FOCUS ON AWARENESS

Congenital CMV infection remains the most common viral infection. It is a major public health problem in the U.S. and in countries around the world. Yet most people still have never heard of CMV and the effects it can have on the fetus and newborn.

Last summer, the Centers for Disease Control (CDC) in Atlanta, Georgia conducted a national multi-center questionnaire to determine knowledge of CMV among women of 18 years and up. Baylor College of Medicine was one of the seven sites chosen from across the U.S.A. to participate in the survey. More than 600 women were recruited to answer the questions (about knowledge of newborn infections, demographics, awareness and general knowledge about CMV, risk factors, symptoms, modes of transmission, and prevention.) After completing the survey, they were given a brochure with information about congenital CMV disease. The CDC brochure is available now at www.cdc.gov/cmv.

Results of the research project revealed that relatively few women have knowledge of congenital CMV disease. Among the group that heard about CMV, there was misunderstanding about the transmission and prevention of CMV disease. Results of the study are now published in *Infectious Diseases in Obstetrics and Gynecology*, Volume 2006, Article ID 80383, Pages 1-7. Also, to increase CMV awareness, the CDC will sponsor the second international conference on congenital CMV infection, November 5 – 7, 2008 in Atlanta, Georgia.

CMV THE FACTS

INCIDENCE & PREVALENCE

CMV is a very common virus that infects people of all ages and in all parts of the world. By the age of 40, approximately 80 percent of the population will become infected with the virus. The incidence of new CMV infection is more prevalent in certain groups of individuals. These groups are: toddler/preschoolers, teenagers, and women of childbearing years.

In normal healthy individuals, CMV is not a health concern. Many persons, or about 90 percent, do not have any signs or symptoms of infection and never know that they ever caught the virus. Others may experience flu-like symptoms such as sore throat, fever, fatigue, and swollen glands.

In persons with a weakened immune system, signs and symptoms of CMV infection can be a serious health threat. Individuals who are infected with HIV/AIDS, bone/organ transplant recipients, cancer patients or those receiving radiation or chemotherapy and persons on steroid therapy are at risk for complications due to CMV.

CMV AND PREGNANCY

Congenital CMV infection is the most common viral congenital infection. Of the approximately 4 million babies born each year in the U.S., 1 percent, or 40,000 babies, are born with congenital CMV infection.

Ninety percent of those babies born with congenital CMV disease each year will have no symptoms of congenital CMV infection at birth, yet 10 to 15 percent will have hearing loss. The remaining 10 percent or 4,000 infants, may have serious illness and long-term developmental disorders and are at risk for progressive hearing loss.

ESPECIALLY FOR WOMEN OF CHILDBEARING AGE

Women of childbearing age should consider knowing their CMV status. Prior to pregnancy, ask your doctor about having a blood sample taken for CMV antibody titer. A CMV IgG and IgM antibody should be performed on the blood sample to determine if you are susceptible (CMV IgG & IgM negative) to catching CMV, have evidence of a current or recent CMV infection (CMV IgM positive), or had CMV protection from a past infection with CMV (CMV IgG positive and CMV IgM negative).

TRANSMISSION AND PREVENTION OF CMV

CMV is spread by coming in direct contact with body fluids such as saliva and urine. Although there are no actions that totally eliminate the risk of catching CMV, precautionary measures can help to control the spread of CMV infection to pregnant women who have evidence of a primary CMV infection.

1. Do not kiss young children on the mouth or cheek. Rather kiss them on the forehead or the top of the head and give them a big long hug.
2. Do not share food, drinks, eating and drinking utensils, or toothbrushes with young children.
3. Wash hands with soap and water after diaper changes or after contact with a child’s saliva or nasal secretions.
4. Toys that young children play with should be washed with soap and water or wiped with a solution of one part bleach to nine parts water, followed by rinsing with tap water.
If your family has been touched by congenital CMV disease, you should know that you are not alone! The National Congenital CMV Disease Registry maintains an International Parent-to-Parent Support Network that consists of a list of families who are raising a child born with congenital CMV disease. The support network gives parents an opportunity to reach out to other families for support and encouragement, sharing useful information, or just know there is a place to go where parents can talk about the special challenges that can come with raising a child born with congenital CMV disease.

