

After Newborn Genetic Testing of Baby is Done

State by State Government Newborn Blood & Baby DNA Retention Practicesⁱ

| STATE | 2002 ⁱ | 2003 | 2004 | 2005 | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 ⁱⁱ | 2014 | 2015 |
|---------------|-------------------|-----------------|-----------------|-----------------|-----------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|-----------------------|-----------------------|--------------|
| Alabama | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo |
| Alaska | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs |
| Arizona* | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 3 mo |
| Arkansas | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 3-6 mo | 3-6 mo | 3-6 mo | 3-6 mo | 3-6 mo | 3-4 mo | 3-4 mo | 2 years |
| California | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely |
| Colorado | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo |
| Connecticut | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 2 yrs | 2 yrs | 6 mo | 6 mo | 2 yrs |
| Delaware | 4 mo | 4 mo | 4 mo | 4 mo | 4 mo | 4 mo | 4 mo | 4 mo | 4 mo | 3 yrs | 3 yrs | 3 yrs | 3 yrs | 3 yrs |
| D.C. | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| Florida | >5 yrs | >5 yrs | >5 yrs | >5 yrs | >5 yrs | >5 yrs | >5 yrs | Indefinitely | Indefinitely | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo |
| Georgia | 6 wk | 6 wk | 6 wk | 6 wk | 6 wk | 6 wk | 6 wk | 6 wk | 6 wk | 12 wk/2 yrs | 12 wks/ 2yrs | 2 mo | 2 mo | 2 mo |
| Hawaii | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| Idaho | Unclear | Unclear | Unclear | Unclear | Unclear | Unclear | Unclear | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| Illinois | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo | 2 mo/4 mo |
| Indiana | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs |
| Iowa | 1 mo | 1 mo | 1 mo | 5 yrs | 5 yrs | 5 yrs | 5 yrs | Indefinitely | 5 yrs | 1 yr | 1 yr | 5 yrs | 5 yrs | 5 yrs |
| Kansas | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo |
| Kentucky | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6-8 wks/ Indefinitely | 6-8 wks/ Indefinitely | 6 mo | 6 mo | 2 mo |
| Louisiana | 2wk/1mo | 2wk/1mo | 2wk/1mo | 2wk/1mo | 2wk/1mo | 2wk/1mo | 2wk/1mo | 30 Days | 30 Days | 1 yr | 1 yr | 1 mo | 1 mo | 1 mo |
| Maine | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely |
| Maryland | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | Indefinitely Since 2004 | Indefinitely Since 2004 | Indefinitely Since 2004 | Indefinitely Since 2004 | Indefinitely Since 2004 | Indefinitely Since 2004 | 25 yrs | 25 yrs | 25 yrs |
| Massachusetts | Since 1991 | Since 1991 | Since 1991 | Since 1991 | Since 1991 | Since 1991 | Since 1991 | Since 1991 | Since 1991 | 22 yrs | 22 yrs | 21.5 yrs | 21.5 yrs | 21.5 yrs |
| Michigan | 21.5 yrs | 21.5 yrs | 21.5 yrs | 21.5 yrs | 21.5 yrs | 21.5 yrs | 21.5 yrs | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely |

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|-----------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|------------------------|--------------------------------|--------------------------------|------------------------|------------------------|------------------------|--|------------------------|
| Minnesota | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | 71 Days | 71 Days/ Indefinite as of 8/1/14 | Indefinitely |
| Mississippi | 3 mo | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 2 yr Minimum | 1 yr Minimum | 1 yr Minimum | 1 yr | 1 yr | 1 yr |
| Missouri | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs |
| Montana | 2 - 6 mo | 2 - 6 mo | 2 - 6 mo | 2 - 6 mo | 2 - 6 mo | 2 - 6 mo | 2 - 6 mo | 3 yrs | 3 yrs | 1 yr/ Indefinitely | 1 yr/ Indefinitely | 1 yr | 1 yr | 1 yr |
| Nebraska | No Data | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo |
| Nevada | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| New Hampshire | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo |
| New Jersey | 25 yrs | 25 yrs | 25 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs |
| New Mexico | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| New York | No Data | No Data | No Data | No Data | No Data | No Data | No Data | 27 yrs | 27 yrs | 27 yrs | 27 yrs | 27 yrs | 27 yrs | 27 yrs |
| North Carolina | 2 yrs | 2 yrs | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs | 5 yrs |
| North Dakota | 10 yrs | 10 yrs | 10 yrs | 10 yrs | 10 yrs | 10 yrs | 10 yrs | Indefinitely | 5 yrs | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Age 18 |
| Ohio | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs | 2 yrs |
| Oklahoma | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 42 Days | 42 Days | 42 Days |
| Oregon | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| Pennsylvania | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 8 mo | 8 mo | 8 mo | 8 mo | 8 mo | 8 mo | 8 mo |
| Rhode Island | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs | 23 yrs |
| South Carolina* | Indefinitely | Parent Choice | Parent Choice | Parent Choice | Parent Choice | Parent Choice | Parent Choice | 2 yrs then Parent Choice | 2 yrs then Parent Choice | 6 mo | 6 mo | 1 yr/ "longer" | 1yr/ "longer" | 1yr/ "longer" |
| South Dakota | 2 mo | 2 mo | 2 mo | 2 mo | 2 mo | 2 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo | 1 mo |
| Tennessee* | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 3 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely | 12 mo/ Indefinitely |
| Texas** | 3 yrs | 6 mo | 6 mo | No Data | No Data | No Data | No Data | 25 yrs Under Review | 25 yrs Under Review | 25 yrs | 25 yrs | 25 yrs | 25 yrs | 2 yrs/25 yrs |
| Utah | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 2 yrs | 2 yrs | 90 Days | 90 Days | 90 Days | 90 Days | 90 Days |
| Vermont | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely | Indefinitely |
| Virginia* | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs | 6 mo/10 yrs |
| Washington | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs | 21 yrs |
| West Virginia | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo | 3 mo |
| Wisconsin | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr | 1 yr |
| Wyoming | No Data | No Data | No Data | No Data | No Data | No Data | No Data | No Data | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo | 6 mo |

