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REPORT TO THE LEGISLATURE

TO: Joint Standing Committee on Health and Human Services
FROM: Maine Center for Disease Control and Prevention, Maine DHHS
DATE: August 2023
RE: Cytomegalovirus Screening Program Report pursuant to PL 2021, Ch. 698

Introduction and Background

The 130th Maine State Legislature enacted Public Law 2021, Chapter 698¹, requiring the Department of Health and Human Services (DHHS or Department) to establish a cytomegalovirus screening program for newborn infants. The Department is to submit a report on the progress made toward implementing the requirements of 22 MRS § 1534, and, in partnership with stakeholders, will report an assessment of the program by February 2026. The Maine Center for Disease Control and Prevention (Maine CDC) received funding to support this work, including funds for education material, a part-time position and system updates. The Maine CDC has posted² for applicants the half-time position tasked with developing Maine's cytomegalovirus screening program and ensuring the statutory obligations are met.

Cytomegalovirus (pronounced sy-toe-MEG-a-low-vy-rus), or CMV, is a common virus that affects people of all ages. Over half of the adults in the United States have been infected with CMV by the age of 40³; and while most infected people show no signs or symptoms, the virus can cause significant health problems for others, especially those with weakened immune systems and unborn babies. CMV is transmitted through body fluids, such as saliva, urine, blood, tears, semen, and breast milk. When a baby is born with a CMV infection, it is called congenital CMV. Approximately one of every 200 babies is born with congenital CMV infection. About one in five babies with congenital CMV infection will experience long-term health problems. Some effects of CMV include brain, liver and growth problems and more commonly, hearing loss.

Summary of Activity and Planning

22 MRS §1534 requires the Department to collect and report CMV screening data, including, but not limited to, the number of infants tested and results; provide public education about CMV transmission, effects and prevention, and available resources; and adopt rules to implement statutory requirements. The Department must allow for families to refuse screening if the screening conflicts with religious tenants and practices. The following information reflects the progress toward compliance with requirements included in PL21, Ch. 698.

The Department shall establish a cytomegalovirus screening program for newborn infants.

The DHHS - Maine CDC, Maternal and Child Health Program (MCH) will establish and publicize the CMV screening program to birthing hospitals and providers. The half-time position allocated in the recent law is essential to establishing the CMV program for Maine. The Maine CDC is taking the necessary steps to establish this position, working with Human Resources through the early phases of

¹<http://www.mainelegislature.org/legis/bills/getPDF.asp?paper=SP0603&item=3&snum=130>

²<https://mainebhr.hire.trakstar.com/jobs/fk0xyf2/>

³<https://www.cdc.gov/cm/overview.html#:~:text=Over%20half%20of%20adults%20have,that%20they%20have%20been%20infected>

the hiring process to complete required forms and obtain approvals to advertise for the position and hire a qualified half-time Public Health Educator position to undertake program development.

The Department may not require that a newborn infant be tested for the presence of cytomegalovirus if the parents of that infant object on the grounds that a test conflicts with their religious tenets and practices.

The Department will create a process for families to request and be granted a religious exemption once the hiring of the approved half-time position is completed. In the interim, through its Newborn Bloodspot Screening Program, the Maine CDC has experience with parental refusal forms and provides guidance for providers when parents refuse screening and referral services.

The Department shall report aggregate data provided by healthcare providers, including the number of infants born, the number tested for cytomegalovirus, the results of the screening and testing, and the type of screening sample used.

Once onboarded as a new hire, the CMV program coordinator will work to establish reporting requirements for healthcare providers specific to the virus. The CMV program will rely on input from medical professionals on best practices in congenital CMV screening to inform data collection. The Maine CDC anticipates that its existing MCH screening programs and reporting mechanisms can serve as models and/or be expanded to accommodate CMV data reporting and analysis.

The Department may solicit and accept the assistance of relevant medical associations or community resources to develop, promote and distribute the required public educational resources to pregnant women and women who may become pregnant that include information regarding the incidence of cytomegalovirus, the transmission of cytomegalovirus during and before pregnancy, birth defects caused by congenital cytomegalovirus, methods of diagnosing congenital cytomegalovirus, available preventive measures and resources for the family of an infant born with congenital cytomegalovirus. Once hired, the CMV program coordinator will collaborate with community providers and partners to develop and disseminate current material to pregnant people and people who may become pregnant through primary care and obstetrician practices.

The Department created a public CMV webpage⁴ that provides information about the virus, including information about identifying the virus and early intervention services. Public education campaign materials can be ordered, free of charge, through the Department's online ordering website⁵. Birthing hospitals and those performing home birth services have been accessing the websites and ordering the materials.

The Department shall convene a group of medical professionals to advise on best practices in congenital cytomegalovirus screening to inform required rulemaking.

The Maine CDC will convene a group of healthcare professionals to inform CMV rule development, pursuant to 22 MRS § 1534(2). Given the complexity of rulemaking and the time investment needed to engage with stakeholders in the process, this work will begin once the program coordinator is hired.

⁴ Maine CDC - Maternal and Child Health, Children With Special Health Needs website: <https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/hearing-screening/cytomegalovirus.shtml>

⁵ <https://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/bloodspot-screening/order-form.html>