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Megan: Hello everyone, and welcome to this Ask the Expert webinar for Healthy Start, "Preeclampsia: Impacting Mothers, Infants and Families. Strategies for Improving Pregnancy Outcomes." I'm Megan Hiltner, I'm with the Healthy Start EPIC Center. We have approximately 60 minutes set aside for the webinar. It is being recorded. The recording, along with the transcript and slides will be posted to the EPIC Center's website following the webinar. And before I introduce your great presenter for today, I have a couple more housekeeping announcements. If you are having any trouble at all hearing the presenter, and by chance you are dialing in through your computer, you may want to dial in through a telephone. You may have a better luck with the audio that way. We also really want your participation today, so if at any point you have any questions or comments, please chat them into the chat box in the lower left corner of your screen. We will only be taking questions via the chat box, and we'll be breaking at the end of the presentation to get to your questions. And also, we do want your feedback. So, at the end of this webinar, please take a moment following and complete the survey that will pop right up on your screen.

So, without further ado, I'm going to introduce your wonderful presenter for the day, Ms. Eleni Tsigas, Executive Director of the Preeclampsia Foundation and Principle Investigator for the Preeclampsia Registry. She's also a two-time survivor of severe preeclampsia. You can read a lot more about Ms. Tsigas and find many more great resources regarding preeclampsia on the Preeclampsia Foundation's website. That's preeclampsia.org. So, without further ado, I'm gonna turn it over to you, Ms. Tsigas, for your presentation today.

Eleni: Thank you so much. Thanks so much for having me. And for everybody who's joined, I understand this has been a popular session to register for, so we're excited to cover a lot of ground today. First of all, I have to say that I really had the enormous pleasure of presenting this information at the National Healthy Start meeting in September in Washington DC. And we purposely developed that as more of an interactive session that allowed Healthy Start directors and caseworkers in the room to provide, really, what turned into quite valuable feedback about what information was most important to this community. And I'm very grateful for that opportunity and hope that, in turn, you find today's information useful. Our goal, of course, is to work together to optimize your role in improving pregnancy outcomes for moms and babies.

So, I'm gonna start as I often do, just kind of grounding you in my personal story because it's very illustrative of a lot of stories that are still

unfolding today. Even though my pregnancy, my first pregnancy, was 18 years ago and that's just ages ago, it is actually a story that is being repeated over and over again in many women's lives today. And that's one of the reasons I consider it a very illustrative story. I also had no idea, 18 years ago, that this first pregnancy would eventually lead to some drastic discoveries, to my drastic discoveries about preeclampsia and, really, a complete re-direction for my life's work. I had no idea that here, in the United States, I could be fighting for my own life from a condition called preeclampsia. I wasn't squatting in a hut in, you know, a low-income country. I wasn't having a water birth with mystical music playing. I was in a mauve-colored birthing suite with a couch for my tired husband, and color-coordinated drapes and very kind nurses. So, I had no idea that that experience would lead me to a grave for my baby daughter, or having to watch my husband and the funeral director lowering her casket into the ground. I had no idea that a human body and soul could endure that degree of anguish, or that I could generate so much guilt and so many "What if?" questions. "What if?" is a common refrain from people who undergo the loss of a child.

Some of those "What if?" questions are these. "What if my doctor had ever told me why my blood pressure was being checked when I was peeing in a cup? What if I knew that, for my body, blood pressure of 140 over 90 was reason enough to go directly to the hospital? What if the nurse didn't skip my urine dip on the last prenatal visit? What if the nurse on the phone took a more cautious approach when I reported severe swelling, and asked me to come in to be checked since I hadn't been seen in three weeks? What if I, or others around me, stopped to notice and comment on my puffy, red face during my birthday dinner three weeks earlier? What if I'd had an accurate and immediate diagnosis when I arrived at the hospital, by a doctor who appreciated the acute dangers of a headache, nausea, visual disturbances, on top of an elevated blood pressure and proteinuria, and then acted with urgency? What if I wasn't left in the Radiology Department several storeys away for two hours, after the test reported a biophysical profile of 2, indicating my baby was in distress? What if there was actually ultrasound equipment in the labor and delivery ward? And possibly, most importantly, mine could very well have been the very best possible scenario, so what could be happening to women with less access to good quality health care or without the health literacy skills that I supposedly had?" And now, I'm the Executive Director of the Preeclampsia Foundation, I'm on a journey with thousands of other women all with vaguely similar "What if?" questions, seeking answers and trying to do something about the problem.

So, what is the problem we're trying to solve? Well, let's start with the fact that pregnancy-related deaths in the United States are actually going up, not down. We actually rank amongst the worst of high-income countries. Hypertension in pregnancy, especially preeclampsia, is one of the leading causes of this trend. And it's not just about mortality, but morbidity. As you can see in this graph, that trend is also going up. Morbidity is, I guess, one casual way of defining it as the really bad outcomes that are associated with near-misses. Morbidity is often reflected as the hidden but hugest part of the iceberg that you can see in this image. In this analysis of all the California births in 2007, just one year, which by the way, is an excellent proxy for what's happening across the country, we see that there are approximately eight deaths that year related to preeclampsia eclampsia among California women. But the rate of near-misses, which defined here are the number of ICU admissions, was 380 for that year. And serious morbidities, which are defined as prolonged postpartum length of stay, 3,400 pregnancies that year.

