

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

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www.stopcmvaz.org



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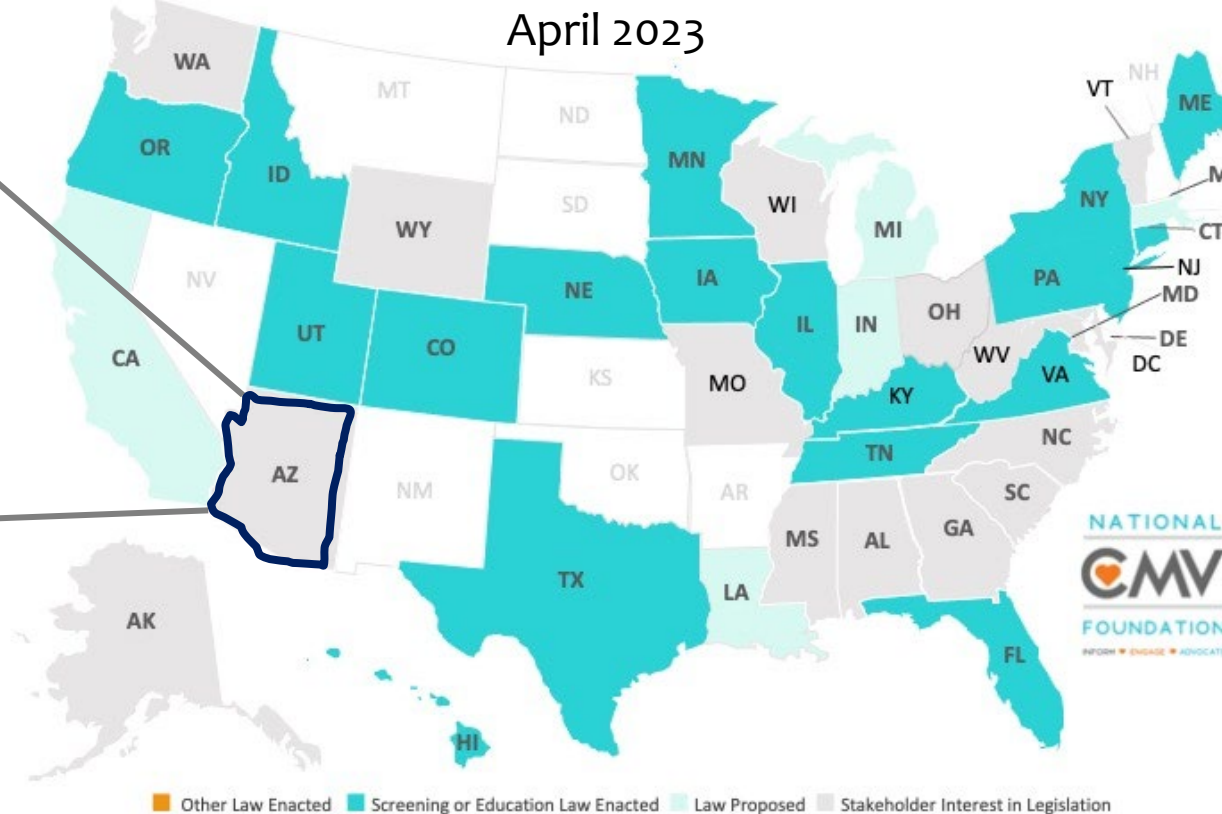
Overview of cCMV advocacy

Congenital CMV Advocacy in the United States

April 2023



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



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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

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

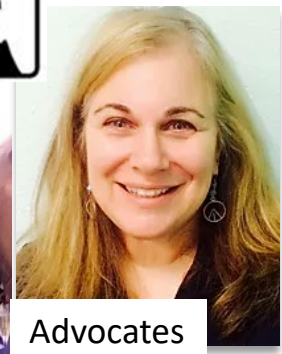


IN WITNESS WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the State of Arizona

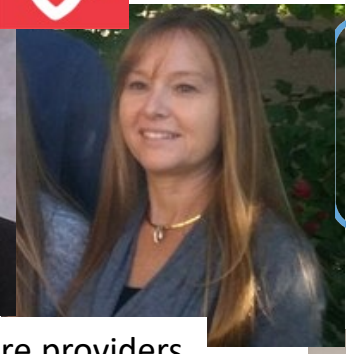
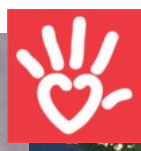
[Signature]
 GOVERNOR

