



A PUBLICATION OF THE STURGE-WEBER FOUNDATION

# Branching Out

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**FREE**  
**MOA**  
**Poster**  
**Inside!**

**THE STURGE-WEBER  
FOUNDATION  
MAGAZINE**

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# Branching Out

Volume 31 Number 1 | MARCH 2017

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*On the cover: The Vititoe children.*

*Turn to page 14 for thoughts on the cover shot.*

Port-Wine Birthmarks (PWB) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck.

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

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

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

### THE SWF POLICY STATEMENT:

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

As a clearinghouse of information, The Foundation will seek information regarding management and treatment techniques and suggestions concerning education and emotional support and will facilitate the dissemination of appropriate information.

If, in facilitating research on PWB, SWS and KT. The Foundation provides financial or other support to a particular research project, The Foundation will base its decision upon need, The Foundation's financial resources, and medical advice.

The SWF is a member of the National Organization for Rare Disorders (NORD), American Brain Coalition (ABC), The Coalition of Skin Diseases (CSD), and the Association for Research in Vision and Ophthalmology (ARVO).



by Karen L. Ball, SWF,  
President & CEO

### SPRING IS FINALLY HERE...

It has been an exciting 3rd quarter for the SWF's fiscal year and we look forward to a robust 4th quarter. The office relocation in October from New Jersey to Houston with a blend of remote staff will save the SWF thousands of dollars a year which will be directly funneled back into member support and research. As with any move, some things may have slipped through the cracks and we appreciate your understanding and support. We continually strive our utmost to keep expenses down so every dollar donated is spent on direct access to care, support and research.

The annual **Reunion of Champions** was another rousing success! We truly appreciate **Dr. Roy Geronemus** as Master of Ceremonies, **Craig Drill** and **Rick Guidotti** as honorees, volunteers **Joan Agnetti** and **Allison McDonough**, and all the corporate sponsors and donors for underwriting the event. As you'll see from the photos a fun time was had by all.

We are looking forward to **Month of Awareness(MOA)** and all the new activities for our army of Champions (a.k.a. YOU) to create awareness and to "friend raise" generating vital donations to fulfill the mission. With every person taking a few minutes in your lil corner of the world we are creating a world of difference with a mighty impact! Kaelin and I look forward to seeing old and new friends in CO when we host our MOA event.

We are excited to welcome new staff **Katrina Nutter** and **Keevin Lee**. The addition of extra hands on deck will increase our ability to bolster the programs and ensure the SWF mission is continually moving forward. The addition of a fresh set of eyes and ideas enlivens our discussions and creates new enthusiasm. I look forward to working with them on your behalf!

Best of wishes and go have some fun...Spring has definitely arrived!

With faith, hope and love,

A handwritten signature in black ink that reads "Karen L. Ball".

Karen L. Ball  
President and CEO  
The Sturge-Weber Foundation

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*We give our heartfelt thanks to Erika Panico and to Bob Wilbur for their service on the Board of Directors as they end their terms.  
We progress as a Foundation by building on the energy and knowledge of our dedicated Board volunteers.  
Erika and Bob have contributed to that progress.*





# SEED MONEY AND YOU:

## *The Rippling Impact*

by Karen L. Ball

SAY IT FAST...30 YEARS! AS WE ARE ENTERING OUR 30TH YEAR OF OFFERING COMPREHENSIVE PERSONALIZED SERVICES, SUPPORT AND RESEARCH FUNDING, I WANT TO SHARE WITH YOU IN A SERIES OF ARTICLES THE RIPPLING IMPACT SEED MONEY AND YOU HAVE HAD AROUND THE WORLD!

WHEN I THINK BACK TO THE FIRST "SEED MONEY", YOU KNOW THE KIND OF MONEY WHERE YOU GATHER A SMALL AMOUNT TO EITHER FUND YOUR CHILD'S COLLEGE FUND, MAYBE SAVE TO BUY YOUR FIRST HOME, OR IN THE CASE OF THE SWF SAVE IT UP TO BRING FAMILIES FROM AROUND THE COUNTRY TO THE FIRST INTERNATIONAL CONFERENCE OR TO FUND RESEARCH. I AM IN AWE OF HOW FAR WE HAVE COME!

I hear many times from individuals, "well I only have \$25. I wish it could be more". So, this 'lil tome is my way of thanking you and impressing upon you how EVERY dollar donated matters and HAS had a VERY huge impact over the years. I marvel at those who hit the send button from Sudan, South Africa, Omaha, NE and thousands of other homes around the world...all seeking support and direction for themselves or their loved one. Let me give you a few examples to illustrate my point:

### THE RIPPLING IMPACT OF NETWORKING

#### NETWORK AND SUPPORT

I remember the very first mama who was like me (Do you remember yours?)...before that conversation I thought I was the only one with a

child with SWS and a birthmark on her face. I had NO idea how to help her or navigate the world in which I was then living in and would for a lifetime. I have been hesitant over the years when visiting with another mom or dad about SWS to say those words...*a lifetime*. Truth is though the impact of a birthmark or a SWS diagnosis IS for a lifetime. Some of us dodge the



proverbial bullet and the medical issues are slight if any but the reality is we are inevitably changed due to the rippling impact the diagnosis has on our world and on those around us.

Seed money sometimes scraped together by families hosting a special event or given in hope for a better world for their loved one or someone they know has had a profound impact on the SWF's ability to bring y'all together face-to-face to share your journey, offer encouragement and hope and share tidbits on coping, medication administration and well just life...you know "my kids driving me crazy, or SOOOOO EXCITED she walked last week!" The SWF carefully saved and invested your seed money to host conferences, educational forums, sponsor events and more so your world would become a little less scary, more informed and more confident in handling anything SWS or a birthmark would throw your way.

