

Finding Your Village: a Family's Guide to Building Your Support Network

Lisa Eickel, MS CCC-SLP
Speech-Language Pathologist
CMV Parent & Advocate

About Me

Lisa Eickel

James Madison University '08, '10M
Masters in Speech- Language Pathology
Undergraduate work in Communication Sciences
and Exceptional Education

Worked in Early Intervention, Private Practice,
Charter Schools & Public Schools as a Pediatric
Speech Language Pathologist

Mom to 3 boys Easton (8), Owen (6), Cameron (3)
National CMV Foundation Community Alliance Chair, Virginia
EHDI Advisory Committee Co-Chair, Virginia
Center for Family Involvement DHOH Family Educator



Contents

- CMV by the Numbers
- Owen's Story
- The Gaps
- Where to Look for Help
- Where Are We Now
- How Getting Involved Helped
- Keep in touch



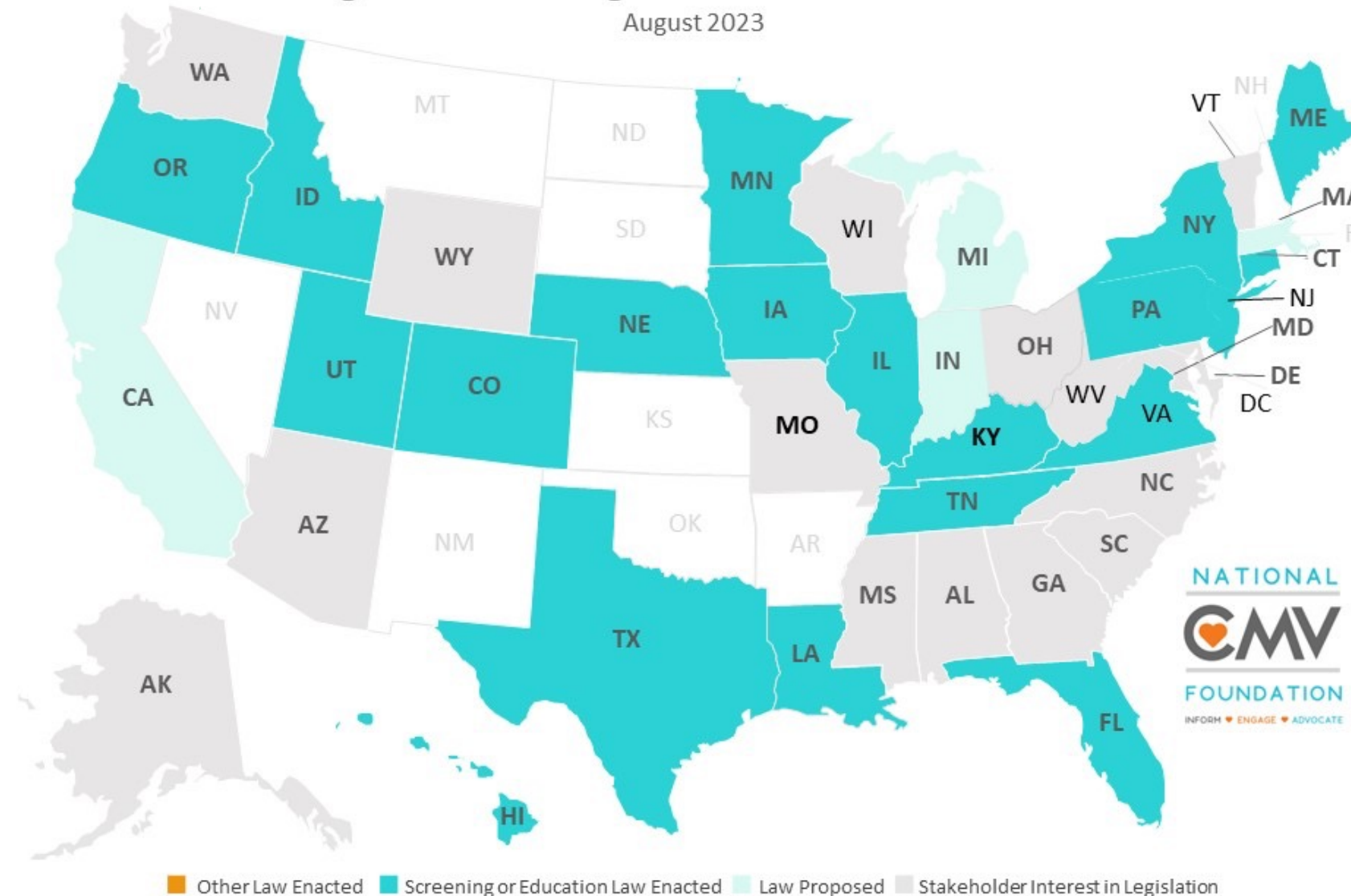
CMV

CMV By The Numbers

- CMV is the leading infectious cause of neonatal disabilities and birth defects
- 1 in 200 babies are born with CMV
- 1 baby every 30 minutes is born with CMV
- 8-10,000 live births with CMV each year
