
From: Demmler, Gail J <gdemmler@bcm.edu>
Sent: Tuesday, February 25, 2014 12:33 PM
To: PHC Testimony; Rep. Wright, Elissa; Daly, MaryAnn
Cc: saundersbooks@aol.com; janelle@stopcmv.org; lenoreper@gmail.com
Subject: Written Testimony in support of HB5147 for Connecticut - CMV Education and Awareness

Attachments: CMV_CDC_Awareness_128_2009_46S_S1-5
_J_Clin_Virol_Congenital_CMV_Public_Health[1].pdf;
CMV_CN_Support_Letter_Untitled.PDF_-_Adobe_Acrobat_Pro[1].pdf;
IDSECTION_LETTERHEAD_CMVLetterCN__DR_DH_SIGNATURE[1][1].doc

I strongly support **HB5147**.

As an expert in congenital CMV infection and CMV infection in pregnant women, with over 30 years experience, and hundreds of scientific presentations and publications in the field of congenital CMV infection, I feel well qualified to provide such expert support for this bill.

Attached is a brief **letter of support and a published KeyNote Address** given by me before the 2nd International Congenital CMV Congress held at the Centers for Disease Control, Atlanta GA. It outlines some of the contemporary public health issues surrounding congenital CMV and CMV infection in pregnant women.

This bill simply supports programs for education that will provide "an ounce of CMV awareness" and valuable knowledge about "three simple hygienic precautions" that may save the life and well being of an unborn child by keeping from being infected with a common virus called cytomegalovirus or CMV.

In addition, it provides for testing newborns for congenital CMV who fail hearing screens or otherwise have CMV symptoms at birth that may need treatment. Treatment in randomized clinical trials shown to be beneficial is now easily available and given orally by mouth and covered by medical insurance policies.

A similar CMV education bill was **recently passed in Utah** and their public health departments now provide educational materials.

The legislation that was passed in Utah was House Bill 81 Legislative Session 2013; now UCA 26-10-10

The Rules, R398-4, which were recently approved can be found at this link:

<http://www.rules.utah.gov/publicat/bulletin/2013/20131201/38139.htm>

The Utah law is entitled "Cytomegalovirus Public Health Initiative and Testing". The Utah Dept of Health have a dedicated CMV website: www.health.utah.gov/cshcn/CHSS/CMV.html

Other states are currently considering similar legislation.

It is Time ... for Connecticut now to provide CMV awareness education for mothers and CMV testing and treatment for their infants.

Thank you for supporting this very important bill.

Gail J Demmler Harrison MD

(aka Gail Demmler MD and aka Gail Harrison MD- all three professional names may appear in pubmed and internet searches)

Professor

Department of Pediatrics, Section of Infectious Diseases

Baylor College of Medicine

Attending Physician

Infectious Diseases Service

Texas Children's Hospital

Director, CMV Registry, CMV Research Program and Laboratory, and CMV Clinic

Texas Children's Hospital Feigin Center

1102 Bates Street, Suite 1150

Houston, Texas 77030

832-824-4330 ph

832-656-2595 mobile

832-825-4347 fax

gdemmler@bcm.edu

gjedemmler@texaschildrens.org

www.bcm.edu/pediatrics/cmregistry/

www.texaschildrensblog.org/author/gdemmler/

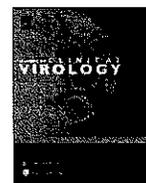
cmv@bcm.edu



ELSEVIER

Contents lists available at ScienceDirect

Journal of Clinical Virology

journal homepage: www.elsevier.com/locate/jcv

Keynote address

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

Gail J. Demmler-Harrison*

Section for Infectious Diseases, Department of Pediatrics, Baylor College of Medicine, Texas Children's Hospital, Mail Code 3-2371, 6621 Fannin Street, Houston, TX 77030, USA

ARTICLE INFO

Article history:

Received 4 September 2009

Received in revised form 7 October 2009

Accepted 7 October 2009

Keywords:

Congenital
Cytomegalovirus (CMV)
Awareness
Action
Public health

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.

© 2009 Elsevier B.V. All rights reserved.

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

[☆] This manuscript represents the Keynote Address at the Second International Congenital Cytomegalovirus Conference 2008 held in Atlanta, GA, USA.

* Tel.: +1 832 824 3280; fax: +1 832 825 4347.

