The Preeclampsia Foundation: the voice and views of the patient and her family

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Preeclampsia is a disease exclusive to pregnancy and the immediate postpartum period, occurring in 4.6% of pregnancies worldwide. Preeclampsia and other gestational hypertensive disorders can affect any pregnant woman. The consequences of developing this disease can lead to severe maternal and neonatal morbidities and mortalities, including fetal growth restriction, placental abruption, preterm birth, stillbirth, and maternal death. When pregnant women recover, they are at higher risk of long-term complications such as hypertension, stroke, heart failure, renal disease, and Alzheimer disease. The consequences extend to the offspring because they are at higher risk of cardiovascular diseases, and female offspring are at greater risk of developing preeclampsia when they become pregnant. For society, preeclampsia presents an economic burden related to the additional healthcare costs associated with low birthweight, prematurity, and adverse outcomes to the mother and baby. This article shares the unique perspective of affected women and their families, the effect preeclampsia has on us, and what we hope the healthcare system can deliver for our sisters and daughters in the future. Patients and their families established the Preeclampsia Foundation 21 years ago. Devoted to education and patient advocacy to raise awareness, improve healthcare practices, and catalyze research, we share some of the Foundation’s realized strategies and achievements. We tell you our stories and struggles, and we issue a call to action for all stakeholders to help fulfill our vision for a world where hypertensive disorders of pregnancy no longer threaten the lives of mothers and their babies.

Key words: Alzheimer disease, cardiovascular disease, chronic hypertension, eclampsia, HELLP syndrome, hypertensive disorders of pregnancy, lived experience, maternal morbidity, maternal mortality, neonatal morbidity, neonatal mortality, patient advocacy, patient driven, patient education, patient perspective, preeclampsia, pregnancy complications, renal failure, stillbirth, storytelling with a purpose

Introduction
The most widely recognized six-word story was written many years ago by Ernest Hemingway: “For sale: baby shoes, never worn.”

For those of us who have lived that story, we need a lot more than six words to communicate the important details of our pregnancy and childbirth experiences. Conveyed properly and to the right audience, the details of our lived experiences can be instructive, evocative, and catalytic.

In fact, storytelling is the basis for the Preeclampsia Foundation’s effectiveness, a patient advocacy organization celebrating 21 years since its incorporation on August 29, 2000. On the occasion of our anniversary, we invite you to learn from and be part of this journey—the personal stories and the collective impact we have had on patient education, raising awareness, improving healthcare practices, and accelerating research for hypertensive disorders of pregnancy.

It was the 1990s, and there are not many diseases that strike healthy pregnant women without warning and can take their lives and the lives of their babies.

Why then were expectant mothers told nothing about this one-in-20 pregnancy complication or its warning signs despite routine antenatal testing for hypertension and proteinuria? By comparison, the risks of their babies having Down syndrome—a one-in-1200 chance—were routinely tested for and discussed as a standard practice. Eclampsia was described more than 2000 years ago. Why has so little progress been made on understanding the pathophysiology of the disease and ways to prevent or treat it?

These and other issues struck a nerve for a three-time preeclampsia survivor, Anne Garrett, and her then husband, Anil Singh-Molares. In gratitude for the care they received, they asked Anne’s physician, Dr Thomas Easterling, how they could financially support his preeclampsia research.

Together with Dr Easterling and another preeclampsia survivor, Joan Lambert, they mobilized to launch a nonprofit organization to help other expectant parents get the information they deserved and to spur much-needed medical research.

The founders made three critical decisions that would establish the organization’s credibility and lay a foundation for long-term impact. First, Dr Easterling declined financial support for his personal research—suggesting instead that a national organization would be more far reaching and have the means to advocate for and promote more research in this field. Second, an all-star cast of preeclampsia researchers and physicians, diverse in their thinking,
were invited to comprise an expert medical advisory board. They responded enthusiastically. Thus, no one expert would define the research agenda for this “disease of theories” that has remained for so long an enigma. Finally, a professional website with evidence-based, well-written, and consumer-friendly patient education was the first major financial investment at a time when the internet was starting to blossom as a source of consumer information.

Twenty years later, under the leadership of Eleni Z. Tsiganis since 2009, the Preeclampsia Foundation serves as one of the world’s largest, most influential nonprofit patient advocacy organizations dedicated to hypertensive disorders of pregnancy.

A grandmother’s story
It was an unusually warm morning in Washington, DC, on March 23, 1998, when I got a call from my son-in-law who lived 3000 miles away with my daughter, in Portland, Oregon. Surprised by hearing his voice, Demetri told me that they were in trouble. When he told me it was the baby and Eleni, my heart lurched. She was only 29 weeks pregnant. “What’s wrong with them?” I asked. “Eleni is in labor and the baby’s heartbeat is dropping.”

