

DEDICATED TO THE LIFE AND CARE FOR PEOPLE WITH STURGE-WEBER SYNDROME AND PORT-WINE BIRTHMARK CONDITIONS

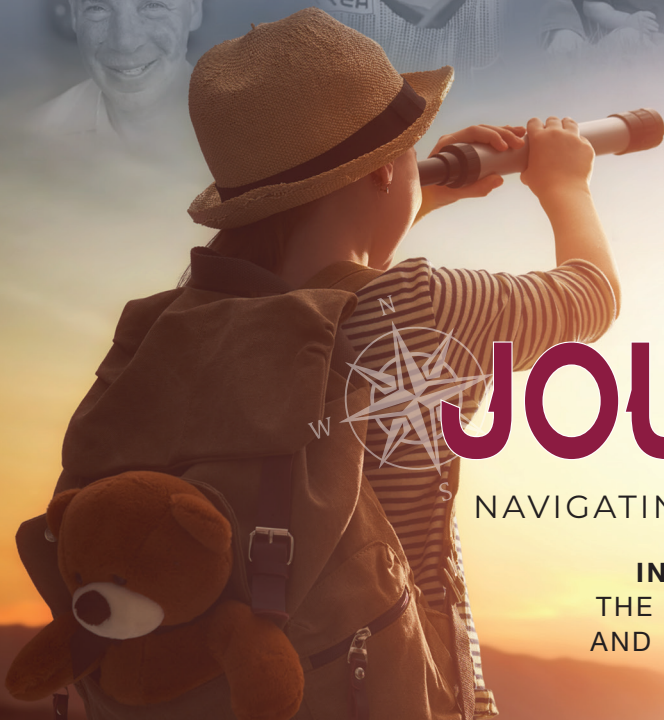


Branching Out

Spring 2022

**FOR 35 YEARS WE'VE
BEEN HERE FOR YOU!**

A reason, a season, or a lifetime.



JOURNEY

NAVIGATING LIFE TOGETHER

IN THIS ISSUE:
THE PAST, PRESENT,
AND FUTURE OF SWF

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

SPRING 2022

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ON THE COVER:

Visions of the Journey of The Sturge-Weber Foundation.

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.



Founder | CEO

Weary traveler

Beat down from the storms
that you have weathered
Feels like this road just might
go on forever
Carry on

Lyrics by Jordan St. Cyr, "Weary Traveler"

Connect with Karen

Blame it on the Weary Traveler!

Jordan St. Cyr wrote that song to honor his wife who holds down the home front with their children and darlin' daughter, who has Sturge-Weber syndrome. The first time I heard it the tears slipped out of my eyes and down my cheeks.

A kaleidoscope of memories and images from 35 years flitted across my mind. Struggles of raising two children with SWS and autism. The never ending battles to get the best medical care and educational rights to learn in the least restrictive environment. The financial challenges of keeping us in the black. The never ending emotional roller coaster rides of angst, anger, isolation, fear, guilt, and shouts of elation with sheer joy when victories ensued. The moments when a marriage was united then crumbled and fell on the front-lines of our war on SWS. The one year of travel for SWF when I made the mistake of adding up how many nights I was gone and it totaled 6 months away from home — time I can never get back.

I've had some time to let the emotions and lyrics settle. Here I sit in another hotel room ready to work on the front-lines again for SWS awareness and to bring people together to heal hearts and expand minds. It's not that I'm less devoted now than I was in all

the years traveling, speaking and learning. It's that the song reminded me how blessed I am to have had Kirk with me on this journey and how blessed we've been. I NEVER could have done all the SWF has done without him taking on the lonely duties of basically a single parent when I was gone. You would not have benefited because of all the connections and successes SWF has achieved to improve your quality of life and care.

I remember when I was starting the SWF and I met Arlene Pessar. Arlene started a rare disease foundation 10 years before we did. She spoke about the willing sacrifices she'd made to get better care, research, and advocacy. My young energetic self was enthralled and ate up every word on how to do it "right". I had many years and plenty of time to invest or so I thought. It all flew by in the blink of an eye! She came to the end of the lecture and someone asked her if she'd do it again and she said no. She shocked audience into silence as she tearfully, guiltily perhaps, relayed while in the fight was noble she had lost precious days of memories. Now her son had passed on and she craved what she could never get back.

Continued on next page >>>

CONTACT US: 973.895.4445 | www.sturge-weber.org | swf@sturge-weber.org



*A Message from the
SWF Board of Directors Board Chair,*

Curt Stanton

The Sturge-Weber Foundation has weathered the last two years of the Pandemic with resolve and as always attention to utilizing your worthy donations to the best use possible. We have had to drastically cut expenses due to a consequential drop in revenue. We closed the Houston office and had two wonderful employees sadly depart to other business ventures. Brian Fisher and Susan Finnell were an integral part to growing the Patient Engagement program and expanding sponsorship opportunities which fund vital programs. We wish them well! All these changes have enabled the SWF to no longer need to draw down on reserve funding.

