



Branching Out

35 YEARS UNITED

FOR 35 YEARS WE'VE BEEN HERE FOR YOU!
A reason, a season, or a lifetime.



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- NIH RESEARCH STUDY
- RESEARCH UPDATES
- SWF ANNUAL REPORT
- Q&A WITH AUTHOR, DIETRA FLEMING

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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).

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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



“Sharing with each other is what makes SWS and life’s journey so wonderful and bearable.”

Connect with Karen

A Time to Mourn

I was recently speaking with a “veteran” mom about their neurology appointment. Her daughter is in her early teens and while facing some cognitive challenges is really navigating life quite well with assistive technology. The mom and I were discussing about how some visits and milestones you mourn again. I know it may sound strange to those of you reading this, that even though a death has not occurred, special needs moms mourn for a reason, a season, or a lifetime. You mourn for that pregnancy filled hope of bringing a new life into being that will have a wonderful life.

The expectations that society puts on all of us through marketing and social media posts that show the “perfect” moments, family photos, and events. Sure thing we better be ready to celebrate the happy events and milestones reached! It takes guts though to report on the “dark” side of our lives whether it is living with a special needs child or just events in life that try our souls. There are milestones that will be severely delayed or never to be reached. There are dances never invited by a date to trip the light fantastic. There are educational IEP meetings and more and more ALL reminding you of lost dreams.

The chat took me back to the early days with Kaelin and the myriad and diverse medical

appointments. I remember going in to the examination room holding my breath that her eye pressures would be in the good range. I prayed the MRI or CT scans would not show any more progression of the vascular malformation that was present at birth. Soooo many days of angst...lol, I can shake my head now because in the reveal of time whether you have a typically developing child or one that takes another path at their own pace I know life is a glorious gift and EVERY day give thanks! EVERY day. EVERY day and every moment seek joy. My family has always been that way because my parents, especially my daddy has tackled adversity with a can do, WILL do attitude. I wish I had a recorder to have captured all the times and things that came out of that man’s mouth that lifted a frown when I was down or put a chuckle in my belly when things were going sideways.

I so appreciate hearing from y’all! Sharing with each other is what makes this SWS and life journey so wonderful and bearable. We are fortunate to have industry partners who not only support programs and research but give their personal support to encourage us to keep going in the good times and in the bad.

Continued on next page >>>

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



Luis Sandoval, PhD

SWF Task Force Leader for Mental Health

Join us for the SWF Teens & Adults with SWS or the SWS Adult Caregivers Chat via Zoom. Luis Sandoval leads a lively discussion on your concerns and mental health issues.

These talks are a huge bonding experience for our participants. Don't be shy, log on with us.

The big takeaway from the talks has been that we are on this journey together, you are not alone, and you can do it with SWS Warriors on your side.

A huge thank you to Luis Sandoval, PhD for giving much insight into the topics, and maybe a little tough love as well. Everyone who has joined in, thank you for being authentic and forthcoming. Everyone has something to share with the next generation.

Don't want to miss the next one? Contact Julia at jterrell@sturge-weber.org for all the details. The chats are held monthly.

If you feel lost, this is it.

This is where you can start your journey.

A Time To Mourn

Continued from page 3...

As we move towards the season of Thanksgiving, just remember that in any good harvest we will reap what we sow. In every way and every day plant good seeds of knowledge and hope. Nurture them with good thoughts by learning all you can about a situation and then acting to make the harvest of those situations a feast for all to celebrate! The SWF has tried to follow that philosophy since our incorporation. We have had some lean harvest years barely able to make payroll and fund programs. We have had bountiful harvest years where GREAT research has been funded which enabled us to make your lives easier and more worry free. This year our harvest is once again going to be leaner but we still celebrate being able to do what we can with what we have for you.

Together with each of us donating what we

can and/or asking others to support the SWF ensures a lasting legacy will continue. Thank you for always being a taker and that after your mourning time whenever that may be you rise UP and support as well as celebrate in joy the life we live. Blessings to you and yours this season and always!