I began to pack for an emergency trip. Then, another call came telling me that Eleni and the baby were being moved to a hospital with a level 4 neonatal intensive care unit (NICU). An hour later, I answered the phone to hear Demetri in tears, “The baby died en route to the second hospital.” I sat down and, staring off into space, kept wondering what went wrong. How could this be? We do not live in the Dark Ages when moms and babies routinely died. I did not want to believe that my daughter’s baby died. Before leaving for the airport the next morning, the phone rang at 4:30 AM. I answered to hear Eleni say, “Mom, I’m holding your granddaughter, Nikonia, in my arms.” For a fleeting moment, I wanted to believe the nightmare of yesterday was just that, a dream. Eleni’s voice was very soft, and she was not speaking too coherently. I told her, “Don’t talk now; I’m leaving for the airport. I’ll see you shortly.”

My tears flowed on the five-hour flight to Portland. This was one crisis that I, as a mother, could not “fix” for my daughter. I felt helpless and distraught.

Nothing could prepare me for what I saw when I walked into the hospital room. I did not recognize my daughter and questioned the nurse, thinking she had sent me to the wrong room. Her body was completely swollen, intravenous lines and tubes attached everywhere. It was then that I learned we were close to losing Eleni, too, after delivery. The thought of losing my own daughter made the pain of her loss even more acute.

As I held Nikonia in my arms, dressed in the tiniest gown, I flashed back to my daughter’s healthy birth. I was looking down at a déjà vu, but so much smaller. Now, many years later, I am certain I know what my granddaughter would have looked like and the joy I would have experienced. Despite going on to have other grandchildren, Nikonia will never be replaced.

Last week, I saw a grandmother standing in front of the preemie clothes at a baby store, crying. As my own memories quickly rose to the surface, I realized I will never again not know that pain.

—JoAnn Zuras, Eleni’s mother

Eleni’s story
“What if?” I asked, repeatedly. I had been invited to speak at the American College of Obstetricians and Gynecologists’ (ACOG) annual clinical meeting as part of the president’s address in 2012. I was to be one of three speakers: a scientist, a clinician, and I, all talking about preeclampsia, the conference’s main theme. What could I offer that 65,000 obstetricians and gynecologists would listen to, care about, and respond to? I kept coming back to the questions that I asked anybody who would listen after my baby girl died in 1998. Haunted by the memory of well meaning, but misguided advice to stop questioning what happened, I persisted. These doctors need to know not only what a mother’s sorrow feels like or what it looks like to watch your spouse lower your baby’s casket into the ground but also what can be done to prevent these senseless tragedies. My questions come with lessons for practical implementation.

I wondered:

1. What if my doctor had ever told me why my blood pressure was being checked and why I was peeing in a cup at every prenatal visit?
2. What if the nurse on the phone told me something other than “drink more water” when I reported severe and persistent swelling and instead asked me to come in to be checked or at least go have my blood pressure taken somewhere—as I had not been seen in three weeks?
3. What if I or others around me commented on my puffy red face during my birthday dinner three weeks before that fateful day?
4. What if I knew that, for my notoriously low blood pressure, a reading of 140/90 mm Hg was a reason to call my doctor urgently or go straight to the hospital?
5. What if I had an immediate diagnosis when I finally arrived at the hospital with a pounding headache, nausea, and blurry vision on top of an elevated blood pressure and proteinuria, and then had a doctor who acted with urgency?
6. What if I was not left in the radiology department several floors away for two hours after the technician recorded a biophysical profile score of “2?” What if anybody answered our questions and listened to our cries for help as I slipped in and out of consciousness? What if there was ultrasound equipment in the labor and delivery unit instead of in a different part of the hospital?
7. What if I did not have a strong faith community to support me through the most difficult experience of my life?

I proposed that every one of those questions had an answer, a practical solution that could be addressed.

Forty-five minutes later, after the line of doctors asking follow-up questions were finally shooed away to get on with the program, I walked backstage with my
fellow presenters and started sobbing. I had left it all on the stage, and whatever it was and whatever it would do, it was done. My quest to give my daughter’s life and death meaning and purpose was done, or so I thought.

