>> Okay. There we go. All right. Welcome, everybody. Thank you so much for coming to my session. Just a brief introduction. My name is Miranda Diaz. I am from Colombia bus Ohio and I'm going to talk to you guys today about parents perspective with congenital CMV. You may have heard from Jami who is amazing.

And she gave you a lot of awesome facts and information. I am going to give you little bit of that, but what I want to talk to you guys about is more of my son's journey with CMV. A little bit more detailed story and just early intervention he was able to get because we knew about his diagnosis early on. So, all right. And I also am, I forgot to say, I'm the Ohio alliance chair for the CMV national foundation, so if any of you are located in Ohio, families in Ohio or working on advocacy in Ohio, I would love to talk to you and meet-up and share some information. But just couple of facts if you are not here for the last session, so it's estimated 50 to 80% of adults will have contracted CMV by the time they're 40. 1 per every 200 children is born with congenital CMV in the United States and it's the most common congenital viral infection affecting newborns. 1 out of 5, which is what my son was of congenital CMV babies will have symptoms or long-term health problems.

It is the number 1 -- I'm sorry, one child is permanently disabled by congenital CMV and it's non-gentle cause of birth defect in children. This is my son Grayson. He is four and a half years old.

He was born with congenital CMV. And a little bit about his diagnosis and our timeline. So, mine is a little bit different than some stories you may hear. So we're going start on Mother's Day, May 13, 2018. We did a peek-a-boo scan at 18 weeks and found out we were having a boy. We were going to Florida with our parents and we were going to do a surprise gender reveal. We kept saying you have to wait 20 weeks to find out and they really wanted to know. So for Mother's Day gift, we got early scan and surprised them with it was a boy. Following Monday, we were traveling back from Florida. And I was in our car traveling. And I specifically remember exactly where we were at. We're just outside of Marion Ohio and I got a call from my OB and they said we got your genetic testing back. Your son is at abnormally at-risk for Down Syndrome and we're going to schedule you with a maternal fetal medicine doctor.

So my husband and I have been together at 6 years at this point. I was 26 years old. I had waited a very long time to start having children, because I wanted to be ready. And I feel like that felt like little bit of a gut punch. Not that there was anything wrong, but it was not what we were expecting.

And so, we were into our 26 week scan in May and confirmed it was still a boy and followed up with genetic testing and that basically looks like a little bit more detailed ultrasound. And they measured the nape of his neck, and size, and he was measuring very, very small. And they knew he had been measuring small. They didn't think anything of it. They just thought maybe the due date was a little bit off. And we went into the doctor's office and she said, based on your genetic testing, and his measurements, we do suspect there's a very high chance that your child has Down Syndrome.

Sorry. That was a little, like a second gut punch. So you hope that it's the best-case scenario. You hope that maybe it was just a little wrong or off. So at that time, my doctor had gotten the counsel genetic testing for us and we sent that out by the time we would be ready for the maternal fetal doctor appointment, so May 31, about two weeks after we got that call was our first appointment. And we went in and they were amazing. I can't say enough good things about them. And they did a scan. And you're sitting there holding your breath. And we go in and sit down with our doctor. And he said, this is not Down Syndrome. Your test came back. Your son has a 1 in 10,000 chance. So I don't think that's what's going on, but they have a lot better ultrasounds at these maternal fetal doctor. So they did see things on the can they didn't previous see at my OB's office. So they had seen an echo genic bowel and calcification in my son's brain and he was measuring small. So that was enough red flag for them to say, we need to continue to follow-up with you. And my doctor had said, it's not Down Syndrome, but I can't diagnosis it until he is here. But I would suspect your son has textbook congenital cytomegalovirus or CMV.

And that was the first time that I had heard the word CMV, the word cytomegalovirus. And I heard all of other things, like Down Syndrome, tox sew plass meal and all the conones. And June 14, my tests came back and these are straight from my chart that I had highly repeat infection and based on the damage, that they had seen on the ultrasound, they suspect I caught a primary infection in my first trimester. So our next steps from there, I remember getting our first list of appointments and saying, oh, my gosh, this is so many appointments. And I don't know how I'm going to fit them all in. And then we got the list of appointments after that, and we were going to bi-weekly. That turned into weekly maternal fetal appointments, to matrix sure my son was growing and he was healthy, and they were tracking him to make sure he had a safe rest of his growth.

