

# Welcome to Utah!

Utah's wide-open skies and our lakes; core principles such as **faith, knowledge**, freedom, **optimism**, and tradition



famous snow.

The red rock canyon represents Southern Utah's majestic landscape. The color symbolizes **perseverance**, and nods to the red strips of the United States flag, but on the Utah flag the value of the red color is slightly warmer in hue.



Utah's new state flag. Utah Legislature

The beehive represents Utah's history and a sense of community, plus "**Industry**," our state's slogan.

At the foundation of the beehive is a five-pointed star, which represents **hope** and 1896, the year Utah achieved statehood and became the 45th star on America's flag, a sign of our loyalty to our country.

A gold rim stands for prosperity, while the hexagon shape – among nature's **strongest** shapes – cradles the beehive and represents unity and the strength of Utah's people.



# Thank you to our prize donors!

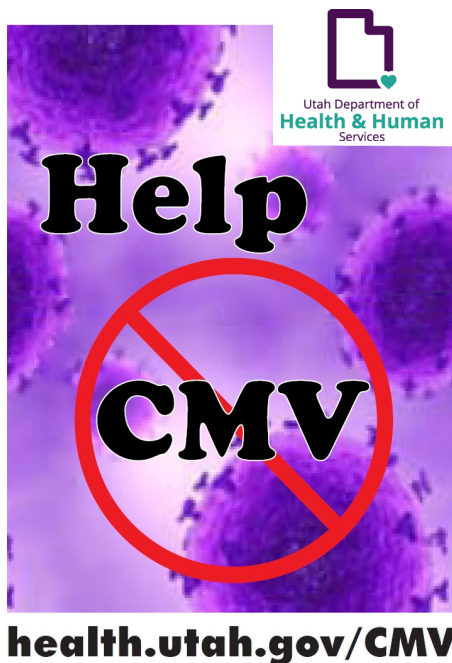


# Advancing CMV education and testing: reflections on a decade of progress

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Stephanie Browning McVicar, Au.D., CCC-A  
Early Hearing Detection and Intervention (EHDI) Programs  
Manager

# Learning objectives



**Learning objective 1:** Describe the evolution and impact of Utah's CMV testing program over the last 10 years

**Learning objective 2:** Cite advancements in legislation and progress around CMV both inside and outside the United States

**Learning objective 3:** Identify the central role of parents in advocacy and education





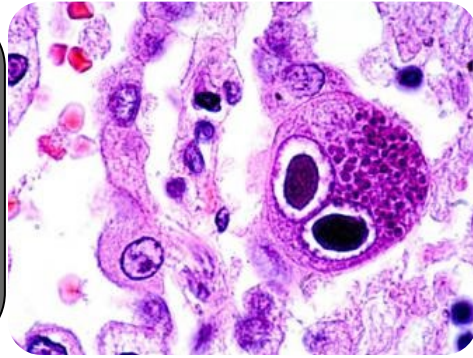
# The Utah EHDI programs

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Early Hearing  
Detection and  
Intervention (EHDI)



Congenital  
Cytomegalovirus  
(CMV) Public  
Health Initiative



Children's Hearing  
Aid Program (CHAP)



# Let's go back in time...



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



**cmv**  
CYTOMEGALOVIRUS  
PUBLIC HEALTH & POLICY  
CONFERENCE

Come learn how you can help reduce the number of babies born with CMV.

For more information go to: [cmv.usu.edu](http://cmv.usu.edu)

### Cytomegalovirus Public Health & Policy Conference

Congenital Cytomegalovirus (CMV) is the most common congenital infection found in developed countries. Pregnant women who contract CMV can pass the virus onto their unborn baby, which can result in multiple disabilities including: hearing loss, vision loss, poor brain growth, cerebral palsy, epilepsy, and, in rare cases, fetal death.

CMV infects about 30,000 babies each year in the U.S. In Utah, this translates to one baby born with CMV every day. Of the babies born with congenital CMV, 1 of every 5 will have permanent disabilities due to the virus. Recognizing the lack of awareness about CMV and its potential devastating effects on babies, Utah lawmakers led the nation by passing a bill that directs the Utah Department of Health (UDOH) to establish a public education program to raise awareness about CMV and ways to prevent its spread.

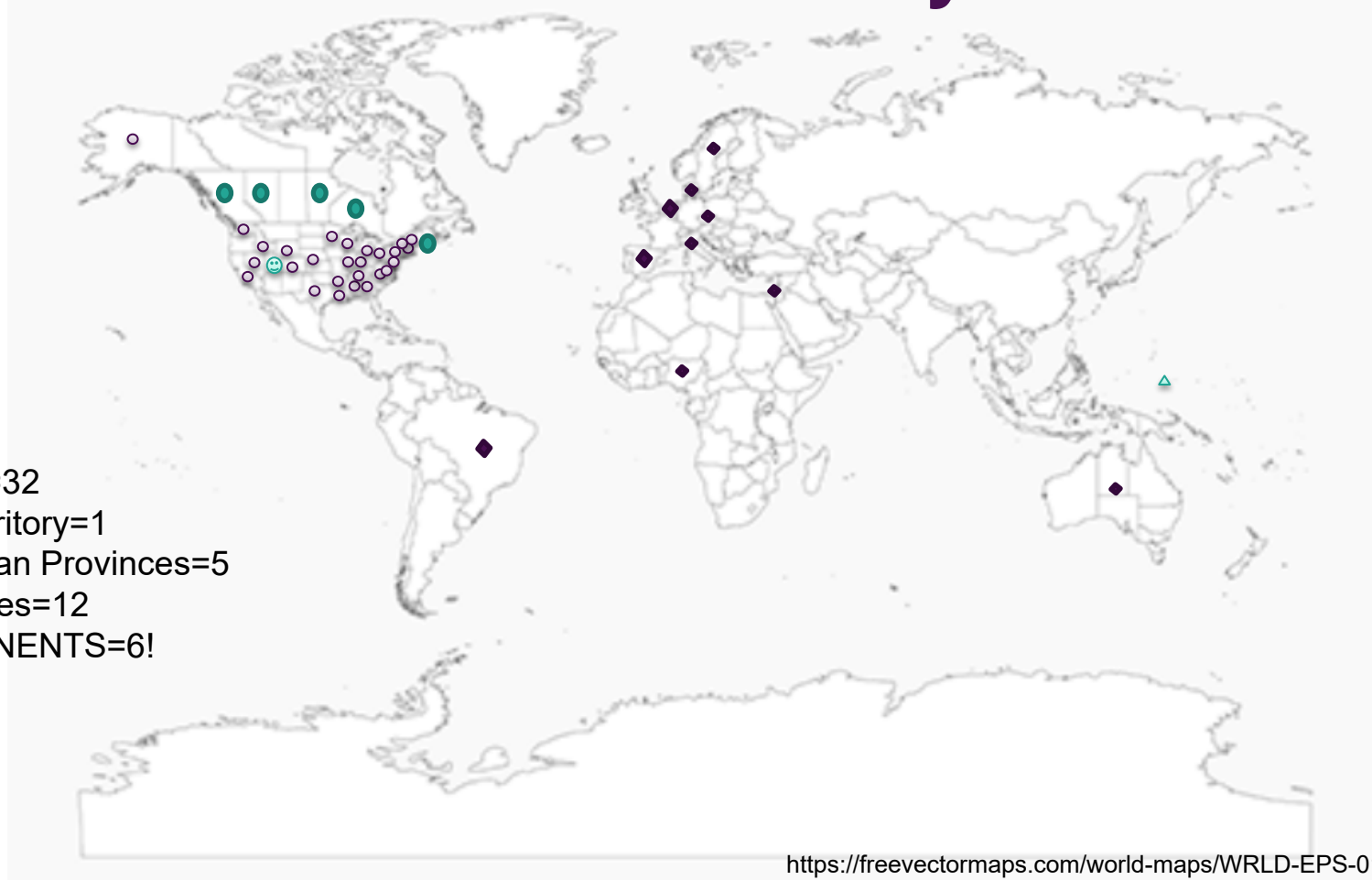
**Continuing Education is available!**

**Who should attend:**

- Clinicians
- Researchers
- University faculty
- Childcare Providers
- Public Health Professionals
- Students
- Advocacy Organizations
- Parents
- Early Intervention Providers
- Policymakers

**September 26 & 27, 2014**  
**Little America Hotel - Salt Lake City, Utah**

# 2014 CMV Public Health & Policy Conference



N=292  
States=32  
US Territory=1  
Canadian Provinces=5  
Countries=12  
CONTINENTS=6!

# Utah CMV law

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

\*Beginning 7/1/2022 UDOH=DHHS (Department of Health and Human Services) Recode: 26B-7-105





## 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](http://health.utah.gov/CMV)

*Sam M. B.*



## Protect the Circle

## Passing down knowledge of Cytomegalovirus (CMV)

Growing your family is an honor and blessing. The mother, father, and all ancestors have a role in preparing for a new child.



# Cytomegalovirus



## What women NEED TO KNOW about CMV

For Women Who are  
Pregnant or Planning to  
Become Pregnant

### 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](http://health.utah.gov/cmv)  
[nationalcmv.org](http://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.



# Educational materials

## 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 1<sup>st</sup>, 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

1



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

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

## CMV/EHDI MATERIALS ORDER FORM

Fax To: (801) 536-0492

**Ship To:**

Utah orders are provided free of charge.

QTY	Item	Description	Spanish



**Toothbrush:**  
ITEM # TB\* Spanish Only



**Travel Toothbrush:**  
ITEM # TT\*



**Flyer: (Two Sided)**  
ITEM # CMVF\*



**Newborn Hearing Screening Brochure: 100 pk**  
ITEM # NBHS\*



**American Indian Items:**  
ITEM # AIP (16" x 20")



**CMV During Pregnancy Can Harm Your Baby**  
ITEM # HP (4 1/2" x 10")



**Brochures: 100 pk**  
ITEM # CMVHL\*  
ITEM # WWTK\*  
ITEM # HP\* (8.5" x 11")



**Hand Sanitizer:**  
ITEM # HS\*



**Lip Balm:**  
ITEM # LB\*

\*Item also available in Spanish

Revised 3.3.2020

## 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.

1

Do U know about the risks of CYTOMEGALOVIRUS during pregnancy?



1 OF EVERY 5 children born with **CYTOMEGALOVIRUS (CMV)** will have **PERMANENT DISABILITIES**;

And yet,  
MOST WOMEN ARE UNAWARE that CMV during pregnancy can harm their baby.

Know the Facts.  
Protect your baby.

Learn more at:  
**HEALTH.UTAH.GOV/CMV**  
or  
**FACEBOOK.COM/CMVUtah**





1 out of 150 children  
born in Utah has Cytomegalovirus (CMV).

1 of every 5 children born in Utah has CMV.

And while it's not a major health problem for most children, it can cause developmental delays and hearing loss.

MOST children born with CMV do not have any symptoms.

LEARN MORE AT:  
[HEALTH.UTAH.GOV/CMV](http://HEALTH.UTAH.GOV/CMV)

Know the facts.  
Protect your child.



CMV).

ProtectYourBaby  
Health Initiative  
[HEALTH.UTAH.GOV/CMV](http://HEALTH.UTAH.GOV/CMV)



**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/cmvm](https://health.utah.gov/cmvm)



UTAH DEPARTMENT OF  
**HEALTH**





# Let's go back in time...

## Bill Sponsor:



Rep. Menlove, Ronda  
Rudd

## Floor Sponsor:



Sen. Bramble, Curtis  
S.



