



# CdLS Foundation

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

**CdLS Foundation Contact:**  
Cornelia de Lange Syndrome Foundation  
Brenda Shepard, 800-753-2357  
[bshepard@CdLSusa.org](mailto:bshepard@CdLSusa.org)  
302 West Main Street #100 Avon, CT 06001

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## **Annual Awareness Day for Rare Disorder Gears Up Nationwide**

*Families across the country unite to raise awareness for rare genetic syndrome.*

Avon, CT (May 1, 2013)— Families across the country have been reaching out for months, raising awareness among politicians, neighbors and members of their community. They are requesting proclamations, distributing bookmarks and hanging fliers.

Their cause is a united one: Cornelia de Lange Syndrome, or CdLS. Their deadline is National CdLS Awareness Day, on Saturday, May 11.

“It’s increasingly important for the country to be aware of rare disorders such as CdLS,” said Marie Concklin-Malloy, executive director of the CdLS Foundation. “Since CdLS is unfamiliar to many people, including professionals in the medical community, CdLS Awareness Day is an opportunity to educate the public and create real action in the rare disease world.”

Events are planned across the country, including a family gathering in Maryland, observances and state proclamations in North Carolina and office “Dress Down Day for CdLS” participation in Texas.

CdLS occurs in about 1 in 10,000 births. An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services.

National CdLS Awareness Day was created in 1989 to raise awareness about CdLS, how it affects those with CdLS and their families, and what the general public may need to know about the syndrome.

Individuals with CdLS often have similar physical characteristics including small size, hands and feet; thin eyebrows that meet in the middle; long eyelashes; an upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Early diagnosis and intervention is essential to ensure proper management of related medical issues.

For more information about CdLS, the CdLS Foundation or to make a donation to support individuals with CdLS, call the Foundation at 800-753-2357 or visit [www.cdlsusa.org](http://www.cdlsusa.org).

### About the CdLS Foundation

Founded in 1981, the Cornelia de Lange Syndrome Foundation is a national 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.

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