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KAITLAN BASTON, MD, MSC, DFASAM Commissioner

Change to Newborn Screening Program Dried Blood Spots Retention Policy

Beginning on November 1, 2024, the default retention period for all Newborn Screening (NBS) dried blood spots submitted to the New Jersey NBS Laboratory will be 2 years, a change from the current 23-year default retention period.

NBS is a public health mandate that screens all newborns for potentially harmful or fatal diseases within the first week of life, through the collection and submission of five dried blood spots to the NBS Laboratory.

All residual dried blood spots that remain after the initial screening of a newborn's sample ("specimen") are currently saved for 23 years. This retention policy is changing so that the default retention period is 2 years, but parents or legal guardians may request extended retention for a total maximum period of retention of 10 years. As is already being done, parents or legal guardians may request destruction of all specimens that are linked to their newborn's identifying information at any time after initial screening and reporting are complete.

When will this new retention policy be implemented?

Beginning on <u>November 1, 2024</u>, the default retention period for specimens will be 2 years, unless extended retention or early destruction are requested by parents or legal quardians using the forms on the NBS Laboratory's website.

What will happen to specimens currently being stored by the NBS Program that are more than 2 years old but less than 23 years old?

All currently stored specimens that are more than 2 years old will be destroyed, unless a request for extended retention is received by October 15, 2024, as explained in more detail below. Destruction of these older stored specimens will begin on **November 1**, **2024**.

What if I do not want an older specimen to be destroyed?

If a parent, legal guardian, or healthcare provider does not want an older specimen destroyed, a request for extended retention can be made by a parent or legal guardian by filling out a form on the DOH website. This form must be received by <u>October 15, 2024</u> to prevent destruction of stored specimens that are currently older than 2 years. Even under the extended retention policy, no specimens will be saved for longer than 10 years from the time of collection.

What if I want to have a specimen sent to another laboratory?

If a parent, legal guardian, or healthcare provider wants to have a portion of a newborn's specimen sent to a different laboratory for further testing, a request can be made by a parent or legal guardian by filling out a form on the DOH website. That request may be made at any time during the applicable retention period (including during extended retention at a parent's or legal guardian's request). For specimens older than 2 years that are slated for destruction, the form must be received by **October 15, 2024** to ensure the release request is fulfilled prior to destruction of the remaining specimens.

Please contact the NBS Laboratory at 609-530-8371 if you have any concerns or questions regarding this policy change. The full policy and all related forms can be found at https://www.nj.gov/health/phel/public-health-lab-testing/newborn-screening-lab or by using the QR code. The policy is in the "For Parents" section and the forms are in the "Forms" section.

