

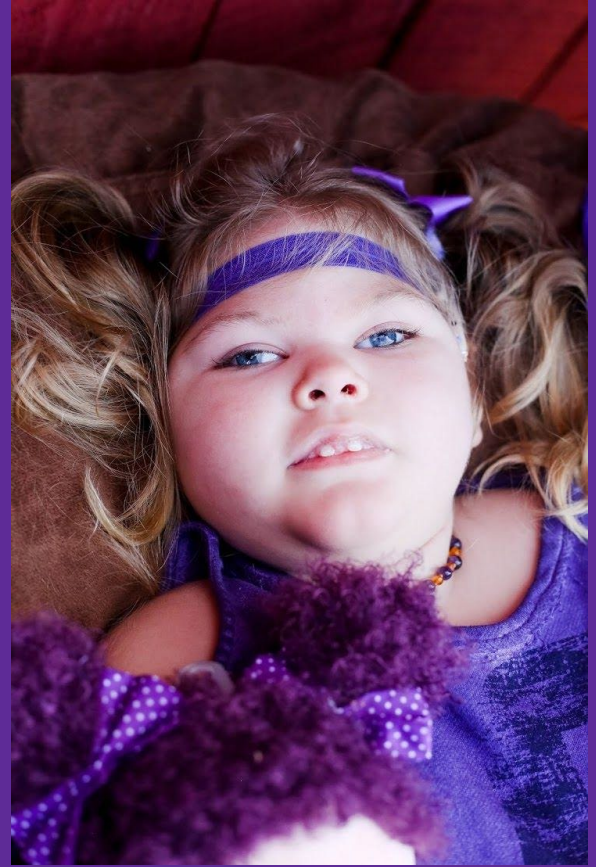
The Path to cCMV Policy Change

Learning from one family's personal journey - Bella's Bill 4 CMV



Bella Dawn Streeval
2/5/2017 - 4/7/2020

“Our Why”



Came into the world on her own way and
in her own time!

