

# **Significant Legislative Rule Analysis (SA)**

WAC 246-650-010, -020 and -030

a Rule Concerning

Severe Combined Immunodeficiency

as a Part of Newborn Screening

August 21, 2013

## **Section 1. What is the scope of the rule?**

Severe combined immunodeficiency (SCID) is a group of congenital disorders characterized by profound deficiencies in T- and B- lymphocyte function. This results in very low or absent production of the body's primary infection fighting processes that, if left untreated, results in severe recurrent, and often life-threatening infections within the first year of life. This proposed rule adds SCID to the list of conditions that are to be included in screening that is required for every baby born in a hospital in Washington, unless parents object on the grounds that such tests conflict with their religious tenets and practices. This testing is performed by the Department of Health (department) using a small specimen of blood that is collected on a specialized paper at the hospital, dried, then sent to the department's public health laboratories. The SCID test will be performed simultaneously with the other required tests in the newborn screening panel. It will use a small portion of blood from the specimen already collected for the current newborn screening testing battery – virtually all specimens sent to the department's public health laboratories currently have enough residual blood to perform the SCID test (i.e. no changes in procedures will be needed at the hospital, birthing center or clinic).

The State Board of Health (board) is proposing this rule because SCID is a deadly congenital disorder that can be prevented if detected and treated before symptoms appear. Babies with SCID have no functional immune systems, so they are at risk for life-threatening infections in the first months of life. Without intervention, babies with SCID die within the first year of life. Early identification and treatment greatly reduces the mortality rate and medical costs because treatment can begin prior to the baby being sick. SCID has been determined to meet all of the board's criteria for addition to the newborn screening panel. Babies with persistently abnormal screening tests will be referred for diagnostic testing called flow cytometry. Babies identified with SCID will be referred to the pediatric immunology team at Seattle Children's Hospital where they will receive immediate care. For the majority of babies, this includes preparing for a bone marrow transplant, which is curative in more than 90 % of cases of early identification. A small subset of babies with a unique type of SCID will be treated with a specific gene therapy rather than bone marrow transplant. The screening test will identify babies with immune system deficiencies other than SCID. These babies will receive appropriate care from the pediatric immunologists depending on the type of immune deficiency. Among approximately 85,700 babies screened each year in Washington State, 1-2 will have SCID. With screening and early treatment it is anticipated that over 90% of these babies will be cured and have no ill effects from the condition. A subset of babies will have false positive newborn screening results, meaning the test was positive, but follow up diagnostic testing results will be normal. Babies with false positive results, after ruling out SCID, will not need further testing.

**Section 2. What are the general goals and specific objectives of the proposed rule's authorizing statute?**

The general goal of chapter 70.83 RCW is to detect as early as feasible and to prevent where possible preventable heritable disorders leading to developmental disabilities or physical defects.

The statute's objectives the rule implements are:

1. Detect severe combined immunodeficiency through a test performed on the blood spot specimen that is collected from every baby within five days of birth and submitted to the department's newborn screening program.
2. Report significant screening test results to the infant's attending physician or family if an attending physician cannot be identified.

**Section 3. What is the justification for the proposed rule package?**

The proposed rule will achieve the authorizing statute's goals and objectives because severe combined immunodeficiency is a deadly heritable condition that can be prevented if detected and treated shortly after birth. Adding severe combined immunodeficiency to the list of conditions tested will reduce morbidity and mortality, as summarized in the following sections.

The department has assessed and determined that there are no feasible alternatives to rulemaking because infants born with SCID appear normal and without required screening are typically not diagnosed until they have suffered significant damage or death due to recurring infections.

If this rule is not adopted, the result would be babies who are born with SCID will continue to suffer significant damage or death due to recurring infections.

**Section 4. What are the costs and benefits of each rule included in the rules package? What is the total probable cost and total probable benefit of the rule package?**

There are three rules identified in the proposed rule. The Non-Significant Rule Identification table below identifies those rules that the department has identified as not meeting the definition of a "significant rule" as defined by the Administrative Procedures Act, RCW 34.05.328.

