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

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

# Branching Out

SUMMER 2024

## TOP 5 SUMMER favorites

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

SUMMER 2024

## *The Spring Issue...*

***Branching Out* Sponsorship Available:**
Contact Julia, jterrell@sturge-weber.org
for more information.

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.

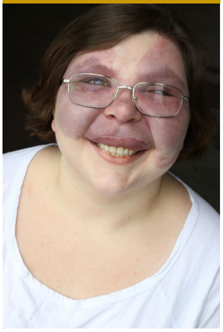
Sturge-Weber Syndrome (SWS) is a rare congenital condition usually consisting of a facial port wine birthmark, glaucoma, and seizures, (although not all of these symptoms may be exhibited).

**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.



Goodwill Ambassador

# Gone are the Days of Old...

Hi Sturge-Weber Family!

Karen had her *2cents* written for this edition, but asked me to write my thoughts instead and she's the boss, so here we go.

Since we came home from the Int'l Family Conference in Philadelphia this July, I have been busy working a "secret" project… digitizing The SWF archives. The SWF became a registered non-profit in September 1987. I was born October 1986. Yes, it is hard to remember my age vs the SWF birthday most of the time. **The Ruby Anniversary (40 years!) will be September 2027**. We are sure to have an epic party to celebrate!

> *Not many foundations make it forty years. You all have been an integral part of this history making foundation. Because of your generous support, donations, fundraisers, and government grants we have been able to keep moving forward in the lean years (we're talking to you, COVID). We have to say that, like many foundations, we are still recovering.*

But I digress. Back to the Ruby Anniversary. My mother has worn (since forever) a beautiful ruby ring she received from her grandmother. That ruby is a constant reminder to her of how important family is. It has been Karen's dream from day one of this Foundation that SWS families and individuals never feel alone in their journey. No matter what has happened in the years between your first call or letter, first conference, and the last time you sent an email or posted a Facebook message needing resources of information, *we* have always been there.

HECK! We have the proof of the first *Branching Out* that was typed on a typewriter and not a computer (see pages 20-21). We have newspaper articles from 1989 before the invention of social media. Publicity once required written pitches as a way to catch the eye of anyone in the media. The SWF archives even held the step-by-step guide to pitching your fundraiser or telling your SWS story during Month of Awareness in May. The 1990s were a time when fundraising and publicity was *really* hard work. The 2000s helped make it easier with the advancement of the Internet, although it has its own challenges, like cutting through the noise on social media.

Is it still hard to get on the local or national news? Is it hard to plan, fundraise, and execute a 5k, softball game, gala, and other elaborate fundraisers? Yes, yes, and yes, but TONS LESS.

During the pandemic I hosted a *Pampered Chef* party online and a percentage from the orders were sent to the Foundation. We raised $300 all online. There are many other companies that host fundraising online but you can also ask your friends for donations instead of presents for your birthday. Facebook provides an easy way to do this.

What if social media isn't your thing? That is okay too! Schools regularly host fundraisers at restaurants or eateries like Chipotle, Dairy Queen, Applebee's, etc. Did you know you can host one of those for The Sturge-Weber Foundation, too?! (BTW, we will help guide you on how to do that.)

Continued on page 9

# BVMC Project is in the Homestretch...please sign up!

**JEFF LOEB, MD, PhD**
The SWF's Chief Scientific Strategist

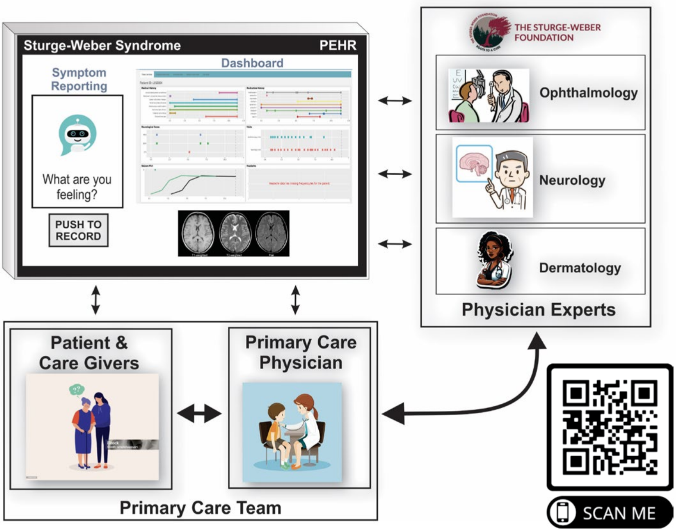
As of today we have over 120 patient enrolled in the Brain Vascular Malformation Consortium to study the natural history of Sturge-Weber syndrome. Our goal is to get this over 180 patient by next March.

Many of you ask me what should I expect will happen as I grow older? Or, should I take aspirin? Is one seizure medicine better than another? What is the best laser treatment? What will happen to my vision?

By hearing from all of you, we will soon have better answers to these questions and be ready to conduct clinical trials for those questions we cannot yet answer. In addition to building a database of what happens to each person with SWS over time, we have recruited an outstanding computer scientists, Dr. Biswajit Maharathi (pictured here). He has built an online database for this research project. This database was converted to a dashboard so that we can view how the disease changes over time in the face, eye, and brain, keeps track of medications and treatments, and links to brain imaging studies.

This project is currently funded by the NIH and funding will soon run out. However, we think that continuing the project should be a priority for the Foundation. We are building a vision for the future where every patient with SWS will have access to their own personal medical dashboard that they can share with their doctors and family. We also plan to enlist our Clinical Care Network experts to help your doctors by sharing the online dashboard with them. The dashboard will also allow you to describe your symptoms in real time and send this information to your doctors as well as plot them out on the dashboard.

*Dr. Biswajit Maharathi*



SCAN ME

So please, sign up to be part of the BVMC. We will be both fundraising, as well as, seeking out a computer whiz experts from our family network to help us make this dream a reality. Stay tuned!

Stay tuned in the next edition for more on tissue donation and updates on science from Matt Shirley, CSO.

# Thoughts on Grief

**JULIA TERRELL**
Director of Community Relations

As I sit here ready to write the next article for the *Branching Out* about all the wonderful things the SWF completed this year and what we have planned, I can't help but feel lost and heart broken. During the past Labor Day weekend I learned of two families that paid the ultimate price. Two of our warriors lost their fight and passed away. One was very young and one older, my age really. This tragedy doesn't happen very often, *thank goodness*. It is never easy and it is never what you want to hear for many reasons.

Like many of us, immediately my heart goes out to those families. For a caregiver or parent, many times it brings us back to the forefront of all the frightening feelings we have tucked away in the darkest corners of the our world. We tend not to go back there until we are forced to.

> Today, I can only ask each of you to give yourself time, have faith, and give yourself a chance to be kind while you heal.

Then you hear the story and all the emotions come flooding back—the fear of the diagnosis; the fear it won't be okay; the fear no one will understand; the fear you can't fix it; and the sickening fear of the unknown. Secretly you may even think to yourself, "Thank God it wasn't us and hope it will never be." Funny thing is if we all lived in the same city we would have one heck of a party to celebrate life, cry our tears away, hug each other and more. Instead, on social media the news spreads like wildfire.

No one deserves to die. It breaks my heart and crashes into my thoughts. No one deserves to feel the pain and agony of this loss. NO ONE! We talk online and give each warrior lots of virtual hugs. We are here if you need us. We offer compassion and so much. Most of all, we hope that family understands they are not alone.

We spread it on airwaves to show others that this sometimes invisible syndrome can really do harm. It's not "just a birthmark." We pray you feel better knowing you aren't alone.

Then you hear people tell you why it can't happen to you. Your inner voice is saying why not why can't it—we aren't that different and for crying out loud it most certainly can!