- 1 out of 3 infected pregnant mothers will pass CMV to their babies in utero
- Nationally, only 7% of CMV positive babies fail the NB hearing screen
- We're still missing the opportunity to identify many CMV babies early.
 - Misdiagnosis or no diagnosis
 - Lack of or late intervention
 - Late onset hearing loss and missed access to learning opportunities with spoken language

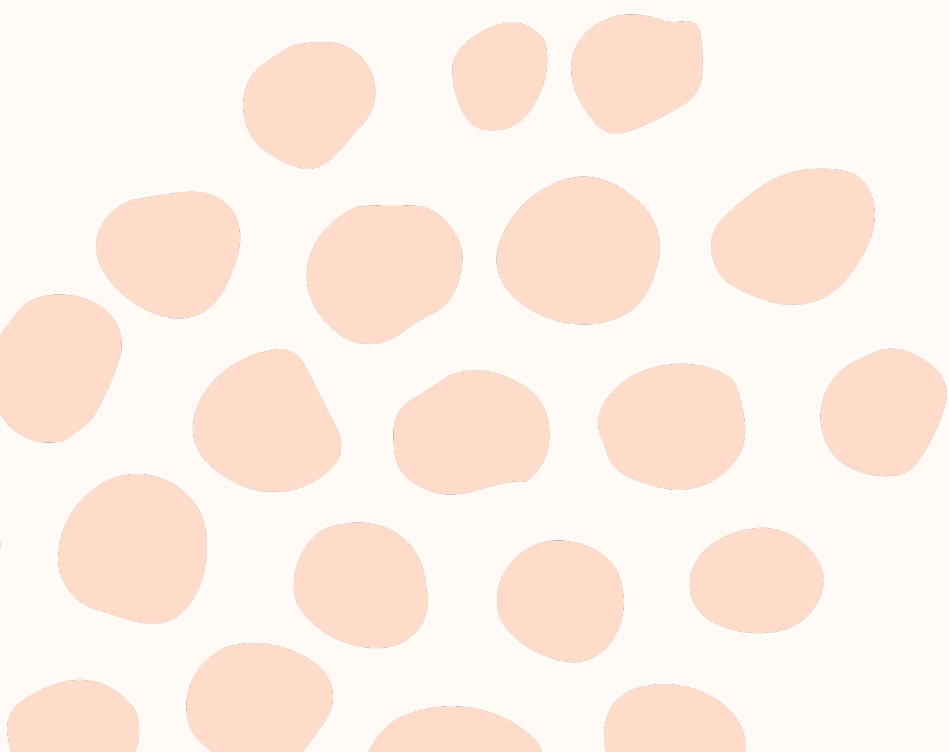
Congenital CMV Legislation in the United States

August 2023



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

Owen's Story



Owen's Story



- Planned second pregnancy
- I worked in a public school that had a Special Education preschool program.
- I had a 1 year old in a center-based child care setting
- I didn't know that women who worked with young children (or had a child of their own) were at greatest risk of contracting CMV.
- I didn't know to avoid sharing cups at the park with my toddler or finishing his snacks
- Routine questionnaire at my initial OB visit led to my CMV diagnosis.

