

# Beyond the Blueprint

## Virginia's Steps Toward Expanding CMV Screening, Enhancing Surveillance, and Strengthening Family- Centered Support

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# Learning Objectives

Comprehension of the cCMV screening process and follow up strategies for timely diagnosis

Review data on CMV prevalence, screening timeliness, and care referrals for confirmed infants

Overview of the family- centered support network in Virginia and share lessons learned from the implementation process

# Overview of cCMV

# Etiology of congenital Cytomegalovirus

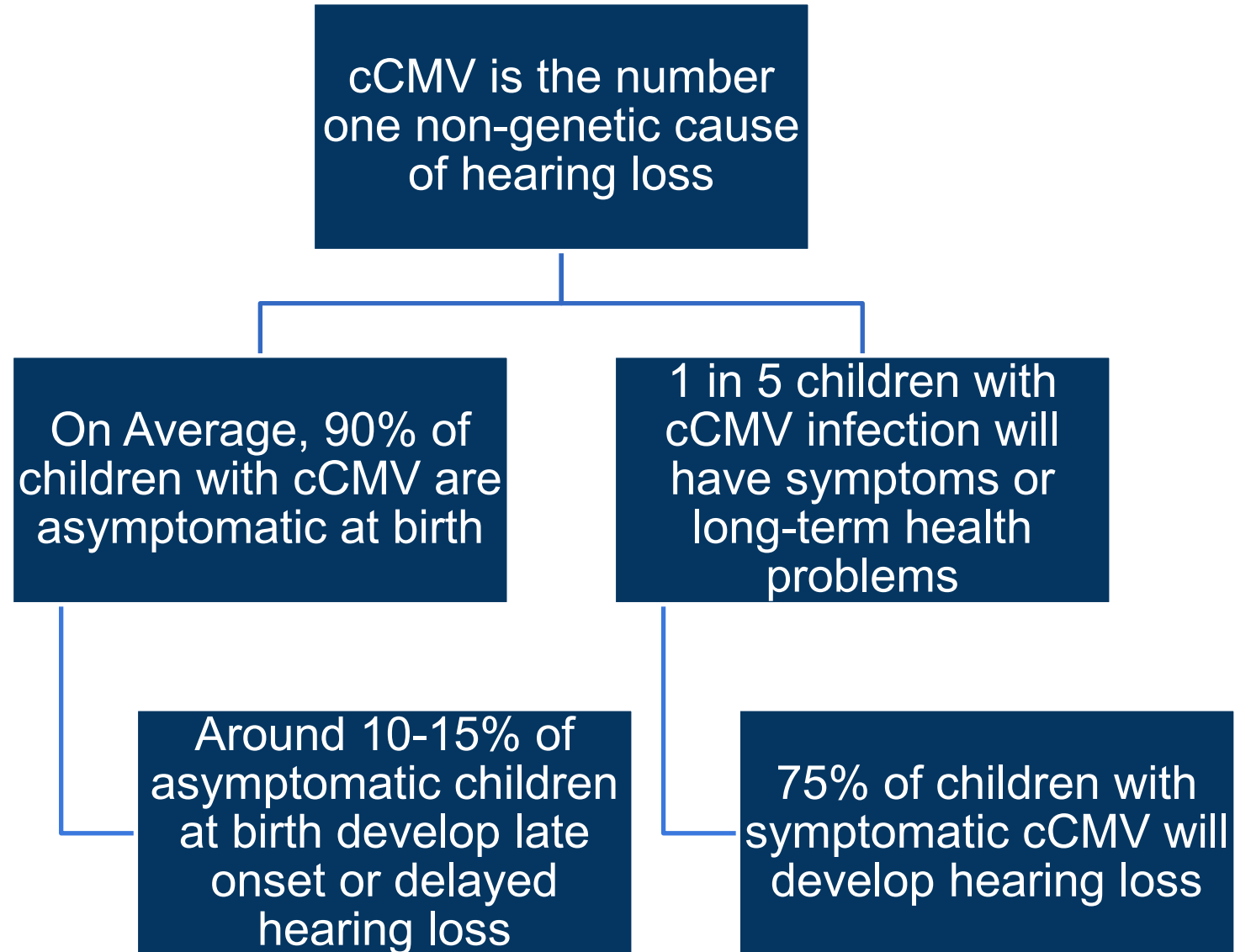
Cytomegalovirus (CMV) is a member of the Herpesvirus family

The virus sheds in bodily fluids such as saliva, urine, breast milk, and blood

CMV is common among healthy children one to three years of age

Contact with the saliva or urine of young children is a major cause of CMV infection among pregnant women

CMV can be transmitted in utero from a pregnant woman with a primary or a recurrent CMV infection causing congenital CMV (cCMV) infection in the infant



# Signs of cCMV at birth

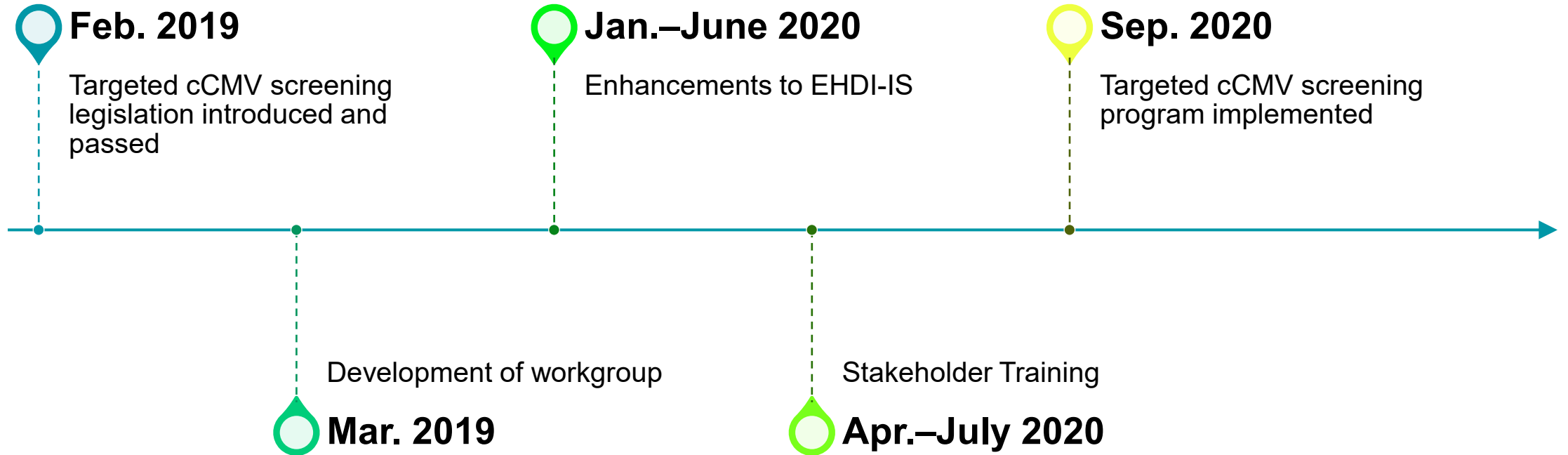
- Petechial rash
- Jaundice
- Microcephaly
- Intrauterine Growth Restriction (IUGR) (Low birth weight)
- Hepatosplenomegaly
- Seizures
- Retinitis
- Hearing loss
- Vision loss

10% of children have signs at birth



# Virginia's Congenital Cytomegalovirus (cCMV) Screening Program

# Timeline



# Stakeholder Collaboration & Education for CMV Screening Program

## CMV Workgroup Established

- Developed legislation, protocols, resources, and materials

## Hospital Training & Education

- Virtual 3-part training series developed with stakeholders

## Primary Care Provider (PCP) Training

- Collaboration with VA-AAP to develop a dedicated training module

## Mass Communication

- Protocols and informational materials mailed to PCP offices statewide

# Importance of Prenatal Education

Information for Expecting Parents  
from the Virginia Department of Health Newborn Screening Programs

## BEFORE THE BIG DAY



In just a few weeks, your baby will enter the world. There is a lot you can do now to plan for their arrival.

For more information check out this video →



VDH VIRGINIA DEPARTMENT OF HEALTH | EHD I VIRGINIA Early Hearing Detection & Intervention | VIRGINIA NEWBORN SCREENING PROGRAM

## PROTECT YOUR BABY FROM CMV





Avoid kissing young children on the lips



Wash hands after changing diapers



Avoid sharing utensils or straws with young children



Never put a child's pacifier in your mouth



Do not share a toothbrush with a young child.

**Did you know:**

- Congenital Cytomegalovirus (cCMV) is the leading non-genetic cause of hearing loss and other birth defects and developmental disabilities.
- CMV is often a symptomless virus spread through contact with saliva, mucus, and urine.
- 1 out of 3 pregnant women who are infected with CMV, in the first or second trimester, will pass the virus to their unborn child.
- Infants who acquire CMV infection in the womb are at risk for complications.
- Only 9% of pregnant women know about CMV. Protect you and your unborn child and ask your doctor about CMV.


