

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

This leaflet is for the parents/guardians of babies who are 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. It also outlines how your baby is tested for cCMV by taking a saliva test sample. Information relating to the audiology test has been sent to you electronically and/or via the **Your baby's visit to the audiology clinic** leaflet.

What is cCMV?

Cytomegalovirus (CMV) is a common virus that is usually harmless. However, if a mother develops this infection during her pregnancy, it can sometimes cause problems for her baby.

Is there a problem with my baby's hearing?

Your baby did not have a clear response on their newborn hearing screen and has been referred for audiology testing. Most babies tested at an audiology clinic are found to have satisfactory hearing, some will have a temporary hearing loss (this needs monitoring but will most likely resolve itself). About one in 15 babies tested at the audiology clinic will have a permanent hearing loss in one or both ears.

Although there are many causes for hearing loss in babies, up to one in four with permanent hearing loss in the UK is thought to be caused by cCMV. Detecting cCMV early gives you options of treatments; therefore, all babies that need to be referred for a further hearing test will be offered a painless saliva swab to test for the infection. For possible treatment, diagnosing cCMV early is optimal. Remember you can withdraw your consent for treatment at any time.



What does the saliva test involve?

A small swab (similar to a cotton bud) will be 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.

Can you treat cCMV?

Research studies show 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, you will be told this in a letter from the East Kent Children's Hearing Service.

If your baby does have cCMV, the hospital will contact you to arrange an appointment with a paediatrician who will be able to examine your baby and discuss with you further management and treatment options.

Your baby has been referred for an in-depth hearing test in Audiology, 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

- **Your baby's visit to the audiology clinic**

Web: www.gov.uk/government/publications/newborn-hearing-screening-first-visit-to-the-audiology-clinic

- **National Deaf Children's Society**

Web: www.ndcs.org.uk/information-and-support/childhood-deafness/causes-of-deafness/cytomegalovirus-cmv/

- **NHS**

Web: www.nhs.uk/conditions/cytomegalovirus-cmv/

Contact information

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

(Office hours 8am to 6pm)

Telephone: 01227 86 64 87

E-mail: ekh-tr.EastKentChildrensHearingService@nhs.net

This leaflet has been produced with and for patients

If you would like this information in **another language, audio, Braille, Easy Read, or large print** please ask a member of staff. You can ask someone to contact us on your behalf.

Any complaints, comments, concerns, or compliments please speak to your doctor or nurse, or contact the Patient Advice and Liaison Service (PALS) on 01227 78 31 45, or email ekh-tr.pals@nhs.net

Patients should not bring in 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 had been handed in to Trust staff for safe-keeping.

Further patient leaflets are available via the East Kent Hospitals web site www.ekhuft.nhs.uk/patientinformation