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Running for his life

Mother whose son suffers a rare disorder will run marathon to help fund research

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Will Smisloff is oblivious to the fact he turned 15 today. He's not a teenager, not really.

He loves Elmo and toys that make noise or light up. He loves music. He loves to go exploring, always in a delightful rush, like he's looking for a missing toy.

His mind never got beyond the innocent wonder, the sanctity of being a 2-year-old. The random cruelty of his birth left him with permanently bent, spindly arms that his mother likens to chicken wings. His hands aren't hands, just a tiny left finger, and two little right fingers.

He makes his own symphony on the piano in the dining room of his Ballston Spa home, banging the keys with his elbows.

"There are hard times. He does have illness issues, and pain," said his mother, Beth Smisloff. "But when he's feeling good, he's the happiest child I know."

Will has Cornelia de Lange Syndrome, a rare disorder that occurs once in every 10,000 births. Those with it resemble each other, small bodies and heads, high-arched eyebrows that meet over a turned-up nose, long, curly eyelashes, low hairlines, thick hair.

Besides stunted cognitive development, CdLS is often characterized by limb abnormalities, and complications like seizures, heart defects and digestive problems. There are severe cases and mild cases, and no cure.

Will's case is severe. He wasn't expected to live beyond early childhood.

He was the third child born to Beth and Mark Smisloff, who have three healthy daughters, Rachel, 19, Grace, 16, and 6-year-old Leah.

There was no joy the day they brought Will home.

"It was terrifying," his mother said. "It was kind of like grieving the loss of a child, the child you expected to have. It was the fear of the unknown.

"What was it going to be like taking care of a baby with mental retardation? He wouldn't know who we were. He had feeding tubes, so he'd be choking. It was sheer terror."

Learning to exhale

The first couple years of life with Will are a blur to his mother now, played out under the stifling fear he wouldn't live long. But before his third birthday Will underwent an operation that his mother said began, ever so slowly, to allow her to exhale.

Surgeons at Boston Children's Hospital cut a valve at the base of his esophagus to stem the acid reflux that tormented his tiny body. Food no longer would inch its way back up his esophagus and into his lungs.

"Before that, he was pretty much medically unstable and probably in a lot of pain," she said.

His difficult recovery from the surgery took close to a year, but finally signs came that Will was improving.

"There was more animation, more interaction," his mother said. "He seemed like he was happier and started to progress physically and socially."

It wasn't a magic-wand turning point, but for a boy like Will, a turning point nonetheless.

"Overall, life with Will has been a roller coaster, so that was sort of a reprieve," she said.

Opening doors

With time, the baby she was afraid to bring home from Albany Medical Center Hospital turned out to be a terrible joy, who has deeply enriched his family's life with lessons in the capacity for love and kindness in others.

"It seems like it's the worst thing in the world to have happen, but he's opened doors that never would have opened unless we had a child like him," she said.

Will was about a year old when Smisloff and her husband first reached out to clear away the cobweb their son's condition had spun around them. They attended their first CdLS medical conference in Boston.

"I met someone who had a son similar to Will," she said. "We became fast friends and have had a strong connection since. How that made me feel is hard to put in words, unless you experience it, just to have people who can finish your sentences and thoughts because they know the life you are living."

Today, the Smisloffs are cushioned in a safety net of support, spawned at CdLS medical conferences both in the United States and Europe.

Smisloff took up running four years ago as much to deal with stress over Will as fitness and, curiously, it led to another CdLS lifeline. On Oct. 22 she will run for the second time in the Chicago Marathon to raise \$50,000 for the Cornelia de Lange Syndrome Foundation, based in Avon, Conn.

Spreading the word

A couple years before she started running, the foundation had begun sending a group of runners to Chicago to raise funds to heighten awareness about CdLS. Once again, Will had touched his mother's life in an unexpected way. She found Web sites for runners and through message boards got marathoners to join Team CdLS.

This year's she's captain of a 17-member team, including four others from the Capital Region. The rest are from across the country, some who were there in 2004 and some who weren't.

"They know about Will and they are willing to join the team, just all great friends, good people," she said.

