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**ACCEPT | RESPECT | CONNECT | HOPE**

For questions, comments or inquiries, please email  
[swf@sturge-weber.org](mailto:swf@sturge-weber.org) or call 973-895-4445.



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A PUBLICATION OF THE STURGE-WEBER FOUNDATION

# Branching Out

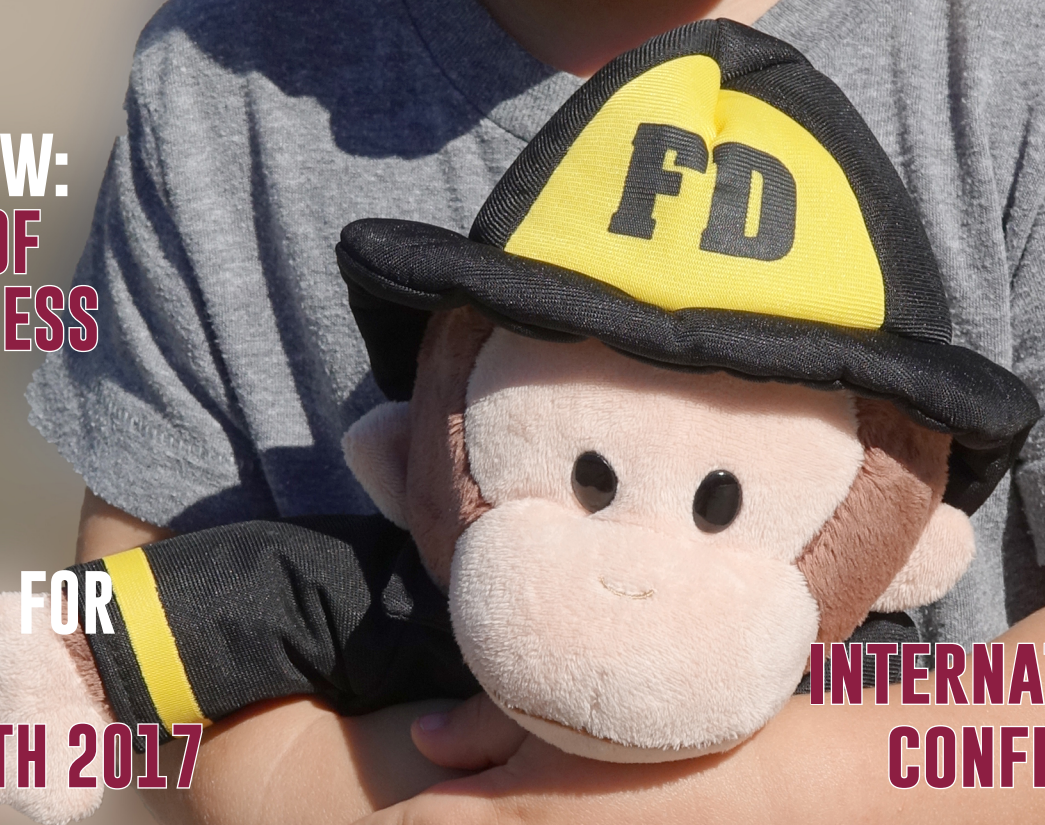
AUGUST 2017

**SWF IS  
TURNING 30:  
THE FUTURE  
HARVEST**

**IN REVIEW:  
MONTH OF  
AWARENESS**

**RUNNING FOR  
SWS:  
FALMOUTH 2017**

**2017  
INTERNATIONAL  
CONFERENCE**



## CONNECTING WITH KAREN



When we started the SWF almost 30 years ago, a 2 cent donation mattered and it still does today! My dad used to say give me your 2 cents (tell me what you think). So, it is fitting as we transition to a new era of care with collaboration, hope, respect and accepting all we have been giving in this life with a SWS, KT or Birthmark, I want to say I am still beyond grateful for literally and figuratively ...YOUR 2 CENTS!

