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- Click Print
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- Click layout
- Choose # of pages per sheet from dropdown menu
- Checkmark Black & White if wanted.

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- Open PDF
- Click Print
- Choose # of pages per sheet from dropdown menu
- Choose Black and White from "Color" dropdown

Congenital Cytomegalovirus (CMV): Advocacy and Legislation

in partnership with Midwestern University and Phoenix Children's Hospital

Stephanie Browning McVicar, Au.D., CCC-A

Stephanie Browning McVicar, AuD, CCC-A

Dr. Stephanie Browning McVicar is the Director of the Early Hearing Detection and Intervention (EHDI) Program, the Children's Hearing Aid Program, and the Cytomegalovirus (CMV) Public Health Initiative in Utah. She works for the Utah Department of Health and Human Services' Children with Special Healthcare Needs Office in Salt Lake City. Dr. McVicar is a pediatric audiologist, an advocate for CMV testing in newborns, and passionate about the prevention of congenital CMV infection. She is originally from Western New York and has extensive experience and knowledge in Audiology and the management of health care programs in both the public and private sectors.

Disclosures

- **Presenter Disclosure**: Financial: Stephanie Browning McVicar is employed by Utah Department of Health and Human Services' Children with Special Healthcare Needs Office. She received an honorarium for this presentation. Non-financial: Stephanie Browning McVicar has no relevant non-financial relationships to disclose.
- **Content Disclosure**: This learning event does not focus exclusively on any specific product or service.
- **Sponsor Disclosure**: This course is presented in partnership with Midwestern University and Phoenix Children's Hospital.

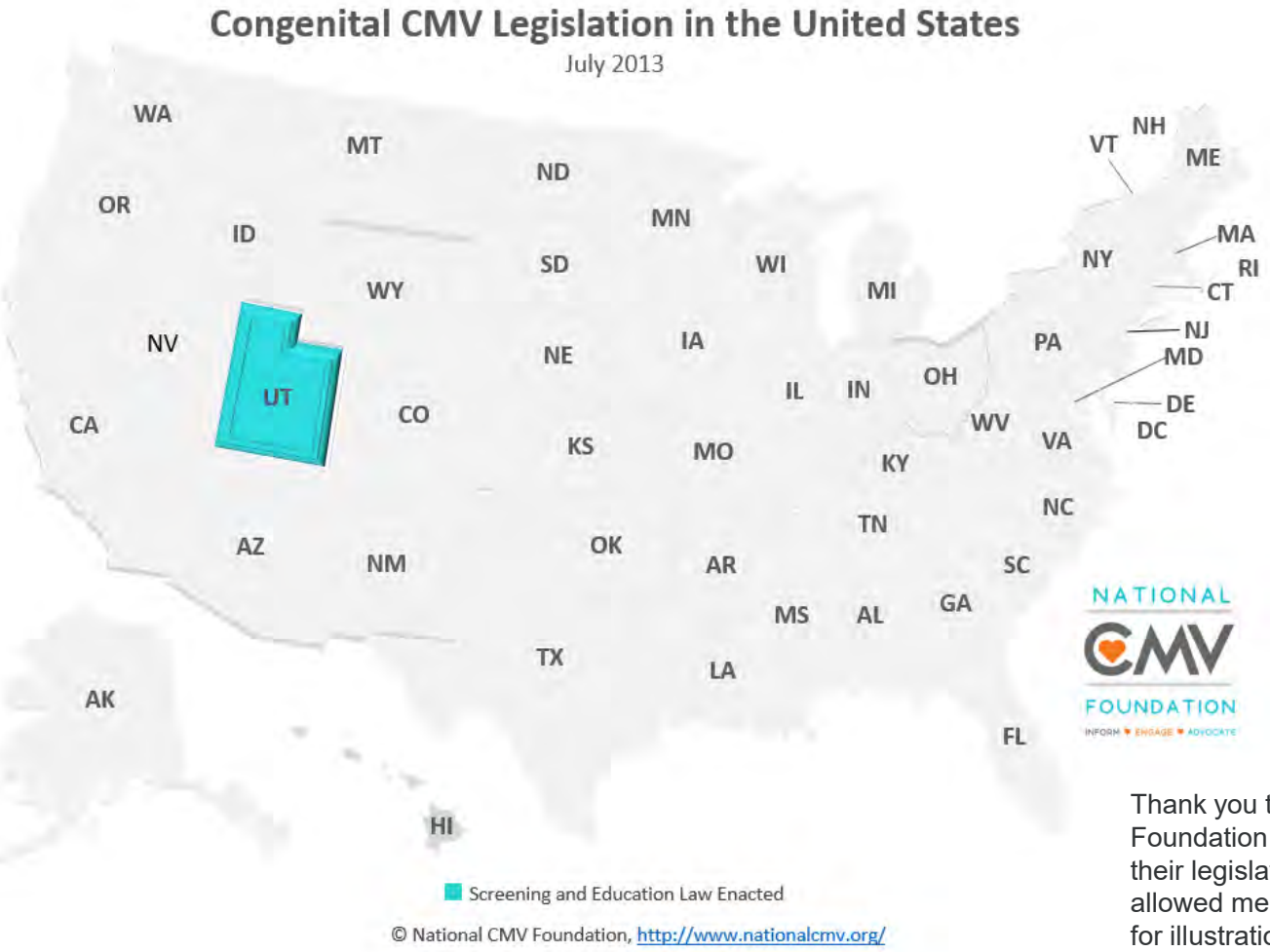
Learning Outcomes

After this course, participants will be able to:

- Describe US legislative mandates involving congenital CMV.
- Compare how CMV testing has evolved over time in Utah.
- List five keys to success for the Utah CMV testing program.

The Advocacy Power of Parents

CMV Legislation: July 2013



Thank you to the National CMV Foundation who let me use their legislation maps and allowed me to adapt them for illustration purposes.

Utah CMV Council

The Advocacy Power of Parents

Janelle Greenlee
Stop CMV
2003

Farah Armstrong
Maddie's Mission
2014

Sara Menlove Doutré

Annie Culley

Abigail Wright

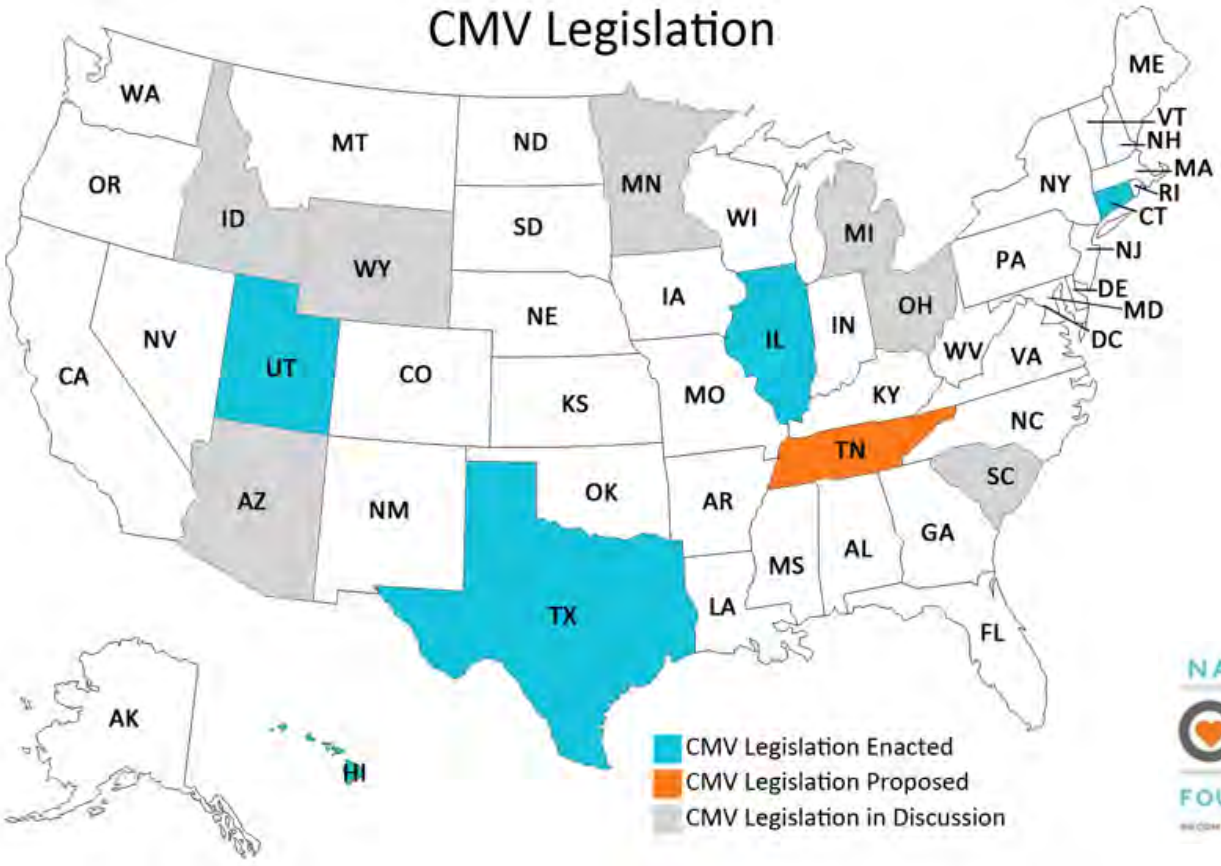
Utah CMV Council
2014

2015

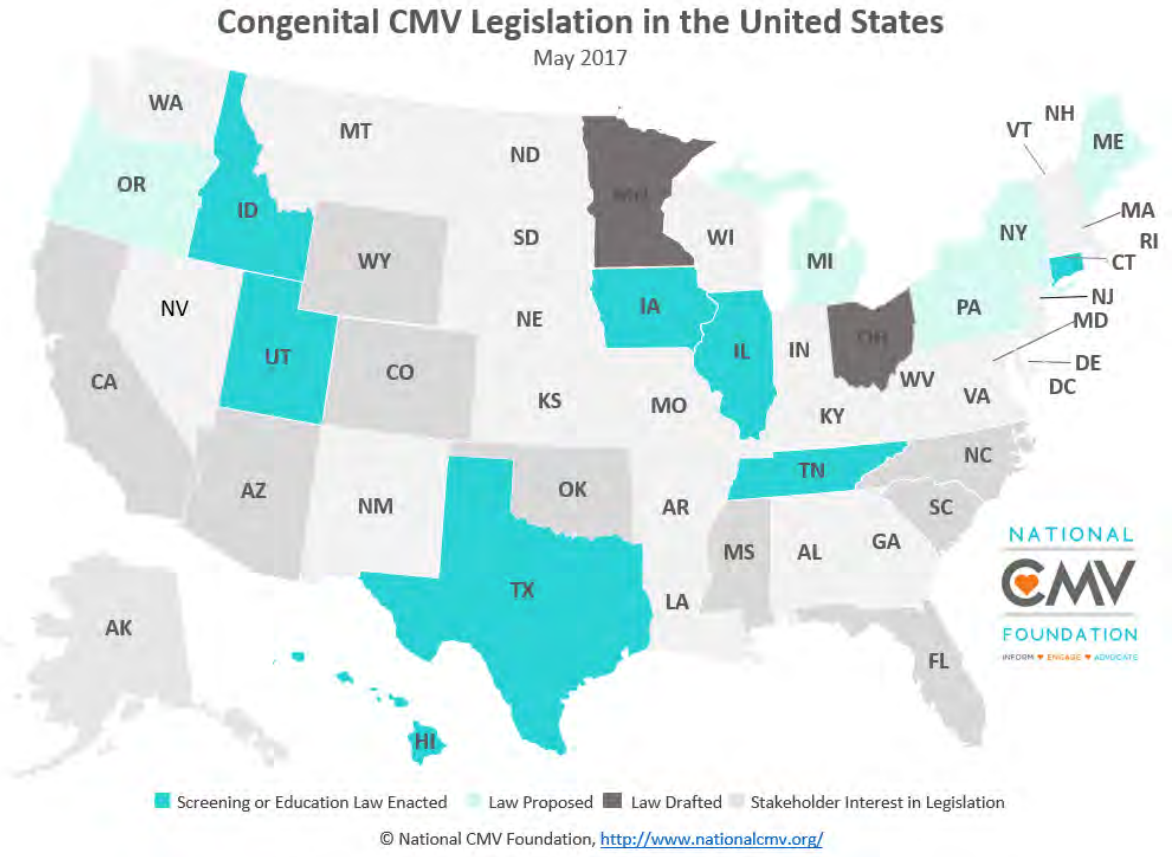
Kristen Hutchinson Spytek

NATIONAL CMV FOUNDATION
INFORM ♥ ENGAGE ♥ ADVOCATE

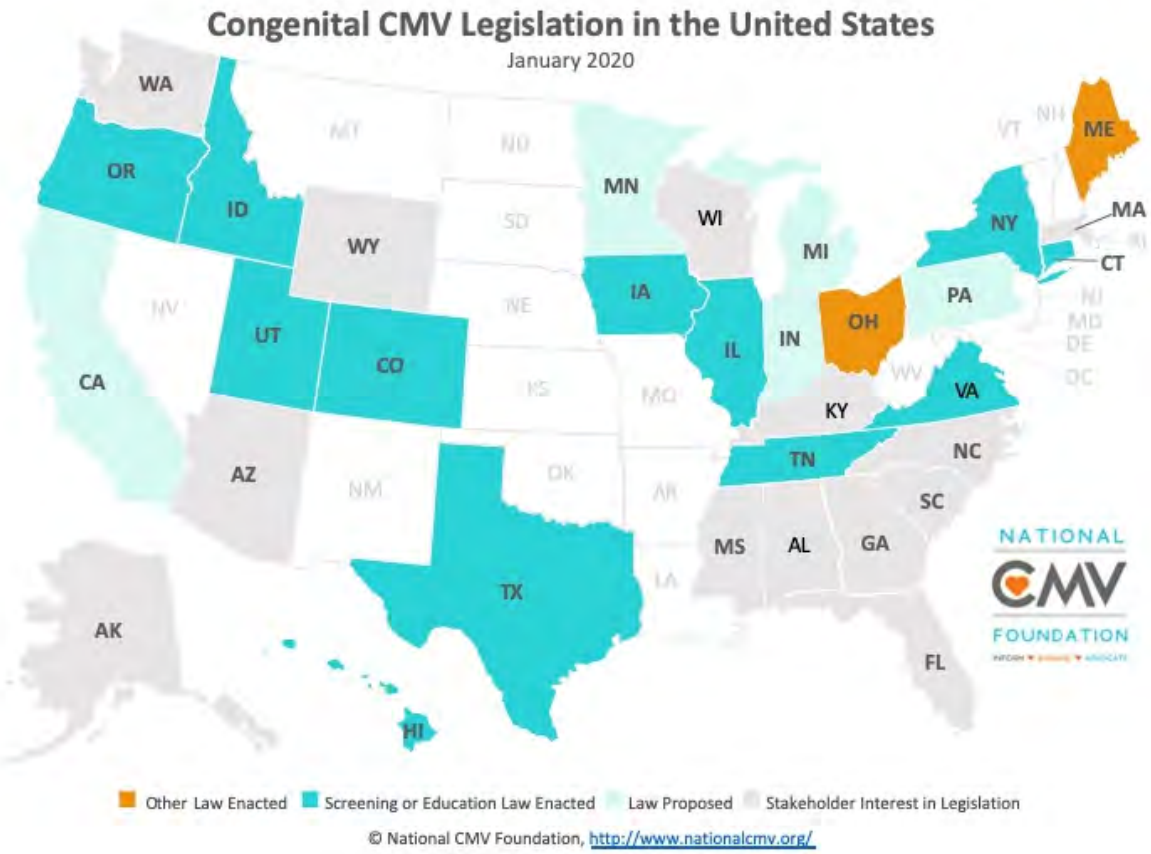
CMV Legislation: November 2015



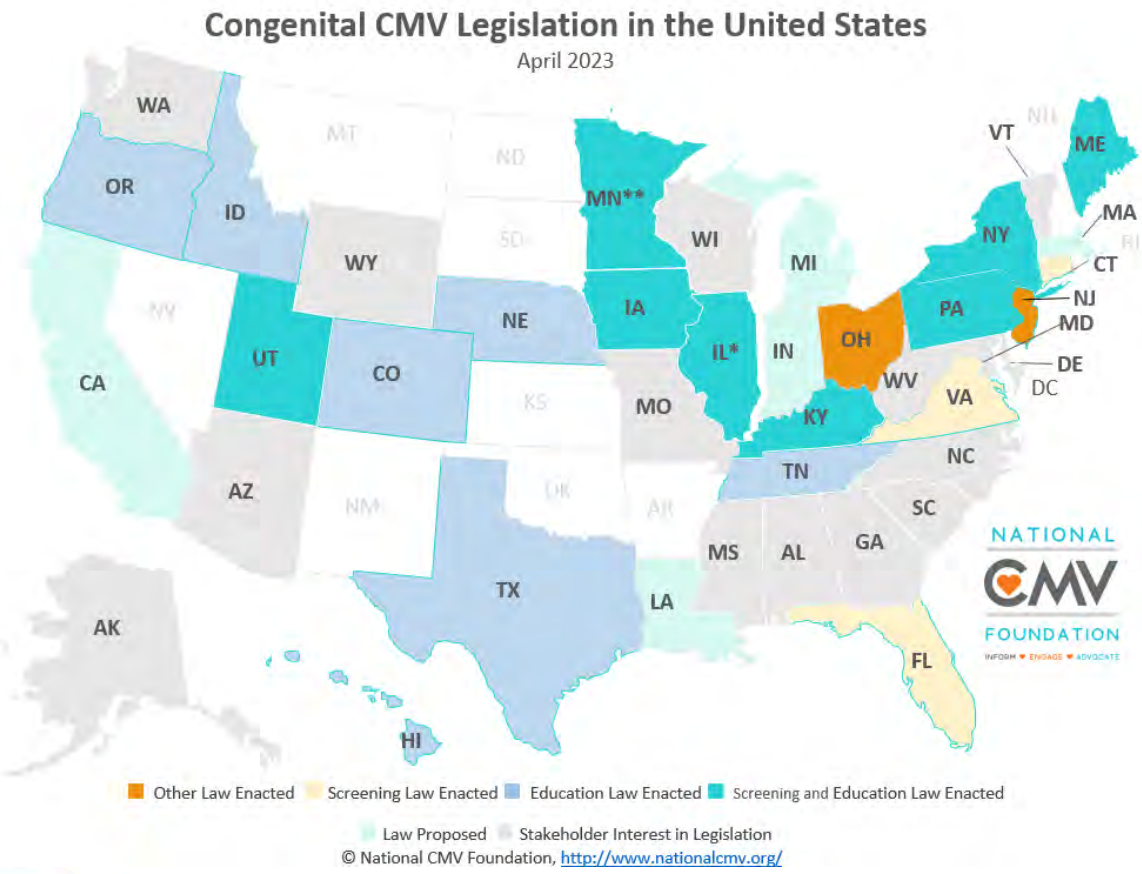
CMV Legislation: May 2017



CMV Legislation: January 2020



CMV Legislation: April 2023



*CMV screening just has to be offered after failing NBHS **Universal CMV screening!

