2015

Washington State Department of Health

Newborn Screening Program

July 2016

Newborn Screening Program Annual Report

Saving lives with a simple blood spot

PUBLIC HEALTH
ALWAYS WORKING FOR A SAFER AND HEALTHIER COMMUNITY

Washington State Department of Health

DOH 951-143 July 2016

acknowledgments

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Executive Summary

This report is presented in accordance with Revised Code of Washington (RCW) 70.83.080 and Washington Administrative Code (WAC) 246-650-040, which require the Department of Health to produce an annual newborn screening report for the Board of Health and the general public. This report summarizes data for the period January 1, 2015 through December 31, 2015.

The Department of Health's Newborn Screening Program tests all infants born in Washington for 28 treatable, but potentially deadly or disabling disorders that the Washington State Board of Health has specified in Chapter 246-650 Washington Administrative Code (WAC).

During 2015 there were 87,769 infants born in Washington. An additional 973 were born at two military facilities[1] in our state that do not participate in the Washington screening program.

During 2015, the Newborn Screening Program identified 177[2] infants with one of the 28 disorders on the screening panel. Among these infants, 98[3] were affected with a severe form of one of the disorders and were quickly referred to appropriate preventive care systems before they suffered irreversible damage from their conditions. The other 79[4] infants were identified with a condition that required treatment or close monitoring[5].

An additional 1,359 infants were identified with abnormalities of hemoglobin that, while not directly harmful, can have important implications for future reproduction choices for the infants and their parents. In these cases, the infants' health care providers were notified of the findings, their implications, and were provided a list of resources to help families understand how the findings might impact them.

Initial newborn specimens are required by state law to be collected no later than 48 hours following birth. For all Washington births in 2015, including hospitals, birth centers, and home births, 98.0 percent of initial specimens were collected in compliance with this timeframe, an improvement of 0.8 percentage points over the first reporting period (July 1, 2014 – December 31, 2014).

Initial newborn specimens are to be received by state law at the State Public Health Laboratories within 72 hours of collection. During 2015, 84.9 percent of specimens were received within the required timeframe. This was a slight decrease of 1.1 percentage points from the previous reporting period (July 1, 2014 – December 31, 2014).

Health care providers are required by state law to notify the Newborn Screening Program of the date they communicated the need for diagnostic testing to the parent or guardian. During 2015, 59.2 percent of the required notifications were received by the program. This was an increase of 0.5 percentage points from the previous reporting period (July 1, 2014 – December 31, 2014).

This report also includes data regarding specimen quality measures. Detailed specimen quality statistics by hospital are included in subsequent sections of this report. All midwife, birth center, clinic and laboratory performance data are reported in aggregate.

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[1] These federal facilities had a contract with a private laboratory for the screening of infants born in their hospitals.
[2] Excludes one infant with mild congenital hypothyroidism not detected by newborn screening. Excludes two infants with congenital hypothyroidism that were born out-of-state.
[3] Excludes one infant with congenital hypothyroidism that was born out-of-state
[4] Excludes one infant with mild congenital hypothyroidism that was born out-of-state.
[5] This number includes mild forms of the disorders on the required newborn screening panel and a small number of non-panel conditions identified through the screening process.

Program Overview

Newborn screening is a population-based, preventive public health program that is conducted in every state in the United States and in many countries throughout the world. It enables early identification of selected disorders that, without detection and treatment, can lead to permanent mental and physical damage or death in affected children. The goal of newborn screening is to facilitate prevention of developmental impairments (such as mental disability and neurological deficits), delayed physical growth, severe illness, and death through early detection and intervention.

Across the United States, there are variations in the disorders for which each state screens. Appendix A includes a list of the national Recommended Uniform Screening Panel (RUSP) and includes the disorders screened on the Washington State screening panel. The Washington State Board of Health adds conditions to the newborn screening panel only after careful consideration of the following criteria:

- Available Technology: Sensitive, specific and timely tests are available that can be adapted to mass screening[6].
- Diagnostic Testing and Treatment Available: Accurate diagnostic tests, medical expertise and effective treatment are available for evaluation and care of all infants identified with the condition.
- Prevention Potential and Medical Rationale: The newborn identification of the condition allows early diagnosis and intervention.
- Public Health Rationale: Nature of the condition justifies population-based screening rather than risk-based screening or other approaches.
- Cost-Benefit / Cost–Effectiveness: The benefits and outcomes outweigh the costs of screening.

A history of the conditions added to the Washington panel are shown in Appendix B. More information regarding the criteria can be found on the Board of Health's website at Washington State Board of Health Process to Evaluate Conditions for Inclusion in the Required Newborn Screening Panel.

Successful newborn screening requires collaboration between the Washington State Newborn Screening Program, health care facilities (hospitals, clinics, laboratories, and birth centers), health care providers (pediatricians, family practice physicians, nurse practitioners, midwives), and families of newborns. It is a coordinated system of screening services comprised of laboratory, follow-up, and support staff.

Responsibilities of the Washington State Newborn Screening Program:

- Perform rapid, efficient screening of children born in the state for the disorders required by state regulation (WAC 246-650)
- Verify each newborn has had access to screening and if not, take action to assure screening is available
- Provide appropriate follow-up and recommendations to health care providers for newborns with abnormal screening test results to facilitate prompt diagnostic and treatment services
- Consult with health care providers regarding test implications and recommend follow-up actions
- Perform long-term follow-up and tracking of affected children to evaluate outcomes of the program, improve effectiveness and promote continued access to appropriate specialty health care
- Collect, analyze, and disseminate data on newborn screening requirements, including cost effectiveness of the system and health outcomes

[6] Sensitivity is the ability of the test to accurately find babies who are affected with a certain newborn screening disorder. Specificity is the ability of the test to accurately find babies who are not affected.

- Provide technical assistance and education regarding all components of newborn screening to hospitals, health care professionals, families of affected children, and the general public

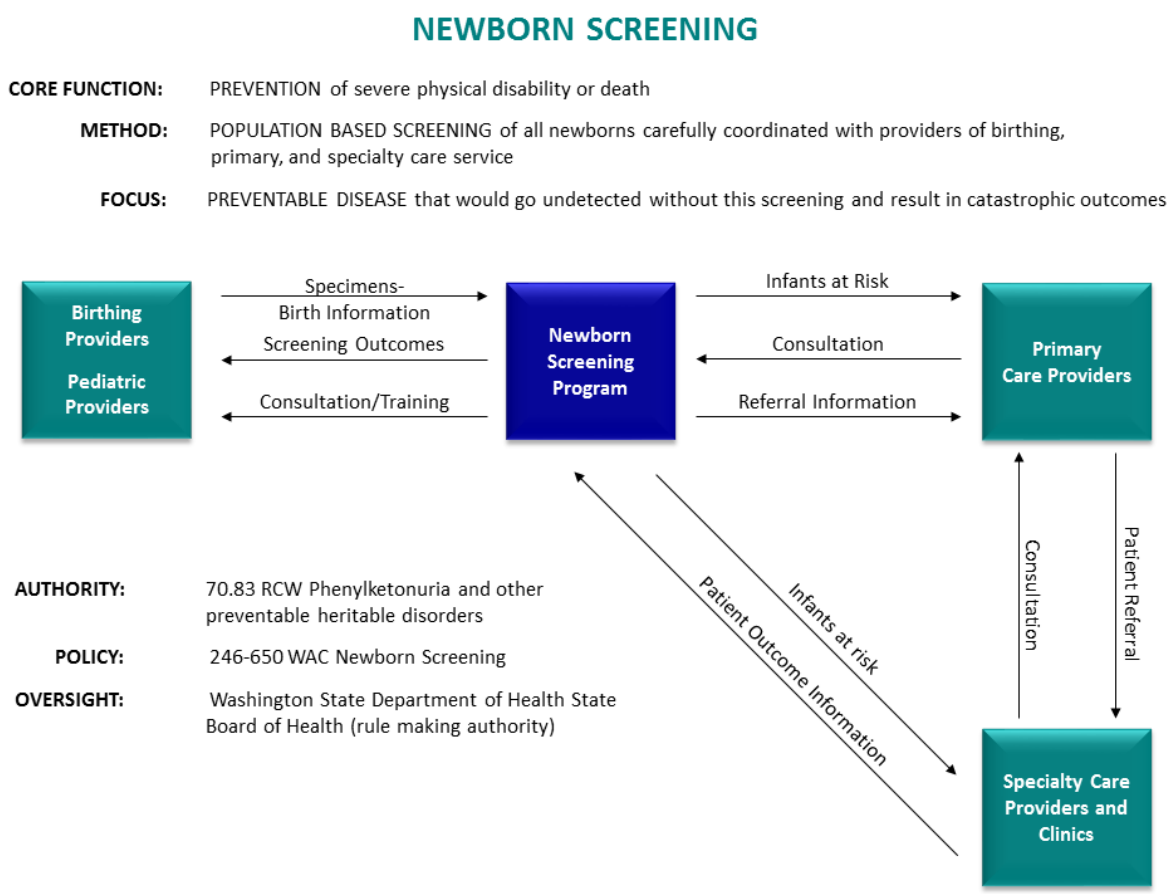
Responsibilities of the health care facilities and providers:

- Collect and send specimens to the state laboratory within the required timeframes (RCW 70.83.020)
- Provide proper collection, labeling, and handling of newborn screening specimens
- Document the screening status of each infant
- Quickly respond to information and specimen requests from the Newborn Screening Program
- Ensure prompt follow-up on infants requiring further testing to rule out or confirm a diagnosis
- Provide parent education about newborn screening and refer for diagnostic and clinical care services as needed
- When appropriate, report to the Newborn Screening Program the date the parent/guardian was notified of the need for further diagnostic testing

Responsibilities of the families:

- Receive education from their health care provider about the newborn screening tests that will be performed on their infant and ask questions if they have any
- Report to their health care provider the presence of a family history of any screened or unscreened disorder
- Respond quickly to requests from the health care provider or Department of Health for repeat screening
- Cooperate with health care providers and institutions when required for follow-up

These interdependencies and synergies are illustrated in the following graphic.



Screening Costs:

The department's cost to operate the program, including laboratory testing, monitoring to assure adequate screening for all infants, follow-up of all abnormal findings, education, and evaluation, is covered through a fee charged for each infant through the facility that collected the initial specimen. In 2015, this charge was $69 for each child, which is typically covered by insurance and other third-party payers. In return, the state's health care system realizes significant savings by avoiding the costs of lifetime treatment for disabling conditions.

In addition to the screening fee, a separate charge of $8.40 per birth was collected during this period to support specialty clinic care for infants diagnosed through newborn screening. This clinic subsidy fee funds clinics with expertise to consult with parents and providers on the rare conditions detected.

Quality Assurance and Development Activities:

To augment general training regarding specimen collection and reporting, the Newborn Screening Program provides outreach and education to Washington State hospitals and other providers regarding their responsibility for specimen collection, specimen transit, and parent notification. The Newborn Screening Program sends quarterly reports on the performance of hospitals and health care providers in meeting these responsibilities along with an itemized list of any instances where these requirements were not met. The program also ensures every baby born in the state receives newborn screening by comparing birth data with specimens received. All instances where an infant does not appear to have a newborn screening specimen are investigated.

2015 Performance Data

Collection and Transport Performance:

During the 2014 legislative session, a revision was made to Chapter 70.83 RCW to specify both collection times and transit times for initial newborn screening specimens. Previously, the law required collecting a specimen prior to discharge from the hospital with no other specific requirements for collection and submission; the newborn screening program had provided only guidelines to providers. The new requirements apply to all hospitals and birthing providers throughout the state.

Under the rule revision, each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory within specified timeframes. These requirements ensure timely testing and diagnostic treatment for the protection of newborns.

> **Specimen Collection:** Initial specimens must be collected no later than 48 hours following birth. It is recommended that initial specimens are collected between 18 and 48 hours following birth. For all Washington births in 2015, including hospitals, birth centers, and home births, 98.0 percent of initial specimens were collected in compliance with this timeframe.
>
> **Transit Performance**: Initial specimens must be received by the State Laboratory within 72 hours of collection (excluding days that the laboratory is closed – Sundays and Thanksgiving.) For all Washington births in 2015, including hospitals, birth centers, and home births, 84.9 percent of initial specimens were received in compliance with this timeframe.

The following table indicates both aggregate and individual submitter performance in meeting these requirements. Further detail on hospital performance by birth volume and geographic location can be found in the appendices.

Table 1: Specimen Collection and Transit Performance Report

Births January 1, 2015 - December 31, 2015

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State Lab within 72 hours of collection (excluding Sundays and Thanksgiving)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Auburn Medical Center	Auburn	1,192	98.7%	90.9%
Capital Medical Center	Olympia	688	95.9%	72.7%
Cascade Valley Hospital	Arlington	188	98.9%	22.9%
Central Washington Hospital	Wenatchee	1,448	98.9%	76.9%
Coulee Medical Center	Grand Coulee	57	98.2%	52.6%
Deaconess Medical Center	Spokane	1,428	99.4%	96.4%
East Adams Rural Health	Ritzville	1	100%	100%
Evergreen Health	Kirkland	4,674	99.1%	99.7%
Forks Community Hospital	Forks	63	95.2%	85.7%
Good Samaritan Hospital	Puyallup	2,356	98.0%	55.3%
Grays Harbor Community Hospital	Aberdeen	516	99.0%	40.9%
Group Health Cooperative - Seattle	Seattle	196	96.4%	95.4%
Harborview Medical Center	Seattle	2	100%	100%
Harrison Medical Center	Silverdale	1,818	99.1%	98.7%
Highline Medical Center	Burien	855	98.4%	97.3%
Holy Family Hospital	Spokane	1,308	98.7%	91.1%
Island Hospital	Anacortes	435	97.9%	83.4%
Jefferson Healthcare	Port Townsend	125	88.0%	33.6%
Kadlec Regional Medical Center	Richland	2,775	99.1%	72.4%
Kittitas Valley Healthcare	Ellensburg	369	97.0%	59.6%
Klickitat Valley Hospital	Goldendale	2	100%	100%
Lake Chelan Community Hospital	Chelan	82	95.1%	48.8%
Legacy Salmon Creek Hospital	Vancouver	3,332	99.2%	97.8%
Lourdes Medical Center	Pasco	1	100%	100%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,940	99.8%	88.4%
Mason General Hospital	Shelton	254	98.0%	55.1%
Mid Valley Hospital	Omak	227	98.2%	74.4%
Mount Carmel Hospital	Colville	234	95.7%	91.9%
Newport Community Hospital	Newport	76	97.4%	89.5%
North Valley Hospital	Tonasket	108	95.4%	71.3%
Northwest Hospital	Seattle	1,240	98.7%	99.9%
Olympic Memorial Hospital	Port Angeles	483	94.8%	59.4%

