



Developing a Mid-Atlantic CMV Consortium and Tips for Collaboration in Your Area

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Learning Objectives

Identify

Key stakeholders within your state/region interested in CMV legislation

List

Three priorities that CMV legislation can potentially address

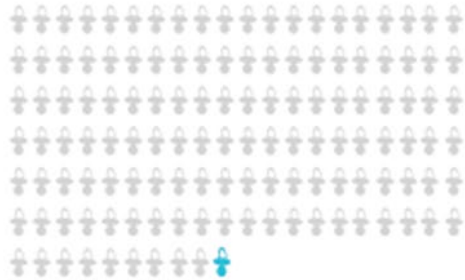
Discuss

Ways to move CMV initiatives forward within the state

CMV is short for **cyto-megalo-virus**

CMV

is common



1 in 150
children are born
with congenital CMV

**Most common virus
transmitted from a
pregnant woman to
her unborn child**



1 in 3

**pregnant women
who get CMV will
pass the virus to
their unborn child**



**More common
than the 29 combined metabolic and
endocrine disorders in the recommended
US newborn screening panel**



Problem Statement

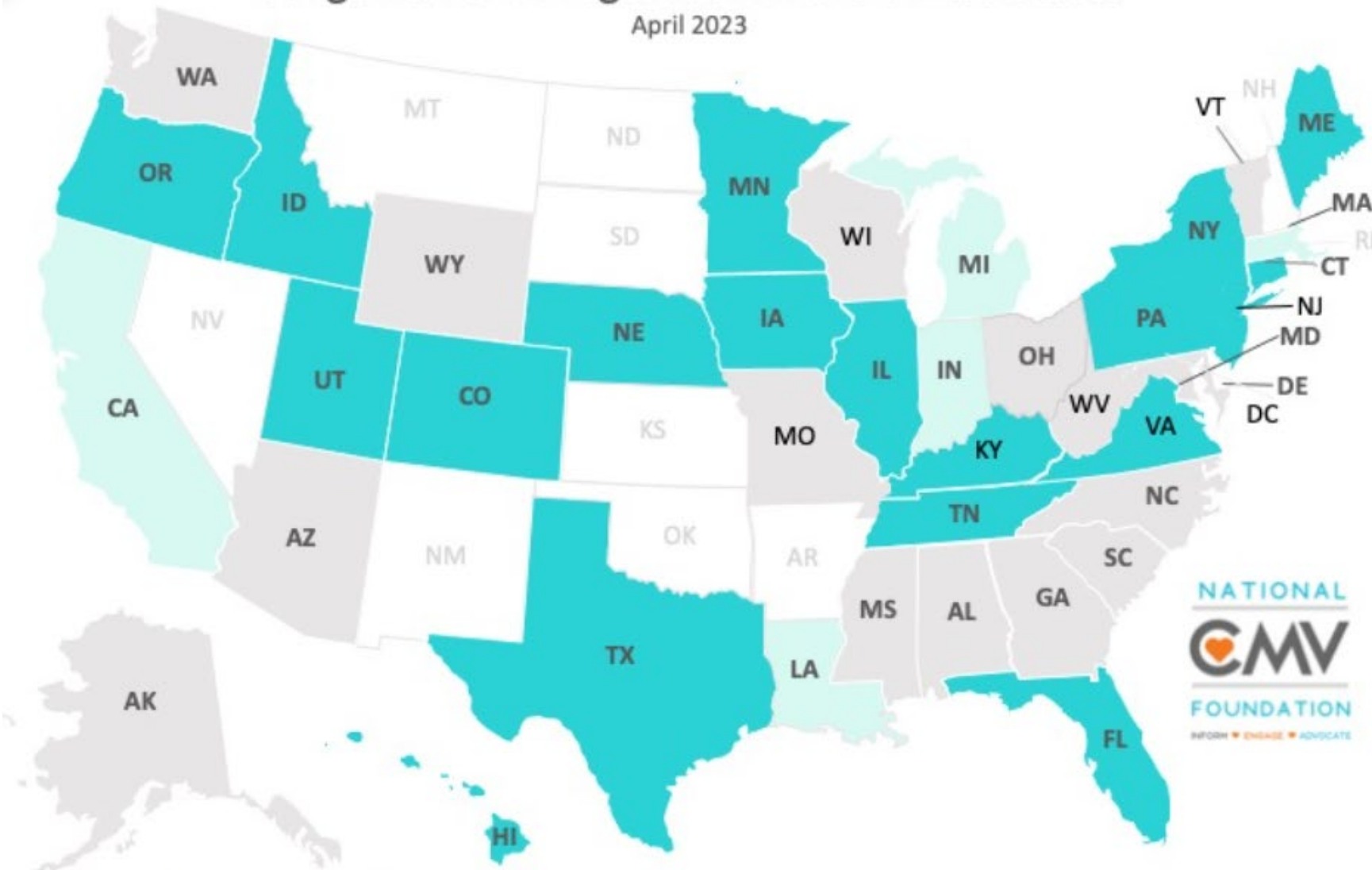
There is significant variation in how states educate expectant mothers and conduct screenings for this common infection.

