

**TESTIMONY OF STACEY D. STEWART
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**BEFORE A HEARING OF
THE HOUSE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE OF ENERGY
AND COMMERCE**

**“ENHANCING PUBLIC HEALTH: LEGISLATION TO PROTECT CHILDREN AND
FAMILIES.”**

**U.S. HOUSE OF REPRESENTATIVES
10:30 A.M. OCTOBER 20, 2021**



Good morning, Chairwoman Eshoo, Ranking Member Guthrie, and members of the Subcommittee. Thank you for the opportunity to testify at today's hearing to shine a light on key programs that improve the public health for children and families.

I am Stacey Stewart, President and CEO of March of Dimes. We lead the fight for the health of all moms and babies. We began that fight more than 80 years ago as an organization dedicated to eradicating polio in the U.S., a goal that we achieved. We continue that fight today as we work to address some of the biggest threats to moms and babies, such as premature birth and maternal mortality, through research, education, programs and advocacy.

March of Dimes' ongoing work to improve maternal and infant health is more important than ever as our nation is in the midst of a dire maternal and infant health crisis. Rates of preterm birth are increasing, the U.S. is one of the most dangerous places to give birth in the developed world, and there are unacceptable disparities in birth outcomes between women and infants of color and their White peers.

We know the pandemic has only worsened this crisis. According to CDC data, expectant mothers with the virus had a 50 percent higher chance of being admitted to intensive care and a 70 percent higher chance of being intubated than non-pregnant women in their childbearing years.¹ The data also shows pregnant Latina and Black women were infected at higher rates than White women.

Pregnancy affects every system in a woman's body and the immune system changes so that it can protect not only the mother, but the baby. This can make pregnant women more susceptible to certain infections as different parts of the immune system are enhanced while

others are suppressed. Therefore, it is crucial that pregnant and lactating women have access to COVID-19 vaccines. They must be included in vaccine trials so that there is data to allow them to make informed decisions with their medical providers about getting the vaccine and to ensure that the vaccine is safe and effective for them.

We also know, the health and well-being of mothers and infants are inextricably linked. By improving the health of women before, during and between pregnancies, we can improve outcomes for both them and their infants. But we have many challenges before us.

RECOGNIZING PREGNANCY AND INFANT LOSS AWARENESS MONTH

We know 1 in 4 individuals and families' lives are affected by the death of their children during pregnancy, at birth, and in infancy. Experiences of loss vary for each individual and family, can include depression, anxiety, changes in relationships, development of unhealthy coping mechanisms, and Post Traumatic Stress Disorder (PTSD). This month, we are honoring babies who left us too soon by raising awareness as part of Pregnancy and Infant Loss Awareness Month – we've invited those who've experienced the loss of a baby or an expectant or new mom, to leave a message on our Wall of Remembrance as a tribute to them who will always be in our hearts. The Wall of Remembrance (marchofdimes.org/remembrance) is a safe space to honor your loved one by sharing a tribute and finding comfort by joining a community of others living with loss.

OUR NATION IS IN THE MIDST OF A MATERNAL AND INFANT HEALTH CRISIS

Nearly every measure of the health of pregnant women, new mothers, and infants living in the U.S. is going in the wrong direction. In many communities, infant mortality rates exceed those

in developing nations.ⁱⁱ Approximately every 12 hours, a woman dies due to pregnancy-related complications.ⁱⁱⁱ

Preterm Birth

Each year, March of Dimes releases its annual Report Card grading the U.S., each of the states, DC, and Puerto Rico, on their progress toward improving maternal and infant health.^{iv} Our most recent 2020 report found the nation's preterm birth rate rose for the fifth year in a row in 2019 to 10.2 percent. This startling increase comes after nearly a decade of decline. As you might expect, the worsening national picture does not signal good news in individual states. Between 2018 and 2019, preterm birth rates worsened in 38 states. What do these statistics mean for the nation's families? They mean 1 in every 10 babies are born preterm, which can lead to life-long health problems and, in the most tragic cases, a baby's death.

