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**An Analysis and Decision Tool to Measure Cost Benefit
Of Newborn Screening for Severe Combined Immune Deficiency (SCID)
And Related T-Cell Lymphopenia**

A Study by the Jeffrey Modell Foundation

Objectives of the Study

1. This study develops a working algorithm or “**decision tree**” that is validated by peer reviewed scientific literature, and harmonized for application to be used by Public Health Departments and Health Ministries in states, countries, and regions throughout the world.
2. Local or regional data can be applied to measure the threshold and economic impact of implementing or not implementing Newborn Screening for SCID.
3. This decision tree will provide the appropriate agency with a usable tool and understandable formula that will assist in deciding upon the willingness to pay for additional years of life utilizing criteria and costs specifically relevant to the locality.



10 Important Facts to Know

1. Infants born with Severe Combined Immune Deficiency (SCID), as well as related conditions with T-cell Lymphopenia, suffer from serious, life-threatening infections, and will likely not survive their first year of life without specific therapy to protect them from infections and restore their immune function[1-3].
2. SCID and related conditions can be detected by a simple screening test (TREC Assay) using the same dried blood spot samples already collected from newborns to screen for other genetic disorders[1,2].
3. The TREC Assay provides earliest possible identification before irreversible organ damage or death. Infants receiving hematopoietic stem cell transplantation in the first few months of life, after being identified through screening, have a high probability of survival, and will have the chance to grow up and live a healthy life[1,3-8].
4. While additional laboratory methods are being developed, the current TREC Assay has proven to have outstanding specificity and sensitivity to accurately identify all infants affected with SCID (the primary targets) as well as additional infants with other T-cell Lymphopenia (secondary targets)[1,2].
5. The screening test is 100% sensitive[9]. There has not been a single missed case of SCID since the program began 5 years ago[9].
6. The U.S. Secretary of Health and Human Services has recommended that ALL newborns be screened for SCID and T-cell Lymphopenia, characterizing SCID screening using the TREC Assay as “The National Standard for Newborn Screening Programs”[10,11].
7. There are established, dedicated, and specialized treatment centers for affected patients to receive care[12].
8. The cost of the screen is \$4-5 per infant. This includes equipment usage, labor and reagents[13]. More than 2.5 million babies have already been screened[2,8]. The actual incidence of SCID was found to be approximately 1:66,000 and T-cell Lymphopenia 1:20,000. The average was approximately 1:33,000[14].
9. There is a 95-100% success rate of survivorship for babies transplanted in the first three months of life[4-6]. However, the survival rate sharply declines with time[11]. SCID is fatal in infancy if not treated, and as more serious infections develop, it is more difficult to successfully transplant[3-8,15].
10. Preeminent physicians from 78 countries were brought together by the Jeffrey Modell Foundation for a three day Global Summit in Berlin, Germany. These expert physicians represent the world’s leadership and are authorities in the diagnosis, treatment and management of Primary Immunodeficiencies. At the conclusion of the Symposium, the physicians signed the “**Berlin Declaration**” calling for the immediate implementation of TRECs screening in order to identify, treat and cure newborn babies born with SCID and related T-cell Lymphopenia (see Appendix 1: “**Berlin Declaration**”).



Economic Analysis

The decision to implement Newborn Screening for SCID and related T-cell Lymphopenia will depend on the cost and effectiveness of the screening test, the incidence of SCID and related T-cell Lymphopenia within a population, the cost ratio of the intervention, and the benefit of earliest possible treatment[13,16]. If we make an assumption that the number of births within a region is 100,000 per year, and the incidence of SCID or related T-cell Lymphopenia is approximately 1:33,000 newborns, this decision tree projects 3 cases per year (See Figure 1).

The cost to screen 100,000 newborns, at \$4.25 per patient, totals \$425,000[13]. The cost to transplant one newborn is \$120,000[17,18]. The cost of post-transplant care over the next five years may be as much as \$200,000 for one newborn. Therefore, the cost to screen 100,000 newborns and treatment of one patient would be approximately \$745,000. The cost to screen 100,000 newborns and treat three patients totals \$1,385,000.

If newborns are not screened at birth, they will sustain overwhelming infections and hospitalizations, averaging costs estimated to be at least \$2 million in the first year of life[19,20]. Given the incidence and population, the total costs of care for the predicted three affected newborns will amount to \$6 million in healthcare costs[19,20].

