Congenital Cytomegalovirus (cCMV) and EHDI's Role in Screening and Follow-Up

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- Explain three different state approaches to CMV testing
- Identify ways EHDI programs can facilitate CMV testing
- Discover ways to easily incorporate CMV testing education into EHDI materials
- EHDI cCMV Awareness Efforts



Learning Objectives

TORCH Infections



Toxoplasmosis

Other (Syphilis, Hep B)

Rubella

Cytomegalovirus

Herpes Simplex

EHDI and cCMV



- Leading viral cause of hearing loss
- cCMV is 2nd leading cause of hearing loss (genetics is #1)
- cCMV testing is time sensitive (<21 days of life)
- NBHS usually in pre-natal counseling

Utah CMV Public Health Initiative (2013)



- Public Education
- cCMV Testing after failing NBHS
- Assigned to EHDI

Utah CMV Public Health Initiative (2013)

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

UDOH 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)

Education: Pre-Natal NBHS BRochure

Pre-Natal NBHS Brochure

CMV and Hearing Loss

What Women Need to Know

Education: Prenatal NBHS Brochure

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:







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
- · 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**

Education: Prenatal NBHS Brochure

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.



Hearing loss is invisible



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.

Education: Prenatal CMV Education

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 yet 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.



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 EHDI Program 288 N. 1460 W. Salt Lake City, UT 84116

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

health.utah.gov/cmv

Dated 7.1.2021

STATE OF UTAH DEPARTMENT OF HEALTH

Cytomegalovirus

What women NEED TO KNOW about CMV



For Women Who Are Pregnant or Planning to Become Pregnant

Education: Prenatal CMV Education

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 swol-len glands.
- A blood test can tell whether you have ever been infected with CMV.
- Healthy infants and children who are infected with CMV after birth rarely have problems.

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;

• **UDOH 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).

Education: CMV and Hearing Loss

THE EARLIER, THE BETTER

As is the case with any baby not passing their outpatient, or 2nd hearing screening, a full hearing test should be completed as soon as possible by a pediatric audiologist.

If you are in need of an audiologist with expertise in diagnosing hearing loss and fitting hearing aids on young children, you can go to https://ehd-pals.org/ to find one in your area.

You can also talk to your hospital newborn hearing screening program or your child's primary care provider for resources.

The sooner your baby's hearing ability is determined, the sooner they will be able to get the help they need.



Even babies with hearing loss may react to loud sounds or appear to hear



Congenital CMV causes almost a third of all childhood hearing losses in Utah



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STATE OF UTAH DEPARTMENT OF HEALTH

Cytomegalovirus

Congenital CMV and Hearing Loss



What Parents Need to Know

Education: CMV and Hearing Loss

CONGENITAL CYTOMEGALOVIRUS AND HEARING LOSS

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

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

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

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

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



Newborn Hearing Screening

If your baby does not pass his/her newborn hearing screening in the hospital, it is very important that he have another (outpatient) screening before 14 days of age. This repeat hearing screening is necessary to complete the newborn hearing screening process, and should be scheduled before your baby is discharged.

Outpatient Re-Screening

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

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

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

What if my baby has congenital CMV?

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

CMV FACTS

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

Congenital CMV is the most common cause of nonhereditary hearing loss in children

Education: CMV Testing

LAB Collection and Testing For CONGENITAL



Cytomegalovirus for PARENTS

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

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



Acceptable

Acceptable

2 hours or more after feeding

UNacceptable

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.

- CMV Detection by PCR CPT code 87496 (qualitative preferred) or CPT code 84797 (quantitative) should be conducted.
- Results should be sent to your baby's requesting physician AND to the Utah Dept. of Health CMV Fax: 801-584-8492



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

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



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 <u>not</u> your patient, please call UDOH at (801) 584-8215.





