



# The Sturge-Weber Foundation

Here for a reason,  
a season,  
a lifetime.

AUGUST 2019 | Edition 3, Issue 6

## 2019 Falmouth Road Race Recap: Epic Outcome

# YOU. ARE. AMAZING!

2019 Falmouth Road Race | 10 Years of Faithful Support



**10 YEARS =  
\$1.02 MILLION!**

The 10th TeamSWF Falmouth Road Race occurred on Sunday, August 18th with an epic outcome. Check this out:

1. 79 runners participated in the 2019 race
2. \$286,470 raised (as of August 23rd)
3. 2,306 individual donors (as of August 23rd)
4. 124.23 average donation
5. Over \$1 million dollars raised in 10 years

We thank the team captains, Pam McIntyre and Jessica Melo, the 79 participants and 2,306 donors for their support. Many of these 79 participants have supported our efforts for 2, 5 and all 10 years. **THANK YOU!** The donations from this event will go towards continuing research, assisting newly diagnosed patients, as well as existing



families find the specialized treatment they need.

## CHECK OUT KAREN BALL'S LATEST BLOG, "THEY SAID!"

### CALENDAR OF EVENTS

#### September

7th: American Academy of Dermatology Advocacy Conference

19th-21st: Annual SWF Clinical Care Network Conference Chicago, IL

#### October

8th: Education Day Conference

UIC Health | Chicago, IL



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

2019 ANNUAL CONFERENCE

SEPTEMBER 19-21, 2019  
**UI HEALTH**  
Chicago, IL

**SAVE THE DATE!**  
Start planning now to attend this conference with other CCN professionals to review 2018-2019 conference initiatives and set goals for 2019-2020.

One member from each CCN is required to attend the 2019 conference.

DETAILS and REGISTRATION coming soon via email.  
QUESTIONS?  
Julia Terrell  
jterrell@sturge-weber.org

UI Health

### Pregnancy and Childbirth Survey

The SWF has never done a formal survey that asks our members to share information about their pregnancy and childbirth experiences. But here is a new opportunity to participate in the knowledge base that all can benefit from.

If you are a woman who has SWS or PWB and you have had a successful pregnancy and childbirth, no matter how recent or long ago it was, please take this survey. It will provide important information and may give some young adults the confidence that they can have a successful life experience.

If you are the parent of a young woman who has SWS or PWB, please share this notice with her.

## Calling All CCN Professionals

2019 Clinical Care Network Conference  
September 19-21  
UI Health | Chicago, IL

Registration is now open for our 3rd CCN Conference.  
**REGISTER TODAY!**

**REGISTER**

### How we connect

The recent Growing Golden article in Branching Out by Ann Nehrbauser about her family's experience has acted like a pebble in a pond – sending off ripples.

One bit of updated information is from Linda Cohen, mom of Marco and his brother Roberto. She shared a photo of Marco at his school's prom, and one of Roberto, who will be going to UChicago and taking his cello with him.

Linda reports that she recently was at Willowbrook which has



The survey can be found at [https://ohio.qualtrics.com/jfe/form/SV\\_9mBz46FbUwCjJR3](https://ohio.qualtrics.com/jfe/form/SV_9mBz46FbUwCjJR3)

We thank Stephanie Tikkanen, the aunt of Jayden Findlater and a professor at the School of Communication Studies at Ohio University, for developing our questions into a useful survey. Also Rebecca Szorcsik and Michelle Daoust, for their help in asking the right questions. Dr. Anna Sarafina of U of IL in Chicago provided information on seizure medications during pregnancy.

been re-purposed for educational seminars and workshops. Her words say it best.

I almost started crying after I read Ann Nehrbauer's story of her son Stephen in the last issue. I visited Willowbrook for 5 days of training in Self Direction for Marco recently and it has been repurposed and reclaimed but watching the videos of the past was hard. But then again, you realize how resilient the human spirit can be. We also heard from people who lived through all that - like Stephen - and now live independently and are happy. Thanks to all those at Willowbrook who advocated for their rights, our kids now have other choices like Self Direction and the HCBS waiver.

