



The Hemispherectomy Foundation

*Dedicated to the children
and families impacted by
Hemispherectomy Brain Surgery*

Hope in One Hemisphere

What is a hemispherectomy?

A hemispherectomy is an operation in which half of the brain is removed or disconnected.

When is a hemispherectomy indicated?

Most often, this surgery is considered in patients with severe seizure disorders coming from one side of the brain. Even then, the procedure is considered only when drugs cannot control the seizures and the patient is increasingly handicapped. Candidates may also show bi-hemispheric EEG abnormalities but be surgical candidates if a lesion is found in one hemisphere. While most have surgery for seizures, there are some unusual cases where patients may not have seizures. Cases such as mostly uni-hemispheric damage from viral or bacterial infections, trauma or tumors. Children with tuberous sclerosis may also be candidates for surgery.

The most common variety of uni-hemispheric neurologic disorders include:

Rasmussen's Encephalitis (RE)



A rare degenerative brain disease that initially affects only one side of the brain. It first manifests in childhood with the onset of epileptic seizures. Later, it can progress to paralysis of one side of the body, field of vision cut in both eyes and loss of mental function.

The seizures in Rasmussen's Encephalitis usually resist therapy with anticonvulsant drugs, but respond well to hemispherectomy.

For more information on RE, contact:

Lynn Miller - Specialty Director Rasmussen's Encephalitis

Email: lynn@hemifoundation.org

Sturge-Weber Syndrome (SWS)



Often characterized by a facial birthmark, this rare and progressive disorder includes symptoms such as glaucoma, seizures and developmental delays. Neurologic involvement is typically limited to one side of the brain. Antiepileptic drugs are often effective in controlling seizures in those with Sturge-Weber. In the rare instance that medication therapy is not effective, hemispherectomy surgery may be necessary.

For more information on SWS, contact:

Rachel Waters - Specialty Director Sturge-Weber

Email: rachel@hemifoundation.org

Hemimegalencephaly (HME)



Hemimegalencephaly is a rare dysplastic malformation of the brain resulting from overgrowth of part, or all, of a cerebral hemisphere. Clinical findings include psychomotor retardation, hemiparesis, and intractable seizures. Early control of seizures is needed to allow maximal psychomotor development. Seizures associated with hemimegalencephaly are difficult or impossible to control medically. Hemispherectomy has been used in several series to effectively control seizures.

For more information on HME, contact:

Holly Pauwe - Specialty Director Hemimegalencephaly

Email: holly@hemifoundation.org

Cortical Dysplasia (CD)



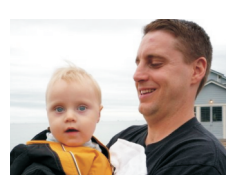
Cortical dysplasia is a congenital abnormality where the neurons in an area of the brain failed to migrate in the proper formation in utero. Occasionally neurons will develop that are larger than normal in certain areas. This causes the signals sent through the neurons in these areas to misfire, which sends an incorrect signal. It is commonly found near the cerebral cortex and is associated with seizures and may be associated with some level of developmental delay(s). Instead of using medication to suppress the seizures, surgery is increasingly becoming a popular solution for the problem.

For more information on CD, contact:

Holly Pauwe - Specialty Director Cortical Dysplasia

Email: holly@hemifoundation.org

Pediatric Stroke



A stroke occurs when the blood supply to any part of the brain is interrupted, resulting in tissue injury and loss of brain function. The severity of impairment resulting from the stroke depends on the location and extent of injury to the brain tissue. Seizures are often associated with the stroke and may or may not respond to anticonvulsant therapy. Hemispherectomy is becoming more and more common in helping control seizures that do not respond to medication as a successful way to reduce or eliminate seizures.

For more information on Pediatric Stroke, contact:

Barbara Frazier - Specialty Director Pediatric Stroke

Email: barbara@hemifoundation.org

Who is affected by hemispherectomy surgery?

The patient, as well as the entire family, is affected in many ways. Aside from the emotional strain of dealing with the diagnosis, the family must make the difficult decision to put their loved one through this extreme operation. There is also the financial burden of the surgery and the multiple rehabilitative therapies required to regain strength and relearn motor functions. These doctor appointments and therapy schedules can compromise a parent's time at work and income.

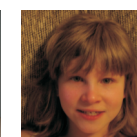


You Are Not Alone

Making the decision to undergo a hemispherectomy is difficult, but often the only choice for a chance at a more quality filled life. At **The Hemispherectomy Foundation**, we support both the patient and their family through all three crucial phases: the decision, the surgery and recovery.

Through this foundation, you will have access to inspirational stories of children and adults who have undergone a hemispherectomy and continue to amaze us with their abilities. Many members of our staff have a child who has undergone a hemispherectomy. Because of our personal experience, we understand how important it is to have someone walk this path with you, guiding you through your questions, doubts and fears.

We've made it our passion to encourage you and to give you hope. As you research the hemispherectomy procedure and its after effects, we will provide our personal experience to help answer your questions and put you in contact with families who have a similar diagnosis as your child.



Our Mission

- To ENCOURAGE and SUPPORT impacted families by connecting them with other families who have had a hemispherectomy or similar surgery.
- To WORK TOGETHER with medical professionals to FUND research into the cause of the diseases that lead to hemispherectomy and the surgery itself.
- To RAISE MONEY for camp fees, scholarships for trade school and higher education as well as provide financial relief for struggling families.

We invite you to visit our website where you will find support, information, family connections and other valuable tools to help you through this journey.

www.HemiFoundation.org



The Hemispherectomy Foundation reminds you that this brochure contains information only and should not be interpreted as diagnostic or medical advice.

Help Us Achieve Our Goals

It is the mission of The Hemispherectomy Foundation to ENCOURAGE and SUPPORT families and friends and WORK TOGETHER with medical professionals to FUND RESEARCH into the cause of the syndromes that ultimately lead to hemispherectomy brain surgery.

Your generous support and participation is crucial to our ability to serve hemispherectomy patients and their families. Getting involved is empowering and provides an opportunity for you to contribute to The Hemispherectomy Foundation's commitment to serving the needs of those affected by hemispherectomy surgery. On our website, www.HemiFoundation.org, we have many ways to help a hemispherectomy patient in need, or you can always call the foundation office at 817-307-9880.

The Hemispherectomy Foundation is a 501(c)3 non-profit organization supported by individual and corporate gifts and grants. All donations are tax deductible and are used ONLY to support the families we serve.



The Hemispherectomy Foundation

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About THF

The Hemispherectomy Foundation, a 501(c)(3) non-profit organization, was founded in 2008 and is dedicated to providing emotional, financial and educational support to individuals and their families who have undergone, or will undergo, a hemispherectomy or similar brain surgery.

We provide help which includes, but is not limited to: college scholarships, trade school scholarships, camp fees, life-aid equipment, travel expenses and other aid as approved by the officers.

We are also dedicated to hemispherectomy education, awareness, fundraising and research of the medical conditions that lead to surgery and the surgery itself.

As the cause of these medical conditions are unknown, research is needed. We invite you to join us in our research efforts to make the future brighter for individuals and their families whose lives have been touched by these conditions.

Contact Us



The Hemispherectomy Foundation

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