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CONGENITAL CMV DISEASE:

THE NUTRITION CONNECTION

All infants and children need to have an adequate healthy diet to gain weight and grow. Some infants and children, including those with cytomegalovirus, have trouble eating enough to gain weight and grow, even when a parent is doing the best job they can feeding their child. If babies and children can't get enough calories and nutrients over a long period of time they may be at risk for malnutrition. Malnutrition can affect not only weight gain and growth but can affect the brain development of a child, slowing their learning processes. Also, malnutrition can affect the child's immune system, making them more susceptible to illnesses like colds and other infections.

There are things you as a parent can be aware of to help detect feeding problems and prevent growth failure and malnutrition. For example, if your infant takes longer than 20 minutes to breast feed or bottle feed they may have a feeding problem (burping does add some extra time). If your baby can't maintain a good suck on the breast or bottle there may be a problem. If your baby is crying with feedings they may be hungry and frustrated because they can not eat enough or may have something called reflux (back flow of stomach contents into esophagus), which is similar to heartburn. Reflux can cause pain with feeding so the child eats only small amounts or refuses to eat. If your child is coughing or choking with most feedings they may be aspirating (taking the formula or breast milk into their windpipe). If your baby has any of these problems it is important to mention it to your pediatrician or family doctor so they can assess the feeding problems. When your child gets older and begins eating solid foods, he or she should be able to drink formula and take baby food. They should be able to gradually eat more solid foods until they can eat a variety of table foods and drink milk. This usually happens around their first birthday. If your child has a hard time taking solid foods, such as refusal to take any solids, or trouble chewing, coughing and choking, texture aversions (such as refusing to eat lumpy foods), and these problems occur over a long period of time, they may have a feeding problem.

If you mention to your pediatrician or family doctor you suspect your child has feeding problems, they can weigh and measure the infant or child to see if weight gain and growth are within normal limits. Regular weight checks are an important part of well baby care. A growth chart showing a pattern or curve over time should be charted. If the growth pattern is abnormal, appropriate referrals can be made to professionals that can help assess and determine the degree of the feeding problems. A pediatric occupational therapist can watch the infant or child feed and determine what, if any, problems exist, and teach feeding techniques for your child. A speech pathologist can assess if there are any swallowing

problems. A dietitian can help you with food choices that provide more calories and other nutrients if necessary. If problems are severe, or complex, then a pediatrician who specializes in gastroenterology or nutritional disorders maybe consulted. If a children's hospital or major medical center is nearby, a feeding disorders clinic maybe available to provide a comprehensive multi-disciplinary approach to solving the problem.

If your infant or child has developmental delays they may not be able to progress through normal feeding stages. If this is the case, your pediatrician and/or feeding specialists can teach feeding techniques appropriate for your child. Some infants are unable to take enough by mouth to gain weight and may only need to have their formula concentrated to a higher calorie level for them to gain weight and grow. Other infants may need a temporary or permanent feeding tube to help provide proper nutrition. An older child may need a high calorie diet with supplements, or may also need a feeding tube. Some children may need continuous occupational and speech therapy to help them learn how to eat by mouth. Each child is different and has different needs. Remember there is help available for your child with congenital CMV disease who is not growing well or has feeding problems. Good nutrition is an important part of helping your child grow and develop to the best of their ability!

Editors Note:

Some of the children in our Houston CMV Longitudinal study have had malnutrition or feeding disorders. We now perform a growth and nutrition assessment on all the children we see with congenital CMV infection or disease. Ms. Anne McMeans, MS, RD, a registered dietitian, has followed these children with us. We asked Anne to share some helpful hints for parents who maybe concerned about their child's growth and nutrition. Thanks Anne!

OUTREACH BULLETIN BOARD

CMV PARENT-TO-PARENT SUPPORT NETWORK BEYOND BORDERS

Recently a parent in France wrote, the support network was instrumental in helping her locate another French family raising a child with congenital CMV disease. She reports that they interact periodically and their conversations have been interesting and productive.

