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Staff of the Iowa Department of Public Health (IDPH) Center for Congenital and Inherited Disorders (CCID) have prepared this summary of Senate File 51 – Cytomegalovirus Public Health Initiative and the Testing of Newborns for Congenital Cytomegalovirus.

SF51 contains two sections: Section 1 is the cytomegalovirus (CMV) public health initiative and describes the activities required of the IDPH CCID; Section 2 is the testing of newborns for congenital cytomegalovirus section, and describes the responsibilities of health care professionals for testing of newborns at risk for congenital CMV.

This summary describes the activities required by each section of the bill and communicates the legislative intent that CMV testing occurs after *results of the newborn hearing screening performed under this section demonstrate that the newborn has hearing loss*.

This summary is not intended to provide any legal advice or to establish policy describing the responsibilities of health care providers under Section 2.

The document provides text excerpted from SF51 in *italics*, and describes relevant activities in underlined text.

Section 1: Iowa Department of Public Health Section

"In accordance with the duties prescribed in section 136A.3, the center for congenital and inherited disorders shall collaborate with state and local health agencies and other public and private organizations to develop and publish or approve and publish informational materials to educate and raise awareness of cytomegalovirus and congenital cytomegalovirus among women who may become pregnant, expectant parents, parents of infants, attending health care providers, and others, as appropriate. The materials shall include information regarding all of the following:

- a. The incidence of cytomegalovirus and congenital cytomegalovirus.*
- b. The transmission of cytomegalovirus to a pregnant woman or a woman who may become pregnant.*
- c. Birth defects caused by congenital cytomegalovirus.*
- d. Methods of diagnosing congenital cytomegalovirus.*
- e. Available preventive measures to avoid cytomegalovirus infection by women who are pregnant or who may become pregnant.*
- f. Early interventions, treatment, and services available for children diagnosed with congenital cytomegalovirus.*

An attending health care provider shall provide to a pregnant woman during the first trimester of the pregnancy the informational materials published under this subsection. The center for congenital and inherited disorders shall make the informational materials available to attending health care providers upon request.

3. The department shall publish the informational materials on its internet site and shall specifically make the informational materials available electronically to child care facilities and child care homes as defined in section 237A.1, school nurses, hospitals, attending health care providers, and other health care providers offering care to pregnant women and infants."

CCID will work with the National CMV organization and its Iowa representatives, maternal-fetal medicine physicians, and pediatric infectious disease experts to develop evidence-based informational materials targeted to Iowa women who may become pregnant, expectant parents, parents of infants, attending health care providers, child care facilities and child care homes, school nurses, hospitals, and health care providers offering care to pregnant women and infants.

The CCID will publish the informational materials on its internet website, and provide the links for the information to the targeted audiences listed above.

Section 2: Health Care Provider Section

“If the results of the newborn hearing screening performed under this section demonstrate that the newborn has hearing loss, the birthing hospital, birth center, physician, or other health care professional required to ensure that the hearing screening is performed on the newborn under this section, shall do all of the following:

*(1) Test the newborn or ensure that the newborn is tested for congenital cytomegalovirus **before** the newborn is twenty-one days of age.*

(2) Provide information to the parent of the newborn including information regarding the birth defects caused by congenital cytomegalovirus and early intervention and treatment resources and services available for children diagnosed with congenital cytomegalovirus.”

Iowa Administrative Code Chapter 641 IAC 3 states that it is the responsibility of the primary care provider (PCP) to ensure that hearing screening is performed on the newborn:

“Primary care provider” means a licensed physician, nurse practitioner, physician assistant or certified midwife who undertakes primary pediatric care responsibility for an infant or child to provide ongoing medical care and referrals to promote overall health and well-being.

All newborns and infants born in Iowa, except those born with a condition that is incompatible with life, shall be screened for hearing loss. For purposes of ensuring the newborn receives necessary follow-up interventions for congenital CMV (cCMV) **before** 21 days of age, hearing loss shall be considered when the newborn has failed to pass the initial hearing screening: the first screening conducted after birth and the second screening if the newborn does not pass the first screen after birth. The initial hearing screening is usually completed before the newborn is discharged from the hospital, or within 24 - 72 hours of life. Diagnostic testing for hearing loss should occur concurrently with the cCMV testing.

“Initial screening” or “newborn hearing screening” means a screening performed in a birthing hospital, birth center or facility other than a birthing hospital within the first month of life.

This subsection shall not apply if the parent objects to the testing. If a parent objects to the testing, the birthing hospital, birth center, physician, or other health care professional required to test or to ensure that the newborn is tested for congenital cytomegalovirus under this subsection shall obtain a written refusal from the parent, shall document the refusal in the newborn’s or infant’s medical record, and shall report the refusal to the department in the manner prescribed by rule of the department.”

The CCID will accept phone notifications, fax, or electronic notifications of written parent refusals of cCMV testing for their newborn. Refusals may be submitted to

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