

Ag family battles hardship, braves unknowns

By Amy Blum for the Chamberlain/Oacoma Sun, April 6, 2016

What would you do if not one but both of your daughters were born too early and spent time in the NICU? What if those same sweet girls were diagnosed with rare, unexplainable diseases within weeks of each other? What if your insurance company fought coverage of treatments for one of those illnesses? What if you and your spouse were working 40 to 50 hours per week in town plus sharing responsibility for your family's ranch while trying to balance doctor visits, family time, and bills?

What if all of the above took place after you personally survived a battle with cancer?

Hard to imagine, isn't it?

Erin (Piskule) Bohon, a rural Gann Valley country girl and SDSU graduate, doesn't have to imagine though. Bohon and her husband David live the answers to the above questions every day.

"I don't even know how to describe this journey," Bohon said. "It can all be so hard and lonely sometimes, but we do our best to talk instead of fight. David and I work through the adult stuff and stay as positive for the kids as we can. He picks me up when I struggle, and I do the same for him."

A diagnosis

With bright smiles, bubbly personalities, and twinkling eyes, Emma and Jade Bohon's biggest decision should be whether to play dolls or tractors first. But, a prolonged and dangerously high

fever for five-year-old Emma in June 2015 added a layer of complexity to the family's life.

What the family doctor first identified as normal "kid stuff", according to Erin, became an emergency trip to Sanford Children's Hospital—aka The Castle—in Sioux Falls. Specialists at the castle diagnosed Emma with Kawasaki Disease.

According to the Kawasaki Disease Foundation, Kawasaki Disease (KD) is a serious autoimmune disease where blood vessels throughout the body become inflamed. The inflammation leads to broken blood vessels, rash, swelling, and more. The disease primarily affects children and is the leading cause of acquired heart disease in children.

"Kawasaki isn't contagious," Bohon said. "There have really been no answers as to why Emma got it, but she did. There is only a 10-day window for treatment, and Emma was on the tenth day when everything fell into place for treatment."

Emma improved with the prescribed treatment and returned home to her family's ranch. Erin and David were able to return full-time to their positions at Noteboom Implement in Chamberlain. Then, about a week later, four-year-old Jade exhibited the same symptoms—high fever being the worst.

"At that point, doctors knew right away and got Jade on the same treatment Emma had, but



everyone was shocked. Kawasaki is rare, but they told me it is unheard of for two children in the same family to be diagnosed," Bohon recalled.

A bump in the road

As both girls healed, the family again regrouped and looked to the future. Weeks passed with regular lab checks and doctor visits, especially for Emma as her heart seemed most impacted by the Kawasaki Disease.

In December, the family's world was shaken again when Erin began noticing bruises on Emma's body. Instinctively, she reached out the child care center.

"It seemed like Emma had bruises on her arms and legs all of the sudden," Bohon recalled. "I went to Rochelle [Shrake] at Children's Ark right away. We trust them with our kids, and they've been so good to us. Rochelle dug right in and began an even closer watch."

Over a weekend at home, Erin and David saw Emma's bruising worsen and her bubbly personality fade.

"Emma was just down and out," Bohon said. "We went online in hopes of easing our minds, but when we researched her

symptoms, we found ITP [a disease that destroys blood platelets, which prevents clotting] and leukemia as the most likely causes. Peace of mind couldn't have been further away."

ITP is believed to affect only eight of every 100,000 US children annually, and it often does not require treatment. Given Emma's previous bout with Kawasaki and her lasting heart issues, treatment was vital.

"The doctors still can't rule out leukemia completely," Bohon said. "The symptoms are so close, but because the additional leukemia tests will mess with her heart even more, they are proceeding cautiously and monitoring her best they can. We hope and pray for the best but try to prepare for the worst."

To add to the family's struggles, their insurance company is fighting payment for anything related to Emma's ITP treatment.

"Because treatment for Kawasaki and ITP are the same, insurance is trying to claim pre-existing condition, but the two diseases have no connection other than the treatment plan," Bohon shared. "Our medical team has written letters and worked on our behalf but no luck so far. It's all really just a lot."

Support from a village

Through everything, Bohon says the couple's work family at Noteboom's has been their biggest support system.

"My dad [Ed Piskule] and his family have been great help, but



this has all been really stressful for them, too," said Bohon, who works alongside her dad on the ranch. "Our work family has just been everything to us. They cover when we have to leave for doctor appointments or sick kids. They are here for us to talk to. They even rallied together and put new tires on our car. We are so appreciative and grateful."

Erin cites the helplessness of the situation as the most challenging. Her daughters who once loved the idea of princesses and castles now dread visiting Sanford Children's Hospital. The little ones who overcame so much as preemies and once played with reckless abandon now become spent quickly.

"I've battled cancer and seen the demons," Bohon said. "All we want is to protect our kids. We want them to be carefree, happy, and healthy. To have such rare diseases strike leaves so many more questions."

Emma will enter kindergarten in Kimball this fall, and Jade will enroll in Kimball's pre-school program. While the family works hard to ensure the girls enjoy all the "normal" joys of ranch life and

child's play, Emma is especially aware of her difference.

"Emma's our quiet, girly-girl. She knows she can't do all the things other little kids do," Bohon said. "Of course, she tries everything she can. When she gets too worked up, she'll come to me saying her chest hurts. Then, she'll sleep for hours. It breaks my heart to see hers hurting."

Anyone interested in helping ease even a little of their financial burden can donate online at <https://www.gofundme.com/nhf2bhzg>.

****July 1, 2016 Update:** A fundraiser will be held for the Bohon Family on July 9 from 11 to 2 at Noteboom Implement in Chamberlain, SD. More information can be found at: <https://www.facebook.com/events/1607672482878910/>**