



Testing for congenital Cytomegalovirus (CMV) infection in newborns

You have been given this leaflet because a hearing test results indicate that your baby is at an increased risk of a hearing loss.

Testing for CMV

Hearing losses can be temporary or permanent in nature. When we assess children referred from the Newborn Hearing Screening Programme with diagnostic tests, results may be normal or they may indicate a temporary or permanent hearing loss. Due to recent advances in treatment, we try to identify any congenital CMV infection early in babies with possible hearing loss (even before the full hearing assessment is completed). If the infection is identified within the first four weeks, there can be a potential option for antiviral treatment. This treatment can reduce the progression of hearing loss, but this is not the case for all children. Therefore, we suggest you provide the sample as promptly as possible, preferably on the same day that you have received this pack as it may take a few days for the results to come back.

What is 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 meaning 'from birth'. Ten to twenty percent 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.

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 may stop the progression of hearing loss. As a result, we offer this treatment to asymptomatic (not showing any symptoms)

babies identified with hearing loss, with the aim of reducing 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 at a saliva sample for the virus. If the sample is collected from a child more than a few weeks old 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.

Testing babies

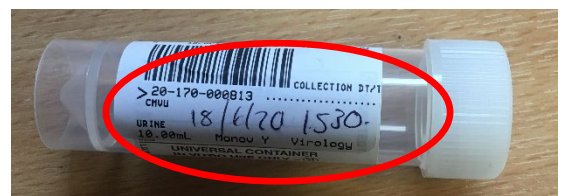
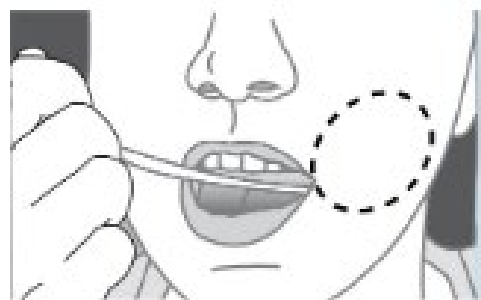
Your audiologist will have given you a testing pack to collect saliva from your baby's cheek. The pack will contain the following:

- A Virocult Saliva Swabbing Pack that contains:
 - Saliva swab.
 - Labelled specimen pot with transport medium.
- Plastic specimen bag, which is labelled to go to St. Peter's Virology Laboratory

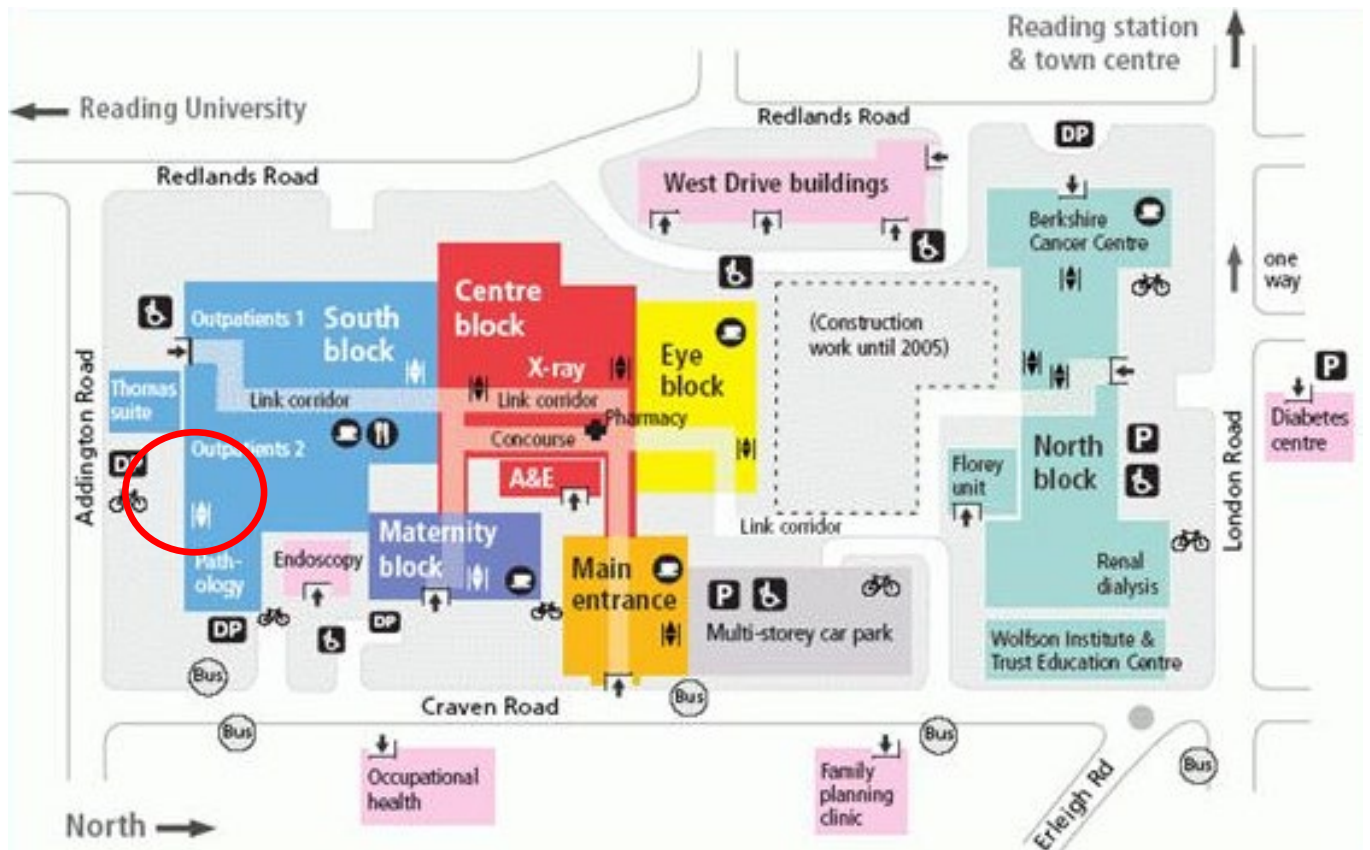
IF YOU ARE BREASTFEEDING, PLEASE DO NOT COMPLETE THIS SWAB UNTIL ONE HOUR AFTER FEEDING YOUR BABY. The saliva swab can be taken at any time for formula fed babies.