One of our fellow warriors said that hearing the news of loss is going to be a problem for many and I agree because I am one of them…

It has been a somber holiday weekend and now it is time to get back to work. For that family—they can't, they need to heal, to mourn, to get mad, to go through all the phases of grief. We all need that as well. I remember saying, when my best friend lost their child, at least I got to grow up with Marissa. And when others told me I still needed to mourn that loss it didn't compute. But you do! "Why–it isn't fair," I said. Grief is unavoidable you can't rush it, skip it or ignore it. You have to feel it. You must find your way to move through it. None of it goes away it just gets easier. My grandfather used to say, "Only time can heal these wounds and nothing else."

Today, I can only ask each of you to give yourself time, have faith, and give yourself a chance to be kind while you heal. Whether you are dealing with changes, like school, IEP meetings, eating issues, struggle with medicines, or the ultimate grief of loss—we want you to take your time and heal. We want you to have faith in yourself that you can do it. Be kind to yourself, none of us really have capes, we just don't. Reach out to your village and do the one thing we aren't good at and ask for help. Maybe you just need a few meals, or you need someone to

*Continued on page* **16**

# We've Walked a Million Miles in Your Shoes–Now we are **Passing the Torch to YOU, Our Members**

## We thank you, The SWF Torchbearers!

Kicking off in New Orleans, LA was **Camyrn Eillers,** Miss Slidell's Teen. Camyrn's sister, Carley, is a SWS Warrior. Camryn has even used her Miss Slidell's Teen platform to shine wherever she goes. a light on SWS A true queen!

**Carley Elliers'** journey with this rare disease gives her a unique perspective. She's all about educating and inspiring. Through every hurdle, she never loses her strength and hope. Living with Sturge-Weber syndrome doesn't dim her shine. She educates, inspires, and never loses hope. Despite her challenges, Carley's rocking college and hitting the dance floor!

**Lanti Carson, MT** is another incredible individual born with SWS in the 1970s when even less was known about this rare disease. His journey is a testament to the progress we've made in understanding and supporting those with SWS.

Over in sunny SoCal, warrior mama **Michelle Findlater** and warrior grandma

**Kathy Robbins** hosted their 8th annual BINGO night. TEAM JAYDEN'S SMILE is back after a pandemic pause! Friends, family, and generous donors made it a night to remember with fun, food, and raffle prizes. Special guests included SWF warriors **Melanie Holmen** and **Adrian** from the Birthmark Society.

All money raised, over $4,200 to date, funded scholarships for appointments with our Clinical Care Network doctors during the July Conference.

Michelle, Jayden, and Kathy are big fans of the SWF Family Conference. They've attended all five conferences since Jayden's birth, and they're super grateful for the support of friends and family in helping others share this experience!

**The Brewbaker family, MI** got involved by recording awareness videos for **Celine**. Big shoutout to Deborah, Harrison, and Kevin for stepping in front of the camera for SWF!

**Justin, Brielle, Heather, and Annette Coutu, RI** (not pictured) made it a family affair as they raised awareness for Sturge-Weber syndrome through July.

**Holly Arndt, MN** shared a fun video of her passing the torch for The SWF.

Let's not forget resident Torchbearers **Molly and Myla Speer**, **Julia and Marissa Terrell**, and **Karen and Kaelin Ball** for sharing their stories with our community. You all rock!

Finally, we wrapped up at our Int'l Family Conference in Philly on the iconic **Rocky Steps**, you passed the torch for Sturge-Weber syndrome awareness! Braving the heat and humidity was our Philly Torchbearer **Morgan**. Cheering her on and getting their chance to also carry the torch were Allison, Edwin, Crystal, Carola, Bucky, Kirk, Marissa, Madison, and Michael and Tom, our new Aussie friends. ❋

# Leaving a Legacy of Hope

I became a Warrior Mama in 1982, though I didn't realize it then.

At 27, I was happily married with a two-year-old son when my newborn daughter, Kimberly, was diagnosed with Sturge-Weber syndrome. Sturge-Weber, what?

Her first surgery for glaucoma was at just six weeks old and was the most challenging moment of my life, handing her over to a stranger I had to trust. Over the years, we faced countless surgeries, seizures, depression, eating disorders, POTS diagnosis, and more. However, her seizures didn't begin until she was thirty.

But let's focus on the triumphs. Kimberly graduated high school with honors and earned her MSW from FSU, graduating cum laude. She became the youngest clinical supervisor in NYC and traveled the world, visiting England, Vietnam, Cambodia, Canada, Israel, France, the Netherlands, and Scotland. While researching her condition in her twenties, she discovered The Sturge-Weber Foundation (The SWF).

You see, my husband and I had given up researching and took things one step at a time. We dealt with whatever was necessary while raising our daughter and now two sons. We didn't know any other family dealing with Sturge-Weber until two years ago when Kimberly (Kimmi) connected us with Karen Ball, CEO and founder of The SWF. What a treasure trove of information and friendship that was! Kimberly became very active, becoming a member of PEN, speaking with numerous SWS patients and families, and even recording a training video for nurses at Bascom Palmer Hospital.

Karen asked Kim to record her experiences with friends and reflections on turning 40. Karen had flown from Colorado to Florida for a birthday party. Sadly, the video was unable to be made. In November 2019, Kimberly was diagnosed with CML Leukemia. They told us it was the "good kind," the treatable kind. Yet, we lost her in March 2023.

This past year, Karen kept putting the word "legacy" in my head. She was referring to fundraising. I kept thinking, "Something handed down from the past." What do you want your legacy to be? How do you want to be remembered? Well, Kimmi took care of Karen's part on her own. However, I have been trying very hard to work on Kimmi's personal legacy. How would she want to be remembered? The ironic part is that Kimberly was terrified she would be forgotten.

My family and I attended the SWF International Family Conference this year in Philadelphia in honor of Kimberly. We were supposed to attend two years ago, but life had other plans. Kimberly left an example of "what you can be." She was stubborn, determined, intelligent, persistent, empathetic, and could not be told "no." She had a smile no one could forget and a heart of gold. She was loving and so loved.

When you hear "Sturge-Weber syndrome," you have two choices:

- Get the best medical care and hide your child from life, trying to protect them.
- Get the best medical care and live life to the fullest! Take your child everywhere, let them participate, and teach them to advocate for themselves.

We chose the latter for Kim, and it made all the difference. We just recently found out how much that was true. We can't believe how many people worldwide have reached out to us or how many new friends we have because of her. It is so overwhelming!

Friends are so important when children are young and older.

*Continued on next page >>>*

Continued from page 3

## ...Days of Old

The “old” ways are still one of the best ways to help get the word out and raise funding. Write a letter to your local, state, and federal government offices. (We can send you the templates to make it easier.) Testifying before Congress is not required but getting government funding can help cut the cost of conferences, provide more free stuff like Webster Bear, and cut down on shipping costs. When was the last time you asked your employer if they matched donations from your paycheck? It has now become as easy to set-up automatic bill payments as it is to auto-donate $10 monthly.

Use those social media skills, use your letter writing chops, stop by your state government and walk the halls. We can give you the templates and directions. (See page 18 for more fundraising ideas.) Let’s pave the funding for your Green Tourmaline anniversary, number 38! ❋

As my mother would say, “With faith, hope, and love,”

Kaelin

Kaelin Ball
Goodwill Ambassador, SWF

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Continued from page 8

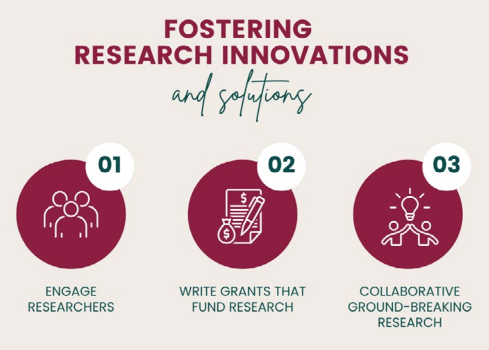
## Legacy of Hope...

Kimberly made sure we would be okay. She had already sent her friends to care for us, left a library for her nephews and nieces, created as many memories with them as possible, and left a myriad of pictures with each of us. She also left a singing tribute for my husband and me and one for her brothers, all of which we did not know about or hear until her memorial. Of course, she basically arranged that herself, too.