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



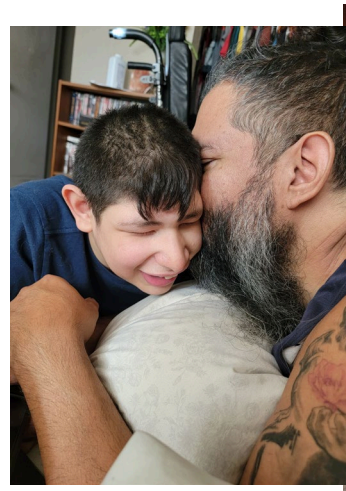
Advocates



Healthcare providers



Teachers and therapists



Parents



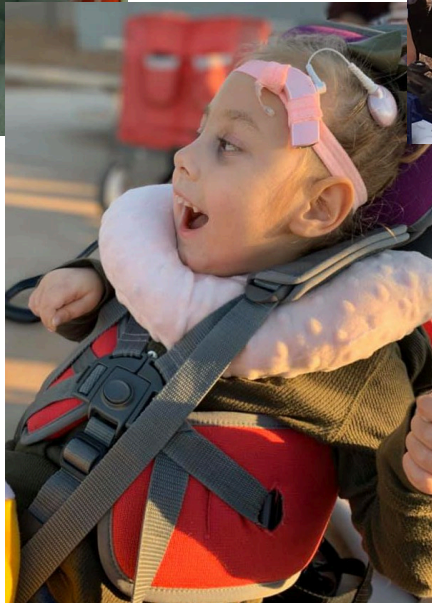
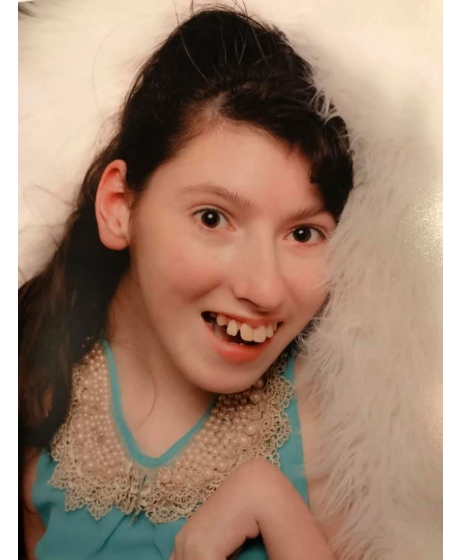
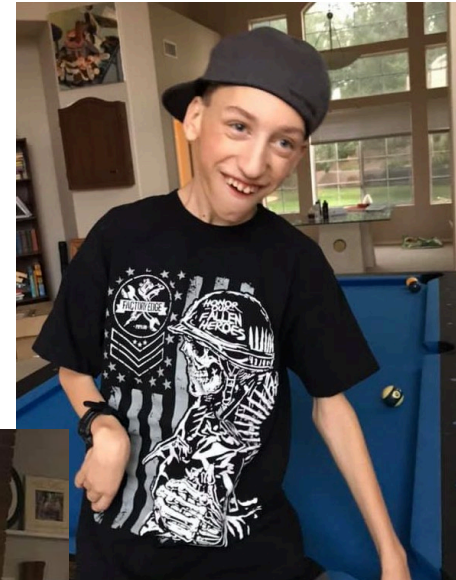
Medical educators/ students