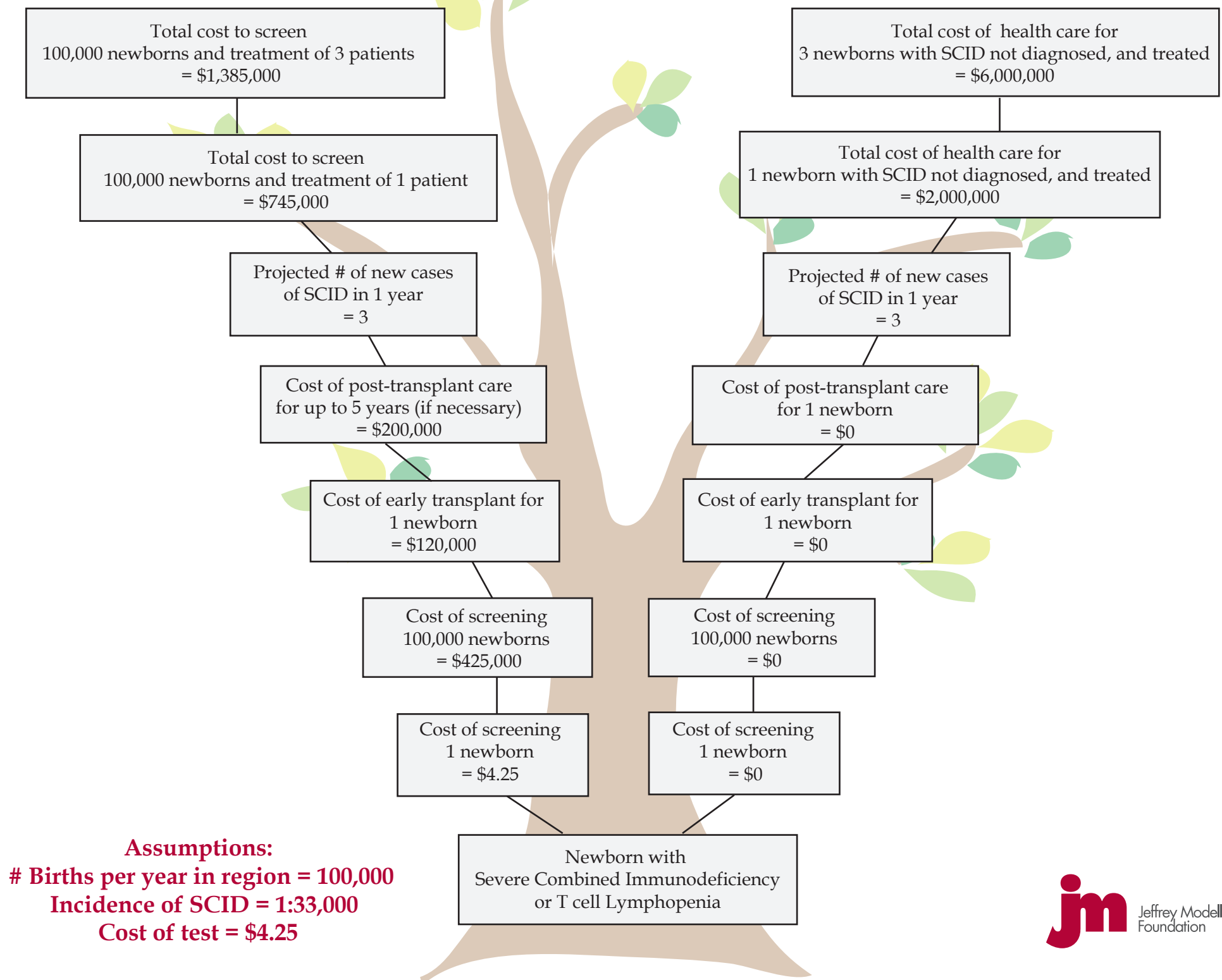
In a previous analysis, Chan et al found that the incremental cost-effective ratio (ICER) was \$27,907 per Quality of Adjusted Life Year (QALY), given 70 years of life saved[13]. This ratio is highly favorable, and also compares closely with other metabolic diseases currently screened[13]. Additionally, this analysis stated that assuming society is willing to pay \$50,000 per QALY, preference for screening occurred if incidence of SCID was at least 1:250,000[13].

