Advocating for Change:

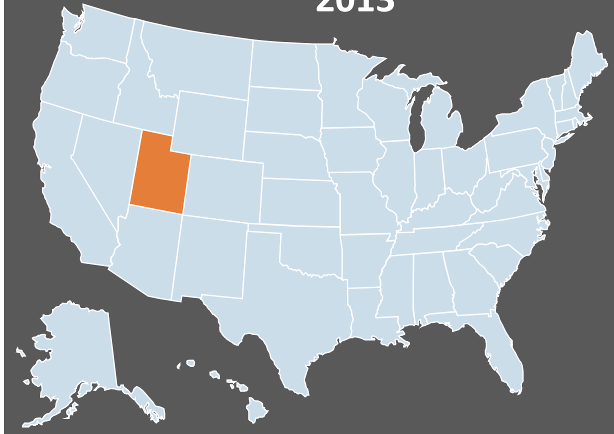
PARENT EXPERIENCES IN POLICY AND COMMUNITY ENGAGEMENT

"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it is the only thing that ever has."

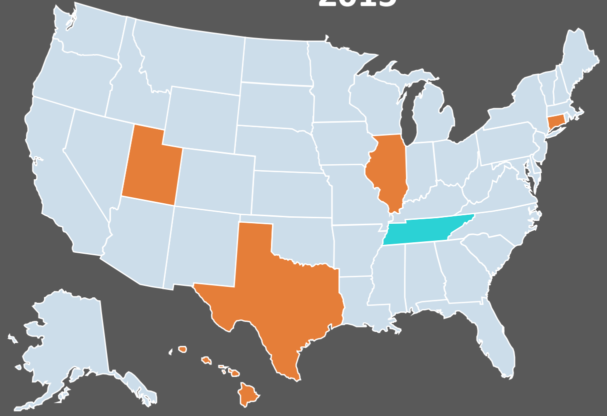
-Margaret Mead

Photo by Scott Dulaney

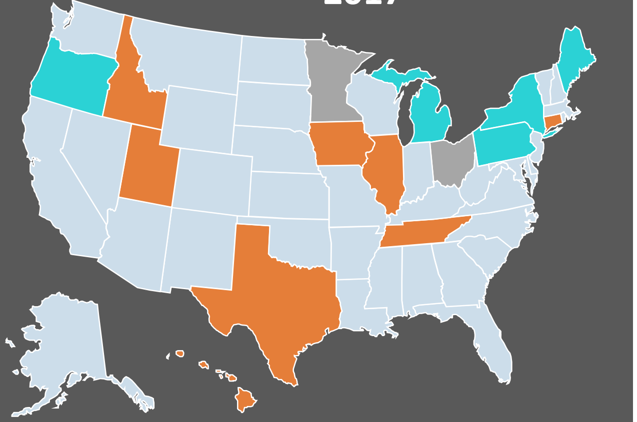
2013