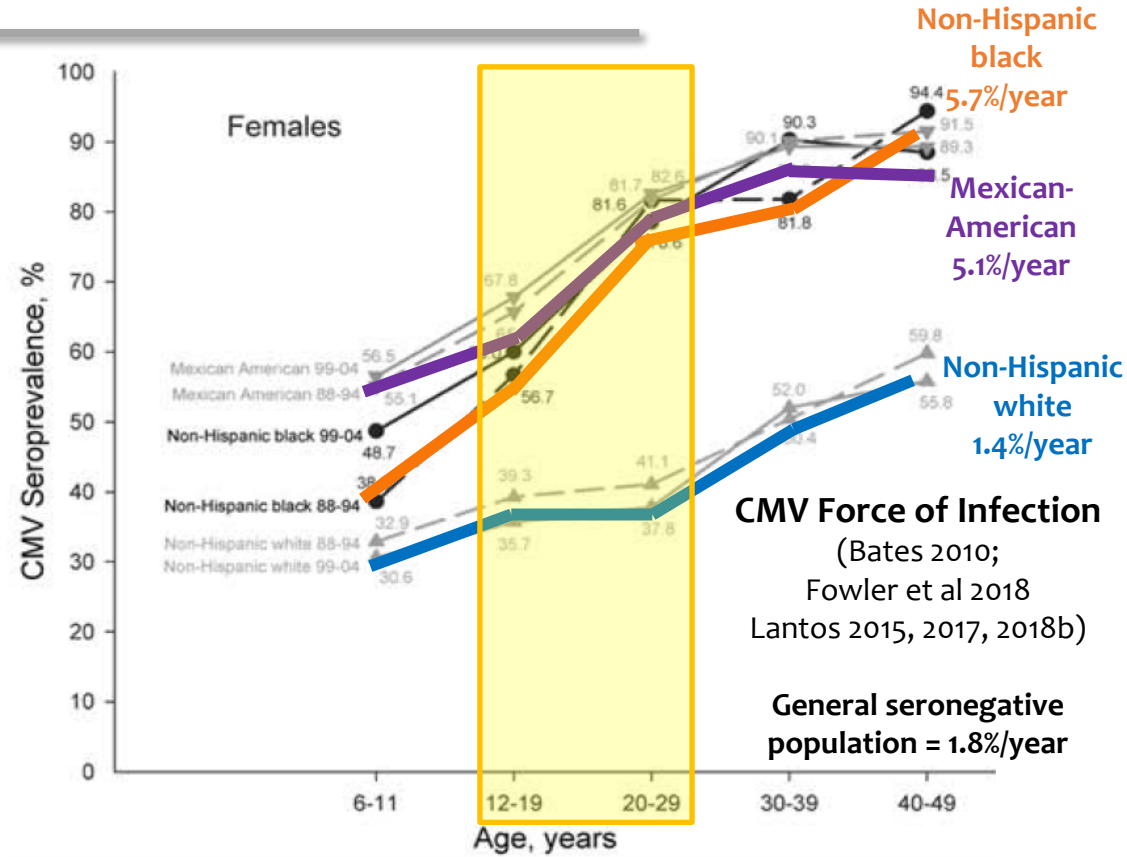
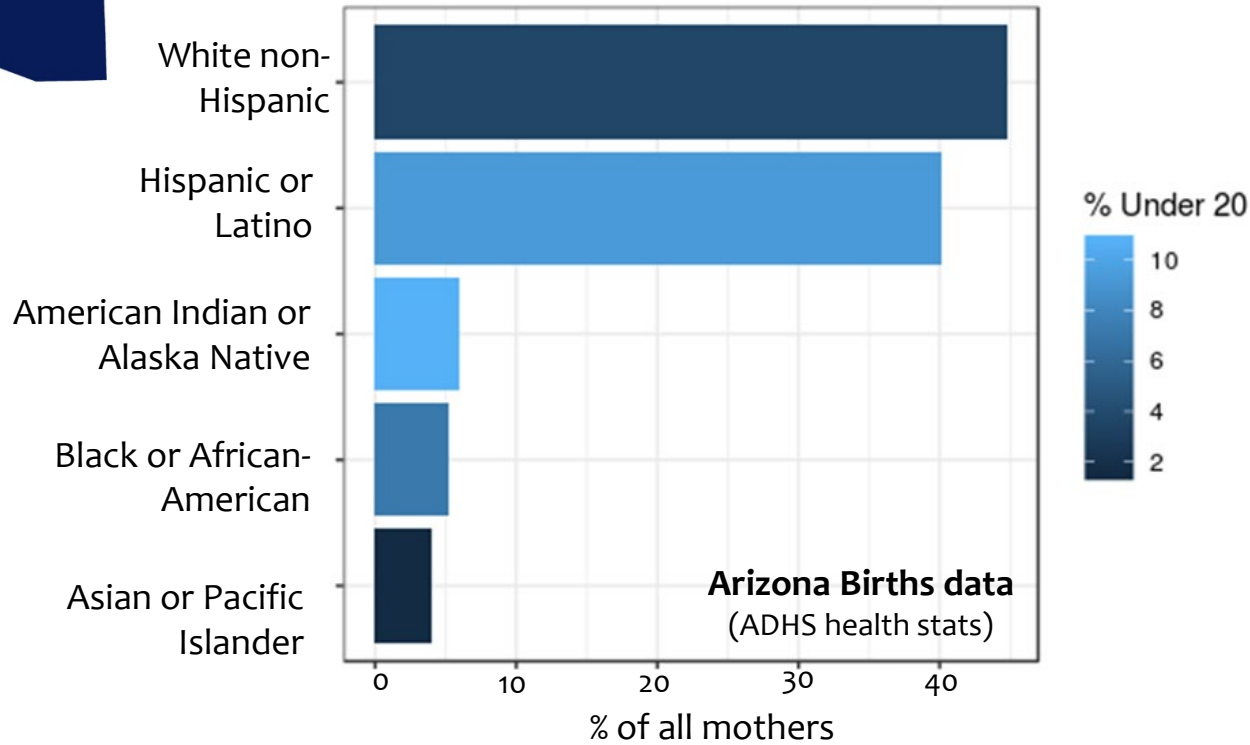
cCMV: Facts & Figures for Arizona

