



MEMORANDUM

January 3, 2020

To: Subcommittee on Health Members and Staff

Fr: Committee on Energy and Commerce Staff

Re: Hearing on “Legislation to Improve Americans’ Health Care Coverage and Outcomes”

On Wednesday, January 8, 2020, at 10 a.m. in room 2322 of the Rayburn House Office Building, the Subcommittee on Health will hold a legislative hearing entitled, “Legislation to Improve Americans’ Health Care Coverage and Outcomes.”

I. H.R. 2271, THE SCARLETT’S SUNSHINE ON UNEXPECTED DEATH ACT

A. Background

Sudden unexpected deaths, often described as sudden unexpected infant death (SUID) occurring to infants under the age of one year and sudden unexpected death in childhood (SUDC) occurring to children between the ages of one through 18 years old, refer to cases where an infant or child dies suddenly without an obvious cause when first discovered.

SUID is a broad term that includes deaths that occur due to sudden infant death syndrome (SIDS), accidental suffocation in a sleeping environment, metabolic diseases, cardiac arrhythmias, infections, and other deaths from unknown causes in children under the age of one year.¹ SIDS is a diagnosis made after a thorough investigation of an infant’s death in which no cause of death can be determined.² If there is some uncertainty about the cause of death—i.e., whether the death was caused by SIDS or another factor—a coroner or death examiner may note the cause of death as “unknown.”³ Although the causes of SIDS are not often known, research suggests infants who die from SIDS often have brain abnormalities or defects (within a nerve cell network that send signals to other nerve cells), are in a critical development period, and are

¹ National Institutes of Health, *Common SIDS and SUID Terms and Definitions* (2019) (<https://safetosleep.nichd.nih.gov/safesleepbasics/SIDS/Common>).

² National Institutes of Health, *What is SIDS?* (2019) (safetosleep.nichd.nih.gov/safesleepbasics/SIDS).

³ *Id.*

exposed to outside stressors.⁴ There is currently no screening test to determine whether infants have certain brain abnormalities that may make them vulnerable to SIDS.⁵

In 2017, there were 3,600 cases of SUID in the United States.⁶ Of these, approximately 1,400 were caused by SIDS.⁷ While SUID affects all demographic groups, significant racial disparities exist: American Indian, Alaska Native, and black infants account for more than double the cases of SUID as white infants.⁸

Even less is known about SUDC. While data points to approximately 400 children ages 1-18 dying each year without a known cause despite an autopsy and investigation, there is very little data collection on SUDC and no code to report SUDC. While the Centers for Disease Control and Prevention (CDC) has a standardized form to collect investigation data on SUID, there is no standardization of investigation into SUDC.⁹

B. Legislation

H.R. 2271, the Scarlett's Sunshine on Unexpected Death Act, introduced by Rep. Gwen Moore (D-WI), would require CDC to revise the Sudden Unexplained Infant Death Investigation Reporting Form to include doll re-enactments and scene investigation information on sleep-related deaths of children under the age of five, and to align the form with the National Fatality Review Case Reporting System. The bill also authorizes CDC to make grants to improve the completion of comprehensive death scene investigations for SUID and SUDC, to increase the rate of comprehensive, standardized autopsies in cases of SUID and SUDC, and to train medical examiners, coroners, death scene investigators, law enforcement, and health professionals on standard death scene investigation protocols.

The bill also authorizes grants through the Administration for Children and Families (ACF) to assist states in investing in core capacity to review 100 percent of all infant and child deaths, and to develop review programs and prevention strategies. Additionally, the bill authorizes grants through the Health Services and Resources Administration (HRSA) to develop and implement educational programs and outreach related to sleep-related SUID, and programs to develop and deploy support services for families who have had a child die of SUID or SUDC.

⁴ National Institutes of Health, *Research on Possible Causes of SIDS* (2019) (safetosleep.nichd.nih.gov/research/science/causes).

⁵ National Institutes of Health, *What Causes SIDS?* (2019) (safetosleep.nichd.nih.gov/safesleepbasics/causes).

⁶ Centers for Disease Control and Prevention, *Sudden Unexpected Infant Death and Sudden Infant Death Syndrome Data and Statistics* (2019) (www.cdc.gov/sids/data.htm).

⁷ *Id.*

⁸ *Id.*

⁹ Laura Crandall and Orrin Devinsky, *Sudden Unexplained Death in Children*, *The Lancet Child and Adolescent Health*, Vol. I, Issue 1, 8-9 (2017).

Finally, the bill states that it is the sense of Congress that additional research is needed to improve the understanding of epidemiology of SUID and SUDC and requires the Department of Health and Human Services (HHS) to report data on SUID and SUDC.