Visit our website at [www.VDHLiveWell.com](http://www.VDHLiveWell.com) for resources, or email us at [va\\_ehdi@vdh.virginia.gov](mailto:va_ehdi@vdh.virginia.gov)

VDH VIRGINIA DEPARTMENT OF HEALTH | EHD I VIRGINIA | NS02 | 3-2020 | [VDHLiveWell.com](http://VDHLiveWell.com)



**1 in 200** babies are born with **CMV** each year.

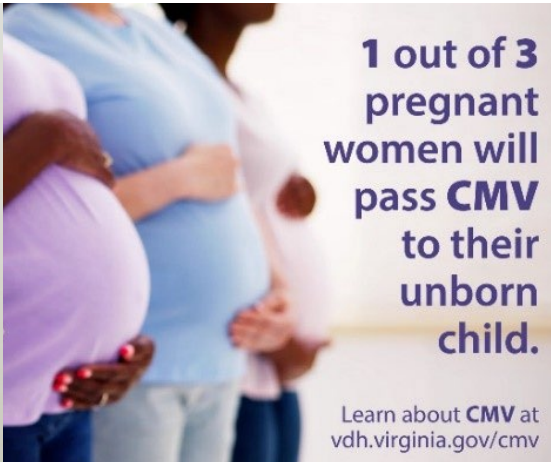
EHD I VIRGINIA | VDH VIRGINIA DEPARTMENT OF HEALTH



**Protect your baby from CMV**

Learn about **CMV** at [vdh.virginia.gov/cm](http://vdh.virginia.gov/cm)


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**1 out of 3** pregnant women will pass **CMV** to their unborn child.

Learn about **CMV** at [vdh.virginia.gov/cm](http://vdh.virginia.gov/cm)

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**Only 9%** of pregnant women know about **CMV**.

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# Overview of Virginia's Program

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Launch Date: September 1, 2020

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Testing Method- Meridian Alethia –September 2020-November 2024; Diasorin Simplexa- December 2024- present

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Screening Population: Infants who fail final hearing screen inpatient

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Testing Laboratory: Division of Consolidated Laboratory Services

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Results Access: Automatic electronic communication of results from DCLS to VDH

## Screening Methodology- Saliva PCR followed by urine PCR

Hearing Screening Result

Recommendation

Passed Initial Hearing Screening

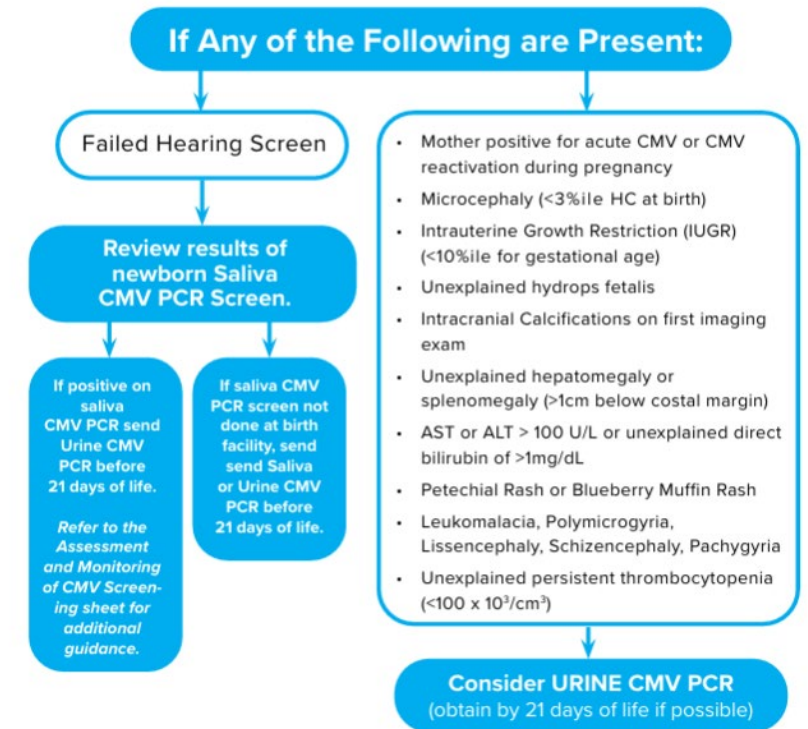
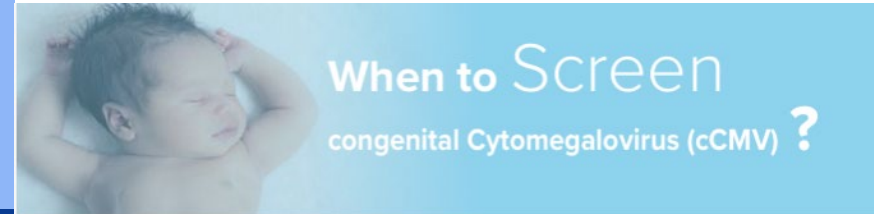
CMV sample not collected

Failed Initial Hearing Screening (before 21 days of life)

Receive CMV screen at birth via Saliva PCR

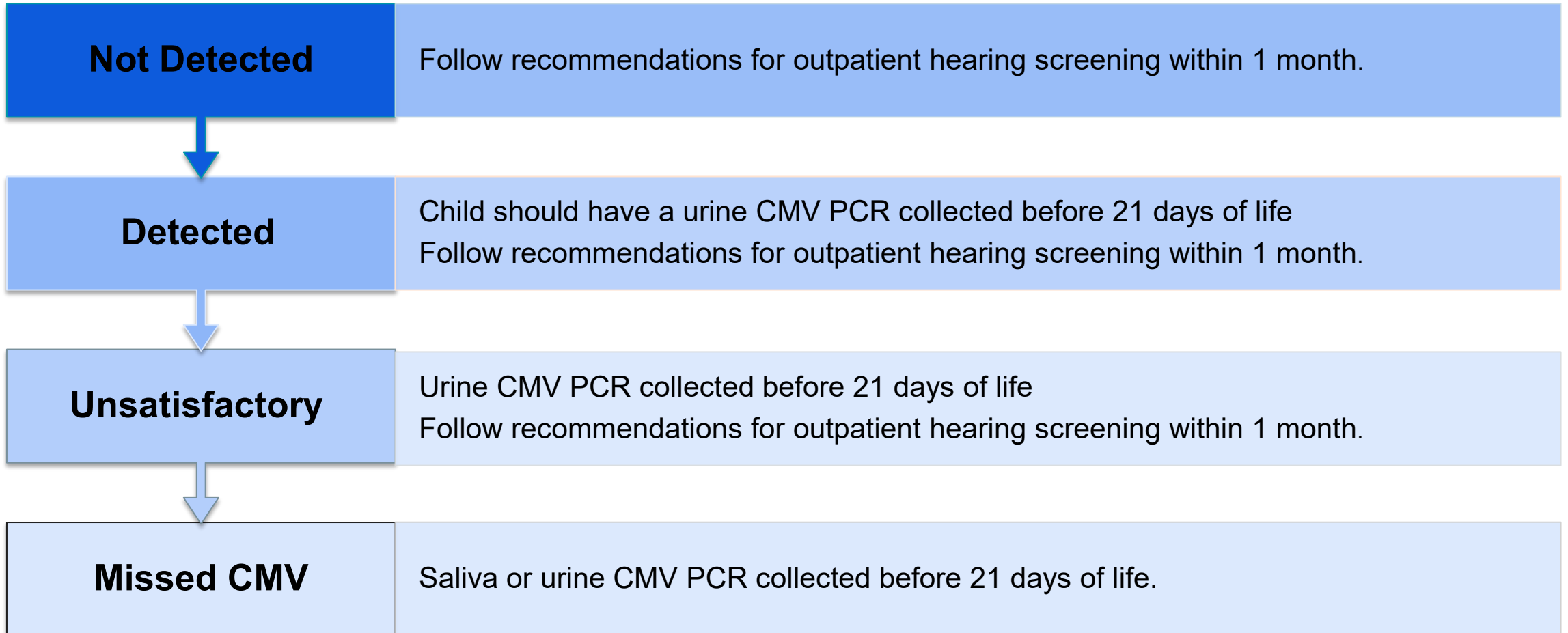
Failed Hearing screening (after 21 days of life)

