

A PUBLICATION OF THE STURGE-WEBER FOUNDATION

Branching Out

JULY/AUGUST 2021



**FREE TO
BE YOU!**



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BRANCHING OUT

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ON THE COVER: *Myla with her friends at the 2021 Myla's Mission 5K Walk in Indiana. Hosted by Molly and Thomas Speer.*

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Port Wine Birthmarks (PWB) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck. Sturge-Weber syndrome (SWS) is a rare congenital condition usually consisting of a facial port wine birthmark, glaucoma, and seizures, (although not all of these symptoms may be exhibited).

SWF POLICY STATEMENT:

In implementing the purpose of The Sturge-Weber Foundation to improve the quality of life for individuals with SWS and their families, the Foundation will act as a clearinghouse of information, provide emotional support and facilitate research on PWB and SWS.

The Foundation will seek information regarding management and treatment techniques and suggestions concerning education and emotional support and will facilitate the dissemination of appropriate information. If, in facilitating research on PWB, SWS and KT, the Foundation provides financial or other support to a particular research project, the Foundation will base its decision upon need, the Foundation's financial resources and medical advice.

ALLIANCES: The SWF is a member of:

The Brain Vascular Malformation Consortium (BVMC)
American Brain Coalition (ABC)
The Association for Research in Vision and Ophthalmology (ARVO)
Alliance for a Stronger FDA
Drug Information Association

SSPORT



HOLLAND. EGYPT. AMERICA.

CONNECTING WITH KAREN



United States of America

When Kaelin, my daughter was born, there was a popular poem going around about visiting Holland (http://www.dsasc.ca/uploads/8/5/3/9/8539131/welcome_to_holland.pdf). It compared preparing to visit another country only to find out you aren't going to go where you expected to that of expecting a healthy child and instead, your child has a health condition. Those of us living with Sturge-Weber syndrome (SWS) or who have a loved one that has SWS, can all relate!

What I have learned over the past 34 years is that many of us choose to visit Egypt - the land of denial. There can be so many unpleasant and painful realities to adjust to and accept that many times it is just easier to be in denial. Ultimately, this is unhealthy for both you and your child.

I know parents who go for years in Egypt. Eventually, they come to grips with reality when a medical crisis occurs over and over. Getting stuck in Egypt is not healthy and has a negative lasting impact.

It has been interesting to watch the first SWF generation of children grow up and navigate their own journeys. It's not dissimilar to a typically developing child who has the need to be accepted - the desire to have SWS be only a part of their life (which is best) and to work on their vulnerabilities as well as their unique strengths.

It takes the whole family and community to raise a child with SWS. Let's give ourselves the freedom to

visit Holland and Egypt while we share compassion, inspiration and direction to America! The land of freedom and opportunity where we have the right to make personal choices and take on personal responsibility to improve ourselves and contribute to those around us.

The Sturge-Weber Foundation is a lot like America. We provide a wealth of knowledge and resources to guide you on your journey. We can assist you in finding guides along the way. We are here every step of the journey, supporting you as you learn about your trip to Holland, end up in Egypt and reach out to land solidly in America and all the opportunities it offers!

There are so many more opportunities in America and SWF compared to other countries and organizations. I am proud of what they call in business, the "value add", in that SWF offers more value add for your donations than other organizations. I am proud SWF offers you the freedom to face your fears with knowledge we provide, friends you meet at SWF events, doctors who provide excellent care and the ongoing advocacy efforts which improve the quality of life and care.

SWF is happy to be your "travel agent" in this business of SWS as you navigate the world! Please send us your summer vacation photos and don't forget to take Webster Bear along for the ride!

Happy trails to you. Faith, hope and love,

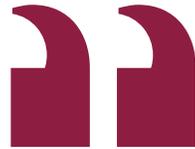
SWF PATIENT ENGAGEMENT

April was a busy month internationally. **Over 15 patients from all over the world. contacted the SWF.** Many looked for referrals to doctors in our network. Some wanted advice about Covid-19 and the vaccine. Many wanted to know they were not alone in their concerns.

