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JUNE IS MIGRAINE AWARENESS MONTH

Dr. Dave Shahani, Neurologist and Epileptologist at Cook Children's Hospital, Fort Worth, TX, provides some important information on what to watch for with SWS migraines.

"Migraines in SWS can be quite painful and are not typical migraines, but rather migraine-like headaches that can be associated with a progression of symptoms."

Things to watch for include:

1. Depending on the location of leptomeningeal angioma, watch for transient one-sided weakness, a transient visual change or preference to one side, transient confusion, or any sudden onset of neurologic symptoms.

2. Poor sleep

3. Dehydration (very critical during the summer)

4. Light or sound sensitivity

5. Unilateral throbbing of pain



The American Headache Society and the American Migraine Foundation can provide a good basic education on the causes and the most recent advances in treatment and therapy. Their websites are reliable and reader-friendly.

Always remember to consult your neurologist, who knows your specific situation better than any website you find, for what would be the appropriate course of action.

Another resource we have mentioned frequently is the magazine **Brain and Life**, a publication of the American Academy of Neurology that you often see in doctor's waiting rooms. It is a print publication that can be sent **free** to any individual requesting it. It is also available on-line.

Each month has articles explaining and enlarging on different neuro syndromes and disorders in non-technical language with additional material that provides specifics. The articles also give many real-life examples of people living with these, including articles on various aspects of seizure disorders.

Each issue highlights a well-known personality - TV, movies, music, sports – people you may have thought were talented and privileged and beyond reach of medical problems. Then you find out that they have, or care for someone who has, a neuro condition.

Go to BrainandLife.org for more information and to sign up for a subscription.



CHILD VISION AWARENESS MONTH

June is also **Child Vision Awareness** month. If you search "Child Vision Awareness" on-line you will find many links to valuable information. One of the main reasons to have an exam for a baby or young child is that children with vision deficits and problems do not know they are experiencing them and cannot express it.

Our SWF consultant Dr. Alex Levin has shared with us some important things to keep in mind especially for children with

SWS.

1. Children should have their vision/eyes screened by their pediatrician at every well child

2. Pay attention to your child's eyes: holding things too close, complaints about vision, or eyes that look different than normal should prompt a visit to the eye doctor
3. Early signs of glaucoma in the first few years of life include bigger eyes, cloudy eyes, sensitivity to light and tearing
4. Even if the eyes look normal, children with Sturge-Weber need regular eye examinations to screen for glaucoma
5. If drops are prescribed for glaucoma make sure you follow the instructions of the doctor and report any concerns or deviations from the prescribed regimen

Alex V. Levin, MD, MHSc, FRCSC

Chief, Pediatric Ophthalmology and Ocular Genetics

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MAJOR MILESTONE!

Jean Schneider of New York has been an active member and supporter of the Sturge-Weber Foundation since 2011, often encouraging her family and friends to become donors. This is a letter she recently sent to her "Dear Friends" email list, which brought successful results. She has asked us to share this letter with our membership. It can be adapted by anyone to suit your circumstances. You will be able to personalize the information any way you want. The sentiment and encouraging fundraising message can benefit us all.



Dear Friends,

It is very hard for me to believe, but in a few days I am having a milestone Birthday. At this stage of life, I am focused on doing something significant to help others, and so, rather than receiving cards, flowers, balloons, cake, etc., I would like to use this occasion to raise money for the Sturge-Weber Foundation.

As many of you know, my granddaughter was born with a rare disorder called Sturge-Weber syndrome. She required immediate care. This condition is so rare that she needed to come to New York when she was six weeks old for more procedures and treatment.

When I returned home after having been away for her birth, the Sturge Weber Foundation "saved me". It provided the support of caring souls to listen to my fears and tears, to provide information about the disorder and resources. They provided a chance to contact other mothers and grandmothers whose children were living with this disorder. Talking to others gave me perspective and increased my fund of knowledge as I also did my own research in the medical journals.

