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# Cytomegalovirus: Educational outcomes and implications for newborn screening

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**CYTOMEGALOVIRUS: EDUCATIONAL OUTCOMES AND  
IMPLICATIONS FOR NEWBORN SCREENING**

by

**Emily Margaret Humphrey**

**Independent Study  
submitted in partial fulfillment of the  
requirements for the degree of:**

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**Approved By:**

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*Abstract: The focus of this study was to review existing literature and analyze a survey of professional opinion regarding how children with hearing loss caused by congenital cytomegalovirus (CMV) function audiotologically and educationally. This study proposes a benefit for adding CMV screening to the battery of tests included in the newborn screening protocol to improve educational outcomes of children deafened from CMV.*

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**ABBREVIATIONS**

CH	Congenital hypothyroidism
CMV	Cytomegalovirus
DBS	Dried Blood Spot
DQ	Development Quotient
GAL	Galactosemia
HL	Hearing Loss
IQ	Intelligence Quotient
OT	Occupational Therapy
PKU	Phenylketonuria
PT	Physical Therapy
SLP	Speech Language Pathology
SNHL	Sensorineural Hearing Loss
TORCH	Toxoplasmosis, Rubella, Cytomegalovirus, Herpes Simplex Virus
UNHS	Universal Newborn Hearing Screening
WPPSI	Wechsler Preschool and Primary Scale of Intelligence

## INTRODUCTION

Congenital cytomegalovirus (CMV) is a common virus that can cause disease in babies infected before birth. Congenital CMV can adversely affect the physical health and cognitive growth of the infected child. Of the 40,000 infants in the United States annually infected with congenital CMV, 6,000 develop sensorineural hearing loss (SNHL) (Dahle, Fowler, & Wright, 2000). In the United States, approximately 12,000 infants per year are born deaf or hard of hearing. Therefore, 50% of infants who present with hearing loss at birth have hearing loss as a result of congenital CMV. Congenital CMV is speculated to be the leading nongenetic cause of congenital hearing loss. Even though congenital CMV contributes as a major cause of hearing loss, Universal Newborn Hearing Screening (UNHS) alone may not detect all cases of hearing loss caused by congenital CMV (Fowler, Dahle & Bopanna, 1999). Approximately 90% of infants infected with congenital CMV are asymptomatic at birth—presenting without symptoms. These infants may pass their hearing screening but suffer from late onset or progressive hearing loss; common hearing loss patterns in this population (Fowler & Boppana, 2006). Universal newborn screening programs do not currently include CMV; however, CMV is more common than all other disorders included in the newborn screening program and is a leading cause of disability in children (Grosse, Dollard, Ross & Cannon, 2009). Perhaps a more comprehensive UNHS program, one with universal newborn CMV screening, would provide more benefit to detecting infants “at risk” of developing hearing loss.

To investigate to what extent congenital CMV causes disability, literature was reviewed analyzing language, speech, cognitive and motor function in children with symptomatic or asymptomatic congenital CMV. The literature reports adverse affects on speech, language, cognition and motor function in children diagnosed with congenital CMV. The following

literature review and study aims to analyze existing information and professional opinion as to the benefits of including CMV screening among the newborn screening protocol. With this knowledge, adequate intervention and monitoring of hearing status could be provided to all children affected by congenital CMV, whether they are symptomatic or asymptomatic at birth.

## **UNDERSTANDING CONGENITAL CMV**

Ross, Dollard, Victor, Sumartojo, and Cannon (2006) defined CMV as “a large DNA virus belonging to the Herpesviridae family and can be transmitted through contact with infected blood, tissues and bodily fluids.” CMV infections occur in all human populations more frequent depending on socioeconomic and ethnic status of populations. African American, inner city populations have a higher incidence of the disease (Schleiss & Choo, 2006). Evidence of past infection occurs in 50% of adults in developed countries and 90-100% in developing countries (Ross & Bopanna, 2004). The Centers for Disease Control and Prevention states that most healthy people experience no symptoms associated with CMV infection. A small percentage of adults who contract CMV do experience mild symptoms, similar to a mononucleosis-like syndrome. CMV poses a problem for certain high-risk groups including unborn babies whose mothers become infected with CMV during pregnancy and children or adults with compromised immune systems (El-Din, 2008). Maternal immune status can determine the likelihood and severity of the disease in the newborn. For example, if primary maternal infection occurs during pregnancy, the average rate of transmission to the fetus is 40% and decreases between 0.5-1.5% with recurrent maternal infection. In either of those cases, congenital CMV could present as symptomatic or asymptomatic; in other words, with or without clinical manifestations of the disease at birth (El-Din, 2008).

