



DHEC storing babies' DNA samples

636 words

10 February 2002

13:27

Associated Press Newswires

English

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GREENVILLE, S.C. (AP) - South Carolina has stored DNA samples for nearly every child born in the state since 1995 - keeping them long after many other states discard the material used to test for disease.

Those samples, stored in a freezer somewhere in Columbia, are raising ethics concerns as DNA research advances.

"This is a brand new era of genetic testing which presents us with problems that are somewhat unique, but somewhat related to other ethical problems - confidentiality, individual choice - and these are legitimate concerns," said Dr. Donald E. Saunders Jr., of the University of South Carolina Center for Bioethics.

"While I understand the state's motivations, there does not seem to be explicit consent by donors or guardians for indefinite storage" or for public health research, Neil Caesar, a lawyer with the Health Law Center in Greenville and a member of the board of the Upstate chapter of the American Civil Liberties Union said.

Every state tests for genetic diseases, said Dr. Harold Dowda, chief of the state Department of Health and Environmental Control's bureau of laboratories. Here, the state tests for six diseases, including sickle cell anemia and phenylketonuria, or PKU, a condition that leads to mental retardation if not treated soon after birth.

The testing of about 55,000 babies yearly costs \$500,000, but catches about 100 instances of conditions that could kill or severely disable a child without treatment and increase health care costs. Dowda said it can cost \$20,000 a year to care for a single child with PKU.

While other states destroy the cards after the tests, as many other states do, South Carolina stores them in a deep freeze at minus 30 Celsius indefinitely.

The samples, stored with bar codes, are protected. The state protects the sample donor identities and bars use by anyone who may use it to discriminate such as insurers, said Dr. Robert Best, director of the division of genetics at the University of South Carolina School of Medicine.

Dowda said only authorized staff can access the test information on a password-protected computer. Access to the information can be given to parents, who give permission for the newborn screening; doctors and through court orders when a suspicious death occurs.

Over the years, Dowda said, stored specimens have been useful in several instances. In one case, the sample from a couple's second child identified the rare disease that had killed their first.

With those benefits come concerns as genetic research advances.

In the past, that type of blood sample on a card had limited uses. "But in the new age, there is a concern that you can find out information about people by having their stored DNA," Dr. Arthur Caplan of the University of Pennsylvania Center for Bioethics.

Human gene mapping has discovered 5,000 genes that can contain information ranging from paternity to the likelihood of a person developing diseases from cancer or Alzheimer's.

"The question raised is, as these genes are discovered, how can or should the stored DNA be utilized?" asked Dr. **Joann Boughman**, executive vice president of the American Board of Genetic Counseling.

"Should we go back and test all those samples for the (breast cancer gene)?"

While parents grant permission, there are questions about how the samples are handled when the child becomes an adult.

"Should that sample be available for future testing without consent of the mother or guardian, and the child if it's kept until the child turns 18 or older?" Saunders asks. "Leaving it optional is probably not a good idea," he said.

"South Carolina's storage of this data is of concern to anyone who values privacy. It's much easier to steal privacy than to protect it in this information age," Caesar said.

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