2015

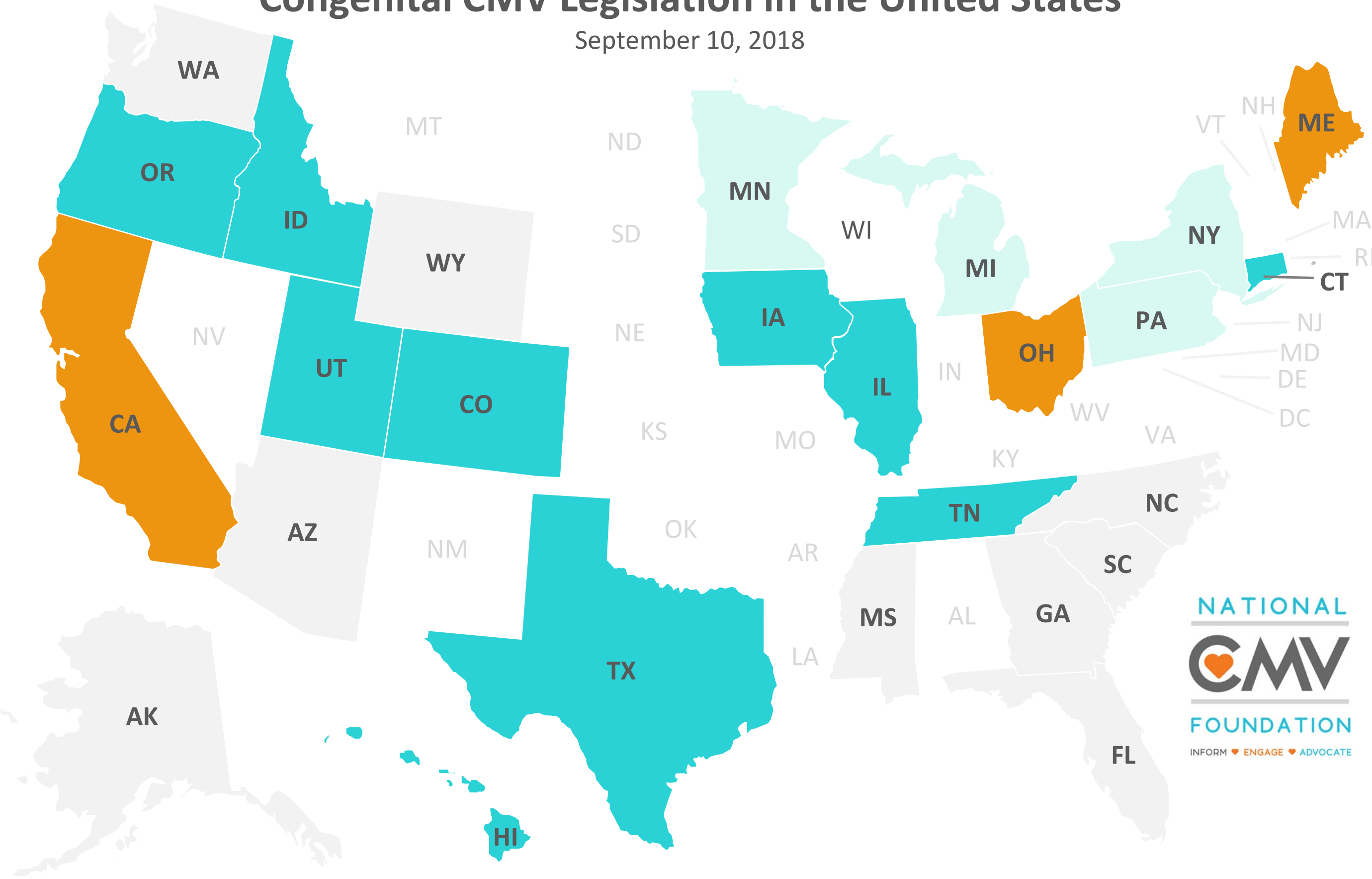


2017



Congenital CMV Legislation in the United States

September 10, 2018



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

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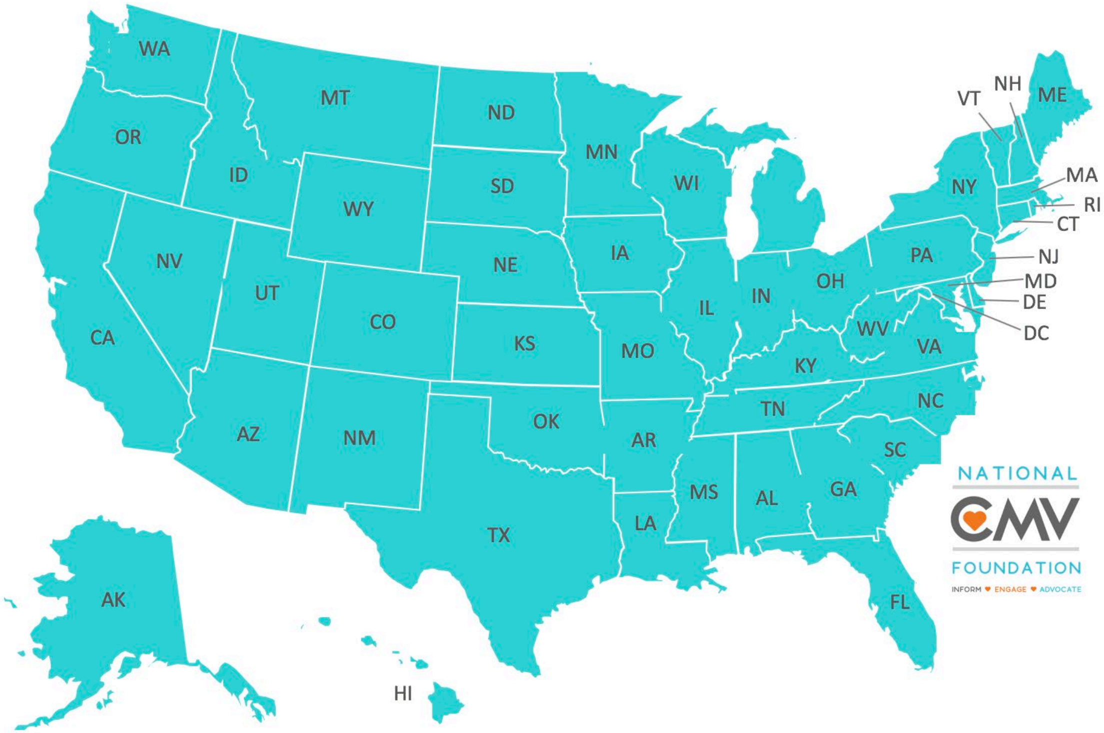
Nomination to the Recommended Universal Screening Panel (RUSP)



