



## CONGENITAL CMV DISEASE: EFFECTS ON VISION

Cytomegalovirus (CMV) is a common virus that infects an average of one out of every one hundred newborn babies, causing a congenital infection that is present at birth. About ten percent of congenitally infected babies will have symptoms at birth (symptomatic) and ninety percent will be "silently" infected, without symptoms (asymptomatic). Children born with either type of congenital CMV infection may have long-term problems, including hearing loss, developmental and motor disabilities, and eye disease. Previous articles for "CMV Updates" have discussed hearing and developmental and motor disabilities, as well as nutritional problems unique to the needs of infants born with

born with congenital CMV infection may experience.

Vision loss and other eye diseases are not as common as hearing loss and developmental delays in these children. Eye involvement occurs in only 10 to 20 percent of symptomatic infants and in one to two percent of asymptomatic infants. Children followed in our CMV Longitudinal Study receive periodic vision and eye checks from our team of pediatric ophthalmologists. Preliminary results of our findings have been published (D. Coats, et. al. AAPOS, 4:10-116, 2000), and this article will share some of those findings with you.

Of the 42 children followed with symptomatic congenital CMV infection, nine have had vision loss in both eyes. The cause of the vision loss in these children included retinitis (inflammation on the back of the eye or retina) with macular scars (scars on the vision portion of the back of the eye), cortical vision loss (inability of the brain to decode or interpret vision signs received from the eyes), and optic atrophy (abnormal optic nerve in the back of the eye). Most of the macular scars at the time of birth appeared inactive (no active infection, only eye damage), but one of our children did have severe, progressive retinitis that improved with ganciclovir therapy. Of the almost 100 children with asymptomatic congenital CMV infection followed in our study, only 2 have had small macular scars, and only one of them had subnormal vision (mild).

Infants born with congenital CMV infection also may experience other eye disorders. One disorder is called strabismus (eyes turn in or turn out). Almost one third of our children born with symptomatic congenital CMV infection have had strabismus, but only one percent of our children born with asymptomatic congenital CMV infection had strabismus. An unusual eye disorder, incomplete formation of the eyes, has been seen in congenitally infected infants by other doctors (Pediatrics 66:763-765, 1980 and Am. J. Med. Genetics 28:61-65, 1987). Also, since other groups have rarely observed late onset or late, reactivation of CMV retinitis (Pediatric Infect Dis J 13:1139-1142, 1994), we

continue to observe our CMV Study subjects for possible late effects of CMV infection in the eyes.

In summary, all children born with congenital CMV infection should have a comprehensive eye examination in the newborn period. Careful follow-up is recommended for all those who have abnormalities as infants, or at any time a congenitally infected child experiences symptoms of concern, such as inability to move the eyes in all directions, vision loss, eye pain, or other concerns about vision or the eye that may occur. We continue to follow our CMV study subjects with periodic, comprehensive eye exams through high school graduation, so we can better understand and document the eye disease in children born with congenital CMV infection, and make recommendations about the need for long-term follow up in these children.

A BIG THANKS to all our kids and parents in our CMV Longitudinal study for putting up with all those eye exams!



### CMV WORKSHOP HELD IN BELGIUM

Basic research and human clinical trials continue in the area of CMV vaccines. Recently, in February a workshop on the possibilities involved in producing a vaccine to prevent congenital CMV infection in the near future was held in Belgium. It was attended by experts, from all over the world who are interested in congenital CMV infection and CMV vaccine development. Look to the next issue of "CMV Updates" for an update on progress and potentials for a CMV vaccine! In the meantime, contact your representative in Congress or any-one you know in the vaccine industry, and let them know how important this vaccine can be! We know it is important, because we have been touched personally by CMV, but the people who have the funds and resources to make a successful vaccine happen, also need to know it is important!

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CMV Updates is produced by the National Congenital CMV Disease Registry. It is a medium for discussion and exchange of ideas and information for parents, teachers, medical personnel, and therapists caring for children with congenital CMV disease.

