



CdLS Foundation
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Family Services

- Ask the Doctor
- Connect with a Family
- Family Gatherings
- National Conference
- Teen/Adult Clinic

Publications

- Quarterly Newsletter
- Awareness Materials

Professional Education

- Scientific Symposium

Research

- Small Grants Program
- CdLS Fellowship



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

Quick Facts about Cornelia de Lange Syndrome (CdLS)

- CdLS is a condition present from birth. There is no cure.
- CdLS results in cognitive and developmental delays.
- Many children struggle to walk, talk and feed themselves.
- Most children with CdLS experience gastroesophageal reflux disease (GERD). They can also have heart defects and seizures.
- Physically, people with CdLS are much smaller than their peers.
- About 25 percent have missing fingers or arms or conjoined toes.

Other characteristics of CdLS include:

- eyebrows that meet in the middle
- long eyelashes
- short upturned nose
- thin downturned lips
- excessive body hair
- The syndrome—caused by a random gene mutation—occurs in approximately 1 in 10,000 live births. It affects males and females almost equally and is seen in every race.
- The severity of CdLS ranges from very mild to quite severe. An estimated 20,000 men, women and children remain undiagnosed or without support.

Quick Facts about the CdLS Foundation

- The Foundation was founded in 1981 by parents of children with CdLS. It's the only organization in the country devoted to CdLS.
- The Foundation is a family support organization that works to ensure early and accurate diagnosis of CdLS; promote research into the causes of the syndrome; and help people with CdLS, and their families, make informed decisions.
- The Foundation serves approximately 2,400 people with CdLS, 10,000 family members / caregivers, and 2,500 professionals.