

# Raising Awareness of cCMV in Arizona: Stop CMV AZ / Alto CMV AZ

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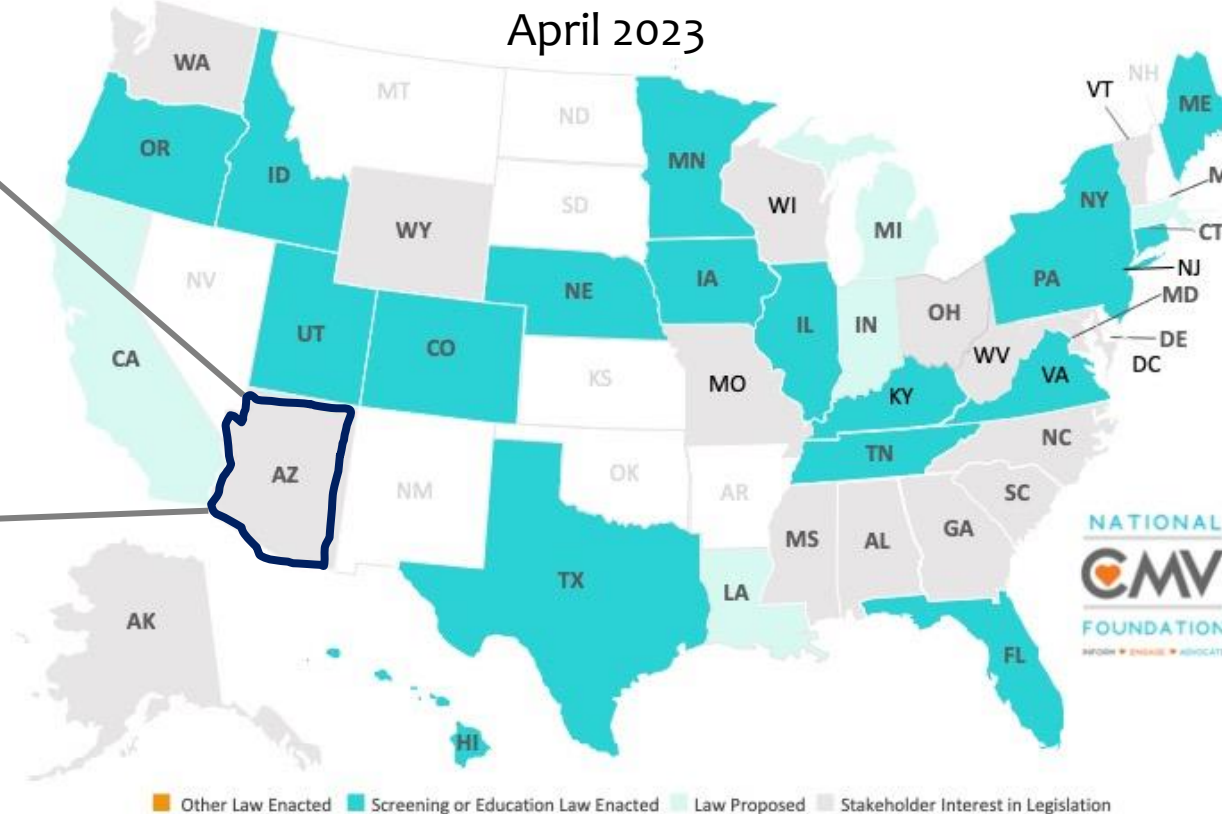




# Overview of cCMV advocacy

## Congenital CMV Advocacy in the United States

April 2023



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Stop CMV (est. 2003) and  
Brendan B. McGinnis  
Foundation (est. 2007)

2013: Utah passed the first  
CMV Public Education and  
[Hearing-targeted] Testing

2015: NCMVF founded by six  
mothers and partnering ENTs,  
audiologists, and infectious  
disease doctors

2021: Minnesota passed The  
Vivian Act for CMV Public /  
HCP education and *Universal*  
Testing

2023: CMV legislation has  
passed in **18 states**, with  
others pending – including  
states working to establish a  
health commission to  
investigate CMV public  
education and testing

NCMVF Grant awarded in 2019  
ACF Grant awarded in 2021  
ongoing funding from  
Midwestern University,  
Ear Foundation of Arizona



OFFICE OF THE GOVERNOR  
**KATIE HOBBS**

# Proclamation

**WHEREAS**, congenital cytomegalovirus (CMV) is the most common congenital infection in the United States with about 1 in 200 children born with congenital CMV; and  
**WHEREAS**, congenital CMV is the most common cause of birth defects in childhood disabilities in the United States, and 40 to 60 percent of infants born with signs of congenital CMV disease at birth will have long-term health problems; and  
**WHEREAS**, congenital CMV is preventable with simple behavioral interventions while pregnant, such as practicing frequent hand washing with soap and water after contact with diapers and oral secretions, not kissing young children on the mouth, and not sharing utensils with young children; and  
**WHEREAS**, most people are not aware of their CMV infection status, with pregnant women being one of the highest risk groups; and  
**WHEREAS**, CMV infection is more common than the combined metabolic or endocrine disorders currently in the United States core newborn screening panel; and  
**WHEREAS**, the incidence of children born with congenital CMV can be greatly reduced with public education and awareness.

