

Washington State Board of Health

Newborn Screening Updates and RUSP Considerations

Kelly Kramer, Policy Advisor – January 8, 2025



Newborn Screening Updates

Recap November Board meeting

The Board approved the following motion:

- The Board accepts the Newborn Screening TAC's recommendation for the Board to assume that conditions on the Federal Recommended Uniform Screening Panel (RUSP) meet the Board's qualifying assumption. The Board directs staff to update the Boards Newborn Screening (NBS) Process and Criteria document and include 2- year timeframe to review RUSP conditions.
- The Board also directs the TAC to continue the review of criteria at the next TAC meeting.

Further Considerations for Petitions:

- Conditions undergoing federal review, the Board will wait until federal review is complete before conducting review
- Conditions previously denied for the RUSP, Board staff will work with petitioner to address issues or concerns raised by the federal review

Newborn Screening Updates

RUSP Conditions not on Washington's Mandatory NBS Panel:

- Mucopolysaccharidosis type II (MPS-II) Added to the RUSP August 2022
- Infantile Krabbe Disease Added to the RUSP June 2024
- Guanidinoacetate Methyltransferase (GAMT) Deficiency Added to the RUSP January 2023
 - CR-101 filed November 2023, hearing pending
- Hearing loss added to the RUSP July 2005

Conditions to be reviewed by the Board:

- Branch-chain Ketoacid Dehydrogenase Kinase (BCKDK) Deficiency
 - As directed by Senate Bill 6234
- Congenital Cytomegalovirus (cCMV)
 - As directed by Senate Bill 5829
- Wilson's Disease
 - By petition received August 2024

Board Member Discussion

Possible action:

The Board may consider the following

- For the conditions MPS-II and Krabbe Disease that were added to the RUSP before the Board's recommendations, the two-year review timeline begins from the November 2024 Board recommendation date instead of the date of the federal recommendations.
 - The TACs for MPS-II and Krabbe Disease must be completed by November 2026





THANK YOU

To request this document in an alternate format, please contact the Washington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Health at 360-236-4110, or by email at wswashington State Board of Wswashington State Board of Wswashington.wa.gov (at a state st



ACCESSIBILITY AND THE AMERICANS WITH DISABILITIES ACT (ADA)

- The Washington State Board of Health (Board) is committed to providing information and services that are accessible to people with disabilities. We provide reasonable accommodations, and strive to make all our meetings, programs, and activities accessible to all persons, regardless of ability, in accordance with all relevant state and federal laws.
- Our agency, website, and online services follow the Americans with Disabilities (ADA) standards, Section 508 of the Rehabilitation Act of 1973, Washington State Policy 188, and Web Content Accessibility Guidelines (WCAG) 2.0, level AA. We regularly monitor for compliance and invite our users to submit a request if they need additional assistance or would like to notify us of issues to improve accessibility.
- We are committed to providing access to all individuals visiting our agency website, including persons with disabilities. If you cannot access content on our website because of a disability, have questions about content accessibility or would like to report problems accessing information on our website, please call (360) 236-4110 or email <u>wsboh@sboh.wa.gov</u> and describe the following details in your message:
 - The nature of the accessibility needs
 - The URL (web address) of the content you would like to access
 - Your contact information

We will make every effort to provide you the information requested and correct any compliance issues on our website.