The critical pathway to these poor outcomes begins with failures such as delayed treatment, delayed diagnosis, the assumption that symptoms that she may be feeling are not significant or symptoms aren't recognized, either by the woman herself or by her provider, leading to serious morbidity, near-misses and, finally, maternal death. The most troubling aspect of these deaths is that review committees have determined that they had a high degree of preventability. That means that there was a strong to good chance to have altered the fatal outcome in 40% of all these pregnancy-related deaths. In 12 of the 25 cases of preeclampsia, so half of them, had a good to strong chance to alter the outcome. In comparison, if you look down to the bottom at amniotic fluid embolism, none of those had a chance of altering the outcome, i.e. they were not preventable. And because we care about the baby as well, let me point out that a paper that just came out a few months ago found that preeclampsia came in right behind a history of pre-term birth as the leading cause of premature births, and this was consistent across several high-income countries. I know the writing on this slide is too small. I don't intend you to read the specific numbers, but I just want you to get the big takeaway that preeclampsia is a very important issue to the babies as well.

And in other exciting news, and I say that with lots of sarcasm, we now know that preeclampsia contributes significantly to a woman's risk for heart disease and stroke as soon as 5 to 15 years after her pregnancy.

In fact, two out of three women who had preeclampsia will die from heart disease. So, that equates to about two and a half, 2.6 million, preeclampsia survivors alive today in the U.S. alone who will die from heart disease. In general, awareness of preeclampsia is getting better among expectant mothers. A lot of our market surveys are finding that. But it still lags where it should be, and it's even lower among low SES women and stay-at-home moms. And more specifically, what's especially low is awareness of specific signs and symptoms.

So, what are we doing about it? Well, "it" meaning the larger problem, and I will say that in good news, there are quite a few state-level and national programs and campaigns underway that include the development of guidelines, bundles, toolkits, training modules, many of them specifically for preeclampsia. On your lower right-hand screen, I have a website there, safehealthcareforeverywoman.org, which is for the council on patient safety in women's health care. I recommend you check that out because there are a lot of the tools that are being recommended at the hospital level and for health care providers are located on that website. Fortunately, a lot of these efforts that you guys just kind of very briefly bolted out here are already starting to pay off. The California team, which has been a leader in many of these initiatives, has already demonstrated 34% and 48% reductions in morbidity...of the preeclampsia toolkit. And that's in both women who have not had a hemorrhage with it.

So, why does all this matter as a sort of background? It's because what we recognize is that, if you do take a concerted effort to address the problem of preeclampsia, you are part of a larger movement that is actually doing something about moms and babies dying or having bad outcomes in pregnancy, and that those of you who are on the call today, I absolutely applaud and congratulate you because you are part of this growing movement to reduce mortality and morbidity related to preeclampsia.

So, let's take a deeper dive into the issue itself. What is it? It's actually part of a larger group of conditions called hypertensive disorders of pregnancy, and we're gonna do a quick interactive poll right now to see how much you know about these disorders. For instance, in 2013, and this is really what it's driven off of, ACOG issued updated guidelines and defined four categories for this pregnancy disorder. So, a question to you all, which of the following is not one of the four categories of hypertensive disorders of pregnancy? Give you a minute or two to read and select. And while you're doing that, I will mention that much of the

confusion around definitions is because preeclampsia is a spectrum disorder, meaning it can occur anywhere from early or late in the second half of pregnancy. It can come on suddenly or creep up slowly. It can also produce many other problems, such as swelling in the brain, retinal detachment, placental abruptions, hemorrhage. So, this concept of preeclampsia as a spectrum disorder is an important one. The other comment I would make while we're just getting everyone to weigh in on their poll is that preeclampsia manifests itself after 20 weeks of pregnancy, generally in the third trimester, but sometimes as early as the second. And manifest is an important word because science has now found that it actually takes root, so to speak, in the first trimester, when the placenta is forming. It's just that the way we're currently diagnosing and recognizing it isn't until symptoms start manifesting themselves later.

So, I think we still have some responses coming in. Let's wrap those up and see where we ended up. So, which of the following is not one of the four categories? So, interestingly, you guys have something new to learn today. The category that is wrong is pregnancy-induced hypertension, the one that seemed to get some of the least votes. PIH, or pregnancy-induced hypertension, is an outdated term. It's not one that is being used clinically or in research, and is not one of the four categories of hypertensive disorders of pregnancy. Chronic hypertension, which would pre-exist the pregnancy, is considered a concern before or during pregnancy. You can also get preeclampsia on top of chronic hypertension. That's a category. You can also get only hypertension in pregnancy, which is called gestational hypertension. That's one of the categories. And of course, preeclampsia and one of the end results of preeclampsia, which is eclampsia, which is when seizures occur, is the fourth category. So, let's go back to the presentation. Thanks for taking some time to test your knowledge. Don't worry, you won't be graded on it. So...

