Always Anniston

The power of one simple test

BY AMANDA JEAN HARRIS

A simple blood test at birth is what stands in the way of a death sentence for children like Anniston Bazar. The Lafayette 2-year-old diagnosed with Krabbe disease after a series of ambiguous symptoms, which began in her first few months of life, has already outlived the average child with Krabbe.

"The doctors told us she may not live until 2," says her mother, Reesa Bazar. "They didn't really know much about it or treatment because it's so rare."

In fact, Bazar is the one who pushed vehemently for her daughter to be tested for the disease that affects one in 100,000 people in the U.S. after recalling her own cousin who had the inherited disorder that destroys the protective coating of nerve cells in the brain and throughout the nervous system.

There is no cure for Krabbe, whose signs mimic other diseases and disorders. The most effective treatment is simple, but there is a catch — it must happen before the first symptoms arise. And the majority of signs appear before 6 months of age. If infants are tested early they can then receive a hematopoietic stem cell transplant, which Bazar explains is similar to having an IV and is not painful or invasive to the child.

"Once the symptoms are there, it's usually too late," Bazar says. "Too much damage has been done."

Such was the case for Anniston.

"At 5 months old she was screaming all day. They said maybe it's reflux, and we tried everything. They did CT scans to ease our minds. There was nothing alarming. We finally went to New Orleans [Children's Hospital], and they basically laughed at me when I asked about Krabbe. I knew something was wrong. She had legs that were stiff and fists clinched. She quit nursing because they lose the ability to suck. After 14 days there they finally tested her," Bazar says.

The results of the test were clear. Her daughter had Krabbe, which meant both she and her husband (unbeknownst to them) were carriers. They have two other healthy children, both of whom will soon be tested because there is a later onset Krabbe as well. The Bazars are now on a mission to raise awareness about Krabbe and the one way to prevent the kind of outcome Anniston is likely to face.

In March, Anniston's Act will be presented in the Louisiana House of Representatives to test infants for the disease. The greatest cost to the state for the new measure would be the lab required to do the testing, which Bazar says has a price tag of $2 million.

"It may cost $2 million to build the lab, but it costs just $6 per kid for testing, and when you think about it, our daughter has already cost the state close to a million dollars because of hospital stays and surgery," she says.

There are few (if any) local resources for Anniston's treatment. The Bazars travel every six months to Pittsburgh, where doctors have been studying Krabbe for 16 years. The journey to treat Anniston's symptoms began with good old-fashioned Google research by the Bazars, and today Reesa Bazar is on a mission to spread not only awareness about Krabbe and the legislation they hope to pass, but about the value of life, as well.

"I was so depressed at first I couldn't speak about her. I just wanted to shut the door. When they told me I was bawling my eyes out and holding my baby," Bazar says. "I would beg God for a miracle, and now I realize she is the miracle. She will change people's lives whether she's here for four years or 24 or 44 years. She will make a difference. You have to start looking at your life differently."

Bazar speaks at local schools and to civic groups — wherever they'll take her, she says, wherever she can speak about how every life matters.

"People look at her. She's artificially fed. She can't speak. Yet she has touched thousands of lives. How can you not say that's an important life? I kept saying I need a miracle, and I realized God gave me one and I was doing nothing with it. We need to show people what it's like to have a special needs child and let other people know they are not alone."

FIGHTING FOR ANNISTON

For more information on how to help, upcoming speaking events and more information as the legislative session arrives, go to Always Anniston on Facebook or check out Reesa's blog "Our Bazar Life" at reesabara.blogspot.com.

KRABBE IN INFANTS

Common signs and symptoms early in the course of the disease include:

- Feeding difficulties
- Unexplained crying
- Extreme irritability
- Fever with no sign of infection
- Declines in alertness
- Delays in typical developmental milestones
- Muscle spasms
- Loss of head control
- Frequent vomiting

As the disease progresses, signs and symptoms become more severe. They may include:

- Seizures
- Loss of developmental abilities
- Progressive loss of hearing and sight
- Rigid, constricted muscles
- Stiff, fixed posture
- Progressive loss of ability to swallow and breathe

SOURCE: Mayo Clinic