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## Tissue Donation

An always important and needed activity all families can participate in is the SWF Tissue Donation program. Scientists need human tissue when they delve into finding out the how and why of SWS and PWB, and, as important as animal models and computer projections are, there is no substitute for human bodily tissue.

It could be cells from a recent lip reduction, or dental procedure. Or, on the extremely serious end, tissue from a hemispherectomy. The SWF works with the Maryland Brain and Tissue Bank to help secure this valuable resource.

Their office procures the tissue from the hospital and keeps it in a repository. The donor's family do not have to do anything except notify the Bank of an upcoming (or emergent) surgery. But before that, the family can register with the Bank so that their information will be already on file. No need to fill out forms when you have enough stress because of a coming surgery.

You can get the forms needed from the SWF and send them to the Maryland Brain Bank. Contact Julia Terrell at [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org) to get them and ask her any questions.

## Thoughts from the Yahoo Group (sturgewebersupport)

Questions came from a SWF family in Canada, replies came from Canada, Israel, Europe, Montana and Illinois.



YAHOO!

The Yahoo! logo is displayed in white, bold, sans-serif capital letters against a solid purple rectangular background.

### Sam Dalton says: Looking for your advice on something.

Gabriel has an upcoming appointment in Montreal. (Plane ride away). Our trips are very short and we don't have much free time. I always make sure the day of his surgery we get to the mall and buy a little gift. The hospital is asking if we would like to see the cranio-facial department while were there. This would mean much longer time at the hospital and perhaps a very short trip to the mall. Although I like them being thorough, I'm wondering if it may be a waste of time. We don't ever plan to put him through that kind of surgery.

However, if any of you have had a procedure done or any of your loved ones have had it done, can you please share if it would be worthwhile/beneficial. If we thought it would benefit him, we would certainly



consider, just kind of scares us thinking about putting him through that type of thing

**Sasa Vujacic says:**

We were to cranio-facial and plastic surgery departments as we were told that we cannot solve Elena's problem with bite with braces. Orthodontists suggested jaw surgery. We did X ray and scan of her jaws and got an opinion. Actually, they helped us learn that she doesn't have to go through such a radical surgery but can wear braces. Then we searched more and found an orthodontist who can do it, although all the big names from orthodontics in our region told us it was impossible...

**Ian Hubling adds:**

My advice is that each person is different. Only you (as parent), your child and the surgeon can answer that. My suggestion is to hear what they have to say. We declined several procedures when our son was young - but we always understood all of the information first.

**Cindy B says:**

No advice on the doctors...definitely each child is quite unique. Our cranio-facial team always looked at many things... like one eye sits farther forward than the other and explains some of the visual issues he has.... nothing we can do about it surgically with today's technology, but it sure helps on accommodating.

But on the toy! Can you pick one out now and hide it in the suitcase? Maybe something a little extra special this once?

**Donna T adds:**

Not quite sure what your cranio-facial team looks at. For us it was a useful visit because they recognized some dental issues that were taking place and referred us to an orthodontist with experience with the overgrowth. Catching and correcting it now (started age 7) should prevent surgical needs in the future.

It was helpful information for us. I like Cyndi's idea of packing a special toy for this round.

**Keren S:**

I am wondering what kind of orthodontic work can be done to prevent overgrowth. My daughter is 10 and she has a tooth that grew in before the baby tooth grew in. It is not situated in the right place now. The orthodontist gave her a bite plate now. The orthodontist is not experienced with the condition. I am wondering if there is any draw back in wearing the bite plate. I would like to hear other people's experience with orthodontics.

## GET CONNECTED

- [CONNECT WITH KAREN](#)
- [SWF ONLINE STORE](#)
- [BRANCHING OUT MAIL LIST](#)



**Believe in progress!**

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Connect with us

