

Addressing the Gaps – Knowledge Among Families Affected by cCMV

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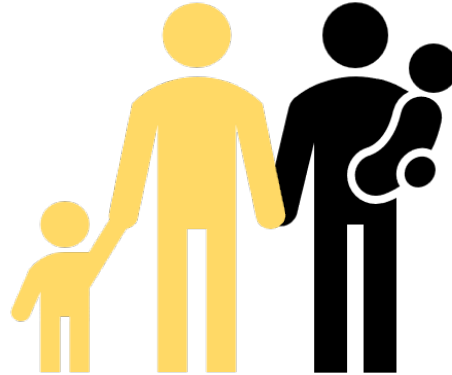


Dedicated to CMV Mommies

A Blessing for Befores and Afters
- Kate Bowler

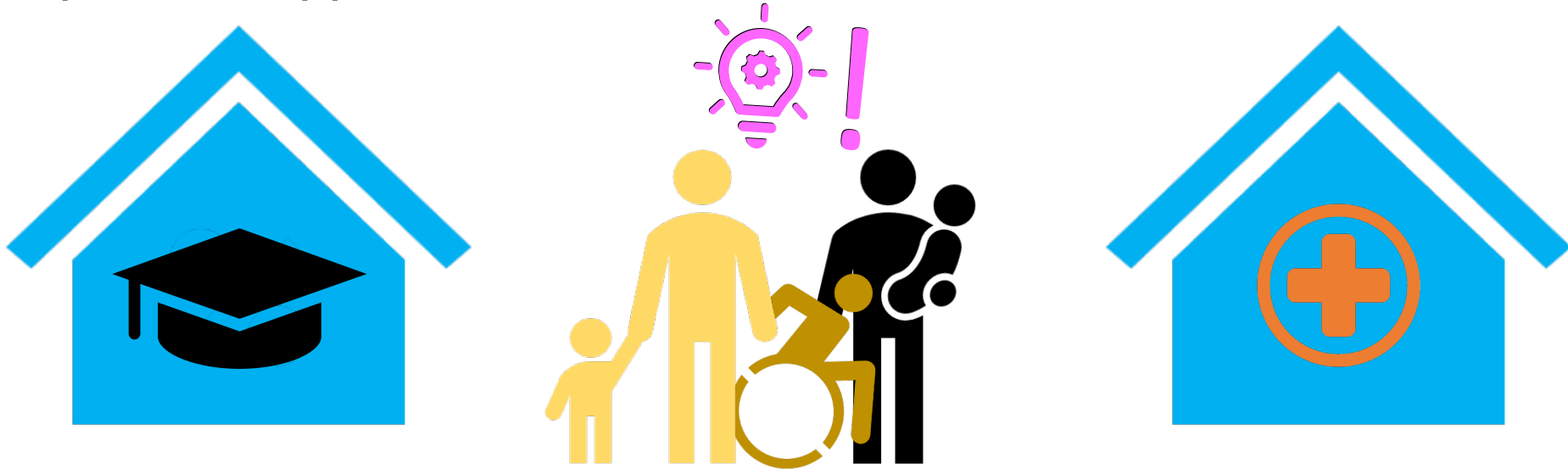
What does *advocate* mean?

- *noun* - a person who publicly supports or recommends a particular cause or policy
- *verb* – to publicly support or recommend



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In most cases, caregivers enter the arena of disability with no previous medical knowledge.

- **Health literacy** - an individuals' skills in obtaining, understanding, communicating, and applying health information to successfully navigate the health management process.

The role of advocacy in parenting a child born with CMV is heightened because caregivers interact with a network of service agencies and healthcare professionals that are likely to have limited knowledge of cCMV.

Study Objectives

- To examine the role of caregiver health literacy in relation to communications with health care professionals, and ability to navigate healthcare services.
- Long-term goal - to focus on the learning curve that caregivers experience as they gain mastery over biomedical facts, care-related roles, and rights and responsibilities that come with parenting children with disabilities.
- **Aim 1:** to collect data on caregiver knowledge of congenital CMV.

