

NCHAM

Webinar Series: Making a Difference Without Legislation

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Captioning

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>> ALYSON WARD: So let's go ahead and get started with the webinar. First of all, this meeting is -- this webinar will be recorded. And posted on infanthearing.org and CMV.us.edu those are on the bottom part of the screen on the left-hand side where I have highlighted so you can access those. Probably the beginning of next week. I'm going to go ahead and hit record right now.

>> OPERATOR: Audio recording for this meeting has begun.

>> ALYSON WARD: Excellent so today's webinar "Making a Difference Without Legislation," will start in just a few minutes. I do just want to welcome you to our webinar which is hosted by the Congenital Cytomegalovirus Public Health & Policy Conference. The main supporter for that conference is the National Center for Hearing Assessment and Management which is the technical Resource Center for all the state and territory Newborn Hearing Screening programs. And we are also -- we have some support from CMV Canada as well as the National CMV Foundation. My name is Alyson Ward. I am the co-director of the CMV Public Health & Policy Conference. And I'm also a staff member at the National Center for Hearing Assessment and Management.

We will start today's webinar with a parent story from Traci Houston. Traci is a CMV mom. Her son Keyan was born five weeks early due to her contracting CMV he was her third child and she had never heard of the virus her pregnancy was normal until the day she had him if she had known about the risk of contracting CMV she would have been much more careful around her older children so Traci's parent story is a recording. So I'm going to just pull that over right now. Let's hear from Traci.

>> TRACI HOUSTON: Hi I'm Traci. My son was born with CMV. We didn't know that he had CMV and we actually didn't know anything about CMV until after he was born. He's my third child. And I had two perfectly normal pregnancies the first time. And even Keyan's pregnancy was normal until I went to my appointment at 35 weeks. And the doctor found that something was wrong.

I was measuring very small and when they did an ultrasound, they found that he was only 4 pounds. And that he was showing signs of distress. So at that appointment it was very chaotic and the doctor immediately said, we have to take him. So I was at 35 weeks sent over to the hospital. And I had to have an emergency Cesarean. Once he was born he was asymptomatic. He was very small. That's really the main thing that the doctors were concerned about.

He was very small. And my placenta, which normally is about this big was this big. Which that really concerned my doctor.

So he sent that off. And at this time we still had no idea that it was CMV. He sent the placenta off. And that's when we found out that the virus had attacked the placenta. So I caught the virus some -- we're not sure when I caught the virus. I actually had no idea. The only thing that I remember is that I was very tired around 31 weeks. Very tired. And I thought it was just normal. But we found out that the virus had attacked my placenta and that's what caused the placenta to die. It was dying. It was -- the doctor told me I had maybe a day before it was completely dead. And you know outcomes would have been different.

Because of all of this, I became aware of CMV and was really curious why that wasn't -- you know, no one told me about CMV before. Why wasn't I aware of it. Why hadn't they been looking at it? And we started you know my son started seeing an infectious disease doctor because we didn't know what this was. He was asymptomatic so we didn't know if he needed to be on medicine.

At the infectious disease doctor, he actually had him see a neurologist. And as he got older, my son is still super tiny. As he got older he sees a neurologist. We found out he has brain damage so the infection that attacked the placenta also attacked -- caused him to have somewhat of a stroke so he had no blood flow going to his brain so he does have brain damage, which causes him to have hypotonia. He has a mild form of cerebral palsy. Hypotonic cerebral palsy. So he's very clumsy. He falls a lot. He has -- his fine motor is delayed. He has a lot of delays. His speech is delayed.

But it doesn't stop him. You know, he has to go to a speech therapist and he has to see an occupational therapist but he is strong and he's a fighter. And it's just something that people need to be made aware of. Because had I known that it was a risk, I would have, you know, watched myself with my younger -- my older children while I was pregnant. I would have, you know, not drank after them or ate after them or did any of that kind of stuff that could have potentially passed this onto me. But we're great. He's great. And you know, whatever the case may be with your child, kids are great. And you know, they are stronger than we ever believe. And they can do more than we think

they can. A lot of times they prove doctors wrong. So that's my story. And I can't wait to hear anyone else's.

>> ALYSON WARD: We really appreciate Traci submitting a video to share Keyan's story. And the CMV Public Health & Policy Conference as well as all of the CMV initiatives in both Canada and the U.S. and elsewhere really do believe in having the power of parents at the center of our advocacy as well as moving toward, you know, getting any types of legislation or awareness campaigns going.

