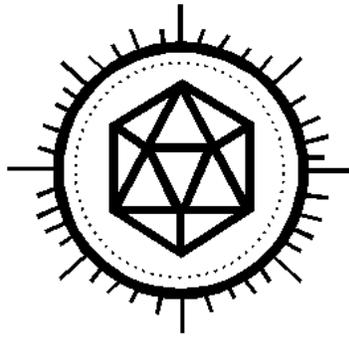


What Everyone Should Know About CMV



What Everyone Should Know about CMV is an outreach program of the National Congenital CMV Disease Registry. The CMV Registry is directed by Dr. Gail J. Demmler, Associate Professor of Pediatrics and Pathology, Baylor College of Medicine; Houston, Texas. The staff includes Carol Griesser, R.N.

We wish to thank the parents, teachers, doctors, therapists and medical personnel who work with children and infants with congenital CMV disease. The time, efforts, and care that you provide are worth much more than you know and are so greatly appreciated by many. We also wish to thank Allison Istas, M.P.H., for her valuable help in producing this brochure and Peggy Sterling, C.P.F.T., for her assistance with the visual artwork displayed in this brochure.



The above figure represents the complex structure of cytomegalovirus

What is CMV?

Cytomegalovirus (CMV) is a common virus that infects people of all ages and in all parts of the world. In the United States, between 50% and 85% of adults will be infected with CMV by the age of 40. However, in many other countries most people acquire CMV as children or adolescents. Most infections with CMV are “silent,” meaning the person infected has no signs or symptoms. However, CMV infection is considered a significant public health problem because it can cause disease in unborn babies and in people with a weakened immune system. Other viruses that are related to CMV include: varicella-zoster virus (VZV) which causes chickenpox and shingles, Epstein-Barr virus (EBV) which causes infectious mononucleosis, herpes simplex virus (HSV) which causes cold sores and genital ulcers, and human herpes virus 6 (HHV-6), which is associated with fever and rash in infants and young children.

About CMV

How do you catch CMV?

Person-to-person contact. - CMV is spread from one person to another, usually by close and prolonged contact with bodily fluids. Bodily fluids in which CMV can be found are urine, saliva, blood, feces, tears, breast milk, semen, and cervical secretions. Several examples of how a person may catch CMV from someone shedding the virus include kissing, sexual intercourse, sharing eating and drinking utensils, and sharing mouthed toys. You cannot catch CMV by merely being in the same room with someone, unless bodily fluids are exchanged. Additionally, there is no information to indicate CMV is transmitted in the air.

Transplants and transfusions. - CMV may be spread to organ and bone marrow transplant recipients and to patients who receive a blood transfusion from a donor with an active or past CMV infection.

Mother to newborn baby. - CMV commonly is transmitted to newborns through the mother's breast milk or by contact with cervico-vaginal secretions at the time of birth. This type of transmission is a natural and usually safe way for a mother to transmit CMV to her healthy infant, full term because the baby has the mother's natural immunity to the virus.

Mother to unborn baby. - CMV can be transmitted to the unborn child of a mother with a primary or a recurrent CMV infection. When a baby catches CMV prior to birth it is known as a congenital CMV infection. Approximately 90% of all infants who are infected with CMV prior to delivery are born without symptoms of the virus; however, the remaining 10% will have varying degrees of abnormalities.

What happens in the body during a CMV infection?

When CMV causes an infection for the first time it is called a primary infection. Just as with all infections, the body begins to fight CMV by producing antibodies and immune cells. While there is an active infection in the body, CMV will be excreted or shed in body fluids. After infection however, the virus remains in the body in a latent or inactive state, usually for life. CMV antibodies will be present for life as well.

Like other viruses in its family, it is possible for CMV to reactivate (act like a new infection). This type of infection is a recurrent infection and may occur at any time, but especially when the immune system becomes altered or weakened. When reactivation occurs, CMV antibody levels may increase and viral shedding may reoccur.

What are the usual signs and symptoms of acquired CMV infection?

When a person is infected with CMV anytime after birth, it is known as an acquired infection. In normally healthy children and adults, CMV infection is usually not a concern. Ninety percent of the time it will not produce any signs or symptoms of infection. However, occasionally a flu-like or mononucleosis type of illness may occur and produce symptoms such as fever, sore throat, fatigue and swollen glands.

