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CONSUMER: CASEY JUDD

EHDI

NARITA A/B – CYTOMEGALOVIRUS (CMV) A PARENT’S PERSPECTIVE

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>> Hi, everybody, thank you for coming. We are going to do our presentation today on cytomegalovirus. A parent's perspective. We're going to touch base on three topics today. Understanding it, coping with it and reducing the risks. My name is Jami Fries and I am with Colorado Hands & Voices. My name is Andrea substantial bough and I'm with Illinois Hands & Voices.
>> So we're going to start out with the basic knowledge of what is CMV it is a very, very common virus. 50‑80% of us have had it. Once you get it it stays with you in your body for life. Nearly one‑third of children by the age of five, school children day care settings have CMV and mostly presents itself as a cold in most cases for adults and children.

So why is everyone talking about it? And why is this such a danger? If you are pregnant or planning to become pregnant CMV can be very, very dangerous especially if it's your first infection we call that your primary infection. If you catch it for the first time or you have a reactivation or you catch a different strain of CMV it can pass to the newborn. It is the most common virus transmitted to the baby during pregnancy. Yet ‑‑ 91% of women have never heard of it.

Congenital, CMV can cause development defects. Microcephaly which is the smaller head size. Calcifications in your brain. Cerebral palsy, feeling issues or failure to thrive. Sleeping, behavioral, sensory issues, seizures and in the rare cases, death. CMV is the leading nongenetic cause of hearing loss in children and it's why we're here talking today at EHDI.

One in every two hundred babies born are born with CMV. It's a very large number especially here in the United States so we're looking at about 30,000 babies a year. We got two different types or classifications for CMV. We have asymptomatic which is the larger group of those children. 90% of these babies are born asymptomatic. There's really, you wouldn't know unless you have a test for the most part. 4‑5 package of these kiddos will have a hearing loss at birth and 10‑15 will eventually have a hearing loss at some point in their life. The loss can be progressive into young adulthood and it can fluctuate. We also have symptomatic CMV which is ten percent of the babies born, these are kids with the jaundice, the smaller head size among other things and approximately 75% of these kids will develop a hearing loss later on in their life. So what is all of this mean for the family? It means lots and lots of different doctors appointments, insurance battles, and a lot of assumptions and unanswered questions. And also causing a label on our children of being contagious and it's something struggle with. The American academy of otolaryngoly just released a statement about a month and a half ago saying that CMV is not an occupational health and safety risk even for pregnant women if you follow the routine practices to help prevention.

Since not all children undergo CMV testing at birth, we have a large population of kids that have CMV that are out there and women should just follow these precautions universal. We're going to kind of jump in. This is my munchkin, Nathan and I want to kind of give you a story of what happened with us. So I had Nathan, my water broke at 30 weeks with him and I had a fairly routine pregnancy. I am a type one diabetic so I was high risk. We went through ultrasounds like every other week. Never got sick not that I know of.

I felt great and I bent down to pick up a fork off the floor and my water broke and they rushed me to the hospital about an hour and a half away from my two‑year‑old at the time Liam and I spent a month away from my child which was difficult. We had sleep overs at the hospital and tried to make it fun for him I had Nathan at 34 weeks via C section. He did not want to come out at that time and it was a really difficult delivery. He was six pounds seven ounces so he was a chunker. He did pass his newborn hearing screening at birth.

And so they randomly tested my placenta to see where my ‑‑ why my water broke to see if they can find out why and they found out that I had contracted CMV. So day three they went ahead and tested Nathan as well and they told me he did not have it. Not to be concerned whatsoever. Came back the next day saying that he had CMV. He was extremely jaundice. We had lights and blankets for three weeks. I was able to hold him for two hours a day during that time period. Liam came when he kid. I went down to the NICU trying to get him to breast‑feed. After discharge, they gave us no information on CMV. They told us to follow up with audiology, and that was about it so at six months old we went to our audiology appointment and did our booth test and he did not pass our booth test. And at that point in time they told us that we should come back in three months. It could have been because he was too little and he wasn't developmentally turning towards the sounds and we pushed to have the AVR done and he had a surgery coming up in a few weeks so we could do anesthesia for one time instead of twice. So we did that. He's a happy little munchkin so we did the AVR. And it and not go as planned and the surgery went great and then they pulled us in. He was severe to profound in his left ear and profound loss in his right and at that point in time I reached out more to the CMV community but we didn't know we had a big problem. He was asymptomatic and all the doctors made it seem like it was not a big deal and at the time we should have met with an infectious disease specialist and were not given the option to do antivirals. We were get a little bit, a little angry that we weren't given the options that we needed. We moved forward. Nathan got hearing aids and audiology told us if we wanted access to sound we needed to pursue cochlear implants. That was very important to my husband and I with the condition we learn ASL so at twelve months old he had his cochlear implant surgery and surgery went amazing. Recovery not so much. He had either an allergic reaction or an overdose of morphine, we're not sure which one and we almost lost him. He started having seizures and difficulty breathing and we got him the PICU for four days. We were very lucky they gave us Narcan and pulled him out of it. Today he just started preschool. He just turned three and he does auditory verbal therapy once a week, speech therapy, and ASL losses and next week we are having him tested for seizures with an AV ‑‑ sorry, an EEG and seeing a neurologist because he's had bad balance issues and no one can tell us why that is. So now Nathan and I go around and we do CMV legislation I got to speak to the house in Colorado and we helped pass the CMV legislation last year and we also do Walk4Hearing so he's are just some pictures of things that we like to do as a hearing to help raise awareness and talk here so.
>> Okay so I'm going to spend a few minutes talking about Axel he is two and a half. I was due with him in 2016 in July.

