>> Okay. All right. Hello, everybody. Looking at these die hards, I didn't know anybody would come to the last session of the last day, but I'm so glad you're here, this has been the best conference

On your tables I'm saying it right now so I don't forget, we are super excited to printing the public health and policy conference back to Salt Lake City. And it's going to be October 8-10. And it's going to be awesome. So we'll celebrate our 10 years an sers rei of the law. I can't believe it's been a decade. It's exciting. You have a bookmark here and I guess you could b use it for a old roadmap we had. I tell my children, before we didn't know how to get anywhere, we had to pull over and look at these maps but that would be a good thing if you have those relics around. Abstracts are open right now until the beginning of April

We'll have rapid fire sessions. If you wanted to even do a quick blurb of great stuff you are doing we'll have rapid fire sessions. Anyway, hope to see you there.

I'm Stephanie Browning McVicar with my counterparts from Minnesota and Nevada. And Kristin from Minnesota and Perry from Nevadament and I am from Utah. So we are going to give you a little bit of information about some ways that EHDI programs can get involved in cytomegalovirus with or without legislation. And these are our learning objectives.

So who here is an audiologist? Yes. Audiology power, okay. Excellent. Um, so we all heard of the torch infections pause because they are associated with a childhood tele. We have the toxoplasmosis the kitty litter and herpes and rubella and of course the C is cytomegalovirus. What better place to have a connection with CMV than EHDI because we are all about Early Intervention of childhood hearing loss. And we know that hearing loss is second in genetics with ideology. And this is time sensitive. We know now that we have to test the baby and get the specimen taken before they are 21 days of age. And that's when you determine congenital versus viral infection

And newborn screening is a part of natal counseling. What better place to pair EHDI education with pregnant women along with CMV

Back in 2013, almost exactly a year ago our legislation was signed on March 12th of 2013. But the law was passed it was two parts. It was our CMV public health initiative. There was the public education portion. And then it also mandated cytomegalovirus testing after the failure of newborn hearing screening. Because of that association with newborn hearing screening it was assigned to EHDI.

And the educational piece did charge the Department of Health. We since become the Department of Health and Human Services but back then we were the Department of Health and the EHDI program was charged with establishing and conducting a public education program. We were supposed to inform pregnant women and women who may become pregnant about the risk of CMV and give them suggestions an how to prevent it

We had as an EHDI program our prenatal hearing screening brochure. So we thought we'll update that. And let's add some CMV education in there to hit pregnant women

And then we also said we need to create a CMV and hearing loss brochures. Because if our hearing screeners out there either the mid wifes to hospital staff if they are making the referral after failing newborn hearing screening, they need to give to the parents information about CMV and hearing loss. And why their child needs to be tested for that. And just the name cytomegalovirus is so scary sounding. So we wanted to be sure like with I don't know if you saw Sirtsten talk about the Minnesota screaming -- screening -- screaming that's the Freudian flip sometimes when you start something new that's the tearing and screaming. But you want to have like the one stop shop for education. And get all the experts at the table so it's a unified message and doesn't matter where someone is in the state they are going to get the same services and the same messaging so we also created what women need to know and that's specifically aimed at women who may be pregnant or

are pregnant. And

This is our prenatal brochure. We updated it. We do have the I don't even know -- yep, you can, our new logo for Department of Health and Human Services. And in this brochure this is a tri-fold so you are looking at the one side of it the backside. We did add in there to our newborn hearing screening the timeline about the importance of testing before 21 days of age. And then on the inside, we had added a section on CMV and hearing loss. And so that was just one way that we updated our newborn hearing screening brochure to include information about CMV and then also about the testing requirements. So that family is prepared. Now this is old. This is in the process of being updated. We found that now with our new department it takes about I don't know seems like 10 years but it's probably several months because we have to have all the same font, same color scheme and has to go through about 17 layers of approval. So we haven't finished updating this one yet

but it's coming and this is what women need to know about CMV. And again, tri-fold that's the outside portion and that's the inside portion. If we get to our testing portion of the law, it's state that had we have to test for CMV after the failure of newborn hearing screening. And we defined it in rule that the baby had to fail their inpatient and their outpatient rescreening. All our babies who fail in hospital have to have a repeat screen before they are referred for diagnostic ABR. And I know some states do it like that and some states do one screening and go right to ABR. It also charged us EHDI program with educating and forming the providers who needed to order the CMV test and also the families about it.