Table 1: Specimen Collection and Transit Performance Report (cont.)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Othello Community Hospital	Othello	484	99.2%	51.9%
Overlake Hospital Medical Center	Bellevue	3,961	99.7%	97.9%
PeaceHealth Southwest Medical Center	Vancouver	2,127	96.7%	90.3%
Prosser Memorial Hospital	Prosser	322	98.1%	39.4%
Providence Centralia Hospital	Centralia	631	98.3%	47.5%
Providence Everett Medical Center	Everett	4,641	98.8%	97.1%
Providence St Peter Hospital	Olympia	2,249	98.4%	75.8%
Pullman Regional Hospital	Pullman	454	98.7%	41.0%
Sacred Heart Medical Center	Spokane	3,257	99.2%	96.2%
Saint Elizabeth Hospital	Enumclaw	321	95.0%	89.4%
Saint Francis Hospital	Federal Way	1,292	98.6%	94.7%
Saint John Medical Center	Longview	861	97.7%	43.2%
Saint Joseph Hospital - Bellingham	Bellingham	2,085	98.6%	68.0%
Saint Joseph Hospital - Tacoma	Tacoma	4,093	98.9%	97.2%
Saint Mary Medical Center	Walla Walla	579	94.8%	60.8%
Samaritan Hospital	Moses Lake	1,010	98.2%	78.7%
Skagit Valley Hospital	Mount Vernon	1,124	98.1%	66.9%
Summit Pacific Medical Center	Elma	2	100%	50.0%
Sunnyside Community Hospital	Sunnyside	582	98.6%	78.5%
Swedish Medical Center- Ballard	Seattle	1,215	99.5%	77.8%
Swedish Medical Center - Cherry Hill	Seattle	1	100%	100%
Swedish Medical Center- Edmonds	Edmonds	1,181	98.7%	43.2%
Swedish Medical Center - First Hill	Seattle	7,265	99.1%	99.5%
Swedish Medical Center- Issaquah	Issaquah	1,292	99.4%	98.4%
Tacoma General Hospital	Tacoma	3,067	99.0%	83.7%
Three Rivers Hospital	Brewster	93	94.6%	64.5%
Toppenish Community Hospital	Toppenish	431	98.4%	92.8%
Trios Health Hospital	Kennewick	1,670	99.3%	87.6%
University of Washington Medical Center	Seattle	1,916	97.4%	98.7%
Valley Hospital And Medical Center	Spokane	689	99.4%	92.9%
Valley Medical Center	Renton	3,798	98.4%	91.9%
Walla Walla General Hospital	Walla Walla	231	98.3%	43.3%
Whidbey General Hospital	Coupeville	190	96.3%	56.8%
Whitman Hospital and Medical Center	Colfax	41	87.8%	56.1%
Yakima Valley Memorial Hospital	Yakima	2,699	99.7%	65.0%
All Hospital Births	**Statewide**	**84,327**	**98.7%**	**85.8%**
All Out-of-Hospital Births	**Statewide**	**3,399**	**80.0%**	**63.8%**
All Washington State Births	**Statewide**	**87,726**	**98.0%**	**84.9%**

Specimen Quality Indicators and Performance:

The Newborn Screening Program tracks and records the quality of specimens received at the laboratory from all submitters. Each quality measure is tracked and reported quarterly to hospitals in order to ensure the best possible testing results. Submitters are contacted and provided guidance when errors occur and the program offers on-site training for hospital staff on demand. The Newborn Screening Follow-up group is available to visit and provide hands-on training and answer questions specific to a given hospital.

Specimen quality measures include information on the number and type of unsatisfactory specimens received and the frequency of incomplete or incorrect demographic information submitted with specimens. Collecting good quality specimens and completing the demographics accurately on the specimen card are critical to the timely identification of babies with newborn screening conditions. These measures assist hospitals in identifying areas for training or improvement.

Unsatisfactory Specimens: Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. In these cases, another specimen must be obtained to complete screening, which could delay diagnosis and treatment of an affected infant or cause undue hardship for the parents. Overall, 1.8 percent of specimens submitted were classified as unsatisfactory for the year. See Key 1: Unsatisfactory Specimen Descriptions, at the end of this report.

Demographic Errors on Specimens Cards: Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Specimens with invalid or missing demographic information could delay diagnosis and treatment of an affected infant. During the 12-month period, 21.4 percent of specimen cards submitted had one or more demographic errors.

The following tables provide performance statistics in aggregate (Table 2) and by submitter (Table 3) for the year ending December 31, 2015.

Table 2: Unsatisfactory Specimens & Demographic Errors Report

Received January 1, 2015 - December 31, 2015

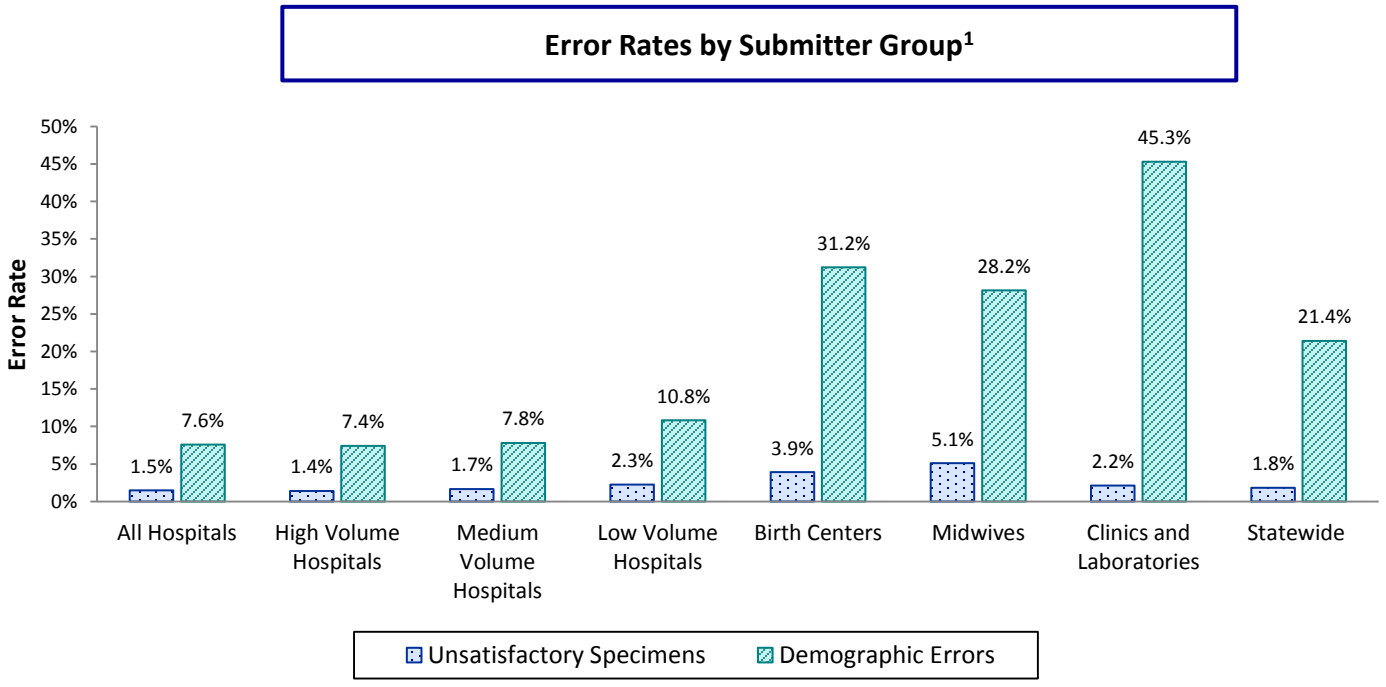
Unsatisfactory Specimens

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Demographic Errors

Some specimens arrive with missing or invalid demographic information. Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Missing or invalid information can delay screening results and could delay diagnosis and treatment of an affected infant.

Submitter Group[1]	Total Specimens	Unsatisfactory Specimens[2]		Demographic Errors	
		Total	Error Rate	Total[3]	Error Rate
All Hospital Specimens	**105,409**	**1,545**	**1.5%**	**7,978**	**7.6%**
High Volume Hospitals	89,008	1,249	1.4%	6,591	7.4%
Medium Volume Hospitals	12,913	217	1.7%	1,009	7.8%
Low Volume Hospitals	3,488	79	2.3%	378	10.8%
All Birth Center Specimens	**333**	**13**	**3.9%**	**104**	**31.2%**
All Midwife Specimens	**5,074**	**259**	**5.1%**	**1,429**	**28.2%**
All Clinic and Laboratory Specimens	**59,416**	**1,279**	**2.2%**	**26,914**	**45.3%**
Statewide	**170,232**	**3,096**	**1.8%**	**36,425**	**21.4%**



[1] See Key 2: Hospital Volume for hospital volume category definitions

[2] See Key 1: Unsatisfactory Specimen Descriptions for descriptions and causes of unsatisfactory specimens

[3] Includes specimen cards with one or more missing or invalid demographic field

Table 3: Unsatisfactory Specimens & Demographic Errors Report by Submitting Facility

Received January 1, 2015 - December 31, 2015

Unsatisfactory Specimens

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Demographic Errors

Some specimens arrive with missing or invalid demographic information. Key demographic fields are necessary for interpreting newborn screening results and for identifying the infant. Missing or invalid information can delay screening results and could delay diagnosis and treatment of an affected infant.

Submitting Facility	City	Total Specimens	Unsat Spec.[1] Error Rate	Demographic Error Rate[2]
Auburn Medical Center	Auburn	1,210	1.5%	10.1%
Capital Medical Center	Olympia	686	0.4%	7.4%
Cascade Valley Hospital	Arlington	220	1.8%	14.1%
Central Washington Hospital	Wenatchee	1,460	0.6%	8.6%
Columbia Basin Hospital	Ephrata	3	0%	100%
Coulee Medical Center	Grand Coulee	106	2.8%	13.2%
Deaconess Medical Center	Spokane	2,051	1.1%	6.6%
East Adams Rural Health	Ritzville	2	0%	100%
Evergreen Health	Kirkland	5,003	0.5%	3.8%
Evergreen Health - Monroe	Monroe	49	0%	20.4%
Ferry County Memorial Hospital	Republic	2	0%	0%
Forks Community Hospital	Forks	120	4.2%	3.3%
Good Samaritan Hospital	Puyallup	2,420	1.1%	10.6%
Grays Harbor Community Hospital	Aberdeen	530	0.4%	10.0%
Group Health Cooperative - Seattle	Seattle	215	1.9%	7.4%
Harborview Medical Center	Seattle	115	3.5%	39.1%
Harrison Medical Center	Silverdale	1,883	2.2%	5.9%
Highline Medical Center	Burien	890	2.6%	5.3%
Holy Family Hospital	Spokane	1,674	0.5%	3.9%
Island Hospital	Anacortes	657	2.7%	11.9%
Jefferson Healthcare	Port Townsend	198	1.0%	4.5%
Kadlec Regional Medical Center	Richland	3,203	0.8%	5.0%
Kittitas Valley Healthcare	Ellensburg	384	3.4%	7.6%
Lake Chelan Community Hospital	Chelan	155	2.6%	9.7%
Legacy Salmon Creek Hospital	Vancouver	3,566	0.6%	10.0%
Lewis County Hospital	Morton	1	0%	0%
Lincoln Hospital	Davenport	28	17.9%	21.4%
Lourdes Medical Center	Pasco	23	4.3%	34.8%
Madigan Army Medical Center	Joint Base Lewis-McChord	4,093	0.5%	3.6%

Table 3: Unsatisfactory Specimens & Demographic Errors Report (cont.)

Submitting Facility	City	Total Specimens	Unsat Spec.[1] Error Rate	Demographic Error Rate[2]
Mason General Hospital	Shelton	271	0.7%	6.3%
Mid Valley Hospital	Omak	228	1.3%	3.9%
Mount Carmel Hospital	Colville	249	5.6%	14.1%
Mary Bridge Children's Hospital	Tacoma	54	3.7%	64.8%
Naval Hospital - Bremerton	Bremerton	1	0%	0%
Naval Hospital - Oak Harbor	Oak Harbor	1	0%	100%
Newport Community Hospital	Newport	141	0.7%	4.3%
North Valley Hospital	Tonasket	145	1.4%	6.9%
Northwest Hospital	Seattle	1,824	0.8%	2.6%
Olympic Memorial Hospital	Port Angeles	975	0.4%	4.8%
Othello Community Hospital	Othello	820	0.5%	3.8%
Overlake Hospital Medical Center	Bellevue	4,172	0.5%	3.4%
PeaceHealth Southwest Medical Center	Vancouver	2,356	0.8%	10.4%
Prosser Memorial Hospital	Prosser	448	0.2%	7.6%
Providence Centralia Hospital	Centralia	637	5.5%	13.7%
Providence Everett Medical Center	Everett	5,242	1.0%	11.3%
Providence St Peter Hospital	Olympia	2,306	4.2%	3.6%
Pullman Regional Hospital	Pullman	451	3.8%	5.3%
Sacred Heart Medical Center	Spokane	5,034	0.7%	7.7%
Saint Clare Hospital	Tacoma	3	0%	33.3%
Saint Elizabeth Hospital	Enumclaw	448	2.7%	6.7%
Saint Francis Hospital	Federal Way	1,835	0.4%	5.9%
Saint John Medical Center	Longview	836	1.8%	6.0%
Saint Joseph Hospital - Bellingham	Bellingham	2,254	1.1%	6.1%
Saint Joseph Hospital - Chewelah	Chewelah	16	0%	12.5%
Saint Joseph Hospital - Tacoma	Tacoma	5,973	0.5%	6.9%
Saint Mary Medical Center	Walla Walla	584	0.7%	3.6%
Samaritan Hospital	Moses Lake	1,061	0.6%	4.1%
Seattle Children's Hospital	Seattle	598	1.0%	25.9%
Skagit Valley Hospital	Mount Vernon	1,169	1.5%	5.5%
Summit Pacific Medical Center	Elma	43	2.3%	25.6%
Sunnyside Community Hospital	Sunnyside	1,095	1.8%	4.7%
Swedish Medical Center - Ballard	Seattle	1,309	1.5%	5.0%
Swedish Medical Center - Cherry Hill	Seattle	3	0%	66.7%
Swedish Medical Center - Edmonds	Edmonds	1,757	1.1%	3.0%
Swedish Medical Center - First Hill	Seattle	8,354	4.0%	17.3%
Swedish Medical Center - Issaquah	Issaquah	1,347	2.4%	5.3%
Tacoma General Hospital	Tacoma	3,903	1.5%	5.2%

Table 3: Unsatisfactory Specimens & Demographic Errors Report (cont.)

