

Sara Dautre HB 5147

Dear Members of the Public Health Committee,

My name is Sara Menlove Dautre and I am pleased to submit testimony in support of HB 5147, AN ACT CONCERNING NEWBORN SCREENING FOR GLOBOID CELL LEUKODYSTROPHY AND CYTOMEGALOVIRUS AND ESTABLISHING A PUBLIC EDUCATION PROGRAM FOR CYTOMEGALOVIRUS.

My background is in special education (I have a Bachelors degree in special education and a Masters degree in education policy studies). I had my first child at age 30 and considered myself well-versed in disability related matters. **I never learned about CMV.**

I was very proactive during my pregnancy. I took the recommended amounts of folic acid to prevent spina bifida. I participated in the recommended screenings for other markers of birth defects. We read every pamphlet provided by the doctors office. We researched pregnancy and precautions I could take to ensure optimal development of our child. **But, we were never warned about CMV.**

In July 2010, we found out we were expecting our second baby. Because of complications in our first pregnancy, we sought out a specialist in high-risk pregnancies at a maternal fetal diagnostic center.

Our daughter was born with minor symptoms of CMV, but they were not recognized as such. She had a head ultra sound and an MRI that were non-conclusive. Pediatricians told me that it was likely I had gotten sick during my pregnancy and that it may have caused a "hiccup" in her development, but that there was nothing to worry about. Daisy also had a newborn hearing screening, which she failed, and follow up tests. The results did show some mild loss, but the audiologist said that it may have been because she woke up during the ABR and that we didn't need to worry about it. **No one mentioned CMV.**

We came home with a "healthy baby." **We didn't know she had CMV.**

Finally at 16 months, because Daisy was losing her hearing, a doctor asked if he could test for CMV. CMV was working on Daisy for 16 months before we even knew what it was. There were signs it was working on her at her birth. We could have known sooner.

Once we knew, we had options. No one forced us to seek treatment or services, but having knowledge and information empowered us to ask for what was best for our daughter. The diagnosis of congenital CMV was a catalyst for us to pursue intensive **early intervention services.**

Despite the interventions we chose, Daisy continued to lose her hearing. She is deaf and has bilateral cochlear implants. She has some sensory impairments and will deal with CMV for her whole life.

Women who are pregnant or might become pregnant should know about CMV. Health care professionals and others who care for children should know about CMV.

This bill will ensure that happens.

In March 2013, the Utah Governor signed into law a similar bill. Almost one year later, significant progress has been made. Materials have been developed, training has been provided, and, most importantly, **many more people are aware of CMV**. I'm attaching a sample of the materials developed by the Utah Department of Health to implement the similar law. More information can be found at: <http://www.health.utah.gov/cshcn/CHSS/CMV.html>

Effective implementation in Utah has been a team approach. The Utah Department of Health, Division for Children with Special Health Care Needs, has included local CMV researchers, physicians, parents, and other professionals on a team to develop effective materials. Utah is willing to assist Connecticut in implementing this bill as well.

Thank you,

Sara Menlove Doutre

Parent

Education Policy Consultant

Doutre Consulting, LLC

Cytomegalovirus - CMV

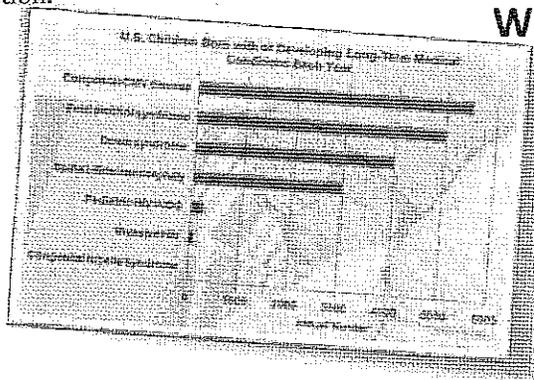
H.B. 81 (2013) Public Health Initiative in conjunction with the Utah Department of Health

What is CMV?

- Cytomegalovirus (sy toe MEG a low vy rus), or CMV, is a common virus that affects people of all ages.
- Most CMV infections are "silent", meaning most people who are infected with CMV have no signs or symptoms. Others may feel like they have the flu.
- When CMV infection occurs during a woman's pregnancy, the baby can become infected before birth. CMV infection before birth is known as "**Congenital CMV**".
- About 1 of every 5 children born with Congenital CMV infection will develop permanent problems due to the infection.



Congenital CMV is the leading non-genetic cause of childhood hearing loss.



