



# Cytomegalovirus (CMV) and Hearing Loss

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Life can only be  
understood  
backwards; but it  
must be lived  
forwards.

Soren Kierkegaard



## About Me

- Special education and early intervention consultant
- Advocate
- CMV Mom
- Founder of the National CMV Foundation
- Ph.D. Candidate in Sociobehavioral Epidemiology, Utah State University



# Objectives

1

WHAT IS  
CMV?

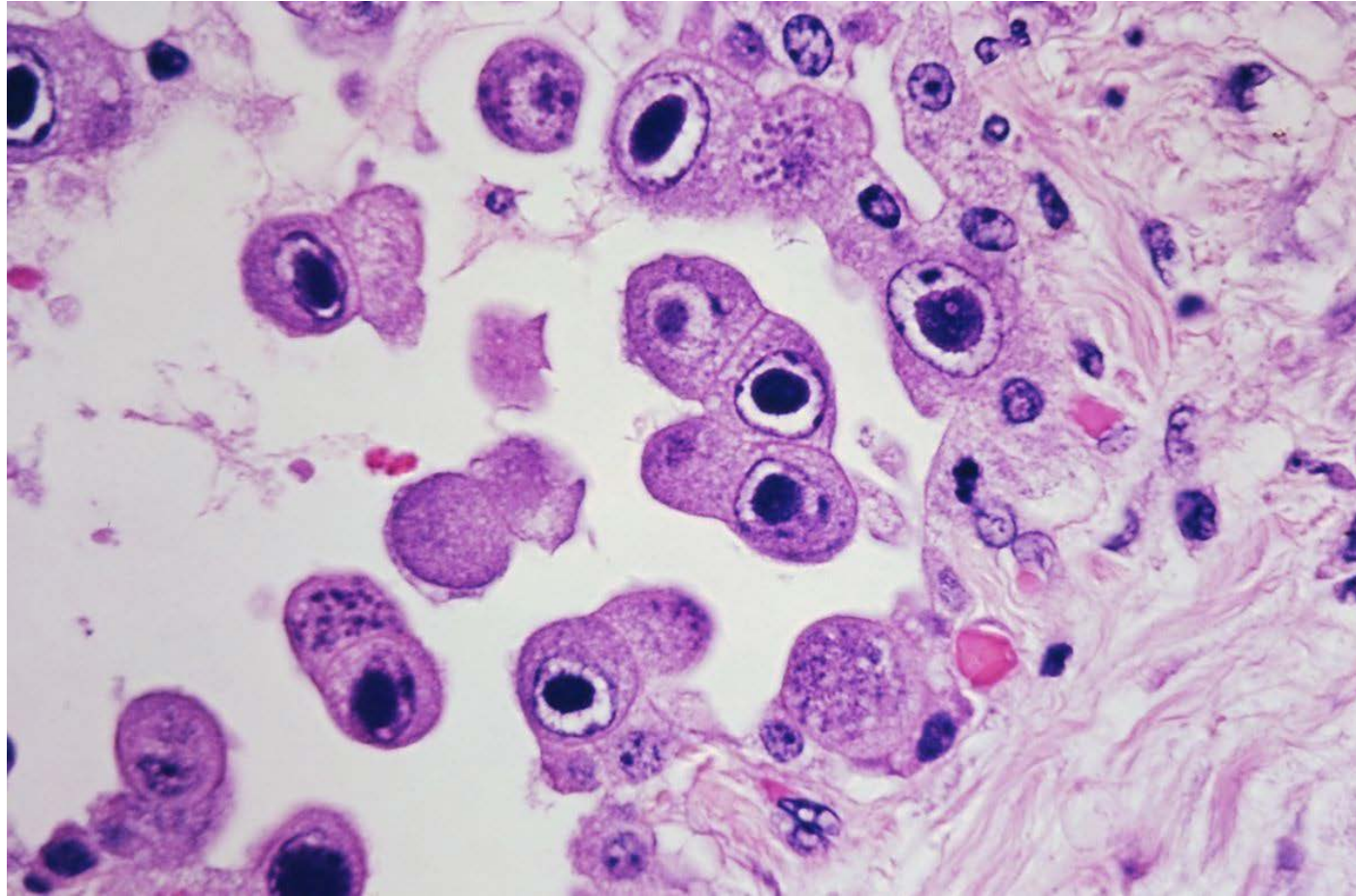
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CMV AND  
HEARING  
LOSS

3

WHAT CAN  
YOU DO  
ABOUT  
CMV?