Submitting Facility	City	Total Specimens	Unsat Spec.[1] Error Rate	Demographic Error Rate[2]
Three Rivers Hospital	Brewster	146	1.4%	4.8%
Toppenish Community Hospital	Toppenish	766	3.0%	4.4%
Trios Health Hospital	Kennewick	2,218	1.7%	5.4%
University of Washington Medical Center	Seattle	2,319	3.1%	8.2%
Valley Hospital And Medical Center	Spokane	1,047	1.1%	13.6%
Valley Medical Center	Renton	4,087	2.2%	7.7%
Virginia Mason Hospital	Seattle	255	0.4%	8.2%
Walla Walla General Hospital	Walla Walla	283	2.8%	10.2%
Whidbey General Hospital	Coupeville	311	3.2%	7.1%
Whitman Hospital and Medical Center	Colfax	93	0%	1.1%
Willapa Harbor Hospital	South Bend	8	12.5%	75.0%
Yakima Valley Memorial Hospital	Yakima	4,986	0.9%	4.9%
All Hospital Specimens	**Statewide**	**105,409**	**1.5%**	**7.6%**
Non-Hospital Specimens	**Statewide**	**64,823**	**2.4%**	**43.9%**
All Birth Center Specimens	Statewide	333	3.9%	31.2%
All Midwife Specimens	Statewide	5,074	5.1%	28.2%
All Clinic and Laboratory Specimens	Statewide	59,416	2.2%	45.3%
All Washington State Births	**Statewide**	**170,232**	**1.8%**	**21.4%**

[1] See Key 1: Unsatisfactory Specimen Descriptions for descriptions and causes of unsatisfactory specimens

[2] Includes specimen cards with one or more missing or invalid demographic field

Parent Notification

When screening results indicate an infant requires further diagnostic testing and evaluation, the Newborn Screening Program contacts the infant's health care provider with disorder-specific recommendations. The provider is then responsible for informing the parents.

Referrals are classified into two types:

> **Standard Referrals**: Due to the potential severity of the condition, clinical evaluation and diagnostic testing should be done immediately. Parents should be notified the same day as the referral. For standard referrals, 63.5 percent of the required notifications were reported to the department. Of the reported notifications, 83.2 percent reported that parents were notified the same day as the referral.
>
> **Non-Urgent Referrals:** Diagnostic testing and evaluation should be done as soon as possible. For non-urgent referrals, 55.1 percent of the required notifications were reported to the department. Of the reported notifications, 79.6 percent reported that parents were notified within three days of the referral.

The following Table 4 details the timeliness of parent notification by their health care provider in 2015.

Table 4: Timeliness of Parent Notification by Health Care Providers

Births January 1, 2015 - December 31, 2015

When screening results indicate an infant requires diagnostic testing and evaluation, the Newborn Screening Program contacts the infant's health care provider with disorder-specific recommendations. The provider is then responsible for informing the parents. Health care providers are required to notify the Newborn Screening Program of the date they communicated the need for diagnostic testing to the parent or guardian (70.83.070 RCW). Referrals are classified into two types:

Standard Referrals

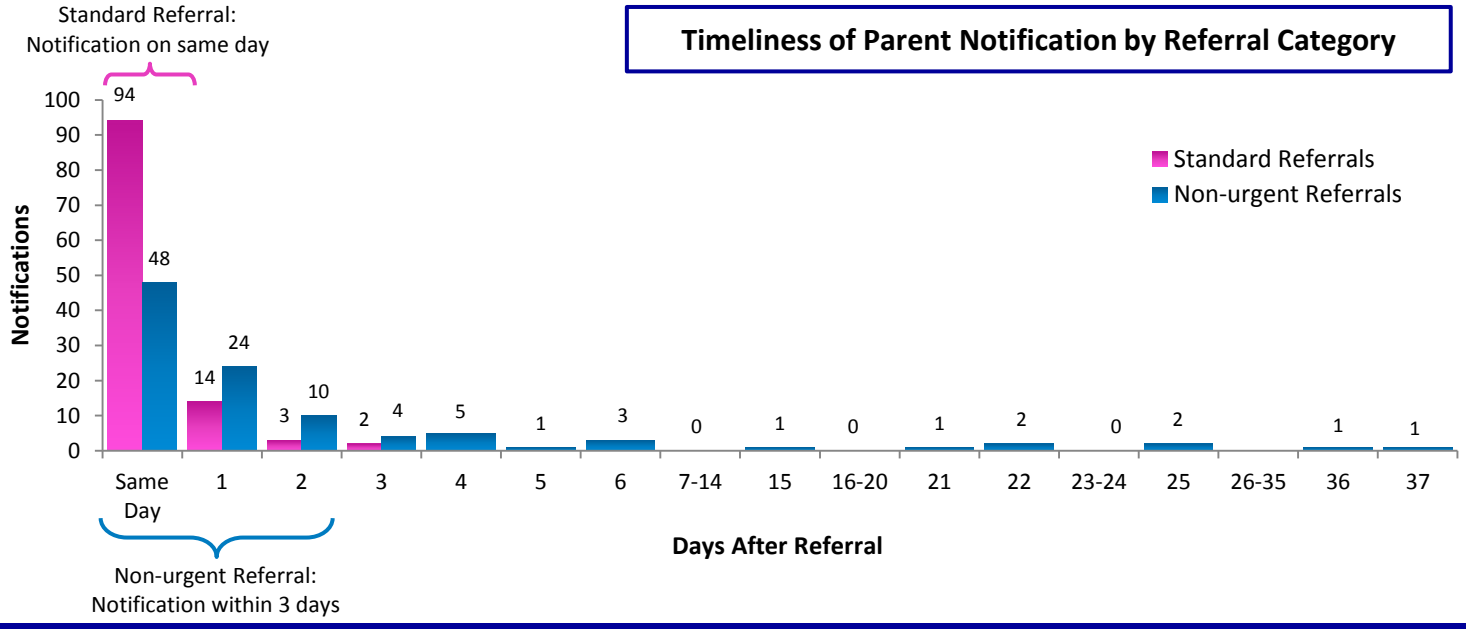
Due to the potential severity of the condition clinical evaluation and diagnostic testing and evaluation should be done immediately. Parents should be notified the same day as the referral.

Non-urgent Referrals

Diagnostic testing and evaluation should be done as soon as possible. Parents should also be notified as soon as possible, ideally within three days of the referral.

Newborn Screening Referral Category	Infants Referred for Diagnostic Testing		Health Care Provider Reported Date of Parent Notification		On-time Parent Notification	
	Total	Percent	Total	Percent	Total	Percent
Standard Referral	178	48.8%	113	63.5%	94	83.2%
Non-urgent Referral	187	51.2%	103	55.1%	82	79.6%
All Referrals	**365***	**100%**	**216**	**59.2%**	**176**	**81.5%**

*Excludes 18 instances where the health care provider began diagnostic testing prior to screening results based on family history, prenatal diagnosis, or clinical symptoms.



Disorders included in Standard Referrals: Argininosuccinic acidemia (ASA), Citrullinemia (CIT), Congenital adrenal hyperplasia (CAH), Congenital hypothyroidism (CH), Galactosemia (GALT), Isovaleric acidemia (IVA), Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency, Maple syrup urine disease (MSUD), Medium chain acyl-CoA dehydrogenase (MCAD) deficiency, Methylmalonic acidemias (MMA), Phenylketonuria (PKU), Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency

Disorders included in Non-urgent Referrals: Biotinidase deficiency (BIO), Cystic fibrosis (CF), Mild congenital hypothyroidism (CH), Carnitine uptake defect (CUD), Partial Galactosemia (GALT), Homocystinuria (HCY), Hemoglobinopathies (HB), 3-hydroxy-3-methyglutaric aciduria (HMG)/ Multiple carboxylase deficiency (MCD), Severe combined immunodeficiency (SCID)

Newborn Screening Disorders Detected

The following is a brief description of the disorders identified through the Newborn Screening Program and abbreviations that are used throughout the report. Statistics on each of the disorders are included in the tables following the descriptions of the conditions.

Amino acid disorders: disorders of metabolism characterized by the body's inability to correctly process amino acids or the inability to process the ammonia that is released during the breakdown of amino acids. The accumulation of amino acids, ammonia or other by-products may cause severe complications including intellectual disabilities, coma, seizures, and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- Argininosuccinic acidemia (ASA)
- Citrullinemia (CIT)
- Homocystinuria (HCY)
- Maple syrup urine disease (MSUD)
- Phenylketonuria (PKU)
- Tyrosinemia type I (TYR I)

Biotinidase deficiency (BIO): deficiency of the enzyme that affects normal recycling of biotin, one of the B vitamins. If untreated, a severe deficiency of biotin can result in metabolic crisis, coma and death. Treatment with biotin can prevent all symptoms.

Congenital adrenal hyperplasia (CAH): excessive production of androgenic hormones due to a defect in the pathway that converts cholesterol into the hormone cortisol. The most common defect, and the primary target of our screening is deficiency of the enzyme 21-hydroxylase. Deficiency of this enzyme accounts for approximately 95 percent of all cases of CAH. If untreated, CAH can lead to an imbalance in the body's concentration of salts which in turn can rapidly lead to shock and death. It also causes excessive masculinization and extremely premature sexual maturation. Treatment consists of providing cortisol which normalizes hormone production. Proper treatment prevents death and stops the masculinization process. Affected females may require surgical correction of masculinized genitalia.

Congenital hypothyroidism (CH): insufficient production of the thyroid hormone thyroxine due to malformation or malfunction of the thyroid gland. If untreated, CH can result in severe neurological and developmental damage. Treatment consists of hormone replacement with synthetic thyroxine. Affected infants develop normally with proper treatment.

Cystic Fibrosis (CF): defect in the cystic fibrosis transmembrane conductance regulator (CFTR) gene which regulates the body's salt and water secretions. This results in the build-up of thick, sticky mucus in the lungs and digestive system. Treatment consists of pancreatic enzymes, vitamin supplements, chest physiotherapy and antibiotics. Early treatment improves physical growth and cognitive function, and lung function.

Fatty acid oxidation disorders: disorders of metabolism characterized by the inability to efficiently use fat to make energy. During times of extra energy need such as prolonged fasting or acute illness, affected infants can suffer dangerously low blood sugar and metabolic crises resulting in serious damage affecting the brain, liver, heart, eyes and muscle, and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- Carnitine uptake deficiency
- Long-chain L-3-OH acyl-CoA dehydrogenase (LCHAD) deficiency
- Medium chain acyl-CoA dehydrogenase (MCAD) deficiency

- Trifunctional protein (TFP) deficiency
- Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency

Galactosemia (GALT): deficiency in one of three enzymes that help convert galactose into glucose. Screening targets the most common, classic form of the disorder. If untreated, an affected baby may develop jaundice, vomiting, lethargy, hepatosplenomegaly, cataracts and failure to thrive. Also, the condition can lead to liver failure, sepsis and death. A galactose-free diet with strict avoidance of lactose (milk sugar) and lactose containing foods prevents death, and assists growth and development.

Hemoglobinopathies:

Sickle cell disease (SCD): a condition marked by a tendency for the blood cells to take on a sickle shape due to an abnormal structure of the hemoglobin molecule. The altered shape shortens the life span of the blood cells, impedes circulation, especially in capillaries, and results in anemia. Children with sickle cell disease are highly susceptible to bacterial infections and rapid pooling of blood in their spleens. Either can rapidly lead to death. Treatment consists of prophylactic penicillin to prevent infection and training parents to recognize splenic crisis. Preventive treatment dramatically reduces infections and death.

Other significant hemoglobinopathies (Hb): other hemoglobin abnormalities that have significant clinical consequences (for example, transfusion dependent thalassemia). These conditions generally don't require immediate treatment but early identification allows families to adjust to the diagnosis, anticipate the medical needs, and begin early treatment plans as necessary.

Organic acid disorders: disorders of metabolism characterized by the accumulation of non-amino organic acids and toxic intermediates. This may lead to metabolic crisis with elevation of acid and ammonia in the blood, and dangerously low blood sugar resulting in severe neurologic and physical damage and possibly death. Early detection and treatment can prevent most or all of these consequences. Disorders are:

- 3-hydroxy-3-methylglutaric aciduria (HMG)
- Beta-ketothiolase deficiency (BKT)
- Isovaleric acidemia (IVA)
- Methylmalonic acidemia (cobalamin A, B deficiency)(Cbl A, B)
- Methylmalonic acidemia (mutase deficiency) (MUT)
- Multiple carboxylase deficiency (MCD)
- Propionic acidemia (PROP)

Severe combined immunodeficiency (SCID): a group of disorders of immune system development characterized by absent or low T-cell counts. Babies with SCID are at risk for developing life-threatening infections within the first year of life. Early detection and treatment allow for curative bone-marrow transplant in the first months of life.

The following tables show the breakdown of the conditions during 2015.

Table 5: Infants Detected with Newborn Screening Disorders by County

Table 6: Infants Detected with Newborn Screening Disorders by Race/Ethnicity

Appendix G: Infants detected with Newborn Screening Disorders 2009-2014

Appendix H: Newborn Hemoglobin Screening – Infants Detected by Phenotype & Race/Ethnicity

Table 5: Infants Detected with Newborn Screening Disorders by County of Residence (births by county of occurrence)

Births January 1, 2015 - December 31, 2015

County	Births	Amino acid disorders	Biotinidase deficiency	Congenital adrenal hyperplasia	Congenital hypothyroidism	Cystic fibrosis	Fatty acid oxidation disorders	Galactosemia	Hemoglobinopathies	Organic acid disorders	Severe combined immunodeficiency	All Infants Detected
Adams	489	-	-	-	-	-	-	-	-	-	-	0
Asotin	1	-	-	-	-	-	-	-	-	-	-	0
Benton	5,458	1	-	-	1	-	1	-	-	-	-	3
Chelan	1,591	-	-	-	1	-	-	-	-	-	-	1
Clallam	587	-	-	-	-	-	-	-	-	-	-	0
Clark	5,606	1	-	1	2	1	-	1	1	2	-	9
Columbia	1	-	-	-	-	-	-	-	-	-	-	0
Cowlitz	863	-	-	-	2[b]	-	-	-	-	-	-	2
Douglas	155	-	-	-	-	-	-	-	-	-	-	0
Ferry	0	-	-	-	-	-	-	-	-	-	-	0
Franklin	2	-	-	-	1	-	1	1	-	-	-	3
Garfield	0	-	-	-	-	-	-	-	-	-	-	0
Grant	1,033	-	-	-	1	-	-	-	-	-	-	1
Grays Harbor	520	-	1	-	-	-	-	1	-	1	-	3
Island[a]	270	-	-	-	1	-	-	-	-	-	-	1
Jefferson	151	-	-	-	-	-	-	-	-	-	-	0
King	30,316	6	-	3	28[c]	1	3	9	9	5	3	68
Kitsap[a]	1,911	-	-	-	-	-	-	-	-	-	-	0
Kittitas	370	1	-	-	1	-	-	-	-	-	-	2
Klickitat	37	-	-	-	-	-	-	-	-	-	-	0
Lewis	707	-	-	-	2	-	-	-	-	-	-	2
Lincoln	0	-	-	-	-	-	-	-	-	-	-	0
Mason	256	1	-	-	-	-	-	-	-	-	-	1
Okanogan	347	-	-	-	-	-	-	-	-	-	-	0
Pacific	1	-	-	-	-	-	-	-	-	-	-	0
Pend Oreille	77	-	-	-	-	-	1	-	-	-	-	1
Pierce	11,918	2	-	1	9	2	3	2	5	-	-	23
San Juan	438	-	-	-	-	-	-	-	-	-	-	0
Skagit	1,244	1	-	-	1	1	-	-	-	-	-	3
Skamania	0	-	-	-	-	-	-	-	-	-	-	0
Snohomish	6,394	2	-	-	13	1	-	-	2	1	-	19
Spokane	6,946	-	-	1	7	3	1	1	-	-	1	14
Stevens	273	-	-	-	1	-	-	-	-	-	-	1
Thurston	3,114	-	-	-	4	1	1	-	-	-	-	6
Wahkiakum	0	-	-	-	-	-	-	-	-	-	-	0
Walla Walla	816	-	-	-	-	-	-	-	-	1	-	1
Whatcom	2,247	-	-	-	2	1	1	2	1	-	-	7
Whitman	497	-	-	-	1[d]	-	-	-	-	-	-	1
Yakima	3,133	-	-	-	3	1	1	-	-	-	-	5
All WA Births[a]	**87,769**	**15**	**1**	**6**	**81**	**12**	**13**	**17**	**18**	**10**	**4**	**177**

[a]Excludes infants born in naval hospitals that do not participate in the State NBS Program. Total births excluded= 973 (305 born at Naval Hospital-Oak Harbor and 668 born at Naval Hospital-Bremerton). Also excludes 440 infants born out-of-state who received one or more screens in Washington.