I can't thank you enough for all your help with finding resources.



An enormous thank you from our family to you! I was able to attend Saturday's session (my second participation) and, again, gained so much insight, inspiration, and fuel in guiding our daughter through her journey with SWS.



- End result, very successful doctor appointments

Four contacts joined the SWF in April. Their needs were fact finding for a baby just days old, to knowing they were not alone. Sometimes the calls the SWF receives are simply reminders to take a breath, take one day at a time and that they are not alone.

A wife called about her husband and how alone he was feeling. We were able to get them in touch with a Dr. Robert Sidbury in Seattle. Dr. Sidbury was very excited to help. We hope for a very successful outcome!

- Follow up after SWF Education Day Mini Summit.

SAVE THE DATES

Education Day Mini Summits

What's Your Plan Series

- August 7th: Back to School
- October 2nd: Bullying and Mental Health
- December 4th: The Holidays

Interviews and Webinars

What's Your Plan Series (dates to be announced)

- Newly Diagnosed in Dermatology, Neurology & Ophthalmology
- Next Steps After Diagnosis
- Dentistry
- Orthodontics

- Endocrinology
- Mental Health (with Dr. Ann Friedman)

SWF Meetings

September 25th: Clinical Care Network Meeting
January 2022: International Organization Meeting
February 2022: SWFIRN Meeting
July 2022: SWF International Family Conference

Detail announcements will be emailed and posted on our social media platforms for these upcoming events!



FIGHTING ON THE FRONTLINES

THROUGH THE YEARS FOR THE RARE DISEASES COMMUNITY

BY KAREN L. BALL

I was introduced into the world of rare diseases on October 11, 1986. My daughter was born with a large Port Wine Birthmark on her face and diagnosed with Sturge-Weber syndrome (SWS). She had her first eye surgery when she was one week old due to glaucoma, and her first seizure at one year old.

Ever since that infamous day and the ensuing 34 years of medical challenges, surgeries, and the associated financial stressors of life with a rare disease, life has been an unimaginable roller coaster ride! I am so honored to contribute a few reflections for this memorable EP milestone and issue.

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

The first NORD conference I attended representing the Sturge-Weber Foundation was so educational and the collaboration amongst the burgeoning rare disease organizations was exceptional. We bonded over shared experiences and parenting matters while we found many common challenges pertaining to governance, fundraising, and communications. The NORD staff were so integral to hosting excellent conferences and networking people and organizations. Jean Campbell particularly was, and is like

Auntie Mame! I was able to find common threads and research leads in Sturge-Weber syndrome after visiting with other leaders and researchers that previously we might not have thought of without the brainstorming.

There was no internet back then and expensive long-distance telephone charges united us to raise our voices to get research funding parity at the National Institutes of Health. Abbey Meyers, NORD President, was and is a force to be reckoned with, and she set an example of how to be a fearless leader who never takes no for an answer! It was a privilege to give back to the community, serving 10 years as a NORD Board of Director.

Since then, there have emerged other umbrella organizations similar to NORD that, in my opinion, have their primary focus on marketing and advocacy. No longer is our world the one-stop-shop for vetted information, which is a blessing and a challenge. Critical thinking is a must, to sift through the plethora of data and hype on the internet. Have articles and facts stated been verified by medical authorities? Is there transparency on where the donations are spent? Is a categorical statement supporting an "xyz" treatment or certain physician by one parent the right fit for you and your family? Only you know, and if you don't, then ask your physician and do your homework.

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



THE FUTURE IS BRIGHT: Karen Ball with daughter Kaelin and family sharing a happy moment. "It's interesting to look back and see the breadth of changes that have occurred in communications, patient engagement and support, physician education and awareness and, of course, research."