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Baylor College of Medicine

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

STANLEY A PLOTKIN, MD
Consultant in Vaccinology

NCHAM
National Center for Hearing Assessment and Management
Utah State University™

Texas Children's Hospital®

MERCK

Pfizer

UNIVERSITY OF MINNESOTA
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UAB MEDICINE
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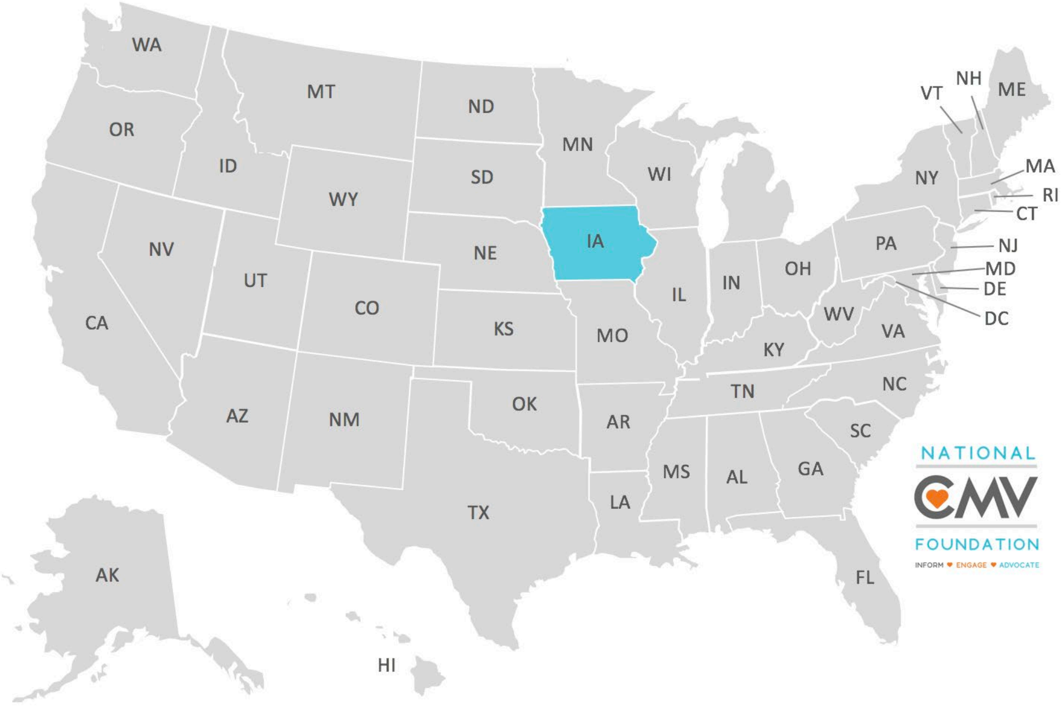
Children's of Alabama

NATIONWIDE CHILDREN'S
When your child needs a hospital, everything matters.℠

THE OHIO STATE UNIVERSITY
COLLEGE OF MEDICINE



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Amanda Devereaux

IOWA, USA

Pippa’s Story

AMANDA DEVEREAUX RN, BSN

PROUD MOTHER OF A CMV WARRIOR!

Objectives

- Describe current CMV law in Iowa
- Describe barriers to CMV advocacy and CMV legislation.
- Describe ideas for success with CMV advocacy.

