

News

Arizona expands newborn testing

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PHOENIX — State health officials are expanding the screening of all Arizona newborns in hopes of finding — and treating — genetic diseases.

The new program will check infants for 28 specific conditions that, if left undetected, could prove fatal or cause serious health conditions.

Now the state screens for only eight — a situation that puts Arizona "right there at the bottom of the 50 states," said Will Humble, the state's chief of public health preparedness. With the change, Arizona will be among the leaders in testing.

The new screening — actually two separate tests days apart — will increase costs, from \$40 to \$70 per child. But hospitals absorb the cost of the first test and private insurance or the state health program for the poor usually will pay for the second, said state Health Director Susan Gerard.

Each of the 28 conditions for which the state will now test, while not curable, can be treated or managed to allow the children to grow up healthy and without problems, said Jan Kerrigan, manager of the newborn screening program.

That point was driven home by Tempe resident Debbie Houk, whose year-old daughter, Lauren, died in 1989 of a condition known as medium chain acyl-CoA dehydrogenase deficiency, or MCADD for short. It was only because a pathologist recognized the condition that Houk got, on her own, a test on David (**from DLG ~ his name should be Austin**), her next child.

It turned out he, too, had the condition. But the potentially fatal disease can be managed simply by ensuring that his blood sugar does not get too low. MCADD is one of the new conditions for which all of the 96,000 babies born in the state every year will be tested.

Gerard said this kind of testing, which is being phased in over the next year, makes sense.

"Infants can appear perfectly normal and not show any signs of any kind of disorder," she said. "This simple blood test can show that they have a problem. Most times very simple changes will mean the difference between a normal life and a life that could be cut very short or going to mean you're going to have profound disabilities through your life."

Gerard said the state tested for only eight conditions until now because the technology did not exist to do mass screenings, at least in an affordable way.

Many of these conditions affect a small percentage of newborns. But Gerard said the screening, and the cost, still make sense.

For example, she said it could be argued that children should not have to be vaccinated against polio because that disease has not been common for half a century and is likely to affect only a few.

"How many people would get very ill and die? Maybe a very small percent," Gerard said. "But by protecting the entire population, we're better off for it." Similarly, she said that preventing even a few dozen cases of these diseases is good for society because it is far cheaper to test — and manage — than for these children to wind up needing very expensive care, perhaps paid for by state taxpayers.

Children are tested twice, first between 24 and 72 hours after birth, and again when they are between five and 10 days old. State health officials said that's because some conditions don't show up until after a newborn has taken food.