The range in mandates spans from requiring education about CMV on a public-access website to mandated universal newborn screening.

These variations make consistent clinical care challenging, especially for institutions that operate in a region such as the Mid-Atlantic.

Congenital CMV Legislation in the United States

April 2023



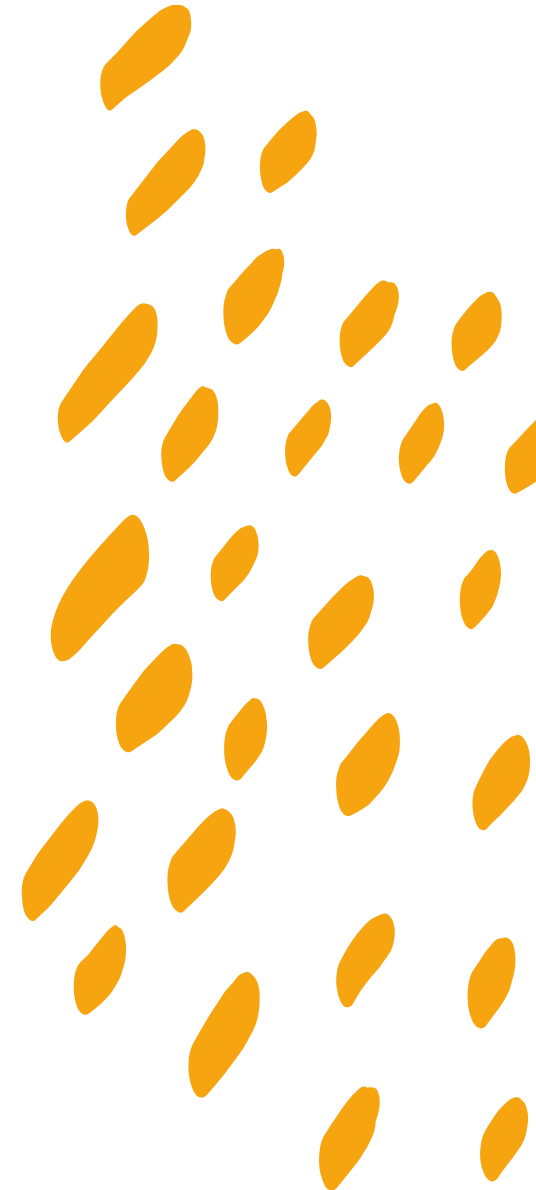
Other Law Enacted | Screening or Education Law Enacted | Law Proposed | Stakeholder Interest in Legislation

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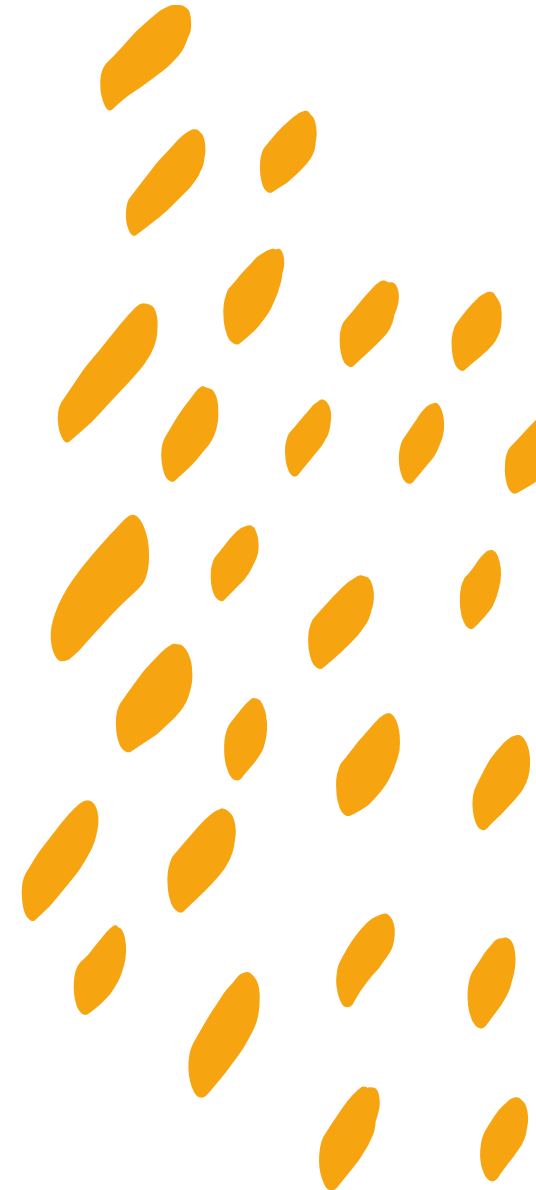
Universal Newborn CMV Screening

- **Minnesota** is the first state to enact universal newborn CMV screening
- **Louisiana** proposed adding CMV to state's newborn screening



Targeted cCMV Screening

- Seven states require each newborn that fails the newborn hearing screening to be tested for cCMV (Connecticut, Florida, Iowa, Kentucky, New York, Utah, and Virginia).



