



CMV UPDATES



Spring 1996

Vol. 2 No. 1

The First Step: ECI

Congenital cytomegalovirus infection is a leading infectious cause of mental retardation and nonhereditary deafness. Although 90 percent (36,000 infants) of all infants born with CMV each year will be symptom-free at birth, the remaining 10 percent (4,000 infants) annually will have varying degrees of abilities and disabilities. Disabilities that result from congenital CMV infection include blindness, deafness, feeding disorders, hypertonia, hypotonia, mental delays, physical delays, and seizures. To help children with disabilities and their families develop, learn, and grow together and reach their fullest potential, programs such as Early Childhood Intervention (ECI) were created.

It has been nearly 10 years since Congress amended legislation that prompted states to develop ECI programs. Using a holistic approach specific to each child and family, these programs have benefited numerous families and they continue to enhance the lives of infants (birth to 3 yrs. old) who have special needs.

Simply, the goal of ECI is "to help children with disabilities reach their maximum potential and become as independent and productive as possible." These federal and state funded programs are available in every state and they are free to families of all income levels. Services provided by each state ECI program include but are not limited to:

- Assistive Technology (services & devices)
- Audiology Services
- Family Counseling & Training
- Health Services
- Home Visits
- Medical Services (for eligibility)
- Nursing Services
- Nutrition Services
- Occupational Therapy
- Physical Therapy
- Psychological Services
- Service Coordination Services
- Social Work Services
- Special Instructions

Some states may also offer:

- Speech-Language Therapy
- Transportation
- Vision Services

To benefit from ECI services children under 3 years of age must have "substantial" developmental delays, a criteria which is set by each state. For the most part, the child must be behind other kids their age in one or more of the following areas:

- Cognitive development
- Physical development
- Language or speech
- Social or emotional skills
- Self-help skills

Also eligible are kids who have been diagnosed by a doctor as having a physical or mental condition, which has a high probability of producing developmental delays, such as:

- Down syndrome
- Deafness
- Blindness
- Metabolism or feeding disorders
- Microcephaly
- Failure to thrive
- Seizure disorder
- Fetal alcohol syndrome
- HIV positive after 15 months

If you would like more information about early childhood intervention programs in your area please call the national ECI "care" line (800) 250-2246.

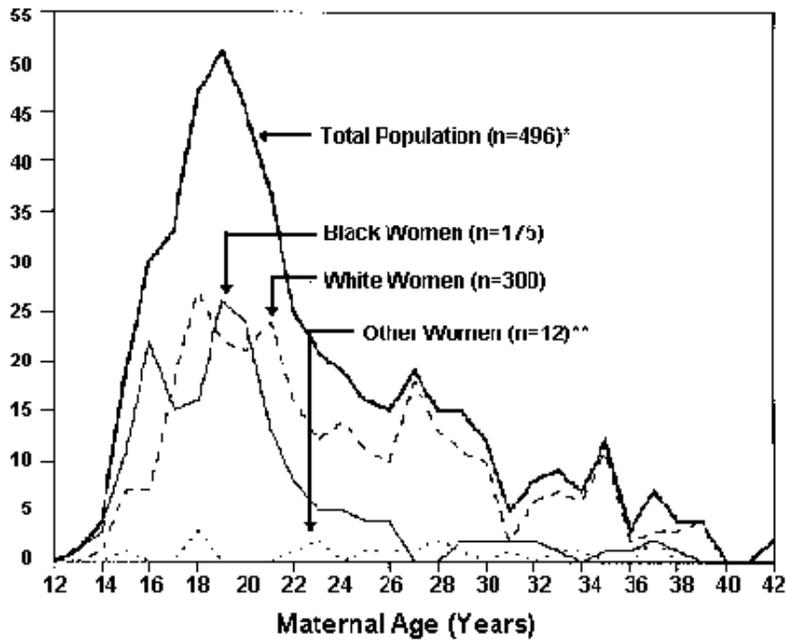
News from the CMV Registry

After 7 years, the National Congenital CMV Disease Registry is still growing. We welcome 3 new participating physicians in St. Louis, MO; Dayton, OH; and La Grande, OR. The number of infants reported to the Registry has now grown to over 500. As you may recall, the Registry captures information through passive surveillance on infants born with symptoms of CMV infection. Therefore we rely on the physician to voluntarily report these infants to us. We appreciate the time and efforts of these physicians, nurses, and researchers. Additionally, several of these physicians also participate in a national study on the treatment of congenital CMV infection with an experimental antiviral medication. Below is a list of the Registry participants and their location.