Please do not be sad. That is not my intention. My intention is to tell you, from one Warrior Mama to the next, do not let Sturge-Weber syndrome define your child or family. We will continue to be Warriors for our daughter. Kimberly’s legacy is to live a large life. ❋

# Advocacy News

Find all sign-ons here: https://sturge-weber.org/get-involved/advocacy.html



The SWF has for over 36 years helped facilitate and foster research in many ways. One of the ways we do this is to engage with researchers who are applying to the National Institutes of Health (NIH) for grant funding.

The Brain Vascular Malformation Consortium (BVMC) was one such grant that we not only wrote a letter of support to fund it but also were active partners during the last 14 years investigating SWS as well as finding the GNAQ gene mutation.

We are pleased to have recently written a NIH letter of support for **Dr. Anna Pinto’s grant application from the SWF Clinical Care Network (CCN)** in Boston in collaboration with **Dr. Anne Comi**. We are truly excited for this groundbreaking research and look forward to engaging patients upon receiving that grant award.

*Continued on next page 18 >>>*

THE STURGE-WEBER FOUNDATION CLINICAL CARE NETWORK

INTERNATIONAL
**SWS FAMILIES**

**APPLY FOR MEDICAL CARE IN THE UNITED STATES**

at our Clinical Care Network
Nemours DuPont Hospital For Children
Delaware

**https://tinyurl.com/NemoursDuPont**












# IT'S A WARRIOR THING

## PHILADELPHIA '24



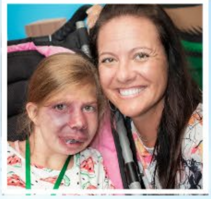
















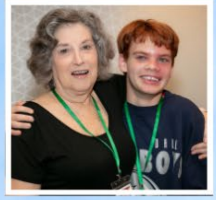








THANK
YOU











I AM
A WARRIOR
MAX

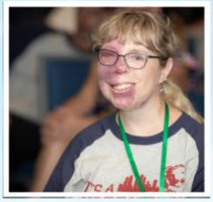

















# IT'S A WARRIOR THING...

The Sturge-Weber Foundation Int'l Family Conference in Philadelphia was one heart-warming and full of laughs event we enjoyed sharing with SWS patients and their family members!

**Here are some of our favorite events from the Conference:**

*Above: Bruce, Lydia, Bryan, and Roger Bedell*

*Left: Aden Rauschbauer & Donnie Hood*

One of the memorable moments was our patient Fireside Chat with the **Bedell Brothers, Aden Rauschbauer, and Donnie Hood.**

The Bedell brothers were born in the 1940s when little was known about Sturge-Weber Syndrome (SWS) or how to treat it. Bruce poignantly recalled that on December 7, 1941— "a date which will live in infamy"— doctors told his family there was nothing they could do for his SWS. They even suggested sending him to an asylum! Thankfully, Bedell Sr. stood firm and declared, "NO!"

**Aden shared some valuable insights on living with SWS:**

- ***Adapt When Necessary:*** Aden started at a private college but had to change his major due to a visual processing disability. And guess what? That's totally okay!
- ***Experience Normalcy:*** Letting kids with SWS experience "normal kid things" helps them discover their strengths and weaknesses.

So, what's next for Aden? He's on the job hunt! If you're in the Los Angeles area and looking for an amazing young man to join your team let us know!

**Donnie Hood**, who lives in Canada, talked about his challenges which include the medical system in that country is different than in the USA. When he sees a new doctor he *is the expert* in the room. Unfortunately, the school system failed him as he struggled to read. Donnie's advice to SWS patients:

- Stay active
- Put together puzzles to keep your mind active
- Don't take life too seriously

# INTERNATIONAL ROLL CALL!

*The Hood Family* | *Deutekom/Storey Family* | *The Duffy Family*

**AUSTRALIA:** The Duffy family from Australia raised funds to help support Australian families living with Sturge-Weber syndrome & new playground equipment for Belmore Special Development School. And, of course, they are committed to helping daughter Emma be the best SWS Warrior she can be.

"Despite all the challenges that have been thrown Emma's way, she remains so full of energy and is such an incredibly brave, strong, funny, happy, and smart little girl," says dad, Michael. @weber_the_wedgie

**CANADA:** This year we had four families from Canada arrive in Philadelphia. Some came by car, some took an airplane, and another came in a tour bus to give us a live show.

First-timers to our Conference were the **Deutekom/Storey family** (Nicole, Max, and Shane Storey) and **Jordan St. Cyr.**

*Tynan and Warrior Dad, Jordan St. Cyr*

@jordanstcyr

Conference regulars, the **Hood family** (Donnie, Maeve, and William) along with the **Roberts/Moon families** (Candice Roberts, TJ, Gavyn, and Harley Moon) met other family members in Philadelphia.

**ARGENTINA:** We want to welcome our family from Argentina, though he came by himself and was a last minute registration we know **Guido Grabivker** gained so much from his adventure. Guido's daughter **Irina** is one lucky gal to have such a devoted Dad to come such a long way to learn all he can about SWS. Great job to this Dad Warrior.

Whether it is your first time or you are a frequent flyer it is always like a reunion and so glad to see you!

For those that didn't know we had a great **silent auction**. We could not do it with out all the wonderful donations!

*Anna Pinto, Steven Falchek, Aimee Laut, and Brian White*

# THANK YOU:

- Tina Alster :
- The Ball Family
- Chris Ellis
- Hand and Stone
- Jewels with a Purpose
- NY Giants
- NY Jets
- Personalized Art Work
- Philadelphia Rock Gyms
- The Philadelphia Art Museum
- Priya Ramesh
- Kathy Robbins
- Personalized Art Work
- Philadelphia Rock Gyms
- The Philadelphia Art Museum
- The Terrell Family
- Wawa

*Just try to keep Rebecca McDonald from wearing that beautiful new ring courtesy of Jewels with a Purpose!*

# Thank you to our Conference Sponsors

ucb Inspired by patients. Driven by science.

ROBERT & JOAN DIRCKS FOUNDATION, INC.

Wawa

QLARIS BIO

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LASER & SKIN SURGERY CENTER OF NEW YORK

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SCHOLARSHIPS MADE POSSIBLE BY:

WEBER the WEDGIE

The HOLMEN Family

THE STURGE-WEBER FOUNDATION JAYDEN'S SMILE :) 2024 CONFERENCE SCHOLARSHIP

The Findlater & Robbins Family

SWAG BAG MADE POSSIBLE BY ONE BY ONE GRANT:

4imprint

# Our Donation System Gets a Makeover

You might have already noticed something exciting—our donation system has had a major upgrade, thanks to Auxilia!

We're thrilled about this new system because it's going to make managing your contributions to The SWF easier and more convenient than ever.

## So, what's in it for you?

First off, you can create your own portal to manage and track your gifts. No more juggling receipts—everything you need is neatly organized in the "History" panel.

Need to update your recurring contributions? Want to change the date or pause them temporarily? Or maybe adjust the amount? You can handle all of that directly in your portal.

Moved recently or changed your email? Got married and need a name update? Want to tweak how we contact you? It's all here for you to update as needed!

Plus, we've added a cool new feature—our Peer-to-Peer Fundraising panel! When we kick off special fundraising events like Month of Awareness or Giving Tuesday, you can easily get involved and track your fundraising efforts under the "My Fundraisers" tab.

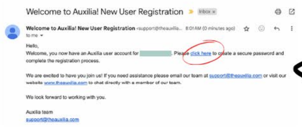
And don't worry—our new system is more secure than ever, so you can contribute with confidence, knowing your support is going towards vital research, awareness, and support for our SWS families.

We're excited about these improvements and hope you are too! ❃

# HOW TO CREATE YOUR DONOR PORTAL

## STEP ONE

From the link in your "Thank you for your donation" email, click the link to complete the registration process.



