

Congenital Cytomegalovirus (cCMV)

Dr Tamsin Holland Brown explains how a region pulled together to tackle a common cause of disability including hearing loss

Background

Cytomegalovirus (CMV) is a very common virus that no one (91% of the public) has ever heard of. It is a leading cause of hearing loss and childhood disability. Recent research demonstrated that children's long term outcomes could be improved with antiviral treatment offered within the first month of life.

Babies on the neonatal unit were sometimes diagnosed early enough to receive treatment, but well babies who were found incidentally to have a hearing loss were not.

Guidelines for many years have been that babies born with any congenital hearing loss should all have a test for CMV as part of their aetiological investigations. This was historically exceedingly difficult to test for because the aim was always to establish if a child had been exposed to CMV in the womb. Oddly enough, CMV is a threat to an unborn baby (and probably to a premature baby) but not to a child who has been born at term.

Testing was a palaver until very recently. It used to involve taking a urine sample (for children under one year of age) or blood sample (for children over one year of age) to see if there was any evidence of the virus. This is because babies born with CMV often excrete the virus for many months after birth. However, this only provided a clue, because a positive result would either mean the child had been exposed to CMV in the womb (congenital CMV) or after birth (a simple viral infection that was not relevant). So, clinicians then had to follow up any positive results by requesting retrieval of the newborn heel prick test (which is usually taken from every baby within the first few days after birth) to be pulled out of storage and sent to the microbiology lab for analysis. To make matters worse, the reliability of the heel prick test was a bit variable: the longer it had been in storage the more likely the sample was to degrade and the less reliable the test result.

This all changed when research emerged showing that treating babies with antivirals (such as ganciclovir and valganciclovir) *within the first month of life* could potentially improve outcomes. In particular, treatment seemed to offer some (but not all) babies protection against hearing deterioration/progression.

This led to early testing to be considered by clinicians. The best method was to test the baby early, within the first three weeks of a baby's life, to be sure that the test was reflective of congenital CMV and not postnatally-acquired CMV.

There have been schools of thought on testing all babies for CMV. But currently national screening bodies feel that more research needs to be collected before every newborn baby is considered for this test. Therefore, only targeted testing for babies with

certain symptoms or signs is agreed.

Hospitals in London, affectionately known as the Northern Line hospitals since they all happened to be connected by the same tube line, were involved in much of the initial research in this area, and they were very generous in sharing their knowledge and information.

The three largest hospitals in the East of England region (Cambridge, Peterborough, and Norfolk and Norwich) audited their practice in 2016 and found that 'well' babies with a hearing loss were not being investigated for CMV early enough; none of them were identified within one month of life, which would be early enough for potential treatment. Furthermore, despite clinicians often requesting CMV testing (most often as a urine sample request in those under one year of age) a result was not available in almost 50% of cases. Audit studies across all three hospitals also showed that antiviral treatment had never been started on any 'well' patients with SNHL (sensorineural hearing loss) within one month of life.

A truly joined-up, multidisciplinary approach was taken across the region in 2018 involving newborn hearing screeners, audiologists, ENT surgeons, virologists, neonatal screeners, community paediatricians, acute paediatricians, pharmacists and ophthalmologists. By February 2019 all participating hospitals had set up saliva sampling within three weeks of life for all babies who 'failed' their newborn hearing screens. Hearing screening staff were crucial to all the teams in achieving this.

Rapid referral of paediatric patients found to be CMV positive, was then made to a fast-track paediatric clinic for a paediatrician to consider management and possible antiviral treatment within one month of life.

The regional hospitals worked together to write the East of England CMV guidelines which were then ratified.

<https://www.networks.nhs.uk/nhs-networks/eoe-neonatal-odn/guidelines/current-guidelines>

Media interest in the new pathway (local and national radio, including Woman's Hour; the BBC 'Inside Out' programme; BBC news segments) drove research interest, improved health visitor awareness and drove midwives to start CMV prevention advice locally for pregnant women.

All three hospitals in the East of England continue to collaborate and share their expertise and patient outcomes, aiming to publish further information to allow other hospitals to follow suit. They also have close links with colleagues in London who continue to support their work.

(After note: In all honesty, this was one of the best things I have ever been involved with in my career in the NHS. The change to the pathway couldn't have happened

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without the generosity of colleagues in London who had done the research, and then a vast collaboration from so many different professionals across the three main hospitals. It was only successful because of the enormous dedication of about 100 NHS staff members in total. The hearing screeners became the critical linchpins to the success of the pathway since they agreed to help the team identify and take swabs from babies who were identified as having a hearing loss at their hearing screen. ■



Dr Tamsin Holland Brown is a Cambridge Community Paediatrician.

The following media links succinctly summarise the CMV pathway.

CMV regional BBC news clip:

www.bbc.co.uk/news/av/uk-england-cambridgeshire-49513693/doctors-tackle-cmv-deafness-virus-in-children

BBC breakfast clip

m.youtube.com/watch?v=LFr-eAeD_6c

Woman's Hour podcast clip (CMV is discussed 15 mins after the podcast starts)

www.bbc.co.uk/sounds/play/m000823k

This link is the official and ratified East of England guideline for CMV management

www.networks.nhs.uk/nhs-networks/eoe-neonatal-odn/guidelines/current-guidelines/congenital-cmv-guideline

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