

# Working to Address the Tragedy of Stillbirth

Stillbirth Working Group of the *Eunice Kennedy Shriver*  
National Institute of Child Health and Human  
Development (NICHD) Council

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*Eunice Kennedy Shriver* National Institute  
of Child Health and Human Development

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Eunice Kennedy Shriver National Institute  
of Child Health and Human Development

# Stillbirth Working Group of the NICHD Council March 2023 Report

## Executive Summary

In 2022, a group of government, academic, nonprofit, and clinical experts convened at the request of Congress to gather information on stillbirth. Stillbirth rates remain unacceptably high, and tens of thousands of families are affected each year in the United States alone. The Department of Health and Human Services (HHS), through its operating divisions, including the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC), recognizes that stillbirth is a tragedy affecting many families and communities, and action is needed to better understand and prevent these deaths.

To develop a plan of action, HHS established the Stillbirth Working Group of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development Council (the WG). The WG focused on the four topics laid out in its mandate:

- Current barriers to collecting data on stillbirths throughout the United States
- Communities at higher risk of stillbirth
- The psychological impact and treatment for mothers following stillbirth
- Known risk factors for stillbirth

Based on key findings in each area, the WG developed a set of recommendations to guide future efforts to improve recordkeeping, data collection, and analysis about stillbirths; to address disparities in stillbirth risk; to better support families after a stillbirth occurs; and ultimately to reduce the U.S. stillbirth rate through research and prevention efforts. In this work, there are vital roles for federal agencies, states, professional societies, public health agencies, researchers, clinicians, families, and advocates.

## Summary of the WG Findings

The WG heard from a broad range of experts, including people with lived experience of stillbirth. Based on presentations covering the four focus areas, the WG identified the key findings, which are summarized below.

### Collecting Data on Stillbirths Throughout the United States

- The current system for obtaining, updating, validating, analyzing, and releasing data on stillbirth in the United States needs substantial improvement.
- Accurate, timely, and detailed vital statistics data on stillbirth are essential to enable researchers to advance the scientific knowledge on stillbirth and stillbirth prevention.

- These data are also urgently needed by families affected by stillbirth.

### **Communities at Higher Risk of Stillbirth**

- Survey and vital records data from CDC on stillbirth indicate that African American women face higher risk of stillbirth, as well as higher risks of other adverse pregnancy outcomes, compared with White non-Hispanic women.<sup>1 2</sup> Disparities across racial, ethnic, geographic, sexual/gender identity, and socioeconomic groups are evident or highly probable.
- Stillbirth in the United States cannot be adequately addressed until stillbirth rates are significantly reduced in population groups and geographic communities at highest risk.

### **Psychological Impact of Stillbirth and Treatment for Mothers Following Stillbirth**

- Stillbirth has a devastating, lifelong impact on affected families.
- The impact of stillbirth is felt not only by mothers but also by fathers, siblings, grandparents, and others.
- Improvements in clinical practice and bereavement care are essential to ensure that families receive the support they need.

### **Known Risk Factors for Stillbirth**

- A wide variety of risk factors—including pregnancy complications, chronic health conditions, genetics, environmental factors, and social determinants of health—have been associated with stillbirth and other adverse pregnancy outcomes.
- However, known risk factors account for a limited proportion of the variation in stillbirth rates.
- More research is needed to discover additional risk factors, delineate the mechanisms of how these risk factors affect stillbirth, explain the racial disparities in their impact, and translate knowledge of risk factors into interventions.

## **WG Recommendations**

Based on these findings, the WG recommends 12 priorities to guide HHS agencies—led by NIH and CDC—together with families, state and federal public health agencies,

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<sup>1</sup> Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>.

<sup>2</sup> Petersen EE, Davis NL, Goodman D, et al. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. MMWR Morb Mortal Wkly Rep 2019;68:762–765. DOI: <http://dx.doi.org/10.15585/mmwr.mm6835a3external icon>; Martin JA, Osterman MJK. Exploring the decline in the singleton preterm birth rate in the United States, 2019–2020. NCHS Data Brief, no 430. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:112969>.

researchers, providers, professional societies, and advocacy organizations in alleviating the tragedy of stillbirth.

## **Recommendations by Focus Area**

### *Current Barriers to Collecting Data on Stillbirths Throughout the United States*

The WG recommends efforts to improve the quality of vital statistics, surveillance, and epidemiologic data on stillbirth at the local, state, and national levels. Specific recommendations are listed below.

1. HHS, led by CDC, can work with state and local officials and birthing institutions to improve procedures to address the barriers to collecting representative, comprehensive, reliable, and sufficiently detailed vital records on stillbirth to support the needs of families, public health officials, and researchers. Changes should include:
  - ▶ Procedures to improve the consistency and quality of data collection
  - ▶ Standardization of case definitions
  - ▶ Improved training with specific information on the fetal death certificate process for hospital and other staff involved in data collection for fetal death certificates
  - ▶ Improved awareness and implementation of processes so that vital records can be changed or amended once additional information is available, including a clear, uniform process for submission of autopsy data and other test results
  - ▶ Outreach to states, jurisdictions, and localities to raise stillbirth awareness and build public health capacity to collect accurate, timely, and complete stillbirth data
2. CDC should expand current population-based surveillance and data collection efforts involving risk factors for stillbirth. These activities may include, for example:
  - ▶ Conducting active population-based stillbirth surveillance in a diverse range of jurisdictions
  - ▶ Exploring opportunities to leverage current data collection systems (e.g., expanding or leveraging CDC's Pregnancy Risk Assessment Monitoring System [PRAMS] and Birth Defects Study To Evaluate Pregnancy exposureS [BD-STEPS] to conduct population-based surveillance among women with a recent stillbirth)
  - ▶ Conducting or supporting validation studies of current data sources
  - ▶ Developing new methods to leverage other surveillance data for stillbirth research
  - ▶ Linking or enriching existing data
3. HHS and professional societies should work together to improve and expand training in perinatal pathology, genetics, and other areas to advance the practice of fetal autopsy.

### *Communities at Higher Risk of Stillbirth*

The WG believes that it is essential to use insights from improved epidemiologic and clinical data to explain and ultimately address disparities in stillbirth and identify prevention opportunities. Additional research will also be needed to accomplish this goal.

4. CDC, NIH, and other HHS divisions should support surveillance and research to investigate health disparities in stillbirth, in conjunction with other adverse pregnancy outcomes. Such research should address racial, ethnic, socioeconomic, geographic, and other disparities.
5. NIH should review its data on inclusion of minorities in its pregnancy and stillbirth studies to ensure appropriate representation.
6. NIH should expand community-based research in maternal health and adverse pregnancy outcomes and ensure that stillbirth is emphasized as a focus for community-based research. These efforts should focus on the patient experience in at-risk populations.
7. Efforts to address the barriers to improving data on stillbirth in the United States should include geographic areas with strong representation of racial and ethnic minority individuals, economically disadvantaged families, and other groups that may experience disparities.

### *Psychological Impact of Stillbirth and Treatment for Mothers Following Stillbirth*

Recognizing the devastating impact of stillbirth and the importance of support for families, the WG believes that implementation research should be conducted to help develop culturally sensitive interventions to support families that have experienced stillbirth.

8. NIH and CDC should support or conduct systematic research to collect data from individuals with lived experience in the psychological impact of stillbirth. Implementation research should be designed to inform efforts on how to develop culturally sensitive programs to support families after stillbirth. Results from this research should be shared with the clinical, research, and advocacy communities and advocacy communities.
9. Professional societies should consult individuals with lived experience regarding the psychological impact of stillbirth, as well as providers who care for those patients, to improve provider training and incorporate supportive practices into the care for affected families.

### *Known Risk Factors for Stillbirth*

The WG recommends the creation and support of a full research agenda, including research on known and unknown risk factors and physiologic mechanisms, to support the development of interventions to prevent stillbirth.

10. NIH should convene a group of basic, translational, clinical, and public health research experts, as well as parents who have experienced stillbirth, to develop a research agenda to advance prevention for stillbirth. The research agenda should include efforts to identify implications for stillbirth prevention from NIH's Human Placenta Project and related research.
11. NIH should conduct or support research to establish baseline normative data on physiology in pregnancy, including potential indicators of health and disease. Such indicators may include, but should not be limited to, placental development and function, fetal movement, fetal growth, and others.
12. NIH and CDC should support additional research on causes and risk factors, as well as prevention of stillbirth more broadly. Specifically, these efforts should:
  - ▶ Focus on un- and under-investigated areas to discover new risk factors and interactions, to help understand the racial and other disparities in stillbirth, and to assess the preventability of stillbirth
  - ▶ Investigate the feasibility and potential usefulness of developing a population-based stillbirth registry
  - ▶ Delineate the mechanisms of how specific risk factors affect stillbirth and explain the racial and other disparities
  - ▶ Develop and test indicators and clinical interventions for the prevention of stillbirth

# Background

## Introduction

Each year, 20,000 or more U.S. families suffer a stillbirth, the loss of a fetus at 20 weeks or more of gestation. Stillbirth is both a tragedy for parents and families and a major public health concern. However, advocates and parents report that stillbirth and its devastating impact can be overlooked and underappreciated, and increased awareness of stillbirth is needed.

Although the trend in fetal mortality rates shows significant overall decreases since the middle of the 20th century, large disparities across certain racial and ethnic groups remain.<sup>3</sup> Among non-Hispanic Native Hawaiian or Other Pacific Islander and non-Hispanic Black women, stillbirth rates are more than twice the rate for non-Hispanic White women. Stillbirth rates in American Indian and Alaska Native communities are also considerably higher than the national average. Fetal mortality rates are significantly higher among mothers younger than 15 or older than 44. By jurisdiction, in recent years, the highest rates for fetal deaths (24 weeks or more) have been in Alabama, Arkansas, Mississippi, and Washington, DC. The lowest rates were in Connecticut, Iowa, Massachusetts, New Mexico, and Texas.<sup>4</sup>

## Congressional Mandate and Formation of the WG

To address the burden of stillbirth on U.S. families, the fiscal year (FY) 2022 Consolidated Appropriations Act (P.L. 117-103) included funds and report language for HHS to establish a Task Force to examine:

- Current barriers to collecting data on stillbirths throughout the United States
- Communities at higher risk of stillbirth
- The psychological impact and treatment for mothers following stillbirth
- Known risk factors for stillbirth

Language in a House report accompanying FY2022 appropriations legislation calls on HHS to establish a task force (Appendix 1). At the request of HHS, NICHD formed the Stillbirth Working Group of Council, a subgroup of NICHD's National Advisory Child Health and Human Development (NACHHD) Council, to take on this task.

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<sup>3</sup> Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>.

<sup>4</sup> Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>.



## Members of the WG

The WG has 21 members. As specified in the mandate, members are affiliated with CDC, NIH, or outside specialty organizations (e.g., March of Dimes, American College of Obstetricians and Gynecologists [ACOG], Society of Maternal–Fetal Medicine [SMFM]) or are specialists in maternal and fetal medicine. The WG also includes representatives of the Indian Health Service (IHS) and the Health Resources and Services Administration (HRSA). NICHD Council member Lucky Jain, M.D., Emory University, and Uma M. Reddy, M.D., M.P.H., Columbia University, served as co-chairs. A full list of the WG members appears in Appendix 2.

## WG Sessions

The WG gathered information from a range of experts on the topic of stillbirth to inform its recommendations. Crucially, the WG heard the perspectives of people with lived experience of stillbirth. The WG also incorporated presentations from government, academic, legal, and clinical experts on stillbirth research, surveillance, data collection and analysis, epidemiology, health inequities, environmental exposures, mental health, obstetric care, genetics, placental pathology, and stillbirth risk factors in its findings.

The WG convened four sessions to discuss its four focus areas and to hear the personal perspectives of people who have experienced a stillbirth. Appendix 3 lists the dates and details of each session. A report on the stillbirth research literature and NIH-supported grants is provided in Appendix 4. A summary of the public listening session is included in Appendix 5.

In January 2023, the WG presented its findings and recommendations to NICHD’s NACHHD Council, which unanimously approved its recommendations. The WG anticipates additional actions in 2023 to further address the implementation of its recommendations.

## Request for Information (RFI)

In addition, to help guide the WG’s recommendations, NICHD issued an RFI ([NOT-HD-22-054](#)) in November 2022. In particular, the institute sought the public’s input on strategies to improve the impact of NIH-funded stillbirth research. Responses were received in early January.

NICHD received 11 responses from advocacy organizations, individuals with lived experience of stillbirth, researchers, and providers. All of the responses addressed current barriers to data collection and known risk factors for stillbirth. About half of the responses also addressed high-risk communities, psychological impact, or both. The

WG incorporated information from the RFI responses into its overall findings and recommendations. The content of the responses is summarized in Appendix 6.

## Findings and Recommendations

### Current Barriers to Collecting Data on Stillbirths Throughout the United States

#### Findings of the WG

- **Current methods for collecting and recording data on stillbirth are not always fully standardized at the state and local levels and do not always follow best practices for the collection of vital statistics data.**

The United States relies primarily on fetal death certificates to understand the scope of stillbirth, contributing factors, and salient details about the families it affects. These documents, which hospitals and other facilities submit to state vital statistics systems, record legal, demographic, medical, and health information about the family and the cause of death. Since the 1930s, CDC has published a standard form for collecting this information. In addition, all states' reporting requirements align with a definition of fetal death in the 1992 Model Vital Statistics Law. However, researchers and state and local officials report that the fetal death certificate form is cumbersome to complete. State and local officials, researchers, and professional societies have noted issues with completeness, standardization, and timeliness in how information on fetal deaths is collected.<sup>5</sup>

“Stillbirth is an issue that we cannot solve without accurate and timely data.”  
—Advocate

Data completeness and quality vary for a variety of reasons, from the individual to the systemic. More than one parent reflected on how stillbirths are not treated like other deaths. While a maternal death in the hospital triggers an investigation, noted one parent, stillbirth is treated as simply a tragic outcome.

Although the model law definition aims to provide uniformity at the federal level for states to follow not all states incorporate the model law definition in their requirements

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<sup>5</sup> American College of Obstetrics and Gynecology, Committee Opinion 748, August 2018, The Importance of Vital Records and Statistics for the Obstetrician–Gynecologist. Accessed at <https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2018/08/the-importance-of-vital-records-and-statistics-for-the-obstetriciangynecologist>, March 1, 2023; A Tessarolo, GM Ramirez, D Contreras. Assessing the value of reviewing all fetal death records for birth defects surveillance, compared to only those with maternal anomaly codes, Birth Defects Research, 2021 Jan 15;113(2):123-127.; C Polen-De, BD Kamath-Rayne, N Goyal, E DeFranco. Regional and practitioner variations in reporting infant mortality. Journal of Maternal Fetal Neonatal Medicine. 2022 Apr;35(7):1278-1285.

for when to report a stillbirth; for example, gestational age at the time of fetal death and fetal weight cutoffs may differ by state.

There is also a vast range in the quality of the data collected in fetal death certificates, including discrepancies in the amount of data collected. For example, where the form requests information about the mother's level of education, analyses of different jurisdictions' records show that in some, these data are included every time, but elsewhere, the majority of forms are marked "unknown."<sup>6</sup> Jurisdictions are encouraged to submit as few records as possible that list cause of death as "unspecified," yet some jurisdictions have submitted records with a high rate of unspecified cause of death, rendering these data less reliable.<sup>7</sup>

In some cases, fetal death records are filed for pregnancy losses at less than 20 weeks. State-level efforts to track stillbirths have detected that a significant number are never issued a certificate at all. Research in Iowa showed that about one-quarter of the fetal death certificates examined did not meet state reporting criteria for fetal death, mostly due to inaccurate information.<sup>8</sup> Such variances clearly contribute to inaccuracy in the overall numbers of stillbirths reported.

The Study of Associated Risks of Stillbirth (SOARS) program, supported by a collaboration between CDC and the Utah Department of Health and Human Services and adapting PRAMS methodology, represents a novel approach to gathering additional epidemiological data among mothers who have experienced a stillbirth. Participants in SOARS are offered a free, in-person or telephone consultation, which has proved to be a valuable source of information. SOARS approach and methodology will help states and localities to raise awareness and build public health capacity to collect accurate, timely, and complete stillbirth data.<sup>9</sup>

At the local level, data collection practices can vary considerably from one institution to the next. Each hospital or birthing center develops its own system for completing the forms, including who fills it out, who signs off, whether it is filled out on paper or electronically, and whether there is specific guidance for completing it. Hospitals and

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<sup>6</sup> Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Fetal Deaths on CDC WONDER Online Database. Data are from the Fetal Death Records 2014-2020, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <http://wonder.cdc.gov/fetal-deaths-expanded-current.html> on Feb 24, 2023 12:00:39 PM.

