>>PATTI: Brandi, it's 7:30, ready to get started? You are muted.

>>BRANDI: Thank you, Patti. Do we have every -- do you want me to wait a couple of minute or just go ahead?

>>PATTI: I’d say let's begin.

>>BRANDI: Let's go. Okay. Welcome, everyone. Welcome to an evening exploring My Family's Journey: Connection, Advocacy, Empowerment. Let's begin with some Zoom housekeeping. For communication accessibility we are using live captioning and ASL Interpreters during this event. A few days after the event, NFADB will have a professionally edited transcript. This transcript can be sent to you and will also be placed on the NFADB website. For viewing, we recommend that you use Gallery View, located in the upper right-hand corner of your screen. Please mute your microphone and turn off your camera using the icons in the lower left of your screen. The chat feature, located at the bottom of your screen has been set so that only Family Panelists and the Zoom Administrators can see the chat entries. We invite you to type into the chat all of your questions for the Family Panelists at any time during this event. Thank you so much. Now, my name is Brandi Hitzelberger. I live in Kentucky and I am on the Board of NFADB. I'm a mom to twins, including my son, who is deaf-blind. I am also one of the Family Panelists today and Moderator for this event. I would like to thank the people behind the scenes who have helped put this event together: Megan Cote and Jana Villemez at the National Center on Deaf-Blindness. And from the State Deaf-Blind Projects: Carol Darrah of Georgia, Danna Conn of Tennessee, Donna Carpenter of Kentucky, Faith Young of Illinois, Mark Campano of Delaware and Robert Hill of South Carolina. NFADB and families in the Deaf-Blind Community send each of you a huge shout-out and thank-you. Now, it's my pleasure to introduce to you, Patti McGowan, the President of the National Family Association of Deaf-Blind.

>>PATTI: Thank you, Brandi. Hello. And I extend a warm welcome to all. My name is Patti McGowan and I'm the President of NFADB. Our family lives in the state of Pennsylvania and I, too, am a parent to an adult son who is deaf-blind. On behalf of NFADB, we thank all of you for being here with us today and supporting NFADB's commitment to family advocacy and empowerment. NFADB is a 501(c)(3) nonprofit organization driven by a working Volunteer Board, mostly family members and a few professionals. We were founded in 1994. NFADB has just begun its 29th year supporting families with individuals who are deaf-blind of all etiologies, all abilities, and across the lifespan. NFADB believes that individuals who are deaf-blind are valued members of their communities and should have the same opportunities and choices as others in the community. This belief drives NFADB's mission as we exist to empower the voices of families with individuals who are deaf-blind and advocate for their unique needs. Today, you are about to hear from seven family members who will share their story of their personal journey. As family members, we know our journeys can be at times, raw and messy, filled with obstacles, barriers, and challenges, but also we know there are great triumphs, blessings, and lessons to be learned. It is important for families to share what they have overcome and gone through, as one day, it may serve as an endurance guide, a plan, or strategies for another family. We must, as families, pave the way for other families that come behind us in their journeys. On behalf of NFADB, our membership, and guests, we greatly thank our seven family presenters today for sharing their family journey of connection, advocacy and empowerment. And I'll hand this back over to you, Brandi.

>>BRANDI: Thank you, Patti. For many of us with family members living with deaf-blindness and complex needs, and possibly others joining us, some stories may be difficult for you to hear and some pictures may be difficult for you to see, taking you back to your own lived experiences that you have not yet processed yourself. If you have some of these triggers, please acknowledge it, breathe and remind yourself you are now in your own journey, being in the moment, breathing, and just joining us here today together with other families who understand. NFADB is here to support and empower you and your family on your journey. Today, the Family Panelists will answer your questions after the final story is told. As you listen to the family stories, please feel free to ask your questions in the chat. I will ask your questions at the end and the families will respond. So let's begin now.

[VIDEO]

>>PATTI: This is Patti. Excuse me, I think we need to unmute the video.

>>NARRATOR: Our first presenter is Donia Shirley from Florida.

[BEGIN VIDEO]

>>DONIA: Hello, my name is Donia Shirley. I’m the Vice President of the National Family Association for Deaf-Blind. I live in Florida and I’m the parent to a 5 year-old Jaxson who is deaf-blind and has CHARGE syndrome. When a baby is added to a family, invisible bonds often quickly form with others who have children of the same age. For families who have children with complex support needs, that community can seem so out of reach especially when they have a child with a low incidence disability such as deaf-blindness. A few days after our 6 week-old son, Jaxson was transferred to our local children’s hospital, we started receiving diagnoses. We learned he was deaf-blind. He was profoundly deaf and had colobomas, an eye condition that cannot be completely corrected and our medical team eventually informed us that Jaxson had CHARGE syndrome. We did not know anyone who had a child with a disability and felt incredibly lost. The community that we had built when we had our older son, people we could call on about changing diapers, and warming milk, didn't understand our new situation. We now had a child with a tracheostomy and medical issues who was deaf-blind and we didn't have anyone to turn to. We decided to look for information about CHARGE syndrome and immediately found the CHARGE Syndrome Foundation. Within a few hours of registering, I received an email from one of the staff members. This was an incredible moment and one of the first times I realized that having connections with other families would be vital for our family’s survival. After connecting with a Foundation staff member, I looked on social media and found another family with a child with CHARGE. Connecting with a mom who had a young child with CHARGE who was thriving, gave me hope for Jaxson. Seeing a child with CHARGE who was walking, communicating and doing all the things his doctors told us he might never do was a really big moment and motivated us to keep going in those early days. Jaxson spent his first 6 months in the hospital and during that time, he received in-patient therapy services. Early on, there was a moment when I recognized that our role in his care was critical. We were working on having him hold his head up and when he finally met this huge milestone, occupational therapists acknowledged his hard work and that what we were doing with him daily, helped him develop. The more I learned about how to support Jaxson’s growth and development, the more I realized that our family would be his biggest champions working to advocate for his future. If we didn't join him in his hard work and connect with other families and professionals who could help us, he would not be able to reach his full potential. At 6 months old, Jaxson was released from the hospital and we started working with the early intervention system. Unfortunately, none of the personnel we encountered had experience with a child who was deaf-blind. I set out to find resources such as a teacher of the visually impaired, a teacher for the deaf and hard of hearing and a state deaf-blind project, the Florida and Virgin Islands Deaf-Blind Collaborative. The project helped us find the resources and services Jaxson needed. Without support, it's really hard to find your footing. Making connections with families is like a snowball effect. You start to feel more connected the more you build relationships, and suddenly, you have a community. And those supports and relationships are vital to helping the whole family thrive. I learned the most about deaf-blindness once I found and began networking with the National Family Association for Deaf-Blind (NFADB). NFADB educated us about the services that Jaxson would need and provided access to professionals who helped us learn about effective strategies for children who are deaf-blind, and showed us ways we could replicate them in our work with Jaxson. Over the years, we have encountered a lack of qualified professionals and as a result, decided to withdraw Jaxson from the public school system and create a learning environment for him at home. Thanks to the support from the Family Empowerment Scholarship, we put together a terrific educational team of therapists, teachers and individuals who work with Jaxson. They see him as an individual and not a specific diagnosis. Since starting his homeschool 2 years ago, Jaxson has made tremendous progress. He can now write, identify and spell about 80 words, communicate using sign language. And he recently taught himself braille without any explicit instruction. He has an amazing speech language pathologist and she's taught herself braille and sign language to support Jaxson more effectively. He is thriving. Our family is thriving and we have found our footing. We wouldn't have been able to come this far without the support, knowledge and connections we have found through family organizations, our State of Florida’s Deaf-Blind Project, the Texas School for the Blind and Visually Impaired’s online resources and the National Center on Deaf-Blindness. No one prepares you to have a child who is deaf-blind or who has CHARGE. We knew nothing before we connected and engaged with other families and the people at these organizations. But thanks to those connections, we are now confident in our ability to be strong advocates for Jaxson. It is truly all about the connections for us and for Jaxson. Thank you.