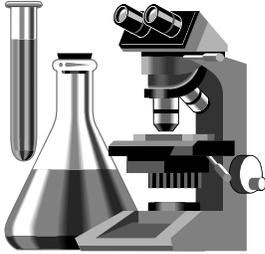
In persons with a weakened immune system, such as patients who are infected with HIV, organ/bone marrow transplant recipients, chemotherapy/ radiation patients, and people on steroid therapy, the signs and symptoms of CMV infection can be serious. Signs and symptoms can occur when an old CMV infection reactivates or when the person catches the virus for the first time. CMV infection in people with a weakened immune system puts them at risk for pneumonia, retinitis (an infection of the eye that can cause blindness), hepatitis (inflammation of the liver), esophagitis and colitis (gastrointestinal diseases), meningoencephalitis (an infection of the brain and the fluid that surrounds it), and even death.

Congenital CMV Infection

How common is CMV in newborns?

CMV is the most common congenital infection that is passed from mother to unborn baby. Of the estimated 4 million infants born each year in the United States, approximately 1% will be congenitally infected with CMV. Most (90% or about 36,000 infants each year) of the congenitally infected infants will be symptom free; however, the remaining 10% (about 4,000 infants each year) may have one or multiple abnormalities.

How do you make a diagnosis of congenital CMV infection?



The diagnosis of congenital CMV infection is confirmed by isolating (growing) the virus from urine, saliva, or tissue that is collected during the baby's first three weeks of life. Urine usually is tested because it contains the highest concentration of the virus. A positive viral culture collected beyond the three-week period but within the first year of life should be considered a possible congenital CMV infection, but also may be an acquired CMV infection.

The three-week period is important because after this time CMV can be isolated from babies that were infected during delivery or just after birth (for example, through breast milk). Unlike congenitally infected babies, infants who acquire CMV during or after birth do not appear to be at risk for physical and mental disabilities.

What are the signs and symptoms of congenital CMV disease?

Signs and symptoms of congenital CMV infection that are observed at birth include: small head size (microcephaly), small body size, little red spots under the skin (petechiae), enlarged liver (hepatomegaly), enlarged spleen (splenomegaly), yellow color of skin and eyes (jaundice), low blood count (anemia and/or thrombocytopenia), pneumonia, seizures, abnormal muscle tone, calcium deposits in the brain (intracranial calcifications), vision loss, and hearing loss. Although some of these conditions may resolve, many children will have life-long disabilities of varying degrees. Possible disabilities associated with congenital CMV disease are deafness, blindness, physical and motor impairment, seizure disorder, developmental differences and learning delays.

What problems are associated with a "silent" CMV infection?

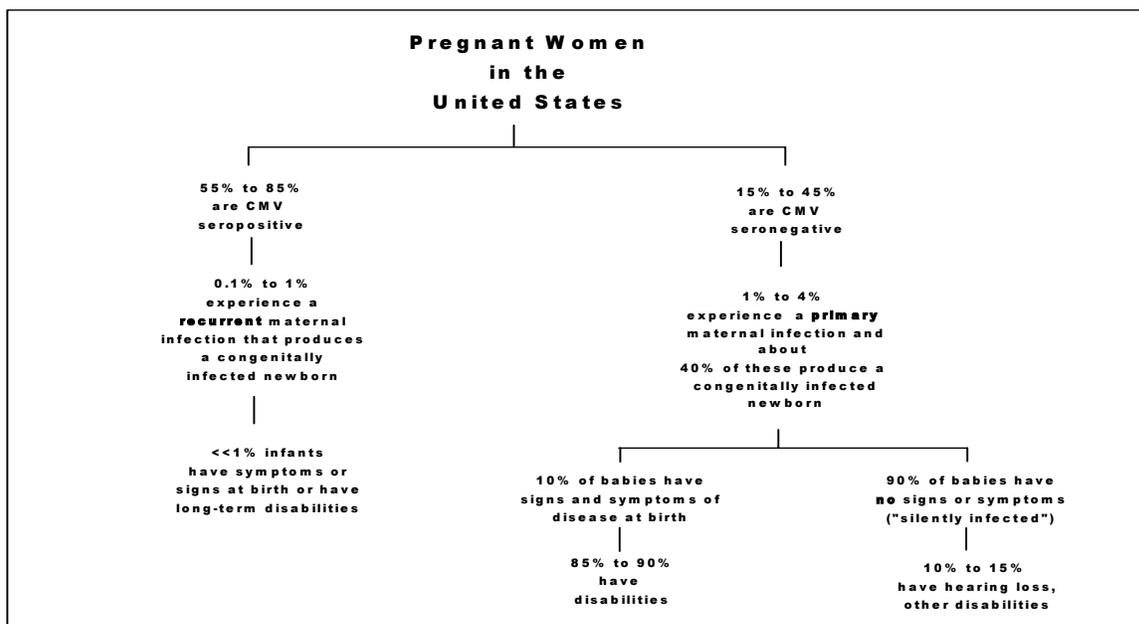
The majority of infants born with congenital CMV infection have a "silent" or symptom-free infection. Because these infants have no symptoms or abnormalities due to CMV at birth, the infection often goes unnoticed and undocumented. Unfortunately, they do not go totally unharmed by the CMV infection. Between 10% and 15% of all children born "silently infected" with CMV will develop varying degrees of hearing loss shortly after birth or during childhood. It is possible these children also may rarely experience vision problems or developmental and learning differences.

