>> Hello. Welcome to additional supports for deaf-plus families. Your presenter is Penni Echols.

>> I am so thankful that we have all had so many opportunities this week, it feels like a week. This conference, to hear the stories from families whose children are more than deaf. And I am -- I feel kind of ridiculous trying to tell mine after other moms have told what they have been through. My talk today will be focused birth to three, but we know it's a lifelong process.

I am the mom to six daughters. My oldest is a freshman at University of Nevada, Reno. My twins are 17. I have a 14-year-old, a 10-year-old, and Martha. Who is 8 now. I am employed by Nevada Hands & Voices as a parent guide and an ASTra advocate. I am the Nevada liaison for the CHARGE syndrome foundation which is Martha's rare genetic disease. I volunteer also as a member of the Board of directors for that. And I won't talk about the specifics of CHARGE syndrome today. If you would like more information on that, I have left some things up front.

I am connected to the national family association for Deaf-Blind because they are truly birth-to-earth and I look forward to, in my future, being able to support families like my own as my child becomes an adult.

And I also sit on the special education advisory committee in the state of Nevada. These are the promises that I made to you. In the program guide. And I intend to keep them. I might need a little help when we get to the end but I think that together we can do this. This is a picture we took of Martha when she had nothing attached to her. Because I'll be damned if a memorial of my child showed tubes. It was very touch and go. High-risk pregnancy even though I was 34 and had four other successful pregnancies. We were under the impression that she would have a successful heart surgery at seven days old and that she would be home by the end of the first month of her life. Just kidding. Didn't happen that way.

Because of the complications with her UV lines, they used her umbilical cord for IV nutrition and medication. And because that was so sensitive, difficult, we weren't really allowed to even touch her.

Heart surgery went well. She had hypoplastic aortic arch. Double outglut right ventrical, ASD, VSD meaning holes between the chambers of the heart and a biscupid aortic valve. Four weeks after successful heart surgery, things weren't going well and she began congestive heart failure. She never fed well by mouth and had an NG tube. She got a G tube before she was allowed to leave the hospital and oh, by the way, as you are leaving the hospital, she has referred hearing. Well, you tested it three times. Yeah, but -- we aren't sure. Maybe she just needs tubes. Maybe she's just got fluid in her ears. I don't care. I want her to breathe. I wanted her to eat. But we settled for a G tube. We wanted her home. She had five sisters who had never met her because at the time, there was an entero virus running through the hospital and they were not allowing any visitors under the age of 14. So, maternal stress, high. Infant stress high. And I want to discuss briefly her hearing diagnosis. We missed one. We missed three. I'll show you we missed six. Here breathing was extremely labored and we had multiple failed AVR tests because we couldn't filter that noise of her breath. And there's no audiologist at the same hospital where the heart surgeon works. So, you have to pick. We picked the heart surgeon's hospital. We really didn't get to pick.

I advocated for her to have imaging above her shoulders when we were looking at some complications with her lungs and her heart. Around 10 months. I really had to beg. So in that imaging, we found the deformities on the inner ear. And at that time, we had already suspected CHARGE syndrome because we had seen the colobomas and understood the nature of her heart. So we never really got a good diagnosis on her hearing until she was 13 months old. And is a picture of that big fat baby on the floor in the audiology booth and we were able to quickly get aided. Following that, we were able to get the official CHARGE syndrome diagnosis. So, delayed, but we were working on it. We had wonderful early intervention providers who encouraged us to sign with her, to just learn five signs a week. Or one activity. And that really was the key for us to learn language. Because, we did bath time, we did -- she didn't eat by mouth but we tried to get her in the highchair and we did snack time. So it was just five different signs a week. That made it easy for us, accessible for her. That was a big help.

