



Ending Preventable Stillbirth

Michigan Maternal Infant
Health Summit
June 21 and June 22, 2023

Elizabeth's Story

"After expressing concerns to my OB that I had not felt movement in 3 days, she told me that it was normal to feel less movement as babies run out of room. 4 days later at an appointment for an ultrasound we were told that our daughter had no heartbeat. It was almost 2 years later that we realized that her death could've been prevented."



Callie Lillian Smith - September 23, 2020



We're on a mission to end preventable stillbirth and we're NOT taking no for an answer.

Who We Are

Through partnerships with health providers and aggressive awareness campaigns, we will **empower every expectant family** with the **equitable, evidenced-based** medical care and education they need to advocate for a healthy pregnancy, giving parents and babies the best possible chance to make it home safely together.



What is Stillbirth?

Stillbirth is defined by the CDC as the death of a baby after 20 weeks gestation. A stillbirth can occur before or during labor.

“Stillbirth affects about 1 in 175 births, and each year about 21,000 babies are stillborn in the United States”



The Stigma of Stillbirth

Taboo

Seen as something to keep hidden

“You should grieve in private”

Contributes to isolation and shame

Misconceptions

“What did the mom do wrong?”

“Isn't that from the Middle Ages?”

“That only happens to poor people right?”



The **stigma** that surround stillbirth negatively impacts families by forcing them to **suffer in silence** and further hinders **prevention** efforts

To address the crisis of stillbirth we must bring it out of the shadows



the spread of misinformation

Any change to your baby's normal patterns of movement should be checked out ASAP

Babies DO NOT Slow Down at the end of pregnancy

PUSH
EMPOWERED PREGNANCY

Misinformation

- Kick Counts - not a fixed number
- Babies do not “run out of room”
- Placental position does not dictate amount of movement
- Ultrasounds do not cause harm
- Non Stress Tests are not predictive

Amanda's Story

"I think if I would've known that a change in movements was a sign of a problem and if I had gone in to be seen, my daughter could be here."



Juniper 10/9/2019

Data Collection

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 (NICHD, 2023)



tinyurl.com/pushNIHvid



Ana's Story

"It took us 6 years to find a cause and we have been attempting for many months to have the doctor update his death certificate with this new information with no luck. We will continue demanding this to be done because we believe it's important for data on stillbirths to be accurate so we can help other families avoid a preventable loss in the future."

Autopsies

Barriers

- Discouraged by providers - Possible liability concerns
- Unknown expenses - What will insurance cover?
- Cultural/religious barriers
- Emotional distress

