Maidstone and Tunbridge Wells NHS Trust

Ref: FOI/GS/ID 8752

Please reply to:
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30 January 2024

Freedom of Information Act 2000

I am writing in response to your request for information made under the Freedom of Information Act 2000 in relation to Congenital cytomegalovirus screening and treatment practices and data.

You asked: All questions are shown as received by the Trust.
The purpose of this FOI request is to ascertain your Trust's approach to screening for and treating congenital cytomegalovirus (cCMV).

The questions have been designed so that they can be answered within the limits (on time, cost, type of information etc.) set out in the Freedom of Information Act and the Information Commissioner's Guidelines. If it is not possible to provide the exact information requested, please supply the underlying information in narrative form or whichever format you have available.

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).

Q1. 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.

Q2. 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:

Q3. 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
❑ Blood test for the infant
❑ Blood test for the mother
❑ Infant blood spot (Guthrie) card testing ❑ Unknown ❑ Other, please provide details:

Q4. 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*
- *Characteristic rashes caused by cCMV (petechiae or blueberry muffin rash)*
- *Intrauterine Growth Restriction*
- *Microcephaly*
- *Jaundice*
- *Hepatosplenomegaly*
- *Neonatal visual signs/symptoms*
- *Neonatal seizures*

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*

Q5. 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*

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.

Q6. 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.

Q7. 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

Q8. 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.

Q9. 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

Trust response:

Please note: any patient who is referred for a fetal medicine opinion based on unusual scan findings (such as small babies, polyhydramnios, echogenic foci or calcifications, echogenic bowel as examples) will always have a comprehensive assessment to review whether the findings could be due to underlying congenital infection including CMV or chromosomal abnormality.

Maternity and Neonatal (NNU) – Q1-Q5 please see the attached documentation.

Redacted Neonatal, Maternity and Paedi

Redacted Neonatal and Maternity - Poly

Q6.
NNU - 2 cases
1. diagnosed on the NNU following admission from another hospital,
2. Known risk factors and diagnosed on the NNU
Q7.
NNU:
a. Not applicable on NNU x 2
b. Not applicable on NNU x 2 Both had referrals made in view of CMV
c.
1 was asymptomatic awaiting urine results on discharge from NNU and not treated
1 was asymptomatic and discussed with specialist centre and did receive treatment while on the NNU
Q8. Zero
Q9. Not applicable