<sup>7</sup> Hoyert DL, Gregory ECW. Cause-of-death data from the fetal death file, 2018–2020. National Vital Statistics Reports; vol 71 no 7. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:120533>.

<sup>8</sup> JA Makelarski et al. Use of active surveillance methodologies to examine over-reporting of stillbirths on fetal death certificates. Birth Defects Res A Clin Mol Teratol. 2011 Dec;91(12):1004-10. doi: 10.1002/bdra.22856. Epub 2011 Sep 30. <https://onlinelibrary.wiley.com/doi/abs/10.1002/bdra.22856>.

<sup>9</sup> CL DeSisto et al. Design and Methodology of the Study of Associated Risks of Stillbirth (SOARS) in Utah. Public Health Reports 2022 Jan-Feb;137(1):87-93.

other facilities with a low volume of deliveries may only occasionally need to fill out a fetal death report and may be unfamiliar with best practices.

- **Stillbirth data are typically based on incomplete underlying information due to lack of autopsy, placental analysis, genomic analysis, and other types of assessments necessary to obtain sufficient information to determine a cause of death.**

The American College of Obstetricians and Gynecologists (ACOG) recommends<sup>10</sup> that evaluations of a stillbirth include:

- Fetal autopsy
- Gross and histologic examination of the placenta, umbilical cord, and membranes
- Genetic evaluation

Research indicates that when individuals with the proper expertise in pathology conduct this type of thorough assessment and additional pieces of information, including maternal laboratory tests, medical records, and interviews with the families affected, are available, experts can attribute a cause of death in about three-quarters of stillbirth cases.<sup>11</sup> However, this type of thorough investigation is only found in research settings. Under typical circumstances, placental examinations are relatively common—conducted in nearly 70% of cases—whereas autopsies are performed only about 20% of the time. However, placental examinations are not always performed by individuals with specific expertise in that area.<sup>12</sup>

Fetal autopsy can be a difficult and distressing topic for surviving family members to consider. Parents, who are shocked and distressed after a stillbirth, may have a hard time deciding on or agreeing to an autopsy. Doctors may downplay the value of an autopsy if they are confident they know the cause or may find it challenging to discuss. Many parents report that hospital staff discouraged them from requesting an autopsy of their stillborn baby because of cost, because it might be inconclusive, or because it would disfigure the baby. Doctors may also be worried about liability. Parents told the WG that making decisions about an autopsy in the immediate grief of losing their child was extremely difficult, but for some who did not

“I was told that an autopsy wouldn’t bring my baby back and I would probably never know the answer . . . Nobody acknowledged my need to know why my baby just died.”  
—Parent

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<sup>10</sup> <https://www.acog.org/clinical/clinical-guidance/obstetric-care-consensus/articles/2020/03/management-of-stillbirth>

<sup>11</sup> Stillbirth Collaborative Research Network. Causes of death among stillbirths. JAMA. 2011 Dec 14;306(22):2459-68. doi: 10.1001/jama.2011.1823.

<sup>12</sup> EA Oliver, MM Finneran, KM Rood, M Ma’ayeh, V Berghella, RM Silver. Fetal Autopsy Rates in the United States: Analysis of National Vital Statistics. Obstet Gynecol. 2022 Nov 1;140(5):869-873. doi: 10.1097/AOG.0000000000004965.

request an autopsy, the thought that they did not do everything possible to determine the cause of their child's death haunted them.

Cost is also a barrier. Medicaid, which covers a large proportion of U.S. pregnancies and births,<sup>13</sup> does not cover autopsy costs. Analysis of genetic causes often cannot be done unless parents pay out of pocket.

“A substantial barrier to conducting clinical stillbirth investigations is a lack of insurance coverage.”  
—State or local official

Some hospitals, particularly those with fewer births, have limited expertise available to them in perinatal pathology. Because of the involvement of the placenta, maternal conditions, and other complexities, perinatal pathology is complex and specialized. Without the appropriate expertise and detailed placental analysis, interpreting the results of fetal autopsy to determine a cause of death can be difficult.<sup>14</sup>

A more comprehensive evaluation of stillbirth cases is necessary to inform prevention science. Several possible options to help increase the autopsy rate are available, and research is needed to help determine which approaches are best for families and most cost-effective. Systematic research could help determine best practices for consenting families for autopsies and determine how to best inform families about their options in a sensitive and culturally appropriate way. This could include research on decision aids for families to increase the use of autopsies, the most effective ways to counsel families, and working with states to do implementation science (e.g., the optimal stillbirth evaluation, how to get the most accurate data into the fetal death certificate, how to conduct interviews with families to capture additional data). Many states have declared sudden infant death syndrome (SIDS) a public health emergency and pay for autopsies after suspected SIDS deaths. This could be a model for jurisdictions to follow to improve data collection on stillbirth.

The SOARS project in Utah, supported by CDC, is one local-level example of a way to close the gap on whether autopsies are offered to respondents who experienced a stillbirth. Other countries that do perinatal audits on their stillbirths may also be valuable sources of guidance. Few individuals have the combination of skills necessary to assess a cause of death in the case of stillbirth. Often a multidisciplinary panel of experts, such as a Fetal and Infant Mortality Review committee, is needed. For many stillbirths, a cause of death is never identified.

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<sup>13</sup> Osterman MJK, Hamilton BE, Martin JA, Driscoll AK, Valenzuela CP. Births: Final data for 2021. National Vital Statistics Reports; vol 72, no 1. Hyattsville, MD: National Center for Health Statistics. 2023. DOI: <https://dx.doi.org/10.15620/cdc:122047>.

<sup>14</sup> Odendaal H, Pattinson R, Schubert P, Mason D, Brink L, Gebhardt S, Groenewald C, Wright C. The key role of examining the placenta in establishing a probable cause for stillbirth. *Placenta*. 2022 Nov;129:77-83. doi: 10.1016/j.placenta.2022.10.001.

Even when autopsies are done, their poor quality can be a barrier to data collection. The low number of trained perinatal pathologists in the United States is a contributing factor.

“ . . . [V]ery few pathologists . . . are able to conduct full perinatal autopsies (in conjunction with placental pathology) and thus evaluate cause of death . . . ”  
—Researcher/clinician

Few programs offer specific training in perinatal pathology. As a result, only a small number of stillbirths receive a comprehensive examination—including both placental pathology and fetal autopsy—to accurately determine cause of death. The placenta reveals the most likely cause of death in about one-third of stillbirths; however, special training is required to examine placentas, and there are few placental pathology experts. In addition, placentas are not always sent for examination.

Parents related many perplexing and frustrating experiences. Some report receiving a fetal death certificate that simply lists the cause of death as “stillbirth.” Others discover that what is listed on the form is inaccurate. Families may go to considerable effort and expense to try to clarify, substantiate, or correct information about the cause of death on the fetal death record. Once the information has been recorded, however, it can be difficult to change. Amending such records may require cooperation from the filing official, institution, or attending physician. Families reported that this could be a challenge, especially in cases where that physician or institution was no longer involved in the family’s regular medical care. According to CDC, on as many as one-third of fetal death certificates, the cause of death is unspecified.<sup>15</sup>

Determining the cause of death through a comprehensive review can help give families and providers answers to the questions of what happened and how. Moreover, a detailed review can validate the importance of the family’s experience, help with grieving and getting closure, and inform care in future pregnancies. For example, a genetic diagnosis can help families identify other family members at risk or prevent recurrence in a subsequent pregnancy.

However, even with complete, accurate information, determining cause of death in cases of stillbirth is challenging. Ultimately, research suggests, even a rigorous examination may not lead to a cause of death determination in 20% to 25% of cases.<sup>16</sup> This underscores the need for further research to identify and address causes, risk factors, and mechanisms of stillbirth.

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<sup>15</sup> Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Fetal Deaths on CDC WONDER Online Database. Data are from the Fetal Death Records 2014-2020, as compiled from data provided by the 57 vital statistics jurisdictions through the Vital Statistics Cooperative Program. Accessed at <https://wonder.cdc.gov/fetal-deaths-expanded-current.html> Accessed February 29, 2023.

<sup>16</sup> Stillbirth Collaborative Research Network Writing Group. Causes of death among stillbirths. JAMA. 2011 Dec 14;306(22):2459-68.



- **Stillbirths are typically not linked to the electronic medical records (EMRs) of the mother, and typically, no EMRs are created for the baby.**

Lack of detail about the circumstances surrounding a death *in utero* can impede efforts not only to come to an understanding about a particular case but to comprehend stillbirth broadly. For other diseases and conditions, researchers have been able to analyze large datasets of medical records to obtain clues about risk factors and disease mechanisms. However, adopting this approach for pregnancy-related conditions, and especially for stillbirth, has been difficult or at times impossible. Without complete medical information about stillbirths, and without being able to link stillbirth information to the mother's medical record, scientists are unable to take advantage of large-scale medical records analysis to explore stillbirth risk factors. Before the pandemic, efforts were underway to establish links between clinical databases with information about mothers and those with data about their babies. Renewing such efforts is a priority.

To understand how best to approach linking EMRs and fetal death certificates, implementation research is a necessity. Such links could also improve the number of completed certificates, improving data collection about stillbirth. Linking related data records would also make it easier to update fetal death records as new medical information becomes available. Electronic mechanisms are well suited to accommodating record updates, and adopting a system for making updates electronically could also make the data more reliable.

Health agencies could also consider creating EMRs for stillborn children. This would allow better tracking of cause of death information. Linked to the parents' EMRs, these records would allow for more comprehensive research.

- **Stillbirth records are often not amended or updated after additional autopsy or other information becomes available, limiting records' usability to researchers and public health officials.**

States may require hospitals and other facilities submitting fetal death reports to meet a filing deadline. Often, this requires medical staff to file the report—including attribution of the cause of death—before autopsy, placental tissue analysis, or genetic testing results are completed.

Such findings are important case details from public health and research perspectives, and they matter to families, too. When information is inaccurate, confusing, or missing, some parents report spending considerable time, money, and effort having independent testing or analysis done. However, parents reported that it can be extremely difficult to get information corrected or updated even when better data becomes available. To

many families, these barriers are another example of stillbirth being underappreciated and unaccounted for.

Updated and accurate data will help researchers paint a clearer picture of stillbirth. At the same time, ensuring that accurate data about their child are available to researchers—and may one day improve circumstances for future families at risk of stillbirth—is a meaningful priority for parents.

Additional resources at the federal, state, and local levels will be required to improve the reporting of fetal deaths.

“Fetal death certificates (from which state and national stillbirth statistics are compiled) are filled before autopsy, placental pathology, and other testing is even completed and are difficult or impossible to amend after the fact.”

—State/local official

- **Barriers to effective collection of stillbirth data may include lack of legal authority to require standardization, limited awareness of the importance of complete and accurate records, lack of appropriate training for individuals involved in gathering and/or reporting data, state and regional differences, and lack of research surrounding best practices.**

Because the vital statistics collection system is a collaboration between state and federal entities, data collection issues cannot be fully addressed with a simple mandate or set of requirements imposed from the federal level. The Model State Vital Statistics Act and Regulations are ways to provide federal guidance. Financial support for states’ vital records collection could also raise the quality of the data. Data collection requires time, dedication, and training, and the supporting infrastructure will need to be sustained over several years.

Another important consideration is that the medical staff filling out the fetal death report may not appreciate its importance for understanding stillbirth on the national scale. Improving awareness could facilitate better data collection. For example, in a facility where labor and delivery nurses typically collect fetal death certificate data, emergency room staff may not know about requirements or processes for completing this record, including the gestational age and weight cutoffs that govern reporting requirements in their state. Such situations lead to incomplete and/or inaccurate data.

Volume can also affect training and awareness. For example, a facility that handles several hundred deliveries may experience only a single stillbirth in a year. Although CDC offers online training for medical examiners and other staff who fill out fetal death certificates, this training is not required.<sup>17</sup> States and other jurisdictions may offer guidance for completing records, but it is unclear who takes them. In lieu of training

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<sup>17</sup> CDC, NVSS. Guide to Completing the Facility Worksheets for the Certificate of Live Birth and Report of Fetal Death. <https://www.cdc.gov/nchs/nvss/facility-worksheets-guide.htm>, accessed February 29, 2023.



requirements, best practices for completing fetal death reports could be compiled from individual states and provided to health agencies and hospitals nationwide.

Perinatal pathology training could be expanded. Research scientists reported that the field of pediatric oncology has benefited from multisite cohort studies and interventional studies that include central review of autopsy findings. Central review of autopsy and placental pathology findings should be incorporated in studies of perinatal loss. Funding of pathological and postmortem examinations will be needed to support the practice of perinatal pathology.

“Even when placental pathology is performed, the quality of the placental evaluation varies widely by hospital.”

—Researcher

To address state and regional differences, uniform reporting standards and funding for trend analyses are priorities. Findings will be widely applicable only if the data are drawn from a population-based surveillance system with a foundation of documented causes of death, autopsy results, and information from medical records. This could expand on the types of data collected on fetal death certificates and would allow researchers to investigate potential causes and do follow-up research to understand the experiences of the registry participants. In development of such resources, it would be important to ensure that those who collect and enter data, as well as researchers, are involved. Review committees that work with CDC on maternal mortality data collection include a diverse range of professionals involved in data collection, clinical care, and research. Considering how to build engagement so data are more robust is an important part of the process.

CDC conducts surveillance on several perinatal topics including live births, maternal mortality, birth defects, stillbirths, and sudden unexpected infant death. These outcomes are closely related and have common themes. However, data collection and research on these topics require a variety of different tools and expertise.

In addition to improving cause-of-death data, making better use of that information is a priority. Studies could investigate what different locations have tried to do to lower the number of fetal death reports with an unspecified cause of death and compare their results to see what works. The lessons learned could be expanded across the country. Auditing the accuracy of autopsies, placental examinations, and other information is also important, beyond identifying a cause of death. Without information about the accuracy of the underlying data, researchers will be challenged to interpret the data to help identify ways to prevent stillbirth.

## Recommendations From the WG

The WG recommends efforts to improve the quality of vital statistics, surveillance, and epidemiologic data on stillbirth at the local, state, and national levels. Specific recommendations are listed below.

1. HHS, led by CDC, can work with state and local officials and birthing institutions to improve procedures to address the barriers to collecting representative, comprehensive, reliable, and sufficiently detailed vital records on stillbirth to support the needs of families, public health officials, and researchers. Changes should include:
  - ▶ Procedures to improve the consistency and quality of data collection
  - ▶ Standardization of case definitions
  - ▶ Improved training with specific information on the fetal death certificate process for hospital and other staff involved in data collection for fetal death certificates
  - ▶ Improved awareness and implementation of processes so that vital records can be changed or amended once additional information is available, including a clear, uniform process for submission of autopsy data and other test results
  - ▶ Outreach to states, jurisdictions, and localities to raise stillbirth awareness and build public health capacity to collect accurate, timely, and complete stillbirth data
2. CDC should expand current population-based surveillance and data collection efforts involving risk factors for stillbirth. These activities may include, for example:
  - ▶ Conducting active population-based stillbirth surveillance in a diverse range of jurisdictions
  - ▶ Exploring opportunities to leverage current data collection systems (e.g., expanding or leveraging CDC's PRAMS and BD-STEPS to conduct population-based surveillance among women with a recent stillbirth)
  - ▶ Conducting or supporting validation studies of current data sources
  - ▶ Developing new methods to leverage other surveillance data for stillbirth research
  - ▶ Linking or enriching existing data
3. HHS and professional societies should work together to improve and expand training in perinatal pathology, genetics, and other areas to advance the practice of fetal autopsy and improve stillbirth assessment.
  - ▶ Exploring opportunities to leverage current data collection systems (e.g., expanding CDC's PRAMS and BD-STEPS to conduct population-based surveillance among women with a recent stillbirth)
  - ▶ Conducting or supporting validation studies of current data sources
  - ▶ Developing new methods to leverage other surveillance data for stillbirth research
  - ▶ Linking or enriching existing data

## Communities at Higher Risk of Stillbirth

### Findings of the WG

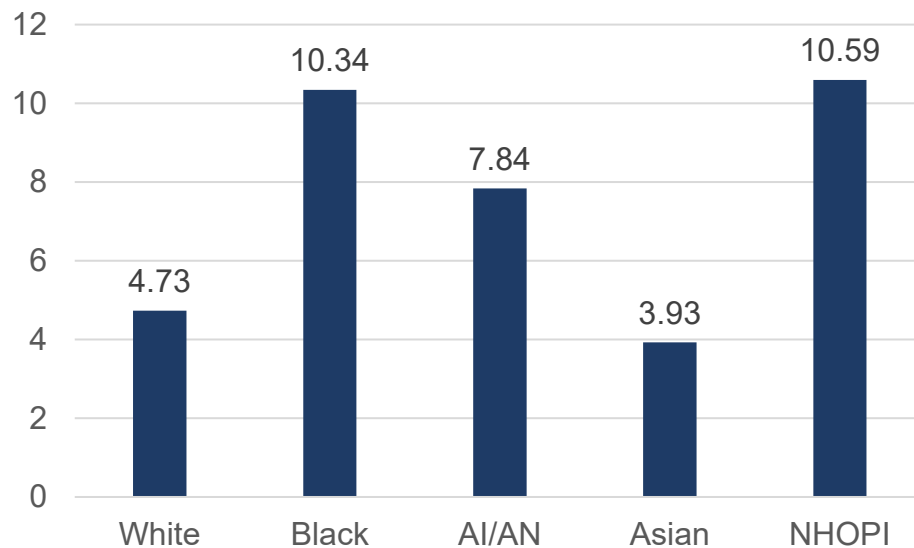
- **Survey and vital records data from CDC on stillbirth indicate that African American women face higher risk of stillbirth, as well as higher risks of other adverse pregnancy outcomes, compared with White non-Hispanic women.<sup>18</sup> Disparities across racial, ethnic, geographic, sexual/gender identity, and socioeconomic groups are evident or highly probable.**

As shown in Figure 1, in 2020 the U.S. fetal mortality rate varied considerably by race. Disparities among White, Black, American Indian/Alaska Native, Asian, and Native Hawaiian and Other Pacific Islander (NHOPI) groups have persisted over a number of years. The overall U.S. rate was 5.74 fetal deaths per 1,000 live births and fetal deaths. As shown in Figure 2, the fetal mortality rate was similar when comparing Hispanic and non-Hispanic White rates.

