



My Baby has Congenital CMV Disease: Infant and Toddler Years

Infants and toddlers born with both symptomatic and asymptomatic congenital CMV infection are chronically infected with the virus for many years. This chronic infection almost always is "silent" and does not cause symptoms. Only a rare child will have persistent problems, such as low platelets or enlarged liver, associated with this chronic infection. Research has shown that both the symptomatic and asymptomatic infants and toddlers excrete the virus for an average of 3 to 4 years. Some children will stop excreting the virus as early as 6 months, and some will continue to excrete the virus for as long as 10 years. There is no reason to continue to routinely monitor the excretion of CMV in your child's urine or saliva. Furthermore, this "silent" excretion of CMV is not a reason to exclude your child from group day care, nurseries, or school environments. Your infant and toddler should receive routine physical examinations and individualized attention from your family physician or pediatrician. All routine immunizations should be administered, unless there is another specific contraindication not to do so. As your baby grows, the enlarged liver and spleen, jaundice, and skin rash will disappear. The abnormal blood tests, such as low platelets and hepatitis, also usually resolve over the first months of life. Special care should be given to note your child's growth. If your baby was born small, then "catch up" growth usually occurs during the first few months of life. If your child is able to breast feed (breast feeding is encouraged for all babies, including those born with congenital CMV infection) or bottle feed normally, then normal growth is expected. However, if your baby was premature, very ill as a newborn, or is developmentally disabled, then he or she may need to be fed by a special tube. An occupational therapist may need to teach your baby oral motor skills. Supplemental feedings through a gastrostomy (G-button) also may be necessary to meet your baby's caloric needs or to avoid aspiration into the lungs

if your baby's oral motor and swallowing skills are still developing. Frequent neurodevelopmental assessments, every 3 to 6 months, are recommended for all infants and toddlers born with congenital CMV infection. These assessments may be performed by your family physician or pediatrician, or by a specialist in developmental pediatrics. During these early months and years, high-severity disabilities, such as cerebral palsy and severe mental retardation, may be discovered. By 2 years of age, a language evaluation should be performed to determine oral expressive and receptive language skills, as well as symbolic play, to uncover important language problems that may need early intervention. Also, some infants and toddlers may develop seizures, and may benefit from medications that control seizures. Infants born with asymptomatic congenital CMV infection usually enjoy normal development during the infant and toddler years. It is important that all infants and toddlers with congenital CMV infection receive the interventions and therapy for disabilities, as needed and as required by federal law. These services are available through your public school system, as well as through private schools and professionals. Many states also offer Early Childhood Intervention (ECI) Services for infants from birth to 3 years who have disabilities or who are at risk for such disabilities. Your infant's hearing should be tested in the first month of life, then at 6 to 9 months of age, then at least annually thereafter. More frequent tests may be done if a progression of the hearing loss is noted. Progressive sensorineural hearing loss (nerve deafness) that worsens over time is experienced in over two-thirds of children with symptomatic congenital CMV infection, and in over 10% of infants born with asymptomatic congenital CMV infection. Infants with severe to profound hearing loss in both ears may be fitted for hearing aids in the first months of life. As they reach toddler age, they also may be candidates for a new technology called

cochlear implants which may restore some hearing. Also, if your child has a cold or ear infection, trapped fluid in the middle ear may cause additional "conductive" hearing loss and temporarily impair his hearing further. It is therefore very important to make sure your infant and toddler have all ear infections evaluated and treated promptly. Consultation with an audiologist and an otolaryngologist, experienced in the care of children with deafness, is recommended for all infants and toddlers with significant hearing loss. Regular examinations by an ophthalmologist are recommended, especially if your child had evidence of CMV eye disease, such as retinitis (infection of the retina or back of the eye), as a newborn. Usually the retinitis is "stable" and a permanent scar is formed that can cause loss of vision. It is extremely unusual, but not impossible, for the retinitis to worsen over time in symptomatically infected infants and toddlers. Children born with asymptomatic congenital CMV infection rarely have vision problems associated with CMV. The infant and toddler years are a time of growth, changes and challenges. With the proper care and appropriate early interventions, each child can reach his or her maximum potential!

INSIDE...

