Against the Odds,
Danica Deneault, now in Kindergarten,
Thriving at Meeting Street

Diagnosed with Aicardi Syndrome—one of the rarest disorders in the world—months after being born, Danica Deneault wasn’t expected to live beyond her 5th birthday. In fact, doctors told her parents, Erik and Dawn, that it was unlikely Danica would ever walk, talk, or eat on her own.

“The news was absolutely devastating; I couldn’t even process what they were telling us,” recalls Erik.

A disorder in which the structure that connects the left and right sides of the brain is partly or completely missing, Aicardi Syndrome affects fewer than 900 girls across the globe. And, Danica may be the only girl in Rhode Island with the disorder.

Determined to give their daughter every chance, the Deneauls turned to Meeting Street’s Early Intervention Program when Danica was just 3 months old.

Danica is now 5 and began Kindergarten at Meeting Street this September. She is one of a very small handful of girls with the disorder to make impressive developmental progress, progress her family credits to Meeting Street.

“Danica has benefited from nearly every intervention and therapy that Meeting Street has to offer,” says Erik. “Each therapy—occupational, vision, swim, speech, and physical—are integrated into her days at Meeting Street.”

While Danica remains non-verbal, Meeting Street’s approach to her intensive therapy helped Danica learn to walk unassisted this past year. She can also breathe and swallow on her own—all of these milestones on full display when the family recently attended a national conference on Aicardi Syndrome in Chicago.

During the conference, the Deneauls met 150 families like their own, but less than six of the girls they met were able to walk unassisted. As Erik fielded question after question about what his family has done to help Danica advance the way she has, he kept coming back to the same response: Meeting Street.

“Too many people fear that there is no hope for their daughters, but that hasn’t been our approach,” says Erik. “Danica keeps surprising us; every week she comes home from Meeting Street able to do something new. Her progress has also continued to impress her team of neurologists that have been treating her for years.”

As Danica embarks on the next chapter of her life, the Deneauls remain optimistic about her future. Already having passed the 5-year life expectancy mark, Erik sees the next benchmark as his little girl turning 7. But, he can already see well beyond that.

“In my mind, I can see Danica as a teenager,” he says.

In part to pay it forward for the ways they’ve been helped, Erik and Dawn created a nonprofit, “Little Heroes,” to provide children with special needs with walkers, wheelchairs, and other needed items. On September 7, they held their “Little Heroes Motorcycle Run” to benefit Meeting Street.

“The integrated classrooms at Meeting Street are a huge benefit to Danica; all of the children learn and play with her and hold her hand to help her walk through the hallways and to class—this is just as important as the therapies they offer,” says Erik. “Meeting Street has helped Danica lead a more normal life, and we’ll be forever grateful.”

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