CONGENITAL CMV INFORMATION

<TARGET><BILL></BILL><SUBJECT>CONGENITAL CMV INFORMATION</SUBJECT><COMM>SHSS27</COMM></TARGET>

Every year, 1 in 150 children is born with congenital CMV.

WHY IS CMV AWARENESS IMPORTANT?

In the United States, about 50 to 60% of women are at risk for contracting CMV infection during pregnancy.

In a recent survey of women in the United States, only 14% had heard of CMV, compared with 97% who had heard of Down Syndrome and 98% who had heard of HIV/AIDS. With CMV prevention measures rarely communicated to women, Stop CMV wants to increase the public profile of congenital CMV to save tens of thousands of babies each year from death and disability.

ABOUT STOP CMV & THE CMV ACTION NETWORK

The mission of Stop CMV and The CMV Action Network is to prevent and eliminate congenital CMV and to improve the lives of all people affected by congenital CMV.

Since 2003, Stop CMV has been working to foster awareness of congenital CMV through internet and public awareness campaigns. The CMV Action Network is comprised of families, friends, and medical professionals personally affected by CMV and committed to public education efforts to prevent future cases of the virus.

HOW YOU CAN HELP

There are many ways to make a difference, whether it be online or volunteering locally--there is always a way to participate in CMV awareness, outreach, and advocacy. Your service, caring and contribution can help change lives and prevent congenital CMV. Visit Stop CMV at www.StopCMV.org for more information about CMV and how you can get involved.

Congenital CMV (cytomegalovirus)

causes deafness, blindness, cerebral palsy, mental and physical disabilities, seizures, and death.

If you are pregnant or planning a pregnancy, learn how you can prevent congenital CMV:

- DO wash your hands after handling babies or small children.
- DON'T share food or drinks with babies or small children.
- DON'T kiss babies or small children on the mouth.

Learn the facts about CMV

- Most common virus transmitted from mother to unborn baby
- More common than Down Syndrome, Spina Bifida and Fetal Alcohol Syndrome
- Spread through saliva, urine, tears, blood, mucus, and other bodily fluids
- Found mostly in healthy babies, toddlers, and young children
- Poses a major risk to pregnant women, especially mothers, daycare workers, preschool teachers, therapists, and nurses

Prevent birth defects. Stop CMV.

For more information, visit Stop CMV at www.StopCMV.org
or the Centers for Disease Control and Prevention (CDC)
at www.cdc.gov/cmv.

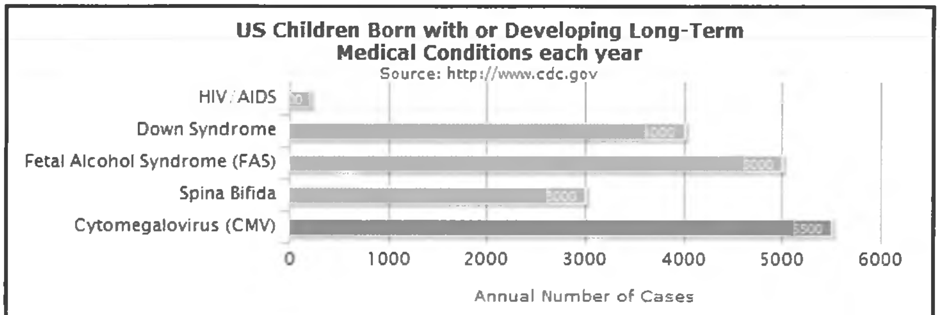
AWARENESS . OUTREACH . ADVOCACY
STOP CMV AND THE CMV ACTION NETWORK INC.

CMV
STOP CMV
The CMV Action Network

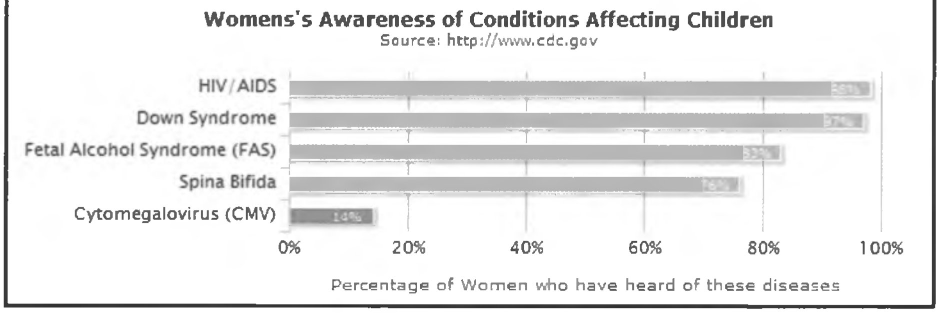
CMV Awareness

More children have disabilities due to congenital CMV (cytomegalovirus) than other well-known infections and syndromes, including Down Syndrome, Fetal Alcohol Syndrome, Spina Bifida, and Pediatric HIV/AIDS.