Megan: But like you said, Eleni, as you're transitioning back to your slides, that is great that where our collective knowledge falls on this topic where your expertise and knowledge can really help us. So, thanks for doing that poll. It is, I must say, as a non-clinician too, it's confusing, all the different terminology. So, I'm glad you're gonna go into more detail.

Eleni: It absolutely is. So, we're gonna talk, you know, a lot of what I'm talking about relates to all of them, but really preeclampsia and therefore preeclampsia's super-imposed on chronic hypertension, are some of the

most dangerous and important and, really, the focal point of our conversation today. So, let's talk a little bit about preeclampsia. Oh, and actually, I'm gonna take a quick side note. You'll notice that, you know, in addition to PIH, another one of the favored terms that still gets thrown around is toxemia, another outdated term that really should not be used anymore. A question we often get is, what about health syndrome? Well, health syndrome is considered a severe variant of preeclampsia, so it would fall under that preeclampsia eclampsia bucket.

So, looking specifically at how preeclampsia is diagnosed, the 2013 ACOG guidelines made some clarifications around this and, actually, some departures from what was previously in place. We still need a blood pressure reading of 140 over 90. In fact, two readings four to six hours apart, plus a proteinuria reading of, as you see here, 300 milligrams in a 24-hour urine collection. I know what women are used to is sort of the dipstick, and that's a good early indicator. But a more definitive reading would come in a 24-hour urine collection or in what's called a protein creatinine ratio, which can be delivered more immediately in a lab environment. So, the traditional definitions of preeclampsia are these first two items here, but one of the things that we realized is that all women don't necessarily present with proteinuria. Proteinuria is evidence of kidney damage. The kidney is starting to fail in its functioning. So, there can be other things that accompany the blood pressure. So, you might have blood pressure and one of these medical terms down here, thrombocytopenia, impaired liver function, renal insufficiency and so on. And I know these are all medical terms, but the important things for you all to see is that these are really technical terms for things like blood clotting issues, liver or kidney failure, fluid in the lungs or fluid or excessive blood pressure in the brain, which can affect eyes or the vision. What's important about this last group of problems is that they're all associated with symptoms that the woman may experience.

So, what are the symptoms of preeclampsia? Well, here's a pretty exhaustive list. And what I would say about these right off the bat is that, if a woman has one or more of these, it does not mean she has preeclampsia. What it means is she should be taken a closer look at, and especially pay attention to her blood pressure and proteinuria at that point. All these are important, though, for her to be aware of, some more than others. And I kind of rank order them in the way that you would most likely see them. Swelling in the face or hands. Notice we're not saying the feet. Most pregnant women end up with fat ankle syndrome, that's not what we're necessarily looking for here. Headaches that won't

go away with Tylenol. Visual disturbances. Some people see stars, some people see an aura, but let's just call it visual disturbances. Epigastric pain or upper-right quadrant pain, which sometimes translates to the neck or shoulder. Nausea and vomiting in the second half of pregnancy, so this is not morning sickness. And then, sudden weigh gain, which very much goes with the swelling. We often sometimes see women with breathlessness, with mental confusion. And the last one which doctors just love, let me tell you, the "Just not feeling right." It's what I call mom's sixth sense, and it's often present when mothers just know something isn't right but they can't put their finger on it. And I guess the guidance here is, don't dismiss it, really encourage moms to be in-tune with that sixth sense.

So, who gets preeclampsia? It's a big question. And the risk factors include, number one, having a history of preeclampsia in a previous pregnancy or in immediate family members. So, if mom had it or a sister had it, that's put her at higher risk. Coming into that pregnancy with chronic hypertension or diabetes, being obese, having multiple gestations, twins, triplets, etc., IVF. The extremes of age, so, really young moms and older moms. Autoimmune disorders like lupus puts you at higher risk. Syncope [SP] puts you at higher risk. African-American women are at higher risk. Sickle cell disease puts you at higher risk. And this one always gets everybody, your first pregnancy which, you know, I always say you're sort of guilty until proven innocent. All of these are risk factors for preeclampsia. Again, the underlying message here is that you can have none of these risk factors, like I didn't have any of these risk factors, and you can you still get preeclampsia.

So, do these risk factors sound like our Healthy Start finds? We analyzed some of the data from the 2014 Healthy Start performance report and found that about half of the clients are black or African-American. And if you'll look below that, so this is actually good news, this is all just based on who reported into the survey, but 69% did enter prenatal care in the first trimester. So, that's good news because that's the place that you can sort of get preemptive with education. Twenty percent entered in the second, and almost 6% entered in the third trimester. Seven and half percent were young moms and 7.5% were older. But of those, about half were black or African-American. And again, that is sort of the higher risk factor for preeclampsia. Interestingly, I know one of the performance measures was the degree to which Healthy Start programs facilitate health provider screening of women participants for risk factors. And in this case, only 58%, a little over half

of the grantees reported facilitating provider screening of women participants for risk factors. This is important, because the risk factors that I know you all are supposed to screen for are things like hypertension, gestational diabetes and being overweight or obese, all three of which definitely contribute to a risk for preeclampsia. So, something to just kind of hone in on as Healthy Start caseworkers or directors.

