## The Courier-Journal; January 13, 2006 Screening For Newborns Expanded

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## SCREENING FOR NEWBORNS EXPANDED More disorders can be found early

By Laura Ungar

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Jamie Lazzaro's 8-month-old son, James William, seemed healthy and strong. Then one summer morning in 1997, he stopped breathing and didn't wake up from his morning nap.

Lazzaro, of Louisville, later discovered that his death was the result of an undiagnosed metabolic disorder in which the boy's body couldn't process a certain type of fat. Some states tested for this disorder, but Kentucky didn't.

Now it does.

At a news conference yesterday, Gov. Ernie Fletcher announced the expansion of newborn screening, which was approved last year and phased in gradually.

"It's a bittersweet day for us," Lazzaro said. "We're thrilled that no one will ever have to go through what we went through. But nothing can bring Jim back."

The state previously tested for only four disorders, but the expanded screening checks newborns for 29 metabolic disorders recommended by the March of Dimes. It also gives them a hearing test.

Lorry Marvin of the local March of Dimes chapter said her group pushed for nine years to convince the legislature to expand newborn screening.

The bill that became law last year -- the James William Lazzaro and Madison Leigh Heflin Newborn Screening Act -- was named after Lazzaro's son and a Lexington girl who died at age 4 last year.

"Now we're on par with all the states around us," Marvin said.

Dr. Steve Davis, deputy commissioner of the state Department for Public Health, said "the stars had to get all lined up" before the change could be made, and that Fletcher and state health officials helped make it happen.

"It took nine years because Kentucky is a poverty state," Davis said. "Kentucky has tremendous needs in a huge number of areas related to health ... and when one has a fixed amount of resources, people have to make difficult decisions and difficult choices" about how to use those resources.

The state phased in the changes between July and Dec. 5, 2005, Davis said. Since Dec. 5, 6,000 newborns have been screened, and three of them were found to have serious metabolic disorders. Davis estimated that the state will probably diagnose more than 100 babies a year with these disorders, which can result in serious problems or death if left untreated.

Newborns are screened before leaving the hospital, and those not born in a hospital must be tested when they are 24 to 48 hours old.

The baby's heel is pricked and a few drops of blood are sent to the state laboratory for analysis. The baby's doctor receives a screening report and notifies parents of the results.

Davis said the expanded screening will save many lives.

"It's a dream come true."

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