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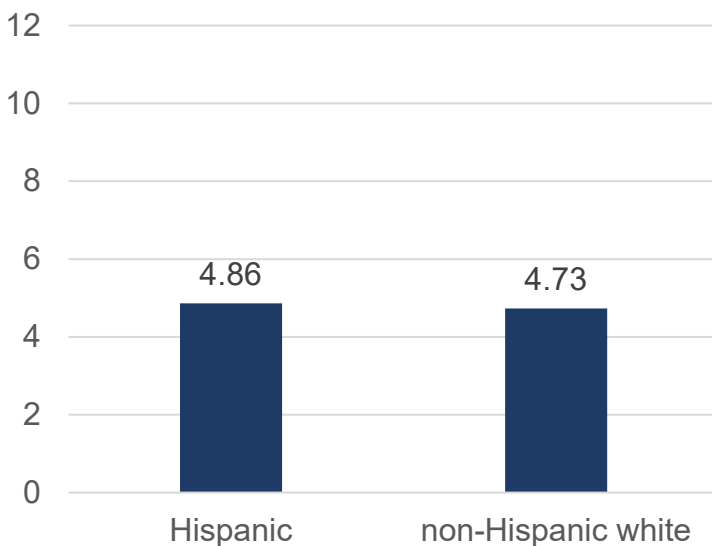
<sup>18</sup> Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>.

Figure 1: Fetal mortality rates per 1,000 births, by race of mother (Non-Hispanic ethnicity only): United States, 2020



*Note: AI/AN denotes American Indian or Alaska Native; NHOPI denotes Native Hawaiian or Other Pacific Islander.*

Figure 2: Fetal mortality rates per 1,000 births, by Hispanic ethnicity of mother: United States, 2020



Source: Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>.

Differences across racial groups are large and not fully accounted for based on social characteristics such as education. For example, research has shown that well-educated African American women are more likely than well-educated White women to deliver infants at extremely low gestational ages, and the disparity for stillbirth risk for infants born to African American women is starkest at very

preterm ages.<sup>19</sup> There are many factors that likely contribute to racial disparities in stillbirth rates. Researchers, parents, clinicians, and advocates indicated that access to care, prevalence of preexisting conditions, and structural racism were likely to affect stillbirth risk, individually and in combination.

“My history of having 4 pregnancies and 2 losses is unfortunately a very common one when it comes to Black women.”

—Parent

- **Elevated risk of stillbirth is associated with higher risks of other adverse pregnancy outcomes.**

Many women who experience stillbirth do not show any sign of complications earlier in their pregnancy. At the same time, most pregnancy complications and other adverse outcomes are also associated with stillbirth risk.

Stillbirth is more common among women with placental complications, hypertensive disorders of pregnancy, or gestational diabetes requiring medication. Women with fetuses that are growth restricted are also at higher risk. Differences in stillbirth rates among racial groups and across communities are often similar to disparities across these same groups in other pregnancy complications.

The commonalities in risk profiles across a range of pregnancy outcomes points to the possibility that stillbirth, hypertensive disorders of pregnancy, preterm birth, placental insufficiency, and maternal complications may arise from common mechanisms. Additional research on common mechanisms for stillbirth and other pregnancy complications is needed. Leveraging cohort studies of other conditions, especially those including large numbers of pregnant women, could be key to advancing stillbirth research. Linking of vital records, as described earlier, could also help scientists discover the underlying mechanisms leading to stillbirth.

“Racial disparities hold true even for wealthy and educated parents who identify as Black or Brown, many of whom report being treated differently once their providers realize that they hold advanced degrees or prestigious titles.”

—Parent

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<sup>19</sup> Gregory ECW, Valenzuela CP, Hoyert DL. Fetal mortality: United States, 2020. National Vital Statistics Reports; vol 71 no 4. Hyattsville, MD: National Center for Health Statistics. 2022. DOI: <https://dx.doi.org/10.15620/cdc:118420>

- **The reasons for stillbirth disparities are not fully clear, but structural factors contribute to differences in stillbirth risk across racial, ethnic, geographic, and socioeconomic groups.**

Structural factors, such as quality of care and systemic racism, may both increase stillbirth risk overall and contribute to disparities across racial groups, urban and rural communities, and other differences. To address these factors, it is essential to develop knowledge and improve clinical education and practice. Many opportunities are available for this work. For example, one possible approach would be to use CDC’s PRAMS data for research into individual and interpersonal risk factors contributing to preterm birth and PRAMS methodology could be leveraged to expand surveillance of known risk factors of stillbirth. Previous findings from PRAMS data indicate that chronic stress and racism may contribute to accelerated preterm birth risk among Black minority women.<sup>20</sup>

“There needs to be more research on exactly why minorities, especially Black women, are at such high risk.”  
—Researcher

Developing clinical education is another priority. The risk of stillbirth in a second pregnancy after the first ended in stillbirth is double the risk of stillbirth in the first pregnancy, and for African American women, the risk is even higher.

“Provider bias merits a stand-alone research focus.”  
—Researcher

Health systems can center patients’ experiences by including them on advisory boards and helping them navigate financial services, insurance, and other aspects of the patient experience to achieve outcomes they desire. Care navigators based on the community health worker model are another possible intervention. Finally, simulation training may help providers repair cultural ruptures, identify implicit bias, and avoid microaggressions. Such training can give providers practice breaking bad news and having respectful interactions with their patients.

## Recommendations From the WG

The WG believes that it is essential to use insights from improved epidemiologic and clinical data to explain and ultimately address disparities in stillbirth and identify prevention opportunities. Additional research will also be needed to accomplish this goal. Specifically, the working group recommends:

4. CDC, NIH, and other HHS divisions should support surveillance and research to investigate health disparities in stillbirth, in conjunction with other adverse

<sup>20</sup> Barber KFS, Robinson MD. Examining the Influence of Racial Discrimination on Adverse Birth Outcomes: An Analysis of the Virginia Pregnancy Risk Assessment Monitoring System (PRAMS), 2016-2018. *Matern Child Health J.* 2022 Apr;26(4):691-699. doi: 10.1007/s10995-021-03223-2. Epub 2021 Aug 20. PMID: 34415471.

pregnancy outcomes. Such research should address racial, ethnic, socioeconomic, geographic, and other disparities.

5. NIH should review its data on inclusion of minorities in its pregnancy and stillbirth studies to ensure appropriate representation.
6. NIH should expand community-based research in maternal health and adverse pregnancy outcomes and ensure that stillbirth is emphasized as a focus for community-based research. These efforts should focus on the patient experience in at-risk populations.
7. Efforts to address the barriers to improving data on stillbirth in the United States should include geographic areas with strong representation of individuals with diverse racial and ethnic backgrounds and other groups that experience disparities.

## Psychological Impact of Stillbirth and Treatment for Mothers Following Stillbirth

### Findings of the WG

- **Stillbirth takes a devastating, lifelong psychological toll on families.**

The trauma of stillbirth forever marks the baby's parents, both living and future siblings, grandparents, and others in the family's network. It is a defining experience, with emotional, psychological, interpersonal, social, economic, physical, spiritual, and existential aspects. Those who grieve a stillbirth have to deal with the unique convergence of birth and death and face substantial stigma.<sup>21</sup> Society is poorly positioned to respond to their loss, and many parents withdraw socially.

"Make no mistake; stillbirth is horrific. And its devastating impacts extend far beyond just the parents, to an entire family and community, and to our society as a whole."

—Parent and advocate

After a loss, families are at higher risk for mental health issues.<sup>22</sup> Research documents a higher risk for depression, post-traumatic stress disorder (PTSD), anxiety, and social

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<sup>21</sup> SL Murphy. 2012. Finding the positive in loss: stillbirth and its potential for parental empowerment. *Bereavement Care*, 31 (3), 98-103. [tandfonline.com/doi/abs/10.1080/02682621.2012.740277](https://doi.org/10.1080/02682621.2012.740277).

<sup>22</sup> KJ Gold, A Sen, and I Leon. 2017. Whose Fault Is It Anyway? Guilt, Blame, and Death Attribution by Mothers After Stillbirth or Infant Death. *Illness, Crisis, and Loss*, 26 (1), <https://doi.org/10.1177/1054137317740800>.



phobia.<sup>23</sup> Mental health outcomes are similar among mothers experiencing stillbirth and those dealing with early childhood death and are similar by race.<sup>24</sup>

The mothers and fathers at the greatest risk of poor outcomes are those with prior losses, mental health struggles, experiences of interpersonal violence, and poor social support. Poor grief support coupled with the shock of stillbirth can increase a family's trauma.

“What goes unnoticed after a stillbirth occurs is that marriages fail, families fall apart, friendships dissolve, and careers are lost.”  
—Advocate, family member

Poor psychological and physical outcomes, including more depressive symptoms and poorer overall health, may develop in the wake of pressure to move on and other social constraints.<sup>25</sup> Such pressure can become a negative cycle as parents try to engage more in their familiar circles and integrate their loss into their daily lives but feel compelled to withdraw by the pressure. These circumstances present opportunities for schools, religious organizations, and communities to learn how to provide better grief support, but there is a need for better models to do this effectively.

In social and interpersonal interactions, marital conflict can follow a stillbirth. Struggling relationships are more likely to be at risk for a poor outcome after a pregnancy loss.

- **Women have reported experiences of having their concerns dismissed or being blamed for stillbirth.**

People who have a lived experience of stillbirth often report poor experiences with medical staff, including having concerns about the progress of their pregnancy dismissed. It is not uncommon for individuals of color, in particular, to speak of healthcare providers who treated them with a dismissive attitude or who feel that there is no point in speaking up about certain concerns because they will not be heard and it will not make a difference. Women may have experienced poor treatment at their regular prenatal appointments or in their delivery and postpartum experience.

Indeed, CDC's HEAR HER seeks to raise awareness and improve communication between patients and their healthcare providers. It highlights the importance of providers really hearing women's concerns during and after pregnancy and engaging in an open conversation to make sure any issues are adequately addressed.

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<sup>23</sup> KJ Gold, ME Boggs, M Muzik, A Sen. Anxiety disorders and obsessive compulsive disorder 9 months after perinatal loss. *Gen Hosp Psychiatry* 2014 Nov-Dec;36(6):650-4. doi: 10.1016/j.genhosppsy.2014.09.008.

<sup>24</sup> KJ Gold, I Leon, ME Boggs, A Sen. 2016. Depression and Posttraumatic Stress Symptoms After Perinatal Loss in a Population-Based Sample. *J Womens Health (Larchmt)* . 2016 Mar;25(3):263-9. doi: 10.1089/jwh.2015.5284.

<sup>25</sup> V Juth, JM Smythe, MP Carey, SJ Lepore. Social Constraints are Associated with Negative Psychological and Physical Adjustment in Bereavement. 2015. *Health and Well Being*, 7 (2) 129-148. <https://iaap-journals.onlinelibrary.wiley.com/doi/full/10.1111/aphw.12041>.



Likewise, in focus groups for the Hearing the Voices of Utah Mothers study, discrimination and dismissal were common themes. Women from the Native Hawaiian and Pacific Islander community who had experienced a pregnancy loss reported trauma and said they felt that providers brushed off their concerns. A lack of cultural humility, for example, created distance between the women and their White healthcare providers. As a result, the women in the focus groups felt that the providers' insensitivity denied them meaningful grieving experiences. At the same time, prospective studies to generate more information so providers can better understand patterns that contribute to increased risk are also needed.

"I was not advised of what to expect my body to do following a birth. I was given little resources to help with or address what happened and any signs of [postpartum depression] and grief. I was not advised of my options and what could be done to figure out what happened to [baby] and brushed aside as if she didn't matter and I could just have another one."

—Parent

It was not uncommon for parents who had lost a child to talk about stillbirth as an experience that is incongruent with our current state of medical knowledge and care. The state of medical care in the United States leaves many to believe that stillbirth is not a current concern. This can create unrealistic expectations; a pregnant person may surmise that a pregnancy that ends in stillbirth must mean that they did something wrong. This tendency to assign blame is starkly illustrated by cases where women—typically marginalized women—have been arrested and in some cases tried for causing their child's stillbirth, experiences that add further to the mother's trauma.

High-quality clinical care that addresses the psychological impact of stillbirth and bereavement was identified as lacking by many parents. Currently, there is little documentation of what types of care hospitals offer and the extent to which follow-up support is provided outside the hospital setting. To improve care for parents, there is a need for research to document the support provided, assess the quality of care, and link specific care interventions to data on outcomes.

- **Families report that obtaining information on cause of death is important.**

Death certificates are vital records not only for governments but for parents as well. In short, they say everyone deserves to know why their child died, and finding out why children die should not depend on whether the family can afford it. Incomplete or inaccurate fetal death records can cause considerable distress, adding to the anguish of experiencing a stillbirth. Correcting the record can give parents some reassurance that they were not at fault or did everything they could to protect and nurture their child.

"We have never received a reason for [my son's] death, and it is very difficult to obtain closure."

—Parent

Yet the cumbersome and expensive process of making sure fetal death records reflect accurate and updated findings is a burden that falls on them.

Coverage of autopsy costs and wider availability of genetic analysis could give some families information they are seeking. However, coverage of these tests are often not covered by insurance, resulting in families paying the cost out of pocket. Many couples want genetic testing before making decisions about whether to try to have another child, but the high cost and lack of availability of such testing can be barriers to obtaining this information.

- **Best practices, such as protocols used in specialty clinics for women who have experienced stillbirth, are available but not widespread.**

One priority in designating best practices for the psychological support and care of women who have experienced a stillbirth is to listen to their priorities and concerns. Facilities need to make training based on parents' voices more common.

Many parents are faced with insensitivity, and there is a general lack of understanding about traumatic grief. Even hospital staff and others providing crisis care and therapists may be insensitive or lack compassion. Parents want people to talk in way that is sensitive and to acknowledge their baby and the death as having as much significance as any other child's death.

Hearing what was helpful and what was painful directly from parents can be persuasive; otherwise, physicians, midwives, and nurses may have trouble understanding their impact or knowing what is needed or helpful. For example, in hospitals where there are no markers on the door for a family who had experienced a stillbirth, a provider could easily walk in and offer congratulations.

Distinctive aspects of services at specialty clinics who take care of patients after experiencing a prior stillbirth include special attention to the heightened anxiety patients often experience, additional prenatal appointments, and special training for providers and staff to help them understand patients' needs. Some of the practices by specialty clinics to support parents could be adopted more generally.

