



Congenital CMV Disease Treatment Options

INSIDE....

- * Feature Article
 "Congenital CMV Treatment Options"
- * Outreach Bulletin Board
 - Parent Support Network Goes Global
 - Cochlear Implant Family Camp
- * Kids Spot
- * Q&A
- * CMV Research Convention News
- * and more

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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Is There a Treatment for Congenital CMV Infection?

Cytomegalovirus (CMV) infects about 1% of all newborns. It is a common congenital infection, but can we, do we, or even should we, treat babies born infected with this virus? It is a controversial issue, because some babies are born with severe symptoms, some have mild symptoms, and most, have no symptoms at birth. Furthermore, congenital CMV infection can cause long term problems, most commonly progressive hearing loss, that can cause problems months or even years after your baby is born. Treatment of CMV with antiviral medications, such as

ganciclovir, valganciclovir, cidofovir and foscarnet is possible in some patients. Other options, such as hearing aids and cochlear implantation are available. All options should be discussed with your baby's doctors, including your pediatrician, neonatologist, developmental pediatrician, otologist and infectious diseases specialist, and individualized to your baby's needs. The information in this article may help you in this process.

Should we treat babies who are silently infected with CMV?

Most of the babies born infected with CMV are "silently" infected, and do not have any symptoms of their infection at birth. However, up to 15% of these silently infected newborns may have hearing loss; sometimes it is detected by newborn hearing screening, and sometimes it is detected only by careful follow up. The hearing loss in silently infected newborns is usually only in one ear, but it can involve both ears. The involved ear also characteristically progresses to have a severe or profound level of hearing loss over months or years. Even one-sided hearing loss can influence your child's speech and language, behavior, and school performance. However, these babies do not appear, at this time, to have significant problems with their IQ or school performance, provided their hearing loss is identified early and they receive appropriate speech and language interventions or hearing aids. Even though they are at risk for hearing loss, most experts do not recommend antiviral treatment for silently infected newborns, because we cannot predict which children will develop hearing loss and which children will retain normal hearing. Also, most experts do not recommend antiviral treatment for silently infected infants and children who develop hearing loss or hearing loss progression, because there are no controlled clinical trials to prove the

effectiveness of treatment. However, some experts have used and advocated treatment with an antiviral medication in some of these children with documented hearing loss, with the goal of maintaining as much hearing as possible.

Should we treat babies who have symptoms of congenital CMV at birth?

Babies who are born with symptoms of their congenital CMV infection may be small for their gestational age (SGA), have enlarged liver or spleen, skin rashes, yellow skin (jaundice), hepatitis, or problems with their blood counts. Some babies may have pneumonia or viral sepsis syndrome, which can be severe or life threatening. Most of these signs will gradually disappear over a period of weeks or months on their own, whether your baby receives antiviral treatment or not. Your baby also may have signs of CMV disease of the brain, such as a small head, or enlarged ventricles or calcium deposits, visible on imaging studies of the brain. Brain involvement makes your baby at risk for problems with IQ or school performances or motor disabilities. Your baby also may have lesions in the back of the eye (retina or optic nerve) that could cause vision loss. Hearing loss is also very common in these babies; and usually affects both ears and commonly progresses.

Antiviral treatment for short-term benefit

Babies with severe life threatening or sight threatening CMV disease should receive antiviral treatment with intravenous ganciclovir, with the goal of reducing the amount of active virus, and allowing your baby to control the infection with his or her own immune system. Examples of such severe infections include severe or

