

Congenital Cytomegalovirus (cCMV) version 1.9 Doc ID 14617

An online self-learning presentation.

Written by Dr John E FitzGerald Consultant Clinical Scientist

In collaboration with CMV Action



Our Vision
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Norfolk and Norwich University Hospitals

NHS Foundation Trust



Learning Objectives

SECTION 1

- ▶ What CMV is, how common it is, how it is spread and how to avoid catching it
- ▶ The risks CMV presents to the unborn child
- ▶ Identification and treatment of cCMV

SECTION 2

- ▶ Who to test for cCMV
- ▶ What to say to parents when consenting for a cCMV test
- ▶ How to take a mouth swab for cCMV
- ▶ Actions following a positive cCMV test

SECTION 3

- ▶ Medical Management of cCMV

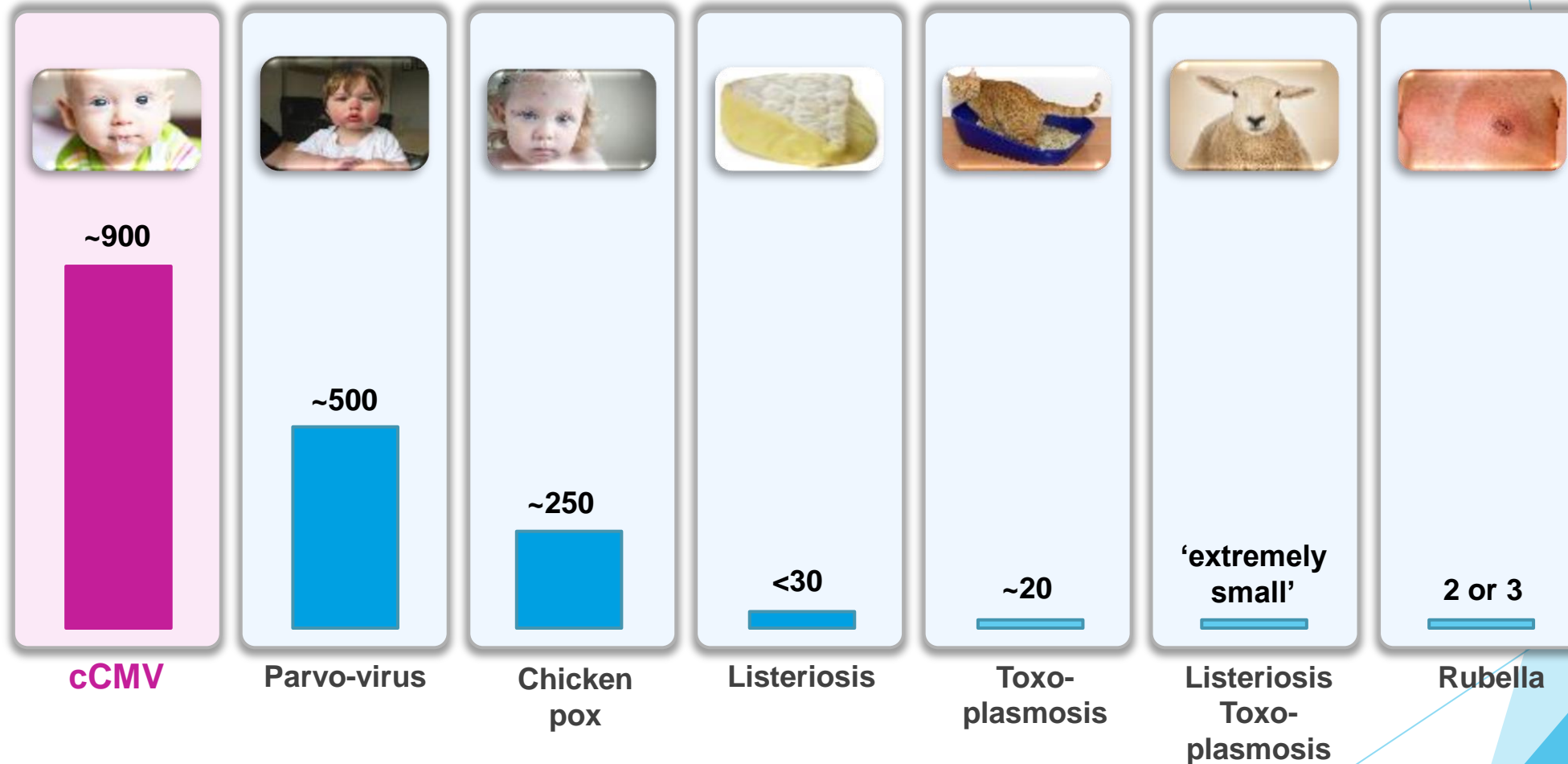
What is CMV?

- ▶ CMV is a common herpes type virus which in most healthy adults causes no symptoms at all or mild flu like symptoms.
- ▶ For women who acquire CMV for the first time during pregnancy there is a 30-40% chance that the virus will pass to the foetus (called congenital CMV) and there is a risk that it can damage the unborn baby.

