



CdLS Foundation

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

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Local Mother Racing in NYC Marathon to Raise Awareness, Funds for Rare Disorder

Portsmouth, NH – (October 16, 2013) Novice marathoner Karen Lyons, of Portsmouth, NH, is preparing for the ING New York City Marathon on November 3. Lyons is running in honor of her 5-year-old son, Luke, who was born with Cornelia de Lange Syndrome (CdLS).

She hopes to raise awareness and funds for the CdLS Foundation, as one of the 10 runners on Team CdLS in the NYC race.

“Luke was tentatively diagnosed just a few hours after his birth, but he looked perfectly normal to me, so I was in denial for weeks,” said Lyons. “When the geneticist confirmed CdLS at 6 weeks old, it was heartbreaking. Now, years later, I’ve learned that having a child with special needs really is no big tragedy; life goes on pretty normally at our house.”

Lyons and her husband, Pat, are active volunteers with the CdLS Foundation, helping to plan golf tournaments, connecting with other families near them, and now joining the Foundation’s race team.

“I think what a gift it is that I have two healthy, strong legs that work, and what a waste it would be for me to not use that gift,” said Lyons. “Luke still can’t walk, and he reminds me every day to not take my health for granted.”

Friends of the Lyons’, nicknamed “The Pentathlons Guys” based on a homemade competition of various backyard game events, decided that they would also support Karen’s race. Event organizer Bryan Raffetto decided to make this year’s “pentathlon” a fundraiser, and together the group donated more than \$600.

“It would be nice if one day I could tell someone that my son has CdLS and they DON’T say ‘What’s that? I’ve never heard of it,’” said Lyons. “I’m really hoping to make people aware of this syndrome, even just a little bit. And of course, I’m also hoping to achieve 26.2 miles!”

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; 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.

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