Commonwealth of Massachusetts

Executive Office of Health and Human Services

Department of Public Health

Bureau of Infectious Disease and Laboratory Sciences

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Newborn Screening Advisory Committee Meeting Minutes

Wednesday, February 12, 2025: 4:00 – 6:00 PM.

Held: Virtually via ZOOM

**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, Zakaria Ahmed- Gas, Tresa Glover-Smith

**Guests and Speakers:** Ryan Colburn, Stephanie Cozine, Megan Colantuoni, Sira Grant, Caroline Villaruz, Davinder aur, Binod Kumar, Justin Serio

**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 eight guests in attendance. Two spoke during the listening session at the end of topic discussions.

**Approval of Minutes**

The minutes from the prior meeting held on January 8, 2025, were approved.

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

January 8, 2025 Meeting Minutes are posted on the NBSAC Web Page at <https://www.mass.gov/orgs/massachusetts-newborn-screening-advisory-committee> .

**Finalization and approval of Newborn Screening Condition Nomination Form**

Committee members raised the question of whether there should be a timeline added to the form. It was recommended to include a time frame of 6-9 months for review of the submission.

Committee voted to approve the Newborn Screening Condition Nomination form with above recommendations addressed.

Vote: 13-Yes, 0-No, 0-Abstain

**Review of Process for Moving Newborn Screening Tests to Mandatory Panel**

Steps for moving screening for a disorder currently in pilot to the mandatory panel were reviewed and described as follows:

1. NBSAC makes recommendation
2. DPH notifies the commissioner
3. Commissioner reviews and approves
4. Submission to EOHHS for approval
5. Submission to Administration and Finance for approval
6. DPH provides an information briefing
7. DPH holds at least one public hearing
8. DPH reviews comments
9. Repeat the entire review and approval process
10. DPH request approval from PHC
11. Submit to the Secretary after approval



**Update on Pilot Screens and Processes** Dr. Comeau presented an overview of the conditions that have been included on the Massachusetts Newborn Screening Program pilot panels. Drs. Sahai and Bodamer presented screening and clinical information about the two disorders, MPSI and Pompe.



**Discussion of Pilots and Screens**

There were comments and questions by Committee members and some of the guests which were addressed,

Committee voted on whether to recommend adding Mucopolysaccharidosis Type I and Pompe Disease to mandated screening panel.

Mucopolysaccharidosis Type I (MPS I) Disease (Hurler, Hurler-Scheie and Scheie Syndromes)

(MPSI Vote):

Yes – 11, No-0, Abstain-0

Approved recommendation to Commissioner to add this to mandated screen panel

Pompe Disease

Yes – 10, No-1. Abstain-0

Approved recommendation to Commissioner to add this to mandated screen panel

**Listening Session:**

**Ryan Colburn, Odimm Inc**.

*Ryan Colburn joined the meeting from Odimm Inc. to support adding Pompe Disease to Newborn Screening. He believes 2-3 weeks target for treating the disease is not fast enough to yield the best outcomes. We need continuous improvement and more communication regarding treatment through APHL with other states for screening. Suggests possibly move listening session before voting on pilots to consider outside input.*

**Stephanie Cozine, National MPS Society**

*Stephanie Cozine joined the meeting from the National MPS Society. She is an advocate for families by offering support groups for MPS. She offered information regarding communicating information to families regarding Newborn Screening for MPS. The National MPS Society provides social workers and genetic counselors that run a comprehensive family support program focusing on newly diagnosed patients and families. Presentation is included in the minutes.*



**Chat Notes:**



**Next Steps:**

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

**Meeting Adjourned**