>> Good afternoon everyone I am Lauren the moderator for today's session and I'm also a student on the EHDI committee so if you have any questions about today's conference reach out to me and I will be sitting in the back of the room and can help answer any questions about the conference or direct you to the right person.

I would like to go ahead and introduce our current session, Breaking Silos, Building Systems: Creating collaboration around congenital cytomegalovirus and newborn screening.

>> NATASHA BONHOMME: Thank you for joining the session today I know it has been a long day, I appreciate you hanging in there as we get through this I am Natasha Bonhomme director of Expecting Health to talk about a workgroup we created Your heap hearing people talk about a topic in one areaand others talking about that same topic another area and we thought it would be great to come together and talk to each other and see how that works.

If you are not familiar with Expecting Health we are an organization that focuses on maternal and child health experience and for us we see what we want to do is replacing the fear and confusion that many people face when they are planning their families and going through prenatal experience or even in those early childhood years to replace that fear and fusion with confidence and agency to be able to make the best decisions for themselves and their families.

We have three main approaches, one is bridging science-based information with real-life strategies, often we see people who say, here is a report that says how we should do things, a new strategy, but we sometimes say, have these people even talk to real family know what they are going through? we focus on making sure and scientific information is really relevant to real everyday challenges that families face.

We also see ourselves contribute into a culture of change around how people are engaging in healthcare systems, promoting the idea of a continuum of care so not just focused on one slice, not just focused on testing or screening or identification but what does the care look like and what are those health outcomes for families?

And lastly we look for opportunities to provide people with chances to connect with each other and build skills. We had a session going two sessions ago, two of my colleagues, Molly Markski and Marianna Reah spoke about our programming that looks at family engagement and giving opportunities for people to build skills.

Let's talk about Connect and Connect stands for – I don't remember – I should note, let's go here, it is a on newborn screening and congenital cytomegalovirus so it is really about bringing together those experts in both fields in terms of newborn screening as well as another condition in this case it is cCMV.

In March of last year our team launched this collaborative workgroup to bring together those experts, as I said, at the beginning we really had a number of people who were calling, the state lab professionals calling and saying have you heard of people want us to start screening for CMV what do you do we can do that we have parents and parent leaders calling us and saying, you know about newborn screening how do we screen for cCMV and I was in the middle and I said,I don't know how but I know the best way is always through collaboration and how do we break those silos, that was key to work. So when we launched the workgroup, those were some of our principles. We said it is okay to talk about your challenges and your concerns, but we really were therefore solutions and to come together and move in that direction so always coming to that connecting, sharing and most importantly building toward solutions.

The structure is virtual meetings using zoom an hour and a half long it is a presentation followed by structured discussion almost like a strategy session, webinars out there and sometimes you see a presentation and have enough time for one or two questions and then you leave and you get backto your day-to-day. we wanted an opportunity for people to see, you presented this data how did you get that data? and I don't want to say a challenge, because that has such a negative sense to anybody really to say, you are able to do that in my state, this is what it looks like, what are your approaches for making my what you think I can do? Having that hour and a half made that feasible, it may seem like a little thing but I think that gave time for some uncomfortable silences, sometimes you need so people can come together and be a bit more solution oriented.

Our work group members are varied, I would say this is a key printable in the work we do at Expecting Health. You will vary, it is unlikely for you to have a committee or workgroup that is only parents, or only lab professionals or only follow-up, we want people to be able to work with each other and be multidisciplinary but also multi-experiential, if that is a word. We have parents, we have state lab as well as follow-up and I think it is important to separate those out especially in a conversation around CMV. We have CMV and EHDI programs and also industry programs and professional organizations, advocacy organizations and researchers so it is a lot of different types of people with different experiences with different opinions about what she we should be doing with newborn screening and cCMV and that was really intentionally wanted to get it all out there so people can hear the opportunities as well as challenges and come together to solve for that.

Our first meeting, to recap, I should have said this before, this would not of been possible without our collaboration and the conversations we had with members of the national CMV foundation we went to them first and said, we are thinking about a workable are you already doing that tomorrow is this something we can be supportive to you? and a great conversation which I really appreciated they said, that sounds great you should do that and we are happy to help and support that in any way and again having that collaboration from the very beginning.

Our first session we had them present and talk about the patient experience and the family experience and really I want to add to that because sometimes I don't think people in this room but sometimes people think, just a family story. They really shared the landscape of cCMV and what screening looks like and what they saw the future and I think that really helped set the tone for the workgroup moving forward, it was not just based on the challenges this brings but you say, this is what we are seeing from our appearances parents and parent leaders in this is why we are so committed to this. I think that really helped all the other groups who were in the virtual room say, this is not just about adding a test or just but how are we going to screen for this but in this is what families are experiencing and how can I contribute that?

