>> Good morning, everyone. all right, I think everyone is getting settled. I have been told by the moderator it is time to start. Good morning, everyone. Thank you for joining me this morning pick my name is Ursula Finland, I'm a research scientist at Nationwide Children's Hospital up the road in Columbus Ohio. I'm going to presenting this on behalf of my co-authors who are listed here. And for those of you who may not have seen previous iterations of this at other EHDI conferences, I wanted to clarify, we are going to talk about community collaborations, coaching too best outcomes. Coach is an acronym that we use in Ohio for the coalition of Ohio audiologist and children's hospitals and we are very lucky in the audience to have the first four founding mothers here with us, so I wanted to recognize [ INDISCERNIBLE ] because they started this whole process nine years ago. At this very conference, just in a different city, so I'm going to be talking about their progress with community collaboration and how we have all pitched in and Ohio to make inroads on our diagnostic process. For babies who are deaf and hard of hearing. I also wanted to start by recognizing all of the people who have worked on this particular project over the last year. We worked to revise our stay indoors too diagnostic testing protocol, and in January we had a call to action to the diagnostic centers, and over 20 audiologists just decided that at least one virtual call with us every single month to do the work. These people worked every single month to get this done. They came from facilities across Ohio, and without them, none of this would have happened. So today we're going to talk about implementing an ongoing monitoring and revision of a statewide evidence-based infant diagnostic evaluation protocol. We are also going to summarize key resources that diagnostic audiologist needed availability to diagnostic and management of hearing loss. Lastly we are going to talk about participatory partnerships with specifically your state EHDI program, and talk about how we can empower practitioners to improve the EHDI process.

So, for those of you who were at Doctor Bosco's talk yesterday morning, we all know that the EHDI pipeline of 136, and we all know that there are leaks along that pipeline and lost to diagnosis makes a huge impact on loss to follow-up. Although we been doing a really good job of increasing the number of babies we identify early who are deaf and hard of hearing over the past several decades, we still have a lot of loss to follow-up across the United States, in terms of the US, usually varies between 25 and 35 percent, but in each state actually ranges from 0 percent to 100 percent depending upon what state you are in. In Ohio, for the past several years, we've really stayed along that 20 to 25 percent lost to follow-up rate. Even though that is not out of the ordinary or kind of the average across the United States, we still wanted to improve it. There's a lot of reasons why kids don't have a follow-up after referral on a newborn hearing screening. Some of them never get referred to a diagnostic facility for testing, and even when they do sometimes the infant doesn't sleep for the appointment, sometimes they have middle ear disease that causes delays in diagnosis or treatment, and sometimes families don't come back for follow-up testing.

Sometimes they get, and what I call the EMT or PCP vortex where we send them to their ENT and they never get -- they never get referred back to us for a follow-up to make sure that transit hearing loss is resolved. We of course have lots of kids who have medical complexities that take a little bit more time to diagnose, and then we have some inefficient or insufficient audio logic protocols that happen, and this is the initial target that the COACH protocol try to look at nine years ago, because we all have all of these different tools in our toolbox to use to do diagnostic tests more efficiently but depending upon where you are in the resources you have, you may not be implementing an evidence-based practice. We have a lot of data to suggest using frequency specific ABR testing, and using click as a check for neuropathy is a very good way of approaching diagnoses and infants. Because really what we want to understand is what are the hearing levels across different pitches, and are those hearing levels going to be developmentally significant? So, as I said nine years ago, this whole thing got kicked off and you can see how many pieces of the puzzle had to happen. Only across the first four years of the process. There were a lot of meetings, a lot of stakeholders working together. There were a lot of entities that work together including the children's hospitals, the Ohio Department of health, and then we also looked to our state homes, professional homes in terms of the Ohio Academy of audiology [ INDISCERNIBLE ] to help us get stakeholders involved and make sure that we could inform an evidence-based practice. So in August of 2016, the Ohio -- the state of Ohio UN HS subcommittee proposed the protocol and then there were trainings that took place with NCHAM and [ INDISCERNIBLE ] children's supporting that training in June of 2018 so that was the start to finish process of trying to implement an evidence base protocol for our state, and what we found, after the implementation, that it did get difference.

