Parents' Knowledge and Attitudes About CMV Screening in Utah

Marissa Diener, PhD

Associate Professor, Family & Consumer Studies

Albert Park, MD

Chief Pediatric Otolaryngology

University of Utah

Disclosures:

- NIH U01 PI CMV multi-institutional study (Park)
- NIDCD R01 co-I Cochlear Implantation (Park)
- Valganciclovir – not FDA approved for congenital CMV

Acknowledgements:

- Stephanie Browning McVicar, AuD, CCC-A
- Jill Boettger, MS, CCC-A/SLP

OTHERS????

Utah Legislative Efforts:

Utah CMV Public Health Initiative (July 2013):

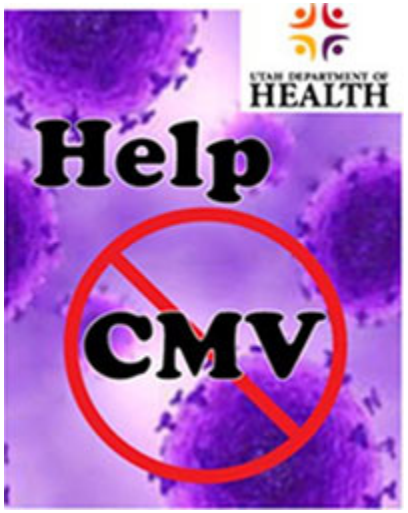
- DOH create education program about birth defects associated with and ways to prevent cCMV
- Annual budget $30,000
- Targets women of childbearing ages, child care and health care providers
- Infants fail NBHS be tested for CMV within first 3 weeks of life

Utah CMV Public Health Initiative (July 2013):

- 21-day period –differentiate cCMV from postnatally acquired CMV
- Rule (R398-4) – eligibility criteria for CMV screening
- Fail both inpatient **and** return outpatient screening or
- Fail first hearing screening if occurs after age 14 days

Utah CMV Public Health Initiative (July 2013):

- Testing designed to identify cCMV infants with hearing impairment
- Special populations(e.g. NICU), testing for cCMV left discretion of medical provider



What do parents know and how do they feel about CMV screening?

- One objection to CMV screening is parent anxiety

- Also interested in what parents know about CMV for prevention

Attitudes towards CMV Screening

- 2009 national survey (HealthStyles, N = 1589 parents of child younger than 19 years)
  - 84% would want to have newborn tested even if not performed routinely
  - 87% would want newborn tested if they had to pay $20
  - 84% would want to know “if my child has CMV even if he or she never develops problems”
  - 47% “would worry that CMV test would lead to unneeded doctor visits and expenses”
  - -32% “think CMV problems are too rare to think about”

Din et al. Attitudes Toward Newborn Screening for CMV. *Pediatrics*. 2011.

Attitudes towards CMV Screening

3 clusters of parent respondents:

- strongly in favor (31%)
- moderately in favor (49%)
- weakly opposed (20%)

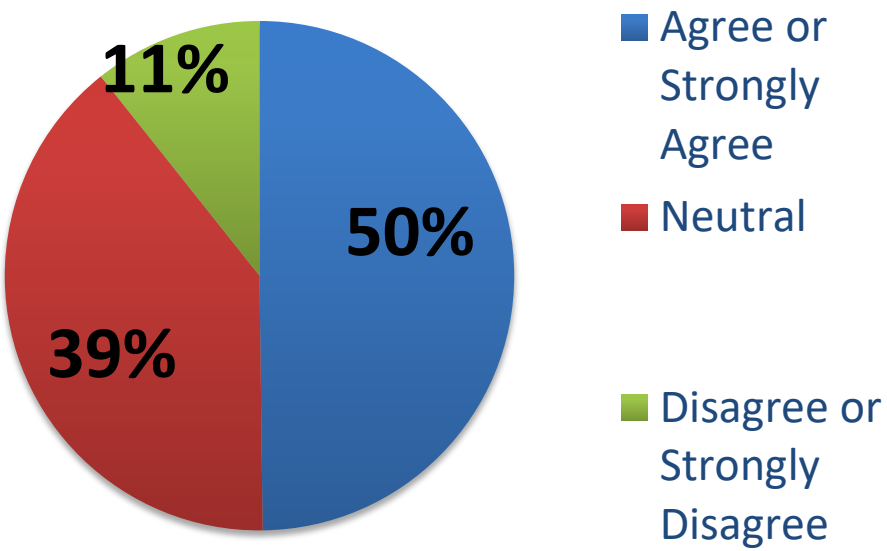
Din et al. Attitudes Toward Newborn Screening for CMV. *Pediatrics*. 2011.

