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Gov. Fletcher Dedicates Lab To Screen Newborns For Fatal Diseases

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GOV. FLETCHER DEDICATES LAB TO SCREEN NEWBORNS FOR FATAL DISEASES

By Maureen Kyle

(LOUISVILLE) -- After several stories done by wave 3 and a seven year fight by two Kentucky families, a new Kentucky law is saving lives. In March, Gov. Ernie Fletcher signed a bill requiring extended screening for newborns. On Thursday the governor dedicated a new facility for conducting the screenings. As WAVE 3's Maureen Kyle reports, lives are already being saved.

"Are you special?" Jason Heflin asked his daughter, Maddie, just before her first birthday.

Maddie will never fully understand just how special she is.

"I think she's got a purpose here," Jason said.

Maddie was born with Krabbe Leukodystrophy -- a neurological disorder that could have been detected with a few simple tests days after her birth. It wasn't detected until she was almost a year old. Had the Heflins known about it in time, it could have been successfully treated.

That fact inspired Maddie's father, mother and lawmakers to join other nearby states in requiring extended newborn screening in Kentucky. For years, Kentucky required metabolic screens for only four disorders, while most other states screen for 30, as recommended by federal guidelines.

"When you have a child dying, as a father, you feel like your hands are tied," Jason said.

Jason's hands may have been tied when it came to saving Maddie, but not when it came to saving other children. He joined the fight for Kentucky to require at least 28 tests for newborns.

In March, he and Maddie saw that bill signed into law, just before

Maddie's fourth birthday.

Then, a few months later, on August 19th, "she took her last breath." She spent most of her life on a feeding tube, unable to move.

Jim Lazzaro was another baby who seemed healthy, but then his parents found out -- too late -- that he had been born with a fatty acid disorder that would have been picked up at birth in most other states.

The Madeline Leigh Helfin and Jimmy Lazzaro bill requiring extended testing was supposed to take effect January 1st.

But in his remarks at Thursday's dedication of a new lab in the Kentucky Public Health Building, Gov. Fletcher said testing actually started on Dec. 5th. "Four days later, we detected a metabolic disorder that has an associated risk of death of about 25 percent from SIDS."

It was an ironic victory for the Lazzaro family. "On Dec. 9th, which is exactly nine years to the day that our son, Jim, would have been tested, they detected VLCADD in a Harrison County baby boy," said Jim's mom, Jamie. That's the exact same disease that killed her son.

Two more positive detections followed just in the month of December. That's three newborns whose potentially fatal diseases would have slipped past doctors if it weren't for the required extra screening and new high-tech lab.

"We were told, it's never going to happen, there's just not enough money," which frustrated Jason. But he refused to give up.

This state lab is now equipped with this one machine which detects 22 of the 28 potentially fatal diseases in newborns.

With three lives already saved, Jason says he's proud of his little angel. "I had to give Maddie a purpose for being here," he said. "So she wasn't here in vain."

The Governor vowed to keep adding tests to newborn screening, and lawmakers expect two more tests to be required by the state in the near future.

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VIDEO of newscast: Extended Newborn Screenings Already Saving Lives