

Contact: Marie Concklin Malloy, Assistant Executive Director
outreach@CdLSusa.org; 800-753-2357



Albuquerque girl named ambassador of area charity marathon team

Team to run the Duke City Marathon on behalf of children with CdLS

Albuquerque, NM (June 1, 2010) – Savannah Fernandez, a five-year-old Albuquerque girl born with Cornelia de Lange Syndrome (CdLS), has been named the 2010 Team CdLS Ambassador for the Duke 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.

Savannah and her family will attend the Duke City Marathon on Sunday, October 17, in Albuquerque to support the 19 Team CdLS participants. Savannah’s father, Dee, is part of Team CdLS, and is excited to support the CdLS Foundation.

“Running in the Duke City Marathon is something new for him, but he is really excited to reach his self goals, and to run on Team CdLS in support of the CdLS Foundation,” says Alicia Fernandez, mother of Savannah.

Savannah was diagnosed with CdLS at 14 months old. When she was born she was not speaking or babbling, she was very small, and had a lot of stomach problems, according to Fernandez.

“Even though Savannah doesn’t necessarily know what it means to be an ambassador, I think this experience will shine a special light on her, which is very exciting for our family,” says Fernandez.

“The CdLS Foundation has helped our family so much with finding information, helping us to provide better care for Savannah, and giving us the emotional support that we needed. Through the Duke City Marathon our family can help educate people about CdLS, and help raise money for the Foundation.”

To learn more about Team CdLS go to www.CdLSusa.org.

[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: 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 a diagnosis of CdLS make informed decisions throughout their lifetime. For more information, call 800-753-2357 or go to www.cdlsusa.org.

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