YOUR 2 CENTS is what continues to uplift and drive all we are able to do through SWF programs. We need to hear your feedback and thoughts on what you need, why it matters and how best to support you and those you love in this journey. We need MANY 2 Cents to create and fund lasting impact in the areas of family support, research. YOUR 2 CENTS is at the heart of all we do! Of course, those of you who know me also know I've never been shy about giving you my 2 cents ... thanks Dad! So, here goes:

If your child had a broken tooth, would you take them to a neurologist to fix it? If they had glaucoma, would you take them to a dermatologist to treat it? Heck no! So with this silly but targeted example I encourage you to be a discerning consumer. Yes, you are a consumer and at the end of the day you live with what happens or doesn't happen to your loved one living with these syndromes. As a discerning consumer, have that due diligence to not just take that provider social media online recommendation because they are the best "xyz" doctor. EACH case SWS is unique as is each child. Most of us have finite time and dollars to spend. We strive to build the most comprehensive system of care and research so you have access to leading expert healthcare providers and researchers. We want you to find that life balance because while some days and maybe for many of you MOST days you are consumed by syndrome related matters ... enjoy it. Find the joy!

I remember eons ago one of my friends said to me after I returned home from flying to California for Kaelin's first PET scan. Are you always going to have to fly everywhere for care and what if something happened to that doctor who would care for Kaelin? So, at the heart of what we do for you and with you everyday is to ensure that just like in any good military unit, if one man goes down there is another to take his/her place. The Clinical Care Network (CCN - previously the Centers of Excellence - COE) and the SWFIRN (International Research Network) have evolved as your needs have grown and the membership in the SWF has grown.

The face to face encounters we host like the most recent International Conference in Cincinnati and the upcoming Chicago Educational Forum this fall and San Diego this spring are crucial to making personal connections to celebrate life and share concerns. It was SUCH fun to watch first time attendees relax into the weekend and to see old friends reconnect! AWESOME Route to a Cure Walk and zoo visit! I miss y'all already and count the days until we meet again!

Thank you to all the physicians, staff and sponsors who give of their time and talents all year long! Together we make a mighty team ... speaking of which Team SWF is out in full force with the annual Falmouth Road Race captained by Pam McIntyre and Jessica Melo. Bring your pom poms and cheer the runners on across the finish line!

Be sure and catch where and when Brian and I will be on the road spreading awareness and advocacy ... we'd love to meet ANYTIME! Oh and don't forget, stock up on SWS/KT/PWB school materials to spread awareness and BEST WISHES for a wonderful school year!

With faith, hope and love,

*Karen*



# THE FUTURE HARVEST

Part 4 in a Series by Karen L. Ball

Today not for profit startups have a plethora of online platforms, software and software integration that makes it more efficient and streamlined to communicate. The ease of which an organization can reach out to other not for profits (npos) for advice is amazing!

Back in the dark ages when npos were really just emerging, especially in the rare disease realm, there were not as many resources to access. We relied on the spirit of generosity to share our collective knowledge of governance, education, patient support, etc. Online social media forums have “been there, done that” expert parental advice that still needs to be tempered with reminders that each case of SWS, KT and birthmark issues are unique. While experiences shared are a great comfort, they are not your personal journey or your personal medical situation.

**The further we reach out, the closer we become.**

SWF has benefited every day from all the latest technology and social media venues as we tailor fit our responses to your inquiries. New volunteers continue to step it up to give back to all of us! Chris and Dana Davis supported the new website which is an internationally respected and vetted resource for patients and caregivers alike. The adjustment from traditional office to a blend of traditional and remote workers who interface with volunteers around the world has put the SWF in a perfect position for rapid response. The tailor fit service, online forums, and vast network of resources ensures you ARE in good hands!

As donations and grants are received, the SWF is able to expand services and programs with knowledgeable staff and volunteers working together to foster the vision and mission. I know what I know and I know what I don't know! I have never been afraid to admit I don't know ... which is why I search out the world to find the brightest researchers and clinicians, volunteers and staff to forge new inroads and plant new seeds of thought and hope!