How common is cCMV compared to other infections that pose a risk to the foetus during pregnancy?

cCMV affects more babies every year in the UK than all other infections added together

Approx number of babies affected per year by pregnancy infections



Sources: Dollard 2007, Griffiths 1991, NHS Choices, Public Health Laboratory Service Working Party 1990, Chapman 1993, Gay 1994, Public Health England 2014

How is CMV Spread?

CMV is mainly spread through small children's bodily fluids

- ▶ CMV is transmitted through close contact with bodily fluids
- ▶ The main way women catch CMV is from the saliva or urine of young children



- ▶ Saliva poses a greater risk than urine
- ▶ Younger children pose a greater transmission risk than older children

Pregnant woman who already have young children or work with young children are at greater risk

Sources: Cannon, 2005. Cannon, 2014



How can pregnant women avoid catching CMV?

Simple hygiene precautions reduce the risks



What harm can cCMV cause?

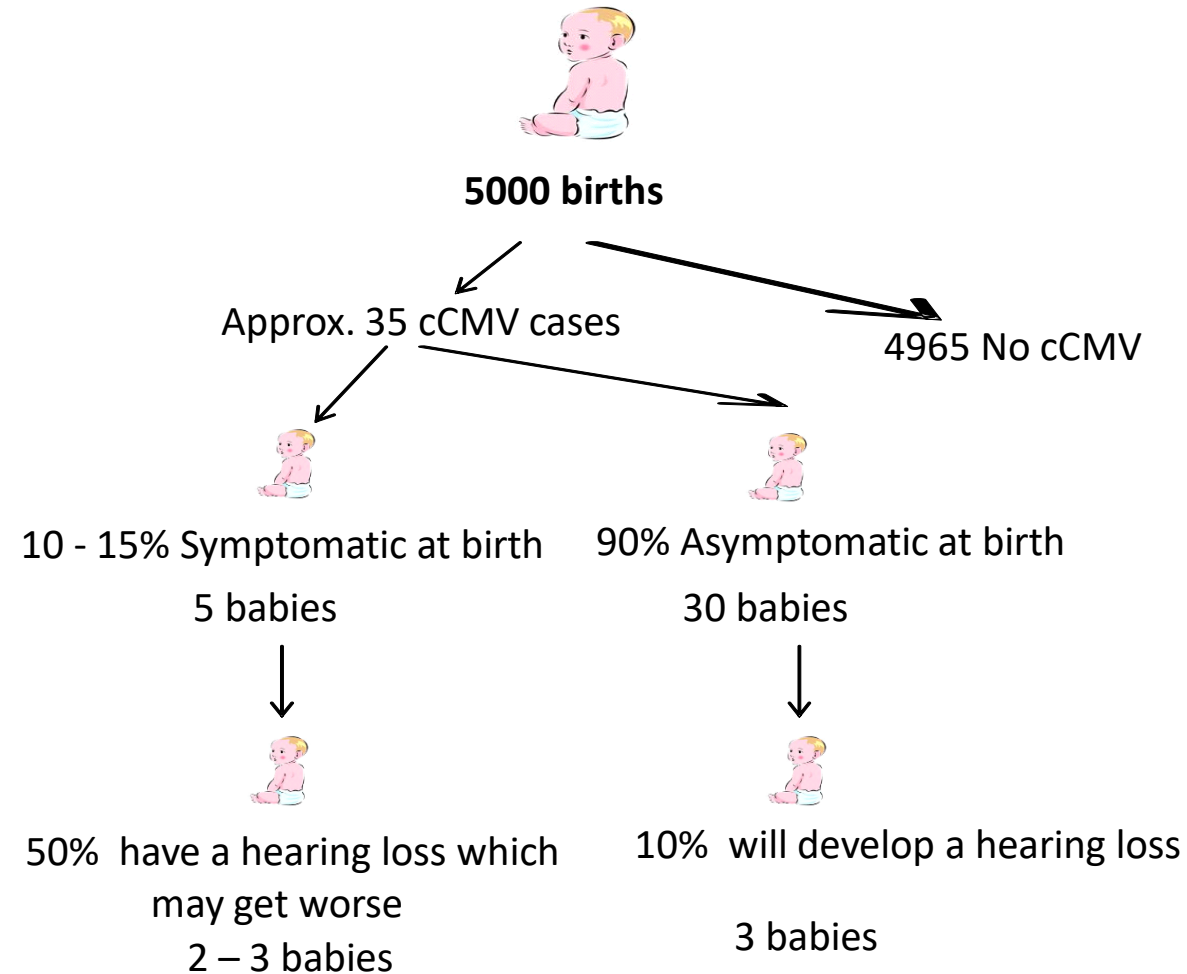
- ▶ The most common disability associated with cCMV is hearing loss. In about half of these cases the hearing loss gets worse over the first 4 years of life. A moderate hearing loss at birth can progress to a profound loss by the age of 4 years.
- ▶ cCMV can also cause blindness, cerebral palsy, mental and physical disabilities and seizures.

How common is cCMV?

- ▶ cCMV is the most common birth disorder in the UK (around 1 in 150 babies in the UK are born with the virus).
- ▶ BUT most are asymptomatic and will remain unaffected.
- ▶ A small proportion, around 1 in 5 of cCMV infected children (900 every year) will develop some of the above serious conditions.
- ▶ cCMV accounts for approximately 25% of permanent hearing loss in children under the age of 4 years.