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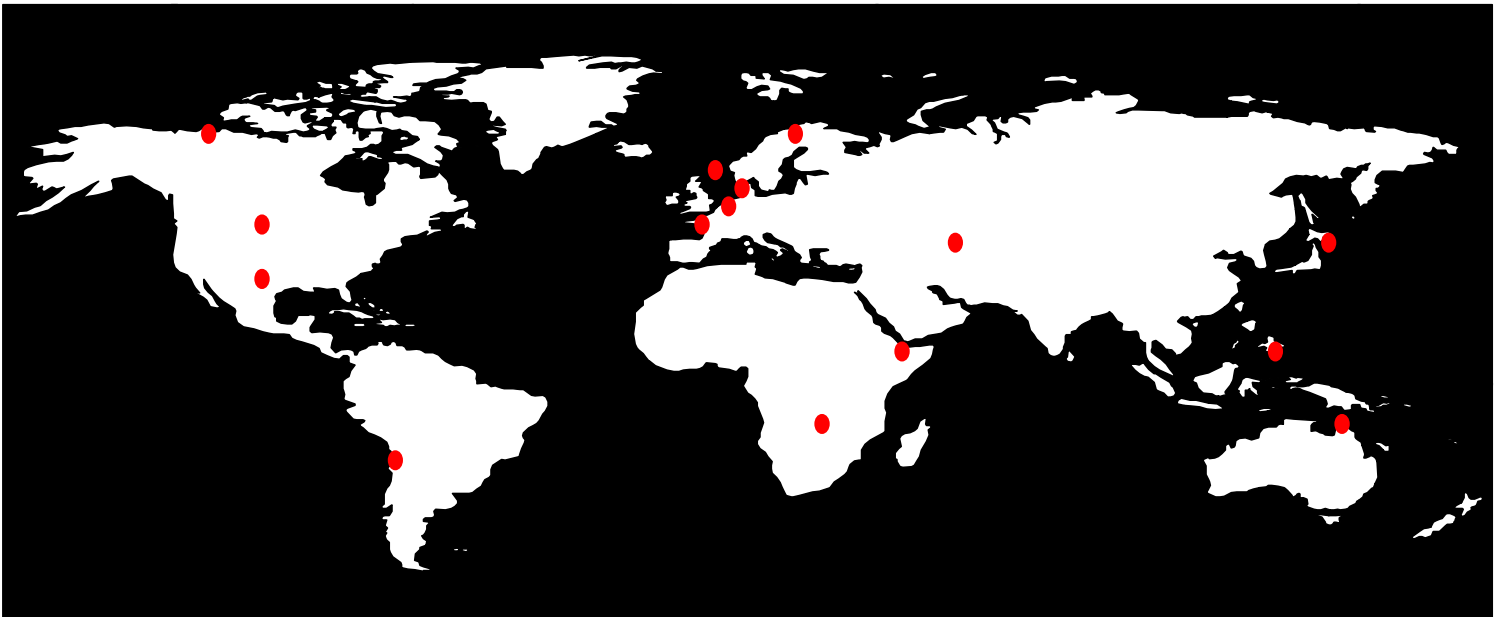
Outreach Bulletin Board

Parent Support Network Goes Global

The Congenital CMV Parent-to-Parent Support Network was established over 10 years ago. The network list started out with just a handful of families who resided in the United States. Currently, over 230 families representing 16 countries, are members. The map below identifies countries where there is at least one family belonging to the parent support network.

The goal of the support network is to provide an understanding haven where families can voice their feelings and concerns, exchange information, and perhaps just talk with someone else who can relate to the struggles and challenges that come with raising a child born with congenital CMV disease.

If you have not joined the support network and are interested, call, email, or fax us and we will mail you the parent permission form. You also may indicate your interest on the back of this newsletter, mail it to us and the parent permission form will be sent to you. After the signed parent permission form is returned to us, a current list of all parents on the list will be mailed to you.



Question and Answer

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Q. My son has been diagnosed with congenital CMV disease. Is there a medicine available to treat his infection?

A. Research studies using the antiviral drug, ganciclovir, have been conducted in newborns with congenital CMV and results have shown improvement in head size growth and slowing in the rate of hearing loss progression. Consult our front page article for more details and then ask your pediatrician to see if this treatment is right for your baby.