Symptomatic at birth

Enlarged Spleen and Liver

Petechiae

Failed Hearing Test

Microcephaly

Brain Calcifications

Polymicrogyria





Full of Spirit and Spunk

Strong Personality



Super Happy

Words Not Needed



Seizures
VNS
Surgery

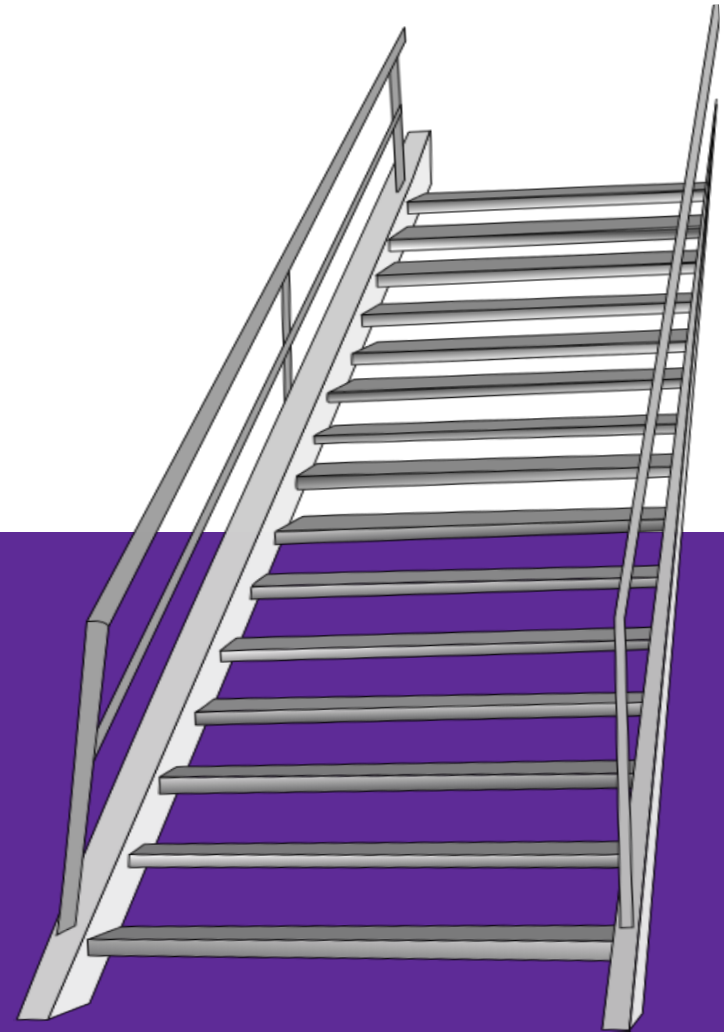
Cerebral Palsy

Other Surgeries
G-tube
Nissen
Pyloroplasty

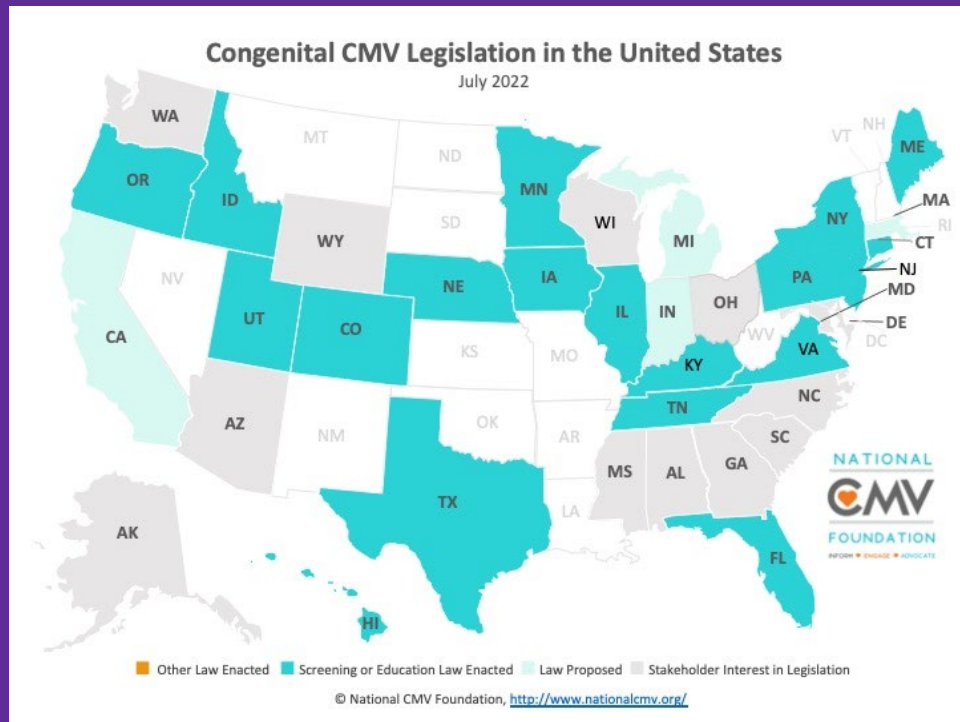


Beginning Steps

- 1. Review Current Law**
- 1. Create a Task Force**
- 1. Gather the Troops**



cCMV Testing in the United States



April 7, 2022

Kentucky became the 7th state to implement both targeted newborn cCMV testing and cCMV education for expectant families.

Before “Bella’s Law” Kentucky did not have standardized cCMV testing.

Kentucky is one of many states that rely upon the Recommended Uniform Screening Panel (RUSP) for standardized newborn screening.