The new changes have brought the home office back to Aurora, CO where the SWF

started in 1987. This transition is a smart move with the Treasurer, CEO, and newly hired Communications/Social Media Director, Jeri Stunkard, residing in the Denver metro area. We have also been busy generating new revenue and sponsorship opportunities to sustain programs and personal service. Your donations continue to create new investigations with research grants and the highly successful, well attended Educational Summits. Thank you! This Journey is richer for you being on it with all of us.

Stay tuned for upcoming events and we look forward to seeing many of you at the International Family Conference in July in Grapevine, Texas.

Connect with Karen Cont...

So, older wiser less energetic but still yearning for answers and cures, I too crave holding my babies in my arms and the busy days and sleepless nights again. When one is called, you must go! Destiny will not allow it any other way but heavy is the price is paid in the end. I hope I've been worthy amidst the let-downs and lost days.

With Faith, Hope and Love,

Karen Ball



Connect with Jordan St. Cyr:

@jordanstcyr @jordanstcyrmusic



Cover story

JOURNEY OF A LIFETIME

Past, Present, and Future

by Karen Ball

will continue to need more of you. Every organization has a life cycle; and a life cycle of employees and volunteers too. Board members serve up to a three-year term for two consecutive terms and then can rotate off to refresh and come back again if they so choose. Staff come into our journey for a reason, a season, or a lifetime.

We have been so blessed to have had our most recent staff member, **Susan Finnell**, steer us in the right direction and keep us moving forward for a reason and a season! She truly is a gift to all who know her, and we wish her well in her new position in children's ministry at a local church. **Brian Fisher** is still with us for a reason, a season, and a lifetime! We're excited to share he has turned to psychology and his other consultant projects. Lucky him and us, he's still with us but once again as a lifetime volunteer! **Emily Varga** has secured a full-time position in HR and we are soooo excited for her new endeavor as we look forward to seeing her at future SWF events!

Just as any journey takes expected and unexpected twists and turns, **Jeri Stunkard** has stepped into Susan's former role and has hit the ground running on communications and social media matters. Jeri is the owner of Have Faith Studio and is still a SWF supporter after first doing graphic design for *Branching Out* and other publications over 25 years ago!

Programs. They are the heart of what we do and how we serve you along the way! We are excited to be developing a video library for use now and for future generations to learn

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Time. Lately, thanks to my friend Kimberly, I have been contemplating time. How quickly and slowly it goes. How we can never get it back and need to be present to get the present of the timeless moments. How many times I have wanted to freeze time for it to stand still! How cherished it is and sometimes how agonizing the moments are in life.

The Sturge-Weber Foundation (SWF) has been a journey of a lifetime for me, and I hope for all of you reading this article. No matter what mile marker you are along in your journey with Sturge-Weber syndrome (SWS) or a birthmark having the SWF resources, programs, and experts at your disposal to serve as a road map to follow (so you don't take too many detours ;) I hope is beneficial. The SWF journey began in 1987 as you can see from our Tree on page 7 and we have all come a long way since then!

But where are we headed and what do we need to prepare for our next journey?

Infrastructure. Yep, it's needed to keep us on the right road! The unfinished basement where we started was the first step to getting organized and having a command post. The SWF has had some amazing staff and volunteers over the years, and we

From the Beginning

by Karen Ball

I was introduced into the world of rare diseases on October 11, 1986. My daughter was born with a large Port Wine Birthmark on her face and diagnosed with Sturge-Weber syndrome. She had her first eye surgery at one week old due to glaucoma and her first seizure at one year old. Ever since that infamous day and the ensuing 34 years of medical challenges, surgeries and the associated financial stressors of life with a rare disease life has been an unimaginable roller coaster ride! I am so honored to contribute a few reflections for this memorable EP milestone and issue.

I remember thinking our family was so alone in coping with all the uncertainties we faced with SWS in our lives. Yet, each day as we navigated the plethora of doctor visits and the usual new parent joys and anxiety we would search in the library and ask doctors for answers. Snail mail and long-distance telephone charges put you in touch with the few families an emerging organization, National Organization for Rare Disorders (NORD) shared with us. We cherished so much the proverbial Light of Hope after visiting with other families with SWS! Awareness and advocacy were just as key as providing support and resources.