And in April I got sick with like a cold and my throat hurt like, whatever it wasn't a big deal. I called the OB and they're like here's some could have syrup, see you later. I did that and it just so happened in two weeks I was having an appointment with the high risk doctor because I have polycystic ovarian syndrome and the doctor is going over his heart and over it a hundred times and I'm young I'm thinking they do this, this is routine at a high risk clinic. Little did I know that the doctor would come in and tell me that Axel would need open heart surgery at birth. We were floored because the rest of my pregnancy was going fine until that point. After that, he stopped growing, he stopped moving around and they were like, oh, he's a heart baby, everything was oh, he's a heart baby, that's normal for heart babies, whatever, so we got four opinions and all of them were that he had the aorta so I live in Illinois in like a rural area about two hours away from the nearest hospital that could do open heart surgery on an infant.

So I was induced at 37 weeks to be there with the heart surgery team so I delivered Axel and they whisked him away to the NICU. And his blood work came out that he had some type of infection and they're like, well, heart surgery's on hold. We don't want to open up his heart and risk infection so they're like we don't know what it is. They did and they came back and told me that Axel had CMV at that time they started him on a general antibiotic to figure out what was going on and after they diagnosed him with CMV they went back and did more heart scans and more things and they realized that Axel never had a heart condition. He ‑‑ his heart swelled up from his trying to fight off the virus and his heart was actually fine. So there was no more need for heart surgery anymore. As things progressed I was discharged from the hospital and he was there and they said tomorrow when you come bring someone with you.

They basically told us that based on his brain scan and on his hearing test and his vision test that he was going to be severely handicapped for the rest of his life. So he stayed in the NICU for fourteen days. We did nine months of Valacet and we call them blood draw Tuesday.

We spent every Tuesday at the hospital getting blood draws. And in his first year it was kind of crazy. We have nine therapies a week. We still have nine therapies a week. Cochlear implants EEGs, I could spend our entire presentation listing off his diagnoses. But some of them hyperplexia, he has all these things but he's doing really, really well.

He did getting a feeding tube. He doesn't eat anything by mouth but we dedicated ourself to CMV advocacy, CMV awareness and, you know, we really just try to do things with Axel that are like every other kid. Even if they're hard we still do it anyways and we find a way to make it work. That is our story with Axel and come and say hi to him before you leave. Now we're going to go in to talking about coping and prevention of CMV. When we've done this presentation in the past we used to have a bajillion slides on how to cope with the diagnosis because it's a big diagnosis especially for those symptomatic kiddos and then recently this poem or whatever you want to call it was posted on the CMV moms page and the amount of people that responded were like oh my gosh, this is so true, lie I really feel this so we ended up taking all the slides, most of the slides out and we added this. So I'll read it. (Reading). There will be days that are hard. Heartbreaking even. It's okay not to be okay. When you think you have it hard, remember it's harder for your child. Find your drive, find those who support you and understand the path that you're walking.

Channel your emotions for your life, the fight for quality of life and never give up. Always have hope that your child is going to teach you so much so we just felt like that really resonated with a lot of our families. I have CMV families in the front of the room now ‑‑ that are crying. So some other things that we have found when you're trying to cope with the diagnosis is you know, really researching the diagnosis and the terminology that your physicians are using with you. If you don't understand then ask questions. Don't let them talk about, I had no idea what hyperplexia was and I was like we'll deal with that later.

And now I wish I would have. You know, asked those questions and researched those terms. So that kind of goes with the next one. Be comfortable with your health care team if you're not comfortable asking questions you need a new team don't go with the motions and let them tell you what's right or wrong. You know your child better than anyone else and expect to remember only some of what you're told which is why we suggest bringing someone with you to take notes and remind you later. This baby is so cute. Okay. We're going to talk about prevention. So CMV is spread by contact. Women who are planning to become pregnant, preschool teachers, anyone who works with small children should know they should use caution when they come into contact with mucus, tears, those kinds of things. We're going to talk about each one quickly.

