



CdLS Foundation

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

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Friends walk, run in memory of local boy with genetic syndrome *Team CdLS debuts at the Manhattan Beach 10K*

(September 9, 2009)—Nearly 40 people take to the starting line of the Manhattan Beach 10K Saturday, October 3, to raise funds for children with Cornelia de Lange Syndrome (CdLS), like Mikey Gonella. Mikey, son of Roy and Julie Gonella of Manhattan Beach, passed away from complication of CdLS nearly three years ago.

To date, 39 friends and relatives of the Gonellas have signed on to run or walk the 10K; another 13 are working at the team's "curb crew."

Team members are raising money for the national CdLS Foundation, which provides service and support to thousands of families, like the Gonellas. The team's goal is \$25,000.

"The Foundation provided the most amazing support to our family for over 18 years," says Julie Gonella. "We've never known an organization of this type that is so personal and comprehensive with its services. Now that our economy is so bad, donations to the CdLS Foundation have not been as generous and services are at risk," she says. "We're doing what we can to make up that deficit."

Among the 52 Team CdLS members and curb crew are Sandy Franchini, current president of Soroptimist International of Manhattan Beach; Pat Beiting, Meadows Elementary School teacher; Eve Stover, Little Company of Mary emergency room nurse; and local student Spencer Hein, all of whom knew Mikey throughout his life.

Supporters include Manhattan Beach Mayor Portia Cohen and Councilman Richard Montgomery, who recently learned about CdLS and are spreading awareness.

Charlotte Marshall of Char Mar PR and Manhattan Beach Mercer Inc. employees Joe Salzillo and Mary Young are hitting the pavement, while Shade Hotel owner Mike Zislis, who has helped the CdLS Foundation in the past, gave a generous donation in support of the team.

To make a donation in support of Team CdLS go to www.firstgiving.com/royandjuliegonella, or for more information, call the Gonellas at 310-546-1354.

CdLS is a little-known genetic disorder that occurs in about 1 in 10,000 births. An estimated 20,000 men, women and children in the U.S. have CdLS but remain undiagnosed or without services.

Although children with CdLS range from mildly to severely affected, most have similar physical characteristics: small hands and head, thin eyebrows that meet, long eyelashes, upturned nose, and thin, downturned lips. Children develop both physically and mentally much slower than their peers. Some have limb differences, missing limbs or partial joining of the toes. Common medical problems include reflux, bowel abnormalities, heart defects, seizures, and cleft palette.

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 make informed decisions throughout their lifetime. More information can be found at

www.CdLSusa.org.

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