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.

Baby has No Clear Response on NHSP – screener explains referral to L+D audiology for diagnostic hearing assessment and referral to neonatal team

Baby presents to neonatologist with symptoms/ signs suggestive of cCMV

Screener contacts neonatal ST4+ on bleep 731, who arranges to see baby on the postnatal ward: Inpatients – same day

Babies already discharged or born in the community – within 24 hours (liaise with PNW)

Neonatal ST4+ explains need for investigations and gives parent an information leaflet

Urine and saliva samples sent for CMV PCR (Take saliva sample at least one hour after breast milk. No restriction in formula-fed babies)

Email sent to CMV champion with hospital number and date of sending specimens

Positive result – an alert will be raised via the NICU daily actionable list

Negative result

Neonatal consultant covering postnatal ward/ CMV champion arranges to see baby on the postnatal ward within 72 hours of alert

Explanation for further tests given along with 'CMV – What to expect' leaflet

FBC, U+Es, LFTs, conjugated bilirubin, blood CMV DNA, CMV viral load taken. MRI head with IAM views under sedation booked highlighting cCMV pathway (should occur by 3 weeks of age)

Refer to Ophthalmology by letter (should be seen by 3 weeks of age)

Refer to CMV champion by letter or email to be seen in clinic

CMV champion will write a letter to parents with copies to GP and audiology

L+D audiology
refer to
community
audiology for
VRAs and sends
results to CMV
champion who
will cancel IAM
views if ABR
results are normal

CMV champion collates results and refers via email to St. Marys' PID team using referral letter template.

Shares results and management plan with family via telephone/ face to face and starts treatment if indicated by 4 weeks of age

Follow up for "treatment given" and "no treatment given" babies with CMV champion as per East of England guideline with audiology every 3 months until 1 year and then 6 monthly and developmental assessment at 1 year with St. Marys' and 2 year with community paediatrics



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

	i			
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				

Child's surname/Family name



To be completed by requestor

Hospital/Institution	
Ward / Department	
Contact number	
Email	
Signature	
Date	
Billing address	
understand the p	ent or guardian above form carefully and ask any further questions if you do not brocedure or investigations which will be carried out re and the release of the newborn blood spot sample for the
investigations described above or	nly and I confirm that I have 'parental responsibility' for this child.
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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.

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

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Cambridgeshire Community Services NHS Trust: delivering excellence in children and adults' community health services across Luton

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

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.