If there is one take away from this I would take them always think when you're pawing together people, what you want that anchoring story to be? what is at first piece when you're building relationships and for us it is always a families.

We had participants have a conversation about what does a successful collaboration look like? And what do they want the results to be? A lot of that teambuilding amongst people, some thought they would get on the call and we were going to talk about this and that and they said no, we are starting here, what does success look like from us coming together?

Our second meeting we went into a bit more detail and we highlighted two screening programs, first, we had Utah present which was really helpful to see, what does this look like in real life, let's learn from each other and really see not just imagining what screening could be but where are we at today and what does this look like?

We also had Minnesota present and I really appreciate that because they came they had more questions than answers and I said exactly, that is what I want this group to hear that we have this law and you as a state program are not trying to say no but what you're really saying is how do we do this, how do we do it well and be inclusive? I just really appreciate that because I know it was a little bit scary for them to do.

As part of that we had a number of different questions that came up and that helped to lead our discussion for that meeting. Mainly around what support and resources do state programs need as they begin planning implementation?

We really emphasize the planning part, many people may get a law they feel we have to do this, but I took the role of challenging that a little bit and say we have been talking about CMV for some time and this is coming, and that is when you start planning and really seeing what would be necessary for that. We had that from the lab perspective what would be helpful, as well as funding and training, not just for lab but for pediatricians and others who are part of the system and I think this was one place where it really became clear for our CMV partners to hear what the concerns were of those states in terms of, I don't know where to go for guidelines, do guidelines exist? Should we be creating those – what does it look like and really feeding into that peeling back those layers and see whether the true concerns so we can get to the true solutions.

Is a number of discussions about tapping into already existing programs such as APHL is a disorders workgroup and would they be the right place to go to create some of these implementation toolkits, making sure people are not just reinventing the wheel We also had, it was not necessarily that this group would solve that by listing out all the questions and really look to our partner organizations to see where is the best place for those solutions to come from?

Really a discussion about, what does it look like when you are encountering that resistance from public health labs about cCMV and around testing for that? Should it be added to the rescue I will say, we are looking yet another meeting of this group and this will be a topic that comes up again and having the conversation about one of the key barriers that state programs had or still have, is the amount of blood that is needed and what does that mean? It was something that had never been verbalized outside of people who work in labs so that gave the group a bit more to think about in terms of, what do the mechanics of this look like? What should we be looking at a testing? What should we go back to Utah and Minnesota to say, how are you doing that?

Another place that we had a lot of discussion was the need for more data and information and how to be able to share that data. And what does that collaboration look like for data when we are talking about both blood spot program and hearing screening program? Is there something that would be helpful in terms of guidelines around that even just data sharing and we know, as was mentioned in a meeting we had earlier this morning that some states are very easy to share data between those two entities, not even two separate entities they are people sit right next to each other. And others, not really possible. Laying that out and seeing what can we be encouraging so even at the data level there is that ability to share and learn from each other.

What does the future look like? There's a lot we can do, so we are looking at different ways to continue supporting this project. I will maybe shamelessly admit it was an idea and how is it funded? And I said we are just doing it because it is really important and so, to be a bit more responsible we have a great conversation about support to be able to continue those conversations. Some of the items that came up was people really wanted a shared place where they could share information and data, share slide with each other that was open enough for people in the group to share but maybe not completely public. As you know people are still figuring out how they will approach screening for cCMV at the state level. There was a discussion of meeting more frequently to be able to build out action items and establish subgroups, I think that was one I really thought, let's pause a moment and see how we will really structure this and be able to make a positive impact we want to. And to create a space where people could catch up and talk to each other so not even just resource sharing platform but even maybe a slack channel they were able to have that to speak to each other as they are building out their screening programs.

For us it was really clear that this model of bringing people together, because that is how we will meet the solutions it is very easy and can be very tempting to stay in our meetings or stay in our silos and say, can you believe what that groups think we can do or can you believe that group is that doing X, Y, or Z but we do get much further when we come together.

Future meetings will be highlighting workaround protocols as well as education and what might be ready to scale right now and what else still needs to be built out.

I am going to switch gears a little bit because this is one thing, when we were pulling together work of a number of partners said, why are you doing this! You education, why are you bringing these people together to talk and we really see education as one slice of that work, we are bringing people together to find solutions and there are many different outputs for that one of which is education. I highlight one of our programs, newborn screening education program that was discussed in another session a little while ago, of all the different places that we see, you can't really get to this point if you don't have clear communication and partnership with all those other stakeholders that are listed on one of those earlier slides. This is not just set-aside but the culture of collaborating in the culture of sharing those experiences and having people understand the family story as well as the challenges of a lab as well as the opportunities and follow-up really bleeds through into this type of work as well.