These topline numbers tell only part of the story. Diving deeper into the data highlights an even starker reality for certain communities. With preterm birth rates as high as 14.6 percent (Mississippi), 13.1 percent (Louisiana), and 12.5 percent (Alabama), infants born in the southeastern U.S. are much more likely to be born early than in other parts of the country. Racial disparities exist across the U.S. Hispanic, American Indian/Alaska Native, and Black babies are born premature at a rate surpassing their White peers. In fact, the preterm birth rate among Black women is 50 percent higher than the rate among all other women-combined.

Maternal Health

The state of maternal health mirrors that of infants born too soon. Outcomes are getting worse and those worsening outcomes are driven by disparities. Each year, about 700 women die from

complications related to pregnancy.^v For every maternal death, another 70 women suffer life-threatening health challenges. That’s over 50,000 women each year.^{vi} While other countries have reduced their maternal mortality rates since the 1990s, the U.S. maternal mortality rate continues to rise.^{vii}

The threat of maternal mortality and morbidity is especially acute for women of color. Black mothers of all ages are three times more likely to die from pregnancy-related complications than their White peers.^{viii} The rates of pregnancy-related death for Black and American Indian/Alaska Native women over the age of thirty are 4 to 5 times higher than their White peers.^{ix} Black women are 27 percent more likely to experience severe pregnancy complications than White women.^x These disparities cannot be explained by differences in age or education. According to the latest CDC data, maternal mortality rates among Black women with a completed college education or higher was 1.6 times that of White women with less than a high school diploma.^{xi}

Maternal mortality is also significantly higher in rural areas, where obstetric providers may not be available^{xii} and delivery in rural hospitals is associated with higher rates of postpartum hemorrhage.^{xiii} In September 2020, March of Dimes released an updated report showing that 2.2 million women of childbearing age live in “maternity care deserts,” which are counties without a hospital, birth center or providers offering obstetric services.^{xiv} An additional 4.8 million women of childbearing age live in counties with limited access to maternity care. Each year, 150,000 babies are born to mothers living in these maternity care deserts.^{xv}

But it is not just access to quality prenatal care that makes the difference. Improving the health of a mom before she becomes pregnant and in the postpartum period are essential to maternal and infant health. Chronic conditions begin long before a woman becomes pregnant, such as high blood pressure, diabetes, heart disease and obesity, putting women at higher risk of pregnancy complications and must be appropriately managed. We know that more than one-third of pregnancy-related deaths from 2011 to 2016 were associated with cardiovascular conditions.^{xvi}

We also know the “4th trimester,” the 12-week period immediately after birth, is a vulnerable time for moms, babies and families and so it is imperative to ensure mothers are receiving adequate care during this postpartum period. About 1 in 8 women experience symptoms of postpartum depression.^{xvii} These conditions are the most common complication of pregnancy and childbirth, impacting an estimated 800,000 women in the U.S. each year.^{xviii}

Sadly, maternal mental health conditions often go undiagnosed and untreated, increasing the risk of multigenerational long-term negative impact on the mother’s and child’s physical, emotional, and developmental health, and the risk of poor health outcomes. Furthermore, women of color and women who live in poverty are disproportionately impacted by both the pandemic and maternal mental health conditions, experiencing both at rates 2-3 times higher than White women.^{xix xx}

A MULTIFACETED RESPONSE IS NECESSARY

This has led to an urgent crisis that demands a comprehensive response by policymakers. The causes of our nation’s maternal and infant health crisis are complex, and there is still much we

do not know. That is why March of Dimes was pleased Congress passed the *Preventing Maternal Deaths Act* (P.L. 115-344) and the *PREEMIE Reauthorization Act* (P.L. 115-328) in late 2018. Both bills enable the continuation of vital programs to collect enhanced data on the causes of maternal mortality and premature birth, respectively, and translate that data into meaningful action to prevent future deaths. We are hopeful new efforts will spur further action. March of Dimes is thrilled to see that the Biden-Harris Administration has made a commitment to ensuring maternal and infant health disparities are eliminated. We look forward to working with the Administration and Congress to enact new policies that will tackle this health crisis head on.

