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Cornelia de Lange Syndrome Foundation
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California Local Races in Honor of Sister with Rare Genetic Disorder

Chino Hills, CA – (September 23, 2013) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is proud to have Mary Drexler representing Team CdLS in the Manhattan Beach 10K on Sunday, October 5. Drexler, who is also on the planning committee for the 2014 CdLS Foundation National Family Conference in Costa Mesa, CA, is running in honor of her sister, Mandy, who was born with CdLS.

This will be Drexler's first time running in the Manhattan Beach 10K, though she has previously run in the America's Finest City Half Marathon for Team CdLS.

"My sister, Mandy, has been the inspiration for my training. There are a lot of things in life that Mandy has not and will not be able to do, and I strive to live my life wanting to do those things for her and for me," says Drexler. "Mandy has been so much stronger in her life than I will ever be. In those tough training moments, I draw strength from knowing all that Mandy has gone through, and how happy and proud she would be knowing that I was doing this for her and for the Foundation."

Unconditional love, patience, and acceptance are a few of the things having a sister with CdLS taught Mary.

"My parents have always instilled in me that any one of us could have been born with CdLS, and that it is important to love Mandy and others how we would have wanted to be treated and cared for if we were in their situation," says Drexler.

"I hope that after the race, people will feel rewarded knowing that all of their hard work and determination has gone to such an amazing cause and will ultimately help the Foundation provide resources that will help children and adults, like my sister, live longer and happier lives," says Drexler. "When Mary laughs, everyone laughs. My favorite thing she does is when she, out of nowhere, will come over and give me a tight hug with a big smile. That is one of her ways of telling me that she loves me, and it warms my heart."

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 are 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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