

Statement of Wanda Irving
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Maternal Health
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Chairwoman Eshoo, Ranking Member Burgess, Chairman Pallone, Ranking Member Walden, and Members of the Committee, thank you for the opportunity to sharing my story with such a prestigious group.

Lately, I've been called brave and courageous a lot. I'm not sure I agree. I am just a grieving mother, trying to move forward by putting one foot in front of the other and taking it one day at a time. What I want you to know as I tell Shalon's story is that I relive Shalon's death every time I share her story. It is painful, and yes – it would be easier not to do this, to sidestep this fresh pain a few times a month. But if my daughter had to leave me, I've got to find some meaning in her death, it must help someone else: save someone else's daughter or sister or wife. That's what my daughter would have wanted.

I am here today to put a face to what decades of research has shown—black women aren't being seen or heard when it comes to their health—especially during and after pregnancy. I want to share with you a remarkable woman, my daughter Dr. Shalon MauRene Irving, who became a maternal mortality statistic and to let you know what the aftermath of her preventable death has been like for her child and me.

Shalon was my only daughter, born between two brothers that she adored. She was an exceptional child. She loved to learn. She was generous, kind, passionate and a staunch champion for equity.

Shalon grew into a strong, vibrant, beautiful woman.

Shalon was fearless. She lived her truth each and every day. She never lost sight of who she was or what she wanted, and she never failed to answer the call when her expertise was needed. She was funny. Her smile was luminous and her melodic laughter touched your heart. She was readily accepting of everyone she met and fiercely loyal to her friends who told me Shalon had a way of making your day brighter and your load suddenly seem lighter.

Shalon was smart

She'd skipped two grades before high school and earned a bachelor's degree, a master's degree and a dual titled PhD in Sociology and Gerontology—the first student to do so at Purdue University—all Summa cum Laude. By the age of 25 she was a college professor at Hofstra University, but decided she wanted to be on the front line working to eliminate racial health injustices. So, she went on to acquire an MPH from Johns Hopkins University—also Summa Cum Laude— while being a weekend caretaker for the older brother she so adored, who was wheelchair bound as a result of multiple sclerosis—and began her career

working to end health disparities. Shalon had an impressive career path that led to her work as a Lt. Commander in the prestigious Epidemic Intelligence Service of the U.S. Health Service, and a well-respected epidemiologist at the Centers for Disease Control and Prevention.

Shalon was well travelled

Over the course of 10 years, we had vacationed extensively throughout the Caribbean and traveled to over 20 foreign countries on three continents. In fact, Shalon wanted to share her love of travel right away with her child. We had just made the final payments for a 2-week vacation to Dubai, which was to begin 5 days after Shalon died.

Shalon was a brilliant writer and published author

She could take even the most complex scientific jargon and rewrite it so a seventh grader could understand it. She was an accomplished author—with major contributions to several scientific books written by colleagues, various published articles in medical journals, plus co-authored an introspective self-help book called “**Beautifully Bare and Undeniably You**” that was published posthumously in 2018

Shalon was the epitome of a modern-day renaissance woman,

She was always thinking, “what’s next” for her. She owned her own home, was an avid gardener, a skilled photographer, and a talented chef and volunteered at several organizations to help young girls become the phenomenal women they were meant to be. Shalon had just launched a consulting firm, called Inclusivity Standard, LLC, to help first-generation college girls prepare for college and enable businesses and schools to embrace inclusivity to assist organizations in becoming more inclusive.

Shalon was a distinguished scientist

She was a Lt. Commander in the globally recognized Epidemic Intelligence Service and a well-respected Epidemiologist at the Centers for Disease Control and Prevention in Atlanta, Georgia.

Most importantly, Shalon had a passion for ending all health disparities

She was dedicated and committed to racial equality and health equity. According to her Twitter profile, Shalon said, *“I see inequity wherever it exists, call it by name, and work hard to eliminate it. I vow to create a better earth”*. Throughout her career, Shalon passionately advocated for a participatory approach to all research so that communities could immediately benefit from the research.

Yet, this vibrant, beautiful, intelligent woman fell victim to maternal mortality exemplifying that maternal mortality can happen to any woman giving birth.

