

Dear Members of the Public Health Committee,

My name is Sara Menlove Doutre and I am pleased to submit testimony in support of HB 5525, AN ACT CONCERNING CYTOMEGALOVIRUS.

My background is in special education (I have a Bachelors degree in special education and a Masters degree in education policy studies). I had my first child at age 30 and considered myself well-versed in disability related matters. **I never learned about CMV.**

I was very proactive during my pregnancy. I took the recommended amounts of folic acid to prevent spina bifida. I participated in the recommended screenings for other markers of birth defects. We read every pamphlet provided by the doctors office. We researched pregnancy and precautions I could take to ensure optimal development of our child. **But, we were never warned about CMV.**

In July 2010, we found out we were expecting our second baby. Because of complications in our first pregnancy, we sought out a specialist in high-risk pregnancies at a maternal fetal diagnostic center.

Our daughter was born with minor symptoms of CMV, but they were not recognized as such. She had a head ultra sound and an MRI that were non-conclusive. Pediatricians told me that it was likely I had gotten sick during my pregnancy and that it may have caused a "hiccup" in her development, but that there was nothing to worry about.

Daisy also had a newborn hearing screening, which she failed, and follow up tests. The results did show some mild loss, but the audiologist said that it may have been because she woke up during the ABR and that we didn't need to worry about it. **No one mentioned CMV.**

We came home with a "healthy baby." **We didn't know she had CMV.**

Finally at 16 months, because Daisy was losing her hearing, a doctor asked if he could test for CMV. CMV was working on Daisy for 16 months before we even knew what it was. There were signs it was working on her at her birth. We could have known sooner.

Once we knew, we had options. No one forced us to seek treatment or services, but having knowledge and information empowered us to ask for what was best for our daughter. The diagnosis of congenital CMV was a catalyst for us to pursue intensive **early intervention services.**

Despite the interventions we chose, Daisy continued to lose her hearing. She is deaf and has bilateral cochlear implants. She has some sensory impairments and will deal with CMV for her whole life.

Women who are pregnant or might become pregnant should know about CMV. Health care professionals and others who care for children should know about CMV.

This bill will ensure that happens.

In March 2013, the Utah Governor signed into law a similar bill. Almost one year later, significant progress has been made. Materials have been developed, training has been provided, and, most importantly, **many more people are aware of CMV.** I'm attaching a sample of the materials developed by the Utah Department of Health to implement the similar law. More information can be found at: <http://www.health.utah.gov/cshcn/CHSS/CMV.html>

Effective implementation in Utah has been a team approach. The Utah Department of Health, Division for Children with Special Health Care Needs, has included local CMV researchers, physicians, parents, and other professionals on a team to develop effective materials. Utah is willing to assist Connecticut in implementing this bill as well.

Thank you,
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Parent
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