

Paediatric infectious diseases

Valganciclovir for congenital Cytomegalovirus infection

Information for patients, relatives and carers

Introduction

Your medical team has recommended that your child should take valganciclovir to treat congenital CMV (cCMV). This leaflet provides guidance and information on the use of valganciclovir. This information is not intended to replace your doctor's advice but offers further support. Please read this information carefully.

If you have any questions, please contact the Family Clinic Specialist nurses' (phone 07500835509) or the department of Paediatric Infectious Diseases 02033121013. If your baby has had a diagnosis of CMV you can also have support from CMV Action. They cannot give you medical advice but can support you and help you contact other families. Freephone 0808 802 0030.

What is Valganciclovir?

Valganciclovir is the oral medication used to treat the Cytomegalovirus (CMV) infection. You might also recognise it by the name "Valcyte"[®], which is the trade name of this medication.

What is it used for?

Valganciclovir is a recommended treatment for babies that have been diagnosed with cCMV and have developed signs and/or symptoms of the infection such as hearing problems, neurological problems or other signs/symptoms of damage to other organs (such as the eyes, liver, bone marrow, or lungs).

Valganciclovir fights the CMV virus (that is why it is called an anti-viral), it prevents the virus from making new copies of itself and puts the virus to sleep, and in this way, minimises the damage CMV may cause to your baby after birth. Valganciclovir may help to prevent any further deterioration (if any) of the hearing and the neurodevelopment of your child by restricting the multiplication of the virus.

Valganciclovir is most effective when it is started within four weeks of birth. However, studies have shown that your baby may still benefit from valganciclovir treatment even if they are older than four weeks old when they start treatment.

How to use Valganciclovir?

Valganciclovir is a liquid medicine that your baby will have to have twice daily, usually for six months. Your doctor will work out the appropriate dose for your baby depending on your baby's weight.

What are some things I need to do while my child takes this drug?

First, you have to inform all of your child's health care providers that your child is taking this medicine, including your child's doctors, nurses, pharmacists, and dentists, in case they want to prescribe any other medications and to make sure the drugs don't clash and will both still be effective.

While your baby is taking valganciclovir, they will need to have two blood tests during the first month and then monthly blood tests to check for side effects.

What are the potential side effects?

As with all medications, valganciclovir has possible side effects that can affect your child. These may be short term or longer term. The short-term side effects get better when the medication is stopped.

The most common short term side effects include:

- a decrease of white blood cells called neutrophils (the cells that help us fight infections). This is called Neutropenia.
- a reduction of the number of platelets (the blood cells that help the blood to clot). This is called Thrombocytopenia.
- Valganciclovir can affect the liver enzymes, but usually only mildly.

Long term effects: There are also some animal studies suggesting that valganciclovir may have the potential to increase the risk of cancer and affect the reproductive organs in the long term. This evidence is based on studies in animals and has not been proven in humans, and not in babies treated for CMV.

If your doctor has advised you to follow this treatment, it means that they believe that the benefits this treatment can have for your baby outweigh the potential side effects.

If a decrease in white blood cells, elevation of liver enzymes, or another side effect happens while your baby is taking this medicine, your doctor may decide to stop or reduce the dose of valganciclovir. Also, if white cells reduce significantly, your baby will be at an increased risk of infections, so if they have a fever or become unwell you must take them for urgent medical assessment, either at the GP or A&E.

What do I do if my child misses a dose?

- as soon as you remember about it, give them the missed dose with milk / food
- if it is close (e.g., within a couple of hours of) the time for your child's next dose, skip the missed dose and give the next dose at the normal time

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- never give two doses at the same time, and never give extra doses

How do I store and/or dispose this drug?

Store it in a refrigerator, out of the reach of children and pets. Do not freeze. Throw away any of the drug that you haven't used after seven weeks. Do not throw away medicine via wastewater or household waste. At the end of the six months treatment, please bring back any spare valganciclovir to your hospital appointment. Our team will dispose of them, and this will help to stop harm to the environment.

How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. The contact details for the CMV clinic are via Miss Joan Farrell 02033121013, or the Infection Clinic Specialist Nurses on 07500835509. Please contact us at any time if you have any concerns.

If you have any suggestions or comments about your visit, please either speak to a member of staff or contact the patient advice and liaison service (PALS) on 020 3312 7777 (10.00 – 16.00, Monday to Friday). You can also email PALS at imperial.pals@nhs.net The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street
London W2 1NY

Email: ICHC-tr.Complaints@nhs.net

Telephone: 020 3312 1337 / 1349

Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:
imperial.communications@nhs.net

Wi-fi

Wi-fi is available at our Trust. For more information, visit our website: www.imperial.nhs.uk