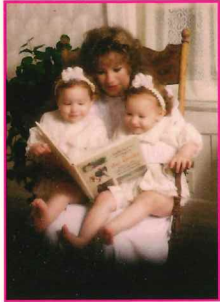


ALEX'S STORY

Our 11-year old daughter's 6 year battle with ALS.

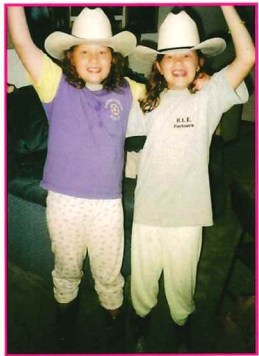
Our twin daughters, Alex and Jaci Hermstad, from Iowa loved horseback riding, the outdoors, and sports. Alex began noticing pain and weakness pitching in Softball as well as weakness holding her clarinet.



Prior to a softball game, her doctor suspected she had a brain tumor and should follow-up at a children's hospital. A parent's worst nightmare was coming true.

This began a long and tumultuous cascade of events where Alex endured literally hundreds of tests and numerous doctors to try to find a diagnosis. We were told that Alex's motor neurons were shutting down and couldn't conclude why, but that it was terminal. Her diagnosis was a mystery. Alex continued to worsen. The only realistic option for treatment was not working.

For the first time, our daughter asked "Am I going to die" and "Will I get to go to high school" but never asks, "why me?" She no longer was able to do the things she loved! The harsh reality of not seeing our little girl grow up was becoming apparent. Our world was at a standstill.



Suspecting her illness was an environmental issue we left our home immediately and everything behind! We were forced to give up our family dog. The simple things we all take for granted such as going to the bathroom, showering, brushing teeth and hair, and even sitting became laborious for her. A fall one day stranded Alex on the floor as her mother could not lift her to her feet. Both her mother and Alex wept as it became painfully obvious that an unforgettable and heartbreaking milestone had been reached.

Alex would never walk again. Without the ability to walk, she could no longer attend school. We suspected an infectious cause and began a course of antibiotics, however, this only seemed to worsen her condition.

Her breathing became more and more labored and she was rushed to a hospital and set up on BiPAP. We were told she wouldn't make it through the night. She beat the odds. Facing so much uncertainty, Alex, only 12-years old, with immeasurable perseverance and determination chose "life," underwent a tracheostomy, and was ventilated.



8-22-93 - 2-14-11

Months later, still on ventilator and with a feeding tube, Alex and her family returned home, which had been turned into a make-shift hospital, storing boxes and boxes of medical supplies. We needed to rely on in-home, around-the-clock nursing care. Remembering the sounds of Alex singing her favorite songs had now been replaced by the "swoosh" and beeping of a ventilator.

We adapted to a "new" normal as our hopes and dreams for watching Alex grow up were shattered.





Alex continued to deteriorate, but not her spirit and will to fight. Somehow she kept her faith and remained hopeful and optimistic. She didn't want people to feel sorry for her and never wanted to give up. She was playful and loved to prank people especially with her nurses. Almost every nurse was initiated with a super soaker!

Alex's family desperately devoted their days searching for answers and help. Her case was so rare that she didn't meet any criteria for any organization or foundation.

Losing her ability speak, we relied on communicating with her beautiful smile. Her family made t-shirts describing her spirit: "Unable to Move – but moving hearts, moving souls, inspiring lives EVERYDAY."

Eventually, she lost her smile – her only form of communication. Her resourceful nature prompted her to communicate through rolling her eyes. At this point, we had watched her go from being a normal, healthy child; playing sports, giggling at silly jokes, playing with her dog, building a snowman, and riding her horse, to being unable to breathe on her own, speak, walk, eat, smile or even give a hug. We were left heartbroken and helpless. Having your child robbed of the mere act of hugging you or hearing her say "I love you" is unimaginable!



Because of the seriousness of her condition, even with around-the-clock nursing care, her needs were so intensive that someone needed to constantly be by her side. We eventually discovered with the help of a world-renowned researcher her illness was due to a mutated gene called, FUS, associated with ALS. (The FUS gene mutation wasn't discovered until 3 years after Alex's symptoms first began). It is our belief that her gene malfunctioned due to environmental and infectious causes.



Feb. 14, 2011 – Alex continued to grow extremely tired. With a heavy heart and after 6 years, Alex peacefully went home fighting an enduring, courageous battle at just 17-years old. Arrangements were made to have her brain tissue donated to researchers in hopes a cure could be found and help others.

We later discovered that Alex has been the youngest girl in history with this disorder, and certainly the only identical twin as far as we knew.

Today, we carry on Alex's Legacy promising her we would never give up fighting for her and what she would have wanted. Her limitless courage and boundless strength will be passed on to all those who are met with such insurmountable challenges.



- ⇒ We are working to bring her story to the forefront for ALS awareness.
- ⇒ We are working to craft legislation to help families with a medical catastrophic illness.
- ⇒ We are working to build a foundation in Alex's memory. Alex's family has created a very simple idea to raise \$100 MILLION/year to devote towards a cure for neurodegenerative disease by conducting highly specific research! But, we need your help and influence for this to make this happen.

Help us by joining Alex's Army and follow her at:

www.caringbridge.org/visit/angelsforalex <<http://www.caringbridge.org/visit/angelsforalex>>

On the night Jesus was born, the wise men used the light of the northern star to find their way. After a storm, clouds typically would slightly part and the sun would peek through with brightness. Her sister Jaci recalled that Alex would always say that this meant that God was bringing another angel home to Heaven. Ironically, late in the night of Alex's passing, the sky was so bright that our Pastor (not knowing what Alex used to say), mentioned on his drive to our home that there was such a glow so bright in the sky that it was as if that glow led him to our home as if he didn't even need to turn his lights on.

"Hardship often prepares an ordinary person for an extraordinary destiny" - C.S. Lewis
Joshua 1:9 "Be strong and courageous! Do not tremble or be dismayed for the Lord your God is with you wherever you go"

