Citizens' Council on Health Care

After Newborn Genetic Testing of Baby is Done

State by State Government Newborn Blood & Baby DNA Retention Practices[1]

STATE	2001	2002	2003	2004	2005	2006	2007	2008	2009
ALABAMA	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo
ALASKA (OR LAB)	3 yr	3 yr	3 yr	3 yr	3 yr	3 yr	3 yr	3 yr	3 yr
ARIZONA	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo
ARKANSAS	1 yr	2 yr	2 yr	2 yr	2 yr	2 yr	2 yr	3-6 mo	3-6 mo
CALIFORNIA	no data	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely
COLORADO	no data	3mo	3mo	3mo	3mo	3 mo	3 mo	3 mo	6 mo
CONNECTICUT	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo
DELAWARE	4 mo	4 mo	4 mo	4 mo	4 mo	4 mo	4 mo	4 mo	4 mo
D.C.	Indefinitely	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum
FLORIDA	>5 yrs	>5 yrs	>5 yrs	>5 yrs	>5 yrs	>5 yrs	>5 yrs	>5 yrs	>5 yrs
GEORGIA	6 wk	6 wk	6 wk	6 wk	6 wk	6 wk	6 wk	6 wk	6 wk
HAWAII	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year
IDAHO	unclear	unclear	unclear	unclear	unclear	unclear	unclear	unclear	1 year
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
INDIANA	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	1 mo	1 mo	1 mo	1 mo	5 yrs	5 yr
KANSAS	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
LOUISIANA*	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**	**2wk/1mo**
MAINE	5 yr	5 yr	5 yr	5 yr	5 yr	5 yr	5 yr	5 yr	Indefinitely
MARYLAND	3 yr	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo
MASSACHUSETTS	Since 1991	Since 1991	Since 1991	Since 1991	Since 1991	Since 1991	Since 1991	Since 1991	Since 1991
MICHIGAN	21.5 yr	21.5 yr	21.5 yr	21.5 yr	21.5 yr	21.5 yr	21.5 yr	21.5 yr	Indefinite
MINNESOTA	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinite
MISSISSIPPI	3 mo	3 mo	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum	2 yr minimum

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MISSOURI	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo	6 mo
MONTANA	2 - 6 mo	2 - 6 mo	2 - 6 mo	2 - 6 mo	2 - 6 mo	2 - 6 mo	2 - 6 mo	2 - 6 mo	3 yrs
NEBRASKA	no data	120 day	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
NEW HAMPSHIRE	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	Indefinitely	6 mo
NEW JERSEY	25 yrs	25 yrs	25 yrs	25 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	3 mo	1 yr
NEW YORK	**no data**	**no data**	**no data**	**no data**	**no data**	**no data**	**no data**	**no data**	**no data**
NORTH CAROLINA	2 yrs	2 yrs	2 yrs	Indefinite	Indefinite	Indefinite	Indefinite	Indefinite	Indefinite
NORTH DAKOTA	10 yrs	10 yrs	10 yrs	10 yrs	10 yrs	10 yrs	10 yrs	10 yrs	10 yrs
OHIO	21 yrs	21 yrs	21 yrs	21 yrs	21 yrs	21 yrs	21 yrs	2 yrs	2 yrs
OKLAHOMA	1 mo	1 mo	1 mo	1 mo	1 mo	1 mo	1 mo	1 mo	1 mo
OREGON	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year
PENNSYLVANIA	5 yr	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	8 mo
RHODE ISLAND	23 yr	23 yr	23 yr	23 yr	23 yr	23 yr	23 yr	23 yr	23 yr
SOUTH CAROLINA	Indefinite	Indefinite	**Parent Choice**	**Parent Choice**	**Parent Choice**	**Parent Choice**	**Parent Choice**	**Parent Choice**	**Parent Choice**
SOUTH DAKOTA	2 mo	2 mo	2 mo	2 mo	2 mo	2 mo	2 mo	1 mo	1 mo
TENNESSEE*	3 mo/ indefinitely	3 mo/ indefinitely	3 mo/ indefinitely	3 mo/ indefinitely	3 mo/ indefinitely	3 mo/ indefinitely	3 mo/ indefinitely	12 mo/ indefinitely	12 mo/ indefinitely
TEXAS**	6 mo	3 years	6 mo	6 mo	**no data**	**no data**	**no data**	**no data**	**no data**
UTAH	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	3 mo	2 yrs
VERMONT	Indefinite	Indefinite	Indefinitel	Indefinite	Indefinite	Indefinite	Indefinite	Indefinite	Indefinite
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/10 yrs
WASHINGTON	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
WISCONSIN	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year	1 year
WYOMING	no data	no data	no data	no data	no data	no data	no data	no data	6 mo

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

****** *In February 2008, the NNSIS showed Texas retention as 6 mo. in 2005, 2006, 2007, and 2008. On March 20, 2009, there was no retention data from 2005 – 2009. 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.*

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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 laboratoreis 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 minumum 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.*
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> *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.*
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> *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.*[2] [our emphasis]

[1] Data taken from the National Newborn Screening Information System (http://www2.uthscsa.edu/nnsis/), March 20, 2009.
[2] "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 - accessed online February 6, 2008.

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