Welcome to Auxilia! New User Registration

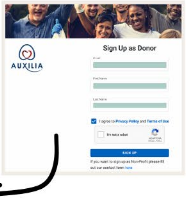
**Welcome to Auxilia! New User Registration** <support@theauxilia... 8:01 AM (0 minutes ago)
to me

Hello,
Welcome, you now have an Auxilia user account for . Please click here to create a secure password and complete the registration process.

We are excited to have you join us! If you need assistance please email our team at support@theauxilia.com or visit our website www.theauxilia.com to chat directly with a member of our team.

We look forward to working with you.

Auxilia team
support@theauxilia.com



Sign Up as Donor

Email

First Name

Last Name

☑ I agree to Privacy Policy and Terms of Use

☐ I'm not a robot

SIGN UP

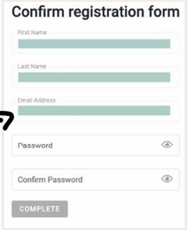
If you want to sign up as Non-Profit please fill out our contact form here

You will receive a confirmation email. Click the link to complete the registration process.

## STEP TWO

Complete your registration by creating a password.

After you click "complete", sign in to the portal.



Confirm registration form

First Name

Last Name

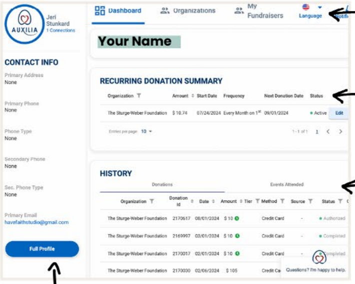
Email Address

Password

Confirm Password

COMPLETE

**This is what the dashboard will look like.**



Jeri Stunkard
1 Connections

Your Name

CONTACT INFO

Primary Address
None

Primary Phone
None

Phone Type
None

Secondary Phone
None

Sec. Phone Type
None

Primary Email
havefaithstudio@gmail.com

Full Profile

RECURRING DONATION SUMMARY

| Organization | Amount | Start Date | Frequency | Next Donation Date | Status | |
|---|---|---|---|---|---|---|
| The Sturge-Weber Foundation | $ 10.74 | 07/24/2024 | Every Month on 1st | 09/01/2024 | Active | Edit |

Entries per page: 10  1 - 1 of 1

HISTORY

Donations  Events Attended

| Organization | Donation Id | Date | Amount | Tier | Method | Source | Status |
|---|---|---|---|---|---|---|---|
| The Sturge-Weber Foundation | 2170617 | 08/01/2024 | $ 10 | | Credit Card | - | Authorized |
| The Sturge-Weber Foundation | 2169997 | 03/01/2024 | $ 10 | | Credit Card | - | Completed |
| The Sturge-Weber Foundation | 2170017 | 02/01/2024 | $ 10 | | Credit Card | - | Completed |
| The Sturge-Weber Foundation | 2170030 | 02/06/2024 | $ 105 | | Credit Ca | | |

Questions? I'm happy to help.

Change Language

Recurring donation payment schedule

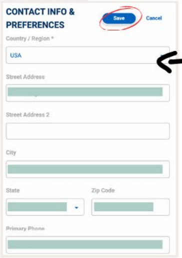
Donation History

Full Profile

## STEP THREE

**IMPORTANT!**

- Update your profile.
- Ensure your address is correct.
- Check your preferred method of contact.
- Be sure to check "Standard mail" if you would like to receive the *Branching Out* newsletter and other mail.



CONTACT INFO & PREFERENCES

Save  Cancel

Country / Region *
USA

Street Address

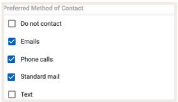
Street Address 2

City

State

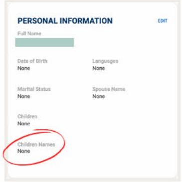
Zip Code

Primary Phone



Preferred Method of Contact

☐ Do not contact
☑ Emails
☑ Phone calls
☑ Standard mail
☐ Text



PERSONAL INFORMATION  EDIT

Full Name

Date of Birth
None

Languages
None

Marital Status
None

Spouse Name
None

Children
None

Children Names
None

**Parents:**
Be sure to add in your children's info here.

## ANOTHER COOL FEATURE

"My Fundraisers" Tab is a new feature we have added.

History

All Fundraisers  Donations  Drafts  Registrations

| Created Date | Fundraiser Name | Goal | Total Donations | Organization | Start Date | End Date | Event Name | Status |
|---|---|---|---|---|---|---|---|---|

Entries per page: 10  0 - 0 of 0

**For SWF fundraisers such as Moth of Awareness, Giving Tuesday, etc.** you can easily participate with us and keep track of your fundraising efforts for Sturge-Weber right in your portal!

Continued from page 5

## Grief...

listen to you, and maybe you just need to scream and they let you. There are no wrong answers to grief.

When the time is right and you will know—you will pick yourself up again. I promise and no matter how hard it is you need to pick yourself up again. The Sturge-Weber Foundation is here always and forever too.

Find YOU again by giving yourself a chance to do something that you are passionate about. For those who have ultimate loss, you have a new guardian angel watching over you. If you want to do something but can't think of anything that seems worthwhile, give us a call, we'll give you some ideas. If you find some of your own worthy ideas, share them too.

As we begin to heal, here are some ideas I know well.

- **Tissue Donation:** One thing we never want to think about is donating tissue but the legacy for research would be a lasting one.

- **Plant Something:** Planting a tree, or flowers can be a way to make a lasting memory of your loved one. Another great option is to name a star after the person you adore. Let looking up at the stars at night in remembrance can be of comfort.

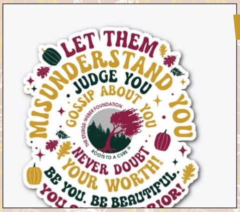
- **The SWF Memorial Garden:** At the Foundation, we have set up a digital memorial garden. For those that want to help in some way, they have a place to go to remember, share, and give back.

- **Awareness Events:** Hosting a walk event for awareness can be a meaningful way to remember the person. It need not be extravagant. Even a get together can help the grieving process and a way to honor the SWS journey. You might be surprised when you start to have fun again.

When the tears settle and you are ready to face the world again—don't feel pressure to do more than you can manage. Your journey through grief is hard, whether you are a patient, a caregiver, family, friend, or spouse, we all play role and we all need time to grieve.

Thank you for being part of our community. YOU are all very special to us! This journey is a marathon and not a sprint, our capes, crystal balls, and wands don't always work the way we want them too. Don't forget to come home, we always leave the lights on. ❋

## New! Fall SWF Apparel Releases



**SHOP FOR A CAUSE:** https://tinyurl.com/swf-shop

# sws month of awareness - *What a May!*

The Speer family was blessed with gorgeous weather and a fantastic turnout at their fundraising event for **Myla's Mission for The Sturge-Weber Foundation** over the weekend.

The numbers speak for themselves:
- More than 100 walkers/runners
- Over 28 vehicles in the ride
- 6 SWS Families from Indiana and Ohio, raising over $23,500!
- The generosity of everyone at this event has left us in awe!

@mylasmissionSWS

**Hailey's Hope for Sturge-Weber Awareness** raised $1,225 by raffling off this stunning quilt! Huge thanks to our SWF Warriors for their tireless work.

@haileyshopesws

We were excited to collab with **Amanda Villarreal** from AV Wellness on our Instagram Takeover Wednesday for Month of Awareness! Hailing from Grand Rapids, Michigan, Amanda is a powerhouse of health, fitness, and wellness knowledge that we believe will serve as a great inspiration to both the Klippel-Trenaunay community and our Sturge-Weber family.

What sets Amanda apart is her dedication to sharing easy-to-implement health solutions. She's all about helping others achieve their health goals and building long-term healthy habits.

She shares a plethora of knowledge — from workout ideas, fitness tips, yummy recipes, healthy supplement recommendations, and insights on chemical-free and non-toxic living.

Remember, we all learn from our own mistakes and from others. Sharing our stories and experiences is crucial, as our journey might be the help someone else needs. Amanda believes in being real and authentic in her posts.