## H.B. 81

## Enrolled Copy

- 30       • child care programs administered at public schools by organizations other than  
31 the public schools if the care is provided under contract with the public schools  
32 or on school properties or if the public schools accept responsibility and  
33 oversight for the care provided by the organizations;
- 34       • child care programs provided by organizations that qualify for tax exempt status  
35 under Section 501(c)(3) of the Internal Revenue Code or that are provided  
36 pursuant to a written agreement with a municipality or county;
- 37       • child care programs provided at residential support programs that are licensed  
38 by the Department of Human Services;
- 39       • school nurses;
- 40       • health educators;
- 41       • health care providers offering care to pregnant women and infants; and  
42       • religious, ecclesiastical, or denominational organizations offering children's  
43 programs as a component of worship services;
- 44       • directs medical practitioners to test infants, who fail the newborn hearing screening  
45 test(s), for CMV and inform the parents of those infants about the possible birth  
46 defects that CMV can cause and the available treatment methods;
- 47       • directs the Department of Health to notify medical practitioners of the CMV testing  
48 requirements; and
- 49       • grants rulemaking authority to the Department of Health.

## Money Appropriated in this Bill:

51       None

## Other Special Clauses:

53       None

## Utah Code Sections Affected:

## ENACTS:

56       26-10-10, Utah Code Annotated 1953

57

# 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)

**UDOH** 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).

# THE

## Utah Chapter of the Message From t



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We hope to accomplish our goal  
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Relations organization, *Absolute*  
website and logo free-of-charge.  
be able to educate the communi  
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ranges and legislators about the

STATE OF UTAH  
DEPARTMENT OF HEALTH

Cytomegalovirus

Congenital CMV  
and Hearing Loss



What Parer

STATE OF UTAH  
DEPARTMENT OF HEALTH

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CMV Congénito y  
la Pérdida de  
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Lo que los Padres Necesitan  
Saber

Summer 2013



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evement Award & Hemond  
When I Grow Up Award

CMV Public Health Initiative

Health Services Available to

Medical Home Portal

blause, Applause

d allergies? If so, we're here to

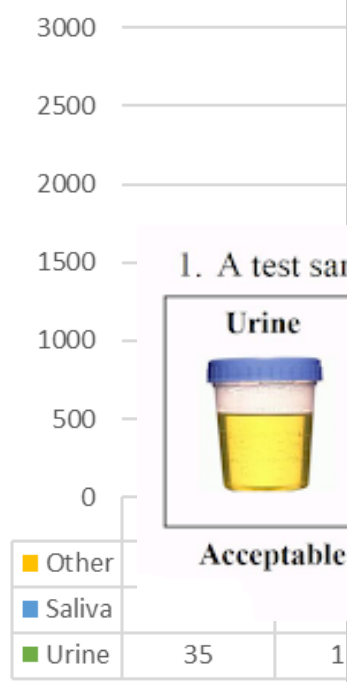
acco dependence be done in

# 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

**OR** (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.



# LAB Collection and Testing For CONGENITAL 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**



**Acceptable**

OR

**Saliva\***



**Acceptable**

NOT

**Blood**



**UNacceptable**

**2 hours or more after feeding**

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**



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](https://Health.utah.gov/CMV)

Only includes one lab result per  
 'Other' includes CSF and IgG/I

**lution of specimens**

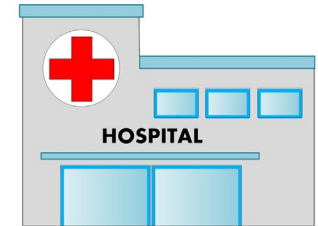
INPATIENT

OUTPATIENT

Hospital  
10 - 12 hrs.

Before  
Discharge  
24 hrs.

7 - 10  
Days



# Utah Newborn Hearing Screening



## OUTPATIENT SCREENING

By 14 days of age

PASS

REFER

MEDICAL HOME

Monitor Development:

- Hearing
- Speech/Language

PEDIATRIC AUDIOLOGIST

By 3 months of age

Auditory  
Brainstem  
Response (ABR)  
Testing



LAB

By 21 days of age

CMV PCR  
Testing



\*

\*2 hours or more  
after feeding

# Utah Newborn Hearing Screening

# 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.





## Evaluation of Suspected Congenital Cytomegalovirus Infection (cCMV)

### If any of the following present:

- 1) Mother positive for CMV infection during pregnancy
- 2) Abnormal head size (OFC <10<sup>th</sup> %ile OR >90<sup>th</sup> %ile at birth)
- 3) Intrauterine growth restriction (weight <10<sup>th</sup> %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/mm<sup>3</sup>)
- 11) Failed hearing screen

Send urine CMV PCR  
(obtain by 21 days of life when possible)

### If CMV +, perform the following tests:

### If any of the following present:

- 1) Mother positive for CMV infection during pregnancy
- 2) Abnormal head size (OFC <10<sup>th</sup> %ile OR >90<sup>th</sup> %ile at birth)
- 3) Intrauterine growth restriction (weight <10<sup>th</sup> %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)
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- 9) Leukomalacia, polymicrogyria, lissencephaly, pachygyria, schizencephaly
- 10) Unexplained persistent thrombocytopenia (platelets < 100k/mm<sup>3</sup>)
- 11) Failed hearing screen

Send urine CMV PCR  
(obtain by 21 days of life when possible)

### At 3mos of age:

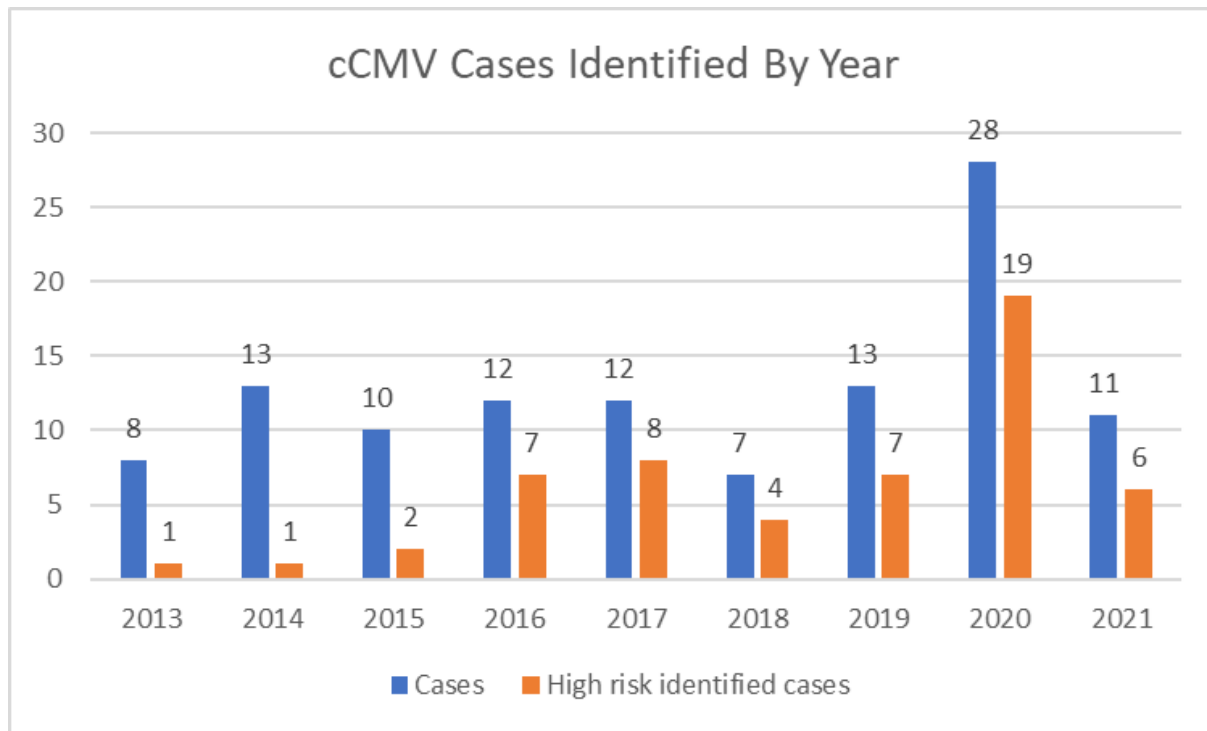
- Follow up with Audiology & ENT

### By 4 weeks of age:

- Consult Pediatric ID to discuss antiviral treatment
- Consult Pediatric Neurology if abnormal HUS or microcephaly

Evaluation in Multidisciplinary Congenital CMV Clinic  
Call (801) 662-1740 to schedule:

- Infectious Disease
- ENT
- Neurology



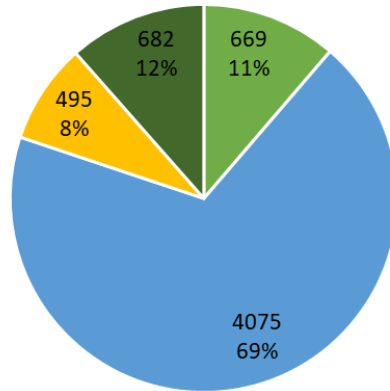
High Risk Testing Protocol had widespread adoption by hospitals (Intermountain) in Utah in the autumn of 2019

**cCMV+ Cases**

# CMV testing by target reason

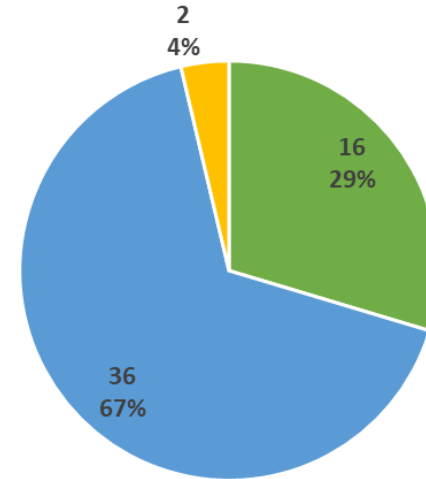
CMV Tests By Target Reason

■ Hearing Targeted ■ High Risk Targeted ■ Inpatient Rule Out ■ Unknown



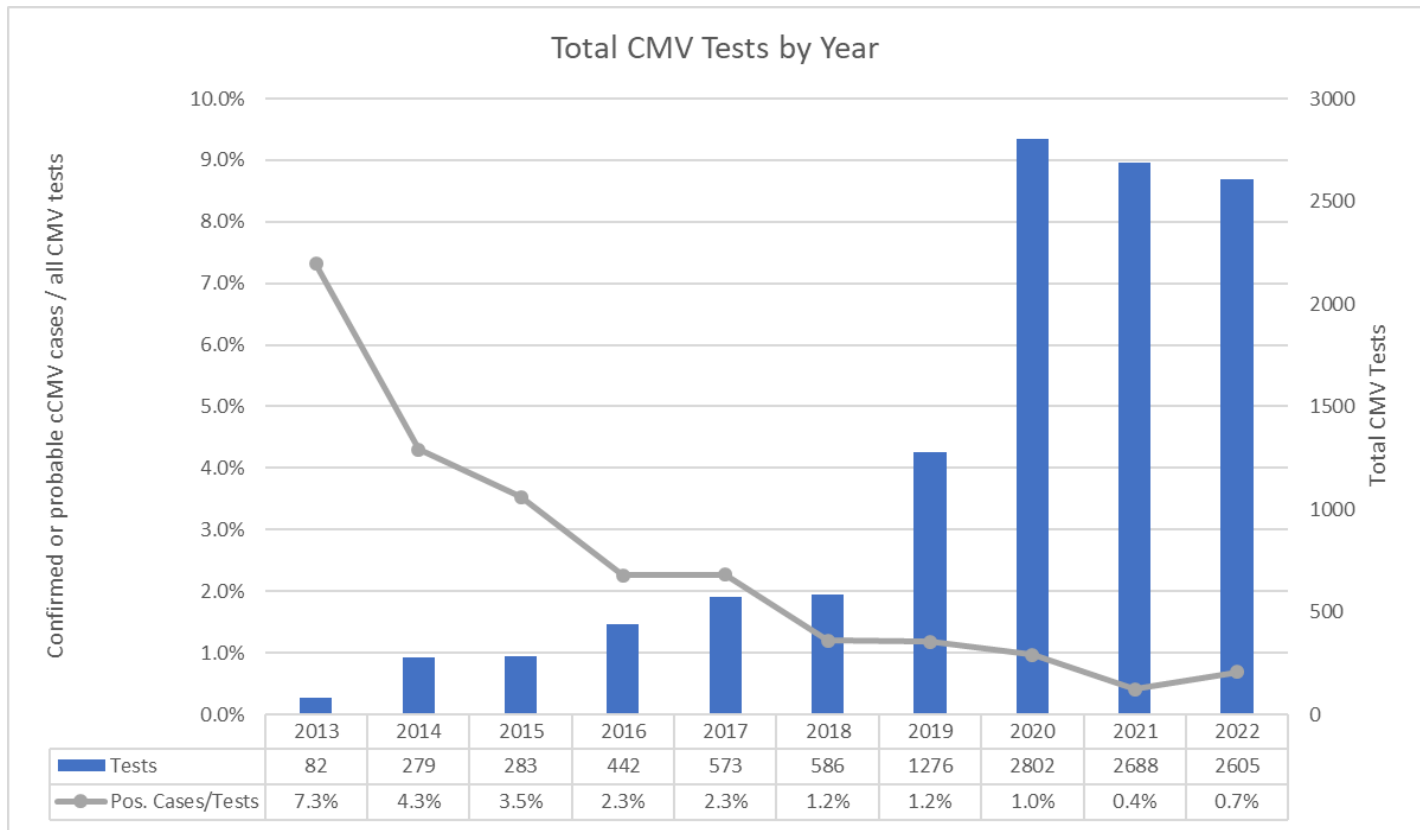
Test By Target Reason for cCMV+ Kids

■ Hearing Targeted ■ High Risk Targeted ■ Inpatient Rule Out



Data from 09/2019 - 06/2022, though 2021 is incomplete (Jan - May, Dec data only for 2021)