In 2011, three U.S. Federal Agencies estimated the value of one life saved to be \$7.7 million[21]. This estimate is an average provided by the Environmental Protection Agency (\$9.1 million), Food and Drug Administration (\$7.9 million), and the Transportation Department (\$6.1 million)[21]. Given this economic information, a newborn baby with SCID or T Cell Lymphopenia that is screened and treated in the first 3.5 months of life, generates a contribution to society that is **at least 15 times greater** than the cost of screening and curative treatment.

The TREC assay is inexpensive, highly sensitive, and has been effectively integrated into public health programs (e.g. Wisconsin, California, New York, Ontario, etc.)[2,14,22]. SCID is a fatal disease that causes accrual of exorbitant healthcare costs in just one year of life[19,20]. The cost of care for just one infant with SCID could be more than the cost of screening for an entire regional population[20]. Implementation of screening through the TREC Assay will provide the earliest possible identification and allow for intervention of early transplantation before infants suffer from severe infections, organ damage, and ultimately death[1]. Newborn screening for SCID and related T-cell Lymphopenia is cost-effective, and most importantly, it is life-saving and allows children with SCID the opportunity to live a healthy life.

FIGURE 1:

**DECISION TREE TO CONSIDER NEWBORN SCREENING FOR
SEVERE COMBINED IMMUNODEFICIENCY AND RELATED T CELL LYMPHOPENIA**





References

1. Puck JM. Laboratory technology for population-based screening for severe combined immunodeficiency in neonates: The winner is T-cell receptor excision circles. In: Boyce JA, Finkelman F, Shearer WT, Vercelli D, editors. *J Allergy Clin Immunol* 2012; 129:607-16
2. Routes JM, Grossman WJ, Verbsky J, Laessig RH, Hoffman GL, Brokopp CD, Baker MW. Statewide newborn screening for severe t-cell lymphopenia. *JAMA* 2009; 302(22):2465-2470
3. Buckley RH, Schiff SE, Schiff RI, et al. Hematopoietic stem-cell transplantation for the treatment of severe combined immunodeficiency. *N Engl J Med*. 1999;340(7):508-516
4. Buckley RH. Transplantation of hematopoietic stem cells in human severe combined immunodeficiency: longterm outcomes. *Immunol Res* 2011; 49:25-43
5. Myers LA, Patel DD, Puck JM, Buckley RH. Hematopoietic stem cell transplantation for severe combined immunodeficiency in the neonatal period leads to superior thymic output and improved survival. *Blood* 2002; 99:872-878
6. Patel NC et al. Outcomes of severe combined immunodeficiency patients treated with hematopoietic stem cell transplantation with and without pre-conditioning. *J Allergy Clin Immunol* 2009 November; 124(5): 1062-9.e1-4
7. Antoine C, Muller S, Cant A, et al. Long-term survival and transplantation of haemopoietic stem cells for immunodeficiencies; report of the European experience 1986-99. *Lancet* 2003;361(9357):553-560
8. Hassan A, Booth C, Brightwell A et al. Outcome of hematopoietic stem cell transplantation for adenosine deaminase-deficient severe combined immunodeficiency. *Blood* 2012 Oct 25;120(17):3615-24
9. Baker M. Universal newborn screening for severe combined immunodeficiency (SCID). [PowerPoint]. Atlanta, GA: APHL CDC Newborn Screening Molecular Workshop; 2012
10. Sebelius, K. (2010, May 21). Letter to the committee chairperson for the Secretary's advisory committee on heritable disorders in newborns and children U.S. Department of Health and Human Services. Retrieved from: <<http://tinyurl.com/19baeng>>
11. The University of Texas Health Science Center at San Antonio (UTHSCSA). National Newborn Screening Status Report. November 21, 2011. Retrieved from <<http://genes-r-us.uthscsa.edu>>
12. Modell V, Gee B, Lewis DB, Orange JS, Roifman CM, Routes JM, Sorensen RU, Notarangelo LD, Modell F. Global study of primary immunodeficiency diseases (PI) – diagnosis, treatment, and economic impact: an updated report from the Jeffrey Modell Foundation. *Immunol Res* 2011; 51:61-70
13. Chan K, Davis J, Pai SY, Bonilla FA, Puck JM, Apkon M. A Markov model to analyze cost-effectiveness of screening for severe combined immunodeficiency (SCID). *Mol Genet Metab* 2011 November; 104(3):383-389
14. Kwan A, Church JA, Cowan MJ, Agarwal R, Kapoor N, Kohn DB, Lewis DB, McGhee SA, Moore TB, Stiehm ER, Porteus M, Aznar CP, Currier R, Lorey F, Puck JM. Newborn screening for severe combined immunodeficiency and T-cell lymphopenia in California: Results of the first 2 years. *J Allergy Clin Immunol* 2013 Jul; 132(1):140 – 150.e7
15. Buckley RH. The multiple causes of human SCID. *J Clin Invest* 2004; 114:1409-1411
16. Lipstein EA et al. Systematic evidence review of newborn screening and treatment of severe combined immunodeficiency. *Pediatrics* 2010; 125:e1226-e1235 doi: 10.1542/peds.2009-1567
17. Hospital Cost and Utilization Project (HCUP), Nationwide Inpatient Database under the auspices of The Agency for Healthcare Research and Quality (AHRQ). ICD-9 CM Principal Diagnosis Code for HSCT
18. Centers for Medicare and Medicaid Services, Hospital Accounting Records, April 28, 2010
19. Caggana M, Brower A, Baker M, Comeau AM, Lorey F. National SCID Pilot Study. Retrieved from: <<http://preview.tinyurl.com/lsanbqh>>
20. Kuehn BM. State, federal efforts under way to identify children with “Bubble Boy Syndrome”. *JAMA* 2010 Oct; 304(16):1771-73
21. Appelbaum, B. As U.S. Agencies put more value on a life, businesses fret [Newspaper]. New York Times, February 16, 2011; Available at: <http://tinyurl.com/mlynth7>. Accessed August 16, 2013
22. CBCNews Canada. ‘Bubble boy’ welcomes new Ontario screening test. Published online Aug 20, 2013. Available at: <<http://www.cbc.ca/news/canada/story/2013/08/20/newborn-screening-bubble-boy-scid.html>> Accessed: August 21, 2013