Pregnancy- 2015

- Planned, second pregnancy, with preconception counseling.
- EDC: 11/15/15
- Prenatal care started at fertility clinic and then moved to OB clinic.
- 6/29/15: 20 week ultrasound showed cerebellum measuring 3 weeks behind.
- Referral made to perinatal specialist for consultation.

Diagnosis

- 6/30/15: Amniocentesis completed
- 7/9/15: Diagnosis received- congenital CMV
  - Options: terminate or "do nothing"
- 7/17/15: Consultation with U of M Maternal Fetal Medicine Clinic
- 7/18/15: Received first of four Cytogam infusions during pregnancy

Delivery

- 10/10/15: Philippa Kay was born
  - 34 weeks gestation, 4lbs 11oz.
- CMV in urine, blood, and saliva.
- Symptoms at birth: intracranial calcifications, thrombocytopenia
- 21 days at U of M NICU, for help with feeding.
- Received 6 months of oral Valgancyclovir (Valcyte).

Current diagnoses

- Receptive/Expressive language disorder- nonverbal
- Polymicrogyria (PMG)
- Seizure disorder
- Developmental delay
- Intellectual Disability

Our Legislative Journey

- Legislation introduced 2016 session, bill did not get a vote.
- Modified legislation introduced 2017 session (prenatal education and targeted screening).
- Bill received bipartisan support, passed House and Senate unanimously.
- Bill was signed into law 4/20/17.
- CMV Public Health Initiative, or “Pippa’s Law” went into effect 7/1/17.
- Iowa was the 8th state with some form of CMV legislation.

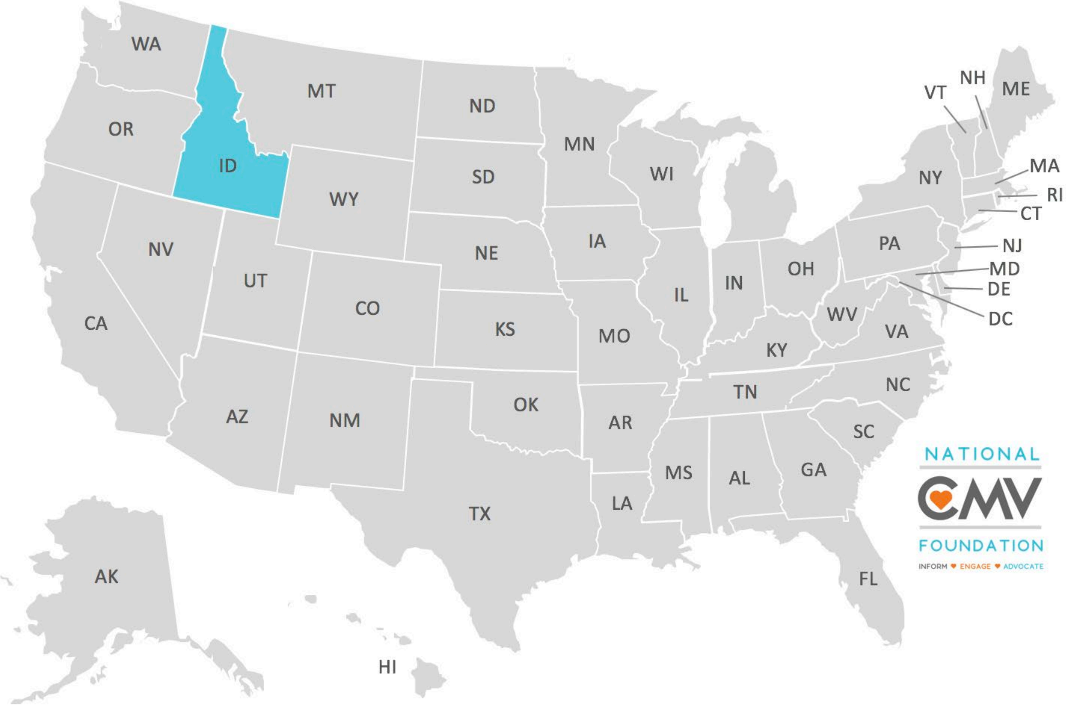
Barriers we faced

- No “CMV champion” in our state.
- Negative editorial in local paper.
- 1 medical group opposed, 2 “undecided”
- Many parents involved were unable to come to the Capitol.
- Normal legislative deadlines, priorities
- Had to change bill sponsor for second attempt

How we succeeded

- We:
  - Recruited other parents
  - Designated group leaders
  - Had a clear goal
  - Engaged legislators early in session
  - Did not stop- EVER!