[END VIDEO]

>>NARRATOR: Our next presenter is Ginger Knowles from Hawai’i.

[BEGIN VIDEO]

>>GINGER: Aloha. I’m Ginger Knowles from Hawai’i. This is the picture of myself and my son, Tre’. Aloha. Pictured are Tre’ and myself in the hospital. I am hugging him and trying to be strong, but there are so many questions and emotions. What is trisomy 12p? What is deaf-blindness? What is my child’s life expectancy? How many doctors appointments do we have today? When will another diagnosis be added to this growing list? Oh, he has autism too? Okay. Will I ever get uninterrupted sleep again? Will my son have friends? What will school look like for my son when daycare wasn't even an option? What happens to me, my life? There are so many questions about the unknown and uncertainties when you have a child with disabilities. I started looking for answers by searching the Internet, asking questions to medical professionals and seeking community help. You wouldn't believe how quickly I felt like I was alone in this new journey that I knew nothing about. During sleepless nights, I searched the Internet trying to gain an understanding of my son’s rare chromosome abnormality called trisomy 12p. I had never heard of trisomy 12p, let alone a trisomy with a letter behind the number. I was like, “What the what? That can't be good.” When Tre’ was born, the geneticist informed me that there are only 40 medical cases in the world. My reply was, “40? Do you mean like, my fingers and toes and your fingers and toes?” I had to wrap my mind around this because there are billions of people in the world, and he just told me there are 40 reported cases. I knew in that moment that this was not going to be an easy journey. Tre’ was discharged from the hospital on a Friday and his first doctor’s appointment was the very next day on a Saturday. And guess what? The doctors appointments have been nonstop. Basically, my life changed instantly. But not just my life, my entire family had to adjust. We quickly went from welcoming Tre’ into our family circle to learning about him and his daily needs. We put aside everything as we knew it and accepted our new way of life with our most unique family member. Here is a picture Tre’ and his family at Christmastime taking their traditional pajama photo. Bottom left, Alexia, oldest sister, Rebecca, future sister-in-law, top left, Carolyn, grandmother, Reggie, brother, Tre’, Ginger, Tre’s mother and Makalyn, youngest sister. Tre’ began receiving early intervention services at a very young age due to having physical and developmental delays. In this picture Tre’ is playing on his colorful drum set and working on sitting independently. The therapists taught me strategies to use daily with Tre’. And due to Tre’s complex needs, he ended up having an occupational therapist, a physical therapist, a speech pathologist, a vision specialist, a hearing specialist, a teacher and assistive technology as part of his team. The team and I will work together to map out Tre’s IFSP, the Individualized Family Support Plan. Having the opportunity to work with early intervention for 3 years, I gained a positive relationship with the team and we became like family. I looked forward to the weekly sessions, what I would learn from the specialists and seeing what progress Tre’ would make. Sadly, when the time came for Tre’ to transition from early intervention to the Department of Education, I was disappointed with my experience. The Department of Education was cold, reserved and impersonal, which left me disappointed, shocked and uneasy about how I could hand over my son to what felt like strangers. Some of these people seemed not to have Tre’s best interests at heart. My son is shown in this picture in his activity chair smiling with a sign below him that says, “I am deaf-blind.” At my son’s first IEP meeting, I felt the team did not validate my input. Critical components to transitioning to the IEP process were missing, such as early intervention being part of the meeting, I knew I had to advocate for my son. I immediately reached out to seek a parent advocate for additional support. The team and I went back and forth, mainly the principal for 2 years. Simple things like switches and assessments were stalled and were not agreed upon until it was evident that I was at my last straw. And I decided to change schools for Tre’. Deciding to transfer Tre’ to a new school was a tough decision, but it was time for a change and I was hoping for the best because I knew my son was not receiving the appropriate treatment or services. And no parent should have to fight constantly for their child’s education that's due to them. But let me tell you, this new school is a breath of fresh air and it's like we've taken a trip to Disney World and we're headed to Cinderella’s castle where everyone is out front to greet us and ensuring our stay will be perfect and memorable. Pictured is Tre’ at his Mickey Mouse-themed birthday party with lots of balloons around us. The staff at the new school has been highly accommodating and stress the importance of getting to know and learning all about Tre’. They have encouraged me to teach them whatever I thought would be beneficial to know about Tre’, which filled my heart with joy. So you know, it took me no time to share the ins and outs of Tre’ with the staff. We formed a bond very quickly. I was impressed when the teacher introduced Tre’ to the other students around campus, making him feel included and giving him a sense of belonging. The school recently went above and beyond as noted in the picture of the classroom with painted walls of black chalkboard paint to reduce visual distractions. The team has studied Tre’s Individualized Education Plan, embraced his strengths, and is working on building upon his weaknesses. They did not judge Tre’ by what was written on paper, his IEP. Instead, they got to know him as a person and that's all a mother wants, for their child to be seen as everyone else. And at that point, I knew Tre’ was at the right school. Who is Tre’? As you can see in this picture, Tre’ is wearing his light blue glasses and smiling. Tre’ is a loving little boy that is determined and motivated to learn. Tre’ is smooth with all the ladies. He knows how to charm them with his irresistible smile. Tre’ loves music and will try to out sing you in a heartbeat. We might not understand the words to his songs, but he is our American Idol. When you care for someone, you learn everything about the person. You recognize every sound, body language, facial expression and nonverbal gesture, you become their voice. I am my son’s voice and advocate. Since having Tre’, my life has changed immensely. Yet, I wouldn't change it for the world. I have been blessed with the happiest, go-lucky, carefree child I have ever known. Tre’ has a smile that will melt your heart and he smiles all day long. So much so, I tell him his jaws must heart from smiling so much. And in this picture Tre’ and I are smiling big together. I also have a new circle of friends who I have met through support groups, fellow FECs and the CSC Ohana Network. I have gained a community of resilient mothers who advocate for their children like no other. I have gained friends who honestly know and can relate to what it's like being in my shoes. I have a new career focusing on my passion, putting the needs of children and families first. I am honored to be the Family Support Specialist for the Hawai’i-Pacific Deaf-Blind Project. Having a deaf-blind child has opened my eyes and ears to my surroundings. And I have gained the knowledge to seeing things differently to understanding my child’s world. I have learned not to dwell on what might look negative, instead, to find the positive in all things. For we all are different, yet the same. We all have needs to be met and we all have a voice to be heard. Parents know their children the best, and we want the best for our children. We are all in this together. Mahalo.

