APRIL 30, 2019 | Edition 3, Issue 3

THE STURGE-WEBER FOUNDATION

Sturge-Weber syndrome is a non-hereditary condition that causes a port-wine birthmark, glaucoma and seizures. No two cases are the same. One in 50K in the US are born with SWS.

Ready to make progress?
www.sturge-weber.org | swf@sturge-weber.org | 973.895.4445

MONTH OF AWARENESS

May is Month of Awareness for SWS! It's just days away to make the biggest impact ever! *Click the photo to the left to download your copy of this year's MOA poster.* through education, fundraisers or just hanging up this poster at a public venue will spread the word! **We are all a part of progress!**

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
CREATED A FUNDRAISING PAGE
CHECKED OUT THE CRUISE

See you July 18, 2019!

LET'S COMMUNICATE!

It's always a good idea to make sure we are communicating well and utilizing the best sources of communication. Please take 4 minutes or less to take the SWF Communication Survey. It's important to hear from you about our method and style of communication!

COMMUNICATE!

THANK YOU DR. ALSTER & CHRISTIAN DIOR

A **big thank you** to Dr. Tina Alster for hosting a special fundraising event at Christian Dior in Washington, D.C.,
during the American Academy of Dermatology's Annual Meeting in March. **A total of $19,212.00 was raised during the 2 hour event!**

CONGRATULATIONS TO KAREN BALL!

Join us in congratulating Karen for being invited to serve on the National Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Advisory Council for 3 years! Karen, along with other council members, will advise, assist, consult with and make recommendations to the Secretary of Health and Human Services and the Director of NIAMS, on matters related to the activities carried out by and through NIAMS and the policies respecting these activities. This includes review of grants, research, training and projects which show promise of making valuable contributions to the general public.

STORIES FROM THE SWF FAMILY

DAD'S CRY TOO

An article by Kevin Brewbaker, father of Celine Brewbaker

When a child is born with a disability, we hear from the mothers and well, we should. In most cases, they bear the brunt of their child's disease. Not much is said about the fathers. True, there are those who choose to run, or to just turn their backs and not get involved. I don't consider them men. However, there are real men who are there constantly and fight for their child everyday. This article is for them.

When my child was born, I held it together for my family in their presence, when I was alone though, I cried.

As I watched countless doctors prod and poke, then deliver the news, I held my wife tightly as I cried inside.

Read More

RESIDENTIAL OPTIONS - PART 2

We always say that each SWS case is different. There are so many aspects of the diagnosis, the symptoms, the presentation of the birth mark, the neurology medications that work and those that do not, the person's cognitive status. And the unexpected progress that each individual person, no matter how young or the degree of disability, has made.

Family stories are no different. Although there will be similarities that may emerge, the outcomes of each family's decisions will be varied. One common thread that shows up is that each family can successfully make use of what they already have. You cannot create an ideal future life for your child, because it just won't fit the circumstances or the personality and temperament of the child.

Read Full Article

#swfdonniesjourney

Donnie Hood's journey culminated on April 27th at the Mallorca 321 in Spain. He has

been training for months and dedicating this journey to raising funds for SWS.

Let's continue to give a "shout out" to Donnie for this amazing endeavor at #swfdonniesjourney!

If you would like to make a donation, click the donate button!

Donnie's Journey

FALMOUTH 2019: 10 YEARS!

Ten years ago, Team SWF took its first position at the starting block with the Falmouth Road Race. Warrior Mom's Pam McIntyre and Jessica Melo, our team leaders, have lead TeamSWF to celebrate its 10th year of participation and fundraising with this race.

This year there will be 75 participating runners in the Falmouth Road Race! **WHAT AN IMPACT THEY WILL MAKE!** Stay tuned for details as TeamSWF prepared for this momentous occasion!

FALMOUTH 2019

THE STURGE-WEBER FOUNDATION
10
ROOTS TO A CURE®

10 Years STRONG!

GET CONNECTED

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

believe

Believe in progress!