Alder Hey Children's NHS
NHS Foundation Trust

Reference Number: FOIAH2324/503
From: Private Individual

Date: 12 December 2023

Subject: Srcreening for and treating congenital cytomeglovirus (cCMV)

Definitions of acronyms and terms used in the FOI request: CMV: cytomegalovirus, cCMV: congenital cytomegalovirus, SNHL: sensorineural hearing loss.

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.

A1 The whole process is a combined effort between Audiologists and Medical teams (Audiovestibular Medicine and Infectious Disease/ Immunology or ID team) working together.

The national NICE-accredited BAAP (British Association of Audiovestibular Physicians - www.baap.org.uk) guidelines for aetiological investigations for sensorineural deafness and auditory neuropathy spectrum disorder (ANSD) is followed.

The following numbers indicate the initial time-critical process (there will be further follow-up clinical appointments with parents - all documented on clinic letters).
1. CMV testing for newborns referred from Newborn Hearing Screening Programme (NHSP) are initiated at the first indication that there is a permanent childhood hearing impairment (PCHI) in the newborn from Auditory Brainstem Response (ABR) tests - we do not wait for final full-frequency results after multiple ABR's.
2. The Audiologists who carry out the ABR's inform the Consultant Audiovestibular Physicians (Audiovestibular Medicine) on the same day - both Audiologists and Audiovestibular Physicians work within the same Audiology & Audiovestibular Medicine Department within an acute tertiary NHS Trust and work within the same clinical and office areas.
3. The Audiologists issue the urine collection pack + urine sample is requested by the Audiovestibular Physicians on the hospital IT system at point-of-request by the Audiologists (without waiting for final PCHI confirmation after multiple ABR appointments).
4. The Microbiology lab or the Infectious Disease medical team informs back the results within approximately 3-4 days.
5. This information is relayed back to parents by the Audiovestibular Physicians on an urgent basis in a formal Hearing Loss Aetiology clinic - This is urgently arranged (especially when the urine test result is positive) by overbooking clinics or sacrificing admin or lunch times - the focus is not just CMV but to initiate time-critical Hearing Loss Aetiological medical investigations including Radiological imaging (as there can be features of CMV on brain images + other progressive hearing loss radiological features

such as enlarged vestibular aqueducts or other cochlear-vestibular dysmorphia on imaging that will have an implication for hearing and vestibular function) e.g. Radiology request for a "feed & wrap" imaging on an urgent basis, especially if the newborn is under 3 months of age.
6. During the same urgent Hearing Loss Aetiology clinic, the parents will be informed of possible implications of cCMV on the baby - including progressive or fluctuating auditory effects and its treatment with different amplification options + need to monitor serially as per national cCMV auditory surveillance guidelines + potential antiviral treatment and referral to ID team (often by email for urgent referral notification) + potential non-auditory effects on rest of the body including neurological effects/ ophthalmological effects/ growth effects/ cognitive issues/ neurodevelopmental effects/ physical growth issues etc.) + consent will be taken from parents to request Guthrie newborn blood spot CMV PCR test + referrals to Ophthalmology & Developmental Paediatrics.
7. Full documentation and information dissemination by formal clinic letters to include - full medical history (including birth& family history), ABR results so far, CMV results, action plan (copied to GP, Parents, Health Visitor for < 5 years + other referring medical teams).

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:"

A2 As per A1 - sample collected by the Audiologist at first detection of SNHL or ANSD.

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:

A3 Within Audiology and Audiovestibular Medicine Department, this is first Urine - if this is positive, then Infant blood spot test. Other Departments such as General Paediatrics (within same NHS Trust) and/or Neonatology (Liverpool Women's Hospital - different Trust) may request the newborn blood spot test directly - please enquire directly.

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. This 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

A4 If the first symptoms are non-auditory, this will not be done within Audiology/ Audiovestibular Medicine. These would be done by other medical teams - Neonatology team (in a different NHS Trust - Liverpool Women's Hospital), General Paediatrics, Developmental Paediatrics.

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

A5 Antiviral treatment and management will be via Department of Infectious Disease & Immunology, led by a number of Medical Consultants and/or General Paediatrics Department. Audiology & Audiovestibular Medicine Department will monitor the hearing and Ophthalmology Department will monitor the vision. Any other medical teams will be involved (e.g. Neurology or Neurosurgery) depending on the medical need of the newborn/ child.

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.

A6 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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

A7 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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.

A8 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.

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

A9 Information not held – the Trust does not routinely collate or hold this information centrally as part of its management or performance data. In order to ascertain the data the Trust would be required to access personal data of the individuals and as such the data is exempt under Section 40: Personal data.