On a personal note, Amanda is a mom of 5 and loves sharing her journey with her kids. She has a degree in Corporate Fitness & Wellness and certifications as a Personal Trainer, Group Fitness Instructor, Health Coach, and Nutritionist.

@avwellness

Advocacy... Continued from page 9

# The SWF Supports These Sign-Ons

*The SWF is proud to support partner organizations by signing on to their Bills and Initiative to advance medical research, facilitate treatment development, and improve the quality and accessibility of healthcare of our members.*

**21st Century Cures Act 2.0 |** This legislation's goal was to accelerate medical innovation and improve care by delivering new advances to people with epilepsy and other disorders. In 2019, Representatives DeGette and Upton introduced the 21st Century Cures Act 2.0 (Cures 2.0) to build upon the efforts of the first bill. Since 2019, parts of Cures 2.0 have been enacted through legislation and regulation.

**LaborHHS - Education Bill for FY 2025 |** This Bill hopes to provide needed services for the American public while ensuring continued support for NDD programs.

**FY 2025 BRAIN Initiative Letter |** The BRAIN Initiative is revolutionizing our understanding of the brain and offering hope for the millions of individuals impacted by brain diseases, disorders, and injuries. This letter was was submitted to the House and Senate Subcommittees on Labor, Health, and Human Services and Education Appropriations.

**Neurology Drug Program (NDP) |** The NDP letter was submitted to the House and Senate Subcommittees on Agriculture, Rural Development, and Food and Drug Administration Appropriations. Support for this program will allow the FDA to gain the expertise to develop policies and guidance that keep pace with emerging brain science.

**Epilepsy Leadership Council Digest |** One in three Americans will have a brain or nervous system disorder sometime in their life, and the cost of treating neurological disorders is nearly $1.5 trillion each year. The BRAIN Initiative is revolutionizing our understanding of the brain and offering hope for the millions of individuals impacted by brain diseases, disorders, and injuries. ❋

### SAYING GOODBYE:

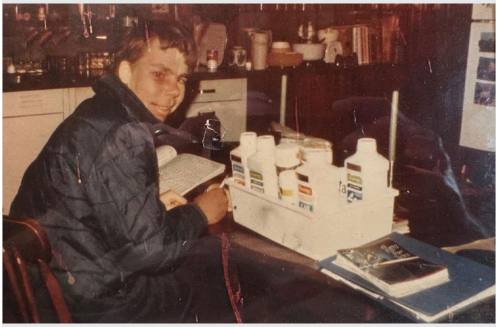
# Jonathan Austin Scales

Jonathan A Scales, 66, of Auburn, ME died peacefully, after a short illness on August 1, 2024.

Jon was born in Lewiston, ME in 1957, the first child of L Damon and June A Scales. He attended Auburn schools and, overcoming many challenges, graduated in the top half of his class at Edward Little HS.

Jon was predeceased by his parents. Survivors include his brothers Tim Scales (Carla) of Mt. Lebanon, PA, Chris Scales (Susan) of Exeter, NH, nieces Laura and Becca, and nephews Matt and Will. He also leaves behind the communities he touched and who supported him throughout his life: High St Congregational Church, Boy Scouts of America, Lake Auburn Towne House and many others. Jon brought out the best in all of us. We will miss his laugh, his smile, and that look he gave us when he disagreed - we all knew that look!

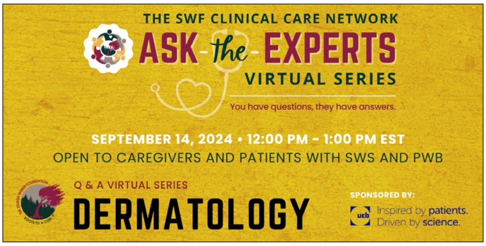
Gifts in his memory may be made to the Sturge-Weber Foundation.



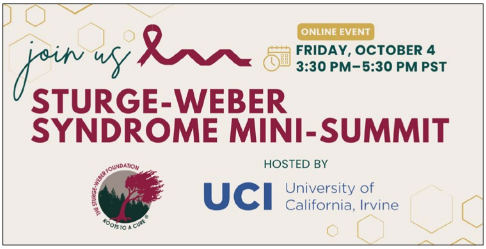
And this is a photo taken when Jon was in his early-20's, learning more about the Amway products he was selling.

# Events Calendar

**LEARN MORE:**
www.Sturge-Weber.org/events

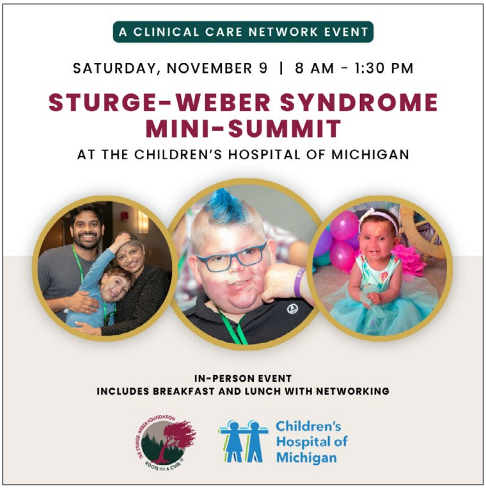


THE SWF CLINICAL CARE NETWORK
ASK the EXPERTS
VIRTUAL SERIES
You have questions, they have answers.
SEPTEMBER 14, 2024 • 12:00 PM – 1:00 PM EST
OPEN TO CAREGIVERS AND PATIENTS WITH SWS AND PWB
Q & A VIRTUAL SERIES
DERMATOLOGY
SPONSORED BY:
ucb Inspired by patients. Driven by science.



join us
ONLINE EVENT
FRIDAY, OCTOBER 4
3:30 PM–5:30 PM PST
STURGE-WEBER SYNDROME MINI-SUMMIT
HOSTED BY
UCI University of California, Irvine

SHIP BOTTOM Brewery
ECTO GHOULER RUN
10.5.24 6 PM
ECTO GHOULER RUN
10.5.24 10 AM
DON'T MISS OUT!
RACE SERIES TO BENEFIT THE SWF



A CLINICAL CARE NETWORK EVENT
SATURDAY, NOVEMBER 9 | 8 AM – 1:30 PM
STURGE-WEBER SYNDROME MINI-SUMMIT
AT THE CHILDREN'S HOSPITAL OF MICHIGAN
IN-PERSON EVENT
INCLUDES BREAKFAST AND LUNCH WITH NETWORKING
Children's Hospital of Michigan

## EVERYTHING BEGINS WITH AN IDEA

### Fall Fundraising Event Ideas

- Fall festival
- Bonfire & S'mores Night
- Chili cook-off
- Pie sampling
- Oktoberfest Happy Hour
- Fall Trivia Night
- Outdoor Movie Night
- Outdoor Paint and Sip
- Bowling tournament
- Friendsgiving
- No Shave November

**National Pumpkin Day • October 26**
Plan a pumpkin carving or painting competition. Supporters vote by making a donation and designating their gift to the pumpkin of their choice.

**Halloween**
A costume run is a new twist on a 5k run for a cause. It's a great opportunity for families to show off their costumes, bring their furry friends, and have a laugh!

**National Hiking Day • November 17**
Work with a local park, local Department of Natural Resources (DNR), or local farm to feature a trail or corn maze. Invite supporters to have fun and raise money for a good cause.

