>> Is this working? Terrific. So, we are going to jump right in if that is alright with everybody. Good morning, my name is Valerie Abbott , I am first and foremost the parent of a child who was later identified , and she was later identified because she has late onset hearing loss, which goes by so many names. That is why I am here today, that's the talk a little bit about this incredible grassroots campaign that our family launched with the help of the Osmond family during Covid and to recruit as many people to join his army of ambassadors as possible. We are going to talk about, a little bit about how this came to be and really hope it will go. I am also cochair of the Virginia EHDI advisory committee and very involved in my state EHDI work and am very excited to share that Tony on May 20, I will be working in early intervention in which he had to get a different perspective. I do have some disclosures that I need to share, I am the author of a children's book that is on the topic of late onset, it is our families experience cold through the lens of children I am cofounder of the late onset hearing loss awareness campaign, but I do not receive compensation for that work. We are going to learn a little bit about key facts about hearing loss, many of these things that we know but also the way we share these with the world, immediate seeds of inspiration. Understand the history of this campaign and hopefully think through what are some ways we can spread this important hearing health message out in communities. This was on the first day of preschool and she was 2.5, thank you. She is our second child, and she watched for a couple of years her holder teacher sibling go to preschool. She passed her newborn hearing screening and had typical hearing when she was born , and we did not notice when it changed . She was identified around 34 months of age after significant, but several language and early literacy issues were shared with us , things we did not notice but were clearly there looking back . It was a mountain to climb to get her language and literacy back on track for kindergarten readiness. So, as many of you , like we, set in our homes or apartments during Covid panicking about all sorts of things, one of the things that I panicked about was how on earth are we going to find children who acquire hearing loss during this timeframe, not because of Covid, but during Covid? At the time we had no idea how long this thing was going to last. Our child was identified because of a very savvy preschool teacher, work performance noticed something is up , specifically with her language and behavior , and call that to her attention in February of that year. What is happening to the children who are experiencing daycare? Experiencing preschool, or not experiencing those things because they are being watched by neighbor and coworker families ? How are we finding those children? That is really where this whole thing started. I had connected with Justin Osmond a few years earlier. He and my daughter were identified at the same age, they both play violins, that is not my DNA . We had connected a couple of years before and I reached out to him and said look, I'm really worried about this population and he shared the same concern . We talked a lot and decided let's create something that doesn't exist which is a homeless people on fire running around talking about this important under discussed health issue, late onset hearing loss. We intentionally did not specify an age range , that is so groups can use this however they think it is important to them. If you wanted from birth to three or birth to five that is great. If you want to use it for grade school, great spirit this is pediatric late onset hearing loss , anything having after the newborn period which can impact early language and literacy. The mission is to improve postnatal hearing loss authentication rates in children , both through school-age weekly there are raising community awareness about the prevalence , how often is this happening, how big of an issue is this , the risk factors both known and unknown . The signs, the common signs that there is an unidentified hearing loss right in front of us . The consequences of late identification , because every month that goes by that child does not have full access to language , there are consequences . We believe the increase community awareness and specific call to action will do several things. The first one is to increase the number of children who were screened for hearing loss before that school-age time when they are in kindergarten enrolling in first grade and we are finding them then, we need to be finding them sooner. To grow early intervention , and or part D enrollment depending on the age of the child, we are finding kids sooner and therefore connecting them to early intervention or part B sooner. Ultimately, to reduce speech language and this does include language deprivation , to include kindergarten readiness and success , most of us in this room but agree that being deaf or hard of hearing is not the issue for kindergarten readiness. It is access to language , access to strong, early, language and literacy which determines kindergarten readiness. Then, to connect families to family-based organizations sooner. Really, this leads to all sorts of things, also the positive things of why we weren't doing this earlier, I don't know. Lastly, to lead to positive outcomes at home, at school and in life. We have heard about a lot of teens, adults, who are deaf and hard of hearing who have had awful experiences, awful experiences because we did not discover them sooner. The long-term ramifications of that mistake have impacted the rest of their lives. We can change that. How can we do this? Community awareness. Prevalence, risk factors, common signs and consequences. How do we do this? Prevalence, risk factors, common signs and consequences. How common is this? Incidences double between birth and school age, why on earth are we not regularly screaming children during this