II. H.R. 4801, THE HEALTHY START REAUTHORIZATION ACT OF 2019

A. Background

Out of every thousand births in the United States, 5.8 infants will die before the age of one year.¹⁰ Although this number decreased by 14 percent between 2007 and 2017, the United States continues to have one of the highest infant mortality rates among large countries with developed economies.¹¹ Large racial disparities also persist.¹² While the infant mortality rate for white infants is 4.9 per 1,000 births, the rate for American Indian and Alaska Native infants is 9.4 per 1,000 births, and the rate for black infants is more than double that for white infants, at 11.4 infant deaths per 1,000 births.¹³ The five leading causes of infant mortality are birth defects, preterm birth and low birthweight, SIDS, maternal pregnancy complications, and injuries.¹⁴

The Healthy Start Program aims to improve these statistics by reducing infant mortality and racial and other disparities in infant mortality and improving perinatal outcomes for women and children in high-risk communities.¹⁵ First begun as a demonstration program at HRSA in 1991, later authorized by Congress in 2000, and last reauthorized in 2008, the program provides grants to state and local community organizations in targeted areas with infant mortality rates that are at least 1.5 times the national average and/or with high indicators of poor perinatal outcomes, particularly among black and other disproportionately affected populations.¹⁶ Grant recipients provide services and community support to: (1) improve women's health before, during, and between pregnancies; (2) promote quality services; (3) strengthen family resilience; (4) achieve collective impact; and (5) increase accountability through ongoing quality

¹⁰ Centers for Disease Control and Prevention, *Infant Mortality* (2019) (www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm).

¹¹ Peterson Center on Health Care and Kaiser Family Foundation Health System Tracker, *What Do We Know About Infant Mortality in the U.S. and Comparable Countries?* (2019) (www.healthsystemtracker.org/chart-collection/infant-mortality-u-s-compare-countries/#item-start).

¹² *Id.*

¹³ *See* note 10.

¹⁴ Health Resources and Services Administration, *FY 2020 Budget Justification* (2019) (www.hrsa.gov/sites/default/files/hrsa/about/budget/budget-justification-fy2020.pdf).

¹⁵ *Id.*

¹⁶ *Id.*

improvement, performance monitoring, and evaluation.¹⁷ Grantees leverage existing resources in their communities and coordinate with other programs such as the Early Childhood Home Visiting Program, the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), Title V Maternal and Child Health Block Grant, Medicaid, and the Children’s Health Insurance Program (CHIP).¹⁸ Despite serving communities that have historically had much higher rates of infant mortality, grantees have shown improved outcomes in the communities they serve, including an overall infant mortality rate of 5.35 per 1,000 births, which is below the national average.¹⁹

B. Legislation

H.R. 4801, the Healthy Start Reauthorization Act of 2019, introduced by Rep. Tim Ryan (D-OH), would reauthorize the Healthy Start Program at \$135 million per year for five years, an increase of \$15 million per year above the last authorized level. The bill also makes technical changes to require HRSA to consider social determinants of health, high infant mortality rates, and poor perinatal health outcomes when awarding grants. The bill would also require the HHS Secretary to ensure coordination between the Healthy Start program and other HHS programs that aim to reduce infant mortality and improve perinatal outcomes. Finally, the bill requires the Government Accountability Office (GAO) to report to Congress on the Healthy Start program.

III. H.R. 2468, THE SCHOOL-BASED ALLERGIES AND ASTHMA MANAGEMENT PROGRAM ACT

A. Background

More than eight percent of children in the United States under the age of 18 live with asthma.²⁰ For these children and children with respiratory issues caused by asthma, access to appropriate treatment and trained personnel can mean the difference between life and death in emergency situations. In 2004, Congress authorized Children’s Asthma Treatment Grants to expand access to medical care for children who live in areas with a high prevalence of asthma. Support from these grants help educate parents, children, and health providers on asthma treatment and symptom prevention, and decrease preventable trips to the emergency room.²¹ The law included a preference in awarding grants to states that allow students to self-administer epinephrine in schools under certain circumstances. In 2013, Congress amended the law to

¹⁷ *Id.*

¹⁸ *Id.*

¹⁹ *Id.*

²⁰ Centers for Disease Control and Prevention, *Most Recent National Asthma Data* (2019) (www.cdc.gov/asthma/most_recent_national_asthma_data.htm).

