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A Father's Effort To Find The Cure For Cooley's Anemia

Bedford Corners dad Peter Chieco works to find the cure to his daughter's rare blood disease.

By Marisa LaScala

Peter Chieco of Bedford Corners isn't just a VP at Morgan Stanley. He's also a crusader for Cooley's anemia, also known as thalassemia major, a rare genetic blood disorder that affects the body's ability to produce normal red blood cells. Cooley's anemia primarily occurs in those of Mediterranean, Asian, and Middle Eastern descent, and, in the past, a person with the disease would have been lucky to live to the age of 10. With advances in treatment, those with Cooley's anemia—like Chieco's daughter, Michelle,

who was diagnosed as a baby—can now live into their 20s and beyond. Michelle is currently 25 years old.

Cooley's anemia doesn't affect a huge proportion of the population; the World Health Organization estimates the worldwide number of cases to be around 300,000. But, for those who do suffer from it, treatment can be intense. "Since she was a year old, my daughter's had to go every two weeks to get a blood transfusion to bring her red blood cell levels up to normal," Chieco says. "But when red blood cells die, their basic component is iron. Iron is something that your body does not normally excrete on its own. And so, when you get extra iron, it's very difficult to get rid of it. If you don't get rid of it, those blood transfusions will give you life, and then the iron in the blood transfusions will kill you."

Until recently, to avoid a toxic buildup of iron, a medicine called Desferal, which helped the body excrete iron, needed to be injected into the stomach and administered by a battery-operated pump for 10 to 12 hours a day, every day. Within the past few years, however, an oral drug has been developed (though it still requires patients to take up to 12 pills a day). "Getting the Desferal allowed our patients to live longer, but the compliance of doing this pump every night for 10 to 12 hours was so difficult that the iron would still accumulate rapidly," he says. "Now, with the addition of the other drugs available, patients can do what my daughter does, which is take the pump and the pill in combination at different times. So if she can't put a pump on one night, she'll use the pills during that day. What we find is that they actually work better together."

Though the advances in treatment may have increased the lifespan of people with Cooley's anemia, the real goal is a cure. "That's what we're really hoping for, with gene therapy," Chieco says. "This disease has been cured through someone getting a bone-marrow transplant from a perfect match. So because they can do it with a bone-marrow transplant, they know that it has the potential to be done with gene therapy. That's what we're very excited about, not only for the patients here in the US, but throughout the world. The US has access to good healthcare. But many countries that are impacted by this disease are so poor that many of the children die at a very young age because they can't even get access to the current treatment."

The biggest hurdle, of course, is that so few have heard of the disease. If you're interested in helping, Chieco recommends reaching out to the Cooley's Anemia Foundation, which is celebrating its 60th anniversary this year. Chieco himself was a past national president of the foundation, and he still runs the Westchester/Fairfield chapter. For more information, visit *www.thalassemia.org*.