timeframe? A question we have not been able to answer, but we can change that. The CDC estimates that 14.9% of students ages six through 19 have enough hearing loss to impact them academically. That is a lot of students and we only know about a certain number of them . Why don't we know about the others? Hearing loss can happen at any age and any stage. Yes, we are here to talk about EHDI and focus on zero 36, but this campaign is here for all. - - Is a list of risk factors that have been out there for a really long time. It is not as well-known as we think that it is, the other thing I wanted to mention is that risk factors are both known and unknown . We had a risk factor in our family that we did not know, our daughter has - - 26. There are families of children that are a systematic, they have a risk factor and they do not know. As wonderful as these risk factors are, there are risk factors that are invisible and unknown. Common science, so we all know the common signs I think of unidentified hearing loss . But, the rest of the world doesn't, really. These risk factors in real life in real time are subtle but still significant. Our daughter cannot understand is if you are not facing her . We did not notice that . She was not replying to her name if I did not screen it . We didn't notice that. Even though these Common signs look good on paper, and real-life it is hard for families and daycare providers to point out wait a minute, something is off. That is especially true when children are not in a large group of children over the age of your watch in progress as a group. Lastly, consequences. The consequences of hearing loss left undetected is insignificant. It really continues to worry me , even though I don't need to be worried because we did find it. What if we do not listen to that preschool teacher? What is that preschool teacher did not know and do not say that something is up? Something is up ? Would you be willing to call early intervention? What would've happened if that didn't happen ? We need to see more frequent screening between birth and school age, more pediatricians need to be referring children for hearing evaluations. The moment a family makes any kind of a comment worried about language, hearing or behavior, anytime, when in doubt, let's check it out. More referrals to pediatric cardiologist, can I hear a man? We have audiologists that are willing to see children , some of them are in EHDI. We need to be referring to pediatric audiologists. We need more intentional monitoring and tracking of development milestones in general. This will benefit children with other disabilities as well. We need to be training on this topic and daycare's and preschools, many more classroom discussions and research. When I'm in classroom discussions, I am talking about those students in communication sciences and disorders program thinking about becoming SLP and audiologist and early childhood education. We need to be talking about this Marco my talk all across the country with students in undergraduate and graduate programs, and this in audiology is a sidebar in a textbook that is not open anymore. We know more children enrolled in therapies for speech and autism and other disabilities to also be screened for hearing loss because the prevalence is higher in those groups. Does anybody feel like oh my God, where are we going to start? The good news is that I've been doing this now for two years , and we can all start tomorrow. We can start with just one audience. The question is, which audience? Lots of them to choose from. Which one will you choose? Lots of different audiences . If you go fishing in the middle of the ocean with one rod and one piece of base, how successfully would you catch a fish versus if you think through what am I trying to catch? What rod do I need? What bait do I need? Where do I need to go? We are fishing, when you think about whose attention are we trying to catch, how are we going to cash it and where are those fish? There are so many examples of how we can go out and do outreach. The first thing is we don't need to re-create the wheel. If something is already happening in your community, let's show up. Distributing information at a community event , writing a blog post , everybody can write a blog post. Submitting an article . Crafting an op-ed and sending it to your paper appeared I submitted two last spring and got two accepted in local papers. We can all do that. Read a couple of them before you submit though, that is my advice. The thing at a conference like this, take this information, the coverage and update . If you are going to a conference and want to present on this but you have a PowerPoint, I will send you the PowerPoint. You stick your name on it, your favorite colors and pictures and it is yours. Discuss hearing training with a preschool, do service, conduct and in-service training anywhere that is willing to take you in and tell them that you will bring donuts. Be a guest speaker at a college. If they are willing to let me in, every August I go to this fishing expedition where at the beach, my family is fishing on the beach and I am fishing for colleges and universities to talk about this. We call it my summer fishing expedition, moms fishing. For every 12 colleges and universities I send out and say hi, my name is Valerie, you don't know who I am. I get between six and eight hits immediately. That is pretty good for some does not have fancy letters after their name. You will probably have fancy letters after your name. Reach out, if you have a PowerPoint, I will send you mine. Present at a civic or service organization. Who here is what the nonprofit I could use the money? There civic service organizations out there that want guest speakers , they are eager to hear people, they are meeting for breakfast and dinner . Reach out, Lions clubs, rotaries, there's a whole bunch of them. Frequently they will say how can we help you ? We they want to spend the money. Tell them about your organization and they will give you money. Share