**NOW, THEREFORE**, I, Katie Hobbs, Governor of the State of Arizona, do hereby proclaim June 2023 as  
**ARIZONA CMV AWARENESS MONTH**

IN WITNESS WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the State of Arizona

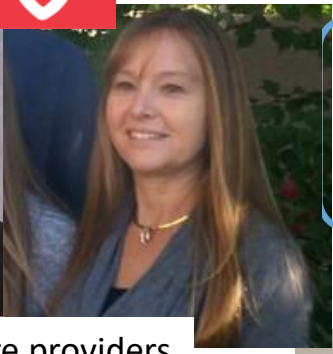
*[Signature]*  
 GOVERNOR

DONE at the Capitol in Phoenix on this twenty-fifth day of May in the year Two Thousand and Twenty-Three, and of the Independence of the United States of America the Two Hundred and Forty-Seventh.

ATTEST:  
*[Signature]*  
 SECRETARY OF STATE



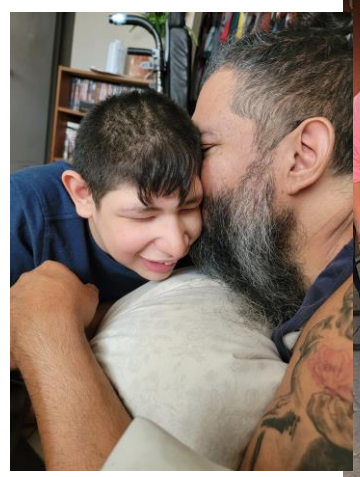
Advocates



Healthcare providers



Teachers and therapists



Parents



Medical educators/ students







# cCMV: Facts & Figures for Arizona

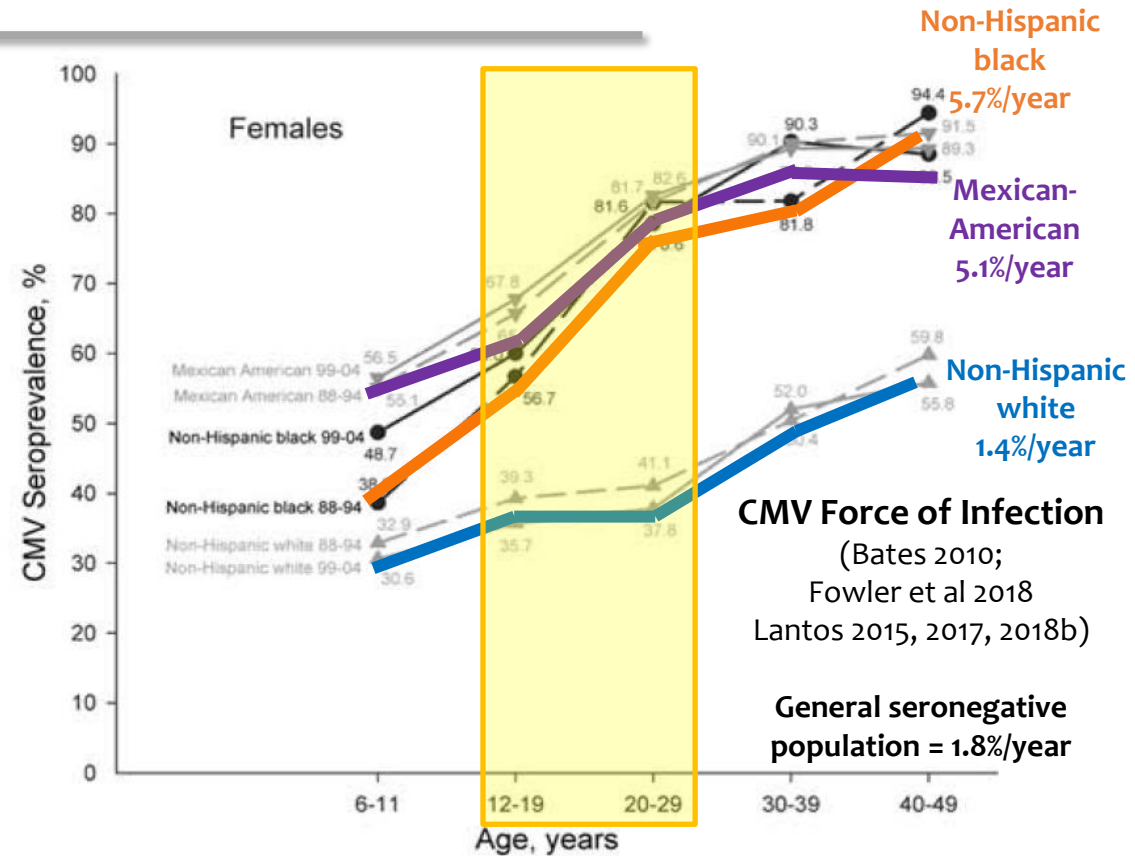
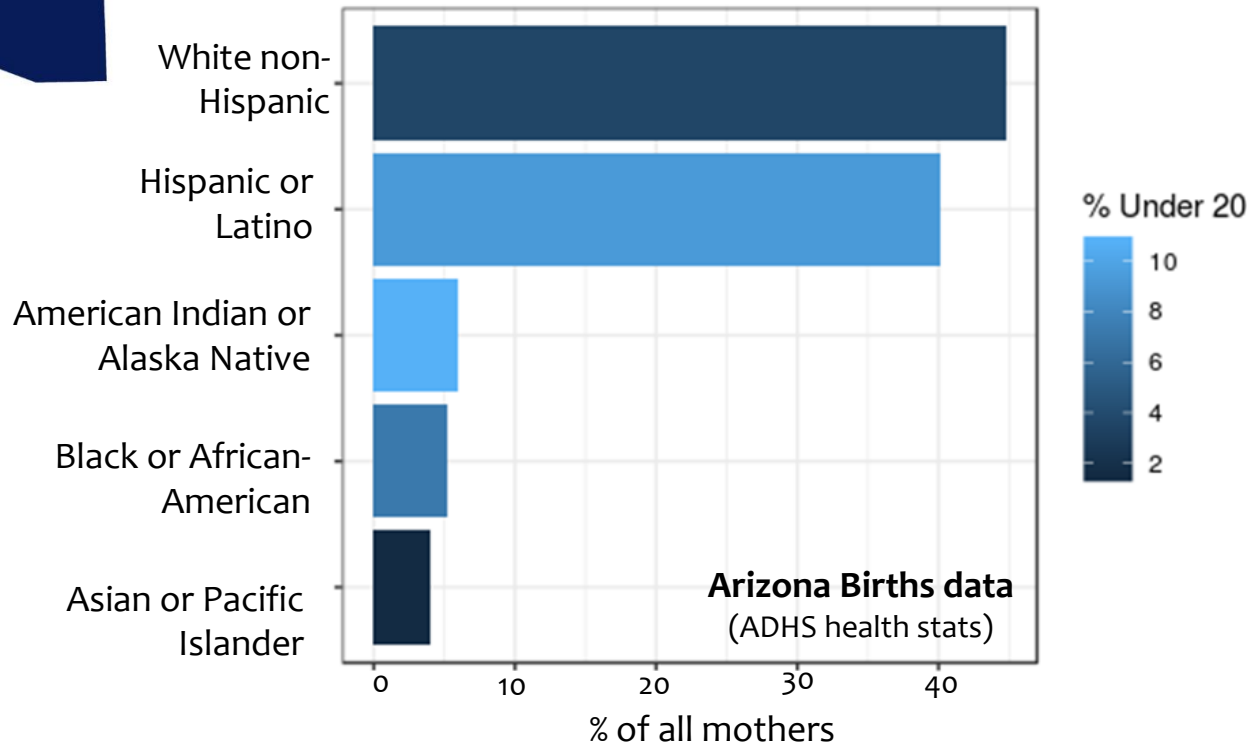
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- In Arizona
- 400-600 babies are born each year infected with CMV.
  - cCMV permanently disables 80-100 babies each year.
  - the cost of caring for children disabled by cCMV is \$25-50 million each year.