Utah Survey

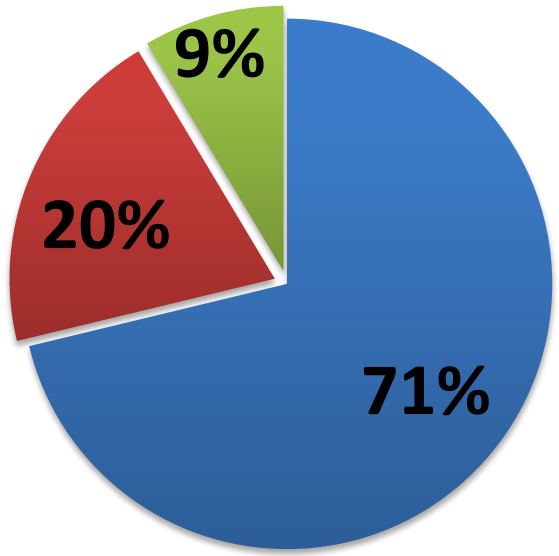
- *N* = 356 parents in ENT clinic (53% male children, M age = 27 months, range 2 weeks to 18 years; 65% 24 months or younger)

Attitudes about CMV Screening

“Would want to have my baby tested even if my doctor/hospital didn't do it routinely”

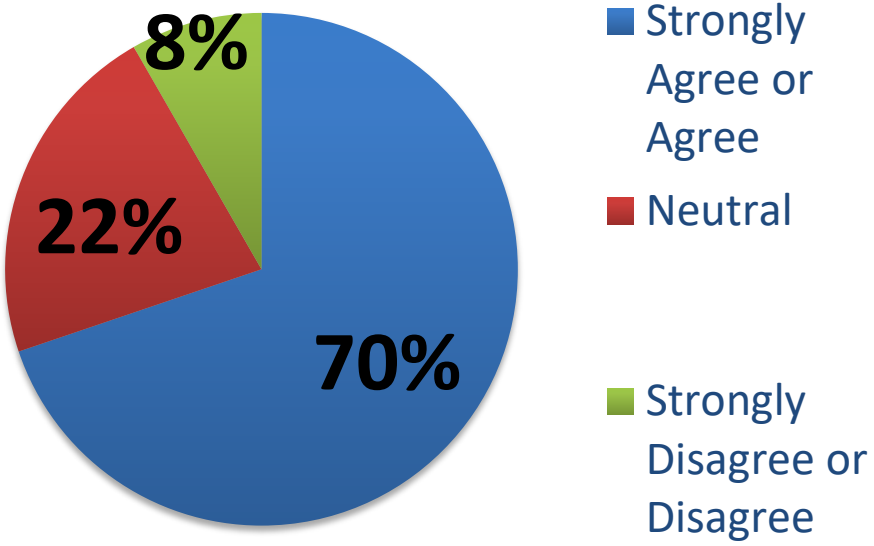


"Would want to know if my child has CMV even if he or she never develops problems