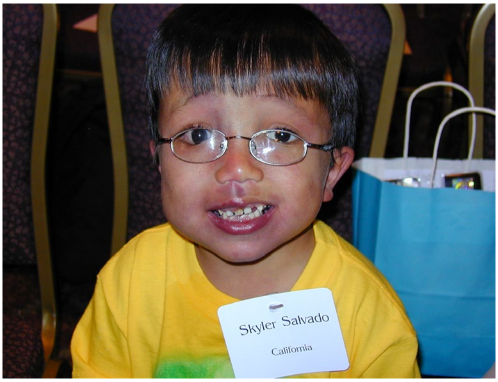
HOW TO RAISE $200 IN 10 DAYS

Start the ball rolling with a $20 contribution = $20
Ask 3 friends to donate $20 each = $60
Ask 2 family members to give $20 each = $40
Ask 1 neighbor to give $20 = $20
Ask 2 co-workers to give $20 = $40
Ask your employer to give $20 = $20
$200

www.Sturge-Weber.org

# Blast from the Past

**SWF Warriors! Your mission, if you choose to accept it...help us locate these members!**
Do you recognize one ore more of these fellow warriors? If so, let us know by dropping a note at kball@sturge-weber.org



From the Archives

THE STURGE WEBER FOUNDATION

*The stronger the wind, the tougher the trees*

Volume 3, Edition 3 Fall 1990

**1990 SWF CONFERENCE HIGHLIGHTS**

The crowd that turned out at the Vista International Hotel August 3-5 in Pittsburgh, Pa. had a super weekend. The weekend began with a reception Friday evening where the participants got to know one another informally.

Dr. Albert Biglan, Dr. Bill Weston, Dr. John Bodensteiner

Saturday brought a packed day of seminars highlighted by Dr. William Weston dermatologist; Dr Albert Biglan, Ophthalmologist and Dr. John Bodensteiner, Neurologist, as keynote speakers. The physicians panel following their seminars elicited some insightful questions. All the physicians had detailed slides to accompany their talks and bits of humor along the way. Those in attendance gave these fellas high marks.

Dr. Eva Sujansky reported on the genetics of SWS and recently mailed out questionnaires (If you haven't turned yours in please do so now). Some fantastic findings were revealed and will be passed along to you at later date. All present were very excited by the future research and study possibilities.

The concurrent sessions went well and elicited feedback of future SWF publications. The headache seminar generated interesting concerns which may culminate in a survey. The dinner Saturday evening was delicious and another fun time was had by all.

Sunday brought financial, educational, psychological, and dental seminars with thought provoking suggestions the participants could utilize upon returning home. Dr. Robert Boose's, DDS seminar on dental aspects was very interesting and will generate future articles to educate professionals on SWS oral complications.

The children had a super time as well. David Newell of "Mr. Rogers' Neighborhood" (PBS) came in the character of Mr. McFeeley and entertained the kids with puppets, signed autographs and took pictures for over an hour. There was a clown in the afternoon as well as videos and games for the kids. Elaine and Ralph Le Blanc (MA) Donated Teddy Grahams for the kids to enjoy.

All in all another terrific conference with some good suggestions for next year.

**A huge thank-you to Mark and Kathy Keffer** for their superhuman efforts and time put forth in planning this conference. Mark's a babysitter par excellence!!

Mr. Mc Feeley & Kids

1991 SWF Conference to be held in Los Angeles area in August.

E-WEBER FOUNDATION
ERENCE HIGHLIGHTS
gust 25, 26 & 27, 1989

cussed various treatment regimens including aspirin therapy.

Dr. Warwick Peacock - conveyed an overview of surgical techniques (hemispherectomy) for epilepsy. Described candidate selection process, post surgery development and detailed the actual procedure.

Dr. Harry Chugani - presented information on using PET scans in neuroradiological diagnosis. Compared PET metabolism scans with CT scans and described how information obtained is utilized.

Dr. Joe Morelli - discussed treatment and techniques for port wine stain removal using pulsed tunable dye laser.

Dr. Allan Eisenbaum - contributed an overview of the ophthalmologic aspects of Sturge-Weber syndrome including treatment techniques for glaucoma.

The day concluded with a dinner at which Karen Ball thanked everyone for coming and singled out the key people in the Foundation for kudos.

**Sunday, August 27**

The day began with an overview of the financial performance of the Foundation by Kirk Ball. The 1989 Annual Report of the Foundation was distributed along with the budget for 1989-1990 fiscal year. For those not attending the conference these will be mailed to you in the near future.

A fund raising seminar was held by Gretchen Pope a professional fund raiser in Denver. She talked on the importance pf networking with professionals and community leaders who can be used to help with our cause, among other topics. Gretchen gave step by step directions for getting a press release published. (Attendees - have you followed through? It's not too late!)

The remainder of the day was devoted to small group breakouts of the following topics:

Behavior Modification - Suzette Anderson presented ideas for implementing behavior modifications techniques.

Port Wine Stain Psychological Issues - Mimi Howe led group discussion on the emotional aspects of port wine stains. Mimi will be collecting thoughts on this topic and will be preparing a brochure to help people deal with this aspect.

Regional Meetings - everyone broke into groups based on their geographical regions. The groups were headed by the respective regional coordinator when present. Broad based discussions included how to get organized as region. Many felt more time could have been spent in these groups.

Next years conference will focus on family issues; legal, financial, education, and emotional aspects. Although children were not encouraged at this years meeting, kids will be welcome next year.

Fall 1989 Vol. 2 No. 3 SWF Newsletter Page 3

Celebrating 20 Years of Compassionate and Professional Service

1990

From the Archives

BRANCHING OUT

The Sturge-Weber Foundation

*The stronger the wind, the tougher the trees*

Vol. 6 No. 3 Fall 1993

Whew! What a whirlwind of activity we had at the Conference. As you can everyone had a great time too! I am always energized after a SWF Conference because of the personal sharing, and the excellent physician lectures presented. Thank you again to all of you who sacrificed to attend—I hope you too left educated and energized!

We had "movie stars" at the Conference too! SWF members Celeste Foster and her husband Danny O'Keefe own Dancel Productions. Dancel is based in New Orleans and specializes in video productions. Danny and Celeste videotaped the physician lectures (see enclosed article) and filmed attendees and physicians for an SWS educational video. Our "movie stars" were unsuspecting physicians we nabbed for their on camera expertise! Dr. Robert Shields was particularly a good sport!! Thanks to all those involved in the project— for more information on the SWS Educational Video see the next issue.

Great news! The Canadians are in the process of forming a SWF Subsidiary. This will allow them to have tax deductions and to bolster our research fund! As of now, they will NOT be a separate entity but will follow the guidelines of SWF. The SWF Board of Directors will oversee the finalization of plans etc. (See associated CANADA article in this issue.)

The SWF Board of Directors met prior to the Conference and had a productive meeting. The minutes of the meeting and the SWF Annual Report are available upon request. I am very thankful for these dedicated individuals who will guide SWF into the future. (See related article.)

Guess I've rambled on long enough but the next year will be an exciting time! I hope you will join all the present volunteers (jewels) this year. Dedicate your service and/or financial support to foster the

*continued on page 2*

*The kids enjoyed the storyteller!*

*Robert & Marion Severns and Peaches*

***You will find as you look back upon your life that the moments when you have really lived are the moments when you have done things in the spirit of love.***
—Henry Drummond

*INSIDE . . .*
- Greetings
- Antiepileptic Drugs
- Corp Sponsors Renew
- Research Fund
- A Gentle Reminder!
- Local Scene
- SWF on the Go!
- Remember Foundation

**Funding for this issue of Branching Out provided by SWF Members**

1991 Conference
rnia, August 2, 1991

n Newport Beach with a rousing good time by all reported.
Zealand) and the National Division winners were 1st place
1993 tournament will have trophies awarded!!

Donna Saunders and Marion Severns

*A Special Thank You To Conference Sponsors:*
- CIBA-GEIGY Pharmaceuticals
- See's Candy
- Mr. & Mrs. Noel Gilbert
- Mr & Mrs. Don Hanley
- Mr & Mrs. Rich Petersen

ge-Weber, epilepsy, glaucoma, lasers, headaches, gum problems, teeth problems, medications, OT, PT, learning disabilities, and I was anxious to see if what I found out was the common and right knowledge to all the other parents. And would my findings be confirmed by the doctors and experts present at the Conference.

First, I found friends. A willingness to share and support one another. I found that we are all experts, super moms, dads, sisters and brothers. Through the support of each other and the support of the fine doctors and researchers, we can learn so much to help our children have the best quality of life possible.

I was truly amazed to learn of the vast scope of this multi-system disease. That just about each and every child has been struck to a different degree. We, as parents, always like to look for comparisons; and we can't do that with Sturge-Weber. But, we can guide one another into the proper directions for treatment of our child's particular weaknesses.