²¹ P.L. 108-377.

award an additional preference to states that allow trained personnel in schools to administer epinephrine.²²

B. Legislation

H.R. 2468, the School-Based Allergies and Asthma Management Program Act, introduced by Rep. Steny Hoyer (D-MD), would add a preference for grants to those states that have additional access to certain healthcare professionals and programs. To be eligible for this preference, states would have to require: (1) the presence of a school nurse or other trained personnel on school premises during school operating hours; (2) that there be a school-based allergies and asthma program, including a method to identify all students in the school with a diagnosis of allergies and asthma; (3) an individual student allergies and asthma action plan for each student with a diagnosis of allergies and asthma; (4) education for staff about allergies and asthma; (5) efforts to reduce environmental triggers of allergies and asthma; and (6) a coordinated support system for students.

IV. H.R. 1379, THE ENSURING LASTING SMILES ACT

A. Background

Congenital anomalies are known as birth defects, congenital disorders or congenital malformations that are present at birth and are of prenatal origin. About three percent of children in the United States are born with congenital anomalies or birth defects that affect the way they look, develop, or function.²³ These individuals require serious medical treatment that can be outside the scope of what is covered by health plans, particularly for craniofacial and dental anomalies. As a result, patients experience significant out-of-pocket costs on medically necessary reconstructive care related to the disorder of the child during the child's lifetime.

B. Legislation

H.R. 1379, the Ensuring Lasting Smiles Act, introduced by Rep. Collin Peterson (D-MN), would require all individual and group market health plans to cover medically necessary treatment resulting from congenital abnormalities or birth defects. The bill requires plans to provide coverage for any service or treatment that is medically necessary to restore or achieve a normal appearance or function of the body.

²² P.L. 113-48.

²³ Centers for Disease Control and Prevention, *Birth Defects or Congenital Anomalies* (2019) (<https://www.cdc.gov/nchs/fastats/birth-defects.htm>).

V. **H.R. 2477, THE BENEFICIARY ENROLLMENT NOTIFICATION AND ELIGIBILITY SIMPLIFICATION ACT OF 2019 OR THE BENES ACT OF 2019**

A. **Background**

Individuals eligible to enroll in Medicare Part A also have the option to enroll in Medicare Part B, which generally covers physician and outpatient services. Those under age 65 who are receiving Social Security benefits or have received Social Security Disability Insurance (SSDI) for at least 24 months are automatically enrolled in Medicare Part A and Part B when they turn 65.²⁴ All other eligible individuals must choose to enroll in Medicare during either their initial enrollment period or the general enrollment period.

The initial enrollment period begins three months before the individual turns 65 and lasts for 7 months total. The coverage start date is determined by the date during the initial enrollment period that the individual enrolls. The general enrollment period occurs annually for three months (January 1 to March 31), with coverage beginning on July 1, in the particular year of general enrollment. A special enrollment period separately exists for those who have been continuously receiving employer sponsored coverage before choosing to enroll in Part B.²⁵

Beneficiaries who decide not to sign up for Part B during their initial enrollment period may be required to pay a permanent late enrollment penalty if they choose to enroll in Part B at a later date.²⁶ The late enrollment penalty could potentially amount to as much as a 10 percent increase in the individual's monthly Part B premium for each 12-month period wherein they delayed or did not enroll under Part B coverage. In 2018, 1.4 percent, or 760,000 Part B enrollees paid the late enrollment penalty. As a result, their premiums were 28 percent higher, on average, than they would have been without the penalty.²⁷

B. **Legislation**

H.R. 2477, the BENES Act of 2019, introduced by Rep. Raul Ruiz (D-CA), would improve beneficiary outreach and education, reduce gaps in coverage, and simplify the Part B enrollment process.²⁸ The BENES Act would require the Federal Government to send advance

²⁴ Congressional Research Service, *Medicare: Part B Premiums* (R40082) (Apr. 4, 2019) (crsreports.congress.gov/product/pdf/R/R40082).

²⁵ Medicare Rights Center, *Enrolling in Medicare with job-based insurance* (www.medicareinteractive.org/get-answers/coordinating-medicare-with-other-types-of-insurance/job-based-insurance-and-medicare/enrolling-in-medicare-with-job-based-insurance).

²⁶ Wall Street Journal, *Medicare Enrollment Can Be Confusing and Lead to Unexpected Costs* (Dec. 12, 2019) (www.wsj.com/articles/medicare-enrollment-can-be-confusing-and-lead-to-unexpected-costs-11576155600).

²⁷ See note 22.