What does this mean for an area with 5,000 births per annum?



For a birth population of 5,000 per annum, **2 – 3 babies** each year could be identified with cCMV by testing babies that fail the newborn hearing screen and through early treatment of cCMV, prevent a hearing loss getting worse

How is cCMV identified?

- ▶ cCMV can be identified from saliva if a sample is taken within 3 weeks of birth. The saliva is obtained from a mouth swab.
- ▶ The saliva is tested for cCMV in a Pathology Laboratory using a 'PCR' assay (Polymerase Chain Reaction assay). This detects and quantifies the amount of CMV DNA.



Why is taking the mouth swab within 3 weeks of birth so important?

- ▶ 1. To distinguish between cCMV and postnatally acquired CMV
 - ▶ CMV present in saliva within the first 3 weeks of birth is due to cCMV.
 - ▶ CMV present in saliva after 3 weeks of birth maybe due to either cCMV or postnatally acquired CMV.
 - ▶ Postnatally acquired CMV, poses no serious medical risks to a healthy baby (perhaps a slight cold or runny nose). Only cCMV is potentially harmful.
 - ▶ A negative saliva sample taken after 3 weeks of birth will exclude cCMV, but a positive sample taken after 3 weeks of birth will not distinguish between cCMV or postnatally acquired CMV. Other testing will then be needed - usually testing the blood on the baby's Guthrie card to identify whether baby has cCMV rather than postnatally acquired CMV.

This extra testing takes longer and is not as good as the saliva test performed within 3 weeks, so it is very important to try and take the saliva swab within 3 weeks. But.... If the 3 week deadline is missed it is still important to check for cCMV in babies with sensorineural hearing loss.

- ▶ 2. To enable treatment to be started within 4 weeks if it is required.

How is cCMV treated?

- ▶ cCMV can be treated by a course of antiviral medication. It is only recommended to be given if started within 4 weeks of birth (based on current research showing it can stop hearing loss getting worse).
- ▶ **BUT....** The antiviral medication also carries risks so it is important to only consider treating those babies with a hearing loss that may deteriorate or that have other serious medical conditions. Results will be discussed with a medical expert. This could include a paediatrician, a virologist (a doctor who specialises in viruses), or audiovestibular physician (a doctor who specialises in hearing loss).



Section 2

- ▶ Who to test for cCMV
- ▶ What to say to parents when consenting for a cCMV test
- ▶ How to take a test sample for cCMV
- ▶ Actions following a positive cCMV test

Who Should be tested?

- ▶ All babies that fail the newborn hearing screen (both unilateral and bilateral referrals)
- ▶ All children diagnosed with a SNHL

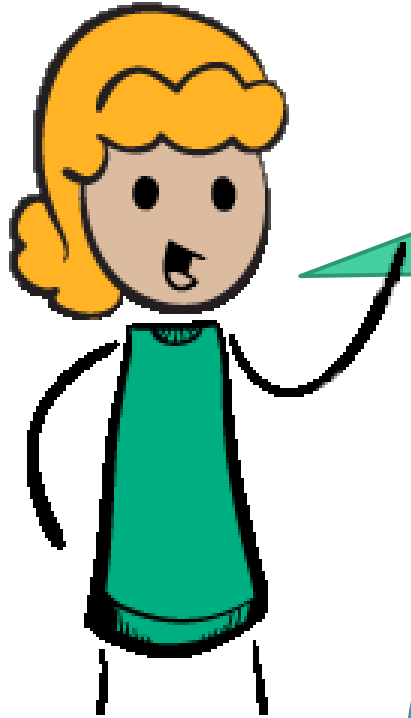
How to obtain verbal consent for a cCMV Test

Explain;

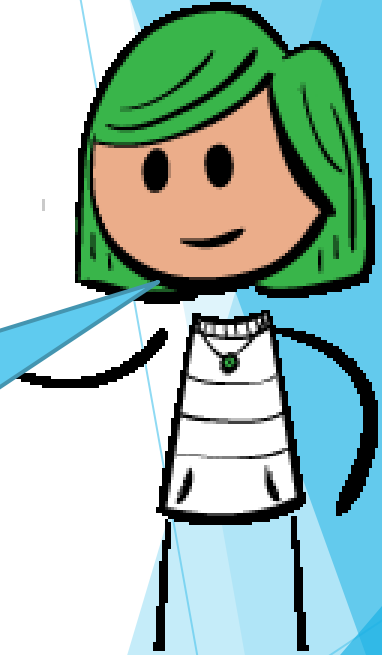
1. That baby has not passed the hearing screen and the possible reasons for this and that a referral on to Audiology is required for further testing.
2. The probability of there being a hearing loss.
3. That about 25% of permanent childhood hearing loss is caused by the cCMV virus and that there is a simple test that can identify this virus.
4. What the cCMV virus is and check they have read the information leaflet about cCMV.
5. That if the virus is found and if there is a hearing loss it might be possible to stop the hearing loss getting any worse if antiviral medication is given within 4 weeks of birth.
6. That you will take a mouth swab from baby, by gently placing a swab in the mouth for 60 seconds and gently moving it around to get a sample of saliva, which will be tested for cCMV by the hospital laboratory.

