

Newborn screening to expand this month
Routine blood scan will now check for 30 serious disorders
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When Candy Kush adopted 5-week-old Kelsea, she knew her daughter had a rare amino-acid disorder that would require dietary vigilance for life. Kelsea tested positive at birth for phenylketonuria, or PKU, one of only a few diseases Ohio hospitals screened for when she was born 16 years ago.

This month, the Ohio Department of Health will start requiring hospitals to screen babies for 30 disorders. In the 1990s, there were five required tests. Since 2002, 13 have been mandatory and 16 optional. The change will make Ohio one of 19 states that require that many newborn screenings. One blood draw is enough to run all the tests.

Kelsea's disease makes it difficult for her to digest an amino acid found in meats and milk. Her treatment is a strict lowprotein diet of mostly vegetables. It affects about one in 17,000 newborns. If the disease isn't found at birth, it can cause brain damage and mental retardation.

Kush considers her daughter lucky. "I guess it's too late for the kids who were born with those rare diseases," said Kush, a 48-year-old West Side resident, referring to the tests. "But it's just in time for babies being born today."

Kush is a member of the Newborn Screening Advisory Council, a group that makes recommendations to the state Health Department. Among the newly mandated tests are a number of metabolic disorders and an enzyme disorder called biotinidase deficiency. Some of the diseases occur in less than one in 1 million babies. They can lead to brain damage or immune system failure. Common symptoms can include weight loss, jaundice and vomiting. Some symptoms don't show for more than a year.

In 2002, the state created a program in which parents could opt to have their newborns tested for the additional 16 diseases at no cost. About 300,000 babies — or 96 percent of those born during the past two years — were tested, said Dr. William Becker, who oversees the state's lab.

Becker said a mass spectrometer has made it possible to perform multiple tests. In 1996, Ohio tested for five diseases and Health Department officials said the cost of adding others outweighed the benefits. That attitude has changed, Becker said. "Right now, the philosophical camp that's winning the tug of war is that camp that supports screening for everything that's possible," he said. Hospitals purchase screening kits from the state for \$33.75 apiece. That is expected to rise to \$45.16 this month to cover the cost of testing for biotinidase deficiency.

Gail Johannes, hospital coordinator for the Ohio State University Medical Center, said false positives will occur but are a necessary evil. "You want to alarm as few people as possible, but you don't want to miss anyone," she said.