



CLOVES SYNDROME COMMUNITY

SUPPORT - EDUCATION - HOPE - EMPOWERMENT

PRESS RELEASE: CLOVES Awareness Day, August 3, 2018

FOR IMMEDIATE RELEASE:

CLOVES Syndrome Community is proud to announce our annual CLOVES Awareness Day on August 3rd in recognition of CLOVES Syndrome, an ultra rare, progressive disorder caused by a somatic, non-hereditary genetic mutation.

CLOVES Awareness day is one day a year - around the world - that we collectively organize and share information about CLOVES Syndrome.

Raising and spreading awareness leads to increased interest, compassion and care for rare diseases like CLOVES Syndrome. With increased awareness and an engaged and active patient population, there will be more opportunities for research, treatment and improved outcomes for our loved ones.

GOALS FOR AWARENESS DAY

- We want medical professionals, especially pediatricians, to learn more about the symptoms and features so they can refer their patients for screening and proper diagnosis in a timely manner.
- We want other professionals that work with children and their families affected by CLOVES to know the symptoms and distinguishing characteristics.
- We want any families who have been diagnosed to find our non profit organization at www.clovessyndrome.org and to join our community.
- We want to promote the need for research, our desire for better treatment options and encourage people to donate to our organization.

WHAT IS CLOVES SYNDROME?

CLOVES is an acronym for an ultra rare disease that encompasses the following symptoms: **C**ongenital, **L**ipomatous, **O**vergrowth, **V**ascular Malformations, **E**pidermal Nevus, and **S**pinal/Skeletal Anomalies.

Approximately 300 people worldwide have been diagnosed with CLOVES Syndrome. However given the recent discovery of this syndrome in 2009, there are likely many more people who remain undiagnosed.

People living with CLOVES often experience neurological complications, pain, and significant and aggressive overgrowth of affected parts of the body.





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About CLOVES Syndrome Community

CLOVES Syndrome Community is a 501(c3) nonprofit organization that supports, educates, empowers and improves the lives of those affected by CLOVES Syndrome.

The organization's main objectives are to provide information and resources to educate others about CLOVES, foster and promote a supportive community and to build a broad base of funding sources to support our mission and goals.

In our seventh year of existence, CSC has provided financial assistance to families worldwide who need specialized medical attention that is currently only available in the United States. We maintain a comprehensive web presence for the disease. We have promoted CLOVES Syndrome research at Boston Children's Hospital and the National Institutes of Health to assist in the complete understanding of the disease. We donated \$20,000 to Boston Children's Hospital in the past year for research initiatives for CLOVES.

We host a Family Conference at Boston Children's Hospital that brings together those affected by CLOVES, their families and medical professionals from across the country who are involved with the treatment of this rare disease.

CLOVES Syndrome Community is a proud member organization of the National Organization for Rare Disorders (NORD)

For more information on the services offered by CLOVES Syndrome Community visit <http://www.clovessyndrome.org/>

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