So let's -- that's a good segue into talking a little bit about the CMV Public Health & Policy Conference. We would be meeting in Ottawa right now, Ottawa Ontario and unfortunately like so many other things COVID has gotten in the way we have been very fortunate we've been able to postpone the conference until August 2021. So please save the dates between August 22nd and 24th to come be with us in-person in Ottawa Ontario, Canada certainly more details will be rolling out in the coming months of what that's going to look like.

And with that I'm going to introduce our plenary presenter, Cara Gluck. Cara has worked in public health for 16 years and was introduced to CMV when her second child, Parker, was diagnosed shortly after birth. Cara has served a number of roles during her time with the Oklahoma State Department of Health where she serves as a preparedness strategist for community health services and was a Regional Director for six county health departments for nearly three years Cara has a Master's of public health degree and a Bachelors of Science in Health Science. Cara is a community alliance chair for the state of Oklahoma through the national CMV foundation and knew early on in her family's CMV journey she wanted to make a difference and increase awareness of congenital CMV Cara and her husband have worked tirelessly to educate people about CMV.

So Cara, I will turn the time over to you. I know you have had some issues with your slides. And so I'm happy to advance those, if that's helpful. And then let's -- I'm going to go ahead and turn the time over to you.

>> CARA GLUCK: Thank you, Alyson I really appreciate the introduction and opportunity to speak to everyone today about my family's story as well as my son Parker. And some of the different things that we've been able to do and make a difference without legislation in the state of Oklahoma.

The environment and the climate just simply has not been ripe for us to have legislation passed in Oklahoma. So I've had to take different pathways, more grassroots pathways, to be able to introduce cytomegalovirus to individuals who need to know as well as to the public health community.

So as you can see here on the first slide, this is my son Parker. This is actually an older slide or an older picture of him. This is when he was 2 years old you can see has a reverse walker. However I keep that picture as my introduction slide because Parker has really come a long way and I like the reminder of just really how far we've come.

Parker is today a seven-year-old thriving vibrant young guy. I'm not saying he

doesn't have challenges. But we are learning to work with him, the role that we have and the cards that we've been dealt. But Parker is an amazing little guy.

So today I'm going to talk a little bit about how I have been able to make a difference in the state of Oklahoma without that legislation. You know, one of the first things that we obviously all want to do is we want to have legislation passed mandating and having some form of legal teeth to say we have to educate pregnant women about cytomegalovirus. And since the environment hasn't been right I've just taken some other avenues to get the information and get the story out. So my objectives today are really to discuss ways to get started. To talk about different partnerships and contacts to help you achieve the goals that you have for yourself and increase awareness in your state and also to discuss a little bit about what we have been able to achieve here in Oklahoma with the Oklahoma State Department of Health and how we've been able to move forward.

So when you're -- I know for myself, when I started this journey, you know, in the introduction it said I really knew that I wanted to make a difference. And I wanted to educate about CMV once our world was impacted by CMV. And me working in public health, I knew that this was a public health issue. Even though I had not been introduced to cytomegalovirus within my public health professional career, I did know that it was a public health issue. And so I started my journey really just talking to my inner circle. My co-workers. The people within my county health department. And those within my circle of influence to start talking about and sharing information about CMV.

And everyone who knows me knows that I am incredibly passionate about sharing information about CMV and to preventing -- trying to prevent one more child from being affected or impacted.

Also, I started talking to our medical providers. You know, when you are pregnant, you have your OB and your OB really just kind of goes through those normal motions of your prenatal appointments. Typically most of my appointments were very, very short. And I will tell you during our time, we did not even know that I had been infected with or transferred the virus to our unborn child, Parker. It wasn't until I was 38 -- 36 weeks. And my water broke. And I went into the hospital to figure out what was going on. To then within the past eight hours -- within eight hours I had a very, very sick little boy on my hands that I didn't even know was sick at that time. I will tell you my water broke. When I went into labor and delivery, they -- I said that I was there to have a baby and they kind of looked at me like I was crazy because I walked in and I wasn't really having contractions quickly. They went ahead and checked me and started me on Pitocin. They put the -- Pitocin they put the fetal monitor on they realized I lost a lot of amniotic fluid and Parker was in distress but they really didn't tell me that, they just told me that I needed to have Pitocin and they needed to help me get my delivery along so they bumped me up really quickly then when it was time for Parker to be born I was waiting on the epidural and the anesthesiologist had three people in front of me and I told the

nurse that it was time to have the baby she said well you can't you haven't had your epidural I said well I'm sorry it's just going to have to happen without it because he's coming and he's coming now by the time they got me set up on the bed, and notified the doctor, the doctor was on the way to the tunnel over into the labor and delivery area and by the time he got into the room Parker was crowing and Parker was born really within about just two pushes.