For all cCMV cases since 09/2019



**cCMV+ Cases**

# Utah CMV rule

## R398-4-5. Reporting Requirements

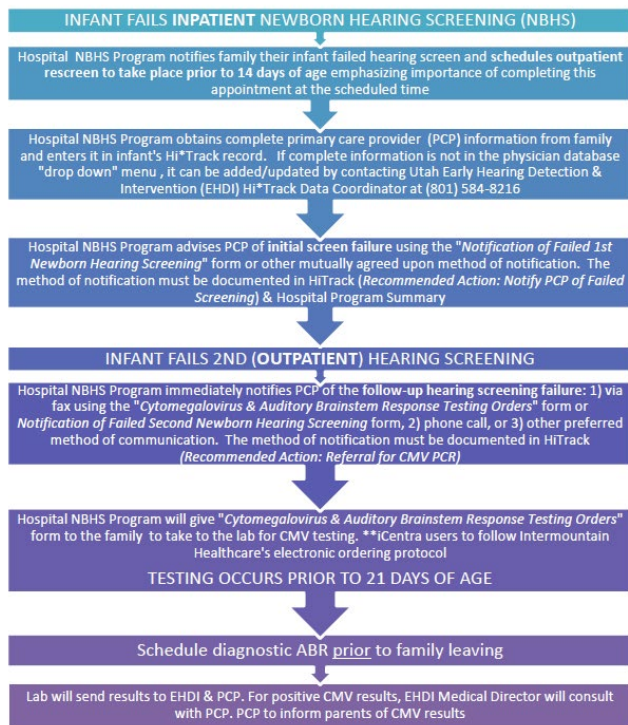
- Medical practitioners are required to **submit** results of the CMV testing **to UDOH** for each newborn under their care who is referred for CMV testing **within 10 days of receiving results.**



# Process maps



## Utah Newborn Hearing Screening & CMV Testing Protocol



# Reporting



## Hospital Births:



### Referral and Testing for CONGENITAL Cytomegalovirus (CMV)

(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

**\*\*>2 hours after feeding**

NOT



Blood

Unacceptable

3. Assist family to the hospital lab
4. Give the parent a "Congenital CMV and Hearing Loss" brochure →
5. Please call the CMV program if you need assistance: 801-273-6600
6. When lab results are received, please **fax results to (801) 536-0492**.



\*CMV & ABR Testing Order Form can be found in the Providers tab at [health.utah.gov/CMV](http://health.utah.gov/CMV).

For more information visit  
**[health.utah.gov/CMV](http://health.utah.gov/CMV)**



# Improving lab test receipt and amending rules

(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;

## R398-2-6. Reporting to Utah Department of Health....

### 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.

(3) The Department may make referrals to help coordinate care and provide resources for the affected child and their family

- (vii) hepatitis A;
- (viii) hepatitis B, including viral loads;
- (ix) hepatitis C, including viral loads;
- (x) HIV, including viral loads and confirmatory tests;

## 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 #: \_\_\_\_\_  
 NBHS Facility: \_\_\_\_\_ Phone #: \_\_\_\_\_

**\*\*For patient-specific questions, contact NBHS facility\*\***

### 1. Diagnostic ABR Testing

CPT code 92652 Diagnosis Code H91.90 (neonatal hearing loss)  
 Diagnostic: 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\*\***

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# 801-536-0492**

ORDERING PHYSICIAN: Michelle Hofmann, MD, MPH, MHCDS, FAAP, EHDI Medical Director



NPI#1760550628 UIC# 282612-1205

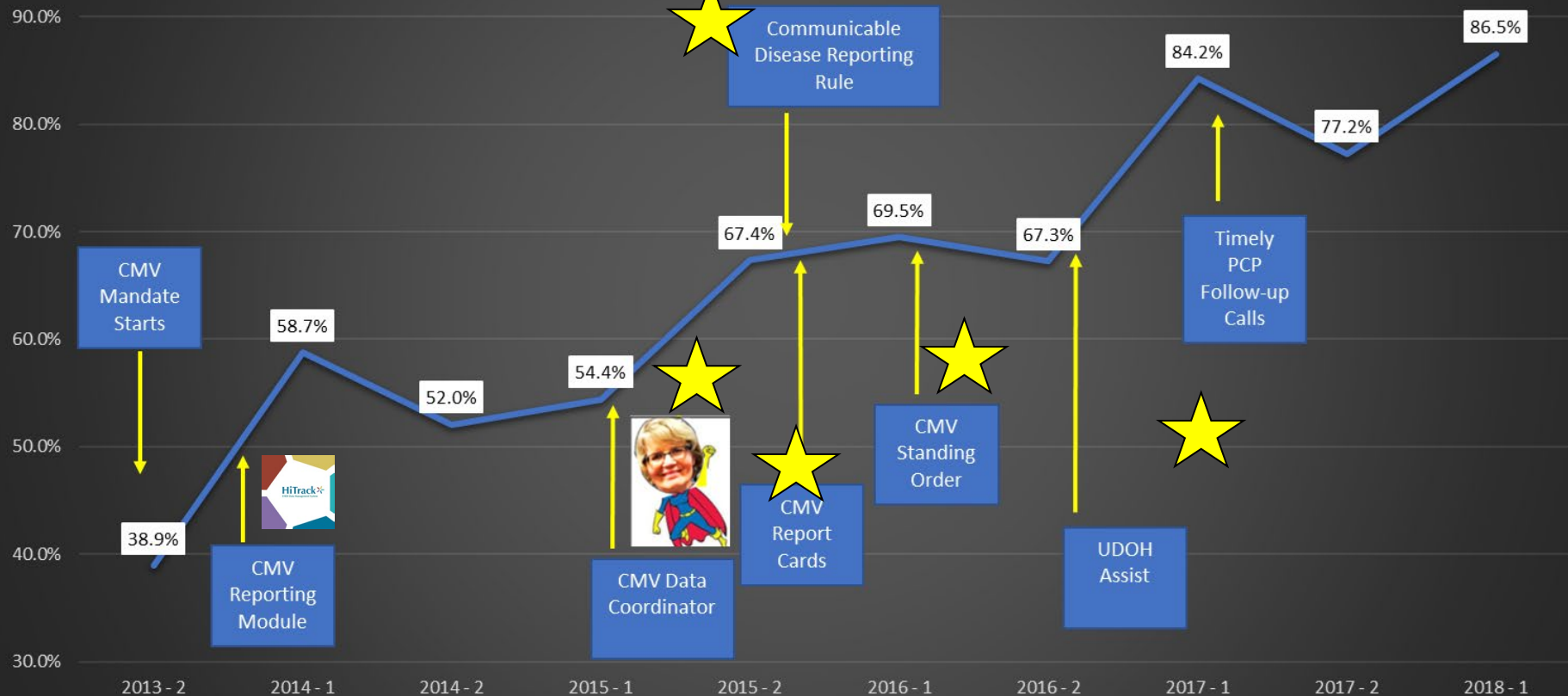
**\*\*QUESTIONS?? Please call 801-273-6600\*\***

Revised 6.7.23

# Utah CMV testing order

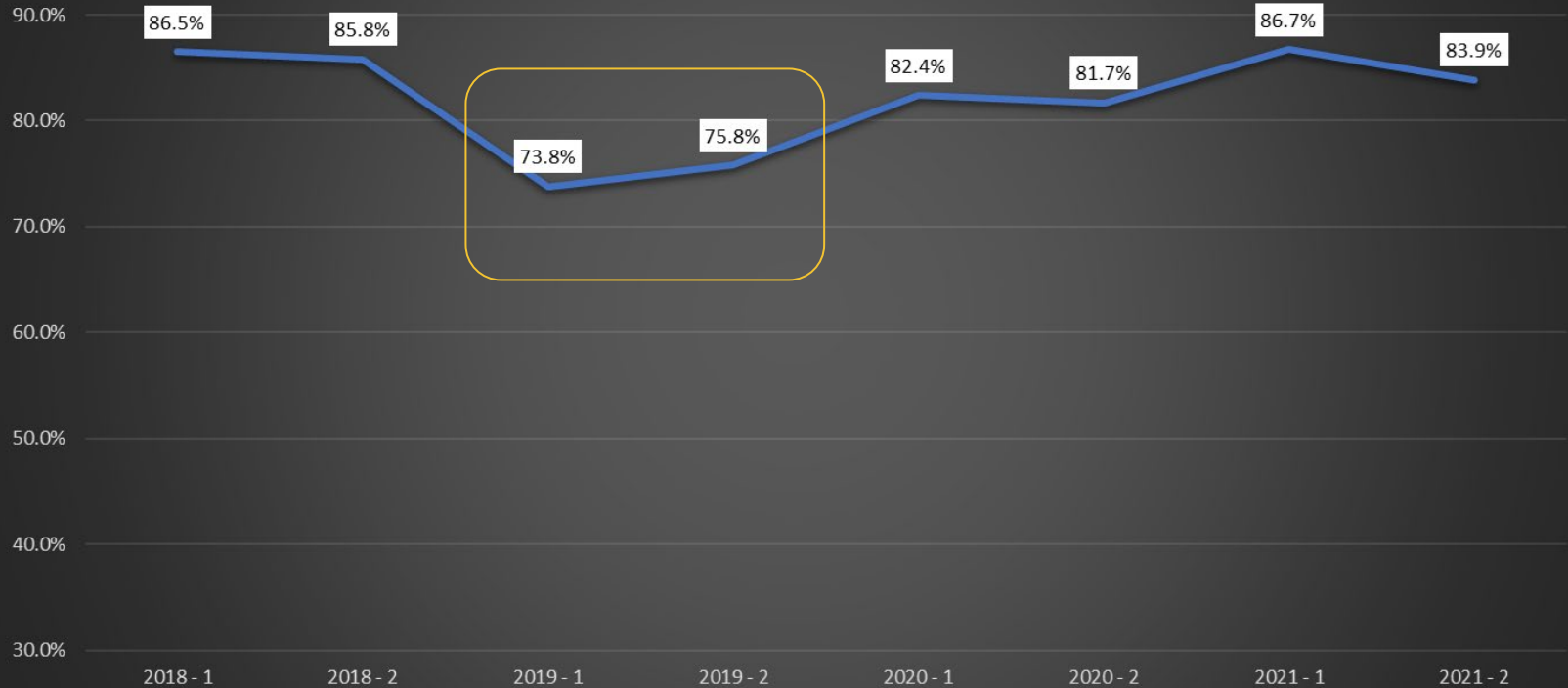
- Educate families regarding CMV testing requirement
- Order CMV testing *before 21 days* of age
- Only use *Urine or Saliva specimen*
- Remind mothers to not breastfeed their baby for **two hours** prior to saliva swab
- Results come to UDOH directly from the lab