[END VIDEO]

>>NARRATOR: Our next presenter is Karonica Mikell from Mississippi.

[BEGIN VIDEO]

>>KARONICA: Wait, don't count me out. Just give me a strong support system is what my daughter, Delilah, has shown me throughout her life’s journey. Hi, my name is Karonica Mikell, we are a family of three. We have dad, who’s Quincy on the left and you have Delilah in the middle and me on the right as shown in this photo. Now that I’ve introduced us, I would like to tell you a little about Delilah’s journey. After suffering a stroke in the womb, Delilah was born at 24 weeks at McGee General Hospital weighing 1 pound and 8 ounces. Immediately, Delilah was airlifted to the University of Mississippi Medical Center NICU unit in an incubator on life support with multiple IVs for emergency access as shown in the picture. After I was discharged, I can remember visiting Delilah and being told that this journey is like a rollercoaster ride, up and down. One minute she could be doing good and the next minute she could be doing bad. What was most hurtful was hearing the doctors say, “We can lose her at any moment.” The first month of life was very critical. I remember sitting by the phone and every time the phone would ring, my heart would race thinking “Is this the call to tell me that Delilah has passed away?” Well, Delilah survived the first month. We were relieved, happy and filled with joy. Then more news came, Delilah needed a VP shunt because she had extra fluid around her brain, hydrocephalus, but she did not weigh enough to have surgery. This is when my husband and I realized that we needed a strong support system. We could not do this alone. So, we began to talk to families in the Ronald McDonald House where we stayed, that had experienced similar things that we were going through. Talking to them gave us hope and strength and belief that Delilah too, could survive because their children survived and not to count her out. At 2 months, Delilah weighed enough to have surgery. I was happy and filled with joy that I didn't count her out. During the next 3 months on NICU, Delilah continued to have ups and downs. Well, after 5 months on NICU, coding twice and having three surgeries, Delilah was ready to come home. Delilah was discharged weighing 4 pounds and 5 ounces. She had a feeding tube, on oxygen and was unable to sit or move on her own because of her lungs. She had to be isolated to prevent her from getting sick. But now that we were home, we began to build a bigger support system. Not only did we have family and friends for support, but we started accepting services from early intervention, First Steps, home health and Hands and Voices referred to us by the hospital social worker. We continued to build our support system by accepting any services offered to Delilah. And if we felt like someone wasn't doing good enough for her or didn't believe in what we believed in, we would discontinue their services. As Delilah got older and stronger, she began to receive more services. She was referred to the University of Southern Mississippi Early Childhood Development Program, Mississippi Hearing and Vision Project, and she also attends Gwyn’s Sparkly Story Time, which she loves. We also attended webinars to help us understand how to support Delilah and help her thrive. Finally, she had a great support system. Delilah was learning and succeeding. I have learned so much through this journey and still learning. Because of Delilah’s diagnoses, her disabilities including hearing and vision impairment, her inability to use her extremities, many counted her out. They believed that Delilah would not be able to do anything. But with a strong support system and me not counting her out and having faith, Delilah is thriving. She is 9 years old, uses a gait trainer, adaptive computer, a power chair. As shown in this photo, she’s driving outside on a cool, sunny day in her hot pink jacket, a blue dress and black tights. She feeds herself small pieces of soft food. Asks for items she recognizes and can count by 1s, 5s, 10s to 100, and can do so much more. By not counting Delilah out, I realized that her accomplishments didn't happen when I wanted them to, but they happened when Delilah was ready. Something I remember a doctor on NICU telling me, “When we take her off a piece of equipment, we have to put her back on. But when she pulls it off, it stays off.” This showed me that I was not the boss and Delilah was. In this photo Delilah is sitting on the couch wearing a black skirt, a white button-up top, orange tie with glasses looking in a calculus book that she grabbed off the couch. This photo reminds me not to count Delilah out because I don't know what her future holds. In conclusion, Delilah’s success could not have happened without me working with a support team and building a strong support team that believe in her. Working together equals success. To families and support teams, don't count a child out because of their diagnoses, their disabilities or their inabilities. Just support them and accept their abilities and meet them in their zone. Remember, their success is not on our time, but on their time. Thank you.

[END VIDEO]

>>NARRATOR: Our next presenter is Ricky Teed from Iowa.

[BEGIN VIDEO]