According to the CDC over 700 women die every year from causes related to pregnancy and childbirth in the United States. Almost 70% of those deaths are

preventable. What's worst, the CDC reports that black mothers in the U.S. die at three to four times the rate of white women, making it one of the widest of all racial disparities in women's health. Let me spell this out another way: a black woman is 22 percent more likely to die from heart disease than a white woman, 71 percent more likely to perish from cervical cancer, but 243 percent more likely to die from pregnancy- or childbirth-related causes than a white woman. Sure, some of it has to do with lack of insurance, no access to medical care, insufficient financial well-being. But, unfortunately, it also has to do with the appalling way black women are—or are not—attended to or listened to. Which was exactly the case for Shalon. She did not live in poverty. She was not uneducated. She was not complacent about her health. She had access to the kind of healthcare that should have saved her life, but she ended up a maternal mortality statistic. You tell me why.

Even though her pregnancy was unexpected, Shalon was overjoyed. She knew her pregnancy was high risk but, at that time, I did not know that she was among the country's most vulnerable pregnancy population. I never thought for a moment that as a black woman my daughter was three to four times more likely to die than a white woman from birth related complications, largely attributed to institutional racism and the stress that our bodies endure because of it.

Shalon did not take her pregnancy lightly. She did everything right. She rushed back from a deployment in Puerto Rico and immediately went to her GYN/OB doctor. She got tested for the Zika virus, which came back negative. She followed her OB's instructions to the letter. She never missed an OB appointment. Several months before she became pregnant, Shalon had discovered she had factor v leiden and took a pill daily to prevent any blood clots. But now that she was pregnant, her hematologist prescribed 2 painful shots into her stomach each day to keep her blood from clotting and protect her baby. Though her stomach resembled a black and blue pincushion, she never complained—not once. Shalon spent days creating a highly detailed birth plan with everything from who could be in the delivery room to the type of music and conversations that could go on in the delivery room. The plan included several tasks for me, starting with—sterilizing her hospital room, bed, chairs and bathroom with disinfectant. Shalon gave a lot of thought to preparing for her baby, but trusted that her doctors to look out for *her* in the days and weeks after her baby arrived.

On January 3, 2017 Shalon underwent a caesarean and gave birth to a beautiful baby girl she named Soleil Meena Daniele. In her journal entry on the morning of Soleil's birth, she wrote:

Good morning! I am up and just sitting in my calming room meditating a bit before we leave for the hospital. I can't believe that the next time I sit in this room it will be as a mother with my beautiful little one. I barely slept (either out of excitement or nervousness), yet I'm not tired nor do I feel any nervousness now. I am prepared. I am surrounded by love (both present and virtual) and I am ready to meet this tiny human that I've been sharing space with for 37 weeks! It is inconceivable that someone so loving, so ready for motherhood, was cheated of the experience.

Though Soleil was delivered three weeks early, with some respiratory problems and suffered from colic, Shalon thought she was perfect—the fulfillment of a mother’s dream. According to Shalon, Soleil was her greatest accomplishment.

However, that euphoria was short lived.

The 3 short weeks that followed Soleil’s birth should have been filled with joy, happiness, and improving health. Instead, Shalon’s general state of health steadily declined during this period. She suffered from elevated blood pressure. She experienced leg swelling. She had decreased urine output. She put on weight. She had headaches. Instead of improving over time, she felt increasingly worse and not her normal self. Shalon and I knew something was terribly wrong. Despite frequent visits to her health care providers during this period, her complaints were not adequately addressed and routinely dismissed with the dismissive words “it’s to be expected; you just had a baby.”

Shalon suffered an arrest at home on the night of January 24, 2017, 21 days after the birth of her daughter and **just a few hours** after returning home from yet another visit to her medical provider. 911 was called, and Shalon was transferred to a local hospital, where we learned that complications from hypertension had led to the cardiac arrest which deprived her brain of oxygen for a significant period of time.