The support network now lists more than 400 families. Families reside in nearly every state from coast to coast, plus also there are another 51 families residing in 17 other countries around the world.

Earlier this year, the Registry was contacted by a mother whose daughter was born with congenital CMV disease more than 25 years ago. Their story is featured in this newsletter. Their family name is Marino and you can find them listed in the parent support network in the New York State page.

If your family is already listed on the support network, we’d like to hear from you for an update about your child’s progress, achievements, and any other information you’d like to share. On the other hand, if you have not joined and want to, simply email, phone, or complete and mail the form on back of this newsletter and we will send you information on how to join.
CMV Research Fund Supporters

Over the past year, we have benefited from the generosity and efforts of individual, who have been in some way touched by congenital CMV and want to take part in helping us promote awareness, educate, and raise funds for CMV research and education.

Listed below are the names of individuals who have made contributions to the CMV Research Fund 2004 to present.

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*indicates ongoing supporters

CMV FUND RAISERS

Since we circulated our last newsletter, we’ve been privileged to benefit from the thoughtful and generosity of families who came up with clever ways to raise funds and awareness about congenital CMV disease and we want to tell our readers about their fund raising events.

BIRTHDAY GIFTS FOR CMV RESEARCH

Lisa and Chad Blakeman, another family personally touched by congenital CMV disease, called us with their idea for a creative and unique event to raise funds for CMV and at the same time celebrate their son Cade’s birthday. Cade was diagnosed with congenital CMV disease shortly after birth and his CMV involvement is limited to a unilateral hearing loss. Otherwise, he is growing and developing normally and his parents are grateful and delighted with his progress.

Last year for Cade’s third birthday party, his parents suggested that instead of giving toys and other gifts to Cade, a donation be made to CMV research. Not only have they helped fund CMV research, they have also helped to promote awareness of congenital CMV disease, and made this birthday celebration a real stand-out!

DONORS RUN FOR CMV RESEARCH

Many supporters “ran for CMV” for the second consecutive year on August 12, 2007 at the 35th Falmouth Road race held in Falmouth, Massachusetts. Thanks for your ongoing support, runners!

CONTRIBUTIONS

You too can help us continue our research and outreach programs such as this newsletter and parent-to-parent support network by contributing to the CMV Research Fund. Gifts of any dollar amount are greatly appreciated. Employer matching funds and gifts in memory of a loved one, or in honor or celebration of someone special to you are also accepted. Donations are tax deductible and should be made payable to: CMV Research Fund. Our mailing address is located on the back page of this newsletter.

We are very grateful and thank each and every one of the supporters to the CMV Research Fund!
In this special section of the newsletter we get to proudly highlight some of the wonderful accomplishments of a few of the CMV Longitudinal Study subjects. Most of the study subjects are now in at least middle school, many are in high school and many more are in college or have joined the work force. During their routine study visit, we get a chance to catch-up on new experiences and the special accomplishments of our dedicated study participants.

Year in and year out, we hear about varied interests and wonderful achievements of many of our study subjects and wish we could share all their stories with our readers, but due to space limitations, we can only print a few stories; however, we applaud all of you for your wonderful accomplishments!

**Dazzling Juggler!**

Ronald or “Ronnie T,” a lifelong asymptomatic CMV study participant, was here this summer to complete his commitment to the CMV Study. At a very young age, Ronnie developed an interest in music and acting and knew performing was for him. He’s also a master juggler. He juggles a variety of objects such as balls, sticks, jugs, plates and even dangerous objects such as sticks on fire and knives!