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

Urine

Acceptable

OR

Saliva*

NOT

Blood

UNacceptable

Acceptable

2 hours or more after feeding

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

- Send the sample to the lab for <u>CMV PCR testing</u> 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).
- 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

cCMV Testing: EHDI Facilitation



Cytomegalovirus & Auditory Brainstem Response Testing Orders

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

Parent: Your baby failed their newborn hearing screening (NBHS) 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 (PCP) 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:	Birthdate:
Mother's Full Name:	Phone #(s):
Primary Care Provider (PCP):	Location:
PCP Phone #:	PCP Fax #:
NRHS Facility:	Phone #

For patient-specific questions, contact NBHS facility

1. Diagnostic ABR Testing

CPT code 92652 Diagnosis Code H91.90 (neonatal hearing loss)
Diagnosit c ABR testing should include BOTH 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 the preferred method; if unable obtain then use Saliva (Blood is 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**

<u>Test name</u>: 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

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# 801-536-0492

ORDERING PHYSICIAN: John C. Nelson, MD, EHDI Medical Director

Revised 7.12.22

QUESTIONS?? Please call 801-273-6600

cCMV Follow-Up:

EHDI Facilitation



- Referral to cCMV Multidisciplinary Clinic at Primary Children's Hospital
- Connect PCP to cCMV
 Specialist
- cCMV Risk Factor added to HT
- Serial audiologic monitoring

EHDI and CMV



- Strong relationship to childhood hearing loss
- Time-sensitive
- Prenatal education
- Information is power / informed choice

Steve Sisolak Governor



Richard Whitley Director

State of Nevada Department of Health and Human Services

Development, Implementation and Results of a Cytomegalovirus Public Awareness Campaign: Nevada's Experience

Division of Public and Behavioral Health

Perry Smith



Development, Implementation and Results of a Cytomegalovirus Public Awareness Campaign: Nevada's Experience

Perry Smith

EHDI Coordinator

Nevada Division of Public and Behavioral Health

Phone: (775) 684-4274

Email: pgsmith@health.nv.gov



- Nevada EHDI
- Finding and building relationships with CMV experts
- Nevada EHDI website CMV page





Cytomegalovirus (CMV)

EARLY HEARING DETECTION AND INTERVENTION (EHDI) - CYTOMEGALOVIRUS (CMV)

Cytomegalovirus (pronounced sy-toe-MEG-a-low-vy-rus), or CMV, is a common virus that infects people of all ages. In the United States, nearly one in three children are already infected with CMV by age five. Over half of adults by age 40 have been infected with CMV. Once CMV is in a person's body, it stays there for life and can reactivate. A person can also be re-infected with a different strain (variety) of the virus.

Most people infected with CMV show no signs or symptoms. That's because a healthy person's immune system usually keeps the virus from causing illness. However, CMV infection can cause serious health problems for people with weakened immune systems and for unborn babies (congenital CMV).

(text borrowed from: https://www.cdc.gov/cmv/overview.html)

- Centers for Disease Control and Prevention Cytomegalovirus
- Centers for Disease Control and Prevention What Women should know about Cytomegalovirus (brochure)
- American Academy of Pediatrics Cytomegalovirus (CMV) Infections
- National CMV Foundation
- Congenital CMV 101: From Prevention to Treatment Dr. Michael Cannon, Epidemiologist, CDC
- Southern Nevada Health District Cytomegalovirus
- Nevada Dual Sensory Impairment Project Etiologies Of Deafblindness: Cytomegalovirus



- Nevada EHDI
- Finding and building relationships with CMV experts
- Nevada EHDI CMV webpage
- Co-brand literature with the National CMV Foundation









Congenital cytomegalovirus (CMV) is the most common viral infection, and the leading cause of non-genetic hearing loss, that infants are born with in the United States.

Every pregnant woman is at risk of acquiring CMV. And 91% of women **DON'T** know about it.

CMV is common, serious and preventable.



