



CMV: Sharing My Journey and Raising Awareness

Kathleen A. Smith

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Introduction Kathleen Smith - Minnesota

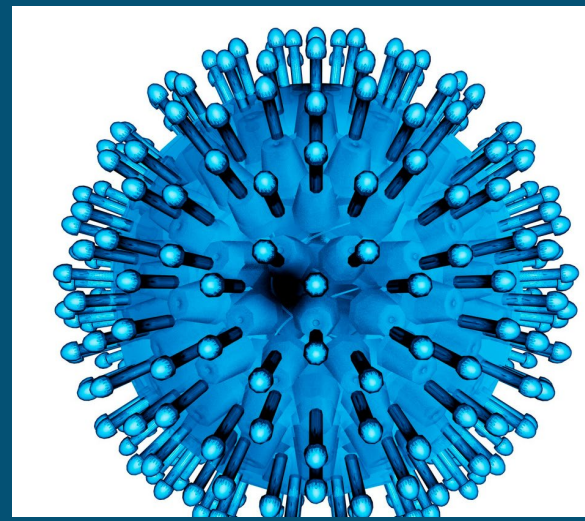
- [Born in April of 1980](#)
- [Diagnosed with CMV six weeks after birth](#)
- [Single mother of 17 year old son](#)
- [DeafBlind Intervener at Metro Deaf School](#)
- [Current President of Minnesota Association of Deaf Citizens \(MADC\)](#)
- [National CMV Foundation Community Alliance Chair for Minnesota](#)



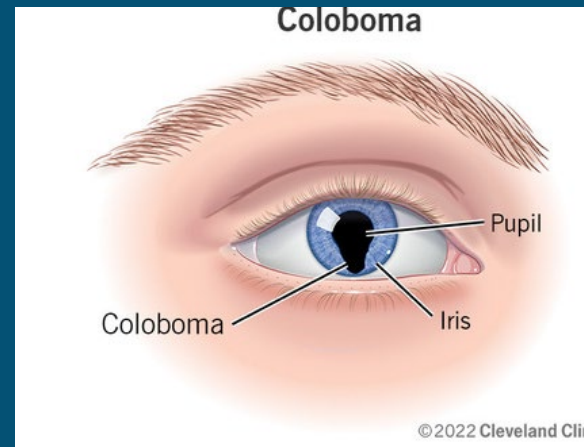
St. Mary's
Hospital
(currently
Riverside
Hospital),
Minneapolis,
MN, April 1980



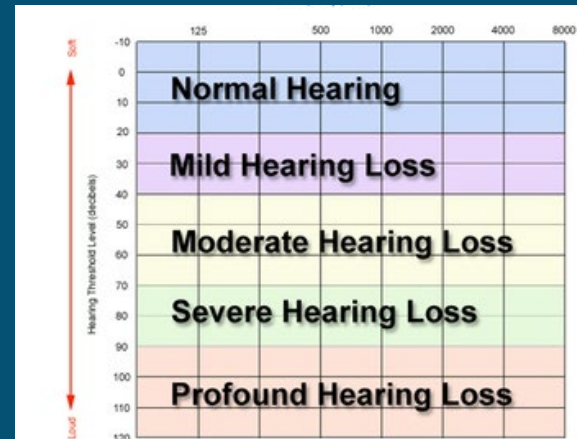
Diagnosis



Cytomegalovirus



Iris Coloboma



Profound hearing
loss



Vestibular Dysfunction

My Education

- Youngest, at nineteen months, to have an IEP in Edina Public Schools
- Attended Harley Hopkins Pre-School with other deaf classmates
- Mainstreamed from kindergarten through high school, had DHH teacher and interpreter
- Attended Gallaudet University

My dad is a retired
Areospace
Engineer.

He developed a
software program
of the manual
Alphabet to help
me to learn sign
language.



Why: My recent involvement in CMV

- I had not encountered another deaf person born with CMV until fall of 2023
- A teacher at MDS mentioned two of her three deaf students were born with CMV
- This information sparked renewed interest in my involvement in CMV education
- My objective is to advocate for increased awareness and prevention to combat CMV