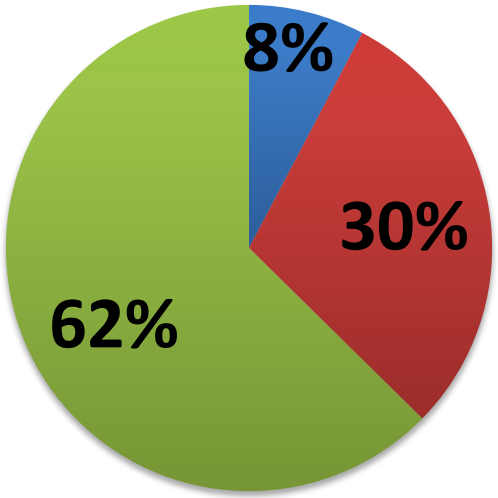


Attitudes about CMV Screening

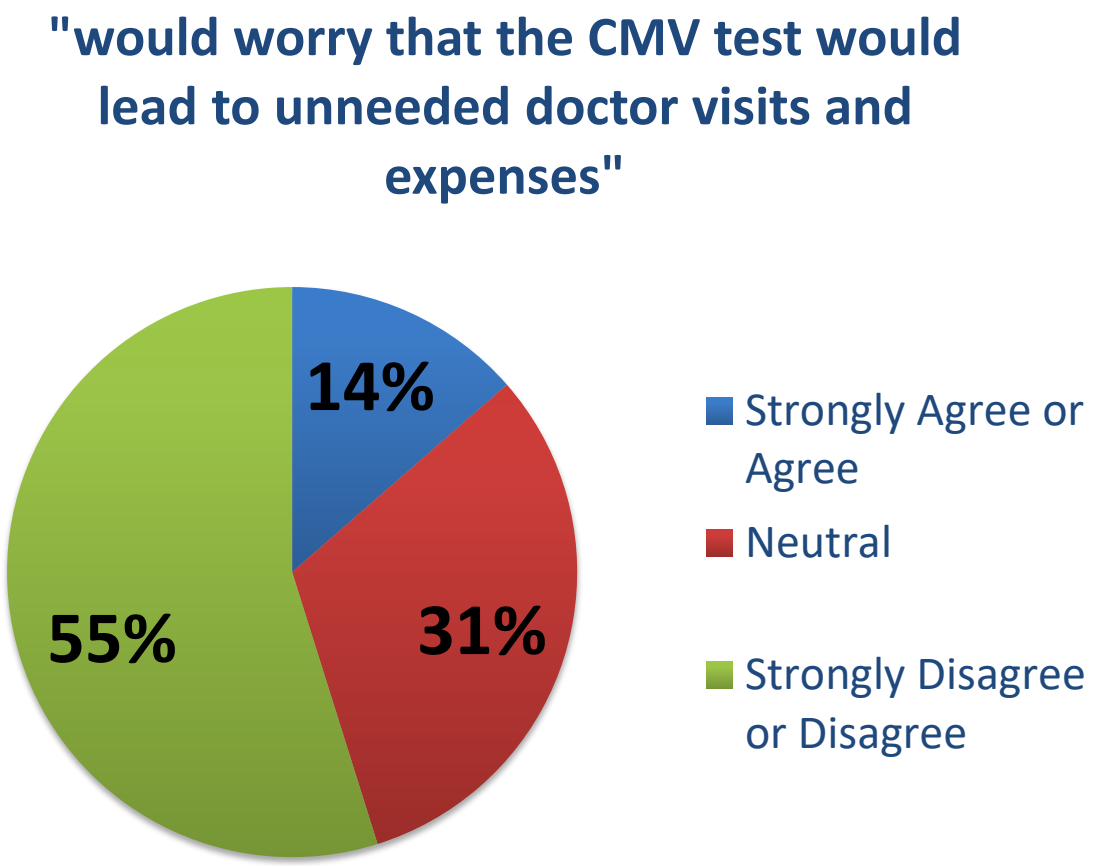
"Would be willing to pay $20 to have my baby tested for CMV"