The first NORD conference I attended representing the Sturge-Weber Foundation was so educational and the collaboration amongst the burgeoning rare disease organizations was exceptional. We bonded over shared experiences and parenting matters while we found many common challenges pertaining to governance, fundraising, and communications. The

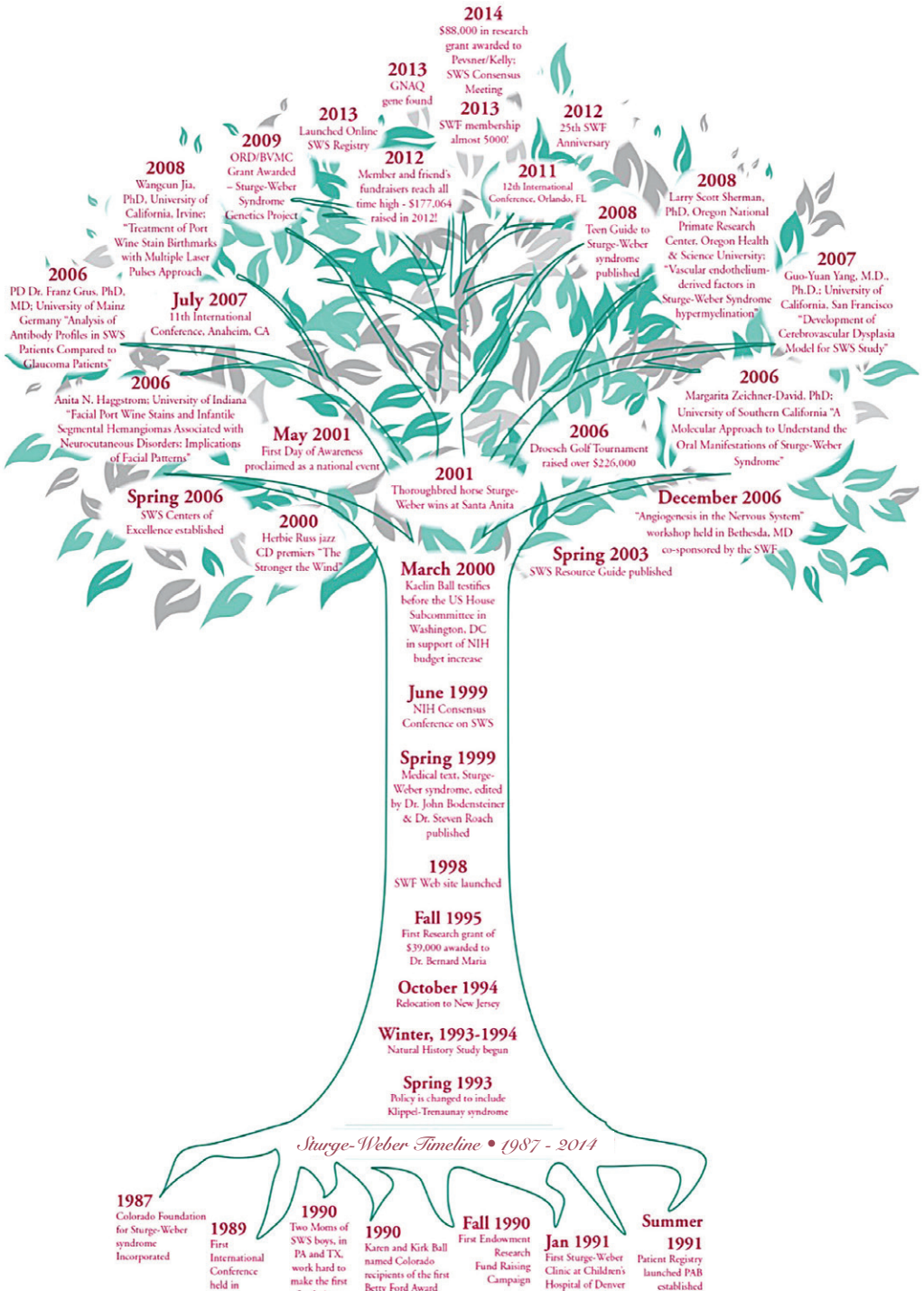
NORD staff were so integral to hosting excellent conferences and networking people and organizations. Jean Campbell particularly was and is like the real-life Rosalind Russell's Auntie Mame! I was able to find common threads and research leads in SWS after visiting with other leaders and researchers that previously we might not have thought of without the brainstorming.

There was no Internet back then and expensive long-distance telephone charges united us to raise our voices to get research funding parity at the National Institutes of Health. Abbey Meyers, NORD President, was and is a force to be reckoned with. She set an example of how to be a fearless leader who never takes no for an answer! It was a privilege to give back to the community serving 10 years as a NORD Board of Director. Since then, there have emerged other umbrella organizations similar to NORD, in my opinion, have their primary focus on marketing and advocacy.

No longer is our world the one stop shop for vetted information which is a blessing and a challenge. Critical thinking is a must to sift through the plethora of data and hype on the Internet. We must ask questions such as, have articles and facts stated been verified by medical authorities? Is there transparency on where the donations are spent? Is a categorical statement supporting an "xyz" treatment or certain physician by one parent the right fit for you and your family? Only you know and if you don't then ask your physician and do your homework.

Not for profit organizations typically know

There was no Internet back then and expensive long-distance telephone charges united us to raise our voices to get research funding parity at the National Institutes of Health.



In Loving Memory

Wayne Rodney Troutman

“Ted,” 86, of York, entered into eternal rest Tuesday, Feb. 15, 2022, in Florida.