Why should I be concerned about CMV?

Congenital CMV infection causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects.

What can I do to prevent CMV?

If you're pregnant or planning a pregnancy, the best way to protect your baby from CMV is to protect yourself.

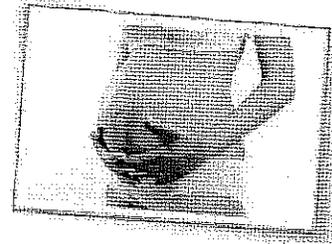
- Wash your hands often with soap and water for 15-20 seconds, especially after
 - changing diapers
 - feeding a young child
 - wiping a young child's nose or drool
 - handling children's toys
- Don't share food, drinks, or eating utensils with a child.
- Do not put a child's pacifier in your mouth.
- Do not share a toothbrush with a young child
- Use soap and water or a disinfectant to clean toys, countertops, and other surfaces that may have a child's saliva or urine on them.
- Avoid contact with a child's saliva when kissing or snuggling.



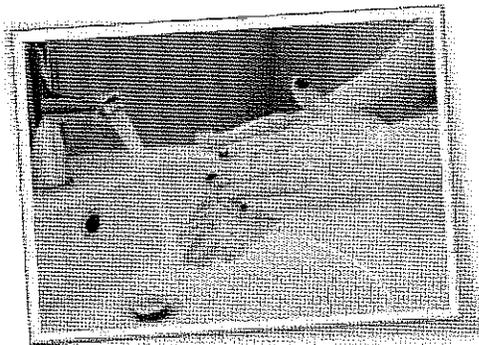
Permanent health problems or disabilities due to congenital CMV include:

- Hearing loss
- Vision loss
- Developmental disability
- Small head size
- Lack of coordination
- Seizures

What happens if a pregnant woman contracts CMV?



- For pregnant women, one of the most common ways they are exposed to CMV is by contact with saliva or urine of children who recently had the virus.
- When infected with CMV, most women do not know it, but some may have symptoms resembling mononucleosis or influenza.
- About 40 of every 100 women who become infected with CMV for the first time during a pregnancy will pass the infection to their infant.



Am I at risk for CMV?

- The risk of getting CMV through casual contact is very small.
- Persons who work closely with children in settings such as child care facilities, can greatly reduce their risk by following the prevention guidelines on page one.

Where can I go for more information?

- **If you have concerns about CMV infection or are pregnant or planning a pregnancy, talk with your healthcare provider.**
- www.MotherToBabyUT.org or (800) 822-2229
- www.cdc.gov/cmV/
- <http://www.health.utah.gov/cshcn/CHSS/CMV.html>
- Utah Early Hearing Detection and Intervention at (801) 584-8215



40% of women who become infected with CMV for the first time during pregnancy will pass the infection on to their infant.

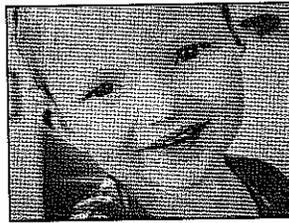
Is there a vaccine for CMV?

There is no vaccine available to prevent CMV. However, a few CMV vaccines are being tested in humans. The Institute of Medicine has ranked the development of a CMV vaccine as a high priority; however, it may be a number of years before the Food and Drug Administration (FDA) approves a CMV vaccine.

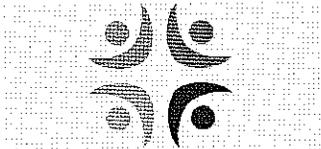


Women who are pregnant or plan to become pregnant, and who have close contact with young children, should discuss their risk for CMV infection with their medical provider.

Congenital CMV infection causes more long-term health problems and childhood deaths than Down Syndrome, fetal alcohol syndrome, neural tube defects (spina bifida, anencephaly) and Pediatric HIV/AIDS.



Congenital CMV is the leading non-genetic cause of childhood hearing loss



UTAH DEPARTMENT OF HEALTH

Early Hearing Detection & Intervention

QUESTIONS?
CALL MOTHER TO BABY UTAH
AT (800) 822-2229

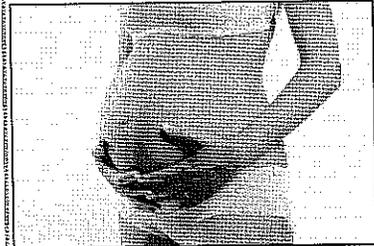
Comprehensive and Special Services
11 North Main, Cooperative Drive
Salt Lake City, UT 84143
Phone: 801-534-6216
Fax: 801-534-2492
Email: amsrjen@utah.gov

Dated 06.26.2013

STATE OF UTAH
DEPARTMENT OF HEALTH

Cytomegalovirus

**What women
NEED TO KNOW
about CMV**



**For Women Who Are Pregnant
or Planning to Become
Pregnant**

CMV INFECTION DURING PREGNANCY CAN HARM YOUR BABY

Cytomegalovirus (say toe MEG a low vy rus), or **CMV**, is a common virus that infects people of all ages.

