Foundation for an Ossining youngster

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Like proud parents everywhere, Terence and Carolyn Finn speak with pride about the little girl with sandy brown hair and a gap in her front teeth who took center stage in their lives, littering their neat living room of art books, fresh flowers and Japanese prints with a toddler's toys.

Their eyes brighten when they talk about Emily's first canoe ride at Lake Mohonk, the meticulous care she took when deciding which cartoon to watch, the little jokes she made on the family couch.

But unlike other parents, the Finns must speak in the past tense about Emily, their only child.

A rare and severe form of a genetic metabolic disease carried her away from her comfortable Ossining townhouse at the age of 2 years and two months. The genetic malady — carnitine acylcarnitine translocase deficiency, or CACT deficiency, part of a larger group of metabolic diseases that affect around 1 out of 15,000 births — made it impossible for Emily to produce an amino acid that processes fatty acids.

As a result, toxins built up inside her body and destroyed her vital organs. The disease finally caused her heart to stop April 3, when she went to sleep in a hospital room at New York Presbyterian Hospital in upper Manhattan with her parents at her side and never woke up.

Emily is still center stage in the Finn household through the creation of a memorial medical fund established in her name. The Emily Finn Thanksgiving Foundation, headed by the Finns in cooperation with an Episcopal church in Scarborough and the Fatty Oxidation Disorders (FOD) Family Support Group, will promote medical research and offer assistance to families facing these types of diseases.

The Finns said they felt obliged to honor Emily's memory by helping others who may face a similar predicament.

"It's what they call an 'orphan' disease. There's no initiative to study it because it affects so few people," said Carolyn Finn, 40, who works in human resources for a Manhattan media firm. "She was our beautiful daughter, and through her short life, she really supplied a lot of medical knowledge, and a part of me would like to continue that element of Emily, helping doctors to understand her condition. Part of me wants to continue what Emily started."

Terence Finn, 32, an information technology specialist, said support from their family, church and community was crucial, and it was time to repay the kindness they had received. "We've been so blessed, we want to help others," he said.

The fund, which has already received several thousand dollars in donations, could provide a few valuable insights into a condition that is little understood.

Dr. Wendy Chung, an assistant medical professor and the director of clinical genetics at Columbia University, said, "We learned a lot about the condition from Emily. Because we only come across children like Emily one or two times a year, it's hard to make great strides forward because the condition is so rare." Small advances into the treatment of the malady "could be incredibly useful," she noted, and medical progress was often propelled by committed group of activists. "A lot can be said for people pushing. Often times it's the squeaky wheel that pushes things forward faster," she said.

Since Emily could not eat normal food or baby formula, she subsisted on a carefully prepared mix of nutritional supplements and oils. The Finns are hoping better treatment options might be developed in the future, and they are also promoting public awareness of metabolic disorders and the need to detect them at birth, since the earlier the diagnosis is made, the better the outcome.

Newborn screening methods are set by individual states and vary widely across the country. Advanced screening methods for babies that can test for more than 40 metabolic diseases, which cost around $40 to $80, are not required in all states. New York state requires that newborns be tested for eight metabolic illnesses, as does Connecticut. Some states like Oregon, Massachusetts and North Carolina require testing for more than 30, while Kentucky requires four, Utah only three.

The foundation for Emily Finn has its address listed at St. Mary's Church in Scarborough, where the Rev. Hillary Bercovici described Emily as "this little pixie of a kid, with a real force of character."

He said the foundation would be a fitting tribute. "Some kind of funding might increase the life span of another child," said Bercovici, a former paramedic. "I can't think of a better way to commemorate her. This kind of transformation, losing a child, is something really awful and to make it healing for others, it's a good way to handle grief. To transform grief into hope, it's a wonderful thing."

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