The following method should be used to collect a saliva swab from your baby:

1. Take the saliva swab from the kit at the non-sponge end.
2. Place the swab in your babies mouth on the cheek .
3. Wait until the swab is fully soaked with saliva. This time varies, depending on your baby.
4. Place the swab into the labelled specimen tube breaking the stick so it fits in.
5. Screw the lid on tightly.
6. **Write the date and time** of when the swab was taken on the label.
7. Place the pot in the plastic specimen bag.
8. Due to the move of the Blood Sciences laboratory and Specimen Reception, on 4th September 2023 to Pathology's Rapid Response Lab, which is in RBH South Block Level 1, all samples will need to be dropped off at Specimen Reception.
9. To access the new laboratories, Specimen Reception signs have been put up to direct you to the new Laboratory:



- From Craven Road main entrance / multi storey car park: follow the signs to South Block, turn left after Jamaica Blue café (in South Block) follow the signs to Pathology and take the lift or staircase down to the new Pathology Rapid Response Laboratory Specimen Reception.
- From North Block follow signs to South Block turn left after Jamaica Blue café (in South Block) follow the signs to Pathology and take the lift or staircase down to the new Pathology Rapid Response Laboratory Specimen Reception.
- From the South Block entrance: turn right at Jamaica Blue café and take the lift or staircase down to the new Pathology Rapid Response Laboratory Specimen Reception

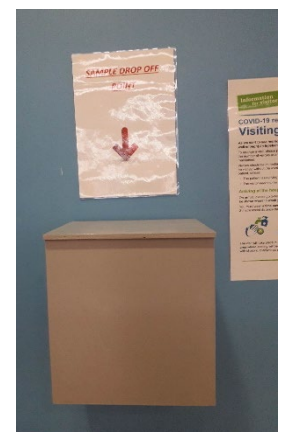


- Or, drop off at the West Berkshire Community Hospital at the Blood test reception in outpatients. The sample needs to be put in the grey box between 8am and 3.30pm.

Results

The saliva test result usually take less than a week to come through. **If you have not heard back from us within 4 days or before your baby is 4 weeks old, please let us know.**

If the result is positive for CMV virus you will be contacted by phone by a paediatrician (doctor) to arrange further testing of your baby's blood spot card. Normal (i.e. negative for CMV virus) results will be communicated either via phone or in the baby's next appointment. 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 have any further questions, please contact:

The Audiology Department on tel: 0118 322 7238

Email: audiology.royalberkshire@nhs.net

Website: www.royalberkshire.nhs.uk/services-and-departments/audiology/childrens-hearing-services

To find out more about our Trust visit www.royalberkshire.nhs.uk

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