

am, Newborn screenings could be a matter of life and death

WASHINGTON (AP) — Debra Gara held 9-month-old Cristal in her arms, singing her to sleep, and then dozed off herself. An hour later, she awoke with a start to find her baby ice-cold and not breathing.

An autopsy diagnosed a rare metabolic disease, one treatable if Cristal's parents had known about it — and one of more than 40 genetic and metabolic disorders that can be diagnosed easily at birth.

But few states require new-

born testing for more than a fraction of those diseases — and less than a fourth tell parents they can get the extra tests on their own for less than \$60, according to a new report by congressional investigators.

"What mother in her right mind would say no to that?" Gara asks, a New Jersey mother who says her hospital never hinted there were extra tests that Cristal wouldn't get when she was born in February 2002. "I'm angry at the state, too, but I'm more angry

at the medical profession for not telling me anything."

Parents' groups argue that where you live shouldn't determine if your baby gets a test that can mean life or death. A federal advisory panel is now debating whether to dramatically increase the list of diseases considered a minimum for newborn testing in every state — and two senators are planning legislation to fund improvements.

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

Using a single drop of a newborn's blood, doctors can test for more than 40 other serious, sometimes life-threatening, inherited diseases.

But 39 states mandate that newborns be screened for no more than eight of them, says a new report by the General Accounting Office, Congress' investigative arm.

Illinois, North Carolina, Oregon and Wisconsin require testing for more than 20 diseases, the most in the nation. Another eight states — California, Hawaii, Idaho, Iowa, Massachusetts, Minnesota, Nebraska and South Dakota — are conducting pilot programs or offer extra testing upon parental request for another 20 or more diseases.

Experts estimate that more diagnosis at birth could prevent several hundred deaths and life-threatening bouts with these illnesses each year.

Many are metabolic diseases with such tongue-twisting names that they go by acronyms, like the VLCAD that killed Cristal Gara. VLCAD and similar "fatty acid oxidation disorders" leave otherwise healthy babies without

enzymes that change stored fat into energy. If they go longer than about six hours without eating — or catch an illness that causes vomiting — they can suddenly die.

Cristal had fasted before simple surgery to put fluid-draining tubes in her ears, and then refused anything but juice for a day afterward. Had doctors known she had VLCAD, intravenous nutrition likely would have protected her — but New Jersey didn't add VLCAD to its newborn screening roster until shortly before Cristal's death.

States told the GAO that tight budgets prevent them from adding more tests, more quickly.

Sens. Chris Dodd, D-Conn., and Mike DeWine, R-Ohio, plan to introduce legislation soon to help states afford special technology called tandem mass spectrometry that allows testing for most of these diseases with just a drop of blood.

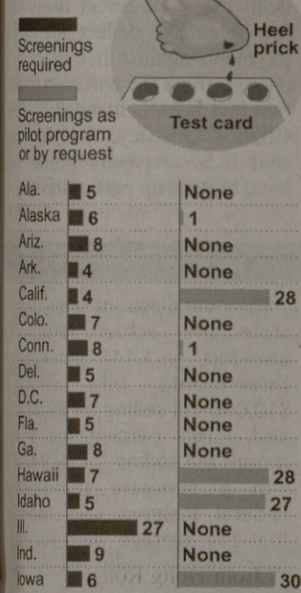
Also, a federal committee of genetics experts expects by next spring to issue a list of diseases that all babies should be screened for — along with criteria for states to use in choosing additional tests. Criteria include whether survival requires early treatment and, for untreatable diseases, if early diagnosis would help in such other ways as planning future pregnancies, says Michael Watson of the American College of Medical Genetics, who heads the panel.

Meanwhile, parents' groups are urging expectant mothers to learn what screening their state requires now — and to ask if their hospital offers supplemental testing. Check <http://genes-r-us.uthscsa.edu> for state lists. If local hospitals don't offer supplemental testing, it is offered by mail through such places as Pennsylvania-based Neo Gen Screening, for \$25 to \$60.

Screenings for newborns vary by state

Newborns in the United States are tested for two inherited diseases — a metabolic disorder called PKU and hypothyroidism. Simple blood tests can detect more than 40 additional diseases, yet which test each baby receives depends on the state he or she lives in. The tests require a drop of blood from the baby's heel blotted onto a test card.

| State | Number of diseases | None |
|--------|--------------------|------|
| Kan. | 4 | None |
| Ky. | 4 | None |
| La. | 5 | None |
| Maine | 9 | 18 |
| Md. | 9 | None |
| Mass. | 10 | 20 |
| Mich. | 7 | None |
| Minn. | 5 | 21 |
| Miss. | 5 | None |
| Mo. | 5 | None |
| Mont. | 3 | 18 |
| Neb. | 5 | 28 |
| Nev. | 6 | None |
| N.H. | 6 | 1 |
| N.J. | 14 | None |
| N.M. | 6 | None |
| N.Y. | 10 | None |
| N.C. | 32 | None |
| N.D. | 4 | 2 |
| Ohio | 12 | 15 |
| Okla. | 4 | None |
| Ore. | 33 | None |
| Pa. | 6 | None |
| R.I. | 9 | None |
| S.C. | 6 | None |
| S.D. | 13 | 29 |
| Tenn. | 5 | None |
| Texas | 5 | None |
| Utah | 4 | None |
| Vt. | 7 | None |
| Va. | 8 | None |
| Wash. | 4 | None |
| W. Va. | 3 | 1 |
| Wis. | 21 | 5 |
| Wyo. | 6 | None |



SOURCE: General Accounting Office

AP

NEWS IN BRIEF

Cancer-resistant mice bred by Wake Forest researchers

WASHINGTON (AP) — A colony of cancer-resistant mice has been developed by researchers at Wake Forest University. The scientists, who hope the mice will help improve the understanding of cancer in humans, reported their findings in Tuesday's online edition of Proceedings of the National Academy of Sciences.

