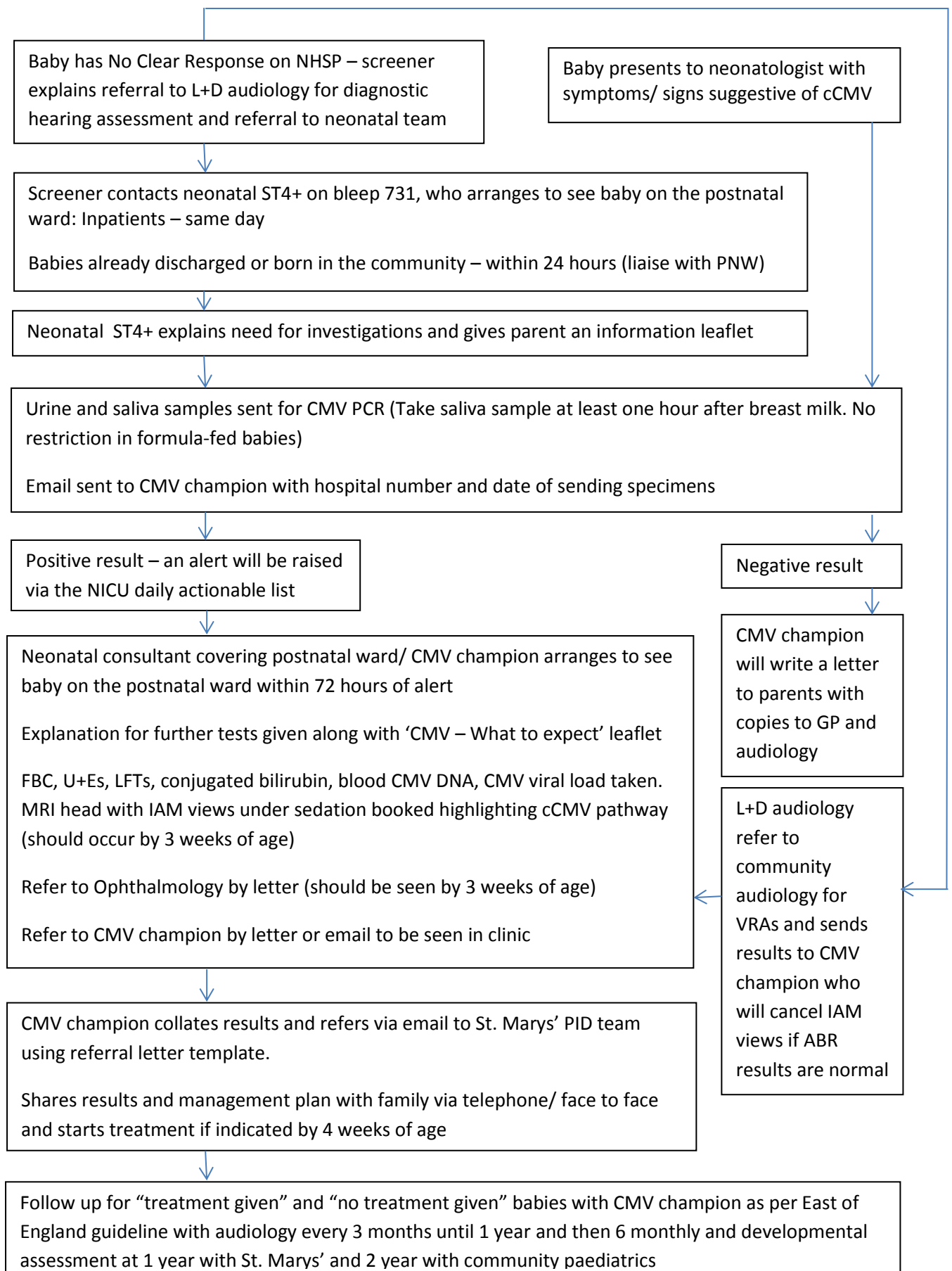


Luton and Dunstable Local Implementation of cCMV Clinical guideline: This pathway is to be used in conjunction with the East of England network guideline entitled “**Clinical Guideline: Diagnosis and Management of Congenital Cytomegalovirus**” version 13.



Newborn Screening Laboratory, Chemical Pathology  
 Camelia Botnar Laboratories  
 85 Lamb's Conduit Street  
 London WC1N 3NN

**Direct line:** 020 7813 8383  
**Email:** gos-tr.Enquiriesgosnbs@nhs.net

## Request for the release of a newborn screening blood spot card

This form should be clearly and fully completed in **CAPITAL LETTERS** by the responsible Health Care Professional when a blood spot sample from a named individual is removed from the custody of the Newborn Screening Laboratory (GOSH) for analyses additional to those required by the Newborn Screening Programme for which GOSH has been contracted.

