



NEWS RELEASE

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Illinois Department of Public Health Expands Newborn Screening

Spinal Muscular Atrophy added as the 49th disorder

SPRINGFIELD – Beginning Monday, the Illinois Department of Public Health will test every baby born in Illinois for Spinal Muscular Atrophy (SMA). SMA is a group of hereditary diseases that progressively destroys motor neurons—nerve cells in the brain stem and spinal cord that control essential activities such as speaking, walking, breathing, and swallowing, leading to muscle weakness and atrophy. When there are disruptions in the signals between motor neurons and muscles, the muscles gradually weaken and begin wasting away.

“Spinal Muscular Atrophy is a disease that robs people of physical strength, including the ability to walk, eat, or breathe,” said IDPH Director Dr. Ngozi Ezike. “It is the number one genetic cause of death for infants. Early diagnosis of babies with SMA can lead to potentially life-saving interventions. By screening every baby born in Illinois, we hope to identify cases early so therapy can begin as soon as possible.”

SMA affects approximately 1 in 11,000 births. Beginning therapy as early as possible is the only way to prevent this motor neuron loss. For babies identified through newborn screening, treatment should begin even before the infant shows symptoms of SMA.

Currently, there are several FDA-approved treatments for SMA, and another six treatments are being tested in clinical trials.

Spinal muscular atrophy (SMA) was added to the federal Recommended Uniform Screening Panel (RUSP) for newborn screening in 2018. Evidence has shown that early diagnosis and treatment leads to better outcomes.

Implementing SMA screening required IDPH to purchase new equipment, develop new test methods, obtain Clinical Lab Improvement Amendments test validation, and modify computer systems to provide laboratory results and facilitate follow up tracking.

Additional information can be found on the dph.illinois.gov [website](#).

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