Consult with pediatric Infectious Disease to discuss next steps



*These recommendations are for outpatient cCMV testing.*

# Outpatient CMV Screening Recommendations



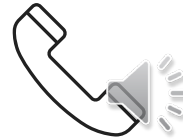
# CMV Follow- Up Communication



**Mailed Letters:** Sent to parents and primary care providers (PCPs)



**Two-Way SMS Communication:** Enables direct interaction with parents



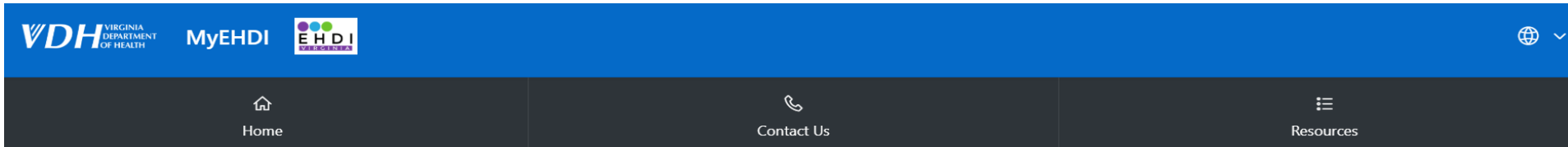
**Automated Robo Calls:** Scheduled reminders and notifications



**Outbound Live Calls:** Personal follow-up by staff for additional support



**Interactive Voice Response (IVR) System and MyEHDl Parent Portal**



## Hello Parents and Caregivers

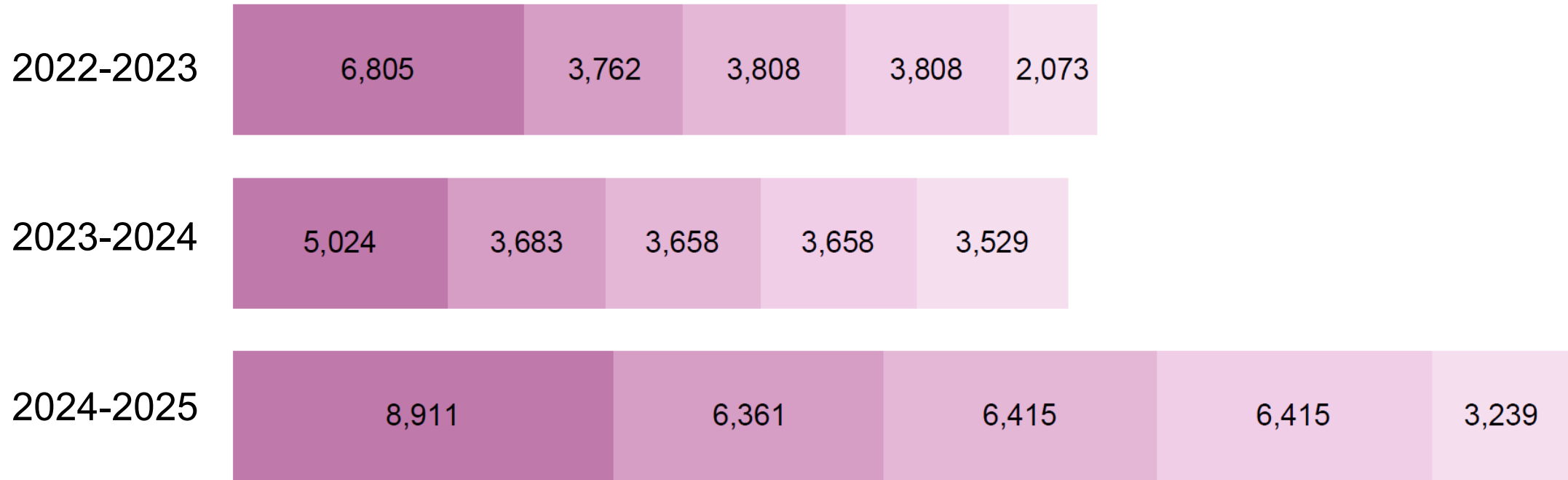
Welcome to the VA EHDl Parent Portal! We would like to share some information and next steps regarding your child. Click the link below to review electronic communication and additional information. If you have any questions, contact the VA EHDl team at 804-212-3020 or [va\\_ehdi@vdh.virginia.gov](mailto:va_ehdi@vdh.virginia.gov).



Electronic Communication



Number of Communications Sent by VA EHDI Regarding Congenital CMV:  
**PCP Letters, Parent Letters, Parent Texts, Parent Robocalls, and Parent Phone Calls**  
*Three Years from September 1, 2022 – August 31, 2025*



# Screening Data

September 1, 2020–August 31, 2025

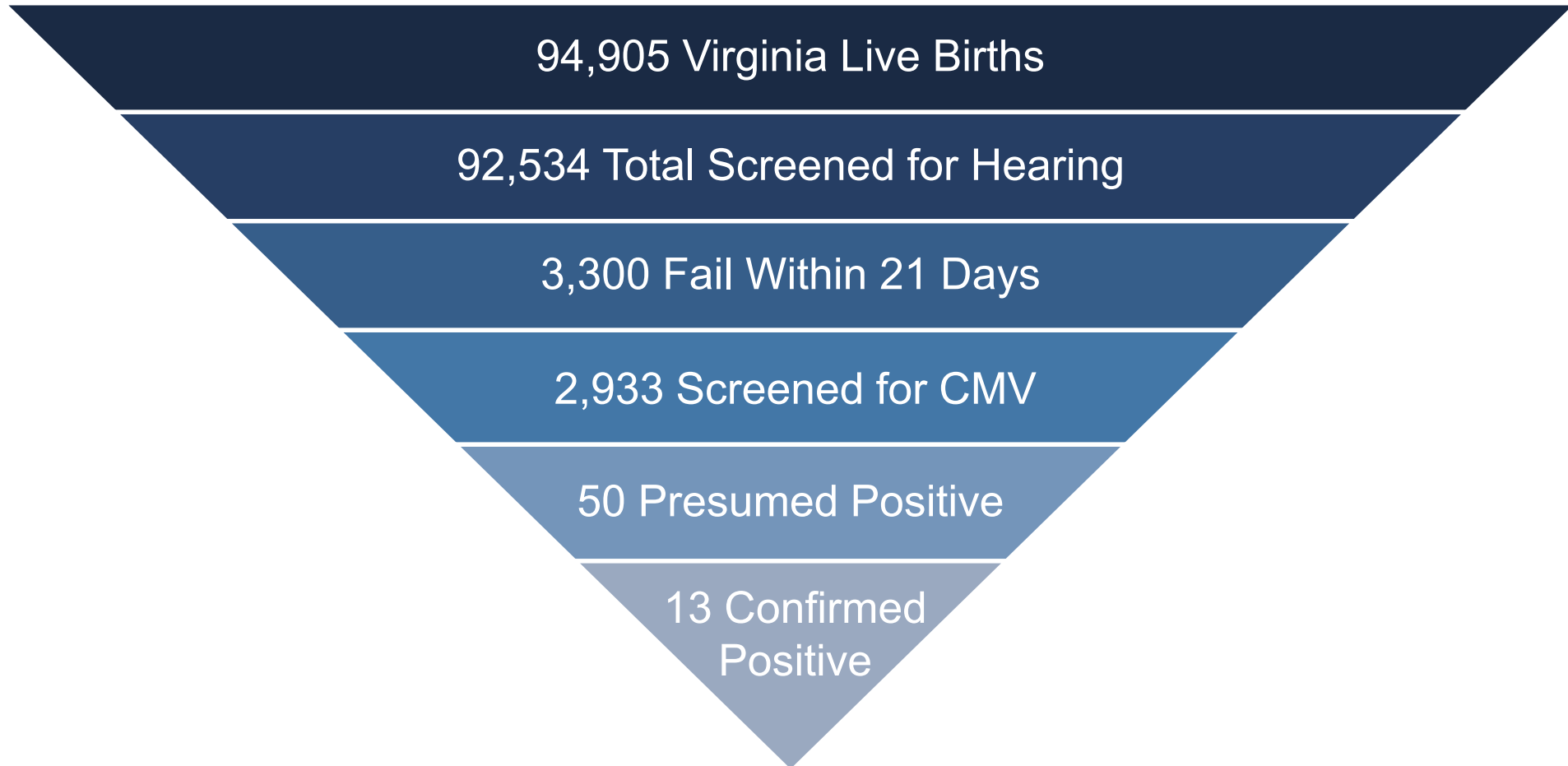
## Observed vs. Estimated Prevalence of Congenital CMV

