

*Testimony submitted via email.*

My name is Amy Nelson-Horton and I am the constituent that helped draft House Bill 2754. House Bill 2754 requires a newborn child with hearing loss to be referred to a health care provider for the purpose of diagnosing whether the newborn child has cytomegalovirus. This bill also directs Oregon Health Authority to compile and disseminate information on congenital cytomegalovirus.

Cytomegalovirus, or CMV, is a public health issue and education is necessary. My son Nolan was born in 2002 and is severely disabled due to this virus. Congenital CMV infection is largely undetected because the majority of affected infants are asymptomatic at birth. Recent evidence suggest that routine screening of newborns could allow infected infants to receive consistent monitoring and treatment if necessary, ultimately increasing his/her chance of optimized developmental care.

In 2013, the Utah legislature passed the Cytomegalovirus Public Health Initiative. Connecticut, Hawaii, Illinois, Texas and most recently, Tennessee have followed suit.

The law in Utah requires the Utah Department of Health to educate pregnant women and women who may become pregnant about the health complications of CMV and how to prevent the virus. It also requires medical practitioners to test newborns for congenital CMV before they are 21 days old if they fail two hearing tests. This public health movement is very important because it deals with a virus that can easily be avoided with good hygiene.

The lack of information about CMV during pregnancy has impacted me personally. If I would have known about CMV before or during pregnancy, I would have altered my behavior to prevent transmission to my unborn child (e.g. not sharing food and drinks with toddlers, hand washing, etc.).

More information about CMV

According to the CDC, CMV is the most common congenital (present at birth) viral infection in the United States. About 50 to 60% of women are at risk for contracting CMV infection during pregnancy.

Babies born with congenital CMV may be born with birth defects and developmental disabilities, including: hearing loss, vision loss, mental disability, microcephaly (small head or brain), intracranial calcifications, lack of coordination, cerebral palsy, feeding issues/failure to thrive (FTT), sleeping disorder, sensory issues, seizures, and death (in rare cases).

1 out of 3 pregnant women who become infected with CMV will pass the virus to their unborn child.

1 child is permanently disabled by congenital CMV every hour.

1 in 150 children is born infected with congenital CMV. Each year, 30,000 children are born with congenital CMV causing 400 deaths and leaving 8,000 children with permanent disabilities such as deafness, blindness, cerebral palsy, mental and physical disabilities, and seizures.

CMV is a very common virus in young children and it is estimated that up to 70 percent of healthy children between 1 and 3 years of age may have CMV. CMV can be transmitted to pregnant women via bodily fluids, including saliva, urine, tears, blood, mucus, etc. To prevent CMV, practice frequent handwashing with soap and water after contact with diapers or oral secretions, especially with a child who is in daycare or interacting with other young children on a regular basis.