

SCR

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Alaska State Legislature

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Senator Lesil McGuire

MEMORANDUM

To: Representative Keller, Chairman
House Health and Social Services Chair

Handwritten signature of Representative Keller.

Cc: Janet Ogan
Health and Social Services Committee Aide

From: Senator Lesil McGuire

Handwritten signature of Senator Lesil McGuire.

Date: April 9, 2012

Re: Hearing Request for SCR 23, "Designating June 2012 as Congenital Cytomegalovirus Awareness Month."

Please schedule SCR 23, relating to Congenital Cytomegalovirus Awareness Month.

Attached to this memo please find:

- A sponsor statement
- The current version SCR23\Version M
- SCR 23
- Back-up materials

The contact for SCR 23 is Amy Saltzman, 465-2995

Thank you.

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Senator Lesil McGuire

Sponsor Statement for SCR23

“Designating March 2012 as Congenital Cytomegalovirus Awareness Month.”

Congenital Cytomegalovirus (CMV) is a common and serious congenital infection in the United States with 1 in every 150, children born with congenital CMV.

Contraction of the disease at birth can lead to permanent health conditions, including hearing and vision loss, mental disability, seizures and in rare cases death.

CMV is most dangerous for unborn babies whose mothers become infected with the disease during pregnancy and children or adults whose immune systems have been weakened by disease or drug treatment.

With pregnant woman as the number 1 population at risk, the American College of Obstetricians and Gynecologists and the Centers for Disease Control and Prevention recommend that OB/GYNs counsel women on basic prevention measures to guard against CMV infection.

CMV is preventable with behavioral interventions, such as frequent hand washing with soap and water after contact with diapers or oral secretions, not kissing young children on the mouth, and not sharing food, towels, or utensils with young children. CMV is found in bodily fluids, including urine, saliva, blood, mucus, and tears.

Please join me in support The incidence of children born with congenital CMV can be greatly reduced with public education and awareness.



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Keynote address

Congenital cytomegalovirus: Public health action towards awareness, prevention, and treatment[☆]

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ABSTRACT

Key awareness issues surrounding congenital CMV infection are outlined and discussed to provide inspirational motivation for many diverse groups who may have the same goal of reducing congenital CMV disease. To this end, steps for public health action towards awareness, prevention and treatment are outlined. These steps include recommendations for universal screening for all newborns for congenital CMV infection at birth to further define the public health impact and facilitate early diagnosis and treatment of newborns, routine prenatal screening of all pregnant women for the presence of CMV antibody to identify women at risk who may benefit most from preventive behavioral interventions as well as to facilitate prenatal diagnosis and therapies, and grass roots efforts to promote CMV awareness in the community.

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The transformation of knowledge into ACTION that can be implemented NOW to alleviate the human suffering and economic and social burdens associated with congenital cytomegalovirus (CMV) infection and disease is the topic of this discussion.

Usually, when experts are asked to speak on congenital CMV infection and disease, an uphill battle is faced, trying to open the eyes of those who do not see, what the experts see, all too well. The importance of congenital CMV infection and disease as a public health problem is self-evident. The experts in this room see it already. Cytomegalovirus infects one out of every 100–150 newborns, making it the most common congenital infection now in most countries around the world.^{1,2} Congenital CMV infection results from virus spreading from infected uterine blood vessels, which then amplifies in decidual cells and disseminates to the placenta and uterus, causing vascular changes that produce a variety of mild to severe signs and symptoms of growth restriction and disease in the fetus and newborn.³ These symptoms are sometimes severe enough to kill up to 8% of newborns *in utero* or during the first months of their precious life, before they even have a chance to know the love of their family who so anxiously awaited their birth.⁴ Cytomegalovirus is a virus that chronically courses through the veins, arteries, and bodily fluids of the fetus, newborn and growing infant who survives the initial attack of this virus in the womb. It causes a wide variety of internal organ damage to the liver, spleen

and blood forming cells, and it causes outward signs of intrauterine growth restriction. The CMV infected fetus must divert much of its cellular growth forces to provide energy to fight the virus that intruded the sanctity of the womb. The effects of congenital CMV infection are due, in part, to direct virus invasion, as well as invasion and inflammation in the nurturing placental, producing placental dysfunction, and reduced fetal oxygenation. The relative importance of either of these processes remains unknown.

