Attachment—Additional Questions for the Record

Subcommittee on Health
Hearing on
"Enhancing Public Health: Legislation to Protect Children and Families"
October 20, 2021

Ms. Stacey Stewart, President and CEO, March of Dimes

The Honorable Kathy Castor (D-FL)

I recently introduced the Stillbirth Health Improvement and Education for Autumn or SHINE for Autumn Act with Reps. Herrera Beutler, Roybal-Allard and my E&C colleague Rep. Mullins. This bill is named after Autumn Joy, who was stillborn on July 8, 2011. Her mother, Debbie, has turned Autumn's tragic death into a mission to increase stillbirth awareness and education and lower stillbirth rates, which is what we aim to do with the SHINE for Autumn Act. I am proud to help lead this legislation and keep the memory of Autumn Joy alive.

As you noted Ms. Stewart, stillbirth rates are unacceptably high, with approximately 24,000 babies being stillborn in the United States each year and we rank 25th among 49 high income countries with respect to stillbirth rates. Stillbirth is 2.1 times more common among Black mothers than white mothers, which is attributed to the impact of racism on health. This heartbreaking loss can happen in any family, and yet there is still so much that we do not know about stillbirth.

That is why the SHINE for Autumn Act seeks to improve surveillance and data collection relating to stillbirth and invest in research to examine the causes of stillbirth and its risk factors. Additionally, it would seek to increase education and awareness around stillbirth.

Ms. Stewart, the March of Dimes is a leader in working to improve maternal and infant health.

1. It is my understanding that just 10 percent of still births are attributed to genetic causes. Can you speak to what we do and do not know about stillbirth and its risk factors? Are there significant disparities in who is at risk of losing a child?

Thank you for your questions, Rep. Castor. March of Dimes is proud supporting organization of your legislation the SHINE for Autumn Act (H.R. 5487). According to the CDC, stillbirth affects one out of every 160 births or approximately 5.7 for every 1,000 births.[i] This is roughly 24,000 babies stillborn in the United States and more than 10 times as many deaths as the number that occur from Sudden Infant Death Syndrome (SIDS). Unfortunately, this number has changed very little over the last 15 years.[ii] At least 25% of US stillbirths are preventable, which could be at

least 5,500 lives saved each year. Comparisons to other high-income countries suggest that as many as 75% of stillbirths in the United States are preventable.[iii]

Stillbirth affect women and babies of all ages and every background. However, current data does show that there is a significant disparity in who is at risk of losing a baby to stillbirth. According to data from the CDC, black mothers have an incidence more than double those of other groups, except when compared with American Indian/Alaskan Native people:

- Non-Hispanic Black, 10.32 per 1,000 births
- American Indian/Alaska Native people, 7.22 per 1,000 births
- Hispanic, 5.01 per 1,000 births
- Non-Hispanic white, 4.89 per 1,000 births
- Asian or Pacific Islander, 4.29 per 1,000 births[iv]

While genetic or structural defects account for approximately 10% of stillbirths, information about the causes of the other 90% of stillbirths is limited.[v] Some of the known causes of stillbirth include infections, birth defects, problems with the placenta or umbilical cord, and pregnancy complications including preeclampsia. Some studies have also shown the chronic stress caused by living in a racist culture is a factor in many health conditions, including having a preterm or low-birthweight baby.[vi,vii] While these studies and statistics mention race as a risk factor for these conditions, we can't yet confirm that race itself is the cause. More research is needed to understand the connections between racism, stress, and health problems.[viii] Additionally, there is also limited information about the near and long-term impact of stillbirth upon mothers and families.

2. We've seen in Florida and across the country during the COVID-19 pandemic that not having standardized data collection and reporting can hamper our ability to crush the virus. I've heard that this is similar for stillbirth since definitions vary by state and there can be missing or inaccurate data. What is the current state of data collection around stillbirths, and do you have any recommendations for ways to improve it?

Reports on stillbirths are vital for tracking and researching who is impacted. They give valuable insight into why women may face stillbirths and for understanding the role disparities have in negatively impacting infant and parental health. Currently in the United States, vital record – also known as fetal death certificates – are the only national source of stillbirth data in the United States.[ix] Four types of tests are currently widely utilized to diagnose the reason for stillbirth:

- Amniocentesis (also called amnio);
- Autopsy;
- Genetic tests;
- Tests for infection[x]

While the CDC provides guidance for stillbirth reporting, definitions and requirements vary by state leading to inconsistencies in national records and hampering studies into stillbirth trends. Furthermore, not all stillbirths are reported because testing is optional for parents following stillbirth and when tests are conducted a significant proportion of stillbirths remains unexplained

even after evaluation. Reporting can also suffer from poor quality because not all requested information is provided, information provided can be incorrect, and reports may be provided months following death.[xi]
Several recommendations to begin addressing this shortfall are:

- Increase resources available to state agencies, health systems and other stakeholders for collecting and ensuring accuracy of reports;
- Strengthen standardization reporting requirements;
- Improve coordination of data collection and distribution by stakeholders;
- Improve the education of stakeholders around testing and reporting, including the parents of the deceased child; and
- Improve funding for analysis of reported stillbirths to provide greater understanding of trends impacting parents.