CMV can be detected in the urine, blood, and/or saliva and can be diagnosed in the mother, congenital fetus, and newborn (Revello & Gerna, 2002). Newborns are not currently routinely screened for CMV infection (Ross, Dollard, Victor, Sumartojo & Cannon, 2006). According to Grosse, Dollard, Ross & Cannon (2009), “CMV screening for newborns suspected of having congenital CMV is often conducted as part of clinical practice, although not consistently.” In order to properly identify congenital CMV, samples of urine, blood, and/or saliva must be taken within the first two weeks of life. After the first two weeks of life virus excretion may represent neonatal infections acquired in the birth canal or following exposure to breast milk or blood products (Revello & Gerna, 2002).

The clinical findings of congenital CMV (symptomatic) include petechiae, tiny red dots resembling a rash due to broken blood vessels; jaundice, yellowing of the skin and whites of the eyes due to excessive bilirubin; microcephaly, an abnormally small head and underdeveloped brain; seizures, convulsions due to abnormal brain activity; sensorineural hearing loss, hearing loss caused by damage to the inner ear and/or nerve pathways, and mental retardation to name a few (Ross & Bopanna, 2004). Prevention of the transmission of CMV to pregnant women represents a safe, effective and simple intervention. Prevention includes practicing good hygiene; hand washing and eliminating exposure to an infected child’s urine or mucus (Cannon & Davis, 2005). Several vaccines for adolescents and adults are currently being tested but not yet available (Ross et al., 2006). Antiviral drugs, such as ganciclovir are being considered and trialed as treatment. Ganciclovir can be used to treat neonates or infants with congenital CMV disease (Adler, Nigro & Periera, 2007). The evidence of said antiviral drugs is undefined due to lack of data (Revello & Gerna, 2002). Early intervention, in addition to medical treatment, is vital as a form of treatment not only for CMV but for SNHL as well. Left undetected, hearing impairment

in infants can negatively affect speech and language acquisition, academic achievement, and social and emotional development. These negative effects can be reduced through early intervention (Declau, Boudewyns, Van den Ende, Peeters & Van den Heyning, 2008).

### **SENSORINEURAL HEARING LOSS AND CMV**

Permanent central nervous system defects characterize a large amount of congenital CMV infections. Central nervous system sequelae include sensorineural hearing loss (SNHL). The American Speech and Hearing Association (ASHA) defines SNHL as damage to the inner ear (cochlea), and or the nerve pathways from the inner ear to the brain. Of the 40,000 infants in the United States annually infected with CMV, upward of 6,000 develop SNHL during early maturation. CMV accounts for 21% of all hearing loss at birth and 25% more is late onset; these numbers suggest that CMV is the leading nongenetic congenital cause of hearing loss (Dahle et al., 2000). Schleiss & Choo (2006) stated “more infants suffer hearing impairment caused by congenital CMV infection than was caused by either rubella syndrome or...meningitis in the prevaccine era for those infectious diseases”.

At the University of Alabama, Dahle et al. (2000) conducted a longitudinal study to investigate the effects of congenital CMV infection on hearing sensitivity. The study included 860 children with documented asymptomatic or symptomatic congenital CMV infection. These children were born between 1966 and 1999 and identified either by referral or as part of routine newborn CMV screening at two hospitals in Birmingham. SNHL occurred in 7.4% of the asymptomatic children and 40.7% of the symptomatic children. Of these children with SNHL, the majority had severe or profound loss (68% of asymptomatic children and 74% of symptomatic children). With regards to both groups (asymptomatic and symptomatic) children

experienced delayed onset of loss, threshold fluctuations, and/or progressive hearing loss.