With Faith, Hope and Love,

Karen Ball

PS. I'm so grateful to all of you who shared your condolences upon the death of my partner, Scott Whitcomb. It's been a difficult time but made easier to bear with your love and fond memories of happier days.

RESEARCH UPDATE



by Lisa Arkin

This Sturge-Weber Foundation and Pediatric Dermatology Research Alliance-funded proposal aims to use non-invasive, in vivo imaging to optimize laser parameters for treatment of facial port-wine birthmarks. The project is led by Dr. Lisa Arkin at the University of Wisconsin School of Medicine and Dr. Kristen Kelly at the University of California Irvine. Together, they follow a large cohort of patients of all ages with port-wine birthmarks, some associated with Sturge-Weber Syndrome. Their project utilizes optical coherence tomography, a non-invasive imaging technique which maps the skin's microangiographic environment through detection of red blood cells, producing in vivo cross-sectional scans of tissue at a depth of 0.5-1 mm. These images facilitate quantitative measurement and further characterization of the microvasculature of the skin.

The overarching goal of the project is to elucidate the vascular characteristics of PWBs in order to predict and optimize response to laser therapy, which is currently our standard of care for treatment of the vasculature in skin. OCT provides information regarding in-vivo vessel diameter, density and superficial plexus depth in the imaged area. We have recruited a cohort of >60 patients ranging from early infancy to adulthood to map the vasculature within these birthmarks, and to identify differences based on genotype. A subset of patients consented to biopsy for genetic testing, and we are in the process of utilizing software to determine if the OCT imaging can predict genotype or enhance our understanding of the vascular biology in GNAQ/GNA11-associated port wine birthmarks. Our hypothesis is that genotype will influence vessel size, with greater cell-cycle activation associated with larger vessel diameters, and greater architectural distortion of the vasculature.

Now on YouTube! Food. Faith. Family. A SWF Holiday Baking Video

We recently filmed a short holiday video just for YOU! Here is a behind the scenes peek of the filming with Karen and Kaelin. Check out our YouTube Channel!

@TheSwffoundation





By Jeffrey A. Loeb, MD, PhD

Longitudinal Studies of Sturge-Weber Syndrome: How the BVMC project can advance new treatments

Sturge-Weber Syndrome (SWS) results from a mutation that occurs during embryonic development leading to abnormal blood vessels on the skin (face), eye, and brain. Each patient with SWS has unique features due to variations on the location and extent of these abnormal blood vessels in each of these 3 body areas and how they change over time. SWS is a rare disease with only a handful of patients at any given medical center making it challenging to study the disorder and develop new treatments for the skin, the eye, and the brain. Within the brain the vascular malformations change nearby brain areas and produce rock-hard calcification deposits within the brain. Often at this time patients begin suffering from seizures, headaches and stroke-like episodes that seem to come from nowhere.

As a means to understand how changes in the brain causes neurological symptoms and to find better ways to prevent and treat these symptoms we have developed research program to study the natural history of SWS. This work is funded by the US Government through the National Institute of Health in a large project called the Brain Vascular Malformation Consortium (BVMC). The goal of the project is to collect medical records and brain MRI scans from as many SWS patients as we can. This is a 'Big Data' project that will follow symptoms in the skin, eye, and brain from clinical medical records over the lifespan of patients with SWS and use artificial intelligence to find answers. When available, we will make copies of MRI or other brain studies at multiple timepoints during the disease. The idea is that by looking at the brain imaging, we will see what changes occur over time and how they

impact neurological symptoms (seizures, headaches, stroke-like episodes). We will determine what medications work and which do not and what treatments work for treating the skin and eye.

To be enrolled in the study, patients and/or families for children, will need to sign a consent form and help get copies of all medical records related to SWS since birth and MRI scans. The BVMC has sites all across the country and the research team will match patients with the closest site. A baseline blood test is part of the study that would be repeated should the patient get sick as a means to identify serum biomarkers, or indicators of more serious disease. All patients will have their privacy and their data will be deidentified to protect their identity.