**Table: Non-Significant Rule Identification**

#	WAC Section	Section Title	Reason
1	WAC-246-650-010	Definitions	The proposed amendments make general housekeeping changes and defines the term severe combined immunodeficiency

			(SCID) as used in chapter 246-650 WAC.
2	WAC-246-650-030	Implementation of screening to detect severe combined immunodeficiency	The proposed amendments provide notice that once the rules are adopted the department will begin screening newborns as soon as possible.

### Significant Rule Analysis

#### **WAC 246-650-020 Performance of screening tests**

##### **Rule Overview –**

The proposed rule makes housekeeping changes by combining like disorders under a general term as defined in the definitions section (WAC 246-650-010), and adds SCID to the list of conditions that the department will test newborn babies for.

##### **Rule Cost/Benefit Analysis –**

There are no probable costs associated with the housekeeping changes.

Probable costs associated with the addition of SCID include the following:

- Cost of the screening test (estimated at \$8.10 per baby; \$694,170 per year for 85,700 babies). This cost is composed of the following:

Item	Direct cost	State Sales Tax	Indirect cost	Total
1 staff FTE	\$82,573	\$0	\$18,083	\$100,656
Equipment <sup>1</sup>	49,391	4,692	425 <sup>2</sup>	54,509
Test Reagents <sup>3</sup>	308,434	0	65,547	375,981
Consumables <sup>4</sup>	124,043	4,508	27,165	162,993
TOTAL	\$564,441	\$16,476	\$113,221	\$694,139

<sup>1</sup> Major equipment costs are prorated over expected life span: 5 years

<sup>2</sup> Represents indirect cost for pieces of equipment that cost \$5,000 or less. Equipment over \$5,000 are exempt from indirect charges.

<sup>3</sup> Test reagents are chemicals and solutions used in the testing procedure. They are exempt from state sales tax.

<sup>4</sup> Consumables are one time use items used in testing (e.g., plates, pipette tips)

- Cost of false positive results. It is estimated that there will be 14.5 newborns that will have false positive results per year, estimated at \$50,355. The false positives fall into three categories:
  - “transient” (\$2,457)
  - “idiopathic” (\$19,784) and
  - “other” (\$28,114)

This includes the costs for diagnostic lab work (including flow cytometry), clinic visits with the pediatric immunologists, and medication. “Transient” cases have abnormal diagnostic test results that are later resolved, “idiopathic” means a case of unexplained T-cell deficiency and “other” is for cases with lymphocyte deficiencies that require clinical monitoring, but are not SCID.

In addition, there is a qualitative cost of false positives of parental stress associated with having a baby with abnormal initial results that will need additional testing and, for some, clinical intervention. These 14.5 babies will require an additional blood sample, to rule out the possibility that the child has SCID. About eight of the 14.5 babies with false positive results will only need one diagnostic test to rule out SCID. The remaining six to seven babies will have abnormal diagnostic tests that will indicate precautionary clinical care through additional testing, clinic visits, and prophylactic antibiotic medication. It is estimated that these babies will need this type of clinical monitoring for one to five years before resolving. This is consistent with other tests on the newborn screening panel: an unintended consequence of screening for severe disorders is that the testing also identifies babies with milder forms or related conditions.

Total Costs<sup>5</sup> = \$ 694,170 + \$50,355 = \$744,525

The benefits associated with the proposed rule include the following:

- The value of deaths averted which can be estimated at 0.36 deaths averted per year and valued at \$7,700,000 per life saved which equals \$2,806,972.
- The savings in treatment costs estimated at \$442,554 saved per year.

Total Benefits<sup>6</sup> = \$2,806,972 + \$442,554 = \$3,249,527

### **Rule Package Cost-Benefit Conclusion**

The department will be required to test all babies (estimated at 85,700 babies per year) for severe combined immunodeficiency. The cost will be \$8.10 per baby for testing and additional costs will be incurred for a small number of babies needing diagnostic testing who will have false positive screening results (these babies will not have SCID). Total costs are estimated at \$744,525 per year. Benefits include preventing death and disability and reducing medical costs for treatment of affected individuals estimated at a savings of \$3,249,527 per year. The ratio of

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<sup>5</sup> See Newborn Screening Cost Benefit Model and Guide for more detailed explanation

<sup>6</sup> See Guide to Newborn Screening Cost-Benefit Model for more detailed explanation

benefits to cost is 4.36. The probable benefits of the rule are therefore greater than the probable costs.