*Data Timeframes and Underlying Populations Vary*

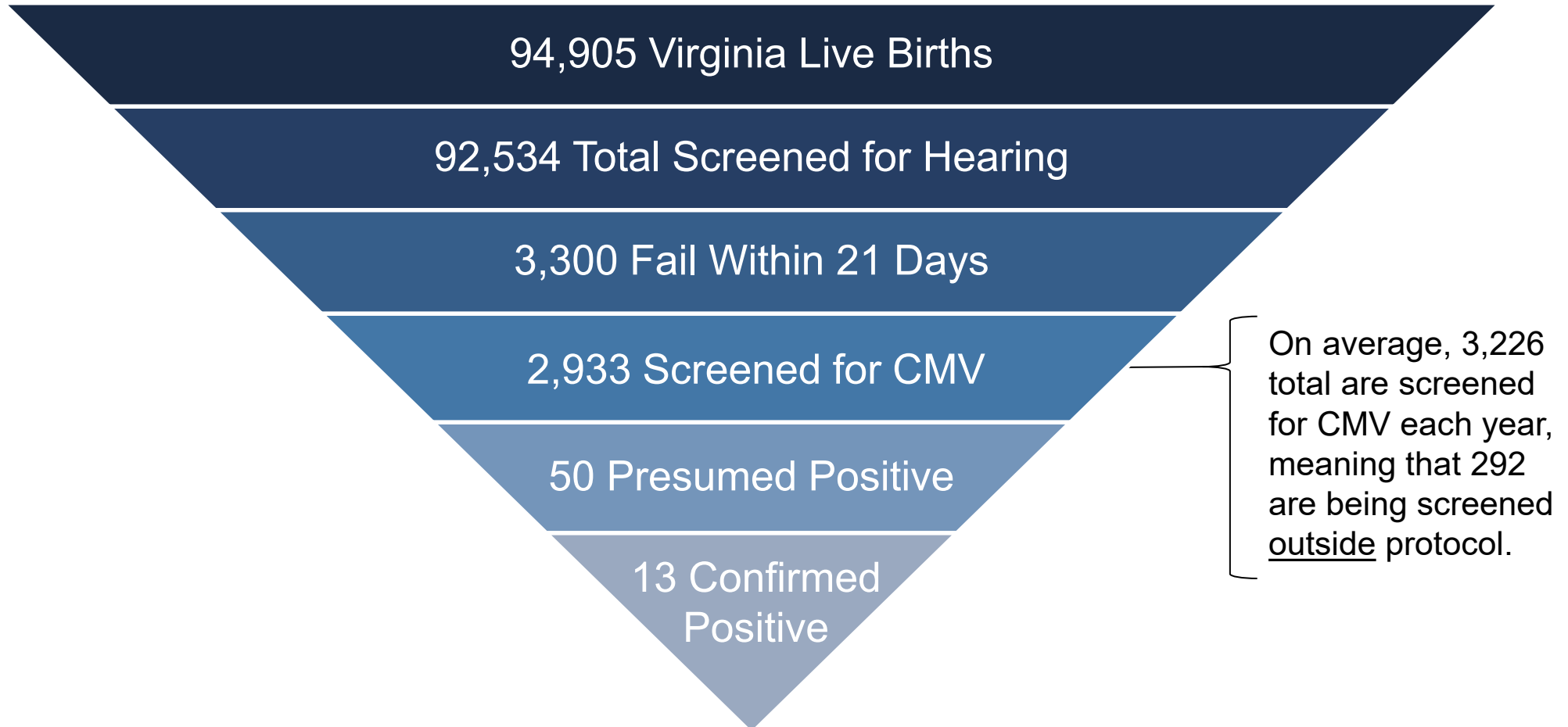


1. Lutz CS, Schleiss MR, Fowler KB, Lanzieri TM. Updated National and State-Specific Prevalence of Congenital Cytomegalovirus Infection, United States, 2018-2022. J Public Health Manag Pract. 2025 Mar-Apr 01;31(2):234-243. doi: 10.1097/PHH.0000000000002043. Epub 2024 Sep 3. PMID: 39231390; PMCID: PMC12068531.

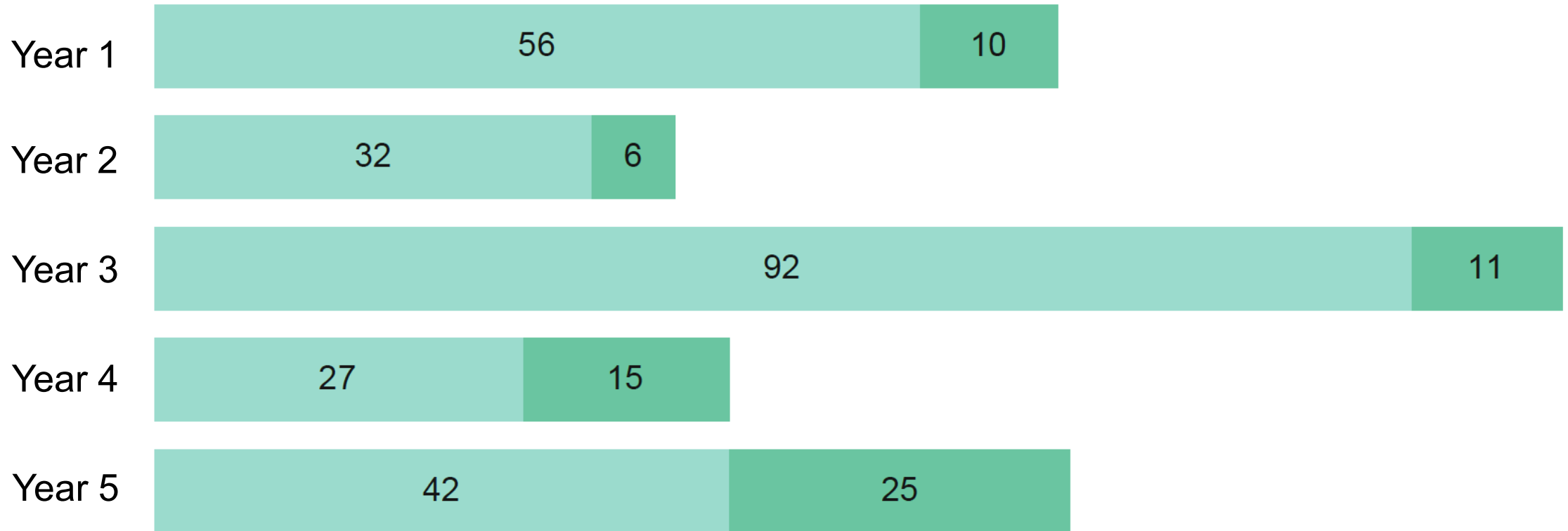
Average Number of Infants by cCMV Screening Stage Each Year in Virginia  
*Five Years from September 1, 2020 – August 31, 2025*



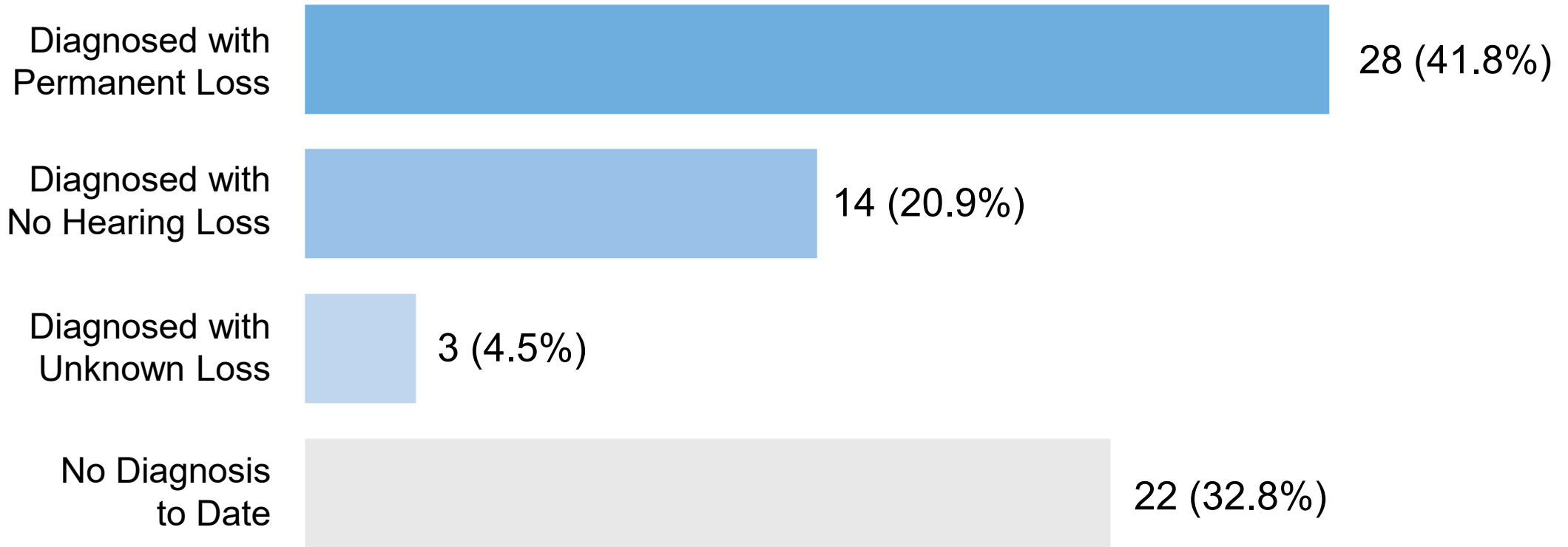
Average Number of Infants by cCMV Screening Stage Each Year in Virginia  
*Five Years from September 1, 2020 – August 31, 2025*