Already a four time medal winner at the Texas Juggling Festival in Austin, TX, last February, Ronald or “Ronnie T” (his stage name), won his first gold medal at age 17 beating jugglers participating in the event from across the U.S.A. and England. Recently Ronnie’s made a huge career decision! He wants to defend the country and has been accepted into the U.S. Army. He starts basic training later this year. We wish him much success and safe travels in his career choice!

**Award Winning Swimmer Beets the Odds!**

Ashton participates as a symptomatic study subject in the Congenital CMV Longitudinal Study. Ashton was born with a unilateral hearing loss, which progressed to a bilateral profound hearing loss by the time she was 3 years of age. She received a cochlear implant at age four years.

Ashton does well in school and is also the star of her local swim team, winning numerous ribbons and recognition for her competitive swimming abilities! Ashton does not wear her external cochlear device when swimming! Her best strokes are freestyle and the backstroke. She tells us that swimming is great fun and she enjoys the team spirit and camaraderie with her teammates.

**Movie Debut- “How to Eat fried Worms”**

Twelve year old sixth grader, Andrew has been participating in the Congenital CMV Longitudinal Study as an asymptomatic study subject since shortly after his birth. He co-starred in, “How to Eat Fried Worms”. The movie is based on a book written in 1973 by Thomas Rockwell. Andrew plays the role of a character, “Techno Mouth” named so because he wears braces. The movie is a comedy that takes a light-hearted look at bullying and how kids deal with it. The major motion picture was a hit last summer and is now available on DVD.

Earlier this year, the movie’s ensemble cast won the Young Artists Award for “Best Performance in a Feature Film.” For more information about this international awards program for young artists, and to view the list of all nominees and winners for this year, visit their web site at: www.youngartistawards.org

This year, Andrew appeared in local and national television commercials for Roadrunner, Reliant Energy, Hasbro Toys, and he also appeared locally in a spot for The Shell Houston Open.
Lisa Saunders whose daughter Elizabeth was born congenitally infected with cytomegalovirus, knows first hand about raising a child born with congenital CMV. Her book, Riding the Train with Elizabeth: Enjoying life with my handicapped daughter, is an inspirational and humorous story of how she found hope and laughter again after giving birth to a disabled child. Here she reflects on life with Elizabeth...

THE SILENT VIRUS THAT SILENCED ELIZABETH

The moment Elizabeth was born, I felt a stab of fear. I knew there was something very wrong. My immediate thought was “Her head looks so small — so deformed.”

The neonatologist entered my hospital room and declared, “Your daughter has profound microcephaly — her brain is very small with calcium deposits throughout. If she lives, she will never roll over, sit up, or feed herself.” He concluded that Elizabeth’s birth defects were caused by congenital cytomegalovirus.

How and why did I catch this virus that I had barely heard of? I read the CMV literature. It stated that women who care for young children in a close setting are at a higher risk for catching it, as preschoolers are the majority of carriers. While I was pregnant with Elizabeth, I not only had a toddler of my own, but also ran a licensed daycare center in my home and cared for infants in Sunday school. I felt sick at what my lack of knowledge had done to my little girl. In milder cases, children with congenital CMV may lose hearing or struggle with learning disabilities later in life. But Elizabeth’s case was not a mild one.

Fifteen years later, I awoke feeling so proud on Elizabeth’s 16th birthday. She had fought hard to stay with us. Weighing only 50 pounds, she looked funny to strangers as a result of her small head and big adult teeth, but she was lovely to us with her long, thick brown hair, large blue eyes and soul-capturing smile. Although Elizabeth was still in diapers, and could not speak or hold up her head, she was still a very happy little girl, with a love of adventures — long car rides being one of her favorites. She especially loved going to school and being surrounded by people, paying no mind to the stares of other children who approached her in public.

