

State's DNA bank: how secure?

Privacy, consent over millions of samples taken from newborns emerge as concerns.

BY PATRICK MCGREEVY

SACRAMENTO — Privacy advocates are calling for more safeguards related to a state collection of DNA samples from 16 million Californians in a nondescript government warehouse in the Bay Area.

The biobank holds blood taken with the prick of a heel from almost every baby born in California for the last three decades. It is used to screen for 80 health disorders, such as cystic fibrosis and sickle cell anemia.

Unlike most states, California keeps the frozen samples indefinitely and shares them with genetic researchers, for a fee.

State officials say the samples are secure and are used to save lives. But the privacy advocates and an influential state lawmaker, concerned about the potential misuse of DNA information, say parents and donors should have a clear choice about whether the state can keep theirs.

"Throughout the process, from the point of screening to the point of storage to the point of third-party use, public understanding, knowledge and consent is almost completely absent," said Jeremy Gruber, president of the nonprofit Council for Responsible Genetics.

The blood samples are stored on special paper cards without names — just numbers that can be used to

[See DNA, A9]

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Concerns over biobank

[DNA, from A1] find identifying information stored separately, according to officials. Names are not provided to researchers.

But Assemblyman Mike Gatto (D-Glendale), chairman of a new committee created to address privacy issues in a world where technology is seen as outpacing the law, says that "whenever data is stored, data can fall into the wrong hands."

"Imagine the discrimination a person might face if their HIV status or genetic predisposition to a mental disorder were revealed to the public," he said.

The lawmaker wants the state to get written consent from parents before storing children's blood samples indefinitely and allowing their use in research after the initial screening. Parents can already opt out if they do so in writing, but Gatto said many don't realize it.

He wants to require that the state get them to opt in, to make sure parents consider the issue. Gatto said he plans to amend such a proposal into a bill he has introduced, AB 170, that would allow the blood donors, when they turn 18, to have their samples destroyed.

He said he may also include stiff financial penalties against researchers if DNA information in their possession is breached or leaked.

One researcher who has used the blood samples to make a breakthrough in public health said requiring parental consent would be "very damaging" to work like hers.

"The parents who don't suspect anything is wrong with their kids are going to say no, because they are not going to understand" how research might help their children or others later, said Jennifer M. Puck, a professor of immunology in the Department of Pediatrics at UC San Francisco.

Puck developed a test for severe combined immunodeficiency, or "bubble boy" disease, using blood samples from 20 newborns who later developed the malady. That test has been used since 2010 to identify dozens of infants who could ultimately lose their immune



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'You assume they will test your child for the disease and then burn the [sample] as medical waste.'

—MIKE GATTO, assemblyman

systems without treatment, Puck said.

California's biobank "has been exceedingly useful in my clinical work and my research."

All 50 states collect and test blood samples from newborns. California is one of 20 that keep blood samples after screening. It has samples dating to 1982 and adds to the collection with every birth.

California is one of seven states that release samples for research without parental consent and one of four that charge a fee for their release, according to a survey

published recently in the medical journal Pediatrics.

The state Department of Public Health collected \$71,000 in processing fees and approved six research requests in the current fiscal year, according to Scott Sandow, a spokesman for the agency.

A 16-page brochure given to all expectant parents when they arrive at the hospital says they may decline to have their child's samples stored after the initial screening by sending a written request to the state, Sandow said.

Gatto, who with his wife has been through the childbirth experience twice in the last four years, says he does not remember anything said about blood samples kept indefinitely and used in research.

"Obviously, when that blood is taken, it's a very emotional time, and it's a very fast-moving time," Gatto said. At the births of both of his daughters, he and his wife were absorbed in "arguing about what we were going to name them."

Gatto said he has spoken to hundreds of parents who were not aware that their children's DNA was kept by the state.

"You assume they will test your child for the disease and then burn the [sample] as medical waste," Gatto said.

Gatto envisions a notice that parents would receive well before entering the hospital to give birth, with a box they could check to allow storage of and research with their child's blood after screening.

Robert Nussbaum, chief of the Division of Medical Genetics at UCSF, said that there is no such thing as a guarantee of absolute security but that new restrictions are unnecessary. The state program is doing a good job of keeping the information stored in the samples confidential, he said.

The program's benefits to healthcare, he said, "outweigh the risks" of any data compromise.

patrick.mcgreevy@latimes.com
Twitter @mcgreevy99

- 1) How many million DNA samples are stored in the Bay Area Warehouse?
- 2) How many health disorders are screened with this information?
- 3) Assemblyman Mike Gatto has suggested introducing a bill allowing individuals to have their samples destroyed when they reach this age.
- 4) The bill is numbered AB _____.
- 5) How many states collect newborn genetic data?
- 6) How many states keep and store the data?
- 7) In what year did the sampling begin?
- 8) Add together answers from questions 1-7. Record your total. _____

Summarize the potential and the concern addressed in the article. (2 points)