My vibrant, brilliant, beautiful 36-year old daughter, with everything in the world to live for, was officially declared brain dead on Thursday, January 26th. There is nothing so heart-wrenching as seeing your child unconscious, connected to instruments that can only say she is dying but cannot save her, unable to open her eyes to tell you she loves you one more time. Even with the dismal diagnosis, I could not let her go. Thursday evening, my cousin who was tasked with getting Shalon’s papers in order found her medical directive and brought it to me at the hospital where I had kept a bedside vigil since my daughter was admitted. In the directive there was a paragraph Shalon had handwritten to me. The last line of that paragraph shattered my heart. She wrote: *“Mommy, I will fight hard, but if there is no hope, please let me go.”* But I couldn’t. I just could not. My bedside vigil continued. It wasn’t until Friday morning when I saw a single tear roll down Shalon’s cheek, I knew my daughter was ready to go. I sat by her bedside again that night and cried. Then on Saturday morning, January 28, 2017, with both her father and me at her bedside, life support was removed. Fourteen minutes later, she was gone.

What infuriates me is that Shalon’s death was a preventable tragedy. She was a 36-year-old woman of color who went to her health care workers again and again in distress – and she was not properly treated. Imagine the many gerontology breakthroughs, health miracles, epidemiology victories and social advancements that Shalon could have generated, if only her medical providers had listened to her and adequately addressed her cries for help. Even Shalon’s many advantages — her B.A. in sociology, her two master’s degrees, her dual-titled Ph.D. in Sociology and Gerontology, her CHES certification, her work as an

epidemiologist, her gold-plated insurance, and rock-solid support system — had not been enough to ensure Shalon's survival. Shalon deserved better. Soleil deserved to know her mother.

Shalon's death has been called "shameful". "Sad". "Senseless". "Tragic". One thing is certain in my mind: it was definitely a tragedy—a shameful, sad, senseless and **preventable** tragedy. IT SHOULD NOT HAVE HAPPENED. My granddaughter will grow up without her phenomenal mother by her side and the incredible influence Shalon would have had on Soleil's life.

Since my daughter's death, my life has been framed by unbearable pain and unrelenting sadness. At this point in my life, I did not expect to be raising my granddaughter. I wanted to be that indulgent grandmother on the sidelines, watching my daughter and granddaughter grow together. Instead, I am acutely aware that I will face the rest of my days without my daughter and my best friend. Her clothes still hang in her closets. Her shoe racks still display all her shoes. Everything is still organized exactly as she left it. Visitors must still remove their shoes before entering her home. The wind chimes she hung on her front porch still add a sense of peacefulness. Her house is still her house. For months after her death I convinced myself that she would be home after work. Day in day out, I looked forward to 4:30pm only to go into a grief spiral the later it got. I still catch myself hoping she will come through the door at 4:30pm. Nights are still the loneliest times of my day, and many a night I don't sleep at all. It is when the tears still come. Even with a very vocal 31month old in the house, it is surprising how quiet my life has become without my daughter. I miss our conversations. I miss her words of wisdom. I miss her insight, which was always right on point. I miss her smile. I miss her laughter. I miss her hugs. Most important, I miss her love. Depression is an ever-present companion now. Shalon loved the holidays. But holidays don't exist at her house now. It seems so wrong without Shalon. No Easter bunny. No 4th of July barbecues. No trick or treating. No Thanksgiving turkey and sweet potato pies. No Christmas trees. No Santa Claus. No joyous and merry holiday seasons. No New Year's Jamaican food extravaganzas prepared by Chef Shalon. I know at some point, for Soleil's sake I must recognize the holidays, especially now, thanks to her I Pad, she knows about Santa Claus and sings Jingle bells on a regular basis.

Soleil is transitioning from a toddler to a little girl. She is 31 months old now. I see Shalon in her daughter. Soleil's smile is every bit as brilliant as her mother's. I only wish Shalon were here raising Soleil and guiding her life. I never meant to be on the front lines, raising a spirited little one who is ramping up her energy and excitement for the world – She constantly amazes me with her rapidly expanding vocabulary, her capacity for learning French, her athleticism as a gymnast and her love for art and ballet.

Each morning Soleil and I say good morning to mommy's picture. I want her to know she had a truly remarkable mother who loved her dearly and would have done anything to be here raising her. But it is no easy task. There are no words in the English language to

adequately portray what our life is like without my daughter—or the pain I feel when Soleil looks up at me and asks “Where is my Mommy, Nona? Why can’t I see her?” Soleil has a favorite picture of her Mommy, which she hugs and tells me “I love Mommy”. It brings tears to my eyes because Soleil should be hugging her Mommy. Shalon did not have to die. Shalon thought Doc McStuffins was a good role model for little girls. Soleil loves Doc McStuffins. She has a doctor’s coat, a stethoscope, and a doctors bag filled with other doctor’s instruments—ironically, the blood pressure cup is her favorite. She gives me regular check ups. Shalon would be so proud of her.