>>RICKY: Hi, I’m Ricky Teed and I’m father of Hannah Teed, who you can see here on the screen. Hannah is almost 13 years old now. She is ecstatic to be a teenager and I want to tell you a little bit about her story about overcoming. This picture here on the left I absolutely love because it shows her overcoming a wall of roots. It's a tree that just has an array of roots that are growing up kind of a steep cliff and she's climbing up this steep cliff along these roots. And the reason why she did this is because her cousins did it. Hannah is a person that has always wanted to do what her peers have done. And she has had a great family to be able to do that too. And not just family, but also support at school, you know, with therapists, doctors, everyone around her has always helped her achieve what she's wanted to achieve. And she's never let her disability of deaf-blindness hold her back. And I sometimes think that she might not even realize that she's that much different although I’m starting to see it a little bit more as she gets older, but she is an extremely happy girl. She loves the sun. We go to Florida every once in a while to the beach. And this is a picture here in the middle of Hannah, you know, hugging a palm tree. She's smiling like the sun that is shining on her. And she's just a happy girl. And then we also have a family picture of her here on the right. So this is the story of Hannah and overcoming, you know, her struggles with deaf-blindness. It's not easy and each child is different, their abilities are different. But I know that they are happy people and as we remove those barriers, they'll be able to achieve great things. And so when COVID hit, that's what these pictures are about, we took her out of the school system because of some of the restrictions they were going to place on her. And we decided to homeschool. And I guess I may not realize all that Hannah goes through. But these are some of her accommodations. Like for typing class here in this picture on the left, is you know, an extra screen with extra-large fonts that she can see the words and type. And the one in the middle is Hannah doing her math problems about 3 or 4 inches from her face. She has to be able to see the normal size font. And then she's doing classwork. And one of the things that we advocated for Hannah was to get the interpreter in our home during COVID which was no small feat. But as Hannah was doing some virtual accommodations, some special education services, her interpreter was on the screen with the other person and with the information and she wasn't able to do it all because it was too small. And so, we got her a larger computer screen. We got an interpreter in our home, which was a fight and struggle with our IEP and administration, but we were able to do it. And I know that we might think, you know, we have a small and insignificant voice in this big system, in this educational system, but I can tell you that your voice brings power, power to your child and then those that come behind you. And that power is because as you educate yourself and understand what you're able to ask for and advocate for, that's truth, you know. As you speak truth, they cannot tell you, “no.” They can maybe ignore you, not return your email or phone call, but if you're persistent, you'll be able to overcome those challenges and get accommodations that your kids need. Hannah only wants to do what her peers are doing. And in this picture in the middle this is her family when we were in Kansas. She's got her little walker that we were at a little athletic event and she would run around with her walker. And I don't think she really ever saw herself as different. Caleb, her older brother, really provided guidance and kind of protection for her and taught her a lot of things. But Zoe, her little sister, who is 20 months younger than her, you know, would show Hannah what she should be doing. And so, Hannah would keep up with Zoe and really pushed her along in those early years of Hannah’s life. And so, she's had a good support and now she has two other younger siblings to, you know, help entertain her. And then that's myself and my wife in the middle. But as Hannah strives to keep up with her peers, she does need different accommodations, but she's happy. You know, she has a 3-wheel bike to ride around the block with her siblings and her friends. And then this picture on the right is her in the middle of a fast-moving creek or river I should say. And mom might not have been too happy about this one, but her other cousins were going out there and sitting on the rocks, so I took her out there and I stepped back and took a picture of her. But she just loves doing what her friends and siblings do. And that's what we do as parents, try to remove those barriers so she can do that. And that's what we need to do when we advocate. And ever since the beginning, we've never set limitations on Hannah. And we always try to remove those barriers because I know that as kids, they are fighters. They're willing to put the work in and overcome those limitations that they may have on their body, but they're willing to work at overcoming that. She does play the piano. She practices usually every week and goes to piano recitals with her siblings, this picture which is what she’s doing in the picture on the left. This picture in the middle is her baking an apple pie. She wanted to make an apple pie. And so, I got all the ingredients and she helped cut up all the apples and put in the oven, so she was able to make an apple pie. And this picture on the right is she had a science project where she planted some seeds and they started growing. And so we put them in the ground on the side of our house. And so this is a picture of her picking those tomatoes from the plant. And I think my teacher, after this summer had said she really enjoyed those plants that you guys did. The teacher was surprised. She thought, you know, you plant them, see them grow a couple of inches and then they'd all die off. But Hannah would water them and watch them grow and was able to eat the tomatoes too. So, she really is enjoying life even among all the struggles that she does go through. And as parents, we try to remove those barriers so she can keep up and keep moving on. I thank you for the time you guys have given to share this story about Hannah and what we've been trying to do to help advocate for her.

[END VIDEO]

>>NARRATOR: Our next presenter is Brandi Hitzelberger from Kentucky.

[BEGIN VIDEO]

>>BRANDI: My name is Brandi Hitzelberger. I live in Louisville, Kentucky with my husband, Eric, and our twins, Alex and Abby. On the screen you will see a slide of our family. It's a picture of all four of us standing with our arms around each other smiling. Alex and Abby were born 19 years ago at 25 weeks. Abby spent about 3 months in the hospital and was fortunate to not have any complications besides retinopathy of prematurity and cataracts and high-functioning autism. She graduated from high school and will be attending college in the fall. Alex spent 4½ months in the hospital. He had a brain bleed, liver abscess, multiple surgeries from gestational issues and multiple complications. Due to his prematurity, he has cerebral palsy and is considered deaf-blind. I started advocating for my kids early since they were premature. First it was the hospital, then the insurance companies, next, therapists and doctors and, of course, their schools. Alex goes to Kentucky School for the Blind in Louisville. In Kentucky, the Kentucky Department of Education makes all the decisions for his school. His school funding isn’t per student like most districts. It comes from one pot given by the state legislators. That pot of money has to include everything from salaries to lodging students in the dorms, transportation and everything in between. Because of this type of funding, Alex and I started going to the capitol to try to request more funding for the school. We found this to be a difficult task. While people understand how most schools work, no one really understands the importance of what a school for the blind or a school for the deaf does and all of its complex needs. I have learned that it's easier to ask for the legislation to change than to ask for funding. Any change or addition to the budget has been a big ask. A big issue that I’ve come to learn about is the way school districts categorize a student’s primary disability. In Kentucky, most students that are deaf-blind are qualified on an IEP as multiple disabilities. We met with legislators to encourage them to provide better training for ARC staff and to place students in a more appropriate category on their IEP. Doing this would enable students to get all the resources that they need. While Alex’s teachers understand the vision side, they struggle to understand that even a mild hearing loss for him can impact his everyday learning. Going to the capitol can be a great learning experience. While there, Alex and I have done everything from attend committee meetings, page for our state senator and schedule individual meetings with our legislators. Of course, this might not work for every child, but if your child is able to participate in some way, having them there can make a difference. If they can't be there physically, definitely find a way to include them. Most states have a page program in place. If your child is comfortable being a page, please sign them up. A page is someone who runs errands for the day and gets to spend the day on the House or Senate floor assisting their representative. It's a great way to get students involved and let them experience government. This is a great way for our students to get on the floor and spread awareness about deaf-blind students and their cause. In the slide shown Alex is standing with his cane next to Senator Julie Raque Adams, they're both laughing and smiling. You can tell they're enjoying the moment. This was a picture of when Alex was on the Senate floor as a page. You can apply for this program online. In Kentucky, they offer a Sunny Page Program. This is a day that allows for children with exceptional needs to spend time with their legislators, get on the floor and be introduced and just feel really special. They get a T-shirt, a certificate and it’s just a really fun day. Check out your state’s website and see if they offer a special day for your child as well. If not, encourage your legislators to start one. Every year we try to make appointments to visit with our state senators in their office. I suggest making appointments with your State House or Senate Representatives. These legislators are more likely to meet with you since you're one of their constituents. After my representative, I try to look for committee chairs, especially one on health or welfare or education committees and anyone in leadership. I try to watch and see who sponsors education or health bills and listen to see who gets things done. Make sure you meet with people who can help your agenda and make a difference. Meeting with someone who's going to retire in the next year may not help you much. In the slide shown, Alex is using his iPad or talker to show a video and show what a day is like for him at school. Alex is learned over next to Senator Gibbons at his desk and Senator Gibbons is really interested in what Alex is showing him. Since deaf-blind is low incidence, it's important to tell your child’s story to help legislators understand why we need their support. I let Alex tell his story in a video we made that tells about his day at school and how he learns. The video is on YouTube and I’m happy to share the link with you sometime. We’ve also made a short iMovie that shows him using tactile symbols, getting O&M and just being Alex. Alex also used his talker to interview people with specific preloaded questions. We've also taken vision goggles, headphones, and asked them to put them on so they can try to understand what it's like for Alex. Take plenty of pictures and share your experience on social media. Social media is a great way to help spread your cause and celebrate the legislative experience your child has had advocating. Most of all, follow up with thank-yous. And if possible, have your child sign the thank-you too. Let them know what a great experience it was and that you appreciate the meeting. In the slide shown is a photo of a thank-you we left this year when the Kentucky Deaf-Blind Project came with us to the capitol. The picture shows a word block with tactile symbols with the words written and brailled, “Together, we make change.” This is an example of a different way you can leave a personal thank-you. And it's a great way for them to remember your visit. If you're overwhelmed with the idea of meeting with political leaders because my goodness, don't we all have enough going on just having deaf-blind children? Don't worry, we have resources. The National Family Association for Deaf-Blind or NFADB is a great place to start. Joining this group can help provide resources on how to learn advocacy at all the levels. I have learned to advocate not only at my state level but also at the federal level with their help. Being a member provides training and networking opportunities, plus information and resources that would take me hours to gather. Also, I love knowing that I have their continued guidance for the rest of Alex’s life. No matter what level you're advocating at, just know that your child’s voice matters. You are making a difference. And together, we can make change. Thank you.

