



Newborn Screening for Cytomegalovirus (CMV)

A new test for all babies

*What you need to know in the first week after birth,
including how to opt out of results*

www.wadsworth.org/newborn



Department
of Health

New newborn screening for Congenital Cytomegalovirus (cCMV)

All newborn screen samples received by the New York State Newborn Screening (NBS) Program will be screened for congenital cytomegalovirus (cCMV) for 1 year beginning in Summer 2023. We predict about one out of every 200 newborns may test positive for cCMV. Some babies who are born with cCMV may develop hearing loss or other health problems.

About 1,100 babies born each year in New York State, or one in every 200 births, is likely to have congenital CMV.

All babies will be tested for cCMV, but you can choose to not receive cCMV results, and have your child's result removed from their newborn screen record. If you do not want to receive these results and prefer to have your child's cCMV test results removed from the newborn screening report, follow the directions on page 6 of this brochure to opt out. Opting out means neither you nor your baby's health care provider will be notified of your baby's cCMV test result, even if the result is positive. You must act quickly if you would like to opt out. Your baby's newborn screen report will be complete 5-7 days after their birth. If the NBS Program does not hear from you before then, your child's cCMV result will be included in their report. You do not need to do anything if you would like your baby's cCMV test results.

What is newborn screening?

Shortly after birth every baby born in the United States is tested for certain health conditions. These tests are called newborn screening (NBS). Each state has a Newborn Screening Program that provides this testing. The New York State (NYS) NBS Program is a free service provided to all babies born in the state. This screen is required by NYS Public Health Law sections 2500-a and 2500-f. The goal of newborn screening is to diagnose and treat babies with these conditions before they become sick.

The NYS NBS Program tests babies for more than 50 health conditions. Many are rare, and they are usually serious. Some can cause early death. Others may slow down a baby's growth. Some may cause learning disabilities. Other signs and symptoms are also possible. Treatments exist for all the conditions tested in NYS. Early treatment is very important! Diagnosing and treating babies can help them live a healthy life. Our website lists the conditions the NYS NBS Program screens for.

For more information visit: www.wadsworth.org/newborn.

Why is the NYS NBS Program doing this extra test for cCMV?

Testing all newborns for cCMV will help answer 3 questions:

1. Can cCMV be detected by newborn screening?
2. How common is cCMV in newborns?
3. How can the test help babies who have cCMV?

Why is it helpful to screen for cCMV?

If a person catches the virus for the first time while carrying a baby, the baby has at least a 4 out of 10 chance of also getting it. A person who caught the virus before pregnancy can still pass it to the baby. Pregnant people are not routinely tested for CMV, so they may not know that they caught the virus during pregnancy. **CMV is often harmless in adults, but babies born with cCMV are at risk for symptoms and long-term health problems.**

CMV is a very common virus. In the United States, nearly 1 in 3 children are infected with CMV by the age of 5 years. By the age of 40, over half of adults in the United States have been infected with CMV. Most adults do not know they have the virus, because most people show no symptoms. Some people with CMV experience cold-like symptoms. Symptoms can include sore throat, fever, tiredness, and swollen glands. **Importantly, pregnant people who don't know they have the virus may pass the virus to their unborn babies.**

Because most babies with cCMV do not show any signs or symptoms at birth, it is important for health care provider to follow the baby's hearing and developmental milestones. Finding hearing loss early in life is important and can prevent developmental delays.

How is the cCMV screen done?

All babies born in NYS have a small blood sample taken for newborn screening. This blood is taken from a heel prick. The blood samples are sent to the NYS NBS Program. This is a routine test done for thousands of babies in the United States every day. **Extra blood is not needed for the cCMV screen.** The cCMV screen will be done on the same blood sample. The cCMV screen looks for signs of the virus in the blood. **There is no cost for this test.**



What are the possible cCMV screen results?

Negative cCMV screen: A negative screen result is a normal result. A negative result means that your baby most likely does not have a cCMV infection. Most babies will have a negative result for cCMV. Because this is a screening test; it is possible that some babies with cCMV may be missed. If your baby has any symptoms of cCMV or hearing loss, their health care provider may order a diagnostic urine test. This urine test will be used to look for the virus.