Progression or further deterioration of loss occurred in over 50% of both groups. These results support previous findings indicating that CMV infection often results in late onset and progressive hearing loss (Fowler & Boppana, 2006).

Fowler & Boppana, recorded the onset of hearing loss to be between 33 months of age and 44 months of age—a critical period for speech and language development (Sharma & O’Sullivan, 2011). The impact of hearing loss on speech and language development is great (Walter et al, 2007) which supports that predicting hearing loss may speed up early intervention, in turn increasing positive educational outcomes. Fowler & Boppana investigated possible risk factors to predict which children with CMV will develop hearing loss or if that hearing loss will progress. The population included 504 children with asymptomatic CMV comparing risk factors of those who developed SNHL to those who did not. Children with SNHL were more likely to be preterm and to have a slightly lower mean birth weight. In the Rivera et al. study (2002), clinical manifestations of symptomatic CMV were examined to evaluate whether these factors could predict which children would develop SNHL. After adjusting for race, insurance status, intrauterine growth retardation, petechiae, hepatosplenomegaly, jaundice, microcephaly, seizures, thrombocytopenia, and referral status, only petechiae independently predicted hearing loss. Fowler & Boppana (2006) evaluated whether an infant’s viral burden, that is the concentration of the virus, in the neonatal period could predict hearing loss due to CMV and suggests that an increased viral burden in infancy might identify those children with asymptomatic infection who are at increased risk for hearing loss. In all of the above studies, it was found difficult to predict which children will have hearing loss and of those, which will deteriorate.

## SCREENING FOR CMV

Currently, 29 recommended tests compose newborn screenings as described by national guidelines. The Missouri newborn screening panel included 27 of the 29 recommended screening disorders (Missouri Department of Health and Senior Services). The goal is to identify 29 potentially treatable congenital disorders which may cause life-threatening health problems if not detected. Individual states can decide how many of these tests to include, but must include: Phenylketonuria (PKU), Congenital hypothyroidism (CH) and Galactosemia (GAL) (“Screening Tests”, 2008). Screening for congenital CMV is not included in the current panel of newborn tests, however congenital CMV meets certain criteria for newborn screening: CMV is more common than all other disorders included in the newborn screening program and is a leading cause of disability in children (Grosse, Dollard, Ross & Cannon, 2009).

Screening for congenital CMV is integrated in the TORCH (toxoplasmosis, rubella, cytomegalovirus, and herpes simplex virus) panel. The TORCH panel is only performed on newborns who have certain symptoms or born to mothers who may have been exposed to certain pathogens—missing children who have asymptomatic congenital CMV infection (Lab Tests Online). “Knowledge regarding the etiology of a child’s deafness is important...such information will help to predict whether the level of HL will remain stable or progressively worsen over time” (Pierson et al., 2007). Declau, Boudewyns, Van den Ende, Peeters & van den Heyning (2008) completed etiologic evaluations on 170 newborns with confirmed congenital hearing loss. Results showed CMV was identified in 18.8% of children proving etiologic evaluations beneficial. With etiologic understanding, these infants can be monitored consistently for SNHL.

Samples must be taken within the first 2 weeks of life to determine if the CMV infection was actually congenital. Since early identification may lead to early intervention, a simple and inexpensive assay for CMV detection is required to implement screening programs for congenital CMV infection (Revello & Gerna, 2002). Considering that 90% of infected newborns are asymptomatic at birth and after the newborn period, congenital CMV screening at birth is essential (Fowler & Boppana, 2006). CMV screening is minimally invasive and there are currently three methods used to test; urine, blood and saliva. Urine analysis is the most widely used form of screening, but storage and shipping to a laboratory present difficulty. Saliva analysis is easier than urine analysis and just as reliable (Balcarek et al, 1993). Dried Blood Spots (DBS) are of increasing interest as a screening method because DBS are routinely collected at birth. Simple, fast, inexpensive and easily stored yet limited by low sensitivity in its value as a screening test.

