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Empowered Patient**The government has your baby's DNA**By **Elizabeth Cohen**, CNN Senior Medical Correspondent

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Anne Brown worries that someone could gain access to the DNA sample from her daughter Isabel with Isabel's name attached.

STORY HIGHLIGHTS

Genetic testing for newborns started in the 1960s

Specimens are often given to outside researchers

Scientists have said the collection of DNA samples is a "gold mine" for doing research

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While grateful to have the information -- Isabel received further testing and she doesn't have the disease -- the Mankato, Minnesota, couple wondered how the doctor knew about Isabel's genes in the first place. After all, they'd never consented to genetic testing.

It's simple, the pediatrician answered: Newborn babies in the United States are routinely screened for a panel of genetic diseases. Since the testing is mandated by the government, it's often done without the parents' consent, according to Brad Therrell, director of the [National Newborn Screening & Genetics Resource Center](#).

In many states, such as Florida, where Isabel was born, babies' DNA is stored indefinitely, according to the resource center.

Many parents don't realize their baby's DNA is being stored in a government lab, but sometimes when they find out, as the Browns did, they take action. Parents in Texas, and Minnesota have filed lawsuits, and these parents' concerns are sparking a new debate about whether it's appropriate for a baby's genetic blueprint to be in the government's possession.

"We were appalled when we found out," says Brown, who's a registered nurse. "Why do they need to store my baby's DNA indefinitely? Something on there could affect her ability to get a job later on, or get health insurance."

According to the state of Minnesota's Web site, samples are kept so that tests can be repeated, if necessary, and in case the DNA is ever need to help parents identify a missing or deceased child. The samples are also used for medical research.

Art Caplan, a bioethicist at the University of Pennsylvania, says he

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understands why states don't first ask permission to screen babies for genetic diseases. "It's paternalistic, but the state has an overriding interest in protecting these babies," he says.

However, he added that storage of DNA for long periods of time is a different matter.

"I don't see any reason to do that kind of storage," Caplan says. "If it's anonymous, then I don't care. I don't have an issue with that. But if you keep names attached to those samples, that makes me nervous."

DNA given to outside researchers

Genetic testing for newborns started in the 1960s with testing for diseases and conditions that, if undetected, could kill a child or cause severe problems, such as mental retardation. Since then, the screening has helped save countless newborns.

Over the years, many other tests were added to the list. Now, states mandate that newborns be tested for anywhere between 28 and 54 different conditions, and the DNA samples are stored in state labs for anywhere from three months to indefinitely, depending on the state. (To find out how long your baby's DNA is stored, see [this state-by-state list](#).)

Brad Therrell, who runs the federally funded genetic resource consortium, says parents don't need to worry about the privacy of their babies' DNA.

"The states have in place very rigid controls on those specimens," Therrell says. "If my children's DNA were in one of these state labs, I wouldn't be worried a bit."

The specimens don't always stay in the state labs. They're often given to outside researchers -- sometimes with the baby's name attached.

According to a study done by the state of Minnesota, more than 20 scientific papers have been published in the United States since 2000 using newborn blood samples.

The researchers do not have to have parental consent to obtain samples as long as the baby's name is not attached, according to Amy Gaviglio, one of the authors of the Minnesota report. However, she says it's her understanding that if a researcher wants a sample with a baby's name attached, consent first must be obtained from the parents.

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Scientists have heralded this enormous collection of DNA samples as a "gold mine" for doing research, according to Gaviglio.

"This sample population would be virtually impossible to get otherwise," says Gaviglio, a genetic counselor for the Minnesota Department of Health. "Researchers go through a very stringent process to obtain the samples. States certainly don't provide samples to just anyone."

Brown says that even with these assurances, she still worries whether someone could gain access to her baby's DNA sample with Isabel's name attached.

"I know the government says my baby's data will be kept private, but I'm not so sure. I feel like my trust has been taken," she says.

Parents don't give consent to screening

Brown says she first lost trust when she learned that Isabel had received genetic testing in the first place without consent from her or her husband.

"I don't have a problem with the testing, but I wish they'd asked us first," she says.

Since health insurance paid for Isabel's genetic screening, her positive test for a cystic fibrosis gene is now on the record with her insurance company, and the Browns are concerned this could hurt her in the future.

"It's really a black mark against her, and there's nothing we can do to get it off there," Brown says. "And let's say in the future they can test for a gene for schizophrenia or manic-depression and your baby tests positive -- that would be on there, too."

Brown says if the hospital had first asked her permission to test Isabel, now 10 months old, she might have chosen to pay for it out of pocket so the results wouldn't be known to the insurance company.

Caplan says taking DNA samples without asking permission and then storing them "veers from the norm."

"In the military, for instance, they take and store DNA samples, but they tell you they're doing it, and you can choose not to join if you don't like it," he says.

What can parents do

In some states, including Minnesota and Texas, the states are required to destroy a baby's DNA sample if a parent requests it. Parents who want their baby's DNA destroyed are asked to fill out [this form in Minnesota](#) and [this form in Texas](#).

Parents in other states have less recourse, says Therrell, who runs the genetic testing group. "You'd probably have to write a letter to the state saying, 'Please destroy my sample,'" he says.

He adds, however, that it's not clear whether a state would necessarily obey your wishes. "I suspect it would be very difficult to get those states to destroy your baby's sample," he says.

CNN's John Bonifield and Jennifer Bixler contributed to this report

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