What this graph shows is the reporting of click only ABR versus tone burst ABR starting in 2017 through 2019 and that red arrow there depicts when the trading happen for our state, so after the limitation of the protocol and the training that happens, for our state, and I should mention that people actually came from all over the country for that training. Other states got training as well on it. We saw a decrease in the number of infants who are having only click ABR completed as their diagnostic assessment and we had an increase in the number of infants who had frequency specific testing completed for their diagnostic assessment after failed a newborn hearing screening.

And what this translated to is that over time, the median age of diagnosis decreased, so it decreased over time by 15 days, and this is consistent with the study we completed at Nationwide Children's Hospital a little bit prior to this time period. So we went to the same process at children's and changed our assessment battery from prioritizing stick stability to the Sunoco and we found the exact same thing, we had last lost to follow-up and mean age of diagnosis decreased over time so there's two things here that it is showing you, this is sufficient way of diagnosing hearing loss.

So after that initial coach project, we didn't want too just stop there, because there's all sorts of things that we can think of that would help families and practitioners move children through the 136 process for affective EHDI, so after the coach protocol happened, we banded together as an audiology workgroup in 2022 provide COVID guidelines, and those were just guidelines to diagnostic centers to make sure that kids who were at the highest risk for hearing loss were prioritized for scheduling during that time period, But to also send the message that we were a service that needed to happen despite the shut down during the pandemic. Those guidelines became a EHDI promising practice from the AAP, and I'm very thankful to tell you that it COVID it did not have a significant impact on diagnosis in Ohio.

So the only thing we found in our data was there was a slight increase in the mean of age for babies born between January and April of 2020, but thereafter, our data look exactly the same as it had been the year before, and so, we are really excited that that worked out that way because we know that's not the case in every single state, that COVID did have a significant impact on screening and diagnosis of early intervention.

That in 2021, we provided some behavioral pediatric guidelines, because once babies grow out of that infant stage and they need to have assessment through behavioral testing, we were also finding that babies may have been missed or not diagnosed with late onset diagnosis efficiently so we put the information available to have practitioners know what things do we need to prioritize, how do we need to be flexible with infants or toddlers and older children, because they don't typically sit there and raise their hand every single time with very good reliability all day long. So after we completed that we knew that revising our coach protocol was on the docket because by this time JCI age 2019 had been released. We actually had a plan to do this earlier in this process, but with COVID happening, things get a little bit protracted, so we set out to revise our COACH protocol in 2022. The collaborative process included a call to action in January 20-2/2. We invited audiologists mall across the state and as I mentioned over 20 audiologists volunteered their time to have virtual meetings altogether and then they also had additional meetings as needed when we broke into sections. We did a literature review and protocol review from March through July. And it wasn't just about looking at JCI age and making sure we were consistent about it, there had been a lot of literature that had been released since 2016 when the original protocol was made and because it's 2022, there is even more literature from 2019 forward that we looked at to make sure that our protocol was within the evidence-based.

Based on the literature review, we broke out into different sections. Some people took OAE, some people to attempt an entrée, some took ABR, but overall through the end of the year from August through December, we had consensus building and the actual revision come together. So even though specific experts worked on different sections, we all came together to build consensus at the end of the year.

What we were able to produce is this revised protocol. All in all, it has 38 pages including tables, appendices with resources and citations. So it is lengthy, but it does provide a really specific way of how to approach her infant testing battery and also tips for what if this happens, how do you do this? When you know when to go and check for neuropathy? And also some counseling information.

'S other substantial changes from the 2016 version versus the 2022 version includes removal of a diagnostic removal option for testing, so the 2016 version allowed for practitioners to do click only ABR and OAE's, and as long as those were each normal in each year and the baby had no known risk factors, they could be done with their diagnostic process. What we found is that actually led to in some cases misdiagnosis. JC that either H recommends that you need to have at least two frequency specific assessments in both ear, along with a test battery to make sure that we have that cross check principle to make sure that every part of the auditory system is working and that the data makes sense.

We also updated our risk factors for following up on risk factors. As you all will know, the previous guidelines allowed a child with a risk factor to wait until 24 to 30 months before they were recommended to come back for testing, and that just wasn't aggressive enough. We were waiting too long to look at late onset hearing loss in these children who had risk factors for hearing loss.