OH: June is designated cCMV Awareness Month to increase public awareness and encourage testing of NB

NJ: public awareness campaign and Universal CMV screening once added to the RUSP (Recommended Universal Screening Panel)

ME: 2017 – committee established to investigate universal CMV screening. 2022 – passed education and hearing-targeted screening.

CT: 2023 – trying to amend from hearing targeted to universal

The Power of Parents

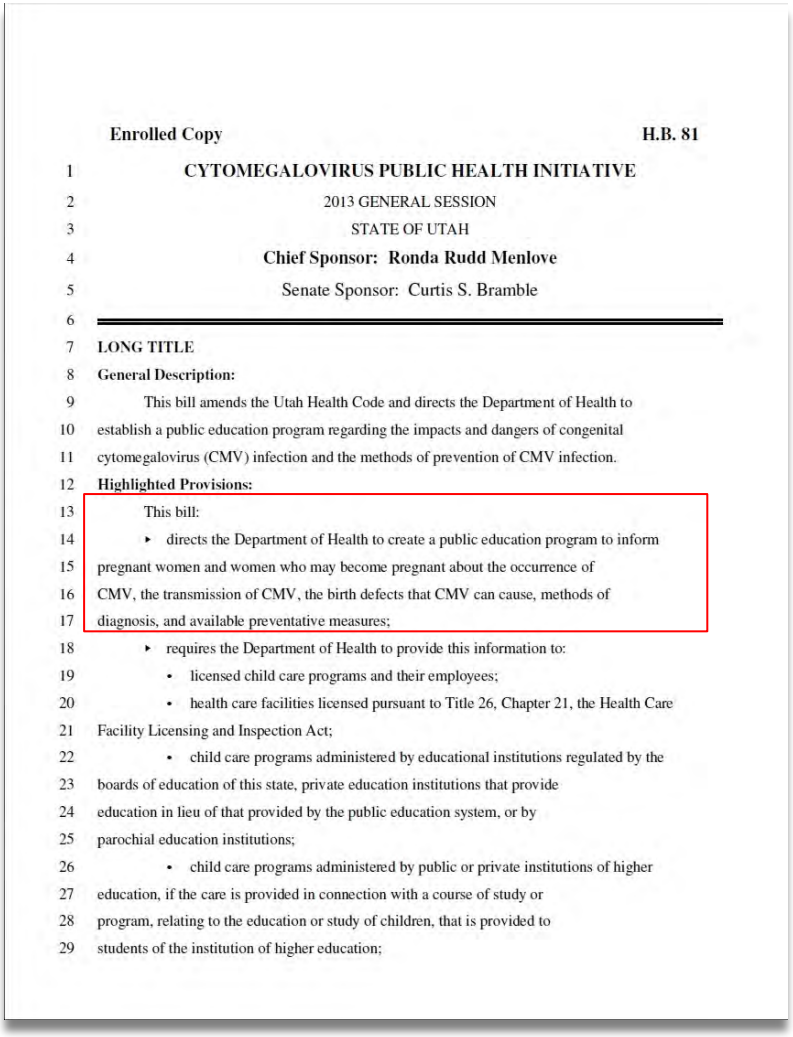
- MN – 2021 – “The Vivian Act”
- KY – 2022 – “Bella Dawn Streeval Law”
- LA – 2023 – “Journie’s Law”

RESEARCH BRIEF REPORT

A Legal Mapping Assessment of Cytomegalovirus-Related Laws in the United States.

Yassine, Brianne B. PhD, MPH; Hulkower, Rachel JD, MSPH; Dollard, Sheila PhD; Cahill, Eric MA; Lanzieri, Tatiana MD, MPH. *Journal of Public Health Management and Practice* 28(2):p E624-E629, March/April 2022. | *DOI:* 10.1097/PHH.0000000000001401

Utah



Enrolled Copy H.B. 81

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 boards of education of this state, private education institutions that provide education in lieu of that provided by the public education system, or by parochial education institutions;
  - child care programs administered by public or private institutions of higher education, if the care is provided in connection with a course of study or program, relating to the education or study of children, that is provided to students of the institution of higher education;

FISCAL NOTE

H.B. 81 1st Sub. (Buff)

SHORT TITLE: Cytomegalovirus Public Health Initiative

SPONSOR: Menlove, R. (Menlove, R. Sub.)

2013 GENERAL SESSION

STATE GOVERNMENT (UCA 36-12-13(2)(b))

This bill costs the Department of Health $30,800 ongoing General Fund beginning in FY 2014 and $4,000 one-time General Fund in FY 2013 for a 0.5 FTE educator and educational materials.

STATE BUDGET DETAIL TABLE	FY 2013	FY 2014	FY 2015
Revenue	$0	$0	$0
Expenditure:			
General Fund	$0	$30,800	$30,800
General Fund, One-Time	$4,000	$0	$0
Total Expenditure	$4,000	$30,800	$30,800
Net Impact, All Funds (Rev.-Exp.)	($4,000)	($30,800)	($30,800)
Net Impact, General/Education Funds	($4,000)	($30,800)	($30,800)

LOCAL GOVERNMENTS (UCA 36-12-13(2)(c))

Enactment of this bill likely will not result in direct, measurable costs for local governments.

DIRECT EXPENDITURES BY UTAH RESIDENTS AND BUSINESSES (UCA 36-12-13(2)(d))

Enactment of this bill likely will not result in direct, measurable expenditures by Utah residents or businesses.

PERFORMANCE NOTE (JR 4-2-404): Not Required

2/8/2013, 08:19 AM, Lead Analyst: Frandsen, R./Attorney: AKJ

State of Utah, Office of the Legislative Fiscal Analyst

+ $40k = $70,800

Until 6/30/2020

Utah CMV Law

26-10-10 UCA, "Cytomegalovirus (CMV) **Public Education** and Testing"

- **Department establish and conduct a public education program** to inform *pregnant women and women who may become pregnant* about CMV (incidence, transmission, birth defects, diagnostic methods, preventative measures)

- Provide information to: *child care providers, school nurses, health educators, health care providers, religious organizations offering children's programs as part of worship services*

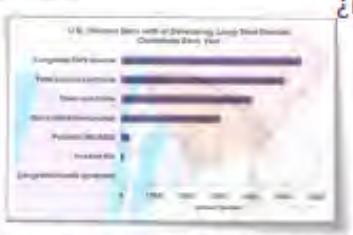
Citomegalovirus - CMV

¿Qué es CMV?

- Citomegalovirus (ci-to-mé-ga-lo-vi-rus), o CMV, es un virus común que infecta a las personas de todas las edades.
- La mayoría de las infecciones por CMV son "silenciosos", es decir, la mayoría de las personas que están infectadas con el CMV no presentan signos ni síntomas. Otros pueden pensar que tienen la gripe.
- Cuando la infección por CMV ocurre durante el embarazo de una mujer, el bebé puede ser infectado antes de nacer. La infección CMV antes del nacimiento se conoce como **"CMV congénito".**
- Alrededor de 1 de cada 5 niños nacidos con infección congénita CMV desarrollará problemas permanentes debido a la infección.

Congénito CMV es la principal causa no genética de la infancia pérdida de la audición.

¿Por qué debería preocuparme por CMV?



La infección congénital CMV causa más problemas prolongados y muertes infantiles, de Síndrome de Down, el Síndrome de Alcoholismo Fetal y Defectos del Tubo Neural.

¿Qué puedo hacer para prevenir CMV?

Si usted está embarazada o planea un embarazo, la mejor manera de proteger a su bebé de CMV congénito es protegerse.

- Lávese las manos frecuentemente con agua y jabón por 15-20 segundos, especialmente después de:
  - cambiar pañales
  - alimentar a un niño pequeño
  - limpiar la nariz de un niño pequeño o baba
  - tocando los juguetes de los niños
- No comparta alimentos, bebidas, utensilios para comer o un cepillo de dientes con un niño.
- No ponga el chupete de un niño en la boca de un adulto.
- No comparta el cepillo de dientes con un niño pequeño.
- Use agua o un desinfectante y jabón para limpiar los juguetes, mostradores y otras superficies que pueden tener la saliva de un niño o la orina en ellos.
- Evite el contacto con la saliva de un niño cuando se besa o acurrucarse.

Problemas de salud permanentes o discapacidades por CMV congénita incluyen:

- Pérdida de audición
- Pérdida de la visión
- Discapacidad del desarrollo
- Cabeza de tamaño pequeño
- Falta de coordinación
- Convulsiones

¿Qué sucede si una mujer **embarazada** contrae la CMV?

- Para las mujeres embarazadas, una de las formas más comunes que están expuestos al CMV es por el contacto con la saliva o la orina de niños que recientemente tuvieron el virus.
- Cuando se infecta con CMV, la mayoría de las mujeres no lo saben, pero algunos pueden tener síntomas similares a la mononucleosis o la gripe.
- Alrededor del 40 de cada 100 mujeres que se infectan con el CMV por primera vez durante un embarazo se transmita infección a su bebé.
- Las mujeres también pueden estar expuestas al virus CMV a través de fluidos corporales durante la actividad sexual.

¿Estoy en **riesgo** de CMV?

- • Las mujeres embarazadas deben evitar que los líquidos corporales entren en sus ojos, nariz o boca. El riesgo de contraer CMV por contacto casual es muy pequeño.
- • La investigación muestra que las mujeres que trabajan estrechamente con niños pequeños en entornos tales como centros de cuidado infantil o aquellas que participan en comportamientos sexuales de alto riesgo tienen un mayor riesgo.
- • Incluso si ha tenido infección por CMV en el pasado, aún corre el riesgo de que el virus se reactive o se infecte con una cepa diferente del virus CMV durante el embarazo.

¿**Dónde** puedo obtener más información?

- **Si usted tiene preocupaciones acerca de la infección por CMV o si está embarazada o planea un embarazo, hable con su médico.**
- healthcurable.gov/CMV o (801) 584-8215
- www.cdc.gov/cmv/
- www.MotherToBaby.org o (800) 822-2229

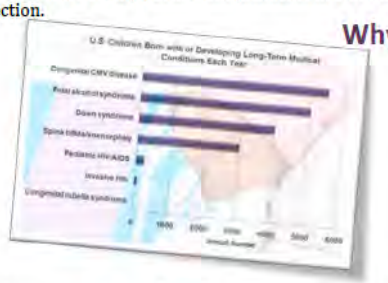
Cytomegalovirus - CMV

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 CM

Congenital CMV infection cause more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrom 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?

- 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.
- 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.
- Women can also be exposed to the CMV virus through body fluids during sexual activity.

Am I at risk for CMV?

- Pregnant women should avoid getting body fluids in their eyes, nose or mouth. The risk of getting CMV through *casual* contact is very small.
- Research shows that women who work closely with young children in settings such as child care facilities or those who participate in high-risk sexual behaviors are at greater risk.
- Even if you have had CMV infection in the past, you are still at risk of the virus re-activating or of being infected with a different strain of CMV virus while pregnant.

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.**
- health.utah.gov/CMV or (801) 584-8215
- www.MotherToBabyUT.org or (800) 822-2229
- www.cdc.gov/cmv/

CMV INFECTION DURING PREGNANCY CAN HARM YOUR BABY

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

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.

Persons who work closely with children in settings such as child care facilities or schools may be at greater risk than those who don't work in such settings.

Wash your hands often with soap and water for 15 to 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.

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.

An infected person can pass the virus to another person even though they do not appear sick

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

Most healthy children and adults infected with CMV don't feel sick 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.

Is there a vaccine for CMV?

At present, there is no vaccine available to prevent CMV. Although it is being researched, it may be years before one is developed.

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: smcvicar@utah.gov

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

Dated 07.01.2013

STATE OF UTAH
DEPARTMENT OF HEALTH

Cytomegalovirus

What childcare providers NEED TO KNOW about CMV

For Women Who Are Pregnant or Planning to Become Pregnant

CMV INFECTION DURING PREGNANCY CAN HARM YOUR BABY

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 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.

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?
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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: smcvicar@utah.gov

health.utah.gov/cmv

Dated 4.24.2014

STATE OF UTAH
DEPARTMENT OF HEALTH

Cytomegalovirus

What women NEED TO KNOW about CMV

For Women Who Are Pregnant or Planning to Become Pregnant

CO

UTAH DEPARTMENT OF HEALTH

Cytomegalovirus (CMV)

What is CMV?

CMV is a common virus that people of all ages can get. People who have it can pass it to others through their body fluids. Most healthy people don't feel sick when they have CMV.

How CMV affects the Circle

When CMV occurs during a woman's pregnancy, the baby can become infected before birth. CMV can cause hearing loss, vision loss, seizures, cerebral palsy and other disabilities in the baby.

Protect the Circle

While Pregnant:

- Try to kiss young children on the forehead rather than the lips.
- Try not to put things in your mouth that have just been in a child's mouth.
- Try not to share food, drinks, utensils or a toothbrush with others
- Wash your hands after wiping a child's nose, mouth, or tears, and changing diapers.
- Use soap and water or a disinfectant to clean surfaces that may have a child's saliva or urine on them.

For more information:
health.utah.gov/CMV

Cytomegalovirus

What women NEED TO KNOW about CMV

For Women Who are Pregnant or Planning to Become Pregnant

Use this milestones chart to help you check your baby's hearing, speech and language development.

By ***2 months*** of age a baby with normal hearing should be able to:

- Quiet when hearing a familiar voice
- Make sounds like ahh and ohh

By ***4 months*** of age a baby with normal hearing should be able to:

- Look for sounds with his eyes
- Make sounds like squeals, whimpers or laughs

By ***6 months*** of age a baby with normal hearing should be able to:

- Turn his head toward a sound
- Make sounds like ba-ba, ma-ma, da-da

By ***9 months*** of age a baby with normal hearing should be able to:

- Imitate speech sounds made by others
- Understand no-no or bye-bye
- Turn his head toward a soft sound

By ***12 months*** of age a baby with normal hearing should be able to:

- Correctly use ma-ma or da-da
- Respond to singing or music

A baby with ***mild or unilateral (in one ear) hearing loss*** may also be able to do these things.

For more information about newborn hearing screening:

www.babyhearing.org

www.hearandnow.org

Special thanks to Arizona EHDI for their help in the development of this brochure

UTAH DEPARTMENT OF HEALTH

Early Hearing Detection & Intervention

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

Phone: 801-584-8215
Fax: 801-584-8492

Newborn Hearing Screening

What you need to know before you have your baby

Many babies with hearing loss will react to loud sounds. The only way to know if your baby's hearing is normal is to have the screening done with special equipment.

Before you leave the hospital, **be sure you know the results of your baby's hearing screening**. If your baby did not pass, he/she should be rescreened **before 14 days of age.**

What can my baby hear during pregnancy?

- By 7 weeks gestation your baby's ear structures are beginning to develop.
- By 25 weeks gestation your baby will begin to hear and respond to sounds.
- Your speech is one of the predominant uterine sounds that your baby hears. He/she is already learning language in the womb!
- Newborns prefer their mother's voice to that of another female.

CMV AND HEARING LOSS

Cytomegalovirus (CMV) is a common virus that infects people of all ages; however, when it occurs during pregnancy, the baby can become infected potentially causing damage to the brain, eyes and/or inner ears.

For more information go to:

www.health.utah.gov/cshcn/chss/cmv.html

Facts about newborn hearing screening

Hearing loss is invisible
Most babies with hearing loss have no signs or symptoms. Infants with hearing loss cry and make other sounds just like babies with normal hearing. The first three years are the most important for learning language and how to communicate.

Hearing loss is a very common birth defect
About 3 in every 1000 babies are born with a permanent hearing loss. Your baby needs normal hearing to develop normal speech and language.

How is a hearing screening done?
Your baby will be screened for hearing loss in the hospital soon after birth. The screening takes 10 - 15 minutes while the baby is quiet or asleep. The screening is done with special equipment that is safe and does not hurt.

If your baby does not pass their screening, the hospital will need to notify your pediatrician.
It is important to have your pediatrician chosen BEFORE you have your baby.

Is my baby at risk for hearing loss?

If your baby has ***one or more*** of the following risk factors or conditions at birth, your baby may be at increased risk for hearing loss:

- Stayed in the NICU for more than 5 days
- Had an infection before or after birth such as Cytomegalovirus (CMV), herpes, rubella or meningitis
- Has a family member with hearing loss from birth or childhood

Babies at risk can pass a hearing screening at birth but will need more testing later. Talk with your baby's doctor and make an appointment with a pediatric audiologist for further testing.

90—95% of children born with permanent hearing loss have normal hearing parents

If you are ever concerned about your baby's hearing ability or language development, have them seen by a **pediatric audiologist**.

To find a clinic near you, visit:

To monitor your baby's hearing and speech development:

Utah Department of Health & Human Services

Important timelines

All newborns should receive a hearing screening before they leave the hospital or before 5 days of age if born elsewhere

For infants who fail the hearing screening, the test should be repeated **before 10 days of age**

For infants who fail the rescreening:*

- Test for Congenital Cytomegalovirus (CMV) infection **before 21 days of age**
- Complete a diagnostic hearing evaluation **before 3 months of age**

For infants who are diagnosed with hearing loss, enroll in Early Intervention services before **6 months of age**

** If an infant has their FIRST hearing screening after 14 days of age and FAILS, they need to be tested for congenital CMV before 21 days of age*

Utah Early Hearing Detection & Intervention (EHDI)

EHDI@utah.gov

801-273-6600

health.utah.gov/ehdi

What you need to know before you have your baby

Newborn Hearing Screening

Hearing screening is simple and painless

Otoacoustic Emissions (OAEs) use an earphone to play sound into the ear canal and record an echo response from the hearing organ, called the cochlea.

OAEs

Hearing loss is invisible

AABR

The **Automated Auditory Brainstem Response (AABR)** plays sound into the ear and uses electrodes placed on the baby's head to detect a response from the hearing nerve and brain.

What can my baby hear during pregnancy?

By **7 weeks** gestation your baby's ear structures are beginning to develop

By **25 weeks** gestation your baby will begin to hear and respond to sounds

Your speech is one of the predominant uterine sounds that your baby hears. They are already learning language in the womb!

CMV and hearing loss

Cytomegalovirus or CMV is a common virus that infects people of all ages; however, when it occurs during pregnancy, the baby can become infected potentially causing damage to their brain, vision, and/or hearing.
CMV is transmitted through direct contact with body fluids, such as saliva or urine.
If you're pregnant or planning a pregnancy, the best way to protect your baby from CMV is to protect yourself.

For more information about CMV:
health.utah.gov/cmv
nationalcmv.org

Is my baby at risk for hearing loss?

The following are risk factors that may increase the risk for hearing loss:

- Stays in the hospital longer than 5 days
- Mom had an infection such as herpes, CMV, toxoplasmosis, or rubella during pregnancy
- A family member was diagnosed with hearing loss as an infant or young child

Babies at risk can pass a hearing screening at birth but need more testing later. Newborn hearing screening can also miss a mild hearing loss.

