

SF1698

VIVIAN♥ACT

STOP Cyto**M**egalo**V**irus
from devastating 400+ MN
families a year



Hi! I'm Vivian.

I'm 7 years old. I'm determined, brave and I love unicorns, stuffed animals and coloring. **I was born with CMV and although it doesn't define me, it's part of who I am.** CMV caused damage to my brain, Cerebral Palsy and unilateral hearing loss. But, **I am lucky.** Lucky because my doctor caught my CMV before I left the hospital so I could start anti-viral treatments that prevented more damage. Lucky because I was in physical and occupational therapy at 2 weeks old. Lucky because when I missed my milestones my Mommy and Daddy were able to get me the healthcare I needed. Lucky because I am living life to my full potential. **Most are not lucky.**



Hi! I'm Vivian.

My mom (Leah) & I started the Vivian Act in 2018 by passing out fliers of my story at my castle (the Capitol). We're thrilled to be back working with Senator Karin Housley to pass my bill. Together, we can stop CMV—a **preventable**, common virus that no one talks about—by starting to educate Minnesotans and adding cCMV to the universal newborn screening. We want to make sure more MN babies are lucky like me because...



We believe every child deserves to live life to their full potential.



Hi! I'm Hank.

I'm 2 ½ years old. I'm determined, brave and I love 4 wheelers, biiiig trucks and my sister. **I was born with CMV and although it doesn't define me, it's part of who I am.** I passed all my newborn screens and was asymptomatic at birth. **I am lucky.** Lucky because my mom opted into the U of M study for cCMV and I tested positive. Lucky because it turned out I had low White Blood Cells, a blind spot in my eye, an abnormal brain MRI & I just found out I'm starting to lose my hearing in one ear. Lucky because I had a diagnosis that allowed me to start early childhood education at 6 months so I'm on track. Lucky because I'm living life to my full potential. **Most are not lucky.**



Hi! I'm Hank.

My mom (Steph) reached out to Leah shortly after I was diagnosed with CMV to see how she could help push awareness and legislation. When she was pregnant with me she avoided sushi, undercooked food and lunch meat (1 in 20k chance of listeriosis), yet had never heard of CMV, a 1 in 150 chance of having a baby born with it. We don't think that's fair and we want to make sure more MN babies are lucky like me. Because...

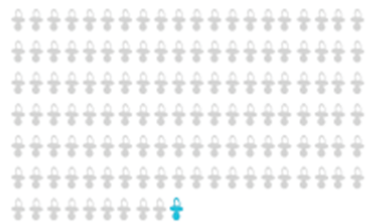
We believe every child deserves to live life to their full potential.



Cytomegalovirus 101

CMV is the most common viral infection (you've never heard of).
When a pregnant mom contracts it, it infects the baby in utero.

