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Agenda

Universal Newborn Screening Advisory Committee (a.k.a Genetic and Metabolic Diseases Advisory Committee) December 1, 2021 9:00 am – 12:30 pm

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

- I. Welcome. Housekeeping
- II. Approve May 2021 Meeting Minutes
- III. Committee Member status: current, pending, vacancies
 - A. Recognize members with terms ended 2021
 - B. Introduce applicants pending
 - C. Review terms ending Spring 2022
- IV. IDPH Reports
 - A. Newborn Screening Laboratory
 - 1. NBS Diagnosed Conditions (Data)
 - 2. Krabbe algorithm updates
 - B. Newborn Screening Follow-Up Program
 - 1. Staffing Updates
 - 2. Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) Update
 - 3. FY22 Grant Programs Update
 - 4. Administrative Rules Update
 - C. Early Hearing Detection and Intervention Program
 - 1. Programmatic Updates
 - 2. Data Review-
 - 3. Family Based Organization Update
- V. Other Reports
 - A. Newborn Screening and Laboratory Subcommittee
 - B. Newborn Screening Hemoglobinopathy Collaborative
- VI. Reports from Partners
 - A. Norton & Elaine Sarnoff Center for Jewish Genetics
 - B. Sickle Cell Disease Association of Illinois
 - C. Illinois Society of Genetic Professionals
 - D. Sudden Infant Death Services of Illinois, Inc.
 - E. Division of Specialized Care for Children
- VII. Other New Business
- VIII. Next Meeting Date
 - A. TBA
 - B. Emergency contact information
- IX. Public Comments