So, going back a second to all of these quality improvement initiatives that are underway at the national and state level, one of the things that it's all sort of bubbled up into is, what can we be doing, what should we be doing better today with what we know to improve outcomes? And it really boils down to just five things, those five items that you see on your screen there. Two of which, I would contend, have a direct impact on Healthy Start, number one and number five. Why is that? Well, because it's all about patient education. So, why do we need patient education? This is a core mission area for the Preeclampsia Foundation, and research has shown that when women recall and understand information, they act upon it. I know that seems self-evident, but I'm just gonna say it again. When women recall and understand information that they've been given, they do act upon it, and our research has demonstrated this over and over again. We know that preeclampsia education is not going to prevent it, but of the thousands of women in our database, an alarmingly high number of them have lost babies or had adverse outcomes that could have been prevented by getting to care earlier in the process. Probably, one of the most common refrains we hear is, "Oh, if only I knew." So in short, patient education improves recognition of symptoms, leading women to seek care and advocate for themselves, allowing for some intervention leading to improved outcomes. That's our goal with patient education.

The evidence supporting the need for more preeclampsia information for patients is clear when you look at some of the state data. So, out of California and Florida, for instance, what we now know is that, in cases of hypertensive disorders and pregnancy, the factors contributing to mom dying that can be attributed to patient education, are things like delays in seeking care or a lack of knowledge regarding the severity of symptoms. So in California, 63% of the maternal deaths and 56% of the maternal deaths were attributed to those two factors. In Florida, the numbers are a little bit better, 47% and 33%, but the really sad thing about those numbers is we're not talking about a high-tech intervention, we're talking about patient education, empowerment and getting them to get to care sooner. So, when you think about your own experience with

providing patient education, see if it correlates to this pilot study that we conducted in one county in Florida. We worked with Healthy Start in this county and found that half of the caseworkers did not routinely educate all their pregnant moms. So, there's an opportunity for improvement.

So, patient education, this is kind of a synopsis of the calls to action, if you will, and why we think it really does matter. Number one, the pregnant mom is often the first responder. She's experiencing these symptoms and can speed time to diagnosis and impact the outcome. What she needs to know is not necessarily obvious in preeclampsia, unlike something like obstetric hemorrhage, which I say is sort of like the universal, "Oh crap, I'm not supposed to be bleeding." Like, that's universally known to some extent, I would think. The preeclampsia symptoms are not necessarily specific to preeclampsia. It could be a perfectly normal pregnancy with just some, you know, the woman not feeling well in a couple of different areas. So, recognizing that those are concerning symptoms that she does need to report is important. With that greater understanding of the seriousness of it, we seek greater compliance, greater reporting. Knowledgeable clients are gonna be more empowered to speak up, more apt to ask questions or to challenge lack of [inaudible 00:25:59] practices. Because let's face it, they're still gonna face some of that from their health care providers. And again, I said this before but I'm gonna reiterate. Although risk factors can help to identify those at higher risk, not having any of the risk factors does not mean the woman won't get preeclampsia.

So, that's why we believe we need to be providing patient education. Now, let's talk about some ideas for how. And most of these strategies are probably ones that you all, as accomplished case managers, are used to working with your women in trying to communicate medical information, of course, using non-medical, plain language. The other piece is organizing information, chunking it up, if it's complex information, into two or three components. Another big one, especially in preeclampsia, is using the concept of teach-back to confirm a woman's understanding of information with open-ended questions. So, what might that look like? You just went through, let's say, a long list of symptoms with her. Instead of just saying, "Do you understand all these symptoms?" which she's probably gonna say, "Yes," you would say something like, "Okay, we just covered a lot of information. What might cause you to call us?" And then, you're asking her to teach you back what she just learned, leaving you an opportunity for clarifying or refining the information. Another important thing, of course, is don't assume her literacy levels. This is where you all have an advantage, because you've

developed relationships with these moms and you know what she needs to know. Stop, look and listen if she does have a complaint. This is one of the most obvious things that we see happening in the hospital environment a lot, is that care providers aren't really stopping, looking at the mom and listening to what she has to say before dismissing her concerns.

Research has also shown that you wanna use proven tools, validate their utility, make sure that they're really gonna work. We also know that messages have to be repeated to be remembered, and it's a good idea to use multiple teaching strategies to accommodate different learning styles because some people learn with visual information, some need to hear something, some need to read. You wanna give them the same set of messages a number of different ways. And again, you know, this is where you all have the advantage in that you know mom and you know why some women don't need more information, maybe some are in denial and need shaking up a bit. Others are overly cautious and concerned, maybe you don't need to be overly alarmist with them.

One of the things that we learned from the in-person session that we did up at the Healthy Start conference, some of the barriers that we identified that you all are experiencing is that moms don't often care for themselves. Kids always seem to be the priority, or the baby is always the priority. So, one of the things that we say is, well, kind of use that to your advantage and say, "You need to do this for the baby," even though it's also for mom. Another idea is really affirming the need for self-care and owning your own body, and that self-care is not the same as selfish. Another barrier is the information overload during pregnancy and the postpartum period, and that often, kind of going with that, is hospitals and doctors can be intimidating scenarios. Women are often afraid to push back. This is where one of the recommendations that came up is expanding this education to partners and family members. Enable other people to be advocates for mom.