E-mail addresses: gdemmler@bcm.edu, gjdemmler@texaschildrenshospital.org.

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-

cussing 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.

References

- Kenneson A, Cannon MJ. Review and meta-analysis of the epidemiology of congenital cytomegalovirus (CMV) infection. *Rev Med Virol* 2007;17(4):253–76.
- Seale H, Booy R, Mactnryre C. Trends in hospitalisations for diagnosed congenital cytomegalovirus in infants and children in Australia. *BMC Pediatr* 2009;9:7.
- Pereira L, Maidji E. Cytomegalovirus infection in the human placenta: maternal immunity and developmentally regulated receptors on trophoblasts converge. *Curr Top Microbiol Immunol* 2008;325:383–95.
- Istas A, Demmler G, Dobbins J, Stewart J. Surveillance for congenital cytomegalovirus disease: a report from the National Congenital Cytomegalovirus Disease Registry. *Clin Infect Dis* 1995;20(3):665–70.

- Noyola D, Demmler G, Nelson C, Griesser C, Atkins J, Rozelle J, et al. Early predictors of neurodevelopmental outcome in symptomatic congenital cytomegalovirus infection. *J Pediatr* 2001;138:325–31.
- Cheeran M, Lokensgard J, Schleiss M. Neuropathogenesis of congenital cytomegalovirus infection: disease mechanisms and prospects for intervention. *Clin Microbiol Rev* 2009;22(1):99–126.
- Coats D, Demmler G, Paysse E, Du, Libby, the Congenital CMV Longitudinal Study Group. Ophthalmologic findings in children with congenital cytomegalovirus infection. *J AAPOS*;2000;4:110–6.
- Pass R. Congenital cytomegalovirus infection and hearing loss. *Herpes* 2005;12(2):50–5.
- Foulon I, Naessens A, Foulon W, Casteels A, Gordts F. A 10-year prospective study of sensorineural hearing loss in children with congenital cytomegalovirus infection. *J Pediatr* 2008;153(1):84–8.
- Williamson W, Demmler G, Percy A, Catiñ F. Progressive hearing loss in infants with asymptomatic congenital cytomegalovirus infection. *Pediatrics* 1992;90(6):8620866.
- Grosse S, Ross D, Dollard S. Congenital cytomegalovirus (CMV) infection as a cause of permanent bilateral hearing loss: a quantitative assessment. *J Clin Virol* 2008;41(2):57–62.
- Yow M, Williamson D, Leeds L, Thompson P, Woodward R, Walms B, et al. Epidemiologic characteristics of cytomegalovirus infection in mothers and their infants. *Am J Obstet Gynecol* 1988;158:1189–95.
- Staras S, Dollard S, Radford K, Flanders W, Pass R, Cannon M. Seroprevalence of cytomegalovirus infection in the United States, 1988–1994. *Clin Infect Dis* 2006;43:1143–51.
- Demmler G. Cytomegalovirus infection: Back to the future or no more elephants? *Clin Infect Dis* 2006;43(9):1152–3.
- Fowler K, Stagno S, Pass R, Britt W, Boll T, Alford C. The outcome of congenital cytomegalovirus infection in relation to maternal antibody status. *N Engl J Med* 1992;326(10):663–7.
- Yow M, Demmler G. Congenital CMV disease: 20 years is long enough. *N Engl J Med* 1992;326:702–3.
- Fowler K, Stagno S, Pass R. Maternal age and congenital cytomegalovirus infection: screening of two diverse newborn populations, 1980–1990. *J Infect Dis* 1993;168(3):552–6.
- Stagno S, Dworsky M, Torres J, Mesa T, Hirsh T. Prevalence and importance of congenital cytomegalovirus infection in three different populations. *J Pediatr* 1982;101(6):897–900.
- Colugnati F, Staras S, Dollard S, Cannon M. Incidence of cytomegalovirus infection among the general population and pregnant women in the United States. *BMC Infect Dis* 2007;7:71.
- Hassan J, Connell J. Translational min-review series on infectious disease: congenital cytomegalovirus infection: 50 years on. *Clin Exp Immunol* 2007;149(2):205–10.
- Kimberlin D, Lin C-Y, Sanchez P, Demmler G, Dankner W, Shelton M, et al. Effect of ganciclovir therapy on hearing in symptomatic congenital cytomegalovirus disease involving the central nervous system: a randomized, controlled trial. *J Pediatrics* 2003;143:17–26.
- Kimberlin D, Acosta E, Sanchez P, Sood S, Agarwal V, Homans J, et al. Pharmacokinetic and pharmacodynamic assessment of oral valganciclovir in the treatment of symptomatic congenital cytomegalovirus disease. *J Infect Dis* 2008;197(6):836–45.
- Arn P. Newborn screening: current status. *Health Aff (Millwood)* 2007;26(2):559–66.
- Joint Committee on Infant Hearing, American Academy of Audiology, American Academy of Pediatrics, American Speech-Language Association, Directors of Speech, Hearing Programs in State Health, Welfare Agencies. Year 2000 position statement: principles and guidelines for early hearing detection and intervention programs. *Pediatrics* 2000;106(4):798–817.
- Dollard S, Grosse S, Ross D. New estimates of the prevalence of neurological and sensory sequelae and mortality associated with congenital cytomegalovirus infection. *Rev Med Virol* 2007;17(5):35–63.
- Fowler K, Dahle A, Boppana S, Pass R. Newborn hearing screening: will children with hearing loss caused by congenital cytomegalovirus infection be missed? *J Pediatr* 1999;135(1):60–4.
- Barbi M, Binda S, Caroppo S, Primache V. Neonatal screening for congenital cytomegalovirus infection and hearing loss. *J Clin Virol* 2006;35(2):206–9.
- Walter S, Atkinson C, Sharland M, Rice P, Raglan E, Emery V, et al. Congenital cytomegalovirus: association between dried blood spot viral load and hearing loss. *Arch Dis Child Fetal Neonatal Ed* 2008;93(4):F280–5.
- Demmler G, Buffone G, Schimbor C, May R. Detection of cytomegalovirus in urine from newborns by polymerase chain reaction DNA amplification. *J Infect Dis* 1988;158:1177–84.
- Balcerek K, Warren W, Smith R, Lyon M, Pass R. Neonatal screening for congenital cytomegalovirus infection by detection of virus in saliva. *J Infect Dis* 1993;167(6):1433–6.
- van der Sande M, Kave S, Miles D, Waight P, Jeffries D, Ojuila O, et al. Risk factors for and clinical outcome of congenital cytomegalovirus infection in peri-urban West African birth cohort. *PLoS One* 2007;2(6):e492.
- Guibert G, Warszawski J, Le Chenandec J, Blanche S, Benmehar Y, Mandelbrot L, et al. Decreased risk of congenital cytomegalovirus infection in children born to HIV-infected mothers in an era of highly active anti-retroviral therapy. *Clin Infect Dis* 2009;48(11):1516–25.

