



CMV UPDATES



Winter 2001

THE HOUSTON NATURAL HISTORY PROJECT MILESTONES

The CMV Natural History Study or the CMV Research Project is a longitudinal study begun in 1982. It was designed to examine the long-term outcome of children congenitally infected with cytomegalovirus. The study hopes to identify and characterize neuro-developmental, audiologic, and visual effects of congenial cytomegalovirus (CMV) infection. Each child is followed periodically throughout infancy, childhood and adolescence. With each visit of our study participants, valuable information is gathered, bringing us closer to unlocking the door to the secrets of this complex virus.

study milestones. Currently study enrollment is 209 children. Over the past two years, five of our oldest study subjects completed their primary commitment to the study by completing their eleven-twelfth grade study follow-up visit. The majority of our Houston participants are now elementary school age through middle school age. The youngest child enrolled in the study is two months of age. A round of applause for these study pioneers and their families! Within the research project there are three distinct study groups: Children born with asymptomatic ("silent") CMV infection, those born with symptomatic ("disease"), CMV infection, and those born without CMV ("control"). The asymptomatic arm of the study has the largest number of study participants making up about one-half of the total enrollment. The remainder of the subjects are divided between symptomatics – 60% and controls – 40%. As the mean age of our study subjects shifts from infancy to later childhood years, we continue to study each child closely to look for any long-term effects of the virus that may become evident at the preadolescent age. We thank all our study subjects and their families for sticking with us in this lifelong task to study natural outcome of CMV infection!

study subject was 9.8 years and the shortest time was 5 months. A second study, (Journal Pediatrics, in press), showed us guidelines on how to predict using birth characteristics such as physical exam findings and imaging studies of the brain, to know what the long term outcome will be in a child. Those children born with small head size and an abnormal CT scan of the brain are very likely to experience mental retardation and major motor disabilities like cerebral palsy. We also have found children born with a normal head size and a normal or only slightly abnormal head/brain CT scan are likely to have a normal outcome. Those children born with a normal head size but an abnormal CT scan are still very difficult to predict. These findings show up to one-fourth to one-third of children with congenial CMV will have normal outcomes, especially if there is no evidence on exam or CT Scan that their brain was injured before birth. These results will help us counsel families of newborns born with CMV and help us plan their follow-up care. A third study on hearing loss and congenial CMV presented at scientific meetings and will soon be submitted for publication. This study shows 65% of children with symptomatic congenial CMV infection and 15% of children with asymptomatic congenial CMV infection will develop hearing loss, and once it develops, will almost always progress to a severe/profound loss in the affected ear or ears of all children. Also, the rate of hearing loss progression appears to be similar in both groups, suggesting a similar process maybe involved. Therefore, hearing tests should be performed regularly on all children with congenial CMV and if a loss, no matter how slight or early it is detected, it should be carefully followed because most, if not all, will progress over time.

In summary, we have learned so much from all of you! The fruits of our labor are finally being seen! If you would like a copy of our scientific articles, contact us and we can send a reprint to you. We will continue to analyze our results, stay tuned for more updates!

Recently, the Houston Longitudinal CMV Study has completed several interim analyses. One study, (Pediatric Infectious Disease Journal 2000, 19;505-510), showed there was no significant difference in duration of CMV urine excretion between children born with asymptomatic and symptomatic congenial infection; furthermore, there was no association found between long term growth and intelligence and duration of CMV excretion in the urine. We did find however that significantly more children who excreted CMV less than four years had hearing loss, suggesting maybe the immune system may play a role in deafness and not just the virus itself. The CMV strains isolated from these samples also may soon be analyzed for "molecular clues". So study subjects, thanks for donating all those urine specimens! As an aside, the longest time CMV was excreted by a

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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 congenial 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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Heading into the new millennium, we are pleased to report some recent

OUTREACH BULLETIN BOARD

PARENT SUPPORT NETWORK NEWS

For those of you who were not aware of the support network and are now reading about it for the first time, the parent support network was created as an avenue for parents to communicate with other parents dealing with the challenges of raising a child born with CMV disease. Parents may join for a variety of reasons, but most are looking for support, advice and some comfort in knowing that they are not alone when it comes to raising a child born with a virus that can be devastating to some.

If you are not yet a part of the network and want to join, contact us or simply indicate your interest on the subscription form located on the last page of this newsletter. We will then send you the parent permission form. Or, you may download the parent permission form from our web site. Complete the form, sign, and return it to us. After we receive it, we will put your name on the network list to be shared with other interested parents and then the current list will be mailed to you. At this time there are approximately 200 families listed in the support network. If you want assistance matching with a family in your corner of the world or a family who may be faced with similar circumstances, contact us and we will do our best to help.

We need your help!

Families participating in the support network, please take a few minutes to update the information we have about your child. Please forward current information about the progress, milestones and /or achievements made by your child since you last wrote us. Also, write us with any changes in your address or phone numbers.

The Parent Support Network List is updated every two months. At that time, the latest edition of the parent support network is mailed to those new families joining the network and families presently listed who have sent us an update on their child and are requesting the current list. Please forward the updated information on your child via, telephone, fax, email or postal letter.

that our CMV informational booklet, "What Everyone Should Know About CMV" is now available in the Spanish Language. To view the Spanish version, visit our website, or contact us and we can mail it to you. Many thanks to Dr. Daniel Noyola for taking time out to translate the newsletter into Spanish language for us.



INFORMATIONAL BOOKLET AVAILABLE IN SPANISH

SUPPORT NETWORK FAMILIES

In Response to numerous requests, we are very pleased to announce

QUESTION AND ANSWER CORNER

Q My daughter was born with congenital CMV disease. Presently she is six years of age and since one year of age her hearing test has remained stable, only showing a mild hearing loss in one ear. Should we continue to worry about her losing more hearing as she gets older?

A *Your daughter may still have a progression in her hearing loss. Research has shown that children congenitally infected with CMV continue to be at relatively high risk for developing a progressive hearing loss through adolescence. Hearing loss left undetected can contribute to developmental delay and affect a child's ability to grow intellectually and academically. Therefore we strongly recommend that all children born with congenital CMV disease have comprehensive hearing don't periodically.*

Q My son was born with congenital CMV disease. He is now 1-1/2 years of age and is having difficulty gaining weight. He is falling of the growth curve. Do children congenitally infected with the CMV ever have difficulty with poor nutrition or weight gain?

A *We have found that some children with congenital CMV disease may experience various nutritional problems that affect good nutrition and proper weight gain. Congenital CMV disease can cause hypertonia and/or hypotonia, also known as cerebral palsy or high or low muscle tone. Tone problems in the intestinal tract can be manifested as a difficulty with coordinating tongue movement or swallowing, or difficulty with the sense of taste and texture of foods. Other intestinal problems that can occur in children with congenital*

CMV diseases are reflux and aspiration. If your child is having difficulty gaining weight or is losing weight, we strongly urge you to seek prompt medical attention from your primary pediatrician. You may also may need the consultation of a nutritionist or specialist in pediatric gastroenterology. Upon proper diagnosis, intervention in the form of therapy, treatments, and dietary supplements can put your child back on a positive a growth track.

OUTREACH BULLETIN BOARD continued

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. For those residing in Texas check their Texas web site: 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 a 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 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*
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 John & Nancy Hazen**
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 Leticia Romero
 Joanne Schroeder**
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 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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