Babies congenitally infected with CMV are born to mothers of all different ages and races. However, there does appear to be some age and race differences among mothers. The average age of mothers delivering an infant with symptomatic congenital CMV infection is 22.7 years of age. Mothers 25 years and under who deliver a CMV infected baby have nearly an equal distribution of nonwhite and white women. On the other hand, white women are almost exclusively in the older age group (>26 yrs) of women delivering infants with congenital CMV disease (see the graph below). Current hypotheses for the age and race differences include (1) the groups have different characteristics that influence their exposures to the virus, and (2) an age-related biologic effect of CMV infection. (References: Fowler, et al. *J Infect Dis* 1993; 168:552-6. Istaq, et al. *Clin Infect Dis* 1995; 20:665-70.)

If you would like more information about the National Congenital CMV Disease Registry contact the Director, Gail J. Demmler, M.D. at (832) 824-4387.

**Congenital CMV Disease Registry Maternal Age Distribution
1990-1996**



* Race or maternal age was unknown for 9 cases
 **Other women = Asians, American Indians/Eskimos, and all other races

National Congenital CMV Disease Registry

Participant	City, State
J. Montgomery	Huntsville, AL
R. Pass	Birmingham, AL
S. Boppana	Birmingham, AL
R. Jacobs	Little Rock, AR
W. Dankner	San Diego, CA
A. Kovacs	Los Angeles, CA
C. Hutto	Miami, FL
M. Newport	Mease, FL
P. Reuman	Gainesville, FL
M. Christensen	Chicago, IL
J. Stamos	Maywood, IL
A. Rowley	Maywood, IL

J. Bale	Iowa City, IA
J. Murph	Iowa City, IA
S. Laudert	Wichita, KS
G. Marshall	Louisville, KY
G. Rabalais	Louisville, KY
D. Sokol	New Orleans, LA
K. McConnell	Minneapolis, MN
T. Gardner	St. Louis, MO
J. Kinney	Kansas City, MO
R. Coen	Great Falls, MT
L. Weiner	Syracuse, NY
L. Givner	Winston-Salem, NC
J. Kenny	Greenville, NC
J. Kothadia	Charlotte, NC
D. Rupar	Charlotte, NC

S. Alter	Dayton, OH
M. Brady	Columbus, OH
M. Kumar	Cleveland, OH
J. Weber	LaGrande, OR
S. Starr	Philadelphia, PA
W. Gruber	Nashville, TN
P. Patamasucon	Knoxville, TN
D. Murphy	Knoxville, TN
J. Atkins	Houston, TX
F. Cho	Austin, TX
T. Chonmaitree	Galveston, TX
J. Courtney	Austin, TX

G. Demmler	Houston, TX
J. Fergie	Corpus Christi, TX
J. Garcia	Houston, TX
C. Leach	San Antonio, TX
M. Shelton	Ft. Worth, TX
S. Adler	Richmond, VA
R. Gehrz	Pulaski, VA
D. Mitchell	Norfolk, VA
J. Gross	Marshfield, WI
E. Ford-Jones	Toronto, Canada

Helpful Hints...

All women of childbearing age -- **Do you know your CMV status??** If you have delivered a child with congenital CMV infection, you already have CMV antibodies. But if you don't know if you have ever had CMV, there are a couple easy ways to find out. First, if you have donated blood recently, call the blood center and ask if they tested your blood for CMV antibodies. As policy, most blood centers randomly test donated blood for CMV antibodies, so there's a chance your blood was tested for free. Another way to find out your CMV status is to ask your doctor. Next time you visit your obstetrician/gynecologist or family doctor, ask her or him to test your blood for CMV antibodies. It's a simple test that may cost between \$10 and \$50 but it is something every woman should consider knowing. Just remember, by knowing your CMV status you will be learning more about your body and you may ultimately bring all of us one step closer to controlling this virus instead of its controlling the lives of innocent babies.

Early Intervention: A parent's perspective

Our youngest child Amy was born on February 12, 1984. She was our third living child, and my fifth pregnancy. When Amy was born, my husband asked the doctor if the baby could be with me in the recovery room, something that we had never experienced, as our other two children had begun their lives in the intensive care nursery. The doctor's response was, "she looks a little floppy; we want to check her out." As her father says, from there it was all down hill.