[END VIDEO]

>>NARRATOR: Our next presenter is Rhonda Bryce from Oklahoma.

[BEGIN VIDEO]

>>RHONDA: Hi, I’m Rhonda Bryce from Oklahoma. This is a picture of my husband and me with our four oldest grandchildren. My granddaughter, Ginny, on the far right is my connection to the National Family Association for Deaf-Blind. Ginny was born in 2008 with a rare genetic disorder that resulted in her progressive loss of vision and hearing. We called her our sunshine. We often sang to her, you are my sunshine. Here is a picture of Ginny and her papa, my husband, Dick, in a special frame that is embossed with the lyrics, “You are my sunshine, my only sunshine. You make me happy when skies are gray. You'll never know dear, how much I love you. Please don't take my sunshine away.” During Ginny’s first year, I felt so excited to have my first grandchild. I was extremely grateful that they lived just four blocks from us, an easy, short walk. But my excitement was tempered by some concerns that I had about Ginny’s development. When Ginny’s diagnosis came just before her 2nd birthday, I was devastated to learn that she would progressively lose her hearing and vision. Seeing my daughter, Melissa, more broken than I had ever seen anyone in my life tore my heart out. It was agonizing to wait for weeks with Melissa until the initial doctor’s appointment for Ginny at Johns Hopkins. We all had so many questions and we wanted answers. It was so frustrating that there was no one in our city or our state who knew anything about Ginny’s disorder. I watched helplessly in the following years as Melissa tried to fit in with her friends who had typically developing children. I tried hard to be the friend that Melissa needed, but I was her mom and that wasn't the same. In this photo you can see Ginny enjoying a stroller ride through the neighborhood as Melissa and I would walk and talk. I treasure those moments. In this photo Melissa and I were participating in a run to raise money for the foundation’s supporting research for Ginny’s disease. We both tried very hard to be strong for each other but there were times we just couldn't. Worry and helplessness would wash over one or both of us. As Ginny’s disease progressed and her vision was diminishing, I had to learn to allow her some space inside my private bubble. As a former kindergarten teacher, I have always been a bit of a germaphobe and there were times that Ginny’s disease progressed that she needed to take ahold of my entire face and hair with her sweet little hands which weren't always clean and see if I was her mom or her mimi. Melissa had long hair and mine has always been very short. We have the same voice tone and inflection. And as Ginny lost more and more of her hearing and vision, this process of identification for her became more and more important and I had to learn to accept out of complete love for her this need that she had and to become more okay with it. I will always remember the fun that I had with Ginny one particular day. Shortly after she received her hearing aids, she was probably 3 years old and for the first time, she was showing signs of being able to hear some things. I was watching her at my house for Melissa. At their house they had two dogs who were always outside and Ginny loved looking out the back door and watching Duke and Duchess play. While with me that day, I noticed that Ginny was looking out my back door intently watching for something. I sat down on the floor and explained “Mimi and papa don't have any dogs.” She looked at me like I was crazy. And I said, “Do you miss Duke and Duchess?” After getting no response, for some reason I just made a little barking sound. Well, Ginny started laughing her cutest laugh ever. So I did what any adult would do, I sat there and continued to bark and howl until she and I were both in tears laughing so hard. Finding sounds and facial expressions as a way to connect with Ginny as she lost her hearing and vision was an important way for me to show my love for her. Taking Ginny to one of her preschool music classes proved especially challenging for me. I was happy that Melissa asked me to take Ginny, but I was on the verge of tears the whole time I was there. The reality that Ginny would never be able to do what these other children her age were doing was very apparent to me that day. I was grieving what could have and should have been. Not only did I have moments of anticipatory grief while Ginny was alive, but my anger hit an all-time high when Ginny was about 4½ years old. She needed a special, very expensive safe bed. Initially, our state healthcare authority denied the claim. And in the courtroom, their attorney stated while looking at Melissa, “She's not glass, you know? She won’t break.” These types of fights and heartaches are no doubt similar to the ones that your families have dealt with. They are exhausting and heartbreaking. I was furious at the lack of understanding shown about my granddaughter’s disability and the lack of respect for my daughter, who is a wonderful mother, who was only asking for what was needed and necessary for Ginny. Ginny died at the age of 6½ in 2015. My first response was concern for Melissa. I put aside my pain and grief to be strong for her. I tried to be available to help her with her other two children. I felt at times, I had nothing more to give, but I wanted to give more. I had sleepless nights and exhausting days before realizing that I couldn't function because my heart was physically hurting. I was literally having chest pains that I had never felt before. I’m certain that I was suffering from a broken heart. I’m so glad that I called my doctor. He called in a prescription for me and thank goodness he did, I needed the help. The prescription helped with my pounding heart and hurting heart. I was able to finally sleep some and I was better able to help Melissa and the kids during those difficult and dark days. There continues to be time when the grief returns and my heart breaks for my loss and for Melissa’s loss. Just recently, Melissa and I attended a school program at the school where her two children now attend. The group of children that would be Ginny’s classmates, played “You Are My Sunshine” on their guitars. Melissa and I both had tears in our eyes and a lump in our throat as we thought about what could have been for Ginny. I know that I’m a better person because Ginny taught me the true meaning of unconditional love. And in this picture as the song in the musical “Wicked” says, “because I knew you, I have been changed for good.”

