>> All right ready to go? okay am just glad there's a handful that showed up so thank you for coming today. I will try to talk fun and fast to keep you awake. I taught high school for five years so if you fall asleep don't worry, I understand. My name is Andrea and I am from Idaho. And I have oh gosh... I have a bunch of different titles. I have been a pediatric and NICU nurse in a prior lifetime I've been a nurse for 23 years. I taught high school at the high school I went to for five years anatomy and physiology. I have worked for the EHDI program in Idaho for 16 years, when my second son, the one on the far left was diagnosed with a moderate severe hearing level and I used to say hearing loss and I have learned hearing level. I love it when I learn new terminology that is more reflective of what our kids have. And my oldest [past] being a pediatric nurse I did not know but hearing difference until my 10 pound are referred and we got the diagnosis. We have two boys. This is my husband and this is a ski trip we took for my middle son's 16th birthday we really got a girl, so they got Kylie who is 12 and also referred and has the exact same hearing level as her brother.

So I have had 16 years To process these diagnoses. The gift of time is huge to gain insight. To orient myself, rebalance myself after kind of feeling like I fell and stumbled for a while and reorient my family to growth.. If I looked and I can really almost be like an out of body experience and look at my younger self and how different I am now with time and all that happens during that.

So then and now, just some cute little pictures. My middle son enjoyed looking through old photos and picking out the ones I would use. This is Ryder at about 2 1/2 and my daughter Kylie. I love how she is looking up to him as this role model. And I don't know if I would have said this a long time ago but I am so thankful I have two kids with the same hearing level that they can relate to each other in a way that I can't [with their older brother]. This is them recently my oldest son is a senior going to college next year. I am getting old.

Okay so need to follow up then and now. I am so sorry this is small. I'm not very technical but this was a referral form I got when my son referred from his hearing screen at the hospital and it was amazing. The nurse who discharged me, I say this because this is not ubiquitous throughout the nations--- he was born February 12 the appointment it is very hard to see, but a fax was sent, evaluation March 5 at 230. Was already booked. This was before EHDI pals, so if this had not been written down for me yes we had the Internet unlike who sees, I didn't know they were pediatric audiologists. All I could think of was my grandma who had hearing aids at school and my dogs would eat them I didn't know anything about this. I hope that this is the norm now. I think it is still not totally. But that was then, and this is now. Let me scoot this forward here.

Texting. And we have EHDI pals which is great. How many of you guys state coordinators use texting for lost to follow-up?so we do, Idaho actually does I do this for my job for kids who refer, may have not gone onto diagnostics. I am getting the list of kids who have not gone on and I try to call [indiscernible] first rarely get anyone to answer, who answers their phone any more. Not anybody. You are like tele-marketer. Then we get text, this is one that I did and I said it's Andrea are in etc. important information do you want a phone call for the messaging or please stop bothering me. I got a one I called her, send her the EHDI pals information let me know if you have questions sometimes I get :-) or thank you so much. People would rather connect this way. Maybe it will be snapped chat one day that's how I try to talk to my teenagers. So that is kind of a nice thing to have.

Early intervention. I had both in the clinic And in the home coach base model with my two kids. But the pandemic if we can kind of look at some of the highlights of it, or some things we pulled from it was early intervention going virtual. Did anyone do that?or like telehealth, yeah, pretty amazing. So great we have that. Able to reach folks let's say you have someone who is sick you can still reach them through that way. I think we learn to be connected in person but what a great backup that we were able to do that and the power of different modalities to get through to families.

Excuse me. When my son was diagnosed in March, was not until that summer when I had a chance to meet other families and their children I was really yearning for that. There just wasn't a connection until something happened the summer that I was able to go to. That was hugely impactful, very impactful for me to be able to do that. I was so thirsty to meet other parents. Kids who were older to kind of see, like you see an adult who is Deaf or you see someone and you figure out here is what I am putting together in my schema. Now we have it at our fingertips so Gretchen is a friend of mine from Idaho. She gave a presentation yesterday. She has a podcast out so that is kind of the new thing. I am older now but where are the younger parents? what are they accessing? probably not Facebook. I have been told that is not cool. But tick-tock, Instagram, podcasts, you have to think generationally and so wonderful we have these different ways.

