

The Saratogian (saratogian.com), Serving the Saratoga Springs, N.Y. region

Bspalife

Behind the marathon mission

Family bond keeps them running

Sunday, October 18, 2009

By CARI SCRIBNER
For Ballston Spa Life

BALLSTON SPA — A family dedicated to caring for their disabled son would do anything to raise public awareness of his rare syndrome, including running a marathon.

Village family members assembled a team to take part in the Chicago Marathon Oct. 11, drawing attention to the genetic condition called Cornelia de Lange Syndrome that affects Will Smisloff, 17, and raising approximately \$80,000 for CdLS research and awareness programs.

Will Smisloff was born with CdLS. Affecting an estimated one in 10,000 births, infants with the condi

tion frequently go undiagnosed for years. CdLS is characterized by small size, reduced mental capacity, missing or malformed limbs and gastrointestinal difficulties.

Will Smisloff was born at Albany Medical Center weighing about 4 pounds, and spent weeks in the neonatal unit. Since that time, he's had health challenges including pancreatitis and infections in his feeding tube, which is now used for liquids and medicine since he learned to eat on his own.

Beth Smisloff said there wasn't any indication about her son's syndrome before his birth, but in time, the family adjusted. Will Smisloff has three sisters, Rachel, now 22, Grace, 19, and Leah, 9.

"The first year or two were rough," Beth Smisloff said. "But he was my third child and I had little ones running around, so I couldn't just curl up and stay in bed."

Will Smisloff doesn't have fully developed hands, his arms are partially formed and he isn't able to speak. But he scoots around his Ballston Spa home, attends school, and conveys affection to family members.

"Will has raised the bar for all of us in our life experiences," Beth Smisloff said. "Having him has helped me face my fears. It's like a marathon; you can't give up when it gets hard."

Beth Smisloff and her daughter Grace ran in the marathon, while Will's father, Mark Smisloff, and other two sisters were the "curb crew." Will attended as the team's ambassador. Another family member, Will's aunt, also joined them in Chicago.

Beth Smisloff said she and Grace trained during spring and summer for the marathon.

"I started running many years ago as a way to get back in shape, and I worked my way up gradually," Beth Smisloff said. "In the beginning, my goal was to complete a mile. I find Will is an inspiration to all of us. Every day you need courage."

This is the ninth year the Smisloff family has organized a team for the marathon.

This year, four children with CdLS were in Chicago, which gave the Smisloffs a chance to talk to other families coping with similar experiences.

"This is a rare enough syndrome that you don't often get face-to-face time with other families," Beth Smisloff said.

Will Smisloff has been in a Ballston Spa Central School District program called Bridges that teaches children life skills and helps students socialize. Although he's picking up skills such as making choices, Will Smisloff will need 24-hour care for the rest of his life, his mother said.

As her son becomes an adult, his parents are wrestling questions about where he will live and who will care for him.

"This is a new life stage for Will, and unfortunately there aren't many options," Beth Smisloff said. "The downturn in the economy has cost adult residential programs a lot of funding. It feels like a family has to abandon their child in order to secure future care."

The family was working on a plan to build a home for disabled young adults, but that project, too, fell through after the construction industry hit a lull and funding dried up.

"There was a proactive time when families could come up with solutions and be creative to meet the needs of the disabled, but that time has come and gone," Beth Smisloff said. "There's a real crisis happening that many people don't know about."

Beth and Mark Smisloff keep a close eye on their son's physical health, which can change quickly.

"At any given time, things can be calm and then suddenly there's a crisis," Beth Smisloff said. "One of the most frustrating things is when Will has pain of unknown origin. He can't tell us where it hurts, so we try soothing activities like riding in a car or being pushed in a stroller."

As they continue to seek options for Will Smisloff's future, family members focus on the improvements he can make with adaptive equipment allowing him to feed himself and increase his physical communication, even to a small degree.

"Our main goals for Will are to keep him happy, stimulated and safe," Beth Smisloff said. "Overall, he's doing pretty well. But we want to raise awareness, money for research and education and support for this syndrome and others leading to disabilities."

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