

Agenda

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

January 30, 2026
9-12:30 am CST

[Webinar Link](#)

Contact: IDPH Staff 217-785-8101

- I. Welcome and housekeeping.
- II. Approve September 2025 meeting minutes.
- III. Committee member status.
- IV. IDPH Reports
 - A. Newborn Screening Laboratory
 - 1. Staffing
 - 2. New disorders update (GAMT/MLD/ALD triplex)
 - B. Newborn Screening Follow-Up Program
 - 1. Staffing
 - 2. Administrative Rules
 - 3. Fee increase
 - 4. Hemoglobinopathy Collaborative
 - 5. Grant programs
 - C. Early Hearing Detection and Intervention Program
 - 1. Program updates.
 - 2. Early Intervention (EI) system guidelines
 - 3. Family Based Organization update
- V. Old Business
 - A. NBS Lab Subcommittee
- 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. TBD
- IX. Public Comments