When Parker was handed to me the very first thing I said is, what is wrong with him? And you may think that that's a very interesting thing to say when you're bringing a -- your brand-new newborn baby is handed to you but he had petechiae or bruises from the top of his head to the very bottom of his feet and purple little hands so I knew something was wrong the OB dismissed it as it was a fast labor don't worry about it. We were moved to a regular floor room and later on that night Parker started having complications with maintaining his body temperature. So we did a lot of skin to skin. And then after that we started having some other issues.

He became very jaundiced. And in about a couple of hours the nurse said that we needed to go ahead and get a bilirubin because he was so jaundiced. So that really began our journey with CMV. And I tell that because that personal story is something that pulls people in to want to know more when I was telling my public health colleagues about CMV, I will tell you, most of my colleagues had not heard of CMV. And they certainly were not aware of the impact or the complications that can affect pregnant women and newborns. And so telling your story is something that is essential. Now, trying to figure out what part of the story you tell or how much you highlight, how in-depth you get or really how much you want to share, that's certainly up to you. But if you can identify one or two or even three different things that would really stand out, I think that that really helps in the long run.

And so I began telling that story to my public health peers. And then also, I started looking at my -- our medical providers, the pediatrician. The neurologist. Because Parker was in the NICU and we had a neurologist. And I started talking to them. I started talking to them about, one, why aren't people -- why aren't moms, women, educated about CMV. And then also, what can we do so that we begin educating about CMV?

I also began going to local groups, whether that be groups that are social or civic groups, professional groups, professional associations. I started talking to and educating residents. And really anybody who would listen. And that's what I say is anybody and everybody who will listen I will talk to about CMV trying to enhance the knowledge about CMV as well as help us get to the end state, which I'll talk about in a little bit.

So in public health I have the fortunate blessing that I work in public health so I have a very strong public health network but just because I work in public health and others on this call may not be working in public health doesn't mean that you can't find a champion in public health.

My recommendation would be to go to your local county or regional health department and ask to speak with the local director or the local nurse or if -- find out if there is an early intervention program within your community. Early intervention is a Federal program that is nationwide. So there are -- there is early intervention. It's just finding somebody who will listen. I also began talking to our Nurse-Family Partnership initiative, which was called Children's First here in Oklahoma. And I started talking to those nurses. Because those nurses are actually working with at-risk mothers. First-time mothers.

So I felt that that was a group that needed to, one, know about CMV. But also, two, they could then begin utilizing that knowledge to help their clients.

The nurses in your county health department, I would say what I have learned is the majority of public health nurses may have heard of CMV. But they really aren't certain as to what it is or the impact that it can have on a pregnancy or an unborn child. And so really taking your story and going to try to talk to those individuals and seeing if you can take the opportunity or make an opportunity to speak with them and educate them.

And see if they are willing to allow you to speak to all of the staff. See if they are willing to partner or collaborate with you for those civic organizations that I spoke a little bit about and I'll talk a little bit more on here in a minute.

And then the State Department of Health. Again, being fortunate that I work in public health, I had probably an easy link per se to our screening and special services division. And that's the division that really looks at services and newborn screening. And within that division, we have the Early Hearing Detection and Intervention program as well as the Birth Defects Registry. And I have had an opportunity to be able to speak and to be a para advocate on Boards that screening and social services has as well as help collaborate on bigger projects as a whole.

So I would recommend -- in Oklahoma our public health system is a centralized system however not all states in the United States are centralized. So I think the first thing if you want to take that public health route is to identify what the structure of your public health system is. And then really start knocking on doors and trying to find that individual who will listen. At this point it's certainly not going to be a champion. You're the champion that is going to be communicating that message. But finding that person who will listen.

And in our current state with COVID, I will tell you, you may not be able to reach somebody right away. But don't take that as a no. Take that as a not right now. And continue to develop and foster and collaborate so that you can develop a relationship.

