



Daughter inspires York dad to run Chicago Marathon

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YORK — Young adults who grew up in York as well as their parents will remember Molly Wagner. Now 28, Wagner is a profoundly disabled young woman who suffers from Cornelia de Lange Syndrome, a congenital syndrome that causes physical, cognitive and development issues. She nonetheless attended York schools until she was 19, providing an entire generation of youngsters with a model of the other-abled.

Molly lives at home with parents Peter and Kathy Wagner, and will for the rest of her life. She is one of a rarified group of people who suffer from the syndrome – an estimated 1 in 10,000. For that reason, said her parents, it can sometimes be tough to raise the funds needed for research. But Peter is working to help change that, one dollar at a time.

Wagner departs for Chicago soon, where he will participate in the Chicago Marathon in support of the Cornelia de Lange Syndrome Foundation on Oct. 9. This will be his third marathon in support of the foundation. The first time, he raised more than \$5,000 asking mostly family members; the second time, more than \$15,000 was raised, primarily from his customers at Camp Eaton, which the couple owns; now, he's shooting for \$20,000 and is nearly halfway to the goal.

“This time, we’re trying to reach people from York who knew Molly – kind of a blast from the past,” said Kathy. “We want to remind people she’s still here, and if they remember her, maybe they will make a donation.”

Cornelia de Lange Syndrome is present from birth, and individuals with CdLS resemble one another, just as, say, those with Downs Syndrome. Common characteristics include a low birth weight, slow growth, small head size, eyebrows that meet in the middle, low foreheads, short upturned nose and thin downturned lips.

The couple says it has been one long and continuous learning curve having Molly a part of their family, that also includes two other grown children.

“Having a good sense of humor has been very helpful because most of the time you could either laugh or cry,” said Kathy. “The early years were much harder. We knew when she was not rolling over at 13 months, that’s not good. It took us a while to recognize how severe she was.”

“We had to grow up pretty quickly when we had her, and advocate for her from the very beginning,” said Peter.

Kathy remembers a gracious school community and a great special education department while Molly was growing up. “When she was at Village Elementary School, they used to fight to have her be their buddy. And she was there for kids who didn’t always fit in. A couple of kids always benefited from having Molly at their table at lunch.”

Still, said Peter, it has been a challenge to parent her. “It’s been really, really hard,” said Peter. “Molly has had a lot of physical issues over the years. The nonverbal piece has been most difficult.”

As an adult, for instance, Molly has had gastrointestinal problems – not uncommon of people suffering from CdLS. “She had her gallbladder out a few years back, and another procedure to help manage constipation that led to scar tissues that led to bowel obstruction,” he said.

Because she’s nonverbal, there was a period “where we knew something was wrong with her but we didn’t know what. Was it dental issues? Was it a GI issue? Or was it a behavioral issue? She can’t point to where it hurts,” said Kathy.

But she loves to cuddle, and will gladly sit on her parent’s lap for long periods of time, they said. And their other children, Kathy said, love Molly as much as they do. “I think they have benefited. I mostly think they are better people for having Molly as a sister.”

Kathy, who has served on the board of the foundation including a stint as board chair, said she knows “a lot of families who have been crippled by the whole thing. Most of them have their child in residential care. We are grateful every day that we have the means to be able to keep her at home. That’s not an option for many families,” she said.

In just the past eight years, researchers in part funded from the foundation, confirmed the gene that causes the syndrome. Those born with it are missing a protein that’s essential for human development, said Kathy. “If they don’t have it, every system in the body is affected,” she said.

Peter said in preparation for the marathon, he's running 40-50 miles every week, and these days, "I need a little more recovery time," he said with a smile. He said the experience of running in the Chicago Marathon has been wonderful. The course winds through dozens of neighborhoods, lined with people cheering them on. He is encouraged to write "Molly's Dad" on his shirt, so that when he passes a band set up on the route, they will sing encouragement to "Molly's dad."

"It's really pretty neat," he said.

The couple said all donations are important toward Peter's \$20,000 goal. Many of the donors in past years have given \$10 or \$25. "They add up really quickly. We just want people to know that Molly is still in the community with us. She may not be out and about as much, but she's still here. A lot of people have a connection to her."

To donate to Peter Wagner's run, visit
