



CMV UPDATES



Fall 1996

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Hello, again! We hope everyone was able to endure the summer heat and is doing well. The National Congenital Cytomegalovirus (CMV) Disease Registry always welcomes your questions and concerns about CMV infection. Since our last newsletter, we have received many very good questions from parents, educators, therapists, and medical personnel. Therefore, to better serve everyone, this issue is largely devoted to common questions about CMV Infection and General information about the virus.

Q Is CMV a new virus?

A *Cytomegalovirus (CMV) comes from the term cytomegalia, meaning "large cells." It was initially described in the late 19th century to early 20th century as a rare cause of "cytomegalic inclusion disease" in the fetus and newborn. The virus was first isolated from tissue culture as recent as 1956. With the ability to grow the virus, more laboratory techniques developed, as did clinical and epidemiologic observations. Research showed CMV infected people of all ages and in all parts of the world. CMV is now well known as a serious viral infection to the fetus, newborn, and the immunocompromised patient. However, despite statistics that suggest 4,000 infants **each year** in the United States are born with signs and symptoms of CMV infection, congenital CMV lacks the public health attention it deserves.*

Q My doctor told me my CMV IgG antibody titer in my blood is positive and my CMV IgM antibody titer is negative. Because I am considering pregnancy, what does this mean to me?

A *A positive CMV IgG antibody titer result indicates you have at sometime during your life been infected with CMV and that you now have antibodies to the virus. A negative CMV IgM antibody titer indicates you do not have an active or current CMV infection. At this point if you should get pregnant, you are at minimal risk for having a child born with congenital CMV infection. On the other hand, if your CMV IgM antibody titer was positive, it suggests you are experiencing a new or recurrent CMV infection and you should consider delaying your pregnancy until your CMV IgM antibody titer turns negative (usually a couple months).*

Q A baby at our hospital has congenital CMV infection. Can this baby breast feed?

A *Because of the numerous benefits of breast feeding, CMV infection usually does not contraindicate breast feeding. For virus infected babies and healthy uninfected babies, a mother that has CMV may wish to breast feed her baby because it is a safe way for the baby to receive the mother's natural immunity to the virus.*

Q Should children with congenital CMV infection receive their normal childhood immunizations?

A *To our knowledge, congenital CMV infection and disease are not a contraindication to routine immunizations and we recommend routine immunizations for these children, as long as they do not have an underlying congenital or acquired immunodeficiency state or syndrome (for example HIV along with congenital CMV infection), or other contraindications to vaccinations.*

Q There are pregnant teachers and other care givers at our school who work closely with children known to have CMV infection. For their safety, should these employees be relieved from their duties in caring for these children?

A *Changing the duties of a teacher or care giver from children known to have CMV infection to other children may not reduce their risk of acquiring CMV. It is a common virus in all children. In fact, studies reveal that between 30 and 80% of children between the ages of 1-3 years of age who attend some form of group care are excreting CMV. In this setting transmission of CMV is usually transmitted from child-to-child by direct contact with bodily fluids such as saliva or urine. It also may be transmitted to care givers. Therefore it is wise for care givers in this type of setting to be aware of CMV and consider knowing their CMV antibody status. If results are negative, they are susceptible to catching CMV for the first time and it is a potential risk to the fetus if they are pregnant. On the other hand, if results of a CMV antibody titer (IgG) is positive, they have already acquired CMV at some time in their life and their risk is greatly reduced. Additionally, it is important for all care givers to practice good hygienic measures.*

This is achieved by hand washing with soap and water, especially after diaper changes and any contact with a child's bodily fluids. Kissing and sharing food or drink also should be avoided.

Q How long can the CMV virus stay alive on objects and surfaces?

