>> Hello, we're getting ready to start. Welcome to parental experiences following the birth of a child with microtia/atresia. Your presenter is Meredith Berger.

>> Having a sense of deja vu.

I'm here to talk about a study we've been working on on parental experiences following the birth of a child with microtia/atresia. Nothing to disclose of significance. So when we started, we knew there was not much research and the way you have to sometimes ask questions that you think you already know the answer to to start research stow kind of set the stage for the other questions to come next. And so we started with asking about what are the experiences, perspectives, challenges, and needs of parents following the birth of a child with microtia/atresia. The first thing is to think about over these last couple of days you've talked a lot and heard a lot of people talking about 1-3-6 and universal newborn hearing screening. And just for a second think about when you hear that, what do you picture? Might be this little baby or this one.

Maybe a newborn, maybe the ABR these are often the children we're talking about when we talk about newborn hearing screening.

But for parents of children with microtia/atresia, their experience and the timing of that experience is very different. So there are often children with microtia/atresia aren't really talked about or thought about when we're talking about newborn hearing screening and again this is something because it's visible at birth, the parent's journey starts then, not two months later when they get the formal diagnosis.

And so the 2019JCIH guidelines talked about a number of things.

Confirmed 1-3-6 but also talked about 1-2-4 for hospitals that were already meeting the 1-3-6 guidelines and I envy those that are, I don't know that I work with any. But there are also things about immediate referrals to early intervention and access to high quality, well fit hearing aids. And the thing that's always left out of 1-3-6 or 1-2-4 is there should be an asterisk next to the 2 or 3 because the recommendation is for amplification within one month of diagnosis if the family chooses it. But they also added some interesting recommendations regarding children with microtia/atresia. She should skip screening and go right to diagnostic audiology. And it could happen in the birth hospital. Not every hospital has their AVR equipment that readily available so they may not be able to, but I have worked with a family who the baby had an ABR bedside at three days old. And they should immediately be referred to early intervention.

And so we know that for many parents of children with mild bilateral or unilateral hearing loss, including those with conductive loss like those with microtia/atresia, there was a lot of uncertainty about the diagnostic process and they often felt that the hearing part of their child's needs was minimized by professionals and that there was a lot of concerns about amplification. This was from 2016 and I would feel pretty confident saying not a lot has changed. Parents in a study in Europe said that they described the initial conversation with someone telling them about their child's microtia/atresia, 60% said it was terrible or bad, 20% received terrible information, and one said it was excellent.

And again the range of incidents is less than one in 10,000 to as many as 17 in 10,000 which also makes it hard because of these pockets of children and so there might be a place like New York City where there are a lot of children relatively speaking versus a small town in Utah.

When with we started this study, our goal was to enroll 15 families at least. And we did our recruiting through social media, so through parent microtia groups and things like that. By the end of the first day, we had 30 families and by the third week we have more than 100. Families that were outside of the age range like they had a 7-year-old or older were contacting us asking to be in anyway because they felt like that period of their life was so engrained on their brain that they remember every detail.

Families of teenagers were saying well if you do another study, we would love to be involved. To me, the impact of those numbers show that this is a low incident population within a low incident population. There are about 500 babies in the U.S.

born with microtia/atresia. And for that many to want to share their story shows how rarely they're asked and not wanting other parents to go through the same thing. So we collected information on some parent stuff and then on the child to have an understanding of different experiences and different characteristics of both the family and child. For the current study, the group that we're talking about involves 21, families of 21 children. 95% had some college or higher. 76% were in English-only homes, which is a limitation of the study. It doesn't necessarily reflect the population that we know has higher incidents. We had 16 boys and five girls. Two families I think it's interesting to see.

We're not sure what their child's hearing loss was. I was surprised by how many actually had amplification. I was not expecting to see that. You all good with this slide? I don't want to move on too fast. Of the families who participated, 16 were white. So clearly there's some work we need to do as well.