Positive cCMV screen: A positive screen result is an abnormal result. A positive result means that your baby most likely has a cCMV infection. A urine diagnostic test will be needed to confirm if your baby has cCMV. See “Positive screen and next steps” on page 5 for more information.

Babies born with cCMV infection

We expect 1 out of every 200 babies will screen positive for cCMV.

For babies that screen positive, the possible outcomes are:

- Baby is healthy at birth and shows no signs or symptoms of cCMV. Baby never develops any health problems from cCMV.
- Baby appears healthy at birth but develops hearing loss and developmental delays from cCMV later.
- Baby shows signs and symptoms of hearing loss at birth from cCMV. ***Babies and children with hearing loss are at risk for speech and developmental delays.**
- Baby is sick at birth and shows additional signs and symptoms of cCMV. **About 1 in 10 babies born with cCMV will be sick at birth.** The symptoms seen in these babies may include rash, yellowing of the skin or whites of the eyes (jaundice), small head size (microcephaly), low birth weight, enlarged liver or spleen, seizures, and eye damage.

Early detection of hearing loss

Hearing loss is the most common result of cCMV infection. Hearing loss can affect a baby's language, speech, and social skills.

NYS Public Health Law section 2500-g requires that all newborns get a hearing screening shortly after birth. If your baby fails their hearing screen, they will be tested for cCMV using a different diagnostic test. This is required by NYS Public Health Law section 2500-a.

If you have any questions or concerns about your baby's hearing test, speak to their health care provider. In NYS, newborn hearing screening results are reported to the Early Hearing Detection and Intervention (EHDI) Program.

For more information on the EHDI Program visit their website:

https://www.health.ny.gov/community/infants_children/early_intervention/newborn_hearing_screening/.

Note: This hearing screen and the cCMV newborn screen are separate. Either test can miss babies with hearing loss.

Positive screen and next steps

This cCMV newborn screen is not a diagnostic test. It cannot tell if your baby definitely has cCMV. You will be called if your baby's cCMV screen is positive. You may be called by your baby's health care provider or by an Infectious Disease Specialist. They will discuss your baby's result with you. They will schedule an appointment for your baby. At that visit, a urine sample will be collected from your baby. A CMV test will be done on this urine sample. This diagnostic test will show whether your baby has cCMV or not. This urine test needs to be done as soon as possible after your baby's birth.

False positive results on the newborn screen are rare but possible. This is why a urine diagnostic test is needed to confirm if your baby has cCMV.

If your baby is diagnosed with cCMV, it is very important to work with your baby's health care provider. Next steps for your baby's care will be planned with you. Your baby's health care provider will help you decide if your baby would benefit from treatment. Some babies with cCMV can be treated with medicine.

Information for families of babies with cCMV

Support groups can help connect families of kids who have cCMV. It can help to talk to people who have experience living with cCMV. These groups help create a community. These organizations offer resources for families, people with cCMV, health care providers, and advocates:

The National CMV Foundation has a website featuring stories of kids with cCMV, as shared by their parents. They also offer several helpful tools and resources for parents who have a child diagnosed with cCMV.

See: www.nationalcmv.org

The National Congenital CMV Disease Registry provides a way to share information with other families to offer help and support to each other:

Visit: <https://www.bcm.edu/departments/pediatrics/divisions-and-centers/congenital-cmv-disease-research-clinic-registry>

I do not want my baby's screen result for cCMV. How do I opt out?