—Eleni Tsigas, preeclampsia survivor and Nikonia’s mother

Patient Education
Story after story from women who have experienced preeclampsia and related complications—such as eclampsia and HELLP syndrome (hemolysis, elevated liver enzymes, and low platelet count)—converged around a few common themes:

- Lack of our awareness about the condition and its threat to our and our babies’ lives
- Lack of our knowledge about the prodromal symptoms we should pay attention to
- Frustration toward providers who did not listen or act more urgently when we expressed concerns or exhibited vital signs indicating something was amiss

Experiences like this led the Preeclampsia Foundation to prioritize patient education and raise awareness among pregnant women and providers.

Straightforward and understandable awareness of signs and symptoms improves outcomes. When women recognize symptoms, they have an opportunity to report them, advocate for appropriate investigations and follow-up, and comply with prescribed management.4,5 The Preeclampsia Foundation funded research to develop and test effective patient education materials and to ensure they did not contribute to anxiety—a concern sometimes raised by healthcare providers.4 Starting with the ACOG’s 2013 hypertension in pregnancy guidelines5,6 and in the subsequent bundles, toolkits, and peer-reviewed publications,7–9 patient education is now recognized as a best practice and included in these standard setting publications.

To date, 2.5 million patient education materials, including tear pads, posters, brochures, and videos (in multiple languages), have been distributed across 49 states, at minimal costs (Figure 1).

We continue to monitor the communication channels women most often frequent, and we only convey expert-approved information, including a website accessed by two million visitors a year, a monthly newsletter, position statements, news alerts, numerous social media platforms, and regular features such as Research Roundup and Ask an Expert. Support is also provided through a warm line, +1 (800) 665-9341, and an email, info@preeclampsia.org.

Raising Awareness
Through the voices of thousands of our women and families, the US Department of Health and Human Services designated May as Preeclampsia Awareness Month in 2012. Each year, hundreds of communication partners rally to share educational messages on topics ranging from the importance of self-measured blood pressure (SMBP), to knowing signs and symptoms, and to participating in research through the Preeclampsia Registry.

Worldwide awareness started with a proclamation signed by the world’s leading scientists and clinicians in 2010 followed by the first World Preeclampsia Day on May 22, 2017.10 Annual awareness-raising campaigns have helped bring preeclampsia to the attention of media,11,12 to Congress,13 and, importantly, to the target audience of preeclampsia survivors. Much work remains as market awareness surveys conducted in 2014 and 2015 found that many newly pregnant women are still not educated by their healthcare providers.14 The Foundation calls on stakeholders and all those in positions of public health education to raise awareness of preeclampsia as a life-threatening disorder of pregnancy that affects any woman in any pregnancy and to advance education and policies that will improve outcomes.

We collaborated on public health education campaigns, such as the Centers for Disease Control and Prevention recent Hear Her campaign15 and the associated list of urgent maternal warning signs developed by the
Council on Patient Safety in Women’s Health Care.16

A husband’s perspective
Joan shifted her baby from one shoulder to the other, trying to ease the tension in her neck and shoulder and trying to get a full breath of air. The secretary at her pediatrician’s office finally called her name. She gingerly hoisted herself off the chair—the cesarean delivery scar still pulled and made her wince—and started shuffling through the waiting room with baby Max. After five steps, she stopped and filled her lungs, trying to get the oxygen she needed to reach the door. She shook her head, clearing her vision, and slowly covered the remaining 10 feet. Every step felt like summiting Mt. Everest.

Our baby would get a glowing report in his medical record. Although born four weeks early because of Joan’s rising blood pressure and a diagnosis of severe preeclampsia, he weighed in at a healthy 9 pounds 10 ounces and was thriving.

However, Joan was not. She had been released from the hospital barely 48 hours after delivery to return home to our two-year-old daughter, Sofie, my nine-year-old daughter, Camille, from a previous marriage, and our newborn son, Max. Diagnosed at 36 weeks’ gestation with severe preeclampsia, after weeks of complications that included erratic potassium, severe preeclampsia, after weeks of complications that included erratic potassium, magnesium levels, gestational diabetes, and hypertension, we were repeatedly convinced delivery was the cure.

In 2017, Shalon Irving, a highly educated public health officer, met a similar fate three weeks after delivering her baby. Already with a host of high-risk factors, Shalon repeatedly asked her healthcare providers to address her alarmingly high blood pressure, new edema, and pain. Her concerns were not met with urgency, and today, Shalon’s daughter, Soleil, is being raised by her grandmother.17

Why were mothers dying from preeclampsia after delivery when all the textbooks and labor room platitudes insisted delivery was the cure?

As the evidence began to emerge from Maternal Mortality Review Committees (MMRCs), it became clear that Joan, Lauren, and Shalon’s stories were not unique occurrences. It also became clear from our work with our global health partners that these were universal themes.