The screening and special services group at the State Department of Health was really able to help propel me into a statewide initiative. And I will talk about that statewide initiative here in a little while. But getting the buy-in from those individuals, and those individuals understanding the necessity and the importance of CMV awareness and education and prevention messaging really has helped the initiatives and the things in Oklahoma that we've wanted to do.

For medical providers, like I talked about, the NICU staff. I will tell you I have been able to collaborate with different newborn intensive care units and provide my contact information to them for if there is another family who has a child in the NICU. For them to provide my name as a resource.

I have been able to do that through the community alliance program with the National CMV Foundation but also just with developing the relationships and talking to the social workers, trying to -- the family outreach services and the different individuals that support system that families have within the NICU.

Also I will tell you that I was in a pretty fortunate spot that the pediatrician that has seen my oldest child as well as Parker, he was the President of the state association of the Academy of Pediatrics. And so he was another individual that I really started speaking to and talking to about the importance of CMV awareness and education and then also prevention.

And I will tell you, in the early days I was very discouraged because most of the responses I got were, oh, but it's not that big of a deal. It's not very common. It's not very prevalent. You don't hear it very often. You don't see it very often. And I have really just had to be very persistent on ensuring that I communicate really how prevalent and common congenital CMV is.

The specialty providers that I have really looked at is, one, the OB office. And going back to that office and explaining that my son wasn't just a fast labor, as well as he had congenital CMV. He had all of the characteristic telltale signs of congenital CMV and then working with them in not an adversarial or controversial manner but really taking the approach of I want to work with you and I want to help educate women. And so one of the things that he was willing to do was to take the basic flyer from the National CMV Foundation the one with the woman with the pregnant body and a little boy holding onto her pregnant belly that just says are you pregnant? Do you know about CMV? And they were willing to put that into all of their new OB packets. So it's a very passive way. And I would like them to do more but at least it was a little win in the beginning.

Other specialty providers that we looked at, the ear, nose and throat provider. Parker's ENT. And started speaking with those individuals. Speaking with our neurologist.

And I will tell you the neurologist that we have for Parker has been with Parker since he's been a year old. And initially when I spoke to her about what I wanted to see with CMV, her response was actually, the very same as everybody else. It's not very common. We don't see it very often. And there's nothing we can do.

However, through the years and every single opportunity that I have to interact with her, I speak about education and prevention and the importance. And just the last time that I had an opportunity to speak with her during Parker's last neurology appointment this summer, I will tell you, her thought process and her willingness to listen as well as her willingness to advocate for universal screening has completely changed.

Part of that is because I think we collectively are starting to get CMV more heard.

But also I think she -- like information that I took to her, she would go back and research and she would learn a little bit more and a little bit more every single time. So for the past six years, there's been just a little bit and a little bit and a little bit. And as a matter of fact this last time she said, if we get to the point of legislation in Oklahoma, or the -- getting it -- getting CMV as universal screening in Oklahoma, I would be willing to support you and put my name behind it as a neurologist.

And so that means a lot and developing those relationships isn't just a one-time thing it's continuously bringing it up and continuously making those points known and talking about it any time you can.

But Allied Health providers that Parker sees, Parker has received outpatient PT, OT and speech services since he was a year old so he started early intervention at six weeks old and then he started outpatient rehab and a year old. And still today is still receiving services. And talking to those Allied Health providers. And educating them. Because they, too, were not educated about really all of the impacts that CMV can have on a child and a child's development.

You know, CMV, if you were able to participate in the presentation yesterday, you got a good understanding of what CMV is and the different impacts that CMV can have on a child. And so talking with those providers and helping them understand that Parker's developmental delays are a result of his congenital CMV, his balance and the vestibular issues and the sensory issues that he has, is a result of congenital CMV. And actually another story this summer where there was a family that was coming in as I was leaving therapy. And the child had microcephaly and I just reached out to the providers and said, I don't know what that child's diagnosis is. But if it is CMV and if that family is interested in talking, would you share my information with them? That child actually doesn't have a diagnosis at this point. But they have shared my information. And that family has reached out to me through Facebook.

And so I'm able to educate a little bit that way. So not only just the providers. But the families that see those providers, as well.

And then teaching universities. I've reached out and been able to reach out to our teaching universities to provide some education to residents. Just basic presentations over CMV 101 per se, basic foundations of what congenital CMV is and how it can affect a growing fetus and a growing baby.