# Cytomegalovirus



# What is CMV?

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- CMV is Common
- CMV is Serious
- CMV is Preventable

# CMV is Common

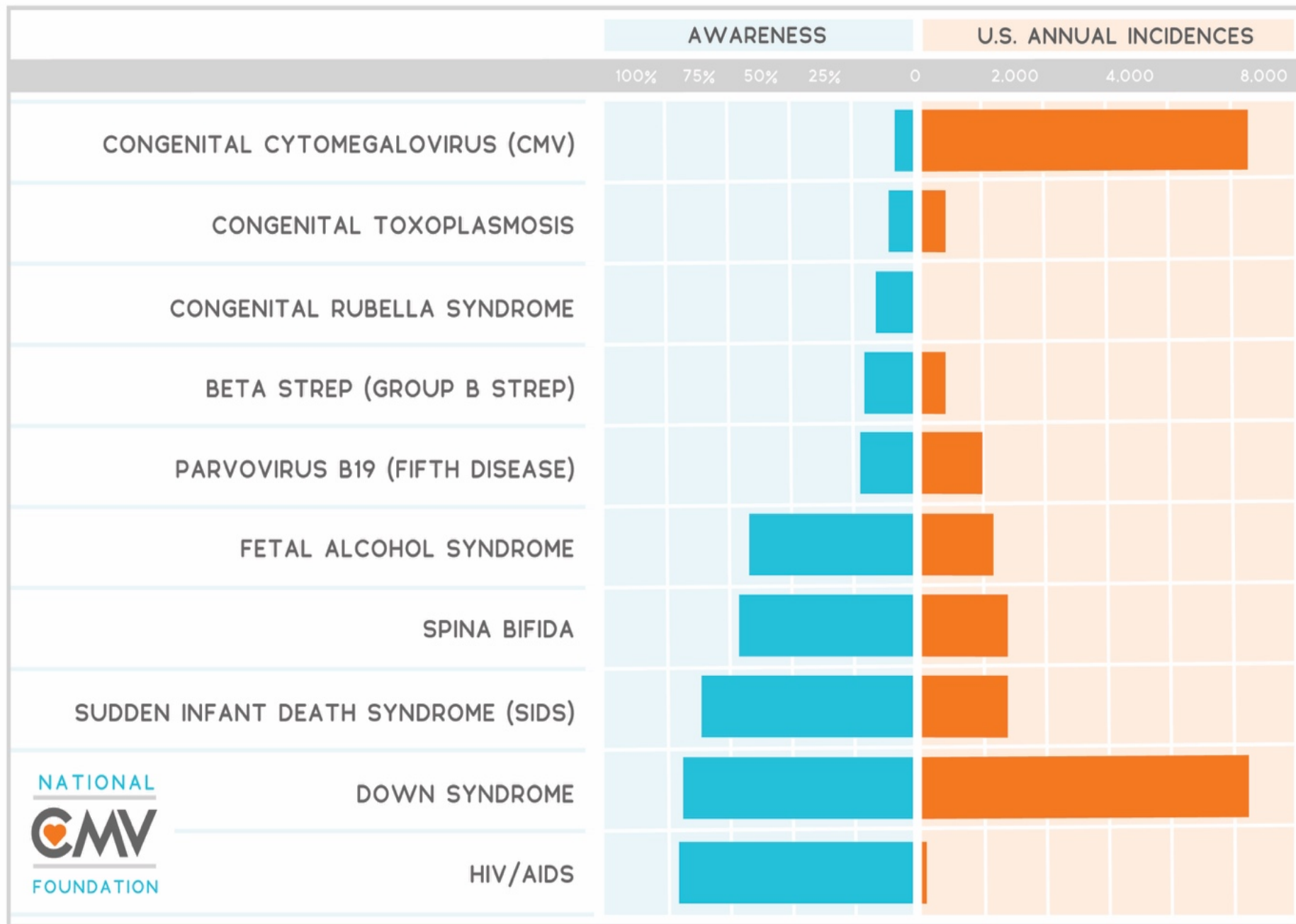
- 1 in 200 babies is born with CMV
- 1 in 1000 babies is disabled by CMV