There are 4,500 known cases in the United States, and the foundation estimates there are 20,000 others with mild cases who have not been diagnosed. The money raised in the marathon will be spent on outreach and awareness to help find some of them.

"With the correct diagnosis, we can prevent potential medical complications," said Dr. Antonie Kline, the foundation's medical director.

Kline said the discovery in 2004 of the gene that causes it was a vital. "It's a great starting point for the investigation into treatment," she said.

The medical complications of CdLS will always be a heartbreaking reality for Will.

"He still has gastric issues, and there are infections that he has because he can't communicate it," his mother said. "Sometimes, he'll bang his head on the floor or the wall or anything he can when he's feeling pain."

Will can't talk and can only see clearly from four inches away, which is why he snuggles up close to a stranger's face for a better look. His mother said it's also a way he shows affection.

There are milestones for babies, sitting up, first steps, first words. The milestone that stands out most for Will's mother was nothing so sweet.

"His learning to eat by mouth was a huge one," she said. "It took years. He had stomach tubes but eventually he got to the point where he was able to eat 100 percent by mouth."

"Beth is a strong individual, very strong-willed," said Shane Kilburn, 29, of Ballston Spa, who will also run in Chicago and is her marathon training partner. "I can see it in the way she prepares for the marathon. She often talks about Will and her other children. Just from the way she speaks you can tell she's a great mother."

Thoughts and images of Will buoyed his mother near the finish line in Chicago two years ago.

"I thought about Will a lot, especially when I was struggling about the 20-mile mark, when your body really starts to ache," she said. "I thought about him and what he goes through and so he's really the one who got me through it."

"This time I'll be thinking of the same things, like what it must be like to live in his shoes every day, the challenges he faces and his pain."

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About Cornelia de Lange Syndrome

* It's named for Dr. Cornelia de Lange, a Dutch pediatrician who in 1933 identified the syndrome through an intensive study of infants and children afflicted by its common symptoms.

* It occurs in 1 in 10,000 births and it is estimated at least one child is born with it each day.

* There are more than 90 children/adults with the disorder in New York, including seven in the Capital Region. An estimated 900 others in the state have it but have not been diagnosed with it. There is no cure, but the 2004 discovery of the gene that causes it could lead to improved treatment.

* Most children with CdLS live well into adulthood; however, each child is evaluated for life-threatening conditions such as heart defects, untreated gastroesophageal reflux and bowel abnormalities.

* A foundation was established in 1981 in Avon, Conn., by Frank and Julie Mairano whose daughter has the syndrome. It's a family support organization that works to ensure early and accurate diagnosis. The organization promotes research into its causes. It serves more than 2,000 individuals with the syndrome, 10,000 family members and caregivers, and 2,500 clinical professionals.

Source: Cornelia de Lange Syndrome Foundation Inc.

About Team CdLS

* What: A 17-member team of runners will participate in the Chicago Marathon on Oct. 22 with a goal of raising \$50,000 for the Cornelia de Lange Syndrome Foundation in Avon, Conn.

* **Area runners:** Ballston Spa's Beth Smisloff, whose son Will has CdLS, is captain of the team, which includes four others from the Capital Region. They are George Super, Ghent; Jessica Patenaude, Saratoga Springs; Mark MacDougall, Watervliet; and Shane Kilburn, Ballston Spa. The other runners are from different parts of the country.

* **Where money will go:** CdLS Foundation director Julie Mairano said the money will be spent on education and outreach to help find individuals with mild cases of the disorder who have not been diagnosed.

* **How to help:** People interested in learning more about CdLS or donating can call the foundation at (800) 753-2357 or go to <http://www.cdlsusa.org>.

Symptoms at birth

* **Confluent eyebrows that appear arched and well-defined (99 percent of cases)**

* **Long, curly eyelashes (99 percent)**

* **Low front and back hairlines (92 percent)**

* **Turned-up nose (88 percent)**

* **Small head (98 percent)**

* **Eye and vision problems (50 percent)**

* **Excessive body hair, which may thin as child grows (78 percent)**

* **Hand abnormalities such as missing fingers, very small hands**

Source: Cornelia de Lange Syndrome Foundation: [Web site outreach@cdlsusa.org](mailto:Web.site.outreach@cdlsusa.org)

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