Participation of families in the CMV Parent Support Network reaches from the east coast to the west coast of the U.S.A. Likewise, we are proud to report that the list has grown to include families who reside outside of the U.S. borders. We are delighted to welcome families to the support network who reside in Israel, Canada, The Netherlands, Indonesia, Kenya, France, and Japan. We wholeheartedly encourage other families from around the world and the U.S. A. to join the parent support network. Nearly 10 years ago, the parent support network was established to give families a forum where they can link up with other families who face many of the same challenges of raising a child born with disabilities associated with congenital CMV disease. Supportive family members and friends can help families face the stresses of raising a child affected by congenital CMV disease. However, sometimes there is no one more supportive and helpful than another parent whose own child was affected by congenital CMV disease. The support network gives parents and other family members a medium to exchange useful information and share experiences as well as the special joys of raising a child born with congenital CMV disease.

The support network list is updated every two months and sent to new participants. For those families currently on the parent support list and who want to receive a current list, we ask that you take a few minutes to send us via email, fax, or postal mail updated information about your child's progress such as newly acquired developmental milestones, other noteworthy accomplishments and achievements that can be used to update the information we have about your child for the list. Then after we update your child's narrative, we will send you the current parent support list. If you are not a member of the parent support network yet and want to join, simply contact us and we will send you the parent permission form. To receive the parent permission form, complete and mail the information form on the back page of this newsletter.

RESOURCE FOR HEARING IMPAIRED CHILDREN

HEAR ME FOUNDATION

The Hear Me Foundation is a non-profit organization founded by parents of hearing impaired children. First and foremost, the goal is to provide a program that provides a wide range of resources that allows parents and family members of oral-deaf and hard of hearing children give their child the opportunity to improve their quality of life and maximize their potential. The organization also works to promote awareness and educate the public on the needs of the oral-deaf and hard of hearing child.

Since 1999, the Foundation has sponsored an annual camp for the oral-deaf and hard of hearing. "Camp Hear Me" located in Burton, TX- offers children and their families numerous recreational activities in a safe and accepting environment conducive for building character, social skills, emotional growth as well as an empathetic understanding of others.

This special camp program includes exhibitors and professionals to discuss new medical advances and technologies now available to the hearing impaired. Also, discussion programs are scheduled for siblings. These programs give them the opportunity to talk about their thoughts, feelings, and experiences growing up with a hearing impaired brother or sister.

To obtain more information about the Hear Me Foundation, visit their website at:

www.hearmefoundation.org

Or contact: Dan Borenstein

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POST IT HERE

The above parent resource was provided by a newsletter subscriber. Parents, educators, and health care professionals are encouraged to write and tell us about beneficial resources or services that you think will be helpful to others. We will pass along useful information in upcoming newsletters and add also add it to the parent resource guide that accompanies the support network list.

NOTES

MALING LIST CHANGES

We appreciate your help in keeping our mailing list current. Contact us via phone, email, fax or postal mail if you have any changes in your mailing address, if you receive duplicate newsletters, or if you want your name removed from the mailing list.

CONTRIBUTIONS

Any donation no matter how modest or grand allows us to continue our work in unraveling the mysteries of cytomegalovirus and is greatly appreciated! Make your tax deductible donation payable to the "CMV Research Fund." Our mailing address is located on the printable donation form of this newsletter.

BILINGUAL SPANISH LITERATURE

Our CMV informational booklet, "What Everyone Should Know about CMV" is available in the Spanish language. To obtain a copy either visit our web site or contact us and the booklet will be sent to you.

Beginning with this issue, we added a new piece to our newsletter that highlights noteworthy accomplishments of children enrolled in the Houston CMV Longitudinal Study. Most of the children enrolled have participated in the study since birth. Now many of these children are elementary through middle school age and there are a few who are in high school and college! During their periodic routine visits, we get a chance to catch-up on new experiences and special events in the lives of our family of dedicated study participants.