Most CMV infections are "silent", meaning the majority of people who are infected with CMV have no signs or symptoms, and there are no harmful effects.

However, when CMV occurs during a woman's pregnancy, the baby can become infected before birth.

CMV infection before birth is known as "**congenital CMV**". When this happens, the virus is transmitted to the unborn infant and can potentially damage the brain, eyes and/or inner ears.

About 1 of every 5 children born with congenital CMV infection will develop permanent problems, such as hearing loss or developmental disabilities.



The best way to protect your baby from CMV is to protect yourself.

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 mouth
- Handling children's toys



Don't share food, drinks, eating utensils, or a toothbrush with a child.

Do not put a child's pacifier in your mouth.

Avoid contact with a child's saliva when kissing or snuggling.



- **The virus is generally passed from infected people to others through direct contact with body fluids, such as urine or saliva.**

Use soap and water or a disinfectant to clean toys, changing tables, and other surfaces that may have a child's saliva or urine on them.



- Most healthy children and adults infected with CMV don't feel ill and don't know that they have been infected; others may have mild flu-like symptoms such as fever, sore throat, fatigue or swollen glands.
- A blood, saliva, or urine test can tell whether a person has ever been infected with CMV.
- Infants and children who are infected with CMV after birth rarely have problems.



**Testimony
Elizabeth Gara
Executive Director
Connecticut Water Works Association (CWWA)
Before the
Public Health Committee
February 28, 2014**

RE: SB-126, AN ACT CONCERNING CHILDREN'S EXPOSURE TO CHEMICALS.

CWWA recommends that **SB-126, AN ACT CONCERNING CHEMICALS OF HIGH CONCERN TO CHILDREN**, *be amended to specifically exempt water utilities* from the scope of the bill because water utilities are already subject to extensive state and federal laws and regulations which ensure the safety of our public water supplies through extensive water quality monitoring and reporting.

The U.S. Environmental Protection Agency (EPA) strictly regulates public water supplies to ensure compliance with the federal Safe Drinking Water Act which requires extensive water quality monitoring and reporting. Federal drinking water quality standards are developed based on a detailed process of risk assessment that considers the potential health impacts of various components in drinking water.

Under the federal Safe Drinking Water Act utilities are required to notify their customers regarding the presence of any chemicals or compounds found in drinking water and provide an annual Consumer Confidence Report (CCR) which indicates which compounds are found in the water and at what level. In addition, the state Department of Public Health, as the primary agency that enforces the SDWA on the state level, may also require more stringent monitoring and reporting.

Public water supplies may, however, contain trace amounts of chemicals at levels considered safe under federal and state law. Many of these substances are naturally occurring, while some are required for public health purposes, such as fluoride, or recommended for use in water treatment, such as chlorine, to ensure the quality of the water.

Given the federal and state laws governing monitoring, reporting and remediation, we believe that public water suppliers should be exempt from the scope of this bill, which would be duplicative and problematic for public water suppliers.



CMV CORE FACTS

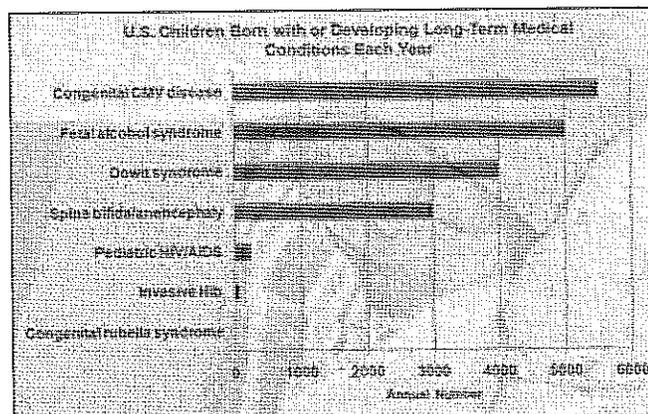
What is CMV?