# Percent of Eligible Babies Tested for CMV with Corresponding Improvement Events



# 2018-2021

Percent of Eligible Babies Tested for CMV - last 4 years



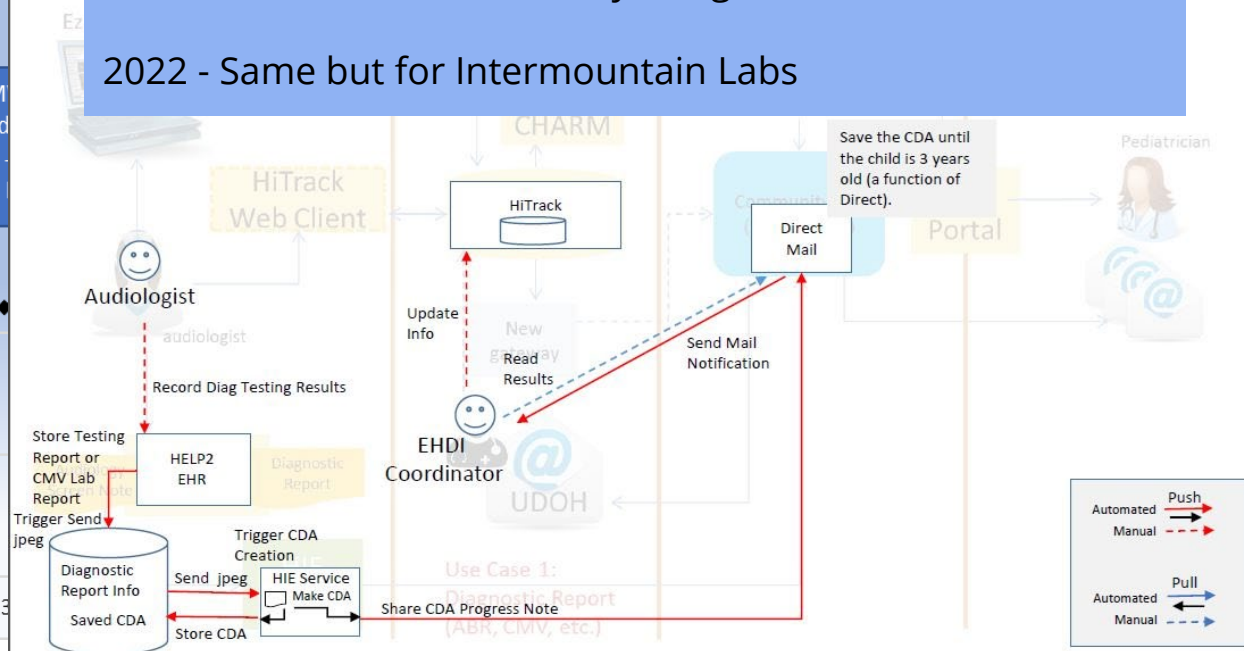
## Lab testing data collection

## Use Case 1: Share Diagnostic Testing with FHDH HiTrack and Utah Informatics Program Project:

2019 - HL7 Messages from ARUP - drop into a secure folder for the EHDI team to manually merge into HiTrack

## 2022 - Same but for Intermountain Labs

\*Not just hearing-targeted testing



# 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

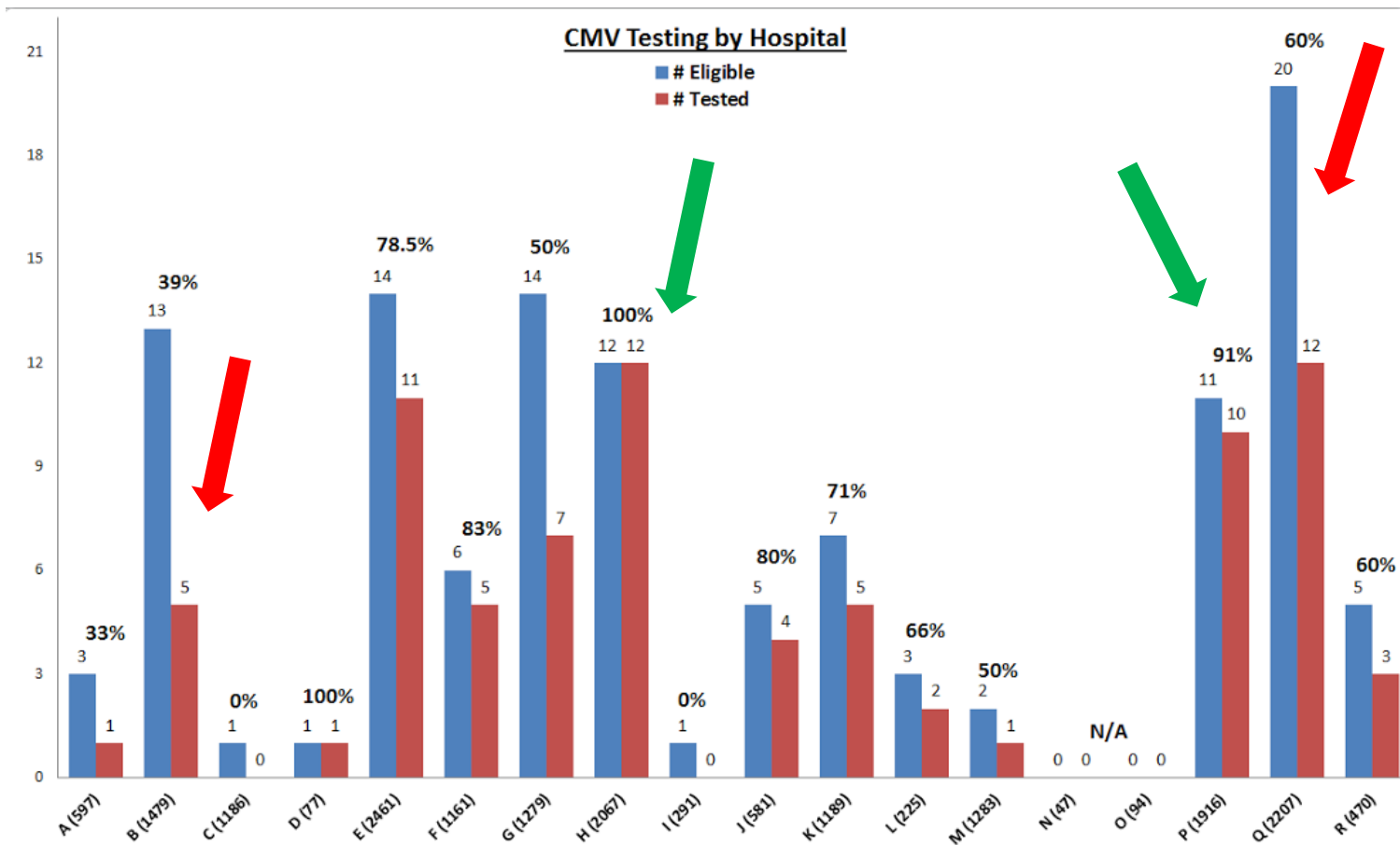
2020 & 2021

- **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

# Reasons for Missed Tests - Additional Examples

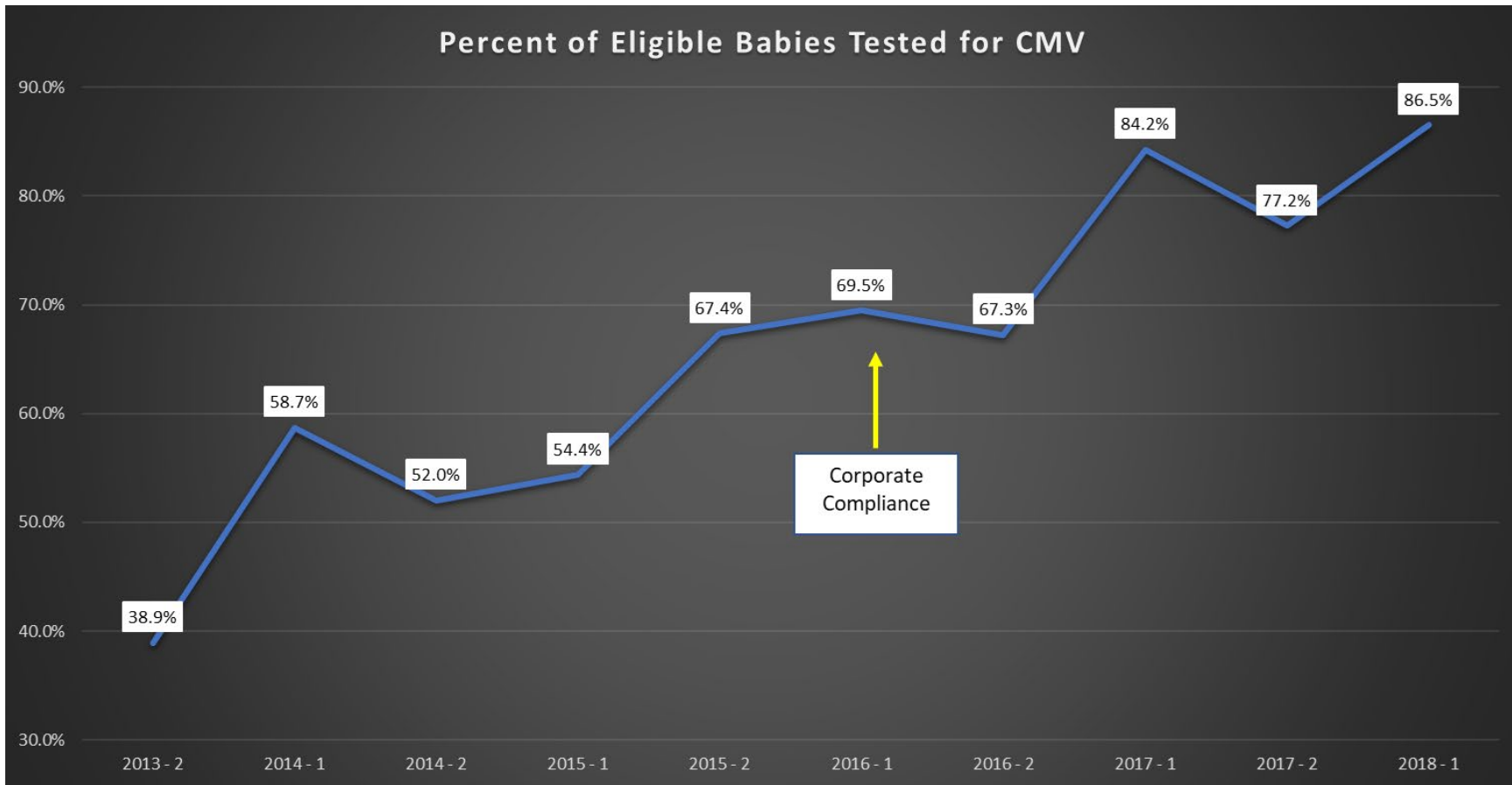
- **2018** - The child was referred to their pediatrician to get testing done, but sample was not collected at next appointment (reason unknown). EHDI CMV coordinator called parents and referred them to ARUP to get testing done. Saliva swab was collected, but unable to be processed. Family was exasperated and refused further testing at that point.
- **2019** - Family had to leave after OP appointment, so they didn't get CMV testing done. EHDI CMV coordinator called both the pediatrician and the family to encourage CMV testing to be completed. Older sibling of the child failed their NBHS and turned out "fine" so the family felt it was unnecessary to follow up with either CMV or diagnostic hearing testing.
- **2020** - Family did not follow up with CMV testing due to COVID-19 concerns.
- **2021** - Baby was medically fragile and prone to UTIs. Hospital doctors had not mentioned CMV test to the family, so they were skeptical of the state health department reaching out. EHDI CMV Coordinator attempted to follow up multiple times with no responses.