Saliva can remain on food cups, cutlery. I don't know if that's how you say that word. So we talk all the time it's really easy, when your kid won't eat their broccoli it's not a good idea because that's a way CMV can spread. This ‑‑ this happens all the time so people will pick up pacifiers and put them in their mouth to clean like the dirt off. I can't even say it ‑‑ anyways. Or if, you know, you're carrying your kid and you only have one hand and you put it into your mouth backwards to hold it for a second. Those are other ways that CMV can be spread. Try not to kiss a child under the age of six on the lips. You make sure you kiss them on the cheek or the forehead we promise they still know you love them. Teeth brushing. A lot of times kids will take your tooth brushing and be like I want to do it like mommy but we would suggest that you not sharing toothbrushes and things with your children and most importantly to wash your hands after wiping your kids noses or feeding them or handling their toys. Things like that.

This chart up here is currently where there is some sort of CMV legislation in our country. Each color represents a different type of law that is in place in that area. So that's helpful. It's on the National CMV Foundation's website which is on the bottom of the PowerPoint for more information for resources for your families there are ‑‑ on the foundation website there are resources for early intervention providers.

There are resources for ‑‑ the reasons why you should not exclude a child with CMV from any type of setting at any point. And there is also information from the CDC and things along those lines also Jami and I's contact information is here as well. Before we take questions we did bring freebies because we're the cool presentation. So there's toothbrushes to remind you to brush your teeth and not share your toothbrush and hand sanitizers. If you want to follow Axel's blog we appreciate, we will share his update and CMV information, awareness are available to share with your families and people you know.

If you could follow his blog. It's called Axel's journey with CMV on Facebook and that's it. I guess we'll take questions if anyone has a question.
>> (Applause).
>> I'm just curious if there's any kind of parent support groups that you would recommend for parents because I have one very young mom that needs somebody to talk to that I can't fill.
>> So my CMV moms are going to laugh at me I'm going to give my database spiel I'm with the national CMF foundation I'm the person behind building a database for families that are effected by CMV. There's a link on the CMV foundation's website for the family to put their information in and it's organized by state so the family can reach out and say, hey, I'm from this state. I don't have ‑‑ I don't know any other CMV families in my area. And we can connect them with all of the families or one of the families that we have in our database for that state. We also will e‑mail the people in that state if there's advocacy things going on, legislation going on in that state. Anything related to CMV those families will get that e‑mail separate. It is not a public database if families are worried about that. There are also on face ‑‑
>> Can I get that.
>> On the CMV foundation's website there's a link or if you want to see me afterwards I can e‑mail it to you. They are also on Facebook is a Facebook page called CMV mommies. It is 2.4, right? Thousand members in it. It's huge. It's other countries as well and it's an amazing resource for families as well. CMV mommies. 3,000. 3,000 members.
>> I will chime in and just say if you have families that are having maybe some depression issues the Facebook group is amazing but it can also be a very hard group for parents to be in. I'm sure most of you have experienced something on social media. So just be aware with that if you're giving that for a resource. And hands is voices.
>> And guide by your side as well.
>> Hello, everyone, my name is Princess. I'm part of the 91% of people that weren't aware of CMV. So I guess I want to get clarification is you all gave preventative tips for how to lessen the risk for children. Is there ‑‑ I don't know if you mentioned that you had it and you transferred it to your child. So is there a preventative things that you can, like, that you all recommend to the parent to do to lessen those chances?
>> So the prevention tips that we were talking about are for the parents. With their children or their day care children, wherever you are if you're a teacher. Those are things that you can do as a parent to reduce your risks of catching CMV. If, for some reason, you catch CMV, one‑third of those women will then pass it onto the child. If your kids get CMV after they're born it's usually just a cold. You're not going to get these ‑‑ the hearing loss and the microcephaly and ‑‑ it's really more if you're in utero that it's a danger. If you're a premie or immune compromised and catch CMV there's some things that can happen but it's not the same problems. Does that make sense?
>> Yes so you didn't have it.
>> So I had not had it before. I got pregnant with my son Nathan. I caught it when I was pregnant with him and then it passed onto Nathan.
>> (Speaker far from mic). Thank you.
>> You're welcome.
>> I was just wondering if there was something as you were going through this process with Axel and with your son, specifically in relation to hearing or language acquisition that you felt you were the most grateful one of your providers told you and you wish one of your providers hadn't said if there was a way you preferred something to be phrased. More of a negative experience potentially.
>> I will say that early on in Axel's diagnosis I got involved in Hands & Voices and at first I felt different than the other moms because a lot of them only dealing with the hearing loss and I had so many other things going on but it's funny because now there's 14 women who are my best friends and I found my place and was able to find a connection with them. So that was huge for me at that point. I was not enrolled in guide by your side. But now I have those friendships as well and I think ‑‑ bless you. I think the one thing that I wish somebody wouldn't have told me is I guess even now, you know, people make assumptions about what Axel's going to be like. Like we go into that room and they're like he's going to be handicapped for the rest of your life. Almost like forget it. He's never going to walk or talk and last week he said mama for the first time. So it's just, like, you know ‑‑ not letting people make assumptions about what your kid can or cannot do.
>> I think for me really quick is my biggest thing and we're out of time but if you guys want, Andrea and I will be out in the hallway if anyone would like to talk or ask more questions we'll be out there and please come and get stuff so we don't have to take it home.
>> (Applause).