- 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.





cCMV: Facts & Figures for Arizona



In AZ (2020):

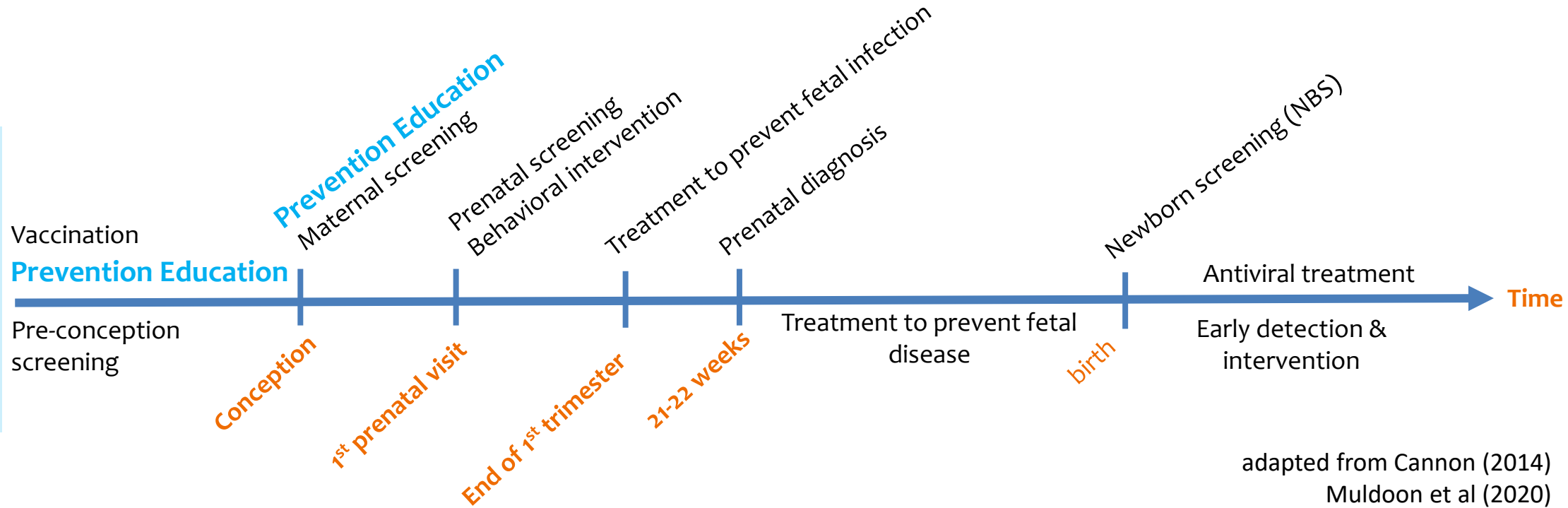
- ~55% of live births within communities of color
- greater proportion of births within communities of color are to **young mothers (<20 years of age)**

