

# Parents' Knowledge and Attitudes About CMV Screening in Utah

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# 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
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  - Christopher Hamilton

# Utah Legislative Efforts:



# Utah CMV Public Health Initiative (July 2013):

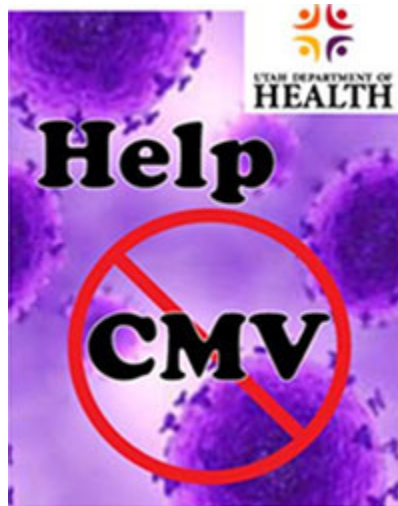
- DOH create education program about birth defects associated with and ways to prevent cCMV
- Annual budget \$30,000
- Targets women of childbearing ages, child care and health care providers
- Infants fail NBHS be tested for CMV within first 3 weeks of life

# 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”



# Attitudes towards CMV Screening

3 clusters of parent respondents:

strongly in favor (31%)

moderately in favor (49%)

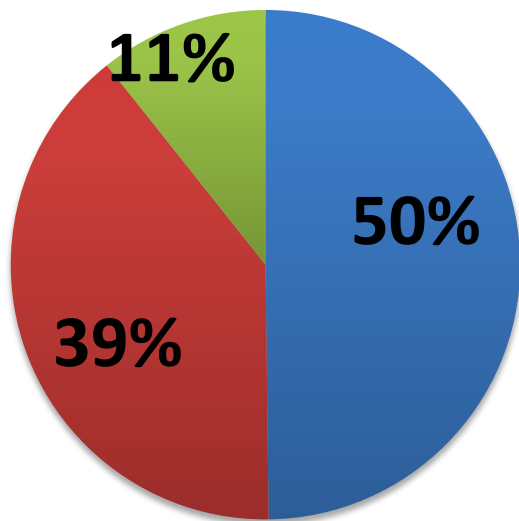
weakly opposed (20%)

# Utah Survey

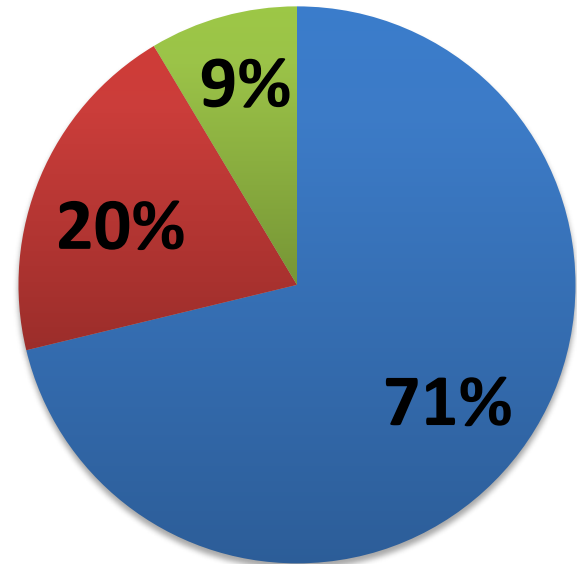
- $N = 356$  parents in ENT clinic (53% male children,  $M$  age = 27 months, range 2 weeks to 18 years; 65% 24 months or younger)

# Attitudes about CMV Screening

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



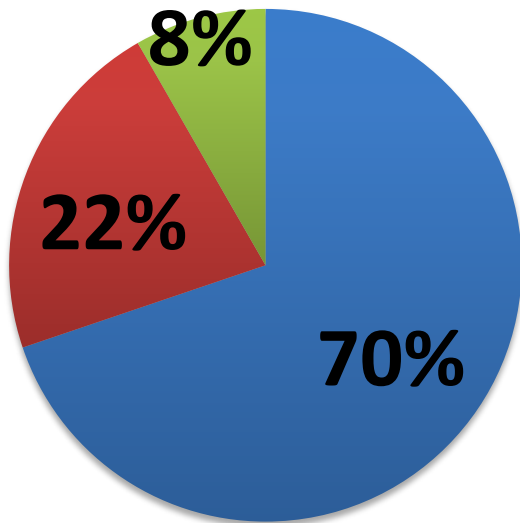
**"Would want to know if my child has CMV even if he or she never develops problems**



