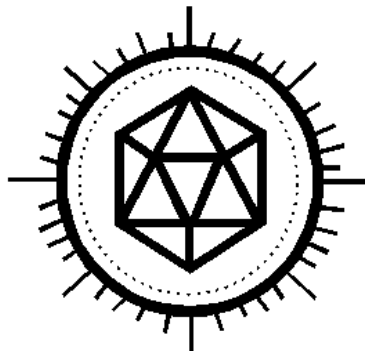




Welcome to the first issue of *CMV Updates*, a biannual informative bulletin about congenital cytomegalovirus (CMV) disease and infection. In each edition we hope to inform our readers of the latest research and knowledge about CMV as well as touch on issues, questions, and concerns of parents, medical personnel, and therapists providing care for children with congenital CMV disease. Through this medium we also hope to increase public awareness of congenital CMV infection and offer a parent-to-parent support network for families coping with CMV.

## What is CMV?



*The above figure represents the complex structure of herpesviruses.*

Cytomegalovirus is a member of the *Herpesviridae* family of viruses. It is a very common virus that infects people of all ages and in all parts of the world. Cytomegalovirus is spread by person-to-person contact with body fluids from a person who is excreting the virus, from mother to fetus, or by blood transfusion or organ transplantation from a CMV seropositive donor. Congenital CMV infection occurs when CMV is transmitted from mother to fetus. Congenital CMV disease is diagnosed when an infant is born excreting the virus and has symptoms of the infection. In the United States, approximately 4,000,000 babies are born each year and one percent (40,000) of them will have congenital CMV infection. The majority of these infected infants will not experience any obvious symptoms of the infection; however, 5 to 10 percent (up to 4,000) will have one or more symptoms and/or abnormalities characteristic of congenital CMV. Some problems at birth will resolve, such as an enlarged liver or spleen. However, abnormalities involving the central nervous system produce chronic conditions, such as deafness, blindness, seizures, cerebral palsy, and developmental delays.

## Did You Know . . .

### There Is a Congenital CMV Disease Registry?

Yes, there is a congenital CMV disease registry and it was established in 1990. In January of 1990, following a meeting of infectious disease specialists from around the country and sponsored by the Centers for Disease Control and Prevention (CDC) and the Infectious Diseases Society of America (IDSA), the National Congenital CMV Disease Registry was formed. Based at Baylor College of Medicine in the Texas Medical Center, the Registry collects information on infants with symptomatic congenital CMV disease born since 1990.

The goals of the Registry generally have been to watch for disease patterns over time, to identify characteristics that may increase a mother's risk of delivering an infant with congenital CMV, and to provide the groundwork for future intervention programs and collaborative research. All newborns with a confirmed diagnosis of congenital CMV disease are eligible to be registered. Here's how it works. Unlike AIDS, chickenpox, or measles, CMV is not a required reportable disease at the national level and only a handful of states require that physicians report cases of CMV to their department of health. Therefore, the Registry relies on dedicated physicians and researchers across the United States that have agreed to voluntarily report all new cases of symptomatic congenital CMV infection in their area. We currently have 42 infectious disease specialists and neonatologists (located in 32 cities in the USA, and one in Canada--see map), who have agreed to notify the Registry of new

patients. Registry reporting forms are completed by a physician or nurse and sent to Baylor. Data collected by the Registry are then shared with the CDC.

Since 1990, 360 cases of symptomatic congenital CMV infection have been reported to the Registry. Therefore, only 2% of the anticipated number of infants born with congenital CMV disease since 1990 have been reported. The most common symptoms and abnormalities at birth shared by infants reported to the Registry are shown in Table 1.

Our recent findings indicate that maternal factors such as age, race, and socio-economic status may be important indicators of what women are at the greatest risk of delivering infants congenitally infected with CMV. Details of this report will be published in the March issue of the medical journal, *Clinical Infectious Diseases*.

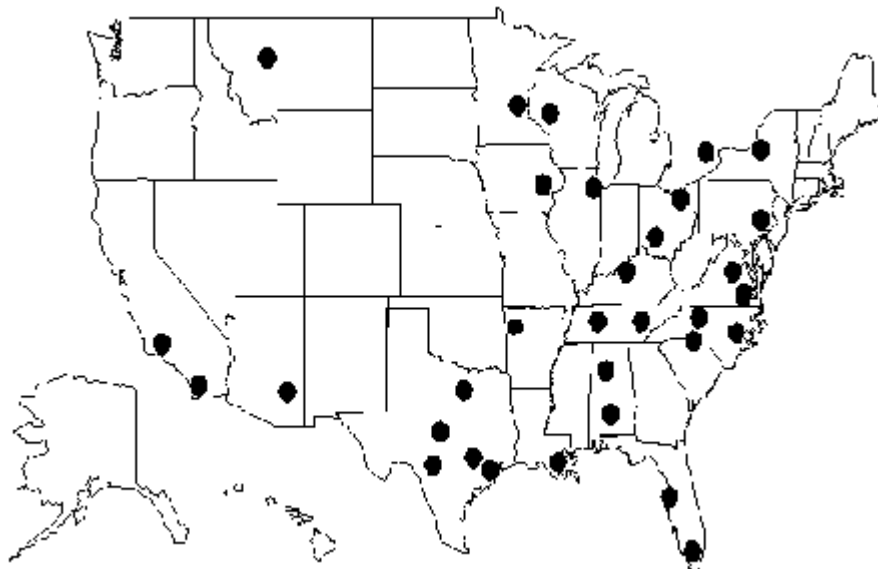
**Table 1: Common Symptoms and Abnormalities at Birth Caused by Congenital CMV Infection--The National Congenital CMV Disease Registry**

