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## Bayside woman running Chicago Marathon to raise awareness of genetic disorder



By Amy Schwabe  
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Running a marathon isn't something you do on a whim.

Colleen McShane-Meyer, a marathon-running teacher who lives in Bayside, said, "At this time of year with school, I'm at my busiest. It's such a tug of war with me because it takes me a long time to do running, then you're tired and beat up for the day, so it really is a big physical commitment, too."

There are many reasons marathon runners put up with the extreme physical and time commitments.

One reason for McShane-Meyer, who is running her seventh Chicago Marathon on Sunday, Oct. 11, is to raise money and awareness for a little-known genetic condition.

Cornelia de Lange Syndrome (CdLS) is a genetic disorder that is thought to occur in approximately 1 in 10,000 births. The syndrome causes a variety of symptoms, such as cognitive delays and intellectual disabilities, gastrointestinal problems, eye abnormalities, and even missing limbs.

And longtime family friends of McShane-Meyer, Marc and Andrea Needlman of Chicago, have a 10-year-old daughter, Mikayla, who has CdLS.

Marc Needlman, who runs marathons himself, coaches Team CdLS at the Chicago Marathon, and McShane-Meyer is a loyal team member.

Runners raise money for the CdLS Foundation, a support organization that provides services and education to families with the condition. Brenda Shepard, communications coordinator for the CdLS Foundation, explained that the foundation is "mainly just a family support organization. We give information to new families who have just had a baby diagnosed. We have hotlines with social workers to provide a little bit of comfort in what can be a very scary time in a family's life."

Runners for Team CdLS are required to raise at least \$1,250 for the foundation in order to participate in the marathon's charity run. McShane-Meyer has been creative in meeting that goal, holding a charity event at the Heiser Ford Lincoln dealership in Glendale over the summer.

"I've always been uncomfortable asking friends for money, so this year I decided to do a fundraiser by Ford and Lincoln," McShane-Meyer said.

Ford's Drive 4 UR Community and Lincoln's Driven to Give campaigns allow non-profit organizations to raise money by donating \$20 for every test drive on a given day.

McShane-Meyer said that one of the biggest challenges in raising money for the cause is that there are not many people who have even heard of CdLS, and when they are educated about the condition, some of the physical characteristics, such as missing limbs and wheelchair bound children, make people uncomfortable.

"Marc drove in to help me at the dealership, and when he showed people the CdLS brochure, the physical deformities, especially around the face area, really catch people off guard," McShane-Meyer said.

It may be difficult raising money for a condition that is so obscure, but marathon runners are no strangers to difficulty.

Needman said, "I'm always mentoring Colleen and encouraging her to stick with it. If you run, there's a lot of suffering that goes along with marathon running, and it's painful, so you have to know how to commit to it. But the highs and the accomplishment that comes along with it, it's spectacular."

Staff at the CdLS Foundation understand the sacrifices the runners make for the cause, and they make sure to express their gratitude.

Needman described the team's typical marathon schedule: "Sunday, we meet at the tent that the foundation provides for us, and we get together and give each other encouragement. Then when we finish, we meet for a post-race dinner and recognize all our runners. It's a really special weekend, and the foundation is the beneficiary of the proceeds."

One thing the foundation does with those proceeds is to educate people about the condition's different degrees of severity. In some cases, families with children who are more mildly affected are committed to helping those with more severe cases of CdLS. Needman said, "Mikayla's 10 years old, and we're very blessed that she's mildly affected. For her, it's primarily delayed development. Cognitively, it may take her five or six extra years to learn things, but she will get there."

In the meantime, McShane-Meyer is doing all she can to spread awareness of CdLS.

"Through the years, as a teacher, when I was really confident that I would be okay in the marathon, I would incorporate it into my math classes," McShane-Meyer said. "Then, as I got even more comfortable, I would start telling kids about the charity and pull up CdLS pictures."

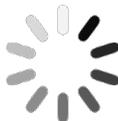
McShane-Meyer also plans on continuing on Team CdLS in next year's Chicago Marathon. She's hoping to move her fundraiser to Bayshore Town Center next year to achieve more visibility for the condition.

"Ultimately, what we really need to do is get CdLS more known in our area, so that next year when I go out to host the event, we'll have more people knowing about this," she said.

For more information about Cornelia de Lange Syndrome, visit the foundation's website at [www.cdlsusa.org](http://www.cdlsusa.org).

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