

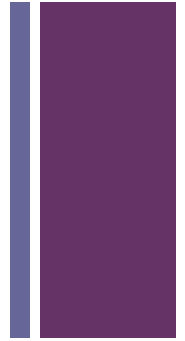
Advocacy through Legislation

Utah's Congenital Cytomegalovirus
Public Health Initiative

+ Daisy's Story



- Born 3/9/11
- Failed NHS in hospital
- Abnormal head ultrasound and MRI
- Released 3/13/11
- Failed follow-up NHS
- ABR at 2 weeks



+ Daisy's Story

- Audiologist @ 1 yr
- ENT @ 17 mos. for tubes – mild loss – CMV antibodies present
- Positive PKR Blood Spot test for Congenital CMV @ 18 months
- First hearing aids @ 18 months



+ Daisy's Story



- Unilateral mild hearing loss @ 17 months
- Early intervention @ 17 months
- Profoundly deaf @ 20 months
- Bilateral cochlear implant surgery @ 21 months

+ What is CMV?

Cytomegalovirus - CMV

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

What is CMV?

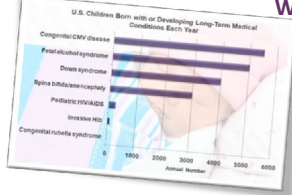
- Cytomegalovirus (sometimes MEGALOVIRUS), or CMV, is a common virus that affects people of all ages.
- Most CMV infections are "silent", meaning most people who are infected with CMV have no signs or symptoms. Others may feel like they have the flu.
- When CMV infection occurs during a woman's pregnancy, 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?

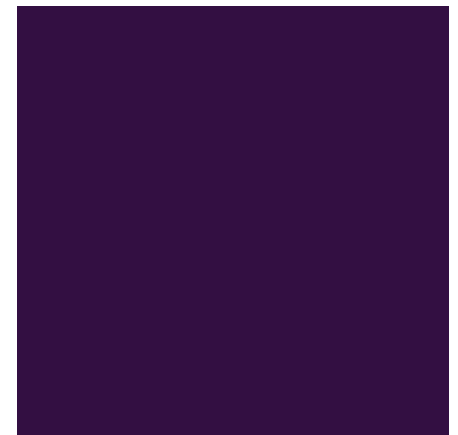
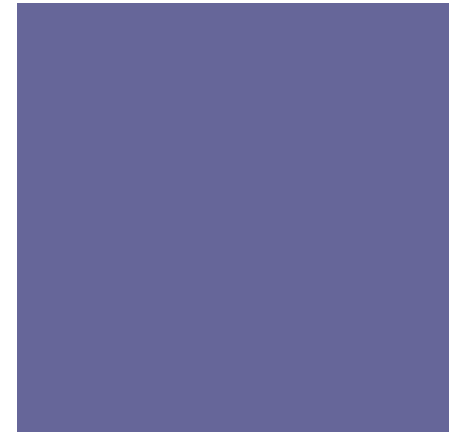
- The risk of getting CMV through casual contact is very small.
- Persons who work closely with children in settings such as child care facilities, can greatly reduce their risk by following the prevention guidelines on page one.



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





H.B. 81 – Cytomegalovirus Public Health Initiative

Utah Legislature – 2013 General Session

CYTOMEGALOVIRUS PUBLIC HEALTH INITIATIVE

2013 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Ronda Rudd Menlove

Senate Sponsor: Curtis S. Bramble

LONG TITLE

General Description:

This bill amends the Utah Health Code and directs the Department of Health to establish a public education program regarding the impacts and dangers of congenital cytomegalovirus (CMV) infection and the methods of prevention of CMV infection.

Highlighted Provisions:

This bill:

- ▶ directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;
- ▶ requires the Department of Health to provide this information to:
 - licensed child care programs and their employees;
 - health care facilities licensed pursuant to Title 26, Chapter 21, the Health Care Facility Licensing and Inspection Act;
 - child care programs administered by educational institutions regulated by the



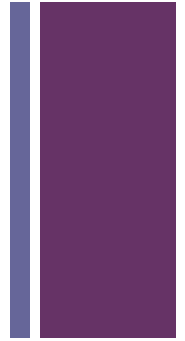
Signed into law March 22, 2013

+ H.B. 81 – Cytomegalovirus Public Health Initiative





H.B. 81 – Cytomegalovirus Public Health Initiative



1. Directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;



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

Children's Hearing and Speech Services
44 North Mario Capecchi Drive
Salt Lake City, UT 84113