### "FRIEND" RAISERS AND AWARENESS

Along the way, **Melanie Wood** and **Kathy Keffer** led early fundraising events in their local communities which kept donations flowing to replenish the coffers and to build a corpus of funds for the next patient conference and research seed grants. Families and individual's sent in donations and held garage sales and more to improve the quality of life and care for diagnosed individuals. **Pamela McIntyre** and **Jessica Melo** compiled a cookbook "Cooking up a Cure" and because they liked to run, the Falmouth Road Race began! **Mark** and **Kellie Kenney** and **Meg O'Leary** loved football and Thanksgiving...*viola*, The Turkey Bowl! **Todd** and **Jackie Brown** loved horse racing and golf so together with **Dr. David Brown** and **Dick Droesch** we had our first racing horse and golf tournament!

These long term events have had a HUGE impact on our ability to keep the SWF viable for the next family and next research investigator in need of funds. They have enabled those of us in medical or financial constraints to take time out before we too can honor those living with SWS, KT, or a birthmark and host our own "give back and hand up" special events. **Routes To A Cure** walks and **Online Mobile Cause** pages make it easier than ever! So many more of you volunteer at education conferences, on Capitol Hill, and thankfully there are not enough pages to list everyone but I am personally grateful and humbled. **Board of Directors** members over the years donated countless hours to ensure the SWF maintained fiscal and governance accountability. **Lauris Partizian** and **Valerie Lano** volunteered for years when the SWF desperately needed administrative help but didn't have the funds for staff. **Ian**

**Hubling** was our first webmaster. His technological ability made it possible for the world to become much smaller and for you to connect with others who spoke your language or had similar issues...snail mail be GONE. They earned gold tipped wings in heaven!

*Few can do what you can do...and think what more can be accomplished with MORE of you on the frontlines in our war on SWS. THANK YOU!*

**YOU** make it possible for their earnest pleas to be read, heard, and answered... every day the SWF is juggling “who can I see about, where can I get, is there a cure, I’m just so scared and frustrated, how do I cope,” and more diverse questions.

**YOU** make it possible to maintain a world class cadre of clinicians and scientists to fight on the frontlines of our war on SWS and birthmarks! They annually convene to set strategic research goals and funding needs, share ideas for collaborations and case studies, and get energized when they hear the latest reports on progress being made.

**YOU** make the SWF advocacy and awareness possible because you care and have committed yourself to our cause and uplift a world class army of Champions that are living a more hopeful life and one focused on a brighter future. **Thank YOU!**

The world has gotten much smaller since 1987 and the days of “snail mail” and expensive long distance telephone calls! Pick up your phone and Facetime your new found SWF friend or shoot them an email or Facebook post for a quick answer to your query! If one isn’t aware, the plethora of resources available, and all those networks managed by the SWF, could be taken for granted. Increased knowledge requires responsibility and one would hope a desire to share it with others. We have seen newly diagnosed patients take on amazing leadership roles within the SWF and I’m so proud of them.

The online and social media platforms provide unimaginable resources in need of careful vetting. The SWF takes a leadership role in being the vanguard

on your behalf...a trusted resource of knowledge. There is a natural evolution of confidence that occurs after a diagnosis especially with so many resources available. We’ve seen people come for assistance and families to network with and then they disappear for 10 years only to resurface when another aspect of SWS occurs or their now teenage child is having emotional issues.

**THE  
SWF MOTTO**  
“FOR A REASON, A  
SEASON, OR A LIFETIME”  
WAS CHOSEN TO REFLECT THE  
PROGRESSIVE NATURE OF THE  
SYNDROME AS WELL AS FOR OUR  
OWN EMOTIONAL EVOLVEMENT IN  
COPING WITH THE SYNDROME.  
BUT MAKE NO MISTAKE...  
YOU DO NEED THE SWF  
FOR A LIFETIME.

I am hesitant to say that to young parents lest it be perceived as hopeless and a life sentence.

**The SWF is needed...** to keep advancing the science and clinical care for our loved ones and those who come after us.

**The SWF is wanted...** to keep bringing families together to create bonds of friendship.

**The SWF is required...** to advocate and generate awareness for those who need a wider voice.

**The SWF is YOU!** Stay involved...  
*The further we reach out, the closer we become.*

*The rippling impact of your cherished participation and vital seed money...minimal or vast has made the SWF a beacon of hope for those confused, afraid, and improved our ability to reach across the world to walk in partnership with them and together create more confident and compassionate families.*

## THE RIPPLING IMPACT OF COLLABORATION AND RESEARCH

It all started innocently enough much as the roots of the Foundation did...a little spark of knowing what needed to happen! So, after about a year of answering people’s mail and phone calls I figured, “well let’s try and get these people together.” I wrote an article for *The Denver Post* on Sturge-Weber syndrome, Kaelin and the fledgling Sturge-Weber Foundation.

While Kaelin was napping, I was sitting at my Amoco donated desk (that I still use today) in my unfinished basement wearing my oh so elegant office attire of sweatpants and tee shirt, when a telephone call came in...“Hello, this is Betty Ford’s secretary and she’d like to honor you...” *Uh, Yeah Right...click!* A minute later it rang again...“Please don’t hang up!” And the rest is history...the Sturge-Weber Foundation Research Fund was established with the **First Lady Betty Ford Award** donation “for tenacity in the face of adversity” and this small “seed grant” of \$5,000 which was to be the corpus of research funding.