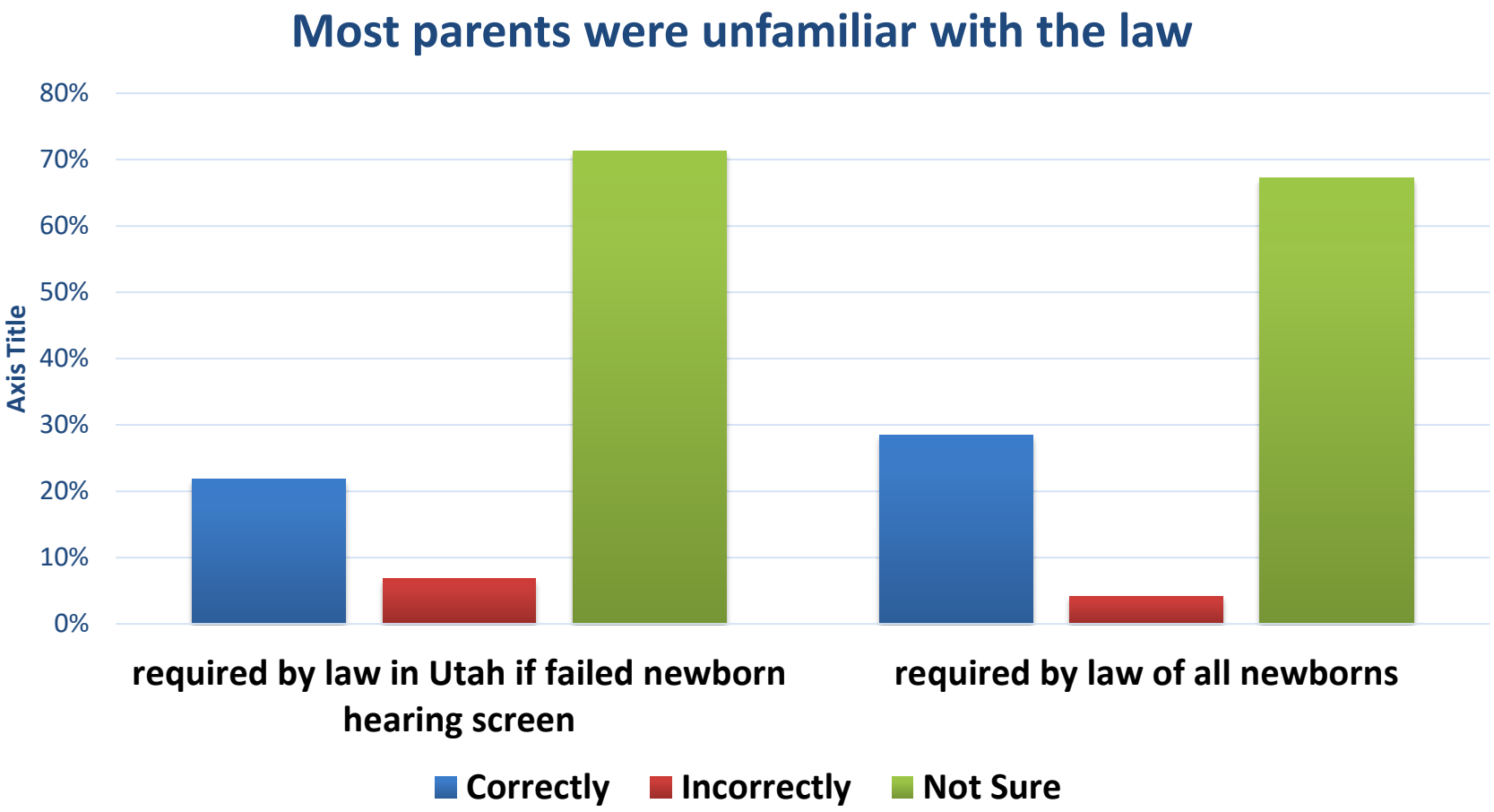
"Would be more worried about the stigma associated with a CMV diagnosis than about the health effects of CMV"



