

SENATE CONCURRENT RESOLUTION NO. 16

BY SENATOR HEWITT AND REPRESENTATIVES BAGLEY, CHANEY, COX,
HOFFMANN, LEBAS, MCMAHEN, MOORE, POPE, STOKES AND
TURNER

A CONCURRENT RESOLUTION

To urge and request the Louisiana Department of Health to take such actions as are necessary to add Spinal Muscular Atrophy (SMA) to the newborn screening panel of this state.

WHEREAS, SMA is a progressive neurodegenerative disease that affects motor nerve cells in the spinal cord, diminishing all physical strength, impeding the ability to walk, swallow, and in severe cases, the ability to breathe; and

WHEREAS, SMA is the leading genetic cause of death for infants today, annually affecting approximately one out of eleven thousand babies born nationwide and approximately six babies born in Louisiana; and

WHEREAS, SMA is detectable through genetic testing, and early detection of this disorder is vital to ensure the expedited treatment and survival of babies born with SMA; and

WHEREAS, newborn screening identifies babies with congenital disorders like SMA; and

WHEREAS, in 2018, United States Health and Human Services Secretary Alex Azar approved the recommendation of the Federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) to add testing for SMA to the Recommended Uniform Screening Panel (RUSP) for newborns; and

WHEREAS, nearly four million newborns are screened annually in the United States for numerous diseases, and seven states are currently screening for SMA; and

WHEREAS, screening for SMA in a newborn is not included in Louisiana's current newborn screening panel.

THEREFORE, BE IT RESOLVED that the Legislature of Louisiana does hereby urge and request the Louisiana Department of Health to take such actions as are necessary to add SMA to the newborn screening panel of this state.

BE IT FURTHER RESOLVED that a copy of this Resolution be transmitted to the secretary of the Louisiana Department of Health.

PRESIDENT OF THE SENATE

SPEAKER OF THE HOUSE OF REPRESENTATIVES