- Cytomegalovirus (sy toe MEG a low vy rus), or CMV, is a common virus that infects people of all ages. Most people become infected with CMV during their lifetimes.
- Most CMV infections are “silent,” meaning most people who are infected with CMV have no signs or symptoms and suffer no harmful effects.
- When CMV infection occurs during a woman’s pregnancy, the baby can become infected before birth. CMV infection before birth is known as “**congenital CMV.**” In this form, the virus can be transmitted to the unborn infant and potentially damage the brain, eyes, and inner ear. CMV is the most common congenital infection in the United States.
- About 1 in 150 children are born with congenital CMV infection. This means that in the United States, about 30,000 children are born with congenital CMV each year. In Utah, that is roughly 1 child per day.
- About 1 of every 5 children born with congenital CMV will develop permanent problems, such as hearing loss or developmental disabilities, due to the infection. In the United States, more than 5,000 children each year have permanent problems caused by congenital CMV.
- Infants and children who are infected with CMV **after** birth rarely have symptoms or problems.

Why should I be concerned about CMV?

- Congenital CMV infection causes more long-term health problems and childhood deaths than Down Syndrome, fetal alcohol syndrome, and neural tube defects. The graph below estimates the number of children in the United States who develop lasting problems from each of these conditions.

(Source: <http://www.cdc.gov/cmvtrends-stats.html>)



- CMV is the leading **preventable** viral cause of developmental disabilities.
- Permanent health problems or disabilities due to congenital CMV infection can include:
 - Hearing loss
 - Vision loss
 - Developmental disability
 - Small head size
 - Lack of coordination
 - Seizures
- Children with congenital CMV infection are more likely to have permanent disabilities if they had signs or symptoms of CMV infection at birth.
- Some children with congenital CMV infection who appear healthy at birth will have a normal newborn hearing screening, but can still develop hearing loss later. It is particularly important that these babies be monitored closely. See “**Congenital CMV and Hearing Loss**”.

Am I at risk for CMV?

- The risk of getting CMV through casual contact is very small.
- The virus is generally passed from infected people to others through direct contact with body fluids, such as urine or saliva.
- CMV is not easily spread; fewer than 1 in 5 parents of children who have CMV become infected over the course of a year.
- Healthy adults face little risk of getting seriously sick from CMV infection.
- Persons who work closely with children in settings such as child care facilities may be at greater risk of CMV infection than persons who do not work in such settings. There are certain steps everyone can take to reduce their risk of exposure to CMV and other infection. Refer to “**What can I do to reduce my likelihood of getting CMV?**”.
- Women who are pregnant or plan to become pregnant and who have close contact with young children should discuss their risk for CMV infection with their medical provider.
- Although CMV is spread through contact with infected body fluids, including urine and saliva, the risk of CMV infection among healthcare workers appears to be no greater than that among the general public. This may be due to standard precautions taken by healthcare providers such as frequent hand-washing or wearing gloves to avoid contact with body fluids.

How do I know if someone has CMV?

- Most healthy children and adults infected with CMV have no symptoms and may not even know that they have been infected.
- People may develop a mild illness when they get infected and may have the following symptoms: fever, sore throat, fatigue, and swollen glands. Since these are also symptoms of other common illnesses, most people don't realize that they have been infected with CMV.

- Most CMV infections are not diagnosed because CMV usually causes few, if any, symptoms. A blood, saliva, or urine test can tell whether a person has ever been infected with CMV.
- CMV infection at birth (congenital CMV infection) can be diagnosed in an infant if the virus is detected in his or her urine, saliva, or blood within 2-3 weeks after birth.
- Infants, children, and adults are not routinely tested for CMV infection.

Is there a treatment for CMV?

- Healthy people who are infected with CMV but who have no symptoms do not require medical treatment.
- There is no drug licensed to treat congenital CMV infection. There are limited data on the use of antiviral medications in infants with symptomatic congenital CMV infection. Studies are ongoing to determine what types of therapy are of greatest benefit to CMV-infected infants. Infants with suspected congenital CMV infections should be evaluated by physicians who specialize in these infections.
- Pediatricians and other specialists play an important role in making sure that children with congenital CMV infection are assessed and treated as needed.
- Some children with congenital CMV infection who appear healthy at birth can still develop hearing loss over time. It is particularly important that such babies be monitored closely. If you know your baby was born with CMV infection, it is important to have his or her hearing tested regularly by an audiologist with pediatric expertise.
- If an infected baby with congenital CMV appears healthy at birth (considered an asymptomatic infection), it is unlikely that there will be vision problems. However, after a diagnosis of congenital CMV has been made, a thorough ophthalmologic (eye) examination is recommended.