We have a group of very active, goal-oriented, and intelligent youngsters with varied interests. Many parents and children submitted accomplishments to the new "Kids Spot" feature. We would like to include more children's accomplishments in this article, but due to limited space, we could not fit everyone in this issue. We'll highlight more kids in upcoming CMV Updates. Below, a few of our study subjects tell us about recent or current notable endeavors.

PERFECT ATTENDANCE RECORD HOLDER & CHEERLEADER!

Jordan, an asymptomatic study subject, holds a record of perfect school attendance, beginning with kindergarten to fourth grade. She is a bright student who proves she enjoys school by never missing a day so that she can take advantage of all that a good education has to offer.

Not only that, Jordan tried out and qualified for her place on the local All Star Cheerleader Squad. Of the 120 girls who tried out for the squad, she was one of only 10 chosen for the Cy-Fair Sports Association Cheerleading Squad. She and the other cheerleaders root for the Ault Falcons Elementary School Football team.

LOCAL HERO!

Thirteen-year old **Richard** participates in the study as a control subject. He is also a Boy Scout. Richard and his other fellow Boy Scouts of Troop 55 were called to action during a devastating flood last summer. Flooding caused by Tropical Storm Allison crippled the Texas Medical Center in Houston, Texas. Along with the other members of his troop, he aided in the evacuation effort by transporting hospital patients on stretchers down nine flights of stairs.

Because the flooding knocked out electricity, there were no lights, air conditioning, or elevator service. They transported bed bound patients in stretchers down as many as nine flights of dark stairwells

with only a flashlight to lead the way. Richard says that it's an experience to will never forget and glad that he could be there to help. Thanks to the heroics and efforts of the Boy Scouts and other local volunteers, many patients were brought to safety in a timely manner.

MULTI-TALENTED ARTIST!

When **Stephen**, an asymptomatic study subject, was eight years old, he was asked if a Christmas card he designed could be printed and sold by Astroworld/Six Flags Amusement Park. Proceeds from the sale of his card benefited The Center for Hearing and Speech, Houston, Texas. His original creative design shows Santa Claus, with his cap and coat flapping in the wind as he and his reindeer ride down an amusement park roller coaster using a sleigh on wheels in the place of a roller coaster car.

Then last summer, Stephen was one of only 30 kids accepted from a nationwide pool of applicants to participate in a special summer computer program at Rice University in Houston, Texas. At Ace Computer Camp he learned Web design that also included animation and computer programming. Stephen now a middle school student with various interests, tells us that art and creative design are some of his favorite pastimes.

2004 OLYMPIC HOPEFUL!

Since the age of three, gymnastics has been an important part of twelve-year old **Meagan's** daily life. It brings smiles to our faces when we remember the time Meagan, an asymptomatic study subject, was here for a study visit at age six and she showed-off her physical dexterity and stamina by doing handsprings and cartwheels up and down the halls of the General Clinical Research Center. Over the years, her gymnastic abilities have soared and her talent has earned her the title of Junior Elite in the U.S.A. Junior National Gymnastics Team.

She is one of only sixteen girls throughout the United States who competes around the country in national championship events. In addition to spending long hours perfecting her gymnastic skills, she excels in eighth grade academics. As Meagan moves up the national ranks, her ultimate goal is being a part of the U.S. Olympic Gymnast Team 2004. We wish her much success and luck in achieving her goal!

**We are proud of the many achievements
of these and all of the children enrolled
in the CMV research project.**

WORDS OF ENCOURAGEMENT & CONCERN

Recently we received a phone call from a 23-year old adult who after finding our web site, wanted to share his experience with CMV from his unique perspective. **Allen** was born with congenital CMV disease. At birth, he had signs of brain damage as well as heart, liver, spleen, and auditory nerve damage and his doctors told his parents that he may live from one to three years of age and even if he did live, he would be mentally retarded and wheelchair bound.