It is **ESSENTIAL** that the parental consent is received to release the sample. The newborn screening laboratory will release the blood spot on receipt of the completed form and once the director of the laboratory or a nominated deputy has countersigned this. Please note that the cost of the retrieval of the sample is £60.

### To be completed by responsible health professional

Child's surname/Family name			
Child's first name			
Date of birth			
NHS number			
Hospital number			
Mother's details			
Place of birth			
Sex (✓)	Male		Female

Reason for release of blood spot card

**Test for congenital CMV infection**

Where would you like us to send the sample for analysis?

**Dept of Virology, Royal Free Hospital, Rowland Hill Street, Hampstead, London NW3 2PF**

**To be completed by requestor**

Name	
Hospital/Institution	
Ward / Department	
Contact number	
Email	
Signature	
Date	

**Billing address**

--

**To be completed by parent or guardian**

**Before signing please read the above form carefully and ask any further questions if you do not understand the procedure or investigations which will be carried out**

*I agree to the above procedure and the release of the newborn blood spot sample for the investigations described above **only** and I confirm that I have 'parental responsibility' for this child.*

Name	
Relationship to child	
Signature of parent/guardian	
Date	

**Laboratory use only**

Laboratory number	
Released to	
Released date	
Release by (Print)	
Signature	

For further information about this service contact:

Dr Sakina Ali  
Consultant in Neonatal Medicine  
Luton and Dunstable Hospital NHS Foundation Trust  
Lewsey Road Luton  
LU4 0DZ

Tel: 01582 497109

## Hearing Screening and Congenital CMV

If you require this information in a different format such as in large print or on audio tape, or in a different language please contact the service on the details above.

If you have any compliments about this service or suggestions for improvements, contact our Patient Advice and Liaison Service on 0300 131 1000 (charges may apply depending on your network) or email: [ccs-tr.pals@nhs.net](mailto:ccs-tr.pals@nhs.net).

For free, confidential health advice and information 24 hours a day, 365 days a year please contact NHS 111.



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

Your baby did not have a clear response on their hearing screen and has been referred for a formal hearing test. The formal test may show there is nothing wrong with your baby's hearing, but it might show that they have a hearing loss.

Although there are many causes for hearing loss in babies, one possible cause is congenital CMV. It is best to diagnose congenital CMV early, so we will ask you to consent for your baby to be tested.

## What is Congenital CMV?

- Cytomegalovirus (CMV) is a common virus what can cause symptoms similar to a cold in adults. However, CMV can sometimes cause more significant symptoms if a baby is exposed to it before they are born. This is called Congenital CMV.
- Most babies who have Congenital CMV are well with no signs of the infection. However, it can cause hearing problems in babies who are otherwise well.

## Why is it important to test babies for Congenital CMV?

- Congenital CMV causes up to 25% permanent hearing loss in young children.
- Babies need to be diagnosed and assessed within the first few weeks of life.
- More information about Congenital CMV please visit [www.cmvaction.org.uk](http://www.cmvaction.org.uk)

## What does the CMV test involve?

- A small swab (similar to a cotton bud) will be placed gently in your baby's mouth against the cheek to collect saliva.
- A urine sample will also be collected.
- These will then be sent to a specialist laboratory to test for the virus. The neonatal team will arrange these for your baby.

## Can you treat Congenital CMV?

- Doctors have been treating older patients who have CMV with anti-viral medicines for many years.
- Research studies show that these medicines can also help some babies with congenital CMV. In some cases, the medicine can stop hearing loss getting worse or may even improve it.
- At the moment we believe the medicine needs to be given early (by 4 weeks of age).

## What happens next?

If your baby does NOT have Congenital CMV;

- If the test is negative, the neonatal team will send you a letter telling you your baby does NOT have Congenital CMV.
- **You will still need to bring your baby for a formal hearing test as they did not have a clear response on their hearing screen.**

## If your baby DOES have Congenital CMV;

The neonatal team will contact you by telephone to arrange appointments - a formal hearing test and a medical review to find out if your baby has any symptoms of Congenital CMV. These will be arranged as soon as possible so treatment can be started early if it is needed. The paediatrician will discuss the treatment options with you.

Your baby will have a formal hearing test as they did not have a clear response on their hearing screening

Your baby will be offered follow-up in clinic including regular hearing tests. Most babies with Congenital CMV have no health problems.