It is important to educate providers and others who interact with patients about everything that is important related to the stillbirth. Patients want their stillborn child to be recognized. Steps in that direction may include putting rainbow footprints on the hospital room door, adding patients' rainbow status to electronic whiteboards, giving priority for a private hospital room, and setting up supportive and follow-up care. When considering effective support for parents who have experienced stillbirth, the emotional needs of providers should not be overlooked.

- **Women who have experienced stillbirth often do not receive timely, sensitive, and effective support.**

Finding good trauma-informed grief counseling after a stillbirth can be challenging. This is reflected in individuals' stories, and research studies consistently show a need that is too often unmet.

Immediately following stillbirth, things that can help grieving parents include having unhurried time with the baby. Most states allow families to take the baby home, and there are a growing number of death doulas. Rituals and artifacts—something that the baby touched—can be meaningful. Notes on the door, in-hospital rituals, and sensitive language are practical ways to help. Having a compassionate provider and a single point of contact for the parents also helps ensure that staff know how to care for people whose baby has just died.

“I had called two health professionals who specialized in grief and child loss and was told they weren’t accepting new patients, or I didn’t receive a call back. My postpartum appointment wasn’t until 8 weeks after, and that’s when I was finally referred to speak with someone.”

—Parent

Many hospitals do not require bereavement training for nurses and physicians. Many academic hospitals have more robust bereavement programs, but many low-cost measures could be offered at smaller hospitals. Studying the impact of such measures on families would be valuable.

Crucially, serious barriers to health equity in mental health treatment should not be minimized or overlooked. For example, African American women are less likely to get certain forms of support, including medication and psychotherapy. Furthermore, for women who receive Medicaid before a child’s birth, Medicaid coverage may end after the birth. Child care, work schedules, time constraints, and transportation can pose additional barriers.

- **Fathers, siblings, grandparents, and other family members also need support but seldom receive it.**

Stillbirth’s impact is deep and wide, and each person’s experience of grief is personal. Yet the bereavement needs of those who are not mothers and how they can be best addressed remains very much unexplored.

As with mothers, for fathers the trauma of stillbirth can challenge core assumptions and paternal identity. In relating their experiences to the WG, fathers who had experienced a stillbirth testified to their grief and their PTSD. Siblings, too, can struggle with their identity. Stillbirth can

“In a few weeks, our family will honor the memory of [the baby’s] 10th birthday with a cake but no [baby]. Families shouldn’t have to celebrate a birthday without the birthday child being there.”

—Family member

affect parenting style, produce intergenerational trauma, and have other impacts on other children in the family, including influencing the way they cope with their grief.<sup>26</sup> It can affect how siblings see the family birth order and their role within the family. Experiencing the stillbirth of a sibling or being born into a family that has experienced pregnancy loss can continue to affect these children as adults, including when they have their own children.<sup>27</sup>

Data on paternal grief, most of which has emerged in the last decade, suggest that men and women may have different grief and forms of expressing it. This is a neglected topic, not only for fathers but for grandparents, LGBT couples, and others, too. In advancing this area of knowledge, identifying those who are most at risk of poor outcomes will be important. As with mothers, those individuals are likely to also have risk factors such as mental health issues, prior traumatic loss, or experience of an unanticipated death.

- **Research on the psychological impact of stillbirth has documented the need for psychological support and bereavement care, but further research is needed to develop more effective interventions.**

In addition to screening and treatment for depression, mindfulness-based therapies are one focus of ongoing research that could be investigated for women who have experienced stillbirth. Research on interventions for PTSD after stillbirth is limited. Other priorities for bereavement research include intervention trials for bereavement care and studies that specifically aim to understand the experience of African American women. Recruitment bias is an important consideration. For example, studies that recruit participants from support groups may overrepresent women from higher-income households with private insurance coverage.

Ongoing studies include research into telehealth and mindfulness for depression prevention among high-risk pregnant women, but few are focused on African American women. Testing an adaptation of the content of care bundles may be a research option to consider. For example, researchers could investigate a PRAMS sample of women who experienced perinatal death and evaluate the receipt of each item, comparing those results with those for women not experiencing a fetal death.

Linking large sets of data could help, as it is rare for a dataset to contain both mental health data and information on pregnancy outcomes in the appropriate time periods. Finding a way to include pregnancy status, pregnancy outcomes, and mental health variables in large cohort datasets would advance research. Researchers should also

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<sup>26</sup> J Cacciatore. 2010. The Unique Experiences of Women and Their Families After the Death of a Baby. *Social Work in Health Care*, 49(2), 134-148.

<https://www.tandfonline.com/doi/abs/10.1080/00981380903158078/>.

<sup>27</sup> P Avelin, G Gyllensward, K Erlandsson, I Radestad. Adolescents' experiences of having a stillborn half-sibling. *Death Stud.* 2014 Jul-Dec;38(6-10):557-62. doi: 10.1080/07481187.2013.809034.

consider how to expand bereavement cohorts to encompass the continuum of loss from early pregnancy to a child's first year.

## Recommendations From the WG

The WG believes that it is essential to conduct implementation research and develop culturally sensitive interventions to support families that have experienced stillbirth.

8. NIH and CDC should support or conduct systematic research to collect data from individuals with lived experience in the psychological impact of stillbirth. Implementation research should be designed to inform efforts on how to develop culturally sensitive programs to support families after stillbirth. Results from this research should be shared with the clinical, research, and advocacy communities.
9. Professional societies should consult individuals with lived experience regarding the psychological impact of stillbirth, as well as providers who care for those patients, to improve provider training and incorporate supportive practices into the care for affected families.

“We need to do more than know the risk factors—we need to know how to move towards prevention.”

—Researcher

## Known Risk Factors for Stillbirth

### Findings of the WG

- **Known risk factors are insufficient to explain why stillbirths occur. In many cases, a stillbirth occurs without any known risk factors.**

There are numerous factors that can increase a pregnant individual's risk of having a stillbirth. Some examples include:

- Maternal risk factors. These include age, chronic conditions such as diabetes, hypertension, pregnancy complications, and substance use.
- Fetal risk factors. Lack of proper growth, birth defects, or genetic abnormalities can increase the fetus's risk of death.
- Placental conditions
- Cord issues
- Infection
- Environmental exposures. These include conditions such as temperature extremes and pollution, as well as social determinants of health.

Yet with the current state of knowledge, early in pregnancy, doctors cannot predict who is at highest risk of stillbirth. Despite many associations with stillbirth, risk factors overall

explain little of the variance in stillbirth.<sup>28</sup> Even taking together pregnancy history, maternal age, chronic conditions, and other baseline risk factors, researchers were able to predict only 19% of stillbirths at the beginning of pregnancy.

- **Improved ascertainment of risk factors for stillbirth is needed for risk stratification, prediction, and ultimately stillbirth prevention.**

The study of risk factors is an active area of stillbirth research. However, providers need to better understand how factors influence stillbirth risk in order to help pregnant individuals understand their risk. Moreover, for known risk factors that can already be addressed (i.e. hypertension), interventions must be developed and tested to give providers the chance to take measures to prevent stillbirth.

Risk factors that could be studied in population-based settings include maternal chronic disease, medication use, environmental exposures, and social determinants of health. Other areas for further investigation to identify risk factors or early clinical indicators of stillbirth risk include placental biomarkers, isolating placental cells and products in the maternal circulation, fetal and placental imaging, and the microbiome. It will also be important to consider the framework of individuals' social context, including incorporating social determinants of health in research, to affect physical health as well as inequities in healthcare. More research is needed to understand the risks pregnant women face and how providers can best counsel them on managing those risks, including stillbirth.

Anecdotally, changes in fetal movement are seen as a possible precursor of stillbirth. Although decreased fetal movement is associated with the occurrence of stillbirth, the evidence for fetal movement counting in low-risk pregnant people as an intervention to prevent stillbirth is mixed and controversial. One systematic review found no significant difference in pregnancy outcomes between groups of women who reported decreases in movement and those who did not.<sup>29</sup> In the United Kingdom, a large randomized trial found no difference in the stillbirth rate of the group provided a care package that increased patient awareness and reporting of reduced fetal movement and standardized management of reduced fetal movement by providers including timely delivery.<sup>30</sup> The intervention group had increased rates of labor induction, cesarean delivery, and prolonged

“I was told I had a perfect pregnancy . . . up until the moment they told me my baby didn’t make it.”

—Parent

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<sup>28</sup> Stillbirth Collaborative Research Working Group. Association Between Stillbirth and Risk Factors Known at Pregnancy Confirmation. JAMA. 2011;306(22):2469-2479. doi:10.1001/jama.2011.1798

<sup>29</sup> F Bellussi, G Po, A Livi, G Saccone, V DeVivo, EA Oliver, V Berghella. Fetal Movement Counting and Perinatal Mortality: A Systematic Review and Meta-analysis. Obstet Gynecol. 2020 Feb;135(2):453-462.

<sup>30</sup> JE Norman et al, Awareness of fetal movements and care package to reduce fetal mortality (AFFIRM): a stepped wedge, cluster-randomised trial. 2018. Lancet, 392 (10158), P1629-P1638.



neonatal unit admissions. Clearly, fetal movement deserves more study.

Research that targets the entire population could improve methods for identifying patients who are at highest risk. Machine learning and artificial intelligence is one promising area of research to improve risk stratification. Markers of placental dysfunction, fetal hypoxia or acidemia, cord compression, and oxidative stress could also be useful. Genomic sequencing could also help determine when genetic factors increase risk in combination with certain exposures. Individually, the conditions detected might be quite rare, but taken together, genetic conditions represent a common risk for stillbirth.

“Genomics and epigenomics are promising realms for reducing unexplained stillbirth numbers but are under-researched.”

—Researcher

Launching a birth defects registry in a specific geographic area with a high stillbirth rate, including a thorough evaluation, interviews with families, and other assessments, could yield clues about how to look further at genetic factors.

“. . . [M]ore research is needed to better understand the role of social determinants on health on the risk for stillbirth.”

—Researcher

Accounting for the larger context in which people live and how it affects child health outcomes will also be important. Society and individuals’ communities carry social drivers of health, which can affect individual biology.

- **Risk factors associated with stillbirth are often also associated with other adverse pregnancy outcomes, suggesting common underlying mechanisms. Research into the pathophysiologic underpinnings of risk factors is needed.**

Many adverse pregnancy outcomes, including spontaneous preterm birth, abruption, preeclampsia, and fetal growth restriction, share common risk factors and might have common mechanisms. Similar conditions might lead to spontaneous preterm birth in one pregnancy and to stillbirth in another.

“. . . [M]aternal conditions need to be examined in association with each other and with the stillbirth outcome.”

—Researcher

Understanding what contributed to a stillbirth also makes it possible to identify a pathway and targets. Risk factors can also be used to examine pathophysiology in more detail. Given how they can interact with each other, with exposures, and with genetic variation, it is important to study risk factors in relation to each other. With a high population-attributable risk—such as obesity, which can contribute to many adverse pregnancy outcomes—it would be useful to aggregate shared mechanisms and disaggregate distinct ones in research to better understand both common and rare outcomes. This approach could lead to better diagnosis and prevention.

- **Numerous risk factors and potential causes are associated with stillbirth. A few examples include:**
  - ▶ Placental conditions
  - ▶ Umbilical cord issues
  - ▶ Infection
  - ▶ Maternal conditions, both pregnancy-associated (like preeclampsia) and chronic preexisting conditions
  - ▶ Genetic conditions
  - ▶ Environmental exposures

Many conditions can increase the risk of a stillbirth. Notably, it can be difficult to distinguish between causes and risk factors with certainty because of significant overlap between the two. In a multicenter, population-based case-control study of stillbirths and live births enrolled at delivery, researchers used a wide range of techniques—maternal interviews, maternal and fetal biospecimen testing, maternal record review, and others—to understand the risk factors and causes of stillbirth. They found that the distribution of causes of death was as follows: obstetric conditions, 29.3%; placental abnormalities, 23.6%; fetal genetic/structural abnormalities, 13.7%; infection, 12.9%; umbilical cord abnormalities, 10.4%; hypertensive disorders, 9.2%; and other maternal medical conditions, 7.8%.<sup>31</sup>

Better understanding known risk factors can perhaps lead to new avenues to prevent or control them. For example, some stillbirths, particularly late fetal deaths, have been associated with potentially preventable maternal diseases such as diabetes and high blood pressure. In addition, it is important to evaluate macroenvironmental stressors, because they can potentially affect many women. These factors—including temperature extremes and pollution—are underappreciated risks.

At the same time, research into risk factors that are still unknown is equally a priority. In the design of future studies, a broad genetic testing approach will help increase the number of conditions that can be identified.

Previous obstetric complications can also increase the risk of stillbirth in a subsequent pregnancy. A larger body of evidence about risk factors will be important for prevention of stillbirth among those carrying a child for the first time and for counseling individuals about a subsequent pregnancy as well.

- **For many known risk factors, interventions addressing the risk are not yet available.**

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<sup>31</sup> Stillbirth Collaborative Research Network. Causes of death among stillbirths. JAMA. 2011 Dec 14;306(22):2459-68. doi: 10.1001/jama.2011.1823



Research on ultrasound, placental function, and other types of monitoring are needed to better understand what causes stillbirth and also to identify prevention opportunities. There are opportunities in research and development for technologies that circumvent or minimize current limitations, as in the use of ultrasound for assessing stillbirth risk in patients with obesity.

Using risk factors to determine optimal delivery windows is another promising area of research. Inducing labor can reduce the risk of stillbirth, but it is not always clear how to balance this advantage against the increased risk of prematurity. Providers would benefit from having more evidence on which to make decisions about the timing of delivery.

“Methodological issues specific to stillbirth pose a challenge to investigating risk factors.”  
—Researcher

## Recommendations From the WG

Understanding risk factors related to stillbirth is an extremely complex and difficult endeavor. The WG recommends creating and supporting a full research agenda, including research on both known and unknown risk factors and physiologic mechanisms, to drive the development of interventions to ultimately prevent stillbirth.

10. NIH should convene a group of basic, translational, clinical, and public health research experts, as well as parents who have experienced stillbirth, to develop a research agenda to advance prevention for stillbirth and other adverse pregnancy outcomes. The research agenda should include efforts to identify implications for stillbirth prevention from NIH’s Human Placenta Project and related research.
11. NIH should conduct or support research to establish baseline normative data on physiology in pregnancy, including potential indicators of health and disease. Such indicators may include, but should not be limited to, placental development and function, fetal movement, fetal growth, and others.
12. NIH and CDC should support additional research on causes and risk factors, as well as prevention of stillbirth more broadly. Specifically, these efforts should:
  - ▶ Focus on un- and under-investigated areas to discover new risk factors and interactions, to help understand the racial disparity in stillbirth, and to assess the preventability of stillbirth
  - ▶ Investigate the feasibility and potential usefulness of developing a stillbirth registry
  - ▶ Delineate the mechanisms of how specific risk factors affect stillbirth and explain the racial disparity
  - ▶ Develop and test indicators and clinical interventions for the prevention of stillbirth

## Appendix 1: Task Force Congressional Mandate

The fiscal year 2022 Consolidated Appropriations Act (P.L. 117-103) included funds and report language for HHS to establish a Task Force to report on four priority aspects of stillbirth in the United States. The mandate is as follows:

“Stillbirth Task Force.—Stillbirth affects one in 160 pregnancies, with 24,000 babies stillborn each year. Despite medical advances, the rate of early stillbirth has remained the same over the past 30 years. The Committee provides \$1,000,000 for the Secretary to develop a task force on stillbirth in the United States. The task force should include the CDC, NIH, outside specialty organizations, and maternal and fetal medicine specialists. The task force should focus on the current barriers to collecting data on stillbirths throughout the United States, communities at higher risk of stillbirth, the psychological impact and treatment for mothers following stillbirth, and known risk factors for stillbirth. The task force should provide a report on these issues within one year of enactment of this Act.”

The 2022 Consolidated Appropriations Act was enacted on March 15, 2022.