And so, lastly as I wrap up I wanted to highlight some of the stats from the work we've done on education and we go from this example conversation around CMV and how challenging it will be and nobody will understand it, we often hear from our lab and program partners that concerns that parents will be overwhelmed and is going to be too much. Based off the work we have been able to do with the right education and time, parents don't necessarily feel overwhelmed from the information but can learn it and see how it can increase their awareness, knowledge and I think most importantly, confidence, to be able to advocate and be part of the newborn screening program.

I think the newborn screen part of this, it can be your healthcare system or anything, if families are given a chance to engage and learn and ask questions.

I believe this is truly my last slide – in terms of what we have seen when we are able to incorporate families from the beginning, even the pre-beginning, which for some states they feel that is where we are with cCMV, it is being able to increase that awareness and education and opportunities to do so. There is an opportunity for bidirectional conversations and if you really see that the success needs to be built in earlier when you are thinking of adding a new condition or building out a new program.

We know that there is real strength in having both organizational and individual partnerships. Sometimes you say I just want one parent on this committee and we will have that parent voice and you say, that is an approach but another approach is having multiple, that wasn't diplomatic? What about multiple parent and family approaches, what about organizations that work on that what about a mixture? There is not just one family story or just one advocacy story. What does it look like to incorporate all that?

Lastly, because we do education or, the opportunities to have innovated online and strategies. I think this is more relevant now than ever, as we are in an age of AI and cease of the region and you don't know if a chat but wrote it or person or who knows – that is not necessarily a bad thing but one really does not replace the other away really need the human touch as well as as much help as we possibly can because we know resources are limited.

With that I will stop and say thank you so much for joining and if there are any questions I am happy to hear them.

I know it is late in the day.

>> When I was – I did not catch all of the different collaborators, but I was wondering, or the state project, one of the collaborators has been around there for –

These are the members of the workgroup, each state has a deaf blind project as well so I was wanting to know, am I in a state that is not? I just wanted to know or why information

>> NATASHA BONHOMME: It is still open so we work with whoever was interested and who heard about but it is not limited to states that are highlighted so I'm happy to have you or somebody joint letter – we would love this to be all the same color and have somebody from each state or territory.

>> A question on that – are you thinking for each state to join workgroup you arty have or starting a workgroup in some of the other states?

>> NATASHA BONHOMME: If states wanted to join our workgroup that would be great, at least as a starting off point and to be able to take at work and especially those partnerships and learning from each other and applying that at the state, but we know again states are at different points in this journey, Minnesota where they are today is probably very different from where they were at the end of last year so really this is meant to be an opportunity for people to hear from each other and see what has already been built and apply that to their state level.

Many people are there so you are not alone.

>> We've been doing this work in Ohio, in a different way, not with workgroup but it would be great to collaborate in my question for you, there are different ways into the system, there is the legislation, Department of Health, we have worked with our Department of Health instead of the legislation because we were kind of told that is a better way to do it although it is far from easy there as well. Does your group, are you able to support those different ways in to get this for different states? Are there people working with different systems in that group tomorrow

>> NATASHA BONHOMME: I work, I will highlight what those opportunities are but not necessarily endorsing one or the other, I may have a side conversation and say, so-and-so has had really good success doing this, and that approach, and are likely than not at that specific level I would say, have you spoken to someone at the national CMV foundation or one of the other partners, for us it is not really getting into that nitty-gritty but to say, let's pull what is happening at a national level or across the nation and see if there is something that you can tap into, is there a methodology that say Minnesota has been able to create that would be helpful to at least be a watching off point. When we started with just realized even those conversations were not happening and how important it was for people to come together to hear what is already out there.

>> That was a great presentation and great you are bringing a group like this together with so many different and the folks and ideas, one of the nice things about when states go on their own is there is an opportunity to find out the benefits of screening outweigh the cost of it and what we would like is to be, easy for every state to follow through and there is funding so is the group thinking about how to collect data on how it is going at the state level so we can learn from these initiatives?

>> NATASHA BONHOMME: That was definitely some they came up in terms of how to really see, almost the difference between what we think could be happening and here is what we started to collect and here is how we are system lysing that approach and so there was conversation about that and how to share that even from a preliminary state, we know states so often, even if they do a great job collecting data that does not mean it is out of the open they are not writing papers and doing that, so even the modality of sharing information beyond just knowing who to call or knowing who to email to say, I think you have done something about this can you shared with me? That came up a number of times it was one of the main reasons they were saying, we should have a SharePoint or this or this infrastructure to share that kind of information.

Again, across different organizations and entities.

>> Thank you!