Q. My daughter was born with congenital CMV disease. She is now nine years of age. Her school-teachers have asked me if she has been tested for Attention Deficit Disorder (ADD). Is there any connection between the congenital CMV and ADD?

A. In Houston, study investigators are looking at the overall I.Q. and intelligence of children born with silent or congenital CMV infection and they appear normal. However, the association with ADD or other learning differences is not clear and is a focus of our current research.

Outreach Bulletin Board

Rocky Mountain Cochlear Implant Camp

Not long ago, we learned about a special family camp devoted to children who have cochlear implants. Beverly, mom to Ryan, one of our CMV study subjects, was so impressed with the camping experience last summer that she asked us to pass along the information to other families.



Ryan, far left at camp and having a great time!

Six-year-old Ryan, a cochlear implant recipient at 1-½ years of age, had a “cool time” on his first camping experience. Ryan and his mom enjoyed fun activities such as nature walks, climbing areas,

ropes courses, games, arts and crafts, “Carnival” and more. Workshops and seminars were held on topics such as insurance, alternative therapy, educational and family issues.

The extended weekend camp provided an accepting, friendly setting where the entire family met and interacted with other families to share personal stories of their unique challenges and those special joys that only other families touched by hearing loss and cochlear implantation know. After hearing about what a wonderful time Ryan and his mom had at camp, his dad and sisters realized they were missing out on too much fun and decided to join them next summer and make NCI Cochlear Kids Camp an annual family tradition.

The NCI Cochlear Kids Camp is a program of the Colorado Neurological Institute’s (CNI) Center for Hearing. It is located on the campus of the Swedish Medical Center in Englewood, Colorado. Cochlear Kids Camp is located at Estes Park in the Colorado Rocky Mountains. Due to the financial support of many generous sponsors the camp is affordable. Admittance to camp is on a first come first serve basis. To find out more about the camp, visit the CNI web site www.thecni.org or phone them at: 303-783-9220.



Contributions

You can help us continue our research and outreach programs by way of a contribution to the CMV Research Fund. Gifts in any dollar amount are greatly appreciated. Employer matching

funds and gifts in memory of a loved one are also accepted. Tax-deductible donations should be made payable to: CMV Research Fund. Our mailing address is located on the back page of this newsletter.

CMV Fund Raiser Planned!!

Lisa and Chad Blakeman, from the Dallas/Forth Worth area in Texas, have a son Cade, who was born with congenital CMV disease. They are in the preliminary stages of planning a fundraising event to benefit Congenital CMV Disease Research. We wholeheartedly back them for their efforts!

If you are interested in helping with a donation or volunteering, please give them a call for further details. The Blakeman’s can be reached at: 817-281-9292 or via email gottu91@aol.com (Please put CMV on subject line of email correspondence.)

CMV Research Fund Contributors

Listed here are the names of those individuals and families who supported CMV research by making a contribution to the CMV Research Fund during the 2003 calendar year. We wholeheartedly thank each of you for your generous donation.

Lisa & David O’Connor
Robert E. Olds*
Nichistin A. Fischer*
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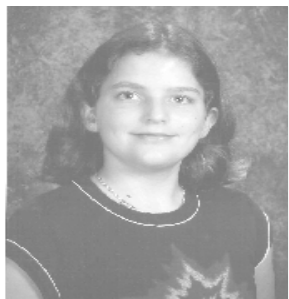
** A special thanks to our donors who continue to support us on an annual basis*

An ongoing feature of the newsletter is devoted to highlighting interesting or unique activities or accomplishments of those children enrolled in the CMV Longitudinal Study. Children featured here were enrolled by their parents in our longitudinal study shortly after birth and they continue to participate actively in the study. It is a delight for us to watch these fine children grow up.

Throughout the year, our study subjects are excited to tell us about their special interests. Since, we have space limitations and are unable to print all the wonderful stories, but we love to hear about all our study subjects, their varied interests and accomplishments. Keep up the good work, kids!

