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DNA databases prelude to return of eugenics?

Warning issued over 'full genomic scans' on babies

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An organization that has been battling Minnesota state procedures in which DNA from every newborn is collected and warehoused says virtually all states do the same thing, and the alarming trend eventually could lead the United States back into eugenics.

The report from Twila Brase, president of the Citizens' Council on Health Care, says, "Throughout history, proponents of eugenics have focused on the reproduction of children, either through encouraging the 'healthy' to reproduce or discouraging the 'unhealthy' from procreation. This focus has been evidenced in history by 29 state sterilization laws … and the horrific Nazi campaign aimed at ridding Germany of the 'unfit' – the Jews, the physically deformed, the mentally retarded, the 'feebleminded,' the inferior, the epileptic, the deaf, the blind, 'those suffering from hereditary conditions,' the deviant 'asocial' and the politically dissident."

The report then continued, "That the focus on reproduction still exists today is more than troubling.

"The authors of a 2001 study 'were struck' by the large number of state government officials who agreed with a specific statement regarding assessment of a child's suitability for future reproduction," the report said. "Nineteen (54 percent) of 35 … respondents who routinely provide counseling – mostly newborn genetic screening follow-up staff at state health departments across the country – thought it important when giving advice to parents to 'identify children who might be, for genetic reasons, unsuitable choices for future reproduction,'" the report said.

The concept of "identifying" those who would be "unsuitable" for reproduction is enough reason for parents to be alarmed, and people should start demanding fully informed consent requirements, Brase said.

"To protect every American's right to self-determination, genetic privacy, and DNA property rights, it is time to require informed written parent consent for all facets of the newborn genetic screening program, including storage and use of genetic test results and newborn DNA," Brase said.

She said most states do not require parental consent for newborn genetic testing now or for the government to keep the genetic results. Most states now keep DNA results for a period of time – some extending indefinitely.

"Most parents have no idea that government is doing the testing or retaining the data and DNA," the report said.

“It is important for policymakers to look beyond the current newborn screening programs which test infants for only 21 to 60-some rare genetic conditions. Supporters of newborn screening appear to be planning for full genomic scans on every baby at birth,” warned Brase.

The organization’s website posted a report from a new grandmother who documented the medical industry’s insistence on taking that information, with or without permission.

In Minnesota, the CCHC has been battling the state Department of Health, which has been taking the DNA samples and warehousing but apparently not following “written consent requirements.”

The anonymous new grandmother there wrote:

“My daughter signed a paper stating she did not want the PKU test done because of the DNA stealing (I was there when she did that). The nurse huffed out of the room saying that stuff doesn’t happen. After my grandchild was born, a different nurse took the baby. My daughter her my granddaughter start crying. She found out her heel was getting pricked. My daughter became furious stating that she signed off on not getting the test. The nurse said there was nothing in her chart saying that. My daughter demanded the blood sample back. The nurse said they’d destroy it, but my daughter demanded it back and got it.”

Brase’s report warns the collection and assembly of DNA on an entire generation of citizens largely is unnoticed, but such newborn screening “represents the largest single application of genetic testing in medicine.”

“Suppose … expanded screening of an infant reveals not a fatal and incurable disease but instead a host of genetic variants, each of which merely confers elevated risk for some condition or other,” the report said. “Who is to say at what point an uncovered defect becomes serious enough to warrant preventing the birth of other children who might carry it? At what point have we crossed the line from legitimate family planning to capricious and morally dubious eugenics?”

The report said the concept that a population of people can be “improved” by eliminating those with any “defects” is relatively ignored these days. But, it said, “proponents are newborn genetic screening are moving toward eugenics – not away from it.”

In the United States, it was in 1927 when the U.S. Supreme Court opined, from Justice Oliver Wendell Holmes Jr.’s pen, “It is better for all he world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes.”

Even now, similar beliefs exist, the report said.

“Is it thus noteworthy that the government-funded Sickle Cell Trust in Jamaica is now providing fifth and sixth grade students with the results of their sickle cell tests on a laminated card with the hope that they will ‘select partners with normal genes and avoid having a child with sickle-cell disease,'” the report said.

“Twenty states store newborn blood samples from one to 23 years,” the report said. ” With four million babies born each year and at least 10 states retaining newborn blood indefinitely, the repository of infant DNA is large and growing. The baby's DNA is considered state government property."

That's even though surveys show one quarter of parents are unwilling to allow the government to use infant DNA information for research even with parental permission, and more than 70 percent oppose it when parents did not give permission.

Within the last month, lawsuits have been filed in both Minnesota and Texas by parents objecting to government collection and use of infant DNA.

If such information was limited to the parents, and eventually the individual person, there probably would be few complications. But the report raises the concern that's not what would happen.

"Even the baby's potential for behavioral problems and political proclivities could become a part of the government's sequenced – and recorded – findings," it said.

"It is not hard to imagine the day when any discovered but non-symptomatic condition could become a 'pre-existing condition' for which private insurers would not pay. The eugenic implications are obvious. Thus, the growing collection of genetic test results and newborn DNA could easily enable a eugenics agenda on the part of government agencies and private industry," it said.

In an interview at the time the dispute over newborns' DNA in Minnesota was heating up, Brase said it's no longer just about diabetes, asthmas and cancer.

"It's also about behavioral issues," she said.

"In England they decided they should have doctors looking for problem children, and have those children reported, and their DNA taken in case they would become criminals," she said.

In fact, published reports in the U.K. note that senior police forensics experts believe genetic samples should be studied, because it may be possible to identify potential criminals as young as age 5.

"If we have a primary means of identifying people before they offend, then in the long-term the benefits of targeting younger people are extremely large," Gary Pugh, director of forensics at Scotland Yard, was quoted saying. "You could argue the younger the better. Criminologists say some people will grow out of crime; others won't. We have to find who are possibly going to be the biggest threat to society."

The U.K. database already has 4.5 million genetic samples and reportedly is the largest in Europe, but activists want to expand it. Pugh said that it is not possible right now to demand everyone provide a DNA sample but only because of the costs and logistics.

One published report cited the Institute for Public Policy Research, which is suggesting children from 5-12 in the U.K. be targeted with cognitive behavioral therapy, and Pugh has suggested adding the children in primary schools to the database, even if they have not offended.

"Not all research is great," Brase said. "There is research that is highly objectionable into the genetic propensities of an individual. Not all research should be hailed as wonderful initiatives."

The Heartland Regional Genetics and Newborn Screening is one of the organizations that advocates more screening and research.

It proclaims in its vision statement a desire to see newborns screened for 200 conditions. It also forecasts "every student … with an individual program for education based on confidential interpretation of their family medical history, their brain imaging, their genetic predictors of best learning methods…"

Further, every individual should share information about "personal and family health histories" as well as "gene tests for recessive conditions and drug metabolism" with the "other parent of their future children."

Still further, it seeks "ecogenetic research that could improve health, lessen disability, and lower costs for sickness."

"They want to test every child for 200 conditions, take the child's history and a brain image, and genetics, and come up with a plan for that child," Brase said. "They want to learn their weaknesses and defects.

"Nobody including and especially the government should be allowed to create such extensive profiles," she said.

The next step is obvious: The government, with information about potential health weaknesses, could say to couples, "We don't want your expensive children," Brase said.

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