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

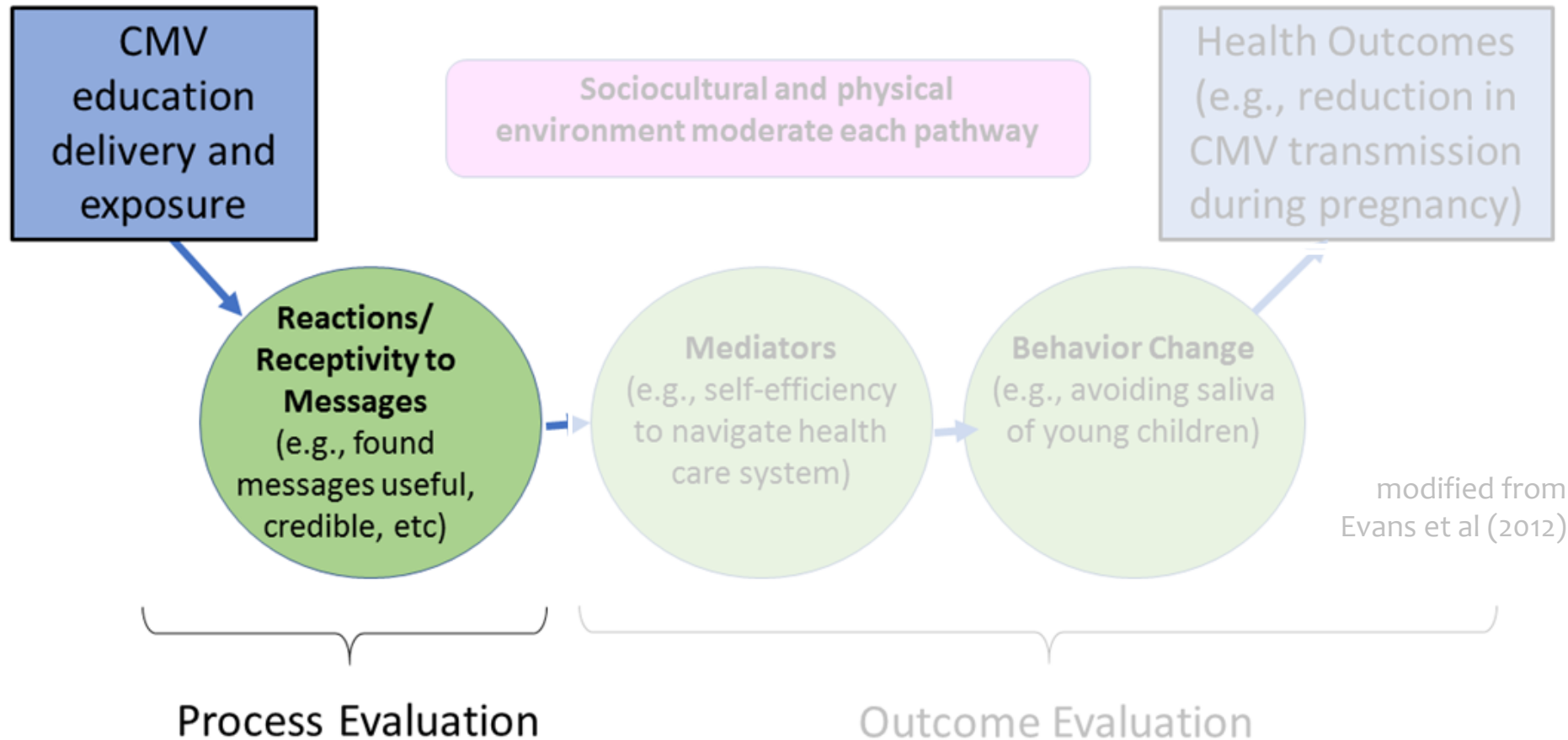


Currently, none of these interventions are routine in Arizona or in the US



Development and Field Testing of cCMV Education Materials

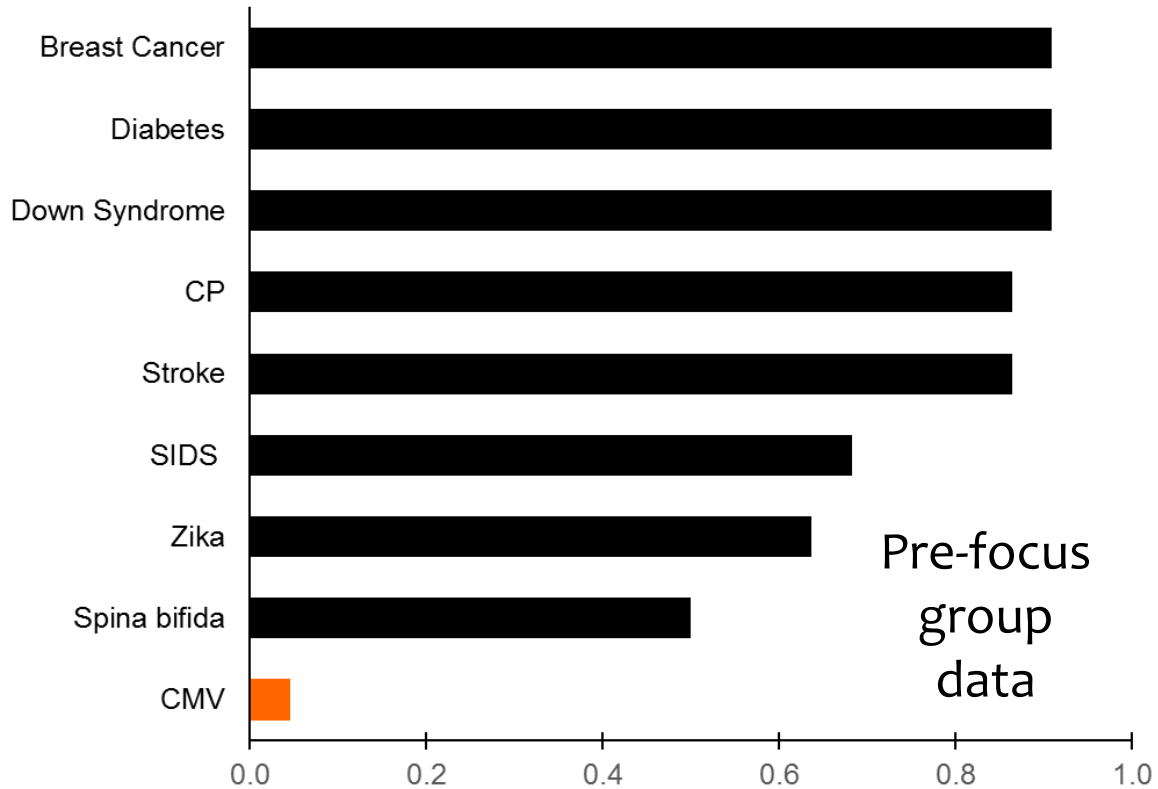
- To **increase awareness and health-risk knowledge of cCMV** in Arizona in order to affect behavior change amongst women of child-bearing age that will **reduce its impact** on all populations, especially marginalized groups





