is a great escape from the pressures of life.
- **Watch Less TV.** This little habit robs you of time and social interaction. Goals fly out the window along with motivation.
- **Unplug.** No emails, social media, internet, phone calls. Nothing - refer back to being still.
- **Embrace Your Imperfections.** Think of it this way, your imperfections are your perfection. Let them reveal your individuality and laugh at them. Perfect can be boring.

Just be You. You are Enough. You are Valuable.

(From strongsensitivesouls.com)

THE SWF NETWORK APPROVED SEAL OF EXCELLENCE

The Sturge-Weber Foundation is always seeking methods to partner the SWS and PWB community together with the corporate community. The SWF Network Approved Seal of Excellence is a newly created service for individuals and the corporate community, to encourage/recognize product innovations that provide benefits and improve the quality of life for not only the patient, but the caregiver as well.

Acceptance of a specific product does not represent an endorsement of the product. Acceptance means that the product has been evaluated and determined to be of value to our membership and the Clinical Care Network.

Products bearing the SWF Network Approved Seal of Excellence become aligned with the preeminent, professional, non-profit voluntary health organization whose mission is to improve the health, care and quality of life for individuals and caregivers with SWS and PWB conditions.

SWF is pleased to announce our first Network Approved Seal of Excellence has been awarded to The HydraFacial Company. HydraFacial has been a continuous supporter of the Foundation through the SWF Reunion of Champions held annually at the American Academy of Dermatology Annual Meeting.

HydraFacial is committed to providing products and services to the SWF CCNs which results in new, innovative treatments for the patient and caregiver.

During the Month of Awareness, HydraFacial will be promoting its newest products and services to the SWF caregiver. Details will be provided through the SWF website, email and social media platforms, so stay tuned and consider treating yourself to this "excellent" service!

www.hydrfacial.com

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THE STURGE-WEBER FOUNDATION



Reunion of CHAMPIONS



The annual SWF Reunion of Champions at the U.S. Grant Hotel Bivouac Ballroom in San Diego, CA. This annual fundraiser honors doctors and researchers who advance and promote the SWF's mission. This year the honorees were Dr. Michael Gold of Gold Skin Care Center, Nashville, TN and Richard Felten, MS of the FDA Office of Device Evaluation. Dr. Gold is well known to many of our SWF families and Richard Felten is the senior reviewer at the FDA for light-based devices, lasers that so many of our families depend on for Port Wine Birthmark (PWB) treatment.

This year's event hosted sponsors from many laser and pharmaceutical companies who support the SWF mission: Merz, Lumenis, Allergan, SkinCeuticals, miraDry, Cutera, Cynosure, HydraFacial, Syneron-Candela, Hint MD, Alastin, Galderma, Thermi, Gold Skin Care, Washington Dermatology, Zimmer SkinMedica, Aerolase, Ortho-Dermatologics, Revance, CoolSculpting and Skin & Laser Surgery of NY.



Top left: Bob Wilbur and Richard Felten; Top right: Dr. Friedman, Dr. Gold and friends; Middle right: Mrs. & Dr. Geronemus; Bottom left: Dr. Patel and Craig Drill; Bottom right: Brian Fisher and Dr. Bernstein.



SHOUT OUT to Megan O'Neil for volunteering at the event!



Top right: Dr. Gold ;Top center: miraDry team; Middle left: Richard Felten and Cindee Gold; Middle center: Dr. Zachary and Dr. Bernstein; Center right: Dr. Alster, Master of Ceremonies

Bottom left: HydraFacial Company; Bottom Center: Megan O'Neil and Susan Finnell; Bottom right: Dr. Anderson, Richard Felten and Dr. Kilmer



AMERICAN GLAUCOMA SOCIETY

The mission of the American Glaucoma Society is to support glaucoma research and education to promote excellence in the care of patients with glaucoma. It was founded in 1985 to maintain and improve “the quality of patient care primarily through improvement, exchange and dissemination of information and scientific knowledge pertinent to glaucoma and related diseases.”

The SWF was able to attend the annual AGS meeting this year and I'm pleased to share a few highlights with you. The AGS meeting typically is at the same time as the American Academy of Dermatology (AAD) so we rely upon our advisors attending the meeting to relay the latest news.