UTAH DEPARTMENT OF HEALTH

CMV CORE FACTS

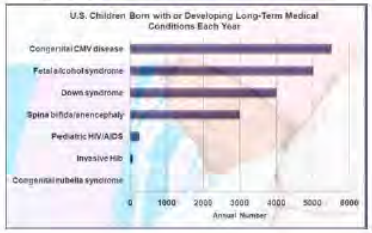
What is CMV?

- 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/cmv/trends-stats.html)



FOR OBSTETRICAL HEALTH CARE PROVIDERS

What should I tell my patients about CMV?

- About 40% of women (40 of every 100) who become infected with CMV for the first time during a pregnancy will pass the infection to their fetus.
- About 1 in 150 children is born with congenital CMV infection. In Utah, this equates to one child per day.
- Congenital CMV infection is a known, but very rare, cause of pregnancy loss.
- About 1 of every 5 children born with congenital CMV infection (1 in 750 children overall) will develop permanent problems (such as hearing loss or developmental disabilities) due to the infection.
- Congenital CMV infections can only be prevented by preventing CMV infection in pregnant women. There is no available vaccine for preventing CMV. However, pregnant women can take steps that may reduce their exposure to CMV.

Talking Points:

- 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.

- The Utah Department of Health CMV Core Facts could be provided to patients as a source of basic information about CMV infection and prevention. There is also a brochure entitled, "CMV What Women NEED TO KNOW", that can be given to your patients.

FOR PEDIATRIC CARE PROVIDERS

The Role of the Primary Care Clinician in Reducing Disability Related to Cytomegalovirus-Associated Hearing Loss

House Bill 81, passed by the Utah legislature in 2013, was created to raise public awareness and provide education re: the prevention of congenital CMV infection to reduce the disability associated with hearing loss due to congenital cytomegalovirus (CMV) infection. This bill requires (1) that infants who fail the first newborn hearing screen undergo follow-up hearing screening before 2 weeks of age, and (2) that infants who do not pass follow-up screening be tested for congenital CMV before 21 days of age.

Why was HB 81 enacted?

- The national Joint Committee on Infant Hearing (JCIH) recommends that all infants failing the initial newborn hearing screen undergo a secondary screen by 1 month of age. Earlier screening (by 2 weeks of age as stated in HB 81) allows more timely determination of the cause and nature of hearing loss as well as education on research/possible intervention strategies if congenital CMV is involved.
- **Congenital 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.**
- Infants with asymptomatic CMV outnumber those that show symptoms three to one. In a large number of children with asymptomatic congenital CMV, hearing loss is the only sequela.
- Research has shown that approximately 50% of hearing loss from congenital CMV infection is either late-onset or progressive in nature.

What is the benefit of testing infants with hearing loss for CMV?

CMV-associated congenital hearing loss may be progressive in nature. Infants with known CMV-related hearing loss should undergo frequent audiologic follow up with an audiologist possessing expertise in the assessment and treatment of infant and pediatric hearing loss to monitor for worsening hearing loss. The timing and frequency of these visits should be individualized for each child based on the audiologist's recommendations. Although there is not a universal consensus, it would not be uncommon for audiologic evaluations to occur every 3 months during the first 3 years of life, and then every 6 months through age 6 years.

When and how should infants who have failed the second hearing screen be tested for CMV?

In compliance with Utah's HB 81, in order to identify infants at risk for congenital CMV-associated progressive hearing loss, infants who fail the second hearing screening, unilaterally or bilaterally, should be tested for CMV no later than 3 weeks of age. This can be performed with a PCR assay for CMV on urine or saliva. After 3 weeks of age, these tests cannot differentiate between congenital CMV and CMV acquired postnatally. Postnatal CMV rarely causes symptoms and is not associated with hearing loss.

If the clinic or hospital is a client of ARUP, they can order the OraCollect OC-100 swabs from ARUP client supplies (item #49295). If they are not ARUP clients, they should contact their reference lab for kit

Early Hearing Detection & Intervention (EHDI)
Cytomegalovirus (CMV) Public Health Initiative

UTAH DEPARTMENT OF HEALTH

Phone: 801-273-6600
Fax: 801-536-0492
cmv@utah.gov

CMV/EHDI MATERIALS ORDER FORM

Ship To:

Fax To: (801) 536-0492

QTY	Item	Description	Spanish

Utah orders are provided free of charge.

Toothbrush:

ITEM # TB*Spanish Only*

Travel Toothbrush:

ITEM # TT*

Posters:

ITEM # HP (43" x 10")

Flyer: (Two Sided)

ITEM # CMVF*

Newborn Hearing Screening Brochure: 100/pk

ITEM # NBHS*

American Indian Items:

ITEM # AIP (16"x20")

Brochures: 100/pk

ITEM # VP (16" x 28.25")

ITEM # HP* (8.5" x 11")

ITEM # CMVHL*

ITEM # CCP*

ITEM # WWNTK*

Hand Sanitizer:

ITEM # HS*

ITEM # AINBHS

ITEM # AICMV

Lip Balm:

ITEM # LB*

*Item also available in Spanish

Revised 3.3.2020

Cytomegalovirus (CMV) PCR Testing

CMV PCR testing for Utah Public Health Initiative (H.B.81 – UCA 26-10-10)

- Many laboratories currently offer PCR-based CMV testing. Testing can be performed on saliva or urine. As of July 1st, 2013, ARUP Laboratories is the only local facility that has a validated test for saliva.
- Each primary care provider should submit specimens through their normal laboratory testing mechanism. If the laboratory service does not normally use ARUP as the referring laboratory and this test is desired, please specify the testing location as ARUP, and include test name and test code listed below. All laboratories have the ability to forward specimens to ARUP through their channels.
- Pricing will vary depending on the laboratory and the specific hospital contract. Primary care providers will need to consult their affiliated hospitals or reference laboratories to obtain pricing information.
- The CPT code for CMV detection (qualitative) by PCR is 87496, and is covered by Medicaid.

Information on ARUP's CMV PCR tests

Specimen type	Saliva
ARUP Test Name	Cytomegalovirus by Qualitative PCR, Saliva
Short Name	CMVPCR SAL
ARUP Test Code	2008555
Specimen Collection	Collect and submit saliva in ORACollect OC-100 kit (ARUP supply #49295)
Stability of Specimen	Ambient: 7 days; Refrigerated: 7 days; Frozen: 3 months
Reported	1-3 days
NOTE:	If a saliva specimen is received in a collection device different from the specified device (#49295), specimen will still be tested but patient report will include a non-validated specimen disclaimer.

Specimen type	Urine
ARUP Test Name	Cytomegalovirus by PCR
Short Name	CMV PCR
ARUP Test Code	0060040
Specimen Collection	Collect and submit 1 mL urine. Sterile urine container, no preservative.
Stability of Specimen	Ambient: 8 hrs; Refrigerated: 72 hrs; Frozen 3 months
Reported	1-3 days

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 qué 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 Declination Form

Health.utah.gov/CMV

Utah CMV PSA


It's time to talk about Cytomegalovirus (CMV).
Every day in Utah a child is born with CMV, putting them at risk for hearing loss and lifelong disabilities
UTAH DEPARTMENT OF HEALTH
Utah Early Hearing Detection and Intervention
Know the facts. Protect your unborn baby.
#UTProtectYourBaby
Utah CMV Public Health Initiative
health.utah.gov/CMV


1 out of 150 children are born with **Congenital Cytomegalovirus (CMV)** each day.
1 of every 5 children born with CMV will develop **permanent disabilities**.
And while it's the most common viral cause of developmental disabilities in children,
MOST WOMEN ARE UNAWARE.
LEARN MORE AT:
HEALTH.UTAH.GOV/CMV
Know the facts. Protect your baby.
UTAH DEPARTMENT OF HEALTH

Know the facts. Protect your baby.

1 out of 5 children born with **Cytomegalovirus (CMV)** will have permanent disabilities.

HEALTH.UTAH.GOV/CMV

UTAH DEPARTMENT OF HEALTH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health.utah.gov/cmv
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1 out of 5 children born with Cytomegalovirus (CMV) will have permanent disabilities.

Know the facts. Protect your baby.

Learn more at: health.utah.gov/cmv or facebook.com/cmvutah

CONTINUED

MIDWESTERN UNIVERSITY

Phoenix Children's

1 out of 5 children born with Cytomegalovirus (CMV) will have permanent disabilities.
Know the facts. Protect your baby.

1 de cada 5 niños que nacen con **Citomegalovirus (CMV)** tendrá discapacidades permanentes.
Conocer los hechos. Proteger a su bebé.

Learn more at:
health.utah.gov/cmv

UTAH DEPARTMENT OF HEALTH

- child care programs administered at public schools by organizations other than the public schools if the care is provided under contract with the public schools or on school properties or if the public schools accept responsibility and oversight for the care provided by the organizations;
- child care programs provided by organizations that qualify for tax exempt status under Section 501(c)(3) of the Internal Revenue Code or that are provided pursuant to a written agreement with a municipality or county;
- child care programs provided at residential support programs that are licensed by the Department of Human Services;
- school nurses;
- health educators;
- health care providers offering care to pregnant women and infants; and
- religious, ecclesiastical, or denominational organizations offering children's programs as a component of worship services;

- 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;
- directs the Department of Health to notify medical practitioners of the CMV testing requirements; and
- grants rulemaking authority to the Department of Health.

Money Appropriated in this Bill:

None

Other Special Clauses:

None

Utah Code Sections Affected:

ENACTS:

26-10-10, Utah Code Annotated 1953

Utah CMV Law

26-10-10 UCA, "Cytomegalovirus (CMV) Public Education and **Testing**"

If a newborn infant fails the newborn hearing screening test(s)...

- **Medical Practitioner** shall: ***Test the newborn infant for CMV before 21 days of age***… unless the parent objects;

- And *provide to the parents information* re: birth defects caused by congenital CMV and *available methods of treatment*

Utah CMV Law

26-10-10 UCA, “Cytomegalovirus (CMV) Public Education and **Testing**”

(continued)

Department shall:

- ***Provide information to the family and the medical practitioner (if known)*** information re: the *testing requirements* when providing results indicating that an infant has failed the newborn hearing screening test(s).

Summer 2013

THE GROWING TIMES

Utah Chapter of the American Academy of Pediatrics

Message From the Past President

The Utah Chapter has teamed up with a new organization, Utah Parents Against Gun Violence, to create a child safety campaign, **BULLETPROOF KIDS.** The campaign emphasizes, *"Owning a gun is a right. Protecting children is a responsibility. Prevent youth suicide and accidental injury. Store your guns safely."*

The goal of the campaign is to educate the public on how to store guns safely with trigger locks, safes, and ammunition separated from unloaded guns. We will do this in an apolitical and non-confrontational manner to reach a broad audience.

We hope to accomplish our goal through partnerships with many local organizations. The University of Utah Student sponsored Public Relations organization, *Absolute Communications,* is developing a website and logo free-of-charge. Through these partnerships we will be able to educate the community, parents, health care professionals, legislators, gun organizations, gun sellers, shooting ranges and legislators about the importance of safe gun storage.

INSIDE THIS ISSUE

State of Utah

GARY R. HERBERT
Governor

GREG BELL
Lieutenant Governor

Utah Department of Health

Joseph Miner, MD
Executive Director

Division of Family Health and Preparedness

Marc E. Babitz, MD
Division Director

Children with Special Health Care Needs Bureau

Noel Taxin, MS
Bureau Director

Early Hearing Detection and Intervention (EHDI) / CMV Public Health Initiative

Stephanie Browning McVicar, Au.D., CCC-A, *Director*

You are receiving this information because one of the children in your care has met CMV testing criteria.

PLEASE add "CC: UDOH CMV (Fax# 801-584-8492)" to your LAB REQUEST

UCA 26-10-10 Cytomegalovirus (CMV) Public Education and Testing Law

(3) If a newborn infant fails the newborn hearing screening test(s) under Subsection 26-10-6(1) (Utah Newborn Hearing Screening Law), **a medical practitioner shall:**

(a) test the newborn infant for CMV before the newborn is 21 days of age, unless a parent of the newborn infant objects; **and**

(b) provide to the parents of the newborn infant information regarding:

(i) birth defects caused by congenital CMV; and

(ii) available methods of treatment.

R398-4-5. Reporting requirements

Medical practitioners are required to submit results of the CMV testing to UDOH for each newborn under their care who is referred for CMV testing **within 10 days** of receiving results. **(Fax: 801-584-8492)**

Important CMV PCR Testing Information

- Many laboratories currently offer PCR-based CMV testing. Testing should be performed only on **SALIVA** (via OraCollect 100 swab) or **URINE**. At present, ARUP Laboratories is the only local facility that has a validated test for saliva. **Saliva samples should be collected at least 90 -120 minutes after breastfeeding** to prevent false positives, as CMV can be present in breast milk.
- Each primary care provider should submit specimens through their normal laboratory testing mechanism. If the laboratory service does not normally use ARUP as the referring laboratory and the saliva test is desired, please specify the testing location as ARUP, and include test name and test code listed below. All laboratories have the ability to forward specimens to ARUP through their channels.
- Many Utah laboratories have validated **qualitative** CMV PCR assay testing on **urine**, including: **LabCorp, Quest, PAML, IHC, and ARUP. Viracor-IBT Laboratories** has quantitative only.
- Pricing will vary depending on the laboratory and the specific hospital contract. Primary care providers will need to consult their affiliated hospitals or reference laboratories to obtain pricing information.
- The CPT code for CMV detection (qualitative) by PCR is **87496**, and is covered by Medicaid and other insurances.
- An appropriate ICD-10 code would be **H91.90** (neonatal hearing loss).

For additional help: Utah EHDI (801) 584-8215 or health.utah.gov/CMV or smcvicar@utah.gov

Revised 11.30.2015

UTAH DEPARTMENT OF HEALTH

What You Need to Know: HB81 Cytomegalovirus Public Health Initiative

Catherine Johna, MD, FAAP
Utah Early Hearing Detection & Intervention (EHDI) Chapter Champion
Email: katiejohna@gmail.com

House Bill 81, passed by the Utah legislature in 2013, was created to raise public awareness and provide education about congenital cytomegalovirus (CMV) infection and to reduce the disability associated with hearing loss due to congenital CMV infection. This bill contains three key elements: (1) it directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about CMV and its transmission, fetal effects of CMV, methods of CMV diagnosis and prevention; (2) it requires the Department of Health to provide this information to licensed childcare programs, school nurses, health educators, and other organizations offering children's programs as a component of worship services; and (3) **it directs medical practitioners to test infants who fail two newborn hearing screening tests for CMV before three weeks of age and inform the parents of those infants about the possible complications that CMV can cause and the available treatment methods.**

This bill was enacted to educate the public about congenital CMV, its prevention and possible complications, particularly with respect to progressive sensorineural hearing loss (SNHL). CMV is the most common cause of nonhereditary SNHL and is thought to account for 20% of all childhood hearing loss in Utah. Most infants with congenital CMV infection are asymptomatic, but one-fifth of these infants (who may or may not have symptoms at the time of birth) may develop permanent disability such as hearing loss or developmental delay. **Approximately 50% of hearing loss from congenital CMV infection is progressive in nature.** Infants with known CMV-related hearing loss should undergo frequent audiologic follow up with an audiologist and a physician with expertise in the assessment and treatment of pediatric hearing loss due to congenital CMV. The timing and frequency of these visits should be individualized for each child.

In compliance with Utah's HB 81, in order to identify infants at risk for congenital CMV-associated hearing loss, infants who fail the second hearing screening should be tested for CMV by no later than 3 weeks of age. This can be performed with a PCR assay for CMV on urine or saliva. After 3 weeks of age, these tests cannot differentiate between congenital CMV and CMV acquired postnatally. Postnatal CMV rarely causes symptoms and is not associated with hearing loss. If the clinic or hospital is a client of ARUP, they can order the OraCollect OC-100 swabs from ARUP client supplies (item #49295). If they are not ARUP clients, they should contact their reference lab for kit supplies or contact the kit vendor directly (DNA Genotek). If kits for PCR on saliva are not available, a PCR for CMV can be sent on a urine sample.

Infants who have a positive CMV PCR assay should undergo a complete diagnostic audiologic evaluation as soon as possible. Frequent audiologic assessment is needed to promptly identify and treat progressive hearing loss. The frequency of this testing should be determined by the child's audiologist.

Children with symptomatic congenital CMV are at risk for ophthalmologic problems. These children need ophthalmologic evaluations early and often due to risk of retinitis. Those without symptoms, however, are at very low risk. Asymptomatic infants should have at least one thorough eye exam by a pediatric ophthalmologist after a diagnosis of congenital CMV has been made.

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. Currently, there are two treatment studies for congenital CMV in Utah. For information regarding clinical trials using valganciclovir and participation in these trials, contact:

- The Department of Pediatric Otolaryngology at Primary Children's Medical Center at (801) 662-1740 or
- The Division of Pediatric Infectious Disease at the University of Utah at (801)581-6791 (NIH sponsored clinical trial pending approval):
  A phase II, randomized, placebo-controlled, blinded investigation of six weeks of oral valganciclovir therapy versus placebo in infants with congenital cytomegalovirus infection and hearing loss

Objectives

1. To define the response of CMV viral load in urine as a measure of the efficacy of ganciclovir
2. To estimate the response of CMV viral load in blood as a measure of the efficacy of ganciclovir.
3. To estimate if a six week course of oral valganciclovir syrup can stabilize the hearing of children with congenital CMV infection who present with hearing loss.
4. To estimate the safety and tolerability of valganciclovir syrup in children of this age.
5. To estimate the pharmacokinetics of ganciclovir when valganciclovir is administered to children of this age.

Inclusion

1. Sensorineural hearing loss (unilateral or bilateral).
2. CMV detected within 30 days of birth (urine tested as neonate, or Guthrie card-positive).
3. CMV detected in urine by PCR or culture within 2 weeks prior to study entry.
4. Children between 1 month and 18 months of age.

State newborn hearing screening protocols have been amended to mandate notification of primary care providers after the first failed (inpatient) newborn hearing screening. Physicians who receive this notice should follow up with the family to ensure the timely completion of the second (outpatient) newborn hearing screening. The primary care provider will then be notified if an infant fails the second newborn hearing screening. As HB 81 directs care providers to perform CMV testing by 3 weeks of age, it is important that this notification be forwarded to the covering physician if the primary care physician is not available. To facilitate communication between facilities conducting hearing screening and primary care providers, it has been recommended that discharging hospitals/physicians provide families with a business card of the chosen primary care physician to bring to the follow up hearing screening appointment.