Is there a vaccine for CMV?

- There is no vaccine available to prevent CMV. However, a few CMV vaccines are being tested in humans. The Institute of Medicine has ranked the development of a CMV vaccine as a high priority; however, it may be a number of years before the Food and Drug Administration (FDA) approves a CMV vaccine.

What happens if a pregnant woman contracts CMV?

- In the United States, approximately 30-50% of women have never been infected with CMV by the age of 40, and can contract CMV while pregnant.
- About 1-4 of every 100 women who have never been infected with CMV have a primary (first) CMV infection during pregnancy.
- About 40 of every 100 women who become infected with CMV for the first time during a pregnancy will pass the infection to their fetus.
- For pregnant women, one of the most common ways they are exposed to CMV is by contact with saliva or urine of children who recently had the virus.

- People who are infected with CMV can pass the virus for months after they first become infected. Studies in child care settings suggest that as many as 75% of toddler-aged children have CMV in their urine or saliva.
- When infected with CMV, most women have no symptoms, but some may have symptoms resembling mononucleosis or influenza. Women who develop a mononucleosis- or flu-like illness during pregnancy should consult their medical provider about possible CMV infection.
- If you find out that you became infected with CMV for the first time during your pregnancy, make sure your infant is tested for CMV as soon as he or she is born.
- If you have concerns about CMV infection and are pregnant or planning a pregnancy, talk with your healthcare provider.

Congenital CMV and Hearing Loss

- When CMV infection occurs during a woman's pregnancy, the virus can be transmitted to the unborn infant and potentially damage the inner ear.
- Approximately 10% of the infants who have no visible symptoms of CMV (considered "asymptomatic" infection) at birth will end up having permanent hearing loss (PHL).
- There are three times as many children that are asymptomatic than symptomatic with CMV infection. In a large number of asymptomatic children with congenital CMV, hearing loss is the only sequelae (known abnormality).
- CMV is the most common cause of nonhereditary sensorineural hearing loss (SNHL) and is thought to account for 20% of all childhood hearing loss in Utah.
- SNHL from congenital CMV has variable presentations; about 50% will show unilateral impairment, about 50% will be bilateral. Some loss may affect all frequencies, others in just the high frequencies; variation in degree and configuration is common.
- Research has shown that more than 50% of children with congenital CMV pass their newborn hearing screening and go on to develop permanent hearing loss through their 6th year of life, as either late-onset or progressive hearing loss.
- Utah House Bill 81 mandates that newborns who fail their second newborn hearing screening should be referred to their pediatrician or primary care provider for congenital CMV testing; this testing should be done by three weeks of age to optimally diagnose this condition. Because of this, it is very important for a family to have chosen a primary care provider for their baby before his/her birth.
- A general recommendation for babies diagnosed with congenital CMV is to have a hearing assessment every three months in the first three years of life, and then every six months through age six years; however, each child should be considered on an individual basis as timing of assessments may need to be more frequent or altered based on antiviral therapy, rehabilitation needs, pediatric audiologist guidance, or parent concerns.

- As is the case with any child not passing their outpatient or 2nd hearing screening, a diagnostic audiologic evaluation should be completed as soon as possible as recommended by the Utah Recommended Infant Audiological Assessment Protocol.
- Children with confirmed hearing losses should follow standard follow-up procedures, including referral to otolaryngology (ENT), ophthalmology, and genetics or other specialists as appropriate, and be referred to the Utah School for the Deaf and Blind (USDB) Parent-Infant-Program (PIP) for early intervention services at 801-629-4741.

What can I do to reduce my likelihood of getting CMV?

- If you're pregnant or planning a pregnancy, the best way to protect your baby from congenital CMV is to protect yourself.
 - 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
 - handling children's toys
 - Don't share food, drinks, eating utensils, or a toothbrush with a child.
 - Do not put a child's pacifier in your mouth.
 - Use soap and water or a disinfectant to clean toys, countertops, and other surfaces that may have a child's saliva or urine on them.
 - Avoid contact with a child's saliva when kissing or snuggling.

Where can I get more information on CMV?

- **If you have concerns about CMV infection or are pregnant or planning a pregnancy, talk with your healthcare provider.**
- www.MotherToBabyUT.org or (800) 822-2229
- www.cdc.gov/cmV
- www.stopcmv.org
- Utah Early Hearing Detection and Intervention at (801) 584-8215