

FEBRUARY 26, 2019 | Edition 3, Issue 2



# 2019 SWF INTERNATIONAL FAMILY CONFERENCE

It's official! Registration now open for the 2019 SWF International Family Conference!

Details & Registration

### **RESEARCH UPDATES**

## CCNs to Be Involved in Research with Dr. Marchuk

Douglas A Marchuk, PhD, Duke University, Department of Molecular Genetics and Microbiology is proposing a research project utilizing blood plasma from SWS patients. More information coming soon as we receive word on which

### **SWF SPECIAL EVENT**

2019 Reunion of Champions in Washington D.C.

#### **FOUNDATION NEWS**

## After the Diagnosis: What's Your Plan?



On Wednesday, February 20th, SWF hosted a webinar on the Inspire Sturge-Weber Community Social Platform. If you missed the webinar, you can still reap some benefit by visiting the website where the presentation and helpful resources are located.

Here's the Plan



Each year the SWF attends the American Academy of Dermatology's Annual Meeting to build awareness for SWS and PWB conditions. For the 17th year in a row, SWF will host the Reunion of Champions honoring Dieter Manstein, M.D., Ph.D. and Kristen Kelly, M.D. on Friday, March 1st in Washington D.C.

This is one of the Foundation's largest fundraisers with the Richard Felten Fellowship Award being a major push this year to support new research!

A full report will be made in the March/April Branching Out Magazine.



### MONTH OF AWARENESS

May is Month of Awareness for SWS! Next month MOA posters will be mailed with the March/April Branching Out, along with ideas to spread awareness through education, fundraisers or just by hanging up a poster at a public venue! We are all a part of progress!

#### LEND US YOUR THOUGHTS

Please lend us your thoughts on the Pros and Cons of things you wrestled with on your child's life journey. No one has to start this journey alone - we all build on what other families have experienced and generously shared with the SWF. Please share your thoughts - it doesn't need to be an essay, just a friendly memo on what your chief decision-making ideas were when you began the next leg of the journey. Please email your comments to Anne Howard, ahoward@sturge-weber.org.



Summer strikes a pose for the CHA 2019/2020 Photo Exhibit.

# SWF MEMBER UPDATES Summer Smiles

Summer Andrews was chosen to be included in the Children's Hospital Association photo exhibit for 2019/2020. She was chosen along with 49 others out of 370 submissions from the hospital's marketing team. Along with her photo will be a brief bio on her diagnosis and struggles.

GREAT NEWS Andrew's family!

### **GET CONNECTED**

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



Believe in progress!

Connect with us







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