



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

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**FOR RELEASE BEFORE AUGUST 9, 2015**

## **Eating Pizza, Raising Funds for Rare Genetic Disorder**

HAMPTON, NH – (July 27, 2015) On August 10, the Community Oven Pizzeria will host a fundraising night for the Cornelia de Lange Syndrome (CdLS) Foundation, from 5-9:00 p.m. Though you may have not heard of CdLS, a rare genetic disorder, event host, Brenda Shepard, bets that it's closer to your community than you think.

"It's such a small world, and once I started working for the Foundation and learning about CdLS, I quickly realized how many people in my life were affected by, or had someone in their family who has CdLS," said Shepard. "I'm so excited to bring awareness of CdLS to my hometown," said Shepard. "I see firsthand how vital funds are used at the organization, and how much families appreciate every dollar that's given. Whether they're in the seacoast area, or around the country, individuals with CdLS deserve the best chance at a happy life, and I'm proud to help support that."

Shepard is hosting the event to raise funds to go toward her fundraising goals as she prepares to run the Bank of America Chicago Marathon for Team CdLS. Charity runners have fundraising minimums, and Brenda must raise \$1,500 before October 11.

"Knowing people from the seacoast area who have children who are affected, makes running the marathon even less about me, and so much more about them. It makes the miles a little easier, knowing that I am helping people I know."

For more information about the CdLS Foundation or to make a donation, call 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.

### 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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