Ask Mum if she agrees to the test being performed and record that verbal consent has been given in the notes.

Questions Parents Might Ask

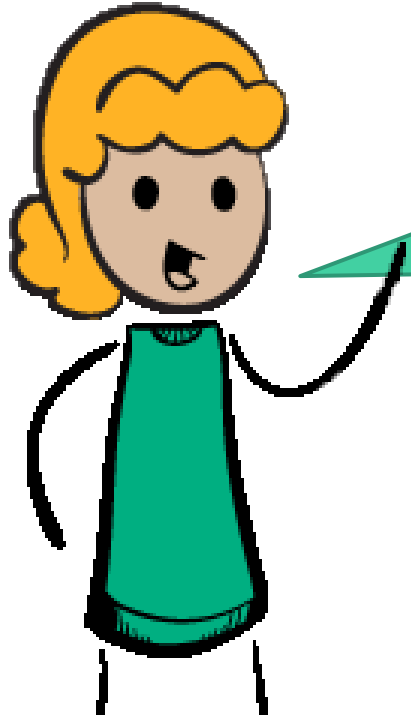


How likely is it that my baby will have cCMV?

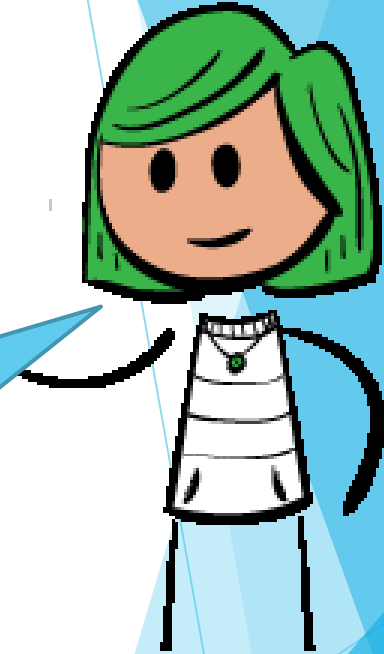


We expect that out of every 5000 babies born each year between 2 - 3 babies that don't pass the newborn hearing screen may have cCMV that causes a hearing loss. But remember most babies with cCMV have no problems and won't need treatment.

Questions Parents Might Ask

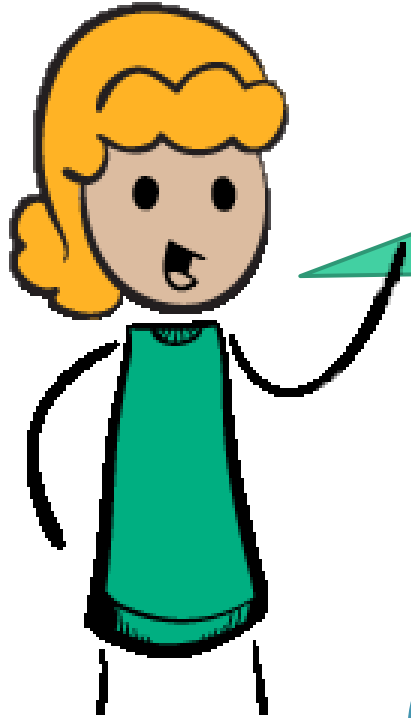


What will happen if my baby has cCMV and a hearing loss?

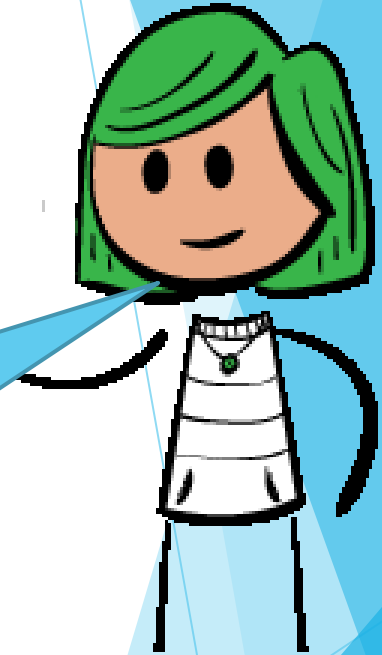


Your baby will see a **paediatrician** and **possibly some other medical experts** for a medical check and an **eye check** and the results will be discussed with you before treatment is considered. The best treatment to stop a hearing loss getting worse must be given within 4 weeks of birth.

Questions Parents Might Ask

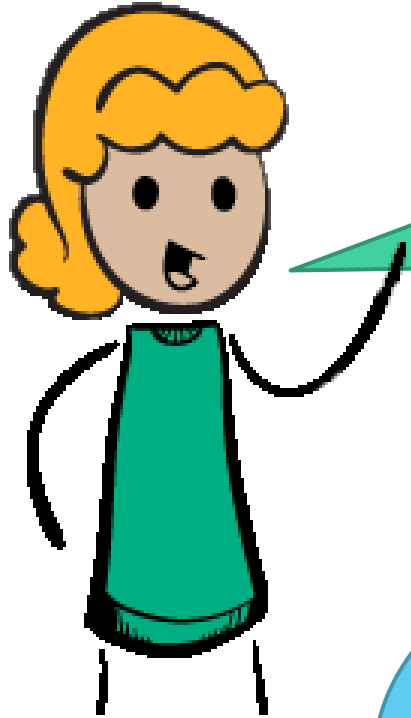


What will happen if my baby has cCMV and normal hearing?