We have a great group called Hatch. I brought some of their brochures out to let you look at them afterwards. One of the Hatch members is in the group here from Idaho and that was wonderful. And then our hospital comedies are to give you ideas. ... my kids were younger to now all the resources we have. Let me do this real quick. I have been a nurse... I will go to it, I have been a nurse at St. Luke's for 23 years. You will love this one, Allison, this is a picture on the parent support group for St. Luke's. This is my husband he is an engineer did not cut his hair through COVID so it looks scary but that is my son Wyatt, Ryder and Kylie and one of my favorite chickens Rebecca. So I'm on the parent support parent mentor for St. Luke's and if you go to this, this website will be up on my PowerPoint we have families who donate their time and write a little spiel about what there is and they will connect through the physicians... with someone with similar diagnoses. So I am a mentor for parents caring for a child with hearing and visual impairments ear nose and throat ideology, ophthalmology. So that gives a little bit about me in case anyone wanted to contact me for help. Okay.

This is our family group. Hands invoices. We have had and we do have, it's kind of going through a reorientation which happens with support groups. It's kind of those hills and valleys so we have a wonderful parent support group which another person from Idaho jumped on the zoom call. Today we are able to get folks around the state we have a lot of rural areas in Idaho so it's a great way for parents to connect and jump on the platform, if maybe they are not ready to meet in person maybe this is an easy way for them to connect. We also have a great Deaf mentor program and snapshots. So the Deaf mentor program is relatively new. They did not have that again when my kids were little so this gentleman Michael Nelson, he was the teacher of the Deaf that came in with my second child, which by that time I'm like second rodeo, I kind of know this. We focus more on linkage acquisition [indiscernible] MacArthur Bates survey if anyone has done that any parents in here who have thrown out the word list. And I was pretty focused on language acquisition. And I wish now my 16 years later I had focused on Deaf culture I was pretty myopic as far as word, word I asked my kids that they wanted to learn ASL we took a class when they were little and they were like no. You really do miss the boat if you don't kind of really integrate them early on. So great that we have that for kids now. Snapshot, does anyone have the Deaf mentor program in the state or snapshot? okay snapshots are like little vignettes I would say that looks inside the life of a person who is Deaf or hard of hearing so maybe one who uses ASL, LSL, spoken language, cued speech which is what I use with my children. You can meet families virtually, family's home, local communities. Snapshot providers are something and if any of these we don't have that where I am from, please email me and I will figure out ways to send resources help you connect with things and help you grow that in your own state sharing seats like I have this plant let me give you the seeds. My son was born in February, paid the deductible up through December he was born in February, pay the deductible again. You are diagnosed with a kid with a hearing difference, kind of a bomb went off. Then they say your child would really benefit from hearing aids. Another bomb like weight, hearing aids, have never seen a kid with hearing aids. They are huge comparative lead to the size I just thought [indiscernible] it was hard. Initially. And my first thought was my maiden name was Corn like that vegetables so I got teased a little bit with that so I think we have all something deep in our psyche where we have been teased for something and that was my first thought is he going to get teased. Just like how is he going to learn to acquire this or that. Then the open wound just dumping the salt rock in it was oh, hearing aids are not covered by, we had to private pay insurances so it was like $4000. It was like well okay it was like $4000 half now and half in six months, not even easy installments. 2000 now and 2000 in six months. And then a group of women got together in Idaho I had emailed my representative years ago after paying when Kylie was diagnosed with hearing loss I was like I can't afford this anymore, emailed the representative and [indiscernible] was not interested in picking that up, but luckily came across this amazing woman, Alana --- whip smart, Harvard educated lawyer, emailed her she was my representative fun fact my representative was my sixth grade teacher in elementary school and Alana took it up and a group of moms that I got a real change done in our state of Idaho to have hearing aid coverage and therapy. So it was a win/win/win package.

I have never been through a legislative process. But it was an incredible incredible experience. Anyone hear from states that do not have hearing aids covered in their state? so everyone here has hearing aids covered in their state? that's awesome. If you know someone who doesn't have it covered email me and I will send you what we used. This is Gretchen, Carrie Baker, Alyssa Coleman and I think Kat, I feel like you are in this picture and this is Alana--- we did it [indiscernible] coverage for kids hearing aids part of the dream to make it happen I reminder that citizen activism really works. I had my kids right cards thinking and so this is Kylie. She said my name is Kylie and I was born hard of hearing thanks for all the work you have done I love my hearing aids I love dancing soccer basketball and my favorite [indiscernible] my son wrote a thank you because it was quite a process we had to testify but what a fun thing to do.

All right, hearing aid technology then and now.