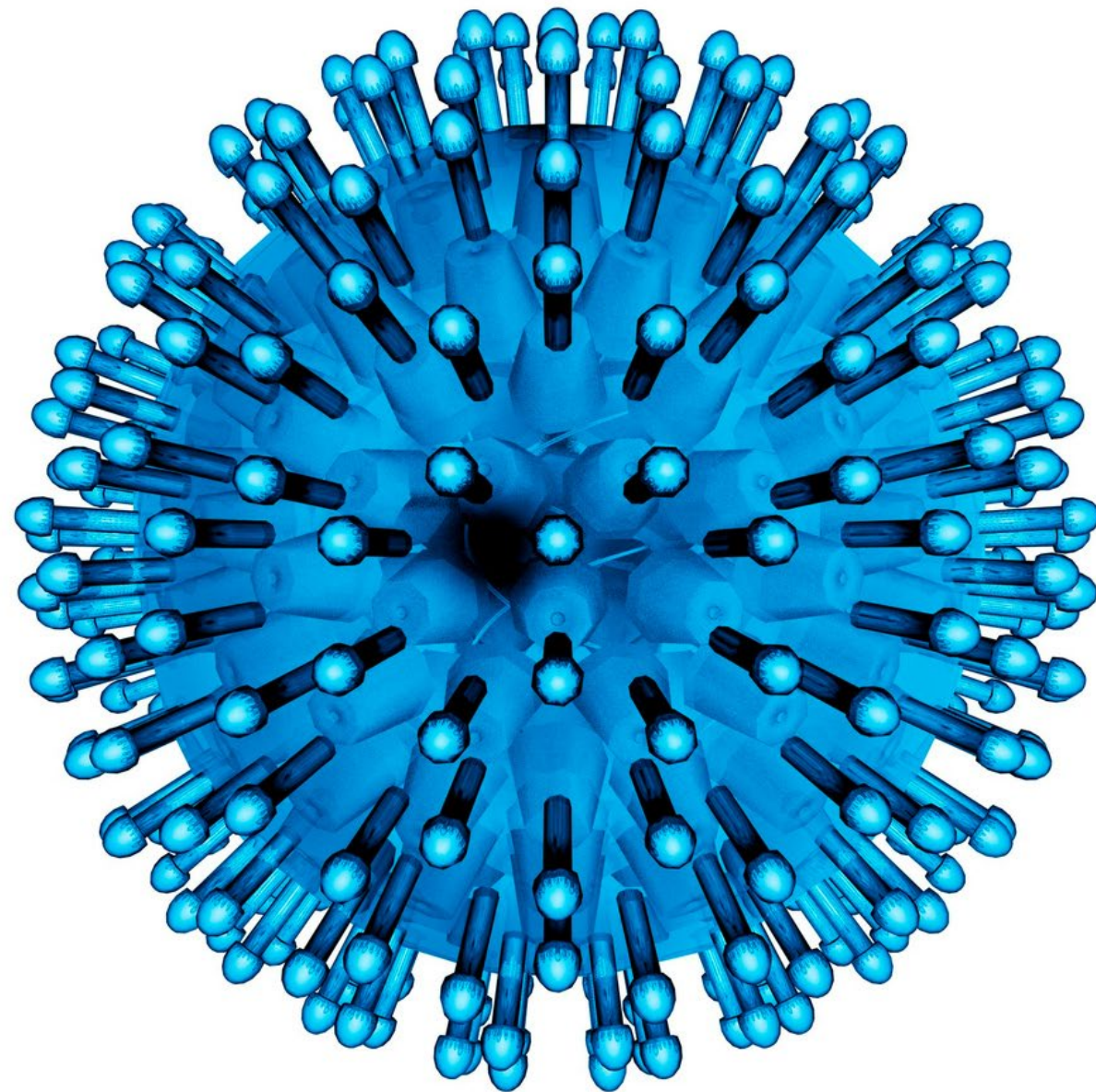
Cytomegalovirus

What is CMV?

- CMV belongs to the herpesvirus family and can pose risks during pregnancy.

What is congenital CMV (cCMV)?

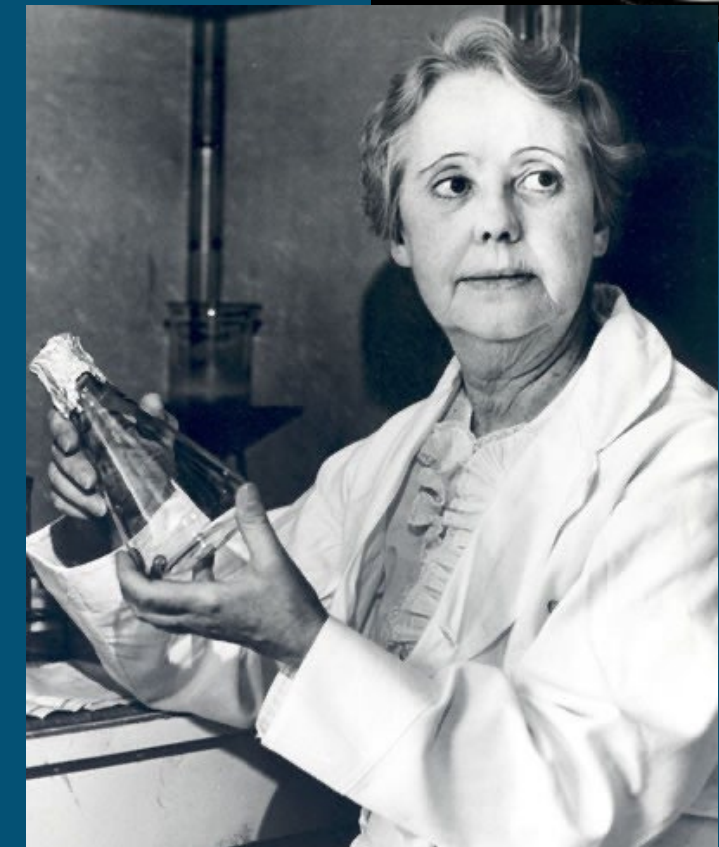
- It is a condition where the infant is born with a CMV infection, having acquired it before birth.