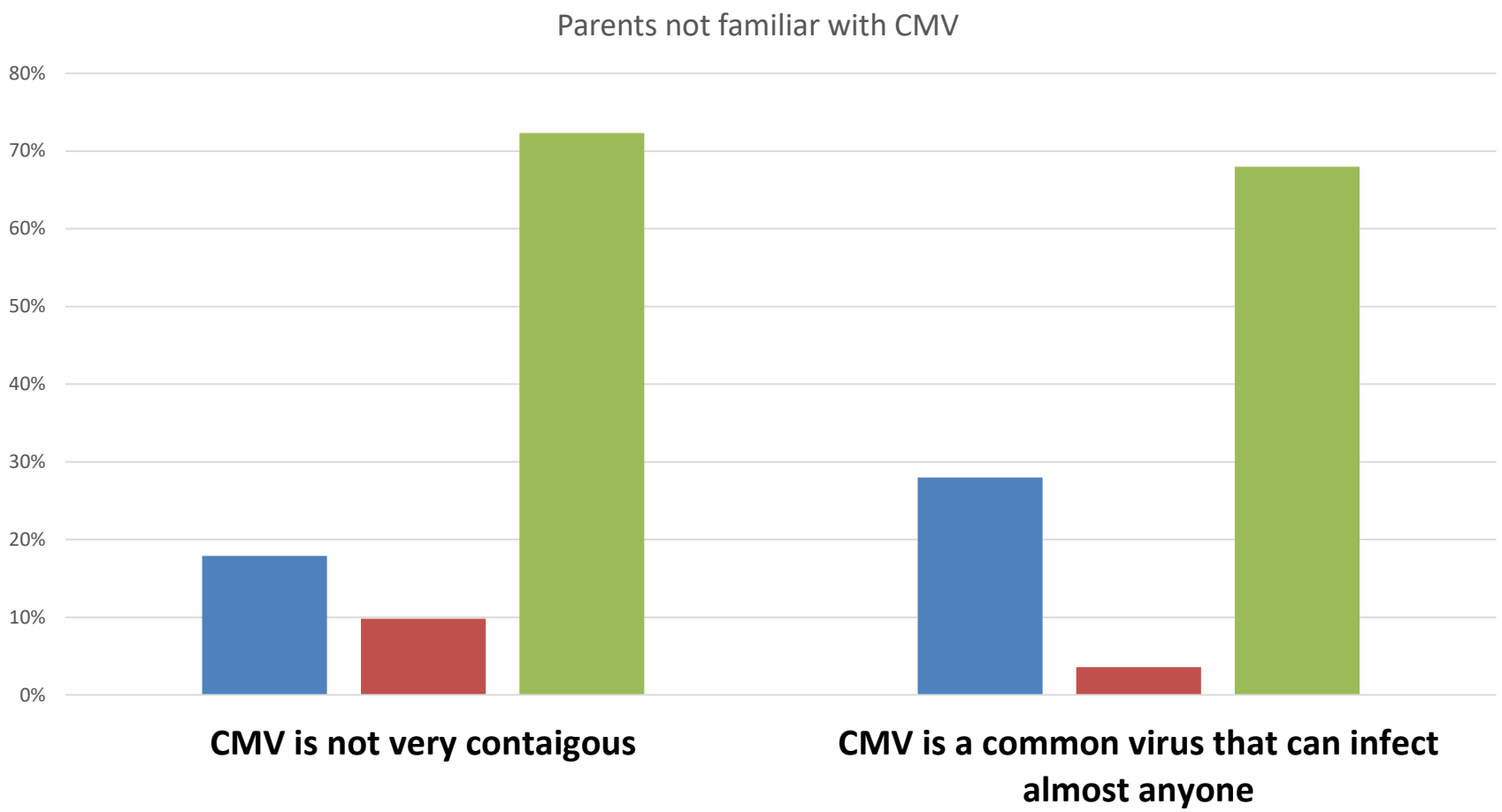
Attitudes about CMV Screening



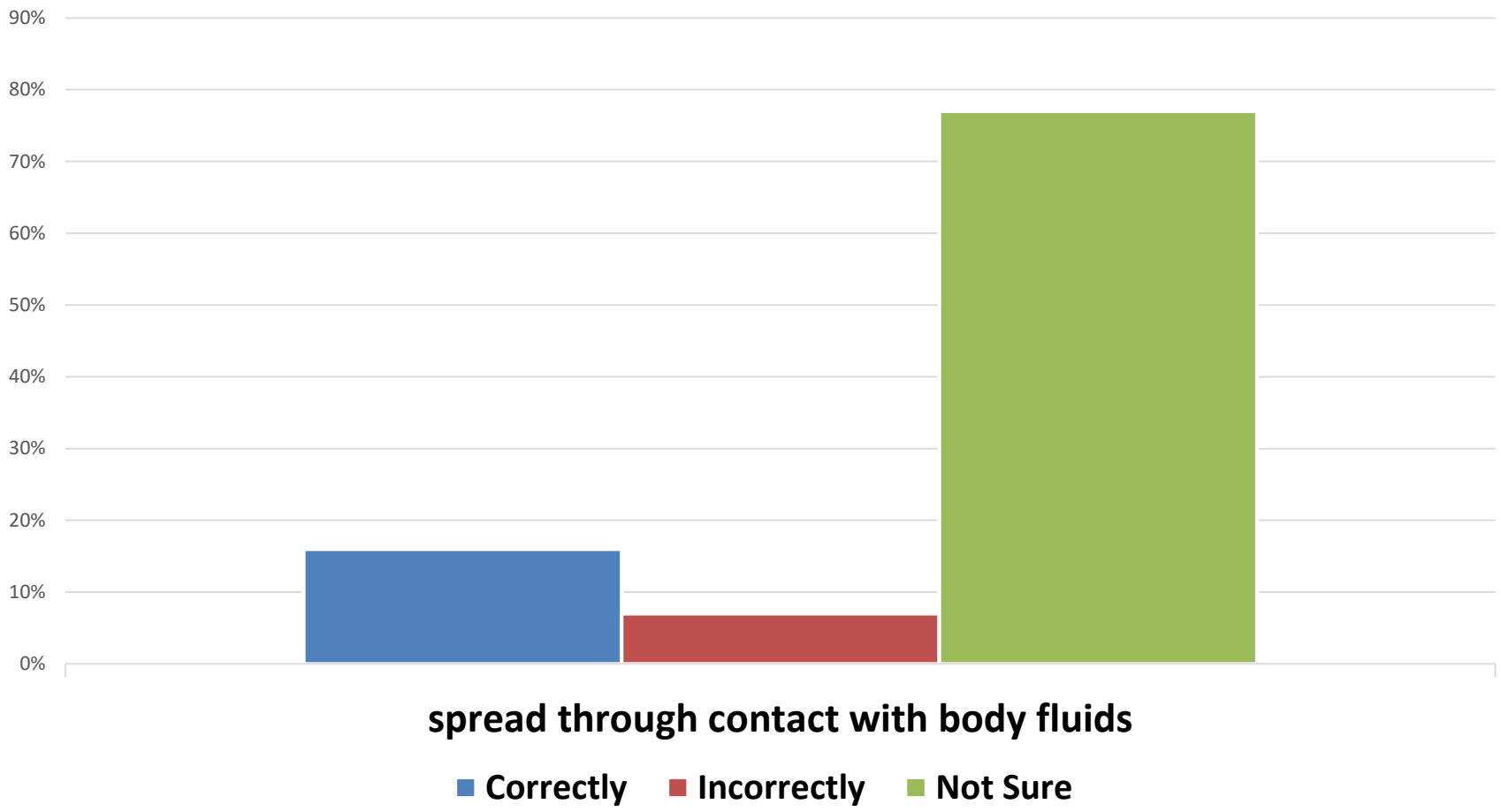
Parents' Knowledge of CMV Law



Parents' Knowledge of CMV



Parents' Knowledge of CMV



Is the Lack of cCMV Awareness in Utah Because we are not screening?

- What have been the results from the Utah mandate?
- Sociodemographic or health care characteristics related to compliance for CMV screening and diagnostic hearing evaluation

Methods:

- Data from Utah DOH early Hearing Detection and Intervention (EDHI) Tracking and Data Management System (HiTrack)
- Utah Vital Records database for births
- Evaluated period 24 before and after law

Methods:

- Descriptive stats on sociodemographic characteristics related to CMV screening and 3 month diagnostic audiologic milestone
- Multivariate logistic regression analyses assessed characteristics linked to CMV screening by 3 weeks of age and audiologic evaluation by 3 months of age

Summary of CMV Screening Outcomes:

- 234/509 (46%) underwent CMV screening within 21 days of age.. improved
- 14/234 (6%) tested within 21 days CMV +
- 6/14 (43%) – hearing loss

- 7/80 (8.8%) tested after 21 days CMV +
- 1/7 DBS +
- 3/7 (42.9%) – hearing loss

Impact HT-CMV Testing on Diagnostic Hearing Testing:

- Timely diagnostic hearing evaluation **56**% (2 years prior) and **77**% (2 years after law)!