Culturing for infections indicated that Amy had congenital CMV, and further testing showed that she had a hearing loss in the 75 to 90 dB range, microcephaly and brain calcification. When I was called and informed of the hearing loss, I immediately called my public school system's early intervention offices and began enrolling her in the hearing impairment program. I have always considered myself a knowledgeable parent, well read in all the standard baby books including Brazelton and Spock. However, I wasn't prepared for the questions I was asked about Amy's development during the initial interview and assessment. She was about 2 months old and I was being asked such questions as "Does she bring her arm to midline or across her chest to the opposite side?" I was stymied by these questions. I knew what most of the normal milestones of development are, but these were new to me. I later read a report that stated "Mom in denial." This seems to be a pretty standard reaction to a normal feeling of stress over the problems with a handicapped child.

Amy's first hearing aids were ready when she was 3 months old. Her first smile occurred within minutes of wearing them. Her dad leaned over her and said "Hi, Amy," and she burst out with a big grin. She was enrolled in the preschool Home Resource program for hearing and speech services and physical therapy two days a week each. The next year we added two days of occupational therapy. Amy still holds the record as the youngest child ever enrolled in Fairfax County public Schools and for having the greatest amount of home-based therapy.

Having a child with many disabilities is quite challenging. It did not help that well-meaning people would send me articles about how parents would add a wing to their house and spend 18 hours a day working with their disabled child, who eventually could walk normally. This would put an additional guilt trip on me. I had a five-year-old and a three-year-old and worked as a family home day care provider. I would take children to the library for story-time each week, to the zoo, the park, etc. How was I going to find time to do even more for Amy?

It was so helpful to have such wonderful therapists coming into my home each week. These professionals helped with me as much as they worked with Amy. They assured me that I was doing a good job with her, providing her with good stimulation in our regular activities. One of the most helpful things anyone ever said to her occupational therapist remark, "I always feel that parents should be parents and teachers should be teachers." Thank goodness! It was alright just to be her mother.

Amy's progress was slowed after a point, as she developed infantile spasms. At first I thought that she was being startled by the noise from the other children, but the therapist recognized what was happening. We were so lucky in that these seizures were quickly controlled. She began taking medication on a Friday and it was like watching a flower unfold as the seizures ceased. She had unusually quick response to the medication, and has been seizure-free and off the meds for several years.

When Amy was two years old, her therapist decided that she was ready for a non-categorical school-based program. We were all ready to start her for three half-days a week. But just before school was to start, we ran into a wall of ignorance from the public health department's infectious disease division. The doctor in charge of the decision concerning Amy's admission to school said that she should be shedding only intermittently, that somehow this would be "safer" for the teachers. However, he retired during the summer and his replacement told me when I questioned him on this, "Lady, I don't care if she's shedding 24 hours a day. These children need to be in school." Of course, the central administrative offices hesitated on the final approval of her admission, claiming that they would have to check with their attorney as to the liability of the school system in the event of a pregnant teacher coming into contact with my child. This was the middle of August and I was told it would take over a week to get a response. I told them that this was only less than a week before school was to open and that they were not giving me much time to take legal action should I not agree with their decision. "What do you mean?" I was asked. "I mean that I will want to contact my lawyer." The magic word was uttered by me. By that afternoon I was informed that there was no problem with my daughter being in a classroom.

Actually, there was a problem. I had to put my little baby on a big school bus and wave bye to her. It really hurt. But she really enjoyed school, although she was often stubborn and refused to do as her teachers wanted. But over the years she has progressed beyond what many people thought she would ever achieve. This is the greatest advantage of our early intervention efforts.

Margaret Daigle
Falls Church, Virginia

Your Child's Development

If your child does not meet these milestones
he or she may be developmentally delayed

- **3 months**
follow objects
Respond to loud sound
Make cooing noises
Grasp at hair/rattle
- **6 months**
Turn to sounds
Pick up toys
Roll over
Sit with support
- **12 months**
Pull to standing
Crawling
Drink from cup
Say 1-2 words
- **18 months**
Walk without help
Stack 2-3 blocks
Follow easy directions
Feed self sometimes
- **2 years**
Use 2-3 word sentences
Feed self with spoon
Build a 6-block tower
Run well
- **3 years**
Use 3-5 word sentences
Hop on one foot
Dress with supervision
Use toilet

Question & Answer Corner

Q My child was born infected with CMV. How long will she [or he] be infected and shedding the virus?