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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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congenital CMV infection. This article will focus on the eye disease that babies

## PARENT SUPPORT NETWORK NEWS

If you are a CMV Updates newsletter subscriber, you probably already know about the Congenital CMV Parent-to-Parent Support Network. However, what you may not know is that as each year passes, the support network continues to grow in the number of families who are part of the group as well as the ever-expanding area of coverage. Presently, there are 180 families listed on the support network representing nearly every state within the U.S.A. The map below indicates the location of support network families throughout the U.S.A. In addition to the increasing number of American families who have joined the support network, now families residing across the globe from countries such as Australia, Belgium, Canada, Chile, England, France, Indonesia, Israel, Japan, Kenya, Mexico, Spain, South Africa, and the Netherlands are part of the parent support network too. No matter where they reside, families who contact us about joining the CMV parent support network join for one main purpose: to reach out and seek the support of other families dealing with the special challenges of caring and raising a child born with congenital CMV disease. Sometimes only those who have walked in your footprints are the ones best able to understand what you are dealing with. The support network was created for the purpose of providing a forum for parents to share their concerns, useful resources, and exchange their unique experiences caring for a child congenitally infected with CMV disease.

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## VIEWPOINT

### LETTER TO THE EDITOR

To whom it may concern:

I am troubled by some inaccuracies as well as an overriding paradigm in Anne McMeans' article, "Congenital CMV Disease: The Nutrition Connection" in the Winter 2002 edition of *CMV Updates*. Our culture, unfortunately, operates under the assumption that artificial baby milk ("formula") is the correct, proper, and natural method to nourish a baby. Ms. McMeans, despite her credentials, perpetuates this paradigm with the inaccuracies regarding time at the breast exceeding 20 minutes equating to feeding problems as well as the statement "...he or she should be able to drink formula and take baby food... This usually happens around their first birthday." My suggestions are as follows:

- 1) Children vary widely in their nursing style; however, most spend much longer than 20 minutes at the breast. Please do not confuse parents in this regard.
- 2) In addition to suggesting parents consult with their child's doctor, suggest that they see a Lactation Consultant or call their local La Leche League for assistance and support whenever they have concerns regarding breastfeeding. Since the unfortunate fact is that so few doctors know much about breastfeeding, it would behoove Ms. McMeans to point parents in a direction in which they might receive beneficial advice.
- 3) The statement quoted above implies that no infant is breastfed at twelve months of age. Messages such as these, from supposed nutritional/medical authorities/experts, reinforce the deleterious assumption that children are to be fed artificial baby milk.

Opting to administer a nutritionally suspect, detrimental substance (given that breastfeeding is the normal, natural way to feed a baby, and studies abound prove that artificially fed children have lower IQs and increased risk and actuality of a host of health problems) to babies in general is a sad state of affairs. But when those children are infected with cytomegalovirus, thus already having the odds stacked against them, forgoing 'Mother Nature' and refusing to feed them (or support and encourage the parents to do so) breastmilk for at least the child's first year (and however long after that is mutually acceptable to both the child and mother) is absolutely tragic.

It would be heartening if these oversights were addressed in the next issue of *CMV Updates*.

Sincerely,

Windee Crow

Former CMV researcher,  
Now Stay-at-Home-Mom

## AUTHOR RESPONSE

In my article "*Congenital CMV Disease: The Nutrition Connection*" I was not trying to imply that formula feeding is better than breastfeeding. Breast-feeding is, in my opinion, the preferred method to feed an infant. However, this is not always the preferred method of the parents or caregivers and is not always feasible when a child has multiple developmental deficiencies. Some children are incapable of breastfeeding and may need to be fed via a nasogastric tube or gastrostomy tube or even with total parenteral nutrition. Some mothers are unwilling to pump their breastmilk, and prefer to use nutritionally adequate formulas, often concentrated at a higher calorie level to provide calories and protein to meet catch up growth needs if the child is malnourished. If development is normal, a child should be able to eat table foods and drink cows milk, breast milk or formula at age one. Breast-feeding after age one is fine as a personal preference but becomes less nutritionally necessary as the child is eating and drinking a variety of foods and beverages.

Also, 20 minutes should be enough time for a child to be sated when breastfeeding. This does not include time to burp and change sides. The entire process will take longer than 20 minutes. The point being made was that it is important to monitor a child's feeding time in order to determine if there may be a feeding problem.

This was not an article to promote a certain type or preference for feeding a child but to point out to parents and caregivers of children with CMV to know your child's feeding habits and to discuss then with a primary care provider if there is a concern.

Anne R. McMeans, M.S., R.D., L.D.

## EDITOR COMMENTS

CMV Updates welcomes the thoughtful exchange of information and points of view on topics related to the care of children born with congenital CMV disease and thank both Ms. Crow and Ms. Mc Means for sharing their expertise. Children born with CMV may have a variety of health care issues, including feeding disorders, and it is important to recognize that the needs of each child should be carefully individualized.