And again this was all EHDI was in charge of this. And then this was our CMV and hearing loss. And again this is one in process for the update. But this was specific to the screeners in the hospitals and and the mid wives when it was time -- when they met the criteria for testing they could go ahead and give this to the family

We also just, FYI, in our rule, it would have been so much easier if we had universal. But in our rule, I say that I'm sure it's not easy at all. But we had these little criterias of fail inpatient and outpatient and then get your CMV test. Or if you have your first screening and it's after 14 days of life then you have to have your CMV test, right? The clock is ticking you really got to make that 21-day window. So this is what the inside looks like. And again it talk answer the screenings. And just facts about CMV and things like that. And that little darling gal, Daisy, who is now 12 years old, you know how they have the vif Vivian's Law named after the family that prompted the legislation. And this is Daisy. So one thing that's not matter of course when you're educating about CMV testing it's really important if it is not a universal screen like Minnesota that's doing the dry blood spot it's only done on urine and saliva

and you don't want blood drawn. So we wanted to be specific in our materials when we were educating about testing that only a urine sample was taken of a saliva sample. And this evolved over time.

We tried to make it as easy as possible to facilitate the test, again, the charge was on us. So we take that responsibility not lightly. So we wanted to make sure that the correct testing was being order. And it was done in the correct manner. So we had one for parents. So when the screener said you need to have your child tested for CMV, they could talk to them and give them the CMV and hearing loss brochure and then they gave them this form. Empowering parents if they know what to expect, they can advocate. Because we don't want someone getting blood drawn or we had, um, spinal taps and super pubic punches and yeah, I know. So only once but that was more than enough. It was terrible. So we're like okay the parents need to go with this when they go to the lab to get this done they'll say this is what we need. And we send it to all the labs and the medical providers as well

And this was a great boon for us. We have any of our insurance companies require an order for the ABR testing to be conducted. And at our like I said if they fail their first and second CMV testing needs to be done but after the first and second the ABR has to be done so we have an order that orders both and it has the correct codes and it's sent to the primary care provider. After about 2016 we got approval to have a medical director at the Department of Health, right, a standing order. So we weren't held to a community provider having to order it.

The easier you can make everything the better off they are going to be. So we did add all the specifics about the CMV testing and the great thing too is because Dr. Nelson or EHDI medical director wrote the order automatically all the results would come back to us so that was a great thing. So -- and then also EHDI's involved of course in the follow-up. If we have a positive test result. Ifs of the done on saliva we have call the family right away. Now I have a CMV data coordinator who will interact with the family and call them and get a confirmatory urine test done, again that needs to be done before 21 days. We now also have a multidisciplinary clinic for congenital CMV at our children's hospital. So it's a one-stop shop. So we counsel the families and then the provider on what the next steps are. we don't have genetic counselors in our program. But as you know, as EHDI coordinators we wear many, many, many hats. We added the congenital CMV risk factor was

to high track. We had a specific one and we used to say infections and now we track very closely the number of tests that were done, positive or negative and false positives we only had one false positive in 10 years. And we are also aggressive about our serial audiologic monitoring and we capture all that data. And we also have a congenital CMV registry we keep that we created in red cap. And that's where we capture all of our infectious disease and ENT, neurology, ophthalmology, MRI, imaging lab data all goes into our registry and that's where we are also tracking the longitudinal outcomes.

So EHDI and CMV are natural partnership. They both have a strong relationship to childhood hearing loss. They are both time sensitive. So they have a sense of urgency the sooner the better. If there was a child who is symptomatic and they could benefit from antiviral therapy it needs to be started in the first month of life. We already are educating pregnant women about newborn hearing screening. So it makes sense even if you don't have legislation if you can. If you can throw on a little thing about congenital CMV. And pushing for testing can be a tricky thing. But all of us up here have information and that can help you

And Virginia is doing it. And we are all in this together. Right? EHDI. What is it again? Thank you.every here doing it together. I have a lot of clothes that have that on there. You would think I would remember. But again information is power. And it's the worst thing I get is when I have a parent that says why didn't anyone tell me about CMV?

So we want to empower these parents we want them to know knowledge is power. They have of the they can handle it. They would rather know. And I'll turn it over to Perry.

>> I guess it's a pleasure to be here. [Laughter]

You know, I'm going to do something that's not a wise thing to do and it's apologize before I even start saying anything. You should always I guess stand up in front and, you know, pretend like you know what you're doing. Um, my name is Perry Smith I'm the EHDI coordinator for the State of Nevada. I've been in that position almost 10 years I guess is what it is right now. My background is actually in hospital health care. Being kind of a middle manager at that point. But through all of that and my training in prior work experiences I have one of those statistics that states, you know, CMV is one of the most common infections that no one knows about. I was one of those statistics and yet I had been in hospital health care for many years. But it happens and it's out there.

