



Lori A. Weaver
Interim Commissioner

Patricia M. Tilley
Director

STATE OF NEW HAMPSHIRE
DEPARTMENT OF HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC HEALTH SERVICES
BUREAU OF POPULATION HEALTH AND COMMUNITY SERVICES
MATERNAL AND CHILD HEALTH SECTION

29 HAZEN DRIVE, CONCORD, NH 03301-3857
603-271-4225 1-800-852-3345 Ext. 4517
Fax: 603-271-4519 TDD Access: 1-800-735-2964 www.dhhs.nh.gov

New Hampshire Department of Health & Human Services
Division of Public Health Services
Newborn Screening Advisory Committee

Meeting Minutes

May 2, 2022

6pm – 8pm

SOPE Hazen Conference Rooms 311/312
NH Department of Health and Human Services
29 Hazen Drive, Concord, NH 03301

Virtual Option:

Microsoft Teams Meeting
Meeting ID: 262 682 617 289
Passcode: gyTjSf

Attendees: Marissa Avolio, Madhumita Chatterjee, Vernon Clough, Anne Marie Comeau, Leslie Dick, Roger Eaton, Amy Girouard, Kate Hartwell, Courtney Keane, Miranda McAuliffe, Amanda Merrill, Sue Moore, Carolyn Nyamasege, Rhonda Siegel, Kristen Smith, Shari Wilmot

- WELCOME AND INTRODUCTIONS
- PROGRAM UPDATE:
 - Amanda Merrill, BSN, RN NBS Program Coordinator
 - Rhonda Siegel, MEd, Administrator Maternal Child Health, co-chair
 - Program (NSP) Updates:
 - 2022 Legislative Report (2021 data) being presented to legislation on June 23, 2023.
 - HB 308- Passed the house, now in senate. Governor will allow legislative committees to not have an in person quorum.
 - SB 105- Will do away with the data on the birth certificate hospital worksheet.
 - Still looking for co-chair for the committee.
 - NSP is sending out quarterly timeliness report, unsatisfactory specimen report, missing demographic report and NBS Newsletter to birthing facilities.
- LAB UPDATE:
 - Roger Eaton, Director, UMass New England Newborn Screening Program

- Roger gave an update on the most recent added RUSP disorders, GAMT and MPS-II. Lab is looking into this, and will be initiating the CLIA process of fully validating testing to be prepared for when states decide to implement the testing.
 - In Feb 2023, Krabbe Disease was nominated for inclusion on the national RUSP, however the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) did not recommend to the Secretary the addition of Krabbe disease to the RUSP as it was a tie vote.
 - Dr. Comeau from the NBS lab discussed the RUSP process. Which includes an evidence review committee, utilizing the Robert's rule for voting. If the ACHDNC recommends a disorder is included in the RUSP, they provide this recommendation to the secretary of HHS. The ultimate decision lies with the secretary of HHS.
- PRELIMINARY 2022 DATA & UNSAT REVIEW:
 - Amanda Merrill, BSN, RN NSP Coordinator, presented the preliminary NSP 2022 data. Preliminary Data Summary shows 22 confirmed cases, with 21 still pending confirmation for calendar year 2022.
 - Total percentage of unsatisfactory specimens received at the newborn screening lab for calendar year 2022 was 1.7%. Majority of Unsatisfactory specimens include Too Early (obtained at < 24 hours of age) and Clotted/Layered specimens. The number of unsatisfactory specimens clotted was reduced from #86 total in calendar year 2021 to #66 total in calendar year 2022.
 - Timeliness of percent of specimens collected 24 to 48 hours after birth among 16 currently active birth hospitals in NH remains above the target of > 95%. This report is sent to birth hospitals quarterly.
- ALD Alliance Presentation:
 - Miranda McAuliffe from the ALD Alliance and a mother of a child affected with ALD, shared with the committee her personal story, as well as presented resources available for families and children affected with this disorder.
 - The next 2023 ALD Newborn Screening Lab & Program Consortium is being held on June 14, 2023. Quarterly consortiums are held virtually for newborn screening labs.
 - New gene therapy treatment is now available for ALD. The FDA approved bluebird gene therapy treatment for childhood cerebral ALD on September 16, 2022. This is an alternative to allogeneic hematopoietic stem cell transplant treatment option for children with cerebral ALD, eliminating the need for a bone marrow match.

ADJOURNMENT