August 1, 2013

Farmingville, NY - On August 5, Supervisor Ed Romaine met with the family of 8 year-old Emily O' Connor near the location where a contractor for the New York State Department of Transportation mistakenly removed the landscaped "Adopt-A-Spot" center median on Ronkonkoma Avenue just north of the Long Island Expressway. The median had been "adopted" by the O'Connor family to bring awareness to San Filippo Syndrome, a rare and fatal genetic disorder that Emily was diagnosed with at the age of 5 ½ years old.

"Emily's family contacted my office seeking help in getting the median restored back to the beautiful garden that they and their friends had created," said Supervisor Romaine. "The median is on Town property and we were not advised that it would be removed. I have received assurances from the Governor's office that the contractor will make good on his promise to make it right again. We will monitor the situation closely and make sure something like this never happens again."

San Filippo Syndrome is a metabolism disorder passed down through families. It prevents the body from properly breaking down long chains of sugar molecules called glycosaminoglycans (formerly called mucopolysaccharides). The syndrome belongs to a group of diseases called mucopolysaccharidoses (MPS). Specifically, it is known as MPS III.

To learn more about Emily's fight against San Filippo Syndrome, go to www.facebook.com/Emilysdance.