**Section 5. What alternative versions of the rule did we consider? Is the proposed rule the least burdensome approach?**

The board considered not adding SCID to the required screening panel, but because early detection through screening is the only reliable way to assure that all babies born with SCID receive treatment in time to cure the disorder before damage or death occurs, and because the benefits of screening significantly exceeds the costs, screening is the least burdensome.

**Section 6. Does the rule require anyone to take an action that violates another federal or state law?**

The rule does not require those to whom it applies to take an action that violates requirements of federal or state law.

**Section 7. Does the rule impose more stringent performance requirements on private entities than on public entities? If so, is the difference required in federal or state law?**

The Department of Health determined that the rule does not impose more stringent performance requirements on private entities than on public entities.

**Section 8. Does the rule differs from any federal regulation or statute applicable to the same activity or subject matter and, if so, did the department determine that the difference is justified by an explicit state statute or by substantial evidence that the difference is necessary?**

The rule does not differ from any applicable federal regulation or statute.

**Section 9. Has the rule has been coordinated, to the maximum extent possible, with other federal, state, and local laws applicable to the same activity or subject matter?**

There are no other applicable laws.

## Guide to the Newborn Screening Cost-Benefit Model for Adding Severe Combined Immunodeficiency (SCID)

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### Introduction

Severe combined immunodeficiency (SCID) is a deadly immune system disorder. In June 2012, the Washington State Board of Health accepted a recommendation to add this condition to the mandatory newborn screening panel provided that it is feasible to obtain sustainable funding. Part of the Board's decision was based on the evaluation of the costs and benefits of adding screening prepared by newborn screening staff which researched the primary literature, reports from states already screening for SCID and consulted with expert immunologists. The accompanying spreadsheet is the medical model for comparing the status quo, or a "No Screening Model" (upper section) with the SCID "Newborn Screening Model" (lower section). The model predicts a benefit-cost ratio of 4.36, meaning that for every dollar of costs to screen newborns for SCID, there will be more than \$4 worth of benefits.

### Model Parameters

This narrative describes the estimates for the parameters in the models. First, we chose numbers for the base case: if we had several estimates from the published data, we either used an average or the middle value. Following the base case is a sensitivity analysis that varies the parameters to give what we judge to be very conservative and moderately liberal estimates of the benefit-cost ratio. Note: the spreadsheet calculates the percentages and estimates, which have in some instances been rounded for simplicity. Subsequent calculations are unaffected by this rounding, so sometimes the numbers appear to not match perfectly.

- **Birthrate.** This analysis is for a hypothetical birth cohort of **85,700 babies** (cells B10 and B37) which is the average number of babies expected to be screened per year in Washington State between 2013 and 2014. This number is based on estimates published in the *November 2011 Components of April 1 Population Change* by the Washington State Office of Financial Management, Forecasting Division (OFM 2011).
- **Prevalence.** The prevalence used was **1 SCID case per 49,827 births** (cells D10 and D28) which is the weighted average of prevalence found among (the number would raise questions on how the rates were combined and summerised) babies tested for SCID by four newborn screening programs (Baker 2011 (1:36,773), Caggana 2011 (1:35,090), Comeau 2011 (1:50,575), Lorey 2012 (1:71,111)). This predicts 1.72 babies born with SCID in Washington each year (this is the weighted average of the four studies).
- **Percent of babies with SCID with a positive family history of SCID.** These babies will be treated early in the "No Screening Model" because of a positive family history of SCID (mostly an older affected sibling). The estimate for this parameter (**20.3%** - cell G5) was the middle value of three reported in the literature (Chan 2011 (20.3%), also Hague 1994 (28.9%) and Myers 2002 (17.9%)). These babies are assumed to derive the same benefits of early treatment that babies screened at birth would enjoy (better survival rate and lower treatment costs).
- **Sensitivity.** The sensitivity, or the ability of the screen to correctly identify babies with SCID, is estimated at **93.8%** (cell G25). This is a conservative estimate as there have been no known cases of SCID missed by newborn screening programs (zero false negatives). The estimate used is the mid-point of the 95% binomial confidence interval calculated from 27 reported cases (Baker 2011, Caggana 2011, Comeau 2011, Lorey

2012) with no false negatives (27 screening successes for the 27 cases). This sensitivity value predicts 1.61 true positives identified early and 0.11 false negatives (missed cases of SCID) per year.

