

Testing for congenital Cytomegalovirus (CMV) infection in children with a confirmed hearing loss

You have been given this leaflet because a hearing test has shown that your child has a sensorineural (affecting the inner ear)*hearing loss. The two most common identified causes for this type of hearing loss are:

1. Genetic (inherited) causes.
2. Congenital cytomegalovirus (CMV) – when a child is infected with a particular virus called CMV before birth.

What happens next?

Your child will be referred to a community paediatrician (doctor specialising in child health care) for a full paediatric assessment and investigation into your child's hearing loss. However, due to recent advances in treatment, we are now trying to identify babies whose hearing loss is caused by CMV as soon as possible, before the full assessment.

CMV

CMV is a very common virus which can cause cold or flu like symptoms, or sometimes no symptoms at all. However, CMV infection can cause more significant illness in anyone with a weak immune system, including unborn babies. CMV infection in an unborn baby is called *congenital CMV* – congenital means from birth. 10-20% of hearing loss in children in the UK is thought to be due to congenital CMV.

Congenital CMV can present in two ways:

– Asymptomatic congenital CMV

Nine out of ten babies with CMV are born with no symptoms or signs. In the past, these children were not diagnosed and less is known about their progress. Most children do not appear to be affected by the virus, but about 10% develop some degree of hearing loss. This hearing loss can get worse, particularly over the first few years of life.

– Symptomatic congenital CMV

One in ten babies with this infection are born with symptoms and signs, including low birth weight, rashes, enlarged liver and spleen, jaundice, fits, patches of calcium on the brain, eye problems and hearing loss. These babies receive treatment soon after birth.

*. Children with auditory neuropathy pattern of results will also be referred for this test

Symptomatic babies are routinely treated with an antiviral drug called gancyclovir, and research studies have indicated that if this is given to young babies, it might stop the progression of hearing loss. This treatment may therefore be offered to asymptomatic (not showing any symptoms) babies identified with hearing loss, aiming to reduce the risk of hearing loss progression, during the first year of life.

Tests for congenital CMV infection

In order to offer treatment as early as possible to babies affected with CMV, it is important that they are identified quickly. In children under the age of 12 months, this is best done by collecting a urine sample and looking for the virus in the urine sample. If the sample is collected from a child older than 3 weeks and CMV is detected, it is difficult to know whether the child became infected before or after birth. Therefore, the baby blood spot card (Guthrie card) can also be tested for CMV to help find out the timing of the infection.

Arrangements for testing babies

Once the audiologists (hearing specialists) have confirmed your baby's hearing loss, they will give you a pack containing this information sheet. You will be telephoned to book a short appointment. This will not be a full paediatric assessment – this will happen later – but the doctor or nurse will be able to answer any questions you might have about the CMV testing. The doctor or nurse will put a urine pad in your baby's nappy at the beginning of the appointment so that the urine can be tested; it is helpful if possible if you can withhold a feed so that your baby can have a feed as soon as the pad is put in, to encourage your baby to pass urine.

Results

The urine result usually takes a week or two to come through. You will be contacted by phone if the result is positive for the virus to arrange further testing of the baby blood spot card. Normal results will be sent by post. If your baby receives a result suggestive of congenital CMV, he/she will be seen urgently by a paediatrician, and if appropriate referred to the Paediatric Infectious Diseases Team in Oxford to decide on whether treatment is recommended.

Further information

www.ndcs.org - National Deaf Children Society website – for information leaflet for families on congenital CMV infection

If you would like this leaflet in other languages or formats (e.g. large print, Braille or audio), please contact the Audiology Department.

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