

**STATE OF CONNECTICUT**  
DEPARTMENT OF PUBLIC HEALTH

Manisha Juthani, MD  
Commissioner



Ned Lamont  
Governor  
Susan Bysiewicz  
Lt. Governor

Universal cCMV Screening Working Group  
Education Subgroup Minutes  
Wednesday, November 1, 2023  
10 – 11 AM

**Subgroup Members**

Present: Debra Ellis, RN, BSN, Marie Burlette, RN, BSN, MPH, and John Lamb

Other: Amaka Atuegbu

1. Review of current available resources
  - a. What is missing/needed?
    - i. The subgroup agreed on the need to send initial cCMV screening notification letters to birth hospitals and PCPs and update newborn screening (NBS) and Early Hearing Detection and Intervention (EHDI) program education materials with information on the recent cCMV legislation. The subgroup also agreed that other subgroups' recommendations on cCMV testing and follow-up will determine the education content and delivery.
    - ii. Regarding current cCMV education materials, John Lamb noted that the EHDI program's education process is limited as CGS§19a-55 does not allocate funding or include language on EHDI education processes. It is strictly limited to the targeted testing requirement. Therefore, EHDI ensures compliance from birth facilities to do the cCMV testing, recommends referral or self-referral to audiologists for hearing testing and monitoring, and for birth facilities to submit their CMV data to DPH.
    - iii. Mr. Lamb also noted that letters are sent to the parents and providers of children who have failed their newborn hearing, but not yet had a hearing test, informing them about the new for diagnostic testing and the importance of cCMV testing. Additionally, EHDI distributes two brochures to birth facilities. One brochure explaining the newborn hearing screening and CMV is given to all parents at birth and the other containing

CMV testing information is given to parents whose babies have failed their newborn hearing screening.

- iv. Mr. Lamb stated that staffing and funding shortages and the current legislation signals priority on testing than education. Mr. Lamb also noted that determining the algorithm for cCMV testing and follow-up will determine how the education materials are written and for whom.
- v. Marie Burlette stated the importance of informing providers that cCMV will be added to the universal blood spot screening, noting that the state can adopt education practices like those of other 60+ disorders screened for in the state.
- vi. Ms. Burlette noted that the NBS program does not spend a lot of time on the education component as it would prefer because its focus is on reporting results and following up. Ms. Burlette also shared the newborn screening flyers distributed to the birth hospitals in the meeting, noting the need to add the universal cCMV screening to an updated flyer.
- vii. Ms. Burlette expressed the NBS program goal to distribute the newborn screening flyers to obstetricians, family practitioners, and birth educators.
- viii. Ms. Burlette also noted that when a new disorder is added to the CT Newborn Screening panel, the newborn screening program sends letters that include screening information, incidence rates, and relevant legislation to birth hospitals and NICUs. The same will be done for CMV
- ix. Debra Ellis expressed the need for multiple layers of education – notifying OBs, sending letters to healthcare providers, and providing follow-up information if cCMV positive. Mr. Lamb shared EHDI information material for obstetricians, noting that it may be easier to create a universal cCMV education resource.
- x. Ms. Ellis stated that Connecticut Children’s has a peds care provider network with physician liaisons who deliver education handouts in person. They also do mass mailing, and target education to practices mostly referred to. Ms. Ellis noted primary care provider concerns about receiving too many emails and their desire for limited and targeted communication
- xi. Ms. Ellis stated that OBs, peds, and hospitals can receive cCMV notification, but some education pieces depend on other subgroup recommendations.
- xii. Ms. Burlette stated that cCMV screening information can be added to the NBS flyers and EHDI brochures and specific materials for parents and providers caring for infants diagnosed with CMV (including what is CMV, and don’t panic messaging) can be developed once we know the algorithm.
- xiii. Mr. Lamb asked if the subgroup is required to discuss prevention. Amaka Atuegbu cited the legislative charge, noting that the subgroup can recommend education on prevention.

## 2. Identification of relevant stakeholders to educate

- a. Birth Hospitals
- b. NICUs
- c. Parents

- d. Obstetricians
  - e. Primary care providers (peds, family care providers, naturopaths, any newborn health care provider)
  - f. Daycares for cCMV prevention materials
3. Who will create materials, edit materials, approve materials, and who/how will they be disseminated?
- a. What format and how will they be delivered?
    - i. public awareness campaign?
      - Ms. Burlette noted the need to allocate funds and contract this service if this dissemination method is adopted
    - ii. Website?
      - Mr. Lamb noted that we can build from EHDI CMV website but noted that this may not be effective tool in creating cCMV awareness
      - Ms. Burlette stated that NBS can also add update website with cCMV information
    - iii. e-course?
      - Ms. Burlette stated that cCMV information may be added to the NBS e-course for hospital providers
    - iv. provider networks?
    - v. Distribution through OB-GYN offices, Birth hospitals, childbirth educators, PCPs?
4. Resources needed/Identification of potential challenges
- a. Additional funding to assist with education efforts
5. Next steps
- a. Ms. Burlette to inquire if there is a way to send out email blasts to obstetricians, peds, and family practitioners.
  - b. Ms. Burlette to follow up with Adrienne on the number of children expected to be identified through blood spots annually.
  - c. Ms. Burlette to coordinate scheduling for next meeting.
  - d. Members to add education materials from other jurisdictions and CDC materials to the shared folder.