Owen's Story



- High- Risk MFM monitoring never showed physical signs of CMV infection in utero
- We were wrongly educated on the potential effects CMV could have on our baby.
- We were told "you only need to be worried about hearing loss."
- Spontaneous pre-term labor, born at 37 weeks
- He "looked good" at first glance
- Despite discouragement from hospital staff, we pushed for CMV testing
- He struggled with feeding immediately but was still discharged home with us

Owen's Story



- Within days of discharge, he was dropping significant amounts of weight and labeled failure to thrive.
- During a weight-check the first week he wouldn't rouse to feed and was rushed to the ER. There he would be diagnosed with CMV due to presence of the virus in his blood, urine (which had just come back from testing at birth) and CSF.
- Started on anti-viral drugs
- Blood draws, MRIs, liver & spleen ultrasounds, invasive eye exams, multiple 48 hour EEGs, and hearing tests



The Gaps



The Gaps



- Started in Early Intervention at 4 months
 - Worked with PT, OT, Feeding, Speech- Language, and Behavioral Health
 - Continued to see Neurology & have abnormal EEGs
 - 3-6 month hearing evals
 - Orthotics for hands and feet
- Graduated EI during the pandemic & didn't refer to Part C
 - Since Owen wasn't DHOH, we struggled to "fit in" and find our place in the disability community
 - Early intervention providers, even Pediatricians never mentioned other CMV families or support networks to us
 - Knowledge gaps for all our providers (except for ID)- educating the medical world was exhausting!
 - Fall of 2018 I saw a Facebook post to run an endurance event for NCMVF. At a pre-race event I finally met another parent of a child with CMV.

Where to Look



Find Your Village

You have to be willing to put yourself out there and be uncomfortable.

1. Ask
2. Volunteer
3. Leave YOUR information
4. Show up
5. Try Again (and maybe again)

**“Get comfortable being uncomfortable”
-The Navy Seals**





Get Looking

- National CMV Foundation parent registry
- Hands & Voices local chapter
- EHDI Advisory Committee
- State-based family to family support network
- DHOH mentor relationships
- DHOH playgroup
 - If you can't find one, host one!
(library, park, independent bookstore)
- Facebook/ social media searches



Where Are We Now



Where Are We Now

OWEN

- Beginning at 4 years old, Owen attended a community-based PS, followed by a private Pre-K program.
- He was formally identified with late onset hearing loss in the fall of 2022.
- Between 3-5 years old, he was also diagnosed with ADHD, ODD behaviors, sensory sensitivities, a feeding disorder and infantile anorexia.
- Received an IEP as a 5 year old PreK student
- Transitioned to Kindergarten at our neighborhood school this fall



He is Also...



Where we are now



LISA

- Connect with newly diagnosed families through family to family in my state as a mentor
- Volunteer as a state representative for NCMVF
- Search for other CMV families in my state through social media & at other non-profits' local events
- Develop & edit state-based educational materials for CMV awareness with DOH
- Elected to serve on EHDI Advisory Committee after speaking at meetings for CMV awareness
- Advocating for inclusion, acceptance & access for Owen and other DHOH students
- Share my knowledge with other families
- Bi-monthly CMV family check-ins





How Getting Involved Has Helped Us

CREATIVITY & PASSION

Developing educational materials & organizing events to raise awareness

INNOVATION

Encouraging DHOH conversations and acceptance in school for Owen & others

CONNECTION

Connecting with families of newly diagnosed kids has opened up avenues for reciprocal support & friendship

HEALING

Maternal guilt for Owen's CMV diagnosis & our lack of support... Making sure others don't go this road alone has healed a long-standing wound.