Make change- you can do it!

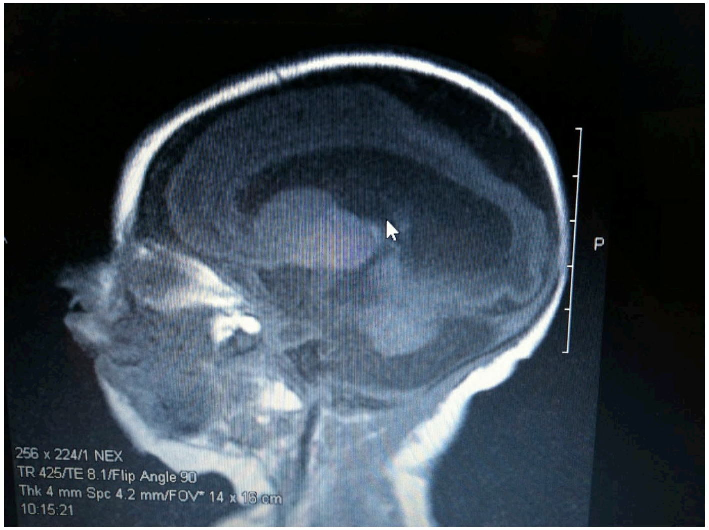


Rebekah Hall

IDAHO, USA

Keira

- Third pregnancy, “boringly healthy”
- Born at 37 weeks, 4 lbs, 13 ounces
- Small head, petechiae, enlarged liver and spleen, etc.
- Diagnosed with cCMV officially at 3 days old
- OB/GYN had “never seen” CMV before



Keira

At age 6

- Cannot walk, talk, or hold up her head
- Many hospitalizations and surgeries

But so much more

- The definition of light and love

Follow her on my blog

- Keepondancinglife.blogspot.com

Advancing the CMV conversation

Beginning stages

- Using natural opportunities (ie. Friends, family, clinics, nursery/daycare)
- Printable resources
- Caring Bridge and personal blog

Advancing the CMV conversation

Middle stage

- Working together with other invested individuals
  - We named ourselves the Idaho CMV Advocacy Project
  - We wrote our own personal stories
  - We wrote cover letters that included why legislation would be good for Idaho
  - We printed available educational resources.
  - We started a Facebook page and website (Idahocmv.com)

IDAHO
CMV Advocacy Project

Advancing the CMV conversation

Advanced stage

- Found a legislative sponsor
- MANY phone calls/emails/meetings with legislators and interested parties
- Attended and spoke at hearings
- Utilized media

Cytomegalovirus (CMV)

What you NEED TO KNOW

BABY IS TO

HELPFUL PREVENTION TIPS

CMV IS TRANSMITTED MOST EASILY FROM WET SALIVA TO WET SALIVA

DO NOT SHARE FOOD, DRINKS, TOOTHBRUSHES, ETC. WITH YOUR CHILD

AVOID KISSING A CHILD ON THE MOUTH

What would CMV legislation mean for Idaho?

Every year, an estimated **150 babies** are born with CMV in Idaho.

Of those, an estimated **30 babies** will have permanent disabilities.

The healthcare costs for just one of these children can cost taxpayers as much as **$1,800,000.** This is for the care of just **ONE CHILD** through the age of 18.

A CMV bill in the state of Idaho would provide for:

1. Increased **education** of healthcare providers
2. Increased **public awareness**
3. **Mandated CMV testing** for infants who fail their newborn hearing screens

It is estimated that to put this legislation into practice would cost the state of Idaho **$60,000** in the first year and **$30,000** each year after.

In other words, if CMV legislation led to the prevention of just one

IDAHO
CMV Advocacy Project

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CMV Legislation

🟥 CMV Legislation Enacted
⬜ CMV Legislation Proposed
🟦 CMV Legislation in Discussion

Image Provided by https://www.nationalcmv.org/cmv-research/legislation.aspx

The result?

In 2017, Idaho passed it’s first CMV bill into law

- The Department of Health and Welfare is now required to spend $15,000 annually on furthering CMV awareness and education
    - Website
    - Printed materials

Good hygiene can help reduce your risk of getting Cytomegalovirus (CMV)

Are you pregnant or planning to become pregnant?

CMV is a common virus that rarely causes problems for healthy people. However, when a pregnant woman is infected with CMV, it may cause serious health problems for her unborn baby.