I want to -- what I'm apologizing for is this particular presentation was given at our EHDI annual meeting in Kansas City. Remember that?

And at that point I was reviewing what the State of Nevada had done in terms of its CMV efforts. We do not have CMV testing in our state. When I first joined up with EHDI many years ago, I was very lucky in that we had an audiology consultant where who was passionate about CMV. And I was bitten by that CMV bug. I got the infection . And now I'm on board with CMV awareness.

And so what we started doing as a state is okay, what can we do about CMV? Um, we tried to find other people that we're interested or had a buy in to CMV. And there really was not anybody. We found occasional people here and there but that was difficult. We added a CMV educational page to our EHDI website. We co-branded some of the literature from the national CMV foundation. They allowed us to put our logo and contact information and we handed those out

We tried to promote CMV-related issues with our partners and stakeholders. These were kind of some of the groups that we were sharing that information with. I'll jump on.

So what was the result of all those efforts? Um, I'm not sure the right word to describe it but it can probably best be described as nothing really happened. You know, we made the effort. We tried to get going with it. But not a lot happened. So we thought, what can we to now? And so we tried to do come up with a public awareness campaign. Here's what I'm apologizing for. Because I quickly scroll through this.

We put together a public awareness campaign trying to get the word out relating to CMV information. We first put together a CMV website not a page that was part of the EHDI website but one that was a stand alone CMV. And that particular website was going to be the landing page for all of our future efforts in public awareness to force or direct individuals to that particular website where they could get basic information about CMV.

Once that website was up and running then we started a digital advertising campaign within Nevada. We worked with an outside company that helped us develop that advertising campaign with the messages we were going to promote. Very tiny video clips maybe 15 seconds long. And we ran an 8-week digital public awareness campaign through Facebook is what we ran it through. And we were able to target those efforts towards women of childbearing years is I think the way it was defined back then. And we ran that for 8 weeks and then we wanted to see, okay, what were the efforts? How many people were directed to the website? How many clicked on the ads within Facebook? So we were trying to collect that kind of information to see what kind of an effect we would have.

>> Every pregnant woman is at risk of getting CMV, a virus that can cause serious health issues in infants including hearing loss. Prevent it through good hygiene habits. Cash your hands frequently don't share utensils. Get more information at Nevada CMV.org

So we had three little ads like that that would play on Facebook. And we had a way to track how many times the videos were watched and how many times someone was directed to our website.

The events of that particular campaign were pretty amazing. 1.7 million total impressions and an impression is defined as a digital media rendering on a user's screen. So something came up on their phone or computer that was considered an impression. So we had 1.7 million impressions from that 8-week course. We had 1.3 million Facebook impressions.

The videos were watched 53,000 times. The website, how many visited during the cam campaign, an average of 230 visits per day. During the campaign and then you can imagine it slowly dropped off.

How many clicks went to the link of the webpage? Not many. How many downloaded information? Not many. And only one actually contacted EHDI. Through all of that. So in one aspect it was very successful in promoting CMV awareness. But directing individuals to us didn't seem to be that -- to work that well.

This is what I want to talk about right now. Where are we right now? After that digital campaign, we put together a list of what our next steps are going to be and we thought we were very knowledgeable at the time we were going to use the EHDI team. We were going to use our EHDI stakeholder committee which is our advisory committee. And we would put a plan together and we would conquer and we would do well

Then COVID hit. Because again I gave this presentation of our last -- our Kansas City conference. And we came home from that EHDI conference and hunkered down for two years. So not much has been done. And the people that we tried to reach out to promote this and take it to the next level, none of that really panned out

But something amazing happened probably within the last 9 months. I sit on ad vise rei committee it's the newborn screening advisory committee. It has individuals from EHDI, CCHD, blood spot, it has physicians and other professionals on there. And over the years I occasionally put in my 2-cents on that committee related to CMV

Well, something happened. I don't know what. But all of a sudden, that group has an interest in CMV. I don't think it was me. I don't know where it came from. Where they picked up that infection. But it's a large number of that group become infected with wanting to promote CMV. At our last meeting, since we are fairly close to Utah, we ask Stephanie if she would attend our one of our meetings and give us some information on Utah's experience with CMV. And where things are.

