



CdLS Foundation

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

FOR RELEASE BEFORE NOVEMBER 18, 2012

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Cornelia de Lange Syndrome Foundation
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Local Man Takes on Ironman Triathlon for Rare Genetic Syndrome

WHO: Local Man Tackles Ironman Triathlon for CdLS Foundation

WHAT: Ford Ironman Arizona

WHERE: Tempe, AZ

WHEN: November 18, 2012

Collinsville, CT (November 9, 2012)— Frank Mairano, of Collinsville, CT, is no stranger to tough races. He has run 20 marathons and sees no sign of stopping anytime soon. Mairano will swim 2.4 miles, bike 112 miles and run 26.2 miles to honor the memory of his daughter, Lisa Marie, who had Cornelia de Lange Syndrome (CdLS), along with raising funds for the CdLS Foundation.

“When we first started Team CdLS at the Chicago Marathon in 2000, it was my daughter’s 28th birthday,” said Mairano. “Although much has changed since I ran my first marathon, the Foundation’s needs remain the same – to be able to offer help and hope to every family, at no charge.”

Lisa Marie passed away in 2007, at the age of 34.

“When people ask me what keeps me motivated, I think about Lisa,” said Mairano. “She didn’t communicate verbally, but would connect with people in an even deeper way. I’ve watched Team CdLS, which she inspired, grow tremendously over the last 12 years.”

Of the 2,700 registrants in this year’s triathlon, there are only six men in the 65 to 69 age group, in which Frank is racing.

“When someone tells me something is impossible, I think about a quote from Frank Lloyd Wright that says, ‘The thing always happens that you really believe in; and the belief in a thing makes it happen’,” said Mairano. “I really believe in the Foundation and what it does for the CdLS Community. I hope to be racing even when I’m 80 to support this cause.”

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. To make a gift for Frank’s race online, visit <http://tinyurl.com/IronmanFrank>.

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.

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