Less than two months after she turned 16, I dropped Elizabeth off at school. Strapping her into her wheelchair, I held her face in my hands, kissed her cheek, and said, “Now be a good girl today.” She smiled as she heard her teacher say what she said every time, “Elizabeth is always a good girl!” With that, I left. At the end of the day, I got the call I had always feared. “Mrs. Saunders, Elizabeth had a seizure and she’s not breathing. We called 911.”

While holding Elizabeth on his lap, my husband looked down into her partially open, lifeless eyes and cried, “No one is ever going to look at me again the way Elizabeth did.” I knew he was right. No one adored us as Elizabeth did.

It has been a year since we lost our little girl. At times I miss her so much I can barely breathe. Yet at other times, I feel happy for her — never again will I see that look of terror in her eyes as a seizure begins and she can’t catch her breath. Never again will she be cold or sick. She is finally free. And for the remainder of my days Elizabeth will be forever “Sweet Sixteen.”

Today, my sorrow is gradually being replaced by a passion to prevent others from going through what Elizabeth did. I have returned to the CMV research and literature. There is still no vaccine against this cruel virus, but there are steps, according to the CDC, that women can take to reduce the risk of infection during pregnancy: For more information, visit www.cdc.gov/cmv.

Lisa Saunders of Suffern, New York, U.S.A. is a freelance writer (www.authorlisasaunders.com). She can be reached at saundersbooks@aol.com.

Do you or someone you know of who is having difficulty obtaining a hearing aid due to limited financial resources?

Recently, we have learned about a national hearing aid program that provides hearing aids to persons living in the U.S.A. who need a hearing aid but are unable to pay for it. The Hear Now Program, a division of the Starkey Hearing Foundation, assists hearing impaired individuals who have financial difficulties get the hearing aid they need so that they can hear. To qualify, the applicant must meet certain financial criteria and show a proof of need for hearing aid.

For more information about the Starkey Hearing Foundation and the Hear Now Program, visit their web site: www.sotheworldmayhear.org or contact the Hear Now Program coordinator, Joanita Stelter at: 800-328-8602 ext. 2358.

Donate to The Hearing Aid Recycling Program

The Hear Now Program is collecting discarded hearing aids for recycling purposes. Any make or model is accepted for donation. All donated hearing aids are tax deductible. A letter of acknowledgment will be sent to donors. To donate a hearing aid, mail the hearing aid in a secure package to:

Hear Now
6700 Washington Ave. South
Eden Prairie, MN 55344
1-800-648-4327
GROWING UP WITH CONGENITAL CMV DISEASE

My name is Kristen and I am 25 years old and I was born with congenital CMV disease. As my mother would agree, my early life included many challenges, a number of setbacks, and difficult times.

As a result of congenital CMV infection, I was born with developmental delay and physical disabilities that affected muscle tone and coordination. As a result, I had three hip surgeries and six years of physical and occupational therapy and rehabilitation. I took my first steps at age two-and-one-half years old.

At the age of six years, the school nurse performed my first hearing test and it showed left ear deafness. Teachers gave me special help, such as preferential seating at the front of the classroom and extra time for tests so that I could maintain placement in a regular classroom. Then when I was in fourth grade, I met a fabulous teacher of the hearing impaired who advocated for me by making sure all of my teachers were aware of what my needs were and helped me stay organized, which was never an easy task! This dedicated woman stuck by me and mentored me through high school.

Around the time of high school graduation, I set my sights on getting my driver’s license. Recalling the difficulties I had when learning to ride a bike, I already knew that learning to drive would take longer for me than most people, but I made up my mind and was determined to learn how to drive. I persevered and after 6 attempts, passed the road test and got my driver’s license!

To the surprise of myself as well as my parents on senior awards day, I was awarded a full scholarship to a local college near home that has a program for students with special needs and did receive a certain amount of classroom accommodations. Mostly, I was given extra time for tests and being able to type assignments rather than hand write them. I graduated from college in 2004 with a BA in English and a minor in Psychology. Later that year, I was offered and accepted a job for a company that processes newspaper subscriptions.

