Facts About Congenital CMV

- **Congenital CMV is the most common cause of birth defects and childhood disabilities in the U.S.**
- It is the most common congenital (present at birth) infection in the United States
- Each year in the U.S. about 40,000 children are born with congenital CMV infection
- **EVERY HOUR** a child becomes permanently disabled because of congenital CMV
- Approximately 1 in every 150 children is born with congenital CMV
- Approximately 1 in 750 children is born with or will develop permanent disabilities caused by congenital CMV (that is 8,000 annually!)
- More children are disabled each year from CMV than from Down syndrome, fetal alcohol syndrome or neural tube defects/spina bifida
- It is the second leading cause of mental retardation, second only to Down syndrome
- It is one of the (if not *the*) leading cause of cerebral palsy in children
- It is the leading cause of non-hereditary deafness in children
- In the U.S. about half of all expectant mothers have never been infected with CMV, which puts their unborn baby at risk!
- There are approximately 400 fatal cases of congenital CMV each year.
- Possible outcomes for a baby born with congenital CMV: death , deafness, mental retardation, cerebral palsy, seizures, blindness, brain damage, growth problems and more.

About the Brendan B. McGinnis Congenital CMV Foundation

The Brendan B. McGinnis Congenital CMV Foundation is a non-profit 501(c)(3) established in 2007 by Tracy McGinnis, whose son Brendan is severely disabled and developmentally delayed due to congenital CMV. The primary goals of the Foundation are to raise public awareness about congenital CMV, to raise donations to support research for a vaccine for CMV, and to affect change in the medical community so that physicians will begin to test women for CMV prior to pregnancy. Ultimately, our mission is to save babies yet to be born from suffering the potentially devastating consequences of congenital CMV.

We need your help.

Please pass this information on to help us educate women about this common virus that is basically unknown to the general public, but is statistically at epidemic levels.

If you are a woman who does not know her CMV status and you plan to have a baby, find out your status. Ask your doctor to do a CMV antibody test or a CMV avidity screen.

Please also remember our foundation when you are making your charitable contributions. We depend upon your financial assistance to help us reach our goals and ultimately save lives by eradicating this potentially life-altering virus.

Brendan B. McGinnis
Congenital CMV Foundation

To contact us, learn more about CMV, or to donate to the Brendan B. McGinnis Congenital CMV Foundation, go to:

www.cmvfoundation.org

P.O. Box 45405, Omaha, Nebraska 68145 USA

For further information go to:
www.cdc.gov/cmv

Why You Need to Know About Congenital Cytomegalovirus (CMV) Infection!

If you are considering having a baby, this is information you need to know!

Do you know that *every hour* another child becomes permanently disabled because of congenital CMV?

What is CMV?

CMV stands for cytomegalovirus. CMV is a common virus that approximately 50% to 80% of adults in America have by the time they are 40 years of age. It is often asymptomatic, meaning showing no symptoms. Most people contract the virus as children. CMV is a virus in the herpes virus family, a group of related viruses that includes Epstein-Barr Virus (mononucleosis virus) and Varicella Virus (the virus that causes chickenpox). When CMV is contracted as a child or an adult, it is essentially harmless. A person will subsequently build immunity to the virus once they have contracted it. However, there are circumstances when the CMV virus can have disabling, even fatal, consequences, such as when the virus infects an unborn baby.

Congenital CMV

Congenital CMV is the most common congenital (meaning present at birth) infection in the U.S. Congenital CMV is the term used in the situation when a newborn infant tests positive for the CMV virus at the time of birth, meaning that the virus was contracted when the baby was still in the womb. CMV is the most common virus transmitted to a pregnant woman's unborn child. The virus is transmitted to the unborn child via the placenta. The virus then enters the unborn baby's system, where it can have devastating, even fatal, effects on the developing baby. The brain of the unborn baby is particularly targeted by the virus, and infection results in a wide range of neurodevelopmental disabilities, including deafness, microcephaly (small brain), cerebral palsy, blindness or retinal scarring, mental retardation and seizures. Other developmental disabilities, such as autism, may be due to CMV infection. Tragically, the most severely affected babies may not even survive the effects of congenital infection.

How is CMV Contracted?

CMV is spread through contact with human bodily fluids, such as urine and saliva. As with many other viruses, it only takes brief casual contact with a contaminated surface, object or person to acquire the infection. For example, all it may take is sharing a glass or eating utensil with a CMV-positive individual, or kissing a young child who has CMV virus in his/her saliva on the mouth, and the virus can be transmitted. In fact, it is not uncommon for women to contract the virus for the first time from their toddlers or pre-school aged children, who in turn have acquired the infection from other children at school or in group daycare. The consequences of a primary (first time) infection in a woman can be tragic if she is pregnant at the time of acquiring the virus. Thus, women who have not been exposed to CMV and have young children (or work with young children) are at higher risk if they are considering future pregnancies, particularly if their young children attend group daycare. The Center for Disease Control (CDC) recommends that pregnant women who are negative for CMV, or who do not know their CMV status, avoid kissing young children, even their own, on the mouth or cheek. See www.cdc.gov/cmv

How Can I Protect My Unborn Baby or Future Pregnancies?

Find out your CMV status prior to getting pregnant. If your blood test indicates that you have never had CMV, discuss the risks with your doctor, and closely follow CDC guidelines for taking extra hygienic precautions while pregnant. Remember, this includes care in handling bodily fluids of your own children, as in kissing your children on the face, changing diapers or sharing utensils with them. Refer to our website, www.cmvfoundation.org, or the CDC website for detailed recommendations.

Is There a Cure for CMV, or a Vaccine?

No, there is no cure and no vaccine, although a drug called ganciclovir is useful for some babies with congenital CMV. If your baby has congenital CMV infection, you should discuss the option of ganciclovir with your baby's doctor. There are only a handful of researchers worldwide who are actively working on finding a vaccine for CMV. Funding to support these researchers is also very limited.

Why Haven't I Heard of CMV Before Now?

In short, there is no answer. One of the primary missions of the Brendan B. McGinnis Congenital CMV Foundation is to educate women about CMV since many of the physicians have failed to do so. As well, we aim to change this lack of CMV education in the Ob-Gyn community and have CMV counseling and testing become a standard part of every woman's care *prior* to pregnancy.

What Can I Do to Help Find a Vaccine?

There is limited funding available for this research. One goal of the Foundation is to contribute to increased funding for research to help enable vaccine research. We know from our experience with congenital rubella (German Measles), a virus infection that used to cause birth defects in newborns a generation ago, that an effective vaccine can effectively eradicate the disease from the population altogether. Through increased public awareness, combined with increased pressure on the medical community to educate and test women, it is our hope that funding for vaccine research will be increased substantially. Until that time, we rely on public donations to support these goals.