A few interesting paper abstracts by title and author are presented here with the purpose and conclusion:

“Higher Levels of Adherence to Topical Glaucoma Medications Decrease Risk of Visual Field Progression” Donald Fong, Michael Batech, Cynthia Mattox, Tiffany Luong, Jennifer Jimenez, Joann Campbell, Hitesh Chandwani -Southern California Permanente Medical Group

Purpose: To determine the effect of glaucoma medication adherence on visual field (VF) progression among newly diagnosed glaucoma patients taking intraocular pressure-lowering medication.

Conclusion: Low and moderate medication adherence are insufficient for reducing the risk of VF progression; only high adherence was associated with a significantly decreased

risk of progression. Additional research is needed to identify facilitators for and barriers to long-term medication adherence, particularly among patients with moderate to very severe glaucoma.

“Resting Nailfold Capillary Blood Flow in Primary Open-Angle Glaucoma” Jonathan Chou, Clara Cousins, Scott Greenstein, Stacey Brauner, Lucy Shen, Angela Turalba, Louis Pasquale-Massachusetts Eye and Ear

Purpose: Ocular blood flow dysregulation in primary open-angle glaucoma (POAG) has been described. POAG patients may also have reduced systemic blood flow. Prior work has shown that patients with normal tension glaucoma (NTG) demonstrate pronounced reduction of nail fold capillary blood velocity in response to local cooling. However, blood flow (blood velocity x cross sectional area of vessel) was not assessed nor did the study account for possible confounding factors. In this project, we sought to determine whether POAG patients have reduced resting nailfold capillary blood flow after adjusting for resting pulse, blood pressure and other factors.

Conclusion: Understanding the etiology behind reduced peripheral capillary perfusion in POAG may lead to additional diagnostic and therapeutic interventions.

“Qualitative Input to Develop a Health Related Quality-of-Life Survey for Glaucoma Patients with Micro-invasive Glaucoma Devices” Qi Cui, Ron Hays, Michelle Tarver, George Spaeth, Ronald Fellman, Joseph Caprioli, Steven Vold, Louis Pasquale, Kuldev Singh, Malvina Edelman-University of Pennsylvania

Purpose: Through a collaborative research effort among the Food and Drug Administration (FDA),

SWF ON THE ROAD

American Glaucoma Society, and UCSF/Stanford University, we constructed a 39-item questionnaire to assess health-related quality of life (HRQOL) in patients undergoing micro-invasive glaucoma surgical (MIGS) devices implantation.

Conclusion: Further refinement of the questionnaire will include cognitive interviews followed by field testing to evaluate relevant psychometric properties and, ultimately, accessible web administration for all who are innovating in the glaucoma surgical arena.

“Identifying and Prioritizing Outcomes that Matter to Patients Considering Minimally Invasive Glaucoma Surgical (MIGS) Devices and Other Treatments for Open-Angle Glaucoma” Jimmy Le, Amanda Bicket, Michelle Tarver, John Bridges, Tianjing Li-Johns Hopkins Bloomberg School of Health

Purpose: The development of minimally invasive glaucoma surgical (MIGS) devices has expanded treatment options for patients with mild-moderate open-angle glaucoma (OAG). Patients have unique perspectives (“preferences”) about the benefits and risks of the treatment. We sought to explore the preferences of patients with OAG and use this information to prioritize outcomes that could be considered in regulatory decision making.

Conclusion: We have identified outcomes that patients with mild to moderate OAG have considered as important. The outcomes could be useful in future evaluations of new treatments such as MIGS devices.

AGS (continued)



“Association Between Visual Field and Cognitive Impairment in Primary Open-Angle

Glaucoma” Makayla McCloskey, Kendall Goodyear, Victoria Addis, Yinxi Yu, GUI-Shang Ying, Prithvi Sankar, Qi Cui, Eddie Miller-Ellis, Maureen Maguire, Rebecca Salome, Joan O'Brien-Scheie Eye Institute University of Pennsylvania

Purpose: Neuropathy in primary open-angle glaucoma (POAG) extends throughout the visual pathway in the brain, but it remains unclear whether this neuropathy affects other functions, such as cognition, in addition to vision. This study examines the potential association between cognitive impairment and the severity of visual field loss in POAG patients.