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

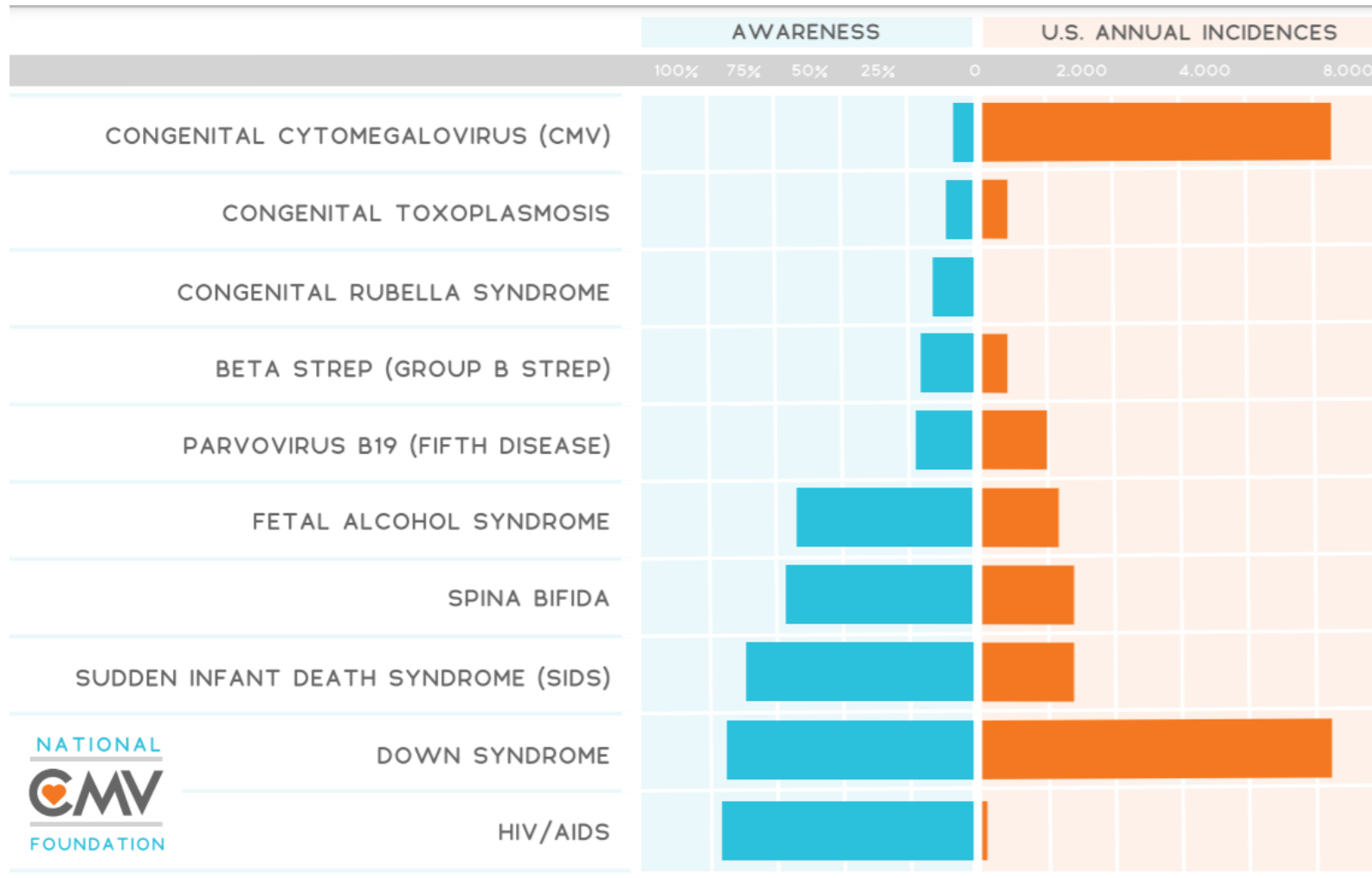


#1 in the worst way
#1 most common
viral infection
#1 infectious cause
of birth defects
#1 cause of non-
genetic hearing loss



Cytomegalovirus 101

Highest annual incidence & lowest awareness



WWW.NATIONALCMV.ORG

"Doutre, S. M. Barrett, T. S. Greenlee, J. & White, K. R. (2016). Losing Ground: Awareness of Congenital Cytomegalovirus in the United States. Journal of Early Hearing Detection and Intervention, 1(2), 39-48."

**91% of women
have never
heard of CMV.**

Lack of awareness
in medical
professionals is
staggering.

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CMV is preventable

If you know about it! MN moms have not been given a chance to reduce their risk of contracting CMV during pregnancy

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

It's often contracted during a 2nd pregnancy with a 1st child in daycare.

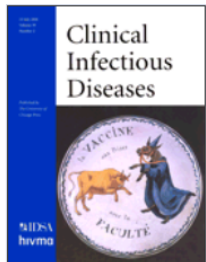
Hey! We're getting good at these!



Public Health Impact

Estimated to cost the US Health care system at least \$1.86 Billion annually, with a cost per child of more than \$300k annually.

Clinical Infectious Diseases, vol 39 issue 2, July 2004



Volume 39, Issue 2
15 July 2004

Article Contents

Abstract

Public Health Impact

Evolving Epidemiology

Cmv Pathogenesis

Control of Cmv by the Immune

progressive hearing damage and as serious consequences of infection, including mental retardation, cerebral palsy, and impaired vision, become apparent. CMV is one of the most important causes, infectious or noninfectious, of deafness in children. Children who are born with symptoms of CMV infection frequently have late-onset hearing loss. Of congenitally infected children who appear to be healthy at birth, ~15% will have progressive hearing loss when examined over the course of several years, and this damage may eventually become profound. Congenital CMV infection is believed to be responsible for one-third of cases of sensory neural hearing loss in children [1–3]. An estimated 8000 newborns have health problems each year as a result of congenital CMV infection [1]. In the 1990s, the overall disease burden associated with congenital CMV infection was estimated to cost the US health care system at least \$1.86 billion annually [4], with a cost per child of more than \$300,000, compared with an estimated cost of \$200,000 per child for rubella had it not been controlled by vaccination (figures are not adjusted for 2003 dollars) [5]. Thus, the problem of congenital CMV infection is enormous, and the damage affects the very young, resulting in long-term morbidity.

