

## Improving South Dakota Parents' Knowledge of Congenital Cytomegalovirus

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### Abstract

**Introduction:** Congenital cytomegalovirus (cCMV) is the most common infectious condition present at birth and the leading non-genetic cause of sensorineural hearing loss in children. Despite cCMV being common and preventable, knowledge of cCMV remains low among individuals in the United States (Doutre et al., 2016). Sudden infant death syndrome (SIDS) is also common among infants in the United States, but unlike cCMV, several studies have researched which educational methods have been most effective for improving parents' knowledge of safe sleep practices. The purpose of this study was to investigate whether educational methods shown to be most effective for improving parents' knowledge of SIDS could also be used to improve parents' knowledge of cCMV.

**Method:** Forty-five participants completed an online study consisting of a pre-education survey on cCMV, written and verbal education on cCMV, and a post-education survey. Methods were based off a SIDS education study conducted by Dufer et al. (2017).

**Results:** Results of this study revealed that the provision of verbal and written education resulted in a significant increase in South Dakota parents' knowledge of cCMV ( $p < 0.05$ ).

**Conclusion:** Educational methods used to improve parents' knowledge of SIDS can also be used to improve South Dakota parents' knowledge of cCMV.

**Keywords:** Congenital cytomegalovirus, sudden infant death syndrome, parent education, parent knowledge

**Acronyms:** cCMV = congenital cytomegalovirus; SIDS = Sudden Infant Death Syndrome

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Cytomegalovirus (CMV) is a common viral condition. By age 40, more than 50% of adults have been infected with CMV; by age 80, that percentage rises to 90% of adults (CDC, 2020; Staras et al., 2006). If the virus passes from a pregnant woman to her child in utero, the infant is born with congenital cytomegalovirus (cCMV). Approximately one out of three pregnant women infected with CMV will pass the virus to their child in utero, leading to an estimated 30,000 annual cases of cCMV in the United States (National CMV Foundation, "What is CMV?", n.d.; National CMV Foundation, "Newborn Screening", n.d.).

In most cases, infected adults present with symptoms that mimic the common cold, or they will show no symptoms of infection (National CMV Foundation, "Signs and Symptoms of CMV Infection", n.d.). Unlike typical CMV infection in adults, cCMV infection in infants can cause severe symptoms. Of the 30,000 infants infected with cCMV each

year, about 6,000 infants (or one in five) will develop long-term health effects (CDC, 2020).

Some of the long-term health effects associated with cCMV include microcephaly, seizures, vision loss, cognitive impairment, and problems of the liver, spleen, and lungs (National CMV Foundation, "Signs and Symptoms of CMV Infection," n.d.). Another common symptom of cCMV infection is hearing loss. In fact, cCMV is the primary cause of non-genetic, sensorineural hearing loss in infants. The hearing loss may be progressive and can have a delayed onset (Goderis et al., 2014). Around 10 to 15% of asymptomatic infants (i.e., no visible symptoms of CMV infection) and up to 75% of symptomatic infants (i.e., visible symptoms of CMV infection) may develop hearing loss (National CMV Foundation, "Possible Outcomes of Congenital CMV," n.d.).

CMV can be spread through bodily fluids, such as saliva, urine, and blood (CDC, 2020). Women who are infected with CMV during pregnancy most commonly contract the virus from children younger than three years of age (Adler & Nigro, 2013). Therefore, women who are frequently in contact with young children (e.g., daycare providers, women with young children of their own) may be at a greater risk for CMV infection. Although CMV infection is common, it is also preventable. Behavioral hygienic practices can reduce one's risk of being infected with CMV. Such practices include the following: not sharing food, utensils, or a toothbrush with young children; not putting a used pacifier in one's mouth; avoiding contact with saliva when kissing a child; and washing one's hands after changing a diaper or touching children's toys (National CMV Foundation, "CMV Prevention and Healthy Pregnancy Tips," n.d.).