Newborns may be born with skin rashes, which doctors call petechiae, purpura and extramedullary hematopoiesis, but which, one father called “bruises from a hard fought battle”.⁴ This virus, reluctantly, opportunistically, and cruelly invades the fetal and neonatal developing brain, leaving swollen ventricles and scars of intracranial calcifications, often severe enough to cause a small brain resulting in microcephaly, leaving a child to live with lifelong neurologic, developmental, and motor disabilities.^{5,6} Key sensory organs, such as the eyes, the window to the brain, can be scarred mercilessly, or the ears, and its nerves, can be involved, producing progressive and permanent “sounds of silence”.^{7–9} There are also the “lucky” CMV infected newborns, who gratefully are acknowledged to represent the vast majority of congenitally infected infants. These “silent majority” will be normal appearing at birth, yet they are born shedding large quantities of the virus in their saliva and urine, and some also have evidence of it present in their blood and brain. Yet, unfortunately, in 10–20% of these apparently “silently” infected newborns, a progressive hearing loss will ensue, causing the voices of their family and friends and teachers, and the sounds of the world around them, to slowly slip away.^{10,11}

Knowledgeable research and clinical scientists, public health and governmental officials, and families know all too well both

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the lyrics and the melody of a life full of the challenges associated with congenital CMV disease. They are a rich tapestry of individuals who bring their own talents, perspectives, experiences, knowledge, and opinions about the controversies surrounding the possible solutions to the relentless and persistent public health problem of congenital CMV infection and disease. So, to them, this discussion is like "preaching to the choir". The late Dr. Charles Alford to whose memory this conference is dedicated, was a leader in congenital CMV research, and many of his followers are considered "CMV cultural icons and should be inspired to action!" Furthermore, some individuals are not CMV experts, *per se*, but nonetheless bring valuable perspectives from other disciplines, with the hopes that a cross-fertilization of two or more disciplines, will lead to a flow of creative juices with practical and real solutions to the problem at hand. And still others are the "real experts": the children infected with CMV, the parents and siblings, the grandparents and the friends, who lovingly and successfully raise these children. And, though they may learn something from the scientific and medical CMV experts, these experts actually stand to learn much more from parents, than parents will ever learn from medical experts. To scientists and policy makers, data are delightful, but the data collectors must remember that behind those data points are real people, and people should always come first.

What bold actions can be taken now, and together, to reduce the disease burden of congenital CMV?

A logical first step for public health action towards awareness, prevention and treatment is to screen all newborns for congenital CMV infection at birth. This public health action will rob CMV of its cloak of invisibility, and expose it to the light of day. It will force clinicians and public health officials to deal with the tens of thousands of newborns that will be identified each year and provide the sensory and neuro-developmental follow-up, the antiviral treatment, the speech and language programs and the educational accommodations these children need and deserve. And, even more importantly, it will drive more practical and effective preventive and treatment measures.

Current knowledge of the epidemiology and prevalence and impact of CMV infection in pregnant women and their infants in most developed countries, including here in the U.S., is based on many well designed and well executed and expertly analyzed, prospective studies of select groups of pregnant women and their infants.^{12–20} But this expertly derived knowledge has not led to public health action, because the issue does need to be faced, year in and year out.¹⁴ Randomized clinical trials have also been conducted, that show early neonatal antiviral treatment provides benefit for newborns diagnosed with congenital CMV disease.^{21,22} A little knowledge that acts is worth infinitely more than much knowledge that is idle or kept secret. Unfortunately, we possess great knowledge about congenital CMV infection, but we do not act upon this knowledge.

Newborn screening programs for congenital CMV infection and disease should be established in each state, and these programs should be endorsed by thought leaders and policy makers, now, and mandated by law. In the early 1960s, newborn screening algorithms were developed for genetic diseases and inborn errors of metabolism.²³ These algorithms evolved from a fragmented, limping system of public and private laboratory services with disjointed follow-up programs for the infants whom they identified. But these early proponents for newborn screening programs were undaunted, and, after a struggling period of 40–50 years, the current smooth and integrated systems evolved. And, from this rocky start, today's improved screening systems insure that virtually all newborns receive metabolic screening for rare disorders. The screening is performed from samples collected from a simple heel

stick from which spots of blood are collected, dried, and analyzed. In addition, newborns in many states now receive expanded dried blood spot screening for heritable disorders, such as sickle cell disease.