So why should you or your family member sign up for this? As a rare disease, we need to work together to collect data from as many patients as we can to understand the disease and develop better treatments. From this study, we will get important clues as to how the brain changes lead to neurological symptoms and identify treatments that look promising. The next step will be to design clinical trials to test these or newer medications to make life-changing improvements and improve quality of life for all with SWS. Stay tuned!

To get full details and become part of this important study go to <https://clinicaltrials.gov/ct2/show/NCT04717427> or contact Julia Terrell at the Sturge Weber Foundation at jterrell@sturge-weber.org.

Working together we can make a difference!

NIH-Funded Brain Imaging and Neurocognitive Study

by Julie Terrell

Marissa and I jumped on a plane in October and headed to Detroit. We arrived at the hospital bright and early and met with Dr. Csaba Juhasz. After some questions, Dr. Aimee Luat and Dr. Nore Gjolaj arrived. The appointment discussed Marissa's history from birth through today. Truly an amazing experience to talk with 2 neurologists and a neuropsychiatrist all at one time that understand Sturge Weber Syndrome. We discussed Marissa's treatment plan and they gave advice.

Then Marissa met with Dr. Gjolaj. While Marissa was having her testing completed I was able to fill out forms about her life as well. The best part in just a few weeks we will have a thorough report explaining how she thinks cognitively, where she has shortfalls and suggestions on how to help her too. As you can guess this was exhausting for all of us and we went to lunch. Marissa was quite sleepy after lunch and it was time for the MRI. She slept through most of it and even when she got a little on edge, I was able to sit with her and we finished the test like a champ. When it was all over Dr. Juhasz went over the differences in her MRIs from the past to present day and a report followed.

The day was truly filled with a lot of mixed emotions. It is never easy talking about or seeing your child's brain especially when you can see the damage first hand. I can tell you though the trip was well worth every moment and it brought much needed evidence and justification for all that we have experienced. As we wait for the final report for the cognitive testing, I realized the work that is being done is truly amazing. So many times as patients we yearn for someone to say they understand our syndrome. In this one appointment, there were two neurologists, two neuropsychiatrists that are weighing

Continued on page 12 >>>

Branching Out



Dr. Csaba Juhasz, Marissa, Dr. Nore Gjolaj, and Julia Terrell



Dr. Jeong and Dr. Csaba Juhasz

“The day was truly filled with a lot of mixed emotions. It is never easy talking about or seeing your child's brain especially when you can see the damage first hand.”



THE STURGE-WEBER FOUNDATION
Memorial
garden



Barbara Osborne • 10/24/2022



Marion Honigman

Grandmother of Kendra who has SWS

Visit the SWF Memorial Garden online: Sturge-Weber syndrome.
www.sturge-weber.org/who-we-are/swf-memorial-garden

Or, contact Julia for more information,
jterrell@sturge-weber.org

Mark Your Calendars

Town Hall Meeting with Karen
Ugly Sweater Party, December 7,
9:00–10:00 pm EST

Special shout out to **Kristen Kelly, MD, Rachel Elsanadi** and our **entire CCN at UC Irvine** team for hosting our virtual mini-summit on October 22nd. Stay tuned we will be announcing our next California Summit next year.

Giving Tuesday • November 29, 2022

2023 Schedule

Educational Mini Summit

12:00–3:00 pm EST

- February 4
- April 1
- June 3
- August 5

March 2023 Reunion of Champions

New Orleans, March 17

Town Hall and Month of Awareness

May 3, 8:00–10:00 pm EST

CCN/SWFIRN Meeting, September TBA

UC Irvine Mini Summit

October 7, subject to change

Town Hall Meeting with Karen

December 6, 8:00–10:00 pm EST



The BVMC identified the cause of SWS in May 2013 thanks to the RDCRN funding. However, more can and should be done. Scan the QR code to the right to learn more today.



What Happened at the CCN Meeting

The Clinical Care Network annual meeting took place on September 15th. The meeting was a hybrid meeting with attendees in Boston and virtually. The doctors enjoyed an activity box for their reception. At the reception conversation was continuous. They talked about research ideas, drank from their United cups, and enjoyed snacks. The next two days were filled with conversations about the latest SWFIRN meeting updates, BVMC project, breakouts in neurology, dermatology and ophthalmology, transition of care, unmet needs and we ended the meeting about psychiatry and what that means going forward.