Although CMV infection is both serious and preventable, few individuals in the United States are aware of the virus. A 2005 *HealthStyles* survey revealed that only 14% of female respondents had heard of CMV (Ross et al., 2008). Five years later, the 2010 *HealthStyles* survey showed that 13% of women and 7% of men (whose responses to CMV questions in 2005 were not reported) were aware of CMV (Cannon et al., 2012). The most recent 2016 *HealthStyles* survey showed that 9% of women and 5% of men were aware of CMV. The decrease in women's awareness of CMV from 2005 to 2016 is statistically significant (OR = 0.94, 95% CI = [0.93, 0.95],  $p < .0001$ ; Doutré et al., 2016). Respondents' awareness of CMV was lower than all other conditions surveyed, such as spina bifida, Down syndrome, and fetal alcohol syndrome.

A previous study by Reimann et al. (2020) looked at South Dakota parents' knowledge of cCMV and found similar trends. South Dakota has no current legislation for cCMV screening; however, the two main hospital systems in the state (Sanford Health and Avera Health) have implemented hearing-targeted cCMV screening protocols (i.e., cCMV is screened for if the infant does not pass the newborn hearing screening). Regardless of whether the infant was born at a hospital with a hearing-targeted screening protocol, parents lacked confidence in their knowledge of cCMV, the problems associated with the virus, and ways to minimize exposure to the virus. This study revealed the need for parent education of cCMV throughout the state of South Dakota.

Although education and behavioral change can prevent the transmission of maternal CMV infection, few studies have researched the most effective means through which to convey this message (Hughes et al., 2017; Revello et al., 2015; Vauloup-Fellous et al., 2009). Like cCMV, sudden infant death syndrome (SIDS), or the unexplained death of an infant younger than one year of age, is common among infants in the United States. In fact, SIDS is the third leading cause of infant mortality (Carrier, 2009). Another similarity between the two conditions is the role of cultural norms in slowing the change of certain behaviors. For example, kissing a child on the lips (a risk factor for CMV

infection) and placing a child to sleep on their stomach (a risk factor for SIDS) are common behavioral practices in the United States, and parents may be more resistant to change these behaviors (Thackeray, 2017).

Unlike cCMV, several studies have identified educational methods and mediums most effective for improving parents' knowledge of SIDS and safe sleep practices. For example, providing parents with verbal and written education on SIDS has been shown to increase parental knowledge of SIDS and compliance to safe sleep practices; modeling safe sleep practices in the hospital has also been shown to help (Burd et al., 2007; Dufer & Godfrey, 2017; Gelfer et al., 2013; Grazil et al., 2010). Using written material alone as an educational method may be unsuccessful when attempting to change safe sleep behaviors (Moon & Omron, 2002).

The effectiveness of educational materials is also dependent on individuals' health literacy levels. Health literacy can be defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Selden et al., 2000, p. vi). Studies have shown that health literacy levels are strongly related to economic status among various other demographic factors (Kirsch et al., 2002). As such, the readability of educational materials should be assessed when designing handouts and programs to accommodate various health literacy levels.

The purpose of this study was to investigate whether educational methods shown to be most effective for improving parents' knowledge of SIDS and safe sleep practices can also be used to improve South Dakota parents' knowledge of cCMV and preventative hygiene behaviors. The study was designed to be highly replicable by other researchers interested in improving parental knowledge of cCMV with written and verbal educational materials.

## Method

### Design

The Institutional Review Board (IRB) at the University of South Dakota approved this research project. Implied consent from the participants was inferred by voluntary completion of the study. G\*Power software (version 3.1.9.4) was used for sample size calculations. A two-tailed *t*-test for dependent means with a moderate (0.5) effect size, 0.05 significance level, and 0.8 power determined the minimum sample size to be 34 participants.