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%)



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)

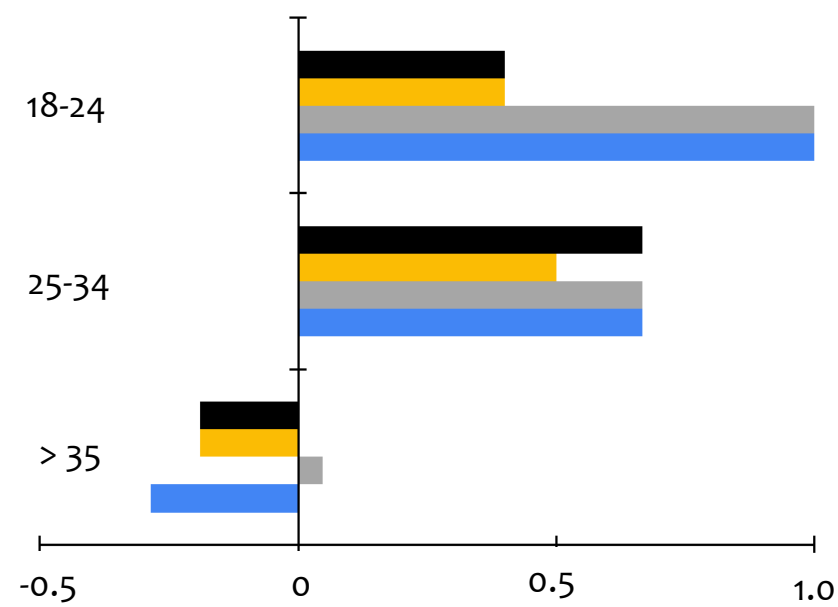
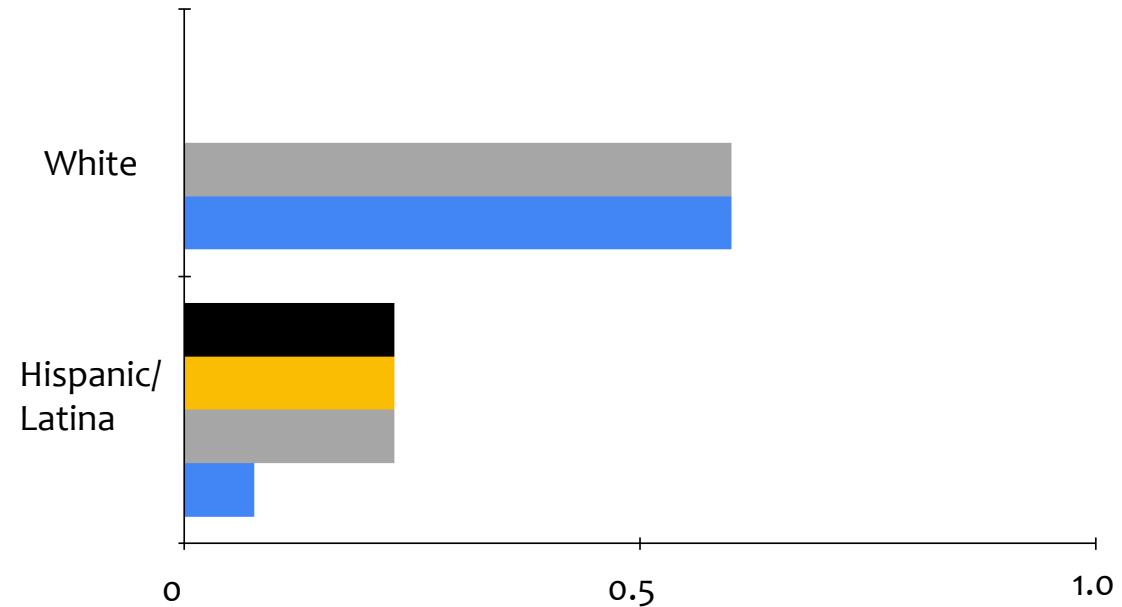


Receptivity to CMV prevention messaging

“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)?