Of most value during the Conference, was the opportunity

**1991 CONFERENCE . . .**

ak with the doctors about our individual children. I would
ssumed a speaker would appear simply to give his talk,
r a few questions and depart. But, our dedicated doctors
the weekend with us to be available for conversation,
zation, and to visit with the children.
lso felt the parent discussion panels were excellent and
ne perhaps more time can be spent sharing our questions
difficulties. Dina Gilbert, Jeff's sister, I think made us realize the importance of including siblings in the discussion groups. Her view, from the younger generation, was most uplifting and emotional.

The weekend went by so quickly. The enthusiasm and energy generated from our small group will sustain me for quite sometime. I thank Karen and Kirk and everyone involved for putting together a wonderful weekend experience. I thank the dedicated doctors who took time from their families and practices across the country to come be with us. Finally, I pray more people with Sturge-Weber in their families find out about our Foundation, so they may be helped, supported and educated as I have been.

*—Donna Garneau Sanders*

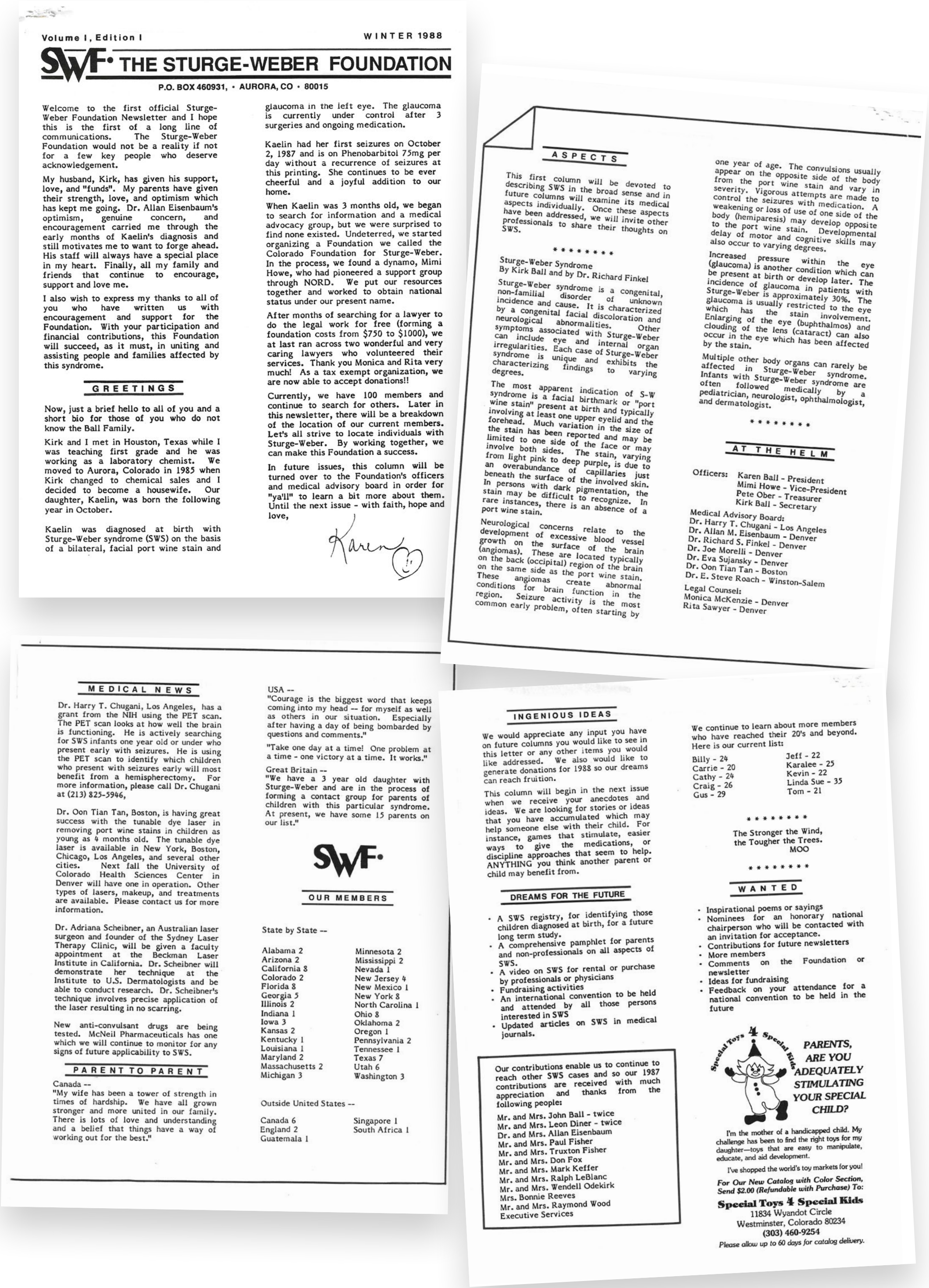
*** Donna's detailed notes on the conference can be obtained from SWF by sending a stamped return addressed envelope. There are no audio tapes this year.**

7

The Sturge-Weber Foundation | www.sturge-weber.org | SWF@sturge-weber.org 17

1993

# 1988–The First Newsletter



Volume I, Edition I
WINTER 1988
SWF• THE STURGE-WEBER FOUNDATION
P.O. BOX 460931, • AURORA, CO • 80015

Welcome to the first official Sturge-Weber Foundation Newsletter and I hope this is the first of a long line of communications. The Sturge-Weber Foundation would not be a reality if not for a few key people who deserve acknowledgement.

My husband, Kirk, has given his support, love, and "funds". My parents have given their strength, love, and optimism which has kept me going. Dr. Allan Eisenbaum's optimism, genuine concern, and encouragement carried me through the early months of Kaelin's diagnosis and still motivates me to want to forge ahead. His staff will always have a special place in my heart. Finally, all my family and friends that continue to encourage, support and love me.

I also wish to express my thanks to all of you who have written us with encouragement and support for the Foundation. With your participation and financial contributions, this Foundation will succeed, as it must, in uniting and assisting people and families affected by this syndrome.

## GREETINGS

Now, just a brief hello to all of you and a short bio for those of you who do not know the Ball Family.

Kirk and I met in Houston, Texas while I was teaching first grade and he was working as a laboratory chemist. We moved to Aurora, Colorado in 1985 when Kirk changed to chemical sales and I decided to become a housewife. Our daughter, Kaelin, was born the following year in October.

Kaelin was diagnosed at birth with Sturge-Weber syndrome (SWS) on the basis of a bilateral, facial port wine stain and glaucoma in the left eye. The glaucoma is currently under control after 3 surgeries and ongoing medication.

Kaelin had her first seizures on October 2, 1987 and is on Phenobarbitol 75mg per day without a recurrence of seizures at this printing. She continues to be ever cheerful and a joyful addition to our home.

When Kaelin was 3 months old, we began to search for information and a medical advocacy group, but we were surprised to find none existed. Undeterred, we started organizing a Foundation we called the Colorado Foundation for Sturge-Weber. In the process, we found a dynamo, Mimi Howe, who had pioneered a support group through NORD. We put our resources together and worked to obtain national status under our present name.

After months of searching for a lawyer to do the legal work for free (forming a foundation costs from $750 to $1000), we at last ran across two wonderful and very caring lawyers who volunteered their services. Thank you Monica and Rita very much! As a tax exempt organization, we are now able to accept donations!!

Currently, we have 100 members and continue to search for others. Later in this newsletter, there will be a breakdown of the location of our current members. Let's all strive to locate individuals with Sturge-Weber. By working together, we can make this Foundation a success.

In future issues, this column will be turned over to the Foundation's officers and medical advisory board in order for "ya'll" to learn a bit more about them. Until the next issue - with faith, hope and love,

Karen

## ASPECTS

This first column will be devoted to describing SWS in the broad sense and in future columns will examine its medical aspects individually. Once these aspects have been addressed, we will invite other professionals to share their thoughts on SWS.

