STATE OF CONNECTICUT
DEPARTMENT OF PUBLIC HEALTH

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Commissioner

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Universal cCMV Screening Working Group
Approved Meeting Minutes
Thursday, January 11, 2024
12 – 1 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, Scott Schoem, MD, MBA, 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: Carlos R. Oliveira, MD, PhD

I. Call to Order
   a. The meeting was held via Teams and Dr. Terranova called the meeting to order at 12:03 PM.
II. Approval of Minutes
   a. Dr. Schoem moved to approve the minutes of December 14, 2023. Ms. Manning seconded the motion. The motion passed unanimously.
III. Public comment
   a. None
IV. New Business
   a. Treatment of asymptomatic positives subgroup presentation
      i. Dr. Terranova noted that the subgroup also worked on the symptomatic algorithm. Drs. Howard and Murray presented the subgroup's proposed recommendations. Dr. Howard began by noting that there are no comprehensive and consistent clinicals practice guidelines for cCMV, but highlighted Rawlinson et al. 2017 as the most cited literature on cCMV treatment guidelines. Dr. Howard also reviewed the cCMV algorithms in Minnesota and Ontario.
      ii. Dr. Howard presented the draft/proposed Connecticut algorithm and emphasized the need for the working group to discuss the feasibility of obtaining urine samples within 21 days and ensuring that evaluations are timely so that treatment, if necessary, can begin early, noting the efficacy of treatment begun within 30 days of life.

iii. Dr. Murray emphasized the importance of understanding the resources available to general pediatricians and how the proposed algorithm will be effectively implemented with those resources, noting concern about including processes in the algorithm that are not attainable within the required timeframe. Dr. Murray expressed the need for more information on how easily patients can access evaluations, such as head ultrasounds and eye exams.
iv. Dr. Murray also stated the need to determine if general pediatricians or pediatric infectious disease specialist handle the initial diagnostic workup, noting that the education subgroup will need to detail what education is provided to general pediatricians and expectations for general pediatricians and referrals to other physicians.
v. Dr. Howard also detailed several considerations for providers and the state to keep in mind with cCMV implementation. Dr. Howard concluded the presentation by summarizing the subgroup's recommendations.

b. Working group discussion
   i. Regarding collecting urine samples within 21 days, Ms. Ellis noted the difficulty that providers and parents face in obtaining urine from newborns and numerous logistics barriers. Ms. Ellis stated that the Connecticut Newborn Screening Network recommends that the urine be obtained within one week or the next two days for critical cases, but this often does not happen as planned. Ms. Ellis noted the likely need to narrow the window of urine collection since there are other steps in the algorithm with timeframes. Dr. Razeq stated that from the time a baby has positive cCMV screen, there could be an educational piece on how to collect urine from a newborn.
   ii. Dr. Schoem asked about the best time to make recommendations on the frequency of audiology testing. Dr. Terranova noted that audiological surveillance will be included in the education materials for follow-up to serve as a guide for providers and parents. Dr. Terranova emphasized that DPH will not provide prescriptive guidelines, such as antiviral dosage and treatment frequency, but will leave it to institutions to create their protocols.
   iii. Dr. Schoem stated that the education subgroup will need to consider two groups of newborns – those with hearing loss identified shortly after birth and those with no identified hearing loss. Dr. Schoem noted that the latter will likely need monitoring for the first 5-6 years of life, similar to current algorithms for other issues. Dr. Schoem proposed to share those algorithms. Dr. Terranova noted that need for infectious disease groups in institutions to incorporate their audiological surveillance pieces as they develop their algorithm. Dr. Schoem noted the need for a unified audiological approach across institutions.
   iv. Dr. Razeq asked about the incidence rate of asymptomatic cCMV and at what point physicians determine that the cCMV result is false positive. Dr. Howard noted that cCMV literature indicates that 90% of newborns are asymptomatic and 10% are symptomatic. Dr. Howard stated that a positive

dried blood spot and a positive urine with no signs is asymptomatic. Dr. Howard also cited several studies indicating risk of hearing loss for some asymptomatic newborns as they develop, noting that asymptomatic findings are not clinical insignificant. Dr. Howard also noted that the shared decision making included in the proposed algorithm for asymptomatic newborns enables parents to discuss the follow-up with an infectious disease specialist.

v. Dr. Murray noted that an anticipated challenge with the universal screening is that many asymptomatic newborns will be identified but with no actions/treatment indicated. Dr. Murray expressed the need to educate parents that treatment may not be necessary.
vi. Dr. Murray stated the importance of rapid data collection within the first three months of cCMV implementation to understand the number of confirmatory urine tests, timing of urine testing, how quickly the diagnostic workup is conducted, if we are missing newborns beyond the 30-day period, who would have qualified for treatment, due to delays.
vii. Regarding capacity concerns, Dr. Terranova asked if the working group will need to be clear on the algorithm that ID referral not be delayed as physicians await results from the initial diagnostic workup. Dr. Murray cited that the Minnesota algorithm uses 'schedule' instead of 'perform.' Dr. Murray noted that the asymptomatic subgroup explored frequency of only chorioretinitis manifestations in active cCMV, stating that there is no urgency for an eye exam if chorioretinitis never happens.
viii. Dr. Terranova noted the need to balance best practices with meeting the needs of cCMV implementation.
ix. Dr. Terranova stated the need to call out the physical exam in the proposed algorithm.
x. Dr. Murray proposed that the algorithm include the timeframe for initial diagnostic workup – within 30 days. Dr. Terranova proposed revising the draft algorithm to include completion of the initial diagnostic workup with 30 days of age with a callout that the pediatric ophthalmology examination should not delay referral to a pediatric infectious disease specialist.
xi. Ms. Ellis asked how long it takes to receive urine test results. Mr. Lamb noted that some larger facilities are able to get the result in the same day, but the max number of days is three.
xii. Mr. Lamb asked about including referral to birth to three in the algorithm. Dr. Terranova stated that it can be specifically called out as part of the developmental surveillance for the symptomatic and symptomatic newborns.
xiii. Dr. Murray asked if the state lab can provide more details about urine collection, volume needed, and storage. Dr. Terranova noted that the state lab will not be handling the urine testing; they would be sent to commercial labs as is current practice, but the state lab will conduct the dried blood spot testing.
xiv. Dr. Terranova noted that DPH will revise the proposed algorithm with the working group's recommendations.

V. Announcements
    a. February meeting (28th at 11 AM) – Planning for Implementation Subgroup presentation
        i. Dr. Terranova noted the working group will review the revised proposed algorithm in the February meeting.
        ii. Dr. Terranova stated that the Planning for Implementation Subgroup will discuss positive cCMV communication, follow-up plans, and educational resources
    b. Upcoming March meeting poll – The Lab Methodology Subgroup will present its recommendations.

VI. Adjournment
    a. Dr. Terranova adjourned the meeting at 12:44 PM.