- Agree or Strongly Agree
- Neutral
- Disagree or Strongly Disagree

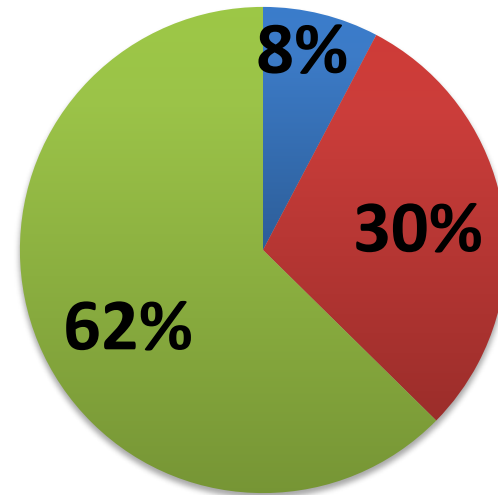
# Attitudes about CMV Screening

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



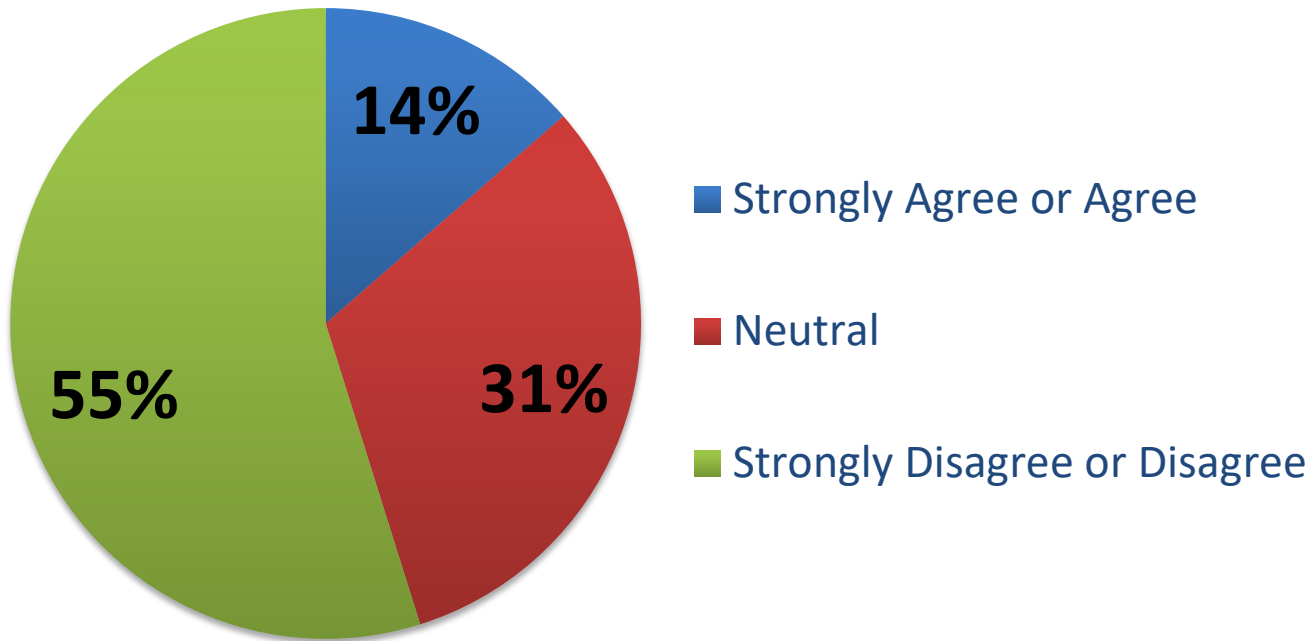
- Strongly Agree or Agree
- Neutral
- Strongly Disagree or Disagree