- **Specificity.** The specificity, or the ability of the screen to correctly identify babies who do not have SCID, is estimated at **99.983%** (cell G47). The value used is the average of specificities from Wisconsin and Massachusetts (Baker 2011 (99.9806%) and Comeau 2011 (99.9857%). The specificity from New York was not used because the program changed cutoffs twice post implementation to reduce the number of false positives. Data from California did not include false positives; therefore no specificity calculation was possible. This specificity value predicts 14.5 false positives per year: these are babies who need diagnostic testing called flow cytometry, and sometimes clinical follow-up for other forms of immune deficiency (they do not have SCID).
- **Mortality of cases identified early.** The numbers used for mortality (**8.6%** - cells J3 and J23) is the weighted average of data compiled from Duke University and the two transplant centers in the UK regarding survival rates of babies with SCID. This estimate is the percent survival of 81 babies with SCID who received early transplants prior to 28 days of age (4.8% - Myers 2002) or had an older sibling diagnosed with SCID (10.0% - Brown 2011). This percentage is used in both models and predicts 0.03 deaths in the “No Screening Model” and 0.14 deaths in the “Screening Model” among the babies treated early. Recent publications from Duke University reported a 6.1% mortality rate for 48 babies with treatment prior to 3.5 months of life (Buckley 2012 and Buckley 2010).
- **Mortality of cases identified late.** The numbers used for mortality (**37.5%** - cells J13 and J32) is the weighted average of data compiled from Duke University and the two transplant centers in the UK regarding survival rates of babies with SCID. This estimate is the percent survival of 144 babies with SCID who received transplants after 28 days of age (26.0% - Myers 2002) or were probands, meaning the first in their family diagnosed with SCID (60.4% - Brown 2011). This percentage is used in both models and predicts 0.51 deaths in the “No Screening Model” and 0.04 deaths in the “Screening Model” among the babies who were treated later. Recent data from Duke University show a mortality rate for 118 babies treated after 3.5 months of life of 31.4% (Buckley 2010).
- **Monetary value of a life.** The value of one life saved is estimated at **\$ 7.7 million** (cell Q35). This is the average of estimates used by three Federal Agencies in 2010 (Appelbaum 2011): Environmental Protection Agency (\$9.1 million), Food and Drug Administration (\$7.9 million) and the Transportation Department (\$6.1 million).
- **Difference in treatment costs: early v. late treatment.** The cost difference between early v. late treatment is estimated at **\$ 350,000/baby** (cell H18 subtract cell H8). This data comes from Dr. Rebecca Buckley’s data on cost of treatments of the two cohorts (estimate of treatment costs for early identification is \$1000,000 per baby and estimate of treatment costs for late identification is \$450,000 per baby - Buckley 2012).

The next step is to evaluate the differences between the models to quantify the benefits of screening. This is done by combining the mortality estimates and assigning a dollar value to deaths avoided and the difference in treatment costs.

- **Deaths averted.** The total number of deaths for each model are compared; there are 0.54 deaths (cell Q2) predicted in the “No Screening Model” and 0.18 deaths (cell Q22) in the “Newborn Screening Model.” The “No Screening Model” has three times the mortality rate of the “Newborn Screening Model.” The difference

between the two models is **0.36 deaths averted** (cell Q34). This means that approximately one baby every three years will not die because of early treatment afforded by newborn screening.

- **Value of lives saved.** The value of lives saved by newborn screening is the number of deaths averted multiplied by the monetary value of a life. The model estimates yearly benefits of **\$ 2,806,972.12** (cell Q36) for saving lives of babies with SCID.
- **Shift in treatment costs.** The early and late treatment costs for each model are calculated and combined to determine the costs of treatment in each model (**No Screening = \$ 652,051.57**, cell Q6; **NBS = \$ 209,496.77**, cell Q26). The annual treatment costs saved by screening (**\$ 442,554.80**, cell Q37) are the difference between these totals.
- **Total benefits.** The total benefits (**\$ 3,249,526.93**, cell Q38) are the sum of the value of lives saved and the treatment cost saved by screening.