[b]Excludes one infant from Cowlitz county with mild CH born out-of-state.

[c]Excludes one infant from King county with mild CH that was not detected through newborn screening. Excludes one infant from King county with CH born out-of-state. Includes one infant born in King county with mild CH who resides in Alaska.

[d]Includes one infant born in Whitman county with mild CH who resides in Idaho.

Table 6: Infants Detected with Newborn Screening Disorders by Infant's Reported Race

Births January 1, 2015 - December 31, 2015

Infants Race	Births	*Amino Acids disorders*	*Biotinidase deficiency*	*Congenital adrenal hyperplasia*	*Congenital hypothyroidism*	*Cystic fibrosis*	*Fatty Acid Oxidation disorders*	*Galactosemia*	*Hemoglobinopathies*	*Organic Acid disorders*	*Severe combined immunodeficiency*	All Infants Detected
White	51,002	10	-	5	32[a]	9	10	14	-	6	1	87
Black	3,197	-	-	-	6	-	1	-	6	-	2	14
Asian	4,719	3	-	-	13[b]	-	-	-	6	-	-	22
Native American	892	-	-	-	2	-	-	-	-	-	-	2
Other[c]	15,262	-	-	-	17	2	1	3	5	3	1	32
Unknown[d]	12,697	2	1	1	11	1	1	-	1	1	-	19
All WA Births[e]	**87,769**	**15**	**1**	**6**	**81**	**12**	**13**	**17**	**18**	**10**	**4**	**177**
Hispanic[f]	12,393	2	1	1	7	2	1	1	-	1	-	17

[a]Excludes two white infants with mild CH born out-of-state.

[b]Excludes one Asian infant with mild CH that was not detected through newborn screening.

[c]Reflects other races not listed above (including Pacific Islander) and multiracial (more than one race designation on the screening form).

[d]Race was not reported on the screening form.

[e]Excludes infants born in military hospitals that do not participate in the Washington State Newborn Screening Program. Total Naval births excluded= 973 (305 born at Naval Hospital-Oak Harbor and 668 born at Naval Hospital-Bremerton). Also excludes 440 infants born out-of-state who received one or more newborn screens in Washington.

[f]Hispanics can be of any race; they are included in the figures above.

Newborn Screening Follow-up

All specimens that are determined to be presumptive positive through the Newborn Screening Program are followed up immediately through direct telephone contact with the child's primary care provider. This is to ensure that diagnostic testing and treatment, if indicated, is initiated as quickly as possible. Specialty care clinics throughout the state are supported by a clinic subsidy fee. Funds from this fee are passed to the clinics to subsidize the consultation and care for babies diagnosed with newborn screening conditions. Following a definitive diagnosis, a long-term, disease-specific medical management program is implemented as follows:

Phenylketonuria (PKU) - Children are seen monthly in Seattle and every other month in Spokane by the DOH-supported University of Washington Phenylketonuria Clinic. An interdisciplinary team consisting of a pediatric metabolic physician, nutritionists, social worker, and genetic counselor work closely with each family to optimize the child's dietary compliance through intensive education and support services. Periodic neuropsychological assessments are also provided for all patients to monitor cognitive and emotional development. For adults with PKU, consultative, support and nutritionist management services are provided at the University of Washington Division of Metabolism and Nutrition. Critical reproductive counseling and maternity services for women at risk of fetal damage due to Maternal PKU are also available. Other program components include a summer camp and Science Night through the private, nonprofit PKU Action Group.

Galactosemia, Biotinidase deficiency, Amino acid, Organic acid, & Fatty acid oxidation disorders - All children with these disorders are seen periodically as needed by the DOH-supported University of Washington or Seattle Children's Biochemical Genetics Clinics or Mary Bridge Children's Hospital in Tacoma. There are twice-yearly satellite clinics held in Spokane. Like PKU, an interdisciplinary team consisting of a pediatric metabolic physician, nurses, nutritionists, and genetic counselor work closely with each family to optimize the child's compliance with the specific treatment plan through intensive education and support services.

Congenital hypothyroidism (CH) - Thyroid hormone therapy is monitored by the child's primary health care provider and/or pediatric endocrinologist. The DOH-supported Congenital Hypothyroidism Developmental Evaluation Clinic located within the Center on Human Development and Disability (CHDD) at the University of Washington provides developmental, neuropsychological and occupational therapy assessments for affected children.

Congenital adrenal hyperplasia (CAH) - All children are seen for a diagnostic work-up by a pediatric endocrinologist to establish appropriate steroid hormone therapy. Long-term management is monitored by the child's primary health care provider and/or pediatric endocrinologist. Affected females with genital abnormalities related to the disorder are referred for surgical consultation.

Cystic fibrosis (CF) - All children with cystic fibrosis are seen periodically, as needed, by one of the four regional CF Foundation accredited clinics – Seattle Children's Hospital (Seattle), Mary Bridge Children's Hospital (Tacoma), Sacred Heart Medical Center (Spokane), or Oregon Health Sciences University (Portland). Like PKU, an interdisciplinary team consisting of a pediatric pulmonologist, nutritionist, social worker, and nurse work closely with each family to optimize the child's growth and minimize medical complications of the condition, particularly lung disease.

Sickle cell diseases and other clinically significant Hemoglobinopathies (Hb) - Affected children receive prophylactic penicillin and folic acid when indicated. Long-term management is provided by a pediatric hematologist or an interdisciplinary team consisting of a pediatric hematologist, nurse, social worker and genetic counselor at a DOH-supported Comprehensive Sickle Cell Clinic – Seattle Children's Odessa Brown Children's Clinic or Mary Bridge Children's Hospital. The clinic staff works closely with each family

to optimize the child's health and well-being through intensive education and support services. Periodic assessments are also provided for all patients to monitor cognitive and emotional development. Other sickle cell disease program components include a summer camp and other educational and support activities through the DOH-supported Northwest Sickle Cell Collaborative.

Severe combined immunodeficiency (SCID) - Affected children receive immediate clinical care by immunologists at Seattle Children's Hospital. Caregivers take preventive measures to avoid exposing the baby to infectious agents while a bone marrow donor is identified (best if there is a sibling match). Transplants are typically performed at two to three months of age at the Fred Hutchinson Cancer Research Center in Seattle. The babies are closely followed for one to two years by immunologists following transplant to ensure that the transplant was successful in establishing a functional immune system.

Table 7: Follow-Up Status of Infants Detected with Severe Forms of Newborn Screening Disorders

Births January 1, 2015 - December 31,2015

Usually babies identified with a newborn screening disorder are referred to a medical subspecialist for clinical evaluation and medical management. In rare instances, a primary care provider will assume medical care with consultation from a subspecialist. This table documents where babies with severe forms of newborn screening disorders were referred for medical care.

Follow-Up	*Amino acid disorders*	*Biotinidase deficiency*	*Congenital adrenal hyperplasia*	*Congenital hypothyroidism*	*Cystic fibrosis*	*Fatty acid oxidation disorders*	*Galactosemia*	*Hemoglobinopathies*	*Organic acid disorders*	*Severe combined immunodeficiency*	**All Infants**
Referred to medical specialist – (i.e., pediatric endocrinologist, hematologist, or comprehensive clinic)	7	1	5	46[a]	12	12	0	10	4	1	98
Followed by primary care provider, with some consultation from specialist	-	-	-	-	-	-	-	-	-	-	0
Infant died or Lost to Follow-up	-	-	-	-	-	-	-	-	-	-	0
Total	**7**	**1**	**5**	**46**	**12**	**12**	**0**	**10[b]**	**4**	**1**	**98**

[a]Excludes one infant born out-of-state with congenital hypothyroidism and referred to an endocrinologist.

[b]See Key 3: Newborn Hemoglobin Screening Explantions and Definitions of Phenotypes

Table 8: Age at which Treatment Began for Infants Detected with Severe Forms of Newborn Screening Disorders

Births January 1, 2015 - December 31, 2015

This table documents the age at treatment for the babies diagnosed with severe newborn screening conditions. Please note that a subset of these babies were referred for diagnostic testing after the second newborn screen (following a normal first test or a pattern of abnormal results), prompting the additional testing and diagnosis.

Disorder	Number of Infants	Age Treatment Began (days)	
		Median	Range
Amino acid disorders	7	8	6 - 42
Biotinidase deficiency	1	18	n/a
Congenital adrenal hyperplasia	5	10	4 - 10
Congenital hypothyroidism	46[a]	7	3 - 33
Cystic fibrosis	11[b]	27	13 - 138
Fatty acid oxidation disorders	12	11	4 - 29
Galactosemia	0	-	-
Hemoglobinopathies[c]	8[d]	23	10 - 37
Organic acid disorders	4	21	4 - 29
Severe combined immunodeficiency	1	7	n/a
Total	**95**	**10**	**3 - 138**

[a]Excludes one infant born out-of-state with congenital hypothyroidism.

[b]Excludes one infant that was diagnosed prenatally.

[c]See Key 3: Newborn Hemoglobin Screening Explanations and Definitions of Phenotypes

[d]Excludes two infants with hemoglobin diseases that do not require immediate treatment.

Newborn Screening Future Activities

Newborn Screening Conditions

In January of 2016, the Washington State Board of Health accepted the Newborn Screening Advisory Committee's recommendation to add X-linked adrenoleukodystrophy (X-ALD) to the Washington mandatory screening panel. X-ALD is a disorder affecting the body's nervous and endocrine systems that can cause death or permanent disability if not detected and treated early. The Department of Health and Board of Health are preparing for this expansion and anticipate implementing routine screening for X-ALD before the end of 2017.

On the national scene, the U.S. Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) have recommended three conditions for addition to the Recommended Uniform Screening Panel (RUSP). The Health and Human Services Secretary accepted the recommendation for Pompe Disease in March 2015. In February of 2016 the recommendations for X-linked adrenoleukodystrophy (X-ALD) and mucopolysaccharidosis type-I (MPS-I) were both accepted.

Newborn Screening Operations

The 2015-2017 Capital Budget included funds for expanding the Newborn Screening Laboratory. Representatives from DOH, Newborn Screening, and Public Health Laboratories are currently working with contracted architects to plan and design the additional laboratory space. The expansion of the laboratory will increase lab capacity and accommodate the addition of new conditions and testing platforms. Contractors are expected to break ground in the fall of 2016 and anticipate project completion in late 2017.

The Washington Newborn Screening Laboratory began testing samples from babies born at two Naval Hospitals in Washington State on May 1, 2016. Oak Harbor and Bremerton Naval hospital previously sent specimens out of state for testing at a private laboratory. With the addition of these hospitals, the Washington Newborn Screening Laboratory will provide testing and follow-up services to *all* of Washington's newborns.

The DOH has approved a newborn screening fee increase of $7.10 per baby to be implemented in 2016. This fee increase will help cover the increasing laboratory costs of newborn screening testing and increase capacity of the newborn screening program. The department is working closely with the medical community to prepare for the increased fee.

In May 2016 the Newborn Screening Laboratory expanded laboratory operations on Saturdays. This increased capacity will improve turnaround time for time-sensitive tests and allows for follow-up of urgent conditions on Sundays.

Education and Compliance Outreach

In addition to general training regarding specimen collection and reporting, the Newborn Screening Program will continue to provide outreach and education to Washington State hospitals and other providers regarding their responsibility for specimen collection, specimen transit, and parent notification. The Newborn Screening Program routinely monitors the performance of hospitals and health care providers in meeting these responsibilities and will work with them to ensure timely testing and specimen submission, and appropriate diagnostic actions in order to protect and improve the health of Washington's youngest citizens.

Supplemental Documents

Appendices

Appendix A: Recommended Uniform Screening Panel (RUSP)

Appendix B: Washington's Newborn Screening Panel - History of Conditions Added

Appendix C: Specimen Collection and Transit Report by Hospital Birth Volume

Appendix D: Specimen Collection and Transit Report by Hospital Geographic Location

Appendix E: Unsatisfactory Specimens

Appendix F: Demographic Errors on Specimen Cards

Appendix G: Infants Detected with Newborn Screening Disorders

Appendix H: Newborn Hemoglobin Screening Infants Detected by Phenotype and Reported Race/Ethnicity

Keys

Key 1: Unsatisfactory Specimen Descriptions

Key 2: Hospital Volume Categorizations

Key 3: Newborn Hemoglobin Screening - Explanations and Definitions of Phenotypes

Appendix A: Recommended Uniform Screening Panel (RUSP)

Each state has autonomy to decide how to operate newborn screening, including the number of conditions on their screening panel. The Secretary's Advisory Committee on Heritable Diseases in Newborns and Children is an advisory committee that makes recommendations for national newborn screening standards. The Secretary of Health and Human Services uses work from this advisory committee to make changes to the Recommended Uniform Screening Panel (RUSP). The conditions on the RUSP at the end of 2015 are in the following table.

Code	Core Condition	Required in WA?	Notes
PROP	Propionic acidemia	Yes	
MUT	Methylmalonic acidemia (mutase deficiency)	Yes	
Cbl A,B	Methylmalonic acidemia (cobalamin A, B deficiency)	Yes	
IVA	Isovaleric acidemia	Yes	
3-MCC	3-methylcrotonyl-CoA carboxylase deficiency	No	Often detected as a differential diagnosis for HMG or MCD*
HMG	3-hydroxy-3-methyglutaric aciduria	Yes	
MCD	Holocarboxylase synthase deficiency	Yes	
ßKT	ß-ketothiolase deficiency	Yes	
GA1	Glutaric acidemia, type I	Yes	
CUD	Carnitine uptake defect/carnitine transport defect	Yes	
MCAD	Medium-chain acyl-CoA dehydrogenase deficiency	Yes	
VLCAD	Very long-chain acyl-CoA dehydrogenase deficiency	Yes	
LCHAD	Long-chain L-3 hydroxy acyl-CoA dehydrogenase deficiency	Yes	
TFP	Trifunctional protein deficiency	Yes	
ASA	Argininosuccinic acidemia	Yes	
CIT	Citrullinemia, type I	Yes	
MSUD	Maple syrup urine disease	Yes	
HCY	Homocystinuria	Yes	
PKU	Classic phenylketonuria	Yes	
TYR I	Tyrosinemia, type I	Yes	
CH	Primary congenital hypothyroidism	Yes	
CAH	Congenital adrenal hyperplasia	Yes	
Hb SS	S,S disease (Sickle cell anemia)	Yes	
Hb S/ßTh	S, βeta-thalassemia	Yes	
Hb S/C	S,C disease	Yes	
BIO	Biotinidase deficiency	Yes	
CCHD	Critical congenital heart disease	Yes	Point of Care Test
CF	Cystic fibrosis	Yes	
GALT	Classic galactosemia	Yes	
GSD II	Glycogen storage disease, type II (Pompe)	No	Added to the RUSP in 2015
HEAR	Hearing loss	No	Point of Care Test: universally offered, but not required by law
SCID	Severe combined Immunodeficiencies	Yes	

* The Newborn Screening Advisory Committee considered adding 3-MCC in 2008. It did not meet the Prevention Potential and Medical Rationale and Public Health Rationale criteria because the expert biochemical geneticists believe it is largely a benign condition.