Academic Achiever

Thirteen-year-old Caroline now attends middle school. She has been participating in the Congenital CMV Longitudinal Study as a symptomatic study subject since birth. She was born with multiple problems as a result of her congenital CMV infection but this bumpy start to life has never gotten Caroline down! All of her problems resolved except for a profound hearing loss of both ears.



We share the pride felt by Caroline and her parents as she was inducted into the National Junior Honor Society (N.J.H.S.) last summer. N.J.H.S. recognizes students who have achieved academic excellence. Students selected for membership must also demonstrate outstanding performance in areas including service, leadership, character, and citizenship. www.njhs.us

Surprisingly, in spite of her hearing loss, Caroline's Mom tells us that she does especially well in her French studies. She tested her abilities on a recent family trip to France and again when the family welcomed to their home a French-speaking foreign exchange student from Quebec. Caroline's teachers say she is a positive role model to fellow students because by her example, she shows that with the right attitude and perseverance many challenges can be met! Caroline's interests include reading, writing, and volleyball. She looks forward to starting high school next fall and hopes to one day try acting.

Varsity Football Jock's Big Game Victory

Jeremy, was born with asymptomatic or "silent" congenital CMV infection. He has been a dedicated Congenital CMV Longitudinal Study participant.

Jeremy is a graduating senior and plays football for Bellaire High School. This year he was one of their top ten defensive players and he was named to the Houston Independent School District Academic Team. www.bhsfootball.net

The football team had the best year in 30 years and made the playoffs. The most exciting game of the season was the game played against Madison High School. Madison was beating up Bellaire pretty bad with a score of 28-0 at the half. Jeremy recounts that things looked mighty grim as they begun the second half. But after a rousing pep talk from the coach, the team got down to business in the second half and tied the game up at 30 seconds left to play. The game went into overtime, and when the Madison quarterback fumbled the ball, Bellaire scored another touchdown winning the game 35 - 28 and breaking Bellaire's 26-year losing streak against Madison. It was the most exciting game he ever played and one he will always remember!!



Aside from football and track, Jeremy enjoys school and does well academically especially in English and Language. His future plans include attending college at Texas Lutheran University, and he is considering a career in communication.

Outdoor Enthusiast



Cooper, now eighteen years old, participates in the Congenital CMV Longitudinal Study as a control subject. On a recent study visit here, he told us about his fascinating part-time job. For the past four years, Cooper has worked as an outfitter for 2 Bayous Hunting Lodge (www.2bayous.com). He leads guided bird hunts along a region of the upper Texas coast and into the Chocolate Bayou area located near Alvin, Texas. On weekends, his workday begins well before the crack of dawn so that he can prepare for the excursion and get acquainted with his next group of hunters. He tells us the groups he guides generally consist of corporate clients having a range of ability in hunting skills. Before sunrise, they set out and depending on the season, the group will get to hunt different types of fowl such as ducks, geese, quail, and pheasant.

Cooper considers his work as an outfitter more of a hobby than a job because he gets so much pleasure and satisfaction from helping people and seeing them have fun. Also, he enjoys spending time outside in the wide, open spaces and away from the city.

In addition to his part-time work, Cooper focuses on excelling in his high school studies. After graduation, he plans to attend Trinity College and then study law.

CMV Study

Subjects are

The Greatest!

