

ACLU OF RI POSITION: SUPPORT

**TESTIMONY ON 25-H 5495
AN ACT RELATING TO HEALTH AND SAFETY – MATERNAL AND CHILD
HEALTH SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS
February 25, 2025**

The ACLU of RI strongly supports this legislation which would provide for the confidentiality of newborn screening specimens and classify this data as protected health information.

We understand the importance of conducting these tests which result in early detection and treatment of various medical disorders a newborn child may have or prone to. But we also greatly appreciate the Department's recognition that these screenings and their results should be strictly treated as confidential health information. A newborn's DNA contains not only information about the newborn, but also their family and can, as the committee is aware, reveal a wide array of personal information. In allowing these screenings to take place for their child's health, no parent should expect it to be shared with any third parties for non-medical related purposes.

A cautionary tale coming out of New Jersey highlights the importance of the privacy protections this bill seeks to codify.¹ The New Jersey State Police subpoenaed a newborn genetic testing program to obtain a nine-year-old blood sample in connection to a crime that the child's father may have committed. Instead of securing a warrant – an action that requires probable cause – law enforcement used a subpoena to access the sample. This raises serious concerns about the potential for similar situations to arise in Rhode Island, where the appropriate legal procedures may be bypassed. In the law enforcement context, a judicial warrant should always be a necessity to obtaining confidential information like this. Strict confidentiality provisions should also be in place when researchers and others seek access to this information, and we appreciate the bill's efforts to respect privacy rights in those situations as well.

We therefore strongly support this legislation designed to safeguard the privacy rights of children and their families from third parties generally. Thank you for your consideration of our views.

¹ <https://newjerseymonitor.com/2022/07/13/newborn-screening-program-used-to-aid-criminal-investigation-public-defender-says/>