### \$5,000 FIRST LADY BETTY FORD AWARD

The First Lady was being honored by the Beaver Creek Hyatt and she wanted to share the event with those who had tenacity in the face of adversity. Jim and Sarah Brady were the national honorees, and Kirk and I were the Colorado honorees. HUGE gala and cocktails at the Ford’s home and many new contacts made to help along the way. The most important moment though was when we were surprised with the \$5,000 award check. Our annual budget was \$2,500! The further we reach out...the closer we become! Just go for it you never know and we need an ARMY of Champions like you and President and Mrs. Ford to maintain the momentum until there are no more children born with SWS!

### VOLUNTEERS AND \$30,000 SEED RESEARCH GRANT

The years flew by while Kaelin stabilized her glaucoma and seizures and the Foundation had an Access database registry of 400 cases of diagnosed SWS. The office moved from my home to a small office with a part

*Continued on next page...*

## SEED MONEY AND YOU

*Continued from page 5*

time administrative assistant, **Marsha Davenport** (who still donates today!) to help juggle the work load. Two young mothers working around naptime and school schedules to connect with other people impacted by a diagnosis and in need of support.

### VOLUNTEERS

**Drs. Bill Weston, Joe Morelli and Allan Eisenbaum** provided expert medical advice and propagated awareness on TV and in print. **Dr. Eva Sujansky** and colleagues published medical journal articles based on the information I had recorded during support telephone calls from the 400 families. Back then patient advocates were not being recognized as authors on papers or I would have another 2 papers to my credit! **Dr. Richard Finkel** put flyers on SWS and the SWF in the bags of doctors attending the **Child Neurology Society** annual meeting inviting them to a meeting to discuss plans for clinical studies. **Drs. Steve Roach, John Bodensteiner and Harry Chugani** took the reins and we were off! They amassed a Medical Advisory Board to write articles, give lectures, review research grant proposals and extend the “SWS experts” around the country. Today we have thousands of healthcare providers in our database and young clinicians being trained around the country and abroad to care for our patients. Of course, as if that wasn’t enough they decided we needed to publish the **first SWS textbook** in forty years and with **Alberta Edwards’** able guidance we did. The second edition is still available to order online.

### \$30,000 SEED GRANT

**Dr. Bernie Maria** received the first research grant. Seed money to make an impact on our understanding of SWS. All your generous donations were carefully saved and spent which enabled us to bring more hands on deck to foster more awareness, clinical studies and attend medical conferences to engage more clinical and research care providers and investigators.

The seed grant also let the medical community know that the SWF, and our supporters, were serious about making strides in our understanding and ultimate goal to find the cause.

### \$50,000 CENTER OF EXCELLENCE-RIPPLING IMPACT

The next phase of organizational growth brought a move to New Jersey and the addition of more staff to handle communication, patient and caregiver networks and “friend” raising special events. It became apparent the SWF needed to expand the knowledge base and established targeted endeavors to shape research.

The SWF awarded a \$50,000 seed grant to establish a **SWF Center of Excellence (COE) at Johns Hopkins Hospital with Dr. Anne Comi** directing that initial center. The initial SWF COE proved to be a good working model and we appreciate Dr. Comi for her dedication and have continued to work with her well after she chose to become an independent and self-funded center. As the SWF membership grew and evolved, we recognized the need to minimize daily life disruptions and the financial burden for families having to travel across country in some cases. We began to expand the network of Centers of Excellence across the country at key universities and hospitals committed to excellence in care and research. Today there are 25 COE's and a burgeoning cadre of young professionals.

### \$25,000 DATA NEEDS A REGISTRY

Those first 11 x 17 papers where I recorded vital statistical data collected from patient reported information was transferred to an Access database with the growth of new software programs. We maintained this data in Access for many years and expanded what we recorded based on the influx of reports by patients. Little did we know we had a “registry”. Today registries are numerous, online and cover a variety of data collected. The registry requires \$25,000 annually to maintain, data mine and engage patient participation. My dad used to say, “From little acorns grow mighty oaks.” No truer words have been spoken! Your vigilance in sharing the natural history of SWS in your life along with thousands

**YESTERDAY, TODAY  
AND FOR THE  
FUTURE...THE RIPPLING  
IMPACT OF YOUR TIME,  
TALENT AND DONATIONS  
PROPORTIONATELY  
IMPACTS THE WORLD  
AROUND US!**

of others diagnosed has shaped our understanding of the course of the disease and treatment.

The corpus of data collected over the years has been used as documentation in many medical journal articles educating a new generation of caregivers and researchers. The profound impact of gathering data, sharing the statistical data while engaging clinicians and researchers has opened up new fields of study and enlightened families and caregivers alike. THANK YOU!

### \$40,000 NIH CSO AND MULTI-MILLION DOLLAR BVMC

The rippling impact of being responsible stewards of the compounding donations gave us the ability to fund the SWF's first **Chief Scientific Officer (CSO)** who was a former program officer at the National Institutes of Health (NIH). This investment provided strategic leadership and established the first strategic research plan to guide us in setting goals and action items. Our CSO's knowledge of the NIH grants and review committees positioned us to submit for what was in **2008** an emerging mechanism of funding to establish Consortiums. These consortiums consisted of 3 disease groups that shared a similar issue. In our case, it was and is brain vascular malformations **The Brain Vascular Malformation Consortium (BVMC)**.

