What is Schizencephaly?

Many sources define Schizencephaly as a very rare cortical malformation that results in grey matter-line clefts that can impact one or both sides of the brain. The brain malformation can occur during the first 5 to 9 weeks of pregnancy. Also known as Split Brain disorder, the first documented case of the disorder was dated in 1946 by Yakovlev and Wadsworth. It's predicted that in 1998, the name Schizencephaly was adopted by the medical community. With only an estimated 7,000 cases report, Schizencephaly is the second rarest known brain malformation. According to a study in the UK, the probability of having Schizencephaly is 1.48 for every 100,000 births (Stang and Dr. Krucik, 2013). These numbers can vary in different countries where the disorder can often be mis-diagnosed for one of its underlying conditions.

What causes Schizencephaly?

There are many possible causes to Schizencephaly but one fact remains, a stroke was involved during the pregnancy. The stimulant that causes the stroke, ranges from genetics, CMV, and environment. Little is known in these areas to determine whether there is one or many root causes.

There are varying arguments over the cause of Schizencephaly. Some are told it's genetic although we have yet to find it in any prior family members supporting that theory. In cases involving twins, the assumption is that Schizencephaly can be due to the fact the womb was shared. Many doctors feel a stroke happens between 4 to 9 weeks gestation for no reason. But the fact remains. There is still not a proven reason for Schizencephaly.
**How is Schizencephaly detected?**

As stated earlier, most cases of Schizencephaly goes undetected because it is often overseen by other medical conditions (i.e. Cerebral Palsy, Epilepsy...). The symptoms of the disorder can vary depending on the location and amount of under-developed portions of the brain.

Sometimes obstetricians can detect Schizencephaly through ultrasounds. The most accurate way to diagnose the disorder is a MRI. A MRI of the brain can take multiple slices in different angles and depths to determine how advance the malformation.

**Symptoms of Schizencephaly**

Many people with Schizencephaly have uncontrollable seizing and severe delays requiring multiple surgeries from hip dislocation, scoliosis, paralysis and low to no vision.

**Scoliosis**

Scoliosis is a huge part of Schizencephaly due to the fact one side of the brain is normally affected more than the other. Causing the child to compensate their usage on the other side of their body can result in over curvature and severe scoliosis. Many children will be braced for prevention but others will endure spinal surgery and rods to help stop the curvature.

**Small Optic Nerves and Blindness**

Schizencephaly is often diagnosed by first noticing pale or small optic nerves. It is a characteristic found in over 70% of cases. Cortical blindness is not a factor, the nerve that relays the picture to the back of the brain is damaged meaning children are pronounced legally blind but Can see. What vision is relayed to the brain is unknown but the brain has amazing healing properties and often children learn ways of seeing with different ways of looking, such as tilting the head to another direction or to the side of the object. Another mystery of Schizencephaly.

**Cerebral Palsy**

An underlying result of Schizencephaly is tight muscles and atrophy (Cerebral Palsy). Surgeries are needed to remove tightness. Those can range from Botox injections to release stiffness or muscle lengthening and adduct releases (cuts into the muscles) to allow muscles...
to grow with the bones.
Due to most children being high tone there is also a need for muscle relaxers to stop muscle spasms and for children with severe tightness the use of a Baclofen pump in necessary. That surgery gives a steady flow of medication to the child through a pump that goes up the spinal cord.

Other symptoms of Schizencephaly
Symptoms of Schizencephaly can include mental retardation, an abnormally small head, poor muscle tone, and partial to complete paralysis. Seizures (Epilepsy) are another common symptom of most cephalic disorders, including this one. Hydrocephalus, or a buildup of cerebrospinal fluid in the brain, may also accompany the other symptoms.

Types of Schizencephaly

Bilateral Schizencephaly

Bilateral Schizencephaly means there are abnormal clefts on both sides of the brain. Bilateral is the more severe case of this disorder.

Though the medical community states many children with Bilateral Schizencephaly will have uncontrollable seizures, limited mobility and wheelchair bound. We learned through the members of our organization that many children with Bilateral Schizencephaly are able to sustain mobility. The children are able use walkers and other equipment to move without parental assistance. In addition, parents have controlled seizure activity through the use of finding the appropriate medication

Most children with Bilateral Schizencephaly have shorter life spans and will incur surgeries throughout life to assist in their health. There are several cases of people living beyond their second decades with Bilateral Schizencephaly which was once discounted by the medical world.
**Unilateral Schizencephaly**

Unilateral Schizencephaly is a term where a cleft is located on only one side of the brain. Whatever side the cleft is on would affect the opposite side of the body. Many people can live with Unilateral Schizencephaly to adulthood and beyond. But they will have cognitive and motor issues and many will still have seizures.

