

Couple Races in Honor of Deceased Son with Rare Genetic Disorder

Manhattan Beach, CA – (September 23, 2013) Six years have passed since Julie and Roy Gonella first mourned the loss of their son, Mikey, who was born with Cornelia de Lange Syndrome (CdLS). To honor his memory, and to help raise awareness of this little-known syndrome, the Gonellas are rejoining Team CdLS for a third time at the Manhattan Beach 10K on Sunday, October 5.

“My husband Roy and I are motivated by the thought that the money we raise will help make the CdLS conference a good one, and that local families, who are already struggling with caring for their loved one with CdLS, won't also have to worry about raising all the money. And we think about our son Mikey and all he meant to us,” said Gonella.

“Mikey was a very sweet soul,” said Gonella. “He could neither walk nor talk, even by the age of 18, but you knew how he felt by his facial expressions. Sometimes we thought angels were tickling him because he would just burst out *laughing* hysterically, which would get anyone else giggling too.”

Gonella's fondest memory of Mikey is when she took him to her son Tony's 3rd grade class for show and tell.

“I was really nervous,” said Gonella, “I had the kids sit on the floor in a circle and I told them all about Mikey. We talked about what was different about him, but what was also the same, like a family that loved him. I asked if anyone would like to hold him, and my favorite memory was passing Mikey from child to child so each could have a turn. Almost every child wanted to feel and hold him, and it so warmed my heart that I cried.”

After the race, Gonella hopes that everyone will go home knowing that there is condition called Cornelia de Lange Syndrome and that there are families out there in need of support.

“With increased awareness of CdLS and funding going towards the CdLS National Family Conference, we can find those who need a diagnosis, and help those who have one,” she said.

For more information about CdLS, 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.