



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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Mother Races in Memory of Son

Local woman raises funds and awareness for rare genetic disorder, in memory of son.

Goldsboro, NC (January 18, 2013)— Baylen was born June 6, 2010. When he was born, Baylen's mother found out he had a rare genetic disorder, called Cornelia de Lange Syndrome (CdLS). His family gave Baylen the nickname, "Super B," because despite the odds, he kept fighting.

"On February 5, 2011, I took my last breath while laying in my mom and brother's arms," said Baylen in a letter, written by his mother, Chanda Chase. "I came to this earth to show my family just how precious life really is, and for them to live on through me."

In honor of her "Super B," Chase, is running in the "Heart and Sole 1 mile fun run" on February 2 at the Village of Walnut Creek in Goldsboro, NC, to raise funds and awareness for the CdLS Foundation, a national nonprofit dedicated to serving and supporting families dealing with CdLS.

"As a mother, Baylen showed me strength I never knew existed and because of him I am a better person. Even at this very moment Baylen is still able to touch lives through this race," said Chase. "Friends, family, and people I don't even know are getting the opportunity to learn about Cornelia de Lange Syndrome and are given generous donations. Baylen is my hero and through him I am able to help other children with CdLS."

Baylen's letter continued, saying, "I have sent my mother a message to spread the word about CdLS, and to do a fundraiser to help others with CdLS. I am an angel on their shoulder everywhere they go, and one day we will meet again."

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.

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.