

Sophie's Story

Sophie, seven years old, is living with a rare genetic disorder. At the tender age of three months old, Sophie's parents noticed she struggled to support the weight of her own head. Concerned about their daughter, they began seeking medical advice. After numerous hospital visits and tests, a bloodwork test revealed Sophie's rare genetic disorder diagnosis known as Malan syndrome. The doctor provided insight into the challenges that lay ahead for Sophie, including grappling with low muscle tone and seizures.

The years went by, and Sophie was doing well with her walker—catching more speed with every step. Shortly after her third birthday, she collapsed. Sophie was hastily moving along with her walker, her favourite thing is speed (next to relishing in music and water play), when a seizure took her completely off balance. This was Sophie's first experience with a seizure, and from that day, they continued to come in clusters of 5 minutes or more. Her and her parents' world was turned upside down. Suddenly, their lives were filled with ambulance rides to the hospital 2-3 times per week, sleeping became difficult, and fear of the unknown sank in.

Today, Sophie uses a wheelchair for the most part, receives medication three times a day, and has home care assistance. "Sophie is thriving!" Kaylee, Sophie's mom, shares how her now seven-year-old daughter is doing. "We've seen amazing results with her medication. She sleeps much better, and it gives her comfort to get through the day." Sophie is a happy child. She loves to explore in her wheelchair and swinging on her swing. Sophie treasures moments with her family, especially while on drives and taking in each tree as they dance by her window. And she loves indulging in all sources of music: watching musicals, creating her own music on toy instruments with her younger sisters, Khloe, and Raelynn, and listening to her favourite band the Glorious Sons.

When Sophie and her family learned she was eligible for a wish it was an unexpected, heartwarming moment of untethered joy that swelled both their hearts and eyes. "Knowing there is going to be some kind of help for Sophie and the thought that it is going to impact her for a lifetime has us excited about brighter days ahead," Kaylee remarked, with heartfelt gratitude. Sophie is still dreaming up her wish. But while she explores endless possibilities of her most heartfelt wish, and the hope it represents for a brighter future, it will provide a source of strength as she and her family have something life-changing to look forward to: Sophie's wish coming true.

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Still wishing

Sophie, 7
rare genetic disorder



believe
in the **POWER** of a
wish