

Coping with a New Diagnosis

Meet the Warner Family

Early Clues

A persistent bruise began appearing on Emma Warner's back when she was only 5 months old and just learning to sit up. Even with the occasional roll backward her parents, Rebecca and Luke, knew something unusual was happening and took her to the pediatrician. The medical team checked Emma's spine for abnormalities but found nothing. The Warner's left the appointment without a clear answer to their questions.

Emma was a careful and cautious baby from the beginning. But after she started crawling, her legs bruised from her knees down her shins. Her parents also noticed that Emma had started crying inconsolably with no obvious explanation. It was a puzzle they were desperate to solve.

Rebecca brought one-year-old Emma back to the pediatrician and advocated for further testing. At that point the pediatrician referred her to a Hemophilia Treatment Center. After the HTC ordered blood work on Emma, the results indicated that she had severe factor VIII deficiency, or Hemophilia A. They initially questioned the results. There was no family history after all, and adhering to the belief in 2010, the Warner's were told "Girls don't get hemophilia". Emma was tested three times before the diagnosis was confirmed.

As an infant, Emma had low muscle tone and needed physical therapy to build up her muscles. She was a cautious child and was late in walking as well. In hindsight, the Warner's wonder if Emma was being cautious to avoid pain; her inconsolable crying, a reaction to bleeds. But because of the confirmed diagnosis, her parents now had hope that something could be done to help their little girl.



Receiving the Diagnosis

Although Rebecca and Luke were grateful to have the diagnosis, they were also afraid of the unknown. With no family history, they had little knowledge about bleeding disorders. Thankfully, they both found that between education provided by the HTC staff and a book called "Raising a Child with Hemophilia", they were able to get a good understanding.

Rebecca, a social worker for Child Protective Services, feels grateful that nobody has ever accused them of hurting their child, and instead recognized a medical issue. She knows that things could have turned out differently. She also feels grateful to have connected with such a supportive medical team at the Helen DeVos Hemophilia Treatment Center in Grand Rapids who have been with the family through all the ups and downs.

Learning to recognize a bleed was the first step in the educational process. Because Emma was young, and unable to tell her parents about a bleed, they learned to feel the area for warmth and look for signs of redness. Rebecca found it helpful, when in doubt, to use a measuring tape to confirm swelling. As Emma grew, she was hesitant to report a bleed in order to avoid an infusion. Knowing what to look for was invaluable.

As with many parents, Luke, more so than Rebecca, was uncomfortable with needles. He was particularly nervous to infuse Emma, but with the help and guidance of the HTC, they were both trained. They would do anything for their daughter, even if it was uncomfortable for them.

Advocacy

When a parent is faced with a sick child, they are understandably afraid. And that fear sometimes turns to anger. The key to successful advocacy is learning to harness that anger in order to effectively communicate with the medical team. To listen to options, but just as important, to speak up.

Like most of us, Rebecca and Luke were taught to listen to the doctor and respect their opinions; almost without question. But their decision to trust their gut when Emma's symptoms were not going away. They were persistent with the pediatrician and, fortunately, had one that listened.

The Warner's advocacy skills have been tested throughout Emma's life. After a minor procedure to correct kidney reflux, Emma had blood in her diaper. The HTC was present in the hospital room to educate the surgical intern in charge of Emma's after-care. The HTC nurse and social worker helped to close the communication gap, and to also alleviate the Warner's anxiety.

The procedure would work for a few years, but Emma continued to have kidney issues that would require reconstructive surgery. Due to Emma's hemophilia diagnosis, her urologist was concerned about performing surgery.

Fortunately, the Warners understood that by giving the urologist the name of their HTC nurse, both teams could work together. They also understood that if the urologist was unwilling to work with the HTC, they could find a new surgeon.



Parents Rebecca and Luke
Daughter Emma (Age: 11.5) and Son Gage (Age: 9)

Getting Involved

Rebecca and Luke found it very helpful to connect with other parents within the bleeding disorder community. They attended events providing consumer education and sought advice from other parents during the early years.

Eleven years into their journey, Rebecca is giving back. She speaks on a panel to educate medical residents from a parent's perspective about bleeding disorders. These panels are an invaluable part of a resident's education and can help personalize the experiences of families with a bleeding disorder.

Rebecca has taken her involvement with the community to a higher level. She participated in Washington Days in DC to ensure that appropriate health care and insurance programs are available to people with bleeding disorders. She has also participated in Cascade's grant committee, helping to designate funding to the bleeding disorders community in Michigan, Ohio and Indiana.

These activities have helped the Warners feel more empowered to better the life of their daughter as well as the lives of others with bleeding disorders.

Emma is Living and Thriving

Emma is now eleven years old and no longer needs a port. She is using a longer lasting product which she injects once a month subcutaneously. Since starting her new treatment, she hasn't had a single bleed. This medical advancement is not lost on the Warners. Emma plays on her school basketball team and is quite the athlete. She also enjoys the piano, guitar and clarinet and is looking forward to participating in marching band.

The Warners are forever thankful that they found a great medical team who educates them, provides emotional support and recommends the best treatment for their daughter. They are also thankful for the educational programs and support of other parents who have helped them along the way.