Learning Objectives:

1. Discuss CMV knowledge in families affected by cCMV
2. Address gaps in CMV knowledge, including prevention, screening and vaccine science
3. Identify how improved understanding of CMV among families affected by cCMV will improve public health outcomes

*This study was approved by MWU IRB (AZ1375)
This study was funded by Midwestern University (to KMM)*

Methods

- **Study population:** purposive sampling of “CMV Mommies” (Facebook support group)
 - 3.4K members
 - included only women caregivers (self-identified mothers, grandmothers, adoptive/foster mothers, legal guardians)
 - included only residents of the United States
- **Mixed methods - survey and interviews (analyzed using RStudio, NVivo)**
 - anonymous 39 question, 30-minute survey
 - participant demographics,
 - general description of family member affected by cCMV,
 - general awareness of several chronic and acute health conditions,
 - specific knowledge of cCMV (transmission, clinical outcomes, treatment),
 - source of participant knowledge of cCMV,
 - impact of cCMV on the affected individual,
 - experiences of the caregiver with the healthcare system.
 - Survey Monkey
 - \$10 gift certificate via Rybbon
 - June-August 2020

Results – Participant Demographics

- **Total sample size (N): 1475 participants** (Q-specific N ranged from 1377-1475)
 - *represents hundreds of thousands of response items!*

Age: 25-34 (N=422, 28.6%)
35-44 (N=636, 43.1%)

**Age when child
with cCMV born:** 25-24 (N=551, 37.4%)
35-44 (N=492, 33.4%)

Employed Outside N=1312, 89%

of Home:

- Full time (N=1056, 71.6%)
- Part time (N=256, 17.4%)

- Stay at home (N=59, 4.0%)

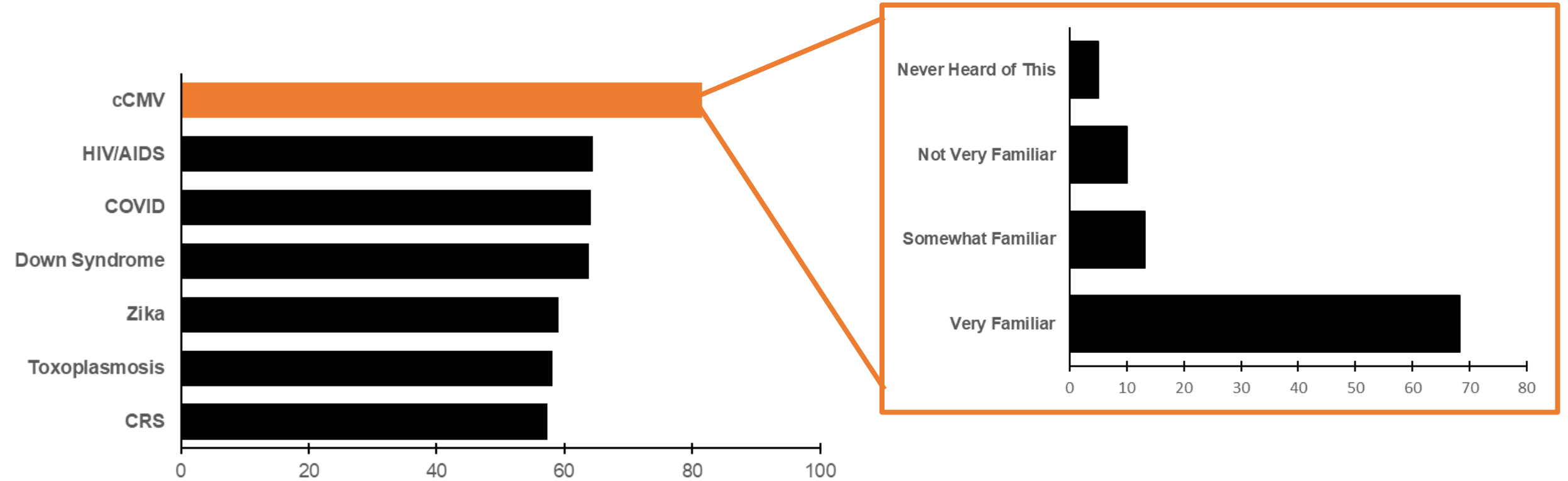
Ethnicity: White (N=781, 56.64%)
Black/African American (N=373, 27.1%)
Hispanic/Latinx (N=169, 12.3%)