1 out of 3 pregnant women who become infected with CMV during pregnancy will pass the virus through to their unborn child



1 child is permanently disabled every hour



1 in 200 children are born with congenital CMV each year





- Nevada EHDI
- Finding and building relationships with CMV experts
- Nevada EHDI CMV webpage
- Co-brand literature with the National CMV Foundation
- CMV Promotion with our partners and stakeholders



- EHDI Advisory Committee
- Nevada Hands & Voices
- Deaf Centers of Nevada
- Early Intervention Services
- Interagency Coordination Council IDEA Part C
- Maternal, Child Health Advisory Committee
- Nevada Commission for Person who are Deaf and Hard of Hearing
- Newborn Screening Advisory Committee



- Nevada EHDI
- Finding and building relationships with CMV experts
- Nevada EHDI CMV webpage
- Co-brand literature with the National CMV Foundation
- CMV Promotion with our partners and stakeholders
- Results of these Efforts



Working with a Public Relations and Digital Marketing Vendor

- CMV Awareness Campaign Guiding Principles
 - Purpose
 - Goals and Objectives
 - Target Audiences
 - Marketing Strategies
 - Scope of Work
 - Stages and Timelines



Working with a Public Relations and Digital Marketing Vendor

Website Development

- A key component of the campaign's marketing efforts was the creation of a Nevada CMV website.
- The website serves as an informational portal for interested parties and as a landing pad location for current and future campaign ads.
- The site provides additional details, materials, contact information and links to local and national partners.
- https://nevadacmv.org/





Working with a Public Relations and Digital Marketing Vendor

Digital Advertising Campaign

- Placement of digital advertising on various online ad platforms.
 (Facebook, etc)
- Native ads: The campaign focused on channels to target our primary audience of women of childbearing age in Nevada.
- The ads were to inform and drive audiences to the CMV website
- Ads ran for 8 weeks
- Three video ads were produced





Working with a Public Relations and Digital Marketing Vendor

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Working with a Public Relations and Digital Marketing Vendor

Digital Advertising Campaign

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- Ads ran for 8 weeks
- Three video ads were produced
- Results of Awareness Campaign





Working with a Public Relations and Digital Marketing Vendor

- Digital Advertising Campaign Results
 - 1.7 million total impressions (digital media renders on a user's screen)
 - 1.3 million Facebook impressions
 - 53,547 videos viewed
 - Website Visits:
 - average of 230 visits/day during campaign
 - 100 visits/day following campaign, then dropping to 30/day after 1 month
 - 5 clicked on a link
 - 8 downloaded literature
 - 1 contacted EHDI



Next Phase of CMV Awareness Efforts

What are Nevada EHDI's next steps

- The EHDI Stakeholder Committee will take the lead in developing and implementing the next CMV awareness efforts.
- Collaborate with the EHDI Partners and Stakeholders
- Continue to use the website as the landing location of future activities
- Continue to use the videoclip ads
- Expand the target audience to other demographics





Kirsten R. Coverstone, AuD

Coordinator,
Early Hearing Detection & Intervention |
Newborn Screening Program

MN approach to CMV screening - Legislation

- Led by parents & advocates
- Attempted & failed several times
- Vivian Act passed in July 2021
 - Directed MDH to provide cCMV education & outreach
 - Directed Newborn Screening Advisory Committee to review congenital CMV to be added
 - Provided funding to support directives



MN approach to CMV screening: Universal

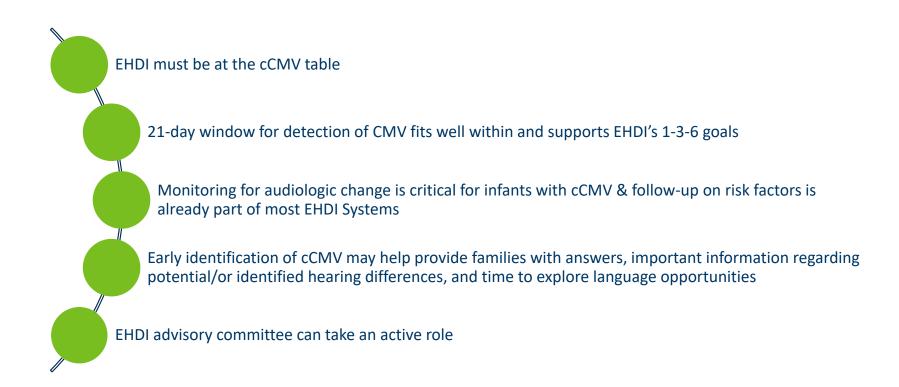
- MDH began program wide planning
- Universal cCMV Screening Study
 - CMV PCR testing used on both saliva and DBS
 - Average DBS sensitivity of 75%; higher than previously reported studies
- Condition readiness work group became implementation workgroup





