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MARCH OF DIMES

BEFORE A HEARING OF THE

**HOUSE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE OF ENERGY AND
COMMERCE**

**“EXAMINING PROPOSALS THAT PROVIDE ACCESS TO CARE FOR PATIENTS
AND SUPPORT RESEARCH FOR RARE DISEASES.”**

U.S. HOUSE OF REPRESENTATIVES

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**HEALTHY
MOMS.
STRONG
BABIES.**



Good morning, Chairman Guthrie, Ranking Member Eshoo and members of the Health Subcommittee. Thank you for the opportunity to testify at today's hearing on "Examining Proposals that Provide Access to Care for Patients and Support Research for Rare Diseases." We commend the Subcommittee for holding today's hearing regarding the need to ensure that our government continues with its commitments to research and prevention programs, in order to eliminate preventable preterm birth and address the worsening maternal health crisis.

My name is Dr. Elizabeth Cherot, and I am Senior Vice President and Chief Medical and Health Officer at March of Dimes. March of Dimes leads the fight for the health of all moms and babies. We began that fight 85 years ago as an organization dedicated to eradicating polio in the United States. The achievement of this goal did not end our mission to strive for better health outcomes. On the contrary, 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.

THE STATE OF MATERNAL AND INFANT HEALTH

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. Today in the U.S., an average of two women die every day from complications of pregnancy and childbirth, and two babies die every hour.¹ On March 16th, the Centers for Disease Control and Prevention (CDC) released its 2021 Maternal Mortality Rates Report which showed an increase of nearly 89% in the maternal mortality rate since 2018. Improving the landscape for maternity care continues to be of utmost importance, as almost two-thirds (63%) of pregnancy-related deaths

are preventable. At the same time, the number of women who experience pregnancy-related complications, or severe maternal morbidity, is steadily increasing. At least 50,000 women are affected each year, and this number is likely an underestimation since no new data have been available at the national level since 2014.²

This problem is exacerbated by the presence of many maternal care deserts that exist in our nation. Maternity care deserts are counties where there is a lack of maternity care resources, such as hospitals, birth centers, and care providers. The resulting lack of access to care presents one of the biggest barriers to safe, healthy pregnancies, and often imposes economic strains on our most vulnerable communities.

Nearly 7 million women, representing 1 in 8 babies, are living in communities with either no access or limited access to maternity care. For some populations, the problem is even worse: 1 in 6 Black babies and 1 in 4 Native American babies are born in areas with no access or limited access to maternity care services.

Furthermore, in 2020, there were 1,347 counties - 42.9% - where every preterm infant was born outside their county of residence, indicating a need for families to travel to receive risk-appropriate care.³ According to the National Center for Health Statistics, Hispanic, Asian and Pacific Islander women are also less likely to receive adequate prenatal care when compared to White women.⁴

PRETERM BIRTH

Preterm birth is a complex expression of many overlapping conditions affecting mother and baby. According to the CDC, "Preterm birth is when a baby is born too early, before 37

weeks of pregnancy have been completed.” In the final weeks of pregnancy, infants undergo vital growth and development, including the development of the brain, lungs and liver.⁵ March of Dimes’ latest preterm birth report card shows that rates of preterm birth have increased for the past decade. 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.

Across the U.S., more than one in every 10 babies is born too early, often resulting in long-term health consequence, and between 2018 and 2019, preterm birth rates worsened in 38 states. Preterm birth, along with low birth weight babies, make up the second leading cause of infant death after birth defects. Preterm birth accounts for 35.8% of infant deaths in the U.S. that is approximately 137,000 children lost and families grieving.⁶

While the most recent preliminary 2022 CDC data on preterm birth is showing a slightly positive improvement, preterm birth rates have only fallen by a mere 1% to 10.38%.⁷ This small decrease in preterm births, while promising, only highlights the need to redouble our efforts to invest in research, support education, and advocate for policy change that will combat chronic inequities among birthing people. Our most recent report found U.S. preterm birth rate has steadily increased since 2014 to 10.5% in 2021, with a significant 4% increase in just one year and the highest recorded rate since 2007. This represented an increase to 383,082 preterm births. This startling increase came after nearly a decade of decline.⁸

Pregnancy can be impacted by a myriad of causes including: individual behaviors and chronic health conditions, psychosocial factors, community and neighborhood characteristics, job

stresses, environment exposures, assisted reproductive treatments, support networks and genetics and other biological factors. Negative impacts from a combination of these factors impact low-income, rural and minority mothers more often.