Some of the topics in the breakouts were classifications of Port-Wine Stains, migraines, studies in glaucoma, transition of care advancement, and our adult talks. Attending were 13 Clinical Care Networks, two researchers from our research team, Joyce Bischoff, PhD and Jan Pruszk, MD from



Care Package for CCN Meeting Participants

Austria attended. Thank you to **Theurin Htoo from Qlaris** for always being a partner. A special THANK YOU to **UCB for sponsoring our meeting.**

Next year we will be combining our CCN Meeting with the SWFIRN meeting. Stay tuned for our next location and if we come to an area near you we hope you can attend too.

New Inclusive Book—Beautifully Blemished

Whether it's a birthmark, eczema, vitiligo, moles, scars or other visible markings; it can be difficult to find the beauty in being different. *Beautifully Blemished: Learning and Celebrating Skin Differences* written by Leanne Stuckey, is a children's book that encourages children to see the unmatched beauty in their imperfections and provides an understanding of various skin conditions.

Having grown up with a visible skin difference, I understand the feelings of insecurity that come along with that reality. This book was written to help kids truly recognize the beauty in their uniqueness—hopefully much sooner than I did. The goal is to empower young boys & girls, while spreading awareness and helping to shift society's narrative of what beauty is and what it looks like.



Leanne Stuckey is running a 30-day Kickstarter campaign to raise funds to get this book to the finish line (funds to print, ship, & distribute) which ends at the end of Nov. The campaign is now live and you can pre-order the book with a donation.

<https://www.kickstarter.com/projects/beautifullyblemished/beautifully-blemished-celebrating-skin-differences>

BeautifullyBlemished365@gmail.com • Socials: @BeautifullyBlemished365 • www.leannestuckey.com

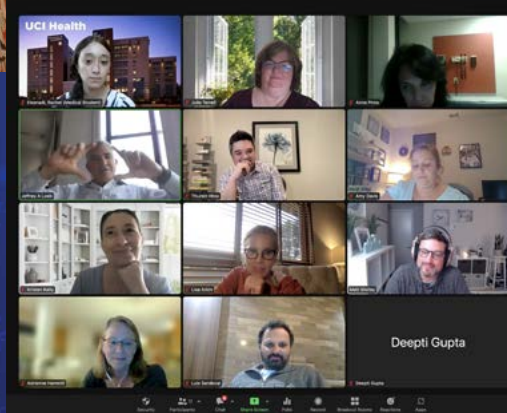
What Happened in 2022...




2022 family Conference




SNF Staff @ Family Conference



SNFIRN Meeting

 **Narda Arballo**
2 wk. ago · View page

86 Miles	\$1.50 Per Mile	\$129 Earned
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 **Narda Arballo**
3 mo. ago · View

65
Miles



Pledge It
Walk



Running with the Sharks



Myla's Mission Fundraiser Walk



Virtual Mini Summits, Caregiver Chats, Teen and Adult Chats



Webster travels to the UK, Germany, Canada, and Australia

view page
\$1.50
Per Mile
\$97.50
Earned



7 Million Miles Challenges



Reunion of Champions

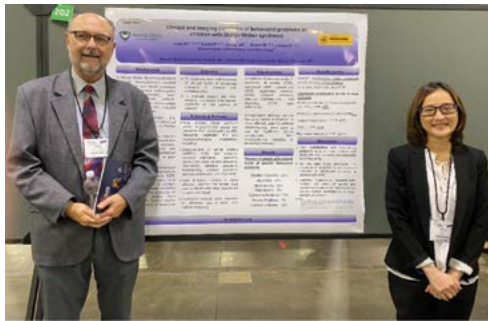


NIH-Funded Brain Imaging

Continued from page 7...

in and an MRI physicist all wanting to know more about Sturge-Weber syndrome. The team is gaining so much information each time a true win/win experience. If you get a chance I truly recommend you take the trip to Detroit. If you have any questions please reach out to me at jterrell@sturge-weber.org and we can get you the answers you need. Below is more information about the study and an explanation about the SWI MRI.