Appendix B: Washington's Newborn Screening Panel History of Conditions Added

In 1963 phenylketonuria (PKU) screening was offered through the state's Public Health Laboratory as a voluntary service. The legislature subsequently adopted revisions to the statute in 1976 to require screening of all infants born in a hospital in Washington State unless the parents refused on religious grounds. The legislation also gave authority to the Board of Health to determine which other disorders should be included in the screening and to adopt rules to achieve the intent of the law. The table below is a timeline of statute revisions and additional disorders added to the panel:

Year	Disorders Added
1963	Phenylketonuria (PKU) - test available, voluntary
1978	Congenital hypothyroidism (CH)
1984	Congenital adrenal hyperplasia (CAH)
1991	Hemoglobinopathies (Hb)
2004	Biotinidase deficiency (BIO)
	Galactosemia (GALT)
	Homocystinuria (HCY)
	Maple syrup urine disease (MSUD)
	Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency
2006	Cystic fibrosis (CF)
2008	Amino acid (AA) disorders:
	· Arginosuccinic acidemia (ASA)
	· Citrullinemia (CIT)
	· Tyrosinemia type 1 (TYR-1)
	Fatty acid oxidation (FAO) disorders:
	· Carnitine uptake deficiency (CUD)
	· Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency
	· Trifunctional protein (TFP) deficiency
	· Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency
	Organic acid disorders (OA)
	· 3-hydroxy-3-methylglutaric aciduria (Hydroxymethylglutaric aciduria - HMG)
	· Beta-ketothiolase (BKT) deficiency
	· Glutaric acidemia type 1 (GA-1)
	· Isovaleric acidemia (IVA)
	· Methylmalonic acidemia - mutase (MUT) deficiency
	· Methylmalonic acidemia – cobalamin A, B (Cbl A,B) deficiency
	· Multiple carboxylase deficiency (MCD)
	· Propionic acidemia (PROP)
2014	Severe combined immunodeficiency (SCID)

In November 2015, a Newborn Screening Advisory Committee convened by the Board of Health considered X-linked adrenoleukodystrophy (X-ALD) as a candidate for screening. The Board of Health accepted the Advisory Committee's recommendation to add X-ALD to the mandatory screening panel. The Department of Health and Board of Health are preparing for this expansion and anticipate starting routine screening for X-ALD before the end of 2017.

Appendix C: Specimen Collection and Transit Performance Report by Hospital Birth Volume

Births January 1, 2015 - December 31, 2015

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State Lab within 72 hours of collection (excluding Sundays and Thanksgiving)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
High Volume Hospitals (> 500 births per quarter)		**52,379**	**98.9%**	**89.4%**
Evergreen Health	Kirkland	4,674	99.1%	99.7%
Good Samaritan Hospital	Puyallup	2,356	98.0%	55.3%
Kadlec Regional Medical Center	Richland	2,775	99.1%	72.4%
Legacy Salmon Creek Hospital	Vancouver	3,332	99.2%	97.8%
Overlake Hospital Medical Center	Bellevue	3,961	99.7%	97.9%
PeaceHealth Southwest Medical Center	Vancouver	2,127	96.7%	90.3%
Providence Everett Medical Center	Everett	4,641	98.8%	97.1%
Providence St Peter Hospital	Olympia	2,249	98.4%	75.8%
Sacred Heart Medical Center	Spokane	3,257	99.2%	96.2%
Saint Joseph Hospital - Bellingham	Bellingham	2,085	98.6%	68.0%
Saint Joseph Hospital - Tacoma	Tacoma	4,093	98.9%	97.2%
Swedish Medical Center- First Hill	Seattle	7,265	99.1%	99.5%
Tacoma General Hospital	Tacoma	3,067	99.0%	83.7%
Valley Medical Center	Renton	3,798	98.4%	91.9%
Yakima Valley Memorial Hospital	Yakima	2,699	99.7%	65.0%
Medium Volume Hospitals (100-500 births per quarter)		**28,762**	**98.6%**	**81.8%**
Auburn Medical Center	Auburn	1,192	98.7%	90.9%
Capital Medical Center	Olympia	688	95.9%	72.7%
Central Washington Hospital	Wenatchee	1,448	98.9%	76.9%
Deaconess Medical Center	Spokane	1,428	99.4%	96.4%
Grays Harbor Community Hospital	Aberdeen	516	99.0%	40.9%
Harrison Medical Center	Silverdale	1,818	99.1%	98.7%
Highline Medical Center	Burien	855	98.4%	97.3%
Holy Family Hospital	Spokane	1,308	98.7%	91.1%
Island Hospital	Anacortes	435	97.9%	83.4%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,940	99.8%	88.4%
Northwest Hospital	Seattle	1,240	98.7%	99.9%
Olympic Memorial Hospital	Port Angeles	483	94.8%	59.4%
Othello Community Hospital	Othello	484	99.2%	51.9%
Providence Centralia Hospital	Centralia	631	98.3%	47.5%
Pullman Regional Hospital	Pullman	454	98.7%	41.0%
Saint Francis Hospital	Federal Way	1,292	98.6%	94.7%

Appendix C: Specimen Collection and Transit Performance Report (cont.)

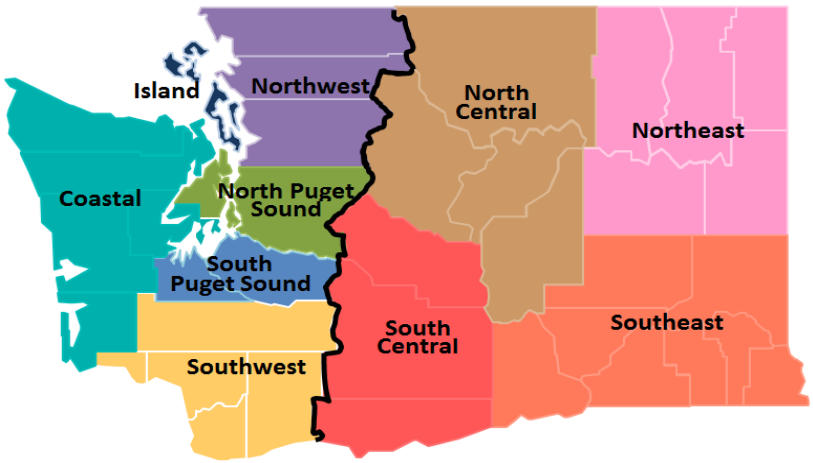
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Medium Volume Hospitals (100-500 births per quarter) cont.		**28,762**	**98.6%**	**81.8%**
Saint John Medical Center	Longview	861	97.7%	43.2%
Saint Mary Medical Center	Walla Walla	579	94.8%	60.8%
Samaritan Hospital	Moses Lake	1,010	98.2%	78.7%
Skagit Valley Hospital	Mount Vernon	1,124	98.1%	66.9%
Sunnyside Community Hospital	Sunnyside	582	98.6%	78.5%
Swedish Medical Center - Ballard	Seattle	1,215	99.5%	77.8%
Swedish Medical Center - Edmonds	Edmonds	1,181	98.7%	43.2%
Swedish Medical Center - Issaquah	Issaquah	1,292	99.4%	98.4%
Toppenish Community Hospital	Toppenish	431	98.4%	92.8%
Trios Health Hospital	Kennewick	1,670	99.3%	87.6%
University of Washington Medical Center	Seattle	1,916	97.4%	98.7%
Valley Hospital and Medical Center	Spokane	689	99.4%	92.9%
Low Volume Hospitals (< 100 births per quarter)		**3,186**	**96.5%**	**62.7%**
Cascade Valley Hospital	Arlington	188	98.9%	22.9%
Coulee Medical Center	Grand Coulee	57	98.2%	52.6%
East Adams Rural Hospital	Ritzville	1	100%	100%
Forks Community Hospital	Forks	63	95.2%	85.7%
Group Health Cooperative - Seattle	Seattle	196	96.4%	95.4%
Harborview Medical Center	Seattle	2	100%	100%
Jefferson Healthcare	Port Townsend	125	88.0%	33.6%
Kittitas Valley Healthcare	Ellensburg	369	97.0%	59.6%
Klickitat Valley Hospital	Goldendale	2	100%	100%
Lake Chelan Community Hospital	Chelan	82	95.1%	48.8%
Lourdes Medical Center	Pasco	1	100%	100%
Mason General Hospital	Shelton	254	98.0%	55.1%
Mid Valley Hospital	Omak	227	98.2%	74.4%
Mount Carmel Hospital	Colville	234	95.7%	91.9%
Newport Community Hospital	Newport	76	97.4%	89.5%
North Valley Hospital	Tonasket	108	95.4%	71.3%
Prosser Memorial Hospital	Prosser	322	98.1%	39.4%
Saint Elizabeth Hospital	Enumclaw	321	95.0%	89.4%
Summit Pacific Medical Center	Elma	2	100%	50.0%
Swedish Hospital - Cherry Hill	Seattle	1	100%	100%
Three Rivers Hospital	Brewster	93	94.6%	64.5%
Walla Walla General Hospital	Walla Walla	231	98.3%	43.3%
Whidbey General Hospital	Coupeville	190	96.3%	56.8%
Whitman Hospital and Medical Center	Colfax	41	87.8%	56.1%
All Hospital Births		**84,327**	**98.7%**	**85.8%**

Appendix D: Specimen Collection and Transit Performance Report by Hospital Geographic Location

Births January 1, 2015 - December 31, 2015

Each hospital or health care provider attending a birth outside of a hospital is required to collect and transport specimens to the Newborn Screening Laboratory within specified timeframes (70.83.020 RCW). These requirements ensure timely testing and diagnostic treatment for the protection of newborns. The timeframes for specimen collection and transport are:

1) Initial specimen collected no later than 48 hours following birth
2) Initial specimen received by State Lab within 72 hours of collection (excluding Sundays and Thanksgiving)



Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Northwest Hospitals		**9,219**	**98.7%**	**78.4%**
Cascade Valley Hospital	Arlington	188	98.9%	22.9%
Providence Everett Medical Center	Everett	4,641	98.8%	97.1%
Saint Joseph Hospital - Bellingham	Bellingham	2,085	98.6%	68.0%
Skagit Valley Hospital	Mount Vernon	1,124	98.1%	66.9%
Swedish Hospital - Edmonds	Edmonds	1,181	98.7%	43.2%
North Puget Sound Hospitals		**31,038**	**98.9%**	**96.7%**
Auburn Medical Center	Auburn	1,192	98.7%	90.9%
Evergreen Health	Kirkland	4,674	99.1%	99.7%
Group Health Cooperative - Seattle	Seattle	196	96.4%	95.4%
Harborview Medical Center	Seattle	2	100%	100%
Harrison Medical Center	Silverdale	1,818	99.1%	98.7%
Highline Medical Center	Burien	855	98.4%	97.3%
Northwest Hospital	Seattle	1,240	98.7%	99.9%
Overlake Hospital Medical Center	Bellevue	3,961	99.7%	97.9%
Saint Elizabeth Hospital	Enumclaw	321	95.0%	89.4%
Saint Francis Hospital	Federal Way	1,292	98.6%	94.7%
Swedish Medical Center - Ballard	Seattle	1,215	99.5%	77.8%
Swedish Medical Center - Cherry Hill	Seattle	1	100%	100%
Swedish Medical Center - First Hill	Seattle	7,265	99.1%	99.5%
Swedish Medical Center - Issaquah	Issaquah	1,292	99.4%	98.4%
University of Washington Medical Center	Seattle	1,916	97.4%	98.7%
Valley Medical Center	Renton	3,798	98.4%	91.9%

Appendix D: Specimen Collection and Transit Performance Report (cont.)

Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
South Puget Sound Hospitals		**14,393**	**98.7%**	**81.8%**
Capital Medical Center	Olympia	688	95.9%	72.7%
Good Samaritan Hospital	Puyallup	2,356	98.0%	55.3%
Madigan Army Medical Center	Joint Base Lewis-McChord	1,940	99.8%	88.4%
Providence St Peter Hospital	Olympia	2,249	98.4%	75.8%
Saint Joseph Hospital - Tacoma	Tacoma	4,093	98.9%	97.2%
Tacoma General Hospital	Tacoma	3,067	99.0%	83.7%
Southwest Hospitals		**6,951**	**98.2%**	**84.2%**
Legacy Salmon Creek Hospital	Vancouver	3,332	99.2%	97.8%
PeaceHealth Southwest Medical Center	Vancouver	2,127	96.7%	90.3%
Providence Centralia Hospital	Centralia	631	98.3%	47.5%
Saint John Medical Center	Longview	861	97.7%	43.2%
Coastal Region Hospitals		**1,443**	**96.3%**	**50.9%**
Forks Community Hospital	Forks	63	95.2%	85.7%
Grays Harbor Community Hospital	Aberdeen	516	99.0%	40.9%
Jefferson Healthcare	Port Townsend	125	88.0%	33.6%
Mason General Hospital	Shelton	254	98.0%	55.1%
Olympic Memorial Hospital	Port Angeles	483	94.8%	59.4%
Summit Pacific Medical Center	Elma	2	100%	50.0%
Island Region Hospitals		**625**	**97.4%**	**75.4%**
Island Hospital	Anacortes	435	97.9%	83.4%
Whidbey General Hospital	Coupeville	190	96.3%	56.8%
North Central Hospitals		**3,025**	**98.2%**	**75.5%**
Central Washington Hospital	Wenatchee	1,448	98.9%	76.9%
Coulee Medical Center	Grand Coulee	57	98.2%	52.6%
Lake Chelan Community Hospital	Chelan	82	95.1%	48.8%
Mid Valley Hospital	Omak	227	98.2%	74.4%
North Valley Hospital	Tonasket	108	95.4%	71.3%
Samaritan Hospital	Moses Lake	1,010	98.2%	78.7%
Three Rivers Hospital	Brewster	93	94.6%	64.5%
South Central Hospitals		**3,501**	**99.3%**	**67.9%**
Kittitas Valley Healthcare	Ellensburg	369	97.0%	59.6%
Klickitat Valley Hospital	Goldendale	2	100%	100%
Toppenish Community Hospital	Toppenish	431	98.4%	92.8%
Yakima Valley Memorial Hospital	Yakima	2,699	99.7%	65.0%

Appendix D: Specimen Collection and Transit Performance Report (cont.)