### Setting and Participants

The study was first piloted with parents whose children are enrolled in a local Head Start program to evaluate the study's design, to assess the efficacy of research materials, and to correct potential errors. Following the pilot study, researchers moved forward with the official study. The official study took place online and included a single group of research participants. Participants were recruited through a social media post on various public

and private Facebook groups, including those groups specifically designed for parents. Interested participants were required to be age 18 or older, a parent of a child younger than age 5, and a resident of the state of South Dakota. The study materials were designed to screen for these criteria prior to allowing participants full access to the study (see Project Development and Procedures). Data collection began on November 30, 2021 and was completed on December 14, 2021.

### Project Development and Procedures

A cCMV educational program with both written and verbal components was created for this study. The written component consisted of a one-page handout with information on cCMV (see Appendix A), while the verbal component consisted of a 3-minute YouTube video with the researcher's voice-over narration. The video can be accessed at <https://youtu.be/UKsFGauCbvl>. These educational materials were approved by the program director of the National CMV Foundation.

Pre- and post-education surveys were disseminated via *Qualtrics* software (see Appendix B). The surveys consisted of the same ten questions and were used to assess parents' knowledge of cCMV both before and after viewing the educational materials. Parents were asked about their understanding of (c)CMV, modes of CMV transmission, and ways to prevent transmission. Readability statistics on Microsoft Word revealed both surveys to have a 10<sup>th</sup> grade Flesch-Kincaid reading level; when the words *congenital cytomegalovirus* were removed, this statistic changed to a 6<sup>th</sup> grade reading level. Since these words were necessary to include in the survey, the reading statistics were acceptable to researchers. In addition, demographic questions were included at the beginning of the pre-education survey. These questions required respondents to provide their age, gender, and educational level. Respondents were also asked if they were previously or currently employed in a healthcare profession; if they have other children at home; and if they have a child with cCMV.

The researchers designed a social media post and provided a single link for all study materials. Three questions were asked at the beginning of the study to ensure participants met the aforementioned inclusion criteria (i.e., age 18 or older, parent of a child younger than age 5, and resident of South Dakota). If participants answered "no" to any of these questions, the study ended. If participants answered "yes" to all three questions, they were given access to the pre-education survey. They were then automatically redirected to the YouTube video (verbal education component) and educational handout (written education component). Following the education session, participants were automatically redirected to the post-education survey. Finally, participants who completed the entire survey were asked if they would like their name entered into a drawing for a \$20 Walmart gift card. These gift cards were mailed to the participants after the study was completed.

This research design was modeled after a one-group, pre-post study completed by Dufer et al. (2017). Their study revealed that parents' knowledge of sudden infant death syndrome (SIDS) and safe sleep practices was significantly higher following a verbal and written educational session. Researchers hypothesized that verbal and written education of cCMV would lead to a change in parents' knowledge of the virus.

### Statistical Analysis

Descriptive statistics (i.e., percentages) were used to compare the change in performance on each individual question between the group's pre- and post-knowledge surveys. In addition, a two-tailed, dependent *t* test ( $p < 0.05$ ) was used to compare the overall change in the group's pre- and post-education survey performance. IP addresses were used to pair the participants' pre-education scores with their post-education scores. If an IP address was found in the pre-education results but not the post-education results, that data was eliminated from the analysis, as the participant did not complete the entire study.

### Results

Forty-five participants completed the official study in its entirety. Partially complete responses were eliminated from the data analysis.

