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**MEMORANDUM**

**TO:** Illinois Birthing Centers, Illinois Hospitals, Obstetrics and Gynecology Centers, Women Health Centers, Illinois Newborn Screening Advisory Committee, Pediatric Genetic and Metabolic Specialists, Pediatricians, Family Practitioners, Midwives

**FROM:** Joshua J. Geltz, PhD  
Chief, Division of Laboratories 

**DATE:** December 5, 2023

**SUBJECT:** Clarification of Newborn Screening for Metachromatic Leukodystrophy (MLD)

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**Background**

In 2023, Illinois passed legislation to include Metachromatic Leukodystrophy (MLD) as part of the State Newborn Screening panel and defined as part of Illinois Newborn Metabolic Screening Act (410 ILCS 240/3.5). The new law takes effect January 1, 2024.

**Status of MLD Testing in Illinois**

While the addition of MLD to the Newborn Screening Act (410 ILCS 240/3.5) goes into effect January 1, 2024, provisions within the enacted legislation indicate that the Department of Public Health shall provide MLD screening to all newborns *only after* certain conditions/milestones have been met. Currently, there is no FDA-approved assay available for MLD testing which requires that prior to making MLD screening available, test development for MLD screening methods is rigorously conducted to ensure that accurate and reliable testing is performed. As a result, the Illinois Department of Public Health will not implement Metachromatic Leukodystrophy (MLD) as part of routine newborn screening on January 1, 2024.

**Notification to Submitters for MLD Screening**

When the IDPH Newborn Screening testing section has, to full effect, validated MLD screening methods in accordance with Federal Testing Requirements (42 CFR 493.1253), the Department will notify submitters, in advance, with an effective date of when Metachromatic Leukodystrophy testing will be implemented as part of the Newborn Screening Act.