He was born on April 16, 1935, in Jordan Twp., and was the son of the late Harvey E. and Carrie V. (Kratzer) Troutman.

The family has requested that, in lieu of flowers, memorial contributions may be made in Wayne’s memory to the SWF, www.sturge-weber.org, click on the Donate tab.

Resources

Facebook Groups

OFFICIAL STURGE-WEBER FOUNDATION AWARENESS PAGE:

A public place created to share your questions, stories, pictures, and videos.
sturgeweberfoundation

SWF ROAD WARRIOR BEAR WEBSTER:

Webster is our Road Warrior who loves to get his picture taken.
SWFRoadWarriorBearWEBSTER



STURGE WEBER FOUNDATION WORLD OF CARE AND SHARE NETWORK:

A place to gather so we as a group have an open forum to ask questions, learn together and brain storm.

Let's Connect



Karen and daughter Kaelin

#TheWarriorMama

Now available from SWF founder and CEO, **Karen Fisher Ball: “The Warrior Mama”.**

Inspired by faith and driven by determination, Karen blazed her own trail and created the Sturge-Weber Foundation to battle SWS. She embarked on a fundraising and research journey through the medical community and the pharmaceutical industry that has helped people worldwide.



There is sadness and joy in these stories, and plenty of hope for anyone who feels they are facing an impossible situation with the health of a loved one.

amazon smile

Don't forget to use your **Amazon Smile** account. Just select **The Sturge-Weber Foundation** and Amazon will donate a portion of your purchase to SWF. **PLUS, 100% OF PROCEEDS BENEFIT RESEARCH AND AWARENESS**

Pick up your copy today in print or digital.

Journey of a Lifetime Cont...

from, heal from and uplift from anytime they need it. Patient Engagement on-line and in person meetings continue to be well attended and the most recent country to add to our SWS family is Bhutan! Clinical consensus driven by the Delphi process will create standards for physicians and SWS experts alike. International research collaborations continue to grow and create NIH funding opportunities to increase the pace of discovery! Advocacy and awareness opportunities provide a platform for you to expand our road crew and get the word out. Look for some new public relations spots too! Our goal is awareness everywhere and everyday. No more questions such as, "What's that on your face?!"

Fund Development. Our pace on this journey is only reined in by the diversity of funding streams and the contributions commensurate with your means. I'm grateful for every penny you send...no amount is too small! Recently, we had an Endowment

Fund established with a \$25,000 initial deposit with future annual contributions promised. Interested in this type of sustaining contribution? Please contact me. Million Miles Walk coming up is a GREAT awareness and fun way to join as we raise donations to support all the above! Grants both private and federal are also being submitted to under-gird the road we are building towards a brighter more informed future. All I know is I started SWF with what I knew, who I knew and a fierce burning desire for answers. No question too stupid, no request not attempted, and a no response was not a full stop but turn around opportunity to clarify. Did you know that "no" is a "not now" or "you never know" moment? We must always keep moving forward despite hearing "no"!

Every journey begins with the first step, the first mile, the first offer to help, the first request and then the end is in sight! Together IS better...see you on the road!



Around the World...

Meet Asha

Asha Reine was born June 8, 1999 at 5:15 a.m. We and staff at the hospital thought her skin discoloration will fade as she grows. For here in the Philippines, less is known SWS. We went home the next day. Then after 2 weeks her tummy grew like a balloon, she was confined for 3 weeks. Still SWS not detected. On her 11th month, she is shaking. None of us thought it was seizure, and how dangerous it was if prolonged. Tests was scheduled; but because both of us have no work...it took sometime for CT Scan be done.

After her 1st birthday, someone sponsored the test and it showed her left brain is smaller. Prescriptions were given, but not much explanations about SWS.

We all gave Asha all the love, care, support



she needs. She knows the power of prayer at a very young age she grew up playing with her friends, and went to school. She may be late or slow in some academic skills. But she is amazing in most ways we never thought she would understand. She is great too on jigsaw puzzles Trials came along as she grow up. We ask for help whenever. Because medical care here is expensive. And I may say from experience, some are heartless, even some of the hospital staff.

Continued on page 16 >>>

@ **SHARE YOUR STORY WITH US. EMAIL:** julia@sturge-weber.org

You Don't Want To Miss This!

YEE HAW

Join us for the 2022 SWF International Family Conference

July 17-19, 2022

The Great Wolf Lodge in Grapevine, Texas USA

WHAT CAN I EXPECT AT THE CONFERENCE?

Much like conferences in the past you can expect:

- Kid's Camp for children during the Conference
- Breakout Sessions you may choose to attend
- Clinic appointments with CCN specialists (limited appointments available, TBA)
- Respite for Caregivers
- Planned activities for the entire family including TikTok Karaoke, swimming in Great Wolf's water park with SWF reserved cabana, Million Miles Walk event, and more surprises!
- Time to do your own thing
- Cowboy theme dinner with dancing and photo booth
- Learn what researchers are

up too

- Meet new friends
- SWF swag bag
- Therapy Dogs & Horses
- Real life cowboys
- Music and art therapy sessions

...and so much more. y'all!

