



On Your Mark, Get Set . . . Falmouth Road Race, August 19, 2019

This is the 9th year a team of runners has represented the Sturge-Weber Foundation in this renowned road race. Each year our team has grown, starting with only 5 runners the very first year. Over \$595,000 has been raised by the runners to date. Once again, Pam McIntyre and Jessica Melo, two champions of the SWF and mothers of sons with SWS, will be leading and motivating the team of runners. We are so grateful for the continued enthusiasm and support of these two women!



Please join us in a big "THANK YOU" to the following runners:

9 Years - Pam McIntyre, Jessica Melo; 7 Years - Chris Marino; 6 Years - Michelle O'Connor, Octavio Melo, Jonathan Desmaris; 5 Years - Nancy Carpenter, Kate Sanders; Year 4 - Erin Kelley, Brent Crouch, Mike Collins, Julie Brady, Woody Crouch; Year 3 - Peter Sullivan, Carol DiPietro, Melanie Arena, Kim Auen, Mark Banks, Olivia Melo, Trish Bourne; Year 2 - Lisa Ballantyne, Alicia Fannon, Kym Fischer, Kate Tiberio, Dan McIntyre, Courtney Mello; Newcomers - Kellie Sadens, Kate Schultz, Jen Pagliuca, Mark Fischer, Graham Ballantyne, Chris Wicken, Jason Cafarella, Jasmin Khamis, Will Carpenter, Josh Reed, Bianca Pyko, Ashley Reed, Paul Grew, Jameson Melo, Ben Bourne, Natalie Bourne, Kelli Ozdemir, J.P. Williams.

[TO DONATE](#)

A SUCCESSFUL DAY OF ADVOCATING ON THE HILL

Marissa Terrell together with her family, The Sturge Weber Foundation, The American Academy of Dermatology Association (AADA) and Coalition of Skin Disease (CSD) set out to Washington DC to advocate on the Hill. This past year in school Marissa learned about the Federal Government, The Branches of the Government and what their responsibilities entail. It was a bit unclear for Marissa as to who does what and where in the government. On July 17th, Marissa and her family got up early boarded a bus and headed to Capitol Hill.

[READ MORE . . .](#)

TEAM BRIELLE, RHODE ISLAND, GOES TO WASHINGTON D.C.



On July 14th part of Team Brielle RI headed to Washington DC with the Sturge-Weber Foundation, CSD (Coalition for Skin Disease) and AADA (America Academy of Dermatology Association) to advocate on Capitol Hill. Brielle's grandmother Annette and grandfather Joel were invited to join other members from SWF to spread awareness of Sturge-Weber Syndrome and to bring awareness of the ever-increasing costs of medications and the lengthy time it takes to get prior authorizations for medications and other medical needs.



[READ MORE . . .](#)

SWF EDUCATION CONFERENCES ACROSS THE COUNTRY!

October 20, 8:00 AM - 12:00 PM, Cook Children's Hospital, Ft. Worth, TX

October 27, 8:00 AM - 2:30 PM, University of California, Irvine, CA - details coming soon

November 10, University of North Carolina, Chapel Hill, NC - details coming soon

RECAP: Nemours duPont Education Conference

On July 14th The Sturge Weber Foundation (SWF) co-hosted an Education Conference at Nemours duPont in Wilmington, Delaware! There were 15 people in attendance.

We began the day with Karen Ball and Carol Greene-Roethke from Nemours duPont welcoming the families. The Nemours duPont team talked about Glaucoma, Behavior Management and Nutrition. Dr. Chugani and Dr. Sperling talked about neurology and the transition into adulthood respectively.



We finished out the day with lunch and time to get to know each other. One great take away from the conference was Dr. Sperling explaining the importance of coming prepared to appointments especially from the beginning. The day was full of topics for everyone and very well rounded! Nice job from our Clinical Care Network Nemours duPont. We hope to see you in California and Texas in October.



THE STURGE-WEBER FOUNDATION
CLINICAL CARE
NETWORK

**2018 ANNUAL
CONFERENCE**

SEPTEMBER 20-22

Nemours duPont
Hospital for Children
Wilmington, DE

SAVE THE DATE!

Start planning now to attend this conference with other CCN professionals to review 2017-2018 conference initiatives and set goals for 2018-2019.

One member from each CCN is required to attend the 2018 conference.

Please submit attendee name and contact information by July 27 to Brian Fisher,
bfisher@sturge-weber.org.



WHAT'S COMING UP . . .

August 19th - TeamSWF at Falmouth Road Race 2018

September 21-22 - Clinical Care Network Conference,
Nemours DuPont, Wilmington, DE

September 24 - September/October Branching Out Release

October 27-30 - American Academy of Ophthalmology
Conference, Chicago, IL



WE ARE BETTER TOGETHER. SUPPORT!

STAY CONNECTED:

SWF CONNECTION by INSPIRE



A COPY OF THE STURGE-WEBER FOUNDATION'S OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE TEXAS DEPARTMENT OF CONSUMER AFFAIRS BY CALLING 214-969-7639 (www.texasattorneygeneral.gov) WITHIN THE STATE OF TEXAS. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE OF TEXAS.