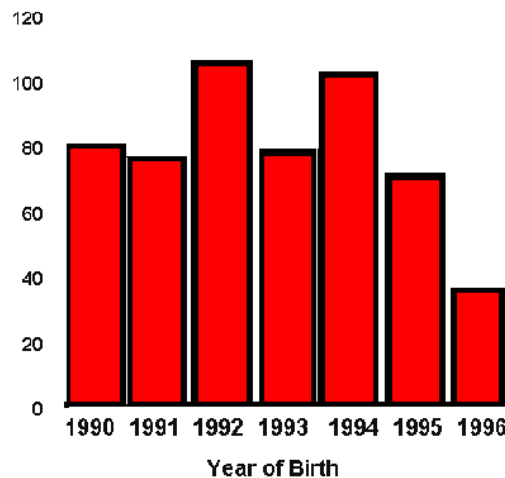
A CMV is a fragile virus and it does not live on objects and surfaces for very long. One study reported that CMV could be isolated from a smooth plastic toy 30 minutes after the child had mouthed the toy and set it down. Toys and other objects mouthed by young children may be easily disinfected by washing them with a solution of one part chlorine bleach to nine parts water, rinsing thoroughly with water, and drying. Non-immersible or stuffed toys should be allowed to air dry for several hours between use.

CMV Research Bulletin Registry News

As of the end of August, 1996, the Registry has received information on 547 babies born with congenital CMV disease since 1990. This number is approximately 2% of all the children born with symptomatic congenital CMV infection in the United States from 1990 -1996. These babies are reported to us from 39 major cities across the country and 1 city in Canada. Figure 1 is a breakdown of the number of reported cases we have received by year of birth.

Diagnosis within the first 3 weeks of life is mandatory to determine "confirmed" congenital CMV infection. This window is so important because positive test results beyond this time period do not differentiate between congenital infections and postnatal infections (acquired either during or after delivery). Ninety percent of the Registry's cases were confirmed within the first 21 days of life. For these cases, the average number of days between the birth of the baby and the date of laboratory confirmation (date the test was ordered in most cases) was 4 ½ days; range 0 - 21days.

**National Congenital CMV Disease Registry
Number of Cases by Year (N=547)**



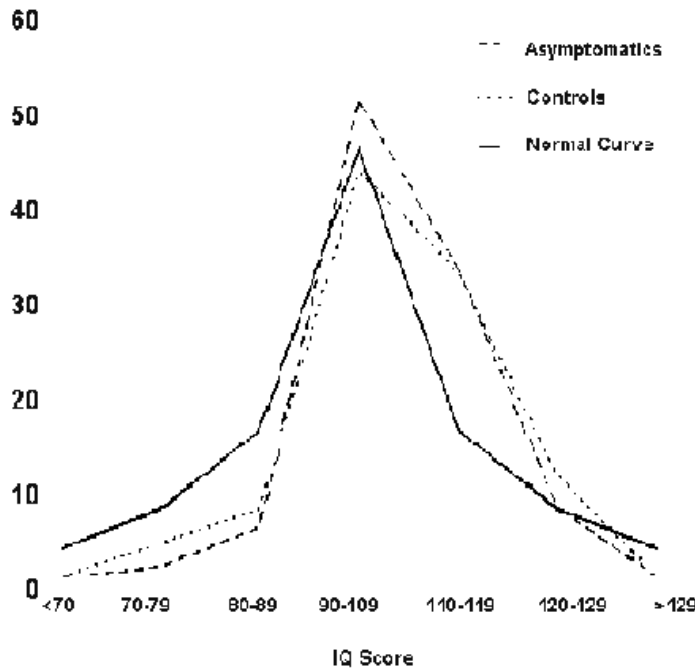
Registry participants, it is time for QC (quality control) tactics. In the next few months we will be sending each of you a list of all the case reports we have received from you since 1990. This will be an opportunity for us to clear up any data gaps and ensure that we have an accurate count of the cases you have sent us. Please help us out and respond to any questions this evaluation may produce. **THANKS!**

Research News

Symptomatic congenital CMV infection has been known to cause varying degrees of neurologic abnormalities, specifically mental retardation, cerebral palsy, blindness, and deafness. Transmitting the virus *in utero* causes serious illness in 10% of all the infected babies; however, 90% are born symptom-free (or asymptomatic). From this evidence the question arises, "Are children with asymptomatic congenital CMV truly unaffected by the virus?"