Phone: 801-584-8215
Fax: 801-584-8492
E-mail: smcvcicar@utah.gov

Dated 06.26.2013

STATE OF UTAH
DEPARTMENT OF HEALTH

Cytomegalovirus

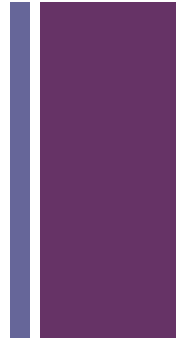
What women
NEED TO KNOW
about CMV



For Women Who Are Pregnant
or Planning to Become
Pregnant



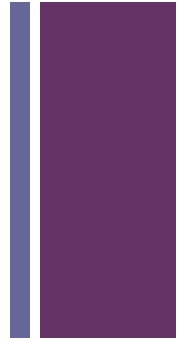
H.B. 81 – Cytomegalovirus Public Health Initiative



2. Requires the Department of Health to provide this information to:
 - Licensed child care programs and their employees;
 - Health care facilities
 - Child care programs
 - School nurses
 - Health educators
 - Health care providers offering care to pregnant women and infants



H.B. 81 – Cytomegalovirus Public Health Initiative



3. Directs medical practitioners to test infants, who fail the newborn hearing screening test(s), for CMV and inform the parents of those infants about the possible birth defects that CMV can cause and the available treatment methods
4. Directs the Department of Health to notify medical practitioners of the CMV testing requirements

CONGENITAL CYTOMEGALOVIRUS AND HEARING LOSS

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

Most CMV infections are “silent”, meaning most 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.

If the inner ear gets damaged, the baby may be born with hearing loss, or develop hearing loss after birth or during early childhood.



Newborn Hearing Screening

If your baby does not pass his/her newborn hearing screening in the hospital, it is very important that he have another (outpatient) screening before 14 days of age.

This repeat hearing screening is necessary to complete the newborn hearing screening process, and should be scheduled before your baby is discharged.

Outpatient Re-Screening

If your baby does not pass this second hearing screening, your pediatrician or primary care provider should talk to you about testing your baby for congenital CMV.

Congenital CMV testing is simple and painless, and can be accomplished using a urine sample or a saliva sample (the inside of your baby’s cheek is swabbed).

In order to accurately detect congenital CMV, **this laboratory testing needs to be performed on samples taken before your baby is 21 days of age.**

What if my baby has congenital CMV?

Your primary care provider will direct your baby’s care and refer to any needed specialists.

CMV FACTS

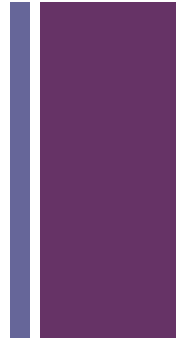
- Most healthy children and adults infected with CMV don’t feel ill and don’t know that they have been infected; others may have mild flu-like symptoms
- Infants and children who are infected with CMV **after** birth rarely have problems
- Congenital CMV-related hearing loss can affect one or both ears; can affect some or all of the pitches a baby hears; can be mild or severe; can be present at birth or appear later; and can be progressive (worsening over time)
- 50% of infants with congenital CMV will pass their newborn hearing screening then go on to develop hearing loss

Congenital CMV is the most common cause of non-hereditary hearing loss in children

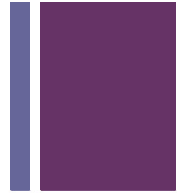
+ Funding for H.B. 81



- One-time funds
- Ongoing funds
- Requires
Coordination
between the
Department of
Health and the
legislature



+ H.B. 81 – Essential Partners



- Department of Health
- Medical Professionals
 - CMV Researchers
 - OB/GYNs;
 - Pediatricians;
 - Audiologists
- Higher Education
- National Center
- Legislature
- Parents

UTAH DEPARTMENT OF
HEALTH



UtahStateUniversity



**Intermountain
Primary Children's Hospital**

The Child First and Always®

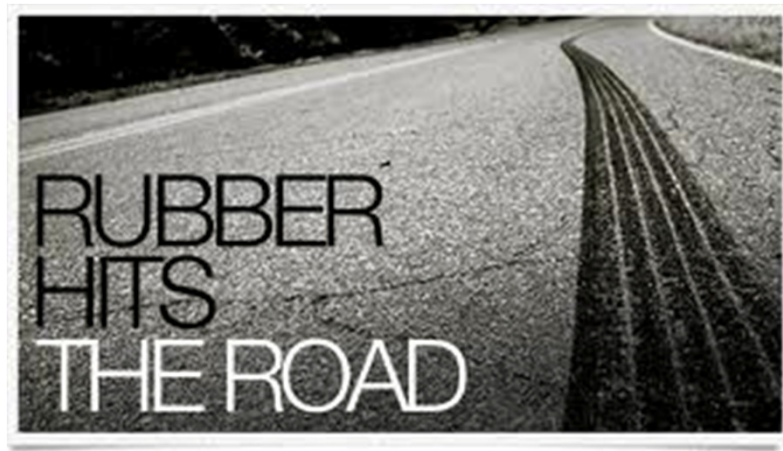

THE
UNIVERSITY
OF UTAH

 **NCHAM**
National Center for Hearing
Assessment and Management
Utah State University™

 UTAH STATE
LEGISLATURE

+ Implementation of H.B. 81

- The signing of the bill is just the beginning
- Leadership of EHDI coordinator
- Follow through by all partners
- Collaboration is Key



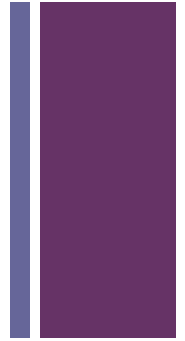
+ Gather your team!

