March of Dimes Foundation

National Office
1275 Mamaroneck Avenue
White Plains, NY 10605
Telephone (914) 997-4710

marchofdimes.org

Statement of Rebecca B. Russell, MSPH
Director, Perinatal Data Center
March of Dimes Foundation

National Committee on Vital and Health Statistics (NCVHS)

Next Generation Vital Statistics:
A Hearing on Current Status, Issues and Future Possibilities

September 11-12, 2017

Chairpersons Cohen and Ross, members of the National Committee on Vital and Health Statistics, it is my honor and pleasure to be here and participate in this hearing on the next generation of vital statistics.

The March of Dimes is a unique collaboration of scientists, clinicians, parents, maternal and child health experts, community organizations, members of the business community, and other volunteers affiliated with offices and staff representing every state, the District of Columbia and Puerto Rico, with **a mission to improve the health of babies by preventing birth defects, premature birth and infant mortality.** As Director of the Perinatal Data Center at the March of Dimes, I am responsible for providing the organization with the data, evidence, and expertise our staff need to advocate for better health for moms and babies; to evaluate and improve our public health programs; to identify and target areas and populations at high-risk in order to improve equity in birth outcomes; and to communicate our mission story. We also serve the public by providing easy and free access to maternal and child health data that are used by program planners, policy makers, researchers, academics, and others interested in perinatal health to advance program planning and inform decision-making.

To do all of this, **we need strong, reliable, and timely public health data sources**. The March of Dimes Perinatal Data Center relies heavily on the natality and linked birth/infant death data as the primary source to drive our work, which is focused in four main areas:

1. **Epidemiologic research**: We have a history of impactful research and publications using vital statistics data that has advanced knowledge in the field of perinatal and maternal and infant health. In my own work, I have analyzed and published data on topics including

multiple births,[1] low birthweight,[2] infant mortality,[3-4] and preterm births.[5-6] Monitoring, tracking, and understanding trends in these outcomes is critically important to the work we do. After decades of increases in the US preterm birth rate, research led by the March of Dimes identified that the majority of this increase was happening in the late preterm period, or just a few weeks early.[5] These findings led to nationwide efforts to better understand the risk of a birth just a few weeks early, including increased mortality and morbidity, and informed transformative initiatives throughout the country to reduce non-medically indicated early deliveries and educate providers and pregnant women of the risk of an early delivery[7]. Vital statistics data made this work possible. Vital statistics data also give us the tools to monitor other outcomes, including low birthweight, fetal deaths, and infant deaths, that may also be impacted by efforts to reduce preterm birth. The latest data from the National Center for Health Statistics shows us that after eight years of declines, the preterm birth rate in the US has increased[8]. We have begun analytic work to help us understand this increase, where it's happening, and which populations are most affected, so that we will be able to target prevention efforts that could reverse this increase.

2. **Reports to engage stakeholders**: The Perinatal Data Center uses vital statistics data to produce nationally-recognized data products that are used by the organization and our partners, both nationally and locally, to raise awareness, build partnerships and affect change in maternal and child health. One example is the March of Dimes' Premature Birth Report Card[9]. Since 2008, the March of Dimes has published Premature Birth Report Cards to spur action by stakeholders on evidence-based interventions and

advocacy priorities to reduce preterm birth and to raise public awareness of the seriousness of prematurity. We publish these report cards annually for all 50 states, the District of Columbia, Puerto Rico, and the US. The Report Cards are rich with natality data, including state- and county-specific preterm birth rates, and indicators of racial and ethnic disparities in preterm birth. State preterm birth rates are used to assess the states' progress towards reaching our ambitious goal of reducing the preterm birth rate to 8.1% by 2020. In 2016, using 2015 final natality data, five states had achieved our 2020 goal of a preterm birth rate of 8.1%, receiving an A on their Report Card. Last year, the Report Cards generated national and local news media coverage nationwide, obtaining about 1,665 media hits and 59 million impressions.

These report cards have proven to be powerful tools in activating our partners in state health departments. In a collaboration between the March of Dimes and the Association of State and Territorial Health Officials, state health officials were challenged to sign a pledge to reduce the preterm birth rate in their state by 8%, and by the following year, the health officials in all 50 states, the District of Columbia, and Puerto Rico had signed the pledge to adopt this goal for their state or territorial health department. As of last year, 28 states and jurisdictions had achieved this goal of an 8% reduction in the preterm birth rate over a six year period, as reported through the vital statistics data system.

3. **Dissemination of data to public health professionals**: Through PeriStats®, a free, publicly available website (marchofdimes.org/peristats), the Perinatal Data Center provides the public with access to aggregated data from multiple federal and national

agencies and organizations. Through a process involving the National Association for Public Health Statistics and Information Systems (NAPHSIS) and the National Center for Health Statistics, we obtain approval and are granted access to natality, linked birth/infant death data, and fetal death data that include geographic identifiers for states, counties, and cities (with a minimum population criteria). Using these files, we provide aggregated data on perinatal outcomes for nearly every county in the United States, illustrating the wide geographic disparities in perinatal outcomes and risk factors for those outcomes. This granularity in the data allows March of Dimes and other health professionals, researchers, and students to better understand and describe disparities in poor birth outcomes, and inform targeted maternal and child health program planning and implementation.