Number of Infants **Presumed Positive with cCMV** and **Confirmed with cCMV**  
*Five Years from September 1, 2020 – August 31, 2025*

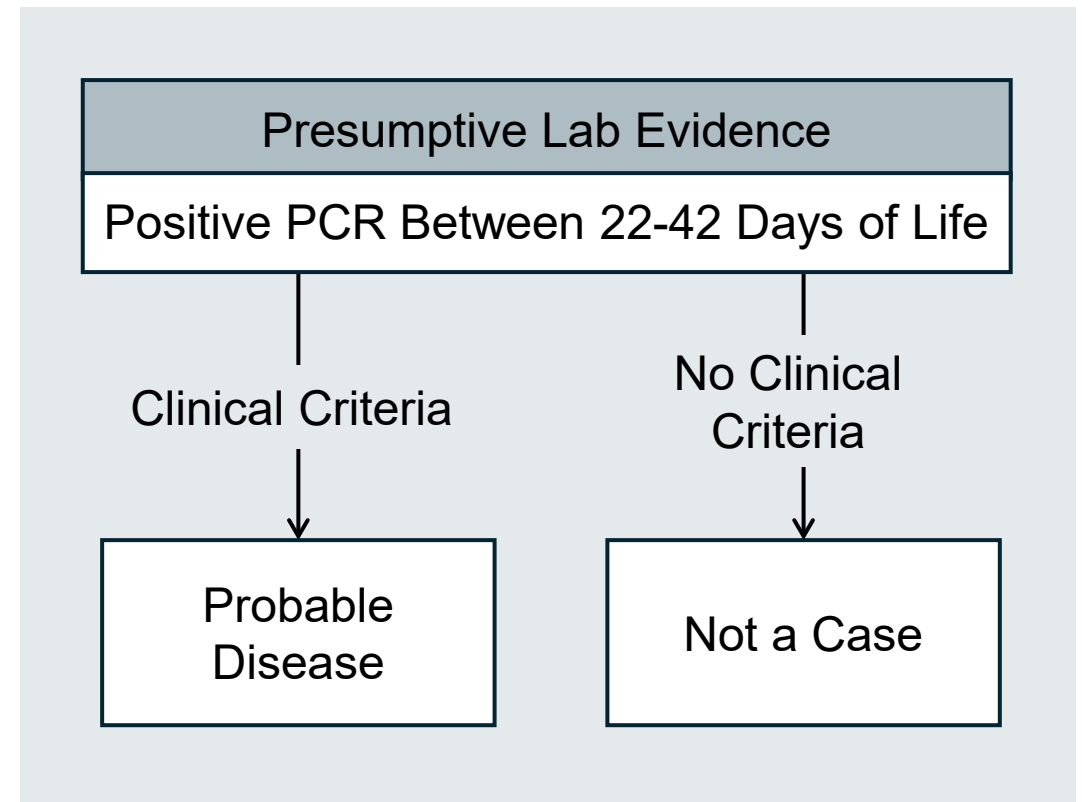
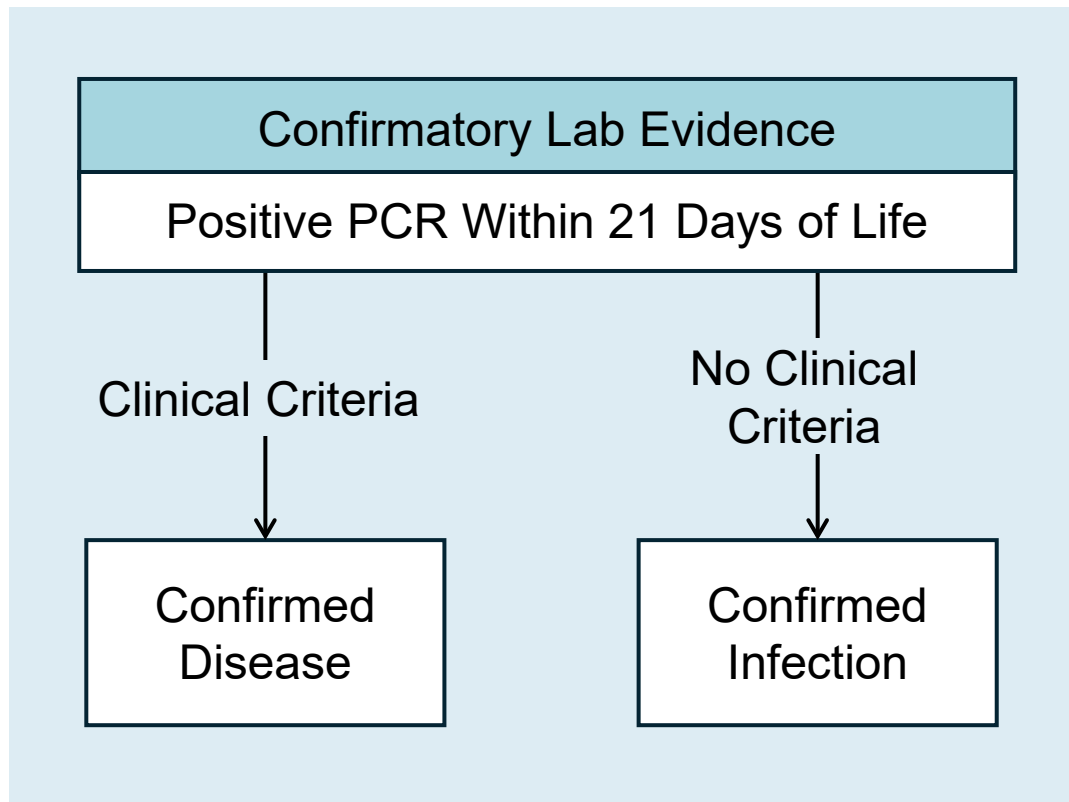


Audiology Results for Infants with Confirmed cCMV Laboratory Results  
*Five Years from September 1, 2020 – August 31, 2025*



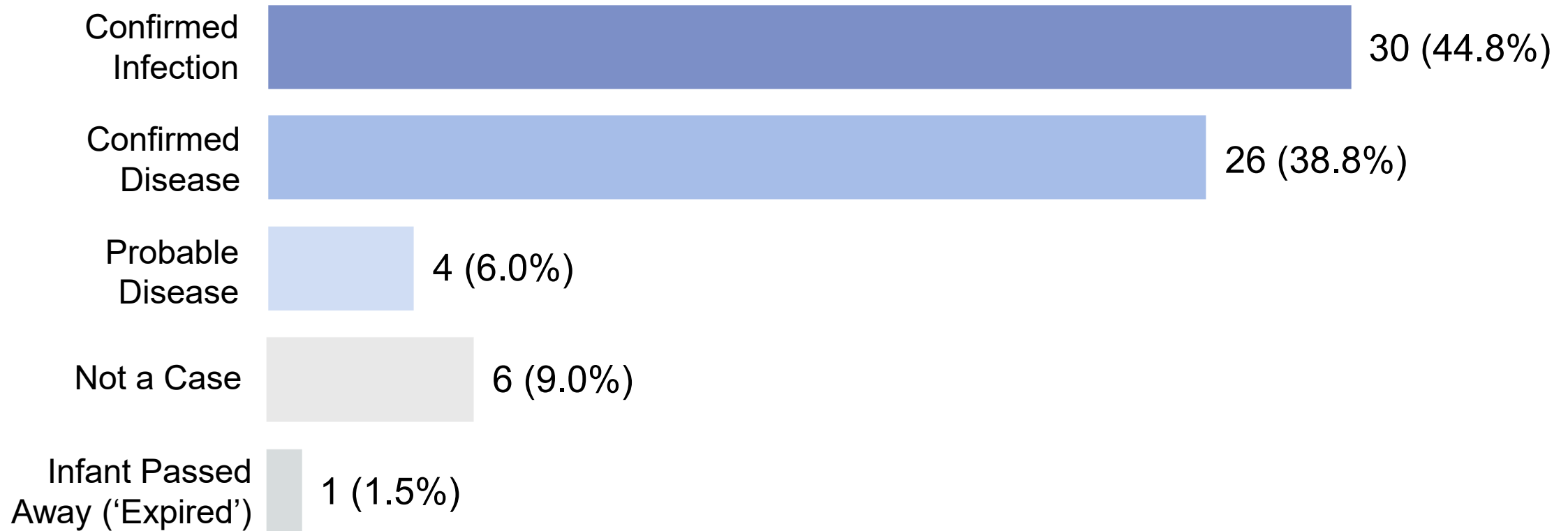
## Virginia cCMV Case Classification Overview