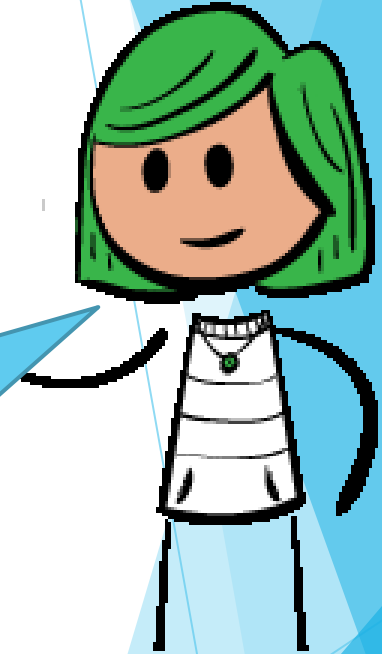


Your baby will see a **paediatrician** for a medical check and an **eye check** and the results will be discussed with you before treatment is considered.

Questions Parents Might Ask



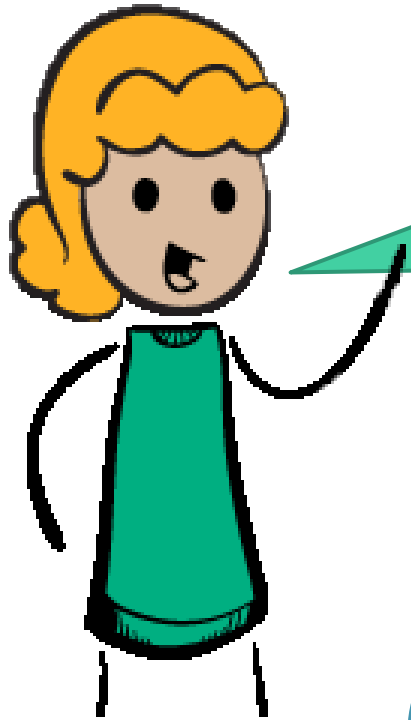
Can I wait until my baby is older before having this test?



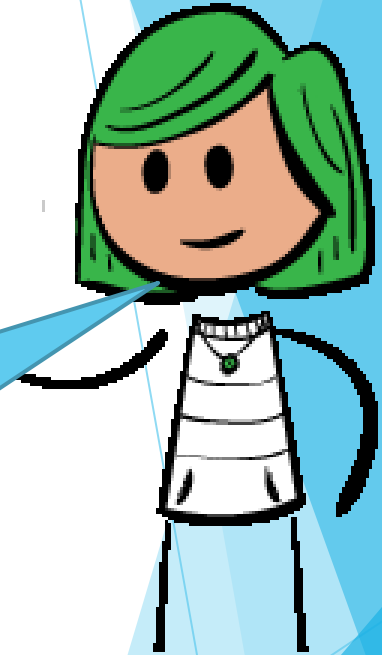
The mouth swab needs to be taken within 3 weeks of birth to be sure a positive result is due to cCMV and treatment has to be started within 4 weeks of birth to give the best chance to stop any hearing loss from getting worse.

Other tests that take longer can be performed after 3 weeks of birth, but the option of early treatment will be missed

Questions Parents Might Ask

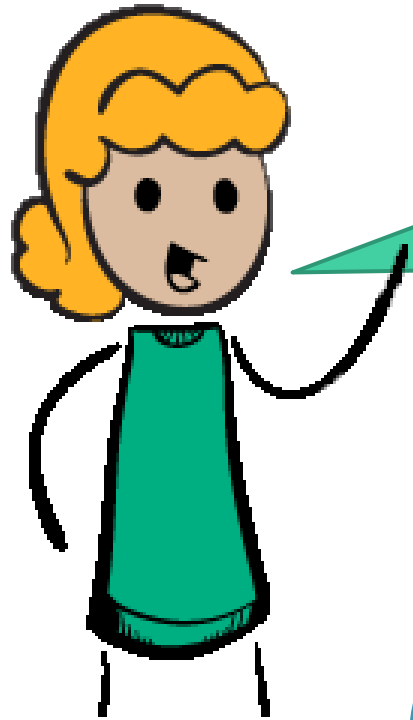


What is the treatment for cCMV?

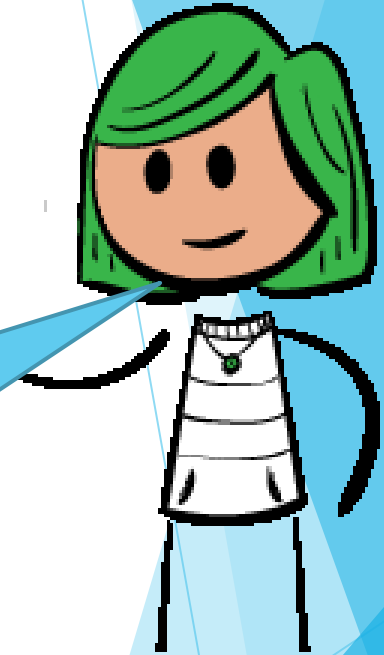


A liquid medicine taken by mouth called an
'antiviral'.

