

STILLBIRTH POLICY IN THE 118th CONGRESS



Two important bipartisan and bicameral stillbirth prevention bills have been reintroduced as SOLUTIONS to the stillbirth crisis in the United States.

Current Stillbirth Issues:

- U.S. stillbirth data suffers from poor quality; not all stillbirths are recorded, not all requested information is provided, and not all provided information is correct. This hinders public health efforts to prevent stillbirths and undermines stillbirth research.
- The current shortage of trained perinatal pathologists in the United States makes it difficult to identify the cause(s) of many stillbirths. Lack of access to a trained perinatal pathologist results either in no autopsy at all, or one that yields incorrect findings.
- The first time someone hears about stillbirth should not be when it has happened to them. Families and healthcare providers need ways to have safe conversations about current evidence-based recommendations on monitoring pregnancies to prevent stillbirths.
- Stillbirth has never been recognized as an allowable use of funds under Title V of the Social Security Act since the introduction of Title V funding back in 1935. Only 17 U.S. states currently use their Title V funds on stillbirth prevention, despite the fact we lose babies to stillbirth 15 times more often than SIDS, according to the CDC.

The Stillbirth Health Improvement and Education (SHINE) for Autumn Act, <u>H.R. 5012/S. 2657</u>

(MCHSPA), H.R. 4581/S. 2231 Bill Summary: The Maternal and Child Health Stillbirth

The Maternal and Child Health Stillbirth Prevention Act

Bill Summary: SHINE aims to prevent stillbirth through enhanced data collection, research, education, and awareness by creating the first comprehensive, federal-state partnership to reduce the incidence of stillbirth in our country. It is the beginning of a longer-term solution towards the prevention of stillbirth in the United States. In the 117th Congress, the SHINE for Autumn Act, H.R. 5487, passed the House of Representatives, under suspension, with overwhelming bipartisan support (408-18) on 12-8-21.

Prevention Act will clarify that stillbirth prevention activities are an allowable use of funds under Title V of the Social Security Act to further support stillbirth prevention programs. This bill recognizes that stillbirth, and the disparity in those impacted by stillbirth, requires further prevention programming. There is proof that babies can in fact be saved when stillbirth prevention programs are in place and when doctors are talking to patients about stillbirth prevention in an empowering way.

Current Status in the 118th Congress: SHINE was reintroduced into Congress on 7/27/23 by Reps. Young Kim (CA-40), Kathy Castor (FL-14), David P. Joyce (OH-14), Robin Kelly (IL-02), along with Senators Cory Booker (D-NJ), and Marco Rubio (R-FL).

Current Status in the 118th Congress: The legislation was introduced into the Senate on 7/11/23 by Senators Jeff Merkley (D-OR) and Bill Cassidy (R-LA) and was introduced into the House of Representatives on 7/12/23 by Reps. Ashley Hinson (IA-02) and Alma Adams (NC-12).

SHINE would authorize funding for:

- Grants to states to support data collection, assessment, and reporting on stillbirth and stillbirth risk factors:
- The Department of Health and Human Services (HHS), in coordination with health care providers, to develop guidelines and educational materials for state departments of health and statistics on stillbirth data collection, data sharing, and educational materials on stillbirth;
- The incorporation of Perinatal Pathology Fellowship Program at the NIH to fund research fellowships on stillbirth, including research and training on fetal autopsies and improved education, research, and data collection; and,
- A report on the effectiveness of the Perinatal Pathology Fellowship Program after five years of enactment.
- Over 100 organizations have endorsed this bill.
- Autumn was stillborn on 7-8-11. Her mother, Debbie Haine Vijayvergiya, has since dedicated her life to stillbirth advocacy in honor of Autumn.

More about the Stillbirth Prevention Act:

- Currently only 17 state health departments are using these funds to address stillbirth, leaving expectant parents in most U.S. states and territories more vulnerable to stillbirth and without proper education on how to potentially prevent a loss.
- This legislation is a technical fix to the language in the Title V Block Grant language and requests NO additional funding.
- Currently 47 organizations have endorsed the bill, including: American College of Obstetricians and Gynecologists (ACOG), Association of Maternal & Child Health Programs (AMCHP), Association of Women's Health, Obstetric, and Neonatal Nurses (AWHONN), Society for Maternal-Fetal Medicine (SMFM), American College of Nurse-Midwives (ACNM), and March of Dimes.
- The bill is championed by Healthy Birth Day, Inc. the 501(c)(3) nonprofit that created the highly effective Count the Kicks stillbirth prevention program.