The Honorable Michael C. Burgess, M.D. (R-TX)

Ms. Stewart, in December of 2018, I was happy to work with the March of Dimes to see "The Preventing Maternal Deaths Act," signed into law. HRSA recently announced the criteria for determining the maternity care health professional target areas, as required by the law.

1. Do you believe that bringing additional maternity care physicians into Health Professional Shortage Areas will improve access to quality maternal care?

    a. What else can Congress do to incentivize additional physicians to become maternity care specialists, or practice in health professional shortage areas?

Thank you for your questions, Rep. Burgess. Yes, I do, especially for communities considered "maternity care deserts." March of Dimes defines a maternity care desert[xii] as any county without a hospital or birth center offering obstetric care and without any obstetric providers. Women may have low access to appropriate preventive, prenatal and postpartum care if they live in counties with few hospitals or birth centers (one or fewer) providing obstetric care, few obstetric providers (fewer than 60 per 10,000 births) or a high proportion of women without health insurance (10 percent or more). Based on our 2020 maternity care desert report referenced above, more than 2.2 million women of child-bearing age lived in a maternity care desert.

Therefore, I believe HRSA's plan will help. However, it will need resources from Congress, including additional support for proposals under the "Maternal Health Quality Improvement Act" (H.R. 4387), which was approved by the Energy and Commerce Committee in July.

I also believe the following efforts would help improve the quality of maternal care, including:

- Extending postpartum coverage under Medicaid to 12 months;
- Expanding Medicaid for those who fall below the federal poverty level;
- Providing coverage for evidence-based telehealth services for pregnant and postpartum women and support alignment of telehealth;
- Implementing perinatal regionalization, a strategy to improve both maternal and neonatal outcomes. By coordinating a system of care within a geographic area, pregnant women

would receive risk-appropriate care in a facility equipped with the proper resources and health care providers; and

- Expanding access to midwifery care and further integrate midwives and their model of care into maternity care in all states. This can help improve access to maternity care in under-resourced areas, reduce interventions that contribute to risk of maternal mortality and morbidity in initial and subsequent pregnancies, lower costs and improve the health of moms and babies.

Regarding your question of incentivizing additional physicians to become maternity care specialists, or practice in health professional shortage areas, I would recommend supporting initiatives that use telehealth delivery. The Data Mapping to Save Lives Act (H.R.1218), which was approved by this Committee in November, and supported by March of Dimes, would help improve that technology and identify maternity care deserts, build partnerships with health professionals, and improve maternal and child health outcomes.

There are two other bipartisan bills that have been referred to the Health Subcommittee that would help address recruiting professionals.

The first is H.R. 1025, the "Kids Access to Primary Care Act of 2021." This bill would align Medicaid rates with Medicare payment rates, expands eligibility for increased payment rates to additional providers (payment rate increases to OB/GYNs, nurse-midwives, nurse practitioners, physician assistants, and pediatric subspecialists), and ensures coverage of recommended developmental screenings such as testing for diagnostics, well-child visits, and other preventive best practices that will help families avoid serious medical issues and costly trips to the emergency room.

Lastly, H.R. 769, the "Rural Moms Act of 2021," would establish rural obstetric networks deigned to foster collaboration to improve birth outcomes and reduce maternal morbidity in rural areas. The bill would also authorize grants to medical schools and other health professional training programs to support education and training on maternal health in rural areas, and incorporate maternal health services in certain telehealth grant programs.

[i] Stillbirth. (n.d.). Retrieved December 17, 2021, from https://www.marchofdimes.org/complications/stillbirth.aspx
[ii] Centers for Disease Control and Prevention. (2020, August 13). *Stillbirth data and statistics*. Centers for Disease Control and Prevention. Retrieved December 17, 2021, from https://www.cdc.gov/ncbddd/stillbirth/data.html
[iii] *Fact sheet*. The 2 Degrees Foundation. (n.d.). Retrieved December 17, 2021, from http://www.the2degrees.org/fact-sheet.html
[iv] Stillbirth. (n.d.). Retrieved December 17, 2021, from https://www.marchofdimes.org/complications/stillbirth.aspx
[v] Ibid
[vi] Ibid
[vii] *Fact sheet*. The 2 Degrees Foundation. (n.d.). Retrieved December 17, 2021, from http://www.the2degrees.org/fact-sheet.html
[viii] Stillbirth. (n.d.). Retrieved December 17, 2021, from https://www.marchofdimes.org/complications/stillbirth.aspx
[ix] Centers for Disease Control and Prevention. (2020, August 13). *Stillbirth data and statistics*. Centers for Disease Control and Prevention. Retrieved December 17, 2021, from https://www.cdc.gov/ncbddd/stillbirth/data.html
[x] Stillbirth. (n.d.). Retrieved December 17, 2021, from https://www.marchofdimes.org/complications/stillbirth.aspx

[xi] Management of stillbirth. ACOG. (n.d.). Retrieved December 17, 2021, from https://www.acog.org/clinical/clinical-guidance/obstetric-care-consensus/articles/2020/03/management-of-stillbirth
[xii] https://www.marchofdimes.org/research/maternity-care-deserts-report.aspx