# Kids Spot

Subscribers to our newsletter remember that last year we added a new regular feature to the newsletter. Again, in this issue we are delighted to highlight the extra-curricular activities of a few more of the study subjects enrolled in the CMV Longitudinal Study. Children featured here were enrolled by their parents in the research project shortly after birth. In addition to other commitments, year in and year out, these fine youngsters remain steadfastly dedicated to doing their part to see to it that children of future generations will not be subject to the disabilities associated with congenital CMV disease.

During the past year, we heard about the varied interests and wonderful successes of many other study subjects but because of space limitations we were unable to include all of you in this issue of the newsletter this time. We are proud of the achievements of these and all the study subjects enrolled in the CMV Research Project!

## LIVESTOCK CHAMPION

Fifteen year old Sarah participates in the research project as a symptomatic study subject. As a result of congenital CMV, she has severe bilateral sensori-neural hearing loss. However the hearing impairment has not slowed Sarah down. In addition to her ninth grade studies she is an active member of the 4-H organization (Texas Division) and the F.F.A. (Future Farmers of America).

As a member of these organizations, she takes part in community service projects such as preparing food baskets for the poor and helping with fundraisers. One such project was a bake-off Sarah won a blue ribbon for her very special Chocolate pie recipe!

Through her involvement with these organizations, Sarah got involved in raising animals for exhibition. Last year she entered her steer, "Big Boy", in the Montgomery County Fair and won \$5,000! Wow! Recently, she entered another steer, "Cy Ridge" in a 4-H competition and received the reserved grand champion award and her steer was auctioned for \$29,000! Wow, again! Sarah tells us she has learned a lot about raising animals and says she is responsible for feeding, grooming, exercising her animal daily and her mother adds that Sarah's participation in these projects has instilled in her a sense of pride of accomplishment and also teaches her responsibility and promotes independence. Sarah is saving the prize money to be used for college expenses. With this victory behind her, Sarah now is raising "Big Man" another steer who she plans to enter in the upcoming Montgomery County 4-H Fair this spring. There's no stopping this ambitious teenager as she sets her sights on raising another winning animal!

## AUTO RESTORATION HOBBYIST

Sean, who since his first year of life has participated in the CMV Longitudinal Study as a control subject. On his last study visit, this sociable teenager told us about his interesting auto restoration hobby. For as long as he can remember, Sean had a fascination with old cars.

Then about two years ago he bought a 1969 Chevrolet Chevelle Malibu 350 using money he saved from working his part-time restaurant job. He tells us that when he first saw the car, it was in poor condition, but was affordably within his means. The barely drivable car had faded rusted exterior paint, only a bare interior shell. Sean knew the restoration project would take lots of hard work, but he could envision a magnificent transformation.

Sean's first step towards getting his dream car back to its original condition was to paint the body. He chose to paint the vehicle bright yellow with a double wide black racing stripe to accent the hood, roof, and trunk. Just about every weekend Sean spends many hours working on his car. Sean's Dad lent a hand and helped with installing the new engine and transmission, but Sean proudly tells us that he does most of the work himself. After restoring or replacing mechanical parts, he plans to focus his attention on the car's interior.

Although a huge undertaking, Sean is pleased with the progress he's made and looks forward to seeing the restoration completed and having a distinctive car that will turn heads for its individuality and uniqueness as well as stand out on a freeway filled with look alike.

At this time Sean, is uncertain about his post high graduation plans, but says that a future in the auto restoration business is a possibility.

## HABITAT FOR HUMANITY VOLUNTEER

Daniel, known to us since the day his mother enrolled him in the Congenital CMV Longitudinal Study shortly after his birth and has been participating in the research project as an asymptomatic study subject. On his last visit with us, he told us about a rewarding and fun experience he had on a mission trip. Last summer, Daniel joined his church youth group and headed to south Texas where they teamed up with a youth group from their sister church in McAllen, Texas to work on a Habitat for Humanity homebuilding project.

During their week-long mission to this Texas border town, the middle school youth did their part by helping with framework and roofing. Daniel says the heat was unbearable at times and the work was exhausting, but said he enjoyed working with old friends and making new friends. After a long, hard day's work, Daniel and the other members of his youth group went door-to-door recruiting neighborhood children for a daily evening Bible study taught by the youth group. Daniel tells us that by the end of the week all their hard work paid off, the home was nearly completed, and a needy family will soon have a home to call their own. Daniel says he learned a lot and especially how the experience allowed him to see how fortunate he truly is.

