

STATE OF CONNECTICUT
DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Universal cCMV Screening Working Group
Approved Meeting Minutes
Tuesday, November 14, 2023
8:30 – 9:30 AM

Working Group Members

Present: Jody Terranova, DO, MPA (Chair), Nancy A. Louis, MD, FAAP, Carlos R. Oliveira, MD, PhD, Ashley C. Howard, DO, FAAP, Thomas Murray MD, PhD, FAAP, Jafar H. Razeq, Ph.D., HCLD/PHLD (ABB), Debra Ellis, RN, BSN, Adrienne Manning, Marie Burlette, RN, BSN, MPH, John Lamb, and Amaka Atuegbu

Absent: Scott Schoem, MD, MBA, FAAP

- I. Call to Order
 - a. The meeting was held via Teams and Dr. Terranova called the meeting to order at 8:33 AM
- II. Approval of Minutes (8:30 – 8:35)
 - a. Marie Burlette moved to approve the minutes of October 24, 2023. Adrienne Manning seconded the motion. The motion passed unanimously.
- III. Public comment (8:35 – 8:40)
 - a. No members of the public were in attendance
- IV. New Business (8:40 – 9:15)
 - a. Education subgroup presentation
 - i. John Lamb presented the education subgroup recommendations with summary recommendations outlined below
 - o Update existing CT NBS and EHDI materials/resources to match legislation.
 - o Create new materials and guidelines to outline the follow-up process and recommended timelines for both families and providers.
 - o Ensure adequate staffing for education, outreach, and education materials.
 - o Create prevention guidelines for those who are pregnant, at risk, and for relevant providers.

- o Create a comprehensive plan to distribute materials to relevant stakeholders.
 - b. Working group discussion and adoption of recommendations
 - i. Ms. Manning noted that the Connecticut Newborn Screening Program (CT NBS) can send both newborn bloodspot screening and EHDI cCMV educational materials at the same time to hospitals and birthing centers. Ms. Manning also noted that CT NBS can conduct more outreach to midwives and send all educational materials to them.
 - ii. Ms. Burlette expressed the need to provide educational materials during prenatal visits with OBGYNs. Dr. Razeq supported this notion, stating the importance of educating families early on the algorithm for cCMV follow-up to mitigate panic if a baby is subsequently diagnosed cCMV positive. Ms. Manning also noted that these educational materials should be distributed to other providers, such as Wheeler Clinics and Planned Parenthood, involved in prenatal care.
 - iii. Ms. Burlette indicated that CT NBS is willing to share its follow-up model for whoever has ownership of the cCMV screening program. Dr. Terranova noted that this will be an important consideration when planning for cCMV implementation
 - iv. John Lamb asked if the Office of Early Childhood (OEC) can be involved in educating childcare providers under the universal cCMV legislation. Dr. Terranova noted the need for consistent messaging, so the educational materials would be developed with any input OEC. Then, OEC can disseminate the materials to childcare providers
 - v. Dr. Razeq stated that, prior to delivery, parents may benefit from a general statement from the ID docs and ENT in the universal cCMV working group on what to expect and what to do if a baby, especially if a baby is asymptomatic positive.
 - vi. Dr. Terranova emphasized that the education subgroup recommendations may evolve as other subgroups provide their recommendations. Dr. Terranova also noted that the working groups' guidelines will be broad and subject to more details when the owner of the screening program is determined.
 - vii. Dr. Terranova called on Thomas Murray, MD, PhD, FAAP to introduce himself since he was absent at the first meeting.
- V. Announcements (9:15 – 9:25)
 - a. December meeting - lab methodology subgroup presentation
 - i. Ms. Manning announced that her subgroup will be presenting on method development for extraction and analysis of cCMV using dried blood spot.
 - b. Agenda and minutes for subgroup meetings
 - i. Amaka Atuegbu announced that the subgroup meetings are also public meetings, so their agendas and minutes will be posted to the public meeting calendar. Ms. Atuegbu noted that the agenda need to be posted at least 48 hours before and the minutes at most 7 days after the meeting.
 - ii. Dr. Terranova noted that Ms. Atuegbu will help the subgroups coordinate times to meet before their presentations to the larger group.
 - c. Consider breakout of planning for implementation subgroup (Algorithm vs. Follow-up)

- i. Dr. Terranova recommended that the implementation subgroup be divided into algorithm for treatment, evaluation, work up, and follow-up (healthcare providers) and DPH follow-up/implementation subsets (EHDI, CT NBS). The working group agreed to the division.
 - ii. Dr. Razeq stated that the working group can draft comments on what the diagnosis means and what to do with cCMV findings to assist PCPs.
 - iii. Dr. Murray stated the importance of providing detailed comments in anticipation of potential education gaps for PCPs. Dr. Razeq supported this notion, emphasizing that CT NBS is working on a new information management system that can mitigate concerns about gaps. Ms. Manning also noted that CT NBS can invite MN stakeholders to discuss their lab and follow-up components.
 - iv. Dr. Terranova encouraged the group to invite stakeholders from other jurisdictions to their subgroup meetings to help inform their recommendations.
 - v. John Lamb asked if it is possible to link the lab information management system and Maven data system, so that audiologists can receive notice of cCMV positive newborns alongside PCPs. Dr. Terranova noted that it should be possible because in the current NBS follow-up specialists are notified when families and PCPs are notified.
- d. Working group availability for 90-minute standing meetings for January – April 2024
- i. The working group agreed that meeting polls will be sent for January – April 2024.

VI. Adjournment (9:30)

- a. Dr. Terranova adjourned the meeting at 9:30 AM.