All newborn screen samples received by the New York State Newborn Screening Program will be screened for cCMV for 1 year beginning in Summer 2023. Parents may opt out of having this result recorded on the newborn screening report. **If you do not want the result in your child's record, you need to opt out before your baby's report is complete. Reports are typically ready within 5-7 days of the baby's birth. Please act quickly if you would like to opt out.** You cannot opt out after your child's report is generated. If you wish to opt out, notify the NYS NBS Program using **ONE** of the following options:

- 1. Scan the QR code** on the front of this brochure. Follow the instructions on our website.
- 2. Remove and fill out the Opt-Out Form (fold out) in this brochure. Give it to the nurse at the birth hospital so it can be attached to your baby's newborn screen sample.** This option must be done within 2 days of birth.
- 3. Email** a picture of the completed opt-out form (fold out) to: cmvnbs@health.ny.gov.
- 4. Call** the NYS NBS Program: **518-473-7552 (option 5)** *Language interpretation is available upon request.
- 5. Mail** the opt-out form to:
Newborn Screening Program
NYS Department of Health
120 New Scotland Avenue
Albany, NY 12208

Important: If you choose to opt out, your baby's result will not be reported at all. Opting out means that you and your baby's health care provider will not be notified even if your baby's result is positive.

(Note: You must have the Lab I.D. (see diagram on fold out), baby's name, baby's date of birth, birth mother's name and birth mother's date of birth)

Please note that by choosing to opt out, you are only opting out of the recording of the cCMV screen results. Your baby will still be tested for the full newborn screen panel. Parents may only opt out of the full newborn screen for religious reasons. Parents opting out of the full newborn screen must complete a separate form.

Contact us for more information using one of these methods:

Phone: 518-473-7552 (option 5)

CMV email: cmvnbs@health.ny.gov

Website: www.wadsworth.org/newborn

References and resources

New York State Newborn Screening Program

<https://www.wadsworth.org/programs/newborn/screening/additional-testing>

American Academy of Pediatrics

<https://www.aap.org/en/news-room/aap-voices/newborn-screening-for-congenital-cytomegalovirus-one-pediatricians-journey/>

Baby's First Test

<https://www.babysfirsttest.org/newborn-screening/conditions/congenital-cytomegalovirus>

Centers for Disease Control and Prevention (CDC)

<https://www.cdc.gov/cmvi/index.html>

U.S. National Library of Medicine, MedlinePlus

<https://medlineplus.gov/cytomegalovirusinfections.html>

Mayo Clinic

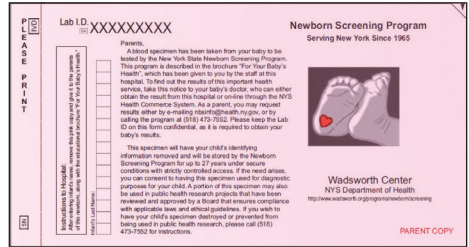
<https://www.mayoclinic.org/diseases-conditions/cmvi/symptoms-causes/syc-20355358>

For more information visit:
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Opt-Out Form

(Optional, tear-off)

Please fill out parts A and B below ONLY if you do NOT want your baby's cCMV results recorded. After you complete the form, carefully remove this section from the brochure. Hand this section to your nurse or birthing staff. Ensure the nurse attaches this form to your baby's newborn screen. You may also send this form to the NBS Program (see address on page 6).



Complete Part A and Part B to opt out:

A. Enter information below:

Newborn screen Lab ID (From pink slip):

Infant's first name:

Infant's last name:

Infant's date of birth (MM/DD/YYYY):

Birth mother's first name:

Birth mother's last name:

Birth mother's date of birth (MM/DD/YYYY):

Hospital of birth:

B. Initial, sign and date to confirm you opt out:

I (initial here) _____ am choosing to opt out of receiving the cCMV test result for my infant, even if the result is positive.

Parent name (print):

Parent signature:

Date signed (MM/DD/YYYY):

Turn over →

Opt-Out Survey

(Optional, tear-off)

We respect your choice. We are trying to learn more about why people may want to opt out. What were your reasons for choosing to opt out? Please choose as many answers as you'd like.

- I don't want my baby's results for this test
- I don't have enough information to make a decision
- I'm too tired/busy/overwhelmed to learn about cCMV
- I'm worried about my baby's privacy
- I don't want to know anything that might worry me
- I do not think my baby needs any additional testing
- I'm worried about the possibility of uncertain results
- I'm concerned that there may not be effective treatment for cCMV
- I don't want my baby tested for a virus that might not affect him/her for years
- I'm worried about my baby's future if he/she has cCMV
- I don't trust science/government
- Other, please specify: _____

- Prefer not to answer