[ photos of Arizona children born with cCMV redacted for handout ]



# cCMV: Facts & Figures for Arizona



## In AZ (2020):

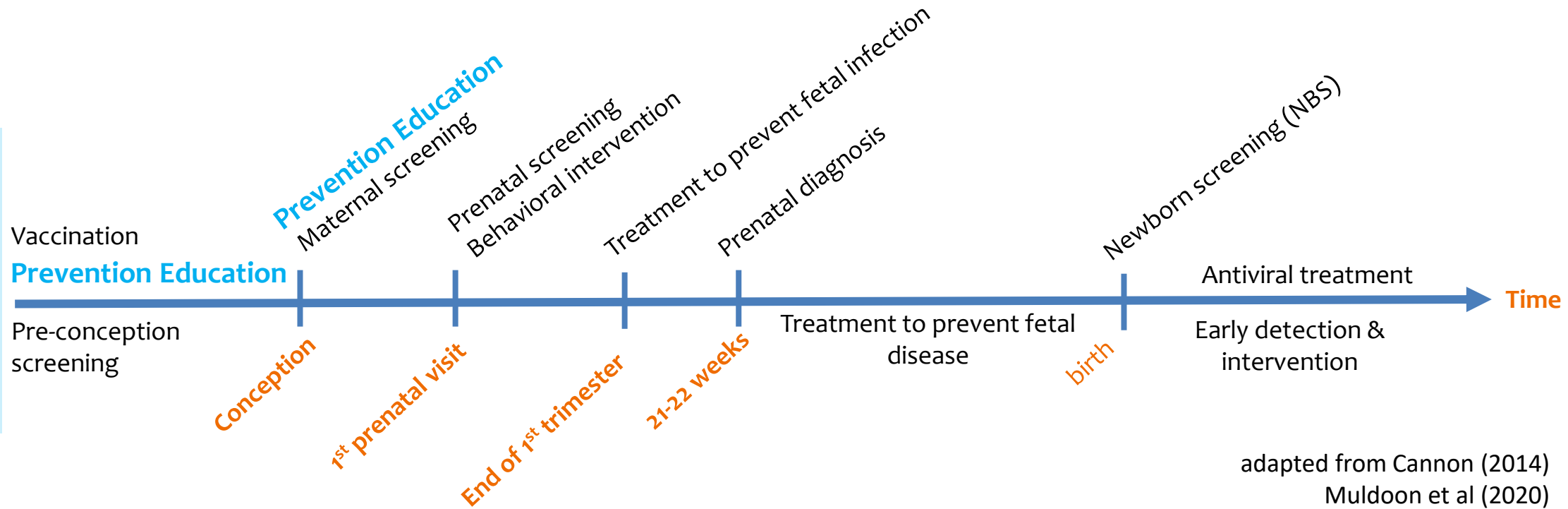
- ~55% of live births within communities of color
- greater proportion of births within communities of color are to **young mothers (<20 years of age)**

