HEALTH AND HUMAN SERVICES

Resolution HHS-20-31

A RESOLUTION ON ACCESS TO LIFESAVING TREATMENTS FOR SPINAL MUSCULAR ATROPHY (SMA) BABIES

WHEREAS, the National Black Caucus of State Legislators (NBCSL) has consistently supported the expansion of statewide screening of newborns;

WHEREAS, the NBCSL supports granting access to treatment to babies diagnosed with Spinal Muscular Atrophy (SMA), a rare genetic disorder that afflicts 1 in 11,000 children;

WHEREAS, the identification of the SMA disorder at birth and subsequent treatment administered immediately after the diagnosis is essential to saving the lives of the majority of these babies born with this disorder;

WHEREAS, SMA babies require diagnosis at birth as part of the approved newborn screening test, and Type 1, the most severe and most common type of SMA, typically leads to death of the infant early in life unless the infant is diagnosed at birth and then immediately treated;

WHEREAS, the NBCSL supports providing safe and effective treatment options to babies who otherwise will suffer irreversible loss of motor nerve cells that rob infants of the ability to walk, eat, or breathe, and for Type I SMA babies the ability to survive beyond the first two-years of life;

WHEREAS, the NBCSL recognizes that new breakthrough SMA treatments for this rare genetic disorder are expensive, and that many families with SMA babies face impossible economic barriers to care, and where many will be forced to become Medicaid eligible;

WHEREAS, states have discretion on which disorder screenings to include in their newborn screening panels;

WHEREAS, only two states currently test for all 35 disorders in the Recommended Uniform Screening Panel (RUSP) as approved by the HHS Advisory Committee on Heritable Disorders;

WHEREAS, the U.S. Congress has incentivized the development of new rare disease therapies, including gene replacement therapies that may save the lives of SMA babies;

WHEREAS, there are not currently adequate cost-sharing financing mechanism to ensure the required immediate treatment of SMA babies is administered, and that imposes an impossible financial burden on state Medicaid programs who are responsible for care of these eligible SMA babies;

WHEREAS, state Medicaid programs are financially stressed and are forced to conduct often lengthy reviews of high-cost treatment for high-cost rare disease patients, and those delays will doom SMA Type 1 babies to a lifetime of profound disabilities or possible death; and

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WHEREAS, the U.S. Congress should develop and enact a rare disease cost-sharing program or other innovative financing model for high cost treatments such as SMA treatments to remove financial barriers to needed SMA treatment, including Medicaid program reimbursement.

THEREFORE BE IT RESOLVED, that the National Black Caucus of State Legislators (NBCSL) calls upon the U.S. Congress to develop and pass a rare disease cost-sharing program or other innovative financing models with state Medicaid programs to ensure SMA babies receive timely treatment and that this situation does not happen for future treatments;

BE IT FURTHER RESOLVED, that the NBCSL calls upon every state to expedite on the addition of the SMA screen to its newborn screening panel by legislative or administrative means as soon as practical;

BE IT FURTHER RESOLVED, that states should expedite the passage of any needed statutory or regulatory policies that allows for safe and effective treatments for babies where the SMA gene defect is identified; and

BE IT FINALLY RESOLVED, that a copy of this resolution be transmitted to the President of the United States, the Vice President of the Unites States, members of the United States House of Representatives and the United States Senate, and other federal and state government officials and agencies as appropriate.

SPONSOR(S): Representative Billy Mitchell (GA) and Representative Vernon Jones (GA)
Committee of Jurisdiction: Health and Human Services Policy Committee
Certified by Committee Co-Chair: Representative David J. Mack, III (SC)
Ratified in Plenary Session: Ratification Date is December 6, 2019
Ratification is certified by: Representative Gilda Cobb-Hunter (SC), President