Guidelines for Prevention Education

- Seven states require both education of pregnant women and targeted newborn screening (Illinois, Iowa, Kentucky, Maine, New York, Pennsylvania & Utah)
- Twelve States require the state to educate the public and professionals about cCMV (Colorado, Hawaii, Idaho, Illinois, Iowa, Kentucky, Minnesota, Nebraska, New York, Oregon, Texas & Utah)

Mid-Atlantic Region

PA: Legislation passed in 2022

Education of pregnant women and hearing targeted screening

NJ: Legislation passed in 2022

Public awareness campaign geared toward pregnant women and universal screening; however, several conditions must be met prior to implementation

DE: Drafting Legislation

Universal screening and mandated education to pregnant women and professionals

MD: Stakeholder Interest in Legislation

DC: Stakeholder interest



Mid-Atlantic Region Overview & Aim



A team of diverse professionals working together to share their diverse knowledge, past experiences, and available resources.



Engage government institutions, hospitals, birth centers, the National CMV Foundation, American Cochlear Implant Alliance, parents, Early Hearing Detection and Intervention programs.

Mid-Atlantic CMV Consortium



**DELAWARE HEALTH
AND SOCIAL SERVICES**
Division of Public Health



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Mid-Atlantic CMV Consortium Actions



Meetings established with multiple stakeholders; parents, physicians, audiologists, and government relations professionals from Delaware, Maryland, New Jersey, Pennsylvania, and Washington DC to share ideas and develop goals.



Hosted guest speakers from around the country to share information with full team



Worked with state newborn screening coordinator on new pathways for successful identification using dried blood spot testing, offering public education and awareness.



Drafting of legislation for consideration at the next Delaware state session by modeling legislation from other states that successfully passed CMV related bills.

Lessons Learned

1

Hearing targeted newborn cCMV screenings yield lower than expected number of cases for a given population size and is challenging due to the 21-day timeline for screening

2

Blood spots can be tested if CMV is suspected as cause of hearing loss but often destroyed before they can be used for testing

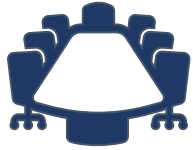
3

Variations in blood spot storage process used from state to state (*e.g., Maryland 14 years vs. Delaware 30 days*)

Takeaways

- Making change requires dedicated individuals such as *physicians, audiologists, educators, parents, government relations, etc.* bring varied perspectives to the table
- Sharing resources from various *organizations, agencies, and institutions* can save time, money and move aims forward more efficiently
- Targeted goals may expand with new data and legislation
- Comprehensive legislation can include universal cCMV screenings and mandated education for *women of childbearing age, expectant mothers, and professions*
- It doesn't stop at screening- Audiology and vestibular monitoring should be conducted even when hearing loss is not diagnosed: *Dx ABR by 1 month, ABR at 4-5 months, every 3 months until age 2, every 6 months from 2-6 years, annually from 6-10 years*

Tips for forming something similar



Engage state and national organizations (*e.g., National CMV Foundation, ACIA, ASHA, AAA, AMA, EHDI, etc.*)



Engage institutional government relations resources



Use video conferencing platform that allows sharing of links, documents, chatting, and sharing of ideas. Encourage cameras ON to help keep focused and in the moment!

Tips for forming something similar



Save time. Have introductions "calling cards" in the chat or agenda rather than re-introducing everyone.



Do not recreate the wheel for infographics and position papers



Bring in guest speakers to your meetings and do not be afraid to get out and speak about what you are doing, even if not yet perfect and complete (like ours!)

Questions

Thank you for your attention



Resources



[National CMV Foundation – Cytomegalovirus \(CMV\) | National CMV Foundation](#)



SENTAC Webinar: Everything you always wanted to know about congenital CMV: But were afraid to ask, Tuesday, May 16, 2023.



Suarez (2023). Analysis of an Expanded Targeted Early Cytomegalovirus Testing Program. *Otolaryngology&Head and Neck Surgery*, 320.



Pesch and Schiess (2002). Emerging Concepts in Congenital Cytomegalovirus, 150 (2) 51-64.



Tapasak et al. (2022). Hearing outcomes in children with Congenital Cytomegalovirus: A multi-center, single-enterprise experience. *International Journal of Pediatric Otorhinolaryngology*, 163.111376