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

There are organizations that have adapted to all these changes and they still thrive and, sadly, many that were splintered by egotistical individuals who watered down the donation and resource pools, only to either merge organizations back again or die off. We HAVE seen many changes at the Sturge-Weber Foundation in 34 years! Thanks to my mentors, cherished volunteers and dedicated donors, we have weathered organizational and economic challenges and reveled in the GNAQ gene mutation discovery. Thanks to the Office of Rare Disease (now at NCATS) and their AMAZING staff, we all put our heads together and learned from one another to develop best research practices, funding opportunities and how to apply for them, and to participate in advocacy on the Hill to spur even more funding for the NIH and FDA. It has been a privilege to fight on the frontlines with so many dedicated men and women and to celebrate so many wonderful milestones together!

The Sturge-Weber Foundation started in an unfinished basement with donated Amoco furniture. The Betty Ford Award and Ann Landers column brought funding and awareness. Building blocks provided by each person bringing what they knew and who they knew to the cause created the successes we have achieved thus far. Today, 27 SWS Clinical Care Network sites are established across the country. Like many organizations, there is an online registry to collect critical natural history data. Volunteers have been and will be

at the heart of organizations who create lasting impact for their respective rare disease. Never think that you are not an important piece to mission success! EVERY dollar raised and EVERY little bit you promote, engage and share is critical. It just takes one person, one moment of coincidence or collaboration and whole new frontiers can be opened that we never thought possible. Just say Yes!

There was a rare disease mom, Arlene, who had a son die from her rare disease. I'll never forget, she said one time she would not have started her organization. It was not because it hadn't done well, but she said you can never get back lost time. So many conferences, meetings, phone calls, communications to keep the momentum going were just part of the job. Today it is even harder to shut out the world and truly focus and be present. After 34 years, I truly understand what she was saying!

Please give yourself a present and BE present. Time flies by way too fast and you can't get it back. The future is bright as we continue the tradition of fighting for rare disease awareness, research and engagement!

I look forward to seeing how the next generation transforms the community and gives back for their loved ones and to honor all those who lead the way. •

ABOUT THE AUTHOR:



Karen L Ball is the founder and Chief Executive Officer of The Sturge-Weber Foundation (SWF). The SWF was incorporated in 1987 following the birth and Sturge-Weber syndrome diagnosis of her daughter, Kaelin. The incorporation of the SWF starting in an unfinished basement today provided the foundation and collaborations which led to the GNAQ gene mutation discovery, first animal model, and a burgeoning 27 site Clinical Care Network. "The stronger the wind, the tougher the trees."

OPPORTUNITIES ABOUND

SWF MONTH OF AWARENESS IN REVIEW

This year's Month of Awareness was full of opportunities to learn and build community!

Even with the setbacks of COVID-19 and precautionary restrictions on public gatherings, SWF has embraced the "new" method of community building. We hope you have joined us along the way!

Even before May, SWF was lining up programming to educate members and the public. Take a look at these past events that YOUR donations helped support.



SWF Educational Mini Summits

With the sponsor support of UCB, the follow Educational Mini Summits began at the beginning of the year:

- February 6: The SWF's first Mini Summit. 35 families registered for this event from all over the US as well as Brazil, Nigeria, India, Israel, England and Puerto Rico. We were fortunate to gather together with 20 plus families. Speakers from 5 of our Clinical Care Networks (CCN) participated - Dr. Kristen Kelly (UC-Irvine); Dr. Peter Chang (Bascom Palmer, Miami, FL); Dr. Anna Pinto (Boston Children's Hospital); and Dr. Ann Friedman (Houston, TX).

- April 3: 29 attendees were present with families representing Israel, India, England, New Zealand, Canada and Romania. A special "shout out" to the SWF Task Force Leaders - Dr. Esteban Fernandez; Dr. Lauren Blieden; Dr. Dave Shani; and Carol Roethke-Greene, RN.
- June 6: UCB provided excellent information about emergency medications. Dr. Falcheck (Nemours duPont Hospital for Children) spoke about a plan for COVID and how to create your plan for the change in seasons and vacations. Dr. Sarat Thikkessey (Cincinnati Children's Hospital) spoke on dentistry, along with Dr. Mimis Cohen and Dr. Neil Warshawsky (UC-Irvine) about the importance of a craniofacial team.



