

# The Norman Transcript

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Transcript Photo by Kevin Ellis

Matt Stringer holds his daughter Isabella while wife Michelle looks on last week. "She is not the most lively of girls," Matt Stringer said of his daughter. "But she knows how to sleep." Isabella was born with a rare condition called Lissencephaly, a disease with no cure.

## It's for Bella

### ► Run to benefit girl with rare disease

**By Michael Kinney**  
Transcript Sports Writer

Isabella Stringer does not have much time left.

The 11-month-old's doctors said she may have one to two years to live.

Those are the cold hard facts of being diagnosed with Lissencephaly, a disease with no cure.

But the reality is that Isabella has shown in her brief time alive that she is a

fighter. And while her life expectancy is short, the effect she has already had on those around has been tremendous.

"She has a fighting spirit. Just from the people that we know she makes them feel that they shouldn't complain so much," said Isabella's mother, Michelle. "Because people are blessed. She is a beautiful girl and has a lot of lessons to teach. I do believe she has a purpose. And that is to show others what they have in their lives."

Michelle hopes that is the message that comes out of Running For Bella, a 5K run created to raise money for Isabella's medical costs and to fund genetic

research for Lissencephaly at the University of Chicago.

The idea of Running for Bella came from a co-worker of Michelle's at Norman Regional Hospital. Allison Doonkeen saw what Isabella and the Stringers were dealing with and decided to help.

"Her mother works at the ER in Norman Regional Hospital, as do those of us putting on the run," Doonkeen said. "We just decided to put on a benefit run to pay for her medical costs."

Isabella was born April 3, 2006. And for the first six weeks she led a normal new-

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# Bella: Family got terrible news after about six weeks

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born's life.

Then one night Isabella started having seizures and her parents rushed her to the emergency room.

"When they told us Lissencephaly, I really didn't hear them," Michelle said. "All I heard was she was going to be severely developmentally delayed. Her brain had not been fully developed in the womb. That's all I heard. So I went home and Googled it.

"And that is when it hit about how serious it was."

What Michelle found did not paint a pretty picture.

Lissencephaly is caused during embryonic development by defective neuronal migration, the process in which nerve cells move from their place of origin to their permanent location, according to the National Institute of Neurological Disorders and Stroke.

Symptoms include unusual facial appearance, difficulty swallowing, muscle spasms, seizures and severe psychomotor retardation. Hands, fingers or toes also may be deformed.

"We were devastated beyond belief," Michelle said. "It was just not a good prognosis. They told us she would never walk or talk and would stay on a three- to five-month-old level. She would

## FYI

**What:** Running for Bella

**When:** 7:40 a.m. Saturday

**Where:** The course begins at the Norman Regional Healthplex off of Interstate 35 and West Tecumseh Road. The route runs west on Tecumseh Road for one mile, circles around the Timber Ridge neighborhood, and continues east on Tecumseh Road back to the Healthplex.

**Registration Packet Pick-Up** Race packets and T-shirts will be available at Brookhaven Clinic located in Brookhaven Village, 3770 W. Robinson St., Suite 116. The dates and times are: Thursday from 6 a.m. to 10 p.m. and Friday from 6 a.m. to 6 p.m. Race packets also will be available for pick-up at the Healthplex from 5:30-6:30 a.m. Saturday.

**Race Day Registration:** Will begin at 6 a.m. and end promptly at 7:30 a.m. For more information contact Allison Doonkeen at 570-0579 or by e-mail at: [runningforbella@yahoo.com](mailto:runningforbella@yahoo.com)

have seizures, phenomena and feeding issues. Just a huge spectrum of problems. We were just in shock and disbelief."

According to Doonkeen, Isabella may be the only person in the state of Oklahoma diagnosed with the disease.

Michelle said she and her husband Matt, went through a grieving process after they found out. Even though their daughter was still alive, they grieved for the loss of the life she could have had.

"Just the loss of her life, her physical life, and the things she will never do," Michelle said. "That has been the hard-

est part for me and my husband. At this point she doesn't even smile. She never laughs. It's a very different existence from a normal child. It just makes us sad that we will never get to see the real Isabella."

But once the grieving ended, the Stringers had to make a decision. Along with Isabella, they have a two-year-old son, Jackson, who loves his little sister. They weren't being fair to either child or to themselves.

"One day I had an epiphany," Michelle said. "I decided to take it to a positive place. I did more research and

found out there was an expert on Lissencephaly in Chicago. I demanded to see him and was told there was a nine month waiting list."

After some persistence, the Stringers were able to get the doctor to see Isabella when she was 12-weeks old.

However, the trip brought even more bad news. The doctor told the family Isabella had Type 1 Lissencephaly. She would never develop past the level of a one-month old.

What was already a difficult situation, became even more unbearable for the Stringers. Children with Lissencephaly often die from aspiration of food or fluids, or from respiratory disease, according to the NINDS.

"We were told she had two years, three at the most," Michelle said. "It was another shock. That was the hardest part for us."

The Stringers decided then and there that no matter how long their daughter had left, they would make her as comfortable as possible. And most importantly, for Isabella to know she is loved.

"She does have a lot of suffering with the seizures and it's hard for her to breathe," Michelle said. "We want what is best for her. When it's her time to die, we want it to be peaceful, for her not to have to fight anymore."



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