HI, MY NAME IS NOLA

Age: 10

Motto: "I Feel Happy"

Diagnosis: SETD1B, ANK3, PANS, CVI, and JIA

Dream Team: Georgetown East View HS Theater

Nola was adopted from China right before her third birthday, and her parents quickly noticed some differences. At first Nola had very little hearing ability, which caused major speech delays until she received a set of ear tubes. Every year for the last six years Nola received a new diagnosis of some kind, including cortical vision impairment, occipital lobe epilepsy, autism, intellectual delay, insomnia, mixed expressive/receptive speech, autoimmune juvenile idiopathic arthritis, and asthma. Nola takes several medications and attends multiple therapies to improve her skills and combat some of her many symptoms.

Through CC4C, Nola's mom learned of The Texome Project that does whole-exome sequencing, and Nola was accepted as a candidate for their research. In April 2023, following a visit with a geneticist at Texas Children's in Houston, Nola's genetic results came back with two rare genetic disorders: SETD1B and ANK3. There are currently only around 40 individuals identified with SETD1B, and Nola is the only one to have both of these disorders.

Nola is very funny and delights in making others laugh. She has a deep appreciation for music and can be found most days with her headphones in, listening to Pandora. She loves anything to do with food, and enjoys playing in the water! She gets really excited when she is praised, which makes her want to work harder. Despite the unknown, Nola's future is bright and full of God's promises.

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