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May 11 is CdLS Awareness Day

BY MAUREEN FEIGHAN 1 COMMENT

 **Maureen Feighan** is a reporter for The Detroit News and a mother of two.



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It's amazing how four letters can change your life. Four letters have had a profound impact on the person I am today, the mother I am, and the wife. The letters are "CdLS" and they stand for a little heard of genetic condition called Cornelia de Lange Syndrome.


Named after the Dutch pediatrician who first wrote about the condition, CdLS is the syndrome my first son was born with eight years ago and the syndrome my 5-year-old daughter has today. I'd never heard of it the first time I saw it in a letter a geneticist sent to my husband and me about the condition he suspected our son had (yes, he sent it in a letter, but that's a post for another time).


Naturally, like any parent who has been told their child may have a serious disability, I was frightened — incredibly frightened. As soon as my husband and I saw those four letters, we did what most modern couples do: we immediately jumped on the Internet. Not the best idea. The Internet is a tremendous resource, but it can also over expose you to too much information.

But eight years after first learning of CdLS, we've persevered and I know so much more about what the syndrome is and what it means. It's a congenital condition, meaning it is present at birth, and it affects one in 10,000 live births. Children born with the syndrome have small stature, small hands and feet, eyebrows that typically meet in the middle, downturned lips, and small heads. At 5, my daughter Hope is only 25 pounds (but 25 pounds of curiosity, determination, and constant motion). She has learning loss and is nonverbal, which also is common with the syndrome. She's also cognitively impaired.

Saturday is [CdLS Awareness Day](#). Researchers believe thousands may have the syndrome — especially those on the milder end of the spectrum — but have never been diagnosed. A correct diagnosis could get those children and adults the services they may need.

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We've come a long way since CdLS first changed our lives. It's a big part of who we are, but it doesn't define us, just as it certainly doesn't define Hope. But anything we can do to raise awareness of this challenging condition is a good thing. Awareness fosters understanding and compassion, which is all any special needs parent wants.



Maureen is a busy mother of two still trying to figure out this crazy journey called motherhood. A Metro Detroit native who lives in West Bloomfield, Maureen is a reporter for The Detroit News who loves cooking, travel, and being outdoors. She has a nearly 3-year-old son and a 5-year-old daughter with special needs which makes life even more zany.

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Heidi Macy

Great blog, [Maureen Feighan-Kurth!](#) Thanks for sharing and spreading awareness about CdLS! Hope is the sweetest thing ever! :)

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