## Healthcare Providers and Investigators

Yesterday's scientists and clinicians are training a new front line of investigators. They are utilizing technology and our increased understanding of SWS, KT and birthmarks since the dark ages of 1986 to improve the quality of care and increase the pace of discovery. Lisa's Research Fellowship provided by Lisa P. and her parents, Steve and Melanie, has fostered excitement for young investigators and increased collaborations. Fellowship recipients then apply to the National Institutes of Health (NIH) for larger grant awards.

With over 25 SWF Clinical Care Network (CCN) facilities, individuals and parents no longer have to trek across country from one coast to the other like I did with Kaelin in 1987. They can rest assured that these CCN facilities have dedicated and knowledgeable staff who will provide the best care and collaborate with researchers around the world. The blend of national facilities with various areas of expertise ensures that collaborations among the CCN and with those from beyond the CCN will keep the SWS clinical and scientific research burgeoning for years to come.

I realize how blessed I've been and how fortunate the SWF has been to have so many dedicated volunteers and families as I look back over 30 years of service and support. I live in hope that new families with a diagnosed loved one and individuals living with a diagnosis don't

take for granted all that has been planted so far. While we continually harvest the fruits of our labors, we need individuals to step up and nurture the SWF with their time, talents and treasure. Your attention and commitment will ensure that the next generation (until we eradicate SWS, KT and birthmarks) will have just as robust, if not more, resources and committed collaborators! Together we have created amazing opportunities and accomplished hoped for and even unimagined goals.

Please do even just one thing with who and what you know ... **Champions are made, not born!**

**Yesterday, Today and  
for the Future ...  
the rippling impact  
of your time, talent  
and donations  
proportionately  
impacts the world  
around us!**

# MONTH OF AWARENESS

## The Face of SWS in Review

One of the eagerly awaited features on Facebook for Month of Awareness was the daily story and photo of some of our SWF young members. This feature was organized by Witney Arch, mom of Beau, who put out a query and then gathered and edited the photos and stories for Facebook.

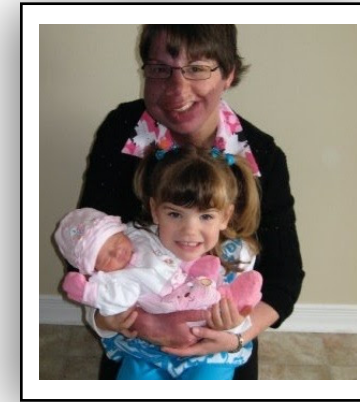
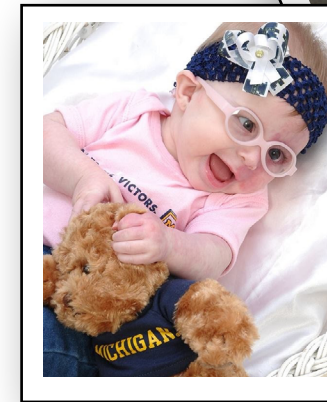
Witney says, “This has been such a rewarding project. I can't tell you how much I have cried this month while talking to these amazing Mamas. I think these stories have helped people feel much less alone. There are other kids out there like theirs. We struggle with the same emotions and fears.”

### Thank you to all the families and children who participated!

Lindy, Taylor and Maley Coleman of Mississippi  
Serenity, Jamie and Tucker DeDear of Arkansas  
Marissa and Lauryn Boruff of Illinois  
Nanna, Niki and Cecilie Nielsen of Denmark  
Lauren, Jordan and Macy Lowe of Georgia  
Jody, Shaun and Wood Bowser of Ohio  
Ashley, Shawn and Reeve Cahoon of Canada  
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Samantha and Allana Wisniewski of Connecticut  
Gabby Mendiola, Pedro and Jaxon Ayala of Indiana  
Catherine Pena, and Lorenzo Jimenez of Dominican Republic  
Stephanie Vazquez, Mark and Noah Peppin of Canada  
Natalie and Olivia Revell of New Zealand  
Elsa Rolon, Emiliano and Rocco Pollacchi of Argentina  
Joy, Nick and Emery Davis of Utah  
Lise Lozelle and Elizabeth Warden of Texas