- A 2008 study, funded by the Center for Disease Control (CDC) found that **only 14% of women in the United Stated had heard of Cytomegalovirus (CMV)**. *Ross DS, Victor M, Sumartojo E, Cannon MJ: Women's Knowledge of Congenital Cytomegalovirus: Results from the 2005 HealthStyles survey, J Women's Health, Vol. 17, 849-858 (2008).*
- The American College of Obstetricians and Gynecologists (ACOG) and the CDC recommend that OB/GYNs counsel women on basic prevention measures to guard against CMV infection.
- Only 44% of OB/GYNs reported counseling their patients about preventing CMV, according to a 2007 survey. *Knowledge and practices of obstetricians and gynecologists regarding cytomegalovirus infection during pregnancy-United States, 2007, MMWR, Vol. 57, 65-68 (January 25, 2008).*


US Children Born with or Developing Long-Term Medical Conditions each year

Source: http://www.cdc.gov


Womens's Awareness of Conditions Affecting Children

Source: http://www.cdc.gov

Preventing CMV among pregnant women

- Women are not routinely screened for CMV during pregnancy.
- Infants are not routinely tested for CMV after birth.
- Behavioral intervention programs need to be developed, implemented, and evaluated
  - A study in France showed that women who were educated about preventing CMV transmission were able to significantly reduce their rates of infection during pregnancy; a similar intervention needs to be tested in the U.S.

CMV has never received dedicated funding

- It is time to fund public education and awareness campaigns to help prevent this common virus.

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94088-2214

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CMV Facts

Incidence

- Congenital CMV is the most common congenital (meaning present at birth) infection in the U.S.
  - 1 in 150 children is born with congenital CMV (approx. 35,000 each year)
- Congenital CMV is the most common cause of birth defects and childhood disabilities in the U.S.
  - 1 in 750 children develops permanent disabilities due to congenital CMV (approx. 5,500-8,000 each year)
- Congenital CMV causes more disabilities than Down Syndrome, Fetal Alcohol Syndrome, and Neural Tube Defects (Spina Bifida, Anacepahly, etc.).
- Congenital CMV is a leading cause of Cerebral Palsy, hearing loss, mental disability, and ADHD/Autism.
- Congenital CMV also causes vision loss, feeding issues/Failure to Thrive (FTT), sleeping issues, sensory issues, small head/small brain (Microcephaly), intercranial calcifications, seizures, and death
- There are approximately 400 fatal cases of congenital CMV each year; this number doesn't include miscarriages.

- CMV can cause symptoms when the baby is born or later in the baby's life; in some infants, symptoms and problems can arise months or years after birth.

Congenital CMV can be diagnosed if the virus is found in an infant's urine, saliva, blood, or other body tissues during the first week after birth.

Congenital CMV cannot be diagnosed if the infant is tested more than one week after birth.

- Anyone can become infected with CMV, which is common and usually harmless.
- Most people don't realize that they have been infected with CMV.
- One of the highest risk groups are pregnant women who have not yet contracted CMV prior to pregnancy, as they will possibly pass the virus to their developing child, causing potential birth defects.

Transmission

- CMV is found in body fluids, including urine, saliva, blood, mucus, and tears.
- CMV is very common in home and daycare settings, especially among healthy children 1 to 3 years of age who are at high risk for contracting CMV from their peers.

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- Mothers and women who work with infants and young children should be educated about the risks of CMV and the precautions they can take to prevent infection.

Prevention

- Simple steps to avoid exposure to saliva and urine that might contain CMV:
    - Wash your hands often with soap and water for 15-20 seconds, especially after changing diapers, feeding a young child, wiping a young child's nose or drool, and handling children's toys.
    - Do not share food, drinks, or eating utensils used by young children.
    - Do not put a child's pacifier in your mouth.
    - Do not share a toothbrush with a young child.
    - Avoid contact with saliva when kissing a child.
    - Clean toys, countertops, and other surfaces that come into contact with children's urine or saliva.

All statistics and information cited from the Center for Disease Control and Prevention (CDC) - www.cdc.gov/cmv

The State of CMV

Background

Promising strategies for preventing and treating congenital CMV are available. They include raising awareness, developing behavioral interventions to prevent infection in pregnant women, and improving outcomes in congenitally infected children through early detection and intervention. To be successful, these approaches require adequate surveillance and laboratory capacity. However, prevention and treatment strategies have never been implemented on a wide scale.

