

# HI, MY NAME IS SOPHIA

I am 10 years old and I have been diagnosed with a rare condition.



At 6 months old, Sophia's pediatrician had a feeling that she may have a genetic disorder, based on her facial features. He referred us to a genetic doctor, as well as a cardiologist, due to the sound of her heart. Sophia was diagnosed with an extra valve on her heart and a very rare chromosome duplication 1Q21.1. No medical knowledge of her chromosome duplication exists. Sophia is currently in two different studies on her specific duplication and is the lead patient for their medical research.

Almost a year later when she was 16 months old, she had surgery to correct the valve on her heart. Less than 6 weeks after that, our lives changed dramatically. Sophia went completely non-verbal and was experiencing severe migraines that caused her to be on a liquid diet for the next 2 1/2 years. Within 4 weeks we would begin our journey.

From January 2012 to December 2012 we had a team of 12 doctors monitoring and giving us a list of diagnoses. Chiari Malformation, Cranial Stenosis, severe sleep apnea, failure to thrive. On December 12, 2012 she had an extensive surgery on her head and neck to relieve pressure on her brain and neck.

Sophia has a "multiple complicated medical diagnosis", a combination of 8 as of today. Sophia has the most beautiful outlook on life. She loves people, nature, and animals. She would love to ride a horse one day. She is so expressive in how she describes beauty. I tell people all the time, "Everyone needs a Sophia in their car."



CHEYANNA'S CHAMPIONS 4 CHILDREN

*Uplifting the Rare and Undiagnosed*

Sophia's Motto:

## “I Can Do It”