Mother of

Cytomegalovirus

- In the 1950s, Dr. Margaret Smith was the first to identify Cytomegalovirus (CMV). Despite documenting her findings in a paper, it was initially rejected-although male scientists had similar papers published!.
- Achieved a Bachelor of Arts degree in Chemistry from Mount Holyoke College in 1918, subsequently pursuing enrollment in Medical School.
- Upon graduating in 1922, she transitioned to the position of a pathology assistant, later advancing to roles as an instructor and pathology associate.
- After the 1918 influenza epidemic, she was motivated to specialize in researching cytomegalovirus (CMV).

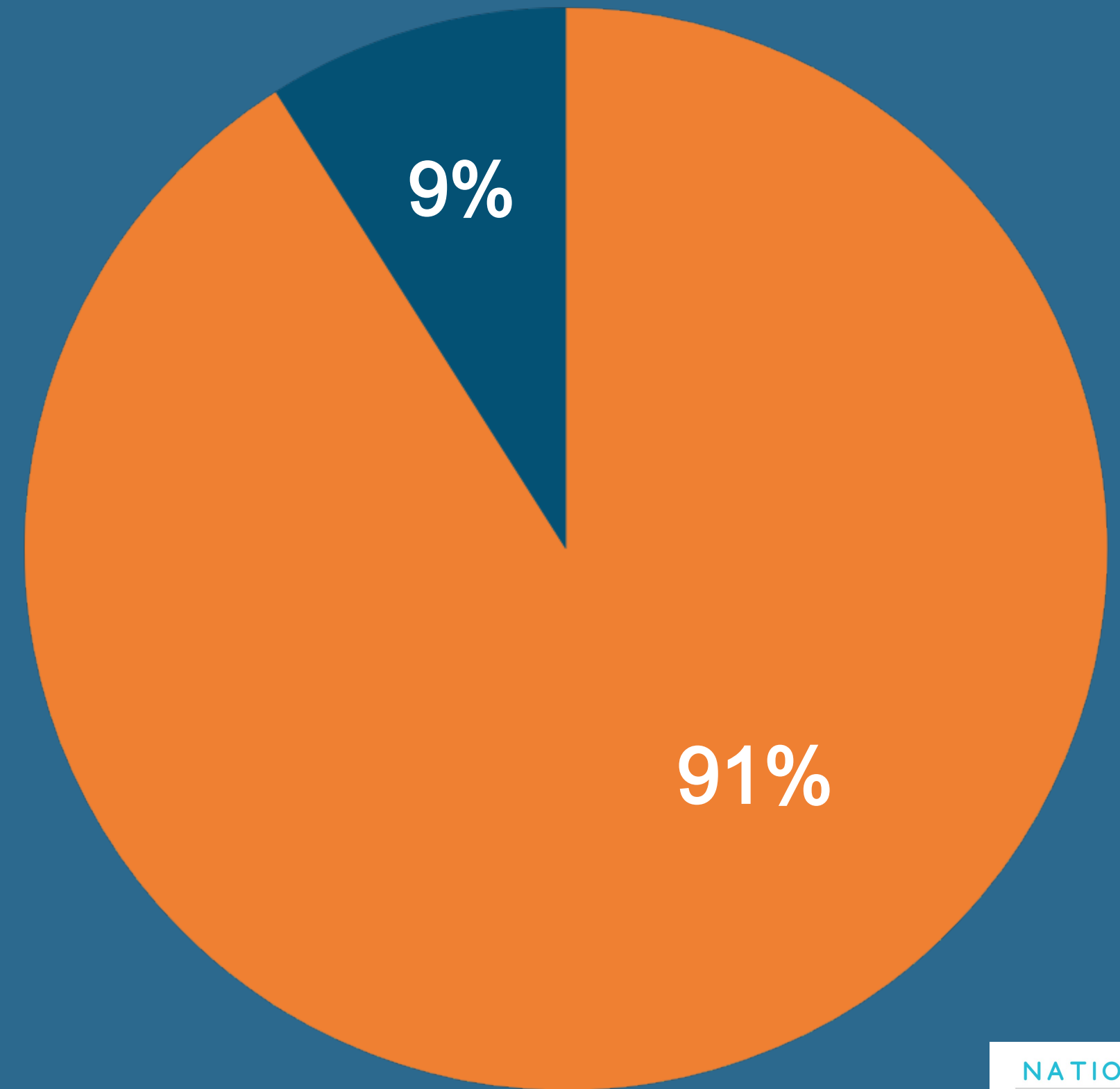


How Common is cCMV?