To read House Bill 81 in its entirety, click on http://le.utah.gov/~2013/bills/hbillenr/hb0081.pdf. For more information contact Utah Early Hearing Detection and Intervention at (801) 584-8215 or **Stephanie McVicar, Au.D., CCC-A,** at smcvicar@utah.gov. ✦

Collection and Testing For CONGENITAL Cytomegalovirus (CMV) for Medical Providers

CMV

1. Receive a referral from a Newborn Hearing Screening Program reporting an infant has *failed* hearing screening(s) and that *CMV testing is needed*

   Fax Referrals for CMV testing look like this:

   - If you receive a fax for an infant that is *not* your patient, please **call UDOH at (801) 584-8215.**

   UTAH DEPARTMENT OF HEALTH

2. Collect a sample **BEFORE** the infant is **21 days** old.

Urine		Saliva*		Blood
	**OR**		**NOT**	
Acceptable		**Acceptable**		**UNacceptable**

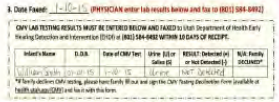
2 hours or more *after* feeding

*Must use ORAcollect-100 kit available from ARUP supply #49295

3. Send the sample to the lab for **CMV PCR testing** with **"CC: Utah Dept. of Health CMV".**

4. Order CPT code **87496** (Viracor-IBT is 87497) with ICD-9 code 389.8 (neonatal hearing loss).

5. When lab results are received, complete Section 3 of Hearing Screening Form and **fax results to UDOH at (801) 584-8492.**



Find Out More

Health.utah.gov/CMV

STATE OF UTAH DEPARTMENT OF HEALTH

Cytomegalovirus

Congenital CMV and Hearing Loss

What Parents Need to Know

STATE OF UTAH DEPARTMENT OF HEALTH

Citomegalovirus

CMV Congénito y la Pérdida de Audición

Lo que los Padres Necesitan Saber

Utah CMV Rule

R398-4-3. Clarification of when a newborn fails a hearing screen.

- The newborn **must fail both hearing screens**, the initial hearing screen routinely done at birth **and** the subsequent follow up screen, **OR**

- **if/when the initial failed hearing screen is obtained after 14 days of age** the medical practitioner is required to test for CMV.

Utah Newborn Hearing Screening

INPATIENT

OUTPATIENT

Hospital
10 - 12 hrs.

Before Discharge
24 hrs.

7 - 10
Days

Utah Newborn Hearing Screening

OUTPATIENT SCREENING

<10 days of age

PASS

FAIL

LAB

< 21 days of age

CMV PCR Testing

*

*>2 hours *after* feeding

MEDICAL HOME

Monitor Development:
- Hearing
- Speech/Language

PEDIATRIC AUDIOLOGIST

<3 months of age

Auditory Brainstem Response (ABR) Testing

Utah CMV Rule

R398-4-4. Special populations of newborns.

- In special populations of newborns where newborn hearing screening(s) cannot be accomplished prior to 21 days of age, **testing for CMV is left to the discretion of the medical practitioner(s) caring for the newborn**
- Special populations of newborns may include, but are not limited to, premature or medically fragile newborns or newborns receiving ongoing medical care.

Utah CMV Rule

R398-4-5. Reporting Requirements

- Medical practitioners are required to **submit** results of the CMV testing **to Department** for each newborn under their care who is referred for CMV testing **within 10 days of receiving results.**

UTAH DEPARTMENT OF HEALTH
Early Hearing Detection & Intervention

H.B. 81 (2013 General Session) Cytomegalovirus Public Health Initiative (UCA 26-10-10) Sequence of Events

INFANT FAILS **INPATIENT** NEWBORN HEARING SCREENING (NBHS)

Hospital NBHS Program notifies family their infant failed hearing screen and **schedules outpatient re-screen to take place prior to 14 days of age** emphasizing importance of completing this appointment at the scheduled time.

Hospital NBHS Program obtains complete primary care provider (PCP) information from family and enters it in infant's Hi*Track record. If complete information is not in the physician database "drop down" menu , it can be added/updated by contacting Utah Early Hearing Detection & Intervention (EHDI) Hi*Track Data Coordinator at (801) 584-8221.

Hospital NBHS Program advises PCP of **initial screen failure** using the "Newborn Hearing Screening / CMV Status Report FAX" form or other mutually agreed upon method of notification . The method of notification must be documented in Hospital Program Summary.

INFANT FAILS 2ND (**OUTPATIENT**) HEARING SCREENING

Hospital NBHS Program immediately notifies PCP of the **follow-up hearing screening failure**: 1) via fax using the "Newborn Hearing Screening / CMV Status Report FAX" form, 2)phone message, (action must be documented in HiTrack), or 3)other preferred method of communication (action must be documented in HiTrack). The method of notification must be documented in Hospital Program Summary. Family is told to contact PCP if does not hear from MD within 24 hours.

PCP discusses congenital CMV with family and orders CMV PCR assay testing via saliva or urine on infant unless parents object.

TESTING OCCURS PRIOR TO 21 DAYS OF AGE

After test results are received, PCP faxes "Newborn Hearing Screening / CMV Status Report FAX" Form to Hospital NBHS Program and to UDOH at (801) 584-8492. PCP consults with family on next steps.

If questions, please contact the Utah Department of Health (UDOH) EHDI program at (801) 584-8215. Created 6/25/13.

UTAH DEPARTMENT OF HEALTH
Early Hearing Detection & Intervention

Utah Newborn Hearing Screening & CMV Testing Protocol

INFANT FAILS **INPATIENT** NEWBORN HEARING SCREENING (NBHS)

Hospital NBHS Program notifies family their infant failed hearing screen and **schedules outpatient rescreen to take place prior to 14 days of age** emphasizing importance of completing this appointment at the scheduled time

Hospital NBHS Program obtains complete primary care provider (PCP) information from family and enters it in infant's Hi*Track record. If complete information is not in the physician database "drop down" menu , it can be added/updated by contacting Utah Early Hearing Detection & Intervention (EHDI) Hi*Track Data Coordinator at (801) 584-8216

Hospital NBHS Program advises PCP of **initial screen failure** using the "*Notification of Failed 1st Newborn Hearing Screening*" form or other mutually agreed upon method of notification. The method of notification must be documented in HiTrack (*Recommended Action: Notify PCP of Failed Screening*) & Hospital Program Summary

INFANT FAILS 2ND (**OUTPATIENT**) HEARING SCREENING

Hospital NBHS Program immediately notifies PCP of the **follow-up hearing screening failure:** 1) via fax using the "*Cytomegalovirus & Auditory Brainstem Response Testing Orders*" form or *Notification of Failed Second Newborn Hearing Screening* form, 2) phone call, or 3) other preferred method of communication. The method of notification must be documented in HiTrack *(Recommended Action: Referral for CMV PCR)*

Hospital NBHS Program will give "*Cytomegalovirus & Auditory Brainstem Response Testing Orders*" form to the family to take to the lab for CMV testing. **iCentra users to follow Intermountain Healthcare's electronic ordering protocol

TESTING OCCURS PRIOR TO 21 DAYS OF AGE

Schedule diagnostic ABR prior to family leaving

Lab will send results to EHDI & PCP. For positive CMV results, EHDI Medical Director will consult with PCP. PCP to inform parents of CMV results

If questions, please contact the Utah Department of Health (UDOH) EHDI program at (801) 584-8215. Updated 9/6/17.

CONTINUED

MIDWESTERN UNIVERSITY

Phoenix Children's

State of Utah

GARY R. HERBERT
Governor

GREG BELL
Lieutenant Governor

Utah Department of Health
W. David Patton, Ph.D
Executive Director

Division of Family Health and Preparedness
Marc E. Babitz, MD
Division Director

Children with Special Health Care Needs Bureau
Noël Taxin, MS
Bureau Director

Early Hearing Detection and Intervention (EHDI) / CMV Public Health Initiative
Stephanie Browning McVicar, Au.D., CCC-A, *Director*

You are receiving this information because one of the children in your care has met CMV testing criteria.
PLEASE add "CC: UDOH CMV(Fax# 801-584-8492)" to your LAB REQUEST

UCA 26-10-10 Cytomegalovirus (CMV) Public Education and Testing Law

(3) If a newborn infant fails the newborn hearing screening test(s) under Subsection 26-10-6(1) (Utah Newborn Hearing Screening Law), **a medical practitioner shall:**

(a) test the newborn infant for CMV before the newborn is 21 days of age, unless a parent of the newborn infant objects; **and**

(b) provide to the parents of the newborn infant information regarding:
(i) birth defects caused by congenital CMV; and
(ii) available methods of treatment.

R398-4-5. Reporting requirements

Medical practitioners are required to submit results of the CMV testing to UDOH for each newborn under their care who is referred for CMV testing **within 10 days** of receiving results. **(Fax: 801-584-8492)**

Important CMV PCR Testing Information

- Many laboratories currently offer PCR-based CMV testing. Testing should be performed only on **SALIVA** (via OraCollect 100 swab) or **URINE**. At present, ARUP Laboratories is the only local facility that has a validated test for saliva. **Saliva samples should be collected at least 90 -120 minutes after breastfeeding** to prevent false positives, as CMV can be present in breast milk.
- Each primary care provider should submit specimens through their normal laboratory testing mechanism. If the laboratory service does not normally use ARUP as the referring laboratory and the saliva test is desired, please specify the testing location as ARUP, and include test name and test code listed below. All laboratories have the ability to forward specimens to ARUP through their channels.
- Many Utah laboratories have validated **qualitative** CMV PCR assay testing on **urine**, including: **LabCorp, Quest, PAML, IHC, and ARUP. Viracor-IBT Laboratories** has quantitative only.
- Pricing will vary depending on the laboratory and the specific hospital contract. Primary care providers will need to consult their affiliated hospitals or reference laboratories to obtain pricing information.
- The CPT code for CMV detection (qualitative) by PCR is **87496**, and is covered by Medicaid and other insurances.
- An appropriate ICD-9 code would be **389.8** (neonatal hearing loss).

For additional help: **Utah EHDI (801) 584-8215** or **health.utah.gov/CMV** or **smcvicar@utah.gov**

UTAH DEPARTMENT OF HEALTH

UTAH DEPARTMENT OF HEALTH

Newborn Hearing Screening (NBHS) / CMV Testing FAX Report Form

Version 5:
May 2014

TO: _____ Clinic _____ Fax _____

FROM: _____ Facility _____ Phone _____

Date Faxed: _____ **OPTION 1 (NBHS Program):**

PER H.B. 81 (2013 General Session | UCA 26-10-10 Cytomegalovirus (CMV) Public Health* initiative, the following infant, who has you as their Primary Care Physician, has **FAILED** the **INITIAL** newborn hearing screen and will require a follow-up re-screen. This follow-up appointment is scheduled as noted. Should you have contact with the family prior to the follow-up date please encourage them to keep the appointment as this should be completed *no later than 14 days of age*. Otherwise, no action on your part is necessary at this time.

INFANT FAILING *INITIAL* HEARING SCREEN – *to be completed by SCREENER*				
Infant's Name	D.O.B.	Mother's Name	Contact#	Follow-up Appt.

Date Faxed: _____ **OPTION 2 (NBHS Program):**

This is to advise you that the following infant has **FAILED** the **FOLLOW-UP** (2nd) **HEARING SCREENING** and is eligible for congenital CMV testing before 21 days of age per UCA 26-10-10. Please see additional CMV TEST INFORMATION page. He/She has also been referred to a pediatric audiologist for a diagnostic hearing evaluation.

INFANT FAILING *FOLLOW-UP* HEARING SCREEN – *to be completed by SCREENER*				
Infant's Name	D.O.B.	Mother's Name	Contact#	Diagnostic Appt.

This is to advise you that the following infant has **PASSED** the **FOLLOW-UP** (2nd) **HEARING SCREENING.** *No further action is necessary.*

INFANT PASSING *FOLLOW-UP* HEARING SCREEN—*no action needed*				
Infant's Name	D.O.B.	Mother's Name	Contact#	Date Passed

Date Faxed: _____ **OPTION 3 (To be completed by PHYSICIAN):**

After congenital CMV PCR assay testing has been completed, please fax this form back to the Hospital NBHS program at the above listed fax # AND to the Utah Department of Health Early Hearing Detection and Intervention (EHDI) program at (801) 584-8492. Utah rule R398-4-5 requires CMV lab results to be sent to UDOH within 10 days of receipt.

Infant's Name	D.O.B.	Date of CMV Test	Urine (U) or Saliva (S)	RESULT: Detected (+) or Not Detected (-)	N/A: Family DECLINED*

*If family declines CMV testing, please have family fill out and sign the *CMV Testing Refusal Form* (available at health.utah.gov/CMV) and fax with this form.

CONTINUED

Midwestern University

Phoenix Children's

LAB Collection and Testing For CONGENITAL Cytomegalovirus

CMV

1. Receive an order requesting CMV lab testing on an infant.

2. Collect a sample **BEFORE the infant is 21 days old.**

Urine		Saliva*		Blood
	**OR**		**NOT**	
Acceptable		Acceptable		UNacceptable

2 hours or more *after* feeding

***Must use ORAcollect-100 kit available from ARUP supply #49295**

3. **CMV Detection by PCR** should be conducted.

CPT code **87496 (qualitative - preferred)** or CPT code 84797 (quantitative) with ICD-9 code 389.8 (neonatal hearing loss)

4. **Send results** to the requesting physician **and to:**

Utah Dept. of Health CMV Fax: 801-584-8492

UTAH DEPARTMENT OF HEALTH

If you have any questions, please call the Utah Dept. of Health at (801) 584-8215

Find Out More
Health.utah.gov/CMV

UTAH DEPARTMENT OF HEALTH

REQUIRED CMV LAB TESTING REPORT

For infants failing newborn hearing screening

Version 4: Dec 2014

TO: _____, Clinic _____, Fax _____

FROM: _____, Facility _____, Fax_____

1. Date Faxed: _____ (completed by NBHS screener, faxed to PCP *AND* documented in Hi*Track):

The following infant, who lists you as their Primary Care Physician, has **FAILED** the **INITIAL** newborn hearing screen and will **REQUIRE** a follow-up hearing screen ***no later than 14 days of age.*** Please encourage the family to keep the following re-screening appointment.

FAILING INITIAL hearing screening				
Infant's Name	**D.O.B.**	**Mother's Name**	**Contact#**	**Follow-up Appt.**

2. Date Faxed: _____ (completed by NBHS screener, faxed to PCP *AND* UDOH, documented in Hi*Track)

The following infant has **FAILED** the **FOLLOW-UP (2nd)** hearing screen. **CONGENITAL CMV testing is required BEFORE THE INFANT IS 21 days of age** per Utah Cytomegalovirus **(CMV) Testing Mandate.**

FAILING follow-up hearing screening

CMV LAB TESTING NEEDS TO BE ORDERED BY PHYSICIAN (Saliva/Urine)

Infant's Name	**D.O.B.**	**Mother's Name**	**Contact#**	**Diagnostic Appt.**

The following infant has *PASSED* the **FOLLOW-UP (2nd)** hearing screening. *No further action is necessary.*

Infant's Name	**D.O.B.**	**Mother's Name**	**Contact#**	**Date Passed**

3. Date Faxed: _____ **(PHYSICIAN enter lab results below and fax to (801) 584-8492)**

CMV LAB TESTING RESULTS MUST BE ENTERED BELOW AND FAXED to Utah Department of Health Early Hearing Detection and Intervention (EHDI) at **(801) 584-8492 WITHIN 10 DAYS OF RECEIPT.**

Infant's Name	**D.O.B.**	**Date of CMV Test**	**Urine (U) or Saliva (S)**	**RESULT: Detected (+) or Not Detected (-)**	**N/A: Family DECLINED***

*If family declines CMV testing, please have family fill out and sign the *CMV Testing Declination Form* (available at health.utah.gov/CMV) and fax it with this form.

Improving Lab Testing Receipt and Amending Rules

- Communicable Disease Reporting
- EHDI and CMV Rule Updates
- cCMV Registry

R386. Health, Disease Control and Prevention, Epidemiology.

R386-702. Communicable Disease Rule.

R398-4-5. Reporting Requirements.

(1) Medical practitioners are required to submit results of the CMV testing to the Department for each newborn under their care who is referred for CMV testing within ten days of receiving results.

(2) Laboratories testing for the presence of congenital CMV must submit results of the CMV testing to the Department within ten days of receiving results.

(7) Laboratory results reportable by electronic reporters are as follows:

(a) In addition to laboratory results set forth in Subsections R386-702-3(2) through R386-702-3(6), entities reporting electronically shall include the following laboratory results or laboratory results that provide presumptive evidence of the following communicable diseases:

(i) influenza virus;

(ii) norovirus infection;

(iii) Pseudomonas aeruginosa, resistant to a carbapenem, or with demonstrated carbapenemase production;

(iv) Staphylococcus aureus from a normally sterile site with methicillin testing performed, reported as either methicillin-susceptible Staphylococcus aureus (MSSA) or methicillin-resistant Staphylococcus aureus (MRSA); and

(v) Streptococcal disease, invasive due to all species.

(b) Entities reporting electronically shall include any laboratory results including positive, negative, equivocal, indeterminate, associated with the following tests or conditions:

(i) CD4+ T-Lymphocyte tests, regardless of known HIV status;

(ii) chlamydia;

(iii) Clostridium difficile;

(iv) novel coronavirus COVID-19 (SARS-CoV-2), including IgM and IgG serology;

(v) cytomegalovirus (CMV), congenital (infants less than or equal to 12 months of age);

(vi) gonorrhea;

(vii) hepatitis A;

(viii) hepatitis B, including viral loads;

(ix) hepatitis C, including viral loads;

(x) HIV, including viral loads and confirmatory tests;

R398-4-6. CMV Registry.

Pursuant to Section 26-1-30, the Department shall maintain a database of infants tested as well as a Positive Congenital CMV Registry that contains results, demographics, symptomology, specialist services, long-term outcomes, and other items as deemed necessary.

R398-4-7 Confidentiality of Reported Information.

(1) The confidentiality of personal information obtained under this rule shall be maintained pursuant to Title 26, Chapter 3, Health Statistics. The reports are confidential and are not open to public inspection.

