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### RECAP: 2018 CCN CONFERENCE IN WILMINGTON, DE

Thursday, September 20-Saturday, September 22, SWF held its annual Clinical Care Network (CCN) Conference at Nemours Alfred I. duPont Hospital for Children, Wilmington, DE. Led by Dr. Jeffrey Loeb, M.D., Ph.D., SWF Clinical Scientific Strategist, medical professionals from various CCN Centers came together to review and discuss treatments and research advancements for SWS patients in dermatology, neurology, ophthalmology and pathology. Details on the meeting will be provided in the next eNews and Branching Out. Stay Tuned!



### BONE HEALTH AWARENESS

*Dr. Jeffrey Loeb, M.D., Ph.D., Neurology | SWF Clinical Scientific Strategist*

All adults should be aware of the health of their bones, but adults who are on anti-seizure medications and have frequent seizures that can induce bone fractures should pay close attention.

We have reports of many SWF members experiencing falls or fractures or being at risk for falls. Often adults with SWS are diagnosed with osteopenia or osteoporosis (a thinning of the bones) which is understandable, since it is a typical aging symptom.

Starting in their 30's, young adults who are on anti-seizure medications can have a DEXA bone density scan to establish a baseline for the future. If abnormal, adjustments can be made and then yearly or more frequent tests could be used to follow. While drugs for gastric problems and high blood pressure may also have an effect on bone density, anti-seizure meds, especially older drugs that have been used for several years, have been shown to carry some risks, particularly if used at high dosages.



Since it depends on the specific medication being used, ask your neurologist what the risk

factors are for yours. **Bottom line - pay attention to your bones. Vitamin D and Calcium** should be a part of your diet, but supplements should be used only after consultation with your physicians.

## GROWING GOLDEN

In an effort to keep pace with our SWF population, we hope to hear from our adults on a regular basis. If you are an adult who has lived and dealt with SWS over time, or if you are the parents of an adult with SWS who is over 40, we invite you to participate and be counted.

We want to hear your concerns about typical aging issues like changes in eyesight, hypertension, weight issues, arthritis and joint pain, diabetes, change of life, emotional ups and downs, skins changes. While many of these may have nothing to do with SWS, some do, and some are impacted by medications you may be taking for SWS related conditions.

We also want to be able to devise a check list of things to anticipate as time marches on.

Your concerns and ideas will be listened to. We now have a Task Force on adult issues and we have a growing list of clinicians who are familiar with treating adults. And don't think you have to just give us the problems. We like to hear about the good things too.

You can email me at [ahoward@sturge-weber.org](mailto:ahoward@sturge-weber.org) and I will see that the Task Force members are in the loop.



## 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  
TO REGISTER, CLICK HERE

**November 10**, University of North Carolina, Chapel Hill, NC  
*Details coming soon*



## REMINDER TO OUR GENEROUS DONORS

Many SWF donors use their banks or employers to send us monthly or periodic donations. These are much appreciated and are efficient ways to keep a steady donation stream coming to the SWF.

However, since the SWF office moved October 2016, the address for donations may not have been updated. If you make donations this way - via bank or employment draft - please notify them of the correct mailing address:

**The Sturge-Weber Foundation**  
**12345 Jones Road, Suite 125**  
**Houston, TX 77070-4958**

Thank you for your continued support!



## GIFT MATCHING GOLD MINE

Every dollar that SWF receives from its donors is a gift of dynamic support and impact for patients and families. Did you know that your dollars can be even more dynamic through Company Gift Matching Programs?

Company Gift Matching is a program that some employers offer to their employees for charitable donations. When you make a donation and report it to your employer through their matching gift program, they will also make a contribution based on a certain percentage of your donation, some even donate 1:1. That's it, no strings attached. This makes your dollars go even further.



To find out more about Company Gift Matching Programs, contact your Human Resources department and ask them if they have a program and how to sign up. If not, maybe you can get one started!

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**THE  
STURGE-WEBER FOUNDATION**

*16th International*  
**FAMILY CONFERENCE**

Nemours/Alfred I. duPont Hospital for Children | Wilmington, DE

**SAVE THE DATE! JULY 18-21, 2019**  
*Detailed information and online registration coming soon.*

### WHAT'S COMING UP ...

**October 16-18** - Child Neurology Society Annual Meeting, Chicago, IL

**October 20** - SWF Ed Conference, Cook Children's Hospital, Ft. Worth, TX

**October 27** - SWF Ed Conference, University of California, Irvine, CA

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

**November 10** - SWF Ed Conference, SWF Ed Conference, University of North Carolina, Chapel Hill, NC



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