And so we are moving forward a little bit better than what we have in the past. Mainly because that newborn screening advisory screening is now involved. So we have plans to put a plan together not sure what that will entail. But we now have some professionals, we have some powerful individuals that can actually move forward with things. Are we going to be fairly close to doing any kind of legislation? That's yet to be seen

But I think the takeaway from what Nevada's experience has been is we continually plug along but we continuous quality improvement. We make those little steps we make those little steps and all of a sudden for whatever reason our state took a big step

So that's kind of where we are and what our journey has been. We are kind of excited right at the moment. We hope things will go forward quicker than what they have in the last 10 years in moving forward with CMV. Thank you.

>> That's right. You're good. Okay. So Perry it's calling wearing them down. [Laughter]

I guess I'll get to it in a little bit. But our EHDI advisory committee years ago, at least I don't know 10 years ago started talking about CMV and the committee was like, until we are screening for CMV we are having it on our agenda at every advisory committee meeting. So in some way, shape, or form, whether a parent story or having someone come in to talk about it. Or us giving an update. We had it on our agenda at some point the EHDI committee did.

And then also had someone sitting on the larger advisory committee for the heritable conditions. And made sure that the EHDI voice was heard supporting CMV on there. So you wear them down

[Laughter]

That's Minnesota has had a long but exciting path forwards CMV. Right now, we do have have legislation it was led by parents and advocates. It was attempted several times. And failed but then through persistence and wearing people down, and getting the right people at the table, the Vivian Act was passed in July of 2021. It directed the Department of Health to provide CMV screening can outreach. And it also directed the newborn screening advisory committee to review CMV to be added to newborn screening. So if you were in my last presentation you heard this, it did not tell us we had to do CMV screening it did not tell us how to do it

It did not say it had to be universal or targeted but it did say that it had -- it was -- Vivian Act basically named nominated it to go through the review process. So the Vivian Act was reviewed and the other big thing funding the legislation or part of the Vivian act is if after review it is approved to be added then here are some funding that can go with it. So if it was approved big funding too. So let's see. Did I say -- oh they added $43 to our blood spot fee in order to -- let me tell ya, we know we are lucky, we are very fortunate. We acknowledge that. We are thankful for it. And like Stephanie said, we -- we are willing to share and learn and we are looking forward to the things that we will be able to do with the funded legislation.

As far as EHDI or I guess Minnesota in general, we really began statewide or program planning within MDH. We utilized the universal CMV screening study information and decided to go forward with blood spot screening for CMV that can be done in our public health lab. So we weren't adding another collection method at the hospital it was something they were already doing. EHDI's EHDI's role in that we were at the table talking about what we knew learning from EHDI. The whole thought of having to train people on, you know, specimen collection and then them testing and us maybe getting results or not getting the results. And all the effort towards that, versus like we have to do for hearing, we really were excited about the possibility of using dry blood spots. There was a condition readiness work group that became our implementation work group. That work group had EHDI representation, audiologists, ENTs, parents. And they spoke up. And they had their

voices heard.

They made sure that the implementation really focused on the follow-up piece and the monitoring. So we do -- we did have a earlier presentation, it will get uploaded. You can go look at that if you want.

So again, EHDI and CMV, these are my main things. EHDI has to be at the table. You have to talk loud, talk often. Wear them down. Share your passion, share your knowledge. Utilize the families that you have in your state. But EHDI has to be at the CMV table. That 21 day window finish detection of CMV fits well and supports EHDI's 1-3-6 goals. So whether you are the ones doing the follow-up. All the follow-up. Or whether you are sharing that with blood spot follow-up. It's still is a collaborative effort.

We know that monitoring for audiologic change is critical for these infants. And following up on risk factors is already part of the EHDI system. So if maybe you are going down the blood spot route and in our case -- or our blood spot follow up team will do that initial notification. And just in time information. But then when they are done, the work isn't done. Right?

So there's additional. Plus the impact on audiology clinics the partners you work with all the time for your normal newborn screening are going to be impacted. That's going to affect them

So you, again, are a voice with them and a con due it. And just being open and willing and collaborative, being ready to learn, I shared before. We didn't think about, oh, the scheduler they need to know a specific piece of information. So reaching out to the audiologists. Um, the EHDI advisory committee taking that active role that was huge. It was any chance we could get we were talking about CMV and how important it was for our Minnesota infants and to increase our timely diagnosis. And increase children -- children being identified early even if they pass the newborn screen.