This time in our lives was complete chaos. This is a picture of my dad who rushed from work to the hospital when I was afraid an ambulance wouldn't be fast enough. And I got yelled at, because I shouldn't have brought her in when she was in respiratory distress. But we are about -- we are 42 minutes from bed to bed. Some other parents may have had to time that themselves. But we never slept in pajamas with a bra on. I could grab the bag by the door in case the hospital called. Anyway, this is a picture of grandpa who loves her very much.

We were just unsure of what would happen and it was very difficult to make plans to allow our kids to continue travel soccer, to participate in church community. I think we are all raised to be independent and to be activities pants in our communities. And when you don't have that capacity as a parent to pay it forward or to participate or to take your turn, I didn't feel welcome.

This guy here, this is the first time he held his daughter. She was seven days old and you can tell she doesn't have her NG tube in and she doesn't have oxygen on. That's because we were waiting for her heart surgery. We were just in surgical waiting. Someone talked this morning about social supports dissolving and that's kind of what I was alluding to. I didn't feel I could be an equal participant. I was always canceling last minute. I still kind of am. It's awkward. People get tired of it. You can see their faces glaze over when they ask you how are you really doing? And you make the mistake of starting to tell them. And they freak out. So -- it's difficult I didn't appreciate at the time how difficult it was for my husband. I expected him to be my decision-making partner. But he had less than half of the information. He was exhausted. The culture in his workplace was not amenable for him to take family medical leave. He had a female partner at his law firm say I only took two weeks off and I was breastfeeding. I don't know why you think you need more time. That was that. And we were very concerned about medical payment, payment for medical bills because we were told when our daughter was in the NICU that because we owned two cars we didn't qualify for Medicaid. Well, technically true. She did qualify for Katie Beckett waivers but that person didn't understand what those were. So just a lot of stress in that time. So I take you on that journey with us so that you can enjoy some of the joy that I will show at the end. But also so that you can get an understanding for why parents are not as receptive to a lot of information in those early years. Just a lot of stress. And it takes a physical toll on your body. Ok.

So the second promise that I made to you was that I would share with you some resources. And, this is basically me sharing some of my favorite things. It's not exhaustive. And it's intended to give you, as providers, some ideas of what to Google. I am serious. No one expects you it know everything. But just have an understanding of the framework that's needed to support families like mine. And, as we are going through the slides, if something jumps out at you that you would like to share that's a resource into some of these topics, raise your hand and we will get you a mic or I will repeat it.

We didn't qualify for Medicaid. But any kid who has been in the NICU for more than 30 days probably will qualify for Katie Beckett waivers on Medicaid and every state is different. Have a working understanding of how your regional centers work, which are federally funded resources. They are supposed to be cradle to grave for children and adults with developmental or intellectual disabilities. In Nevada, that's an important resource for respite.

Tell parents that you work with how to complain. Governor's disability council and the state commission for the deaf. Anything else? Ok. A new resource to me is the regional genetics networks who are tasked with helping families get a diagnosis. Now, for us, we are really lucky to know what's wrong. We are really lucky to have a community, even though Martha is rare, we belong to the CHARGE syndrome family and that's provided a lot of comfort and guidance for us. Not every family will have that. This resource helps get the testing that is needed.

Shriner children's is really helpful for cranial facial and for orthotic help, free of charge. State of Nevada has something called the family navigation network that operates on a federal grant, which is just resource navigation which will help families apply for Medicaid for Social Security. So we, as Guide by your Side people don't have to do that. That's another handoff that we have. And the office of minority health and equity, in our state, it's been really helpful in ensuring access at appointments so if you are coming up with clients with difficulty in languages other than ASL or English, that can be helpful.

Educational support. As a parent advocate, I have relied on the ECTA for best practices and information on what should my child be receiving? What are the options and standards of Part C? I didn't do that as a parent but now as I work with families that are having difficulty in getting what they need, we use that. And, we have a library that has special-needs resource center in it. They have toys and equipment. They have books that are tactile. It's all free.

Death line network. Any families here? Ok. These are your people. If your child has any degree of vision and hearing complexities or needs, they are super connected. Super understanding really great people.