[Audio quality deteriorating]

>> This is Ryder and Kylie when they were little, the sheet has [indiscernible] 12 to 1 this was put out like a trifold, that was not around then. So I am getting a set of hearing aids and [indiscernible] they had batteries, now they are rechargeable, but they put them in their mouth and would fling them off and it was terrifying because we paid out-of-pocket. I had them on my insurance and I was like if we lose these, we are done for it while. Somehow stumbled across pilot caps now there are tons made on Etsy. I went and got some weak tape. Pretty cool leagues out there that I didn't know existed first I got a hat and cut holes and I had to rip put Velcro on because they ripped continuously really had to figure it out for myself. Now so much more information on how to keep these things in kiddos which is wonderful you are not making parents have to reinvent the wheel. So great resources out there I cannot say anything enough about ear gear. There is great stuff out there. I'm not going to go over this but you can't really see Ryder's hearing aids that kept him from getting [indiscernible] falling in there and getting soaked. There's amazing stuff and hearing a technology that you may not be aware of because you have kids 0 to 3 and they may not need the bells and whistles but babies grow up really quickly and it's pretty cool having... And I'm not a tech person, I barely how to operate my phone but when I started researching the technology I am like this is amazing. The hearing aid technology compared, and it is also paired now with AI. Does anybody know this that hearing aid technology... That people have artificial intelligence AI looks at what the environment does and responds accordingly. So there are three brands, Otocon More Starkey AI and another one, they go deep... They onboard deep neural networks, trained easy and 12 million+ worldwide sounds and the Starkey AI has a built in fitness tracker, and noticed [indiscernible] risk for dementia my mom has had dementia for six years and [indiscernible] that's pretty cool and especially to get excited about my kids never [indiscernible] my daughter wears her hair back and people --- we are so excited that the awesome technology is here for them. It's incredible. My son Bluetooths music through them. There is an app called Otter AI that download speech to text that he uses. Just incredibly cool stuff there is a live scribe pen. It's a cool time to be involved in this because of the cool technological advances. Which is pretty awesome. And about the different gear now that you can find hearing aid pilot caps cochlear implant hats, ear gear, tiles and air tags I can't tell you how many times my son had the clip, he would rip it off and tomahawk it up in a tree and it was green. So it would be camouflaged. One flew out when I was pushing on --- I got a metal detector. Now we finally found it, now there are tiles you can put on theirs apps on the iPhone to track these. Think about the amount of heartache saving parents has anyone had the [indiscernible] parents so this is a great thing. This is just really 10 to 16 years. So cool accessibility on smart phones if you have not looked up accessibility features on your phone for hearing, please do. Even though your kid is younger there's amazing stuff that they can access on their phones. To make school as they get into more advanced schooling and grade school and junior high, high school and things become college very quick, learning the technology is pretty awesome.

Okay so being a nurse, when my son was born in 2007, there is no genetic testing available but being a nurse I was like the [indiscernible] toxoplasmosis, no I don't have cats, there is no [indiscernible] tested was negative, did not have herpes so I couldn't figure out what happened. I was extreme in wanting to find out the cause of my kids' at that point in 07, Ryder's hearing loss I went to a genetic counselor. Did I marry my cousin? No. I did not, we are not related. I have had blood testing done. I mean almost neurotic when I look back at my brain back then put my husband is an engineer. He was like... It's whatever. He didn't seem to care but I was determined to find out. I could not find out. I kind of let it go.

What I imagine in my mind... To be, to come to fruition never did. So nothing that I worried about ever really came about. All of those worries that I told myself back then, don't worry about that. Really shouldn't have. So the hearing loss was manageable. We started going, we went to speech therapy, he started speaking. It was not the monster that I thought it would be. Really wanted a girl. So we tried and we got Kylie. She was born with a hearing loss too. So then I was like okay it's got to be a recessive gene. But which one? so a lady I know who is in Oregon who has three kids whose parents are similar with all three different hearing levels told me this huge testing Iowa that looks at all the genes that cause hearing loss, so we had our blood taken and sent off. And this was in March 2012 I believe. 2011. And I got the results back from the University of Idaho healthcare. It was, I have my notes here. When was it? the blood was sent off in 2011, reported June 25 the 2012. Then I got the call on my birthday July 17, 2012. So about 16 months later we got genetic results. Okay and we were part of a huge study that was giving the blood out to figure out all the genes, recessive, dominant that cause hearing loss. Found out that my kids hearing loss was caused to Usher syndrome type II C.

now concurrent screening with traditional audiological measures and genetic tests and improved accuracy and prognosis of hearing loss. Now the turnaround time for genetics... Anyone want to guess? it is not 15 months. It's about 3 to 5 weeks. The people can get that information back. So I have met parents here whose babies, a woman I met at another presentation her baby was four months old when they got the diagnosis of Usher I think it is type IIA. there are different subsets and categories. Very quick turnaround.