The Sturge Weber Foundation provides social media and group emails for questions, comments, as well as sharing experiences and suggestions about what to do when your child is hospitalized. You get ideas on how to handle the problems that arise with children with this syndrome.

The medical profession is generally not experienced or savvy in dealing with the complex symptomatology youngsters with Sturge-Weber present. The Foundation helps support basic

research in search of a cause of Sturge-Weber and develop treatments for this life long, rare syndrome. As I have received help and support, I have also helped many other parents and grandparents as they confront the challenges of having a child with this syndrome.

Beginning in 2011, I provided ongoing support, housing and care for a 6-week-old baby boy from Costa Rica as he needed treatment on a monthly basis in New York. I had met his mother in the waiting room of a dermatologist's office. He and my granddaughter have the same syndrome. He is now 9 years old and considers me his "American grandmother."

It would be very meaningful to me if you would honor my birthday by making a donation to the Sturge Weber Foundation. The Foundation has helped me so much and I continually want to help them help others. Any amount you would like to send is very much appreciated.

Contact www.sturge-weber.org to make a donation online or you can phone 973-895-4445 Thank you and may we all stay safe and healthy.



CONGRATULATIONS!

Makayla Vaquilar has graduated from 8th grade this year! Our hope is that High School will be full of more opportunities and success! Way to go!



SENIOR 2020!

Congratulations to Jeremy Huston, 2020 Senior graduate! We are so proud of you! May your future dreams all come true!



PLEASE WELCOME DEBBIE LONERGAN!

Join us in welcoming Debbie Lonergan to the SWF staff! Debbie fills the position of Office Manager. She has worked with the Foundation before while the home office was located in New Jersey. She will be organizing staff projects and tasks to meet everyday deadlines along with other administrative duties. Debbie has her own business as a "Virtual Assistant" and has worked in many different industries over the last eighteen years in positions varying from sales assistant to office and HR manager. The industries she worked in were varied, and each added unique skills to her repertoire of experience.

"I have enjoyed learning through my various opportunities and every one offered me new opportunities to sharpen my already strong organization and time management skills; further

develop an attention to detail that I come by naturally, and put into practice my ability to multi-task and meet deadlines."

We welcome you Debbie and are so glad you are a part of the SWF team!



SWF FAMILY SUMMER GAME NIGHTS

Family game nights are 6-7 PM Central (Eastern - 7-8 PM; Mountain - 5-6 PM; Pacific - 4-5 PM)

Prizes for the biggest winner and biggest loser!

July 15th - Pictionary Night
August 12th - World Scramble Night

Please register for the game nights you wish to attend using the form below. Once registered, we will send you the RingCentral connection information (you will be prompted to install the RingCentral app upon connection), along with any materials you will need to play the game.

Let's Play!



SEND US YOUR "DAD" JOKES! THE GOOD AND BAD

In honor of Father's Day, SWF is compiling a montage of father's and their "Dad" jokes. Please send photos or videos with your dad telling his favorite jokes!

Submit jokes to swf@sturge-weber.org by Thursday, June 18th!!

Questions? Contact sfinnell@sturge-weber.org.



THE RESULTS ARE IN!

Join Us, July 25, 2020
Myla's Third Annual 5K Walk for Sturge-Weber Awareness
 All proceeds go to the Sturge-Weber Foundation




This year Myla's Mission 5K Walk will be held virtually! That means you can walk with Myla from near or far for Sturge-Weber Awareness!

- Sign up at <https://www.mylasmissionsws.com/>
- You choose your own safe route
- Indoors or outdoors, it doesn't matter - just walk (or run!)

With your registration, you will receive this year's Myla's Mission t-shirt. Shirts will be shipped to your mailing address. We will do our best to get them delivered before the walk, but this may not be the case if deliveries are still slow in your area.

If you decide to time yourself, please submit your time as well as pictures! Send them to mylasmissionsws@gmail.com.

Founded by Thomas and Molly Speers, for their daughter, Myla Speers.



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If you have any changes in email or primary mailing address, let us know via email: swf@sturge-weber.org

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