# Hospital variability





# Non-compliance?



# CMV report cards

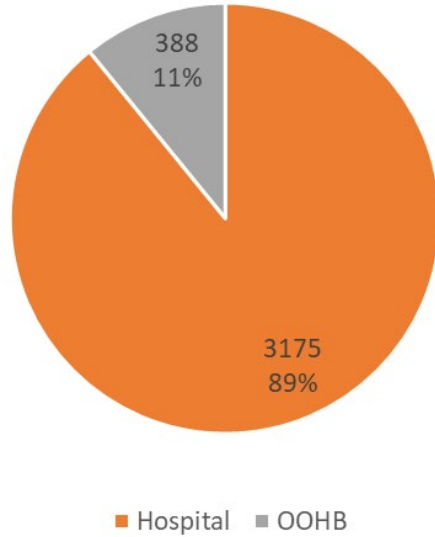
## Early Hearing Detection & Intervention (EHDI) NEWBORN HEARING SCREENING PERFORMANCE REPORT



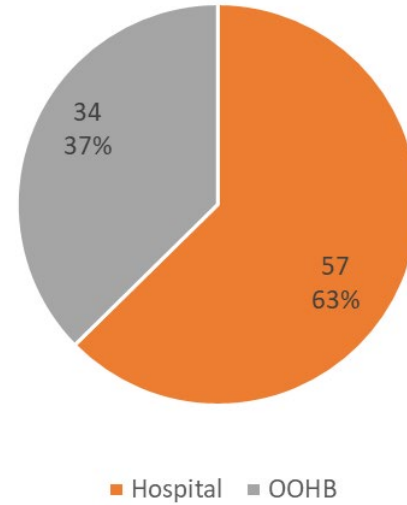
**Comments:** Great job screening and rescreening all of your infants. Your referral rate is high so be sure you aren't screening too quickly after birth. One infant did not receive follow-up audiological testing and then moved out of state. Per mom's report, this family was also unaware of the need for CMV testing, however did have it completed after outreach from the EHDI team. One CMV eligible infant refused CMV testing, and the two other eligible infants were tested after 21 days. If the CMV tests had been positive, it would have been difficult to differentiate between congenital vs postnatal (acquired) CMV infection. Please be sure you are assisting families with receiving CMV testing on eligible infants. All of your 2022 infants received their hearing screening before 1 month of age, meeting the 1 month milestone. Of those with diagnostic testing, both received it prior to 3 months of age. And the one infant with permanent hearing loss was enrolled in Early Intervention prior to 6 months of age. Thank you to your staff for always being responsive when further hearing information is needed. We appreciate you all. Thank you for all you do for the health of infants in Utah!

National EHDI milestones are: 100% of infants screened by 1 month of age, 90% diagnosed before 3 months of age, and 90% enrolled in Early Intervention (EI) before 6 months of age.

All Births CMV Eligible 2013-2021

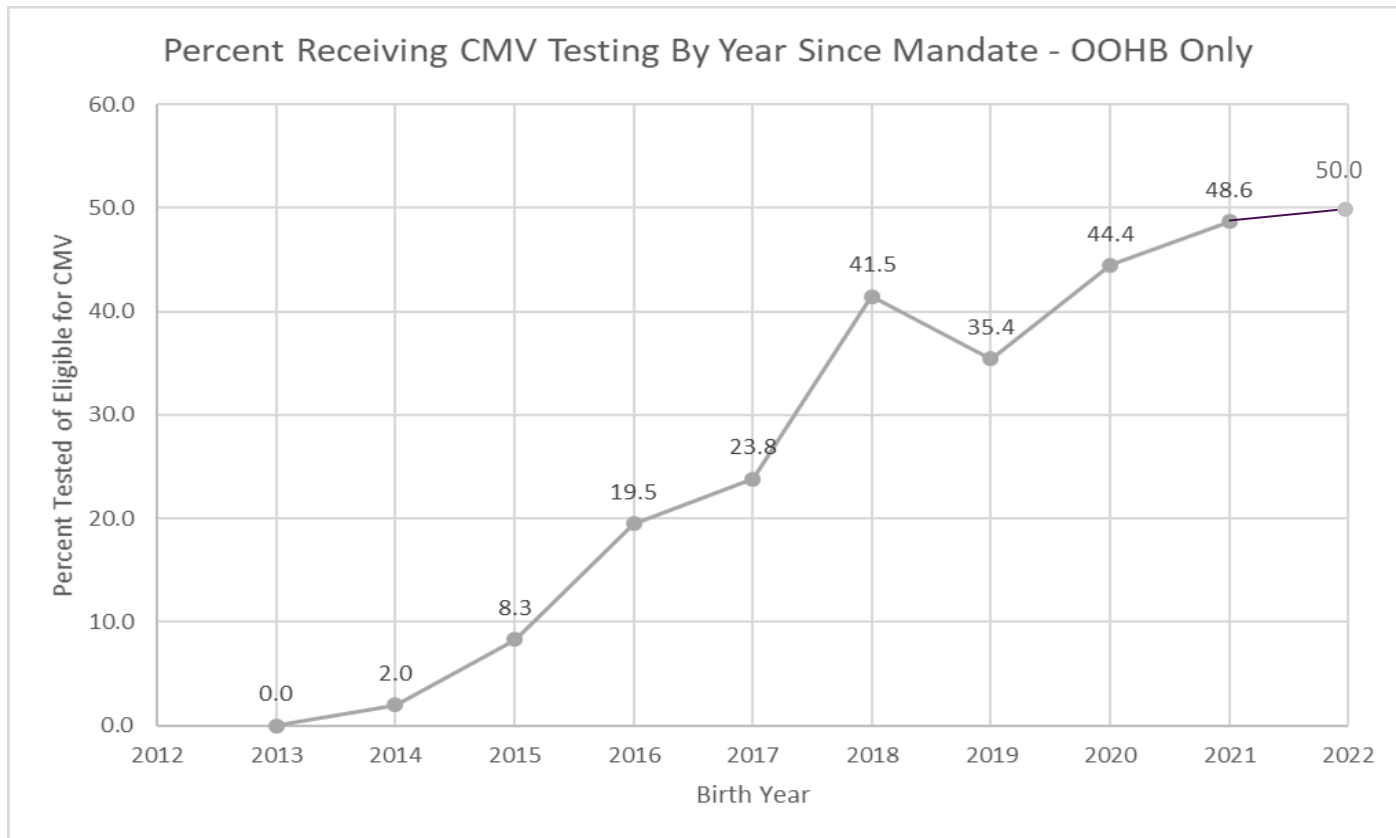


All CMV Eligible Babies Marked as 'Refused' 2013-2021



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) CMV data**



**OOHB Data**

# Early Hearing Detection and Intervention Program

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Out of Hospital Births

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Shannon Wnek, AuD, CCC-A, EHDI Audiology & Compliance Coordinator

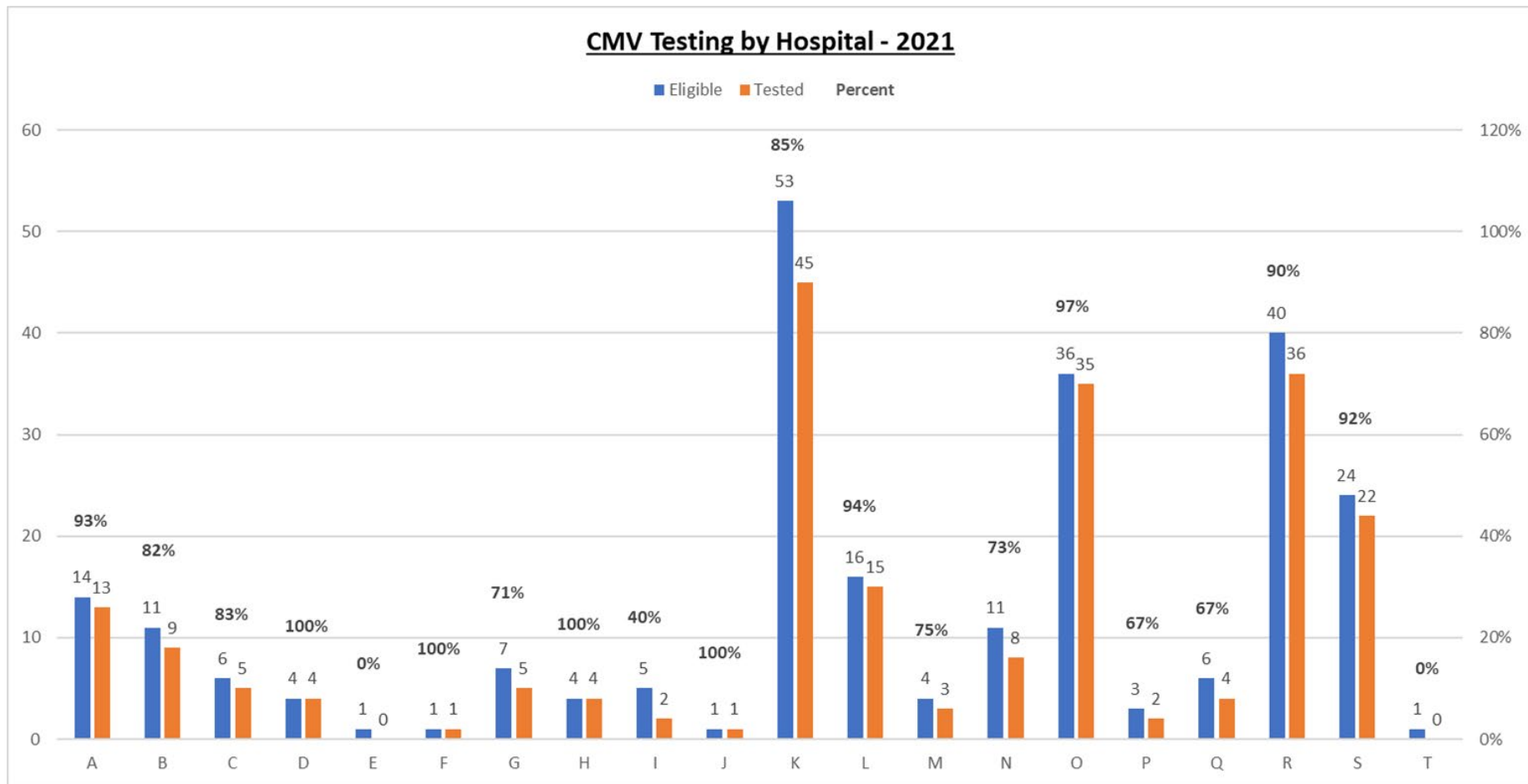
Holley Ezzell, BS, EHDI Follow-up Coordinator

