

# Hunter Nelson

## STURGE-WEBER CENTER

*In my mind, I am very brave. I can do anything. I fly like the wind. I am amazing. In my mind, I roar like a lion. I have lots of friends. I am 10 feet tall. In my mind, I have a lot to give. I make my Mom smile. I am never afraid. In my mind, I am always smiling. I am a champion. In my mind I am full of dreams. I win every race. In my mind, I am very brave. I can do anything. I fly like the wind.*



Hunter Nelson  
1999 - 2005

Every child is born with great potential.  
Shouldn't every child have the chance to achieve it?



Hunter Nelson Sturge-Weber Center  
at Kennedy Krieger Institute

*Dream. Discover. Cure*



## What is Sturge-Weber Syndrome?

Sturge-Weber syndrome is a multisystem disorder, usually indicated at birth by a facial port-wine birthmark and accompanied later by abnormal blood vessels on the surface of the brain or the eye. The disorder can result in seizures, mental retardation, weakness on one side of the body, epilepsy, glaucoma, developmental delays, migraines, and vision problems.

## Who is at Risk?

Children born with a port-wine birthmark on the forehead and upper eyelid area are most at risk for the syndrome, which occurs in all races and ethnicities. While the port-wine birthmark is evident at birth, the disorder's other symptoms often don't appear immediately. That's why it's important to have children evaluated as soon as possible.

Kennedy Krieger Institute provides care in accordance with all constitutional rights and without discrimination as to race, color, sex, age, national origin, religion, marital status, sexual orientation, genetic information, physical or mental disability, veteran status, or sources of payment for care. Additional safeguards include the preservation of personal dignity as well as cultural, psychosocial, spiritual, and personal values, beliefs, and preferences.

## Our Program

The Hunter Nelson Sturge-Weber Center at the Kennedy Krieger Institute is devoted to the diagnosis, treatment, and research of Sturge-Weber Syndrome. We strive to provide comprehensive diagnostic evaluation and coordination of clinical services. We also offer patients, their families, and physicians the medical and educational services needed to maximize patient function. Additionally, we conduct clinical research to improve the understanding and treatment of the disorder.

The center was founded in 2002 through Kennedy Krieger's University Center for Excellence in Developmental Disabilities in collaboration with Johns Hopkins University. Since the center's inception, we have evaluated, studied, diagnosed, and treated hundreds of patients with the disorder.

We are dedicated to ensuring that patients, families, and physicians around the world have a better understanding of Sturge-Weber syndrome, its treatment, and prevention of seizures and other complications associated with the disorder.

## Our Team

Led by Dr. Anne Comi, one of the world's leading experts in Sturge-Weber syndrome, our physicians collaborate with other healthcare professionals to provide optimal interdisciplinary care for patients. Our faculty members, who are committed to the care of our patients and research of Sturge-Weber syndrome, are specialists in the following fields:

- Neurology
- Ophthalmology
- Dermatology
- Neuroradiology
- Rehabilitative medicine
- Endocrinology
- Epilepsy
- Neuropsychology
- Psychiatry



### Who We Treat

We work with patients ranging from day-old babies to adults in their sixties. Though the average age of our patients is nine years, the majority are infants and young children.

### Our Treatment Approach

Though there is no known cause or cure for Sturge-Weber syndrome, we offer a variety of treatments to minimize the syndrome's effects, including:

- Hydration, medications, and trigger avoidance to alleviate headaches.
- Antiepileptic drugs and surgical interventions to treat seizures.
- Laser treatment of port-wine birthmarks to reduce appearance and prevent progression.
- Medical and surgical procedures — including eye drops, trabeculectomy, and tubeshunt — to treat glaucoma.
- Occupational, physical, and speech therapy, as well as adaptive equipment and orthotic devices.
- Cognitive behavioral and family therapy.
- Growth hormone or thyroid hormone replacement, when needed.

