

# ORANGE COUNTY BOARD OF HEALTH AGENDA ITEM SUMMARY

**Meeting Date:**

Wednesday, February 25, 2026

**Agenda Item Number:**

VII.B.

**Agenda Item Subject:**

Resolution in Support of Expedited Evaluation of Newborn Screening for Metachromatic Leukodystrophy and Duchenne Muscular Dystrophy in North Carolina

**Attachment(s):**

Resolution in Support of Expedited Evaluation of Newborn Screening for MLD and DMD in NC.doc

**Staff or Board Member Reporting:**

Jean Phillips-Weiner, Board of Health Strategic Plan Manager

**Purpose:**

Action

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**Summary Information:**

At the January 2026 BOH meeting during the presentation on Metachromatic Leukodystrophy (MLD) and Duchenne Muscular Dystrophy (DMD) by Vrinda, founder of the nonprofit Youth for Rare Diseases, the Board of Health expressed interest in passing a resolution supporting the expedited evaluation of MLD and DMD for the NC Newborn Screening Panel Program.

**Health Equity Impact:**

With early detection and gene therapy treatment, much of the damage of MLD and DMD can be averted. Early detection and treatment also reduce costs associated with long-term care, benefiting un-insured, under-insured, and low-income parents. Additionally, DMD disproportionately affects males, who will benefit from early detection.

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**Recommended Action:**

Revise & schedule for future action.



**RESOLUTION IN SUPPORT OF EXPEDITED EVALUATION OF NEWBORN SCREENING FOR METACHROMATIC LEUKODYSTROPHY AND DUCHENNE MUSCULAR DYSTROPHY IN NORTH CAROLINA**

**WHEREAS**, Metachromatic Leukodystrophy (MLD) is a neurodegenerative disorder causing irreversible neurological damage<sup>1</sup>, and Duchenne Muscular Dystrophy (DMD) is a progressive disorder causing muscle wasting<sup>2</sup>; and

**WHEREAS**, diagnosis of MLD is frequently delayed for months or even years, during which patients experience irreversible neurological damage<sup>3</sup>; and

**WHEREAS**, diagnosis of DMD is delayed by an average of approximately of 2.5 years between symptom onset and definitive diagnosis<sup>4</sup>; and

**WHEREAS**, FDA-approved therapies, such as Lenmeldy<sup>3</sup> for MLD and various gene therapies<sup>5</sup> for DMD, are most effective when administered prior to the onset of symptoms; and

**WHEREAS**, the United States Secretary of Health and Human Services, Robert F. Kennedy Jr., formally added both MLD and DMD to the federal Recommended Uniform Screening Panel (RUSP) on December 16, 2025<sup>6</sup>; and

**WHEREAS**, disorders on the RUSP are “chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments,” and it is recommended that all states adopt all disorders on the RUSP for their state Newborn Screening Panel Programs<sup>7</sup>; and

**WHEREAS**, incidence of MLD and DMD is comparable to conditions already included on the NC Newborn Screening Program Panel Program<sup>8</sup> – MLD is estimated to occur in between 1 in 40,000 and 1 in 160,000 births<sup>9</sup> while DMD affects males almost exclusively and is estimated to occur in about 1 in every 3,500 live male births<sup>10</sup>, comparable to or more frequent than conditions such as Argininosuccinic Aciduria (1 in 70,000 to 1 in 218,000 live births)<sup>11</sup> and Glutaric Aciduria Type II (1 in 200,000 live births)<sup>12</sup>; and

**WHEREAS**, North Carolina already has screening infrastructure in place and has screened over 13,354 babies for DMD through the Early Check program, diagnosing two babies with DMD<sup>13</sup>; and

**WHEREAS**, timely newborn screening improves outcomes for children and families in North Carolina by enabling earlier diagnosis and access to medical care.

**NOW, THEREFORE, BE IT RESOLVED**, on this DATE 2026 that we, the Orange County Board of Health, support the expedited evaluation of MLD and DMD for inclusion in the North Carolina Newborn Screening Panel Program. Such action will ensure that affected families receive timely diagnosis, providing them the earliest possible opportunity to evaluate therapeutic and medical options before irreversible damage occurs.

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Tony Whitaker, PE  
Chair, Orange County Board of Health

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Quintana Stewart, MPA  
Orange County Health Director



## REFERENCES AND RESOURCES:

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3. Laugwitz, Lucia, et al. "Newborn screening for metachromatic leukodystrophy: A systematic literature review." *International Journal of Neonatal Screening*, vol. 11, no. 4, 5 Nov. 2025, p. 103, <https://doi.org/10.3390/ijns11040103>.
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10. "Duchenne Muscular Dystrophy - Symptoms, Causes, Treatment | Nord." *RareDiseases.Org*, National Organization for Rare Disorders, 15 July 2024, <https://rarediseases.org/rare-diseases/duchenne-muscular-dystrophy/>.
11. "Argininosuccinic Aciduria - Symptoms, Causes, Treatment | Nord." *RareDiseases*, National Organization for Rare Disorders, 11 May 2023, <https://rarediseases.org/rare-diseases/argininosuccinic-aciduria/>.
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