So what else did we find? The first thing that happened quite naturally which was really interesting to me was that my research partner and I split up the interviews, we recorded them and analyzed them later. And we did the first couple and got back together to talk about procedures and interview questions, how things went to make sure that there was reliability on what we were doing. And we realized really again organically that at the end of the interviews we both ended up leaving time for the parents to ask us questions because we were often the most knowledgeable person they had met on microtia/atresia, which is a sad commentary on the experiences they had had. We continued that for all of the interviews that we did, and in some cases outside of the 21 families for this study, we had of the I think 120 or so that we ended up with, there were a lot that were outside of the U.S., and there were times we were able to connect to families like in Nigeria that didn't know there was another person in the country whose child had this. So when they both gave consent, we introduced them. Interestingly, the decision making regarding amplification but communication modality was really a nonissue for these families. So we hear a lot of discussion about how our families counseled about language choices and modality and all of that. This was really a nonissue for these families.

It wasn't a source of stress. It didn't come up as something they felt I don't know pressure or guilt or concern about. So I thought it was a really interesting distinction compared to children with sensorineural hearing loss. And then looking at what the sources of information were for them and advice they may have for other parents or professionals. I'll give you a second to read this.

So overall parents felt not supported and overall most of them were given no information or misinformation. It was very frustrating for families. Many of them Googled to find out a diagnosis. And they felt often that there should have been more the birth maternity ward staff could have done even if they couldn't do a lot because of liability, like is there a handout, is there something. And so families were really left feeling on their own. As much as we say to people don't Google too much, don't self-diagnosis, for many of these families, this was actually a good resource because they would put something into Google like baby with no ear, baby with small ear, something like that. And they would see pictures and say oh I think that's what it looks likes. And it doesn't seem like it's that serious, it doesn't seem like he's having trouble breathing or something else. So maybe this will be okay. There were a couple of parents who commented about coming across the CDC website and seeing their baby's ear described as a defect. It's a birth defect registry that tracks craniofacial malformations.

Unsurprisingly parents worry about if they did something wrong or if it was their fault.

Now I never know whether I should edit out the actual language used. Of course there are concerns for their future, particularly around bullying.

Some parents had okay experiences with the diagnostic process, but overall parents didn't feel supported. They often felt like people around them kind of were reactive, didn't realize what they were walking into and said something hurtful, ignorant but hurtful that really frustrated the parents in terms of looking to the parents to have more information for them. It is not unusual for participant --

parents to feel like they were teaching the professionals and they were a curiosity to the professionals instead of professionals having information to teach the parents what to do.

And for families who declined EI services or didn't pursue it because someone said you didn't need to do anything, the guilt of not being more assertive or of being trusting stays with them years and years later.

Regardless of how their child is doing. But there are some supports and sources of information out there that were helpful. Parents recommend for professionals to try to provide clear steps or a single point of contact to support them in this journey and to find resources of information. They really hope that there will be an increase in awareness of the general medical field about microtia/atresia particularly related to the birth centers and maternity departments. They don't expect them to know everything, but they expect them to know something. They also feel like that they got a lot of opinions from medical and intervention professionals as opposed to information for them to make their own choices. As one parent said, it might hurt us at the beginning, but we want the information. A lot of parents that we interviewed belong to Facebook groups. Two of them, there's one that's microtia parents that's specifically for parents of children with microtia/atresia.

There's another adoptive parents of children with microtia/atresia, because there are a pretty sizable number of adoptive families with children.

Myface.org is an organization that provides support and sometimes financial support for medical travel for individuals with craniofacial differences which includes microtia/atresia.

The ear community is a big source of support, both their website and the Facebook group.

They also hold ear community picnics in the summer. And so you can go to their website to look at the 2023 picnics that are available. Many parents will drive four hours, five hours to get to one near them. And the power of that parent connection is really incredible to see and the amount of support particularly for families with rare, their child has rare needs really often the greatest source of information that they get.