*Adapted from CSTE's Standardized Case Definitions*

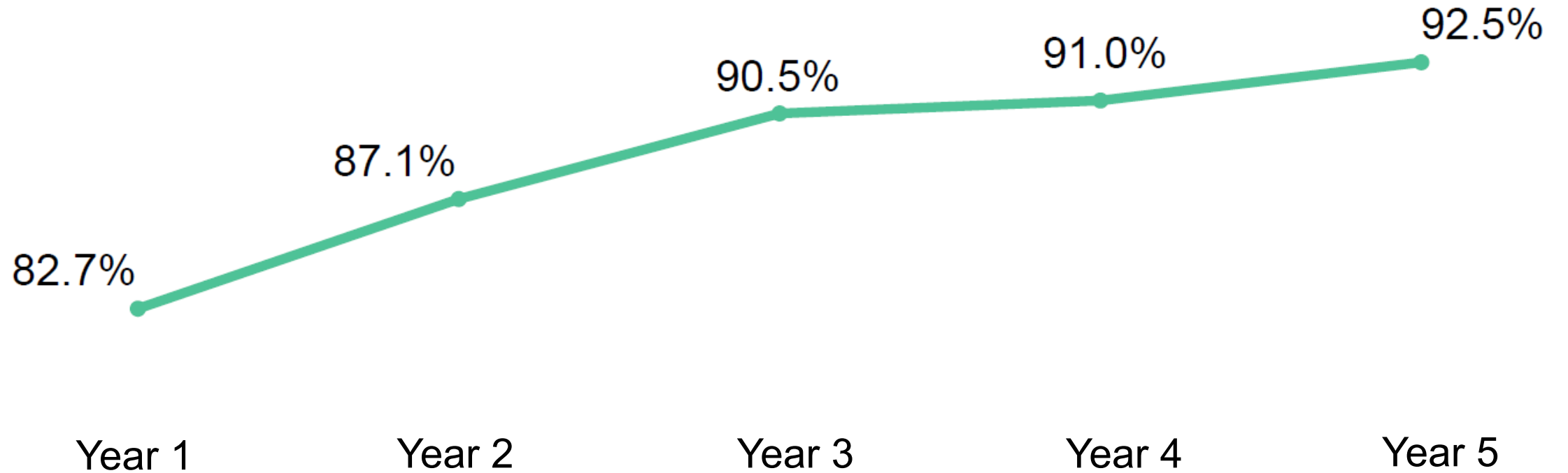


## Case Classification for Infants with Confirmed cCMV Laboratory Results

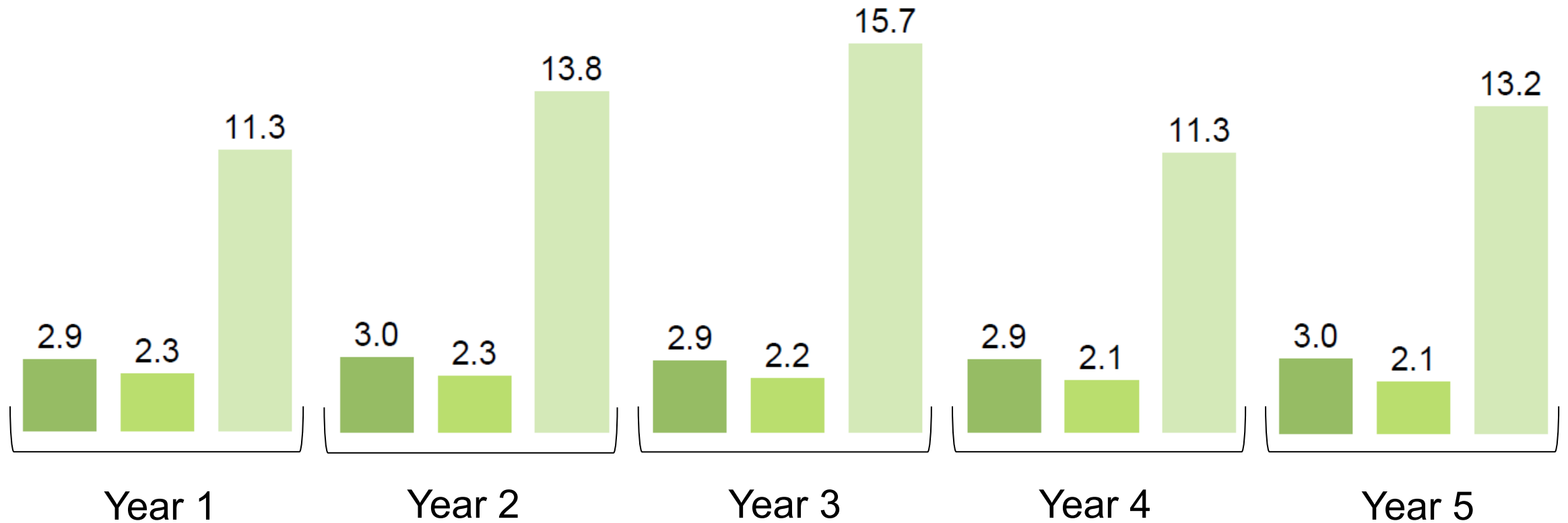
*Five Years from September 1, 2020 – August 31, 2025*



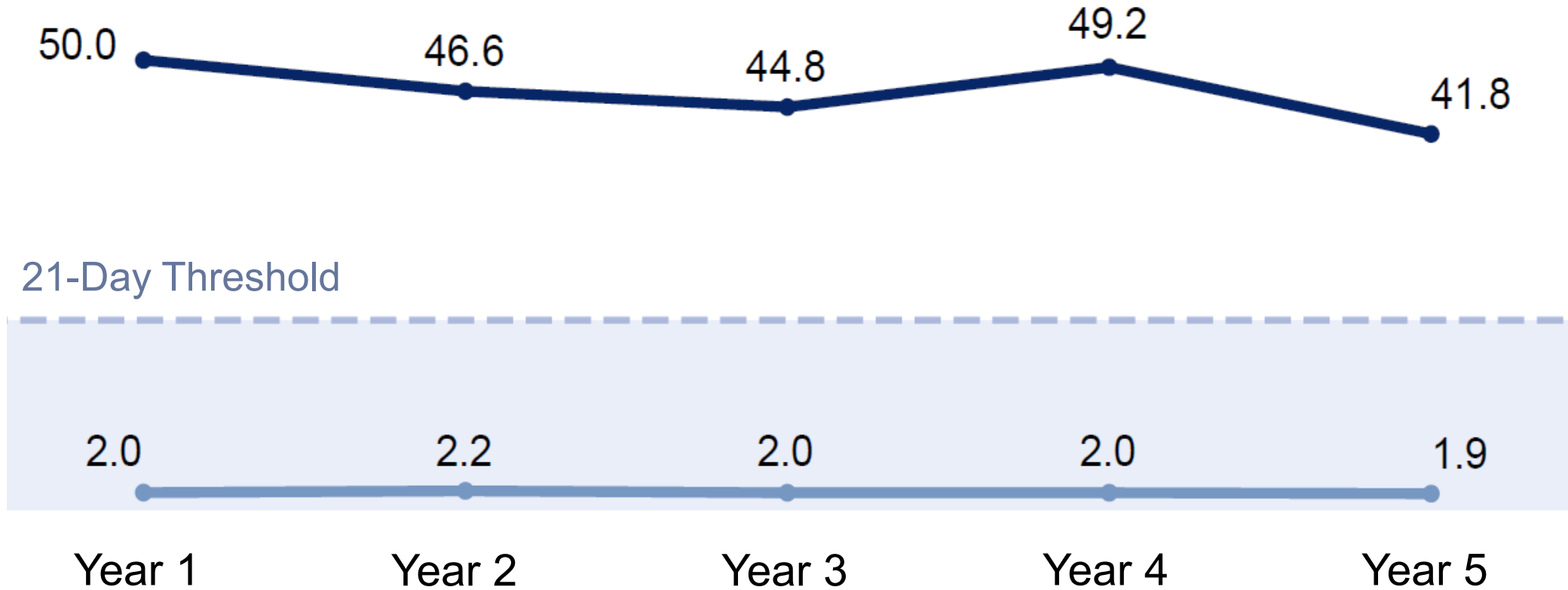
Percent of Infants Screened for cCMV among those with a 21-Day Failed Hearing Screen  
*Five Years from September 1, 2020 – August 31, 2025*



