We Are Working To Provide A Better Future For The People Affected By CLOVES Syndrome

CLOVES Syndrome is an extremely rare progressive overgrowth disorder, affecting approximatley 100 people worldwide. The symptoms vary from mild soft-tissue tumors to Vascular Malformations encompassing the spine or internal organs. CLOVES Syndrome is closely linked to other overgrowth disorders like M-CM (Macrocephaly-Capillary Malformation) Syndrome, Klippel-Trénaunay-Weber Syndrome, and Proteus Syndrome.

We Need Your Help

CONTACT US

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CLOVES Syndrome Foundation, I am submitting a tax deductible donation for:

__$500.00 __$250.00 __$100.00
__$50.00 __$25.00 __ Other

Tax Deductible Receipts Will Be Forwarded To Address Of Record. Thank you for your support!

Cloves
SYNDROME FOUNDATION

Help us help them through research, educational literature & support.

CLOVES Syndrome Foundation is focused on improving the lives of CLOVES patients by funding Overgrowth and Vascular Anomaly research. Our foundation is committed to raising public awareness and providing member support by offering educational literature and resources while also establishing support networks within the medical and overgrowth communities.

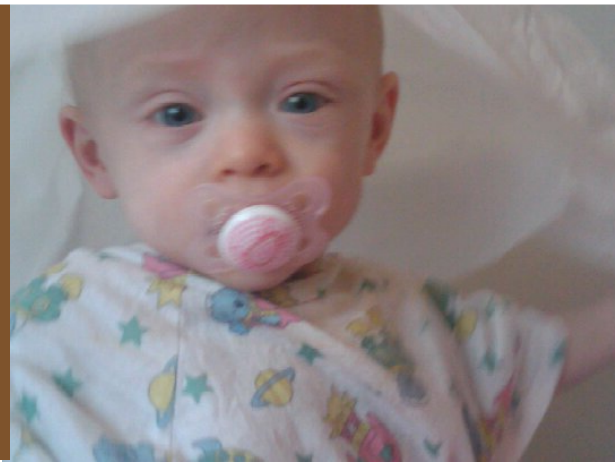
WE LISTEN. WE ACT. WE CARE.

"Research Committed to Finding a Cure in Hope For a Better Future"

Please help us make an IMPACT on the lives of these children

In May of 2012, Children's Hospital Boston discovered that a mutation during early embroyonic development in the PIK3CA gene is responsiible for CLOVES Syndrome. We are excited to move our focus to funding reasearch for medication and new treatment options for those affected by CLOVES Syndrome.

Cloves SYNDROME FOUNDATION



What does CLOVES stand for?

Congenital

This is something existing at birth and often before birth, or that develops during the first month of life, regardless of the causation.

Lipomatous

Means pertaining to or resembling a benign tumor made up of mature fat cells. Most CLOVES patients present with a soft fatty mass at birth, often visible on one or both sides of the back, legs and/or abdomen.

Overgrowth

Means there is an abnormal increase in the size of the body or a body part that is often noted at birth. Patients with CLOVES, may have affected areas of their bodies that grow at a faster rate than other people. Overgrowth of extremities (usually arms or legs) is seen with large wide hands or feet, large fingers or toes, wide space between fingers and asymmetry of body parts.

Vascular Malformation

Is a term used to refer to blood vessel abnormalities. Patients with CLOVES have different venous, capillary, and lymphatic pathways - typically capillary, venous and lymphatic malformations are known as "slow flow" lesions. Some patients with CLOVES have combined lesions (which are fast flow) and some have extremely rare and aggressive vascular malformation known as Arterio-Venous Malformation (AVM). The effect of a Vascular Malformation varies per patient based on the type, size, and location of the malformation.

Epidermal Nevi

This is the medical term for sharply-circumscribed and chronic lesions of the skin and benign by definition. These are often flesh-colored, raised or warty.

Spinal/Skeletal Anomalies, and/or Scoliosis

Some patients with CLOVES have tethered spinal cord, Vascular Malformations in or around their spines or other spinal abnormal-ities. High flow aggressive spinal lesions (like AVM) can cause serious neurological deficits/ paralysis.

There are a variety of signs and symptoms not covered in the CLOVES acronym - they include reddish/pinkish birthmark or port wine stain, a sandal gap in one or both feet, other skin abnormalities include prominent veins, and lymphatic vesicles (similar to blisters). Wilms Tumor is more common, so quarterly ultrasounds are recommended to monitor kidney abnormalities.