



1st December 2022

Dear National Screening Committee,

Please find attached a group submission to propose the topic: Targeted Screening for Congenital CMV for review. We are writing as medical and audiological professionals and parent/patient representatives to outline this proposal.

The Newborn Hearing Screening Programme (NHSP) is highly effective in early identification of sensorineural hearing loss (SNHL), which greatly improves educational outcomes and life opportunities for the children affected.

The only cause of SNHL for which there is a medical treatment is congenital CMV. Congenital CMV (cCMV) is the commonest congenital infection, affecting 1 in 200-300 live births in the UK, and it is also the commonest non-genetic cause of SNHL in children. The SNHL gets worse (called 'progressive' hearing loss) in half of cases. Progression often occurs in early childhood, and severe/profound hearing loss, requiring cochlear implantation for affected individuals, is not uncommon. Randomised controlled trials (RCTs) show that antiviral treatment has benefit (hearing either improved or was less likely to progress in the treatment group) for newborns with central nervous system involvement when started by age 4 weeks. Later RCTs of oral treatment confirmed benefit to hearing, and showed modest benefit to neurodevelopment, whilst a recent placebo-controlled RCT showed no evidence for starting treatment in children over age 4 weeks, making it even more important to detect cCMV within the first 4 weeks.

Diagnosis of cCMV requires a sample of saliva or urine taken before age 3 weeks. Various studies of targeted screening have shown:

- urine and saliva samples have similar sensitivity and specificity
- the saliva swab sample is more practical and feasible to collect than a urine sample
- CMV testing using saliva swabs taken by newborn hearing screener was acceptable to parents and the screeners
- parental anxiety levels were not increased
- newborn hearing screeners and parents thought that testing for cCMV was worthwhile.

Consequently, a few UK regions have implemented early detection pathways involving newborn hearing screeners taking a saliva sample at the time of referral to audiology, which have been working well for several years. Treatment is only offered to eligible infants. In one region, this has resulted in one infant treated for every 400 swabs taken. Infants with cCMV, with no symptoms of cCMV, and normal hearing, receive paediatric infectious diseases advice, and audiological monitoring for a progressive SNHL: a pathway already routinely accommodated within audiological services. Educational materials for newborn screeners and information for parents have been developed, and multiple virology laboratories can perform the CMV saliva test in the UK. However, currently access to timely CMV testing is extremely variable, and inequitable, by region.

Every week in the UK, several infants narrowly miss out on the opportunity to benefit from antiviral treatment to improve their long-term outcomes. A national, targeted screen for CMV based on the NHSP would address this; enabling timely CMV testing and the opportunity for treatment and tailored follow-up for infants in all regions. We appreciate the programme will require training for newborn hearing screeners and information for parents. Training materials and information leaflets have already been designed, trialled and refined, with newborn hearing screener and parent input. These resources are being used in several Trusts and can be shared. A phased regional uptake, or stepwise introduction, may be practical approaches to implementation.

Thank you for considering this proposal.

Yours faithfully, multiple signatories (also continued overleaf):

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Dr Anne Marsden, Consultant Paediatrician, Chair of British Association of Paediatricians in Audiology, (BAPA, an RCPCH Special Interest Group)

Dr Doug Simkiss, Consultant Paediatrician and Associate Professor of Child Health, Chair of British Association of Community Child Health, (BACCH, an RCPCH Specialty Group)

Dr Seilesh Kadambari, Consultant in Paediatric Infectious Diseases and Honorary Associate Professor at UCL Great Ormond Street Institute of Child Health

Susan Daniels OBE, Chief Executive, National Deaf Children's Society (NDCS)

Sharon Wood, Project Manager, on behalf of CMV Action

Donna Corrigan, Chair of British Society of Audiology (BSA)

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East of England Team:

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