

# All together now . . .



JULY 31, 2019 | Edition 3, Issue 5



2019 SWF International  
Family Conference

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



## 2019 SWF International Family Conference

The 2019 SWF International Family Conference has come and gone, but left a lasting impression of community on all that attended. Over the next few weeks, we will be reviewing surveys from attendees at the conference, and will provide a full report with pictures from the conference in the September/October SWF Branching Out. Thanks to everyone for making this event **AMAZING!**

### CALENDAR OF EVENTS

#### August

18th: Falmouth Road Race

#### September

7th: American Academy of Dermatology Advocacy Conference

#### October

8th: Education Day Conference  
UIC Health | Chicago, IL

### Chat on Yahoo

Before the popularity and presence of Facebook, Instagram, Twitter and other social media platforms, in 2000,



the SWF started the sturgewebersupport chat group on Yahoo Groups. It was the first easy access group for our members and we soon had well over 700 members who joined. For several years it was the only group our members could use to communicate with each other to ask questions about their SWS concerns, get support and ideas, and reach out to other families.

The group is still here and active – though not as busy as it once was. Many adult SWF members still use it to find suggestions on medical and non-medical concerns, and to just keep connected – sometimes at great length.

### Is there a Connection?

A question arose if there is a connection between SWS and any auto-immune disease

The posts are not limited to short chatty nuggets – there is no word or character limit. It is a private group and your concerns will not be broadcast to a universe. Karen, Julia and Anne get the postings and are ready to step in with helpful

such as MS or rheumatoid arthritis or lupus. Many of our adult members also have conditions that are present in the general population and wonder if there is a pre-disposition or tendency because of their SWS.

Dr. Jeffrey Loeb reassures us that "a somatic mutation in the brain/skin/eye is unlikely to affect the immune system".

So, disorders such as MS or RA can be present in persons with SWS just the same as in the whole adult population and SWS has nothing to do with causing it. (but it sure adds to the list of things we have to worry about, doesn't it?)



## 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**

*Please Note: Each CCN must have one participant at the conference to represent each CCN institution.*

replies.

If you have been in the Yahoo Group, please be alert in your "In" box to see if any messages come there. You can reply to the group or to the message with a click. We would love to hear from you – adult to adult – and be able to give voice to your concerns and suggestions.

## Sad News

We were saddened to learn of the death of Cyprian Sanders of Atlanta, GA who died in an auto accident in mid-July. We send our sincere sympathy to his mother, Kathleen Cosper Sanders and his sister and father. Cyprian was 25 years old.



## Agging-Up

Is there such a word?

If you have a diagnosis of SWS/PWB and are now 18 or older and your parents or guardian joined the SWF when you were a child, do you want to become a registered SWF member on your own?



That way, if we have your current contact information (email, phone, postal address) you will become informed of all SWF activities, invited to meetings and conferences, and to participate in patient-oriented programs geared to young adults. You will also receive your own monthly E-news and links to, or print copies of, Branching Out, whether you live with your family or independently.

And more important, you will be able to give consent for the SWF Registry, ask questions about your own medical concerns, and give the SWF consent to update your medical data that we record periodically. All this was previously consented to, by your parents. Our Tissue Donation program also needs current

willing participants – if you anticipate any surgery, whether serious or routine you can become a tissue donor. You can register and give consent and the medical tissue bank takes over the details when notified of any surgery.

Let us know by emailing Julia Terrell, at [jterrell@sturge-weber.org](mailto:jterrell@sturge-weber.org).

## GET CONNECTED

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



Believe in progress!

The Sturge-Weber Foundation  
973-895-4445  
[swf@sturge-weber.org](mailto:swf@sturge-weber.org)  
[www.sturge-weber.org](http://www.sturge-weber.org)

Connect with us

