



## My Baby has Congenital CMV Disease: Preschool and Early School Years

Editor's Note: This article is the third in a series of articles designed to provide practical information for parents, physicians, and other health care workers caring for children born with congenital CMV infection and disease. The first two articles described the newborn and the infant/toddler years. This third article describes the preschool and early school years. Reprints of the articles in this series can be obtained from The National Congenital CMV Disease Registry. Children born with congenital CMV infection or disease who are between the ages of 3 and 6 years should continue to receive routine pediatric care from your family physician or pediatrician. All routine immunizations should be administered, unless there is another specific contraindication not to do so. Also, by this time, your child should be enjoying a normal or near normal growth curve for weight and height. All signs of enlarged liver and spleen, jaundice and skin rash should have disappeared. Also, any abnormal blood tests your baby may have experienced during the infant period should be normal. If abnormalities remain or recur, you should seek the advice of your physician regarding other possible causes. It also is possible your child will continue to shed CMV in the urine or saliva during this time of life, although most children will cease shedding. Remember it is not necessary to monitor routinely the excretion of CMV in your child's urine or saliva and this "silent" excretion is not a reason to exclude your child from school.

If your child was born with asymptomatic congenital CMV infection, then weight, height, and head size growth should be normal. Also, your child's vision and development should be normal for age. It is possible your child may experience a progressive hearing loss, since this occurs in about 10 to 15% of children with asymptomatic or "silent" congenital CMV infection. For this reason, all children with congenital CMV infection should receive hearing tests annually. It is not necessary, however, to see an ophthalmologist every

year, unless a specific problem is noted. Since some experts believe even "silently" infected infants may develop learning disorders, your child should be watched carefully through the preschool and school years for school and academic problems. If your child was born with symptomatic congenital CMV infection, then abnormal development, such as mental retardation or cerebral palsy may occur, especially if your child had evidence of neurologic (brain) involvement at birth.

Children with microcephaly (small head size) and brain calcifications at birth are at the greatest risk for severe developmental disorders, and by age 3 years may already have shown problems. Some children may benefit from occupational therapy to assist in feeding and other self-help skills and physical therapy to assist in motor skills and tone problems. The most severely affected children may need special supplemental feeding through a gastrostomy (G-button) to meet caloric needs or to avoid aspiration into the lungs if oral motor and swallowing skills are still developing. It also is possible your child may enjoy normal growth and development if there was no or just minimal evidence of CMV involvement of the brain at birth. All children with symptomatic congenital CMV infection should receive hearing tests at least annually, since up to two-thirds of these children will have a progressive hearing loss. If your child had evidence of eye disease, such as chorioretinitis, at birth, then it also is important to maintain regular visits with an ophthalmologist. Since it is difficult to accurately predict which children born with congenital CMV infection and disease will have developmental problems, it is important all have a comprehensive developmental assessment by a general, or preferably, developmental pediatrician at age 3 years. At this time, the developmentalist can determine your child's cognitive (I.Q. or its equivalent) skills, as well as assess expressive and receptive language skills, and gross and fine motor function. If problems are discovered, then

intervention therapies can be started. Your child at age 4 or 5 years of age, just before entering kindergarten, should be assessed again to see if your child is "school ready." Special needs in the classroom, as well as special tutoring, can be planned. At the end of first grade, your child should once again see a developmental specialist. At this age, children who have had mild language or motor problems may continue to have problems and academic difficulties, and will continue to need the help of special tutors. Some children may appear to be doing satisfactorily in school, but they may have specific developmental disabilities, such as dyslexia, dysgraphia, attention deficit disorder or higher level language disorders that make academic studies more difficult. These developmental problems are not usually evident in the younger years and require the help of experts to identify. Their association with congenital CMV infection and disease has not been clearly established, but some studies have suggested these children may be at risk. With proper tutoring, these learning disorders can usually be corrected.

### 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

## NEWS FROM THE CMV REGISTRY

The common symptoms and abnormalities observed in newborns registered in the National Congenital CMV Disease Registry are shown in the table as a percentage of the number of cases in which that particular abnormality was reported on the case reporting form.

The number of cases reported to the Registry has decreased over the past couple of years. Although we would like to see the incidence of congenital CMV disease decline, these numbers more likely represent under reporting of cases. So, if you are a participant in the Registry, remember to submit your 1999 case reporting forms by fax or by mail before the close of the millennium!

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

Characteristics	Infants (%)
Petechiae or purpura	372 (53)
Small for gestational age	330(47)
Thrombocytopenia	359 (54)
Enlarged liver	332 (48)
Enlarged spleen	313 (45)
Intracranial calcifications	264 (43)
Jaundice at birth	249 (36)
Microcephaly	272 (40)
Hearing impairment	200 (43)
Hemolytic anemia	77 (13)
Chorioretinitis	64 (11)
Seizures	57 ( 8)
Pneumonia	66 (11)
Neurological abnormalities	185 (29)
Bilirubin	252 (41)
ALT	162 (30)
Death	47 ( 8)
Coinfection	15 ( 7)
Treated	51 (22)

## QUESTION AND ANSWER CORNER

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**Q** What is cochlear implant and how does it differ from a hearing aid?

