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Request for Information Reference: 12.23.45

FOI Direct line: 01325 743700
Email: cdda-tr.cddftfoi@nhs.net

Email only

15th January 2023

Dear

Freedom of Information Act 2000 – Request for Information

Thank you for submitting a request for information which we received on 19th December 2023 in relation to County Durham and Darlington NHS Foundation Trust (the Trust). Your request has been processed under the provisions of the Freedom of Information Act 2000 and I am now able to provide you with a response.

Your request was in relation to Congenital Cytomegalovirus Screening and I am providing the following information in response to your specific questions:

The purpose of this FOI request is to ascertain your Trust's approach to screening for and treating congenital cytomegalovirus (cCMV).

Definitions of acronyms and terms used in the FOI request:

CMV: cytomegalovirus

cCMV: congenital cytomegalovirus

SNHL: sensorineural hearing loss

'Practices' refers to any standard operating procedures or clinical protocols, guidelines, practices or pathways.

'Information' refers to any recorded information required to be disclosed in response to requests under the Freedom of Information Act.

If different hospitals or services within your Trust have different Practices or data availability, please provide separate Information or data for each hospital or service (indicating clearly which hospital or service the Information relates to).

- 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.**

The Trust does not provide all of this service. The newborn hearing screening service is provided between CDDFT, North Tees & Hartlepool and South Tees Trusts. If you wish to contact North Tees & Hartlepool and South Tees Trusts in accordance with Section 16 of the Act (duty to provide advice and assistance) you can do so via the following address:

North Tees and Hartlepool NHS Foundation Trust:

FOI Officer

North Tees and Hartlepool NHS Foundation Trust

University Hospital of North Tees

Hardwick

Stockton on Tees

TS19 8PE

Email: nth-tr.foi@nhs.net

South Tees Hospitals NHS Foundation Trust:

Murray Building

The James Cook University Hospital

Marton Road

Middlesbrough, TS4 3BW

Email: stees.foi.admin@nhs.net

- 2. 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**
 - **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**
 - **At detection of SNHL in older babies and children (i.e. after the newborn hearing screening and testing period)**
 - **Unknown**

- **Other, please provide details:** - samples are taken at the point the Paediatrician sees the child following referral.
3. **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
- Urine - If the child is under 1 year
- Blood test for the infant - If the child is over 1 year
- Blood test for the mother
- Infant blood spot (Guthrie) card testing
- Unknown
- Other, please provide details:

4. **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, if indicated
- Characteristic rashes caused by cCMV (petechiae or blueberry muffin rash) - Yes
- Intrauterine Growth Restriction - Not as a routine
- Microcephaly
- Jaundice
- Hepatosplenomegaly - Yes
- Neonatal visual signs/symptoms
- Neonatal seizures - Yes

Symptoms of congenital infection in older children, such as:

- Neurodevelopmental delays
- Special educational needs and disabilities (e.g. autism, ADHD)
- Cerebral palsy
- Seizures
- Visual or sensory impairment

The Trust does not have a guideline.

5. **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

No information available regarding this.

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.

6. 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.
7. Of the children who were diagnosed with cCMV within 28 days of birth in this time period (Q6), how many:
 - a) Previously had a newborn hearing screening test
 - b) Had been referred to audiology following their newborn hearing screening test
 - c) Were given antiviral treatment for cCMV following diagnosis
8. 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.
9. Of the children who were diagnosed with cCMV between 28 days and 18 years of age in this time period (Q8), how many:
 - a) Previously had a newborn hearing screening test
 - b) Had been referred to audiology following their newborn hearing screening test
 - c) Were given antiviral treatment for cCMV following diagnosis

The numbers of these babies are very small so assessment and treatment is often arranged on a case by case basis.

The comments below relate to experience of babies across the 3 Trusts.

Whenever screeners are advised that a baby is being tested or treated for cCMV, the service make a note on the software system S4H. All screeners have access to Badgernet so can check notes on the system if they are given the information verbally.

The screeners then chase up the results of any cCMV test or confirmation. If cCMV is detected, the baby will not have a newborn hearing screen but will be fast tracked to Audiology for hearing assessment. If a hearing loss is confirmed, this will be fed back to the neonatal team to inform their treatment.

If cCMV is negative, then the baby will follow the normal screening pathway.

If the baby has a newborn hearing screen before the cCMV is suspected/confirmed then the baby will still be fast tracked to Audiology, irrespective of the hearing screening result.

Hearing screeners do not undertake routine cCMV swabbing of any babies who are referred to Audiology.

If babies are sufficiently unwell for the neonatal team to be confident they have cCMV, antiviral treatment is sometimes started before the cCMV result is known as there can be a delay receiving this back from external labs.

In line with the Information Commissioner's directive on the disclosure of information under the Freedom of Information Act 2000 your request will form part of our disclosure log on the Trust's website. However please be assured that we anonymise all responses prior to adding them to the disclosure log.

I hope that this response has provided you with the information you had requested. If you have any queries or wish to discuss the information supplied, please do not hesitate to contact me by telephone or in writing. If however, you are dissatisfied with the way in which your request has been handled and would like an internal review, you will need to contact me in writing at the above address or via cdda-tr.cddftfoi@nhs.

If you remain dissatisfied with our response following an internal review you have the right to appeal to The Information Commissioner at Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF. More information is available on their website; www.ico.gov.uk.

Yours sincerely

Corporate Records and Freedom of Information Facilitator