The main disability in children resulting from congenital CMV is SNHL so it has been assumed that universal newborn hearing screening alone will identify these at risk children. Fowler, Dahle, Boppana & Pass (1999) routinely evaluated hearing status in a cohort of 388 children born between 1980 and 1986 with confirmed congenital CMV. Within this population, less than half (5.2%) with SNHL were detected by newborn hearing screening. By 72 months, 15.4% of children with confirmed congenital CMV had documented SNHL. These findings give a startling picture of how many children with congenital CMV are at risk for developing potentially unnoticed and untreated late onset SNHL. Undetected and untreated SNHL cause speech, language and learning setbacks (Cole & Flexer, 2007). Schleiss and Choo (2006) agree that in order to instill a comprehensive early hearing loss identification program, universal screening of all infants for CMV should be included. Best said by Moeller et al. (2010):

“Knowledge of the risk factors for late-onset hearing loss and continued vigilance in screening, monitoring and referral are vital”.

## **EDUCATIONAL OUTCOMES**

Considering that congenital CMV is a leading cause of hearing loss and hearing loss is detrimental to speech, language and learning, it may be of interest to look at the educational outcomes in children with congenital CMV. The following studies aim to portray children with congenital CMV regardless of hearing status. Children with congenital CMV may be symptomatic or asymptomatic at birth. The majority of the following studies focus on educational outcomes of children with symptomatic congenital CMV. These results are important to consider when looking at children with asymptomatic congenital CMV; children with asymptomatic congenital CMV may be at risk for any or all of these negative educational outcomes. The strong correlation between low intellectual development and symptomatic congenital CMV suggest that the population of children with asymptomatic congenital CMV may be affected in a more subtle manner (Conboy et al., 1986).

Madden et al. (2005) studied a cohort of 21 patients with symptomatic congenital CMV and diagnosed SNHL. These children’s clinical data, audiometric thresholds, radiographic abnormalities, communication and educational achievements were used as outcome measures. Average age of participants was 12 years old. Of the 21 participants a variety of educational settings were observed with the majority of children in special needs settings: 19% mainstream setting, 24% school for the deaf, 9% hearing impaired classroom, and 48% special needs setting. Communication modes included manual communication (7), total communication (9) and oral communication (5). The use of non oral communication was significantly associated with the

presence of mental retardation. Results concluded that children with evidence of neurologic disease were significantly associated with the need for greater educational support. These findings are particularly true of children with a history of microcephaly, cerebral palsy and mental retardation.

Noyola et al. (2001) investigated neurodevelopmental outcome in symptomatic congenital CMV. Patient population included 41 children diagnosed with symptomatic congenital CMV who were enrolled in a previous study; the Houston CMV longitudinal follow-up study. Evaluation of participants included age-appropriate neurodevelopmental assessments. Assessments consisted of: Bayley Scales of Infant Development, Kaufman Assessment Battery for Children and the Wechsler Intelligence Scale for Children Revised. Intelligence quotients were reported as follows: 29.9% with an IQ>90, 24.3% with an IQ 70-89, 9.7% with an IQ 50-69, 36.5% with an IQ<50. In addition 36.5% of the population presented with a major motor disorder. Microcephaly was the most specific predictor of mental retardation. Of this population with symptomatic congenital CMV, 28 children were diagnosed with SNHL. These 28 children were compared to the remaining 13 children with normal hearing. A significant difference in cognition and motor skills were noted; 50% of the children with SNHL display motor disability. The mean IQ of the children with SNHL was 65.3.

Zhang et al. (2007), conducted a longitudinal study researching physical and intellectual development in children with asymptomatic congenital CMV infection. The study took place in the Qinba mountain area, China. Unique to this study, the Qinba mountain area has a high incidence of mental retardation and high incidence of CMV active infection in pregnancy (Yan et al., 2000). The participants included 49 children born between 1997 and 2000 and diagnosed with CMV infection within the first week of life but presented with no symptoms. Although the

article recognizes SNHL as a manifestation of CMV, the study population does not distinguish between those with SNHL and those without. The participants were matched with 50 control subjects by age, race, school grade, parent education and socioeconomic status and tested over a four year period. Testing methods included different scales according to age; Gesell Developmental Schedule for infants between 18 and 36 months corrected age and the Wechsler Preschool and Primary Scale of Intelligence (WPPSI) for preschool children between 48 and 72 months. Results on the Gesell Developmental Schedule were measured by Developmental Quotient (DQ). The delay in language development in the infection group was of statistical significance. Results on the WPPSI found significant differences in full-scale and verbal IQ scores between asymptotically infected children and the controls proving a significant difference in cognition. The results of this study suggest cognitive function and language development may be compromised in these individuals—regardless of hearing status.