To answer this question and others, investigators at Baylor College of Medicine, Houston, TX, initiated a study of the long-term neurodevelopmental outcome of asymptotically infected children. This study has been ongoing for 15 years and during this time parents of our study patients with asymptomatic congenital CMV infection have been interested in our findings. In the area of neurodevelopmental outcome, we have some good news to share with you. In May of this year, **preliminary** findings were presented at a national pediatric research conference. The average IQ scores of asymptomatic CMV patients (avg. 105, range 79-126) were not statistically different from the average IQ scores of the uninfected patients (avg. 105, range 76-127). It is documented, by this study and others, that up to 15% of all asymptotically infected infants may develop sensorineural hearing loss, usually by 3 years of age. Thus, asymptomatic congenital CMV infection does have a neurologic affect (hearing loss) but does not appear to cause psychointellectual delays.

Neurodevelopmental Outcome in Asymptomatic Congenital Cytomegalovirus (CMV) Infection



Reference: *Pediatric Academic Societies' 1996 Annual Meeting (May 6-10, Washington, D.C.) Abstracts.*

More Vaccine Research

Important news for those of us who wish to prevent congenital CMV disease! The prestigious Institute of Medicine of the National Academy of Sciences, Washington, D.C., has been asked by the National Institute of Allergy & Infectious Disease (NIAID) to make an assessment of priorities for the development of new vaccines. A committee of experts to study priorities for vaccine development has been formed this year. We are pleased to report that a cytomegalovirus vaccine is one of the vaccine candidates under consideration. While there are many diseases worthy of prevention, we hope the committee will carefully study the impact of congenital cytomegalovirus disease on the infants and children in this country. For further information, or to make your wishes and concerns known, contact:

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Getting the help your child needs ...

A paramount obstacle parents who have a child with disabilities due to CMV infection may face is finding out about available resources in their area. In our last newsletter we featured an article about Early Intervention (EI) programs and the numerous services they have for children birth to 3 years of age who are developmentally delayed. But what happens when the children with disabilities turn 3 years old? They go to school!

The federal law that was amended to establish EI programs has been around for over 25 years and is now known as *IDEA* (the Individuals with Disabilities Education Act). This law requires that all states and territories provide a public school education for children with disabilities from 3 to 21 years of age, regardless of the severity of the disability. On a child's third birthday through 5 years of age they can be in programs called "special education programs and services for preschoolers with disabilities." Programs and services for preschoolers and those beyond preschool are provided by the state's department of education. These public school education programs promise a full range of educational services and depending on the child's needs, additional services:

- speech/language therapy
- occupational therapy/physical therapy
- orientation/mobility therapy
- psychological evaluation
- school health services
- parent training
- social work services
- counseling
- audiology
- transportation

To find out if a child is eligible, contact the local public elementary school and speak with the principal or someone in charge of special education. Enrollment is based on an **evaluation**, (procedures to determine whether the child has a disability and the special education and related services the child needs), which is commonly conducted by a team or multidisciplinary group using doctors' reports, developmental test results, medical history, and observations by the team. Parents are also included in making decisions about their child's educational needs and can challenge any decision through a "due process procedure." Another way for parents to get involved may be through support groups and meetings that may be provided by the school's staff or parent groups. *IDEA* provides a "free appropriate public education" at no cost to the family of a child with disabilities from ages 3 to 21 years of age, which does include the evaluation. Some people feel that a drawback of this program is that the law requires children with disabilities to be educated in the "least restrictive environment" (LRE), which is a setting with children who have no disabilities, with special help for those who need it. However, although public school education may not be the choice for everyone, it is available to **all** by law.

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**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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