**A** *The cochlear implant is a hearing device designed to allow a child or adult with sensorineural hearing loss to process sound information. A cochlear implant functions differently than a hearing aid. Hearing aids amplify hearing to make sounds louder, cochlear implants work by stimulating the auditory nerve fibers in the inner ear or cochlear. Auditory nerve fibers are stimulated by an electronic device and sound information is transmitted through electrodes or channels.*

*A set of internal and external components comprises the cochlear implant (see picture of device). The internal components are surgically implanted under the skin and behind the ear. This apparatus consists of a receiver connected to tiny electrode bands. The external components include a speech processor and a headset or microphone. The external portion is worn like a hearing aid. The cochlear implant works by transmitting sound information from the microphone to the speech processor. The processor is a powerful tiny computer that is worn as a small backpack outside the body. This minicomputer processes sound into coded signals that are sent across the skin to the implanted electrodes within the receiver. The electrodes stimulate the auditory nerve fibers in the cochlear*

and transmit this information through the auditory system to the brain for interpretation.

A thorough screening process is involved to determine eligibility for cochlear implants. If you think that your child may benefit from a cochlear implant, we recommend that he or she be evaluated by an otolaryngologist (ear, nose and throat specialist) who has experience in treating children with sensorineural hearing loss.

Cochlear implant internal device with electrodes.

External cochlear implant device (l-r: microphone, transmitting coil, speech processor)

This CMV study patient (above) was born with bilateral sensorineural hearing loss due to congenital CMV disease and participates in our Houston CMV study. He is an active three-year-old and enjoys his cochlear implant that was placed this year.

**Q** I am pregnant and found out that I had a recent CMV infection. Will breast feeding pose a health risk to my baby?

**A** CMV may be transmitted to your baby congenitally (before birth), during the birth process, or through breast feeding. In most instances, transmission of CMV through breast milk to an

uninfected baby results in a silent infection and does not put a normal newborn at risk for any of the disabilities seen in children congenitally infected with the virus.

Additionally, antibodies to CMV in your blood will be passed along to your baby providing protection in your newborn against CMV. Breast milk is a complete source of total nutrition for your newborn and provides protection against a variety of infections. Therefore, we encourage and recommend breast-feeding in most instances. However, if your baby is a premature infant or has underlying medical conditions, consultation with a specialist in neonatology or infectious disease is recommended to see what is best for you.

### To Our Readers

Are there any questions that you have about congenital CMV disease? If so, please phone, fax, e-mail, or write to us with them. We will answer them in our next newsletter.

## A Mother's Story

This is a true story about my son who was born with congenital CMV disease. He is 14 years old and is in the eighth grade. I was 24 years old when he was born in Lufkin, Texas, and I had a seemingly normal pregnancy, even though I only gained 8 pounds. Joshua was born by a natural delivery. When our son came into the world he looked fine to me. But he was a small baby weighing only 6 lbs 2 oz.

While I was in the recovery room, the nurses started asking questions about my pregnancy and I asked them what is wrong with my baby. Joshua had an enlarged liver and spleen, purple spots, and he was jaundiced. The doctor (a pediatrician) came to talk with us and said he didn't know what was wrong with our baby. Later that day he drew blood for a TORCH titer test and said he needed to have a CT scan on his brain. When Joshua was one day old, he had a CT scan that showed he had two calcification spots on his brain.

While we were in the hospital, they would not keep Joshua in the nursery where the other babies were. They kept him in a closet by the nurses station. So, needless to say, I kept Joshua in my room a lot, but it broke my heart to go by the nursery and not see my baby there but rather see him in a closet. They told me I could only have grandparents in my room and they had to wash before and after holding Joshua, and had to wear a disposable gown and mask. I felt like I had something that would endanger everyone with whom we came in contact. We were first told Joshua may have to stay six weeks in the hospital, so most of the family went back to work so they could take off when Joshua came home. But then the doctor came later that day and told me what Joshua had. I was alone in my room and did not understand what the doctor just told me. I had never heard of cytomegalovirus. He told me to take Joshua home and love him because he was going to die, or if he lived he would be severely mentally retarded or he would be a vegetable. I told him I didn't understand and my family would have

lots of questions, so we had a family meeting when Joshua was two days old. The doctor told my family the same things he told me and we asked about taking our son to Texas Children's Hospital, in Houston, and he said he had already talked with someone down there and that there was nothing they could do either. My family told the doctor we would be taking Joshua to the highest physician.

Then about 8 o'clock that night, they said we could take Joshua home. It seemed strange to me that they let us go home so late at night. The doctor told me that when we got home Joshua should not go out in public and I could not have any of my friends who were childbearing age in my home. He also told us to burn his diapers. Since I was told he was going to die, I hardly ever left Joshua and I looked at him a lot when he was sleeping. My friends had to look at him through the window. When we went to see the doctor, he would tell us to knock at the back door and they would let us in. The only outings we ever had were on Sundays when we would put Joshua in our truck and go for a drive. We never got out and went in anywhere. This went on for 5 months.