## **SUMMARY OF LITERATURE REVIEW**

The goal of this literature review was to examine the value of mandatory universal newborn screening for CMV. The above review of literature supports a benefit to such screening.

Congenital CMV accounts for 21% of all hearing loss at birth and 25% more is late onset (Dahle et al., 2000). CMV can be symptomatic or asymptomatic, that is with or without symptoms present at birth. Symptomatic newborns will be tested for CMV, but asymptomatic newborns will not automatically be tested for CMV. Newborns that refer on newborn hearing screening will also be tested for CMV. Since both asymptomatic CMV and late onset hearing loss are characteristic of CMV, a large amount of infants with CMV will be missed (Fowler, Dahle, Boppana & Pass, 1999). A comprehensive newborn screening program including CMV

screening would identify infants “at risk” of developing late onset SNHL. SNHL adversely affects speech and language acquisition, academic achievement, and social and emotional development. These negative effects can be reduced through early detection leading to early intervention such as counseling and audiologic monitoring and management (Declau et al., 2008).

Life-threatening health problems and serious lifelong disabilities can be avoided or minimized through newborn screening of congenital disorders. For a disorder to qualify to be added to newborn screening, it must be more common than all other disorders included in current screening and must be a leading cause of disability in children. Congenital CMV is more common than all other disorders included in the newborn screening program and is a leading cause of disability in children (Grosse et al., 2009). CMV screening is a potentially inexpensive, minimally invasive way to predict and minimize complications surrounding congenital CMV. The virus is only proven to be congenital within the infants first two weeks for life, therefore must be screened at birth (Revello & Gerna, 2002).

The aforementioned research studies all shed negative light on educational outcomes for children with CMV. Madden et al. (2005) studied symptomatic children with CMV and hearing loss and concluded that the majority of children were educated in a support setting other than the mainstream. Noyola et al. (2001) investigated neurodevelopmental outcome in 41 children with symptomatic CMV regardless of hearing status. This study reported a significant percentage of children with low IQ scores and major motor disability. 28 children were diagnosed with SNHL and compared to the remaining 13 children with normal hearing, a significant difference in cognition and motor skills were noted. Zhang et al. (2007) researched physical and intellectual development in children with asymptomatic CMV as compared with a like group of children

without CMV. The children with asymptomatic CMV displayed significant delay in language and cognition. These studies illustrate just how different children with CMV may be from typically developing children. The research provides insight into what sort of additional educational needs these children require. Early detection through screening will likely lead to early intervention; early intervention will likely improve educational outcomes in this population.

## **SURVEY**

The above literature review supports the idea that children with congenital CMV have additional audiologic and educational needs which not only suggest a need for newborn screening but also additional support in the school environment. To investigate whether children with a confirmed or suspected diagnosis of CMV, particularly those with hearing loss, exhibited additional needs, the examiner surveyed teachers of the deaf in OPTION schools throughout the nation. OPTION schools are private Listening and Spoken Language schools dedicated to providing services to teach children who are deaf to listen and talk. The examiner also determined teachers' knowledge surrounding CMV and inquired about what sort of additional information would help them educate children with CMV. The examiner used a ten question survey as a gauge of teacher opinion to examine if classroom observations coincided with the literature. Hopefully this survey will provide a greater understanding of how children with CMV behave in the classroom environment. The information gathered in this study may benefit teachers of the deaf by drawing attention to the fact that children with congenital CMV require specialized instruction in addition to that typically offered to children diagnosed with a hearing impairment of different etiologies.

