>> Okay, check, check. So we're going to get started. I appreciate and recognize that this is the last session of the day, that we're all exhausted, and that we're standing between you and perhaps a beverage or dinner, or drinks. So we're going to have a little fun in the last 30 minutes and thank you, first of all, for being here. My name is Marianna Raia. I'm the assistant director of organization called exec expecting health. And I'm excited to be joined by Michelle in our session. And we're going to learn about the leadership program. This program is one of my faith things I get to work on. So little bit of context, my background is as a trained genetic counselor. And I've been working with families for a long time in a variety of different ways. But what we've been able to do together through this navigate newborn screening family leadership program has been one of the highlights work with the families I've had. On both of Michelle and I and on number of families who participated in this program already and some that are here today that are currently in the program, we just want to thank you for being a part of it.

What am I doing wrong? Awesome. So as I mentioned, the newborn screening family education program is the program that this work has been completed under. And we are a HRSA funded program. So this program is currently in its last year of five years and we've been very fortunate through this funding to be able to facilitate the Ambassador program starting last year and we're in our second year of the program right now. Or second year of the Ambassador program right now. So I want to do start with the why. It's really easy to talk about what we did, how we did it, and it's also very easy to skip over why a family leadership-training program like this is important. And I appreciate and recognize that many of you in the room have probably been through family leadership programs, have participated in them. So you're already aware of why it's important. But specifically, when we think about the newborn screening program, one of the things I picked up on pretty quickly was how siloed and how individual different aspects of newborn screenings are. It's such a complex system. And I know this room knows very well, particularly, in EHDI, that's very siloed from other parts of newborn screening. And so one of the things we're trying to accomplish through this leadership program is to train families to be part of the newborn screening system in all aspects of the newborn screening system. So I invite you to look at the questions you see on the screen. These are all questions we hear on a regular basis. And you probably hear them as well. How can we improve communication across newborn screening within the newborn screening system? How do we coordinate efforts across the system? How do we get different groups more involved? How do we educate the general public? How do we make more people aware of what newborn screening is and why it's so important? And if we're really honest with ourselves, we probably never truly answered those questions, because families haven't always been integrated and involved in the discussions. And so this program we set out to identify and work with family leaders, and help train them to get involved in those conversations.

So what are we going to cover quickly in these 30 minutes? First we're going to share little bit and build your knowledge about, again, this specific program, what we d how we did it. And then we're going to learn and hear specifically from Michelle who participated as an Ambassador in the first year of this program. And then last we're going to leave you with some action. How can you continue to support this program and get involved yourself? So we'll start with what is the navigate your newborn screening Ambassador program. It's really a network of family leaders representing diverse perspective and family experiences in newborn screening. And I really want to stress the point of diversity. It has been extremely important to us to identify family from every aspect of diversity that we can think of.

So not just race and ethnicity, but also really thinking about different conditions that these family leaders represent. Different parts of the country. We do have some states where you've had more than one Ambassador participate. So we're trying to think about are some from more rural communities? Are some from larger communities and really trying to be intentional about the different types of family leaders involved in this program and the benefit that diversity brings to the group. Basically, it is a yearlong program. And again, we recruited for our first year in 2021 to 2022 and we're currently in our second year of having a group of ambassadors. And, really, it's a mixture of online and live training sessions. So as a group, we meet quarterly for a live discussion. And prior to that meeting, each quarter, we have a designated online training program that ambassadors can access at their own convenience.

So I'll cover the topic we typically focus in on in terms of our training. But really, the idea is to combine self-learning with a group collaborative. And then in addition to that, we have couple of other activities in ways that we connect and provide opportunities to further their leadership development. So in the map that you see here on the screen, this just highlights the states where we've had ambassadors participate in either of these. And you can see we're trying to grow and expand the Ambassador group that we have and the network we have. So what do they do? They go through this training program. What does that training program actually training them to do? It's really centered around three main pillars. And the first and what has ultimately kind of come to be, one of the best parts of this program is to connect. And we really think about that in couple of different ways. First of all, it's to connect with each other, to connect with other families, and I don't want to steal any surprises from Michelle, but I think one of the things we heard from a lot of our ambassadors is that it's been incredibly beneficial to connect with family who are outside of the communities they're already a part of. So newborn screening may be the common theme, or the common thread, but families that are participating will say, I know so much about the condition that my child has, or the condition group that I'm a part of. But I didn't know anything else about these other conditions. And it's amazing to see how similar we all are. So first, it's to connect with each other. But it's also to connect these family leaders through this program to other components and other stakeholders within the newborn screening system.