- After the law, **86.6%** diagnostic hearing evaluation among CMV screened vs **61.5%** diagnostic hearing testing among non-CMV screened group
- **HT-CMV benefits not just CMV infected but ALL children who fail their newborn hearing screen**
- **Currently screening over 90%**

Diener M et al. Outcomes From a Hearing-Targeted Cytomegalovirus Screening Program. Pediatrics. 2017.

Awareness Results Similar Elsewhere:

- National Survey 4184 participants (2181 women; 2003 males)
- 2010 Health Styles Survey
- 7% males; 13% women heard of CMV
- Many women practiced high risk behavior at least weekly w youngest child:

Kissing lips (69%), sharing utensils (42%), sharing food (62%) and not washing hands after handling child's toys (74%)

Cannon M et al. Preventive Medicine, 2012

Awareness Results Better in Italy:

- Computer-assisted web questionnaire (Milan University, Italy)
- N=10,190 respondents
- 52.5% heard of CMV
- 31.8% know **congenital** infection
- < 50% know **symptoms** from CMV
- Hygienic measures known 55-75%

Binda et al. BMC Infect Dis 2016

Mothers' attitudes towards prevention behaviors

- Women amenable to hand washing and not putting pacifier in mouth

Women less positive about:

- not food sharing
- not kissing child on lips

Thackeray & Magnusson. Women's attitudes towards practicing CMV prevention behaviors. Prev Med Reports. 2016

Where to go from here?

