

Laura Sweet
3 Cottage Farms Road
Cumberland, ME 04021

January 12, 2022

**Testimony of Laura Sweet to the Joint Standing Committee on Health and Human Services
In Support Of
LD 1747, An Act to Require Screening for Cytomegalovirus in Certain Newborn Infants**

Good afternoon Senator Claxton, Representative Meyer, and members of the committee. My name is Laura Sweet and I live in Cumberland. I am speaking in support of LD 1747. I am the mother of two children. My youngest, Jane, is seven years old and one of the thousands of children born each year with a permanent disability due to congenital cytomegalovirus (CMV). I have served as the parent representative of the Maine CDC CMV Workgroup since this committee convened the group in May 2017. I am here today to share my family's experience and why this legislation, based on the Workgroup's recommendations, is critical for families in Maine.

Like me, most people do not even realize they have been infected with CMV. I had a seemingly normal full-term pregnancy with Jane, and she appeared a healthy, thriving newborn. We were devastated when we eventually learned I had passed the virus in utero to Jane, causing damage to her brain, one of her eyes, and her hearing. As a result, Jane is at greater risk for developing seizures, learning disabilities, vision problems, and she is profoundly deaf. I was shocked that CMV is such a common and preventable virus and frustrated that I, and so many other women, had never been educated about its risks or preventive measures.

During my pregnancy with Jane our older son was a toddler attending daycare full time. I was completely unaware that CMV is very prevalent among toddlers and in daycare settings, and commonly passed through their bodily fluids. Had I known the risks CMV posed to my unborn daughter, I absolutely would have altered my behavior accordingly. Simple preventive measures such as avoiding shared utensils, food, or drinks with my toddler, and being more vigilant about handwashing while caring for him, could have made all the difference. I followed all other guidance given by my prenatal care team and would have adhered to these simple precautionary recommendations as well.

Fortunately, newborn hearing screening identified the potential for Jane's hearing loss at birth. This prompted follow-up audiology visits, critical early intervention services, and care from specialists at Boston Children's Hospital, eventually leading to two cochlear implant surgeries. It took nearly a year though for her to be diagnosed with congenital CMV, and it was only possible after we insisted on obtaining and testing her newborn bloodspot sample. We unfortunately missed the optimal window of

opportunity for antiviral treatment as a result. Jane endured countless evaluations, appointments, and trips to Boston searching for a diagnosis that we could have gotten before leaving the birth hospital, if targeted newborn CMV screening had been the standard of care.

Thanks to ongoing CMV Workgroup efforts there has been progress, but the recommendations made five years ago have not been widely implemented. Educational resources and flyers have been developed and are ready to be distributed to healthcare providers and families. Targeted newborn screening protocols have been piloted by a small handful of dedicated providers that could be shared with other hospitals and pediatric practices across Maine. The groundwork has been laid and LD 1747 would finally make statewide implementation possible.

The lack of public and provider awareness cannot continue. Women must be educated about CMV risks and simple preventive measures during pregnancy. Babies with congenital CMV need be identified at birth and receive care right away. I hope this committee will join us in supporting LD 1747. Thank you for your time and consideration.

Sincerely,

Laura J. Sweet