Characteristics	No. Infants (%)
Petechiae or purpura	189 (53)
Small for gestational age	170 (48)
Thrombocytopenia	171 (48)
Enlarged liver	162 (45)
Enlarged spleen	153 (43)
Intracranial calcifications	134 (37)
Jaundice at birth	130 (36)
Microcephaly	128 (36)
Hearing impairment	87 (24)
Hemolytic anemia	39 (11)
Chorioretinitis	34 (10)
Seizures	31 (9)
Pneumonia	31 (9)

The Registry exclusively contains information recorded at or near birth and at this time does not seek follow-up information on any reported cases. The Registry is a confidential data base of symptomatic congenital CMV disease cases.

For further information about the National Congenital CMV Disease Registry, please contact us via the address and phone numbers listed below.

## Locations of Congenital CMV Disease Experts Working with the CMV Registry



### Question & Answer Corner

**Q** How do you make a diagnosis of congenital CMV infection?

**A** The diagnosis of congenital CMV infection is established by isolating the virus from urine, saliva, or tissue during the first three weeks of life. Urine is usually cultured because it contains the highest concentration of the virus. If the specimen is not collected within the first three weeks of life and the result is positive, the child could have been perinatally or postnatally infected. Serology testing for antibodies to CMV or TORCH titers are usually not helpful.

**Q** When a diagnosis of congenital CMV has been made, what type of follow-up would you recommend?

**A** As with any newborn, regularly scheduled follow-up visits with the child's primary pediatrician are advised. At birth he or she should have a baseline CT scan of the brain, eye exam, and hearing test to see if the virus has damaged the central nervous system. Because a child with congenital CMV infection has special needs, his or her development should be followed carefully, at least on an annual basis. A diagnostic Auditory Brainstem Response (ABR) evaluation should be done yearly during infancy and behavioral audiograms should be conducted on a routine basis thereafter. After the initial eye exam, ophthalmologic follow-up should be done as advised by the primary pediatrician or ophthalmologist. Very recent information suggests regular eye exams should be considered in all children with congenital CMV infection or disease, whether or not eye disease was discovered at birth. (Reference: Boppana, et al. *Pediatric Infectious Diseases Journal* 1994;13:1139-1142).

Answers were provided by Carol Griesser, R.N., and Gail Demmler, M.D.

Do you have questions or maybe answers about CMV that you would like published? Write to us; we would like to hear from you.

### Parent-to-Parent Support

Do you feel like you are the only person in the world with a child that has congenital CMV disease? You are not alone. If you would like to contact other parents that may be dealing with situations similar to yours, become part of the CMV Parent-to-Parent Support Network. Call or write to us (see address and phone numbers below) and we will match you to parents or guardians of other children with congenital CMV infection that are in your region. When you contact us we will also put your name on the list to be shared with other interested parents. At this time our network is growing but it needs your help to blossom. Another parent network source is Mothers United for Moral Support, Inc. (MUMS). MUMS has a national parent-to-parent network for matching families of children with rare disorders or special needs. Contact Julie Gordon at (414) 336-5333 for more information.

## How are we doing?

To serve you best and to have an informative newsletter, we need your help. Please write in with your questions about CMV and comments about the newsletter. We are interested in knowing if there are certain topics that are of interest to you. Chances are that you're not alone and that someone else may be experiencing similar circumstances or have the same questions and concerns that you do. You may contact us at the following address or phone numbers:



*National Congenital CMV Disease Registry  
Feigin Center, Suite 1150  
1102 Bates Street, MC 3-2371  
Houston, TX 77030-2399  
Phone: 832-824-4387  
FAX: 832-825-4347  
[cmv@bcm.edu](mailto:cmv@bcm.edu)*

To be added to our mailing list, please send your request to us by the Subscription Form, or by postal mail or e-mail.

## NEWSLETTER SUBSCRIPTION AND PARENT SUPPORT NETWORK INFORMATION

### MAILING ADDRESS CHANGES CMV RESEARCH DONATIONS

- I would like to be (added to / deleted from) the CMV Updates mailing list.
- I would like to be added to the CMV Updates email list.
- I have an address change.
- I would like to receive information about the congenital CMV disease Parent-to-Parent Support Network.
- I would like to be deleted from the Parent-to-Parent Support Network.
- Enclosed is my \$\_\_\_\_\_ donation to continue research on congenital CMV disease and infection. Please make checks payable to the "CMV Research Fund," which is affiliated with Baylor College of Medicine and Texas Children's Hospital, Houston, Texas. All donations are tax deductible.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: (\_\_\_\_\_) \_\_\_\_\_

What is your interest in CMV infection?

- Parent/Family member of a child with congenital CMV disease or infection.
- Health care professional. Specify: \_\_\_\_\_
- Other. Specify: \_\_\_\_\_

### Detach and mail this form to:

CMV Registry, Feigin Center, Suite 1150 • 1102 Bates Street, MC 3-2371 • Houston, Texas 77030  
Telephone: 832-824-4387 • Fax: 832-825-4347 • E-mail: [cmv@bcm.edu](mailto:cmv@bcm.edu)