“

NEVER DOUBT THAT A SMALL GROUP
OF THOUGHTFUL COMMITTED CITIZENS

**CAN CHANGE
THE WORLD;**

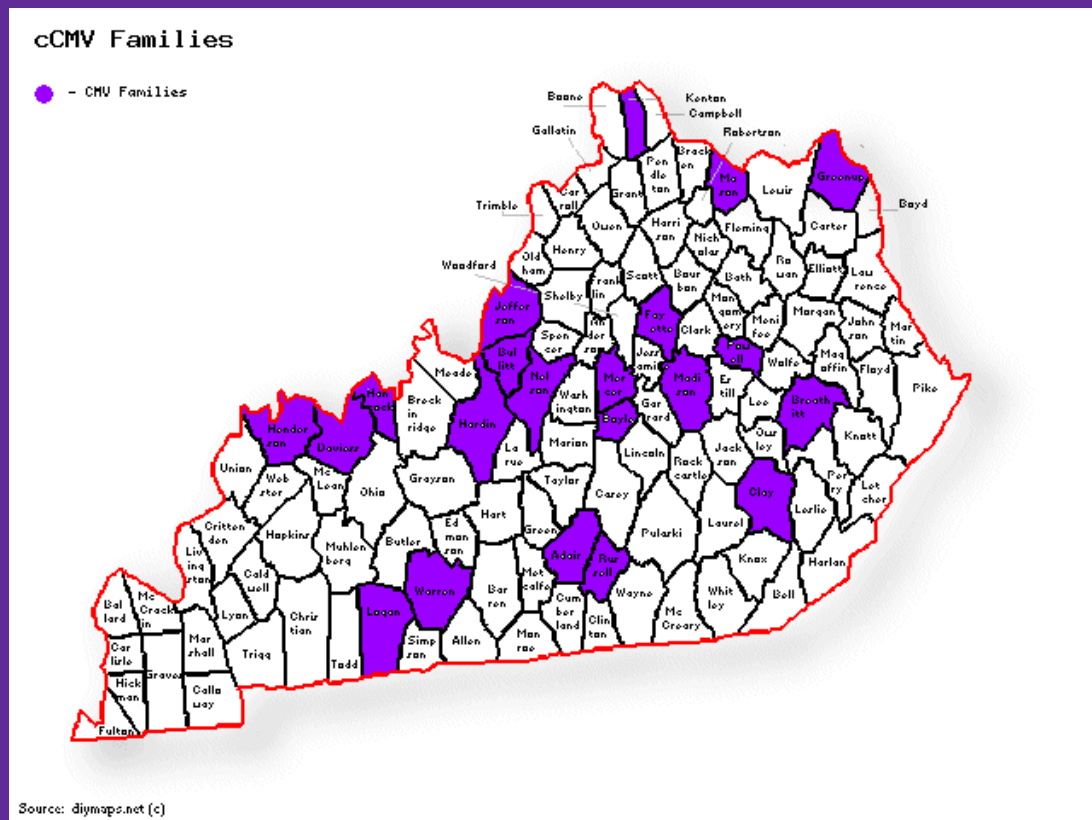
INDEED, IT IS THE ONLY THING THAT EVER HAS.

”

- Margaret Mead (1901-1978)



21 counties





Know Your Stakeholders

1. The Families
2. Medical Professionals
3. Early Intervention Providers
4. Legislators

Dr. Shelley Moats, Au.D., PASC - Board Certified Pediatric Audiologist and Director of Audiology at our Little Ears Hearing Center.

Dr. Laura Stadler, MEd, MD, MS, FAAP - Professor of Pediatric Division of Infectious Disease at UK College of Medicine

Stephen Church, MD - past president of the KY Chapter of AAP and is now President of their Foundation.

Kenneth Iverson, MD - ENT-otolaryngologist at University of Kentucky

Dan Stewart, MD - President of the KY Chapter of the American Academy of Pediatrics and established the KY Pediatric Society Foundation.

Arpita Lakohtia, MD - Assistant Professor of Pediatric Neurology at U of L

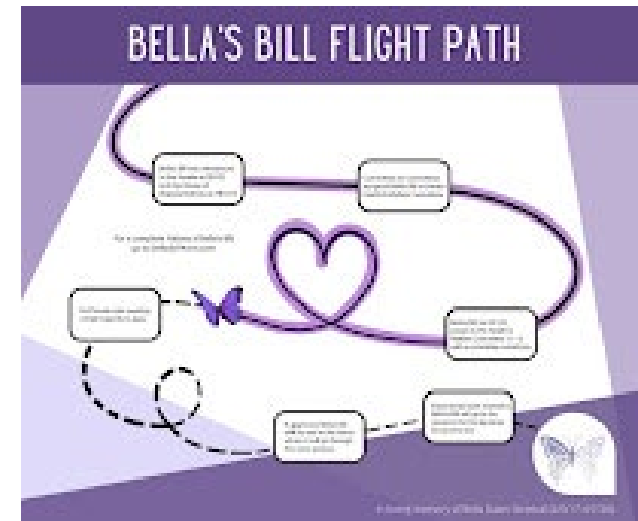
Dr. Connie White - Deputy Commissioner at Kentucky Department for Public Health