Improving Healthcare Practices
In 2011, we began to advocate for professional societies to develop guidelines and train healthcare providers using the latest techniques in professional education, such as practice-based learning (ie, obstetrical emergency drills), incorporating checklists, team training, and accountability and using aggregate databases, such as closed claims to identify trends and opportunities for improved patient safety and quality for practice bulletins.

Today, we work to strengthen healthcare practices by securing universal adoption of hospital-based hypertension guidelines, boosting community-level readiness and response, and driving toward innovations in interpregnancy, prenatal, and postpartum care. The baseline of our expectation is that all providers implement what we know works, correctly and consistently, for every woman, every time.

For example, we brought important patient perspectives to the development of the Severe Hypertension in Pregnancy bundle, related publications and state-level toolkits that help standardize care. We serve as a partner for the Alliance for Innovation in Maternal Health and a voting member on the Council on Patient Safety in Women’s Health Care and were honored to serve on the 16-member ACOG task force, which created the Hypertension in Pregnancy Guidelines.3

The Foundation not only supports improvement in implementation of best practices but also supports and advocates for research and healthcare practice innovations, such as molecular biomarkers for screening and diagnosis15; aspirin prophylaxis; telehealth practices, such as remote blood pressure monitoring or “connected care” models; group prenatal care; and other cost-effective innovations to improve outcomes.20 We are also questioning whether hypertension needs to be more closely managed before, during, and after pregnancy and long before emergent values (160/110) are reached.

Looking closely at postpartum practices, such as self-measured or remote-monitored blood pressure and follow-up within one week after delivery, the Foundation funded a multisite research study to examine the efficacy of text-based remote blood pressure monitoring across three sites. In related studies, this approach was found to eliminate racial disparities in postpartum follow-up care, reduce readmissions, and save unnecessary visits for new mothers.21 These are the kinds of patient-centered practices that our lived experiences support.

We are also testing our hypothesis that augmenting care with SMBP could improve outcomes, by means of the Cuff Kit Project.22 It puts high-quality blood
pressure cuffs and patient education materials into the hands of the highest-risk and most vulnerable women. It extends our “Check Know Share” campaign, which encourages women to take their blood pressure, recognize what the numbers mean, and know how to respond. Accelerated by the coronavirus disease pandemic’s telehealth conditions that have compelled pregnant and postpartum women to take their blood pressure at home, the Foundation intends to analyze the impact of this program on women’s self-efficacy and providers’ use of the SMBP logs.

**Advocacy**

Disease advocacy efforts often need a financial justification. Health economics studies encouraged by the Foundation have been published in recent years using a combination of population-based and administrative data sets for mother-baby dyads. Preeclampsia is a $2.18 billion (USD) per year problem, and those pregnancies are three times more expensive than uncomplicated pregnancies, points we emphasized in an editorial and later studies confirmed.

As data from the MMRCs were reported in mainstream media, the court of public opinion helped fuel federal legislative efforts. The Foundation, working closely with partners (the ACOG, March of Dimes, Association of Maternal and Child Health Programs, and Society for Maternal-Fetal Medicine) and fueled by dozens of patient organizations, successfully shepherded the Preventing Maternal Deaths Act through a multiyear, bipartisan effort that President Trump signed into law in December 2018.

The law is intended to help eradicate preventable maternal death and improve maternal and infant health by ensuring that every state has a high-functioning process for identifying the causes of maternal mortality and translating recommendations made by the MMRCs into meaningful action. This legislation is also standardizing the collection and analysis of state data to develop a national understanding of why US mothers are dying and what it will take to reverse this tragic trend.

The Foundation’s leadership on that bill brought an unmet need to light, the inclusion of patient voices in legislative efforts. With leaders from other patient advocacy organizations, we formed MoMMA’s Voices, which stands for Maternal Mortality and Morbidity Advocates. Made possible by a Merck for Mothers grant, MoMMA’s Voices is a coalition of 19 patient organizations and hundreds of individuals with “lived experiences,” amplifying their voices to reduce maternal complications, often by serving as patient family partners on local or statewide safety and quality initiatives, in media coverage, and with legislative initiatives. MoMMA’s Voices offers training and resources advocates need to actively and effectively participate as patient family partners.

MoMMA’s Voices allows survivors to transform their pain, healthily, into a meaningful action, telling their stories and using their lived experiences to engage in quality improvement, research, community building, and education and find personal healing.

**Long-Term Effects**

**Kelsie’s story**

Some days, I can only carry the groceries halfway up the stairs to our apartment before the leg pain prevents me from taking another step. That is when I set the bags down, and that is when Emoree picks them up and carries them the rest of the way.