- Excellent results from HT-CMV- providers
- Need to improve campaign on awareness to the public
- Prevention for now may be the key

Hygiene and its impact on primary CMV infection:

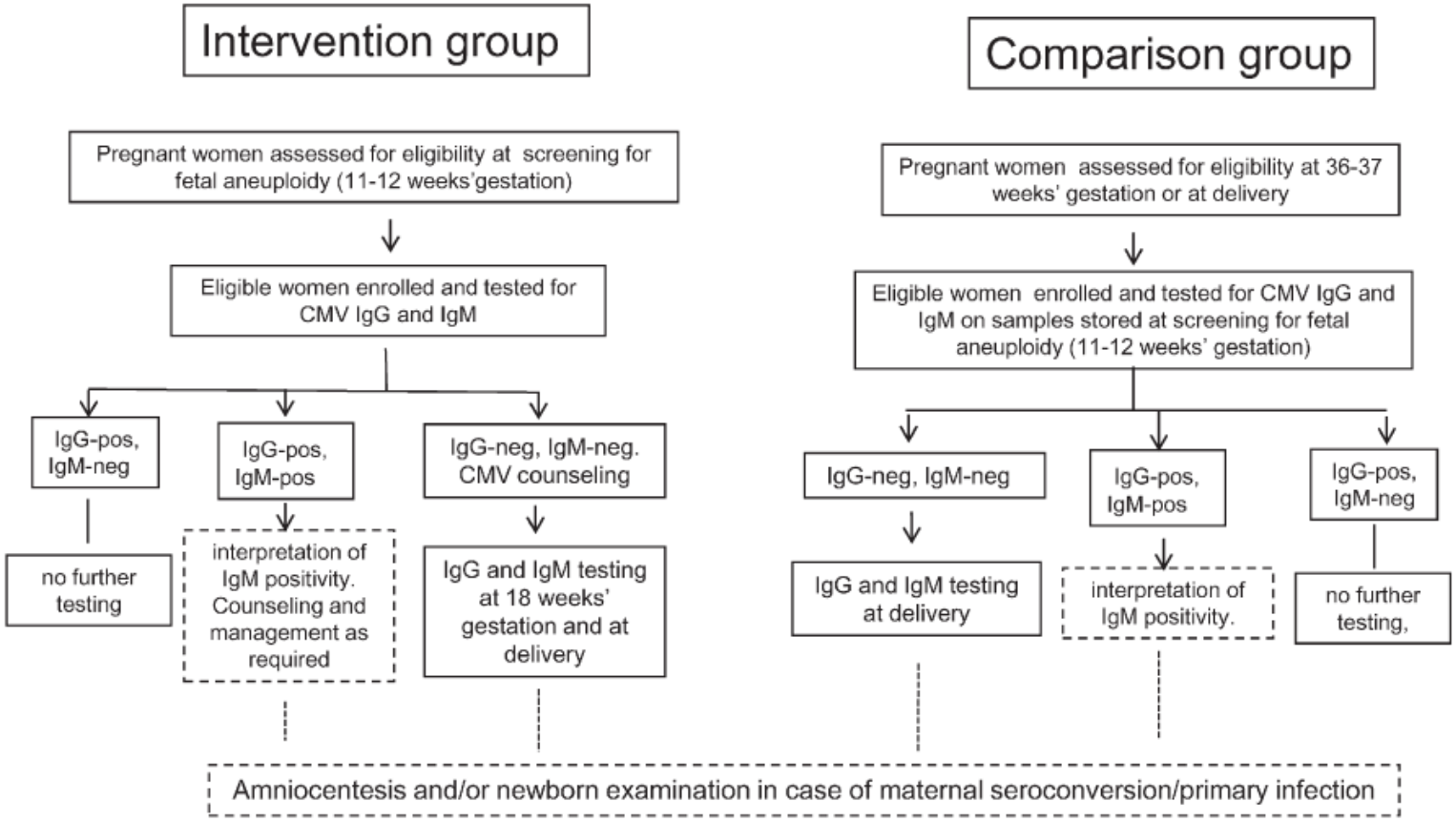
- Prospective study
- Pregnant patients informed of CMV and measures for prevention
- N=5312 seronegative initially
- 16 developed primary infection→ 3 newborns infected, one sCMV
- Rate lower than historical uneducated patients

Vauloup-Fellous et al. J Clin Virol 2009

Role Prevention:

- Protective measures relied on frequent hand washing, especially after exposure to a child's saliva or urine (e.g., diaper changes, handling dirty laundry, touching the child's toys, etc)
- Avoid intimate contact with young children (e.g., kissing on the mouth, sleeping together, sharing washcloths, utensils, food or drink, etc.)
- Counseling provided by obstetricians or midwives at the first general visit, and lasted about 5–10 min.

