The Dudley Group
NHS Foundation Trust

Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ

Ref: FOI-012024-000585

Date:

Address / Email:

Dear

Request Under Freedom of Information Act 2000

Thank you for requesting information under the Freedom of Information Act 2000.

Request

Please provide answers in relation to your Trust's approach to screening for and treating Congenital Cytomegalovirus (cCMV).

Response

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.	**The referral and screening process for cCMV is not done within Audiology.** ***Whereby newborns who are referred to audiology following their newborn hearing screening test*** **- they are not routinely screened for cCMV as far as I am aware – if a hearing loss is identified baby is referred to ENT for consultation who refer on to Paediatrics when necessary and they then request screening tests they require.** ***or newborns/children who demonstrate abnormal hearing at a later stage, are tested for cCMV*** **– as above – Audiology refer to ENT for consultation who refer on to Paediatrics when necessary and they then request screening tests they require.**

	On S4H where all newborn hearing screening and diagnostic tests are downloaded/added there is a section for Aetiology where clinical examinations/investigations can be recorded by Paediatrics, but it is not used by our Paeds team.
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:	**N/A** **We are unable to answer this as we do not hold the information you have requested in a reportable format.** **When information is not in a reportable format, the ICO guidance clearly states "FOIA only applies to information that a public authority already holds in recorded form at the time of a request. If you don't hold a particular piece of information that someone has asked for, you don't have to create it."** Audiology refers to ENT if referred to PAEDS a decision is made on the individual patient. However, we don't routinely investigate cCMV, we only screen if indicated following confirmed sensorineural hearing loss and request form (ENT).
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	
❑ Infant blood spot (Guthrie) card testing	
❑ Other, please provide details:	**Urine for CMV if we are concerned antenatally and immediately after birth. If hearing issue, then it will be tested on Guthrie card.**
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:** **Please find attached Network Guidelines.**	
• 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: **Same as above response.**	

• Information about any Practices involving the prescribing of antiviral treatments	
• Details of the department(s) that the child would be referred to	

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.	**< 5** **As per NHS Digital rules the Trust does not publish numbers lower than 5 as this could lead to the identification of the persons involved and cause distress to Families or Friends. The number of children diagnosed with cCMV between the years requested is less than 5, so Exemption Section 40(2) of the Freedom of Information Act is applied.**
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	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**
b. Had been referred to audiology following their newborn hearing screening test	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**
c. Were given antiviral treatment for cCMV following diagnosis	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**
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.	**0**
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	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**

b. Had been referred to audiology following their newborn hearing screening test	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**
c. Were given antiviral treatment for cCMV following diagnosis	**Unable to provide a response for this question as we do not record any procedures for hearing screening or antiviral treatments within our Coding.**

If you are dissatisfied with our response, you have the right to appeal in line with guidance from the Information Commissioner. In the first instance you may contact the Information Governance Manager of the Trust.

Information Governance Manager
Trust Headquarters
Russell's Hall Hospital
Dudley
West Midlands
DY1 2HQ
Email: dgft.dpo@nhs.net

Should you disagree with the contents of our response to your appeal, you have the right to appeal to the Information Commissioners Office at.

Information Commissioners Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF
Tel: 0303 123 1113
www.ico.org.uk

If you require further clarification, please do not hesitate to contact us.

Yours sincerely

Freedom of Information Team
The Dudley Group NHS Foundation Trust

CMV

In-utero transmission of CMV can occur during primary maternal infection, reactivation, or reinfection of seropositive mothers

MATERNAL TESTS

CMV serology (IgG and IgM) and viral loads

- Both IgG and IgM negative: unlikely to be CMV infection
- IgG negative at booking, then IgG positive later in pregnancy: new infection
- IgG positive, IgM negative: past maternal infection
- IgG positive, IgM positive: check CMV IgG avidity
  - if low avidity likely to be maternal CMV infection within last 3–4 months

Antenatal ultrasound

Features include:

- IUGR
- Intracranial ventriculomegaly/calcification, microcephaly, periventricular leukomalacia
- Hyperechoic ('bright') bowel
- Ascites, hydrops fetalis
- Pleural or pericardial effusions
- Oligo- or polyhydramnios
- Hepatomegaly
- Abdominal calcification
- Pseudomeconium ileus
- Thickened placenta

NEONATAL FEATURES

Indications for testing

- Evidence of maternal primary CMV infection in pregnancy
- Antenatal ultrasound suggestive of congenital CMV (cCMV)
- Petechiae/purpura
- Hepatosplenomegaly
- Prolonged or conjugated hyperbilirubinaemia with transaminitis
- Unexplained thrombocytopenia
- Microcephaly
- Intracranial calcification or ventriculomegaly
- Chorioretinitis
- Seizures with no other explanation
- Severe pneumonia
- Cataract
- Failed hearing screen

Investigation results

- CMV PCR urine or mouth swab (do not send blood PCR for congenital CMV)
  - soak mouth swab in saliva for 1 min; send in viral transport medium to regional laboratory
  - if negative and high-risk CMV also send urine

Other congenital infection screen depending on features (not exclusive):

- Toxoplasma (hydrocephalus, microcephaly, convulsions, generalised infection)
- Syphilis (rash, rhinitis, hepatosplenomegaly, jaundice, thrombocytopenia)
- Rubella (cataract, deafness, microcephaly)
- Zika (maternal/paternal travel, microcephaly)

CMV POSITIVE

Further investigations

- Full blood count, liver enzymes, bilirubin, renal function
- Blood CMV viral load
  - if unknown whether infection is congenital request initial bloodspot card to be tested for CMV PCR
- Ophthalmic assessment
- Audiology: brainstem-evoked response – urgent (to offer treatment by aged 4 weeks)

- Head ultrasound
- if ultrasound head abnormal or seizures, MRI head

TREATMENT

- Postnatal acquired CMV – no treatment

Mild cCMV

- Asymptomatic – no CNS involvement, including sensorineural hearing loss
- isolated IUGR
- hepatomegaly with normal liver enzymes
- isolated raised ALT/AST
- mild thrombocytopenia
- No treatment

Moderate cCMV

- Discuss with infectious diseases specialist if:
- >2 weeks mild features
- >2 mild features

Severe cCMV

- Significant organ involvement:
- significant liver enzyme abnormalities
- marked hepatomegaly
- Any CNS disease
- isolated sensorineural hearing loss
- retinitis
- microcephaly
- cranial ultrasound or MRI brain abnormalities
- Treat: valganciclovir 16 mg/kg oral 12-hourly for 6 months
- if **not** tolerating oral feeds, ganciclovir 6 mg/kg IV [prepared by pharmacy (cytotoxic)] over 1 hour, 12-hourly for 6 weeks
- Discuss side effects vs benefits with parents:
- **advantages**: potential reduced risk of deafness and developmental delay
- **disadvantages**: during treatment reversible blood dyscrasia; long-term unknown risk to fertility and malignancy
- Start treatment as soon as possible
- if diagnosis delayed can be started aged ≤1 month

FEEDING

- Do not discourage infected women from breastfeeding their own uninfected, term babies (CMV can be transmitted via breastfeeding, but benefits of feeding outweigh risks posed by breastfeeding as a source of transmission)
- Avoid breastfeeding of premature baby if mother is positive and baby asymptomatic

FOLLOW-UP

- Enter on CMV surveillance register (discuss with paediatric infectious disease specialist)
- Ganciclovir IV: FBC, LFT, U&E at least twice weekly
- Valganciclovir oral: FBC, LFT, U&E weekly for first 4 weeks, then monthly until completion
- Audiology: 3 monthly for first year,
- 6 monthly for 3 yr,
- annually until aged 6 yr for both asymptomatic and symptomatic congenitally infected babies
- Paediatric infectious diseases specialist: as soon as possible in first month, then annually until aged 2 yr
- Ophthalmology: at least annually until aged 5 yr if symptomatic/signs at birth
- Neurodevelopmental assessment: aged 1 yr
- if delayed development discuss MRI brain with radiology