I'm Jami Fries. I'm going to do my best to do her story justice as well. I have done this presentation quite a few times with her, so if you have questions, I'm sure I can help answer them. Today's presentation is going to be on CMV cytomegalovirus, parents perspective. We're going to tackle understanding it, coping with it, and reducing the rest. And what exactly is CMV and this is a typical virus. 50 to 08% of adults had CMV by the time we reach adults. Nearly one-third of children in daycare settings and in school settings have had it by the time they reach the age of 5. CMV precepts itself as a cold in most cases. Sometimes it pops up feeling like mono, so swollen lymph nodes, tireness, nausea, really common things, right and if you're already pregnant, you go to the doctor and they tell you you're probably tired from being pregnant or taking your children around. Why are we concerned about this? CMV is dangerous when you're dangerous or trying to become pregnant. One-third of women that catch this during their pregnancy will transmit it and it will pass over the placenta to the baby and that's when we start getting concerned. That's called congenital CMV or congenital cytomegalovirus. It's the most common virus transmitted from a pregnant woman to her child.

There are 3 different types of transmission or infections, excuse me, during your pregnancy. There's a primary infection, which it means it's your first time. Secondary infection, meaning that you are catching a new strain of CMV. And then there can also be a reinfection where your primary infection is inflamed again. Yet, 91% of women have never ever heard of this virus which is scary, when a lot of us want to have children and we don't know how to protect ourselves.

CMV is serious. Congenital CMV can cause multiple birth defects and disabilities. Vision loss, developmental, and intellectual disabilities, microcephaly which is small head size, intracranial calcification on the brain, lack of coordination, Cerebral Palsy, sensory issues, seizures and rare cases are death. As I remember is the leading non-genetic cause of hearing loss in children. Which is why we're here talking about this today.

1 in every 200 children or approximately 30,000 children are born with CMV every single year in the United States. CMV can get broken down into 2 different categories. There's asymptomatic CMV and symptomatic CMV and categories can change depending on the hospital you have your child at. But 90% of babies are born asymptomatic. That means children that look healthy at birth, they overall are happy, ready to go home at discharge, 4 to 48 hours later. 4 to 5% of this population will have a hearing loss at birth. But 10 to 15% of this population will go ton have a hearing loss at some point in their lives.

The percentage, and the risk factors of hearing loss start out when they're younger and as they get older, that risk factor starts to decrease. But it can go all the way up to adolescents and all the way up to age 18. Loss can be progressive and it can fluctuate so it's really hard to catch.

So then we go into the symptomatic category for CMV. This is only 10% of our kids. These are kids that have the smaller head size. They're going to have the jaundice, petechiae or blueberry muffin rash and these are the ones we catch and test. Approximately 75% of the population will go on to have a hearing loss. I want to touch on this because it has been thought, most of our infections go on from a primary infection or the first in session that you get. Recent studies are showing that the symptomatic kids with hearing loss might actually be coming from non-primary infections of women. And so I did put the link down in the bottom for the study if anybody is interested in looking at that. Perceptions are changing on how that looks and what that could develop, and ideas of whether or not we should be testing pregnant women for CMV for primary infection if they've ever had it before, because that can give off some mix messages so, what does this mean for the families? It means lots of doctors appointments, lots of hospital stays, surgeries, a lot of medical equipment, insurance battles, which are our favorite things, and lots of assumptions of unanswered questions. It means unfair label of being contagious. We have had a lot of children come in and be taken out of therapy appointments because their provider is trying to become pregnant or is pregnant and they decide it's a risk factor for them to be taking care of or providing for this child.

Can I answer your question at the end? I have time for it. I want to touch on it though, because American academy of otolaryngology put out a mission statement few years ago that CMV is not an optional health and safety risk for pregnant women. And for workers if routine healthcare practices are followed. And with COVID, we all kind of gotten into the routine healthcare practices work just as a second nature, but I'm going to touch on that at the end of the presentation. Since not all children undergo S.I.M. testtion and most CMV shows no signs of infection at birth, workers and staff need to follow precautions with all children, not just CMV children and most of these kids, one-third of the kids in daycare settings have a CMV infection. So by taking the children that we know have CMV and putting a label on them of being contagious, we're doing an unfair practice on ourselves and putting them at-risk with all kids.

So then I kind of go into our journeys. This is my son, Nathan. He was born at, my water broke with him at 30 weeks. I had a fairly healthy pregnancy up until that point. Well, that's helpful. Okay. I'm going to keep going until then, and you just won't see the pictures. I'm sorry.