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You are welcome to duplicate this annually printed newsletter. Please direct your questions, comments, or helpful hints to:

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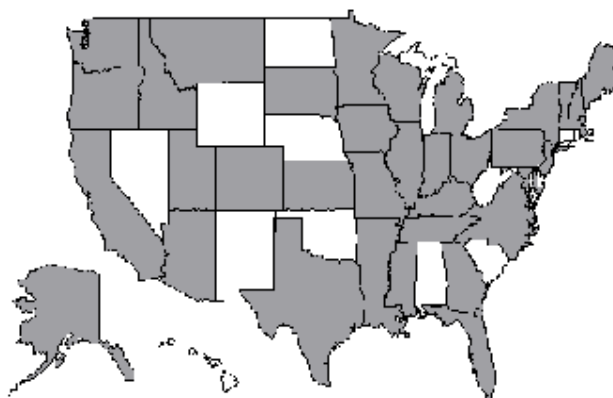
OUTREACH BULLETIN BOARD

Parent-to-Parent Support Network

Many times when parents learn that their child is born with congenital CMV infection, they are completely unaware that the virus exists; let alone that their baby is infected with it. The effects of CMV can vary greatly and in many cases outcome is nearly impossible to predict. When a family is faced with the many uncertainties of raising a child born with CMV, sometimes it is comforting to know that there are other families out there who are dealing with similar challenges.

One of the services of the CMV outreach program, here at the Registry, is to provide assistance through the National Parent-to-Parent Support Network. The network is a medium created for parents to share experiences, helpful information, or encouragement in caring for a child born with the virus. Our list of families on the network continues to grow. Nearly every U.S. state now has at least one family participating in the network. Also, we are delighted to report that we have several Canadian families who have added their names to the list. Shaded areas on the maps below indicate the states and Canadian provinces where families live who have joined the network. Incidentally, one family from Japan also is on the support list.

If you are interested in joining the network, either call or indicate your interest on the Subscription Form. If you choose to fill out the form, simply fax or mail it to us and then we will send you the parent permission slip for the network. After the signed parent permission slip is returned to us, a current list of all parents on the network will be mailed to you.



ATTENTION
Members of the CMV
Parent Support Network

We need your help with a couple of matters. First, we would greatly appreciate it if you would take a few minutes to update the information about your child on the list. Call, fax, e-mail, or write to us at your earliest convenience. Also, to help facilitate communication between parents, if you have e-mail, please forward it to us so that we can add it to the list. Many thanks to those parents who have already sent an update.

Second, if anyone knows of any helpful resources or services that he/she has found helpful in the care of a child with CMV, and you would recommend them to others, please let us know so that we can add the information to the parent resource list.

Study Participants Wanted

Babies are still needed for enrollment into the CASG (Collaborative Antiviral Study Group) Phase III Study to evaluate the safety and efficacy of ganciclovir (DHPG).

To be considered for enrollment, a baby must present with congenital CMV disease with CNS involvement, be screened for enrollment before 28 days of age, and have a positive CMV culture.

Please note that as of June 4, 1998, enrollment was closed for the MSL-109 study. If you have any questions regarding this study, contact the Central Unit.

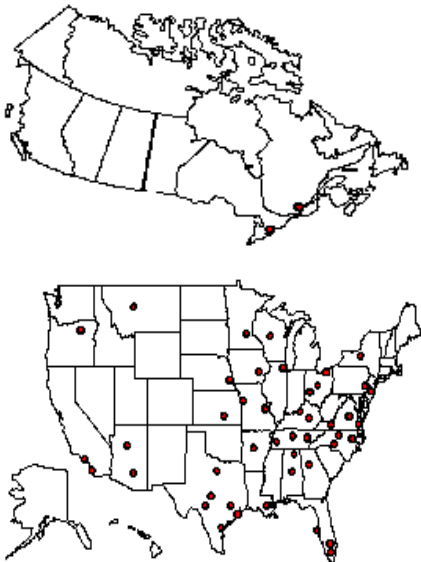
If you are a physician and have a patient to be considered for possible study enrollment, or if you want information on becoming a member of the CASG, please contact Jan Kiell, R.N., at the Central Unit of the CASG.