## Appendix 2: Stillbirth Working Group of Council Members

- Lucky Jain, M.D., Emory University, co-chair
- Uma M. Reddy, M.D., M.P.H., Columbia University, co-chair representative of American College of Obstetricians and Gynecologists (ACOG)
- RADM Wanda D. Barfield, M.D., M.P.H., Centers for Disease Control and Prevention (CDC)
- CAPT Amanda Cohn, M.D., CDC
- Deborah Conway, M.D., University of Texas Health Science Center, San Antonio
- Carla DeSisto, Ph.D., M.P.H., CDC
- Ada Dieke, Dr.P.H., M.P.H., CDC
- Donald Dudley, M.D., University of Virginia
- Andrew Fullerton, M.P.P., March of Dimes
- Isabelle Horon, Dr.P.H., CDC
- Denise Jamieson, M.D., M.P.H., Emory University
- Stephanie Leonard, Ph.D., Stanford University
- Monica Longo, M.D., Ph.D., *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
- Jenna Nobles, Ph.D., University of Wisconsin–Madison
- Tina Pattara-Lau, M.D., Indian Health Service
- Sonja Rasmussen, M.D., M.S., Johns Hopkins School of Medicine
- Jennita Reefhuis, Ph.D., CDC
- Robert M. Silver, M.D., University of Utah Health Sciences Center and representative of the Society for Maternal-Fetal Medicine (SMFM)
- Catherine Vladutiu, Ph.D., M.P.H., Health Resources & Services Administration
- Maeve Wallace, Ph.D., M.P.H., Tulane University
- Monica H. Wojcik, M.D., Boston Children’s Hospital

## Appendix 3: Stillbirth Working Group of Council Meetings

The WG held four sessions to gather information on its topics of focus. This appendix lists the topics covered and the experts who presented at each session.

- October 20, 2022: First Meeting
  - ▶ Scope of the WG
    - Natasha Williams, Ph.D., J.D., L.L.M., M.P.H., Chief, Legislation and Public Policy Branch, NICHD
  - ▶ NIH Portfolio Analysis
    - Sarah Glavin, Ph.D., Deputy Director, NICHD Office of Science Policy, Reporting, and Program Analysis (OSPRA)
  - ▶ Fetal Deaths in the United States
    - Elizabeth Gregory, Ph.D., Health Scientist, CDC, National Center for Health Statistics (NCHS)
- November 22, 2022: Second Meeting
  - ▶ Current Barriers to Collecting Data on Stillbirths
    - Donald Dudley, M.D., University of Virginia
    - Kimberly Noble Piper, Iowa Department of Public Health
    - Jennita Reefhuis, Ph.D., CDC
    - Jill Wieber Lens, J.D., University of Arkansas School of Law
  - ▶ Communities at Higher Risk
    - Michelle Debbink, M.D., Ph.D., University of Utah
    - Carol Hogue, Ph.D., M.P.H., Emory University
    - Donna Hoyert, Ph.D., CDC
    - Pauline Mendola, Ph.D., University of Buffalo
- December 9, 2022: Third Meeting
  - ▶ Role of Federal Agencies
    - Alison Cernich, Ph.D., NICHD
  - ▶ Psychological Impact and Treatment for Mothers Following Stillbirth
    - RADM Wanda D. Barfield, M.D., M.P.H., Centers for Disease Control and Prevention (CDC)
    - Joanne Cacciatore, Ph.D., Arizona State University
    - Ada Dieke, Dr.P.H., M.P.H., CDC
    - Katherine Gold, M.D., M.S.W., M.S., University of Michigan
    - Joanne Stone, M.D., M.S., Mount Sinai
  - ▶ Known Risk Factors for Stillbirth
    - Drucilla Roberts, M.D., Harvard University
    - Robert M. Silver, M.D., University of Utah Health Sciences Center and representative of the Society for Maternal-Fetal Medicine (SMFM)
    - Hyagriv Simhan, M.D., M.S., University of Pittsburgh
    - Monica H. Wojcik, M.D., Boston Children's Hospital

- January 5, 2023: Listening Session
  - ▶ Impact of Stillbirth on Families and Communities
    - Members of the public with personal experience of stillbirth

## Appendix 4: NIH Stillbirth Research Portfolio

The devastating toll that stillbirth or fetal death takes on parents, families, and entire communities has made stillbirth research a matter of urgency for scientists across the globe. To set the stage for the working group's deliberations, NIH conducted a literature analysis to assess the characteristics of the overall literature on stillbirth and NIH's role in expanding scientific and clinical knowledge to inform stillbirth prevention efforts.

### Scope and Methodology

NIH staff conducted literature searches using the PubMed and Scopus databases. Search terms were developed from the scientific thesaurus NIH uses for its categorical reporting as part of the NIH Research, Condition and Disease Categories (RCDC) reporting system. The search covered the years from January 1, 2005, to September 1, 2022, to allow for assessment of trends over time. Publications were linked to supporting NIH grants using internal NIH tools and Scopus data on funding sources. Scopus indexed terms were used to identify subtopics within the literature. After the initial search, the following exclusionary criteria were applied:

- ▶ Articles published in veterinary journals<sup>32</sup>
- ▶ Review articles
- ▶ Case reports
- ▶ Editorials and commentaries
- ▶ Articles for which no English title or abstract was available
- ▶ Conference presentation abstracts
- ▶ Errata
- ▶ Retracted articles
- ▶ Articles with no indexed or other keywords and no abstract or other text from which content could be assessed

A total of 19,916 articles were included in the analysis.

Using NIH's RCDC reporting system, NIH grants relating to pregnancy for the years 2018–2021 were reviewed to assess their relationship to stillbirth. NIH has reported pregnancy-related research only since 2018. Text and natural language processing tools were used to identify grants and projects from preceding years (2008–2017) that are similar, using an algorithm based on the terms used to create the 2021 category. These data are unofficial and were not subject to the normal NIH review, validation, and quality control processes.

Two types of analyses were conducted based on the results of the literature searches and the pregnancy grant portfolios: (1) an examination of the descriptive characteristics

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<sup>32</sup> Veterinary or animal research published in non-veterinary journals was included.

of grants linked to stillbirth publications and (2) an assessment of publications associated with the NIH grants related to pregnancy and stillbirth. The first analysis characterizes the NIH pregnancy research portfolio according to how it incorporates stillbirth as a pregnancy outcome, and the second shows how NIH contributed to the stillbirth literature over a 15-year span.

These analyses are subject to several important limitations. The automation tools and keyword searches used to identify literature relevant to stillbirth are subject to error and were not validated/screened manually. Moreover, some important subtopics could not be well addressed by automated methods. NIH has reported pregnancy-related research only since 2018. Text and natural language processing tools were used to construct portfolios from preceding years (2008–2017) using an algorithm based on the terms used to create the 2021 category. These data are unofficial. Because scientific terminology changes over time and these data apply 2021 terminology to earlier grants, some items from early years may be included or excluded incorrectly. Data prior to 2018 are unofficial and were not subject to the normal NIH review, validation, and quality control processes. These data should be used with caution.

### **Stillbirth Research Literature (Irrespective of Funding Source)**

A total of 19,916 articles were identified by the literature search. The number of publications identified through the literature search increased substantially over the years, as shown in Figure A4.1. NIH-supported publications accounted for a small percentage of this total—about 7 percent over all years—and the number of NIH-supported publications has grown more slowly than the overall total since 2015. These figures reflect the global interest among researchers in stillbirth prevention. NICHD accounted for roughly half of the NIH-supported publications.

Figure A4.1: Number of Stillbirth Publications, 2005–2021, by Year Published

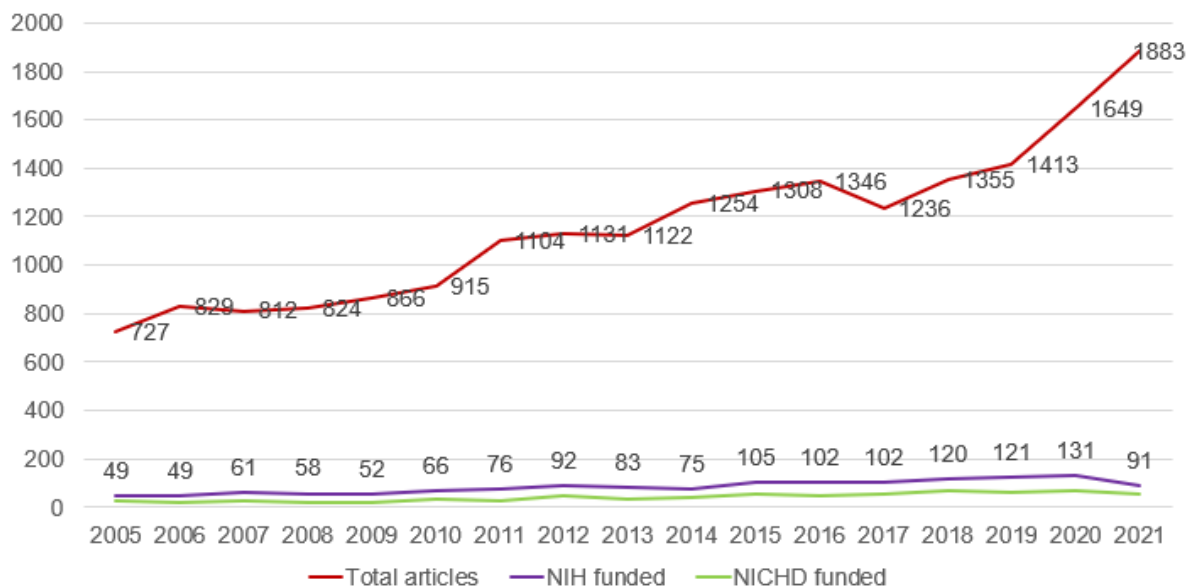
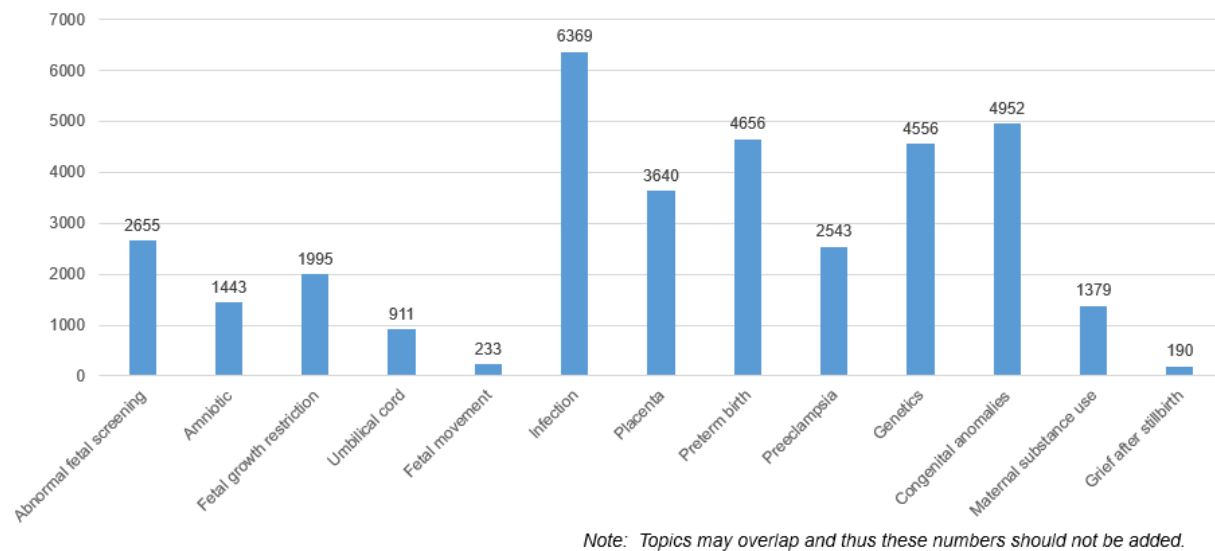


Figure A4.2 shows the number of articles associated with specific indexed keywords within the stillbirth literature. Even though the bulk of the time period for this analysis occurred before the COVID-19 pandemic, maternal infection was the most common subtopic examined, followed by preterm birth, genetics, and genetic disorders. Grief and support after stillbirth were the most poorly researched of the subtopics examined. The most highly cited publications (i.e., in the top 15 percent of cited works) were similarly represented among subtopics. Unsurprisingly, the two most highly cited publications on stillbirth provided epidemiology data. Many other highly cited articles documented risk factors associated with stillbirth.

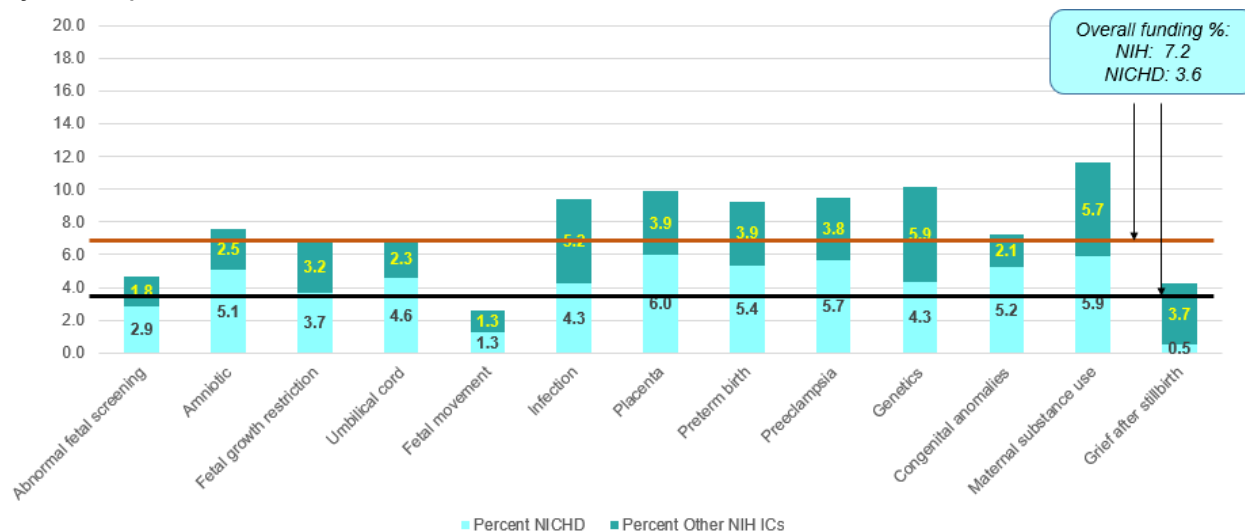


Figure A4.2: Number of Stillbirth Publications, 2005–2021, by Subtopic



Among NIH-supported publications, the pattern of research by subtopic was somewhat different from the overall sample. As shown in Figure A4.3, compared with the overall literature, the subtopics of maternal substance use, genetics, and the placenta were more strongly represented in the NIH group than in the overall group. Grief and support after stillbirth were the subject of a higher proportion of NIH-supported publications, although the total was still low. Most of the publications on grief after stillbirth were supported by institutes other than NICHD, most notably the National Institute on Mental Health (NIMH).

Figure A4.3: Percent of Stillbirth Publications, 2005–2021, Funded by NIH and NICHD, by Subtopic



## NIH-Funded Grants and Projects Related to Stillbirth

In NIH's scientific category reporting, stillbirth research is reported within the Pregnancy category. These data are available at <https://report.nih.gov/funding/categorical-spending#/> under the heading Pregnancy.

Using text analysis tools, NIH-funded grants and projects related to pregnancy were classified into three mutually exclusive categories:

1. **Stillbirth-focused:** These grants explicitly include stillbirth as the sole or primary focus of the research effort. Many of these grants are epidemiologic or clinical research studies of precursors of stillbirth. For example, the NICHD Stillbirth Collaborative Research Network (SCRN) conducted a multicenter, population-based case-control study of stillbirths and live births enrolled at delivery to understand the risk factors and causes of stillbirth in the United States. Scientists analyzed genetic data this cohort, and they found that whole exome sequencing could identify genetic causes in 6 percent of stillbirth cases examined, and most of these resulted from mutations in single genes.<sup>33</sup>
2. **Stillbirth-inclusive:** These grants explicitly include stillbirth as an outcome measure, and stillbirth is measured as an outcome separately from other adverse pregnancy outcomes such as preterm birth. However, for grants in this category, stillbirth is not the sole or primary focus of the research. For example, in 2010, researchers in NICHD's Global Network found that after the introduction of Essential Newborn Care training of community-based birth attendants in resource limited countries, the rate of stillbirth was reduced, although the rate of neonatal mortality was not.<sup>34</sup>
3. **Stillbirth-adjacent:** For these pregnancy research grants, the research clearly has implications for stillbirth, but stillbirth is not included in the original research design as a separate outcome measure. For many of these grants, stillbirth is included as part of a composite outcome; for others, the researchers set out to measure upstream factors rather than pregnancy outcomes. As the data come in, the researchers may then investigate stillbirth or stillbirth-related outcomes, although it was not a primary research objective. For example, National Institute of Allergy and Infectious Diseases–supported scientists found that cytomegalovirus infection was associated with adverse pregnancy outcomes, and only weakly associated with stillbirth risk, in a cohort of HIV-positive

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<sup>33</sup> KE Stanley et al, Causal Genetic Variants in Stillbirth. N Engl J Med 2020 Sep 17;383(12):1107-1116. doi: 10.1056/NEJMoa1908753.