The legislation did talk about education. And there is we collaborate again with blood spot in this education efforts

The education has to be up-to-date. Evidence-based. Available to everyone that everyone is already talked about. And include in an outreach program

We started with the education pieces. We are still working on our outreach and public awareness. But again we are using our resources and the professionals that have gone before. And working to put together the best information that we have. It's important as an EHDI program or a stakeholder in your state to know what that education is. Be part of reviewing it. Making sure that the hearing component is front and center.

I guess again thinking about EHDI and CMV just an easy thing to do is to just keep CMV in mind when you are reviewing your EHDI materials whether that's an old or a you are creating new ones is it your website or your presentations, have one slide in there about it. Stakeholder meetings have it as an agenda item. So just that that's an easy win for any state. Right? Of what you can do. That consistent and coordinated messaging I think is so important. We know that from EHDI. We know how important that we know when it's not consistent then kiddos get lost

So start out strong with consistent and coordinated messages

I remember going to your presentation, Perry, and coming away going, oh my gosh, we need to keep replicate what they did those PSA announcements are fabulous. So utilizing various education platforms. I am going to go back and share that again with what we have but using all of the different avenues of just in time information, community parents, professionals, Facebook. Social media. And then steal shamelessly, share seamlessly or vice versa. Adapt and use what's already been done. Make it your own. Keep it real. I guess I would say. But we are all in this together. And everyone is happy to share. I can't remember how many times Stephanie would send me her big old file of materials. Use whatever you want.

So and we did. And slowly getting it there. So the other thing I would say for EHDI programs is really thinking towards capacity building and sustainability. Again, we know that we are fortunate. We have great funding. If you can help with that in my way at your state, I know there's so many EHDI programs that don't seem to have adequate funding and it is -- it is difficult to do all of the things that you want to do without it

But utilize those stakeholders. The other thing the EHDI advisory community members became really key advocates for the legislation efforts. They were writing letters of support. So on our advisory committee we have physicians we have parents we have audiologists.

The members on our committee reach ped out the to their statewides ors. So the Minnesota academy of audiology we have had them write a let and he we are had an AAP person on our committee and he wrote a personal. We had educational audiologists. They showed up the for the legislation. They made a concerted effort. They happened to be in the district where the person making the decisions was from. And so really laid it on thick in her district. So utilize your EHDI resources to support your CMV efforts

Okay. I'll actually go through this. So we did go live. February 6th. So about a month ago we had big prez release and media coverage it was very exciting to see all the different stories coming out about CMV in Minnesota. Um, it was emotional. And exciting. It felt like a long time coming and is this really happening? But in the first week, we had positive results. Currently we had six positives that have been confirmed through confirmation through urine testing five of them passed their newborn screen so it wouldn't have been tested if we didn't have universal screening

And this picture has Leah and Vivian and her brother who spent a lot of time at the Capital make sure this can happen. And that's you. I think that's it.

>> This is courtesy of the national CMV foundation website. And this was from February of 2023. So very current. So just to give you this date of where the U.S. is at with CMV screening and education. So there are screening laws in Connecticut, fleered, and Virginia and laws in [listing]

New Jersey, and Tennessee. And then laws in the following states that have both educational and testing components. So Illinois, Iowa, Kentucky, Maine, Minnesota, New York, Pennsylvania. And then and Utah.

So in 10 years, all of these states have gotten on board. And when we had our legislation pass, we were given an appropriation of $4,000 to help prepare materials. The law was signed in the middle of March of 2013 and it went ours went live on July 1st of 2013. And then they gave us $30,000 and $800. 30,800 and that wrote it for a part-time educate or the. So that was the only funding that we had. But turns out the part-time educator was a full-time EHDI coordinator that took on part-time educator role

[Laughter]

And then when we held the first public health and policy conversation in 2014, our representative who was responsible for the legislation got us an additional 40,000. So we were lucky to have $70,800 up until 2020. In the legislative session in 2020 stopped the program and the funding for it. So we haven't had funding since 2020. But basically what I had used that for was printing and materials.

But the large-scale public awareness campaigns so I use that funding for the billboards and the transit campaigns and posters in and out of the tracks and the trains and the buss and our play bills, sport programs and things like that, all those big campaigns so I don't have the funding for that. But you don't need funding I don't think you like these guys are said EHDI is just such a natural fit sometimes you have to tweak a little bit and I love that. I had to slide in, EHDI is always doing EHDI 101s and presenting to all our stakeholders. Be that voice.

If you are presenting already on EHDI, throw in that CMV slide. And it's all worth it. Because even if you -- if you just presented -- prevented one case of CMV or got one early treatment, it changed the world for that one family. And that one child.