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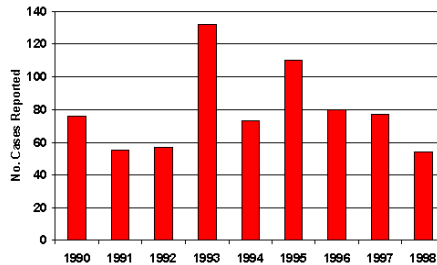
NEWS FROM THE CMV REGISTRY

The National Congenital CMV Disease Registry has now completed its ninth year! Established in January of 1990 at a workshop sponsored by the CDC and the IDSA and attended by 30 physician scientists, this national voluntary surveillance system records the maternal demographics and clinical manifestations of newborns born with congenital CMV disease. We now have 58 physicians from 48 institutions (see Graph 1) who have reported 677 cases of congenital CMV disease. The annual number of reported cases has remained relatively constant (Graphs 2 and 3). An update of the Registry activities was presented by Dr. Gail Demmler at the Perinatal Infection Section Program at a recent American Academy of Pediatrics meeting in San Francisco. A manuscript is in preparation and will be circulated in the near future to all Registry participants for review. So, if you are a participant and have a case or two you have been meaning to report, now is the time to send it in!!!!

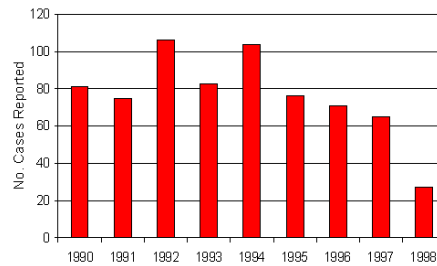
Graph 1:
**Location of Congenital CMV Registry
Participants in the U.S.A. and Canada**



Graph 2:
**National Congenital CMV Disease
Registry
No. Cases Submitted each Year**



Graph 3:
**National Congenital CMV Disease
Registry
No. Cases each Year by Birth Date**



The clinical characteristics of the infants reported are listed in Table 1. The most common clinical sign reported was petechiae or purpura, with small for gestational age, hepatosplenomegaly and thrombocytopenia also relatively common. It also is important to note that, despite numerous advances in the 1990s in fetal medicine and neonatal intensive care, 9% of reported cases of congenital CMV disease died.

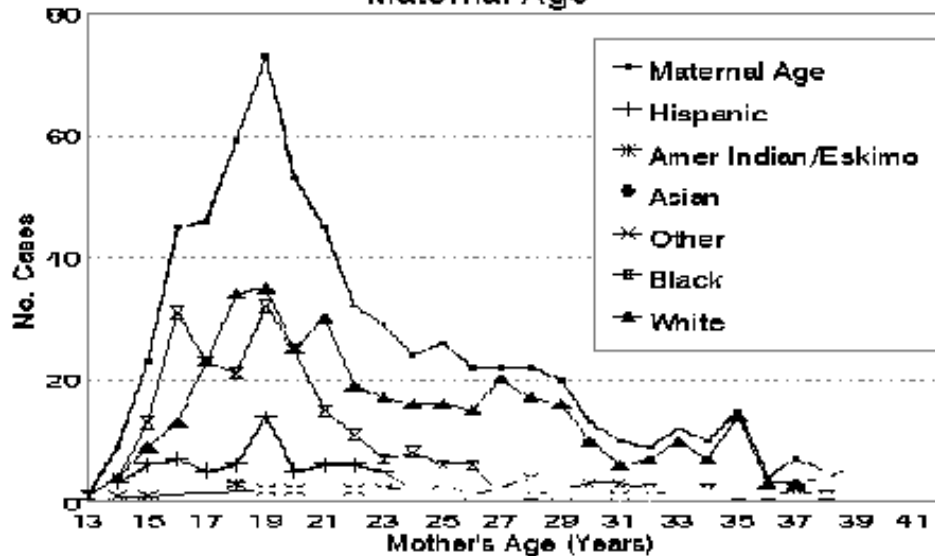
TABLE 1:
**Common Symptoms and
Abnormalities at Birth Caused by
Congenital CMV Infection
The National Congenital CMV Disease
Registry**

Characteristics	Infants (%)
Petechiae or purpura	358 (54)
Small for gestational age	309(47)
Thrombocytopenia	333 (53)
Enlarged liver	317 (48)
Enlarged spleen	298 (45)
Intracranial calcifications	252 (44)
Jaundice at birth	240 (37)
Microcephaly	257 (40)
Hearing impairment	189 (43)
Hemolytic anemia	72 (13)
Chorioretinitis	62 (12)
Seizures	55 (9)
Pneumonia	60 (11)
Neurological abnormalities	174 (29)
Bilirubin	242 (42)
ALT	156 (31)
Death	46 (9)
Coinfection	14 (8)
Treated	47 (24)

Another important piece of information gleaned from the CMV Registry data is the importance of maternal age (Graph 4). The mothers of reported infants appear disproportionately young, with a mean age of 22.6 (range of 13 to 42 years), with 40% of them being 19 years of age or younger. They also are commonly single (49%), and experiencing their first pregnancy (42%). Over

half of the mothers received Medicaid, and another 8% were uninsured at the time of their delivery. If intervention strategies, such a CMV vaccine, are implemented in the future, it will be very important to include teenaged mothers of lower income families.

