



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

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FOR RELEASE BEFORE SEPTEMBER 16, 2012

Locals Raise Awareness, Funds for Rare Genetic Disorder

Saratoga Springs, NY – (September 11, 2012) The Cornelia de Lange Syndrome (CdLS) Foundation, a national nonprofit family support organization, is thrilled to have 21 runners as part of Team CdLS in The Saratoga Palio Melanie Merola O'Donnell Memorial Race. Each Team CdLS runner raised funds to benefit the CdLS Foundation and raise awareness for this little-known syndrome in the Saratoga Springs area.

No matter the distance, Team CdLS runners, such as Cathy Roy of Ballston Spa, have come together as a community to support families around the country dealing with CdLS.

Roy and her family joined Team CdLS in support of her best friend, whose son, Will, was diagnosed with CdLS at birth.

"I was there when Will was born and the doctor was not hopeful. He's come so far and the Foundation has been such a wonderful resource. It's been their family's lifeline," said Roy.

Will, whose birthday falls shortly after the race, will turn 21 years old.

"Knowing what I am running for always helps me through the last tough miles," said Jessica Patenaude, Will's cousin, of Saratoga Springs. "Beyond the generous donations we've been able to get, the amount of awareness that we've raised is huge, and I know that will continue to spread long after race day."

Team CdLS runners feel the support at every turn, with a "Curb Crew" and other family members posted along the route. Just when they may feel like giving up, they see other Team CdLS t-shirts running by and feel inspired to keep moving forward.

"We're doing this for him and for everyone with CdLS," said Will's aunt, Lorrie Patenaude of Gansevoort. "Being able to give back to the Foundation is wonderful. They've been a rock for my sister's family and my own. I truly don't know what we would have done without them and their support over the years."

Post race activities include live music by The Remainders, delicious post-race beverages, fruit and goodies at the Hospitality Tent at High Rock Park, and a "Fun Run" beginning at 11:00 a.m. The Awards Ceremony will be at High Rock Park at 11:30 a.m.

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; 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 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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