

Public Trust & Privacy at Stake: Newborn Genetic Screening Data Used in Criminal Investigations

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Investigative Genetic Genealogy (IGG) is the process of creating genetic profiles from crime scene samples and uploading them to genealogy websites to map out family trees. Such data has been used in about 200 criminal investigations in the past four years. Although this may seem innovative initially, the concern is now heightened as law enforcement turns to newborn blood samples, a move that threatens not only privacy but also the delicate balance of public trust in the newborn screening program.

In the United States, the routine blood testing of newborns for potential genetic disorders is a critical public health initiative. The newborn screening system is built on the foundation of public trust, with the understanding that the benefits of early detection far outweigh the temporary discomfort for newborns and the associated costs for parents. However, this equilibrium is disrupted when genetic data collected for public health reasons is repurposed for criminal investigations. The absence of a uniform national policy further exacerbates the issue, with over a quarter of U.S. states lacking clear guidelines on law enforcement access.

Recent developments reveal a concerning trend: law enforcement agencies seeking access to these invaluable genetic samples for criminal investigations. A public records lawsuit in New Jersey highlights the police subpoena of a newborn blood sample in a cold case from 1996, raising significant questions about the intersection of genetic privacy and criminal justice.

The potential consequences are severe. With IGG investigations, police access to newborn genetic screening samples could transform a successful public health intervention into a tool for mass genetic surveillance, allowing authorities to trace familial ties back for generations. This prospect may lead states to reconsider their screening programs, parents to opt-out, and citizens to demand stricter privacy safeguards.

This threat to privacy and public trust is not limited to newborn genetic screening. If you've ever uploaded your genetic information to a website like 23andMe or Ancestry.com, you may have contributed to an investigation like the New Jersey case without even knowing.

To restore public trust and safeguard genetic privacy, states must proactively identify instances of potential abuse of newborn screening data by law enforcement. Additionally, policies restricting police access to these samples in criminal investigations, as seen in the state of Iowa, should be implemented. Setting limits on sample storage duration in alignment with medical best practices and requiring informed consent for any use beyond screening are vital steps to ensure the continued success of newborn screening without compromising individual privacy rights. States must act promptly to preserve the integrity of this essential public health program and protect the genetic privacy of future generations.

For more information, check out the full article [here!](#)