

Hello! Our twin daughters Eliza and Adeline (Addy) are in the incoming kindergarten class with your child at Jason Lee.

All children have strengths and weaknesses, challenges and differences. And our daughter Addy has some physical differences that may be something your child notices and speaks with you about. We hope that with this letter, we can reduce any discomfort for your child and help foster understanding and acceptance.

Addy has **Moebius Syndrome**. It is a very rare disorder (1-20 in a million) that affects facial movement and muscle function due to underdeveloped or missing cranial nerves in the brain. So Addy cannot smile or frown, or make any facial expressions involving her cheeks, lips, or eyebrows. She also cannot blink or squint, or move her eyes from side to side, so she can appear to be staring or unhappy. We give Addy eye drops to keep her eyes hydrated. People with Moebius Syndrome roll their eyes to hydrate their eyes (apparently we all do when we blink!), so don't take it personally if she rolls her eyes while you are talking to her. :)

Addy also has challenges with gross motor skills and eating. Her muscles are weaker than other children her age. She will be monitored on the playground, because if she is bumped or pushed, she may easily lose her balance and fall. We would love for you to talk with your child about being aware of this and making sure they try to always have a safe body around Addy. Eating can be tricky, too. Her tongue isn't able to move as much as ours, and she also is unable to chew with her mouth closed. So please don't think she has bad manners, it's just the only way she can eat!



Other than these differences, Addy is just like many other five year olds. She is social, affectionate, loving, and silly. She loves music, singing, dancing, pretend play, Trolls, My Little Pony, and unicorns!

A big question we get is, "How can you tell how Addy is feeling?" Addy is very communicative in her words/voice (she can answer how she is feeling, and she yells when she is upset), and body language (bouncing or clapping when she is happy or excited, stomping when she is angry). It's really not hard to tell how she's feeling. :)

If your child asks you about Addy, we want to assure you, and them, that she is generally happy, even though it may not appear that way. Addy is not mentally impaired, and the condition is not progressive.

You may have some questions, and we will be happy to answer any of them. Questions, from adults and children, are always welcomed! We also always celebrate *Moebius Syndrome Awareness Day*, which occurs each January 24th (everyone wears purple). Thank you for taking the time to read this, and we look forward to many school years together!

Brittni & Kyle Jones