



Hunter Nelson
Sturge-Weber Center

Research Update 2024

Our Research

Each year, our team of experts completes novel research and tests that seek to improve outcomes for individuals with Sturge-Weber Syndrome and eliminate it for future generations. Please take a moment to view the research we've published in 2024!

1. Valery CB*, Iannotti I*, Kossoff EH, Zabel A, Cohen B, Ou Y, Pinto A**, Comi AM **. **Retrospective Analysis of Presymptomatic Treatment In Sturge-Weber Syndrome.** Ann Child Neurol Soc. January 10, 2024. **Shared senior author.
2. **Time to change our approach to presymptomatic treatment of Sturge-Weber syndrome.** Anne M Comi 1 Dev Med Child Neurol 2024 Jun 12. Online ahead of print.
3. **Longitudinal prospective study of Sturge–Weber syndrome urine angiogenic factors and neurological outcome.** Brooke Kimbrell, Kieran D. McKenney, SangEun Yeom, Isabelle Iannotti, Alyssa Day, Kelly Harmon, Alison Sebold, Lindsay Smegal, Katherine Kaplan, Cassie Daisy, Rama Aldakhlallah, Michael Taylor, Anna Pinto, Adrienne Hammill, Marsha A. Moses, Anne Comi; Annals of the Child Neurology Society, Volume 2, Issue 2. First published: June 3, 2024.
4. **R183Q GNAQ Sturge–Weber Syndrome Leptomeningeal and Cerebrovascular Developmental Mouse Model.** Solomon, Chase; McCann, Meghan; Singh, Pratibha; More Journal of Vascular Anomalies. 5(4):e099, December 2024.
5. **Paternal, Maternal, and Familial Factors as Predictors of Sturge–Weber Syndrome Neurological Outcome.** McKenney, Kieran D.; Zabel, Andrew T.; Harris, Jayda M.; More Journal of Vascular Anomalies. 5(4):e097, December 2024.

Funding a Cure

Our team continues to seek funding for drug trials for SWS. In drug development, the “preclinical phase” is a stage of research that begins before we begin testing on

individuals with SWS. It's an important step to help us determine the feasibility and safety of our proposed treatments. Our team has submitted grant applications to the National Institute of Health requesting funds for preclinical trials. We also hope to fund continued progress in new biomarker development in SWS. A biomarker is a characteristic that is measured as an indicator of responses to an exposure or intervention, such as a drug or therapy. We are hopeful that the NIH will fund this next stage of research!

SWS Clinical Services Expands to Offer Telehealth!

Our SWS Center offers vital services for individuals with SWS, including visits with Dr. Comi, and evaluations from a variety of specialists in vascular dermatology and ophthalmology. And new this year, we are pleased to share the recent expansion of our SWS clinical services to offer telehealth! Dr. Comi can now provide telehealth services in Maryland, Nevada, Minnesota, and Tennessee on her clinic days, which are currently Wednesday and Friday.

Additionally, telehealth appointments are available for in-state Maryland patients and many international patients. The SWS Center also hosts a monthly clinic for patients with SWS and medically refractory seizures with Dr. Comi and Dr. Ahmad Marashly, a pediatric epilepsy specialist at Johns Hopkins. In addition, the SWS Neurorehabilitation clinic continues, with Dr. Comi, Dr. Suskauer, Dr. Zabel and physical therapy and occupational therapy visits offered all on the same day.

Thanks to our Partners

Our work would not be possible without the generous support of many individuals and organizations. We'd like to especially acknowledge and thank the **Faneca 66 Foundation** and the **Celebrate Hope Foundation** for their generous support of SWS translational lab research. Translational lab research is the crucial bridge that converts basic research results into results that directly benefit individuals with SWS. Because of their support, we can explore the practical applications that benefit our clients.

Educational Efforts

Each year we host a symposium for people whose lives have been touched by SWS to inform patients, their friends and families, and providers about the latest progress in Sturge-Weber syndrome. The **6th annual 2024 Hunter Nelson Sturge-Weber Center Annual Virtual Sturge-Weber Family Webinar** took place on May 25, 2024 and featured speakers on the topic of early diagnosis and presymptomatic treatment in SWS. You can find these helpful topics [here](#). We hope you'll check out this valuable resource.

The annual symposium's topics vary each year and may be related to identifying and responding to symptoms, treatment options, innovations in standard of care, or other topics pertaining to Sturge-Weber syndrome. Stay tuned for more information about our 2025 symposium planned for May 2025!

Event Highlights from 2024

The SWS community includes SWS supporters from across the country! Last year, individuals and organizations of all backgrounds hosted events to raise money and awareness for SWS. Take a look at highlights from the past year—and keep an eye out for opportunities to participate in an event in 2025!



L to R: Katie Irvine, Natalie, Calvin, James and Eloise Torrance and Nanette and Bob Harford.

Calvin's Crusade 5K Walk/Run: The second annual Calvin's Crusade 5K Walk/Run for Sturge-Weber Syndrome Awareness was held in May 2024 in Pennsylvania. The event brought in more than \$24,000 for SWS research at Kennedy Krieger. Special thanks to the 150 participants, sponsors, volunteers and all who made this special event possible!



The Rooting for Rainey team hosted the 4th annual benefit for SWS 2024 in Texas. This year's event featured a silent auction and raise \$12,000 for SWS research at Kennedy Krieger. Thank you to all who made this event such a success. This family has raised a total of over \$100,000 from a variety of events that are held each year for SWS research at Kennedy Krieger!

At left, Rainey LaPrade and Coach Shane at the Rooting for Rainey Benefit Baseball Tournament.

About the Hunter Nelson Sturge-Weber Syndrome at Kennedy Krieger

Sturge-Weber Syndrome impacts thousands of individuals across the globe. The Hunter Nelson Sturge-Weber Syndrome Center at Kennedy Krieger Institute is the was founded in 2002 through the Kennedy Krieger's University Center for Excellence in Developmental Disabilities Education, Research and Service (UCEDD) collaboration with Johns Hopkins University.

This Center is dedicated to caring for patients with Sturge-Weber syndrome (SWS). Its goals are to provide:

- Comprehensive diagnostic evaluation and coordination of clinical services
- Patient, family and physician medical educational services to maximize patient function and
- Clinical and translational laboratory research aimed to improve the understanding and treatment of this disorder.
- Expert physicians and health care professionals from a variety of disciplines including: neurology, ophthalmology, dermatology, neuroradiology, rehabilitation medicine and physical, occupational, and speech and language therapy, and neuropsychology work together to provide optimal treatment to meet the needs of these patients.

Learn more about the Hunter Nelson Sturge-Weber Center by visiting our [website](#).

Support Our Work

Make your [tax-deductible donation](#) to support Kennedy Krieger's dedicated efforts to cure Sturge-Weber Syndrome.