Beyond the impacts to the private insurance market, there are significant impacts to state Medicaid budgets as Medicaid pays for 40% of all deliveries and an estimated 40% of the medical costs associated with preterm birth. In 2019, the annual societal economic cost was an estimated \$25.2 billion:

- \$17.1 billion is spent on the babies' medical care services;
- \$2 billion for maternal delivery costs, \$4.8 billion on indirect costs associate with lost labor market productivity;
- \$700 million on intervention; and
- \$620 million on special education services.

The entirety of costs associated with preterm birth extend far beyond just medical costs associated with a preterm birth. The above estimate does not include certain costs, such as caregiver costs and lost earnings, which are likely substantial. It also does not include lifetime costs associated with certain disabilities associated with preterm birth.⁹ Information on the magnitude of the extended public liability is also limited, which includes services and social support, educational costs, income supports and many other public programs for the family and infant through their lifetime, an average of 77 years.¹⁰

Racial disparities exist across the U.S., with Black, Native American, and Hispanic babies born premature at a rate surpassing their White peers. In fact, Black and Native American women

are 62% more likely to give birth preterm and their babies are twice as likely to die as compared to White women.¹¹ Our 2022 March of Dimes Report Card found the following disparities:

- Black women: 14.7% in 2021, up from 14.4%;
- Native American/Alaskan Native women: 12.3% in 2021, up from 11.6%;
- Hispanic American women: 10.2% in 2021, up from 9.8%;
- Asian/Pacific Islander women: 9.2% in 2021 up from 8.5%; and
- White women: 9.5% in 2021, up from 9.1%.

These broad national numbers only tell a part of the story, with vast differences in pregnancy outcomes between states. Our 2022 March of Dimes Report Card shows:

- Kentucky received a grade of F in our Report Card due to a 12% preterm rate and the infant mortality rate of 6.2 per 1,000 births. Preterm birth cost Kentucky's citizens and health care system nearly \$368.6 million in 2016.
- Indiana received a D with 10.9% of births preterm, an infant mortality rate of 6.6 per 1,000 births and cost \$518 million.
- Texas was graded D- due to its 11.4% preterm birth date and mortality rate of 5.2 per 1,000 births. Texans paid an astonishing \$2.562 billion in 2016.
- In contrast, California received a B- due to its 9.1% preterm birth rate and infant mortality of 3.7. However, even with its improved rates, preterm birth cost California more than \$3.165 billion.

- Similarly, although Idaho also received a B- as well with a 9% preterm birth rate and infant mortality of 5.1 per 1,000 births, preterm birth cost Idaho more than \$110 million.^{12,13}

The current methods for diagnosis and treatment are based on inadequate research and not enough is known about how preterm birth can be prevented from occurring. Two-thirds of preterm birth occur without any evident risk factor.¹⁴ Part of the reason for this is that only some risk factors associated with preterm birth have been identified, such as preeclampsia, and the “biological basis for many of these risk factors and the underlying mechanisms remain poorly understood,”¹⁵ impacting our understanding and ability to address preterm birth through effective prevention and treatment. This uncertainty is even greater concerning the non-medical causes of preterm birth, in which to date, there is limited research and few prevention programs developed from it.

Many treatments have focused on inhibiting contractions, which does not prevent preterm birth, but only delays delivery long enough to care for a mother in the hospital where she can receive treatment. Because of the overlapping factors impacting mother and baby, it is difficult to pinpoint a single cause or a “silver bullet” cure. Due to the complexities of pregnancy complications, practitioners and parents are most often lead to deliver preterm and try their best to care for babies born preterm if they survive. Babies born preterm may suffer long-term impacts such as intellectual and developmental delays, behavioral problems, neurological disorders, visual and hearing impairments, cerebral palsy, and respiratory or intestinal insufficiency.¹⁶

While 70% of preterm births occur between 34-37 weeks, those babies born preterm, particularly before 32 weeks are at higher rates of death and disability.¹⁷ Preterm babies have a greater chance of survival when born later in pregnancy, with 94% of those born at 28 weeks surviving to hospital discharge and roughly 11% born at 22 weeks surviving to discharge.¹⁸ This reflects the enormous gains made in treating infants born preterm and improving survival. Unfortunately, these statistics also underscore the case for prevention, where we need to make significant strides moving forward if we are to prevent preterm birth and the need for expensive and emotionally challenging NICU stays for families.

