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Marathon run backs son's rare disorder

BY KATHY PARKER Gazette Reporter

William Smisloff is a loving child with a rare genetic disorder that has left him without hands or speech. The Ballston Spa boy will be 15 in a couple of weeks, but he is roughly the same size as his 6-year-old sister Leah and weighs 58 pounds, according to his mother, Beth Smisloff.

Smisloff spends the majority of her time watching out for Will as well as caring for three daughters and a big house on Chapman Street in Ballston Spa.

Will has Cornelia de Lange Syndrome or CdLS, which is believed to occur in approximately 1 in 10,000 live births.

"The condition was a surprise to us when he was born," said Beth Smisloff. "We had some red flags, but didn't know what was going on."

She said her obstetrician detected that the baby had stopped growing at about 34 or 35 weeks and an ultrasound examination was conducted, but there were no obvious anomalies seen.

"I remember the doctor commenting on the baby's eyelashes, but at the time we didn't know that long eyelashes are a feature of the syndrome," she said.

Other features include small stature and small head size as well as thin eyebrows, which frequently meet in the middle, and a short, upturned nose as well as missing limbs or portions of limbs, according to the Cornelia deLange Syndrome Web site. A degree of mental retardation is also a sign of the syndrome.

"The doctor was devastated later that she hadn't notices the problems with Will's arms in the ultrasound," Smisloff said.

She said Will was born at Albany Medical Center Hospital and weighed 4 pounds, 2 ounces. He spent the first six weeks in the neonatal intensive care unit.

"He experienced many difficulties at the start and had trouble coordinating breathing and feedings," she said. "He couldn't tolerate much food at the beginning. Most kids with this syndrome have gastroesophageal reflux, which means they lose most of the food they take in."

Will Smisloff has had several surgeries, including one to insert a permanent feeding tube in his abdomen.

His mother said he is given water and medicine through the tube.

"It took years to get there, but 100 percent of his eating is now through his mouth," she said.

Smisloff said she has an incredible support system locally and on the Internet.

"Families facing these challenges today are lucky their children are being born in the Internet age. The CdLS Foundation [based in Avon, Conn.] has wonderful resources and support," she said.

She said she and her husband Mark made fast and lasting friendships through the foundation when they attended a conference in Boston when Will was about 9 months old.

"We met parents with children who were about the same age as Will and we've kept in touch," she said. "It can be a life line in times of crisis to have someone who understands."

She said the medical staff at the foundation has also been helpful to local doctors who aren't well versed on the condition.

"A couple of years ago, Will got really sick and nobody knew what it was," Smisloff said. "We got in contact with a world-renowned geneticist, Dr. Laird Jackson, who suggested it could be pancreatitis, and that's what it was."

Smisloff and several friends will join dozens of other runners in the Chicago Marathon next month hoping to raise money and public awareness for CdLS.

She calls herself a "mid-pack runner" although she runs seven days a week usually starting at 5 a.m.

"It's a great stress reliever," she said.

Most of the people running for the foundation are strangers to Smisloff and come from around the country.

"We've set a goal of \$50,000 for the marathon but raising awareness is just as important as raising the money," Smisloff said.

Donations to the cause can be made on the foundation's Web site, [www. CdLSusa.org](http://www.CdLSusa.org). The mailing address is: 302 West Main St., #100, Avon, CT. 06001.

Smisloff said she and her husband have tried to make their home as normal as possible for themselves and daughters Rachel, 19, Grace, 16, and Leah, 6.

"We are used to Will's needs and his habits, but there are things he can't do, like going on vacations or downhill skiing," she said.

Smisloff's aunt, Kay Wagner, has been the family's backup caretaker for Will since he was 6 weeks old.

"She doesn't have grandchildren, but Will is like a grandson to her. He visits her once a week after school and on weekends and that gives us a chance to get out and do other things," said Smisloff.

She said a former teacher's aide who worked in Will's classroom has also become a family friend and hosts Will when the rest of the family goes away for more than a night.

"I can't say how lucky we feel that we have outside helpers that love him and will take care of him so we don't have to go to outside agencies," she said.

Will is very active and rarely sits still for very long. In addition to free range throughout the house, a special screened-in porch allows him to be outdoors and safe.

"We recently put in a hot tub and he loves it," said Smisloff. "He has a sensitivity to temperature changes, but he adores the hot tub," she said, noting the water is kept in the high 90s, or about body temperature.

"We have a pool but it's usually too cool and uncomfortable for Will," she said.

A piano in the family room is another favorite spot for Will, who taps out notes with his elbow, chin or toes for several minutes at a time.

"He'll repeat patterns of notes. He doesn't just bang on the keys," Smisloff said. She said her aunt was the first to notice that he liked musical toys that lighted up or musical activities when he was younger, and she bought him those and then let him play on her piano."

Will is very affectionate with his mother and returns often to her side for hugs and kisses.

The family has a large gray cat and a medium-sized mixed dog, but Will's not interested in either of them.

"They stay clear of each other," she said.

Smisloff said she's looking forward to returning her children to school next week and believes Will does better with structured weekdays.

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HANS PENNINK/GAZETTE PHOTOGRAPHER Beth Smisloff holds her son Will, 14, who has Cornelia de Lange Syndrome, at her Ballston Spa home on Thursday. Smisloff and a group of other runners will take part in the Chicago Marathon in October in honor of her teenage son.