CMV is the most common infection infants are born with. CMV causes more cases of congenital disease than the combination of 19 currently screened conditions in most American states.

(CDC, 2008; Impact of expanded newborn screening, 2006)







# CMV is Serious



CMV causes disabilities including **hearing loss**, cerebral palsy, seizures, and other developmental disabilities.

Born symptomatic

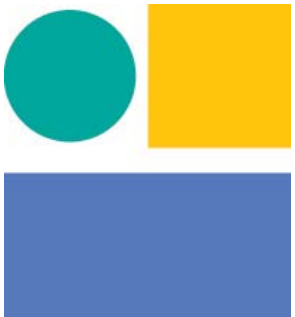
Born asymptomatic

<b>Death</b> Miscarriage, stillbirth, infant or child loss	<b>Medically fragile</b> Cerebral palsy, Seizures, Failure to Thrive, Hearing loss, Vision loss	<b>Multiple impairments</b> Cerebral palsy, Vision loss, Hearing loss	<b>Developmental delays</b> Cognitive delays, Learning issues, Feeding and sleeping issues, Vision loss, Hearing loss	<b>Hearing loss</b> Hearing aids, Cochlear implants, Communication and learning issues, Mild vision disorders	<b>None</b> No visible delays or impairments
Severe			Moderate		Mild



# CMV is Preventable

- A pregnant woman has to have an active CMV infection to transmit CMV to her unborn baby.
- Many women transmit CMV to unborn babies during a reactivation or infection despite having had CMV in the past.