Without your hard earned and generous donations, the SWF would not

*Continued on page 14...*





# MONTH OF AWARENESS IS ALMOST HERE!

*Are you ready?*

The first SWS Day of Awareness was held in May 2001 and got off to an enthusiastic start, setting the stage for the activities we have built on since then. In 2004 the events were expanded into a Week of Awareness because there were enough things people wanted to do that took more than a Day.



JOHANNA AND CARLY PHILBOOK GETTING US OFF TO A GOOD START IN 2007

In 2007 we grew into a Month of Awareness, which now continues to focus on doing whatever you can, wherever you are. This year the month of May, 2017 is the SWF Month of Awareness

That can be a fund raising event, a classroom program at your child's school, a DressDown day event at your place of business where people get a pass to wear informal attire for a donation to the SWF, hanging a Month of Awareness poster in your local supermarket,

hair salon, gas/service station, doctor's office, office coffee break room, church Sunday school bulletin board, apartment laundry room – the list is wide open.

To help you do that more effectively, this issue includes an innovative double sided poster. One side is Harley and her mom, photo by beckyhinch [www.beckyhinch.com](http://www.beckyhinch.com); the other side is Ethan and his friend Monkey, photo by his dad.

Awareness is not only for a Month, it is what people with SWS and port wine birthmarks bear witness to every day. To help you spread more detailed information, we have materials we can provide you with.

**The Check it Out Cards** are an excellent way to answer those curious stares when you don't have time to go into a long explanation.

**The Info Brochure** is a standard tri-fold brochure that give a very comprehensive picture of SWS.

For grade schools there is **Color Me Different** coloring books, **Someone Special** picture books for early grades, and the Kids Guide to SWF for middle schoolers (but full of information for adults too).

SWF families can ask for a supply of these Awareness boosters. Email [swf@sturge-weber.org](mailto:swf@sturge-weber.org)



## On the Road

SWF CEO, **Karen Ball**, and VP, **Brian Fisher** attended the American Epilepsy Society meeting in Houston, TX which sparked many new partnerships with industry and renewed collaborations. These interactions are key to building an extensive network of partnerships to drive the mission and increase funding for support and research.

**Coalition of Patient Advocacy Groups (CPAG)** meets annually to share successes with their individual consortiums and to engage with the National Institutes of

Health. SWF VP, Brian Fisher attended the recent meeting in Philadelphia and moderated a panel discussion.

**Orphan Drug World Congress** will meet in Washington DC in April.

**Cy Simonsgaard**, SWF parent and active member of our Grassroots Advocacy Committee, attended the Rare Disease Day at the NIH on 2/27/17 (Rare Disease Day).



- Friday, March 3, 2017, 6:30-9:00 PM -

# Reunion of CHAMPIONS

"Facing the Future of Innovation"  
benefiting The Sturge-Weber Foundation

Honoring Craig A. Drill  
and Rick Guidotti

Roy G. Geronemus, MD,  
Master of Ceremonies

Rosen Centre Hotel  
9840 International Drive  
Orlando, Florida  
Details and registration coming soon  
at [www.sturge-weber.org](http://www.sturge-weber.org)



Craig A. Drill  
President Emeritus  
Craig Drill Capital



Rick Guidotti  
Founder and CEO  
Future Exposure



The Sturge-Weber Foundation  
The stronger the wind, the tougher the trees.



JOHN RICH AND ERIN O'BRIEN RICH



RICK GUIDOTTI AND BRIAN FISHER



CRAIG DRILL, KAREN BALL AND BRIAN FISHER



TINA ALSTER



ABOVE: SUSAN FINNELL, CRAIG DRILL, KAREN BALL,  
TRACY IRELAND, BRIAN FISHER AND RICK GUIDOTTI



RIGHT: CRAIG DRILL, DIETER MANSTEIN,  
ROX ANDERSON





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SKINCAREPHYSICIANS

ERIC BERNSTEIN, MD

The 15th Tribute Dinner to honor doctors and professionals in the dermatology profession was held Friday, March 3, 2017 in the Junior Ballroom at the Rosen Centre Hotel in Orlando, FL. This year's event honored two long-time SWF supporters.

**Craig Drill** has been allied with the dermatology and laser industry and is a financial supporter of the SWF. He has been the principal of Craig Drill Capital, a private investment firm, since 1988.

**Rick Guidotti**, photographer and moving force behind Positive Exposure, has brought his vision and talent to the SWF families of children and adults since the 1990s. As a former fashion photographer, he knows how to find the unique spark in every person.

**Roy Geronemus, MD** again returned as the Master of Ceremonies.

This year's fun event, aptly named **The Main Event**, featured a photo corner with boxing gloves and championship belt props and a ringside bell to announce additional donations received on the spot.

The two honorees received boxing robes embroidered specially for them!

**There were 160 guests** who came to show their support and learned more about what SWF does to raise awareness, fund research, and assist patients and families with SWS. With a portion of the donations received, SWF is closer to creating a Dermatological Fellowship for a young dermatological professional whose interest is in treating SWS and other port wine birthmark conditions. Another great success to expand the growth needed to find a cure!



MARK FOLEY AND CREW



PHOTOS BY:  
HELLO! DESTINATIONS





# 2017 INTERNATIONAL CONFERENCE

## KINGSGATE CONFERENCE CENTER AT THE UNIVERSITY OF CINCINNATI

**The 2017 International Conference will be in Cincinnati, Ohio July 27-29th.**

The full information is on the SWF website and links have been sent to everyone we have an email address for, plus promoted on our Facebook pages. If you have questions, our Conference Coordinator Julia Terrell would be happy to chat with you by phone or email. 973-895-4445 or [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org)



Our International Conference is planned every two years to be held in a different part of the U.S., so that more families can have a chance to get to at least one conference. Families who have experienced the Conference all say it is a bonding and heart-warming experience. These are some views of recent conferences.