FOLLOW THESE **HYGIENE TIPS**

- Wash your hands for 20 seconds with soapy water.
- Don't put a child's pacifier in your mouth.
- Regularly disinfect toys, countertops, and other surfaces.
- Wear gloves when changing diapers.
- Don't share food, drinks, or eating utensils.
- Avoid contact with a child's saliva or fluids.

For more info about CMV, contact your health care provider or visit cmv.dhw.idaho.gov

Idaho **maternal** & **child health**

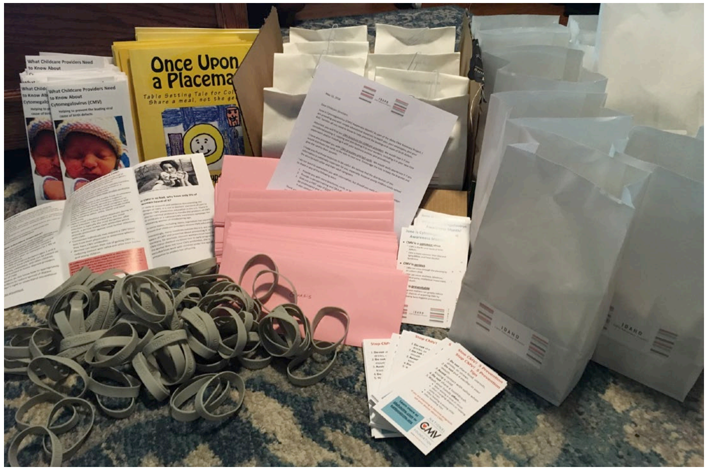
DIVISION OF PUBLIC HEALTH

Using the momentum….

Many opportunities to speak for groups (board of medicine, board of nursing, speech and language pathologists, midwives, etc.)

2018 Resolution to make June Idaho CMV Awareness month

2018 Awareness month focus on caregivers/daycare centers



Success!

Relied heavily on what others had already done

- National CMV Foundation website, printable handouts, and legislative tools and resources

Look and act professionally

Learn as you go and keep going

Money talks

- Find out how much your child costs
- Estimate the cost of CMV to your state each year

The Hard Parts….and how to survive

Minimal support from physicians….

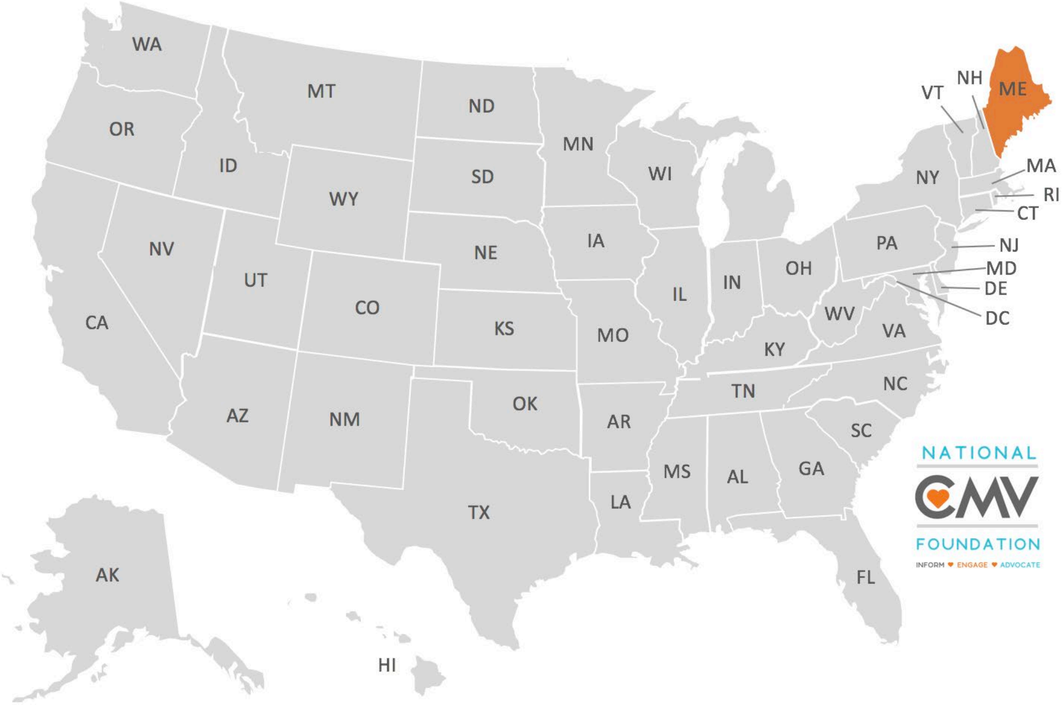
- ……focus on parents, caregivers, and the many others who are interested in knowing more

No FDA approved treatment or cure….