So what does that look like? Maybe it's meeting some of our federal partners. Maybe it's attending some of these meetings. Maybe it's joining us for webinars. We do a lot of student training programs where we connect students with our ambassadors. So it's really thinking about, again, how do we intentionally involve family leaders throughout the newborn screening system? A major part of this training is to build knowledge and experience and we've done that through some structure training and through online and discussion groups offer that. But again, some of it is just experience and connecting with others in the group to continue to build the knowledge of what, when we say this complex newborn screening system, what does that really mean? And what are the parts as an individual of this group that I may not have touched already? And last, but certainly not least in what we're aiming towards is to raise confidence so that the individuals that complete this program will go off on their own and find additional ways to continue leading within that newborn screening system. And, ultimating, to drive important change for improvement of newborn screening. So what are the specific topics we provide more structure on? And we do this intentionally in a series to just allow some time for each of these topics to really sink in. But first is connecting with others. While that may sound sort of obvious. And it certainly happens organically. There are some strategies that through this training we share with individuals that are a part of this group. And just specific ways to really be thoughtful about the connections that you're making, and also to set goals.

So one of the things that from the first group we learned and we've implemented for this year, we had a training workbook that accompanied these online training. But we actually built that out little bit more for the group this year, and in addition to support the online training, we also created opportunities where we allowed the ambassadors to reflect and set some goals.

So really thinking about who are the groups, who are the individuals within my communities, whether that's locally, at the state, or national level that I like to connect with, and how do I wanted to that? We also have a module or training on quality improvement. When we first started the question of do families want to learn about quality improvement? We were kind of like, mmm, I'm not sure we need to learn about this. But after going through that training, it became very, very clear that families need to be part and involved from start to finish of quality improvement projects to be part of newborn screening. So to be part of that was helpful to be part of that process. So we've had great discussions and conversations, and, again, that challenge of how do you want to get involved in quality and improvement and communities you're already a part of and taking that knowledge back and bringing it there.

And then we also had a number of additional conversations and trainings around story sharing, and storytelling. And, again, while that may feel natural to many of us, there are strategies to help improve that process. And so one of the things that we did was to offer a live training where we brought in a panel of speakers, each of which represented a different stakeholder group within the newborn screening system. So we had someone from policy and legislation, we had someone from advocacy, we had someone from the healthcare provider and research perspective, and we also worked with some of our federal partners to share with our ambassadors when you're sharing your story with our groups, what really resonates? What helps convey the message you're trying to convey?

And then we wrapped up with training on newborn screening resources. And, really, as ambassadors of this program, but more importantly of newborn screening, what does it look like to share those resources and how do we make sure we're all participating in that? Now, I'll go through this quickly and I'll preface I have couple of data slides and I won't go in-depth today. That is available if anybody is interested in more information on the data, but what I want to highlight is that a high-level, again, we wanted to do was this program successful? And what does it look like for this program to be successful? And so we did do some assessments at the beginning and end of the overall program. And we also did some individual assessments with each of the trainings. And one of the most interesting findings, I think, we expected or anticipated that people coming into this program would start out really confident about newborn screening. And with the high-level of sort of knowledge. And we were a bit surprised to see that when we asked, most people said, yeah, I don't feel like I know whole lot about the newborn screening system. And by the end of their program, we saw a huge shift in that. And that confidence, and in that knowledge. So we were really excited to see that, of course. I know this is busy but simply to point out we asked targeted and simple questions around how do you feel? How confident do you feel in your leadership skills, both before starting the program and at the end? And again, we saw that after completing this program, that confidence went up across all the questions that we asked. And similarly, because we spent time talking about the importance of sharing your story to different communities and places you can share your story, we asked again, do you feel more confident? Or do you feel confident to share your story in a variety of different places and and, again, we saw huge shift in confidence where people were more encouraged, more inclined, and more willing to share their story with different groups. So I'm going to play a short video. One of the most fun things we got to do and there were a lot of them. We did have the opportunity, it was bit unexpected and great opportunity to have some of the ambassadors meet together in person over the summer last summer. And the purpose of that meeting was really to film and record individual stories. And in addition to individual stories, we actually had some group round table discussions that were also filmed. And the output of that is the most amazing video series that this QR Code will take you to.

We're really through the experience of each family, you learn more, not only about the individual experiences, but what families think about the barriers and newborn screening and what families want to see for the future of newborn screening and the change that, including families in the process can bring. So it's a really incredible video series. It's available on our YouTube Channel, expecting health does have a YouTube channel along with many other resources there. And please, we encourage you all to share these videos. They were designed and meant to be shared as a resource. So I'm going to play one of the shorter ones. It's only a minute long just to give you a sense for what these videos can do. I hope the audio works. That's okay. Let me go back here. I'm going to skip this slide. Sorry about that. As you said earlier, there's always a technical glitch. Again, I'll just flash this QR Code. I apologize that didn't work. But if you're interested in seeing that video. If there are others, please feel free to check that out. With that, I'm going to turn it over to you, Michelle, who I mentioned earlier completed the program. Was one of our first ambassadors and she's going to share more about her experience.