Krysta Badger, BS, EHDI Data Coordinator

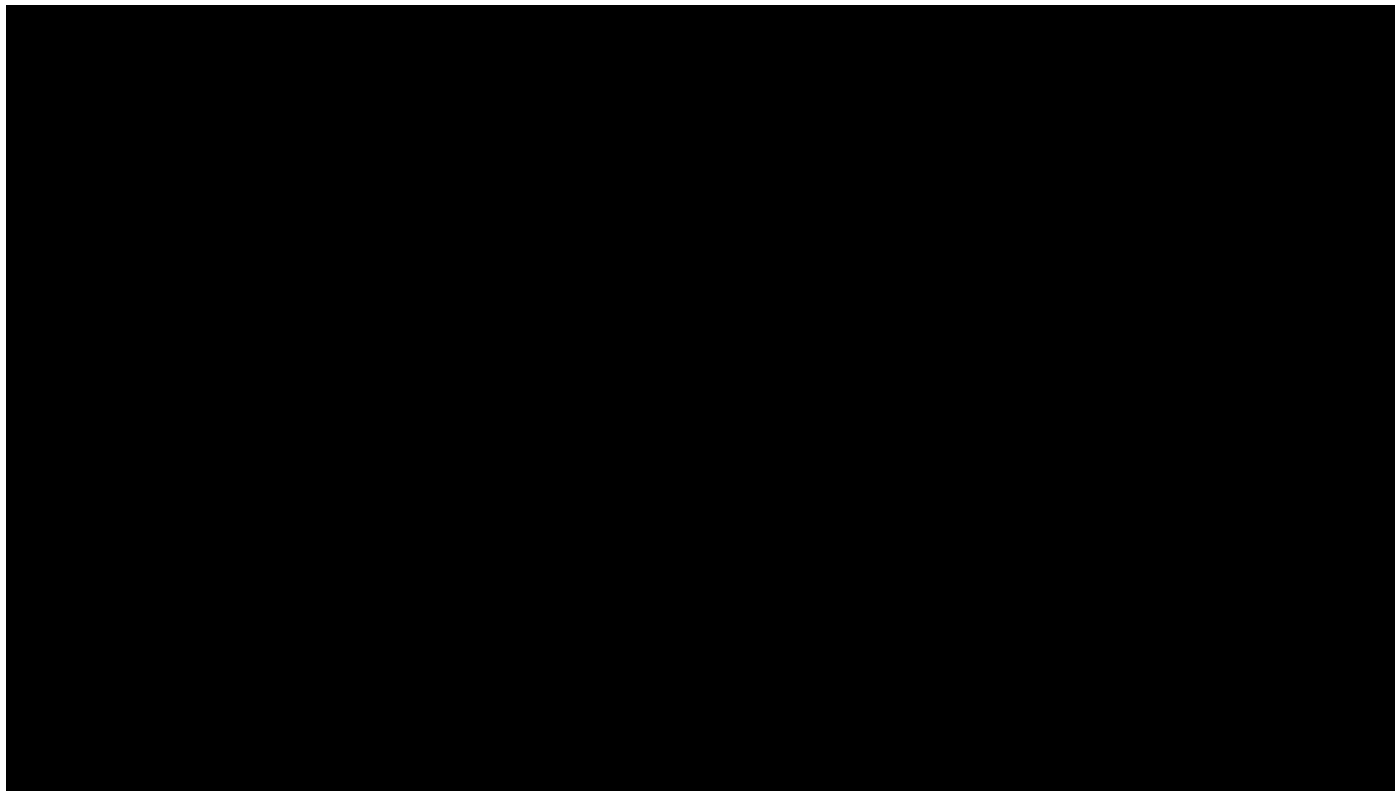
Max Sidesinger, MPH, EHDI Epidemiologist, CMV Data Coordinator

Jenny Pedersen, AuD, CCC-A, Hearing Aid Programs Coordinator

# Hospital performance

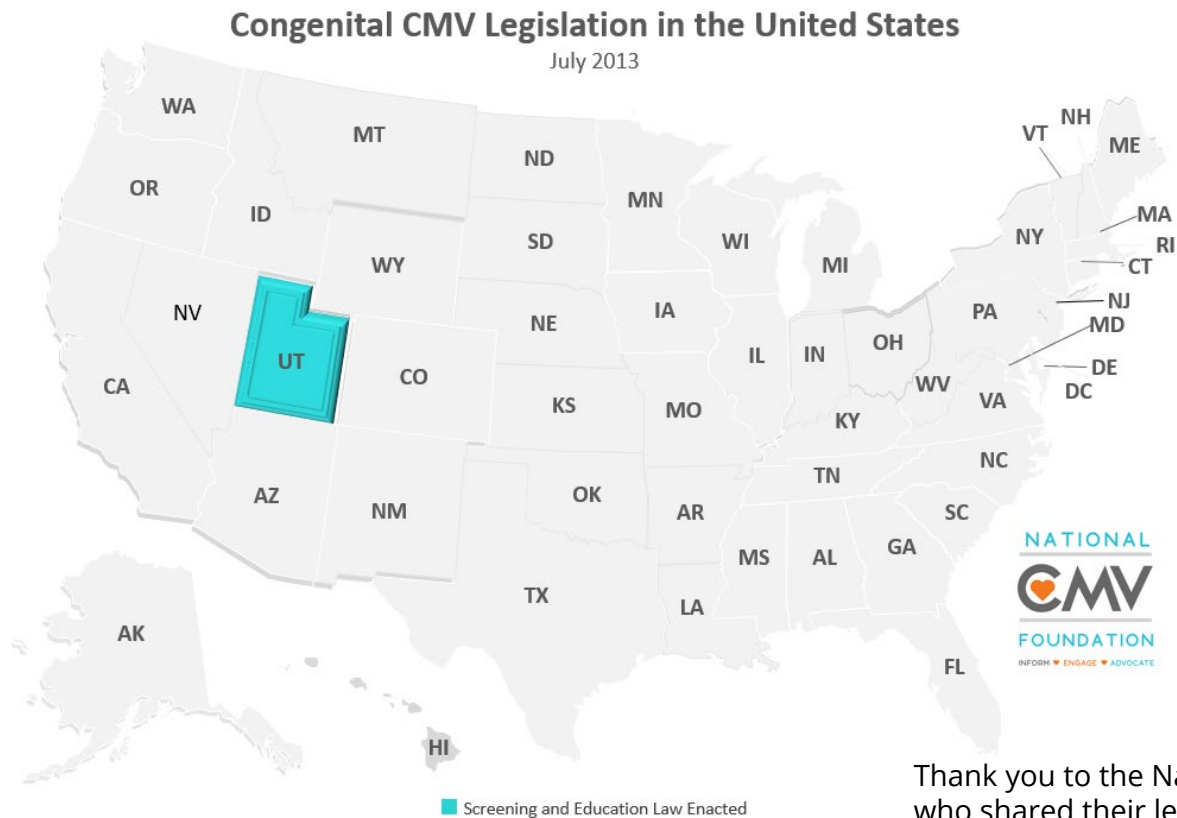


# The advocacy power of parents



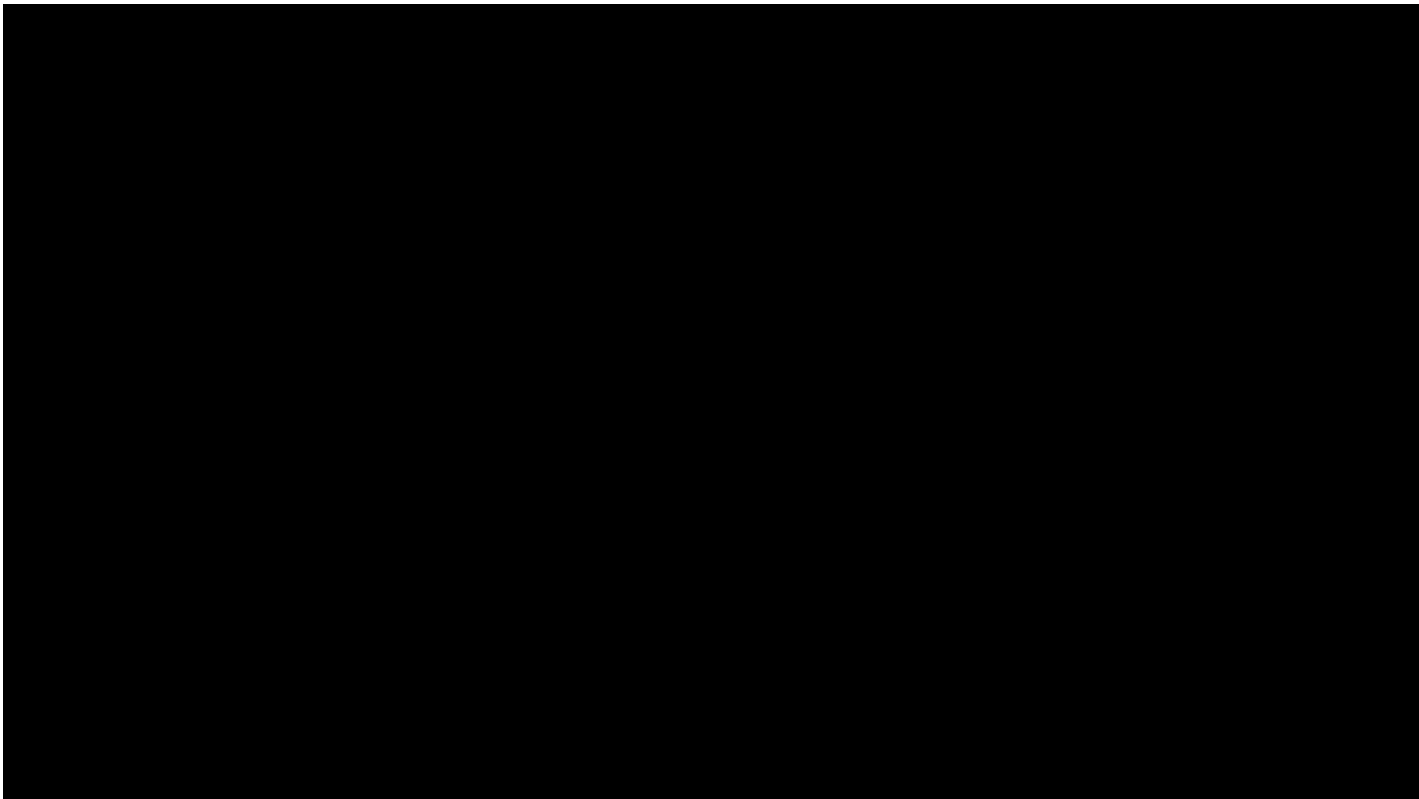


# CMV legislation: July 2013



Thank you to the National CMV Foundation who shared their legislation map template and allowed me to adapt for my presentation.

# Utah CMV Council



# The advocacy power of parents



Janelle  
Greenlee  
Stop CMV  
2003



Farah Armstrong  
Maddie's Mission  
2014



Sara Menlove Doutré

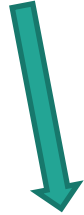
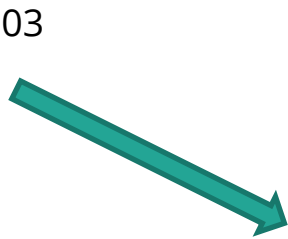