ACCOMMODATIONS:

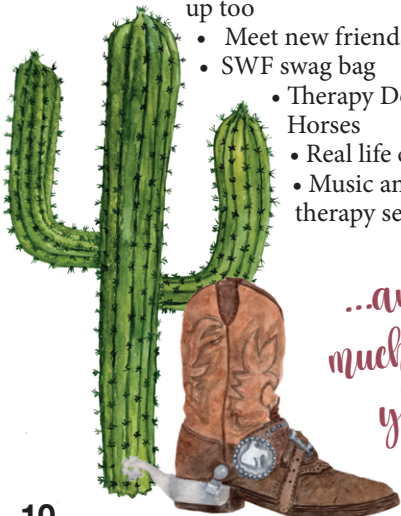
The Great Wolf Lodge is a wonderful adventure filled experience for the entire family.



NOTE: Each reservation will receive up to a \$300 discount (\$100 per night) provided by SWF and \$25 discount per night on water park tickets.



- \$260/night plus taxes + \$9.99/night reservation fee.
- Rooms sleep up to six people (\$50 extra per person over 6).
- Waterpark Fee: \$9.99/night (this includes the \$25 discount).



Things to Do

The Great Wolf Lodge is located in Grapevine, Texas just outside the Dallas/Fort Worth Metroplex area. With the DFW airport so close, as well as other small towns and attractions, there's so much more to see while you are in Texas!

ATTRACTIONS IN GRAPEVINE

- LEGOLAND® Discovery Center
- Peppa Pig World Of Play
- SEA LIFE Grapevine Aquarium
- Bass Pro Shops Outdoor World
- Grapevine Mills Mall
- Nash Farm
- Historic Main Street

ATTRACTIONS IN DALLAS/ FT. WORTH

- Dallas World Aquarium
- Fort Worth Zoo
- Golf Courses
- Louis Tussaud's Palace of Wax and Ripley's Believe It or Not!
- Museums and Cultural Centers

Check out the additional activities at The Great Wolf Lodge! Water Park Information check out www.greatwolf.com.

To make reservations call

844-554-9653 by June 25, 2022 and provide the SWF Guest number: @2207Sturge

CONFERENCE REGISTRATION FEE EARLY BIRD SPECIAL

NOW through April 1, 2022 (NO JOKE)

Adults: \$175 each, Children (3-17 years): \$125 each, Children (1- 2 years): \$50 each
Dinner Party only on 7/19: \$50 each

REGULAR REGISTRATION FEE (April 2 - June 25, 2022)

Adults: \$200 each, Children (3-17 years): \$150 each, Children (1 - 2 years): \$75 each
Dinner Party only on 7/19: \$50 each

REGISTER TODAY:

sturge-weber.org/participate



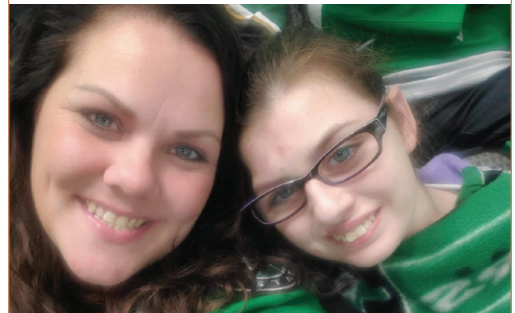
SCAN ME



Our Hosts

The Walsh Family

Read their story on page 13...



Head of Wranglers
Laura Embrey

DON'T FORGET TO PACK:

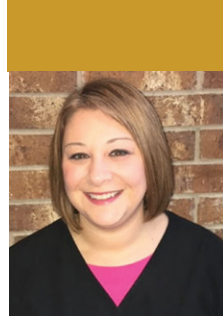
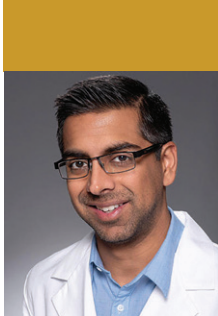
- ✓ Sunscreen and Swimsuit
- ✓ Western attire encouraged
- ✓ Comfortable shoes
- ✓ Questions for Researchers



See y'all there!

Hometown Hosts:

Dr. Dave Shahani & Amy Davis, RN



Welcome to the Great State of Texas! We are more than cowboys, longhorns, oil, BBQ and The Alamo—even though those are all great things! We look forward to hosting the 2022 Sturge-Weber Foundation International Family Conference and International Research Network Meeting. Come join us in July, along with other members of the Clinical Care Network, to learn more about Sturge-Weber Syndrome and connect with other families affected by Sturge-Weber. We can't wait to meet y'all!