4. **Technical assistance for March of Dimes staff and volunteers**: The Perinatal Data Center provides expert interpretation of vital statistics data for use by the March of Dimes staff and volunteers who are on the front lines of our mission. In addition to PeriStats, we use vital statistics data to produce rich and easily digestible data-driven products like charts, tables, maps, talking points, topic-specific fact sheets, and reports so that our staff are informed and equipped with the most current maternal and child health data. These timely and informative data products allow March of Dimes staff to educate stakeholders; advocate nationally and locally for the improved health of mothers and babies; raise public awareness on our mission areas; strategically plan for the investment and allocation of funds into public health programming; and initiate and engage in

conversations with key stakeholders working towards reducing prematurity, infant mortality, and birth defects.

The March of Dimes has used vital statistics data for decades to accomplish this work and more. Over the span of my nearly 20 years using these data, I have seen **many achievements and improvements in our vital statistics system.**[10] Several more recent improvements have significantly enhanced our ability to use these data to help us achieve our mission goals.

1. The first is the **improved timeliness** of the data releases. In June of this year, only six months after the close of the 2016 calendar year, NCHS released provisional data for the entire 2016 calendar year.[8] That's less than six months to collect, aggregate, clean, and analyze data on the nearly four million babies born in 2016. **Federal investment in state and national vital statistics systems has resulted in vast improvements in timeliness.** Having this timely data at both the national and state level allows us to assess our progress, examine trends, and reset or refocus our efforts effectively. The launch of the rapid release data for birth and death surveillance has also provided us with more timely data. By releasing data on a quarterly basis on major maternal and child health indicators, such as teen births, preterm births, and C-sections, NCHS has informed public health professionals on the status of key indicators of health well before the end of the year, again providing opportunities to assess progress and monitor changes that may require quick and focused attention. The March of Dimes uses these quarterly estimates to update our messages and outreach based on the most recent data, activating stakeholders and the public quickly to help drive change.[11]

2. The second achievement is the **full implementation of the 2003 revision of the birth certificate** in all 57 states and jurisdictions. While it has taken nearly 15 years, all jurisdictions are finally using this same birth certificate. The 2003 revision provides us with valuable information not available previously and improved data for several indicators. With the 2016 data, we now have national data on indicators such as timing of entry into prenatal care, demographic information using race/ethnicity categories that follow the Office of Management and Budget (OMB) guidelines, and data on the expected payer of the delivery (i.e. Medicaid, private insurance, uninsured, etc). A pregnant woman's access to high quality, timely prenatal care is imperative to reducing her risk for poor birth outcomes, and the 2016 provisional data show that 1 in 5 women did not get into care early or received no prenatal care at all.[8] The newly-available race/ethnicity categories have highlighted the increased risk of preterm birth among Native Hawaiians/Other Pacific Islanders, American Indians/Alaska Natives, and non-Hispanic black women, allowing March of Dimes to more accurately focus our work on health equity. Using vital statistics data, we can identify states and communities with a large number of births to women in high risk groups, and work with communities to develop programs aimed at increasing access to care, and planning programs and policies to reduce risk factors for poor birth outcomes.

3. The third area of improvement that has impacted our work directly has been **improvements in the quality and validity of the data**. Work done at both the national and state levels to improve the data quality[12,13,14] and validate the accuracy[15,16,17,18] of the items, through focused studies of specific indicators, training for personnel involved with

data collection, and guidance to data users on both good and poor quality indicators, have increased our confidence in the data and our understanding of the complex issues that we are learning about from these data. In 2014, NCHS changed the data source used to determine the gestational age of the baby, from a calculation based on the date of the mother's last menstrual period to the birth certificate item "obstetric estimate of gestation." [19] This change happened after a thoughtful process that involved studies with states to assess the accuracy of the data, thorough analysis of the impact of the switch on the preterm birth rate and our understanding of the issue, and engagement with data users like myself. As an issue that is forefront in our mission, making sure that we are using the item that best measures the true gestational age of the infant is critical to our understanding of preterm birth and our ability to find solutions.

As we look to the next generation of vital statistics, continued investments in these areas and others would enable us to do an even better job of providing these data to the public and empowering people to use the data for action to improve the health of every mother and baby, move us towards our goal of increased equity, and give every baby the opportunity to live their best lives. Specifically, we envision a future for the vital statistics system that includes the following:

1. **Continued federal support for states** to update their electronic vital statistics registration systems to further improve this critical data is important, especially among states who adopted the revised certificates early, and may benefit from updates in technology since 2003.

2. **A strong network of data users and greater engagement of source agencies with data users** to support technical assistance needs.
3. **Increased ability to use data from vital statistics to address social determinants of health**, either through enhancements to the data collected or linkage with other data sources. Disaggregating data on racial groups where possible will also help us to better understand risks associated with certain populations, such as the recent disaggregation of Native Hawaiian/Other Pacific Islander from the larger group of Asian/Pacific Islander.

Quality, timely, and nationally representative vital statistics data serve as a strong data source for the March of Dimes' work to reduce prematurity, infant mortality, and birth defects, because they help us accurately and rapidly tell the collective story of the four million babies born annually in the US. We tell the stories of the 380,000 babies born preterm each year and the 24,000 babies who do not live to see their first birthday.[20],[21] These stories include the story of my own twin sons, born 10 weeks early, weighing 1,800 grams apiece, delivered via C-section, admitted to a NICU, and requiring assisted ventilation immediately following delivery. All of these pieces of information are captured on the birth certificate. And, in telling their stories and the hundreds of thousands of others like them, we can understand the causes of prematurity and other poor birth outcomes, find solutions, and target the appropriate interventions to improve maternal and infant health. Hopefully one day, all the stories told in these data will have happy endings.

Thank you for this opportunity to address the committee. I look forward to identifying ways for the March of Dimes to continue to support the vital statistics system in this country, which

provides such an incredibly important resource for us to improve the health of every mom and baby.

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