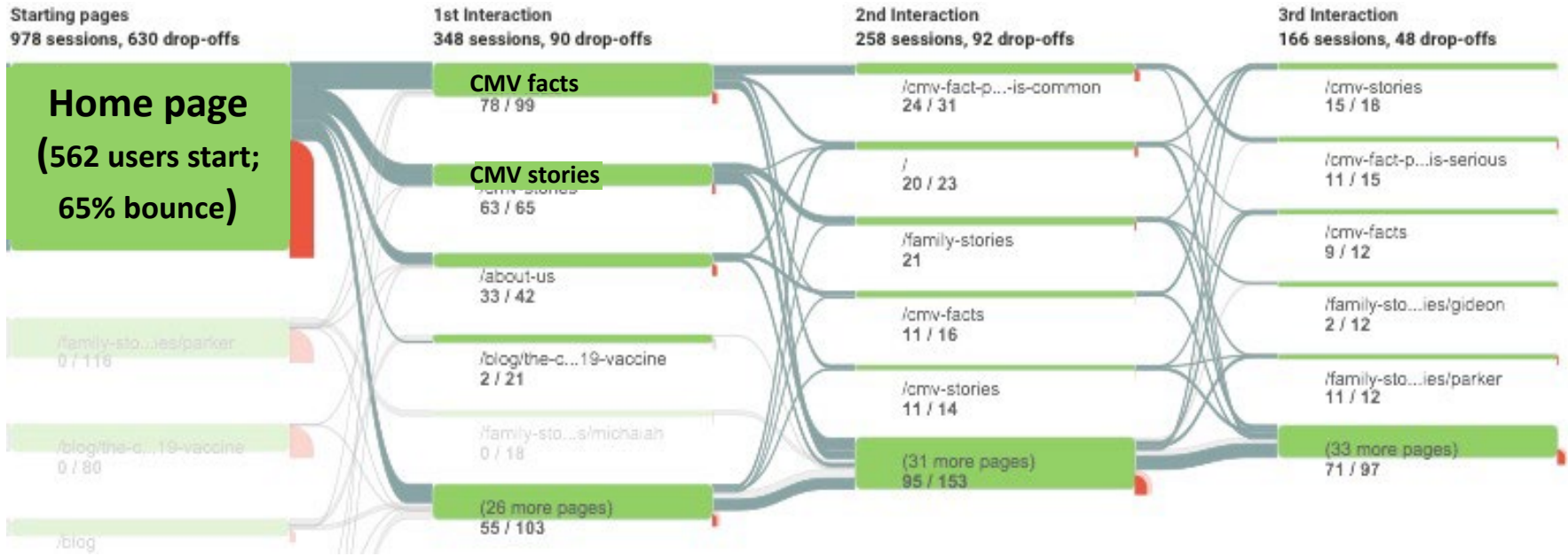
Our website is now live!