Back home in Houston, Daniel excels in his eighth grade studies and in his spare time he enjoys taking tennis lessons and playing tenor saxophone in the school band.

## YOUNG ARTIST AWARDED

We are pleasantly surprised recently when we opened a holiday greeting card designed by one of our CMV study participants. Carli entered her original holiday card design into a greeting card design contest and out of hundreds, her card was one of 10 chosen as a winning design. Carli tells us she enjoys drawing for fun and neverknew that she could draw well enough to ever win a contest. Her proud mother chimes in that the sponsors of the contest held a wonderful awards dinner at a local restaurant along with presenting each child with their winning card framed as a memory keepsake. All the winning cards were printed and distributed for sale at restaurants grocery stores, and shops in Vidor, TX and the surrounding area. Not only that, it appears Carli's holiday card is a most popular card because it was the first card to sell out in many stores and businesses. Proceeds from the sale of the cards benefits Shorkey Education and Rehabilitation Center of Southeast of Texas. Carli, and outgoing fifth grader, beat the odds when it comes to being diagnosed with symptomatic congenital CMV disease. Besides enjoying drawing and her fifth grade studies, she likes playing third base on the girls softball team and has fun socializing with her many friends. One of her favorite activities lately is to have slumber parties or sleepovers where she and her friends watch movies, play video games, and stay up and yak until the wee hours of the morning.

### *Study Subjects We Salute You!*

## PARENT SUPPORT NETWORK NEWS

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If you are a parent of a child born congenitally infected with CMV and the parent support network interests you, complete and send us the form on the back cover of this newsletter, or email, fax, or phone us to request the parent permission slip so that you may join the support network. For those health care professionals, educators, or other care providers who know a family interested in joining the support network, please contact us and we will forward you the support network information so that you can pass along it along to them.

We ask those families already listed on the support network to annually update the information we have about your child. Providing current information about your child allows us to continue to disseminate up-to-date information to those new families searching the list for a family dealing with similar issues or whose child is around the same age as their own. Please take a few minutes to let us know about those acquired milestones and achievements, your child made since you last wrote us.

Also, please keep us informed of changes in your address or phone number. After receiving your updated information, we will add information to the database and send you the latest edition of the support network list.

## QUESTION AND ANSWER CORNER

**Q** What is the prognosis for children born with congenital CMV and calcifications (calcium deposits) in the brain?

**A** *After a definitive diagnosis of congenital CMV has been made in a newborn infant, it is recommended that a diagnostic imaging evaluation, such as a CT of the brain without contrast, be performed. This diagnostic tool can determine the presence of brain calcifications. Children born with calcifications as a result of congenital CMV disease, are at higher risk than those born without calcifications.*

**Q** Is hearing loss related to congenital CMV disease progressive? If so, for how long?

**A** *Hearing loss is the most common disability associated with congenital CMV disease. A unique characteristic of hearing loss in children with congenital CMV is that it almost always progresses. Children enrolled in the Congenital CMV Longitudinal Study here are followed from birth until the age of 18 years. Clinical research has shown that most children will first show evidence of hearing loss in the first year of life. However, our research has seen progressive hearing loss occur as late as 8 years of age and hearing loss was seen in one child for the first time at age 17. We therefore, recommend periodic comprehensive audiograms or hearing evaluations be performed by an*

*audiologist through adolescence and early adulthood.*

**Q** My daughter was born with congenital CMV disease. She has developmental disabilities associated with the virus. What are my chances of giving birth to another child born with the virus?

**A** *It is possible that you may experience a recurrent CMV infection during a subsequent pregnancy. This occurs less than one percent of the time. However, if you have another child born congenitally infected with CMV, rarely will there be any disabilities. We suggest that if you give birth to another child, have a CMV urine culture tested performed. If the results are positive, we recommend that his or her growth and development be monitored and that periodic hearing tests be performed.*

## TIME FOR FUN A SPECIAL CAMP

April, a seven year old symptomatic congenital CMV study subject with hearing impairment and a recipient of a cochlear implant, had tons of fun last summer on her first weeklong camping trip. It was also the first time she was away from home without her family, but she added that she was having so much fun that the week flew by and she hadn't had much time to miss anyone. At camp, April was able to swim, hike, fish, and try out new activities such as horseback riding and repelling. Her mom, Cara, told us that she was a little reluctant to allow April to be away from home for so long, but after visiting the camp for part of the day and interacting with the staff, she was reassured and felt comfortable leaving her daughter there. Her mom also tells us that the camp was especially beneficial for April because it was a place where her daughter met other children and could share their special challenges. She also feels that the camping experience helped build self-esteem and a "can do" attitude. She feels strongly about the positive effects the experience had on April and Cara asks us to let other families know about the camps.

