

# The Hunter-Nelson Sturge-Weber Syndrome Center

*At the Kennedy Krieger Institute*

## Who We Are

The Hunter Nelson Sturge-Weber Center provides interdisciplinary clinical, diagnostic, and educational services to maximize patients' functioning and improve their quality of life. Since opening in 2002, our center has evaluated, studied, diagnosed, and treated hundreds of patients with Sturge-Weber syndrome. We provide comprehensive diagnostic evaluations and high-quality, coordinated clinical care. With an additional focus on clinical and translational research, we aim to improve the understanding and treatment of Sturge-Weber syndrome, not only for our patients, but for patients everywhere. In 2013, researchers at Kennedy Krieger's Hunter Nelson Sturge-Weber Center discovered the cause of Sturge-Weber syndrome and port-wine birthmarks. We now know that Sturge-Weber is caused by a DNA change in the gene, GNAQ.

## Who We Serve

Our diverse faculty of expert physicians treats patients from infancy to adulthood. The majority of our patients are infants and young children. Sturge-Weber syndrome is a multisystem disorder characterized by a facial port-wine birthmark, which manifests at birth. The disorder affects children of all races and ethnicities, and causes symptoms such as seizures, glaucoma, developmental delays, migraines, and vision problems. Because many of these symptoms do not appear immediately, children born with a port-wine birthmark should be evaluated as soon as possible.



## Our Team

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Our team is led by Anne Comi, MD, one of the world's leading experts on Sturge-Weber syndrome. Our physicians collaborate with other healthcare professionals to provide optimal interdisciplinary care for our patients. Our faculty members include specialists in:

- Neurology
- Neuropsychology
- Rehabilitative medicine
- Occupational therapy
- Ophthalmology
- Dermatology
- Neuroradiology
- Epilepsy

*"We feel so lucky to have met doctors who are so knowledgeable. The team at Kennedy Krieger gave us information and helped connect us with other families who were dealing with Sturge-Weber."*

- Brandi Shamberger, parent

## Our Treatment Approach

Our physicians focus on a three-pronged mission that includes education, research, and comprehensive clinical care. We now know that Sturge-Weber syndrome is caused by a DNA change in a gene called GNAQ, and this recent discovery brings hope for new treatments in the future. In the meantime, we offer a variety of treatments to mitigate the disorder's effects, including:

- Hydration, medications, and trigger avoidance methods to alleviate headaches
- Anti-epileptic drugs and surgical interventions to treat seizures
- Laser treatment of port-wine birthmarks to reduce their appearance and prevent progression
- Medical and surgical procedures—such as eye drops, trabeculectomy, and tube shunts—to treat glaucoma
- Occupational, physical, and speech therapy, as well as adaptive equipment and orthotic devices
- Growth hormone or thyroid hormone replacement

Patients' visits are tailored to meet their individual needs, and clinical services are coordinated accordingly, so that the most relevant diagnostic testing can be performed. Every effort is made to assist patients, their families, and referring physicians in caring for patients with Sturge-Weber syndrome by providing education about the disease.



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at Kennedy Krieger Institute

Dream. Discover. Cure.

## Our Research Initiatives

In collaboration with Dr. Comi, our researchers are pursuing groundbreaking research building upon the recent discovery, including:

- Screening of novel potential treatments in the laboratory
- Development of new biomarkers for diagnosis and monitoring of treatment response
- Assessment of treatments, therapies, & drug trials
- Laboratory research to understand gene mutations in Sturge-Weber syndrome

For more information or to schedule an appointment, please give our center a call at 443-923-9127 or 443-923-9569.

You may also reach us by email at [sturgeweber@kennedykrieger.org](mailto:sturgeweber@kennedykrieger.org). Our fax number is 443-923-9540

To reach Dr. Anne Comi, please email [comi@kennedykrieger.org](mailto:comi@kennedykrieger.org), or call 443-923-9172 (office).



You may also find more information about Sturge-Weber Syndrome as well as about the services we offer at our website at [www.kennedykrieger.org/patient-care/patient-care-centers/sturge-weber-center](http://www.kennedykrieger.org/patient-care/patient-care-centers/sturge-weber-center).



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