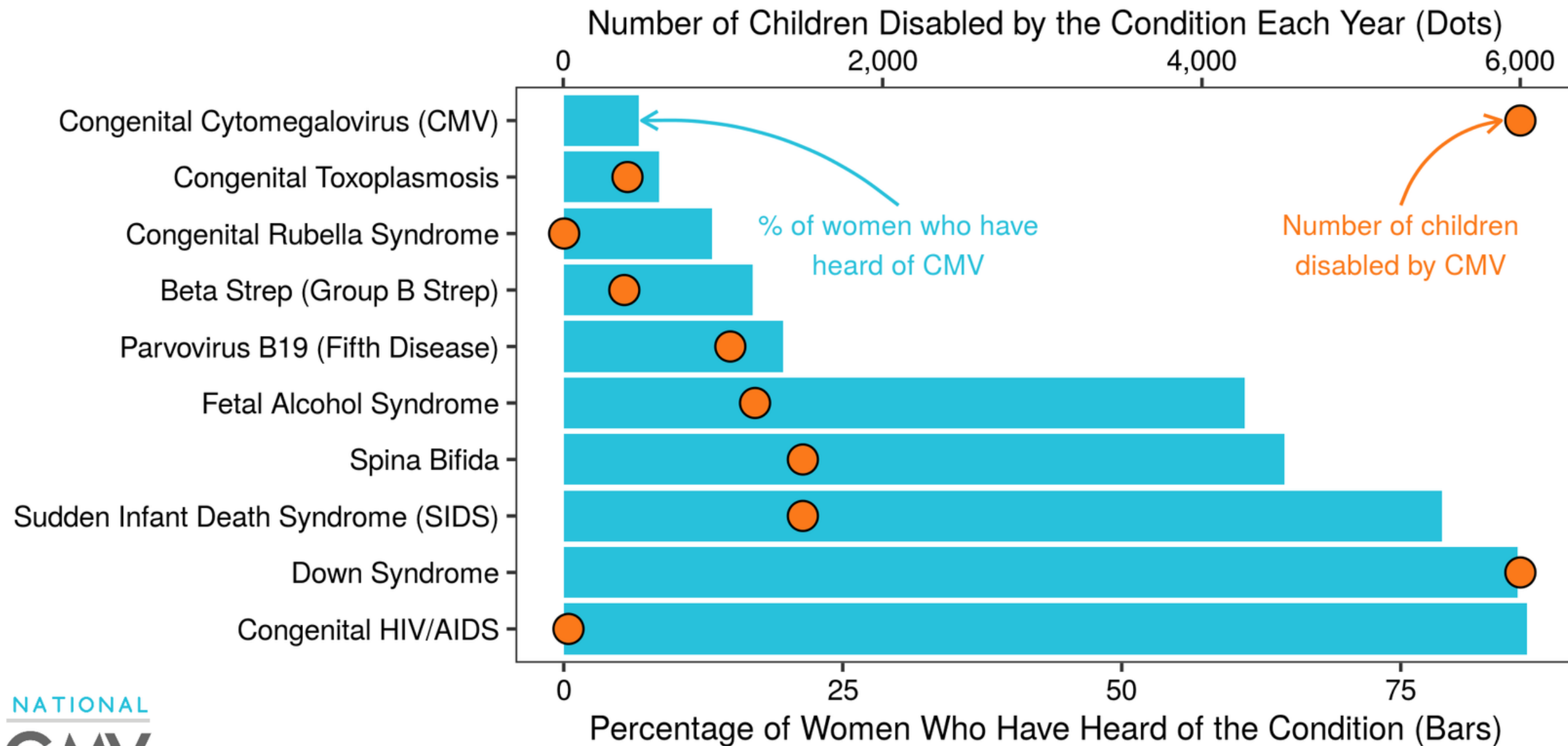
- One in three pregnant women infected with CMV will transmit the virus to their unborn baby.
- Every hour, one child is left permanently disabled due to cCMV.
- One in every two hundred children are born with cCMV each year.

Statistics

Ninety-one percent of women and healthcare providers are unaware of CMV, and only nine percent of women are informed about CMV.