Costs are estimated next.

- **Cost of screening.** The estimated costs of TREC analysis are **\$ 8.10 per baby** (cell B40).
- **Costs of clinical care and diagnostic testing for false positives.** Only the false positive babies are counted for diagnostic testing costs because the babies with SCID will have clinical evaluation and diagnostic flow cytometry testing regardless. Based on discussion during the advisory committee meeting, we looked carefully into potential costs for babies that have abnormal TREC screening but do not have SCID. We consulted with Dr. Skoda-Smith and the team of immunologists for treatment and cost estimates, which included additional diagnostic testing, clinic visits and prophylactic antibiotics. The false positives fall into three categories with the following estimated costs based on the outcomes from the four states doing SCID newborn screening:
  - Transient: 0.73 babies/year costing \$3,370/baby (\$2,456.76 for 1 year of follow-up).
  - Idiopathic: 2.31 babies/year costing \$8,570/baby (\$19,784.09 for 5 years of follow-up).
  - Other: 3.28 babies/year costing \$8,570/baby (\$28,114.24 for 5 years of follow-up).

This includes the costs for diagnostic lab work (including flow cytometry), clinic visits with the pediatric immunologists and medication. “Transient” cases have abnormal diagnostic test results that are later resolved, “idiopathic” means a case of unexplained T-cell deficiency and “other” is for cases with lymphocyte deficiencies that require clinical monitoring, but are not SCID. In addition, there is a qualitative cost of false positives of parental stress associated with having a baby with abnormal initial results that will need additional testing and, for some, clinical intervention. These 14.5 babies will require an additional blood sample, to rule out the possibility that their child has SCID. About eight of the 14.5 babies with false positive results will only need on diagnostic test to rule out SCID. The remaining six to seven babies will have abnormal diagnostic tests that will indicate precautionary clinical care through additional testing, clinic visits and prophylactic antibiotic medication. It is estimated that these babies will need this type of clinical monitoring for one to five years before resolving. This is consistent with other tests on the newborn screening panel: an unintended consequence of screening for severe, disorders is that the testing also identifies babies with milder forms or related conditions.



Please note: Ideally, we would also include the benefits to the babies of early identification for these infants. However, we lack sufficient data to adequately estimate their value. The benefits include: not administering live virus vaccinations (the live virus can cause dangerous infections in babies with impaired immune systems), avoiding resource-intensive diagnostic odysseys, and preventing infections that could range from chronic to severe, even life threatening.

- **Total costs for SCID newborn screening.** The birthrate multiplied by cost per baby is **\$ 694,170.00** (cell Q41).
- **Total costs for clinical care and diagnostic testing of false positives.** The total cost per year for the false positive cases outlined above is **\$50,355.09** (cell Q42)
- **Total costs of Newborn Screening Model.** The annual costs of NBS for SCID are estimated to be **\$ 744,525.09 = \$ 694,170.00 + \$ 50,355.09** (cell Q43).

Finally, the ratio of benefits to cost is calculated. Any ratio greater than 1 signifies that the benefits outweigh the costs.

- **Benefit/Cost Ratio.** \$ 3,249,526.93 of benefits divided by \$ 744,525.09 of costs yields a benefit/cost ratio of **4.36** (cell Q47).

After completing the base case benefit-cost ratio, we performed a sensitivity analysis to evaluate how the benefit-cost ratio changes when estimates for the parameters are varied.

- **Sensitivity Analysis.** Table 1 contains three estimates for each parameter, the best guess estimate used in the base case followed by conservative and liberal estimates. Only one parameter was changed at a time to generate unique benefit/cost ratios for each of the scenarios. The only exception is that the parameters for mortality of early versus late identification were varied together to achieve a larger difference between the conservative and liberal estimates. References are included within the table for the conservative and liberal estimates that are based on published data and personal communications.

