

Occupational Therapy Services for Patients with Sturge-Weber Syndrome

You have been referred for occupational therapy services by the Sturge-Weber Center. Patients diagnosed with Sturge-Weber syndrome (SWS) may have functional impairments that occur as a result of the disorder. These can include impaired hand and arm function (hemiplegia). Patients with SWS who have hemiplegia can often benefit from an occupational therapy (OT) evaluation. OT services are available through the Fairmount Rehabilitation Programs at Kennedy Krieger Institute. The Fairmount Rehabilitation Programs also offer an array of interdisciplinary therapy programs that can be advantageous to patients with SWS-caused hemiplegia. Our therapists are specifically trained in the evaluation and treatment of children with hemiplegia, and are certified in evaluation tools designed for children with hemiplegia.

What is the benefit of an OT evaluation?

The therapists at the Fairmount Rehabilitation Programs are highly trained in the treatment and evaluation of children with hemiplegia. We have one of the longest running Constraint-Induced Movement Therapy clinical programs in the country, established in 2004. This is just one of the many therapies available at the Fairmount Rehabilitation Programs that can benefit patients with SWS.

When you come to Fairmount Rehabilitation Programs, you get more than an evaluation. After the evaluation, you will receive an extensive, customized home program with recommendations tailored to your child's specific needs. In addition, your child's therapist will connect you to more resources that may be beneficial to your child. This therapy evaluation can also aid in planning for school, outpatient therapies closer to home, or writing/consulting on an Individualized Education Plan (IEP).

How does an OT program help patients with SWS?

Patients with SWS who have hemiplegia caused by a stroke could particularly benefit from our program's strong emphasis on bimanual coordination. Our therapist will work with your child to develop strategies that will not only help to improve his or her unilateral function, but also enable your child to be more independent with two-handed self-care tasks. We have demonstrated that our therapy protocols are effective through a



recent publication of our program outcomes in a scholarly journal (Garcia Reidy, T., Naber E., et al. [2012] Outcomes of a Clinic Based Pediatric Constraint-Induced Movement Therapy Program. *Physical and Occupational Therapy in Pediatrics*).

What is the Assisting Hand Assessment?

The Assisting Hand Assessment (AHA) is part of your child's OT evaluation. It measures and describes how effectively a child with hemiplegia uses his or her involved hand collaboratively with the other well-functioning hand to perform bimanual tasks. For children, the AHA is an enjoyable 10- to 15-minute, semi-structured play session that uses a test kit of toys requiring bimanual use. The AHA is scored from structured video recordings of the performance skills observed during this play. AHA is a standardized test intended for children between the ages of 18 months and 12 years.

We are all born with great potential.
Shouldn't we all have the chance to achieve it?

What can the Assisting Hand Assessment tell me about my child?

The AHA is unique because it is the child's spontaneous and normal way of handling objects when playing that is assessed, not their best capacity to grasp, release, or manipulate objects when prompted to use their affected hand. This makes the AHA a measure of usual performance. The outcome of the AHA provides a description of how the child uses the affected hand. For example, how does the child grasp objects—from the table or from the other hand? How stably does the child hold objects in his or her hand? There are 22 test items, each with criteria describing object-related hand actions. Thus, the AHA provides a comprehensive ability profile of how the individual child uses the affected hand. This description can then be used to determine the next appropriate goals in treatment, whether in outpatient therapies, at home, or in school-based situations. It can also be a tool used over time to track progress, and may identify regressions in hand skills after a neurological event.

About Fairmount Rehabilitation Programs

The Fairmount Rehabilitation Programs are unique, interdisciplinary outpatient programs that specialize in treating and evaluating children with disorders of the brain and spinal cord. We serve a wide population of patients from 8 months to 21 years old. In addition to occupational therapists, we have physical therapists, special educators, speech therapists, neuropsychologists, behavior psychologists, nurses, and doctors on staff. Multiple disciplines can be consulted and involved in your child's care if needed. For children who can benefit from ongoing services or attending one of our intensive therapy programs, we have equipment resources such as electrical stimulation, taping techniques, robotics, and game systems that can maximize your child's therapy.

Contact Information

Fairmount Rehabilitation Occupational Therapy at Kennedy Krieger Institute

For more information or to schedule an appointment, please call Kristine Mauldin at **443-923-4587** or email at

Mauldin@KennedyKrieger.org

TTY: **443-923-2645** or Maryland Relay **711**

SturgeWeber.KennedyKrieger.org

Physicians & Healthcare Professionals

To make a referral, call our Physician Referral Line at **443-923-9403**.

Clinic Location:

1750 E. Fairmount Avenue
Baltimore, MD 21231

Mailing Address:

707 North Broadway
Baltimore, MD 21205

Kennedy Krieger Institute recognizes and respects the rights of patients and their families and treats them with courtesy and dignity. Care is provided in a manner that preserves cultural, psychosocial, spiritual and personal values, beliefs, and preferences. We encourage patients and families to become active partners in their care by asking questions, requesting resources, and advocating for the services and support they need.



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