In 1999, the American Academy of Pediatrics (AAP) endorsed and congress passed into law, a somewhat controversial national program to develop and support universal newborn hearing screening.²⁴ Through appropriate outcome data and system evaluations, and through studies also conducted by CMV experts, newborn hearing screening programs have been shown to fall short of expectations, because not all children who have hearing loss at school entry are detected by newborn hearing screening program, likely because most of them have late or progressive hearing loss as a result of a congenital CMV infection that was not detected.^{25,26} A combined newborn hearing and newborn CMV screening program therefore makes sense. Many investigators have successfully conducted newborn screening programs for congenital CMV infection. It is not that hard, and, if fluids in which the virus is present in high quantities, such as the urine and saliva, are used, virtually no newborn will be missed.

However, the thrust of most currently funded CMV newborn screening efforts have focused on detecting CMV IgM antibody or CMV DNA from dried blood spots collected for metabolic screening.^{27,28} However, by insisting samples and technology that conveniently and seamlessly blend with newborn metabolic screening programs already in place be adapted for CMV screening, newborn CMV screening may be doomed to failure. Previous studies have shown the level of virus in the blood of newborns, especially those newborns who are asymptomatic at birth, is much less than the amount of virus in urine and saliva.^{29,30} Therefore, the prevalence of congenital CMV infection and disease may be under represented, and large numbers of congenitally infected newborns may be missed and denied the benefits of early interventions. The early proponents of dried blood spot proponents should be applauded for evaluating this strategy for newborn CMV screening programs, but investigators should re-consider and "go where the money is" and develop newborn screening methods that make sense for congenital CMV infection. No one expected newborn hearing screening programs to use the convenient dried blood spots to detect congenital hearing loss and it may be equally unfounded to expect them to reliably work for CMV.

Diagnostics industries should be encouraged to resist the temptation to develop yet another rapid test for influenza, with the misguided financial hopes of capturing a piece of an already crowded market, and consider putting research and development efforts towards a point – of – care screening test for congenital CMV infection. Such a test could be used to screen three to four million births annually in this country, and with such a high concentration of viral target in readily available bodily fluids, such as urine or saliva, and no competitor, such a test cannot help but be profitable for a company willing to take action and tackle the challenge.

Reliable data on the prevalence of congenital CMV infection in developing countries are also lacking.³¹ To make a global impact on this disease, the public health impact of congenital CMV infection and disease in all countries must be known. With the current blossoming interest in global health, such research programs no doubt would be embraced. In addition, information on the prevalence and outcomes of congenital CMV infection in special populations, such as teenagers and immune compromised mothers, would provide rational preventive strategies for these potentially high risk groups.³²

A second logical step for public health action towards awareness, prevention and treatment is to mandate routine prenatal screening of all pregnant women for the presence of CMV IgG antibody. This mandate would increase CMV awareness because the mere action of conducting CMV antibody testing requires dis-

Discussing the results with the mother during her prenatal visits.^{33–35} It also provides the opportunity to discuss the most likely sources of CMV for the vulnerable CMV sero-negative mother, and provide recommendations for routine hygienic precautions that will reduce her risk of acquiring this potentially deadly virus from such innocent sources as her own toddlers.^{36,37} It also may reduce her risk for other transmissible agents, providing added benefit. Furthermore, CMV sero-positive pregnant women may also be at risk, so they also should be informed and counseled as well, and encouraged to spread CMV awareness to their friends and colleagues. Studies on the transmission of CMV to women of childbearing age have shown that individuals, such as young toddlers, in her family or child care workplace, who may be silently shedding CMV, are a likely source for CMV transmission.^{38,39} Transmission through close contact and sexual intimacy may also be an important mode of transmission, especially for adolescents.⁴⁰ If a brief discussion is too time consuming for a busy physician's office, then pamphlets or a waiting room video can be made available with every prenatal visit.