Asian (N=67, 4.9%)
Native American (N=45, 2.6%)
Native Hawaiian (N=36, 2.6%)

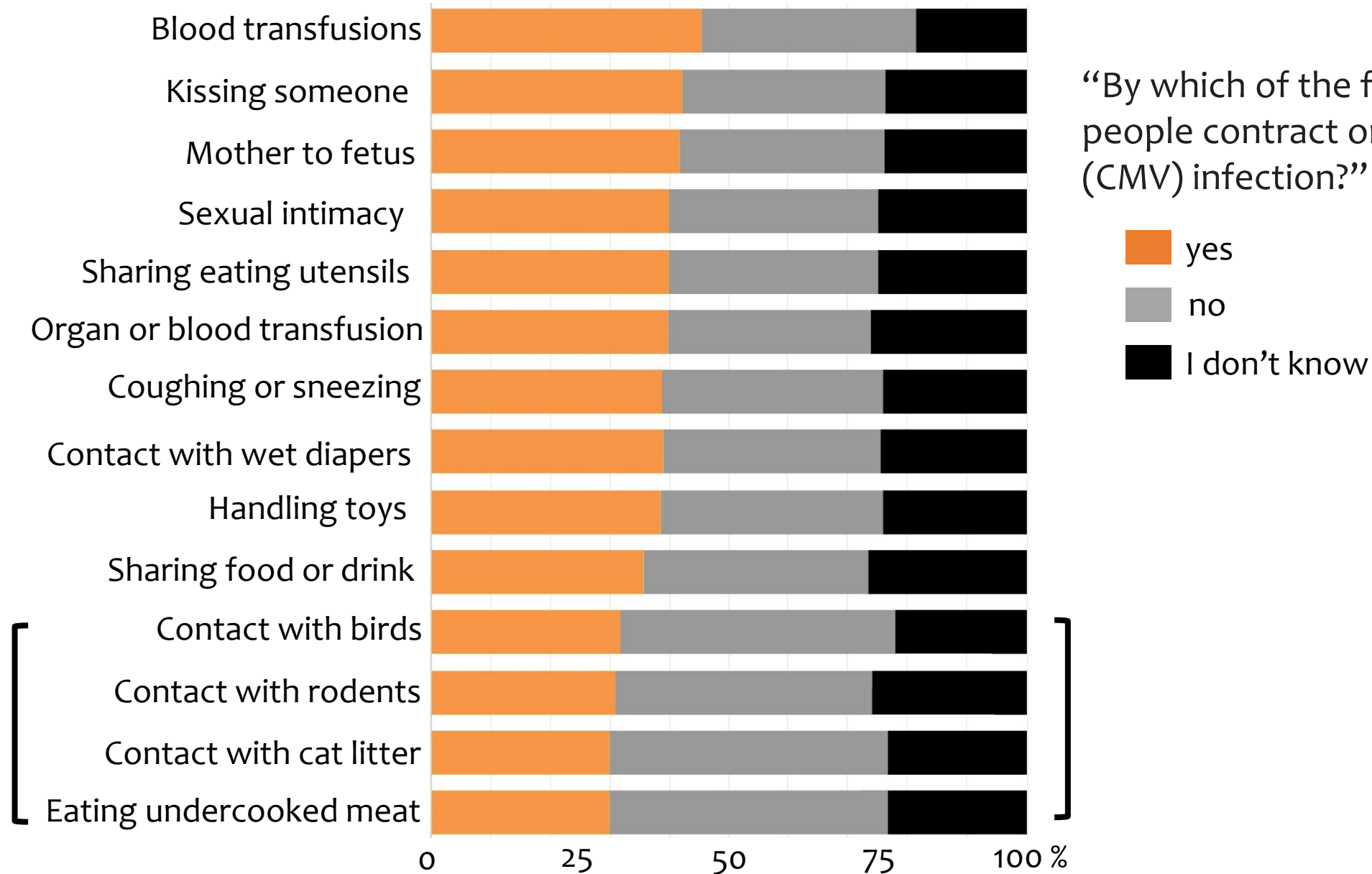
**Current Source of
cCMV Information:**

- Social media (N=408, 29.4%)
- Internet (N=393, 28.3%)
- PCP (N=335, 24.1%)
- TV/radio (N=282, 20.3%)
- Friends (N=277, 20%)
- OB/GYN (N=247, 17.8%)