Texas Lions Camp is affiliated with the International Lions Clubs and provides a camping experience for physically disabled children, hearing and visually impaired, and diabetic children. Admittance to camp is free for children with disabilities, but requires sponsorship from a Lions member and meeting certain camp criteria. Local Lions chapters set-up camp entry policy, so if you are interested, contact the Lions in your area. Generous monetary contributions along with the time and effort of many volunteers make the camp possible for children with special needs. The purpose of the Camp is to provide a place where children can have fun and learn enjoying new experiences in a safe specially adapted environment thereby helping to maximize personal growth.

Lions Clubs International is the world's largest service club organization with over 44,000 clubs located in 190 countries around the world. Youth outreach programs are only a small part of the Lions Club mission. To obtain more information about the Lions Camp or other Lions Club programs, visit their web site: [www.lionsclub.org](http://www.lionsclub.org). For those residing in Texas check their Texas web site: [www.lionscamp.com](http://www.lionscamp.com).



## POST IT HERE

The "special camp" story at left was told to us by the mother of one of our study participants. If you are a parent, health care professional, or educator and know of an unique or useful resource or service to enrich or enhance the quality of life for a disabled child, please take a few minutes to write us about it. We will pass along your suggestions in the upcoming issue of *CMV Updates*.

## MAILING LIST CHANGES

Please help us keep our mailing list up to date. Contact us via phone, email, fax, or postal mail with any changes in your mailing address. Also, help us conserve resources and save trees by contacting us if you receive duplicate copies of the newsletter, or if you want your name removed from the mailing list. We are delighted to tell our readers that we are developing an electronic version of our annual newsletter. If you prefer to receive "CMV Update" by email, let us know. The form on the back page of the newsletter can be utilized for any mailing changes.

## WEB SITE

Did you know the CMV Registry created a web site where those interested in learning more about congenital CMV disease can find factual information about the virus? The web site contains general factual information about cytomegalovirus as well as all past issues of our newsletter dating back to the first issue of the newsletter printed Fall, 1995. Our web site counter calculated that for the first two months of 2003, the CMV Registry web site received more than 4,800 (hits) viewers seeking information about CMV. Take a cyber tour to our web site at: [www.bcm.tmc/pedi/infect/cmv](http://www.bcm.tmc/pedi/infect/cmv) and feel free to download and copy any of the literature that you want to share with others.

## CMV RESEARCH FUND CONTRIBUTIONS

Listed below are the names of those who have made a contribution to the CMV Research Fund in the 2002 calendar year. We greatly appreciate and thank all of you for supporting the advances being made in congenital CMV Research.

Nathaniel & Margaret Clinton\*\*  
 Martin & Kay Denbraber\*  
 Dallas & Christine Duell\*\*  
 Mr. & Mrs. Bryan Duff \*\*  
 Bart & Cindy Faris\*  
 Samuel & Lin Felton\*\*  
 Rafael Figueroa\*\*  
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 Leticia Romero  
 Joanne Schroeder\*\*  
 Brenda Schwartz  
 Paul & Lori Swenson  
 Don & Marilyn Turowski  
 Maria Vincenty  
 Jay & Kim Williams  
 \* Kudos to those donors who make annual contributions.  
 \*\*A special thanks to Microsoft corporation for generously matching the donations of their employees.

## CONTRIBUTIONS

Occasionally, we are contacted by individuals who want to know how they can help with the research we do here. Making it possible for us to continue our research by way of a donation to CMV research is one of the best ways to assure that work of the CMV Registry and the CMV Longitudinal Study continues. Tax deductible contributions can be made payable to the "CMV Research Fund" and our mailing address is located on the back page of this newsletter.

## SPANISH CMV INFORMATION BOOKLET

To accommodate our ever-increasing audience from various backgrounds and localities, our CMV general informational booklet, "What Everyone Should Know about CMV" has been translated into the Spanish language. It too, can be found on our website.

**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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