### Demographic Factors

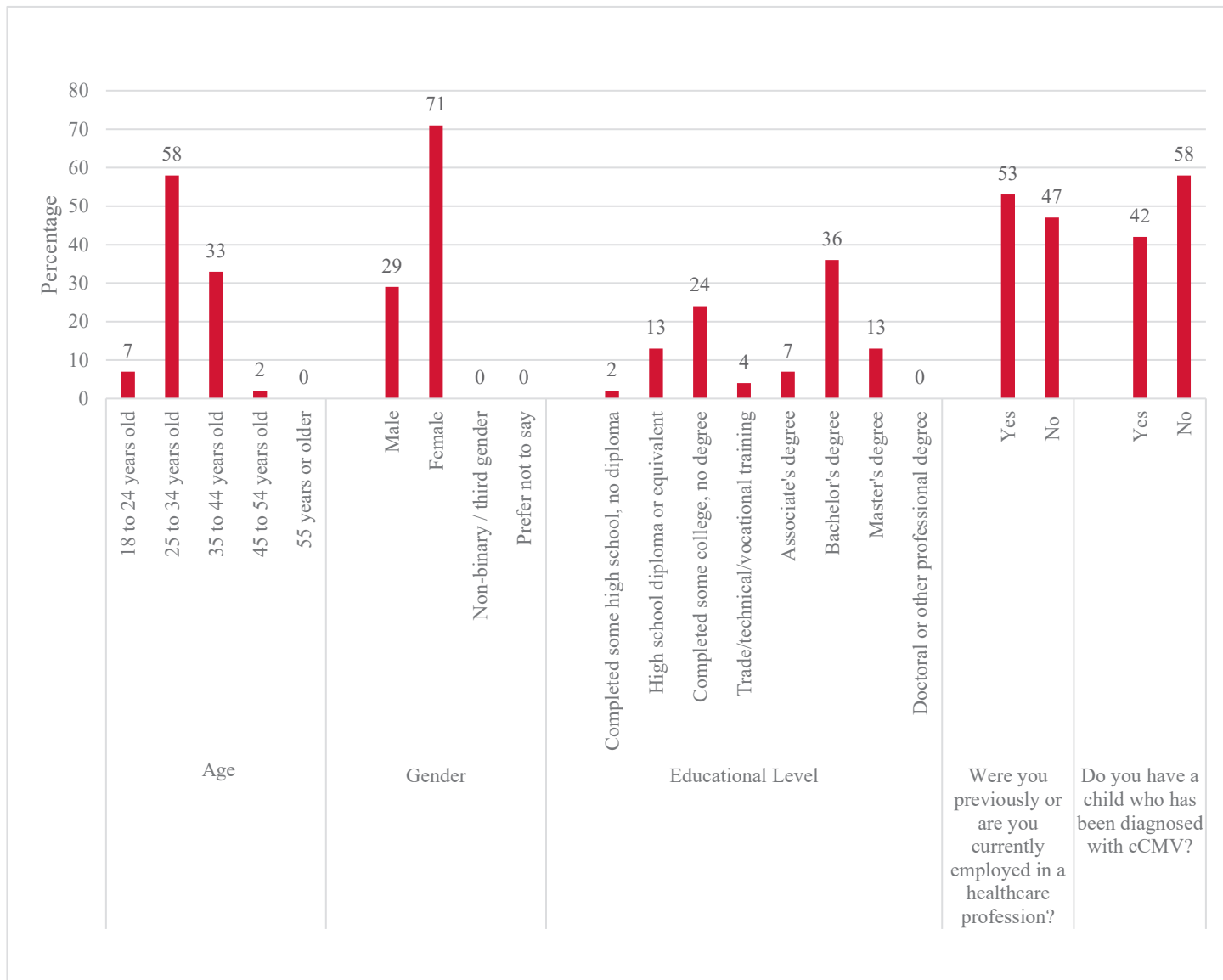
Answers to the demographic questions on the pre-education survey were analyzed (see Figure 1). The most commonly selected age range was 25 to 34 years old ( $n = 26, 58\%$ ), and the majority of participants identified as female ( $n = 32, 71\%$ ). When asked about their educational level, the most commonly selected option was bachelor's degree ( $n = 16, 36\%$ ), and the second most commonly selected option was "completed some college, no degree" ( $n = 11, 24\%$ ). When asked if they were previously or currently employed in a healthcare profession, 53% of participants responded with yes and 47% responded with no. Finally, when asked if they have a child who has been diagnosed with cCMV, 42% of participants selected yes and 58% selected no. The high percentage of participants who reported that their child has been diagnosed with cCMV may be due to the specific Facebook groups that shared the social media post to their pages.