Assembling an extended family village for Soleil was very important to Shalon. She had some incredible friends who have tried to be there for me in everyway, for which I am eternally grateful. They have been there to celebrate each of Soleil’s milestones. Shalon would definitely be thankful that her village stepped up and rallied around Soleil and me. What I have trouble explaining to them is that as much as they love Soleil and me, some days we must walk this difficult journey alone. I take it day by day. It is only my granddaughter’s smile that motivates me to get up every morning, with the same goal each day—wake up, honor Shalon’s legacy, take care of her daughter, as she would have wanted. This goal keeps me moving forward. That, and a letter Shalon wrote two years preceding her death, and left for me in the event of her death. Following is the last paragraph of that letter:

Mommy, I am sorry that I have left you. On the particular day that I am writing this I have no idea how that may have occurred but know that I would never choose to leave you. It troubles me deeply that you are grieving. I know it seems impossible right now, but Mommy please do not let this break you. I want you to be happy and smile. I want you to know that my brothers and grandma are watching over me and that we are all watching over you. Mommy, please try not to cry. Use your energy instead to feel my love through time and space. Nothing can break the bond we have and you will forever be my mommy and I your baby girl! I love you for always! Lon

I have spent the last year trying to use my energy to feel her love by continuing her work. There is no mistaking the difference Dr. Shalon MauRene Irving made in this world. The difference her story continues to make every time I share it. Given the pain and turmoil I have experienced, I can never return to the ME that existed before losing my daughter. If I could go back in time and save my daughter, I would do anything. GIVE ANYTHING. If only I knew then what I know now. But, I take a small measure of comfort in knowing that Shalon’s story has ignited a passion in some legislators, doctors and health care advocates to transform the health care system when it comes to lowering the maternal mortality rates and making changes to postpartum care protocol. To paraphrase a line from Abraham Lincoln’s Gettysburg Address “it is the cause for which Shalon gave her last full measure of devotion”. It is up to us the living to carry on. Babies deserve a lot of care and attention after birth, but I can’t emphasize enough that mothers are equally as important. They

deserve care and attention after birth as well as before giving birth. I know my daughter did. **Shalon did not have to die.**

Dr. Brian Yablon, an EIS colleague of Shalon and internist at Hennepin Healthcare said, “Shalon was a kind, thoughtful, and principled woman. As a sociologist, she brought a unique and much needed perspective to the science of epidemiology. She advised that we not get so caught up in the science that we forget the people behind the numbers. Her wisdom and moral compass were just two qualities that made Shalon an exceptional human being.”

If Shalon were here today, she would also caution you not to get so caught up in the data, the maternal mortality statistics that you forget that behind every single number there is a face. The face of a woman who is loved. The face of a woman who had so much to offer the world. The face of a woman who will not get the opportunity to raise her beloved baby. If you take that face and multiple it, that one statistic not only includes the face of a woman who will be immeasurably mourned and forever missed but also the families left devastated by her death—the babies, the other children, the woman’s mothers, like me, the fathers, the husbands, the friends, the colleagues. The domino effect of that one statistic is incomprehensible. So whenever you are tempted to think of maternal mortality statistics as just data or numbers, put Shalon’s face in front of that number and remember my words.

In closing, I ask you, no I implore you to take 3 points from my words today.

One: Not every maternal mortality is because of lack of insurance, non-access to care, poverty or lack of education.

Two: The majority of maternal deaths are preventable.

Three: We must demand that postpartum care be redefined and optimized. We must hold health care professionals accountable for improving the quality of care and ensuring equity.

Sending folks to cultural sensitivity or implicit bias training is not going to fix the problem. We must demand the transformation of the health care systems in order to better respond to the needs and priorities of women, especially women of color. The reduction of preventable maternal deaths **must** become a national priority. It is for me. It was for Shalon. It should be for you too.

Thank you.