



# CdLS Foundation

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

**CdLS Foundation Contact:**  
Brenda Shepard, 800-753-2357  
[bshepard@CdLSusa.org](mailto:bshepard@CdLSusa.org)

Cornelia de Lange Syndrome Foundation  
302 West Main Street #100 Avon, CT 06001

## **National Nonprofit Makes Historic Board of Directors Appointment**

*Greensboro resident joins the Board of Directors of the CdLS Foundation, giving a voice to others with CdLS.*

Greensboro, NC (February 19, 2013)— The Cornelia de Lange Syndrome (CdLS) Foundation is proud to announce that Maegan Lowrey has joined its Board of Directors, which serves as a guide for the national nonprofit, located in Avon, CT.

Lowrey is the first person with CdLS to serve on the Board of Directors for the Foundation.

“We are so happy to have Maegan join our Board of Directors,” said Marie Concklin-Malloy, executive director of the CdLS Foundation. “As someone with CdLS, Maegan will bring a different perspective to the Board, as well as a unique set of experiences. She will make the Board stronger and more in tune with what people with CdLS and their families may need most.”

Lowrey, of Greensboro, NC, has CdLS and is a self-advocate and artist. She attended Barton College, to study visual arts.

“I am excited but very nervous. Like a lot of things, though, once I “warm up” I am a little sharp-shooter,” said Lowrey. “I am truly looking forward to being part of the board.”

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

### About CdLS

Cornelia de Lange Syndrome 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. 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 in the middle; long eyelashes; an upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms. Common medical problems include GERD, bowel obstruction, hearing loss, and congenital heart defects. Early diagnosis and intervention is essential to ensure proper management of related medical issues.

### About the 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.