### And other SWF families who also lent their voices!

Kellie, Kris and Silas Sadens  
Crystal, Shad and Carley Elliers  
Oom Siriyakorn, Chris and Annika Marquardt  
Candice Roberts, Donald and Harley Moon  
Michelle and Jayden Findlater  
Pam, Dan and Ryan McIntyre  
Karen and Kaelin Ball  
Witney, Jason and Beau Arch  
Gloria Gomez  
Sherri, Curt and Sarah Faulkner  
Hayley and Amelia Zinski  
Deborah, Kevin and Celine Brewbaker of MI



# ON THE WEB | IN THE NEWS

[www.sturge-weber.org/who-we-are/foundation-news-and-blogs](http://www.sturge-weber.org/who-we-are/foundation-news-and-blogs)

You can find the following stories and news of past events on the SWF website. Click “Who We Are” and follow the link to “Foundation News and Blogs”.

## Spreading a Little Sunshine

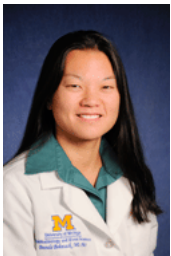
Julia Terrell, SWF Social Media Director, writes a wonderful Day of Service she shared with her second grade daughter, Marissa, and her classmates as they planted Sunflower seeds for Month of Awareness and learned just how symbolic these little seeds can be. These young little minds were taught how we all need nurturing, sun and care to grow into our greatest potential!



## Healthcare Provider Recognition

This year, during the Month of Awareness, we asked our families to recommend a clinician - doctor or nurse, or allied medical staff - that they would like to recognize as a special healthcare provider. These may not be the attention-getting doctors in the headlines, or the award winning Person of the Year, however, they are the professionals who, time after time, make you, the patient and caregiver, feel safe, comfortable and valuable as you come to their office for your medical concerns and treatment. They LISTEN! They treat you and your child like unique individuals, not just medical cases. They go above and beyond!

The 2017 SWF Healthcare Providers chosen to be recognized were:



Dr. Brenda Bohnsack, MD  
University of MI, Mott’s Children’s Hospital (Kellogg Eye Center)  
Nominated by Deborah Brubaker, Ann Arbor, MI



Dr. James Olson, MD  
Kid’s Health Partners, Skokie, IL  
Nominated by Donna Tilley

See the full story on the web - [www.sturge-weber.org](http://www.sturge-weber.org)!



THE STURGE-WEBER FOUNDATION  
**CLINICAL CARE**  
NETWORK

# 2017 CONFERENCE

Sunday, October 1 - Tuesday, October 3, 2017  
The Saint Hotel | New Orleans, LA

If you haven’t heard yet, the Sturge-Weber Foundation has officially formed the SWF Clinical Care Network, formerly known as the Centers of Excellence.

Due to the the overwhelming interest in collaboration and care for SWS patients, medical and clinical centers internationally have requested and applied to become a partner with SWF. To encompass the current and future growth, SWF created the Clinical Care Network (CCN).

In October, the centers that make up the CCN will come together to plan, discuss and implement better care for SWS patients. Dr. Jeffrey Loeb, SWF Chief Clinical Strategist, will lead these medical professionals to find a

consensus and make standards for all CCN centers on the following:

- Basic diagnosis for SWS
- Imaging and how often (C-Scan, MRI, x-ray)
- Laser treatments for PWB, how early and how often
- Glaucoma - treatment, for early and method

In answering these vital questions, the science of treating SWS will become translational. Medical professionals in all fields will be able to provide a more knowledgeable and beneficial treatment for the patient when provided with concrete standards for all the variables of SWS.