The Berlin Declaration

Jeffrey Modell Centers Summit – July 17 – 20, 2013

Immunologists from all Jeffrey Modell Diagnostic and Research Centers were brought together by the Jeffrey Modell Foundation for a three day Global Summit in Berlin, Germany. The physician-experts represent the world's leadership and are authorities in the diagnosis, treatment and management of Primary Immunodeficiencies. At the conclusion of the Symposium, the physicians agreed to the following guiding principles:

Whereas infants born with Severe Combined Immune Deficiency (SCID) as well as related T cell Lymphopenia, suffer from serious, life threatening infections, and will likely not survive their first year of life without curative stem cell transplantation;

Whereas the condition can be detected by a simple screen using the same Guthrie dried blood spot samples already collected from newborns.

Whereas the TREC Assay will provide earliest possible identification before irreversible organ damage or death, and will allow children the chance to grow up and lead a normal life;

Whereas additional laboratory methods are still being developed, but, the current method of screening using the TREC Assay has the specificity and sensitivity to accurately identify affected newborns, with better than 99% accuracy;

Whereas the U.S. Secretary of Health and Human Services recommended that ALL newborns be screened for SCID and related T cell Lymphopenia, characterizing SCID screening using the TREC Assay as "The National Standard for Newborn Screening Programs";

Whereas there are established, dedicated, and specialized treatment centers for affected patients to be managed and receive care;

Whereas the cost of the screen is \$4-5 per infant, and more than 2.5 million babies have already been screened. To date, the incidence of this condition has ranged from 1:35,000 to 1:60,000 of all newborns;

Resolved by the undersigned, calling for the immediate implementation of TRECs screening in order to identify, treat and cure newborn babies born with SCID and related T cell Lymphopenia;

Resolved by the undersigned, calling for continuing encouragement and support of physician education and public awareness relating to all 200 Primary Immunodeficiency disorders. This program has generated a 70% increase in identified patients worldwide over the past 18 months, and includes activities in connection with World Primary Immunodeficiency Week (WPIW) that takes place annually throughout the world during the last week in April.

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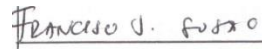

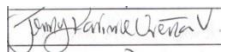

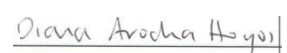
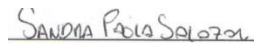
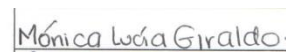
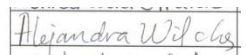
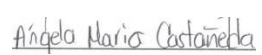

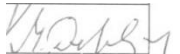
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