posturing of late onset hearing loss awareness week . Great example, so New York State has a lot of stuff, is anyone here from New York State? Good, I totally messed this up, no one is going to now. So, New York State has, I will paraphrase all of this, they have an inner agency group that was appointed at a state level that works or supposed to be an advocacy group or advisory group , it is still on the books but it is totally defunct. People that were supposed to be advising and supporting and advocating on behalf of deaf and hard of hearing individuals, there is like nobody there and nobody working, there is nobody in the room. New York City had recently doesn't screen kindergartners and first graders in the New York City school system . I did some research on that, that is true. There is a woman in New York, I am originally from Long Island , she is from Long Island, we were friends. She is with a dash hearing find New York chapter. She called me and was like New York is falling apart, I just discovered this, what can we do? I said you can do anything you want. She reached out to the Islanders, is anyone in Islanders fan? I live in Garden City and I could literally if I was strong enough, throw a football to Nassau Coliseum , that's how close I was to Islanders where they played, they have since moved she reached out that hey, we want to partner with you. We are nonprofit trying to raise money but we are trying to raise awareness about pediatric hearing health. They are like oh my gosh, did so-and-so call you? They were specifically looking for something like this for this year. They took an entire game on the weekend and devoted it to hearing health awareness and raising money for the hearing fund chapter of New York. They did their 50-50, they got half of that in their stadium. They had the big screen , that whole thing during breaks was dedicated to information about pediatric hearing health, her story of late identification, I mean come on. We don't have to reinvent the wheel, because have to make plans with new people. The original information for this program is on the hearing fund website , I am very grateful that the hearing fund and the Osborne family , yes it is the famous Osborne family , that they allow me to park information here as kind of the permanent original hub. Every single thing that you find on your is scalable with the exception of the butterfly, that is the logo . You can steal it, if you don't cite it, take it as your own. As my mother would do, sprinkle paprika on it, it is homemade. That is true actually, she still does it. These are all shareable for last year, but they'll have a year on them so you can use them again and again. If you take the text from your and you change a word and put your own logo on it and sprinkle paprika on it, it is your own. Literally what we are trying to do is everyone can own this, everyone can take this, everyone can steal this, we are promoting stealing. One of the only place in the world where you might actually hear that. We are on Facebook, we are on Instagram . Last year at the privilege of working with two student interns from the University of Florida because I was still relatively new to Instagram and I did a presentation there they reached down said do you need interns? I said yes. So, they worked on creating some really fun stuff because remember, they are the generation of the speech language audiologist, teacher of the deaf, I as a 52-year-old mother do not. Take it, just that, call it your own. Here's an example . Join the village, this is our village. It is not mine, it is all of ours . This is an example of stealing . You take these words and you put it on. He sprinkle paprika on it and it is yours. You claim the idea as yours. If I ever hear that you are at a presentation and you were the original founder , I will find out who said that because you all are the founders were you are. I am willing to accept an invitation that comes to me, partially because yes, it turns to three and four more yeses . I really want to talk with people and I'm eager to hear other groups are doing. The other thing I'm glad to see this, I have no pictures of myself during this presentation. So, feel free to email me if you took any pictures because I would love to have some. Some examples of the type of work that we're doing is a family is that we worked with the Lions Club in Virginia to come up with a program that can be utilized anywhere and recall it listen up. Let's talk about early childhood hearing loss. We created materials that are scalable and shareable. This is an example of a pamphlet they can be customized. You can steal it, put your own logo on it, but your own information on it. We have also had it professionally translated into Spanish . I had other people look at it and said who did you get through this work? This is an example of the type of stuff that you can put in pediatricians offices , and day cares, and whatever. Wouldn't it be amazing if in every target about the changing table and every Walmart about the changing table if we had information about pediatric hearing loss and every time they were seen changing the baby they were reminded that hearing loss can happen at any age or stage. I have a handful of the pushers available in the back, so if you want one, please take one. They are in English and Spanish and I also have plenty of these . This, if you're interested in working with me directly and really brainstorming a plan like you know what? You want some of the facilities in brainstorming, you can reach out to me directly. This one to monitor look similar , I love my daughters pictures and after slapping on everything. This one is where the face is a little bit lower and it is everything that you need to know about this campaign, this program and how to reach me . So I would love to hear any questions you may have or comments, yes? We have one over here . I would prefer that you didn't . I just wrote an article, look at my Facebook page about the importance of using microphones .

