



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

CdLS Foundation Contact:
Brenda Shepard, (312) 912-7198

bshepard@CdLSusa.org

Cornelia de Lange Syndrome Foundation
302 West Main Street #100 Avon, CT 06001

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Locals Run Saratoga Palio for Rare Genetic Disorder, Family Members

Saratoga Springs, NY - (September 15, 2014) Local families will join together as part of Team CdLS at the Saratoga Palio 5K and Half Marathon on September 21. These 36 runners are hitting the pavement for a cause close to their hearts, the Cornelia de Lange Syndrome (CdLS) Foundation.

"My family looks forward to the Saratoga Palio all year," said Jen Koscielniac, mom to Jenna (age 8) who has CdLS. "The most important part of the weekend for me is seeing the other families affected by CdLS. We catch up from the past year, share the struggles and celebrate the accomplishments of our loved ones with CdLS. They have become like a second family to us. We are really looking forward to the race and reconnecting with all our family, friends, co-workers and neighbors who have been so supportive."

Since 2011, Team CdLS Saratoga Palio has raised more than \$30,000 to help people with CdLS live better, fuller lives. All proceeds benefit the CdLS Foundation, a national nonprofit family support organization, which supports individuals with CdLS, a genetic disorder that causes a variety of physical, cognitive and developmental disabilities.

Beth and Mark Smisloff and their family have spearheaded the team on behalf of their son, Will (age 22) who has CdLS. "Will was diagnosed with CdLS at birth and was given a horrible prognosis and not expected to live through early childhood," she said on her fundraising page. "He has faced many obstacles and challenges but the information and support of the CdLS Foundation helped us help him through these difficulties. Many times they were the only source of up to date and accurate information available."

For more information about the CdLS Foundation or to make a donation, call 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.

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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