The NIH-funded imaging study, led by Dr. Juhasz and his team at Wayne State University and the Children's Hospital of Michigan in Detroit, now recruits participants of a wide age range, from young children to adults up to 30 years of age. The team includes Dr. Aimee Luat (pediatric neurologist), Drs. Mike Behen and Nore Gjolaj (neuro-psychologists), and Dr. Justin Jeong, MRI physicist. The study has been funded since 2003, and the imaging

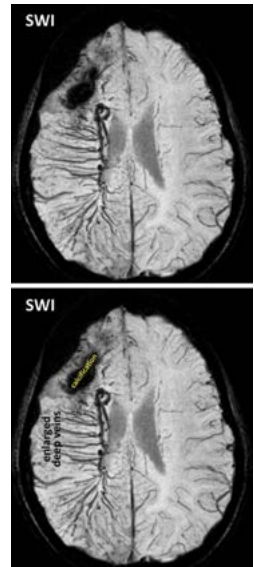


Dr. Csaba Juhasz and Dr. Aimee Luat at Child Neurology Society Meeting

methods evolved over time. The current brain MRI (magnetic resonance imaging) includes a completely non-invasive scanning protocol with innovative imaging sequences to obtain, among others, a high-resolution SWI (susceptibility-weighted imaging) that has been developed and improved by the Wayne State MRI research team. SWI can visualize fine details of the brain's blood vessels even without contrast injection, and it is particularly sensitive to detect enlarged deep veins that can provide compensatory blood flow to relieve brain regions affected by the SWS vascular malformation. Detailed mapping of these veins can have prognostic implications, along with the other imaging

findings. SWI is also an excellent imaging tool to demonstrate fine details of calcifications that often build up in the brain in SWS and may contribute to seizures and cognitive problems. The study also includes a detailed neuro-cognitive evaluation, and the results of this are correlated with the imaging findings and also previous

clinical and imaging data. A new aspect of the study is the option of brain imaging and cognitive screening for healthy siblings too, whose data can serve as controls for the quantitative analysis of the images. The study team generates a detailed report of both the imaging and neuro-cognitive findings for all participants, and these are provided to the families.



Wayne State University School of Medicine Children's Hospital of Michigan Detroit

clinicaltrials.gov NCT04517565
NIH/NINDS R01 NS041922

Non-invasive brain MRI with advanced sequences

- Neuro-psychology evaluation
- Neurology consultation
- Full study reports
- Travel cost reimbursement

Eligibility: - age >3 months-30 years

- diagnosis of SWS and/or facial port-wine birthmark
- no metal around head (e.g., dental braces)
- ability to stay in scanner for up to 30 min
- healthy siblings are also eligible (optional)
- Study contact: Prof. Csaba Juhasz MD, PhD csaba.juhasz@wayne.edu

SWF on the Road in Ohio



Dr. Chuck Gay, Karen Ball, Dr. John Bodensteiner

51st Child Neurology
Society Meeting
Duke Energy Center
Cincinnati, Ohio



Molly Speers, SWF Vice-Chair Secretary & daughter, Myla



Dr. Csaba Juhasz, Dr. Juhasz, Dr. Harry Chugani, Dr. Gyula Acsadi, & Karen Ball

NEW IN THE OFFICIAL SWF STORE

WWW.STURGE-WEBER.ORG



SAVE 15% NOW Code: 35UNITED

Dietra Fleming

Dietra Fleming, whose son has Sturge-Weber syndrome, wrote a children's book! We asked Dietra about her family, the process, and advice she would give to others. This is what she had to say:

Tell us a little bit about yourself.

I am very laid back, and down to earth. I love to work on crafts, read books, spend time with my family and friends, my husband Bobby and I enjoy our date nights when we can. My children are Chance who is the oldest, Jaylon my middle son, and Bailey my daughter is the youngest.

What or who was the inspiration for writing "Jaylon's Story: Living with Sturge-Weber Syndrome"?