We saw a fetal cardiologist, because CMV can affect the heart. And they did about a 3 hour fetal echocardiogram on him. We started seeing infectious disease. We started seeing nephrologist because it can affect the kidneys and liver. We met with a neurologist because we knew he had some type of brain damage. And we were more likely than going to have seizure-like activities, things that had to do with the brain that we needed a specialist for and started doing weekly non-stress test just to make sure he was viable and moving.

So I hit my 38 week appointment. And they said, just so you know, we're going to schedule you for you're in deduction, which I had no conclude they were going to do. And September 23, 2018, Grayson was born. He was born 5 pounds 3 how do you knows and he was still small. And they knew to test him. And this is a really big thing, I guess, from a parent's side. Knowing from day one, it literally says on here, cytomegalovirus detected at day one. I don't know if you guys know or if you're parents of children affected, but knowing from the very beginning of his life that he has this, so I can provide the best care possible, I can make sure he sees a specialist he needs to see and get the interventions he needs to get, that's really big.

And when I asked my doctor when he was born why I never heard of CMV before, he said we don't want to scare women. We don't want to scare pregnant women. Which fair enough. No one wants to be scared when you're pregnant. There's a thousand things that could go wrong. But more I got into his journey and did more research on it, finding out that is the number one non-genetic defects of birth in women, I think that needs to be known. I'm a person who wants to know the information, so that way, when my child comes out, I'm not surprised, right? And my child can get the care he needed. So I'm incredibly grateful for having an amazing doctor, and amazing team that knew to look for this. But that's not everybody's case and that's not a lot of people's case.

So from, like I said the beginning, he has been getting interventions. He did have excess fluid in his brain and ventricles were enlarged and he would get monthly ultrasound on his head and as well as MRI to check if he needed a shunt. We're grateful the fluid stopped literally on the border line of him needing to get one. But we had to go through all the fun testing to keep track of that. My son was born with mild hearing loss in his right ear. That was present at birth. And something we talked about earlier today in our stakeholder meeting was the doctor said knowing that he had a CMV infection, it's probably just fluid. Yeah. How many of us have heard, it's probably just fluid. I'm sure it's fine.

So it gives you that, I don't want to say hope, but it gives you that feeling, okay, maybe it's just fluid and don't knee to worry about not knowing how severely CMV can affect the child's hearing. And we did testing and in fact, he had permanent neural hearing loss.

And he was sent to Children's Hospital. He also, one month, this is a picture from his appointment, one month after he was born started seeing the neurologist and EEG because of the brain damage that was caused from the CMV. He at that point didn't have any seizure-like activity. However, at 3 months old, he did start having seizures. Around that one month mark, we did start working with early intervention. And coincidentally, December was infantile spasm awareness month and my early intervention specialist, knowing he had some risk for having seizures actually told me that, hey, this is what this looks like, seizures, in and my mind, my sisters had seizures. And all I knew was they convulsed. That's what I pictured. So when he showed me, that's helpful. That's the information I need to look out for. And not even two weeks later, my son woke up in the middle of the night, and he was crying. And he was throwing up his arms up in the air. And I thought it looked wrong. I thought it looked like what that was, infantile spasm. And I took him to a hospital and they said it's a startle reflex. He's fine. And my favorite part was, they said, well, I think that's what it is. I don't know. And same thing, we're in little bit of a rural area, and my mom brain would say, if you don't know, why don't you refer him to somewhere where they know? So luckily, I have an amazing pediatrician. I usually don't take no for an answer and they called nationwide and they were amazing and their doctor said it was absolutely an infantile spasm. They put him on the EEG machine and at 3 months old, he was diagnosed with seizures.

So he is 3 months old. And he has permanent loss. He has brain damage, and he has seizures. And he's my first baby and I felt like I was little bit by myself. The fact that I didn't -- I never heard of it and I didn't know anybody in my area who had children with hearing loss. Anybody in my area are that had a child with CMV. So he did the ultra sound testing and EEG and he struggled with eating, swallowing. Because of the brain damage, his tongue did not move properly and he was at high-risk for choking until he learned how to move his tongue appropriately. And monthly blood draw, once again, we had that early detection, which I can't stress how important that is. He was able to be put on antivirals. They're not guaranteed to work, but I would rather try something that could save his hearing and could reduce the damage than not.