This is all of our contact information but we wanted to get through this. So we had time to discuss with you guys because we would love to hear where you guys are at. And see if we can be of any help. And to get us start started I wanted to ask Perry. So where did you get the funding for your wonderful awareness campaign? How did you get buy in for it?

>> Um, if I remember right, um, we had some hersa carry over from one work to the next. And when we applied to that for HRSA we asked if some of that could be used towards CMV and they approved that

>> I wondered. So that's good to know

>> Because CMV is a high-risk indicator for hearing loss.

>> Right. So if you have HRSA funding and sometimes normally we all fully expend our funds but once in a while there's a finance accounting error and you end up if you're lucky that's a great use of that carry over funds. So I'm just curious, who here has EHDI program actively working with CMV, either education wise? Excellent. And are you Texas? Yes, you're Texas. Maine. Okay.

Say what? Pennsylvania. Okay was there someone else over here? [Laughter]

Arizona and Illinois. I know these guys. So, um, did I say education or testing? Did I start with? Education. So is there any EHDI program that's actively facilitating the testing? Okay, so Florida. And then Maine. And Pennsylvania. And Arizona kind of. Oh, you're doing a pilot. Tell us about that pilot. Can you tell us about that pilot?

That's what you get for opening your mouth

>> I work for a nonprofit I'm the EHDI cord coordinator. But the nonprofit I work for has a group that's working on CMV. And they wrote a couple research grants and community grants to do various CMV projects some of which were educational. And the one they currently did was to do a small pilot project to do buckle swabs at a certain hospital to show it's -- you know you have to show them over and over again that yes you can do it in Arizona even though they do it in other places so they are doing that. And they hope to expand that to other hospitals and the thought is the way our legislation is written until it's on the rusp which is recommended universal panel it's not coming to Arizona's newborn screening. However if it gets on the RUSP they have two years to get it on the panel automatically. And that's where we are at. We are -- of that panel that's working on that, one of them is a professor at a medical college. And one of them is an ENT, ot olaryngologist

who is our chapter campaign and then the foundation representation.

>> That's awesome. Perry.

>> Just to add to that, I'm in that group that's working on all of it. We screened 250 kids just from the newborn nursery the first 250 we could get parent authorization to screen. We found four who were asymptomatic who had cCMV. So that's good that's a good start

>> Wow that's amazing. Was it based on failing newborn hearing screening or a universal? Universal saliva?

>> Yep

>> Wow and the more people do pilot studies the more the information and data is shared the more people are apt to get on board. So Kirsten I know everyone is going to look at the universal screening results you have, no pressure. The RUSP from the national CMV foundation may not be eminent. There is definitely hesitation. Is Amanda in here? No, okay because they did put it forth a nomination again. And it doesn't seem promising it's going to be approved in the near future. Hopefully in the not too far future. But getting more data and looking at even just the fact that you had five out of the six kiddos that were positive in one month pass their newborn hearing screening. It was a great start but we know that we are missing these children. We are missing them big time. So I am curious if we have students in this room?

Okay. Ya where,, students, yay. Yeah, are you an AUD student? I'm cure use in your program how much did they spend on cytomegalovirus

>> I spent as a small amount but I work as a newborn hearing screener and I have since January of 2021. I'm from Cincinnati and I go to University of Cincinnati and Dr. Kettle are the director of audiology at Cincinnati children's was my pediatric professor so she helped me feel confident that I can be an up and coming advocate for CMV screening since I started as a newborn hearing screener most of the pediatrician trigses and neo naytologists that I work with are good about doing newborn hearing screening and Maggie Kettler has done great work in the Ohiing o Department of Health and the Department of Health recommended all babies are screened and they are in the works of deciding what will that look like

>> Excellent. Sometimes it takes just the seed is planted and then it's amazing how it can grow. When our laws was passed physicians weren't too happy about it because they didn't want the state -- I understand, telling them how to practice -- telling us telling them you have to order this test. But as time went on and they learned more about the prevalence of congenital CMV and infections, all of a sudden, in 2014? Summer of 2014 so we were just a year into it the neonat lost got together in our large corporation and put together a recommendation to screen the NICU babies if they have a high risk criteria. In there they said it's probably more common than we think in our kiddos and it's a time sensitive test. So we should think about screening these babies and fast forward to 2019, and official test protocol was put forth by that large corporation and also the second largest health care corporation where they said if this baby presents with any

of these 11 symptoms or signs, one of them was failing newborn hearing screening but there are a lot of other ones you are to test to rule out congenital CMV. So sometimes that takes a little seed. And bringing top of mind awareness is something that everyone in this room can do. The more you talk about it, the more you present on it. And make it in the minds of everyone you meet, it helps.