And then the long-term implications of congenital CMV or potential implications of long-term effects of CMV.

And so again, it's just one of those things where I have just really gotten out and talked to everybody and anybody -- I'm sorry; my slides just . . . advanced too many times here.

Okay. Local groups that I talked to. I partnered with our health educators. And I've been able to talk to Kiwanis and Lions and Rotary and we have talked to AMBUCs. And really I have tacked on my information for infant mortality. I've provided my information at different times throughout the year. Obviously June being CVS Awareness Month but

then also Birth Defects Awareness Month. And different Awareness Month activities. And then a lot of those groups are always looking for somebody to come and speak. Because the members have a requirement to get a speaker. And so if you can find somebody or know somebody who is in one of those clubs and say hey I would like to go and talk to your group a little bit about congenital CMV. And really that's where you just have the opportunity to tell your personal story. You don't have to have a background in public health. You don't have to have a Master's Degree. Really all you need to have is your personal experience and the passion and people will listen to you.

I was also able to collaborate with the local hospital and present during a Lunch and Learn. Where the employees of the hospital had the opportunity to come down and listen to a 30-minute presentation and really it was mainly an introductory presentation but those introductory presentations, typically you have several people at the end come and say, I had no idea. I have never heard of this before. I have a daughter who is pregnant or I have a family member who is pregnant or I am pregnant and my OB hasn't talked to me about this and my recommendation to them is, go back to your OB and ask them about congenital CMV. And then I recommend that they go to the CDC website. And go to the national CMV website just to get some basic information and I will tell you Dr. Google is very intimidating and very scary when you first go on. And start learning about congenital CMV. But the information and then you can take that information and go back to your providers and say, help me understand. And then go from there.

So additional groups that I have been able to leverage and work collaboratively with is the Oklahoma Family Network, that family support network that you have within your state. I was able to link up with that network through the NICU actually. And then I became a parent peer-to-peer support group and I've been able to speak at their conferences. And provide information that way. And then we within the past I guess it's been about 18 months, we partnered up where I provided some training to all of their advocates and peer-to-peer partners that work in NICU. And all of them now have my business card so they can provide that information to a family who has just received a diagnosis and I am a resource, I'm willing to talk to anybody and everybody that I can, like I said earlier.

I also have partnered with Oklahoma child advocacy group. And this group is really one that I'm still fostering and developing the relationship with. But being in the same room as individuals who support child advocacy initiatives can help you with your overall big picture, whether that's legislation or more of this grassroots campaign that I've been talking about. Or however it is that you're wanting to make a difference without that legislation piece and with that legislation piece. Because they have connections and they know people who are in the Legislature. So if you can get those advocacy groups on your side and understanding and hearing your story, then they are more willing to help speak with you and help be with the group and work with you.

Sooner Success is just another resource initiative that I've been able to work with here within my local geographic area. And then the National CMV Foundation. As I

said earlier, I am an alliance Chair with the CMV Foundation. This is my second year doing that. And really just getting involved with the group and speaking any time you have the opportunity.

This past year being a public health professional, I have been inundated with COVID-19 and really have not been able to spend a lot of time working on CMV awareness. But I have had the opportunity to do a few things and I'll show a couple of those things here in just a bit.

So these are just some faces of families and children that are impacted by congenital CMV here in the state of Oklahoma that I have had the opportunity to meet and become friends with and be a peer-to-peer support group with.

So another thing that I've done is we have a local -- we've got local community baby showers that are put on through the health department. And I have a booth at the community baby shower where during the baby showers that I'm involved with, they have made CMV awareness as a mandatory booth for participants to stop at for them to get information about CMV. And then I stamp their passport and then their passport has to be full for them to be entered into door prizes so they are very motivated by getting those gifts and some of those gifts are really nice gifts like glider rockers and cribs and those types of things.

So they have the desire to come, listen, I do a really brief about eight to ten-minute presentation over what congenital CMV is and why pregnant moms need to know about it but more importantly I tell them to go back and talk to their provider and get information.

I also have been able to do some stories on our local news channel.

I've been able to do a MedWatch which is simply a segment that's targeted to medical issues. So I've been able to do some education through that avenue. And then I have done for the past four years, I didn't do it this year just because of COVID. But I did an awareness run and walk at our university here. They have got what they call the Aggie mile. So it's already a laid out track. And we do a one, two or three mile fun run or walk for participants in the community. And then throughout the walk we actually have some very basic facts for the participants.