So they had to do monthly blood draws to make sure it wasn't causing any problems within his body, because it can. I started early intervention. He had to do behavioral therapy because he had a head banging problem. And of course speech therapy and physical therapy because he was at a year old diagnosed with mild Cerebral Palsy. So here's a list of, you know, we have experienced with him so far. He was born with a small head. The calcification, hypertension, developmental dlie, access fluid in the brain, epilepsy, sensorineural hearing loss, Cerebral Palsy, proreceptive sensory and he likes are tight spaces. And we had a TV stand and he put himself in a cubby and he shut the door and look at us happy as he can be. But once we had that diagnosis, it made sense. You know, I think people are afraid of the diagnosis. They're afraid of somebody labeling your child, you know, with a delay, or autism, or behavioral issues, or Cerebral Palsy, because they think the diagnosis is bad. And the diagnosis isn't bad. It is what it is. But what you can do when you have that and know that is you can help your child. Without that, you're just, oh, they're acting up because they're a bad kid. Or they're struggling to learn, because they don't want to. Or they're not listening to me, because they're a toddler. When in reality, they have these delays that they need help with and it's our job to be that person to help them.

So you know, in looking at through all the pictures I had of him, I was thinking, you know, these are just some of them since birth. His date of ABR, his infectious disease appointments, his neurology appointments, he has been in a doctor's office more than most people have in their adulthood, right? From birth, he's been living in a doctor's office. And once again, I'm grateful, because he has that help, but it makes you feel like they're missing out on stuff. It makes you feel like -- it makes you sad they're struggling. It's hard. I try to be the most positive person I can be, because my son needs that from me, and he needs me to be his voice and he needs me to advocate for him, and he needs me to be that "no matter what attitude" because he does have delays and have extra struggles, but that's not going to stop him and it doesn't have to stop him.

But when you look at it, it definitely feels heavy as a parent. I like this picture. He was waiting to get his sedated ABR and he had this thing around him and he looked like ET. [Laughter] And he's also at-risk for issues with his eyes. So eyes, ears, heart, liver, spleen, it's like what are they not at-risk for? And I'm also grateful for the fact he is only affected as much as he is, because there are some families who have severely affected children or have children who have passed due to CMV complications. So I don't want anyone to think I'm not appreciative of where we're at, but as a parent, it's heavy. So at 4 months old, he did receive his hearing aid. And he did pretty good when he was little. He didn't pull it out. Once he became a toddler, when he was done hearing, he will take it out and hide it in toys and very good at it. He would throw it down in the floor and I couldn't reach it. So he tucked it down there, he wouldn't have to wear it until dad got home. Yeah, they're creative. (Chuckles softly)

Yeah. This picture actually in the yellow is 3 years apart. Same appointment. And the one in the yellow is the most recent appointment we had. As I said, he started with the mild loss in the right ear. And for three years, it progressed slowly. So every appointment I went into, we were told he was losing more and more hearing in that ear. And then at 3, it halted. It had not progressed anymore. And we just went back in December, and after about a year-and-a-half of no progression, we found out he has gone completely deaf in his right ear. Which was kind of hard for me to take. I gotten used to the hearing aids and got used to that. It's something new and we're going to adjust. But for whatever reason, it felt like a lot. And after four and a half years, he started losing hearing in his left ear. So I always think about the kids who didn't have hearing loss at birth that weren't followed up at birth because they didn't have that, so they didn't test him for it. But CMV has a huge impact on hearing.

And, yeah, that's our next journey. And he will be receiving a cochlear implant on the 29th of this month. And I'm really grateful for this conference, because I'm learning a lot about them from all of you. So thank you for that. Like I said, my son started having seizures at 3 months old. This is my little baby in the hospital hooked up. He gets yearly 3-day long EEG tests which are tough to tell a child you have to stay in this confined space. The picture of him in his pajamas he woke up one night and he was running back and forth. And he was very hyperactive. We didn't think anything of it. He doesn't sleep great. And next day, we had the first day of preschool. And he woke up looking like this. And it might be hard. But he was having seizures in the middle of the night. And we didn't know. He was running at the time. I was in a different room. He was running between the rooms, and we just thought he was being wild like he does. It's not uncommon. And when I saw him the next morning, I felt like the worst mom in the world, because our child was trying to tell us something was wrong. And we didn't catch it. So he didn't get to go to pictures. He had a swollen face, swollen lip, his mouth was bleeding. And that is after four years of being on the medication that has for the most part kept him at Bay. But he does occasionally have breakthroughs.