Conclusion: The association between visual field loss in glaucoma and more global neurodegeneration warrants a further investigation to evaluate any clinical significance.

“A Randomized Double-Masked, Placebo-Controlled Trial of the Efficacy of a Novel Neuro-protective Combination for Reversing Mitochondrial Dysfunction in Glaucoma”

Robert Ritch, Yanin Susan, Richard Rosen, C. Gustavo De Moraes-New York Eye and Ear Infirmary of Mount Sinai

Purpose: To determine whether a combination of over-the-counter supplements with anti-oxidant and mitoprotective properties could reverse mitochondrial dysfunction in treated glaucoma patients by

reducing mitochondrial flavoprotein fluorescence compared to placebo.

Conclusion: GlaucoHealth™ reverses mitochondrial dysfunction and may be neuroprotective in glaucoma. This finding serves as a proof-of-concept for future trials testing neuroprotective effect of supplement combinations in glaucoma.

“Patients’ Perspectives on Follow-up Interval, Testing and Length of Visit in Glaucoma Practice”

Anna Djougarian, Luke Schwartz, Andrew Tigris, Jung Lee, Celso Tello, Sung Chui (Sean) Park-Manhattan Eye, Ear and Throat Hospital

Purpose: We aimed to assess patients’ perspectives on follow-up interval (FUI), testing, and length of visit in Glaucoma practice. We further sought to identify subjective and objective (demographic/clinical) factors affecting their perspectives. This knowledge would be useful in patient-centered glaucoma care.

Conclusion: Understanding patients’ perspectives on FUI, glaucoma testing and length of visit may facilitate more personalized glaucoma care and improve patient satisfaction.

“Trends in the Use of Medical Marijuana for Glaucoma from 2012-2016”

Aliya Rogniel, Anand Gopal, Ann Shue, Joshua Warren, Joseph Ross, Lucian DelPriore, Christopher Teng-Yale School of Medicine

Purpose: Twenty-nine U.S. states have legalized marijuana for medicinal use, despite its federal designation as a Schedule I drug. Glaucoma is among the approved indications for medical marijuana, as marijuana may be an effective ocular hypotension agent. This study aimed to characterize trends in the use of medical marijuana for glaucoma in 2012 through 2016 for glaucoma and all other indications was calculated, and its change with time was analyzed by linear regression analysis. Analyses were performed in Excel v15.21.1.

Conclusion: Our results suggest that medical marijuana use for the treatment of glaucoma is becoming increasingly common among patients in several U.S. states. It may be useful for physicians to have a thorough understanding of the risks and benefits of medical marijuana use, so that they can effectively counsel their patients.

RARE DISEASE WEEK 2018 IN WASHINGTON D.C.



Webster Bear and Julia Terrell headed to Washington DC on Sunday, February 25th to take part in Rare Disease Week. We began the adventure by going to the Rare Disease Documentary Screening and Cocktail Reception at the US Naval Heritage Center. We got to see the film *The Ataxian*, a great story about motivation and drive in a rare disease called Friedreich's Ataxia (FA). We also got to talk with a panel including the star Kyle Bryant. We finished out the evening with meeting others with rare diseases of all ages. A truly inspiring evening.

The next two days we learned about advocating and the dos and don'ts. There were 400 people in attendance from 49 states all having to do with different rare diseases. There are over 7000 rare diseases and rare diseases can affect 1 out of 10 people in the United States. On Tuesday was our day to shine. We were able to advocate for our diseases with Senators and Representatives from our States. The biggest take away was that we know our story the best and we got to tell our story!!

We got to ask for our Congressmen to support bills like the Open Act, and to ask each one to become a part of the Rare Disease Caucus. I was able to Thank those that were already supporting the Bills and were a part of the Caucus too.

The Foundation also awarded Congressman Rodney Frelinghuysen a Certificate of Appreciation for all his help over the years!! He mentioned that our Foundation was one of the first ones that came to speak with him when he was elected. This day was so empowering and each person we met with were so encouraging and open to Rare Disease. The week ended at the NIH which was a perfect ending to the week.

