Washington State Department of HEALTH

WASHINGTON STATE BOARD OF HEALTH

Newborn Screening Technical Advisory Committee (TAC)

Newborn Screening Process and Criteria Review Technical Advisory Committee (TAC) Problem Statement:

KEY POINTS:

- Newborn screening programs across the U.S. are struggling to keep pace with rapid advancements in technology and treatments, compounded by inadequate resources and infrastructure.
- Washington, like many other states, is facing challenges with the growing number of requests to add new conditions to its required newborn screening panel. Evaluating these conditions takes a lot of time and resources.
- To address this issue, the Washington State Board of Health and the Department of Health are forming a TAC. The TAC will help to identify strategies to streamline the condition review request process, modernize the evaluation criteria, and strengthen the overall process to address current demands better.

OVERVIEW:

Over the last 60 years, newborn screening has emerged as a major public health achievement in the United States (CDC, 2011). Rapid advancements in screening technology and treatments for rare diseases pose a challenge for newborn screening programs nationwide, which struggle to keep up with these developments (Watson et.al, 2022). Many state programs face significant obstacles, including inadequate resources, limited funding, and insufficient infrastructure for equipment, staffing, and follow-up services necessary to test for new conditions.

In Washington State, the Newborn Screening Program, managed by the Department of Health, utilizes dried blood spot samples to identify rare but treatable health conditions in newborns. Annually, the program conducts approximately 12 million tests on over 172,000 specimens from about 84,000 births, identifying about 200 cases of the 32 conditions currently on the state's screening panel (DOH, n.d.). Early detection through this screening saves lives and improves health outcomes.

Washington law (RCW 70.83.050) requires that the Washington State Board of Health (Board) establish rules for newborn screening, detailed in Chapter 246-650 WAC. This includes WAC 246-650-020, which specifies the conditions for which all newborns must be screened.

The public, Legislature, Department staff, or Board members can request the Board to review potential new conditions for inclusion in the screening panel. The Board may convene an advisory committee to evaluate these conditions based on three guiding principles and an established set of five newborn screening criteria. The process and criteria were last reviewed in 2015.

Since 2023, the Board has received four petitions for new conditions to be considered for the screening panel. These conditions were: Mucopolysaccharidoses II (MPS II), Guanidinoacetate methyltransferase (GAMT) deficiency, Arginase 1 deficiency (ARG1-D), and Wilson's Disease. Additionally, by 2025, at the Legislature's direction, the Board must review two other conditions: branched-chain ketoacid dehydrogenase kinase (BCKDK) deficiency and congenital cytomegalovirus (cCMV). The Department is also monitoring 5-7 other potential conditions that may soon be proposed for review.

Given the increased volume of requests and anticipated workload, the Board and Department recognize the need to review and update the current process. The purpose of convening this Technical Advisory Committee (TAC) is to identify strategies to streamline the condition review request process, modernize the evaluation criteria, and strengthen the overall process to address current demands better.