## **METHODS**

### *Participants and Procedures*

The examiner designed a survey using the online survey database, Survey Monkey. The survey was comprised of 10 questions and available from 2/16/2012 to 5/5/12. The questions were meant to determine each participants experience teaching children with CMV and to determine how children with CMV behaved and the accommodations they required (See Appendix A). The examiner recruited participants by e-mailing the designated contact for all 47 OPTION schools listed at [www.auditoryoral.org](http://www.auditoryoral.org) . Of these 47 schools, 7 contacts replied and agreed to distribute the survey link to their staff. 21 surveys were collected. One survey was excluded based on inconsistent answers. Of the 20 included surveys, 15 participants answered that they had taught a child with CMV over the course of their career. The data in these 15 surveys were analyzed regarding their answers to the follow-up questions. The remaining 5 participants answered either “no” or “I don’t know”. Of these 5 participants, no one completed the follow-up questions regarding disabilities and accommodations; however they provided information relating their own knowledge of CMV and their perceived ability to teach children with CMV.

## **RESULTS**

In response to the question “*Have you ever heard of congenital cytomegalovirus (CMV)?*” 25% (5 out of 20) stated “I have heard of CMV and feel knowledgeable on the topic” and 70% (14 out of 20) stated “I have heard of CMV but do not feel knowledgeable on the topic”. The 5 participants who had never had a child with CMV in their class unanimously answered that they do not feel knowledgeable about CMV. The subsequent question asked

participants to explain CMV to the best of their knowledge. Only 19 participants chose to complete this question. The majority, 53% (10 out of 19), of responses included the words (or other closely related words) “virus, pregnant, hearing loss”. 42% (8 out of 19) mentioned additional developmental delays.

The next question, “*Have you ever taught a child with congenital CMV?*” yielded 70% (14 out of 20) “yes” responses and 24% (5 out of 20) negative responses. The next question was a follow up question that inquired about observed CMV symptoms. The question stated, “*For the children you have taught with CMV, check the following that apply*” and included a table with 8 known symptoms of congenital CMV. The symptoms included: progressive hearing loss, vision loss, gross motor delay, fine motor delay, balance problems, speech deficit (greater than a hearing impaired child without CMV) and language deficit (greater than a hearing impaired child without CMV). Participants were asked to check “yes” corresponding to each symptom they observed. Table 1 represents the results collected from the 14 participants who answered “yes” to having taught a child with congenital CMV. The remaining 5 participants answered “no” or “I don’t know” to having taught a child with CMV did not answer the questions regarding observed behavior.

The next question inquired whether the participants thought children with CMV required specialized services or a different approach to instruction. 65% (13 out of 20) answered “yes” and 20% (4 out of 20) answered “no”. As a follow-up question, the participants were asked to record which additional services children with CMV required. 6 common services relating to known symptoms of CMV were listed. The services are: Occupational Therapy (OT), Physical Therapy (PT), Speech Language Pathology (SLP), Manual Communication, Modified Curriculum and Visual Accommodations. Table 2 depicts the results from the 14 participants

who had taught a child with CMV. The remaining 5 participants had never (to their knowledge) taught a child with CMV. These participants did not answer the questions regarding observed services.

For the question, “*My knowledge of CMV is adequate to provide appropriate educational services to the students I serve*” 40% (8 out of 20) agreed, 30% (6 out of 20) did not agree, and 30% (6 out of 20) said “maybe”. Subsequently an open-ended question was used to determine what additional information regarding CMV would be helpful. Only 11 participants answered this question. 73% (8 out of 11) responses indicated they wanted to know more about how CMV affects education and what sort of accommodations or strategies children with CMV need. Of these results, verbatim answers included “Basic information on causes, symptoms and educational implications”, “I’d like to know more about what delays, academic difficulties, to expect and suggested accommodations”, “more information on the areas of development that are affected by CMV, how to address their needs in the classroom”, and “If there are studies that show specific strategies work best with children with CMV”.