Awareness vs Incidence of Congenital Conditions



Spectrum of Symptoms

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

Vision

problems/loss

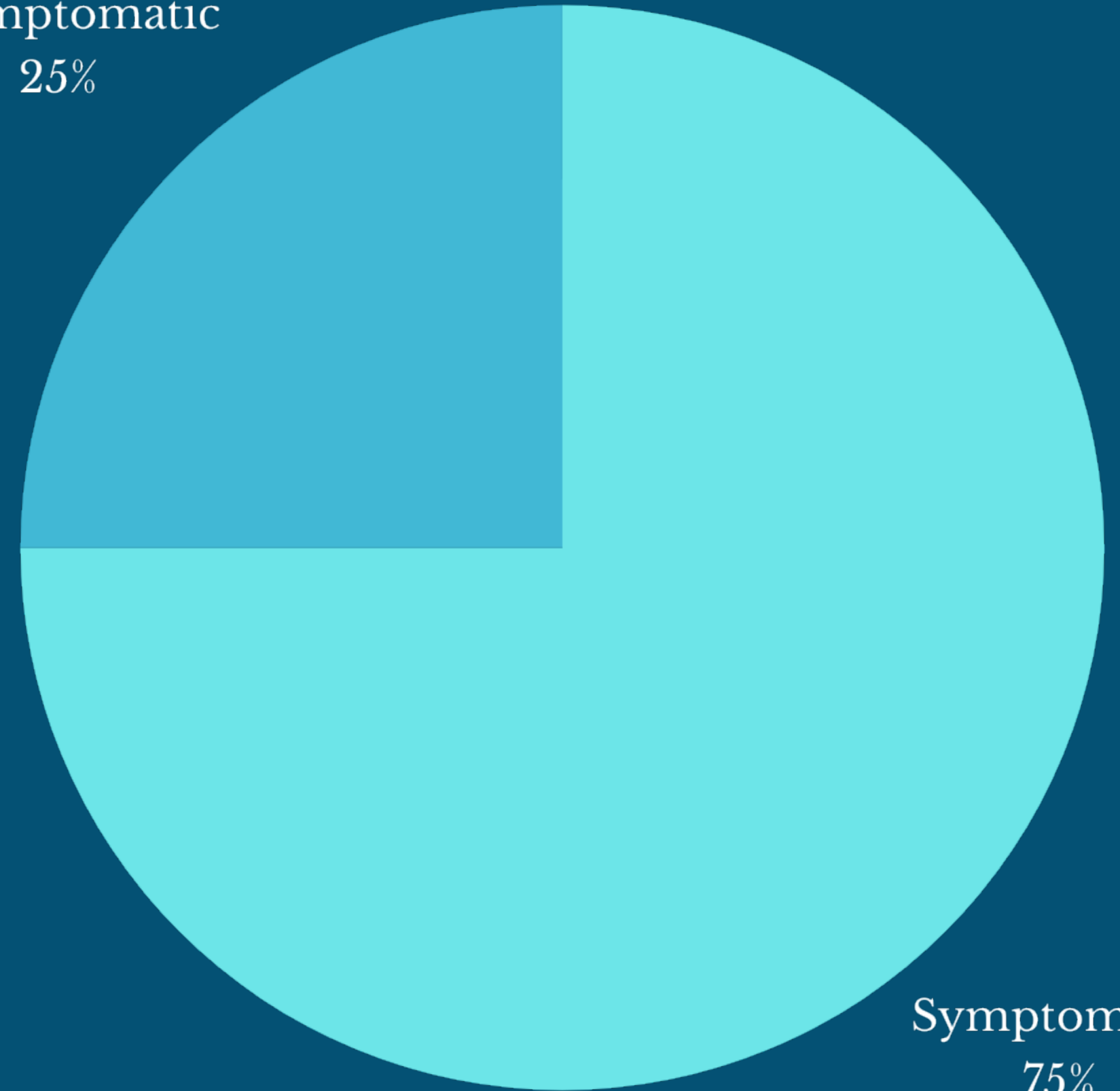
Vision problems can affect 10-20% of children with symptomatic congenital CMV (cCMV), presenting as various abnormalities, including retinal scars and Cortical Vision Impairment (CVI).

It is recommended to have their eyes examined at birth and during adolescence.

Hearing Loss

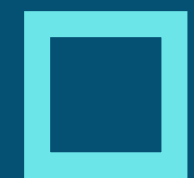
3-5% of babies exposed to CMV in womb develops bilateral moderate to profound sensorineural hearing loss