In a way, five-year-old Emoree has been carrying me since she was three weeks old. That is the first time I saw her, when the nurses brought my premature daughter to the critical care unit where I have been in a drug-induced coma since her birth, my body retreating and my kidneys and liver failing. I was being prepped for a flight to a medical center for a possible liver transplant, and my prognosis was poor. As the nurse gently laid her on my arm, I reached over and moved my fingertips to hers, but I could not hold her—not even a three-pound baby. The pain of knowing this was the first and possibly last time I would ever see my daughter was gripping.

Emoree and I decided we would see each other again. After 79 days in the hospital, I came home. Emoree had already settled in a month earlier. Because I was in a wheelchair and could not go to her if she started to cry in the middle of the night, she slept in her grandparents’ room. Eventually, I grew strong enough to push a walker, but the months of recovery led to another complication—avascular necrosis. Because of a loss of blood supply to the bones in my ankles and hips, the tissue had started to die, and my bones were collapsing.

After multiple surgeries and five years of recovery, I can walk again, but some days the pain is too obvious. Emoree knows when I am hurting. If she sees me limping, she will ask, “Mommy, your leg hurt today?” If I nod, she will run and get a bottle of lotion and start massaging my legs. Sometimes, she will ask me to tell her our story again. I show her my scars. We talk about how blessed we are that she has no scars.

That little girl, born two months too soon, is every little girl. She loves cinnamon sugar toast. She wants to have her nails painted, but it is hard for her to wait for them to dry. At some point on almost every nature walk, she will bend down, look closely, and ask, “Is this a weed or a flower?”

Emoree loves gymnastics, but that is an area where we disagree. She wants to do flips with no hands, and I am not ready to let go of her hands yet. I never was and maybe that is why we are both still here.

—Kelsie Thirtyacre, preeclampsia survivor

Although Kelsie’s story is an example of the long-term effects of acute complications from severe preeclampsia and HELLP syndrome, numerous studies demonstrate that pregnancy history can serve as a window into a woman’s long-term health.

At a press conference with the American Society of Hypertension (ASH) in 2009, the Foundation participated in the announcement of ASH’s first ever position paper on preeclampsia. This was followed by groundbreaking guidance by the American Heart Association in 2011 and later the American Stroke...
Association to include preeclampsia as a measurable risk factor for cardiovascular disease in women, position papers we heartily endorsed.

Preeclampsia, especially recurrent, early onset, or resulting in growth-restricted babies, is linked to cardiovascular disease in the five to 15 years following that pregnancy, often far earlier than when women's heart disease most often presents. The Foundation's work to educate women about this risk and the importance of addressing modifiable risk factors is often the only relevant information they receive. Healthcare providers have been slow to adopt pregnancy history into health history records or to conduct more deliberate cardiovascular assessments for preeclampsia survivors. As such, our work with Million Hearts, National Heart, Lung, and Blood Institute's the Heart Truth, Healthy Hearts Network, ACOG's Pregnancy and Heart Disease Task Force, and research collaborations with Harvard investigators to create the Heart Health 4 Moms (HH4M) program has been aimed at addressing the life course implications of hypertensive disorders of pregnancy. HH4M, designed to reduce cardiovascular risk and improve self-efficacy in preeclampsia survivors, was the product of a true provider-patient research collaboration.

Furthermore, the Preeclampsia Foundation's work on the Brain Study found mental and cognitive implications, a finding now replicated in other studies.

Jaye's story

The table in the examination room was cold. So was the doctor's demeanor.

I was 19 years old, eight weeks pregnant, and being seen for my first prenatal appointment. “Yes, you're pregnant,” said the doctor. “You're spilling protein in your urine, you have preeclampsia and need to terminate this pregnancy.” As an unmarried black woman, I already felt vulnerable. Now, I was scared. The doctor was stern and matter of fact as he told me it was literally a life-and-death situation, and I had to decide between my life and my baby's life. There was never a discussion about my underlying kidney disease and chronic hypertension, both likely the cause of my proteinuria and the erroneous preeclampsia diagnosis.

“When do you want to come in for the termination?” That was the question that day on everybody’s lips as I struggled with my emotions. I felt small and helpless, like I did not even have a say in the matter.

By 14 weeks’ gestation, the pressure to abort was too great, and I relented, regretting the decision to this day.

I needed support and information. A thorough analysis of my personal and family history would have established

![FIGURE 2](https://example.com/image2.png)

**Jaye Wilson with her daughters, Nadiyah and Ava**

Jaye Wilson’s daughters, Nadiyah (translating to hope) and Ava (translating to life), gave her a new perspective on how beautiful motherhood is, even when it seems impossible.

me as a high-risk pregnancy. Proper medications and careful management, as I had with a later pregnancy, may have led to better outcomes and no regret.