33. Lazzarotto T, Guerra B, Lanari M, Gabrielli L, Landini M. New advances in the diagnosis of congenital cytomegalovirus infection. *J Clin Virol* 2008;41(3):192–7.
34. Griffiths P. Strategies to prevent CMV infection in the neonate. *Semin Neonatal* 2002;7(4):293–9.
35. Demmler G. Screening for congenital cytomegalovirus infection: a tapestry of controversies. *J Pediatrics* 2005;142(2):162–4.
36. Cannon M, Davis K. Washing our hands of the congenital cytomegalovirus disease epidemic. *BMC Public Health* 2005;5(1):70.
37. Harvey J, Dennis C-L. Hygiene interventions for prevention of cytomegalovirus infection among childbearing women: systematic review (JAN review). *J Adv Nurs* 2008;63(5):440–50.
38. Taber L, Frank A, Yow M, Bagley A. Acquisition of cytomegaloviral infections in families with young children: a serological study. *J Infect Dis* 1985;151(5):948–52.
39. Marshall B, Adler S. The frequency of pregnancy and exposure to cytomegalovirus infections among women with a young child in day care. *Am J Obstet Gynecol* 2009;200(2):163.
40. Staras S, Flanders W, Dollard S, Pass R, McGowan J, Cannon M. Influence of sexual activity on cytomegalovirus prevalence in the United States, 1988–1994. *Sex Transm Dis* 2008;35(5):472–9.
41. American College of Obstetrics and Gynecologists. *Perinatal Viral and Parasitic Infections. ACOG Practice Bulletin 20*. Washington, DC: ACOG; 2000.
42. Knowledge and practices of obstetricians and gynecologists regarding cytomegalovirus infection during pregnancy—United States, 2007. *MMWR Morb Mortal Wkly Rep* 2008;57(3):65–8.
43. Jeon J, Victor M, Adler S, Arwady A, Demmler G, Fowler K, et al. Knowledge and awareness of congenital cytomegalovirus among women. *Infect Dis Obstet Gynecol* 2006;80(383):1–7.
44. Ross D, Victor M, Sumartojo E, Cannon M. Women's knowledge of congenital cytomegalovirus: results from the 2005 Health Styles survey. *J Womens Health (Larchmt)* 2008;17(5):849–58.
45. Adler S, Finney J, Manganello A, Best A. Prevention of child-to-mother transmission of cytomegalovirus among pregnant women. *J Pediatr* 2004;145(4):485–91.
46. Nigro G, Adler S, La Torre R, Best A. Passive immunization during pregnancy for congenital cytomegalovirus infection. *N Engl J Med* 2005;353(13):1350–62.
47. Jacquemard F, Yamamoto M, Costa J, Romand S, Jaqz-Agrain E, Dejean A, et al. Maternal administration of valaciclovir in symptomatic intrauterine cytomegalovirus infection. *BJOG* 2007;114(9):113–21.
48. www.stopcmv.com.
49. www.cmvsupport.org.
50. www.bcm.edu/ped/infect/cmv.
51. <http://www.congenitalcmv.blogspot.com>.
52. www.cmvkids.com.
53. www.cmvfoundation.org.
54. cmv@listserv.edu.
55. www.apps.facebook.com/causes.
56. Saunders L. *Anything But a Dog!*. Unlimited Publishing LLC; 2009. www.UnlimitedPublishing.com.
57. www.cdc.gov/cmvmv.
58. McCormick A, Roback L, Mocarski E. HtrA2/Omi terminates cytomegalovirus infection and is controlled by the viral mitochondrial inhibitor of apoptosis (vMIA). *PLoS Pathog* 2008;4(5):e1000063.
59. Pass R, Zahang C, Evans A. Vaccine prevention of maternal cytomegalovirus infection. *N Engl J Med* 2009;360(12):1191–9.
60. Morello C, Kelly L, Munks M, Hill A, Spector D. DNA immunization using highly conserved murine cytomegalovirus genes encoding homologs of human cytomegalovirus UL54 (DNA polymerase) and UL105 (helicase) elicits strong CD8 T-cell responses and is protective against systemic challenge. *J Virol* 2007;81(14):66–75.
61. Bolovan-Fritts C, Spector S. Endothelial damage from cytomegalovirus-specific host immune response can be prevented by targeted disruption of fractalkine-CX3CR1 interaction. *Blood* 2008;111(1):175–82.
62. Plotkin S. Rubella eradication. *Vaccine* 2001;19(25/26):3311–9.
63. Ross D, Dollard S, Victor M, Sumartojo E, Cannon M. The epidemiology and prevention of congenital cytomegalovirus infection and disease: activities of the Centers for Disease Control and Prevention Workgroup. *J Womens Health (Larchmt)* 2006;15(3):224–9.