>> MICHELLE JOHN: I swear the video worked in the presenter ready room. Sorry. So for me, this was interesting trial and learning about newborn screening. I, obviously, know it occurs. But when Marianna and I first spoke, I was, oh yes, and hearing test and I had the Deafblind son. Of course I know all about hearing. And then I met the first time with the group and went, oh, none of them know about hearing. And I don't know what they're talking about. So it was really interesting. And certainly, there were a lot of lessons learned from each other to each other. So we want to reflect real quick about what's been done so far. You need to meet families where they are. You need to discuss how are you collecting and sharing family stories? Where can you go to meet families that makes them feel comfortable to share these stories? It can be really hard when you feel like you don't belong. For me, when I first started with these sessions, I thought I don't belong here. All of these people have children with conditions, or this, or that. They don't know what I'm talking about. This is not for me. And, yet, there were others who felt the same way. There was one Ambassador who had a child who passed away. There was one who had this or that. And they just said, oh, I don't think I belong here. Once we all got together and we all said we don't feel like we belong there, it really made us realize what happened. Each of us in the beginning thought, oh, we don't belong here. Then we got to know each other. We got comfortable. We felt comfortable in those Zoom meetings, sharing being honest, and truthful and learning together. Which is why education in not one way. How can we include families in educational activities? And what training are we giving with the families? It's not to the families. It's "with." It relies on trusted relationships. That's "the" most important thing I learned during this Ambassador program. If I hadn't trusted Marianna or Tuyan who, I felt safe with them and I can certainly speak for other ambassadors they did as well so, when I meet a new Ambassador in the current cohort, I wasn't uncomfortable with them, even though I didn't know them. Because I knew these people have been vetted. And I felt safe enough to say, yeah, I can have this very open honest conversation about my newborn screening story. And take theirs in as well and hold it appropriately.

So we really need to think about what opportunities are being created for families to lead program improvements. Much as Marianna alluded to, most of us were wondering why in the world are you making us learn about quality improvement? And, yet, it's so important. If we don't understand what that looks like, what is that process? Then we can't help facilitate change. We can't sit at the table and not understand it. Otherwise, we're looked at as unimportant and the opinions just don't matter.

Finally, we wondered what can you do? "You" being all of you, all of us, everywhere. Sharing family stories is critically important. Yes, data is also critically important. But they don't need to be separate entities. You need both. So we need to share family stories and allow those stories to change the program. Do not just nod your head and smile and do nothing with it. It's critically important that you acknowledge family voices and allow them to be heard.

Ask questions and then listen. Go to where families are having discussions. Invite yourselves. Inquire if you can be invited to support groups, coalitions, committees, to really hear what people are saying. If you only go to those who are going to have the same opinion as you, things will never change. It's important that you hear from a variety of stakeholders. Lastly, you should build capacity. Utilize your existing resources, toolkits, and frameworks to help you. You don't always have to reinvent the wheel. You can use others. Many, many people will share resources. That's a little secret for you. [Laughter] That everyone wants best practices, best information to go out. It's the only way to create change. You don't have to start everything from scratch. Lastly, this is a really helpful resource. It's to navigate newborn screening. It's a toolkit. Feel free to scan the QR Code and it will give you lots of great information. And thank you very much. If there are questions or comments, we're happy to take some or I can slide back if you want to go back. Yep, go back. There you are. [Laughter] So I can bring the mic out to the audience if that would be helpful. If not, thank you.

(Applauds) Yeah, go for it.

>> MARIANNA RAIA: I was going to take a moment to elaborate on the toolkit a bit more. This toolkit actually includes all of the resources, most of the resources that have been developed through the newborn screening family education program. So this leadership training is one specific thing that we've done. But there are number of other resources to support awareness building, education, and knowledge building, and family leadership training. And so we have various different free online modules that any family can take to learn more about the newborn screening system. You don't have to be part of the Ambassador program to access that.

It teaches you, it's a 5 part series that teaches you not just about what newborn screening is, the parts to newborn screening, and why it's important, but it also walks through the role of the Federal Government and newborn screening, the role of states and newborn screening. And so it's a really great course for families that may want to learn more about that. It's great for individuals learning for newborn screening. If you're a volunteer role or learning you this things for that role, it's great there. We also have video education for newborn screening, different aspects of that process. And so all of that is available through this toolkit. And if there's something you like to see that you don't see there, my contact information and Michelle's as well, we can share that again. Please reach out. We definitely partner with a lot of different individuals and organizations. Many of which are families. And so we don't have any of these resources without input from families. And we're always open to collaborating further. Happy to answer any questions? Okay, sounds good. Thank you. Thank you for attending. Go have a great evening. Safe travels, if anybody is leaving from here.

(End of presentation).