**TOGETHER,  
WE CAN MAKE CHANGE!**

# TEAM SWF ON “FRIEND”RAISING

Falmouth Road Race 2017:August 20th



For 6 years, the Sturge-Weber Foundation has benefitted from the generous support of two “warrior mamas” who have tirelessly created teams to run. **Pam McIntyre and Jessica Melo**, two champions and mothers of sons with SWS started out with only 5 runners in 2010. Each year they have led and motivated others to join the cause, resulting in 42 runners in 2017! We can’t begin to express how thankful we are.

The Falmouth Road Race provides an incredible opportunity to raise money and awareness for the Sturge-Weber Foundation. Over the years, **\$466,000** has been raised in support of the Foundation’s efforts to carry out it’s mission.

**Cynosure**, a faithful sponsors in years past, and **Liberty Mutual Insurance Company** are TeamSWF’s corporate sponsors for 2017. With their help, the Foundation is able to register all runners in the event. We are honored to have such generous sponsors this year!

Here is a list of our faithful runners. Whether this is their first race, or their seventh, everyone is a winner to us!

### Honor Roll of Falmouth Road Race Warriors

- 8 Years - Pam McIntyre, Jessica Melo
- 7 Years - Kevin Melo
- 6 Years - Chris Marino
- 5 Years - Jonathan Desmarais, Charlene Johnson, Ellen LaMarche, Octavio Melo, Michelle O’Connor
- 4 years - Nancy Carpenter, Ellen LaMarche, John O’Day, Kate Sanders, Jamie Trickett
- 3 Years - Julie Brady, Mike Collins, Brent Crouch, Woody Crouch, Coralee Craig, Rob O’Neill, Deb Shea, Heather Wicken
- 2 Years - Melanie Arena, Kim Auen, Mark Banks, Jen Barbato, Nick Carpenter, Nina Conway, Carol Di Pietro, Olivia Melo, Peter Sullivan, Dan Torgerson
- Welcome Newcomers - Kunal Bhalla, Kym Fischer, Lynn Hannan, Chris Karavolas, Adam Lavelle, Leah McCann, Kait Roweton, Ryan Sfreddo, Kate Tiberio



**BOOM!**

# It Happened in Cincinnati!

**COOL!**

The Sturge-Weber Foundation 2017 International Conference was held July 27-29, 2017. A total of 150-plus members, staffers, clinicians, researchers and committed supporters were in attendance. Turn the page and see what happened in CINCINNATI!

L-R: Kalee Embrey, Harley Moon, Sydney Willard, Marissa Terrell

# 2017 INTERNATIONAL CONFERENCE

Kingsgate Conference Center at the University of Cincinnati

The conference is held every two years in a different part of the U.S. so that more families can have a chance to get to at least one conference. Some families, with enough advance planning and loyal dedication, have been to two or more conferences.

Attendees at past conferences all report it as a bonding and heart-warming experience. This year's conference was no exception. The sessions were led by clinicians and researchers, who reported on latest treatments and research. But they are also experienced and knowledgeable enough to know that some families are discovering SWS for the first time and have young children. So they don't assume that everyone knows about SWS and has experience. Hearing the basics of SWS is always a good education as well as a refresher for those with more time in the ranks.

Families also had a chance to get to know each other in a more relaxed and social setting. With the advent of cell phone technology, more and more families can trade photos, emails and the chance to connect more personally after the Conference is over.

The Kids Camp made sure that kids are supervised and engaged in making friendships, learning crafts and having fun, all in a secure place while their parents were attending the more information-based sessions.

This Conference had two new special events. The group took a Route to a Cure Walk through the Cincinnati Zoo followed by a picnic supper at the Maasi Mara Shelter. And small groups toured the University of Cincinnati labs to get a better idea of how research comes about in reality.

The highlight event was the Dinner Dance where everyone got to be a "superhero" and strut their stuff out on the dance floor to familiar tunes!