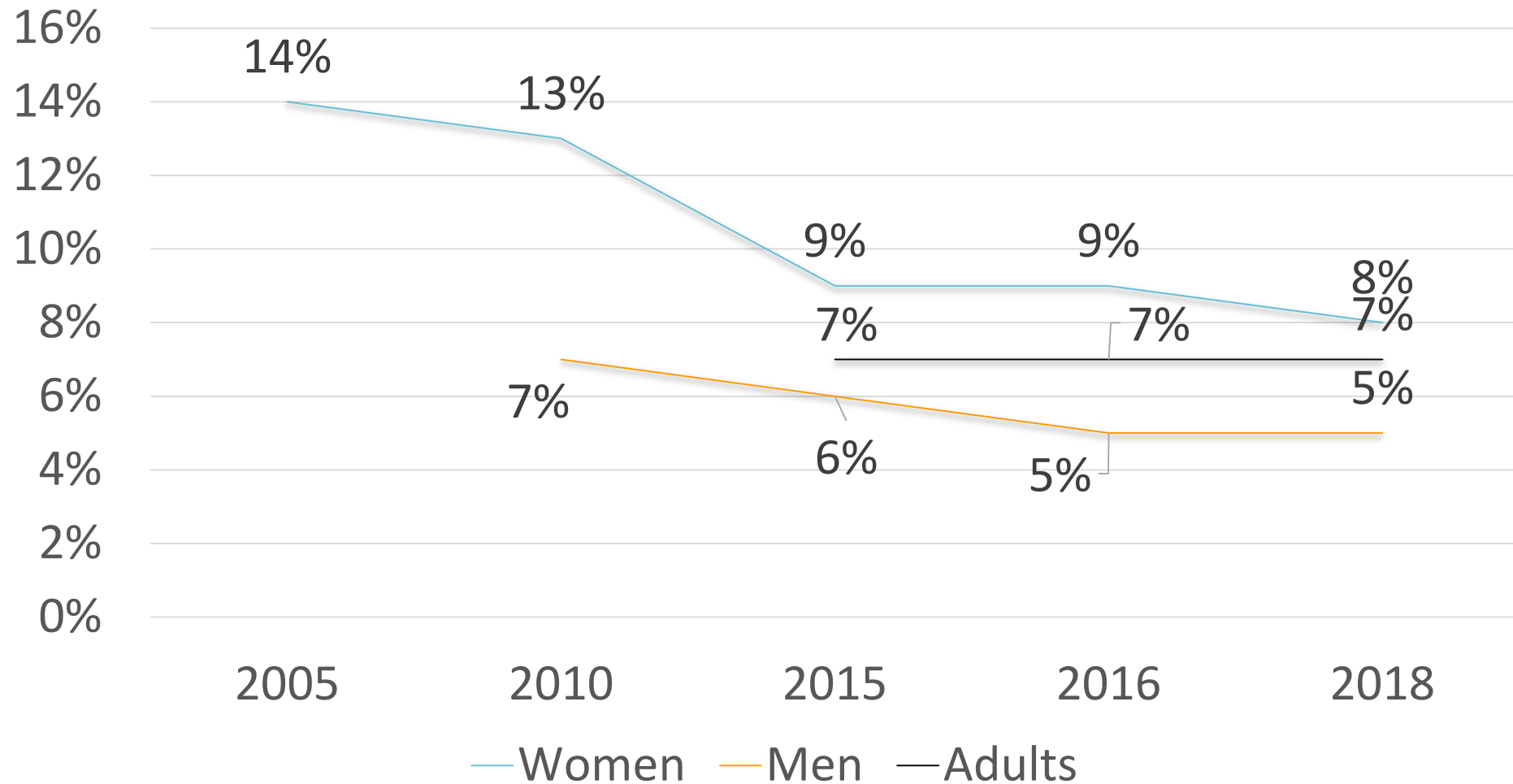


- CMV lives in bodily fluids like urine and saliva.
- It can live in crackers or bread crust for up to six hours.

(Cannon, 2014)



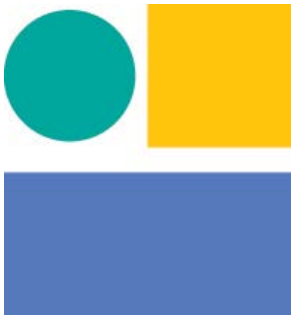
# We can't prevent what we don't know about



# CMV and Hearing Loss

- CMV is the leading non-genetic cause of childhood hearing loss.
- CMV accounts for approximately 25% of SNHL in children.
- About 15% of infants with congenital CMV will not have symptoms at birth but **later develop hearing loss**.
- The AAP recommends hearing tests at least every six months.

(<http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/CMV.pdf>)



Congenital CMV has been labeled as one of the *Neglected Infections of Poverty* in the United States as it is poorly known by the US public-health community, it has a disproportionate impact on the health of the poorest Americans, and it promotes poverty via its negative impact on child development and pregnancy outcomes.

Bristow et al. 2011



# International Consensus - 2015

- Consensus group convened at international CMV conference in Brisbane, Australia in 2015
- “...consideration should be given to universal neonatal cytomegalovirus screening to **enable early detection of congenital cytomegalovirus-infected infants, facilitating early detection and intervention for sensorineural hearing loss and developmental delay** where appropriate (level 2b evidence).”
- “The consensus recommendations from the group were that the diagnosis of congenital cytomegalovirus infection in neonates should include **real-time PCR of saliva, urine, or both, as soon as possible after birth** but within the first 3 weeks of life, with **saliva as the preferred sample** (level 2b evidence).”