Beginning in August, the mini summits will focus on "What's Your Plan?", a program that SWF is truly passionate about. Having a plan for your SWS child, whether a new born or adult, is vitally important to have in place to meet their special needs, while you are able and when you are not.

August 7: What's Your Plan for Back to School?

October 2: What's Your Plan for Combating Bullying and Mental Health?

December 4: What's Your Plan for the Holidays?

Look for details and registration for these events in your email box, SWF social media and website.

SWF Wellness Webinars with a Caregiver Focus

Month of Awareness focused on the Caregiver this year. As important as the SWS patient is, caregivers are just as important and need CARE as well. With the support of the professional teams at several of SWF's CCNs, caregivers and patients were able to participate in wellness programs for the mind, body and spirit. Check out the great line-up!

April 20: The Importance of Nutrition

Sponsored by the University of CA-Irvine, Sherry Schulman discussed realistic lifestyle modifications to enhance sustainable health and wellbeing through nutrition. This was a great opportunity for caregivers and patients to improve health and quality of life.

April 29: Mindfulness: The Light That Shines Within

Sponsored by the University of CA-Irvine and presented by Jessica de Paz, Ph.D. Mindful is an important factor in wellbeing. As stated in the title, each of us has a special light that shines from within that bolsters our wellbeing and illuminates our wholeness. Dr. de Paz provided evidence-based practices that cultivate mindfulness and self-compassion in people of all ages.

May 20: The Benefits of Yoga

Also sponsored by the University of CA-Irvine with yoga therapist, Katie Allen. Practical yoga therapy tools were provided to improve physical, mental and emotional wellbeing. Yoga postures, breath-work and meditation practices are beneficial for students with SWS, as well as knowing which ones should be avoided. The session also included a 10-minute all-levels experiential yoga therapy practice.

Sundays in May: Mindful Being Caregiver Series

Sponsored by Dr. Ann Friedman, this 5 part series provided essential information on the importance of self-care, sleep, nutrition, exercise, connection with loved ones, relaxation and play. To be mentally and physically healthy, caregivers must make time for themselves. Stressful thoughts or false guilt will only hinder the benefits of self-care. Your mind is a gift, but needs to be trained to focus on the present and not drift to unresolved issues or worries about the future.

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<https://smile.amazon.com>

CLINICAL TRIAL OPPORTUNITIES

SWF Clinical Care Network Center - Michigan Children's Hospital with Dr. Csaba Juhasz, Neurology

Clinical study for Neurology (MRI and Neuro-Psych Examination). Dr. Juhasz is seeking siblings to participate as well as SWS patients to participate. Travel will be reimbursed.

To obtain additional information and participate, please email swfclinicaltrials@sturge-weber.org.

Clinical Trial Link - <https://clinicaltrials.gov/ct2/show/NCT04517565?cond=Sturge+Weber&draw=2&rank=2>

Qlaris - Ophthalmology Clinical Trial

If you have glaucoma, we want to hear from you. Qlaris is preparing for a clinical trial on glaucoma with SWS patients. To obtain additional information and register, please email swfclinicaltrials@sturge-weber.org.



Please provide your contact information and eye doctor's information to request medical files. With this information we will also be able to update your information in the SWS registry and see if you qualify for the glaucoma study.

SWF Education Mini Summit Series RESEARCH UPDATE & WHAT'S YOUR PLAN?

Don't forget to join us for the next SWF Education Mini Summit, **August 7th**. This event is absolutely free. To follow is the line-up of what you can expect to hear about from the professionals!