I learned many things this week. Hearing the stories of so many with much rarer diseases with no treatments and/or cures was very disheartening. I realized how lucky we are that we have so much knowledge and treatments already. I am excited that we have so many Clinical Care Networks all over the country to either meet with or consult with on our disease. I also realized how important it is to have a plan not

just for awareness but for education, worklife and for emergencies too. The next time you see your doctor make sure you put together a plan in case of a seizure or illness and agree upon it. Work together with your team of doctors locally to make sure everyone is on the same page. We are our own advocates and it is so important that you take charge and own it. That was my biggest takeaway from the week of advocating. If you need help setting up a plan please don't hesitate to reach out to the Foundation and we would be happy to help.

Life is very busy but it is so important to get our voices out to our Legislatures at all levels. I hope next year I will see more of you at Rare Disease Week advocating for our patients and caregivers.



Top left: Julia Terrell with Congressman Rodney Frelinghuysen; Bottom left: Julia Terrell at Capitol Hill; Bottom right: Julia Terrell with other Rare Disease advocates.

Rare Disease Advancement, Research and Education (RARE) Act Introduced At Rare Disease Week

On February 28, 2018 during Rare Disease Week in Washington, D.C., Congressmen Andre Carson and Ryan Costello introduced the RARE Act. The Act would address some of these commonalities, aiming to improve rare disease treatment, research, and diagnostics.

Rare Diseases Clinical Research Network/Centers of Excellence

The RARE Act would enhance an existing and successful program of the National Institutes of Health (NIH), the Rare Diseases Clinical Research Network (RDCRN). This unique Network is made up of 21 research 'centers of excellence' studying rare diseases in an interdisciplinary way, working with patients and others on clinical studies and other research. The RARE Act would increase and extend the RDCRN's funding authorization.

Surveillance of Rare Diseases

The RARE Act would require the Centers for Disease

Control (CDC) to create a National Rare Disease or Condition Surveillance System. Modelled off of similar systems for other conditions, this formalized infrastructure would fill critical gaps in tracking rare disease data, helping researchers to understand commonalities between diseases.

Health Professionals' Awareness of Rare Diseases

The RARE Act would require the Agency for Healthcare Research and Quality (AHRQ) to expand and intensify its work to ensure that health professionals are aware of rare disease diagnoses and treatments.

Report

The RARE Act would require the National Academies of Sciences, Engineering, and Medicine to update its 2010 report "Rare Diseases and Orphan Products: Accelerating Research and Development," to evaluate rare disease efforts and make further recommendations to policymakers.



“Join others who understand what you’re going through.”



Sturge-Weber Connection

The Sturge-Weber Foundation Support Network and Discussion Community

Now there is another way to connect with others who live with Sturge-Weber syndrome and Port Wine Birthmark conditions. Introducing the Sturge-Weber Connection, an online global community by Inspire.

The Sturge-Weber Connection is very similar to Facebook, but provides a much more **private and safe** environment for discussion on sensitive details about SWS and PWB. Our community will have control over personal information and how it is shared. Patient, caregiver and professional will be able to collaborate, share stories and discuss questions and concerns. **And the best part is, it's totally FREE to you.**

Ready to join? Let's get started then!



- Go to: <https://www.inspire.com/groups/sturge-weber-connection/>
- Click on the button "Join This Community"
- Follow the basic instructions and register yourself.
- Once completed, you will receive a confirmation email.

That's it, you are all set and ready to CONNECT!

Questions? Contact the Foundation at swf@sturge-weber.org or 973-895-4445.

MY FOUNDATION | MY FAMILY OFFICE NEWS



OFFICE SPACE

As many of you know, the Sturge-Weber Foundation moved its home office from Mount Freedom, New Jersey to Houston, Texas in November 2016, generating a cost savings of \$17,000 a year. When making donations or inquiries by mail, please send to the following address:

**12345 Jones Road, Suite 125
Houston, Texas 77070-4958**

The Foundation office hours are Monday - Friday, 8 AM - 4 PM CST. The telephone number and web address have not changed and are still as follows:

Office Number: 973-895-4445
Website: www.sturge-weber.org
Foundation Email: swf@sturge-weber.org

Our staff consists of 6 dedicated employees. Not everyone works at the Houston office. Two are in New Jersey and one is in Colorado. Below is a list of our staff, their position, a brief description of their responsibilities at SWF, contact information and location. If you are in the Houston area, please stop by for a visit!