But my pregnancy was fairly healthy up until that point. I'm a Type I diabetic and I was followed by high-risk OB. No risk factors came up. I had lots of ultrasounds and everything looked healthy until my water broke at 30 weeks and when I went into the hospital, they told me that I was, that my water didn't break and I was just fine and then I went in and sure enough, my water had broke. They transferred me via ambulance to I spent 4 weeks at hospital bed rest and we did lots of doctor's visits with him and he came over with sleepover to the hospital and we tried to make it not as traumatic as we could for him. Nathan was born 4 weeks later at 34 weeks gestation. He weighed 6 pounds 7 pounds so he was a chunker. And for all intents purposes, he was a healthy baby. He had some symptoms that came off as being from prematurity. He was on a CPAP machine. He was jaundice and he was not eating on his own and had a feeding tube. All kinds of things were brought up to having a 30 week old baby. I will forever be thankful for the doctor who checked our test mark my placenta for CMV. They were trying to figure out why my water broke early. And my placenta tested positive. And at 3 days old, he was diagnosed with CMV and when they ran the test, the nurses said he was healthy and did not have CMV and the test came back positive. So we waited in the NICU for a month and a half and for him to eat and breathe on his home and waiting for him to come home. We did all the tests of his brains and kidney test and everything came back looking good.

So when we got to go home, I should say in between the time of NICU, we weren't given any information on CMV and the diagnosis. I went to Google. Which is bad. Don't do the Dr. Google thing and found out more information. Found some Facebook groups that were CMV support Facebook groups and they told me to see an infectious disease specialist which was not given in NICU and that was after discharge. I'll tell you why that's a problem here in just a second. Follow-up with urologist and audiologist at 6 months old was only information we were given. CMV has to be diagnosed 6 days afterlife and we couldn't advocate for antiviral or any information regarding treatment for my son. We did not get to go an antiviral. At 6 months old, he went to do his sound booth test with the audiologist and he did not have pass his hearing screening at that point. And the doctors wanted us to come back after 3 snunts said it might be developmental. He was a preemie. He's not turning to the sounds as he should be. And I said I've done some research. I know CMV is a risk factor for hearing loss. We have a surgery scheduled in 3 weeks for urology appointment, can we do an ABR at that point so we don't have to do two rounds of sedation and she said yes, we can do that. And so we went in and did that. And come to find out by 6 months old, he was profounded deaf in both ears. He did Paz his newborn screening and we were discharged from the hospital. So during that time, he essentially lost all his hearing. We started ASL. And researching with other families, kids with CMV will sometimes get cochlear implant and have access to sound, but they are still non-verbal and we wanted to make sure my son had access to communication, so we have gone with the total communication approach with my son. And he does do sign language. He attends total communication preschool. Actually he's not in preschool anymore. He's in first grade now.

And so he does have access to the whole spectrum. We did cochlear implants day after his first birthday. Very successful with those. We had a very rough recovery with the cochlear implant in where we actually found out he was allergic to morphine and I almost lost him in the hospital after surgery. Grateful again we were in a hospital and not a dentist office when we found that out. So he is doing great. At this point in time, years 1 through 5 with weekly audiology and verbal taper, so AVT, speech that is a, and ASL classes. At school, he started right at 3 years old and at that point, we continued speech therapy, physical therapy, occupational therapy and total communication classroom. So we've got a lot going on. He is also Type I diabetic and we have that on the plate as well. But he's a pretty happy hill guy. Can you see it now? No? I'm going to keep going.

Today we do not stimulate and push him to the adventurous and advocate for himself. He's a great advocate for himself at 7. And in doing so, we continue to grow in new environments with language. He also has Jess tibular dysfunction. And anything we can do that's new and exciting for him to boost his balance and vocabulary and communication skills, we are very adamant about doing those. And next is Axel. And Axel is Andrea, me co-presenter's son. My son Nathan is fairly mild in case of CMV. Andrea's son is -- we good? All right. Perfect. So Andrea's son Axel is more on the symptomatic side. Andrea's pregnancy was a healthy pregnancy as well. Right around 30 weeks, started noticing he was having heart complications. And so they were watching her very closely.

He was born at 37 weeks. And they were prepped for him to go into heart surgery right after he was born, because his heart was very enlarged. When he was born, they did a white blood cell count, and it was very, very high and they decided they did not want to put him in surgery without figuring out if there was an infection. When that happened, they tested him for CMV and he tested positive for CMV. He never had a heart condition. His heart was swollen from trying to fight off the virus that his heart swelled. So he never went into surgery, thank goodness. And they started him on antivirals.

So this is their first year, like I said, Axel is more on the symptomatic side. He does have -- I'm just going to keep going. I'm just going to keep going. My presentation is on the site, the app. So if you want to go look at the pictures, please feel free. But Axel never had the heart surgery. They ended up, he's microcephaly so he's small head size. He has oral version so he doesn't drink or eat anything by mouth so he's G-tube fed. And he has epilepsy. And he has seizures and they get in and out of control. I can go on and on with him, he's the happiest little boy. Still no pictures? Okay.