Meet our Speakers:

Amy Davis, RN

Amy Davis is a Registered Nurse and the Epilepsy Coordinator at Cook Children's Medical Center in Fort Worth, Texas. She has over 20 years of pediatric nursing experience, 10 years of which are pediatric neurology. Amy enjoys educating families and collaborating with other specialties to help create positive outcomes for patients and their families.

Dave Shahani, MD

As a native North Texan, Dr. Dave Shahani has been itching to return to DFW and has proudly found his home at Cook Children's. His journey home took him near and far. He completed his undergraduate training at the University of North Texas and Austin College followed by his medical school education at the University of Texas Health Science Center in San Antonio. He completed his residency in Child Neurology at the University of New Mexico where he remains a volunteer faculty to continue his passion for education while serving as medical director for Camp Rising Sun, a summer camp for children with autism. He then braved the Chicago winter to complete his fellowship in Epilepsy at

Northwestern University before following his calling to Fort Worth.

With gratitude, Dr. Shahani has what he believes is the greatest job in the world, to be able to care for children and their parents, often through their most challenging moments. His clinical interests include caring for children with complex seizures, headaches, and any other neurologic ailment. He values a treatment approach that considers lifestyle modifications alongside medications, dietary therapies, and/or surgery when appropriate. His primary passion is education for all - so he asks his patients, students, and colleagues to never be afraid to ask about anything on their mind. If we don't know the answer, we can work to find it.



Outside of his clinical interests, he enjoys spending time with his loved ones, watching football, gardening, music, and being outdoors as often as possible.

READ MORE ONLINE:

www.sturge-weber.org/for-patients/cook-childrens-medical-center.html

Meet the Walsh Family

By Daniel Walsh

October 29, 2003 was a day of great expectations. We were anticipating the arrival of our second son. We all went to the hospital. Aidan came quickly and I almost had to catch him because the doctor was not in the room. We were filled with joy and happiness as he came into the world. Immediately, I saw the mark on his face and asked if he was alright. The nurse said it could be bruising from the birth canal. We held him for a few minutes then they whisked him away to get cleaned up and checked out. The attending pediatrician came in next. She told us the red mark was a port-wine stain, it would never go away, there were no treatments, it was accompanied by seizures and brain damage, and he would never be able to care for himself. She left out the glaucoma. After she left the room, Caroline and I held each other and cried.

Within the hour we called our families to let them know Aidan was here and healthy with the exception of what could possibly be Sturge-Weber Syndrome. We had never heard of it, and I think the attending pediatrician had only read about it before she told us. My parents found the

Sturge-Weber Foundation online and were in touch with Karen that day. We were home the next day and spoke with Karen and Jan as well. She was a level head and started our education. We found doctors for Aidan.

He was diagnosed with glaucoma and at two months had his first surgery. We thought we had avoided the seizures,



but we were wrong. At six months, he had his first seizure. It was massive and caused a stroke which decimated the top section of his right hemisphere. Essentially he performed his own hemispherectomy. He was

Continued on page 16 >>>



Webster's Travel Log

Webster Needs a Ride to the Conference



In 2017, mother and son duo, Debra and Cody traveled from Irving, Texas to the SWF Family Conference in Ohio. They had Webster Bear in tow and from the looks of it, he had lots of fun on his road trip! Webster is looking to hitch a ride this year too. **Anyone have room for Webster on their journey to Grapevine?** Drop us a line at jterrell@sturge-weber.org.

Lace up your shoelaces for Routes to a Cure!

THE STURGE-WEBER FOUNDATION

MILLION MILES WALK

BIRTHMARKS | GLAUCOMA | SEIZURES



WE ARE ON A JOURNEY

NAVIGATING LIFE TOGETHER

For 35 years the Foundation strives to find answers, improve medical treatments and forge opportunities in research to combat this rare disease that affects only 2% of the population.

IT IS THE FOUNDATION'S HOPE THROUGH THE MILLION MILES WALK EVENT TO:

- Raise funding for research
- Team-building for our existing community of members
- Raise awareness of this rare disease to the general public
- Offer a healthy exercise opportunity for a cause
- Grow our volunteer and donor potential

The SWF Million Miles Event begins April 1, 2022, and ends July 19, 2022, with a special walk at the 2022 International Family Conference in Grapevine, Texas. SWF will announce special “Mile Marker” incentives during this event.

Create a Team, register as part of an existing team, go for a virtual walk, or walk as an individuals. It's all about the journey to a million miles so, get creative!

Planning a fundraiser might sound intimidating but you can keep it super simple or go all out. It's completely up to you! Listed on the right are some ideas to get your creative juices flowing. And, you can always reach out to the SWF team with any questions you may have. Email us at swf@sturge-weber.org.