Most obstetricians are not aware of the exposures risks for CMV, even though the American College of Obstetrics and Gynecology recommends they should counsel women regarding CMV.^{41,42} To possess the knowledge that young toddlers close to a pregnant woman are likely sources of a virus that has potentially deadly complications for her unborn baby, and not share that knowledge with her, and provide options for prevention is unethical. And, well meaning, paternalistic critics who suggest pregnant women will be needlessly worried and suffer anxiety if such a precaution program is adopted, are misguided, because studies have shown most women view CMV prevention measures positively.^{43–45} How can there be no action, when the mothers who have given birth to babies born with congenital CMV disease, look up and cry "Why did those of you who came before me, not warn me?"

Pregnant women welcome any knowledge that can help them have a healthy baby. Just ask them! They deserve to make an informed choice about their lifestyles and careers. But they feel betrayed, guilty, and angry, and some even suffer paralyzing depression, when they give birth to a baby with congenital CMV disease, and later learn, from the internet or other sources besides their own trusted physicians and public health officers to whom they look for guidance, that their baby's congenitally acquired CMV disease potentially could have been prevented by an ounce of CMV awareness and three simple hygienic precautions: do not kiss toddlers on the mouth or face (give big hugs or kisses on top of the head instead), do not share food, drink or utensils (refrain from "one for mommy and one for baby"), and wash hands carefully after changing diapers and wiping away saliva or nasal secretions.^{36,37,45}

Furthermore, the emergence of potentially effective prenatal therapies for women experiencing primary CMV infections during pregnancy and their fetuses who may be suffering *in utero* with CMV disease, makes mandated prenatal screening for CMV infection even more of an action priority. The presence of CMV IgG antibody should then trigger a more detailed investigation of the timing of the pregnant woman's CMV infection, with measurement of CMV IgM antibody and the more specific and useful CMV avidity index assay. Presence of a recent or current CMV infection should trigger a consideration of investigating whether or not the fetus was infected or was having complications. If the fetus appears involved, then evaluation of the fetus with ultrasound and other interventions should be considered. Case reports and nonrandomized studies of pregnant women experiencing primary CMV infections who receive infusions of hyper-immune CMV immunoglobulin have now been published.⁴⁶ These gutsy investigators and their courageous patients were tired of doing nothing; rather they have presented evidence that prenatal treatment appears to reverse placental thickening and inflammation, reverse fetal abnormalities, and reduce sequelae in the postnatal period. Such provocative

findings demand us to conduct randomized clinical trials to scientifically confirm or deny the benefit of this difficult and expensive, but potentially valuable intervention. In addition, prenatal treatment with oral valaciclovir has been attempted with provocative results.⁴⁷ Registries of mothers receiving prenatal treatments, and the outcomes of their fetuses, should be established, so that at least some level of evidence based medicine can be collected and analyzed. Furthermore, randomized clinical trials are urged, so recommendations for prenatal treatments can be made in a financially responsible and clinically realistic manner. The issue of prenatal diagnosis and treatment will not go away, because desperate women and their compassionate physicians seek help anywhere they can find it, because they find it difficult to watch the *in utero* destruction of an unborn's body and brain, and not take some kind of action.

The third logical step for public health action towards awareness, prevention and treatment is community, grass roots CMV awareness. "Mobilize the Moms"! And also, of course, involve the dads, the siblings, the grandparents, and the friends. Scientific conferences should invite families affected by the disease, to become an integral part of the program. The families, sitting and presenting, side by side with scientists and other professional experts, and contributing to the discussions and calling us to action, would be valuable additions to the process. For then they are not just considered delightful data points in a table or graph, they are appreciated as real kids from real families who hopefully and courageously enroll in clinical trials evaluating the accuracy of diagnostic tests and the benefits of new treatments and novel vaccines. Some families may travel to conferences carrying their CMV loved ones in their arms and their wheelchairs. Others may carry their CMV affected children in their hearts, leaving them in the care of family or friends, so they could focus on the task at hand. Unfortunately, some of our CMV families may travel to this conference, in despair, comforted only by the memories of their lost CMV loved ones, knowing they rest peacefully in the hands of God.