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



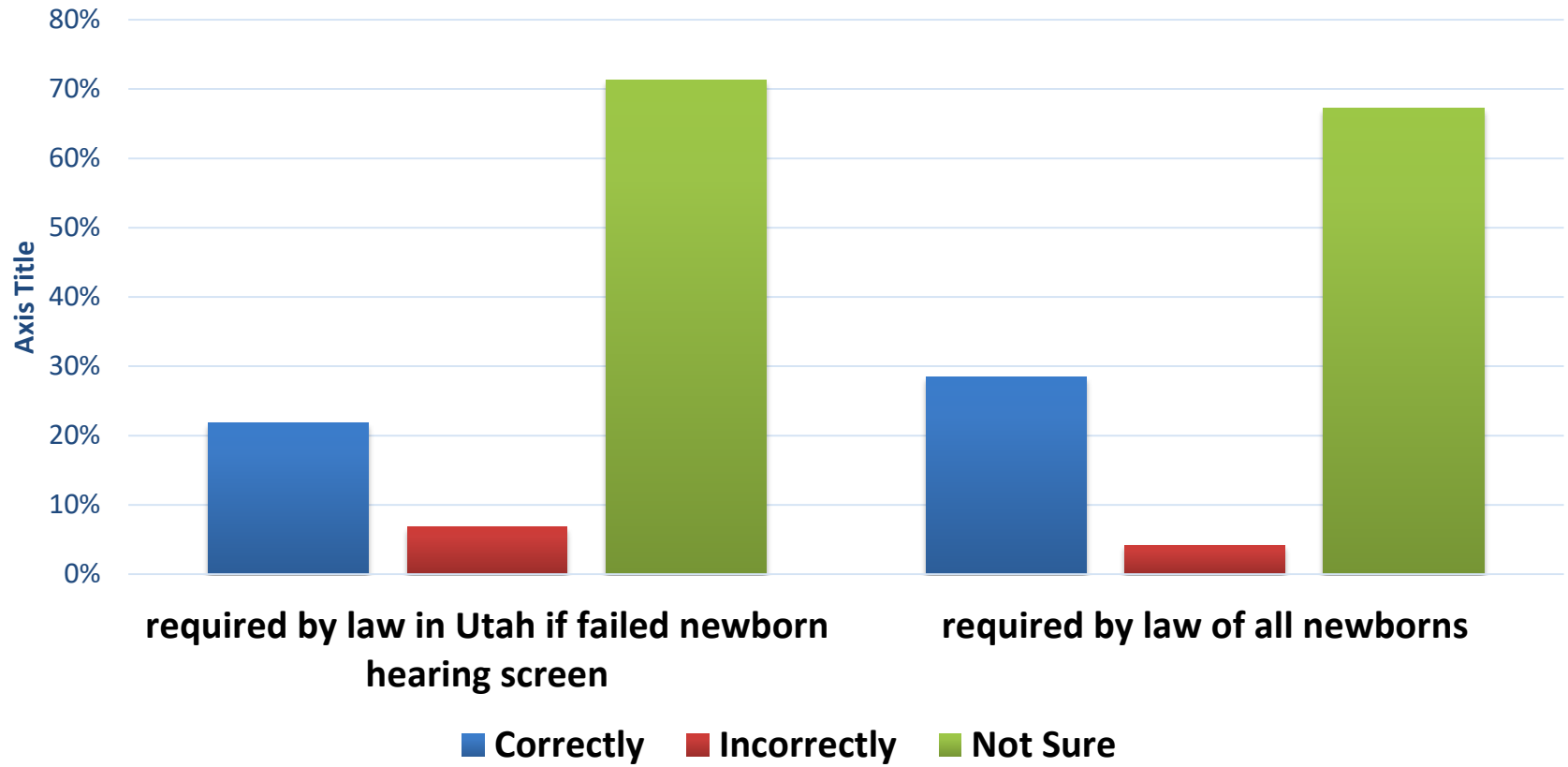
# Attitudes about CMV Screening

"would worry that the CMV test would lead to  
unnecessary doctor visits and expenses"