However, we must continue to also focus on the other public health challenges facing us and utilize the tools at our disposal to improve the health of children and families.

H.R. 5487, “Stillbirth Health Improvement and Education for Autumn Act of 2021” or SHINE for Autumn Act

Stillbirth is a pregnancy loss of a baby at or after 20 weeks of pregnancy. Stillbirth impacts 1 in 160 births, and each year 24,000 babies are stillborn in the United States.^{xxi} Despite, medical innovations, stillbirth has remained relatively unchanged. Stillbirth occurs in all races, ethnicities, income levels, and to women of all ages – leaving no pregnancy immune. However, there are longstanding and persistent racial, ethnic, age, and educational disparities. Stillbirth has serious psycho-social consequences on parents and families. Women suffer from serious forms of anxiety, depression, loss of self-esteem and guilt, sometimes aggravated by the insensitive health system, as well as strained marital relationship and financial burdens.

This bill will take critical steps to invest in research and data collection to better understand stillbirth in the U.S., with the goal of lowering the stillbirth rate. Additionally, it will provide critical resources to the CDC, NIH, and local state departments of health to improve stillbirth data collection and increase education and awareness around the issue of stillbirth. It is the beginning of a longer-term solution towards the prevention and reduction of incidences of stillbirth. This legislation will allow us to better track and research stillbirths and who is impacted and the role disparities have in negatively impacting infant and parental health.

H.R. 5551, the "Improving the Health of Children Act"

March of Dimes is a proud partner of the National Center for Birth Defects and Developmental Disabilities (NCBDDD). Since 2001, the Center has been instrumental in advancing the health and well-being of our nation's most vulnerable populations, with a focus on four critical areas:

- o Saving babies through surveillance, research, and prevention of birth defects and infant disorders;
- o Helping children live to the fullest by understanding developmental disabilities;
- o Protecting people by preventing the complications of blood disorders; and
- o Improving the health of people living with disabilities.

This legislation would reauthorize the Center for the first time in 15 years. It would both expand the Center's role and authorize new funding enabling the agency to continue carrying out more than a dozen programs. It makes critical investments to support the Center's tracking and public health research system that provides a wealth of information used to identify causes of birth defects, find opportunities to prevent them, and improve the health of those living with

birth defects. The Center works closely with states, academic centers, healthcare providers, and other partners to advance this work.

The Center has accelerated the search for the causes of autism and ways to address the needs of families and communities.^{xxii} Their tracking system provides an accurate picture of autism across the United States, and they conduct the largest study of its kind to better identify risk factors and causes. Better tracking, research, and improved early identification are leading us to a better understanding of autism and better results for children.

The Center has also focused on addressing blood disorders that affect millions of people each year in the United States, cutting across the boundaries of age, race, sex, and socioeconomic status. With proper preventive actions and early intervention, many of these disorders and their complications could be eliminated.

The Center's work has been critical in advancing health care for people with disabilities so they can stay well, active, and a part of the community. When children and adults with disabilities receive needed programs, services, and health care they can have an improved quality of life and experience independence. In addition, for the first time, this bill would provide funding for folic acid education and outreach. March of Dimes has long supported the inclusion of folic acid in the diet of pregnant women. Most recently, we funded a four year study on the inclusion of folic acid in corn masa flour that led to the FDA approving a 2016 petition to ensure producers of masa flour can fortify their product with folic acid and do their part to improve the health of mothers and babies.^{xxiii}

March of Dimes is a strong supporter of the CDC's Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET) within NCBDDD. SET-NET was created during the Zika outbreak,

which allowed CDC to create, a unique nationwide mother-baby linked surveillance network to monitor the virus' impact in real-time to inform clinical guidance, educate health care providers and the community, and connect families to care. Unfortunately, states were unable to sustain systems due to the program due to chronic underfunding, and we were left without a national system to mobilize when the COVID-19 struck.