### Change in Performance on Individual Questions

For all ten questions included on the pre- and post-education surveys, the researcher used descriptive statistics to compare the change in performance on each individual question (see Table 1). Eight of the ten questions showed an increase in correct responses on the post-education survey as compared to the pre-education survey. Two questions (questions 8 and 9) showed a decrease in correct responses on the post-education survey as compared to the pre-education survey. Question 8 stated, "Cytomegalovirus (CMV) can spread from one person to another through..." and participants were required to pick from the following options: (a) saliva, (b) urine, (c) blood, or (d) all of the above. The correct answer

**Figure 1**

*Analysis of Participants' Demographic Factors (n = 45)*



was all of the above, which 25 participants answered correctly on the pre-education survey and 20 participants answered correctly on the post-education survey. Question 9 asked, “When is a child with congenital cytomegalovirus (cCMV) at risk for developing hearing loss?” Participants were required to pick from the following options: (a) at birth, (b) sometime after birth, (c) both at birth and sometime after birth, or (d) none of the above. The correct answer was both at birth and sometime after birth, which 28 participants answered correctly on the pre-education survey and 27 participants answered correctly on the post-education survey.

The decrease in performance on these two questions may be explained by several factors. Participants may have fatigued toward the end of the study and spent less time reading the questions. It is also possible that some participants may not have completed the educational session in its entirety, which is a limitation of conducting an online study.

### Overall Change in Performance

After reviewing the change in performance on each individual question, the researcher analyzed the overall change in performance on the post-education survey as compared to the pre-education survey. Data analysis revealed a statistically significant increase in scores on the post-education survey as compared to the pre-education survey ( $p < 0.05$ ).

### Discussion

The statistically significant increase in post-education scores as compared to pre-education scores supports the researchers' hypothesis that verbal and written education of cCMV would lead to a change in South Dakota parents' knowledge of the virus. Just as providing parents with verbal and written education on SIDS has been shown to increase parental knowledge of SIDS and compliance to safe sleep practices (Burd et al., 2007; Dufer & Godfrey, 2017; Gelfer et al., 2013), the same educational methods

**Table 1**  
*Change in Performance on Individual Quiz Questions*

Question	# Correct Responses / Total Responses		Direction of Change
	Pre-Education Survey	Post-Education Survey	
1) Based on the number of children born with each condition per year, congenital cytomegalovirus (cCMV) is more common than most other conditions, except for...	$\frac{17}{45}$	$\frac{20}{45}$	↑
<b>Correct answer: cCMV is more common than A, B, and C</b>			
2) How many children are born with congenital cytomegalovirus (cCMV) each year?	$\frac{17}{45}$	$\frac{32}{45}$	↑
<b>Correct answer: 1 in 200 infants</b>			
3) True or False: An adult infected with cytomegalovirus (CMV) usually experiences severe symptoms.	$\frac{20}{45}$	$\frac{27}{45}$	↑
<b>Correct answer: False.</b>			
4) True or False: All symptoms of congenital cytomegalovirus (cCMV) infection can be seen at birth.	$\frac{23}{45}$	$\frac{26}{45}$	↑
<b>Correct answer: False</b>			
5) Which of the following options is the most common long-term health problem caused by a congenital cytomegalovirus (cCMV) infection?	$\frac{20}{45}$	$\frac{29}{45}$	↑
<b>Correct answer: Hearing loss</b>			
6) Women who are infected with cytomegalovirus (CMV) during pregnancy most commonly acquire the virus from...	$\frac{24}{45}$	$\frac{31}{45}$	↑
<b>Correct answer: Children under the age of 3</b>			
7) All the following activities place a pregnant woman at risk for cytomegalovirus (CMV) infection except for...	$\frac{26}{45}$	$\frac{32}{45}$	↑
<b>Correct answer: Scooping a cat's litter box</b>			
8) Cytomegalovirus (CMV) can spread from one person to another through...	$\frac{25}{45}$	$\frac{20}{45}$	↓
<b>Correct answer: All of the above (i.e., urine, saliva, and blood)</b>			
9) When is a child with congenital cytomegalovirus (cCMV) at risk for developing hearing loss?	$\frac{28}{45}$	$\frac{27}{45}$	↓
<b>Correct answer: Both at birth and sometime after birth</b>			
10) True or False: Practicing simple, healthy habits, such as hand washing, cannot reduce a pregnant woman's risk of being infected with cytomegalovirus (CMV).	$\frac{16}{45}$	$\frac{20}{45}$	↑
<b>Correct answer: False</b>			