Questions Parents Might Ask

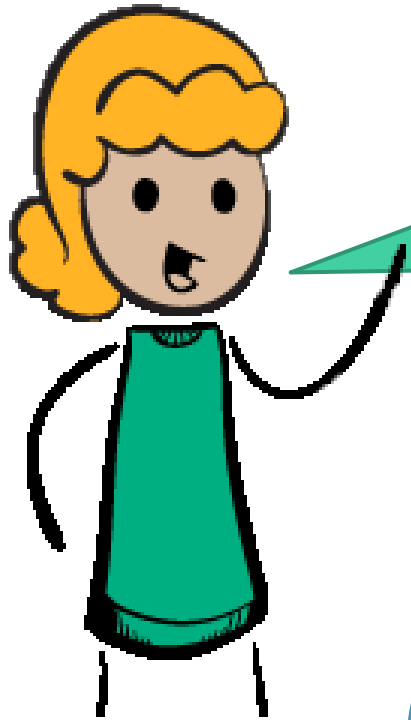


I have heard the treatment has side effects, what are they?

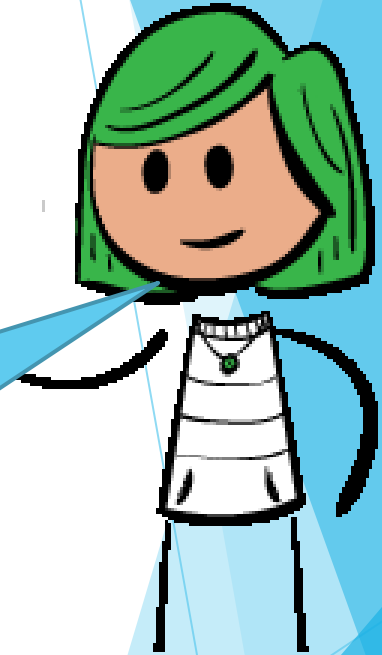


Your paediatrician will discuss the **benefits** and any **risks** of the medication and how these will be **monitored** if medication is necessary

Questions Parents Might Ask

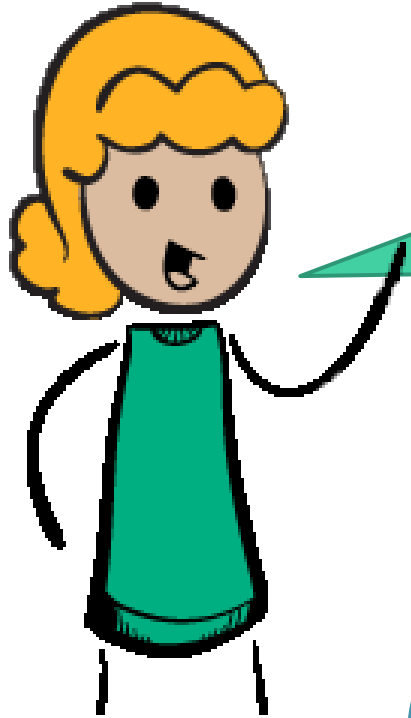


How long will my baby need to take the treatment if they have cCMV?

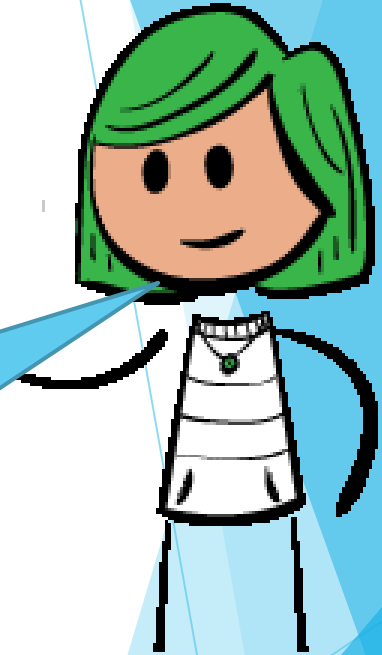


This depends on a **number of factors** which your **paediatrician** will discuss with you.

Questions Parents Might Ask

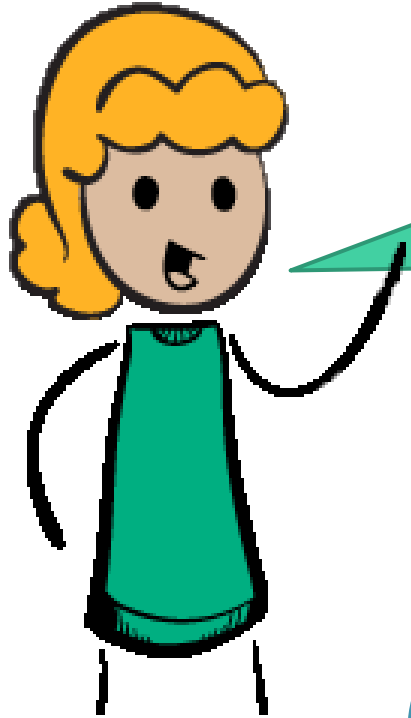


What if my baby gets CMV now (after they have been born)?

