October 19, 2021

Dear Honorable Chairman Pallone, Ranking Member McMorris Rodgers, Health Subcommittee Chairwoman Eshoo, and Health Subcommittee Ranking Member Guthrie:

As you know, tomorrow, Wednesday October 20th, there is a hearing on "Enhancing Public Health: Legislation to Protect Children and Families." I am reaching out to share my story with you and hopefully it will SHINE a light on the urgent need to address the taboo issue of stillbirth in the United States.

Debbie and Autumn's Story

My name is Debbie Haine Vijayvergiya, and I am a stillbirth parent advocate.

Since I was a young girl, the one and only thing that I was 100% certain of was that one day I would be a mom.

My first pregnancy was completely normal and resulted in a healthy picture-perfect baby girl. However, things became eventful a week later, when a late presentation of Group B Strep nearly killed me. Let me tell you, I had never been so grateful for modern medicine - without it, I wouldn't be here today.

A year later, I suffered my first miscarriage. I was able to quickly make peace with my loss as I had a one-year-old at home and was still recovering from complications from my Group B Strep infection. It had been very easy to convince myself that everything happens for a reason.

The following year I suffered my second miscarriage, which was a much bigger pill to swallow. It resulted in an ambulance ride, 10 hours in the ER, and a D&C (dilation & curettage). The whole experience was a nightmare that left me traumatized and distraught. At that point, I didn't think things could get any worse.

When I found out I was pregnant for my 4th time in 4 years, I truly believed that I had paid my dues to the fertility god and that everything would be ok. Once I successfully made it through my 1st trimester, I allowed myself to take a deep sigh of relief and immediately began to embrace my pregnancy.

Unfortunately, I wasn't that lucky. On July 7th, 2011, I was suddenly thrust into any expectant mother's worst nightmare when, without any warning, at a routine 2nd trimester checkup, my obstetrician could not detect my daughter Autumn's heartbeat. As I lay there motionless and breathless on the examination table, my whole world came crashing down around me.

Much of what happened after this is a blur. Except for her birth. Her stillbirth. Nothing can ever prepare you for the moment you bring your lifeless baby into the world. It has been 10

years and I still find words inadequate to describe the experience. The silence at her delivery still brings tears to my eyes and chills down my spine. Time stopped moving for me that day, and my life has never been the same since.

I became a tortured soul. In my mind, I had failed not only Autumn but both my husband and young daughter. The expectations and plans that we had for Autumn, for our family of "4", were gone.

I was devastated and broken, leaving my husband unable to grieve himself because he was too busy trying to put me back together. And my heart still aches when I think back to how my 3.5-year old's life was turned upside down. She was expecting a baby sister and instead all she got was a broken mommy. I was completely paralyzed by my grief. At this point, I seriously began to question my ability to be a mom, as I couldn't keep one child alive and was completely incapable of being there for the other when she needed me most.

My doctors did me a huge disservice by convincing me that my losing Autumn was as rare as being struck by lightning— which I soon learned wasn't necessarily the case.

The months following Autumn's death were excruciating for our family. I was embarrassed and ashamed. I was forced to suffer in silence because no one knew how to talk about Autumn and what had just happened; myself included. I was drowning in my grief, barely able to keep my head above water. The only thing saving me at that point was my anger — it kept me afloat as it consumed me. I was mad that my baby died. I was mad that I didn't know something like this could happen to me. And I was mad that I couldn't save her. I spent my time incessantly seeking out answers, explanations, and assurances.

I soon learned that stillbirths are not rare and are one of the most common adverse pregnancy outcomes. I was stunned to learn, at the time, that we were losing approximately 25,000 babies to stillbirth every year in the United States and that very little was being done to improve outcomes.

I suddenly found myself faced with the reality that this tragic maternal health issue was being seriously neglected. I couldn't sit idly by and let others suffer like we had. I was compelled to help them. Not just for me, but for Autumn, and all the babies that are lost too soon.

Stillbirth in the United States: Where are we?

According to the CDC, stillbirth is truly a public health crisis, with nearly 23,000 babies born still each year. In the United States, stillbirths are defined as the death of a baby in utero, any time from the 20th week of pregnancy onward. To put these numbers in perspective, this is approximately 65 babies dying every day, or approximately the **loss of three classes of kindergarteners each day**. In the US, the annual number of stillbirths far exceeds the number of deaths among children aged 0-14 years from preterm birth (3,679), SIDS (1,334), accidents (1,208), drownings (689), guns (305), fire (291), and flu (142) **combined**.

No pregnancy is immune to stillbirth – stillbirths occur in all races, ethnicities, income levels, and to women of all ages. However, there are longstanding and persistent racial and ethnic disparities with Black women experiencing stillbirths at 2 times the rate of White women.

The picture today is pretty bleak, but we may wish to take a look back to see if we have made any improvements over time. From 2009-2019, the US experienced only a 3.4% reduction in the stillbirth rate. During that same period, infant mortality (the death of a child anytime between delivery and their first birthday) decreased more than three times this, with a reduction of 12.4%. The improvements in infant mortality are encouraging, yet also provide a stark reminder that there is much more to do to reduce stillbirth rates.

Another important metric of our success in reducing stillbirth in the United States is a comparison to other countries. In 2016, The World Health Organization ranked the U.S. stillbirth rate at 34th in the world (i.e., there are 33 countries with stillbirth (28+ weeks) rates that are lower than ours). Even more dismal is the global comparison of our progress in *reducing* stillbirth rates: between 2000 and 2019, the U.S. stillbirth rate only declined by 0.4 percent per year, putting us at 183rd out of 195 in the world. It is appalling that one of the 10 wealthiest countries in the world – that spends more money than any other country on health care – is ranked so low on both of these scales.