Among adolescents, primary CMV infection is **50 times more likely within seronegative non-Hispanic Black** & **15 times more likely within seronegative Latina** populations than in **non-Hispanic white** populations.

**Demographic differences in CMV prevalence suggest that we need to target higher risk persons from marginalized communities for public health interventions in Arizona.**

# Potential clinical and public health interventions for cCMV

CMV prevention & treatment education among health care professionals and students

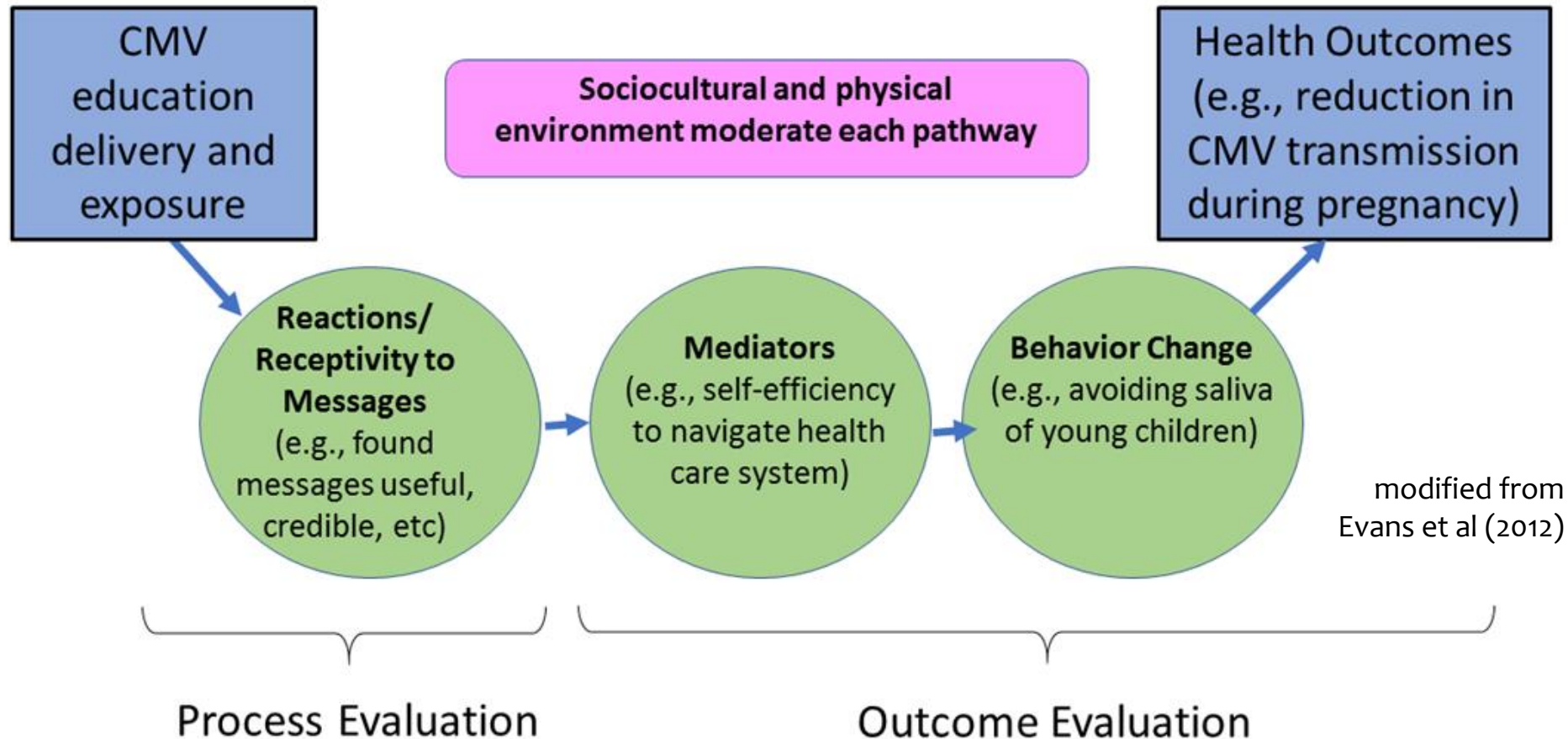


Currently, none of these interventions are routine in Arizona or in the US



# Development and Field Testing of cCMV Education Materials

- To **increase awareness and health-risk knowledge of cCMV** in Arizona in order to affect behavior change amongst women of child-bearing age that will **reduce its impact** on all populations, especially marginalized groups