CMV Research Recognized at National Convention

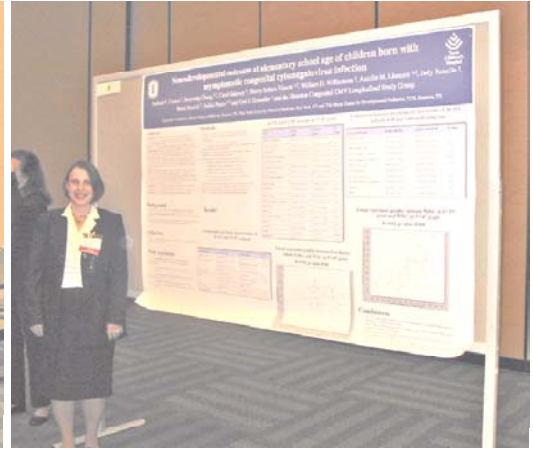
Congenital CMV Infection was highlighted in a special research symposium at The Pediatric Academic Societies (www.aps-spr.org) Annual meeting in San Francisco, CA on May 8, 2004. Dr. Gail Demmler, Baylor College of Medicine, Texas Children's Hospital, Houston, Texas and Dr. Robert Pass, University of Alabama at Birmingham, Birmingham, Alabama, co-moderated a special scientific symposium, titled "Congenital Cytomegalovirus Infection: Continued Progress." CMV Researchers from around the world presented new findings & discussed the implications of their work. Two presentations were made by our own research group.



Dr. Niri Maduri, Baylor College of Medicine, Houston, Texas. Presented her research on children who received cochlear implants. CMV Study subject, Ryan is featured on the poster!



Dr Gail Demmler President SPR 2003-2004, organized and co-moderated the symposium.



Dr. Andreea Cazacu, Baylor College of Medicine, Houston, Texas, presented her award winning research on the cognitive outcome of children born with silent congenital infection.

Continue d from page 1...

persistent low blood counts (white blood cell, red blood cells or platelets), pneumonia severe enough to require oxygen or mechanical ventilation, or viral sepsis syndrome. Retinitis that is active and threatening vision also should be treated. Other diseases such as esophagitis, colitis, and hepatitis with jaundice may improve with treatment, but there are no controlled trials to tell us for sure.

Antiviral treatment for long-term benefit

Newborns with symptomatic congenital CMV who have hearing loss may also benefit from antiviral treatment, because a recently published multi-center controlled clinical trial (Kimberlin, et al in Journal of Pediatrics, July 2003) showed treatment with ganciclovir was beneficial, and may help your baby retain normal hearing or slow progression of his or her hearing loss for 6-12 months, maybe longer. Some babies who receive ganciclovir will have improved head size. However, there is no evidence, at this time, that treatment with ganciclovir will improve your baby's IQ or school performance.

How is treatment given?

Treatment of newborns with ganciclovir is a challenging procedure and usually requires 6 weeks of medicine given through a central intravenous line. The usual dose is 6 mg per kg per dose, and a dose is given over a one-hour infusion every twelve hours. If your baby is premature or has problems with kidney function, your doctor may adjust the dosage of the medication. Also, most doctors will require your baby be in the hospital for the entire length of treatment. However, under special circumstances, it may be safe to administer treatment at home. At least every week, or more often if your doctor feels it is necessary, your baby will be examined, and blood and urine tests will be performed to make sure the level of CMV is reduced and that the medication is not harming your baby. The most common side effect is a decrease in the blood count and infection fighting cells. There may be unexpected long-term effects of treatment, especially on growth and development, and this issue is currently being studied. Also, even though

benefit has been shown, some insurance agencies may not cover some or all of the costs associated with this treatment. Appeals may be successful if a letter of medical necessity and results of clinical trials are made available to your insurance agency.

Other Treatment Options for Congenital CMV Infection

Whether or not your baby receives antiviral medication, such as ganciclovir, as a newborn, remember that careful follow up to identify progressive hearing loss is important, so that other treatment options, such as hearing aids or cochlear implants, can be considered, when indicated. Speech and language therapy also help children with hearing loss acquire necessary language skills and referral to a center for deafness education may be necessary if your child has severe or profound hearing loss in both ears. Also, occupational and physical therapy may help rehabilitate children with motor disabilities. Feeding disorders may cause malnutrition in severely impaired babies, and seizures should be controlled with anti-convulsant medications.



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