LIVED EXPERIENCES

Let me share two stories with you that personify the various lived experiences faced by families with preterm children who have survived.

The Wilton's

- *The first is Katie Wilton of Phoenix, Arizona showing the need for research to support medical care, the impact it can have in protecting preterm children, and the impact of preterm birth on parents. After discovering she was pregnant at her first wedding anniversary, she began facing life threatening complications at 22 weeks when she began hemorrhaging.*

While Katie was experiencing guilt regarding the “failure” of her body, her husband Kevin was faced with a different set of questions: “What can I do to help my wife in this situation? How can I be supportive? How do I fix this?” The hardest part for him, on top of having no answers, was not being able to do anything.

During the next eight weeks she suffered two more bleeding episodes and her doctors had no idea what was causing the bleeding. At 29 weeks and 2 days, Katie found herself in preterm labor. When she arrived at the hospital she was given many medications to slow her labor and prepare for Collette's early arrival. Unknown to her, Katie was having chronic placental abruption where the placenta prematurely separates from the uterine wall during her pregnancy. Colette was born at exactly 30 weeks gestation at 3 lbs., 1 oz. and was 14 inches long. Colette had Intrauterine Growth Restriction and her length was so stunted in utero and wasn't even on the premie growth curve at birth. Colette was given live-saving medications including surfactant therapy, a treatment developed by March of Dimes-funded research, to advance her lung development. As a result, she spent 63 days in a NICU with her mother spending 12 hours a day with her.¹⁹

The Baldwin's

The next story is representative of what could be achieved for all families if medical science and preterm research are supported. Hannah Baldwin, from Maryland, gave birth to micro-preemies on September 25th, 2021 at 23 weeks and 5 days pregnant. Her girls faced many challenges and she would later find out that statistically, the survival rate for a single child, let alone twins, was about 25%.

Twin A had a Patent ductus arteriosus, or PDA, that needed to be closed surgically. She had brain bleeds, Bronchopulmonary Dysplasia (BPD) and Retinopathy of prematurity (ROP) which needed laser eye surgery, along a whole list of other complications that would pop up. Twin B, had a stroke in her brain, and also suffered from PDA, BPD, ROP

and just like her sister, a long list of things that would pop up throughout their time in the NICU.

During their twins' 136 and 137-day NICU stays, Hannah and her husband would hold them for as long as they could, would change their diapers, help with care, and do anything they could to feel like "normal" parents. They prayed over them at every visit, sang to them, read books, and sometimes, would just stare at them overcome with both love and fear. Their miracle girls came home without any medical equipment and taking full bottle feeds, something they were told would not happen. Without advances in premie care, these two beautiful twins would not have survived to come home to their loving parents.²⁰

These stories, and the hundreds of thousands of others a year like them, highlight the need for us to do more. This is why we need to reauthorize and update the PREEMIE Act.

THE PREEMIE REAUTHORIZATION ACT OF 2023

First, I would like to thank Representatives Michael Burgess (R-TX), Anna Eshoo (D-CA), Mariannette Miller-Meeks (R-IA), Robin Kelly (D-IL), Jen Kiggans (R-CA) and Lisa Blunt Rochester (D-DE) for working together on a strong bipartisan basis to introduce this critical legislation.

Last reauthorized in 2018 and expiring this year, the PREEMIE Reauthorization Act of 2023 (H.R. 3226) represents the federal government's commitment to preventing preterm birth and its consequences, a leading contributor to infant death. Through improved prevention programs and research, it will help reduce preterm birth, prevent newborn death and disability caused by

preterm birth, expand research into the causes of preterm birth, and promote the development, availability, and use of evidence-based standards of care for pregnant women.