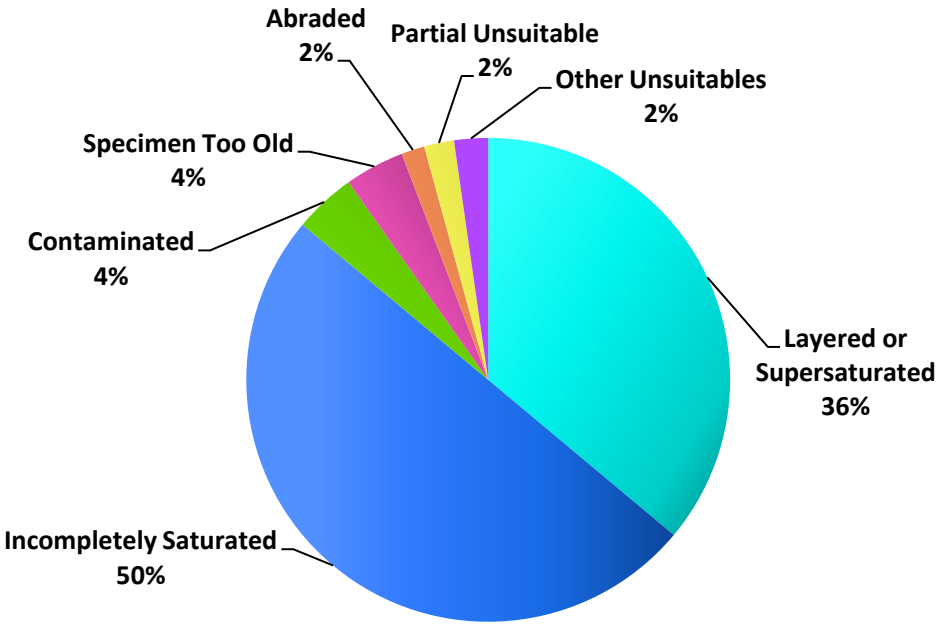
Hospital of Birth	City	Eligible Infants	1) Collection Compliance	2) Transit Compliance
Southeast Hospitals		**7,140**	**98.6%**	**69.6%**
East Adams Rural Hospital	Ritzville	1	100%	100%
Kadlec Regional Medical Center	Richland	2,775	99.1%	72.4%
Lourdes Medical Center	Pasco	1	100%	100%
Othello Community Hospital	Othello	484	99.2%	51.9%
Prosser Memorial Hospital	Prosser	322	98.1%	39.4%
Pullman Regional Hospital	Pullman	454	98.7%	41.0%
Saint Mary Medical Center	Walla Walla	579	94.8%	60.8%
Sunnyside Community Hospital	Sunnyside	582	98.6%	78.5%
Trios Health Hospital	Kennewick	1,670	99.3%	87.6%
Walla Walla General Hospital	Walla Walla	231	98.3%	43.3%
Whitman Hospital and Medical Center	Colfax	41	87.8%	56.1%
Northeast Hospitals		**6,992**	**99.0%**	**94.7%**
Deaconess Medical Center	Spokane	1,428	99.4%	96.4%
Holy Family Hospital	Spokane	1,308	98.7%	91.1%
Mount Carmel Hospital	Colville	234	95.7%	91.9%
Newport Community Hospital	Newport	76	97.4%	89.5%
Sacred Heart Medical Center	Spokane	3,257	99.2%	96.2%
Valley Hospital and Medical Center	Spokane	689	99.4%	92.9%
Western Washington Out-of-Hospital Births		**2,430**	**84.5%**	**68.8%**
Eastern Washington Out-of-Hospital Births		**447**	**70.9%**	**44.3%**
All Hospital Births	**Statewide**	**84,327**	**98.7%**	**85.8%**
All Out-of-Hospital Births	**Statewide**	**3,399**	**80.0%**	**63.8%**
All Washington State Births	**Statewide**	**87,726**	**98.0%**	**84.9%**

Appendix E: Unsatisfactory Specimens

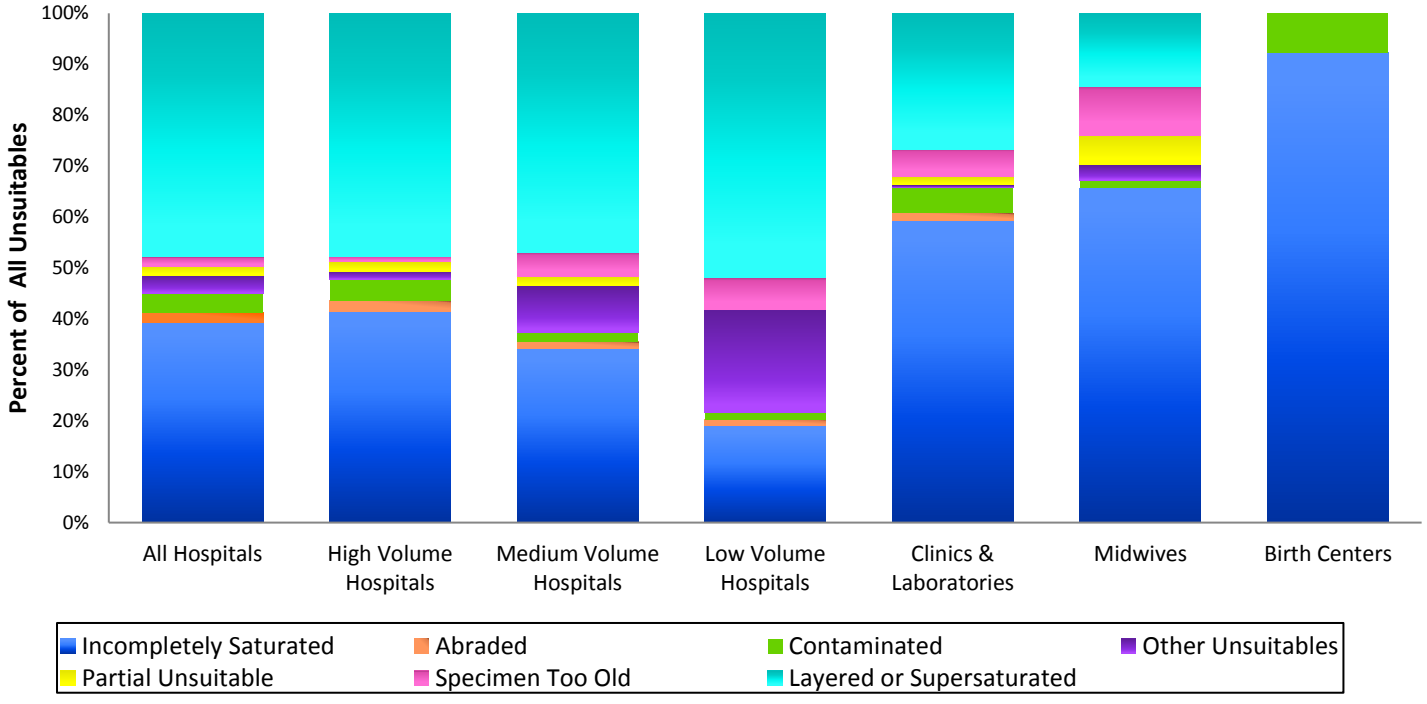
Received January 1, 2015 - December 31, 2015

Unsatisfactory Specimen Error Types[1]

Statewide: 3,096 specimens were unsatisfactory (1.8% of all specimens)



Unsatisfactory Specimen Error Type by Submitter Group[2]



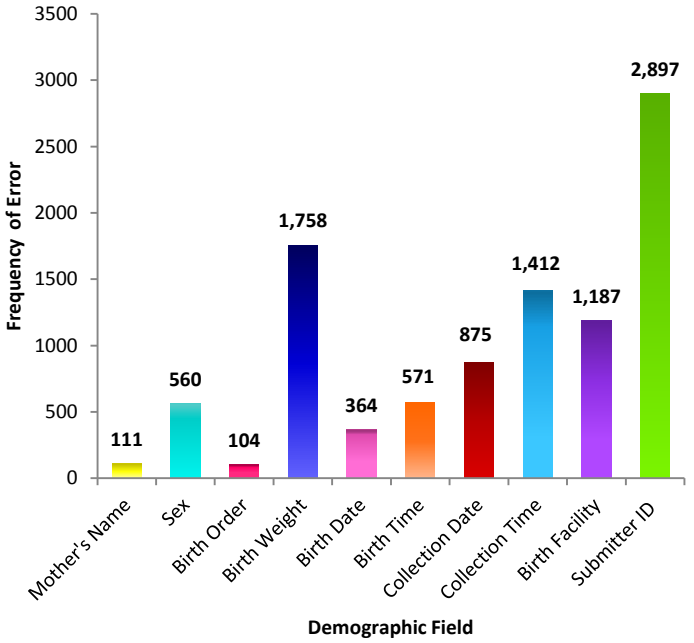
[1] See Key 1: Unsatisfactory Specimen descriptions for descriptions and causes of unsatisfactory specimens

[2] See Key 2: Hospital Volume for hospital volume categorizations

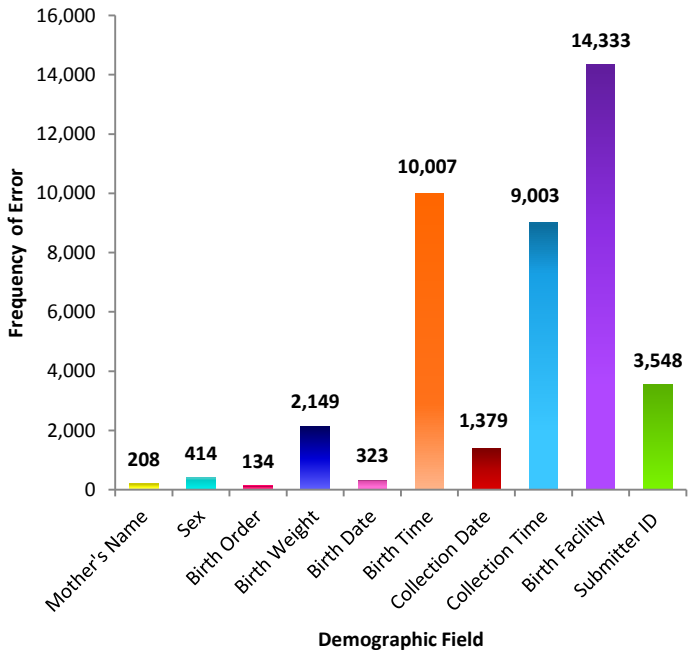
Appendix F: Demographic Errors on Specimen Cards

