

Agenda

Universal Newborn Screening Advisory Committee
(a.k.a Genetic and Metabolic Diseases Advisory Committee)

September 15, 2025
12:00 – 3:30 pm CST

[Webinar Link](#)

Contact: IDPH Staff 217-785-8101

- I. Welcome and housekeeping.
- II. Approve April 2025 meeting minutes.
- III. Committee member status.
- IV. IDPH Reports
 - A. Newborn Screening Laboratory
 - 1. Staffing
 - 2. New disorders update (GAMT/MLD/ALD triplex)
 - 3. Neobase2 (NBS2) cutoff updates
 - 4. Hemoglobinopathies HPLC method update
 - 5. Krabbe algorithm update
 - B. Newborn Screening Follow-Up Program
 - 1. NBS Awareness
 - 2. Staffing
 - 3. Administrative Rules
 - 4. Hemoglobinopathy Collaborative
 - 5. Grant programs
 - C. IDPH Newborn Screening Budget Picture
 - 1. NBS Lab/NBS Metabolic Follow Up/EHDI Program
 - D. Early Hearing Detection and Intervention Program
 - 1. Program updates.
 - 2. Early Intervention (EI) system guidelines
 - 3. Family Based Organization update
- V. Old Business
 - A. Re-establish NBS Lab Subcommittee and identify Chair.
 - B. Re-establish NBS Expansion Subcommittee and identify Chair.
- VI. New Business
- VII. Reports from Partners
 - A. Division of Specialized Care for Children
 - B. Illinois Rare Disease Commission
 - C. Illinois Society of Genetic Professionals
 - D. Norton & Elaine Sarnoff Center for Jewish Genetics
 - E. Perinatal Advisory Committee
 - F. Sickle Cell Disease Association of Illinois
- VIII. Next Meeting Date
 - A. October 24, 2025 (Friday) 12-3:30 pm (Virtual)
- IX. Public Comments