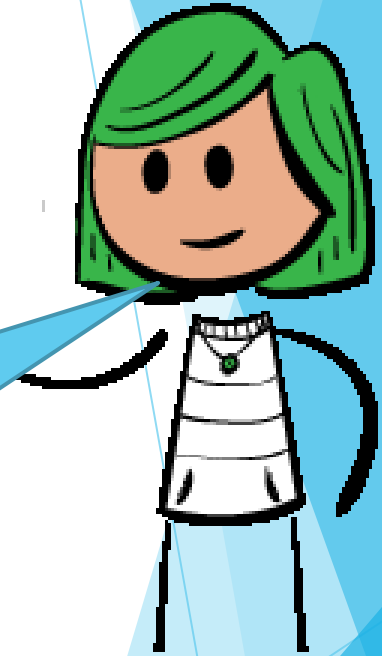


The virus is not dangerous if contracted by a healthy baby after birth. It is likely only to cause a slight cold. It is only dangerous to the foetus during development before birth.

Questions Parents Might Ask

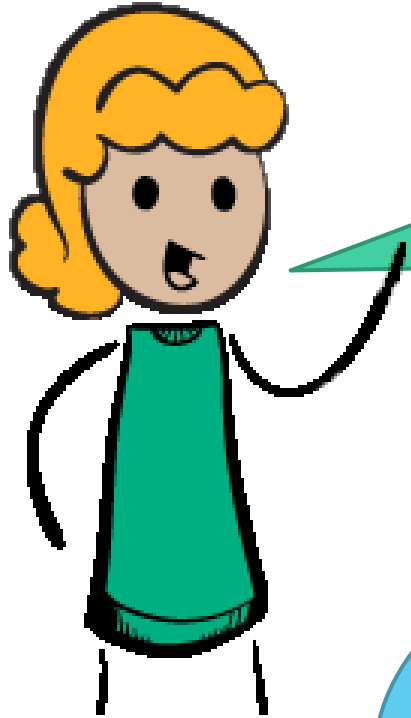


Can the virus be passed on to my other children and how will it affect them?

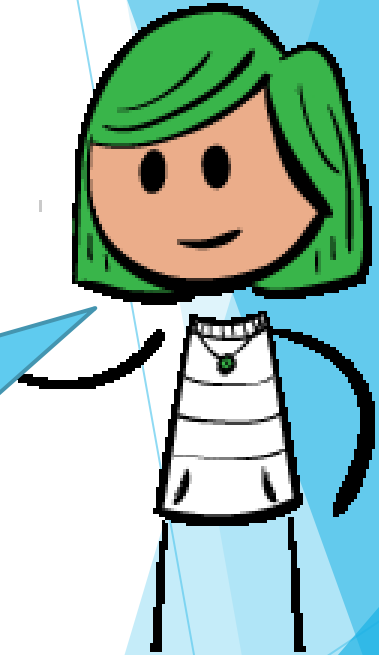


The virus can be passed on via **saliva** and other **bodily fluids** so don't encourage your other children to kiss baby on the lips. Also wash your hands thoroughly after nappy changes. If your other children **do catch the virus** it is not dangerous and is only likely to cause a **slight cold**.

Questions Parents Might Ask



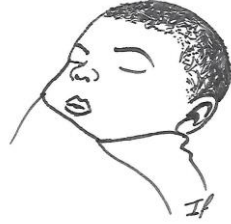
What happens if my baby is older than 4 weeks - Can treatment still be given if needed?



Research looking into the possible benefit of starting treatment upto 12 weeks after birth in babies who have cCMV and hearing loss has recently been completed. Your paediatrician can give you more information about this.

Taking the Mouth Swab

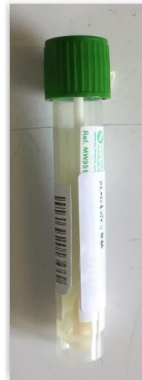
- Baby must not have been breast fed for at least 1 hour before the swab is taken.
- (No restrictions for bottle fed babies on formula milk)
- **Wear Gloves**



- Use the green lid VTM tube. Do NOT put the swab stick in the tube before taking the mouth swab



- Place the swab in the babies mouth, between the gum and upper and lower lips moving it around gently for 60 seconds to ensure it is saturated with saliva.



- Break the swab stick at the join of the thick and thin part and place it into the sample tube.

- Label the tube with the name, DOB, hospital number, sex and the date and time the swab was taken.

Request the cCMV test with the laboratory. Place request form and sample tube in the specimen bag and send to the laboratory.
Mark as Urgent

Check correct mobile contacts for parents in case results are positive

The sample is tested using the 'PCR' assay (Polymerase Chain Reaction assay) that detects and quantifies the amount of CMV DNA.

What to do if the offer of a test is declined?

