

Chayse's Story ★



Born just 15 months apart, brothers Chayse and Cruze were inseparable. They shared a love of the great outdoors and were best mates. Sadly, the boys also shared a rare genetic disorder known as LPIN1 causing the body to attack itself – where muscle cells become stressed and leak protein into the bloodstream.

6 y/o Cruze tragically lost his life from the condition after going into cardiac arrest in 2018.

“Our lives were torn apart when we lost Cruze,” mum Kristen said. “He’d just had a sore tummy and a mild fever and three days later, he was gone.” After Cruze’s shock passing, Kristen and dad Michael decided to have Chayse, 5, and his brothers Talon, 10, and Jordon, 17, tested for the genetic disorder.

They were still anxiously waiting for the test results when Chayse started developing sore hips and was having trouble walking. Chayse was admitted to hospital with dangerously high levels of a muscle protein which can lead to heart failure. His muscle protein levels were 7,000 when normally they’re between 2–200.

Then came the test results his parents had feared. Five-year-old Chayse tested positive for the same genetic disorder as Cruze and his older brother, Talon, was a carrier of the gene deletion. Fortunately, their eldest son, Jordon, is free from LPIN1.

“I had the terror of knowing that what happened to Cruze could happen again. I remember Chayse asking me if he was going to die,” mum Kristen recalls.



Chayse was immediately transferred to Melbourne’s Royal Children’s Hospital and during that agonising time getting their heads around Chayse’s prognosis, the family discovered Starlight.

“Spending over 40 nights in hospital between May and December showed me just how important Starlight is. We were constantly on edge, so to have a little bit of happiness for Chayse really took the pressure off.”

When Captain Starlight visited Chayse on the hospital ward, he could play, laugh and be a kid again.

Kristen said Captain Starlight helped Chayse cope with everything he was going through. “Knowing that there is something to break up time in hospital and bring us joy is essential to our family’s wellbeing.”

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When he’s well enough to leave his hospital bed, Chayse loves going to the Starlight Express Room to play video games with the Captains and loves to make an appearance on Starlight TV.

Kristen said the family cherish every moment together and try to live a normal life as possible while managing the ongoing stress associated with Chayse’s condition. The family can no longer travel freely without Chayse’s ‘home’ hospital notifying the destination hospital to ensure they have adequate medical care should they need it when outside of Melbourne. “We live with the constant worry that one episode will take him away from me like Cruze was.”

And to Starlight supporters she said, “You have shown us that there are people in the world who care.”