



CLOVES SYNDROME COMMUNITY

SUPPORT - EDUCATION - HOPE - EMPOWERMENT

PRESS RELEASE: CLOVES Awareness Day, August 3, 2017

FOR IMMEDIATE RELEASE:

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

Families and friends around the world will celebrate the diverse people affected by CLOVES Syndrome and expand recognition for the disorder in order to increase awareness and funding for research towards effective treatment.

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 support group at www.clovessyndrome.org and join our dialogue
- We want to promote the need for research, our desire for better treatment options and encourage people to donate to our organization

SUGGESTIONS TO CELEBRATE CLOVES AWARENESS DAY

- Make our Awareness Logo photo your profile picture.
- Wear green and post your pictures to our Facebook Page
- Write your or your child's story about living with this rare disease and share with your friends/family and the news media
- Make a donation to our organization to ensure a better quality of life for people with CLOVES.

WHAT IS CLOVES SYNDROME?

CLOVES is an acronym for a very 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 200 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. CLOVES Syndrome is not gender specific and is not limited to a specific ethnic background.





CLOVES SYNDROME COMMUNITY

SUPPORT - EDUCATION - HOPE - EMPOWERMENT

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 6th 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 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/>

For more information, please contact:

Kristen Davis, Executive Director

T: 833-425-6837

E: clovessyndrome@gmail.com

Website: <http://www.clovessyndrome.org>