This is fascinating. These are just, going to talk about genetic carrier screens. So I still teach classes at St. Luke's IA teach breast-feeding and childbirth prep. I was teaching a class probably in January and they are all pregnant and I told him about the hearing screen and I get on my soapbox and I say if your babyrefers you're going to get this screening and follow up with an audiology clinic and I showed in the pamphlet of Ryder. in this couple comes up to me after class and they said thanks for sharing that we know we have a 25% chance of the baby having a hearing loss. I was like, how?has anyone heard about this?

No... I was like how do you know? and they did genetic carrier screening. So where is my folder. So as I kind of was blown away by this. So you can look up, I have all these handouts here, so inherit test, carrier screen, single gene screen, Natura. Either when you are pregnant or when you and your partner can get your blood screen for a whole host of recessive Lee inherited conditions. I looked through this. So they know 25% ahead of time pregnant that their baby is carrying, they could be either a carrier or getting the recesses for [JJB2]

[indiscernible background voice]

>> Natera does it? okay and it must be... Right. Well they had done one of these, and I don't know which one, okay interesting. Which one did you do? Natera? okay so you can look through this but some of these have Usher syndrome..CF... Just a ton of interesting stuff. So do you know if you are carrying? or do you know anything? Okay interesting. Yes and they just did a blood test so I don't know which one they used but I was kinda blown away because it is going to change the face once they get even more and more precise. I went to the dB program yesterday and Dr. Shearer who actually was on the lab when I had my blood done for kids with Usher syndrome they are doing embryonic counseling so parents know at an early stage of the kids have whatever it may be. That's going to change the face of this because parents will come armed knowing that they will be able to research this exhaustively throughout the pregnancy and say okay before when they refer I want to make sure the baby gets screened and if they refer and they are Artie going to be 20 steps ahead. I don't need to add anything to that because you have gone through this. But that kind of blew my mind.

Okay. They must have used something different because that is what they told me at least in Idaho.

[Indiscernible background voice]

>> Oh, interesting. Okay. So if they did health plus health one, not just ancestry. Okay interesting. I have got to look at that. I got 23 and I was like I don't need to know anymore genetic so I gave it away. I was like I don't want to open the box. It's a very interesting and kind of some interesting ethical things to think about as well with that. So I will leave it at that. Pretty interesting. Dr. Shearer said that it's kind of the wild West right now. I don't know if you have heard that. Okay so kind of a little heavier topic there. --- A long time ago I got this book choices in Deafness. You are like okay, kind of heavy, huge and a resource three ring binder that I have a picture my husband fell asleep reading it. It was like very heavy with information. I love to read. So I love all the books that are out there now. By deaf authors, kids books, Kambersky. This is a book written by a Deaf author, poet and different hearing children's illustrator. So can bears ski... Can you hear me, can bears ski? has anyone read El Deafo? this is my daughter's favorite book. It's very worn. She has read it about 10 times. I think literature transforms human experience when it mirrors and reflects it back to us, that reflection that we see we see our own lives and experiences woven into the larger context of our human experience. So please type in like books with Deaf characters and authors and you will find a whole bunch of books that you can check out for your kids to read. [Indiscernible] is supposed to be great. Just great ones out there. It is so awesome. I love reading. This one gets me really excited.

So when my kids were diagnosed with Usher, I went back to school in my absolute shattered grief feeling and became a teacher of the blind and visually impaired and orientation rehabilitative specialist so I have pictures because this brings me a lot of joy. A girl I work with [indiscernible] pumpkin this sweet little boy we had a park plated and these parents giving permission just some other great kids on the caseload. This kiddo who is rocking the cutest man bun I have ever seen a kid have. He is deaf/blind and the joy that the kids bring the family I have the privilege of coming into their homes and their lives. So when you look at the horizon, as you're going to sleep early tonight or taking a flight out kind of think about what is on the horizon for your goals when you bring it back to your state or whatever you might be working with. Or working for. You want to increase your [indiscernible] follow-up maybe take a cued speech workshop or sign up for ASL class maybe say I will read four books via Deaf author or character in it by the end of the year. Maybe look at a Deaf mentor snapshots for your state. Go to an event that is kind of out of your comfort zone and bring the horizon there. So I love this proverb didn't look to the ground for your next step should greatness lies for those who look to the horizon. Thank you so much for bearing with me. I hope I did not put you to sleep. I appreciate you guys. If there's any questions I would be happy to help or answer them. My email will be on the EHDI thing so if you have questions about legislation or anything like that send me an email and I'm happy to help. Thanks so much.

[Applause]