So, this is one area where the Preeclampsia Foundation can really be a resource for you. Our first education tool was developed by health communication experts and researchers at Northwestern University in a randomized controlled trial, so that [inaudible 00:29:51] gold-standard of an RCT and it was published in a high-impact, peer-reviewed journal. As a result of that and what we learned through that process, we've been able to produce evidence-based CarePads, posters that can go up in clinics in a number of different scenarios, as well as an explainer video that are all available in multiple languages. And all of these can be

ordered on our website, preeclampsia.org/store, and this is available in print, as well as some digital licenses because I know some people like to use electronic mechanisms, maybe for showing things on an iPad, that sort of thing. In addition to these evidence-based tools, all of this is super critical. Like, I would say if you do nothing else from this session, take home the concept that these are tools that you can incorporate into your prenatal and postpartum patient education. There are sometimes women who want more explanation about the issues, and for them we do have a series of brochures that are a little bit more expansive in the information that they cover.

So, I wanna focus on, switch topics here a second and talk about one of the most commonly repeated myths about preeclampsia, and therefore one of the most dangerous. Is delivery the cure? So, let's spend a few minutes talking about the postpartum period. And I'm gonna do that by telling a story about Joan Donnelly from Orlando, Florida, who had a few complications in her first pregnancy. She had gestational diabetes, it was diet-controlled, but she delivered a baby girl about six weeks early. And now, it's a couple of years later and she's in her second pregnancy. Her diabetes now escalates and she's actually requiring insulin shots. She undergoes an enormous amount of weight gain, shortness of breath. She's in and out of the hospital for potassium and magnesium level fluctuations. Her blood pressure goes up, then it goes back down, then it goes up. Eventually, she ends up in the hospital with a diagnosis of preeclampsia at 35 weeks and 4 days. And her husband Todd says, "You know, all along, we were told that the cure for preeclampsia was delivery." The cure for preeclampsia is delivery, that was the message.

So, that made a big difference because she had a C-section. Forty eight hours after spending some time bonding with the baby and getting cleared to go home, her blood pressure was 140 over 85 and her discharge instructions included the typical things that you guys are probably familiar with, caring for the surgical wounds since she had a C-section, what to do about blood loss, caring for the baby. But she's home for two days and she struggles with shortness of breath. She even took her child to the pediatrician and barely could take step after step, being so breathless. And so, that night, her second night at home, she awoke Todd, her husband, frantic that she could not breathe. Her husband didn't know what to do, he called 911 as she collapsed in his arms on their kitchen floor. And her last words to him were she loved him. Sadly, the paramedics did regain a pulse after 25 minutes, but her brain-dead body was pulled off life support 17 days later, and now Todd is raising their daughter and son alone.

This concept of postpartum preeclampsia, actually there is evidence for it in the literature. And while it's not as robust as we'd like it to be, researchers have found that nearly all of the late postpartum eclampsia in this particular study had at least one symptom before the seizures, and half had more than one symptom that heralded the seizure. But only 33% of these women sought care for their symptoms, and we have to recognize that the postpartum period is a very vulnerable time. Women are undergoing hormonal changes, they have their natural rise in blood pressure, you're sleep-deprived, everybody's focused on the baby. And for first-time moms, this is an unknown experience. And since there's no longer a baby on-board, mom's probably gonna end up in the ER if she's having an issue where her caregivers are not nearly as tuned in to obstetric issues.

Part of the problem is that discharge instructions don't include any mention of the preeclampsia symptoms, and I'm just showing you one example here. I suspect that all of you go back to your local community, you're gonna find discharge instructions are woefully lacking in the list of preeclampsia symptoms. The key clinical [inaudible 00:34:33] identified by the California Task Force is that there needs to be early follow-up for all patients with preeclampsia, and especially note that bottom of the list. Discharge instructions should always include preeclampsia symptoms. This is a huge opportunity for Healthy Start caseworkers because you do see your moms postpartum, and this is an opportunity for you to intervene if there are issues going on.

So, we're gonna change gears a bit in these last few minutes and talk a little bit about how preeclampsia affects our mental health. There's actually a considerable body of evidence that supports the psychological impact of preeclampsia. Some of the findings include that this life-threatening nature of preeclampsia takes a far greater toll on mom, and often her partner's emotional health, on their coping skills, care-giving ability, as well as a lot of other quality of life issues. We have so many stories of marriages even crumbling under the strain of life-threatening emergencies or the death of a baby. Long-held family planning intentions are uprooted. All of a sudden, what started as, "I'm gonna have three babies, three kids," goes to, "Oh my gosh, I don't know if I can have more than one." And then, that leaves a lot of regret, and sometimes even unspoken blame.

