

Reno Gazette-Journal

Newborns' disorder tests grow

Carla Roccapriore

Email: croccapr@rgj.com

RENO GAZETTE-JOURNAL
9/14/2003 12:33 am

Nineteen disorders have been added to the list of tests for infants born in hospitals, including one approved last week, officials said.

Babies born in Nevada hospitals before July 1 underwent tests for phenylketonuria, maple syrup urine disease, biotinidase, galactosemia, sickle cell disease and congenital hypothyroidism.

But now children also are tested for 18 other conditions, including amino acid and fatty acid oxidation disorders. Parents and family physicians are informed of any positive results.

The addition is the result of Tandem Mass Spectrometry, a new technology that allows widespread testing, said Martha Framsted, state health division spokeswoman.

Using Tandem Mass Spectrometry increases the amount of disorders that can be detected from one blood specimen, usually taken when a baby's heel is pricked. Such a process now is responsible for testing 20 of the disorders.

Health board members voted unanimously Friday to add a 25th test — congenital adrenal hyperplasia (CAH) — to the panel. That condition causes males to go through puberty as a female would, and females to develop male genitals. CAH testing will begin within days.

"They heard testimony from the health division and heard testimony from parents and made a decision about information placed in front of them," Framsted said. "We feel it's an important condition to be testing for."

Reno resident Alesia Pinson, who has a 21-year-old son with CAH, said she is pleased with the board's decision. She recalled how long it took to properly diagnose her son when he went into distress at 3 weeks old while still in the hospital.

"It was a process of elimination because they didn't know what he had," Pinson said. "Twenty-one years ago, they didn't (automatically) test for this."

Gretchen Lin of Las Vegas, who is expecting a child in December and has a toddler son who was diagnosed with CAH in 2001, also was glad the condition was added to the panel.

"We're excited, elated and relieved that no other family needs to go through watching their child die and not knowing what's wrong," Lin said.

Framsted said the state bid the current 24 tests earlier this year in a bundle because bidding each test separately would've cost more.

Hospitals now spend \$44 per infant but will pay \$48 per infant with the CAH test, compared with \$21.25 for the six tests conducted before July 1, she said. Hospitals pay laboratory fees but can seek reimbursement from families with insurance.

Newborns were tested for CAH between July 1 and mid-August and one infant tested positive for the most severe form. The test was stopped because the \$4 test and laboratory fees were too expensive, but they will be reinstated once all laboratory equipment is in place, Framsted said.

CAH affects one in every 15,000 newborns worldwide, and 35 states did automatic testing as of 2002, according the Short Hills, N.J.-based CAH Research, Education and Support Foundation.

Copyright © 2002 The Reno Gazette-Journal