However, Allen beat the odds and proved them wrong. He told us that he experienced unique challenges throughout his childhood. Nonetheless, he attended regular classes at school and participated

in sports such as football and wrestling. Currently Allen is studying computer science in college and sets his sights on starting a computer service business upon graduation.

Of particular note is that Allen tells us he has experienced further hearing loss within the past year or two for which he has needed for additional amplification. He now has lost 67% of his hearing. Allen's progressive hearing loss beyond the childhood and adolescent years, emphasizes the importance of periodic hearing evaluations for all children congenitally infected with CMV disease and shows the need for continued research on the long term effects of being born congenitally infected with CMV.

QUESTION AND ANSWER CORNER

Q: My newborn daughter was born with congenital CMV disease and the pediatrician recommended an eye exam. What kind of damage can the virus do to the eyes?

A: We agree with our pediatrician. Many studies have shown that CMV can affect the eyes and vision of newborns. Results from the Houston Congenital CMV Longitudinal Study Group showed nine of forty two (22%) children with congenital CMV disease (symptoms at birth) had moderate to severe vision problems. These problems included optic atrophy (shrinking of the optic nerve), macular scars (scars on the vision-producing areas on the retina in the back of the eye), and cortical blindness (loss of ability of the brain to "see"). Strabismus (crossed eyes) also occurred in 29% of our subjects. Vision and strabismus problems may also occur in children "silently" infected with CMV at birth, but this occurs only in one to two percent of children. (J. of A.A.P.O.S., 2000; 4:110-116).

Q: Sometime ago I read a newspaper article saying that a CMV vaccine was being developed. If this is true, how much longer will it be before the vaccine is available?

A: Congenital CMV disease is a major public health problem that is not likely to be resolved without the use of a generally available vaccine. So critical the need for a CMV vaccine that, in 1999, the Committee to Study Priorities for Vaccine Development from the Institute of Medicine at the prestigious National Academy of Sciences proclaimed a CMV vaccine to be one of the top three vaccines priorities for the 21st century. In addition to relief of human suffering, routine immunizations with a safe and effective CMV vaccine has been shown to be cost beneficial if used to prevent congenital CMV disease. The first CMV vaccine research began in the 1970's, but the quest for safe and effective vaccine has proven very challenging and, unfortunately, a vaccine against CMV is not currently available for general use. However, research presently being conducted by several investigators on different vaccine formulations is producing encouraging results. You can help by contacting your representatives in Congress and encouraging them to support funding for this important research endeavor.

REGISTRY NEWS

In this eleventh year of the CMV Registry, 786 babies with congenital CMV disease have been reported. The number of babies reported to the Registry is a mere fraction of the thousands of babies born with this disease every year. It does however allow us to continue to learn about the signs and symptoms of CMV seen in newborns. Note that 8% of babies with congenital CMV disease die and treatment is attempted in 22% (Table 1.) A ten-year summary of the cases is being analyzed and will be submitted for publication.

**TABLE 1: Common Symptoms and Abnormalities at Birth
Caused by Congenital CMV Infection**

The National Congenital CMV Disease Registry

<u>Characteristics</u>	<u>Infants(%)</u>
Petechiae or purpura	417 (54)
Small for gestational age	362 (47)
Thrombocytopenia	392 (54)
Enlarged liver	360 (47)
Enlarged spleen	336 (44)
Intracranial calcifications	288 (43)
Jaundice at birth	272 (36)
Microcephaly	301 (40)
Hearing impairment	213 (41)
Hemolytic anemia	83 (13)
Chorioretinitis	67 (11)
Seizures	59 (8)
Pneumonia	77 (11)
Neurological abnormalities	197 (28)
Bilirubin	274 (40)
ALT	175 (30)
Death	49 (8)
Coinfection	19 (7)
Treated	62 (22)

CMV RESEARCH FUND

We thank all of those who have made a donation to the CMV Research Fund. Listed below are the names of families and individuals who have shown support of CMV Research with their generous contribution during the year 2001.

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ABOUT THIS NEWSLETTER

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