So that JCH updated that, and if you look at those risk factors not one of them has follow-up after nine months of age in fact many of them have follow-up in a more aggressive timeline, specifically things like congeni Magalovirus and Zika -- the risk for hearing loss is so high.

We updated this in 2019. Lastly, we increased a lot of information about counseling and resources for counseling for families and connecting families for family to family support. For those of you who are audiologists or speech in which pathologists in the room, we don't get enough counseling in our training programs, especially when it comes to counseling things like congenital hearing loss when you have a three week old and parents, new parents in the room. So we provided a lot of resources about informational counseling versus adjustment counseling. We provided a model to make sure that all of the environmental -- to the environment is set up before giving sometimes difficult or unexpected information, and then we also provided some different links that families could have two get more information about how to adjust to this and what they needed to know, but also for audiologists who are actually providing the diagnosis, things like the Aita instituted that they can look at for more information about counseling in general.

This is a very tiny flowchart I don't expect you to read, but this is a full page in the actual diagnostic protocol workup. The reason why it is so busy is because yes, we know we go from one test to the next, but we provided tips of the trade and other boxes to kind of help troubleshoot things if things don't make sense, and as much as we know that expert audiologists know all of these things, we also wanted novice audiologists may be in an underserved area who may not become Cabal with doing ABR testing, to see this and say I can do this because I have some guidance here, so it is really meant for people from any experience level, but particularly to make sure that audiologists who want to do this testing can, and have the resources to have the training to do it.

During this time period, our LDH newborn hearing screening program also sent out a survey too diagnostic providers to understand the impact to any of these changes would have on them, providing services and our state. So the three key things we learned from that survey was that there was a real need for training and mentorship and our state.

We do plan to do a webinar review of the changes of the protocol once it is endorsed by the UNH subcommittee, but we also wanted to make sure that we could reach out to novice providers and underserved areas, and set up a mentorship network that could provide experience audiologists helping novice audiologists help through all the things we have to work through as begin experience in testing infants.

We learned from some facilities that they did not have updated equipment to be able to do frequency specific testing, and that is a real barrier to testing. So in terms of this aspect of what you need, we did have a facility recently successfully get a grant to replace one of their -- there only AB that are machined to be able to do diagnostic testing again in Columbus, so I think it would be something that is needed, to understand what funding options are needed out there for agencies and clinics to be able to get new equipment at that is what they need to provide the service. So that is something we will be looking into pick lastly, we learned that there sometimes are barriers in terms of administrative support. We have five freestanding children's hospitals in the state of Ohio, and most of them are set up to efficiently and ideally do this testing. So they have two hours usually for a testing appointment, because we all have to wait for babies to fall asleep, even if we send out instructions to parents and say can you please prep them this way, it would be helpful if you kept them awake, we all know that some of those parents drive from many many miles away and keeping a baby in a little carrier awake for 45 minutes or even several hours is not always possible.

So our facilities usually allow for a lot of time for babies to fall asleep so we can do the testing in one appointment. That was not the feedback we got back on the survey. Some of the facilities say they are stretched for time, they don't have staff to help them, they don't have officially trained staff, so that is also a barrier that we recognize and will have to help different facilities kind of problem solve as we try to implement this new protocol. So we really believe in Ohio, that collaboration of partners for many different areas of expertise is very important, as long as that expertise is seen and heard is useful and being fully committed to a partnerships of equals produces outcomes that are usable to the community, and the way that we have done this over the years is really to engage people and invite everyone to the table, but also make projects very meaningful to them.

We have been successful in partnering with our EHDI program, and having our community provided expertise provide things like statewide protocols. We have implemented training and will continue to implement training for audiologists and it's important to implement cycles in general because a lot of times audiologists, speech language pathologist or people in the field speak one language and administrators speak a different language. And in order to understand each other and figure out how do we get to our common goal, we need to learn from each other in these collaborations and I think we have done that very successfully over the nine years that we have been together.