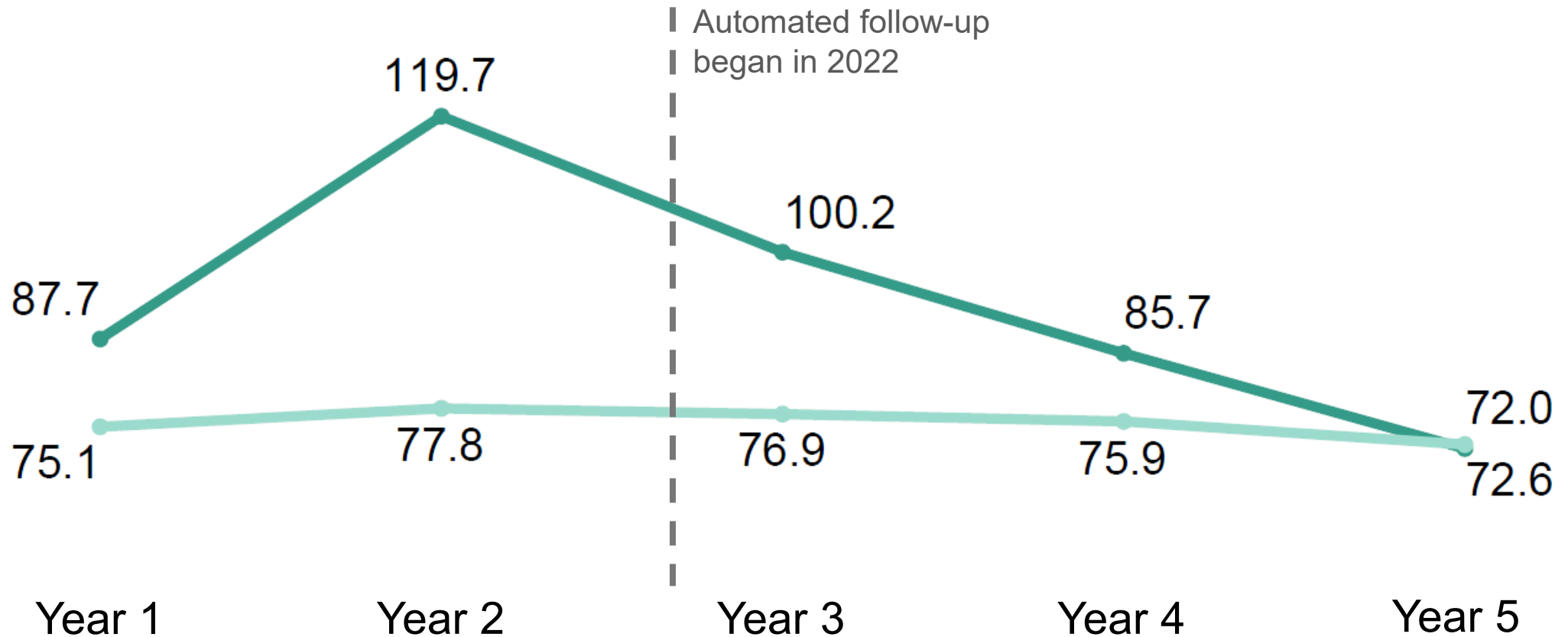
Average Infant Age in Days at **Hearing Screening**, **cCMV Screening**, or **cCMV Confirmation**  
*Five Years from September 1, 2020 – August 31, 2025*



Average Age in Days at Failed Hearing Screen for Infants in **NICU** vs. **Well-Baby Nursery**  
*Five Years from September 1, 2020 – August 31, 2025*

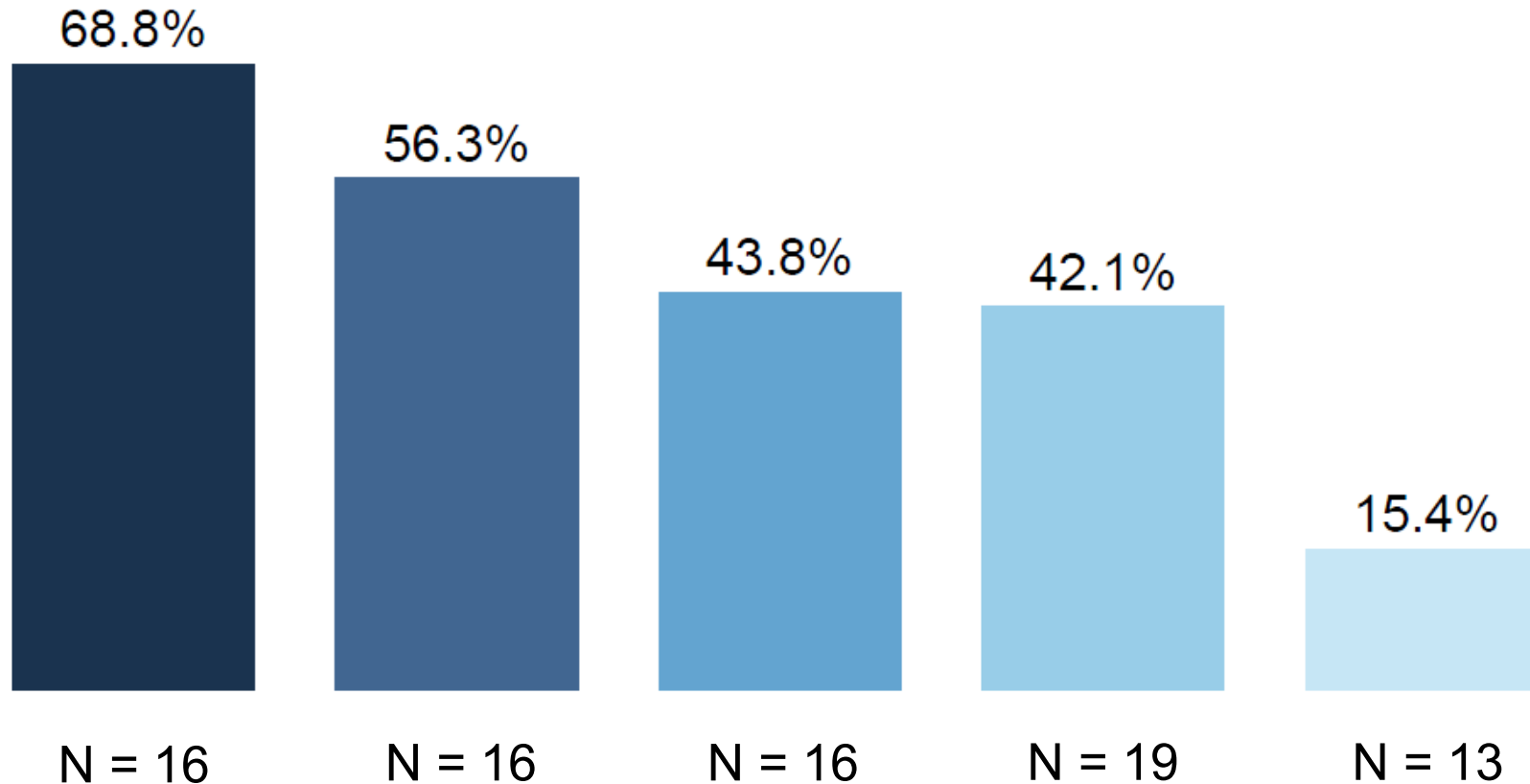


Average Age in Days at Diagnosis with **Permanent Loss** vs. **Hearing Within Normal Limits**  
*Five Years from September 1, 2020 – August 31, 2025*



Percent of Infants with cCMV Receiving the Following Services or Care, of Total Referred:  
**Family to Family, Ophthalmology, ENT, Early Intervention, or Genetics**

*Five Years from September 1, 2020 – August 31, 2025*



# Family- Centered Support

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# What is Family Engagement?

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It's not what we do *to* families, it's what we build *with* families!

It's a **full, equal** and **equitable** partnership among families, educators and community partners to promote children's learning and development, from birth through college and career.



## **CENTER FOR FAMILY INVOLVEMENT**

CFI is Virginia's state- supported Family Based Organization (FBO). We are Virginia's Parent to Parent USA representative as well.

We have provided family to family support in VA for over 35 years and support to families whose children receive a diagnosis of DHH specifically through our DHH Family Navigator program for more than 10 years. Since Virginia's adoption of hearing- targeted CMV screening in 2020, we have had volunteers and/ or staff who can support families navigating this diagnosis.