[END VIDEO]

>>NARRATOR: Our final presenter is Faye Manaster from Illinois.

[BEGIN VIDEO]

>>FAYE: I’m Faye Manaster from Illinois. I’d like to tell you about living and learning with my daughter, Maya, who’s deaf-blind. I’m very proud of her and want to thank you all for joining us today. Here is a picture of Maya and me where I’m standing behind her, she swings on an accessible swing outside a building at a park in our neighborhood. We're both wearing fleece jackets. My daughter, Maya Eldar, celebrated her 41st birthday last month just about the same time I learned that I was honored with receiving the Steve Perreault Professional Award from the National Family Association for Deaf-Blind. This award is given to a professional who has created a lasting and profound impact on quality of life for individuals with deaf-blindness and their families. Maya and I have had a long and complicated series of adventures and learning activities since the day she was born, learning new lessons with each uncharted step and barrier encountered along the way. Maya was born in 1981 shortly after the federal special education law, now IDEA passed but before Part C of IDEA which mandated early intervention came into effect. I had been a professional in the special education field focused on students with learning and behavioral challenges. I had experience as a classroom teacher, guidance counselor and school administrator in a variety of settings. And I earned my master's degree in special education in 1979. In no way did my prior professional educational work experience prepare me to be Maya’s mother and advocate despite what some professionals thought. The many lessons I continue to learn as a parent, however, have informed me to become a better professional. Computers, the Internet and social media were not part of daily life in the 1980s. Back then the only relevant skill and self-educational option I had was to go to the library in person and look up published research studies pertaining to children who were blind or who had multiple disabling conditions. Fortunately, I did have the courage to ask questions and to challenge the many professionals who expressed negative opinions about Maya and her ability to learn. I’ve often been asked to share my perspective on what works for Maya and I always go back to my umbrella paradigm. In order to interact with Maya, her hands must always be free to support her in terms of communication and navigation. If you and Maya are out in the rain, it will be impossible to support her effectively if you insist on using an umbrella. This is one of the reasons that raincoats with hoods exist. And if you can't give up your umbrella, you won’t be able to safely and effectively interact with Maya. Here is a picture of Maya as a baby crawling in the house. She has curly hair and a barrette on top of her head. She's wearing a pink shirt and light and dark green striped leggings. Maya was born prematurely and spent 14 weeks in the Neonatal Intensive Care Unit, the first 9 of those weeks on a ventilator. She was discharged to home on room air and oral feeds. Prior to her discharge, she was seen by an ophthalmologist. The next day I got a message on my answering machine stating “The ophthalmologist saw your daughter and she is blind.” When I came in to visit her later that day, I spoke with the neonatologist and requested that Maya receive a hearing test. Obviously, this was well before passage of the Newborn Hearing Act in 1999. I was told not to worry about this because an audiologist saw Maya and she doesn't act deaf. I asked about early intervention and I was told that it was not really necessary. Each month I brought Maya back for a neonatology follow-up visit and I got the same message. It was only when a young covering neonatologist saw Maya and agreed with me that there was something else wrong with her. Then Maya was referred to ENT, Audiology, Neurology and PT. At the time of her first birthday, she received the additional diagnoses of deaf-blindness and cerebral palsy. At that time, Maya was enrolled in a community early intervention program even though there was no EI mandate. When I shared her new evaluation, Maya was expelled from this program. I was told that “Your daughter is too severely handicapped and could not be helped.” I then asked where she could receive EI therapy services, they replied, “Elsewhere, but we have no idea where.” This experience marked a turning point in Maya’s life that connected us to the world of deaf-blindness. The first major changes included connecting us to the National Lekotek Center, a now closed toy library for families of children with disabilities where information was shared about a program that is now our State Deaf-Blind Project. Maya’s pediatrician referred her to a newly-minted developmental pediatrician, the first medical professional who believed that Maya had the potential to learn, the precursor to our State Deaf-Blind Project, arranging for a teacher to come for weekly instructional home visits, inviting us to participate in family training events. In Maya’s early years, I connected with the International Association for Education of the Deafblind, now called, Deafblind International and attended their second international conference in New York where I heard Peggy Freeman speak and I met parents from other states. I also learned about Sense, the deaf-blind organization in England and CDBRA, now Canadian Deafblind National and attended some conferences in Canada. All of this took place in the pre-Internet years. I joined each of these organizations as a family member, subscribed to their publications and accessed helpful books published by their members. Maya’s life was also marked by many challenges and barriers in efforts to obtain an education and participate in community activities. Fortunately, our now State Deaf-Blind Project always had Maya’s back. For example, at age 3 a nearby special education school with a deaf hard-of-hearing program refused to enroll Maya, saying that she was too low-functioning. Our deaf-blind consultant contacted our state’s board of education and Maya was able to enroll. During her first year there the teacher of the deaf and hard of hearing worked closely with Maya and she made 24 months’ of progress in language development in just 9 months. I was able to join sign language classes for parents, a great help in the need to learn a new language to raise my child. Later, our homeschool district sent Maya to Perkins for an evaluation, and she was able to transfer to our local grade school with support of a one-on-one teacher. Here is a picture of teenage Maya. She's sitting at a desk wearing glasses and an auditory trainer and she's sitting at a desk reading an article in braille. Here is another teenage Maya picture using tactile sign language with a staff member. The photo only shows the staff member’s hands. Maya had a wide variety of experiences and challenges during her school years. With the assistance of her dedicated itinerant teachers, therapists and deaf-blind educators, she learned to read and write braille to communicate via tactile sign language, to ride a tricycle and to walk without a walker. Here is a picture of Maya’s high school graduation day with me and her grandfather and two school staff members. For high school, Maya attended a deaf education regional program at a high school in a different school district. She was the first deaf-blind student to attend this school. She earned a regular diploma, graduating in 2002. She then spent a year at the Helen Keller National Center in the traditional program. Our state’s Deaf-Blind Service Center, now called, Project Reach, supported training for families and stressed the value of networking with other families. Some of the families whom we met in Maya’s early years, remain close friends today. As a professional, I continue to advocate for family-professional partnership with collaboration as a take-home message which must be built into the array of training opportunities available today. Here is a picture of Maya. She's sitting on an upholstered chair and she's massaging a golden retriever standing in front of her. This actually is a picture from HKNC. The years following Maya’s studies at HKNC have been very challenging. Our state, unfortunately, has been notable for long waiting lists and lack of options for adult community living. Maya’s diagnoses of deaf-blindness and cerebral palsy together with her ongoing need for tactile interpreters as well as braille often exacerbate these barriers. We have tried a variety of programmatic options over her adult years. All programs have pluses and minuses. Although Maya completed a training program in dog massage and dog Reiki which was supported by our state’s vocational rehabilitation program, we've never been able to find any entity to support her ongoing customized employment. Here is a picture, a recent picture of Maya sitting in her wheelchair at a table wearing a blue paisley dress covered by a white smock with clay stains. Her left hand steadies a shaped bowl while her right hand is running a sponge inside it. Fortunately, for the past nearly 8 years, Maya has achieved her dream of living in an adult apartment, and lives in an accessible CILE (Community Integrated Living Environment) often referred to as a group home with some dedicated staff who have learned to sign. She is currently dealing with some very significant health issues however. Just over 10 years ago, she developed secondary dystonia and lost most of her gross motor skills. She's had a Baclofen pump implanted and is able to transfer and to walk in doors with a specialized walker. Two years ago, Maya was diagnosed with cancer and underwent surgery and radiation therapy. Many complications ensued, resulting in 16 hospitalizations over the past 2 years. Here is a picture of Maya and I sitting outside during the height of the pandemic with our PPE. I was informing Maya of her diagnosis and upcoming medical procedures. Dealing with the COVID restrictions at the same time has been an enormous challenge. Several times I have rushed to the hospital to be with her only to find her in restraints and staff attempting to use a video relay system to communicate with her. Maya continues to ask when the COVID virus rules will be finished and we've both had to learn new signs to add to our vocabulary specific to the pandemic. We continue to face new, undreamed of challenges. We live from one day to the next with the support of caring and concerned professionals in Maya’s life. I continue to learn from and with Maya. We continue to stay connected with other families of deaf-blind children. We often say that without our children, we never would have gotten to know each other. We are also fortunate to stay in touch with some of the outstanding caregivers and professionals who have been part of our lives over the decades. This is our life. We continue to move forward day-by-day and we still leave our umbrellas in the closet and rely on our raincoats and ponchos with hoods.

