**CYTOMEGALOVIRUS (CMV) LEGISLATION**

Public Act 099-0424, effective January 2016, makes Illinois one of six states educating about CMV to reduce associated disabilities. This law was created to raise awareness of women who may become pregnant, expectant parents and parents of infants and to educate health care providers who care for expectant mothers or infants about CMV in an effort to reduce disabilities associated with hearing loss due to congenital CMV. Congenital CMV is the most common cause of non-hereditary sensorineural hearing loss. The majority of infants with congenital CMV infection may not show signs of illness at birth, yet a significant percentage will have a congenital hearing loss or will develop hearing loss after birth.

This law requires: *If a newborn infant fails the two initial hearing screenings in the hospital, then the hospital performing that screening shall provide to the parents of the infant information regarding: (i) birth defects caused by congenital CMV; (ii) testing opportunities and options for CMV, including the opportunity to test for CMV before leaving the hospital; and (iii) early intervention services.*

When the Medical Home tests for congenital CMV, after an infant fails the second hearing screening, testing must be completed by ***21 days*** of age. Families should be informed of complications that CMV may cause and available treatments.

*“The pediatrician or primary care physician should review every infant's medical and family history for the presence of risk indicators that require monitoring for delayed-onset or progressive hearing loss and should ensure that an audiological evaluation is completed for children at risk of hearing loss at least once by 24 to 30 months of age, regardless of their newborn screening results. Infants with specific risk factors, such as those who received ECMO therapy and those with CMV infection, are at increased risk of delayed-onset or progressive hearing loss and should be monitored closely. In addition, the primary care physician is responsible for ongoing surveillance of parent concerns about language and hearing, auditory skills, and developmental milestones of all infants and children regardless of risk status, as outlined in the pediatric periodicity schedule published by the AAP.” – JCIH 2007*

A general recommendation for **all** babies with congenital CMV (regardless of their newborn hearing screening results) is to have periodic hearing re-assessments. Each child should be considered on an individual basis as timing of assessments may need to be more frequent or altered based on parental concerns or guidance of a pediatric audiologist. If you do not receive a copy of the hearing screening results post hospital discharge, please contact the birth hospital or the Illinois Department of Public Health at 217-782-4733.

If you would like information regarding audiology providers or care coordination for families of children with special health care needs, please contact UIC- Specialized Care for Children at 800-322-3722.

**For more information on CMV, please visit:**

American Family Physician: <http://www.aafp.org/afp/2003/0201/p526.html>

The National Center for Hearing Assessment and Management (NCHAM) EHDI e-book Chapter 7, "Cytomegalovirus

and Hearing Impairments":

<http://www.infanthearing.org/ehdiebook/2013_ebook/8Chapter7CMV2013.pdf>

Healthy Children, American Academy of Pediatrics:

[https://www.healthychildren.org/English/health- issues/conditions/infections/Pages/Cytomegalovirus-CMV-Infections.aspx](https://www.healthychildren.org/English/health-%20issues/conditions/infections/Pages/Cytomegalovirus-CMV-Infections.aspx)

Centers for Disease Control & Prevention: <http://www.cdc.gov/cmv/congenital-infection.html>

National CMV Foundation: <https://www.nationalcmv.org/>

IL EHDI Program, CMV Legislation: <http://www.illinoissoundbeginnings.org/page.aspx?item=5>