The best way to reach any of the staff members is by email, however, if you need immediate assistance, please call the SWF main office number listed above.



Karen Ball, Founder & CEO
Oversees all aspects of foundation work to meet mission and vision.
Aurora, Colorado
kball@sturge-weber.org



Anne Howard, Writer & Editor
Writes articles for the Foundation communication pieces as well as editor of all communication provided by SWF
Randolph, New Jersey
ahoward@sturge-weber.org



Brian Fisher, VP of Operations & Corporate Partnerships
Oversees Foundation operations, annual planning, and develops corporate partnerships to support the mission of SWF
Houston, Texas
bfisher@sturge-weber.org



Keevin Lee, CCN, SWFIRN and Research Coordinator
Oversees all communication between Foundation and CCNs, specialists, and researchers, assists with member inquiries (adult), applies for grants to assist Foundation in clinical and research operations
Houston, Texas
klee@sturge-weber.org



Susan Finnell, Marketing Director & Programs/Office Management
Oversees Foundation marketing and communications, Foundation fundraisers and programming, Houston office management, donation information, applies for grants to assist Foundation operations
Houston, Texas
sfinnell@sturge-weber.org



Julia Terrell, Community Relations Director & Events Director
Oversees new-patient introductions, assists with member inquiries (child and adolescent), social media, and direction of Education Days and International Conference
Sicklerville, New Jersey
jterrell@sturge-weber.org

WE ARE BETTER TOGETHER!



MY FOUNDATION | MY FAMILY MEMBER SPOTLIGHT

My name is Kimberly Slater. I am 35 and have Sturge-Weber Syndrome. I was born on Long Island New York but grew up in Miami with 2 brothers, one older and one younger. I was born with glaucoma and a Port Wine Stain on the left side of my face. I have lived through countless eye surgeries (beginning at 6 weeks old), radiation for a detached retina (age 12), seizures (onset age 30), an enucleation (eye removal, age 31), and 69 (and counting!) pulse dye laser treatments. As if Sturge-Weber was not enough to deal with, I was diagnosed with POTS (postural orthostatic tachycardia syndrome at 30). This is a fairly rare illness that, in short, gives me extremely low blood pressure that when I shift positions (ex. laying down to standing) my heart rate spikes and I get lightheaded and often faint. No one really knows what causes this and can not predict who will be stricken with it, sound familiar?

I attended public schools through out my childhood/adolescence, sleep away camp in the Pocono Mountains for 11 years both as a camper and a counselor, Florida State University where I earned my Bachelors degree, completed an advance standing Master's degree program in Clinical Social Work and finally a License of Clinical Social Work (LCSW) as I acquired over 500 hours of supervised clinical work and passed State Licensing Exams. As internships for my University degrees I was fortunate enough to be placed in Vietnam and won a prestigious placement in London. I moved to New York city to begin my career starting out as a harm reduction specialist and moved up the ladder to a case manager/counselor for an Adult Health Day Center, Clinical Supervisor for Catholic Charities in their Day Mental Illness Program and finally as a Clinical Director for an Adult Day Health Center in Harlem overseeing 200 clients, 25 clinical staff members, and numerous front line staff members. My professional focus has been working with those who have chronic illness (predominately HIV and Hep C) accompanied by substance dependence and chronic mental illness. I share all of this not to brag or toot my horn. I share this with you because I want other Sturge-Weber patients, their family, their caretakers, and their medical professionals to know that Sturge-Weber may be our diagnosis, but it does not define us. We are strong. We are resilient. We are united. We are family.

