

BE YOUNIQUE



THE STURGE-WEBER FOUNDATION OCTOBER 2019 | Edition 3, Issue

7

Growing Golden: Nugget #1

This is the time of year when we remind you to get those flu shots. Also on your to-do list might be a medical ID bracelet or necklace - not the kind that alerts the local system that you have fallen and can't get up, but the kind that lists your medical conditions. EMTs and ER staff usually know to look for these along with pertinent ID cards in your wallet or handbag. This gives info on seizures, medications and physical things like facial birthmark or prosthetic eyes.

There are many kinds of IDs available commercially - you can ask your local pharmacist or your primary doctor for ideas. The choices you find on-line can be a starting place. Any Golden SWF member who has one and can suggest details is welcome to contact me, ahoward@sturge-weber.org and I will pass the info along.

RECAP: 2019 Clinical Care Network Conference

Friday, September 20 through Saturday, September 21, SWF held its annual CCN Conference in

Chicago, IL. The conference was held at UI Health, Chicago, with Dr. Jeffrey Loeb, SWF Chief Clinical Strategist as the facilitator. There were 25 professionals physically present, with over a dozen other professionals attending through the internet.



It was an intense two days of discussion on all areas - dermatology, neurology and ophthalmology. There was also a special discussion on mental health and SWS presented by Dr. Miller Shivers. The topics of discussion were:

- Transition of Care and creating a task force to build a consensus for each specialty
- The development of "my health passport" specific for SWS that is portable and easily updated
- The need to cultivate an adult healthcare workforce that is able to provide information during transition
- Transition of Care Guidelines
- SWF Tissue Banking
- Clinical Trials

A more detailed article about the conference will be in the December/January Branching Out Magazine.

**SWS Homeschoolers:
We Want to Hear From**



You

Who among our SWF families are home schoolers? Is it because of your child's disability? How do you access other services like therapy through the school district? Is your state or district easy to get along with, or did you have challenges getting started?



What device do you use? What apps? Send us your comments - ahoward@sturge-weber.org.

In Loving Memory

Mary M. Gilbert, age 69, passed away on Saturday, October 5, 2019. She is the mother of our SWF colleague, Julia Terrell, and grandmother to Marissa. Before her retirement, she had been a medical technician. Her love and devotion to her three grandchildren were an important part of her life and she gave generously in supporting Marissa's parents and the SWF through awareness activities.

Our condolences go to Julia, Scott and Marissa. She leaves a wonderful legacy as a grandmother.

CHECK IT OUT!

Interesting Article on *Neurological Complications of Sturge-Weber Syndrome: Current Status and Unmet Needs*



CHECK IT OUT

PLEASE
SHARE YOUR
PHOTOS ON
THE SWF
FACEBOOK
PAGE!



'Tis the Season!

It is difficult to believe that Christmas is just two months away! When you begin to make your gift shopping list, please consider going through Amazon Smile for your online orders! Amazon Smile gives a percentage of your purchases to charitable organizations, and SWF is a part of their program. **To date, SWF has received \$3,797.95 in donations from Amazon Smile just within this year! Thank you so much! Let's keep the momentum up!**

amazonsmile
You shop. Amazon gives.

Just recently, Amazon Smile added support for Android devices to their Amazon Shopping App. Now Android users can load the latest version of the Amazon Shopping App and select Amazon Smile for their purchases. (go to settings in the app, select Amazon Smile and follow the in-App instructions).

No matter how big or small the purchase is, SWF will receive a donation from your purchases, it's that easy!

Cranio-Facial Department Recognizes Dental Issues

Isn't it interesting how one thought leads to another and that blossoms into a whole bouquet of queries and ideas? Back in August we shared a question about the benefit of having your child seen by the cranio-facial department of your hospital.



Among the responses then was the opinion that it was useful for their family because the team recognized some dental issues and recommended an orthodontist to prevent future concerns.

The next question to emerge was "what kind of orthodontic work can be done to prevent tooth overgrowth". The child had a tooth that grew in before the baby tooth grew out and is not situated in the right place. The consulting orthodontist, who was not experienced with SWS, prescribed a bite plate for now. These questions and concerns are from parents of 8, 9 and 10 year old children. In response to this concern, a mom of a 9 year old girl shared this:

As far as the cranio-facial team goes, we have been seeing them one every 2 years or so for the past 8 years. There is nothing they can do for her surgically because they have to wait until she is fully developed as an adult. We have been using the Invisalign treatment to straighten her severe overbite and crooked teeth. We have been using muscle treatment – having her chew less on her PWS side – to strengthen her other side, so it will help with facial asymmetry. Her orthodontist will do at least two rounds of Invisalign treatment in hopes that it will decrease the severity of the jaw surgery later on.

Invisalign is advertised on TV as an orthotics treatment, as well as in dental offices. It is different from metal braces, but still realigns the teeth.

The experienced mom adds this: *Invisalign uses a series of plastic trays that are molded to her teeth to slowly pull her teeth into place. It is a lot less painful and easier to clean than metal braces. It does require the child to have some adult teeth as anchors.*

Don't do the online or TV advertised Invisalign program – it is a lot cheaper than an office setting but the hands-on care and close attention make a huge difference especially for kids. They are still losing baby teeth and learning about being responsible. My daughter had to have many visits to the orthodontist to fix broken or lost trays. She started when she was 7.

Her orthodontist told us upfront that Invisalign will only fix her misaligned teeth, not her jaws. Only jaw surgery can fix that but it cannot be done until she is done growing.

(Please note: as always, the SWF advises you to consult with your dentist or orthodontist. We encourage you to share your experiences with other families, but this is not something you can undertake without the care and guidance of a professional.)

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- SWF ONLINE STORE



- BRANCHING OUT MAIL LIST

Believe in progress!

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