Although, this is my first full time job and I am pleased with my accomplishments, I am not sure what I ultimately want to do with my life. My parents have raised me to have a “can-do” attitude, and focus on my abilities, rather than my disabilities. So whatever I end up doing, I’m sure I won’t be defined by my CMV.

Editors note: We are very grateful to Kristen and her mother for sharing their story. It is our hope that Kristen’s story can be a source of inspiration and hope for other families who feel they are facing infinite challenges. Via the CMV parent-to-parent support network, Kristen and her Mom are available to speak to families, answer questions and offer support. To join the CMV Parent-to-Parent Support Network and talk to them, complete the subscription form located on the last page of the newsletter and mail it to us or download the permission form from our website and email it to us.

Throughout the year, we receive many questions about CMV from parents, teachers, educators and health care professionals. Here are answers to a couple of good questions we’d like to share with our readers.

Q: My newborn son was diagnosed with congenital CMV and we plan to visit my pregnant sister who is CMV sero-negative and has never had CMV infection. Are there any special precautions we should take?

A: CMV is spread when an uninfected individual comes in direct contact with the body fluids of anyone who has an active CMV infection. Using good hygiene and practicing universal precautions prevents the spread of CMV and other infectious diseases. Practice good hand washing technique by washing hands especially after diaper changes and after contact with saliva and mucosal secretions of a runny nose. Good hand washing technique is carried out by lathering hands with warm soapy water for 15 seconds, rinsing thoroughly, and drying hands with a clean towel. Also, avoid kissing all young children on the face, cheek, or on the mouth; instead kiss them on the top of the head or give them a big hug! Toys or other objects mouthed by young children should be disinfected by washing them with a solution of one part chlorine bleach to nine parts water, rinsing thoroughly in water and drying. Stuffed toys or other non-immersible objects should be allowed to air dry for a couple hours between each use.

Consult our website brochure, “What Everyone Should Know About CMV” at www.bcm.edu/pedi/infect/cmv or the CDC website handout, “What Every Woman Should Know About CMV” at www.cdc/cmv.

Q: Is there a CMV vaccine available to prevent birth defects due to congenital CMV disease?

A: Unfortunately there is no CMV vaccine available yet to prevent congenital CMV infection or disease. The National Institute of Medicine named CMV vaccine as a top three priority for vaccine research and development. Currently several clinical trials are being conducted on promising new vaccines. The most recent report was presented in October 2007 at the Infectious Disease Society of America meeting in San Diego, California by Dr. Robert Pass. A new CMV vaccine that contains a piece of CMV (g B protein) attached to a powerful adjuvant (booster protein) showed promise by preventing CMV infection in women.
We are “all ears” when it comes to hearing about special camps for children with disabilities. Our CMV study subjects have enjoyed a couple of special camps that are described here.

**C.A.M.P.**
Camp C.A.M.P. (Children’s Association for Maximum Potential) located in the Texas Hill Country, has facilities equipped for special needs of children with physical disabilities and medical conditions. C.A.M.P. provides summer camp experience for children with no verbal communication or self-help skills or with need for multiple medications and require around the clock care.

The program is a series of 5 day summer camp programs that provides a recreational environment for children and adults with disabilities. A variety of activities are offered such as boating, swimming, horseback riding, arts, crafts, karaoke, carnival, and dance. Activities are modified to meet a child’s abilities or limitations. For more information about C.A.M.P., visit their website at: www.serve.com/CampCamp.htm

**CAMP SIGN**
Camp Sign, located in Conroe, TX, is open to all children between the ages of 8 – 17 in the state of Texas who are hearing impaired. They also run an outdoor training program for developing leadership skills and preparing boys and girls aged 16 and 17 to become future camp counselors and leaders. The goal of Camp Sign is to provide an environment of acceptance and encouragement for children without regard to their method of communication.

