

***** NEWS RELEASE *****

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Reclaiming Your Baby's DNA: First-of-Its-Kind Repository Enables New Breaches in Patient Privacy and Parental Rights

*Citizens' Council for Health Freedom Urges States to Enact Legislation to
Require Informed Parental Consent Regarding Newborn Screenings*

Key Facts:

- New federal repository created and maintained by the Newborn Screening Translational Research Network (NBSTRN) is a virtual, web-based repository of newborns' DNA, obtained through dried blood spots.
- Though touted as a means to increase newborn screening research, there are no limits on the types of research that can be conducted on the DNA specimens once requested and obtained.
- Though de-identified in the repository, DNA in and of itself is a human identifier, since no two people have identical DNA. Re-identification of the individual DNA specimens is possible.
- In most states, neither children nor parents have any say in whether their or their child's DNA is kept in the repository.
- The only way to protect DNA is to enact legislation requiring informed parental consent regarding the collection, storage, and use of infant DNA.

ST. PAUL, Minn. – In yet another federal over-reach that breaches parental rights, the Newborn Screening Translational Research Network (NBSTRN) announced last week that it had developed a centralized, virtual, web-based repository of newborns' DNA, obtained through dried blood spots. DNA samples are collected from infants at birth and often saved, stored, and used for research without the knowledge or consent of an infant's parents.

The issues surrounding this move are many and the bio-ethical implications unclear, according to the *Citizens' Council for Health Freedom (CCHF)*. First, and perhaps most critical, are the privacy breaches and the potential for unethical or morally objectionable use.

“Few people object to the idea of testing newborns to ensure they don’t have diseases that can be treated from birth but which could cause harm or even death if left undiscovered, like phenylketonuria,” said Twila Brase, President of the Citizens’ Council for Health Freedom. “But the central repository does not directly limit the nature or scope of the research that can be conducted on a baby’s DNA specimen, and researchers are able to request samples for research that goes far beyond improvement of newborn screenings, all without parental knowledge or consent. The question becomes, do parents have the right to limit medical testing on what is essentially the very essence of their child – his or her DNA? At CCHF, we support parental rights to limit such testing as they see fit, and encourage states to adopt laws that help parents know and understand exactly how DNA obtained from a simple heel prick test will be used and stored.”

In addition to the potential for unauthorized testing, the central repository also poses a potential breach in privacy in that each state which maintains newborn DNA has different rules regarding sharing and dissemination of samples, and few states have laws which protect them. The *CCHF* asserts that when you add to this the fact that DNA by its very nature is a human identifier and that it is easy to re-connect identifying information that links a patient to his or her DNA, the identification and patient targeting that can occur is morally suspect at best and potentially outside of the law at worst.

The *CCHF* points to two recent studies from the Hastings Center and the Council for Responsible Genetics which show that an increase in informed consent for storage and usage of baby DNA for medical testing and research has the potential to help earn and maintain parental trust as well as increase parental compliance with needed screenings.

“We certainly don’t advocate parents forgoing these important newborn tests, however it is important to understand exactly where and for how long your child’s sample will be stored, as well as what the rules are in your state regarding research and sharing samples with researchers and other entities,” said Brase. “Understanding these key practices and agreeing to them ahead of time, at a less emotional time than at or just following the delivery of your child, is critical to maintaining the privacy of your child and his or her DNA.”

The *CCHF* is urging states to enact legislation like that which was proposed and passed in Minnesota, requiring parents to make a decision about consent for newborn DNA storage and subsequent research testing after a thorough explanation of what this practice actually entails. Such laws protect infants and families from the breach of privacy and potentially unethical use of a baby’s DNA for research that parents have not consented to.

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