



CdLS Foundation

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

CdLS Foundation Contact:

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Cornelia de Lange Syndrome Foundation
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WHO: Cornelia de Lange Syndrome Foundation

WHAT: de Lange Society Induction honoring leaders and volunteers

WHEN: April 6, 2013

WHERE: Avon, CT

National Nonprofit Honors Volunteers from Around the Country

Renowned geneticist to speak at induction ceremony honoring leaders and volunteers

Avon, CT (March 19, 2013)— The Cornelia de Lange Syndrome (CdLS) Foundation is proud to induct 40 individuals from around the country to the first annual de Lange Society.

“We are so thankful for these volunteers who have given so much time and dedication over the last 20 years, and beyond,” said Marie Malloy, Executive Director of the Foundation.

The volunteers, leaders and professionals in various fields were chosen based on their length of service with the Foundation. Some of the inductees were even active before the Foundation was created, in 1981.

The individuals being inducted have brought creative vision, innovative ideas, vital assistance and leadership to the Foundation. Their contributions enhance the quality of service and programs offered to individuals with the syndrome and their families.

The de Lange Society, named after the doctor who cared so much about children with the syndrome, publicly recognizes individuals and volunteer groups, who, like Dr. Cornelia de Lange, lead the way for others.

The inductions will take place at a luncheon at Belle Terrace in Avon, CT.

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.

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.