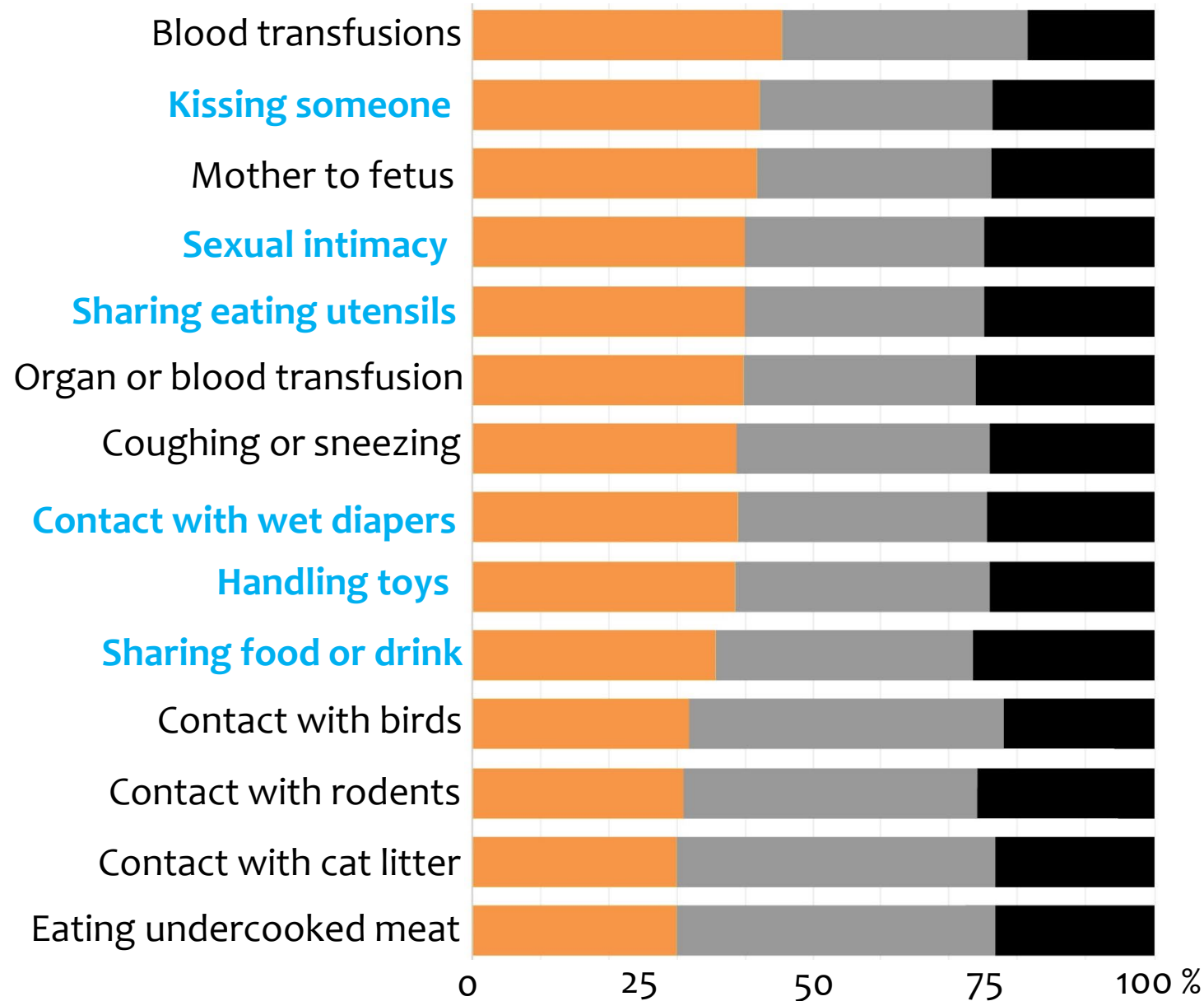
Self-reported familiarity



CMV transmission



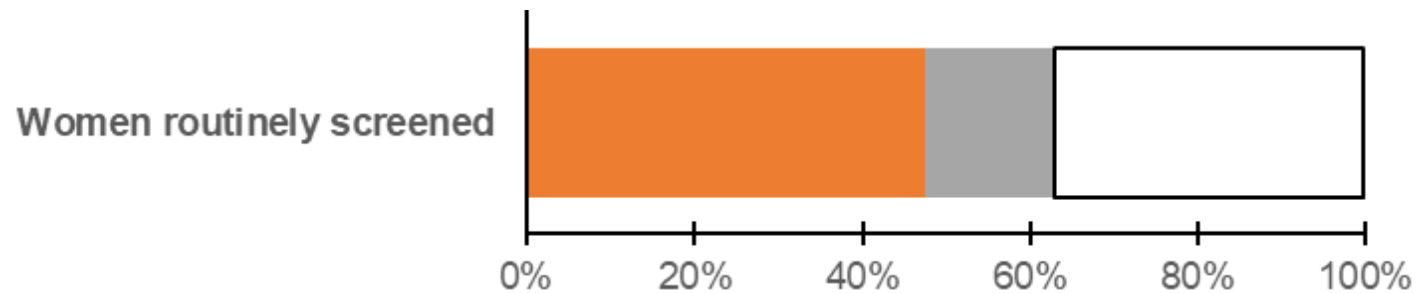
CMV transmission



“By which of the following behaviors can people contract or spread cytomegalovirus (CMV) infection?”



Screening programs



“Are women routinely screened for cCMV?”

