

# Federal advisers back more testing of newborns

## Study urges check for 30 diseases

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Associated Press

WASHINGTON — States should test every newborn for 30 rare but devastating inherited diseases, a government advisory committee recommended yesterday.

Advisers to Health and Human Services Secretary Tommy Thompson endorsed a long-awaited study from leading geneticists that called for the 30-disease check, although ex-

actly how to implement the change is still under discussion.

A spokesman couldn't say how quickly Thompson would decide whether to accept the recommendation.

In the meantime, the endorsement likely will increase pressure on many states to add to the newborn testing they currently offer. There's tremendous geographic variation: Fifteen states require testing for five or fewer of these diseases, 19 test for 25 diseases or more, and the rest fall in the middle, according to the U.S. National Newborn Screening and Genetics Resource Center.

"There's evidence that states

are not moving ... and that babies are dying," said University of Miami pediatrician Dr. R. Rodney Howell, chairman of the advisory panel.

Today, every U.S. baby is tested for two rare diseases that can cause retardation if untreated: hypothyroidism and the metabolic disease phenylketonuria. Most also are tested for sickle cell anemia, a blood disease.

But with a single drop of blood, new technology can check babies for several dozen other serious, sometimes life-threatening, genetic diseases. Each is very rare, but many are treatable if discovered early.

The testing costs about \$50

per person, covered by insurance, but requires states to invest in expensive equipment and training of lab workers.

At the federal government's request, the American College of Medical Genetics studied which of 84 genetic diseases come with accurate enough tests, and for which early diagnosis is important, to recommend for standard screening. It settled on a core list of 30.

For more information on state test requirements and supplemental testing, check a national database at <http://genes-r-us.uthscsa.edu>. The March of Dimes lists the 30 diseases at <http://modimes.org>.