### Overview of Research Initiatives

Along with providing the latest diagnostic tests and treatments for the disorder, the Hunter Nelson Sturge-Weber Center is leading the way for groundbreaking Sturge-Weber syndrome research. Completed and ongoing research includes the following:

- Safe screening which is the quantitative electroencephalogram (EEG) approach is a noninvasive, safe way to assess brain function and is being developed as a tool to diagnose the disorder early on.
- Transcranial Doppler, this a safe, noninvasive tool looks at a patient's blood flow in the brain and eye.
- Inheritance risk factors for stroke that could guide recommended treatments.
- Prevalence and treatment of growth hormone deficiency and other hormonal disorders in patients with Sturge-Weber syndrome.
- Effect of a modified Atkins Diet for treating intractable seizures.
- DNA microarray analysis to identify genes relevant to the disorder.
- Assessment of the safety and effectiveness of low-dose aspirin treatment.
- Perfusion MRI imaging and neuropsychological/behavioral issues in patients with the disorder.
- Constraint and activity-based therapy for hemiparesis associated with Sturge-Weber syndrome.
- A study to determine the best timing of laser treatment and to understand whether the extent of skin involvement predicts brain and skin involvement.
- Improving the treatment of migraines in patients with the disorder.

*“Every physician and specialist went out of their way to make us feel valuable and welcomed.”*

-Parent of Sturge-Weber Center patient

# Christian's Story

His [Christian's] mother, Kristina Amos, sits beside him on the exam table, a worried expression on her face.

Christian's brown skin makes the birthmark harder to see, but appearances are deceiving: He has been diagnosed as having Sturge-Weber syndrome, suffering seizures and showing signs of developmental delays. As Comi looks him over, Christian smiles and eats plump grapes, leaving light-purple juice stains down the front of his white T-shirt.

During the exam, Comi notices more signatures of the disorder—his foot turns outward slightly when he walks, and he has stopped gaining weight. But he's putting words together, and as Comi leans in close and waves her hands next to his face, she finds another sign of improvement.

"He's blinking now, on both sides," she tells Christian's mother. "I think he's seeing more off to his side, so that's good." Amos brightens at the news that her son's medications might be helping.

"Yay!" she says, raising Christian's hands over his head in a victory cheer.

"Yay," echoes Christian, his chin shiny with grape juice. Comi smiles and cheers with them at the small sign of progress.

But the moment is fleeting. The exam finished, she hurries down the hall to her next appointment.

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Photograph: A technician prepares Christian to undergo an EEG as part of a research study to determine if the noninvasive test can spot the earliest sign of Sturge-Weber syndrome.



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## Collaborative Relationships

**Hunter's Dream for a Cure:** A nonprofit organization dedicated to finding a cure for Sturge-Weber syndrome and supporting programs for children with special needs, Hunter's Dream for a Cure provides essential collaborative support for our center. This organization, along with our Center, is named for Hunter Andrews Nelson, a courageous 5-year-old who suffered from Sturge-Weber Syndrome. Funding from Hunter's Dream for a Cure helped establish our center and continues to fund its neurological research efforts today. For more information, please visit [www.huntersdream.org](http://www.huntersdream.org) or call 970-686-7459.

**Bands on the Bay:** Each spring, the DeCesaris/Heck and Faneca families host this annual fundraiser that features musical entertainment, auctions, and food. These funds also support our clinical and research efforts. For more information, please visit [www.bandsonthebay.org](http://www.bandsonthebay.org).

**The Sturge-Weber Foundation:** Since 1987, this foundation has provided worldwide education and support for Sturge-Weber syndrome, Klippel-Trenaunay syndrome, and related port-wine birthmark conditions. The foundation has also provided research and start-up funding for our programs and continues to collaborate in patient care and research initiatives. For more information, please visit [www.sturge-weber.com](http://www.sturge-weber.com).



*"Meeting with the doctors gave my husband and me great peace of mind that we are doing everything we can for our daughter. Traveling to Baltimore was well worth the trip!"*

-Parent of Sturge-Weber Center patient





Kennedy Krieger Institute

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## *Our Mission*

We at the Kennedy Krieger Institute dedicate ourselves to helping children and adolescents with disorders of the brain and spinal cord achieve their potential and participate as fully as possible in family, school, and community life.