*Rubella pre-vaccine control was estimated to cost \$200k per child. The problem of congenital CMV infection is **enormous**.*



Public Health Impact

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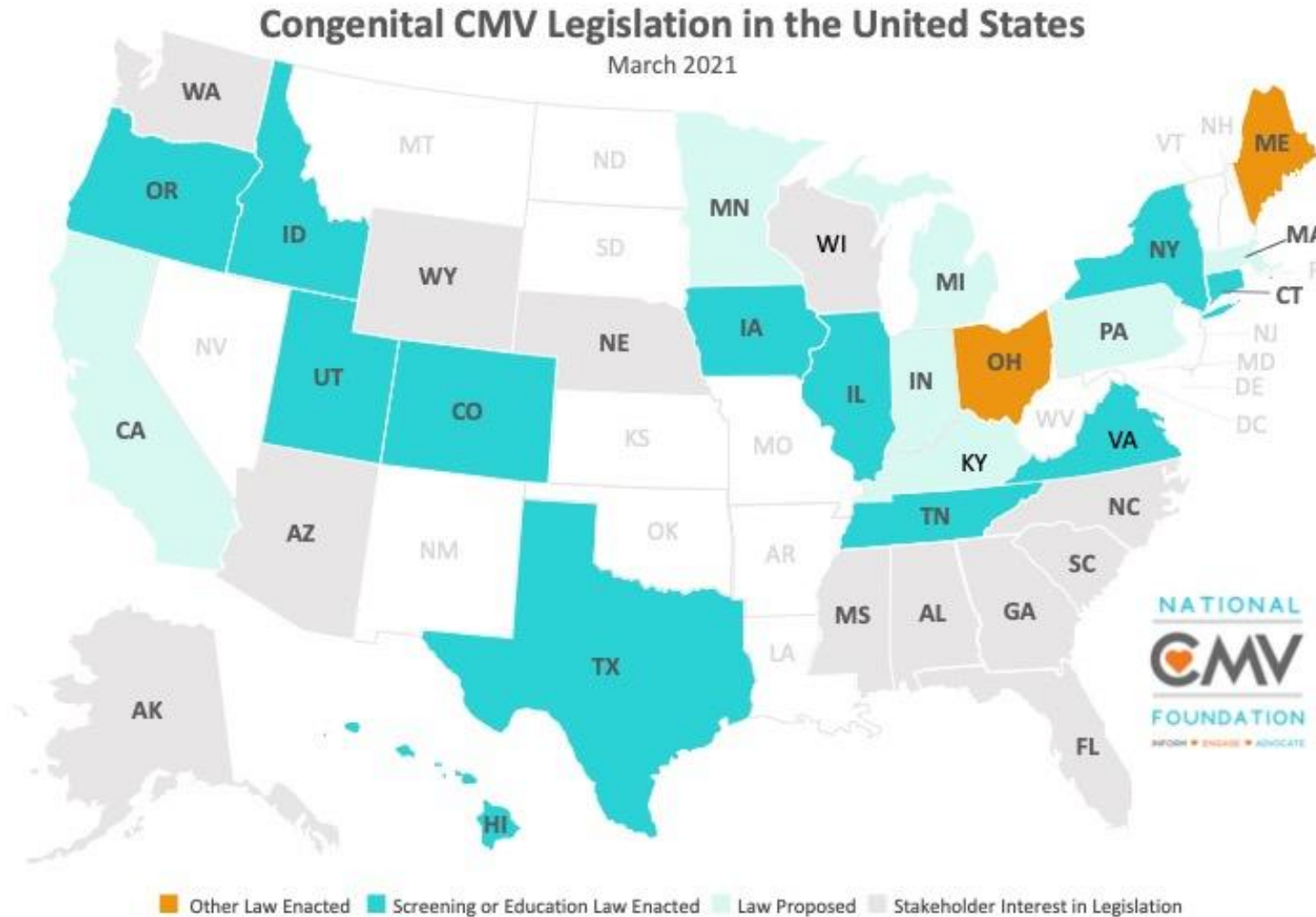
That's est \$120 MILLION a year in MN healthcare costs. (\$300,000 x 400 MN babies born with CMV a year).

With 40% of MN babies born on MA, **that's \$48 MILLION a year of taxpayer dollars.** (\$120 million x 40%).

The problem of congenital **CMV** infection in MN is **widespread and costly.**



Minnesota families are counting on us



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

We'd become the **14th state with education legislation** or the **1st state** to adopt universal newborn screening



Step 1: Pass Vivian Act

STEP 1

**EDUCATE
+
PREVENT**
Vivian Act

STEP 2

**DIAGNOSE
+
CARE**
Universal Newborn
Screening

STEP 3

**VACCINATE
+
ERADICATE**
U of M leading the way,
moderna working here

moderna

Investigational *CMV vaccines* that
are in clinical trials.