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



Learn how to make a difference.
stopcmvaz.org

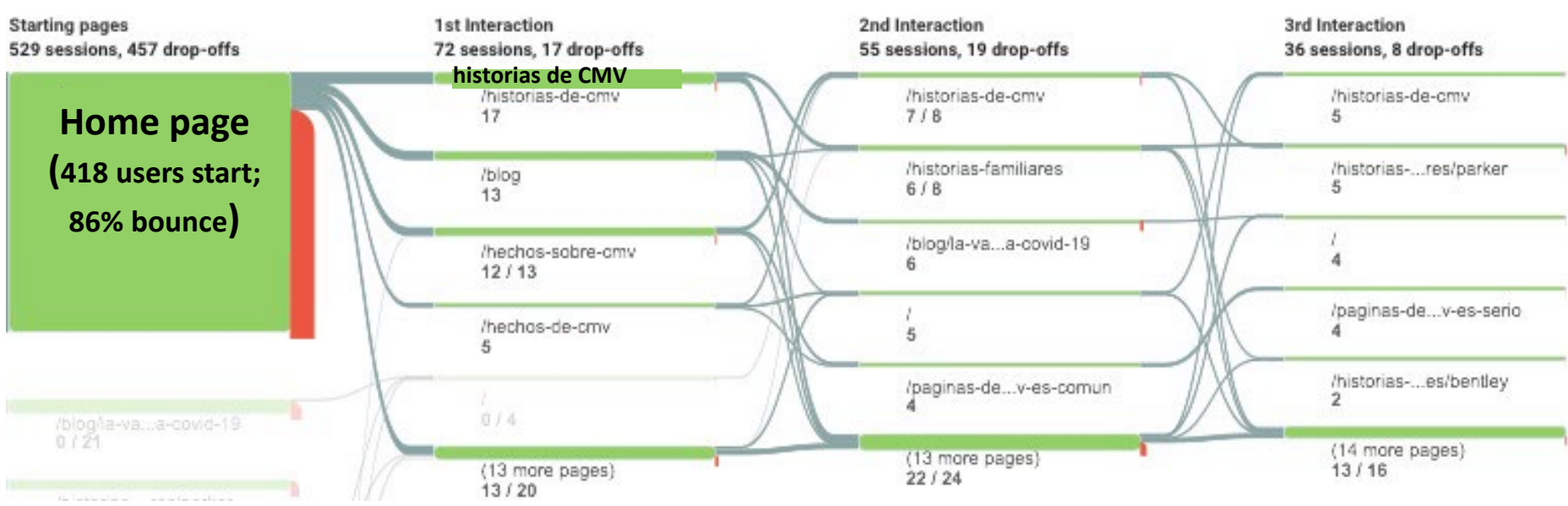


Website analytics,
 Dominik Kaltenbach
 (MWU AZCOM,
 MS III)

¡Queremos anunciar que nuestro sitio web está activo!



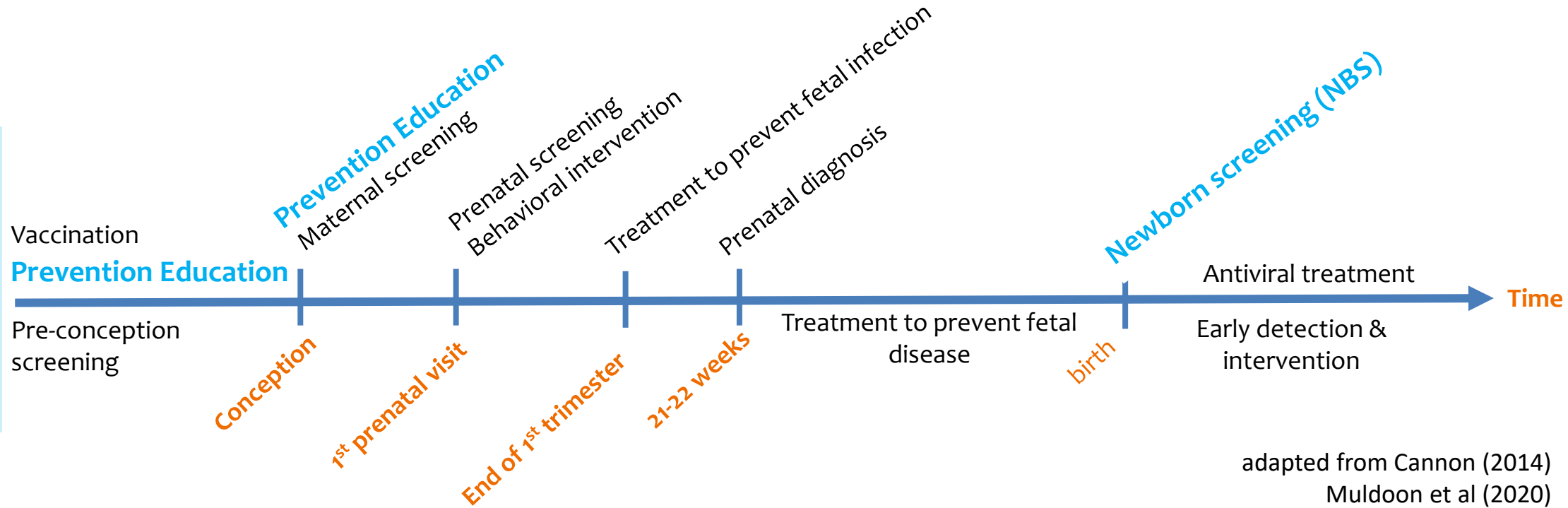
El CMV es el virus más común que puede dañar al bebé en desarrollo durante el embarazo. Aprenda cómo marcar la diferencia en altocmvaz.org

Website behavior flow and interactions June 1st 2021 to March 31st 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



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



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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



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Strengthening partnerships to promote healthier pregnancies and family empowerment.

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



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Strengthening partnerships to promote healthier pregnancies and family empowerment.