## **DISCUSSION**

Research suggests children with congenital CMV present with significant cognitive and language deficits. This survey aimed to investigate whether children with a confirmed or suspected diagnosis of CMV, particularly those with hearing loss, exhibited additional educational needs. In addition, this survey evaluated teachers’ knowledge surrounding CMV and what sort of additional information would help them educate children with CMV. This ten question survey, offered as a measure of teacher opinion, was used to determine if classroom observations matched with the literature. Results from the survey suggest children with CMV

and hearing loss do in fact exhibit an assortment of symptoms characteristic of CMV that require additional educational support.

Considering that CMV is the leading nongenetic cause of hearing loss, it is extremely likely teachers of the deaf have or will have a child with congenital CMV in their class. This study revealed 5 out of 20 participants stating they had either never had a child with CMV in their class or that they didn't know if they had. The examiner speculates this is due to a lack of diagnosis which is a direct result of no universal screening at birth. Those particular participants who said "no" to having taught a child with CMV also stated: "I have heard of CMV but do not feel knowledgeable on the topic". Perhaps the participants who had taught a child with CMV before were prompted to review that child's case history and research CMV whereas the participants without a child with CMV never felt that need.

Questions regarding observed symptoms and accommodations of children with congenital CMV aimed at understanding how children with congenital CMV function in the school environment. In addition, the examiner wanted to investigate how participant's observations compared to the literature. Due to lack of knowledge of the children observed, differences in symptomatic or asymptomatic CMV is unknown; however interesting parallels between findings and the literature can be noted. Noyola et al. (2001) reported low IQ scores and 36.5% of the population displayed major motor disability. 93% of participants observed major motor problems in children with CMV. Not surprisingly, participants of the survey stated 71% of children they observed with CMV required physical therapy and 83% required occupational therapy. A common sequelae of CMV is cerebral palsy which could attribute to the motor disorders in children with CMV. Zhang et al. (2007) researched physical and intellectual development in children with asymptomatic congenital CMV as compared with a like group of children without

CMV. The children with asymptomatic congenital CMV displayed significant delay in language. In the survey, greater than half of participants observed a language delay beyond what would be expected in children with hearing loss in children with congenital CMV. 71% of students required additional support of a Speech Language Pathologist.

60% of participants did not agree or answered “maybe” to the question: “*My knowledge of CMV is adequate to provide appropriate educational services to the students I serve*”. When asked to expand on their reply, 73% of responses indicated they wanted to know more about how CMV affects education and what sort of accommodations or strategies children with CMV need. These answers demonstrate that teachers may not have an adequate level of knowledge pertaining to CMV which indicates two things; teachers of the deaf need to be better educated about CMV and more research needs to surround educational needs of children with CMV. The teachers want more information, however, information is lacking due to minimal studies on the topic of educational outcomes in children with congenital CMV. The small number of studies can be explained by the fact that children with CMV are a difficult study population. Many children with CMV are undiagnosed due to lack of universal screening at birth. A universal screening program at birth would allow for a larger study population and ultimately benefit infected infants and their families.

### *Limitations*

This survey included 20 participants from 7 schools. A reason only 7 schools may have participated was due to their inexperience with CMV and decision not to partake in a study about CMV. Another speculation is that contact e-mails for the schools were incorrect or never forwarded to an accurate contact. Only OPTION Schools were asked to participate to narrow the

population. OPTION Schools use the auditory oral mode of communication which is only one representation of communication options for children who are hearing impaired. These schools are not a comprehensive representation of children who are hearing impaired. In fact, hearing impaired children who attend Option schools typically need additional educational support as compared to hearing impaired children who attend mainstream schools. Additionally, the literature points to the need for a significant number of children with congenital CMV to communicate using sign language or another visual communication mode, therefore, it is likely that a large percentage of children who have SNHL as a result of congenital CMV are not education in OPTION Schools that only utilize listening and spoken language for communication.

This was a survey based on observations and opinion therefore no factual data was reported. Only those teachers who had experience teaching hearing impaired children with CMV completed the observation portion of the survey. They drew upon their experience to answer these questions, meaning that only a small group of students with CMV were considered—not a solid representation of children with CMV. Arguably, these results give an idea of how children with hearing loss and CMV function in their academic environment. Since the results were comparable with the literature, a larger scale survey may be useful. In addition since this survey did not include any comparisons, it would be beneficial to compare children with CMV and hearing loss to children with a differing etiology of hearing loss.