Post-traumatic stress disorder impacts a parent's ability to effectively care for her children and the normal responsibilities of life. We know,

through a lot of the literature on this topic, and experience, that mothers with PTSD symptoms are less sensitive and effective at structuring interaction with her infant. And this is what we find interesting, fathers are affected by PTSD but they show a delayed onset of their symptoms, sometimes four to six months later. Obviously, at the Preeclampsia Foundation, we have collected thousands and thousands of stories from thousands of women. It's not a stretch for me to say that suffering a loss during what is supposed to be one of life's most joyful, life-affirming events is especially emotionally devastating. It's that juxtaposition that makes this so hard to deal with. Here's just one example of a survivor, who said, "I suffered with anxiety and stress for nine months after my son was born. I didn't get any medical help until I was taken to the ER from work due to an anxiety attack." She thought she was having a stroke.

So I wanna tell you a story about Tia, one of our moms from Miami, who suffered from sudden and extreme health syndrome. She spent three months in the ICU, fighting for her life. And despite her not-quite-complete physical recovery, she is just now coming to terms with the mental health impact of that experience. I'm gonna play a short video, where we can hear from her in her own words as she talks about her feelings.

Tia: Preeclampsia was definitely one of those things that kind of snuck up and just changed my life. It really just took a toll on me. You know, emotionally, my thoughts were all over the place. I kind of went through my entire pregnancy with no symptoms, and so, I think that was the part that baffled me the most. I think that that, combined with just the stress of rebuilding my life all over again, just caused me to go into a depression. And I had, you know, anxiety just from the nightmare from the hospital, and I remember being with the [inaudible 00:38:34]. And with the [inaudible 00:38:35] you have all of these pieces, and if you move the wrong way, or if you shift this way or that way and it comes apart, you're almost suffocating. So, it was difficult because I would dream that. You know, I would wake up thinking I was in the hospital and I can't breathe or, you know. It was those kind of flashbacks that, you know, just trigger anxiety attacks. And that went on for months. My outlook on life has changed, you know. And being a part of the Preeclampsia Foundation has definitely helped to relieve me a lot of the blaming and the depression that came along with my situation, because then I was able to see that I wasn't the only one who...you know, an illness that you never hear of, and then all of a sudden, you see thousands and thousands of people who have experienced it makes a

difference, because now you don't feel alone.

Eleni: So, I hope that illustration just helped bring it home, why this can be so impactful for women who have gone through this. You know, you see a scene like this, and I realize that most of us on the call are not doctors or nurses, but I think the important thing to realize is that for most women having a baby, this is their first exposure to a serious medical complication. Not just having a baby, having a baby with a complicated pregnancy like this. And to doctors and nurses, this kind of a scene may look like a very normal-faced, controlled birth environment, but this is what it feels like to us. And so, with that, I would just sort of emphasize that, even with the literature review that we've done, findings, you know, they're somewhat mixed, but generally they really point to a positive association between anxiety, depression, post-traumatic stress symptoms and a previous history of preeclampsia health syndrome. So, women who had a birth trauma may need a referral.

And there are other ways that you could help women or think about giving them some support that are listed here, including connecting them with a chaplain or spiritual leader, local support groups peer support is a big piece. You know, one of the things we hear over and over again is that the women who can most help you are the ones who have been through this exact experience. And in that way, whether it's organizations like the Preeclampsia Foundation or some of the Facebook support groups, etc., we find a lot of peer-to-peer support. The Patient, Family and Staff Support Bundle that's put out by the Council on Patient Safety in Women's Health Care also has some resources there. I think some of the most important things, though, that you all Healthy Start caseworkers can do, is really affirming her feelings. She's gonna feel failure, anger, guilt, depression, anxiety. All of those are normal. Just because they're normal doesn't mean she just has to tough it out, though. We definitely wanna get her some help.

So with that, I'm gonna close my prepared comments and just encourage you all to check our preeclampsia.org. It is a trusted resource for your women, for your moms, because we do have an awesome medical advisory board. We have social media, a very robust social media presence, a community forum, all of which can be very supportive for women who go through preeclampsia, as well as the patient education materials that I commented on earlier in the presentation. The last thing I wanna comment on is, preeclampsiaregistry.org is the research asset that we operate and make the data from it available de-identified. So privacy is maintained, but that data is made available to

researchers, many of whom are already actively using it. And I mention this not just because we wanna encourage preeclampsia research, but one of the things that we've learned is, for women who have gone through particularly severe preeclampsia, feeling like you can turn your story and your experience into meaningful, useful information for researchers is very healing for women. And to the extent that they can go to preeclampsiaregistry.org, enroll themselves, know that their information is kept confidential, de-identified when we share it out is, like I said, it's the healing process for the women themselves, not to mention how much it does advance preeclampsia research. So with that, I will slow down, because I know I flew through a lot of material in a very quick 45 minutes here. And I think we have time for questions, and anything...

Megan: We do, we do.

Eleni: Great.

Megan: Oh, thank you so much, Eleni, for that moving presentation and those really powerful stories you shared. We have some really good questions in the chat box already. And I just wanna let everybody know that we have about 15 minutes left for Q&A with Eleni, so if you do have questions, chat them into the chat box in the lower-left corner of your screen. So, the first question here is, do you feel preeclampsia is over-diagnosed or misdiagnosed, sort of in the way of a doctor not looking at the whole picture, and just checking off symptoms and then saying, "Yeah, that's what it is?"

