



# CdLS Foundation

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

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Cornelia de Lange Syndrome Foundation  
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## Charity Team Raises Awareness, Funds for Rare Genetic Disorder

*Team CdLS to run in Bank of America Chicago Marathon*

Chicago, IL – (September 25, 2012) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is thrilled to have 13 runners from around the country as part of Team CdLS in the Bank of America Chicago Marathon.

Runners fundraised to benefit the CdLS Foundation and raise awareness for the little-known syndrome. Team CdLS runners come together as a community to support families around the country dealing with CdLS. Together, the team has raised over \$559,339 over the past 10 years for the CdLS Foundation, based in Avon, CT.

"It's a great group of people, with a fabulous coach and terrific captains," said Ava Frank of Sudbury, MA, who is running her fourth Chicago Marathon.

"There is one thing that really powers me through sore ham strings, long crack-of-dawn runs and too much Gatorade: my daughter, Tanaya, who has CdLS. It's her, and all those with CdLS, that keep my feet moving," said Frank.

Team CdLS has been active since the 2000 Chicago Marathon, when runner Frank Mairano of Collinsville, CT—the father of a child with CdLS—used the race to raise funds for the Foundation.

This year, in addition to Mairano, Team CdLS members running in Chicago are Jeff Beaumont of Mt. Prospect, IL; Jill Kaufman of Plantation, FL; David B. Fowler of New York, NY; Colleen McShane Meyer of Bayside, WI, and Jane Champion of Andover, MA; Greg Brown of Cincinnati, OH; David Ghabrial of Canton, CT; Beth Smisloff of Ballston Spa, NY; Tara Zink of Bristol, CT; and Hamlet Tibbs of New York, NY.

For more information about the CdLS 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; 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 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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