* * * * * * * *

### Sturge-Weber Syndrome

By Kirk Ball and by Dr. Richard Finkel

Sturge-Weber syndrome is a congenital, non-familial disorder of unknown incidence and cause. It is characterized by a congenital facial discoloration and neurological abnormalities. Other symptoms associated with Sturge-Weber can include eye and internal organ irregularities. Each case of Sturge-Weber syndrome is unique and exhibits the characterizing findings to varying degrees.

The most apparent indication of S-W syndrome is a facial birthmark or "port wine stain" present at birth and typically involving at least one upper eyelid and the forehead. Much variation in the size of the stain has been reported and may be limited to one side of the face or may involve both sides. The stain, varying from light pink to deep purple, is due to an overabundance of capillaries just beneath the surface of the involved skin. In persons with dark pigmentation, the stain may be difficult to recognize. In rare instances, there is an absence of a port wine stain.

Neurological concerns relate to the development of excessive blood vessel growth on the surface of the brain (angiomas). These are located typically on the back (occipital) region of the brain on the same side as the port wine stain. These angiomas create abnormal conditions for brain function in the region. Seizure activity is the most common early problem, often starting by one year of age. The convulsions usually appear on the opposite side of the body from the port wine stain and vary in severity. Vigorous attempts are made to control the seizures with medication. A weakening or loss of use of one side of the body (hemiparesis) may develop opposite to the port wine stain. Developmental delay of motor and cognitive skills may also occur to varying degrees.

Increased pressure within the eye (glaucoma) is another condition which can be present at birth or develop later. The incidence of glaucoma in patients with Sturge-Weber is approximately 30%. The glaucoma is usually restricted to the eye which has the stain involvement. Enlarging of the eye (buphthalmos) and clouding of the lens (cataract) can also occur in the eye which has been affected by the stain.

Multiple other body organs can rarely be affected in Sturge-Weber syndrome. Infants with Sturge-Weber syndrome are often followed medically by a pediatrician, neurologist, ophthalmologist, and dermatologist.

* * * * * * * *

## AT THE HELM

Officers:
Karen Ball - President
Mimi Howe - Vice-President
Pete Ober - Treasurer
Kirk Ball - Secretary

Medical Advisory Board:
Dr. Harry T. Chugani - Los Angeles
Dr. Allan M. Eisenbaum - Denver
Dr. Richard S. Finkel - Denver
Dr. Joe Morelli - Denver
Dr. Eva Sujansky - Denver
Dr. Oon Tian Tan - Boston
Dr. E. Steve Roach - Winston-Salem

Legal Counsel:
Monica McKenzie - Denver
Rita Sawyer - Denver

## MEDICAL NEWS

Dr. Harry T. Chugani, Los Angeles, has a grant from the NIH using the PET scan. The PET scan looks at how well the brain is functioning. He is actively searching for SWS infants one year old or under who present early with seizures. He is using the PET scan to identify which children who present with seizures early will most benefit from a hemispherectomy. For more information, please call Dr. Chugani at (213) 825-5946,

Dr. Oon Tian Tan, Boston, is having great success with the tunable dye laser in removing port wine stains in children as young as 4 months old. The tunable dye laser is available in New York, Boston, Chicago, Los Angeles, and several other cities. Next fall the University of Colorado Health Sciences Center in Denver will have one in operation. Other types of lasers, makeup, and treatments are available. Please contact us for more information.

Dr. Adriana Scheibner, an Australian laser surgeon and founder of the Sydney Laser Therapy Clinic, will be given a faculty appointment at the Beckman Laser Institute in California. Dr. Scheibner will demonstrate her technique at the Institute to U.S. Dermatologists and be able to conduct research. Dr. Scheibner's technique involves precise application of the laser resulting in no scarring.

New anti-convulsant drugs are being tested. McNeil Pharmaceuticals has one which we will continue to monitor for any signs of future applicability to SWS.

## PARENT TO PARENT

Canada --
"My wife has been a tower of strength in times of hardship. We have all grown stronger and more united in our family. There is lots of love and understanding and a belief that things have a way of working out for the best."

USA --
"Courage is the biggest word that keeps coming into my head -- for myself as well as others in our situation. Especially after having a day of being bombarded by questions and comments."

"Take one day at a time! One problem at a time - one victory at a time. It works."

Great Britain --
"We have a 3 year old daughter with Sturge-Weber and are in the process of forming a contact group for parents of children with this particular syndrome. At present, we have some 15 parents on our list."

## OUR MEMBERS

State by State --

Alabama 2
Arizona 2
California 8
Colorado 2
Florida 8
Georgia 5
Illinois 2
Indiana 1
Iowa 3
Kansas 2
Kentucky 1
Louisiana 1
Maryland 2
Massachusetts 2
Michigan 3
Minnesota 2
Mississippi 2
Nevada 1
New Jersey 4
New Mexico 1
New York 8
North Carolina 1
Ohio 8
Oklahoma 2
Oregon 1
Pennsylvania 2
Tennessee 1
Texas 7
Utah 6
Washington 3

Outside United States --

Canada 6
England 2
Guatemala 1
Singapore 1
South Africa 1

## INGENIOUS IDEAS

We would appreciate any input you have on future columns you would like to see in this letter or any other items you would like addressed. We also would like to generate donations for 1988 so our dreams can reach fruition.

This column will begin in the next issue when we receive your anecdotes and ideas. We are looking for stories or ideas that you have accumulated which may help someone else with their child. For instance, games that stimulate, easier ways to give the medications, or discipline approaches that seem to help. ANYTHING you think another parent or child may benefit from.

## DREAMS FOR THE FUTURE

- A SWS registry, for identifying those children diagnosed at birth, for a future long term study.
- A comprehensive pamphlet for parents and non-professionals on all aspects of SWS.
- A video on SWS for rental or purchase by professionals or physicians
- Fundraising activities
- An international convention to be held and attended by all those persons interested in SWS
- Updated articles on SWS in medical journals.

Our contributions enable us to continue to reach other SWS cases and so our 1987 contributions are received with much appreciation and thanks from the following people:

Mr. and Mrs. John Ball - twice
Mr. and Mrs. Leon Diner - twice
Dr. and Mrs. Allan Eisenbaum
Mr. and Mrs. Paul Fisher
Mr. and Mrs. Truxton Fisher
Mr. and Mrs. Don Fox
Mr. and Mrs. Mark Keffer
Mr. and Mrs. Ralph LeBlanc
Mr. and Mrs. Wendell Odekirk
Mrs. Bonnie Reeves
Mr. and Mrs. Raymond Wood
Executive Services

We continue to learn about more members who have reached their 20's and beyond. Here is our current list:

Billy - 24
Carrie - 20
Cathy - 24
Craig - 26
Gus - 29
Jeff - 22
Karalee - 25
Kevin - 22
Linda Sue - 35
Tom - 21

* * * * * * * *

The Stronger the Wind,
the Tougher the Trees.
MOO

* * * * * * * *

## WANTED

- Inspirational poems or sayings
- Nominees for an honorary national chairperson who will be contacted with an invitation for acceptance.
- Contributions for future newsletters
- More members
- Comments on the Foundation or newsletter
- Ideas for fundraising
- Feedback on your attendance for a national convention to be held in the future

MARK YOUR CALENDARS:

# Giving Tuesday, December 3, 2024

THE STURGE-WEBER FOUNDATION
ROOTS TO A CURE®

STRONGER BECAUSE WE ARE

# UNITED

## Your donation is 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

○ Stock 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: ______________________________________

City, State, Zip: ______________________________________

Email: ______________________________________

Mobile Phone #: ______________________________________

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

## SAVE THE STAMP!

**Use the QR Code to the right to donate securely on-line or fill out this form and mail to:**

The Sturge-Weber Foundation
6105 S. Main Street, #200
Aurora, CO 80016

SECURE DONATIONS

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www.sturge-weber.org/donate-today

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SEIZURES
PHILADELPHIA'24

Thank you for joining us!