With all of the negative, [Laughter] That can come, there are also a lot of positives, like any other child. He's a little delayed, but in that first picture, he see him crossing his arm. That was the first time I saw him mock somebody. [Laughter] And he was mock, his dad, which was even better. You know, he just actually past summer learned to start riding a bike at 4. And then the picture. His birthday, he doesn't speak. He says some words here and there. Mom was his first word and then we went about 2 years without him saying that which was really tough. And we started teaching him son sign with his progression. And we did the sign for mom.

And he said, mommy. And we burst into tears. His 4th birthday in September, we got a cake out. And he sang happy birthday to himself, which was a pretty cool first. We never heard him do that before. But he sang that to himself.

His first day of preschool. His dad has D J'd forever. And he started to get into acting like he's DJing. And he wants to be just like dad. And he wants to talk on the microphone and speak and sing. And any singing movie, he's for. And he watched the new addition and he was twilling, and bowing, and clapping for himself. So he's just, there's a lot of positive that came with the negative. And I'm grateful for that. But it's been a journey. And he just became a big brother 7 months ago.

(Applauds)

So it's been an adjustment. He either ignores her. Or if you've ever seen Despicable Me where she has the Unicorn and says it's so fluffy and she squeezes. It that's the other side. And he's becoming the best big brother. And the coolest part that I talked to couple of people about is my daughter is going to grow up in a home with a child who has some extra needs, and that's going to be normal for her. So when she goes out into the world and is interacting with other children who maybe aren't the same, she's already going to know that's normal. Right?

So this, I put this in here. Some may -- I don't know. As a parent, like I said, I felt like I was on an island alone, sort of like Tom Hanks talking to myself, probably looked fairly similar to that as well. [Laughter] So, you know, just couple of things if I can provide anything to you guys as a parent who goes through, has gone through all of these things with her child is don't be afraid to educate people. I know people say, we don't want to scare people. But for me, it's more scary not knowing. Not knowing where to find the information. Not knowing what to do in a certain scenario. Not knowing what to expect, because the unknown is so big.

And providing organized resources, there's not like, like our early interventions were amazing, but they did throw 800 pamphlets at me and you have to sift, sift through the things that are applicable to you. So organized resources. Contact points, direct contact points. Like I said, I'm an advocate in Ohio for the national CMV foundation. If you need information, or contact points for different states, reach out. We can get those to you. But there's nothing quite like having other parents to relate to. Other parents who maybe have gone through it and other parents who can give you insights. Maybe if you're a healthcare provider, listening to those advocating for their Charen. They're not trying to make your life harder. They just want what's best. In worst-case scenario, it turns out to be nothing. But it could be something. And just reassuring people they're doing a good job. Because I've had a lot of people tell me that over the last couple of years, and I think hearing that from my pediatrician, and my doctors, and, you know, the people that see parents and kids interacting daily, that was really, really big for me. So here's my contact information. Take a picture if you like.

I am actually at national CMV booth which is 17. If you want to talk or get more information or get a card or anything like that. But that's my parent perspective. Does anybody have questions? We have like 2 minutes left here. Yeah. Who's up?

>> Good afternoon. I don't have a question. But I was just sitting here and I'm so moved by your strength and your courage. You're doing a great job. I just want to be part of that world. I appreciate your strength. I applaud you. And much like to you and your family, and I hope, and in my world, I'm going to put that hope, I pray that you will continue to be used, because there's so many mothers and so many different arenas that need to hear this. You know, unmarried mothers, and even with all the help, I'm sure you've received, you have heard stories on how they wish they could be in your shoes. So much blessings to you and your family and continue to keep doing what you're doing.

>> Thank you so much. I appreciate that. Like she said, I'm grateful. Because we've had a great resource group and not everybody has that. So thank you for acknowledging that. Anyone else?

>> Thank you so much for a moving presentation and it will move us to action, which is incredibly important. For those of you who would like a snack, you get to go all the way back down to the ballroom in the exhibit hall for a drink. There are also evaluations on the app. So please don't forget to fill those out. Thank you so much and thank you to our interpreters.