

Spreading CMV Awareness: How You Can Get Involved in Your Community

Amanda Devereaux RN, BSN
National CMV Foundation
Program Director



Objectives

- Describe 3 ways to increase CMV awareness in your area
- Describe 3 ideas to start a CMV related event in your area
- Describe 3 objectives of the Community Alliance Program at The National CMV Foundation



CMV Awareness

Tell Your Story

- Write it out, include photos
- Share on social media
- Share with television/print media
- Submit to organizations you are affiliated with:
 - High school newsletter
 - Workplace newsletter
 - Professional organizations
- Host a booth or submit a presentation at a conference



Move Over Zika, We Need To Talk About CMV

THE BLOG

While still pregnant, Amanda and Paul decided to initiate legislation here in Iowa. After months of hard work, including help from Senators Janet Petersen, Jake Chapman, Brad Zaun and Representative Peter Cownie, "Pippa's Bill" (Bill 51) was signed into law on April 20, 2017 making Iowa the eighth state to pass some form of CMV legislation.

The New York Times

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

"Pippa's Bill" (Bill 51) was signed into law on April 20, 2017.

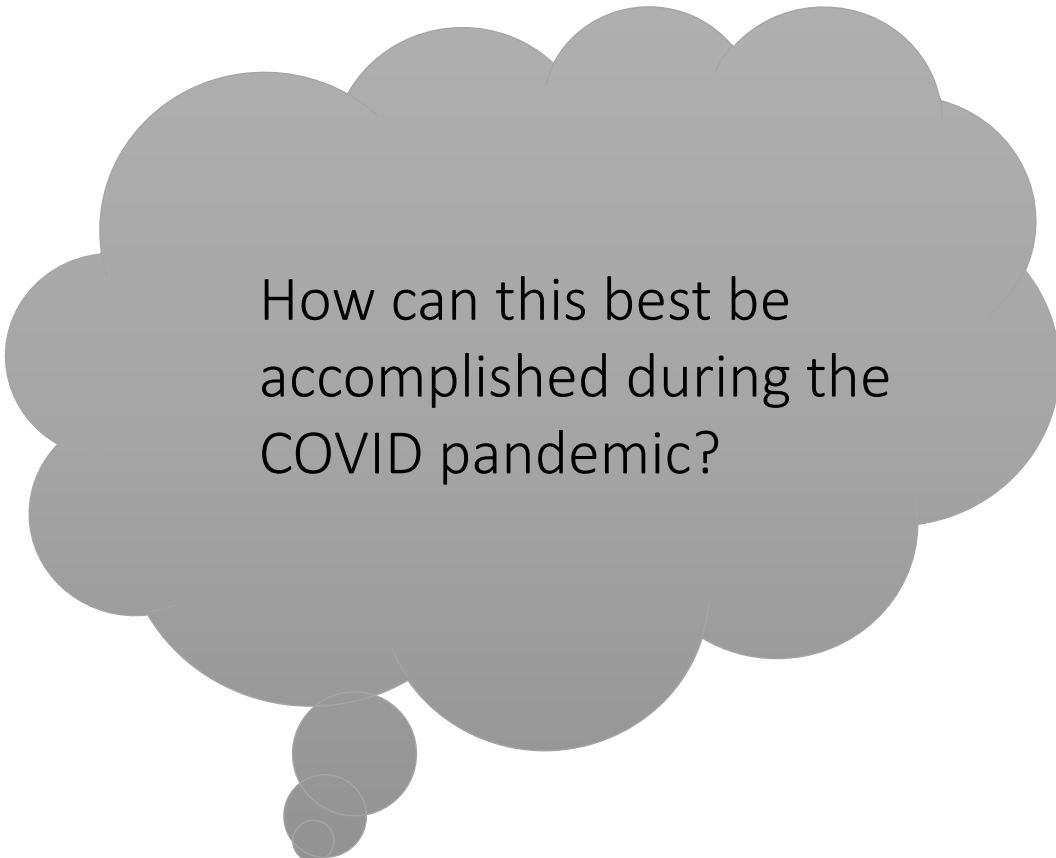


Amanda reports that Pippa is doing well. She is now 18 months old and is moderately affected by CMV. Her brain was permanently damaged by the virus causing developmental and motor delays as well as seizures. However, she is a very happy girl, and for that the Devereaux family is very grateful. They hope that this bill will help improve the lives of families throughout Iowa.

