Commonwealth of Massachusetts

Executive Office of Health and Human Services

Department of Public Health

Bureau of Infectious Disease and Laboratory Sciences

250 Washington Street, Boston, MA 02108-4619



MAURA T. HEALEY

Governor

KIMBERLEY DRISCOLL

Lieutenant Governor

KATHLEEN E. WALSH

Secretary

ROBERT GOLDSTEIN, MD, PhD Commissioner

**Tel: 617-624-6000**

**www.mass.gov/dph**

Newborn Screening Advisory Committee Meeting

Wednesday, April 9, 2025: 4:00 – 6:00 PM.

Held: Virtually via ZOOM

**Minutes Approved**: Pending Review

**Members in Attendance:** Karen McAlmon, Nicolas Epie, Catherine (Katie) Brown (DPH), Geoffrey Binney, Anne Comeau, Henry Dorkin, Mary-Alice Abbott, Monica Liao Chang, Dallas Reed, Chloe Schwartz, Feria Ladha, Inderneel Sahai, Yvonne Sheldon, Richard Parad, Olaf Bodamer, Christie Higuera

**Department of Public Health and New England Newborn Screening Program Staff in Attendance:** H. Dawn Fukuda, Mahsa Yazdy, James Ballin, Roger Eaton, Thera Meehan, Tresa Glover-Smith, Dylan Tierney

**Guests and Speakers:** Jamie Hale, Davinder Kaur

**Determination of Quorum:** Confirmed, therefore committee was able to begin meeting.

**Welcome and Introductions:**

Dr. McAlmon welcomed all to the meeting and introductions were completed. There were guests in attendance, but none participated in the listening session at the end of topic discussions.

**Approval of Minutes**

The minutes from the prior meeting held on February 12, 2024, were approved.

Vote: 11-Yes, 0-No, 0-Abstain

Meeting Minutes are posted on the NBS Web Page.

**Addition of Newborn Screening Program Recommendation Form to Website**

Add 6–9-month approval timeline for approval of submission to form.

Add RUSP question to form.

Vote to approve form for posting to website:

13-Yes, 0-No, 0-Abstain

**Remaining Pilot Screening Disorders**

Dr. Comeau gave a brief overview of the histories of the conditions that have been included on the Massachusetts Newborn Screening Program pilot panels whose future disposition was not yet determined. This included results to date of the screening in Massachusetts. Each condition was discussed with questions addressed then a vote was taken on its future status.

**De Red:** Dienoyl-CoA Reductase deficiency

**Motion to continue as pilot**

**Vote: 5 Yes, 6 No**

**Will not continue as pilot**

**MAL**: Malonic acidemia

**No motion, leave as pilot**

**HADD** Hydroxyapatite Deposition Disease

**No motion, leave as pilot**

**HHH** Hyperornithinemia, Hyperammonemia, Homocitrullinuria Syndrom

**Motion to remove as pilot**

**Vote: 10 Yes, 2 No**

**Will not continue as pilot.**



**Planning for Legislator Education**

The Committee was in the process of evaluating whether DMD should be added to the panel when legislation was passed to add DMD to the mandated newborn screening panel. We feel there is a need to educate legislators and plan to meet with Massachusetts Legislators to discuss the role of the Newborn Screening Advisory Committee in determining which disorders are included in the newborn screening panels. We will educate the legislators on how the Committee evaluates disorders and the process for adding them, if appropriate, to the newborn screening mandated or pilot panel. They will be presented with a packet of information about the Committee. Once the packet is complete it will be shared with the Committee to ensure that all the appropriate information is included. We need to determine which members of the Joint Committee on Public Health we should speak with. If Committee members feel there are specific legislators we should speak to, please let Dr. McAlmon or Dawn Fukuda know.

**Listening Session:**

There were no requests for participants in the listening session.

**Next Steps:**

* The next NBSAC meeting is scheduled for Wednesday, July 9, 2025

**Meeting Adjourned**