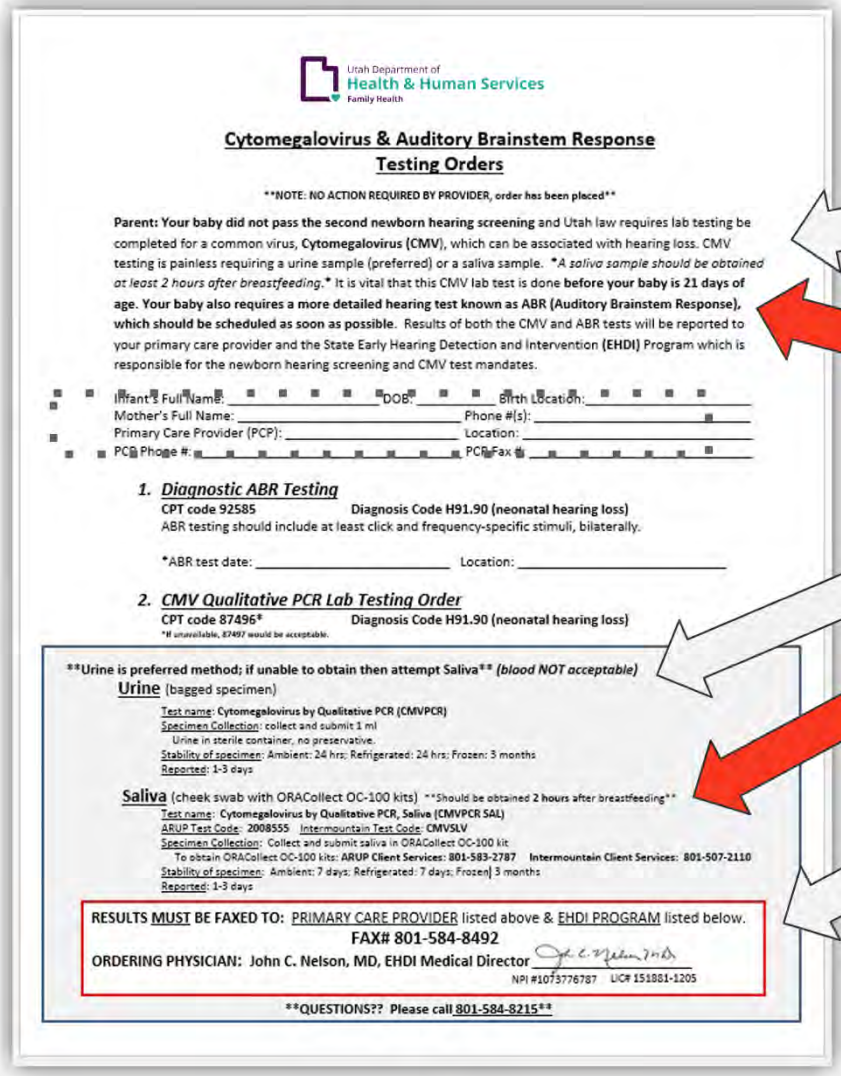
(2) Pursuant to Title 26, Chapter 25, Confidential Information Release, persons who report information covered by this rule may not be held liable for reporting the information to the Department.

R398-4-3. Clarification of When a Newborn Must Be Referred for CMV Testing.

(1) The newborn must be referred for CMV testing if the infant fails both the initial hearing screen routinely done at birth and the subsequent follow-up screen.

(2) The newborn must be referred for CMV testing when the initial failed screen is obtained after 14 days of age.

(3) The newborn must be referred for CMV testing if they have failed an inpatient screening and have not completed or been able to complete the outpatient screening before 14 days of age.



Utah Department of Health & Human Services
Family Health

Cytomegalovirus & Auditory Brainstem Response Testing Orders

NOTE: NO ACTION REQUIRED BY PROVIDER, order has been placed

Parent: Your baby did not pass the second newborn hearing screening and Utah law requires lab testing be completed for a common virus, **Cytomegalovirus (CMV)**, which can be associated with hearing loss. CMV testing is painless requiring a urine sample (preferred) or a saliva sample. **A saliva sample should be obtained at least 2 hours after breastfeeding.** It is vital that this CMV lab test is done **before your baby is 21 days of age. Your baby also requires a more detailed hearing test known as ABR (Auditory Brainstem Response), which should be scheduled as soon as possible.** Results of both the CMV and ABR tests will be reported to your primary care provider and the State Early Hearing Detection and Intervention **(EHDI)** Program which is responsible for the newborn hearing screening and CMV test mandates.

Infant's Full Name: _____ DOB: _____ Birth Location: _____
Mother's Full Name: _____ Phone #(s): _____
Primary Care Provider (PCP): _____ Location: _____
PCP Phone #: _____ PCP Fax #: _____

1. ***Diagnostic ABR Testing***
CPT code 92585 **Diagnosis Code H91.90 (neonatal hearing loss)**
ABR testing should include at least click and frequency-specific stimuli, bilaterally.

*ABR test date: _____ Location: _____

2. ***CMV Qualitative PCR Lab Testing Order***
CPT code 87496* **Diagnosis Code H91.90 (neonatal hearing loss)**
*If unavailable, 87497 would be acceptable.

Urine is preferred method; if unable to obtain then attempt Saliva *(blood NOT acceptable)*

Urine (bagged specimen)
Test name: **Cytomegalovirus by Qualitative PCR (CMVPCR)**
Specimen Collection: collect and submit 1 ml
Urine in sterile container, no preservative.
Stability of specimen: Ambient: 24 hrs; Refrigerated: 24 hrs; Frozen: 3 months
Reported: 1-3 days

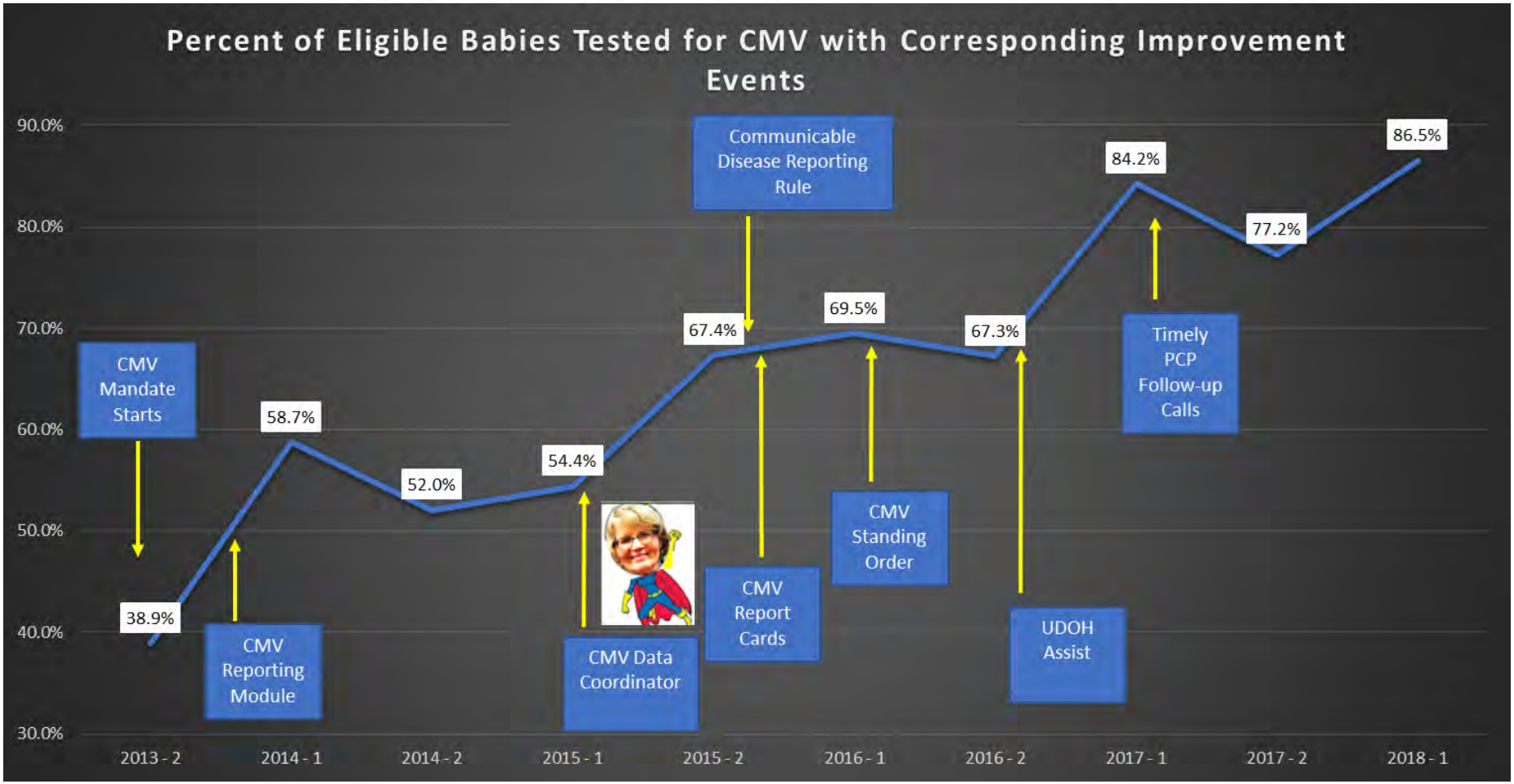
Saliva (cheek swab with ORACollect OC-100 kits) **Should be obtained 2 hours after breastfeeding**
Test name: **Cytomegalovirus by Qualitative PCR, Saliva (CMVPCR SAL)**
ARUP Test Code: **2008555** Intermountain Test Code: **CMVSLV**
Specimen Collection: Collect and submit saliva in ORACollect OC-100 kit
To obtain ORACollect OC-100 kits: **ARUP Client Services: 801-583-2787** **Intermountain Client Services: 801-507-2110**
Stability of specimen: Ambient: 7 days; Refrigerated: 7 days; Frozen: 3 months
Reported: 1-3 days

RESULTS MUST BE FAXED TO: PRIMARY CARE PROVIDER listed above & EHDI PROGRAM listed below.
FAX# 801-584-8492
ORDERING PHYSICIAN: John C. Nelson, MD, EHDI Medical Director _____
NPI #1073776787 LIC# 151881-1205

QUESTIONS?? Please call 801-584-8215

Utah CMV Testing Order

- Educate families regarding CMV testing requirement
- Order CMV testing *before 21 days* of age
- Only use *Urine or Saliva specimen*
- Remind mothers to not breastfeed their baby for **two hours** prior to saliva swab
- Results come to UDOH directly from the lab



Education, Training, Material Dissemination

Reasons for missed tests

2018 & 2019

- **155** eligible babies did not receive CMV testing
  - **34 (22%)** passed a second OP screen (or first OP screen if IP screen was after 14 days)
    - Half of this group were out-of-hospital births
  - **31 (20%)** had a normal hearing diagnostic ABR

2020 & 2021

- **138** eligible babies did not receive CMV testing
  - 55 (40%) passed a second OP screen (or first OP screen if IP screen was after 14 days)
    - More than half of this group were out-of-hospital births
  - **32 (23%)** had a normal hearing diagnostic ABR

CMV Report Cards

UTAH DEPARTMENT OF HEALTH

CMV Mandate Report

[redacted] Medical Center

7-1-16 to 12-31-16

1-1-17 to 6-30-17

Audiologist: [redacted]

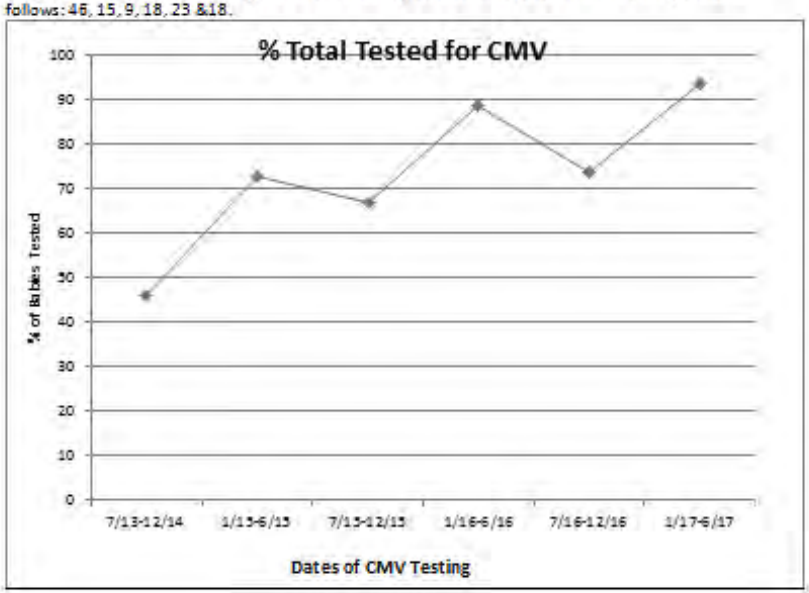
Program Coordinator: [redacted]

CMV Testing

- # of infants eligible- 23(2 refusal not included) in 2016 and 18 in 2017
- # of infants tested – 17/23 (74%) in 2016 and 17/18 (94%) in 2017
  - 31/34 (91%) were tested before 21 days
- # of infants not tested 6/23 (26%) in 2016 and 1/18 (6%) in 2017
  - # of infants exempt by "special populations" of newborns - 2 (1 was tested for CMV) in 2016 and 4 (3 were tested for CMV) in 2017

CMV Testing Over Time

This graph shows the progress of CMV testing at your hospital since the beginning of the mandate in 2013. The number of babies eligible for CMV testing for each time period from left to right was as follows: 46, 15, 9, 18, 23 &18.



Test Results (FYI)

- CMV Positive - 1
- CMV Negative – 33
- False Positive – 1
- Refused Testing – 2
- Tested by Saliva –9, Urine –26, Blood –1 Dried blood spot). **Multiple tests-1**

Reasons Found for Not Testing Eligible Infants

- **Fax forms were not received by the PCP - 4**
- **Parent did not follow through with testing – 1** (PCP wrote a lab order but parent did not follow through, parent reported she had no recall of CMV testing.)
- **PCP chose not to test after baby passed the second OP screen – 1**

Comments and Recommendations

1. Nice job getting 91% of the CMV testing for 34 babies completed by 21 days.
2. *We are hoping the new CMV order will help with old problems such as the PCP not receiving the fax requesting testing. If possible walking the parents to the lab immediately after failure of the first OP screen will help with parents with following through with testing.*
3. Keep up the great work. IMC has the most babies eligible for CMV testing so there is a lot to keep us with!

Report prepared by: Jill Boettger, MS, CCC-A/SLP
CMV Public Health Initiative
Data Coordinator

Completed: 9/17

Early Hearing Detection & Intervention (EHDI)

HOSPITAL PERFORMANCE REPORT

Utah Department of Health & Human Services

[redacted] HOSPITAL

PROGRAM AUDIOLOGIST: [redacted] PROGRAM COORDINATOR: [redacted]

Rating period: January 1, 2022 - December 31, 2022

SCREENING													
		WELL BABY						NICU					
			State Standard 100%	< 4%	50%								
	Births Responsible for	Total Babies	% IP Screened	% IP Referred	% OP Complete	Missed	Refused	Total Babies	% IP Screened	% IP Referred	% OP Complete	Missed	Refused
2021	1079	1024	100%	6.05%	96.77%	1 OP		55	96.36%	7.55%	83.33%	2 IP, 1 OP	-
2022													

IP = Inpatient OP = Outpatient

DIAGNOSTICS										
	# Need Evaluation	% Completed Evaluation	No Diagnostic	Refused	Out of Jurisdiction	Deceased	Normal Hearing	Fluctuating Loss	Undetermined Loss	Permanent Hearing Loss
2021	12	100%	-	-	1	-	6 (1*)	2	1	3
2022										

* Atypical (passed screening and then had diagnostics)

CMV TESTING						
	WELL BABY % eligible tested	NICU % eligible tested	SPECIAL POPULATION % eligible tested	Refused (N)	% CMV testing < 21 days of age	CMV Detected (N)
2021	100 % 11/11	66.7% 2/3	-	-	92.3% 12/13	0
2022						

Centers of Excellence

Criteria for selecting programs:

- IP and OP screening
- CMV testing
- Lost to Follow-Up
- Timeliness of reporting
- Data Quality
- Communication with State EHDI
- Diagnostics
- EI Enrollment
- Program Summary

Large Hospital: ≥ 2000 births
Medium Hospital: 700-1999 births
Rural Hospital: 200 - 699 births
Frontier Hospital: ≤ 199 births

Phoenix Children's

Utah Department of
Health & Human Services
Family Health

Certificate of Award

This certifies that

The Newborn Hearing Screening Program at

Utah Hospital

by virtue of its consistent, quality performance and dedication,
is hereby considered to be a

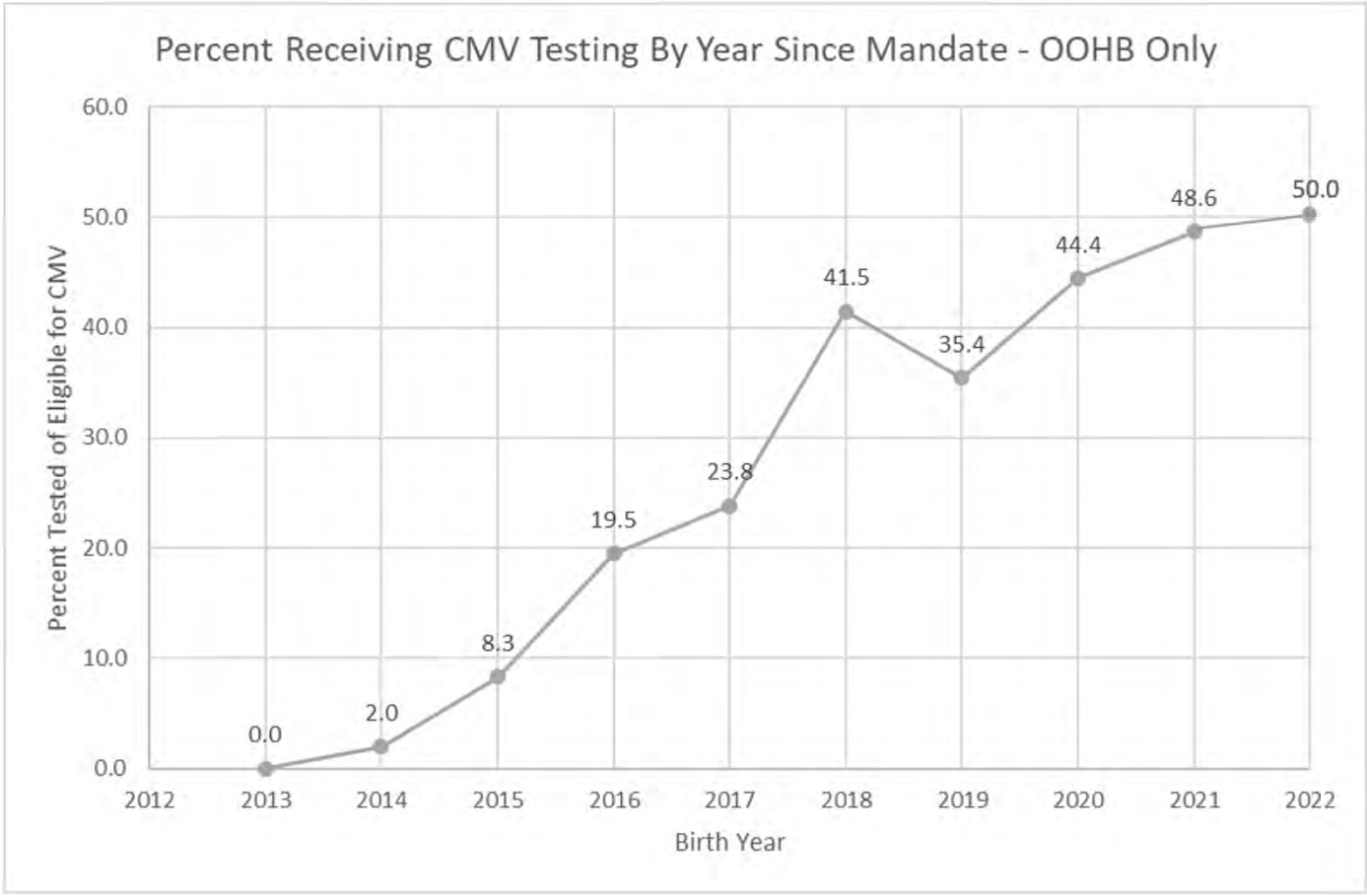
2022 CMV Center of Excellence

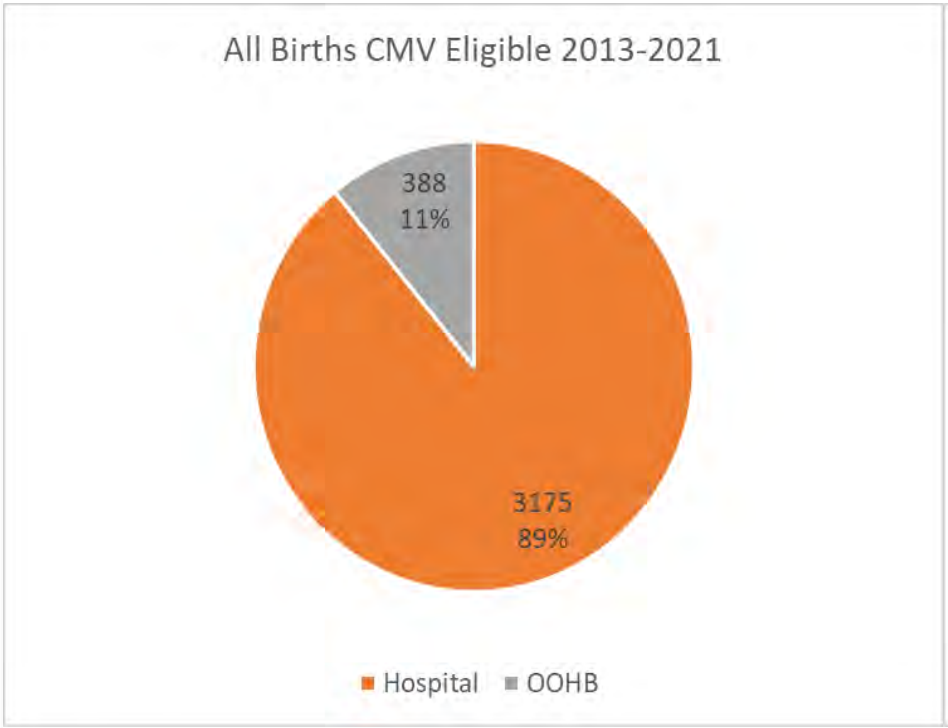
in Newborn Hearing Screening and Follow-up

