



MAY 28, 2019 | Edition 3, Issue 4

Month of Awareness = Progress!

What an amazing Month of Awareness May 2019 has been! The stories on Facebook of courage and amazing progress truly were the highlight of the month. Thank you Julia Terrell and Witney Arch for coordinating this effort and thank you all 31 families and caregivers for sharing your precious stories.



Many of you held fundraisers or hosted educational programs this month. Thank you for making your own personal impact to spread awareness. *A special "shout out" to the following fundraisers that we know of:*

- Jessica Melo - Fitness Fundraiser for SWS
- Molly and Thomas Speer - Arby's Dinner Fundraiser, May 15th
- Molly and Thomas Speer - Myla's Mission Walk for SWS, May 18th
- Pam McIntyre - Fit Revolution Fundraiser
- CooliBar - donation of SPF Hats for Route to a Cure Walk at Conference
- Tina Alster - donation of skin care products for conference registrants
- The Terrell, Ball, Roffer families all hosted individual fundraisers
- 4900 Facebook Followers
- Individual Facebook fundraisers and more!

Additionally, *a big "shout out" to Donnie Hood for his amazing bike ride in the Mallorca 167 in Spain on April 27th.* He completed the course and spread global awareness!

Here is a special message from Sam Daulton, The Sturge-Weber Foundation, I know Karen! We are still grateful for you starting up the foundation. Wow, what would it have been like without you? Being and feeling part of a community really helped us in our journey. We can't thank you enough. (and of course your wonderful staff, Anne especially).

If we missed you or didn't know about your event this month, please let us know! A FULL report with photos will be in the June/July Branching Out and the SWF website.

THANK YOU for your continuous support and
for sharing your stories with us!



2019 SWF International
Family Conference

Nemours / Alfred I. duPont Hospital for Children
July 18 - 20, 2019 | Wilmington, DE



2019 SWF International Family Conference

As you get ready to attend, have
you:

REGISTERED
BOOKED YOUR HOTEL
SIGNED UP FOR ROUTE TO A
CURE
CREATED A FUNDRAISING PAGE
CHECKED OUT THE CRUISE

See you July 18, 2019!



Calling SWF Professionals SAVE THE DATE! *SWF Clinical Care Network Conference*

September 19-21, 2019
UI Health, Chicago, IL

*DETAILS & REGISTRATION
COMING SOON.*



CALLING SWF Researchers! 2019 SWF International Research Network Conference

July 19-20, 2019
Nemours/Alfred I. duPont
Hospital for Children
Wilmington, DE

REGISTER

Houston Coffee Lovers

Sunday, June 23rd, 9 AM - 12 PM,
SWF will be hosting a brunch for area
businesses and residents in an effort to
spread awareness. If you live in the
Houston area, please join us for this
special event! Our special host is the
Crescent Moon Coffee Bar at 12333

THE STURGE-WEBER FOUNDATION
Coffee Lovers for a Cure Brunch

Sunday, June 23, 2019 | 9:00 AM - 12:00 PM

Crescent Moon Coffee Bar
12333 Jones Rd., Houston, TX 77070

Join Karen Ball, CEO and SWF staff for a special awareness event to support research for Sturge-Weber syndrome, Port Wine birthmarks and other vascular congenital disorders!

Free coffee and gourmet muffin to the first 30 visitors attending the event.

In addition, Crescent Moon Coffee Bar offers a wonderful breakfast bar with delectable choices of danishes, muffins, quiche, Katz coffee, specialty drinks and even made to order omelet bar.

Come visit with other SWF families and friends. Show your support in spreading awareness! Make an impact!



No RSVP necessary.
See you then!



Jones Rd., across the parking lot from the SWF office. Karen Ball will be in town, so please join us! No RSVP necessary.

Free coffee and gourmet muffin to the first 30 visitors!

CALENDAR OF EVENTS

June

4th: NIAMS Advisory Council
12th: BVMC Annual Meeting
16th: Branching Out -
June/July

July

18th-20th: Family Conference
19th-20th: SWFIRN
Conference

August

18th: Falmouth Road Race

September

7th: American Academy of
Dermatology Advocacy
Conference

UPDATE: SWF Communications Survey

Thank you for taking the time to take the SWF Communications Survey in the April eNews. Your feedback is essential to making sure we are providing the information you are interested in, and putting it into a format that is easiest for you to read and refer back to.

From your comments, we are pleased to report that we are "on target" providing you with information across our various communication platforms.

One request made was to include the entirety of articles in the eNews instead of a "Read More" button that takes you to another online destination. We will begin that with this issue!

Please keep us posted on how we are doing, we are here to make sure you stay informed!



Growing Golden Legacy

Before the progress in diagnosis and treatment of rare disorders like SWS, before the anti-seizure meds, before even the information for parents from medical sources, or the emotional and community support that comes from awareness, a family given a diagnosis of SWS for their loved one (usually a child) had only their own instinctual strength to guide them. So, they called upon their love for their child and persistence in the face of adversity to live with the challenges.

As we mark the passing of many parents and of adults with SWS, we always want to remember and pay tribute to the day to day courage and hard-won wisdom they have passed along.

When Tim Fitzgerald died in April, at age 65, he left a legacy of love

and caring that truly branched out to his siblings and extended family. His parents, Herbert and Elaine, had joined the SWF in 1990 to learn what they could for Tim. When they passed in 2013 and 2015, his brother Kevin took the reins as guardian when Tim was in a nearby skilled nursing facility.

In a touching memorial eulogy, Kevin shares:

To grow up with Tim was to see and experience early on that life often isn't simple, or fair, or easy, or pain-free but also to learn through the other-worldly, relentless love and devotion of our mother, and the gritty dedication of our father, that these troubles in life that so often threaten to – and often do – consume is, aren't to be mistaken for life – rather life is given meaning and is sustained by the unyielding power of love. And through that power, one frail, damaged baby that was Tim in 1954 and thought destined to be with us perhaps 6 months or 6 years, left is instead more than 6 ½ decades later at a ripe old age.

Our condolences go to Kevin and Marie Fitzgerald, siblings Anne, Dan and John and especially to aunt Ruth Eagan who sent us a sweet letter and a copy of Kevin's remarks.

And in this same month, we heard of the passing of the father of our SWF member Patricia Hill Grim. William David Hill was a retired State of NJ Supervising Judge. He was a decorated Army veteran of the Korean era. Kathy Hill, Pat's mother, who passed away previously, had often called the SWF office in NJ for information on medical suggestions and contacts. Pat Grim, who now lives in GA, is the mother of two young adults.

The legacy of these families is shared by every family that learns the lessons of living with SWS. Like the ripples in a pond, once begun, it touches unknown shores.

GET CONNECTED

- **CONNECT WITH KAREN**
- **SWF ONLINE STORE**
- **SPOTLIGHT ON RESEARCH**
- **BRANCHING OUT MAIL LIST**

The logo for 'believe' features the word in a lowercase, sans-serif font. The letters 'b', 'l', 'i', 'e', and 'e' are in a dark red color, while the 'v' is in a bright yellow color. A stylized red silhouette of a person with arms raised is positioned behind the 'b'.

Believe in progress!

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Connect with us