Members Taking The Lead



Hailey's Hope
www.haileys hopesws.com



Myla's Mission
 [mylamissionforSWS](https://www.facebook.com/mylamissionforSWS)

Fundraising Walk Ideas

- Get the community involved (school, church, professional organization, or your company).
- Ask your company about matching donations for your walk fundraiser. It's a great way to double your efforts. Make them a sponsor to give them recognition.
- Host a bike and/or walk at your child's school track. Encourage decorating of the bikes. Ask participants to collect donations for each lap around the track.
- Host a bake sale in conjunction with a car show and walk.
- Host a "Family & Friends" picnic at a local park with fun games with a 1 mile walk, collect donations.
- Track your walking with family and friends across the country using a walking app or purchase our Million Miles pedometer. Ask them to get others to sponsor their walking with a donation per mile they walk.
- Turn your walk into a pup walk. Encourage participants to dress up their pups for the walk. It's a huge win for you and the pups!
- Host a BBQ in your backyard then take an evening stroll around the neighborhood. Charge a "cover charge" to your event which is a donation.
- Host a Treadmill Challenge with your gym buddies.

Raise \$100 to receive SWF Swag!



Visit the Official SWF Shop for more gear!



Use code **MILLION22** and **SAVE 10%**

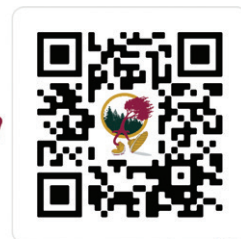


OUR SPONSORS:



REGISTER TODAY:

sturge-weber.org/participate



SCAN ME

Meet the Walsh Family Cont...

paralyzed on the left side of his body. Rehab ensued and today his body and mind has recovered.

The Sturge-Weber Foundation has been there with us throughout Aidan's life. Helping to find doctors, educate us, and provide a community of people who understand. Through this community we have been able to partake in the wonderful opportunities of study with Dr. Juhasz at Wayne State University and Children's Detroit.

We have been blessed with Aidan and his health. He has been active in theater and been in over 14 shows through high school and local community theater in Grapevine, TX. He will graduate this year from high school, and was accepted to 5 colleges, along with scholarships. He plans to attend Hendrix College to study psychology and theater.

We are grateful for the education, resources, guidance, compassion, and community we have received from the Sturge-Weber Foundation.

Mark your calendar

Upcoming Events

MARCH 29

SWF Modeling Meeting

MAY 4

May the Force Be With YOU Town Hall Meeting

JUNE 4

Education Mini Summit

JUNE 21

SWF Modeling Meeting

JULY 17

Board Meeting in TX

JULY 17-19

2022 International Family Conference Grapevine, Texas

JULY 19-20

SWFIRN Meeting

SEPTEMBER 3

Mini Summit

SEPTEMBER 15-17

CCN Meeting in Boston

OCTOBER 18

SWF Modeling Meeting

NOVEMBER 3

Mini Summit

DECEMBER 7

Town Hall with Karen End of Year

Meet Asha Cont...

When she was 15 she was seen by an ophthalmologist and requested for several eye tests. Again her tests were seen by different people. Because we are lesser than less. Results came and she was diagnosed with glaucoma and needed eye laser ASAP.

No matter how hard I try to control my tears, I can't help it. I said to myself, my dear Asha is having another challenge in life and where will we get the money. She was just looking at me as I cry, then she hugged me. I was somehow ashamed because she was the one comforting me. She is so brave, faithful and so positive in life. She told me "Mama, all will be fine, Jesus is with me always and He will help me. I will make jewelries and let's post it on Instagram so we can raise funds. And I am okay don't worry. All will be fine." She was also a former *Make A Wish* kid. And after her wish was granted. She viewed to grant wishes every December. She said it is her gift to Jesus. She wanted them to feel how she felt when her wish was granted.

Since the pandemic, we are all having a hard time raising funds for all her medical needs. Tests need to be done. She has a sponsor in America who sends all the dolls she uses.

In all the adversities; trials. God is always with us. And He never fails to amaze us with His miracles. All we pray for and ask God is for Asha to stay healthy, happy, and strong. She dreams of going to America someday. And we believe by God's grace...SHE WILL

Thank you so much Ms. Julie. God bless you.

Watch more of Asha's story on YouTube:

<https://www.youtube.com/watch?v=N-vW2yPR5LME>

And follow her on Instagram:

 @ramireginareine

From the Beginning Cont...

how to watch expenses and maximize contacts to ensure that patients and their families get the most bang for their donation dollars! Kathy Hunter, International Rett Syndrome Association (IRSA) Founder, was the best at optimizing donations and getting donated products and services! She taught all of us who were new to operating organizations how to partner with pharmaceutical companies. There just wasn't any doubt that we would all succeed by sharing resources, contacts, and concepts. The camaraderie was and still is the best part of coping with a rare disease and operating a not-for-profit organization.

It's interesting to look back in the reveal of time and see the breadth of changes that have occurred in communications, patient engagement and support, physician education and awareness, and of course research. Each generation has something new to offer to improve in all these areas which leads to faster and greater impact. Tweaking ideas and pulling in new technologies to meet the patient, family, doctor, and researcher right where they are in their respective rare disease journey has been key to many breakthroughs and research successes.