Congenital CMV Infection

What are the chances my unborn baby has CMV?

The effect of CMV on the unborn baby is may be serious when a woman catches the virus for the first time when she is pregnant. Between 1% and 4% of healthy women will catch CMV for the first time while they are pregnant (primary infection). Less than half (about 40%) of these women will pass the virus to the fetus and only 10% of the infected infants will have symptoms or abnormalities at birth.

Almost always less severe are congenital CMV infections caused by a mother's recurrent CMV infection. When a woman previously infected with CMV becomes pregnant, it is possible for her to pass the virus to her unborn child through a recurrent infection. However, less than 1% of pregnant women that had CMV prior to pregnancy may experience a recurrent infection and less than 1% of those recurrent infections will result in a baby being born with problems associated with CMV infection. See the chart below



Should I find out if my child is still shedding the virus?

CMV is a common virus that is shed by many young children, not just those who have congenital CMV infection. Most children who are congenitally infected with CMV will shed the virus through toddler and preschool age. Infants and children who acquire CMV after the newborn period also may shed CMV for a prolonged period of time. The virus will affect each child differently and the length of viral shedding may vary. Viral shedding can range from just a few months to eight years of age, and possibly longer.

It is not necessary to routinely determine if your child still has the virus active in the urine or saliva because its presence does not appear to influence or predict problems. Furthermore, schools, teachers, and therapists should not require your child to be tested for CMV shedding before being accepted into a program.

Congenital CMV Infection

When a diagnosis of congenital CMV has been made, what type of follow-up is recommended?

As with any newborn, regularly scheduled follow-up visits with the child's primary pediatrician or family doctor are advised. At birth he or she should have baseline laboratory tests to determine what organs in the body have been affected by the virus. These tests include: complete blood count, platelet count, and liver function tests. If laboratory results are abnormal, follow up testing should be conducted. Also at birth, to see if the virus has damaged the central nervous system, children with congenital CMV infection should have a computerized tomography (CT) scan of the brain, an eye exam by an ophthalmologist, and a hearing test. Thereafter, at least annual hearing and visual exams are recommended. Because a child with congenital CMV infection may have special needs, her or his growth and development should be followed carefully. Also, unless there is a specific contraindication known, children with congenital CMV infection should receive the routine immunizations recommended for all children.

Will my child's hearing loss get worse?

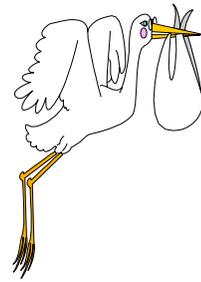
The most common disability associated with congenital CMV infection is hearing loss that is almost always progressive (worsens over time). Tcareful follow-up with an audiologist annually is recommended to monitor for changes. Early detection of hearing loss and proper intervention improves a child's ability to keep pace with developmental milestones, especially ladevelopment. Children with a significant hearing loss may benefit from hearing aids or other devices (check with an audiologist). Unfortunately, there ismedical treatment available at this time to prevent or lessen the effects of the hearing loss associated with congenital CMV infection.



CMV and Pregnancy

I am thinking about becoming pregnant. Is there any test that can be done to show if I could be at risk for catching CMV?

Every woman of childbearing age should consider knowing her CMV status. Prior to pregnancy, consult your doctor to have a blood sample drawn and a CMV antibody test performed. If results are positive for CMV IgG antibody, you most likely had CMV sometime before in your lifetime. A positive CMV IgG antibody result rarely means you are experiencing a new infection. A CMV IgM antibody test may help distinguish between a new infection (IgM positive) or an old infection (IgM negative).



If, on the other hand, the original CMV IgG antibody test result was negative, you have no CMV antibodies; and thus, you are susceptible to catching the virus for the first time. In this case it is wise to practice the precautionary measures (see page 10) that may reduce your risk of catching CMV during your pregnancy.

If I have given birth to a baby with CMV, should I be concerned about future pregnancies?

The risk of delivering a second child with congenital CMV disease is remote. It is possible for your previous CMV infection to become active like a new infection again (recurrent infection). However, in healthy pregnant women, recurrence does not pose the same risk for serious disease in the newborn as a primary or first-time CMV infection. If you have previously had the virus, your body has antibodies against CMV which, along with other immune factors, appears to protect the fetus from serious illness due to CMV infection.

