



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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Pennsylvania Family Runs to Raise Awareness for Rare Genetic Disorder

Philadelphia, PA (July 2, 2013)— Mary Ann Feehan is leaving her good shoes at home for the 2013 Merrell Down & Dirty 5K in Philadelphia, PA, to cheer on her son.

On Saturday, July 13, Mary Ann will watch her son, Michael Feehan, run over three miles through mud and obstacles on behalf of his five-year-old son, Connor, who was diagnosed with Cornelia de Lange Syndrome (CdLS) at 11 months old.

“Once the diagnosis came back and we grieved the loss of the child we did not have, I watched my son and his wife take the gift that they were given and accept their challenge. No child has been more loved nor better cared for, and with their endless time and efforts, Connor has been able to meet his potential,” says Feehan.

Michael is a seasoned member of Team CdLS, and has helped raise funds and awareness for the CdLS Foundation in years past. This will be Michael’s third year running the Merrell Down & Dirty and his fourth running for Team CdLS, which raises funds and awareness for the CdLS Foundation.

“I see hundreds of people running for so many different reasons. So many people are raising money for one group or another and it makes me aware of the unending difficulties and problems that affect the lives of so many of us. I look forward to seeing the pride in my son’s face as he finishes knowing that he, again, raised money for CdLS. Me? I will be thankful once again for my son, his wife, and my grandson,” said Mary Ann.

At last year’s race, Mary Ann recalls meeting another grandmother on the sidelines. “Their child was a few years younger than ours. I told her that the pain softens with time and it is the beauty we find in our little ones that helps us make sense of why life does what it does.”

Connor will join JJ, another young boy with CdLS, as the Team CdLS Ambassador for the Merrell Down & Dirty race in Philadelphia.

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.