Department of Health – Children with Special Health Care Needs Bureau Director, Medical Director, EHDI Coordinator

Physicians – AAP EHDI Chapter Champion, Maternal Fetal Medicine, Pediatric Otolaryngologist, Pediatric Neurologist, Pediatric Ophthalmologist, Infectious Disease, CMV Researchers

CMV Experts – Lab, CDC, CMV Researchers, Parents

NBHS Stakeholders – NCHAM, Coordinators, Audiologists, Screeners, Hospitals, Midwives, Families



+ Prepare Educational Materials

[CMV Core Facts \(Datos Fundamentales de CMV\)](#)

[CMV Utah Flyer \(Citomegalovirus\)](#)

Brochures:

[Congenital CMV and Hearing Loss \(CMV Congenito y la Perdida de Audicion\)](#)

[CMV What Women NEED TO KNOW \(Lo Que Una Mujer Necesita Saber Acerca de CMV\)](#)

[CMV What Childcare Providers NEED TO KNOW \(Lo que los proveedores de cuidado infantil NECESITAN SABER sobre CMV\)](#)

For Health Care and Newborn Hearing Screening Providers:

[CMV for Pediatric Care Providers \(PCP\)](#)

[CMV for Obstetrical Health Care Providers](#)

[CMV PCR Testing](#)

[CMV Newborn Hearing Screening \(NBHS\) and PCP Flowchart](#)

[CMV and NBHS Testing Status FAX Form](#)

[CMV Testing Refusal Form](#)



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Utah's materials are available online at:

<http://www.health.utah.gov/cshcn/CHSS/CMV.html>



UTAH DEPARTMENT OF
HEALTH
Early Hearing Detection & Intervention

+ Get the word out!

Email blasts and posts on websites: Utah AAP, Utah AFP (Family Physicians), Insurance industry, labs, pediatric audiologists, school nurses, special educators, early intervention, home visitors, child care licensing, religious organizations, etc

Website: Information and educational materials easily accessible

Media: newspaper, TV, radio

Newsletters: articles, updates, helpful hints

Presentations: physicians, residents, fellows, neonatologists, all stakeholders, etc etc etc

Health Fairs/Conferences: flyers, booths, seminars

Webinars: NBHS stakeholders, Roll-out, Introduction of new forms, protocols processes, pilot groups

+ Keep communication coming!

Welcome comments, suggestions, anecdotal information, be open to new ideas

Be responsive to concerns

Continue to improve and refine forms, processes

Educate, **LISTEN**, *invite partnership*, focus on the **GOOD**

Expand your team

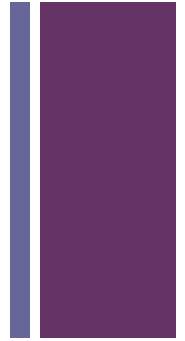
SHARE!!



+ Impact of H.B. 81

- CMV Awareness
 - Legislature
 - News/Media
 - Required Education
- Individual Child Impact
- Early Identification and Access to Early Intervention
- Parents have Options





Impact of H.B. 81 Beyond Utah

- Bills introduced in 2014 in the Connecticut and Illinois legislatures
- Parents working to build relationships and promote similar legislation in almost all 50 states
- Statement - CMV Awareness and Prevention is a national priority



+ Questions?



Ronda Rudd Menlove, PhD; Utah House of Representatives; Senior Vice Provost and Associate Professor of Special Education, Utah State University

Sara Doutre, MA; Parent; Education Policy Consultant

Stephanie McVicar, AuD, CCC-A; Utah EHDI Director

+ Contact Us

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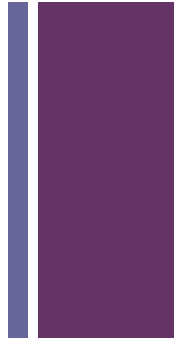
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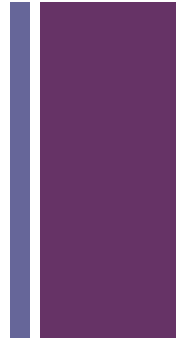
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