

Neal and Sandra Salerno

AS A CONGENITAL CMV MOTHER.....

I support Bill HB 5147 for CMV awareness, and CMV education for all pregnant women and CMV testing and treatment for newborns !

And here is my story:

My daughter Lillian was born 12.28.2011, with no signs or symptoms of problems. By the time she was 8-10 months old we found out she was having multiple seizures daily and also had a profound unilateral hearing loss. She also had a condition called microcephaly (small head) and a brain malformation called Polymicrogyria (too many small folds).

We requested her newborn bloodspot from the state of TX and had it sent on to the Centers for Disease Control for further testing. Testing revealed she was born with a virus called Congenital CMV. This virus is VERY COMMON (feels like a common cold) yet only harmful when the mother contracts it during pregnancy for the first time. It is NOT currently included in the newborn screen program. There is also NO requirement for OBGYN's to educate expectant mothers about this virus. My daughter passed her newborn hearing screen and by 8 months she was deaf in one ear. Genetic testing revealed NO anomalies and it was concluded that ALL of Lillian's problems were caused by Congenital CMV.

Had we known about this when I was pregnant or even right at birth there would have been treatment options (valganciclovir) that could have potentially decreased the negative outcome for our daughter. In addition the added stress of spending months and months without a diagnosis is something I do not wish on any other families.

So please Connecticut consider this bill to save many other families from the stress and diagnostic dilemma that our family faced!!

Sincerely,

Neal and Sandra Salerno

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