[END VIDEO]

>>BRANDI: Hello, again. We will now bring the Family Panelists on the screen to answer questions. Just a reminder, feel free to submit any questions in the chat to any of the Panelists. We're happy to answer any of your questions. And Panelists, thank you for your time in telling your stories. I'm going to ask you a question and feel free to unmute yourself and answer your questions. Okay. Have patience with me because I've got multiple things going here. Okay. Donia, you're on the hot seat first. Can you tell us the reason for joining multiple state and national organizations?

>>DONIA: Hi, thank you for the question, Brandi. This is Donia. As I mentioned in that video, kind of there was that moment when I first was in the hospital with Jaxson where I connected with the outreach person from the CHARGE Foundation and also connected with other families. From that moment I realized how important it was to be connected in this community. And as Jaxson got older and I needed more resources, I think one of the driving factors behind me connecting to certainly local resources like our State Deaf-Blind Project was to just get information. And then as I got more information, I realized how great it was to be involved, to connect with other families, to share our story, share the resources that worked for us, and also, to hear what resources and information was working for other families. And that led me to being a Parent Liaison for the CHARGE Syndrome Foundation. I'm on the Board of NFADB, and just really wanting to connect more at a national level to be able to meet more families in different states. And in making those connections, as I shared in the video, I learned what was happening in other states. You know, in Florida we don't have the same kind of early intervention supports that say, Texas has. And in learning what other states are doing and kind of having the ability to speak to people from different spaces, it's really helped us with Jaxson. And so, I think ultimately it's been to connect not only for ourselves, but to connect with other families so we can all share our resources and stories. Thank you.

>>BRANDI: Thank you, Donia. I'm talking to myself because I'm on mute. Okay. I'm going rogue for a minute and I have a question for Ricky that I didn't submit, so if I get slapped on the hand by Patti tomorrow and Mary, I'm just going to take the brunt of it. So, Ricky, I love the comment that you made, I can't remember exactly, I'm killing myself now for not writing it down, but you said something about keep advocating for your child because it makes the difference, not only for your child, but for other children in the future. And I'm a huge proponent of that and I think sometimes it's not a bad thing, right? But as parents we can get so caught up in our children and what we are doing for our children, we can forget that our advocating, you know, has a chain and it affects everybody. So I don't know, I mean, can you just add on to that a little bit and tell maybe, you know, how it can affect others? And, you know, how your passion can, even though it doesn't affect your child necessarily, how you can keep going to continue the fight, even though you won't see it for your child, it might affect somebody else. Does that make sense?

>>RICKY: Yes. No, that does make sense. And I think a lot of what we see in parents, you know, when we have something that we want to change in our own child's life, whether it's in the education system or some kind of accommodation, I think a lot of times if we can think bigger picture and realize that there are so many other people that are going through this. And listening to Faye's story about the pre-Internet time and that she had to go, you know, gather the information. And then when she went to the International Conference, she saw all these other people. And I just think, you know, as we can advocate for our own families, we need to also step back and reach out to our legislators and try to change those laws because there's other people that don't advocate as much and we need to help those people out as well. Because what I've learned from all these stories is that these kids, even with the multiple disabilities that they have, they can learn. And if we can remove them from all these distractions and give them exactly what they need, they will learn and be an asset to society and have a wonderful and happy life.

>>BRANDI: I agree. Thank you. Let's see, I've got -- Okay, it says: Brandi, how difficult has it been to get legislators to listen to you and to help you change legislation for such a low incidence disability of deaf-blindness? Is there one thing that you have found to be more effective? Actually, at the state level here what I have done is I've done a lot of research and I have tried to find legislators that have connections or children with some type of disability or some connection to -- I guess to that network and I try to connect with them. And I also connect, like I said, with health and welfare and the education committees. I have found that they tend to be people that will listen to you and have a little bit more compassion. We, I think, have been very fortunate, when we went into our meetings, we went in thinking we were going to get 15 minutes and they gave us 30 or 40. Because I don't think they've ever -- they didn't have any knowledge of our community and they've never met with anybody, they were really interested in what we had to say and they really wanted to learn about it. So they were really interested and so they were like, “Hey, if you can work a letter up on these facts, we'll help support you with the state.” So, you know, I think just you might be surprised if you even, you know, reach out to your local legislator and say, “Hey, my child is your constituent and this is our need.” Because I think we just found they just don't know what they don't know, right? And I think this year we'll find out they want us to come talk to the education committee because they just don't hear about this population much. So that's kind of what I've done. I just try to dig and find who has this interest in these low incidence kids. Ginger: Good for you for finding an alternative school. Is the school a private school or do you have an out-of-pocket expense? And is there state funding if you do?