Thirteen-year-old CMV Study Subject, Lucas, who communicates using sign language, attends Camp Sign every summer. He tells us his favorite activities at camp are swimming and playing with his newfound friends. His mom tells us Camp Sign provides a welcoming and safe environment for children with hearing loss. She also says that it’s a great place for Lucas to go and enjoy the company of other children like him who share a common bond of communication via sign language and gives him the opportunity to interact and talk with peers about challenges they face as they grow up. For more information about Camp Sign, visit their website at: www.dars.state.tx.us/dhhs/camp.shtml or google Camp Sign.

**EQUESTRIAN THERAPY**
Did you know Equestrian Therapy (horse therapy) or Hippotherapy can be therapeutic for children with physical and mental disabilities?

Although the origin of Equestrian Therapy (E.T.) dates back to the middle ages and is well established in Europe, centers for E.T. began forming in the U.S.A. in the 1960’s and have recently gained popularity. Experts in the field say the movement of the horse stimulates a person’s gait, helping the rider with balance, posture, and other skills. Riding improve muscle tone, coordination, circulation, and emotional health.

Fifteen-year-old David, who has multiple disabilities associated with congenital CMV has benefited from E.T. through an organization known as S.I.R.E. E.T. therapy relaxes and stretches his tight muscles, improves his sleep, and helps improve his overall well-being and quality of life. For a list of animal assisted therapy programs and services, visit www.therapypets.com

**FOCUS ON AWARENESS...** Continued from page 1

**VACCINE, ANTIVIRALS, AND IMMUNOGLOBIN THERAPY**
At this time, there is no vaccine available against CMV. However, studies are being conducted at research centers around the country looking at the safety and effectiveness of experimental vaccines.

There are several antiviral medications used in the treatment of serious CMV disease. Clinical research trials conducted around the country have shown this treatment helps babies born with severe CMV disease. Consultation with a pediatric infectious disease specialist may help. Also, recent clinical studies suggest CMV immunoglobin given to a pregnant woman with primary CMV infection may reduce CMV transmission in the fetus. Consultation with a prenatal fetal medicine expert may help.

For more information, about congenital CMV, visit our website at: www.bcm.edu/pedi/infect/cmv or the CDC website at: www.cdc.gov/cmv and other websites of families personally affected by congenital CMV in children (www.stop.cmv.com).

**ARM YOURSELF WITH KNOWLEDGE!**
IMPORTANT ANNOUNCEMENT

International Conference on Congenital CMV

November 5-7, 2008
Atlanta, Georgia

Tom Harkin Global Communications Center
Centers for Disease Control and Prevention

The conference will bring together an international community of scientists and practitioners to discuss how to translate current knowledge about congenital CMV into public health action that will directly benefit women and children.

Conference topics will focus on:
• Public health issues and initiatives
• Raising awareness of Congenital CMV
• Proposing preventative guidelines
• Setting testing and screening standards
• Advancing treatment options
• Solutions to help alleviate burden
• Developing a vaccine

NEWSLETTER SUBSCRIPTION AND PARENT SUPPORT NETWORK INFORMATION
MAILING ADDRESS CHANGE / CMV RESEARCH DONATION

I would like to be □ added, or □ deleted from (check one) the CMV Updates email list.
Email: ________________________________

I would like to be □ added, □ deleted, or have an □ address change (check one) to the CMV postal address list.
Name: ________________________________
Address: _____________________________________________
___________________________________________

□ Switch us from the CMV postal address list to the email list.
Name: ________________________________
Address: _____________________________________________
___________________________________________
Email: ________________________________
Phone: ________________________________

I would like to □ receive information about, or be □ deleted from (check one) the Parent-to-Parent Support Network.

□ Enclosed is my $__________________________ donation to continue research on congenital CMV disease and infection. Please make check 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: ___________________________________________
Email: ___________________________________________

Detach and mail this form to:
National Congenital CMV Disease Registry, Texas Children’s Hospital • Mail Code 3-2371, 6621 Fannin Street • Houston, Texas 77030-2399
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