

# Valley Community Raising Awareness for Girl with Rare Disorder

THURSDAY, 07 MAY 2015 00:00



In honor of National Cornelia de Lange Syndrome (CdLS) Awareness Day, and also a special little girl named Chloe, community members, family and friends will come together at Valley Park in Valley on May 8 at 3 p.m. to understand differences and learn about acceptance.

To recognize National CdLS Awareness Day, Chloe's mom, Heather Gilbert-Cliett, is organizing an event to support and learn about CdLS. She hopes the community will learn important lessons about CdLS, and Chloe as well. The event will also include a bake sale from 3-5 p.m.

National CdLS Awareness Day is observed the second Saturday of May each year in order to shed light on this often misdiagnosed, little-known genetic syndrome. Since CdLS is unfamiliar to many, including professionals in the medical community, Awareness Day—celebrated since 1989—is an opportunity to educate all segments of the population.

## About Cornelia de Lange Syndrome

An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services. Individuals with CdLS range from mildly to severely affected, though most have similar physical characteristics including small size, hands and feet; thin eyebrows that meet; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Common medical problems include GERD, bowel obstruction, and congenital heart defects.

Founded in 1981, the Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS and their families make informed decisions throughout their lifetime.

**-Submitted by CdLS Syndrome**