

Benjamin Merck was adopted as an infant by Mark and Linda Merck. He had a healthy and active childhood, participating in several sports, school and church activities in his home town, West Fargo, North Dakota.

In the spring of 2019, Benjamin started to display symptoms that caught his parents off guard. His speech was spurred. Swallowing became difficult. He had weakness in his right arm. A visit to the doctor started a string of medical tests, hospital stays and intense worrying for the Mercks.

Doctors in Fargo and Sioux Falls, South Dakota, were mystified by the symptoms in a 15-year-old. Eventually, a trip to the Mayo Clinic in Rochester, Minnesota, provided an answer. Benjamin was diagnosed with ALS in October of 2019. He was a carrier of a mutation in the FUS gene. Benjamin died November 26, 2019, five days after his 16th birthday.

Family and friends mourn his loss still, but they remember the joy Benjamin brought with his happy-go-lucky attitude and kind heart.