



**House Energy & Commerce Committee Health Subcommittee Hearing on
“Better Data and Better Outcomes: Reducing Maternal Mortality in the U.S.”**
September 27, 2018
Testimony for the Record
Submitted by Eleni Tsigas
Chief Executive Officer, Preeclampsia Foundation

Chairman Burgess, Ranking Member Green, and distinguished members of the subcommittee, thank you for holding today's hearing to address "Better Data and Better Outcomes: Reducing Maternal Mortality in the U.S." I am Eleni Tsigas, Chief Executive Officer of the Preeclampsia Foundation, and I am so pleased for the opportunity to submit testimony for this hearing in support of the discussion draft of H.R. 1318, the *Preventing Maternal Deaths Act*. I would also like to recognize the hard work of Representatives Jaime Herrera Beutler (R-WA) and Diana DeGette (D-CO) for their efforts to address the crisis of maternal mortality in the U.S. and to introduce and advance this important legislation.

Preeclampsia is one of the leading causes of mothers dying from pregnancy-related issues. It is a hypertensive disorder of pregnancy characterized by high blood pressure, protein in the urine, and sometimes failure of the kidneys, liver and other organs. It can affect up to one in 12 pregnancies, and there is no cure, only management.

Nineteen years ago, I held the still warm body of my baby daughter in my arms and kissed her desperately, trying to will her back to life. My kidneys had failed. I had lost half of my body's blood volume when I delivered her because of an undetected placental abruption due to



preeclampsia, and I almost died. So many other women like me have faced similar circumstances, but sadly, many of them did not survive and cannot offer their testimony here today.

As an organization, the Preeclampsia Foundation is focused on educating patients, their families and health care providers to recognize the preeclampsia warning signs and ensure that timely care is provided so no woman dies during pregnancy, delivery, or during the postpartum period. Moving this agenda forward has required solid data proving that a lack of patient knowledge of preeclampsia is a factor in a large percentage of preventable deaths. We have been able to obtain much of this data from existing state maternal mortality review committees, but much more data is needed. The data from state maternal mortality review committees is utilized to ensure healthcare providers accept and adopt the Preeclampsia Foundation's call to action to educate women about the signs and symptoms of preeclampsia and appropriately respond with timely diagnosis and accurate clinical management when they do.

Thanks to the work of existing maternal mortality review committees, the Foundation is sending out hundreds of thousands of pieces of patient education materials every year that are used in hospitals, and often in prenatal care settings. We strive to push out millions of educational materials, and women should be getting them at every prenatal visit, but unfortunately, too many states have not yet been able to - or understood how to - appropriately collect and assess their maternal mortality data that is linked to hypertensive disorders of pregnancy or other pregnancy-related complications.



The Preeclampsia Foundation ultimately strives to prevent maternal mortality and severe maternal morbidity and help states and communities establish protocols that save lives. We view this as a data-to-action initiative. There is so much to be learned from maternal mortality reviews that can improve healthcare practices today. For example, in Florida, based on their maternal mortality reviews, the state found that hospitals were taking too long to treat pregnant women that had severe high blood pressure. These women were dying from stroke and other preventable sequelae. Armed with data, new standards and protocols were set. In less than a year, 90 percent of women with persistent new onset severe hypertension were treated within one hour in hospitals using a new hypertension in pregnancy protocol. Before that time, only 20 percent were being treated within one hour.

Another example of where data can impact care is in addressing postpartum preeclampsia. One of the most common myths associated with this disorder is that “delivery is the cure for preeclampsia.” This is not true. Women are still at risk from preeclampsia and related hypertensive disorders following delivery, sometimes for weeks, particularly as most care is directed to the baby. Analyses from some states’ data has reinforced this by reviewing the number of mothers that die after they have returned home post delivery. We need far better postpartum surveillance, and we need to train emergency departments for when these women present with signs of preeclampsia-related distress. We cannot let up after delivery. There are states to learn from that have successfully begun to address postpartum preeclampsia. The legislation the Committee is reviewing here today would do much to support this type of information exchange to share best practices with other states.



Preeclampsia costs the U.S. health care system \$2.18 billion dollars a year – about half due to maternal health care costs and half for the care of the infants born to those mothers. To put that into perspective, these preeclampsia-related costs comprise about 1/3 of the costs for these entire pregnancies in just one year. The long-term costs associated with prematurity and long-term maternal health consequences are not included in these numbers.

A long time health activist, Mary Lasker, once said, “Research is expensive, but disease is more!” In the case of maternal mortality reviews, the research that is collected, assessed, and released by the state committees almost immediately leads to health care improvements and is nowhere near as expensive as the health conditions and complexities we would otherwise face. There are system factors, patient factors and provider factors that contribute to maternal mortality and severe morbidity today. We can do so much more with a small investment of time and resources for states and ultimately improve outcomes for thousands of lives. This must be a public health priority. Maternal health is the building block upon which all other health issues are based. We need compelling, instructive data to move healthcare providers and institutions to action and to support patient and family engagement in their health care.

Support the H.R. 1318 Discussion Draft

Mr. Chairman, Ranking Member Green and members of the Subcommittee, the discussion draft of H.R. 1318, *The Preventing Maternal Deaths Act*, sponsored by Representatives Jaime Herrera Beutler (R-WA), Diana DeGette (D-CO), and Ryan Costello (R-PA) mirrors S. 1112, the



Maternal Health Accountability Act, as recently passed by the Senate Committee on Health, Education, Labor and Pensions.

This legislation will help support state efforts to get at solutions – affordable and actionable efforts that can save lives. The bill, with the support and expertise of the Centers for Disease Control and Prevention (CDC) will help states understand how to identify local problems that contribute to rising rates of maternal mortality and derive local solutions. It will also help states that have been unable to get a maternal mortality review committee launched or operating. Despite the pockets of successful committees, the fact remains that today no state has a fully functioning maternal mortality review committee; even the best of them are handicapped by inadequate information, resources or know-how. For too many, the investment that has been made to date in databases, training, and tools will have been wasted if we cannot create a sustainable maternal mortality review system and thereby demonstrate what we value most: our mothers.

The Preeclampsia Foundation believes the discussion draft of H.R. 1318 will work to put an end to the rising rate of maternal mortality in the United States, protecting our mothers and saving health care resources. On behalf of the Foundation and all of the families we represent, we urge the Committee to prioritize this legislation and for Congress to pass it this year.