- UCB, SWF's Mini Summit sponsor, will review emergency medications.
- Matthew Shirley, Ph.D., newly appointed Chief Scientific Officer, (CSO) of the Sturge Weber Foundation. Dr. Shirley discovered the gene (GNAQ) in Dr. Jonathan Pevsner's lab. He will discuss current research being done and what the future holds.
- Dr. Jeffrey Loeb, SWF Chief Scientist Strategist (CSS) and Adult Neurologist, will talk about clinical science.
- Dr. Csaba Juhasz, Neurologist at Detroit Children's Hospital, will discuss the most recent clinical study he is working on.
- Dr. Aimee Luat, Neurologist at Detroit Children's Hospital, will begin the discussion on What's Your Plan for Back to School and Work with Covid.
- Professional panel for discussion questions during this session will be Dr. Denise Metry, Dermatologist at Texas Children's Hospital and Dr. Eniolami Dosunmu, Ophthalmologist at Cincinnati Children's Hospital.



To register, visit the following website page: <https://sturge-weber.org/participate/swf-education-days.html>.

IT'S A RAP!

THE STURGE-WEBER FOUNDATION MILLION MILES

for Sturge-Weber Syndrome

Birthmark | Seizures | Glaucoma



The 1st Million Miles for Sturge-Weber Syndrome has been accomplished! Thank you everyone that participated in this 3 month campaign, whether as a fundraiser or donor! Your support kept the Foundation viable during this season of change we all experienced. To follow is a recap of all the amazing work that took place across America! Be inspired by what you read and prepare to join us next year as we continue this million miles for SWS.



Encouragement for the Journey

Jordan St. Cyr, a gifted singer from Canada, granted the SWF to use his song "Fires" as a message of encouragement for the Million Miles Campaign and Month of Awareness. Jordan and his family knows first hand the journey of SWS. Emery, his daughter has SWS. It was with her diagnosis that Jordan was inspired to release this song that encourages all of us to never give up hope, even under pressure and the unknown.

Thank you Jordan for this message and for bringing public awareness to SWS.

To hear the song "Fires", and other music by Jordan, visit his Youtube Channel at [jordanstcyr](http://jordanstcyr.com).



Musician, Jordan St Cyr, with his daughter, Emery.



Carley Elliers, Slidell, LA, displays her MOA knitting project in SWF "team" colors!

April 10: Texas Million Mile Kick-off Party

Million Miles for Sturge-Weber syndrome was kicked off in Houston, Texas as the home of Dr. Denise Metry and the Texas Children's Hospital team. There were 52 participants ready to walk.

The weather was perfect (not the usual hot and humid), lots of games, conversation and new friends made. The Texas Children's Hospital team provided great information on current research and treatments for all aspects of SWS.

THANK YOU DENISE AND TEAM TEXAS FOR A GREAT SHOW OF SUPPORT AND KICKING OFF THE FIRST SWF MILLION MILES CAMPAIGN!



May 15: Myla's Mission for Sturge-Weber Awareness 5K

In conjunction with the Million Miles Campaign, the Speer Family hosted it's 4th Annual 5K walk, Myla's Mission, named after their daughter. Also included at the event was a luncheon and silent auction. As usual this Indiana community came out and showed their support resulting in over **\$6,600.00 raised for research and public awareness.** "We cannot thank our sponsors, community and family enough, but thank you", said Molly, Myla's mother and member of the SWF Board of Directors.

Grow Awareness with SWF Merch!

Visit the SWF ONLINE STORE!

A portion of your purchase goes directly to helping newly diagnosed patients. Share the link on Facebook and Instagram!



<https://the-official-swf-store.creator-spring.com>

May 22: SWF Family Game Day with the Atlanta Braves, Truist Stadium

Finally! An opportunity to get out and be with others! As part of public awareness and patient engagement, SWF held a Family Game Day in Atlanta, GA to watch the Braves at Truist Stadium. The event was hosted by Dana and Chris Davis and their 3 children.

The day started at the Punch Bowl, a family eatery and game location next to the stadium. From there, everyone gathered at the stadium for the 4:10 PM first pitch of the game. 100 tickets were sold for this event! It was a GREAT turn out and so much fun to reconnect with everyone.