Now as the pandemic continues, we must ensure that SET-NET is taken to scale nationally so that we have a complete picture on how to best care for mothers and babies with confirmed or suspected viral infections. We hope the resources authorized under this legislation will allow CDC to address current knowledge gaps and expand the initiative to provide real-time clinical and survey data from all 50 states, territories and jurisdictions on the impact of COVID-19.

H.R. 5552, the "Lead Poisoning Prevention Act"

Lead poisoning can have a serious impact on pregnancy as lead can be passed to a baby through the placenta. Exposure to high levels of lead before and during pregnancy can cause fertility problems, hypertension, abnormal brain development of a baby, premature birth, low birthweight and miscarriage.^{xxiv} Children younger than six years can be severely affected by lead's impact on the development of the brain and body. Very high levels can cause death. Signs and symptoms of lead poisoning in children include fatigue, abdominal pain, developmental delays and learning problems, hearing loss, loss of appetite and weight loss, and vomiting.^{xxv} Lead poisoning contributes to our country's maternal health crisis, which has been particularly devastating for underserved families of color. A 2020 study demonstrated the risk of lead poisoning falls disproportionately on minority children, as well, with black children nearly four times more likely than white children to have elevated blood-lead levels.^{xxvi} This

legislation would continue to provide critical resources for educational outreach, screenings, and referrals, as well as codify the CDC's Advisory Committee on Childhood Lead Poisoning Preventions. Most importantly, it would help prevent lead exposure to children before they are harmed.

H.R. 5561, the "Early Hearing Detection and Intervention Reauthorization Act"

This legislation reauthorizes the national program administered jointly through the Health Resources and Services Administration (HRSA), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) for the early identification and diagnosis of hearing loss and intervention services for deaf and hard-of-hearing newborns and infants, and young children who are at risk of losing their hearing during childhood from infection, harmful noise exposure, or genetic causes.

According to NIH, prior to the establishment of a federal universal newborn infant hearing screening program in 1999, less than 10 percent of newborns in the U.S. were screened for hearing loss. As a result, 47 percent of children born with hearing loss were not diagnosed until their third birthday or later, missing a crucial period for language acquisition.^{xxvii}

According to the CDC, currently around 98 percent of newborns are screened for hearing loss in the U.S. annually.^{xxviii} Up to 3 in 1,000 babies (less than 1 percent) are born with some kind of hearing loss in the United States each year.^{xxix} Since 2005, more than 50,000 infants who are deaf and hard-of-hearing have been identified within the first year of life. Unfortunately, some infants needing additional testing or early intervention did not receive these important follow-up services.^{xxx}

HRSA provides grants to States to support continuous improvement of Early Hearing and Detection programs through the development of early hearing detection and intervention systems; recruitment, education, and training of staff and health care providers with current knowledge, evidence-based practices, and national EHDI system goals; ensuring families have access to information that is accurate, comprehensive, up-to-date, and evidence-based allowing families to make crucial decisions for their children in a timely manner, including decisions concerning the full range of assistive hearing technologies and communication modalities; and establishing and fostering family-to-family and consumer-to-family supports and health care provider education that are important after a child has been identified as deaf or hard of hearing. Additionally, CDC has awarded funding to support NCBDDD's Outcomes and Developmental Data Assistance Center for Early Hearing Detection and Intervention. This new Center will expand public health capacity to gather, analyze, and use intervention and developmental outcome data of children who are deaf or hard of hearing.

CONCLUSION

March of Dimes thanks the Subcommittee for focusing attention on some of the nation's most important public health challenges. As we continue to work on advancing new policies, our nation must continue to invest in the programs already in our toolbox to improve the health of mothers, infants, and families. With your help, we can make strides to prevent pregnancy loss, preterm birth, end preventable maternal deaths, and improve the health of children through better prevention. March of Dimes stands ready to work with you to achieve that change. I look forward to your questions.

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