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Minnesota pioneers universal screening for common source of birth defects

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Minnesota is the first U.S. state to universally test newborns for cytomegalovirus, an easily transmissible virus and a leading cause of infant hearing loss and congenital birth defects.

The announcement Wednesday follows a year of work to create a state protocol for testing at birth for the virus, known as CMV, and two decades of research at the University of Minnesota on ways to identify, prevent and treat the infection.

"We did it!" said an excited Dr. Mark Schleiss, the U expert in pediatric infectious diseases who led the research. "We got it to the finish line."

CMV is among more than 60 conditions for which newborns are screened in Minnesota, which started checking infants in the 1960s for a condition called phenylketonuria that could upset brain development. The state has been at the forefront of newborn screening—both in its ability to protect children from harm and to raise privacy debates about the storage and usage of the blood samples and other information collected.

About one-third of U.S. children carry CMV by age 5, and it can easily spread via bodily fluids such as saliva. However, serious complications are far more common among children infected in utero.

A test within 21 days of birth was urgently needed to identify congenital infections, and differentiate them from lower-risk infections that newborns could contract at home. The urgency for testing also has increased over the past decade with the expansion of antiviral therapies that can treat the infection and prevent its disabling results.

"Parents of children at risk for permanent hearing loss will receive early support that can help them prevent potential developmental delays," said Dr. Brooke Cunningham, commissioner of the Minnesota Department of Health.

Earlier trials of experimental vaccines failed to protect against CMV, but U research is ongoing.

Screening for CMV involves dried blood spots that are collected from all newborns in Minnesota unless parents opt out. The blood specimens are then held indefinitely, unless parents request they be destroyed, under a narrow state law that permits their storage and use for the identification of other disorders or the creation of more effective tests.

The requirements were set nearly a decade ago in legislation following a court battle over the health department's collection and long-term storage of blood spots from newborn screening. A 2014 settlement in that case resulted in the destruction of 1.1 million older samples.

Schleiss' research proved that CMV could be detected from blood spots, hastening Minnesota's screening program because it was already collecting those samples, said Jill Simonetti, manager of the state's newborn screening program. The health department is researching the utility of older blood spots, expecting that parents whose newborns test positive for CMV will want to go back and check older siblings, she added.

Most children born with CMV infections show no initial symptoms, though some may have jaundice or developmental indicators such as low birth weight or small head size. Long-term complications beyond hearing loss can include seizures, balance problems and developmental delays.

About 300 of 65,000 babies born in Minnesota each year have congenital CMV, according to state estimates. One-fifth of the infected babies are likely to have symptoms at birth or be at risk for hearing loss or other complications. Screening won't identify which infected children are at elevated risk, but it will allow doctors to monitor them and conduct more frequent hearing exams.

Screening and treatment are only part of the public health strategy to reduce the spread of CMV and congenital infections. Given the ease

with which the virus can spread through fluids, doctors discourage pregnant mothers from sharing food or drink with children.