Currently, there is no vaccine available to prevent CMV. However, many experts believe that a vaccine to prevent congenital CMV infection may have an impact on child health. CMV vaccines are being researched and developed right now.^{18,19}

It is important to continue to raise awareness and educate on the risks of CMV and encourage people to follow proper hand hygiene guidelines to help prevent the spread of CMV.⁵



Dr. Mark Schleiss has dedicated 30 years to CMV research + identified a screening technique with 90% accuracy—our hero!

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Convos are starting

The New York Times

CMV Is a Greater Threat to Infants Than Zika, but Far Less Often Discussed

HEALTH

Families fight for screenings of little-known virus that can cause permanent health problems in unborn babies

Cytomegalovirus is the most common virus in the know it can cause permanent health problems in

HEALTH

U of M researcher develops new way to screen for virus impacting babies in utero

VACCINE AWARENESS

Why All Expecting Mothers Need to Know About CMV



Bill Filed to Mandate Universal Newborn Screening in Massachusetts for Highly Debilitating Congenital Cytomegalovirus

Bill also Requires Critical Prenatal Education and Data Reporting for

Virus, which has Low Awareness en.



After loss of son, Oxford mom pushes for universal newborn screening for congenital CMV

Nicole Shih Telegram & Gazette

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**We must act. No more
unlucky babies.** Every
child deserves to live life
to their full potential like
Vivian + Hank.

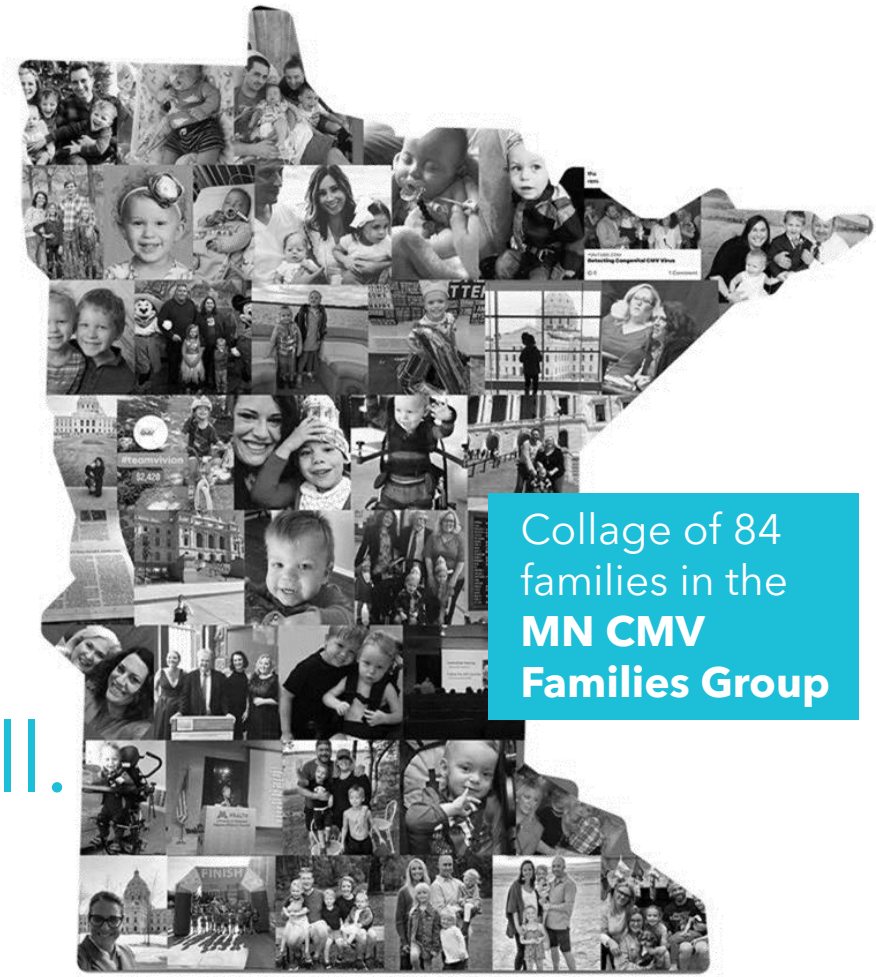


Pass

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VIVIAN♥ACT

Vivian Henrikson. **Hank** Steidl.
Cody Hagstrom. **Sadie** Petersen.
Natalie Pelletier. **Rory** McDermott.
Sawyer Anderson. **Lucah** Green.
Pippa Devereaux. **Hayes** Stanton.
Bowen Zawchenuk. **Amelia** Gladhill.
Brynlee Koch. **Hudson** Wiorek.
**Minnesota babies are
counting on you.**



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