One day my mother was reading the Houston newspaper and saw an article about a group of doctors' wives who were raising money for the CMV study and there was a phone number in the article. My mother called this number and talked with a research doctor Dr. Martha Yow who asked if Joshua's hearing had been tested or his muscle tone and development checked or vision tested. My mother told her, "no." She said she had one bed left in the Clinical Research Center and for us to bring Joshua down to Houston to be tested. So when Joshua was five months old, he had his hearing tested. He had a mild loss in one ear. He was hypotonic (low muscle tone) and needed physical therapy. They told us his spleen and liver would go down to normal size and the jaundice would go away. They told me we did not have to burn his diapers and they wrote a letter to the doctor in Lufkin and said we could come in the

front door like everybody else. The doctors in Houston said my friends could come in my house and hold Joshua. All they needed to do was wash their hands afterward. Joshua and I started going out to the stores or wherever we needed to go. Joshua started going to physical therapy and a little later we started occupational therapy. He started speech therapy at 13 months. Joshua walked at 14 months. A speech therapist in Houston tested Joshua when he was 2 1/2 years old because he still was not talking. She said Joshua was going to talk but he had to learn sign language first to use for his communication. We found a wonderful speech therapist and Joshua learned over 100 signs in a short period of time. Then he started saying the word for the signed word. The speech therapist wanted Joshua to keep using the sign with the spoken words but he refused. The speech therapist was always amazed by how well Joshua did.

Joshua's hearing was tested every year and he had a gradual loss in one ear until he went deaf in that ear. They told us as long as Joshua had one ear which had normal hearing he did not need to wear a hearing aid. Eventually, between kindergarten and first grade Joshua started losing his hearing in the other ear in the low frequencies. So he started wearing a hearing aid in the first grade.

Eventually his hearing loss continued to progress and he needed a more powerful hearing aid. Joshua adjusted well to his hearing aid and made good progress in speech. Joshua went to a private school when he was three and stayed there through the fifth grade. God blessed Joshua with a very outgoing personality and great self-esteem. This is Joshua's third year at public school and he is doing very well. Last year, he was class president and involved in athletics. He has won ribbons in

science fairs and loves Texas history. He is an avid reader.

This summer, Joshua's hearing was tested and he has lost more, and Dr. Demmler has referred us to Dr. Daniel Franklin, an ear, nose and throat doctor who performs cochlear implants on children. Right now, Joshua functions very well with his hearing aid and has good speech. Dr. Franklin recommends Joshua's hearing be tested every three months and if he loses more we will explore the cochlear implants further. In conclusion, it is a miracle that our experiences when Joshua was a baby did not damage his outlook on life; but we had strong family support and love. Joshua has come a long way. He is a true blessing in our lives and he impresses everyone he meets with his wonderful personality.

Editor's Note:

Joshua's poignant story illustrates many misconceptions about congenital CMV infection, some of which unfortunately still exist today. While just about everyone realizes it is not necessary to burn the diapers of an infant with congenital CMV disease, many people believe these infants should be treated differently and kept "away" from others. CMV is a very common virus that usually produces minimal problems and only those persons who are pregnant or whose immune system is abnormal should take special precautions to avoid contact with infected urine or saliva. Furthermore, many families receive only "bad news" about the outcome of infants born with congenital CMV disease. While it is true many of these children do experience challenges in life, Joshua is living proof that many infants with congenital CMV disease can and do grow up to become happy and productive members of our society. We're proud of you, Joshua! Thank you so much for sharing your inspiring story! With love and admiration,  
Dr. Gail

### **PARENT-TO-PARENT SUPPORT NETWORK**

More than 165 families have joined the parent support network. Most of the families reside in the United States; however, there is an every increasing number of families joining the network who live abroad. Recently we welcomed

the Madle family of Kenya, Africa, to the support network!

If you have a child congenitally infected with cytomegalovirus, you do not have to feel like you are alone. The parent support network provides a medium for parents to voice their concerns, offer and receive advice and exchange information when faced with the challenges that come with raising a child affected by congenital CMV disease. Also, if personally requested, we will do our best to link families. If you are interested in joining the network, either call, [e-mail](#), fax, or write us, or indicate your interest on the subscription form located on the last page of this newsletter and send it to us.

### **A Reminder to Our Current Support Network Families**

Current support network families please take a few minutes and provide us with some up-to-date information about your child. Please forward the updated information about your child to us by telephone, [e-mail](#), fax, or letter. After we receive it, the current list of all families on the network will be sent to you.

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:  
National Congenital CMV  
Disease Registry  
Feigin Center, Suite 1150  
1102 Bates, MC 3-2371  
Houston, TX 77030-2399

Phone: 832-824-4387  
FAX: 832-825-4347  
[cmv@bcm.edu](mailto:cmv@bcm.edu)

### **CMV RESEARCH FUND**

We wholeheartedly thank each and every one of the families and individuals who generously contributed to the CMV Research Fund in 1999.



**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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