



# Testing for congenital Cytomegalovirus (cCMV) following referral from the Newborn Screening Service: your questions answered

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## Information for parents from the Newborn Hearing Screening Service

This leaflet is for the parents / guardians of babies who have been referred from the Newborn Hearing Screening Service to the Audiology Department for a more in-depth hearing test.

This leaflet explains:

- the link between a condition called congenital Cytomegalovirus (cCMV) and progressive permanent hearing loss, and
- how your baby is tested for cCMV by taking a saliva test sample.

Information about your audiology test has been sent to you electronically and / or via the Your baby's visit to the audiology clinic (/your-baby-s-visit-to-the-audiology-clinic) leaflet.

### What is cCMV?

Cytomegalovirus (CMV) is a common virus, that is usually harmless. However, if you develop this infection while pregnant, it can cause problems for your baby.

### Is there a problem with my baby's hearing?

Your baby did not have a clear response on their newborn hearing screen. As a result they have been referred for audiology testing.

- Most babies tested at the Audiology Clinic are found to have satisfactory hearing.
- Some will have a temporary hearing loss. This will need monitoring, but will most likely resolve (get better) by itself.

- About one in 15 babies tested at the Audiology Clinic will have a permanent hearing loss in one or both ears.

There are many causes for hearing loss in babies. However, up to one in four with permanent hearing loss in the UK are thought to be caused by cCMV.

Detecting cCMV early gives you treatment options. Therefore, all babies referred for a further hearing test are offered a painless saliva swab to test for the infection.

### What does the saliva test involve?

A small swab (like a cotton bud) is placed gently in your baby's mouth, against their cheek to collect saliva. It takes a few seconds and does not hurt. The sample will then be sent to a specialist laboratory to test for the virus.

### How is cCMV treated?

Research shows that antiviral medication can help some babies with cCMV. In some cases, the medicine can stop hearing loss getting worse. Currently, studies show that the medication needs to be given early (by four weeks of age).

### What happens next?

- **If your baby does not have cCMV**, the East Kent Children's Hearing Service will tell you by letter.
- **If your baby does have cCMV**, the hospital will contact you to arrange an appointment. This will be with a paediatrician, who will examine your baby and discuss with you further management and treatment options.
- Your baby has been referred for an in-depth hearing test in the Audiology Clinic. This test should take place regardless of the outcome of the saliva test.

### Why is testing my baby for cCMV important?

Early diagnosis means that treatment options may be available.

### Further information

- National Deaf Children's Society: Cytomegalovirus (CMV) (<https://www.ndcs.org.uk/information-and-support/childhood-deafness/causes-of-deafness/cytomegalovirus-cmv/>)
- NHS: Cytomegalovirus (CMV) (<https://www.nhs.uk/conditions/cytomegalovirus-cmv/>)
- Your baby's visit to the Audiology Clinic ([/your-baby-s-visit-to-the-audiology-clinic](#))

### Contact details

- **East Kent Children's Hearing Service**

Office hours 8am to 6pm

Telephone: 01227 866487

Email ([ekh-tr.EastKentChildrensHearingService@nhs.net](mailto:ekh-tr.EastKentChildrensHearingService@nhs.net))

**This leaflet has been produced with and for patients.**

**Please let us know:**

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

**You can let us know this by:**

- Visiting the Trust web site (<https://www.ekhft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

**Any complaints, comments, concerns or compliments**, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email ([ekh-tr.pals@nhs.net](mailto:ekh-tr.pals@nhs.net)).

**Patients should not bring large sums of money or valuables into hospital.** Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

**Further patient information leaflets** are available via the East Kent Hospitals' web site (<https://www.ekhft.nhs.uk/patient-information>).

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