



Date: April 8, 2020

To: Washington State Board of Health Members

From: Thomas Pendergrass, MD, MSPH, Vice Chair

Subject: Briefing – Newborn Screening Rulemaking for Spinal Muscular Atrophy – Chapter 246-650 WAC

Background and Summary:

The Washington State Board of Health (Board) has the authority under RCW 70.82.050 to define and adopt rules for screening of Washington-born infants for hereditary conditions. WAC 246-650-010 defines the conditions and WAC 246-650-020 lists conditions for which all Washington-born newborns are to be screened. The Board convenes a technical advisory committee (TAC) in order to determine which conditions to include in the newborn screen (NBS) panel. The TAC evaluates candidate conditions using an established set of criteria.

On January 9, 2019 the Board approved a motion directing Board staff, along with the Department of Health, to convene a technical advisory committee to evaluate the inclusion of spinal muscular atrophy (SMA) in the NBS panel. On April 29, 2019 the TAC convened to evaluate SMA for inclusion on the NBS panel by considering how the condition compares to the Board's five screening criteria. Following the discussion, the TAC unanimously voted to recommend the inclusion of SMA in the NBS panel.

On June 12, 2019 staff presented the findings and recommendation of the TAC to the Board, at which time the Board approved a motion to initiate rulemaking for the inclusion of SMA to the NBS panel. Board staff filed a CR-101 on July 19, 2019 to initiate the rulemaking process.

The inclusion of a SMA in the NBS panel, as indicated in the Department's cost-benefit analysis, would require an increase to the NBS fee. This fee is collected for each infant in Washington State and covers the costs of the screening, follow-up services, and coordination with specialty services. The addition of SMA to this panel would require additional funding appropriated by the Legislature for the additional resources needed from adding a test. In the 2020 supplemental budget, the Legislature provided the funding to cover these additional costs and the authority for the Department to increase the fee by the necessary \$4.30.

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I have invited Dr. John Thompson, Director of the Newborn Screening Program at the Department of Health, and Samantha Pskowski, Policy Advisor to the Board, to provide an update on the current progress of the rule update ahead of an anticipated rules hearing in June.

Staff

Samantha Pskowski

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