- yes
- no
- I don't know
- in some cases

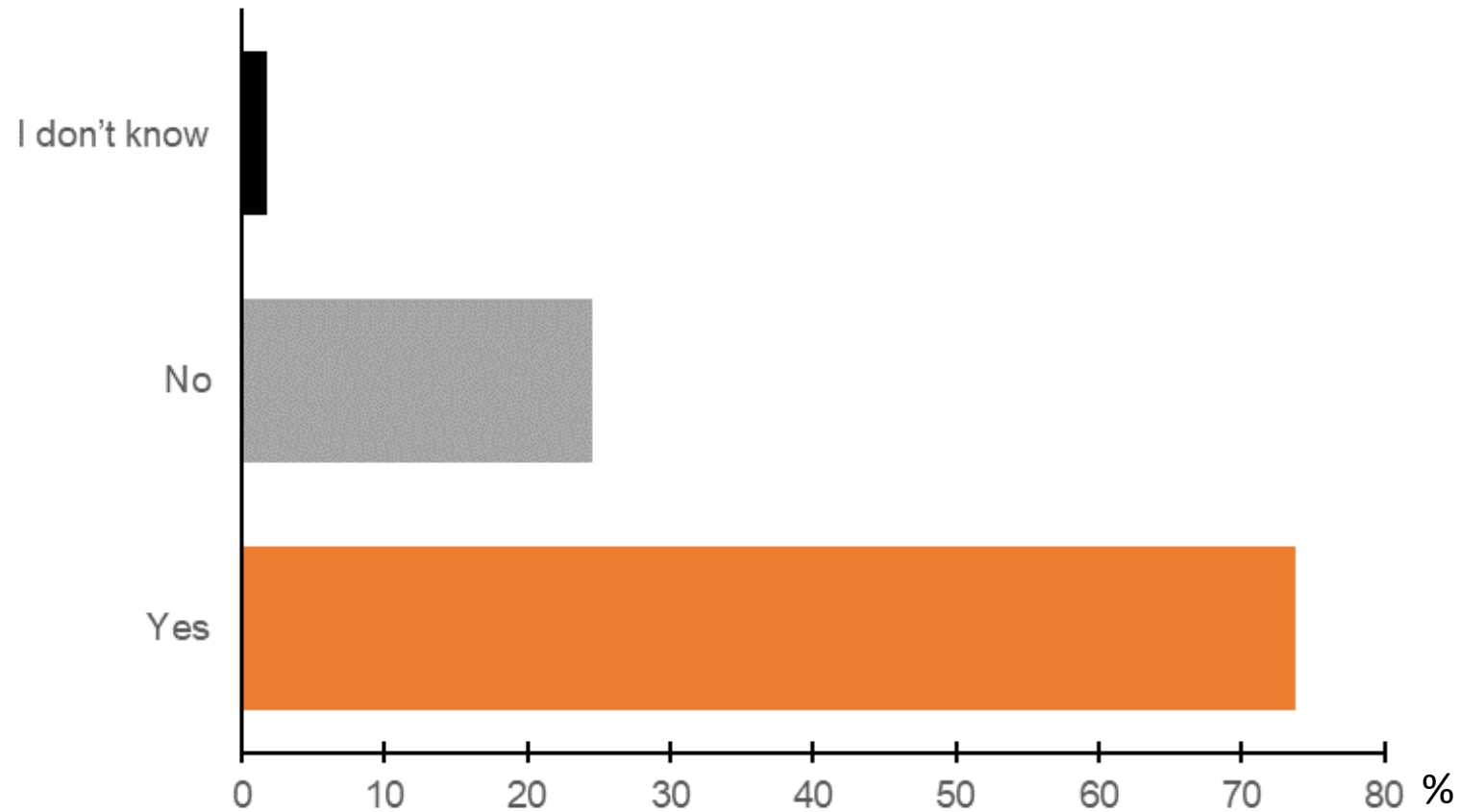
64% - Multiple sexual partners

62% - ART/IVF