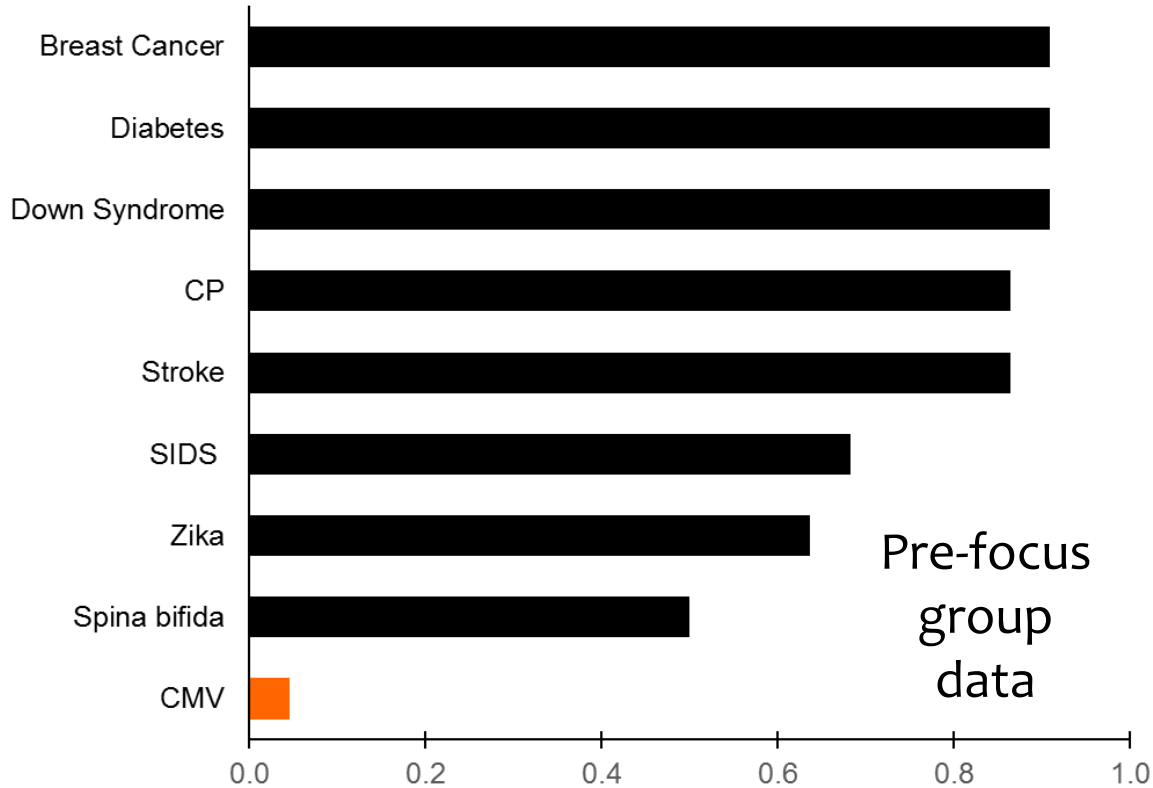






# Community Focus Groups

- Ten focus groups in English and Spanish with women in Arizona (2019-2021).
- N = 50 focus group participants
  - Majority of participants had not completed high school (48%) or had earned a bachelors' degree (30%), were 18-35 years of age (48%), and identified as non-white Hispanic/Latina (61%)



Pre-focus group data

Proportion of participants with self-reported familiarity of CMV

**NONE (0%)** had health risk knowledge of CMV (e.g., unable to identify the behavioral modes of transmission) (see Muldoon et al 2017)

