Cale Ferrin, Age 7

Anna (2 ½), Cale (7), JJ (8)

We would love for you to meet our son, Cale. He is our 2nd child, and was born at 38 weeks on September 14, 2006. At 20 weeks in-utero, Cale was diagnosed with hydrocephalus (fluid on the brain), and was closely monitored for other related serious health problems. His brain cavities were so full of fluid, that it was very hard to tell if he would have any normal brain activity at all. At delivery, the doctors were stunned to see his abnormal growth in arms, missing bones, and other anomalies. It turns out that his hydrocephalus is a side-effect of a rare genetic disorder, Fanconi Anemia (FA).

Cale was diagnosed with FA when he was 10 days old. That was when we learned what FA really meant, for Cale and our family. Since that point, our lives have been turned upside down. Fanconi Anemia is a rare life-threatening blood disorder, which through a lack of the normal DNA repair functions, creates a predisposition to cancer. FA causes many different types of cancers, solid tumors, leukemia, and ultimately leads to bone marrow failure.

Because of FA, Cale has many organ and system abnormalities that require attention from multiple medical specialists. He has a missing bone in each forearm, missing thumbs, malformations of the kidney, heart, bladder and other organs, strabismus of the eye, and low growth rate. Along with FA and hydrocephalus, Cale is physically disabled and has severe ataxia. Ataxia is a condition that creates the lack of muscle coordination, and has severely affected Cale's balance and coordination. Cale didn't start to walk until he was 4 years old, due to a tethered spinal cord. Cale is now 7 years old, only weighs 32 lbs, and has had over 26 surgical procedures and nearly 100 hospital visits.

The scariest part of FA is the unknown. We don't know if, or when cancer will hit, when he will need a bone marrow transplant, or how long will he live. The sadness of knowing that your child has a life-threatening disorder that will overcome his daily life, his future, and our family, is a very overwhelming thought. There are many sleepless nights, endless questions, and constant worry. But the one thing that I learned very quickly is that we do not have the luxury of time.

As we struggle with the complexities that FA brings, we continue to plan for Cale's future. Knowing that he will need a bone marrow transplant, we went through the PGD in-vitro process to find a perfect sibling bone marrow match. After 3 failed attempts, we had success! Our 4th attempt lead to identical twins, that would be identical bone marrow matches for Cale. Our joy quickly turned to total sadness, when one of the twins, Avery, died from complications of twin-to-twin transfusion syndrome (another rare syndrome to affect our family).

Our surviving twin, Anna, was born 7 weeks premature, but we were able to save her umbilical cord blood for when Cale needs his bone marrow transplant. We welcomed Anna home after 3 weeks in the NICU; and laid her twin sister to eternal rest shortly thereafter.

We continually try to help Cale lead a "normal" life. As a child that needs so many medical procedures just to function, this leaves for a heightened level of uncertainty. We continually need to monitor his health on a regular basis. We watch his blood every few months for signs that his blood quality is failing. We watch fevers very closely. We try to adapt his environment to help him be an active 7 year-old, without the risk of injury.

Fanconi Anemia is a life-threatening blood disorder that leads to bone marrow failure.

Most things we take for granted in our daily life has to be adapted to help Cale function. We work daily with the school to ensure that Cale has a good day. With his textbook FA hands and ataxia, Cale works so hard with fine and gross motor skills, but he gets so tired from working hard at things like writing, or eating. He is working on his writing skills, using a zipper, dressing himself, eating and other life essential skills. He just learned to button a shirt by using his teeth. He also works hard on his balance, sitting on a chair, running and walking- all without getting hurt.

Each day, we witness Cale's heroism through his courage and unique abilities. Despite his daily struggles, Cale is determined to bring warmth and kindness to everyone he meets. He truly lights up a room, with his sweet little voice, his smile and BIG hugs. His doctors call him a Rock Star, and we can't agree more. Through Cale's story, we hope to encourage others to embrace that which makes us different; to be kind, and to live life with strong conviction and purpose, directed by Faith. He is meant to bring people together for a common cause. What makes him unique, makes him Cale; and I am so proud to be his Mom.

How can you help?

We need to spread awareness of Fanconi Anemia. Cale is only 1 of 392 people in the United States with FA. Over 90% of the Fund's income comes directly from families, just like us, fundraising in honor of our child. The effort behind the research also benefits the general population as it is focused on cancer research, the effects of bone marrow transplant procedures, and to find better therapies for those going through transplant. But all of this takes money. With your help, we can continue to raise funds for research to help us find hope for a cure. We can't fight this fight alone. We need your help!

We hope Cale's story inspires something great- because he is a true *Miracle!*

You can read more on Cale and his journey on his caringbridge website, www.caringbridge.org/visit/caleferrin.
To learn more about Fanconi Anemia, and how you can help, visit www.fanconi.org.