But there are also some really cool books out there. My favorite is hi I'm me and hi I'm me in kindergarten which was written by the parent of a child and it's all about this little girl meeting people and she looks different. And I just recently became aware of the Ricky the rock that couldn't roll. And a parent noticed that in the background Lisy the rock has a bone conduction device on a soft band, and there's a whole series of books that I think she's also in. But she's not the rock with a problem, she's a supporting character which is really nice to see. It's not always about the child with the ear or the hearing aids or what have you who has a problem to be fixed, they're helping fix somebody else's problem, I guess. Ricky the rock that couldn't roll I guess had that problem. And I have a bunch of references as well I'm more than happy to share information if I can help it. I'm going to go back to the beginning where my email address is because I forgot to put it on the last slide. I didn't put it there, sorry. It's Mberger@Clarkeschools.org and feel free to contact me if you're looking for additional info or any of the references that I sited. I have the articles saved and I'm more than happy to share them. Any questions?

>> I have two quick questions I think, first when you talk about parents or children of families don't stress about the communication modality, is that because they're all just using spoken language?

>> In this study, they weren't.

There were some families that were signing or were signing and using spoken language. It just didn't seem to be the stressor.

I think that the majority of kids are unilateral so they do have access to sound on one side and then bilaterally if they're amplified. So I think there is a kind of default assumption that they'll listen and talk regardless of like outside of fie soft Cal reasons.

>> And then my other question, I think I've been to a talk of yours before and I heard the 500 number of 500 kids are born with microtia/atresia. Do you feel like this is an unreported number? I feel like I get 1 to 3 kiddos a year on my caseload and I'm just one little person in one little corner of the world. I didn't know if you felt like that was an underreported number?

>> It definitely could be because the EHDI 1-3-6 data doesn't report by ideology. It reports by conductive sensorineural or mixed. So it is the birth defects registry for as much as I hate that term that collects information on a range of birth defects. And those registries like they collect information on microtia/atresia but I think they really are more sensitive to like serious cardiac issues, missing limbs, things like that. And I know in New York when I looked at the Department of Health section on the monitoring for birth defects, there was a statement saying that the information, you should be cautious about using the information because it wasn't accurate. So it could be that there are kids we don't know about or kids who have the grade two or grade one microtia and maybe a canal instead of a full closure. There was a recent article I can look up. I want to say the last name was Collins from 2019 that they were looking at the prevalence so their assessment was that 15% of children diagnosed annually have conductive hearing loss. And of those, half are related to other issues and half related to microtia/atresia. And so that's where I get my 500 from. So it definitely could be more. I'll say there are a bunch of studies that have come out recently from different countries indicating that the prevalence is increasing. So it's hard to know if that's actually increasing or is it better reporting? I don't know.

>> This was so good, thank you so much for doing this study. It really elucidates some things that are suboptimal for these families. Has this been published already or will you be publishing it?

>> Yes, as soon as I finish writing it.

>> Awesome. Thank you.

>> We're so close. It's because of the pandemic. That's going to be my excuse for everything now.

>> Anyone else? Any other questions?

>> I just wanted to ask what is your advice and recommendation for the birth hospital? Most hospitals our expectations are doing the universal newborn hearing screening. And then there would be somebody who's an expert in the field to some degree, even if they don't have a lot of experience with microtia/atresia, but as some type of UNHS guidelines, if a child is born with microtia/atresia, here's a nice handout on it or a guide on it so it goes home with them that day so they have really good resources from the get go.

>> I think it's harder than it sounds because we're dealing with public health systems. It seems like it would be an easy fix, but even getting like a basic pamphlet approved from a department of health requires so much work. I agree there should be something even for the newborn hearing screeners, because they shouldn't be screening those babies, they should be referring them. So it's a weakness in the system that we I think on a state by state level will probably end up having to work harder to address.

>> I'm wondering if you can talk about why there isn't much research in this area?

>> Because there's 500 babies born each year. I don't know if there was a tremendous amount of research for hearing kids, there was research but not as much when cochlear implants started.

Because it was interesting for researchers to study, but it was still a low incident birth event. And so I think it's the same issue and they're so spread out that the getting to research subjects is hard. Even for this, we recruited virtually and 70% of our participants were white which is not the population. I want to be respectful of everyone's time and the interpreters time. I'm willing to stay for a couple of minutes if people have other questions.

And definitely reach out to me for either the resources or articles or whatever. Thanks everyone.