Rawlinson, et al. (2017) Congenital cytomegalovirus infection in pregnancy and the neonate: consensus recommendations for prevention, diagnosis, and therapy. *Lancet Infectious Disease*.

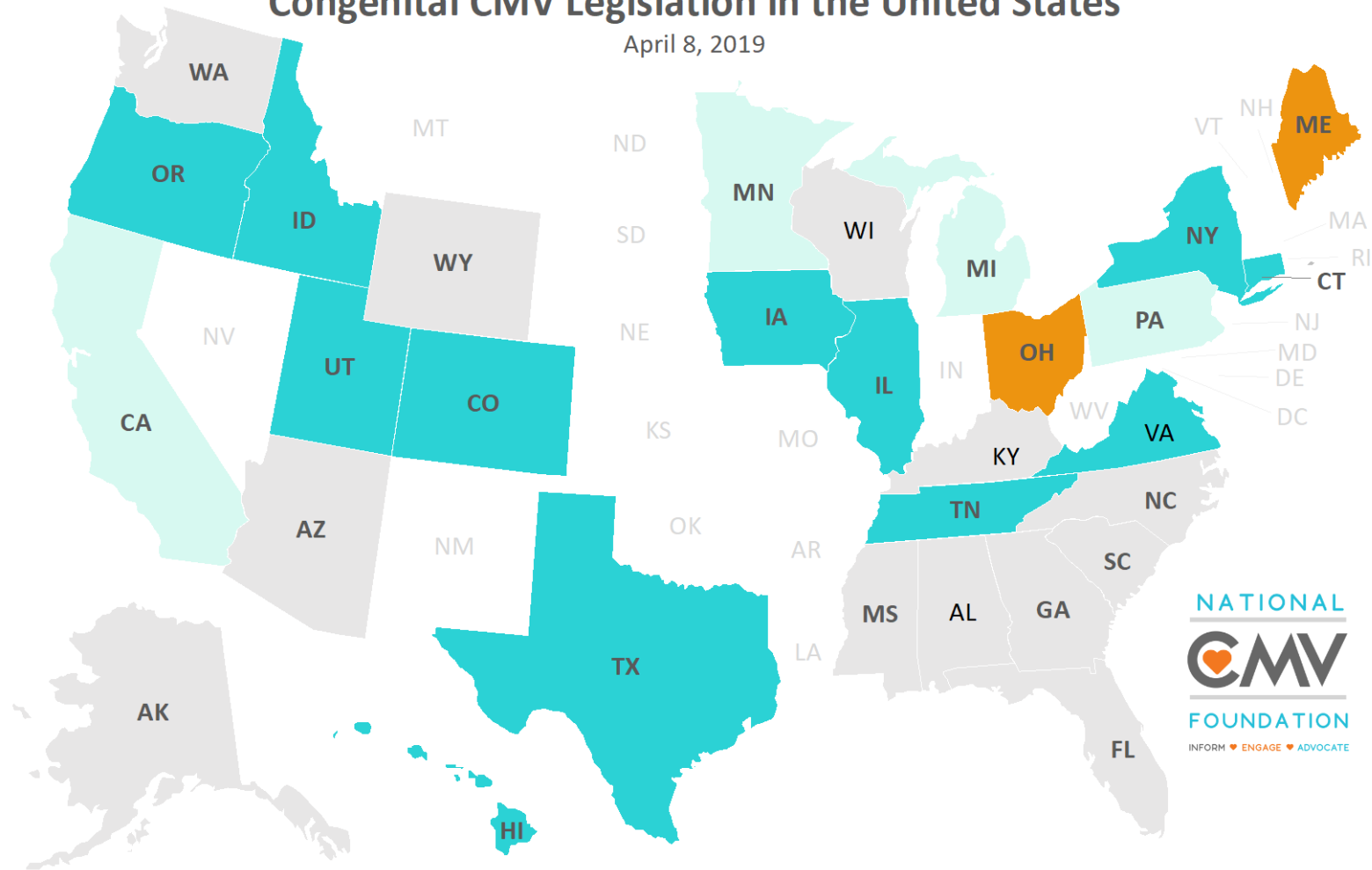




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# Congenital CMV Legislation in the United States

April 8, 2019



Other Law Enacted Screening or Education Law Enacted Law Proposed Stakeholder Interest in Legislation

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# Summary of State Mandates



In the United States, legislation has effectively passed in 12 states, with additional states in progress.

