



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

*Reaching Out, Providing Help, Giving Hope*

*FOR IMMEDIATE RELEASE*

**Contact:** Jennifer Sangeloty  
Communications Coordinator  
CdLS Foundation  
800-753-2357  
[communications@CdLSusa.org](mailto:communications@CdLSusa.org)

## **Local teen named ambassador of charity marathon team**

*Team to run the Chicago Marathon on behalf of children with Cornelia de Lange Syndrome*

**BALLSTON SPA, NY – April 29, 2009** – Will Smisloff, a 17-year-old Ballston Spa resident born with Cornelia de Lange Syndrome (CdLS), has been named the 2009 Team CdLS Ambassador. Since 2000, Team CdLS has raised more than \$335,000 to benefit the CdLS Foundation, a national support organization dedicated to serving families of children affected by CdLS.

Will travels to the Bank of America Chicago Marathon, October 11. He will cheer on his mother, Beth Smisloff, as she runs her fifth Chicago Marathon as part of Team CdLS. This year, Smisloff is joined by her 19-year-old daughter Grace, who is running her first marathon.

Will was diagnosed with CdLS at birth. He has experienced a variety of medical complications throughout his life, including gastrointestinal-related illnesses; chronic ear infections; severe teething pain resulting in behavioral changes; and multiple corrective surgeries. Will does not speak, yet he communicates effectively through gestures and eye gazes, according to Smisloff.

- MORE -

“When Will is feeling well, he is the happiest person I know. He brings much joy and love to all those who are lucky enough to know him,” says Smisloff.

As a veteran team member and co-captain, Beth believes Will serves an important role as Team CdLS ambassador. “Will is an inspiration to everyone,” she says. “He faces marathon-like challenges every day, and he comes out smiling despite the pain he endures.”

Will’s father, grandparents and other two sisters will also travel to Chicago as members of the Team CdLS “curb crew,” ensuring runners have water, snacks and support during their 26.2-mile run through the city streets.

“This is our way of giving back to the CdLS Foundation after all they’ve done for our family over the past 17 years,” says Smisloff.

“I want to ensure that the services provided by the Foundation continue to be available for Will and all others with CdLS. I hope that our support helps fund research into the more complex issues that Will faces.”

To learn more about Team CdLS and the Bank of America Chicago Marathon, visit [http://www.cdlsusa.org/teamcdls/teamcdls\\_2009.shtml](http://www.cdlsusa.org/teamcdls/teamcdls_2009.shtml).

### **What is CdLS?**

CdLS is a genetic syndrome that 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.

Although individuals with CdLS range from mildly to severely affected, most have similar physical characteristics: 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, and partial joining of the toes. Common medical problems include gastroesophageal reflux, bowel malrotation, hearing loss, and congenital heart defects.

***About Team CdLS***

The 2008 Team CdLS, which consisted of 18 runners, raised more than \$85,000. The team's average amount raised per runner was \$4,522.56—the highest of any charity team in the race.

***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 make informed decisions throughout their lifetime. For more information, call 800-753-2357 or go to [www.CdLSusa.org](http://www.CdLSusa.org).

XXX