

Agenda

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

April 11, 2025
9:00 am – 12:30 pm CST

[Webinar Link](#)

Contact: IDPH Staff 217-785-8101

- I. Welcome and housekeeping
- II. Approve April 2024 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 update
 - B. Newborn Screening Follow-Up Program
 - 1. Staffing
 - 2. Administrative Rules
 - 3. Hemoglobinopathy Collaborative
 - 4. Grant programs
 - C. IDPH Newborn Screening Budget Picture
 - 1. IDPH - federal funding picture overview
 - 2. 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. Illinois Society of Genetic Professionals
 - B. Division of Specialized Care for Children
 - C. Perinatal Advisory Committee
 - D. Sickle Cell Disease Association of Illinois
 - E. Norton & Elaine Sarnoff Center for Jewish Genetics
 - F. Illinois Rare Disease Commission
- VIII. Next Meeting Date
 - A. TBD (Virtual, In-person, or Hybrid)
- IX. Public Comments