However, it took yet another pregnancy two years later that resulted in a placental abruption and the horrific stillbirth of my daughter at 22 weeks’ gestation to send me into an emotional spiral. At that point, I was married, and I desperately wanted this baby. I felt like her death was punishment from God. It felt like I threw away a baby so God took this baby away from me.

A series of unexpected events and insights lead me back to God, to nursing school, to a place of healing and strength, and eventually, with proper care, two more preeclamptic pregnancies with much better outcomes. My “babies” are now nine and 11 years old.

The journey was not without pain as I lived with stigmas I felt at every prenatal appointment. “Are you looking for the Medicaid clinic?” asked one nurse. My husband did not attend my appointments, but as I looked around at the mostly white women with their spouses, I felt like I did not belong at this private practice.

Before, I did not know a person could be a racist in healthcare. As a nurse, I knew I did not treat my patients any differently, so I assumed all my colleagues did the same.

These experiences proved to be a catalyst for change. I eventually founded Melinated Moms to build a community for me and women like me. The group’s most profound meeting was one that explored childbirth in communities of color. Woman after woman shared stories filled with confusion, fear, and voicelessness. They all felt like they could not ask any more questions. When they did try to speak up, nobody listened. For the first time, I and those in that session did not feel alone. It was the first time we could say those things out loud.

I still cry when I talk about my two babies who died, but I recognize that out of that suffering emerged a purpose that is more than just the pain. I am grateful I am able to tell my story because I know there are moms who look like me who never had the chance to do so.

—Jaye Wilson, preeclampsia survivor

Jaye brings her newfound voice and critical point of view to her work on the Foundation’s Patient Advisory Council, a 12-member panel with diverse experiences and perspectives that actively inform the work of the Foundation and the Preeclampsia Foundation’s Racial Disparities Task Force (Figure 2).

With new data emerging about racial disparities in maternal health outcomes—in both mortality and morbidity—the Foundation has taken a deep dive to understand how this issue manifests in hypertensive disorders. The Racial Disparities Task Force will soon be publishing clinical and community recommendations based on what is known and research recommendations to fill the gaps for what is not known.

It is clear to us that special efforts must be made where the impact is the most acute. Globally, this means low- and middle-income countries where 99% of maternal deaths occur, and domestically, this means in communities affected by racial, ethnic, or rural health disparities.

**Patient and Family Support**

The psychological, physical, mental, and spiritual effects of traumatic birth experiences, either with or without loss of life for mother and/or baby, can be substantial and long lasting. “Near-miss” events can provoke posttraumatic stress disorder. The stories shared in this article provide some insight into preeclampsia’s emotional impact: the isolation, guilt, and anger it often provokes.

The importance of the community cannot be overstated as a strategy for healing. Our objective is to improve the lives of those affected by providing education, support, meaningful engagement, and a lifetime home at the Foundation. As the Foundation’s signature community event, the Promise Walk for Preeclampsia, held every year in dozens of cities (mostly virtual in 2020 and 2021), has become an important way for survivors and families to connect
and heal. With guidance from the Foundation staff, hundreds of volunteers organize these events that draw thousands of participants. Since 2010, 373 local events have been held (Figure 3).

Advancing the Science
A dad’s story
I stood at the door of the operating room, watching helplessly as Lauren was wheeled in for emergency surgery to deliver our son, Peter Joseph, at 29 weeks’ gestation. Damn it! It is too soon. I pounded my fist into my hand. This impotent feeling was unnerving me. It was not me. I was a doer, I ran a large business, and I was used to solving problems.

Peter—named after my father who had died five years earlier—was taken directly to the NICU. There was no “baby’s first cry” or sweet picture of my beautiful wife glowing as she held our precious baby. Weighing just two pounds at birth, Peter’s lungs and immune system were underdeveloped. He fought for six days before a central line infection tore through his little body, and we had to say goodbye (Figure 4).

Lauren had suffered a very severe and potentially fatal form of preeclampsia known as HELLP syndrome. Looking back, the warning signs were there, but they were disregarded. Several weeks before Peter was born, Lauren started having severe stomach pain and called her obstetrician’s office only to be told she was probably experiencing heartburn, which was very common in pregnancy. When the pain continued over the next several weeks, we kept calling the doctor but were reassured it was “just heartburn.” The pain eventually became so severe that Lauren went to a gastroenterologist who performed some tests and then immediately sent her to the hospital for admission to the labor and delivery unit. An emergency cesarean delivery saved her life, but had it been delayed hours or even minutes later, she might not have lived.

