

MDH Responds to CCHF Data Request on Current Storage of Newborn DNA

Response to February 27, 2015 and April 30, 2015 data requests from Citizens' Council for Health Freedom

Newborn Screening Program data is not structured such that every element of this data request can be answered exactly as asked. The responses provided here are the results of the program's best effort to be as responsive to the request as possible.

If a number is qualified by an indicator that it is *as of* a certain date, it is a number that changes or may change over time.

Newborn Screening Data

- Number of newborn dried blood spots stored *before* November 16, 2011 for which the department has obtained parent consent for storage.

The Newborn Screening Program received written parental consent to store 134 blood spots from the period before November 16, 2011.

- Number of newborn dried blood spots stored *before* November 16, 2011 for which the department has obtained parent consent for storage *and* use.

The Newborn Screening Program received written parental consent to store and use 134 blood spots from the period before November 16, 2011.

- Number of newborn dried blood spots stored between November 16, 2011 and August 1, 2014 for which the department has obtained parent consent for storage.

The Newborn Screening Program received written parental consent to store 530 blood spots from the period November 16, 2011 through August 1, 2014.

- Number of newborn dried blood spots stored between November 16, 2011 and August 1, 2014 for which the department has obtained parent consent for storage and use.

The Newborn Screening Program received written parental consent to store and use 530 blood spots from the period November 16, 2011 through August 1, 2014.

- Number of newborn screening bloodspot test results stored between November 16, 2011 and August 1, 2014 for which the department has obtained parent consent for storage.

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The Newborn Screening Program received written parental consent to store 523 bloodspot test results from the period November 16, 2011 through August 1, 2014.

- Number of newborn screening bloodspot test results stored between November 16, 2011 and August 1, 2014 for which the department has obtained parent consent for storage and use.

The Newborn Screening Program received written parental consent to store and use 523 bloodspot test results from the period November 16, 2011 through August 1, 2014.

- Number of newborn dried blood spots still in storage that were collected between November 16, 2011 and August 1, 2014 for which the department has not obtained parent consent.

As of April 1, 2015, 1283 blood spots from the period November 16, 2011 through August 1, 2014 for which MDH did not obtain written parental consent were still in storage at MDH.

- Number of newborn bloodspot screening test results still in storage that were collected between November 16, 2011 and August 1, 2014 for which the department has not obtained parent consent.

As of April 1, 2015, 98598 bloodspot screening test results from the period November 16, 2011 through August 1, 2014 for which MDH did not obtain written parental consent were still in storage at MDH.

- The date remaining newborn dried blood spots stored before August 1, 2014 are scheduled for destruction because the department has not received consent as required before August 1, 2014.

The last of the blood spots from the period before August 1, 2014 for which the department has not received written consent for storage and use are scheduled to be destroyed on August 8, 2016.

- The date remaining newborn bloodspot screening test results stored before August 1, 2014 are scheduled for destruction because the department has not received consent as required before August 1, 2014.

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The last of the bloodspot screening test results from the period before August 1, 2014 for which the department has not received written consent for storage and use are scheduled to be destroyed on September 15, 2016.

- Total number of newborn dried blood spots remaining in storage from children born before August 1, 2014.

As of April 2, 2015, 2105, 1959 blood spots remained in storage from the period before August 1, 2014.

- Total number of newborn dried blood spots retained from babies born between August 1, 2014 and December 31, 2014.

As of April 2, 2015, 29699 blood spots remained in storage from the period between August 1, 2014 and December 31, 2014.

- Total number of newborn bloodspot screening test results remaining in storage from children born before August 1, 2014.

As of April 2, 2015, 99495 bloodspot test results remained in storage from the period between August 1, 2014 and December 31, 2014.

- Total number of newborn bloodspot screening test results remaining in storage from children born between August 1, 2014 and December 31, 2014.

As of April 2, 2015, 30174 bloodspot screening test results remained in storage from the period between August 1, 2014 and December 31, 2014.

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Post-August 1, 2014 Specifics

- A month-by-month tally of the number of children screened by the state newborn screening program from August 1, 2014 - April 30, 2015.

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As of April 2, 2015, the following numbers of infants were screened and matched to Minnesota birth certificates:

Month	Year	Count
August	2014	5738
September	2014	5879
October	2014	5946
November	2014	4968
December	2014	6219
January	2015	5260
February	2015	5044

As of June 8, 2015, the following numbers of infants were screened and matched to Minnesota birth certificates:

March	2015	5648
April	2015	5663

- A month-by-month tally of the number of newborn dried blood spots retained from August 1, 2014 - April 30, 2015.

As of April 1, 2015:

Month	Year	Count
August	2014	5985
September	2014	6094
October	2014	6124
November	2014	5504
December	2014	6061
January	2015	5717
February	2015	5284

As of June 8, 2015:

March	2015	5914
April	2015	5884

- A month-by-month tally of the number of parents that refused each of the following from August 1, 2014 - April 30, 2015:
 - Newborn Screening

As of April 1, 2015:

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Month	Year	Count
August	2014	9
September	2014	21
October	2014	22
November	2014	14
December	2014	12
January	2015	15
February	2015	10

As of June 8, 2015:

March	2015	19
April	2015	13

- Retention of newborn dried blood spots

As of April 1, 2015:

Month	Year	Count
August	2014	18
September	2014	13
October	2014	7
November	2014	11
December	2014	13
January	2015	9
February	2015	218

As of June 8, 2015:

March	2015	241
April	2015	57

- Retention of newborn screening results

As of April 1, 2015:

Month	Year	Count
August	2014	16

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September	2014	12
October	2014	7
November	2014	11
December	2014	12
January	2015	9
February	2015	218

As of June 8, 2015:

March	2015	241
April	2015	57

- Retention of newborn hearing results

As of April 1, 2015:

Month	Year	Count
August	2014	12
September	2014	6
October	2014	5
November	2014	5
December	2014	10
January	2015	2
February	2015	180

As of June 8, 2015:

March	2015	194
April	2015	42

- Retention of newborn pulse oximetry results

This information is not readily available because the program does not enter this explicit information in its data system. It is not necessary to do so because the program's plan for addressing the destruction of pulse oximetry results does not require it. The plan is to destroy any pulse oximetry results on file in all instances where the program receives a directive to destroy bloodspot test results. (Put another way, directives to destroy bloodspot test results will simply trigger the corresponding destruction of any pulse oximetry results on file.)

Research/Newborn Studies Information

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The Newborn Screening Program has not approved or performed any research or studies using newborn dried blood spots, newborn bloodspot screening test results, newborn hearing results or newborn pulse oximetry results from August 1, 2014 through April 30, 2015.

The Newborn Screening Program has not approved or performed any research or studies related to newborn dried blood spots, newborn bloodspot screening test results, newborn hearing results or newborn pulse oximetry results from August 1, 2014 through April 30, 2015.