Among the Centers for Disease Control and Prevention (CDC) and the Health Resources and Services Administration (HRSA) programs authorized by the PREEMIE Act is the CDC's highly successful Pregnancy Risk Assessment Monitoring System or PRAMS. PRAMS collects site-specific, population-based data in 50 jurisdictions tracking maternal attitudes and experiences before, during, and shortly after pregnancy on 81% of births and is used by researchers and state, territory, and local governments to plan and review programs and policies aimed at reducing health problems among mothers and infants. This data, which is not available from other sources, highlights the vital nature of this program in improving the understanding of the risks facing moms and babies.

PREEMIE also seeks to further coordinate and align Department of Health and Human Services (HHS) activities and programs related to preterm birth, infant mortality, and other adverse birth outcomes by creating a new interagency working group. This will improve our government's endeavors to better understand and prevent preterm birth through improved efficiencies while reducing duplication of activities.

Discovery research to expand the quality and volume of data will continue to remedy the continuing knowledge gap which may lead to more avenues for prevention and treatment. Vitality, PREEMIE will also provide for a new study by the National Academies of Sciences, Engineering, and Medicine to better understand the:

- The financial costs of premature birth to society, including long-term costs to society and families of NICU stays and post-discharge care;
- The factors that impact preterm birth rates;
- Identifying gaps in public health programs that have caused increases in premature birth
- Identifying gaps in information from States on preterm birth;
- Provide an analysis of 1) research strategies to develop effective drugs, treatments, or interventions to bring at risk pregnancies to term, 2) State and other programs' best practices with respect to reducing premature birth rates and 3) precision medicine and preventative care approaches starting early in the life course; and
- All raw data collected through the study will be made available to researchers allowing and promoting independent research on preterm birth.

With preterm birth increasing at startling rates across the country, impacting 383,000 babies each year, we must act to increase our efforts. We must better understand the cause of preterm birth, what has caused this shocking increase, and what we can do to prevent preterm birth to allow our moms and babies the best start at life possible.

March of Dimes, through our five Prematurity Research Centers (PRCs), is working to make an impact to end preventable preterm birth by approaching research in several key ways - through descriptive research that aims to characterize and understand the factors that lead to preterm birth and other adverse outcomes; and through work that leads to mitigation and prevention of preterm birth - through therapeutics, diagnostics, and policy changes.

This has led to impactful discoveries, including microbiome studies leading to bedside testing; rapid, low cost predictive testing; early detection of preeclampsia and other adverse pregnancy outcomes through several approaches, including cell-free RNA, data analytics, and other diagnostic markers; and understanding maternal-infant nutrition, and how breastfeeding can improve outcomes. However, we need the support of Congress to fund necessary research beyond these examples and create prevention programs that will make a meaningful impact.

The PREEMIE Act would do exactly that. We look forward to the PREEMIE Act's passage this Congress.

PREVENTING MATERNAL DEATHS REAUTHORIZATION ACT OF 2023

The United States has one of highest maternal mortality rates in the developed world, and women die every day from pregnancy-related complications. In a bipartisan effort to address this crisis, Congress passed the Preventing Maternal Deaths Act of 2018.²¹ Led by Representatives Michael Burgess (R-TX) and Diana DeGette (D-CO), H.R. 3838, the Preventing Maternal Deaths Reauthorization Act of 2023 would strengthen and expand federal support for Maternal Mortality Review Committees (MMRCs).

This legislation provided for federal support to states to create MMRCs that are tasked with identifying maternal deaths, analyzing the factors that contributed to those deaths and translating the lessons into policy changes. MMRCs are staffed by representatives in public health, obstetrics and gynecology, maternal-fetal medicine, nursing, midwifery, forensic pathology, mental and behavioral health, patient advocacy groups, and community-based organizations.

MMRCs play an invaluable role as they are critical to understanding and narrowing racial disparities in outcomes. For example, MMRCs have revealed that cardiac-related issues are the leading cause of death for mothers and that the majority of deaths don't occur during childbirth but in the days and weeks after childbirth.

Currently, CDC supports MMRCs in 39 states and one territory under the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) Program. This funding directly supports agencies and organizations that coordinate and manage MMRCs to identify, review, and characterize pregnancy-related deaths; and identify prevention opportunities. Specifically, the goal is:

- Facilitating an understanding of the drivers of maternal mortality and complications of pregnancy and better understand the associated disparities;
- Determining what interventions at patient, provider, facility, system, and community levels will have the most effect; and
- Informing the implementation of initiatives in the right places for families and communities who need them most.