**Table 1**

Parameter	Base Case	Conservative Estimate	Liberal Estimate	B/C Ratio Swing
Prevalence	~1:49,000	~1:71,000 (Lorey)	~1:37,000 (Baker)	3.06 to 5.88
% early ID – family history of SCID	20.3%	28.9% (Hague)	17.9% (Myers)	3.85 to 4.50
Sensitivity	93.8%	86.7%	100%	3.94 to 4.73
Specificity	99.983%	99.886% (Caggana)	99.986 (Comeau)	3.14 to 4.42
Mortality – early ID	8.6%	10.0% (Brown)	4.8% (Myers)	2.69 to 7.87*
Mortality – late ID	37.5%	26.0% (Myers)	60.4% (Brown)	
Monetary value of a life	\$ 7.7 million	\$ 6.1 million	\$ 9.1 million	3.58 to 5.05
Δ in treatment costs: early v. late tx	\$ 350,000	\$ 0	\$ 475,000	3.77 to 4.58

**\* The mortality estimates for early and late identification were varied in the sensitivity analysis simultaneously. The higher estimate for mortality – early ID was used in conjunction with the lower estimate for mortality – late ID to bias against screening in creating the conservative estimate. The lower estimate for mortality – early ID was used in conjunction with the higher estimate for mortality – late ID to bias in favor of screening in creating the liberal estimate.**

## Conclusion

Early identification of babies with SCID is critical to their health. The mortality rate is greatly reduced with early treatment and medical costs are dramatically lower compared to babies treated after becoming symptomatic (the last baby born with SCID in California prior to starting screening generated more than \$4 million in medical bills) (Puck 2012). This analysis used data from the first four newborn screening programs to begin testing for SCID to predict the medical outcomes for a hypothetical birth cohort of Washington babies. We used data from the primary literature and expert opinion to quantify the costs and benefits of treatment for babies with early and late treatment. The benefit-cost ratio was 4.36, meaning that for every dollar of costs to provide SCID screening, there will be \$4.36 worth of benefits. The sensitivity analysis showed that the model is robust because the benefit-cost ratio did not change much when more conservative or liberal estimates for parameters were made in the model.

## References

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WA State Cost-Benefit Analysis for adding NBS for SCID

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q
1																	
2	No Screening Model			rate			rate			rate	death				No Screening	deaths	0.54
3										0.086	0.03					surviving	1.18
4							0.203	early ID - family hx								early tx costs	\$ 34,834.14
5								0.35								late tx costs	\$ 617,217.43
6										0.914	0.32					total tx costs	\$ 652,051.57
7								early tx cost/baby									
8								\$ 100,000.00									
9		Birthrate		Prevalence	# SCID												
10		85,700		0.0000201	1.72												
11				1 in: 49,827													
12																	
13																	
14								late ID - clinical sx		0.375	0.51						
15							0.797	1.37									
16																	
17								late tx cost/baby		0.625	0.86						
18								\$ 450,000.00									
19																	
21	Newborn Screening Model			rate			rate			rate	death				Screening	deaths	0.18
22										0.086	0.14					surviving	1.54
23							Sensitivity	early ID - true (+)								early tx costs	\$ 161,278.37
24							0.938	1.61								late tx costs	\$ 48,218.40
25										0.914	1.47					total tx costs	\$ 209,496.77
26								early tx cost/baby									
27				Prevalence	# SCID			\$ 100,000.00									
28				0.0000201	1.72												
29				1 in: 49,827													
30																	
31																	
32								late ID - false (-)		0.375	0.04						
33							0.062	0.11							SHIFT		
34															Benefits	deaths averted	0.36
35								late tx cost/baby								value of a life	\$ 7,700,000.00
36		Birthrate						\$ 450,000.00		0.625	0.07					value of lives saved	\$ 2,806,972.12
37		85,700														less tx costs	\$ 442,554.80
38																TOTAL benefits	\$ 3,249,526.93
39		cost per baby						false (+)									
40		\$ 8.10					0.00017	14.5									
41					unaffected										Costs	costs of screening	\$ 694,170.00
42				0.9999799	85698.28											costs: false(+) dx	\$ 50,355.09
43																TOTAL costs	\$ 744,525.09
44																	
45																	
46							Specificity	true (-)									
47							0.99983	85683.8								Benefit/Cost ratio	4.36