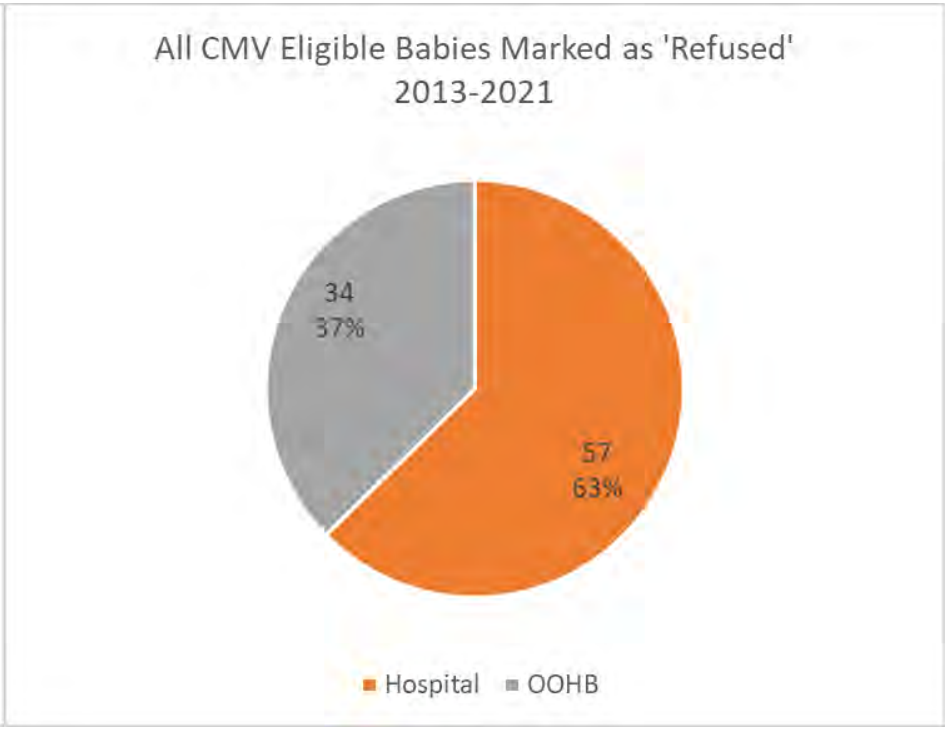
Stephanie Browning McVicar, Au.D., CCC-A
Dr. Stephanie Browning McVicar
Utah EHDI Programs Director

Shannon Wnek, Au.D., CCC-A
Dr. Shannon Wnek
Utah EHDI Audiology Coordinator

Out of Hospital Births (OOHB)

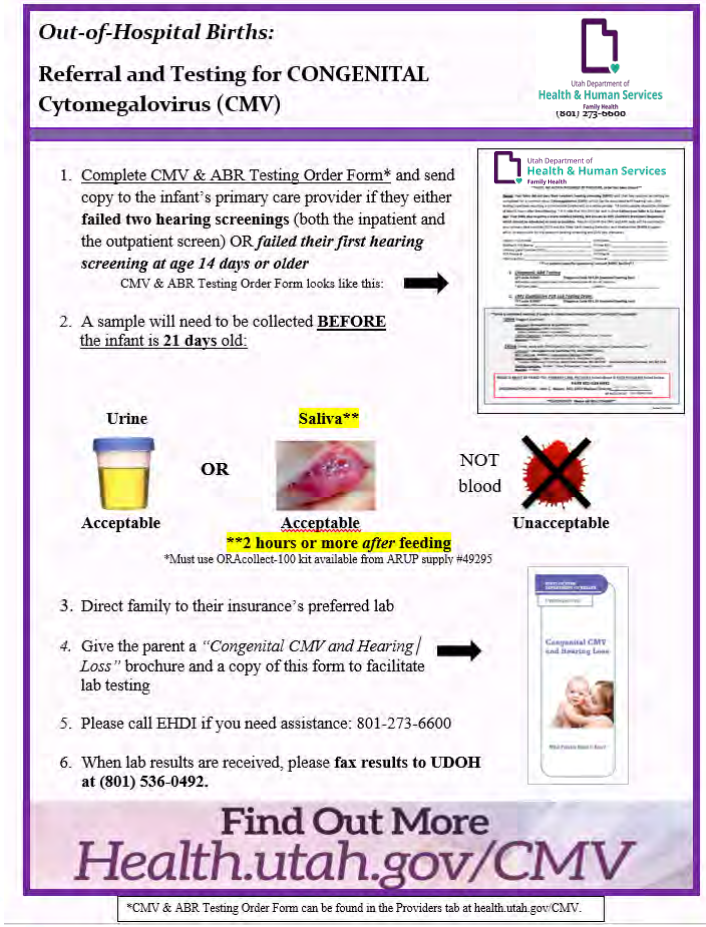






While out of hospital births only comprise about **1/10th** of all CMV-eligible babies, they make up over **1/3rd** of all CMV-eligible babies whose parents refuse testing.

Out of Hospital Births (OOHB)



Out-of-Hospital Births:

Referral and Testing for CONGENITAL Cytomegalovirus (CMV)

Utah Department of Health & Human Services
Family Health
(801) 273-6600

1. Complete CMV & ABR Testing Order Form* and send copy to the infant's primary care provider if they either **failed two hearing screenings** (both the inpatient and the outpatient screen) OR ***failed their first hearing screening at age 14 days or older***
   CMV & ABR Testing Order Form looks like this:
2. A sample will need to be collected **BEFORE** the infant is **21 days** old:

Urine — **Acceptable**

OR

Saliva** — **Acceptable**

NOT blood — **Unacceptable**

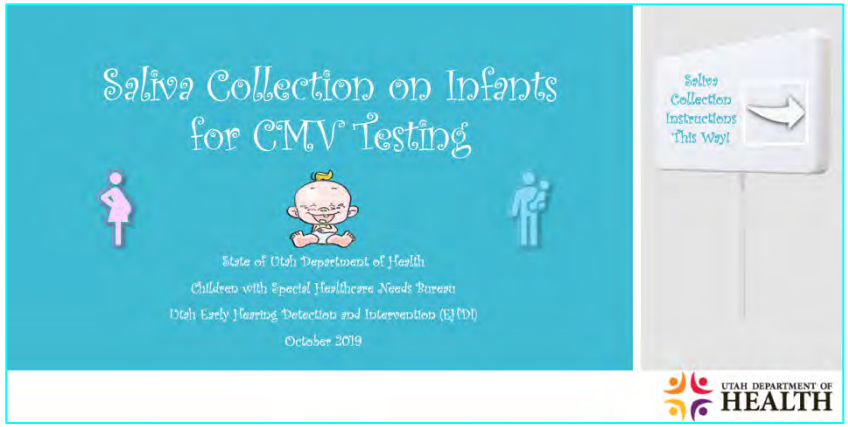
****2 hours or more *after* feeding**

*Must use ORAcollect-100 kit available from ARUP supply #49295

3. Direct family to their insurance's preferred lab
4. Give the parent a *"Congenital CMV and Hearing Loss"* brochure and a copy of this form to facilitate lab testing
5. Please call EHDI if you need assistance: 801-273-6600
6. When lab results are received, please **fax results to UDOH at (801) 536-0492.**

Find Out More
Health.utah.gov/CMV

*CMV & ABR Testing Order Form can be found in the Providers tab at health.utah.gov/CMV.



Benefits

August 20, 2016

Screening for Congenital CMV in NICU infants at ≤3 weeks of age

In Utah, screening for congenital CMV in newborn is already linked and required by statute to be performed with failed sensorineural hearing screening. Clinical data and published guidelines strongly support that treatment of infants with symptomatic (includes hearing loss as the only symptom/sign) congenital CMV infection with antiviral agents may reduce hearing loss and may improve neurodevelopmental outcome (although treatment is not totally benign and careful consideration of pros and cons in concert with the pediatric infectious disease service is warranted). A variety of factors prompt strong consideration of an alternative approach in NICU infants:

1) Many/most are not screened until long after 3 weeks, when it is much more difficult to determine if the infection is congenital or not.
2) Many infants with congenital CMV infection who appear asymptomatic are symptomatic if systematic assessment is conducted.
3) Many infants with congenital CMV infection do not have sensorineural hearing loss in the newborn period, although the incidence progressively increases with age as serial audiologic assessment is conducted.

Benefits

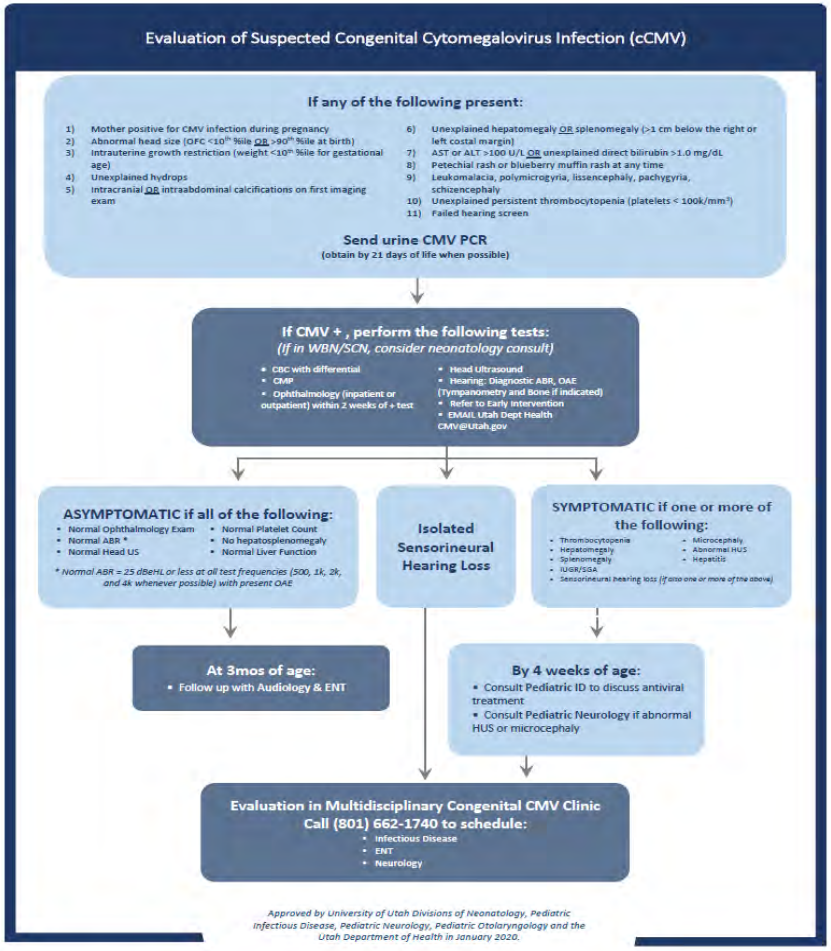
It is therefore recommended that strong consideration be given to testing NICU infants with **any** (even if only 1 is noted) of the following signs for congenital CMV infection in the first 3 weeks of life, even if alternative explanations are possible or even probable:

1) Abnormal head size (microcephaly [<10th %ile] OR macrocephaly [>90th %ile]) at birth
2) Intrauterine growth restriction (weight <10th %ile for gestational age) at birth
3) Hydrops
4) Intracranial OR intraabdominal calcifications on first imaging exam
5) Hepatomegaly OR splenomegaly (>1 cm below the right or left costal margin) in first 72 hours
6) AST or ALT >100 U/L OR direct bilirubin >1.0 mg/dL in first 72 hours
7) Petechiae at any time OR thrombocytopenia (<100,000/mm^3) on ≥2 occasions in first 72 hours
8) 'Blueberry muffin' appearance
9) Neuronal migration disorders (e.g., polymicrogyria, lissencephaly, pachygyria, schizencephaly) on first imaging exam
10) Unexplained brain lesions or neurologic findings

Benefits

Testing for CMV in the first 3 weeks is best done by PCR of urine. Saliva can also be tested (ARUP is the only lab that will test saliva in Utah at present), but contamination by infected maternal breast milk may be problematic. Such testing will currently be charged to the patient, since this is not a research study and is done to seek a potentially treatable cause of the presenting abnormality. If PCR is positive, strongly recommend: 1) consult the pediatric infectious disease service re: evaluation for treatment, 2) assessment of the infant for evidence of other clinical abnormalities potentially attributable to CMV. This assessment should include, AT LEAST, careful systematic physical examination, CBC with differential and platelet count, liver function profile, ophthalmology exam, brain imaging (preferably MRI, with radiologists being informed that congenital CMV is the indication), liver imaging and, if possible, hearing assessment (brainstem evoked audiometry is preferred), and 3) consult the pediatric ENT and neurology services.

Benefits

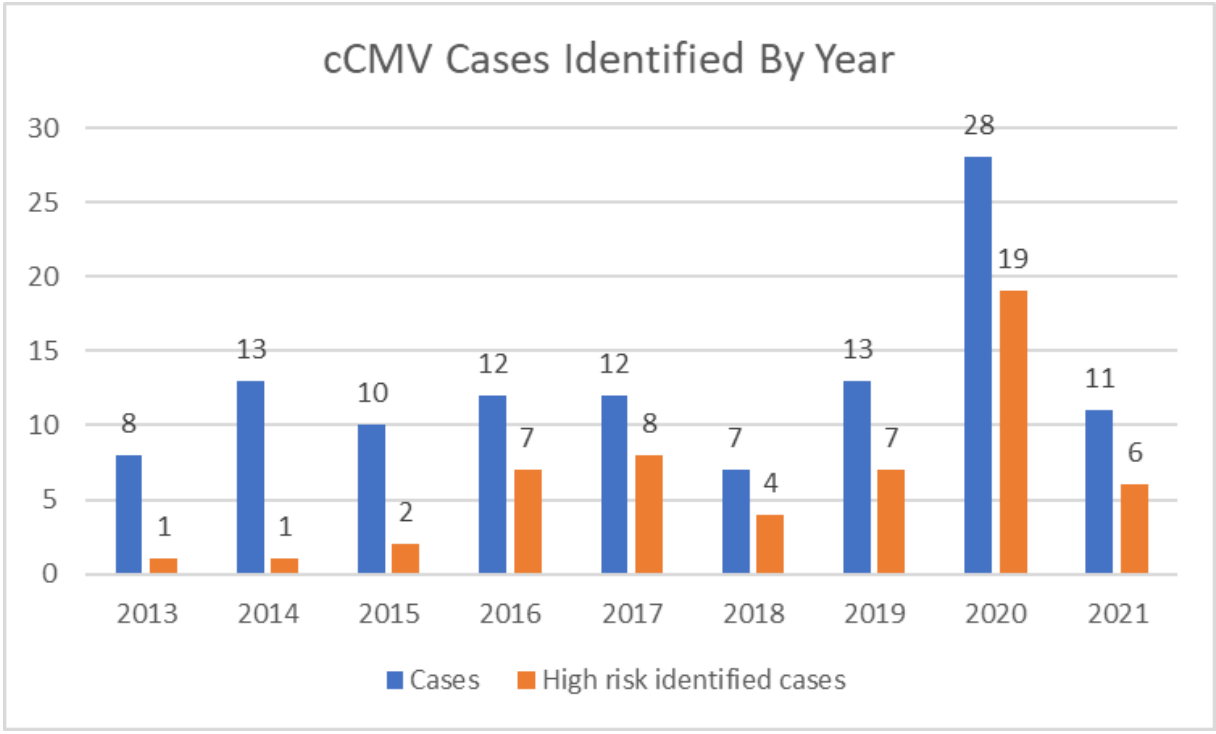


If any of the following present:

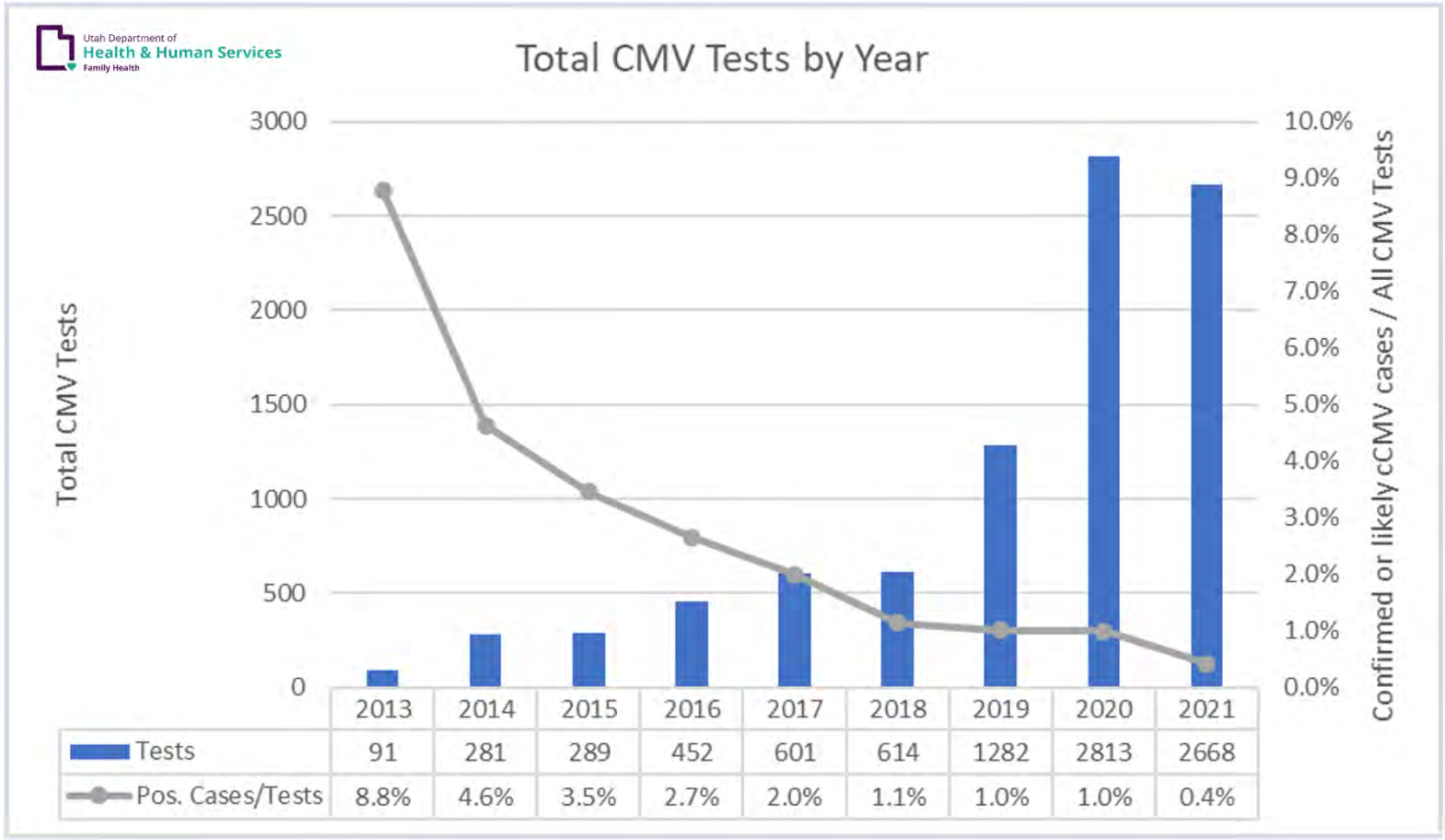
1) Mother positive for CMV infection during pregnancy
2) Abnormal head size (OFC <10th %ile OR >90th %ile at birth)
3) Intrauterine growth restriction (weight <10th %ile for gestational age)
4) Unexplained hydrops
5) Intracranial OR intraabdominal calcifications on first imaging exam
6) Unexplained hepatomegaly OR splenomegaly (>1 cm below the right or left costal margin)
7) AST or ALT >100 U/L OR unexplained direct bilirubin >1.0 mg/dL
8) Petechial rash or blueberry muffin rash at any time
9) Leukomalacia, polymicrogyria, lissencephaly, pachygyria, schizencephaly
10) Unexplained persistent thrombocytopenia (platelets < 100k/mm3)
11) Failed hearing screen

Send urine CMV PCR

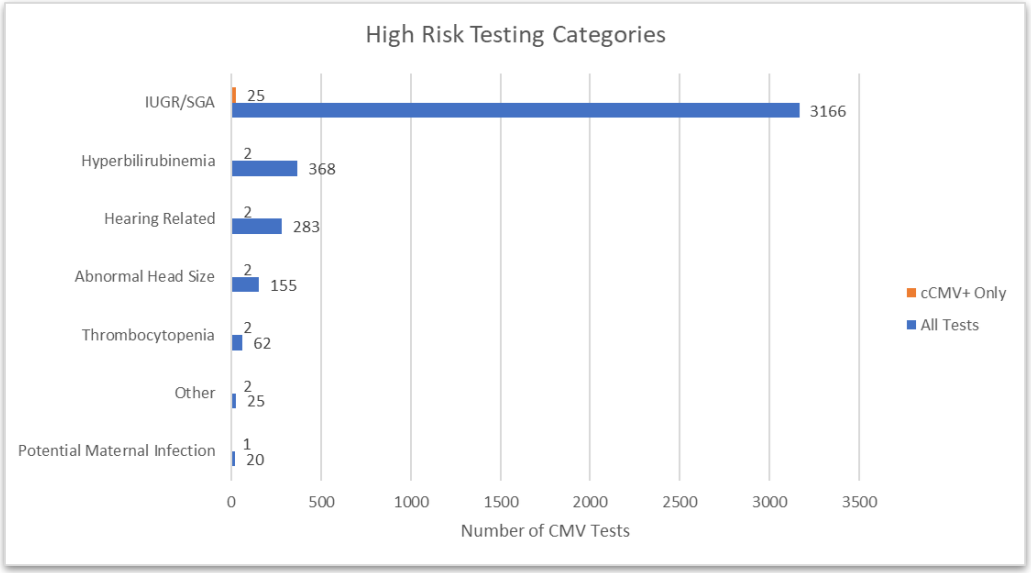
(obtain by 21 days of life when possible)

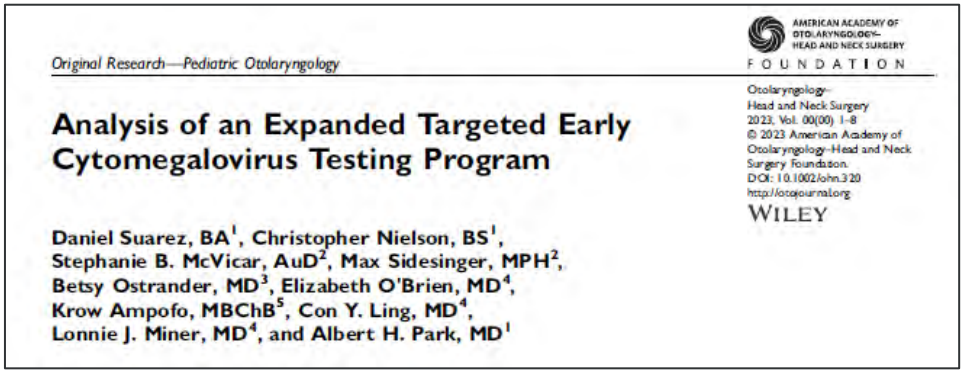


High Risk Testing Protocol had widespread adoption by hospitals (Intermountain) in Utah in Fall of 2019


Utah Department of Health & Human Services
Family Health
Total CMV Tests by Year
Total CMV Tests
Confirmed or likely cCMV cases / All CMV Tests
3000
2500
2000
1500
1000
500
0
10.0%
9.0%
8.0%
7.0%
6.0%
5.0%
4.0%
3.0%
2.0%
1.0%
0.0%
2013 2014 2015 2016 2017 2018 2019 2020 2021
Tests 91 281 289 452 601 614 1282 2813 2668
Pos. Cases/Tests 8.8% 4.6% 3.5% 2.7% 2.0% 1.1% 1.0% 1.0% 0.4%

CMV Testing by Target Reason – Preliminary Data*





Original Research—Pediatric Otolaryngology

Analysis of an Expanded Targeted Early Cytomegalovirus Testing Program

Daniel Suarez, BA[1], Christopher Nielson, BS[1], Stephanie B. McVicar, AuD[2], Max Sidesinger, MPH[2], Betsy Ostrander, MD[3], Elizabeth O'Brien, MD[4], Krow Ampofo, MBChB[5], Con Y. Ling, MD[4], Lonnie J. Miner, MD[4], and Albert H. Park, MD[1]

AMERICAN ACADEMY OF OTOLARYNGOLOGY–HEAD AND NECK SURGERY FOUNDATION

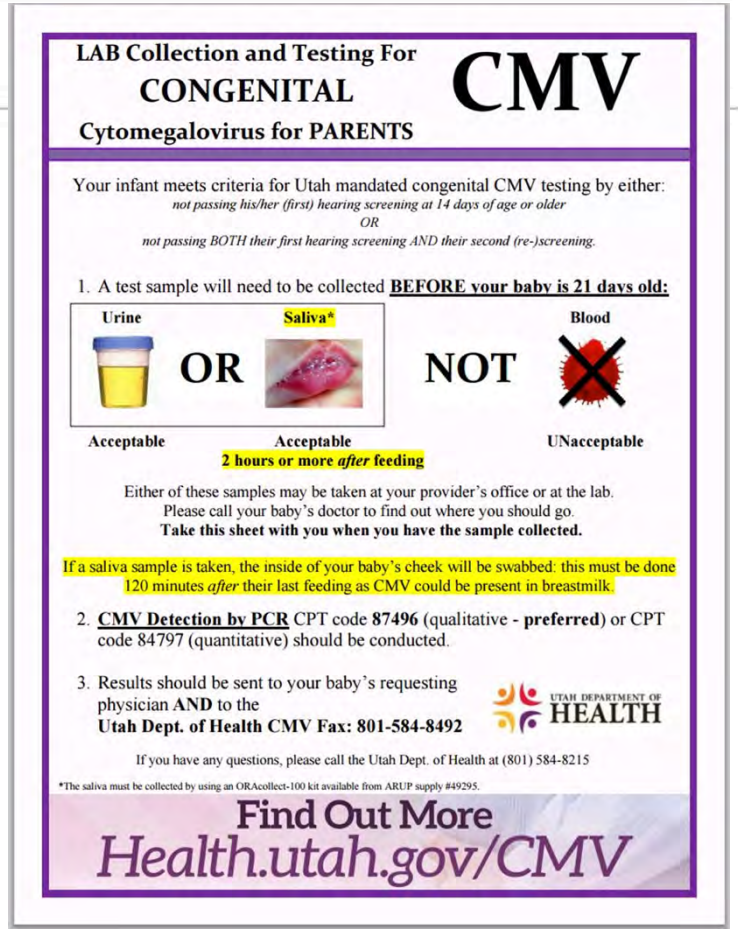
Otolaryngology–Head and Neck Surgery
2023, Vol. 00(00) 1–8

DOI: 10.1002/ohn.320
http://otojournal.org
WILEY

- Estimated prevalence of cCMV in the US: **0.5%** of all live births
- Percent of high risk targeted tests resulting in a positive cCMV case: **0.9%** (*80% higher* than universal cCMV prevalence)
- Percent positivity of notable high risk categories:
  - IUGR/SGA: **0.8%**
  - Hyperbilirubinemia: **0.5%**
  - Hearing related: **0.7%**
  - Micro/macrocephaly: **1.3%**
  - Thrombocytopenia: **3.1%**
  - Potential maternal infection: **5%**
  - Other: **8%**

*9/2019-6/2022 with partial 2021

CMV Test Specimen



LAB Collection and Testing For CONGENITAL Cytomegalovirus for PARENTS **CMV**

Your infant meets criteria for Utah mandated congenital CMV testing by either:
not passing his/her (first) hearing screening at 14 days of age or older
OR
not passing BOTH their first hearing screening AND their second (re-)screening.

1. A test sample will need to be collected **BEFORE your baby is 21 days old:**

Urine		Saliva*		Blood
	OR		NOT	
Acceptable		Acceptable		UNacceptable

2 hours or more *after* feeding

Either of these samples may be taken at your provider's office or at the lab.
Please call your baby's doctor to find out where you should go.
Take this sheet with you when you have the sample collected.

If a saliva sample is taken, the inside of your baby's cheek will be swabbed: this must be done 120 minutes *after* their last feeding as CMV could be present in breastmilk.

2. **CMV Detection by PCR** CPT code **87496** (qualitative - **preferred**) or CPT code 84797 (quantitative) should be conducted.

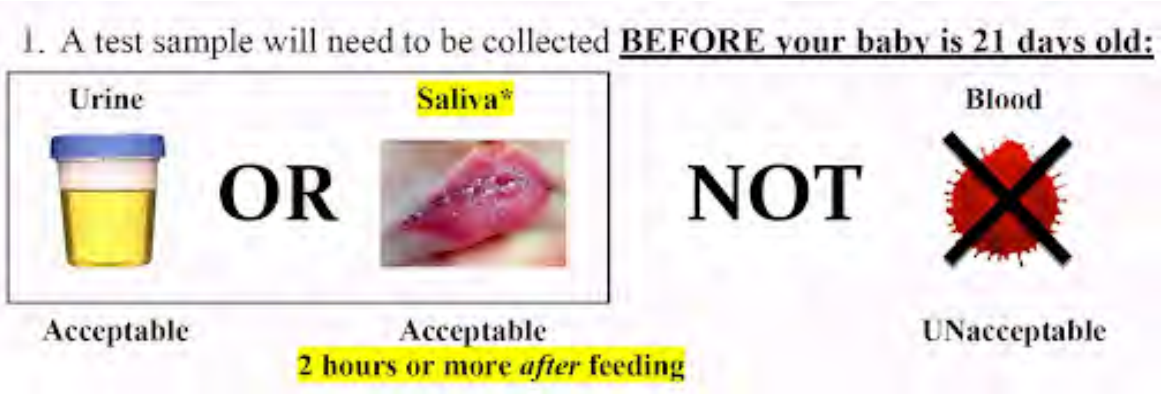
3. Results should be sent to your baby's requesting physician **AND** to the **Utah Dept. of Health CMV Fax: 801-584-8492**

UTAH DEPARTMENT OF HEALTH

If you have any questions, please call the Utah Dept. of Health at (801) 584-8215

*The saliva must be collected by using an ORAcollect-100 kit available from ARUP supply #49295.

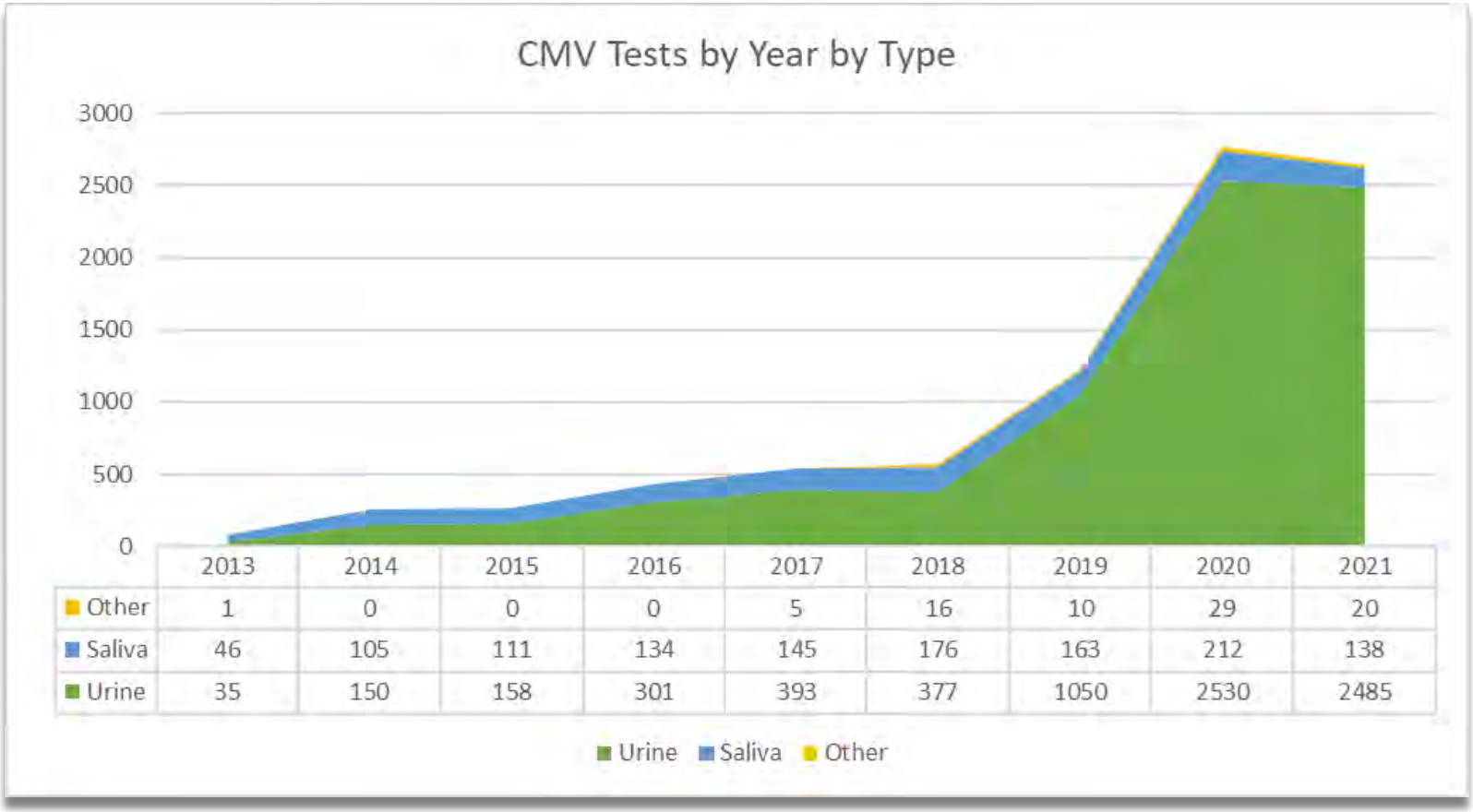
Find Out More
Health.utah.gov/CMV



1. A test sample will need to be collected **BEFORE your baby is 21 days old:**

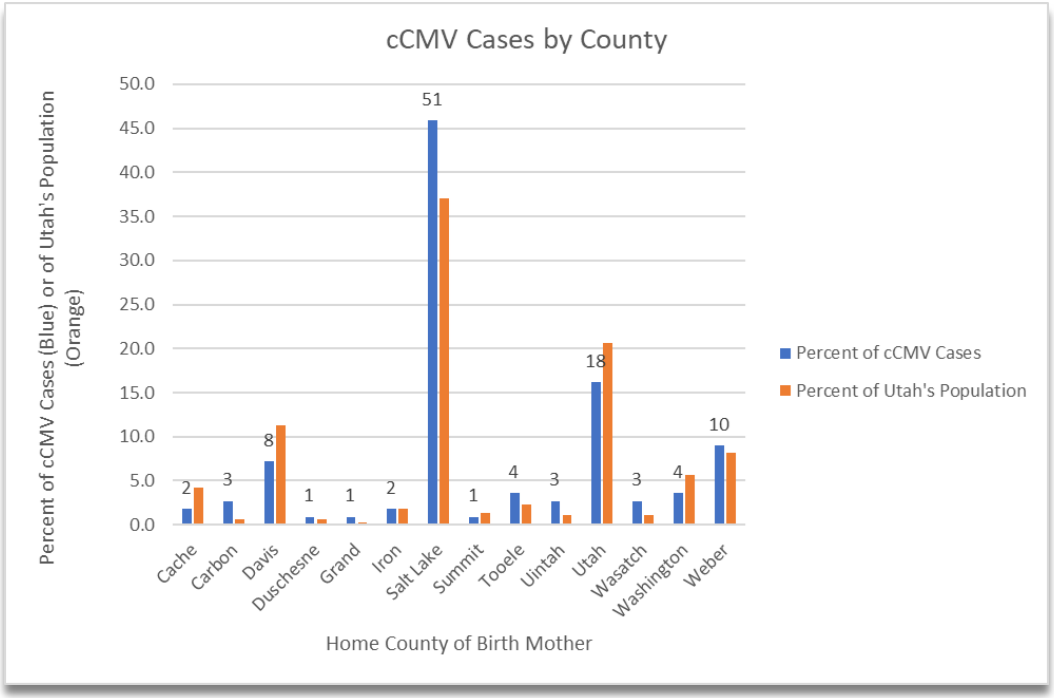
Urine		Saliva*		Blood
	OR		NOT	
Acceptable		Acceptable		UNacceptable