Annie Culley

Utah CMV Council  
2014



Abigail Wright



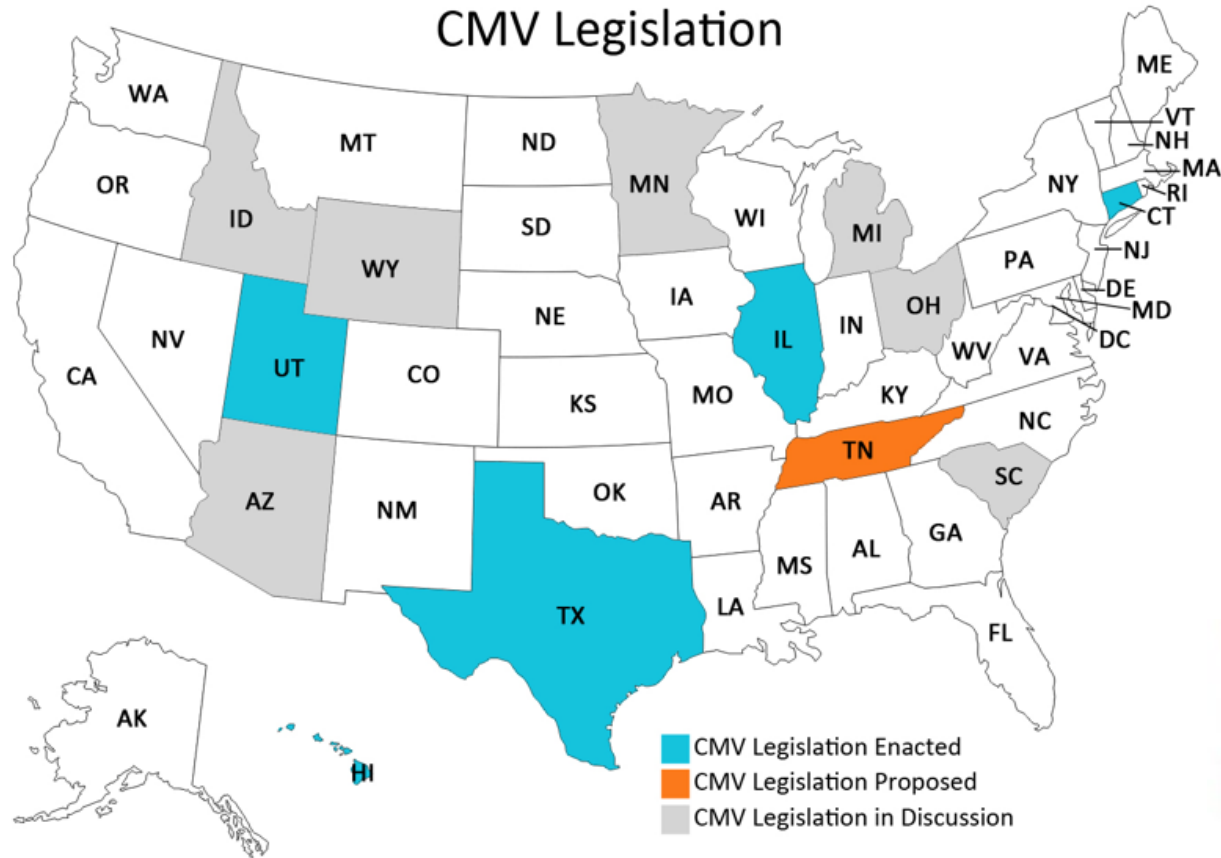
2015



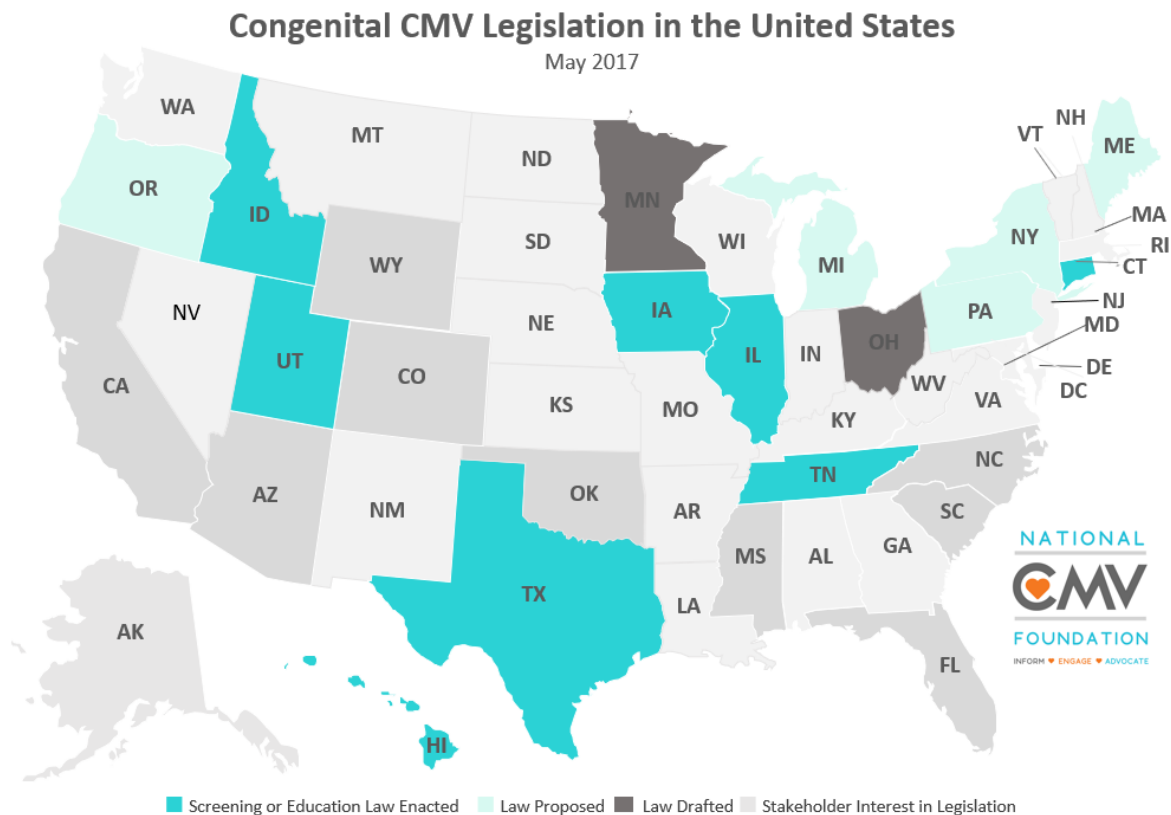
Kristen Hutchinson Spytek



# CMV legislation: November 2015

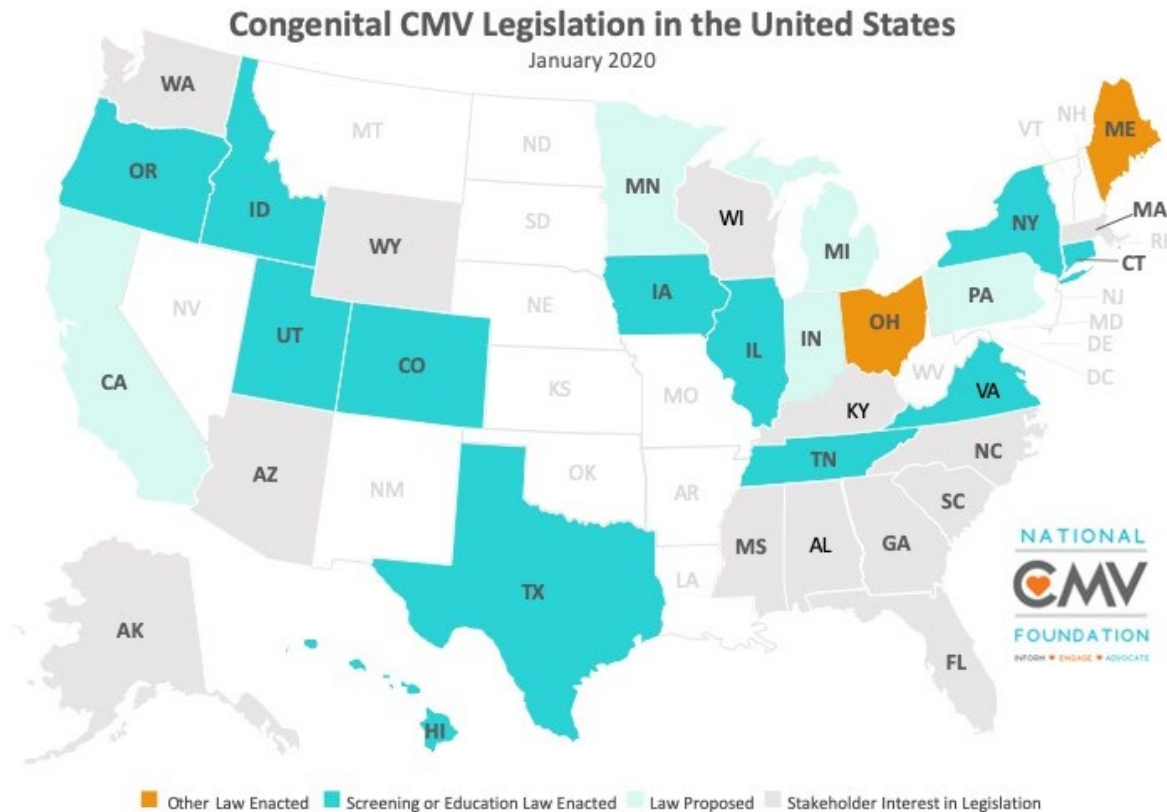


# CMV legislation: May 2017





# CMV legislation: January 2020



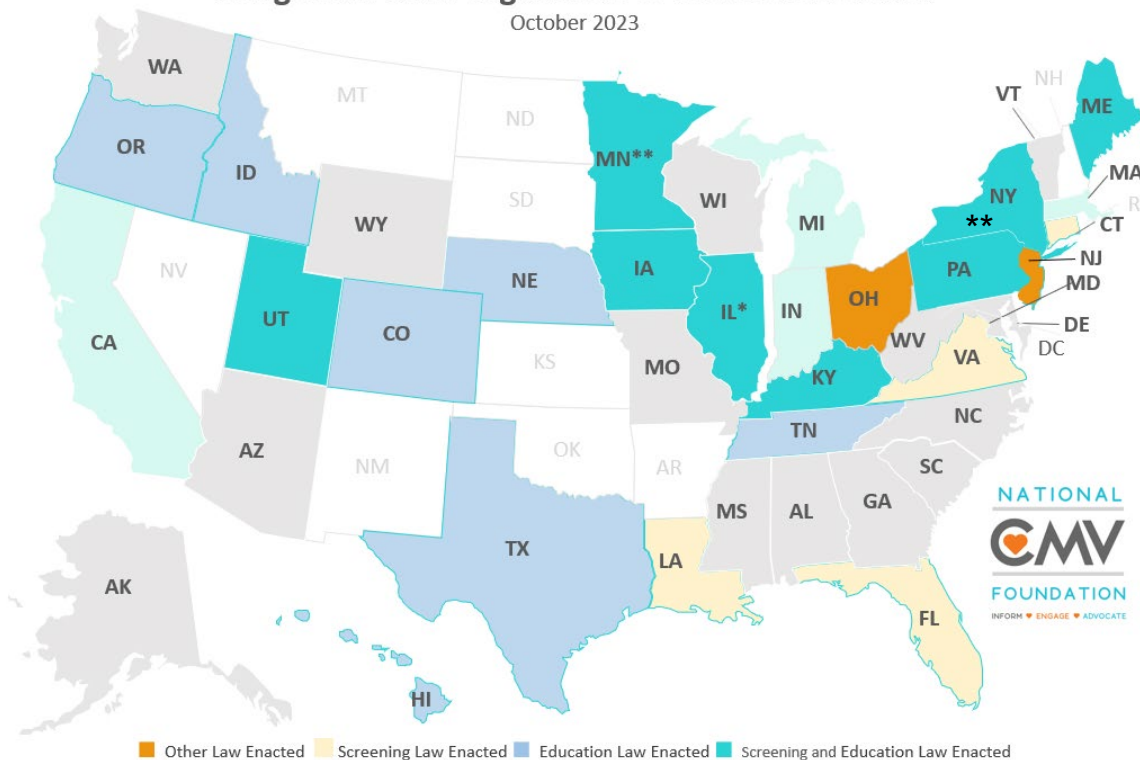
# CMV legislation: October 2023

\*CMV screening has to be offered after failing NBHS

\*\*Universal CMV screening!

## Congenital CMV Legislation in the United States

October 2023



© National CMV Foundation, <http://www.nationalcmv.org/>

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 – amended current hearing-targeted legislation to be universal in 2025

# The power of parents

- Minnesota – 2021 – “The Vivian Act”
- Kentucky – 2022 – “Bella Dawn Streeval Law”
- New York – 2022 – “Elizabeth’s Law”
- Louisiana – 2023 – “Journie’s Law”



Elizabeth Saunders died at 16 years old from a seizure after she contracted congenital cytomegalovirus, or CMV, as a newborn, leading to severe health issues throughout her life. Her mother, Lisa Saunders, has advocated to prevent more health issues from CMV after her daughter's death. Provided: Lisa Saunders

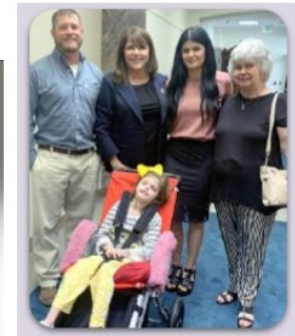


Leah Herrikson and her kids Vivian and Asher address reporters Wednesday. The Vivian Act was named after Leah's daughter, who was born with congenital cytomegalovirus. Minnesota officials announced the state will be the first in the nation screening all newborns for CMV. 🍌 Michelle Wiley | MPR News

## Loss to law; Adair Co. mother raises awareness for virus that took young daughter's life



An Adair County mother is taking the tragic death of her daughter, and using it to raise awareness of a deadly and common virus not many people know about.