## Summary of Complete Legislative Mandates

### **Education**

- Nine states require the state to educate the public and professionals about congenital CMV: Hawaii, Idaho, Illinois, Iowa, New York, Oregon, Texas, Utah.
- Tennessee requires healthcare providers to educate women of childbearing age.
- Only Utah has legislation that is accompanied by ongoing funding (\$70,000 per year). Idaho has proposed \$15,000 per year.

### **Screening**

- Five states (Connecticut, Iowa, New York, Utah, and **Virginia**) require each newborn that fails the newborn hearing screening to be tested for congenital CMV.
- Illinois requires that a CMV test be offered to the parents of every child who fails the newborn hearing screening.



## Our purpose is to prevent CMV infection in women of childbearing age by:

- Empowering women, parents, families, and local community networks through grassroots engagement to facilitate conversation and champion the cause.
- Delivering consistent, clear messaging, and evidence-based data that aids in prevention, educates the public, and increases its understanding of congenital CMV.
- Influencing CMV research priorities regarding CMV prevention, treatment, and intervention.
- Advocating for a CMV vaccine.



# National CMV Foundation by the Numbers:

5 

Years Young

6 

Co-Founders

9 

Board of Directors

2 

Staff Members

60 

Active Volunteers

50 

States with CMV Champions

19K 

Social Media Followers

25K 

Average Monthly Unique Visitors

## Our Dollars at Work:

\$75K 

to Early Career  
Research Funding

\$160K 

in Public Health Awareness  
Activities and Grants



# 2019 Campaign Teaser

## Awareness: Updates

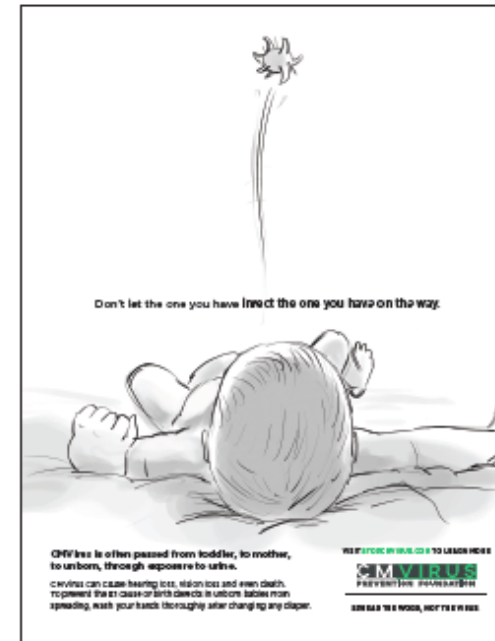
The threat of CMVirus is invisible to most. So let's make it as plain as day in the every day ways it gets transmitted. Seeing the threat, is believing the threat.



AD 1



AD 2



AD 3





Mom, why didn't you  
know the facts? Why  
didn't you protect me  
from CMV?

Daisy, age 8



# What can you do?

- Talk to women of childbearing age about CMV
- Encourage parents whose children's cause of hearing loss is unknown to have them tested for CMV
- Advocate for awareness and screening
- June is CMV Awareness Month
- What else?







# THANK YOU

Get Involved

[www.NationalCMV.org](http://www.NationalCMV.org)

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CMV.org





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**Building Success  
One Step at a Time**  
Hearing-Language-Literacy



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[Questions and Comments](#)

