

Agenda

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

December 13, 2023
9:30 am – 12:00 pm CST

WebEx Virtual Meeting
Contact: IDPH Staff 217-785-8101

- I. Welcome and housekeeping
- II. Approve May 2023 meeting minutes
- III. Committee member status
- IV. IDPH Reports
 - A. Newborn Screening Laboratory (*Tate Kappell*)
 1. Organizational structure and staffing updates
 2. Neobase 2 progress
 3. GAMT update
 4. MLD update
 5. Other
 - B. Newborn Screening Follow-Up Program (*Joan Ehrhardt*)
 1. Organizational structure and staffing updates
 2. Metabolic formula program
 3. Courier updates
 4. Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)
 5. Administrative rules
 6. Grant program (*Rebecca Barnett*)
 7. Other
 - C. Early Hearing Detection and Intervention Program
 1. Programmatic updates
 2. Data review
 3. Family Based Organization update

V. Other Reports

- A. Newborn Screening Lab Subcommittee, no activity
- B. Newborn Screening Hemoglobinopathy Collaborative

VI. Old Business

- A. Re-establish NBS Lab Subcommittee, and identify Chair
- B. Re-establish NBS Expansion Subcommittee, and identify Chair

VII. New Business

- A. Request to vote on formal recommendation to add GAMT to IL NBS Panel

VIII. Reports from Partners

- A. Norton & Elaine Sarnoff Center for Jewish Genetics
- B. Sickle Cell Disease Association of Illinois
- C. Division of Specialized Care for Children
- D. Illinois Society of Genetic Professionals
- E. Perinatal Advisory Committee

IX. Next Meeting Date

- A. TBA (March 20, 27 or April 3, 10, 17, 24?)
 - 1. In-person meeting with virtual attendance option
 - 2. Site option: IDPH Office of the Director, 69 W Washington, Chicago

X. Public comments