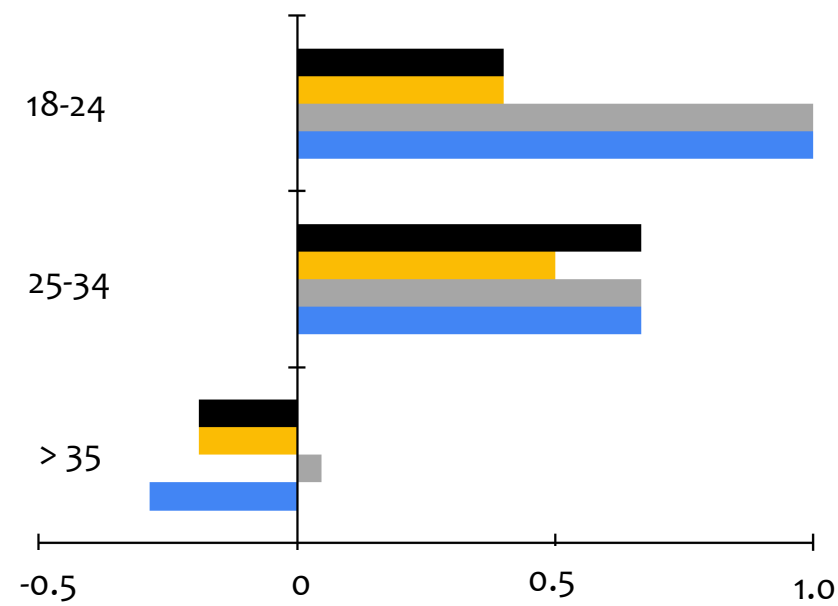
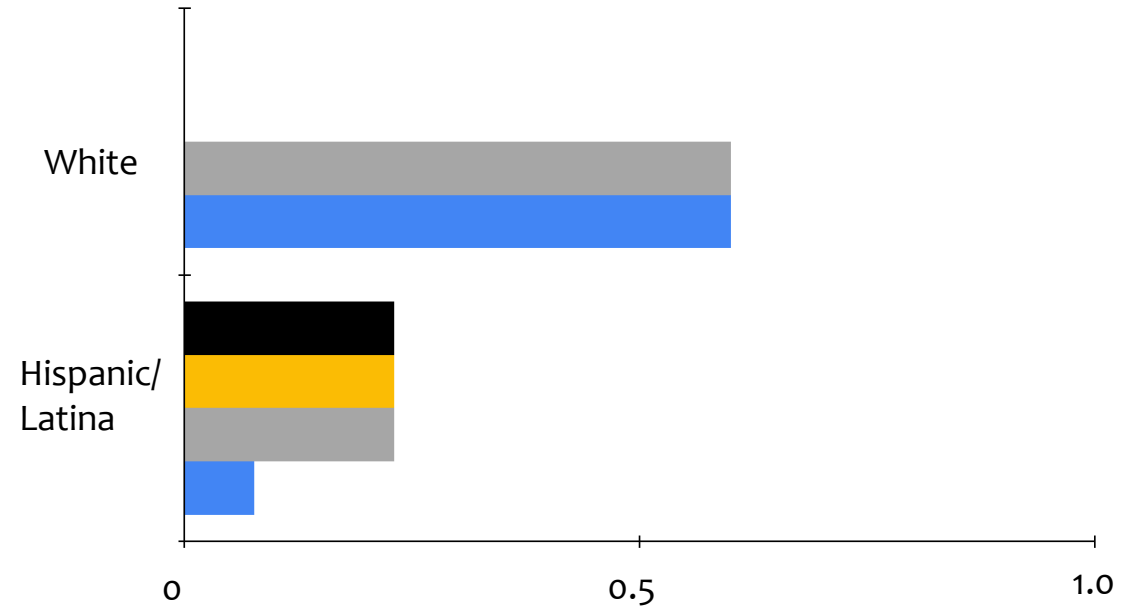


# Receptivity to CMV prevention messaging

“In order to avoid CMV affecting my pregnancy, I would agree to follow these behaviors while pregnant”  
(No = -1, Neutral = 0, Yes = 1)

Average participant response by  
**ETHNICITY**  
(for groups with n ≥ 5)

Average participant response by  
**AGE**



Other factors that affect willingness to adopt behavior changes:

- Education
- Contact with kids
- Being a parent

- not kiss a child on the lips
- not share food with a child
- not share utensils with a child
- not share cup with a child



# Focus group feedback

Focus group leader Alejandra Arroyo (NAU, OTR/L)

Receptivity to prevention message varied by ethnicity, age, contact with children, being a parent



- Diverse images preferred across groups
- Information in Spanish for Spanish speakers
- Spanish speakers preferred images of families, personal family stories (*English-speaking participants more likely to negatively comment on lengthiness of material*)

- Images of “sick” children (e.g., with disabilities, especially alone) evoked feelings of sadness, wanting to look away
- Images of screening / intervention evoked feelings of hope



What is Congenital Cytomegalovirus (CMV)?





