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**PUBLIC NOTICE OF  
CHANGE TO NEWBORN SCREENING PROGRAM'S RETENTION POLICY**

**June 20, 2024**

As in all States, each baby born in New Jersey must be screened for certain disorders that can cause serious health problems. New Jersey law requires that babies born in our State be tested for 61 disorders within 48 hours of birth, a process that starts with a "heel prick" blood draw that generates five spots of blood, or "bloodspots," that can be used as test samples. The Department's lab then conducts tests and shares the results with the baby's doctor.

This notice describes changes to the Department's policy for retaining newborn screening bloodspots. Currently, the Department retains bloodspots for 23 years. **Under the new policy, the Department will retain identified bloodspots for only two years, unless a parent or legal guardian expressly requests a shorter or longer retention period as described below.** The Department has begun taking steps to implement the new policy, though destruction of existing samples will not begin until November 1, 2024, and will take some time. Under the new policy:

- The Department will use retained bloodspots only for the following purposes: (1) newborn screening for a child; (2) routine laboratory quality assurance and quality control; and (3) the development of new tests for disorders. Any bloodspots used for the second or third purposes will be de-identified prior to that use.
- Any retained bloodspots will not be released to any other third-party in **identified** form (*i.e.*, with identifying information about the child), without the consent of a parent or legal guardian.
- Any retained bloodspots will not be released to any other third-party in **de-identified** form (*i.e.*, without any identifying information about the child), unless consistent with federal statutes and regulations.
- Parents and legal guardians who want the Department to **retain** bloodspots linked to their child for more than two years may request that the Department do so (for up to ten years) by submitting the Extended Retention Form, available [here](#). The Department will be conducting outreach regarding the new policy to doctors and other stakeholders involved in caring for children who tested positive for one or more of the conditions on the newborn screening panel.
- Parents and legal guardians who want the Department to **destroy** all bloodspots linked to their child may, at any time after the initial screening (including before their child is two

years old), direct the Department to do so by submitting a Destruction Form, available [here](#).

- For bloodspots that tested negative, unless a parent or legal guardian has directed otherwise, the Department will queue the bloodspots for destruction at the two-year mark.
- For bloodspots that tested positive for any of the 61 conditions:
  - The Department will de-identify one bloodspot and retain that de-identified bloodspot no longer than 10 years, using it for routine laboratory quality assurance, quality control, and the development of new tests for disorders.
  - The remaining four bloodspots will be queued for destruction at the two-year mark, as with bloodspots that tested negative.
- Bloodspots never have been and **never will be sold** to any person or entity.
- The New Jersey Attorney General has recently issued a binding Law Enforcement Directive that limits the circumstances under which state and local law enforcement may seek to obtain information from the newborn screening program, available [here](#). The Department will not release such information to law enforcement without the consent of a parent or legal guardian, except as consistent with the Attorney General's Directive.