<sup>34</sup> WA Carlo et al, Newborn-care training and perinatal mortality in developing countries. New England Journal of Medicine, 2010 Feb 18;362(7):614-23.

women.<sup>35</sup> A Randomized Trial of Induction Versus Expectant Management, funded by NICHD, used a composite primary outcome that included stillbirth. This study found that induction of labor at 39 weeks was not associated with adverse pregnancy outcomes overall.<sup>36</sup> For more examples, see Table A4.1.

**Table A4.1: Key NIH Grants Contributing to Stillbirth Literature**

Category	Grant or Program	Selected Key Findings
Stillbirth-focused	Stillbirth Collaborative Research Network (NICHD)	After thorough, multifaceted review, a possible or probable cause of death was identified in 77% of stillbirth cases. Most common causes were obstetric, placental, fetal genetic/structural, infection, and umbilical cord issues. <sup>37</sup>
		Multiple preexisting risk factors were associated with stillbirth, but accounted for only a small amount of the variance. <sup>38</sup>
	Prenatal Alcohol, SIDS, and Stillbirth Network (NICHD and NIAAA)	Drinking and smoking thru and beyond the first trimester were associated with a significantly higher risk of late stillbirth. <sup>39</sup>
Stillbirth-inclusive	Maternal Fetal Medicine Units Network (NICHD)	COVID-19 infection was associated with increased risk of stillbirth and neonatal death but not preterm birth or other adverse outcomes. <sup>40</sup>
		Treating mothers with subclinical hypothyroidism during pregnancy did not reduce stillbirth risk. <sup>41</sup>
Stillbirth-adjacent	Superfund Research Program (NIEHS)	Prenatal drinking water exposure to tetrachloroethylene was linked to stillbirth and placental abruption but not to other adverse outcomes. <sup>42</sup>

<sup>35</sup> NO Moraka et al. Cytomegalovirus Viremia in HIV-1 Subtype C Positive Women at Delivery in Botswana and Adverse Birth/Infant Health Outcomes. *J Acquir Immune Defic Syndr*. 2019 May 1;81(1):118-124

<sup>36</sup> WA Grobman et al. Labor Induction versus Expectant Management in Low-Risk Nulliparous Women. *New England Journal of Medicine*, 2018 Aug 9;379(6):513-523.

<sup>37</sup> Stillbirth Collaborative Research Network. Causes of death among stillbirths. *JAMA*. 2011 Dec 14;306(22):2459-68. doi: 10.1001/jama.2011.1823

<sup>38</sup> Stillbirth Collaborative Research Network. Association between stillbirth and risk factors known at pregnancy confirmation. *JAMA*. 2011 Dec 14;306(22):2469-79. doi: 10.1001/jama.2011.1798.

<sup>39</sup> H Odendaal et al. Association of Prenatal Exposure to Maternal Drinking and Smoking With the Risk of Stillbirth. *JAMA Netw Open*. 2021 Aug 2;4(8):e2121726.

<sup>40</sup> BL Hughes et al. First- or second-trimester SARS-CoV-2 infection and subsequent pregnancy outcomes. *Am J Obstet Gynecol*. 2023 Feb;228(2):226.e1-226.e9. doi: 10.1016/j.ajog.2022.08.009.

<sup>41</sup> BM Casey et al. Treatment of Subclinical Hypothyroidism or Hypothyroxinemia in Pregnancy. *New England Journal of Medicine* 2017 Mar 2;376(9):815-825.

<sup>42</sup> A Ascengrau et al. Modeled exposure to tetrachloroethylene-contaminated drinking water and the risk of placenta-related stillbirths: a case-control study from Massachusetts and Rhode Island. *Environ Health*, 2018 Jul 3;17(1):58. doi: 10.1186/s12940-018-0402-1 and JL Carwile et al. Prenatal drinking-water exposure to tetrachloroethylene and ischemic placental disease: a retrospective cohort study. *Environ Health*. 2014 Sep 30;13:72. doi: 10.1186/1476-069X-13-72.

Category	Grant or Program	Selected Key Findings
	Malaria and Nutrition in Pregnancy (NICHD) and Center for Environmental Health (NIEHS)	Exposure to indoor air pollution was associated with fetal thrombotic vasculopathy and stillbirth in Tanzania. <sup>43</sup>
	STI Screening and Treatment (NICHD)	Treating chlamydia infections in pregnancy was not associated with a reduction in stillbirth risk. <sup>44</sup>

The initial automated results included a significant number of false positives and incorrect classifications, so the classification of stillbirth-focused and stillbirth-inclusive projects were validated by hand coding. For four subcategories that were amenable to text analysis—congenital anomalies, preterm birth, infection, and maternal substance use—automated tools were used to identify grants relating to these specific subcategories in all three classifications over a longer period of time. Institutional training and career development grants (such as T32 or K12 grants) were excluded.

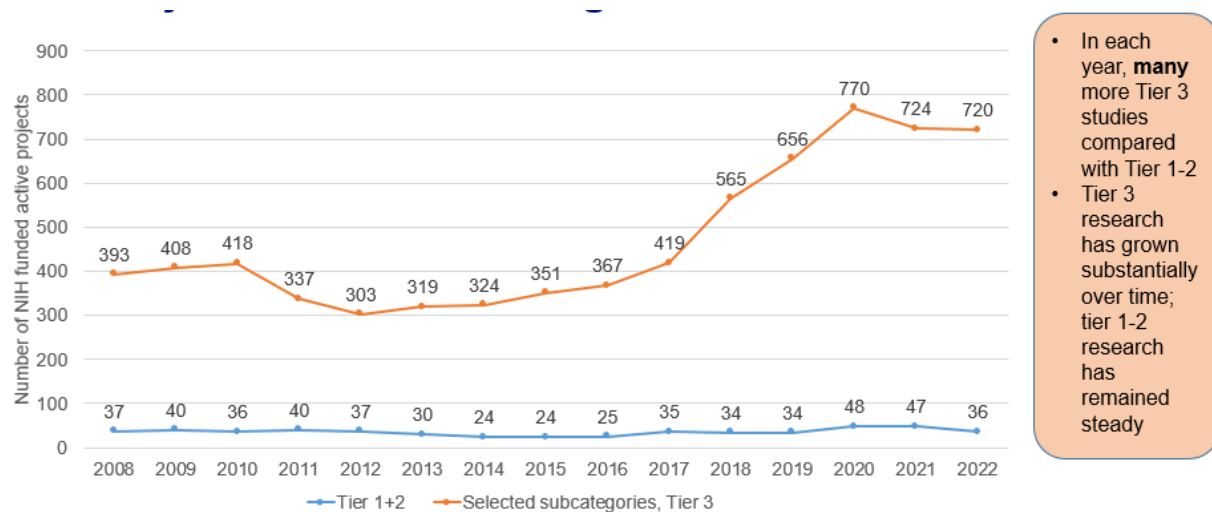
Among stillbirth-focused and stillbirth-inclusive publications, about three-quarters (76 percent) were funded by NICHD, and the remaining 24 percent were funded by other NIH Institutes and Centers. If all pregnancy research grants and projects are considered together, only about 40 percent were funded by NICHD. Centers and networks played a major role, with about two-thirds of projects in the stillbirth-focused and stillbirth-inclusive categories supported by center or network programs.

For four subcategories of research relevant to pregnancy and stillbirth—congenital anomalies, preterm birth, infectious diseases, and maternal substance use—automated tools could be used to identify related grants over a longer period of time. Figure A4.4 shows the trends over time in the number of NIH-supported grants and projects in this subset. In each year, the number of stillbirth-adjacent projects greatly exceeded the number of focused and inclusive projects. Over time, stillbirth-focused and stillbirth-inclusive research remained relatively steady within these four subcategories, while stillbirth-adjacent research grew. Preterm birth research showed the largest growth over time. A growth in substance use research reflected the opioid use and addiction problem in the United States.

<sup>43</sup> BJ Wylie et al. Placental Pathology Associated with Household Air Pollution in a Cohort of Pregnant Women from Dar es Salaam, Tanzania. *Environmental Health Perspectives*. 2017 Jan;125(1):134-140. doi: 10.1289/EHP256.

<sup>44</sup> PC Adamson and JD Klausner. Treating chlamydial infections in pregnancy and preventing adverse birth outcomes. *Lancet Infect Diseases* 2018 Apr;18(4):368-369. Doi: 10.1016/S1473-3099(18)30049-5.

**Figure A4.4: NIH-Supported Grants and Projects Related to 4 Subcategories of Stillbirth Research: 2008-2021**

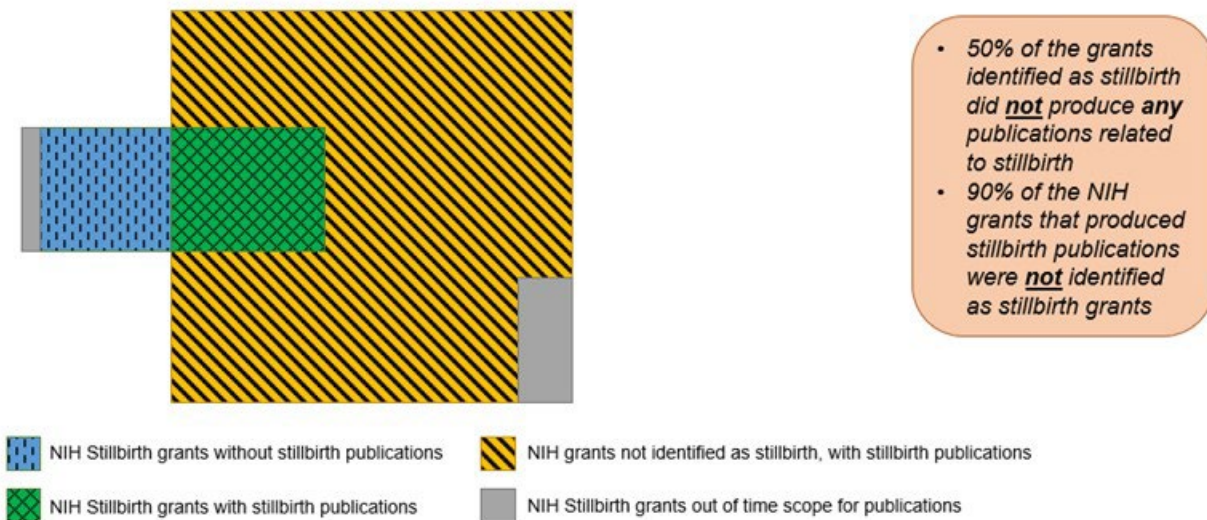


## Stillbirth Grants and Publications

Over the past two decades, researchers have confirmed many causes and risk factors linked to stillbirth. These include a wide range of pregnancy complications, such as preeclampsia, placental conditions, and fetal growth restriction. Interventions to prevent such conditions and reduce the prevalence of such risk factors would be expected to mitigate stillbirth risk. However, studies of these interventions may be stated in terms that do not include a specific stillbirth focus, because the connection may be assumed rather than stated explicitly. Moreover, stillbirth tends to occur in small numbers in most clinical samples. Studies that use clinical data to assess stillbirth risk may run into difficulties publishing results that are ultimately based on a small number of cases.

For these reasons, it is perhaps not surprising that outside of research networks, many NIH-supported grants that initially stated stillbirth-focused or stillbirth-inclusive research aims ultimately did not yield publications that add to the scientific research literature specifically on stillbirth. Similarly, many publications that did add directly to the scientific knowledge specifically on stillbirth come from more general, or stillbirth-adjacent, pregnancy research publications. Figure A4.5 shows that of the NIH-supported stillbirth-focused grants from 2008 to 2021, only about half produced stillbirth research publications. Conversely, of the NIH grants that produced stillbirth research publications, only about 10 percent would be initially identified, based on their grant description, as stillbirth-focused grants. Because most of stillbirth literature supported by NIH is linked to “stillbirth-adjacent” projects, rather than studies with a specific stillbirth focus, in considering expanding its contribution to stillbirth research, NIH will need to assess a wide range of pregnancy-related studies that ultimately can contribute to stillbirth prevention efforts.

Figure A4.5: NIH Stillbirth Grants and NIH-Supported Stillbirth Publications





## Appendix 5: Public Listening Session Summary

On January 5, 2023, NICHD held a listening session to gather information from the public on the topic of stillbirth. The following summary of the session was published online: <https://www.nichd.nih.gov/about/advisory/council/stillbirth-working-group-of-council/public-listening-session-summary-010523>.

### Welcome and Overview

*Alison Cernich, Ph.D., Deputy Director, NICHD*

Dr. Cernich welcomed the participants and reviewed the logistics of the day.

### Public Listening Session

#### Moderator

Alison Cernich, Ph.D.

#### Speakers

**Susannah Leisher, Ph.D., M.Phil., M.Sc., M.A.**, representing the **International Stillbirth Alliance**, acknowledged the work of Debbie Haine Vijayvergiya, culminating in the passage of the federal Stillbirth Health Improvement and Education (SHINE) for Autumn Act, named in honor of Debbie's stillborn daughter, Autumn Joy. The act is designed to improve data collection on stillbirths. Dr. Leisher described her own experience with the birth of her son Wilder, who was stillborn nearly 24 years ago, 11 days before his due date. Dr. Leisher said that despite doing everything right during her pregnancy, she became concerned when the baby stopped moving. She immediately went to the hospital, where an ultrasound could not detect a heartbeat. An autopsy and other tests did not reveal the cause of death, and Dr. Leisher was told that "sometimes these things just happen." She has devoted her work to improving stillbirth research and offered the following points to help achieve that goal:

- Use global metrics to acknowledge the poor performance of the United States on the global stage. The stillbirth rate is higher in the United States than it is in 25 other high-income countries.
- Collaborate with global high performers, such as Australia, on reducing the risk of stillbirth; Ireland on national stillbirth bereavement, care, and standards; the Netherlands on parental involvement in perinatal audits; and Canada on extensive research approaches.
- Redefine "preventable" using the 28-week definition. If the United States matched the lowest national stillbirth rate, which is Japan's 1.4 stillbirths per 1,000 total births, 53% of stillbirths at this gestational age could potentially be prevented.



- Acknowledge parents as experts in the production of research.
- Focus research on un- and underinvestigated areas to uncover new risk factors and interactions. With stillbirths, 31% have no identified cause, and there are persistent racial disparities (e.g., Black families have at least double the risk of stillbirth that White families do) that must be addressed.
- Prioritize timely and accurate data collection, such as improving birth certificate data to address the quality of fetal death certificates.

**Samantha Banerjee** is the executive director of **PUSH for Empowered Pregnancy (PUSH)**, an organization whose mission is to reduce the incidence of preventable stillbirths in the United States. Her daughter, Alana, was stillborn 2 days before her due date after an uneventful pregnancy. Ms. Banerjee focused her comments on marginalized families and particularly Black parents who are bearing the brunt of the silent epidemic of preventable stillbirth, and she introduced **Jaye Wilson**, founder and CEO of **Melinated Moms**. Ms. Wilson said her daughter, Nyima Renee, was stillborn at 22 weeks because of placental abruption caused by severe preeclampsia. Ms. Wilson said that even though she is a nurse, her questions and concerns during her pregnancy were constantly dismissed or challenged. She described this dismissive attitude as a common experience for Black women, who feel that there is no point in saying anything, because nothing is going to change, and lauded Ms. Banerjee's organization for creating a space to create the visibility and accountability that will be catalysts for change. **Ms. Banerjee** resumed the presentation, saying that closing the gap in disparities in pregnancy outcomes for White and Black parents would avert 4,000 stillbirths annually in the United States, a 17% overall reduction. The uniquely American stillbirth crisis—the United States has higher rates of stillbirths than nearly every low-, middle-, and high-income country worldwide, ranking 183 out of 190—exists because of racism and a collective inability to face death and grief. She noted since the NICHD Stillbirth Working Group (WG) of Council was established in September 2022, more than 7,000 U.S. babies have been stillborn. A large percentage of these stillbirths were preventable losses. Ms. Banerjee said that if the United States matched the stillbirth rate of Japan, where stillbirth is defined as beginning at 22 weeks, nearly 75% of U.S. stillborn deaths would be averted. The number of U.S. stillbirths is staggering, and the suffering caused by these deaths is unfathomable. She asked NICHD to consider stillbirth a public health crisis, not just a data collection problem, and to use its influence to end preventable stillbirth.

