

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 Wednesday, February 28, 2024 11 AM – 12:30 PM

Working Group Members

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

Absent: Jafar H. Razeq, Ph.D., HCLD/PHLD (ABB) and 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 11:03 PM.
- II. Approval of Minutes
 - a. Dr. Murray moved to approve the minutes of January 14, 2023. Dr. Louis seconded the motion. The motion passed unanimously.
- III. Public comment
 - a. None
- IV. Old Business
 - a. Review updated draft/proposed Connecticut cCMV Algorithm
 - i. Dr Terranova noted that the algorithm was revised to include confirmatory urine test as soon as possible, preferably within one week of age, not delaying referral to a pediatric infectious disease (ped ID) specialist after scheduling eye exam, and possible referral to a pediatric infectious disease specialist while some diagnostic results are still pending to prevent treatment delay.
 - ii. Dr. Murray suggested that only pediatricians should conduct developmental surveillance of cCMV symptomatic infants and the reference to pediatric infectious disease doctors be removed.
- V. New Business
 - a. Planning for Implementation Subgroup presentation
 - i. Ms. Manning presented on behalf of the subgroup, elaborating on the six questions the subgroup discussed

- What are the follow-up plans after a positive newborn dried blood spot (DBS) screening for cCMV?
 - What are the follow-up plans after a failed hearing screening for determining cCMV status?
 - What is the recommended length of follow-up? What kind of follow-up data should be collected? Who should be responsible for collecting the named data?
 - What is the cCMV information to include in education materials/packets for families and pediatricians?
 - How should the education component be implemented?
 - What additional resources would be needed for a follow-up program and the education component?
 - ii. Ms. Manning presented the subgroup's summary recommendations outlined below
 - The Connecticut Newborn Screening (CT NBS) Program should be responsible for cCMV DBS laboratory testing and follow-up/tracking and the EHDI Program should be responsible for the hearing screenings.
 - CT DPH should track short-and long-term follow-up data.
 - CT DPH may contract with outside entities to provide care coordination for diagnostic and treatment services and long-term follow-up.
 - Education materials should be provided for expectant families and those who want to become pregnant through birth hospitals, OB/GYNs, and midwives. Furthermore, education materials at the time of cCMV diagnosis should be targeted at the relevant audience.
 - Pediatric ID and Audiology specialists should determine the long-term metrics to follow. Some metrics include hearing diagnostics over time, treatment(s) received, and developmental milestones.
- b. Working group discussion
- i. Dr. Murray noted that recommendations seemed to place sizeable follow-up responsibilities on peds ID specialists who do not have the resources to conduct such follow-up. Dr. Howard also expressed similar concerns. Dr. Terranova clarified that the plan was modeled after current NBS practice, but Dr. Murray noted that majority of infants will not need to see peds ID (the majority of cCMV infections are asymptomatic).
 - ii. Mss. Burlette, Manning, and Ellis provided additional clarification that, currently, the Connecticut Newborn Diagnosis and Treatment Network establishes a protocol with peds ID specialists ahead of time and will consult with ID when someone falls outside the parameters of the protocol.
 - iii. Dr. Oliveira stated the need for resources to analyze the short- and long-term data, which could result in changes to the state's cCMV protocols. Dr. Terranova supported the suggestion.

- iv. Mr. Lamb asked if child and healthcare workers and their partners would be included in the follow-up. Dr. Terranova noted that the Education Subgroup identified these stakeholders in their recommendations, so it would be important to include education materials that can be distributed to them.
- v. Dr. Murray asked Dr. Terranova to consider seeking feedback from pediatricians on the feasibility and burden of the proposed cCMV follow-up.
- vi. Ms. Ellis asked when the universal cCMV screening will begin. Dr. Terranova responded that screening will begin July 1, 2025, per statute.

VI. Announcements

- a. March meeting (Thurs 3/14, 12 – 1 PM) – Lab Methodology Subgroup presentation
 - i. Dr. Terranova announced that Ms. Manning and Charbel Khalil will present the lab methodology testing results and the process the lab will adopt. Dr. Terranova noted that this will be the last meeting with any new presentations.
- b. Upcoming April meeting poll – DPH to present summary of all recommendations and Working Group to review the draft report
 - i. Dr. Terranova stated that Working Group will review and finalize the report and the report will be delivered to the Commissioner. Dr. Terranova also noted that this timeline allows CT DPH to prepare for cCMV implementation before 2025.
 - ii. Dr. Terranova thanked all the working group members for their time and contributions.

VII. Adjournment

- a. Dr. Terranova adjourned the meeting at 11:45 AM.