**Morphological Types**

Whether a person has Unilateral or Bilateral Schizencephaly, they will either have what's called an open or closed lip.

**Open Lip**

Open lip means the cleft walls are separated and filled with cerebrospinal fluid (CSF). It is the most common morphological type in bilateral cases.

**Close Lip**

Close lip is most common in Unilateral Schizencephaly. The cleft walls are in apposition. (Dr. Bickle and Dr. Gaillard)

**Is there a Cure?**

Presently, there is no cure for Schizencephaly; however, there is great interest in medications such as stem cell regeneration medications that shows great hope in repairing brain damage. However, it is currently not available in the United States and many other countries.

**Medical Care**

Since the degree of symptoms from Schizencephaly can vary, the type of medical care provided can differ.

**Therapy**

Therapy is essential and key to helping children with Schizencephaly. Early intervention is available to children between birth to three years old and that is a critical time for development. Normal therapy options include behavioral, feeding, physical and occupational but we are going to provide additional therapy options which have proven success.

**Conductive Education**

Conductive education has shown positive results on children with Schizencephaly. Their programs can be found across the US and is based out of Hungary. The technique is similar to patterning in that the brain is taught to know specific time to do things, eating, physical walking, eating. It is very hands on and has shown huge strides for children with cerebral palsy. (CECO)

**Hippotherapy**

Hippotherapy has been used to treat patients with neurological or other disabilities, such as autism, cerebral palsy, arthritis, multiple sclerosis, head injury, stroke, spinal cord injury, behavioral disorders and psychiatric disorders. The effectiveness of hippotherapy for many of
these indications is unclear, and more research has been recommended. (Wikipedia)

**Hydrotherapy**
Hydrotherapy is considered an effective method for the relief and treatment of multiple conditions, including wound care, increasing circulation, reducing inflammation and swelling and boosting immune system function. Hydrotherapy comes in many forms, including warm or cool water, steam, vapor or ice. Some forms of hydrotherapy direct firm streams of water toward areas of the body damaged by injury or disease to relieve pain and invigorate the area with gentle massaging pressure that helps loosen muscles, tendons and ligaments. (Stern, 2011)

**Island Dolphin Care**
Island Dolphin Care, Inc. (IDC) was developed to help children with special needs and their families who are dealing with developmental and/or physical disabilities, emotional challenges, and critical, chronic or terminal illness. Island Dolphin Care, Inc., was created by Ms. Deena Hoagland, LCSW, after witnessing the remarkable recovery of her son, Joe, after he began swimming with dolphins at the age of three. A variety of children with special needs could experience therapeutic success in an environment less threatening than standard medical settings.

**Stroke Therapy**
Stroke therapy focuses on repetitive motions to train the functional part of the brain to compensate for the abnormal portion. Although it is mostly used for adult stroke victims, it has proven to be very beneficial for children with Schizencephaly.

**Shunts**
Often times a person with Schizencephaly brain can tell the body to not function properly. In these cases, especially those that are complicated by hydrocephalus, a surgically implanted tube called a shunt is used to divert fluid to another area of the body where it can be absorbed.

**Supporting the Need for Research**
There is little to no information available for parents dealing with Schizencephaly and many are left learning from other parents. We find the medical field has made no advancements in cases especially research. There is simply not enough research and education happening.

WeAreR.A.R.E is working to change that. Currently we spend a vast amount of time talking with hospitals around the world so we can not only train then and provide more information to grief counselors but also to become the first point of contact for new parents seeking accurate information not being provided. Research is crucial in finding answers and helping to prevent disruptions of the brain formation.

Sources:
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Conduction Education Center of Orlando (CECO) – Conductive Education (http://www.cecfl.org/)
Conduction Education Center of Orlando (CECO) – Conductive Education (http://www.cecfl.org/)
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CATEGORIES
Recommended Professionals (http://www.wearerare.org/category/recommended-professionals/)
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OFFICIAL DOCUMENTATION
Fundraiser Request Form (http://www.wearerare.org/documents/Fundraiser_Contractual_Agreement.pdf)
Schizencephaly Fact Sheet (http://www.wearerare.org/documents/Schizencephaly_Fact_Sheet.pdf)

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