**Tomeka James Isaac**, the founder and executive director of **Jace's Journey**, said that when she became pregnant with Jace at the age of 40, she was told she had a high risk for preeclampsia. Despite this risk, she was given no urine tests and only one blood test, which was done on the first day of her third trimester. Subsequently, Jace presented with intrauterine growth restriction (IUGR). After an inconclusive ultrasound, no additional testing was done. The cause of the IUGR was never determined or mentioned. At 35 weeks, just 2 weeks before the planned delivery, Ms. Isaac rushed to the hospital after a bout of vomiting in the middle of the night and was told by hospital staff, emotionlessly, that Jace had died. She learned she had a syndrome that could

have been diagnosed with a blood test. The severity of her life-threatening condition required seven surgeries over the next 45 days, forcing her to miss Jace's funeral. One simple test could have saved Jace's life, but urine protein testing is no longer considered a best practice because of how much time nurses must devote to it. Ms. Isaac said that Jace's preventable death has forever changed her family. Each day 65 families are affected by a stillbirth, with Black women twice as likely to experience stillbirths. These deaths are preventable, and the time to start preventing them is now.

**Marjorie Vail** said that her loss occurred 18 years ago and that it is very sad to see families experiencing the same tragedy nearly 2 decades later. Ms. Vail said that during her stay at a birthing center in a Manhattan hospital, her requests for help went unheeded until it was too late. Her son was stillborn due to a cord insertion abnormality. The issue could have been detected with an extra sonogram, but that was not done because it was not standard of care. Had the sonogram been done, a cesarean section (C-section) could have been performed and her son would have lived. Ms. Vail said her charge to the committee is to make extra sonograms the standard of care so that conditions like cord insertion can be discovered, treated, and tracked.

**Christian Ortiz** said his daughter, Valentina, was stillborn at term a year ago at Christmas. Her death was preventable, as determined by reports from expert obstetricians and an autopsy. These reports were not offered to him; he paid thousands of dollars to independent experts to understand what happened to Valentina, both for closure and in the hope that her case could be studied for prevention purposes. Research is needed to understand how to prevent stillbirths, but there is a lack of clean autopsy data. Mr. Ortiz noted that there are 22,000 stillbirths per year that could be autopsied, but there is no funding for this type of research. When money is allocated to research aimed at stillbirth prevention, the number of these deaths will go down.

**Yuvelca Magdalena Reyes** is a full-spectrum birth and death doula and an ambassador for **Count the Kicks**, a system that uses an app to teach pregnant women how to monitor and track fetal movement during the third trimester by counting their babies' kicks each day. Ms. Reyes said stillbirth is a traumatic event that should be acknowledged and treated with the support given to other emotional traumas. The trauma of stillbirth changes the brain, and these parents have a hard time moving on even years later. Ms. Reyes noted the disparate effect of stillbirth on Black women due to structural racism and asked NICHD to address the public health issue of too many preventable stillbirths occurring.

**Katherine Hyde-Hensley** recounted her experience after her daughter, Helen, was stillborn at 38 weeks in November 2006, 3 days before a scheduled C-section. She and her husband faced stigma, isolation, and feelings of failure. Ms. Hyde-Hensley endured severe postpartum depression, struggled to care for her other children, and found that little mental health support was available. The trauma affected her parenting, her family's finances, and her and her husband's careers. Today, as a licensed clinical mental health counselor, Ms. Hyde-Hensley asked the committee to consider the

complex trauma that occurs after a stillbirth that impairs intimate relationships and emotional health and puts women at risk for long-term adverse social and psychological outcomes. She urged a paradigm shift toward systematic changes aimed at prevention, because stillbirths will only be reduced through research, education, and awareness campaigns.

**Christine Chang** said that at 38 weeks of an uneventful pregnancy she was told that her baby girl, Madison, had no heartbeat. Ms. Chang hemorrhaged as she delivered the placenta and awoke to find her husband holding their lifeless daughter in his arms. Over the following weeks and months, Ms. Chang, a healthcare professional, looked for answers. She knew that her baby's fetal movements had changed toward the end of her pregnancy, but the nurses did not take that seriously. Five years later she learned that the baby's placenta had been extremely small. Her subsequent pregnancies resulted in live births, but she wonders whether she had a small placenta with her other three pregnancies or whether her children will have similar problems. She experienced post-traumatic stress and postpartum anxiety after the births of her other children. Ms. Chang said that reducing the number of preventable stillbirths requires better data collection, more research, comprehensive education for parents and providers, and a willingness to listen to the parents who have experienced such losses.

**Michelle Alette Harris**, representing **Elijah's Purpose**, was unable to attend. In Ms. Harris's absence, **Kenya Kirkman** said that Elijah's Purpose is an organization that provides resources (e.g., baby supplies, grief counseling, financial burial assistance) to families experiencing stillbirth or pregnancy loss. Ms. Harris was pregnant with twins in 2014 but was unable to access her Veterans insurance and get prenatal care until she was 28 weeks pregnant. At her first appointment, she was told that one of the twins, Elijah, had died about 3 weeks earlier. She carried the other twin to term and delivered both of her sons. She did not have the resources to provide for Elijah's burial. In 2020, Ms. Harris founded Elijah's Purpose. Ms. Kirkman said that she too had been pregnant with two boys, both stillborn in 2018, although she had been conscientious about prenatal care. She was told the cause was an incompetent cervix, although no cervical issues had been noted at her checkup 2 weeks earlier. The stillbirth has caused her great emotional distress. Ms. Kirkman noted that the rate of stillbirths in the United States is equivalent to losing a school bus full of children every day. Moreover, Black women are twice as likely to experience stillbirth as people of other races, and nearly 30% of stillbirths occur in Black families, even though Black people are only 13% of the population. The aftermath of a stillbirth is a place of loneliness, but there is an expectation that the bereaved family should just "move on." Ms. Kirkman suggested that aftercare teams should be provided to parents to counsel them and provide them with resources following stillbirth. Detailed protocols for prevention are also needed.

**Sebrena Tate** said her daughter, Lily, was stillborn in 2020. Her cervix opened at the 20-week checkup. After Lily's stillbirth, the doctors, saying that "these things happen," told her that next time there were other things they could do to address her incompetent cervix. Ms. Tate suggested that rather than waiting until "next time," routine cervical

checks should be part of the standard of care. Families should not have to wait until they experience a loss to be told that the doctors will do things differently “next time.”

**Katherine Cox** said that hers was a high-risk pregnancy due to conception by *in vitro* fertilization (IVF) and controlled hypertension. Despite these risks, her pregnancy went well. She contracted COVID-19 at 30 weeks, and a blood clot was discovered on her cervix. She was hospitalized for observation for a number of days and then sent home. At 33 weeks a nonstress test (NST) was conducted, and Ms. Cox returned home. Less than 36 hours later, her son was dead. The cause of death was listed as unknown. However, Ms. Cox was subsequently diagnosed with antiphospholipid syndrome, which could have resulted in a placental infarction leading to her baby’s death. Ms. Cox questions why, with her high-risk pregnancy and a blood clot of unknown origin, she did not receive weekly double Doppler ultrasound or other additional testing. Today, 5 months and 6 days since her son’s death, Ms. Cox says she lives in a catatonic state and no longer sees friends or family. Stillbirth destroys lives and families. Ms. Cox said that she believed her son’s death was preventable, and she asked the WG to address stillbirth prevention as an urgent priority.

**Angelica Kovach** said her son was stillborn at 33 weeks because of several days of umbilical cord compression. Ms. Kovach, a nurse, realized while she was at work that she had not felt the baby move. She delayed care for 4 hours, not wishing to be a burden to her co-workers and also being aware of disparaging comments from hospital staff about overly anxious parents who seek help when everything is fine. Later that night, when she went to triage, her baby had been dead for a couple of hours. She still cannot understand how she could not have known he was fighting for his life inside her own body. In the 2 years since her baby’s death, Ms. Kovach has had countless parents tell her that all they wanted was for one person to validate their feelings of urgency and concern and to be welcomed by their provider when they wanted to check on their baby. She asked the committee to consider the following three noninvasive stopgap practices to prevent stillbirth losses while research is ongoing to provide more guidance:

- Have parents establish their baby’s normal fetal movements using tools like Count the Kicks.
- Have providers go beyond simply asking about the baby’s movements by assessing the adequacy of the fetal movement.
- Modify prenatal education to make it clear that healthcare providers are there because of and for the patients and empower expectant parents to speak up when they have a concern about their baby.

**Camila Caster** said that after her own two uneventful pregnancies, she volunteered to be a surrogate for friends who were struggling with infertility. Her physician told her that an IVF pregnancy did not add risk, but Ms. Caster later learned that with IVF women are 4 times more at risk for stillbirth. Ms. Caster went to doctors trained in high-risk pregnancies and underwent extra sonograms and appointments. At 38 weeks she noticed that she had not gained weight, but the doctor was not concerned. Ms. Caster returned 5 days early for her 39-week appointment (which was her scheduled due date)

because she had noticed reduced fetal movement. The doctor refused her request for a sonogram, saying her insurance would not cover it, but a normal Doppler was completed, and Ms. Caster was sent home to await her C-section 5 days later. Three days later she experienced vomiting and reduced fetal movement. She was given a prescription and told to wait for the delivery date. When she arrived at the hospital 2 days later with both her family members and the baby's parents' family members, she was told the baby had died. She was left alone in a room for 3 hours, hearing the cries of both grief-stricken families in the next room. She endured the C-section and was told by the doctor that this was a very rare occurrence. Ms. Caster said she now knows that every day 65 mothers will wake up with a dead child in their womb. The baby's parents, whom she was trying to help, felt extreme guilt, stopped speaking to Ms. Caster, and tried to sue her. Now, a year later, Ms. Caster is still dealing with the trauma and going to therapy every day. Ms. Caster said providers are not fully educated about teaching parents to track fetal movements or how to deal with parents after a stillbirth. Ms. Caster said she was treated as if the stillbirth had been her fault, and it turned something wonderful into the worst experience of her life. She asked the committee to treat stillbirth prevention with the national urgency it deserves.

**Ana Vick** said her son, Owen Nathaniel, was stillborn 7 years ago. When Ms. Vick reported feeling weak during her third trimester, her concerns were swept aside, and she now wonders whether an extra ultrasound would have shown what she later learned was cord compression. She was never told about fetal movement, but having read about it, she started kick counting and felt that her son was not responding well. Concerned, she left her husband with their daughter and went to the hospital, where she was told Owen's heartbeat was crashing and they needed to take him out.

**Joshua Vick** recalled how he raced to the hospital, arriving at his wife's room before the doctor, and being sent to the waiting room. Mr. Vick was soon to be told that his son had died. He was holding his lifeless son when his wife awoke and had to tell her that Owen had died, which was like living the nightmare twice. The Vicks were determined to find the cause of death, but the doctors discouraged an autopsy, citing the cost and the possibility that it would be inconclusive. However, 6 years later, placental pathology showed that Owen died of cord compression, and the Vicks are working to make sure his cause of death is updated. They suggest that parents should not be responsible for insisting on and paying for an autopsy but rather that autopsies should be standard in cases of stillbirths. Everyone deserves to know why their child died.

**Meredith McLeod-Cobb**, representing **Oliver's Way**, said that although she had a very experienced medical team, her son Oliver's death was due to an incorrect interpretation of an NST (i.e., incorrect baseline reading), leading the doctors to dismiss her concerns about Oliver's reduced fetal movement that was followed by frantic movements. After Oliver's death, the family was forced to initiate its own investigations, including an autopsy with placental and neurological pathology, with no help from the hospital. Given Ms. McLeod-Cobb's many risk factors for stillbirth (fibroids, cervical dilation, history of gestational hypertension), doctors should have been aware of hypercoiling and marginal



insertion of the cord into the placenta. Although all signs pointed to an impending stillbirth, no one discussed it. Ms. McLeod-Cobb said that physician attitudes clearly affect stillbirth outcomes, noting that maternal death in the hospital triggers an investigation, while stillbirth is treated as simply a tragic outcome. Oliver would have lived if he had been delivered when his mother presented at the doctor's office with her concerns about his fetal movement and ongoing contractions. After Oliver's death, the family moved to a state with better care, spent thousands on grief therapy for all family members, and invested in personalized care for a subsequent pregnancy. Ms. McLeod-Cobb asked the committee to consider the following interventions to help prevent stillbirth:

- Fund research to create a risk profile in all pregnancies for stillbirth and maternal death so that the relative risks are tracked as new events occur in the pregnancy. The risk score should be at the top of the chart so that everyone involved is aware of the risks.
- Create a third-party stillbirth oversight committee and a ground team, independent of the hospital management or physicians involved in the care, to manage the investigation of all stillbirths and help compile accurate records of cause of death.
- Create a right, covered by insurance, for women to get a second opinion with a higher-level provider.
- Require all obstetricians and gynecologists to undergo yearly NST certification.
- Require financial remuneration of all autopsies in stillbirth, so that the cause of death can be determined and the data used to help prevent future stillbirths.

**Jasmine Abraham**, an ambassador for Count the Kicks, noted the 32% stillbirth reduction rate in Iowa between 2008 and 2018, with Iowa's African American stillbirth rate decreasing by 39% in the first 5 years of the program. The difference between the progress in Iowa (stillbirth rate going down 1% every 3 months) and that of the United States in general (stillbirth rate going down 0.8% per year) is striking. Ms. Abraham said she learned about Count the Kicks too late; her doctor said her baby was so active that she did not need to worry his movements. Her son, Clawson, was stillborn at 37 weeks. Ms. Abraham said that more than half of mothers who experience a stillbirth notice a change in their baby's movements before the baby dies, and she cited the need to educate patients and providers about the importance of monitoring each baby's specific fetal movements.

**Allie Felker**, director of policy at **PUSH**, said her son, Hank, was stillborn in 2020. The day before he died, Ms. Felker went to the doctor, concerned about reduced fetal movement. She underwent an ultrasound during which the technician had her jump up and down while counting the changes in Hank's foot position, an incorrect procedure. After Hank's birth, Ms. Felker's provider said simply, "These things happen." A cause of death for Hank was never filed, but Ms. Felker said his death could have been prevented had her pregnancy been given the correct standard of care. She had done the right thing by going to the doctor to report reduced fetal movement, and her provider

made the wrong decision. Ms. Felker warned against a system of paternalism among providers. She asked three things:

- That providers be more aware of their own practices and identify their own racism and/or paternalism
- That NIH consider ways to build a successful information campaign, as it has done with Sudden Infant Death Syndrome (SIDS), to increase the awareness and prevention of stillbirths
- That the NICHD WG report make it clear to policymakers that the system of data collection for stillbirths must be improved

**Bobbie Cohan** said her grandson, Oliver Cohan Hughes, was stillborn on January 25, 2013. Two days earlier, Ms. Cohan's daughter had told her that Oliver was moving less. The next day, at her 35-week checkup, her daughter told the doctor about the baby's reduced movements, and the doctor said, erroneously, "Babies don't move so much in the last trimester." An ultrasound at this appointment detected no heartbeat, and Oliver was born still the next morning. Ms. Cohan said her daughter should have been told about tracking the baby's movements. An autopsy, paid for by the hospital, found that the cause of death was fetal-maternal hemorrhage (FMH). The number of stillbirths in the United States, about 23,000 per year, has not changed in years. Ms. Cohan asked the NICHD WG to address the "silent epidemic of stillbirth" by facilitating funding for research on the causes of stillbirth, such as FMH, and highlighting the need for autopsies and placental review to provide more data that will lead to a reduction in the incidence of preventable stillbirths.

**Shawn Soumilas** said her son Zachary was stillborn in 2010 at full term after an uneventful pregnancy during which she did everything right and did not exhibit any of the health risks for stillbirth. Although she had noticed a decrease in Zach's movements 2 days before his birth, her provider dismissed that as just the baby "settling down for birth." Ms. Soumilas lost considerable blood volume, nearly died after the birth, and was given just a 20% chance of survival. She continues to face significant health issues. Ms. Soumilas is now an ambassador for Count the Kicks and a member of the Child Health Translational Research team at Arizona State University, and she is working with the Arizona Department of Health Services to write the state's Fetal-Infant Mortality Action Plan. She called on NIH to fund more stillbirth research, provide clear information about kicks and fetal movement, listen to the lived experience of stillbirth families to identify effective stillbirth prevention initiatives, and focus on implementing a national stillbirth data collection system, an approach that has helped reduce the number of stillbirths in other countries.