Precautions & Preventions

Can I prevent catching CMV?

CMV infections are common in toddlers and preschool age children, and the virus frequently is transmitted in family or group day-care settings. In fact, most people will experience a CMV infection at sometime. However, there are special times, such as during pregnancy, when CMV infections should be avoided, if possible. The spread of the virus can be controlled by practicing good hygiene techniques.

The "Universal Precautions" practiced by health professionals and others who come in contact with body fluids are sufficient to prevent transmission of CMV.

Although no actions can totally eliminate all risks of catching CMV, precautionary measures that can be taken to help control the spread of infection in the home and other settings include:

Do not kiss young children under 5 or 6 years of age on the mouth or cheek. Instead, kiss them on the forehead or the top of the head and give them a big long hug.

Do not share food, drinks, or items such as utensils or toothbrushes with young children.
Wash your hands with soap and water after diaper changes or after contact with a child's saliva. Day-care center workers also may wear gloves when changing the diapers of young children.

Since young children, especially toddlers, frequently put toys in their mouth, it is recommended the toys be washed with soap and water or wiped with a solution of one-part chlorine bleach to nine-parts water, followed by a tap water rinse.

Is there a vaccine against CMV?

There is no licensed vaccine against CMV at this time. However, research is being conducted on the safety and effectiveness of different experimental CMV vaccines.

Precautions & Preventions



Do wash hands after diaper changes and contact with bodily fluids.



Do not share food, cups or eating utensils.



Do kiss young children on the head or give them a big hug.



Do not kiss young children on the face or lips.

Therapy & Support

Can congenital CMV infection or disease be treated?

There are now several antiviral medications licensed for the treatment of serious CMV disease. Clinical research trials also are being conducted nationwide to see if antiviral treatment helps babies with severe disease at birth due to CMV infection. You may contact your doctor or the National Congenital CMV Disease Registry for the names of participants near you who are conducting these research treatment trials.

Is there a CMV support group?

It is important for you to know you are not alone and that many people can help you and your family. CMV is a misunderstood virus and the latest factual information about this virus is available for you, your family and friends, teachers, and health professionals.

A parent-to-parent support network also has been established. The support network is a list of families from all across the country who have a child with congenital CMV disease. Parents join for a variety of reasons but they mostly want support and advice from other parents with similar experiences. For more information about CMV, our parent-to-parent support network, or other services, please contact the National Congenital CMV Disease Registry.



This pamphlet has been made possible by the generous donations to the CMV Research Fund Baylor College of Medicine, Houston, Texas. Your donations to continue research on congenital CMV disease and infection are tax deductible and are greatly appreciated. Please make contributions payable to the “**CMV Research Fund**” and mail them to the following address:

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Visit us at our web site: <http://www/bcm.tmc.edu/pedi/infect/cmV>

Glossary

Antibody	Immune substance in the serum portion of the blood that helps fight off and control the infection or disease. There are at least two types of antibodies, IgG and IgM, produced in response to a CMV infection.
CMV IgG	Antibody made at the time of first infection. It persists throughout life after a CMV infection.
CMV IgM	Antibody made early at the time of the first infection with CMV. It usually disappears within 12 to 18 weeks and, therefore, can be used as indication of a recent infection in healthy individuals.
Seropositive	Antibody (IgG) <u>present or positive</u> in serum ("immune").
Seronegative	Antibody (IgG) <u>absent or negative</u> in serum ("non-immune").
Infection	Entry of an agent, such as the virus called CMV, into the body. Usually there is production of an immune response. Infection may or may not be associated with disease.
Disease	Damage to tissues that gives signs and symptoms.
Acquired Infection	Infection with CMV that occurred sometime after birth.
Primary CMV Infection	The first time someone catches CMV infection.
Reactivated CMV Infection	A type of recurrent CMV infection. It is a prior infection that has become active again, usually causing viral shedding and rarely causing symptoms of infection and viral shedding.
Re-infection	A type of recurrent CMV infection. It is a repeat infection with a new strain of the CMV virus. This type of infection is very unusual and may only occur during special circumstances. Its consequences are unknown at this time.
Congenital Infection	Infection passed from mother to unborn child prior to birth. It is documented by isolation of the virus from a body fluid, such as urine, collected in the first 3 weeks of the baby's life.
Virus Shedding	Presence of the virus active in body fluids, such as urine, saliva, breast milk, semen, and cervical secretions. Virus shedding can be detected by a viral culture. It also may be called virus excretion.
Immunity	Body's ability to resist infection based on the production of antibodies and white blood cells.

Notes