>> I was just going to ask you a question. So then if they are testing the kiddos in the NICU and they pass their hearing screen are you getting those results?

>> We get every CMV test, yeah. So in our communicable disease rule I know you said you were working on that, right? One of the things before we had our standing order, it was -- we were dependent on the ordering physician to send the results which I thought we would get them all. Just like audiology reporting diagnostics. So in 2015, we added to the communicable disease reporting rule any child tested for cytomegalovirus under the age of 1 years had to be reported to EHDI. And that was any test

So not just positive but any testing that was done. And that was a game changer. Because then we had to get those results. So that was a great question. Yeah.

>> I have a just a curious question. Um, what is the recommendation for the follow-up for a baby who tests positive but doesn't fail their hearing screen?

>> So if a baby tests positive they are going to get hooked up with our CMV specialist and our multidisciplinary congenital CMV clinic. It is up in Salt Lake City. What they'll do if a child is born off the Wasatch front where is the front mountain range where we have most of our population the team will schedule the child to come up to salt lake and they'll have them be admit as inpatient and see all the specialists so they'll get a team of specialists looking at their case, deciding -- had a ultrasound done by a sonographer versus a neurologist is a lot different. They'll decide if they need MRI testing and they'll run the labs. If the family can't come up to Salt Lake and spend a weekend which it's not easy for many families to do that, the team will counsel their primary care provider to help get their lab work done. And help the child will get enrolled in early intervention it's a qualifying diagnosis. Even if they don't have hearing loss they'll get enrorolled in EI and have their development monitored.

Even if they are not symptomatic or didn't fail their hearing screening they still will get a full blown diagnostic evaluation. We know half of these babies will have a late onset on their hearing loss. So there's a lot that can be done. One of the things that was physicians are like, well, if the child is positive and with congenital CMV there's nothing we can do. But there's a lot that can be done. And sometimes, that CMV test that it might have been prompted by a failure of a newborn hearing screening when they are investigated further they are finding neurological and brain imaging. Abnormalities. They are finding the intracranial calcifications and it ends up these babies are end up being considered symptomatic and again the clock is tickeninga antiviral treatment and that can make a big difference in their cognitive neural development even at age 2. There's been studies. Great question. Kim.

>> [off microphone]

>> Can you hear me, did you hear any of that?

>> I did but say it for our interpreter

>> Sure, so Florida screening we had some conversations with Utah. One thing we talked about is that put disciplinary team. And it didn't exist when you started in Utah. Can you talk about how long it took you and the pres for that?

>> You bet. It's great to be able to sit here 10 years down the line and say we have this and this is happening and that. But gosh, it take take a while. We had some CMV champions already. Dr. Albert Park a well-known CMV researcher in studying antivirals and specialist with hearing loss. And we had in our state a CMV working group where we had CMV researchers. I was on that committee for years, even before we had our legislation before it was on the horizon we were already talking and studying CMV. And its correlation to hearing loss. So we already had a huge champion. We were already talking about CMV. And then when the legislation was passed, those CMV researchers jumped to the forefront as being our champions and helping to educate other providers that was huge

Sharing their data. And then the more that it was talked about, and it was something really exciting, the more other providers were like, oh, I want to be -- I -- okay, I see this. This is a great thing. I want to be a part of this. So it kind grew. And then they were seeing our kiddos so we knew who the specialist were for OPTHO and ENT but we wanted to one stop shop. But the so the research researcher the physician said we need to make this easier for our children and collaboratively get together and form a official clinic. That was formed about 2019. So that's 6 years even though they were doing evaluations but not together. So it took six years to get a full blown laboratory clinic. And then COVID hit and they were doing telehealth appointments and which they are still doing but they come now in person. And it included the audiology [off microphone] since it was at the children's hospital. Go Perry, go.

>> Thank you, I have a parent on assignment I'm EHDI coordinator in Oregon, sorry if this is a naive question. But seems like the standing order cut through red tape for you in terms of having access to the testing

>> Yes

>> How difficult was that to obtain it was not costly. It was wearing them down. Wearing them down. Because we would show we know we are missing results or when we're getting result it's way past the window when we can intervene to facilitate prompt testing and we were told oh no the state can't do a standing order, they can't

Then we got a new medical director and they said yeah, we can do that

So sometimes, it's just a person that is like, oh, yeah, we can do that. So --

>> As Lilah and Ginger said, retire, move on, or die. Sometimes you have to wait for a person to retire, move on, or die.