- ……focus on prevention

The psychological toll of the discrepancy between radical acceptance and advocating for change…..

- ……learn to take breaks and learn to say "no." There is more than enough work to go around and it doesn't have to be done today.



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Laura Sweet

MAINE, USA

Our CMV Story

- We live in Cumberland, Maine
- Laura, Joe, Henry (6), and Jane (3… almost 4)
- Our CMV story is far too common: I'd never heard of CMV, had a toddler in daycare, had no idea I was putting unborn baby at risk, was unaware of simple preventive measures during pregnancy
- Jane born in November 2014, seemingly normal, full-term pregnancy
- Failed newborn hearing screening at hospital

Jane’s CMV Story

- Moderate/severe hearing loss at birth, profoundly deaf by 7 months old, bilateral cochlear implants at 1 year old
- Seemingly asymptomatic – but also significant white matter abnormalities & retinal scar in eye
- cCMV diagnosed at 11 months old with newborn bloodspot CMV test
- Mild early gross motor delay, remedied with PT
- Weekly in-home AVT/speech therapy until she turned 3
- Early intervention was critical - now at same speech/language level as typically hearing peers.

CMV Advocacy in Maine

- **September 2016**: CMV Conference in Austin – parent advocacy stories inspired me to take action!
- **October 2016**: Contacted State Senator Cathy Breen, sent her copies of other states' bills
- **January 2017**: Senator Breen introduced LD 87, "An Act To Require Screening for Cytomegalovirus in Newborn Infants" – proposed universal CMV screening and CMV education in Maine
  - LD 87 referred to the Legislature's Joint Standing Committee on Health and Human Services
- **February 2017**: Testified at public hearing and work session

Maine’s CMV Work Group

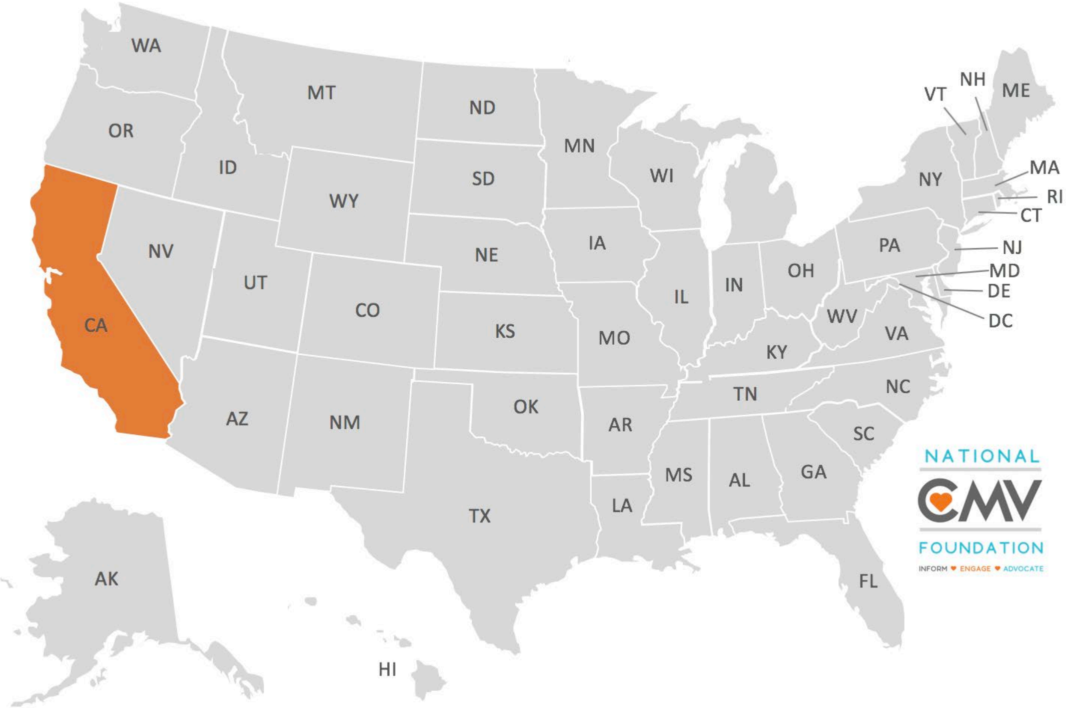
- HHS Committee voted not to pass the bill, **BUT…** Resolve was written, directing Maine CDC to convene a CMV work group
- Group met four times over one year, and included about 25 members:
  - Pediatricians and family physicians
  - Infectious disease specialists
  - Otolaryngologists
  - Neonatal intensive care unit physicians
  - Obstetrician, midwives, and L&D nurses
  - Audiologists
  - Early intervention specialists
  - Program managers from Maine CDC, Maine newborn hearing program
  - Representative from March of Dimes
  - CMV expert (Dr. Mark Schleiss)
  - CMV parent representative (me)