Eleni: Well, of course, misdiagnosis can work both ways, right? So, it can be over-diagnosed, and the downside to that is babies might be delivered sooner than they need to be, or inductions might be happening when, perhaps, they don't need to be. You know, that kind of unhelpful early delivery is something that we are hoping, and what we're aiming for with a lot of the biomarkers that are in development now is that we're gonna be able to rule out when preeclampsia is not present, so that we don't have to do early delivery on babies. That is definitely a work in progress and, as much as possible, we certainly don't wanna do that. Misdiagnosis on the other side of the spectrum though, in some ways, is more dangerous. Missing a diagnosis means that babies can die or have severe problems because of not getting the nutrition they need in utero. And of course, as we talked about in this presentation, bad outcomes for the mom, worse of course being maternal death, but even some of the morbidity that could have been alleviated by delivering the

baby at an earlier time. It's probably one of the areas that the most head-scratching happens around, because it is not an exact process at this point. We do need a much more specific way to diagnose preeclampsia, so that we don't have unnecessary pre-term births.

Megan: Great. Okay, another question. So, what about breastfeeding in preeclampsia? This person often sees mothers that didn't breastfeed because their doctor doesn't have up-to-date information on medication in breastfeeding, and they don't put the importance of how breastfeeding could possibly help with some of the issues of preeclampsia.

Eleni: So yeah, big hot button for me. It is very important that we do everything we can to support our moms breastfeeding. Not just for all the usual reasons but, in addition, the fact that the babies born of preeclampsic pregnancy actually start off life in kind of a more negative or compromised position. And so, probably even more so than for healthy babies, breastfeeding is gonna be super important for them. Wherever possible, you know, there are certain drugs that she may be on, like magnesium sulfate or certain anti-hypertensives that may mean that that first milk has to be pumped and dumped, and we hate that. But it's better to do that and keep her breastfeeding mechanisms working, so that as soon as able, she can start breastfeeding that baby. Having said that, and this is a big one, in some women, their condition is so dire, right? A mom in ICU fighting for her life is probably not gonna be able to breastfeed. And you know, everything is probably gonna dry up and she's gonna come out of that with another layer of guilt, because she wanted to breastfeed and now she can't. So, we need to be sensitive to that, we need to be sensitive to not layering more guilt than she's already gonna layer on herself. But to your point, if the obstacle is bad information on the part of the health care providers, I would say trying to work with lactation experts or others. I know that's one of the things we try to do, is make sure that there is greater awareness that breastfeeding absolutely can and should happen as much as possible, especially because these babies are more compromised and need the added support of breast milk.

Megan: Great, okay. So, an important part of Healthy Start is focused on the inter-conception phase, so how can Healthy Start programs or those working with moms during the interconception phase, how can they advise them and work with them if they've had preeclampsia before?

Eleni: Good question. One of the things that, you know, if you think back to that slide of some of the risks factors that we talked about and, I don't

know, let me see if I can go back to it super quickly. But I think one of the messages, and interconception care is a huge thing, it's a huge opportunity. And the opportunity is to be able to say to women, "You can actually reduce your risk for getting preeclampsia next time by looking at any of these that are modifiable risk factors and trying to do something about them." So, going into that next pregnancy healthier than you went into the first pregnancy. Things like getting any kind of underlying conditions under control, which might mean figuring out if you have underlying conditions, like some of these autoimmune disorders. The other piece, of course, is reducing weight if obesity is an issue, getting diabetes under control, getting hypertension under control. Any of those things that can be sort of mitigated moving into a second pregnancy are gonna reduce your risk for getting it the second time. Woman, even if they do nothing, the chances of getting it a second time are lower. But anything you can do to help that is a good thing, and I think that's part of interconception care and where you all can play a role.

Megan: Great. And this is the last question I have in the chat box. So, folks there, we still have a little time if you do have any questions you'd like to ask. So, of the materials that you've posted on preeclampsia.org, that have been posted, I know you mentioned that they were available in other languages. Can you speak to some of the other languages or the materials that are available, and what they are available in?

Eleni: Certainly. So, I just pulled that slide back up again. The CarePad that you see on the far left, which is the piece that we really recommend you use on a regular basis during all prenatal visits, is available in English, Spanish, French and Creole. The poster, that's the middle item that you see on your screen now, is available in English and Spanish. And by the way, one of the things that I'll just point out to you is, while most of that information mirrors what we had in the CarePads, you see that one box that says, "Routine Tests During pregnancy?" That was actually requested by a lot of the health care providers who said, "You know, it would really help us to explain to women why these routine tests are being done." And so that's added there, as well as an opportunity to localize. That blank, white box in the lower-right. So, let's say you have one of these up in a public health department or another center, that's where you might put in, you know, "If you experience any of these symptoms, call the nurse hotline," and put in the number, or those kinds of localized information can be included there.

