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Cornelia de Lange Syndrome Foundation
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Family Races in Honor of Newborn with Rare Syndrome
NYC Family and National Foundation Staff running to benefit genetic disorder

Avon, CT (June 11, 2013) – The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is proud to have eight runners representing Team CdLS in the 2013 Merrell Down & Dirty 5k in Hartford on Sunday, June 23.

Among the Team CdLS runners is Barbara Martinez, who will be running on behalf of her newborn son, Khaif Randall, who was born with CdLS.

“Khaif is my fourth and last child, and he is also a twin. In the beginning I was in denial and afraid,” said Martinez. “But since being connected with the Foundation I feel much better. It has gotten much easier with all of the support that I have been getting.”

Martinez will be traveling from the Bronx, NY, to participate in the race along with her sister, Carmen Muniz, and daughter, Tyana Colon. “I love the fact that they will be participating with me,” said Martinez. “I really think that it’s going to be a fun day.”

Martinez hopes to bring Khaif with her on race day.

Each Team CdLS runner commits to raise funds to benefit the CdLS Foundation and to raise awareness for this rare syndrome. Last year alone, Team CdLS runners around the country raised \$179,721 to support programs and services that the Foundation provides individuals with CdLS and their families.

Also running in the Merrell Down & Dirty in Hartford are Marie Malloy of Riverton and Brenda Shepard of Avon, who both work at the Foundation.

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.

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