But action is the antidote to despair. These families represent the most potent solution for action and change in favor of CMV awareness, prevention and treatment. Listen to them! The voices of the first action moms, squeaked timidly, like mosquitoes buzzing around our heads that made us say, "What was that I heard?" Some families courageously enrolled in clinical trials, choosing to change the world one precious child at a time, and also encouraged and supported others, one by one, to do the same. Other moms and their physicians needed to reach out further, and used the internet, and produced the first CMV websites and CMV listservs and parent support networks to help each other navigate the daily challenges of raising a child with congenital CMV disease, and "warn those that may come after them" about CMV.^{48–55} And now there is a great rumbling of surround sound caused by a growing grass roots effort of CMV moms who are lionesses for the cause, and determined to spread and promote CMV awareness.

Fueled by the energy and passion of CMV action moms, and facilitated by communication technology and increasing Internet access around the globe, they make their own pamphlets, T-shirts, and bumper stickers and distribute them wherever women congregate. They design and maintain their own websites, blogs, forums, and twitters and they use popular non-synchronous electronic communication tools, text messaging, and internet social networking sites to reach out to each other and to reach out to those young women of child bearing age "who may come after them".^{51–54} Frustrated by the lack of priority for funding congenital CMV research, they also hold their own fundraising activities.⁵⁰ They raise CMV awareness and funds for CMV research by creatively holding birthday parties where donations to CMV research may be given in lieu of gifts, they sell T-shirts and bumper stickers, they run marathons and walk walk-a-thons, they ride motorcycles, and they hold family concerts

and attend sports events. Also, CMV moms have started their own non-profit foundations to support the CMV awareness cause, while others use their own personal talents, and write books or express themselves through art.⁵⁶ A small group of thoughtful and committed citizens can change the world, and, in reality, it is the only thing that ever has.

Physicians and public health and government officials should get behind the CMV families who campaign on behalf of CMV awareness. Physicians should discuss CMV with patients who come to offices and clinics, and post CMV information on professional and public health websites, warning young mothers about how they can avoid infection with CMV.^{50,57} Furthermore, it should be mandatory that all licensed day care and child care sites, including small child care venues in private homes, inform the workers and the mothers whose children attend child care, about how to avoid CMV infection while pregnant.

And while CMV awareness is promoted through public health action now, basic and clinical scientists, as well as those investigators in vaccine research and development, should be encouraged to push forward, thoughtfully, but as quickly as possible, for effective treatment and prevention strategies.^{58–61} Contemporary CMV vaccine researchers should reflect on the historical successes of the rubella vaccine program.⁶² Congenital rubella syndrome was discovered in the 1940s, and rubella virus was isolated in the early 1960s. The virus is passed from child to mother, and epidemics occurred every 7–8 years. Vaccine development was spurred by a rubella outbreak between 1963 and 1965 in the United States that infected 1% of all births in New York and led to 20,000 newborns with congenital rubella syndrome, 10% of whom died as neonates, leaving 12,000 survivors deaf, 3500 survivors blind, and almost 2000 survivors with permanent developmental disabilities. The parallels with congenital CMV disease are uncanny. And through an amazing collaboration of community, industry, and government health officials, a rubella vaccine was licensed in 1969, and now less than ten cases of congenital rubella syndrome a year are reported. Unfortunately, that is where the parallels end. Ironically, more women of child bearing age have heard of congenital rubella syndrome, now a vaccine preventable disease that is rare here in the United States, than have of CMV, the most common congenital infection.

In a democracy, the responsibility for decisions on health policy should lie with the public, but instead it often serves critical and vocal social and political agendas, power, economic efficiency and national defense. Well meaning, reactive public health officials have largely ignored the silent, endemic problem of congenital CMV infection and disease, in favor of HIV/AIDS, bioterrorism, epidemic influenza, and even chronic fatigue and Lyme disease. The current support from the Centers for Disease Control to promote CMV research and awareness provides a spark of hope that it will ignite a fire of CMV public health policies of awareness, acceptance and action.⁶³

Conflicts of interest

The author has no conflicts of interest to report.

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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.

About Stop CMV and The CMV Action Network

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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

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



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

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 families, 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.

About Stop CMV and The CMV Action Network

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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.

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

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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.