And then, "The Seven Symptoms Every Pregnant Woman Should Know." That video, if you go to YouTube and just type in, "Seven

symptoms every pregnant woman should know," you will find in English and in Spanish. And it's available if you wanna just show it to them, just pull it up on YouTube and watch it in real time. If you wanna take the code for it and embed it in a website that you're operating, those are some different things that you can do with that video.

Megan: Great. Thank you for those resources. We have two more questions that came in. The first one is, many women think preeclampsia is just high blood pressure. How can we, as Healthy Start care coordinators, explain in clear and simple terms what preeclampsia is, what it can affect and why they may have problems in the future? What is the easiest way to explain what preeclampsia is?

Eleni: So, that's a great question. And I almost, you know, this is one of the things that if we were all together I would actually get a group discussion going on this. But here's one thing that I would suggest, because the myth that you're talking about, the, "Oh, it's just high blood pressure," I think actually works against us in terms of demonstrating the seriousness of this. Because in our society as a whole, high blood pressure has become so present everywhere and people just assume that, "I just need to pop my high blood pressure pills and everything's okay." They don't realize that, in pregnancy, high blood pressure and the levels that you reach, it's far more dangerous. And what I would say, let me answer your question more specifically, I would actually explain preeclampsia as a disease of the placenta. And I know placenta is not an everyday word, but if we help our women understand that the placenta is what links mom and baby, and when the placenta is sick it has an impact on the mom and it has an impact on the baby. In the mom, it causes her blood pressure to go up and it causes many of her organs to fail. In the baby, it can cause their growth to be restricted and for them possibly even to die before being born. So, if you think of it as a disease of the placenta and that things are not happening as they should be right there, and that because that sits at the intersection of mom and baby, it has an impact on mom and it has an impact on baby.

Megan: That was beautiful, and I liked the way you took any sort of shame and blame out of it. It seemed much more clear and descriptive. So I think, maybe, that's a good description for a resource, or a guide, or a script or something like that. That was great. So, one more question here and then we'll wrap up. So, this person heard you say, in one of your previous responses, that the chance of getting preeclampsia in the second pregnancy is lower. Can you give a little bit more detail about why it is lower in the second or subsequent pregnancies?

Eleni: So I will, although here's my little caveat. One of the things that you hear about preeclampsia is it's often called the disease of theory. And the reason it's called that is because there's a lot of research happening right now around preeclampsia to understand what even causes it. We don't really have a firm grasp on what causes it. So, one of the theories is that it is an inflammatory response, and there's almost like an immunological thing that happens, right? And so, what that means is, the mom's body is rejecting this baby as a foreign object. In normal pregnancy, right...so, that's how our bodies are designed to operate, is that we wanna reject foreign objects, we wanna reject disease and cells that shouldn't be forming. And in pregnancy, that response is suppressed. So one theory is that, in preeclampsia, those women's bodies aren't doing a good job of suppressing that immune response, and so she's kind of having a reaction, if you will, to the baby. So, why does that matter in terms of second pregnancies? Because she's been exposed to a father's DNA, and in a second pregnancy she's been exposed to it more often. And so, she's developed a resistance, if you will, to it being a "foreign body." So, that's one theory why second pregnancies don't see as much preeclampsia, and another reason why people will say, "If you have a second pregnancy with a new partner, you actually zero out your risk and it's just like having it in a first pregnancy."

Megan: Great. Well, thank you so much again, Eleni, for all of this great information. I would love to give you a chance to provide any closing remarks, and then I'll wrap things up with a quick reminder to everybody about upcoming webinars. And I did wanna let you know that that one person did chat in, another person chatted in and said they did really appreciate your simple explanation of preeclampsia. And so, we can follow-up among the Healthy Start group world, and talk about how we can maybe get that description you provided out a bit more, and circulate that a bit more.

Eleni: Absolutely.

Megan: So, do you have any closing remarks?

Eleni: No. I just really wanna thank you for the opportunity to communicate with this group. This is increasingly an area of interest for us, is to help get this information out to women who may have less access to care or just, you know, lower socioeconomic-level women, etc. And I think Healthy Start is a great conduit to that, especially

because so many of you have one-on-one connections with the moms that we're targeting. So, I would also say, feed back information to us if you have ideas about how to more effectively do patient education to a very diverse population. Thank you. Most especially, I just wanna thank you for the opportunity to do this. And you know, we're a non-profit organization seeking to make this better for all moms and babies, and we love partnering with organizations like yours.

Megan: Well, thank you again for all of your expertise and wisdom on this topic. And folks, again, this recording and transcript and slides will be available on the healthystartepic.org website following this. I did just wanna let you know that we have a few webinars coming up in December and in January, mostly centered around the implementation and roll-out of the screening tools. And the easiest way to get information on that is to go to the healthystartepic.org training tab and click on the training calendar, and you can see and read more about the upcoming webinars available. So again, thank you to you, Eleni, for sharing your expertise with us and thank you to you all for participating in the webinar today. Go check out preeclampsia.org for a lot of those wonderful resources that Eleni talked about and shared. And we will work on getting some of this great sort of simple descriptions of preeclampsia out and circulated among the Healthy Start community. Thanks again to everybody for participating. This concludes the webinar for today.