



STATE OF WASHINGTON

DEPARTMENT OF HEALTH

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September 15, 2025

Leticia Manning, MPH

Newborn Screening Team Lead, Division of Services for Children with Special Health Needs

Health Resources Service Administration/Maternal and Child Health Bureau

5600 Fishers Lane, Rockville, Maryland 20857

Re: Notice With Request for Comment on Consideration of Adding Duchenne Muscular Dystrophy to the Recommended Uniform Screening Panel [FR Doc. 2025-15433].

Dear Ms. Manning,

The Washington State Department of Health (DOH) does not recommend that Duchenne Muscular Dystrophy (DMD) be added to the Recommended Uniform Screening Panel (RUSP). A common criterion for evaluating candidates for mandatory newborn screening is evidence that early identification provides direct benefit to the newborn. The recent Kemper et al. article in the medical journal Pediatrics linked in the request summarizes treatment for DMD and cites more than 20 unique references in the “DMD Treatment” section of the paper. Published data on DMD treatment show that efficacy is limited in impact and duration, or altogether unclear. Additionally, several of the DMD treatments reviewed resulted in significant mortality or morbidity.

Another important consideration is the quality of the screening test. The largest published study reported 13 false-negative results among more than 300,000 newborns screened in Wales; the program correctly identified only 81.2% (56 true-positives among 69 total DMD cases). It is difficult to justify mandating screening for all newborns when 19% of affected babies will be missed by screening. DOH expects that the cited pilot studies and early adopter states (Ohio, Minnesota, and five other states not yet screening) will provide better information on the quality of the screening test with time.

DOH recognizes that DMD is a prevalent condition with large consequences for patients, their families, and medical providers. However, the limited efficacy of early intervention and the poor-quality screening test argue against adding DMD to the RUSP. DOH believes that new data in DMD treatment efficacy and screening test performance will become available to justify re-evaluating DMD as a candidate for the RUSP in the coming years.

Thank you for the opportunity to provide these comments. If you have any questions, please contact Mike Ellsworth at Michael.Ellsworth@doh.wa.gov or the Director, Federal and Inter-State Affairs for Governor Ferguson’s Washington, D.C. office Rose Minor at Rose.Minor@gov.wa.gov

Sincerely,

Angi Miller

Acting Assistant Secretary

Disease Control and Health Statistics

Washington State Department of Health