

# Fact Sheet: Congenital Cytomegalovirus (CMV)



## **What is congenital Cytomegalovirus (CMV)?**

The #1 viral cause of birth defects. It causes more disabilities than Down syndrome. After genetics, it is the second most common cause of hearing loss. Between 50% and 80% of adults in the U.S. are infected with CMV by 40 years of age. According to the CDC:

- Every hour, congenital CMV causes one child to become disabled.
- Approximately 1 in 150 children is born with congenital CMV infection (30,000 in the U.S. each year).
- About 1 in 5 of congenitally infected children is permanently disabled.

## **Why don't doctors warn women of childbearing age about CMV?**

They don't realize how prevalent it is. Fewer than half (44%) of OB/GYNs surveyed reported counseling their patients about preventing CMV infection. "The virtual absence of a prevention message has been due, in part, to the low profile of congenital CMV. Infection is usually asymptomatic in both mother and infant, and when symptoms do occur, they are non-specific, so most CMV infections go undiagnosed," according to CDC's Dr. Cannon, co-author of "Washing our hands of the congenital cytomegalovirus disease epidemic."

## **What percent of women of child-bearing age know about CMV?**

Only 22% of women surveyed know about CMV prevention.

## **What is the annual cost of caring for children disabled by congenital CMV?**

\$1-2 billion according to the CDC's Dr. Michael Cannon.

## **Which women are most at risk for contracting CMV?**

"75% of women with a primary infection during pregnancy acquire CMV from their own child under two years of age," said Stuart Adler, M.D., Stuart Adler, M.D., Professor Emeritus of Pediatrics and Professor of Microbiology and Immunology Virginia Commonwealth University.

Data from a variety of day care center studies indicate that between 44 to 100% of two year olds at a single given time were shedding cytomegalovirus. Day-care workers are at greater risk than people who don't work in such a setting.

## **Will it really make any difference if women learn how to prevent contracting CMV?**

Yes. A study in France and in U.S. proved women educated about prevention reduced transmission to their unborn by at least 50%.

## **How can CMV be avoided?**

- Wash hands often with soap and water for 15-20 seconds, especially after wiping runny noses, changing diapers, picking up toys, etc. If soap and water are not available, use alcohol-based hand gel.
- Use soap and water or a disinfectant to clean hard surfaces that have been contaminated by secretions (the virus lasts approximately 30 minutes on surfaces).
- Don't share food, drinks, or eating utensils with young children.
- Don't kiss young children on the lips—give them a big hug and a kiss on top of the head.
- If you work in a day care center, limit close contact with children younger than 2½ years of age, especially if you've never been infected with CMV or don't know if you've been infected. CDC: CMV Prevention Flyer available.



**Can you treat CMV?** "CMV infection in newborns can be treated with ganciclovir by IV or valganciclovir by oral route - treatment reduces hearing loss progression and improves growth and head size/brain growth and improves developmental milestones. It is now recommended for newborns with symptomatic CMV disease at birth and even those that appear healthy yet fail their newborn hearing screens because of deafness," says Dr. Demmler-Harrison, Director, Congenital CMV Disease Registry and Research Program.

## **What can our state do to protect our children from congenital CMV?**

Pass a bill similar to Utah's H.B 81 (2003) requiring its Health Department (Children's Hearing and Speech Services) to teach CMV prevention and test newborns for the disease if they fail two hearing screen tests so their families can be educated about treatment options.

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**Photos:** Elizabeth Saunders (born with congenital CMV) with her big sister in '89 and shortly before she died of a seizure at 16 in '06. Her mother, Lisa Saunders of Mystic, Connecticut, is the parent representative of the Congenital CMV Foundation and author of memoir, Anything But a Dog! The perfect pet for a girl with congenital CMV. Contact: LisaSaunders42@gmail.com or 845-222-8593.