Role Prevention



Revello et al. EBioMedicine 2015

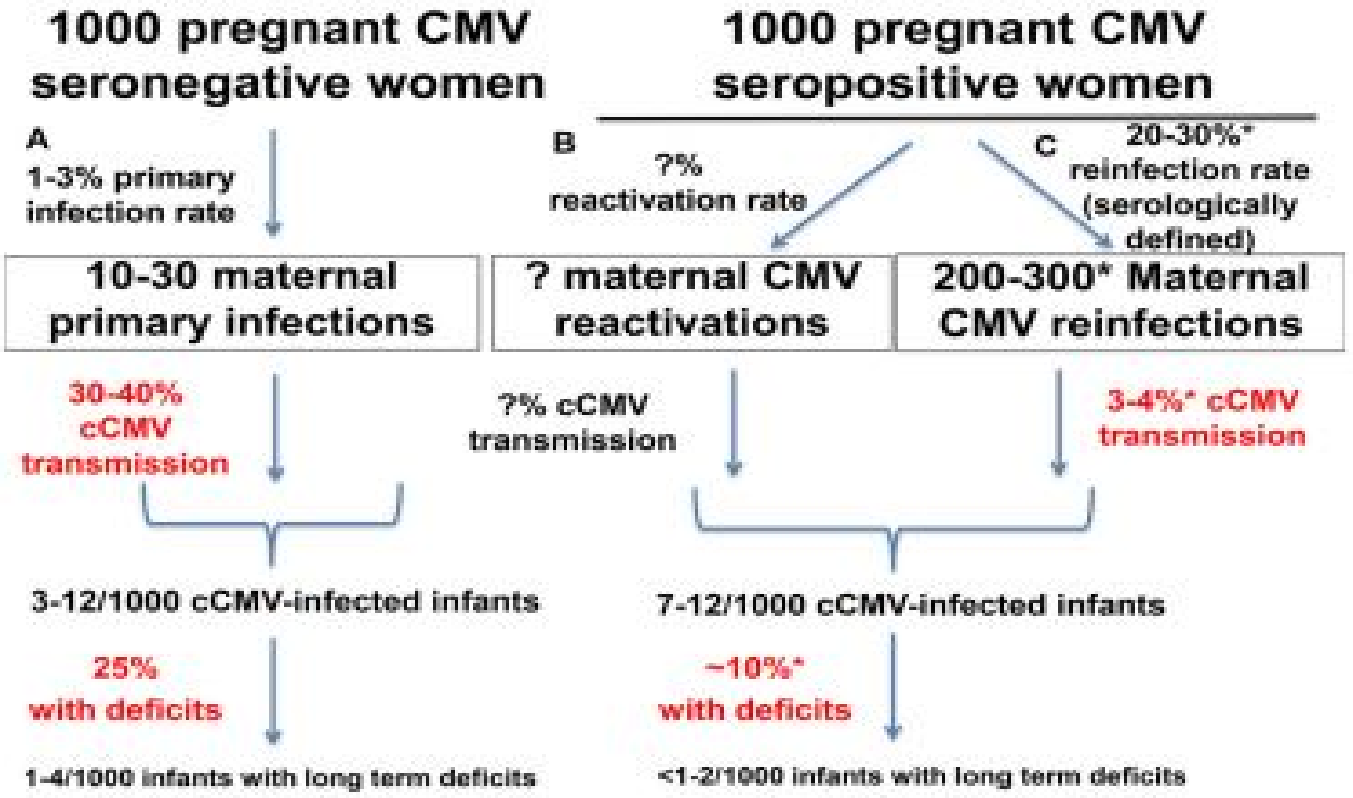
Role Prevention:

- Women caring for young children and pregnant
- Seroconversion Intervention: 4/311 (1.2%) vs
- Control: 24/315 (7.6%) $p < 0.05$
- Congenital infection: 3/311 (1.0%) vs 8/315 (2.5%) cCMV
- Not a randomized clinical trial

Role Prevention:

- RACE-FIT: Reducing Acquisition of CMV through Education
- Phase 1 – educational film
- Phase 2- randomized trial CMV seronegative pregnant women a) rx as usual b) educational intervention
- Jan. 2017-Sept 2019
- Outcomes: incidence CMV newborns, parental adherence, knowledge, acceptability, anxiety

Importance of Serologic Status:



Pemar, Schleiss, Plotkin. J. Virology 2018

Conclusion:

- Favorable attitudes towards CMV screening
- Despite successful Utah mandate- low awareness among families
- Efforts should be directed at prevention in **ALL** pregnant moms
- Prevention measures should improve awareness