FOI 2784

Date 16/01/2024

Dear Requester,

Thank you for your Freedom of Information request. Please note, this is a cross-site response for Bedford site and Luton site.

You asked:

1. Please provide copies of any Information containing or evidencing Practices used within your Trust whereby newborns who are referred to audiology following their newborn hearing screening test, or newborns/children who demonstrate abnormal hearing at a later stage, are tested for cCMV. Such Practices could include, but are not limited to, early cCMV detection pathways whereby newborns are tested at point of referral to audiology from the newborn hearing screening programme. Please include details about the intended timescales for testing, carrying out tests and returning test results, if this information is recorded.

Please see attached

1. If your Trust does employ Practices whereby newborns/children with abnormal hearing are tested for cCMV, please indicate at which stage samples are taken (you may select more than one):
* By the newborn hearing screener at the point of referral - Yes at Luton & Dunstable
* By the audiologist at the first appointment after babies have been referred from the newborn hearing screen
* By the audiologist at detection of SNHL in a baby referred from the newborn hearing screen
* By another healthcare professional (not an audiologist) following detection of SNHL in a baby referred from the newborn hearing screen - Yes at Bedford
* At detection of SNHL in older babies and children (i.e. after the newborn hearing screening and testing period)
* Unknown
* Other, please provide details:
1. If your Trust does employ Practices whereby newborns/children with abnormal hearing are tested for cCMV, please indicate what type of sample is taken (you may select more than one):
* Saliva swab - Both sites
* Urine - Both sites
* Blood test for the infant
* Blood test for the mother
* Infant blood spot (Guthrie) card testing
* Unknown
* Other, please provide details:
1. Please provide copies of any Information containing or evidencing Practices used within your Trust whereby children are tested for cCMV as part of investigations of symptoms (in either the mother or child) that are unrelated to hearing. These could include:

Maternal symptoms of CMV (flu-like symptoms)

Symptoms of congenital infection identified before or after birth, such as:

* Antenatal abnormalities e.g. on ultrasound scan - Yes at Bedford if suggestive of congenital CMV
* Characteristic rashes caused by cCMV (petechiae or blueberry muffin rash) - Bedford
* Intrauterine Growth Restriction - Yes at Bedford. Only at Luton & Dunstable if asymmetrical but at the discretion of the consultant
* Microcephaly - Bedford
* Jaundice - Yes if there are other features suggestive of CMV at Bedford. Not routinely at Luton & Dunstable unless clinical suspicion from history or other clinical features
* Hepatosplenomegaly - Bedford
* Neonatal visual signs/symptoms - Bedford
* Neonatal seizures - referred to NICU for Bedford

Symptoms of congenital infection in older children, such as:

N/A as these are under the remit of Community paediatrics

* Neurodevelopmental delays
* Special educational needs and disabilities (e.g. autism, ADHD)
* Cerebral palsy
* Seizures
* Visual or sensory impairment
1. Please provide copies of any Information containing or evidencing Practices used within your Trust following a diagnosis of cCMV in a child. This could include, but is not limited to:
• Information about any Practices involving the prescribing of antiviral treatments
• Details of the department(s) that the child would be referred to

We follow EOE CMV guidelines – please see attached

Questions 6-9 relate to the provision of data for a specific five-year period. If you do not hold data for this time period, please supply data for any period for which you have available data (preferably a recent five-year period) and specify the beginning and end dates. If the answer to any question is between 1 and 5 (and therefore the true figure cannot be shared in accordance with Section 40 of the Freedom of Information Act), please indicate this by giving the answer “<5”. Please also indicate if the relevant hospitals or services within your Trust have changed during this period.

Currently we do not have a database to share.

1. Between 1 January 2018 and 31 December 2022, how many children were diagnosed with cCMV within 28 days of birth, within your Trust? This should include children born outside of your Trust who were diagnosed by services within your Trust.
2. Of the children who were diagnosed with cCMV within 28 days of birth in this time period (Q6), how many:
3. previously had a newborn hearing screening test?
4. had been referred to audiology following their newborn hearing screening test?
5. were given antiviral treatment for cCMV following diagnosis?
6. Between 1 January 2018 and 31 December 2022, how many children were diagnosed with cCMV between 28 days and 18 years of age, within your Trust? This should include children born outside of your Trust who were diagnosed by services within your Trust.
7. Of the children who were diagnosed with cCMV between 28 days and 18 years of age in this time period (Q8), how many:
8. previously had a newborn hearing screening test?
9. had been referred to audiology following their newborn hearing screening test?
10. were given antiviral treatment for cCMV following diagnosis?

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 Please note that the Trust has a formal internal review and complaints process which is managed by the Information Governance Manager/Data Protection Officer. Should you have any concerns with our response, you can make a formal request for an internal review. Requests for internal review should be submitted within three months of the date of receipt of the response to your original letter, and should be addressed to: dataprotectionofficer@ldh.nhs.uk. This option is available to you for up to three calendar months from the date your response was issued.

If you are not satisfied with the Trust review under the Freedom of Information Act 2000 you may apply directly to the Information Commissioners Officer (ICO) for a review of your appeal decision. The ICO can be contacted at: ICO, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF www.ico.org.uk

 Yours sincerely,

 *FOI Officer*

 Bedfordshire Hospitals NHS Foundation Trust