### THIS CONFERENCE WILL FEATURE THESE EXPERIENCED AND KNOWLEDGEABLE SPECIALISTS:

**Dr. Adrienne M. Hammill**, of Cincinnati Children's Hospital is trained in pediatrics and hematology/oncology and is particularly interested in bringing new and/or better medical therapy options to the treatment of vascular anomalies. She is one of the medical physicians for the Hemangioma and Vascular Malformations team. Cincinnati

Children's has been named a site for the brain vascular malformations consortium, which is a clinical research group funded by National Institutes of Health and the rare disease network and more recently a SWF Center of Excellence.

**Dr. Jonathan Pevsner, PhD**, SWF Chief Scientific Officer. Dr. Pevsner is a professor and research scientist at the Kennedy Krieger Institute. He also holds a primary faculty appointment in the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine.

**Dr. Jeffrey A. Loeb, M.D., Ph.D.** SWF Chief Clinical Strategist, currently serves as the department head of the University of Illinois at Chicago Department of Neurology & Rehabilitation and previously was a professor in the department of neurology and the associate director of The Center for Molecular Medicine and Genetics at Wayne State University School of Medicine in Detroit, Michigan.



**Dr. E. Steve Roach, MD**, is Chief of Pediatric Neurology and Vice-Chair of Pediatrics at Nationwide Children's in Columbus. He is also Professor of Pediatrics and Neurology at The Ohio State University College of Medicine. He co-edited the *Sturge-Weber Syndrome Book*.



**Rick Guidotti**, the founder and director of Positive Exposure, an innovative arts, education and advocacy organization working with individuals living with genetic difference. Positive Exposure utilizes the visual arts to significantly impact the fields of genetics, mental health and human rights.

**Dr. Andrea Paulson, MD, PHD**, Pediatric Rehabilitation Medicine

**Lauren Szulczewski, PsyD**, Pediatric Psychologist, Behavioral Medicine and Clinical Psychology

**Dr. Anna Pinto, PhD, MD**, Neurology, received her Medical Degree from Federal University of Rio de Janeiro in Rio de Janeiro, Brazil and her PhD in Neurology at the University of Sao Paulo School of Medicine in Sao Paulo, Brazil. She completed her epilepsy and neurophysiology fellowship, neurology residency program, and neurogenetics fellowship at Boston Children's Hospital. Her clinical interests include pediatric epilepsy, developmental disorders and Sturge-Weber Syndrome.

**Dr. Anna Byers, PhD, ABPP-Cn**, Pediatric Neuropsychologist, Division of Neurology.

*Continued on page 11...*





CONNOR GREENE THE SCOUT

**Connor** is a Scout in Toronto, Ontario and an enthusiastic skateboarder, as evidenced by his model skateboard ramp/truck on which perches the well-known skateboarder Bart Simpson.

**Kate Brown** in Locust Valley NY is a senior in high school and is making incredible progress in reading and math thanks to a program called Fit Learning. (see shaded box below). Kate and parents Jackie and Todd have been visiting some colleges with Special Ed inclusion programs and she will be applying next year.

### HELP YOUR TEEN ACHIEVE

**Jackie Brown** in Locust Valley, NY sends along this helpful information she found while searching for college options for her 17 year old daughter.

**Fit Learning** is a method to help students which uses individual and personal tutoring. They have centers in NYC, Long Island NY, Reno NV and Australia. You can search [www.fitlearning.com](http://www.fitlearning.com) for more information.

Even better is the website [www.thinkcollege.net](http://www.thinkcollege.net) which gives a listing of options by state of the higher education possibilities for students with cognitive disabilities.

### MESSAGE FROM OUR FRIENDS IN INDIA



LAKSHMI WITH VINAYAK, AND DAD, NARY

**Lakshmi Menon** reports: I am happy to inform you that our long due meeting (with Geetha and Nary) finally materialized.

After over five years of corresponding and telephone communications we met and found we were on the same wavelength. Also my meeting with their son Vinayak was delightful. We could relate to each other rather well – a 45-year age gap notwithstanding.



LAKSHMI MEON AND VINAYAK NARAYANASWAMY, GEETHA'S SON

Our SW India meeting was very fruitful.

We will soon act on our decisions and hopefully we will move forward well.



ANNIKA MARQUARDT AND MOM OOM PRACTICING FOR THOSE FIRST STEPS.

### CINCINNATI

*Continued from page 10*

**Dr. Harry Chugani, PhD, MD**, Division Chief of Neurology at the Nemours Neuroscience Center at AI DuPont Nemours Hospital in Wilmington. Dr. Chugani's research has been in the area of cerebral metabolism in brain development, epilepsy surgery aimed at stopping seizures, and the use of PET techniques in children.

**Dr. Craig Burkhardt, MD**, Dermatologist at UNC School of Medicine in Chapel Hill, NC



**Special event—**  
Route to a Cure  
Walk, 4:00 pm to  
8:00 pm.

Our walk will begin at the hotel to The **Cincinnati Zoo** where we will walk through the zoo. You will be able to see the exhibits and the evening will end with dinner at the Maasai Mara Shelter. Make sure you Register for The SWF Route to a Cure Walk Today!