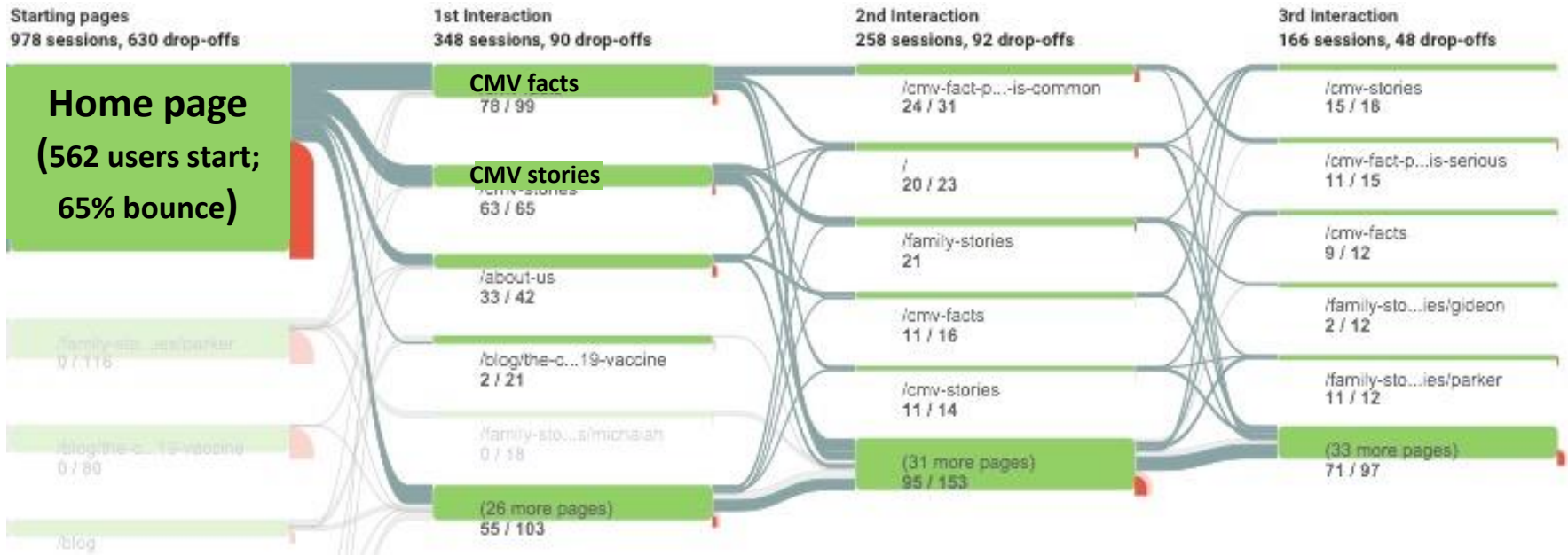
**Our website is now live!**



CMV is the most common virus that can harm your developing baby during pregnancy.



Learn how to make a difference.  
[stopcmvaz.org](http://stopcmvaz.org)

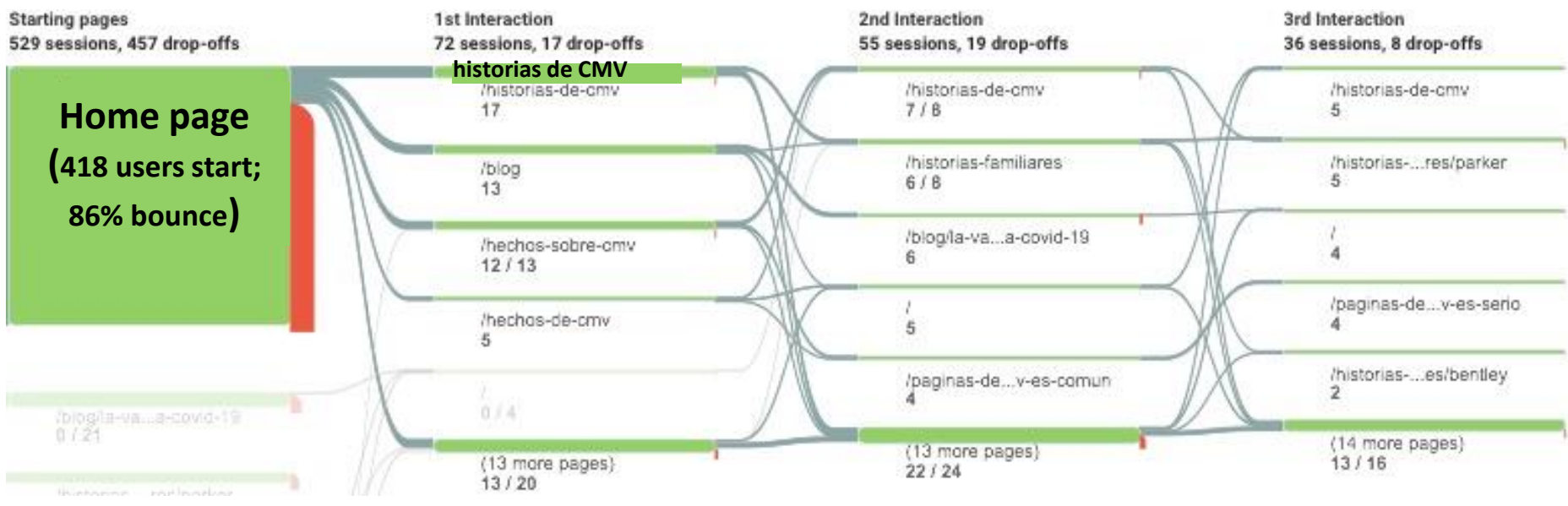


Website analytics,  
 Dominik Kaltenbach  
 (MWU AZCOM,  
 MS III)