The Cincinnati Children's Hospital, a center in the SWF Clinical Care Network, hosted and organized a large portion of the speakers at the conference. Some of the speakers who presented were:

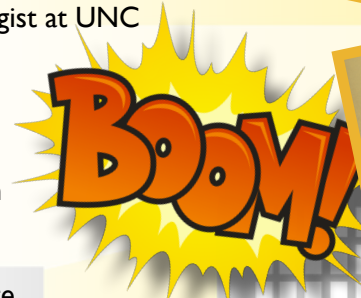
- Adrienne Hammill, MD, a member of the Hemangioma and Vascular Malformations team

- Jonathan Pevsner, PhD, the SWF Chief Scientific Officer, a professor and research scientist at the Kennedy Krieger Institute at Johns Hopkins School of Medicine
- Jeffrey Loeb, MD SWF Chief Clinical Strategist, of the University of Illinois at Chicago Department of Neurology and Rehabilitation.
- E. Steve Roach, MD chief of Pediatric Neurology at Columbus Children's Hospital. He is the co-editor of the medical textbook Sturge-Weber Syndrome.
- Andrea Paulson, MD Pediatric Rehab
- Lauren Szulczewski, PhD, Pediatric Psychologist, Behavioral Medicine and Clinical Psychology at University of Cincinnati
- Anne Pinto, MD Boston Children's Hospital and Medical Advisor to the SWF PEN
- Anna Byers, PhD, Neuropsychologist
- Harry Chugani, MD Chief of Neurology at Ai Dupont Nemours Hospital in Wilmington, DE. Dr. Chugani has been instrumental in SWS research through the NIH and has been a SWF consultant for many years.
- Craig Burkhardt, MD, Dermatologist at UNC

If you were unable to attend the conference this year, some of the presentations will be available on the SWF website soon. Information will be sent out in the monthly SWF eNews on where to view the presentations online. The website will also have photos and videos to view from the conference.

A big thank you to our host CCN, Cincinnati Children's Hospital, the speakers, volunteers, parents and patients for making this one of the best conferences yet. You are all CHAMPIONS!

We look forward to the 2019 Conference!!



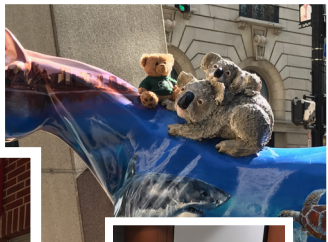
# MEET WEBSTER! SWF'S RARE BEAR CHAMPION

SWF's new champion is a serious road warrior, traveling coast to coast to visit SWS patients, families, doctors and researchers. He's collecting stories to build awareness across the globe!

Meet Webster, SWF's rare bear extraordinaire! Webster had the privilege to travel with **Cody Marshall** to the 2017 International Conference in July. This was Cody's first conference, as well as Webster's, so it was quite an experience for both!

Cody and his mom, Michelle Marshall, left Sunday, July 23rd, with Webster as co-pilot, and drove to Cincinnati, Ohio arriving Wednesday, July 26th. Once at the conference, Cody, Michelle and Webster met new friends and learned valuable information about SWS and new research on the horizon.

Webster didn't end his journey in Cincinnati though. Cody bid adieu to Webster as Webster packed up and headed home with **Brielle Coutu** and her family in Rhode Island. The journey continues and the stories will follow about other SWS champions.



**Interested in Webster visiting you?**  
**Details coming soon about how Webster can come to your town, home or fundraising event!**



# RECAP: 2017 INTERNATIONAL CONFERENCE

the survey says . . .



## We asked and you answered!

During the 2017 International Conference, we provided a survey for registrants to fill out as they attended the various talks and breakout sessions. The information provided in the surveys is very important to SWF as it assists us in planning the next conference and doing our job better to provide more useable information, more interaction and fun!

