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HI, MY NAME IS NINA

I was born in 2013... and have been diagnosed with STX BP-1

As a baby, Nina missed every milestone, and by 7 months, we had her in every kind of therapy we could think of - PT, OT, and aquatherapy. After years of extensive testing that had not provided us with an answer, this fall, we were able to have the whole exome test done, and Nina received her diagnosis in January. She has a rare, non-inherited genetic disorder caused by a mutation on the STX BP-1 gene.

This disorder doesn't have a catchy name - it's simply called STX BP-1. The gene was identified in 2008, and there are only about 300 reported cases worldwide to date. Most of what is known is anecdotal, and there is a dearth of research and knowledgeable specialists. STX BP-1 is responsible for producing a protein that controls how neurotransmitters are released; because of her mutation, Nina's neurotransmitters are not firing correctly, leading to significant intellectual disabilities, gross and fine motor difficulties, and some sensory issues. Nina requires constant supervision since she is essentially a young toddler with no sense of danger. She is non-verbal, but has some ASL signs and is able to communicate a great many things with her own unconventional system of gestures and noises.

Our Nina is loving and affectionate, joyful and happy. When she was two and a half, she took her first steps and hasn't stopped moving since; she runs, she jumps, she climbs, and she's fast! She is quite mischievous and is able to reach things that are seemingly out of her reach in the blink of an eye, earning her the nickname "Nina the Ninja." She loves hugs, silly noises, Curious George, swimming, stuffed animals, musical theater, and our family dog.

High School Team
Placeholder team name

Champion Teammate
Placeholder teammate

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CHEYANNA'S CHAMPIONS 4 CHILDREN
uplifting the rare & undiagnosed

Nina's Motto:
"Joy and Love"