>>GINGER: Aloha. So my son goes to a DOE school. Interestingly enough, my parent advocate and the district educational specialist suggested the current school that my son is attending. After fighting constantly with the previous principal, my parent advocate said, “Hey, Ginger, there's a school right down the street that we think you might be interested in.” And I kind of was just like, “Eh, I'm not sure.” And just like Ricky had said how he advocates for his daughter, I felt like for a long time I needed to stay put and advocate for my son. But there was an IEP meeting when something happened and I ended up -- Oh, I'm sorry, I must go back and say at the time my son was on a homebound setting because he had seizures. Every time I would take him on campus, he would have 5 seizures in like a 40-minute time span, so he was on a homebound setting. I had invited the district educational specialist to come meet Tre' at my home because he had said something about not really meeting Tre' or seeing Tre', but he has heard so many wonderful things about Tre’. And I said, “Oh, would you like to meet him?” And he was like, “Is that an invitation?” I said, “Yes.” And he said, “Sure.” I said, “Okay, well come to the house.” So he came over and he observed Tre' and it was like a special observation. And shortly after, he contacted me and he, too, said he thinks I would like the school in the opposite direction from my house. And I thought about it for a while and I said, “Okay, this is two people telling me about this other school.” And when I finally decided to move my son, it was a complete opposite experience. I was like, “Why didn't I do this sooner?” You know? And it's so funny, I think things happen for a reason and I think things happen at a particular time, but even -- We had a parent/teacher conference just the other day and I was explaining to the teacher, I said, “You know, I would like for Tre' to do some more sign language” because here we don't have interveners here. And I said, “Does anybody on campus do sign language?” And she says, “You know, I know sign language.” And I said, “Get out of here.” She said, “My brother was deaf.” And I said, “Really?” And I just lit up. I was like yay! She said, “Yeah, we can start doing sign language with Tre’.” And I was just like, “Look at this.” You know? So I think us as parents, we go through tough times because, one, we're learning a lot of different things and also to help other people, but I think along our journey things do get easier as time goes on. So, yes, it was another DOE school. My parent advocate and the district specialist, they referred me to the opposite school, for the new school. So no out-of-pocket costs, so yay to that.

>>BRANDI: Exactly. Thank you. I don't know if this is really for any of the Panelists, but maybe Patti can help with this: How did each of you find your State Blind Project? I'm sorry I read that wrong. I was put in touch with mine. I don't know how anybody else found theirs.

>>FAYE: Well, this is Faye. That was part of my presentation that my daughter had been referred by the NICU follow-up through the National Lekotek Center, that unfortunately, is not around anymore. And they knew about the Deaf-Blind Service Center and they referred us. But in those days, they weren't funded year-round. So we had to wait for the school year to start again in September. But again, you know, that was in the prehistoric times before the Internet was part of people's lives.

>>RICKY: This is Ricky. I don't remember exactly how we got connected, but I know it was very early on, probably when we were still in the hospital. My daughter was diagnosed with CHARGE syndrome at 2 days old. And I just remember going to a conference in Iowa, too, as well. So I know we were connected early on and we had probably one of the best Deaf-Blind Project programs in the country because Megan Cote was over that project. So we had a lot of good support and it was a good time and we learned a lot. But it was definitely when we were still in the hospital, we learned about the CHARGE Syndrome Foundation and the Deaf-Blind Project.

>>KARONICA: This is Karonica. We were sent to the Deaf-Blind Project through the University of Southern Mississippi. Once we accepted them, then they introduced us to our Deaf-Blind Project.

>>DONIA: This is Donia. Our Deaf-Blind Project found us. One day I got a call from our family engagement coordinator, Pam Kissoondyal and she introduced herself. Somehow she got my number, I don't know how. And that was amazing because I don't think I would have found it otherwise at that point.

>>GINGER: This is Ginger speaking. Like Donia, the Deaf-Blind Project contacted me. Possibly they got my information from the hospital, maybe through their Comprehensive Service Center. I believe I went through the Comprehensive Service Center for an event and maybe sign language and then I got connected with the Deaf-Blind Project.

>>FAYE: I mean, I can let everybody know how the hospitals got your contact information because I have worked for many years in public health and maternal child health sector and now that there are Federal laws, there’s mandated newborn hearing screening, and in every state they must be involved with the Title V Children with Special Healthcare Needs Program. And they have something in Illinois, it's called APORS, but it's for neonatal follow-up. And we advocate all the time to change the name because, unfortunately, it stands for Adverse Pregnancy Outcome Reporting System, which, you know, is very negative. Any time there is a diagnosis or they're suspecting that the child will have some type of diagnosis, the Early Intervention Mandate is required and, you know, pediatricians also have a mandate to refer children to early intervention. So a lot has changed, but there's still a lot more work to do.

>>BRANDI: Rhonda, did you say how you were in touch? How were you in touch?

>>RHONDA: Well, my situation is somewhat different in that my granddaughter, Ginny, was born and appeared to be fairly healthy. I mean, she kind of needed a little physical therapy. She was a full-term baby, but that was the healthiest that she would ever be. Her diagnosis of Peroxisomal Biogenesis Disorder is a progressive disease. So she progressed from her healthiest at birth to, you know, losing her vision, her hearing. She had problems with bone density. She needed a feeding tube. But anyway, there were a lot of issues that she went through in her 6½ years of life. When Melissa received Ginny's diagnosis, Ginny was nearly 2 years old and there was no family support group. There was a small Yahoo, if you can go back that far, Yahoo group that met, I guess it was an email-type group of about, I don't think more than 20 people. The doctor at Johns Hopkins that met with them and explained Peroxisomal Biogenesis Disorder to them told them there was no support group, but there was one person who was kind of interested in keeping this Yahoo group going. So Melissa asked would the doctor please share her contact info. And these two women then cofounded the Global Foundation for Peroxisomal Disorders back in 2010 or 2011. And it is a 501(c)(3) foundation now serving hundreds of families around the world with this very rare genetic disorder. So I was kind of connected. Jana connected me with this group through the GFPD. A long answer for a short question.

>>BRANDI: I know that we're running really close on time, so Patti, I guess, Mary, should we wind it up? We have a couple more questions, but --

>>PATTI: This is Patti. I know we have to be very respectful to our ASL Interpreters and our Captionist tonight, so we could always send the questions to our Panelists --

>>BRANDI: Okay.

>>PATTI: -- and send them back out, if that would be okay. I know we could all stay on here for hours.

>>BRANDI: Right.

>>PATTI: And what wonderful stories and how we are all learning. And I just have to say this has been wonderful and thank you, presenters, and thank you to everyone that attended, and especially to those that have helped and supported NFADB to make this a success tonight.

>>BRANDI: Okay. So now if we can bring everybody on the screen, turn on your cameras and switch to Gallery View so we can all see each other that would be wonderful. And, of course, thank you to all the Panelists. So just a couple of fun facts, this webinar resonated with households from 30 states, 3 countries: USA, Germany, and Zambia. So please join me in giving our Family Panelists and everyone here a round of applause in ASL as we continue our journey of connection, advocacy and empowerment. Thank you so much to everyone who attended today. Please remember to connect, advocate, and farewell to everyone. Thank you so much. Bye.

>> PATTI: Thank you, Interpreters. Thank you, Captionist.

>>BRANDI: Yes.