Team #StopCMV Virginia

First annual event in 2023

Raised over \$8,500 for the
National CMV Foundation

More than 84 donors & 40 race
day participants

5 VA CMV families represented—
several meeting in person for the
first time!



2024

Team #StopCMV Virginia

Strides 4 CMV 5k will be held on
Saturday, June 22, 2024
in Ashburn VA

Goals:

- to raise \$10,000
- 10 VA CMV families represented



References

- Adler, Stuart P, Nigro, G. Prevention of Maternal-Fetal Transmission of Cytomegalovirus. Clinical Infectious Diseases 2013; 57(S4):S189-92
- Boucoiran, I, Yudin, M, et. Al. Guideline No. 420 Cytomegalovirus Infection in Pregnancy. Journal of Obstetrics and Gynecology Canada. 2021; 43:7 893-908
- Pass RF, Hutto SC, Reynolds DW, Polhill RB. Increased frequency of cytomegalovirus infection in children in group day care. Pediatrics 1984;74:121-6
- <https://nowIknowCMV.com>
- <https://www.cdc.gov/cmvi/index.html>
- www.NationalCMV.org



”

Owen brings so much fun and laughter to our lives. **He teaches us a lot about not giving up, even when the odds are stacked against him.** He loves hockey, baseball, drawing & chess. We know he will move mountains!

LISA - C **CMV** MOTHER

NATIONAL
CMV
FOUNDATION
INFORM • ENGAGE • ADVOCATE



Finding Your Village: A Family's Guide to Building Your Support Network

National CMV Foundation: nationalcmv.org

Hands & Voices: Handsandvoices.org

Early Hearing Detection & Intervention: <https://www.cdc.gov/ncbddd/hearingloss/>

NCHAM: National Center for Hearing Assessment and Management: infanthearing.org

Family to Family Support: Department of Behavioral Health & Developmental Services
(search "family support," "family connections" or "family support services for disabilities" +
your state)

State Department for the Deaf and Hard of Hearing
(search DHOH + your state)

Deaf & Hard of Hearing Mentor Programs:
Hosted by H&V, state behavioral health programs, state-based schools for DHOH, university
programs

Hearing Loss Association of America: hearingloss.org
Regional walks or events

National Association of the Deaf: nad.org

American Society for Deaf Children: deafchildren.org
(state & local resource list for deaf children)

Regional Hospital Networks outreach events

Birth to Three/ Early Intervention program outreach events

Parent/ Caregiver support groups and social media pages
-search for both 'groups' and 'pages' on Facebook
-look by school district/ county, state and region as well as national groups
-playgroups/ playdates hosted by private practice therapy centers
-follow and like posts from other CMV advocates




Children's Books for DHOH Kids

Ada and the Helpers by Travis Peterson
Can Bears Ski by Raymond Antrobus
Gracie's Ears by Debbie Blackington
Mighty Mila and Mighty Mila Dream Job by Katie Petruzzello
Padapillo by Valerie James Abbott
Princess Lizzie Wears Hearing Aids by Tosombra Kimes
Ranvir Cannot Hear by Genevieve Yusuf
Super Hearing by Jennifer Whitehead
Super Kena: A Girl Made Fierce with Hearing Aids by Becky Cymbaluk
The Quest for the Cockle Implant by Maya Wasserman

**National Deaf Children's Society: UK has an extensive list of books with DHOH
characters (reviewed by families) ndcs.org.uk*

Etsy Shops:

Embracing Differences (hearing aid & Cochlear Implant retention clips)
TheBeBopshop (HA & CI retention clips)
RaydiantGoods (personalized HA & CI stickers for cases, folders, etc)
JaaCreations (HA & CI skins/ tickers)
TheCochlearMom (HA & CI skins/ stickers)
TheButterflyPig (HA + AAC & other medical equipment for doll or stuffed animal)
ArtsyAntonelli (HA & CI for doll or stuffed animal, retention headbands & more)
ToyLikeMeShop (HA, CI & BA for doll or stuffed animal)



**This list is not intended to be all encompassing.
The presenter has no financial connections with
any of the Authors, shop owners or organizations listed above.
These are just a sample of the resources that the presenter
has found helpful in her own family's journey and that are
available to families of children who are DHOH.*



Questions &
Comments



Keep
in touch

Lisa Eickel, MS CCC-SLP

Eickel.Lisa@gmail.com

NationalCMVVA@gmail.com

540-840-9195

Ashburn, VA