- Make sure Mum or Dad has received the information leaflet on cCMV.
- Make sure Mum or Dad understand that the saliva swab can only be conducted within 3 weeks of birth to identify cCMV and that the best treatment is only available within 4 weeks of birth to stop a hearing loss, if present, from getting worse.
- Ask Mum or Dad to read and sign a declination form and file it in the hospital notes.



What happens if the test result is Positive?

- ▶ The test result will be sent to a consultant **Paediatrician** and to **Audiology**
- ▶ Baby will be offered an urgent paediatric appointment for a medical examination which will include;
 - a **blood test** to assess liver and kidney function and to measure red blood cells, white blood cells and platelets, (cCMV can cause a reduction in the number of red and white blood cells and inflammation of the liver).
 - a **brain scan** (ultrasound) to assess neurological involvement.
- ▶ Baby will be offered an urgent **eye test** (to check for any inflammation or scarring on the retina).
- ▶ Baby will be offered an urgent hearing test.
- ▶ Test results and anti-viral treatment options will be discussed with a medical expert (this could include a paediatrician, virologist, or audiovestibular physician).



What happens if the test result is Negative?

- ▶ The parents and GP are informed that baby does not have cCMV (see your local guideline as to who sends this)
- ▶ Antiviral medication is not needed



Target pathway timescales to ensure the time critical deadlines are met

- ▶ Time critical deadlines:
 - ▶ 1. The mouth swab must be taken within 3 weeks of birth to ensure a positive result relates to cCMV rather than postnatally acquired CMV.
 - ▶ 2. Treatment must be started within 4 weeks of birth to maximise the chance of stopping a progressive hearing loss due to cCMV.
- ▶ In order to meet these time critical deadlines and ensure all the medical and physiological tests can be done to help decide if treatment will be beneficial, a target of **2 weeks** from birth has been set for the mouth swab and **3 weeks** from birth for the other tests (hearing test, eye test, medical and physical examination, blood test and brain scan).

Section 3. Medical Management of cCMV

Medical Management for cCMV (Treatment)

- ▶ Babies with cCMV will be seen by a virologist and a paediatrician for discussion of the results and treatment options.
- ▶ Most babies don't need treatment.
- ▶ Babies with a hearing loss or a central nervous system disease will be considered for treatment.
- ▶ Valganciclovir is an antiviral medication which may be considered. This is an oral medication (it is given by mouth). Current evidence shows that if this is given within 4 weeks of birth it may stop a hearing loss getting worse, but other treatments maybe available to older children, so it is important that cCMV is investigated in all babies with sensorineural hearing loss.

The background features abstract, overlapping geometric shapes in various shades of blue, ranging from light sky blue to deep navy blue. These shapes are primarily located on the right side of the image, creating a modern, layered effect. The rest of the background is a solid, very light blue-grey color.

Quiz

How soon after breast feeding can a swab for cCMV be taken?

1. 1 hour
2. 2 hours
3. 3 hours

Answer

1- 1 hour.

It is important not to take a swab within 1 hour of breast feeding to avoid breast milk that may contain CMV contaminating the saliva sample.

Why is it important to ensure the cCMV swab is taken within 3 weeks of birth

1. Babies cry more under 3 weeks of age and its easier to put the swab in the mouth.
2. After 3 weeks of age the test is not able to distinguish between cCMV and postnatally acquired CMV.
3. Mothers are less likely to consent to testing after 3 weeks.

Answer

2- After 3 weeks of age the test is not able to distinguish between cCMV and postnatally acquired CMV.

Postnatally acquired CMV will also give a positive test result, but does not pose any serious health risks (perhaps a mild cold), so does not require treatment with anti-viral medication. Only by testing in less than 3 weeks can there be certainty that a positive result is due to cCMV.

All babies with cCMV need treatment

▶ True

▶ False

Answer

False

- ▶ The majority of babies with cCMV will be asymptomatic. The medical investigations, hearing tests and eye tests will identify those likely to suffer symptoms and following discussions between the medical experts (paediatrician, virologist, audiovestibular physician) and the parents a decision to treat or not will be made.

Testing babies for cCMV who fail the new-born hearing screen will identify all babies that will develop a hearing loss due to cCMV

▶ True

▶ False

Answer

- ▶ False - Testing babies who fail the new-born hearing screen for cCMV will not identify all babies who will develop hearing loss due to cCMV as some babies are asymptomatic at birth and will pass the hearing screen, and these may go on to develop a hearing loss in the months or early years after birth.
- ▶ However for an annual birth rate of 5,000, the hearing screening service can expect to identify 2 - 3 babies each year where hearing loss is caused by cCMV and early treatment may prevent the hearing loss getting worse. It may also help identify other conditions caused by cCMV at an earlier stage.

Further Information

- ▶ For further information about cCMV please see the CMV Action website;
cmvaction.org.uk

Acknowledgements

- ▶ Caroline Star, Chair CMV Action for access to and use of their training material and advice
- ▶ Healthy Hearing Program, Children's Health Queensland Hospital & Health Service, Australia, for permission to use photographs of a baby undergoing a saliva swab
- ▶ Heather Valentine, Audiologist, Norfolk & Norwich University Hospital for help in preparing the PowerPoint slides