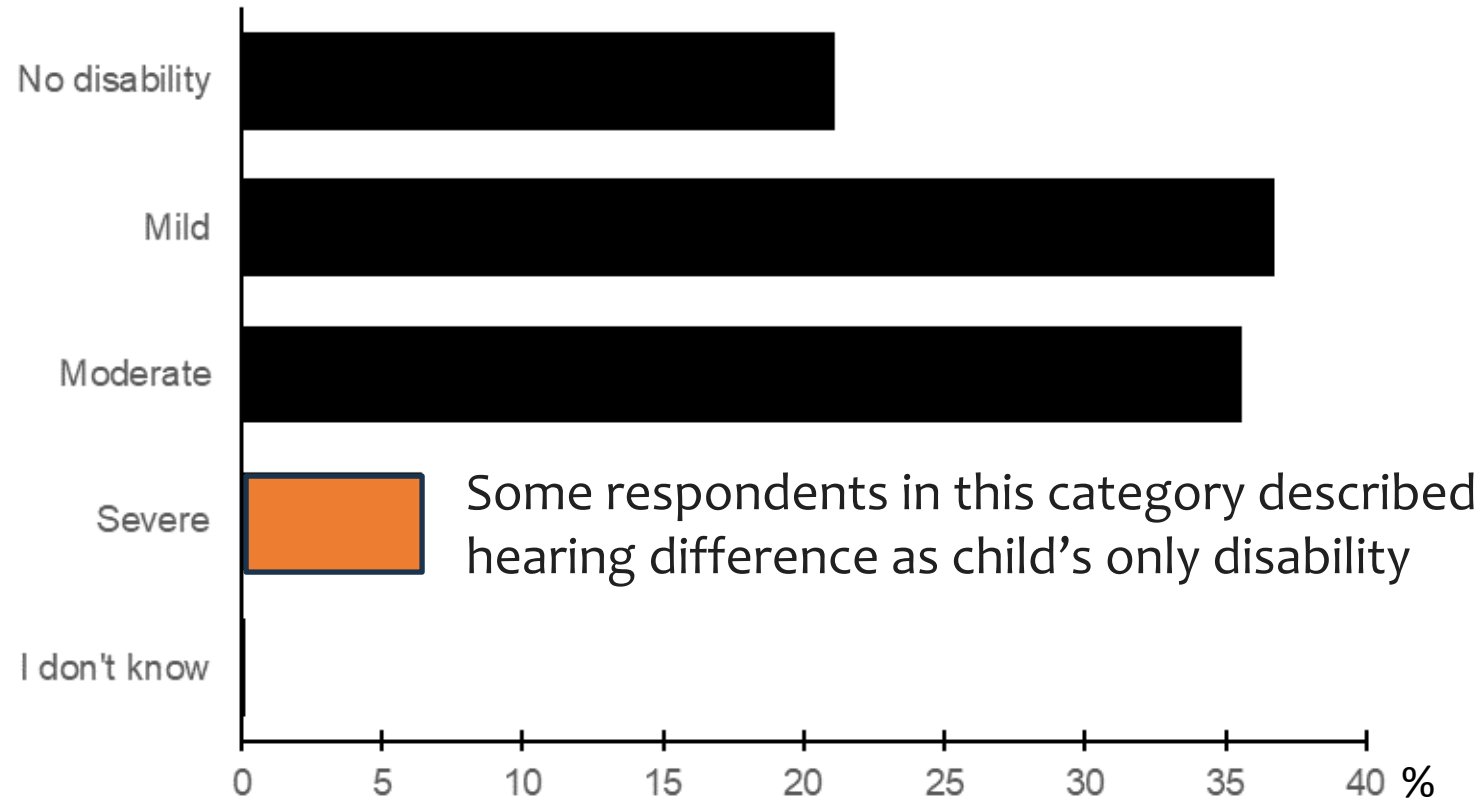
61% - All women

56% - Women with >1 child

Is there a licensed vaccine to prevent cCMV?



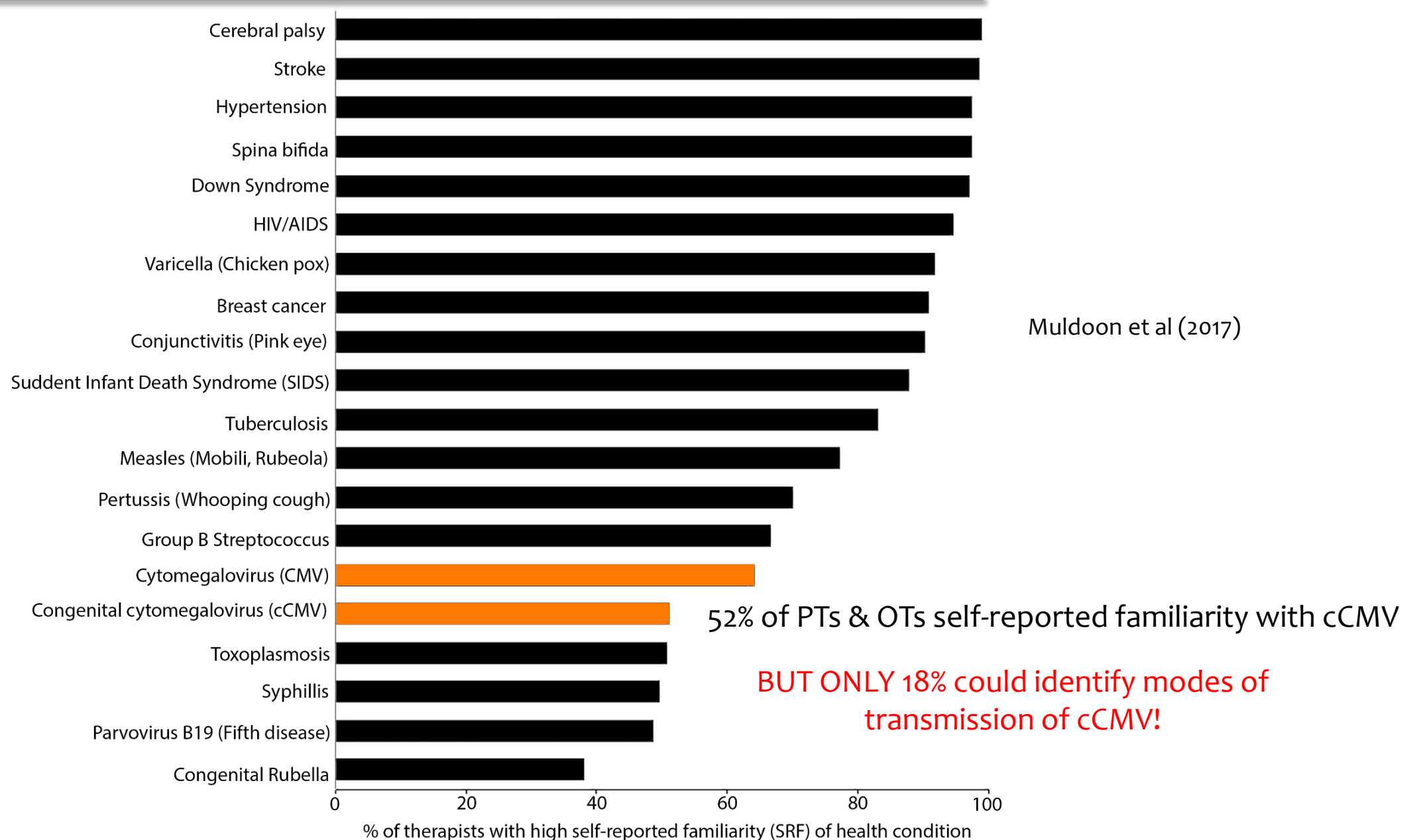
How would you describe the level of disability for your child or other family member who was diagnosed with congenital CMV?