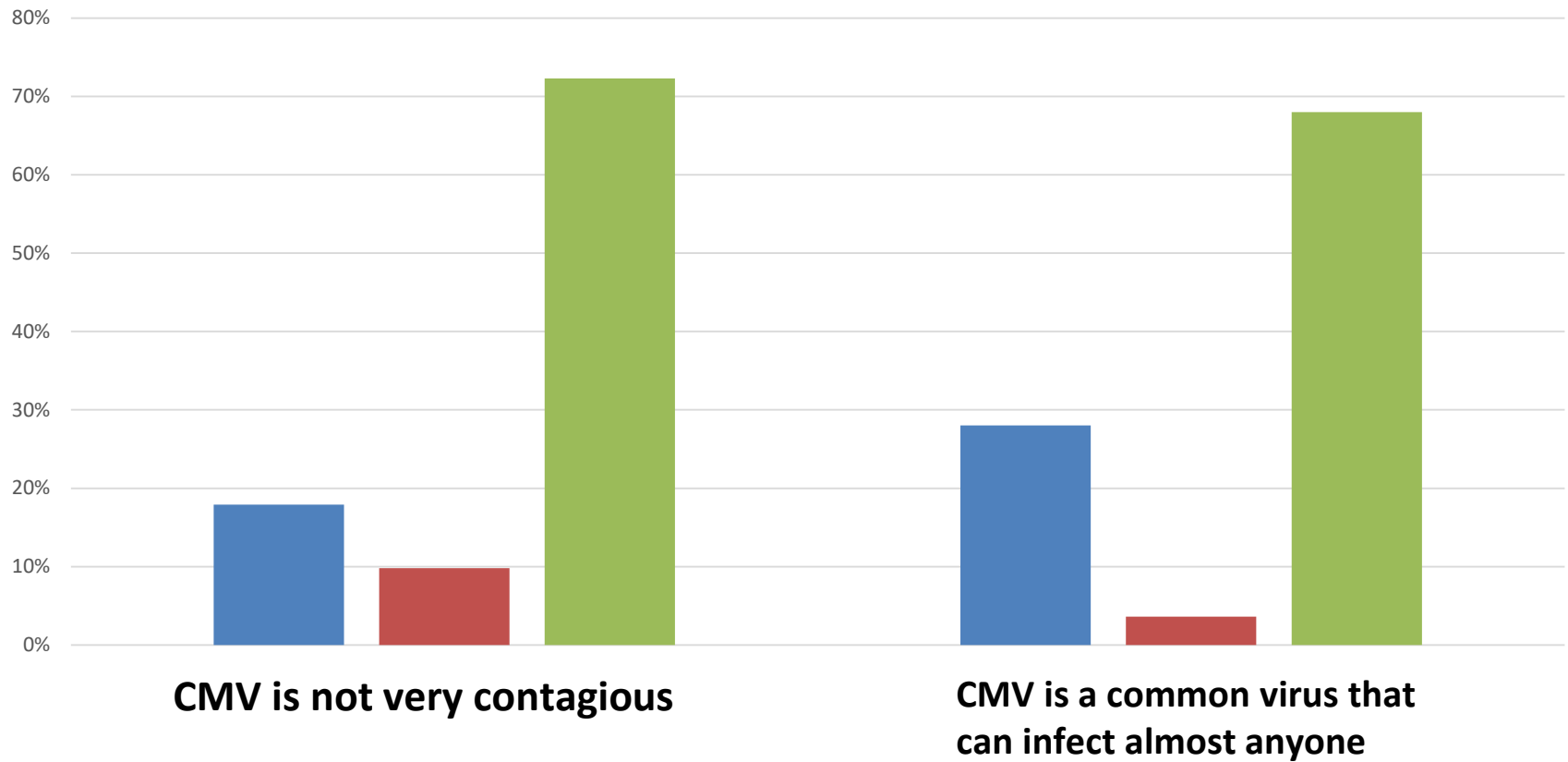
# Parents' Knowledge of CMV Law

Most parents were unfamiliar with the law

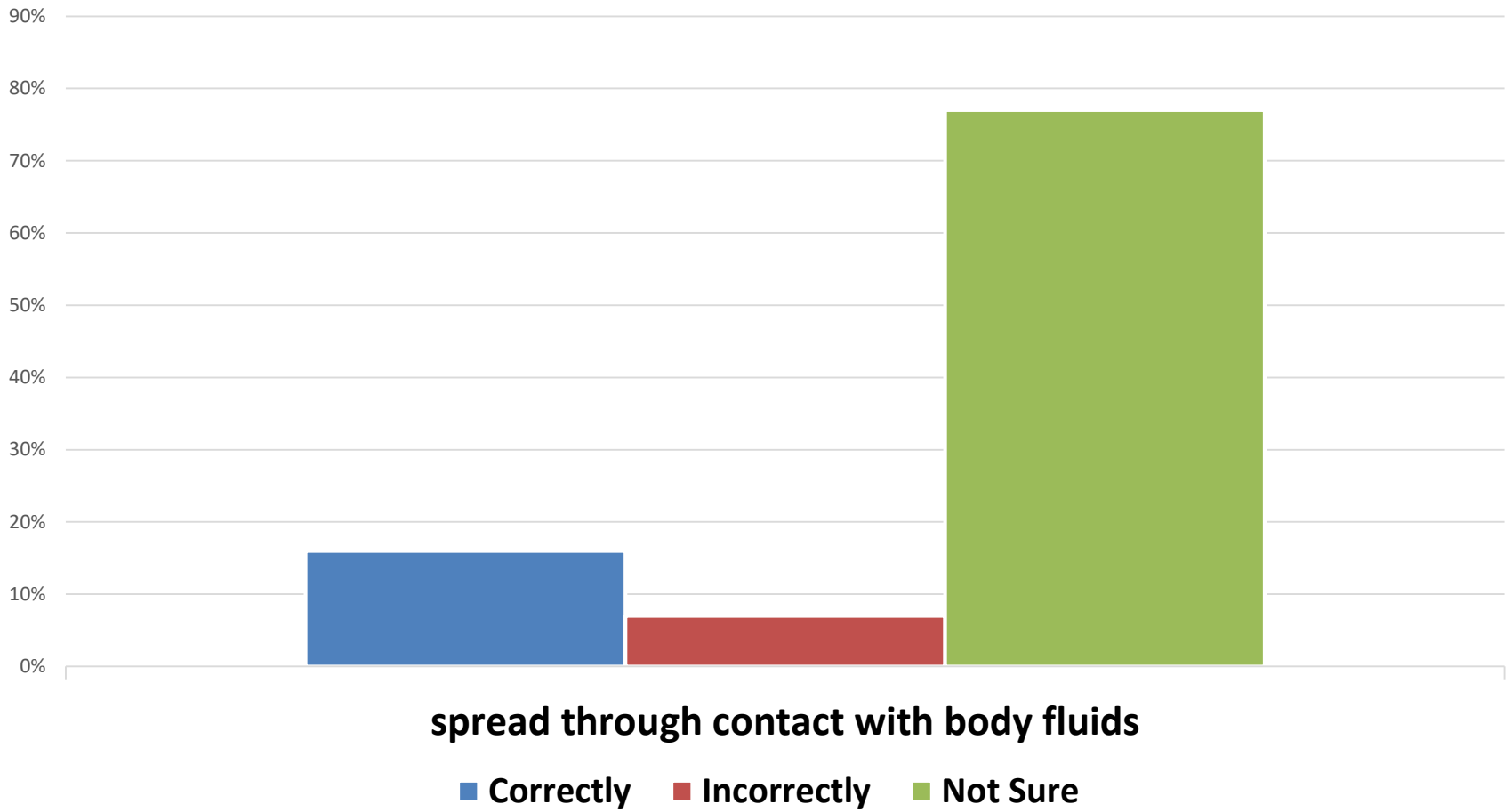


# Parents' Knowledge of CMV

## Parents not familiar with 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
- 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**

# 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%)

# 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%

# 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





# 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:

- 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

# 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