



## **MADDIE MENDRALA** **6 YEARS OLD**

**Motto: Proverbs 23:19**

**High School Team: Cedar Park Cheer**

**Champion Teammate: Talaya  
Frazier**

Since birth there were small things we noticed that were odd with Maddison. When she turned two we decided there was definitely something wrong and started our long journey of specialists. It was in Baltimore that a bone disease specialist confirmed that it was an unspecified bone disorder similar to Osteogenesis Imperfecta. Shortly after that we saw our 4th geneticist at Texas Children's Hospital, who agreed. He helped us enroll in a Whole Exome research study through Baylor College of Genetics. Two years later we were finally given an answer. She has a de novo mutation (meaning neither mom nor dad have it) that they believe is causing her issues. To date she is the only one in the world with this mutation so there is no information on what this disease is or potential complications.

Over the last 4 years Maddie has had over 25 fractures, chronic pain and fatigue and other conditions to name a few. She has had over 10 anesthetized procedures in four years, and countless X-rays. She spent four years in speech, occupational and physical therapy. She has done two years of three day inpatient Pamidronate (osteoporosis medicine) infusions every three months to strengthen her bones and reduce pain. She is currently under the care of a pain management specialist to reduce her chronic pain. Overall, she is a happy healthy little girl who loves dancing and playing with her friends. She has an amazing personality and you would never know everything she's been through.



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