* States that have extended retention for positive results (from 10 yrs to indefinitely) as of 2013.

** In February 2008, the NNSIS showed Texas retention as 6 mo. in 2005, 2006, 2007, and 2008. On March 12, 2009, the Texas Civil Rights Project sued the Texas Department of Health after a newspaper in Austin, Texas reported that the Texas Department of Health has been keeping newborn blood indefinitely for the past six years. On March 20, 2009 there was no retention data from 2005 – 2009.

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Minnesota's National DNA Repository for Cancer Research - 2005

“The Children’s Oncology Group (COG Epidemiology Committee...has established a bank for NBS [newborn blood spots] under the stewardship of Drs. Logan Spector and Julie Ross. Randomly selected, anonymous NBS obtained from United States public health laboratories will be kept at the University of Minnesota Children’s Cancer Research Fund Molecular Epidemiology Laboratory. Aliquots of DNA extracted from NBS will be released to researchers after approval by the COG Epidemiology Committee...The number of NBS or portions thereof available to the COG Epi committee will vary by state. For the purposes of banking the minimum acceptable amount is ½ of a full spot...Accompanying data will be requested for each NBS as available. The particular data points are child’s sex, child’s year of birth, child’s birth weight, child’s gestational age, parental age of birth of child, parental race or ethnicity, and parental education...There are no benefits to participants. There may be a benefit to general knowledge as research reveals genetic polymorphisms that influence the risk of childhood cancer. Ultimately, NBS may be a screening tool used to predict future cancer risk.” – *University of Minnesota application to MN Dept. of Health IRB, Received by MDH on 10/12/2005.*

CDC Proposes National Databank of DNA - 2002

The Centers for Disease Control and Prevention in Atlanta, Georgia has contemplated creating a databank of the DNA-filled newborn blood spots and using them—seemingly without parent consent—for additional purposes beyond the newborn genetic screening program, specifically genetic and other research:

Newborn screening (NBS) programs collect dried blood spots (DBS) in every state for the approximately 4 million children born each year. Leftover DBSs are available after routine metabolic, endocrine, hematologic and other screening tests so re-testing can be performed, if needed. Over 95% of newborns have leftover DBS retained by state programs for some time period.

These leftover DBS specimens are a unique, valuable population-based source for important public health surveillance and potential epidemiologic research, including population-based data on prevalence of genetic variants, markers of environmental exposure and infectious disease and constitute a specimen bank of a large cohort of state populations...

Assessing the impact of genetic variation on the health of populations will be critical to guide public health research, policy, and practice on using genetic information to prevent disease. In collaboration with state health departments and other partners, we would like to examine the feasibility of establishing a bank of leftover newborn dried blood spot (DBS) specimens and assess the logistical structure for controlled access to a multi-state spot banks or a central spot bank.

The purpose of the banks would be to provide a unique resource for obtaining population-based data on prevalence of gene variants of public health significance, and the association of gene variants with disease and risk factors, including measuring markers of environmental exposure, infectious disease, or risk factors associated with developmental disabilities and chronic disease.ⁱⁱⁱ [our emphasis]

ⁱ 2002– 2012 data taken from the National Newborn Screening Information System (<http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=10&FORMID=13&FCLR=1>). The 2001-2009 data are final, The 2010-2012 data may have changed Since April 12, 2012 when the data was updated. However, due to the change in online location of the data (NNSIS lost funding and the data reporting website transitioned to NSTAEP), the 2010 – 2012 data cannot be checked for any changes that may have occurred between April 2012 and December 2012.

ⁱⁱ 2013-2015 data taken from The Newborn Screening Technical Assistance and Evaluation Program (https://data.newsteps.org/newsteps-web/stateProfile/input_action) Last updated November 3, 2015.

ⁱⁱⁱ “Banking Newborn Blood Spots for Public Health,” a workshop convened by the CDC. 9/23-24/2002 in Atlanta, GA. <http://www.cdc.gov/genomics/training/conference/Spotbank.htm>