



## Congenital Cytomegalovirus (cCMV) Newborn Screening Frequently Asked Questions

As of Monday, October 2, 2023, all samples received by the New York State (NYS) Department of Health Newborn Screening (NBS) Program are screened for congenital Cytomegalovirus (cCMV). The NYS NBS Program was recently awarded a contract from the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) to provisionally add cCMV to its screening panel for a period of one year. The free testing will be conducted during a baby's routine newborn screening.

Babies who screen positive for cCMV will be referred to Infectious Disease Specialists across the state for follow-up and evaluation. Parents may opt-out of having the screening results recorded in their baby's newborn screening report.

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Below are answers to the most frequently asked questions the NBS Program has received about this new cCMV screen:

### **When will my hospital receive the cCMV parent brochures?**

The educational brochures began shipping out from the Department of Health's Distribution Center on September 21, 2023. Each birth hospital in the state will automatically receive a shipment of brochures. In addition to English, the parent brochures were translated into 17 languages spoken in NYS. A subset of Spanish brochures was included in the shipments to the hospitals. Brochures in any of the 17 languages may be ordered from the NBS Program website at the following link:

<https://www.wadsworth.org/programs/newborn/screening/providers/request-materials>

### **Does CMV testing still have to be completed for babies who fail the hearing screen at birth?**

New York State Public Health Law 2500-a states that any newborn who fails their hearing screen should have a urine PCR to rule out cCMV. The dried blood spot newborn screen will not suffice for infants who fail their hearing screen because the newborn screen is a screen and not diagnostic. Additionally, blood is not the best sample type to detect CMV infection – as a result the newborn screen may miss some infants who do in fact have cCMV. If you identify any babies in this scenario (i.e., false negative on their newborn screen but known congenital infection) please notify the NBS Program by calling 518-473-7552 or emailing [cmvnbs@health.ny.gov](mailto:cmvnbs@health.ny.gov).

### **Is the opt-out form being included in the pink slip that is given to the caregiver at discharge?**

The opt-out form is a separate brochure to be given to parents/guardians at the time their infant's newborn screen sample is collected.

**How do I order brochures and other materials?**

Hospitals were sent brochures and posters at the beginning of the pilot study. Midwives, primary care offices and those in need of more materials can order them from our website at the following link: <https://www.wadsworth.org/programs/newborn/screening/providers/request-materials>

**What happens if a baby tests positive for CMV on the newborn screen?**

Babies that test positive will be referred to a specialist for confirmatory testing and the baby's primary care provider (PCP) will be notified as well. The cCMV result will be included on the newborn screen report. The location of the specialist will be determined by geographic proximity to the hospital of birth. Specialist contact information will be provided to the PCP at the time of the abnormal result notification.

**What is the detection rate for this newborn screen?**

The screen is expected to detect 75% of infants with CMV infection.

**What if I have questions about CMV?**

You can call us at (518) 473-7552 or email [cmvnbs@health.ny.gov](mailto:cmvnbs@health.ny.gov).