Jaylon was my inspiration for this story, because he has been through so many adversities throughout his life. I know that God's grace and mercy has always been with Jaylon. My husband, and I will be forever grateful for my parents, his mom, just an entire village of family and friends that never stopped praying for Jaylon. He has a part time job now working after school. We are all so proud of him, and his accomplishments.

Is this your first book?

Yes, this is my first book.

What inspired you to start writing?

I have always enjoyed writing, letters, or journals whenever I made the time to do it. What inspired me to write was sharing Jaylon's story, I knew that other families would be encouraged by his story, because

if they were in a similar situation, his story would be inspirational.

What was the most difficult part of writing this book?

The most difficult part for me was allowing myself to open up enough to share our story. I have always been a private person for the most part, of course this wouldn't be a surprise to my close friends, and family members, but to reveal this information to people that I don't know was a huge step for me.

Did you do the illustrations in the book? If not, who did, and what was it like working with an illustrator?

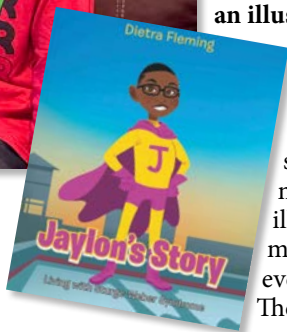
Christian Faith Publishing did the illustrations for the book. I sent pictures of my family to their illustrator, it was so much fun watching everything unfold. The process was so exciting from

beginning to end. I would recommend Christian Faith Publishing to any author because they made the process seem so effortless.

What is the biggest takeaway you want people to know about this story?

The biggest take away that I would love for people to have is stay encouraged, and uplifted. Also, to remember that no matter how bad things may seem, there will always be light at the end of every tunnel. When Jaylon was diagnosed with Sturge-Weber Syndrome, we had never heard of it before.

Continued on page 15 >>>



Positive Change Gala



Kaelin Ball traveled to NYC on October 24th to celebrate with Positive Exposure and photographer Rick Guidotti.

We love POSITIVE EXPOSURE, which “promotes a more inclusive world through award-winning photography, films, exhibitions, lectures, and educational programs.”

“Change how you see, see how you change.” ~Positive Exposure

Positive Exposure has been an SWF photographer, capturing the beauty and uniqueness of our members for many years.

To learn about Positive Exposure:
www.positiveexposure.org

©Positive Exposure, 2022



Continued from page 12
Dietra Fleming...

Facebook was still fairly new, so I could never connect with anyone that had or knew someone with Sturge-Weber. So I never got to connect with someone that was familiar with this syndrome. Of course, this doesn't have to be just for Sturge-Weber patients. This is for anyone with a special need that may need a little encouragement. Don't ever give up!



Do you plan on writing more books?
Yes, I definitely plan on writing more books. My daughter said that it's her turn to have a book about her, so I will have more books out in the future.

You can find Dietra's book *Jaylon's Story* can be purchased on Amazon.