A BIG THANK YOU TO THE DAVIS FAMILY FOR THEIR COORDINATION AND FINANCIAL SUPPORT FOR THE PRE-GAME PARTY AT PUNCH BOWL & HOSTING EVERYONE AT THE GAME!



June 13: Running With the Sharks 5K in Beach Haven, NJ

A HUGE THANKS TO GINA, ROB & CHLOE ZARKO, AND THEIR BUSINESS, THE SHIP BOTTOM BREWERY for including the SWF in the this special fundraising event. There were 226 registered runners. The Terrell family, Kremena Liguiti, SWF Board Member and her daughter, Emily were all in attendance to represent the Foundation.

The day began at 8:00 AM with the sound of a bull horn and everyone made their way across the starting line. The announcer at the event did a wonderful job talking about Sturge-Weber syndrome several times. At 10:00 AM the last runners were making their way across the finish line. It was then that our team as able



to spread even more SWS awareness by passing out Million Mile t-shirts and shoe laces.

The event proceeded over at the Bayviw Village where there was a tent where brunch was served and everyone was able to connect.

If you live in the area of Beach Haven, NJ, stop by and say hello to the Zarko's!

Ship Bottom Brewery
830 North Bay Avenue Store 23
Beach Haven, NJ 08008
www.shipbottombrewery.com

June 19: SWF Families of Texas and Beyond Reunion

On June 19th we gathered for a Sturge Weber families of Texas reunion at Morgan's Wonderland in San Antonio, Texas. This was a special time of connecting with old friends and meeting new friends too. It is an inspiration for me as a parent, who has a six year old with Sturge Weber Syndrome, to see an adult like Jason Fedelem (also with SWS) who came with his beautiful family. His story gives me such hope for my son and his future. Besides Jason, we also had Millie Zinski, Camilla Werline, Kaylee Embrey, Landon Kelley, Reagan Tumlinson, Caleb Pelka, Buddy Fingers, and James Gallegos, along with their families, join us for rides and water park fun on this special day. While these Sturge Weber warriors do share a common story, each one has unique challenges and obstacles that they are overcoming. It's absolutely inspiring to observe their journeys and see just how resilient they are. We are all looking forward to meeting next year!



June 27: Million Miles in the Mile High City

Karen and Kaelin Ball, along with Steve Emmons, SWF Board Treasurer and Jim Gilbert of Jim Gilbert, CPA hosted a special million miles event at three locations in Denver, CO. They raised \$2,000!

The day began at 7:30 AM climbing Challenge Hill at Miller Park. From there they joined together at Confluence Park to walk the well known Cherry Trail in the middle of Denver. A celebration after-party was held at the R.E.I. Starbucks across from Confluence Park.

SWS families and friends celebrated the culmination of 3 months of support across America for SWS, providing much needed funding to keep patient assistance, public awareness and research going!



Colorado SWF Team at Challenge Hill, Miller Park.



Cherry Trail at Confluence Park.

BUT WAIT! *theres more . . .*

2021 SWF MILLION MILES OUTCOME

Total Participants	49
Total Clinical Care Network Teams	9
Total Sponsors	3
Total Raised by Individuals	\$7,585.25
Total Raised by CCN Teams	\$20,807.50
Total Sponsorships	\$35,000.00
GRAND TOTAL	\$55,807.50

The SWF Board and Staff cannot thank our supporters enough for their participation in the first year of SWF's Million Miles Campaign.

Thank you to our donors for their continuous support financially. **Thank you to our CCNs and individual participants** for volunteering your time

and effort in forming teams and donating financially as well. **Thank you to our Sponsors**, without your support, this campaign would not have been possible.

**THANK YOU ALL,
for making us
better together!**



2020-21 year in review

What a year it has been for each of us. So much has occurred since July 2020 to June 2021. Years from now we will look back and ask ourselves, what happened?