Here is a brief summary of what was received:

### Registration

- The website was great and easy to navigate
- It was a little confusing with all the different forms to fill out for the conference, dinner and walk

### Accommodations

- Hotel was very nice and the food was good
- Dorm was great, fit our families needs
- Would like to have tables to sit at during continental breakfast
- Would like to have had more of a reception during the meet and greet meeting

### Route to a Cure Walk

- Wonderful walk, much better than riding on a bus or van
- Enjoyed having zoo to ourselves
- Would like to have had more time to see the exhibits
- Picnic was very relaxing

### Speakers

- Good variety of speakers
- Enjoyed hearing from the SWF staff and what they do
- Would like more information for teens and adults with SWS

- Would like more information and discussion on psych-social

### Breakout Sessions

- Great addition - doctor's appointments
- Would like more time in the Mom, Dad and Sibling talks
- Enjoyed the age appropriate sessions with doctors, would have liked more time during this session

### Kids Camp

- Great activities, my child loved it
- Would like to see more activities in camp for older children

### Overall Conference

- Great Conference
- I learned so much
- Would like to see more sessions for teens and adults
- It's expensive to attend for a family, however I do understand now why the expense due to all the speakers, accommodations and food

SWF clearly sees a need for having a child tract and a teen/adult tract. SWS is unique to each patient at each age. It is the intent of the Foundation to provide the most information possible that is relevant to the patient in their life journey. This and many other ideas will be considered for the next International Conference in 2019!



## Remembering Loved Ones

**Calvin Hubling**, age 24, passed away unexpectedly on June 4, 2017. Calvin, his parents, Ian and Linda, have been part of the SWF family since shortly after he was born. Calvin was the inspiration for Ian and Linda to start the Pediatric Glaucoma and Cataract Family Assn of Canada. The Hublings, with Calvin's younger sister, live in Courtice, Ontario, Canada. Many messages of condolence came via the SWF support groups.

His dad remembers - "He touched so many lives. He loved to travel and camp. He especially loved country music. For a boy who was not supposed to live past the age of 5, not supposed to utter a sound, not supposed to interact or communicate with others, he certainly managed to show the doctors that boundaries are for sissies."



**Michigan to Las Vegas**  
**Deborah and Kevin Brewbaker** took advantage of their recent trip to Las Vegas to introduce their 1 year old daughter Celine to her namesake, headliner Celine Dion.

## FAB Music for Sturge-Weber

In January, as a tonic for the mid-winter blues, the Highland and Milford MI communities, urged on and organized by **Brigitte and Matt Biondo-Smith** and their daughter **Annika**, came together to enjoy an afternoon of music, food and a silent auction to benefit the international conference scholarship fund of the SWF. Merchants and businesses in the towns of Milford and Highland donated gifts, services and gift certificates.



## On the Road

**Francis Collins, MD** will continue to serve as the director of the National Institutes of Health. Dr. Collins assumed leadership of the NIH in 2009 after serving as director of the National Human Genome Research Institute.



A physician and geneticist, he is credited with the discovery of several important genes, including those responsible for cystic fibrosis, neurofibromatosis, and Huntington's disease. He also led the International Human Genome Project.

## Washington to Montana to Ohio

**Abigail Fredrickson** of Seattle graduated from the University of Montana in May with a BA in Anthropology. She is now doing an internship with Kappa Kappa Gamma National Headquarters in Columbus, OH at the Snowden-Grey Victoria House Museum. She hopes to continue in the museum field in Seattle. Abby and her proud mom, Elisabeth Fredrickson, have been part of the SWF since 1998.



## Where In The World Are Karen and Brian

**Karen and Brian** are always on the move, spreading public awareness of SWS, advocating for patients and families, and advancing research for SWS, K-T and PWB. To follow are just a few of the events they will be involved with in the coming months:

- American Academy of Dermatology sponsored Lobbying on the Hill, September 9-12, Washington DC
- CCN Conference, October 1-2; New Orleans, LA
- Child Neurology Society Annual Meeting, October 4-7, Kansas City, MO
- SWF Chicago Education Forum, October 12, Chicago, IL
- PCORI Meeting, October 31-November 2, Arlington, VA
- American Academy of Ophthalmology Annual Meeting, November 11-14, New Orleans, LA



"Sharing stories gives hope and encouragement to others in similar situations. I am touched by every story and each success warms my heart."