>> So just stay the course and be persistent.

Perry and we'll get you.

>> Hi, so this is for Utah, Stephanie. You've been doing the education for 10 years do you see a decrease in the numbers of positive CMV?

>> Yeah, I should have brought my slide. We did a presentation at the CMV conference in Ottawa in August. And you see an exponential rise in the number of tests that were completed because of in 2019 the high risk testing that occurred. So you see this huge rise in number of tests and you see the incidents drop

So that was -- that was key. That was huge. So yeah, we have seen. And I wish I would have brought the graph because it makes us do the happy dance.

>> [off microphone]

>> Oh, no, yeah. So go ahead -- I want you to --

>> [off microphone]

>> Okay. So the comment was she wondered if COVID because it was already a matter of course COVID didn't effect the testing? Or --

>> [off microphone]

>> Yeah, exactly. So she said does that order in the protocol does it make it a lot easier? Yeah , any time you have a protocol a best practice where people know what's expected and if you tell them how they can fulfill the expectations and you give them the tools to make it easier the better off you are going to be.

>> Hi everyone. My name is Michelle from Gaum so thank you for this session it's late in the afternoon but it's so interesting that it woke me up.

>> Yay, normally I put people to sleep

>> I still have jet lag it took 24 hours to get here. Anyway, I was hesitant to raise my hand earlier when you asked how much are educating the community. And we are in that stage we passed out hundreds and hundreds of pamphlets. We developed brochures ands the and the standing up right banners and placed them in the pediatric clinics and all that. But the testing and how it's done, right now every single hearing screening test is done for newborns at our own public hospital. We only have one on the entire island. So we have about 2,000 babies born.

So I'm thinking if they are doing that and they are probably sticking it into the billing of some sort of the parents whether it be their private insurance or whether it be the public insurance is this something that we can possibly do since I mean it's nice, central location. They are already doing the hearing screening. Is this covered by insurance?

I mean, I'm sure [off microphone] is

>> I'm going to say yes because I know you can to it. Right? No, but I believe in you [Laughter]

But I know for Utah when the law was passed I contacted all of the insurance providers and we sent out through the Utah insurance association information that you are going to start seeing an influx of these tests and this is why. And I had in there so you have to cover it. They made me take that out. But they all -- [Laughter]

Have you notice that had EHDI coordinators are really bossy people? But anyways. All public and private insurance everything covers it and the good thing is as time has gone on the cost of the testing has gone down too so now it's under like 90-some dollars we got it down to

It started off with like 900 when one lab could do it. And the other labs were like, hey, I want to do this

So you see a decrease. So I think you are well situated

>> The second part is we are very remote. We lack a lot of specialist so it's scary if you share a baby tests positive they must be referred for to a specialist for more testing so I'm thinking we don't have that on Guam, I don't think we have that on Guam, can a pediatrician do that?

>> There's a -- there's a lot that can be done because they can order -- they can order the additional lab work. They can order -- do you have a neurologist?

>> One.

>> And you can also telehealth. I know for a --

>> I know telehealth. And like what we're doing if there aren't symptoms, often the infectious disease act will just counsel the pediatrician on what needs to happen, what to watch for, what to -- so that will be the majority of the kids anyway. Could be followed that way.

>> And last question.

>> Yeah

>> So no offense to our public health folks here. But normally like we talk about legislation and all that. So really when we're -- when we have got contracts under USAID so our EHDI program is under USAID in Guam. We learned it's best to write everything up for a public health folks and have every answer to every question they may have. And say it is ready for you to sign. And we'll even draft up the MOU for you.

>> Absolutely, see?

>> But [Laughter]

So, um, when you -- when we do that, I'm not -- you mentioned I know we have to speak with our EHDI advisory and all the other folk, pediatricians and all that. So when you get your legislator to sign off on it, do you have some sort of template that you can show us on how your law is written? Is that somewhere?

>> Yeah it's all on our website. Did I put the website? Yeah, visit health.utah.gov/CMV on our CMV website it has all the information, all the resources all our materials and on the right-hand side of the home page there's a link to our law and our rule.

And you'll see how they were written. And I think the same thing with the Vivian act is available on the website. And I know we went over and I'm sorry, thank you so much for staying but I believe in all of you, you can do it. And you got friends here that will help.