## Sleep tight

PARENTS ALWAYS HAVE A CONCERN ABOUT THEIR CHILD AT NIGHT. HOW MANY TIMES HAVE YOU “LOOKED IN” TO THE BEDROOM JUST TO SEE YOUR SLEEPING CHILD? PARENTS WHOSE CHILDREN ARE AT RISK FOR SEIZURES HAVE AN ADDED ANXIETY. OUR SUPPORT FORUM RECENTLY SHARED THESE THOUGHTS.

### BARI IN FL ASKS:

*Does anyone have any good recommendations on a baby monitor or a monitor that can detect seizures at night? We still use a baby monitor (it's 5 years old) on Cole and probably will until he moves out (that's if I let him). Thinking about getting a new one since there are better ones out there.*

*Long story, but we used to sleep with him and for some reason I did this last Sunday. As he was falling asleep, he had a seizure. My concern is, what if I didn't sleep with him, is he having these on a regular basis? Spoke to Dr. Comi and we're going to do an overnight EEG to see what's going on while he sleeps.*

*We also added .5 ml of Keppra and Trileptal as soon as he gets home from school. He burns more calories during the day so maybe his morning dose is not covering him until his night dose.*

*We log everything and all his seizures happen anywhere between 5 pm-9 pm. A few things to think about: Should I look into buying a different one or just keep the one I have. What kind of monitor do you have? My son has complex partial seizures as well.*

*This evening seizure is new to us and we want to make sure that these are not happening at night.*

### ANNIE, IN FL SHARES:

We have a Sami alert seizure monitor and we still use a baby monitor for Arayah. The Sami has really given me peace of mind. Before, I was barely sleeping. Now I know I can see her on the monitor at all times and it will alert me of movement.

### FROM DAVID IN FL SHARES:

Our neurologist recommended, and we followed his advice to use a pulse oximeter. The logic is that the onset of a seizure will usually cause a reduction in oxygen saturation, which a pulse oximeter (which clips on to a finger) will quickly detect and give an audible alarm. We bought a Nonin pulse oximeter and that literally allowed us to sleep at night as like you, we were worried that our son would go into seizure while we were sleeping. The oximeter worked perfectly and alerted us to seizures on several occasions that we otherwise would have missed. This was about a decade ago and fortunately Matthew is stable now so we no longer need to use it. The technology has improved a lot over the past 10 years—the unit we had was bulky and outrageously expensive back then, but now apparently they are much smaller, available on Amazon and quite affordable.

### SHERRI FAULKNER IN CA SHARES:

We have the original baby monitor we got at our Baby Shower before Sarah was born (that was 14½ years ago). I will probably use this until she moves out (YIKES!) or tells me she wants her privacy. The baby monitor we have is just for sound, but it picks up EVERYTHING. I can hear paper move when the fan is on! We also bought a video monitor, so if I heard a sound, I could roll over and SEE her before jumping out of bed and running down the hall. I've heard her have complex partial seizures on that monitor when my husband hasn't heard anything—maybe I'm just more in tune with her—being the Mother?

I don't know if it gets any easier...even though Sarah had surgery 2½ years ago and she hasn't had a seizure since and her hospital EEG's are good, I can't sleep without the monitor on. Those seizures did a number on ME and I am scared to death that they will come back. I have heard great things about the SAMi system. It sounds easy to use and fool proof.

Our monitor is Safety 1st. The plastic part that used to be white is now turning YELLOW! But, it is FAITHFUL and has worked for us! There was an early morning where my husband came home from work and had gone to Sarah's room to check on her before going to bed...literally 2 seconds later as he was walking down the hall, in my sleep, I heard a noise. I knew in a second it was Sarah having a seizure. My husband entered our bedroom and I sat bolt upright in bed and pointed, "She's having a seizure!" He said, "I was just in there and she is fine." I said, "NO! She is having ONE—RUN!!!" Sure enough, that baby monitor was CLEAR enough for me to hear a tiny noise that she made—enough to know she was in trouble.

The video monitor (only 3 years old) is only good for SEEING her on it. The sound just isn't clear and there seems to be a lot of static.

### IAN HUBLING IN ONTARIO SHARES:

We purchased a pulse oximeter some time ago for our son Calvin. However, in his case, we use it for both seizure monitoring and when he has issues with his breathing. Calvin has a trachiotomy.

Regardless of the reason, I recommend a good quality pulse oximeter. The one we bought was from ebay—used. Full price it would have been about \$600 to \$800. I got mine for less than \$150. It uses various types of pickups, including reusable finger clips, rubber sleeves, and the best...disposable bandage style probes. Mine is a Massimo.

Our son was an infant when we were using the pulse oximeter and we didn't have any problems with getting the clip to stay on his finger. A Band Aid work well if required to help ensure it doesn't come lose.

Think of it as a life long investment.

*Continued on next page...*





## WE WELCOME THESE TWO NEW PART TIME EMPLOYEES TO THE SWF FOLD.



### KATRINA NUTTER: PART-TIME

Administrative Assistant in Houston Katrina comes to work for the Sturge-Weber Foundation as an administrative assistant. She will assist with various office duties at the Houston home office such as filling brochure requests, database updates, answering general questions and e-mails, office organization, etc. Katrina has worked in administration and retail, and enjoys designing jewelry when not at work. She is excited about this position and mentioned, "I am excited about doing something that I know will make a difference in other's lives."



### WHEN YOU ARE CHATTING:

remember not every Facebook page that has Sturge-Weber in its title comes from us – we have an official general page – **THE STURGE-WEBER FOUNDATION** – and a private (secret) page only for SWF members who ask to be in – **WORLD OF CARE AND SHARE NETWORK**. Spreading the word is great – but only the messages on those two pages are sent by the SWF and come to the SWF.