February 24, 2014

Re: Raised Bill No. 5147 "An act concerning newborn screening for globoid cell leukodystrophy and cytomegalovirus and establishing a public education program for cytomegalovirus"

Dear Members of the Connecticut Senate and House of Representatives in General Assembly,

This letter is in support of the Bill No. 5147 which includes

Section 1

(b) newborn screening for several very important newborn illnesses amenable to early treatment and interventions, including but not limited to, cytomegalovirus (CMV) in any newborn infant who fails a newborn hearing screening

Section 2

(a) to establish a public education program to inform pregnant women and women who may become pregnant, about a common virus, called cytomegalovirus (CMV), which is a leading cause of birth defects and deafness in this country.

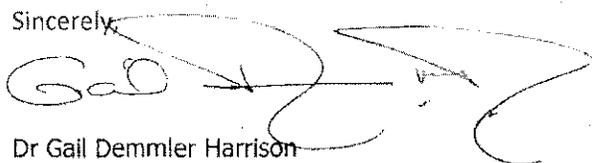
(b) to provide an education program about testing and treating newborns diagnosed with congenital CMV

Cytomegalovirus (CMV) is the most common cause of hearing loss and neurodevelopmental disabilities in this country, and clinical trials have now shown preventive measures for pregnant women and treatment measures for CMV infected newborns are beneficial.