[Click here for specific information within Bill 51.](#)

Talk with Stakeholders

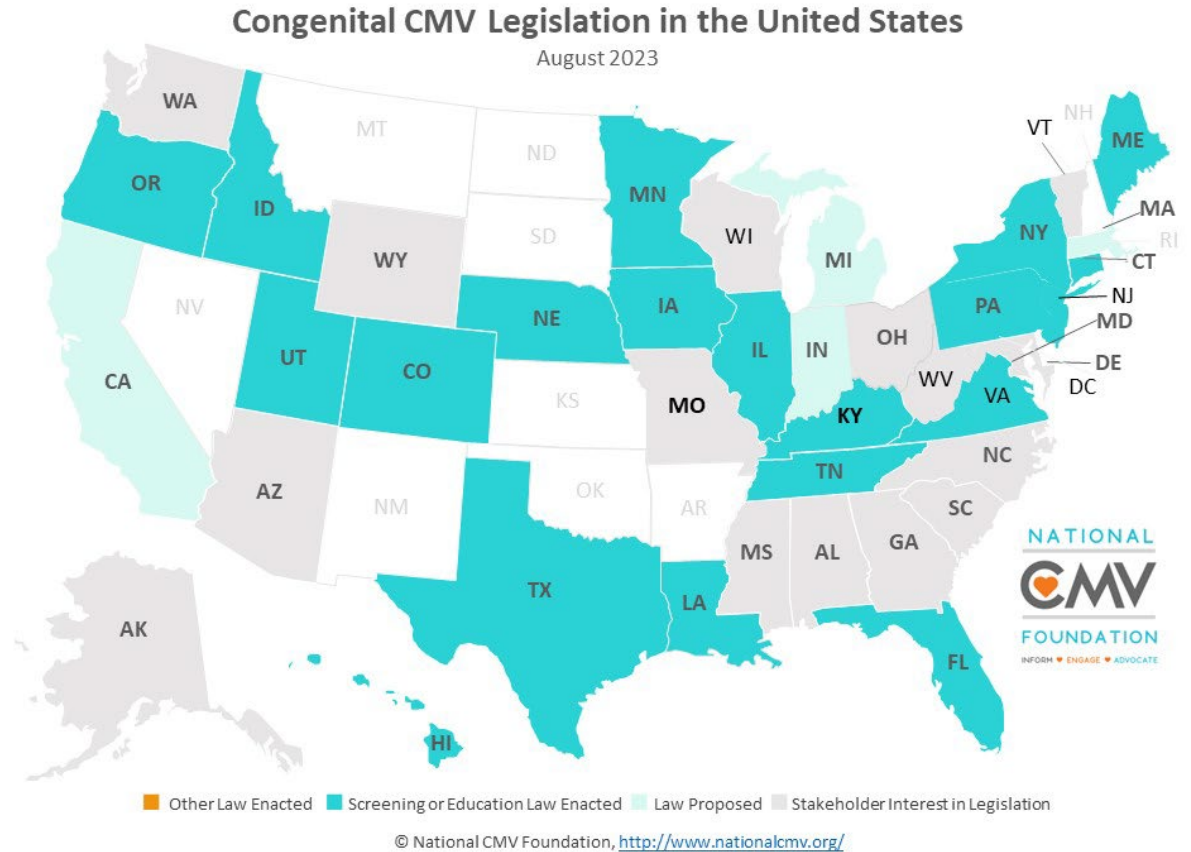
- Public Health
- Medical Clinics/Providers
- Therapy Clinics
- Childcare Providers
- Early Intervention
- Disability Rights Groups



How can this best be accomplished during the COVID pandemic?

Consider Legislation in Your State

- Usually multi-year process
- Variable success depending on legislative climate and state culture
- Can be effective way to make change and raise awareness
- Contact NCMVF to start learn how to get started



Other Awareness Ideas

Join a Committee:

Congenital and Inherited Disorders
Newborn Hearing Screening
Hands and Voices

Apply for a CMV Awareness
Day/Month in Your State

Nominate CMV for Newborn
Screening in Your State



Hosting an Event/Fundraiser

Planning an Event

- Decide on an objective for your event
 - Raise funds, spread awareness, both?
- Choose an event that interests you and that is realistic for you
- Plan early
- Recruit a team/committee
- Think about your entire state and/or region for events
- Connect with other CMV parents in your area
- Speak with like-minded organizations in your area (e.g. NCDB), to increase CMV awareness and participation in your event
- Leverage activities you're already a part of
- Keep it simple

Event Ideas

FUNDRAISING

- PaintNite
- CrossFit group workout
- Spin or Yoga class
- Golf tournament
- Walk/Run (local or virtual)
- Themed dance
- Giveback night
- Join our Compete4CMV team
- Facebook fundraiser

EDUCATIONAL

- “Awareness Day”
- Conferences
- Grand rounds
- State meetings
- Local colleges or universities
- Guest speaking engagements
- Baby fairs
- Work with professional organizations
- State or regional multi-disciplinary workgroup



NCMVF CMV Community Alliance (CCA)

- Program of the National CMV Foundation (NCMVF)
- Empowers advocates to work on CMV advocacy in their area
- NCMVF provides support and resources
- Goals:
 - Increase awareness of cCMV
 - Increase revenue to support the cause
 - Increase CMV newborn screening
 - Increase local partnerships



Panel Discussion

THANK YOU!

Amanda Devereaux RN, BSN
National CMV Foundation
Program Director

amanda.devereaux@nationalcmv.org

Stay Connected

www.nationalcmv.org



/NationalCMV



@NationalCMV



@NationalCMV