Lakshmi, Our Family in India

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# Branching Out

AUGUST 2017

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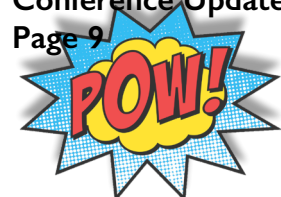
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Port Wine Birthmarks (PWB) on the skin are developmental abnormalities in blood vessel formation (capillary malformations) that are more extensive and darker than the pink capillary birthmarks often seen at the nape of a baby's neck.

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).

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.

## SAVE THE DATE

- ★ Falmouth Road Race  
August 20
- ★ Clinical Care Network  
Conference  
October 1-2
- ★ Chicago Education Forum  
October 21
- ★ Raising HOPE Campaign  
November-January



BVMC Registry Website:  
[rarediseasenet.org/cms/bvmc](http://rarediseasenet.org/cms/bvmc)



SWF International  
Registry

SWF International Registry:  
<https://swfregistry.patientcrossroads.org>

### 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 a 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 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).

## THE NEW ...



THE STURGE-WEBER FOUNDATION  
CLINICAL CARE  
NETWORK

(formerly the Centers of Excellence)

CA: UC Irvine - Beckman Laser  
Institute-Irvine  
Primary Contact: J Stuart Nelson, MD,  
Dermatology

CA: UCSP Medical Center-  
San Francisco  
Primary Contact: Ilona Frieden, MD,  
Dermatology

CA: Rady Children's Hospital -  
San Diego  
Primary Contact: Lawrence  
Eichenfield, MD, Dermatology  
Sheila Friedlander, MD, Dermatology

DE: Nemours/Al 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

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  
Primary 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 Mill  
Primary Contact: Craig Burkhart, 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 U. 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: Cook Children's Medical Center  
- Fort Worth  
Primary Contact: M. Scott Perry,  
MD, Neurology



THE STURGE-WEBER FOUNDATION  
PATIENT  
ENGAGEMENT  
NETWORK

Anna Pinto, MD-Advisor  
Kellie Sadens, Parent-Chair, Chicago, IL  
Witney Arch, Parent, LA  
Davis Argersinger, Sibling, MI  
Emily Argersinger, Patient, MI  
Kaelin Ball, Patient, CO  
Karen Ball, Parent, CO



## SWF RESOURCES

Jillian Barnes, Patient, ON, Canada  
Michelle Daoust, Patient, ON, Canada  
Laura Embrey, Parent, TX  
Brian Fisher, Relative, TX  
Gloria Gomez, Patient, PR  
Tom & Mary Leonard, Parents, IL  
Jeff Needham, Patient, CA  
Madhuri Paturi, Parent, FL  
Candice Roberts, Parent, ON, Canada  
Kim Slater, Patient, FL  
Julia Terrell, Parent, NJ  
Stephanie Tikkanen, Researcher, OH  
Ann-Marie Vititoe, Parent, FL



Jack Arbiser, GA  
Karen Ball, CO  
Joyce Bishoff, MA  
Harry Chugani, DE  
Marianne Clancy, MD  
Dewi Clark, ON, Canada  
Michael Derby  
Heather Echevers, France  
Brian Fisher, TX  
Lan Huang, MA  
Adrienne Hammill, OH  
Brandy Hutchinson, FL  
Serquiz Jozwiak, Poland  
Csaba Juhasz, MI  
Veronica Kinder, UK  
Kristen Kelly, CA  
Michael Lawton, CA  
Jeffrey Loeb, IL  
Emily Lund, IL  
Douglas Marchuk, NC  
Charles McCulloch, CA  
Leslie Morrison, NM  
Ludmilla Pawlikowska, CA  
Jonathan Pervsen, MD  
Melinda Rainey, TX  
Kiersten Ricci, OH  
David Siderovski, WV  
Rachel Swerdlin, GA  
Megha Tollefson, MN  
Catherin VanRaansdonk, BC, Canada  
Sarah Wetzels-Stron, NC  
Michael Yang  
Akira Yoshii, ILL