### KEEVIN LEE: PART-TIME RESEARCH COORDINATOR IN HOUSTON

Keevin Lee comes to The Sturge-Weber Foundation as the primary contact for all Centers of Excellence, Sturge-Weber Foundation International Research Network, and special projects. Keevin is currently seeking a Bachelor of Science in Bio-Technology at the University of Houston (graduation May 2018). Currently he holds an Associates of Science–Biological Sciences, Lone Star College, May 2016.

He has previously worked at Memorial Hermann Hospital, The Woodlands, Texas as a Patient Care Technician and at the Heart Hospital Baylor Plano, in Plano, Texas as a Patient Care Technician and Unit Administrator.

Prior to immersing himself into the bio-technology field, Keevin has held managerial and development positions at Reliant Energy, the Michigan Institute of Aviation and Technology and the Hewlett-Packard Company.

Keevin brings not only great management skills to the Foundation, but a contagious enthusiasm to work with others, collaborate efforts, and learn more about the research and treatment of SWS. He has two lovely daughters Simone (17) and Sanaa (16).

### REGULAR REMINDER

MUCH HAS HAPPENED IN DAILY LIFE SINCE WE FIRST BEGAN COMMUNICATING WITH OUR SWF FAMILIES. TO KEEP IN THE LOOP, PLEASE MAKE SURE WE HAVE YOUR EMAIL ADDRESS. BRANCHING OUT IS SENT 4 TIMES A YEAR BUT OTHER THINGS HAPPEN ALL THE TIME. WE WANT TO BE ABLE TO KEEP IN TOUCH WITH YOU.



### SLEEP TIGHT

*Continued from page 12*

### DONNA IN CHICAGO SHARES:

We just used a basic baby monitor where you can listen because he usually made noises before a seizure. We looked into the visual monitors that are available now, but by that point he always had someone to sleep with him because the seizures were so frequent, so we didn't need to go that route.

You should also visit the Chelsea Hutchinson Foundation website. They make monitors available to families in need. They are also a resource for seizure alert dogs.



### COVER PHOTO THOUGHT



ANN-MARIE VITTOE SENT US THIS PHOTO OF HER 3 CHILDREN AT A WILDLIFE REFUGE IN FLORIDA. HERE THEY ARE AT THE END OF THE CLIMB.

Figures on the top of a hill—looking forward or looking back? Looking down at where they have to travel, or taking a rest after they have climbed the rough path to get to the top?

The journey for SWS patients and families is much the same. The path up the hill may be dark and muddy and strewn with obstacles. And when you finally get to the top, what then?

### PARENTS REMEMBER

IN 1971 WE WERE AT CHILDREN'S HOSPITAL IN PHILADELPHIA. THE CHIEF OF NEUROLOGY SAID THAT OUR SON WOULDN'T LIVE PAST 4 YEARS OF AGE. WELL, EVERY TIME HE HAD A COLD OR SEIZURE, I THOUGHT "THIS WAS IT". HE TURNED 46 ON NOVEMBER 4TH. THE DOCTOR'S OBITUARY WAS IN THE PAPER A FEW MONTHS AGO.

WE VISITED TWO PEDIATRICIANS THERE, ONE OF THEM ASKED HOW HE GOT SO BADLY BURNED, AND ANOTHER SAID HE HAD ROSEOLA FEVER, WHICH IS WHY HIS FACE WAS RED. WELL, THAT WAS THE EARLY 70'S. WE COULDN'T HAVE GOTTEN THROUGH ANY OF THIS WITHOUT HELP AND FAITH.

### SEED MONEY AND YOU

*Continued from page 6*

have been in a financial position to hire an expert to coalesce and collaborate with an amazing team of scientists.

Thanks to the NIH, our Sturge-Weber staff and team of researchers, patients participating in research and tissue donation the **cause of SWS with the GNAQ gene discovery was made in 2013.** A dream come true...*for a reason, a season, or a lifetime!*

#### **\$50,000 AND ANOTHER YOUNG INVESTIGATOR OFF AND RUNNING**

**Lisa's Research Fellowship** was established in 2015 to support young investigators and to build a new generation of Sturge-Weber syndrome key opinion leaders. The humble and faithful family who established the fund gave all of us an immense gift that will have impact long after we are gone. Investing in the future of clinical care and scientific investigations is key to maintaining the momentum since our incorporation. Each of us doing our part whether minimal or vast increases the pace of discovery and brings us closer

together! Why \$50,000? A fellowship pays their salary so they can work with a mentor and investigate their hypothesis which oftentimes leads to new discoveries and treatments. It's an investment in our future and theirs.

#### **THE STURGE-WEBER FOUNDATION INTERNATIONAL RESEARCH NETWORK (SWFIRN) AND PATIENT ENGAGEMENT NETWORK (PEN)**

The SWFIRN and PEN met in September 2016 to discuss research needs best practices and to establish strategic research goals. Participants came from around the world to unite and ignite collaborations to drive discovery. This meeting was possible because the *National Institutes of Health (NIH)* invested in patient participation through the **Patient Centered Outcomes Research Initiative (PCORI)** which promotes patient input as integral to propagating ethical and effective research. Industry leaders also participated with exciting collaborations between attendees and the SWF currently in development! Regularly scheduled

teleconferences keep everyone on task and united so your hope for answers or direction becomes a reality realized through improved quality of care and treatments.