I have transitioned from childhood to adolescence to adulthood not seamlessly and not easily, but with ongoing familial support, support from friends, and from educating everyone around me I have not only survived, I have thrived. How? Often, I do not know. Often, I have wanted to through the towel in,



I have wanted to crawl under the proverbial rock and hide away from the hospitals, from the public stares, from the snickering, from the questions, and honestly, from the mirror. I have dealt with feelings of low self-worth, anxiety, and depressions. These feelings ebb and flow. I feel that I have always had to fight harder than a person without Sturge-Weber to prove myself to others. I have had to develop a strong personality so that I could get people to see past my port-wine stain and to see me for who I really am. I feel that I have needed to smile outwardly to the world, so they sensed no weakness and allow myself to cry internally where no one else could see. My closest friends are friends who I met in childhood and who have seen me through the ups and the downs. I have dated and have loved. I have accomplished so much and yet I still question my worth.

At age 30 with the onset of POTS and at 31 with the onset of seizures I had to leave my NYC life, the career I worked so hard to make/ crossed so many barriers to achieve, the life I had finally been able to carve out for myself, and move back to Florida to be cared for by my family who have always loved me unconditionally. I am at a place in my life that very possibly has been the hardest place thus far. As I write this I reflect to what I accomplished and wonder what will be in store for me. I often have feelings of despair, sadness and find myself again asking the good ole' fashioned question of "why me?" While I do not yet know the answer and I do not have a crystal ball that tells me my future, I know there are things that can never be taken away from me and I am referring to the positive things I have experienced. No one can take away my girl scout sleep overs, the competition choruses I sang in, the blue berries I learned to pick at camp, the exhilaration of riding roller coasters, the thrill of hearing 'mind the gap' on the London tube every morning as I traveled to my internship, the excitement of signing my first lease, the depth of pride I felt when I nailed my first job interview, the awe of holding my brother's first, second, and third child, and the love I have always been surrounded by.

Life is uncertain. We are all dealt a deck of cards and some of us have more cards stacked against us than others, but we are all human. There are universal feelings we will all experience at one time or another. Please believe, and help to remind me, that life is a journey with unforeseen forks and speed bumps but together as a unified community together we are here to cheer each other on; to provide support when others can't comprehend what we go through. Together we are strong. Together we can stand tall. Together we are one.



MY FOUNDATION | MY FAMILY MEMBER NEWS

THE SPEER FAMILY

Molly and Thomas Speer from Indiana are planning their first SWF fundraising walk - "Myla's Mission for Sturge-Weber Awareness", on May 19th. Myla is the precious "angel" pictured on the cover of this issue of Branching Out. Pictures and post walk results to come in our next issue.

THANK YOU SPEER FAMILY!



MEET OUR NEW SWF BOARD TREASURER

The Sturge-Weber Foundation (SWF) is honored to have Stephen Peltier join its Board of Directors as Treasurer. Originally from the Kansas City area, Steve moved to the southwest in 1972 and was a CPA for 42 years, primarily in Albuquerque, New Mexico. Together with his wife Lanie, they raised three children, one of whom has Sturge-Weber syndrome (SWS). Steve has an undergraduate degree in accounting from the University of Kansas and a Master's degree in accounting from Arizona State University.



Now retired, Steve and Lanie moved to the Denver area in 2017 to be closer to family. Steve and Lanie are committed to Sturge-Weber research, hoping to make a difference in the quest for solutions to issues that affect people with SWS and Port Wine Birthmark conditions (PWB).

HOUSTON OFFICE VISIT

The Werline Family from San Antonio, James, Marla and Camila, visited the Houston office on Friday, March 2nd while they were in town for Camila's eleventh laser treatment at Dr. Friedman's office.



Marla mentioned that Camila was a recipient of a Webster bear during the "buy one, give one" campaign. "I was having a really bad day when the box arrived with Webster. When I opened it, I just started to cry. It made me feel better to know that someone actually cared," she said. Crystal Elliars of Slidell, LA was the donor. Marla contacted Crystal to thank her and they have been able to connect in a very special way!

THANK YOU WERLINE FAMILY FOR VISITING US AND SHARING THIS WONDERFUL STORY!

"I know there is strength in the differences between us. I know there is comfort, where we overlap."

- Ani DiFranco

SWF CALENDAR VIEW



SWF EDUCATION FORUM IN OCTOBER

The SWF in cooperation with our CCN at the Beckman Laser Institute at UC Irvine, CA, will hold an Education Day for patients and families October 27, 2018. Save the date, more details to come.