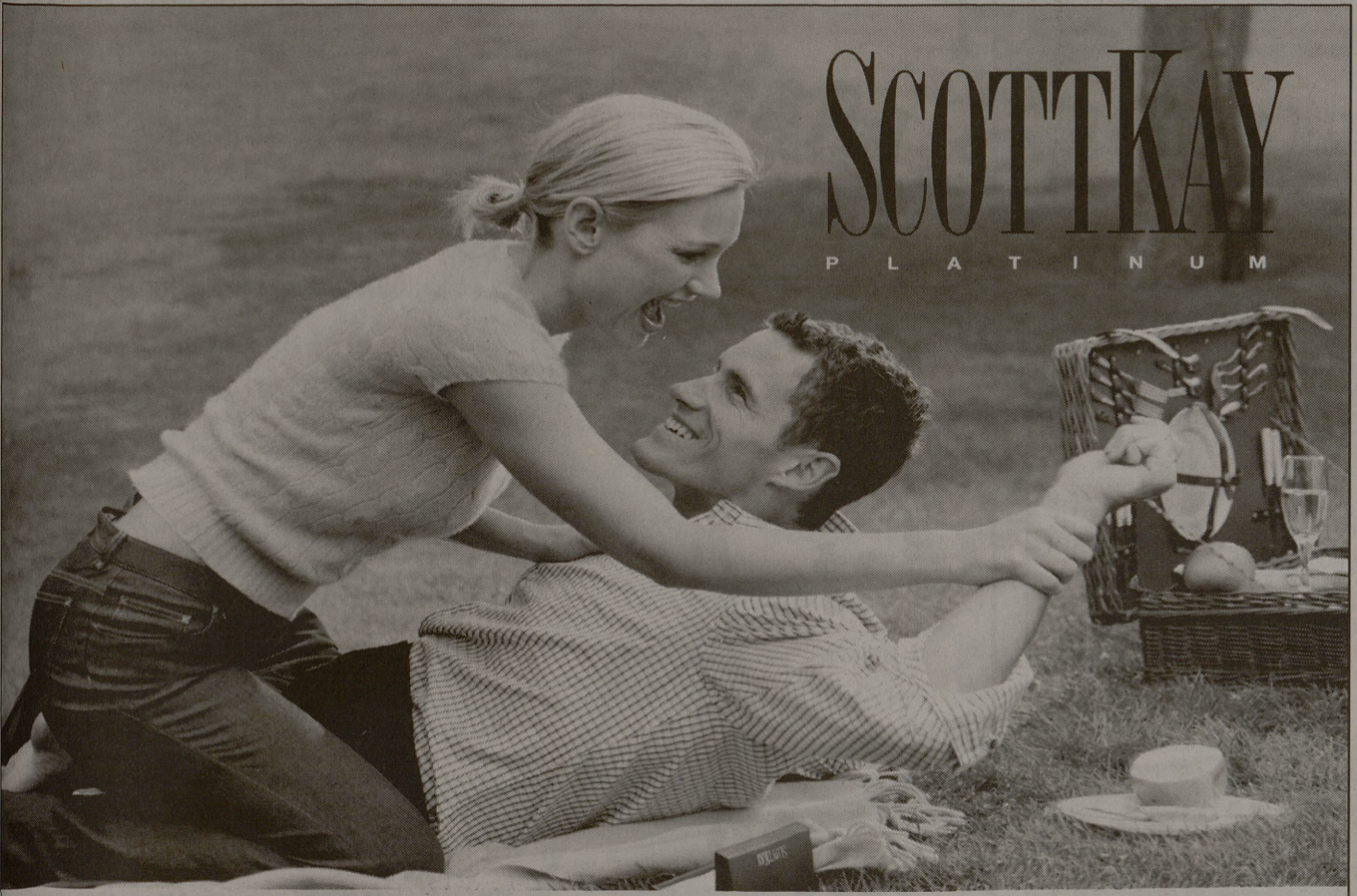
The team, led by Dr. Zheng Cui, was studying cancer in mice by injecting a virulent form of the disease into test animals. One male mouse did not develop the disease, despite repeated exposure, they reported.

Migratory birds may have better memories

WASHINGTON (AP) — Birds that migrate seem to have better long-term memories than ones that don't find their way back to

the same place year after year. In what they say may be the first scientific evidence that memory duration is related to migration, a team of German researchers tested the idea and reported their results for Tuesday's online issue of Proceedings of the National Academy of Science.

The memories of garden warblers, which migrate, were tested against the closely related Sardinian warblers, which do not, by Claudia Mettke-Hofmann and Eberhard Gwinner of the Max Planck Research Center.



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 - explanation of extenuating circumstances (if any)
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