August 20, 2024

Dr. Sihoun Hahn, M.D, Ph.D.
Key Proteo
720 Broadway
Seattle, WA, 98122

Sent Via Email

Dear Dr. Hahn:

Thank you for the rulemaking petition you submitted to the State Board of Health (Board) on July 26, 2024, requesting to amend Chapter 246-650 WAC to add Wilson's Disease as a condition for newborn screening.

The Board met on August 7, 2024, and after reviewing and discussing your petition, voted to deny your request at this time. The Board concluded that there was not enough information to accept the petition to begin rulemaking and instead instructed staff to follow the Board's process for evaluating candidate conditions.

The Board directed staff to work with the Department of Health to convene a technical advisory committee (TAC) to evaluate Wilson's Disease using the Board's process and criteria to evaluate conditions for inclusion in WAC 246-650-020. Our staff are currently planning TACs for a queue of conditions, we anticipate the TAC will review Wilson's Disease in Spring 2025. After the TAC completes its review of Wilson's Disease using the Board's process for evaluating candidate conditions, staff will present its findings to the Board, likely Spring or Summer 2025. The Board will then revisit whether to add Wilson's Disease to the state's newborn screening list at that time. If the Board decides to add Wilson's Disease to the state's newborn screening list, the Department of Health must ensure funding is approved by the legislature before screening for Wilson's Disease is implemented.

Under RCW 34.05.330, a petitioner may appeal an agency's decision to deny a petition to repeal or amend a rule. An appeal must be made to the Governor within 30 days of denial.

If you require further assistance, please don't hesitate to contact Kelly Kramer, Health Policy Advisor in our office, at (564) 233-5340 or at kelly.kramer@sboh.wa.gov.

Sincerely,

Kelly Oshiro, Vice Chair