Discussion

- Our study establishes a baseline of caregiver knowledge about CMV and identify gaps that can be addressed with educational materials.
- Although participants self-reported high levels of familiarity with CMV, significant knowledge gaps exist
 - Important to be mindful of the discrepancy between **self-reported familiarity** (“awareness”) and demonstrated understanding of **health risk knowledge** (Muldoon et al 2017, Muldoon and Dobson 2018)

Reminder: Self-reported Familiarity (SRF) vs. HRK of cCMV

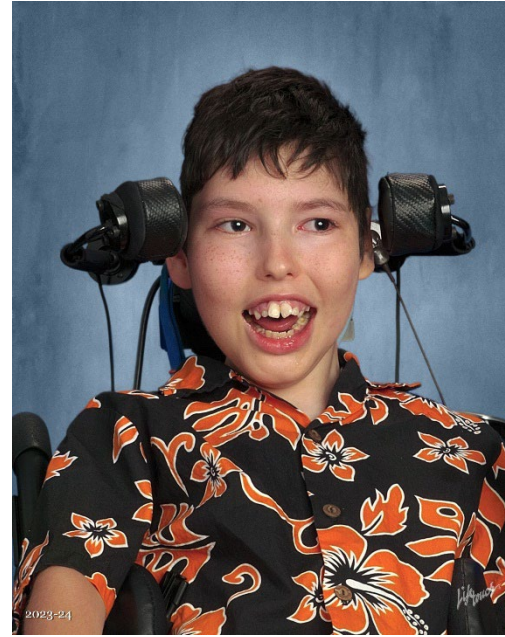


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 - Important to be mindful of the discrepancy between self-reported familiarity (“awareness”) and demonstrated understanding of health risk knowledge (Muldoon et al 2017)
- These gaps are opportunities for education of caregivers
 - role of social media
 - role of Community Alliance Chairs (NCMVF parent partners) in local communities
 - role of Scientific Advisory Committee (NCMVF)
 - Importance of community-level engagement with families (Guide by your Side)

This work is ongoing

Thank you



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- National CMV Foundation
- Utah State University
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