Kentucky Organizations

- Hands and Voices
- Deafblind Project
- Early Hearing Detection and Intervention
- Kentucky Council on Deaf Hard of Hearing
- Developmental Disability Council
- Advocacy and Accessible Living



Making Changes



1. Increasing Education and Awareness
2. Write a Bill
3. Secure Legislative support
4. Empowering Families

How to Educate and Build Awareness

- Create a Website
- Open Targeted Social Media Accounts
- Host Educational Webinars
- Utilize Media Outlets

“Awareness is the greatest
agent for **change**.”

-Eckhart Tolle



Bella Dawn

Bella was a spunky little girl born with cCMV, but due to complications of the virus she gained her wings in 2020 at the age of 3. Bella was full of spirit and loved dearly by her family, who continues to honor her legacy by fighting for CMV awareness. Bella loved listening to music with her cochlear implants, and water was her magic.

"We continue to fight for her, and she taught us how to do that."
- Bella's mom

What is CMV?

Cytomegalovirus (sy-toe-MEG-a-low-vy-rus) or CMV, is a member of the herpes virus family. Coming into contact with CMV is a common occurrence, typically harmless to the general population. A CMV infection causes cold-like symptoms, such as a sore throat, fever, fatigue and swollen glands. These mild CMV symptoms last for only a few short weeks and are rarely a cause for concern for healthy kids or adults.

CMV, however, can cause severe disease in babies who were infected before birth (referred to as congenital CMV or cCMV).

Congenital CMV affects one in every 200 babies born each year (approximately 30,000 children annually), making it the most common congenital viral infection in the United States. Furthermore, one in every five children born with cCMV will develop permanent health problems (roughly 6,000 children) with as many as 400 infant deaths annually.

National CMV Foundation
www.nationalcmv.org

INFORM ♥ ENGAGE ♥ ADVOCATE

Congenital cytomegalovirus (CMV) is the most common viral infection, and the leading cause of non-genetic hearing loss, that infants are born with in the United States.

Every pregnant woman is at risk of acquiring CMV. And 91% of women **DON'T** know about it.

CMV is common, serious and preventable.



1 out of 3 pregnant women who become infected with CMV during pregnancy will pass the virus through to their unborn child



1 child is permanently disabled every hour



1 in 200 children are born with congenital CMV each year



CMV in Kentucky

Approximately 257 babies will be born each year in Kentucky with cCMV. Of those, 51 babies will have birth defects and long-term health issues.



In 2020, a passionate group of parents and professionals came together to focus on the impact of cCMV in the state and to address changes that need to be made. This group is pursuing legislation to allow for universal newborn CMV screening in Kentucky. In addition, the group's purpose includes educating women of childbearing age, the general public, healthcare providers and departments of health about the prevalence and effects of CMV, as well as advocating for vaccine development.

"We fight for Destiny and all the other cCMV warriors throughout the state."

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

Sarah Streeval (Bella's Mom)

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Follow us on Facebook @bellashill4cmv

Has your family been affected by CMV?

Call or text Sarah at 270-250-5931
or e-mail sdurbin85@gmail.com
to share your story and
help make changes for current and
future CMV families in Kentucky.



Like our Facebook page
@bellashill4cmv to get involved!