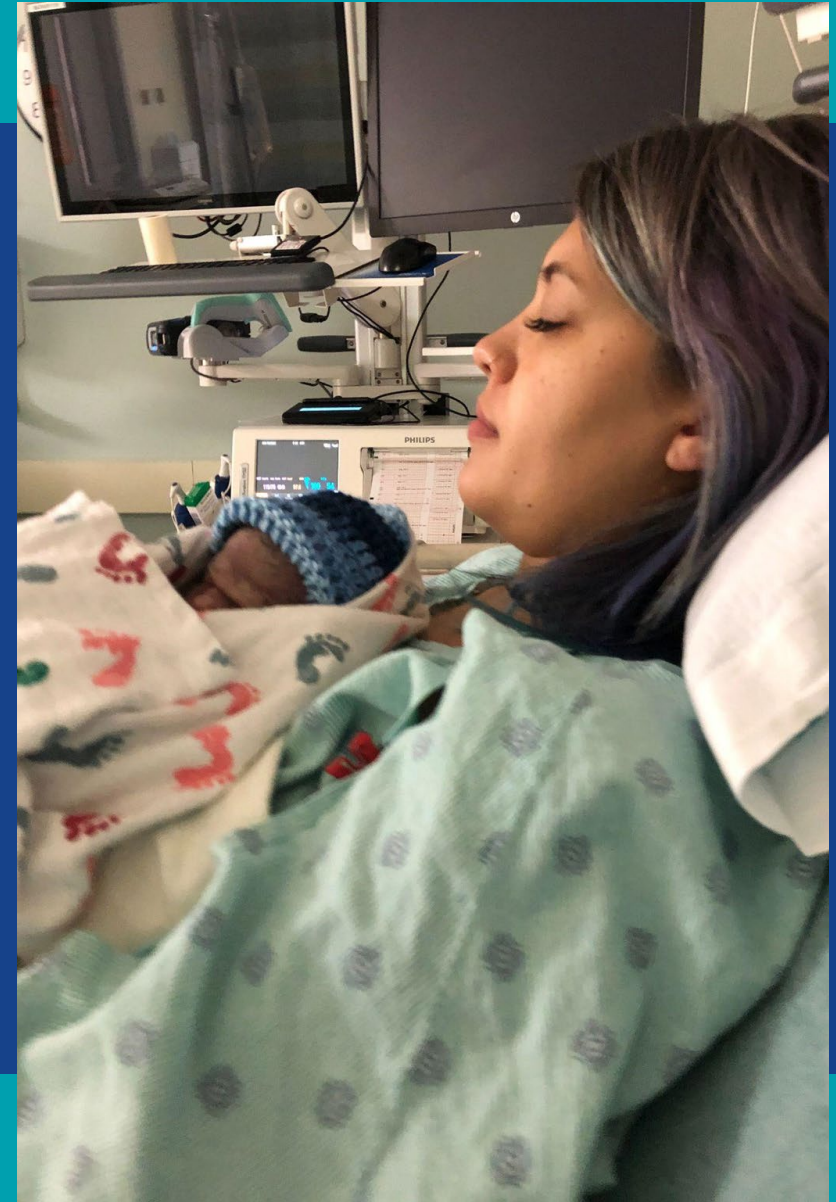
Benefits

- Best chance to explain why a stillbirth occurred
- Information aids planning and managing future pregnancies
- Unexplained cases can be reduced to less than one in seven
- Autopsies can reveal cause of death not previously expected
- Helps reduce parental guilt
- Reassurance that death was investigated



Allie's Story

"We declined an autopsy after a terrible encounter with a social worker who explained the process in horrific detail. We were also discouraged by my doctor who told us we wouldn't find answers. I spent an entire subsequent pregnancy not knowing the true cause of Henry's death"



Henry (Hank) 7/1/2020

Placental Pathology



Barriers

- Limited access to pathologists and resources
- Need for placental pathologists in MI

Benefits

- Placental pathology identifies cause of stillbirth in 84% of cases
- Placental abnormalities make up nearly half of all stillbirths
- Provides insights into the timing of stillbirth
- Informs management strategies for future pregnancies.
- Placental pathology can guide further investigation when there is no obvious cause



Joanna's Story

"My doctor discouraged an autopsy because she was 99% sure [an umbilical cord clot] was the cause of death. After getting a private autopsy anyway, the autopsy showed brain sparing which is consistent with placental insufficiency caused by my pre-eclampsia. No clot in the umbilical cord was found."



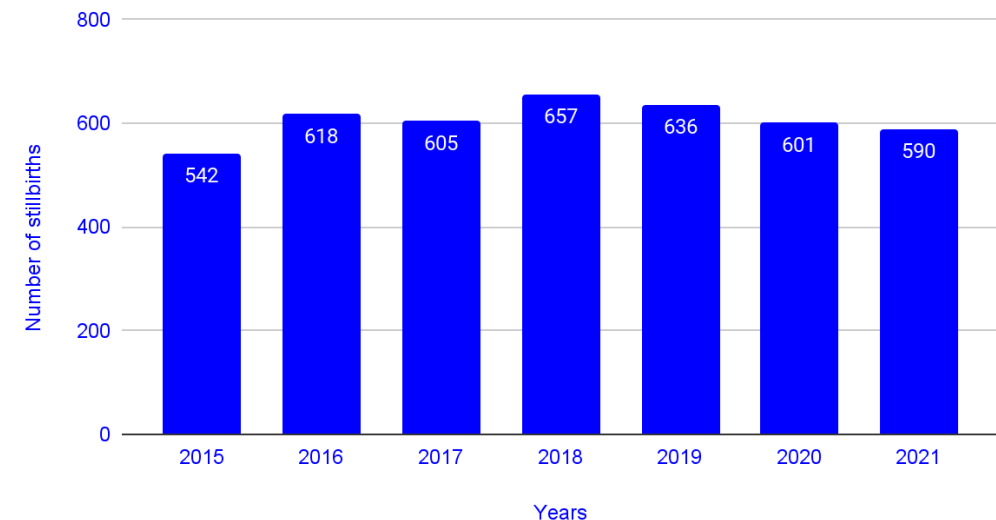
Landon born at 37 weeks weighing 6lbs 13 oz