**Alex Abend** said her son James was stillborn at 34 weeks. She had gestational hypertension. At her 34-week checkup, James' heartbeat was slow, and Ms. Abend was sent directly to the hospital, where James was found to have no heartbeat. She delivered by C-section 9 hours later. A week later she was readmitted with postpartum preeclampsia and high blood pressure. James was found to have died from a marginal insertion of the cord, which was seen at the 20-week anatomy scan, and a kink in the



cord. Now 19 weeks pregnant with her second child, Ms. Abend still struggles with flashbacks, stress, and grief. She spoke at this meeting because it is unacceptable that women's pregnancy outcomes are given so little consideration in the United States and the causes of stillbirth are not a top priority in a country with such vast scientific resources. She asked the NICHD WG to increase stillbirth research and elevate the standard of care around pregnancies.

**Ann O'Neill, Ph.D., M.S.**, director of **Measure the Placenta**, said that the organization's single goal is to have placenta size measured during pregnancy as a risk factor for poor outcomes. Dr. O'Neill's son, Elijah David, was stillborn on his due date in July 2018 after an uneventful pregnancy. Although his cause of death was listed as "unknown," she later learned that while her son was a big baby in the 80th percentile, his placenta size was less than the third percentile. Dr. O'Neill discovered a research study from 2012 showing that the probability of stillbirth increases with low placental weight z-scores, independent of birth weight. Numerous other papers also linked abnormal placenta size to poor birth outcomes. Dr. O'Neill described the work of Harvey Kliman, M.D., Ph.D., the inventor of a simple placenta measurement called estimated placental volume (EPV) that requires only a standard ultrasound. She said that EPV measurement should be a standard of prenatal care. Dr. O'Neill called on NICHD to fund a large prospective study on EPV to address this significant research gap and get this risk factor accounted for during pregnancy.

**Laura Drake** said her daughter was stillborn 2 years ago after prolonged induced labor. The impact of the loss was devastating to her mental health. Ms. Drake said she was neither well informed about fetal movement during the pregnancy nor educated about the frantic movement, which did occur. The cause of death was found to be FMH. Ms. Drake and her husband had limited precious time with their daughter after her birth before she was taken for an autopsy. Ms. Drake's placenta did not detach, and she had emergency surgery, requiring blood transfusions, that left scarring that makes it unlikely that she could carry another pregnancy. She urged action to save babies who are dying preventable deaths.

**Elaina Vietz** said her son, Dylan, was stillborn 8 years ago after a normal, healthy pregnancy. Expensive testing undertaken after he died revealed no cause for the placental abruption that occurred. Ms. Vietz had seen the doctor the day before Dylan died, presenting with cramps and discomfort. After 2 hours of monitoring Dylan's heart and finding it normal, the doctor sent Ms. Vietz home; Dylan died 12 hours later. Ms. Vietz said she spoke today as part of the PUSH organization and called for an increase in research to understand why stillbirths occur, particularly as related to complications with the placenta.

**Rachel Unkovic** said her daughter, Ruthie Mae, was stillborn at 37.5 weeks in 2020. The baby was named after her great-grandmother, who had just died of pancreatic cancer. Ruthie Mae's death was attributed to repeated cord compressions, an expensive diagnosis that the family paid to have made. Ms. Unkovic had told the

doctors about Ruthie Mae's reduced movements 2 weeks earlier, but they dismissed the change as a normal occurrence. Ms. Unkovic said she blames the lack of funding for meaningful research, the lack of stopgap safety measures while research is being conducted, the broken system that trains doctors with incorrect information, and the profit-based medical system that rewards doctors for speed rather than quality of care. Ms. Unkovic's C-section never healed correctly, and she required corrective laparoscopic surgery to restore fertility. She is now pregnant with Ruthie Mae's little brother and is beset with anxiety about the baby's movements.

**Marny Smith** said her son, Heath, who was stillborn in 2019, would have been 3 years old on this day. She emphasized the power of NIH and its success in saving babies, referencing the work of Marian Willinger, Ph.D., and the Safe to Sleep® campaign, and the fact that the rate of SIDS deaths has gone down by 50% in 15 years. She implored the WG to demand the research and resources that will drive stillbirth prevention through implementation science. She asked the WG members, who are highly esteemed professionals with incredible privilege and power, to use their influence and power to be healing voices to stem a stillbirth epidemic fueled by racism, complacency, fatalism, poverty, and injustice and to help prevent 23,000 babies from being stillborn every year.

**Domenique Rice** addressed the WG members, reminding them that they have spent the past hours in a sacred space with the parents of stillborn babies. She and all of these parents live this experience every minute of the day and are entrusting their hearts and missing children to the WG members to implement much-needed change. She acknowledged the emotional toll of hearing so many stories of loss but urged members not to look away. She believes that her son, TJ, suffered a preventable death. The educational discrepancies among practitioners must be addressed. The solutions must be equitable and address Black families. She called on the WG to look at all factors, not just traditional factors that are rooted in racism. She invited members to walk hand in hand with those who have experienced stillbirth loss, because they are the ones who live their children's deaths every day and have educated themselves to try and save others. She asked the WG to partner with these parents and provide equitable research and resources.

**Rosemary Fournier** represented the **National Center for Fatality Review and Prevention**, which is a federally funded data and resource center that supports child death review and fetal and infant mortality review (FIMR) programs across the country. She offered her condolences to all the participants and said that she admired their courage in bringing their experiences forward. She discussed the FIMR program, noting that each year 21,000 infants who are born alive die before their first birthday, and there is an equal number of stillbirths. The FIMR program provides multidisciplinary teams to examine these deaths, with the goal of learning how to prevent them. FIMR focuses on systems issues, not personal blame, and many parents who are interviewed speak of the need for more data, which FIMR strives to provide. FIMR, which currently operates in 26 states and the District of Columbia, makes recommendations focused on

prevention and informed by the voices of those who have lost an infant. Ms. Fournier, a registered nurse, said FIMR findings have spurred communities to enhance their bereavement and support services for families, get a clearer understanding of underlying risk factors and inequities, and embrace evidence-based prevention efforts such as Count the Kicks.

**Amanda Feltmann** said she was angry about her daughter Juniper's preventable death. She had trained as a stillbirth photographer but was not aware of the need to monitor fetal movements. When ultrasound found her daughter to be small, Ms. Feltmann was sent for weekly and then twice-weekly NSTs and biophysical profiles. After Juniper's death, the doctors discouraged Ms. Feltmann's questions, pointing out that she had had very intense care. When she later learned about EPV, she wondered whether that would have prevented Juniper's death. She has since delivered a second daughter alive but found her maternal-fetal medical specialists unwilling to entertain EPV testing, saying they did not know how to do it and calling it unnecessary. Ms. Feltmann has become an advocate on Instagram, sharing information about the grief experience, the need to monitor fetal movements, and the importance of measuring the placenta. She returned to photographing stillborn babies, noting that her latest pictures were of a baby boy whose mother reported reduced movements to her doctor, but nothing was done. Ms. Feltmann said the system is not working. Improvements are needed in the standard of care to ensure that she stops getting calls to photograph babies who have died.

**Kelly Friedrich** said her son, William James, was stillborn in 2021 at 36 weeks after a normal pregnancy. Early one morning Ms. Friedrich realized she had not felt Will move in a while and went straight to the doctor. There was no heartbeat, and Ms. Friedrich and her husband returned home to await plans for her to deliver a dead baby. After his birth, she held her perfect baby and was then discharged to home not knowing the cause of Will's death. After an expensive autopsy, the Friedrichs consulted with an EPV specialist and learned that Will's placenta was in a low percentile for his weight. Ms. Friedrich believes Will's death could have been prevented if the placenta had been measured during pregnancy and she had been educated on counting kicks to know Will's normal movement pattern. She asked the WG to change the trajectory of stillbirth in the United States.

**Debbie Haine Vijayvergiya** said that the stillbirth of her daughter, Autumn Joy, in 2011 irrevocably changed her life. Bringing a lifeless child into the world changes a person fundamentally, and Ms. Vijayvergiya has spent the last decade working to shine a light on the stillbirth crisis in the United States. Stillbirth is one of the most common adverse pregnancy outcomes in the United States; since Autumn died, 260,000 babies have been born still in this country. Yet stillbirth, which destroys families, friendships, and careers, remains one of the most understudied and underfunded public health issues. Ms. Vijayvergiya cited the lack of prioritization for collecting and releasing accurate stillbirth data, the lack of research on stillbirth, and the shortage of trained perinatal pathologists as areas that need immediate attention, and she expressed hope that the

SHINE for Autumn Act of 2021, which addresses stillbirth data collection issues, will be enacted by the current Congress.

**Megan Aucutt**, program director of **Healthy Birth Day, Inc.**, the Iowa-based nonprofit organization that created the **Count the Kicks** stillbirth prevention program, said work is ongoing to bring Count the Kicks to all 50 states. If every state replicated Iowa's success, 7,500 babies could potentially be saved from preventable stillbirth each year. She noted that women are 4 times more likely to die after having a stillbirth. Addressing the stillbirth crisis requires multiple organizations—along with state, local, and federal governments—to work together to fix the system and develop a standard of care that is effective in preventing stillbirths. She urged the WG to help make these partnerships a reality.

**Emily Price**, CEO of **Healthy Birth Day, Inc.**, said there is still a learning curve for health professionals, some of whom do not know the difference between miscarriage and stillbirth. She noted that nothing she could say at this meeting would be as important as the parents' stories that had been told. Recently, as she was speaking with congressional staffers about the status of the Maternal and Child Health Stillbirth Prevention Act, Ms. Price was told, "Stillbirth just isn't a priority right now." The staffer was right: It isn't. But it must become one, and the WG has the power to begin to make it a priority. Ms. Price noted that many women not only endure losing their baby to stillbirth but also come close to losing their own lives from complications of stillbirth. Ms. Price said she was counting kicks during her own pregnancy in 2010 when she noticed a change in her son's movements. Her doctor took her concerns seriously and took measures to ensure her son was safely delivered at 40 weeks. The United States can no longer roll the dice on stillbirth prevention in some states but not others. Ms. Price urged the WG to wage a stillbirth prevention campaign, similar to what was done to reduce the risk of SIDS, and come together with her organization and others to raise awareness about proven prevention efforts. She also encouraged NIH to consider a large-scale study of Count the Kicks across the United States. After the meeting concluded, the following two testimonials were received:

**Elizabeth Smith** said her daughter, Callie, was stillborn in 2020 at 36 weeks. At her 35-week checkup, Ms. Smith told her doctor that she had not felt distinct fetal movement for the previous 3 days. At that visit, Ms. Smith was not informed that her blood pressure was elevated and was instead advised that babies move less because they run out of space (false) and to look for 10 movements in 2 hours (inaccurate and outdated). At her 36-week checkup, Ms. Smith was told that her daughter was dead. Ms. Smith was persuaded not to have an autopsy performed, because it was unlikely to be dispositive. Later, after joining PUSH and learning about perinatal pathology, Ms. Smith discovered that she had had a large placenta and experienced FMH. Ms. Smith wonders whether her daughter would have lived had Ms. Smith been sent to the hospital for tests when she reported reduced fetal movements. After the birth, Ms. Smith felt alone with her grief and brushed aside, as if she should just go have another baby. She entered therapy, but it took almost 2 years to find the support from PUSH that has been so helpful. Ms. Smith

asked for research into the causes of stillbirth; better data collection from those who have experienced stillbirth; clearer provider guidelines on measuring the placenta, widespread fetal movement awareness, and monitoring; and resources to help grieving parents.

**Fernanda Sheridan** said her daughter, Natalie, was stillborn at 38 weeks in 2018. Ms. Sheridan informed her doctor about frantic fetal movement followed by reduced movement but was told not to worry. That night she went into labor and found that Natalie had died. She asked that NICHD partner with parents and advocates to decrease stillbirths by improving data collection and implementing changes in the standard of care that include understanding fetal movement and having providers be receptive to taking expectant families' concerns seriously. Stillbirth affects more than 588 out of 100,000 births, which is not the definition of rare. Ms. Sheridan noted that NICHD helped form the Stillbirth Collaborative Research Network to study the scope and causes of stillbirth, yet stillbirth deaths occur at the same level today. She wondered how those research funds were used and suggested that NIH should not need or wait for pressure from the media to act on this crisis.

## Wrap-Up

*Alison Cernich, Ph.D.*

Dr. Cernich thanked all the speakers. She acknowledged their pain and grief and honored the power of their stories and the courage it took to share them publicly in order to help others. She assured the participants that NICHD heard them, appreciates their knowledge, and understands the need to pay attention to equity, the need to address mental health issues, the need for autopsies, the importance of fetal movement, the benefit of measuring the placenta, and the need for more data and research on stillbirth prevention to spare other families such trauma. Dr. Cernich offered her sincerest condolences to the families and said that NICHD will continue to listen and will share preliminary reports and recommendations at the January 24 National Advisory Child Health and Human Development Council meeting.

## Appendix 6: Summary of Responses to the RFI

Recognizing the importance of obtaining input from advocacy organizations, researchers, clinicians, and especially those with lived experience of the tragedy that stillbirth brings, NICHD issued an RFI in November 2022 as one method for obtaining public input to inform the deliberations of the WG. A total of 11 responses were received. Characteristics of the respondents are shown in Table A6.1. Some respondents were classified in more than one of these categories.

Table A6.1: RFI Responses by Type of Respondent

Respondent Type	Number of Responses
Individuals with lived experience	5
Advocacy organizations	6
Providers/clinicians	1
Researchers	4

Some of the responses addressed all four of the WG's focus areas, and some included comments on only one or two focus areas. Table 2 shows that all respondents addressed the current barriers to collecting data on stillbirth and known risk factors for stillbirth. Moreover, individuals with lived experience, advocates, and researchers submitted comments with similar areas of emphasis, although (as might be expected) individuals with lived experience were more likely to submit comments on the psychological impact of stillbirth on families.

Table 2: RFI Responses by Focus Area and Type of Respondent

Focus Area		Number of Respondents by Respondent Type				
		Individuals With Lived Experience	Advocacy Organizations	Providers/Clinicians	Researchers	Total Distinct (of 11)
1	Current barriers to collecting data on U.S. stillbirths	4	4	1	4	11
2	Communities at higher risk for stillbirth	1	2		1	4
3	Psychological impact and treatment for mothers following stillbirth	4	1		1	5
4	Known risk factors for stillbirth	4	5	1	3	11



Common themes among the responses included the inadequacy of the current systems for obtaining, updating, validating, analyzing, and releasing data on U.S. stillbirths; addressing disparities in stillbirth rates by racial group; addressing families' need for information related to their specific case and improving support for affected families; and addressing risk factors related to the placenta.

## **Inadequacy of Current Data Collection Systems**

There was strong agreement among RFI respondents that the current system for obtaining, updating, validating, analyzing, and releasing data on U.S. stillbirths is deeply flawed at every step. Multiple respondents pointed out that initial data collection is conducted before accurate information on cause of death can be obtained. Respondents described a system where neither data collection elements nor procedures are standardized, quality assurance is not conducted, data elements are not sufficiently comprehensive to support research, best practices in perinatal pathology are rarely employed, data are not updated once better information is obtained, data are released infrequently, and the quality of the data overall is poor. Two respondents also pointed out that the data commonly collected on stillbirth exclude key variables that are important to researchers seeking to improve knowledge on risk factors and develop prevention strategies.

In addition to the inadequacy of data collection for surveillance and research purposes, respondents—especially those with lived experience—stressed the importance of obtaining cause of death data for families. They emphasized that the devastation of stillbirth is made even worse when no information on cause of death is available, especially when families are discouraged from having an autopsy done and may feel dismissed.

## **Disparities in Stillbirth Rates by Race**

Several individual and group respondents pointed out the U.S. stillbirth rate is significantly higher among Black pregnancies than among White pregnancies. One respondent also commented that stillbirth rates may also be higher among other racial and ethnic minority groups and called for research on the causes of disparities. Another respondent suggested increased public education targeted at groups with higher risk.

## **Improving Support for Affected Families**

Respondents, especially those with lived experience, called for improved support for affected families. Two respondents pointed out that not only mothers but also other family members—fathers, siblings, grandparents—are affected. Respondents stressed the need for information related to each specific case, mental health support, better training for clinicians about how to respond sensitively, dissemination of best practices for supporting families, and research about how to support bereaved parents.



## **Addressing Risk Factors, Especially Placental Factors**

All respondents discussed the need to translate risk factors for stillbirth into effective interventions. Several respondents, from advocacy and research communities, emphasized factors related to the placenta, including placental size and volume. One advocacy respondent called for specific research studies to determine whether measurement of placental volume could be used to identify elevated risk for stillbirth and whether such fetuses should be induced early.