Received January 1, 2015 - December 31, 2015

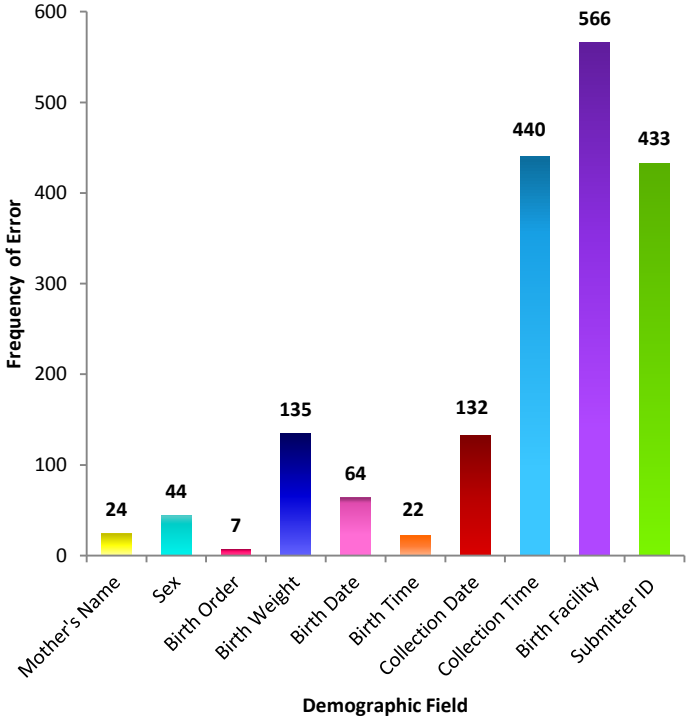
All Hospital Errors



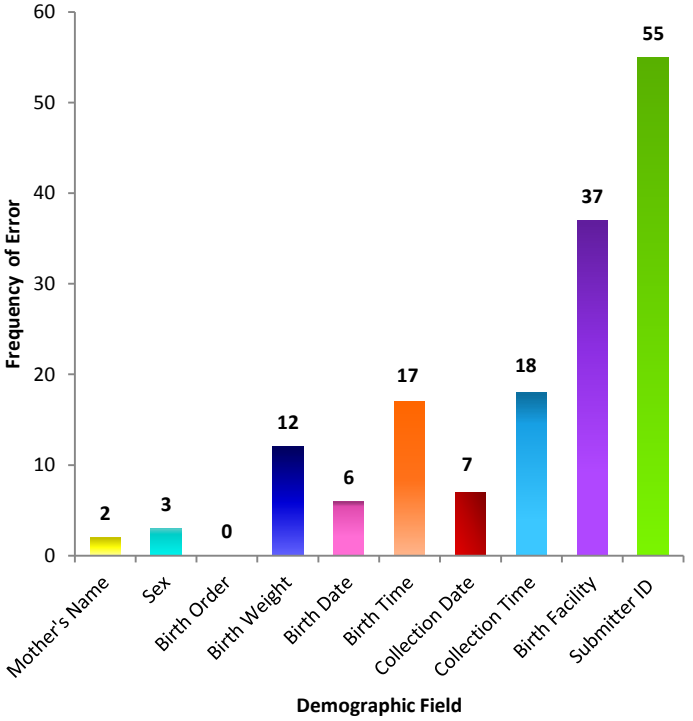
Clinic and Laboratory Errors



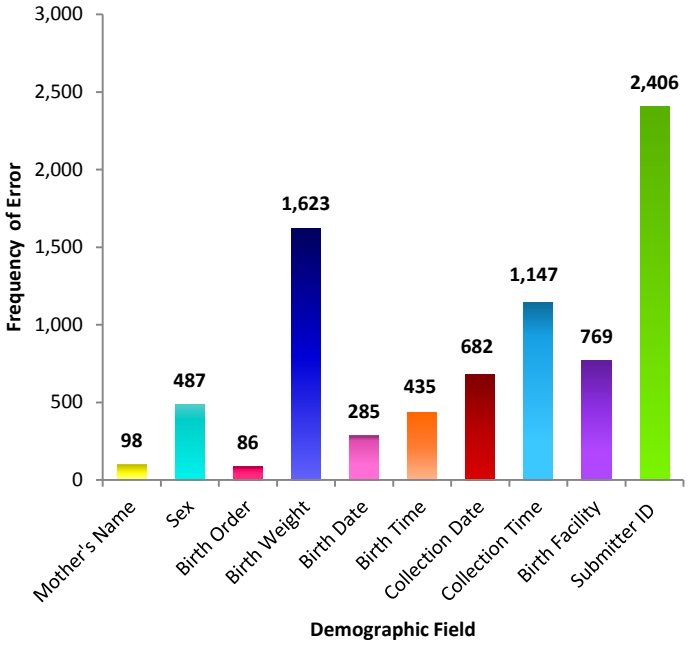
Midwife Errors



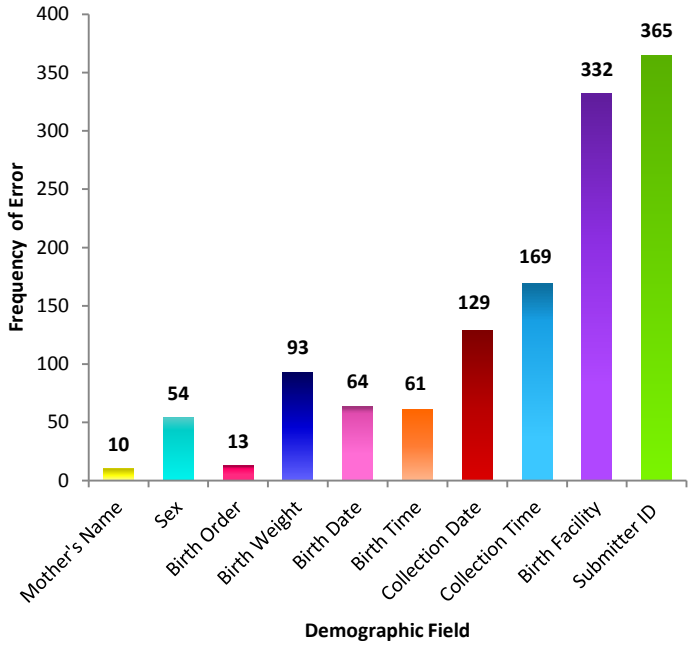
Birth Center Errors



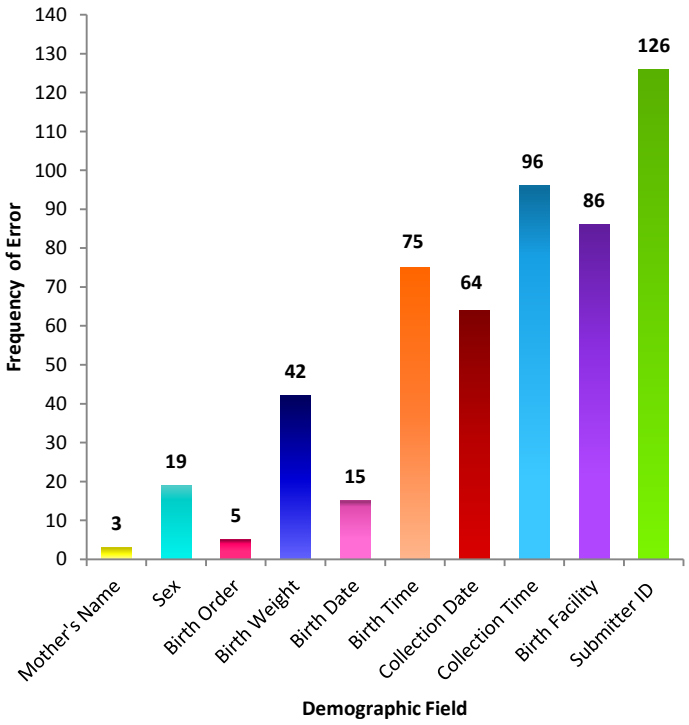
High Volume Hospital Errors
> 3 specimens/day



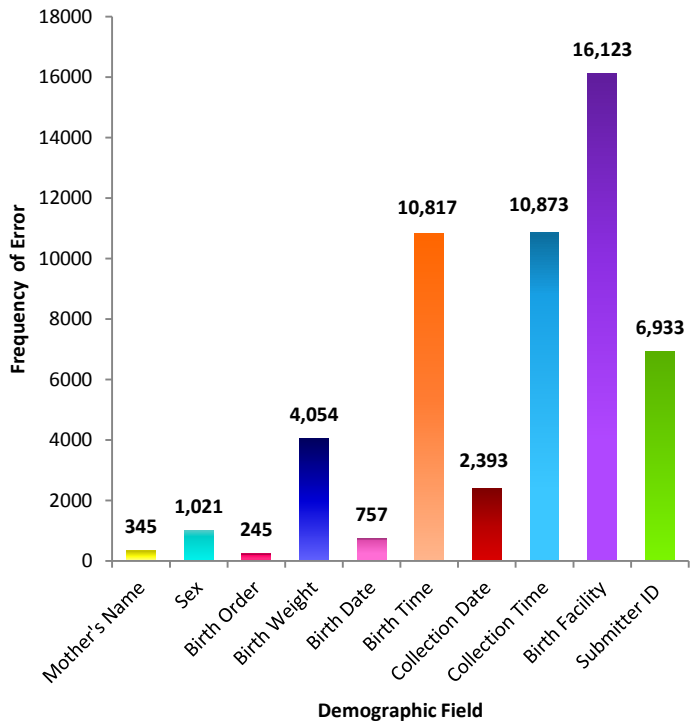
Medium Volume Hospital Errors
1 to 3 specimens/day



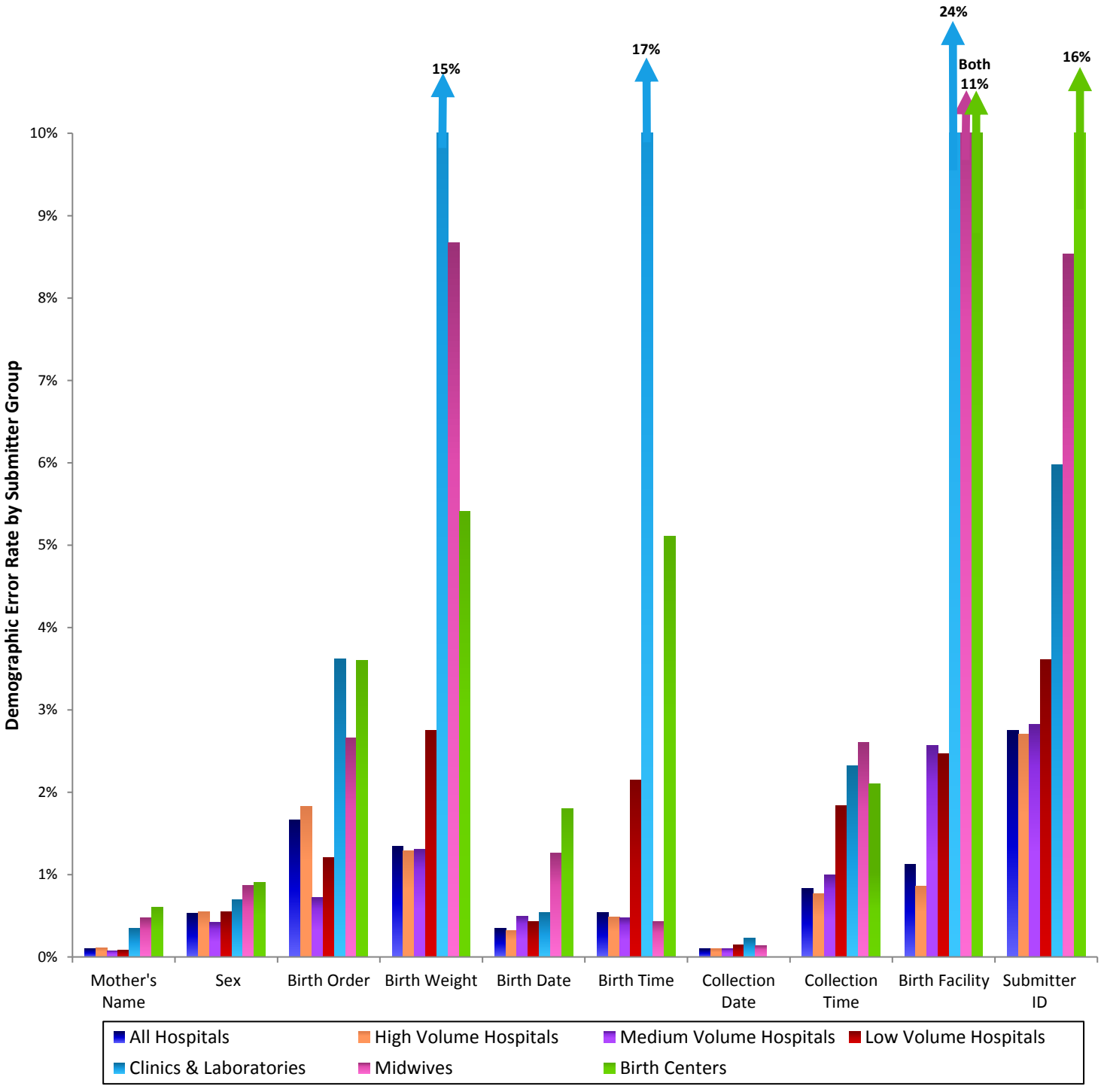
Low Volume Hospital Errors
< 1 specimen/day



Statewide Errors



Demographic Field Error Rates for All Specimens by Submitter Group[1]



[1] See Key 2: Hospital Volume for hospital volume categorizations

For example: 17% of specimens submitted by Clinics & Laboratories have an incorrect or missing time of birth

Appendix G: Infants Detected with Newborn Screening Disorders
Births 2009-2014

Disorder	2009	2010	2011	2012	2013	2014
Amino acid disorders	**6**	**7**	**10**	**10**	**9**	**6**
Arginosuccinic acidemia (ASA)	0	0	0	0	0	1
Citrullinemia (CIT)	0	0	1	0	0	0
Homocystinuria (HCY)	0	0	1	1	0	0
Maple syrup urine disease (MSUD)	0	0	1	0	3	1
Phenylketonuria (PKU)	6	7	6	9	5	4
Tyrosinemia type 1 (TYR-1)	0	0	1	0	1	0
Biotinidase deficiency (BIO)	**0**	**0**	**2**	**3**	**1**	**1**
Congenital adrenal hyperplasia (CAH)	**4**	**3**	**11**	**10**	**6**	**5**
Congenital hypothyroidism (CH)	**73**	**77**	**104**	**117**	**98**	**116**
Cystic fibrosis (CF)	**14**	**23**	**17**	**16**	**20**	**14**
Fatty acid oxidation disorders	**6**	**11**	**6**	**7**	**3**	**10**
Carnitine uptake deficiency (CUD)	0	1	0	0	0	0
Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency	4	7	5	4	2	4
Long-chain L-3-hydroxy acyl-CoA dehydrogenase (LCHAD) deficiency	0	0	0	0	0	2
Very long-chain acyl-CoA dehydrogenase (VLCAD) deficiency	2	3	1	3	1	4
Galactosemia (GALT)	**1**	**3**	**11**	**17**	**6**	**10**
Hemoglobinopathies (Hb)	**17**	**17**	**15**	**24**	**17**	**26**
Sickle cell diseases	7	9	7	12	8	15
Hemoglobin E-beta thalassemia	1	1	3	2	2	0
Hemoglobin H disease	5	6	4	7	6	6
Other moderate to severe hemoglobinopathies	4	1	1	3	1	5
Mild hemoglobin conditions & traits*	1158	1199	1130	1244	1330	1339
Organic acid disorders	**4**	**2**	**4**	**3**	**2**	**3**
Beta-ketothiolase (BKT) deficiency	1	1	0	0	0	0
Glutaric acidemia type 1 (GA-1)	3	0	0	0	0	0
Isovaleric acidemia (IVA)	0	0	0	0	1	1
Methylmalonic acidemias (MMA)	0	1	2	2	1	2
Propionic acidemia (PROP)	0	0	2	1	0	0
Severe combined immunodeficiency (SCID)	**-**	**-**	**-**	**-**	**-**	**1**
Non-panel Disorders	**1**	**2**	**5**	**2**	**4**	**13**
2-methylbutyryl-CoA dehydrogenase (2-MBD) deficiency	0	0	3	0	0	0
3-methylcrotonyl-CoA carboxylase (3-MCC) deficiency	1	0	1	1	3	3
3-methylglutaconic aciduria (3-MGA)	0	0	1	0	0	0
Carnitine palmitoyltransferas II (CPT-II) deficiency	0	0	0	0	0	1
Glutaric acidemia type II (GA-II)	0	1	0	0	0	0
Methionine adenosyltransferase (MAT-II) deficiency	0	0	0	1	0	0
Methylmalonic acidemia Cbl C	0	1	3	0	1	0
Other T-cell lymphopenias	0	0	0	0	0	9
Total Infants Detected*	126	145	188	209	166	205
Total Infants Screened*	84,871	83,086	84,918	86,180	85,427	87,415
Overall Frequency*	1 in 674	1 in 573	1 in 452	1 in 412	1 in 515	1 in 426

*Excludes mild hemoglobin conditions & traits

Appendix H: Newborn Hemoglobin Screening Infants Detected by Phenotype and Reported Race/Ethnicity

Births January 1, 2015 - December 31, 2015

Phenotype[a]	Total	White	Black	Asian	Native American	Other[b]	Unknown[c]	Hispanic[d]
Severe Disease	**9**	**-**	**6**	**1**	**-**	**2**	**-**	**-**
FSS	5	-	3	-	-	2	-	-
FS-	1	-	1	-	-	-	-	-
FSC	2	-	2	-	-	-	-	-
FE-	1	-	-	1	-	-	-	-
Moderate Disease	**9**	**-**	**-**	**5**	**-**	**3**	**1**	**-**
FSE	1	-	-	-	-	1	-	-
FAA + High Bart's	6	-	-	4	-	1	1	-
FAE + High Bart's	1	-	-	1	-	-	-	-
FCE	1	-	-	-	-	1	-	-
Mild Disease	**11**	**-**	**-**	**9**	**-**	**2**	**-**	**-**
FEE	10	-	-	8	-	2	-	-
FEE + Bart's	1	-	-	1	-	-	-	-
Trait	**1,359**	**184**	**301**	**246**	**8**	**467**	**153**	**239**
FA + Var + Bart's	2	1	-	1	-	-	-	-
FAA + CS + Bart's	14	1	-	7	-	6	-	1
FAE + CS + Bart's	3	-	1	1	-	1	-	1
FAS + Bart's	5	-	4	-	-	1	-	-
FAC + Bart's	2	-	2	-	-	-	-	-
FAE + Bart's	6	-	1	4	-	1	-	-
FAA + Bart's	261	18	51	82	2	83	25	23
FAS	470	52	169	5	2	174	68	117
FAS + Var	249	1	1	-	-	-	-	1
FAE	120	5	4	127	1	108	4	19
FAC	30	9	55	-	1	47	8	16
FAD	2	13	1	7	-	7	2	3
FA + Var	195	84	12	12	2	39	46	58
Total	**1,388**	**184**	**307**	**261**	**8**	**474[e]**	**154**	**239**

[a]See Key 3: Newborn Hemoglobin Screening Explantions and Definitions of Phenotypes

[b]Includes other races not listed above and multi-racial (more than one race designation on the screening form)

[c]Unknown race (no designation made)

[d]Hispanics can be of any race, they are included in the figures to the left

[e]Excludes one baby of Other race where the hemoglobin phenotype has yet to be determined

Key 1: Unsatisfactory Specimen Descriptions

January 1, 2015 - December 31, 2015

Some specimens are considered unsatisfactory due to the quality of specimen collection or handling. These specimens are tested for extreme values but another specimen must be obtained to complete screening. The need to obtain a repeat specimen could delay diagnosis and treatment of an affected infant.