Stillbirth in Michigan

Michigan's Stillbirth Rates:

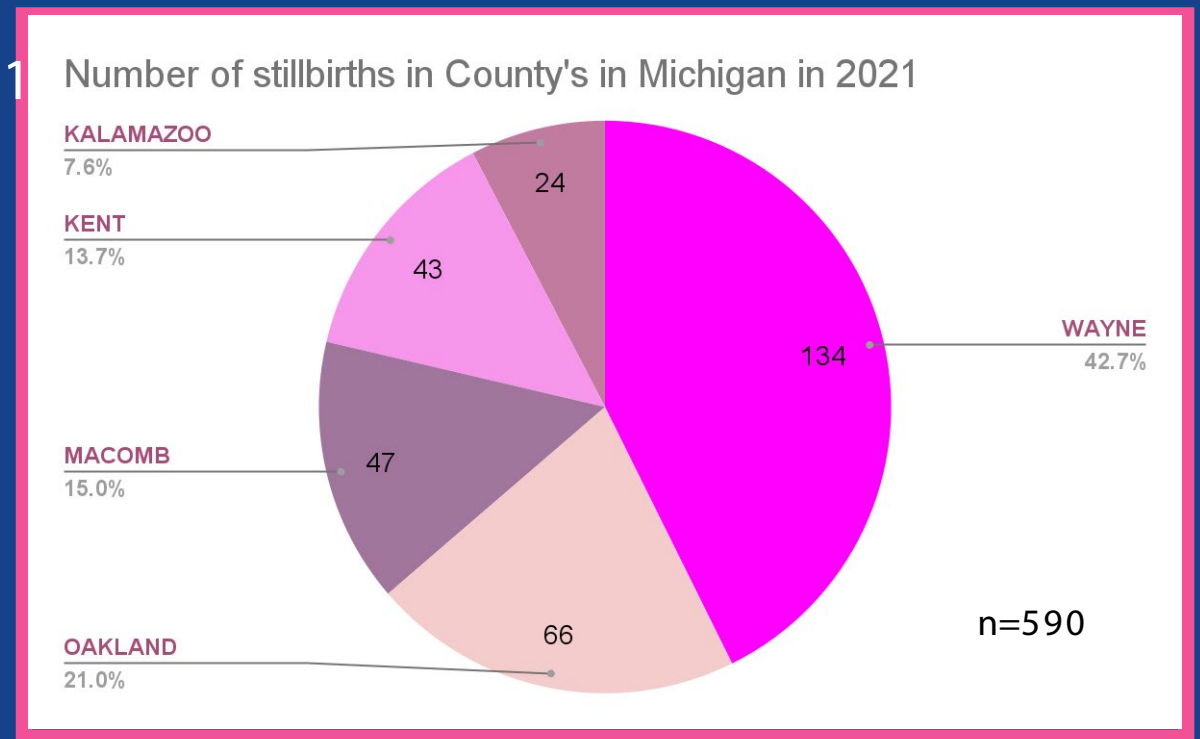
- Michigan has made significant strides in reducing stillbirth rates in recent years compared to other states in the U.S
- In 2020, there were 590 stillbirths in Michigan
- Electronic records for stillbirths in Michigan
 - Improved data outcomes by using the EHR
- Fetal Death Certificate (FDC)
 - \$5,000 for number of certificates of stillbirth from MDHHS
- Michigan Alliance for Innovation on Maternal Health
 - Preventing maternal and infant morbidity and mortality
- Michigan Department of Health and Human Services Fetal Infant Mortality Review (FIMR) Program
 - Conducts reviews of stillbirths and infant deaths to identify areas for improvement in care and prevention

Number of Stillbirths in Michigan, (2015-2020)



