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For teachers, a marathon quest to end a daughter's disease

October 31, 2009 By LAUREN CIOFFI. Special to Newsday

When Laura Perfetti, a fourth-grade teacher at Robins Lane [Syosset](#) Elementary School, gets dressed for Sunday's ING [New York City Marathon](#), she will put on her sneakers, slip into running shorts and strap on a set of antennae and ladybug wings.

After raising \$17,283 for neurofibromatosis research, Perfetti, of [Glen Cove](#), and seven other teachers will be representing Perfetti's daughter, Julia Perfetti, 7, who was diagnosed with the disease when she was 4.

"It's going to be a girl, and her name is Ladybug," Perfetti's son, Jacob, said seven years ago, pointing at Perfetti's belly.

When her daughter was born with a coffee-colored birthmark on her stomach, the nickname stuck. The family was unaware that four years later, Julia's spots would multiply and small, benign tumors would form on her toes.

In neurofibromatosis, tumors grow on nerves and produce other abnormalities, such as skin changes and bone deformities, according to the National Institute of Neurological Disorders and Stroke. An estimated 100,000 Americans are born with the disorder.

"With NF, your cells are going on a highway at 90 miles an hour," Perfetti said. "Normally, they get off the highway when they are supposed to and they go at the right speed, but with NF, the cells start multiplying too fast."

Perfetti and her family have raised more than \$75,000 for research and are looking forward to the race. "It does matter that you raise money," Perfetti said. "But it also matters that you raise awareness."

Since Julia was diagnosed, MRIs and doctor's visits have made her family's life much different from before.

"All these teachers, they live with me day to day," Perfetti said. "They are my co-workers and they see how my family is affected."

Last June, Lori-Ann Pizzarelli, an art teacher at the school, joined with five other teachers to help support Perfetti and her fundraising. Perfetti said the seven women trained on a trail in [Bethpage](#) and together ran a half-marathon in [Queens](#) on Sept. 20.

"We always think about why we are running," Pizzarelli said. "I think this is life-altering, what we did, and we are starting the marathon off flying."



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