Current efforts

Congenital CMV does not receive dedicated federal funding. Fortunately, people have realized a need to address this issue. By using CDC general funds and external grants, small research activities have been funded, including:

- Study of the natural history of CMV infection among women
- Surveys of women's knowledge, attitudes, and behaviors related to congenital CMV
- Laboratory assessments of CMV persistence in the environment and the efficacy of hand washing for removing CMV from hands
- Study of long-term outcomes in a cohort of children born with congenital CMV

Issues needing immediate attention

Awareness – Awareness campaigns are needed to explain the dangers posed by CMV and how they can be prevented

- Only 14-22% of women have ever heard of CMV.
- Most obstetricians do not discuss CMV or CMV prevention with their patients.

Preventing CMV infection among pregnant women – Behavioral intervention programs need to be developed, implemented, and evaluated

- A licensed CMV vaccine is unlikely to be available for many years.
- A large intervention study in France showed that women who were educated about preventing CMV transmission were able to significantly reduce their rates of infection during pregnancy; a similar intervention needs to be tested in the U.S.

Evaluating newborn CMV screening – Research and pilot screening programs are needed to determine whether benefits of screening outweigh costs and potential harms

- Congenital CMV infections are more common than the combined metabolic or endocrine disorders currently in the U.S. core newborn screening panel.

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- Newborn CMV screening has significant potential for improving children's functional outcomes (e.g., language and educational development) through early detection and intervention.

Surveillance – Ongoing surveillance is needed to assess the burden of congenital CMV and to make it possible to monitor the effectiveness of future prevention programs.

- There is no ongoing assessment of the occurrence of CMV infection among pregnant women, rates of congenital infection among newborns, or rates of disability among infected newborns.

Laboratory capacity – Diagnostic methods are not yet sufficient for universal CMV screening programs.

- Standards and controls need to be developed for quality control of newborn CMV screening.
- Improved diagnostic tools are needed for prenatal maternal screening and diagnosis.

Stop CMV and The CMV Action Network

Who we are

Since 2003, Stop CMV has been working to foster congenital CMV awareness via internet and public awareness campaigns. The CMV Action Network is comprised of families, friends and medical professionals personally affected by CMV and committed to public education efforts to prevent future cases of the virus. We realize that the incidence of children born with congenital CMV can be greatly reduced with grassroots public education and awareness. Additionally, we hope that women, families and friends will become familiar with CMV and will take vigilant steps to prevent infection. We believe that it is better for women and their families to learn about CMV prior to pregnancy in order to be well informed and take preventative actions.

Mission

The mission of Stop CMV and The CMV Action Network is to prevent and eliminate congenital CMV and to improve the lives of all people affected by congenital CMV.

Strategic Goals

Organization – Develop and maintain an efficient organization to cost-effectively fulfill the mission and increase the quality, consistency and scope of The CMV Action Network

Funding – Develop and maintain annual revenue sources sufficient to fulfill the mission and support an appropriate capital reserve

Awareness – Support media and education programs to improve awareness and help decrease the incidence of congenital CMV affected pregnancies

Outreach – Facilitate open communication and gatherings among active Stop CMV members and provide support and resources to all CMV families in need

Advocacy – Serve as a key congenital CMV advocacy group, the unified voice of CMV familes, and increase funding for congenital CMV related research and awareness projects

June is National CMV Awareness Month

Through the efforts of Stop CMV, June was listed as National Congenital Cytomegalovirus Awareness Month, a National Health Observance (NHO) with the U.S. Department of Health and Human Services.

Your support is urgently needed to stop the spread of congenital Cytomegalovirus (CMV) and specifically to assist Stop CMV and The CMV Action Network with legislation to raise awareness of congenital CMV.

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CMV Vaccine

Vaccines for preventing CMV infection are still in the research and development stage.

Vaccine Progress

- CMV vaccines are still in the research and development stage
- Phase I trials can be done (with a small number of subjects) and can cost under $1 million.
- Phase II trial costs can vary. A recent trial took 10 years and cost $7.5 million.
- Phase III trials can cost anywhere from $10 million-$100 million depending on FDA subject requirements.

Economic Burden/Cost Impact

- The annual cost for caring for CMV children is estimated at $1billion-$2 billion for the U.S. alone. *Institute of Medicine Committee to Study Priorities for Vaccine Development. Vaccines for the 21st Century: A Tool for Decision Making. Washington, D.C.: National Academy Press; 2000*
- The cost of vaccine development is dwarfed by the economic burden of caring for CMV children.