Michigan

- Counties in Michigan with the highest number of stillbirths in 2021
 - Wayne County
 - Oakland County
 - Macomb County
 - Kent County
 - Kalamazoo County



Racial Disparities

- Black women are 2-3 times more likely to experience stillbirth compared to White women, even when they receive the same level of prenatal care
- Systemic racism, implicit bias, and social determinants of health contribute to higher rates
- Black women are more likely to experience stress, poverty, inadequate housing, and limited access to healthcare, which can increase stillbirth risk
- BUT disproportionate rates even among higher levels of education & income
- Why? Studies have also shown that medical racism and implicit bias can lead to delayed or inadequate medical care, which can contribute to poor pregnancy outcomes, including stillbirth
- **How we fix it:** Address racial disparities in stillbirth with systemic change in healthcare, including anti-racism training for healthcare providers, increased access to care and resources for Black women, and improved overall quality of care for *all* pregnancies

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PREGNANCY

#bigpush2022

**BLACK MOTHERS
ARE 2 TIMES AS
LIKELY TO SUFFER
A STILLBIRTH**

**THIS IS
RACISM**



Jaye's Story

“As a Black woman, I understand my story may not be unique, but it is too common for Black women. Stillbirth in Black women accounts for 2x’s more than our White counterparts, but yet it’s still not a topic of discussion in the communities I serve.

As a maternal health equity activist, changemaker and most importantly a mom, I know how pivotal it is to share my experiences with the world because there are many women who never take their babies home or never get to go home themselves.”



Jaye Wilson Founding President/CEO Melinated Moms



Maternal Mortality

- 80-90 maternal deaths occur each year in Michigan
- Nearly 50% of pregnancy-related maternal deaths are preventable in Michigan
- Women who experience stillbirth are >4x more likely to experience poor maternal outcomes.
- More than 15% of maternal deaths within 42 days of delivery occur in women who experienced a stillbirth.

(Michigan's Maternal Mortality Surveillance (MMMS) Project, 2020)
(PUSH, 2023)

The Solutions

Fetal Movement Monitoring

- Educate pregnant individuals about the significance of regularly monitoring fetal movements
- Provide resources and guidelines for monitoring fetal movement and identifying any abnormalities.

Data Collection

- Standardize stillbirth data collection, including pregnancy, medical history, and risk factors.
- Establish current state and nationwide stillbirth databases
- SHINE for Autumn Act

Autopsy Procedure

- Train healthcare professionals on autopsy discussions and trauma informed care.
- Increase access to perinatal pathologists

Individualized Care

- Treat every patient as an individual
- Incorporate implicit bias and anti-racism training and address racism
- Train healthcare providers to actively listen, address problems, and offer empathy

Encourage Fetal Movement Monitoring

- Fetal Movement Monitoring
 - 1. How **FREQUENTLY** does your baby move?
 - 2. How **STRONG** are your baby's movements?
 - 3. What **PATTERNS** does baby typically show?
- Count the Kicks is an evidence-based stillbirth prevention campaign importance of tracking fetal movement in the third trimester and to understand their baby's normal movement pattern



When should I start to feel movement?

You should start to feel your baby move between 16 to 24 weeks of pregnancy. A baby's movements can be described as anything from a kick, flutter, or swish to a roll.

How often should my baby move?

There's no set number of movements you should feel each day – every baby is different. It's important to get to know what's normal for **your baby**. Your baby's normal will become clear from 24–28 weeks. Your baby should not slow down.

What should I do if I notice a change in movements?

→ Go to the hospital immediately

They are available 24/7 for you and your baby to get checked. If you feel concerned, don't put off getting checked until the next day or wait until your next scheduled appointment.

You can call your provider to let them know you are coming. Printer ver, you do not need their permission to go in or to get checked. Decreased movements cannot be checked from home – you need to go to hospital *immediately*.

→ Act swiftly & trust your instincts

A change in movements can be an early sign and sometimes the **ONLY** warning sign that your baby *needs help*. If reported promptly, there is a window of opportunity in which the baby's life may be saved. Some examples of a change include less movement, weaker movements, or an unusual rapid increase in movement.² Trust your gut instincts.

55% of mothers who have a **stillbirth** are

NEVER TOLD



by their provider about the **importance** of fetal movement



Enough is enough.
It's time to
end preventable stillbirth.