So what Andrea and her husband has been amazing with Axel and keeping him going with communication. They started with the buttons to talk. So that way he can have yes/no answers. If they have the AAC devices. They work with ASL with him, but because he has such severe Cerebral Palsy his hands doesn't work well. He's developmental and globally delayed as well. So they're trying to just work with him at his own pace. He does attend a life skills program at his school and has a great system there. So they are just working to keep him going and like I said, he's a happy, happy kid and I love him. Andrea's story is very unique in the fact that she also has had two more pregnancies after. She's actually pregnant right now.

And it's really inspiring for us parents to see families have another pregnancy after their CMV pregnancy. It's scary. Wondering if it's going to happen again. So she's been amazing with that. And her contact information is on here if you have any questions I can't answer, she would be a great one to ask.

We do have a quote that I'm going to read really quick since it's not popping up. We always like to do this one. Parents of newly diagnosed kids, it's going to be okay. Your child is still the same child. Your love for them won't ever change. There will be days that are hard, heartbreaking even, and it's okay to not be okay. Just don't get stuck there, because your child needs you to be strong. When you think you have it hard, remember it's harder for your child. Find your tribe. Find those who support and understand the path that you're walking. Channel your emotions towards the fight, the fight for services, quality education and a quality of life, never give up and always have hope, because your child is going to teach you so much.

So now moving forward we talk about what can families do? One, research. Learning about your child's diagnosis, treatment, and outcome and truly understanding the language being used in the medical community, if you don't know ask, and ask again until you understand. Providers, please keep trying to rephrase it to us, because the big medical terminology gets confusing. Break it down for us, but still give us the big technology, the big words, so we can research it later on.

Be comfortable with your healthcare team. We want to make sure you're comfortable asking the questions. And that you're knowledgeable about the diagnosis. Not every single provider is going to be the right one for your family. Expect to remember only some of what you're told. So we ask parents to either have someone come with you. Providers, if you can have someone else sit in the meeting with the families, have them write things down. We have the technology now. Have them recorded on their cell phone so when they go home, they can listen to the conversation again.

And now we go into prevention. Oh, you can see it. Yay. So women who are pregnant or planning to become pregnant, including mothers, daycare workers, preschool teachers, therapists, and healthcare workers should use caution around all children, because CMV is found in bodily fluid including urine, saliva, mucous, and tears. As much as we love children they're like little Petri dishes and they love to share everything. Wash your toys, hands, and everything all those fun things. Saliva can remain on cups and pantry and can are cause infection to you and your babies. And we often finished off kid's lunches and eat off their plates and give them a bite from your own plate. Use your own fork and chopsticks and drink your own water. We don't want to share germs. We have seen this over and over again. Putting your pacifier back in your mouth because your germ is helping their immune system. I think it's disgusting and I see a lot of your faces that I'm not the only one. So same thing though. You're putting your child's germs in your mouth. It goes both ways. Don't do this. This is how CMV is transferred back and forth.

Trying to avoid kissing a child on their lips or around their cheeky area. Again, CMV is a cold. So when you think about your children crying, you're kissing away their tears and you're taking all those burgers and mucus. It's gross. So make sure jour kissing them up on the forehead. You're not going to damage the child by giving them love in the forehead, giving them hugs, and telling them you love them. Toddlers love to imitate everything you do. Don't share toothbrush. I don't know why people do. Again, but, don't do that.

Washing your hands. So making sure that you're washing your hands with soap and water for 15 to 20 seconds. Again, what we learned a lot with COVID. Wiping you're child's nose and drools. Changing diapers. Making sure you're washing your hands after every single one of those. I'm going to leave this up and then take questions. I usually go to a longer presentation with Andrea, I don't want to misspeak on her story.

So are there any questions? She's going to come around with a microphone.

>> I think you had a question early?

>> So, obviously, we met last night. But my name is Pamela Holler and my daughter has CMV. I have couple of questions. The first one is how long is CMV active where they can transmit it to other kids?

>> JAMI FRIES: Hats a really hard question to answer. It can be different. When they're transmitting, it's called shedding the virus. Some kids shed it for days and some will shed for couple of months. And some will stop and then resaid it. Be you will hear about retesting the child to see if they're reshedding the virus. Unless your child is declining in health because of the virus reactivating again in their system, if you're worried about infecting another person, there's so many other people out in the community that have an active CMV virus.

>> So to kind of go off that, she got blood tests for CMV. Will it show positive or negative?

>> JAMI FRIES: Blood tests are hard ones. Urine is the gold standard. I'm going to go off urine because it might be easier way for me to answer this.

>> And I'm meaning, she's 7 now.