Timing

- In 2000, the Institute of Medicine (IOM) ranked the development of a CMV vaccine as a highest priority because of the lives it would save and the disabilities it would prevent.
- It may be a number of years before there is a Food and Drug Administration-approved CMV vaccine.

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CMV Stories

Every year in the United States alone, thousands more children are born with congenital CMV. Their parents experience an unspeakable fear and pain as they learn more about CMV and its effects as they piece together what life will look like for their children and their families.

"The first time I see my daughter, we are baptizing her because she may not live. She is dying. There is no moment where they hand her to me. The moment when I take her face in and I know that she is mine. There is, instead, a moment when I look at her and I don't understand what went wrong. Why it is that I expected a healthy baby girl and instead I am looking at a dying neonate. Her skin is covered in red blotches, she has a wealth of black hair. She seems to have my nose. I cannot see her mouth because a tube is down her throat and tape covers the better portion of her chin, mouth and upper lip. I make myself take pictures of that moment, of us as a family. Because I still hope that someday this moment will just be ancient history." – Lauren Grace's Story, Iowa

"He was a very bright boy early on, teaching himself how to read at age two, but not learning how to walk until age 2-1/2. At age 5, he was diagnosed with ADHD and takes medication to help him at school. At age 7, Jeb was diagnosed with an autism spectrum disorder, pervasive developmental disorder (PDD-NOS)." – Jeb's Story, Wisconsin

"I remember sitting in the doctor's office at 22 weeks. They told me if I wanted to terminate, they would set me up with a doctor in another state, since it was no longer legal in my state. I was a single 19-year old sitting in a doctor's office in tears. It was the most important decision of my life. I had no one to talk to. I wish I had known about Stop CMV." – Logan's Story, Connecticut

"When I looked at him I noticed he was covered in red dots...I asked the nurse why he was covered in dots and she said some babies are born like that…When she came back she had the pediatrician with her. He told us that Dalen would have to stay in the NICU because he had an enlarged spleen and liver also that he didn't know what was wrong with him. My heart sank. I felt like I was in a show on Discovery Health Channel." – Dalen's Story, Mississippi

"I am only 16 and it's hard to process things in my mind when the doctors were telling me that she might come out like this or like that, so I just shut them all out and hoped for the best… She is 1 year old now. I don't think she can see because she doesn't follow or look at me. She laughs a lot, can't sit up yet or walk but I'm working on it." – Angelina's Story, Rhode Island

"I received two IV infusions of CMV immunoglobulin and went for another ultrasound at the end of the week. Two perinatologists came in to complete the ultrasound. As they looked at the monitors in silence, I began to cry. The ascites in our baby boy's belly had gotten so much worse. It had also spread to his chest, arms and legs. His liver was enlarged and damaged. I had barely any amniotic fluid left. I was 23 weeks pregnant. I was induced that night. We sat outside of the hospital and cried for most of the day before finally going to labor and delivery. We understood that our baby would die during the labor and delivery process." – Milan's Story, Illinois

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"I was depressed and confused. I didn't know what to think anymore. I was shaking the entire morning and thinking where did I get this virus, what I did wrong. I couldn't believe what was happening. All the care I had, I never drink or smoke. I was very careful with my food, with my environment, taking all the precautions and I got CMV." – Zachary's Story, Texas

"While in the NICU he stopped eating and a NG tube was placed through his nose. It was a rough month for all of us. Kaden was such a strong baby. He hardly ever cried and just seemed to take everything that was thrown his way. It was very clear he was going to be a fighter." – Kaden's Story, Washington

Read any of the over 100 CMV parent stories from around the United States and the world at www.stopcmv.org/stories.