may also be used to improve South Dakota parents' knowledge of cCMV. Future research should evaluate whether cCMV education may also be used to increase parental compliance to preventative hygiene behaviors.

Limitations must be considered when reviewing the results of this study. First, an online study requires a certain amount of trust in research participants. Researchers cannot guarantee that participants watched the educational video in its entirety or read through the educational handout. Creating more interactive handouts and/or videos may increase participation in the educational component. In addition, results may not be representative of the entire state of South Dakota. As the study was disseminated on a social media platform, the geographic location of participants could not be controlled. Some regions of the state may be overrepresented in the data while other regions may be underrepresented, and participants' demographic factors (e.g., 42% report having a child diagnosed with cCMV and 53% report working in the healthcare field) could bias test results. Selecting a participant recruitment strategy more inclusive of geography and demographic factors may change future test results.

### Conclusion

Educational methods shown to be most effective for improving parents' knowledge of SIDS (i.e., written and verbal education) can also be used to improve South Dakota parents' knowledge of cCMV. This finding has implications for future education of parents on cCMV, problems associated with the virus, and ways to minimize exposure to the virus. Further research will be needed to assess the efficacy of these educational materials on parents residing in other geographic regions. In addition, future research should assess the change, if any, in parental compliance to preventative hygiene measures both before and after receiving education on cCMV.

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cCMV Handout

FACT SHEET

# cCMV

## Congenital Cytomegalovirus

### What is cCMV?

Congenital cytomegalovirus (cCMV) is one of the most common conditions present at birth, having a higher incidence rate than Down syndrome, spina bifida, and fetal alcohol spectrum disorder. It is also the leading non-genetic cause of hearing loss in infants.

Most adults have been infected with CMV, and symptoms often mimic the common cold.

However, if CMV passes from a pregnant mother to her child in utero, the infant is born with congenital cytomegalovirus (cCMV). Unlike CMV in adults, cCMV in infants may cause

#### long-term health problems:

- Hearing loss (at birth or delayed onset)
- Vision loss
- Microcephaly
- Seizure disorders
- Cognitive impairment

*\*Not all symptoms are visible at birth.*

### How is CMV spread?

CMV is spread through bodily fluids, such as saliva, blood, and urine. Women who acquire CMV during pregnancy most commonly acquire the virus from a child younger than three years of age. Therefore, women who are frequently in contact with young children (e.g., nurses, daycare providers, teachers, women with young children of their own) and who are or plan to become pregnant should adhere to **hygienic precautions**.



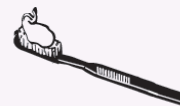
Do not share food, utensils, drinks, or straws.



Do not put a pacifier in your mouth.



Avoid kissing a child directly on the lips.



Do not share a toothbrush.



Wash your hands after changing diapers or handling kids' toys.

Information from the  
National CMV Foundation

[nationalcmv.org](http://nationalcmv.org)



**1 in 200**

infants in the U.S. is born with congenital CMV infection.

**1 in 5**

infants with congenital CMV infection will have long-term health problems.

Hearing loss is the most common symptom.

Only **9% of women** and **5% of men** in the United States know about congenital CMV!