Steve, Miranda, and Journie Bailey, Rep. Horton, and Karen Young

### HB 643

Enacts  
“Journie’s Law”  
to require  
cytomegalovirus  
(CMV) testing for  
children who fail  
their newborn  
hearing  
screening.

# CMV testing: Canada



## Newborn Screening **Ontario:**

- May, 2018 -July 29,2019: CMV screening offered if infant did not pass NBHS
- After July 29,2019: CMV screening offered for all Infants

## **Manitoba:**

In 2020, bill introduced for universal newborn CMV Screening. Some targeted screening is conducted.

## **Saskatchewan:** universal newborn CMV screening in 2022

HEALTH | News

Father pushing Manitoba to follow Ontario, Saskatchewan in screening for CMV



Map source: Wikipedia

January 29, 2023

# CMV testing: Canada



Map source: Wikipedia




[Article](#) [External Article](#) [Medical Expert Insights](#)


## Position Statement on Universal Congenital Cytomegalovirus Screening in Canadian Newborns

The Canadian Infant Hearing Task Force, in collaboration with Speech-Language & Audiology Canada, the Canadian...


May 18, 2022




Canadian Infant Hearing  
Task Force  
Groupe de travail canadien sur  
l'audition des nourissons



CMV  
CANADA



SAC  
Speech-Language &  
Audiology Canada  
Communication



Canadian Academy of Audiology  
Académie Canadienne d'Audiologie



# CMV testing: Canada

**Alberta:** government invested \$6 million to expand the Alberta Newborn Screening Program to include 5 new conditions, including cCMV in August, 2023



Map source: Wikipedia

CALGARY | News

Parents applaud Alberta's commitment to expand newborn screening to include congenital CMV



The Craig Family



# CMV testing: Europe

**Alberta:** government invested \$6 million to expand the Alberta Newborn Screening Program to include 5 new conditions, including cCMV in August, 2023



Map source: Wikipedia



# RUSP application



Dr. Megan Pesch

2021

ACHDNC Form for Nomination of a Condition for Inclusion in the Uniform Screening Panel

DATE: September 30<sup>th</sup>, 2021

NAME OF NOMINATOR AND ORGANIZATION (include professional degrees)	INDICATE AFFILIATION (i.e., Health Professional, Subject Matter Expert, Researcher, Clinician, Advocate, etc.)
National CMV Foundation	Advocacy Organization

CO-SPONSORING ORGANIZATIONS (include professional degrees)	INDICATE AFFILIATION (i.e., Health Professional, Subject Matter Expert, Researcher, Clinician, Advocate, etc.)
National CMVF RUSP Nomination Team (see enclosure for membership list)	Advocates, Public Health Professionals, Researchers, Subject Matter Experts, Legislator, and Clinicians (see enclosure for individual affiliations)

*\*Note: Please reference each statement/answer with the corresponding reference number listed in Section III – Key References.*

## SECTION I – CONDITION INFORMATION AND TREATMENT

### SECTION I, PART A

Condition	Statement
Nominated Condition	Congenital Cytomegalovirus (cCMV) Infection
Type of Disorder	Congenital viral infection
Screening Method	The presence of cytomegalovirus (CMV) can be detected at birth using nucleic acid amplification tests (NAAT), which include polymerase chain reaction (PCR) or isothermal amplification (e.g., loop-mediated isothermal amplification or 'LAMP'). Saliva is the preferred specimen for congenital CMV (cCMV) screening, with urine used for confirmatory testing <sup>1-4</sup> .
Gene	NA
Locus	Include CinVar link if applicable. NA
OMIM or other names for condition	Include Genetics Home Reference link if applicable. NA

If you have any questions about the additional information requested or when you are ready to submit an updated package, please contact me at [achdnc@hrsa.gov](mailto:achdnc@hrsa.gov).

Thank you for your nomination of cCMV for inclusion on the RUSP. I look forward to hearing from you soon.

Sincerely yours,

/s/

Ned Calonge, MD, MPH  
Chairperson

ATTACHMENT: Summary of Nomination Requirements and Key Considerations

Cc: Soohyun Kim, MPH  
Acting Designated Federal Official  
Health Resources and Services Administration



# CMV position statements



23-ID-02

Committee: Infectious Disease

Title: Standardized Surveillance Case Definitions for Congenital Cytomegalovirus (cCMV) Infection and Disease

☐ Check this box if this position statement is an update to an existing standardized surveillance case definition and include the most recent position statement number here: N/A.

Synopsis:

- This position statement creates standardized case definitions for cCMV infection and disease.
- Standardized case definitions for cCMV infection and disease are needed because multiple jurisdictions in the United States are conducting cCMV screening and surveillance activities but are using various methods and inclusion criteria for case ascertainment, reporting, and classification. As more jurisdictions pass legislation for newborn screening for cCMV, standardized case definitions for cCMV infection and disease can be used to understand the epidemiology of cCMV and compare trends across the United States.
- Case ascertainment criteria include laboratory criteria (the detection of CMV in neonatal urine, saliva, whole blood, or cerebrospinal fluid specimens, in amniotic fluid specimens, or umbilical cord or autopsy specimens), vital records criteria (infant death certificates), and healthcare records criteria (e.g., using ICD-10 diagnostic codes).
- Case classification criteria include clinical and laboratory criteria.
- Case classifications include confirmed cCMV infection, confirmed cCMV disease, and probable cCMV disease.

I. Statement of the Problem

Cytomegalovirus (CMV) infection during pregnancy can cause stillbirth, infant death, and a myriad of birth defects.<sup>1-3</sup> In the United States (U.S.), approximately 1 in 200 babies is born with congenital CMV (cCMV) infection; one out of 5 of these babies will present with clinical signs of cCMV disease in the neonatal period and/or have long-term health conditions.<sup>4</sup> cCMV is the most common infectious cause of developmental disabilities and non-genetic sensorineural hearing loss (SNHL) in U.S. children.<sup>5-8</sup> Nonetheless, the burden of cCMV disease is not fully understood.<sup>9-11</sup>

Surveillance of cCMV in the U.S. is complicated by several factors. First, most newborns with cCMV infection have no clinical signs at birth and, without universal cCMV screening, are not identified.<sup>12,13</sup> Second, neonatal clinical signs of cCMV disease are nonspecific and may be attributed to other conditions.<sup>14</sup> Third, postnatal CMV infection is common among infants, and a reliable diagnosis of cCMV infection or disease may not be possible unless specimens are collected within the first three weeks of life.<sup>15</sup> Finally, not all newborns with a laboratory diagnosis of cCMV infection receive a diagnostic code that would allow cases to be ascertained through a review of administrative data.<sup>16</sup>

II. Background and Justification

cCMV infection is responsible for an estimated 5-10% of cases of prelingual hearing loss among children less than 2 years of age, and an estimated 15-20% of moderate to profound bilateral SNHL among all U.S. children.<sup>7,17</sup> A substantial proportion of cCMV-related SNHL cases occur in children with cCMV infection who do not have apparent clinical signs at birth, including those who pass the newborn hearing screen.<sup>18</sup> Early identification and timely and appropriate intervention services are critical for improving developmental outcomes of deaf or hard-of-hearing children.<sup>19-22</sup> Consequently, the Joint Committee on Infant Hearing recommends that all infants who test positive for cCMV receive periodic audiologic monitoring beginning no later than three months of age to allow for the provision of appropriate amplification, early intervention, and family support.<sup>23</sup> Jurisdictional programs that monitor children with

# cCMV surveillance grants



SET-NET:  
Surveillance for Emerging Threats to Pregnant People and  
Babies Network  
8/1/22 – 7/31/24

Iowa, LA County, Minnesota, New Jersey, New York, Utah,

CDC-RFA-DD-23-0003 “Pregnant People-Infant Linked Longitudinal Surveillance”  
9/30/2023 - 9/29/2027

Illinois, New Jersey, Virginia  
UMN, Baylor

## CMV vaccines

# CMV Vaccine Development: How Close Are We?

**WE ARE GETTING  
CLOSER!!**

NIAID Conference Center

CMV RNA vaccine

VSV vectored gB/VLP CMV vaccine program

CMV polyepitope-gB bivalent vaccine

CMV-MVA-Triplex vaccine

CMV vectored vaccine program

nanoparticle CMV vaccine program

mRNA-1647 vaccine program

dense body vaccine candidate

Replication-defective human CMV  
vaccine





ect on public health

m, were shocked to  
in our communities  
ce those risks. The  
an injustice, she set  
on 1 July, 2013  
women of  
able preventative  
the presence of  
n initiative until a  
erting their

**Monday:**

UT/CDC | Establishing standardized case definitions for cCMV infection and disease in the US  
| Room 6613 | 2:30 – 2:55 PM

**Tuesday:**

UT | An analysis of cCMV cases identified in Utah, 2013-2023 | Flynn Room | 1:30-2:30

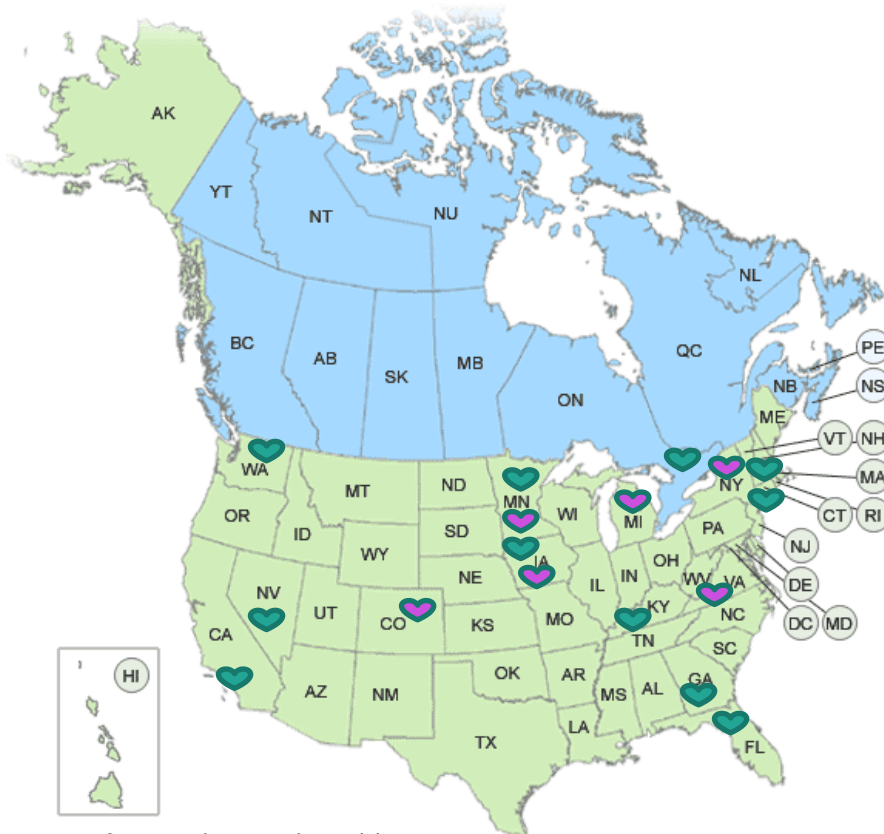
UT | An overview of the CSTE cCMV position statement's impact on Utah's case classification  
| Room 6619 | 2:45 – 3:10 PM

Max Sidesinger



Jacinda Merrill

# Utah Sessions



Map from Behavioral Health Resources, LLC

I know it seems hard  
sometimes, but remember  
one thing. Through every  
dark night, there's a  
bright day after that. So  
no matter how hard it  
gets, stick your chest out,  
keep ya head up and  
handle it.

*Tupac Shakur*

[positivityblog.com](http://positivityblog.com)

**We are all in this together!**

**Thank you!**

**[smcvicar@utah.gov](mailto:smcvicar@utah.gov)**

**801-273-6600**