



NEW YORK STATE SENATOR

John W. Mannion

Senator Mannion and Assemblymember Rosenthal Announce Addition of Congenital Cytomegalovirus (CMV) to State's Routine

JOHN W. MANNION September 27, 2023

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Mannion and Rosenthal have championed CMV awareness and passed Elizabeth's Law, inspired by Central New York family's loss of daughter to CMV infection

Currently a one-year pilot program, Mannion and Rosenthal introduce legislation to make CMV screening for newborns permanent

SYRACUSE, NY – Senator John W. Mannion and Assemblymember Linda B. Rosenthal today announced the addition of congenital cytomegalovirus (CMV,) the leading cause of viral birth defects, to the New York State Department of Health's routine newborn screening panel. The virus is transmitted through infectious body fluids and is commonly passed in utero, affecting one in 200 births. If not identified quickly, CMV can lead to permanent hearing and vision loss, developmental and motor delays, microcephaly and seizures.

The New York State Newborn Screening Program was awarded a contract from the Eunice Kennedy Shriver National Institute of Child Health and Human Development

(NICHD) to provisionally add CMV to its screening panel for a pilot period of one year. The free testing will be conducted as part of an infant's routine newborn screening. Senator

Mannion and Assemblymember Rosenthal currently sponsor legislation (S.7659/A.7997) to require universal screening for CMV, which is pending before the State Legislature.

Senator Mannion and Assemblymember Rosenthal have championed CMV awareness and passed Elizabeth's Law (S6287C/A7460) which provides child care workers with information to understand and protect themselves from CMV. Pregnant women, or those who may become pregnant, who look after young children in day care and similar settings are most at risk. Elizabeth's Law was inspired by the advocacy of the Saunders family from Central New York who lost their daughter to CMV. The passage of Elizabeth's Law followed Rosenthal's 2018 law requiring hospitals to test all newborns for CMV who fail their initial hearing screening, often a sign of infection.

Senator John W. Mannion (SD-50) said, "CMV is a serious threat to newborn health, but it's also preventable. The inclusion of CMV screening in the New York State Newborn Screening Program along with the education and awareness prescribed by Elizabeth's Law are major steps forward in protecting babies and families. I am grateful to Assemblymember Rosenthal for her partnership in this effort, and to the Saunders family for their advocacy on behalf of all children."

Assemblymember Rosenthal (AD-67) said, "More than 30,000 babies are born with a CMV infection nationwide each year and all too often, families do not realize until symptoms have worsened, often leading to deafness or developmental disabilities. New York State has proven itself as a leader in CMV testing and prevention and the pilot program led by the Department of Health will help more families seek treatment early on and protect their children from the potentially devastating effects a CMV infection can bring. I look forward to partnering with Senator Mannion, Lisa Saunders and other advocates again next session to make universal screening permanent."

Lisa Saunders, founder of NY Stop CMV and mother of Elizabeth Saunders said, "I'm delighted about the one-year program to test all newborns in New York for cytomegalovirus (CMV), the leading viral cause of birth defects. This will help identify babies who can benefit from early intervention and/or antiviral treatment. In addition to being helpful for research purposes, it will further educate healthcare professionals about CMV as too many children with disabilities have never been identified as having been born with congenital CMV. Thankfully, through Senator Mannion and

Assemblymember Rosenthal's efforts to make women aware of CMV, New York passed "Elizabeth's Law," named in memory of our daughter, in 2022. The law requires the provision of CMV prevention education materials to pregnant women and child care providers. Our daughter Elizabeth was born with severe brain damage in 1989 because I contracted CMV just prior to or during my pregnancy. If I had been educated on CMV prevention, especially since I was at higher risk as a childcare provider and the mother of a toddler, Elizabeth might have had a healthy life. Instead, she died at the age of 16 during a seizure. The CDC says a person may be able to lessen their 'risk of getting CMV by reducing contact with saliva and urine from babies and young children...not sharing food, utensils, or cups with a child'."

Babies who screen positive for CMV will be referred to Infectious Disease specialists across the state for follow-up and evaluation. Parents may opt out of having the screening results recorded in their baby's newborn screening report.

For more information on CMV panels for newborns, please visit:

<https://www.wadsworth.org/news/congenital-cytomegalovirus-ccmv-screening>

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