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FOR IMMEDIATE RELEASE

A LENEXA, KANSAS FAMILY HONORS THE MEMORY OF THEIR DAUGHTER ANNA BY STARTING THE MUSCLES FOR MYOTONIC 5K FAMILY FUN WALK

SAN FRANCISCO, CA (May 22, 2014): In 2010, Kelly Bormann and her husband Steven were expecting twins. At 29 weeks Kelly had an emergency cesarean section, and the twins, Reed and Anna, were born at 3 lbs each. Both were placed on ventilators immediately after birth, although Reed, the baby boy, was off his within 6 hours. After a long and heartbreaking struggle for life, Anna passed away at 6 weeks of age. “She was a tough little girl who tried her hardest to hang on despite all of her issues,” says Kelly.

In the last weeks of Anna’s life, the Bormanns learned that Anna had myotonic dystrophy (DM). “We were told by doctors that Anna inherited DM, a neuromuscular genetic disorder, from one of her parents. Steven and I were unaware of any family history,” explains Kelly. “Right there, doctors had us both make a fist and then release our grip. My fist didn’t open. A blood test followed and confirmed what doctors suspected after that simple grip test: I was the carrier for DM.” There is a 50 percent chance that DM carriers will pass the disorder onto their children. Anna's twin brother Reed does not have the disorder.

Looking back at her health history, Kelly has since realized she had experienced symptoms of DM for years. She and her father had cataracts at an early age, one of many symptoms of the disorder, but thought it just ran in the family. Muscle weakness was also present throughout Kelly’s childhood in spite of her active youth filled with gymnastics and cheerleading. Kelly says of her early symptoms, “I just pushed through it. I think my active lifestyle early on has enabled me to continue to be as active as I am today.” Kelly also suffers from fatigue, another common DM symptom. The DM diagnosis has helped Kelly and her father, who was also diagnosed after Kelly and Anna, better understand their lifelong health issues. The Bormanns have since had a second daughter, Adalyn, who is three-years-old thanks to in vitro fertilization (IVF).

The good news is that researchers and pharmaceutical companies are getting closer to unlocking the mysteries that surround complex genetic disorders such as DM. “There is hope for better treatments and even a cure for myotonic dystrophy. That’s why we started the Muscles for Myotonic 5K Family Fun Walk. We wanted to honor the memory of our little angel Anna by raising money for DM research and awareness about the disorder.”

Last year’s Muscles for Myotonic Walk was the first of its kind and had over 250 participants. The walk benefits the Myotonic Dystrophy Foundation (MDF), an organization dedicated to care and a cure for those living with DM. “MDF provides valuable information and services to those affected by DM while also funding research and outreach to the medical community,” says Kelly. MDF also maintains the Myotonic Dystrophy Family Registry, the world's largest web-based DM registry which collects information on disease symptoms, demographics, and quality of life in order to support clinical trials, research studies, and advocacy efforts.

The 2014 Muscles for Myotonic 5K Family Fun Walk will be held on Saturday, May 31, 2014 at Heritage Park - Shelter #1 in Olathe, KS. To learn more about the Bormanns and the walk, please visit www.myotonic.org/muscles-myotonic.

About Myotonic Dystrophy: Described as the most variable of all diseases found in medicine, myotonic dystrophy is an inherited disorder that can appear at any age and manifests differently in each individual. The most common form of adult-onset muscular dystrophy, DM affects somewhere between 1:3000 and 1:8000 people worldwide, and can cause muscle weakness, atrophy and myotonia, as well as problems in the heart, brain, GI tract, endocrine, skeletal and respiratory systems. There is currently no treatment or cure for DM.

About the Myotonic Dystrophy Foundation: The Myotonic Dystrophy Foundation (MDF) is the world’s largest DM-only patient organization. Its mission is Care and a Cure: to enhance the lives of people living with myotonic dystrophy, and advance research efforts focused on finding treatments and a cure for this disorder through education, advocacy and outreach.

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