*Yesterday, Today and for the Future... the rippling impact of your time, talent and donations proportionately impacts the world around us. Stay in touch. Stay involved. You will ALWAYS be needed and matter!*

*The rippling impact of your participation in research, the registry and financial support has enabled the SWF to seek out around the world the best and brightest clinicians and scientists to jumpstart a career, to launch a SWFIRN for global collaboration, and to fund promising investigations to find the cause of SWS and more!*

**\*FOR THE FINAL INSTALLMENT, PLEASE READ THE NEXT ISSUE OF BRANCHING OUT!**



# SWF RESOURCES

{INFORMATION TO KEEP}



## CENTERS OF EXCELLENCE

**CA:** UC Irvine - Beckman Laser Institute - Irvine

**Primary Contact :** J Stuart Nelson, MD, dermatology

**CA:** UCSF Medical Center-San Francisco

**Primary Contact:** Ilona Frieden, MD, dermatology

**CA:** Rady Children's Hospital-San Diego

**Primary Contacts:**  
Lawrence Eichenfield, MD, dermatology  
Sheila Friedlander, MD, dermatology

**DE:** Nemours/AI duPont Hospital for Children-Wilmington

**Primary Contact:** Harry Chugani, MD, neurology

**IL:** U of Illinois at Chicago Medical Center-Chicago

**Primary Contact:** Jeffrey Loeb, MD, neurology

**IL:** Lurie Children's Hospital-Chicago  
**Primary Contact:** Sarah Chamlin, MD, dermatology

**MA:** Boston Children's Hospital-Boston  
**Primary Contact:** Mustafa Sahin, MD, neurology

**MI:** Children's Hospital of Michigan-Detroit

**Primary Contact:** Csaba Juhasz, MD, neurology imaging

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

**Principal Contact:** Jennifer Reeve, MD, dermatology

**MN:** Mayo Clinic : Rochester

**Primary Contact:** Megha Tollefson, MD, dermatology  
Satellite Clinic in Phoenix, AZ  
Satellite Clinic in Jacksonville, FL

**NC:** UNC Children's Hospital-Chapel Hill

**Primary Contact:** Craig Burkhardt, MD, dermatology

**NJ:** Northeast Regional Epilepsy Group -Hackensack

**Primary Contact:** Eric Segal, MD, neurology

**NY:** NYU Medical Center-NYC

**Primary Contact:** Daniel Miles, MD, neurology

**OH:** Cincinnati Children's Hospital-Cincinnati

**Primary Contact:** Adrienne M. Hammill, MD, hemangiona and vascular malformation

**OH:** Nationwide Children's Hospital-Columbus

**Primary Contact:** Warren Lo, MD, neurology

**PA:** Thomas Jefferson Univ. Medical Center-Philadelphia Wills Eye Institute  
**Primary Contact:** Alex Levin, MD, ophthalmology

**PR:** Centro Medico de Puerto Rico-San Juan

**Primary Contact:** Rafael Rodriguez Mercado, MD, endovascular

**TX:** Dell Children's Medical Center-Austin

**Primary Contact:** Moise Levy, MD, dermatology

**TX:** Texas Children's Hospital-Houston

Jeff Needham-CA, patient  
Madhuri Paturi-FL, parent  
Candice Roberts-ON, Canada, parent  
Kim Slater-FL, patient  
Julia Terrell-NJ, parent  
Stephanie Tikkanen-OH, researcher  
Ann-Marie Vititoe-FL, parent



Amy Aker-NC  
Jack Arbiser-GA  
Karen Ball-CO  
Joyce Bishoff-MA  
Harry Chugani-DE  
Marianne Clancy-MD  
Dewi Clark-ON, Canada  
Anne Comi-MD  
Michael Derby  
Heather Echevers-France  
Brian Fisher-TX  
Lan Huang-MA  
Adrienne Hammill-OH  
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Kiersten Ricci-OH  
David Siderovski-WV  
Rachel Swerdlin-GA  
Megha Tollefson-MN  
Catherine VanRaansdonk-BC, Canada  
Sarah Wetzel-Strong-NC  
Michael Yang  
Akira Yoshii-IL



THE STURGE-WEBER FOUNDATION

## PATIENT ENGAGEMENT NETWORK

Anna Pinto-MD, Advisor  
Kellie Sadens, Chair-Chicago IL, parent  
Witney Arch-LA-parent  
Davis Argersinger-MI,sibling  
Emily Argersinger-MI, patient  
Kaelin Ball,-CO, patient  
Karen Ball-CO, parent  
Jillian Barnes-ON, Canada, patient  
Michelle Daoust-ON, Canada, patient  
Laura Embrey-TX, parent  
Brian Fisher-TX, relative  
Gloria Gomez-PR, patient  
Tom and Mary Leonard-IL, parents

*The stronger the wind, the tougher the trees*



**THE STURGE-WEBER FOUNDATION**

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CONFERENCE  
CINCINNATI**

**THIS ISSUE IS BROUGHT TO YOU  
IN PART THROUGH THE GENEROUS  
CONTRIBUTION OF THE  
ALLERGAN FOUNDATION.**



MORGAN McDONALD

**“ WISHING YOU ALL  
THE JOYS OF THIS  
SPRING. ”**

**IF YOU HAVE OPINIONS, QUESTIONS, OR ARTICLES FOR BRANCHING OUT, WE  
WOULD LIKE TO HEAR FROM YOU. PLEASE FAX, MAIL, OR E-MAIL YOUR MATERIAL  
TO THE SWF OFFICE (SWF@STURGE-WEBER.ORG).  
WE RESERVE THE RIGHT TO EDIT ALL MATERIALS.**