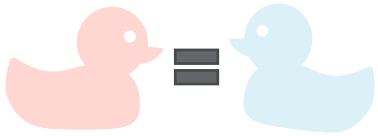
2 hours or more *after* feeding

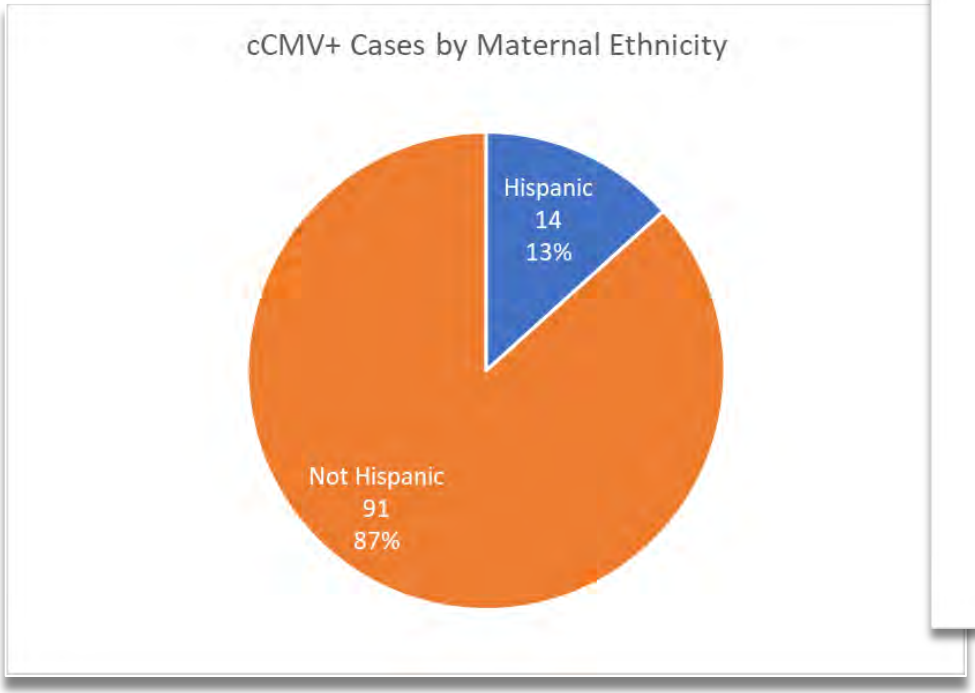


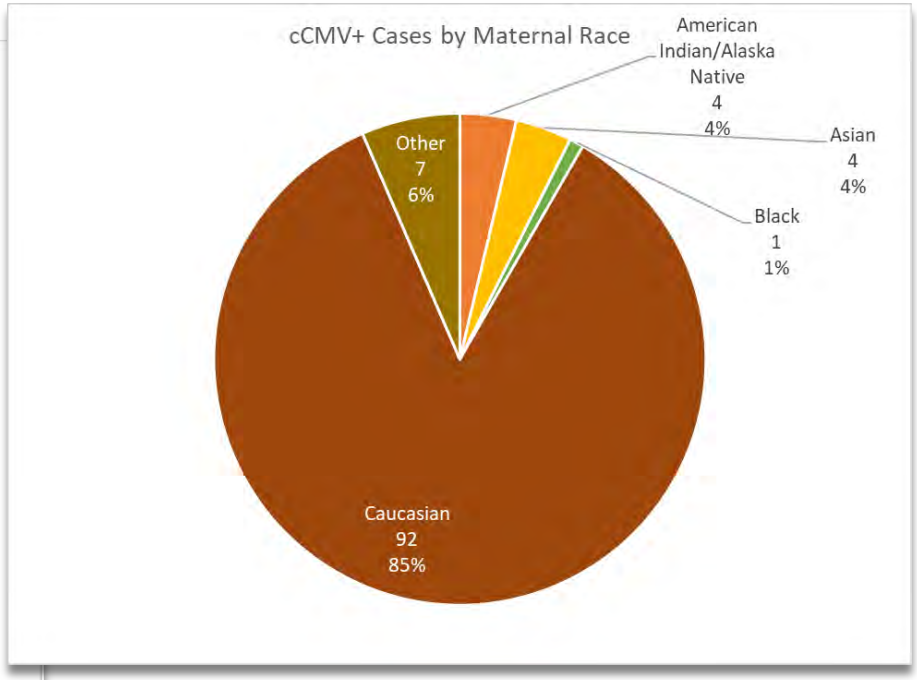
	2013	2014	2015	2016	2017	2018	2019	2020	2021
Other	1	0	0	0	5	16	10	29	20
Saliva	46	105	111	134	145	176	163	212	138
Urine	35	150	158	301	393	377	1050	2530	2485

- Only includes one lab result per child (1st)
- ‘Other’ includes CSF and IgG/IgM


cCMV Cases by County
Percent of cCMV Cases (Blue) or of Utah's Population (Orange)
50.0
45.0
40.0
35.0
30.0
25.0
20.0
15.0
10.0
5.0
0.0
2
3
8
1
1
2
51
1
4
3
18
3
4
10
Cache
Carbon
Davis
Duschesne
Grand
Iron
Salt Lake
Summit
Tooele
Uintah
Utah
Wasatch
Washington
Weber
Home County of Birth Mother
Percent of cCMV Cases
Percent of Utah's Population







Utah's Population According to census.gov:
By Ethnicity

14.4% Hispanic
85.6% Not Hispanic

Utah's Population According to census.gov:
By Race

1.6% American Indian/Alaska Native
2.7% Asian
1.5% Black
90.6% Caucasian

Hearing Loss for CMV Positive Babies 2013 – 2021 (Analyzed mid-2022)

	Hearing At First Diagnostics N=113	Hearing At First DX of Babies with Diagnosed HL at Some Point N=67	Hearing At Most Recent DX of Babies with Diagnosed HL at Some Point N=67
Normal Hearing	**47.8% (54/113)**	12% (8/67)	10.4% (7/67)
Hearing Loss	**52.2% (59/113)**	88% (59/67)	89.6% (60/67)
Laterality	Unilateral 54.2% (32/59) R- 44% L- 56% Bilateral –42.4% (25/59) Unknown - 3.4% (2/59)	Unilateral 54.2% (32/59) R- 44% L- 56% Bilateral –42.4% (25/59) Unknown - 3.4% (2/59)	Unilateral –45% (27/60) R –44% L –56% Bilateral –51.7% (31/60) Unknown - 3.3% (2/60)
Type	SNHL –64.4% (38/59) FC – 13.5% (8/59) Undetermined–13.5% (8/59) Mixed - 6.8% (4/59) Unknown - 1.8% (1/59)	SNHL –64.4% (38/59) FC – 13.5% (8/59) Undetermined–13.5% (8/59) Mixed - 6.8% (4/59) Unknown - 1.8% (1/59)	SNHL –86.7% (52/60) FC – 10% (6/60) Undetermined–5% (3/60) Mixed - 0% Unknown - 1.7% (1/60)*
Degree by Ear	Mild-Moderate - 44% (26/59) Moderate-Severe - 22% (13/59) Severe-Profound – 32.2% (19/59) Unknown - 1.8% (1/59)	Mild-Moderate - 44% (26/59) Moderate-Severe - 22% (13/59) Severe-Profound – 32.2% (19/59) Unknown - 1.8% (1/59)	Mild-Moderate –31.7% (19/60) Moderate-Severe- 23.3% (14/60) Severe- Profound –43.3% (26/60) Unknown - 1.7% (1/60)

Hearing Loss Progression

cCMV+ Kids w/ HL at First Dx (N=59)

- 2 progressed from NL hearing to bilateral SNHL
- 3 progressed from unilateral SNHL to bilateral SNHL
- 20 out of 59 or 34% had progression in hearing loss (severity or laterality) - 4 kids progressed twice
  - ❑ 13/24 or 54% showed progression by 12 months
  - ❑ 3/24 or 13% progressed between 12-18 months
  - ❑ 2/24 or 8% progressed between 18-24 months
  - ❑ 6/24 or 25% progressed between 30-80 months

  - 12 children have cochlear implants
  - Average age at progression - 18.5 months

Utah Ongoing Monitoring Schedule

General Guideline:

- Baseline Auditory Brainstem Response (ABR) test
- Every 3 months until the age of 3 years
- Every 6 months until the age of 6 years
- Annually thereafter
- Sooner if concerns arise

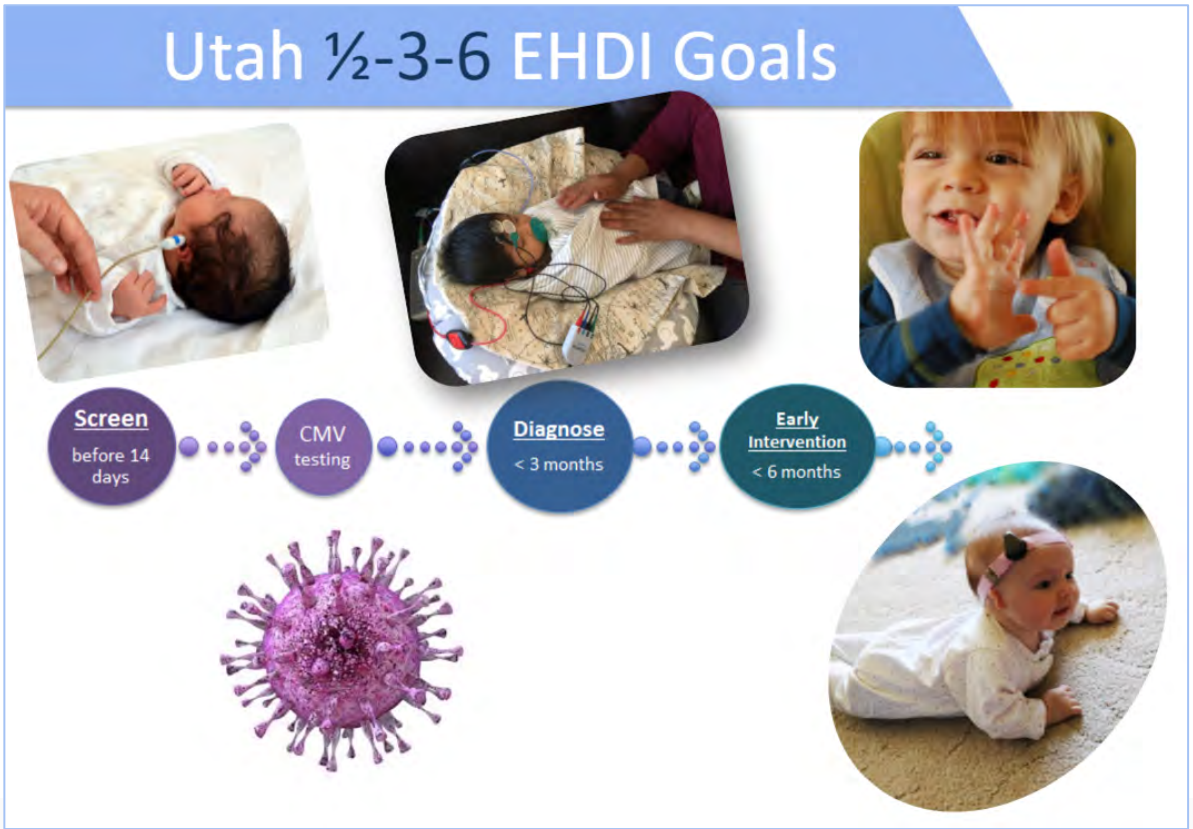
CMV and Changing Hearing Loss

8 Special Cases

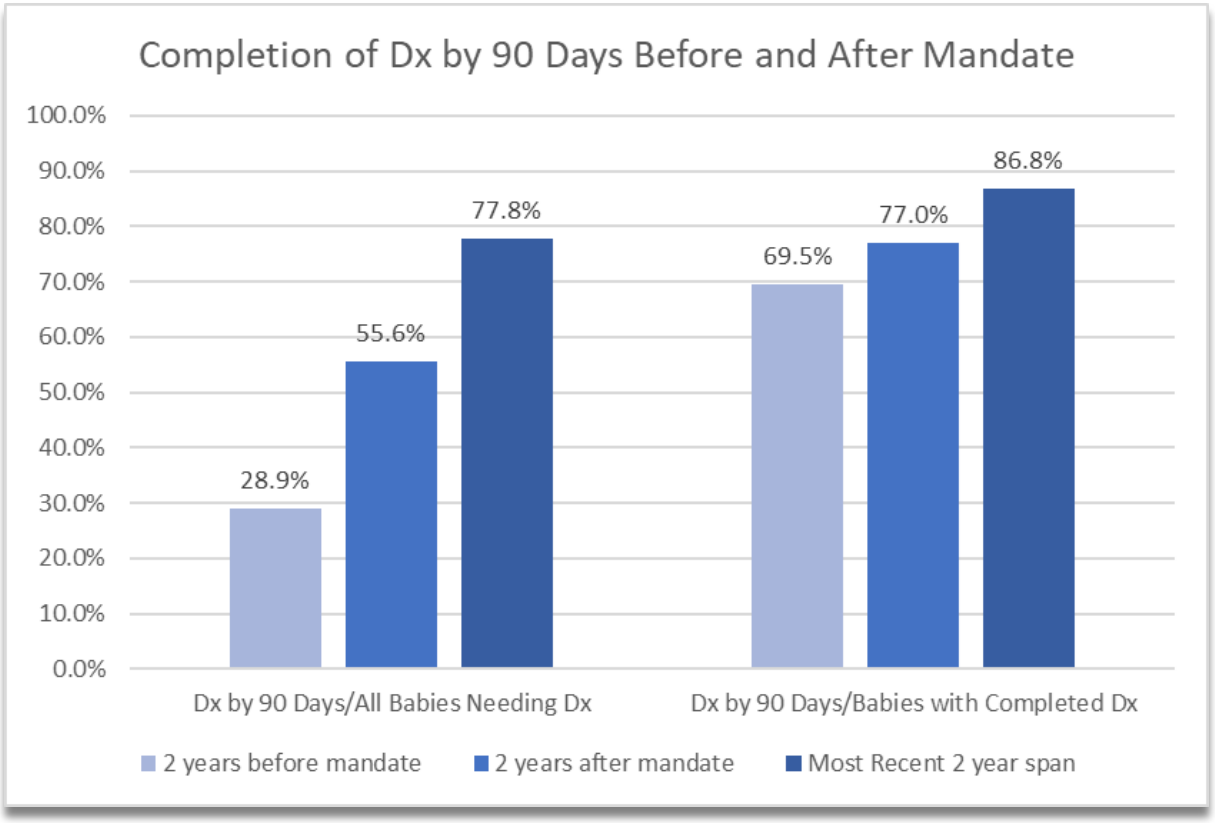
- HL progressed @ 8 months, then improved @ 13 months
- HL improved @ 4 months, then progressed @ 42 months, then improved again @ 60 months
- HL progressed @ 1.5 months, then progressed further @ 2.5 months, then improved @ 5 months
- HL progressed in left ear @ 6 months, then right ear progressed, but left ear improved @ 13 months
- HL progressed @ 2 months, then improved @ 13 months
- Uni to Bilateral @ 1.5 months, back to Uni @ 3 months
- HL progressed @ 4 months, then progressed again @ 8 months, then improved @ 11 months, then progressed again at 12 months and progressed again @ 19 months
- HL progressed @ 14 months, then improved @ 22 months

Severity of most recent HL compared to initial: **5** - more severe, **2** - less severe, **1** - ended up the same

Early Hearing Detection & Intervention (EHDI) Milestones



EHDI Benefits



2 years before mandate: 7/1/2011 - 6/30/2013

2 years after mandate: 7/1/2013 - 6/30/2015

Most recent 2 years: 1/1/2020 - 12/31/2021

Marissa L. Diener, Cathleen D. Zick, Stephanie Browning McVicar, Jill Boettger, Albert H. Park; Outcomes From a Hearing-Targeted Cytomegalovirus Screening Program. *Pediatrics* February 2017; 139 (2): e20160789. 10.1542/peds.2016-0789

cCMV Positive Cases

- If tested with saliva, confirm with urine
- Referred to cCMV multi-disciplinary clinic
  - Pediatric ENT, ID, Neurology, Ophthalmology, Audiology
  - Bloodwork, Scans, HUS
  - Benefit from antiviral therapy?
- Referred to Early Intervention
- Entered into cCMV Registry and tracked for longitudinal outcomes

R398-2-6. Reporting to Utah Department of Health….
(4) The Department shall have access to infants' medical, diagnostic, amplification, implantation, and early intervention records to obtain information necessary to ensure the provision of timely and appropriate follow-up diagnostic and intervention services, including CMV testing results and follow-up, congenital CMV sequelae, treatments, and anything else deemed necessary to determine long-term outcomes.

Highlights of Utah Hearing-Targeted CMV Testing

- cCMV is now a qualifying diagnosis for EI
- Increased overall awareness of cCMV in the medical community, e.g. NICU testing and then High Risk Protocol
- Improvement in EHDI 3 month dx milestone attainment
- Formation of multi-disciplinary “cCMV Clinic”
- cCMV testing precipitated by failed NBHS allowed for further diagnostic testing which informed treatment options (e.g. abnormal imaging or HUS)

- Any CMV testing for infants < 1 year of age, direct reporting to DHHS (Division of Disease Control and Prevention)
- Standing CMV/ABR order facilitates quick and easy testing for families and providers

- CMV Champions!
- State Lab CMV testing
- Dedicated CMV Data and Follow-Up Coordinator essential
- Electronic Lab Reporting is best!
- Education never stops
- Ongoing stakeholder engagement and training

Thank You!

- https://cmv.usu.edu

smcvicar@utah.gov

health.utah.gov/CMV
nationalcmv.org

References

- nationalcmv.org
- health.utah.gov/CMV