Growing privacy concerns over California DNA collection

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.

Read full, original article: Millions of DNA samples stored in warehouse worry privacy advocates