



## Community to host fundraiser for Siouxland girl with rare genetic disorder

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HUBBARD, Nebraska (KTIV) - 3-year-old Ella Watkins, her three brothers, and their two loving parents have a beautiful and happy life, but they have had their share of challenges.

"We have a speech therapist, an occupational therapist, they come to our home and work with Ella and work with us, also, so we can be able to communicate with her," JJ Watkins said.

Ella was born with Cornelia de Lange Syndrome, or CdLS. It's a genetic disorder that delays development. It's so rare that only one in ten thousand children are diagnosed, which makes finding treatment difficult.

"A lot of doctors, even, have never heard of this. So a lot of the doctors that we see, she's the first case that they've ever seen," Maria Watkins said.

But JJ and Maria say it's all worth it.

"We want to just be able to be the best parents that we can for Ella," JJ Watkins said.

A CdLS Conference in Costa Mesa, California brings together families and doctors dealing with CdLS, and JJ and Maria want to get Ella there.

"We are then just given that reassurance that we need that we're getting the proper care for Ella," JJ Watkins said.

Their hometown of Hubbard, Nebraska, is stepping up to the challenge. Over 80 people in the 235-person town have signed up for Ella's Run, a 5K fundraiser complete with a spaghetti supper and a raffle.

"We've been very, very blessed to have so many people support us and just support Ella. Everyone just loves her, and we're overwhelmed by that," Maria Watkins said.

And as registration for the event continues, the Watkins say they know they'll get little Ella to California.

The fundraiser is open to the public in Hubbard, Nebraska on May 18 and starts at 4 p.m.

There will also be a free will donation rummage sale on Friday night and Saturday on Highway 75 just outside of Hubbard.

If you'd like to help get Ella to California, click [here](#) for more information on the Emerson-Hubbard Schools website, or click [here](#) for the Ella's Run Facebook page.