Here I am now, wondering what could have been different, how could I prevent this from happening again to us, our future children, or anyone else? Another problem to solve. No doubt a daunting one, but one that must have a solution.

Although this pregnancy disorder was first described by Hippocrates in BC 400, we still have not made substantial progress. I learned that preeclampsia and other related disorders, such as HELLP syndrome, remain a leading cause of deaths worldwide, estimated at 76,000 maternal and 500,000 infant deaths each year. Research is the only way we are going to solve a problem that does not have any good answer.

However, preeclampsia research remains woefully underfunded, so with family and friends anxious to help, we would raise $1 million (USD) and put it to work. However, what was the right approach? How would we select the researchers? This was beyond our personal expertise. After doing due diligence, we decided to work with the Preeclampsia

FIGURE 4
Lauren, Clement, Peter and Pappas

During their time together, Lauren and Clement were only able to place a finger into Peter’s tiny hand.

FIGURE 5
The Preeclampsia Foundation’s 3 pillars

The 3 Pillars of our Purpose (mission) are Symbiotic

Supporting and educating our community with the best research evidence provides direct value to them

Our collective data and lived experiences inform our advocacy for improved healthcare practices

Gaps in diagnosis, management, treatment, prevention inform our research agenda

Our community is a huge asset for advancing research

And for becoming donors and volunteers

And for engaging as advocates for quality improvement in healthcare

Research findings inform advances in healthcare practices

And improve the lives of our community and beyond...

It’s a “3-legged stool” requiring all 3 elements to thrive

The Preeclampsia Foundation’s 3 pillars work in concert to advance research and healthcare practices while supporting, educating, and engaging the community.

We invite healthcare partners to respond to our call to action in the following ways:

- Provide patient education materials through physician practices, hospitals, and healthcare systems (www.preeclampsia.org/educating-patients)
- Encourage hospitals and healthcare systems to adopt the Severe Hypertension in Pregnancy Bundle
- Refer patients to the Preeclampsia Foundation website for information and support (www.preeclampsia.org)
- Inform patients who have experienced preeclampsia about the Preeclampsia Registry so they directly affect research (www.preeclampsia.org/participate)
- Apply for research funding (www.preeclampsia.org/research/research-funding)
- Sign our petition to demonstrate your support for and role in advancing biomarkers (www.preeclampsia.org/biomarkers)
- Join or start a Promise Walk for Preeclampsia event in local communities (www.promisewalk.org)

To contact the Preeclampsia Foundation, call +1 (321) 421-6957 or email info@preeclampsia.org.


Foundation. Their Scientific Advisory Committee is highly respected, and their medical advisory board is considered the “who’s who” of the field. The Foundation is also well regarded in the not-for-profit community with top ratings and solid finances.

Now, I have a response when well-meaning friends and family grasp my hand and offer their help. There has to be a better answer than delivering a baby too early. Together, we will solve this problem.

—Clement Pappas, Lauren’s husband and Peter’s father

The Preeclampsia Foundation’s strategic plan has set the research bar high—find a cure by creating a scientific roadmap, increasing external funding for research, and engaging scientific investigators and the affected community. Much of our strategy has been underway for years, evidenced by the growing investment in preeclampsia research at the National Institutes of Health. Some will require new partners.

Research funding

The Preeclampsia Foundation funds several research programs. The Peter Joseph Pappas Research Fund awards up to $200,000 (USD) each year to drive research that will eliminate the delivery of preterm babies as an intervention for severe preeclampsia and HELLP syndrome. By 2020, the Peter Joseph Pappas Research Grant program has awarded seven two-year grants totaling $635,000 (USD).

Established in 2007, Vision Grants of $20,000 (USD) to $25,000 (CAD) are meant to catalyze pilot projects that will lead to larger, more definitive studies. Awarded by the Preeclampsia Foundation and its Canadian affiliate Preeclampsia Foundation Canada, these highly competitive monetary awards recognize the best young investigators with novel hypotheses. A 2017 analysis of the program found a 20-fold return on this investment with more than $10 million (USD) in research funding secured by the pilot projects. Some of these initial projects have gone on to inform current clinical care, such as the role of sleep apnea in prediction and prevention.5 These grants are supported through individual donations, and fundraising efforts by affected families are not lost on the researchers. Every application includes a requirement to write a letter to a patient.

Additional research funding programs include Empowering Progress in Obstetric and Women’s Health Research, which helps investigators in low- and middle-income countries conduct studies and build their local research capacity, has expanded to include cofunders of the Global Pregnancy Collaborative and the International Society for the Study of Hypertension in Pregnancy.