Unsatisfactory Specimen Errors		
Error		**Description**
Layered or Supersaturated		Blood was layered, clotted or supersaturated. Caused by: • Repeated application of blood to the same filter paper circle • Blood applied to both sides of the filter paper • Blood clotting in a capillary tube • Application of too much blood
Incompletely Saturated		Blood did not completely soak through the filter paper or not enough blood on the filter paper. Caused by: • Filter paper circles not fully saturated or not completely filled • Application of small blood spots • Blood applied to both sides of the filter paper
Contaminated		Blood was diluted, discolored, contaminated or exhibited serum rings. Caused by: • Alcohol not completely drying before skin puncture • Puncture site squeezed or 'milked' to expel blood • Improper drying of specimen • Exposure to high temperatures • Filter paper contact with gloved or ungloved hands, or by substances such as alcohol, feeding or antiseptic solutions, hand lotion or powder
Specimen Too Old		Specimen was delayed in transit and is too old for testing due to deterioration of the dried blood spots. • Specimens received more than 14 days after collection are too old for hemoglobin and galactosemia testing • Specimens received more than 30 days after collection are too old for all tests
Abraded		Specimen surface was scratched, dented, or abraded. Caused by: • Improper application of blood with capillary tube or other device
Partial Unsuitable		Validation of the preliminary screening results was not possible due to the unsuitability of the residual blood. Caused by: • Partial abrasion, contamination, damage, or oversaturation of residual blood • Insufficient quantity of blood
Other Unsuitables	Ambiguous Degradation	Hemoglobin screening results indicate degradation or chemical modification of hemoglobins present causing assay interference.
	Damaged Specimen	Specimen was damaged during transport and blood sample may be torn or contaminated by rain and/or other substances.
	Old Collection Card	Specimen was submitted on a collection card past its expiration date. Cards expire three years after their manufacture date.
	Received in Plastic	Specimen was received in a sealed plastic bag and may be damaged by heat exposure and moisture accumulation.
	No Blood	Specimen card received with no blood on filter paper nor valid refusal signature.

Key 2: Hospital Volume Categorizations

January 1, 2015 - December 31, 2015

Hospital Birth Volume

Average number of hospital births quarterly

High Volume: > 500 births/qtr

Medium Volume: 100 to 500 births/qtr

Low Volume: < 100 births/qtr

Hospital Specimen Volume

Average NBS specimens submitted daily

High Volume: > 3 specimens/day

Medium Volume: 1 to 3 specimens/day

Low Volume: < 1 specimen/day

Hospital	City	Births per qtr	Birth Volume	Specimens per day	Specimen Volume
Auburn Medical Center	Auburn	298	Medium	3.3	High
Capital Medical Center	Olympia	172	Medium	1.9	Medium
Cascade Valley Hospital	Arlington	47	Low	0.6	Low
Central Washington Hospital	Wenatchee	362	Medium	4.0	High
Columbia Basin Hospital	Ephrata	-	-	< 0.1	Low
Coulee Medical Center	Grand Coulee	14	Low	0.3	Low
Deaconess Medical Center	Spokane	357	Medium	5.6	High
East Adams Rural Health	Ritzville	< 1	Low	< 0.1	Low
Evergreen Health	Kirkland	1,169	High	13.7	High
Evergreen Health - Monroe	Monroe	-	-	0.1	Low
Ferry County Memorial Hospital	Republic	-	-	< 0.1	Low
Forks Community Hospital	Forks	16	Low	0.3	Low
Good Samaritan Hospital	Puyallup	589	High	6.6	High
Grays Harbor Community Hospital	Aberdeen	129	Medium	1.5	Medium
Group Health Cooperative - Seattle	Seattle	49	Low	0.6	Low
Harborview Medical Center	Seattle	< 1	Low	0.3	Low
Harrison Medical Center	Silverdale	455	Medium	5.2	High
Highline Medical Center	Burien	214	Medium	2.4	Medium
Holy Family Hospital	Spokane	327	Medium	4.6	High
Island Hospital	Anacortes	109	Medium	1.8	Medium
Jefferson Healthcare	Port Townsend	31	Low	0.5	Low
Kadlec Regional Medical Center	Richland	694	High	8.8	High
Kittitas Valley Healthcare	Ellensburg	92	Low	1.1	Medium
Klickitat Valley Hospital	Goldendale	< 1	Low	-	-
Lake Chelan Community Hospital	Chelan	21	Low	0.4	Low
Legacy Salmon Creek Hospital	Vancouver	833	High	9.8	High
Lewis County Hospital	Morton	-	-	< 0.1	Low
Lincoln Hospital	Davenport	-	-	0.1	Low
Lourdes Medical Center	Pasco	< 1	Low	0.1	Low
Madigan Army Medical Center	Joint Base Lewis-McChord	485	Medium	11.2	High
Mary Bridge Children's Hospital	Tacoma	-	-	0.1	Low
Mason General Hospital	Shelton	64	Low	0.7	Low
Mid Valley Hospital	Omak	57	Low	0.6	Low
Mount Carmel Hospital	Colville	59	Low	0.7	Low
Naval Hospital - Bremerton	Bremerton	-	-	< 0.1	Low
Naval Hospital - Oak Harbor	Oak Harbor	-	-	< 0.1	Low

Key 2: Hospital Volume Categorizations (cont.)

Hospital	City	Births per qtr	Birth Volume	Specimens per day	Specimen Volume
Newport Community Hospital	Newport	19	Low	0.4	Low
North Valley Hospital	Tonasket	27	Low	0.4	Low
Northwest Hospital	Seattle	310	Medium	5.0	High
Olympic Memorial Hospital	Port Angeles	121	Medium	2.7	Medium
Othello Community Hospital	Othello	121	Medium	2.2	Medium
Overlake Hospital Medical Center	Bellevue	990	High	11.4	High
PeaceHealth Southwest Medical Center	Vancouver	532	High	6.5	High
Prosser Memorial Hospital	Prosser	81	Low	1.2	Medium
Providence Centralia Hospital	Centralia	158	Medium	1.7	Medium
Providence Everett Medical Center	Everett	1,160	High	14.4	High
Providence St Peter Hospital	Olympia	562	High	6.3	High
Pullman Regional Hospital	Pullman	114	Medium	1.2	Medium
Sacred Heart Medical Center	Spokane	814	High	13.8	High
Saint Clare Hospital	Tacoma	-	-	< 0.1	Low
Saint Elizabeth Hospital	Enumclaw	80	Low	1.2	Medium
Saint Francis Hospital	Federal Way	323	Medium	5.0	High
Saint John Medical Center	Longview	215	Medium	2.3	Medium
Saint Joseph Hospital - Bellingham	Bellingham	521	High	6.2	High
Saint Joseph Hospital - Chewelah	Chewelah	-	-	< 0.1	Low
Saint Joseph Hospital - Tacoma	Tacoma	1,023	High	16.4	High
Saint Mary Medical Center	Walla Walla	145	Medium	1.6	Medium
Samaritan Hospital	Moses Lake	253	Medium	2.9	Medium
Seattle Children's Hospital	Seattle	-	-	1.6	Medium
Skagit Valley Hospital	Mount Vernon	281	Medium	3.2	High
Summit Pacific Medical Center	Elma	< 1	Low	0.1	Low
Sunnyside Community Hospital	Sunnyside	146	Medium	3.0	Medium
Swedish Medical Center - Ballard	Seattle	304	Medium	3.6	High
Swedish Medical Center - Cherry Hill	Seattle	< 1	Low	< 0.1	Low
Swedish Medical Center - Edmonds	Edmonds	295	Medium	4.8	High
Swedish Medical Center - First Hill	Seattle	1,816	High	22.9	High
Swedish Medical Center - Issaquah	Issaquah	323	Medium	3.7	High
Tacoma General Hospital	Tacoma	767	High	10.7	High
Three Rivers Hospital	Brewster	23	Low	0.4	Low
Toppenish Community Hospital	Toppenish	108	Medium	2.1	Medium
Trios Health Hospital	Kennewick	418	Medium	6.1	High
University of Washington Medical Center	Seattle	479	Medium	6.4	High
Valley Hospital And Medical Center	Spokane	172	Medium	2.9	Medium
Valley Medical Center	Renton	950	High	11.2	High
Virginia Mason Hospital	Seattle	-	-	0.7	Low
Walla Walla General Hospital	Walla Walla	58	Low	0.8	Low
Whidbey General Hospital	Coupeville	48	Low	0.9	Low
Whitman Hospital and Medical Center	Colfax	10	Low	0.3	Low
Willapa Harbor Hospital	South Bend	-	-	< 0.1	Low
Yakima Valley Memorial Hospital	Yakima	675	High	13.7	High

Newborn Hemoglobin Screening
Explanations and Definitions of Phenotypes
January 1, 2015 - December 31, 2015

Hemoglobins are perhaps the most complex of the conditions detected by newborn screening. More than a dozen genes are involved in hemoglobin production and over 700 abnormalities have been described by researchers and clinicians. Also, a variety of combinations are possible for any individual. Many of the abnormalities are rare and most have no clinical implications. A primary objective of our program is to identify those infants with sickle cell disease because these infants will suffer far less illness and death if they are promptly entered into a comprehensive health care program that includes prophylactic treatment with penicillin.

Phenotype	Most Likely Genotype/Clinical Implications
Severe Hemoglobin Disease	
FSS	Homozygous for hemoglobin S. Results in sickle cell anemia, a severe form of sickle cell disease.
FSS + Bart's	Homozygous for hemoglobin S in combination with α-thalassemia[b]. Results in sickle cell anemia, a severe form of sickle cell disease.
FS–	Hemoglobin S in combination with b-thalassemia[a] major. A severe form of sickle cell disease.
FSC	Hemoglobin S in combination with hemoglobin C. Results in sickle C disease, a moderate to severe form of sickle cell disease.
F-Only	β-thalassemia[a] major. A severe hemolytic anemia requiring regular blood transfusions.
FE–	Hemoglobin E in combination with β-thalassemia[a] major. A moderate to severe hemolytic anemia.
FAA + CS + High Bart's	High level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H/Constant spring disease, a moderate to severe hemolytic anemia.
FAE + CS + High Bart's	Hemoglobin E trait with combination with two hemoglobins (Constant Spring and Bart's) indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H/Constant Spring disease, a moderate to severe hemolytic anemia (might be somewhat ameliorated by presence of hemoglobin E).
Moderate Hemoglobin Disease	
FSA	Hemoglobin S in combination with β-thalassemiaa intermedia. A moderate to severe hemolytic anemia.
F-beta+	β-thalassemia[a] intermedia. Ranges from mild to moderate hemolytic anemia and may require blood transfusions.
FSE	Hemoglobin S in combination with hemoglobin E. Results in sickle E disease, a moderate form of sickle cell disease.
FSD	Hemoglobin S in combination with hemoglobin D. Results in sickle D disease, a moderate form of sickle cell disease.
FSV	Hemoglobin S in combination with unknown variant hemoglobin. Depending on the unknown variant may result in a mild to moderate sickle cell disease.
FEA	Hemoglobin E in combination with β-thalassemia[a] intermedia. A mild to moderate hemolytic anemia.
FAA + High Bart's	High level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H disease, a moderate to severe hemolytic anemia.
FAE + High Bart's	Hemoglobin E in combination with high level of hemoglobin Bart's indicative of multiple α-thalassemia[b] genes. Likelihood of Hemoglobin H disease, a moderate to severe hemolytic anemia (might be somewhat ameliorated by presence of hemoglobin E).
FCA	Hemoglobin C in combination with β-thalassemia[a] minor. A mild to moderate hemolytic anemia.
FCC	Homozygous for hemoglobin C. A mild to moderate hemolytic anemia.
FDD	Homozygous for hemoglobin D. A mild to moderate hemolytic anemia.

[a] Decreased production of β globin chains; benign to severe anemia. Significant interaction with other β chain variants such as hemoglobin S, E, and D.

[b] Decreased production of α globin chains; benign to severe anemia depending on how many of the four α globin genes are affected.

Newborn Hemoglobin Screening (cont.)

Phenotype	Most Likely Genotype/Clinical Implications
Mild Hemoglobin Disease	
FEE	Homozygous for hemoglobin E. Mild anemia.
FEE + Bart's	Homozygous hemoglobin E in combination with α-thalassemia[b]. Mild anemia.
Hemoglobin Traits	
FA + CS + Bart's	Two hemoglobins (Constant Spring and Bart's) indicative of α-thalassemia[b] genes. Mild anemia.
FAE + CS + Bart's	Hemoglobin E trait in combination with two hemoglobins (Constant Spring and Bart's) indicative of α-thalassemia[b] genes. Mild anemia.
FAS + Bart's	Hemoglobin S trait in combination with α-thalassemia[b]. No clinical implications for S trait (see FAS, below). Benign to mild anemia.
FAC + Bart's	Hemoglobin C trait in combination with α-thalassemia[b]. No clinical implications for C trait (see FAC, below). Benign to mild anemia.
FAE + Bart's	Hemoglobin E trait in combination with α-thalassemia[b]. No clinical implications for E trait (see FAE, below). Benign to mild anemia.
FAA + Bart's	α-thalassemia[b]. Benign to mild anemia.
FA + Var + Bart's	An unidentified hemoglobin variant trait and α-thalassemia[b]. Benign to mild anemia.
FAS + Var	Hemoglobin S and unidentified variant trait. No clinical implications for S trait; clinical effects from variant trait unlikely. Family may be at risk for sickle cell disease.
FAC + Var	Hemoglobin C and unidentified variant trait. No clinical implications for C trait; clinical effects from variant trait unlikely. Family may be at risk for hemoglobin C diseases.
FAE + Var	Hemoglobin E and unidentified variant trait. No clinical implications for E trait; clinical effects from variant trait unlikely.
FAS	Hemoglobin S trait. No clinical implications for child. Family may be at risk for sickle cell disease.
FAE	Hemoglobin E trait. No clinical implications for child. Family may be at risk for hemoglobin E/β-thalassemia[a], a significant hemoglobin disease.
FAC	Hemoglobin C trait. No clinical implications for child. Family may be at risk for homozygous C, a mild to moderate hemolytic anemia or hemoglobin SC, a moderate to severe form of sickle cell disease.
FAD	Hemoglobin D trait. No clinical implications for child. Family may be at risk for hemoglobin SD, a moderate to severe form of sickle cell disease.
FA + Var	Unidentified variant trait. Clinical effects unlikely.

[a] Decreased production of β globin chains; benign to severe anemia. Significant interaction with other β chain variants such as hemoglobin S, E, and D.

[b] Decreased production of α globin chains; benign to severe anemia depending on how many of the four α globin genes are affected.