>> I am the Illinois Chapter champion pediatrician , father of two deaf children. One deaf child for 20 years, three boys, two deaf children for 16 years. Pediatricians take a bad rap on this , but we do and almost all pediatricians to develop medical questionnaires. Parents actually do not want to fill those out. We have a computer way of doing it in my office but they don't want to fill them out. There are communications milestones on there. By six, nine, 12 months, pediatrician is to tell you. But, parents are usually worried about rashes and feeding and reflux were sleep and their own depression. They don't know any deaf people . My wife is a speech pathologist I'm a pediatrician, our first daughter was diagnosed as deaf in the nursery , that is where we learned about it. You can go to medical schools , anyone in the room probably does not get a lot of education on this company to other things. Residents may do a day in ENT clinic and see some deaf children . But, they are not in, they might be in surgery for cochlear implant or they might do a day or two with the audiologist . It is a lot of lack of awareness. Every field is doing this. I am trying to educate doctors about it and do our lists of late onset hearing process, I have a slide that is a whole screen of late onset factors. I don't know if your baby was premature, sometimes the rays of light red flags right away. Reflux to talk about my poor sleep. Those are the questions that pediatricians get every day. They say do they react? I will say my kids did , my kids jumped the deaf once and that hearing once. Tuning fork doesn't work , it works for some things but are they meeting milestones? If somebody is feeling the communication score time after time after time after time, I just say do you think they here? Of course I think they here .

>> Thank you so much for sharing that .

>> Is this her second year at EHDI?

>> No, I becoming the EHDI for many years .

>> I been for eight years but I'm at parent of a deaf child. And every field if we are saying is being missed , it is not being asked about or thought about before is being missed .

>> That is why is important for all of us to carry the torch. We need to be coming out from any angle we can. Any other questions? I would love to take any others . We are doing okay on time by the way, I don't know that there is anyone immediately coming after this .

>> I just wanted to comment as someone who was diagnosed with late onset hearing loss at the age of 10 . A, absolute love this campaign, but two, I did not show any risk factors at all. I was a straight a student, there were not any that I can remember. I failed a baritone test they did at my school every year. From there, I was taken to an audiologist and did all the diagnostic fun stuff . This campaign was absolutely beautiful but also the professionals and the parents , sometimes they really are not respected shown .

>> There are not our daughter was born at full term, 9 pounds, never went to the pediatrician, never had an ear infection, crazy healthy child. Connexin 26 is invisible. What other questions? Yes, back here. If I can figure question to the side ? And Cupid I will be hanging on the back , please take some materials and thank you so much for your enthusiasm.