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**Long Island girl named ambassador of Team CdLS' New York City Marathon team**

*Team CdLS to run the ING New York City Marathon on behalf of individuals with Cornelia de Lange Syndrome.*

**Wantagh, NY (June 8, 2011)** – Jenna K. of Wantagh, NY, has been named the 2011 Team CdLS Ambassador for the ING New York City Marathon. Team CdLS raises money to benefit the CdLS Foundation, a national support organization dedicated to serving families of children affected by CdLS, a little-known genetic condition. Jenna, 4, was diagnosed at birth with CdLS.

Jenna's mom, Jennifer, describes Jenna as, "The happiest girl ever." Jenna loves going to pre-school and enjoys coming home to her toys, especially her miniature piano. "She loves music. Listening to music, toys that play music and banging on things to make her own music," says Jennifer. She also enjoys walking to the park and playing with her two brothers and sister.

Jenna, her family and Team CdLS members will attend the ING New York City Marathon in New York City on Saturday, October 15. "I am so excited for Jenna to be surrounded by all the excitement and have people meet her," says Jennifer. Jenna's aunt, Tracey, ran with Team CdLS at the Chicago Marathon in 2009 and 2010 and may run with the team in the New York City Marathon.

Jennifer attended the Chicago marathon two years ago and says that it was a great feeling to support and raise money for the CdLS Foundation. "It really means a lot to participate in these marathons. Simply cheering on the sidelines and seeing everyone come together is a great experience."

She says the marathon is also a great opportunity to raise awareness about CdLS. "We definitely never heard of CdLS before Jenna was born, and it may have been helpful if we had."

**About 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:

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*Team CdLS ambassador, Cont.*

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 obstruction, hearing loss, and congenital heart defects.

***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 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).

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