As an expert in congenital CMV with over 30 years experience, and as a doctor who knows families in your state who have been affected by congenital CMV, I am excited and pleased to support this important legislative effort.

A similar CMV education bill was recently passed into law in the State of Utah in 2013. Please support this very important public health bill for Connecticut!

Sincerely,

A handwritten signature in black ink, appearing to read "Gail", followed by a large, stylized flourish that loops back to the left.

Dr Gail Demmler Harrison
aka Gail Demmler MD

aka Gail Demmler-Harrison MD
(you will find me via all three names in medical literature and google)

Professor Department of Pediatrics, Section Infectious Diseases
Baylor College of Medicine
Attending Physician
Infectious Diseases Service
Texas Children's Hospital
CMV Registry, CMV Research and CMV Clinic

Texas Children's Hospital Feigin Center
1102 Bates Street, Suite 1150
Houston, Texas 77030
832-824-4330 ph
832-656-2595 mobile
832-825-4347 fax
gdemmler@bcm.edu
gdemmler@texaschildrens.org
www.bcm.edu/pediatrics/cmvregistry/
www.texaschildrensblog.org/author/gdemmler/
cmv@bcm.edu



Located in the Texas Medical Center

Infectious Disease Service
Feigin Center, Suite 1150
Texas Children's Hospital
1102 Bates Street
Houston, Texas 77030-2399
Tel: 832 824 4330

Infectious Disease Section
Department of Pediatrics
One Baylor Plaza, MS: BCM 320
Texas Medical Center
Houston, Texas 77030

Carol J. Baker, M.D.
Judith R. Campbell, M.D.
Gail J. Demmler-Harrison, M.D.
Morven S. Edwards, M.D.
C. Mary Healy, M.D.
Kristina Hultén, Ph.D.
Sheldon L. Kaplan, M.D.
Edward O. Mason, Jr., Ph.D.
Flor M. Muñoz, M.D.
Debra L. Palazzi, M.D.
Jeffrey R. Starke, M.D.
Jesús G. Vallejo, M.D.

February 24, 2014

Re: Raised Bill No. 5147 "An act concerning newborn screening for globoid cell leukodystrophy and cytomegalovirus and establishing a public education program for cytomegalovirus"

Dear Members of the Connecticut Senate and House of Representatives in General Assembly,

This letter is in support of the Bill No. 5147 which includes

Section 1

(b) newborn screening for several very important newborn illnesses amenable to early treatment and interventions, including but not limited to, cytomegalovirus (CMV) in any newborn infant who fails a newborn hearing screening

Section 2

- (a) to establish a public education program to inform pregnant women and women who may become pregnant, about a common virus, called cytomegalovirus (CMV), which is a leading cause of birth defects and deafness in this country.
- (b) to provide an education program about testing and treating newborns diagnosed with congenital CMV

Cytomegalovirus (CMV) is the most common cause of hearing loss and neurodevelopmental disabilities in this country, and clinical trials have now shown preventive measures for pregnant women and treatment measures for CMV infected newborns are beneficial.

As an expert in congenital CMV with over 30 years of experience, and as a doctor who knows families in your state who have been affected by congenital CMV, I am excited and pleased to support this important legislative effort.

A similar CMV education bill was recently passed into law in the State of Utah in 2013. Please support this very important public health bill for Connecticut!

Sincerely,

Gail J Demmler-Harrison MD (aka Gail Demmler, aka Gail Harrison- all three names in pubmed and internet searches)

Professor Department of Pediatrics Section Infectious Diseases
Baylor College of Medicine

Attending Physician
Infectious Diseases Section
Texas Children's Hospital
Director, CMV Registry, CMV Research Program and Laboratory, and CMV Clinic

Texas Children's Hospital Feigin Center
1102 Bates Street, Suite 1150
Houston, Texas 77030
832-824-4330 ph
832-656-2595 mobile
832-825-4347 fax
gdemmler@bcm.edu
gidemmler@texaschildrens.org
www.bcm.edu/pediatrics/cmregistry/
www.texaschildrensblog.org/author/gdemmler/
cmv@bcm.edu