>> JAMI FRIES: Okay. It depends. You won't always show she's shedding the virus. If it stays in the system, you'll always test positive for CMV once it's there. You won't always be shedding it or always be infectious with it. You can be shedding it. So for example, your daughter, and I don't know her, so I'm not a doctor, I'm a parent. But from what we have known is that the virus can shed, again, depending on the child. So the child could be infectious with it for couple of days if they don't have a very high viral load F they have a high viral load, they can be infectious for couple of months. It really is an individual case-by-case.

>> So is that the gold standard for anybody? Anybody could be shedding it if any time they have it before. So people are concerned about the one child with CMV, when mostly everybody has CMV.

>> JAMI FRIES: Exactly. It's important that we use Universal health precautions with all kids. Kids are ones we want to worry about. You're not going to go around and share your drink with your, I don't know, some random stranger you just met down the street, right? It's usually our kids. And CMV is not a virus that is easily caught. Like we're super cautious with COVID sitting next to people. That's not how CMV is transmitted. It's over, and over, and over again when you have exposure to it. So it's usually the healthcare workers. It's usually, again, the parents taking care of your own children that are constantly kissing your kids when they are shedding the virus.

So it's not like you're going to be sitting next to someone and catch CMV. Are.

>> Do you know the studies on if or when they become new mothers or are pregnant, ask their doctor to get a S.I.M. test?

>> JAMI FRIES: There's mixed feelings on getting CMV test. I want to put this the other way. If you had a CMV infection before, it comes back you had immunity to it. You're not immune. How your body has built up antibodies to help fight off new strain. That does not mean you can't get a new strain. It does not mean you're in affection before can't flare up again. CMV is along the same family as herpesvirus. So if you think about herpes, you can have a flare you'll when your immune system goes down. When you're pregnant, you can have a immune system go down. You can always have a new strand or where that flare up can be active again. I do tell providers and parents what exactly this is, and I tell the term herpes in here. Herpes is a sensitive topic when you're talking to families. It makes you think your significant other or you have caught an STD.

When I talk to new families, if I say the word "herpes" I go into more details and say it's the same family as chickenpox. Chickenpox is more common known and it doesn't come off as when they told me I had caught it and it's a herpes virus, well, great. Where did I catch this? You know? So I went home and had a conversation with my husband. Conversation that did not need to be had. [Laughter]

So, just think about things when we're saying it. Talk about a more common level virus. We have 5 minutes. Question over here.

>> I'm curious what state your son was born in? Was it rural Metro? And have you talked to other people? Did they have similar experiences?

>> JAMI FRIES: So my son was born in Colorado. And yes and no. My son was born 7 years ago. So things have changed quite a bit in Colorado since he has been born. The thing that was really frustrating for us was, and we're born in a very large hospital in the Denver Metro area. Education was not there, which should have been from my providers to me. And support should have been there. Talking with my OGYYN, it's not a common virus and there's no need for testing for it, which is frustrating because he's a high-risk OB and I do not see him anymore.

Again, there's a lot of misinformation out there about CMV. And so I think the parent-to-parent connection piece, I work with Colorado Hands & Voices. I'm actually the director and I'm a parents guide for children that are deaf and hard-of-hearing + and for the CMV families that come in. And when those families come in, we get a lot of varying stories. Either they have had great support, great education, great outreach. They've been connected with the right professionals. Usually the infectious disease specialists at Children's Hospital who have a CMV clinic to help guide them.

That was not there when my son was born. And so things have worked in a very progressive way in our state, which I'm very grateful for. But we like to share the two different sides during this, because there is a huge, you're going to have children born with CMV that have absolutely no symptoms and will never have symptoms of CMV. And then you can have kids that are severely disabled from it. Two minutes.

>> Earlier, you said that you don't advise Google for parents to go on. So if the provider is not providing you the information that you want, where would you suggest parents go to get information on CMV?

>> JAMI FRIES: In Colorado, we have built, short answers I would say go to the national CMV foundation. They have an amazing website and it's completely up-to-date. It's honestly the best information regarding CMV. In Colorado, we have built handouts for providers to give to families. One that says this is why your child is being testedded with CMV. And some information for them to have, and contact points for information so they're not going to Google.

And it gives things like the date they were tested and who to call if they don't get the test results back. Then we have another worksheet that we give out to families that will give you resources if your child test positive for CMV and what the next steps are. And it has a beautiful color wheel of support and providers your family should have, very well-rounded support system for your family so they have a successful journey as they can with CMV.

Any other questions? I think we're probably out of time. So thank you so much. My contact information is up here. Please feel free to email me or text or call if you have any questions.

>> Thank you so much. If you have additional questions, Jami can meet you out in the hallway on CMV. And then we'll have our next presentation. Apologies for the PowerPoint.

>> JAMI FRIES: Don't forget to do the survey.