

STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD
Commissioner



Ned Lamont
Governor
Susan Bysiewicz
Lt. Governor

Universal cCMV Screening Working Group
Planning for Implementation (DPH follow-up) Subgroup Minutes
Tuesday, December 19, 2023
1 - 2 PM

Subgroup Members

Present: Jody Terranova, DO, MPA (Chair), Adrienne Manning, Marie Burlette, RN, BSN, MPH, Debra Ellis, RN, BSN, and John Lamb

Absent: Jafar H. Razeq, Ph.D., HCLD/PHLD (ABB)

Other: Amaka Atuegbu

1. Call to Order
 - a. The meeting was held via Teams and Ms. Atuegbu called the meeting to order at 1:10 PM.
2. Welcome and Introductions (1 – 1:05)
3. Public comment (1:05 – 1:10)
4. New business (1:10 – 1:50)
 - a. Subgroup discussion
 - i. Ms. Manning noted that both EHDI and CT NBS will have to work together for DPH cCMV follow-up implementation.
 - ii. Mr. Lamb asked if infectious diseases will be involved, noting that they have the capacity to communicate results. Mr. Lamb noted that if they are not involved and EHDI is responsible for the follow-up, there will be a need for resources in EHDI, including staff, Maven data system updates, track outreach activities, and operational funding.
 - iii. Ms. Manning stated that CT NBS and EHDI do not have the capability, such as staffing, to handle long-term and hearing follow-up, respectively for positive cases as they anticipate an increase in cases. Ms. Manning also added that about 120 infants will require long-term follow-up.
 - iv. Mr. Lamb noted that EHDI is unable to obtain and share results and expressed concern about violating HIPAA. Mr. Lamb noted that EHDI does not currently send out letters to families if a child is cCMV positive

or if they have risk factors for hearing loss. Ms. Burlette and Ms. Manning noted that the universal cCMV is different as CT DPH would have to release the testing results since it was conducted in the state lab.

- v. Ms. Manning stated that the state lab is developing a new LIMS (lab info management system) that can enable CT NBS to electronically share results with EHDI and ease the information sharing process. Ms. Manning emphasized concern about volume of results following universal cCMV implementation. Ms. Manning noted that preliminary data from other states show that 80-85% newborns are asymptomatic and 10-15% are symptomatic.
- vi. Mr. Lamb noted that in the current targeted cCMV screening, 50% of newborns develop hearing loss within a year or two. Thus, we should anticipate a high number of hearing follow-up. Mr. Lamb added that cCMV infected newborns typically have peds audiologist conduct hearing follow-ups every 3-6 months for up to 3 years.
- vii. Ms. Burlette noted that there are other medical impacts of cCMV beyond hearing. The subgroup also expressed concern about other adverse effects of cCMV infection beyond hearing loss and implications for follow-up.
- viii. Ms. Manning reminded the subgroup that some symptomatic cases will not be picked up on screening if newborns are infected early in gestation.
- ix. Ms. Burlette noted the need to determine the length of follow-up, noting the need to determine short- and long-term follow-up.
- x. Ms. Ellis asked if the first step would be a letter/document/algorithm to PCPs approved by immunology on next steps after cCMV confirmation. The subgroup also asked if the pediatrician or peds ID doc will be responsible for follow-up.
- xi. Mr. Lamb noted that with targeted screening cCMV newborns who do not have hearing loss are not followed. Mr. Lamb expressed optimism that birth facilities share cCMV results with parents.
- xii. Mr. Lamb stated that cCMV positive newborns will likely be automatically referred to peds audiology under universal screening, but expressed uncertainty about who will be responsible for making the referrals.
- xiii. Ms. Burlette provided an overview of CT NBS follow-up and work with NBS Network. Ms. Ellis noted that it may be confusing if pediatricians had different disorders following different follow-up pathways.
- xiv. Ms. Ellis expressed that the subgroup may be unable to plan for implementation without the symptomatic and asymptomatic algorithm. Dr. Terranova noted that the subgroup can brainstorm implementation considerations without algorithm specifics.
- xv. Ms. Burlette asked how NBS Network determines the data to collect for follow-up. Ms. Ellis noted that the Network typically consults with the relevant specialists to determine the data to collect for long-term follow-up.
- xvi. Mr. Lamb stated that EHDI does not currently track follow-up data for cCMV infected newborns, but that EHDI can check if the newborn has

had a diagnostic audiology. Mr. Lamb also noted that any tracking EHDI does is from 0-3, an important consideration as the subgroup considers long-term follow-up.

5. Next steps (1:50 – 2)
 - a. Next meeting date
 - i. Ms. Atuegbu to send January subgroup meeting poll.
 - ii. Ms. Atuegbu to follow-up with the subgroup on narrow questions to focus on.
6. Adjournment (2)
 - a. Ms. Atuegbu adjourned the meeting at 2:05 PM.