Asymptomatic
25%



Symptomatic
75%

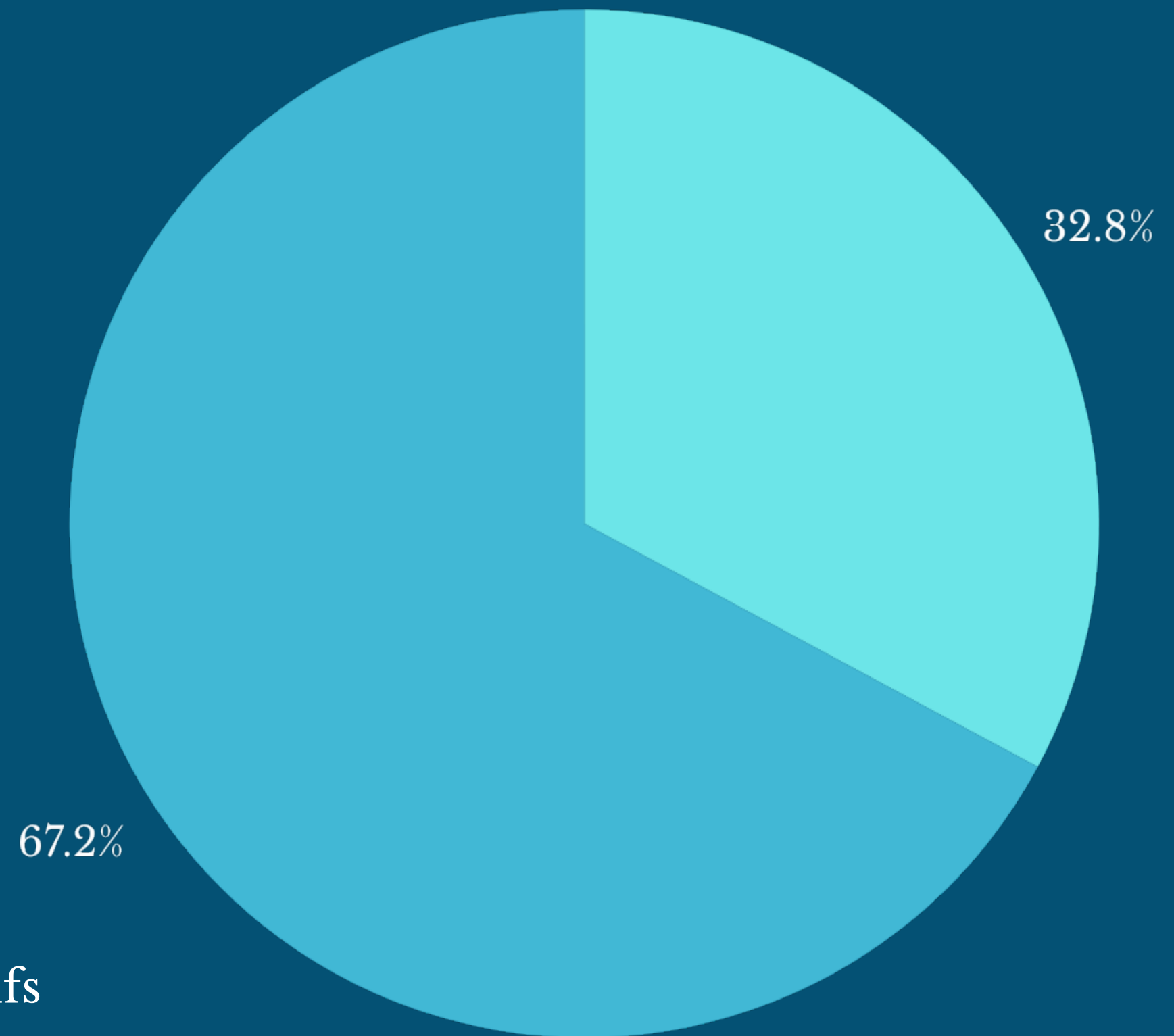
Vestibular Dysfunction and cCMV



Asymptomatic



Symptomatic



https://ehdiconference.org/System/Uploads/pdfs/3478265_16243KarenHendrick.pdf?v=1.83

5 Simple Tips to Help Prevent CMV



Avoid contact with saliva when kissing a child



Do not put a pacifier in your mouth



Do not share food, utensils, drinks or straws



Do not share a toothbrush



Wash your hands after changing a diaper

Minnesota laws that were passed

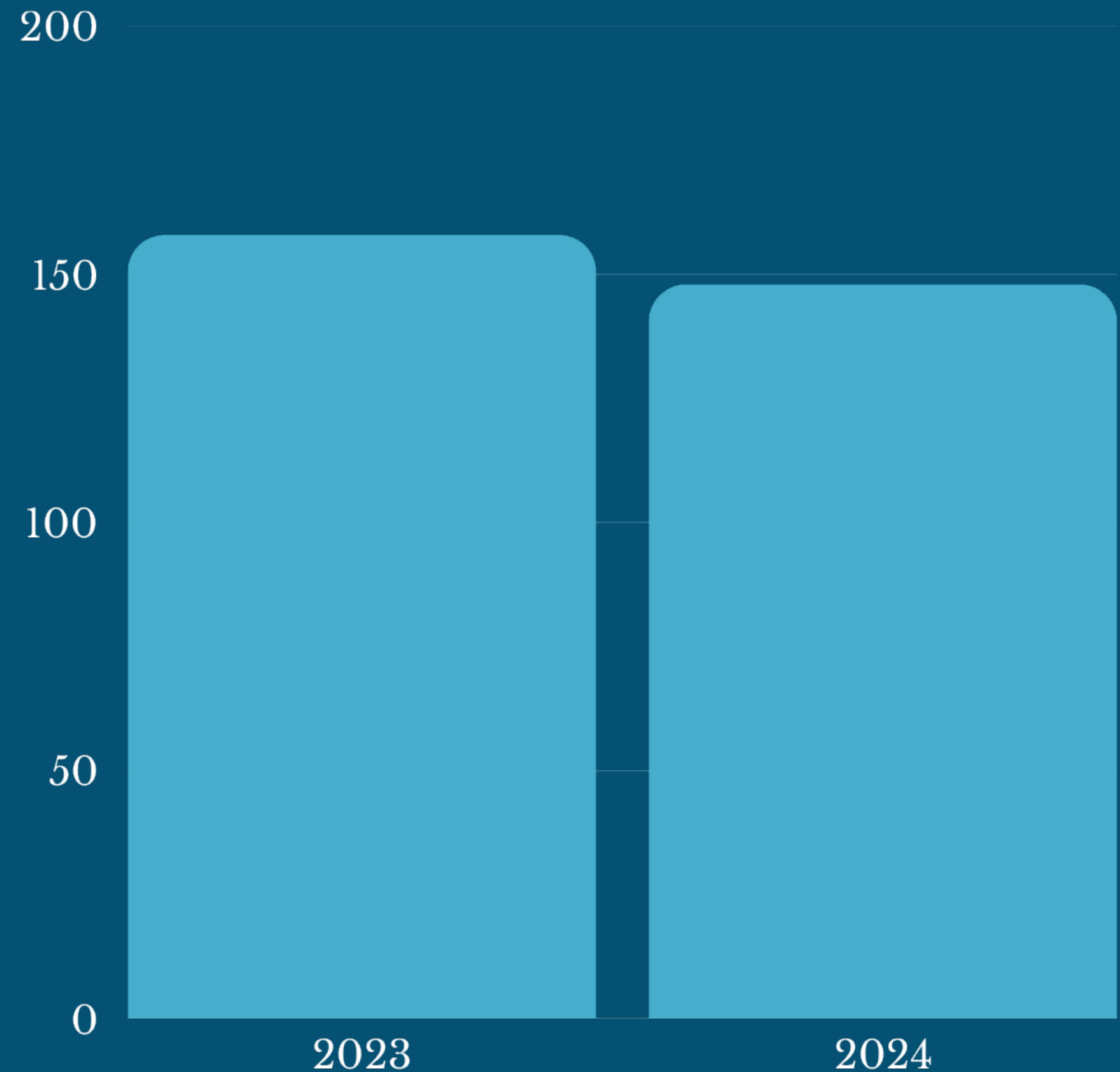
Universal newborn
Hearing Screening
in 2007