²⁸ Medicare Rights Center, *Congress Must Streamline and Simplify Medicare Enrollment* (2019) (www.medicarerights.org/pdf/2019-benes-act-factsheet-long.pdf).

notice about the enrollment process to individuals approaching Medicare eligibility. It would also require that Part B coverage begin during the first month after an individual enrolls, through either the initial enrollment period or general enrollment period. The bill would further align the general enrollment period with the annual enrollment period for Medicare Advantage (MA) and Part D prescription drug plans, and it would also allow for the creation of a new Part B special enrollment period for “exceptional circumstances.”

VI. H.R. 5534, THE COMPREHENSIVE IMMUNOSUPPRESSIVE DRUG COVERAGE FOR KIDNEY TRANSPLANT PATIENTS ACT OF 2019

A. Background

Kidney transplant patients must take immunosuppressive drugs for the life of their transplant to reduce the risk of organ rejection. The Medicare End Stage Renal Disease (ESRD) program currently covers dialysis or transplantation regardless of a person’s age. However, if an individual who receives a kidney transplant is only eligible for Medicare coverage due to permanent kidney failure, Medicare will end coverage of immunosuppressive drugs for that person 36 months following the transplant procedure.²⁹ Without Medicare coverage the costs of these drugs may be prohibitive for some individuals, thereby increasing noncompliance and the risk of organ rejection. Organ rejection would cause the development of ESRD and require dialysis, which could potentially lead to a subsequent transplant. Recent analyses by HHS have found that extending Medicare coverage of immunosuppressive drugs for the life of the transplant would result in savings to the Medicare program by decreasing the instances of costly dialysis treatments.^{30,31} One analysis also found that 375 kidney transplant failures in 2015 alone were preventable had immunosuppressive drug coverage been extended.

B. Legislation

H.R. 5534, the Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2019, introduced by Rep. Ron Kind (D-WI), would permanently remove the 36-month limit for Medicare coverage of immunosuppressive drugs post-kidney transplant.

²⁹ Centers for Medicare and Medicaid Services, *Kidney Transplants* (www.medicare.gov/coverage/kidney-transplants).

³⁰ Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, *Assessing The Costs And Benefits Of Extending Coverage Of Immunosuppressive Drugs Under Medicare* (May 10, 2019) (aspe.hhs.gov/system/files/pdf/261746/Savings_From_Extending_Coverage_For_Immunosuppressive_Drugs_Final.pdf).

³¹ Department of Health and Human Services, Office of the Actuary, *Proposal to Extend Coverage of Immunosuppressive Drugs* (May 22, 2019) (www.documentcloud.org/documents/6193012-OACT-Estimate-Extension-of-Immunosuppressive.html).

VII. H.R. 3935, THE PROTECTING PATIENTS TRANSPORTATION TO CARE ACT

A. Background

Medicaid provides health insurance to approximately 70 million low-income and disabled individuals every year. Many of these individuals lack access to reliable transportation. In order to ensure that beneficiaries can reach medical providers, long-standing federal regulations require state Medicaid programs to cover non-emergency medical transportation (NEMT) as a mandatory benefit.³² NEMT covers a variety of transportation options, including public transit, taxis, and van services. It is available for beneficiaries in both rural and urban settings. The NEMT benefit is unique among mandatory Medicaid benefits in that it is not mandated pursuant to statute but is required through regulations. It is estimated that the NEMT benefit makes up less than one percent of annual Medicaid expenditures.³³

B. Legislation

H.R. 3935, the Protecting Patients Transportation to Care Act, introduced by Rep. Earl “Buddy” Carter (R-GA), would amend the statute to include NEMT in the list of mandatory Medicaid benefits by codifying current Medicaid NEMT regulations. The bill would also require state Medicaid programs to have in place a prior authorization or utilization management process for the benefit.

VIII. WITNESSES

Panel I:

Lee Beers, M.D.

President-Elect
American Academy of Pediatrics

Kenneth Mendez

President and Chief Executive Officer
Asthma and Allergy Foundation of America

Stephanie Zarecky

Mother of Scarlett Pauley
Ambassador Program and Public Relations Manager
SUDC Foundation

³² Kaiser Family Foundation, *Medicaid Non-Emergency Medical Transportation: Overview and Key Issues in Medicaid Expansion Waivers* (Feb. 24, 2016) (www.kff.org/medicaid/issue-brief/medicaid-non-emergency-medical-transportation-overview-and-key-issues-in-medicaid-expansion-waivers/).

³³ *Id.*

Panel II:

Matthew Cooper, M.D.

Director, Kidney and Pancreas Transplantation
Medical Director, Transplant QAPI
Medstar Georgetown Transplant Institute
Professor of Surgery
Georgetown University School of Medicine

Kevin Koser

Patient Advocate

Fred Riccardi

President
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