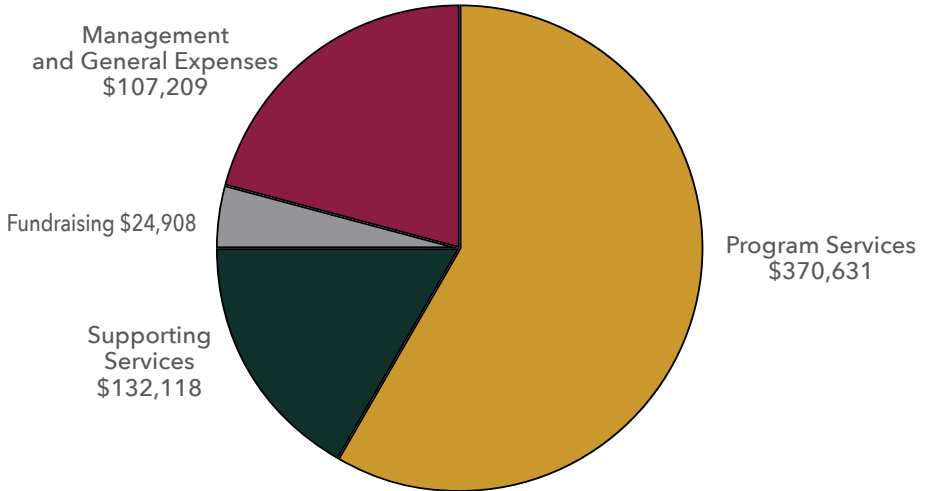
 @DietraWilliams-Fleming

 @Dietra1

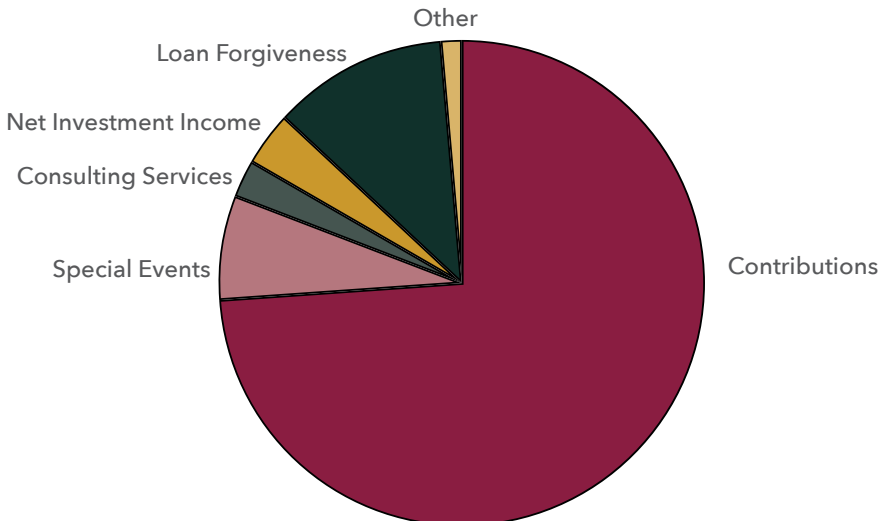
SWF Statement of Functional Expenses

for year end June 30, 2022

Total 2022 Fiscal Year Expenses \$502,738



Revenues and Other Support \$376,017 (-\$126,721)



SWF Announcements



SWF Memorial Garden is Blooming

The Memorial Garden is dedicated to those we have lost to Sturge-Weber syndrome.

May they never be forgotten.

Do you have someone you would like added to the garden?

Contact Julia at jterrell@sturge-weber.org



35th Birthday Celebration

Thank you for a wonderful 35th Birthday! You helped us light the way for future generations by generously giving \$3,535. We cannot thank everyone enough for celebrating 35 years with us. Here's to 35 more!

Branching Out



SWF YouTube Channel

Check out our YouTube Channel at www.youtube.com/@TheSwffoundation

You have added new videos including our new series "SWF Talks". Our first video in the series is, "Let's talk about seizures with Dr. Dave Shahani, Cooks Children's Medical Center."

Be sure to check out "Journey to a Breakthrough: Interview with Thurein Htoo, Chief Executive Officer and co-founder Qlaris Bio, Inc."



Running with the Sharks

in Beach Haven, NJ raised \$500 for The Sturge-Weber Foundation. Thank you again to Ship Bottom Brewery and present-

ed by Second Capital Running for this event. We'll see you next year!



2023 Reunion of Champions

March 17, 2023 at the The Chicory in New Orleans. Honoree: Mathew M. Avram, M.D., J.D., Mass General Dermatology Laser & Cosmetic Center. Corporate Sponsorships Available. *Let the good times roll!*

For a reason, a season, or a lifetime.

this is *our why*



When you support The Sturge-Weber Foundation you are making a difference to help The Sturge-Weber Foundation continue to support families and patients while investing in important research and awareness efforts.

we are *united*

HELP US LIGHT THE WAY FOR FUTURE GENERATIONS.





STRONGER BECAUSE WE ARE



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
- 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: _____
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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 form and mail to:

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



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Contact Julia, jterrell@sturge-weber.org
for more information.



Fall/Winter 2022