**Graph 4:
National Congenital CMV Disease Registry
Maternal Age**



THE CMV REGISTRY IN CYBERSPACE

Yes, the CMV Registry is now on the information superhighway with our web site. All back issues of CMV Updates, our recently published informational CMV brochure, and other literature can be found at the site. Please visit us at:

www.bcm.tmc/pedi/infect/cm
and let us know what you think of it.

QUESTION AND ANSWER CORNER

Q My child is deaf from congenital CMV infection and wears hearing aids. Can I donate the used hearing aids he has outgrown?

A *New Eyes for the Needy will gladly accept a donation of your child's used hearing aids. This non-profit organization established in 1932 has helped millions of individuals who have visual and hearing impairments. The program receives and recycles donated hearing aids and eyeglasses that are then made available to needy individuals in the United States and other countries. In fact, donations of eyeglasses, hearing aids, and other items are essential to the success of this helpful program. For further information and to find out about other items they accept, you can reach them by calling: 973-376-4903. Or you can simply mail your child's used hearing aids to: New Eyes for the Needy, Inc., Dept. H, 549 Milburn Ave., Short Hills, NJ 07078. If any of our readers know of other agencies who would accept donations of used hearing aids or glasses, please let us know.*

Q My child's preschool teacher recently found out that my daughter was born with congenital CMV infection. Now they want to remove my child from the classroom because they are afraid of catching CMV from her. What should I do?

A *First of all, it is important to remember that many persons including teachers, therapists and others who have fears about catching CMV have incorrect information about the virus. Providing factual information about the transmission of CMV is the best way to calm their fears. Contact your child's teacher and offer to answer questions about CMV and if necessary, distribute literature about the virus. Informational material can be obtained from our website: www.bcm.tmc.edu/pedi/infect/cmV or by calling the National Congenital CMV Disease Registry at 713-770-4387. If after answering questions and providing factual information about CMV, your child is still faced with exclusion from the classroom, it is then important for you to know that exclusion from classroom or special education activities may be a violation of your child's civil rights. CMV is not*

characterized as a "communicable disease," and therefore, cannot be used as the sole reason to exclude your child. Furthermore, federal and state antidiscriminatory statutes have been enacted to protect the rights of handicapped persons. Consequently, if all else fails and you are unable to resolve the matter, you should consider seeking legal counsel. Always keep in mind that as a parent you are your child's advocate!

Do you have any questions about congenital CMV infection or related issues that you would like to be answered? If so, contact us with your queries and we will gladly answer them in the next issue of our newsletter.

OUTREACH BULLETIN BOARD continued

Look Who's in the News!

CMV Study Subject Gets Picture in Local Newspaper

Lucas Jardon, Houston CMV study participant, is pictured here along with his teacher Ms. Andrea Dejean, and some of his other classmates. Three-year-old Lucas attends Carpenter Elementary School in a rural East Texas town. Because Lucas is hearing impaired, he deals with special challenges. Lucas' mother Julie Corder, who undoubtedly is very proud of her son's many accomplishments, sent the article and newspaper picture to us. She tells us that Lucas is very fortunate to be in Ms. Dejean's class especially because she is also deaf and can better relate to others who deal with hearing loss in their everyday lives.



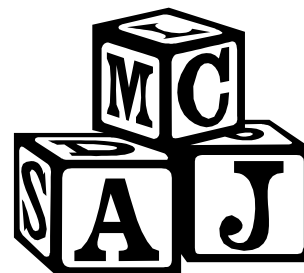
Lucas Jardon (1st child on the left) next to his teacher Andrea Dejean.

Support Network Family Highlighted on TV Feature

The Nickol family of Cincinnati, Ohio (members of the parent support network) participated in a television spot looking at congenital CMV disease. General factual information about the virus was presented and the Nickol family was interviewed. They were asked questions about how raising a child with congenital CMV disease has impacted their lives. This feature first aired on February 27, 1998, local Cincinnati ABC TV Station WCPO, Channel 9. For those interested in having this tape aired in their area, call your local ABC affiliate and ask them to request the tape from Station WCPO.

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

Please send correspondence to:
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 FAX: 832-825-4347
cmv@bcm.edu



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:

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