Much like living with SWS, this past year was a journey of unpredictable circumstances and outcomes. As if traveling at the speed of light, here we are one year later.

Although much of what we all had to contend with over the past year was not something we chose willingly, it did provide a blank canvas to create new ways of serving our community and strengthening our resolve to meet our mission.

To follow is a financial snapshot of our past fiscal year and of the new year to come. As we continue to change as the world we live in does, our financial planning is conservative knowing that we are all in a state of recovery. This does not mean resources and assistance will be limited.

We continue to develop new opportunities and keep you up to date with the latest in research and pertinent information. The virtual meeting platforms have opened up new exciting ways to communicate that allow for larger attendance than physical events ever did!

YEAR IN REVIEW: July 1, 2020-June 30, 2021

	Development/ Patient Engagement	Research	Total
Donations	\$203,134.66	\$14,859.84	\$217,994.50
Corporate Match	\$857.43		\$857.43
Grants		\$3.98	\$3.98
Royalty	\$1,601.81	\$2,477.86	\$4,079.67
Research Fund		\$75,000.00	\$75,000.00
WIP Revenue	\$469.48		\$469.48
Total Revenue	\$206,063.38	\$92,341.68	\$298,405.06

	Patient Engage./Dev./Admin.	Research	Total
Total Expense	\$340,286.64	\$130,540.39	\$470,827.03

LOOKING AHEAD: July 2021-June 30, 2022

	Patient Engagement	Research	Total
Donations	\$192,000.00	\$80,000.00	\$320,000.00
Fund Development	\$30,000.00		\$30,000.00
Corporate Match	\$40,000.00		\$40,000.00
Grants	\$71,250.00	\$23,750.00	\$95,000.00
Royalty	\$3,000.00		\$3,000.00
Research Fund	\$35,000.00		\$35,000.00
Fellowship Grants	\$36,000.00		\$36,000.00
TOTAL	\$407,250.000	\$103,750.00	\$559,000.00

The SWF Board of Directors and Staff thank you for helping us continue our work to serve you and those to come.

*Karen Ball, Curt Stanton, Crystal Elliers, Steve Emmons,
Witney Arch, Woody Crouch, Jeffrey Needham, Molly Speer,
Maristel Aguilar, Susan Finnell, Julia Terrell, Emily Varga*



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A MESSAGE FROM CURT STANTON ***SWF Board Chairperson***

Thank you! Thank you for supporting The Sturge-Weber Foundation during the last tumultuous year ensuring the staff and volunteers had the necessary resources to continue to meet membership requests and critical leads on direction. Your continued generosity through donations, time and talents keeps the SWF at the forefront of facilitating exciting research partnerships and clinical studies. All the collaborations across specialties have generated a new clinical trial with Qlaris, brought dermatologists and pharmacists together to identify potential small molecule research projects and fostered support for Dr. Csaba Juhasz latest National Institutes of Health grant!

The Educational Summit teleconferences held throughout the year brought together experts at various Clinical Care Network (CCN) sites addressing topics of interest to many in the SWF. The new partnership with Dr. Ann Friedman on Mindfulness expanded the SWF resources and outreach to those in need of quality of life care and

suggestions. The Brain Vascular Malformation Consortium (BVMC) has started enrolling patients at a few key CCN sites and we welcome you to join in this vital research which lays the groundwork for advancement through technological tools! The SWF also continues to partner with the NIH, FDA and related umbrella groups to sponsor support for key legislation which impacts your life and prepares a brighter future for those to come.

I am most proud of the SWF staff that facilitates programs and projects while personally ensuring your individual needs and questions are expeditiously handled. There are now more SWS related start ups for you to reach out to but I believe the breadth and network connections the SWF has fostered over the last 34 years and new inroads with biotech and pharmaceutical companies makes us a unique organization for a reason, a season or a lifetime. Stay tuned in and get turned on with excitement as we look to an improved new fiscal year and more interactions which benefit you and yours!