# BIG impact. REAL families. LASTING change.



693

FAMILIES HELPED THROUGH 1:1 SUPPORT

5,062

TOTAL FAMILY CONNECTIONS

928

LOCAL | NATIONAL EVENTS | COMMITTEES

5,503

PROFESSIONALS TRAINED

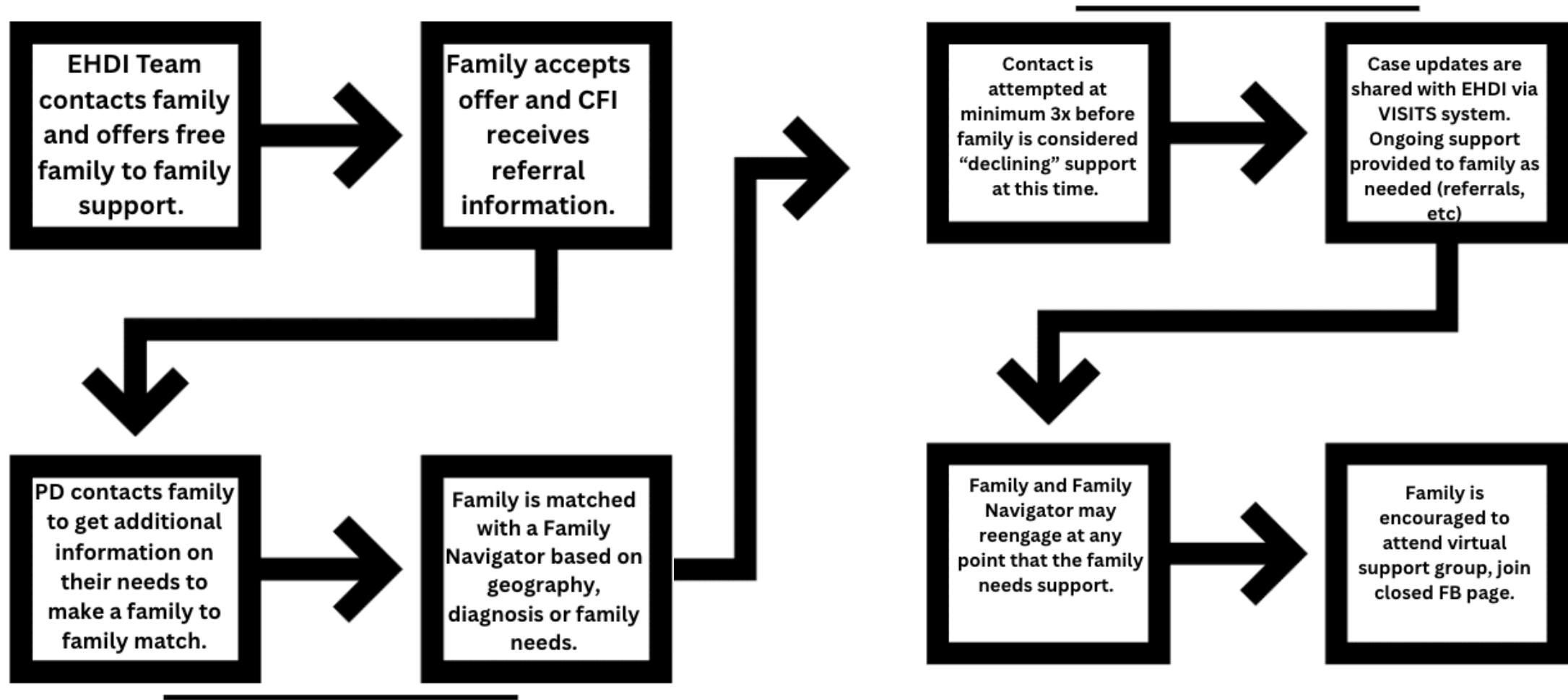
5K

HARD COPY RESOURCES SHARED

42

NEW LOCAL PARTNERS

# Virginia's Process



# Meet The Team

## DHH Family Navigators at The Center for Family Involvement

# Family Navigator Team



Megan Becker

FAMILY NAVIGATOR

Chesterfield, VA  
Son, 2 y/o  
Unilateral HA user  
Listening/ Spoken  
Language



Melissa Colley

FAMILY NAVIGATOR

Virginia Beach, VA  
adult son & daughter  
Connexin 26  
Bilateral CI users  
Listening/ Spoken Language



Kristin DeRamus

FAMILY NAVIGATOR

Leesburg, VA  
DHH Adult  
Bilateral HA user  
Listening/ Spoken  
Language



Shelley Herzing

FAMILY NAVIGATOR

Chesterfield, VA  
daughter, 9 y/o  
Microtia/ Atresia  
Bone-Anchored HA user  
Listening/ Spoken Language



LaDonna Martin

FAMILY NAVIGATOR

Woodbridge, VA  
daughter, 9 y/o  
Unilateral HA user  
Listening/ Spoken  
Language



Bonnie Morales

FAMILY NAVIGATOR

Mechanicsville, VA  
Adult daughters DHH  
American Sign  
Language



Jessica Sheffield

FAMILY NAVIGATOR

Hampton Roads, VA  
DHH Adult  
Son, 4 y/o  
Auditory Neuropathy  
American Sign Language  
Listening/ Spoken



Silvana Thorpe

FAMILY NAVIGATOR

Glen Allen, VA  
Son, 8 y/o  
Bilateral CI user  
Listening/ Spoken  
Language  
Spanish Speaking



Lisa Eickel

DHH PROJECT DIRECTOR CFI

Ashburn, VA  
Son, 8 y/o  
Unilateral HA user  
Listening/ Spoken  
Language



Tracey Yurechko

PROJECT DIRECTOR  
TAC-DHH

Richmond, VA  
Teacher of the Deaf  
Certified Interpreter

# Lessons Learned from Implementation process

- Cultural Competency and connection for linguistically diverse families
- Reaching out via text messages and emails before phone calls
- Emphasis on Family Navigators have the lived experience of cCMV as parents
- Reminding that services and support are always free and never expire

# Steps Taken to Address Challenges

- More virtual events
- Partnering with Authors in the DHH space to provide free books to families at Author- led events
- Mini-grant program to diversify financial support throughout the state to family groups and organizations to hold events



# HAPPY BIRTHDAY TO YOUR LITTLE ONE!

This is such a special milestone—not just for your child, but for you as a family. One full year of growing, learning, loving, and navigating the incredible journey of parenthood. What a joy and accomplishment!

As you celebrate today, we want you to know that you're not alone on this journey. Every child is unique, and every parenting experience is filled with questions, hopes, and challenges. That's why we'd love to invite you to connect with Family-to-Family Support through The Center for Family Involvement—a network of parents who've walked a similar path.

Whether you're looking for a supportive presence, resources, encouragement, or just someone who "gets it," our trained Family Navigators are here for you. These Family Navigators have lived experiences raising a child with hearing loss or being an adult who has navigated hearing loss throughout their own life.

To help you celebrate this beautiful milestone, please accept this book as a gift—a small token of joy, imagination, and connection to enjoy together during story time or snuggles. We hope it brings as many smiles as your little one has already shared with the world.

If you'd like to connect with a fellow parent, ask questions, or simply share, we're here.

To learn more or be matched with a Family Navigator,  
please go to: [tinyurl.com/DHH-intake](https://tinyurl.com/DHH-intake)

With heartfelt wishes and warmest congratulations,  
Lisa Eickel, DHH Project Director: Center for Family Involvement



# Family- Centered Events



**CENTER FOR  
FAMILY INVOLVEMENT**

Virtual Support Group  
for families with DHH  
Children in Virginia

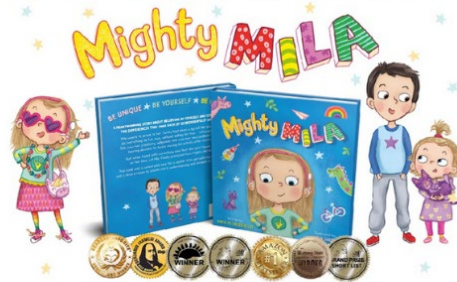


Join us Tuesday, April 8 at 7:00 pm

for a pajama party and  
author reading with  
Katie Petruzziello,  
Author of Mighty Mila  
& Mighty Mila: Dream Job  
and parent to two DHH  
children!



The first 50 registrants will receive a  
complimentary *signed* copy of Mighty Mila!



Registration required!  
[Tinyurl.com/DHH-Author-Event](https://tinyurl.com/DHH-Author-Event)



**CENTER FOR  
FAMILY INVOLVEMENT**

Virtual Support Group for  
families with DHH Children  
in Virginia



Join us Wednesday, April 23 at 7:00 pm

for an Author Q&A with  
Valli Gideons, Author of Through the Fog,  
parent of two DHH teens  
and Hearing Loss Advocate



The first 50 registrants  
will receive a  
complimentary copy of  
Through the Fog!

Registration Required!  
[Tinyurl.com/DHH-Parent-Event](https://tinyurl.com/DHH-Parent-Event)

EDUCATIONAL HUB FOR SENSORY DISABILITIES

# DHH FAMILY SUPPORT GROUP

Free monthly Deaf/ Hard of  
Hearing virtual family support  
group for Virginia families!

CONNECT WITH OTHER FAMILIES,  
RESOURCES & MORE!



SCAN TO SIGN UP



EDUCATIONAL HUB FOR SENSORY DISABILITIES

# GRUPO DE APOYO FAMILIAR

Acceso Libre a la reunión  
mensual de apoyo familiar para  
familias con problemas de  
audición o sordera, en Virginia.

¡CONÉCTATE CON OTRAS FAMILIAS,  
RECURSOS Y MUCHO MÁS!



SCAN TO SIGN UP



# Questions?

[va\\_ehdi@vdh.virginia.gov](mailto:va_ehdi@vdh.virginia.gov)