A When a child is shedding CMV, she or he is considered to have an active infection of the virus. Shedding the virus means that CMV is found in bodily secretions. Cytomegalovirus is frequently isolated from the urine, saliva, blood, and other bodily secretions. Children congenitally infected with CMV commonly shed the virus for several years. In fact many of these children continue to shed the virus until five years of age and sometimes longer. When a child is no longer shedding CMV, the virus remains in the body in a dormant state for the rest of their life. During a person's lifetime, for various reasons, CMV infection can reactivate, and there is again shedding of CMV in bodily secretions. Ordinarily recurrent shedding does not cause symptoms and the person does not feel sick.

Q Last issues's "Mailbag" question: Why won't they [educators and therapists] work with my child?

A The consensus was to educate people about CMV. If someone is refusing to work with a child who has CMV infection it is likely they actually know very little about the virus. Parents, educators, and therapists need to know basic information about CMV, such as:

1. CMV is a common virus that infects most people at some time in their life.
2. Most healthy people who are not pregnant have no problems with CMV infection.
3. Routine hygiene precautions, such as good hand washing and not sharing food, drinks or eating utensils, are sufficient to prevent the transmission of CMV.

Answers were provided by Carol Griesser, R.N., and Gail J. Demmler, M.D. For more detailed information on these and other questions about CMV infection please consult previous issues of *CMV Updates* or contact the CMV Registry.

The Mailbag

We always like to get letters and phone calls from parents and others who work with kids who have congenital CMV infection. Most especially, we are encouraged to learn of all types of resources we can share with parents. This time, however, we don't want you to write us, we want you to write the President. To increase awareness about congenital cytomegalovirus infection and its disabling effects, let your voice be heard.

Write to or call: President's Commission on Mental Retardation,
 c/o Ms. Laverdia Roach
 Wilburn J. Cohen Bldg., Room 5325
 330 Independence Ave S.W.
 Washington, D.C. 20201
 Phone: 202-619-3636

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

Resources for Parents John Tracy Clinic

Rapid changes in a child's growth and development start at birth. But when that child has hearing and/or vision loss, development can be slowed partly because parents may be unaware of what resources are available. What some parents of children with CMV infection have learned is that the John Tracy Clinic (JTC) can help. Started in 1942 with a goal "to find, encourage, guide and train the parents of young deaf children to reach and help their children." JTC is an educational facility which offers families a variety of services worldwide. If you live in the Los Angeles area, children under six years of age with hearing loss can receive free audiologic services as well as participate in parent/infant educational programs and support groups and other educational programs. However if you are not in the Los Angeles area you can also benefit from JTC's free worldwide correspondence courses for parents and their summer intensive programs for parents and children.

The Clinic offers 3 correspondence courses to parents, all of which are available in English and Spanish. These courses guide parents in developing and improving their child's communication skills. And lessons focus on whole child development (physical, cognitive, social, & emotional). One course is for parents of babies from birth to eighteen months of age and another program is for parents of preschool children ages eighteen months through five years. Both courses involve between 10 and 11 lessons and the programs take up to a year to complete. A third program is for parents of children with both vision and hearing handicaps and there is no age limit. This program may take one to two years to complete.

Additionally, for families enrolled in a correspondence course there are two summer programs (each 3 weeks long) that can give you more hands-on learning. These international sessions are for hearing impaired children age two to five years, their siblings ages 6-12 years, and their parents.

All Clinic services are free of charge to parents of deaf or deaf-blind children. To enroll, families may contact the Clinic directly. When writing to request a Course, please give the child's name and age and your complete address in the first letter. To find out detail about any of JTC's programs simply write to the address below or call their toll free phone number: 1-800-522-4582

Director, Correspondence Education
 John Tracy Clinic
 806 West Adams Blvd.
 Los Angeles, CA 90007

Support across the miles

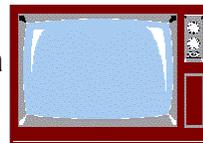
We are not alone in our fight against CMV infection. For several years now Fay and Stan Courtney have been the backbone of a CMV support group in England. They formed the "Congenital CMV Association" (CCA) after they discovered their daughter was born with CMV in 1986. Since then they have been publishing a newsletter for other affected families in the United Kingdom and they keep in touch with research in their area.

If you would be interested in contacting CCA to share support and information from the U.S.A. write to:

Fay & Stan Courtney
69, The Leasowes
Ford, Shrewbury SY5 9LU
England

CMV on CNN

Did anyone happen to see CNN's segment "Your Health," on Saturday, March 2, 1996, at 2 P.M. (E.S.T.)? CMV was featured in that episode. In the story current vaccine research was discussed and they interviewed a family who is dealing with congenital CMV infection. For a tape or transcript call Journal Graphics at 800-255-6397.



**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