## **CONCLUSION**

The purpose of this study was two-fold: To investigate whether adding CMV screening to universal newborn screening programs would benefit children who are at risk for developing

hearing loss and to explore how children with congenital CMV behave in an educational environment and whether specialized instruction is required. To explore these points, an exhaustive review of past and present research was compiled and an opinion survey was administered to teachers of the deaf reviewing their observations of children with congenital CMV and hearing loss.

The included survey provides insight into how children diagnosed with congenital CMV and hearing loss behave in their educational environment as observed by teachers of the deaf. Results from the survey suggest children with CMV and hearing loss do in fact exhibit symptoms characteristic of CMV that require additional educational support. In addition, the participants were forthcoming in their desire for additional information concerning how best to educate children with hearing loss caused by congenital CMV. Currently, no research is dedicated to analyzing what kind of specialized instruction is needed for these children. Knowledge of specialized instruction as it pertains to this population of children could improve the field of deaf education. This knowledge could provide educators with the resources and ability to best serve this population.

In order to ensure appropriate research concerning educational outcomes of children diagnosed with congenital CMV, proper diagnosis of congenital CMV must occur. Upon review of the literature, evidence points to a major benefit of adding CMV screening to a universal newborn screening program. “Knowledge of the risk factors for late-onset hearing loss and continued vigilance in screening, monitoring and referral are vital” (Moeller et al., 2010). A case can be made for adding CMV to the battery of tests included in newborn screening. CMV is one of the most common viral causes of congenital infection and is the leading non-genetic cause of hearing loss, CMV meets important screening criteria, and congenital CMV may affect

educational outcomes in children. Screening for CMV at birth may accelerate early intervention and improve these negative educational outcomes.

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Table 1

*Observed Symptoms in Children With CMV*

	<b>Progressive HL</b>	<b>Vision</b>	<b>Gross Motor</b>	<b>Fine Motor</b>	<b>Balance</b>	<b>Speech</b>	<b>Lang.</b>	<b>IQ</b>
<b>Observed Behaviors</b>	10/14	8/14	13/14	12/14	13/14	8/14	9/14	4/14
<b>Percent of Observed Behaviors</b>	71%	57%	93%	86%	93%	57%	64%	29%

Table 2

*Observed Services Children With CMV Required*

	<b>OT</b>	<b>PT</b>	<b>SLP</b>	<b>Manual Communication</b>	<b>Modified curriculum</b>	<b>Visual accommodations</b>
<b>Observed services</b>	12/14	10/14	10/14	4/14	7/14	1/14
<b>Percent of observed services</b>	86%	71%	71%	29%	50%	7%

## APPENDIX A

### Survey Questions

1. How many years have you been teaching children who are deaf and hard of hearing?
2. Have you ever heard of congenital Cytomegalovirus (CMV)?
3. To the best of your knowledge, describe CMV.
4. Have you ever taught a child with congenital CMV?
5. Do you currently have a child with congenital CMV in your class?
6. For the children you have taught with CMV check the following that apply:
  - a. Progressive hearing loss
  - b. Vision loss
  - c. Gross motor delay
  - d. Fine motor delay
  - e. Balance problems
  - f. Speech deficit (greater than a hearing impaired child without CMV)
  - g. Language deficit (greater than a hearing impaired child without CMV)
  - h. Low IQ
7. In your opinion, in comparison to children without CMV, did any of the children with CMV require specialized services or a different approach to instruction?
8. If yes, which of the following apply:
  - a. Occupational therapy
  - b. Physical therapy
  - c. Speech language pathology
  - d. Use of sign language or fingerspelling
  - e. Visual accommodations

9. My knowledge of CMV is adequate to provide appropriate educational services to the students I serve.
  - a. I agree
  - b. I do not agree
  - c. Maybe
10. If you disagreed or checked 'maybe' to the above statement, please describe what additional information would be helpful.