**¡Queremos anunciar que nuestro sitio web está activo!**



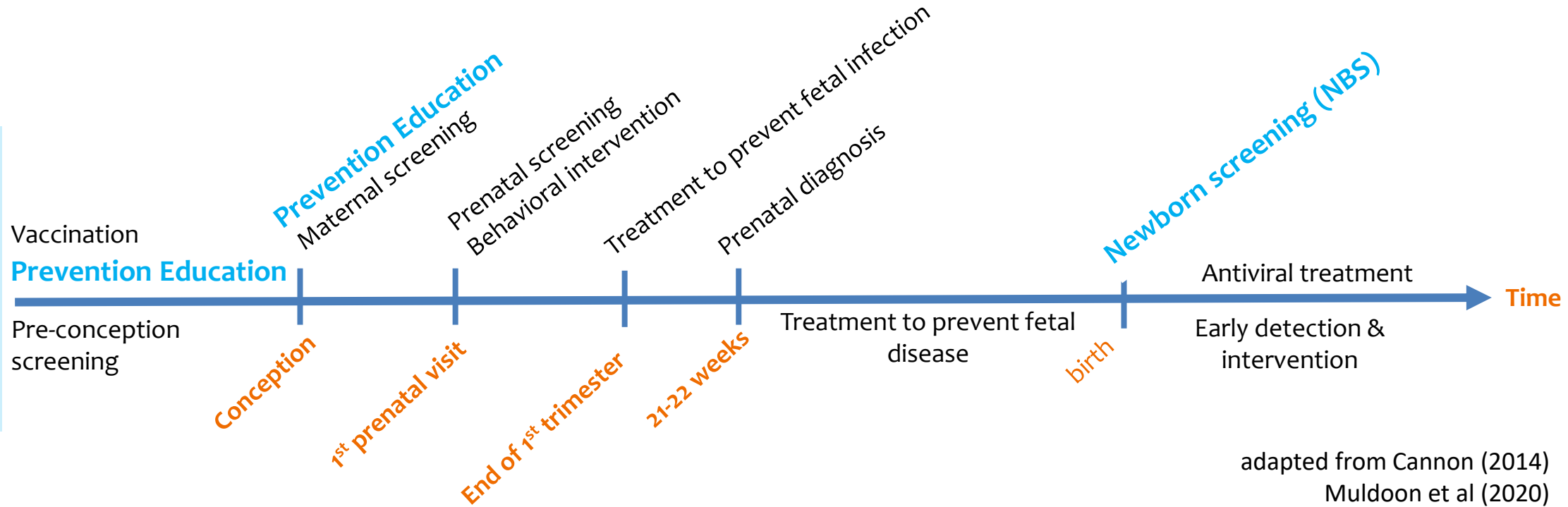
El CMV es el virus más común que puede dañar al bebé en desarrollo durante el embarazo. Aprenda cómo marcar la diferencia en [altocmvaz.org](http://altocmvaz.org)

Website behavior flow and interactions June 1<sup>st</sup> 2021 to March 31<sup>st</sup> 2022. TOP: Stopcmvaz.org users: 562 sessions started on the stopcmvaz.org landing page, 35% continued exploring, from which the majority (28%) decided to explore 'facts about CMV'; BOTTOM: Altocmvaz.org users: 418 sessions started on the altocmvaz.org landing page and 14% continued exploring, from which the majority (24%) decided to explore CMV stories.

# Potential clinical and public health interventions for cCMV

CMV prevention & treatment education among health care professionals and students



Currently, none of these interventions are routine in Arizona or in the US

# CMV Advocacy – why we need to add CMV to the newborn screen

- Most infants born with congenital CMV are not identified at birth (90% of births asymptomatic, symptomatic infants often missed based on clinical suspicion alone)



Can you tell if one of these babies will be deaf or hard of hearing by the age of 5?

- **Newborn CMV screening** is needed to identify infants who have asymptomatic cCMV, who are at risk for CMV-related hearing differences and other long-term health outcomes.
  - **Urine (98%)** and **saliva (93%)** are reliable specimens for CMV screening; DBS less sensitive (~77%)
- Universal CMV screening does not currently occur in the US
  - MN first state to universally screen all infants for cCMV
  - Some states legislate & numerous hospitals have proposed targeted CMV screening of newborns who refer from newborn hearing screen (but only identifies ~57% of CMV-infected newborns)





# Universal Newborn CMV Screening – pilot study

- AZ has no mandatory reporting or cCMV screening program
- Pilot prospective cohort study in which 250 newborns were universally screened for cCMV infection at SJHMC, using saliva as the primary (urine as secondary) diagnostic specimen (approved by St. Joseph’s Medical Center Institutional Review Board [#PHX-22-500-305-70-37], funded by MWU & ACF; PIs Nathan Page, Kathleen Muldoon)



For more information:



Find Nathan Page  
and

come to our presentation: Page et al (2023): Tuesday October 10 12:30-1:35 pm



ARIZONA  
COMMUNITY  
FOUNDATION



Phoenix  
Children's



Dignity Health™  
St. Joseph's Medical Center



# Arizona CMV Advocacy –Where We Are; Where We’re Going



- ❑ Develop best practices for newborn cCMV screening
- ❑ Continue to empower diverse family voices through community and clinical partnerships



- ❑ Refinement of materials for at risk populations with culturally appropriate messages and trusted messengers
  - Not enough to translate materials
  - Use lens of cultural humility & “the platinum rule”



# Join our collaboration! Prevent cCMV from affecting someone you love by practicing healthy pregnancy tips to avoid ALL GERMS



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ARIZONA DEPARTMENT  
OF HEALTH SERVICES  
ARIZONA BIOMEDICAL RESEARCH COMMISSION



**Phoenix  
Children's**



**moderna**



**Strengthening partnerships to promote healthier pregnancies and family empowerment.**



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AZ Dept of Economic Security

**Lylis Olsen**  
AzEHDI Coordinator, HEAR for Kids

Strengthening partnerships to promote healthier pregnancies and family empowerment.