CMV Screening
Vivian Act 2021

This was named after Vivian
Henrikson, who was identified with
congenital cytomegalovirus (cCMV)
shortly after birth

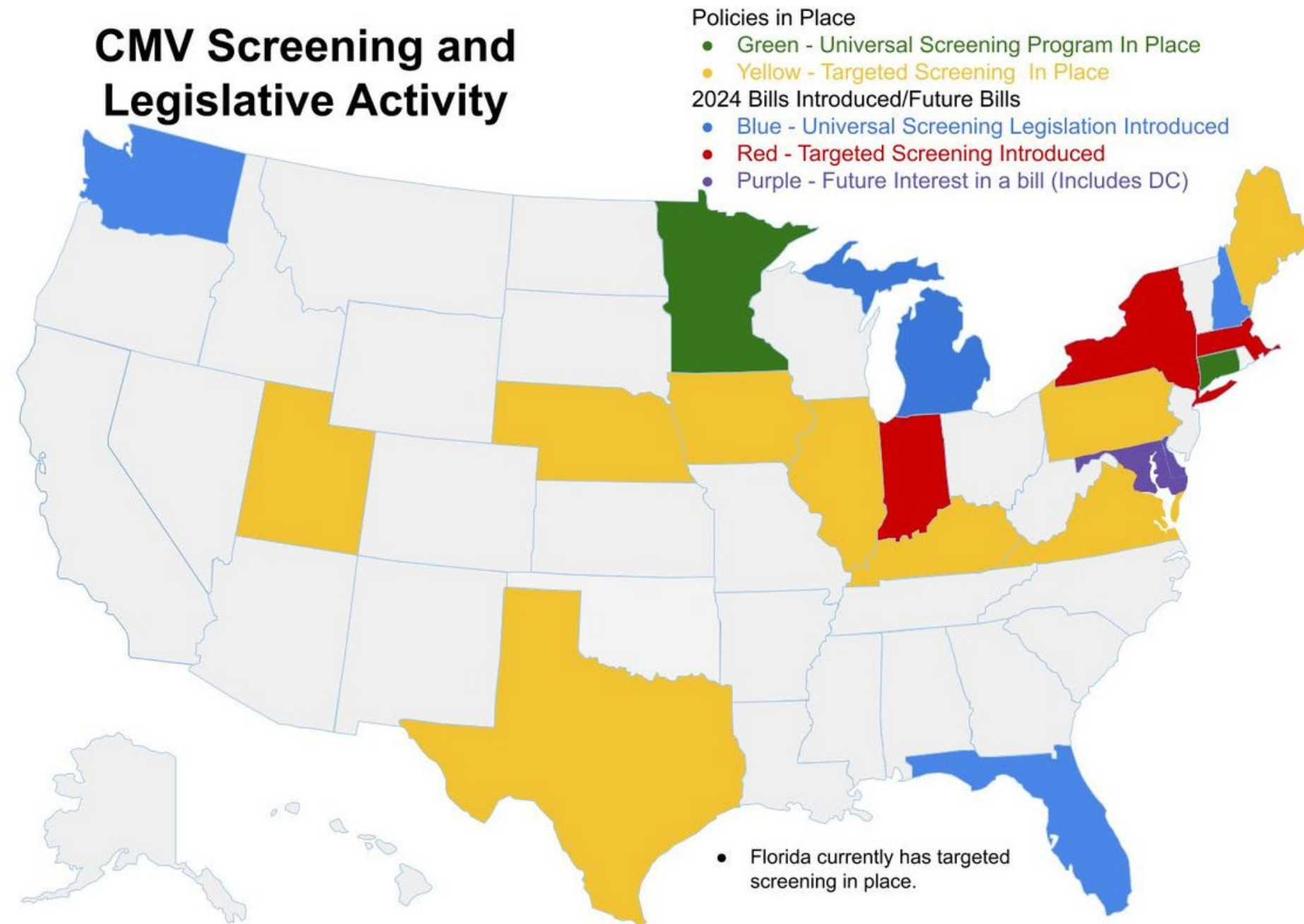
*Minnesota CMV Data from the Minnesota Department of Health**

- Universal screening for Cytomegalovirus (CMV) commenced in February 2023; data from previous years (2016-2022) obtained by Dr. Mark Schleiss (doi: 10.1001/jamanetworkopen.2022.30020).
- Cases were identified through newborn screening and various diagnostic methods.
- 57% of cases are located within the seven-county metropolitan area.
- There were 158 reported cases in 2023.
- There were 148 reported cases in 2024.