>> Social and recreational support. This isn't necessarily something that is a concern for families birth to 3, but it's good to get connection and familiarity with. Care giver action network has regular parent supports. They have also kind of an arm of political action. And helping families know how to advocate. So, I like that about them. Lighthouse guild has a monthly CHARGE syndrome phone call support for parents run by my friend Sherry Stenger. National organization for rare disease is really at the forefront of helping families tell their stories. They also have resources for children diagnosed with rare disease to pay for medications that are not covered, or that need additional funding.

And the Hands & Voices DHH plus parents Facebook group. Christina is the moderator with me. It's a great place to ask questions. Especially surrounding educational stuff, social stuff. It's a great place that's safe and that we don't feel embarrassed for being different. I think some other families have said that we don't feel like we fit in all the time. But I think together we do. The last thing I promised you was state or local specifics. The one I am sure I can give you is from the charge foundation. I work on the family engagement group. We are in charge of recruiting and treating liaisons for every state and some special populations. We are trying to find someone in every state. We have military family, we have adoptive parents. We have grandparents. Every liaison in their onboarding process fills out this state resource guide so that's one step if you are working with a child with that diagnosis. But let's think about some others.

I know that currently on my caseload, I have some families that are really rare. So, what I try to do, as a parent guide, is to thoughtfully connect them to each other. They may not have the same diagnosis. But maybe they share a commonality in another way. Maybe they have a tracheostomy. Maybe they have a G tube or need supplemental oxygen. Even if those parents are not willing or able to connect directly, I ask. What is one thing that helped you the most in the first six months in what is one piece of advice that I could share with that other family? I think that, as parent professionals working in parent-to-parent support, my job is not just to help you. My job is to help you help someone else. Because once we reach that level of self-efficacy, we are able. We are ready.

So I invite you, as providers, as parents, to build your own network. To make your own spreadsheet. To download my slides and make a piece of notebook paper with ideas that you can Google when your families need them. To host joint family events. I learned so much about -- I don't like the word comorbidity, maybe co-diagnosis this week here at the conference, that there are many other organizations that we as Nevada Hands & Voices to work with so we can make sure all kids with a hearing different can feel welcome and get the support they need.

You will hear this all the time. Ask families what they need. We don't always know what we need. Give us some suggestions. And I also think that something that has been difficult for me as a parent leader to understand is that passive information is still good information. I hate Facebook. I think it becomes an echo chamber. I don't think that it's truly accessible or equitable. I think we miss a lot of families by thinking that posting things on Facebook is reaching everyone that needs to see it. But it's a start. And passive information is still good information. I just want to encourage you to create relationships and not spreadsheets even though I said to create a spreadsheet. I know. But it's so much more effective when your parent guide says can I bring someone from the Deaf-Blind project next time?

This is my friend at the audiology office. Give her a call. It makes it so much easier. So -- does anyone have resources they would like to share? Or I will open it to questions or to early snack time. I will tell you that I love this quote from Helen Keller. The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart. And that's what it is. That parent-to-parent connection is heart to heart. Truly. So this is Martha this winter. She feels like God made it snow just for her. Because when we were visiting my husband's family in Utah, it dumped on us the day after Christmas. And she got to go to the canyon and sled. She had also been begging us to take her to a hockey game and when there was a daytime middle of the week hockey game, because that's the only time mom can take her downtown -- I can't go at night. She makes me crazy -- we made her a sign under her very specific directions and she got on the Jumbotron, you guys. That's all she wanted. Didn't care that they lost really bad to Dallas Stars. She got on the jumbotron. So there is joy. It is worth the effort. So -- I just want parents to know they aren't alone and to reach out if they need a reminder that they're not. If you have any questions, if not, that's fine, too. [Applause] thanks.

Cool.

>> Thank you. And again I -- I do have information about CHARGE syndrome and about our conference this summer so you are welcome to grab one of those on your way out.