Here are a few examples of how state MMRCs have taken on this charge and implemented best practices:

In California, the state MMRC developed a series of practices, including a toolkit²² to respond to obstetric hemorrhaging, which serves as a guide and support providers, staff, and hospitals to develop methods within their facilities for timely recognition and an organized, swift response

to hemorrhage. The toolkit was recently revised to address best practices on risk assessment, active management of third stage labor, and prevention and treatment recommendations.²³

In Kentucky, the state's newly formed Perinatal Quality Collaborative (PQC) have developed a working group to incorporate the recommendations of the MMRC into the appropriations for health agencies and programs.²⁴

In Florida, the state MMRC partners with other health agencies to provide telephone consultations with psychiatrists for prenatal and postpartum health care providers who are seeking resources, including perinatal mental health management, assessment tools information, a mental health provider list, and patient resources.²⁵

In Montana, the state established a telemedicine network that provides specialist consultation to rural area health care providers treating high-risk pregnant and postpartum women including women with substance use disorders.²⁶

Additionally, this legislation would help continue to promote and disseminate best practices that help MMRCs with the case reviews to reliably determine and include all pregnancy-associated deaths and pregnancy-related deaths, regardless of the outcome of the pregnancy. For example, during a recent peer-to-peer visit between Indiana and Wisconsin in 2020, the Indiana MMRC identified a new strategy at enhancing pregnancy-associated identification practices through a direct call to death certifiers in order to solicit confirmation of "pregnant at the time of death" status. Continued investment would help programs like this one continue to expand.

While the enactment of the Preventing Maternal Deaths Act of 2018 was a major step forward, much more is needed and Congress must reauthorize this bill. March of Dimes strongly urges Congress to pass it as soon as possible and send to President Biden for his signature.

CONCLUSION

March of Dimes thanks the Subcommittee for focusing attention on these two public health crises. As we continue to work on advancing new policies, our nation must continue to invest in the programs to improve the health of mothers, infants, and families. With your help, we can make strides to prevent pregnancy loss, preterm birth, and end preventable maternal deaths. March of Dimes stands ready to work with you to achieve that change. I look forward to your questions.

¹ You can help improve the health of all moms, babies and families ... (n.d.).

<https://www.marchofdimes.org/sites/default/files/2022-10/2020-Maternity-Care-Report.pdf>

² Nowhere to go - marchofdimes.org. (n.d.-a). https://www.marchofdimes.org/sites/default/files/2022-10/2022_Maternity_Care_Report.pdf?PersonId=7166036

³ You can help improve the health of all moms, babies and families ... (n.d.).

<https://www.marchofdimes.org/sites/default/files/2022-10/2020-Maternity-Care-Report.pdf>

⁴ Stet

⁵ Centers for Disease Control and Prevention. (2022, November 1). Preterm birth. Centers for Disease Control and Prevention. <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pretermbirth.htm>

⁶ A profile of prematurity of United States | PeriStats - March of dimes. (n.d.-a).

<https://www.marchofdimes.org/peristats/reports/united-states/prematurity-profile>

⁷ Births: Provisional data for 2022 - Centers for Disease Control and ... (n.d.-e).

<https://www.cdc.gov/nchs/data/vsrr/vsrr028.pdf>

⁸ 2022 March of Dimes Report Card. Help us improve the health of all moms and babies. (n.d.).

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⁹ Acknowledgment: The authors would like to acknowledge the insights ... (n.d.-b).

https://www.marchofdimes.org/peristats/assets/s3/reports/documents/Cost_of_Prematurity_2019.pdf

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¹¹ 2022 March of Dimes Report Card. Help us improve the health of all moms and babies. (n.d.).

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¹² Stet

¹³ Acknowledgment: The authors would like to acknowledge the insights ... (n.d.-b).

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<https://www.marchofdimes.org/about/news/23-preterm-births-have-no-known-biological-explanation-finding-comes-first-comparative>

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²⁰ YouTube. (2023, June 2). 8 2023 advocacy videos march for change testimonial Hannah Baldwin V5. YouTube.

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<https://www.congress.gov/bill/115th-congress/house-bill/1318/text>

²² <https://www.cdph.ca.gov/Programs/CFH/DMCAH/CDPH%20Document%20Library/PAMR/CA-PAMR-Report-1.pdf>

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