So how have we sustained this? First of all, we welcome all collaborators but we set expectations from the beginning. That call to action when out in January 20-2/2. The people who e-mailed us back and said I'm interested in doing this, I provided them with this is what you can expect, this is the timeline we hope to meet and this is kind of the plan of what we are doing, so they understand before they say yes, I want to help and I want to volunteer my time, that they can have -- they can expect at least one virtual meeting a month, maybe a couple more during the months when they are assigned a specific section. We also welcome all collaborators to disseminate this information so I'm here now talking to all of you at EHDI, but we had a couple of our collaborators present a poster at the Ohio Academy of audiology conference up in Columbus, that happened this past weekend Sunday through Monday so they presented a poster yesterday, so it is not just about collaborating and using expertise, but if people want to do those types of presentations, they are welcome to do it as well. We also choose projects that are meaningful to the group and have measurable outcomes. It is really important that these outcomes are measurable so that you can show what your outcomes are, because if you do a project and then there's nothing on the back and to say this worked or this didn't work, it is going to cause volunteers to not want to partner again and did not want to come back and help even though their efforts were probably really well received and did make a difference but if there's nothing telling them that, they may be more apt to not volunteer for another project.

That we keep evolving with our program's needs, so as I said, back in 2014, we identified a need for a standardized assessment battery or approach to diagnosis, but since that time, we have done a couple of different projects, and they have all evolved with needs. We weren't planning on doing COVID guidelines but that is what our program needed at the time. We plan to do this revision earlier but we actually decided oh, we should really look at behavioral guidelines, too, because we are seeing some interesting things both reported to ODH but also to our facilities about how young infants and children are tested. So because we evolved, we come up with projects that are meaningful and useful to our program and that has made the biggest difference.

So for future directions, we are going to continue\ to support this COACH protocol. We have requested that the subcommittee endorse the protocol as our statewide protocol. We are waiting on a vote for that and then we plan to provide training and mentorship to provide access to evidence-based diagnostics across Ohio, hoping that we might be able to recruit some maybe not as ABR testers and underserved areas to mentor through a mentorship network and be able to increase access too rural kids.

Next we are going to work on regional aspects to our EHDI program. We are currently quite sideload in a sense that we have a screening and diagnostic process under the Ohio Department of health and early intervention is seen by our Department of development of disabilities, so we have established champions in five regions of Ohio and the idea is for those champions to reach out to their birthing hospitals to connect them to their diagnostic facilities in their region, and then connecting their diagnostic facilities too early intervention coordinators including service coordinators by very specifically our during service providers who are the ones providing specific intervention for hearing loss.

And so, we are just starting that project and I hope to have some measurable outcomes to share with you at a future EHDI.

So with that, there are some resources. These are the websites for OTH EHDI program and the behavioral program, the behavioral protocol guidelines. The original COACH protocol is on the ODH website. The proposed protocol lives in my Google drive. It says proposed on it because it hasn't been accepted yet, but it is in the format that we are proposing to our state to adopt.

So you are welcome to grab those resources from the web but you are also welcome to e-mail either me or Doctor Rena Kothari and we are happy to send you anything that you need. I can take any questions. Thank you so much for your time this morning.

[ APPLAUSE ]

You have a question, I think we need a microphone for the CART person. Yeah, I know, we have two minutes left and it is a mad dash To wherever you are going next. That's okay, I welcome questions.

>> Allison from NCHAM. I'm just wondering about the involvement of parents in creating your protocol.

>> So because it is a diagnostic protocol and we have to kind of rely on evidence-based for audiology, we didn't involve parents in a specific protocol, however, when we think about regional networks, and we are trying to kind of thread the needle of screening to diagnosis and diagnosis too early intervention, we are going to try to involve parents with that process, because they know what they experienced, and they know how it went for them and how it didn't go for them in terms of what was successful and what was not, so we are just in the fledgling stages of this, but when I e-mailed out kind of an outline of the vision, we kind of defined stakeholders as anyone, including audiologists, screeners, PCPs, ENTs, parents, adults who are deaf and hard of hearing. Anyone who has experienced this process or this program, so we can get information from them to be able to link parts of our EHDI systems together.

>> I think it is time, but if you have questions you can probably go ask her because our interpreters to have to go to their next.

>> I'm happy to stay.