The Preeclampsia Registry

Possibly more important than the ability to fund research is the unique asset that survivors bring to the research community—themselves—as partners in research studies and as subjects with rich lived experiences.

More than 7000 participants strong, the Preeclampsia Registry unites the patient experience with clinical data, natural history, qualitative insights, biospecimens, and annual health updates, creating a significant and unique resource for researchers.

Launched in 2013, it is the first registry to focus solely on hypertensive disorders of pregnancy and is overseen by an institutional review board. Participants include women (and many of their offspring) from every state and 67 countries. Over a dozen research studies are underway or were completed utilizing the registry.

One major study utilizing the registry, published in Circulation, demonstrates that gene variants related to some types of heart disease, such as idiopathic and peripartum cardiomyopathies, are also associated with preeclampsia. These findings have the potential to better determine a woman’s risk for heart disease after preeclampsia and may also inform future studies that seek to define and predict both preeclampsia and heart disease.36

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<tr>
<td><strong>A call to action</strong></td>
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We invite healthcare partners to respond to our call to action in the following ways:

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<tr>
<th>Action</th>
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<tr>
<td>Provide patient education materials through physician practices,</td>
<td><a href="http://www.preeclampsia.org/educating-patients">www.preeclampsia.org/educating-patients</a></td>
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<td>hospitals, and healthcare systems</td>
<td></td>
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<tr>
<td>Encourage hospitals and healthcare systems to adopt the Severe</td>
<td><a href="http://www.preeclampsia.org">www.preeclampsia.org</a></td>
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<td>Hypertension in Pregnancy Bundle</td>
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<td>Refer patients to the Preeclampsia Foundation website for information</td>
<td><a href="http://www.preeclampsia.org">www.preeclampsia.org</a></td>
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<td>and support</td>
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<tr>
<td>Inform patients who have experienced preeclampsia about the</td>
<td><a href="http://www.preeclampsia.org/participate">www.preeclampsia.org/participate</a></td>
</tr>
<tr>
<td>Preeclampsia Registry so they directly affect research</td>
<td></td>
</tr>
<tr>
<td>Apply for research funding</td>
<td><a href="http://www.preeclampsia.org/research/research-funding">www.preeclampsia.org/research/research-funding</a></td>
</tr>
<tr>
<td>Sign our petition to demonstrate your support for and role in</td>
<td><a href="http://www.preeclampsia.org/biomarkers">www.preeclampsia.org/biomarkers</a></td>
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<td>advancing biomarkers</td>
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<tr>
<td>Join or start a Promise Walk for Preeclampsia event in local</td>
<td><a href="http://www.promisewalk.org">www.promisewalk.org</a></td>
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<td>communities</td>
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To contact the Preeclampsia Foundation, call +1 (321) 421-6957 or email info@preeclampsia.org.

A Call to Action
The Preeclampsia Foundation envisions a world where hypertensive disorders of pregnancy no longer threaten the lives and well-being of mothers and their babies.

We are relentless and not complacent to stand on yesterday’s solutions when change is needed, not only supported by evidence and data but also colored by and informed by real-life experiences. We walk beside women and families who are suffering and hurting. We believe that true advocacy happens at the table with collaborators and stakeholders, even if—and especially when—we disagree. It is our job to hold governments, providers, and other stakeholders accountable and ensure that commitments are translated into concrete action.\(^8\) Why we exist, our purpose, and how we accomplish it are woven together by three symbiotic pillars of our mission and driven by consistent values over our two-decade history: courage, collaboration, compassion, credibility, catalytic, and patient driven (Figure 5).

This year we celebrate our 21st year of commitment to this vision with renewed enthusiasm and a call to action for partners to join us in the journey ahead (Table).

ACKNOWLEDGMENTS
We gratefully acknowledge Kate Arthur, Valerie Holloway, Debbie Helton, and Dr Tom Easterling for their valuable editing assistance; the Preeclampsia Foundation founders Anne Garrett, Anil Singh-Molares, and Joan Lambert for their vision and investment; Todd Heiden, Clement Pappas, Kelsie Thirtyacre, Jaye Wilson, and JoAnn Zurias for permitting us to tell their deeply personal stories; and the tens of thousands of women and families who have allowed us to walk with them through trauma, grief, questions, and pain and from whom we learn every day what matters most and what must be done.

REFERENCES
Potential “call out” quotes

- We were repeatedly reassured, “delivery is the cure for preeclampsia” (line 370).
- As an unmarried black woman, I already felt vulnerable. Now I was scared (lines 592).
- Looking back, the warning signs were there, but they were disregarded (line 777).