Data Collection

- Standardize stillbirth data collection procedures
- Vital Statistics training for hospital workers
- Electronic Fetal Death Certificates
- Establish state and nationwide stillbirth databases
- Create process for editing records

We count what matters to us.
Every stillbirth matters.



The SHINE for Autumn Act

- A critical piece of legislation aimed at improving understanding of and preventing stillbirths
- \$9 million a year for five years in federal funding for research:
 - Grants to states to support data collection and reporting on stillbirths and contributing risk factors
 - Establishes a Perinatal Pathology Fellowship including training on fetal autopsies and placental pathology
 - HHS to create stillbirth data collection and sharing protocols and educational materials for State Health Departments and Vital Statistics units in collaboration with healthcare providers and community groups.

The passage of the SHINE for Autumn Act is critical to improving outcomes for families affected by stillbirth and addressing this public health crisis.



Improving Autopsy Procedure

- **IMPROVE: IMproving Perinatal Mortality Review and Outcomes Via Education**

- Based on the Perinatal Society of Australia and New Zealand's Perinatal Mortality Guidelines
- Face-to-face workshops and eLearning courses are offered.
- Designed to meet the education needs of healthcare workers involved in perinatal death investigations.

- **Objectives**

- Enhance understanding of autopsy procedures.
- Improve accuracy and quality of perinatal death investigations.
- Foster multidisciplinary collaboration among healthcare professionals.

- **Benefits**

- Improved identification of causes and contributing factors to perinatal mortality.
- Enhanced knowledge for healthcare workers involved in perinatal death investigations.
- Potential to inform preventive strategies and improve patient care.

- **Improve doctor-patient communication:**

- Counseling patients on autopsy procedures with compassion and knowledge.
- Highlight that an autopsy may often reveal the reason of a stillbirth, providing closure and knowledge that may avoid future losses.

- **Patient-centered approach**

- Recognizing stillbirth emotional pain, describe autopsy procedures sensitively and respectfully.



Providing Individualized Care

- Invest in anti-racism and implicit bias training
- View every patient as an individual
- Listen to concerns and provide a safe place
- Offer telehealth services to improve access
- Training in trauma informed care
- Preventing future losses

The Rainbow Clinic



Caring for PAL Patients – Guidance for Rainbow Clinic Providers

This eLearning Module is intended for Rainbow Clinic prenatal medical providers and staff who strive to provide sensitive, trauma-informed care to patients who are pregnant again after a previous stillbirth or other pregnancy/infant loss.



*Delivering hope, one
baby at a time*

- The Rainbow Clinic offers the following services to help parents who have experienced a stillbirth:
 - Help determine the cause of any previous stillbirth(s) or losses, even if no cause has been found before
 - Plan prenatal care in partnership with patients, offering the right amount of appointments, ultrasounds, and testing that make sense for each specific situation – not just what’s dictated by the usual protocols
 - Bring emotional support throughout the pregnancy from well-trained and empathic staff who understand the co-existence of hope and fear
 - Never question any expectant person’s need or request to have more appointments or monitoring for reassurance.
 - Rainbow Clinic Training access:
 - <https://pushpregnancy.thinkific.com>

 Ari Rubin, MD, FACOG Mount Sinai, New York	Ari Rubin Rainbow Clinic	Los Angeles	CA	To register, please call the number listed on Dr. Rad's website or email manager@drsteverad.com . Dr. Rad is in private practice and delivers at Cedars-Sinai.
 Mount Sinai	Mount Sinai – Rainbow Clinic	New York	NY	To register, please use the Request an Appointment button on the Mount Sinai website and mention "Rainbow Clinic" under Reason for Visit or Diagnosis. Expect a reply in 24-48 hours.

Bereavement Programs

- **Jen Hamilton/AW HONN**

- Bereavement programs led by Jen Hamilton and supported by AW HONN aim to provide essential support and resources for individuals and families navigating the challenges of pregnancy or infant loss.

- **Aaliyah in Action Boxes**

- Self-care packages for women and birthing people distributed at hospitals and ordered by medical providers, doulas or loved ones
- Resources for local and national bereavement support



THANK YOU

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