There are organizations that have adapted to all these changes and they still thrive. Sadly, many that were splintered by egotistical individuals who watered down the donation and resource pools only to either merge organizations back again or die off. We HAVE seen many changes at the Sturge-Weber Foundation in thirty-four years! Thanks to my mentors, cherished volunteers, and dedicated donors we have weathered organizational and economic challenges and reveled in the GNAQ gene mutation discovery. Thanks to the Office of Rare Disease (now at NCATS) and their AMAZING staff we all put our heads together and learned from one another to develop best research practices, funding opportunities and how to apply for them and to participate in advocacy on the Hill to spur even more funding for the NIH and FDA. It has been a privilege to fight on the frontlines with so many dedicated men and women and to celebrate so many wonderful milestones together!

Each generation has something new to offer to improve in all these areas which leads to faster and greater impact.

The Sturge-Weber Foundation started in an unfinished basement with donated Amoco furniture. The Betty Ford Award and Ann Landers column brought funding and awareness. Building blocks provided by each person bringing what they knew and who they knew to the cause created the successes we have achieved thus far. Today, twenty-seven SWS Clinical Care Network sites are established across the country. Like many organizations there is an online registry to collect critical natural history data. Volunteers have been and will be at the heart of organizations who create lasting impact for their respective rare disease. Never think that you are not an important piece to mission success! EVERY dollar raised and EVERY little bit you promote, engage, and share is critical. It just takes one person, one moment of coincidence or collaboration and whole new frontiers can be opened that we never thought possible. Just say, "Yes!"

There was a rare disease mom, Arlene, who had a son die from the same rare disease. I'll never forget she said one time she would not have started her organization. It was not because it hadn't done well but she said you can never get back lost time. So many conferences, meetings, phone calls, communications to answer to keep the momentum going forward were just part of the job. Today it is even harder to shut out the world and truly focus and be present. After thirty-five years, I truly understand what she was saying!

Please give yourself a present and BE present. Time flies by way too fast and you can't get it back. The future is bright as we continue the tradition of fighting for rare disease awareness, research, and engagement! I look forward to seeing how the next generation transforms the community and gives back for their loved ones and to honor all those who lead the way.

Because of you...

CARING today will provide CURES tomorrow!

Programs under the umbrella:



A few ways we use YOUR donation:

RESEARCH:

Seed Grants, CCN Meetings, SWFIRN Meetings, New Researchers

TECHNOLOGY:

SWF App Development

EDUCATION:

Mini Summits, Fact Sheets

PATIENT ENGAGEMENT:

Family Conference, Patient Engagement Events

ADVOCACY:

Advocate on The Hill, at schools

2021 Total revenue raised	\$298,405.06
Total # donors for last fiscal year	639
Individual donors \$100 or less total for year	433
Individual donors \$100-500 total for the year	296
Individual donors \$500 and up total for year	76
Average donation amount per individual	\$150-350
Total income from individuals	\$217,994.50
Total income from Corps/Companies/Grants	\$75,000

8,049

Families Supported

560

Professional Support

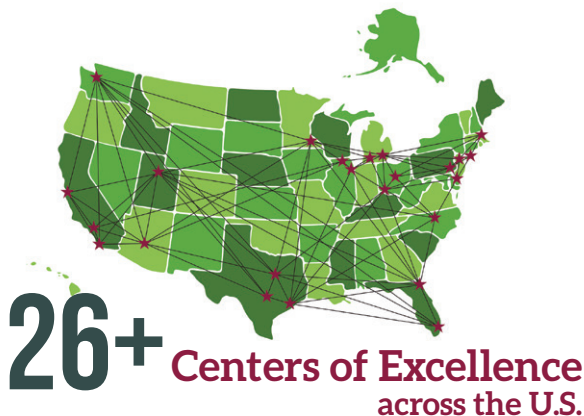
15,000

Faithful Donors

1

YOU

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JOURNEY

S NAVIGATING LIFE TOGETHER

Because of your donation we are driving change

- YES!** I will make a tax deductible donation of \$_____.
- YES!** I want to make an ongoing monthly pledge of \$_____.
- In **MEMORY** of: _____
- In **HONOR** of: _____
- Endowment Donation
- I have enclosed a check
- Please pay by credit card* VISA MasterCard Amex Discover

Name on Card: _____

Credit Card #: _____

CSV: _____ Exp. Date: _____

**You may also make a secure donation at www.sturge-weber.com/donate or scan the QR Code below. Please provide your contact information in the area above for credit card donations.*

***You may also **donate gifts of stock or real estate** to the Sturge-Weber Foundation.*

Name: _____

Address: _____

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Mobile Phone #: _____

By providing your email and mobile number, we are able to send you news updates immediately!

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6105 S. Main Street, #200
Aurora, CO 80016

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Look Inside...

- SWF: Past, Present, and Future
- 2022 SWF Int'l Family Conference
- Million Miles Walk

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Spring 2022