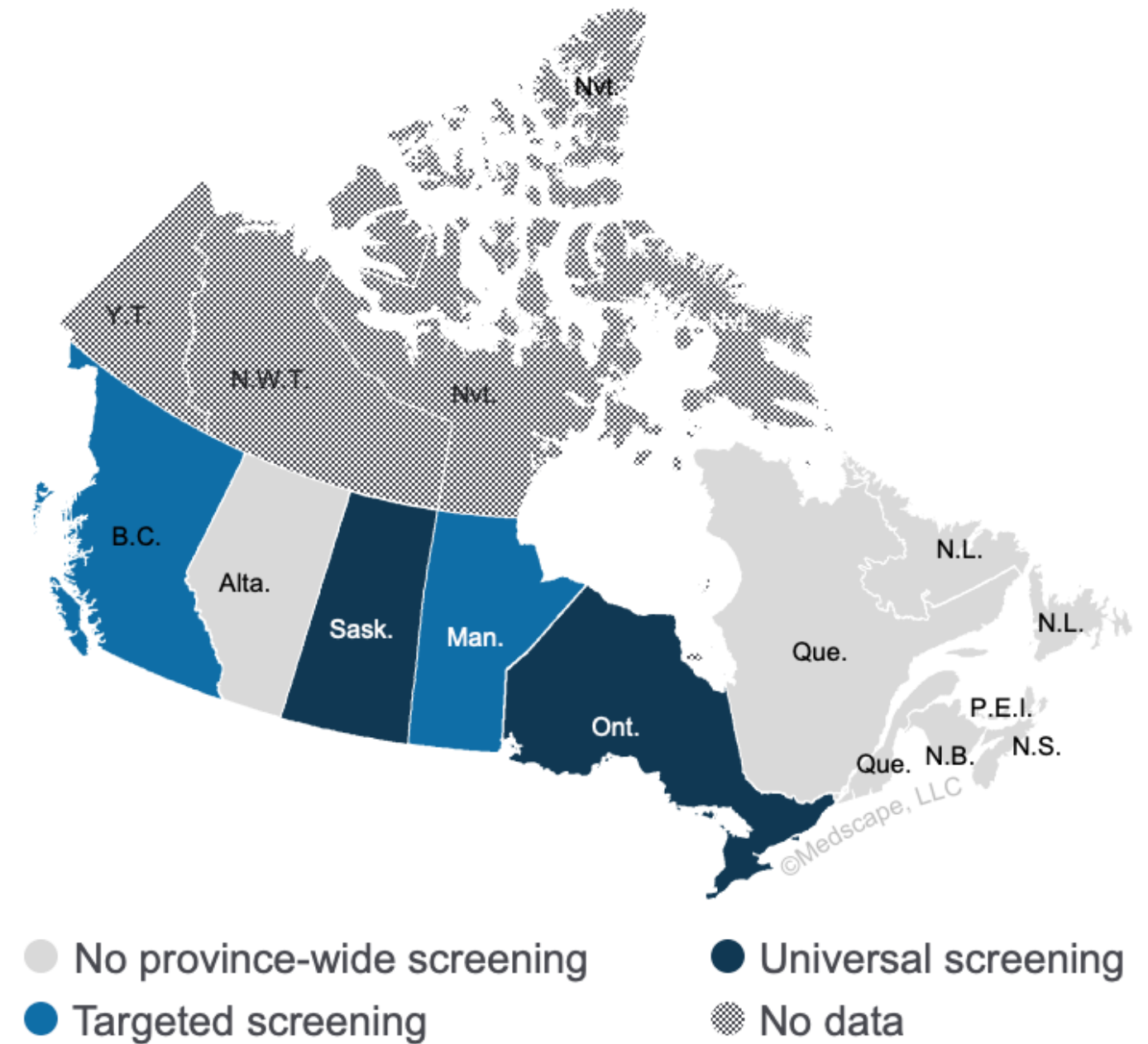
<https://www.health.state.mn.us/diseases/cytomegalovirus/congenital.html>

CMV Screening and Legislative Activity



www.acialliance.org/page/CMVandHearingLoss

Congenital CMV Policies in Canada



Silent Global Burden

- Why is attention to CMV low?
 - Maternal and newborn infections are usually asymptomatic
 - Sequelae are usually delayed, and once visible testing for cCMV may not be possible
 - False belief that congenitally infected children who are born to women with preexisting antibodies have typical outcomes
 - 2/3 of infants with congenital CMV are born to mothers who were seropositive before conception and these infants can have consequences of the virus

CMV Vaccine

Dr. Mark Schleiss, our own CMV expert, and several other physicians have conducted extensive research to develop vaccines for CMV, with promising availability anticipated in the coming years.

National CMV Foundation

OUR VISION: To eradicate congenital CMV in the United States for the forthcoming generation.

OUR MISSION: To prevent pregnancy loss, childhood death, and disability due to congenital CMV.

OUR PURPOSE: to prevent CMV infection in women of childbearing age.

www.nationalcmv.org



Save the Date

Congenital CMV Public Health and Policy Conference

Minneapolis, Minnesota

<https://cmv.usu.edu> **September 7th-9th, 2025**

**McNamara Alumni Center
at the University of Minnesota**

4th Congress on Congenital Cytomegalovirus

November 20-21, 2025

Naples, Italy



Please reach out via email me
at
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for any questions or concerns

Reference S

<https://www.health.state.mn.us>

www.acialliance.org/page/CMVandHearingLoss

<https://www.health.state.mn.us/diseases/cytomegalovirus/providerfs.pdf>

<https://www.health.state.mn.us/diseases/cytomegalovirus/congenital.html>