No matter how you slice the data, we cannot deny that we have a legitimate problem. Despite all of this evidence, stillbirth has remained one of the most understudied and underfunded public health issues to date in our country.

Stillbirth Data in the United States

In order to address stillbirth rates, we must have accurate and timely data to help understand the underlying causes of stillbirth and identify strategies for prevention.

Unlike other countries, the United States does not have a national system to report and investigate stillbirths. Instead, national stillbirth data come from vital records (in the form of fetal death certificates), which is administered at the state-level. The US Centers for Disease Control and Prevention provides guidance to states for stillbirth reporting; however, stillbirth definitions and the quality of data vary from state-to-state. These data suffer from poor quality: not all stillbirths are registered, not all requested information is provided, and not all information is correct. Since fetal death certificates are often filed weeks before families receive any testing results, the cause of death is rarely noted.

Substantial effort has gone into improving the quality of *birth* certificate data – with great success. Similar efforts, supported with adequate financial and personnel resources are needed to make progress in improving stillbirth data quality. If we are not accurately capturing information about the stillbirths that occur, we cannot determine why they are happening, and thus will never be able to prevent them.

It is because of these gaps in data quality and awareness, that the number of stillbirths in our country have remained frustratingly stable for over ten years since Autumn was born, despite

improvements and advancements in obstetrical and neonatal care that have greatly reduced infant mortality. Ultimately, we have a responsibility to understand why stillbirths are happening and identify what can be done to combat this crisis.

Stillbirth: Hidden in the Shadows

Perhaps two of the greatest misconceptions about stillbirth are 1) that they don't happen very often in the United States and 2) when they do happen, they are inevitable and linked to some genetic abnormality. The data described above demonstrate that the first misconception is false, and when it comes to genetic causes, these only account for about 10% of stillbirths. We must find a way to have a safe conversation about the risk and realities of stillbirth, because the first time someone hears about stillbirth should *not* be when it has happened to them. As we consider the causes of stillbirth, as many as *half* of stillbirths have no identified cause of death: that is over 10,000 families annually enduring the tragic death of their child, with no answers as to why it occurred.

To bring stillbirth out of the shadows, we must address these gaps in awareness and in identifying the causes of death. Although mental illness was a taboo subject over 50 years ago, we've been able to establish a social dialogue that has created considerable change in how we talk about, deal with, and support those with mental illness – these efforts are much needed, and overdue, for stillbirth.

Another sign of the values of a country is where its investments are made. Stillbirth remains in the shadows when it comes to federally funded research. According to the National Institute of Health only $4.7 million was spent on stillbirth research in 2016. This is 29% of what was spent on sudden infant death syndrome (SIDS), 2% of what was spent on preterm birth, low birth weight, and health of the newborn, and 1.3% of what was spent on pediatric cancer. The death of any child is tragic, but with an outcome that results in far more deaths than these combined, the disparity in urgency, funding, and prevention is truly unacceptable.

A Ripple of Health Effects

It's important to note that stillbirths do not occur in a vacuum; and that there is a relationship between stillbirth and maternal morbidity and mortality. Severe maternal morbidity is nearly five times more common in women who have a stillbirth than in women whose babies are born alive. Women who experience a stillbirth are also more likely to die after delivery, often related to complications such as obstetric hemorrhage and preeclampsia.

Research has shown that there is a tremendous return on investment for reducing stillbirths. Efforts to improve stillbirth rates will also see a reduction in maternal morbidity and mortality, as well as other complications of the newborn. To put it simply: it's a win/win.

The Solution: The SHINE for Autumn Act

As dire as this picture looks, we *can* do something about it. With increased awareness, better data, and funding, we can achieve the goals that advocates, maternal health stakeholders, and stillbirth researchers have been working towards for far too long.

The Stillbirth Health Improvement and Education (SHINE) for Autumn Act is the beginning of a longer-term solution towards the prevention of U.S. stillbirths. This bill will make critical steps to invest in research and data collection required to better understand stillbirth in the United States. Additionally, it will provide critical resources to the CDC, NIH, and local state health departments to improve stillbirth data collection and increase education and awareness about stillbirth.

This bill will create a greater sense of urgency around the unmet needs in stillbirth research to raise our social conscience on the topic. We can finally address the negative impact stillbirth has on our society and reduce the shame associated with stillbirth that forces families to suffer in silence. The SHINE for Autumn Act will allow us to work together to overcome the stigma, identify the hidden causes of stillbirth, and provide more support for families that have experienced a stillbirth.

Closing

According to public health experts, the stillbirth rate is a critical measure of a populations' health. If that's the case, what does this say about the well-being of our nation?

I have spent the past 10 years, 3 months, and 13 days working tirelessly to bring stillbirth out of the shadows. And let me tell you, it hasn't been easy. In the end, though, it brings me peace to know that from our tragedy there is an opportunity to have a positive impact on someone else's future. If there is something that I can do that can change a negative outcome to a positive one for others, then I can believe that Autumn's life was not lost in vain.

To that end, please join me in putting stillbirth on the map in the United States. The time is now for stillbirth to be recognized as the tragic maternal and family health crisis that it is. We can no longer ignore this issue. We can – and must – do better.

Every family deserves a fighting chance against stillbirth!

Thank you for your time and consideration,
Debbie Haine Vijayvergiya, Autumn's mom
The 2 Degrees Foundation