Raelyn - Missouri
born September 4, 2010

Ashley - Michigan
born August 9, 1989

Carson - North Carolina
born August 22, 2007

Chelsea - Louisiana
born April 15, 1996 - passed away April 13, 2000

Rachel - Ireland
born February 26, 2009

Alan - Ohio
born August 9, 1994

Ashley - South Africa
born May 14, 2001

Cameron - Arizona
born November 21, 2004

Scarlett - Idaho
born October 28, 2006 - passed away November 14, 2006

Gabriel - Florida
born October 26, 2009

Reese - North Carolina
born August 4, 2010

Aedan - South Africa
born October 24, 2006 - passed away July 7, 2010

Lowee - Arizona
born June 15, 2007

Jack - Georgia
born January 7, 2005

Precious - United Kingdom
born May 18, 2007 - passed away June 14, 2007

Carmine and Giulliana - Connecticut
born May 3, 2009

Abby - Georgia
born April 1, 2004

Melissa - Mexico
born January 21, 2002

Angelina - Rhode Island
born August 6, 2009

Evie - Iowa
born October 31, 2007

Maria - Portugal
born December 12, 2007

Milan - Illinois
born and passed away July 17, 2010

Amber - Texas
born September 12, 2000

Kaitlyn - North Carolina
born July 23, 2009

James - Canada
born October 22, 2007

Jenna - Arizona
born June 23, 2009 - stillborn

Mia - Australia
born March 30, 2007

Noah - New York
born October 11, 2004

Kaileigh - Canada
born June 20, 1998 - passed away September 12, 2009

Musa - Australia
born October 15, 2007

Lauren Grace - Iowa
born February 12, 2010

Giuliano - New York
born April 2, 1996

Caiti - Arizona
born August 25, 2001

Zach - Florida
born September 8, 2001

Madison - Texas
born August 1, 2000

Emma - Michigan
born August 14, 2007

Logan - Connecticut
born August 17, 2009

Cruz - Australia
born May 5, 2005

Elijah - Texas
born November 28, 2006

Alexis - Florida
born August 3, 2008

Jayden - Colorado
born January 17, 2008

Kylee - Oklahoma
born May 24, 1999

Jakob - Georgia
born November 19, 2000

Starlitt - Connecticut
born January 30, 2010

Ryan - New Jersey
born August 1, 2001

Riley - Florida
born and passed away November 27, 2009

Daniel - Georgia
born July 2, 1983

Gracie - Connecticut
born March 2, 2009

Liam - Virginia
born February 6, 2007

Chloe - Michigan
born December 16, 1998

Zachary - Texas
born May 9, 2009

Krystal - Utah
born July 9, 1995

Michael - Texas
born December 17, 2003

Bailey - Alaska
born September 30, 1995

David - Florida
born March 3, 1997

Trenton - Missouri
born July 26, 2006

Portia - Michigan
born August 17, 2007

Joshua - New York
born March 28, 2008

Jeb - Wisconsin
born December 24, 1999

Addison - Georgia
born March 27, 2009

Katie - Indiana
born August 30, 2006

Isaiah - Nebraska
born December 28, 2001

Kristen - New York
born April 5, 1982

Danny - Missouri
born March 11, 2008

Samantha - Colorado
born April 1, 2010

Avery - Minnesota
born June 5, 2008

Amari - California
born September 12, 2007

George - Virginia
born July 30, 2005 - passed away April 17, 2007

Amilia - Connecticut
born September 27, 2006

Leah - Tennessee
born July 17, 2008

Dalen - Mississippi
born May 25, 2009

Landon Joe - North Carolina
born August 11, 2007

Rachael - Tennessee
born September 4, 1995

Andrew - Missouri
born March 19, 2009

Miranda - Florida
born 2008

Aydon - Alabama
born July 2, 2008

Riley Jean - Florida
born October 30, 2008

Tanner - Alabama
born December 13, 2008

Laney - Texas
born April 20, 2008

Jamie - United Kingdom
born January 9, 2007

Austin - Florida
born October 21, 1992

Kyra - Kentucky
born March 27, 2002

Cassie - Wisconsin
born September 20, 1988

Matthew - Michigan
born August 30, 2008

Ruth Elyse - Illinois
born August 28, 2008 - stillborn

Elias David - Arizona
born October 30, 2008 - stillborn

Savanah - Utah
born March 25, 2004

Jeremiah - Virginia
born June 22, 2005

Kaiden - Australia
born July 4, 2007

Audrey - North Carolina
born July 26, 2006

Kaden - Washington
born January 1, 2006

Leah - Washington
born January 15, 2008

Colby - Georgia
born September 14, 2006

Jaxon - Alabama
born November 25, 1998

Riley and Rachel - California
born August 9, 2003

Brayden - Pennsylvania
born July 12, 2006

Jacob - Virginia
born September 2, 2006

Katelyn Marie - Arizona
born November 6, 2003

Joshua Daniel - Nevada
born February 8, 2007

Elizabeth - New York
born December 18, 1989 - passed away February 9, 2006

Tobias - Florida
born January 12, 2008

Bryson - Texas
born February 25, 2009

Gabriela - California
born July 14, 2005

Maeve - New York
born November 30, 2008

Audrey - Poland
born July 30, 2007

Nolan - Oregon
born November 27, 2002