MN presentation for more details: cCMV Screening & Follow-up in Minnesota: Process and Lessons Learned to Date

EHDI & cCMV



cCMV Education

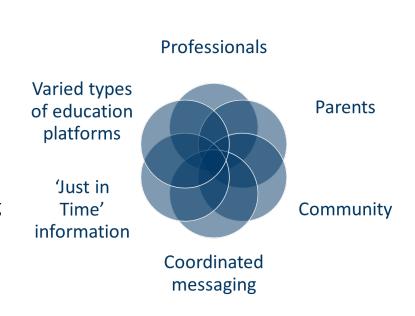
CMV education shall:

- be up to date, evidence-based, & reviewed by experts
- be culturally & linguistically appropriate for all recipients
- Be available to health care practitioners, women who may become pregnant, expectant parents, & parents of infants
- include an outreach program to educate
 & raise awareness



Incorporate CMV education into EHDI materials

- Keep cCMV in mind when reviewing existing or creating new EHDI education
 - Website
 - Education/Presentations
 - Stakeholder meetings
 - Risk factor materials
- Use consistent and coordinated messaging
- Utilize varied education platforms
- Adapt & use what has already been created (steal shamelessly/share seamlessly)



cCMV Capacity Building & Sustainability



- Although there is some overlap with EHDI follow-up, just adding cCMV to current EHDI program staff would not be feasible or sustainable
- How to best utilize & support stakeholders
- Organizational support for increased informatics, communication, data analysis, etc
- GREAT funding from the start is supporting implementation of a robust screening & followup program that will be sustainable

MDH cCMV



Blood Spot screening, result notification, 'Just in Time' education, confirmation results



Connect families to information, resources, and support



Complete ongoing data collection, integration, and analysis for public health surveillance and program improvement



Build NBS system capacity and ensure equitable access and interventions

MN Universal cCMV Screening

- Successful GO LIVE February 6, 2023
- Press Release & Media Coverage Feb 8, 2023

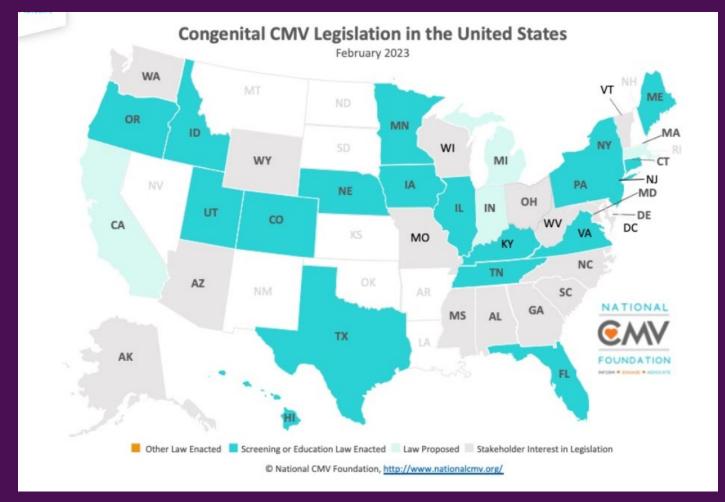




Minnesota becomes first state to screen all newborns for congenital cytomegalovirus

Common virus can lead to hearing loss in about 20% of diagnosed cases

BOTH: *Illinois*, <u>Iowa</u>, <u>Kentucky</u>, <u>Maine</u>, <u>Minnesota</u>, <u>New York</u>, <u>Pennsylvania</u>, <u>Utah</u>



EDUCATION:
<u>Colorado</u>, <u>Hawaii, Idaho</u>,
<u>Nebraska</u>, <u>New York</u>,
<u>Oregon</u>, <u>Texas</u>, <u>NJ</u>, <u>Tenn</u>

SCREENING: <u>Connecticut</u>, <u>Florida</u>, <u>Virginia</u>

Questions?

UTAH:

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https://www.health.state.mn.us/diseases/cytomegalovirus/index.html