Work Group’s Recommendations

- Submitted final report to Legislature in January 2018 with following recommendations:
    1. Provide education on the causes, symptoms and prevention of cCMV to all parents, caregivers, and providers working with children, infants, and pregnant women.
    2. Convene a work group to develop and disseminate educational information and materials to key stakeholder groups.
    3. Require a targeted screening approach with the long-term goal of universal screening.
    4. Explore the option of utilizing bloodspot tests to screen for cCMV.
- Work group met again in May 2018 (independent of Legislature) to begin planning for implementation phase

Lessons Learned

- “Failed” legislation not such a failure after all!
- Work group approach could be a model for other states – buy-in and support of wide-ranging group of stakeholders is invaluable
- Encourage individual doctors, medical practices, other professionals to take action themselves in the meantime – it CAN make a difference
- Leverage local media and look for other outreach opportunities – for example: local universities, Hands & Voices chapters
- And most importantly… remember why this work matters so much!!



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Janelle Greenlee

CALIFORNIA, USA

Advocating for Change: Parent Experiences in Policy and Community Engagement

California

Janelle Greenlee
National CMV Foundation
janelle.greenlee@nationalcmv.org

Riley and Rachel Greenlee

- Born in 2003 with congenital CMV
- Riley (15) – bilateral hearing loss, cerebral palsy
- Rachel (passed away at 11) – bilateral hearing loss, cerebral palsy, vision loss, G-tube, medically fragile

California – Spring 2017

- CA Health department outreach
- Committee research (Health & Approps)
- Support website created with basic CMV info
- Email to CA parents, supporters
- Legislative mapping to target legislators
- Parent, supporter contact with legislators
- District meetings with committee members
- Sacramento meetings scheduled for June
- Sample bill language drafted

California – Spring 2017

1 IN 200 BABIES IS BORN WITH CMV.

Over 3,000 babies are born with CMV (cytomegalovirus) in California every year.

California – Summer 2017

- Meetings with health lobbyists
- Meetings at Capitol to find author
- Asm. Adrin Nazarian offers to carry bill
- Legislation calls for universal newborn screening

California – Winter 2018

- Introduced January at legislative session start
- Designated at Assembly Bill 1801 (AB1801)
- Assigned to Health staffer in author’s office
- Creation of fact sheets, supporting materials
- Capitol meetings with professional orgs (AAP, AMA, ACOG, etc)
- Assignment to Health Committee for hearing
- State CMV expert testimony confirmed
- Letters of support from parents, supporters
- Letters of support from stakeholder orgs

California – Winter 2018

- Amendments written
- Amendments written
- Amendments written
- Bill language amended to a state commission

California – Spring 2018

- Assembly Health hearing, passes unopposed
- Referred to Approps Committee
- Assembly Approps hearing, passes unopposed
- Full Assembly floor vote, passes unopposed
- Referred to Senate

California – Summer 2018

- Jockeyed by Senate Health chair, Dr. Pan
- Senate Health hearing, passes unopposed
- Referred to Approps Committee
- Senate Approps hearing, passes unopposed
- Full Senate floor vote, passes unopposed

…see where this is going?

California – Fall 2018

- Waiting for Governor Jerry Brown to sign bill

California – Lessons Learned

- Get Health department support early and often
- Use CMV network for stakeholder outreach
- Don’t be afraid to start with a BIG ask
- Rally support from state experts, parents, etc
- Leverage support from other state parents
- Understand your goal and concessions
- Understand your goal and concessions
- Understand your goal and concessions

Thank you!