Education Forums are geared to parents' and patients' questions and concerns. Dr. Kristen Kelly at Beckman has line up doctors in the fields of dermatology, anesthesiology, neurology, ophthalmology, surgery and research. It already looks like a full and robust agenda.

Education Forums are not as big as our International Conferences, and not as informal as Family Days. However, these events do pack significant information in one day as well as allow families and patients an opportunity to meet and share with one another.

Additional Education Forums are being planned and will be announced as they are confirmed. Stay tuned!

March 30:	Office Holiday, Good Friday
May 1-31:	Month of Awareness "Care for the Caregiver"
May 4:	CCN MOA Day
May 5:	"Step Up for Caregivers" Fundraiser
May 28:	Office Holiday, Memorial Day
June 1:	Open Application for Lisa's Research Fellowship Award
June 23:	SWF Board of Directors' Retreat
July 4:	Office Holiday, Independence Day
August 19:	TeamSWF Falmouth Road Race



THE STURGE-WEBER FOUNDATION
CLINICAL CARE
NETWORK

CA: UC Irvine

Primary Contact: Kristen Kelly MD,
Dermatology

CA: UCSP Medical Center-
San Francisco

Primary Contact: Ilona Frieden, MD,
Dermatology

CA: Rady Children's Hospital -
San Diego

Primary Contact: Lawrence
Eichenfield, MD, Dermatology

DE: Nemours/Al duPont Hospital for
Children-Wilmington

Primary Contact: Carol Roethke,
CRNP-APRN

IL: Ann and Robert H. Lurie
Children's Hospital Chicago

Primary Contact: Sarah Chamlin, MD
Vascular Clinic Director

IL: U of Illinois at Chicago Medical
Center-Chicago

Primary Contact: Jeffrey Loeb, MD,
Neurology and Akira Yoshi, MD,
Neurology

MA: Boston Children's Hospital-
Boston

Primary Contact: Mustafa Sahin, MD,
Neurology and Anna Pinto, MD,
Neurology

MI: Children's Hospital of Michigan-
Detroit

Primary Contact: Csaba Juhasz, MD,
Neurology Imaging

MI: U of Michigan Mott Children's
Hospital-Ann Arbor

Primary Contact: Jennifer Reeve,
MD, Dermatology

MN: Mayo Clinic: Rochester

Primary Contact: Megha Tollefson,
MD, Dermatology

NC: UNC Children's Hospital-
Chapel Hill

Primary Contact: Craig Burkhart,
MD, Dermatology

NJ: Northeast Regional Epilepsy
Group-Hackensack

Primary Contact: Eric Segal, MD,
Neurology

NY: NYU Medical Center-NYC

Primary Contact: Daniel Miles, MD,
Neurology

OH: Cincinnati Children's Hospital-
Cincinnati

Primary Contact: Adrienne M.
Hammill, MD, Hemangioma and
Vascular Malformation

OH: Nationwide Children's Hospital-
Columbus

Primary Contact: Warren Lo, MD,
Neurology

PR: Centro Medico de Puerto Rico-
San Juan

Primary Contact: Rafael Rodriguez
Mercado, MD, Endovascular

TX: Cook Children's Medical
Center-Fort Worth

Primary Contact: Saleem Malik, MD,
Neurology

TX: Dell Children's Medical Center
-Austin

Primary Contact: Moise Levy, MD,
Dermatology

WA: Seattle Children's Hospital

Primary Contact: Jonathan Perkins,
DO, Vascular Clinic Director



The Sturge-Weber Foundation
12345 Jones Road, Suite 125
Houston, TX 77070

**ACCEPT
RESPECT
CONNECT
HOPE**



This publication is brought to you by the generous contribution of the Allergan Foundation.

The Sturge-Weber Foundation

Care ^{for the} Caregiver



Living with Sturge-Weber syndrome and Port Wine Birthmark conditions not only impacts the patient, but those who provide their care.

Whether it's seizures, glaucoma or Port Wine Birthmarks, let's give back to the caregivers that nurture so **careFULLY!**

Let's Celebrate the Caregiver!

Visit www.sturge-weber.org and click the **DONATE** button!

THE STURGE-WEBER FOUNDATION



www.sturge-weber.org

