

CDKL5. A rare disease with no apparent cause, no cure, and a very clinical name.

Avery Rose Leopoldino of Westbrook, now 5 years old, was diagnosed at two years old with this extremely rare disease. Avery's parents, Mark and Kristin, partnered with the Community Foundation of Middlesex County, creating Avery's Fund, a donor advised fund which supports research into the cause of CDKL5 and a cure. Friends, neighbors, and businesses, including Bill's Seafood in Westbrook, have taken up the cause to bring attention to this disorder and to aid in raising money for the support of research.



What is CDKL5? CDKL5 is a rare X-linked genetic disorder that results in early onset, difficult to control seizures, and severe neuro-developmental impairment. There are fewer than 200 cases worldwide, however, more and more children are being diagnosed as awareness of CDKL5 spreads.

Most children affected by CDKL5 suffer from seizures. Most cannot walk, talk or feed themselves, and many are confined to wheelchairs, dependent on others for everything. Many also suffer with scoliosis, visual impairment, sensory issues and various gastrointestinal difficulties.



Avery with Mark Leopoldino, Donny Marshall, Greg Rainey, and Cynthia Clegg at the 2013 Rainman Invitational.



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