## Appendix B

### *Surveys*

Demographic questions (only included on pre-education quiz):

- Age
  - Under 17 years old
  - 18 to 24 years old
  - 25 to 34 years old
  - 35 to 44 years old
  - 45 to 54 years old
  - 55 years or older
- Gender: How do you identify?
  - Female
  - Male
  - Non-binary/third gender
  - Prefer not to say
- Educational Level
  - Completed some high school, no diploma
  - High school diploma or equivalent
  - Completed some college, no degree
  - Trade/technical/vocational training
  - Associate's degree
  - Bachelor's degree
  - Master's degree
  - Doctoral or other professional degree
- Were you previously or are you currently employed in a healthcare profession?
  - Yes
  - No
- Do you have other children at home younger than age 18?
  - Yes
  - No
- Do you have a child who has been diagnosed with congenital CMV?
  - Yes
  - No

## Appendix B (cont.)

Quiz Questions (included on both pre- and post-education surveys):


### Answers in bold text

1. Based on the number of children born with each condition per year, congenital cytomegalovirus (cCMV) is more common than most other conditions, EXCEPT FOR:
  - a. Down syndrome
  - b. Spina bifida
  - c. Sudden Infant Death Syndrome (SIDS)
  - d. **cCMV is more common than A, B, and C.**
2. How many children are born with congenital cytomegalovirus (cCMV) each year?
  - a. 1 in 10 infants
  - b. 1 in 1000 infants
  - c. **1 in 200 infants**
  - d. 1 in 500 infants
3. An adult infected with cytomegalovirus (CMV) usually experiences severe symptoms.
  - a. True
  - b. **False**
4. All symptoms of congenital cytomegalovirus (cCMV) infection can be seen at birth.
  - a. True
  - b. **False**
5. Which of the following options is the most common long-term health problem caused by a congenital cytomegalovirus (cCMV) infection?
  - a. Jaundice
  - b. Kidney disease
  - c. Vision loss
  - d. **Hearing loss**
6. Women who are infected with cytomegalovirus (CMV) during pregnancy most commonly acquire the virus from:
  - a. Teenagers
  - b. Children ages 5 to 7
  - c. **Children under the age of 3**
  - d. College students
7. All the following activities place a pregnant woman at risk for cytomegalovirus (CMV) infection EXCEPT FOR:
  - a. Not washing your hands after picking up children's toys
  - b. **Scooping a cat's litter box**
  - c. Putting a used pacifier in your mouth
  - d. Kissing a child on the lips

## Appendix B (cont.)

8. Cytomegalovirus (CMV) can spread from one person to another through:
  - a. Saliva
  - b. Urine
  - c. Blood
  - d. **All of the above**
9. When is a child with congenital cytomegalovirus (cCMV) at risk for developing hearing loss?
  - a. At birth
  - b. Sometime after birth
  - c. **Both at birth AND sometime after birth**
  - d. None of the above
10. Practicing simple, healthy habits, such as hand washing, cannot reduce a pregnant woman's risk of being infected with cytomegalovirus (CMV).
  - a. True
  - b. **False**

### EHDInfo



The banner features the text 'CMV CONGENITAL CYTOMEGALOVIRUS PUBLIC HEALTH & POLICY CONFERENCE' on the left, a silhouette of a fetus in a circle, the word 'UTAH' in large blue letters with a yellow sun behind the 'H', 'Salt Lake City' in a cursive font over a mountain range, and 'OCTOBER 8<sup>TH</sup>-10<sup>TH</sup> 2023' in large yellow letters on a blue background on the right.

The goal of the congenital CMV Public Health and Policy Conference (CMV-PHP) is to present the latest research on diagnosis and treatment, raise awareness, delineate prevention efforts, provide information about early intervention options, and disseminate family support resources in an effort to reduce the number of babies born with CMV and connect families affected by CMV with the resources they need to improve their quality of life.

**With your help, we can reduce the number of babies born with CMV!**

**REGISTER NOW**