Supported by:
NATIONAL
CMV
FOUNDATION
RESEARCH • EDUCATION • ADVOCACY

FOLLOW US ON

Instagram
& twitter

@bellashill4cmv & @bellashill4cmv



BELLA STREEVAL — CMV ANGEL — COLUMBIA, KY

Bella came into this world on her own terms and started breaking all the rules. She had the most gorgeous blond curls and the biggest blue eyes that twinkled with pleasure but also a brutal side-eye. Bella always knew exactly what she wanted, and she never hesitated to let you know. She loved to be outside watching the wind blow through the trees. Music was her magic and water made her melt. Bella had this personality that drew people to her. She drew them to her and then she started bossing them around until the world was just the way she wanted. We had a normal pregnancy without concerns and delivery went as expected. However, things were not as expected. Bella had to immediately be life fought to our nearest Children's Hospital 2 hours away. It was in the NICU that we found out Bella had CMV, a virus we had never even heard of before, a virus that was unfamiliar to many of our professional's. At 3 months old, we discovered Bella was profoundly deaf in both ears due to CMV. Three months later, Bella began to have seizures and severe muscle contractions. At a year old, she was diagnosed with Cerebral Palsy. At two, Bella was diagnosed with Lennox-Gastaut Syndrome, which is a rare and severe seizure disorder that often is medication resistant. When Bella was three, her autonomic dysfunction became more severe until the combination of uncontrolled seizures, abnormal muscle tone, and physical dysfunction were too much for her little body. CMV stole so much! Our little girl was never able to walk and would have required a wheelchair for her entire life. She was nonverbal and could not use her hands to form gestures or sign language. Bella required machines and medications for the largest part of her short life. CMV took away our Bella Dawn on April 7, 2020, just after her third birthday. Forever our CMV Angel.



From Bill to Law

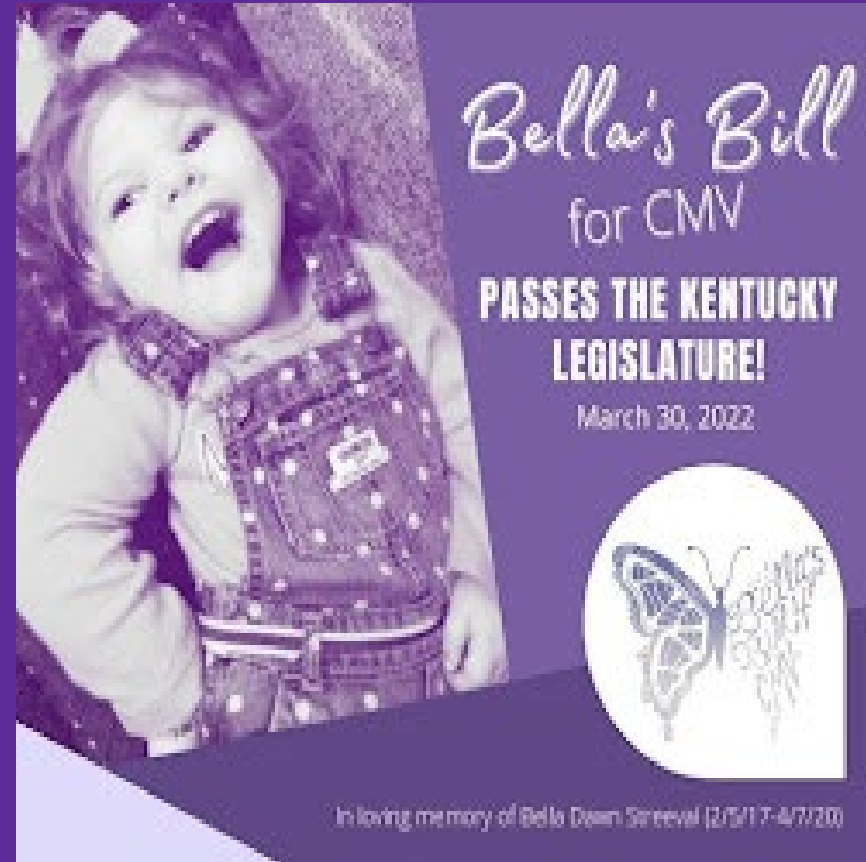
Know your Legislators

Have multiple supporters

Go to session in person

Give them the numbers

Give them a “why”



Empowering Families



Cabinet for Health and Family Services : Education for expectant families

Bella's Law for CMV : Enacted on April 7, 2022, provides education for expectant families and targeted CMV testing for babies they may fail the hearing test or have other CMV symptomatology

KY Hands and Voices Guide By Your Side (GBYS) : provides CMV families with a point of contact, a peer that can help with resources, education, and support.

GBYS Hosted CMV Family Cafe' : gives families a safe place to connect with other families and to process specific struggles and beautiful moments in their lives in a group setting. We have had both in person and virtual.

Website:

<https://bellasbill4cmv.com/>

FaceBook Page:

<https://www.facebook.com/bellasbill4cmv>

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