Support the Stop CMV Act – S. 3864/H.R. 7542

Congenital Cytomegalovirus (cCMV) affects approximately 1 per every 200 births in the United States. It is the most common viral cause of birth defects and of non-hereditary hearing loss. The bipartisan, bicameral Stop CMV Act authorizes new funding to incentivize hospitals and other health care entities that care for children to screen babies for cCMV within the first 21 days after birth. The bill also authorizes funding to collect data on cCMV and to assist in the education and training of health care providers, patients, and the public. Finally, the legislation directs the National Institutes of Health (NIH) to conduct research into congenital cCMV.

Universal screening for cCMV is critical for the following reasons:

- 50% of adults are infected by age 40, with minimal symptoms or consequence. However, a newly acquired infection during pregnancy can be passed to the developing baby causing serious impacts.
- Despite not being part of standard newborn screening, the incidence of cCMV is higher than any currently screened disease including cystic fibrosis (1 in 3500 births), congenital hypothyroidism (1 in 4,000 births), sickle cell anemia (1 in 375 African American infants) and severe combined immunodeficiency (1 in 75,000 births).
- More prevalent in Hispanic, Black and in lower income households showing critical need for education in medically underserved communities.
- Causes long-term neurodevelopmental disabilities including sensorineural hearing loss, cerebral palsy, intellectual disability, visual impairment, lack of coordination and seizures.
- Responsible for hearing loss in 1 in 5 hearing-impaired children with no known risk factor/cause and 1 in 10 hearing-impaired children overall.
- Approximately 33–50% of cCMV hearing loss is delayed in onset. These infants would not be captured by the newborn hearing screening.

Early diagnosis of cCMV is essential for appropriate intervention. It not only targets infants at risk of progressive hearing loss for audiological monitoring, it provides an opportunity for antiviral therapy should it be deemed an option. Infants who are diagnosed early tend to perform better on social, emotional, and educational levels and allow for careful monitoring from specialists in infectious disease, neurology, ophthalmology, and audiology. It allows for proper fitting of hearing aids or cochlear implants, glasses, and occupational, physical and speech therapy.

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1 https://www.cdc.gov/cmv/congenital-infection.html
4 Diener ML, Shi K, Park AH. A cross-sectional study of caregiver perceptions of congenital cytomegalovirus infection: knowledge and attitudes about screening. J Pediatr 2020; 218:151–156.e2
6 https://www.cdc.gov/cmv/congenital-infection.html