



**Testimony of the Connecticut Children's Medical Center
to the Public Health Committee regarding
*HB5271 An Act Concerning Newborn Screening Tests for Cytomegalovirus and Globoid Cell
Leukodystrophy and Establishing a Public Education Program for Cytomegalovirus and
HB 5525 An Act Concerning Cytomegalovirus*
February 20, 2015**

Senator Gerratana, Representative Ritter, members of the Public Health Committee, thank you for the opportunity to share our thoughts about *HB5271 An Act Concerning Newborn Screening Tests for Cytomegalovirus and Globoid Cell Leukodystrophy and Establishing a Public Education Program for Cytomegalovirus* and *HB 5525 An Act Concerning Cytomegalovirus*. We are Scott R. Schoem, MD, FAAP, Division of Otolaryngology – Head and Neck Surgery, and Nicholas Bennett MA(Cantab), MBChir, PhD, FAAP, Division of Infectious Diseases at Connecticut Children's Medical Center. We are submitting this testimony regarding the above referenced bills because our joint expertise in Otolaryngology and Infectious Diseases makes us concerned about the effective implementation of public policies aimed at preventing the impact of cytomegalovirus, a known cause of congenital bilateral hearing loss.

Connecticut Children's Medical Center is a nationally recognized, 187-bed not-for-profit children's hospital serving as the primary teaching hospital for the University of Connecticut School of Medicine Department of Pediatrics. Connecticut Children's Medical Center is consistently named among the best in the nation for several of its pediatric specialties in the annual *U.S. News & World Report* "Best Children's Hospitals" rankings.

A comprehensive array of pediatric services are available at our hospitals in Hartford and Waterbury, with neonatal intensive care units in Hartford (Level 4) and the University of Connecticut Health Center (Level 3), along with a state-of-the-art ambulatory surgery center, five specialty care centers and 10 practices across the state and in Massachusetts. Our Level 1 Pediatric Trauma Center and Primary Care Center are the busiest between Boston and New York. Connecticut Children's has 2,200 employees with a medical staff of nearly 1,100, practicing in more than 30 subspecialties.

If the State of Connecticut wants to maintain access to the full spectrum of pediatric health care services for all of its children, there must be a relationship between Medicaid cost coverage for the services Connecticut Children's provides and Medicaid volumes. While the number of children served by Connecticut Children's has risen, Medicaid cost coverage has decreased since 2008 from 91% to 64% in 2014. This has resulted in Connecticut Children's Medicaid shortfall increasing from \$7.6 million to \$63 million per year during the same time period.

Cytomegalovirus (CMV) is a known cause of congenital bilateral hearing loss. It can be passed from a mother to her baby before the baby is born, and it can also be acquired in the community after birth. It is important to identify quickly if an infant's hearing loss is the result of CMV because antiviral treatment may stabilize the hearing to prevent further deterioration of hearing levels and in some cases improve the hearing status if started promptly. Our testimony on these two bills is intended to offer recommendations about the best way to implement a program to address CMV and minimize its impact on infant hearing loss.

To confirm that CMV is the cause of an infant's hearing loss, testing must be performed in the newborn by 21 days after birth. After that time, CMV may have been acquired through community transmission and may not be the cause of the hearing loss. It is therefore our recommendation that CMV testing be done before leaving the birthing facility if the newborn does not pass the initial hearing screening test. Testing later may cloud the clinical picture of congenital versus community exposure.

Typically, if a newborn does not pass an initial hearing screening test, a second screening test is performed within 3 weeks. When an infant needs to be screened for CMV, the urine shell vial culture is the most cost effective test. If CMV is confirmed and the infant requires treatment, the oral antiviral medication valganciclovir is preferred because it has demonstrated no significant adverse effects compared to untreated CMV patients.

Since time is of the essence for newborns who may have hearing loss that is caused by CMV, it is very important to implement tests for hearing loss and CMV that are effective, timely, and cost-efficient so needed antiviral treatments can begin as soon as possible. We would be happy to serve as a resource for you as you debate this proposed legislation.

Thank you for your consideration of our position. If you have any questions about this testimony, please contact Jane Baird, Connecticut Children's Director of Government Relations, at 860-837-5557.