Like 1 in 200 live births are affected. Pregnant women have a right to know basic information like that.

So I have about 100 participants in that group. I also have worked with our city and county elected officials to get just a basic proclamation and the National CMV Foundation has that information, just the basic template on the proclamation.

And I do most of those activities during the month of June, during CMV Awareness Month. The past three years I have asked our Governor for -- our governors for a proclamation, as well. And you can see we're with the Governor. And then different families and different children have an opportunity to take a picture. Really that just continues to enhance that information.

This is just a little bit more information about my run that I have. During the

awareness run or walk, we have ambassadors. And those ambassadors are children or adults who are impacted by congenital CMV. And they start our race. And we do a little bit of information. We've had honorary ambassadors who are for individuals who have passed away from CMV and we have had angel and honorary ambassadors for families or children who were not able to be onsite but wanted to participate at their home virtually.

These are just some images.

And then I want to talk to you about the initiatives that we have with the State Department of Health. The State Department of Health initiatives really has blossomed through all of these things that I've been talking to you about. But in 2019 we actually had a statewide sponsored awareness campaign.

And you can see this is just a visual from that awareness campaign. And we chose to go with animals. And this really catching scenery.

And with this campaign, we actually ended up developing brochures. You can see, this is a brochure. And then there's hand sanitizer, as well. All with this really catchy appealing cute visuals for people -- for pregnant women to want to pick up. And these have been distributed to OB providers throughout the state of Oklahoma.

We also developed these nice posters. And then we did -- there's actually a dedicated website.

I'm going through these a little bit fast because I've been a little bit long winded early and I want to get to some videos so you guys can see them. There's a website. You can see the link here. And it has one of the videos that we have been able to develop.

There was a social media campaign that we have in the month of June. So once a week we have a social media message. And you can see again these really just cute catchy characters for people to see.

We have on social media we did Facebook. We have done Twitter. As well as Instagram.

And then also we developed videos.

And for the videos, I don't know -- I'm hoping these videos will work. Alyson --

>> ALYSON WARD: Yeah, we'll get them to work. Go ahead -- are you ready for the first one.

>> CARA GLUCK: Yeah, I want you all to be able to see the videos that we've been able to pull together not only with myself but other families within the state of Oklahoma.

>> ALYSON WARD: Okay. And before I start this video, I just want to let everybody know that I will be opening a Q&A text box over on the left-hand side in just a few minutes. So you will be able to have the opportunity to ask Cara some questions. So let me go ahead and start this video.

>> Cytomegalovirus.

>> Cytomegalovirus.

>> Cytomegalovirus.

>> Cytomegalovirus.

- >> Everyone needs to hear cytomegalovirus and what it can do to unborn babies.
- >> Children with hearing loss, you have children with vision loss.
- >> Significant brain damage.
- >> Cerebral palsy.
- >> Seizures.

>> Any pregnant woman has the potential of being exposed to the virus and acquiring the virus and transferring that virus to her unborn child.

>> If I would have had any idea of that word, cytomegalovirus, I could have taken precautions.

>> ALYSON WARD: Okay.

>> CARA GLUCK: Sorry, Alyson. So that PSA was just a 30-second PSA that ran and that was broadcast through a contract with the Association of Broadcasters. Within the state of Oklahoma. And so all of the broadcasters and media outlets within the state of Oklahoma had the opportunity to air that 30-second PSA during their contracted time.

So the next one I want to show you is a little bit longer and I think really this is the only other one that we're going to have time for, Alyson. But then I can talk about the other ones if we want to make those available, I can certainly do that later.

>> ALYSON WARD: Okay. I'll go ahead and play this one.

>> CARA GLUCK: Thank you.

>> I was not aware of it during my pregnancy.

>> There really is not a significant level of awareness.

>> Everything was unknown.

>> We don't know what his future is going to be like.

>> I don't think many people are talking about it.

>> My OB never discussed CMV with me.

>> I was one of those parents that had to diagnose myself.

>> Women have the right to know.

>> I don't know what will happen for my baby.

>> I wanted to tell myself that it couldn't be prevented.

>> This is a preventable disease.

>> This one is for the most part fairly preventable.

>> It's a word none of my family or friends ever knew.

>> Cytomegalovirus.

>> Cytomegalovirus.

>> Cytomegalovirus.

>> Cytomegalovirus.

>> Cytomegalovirus. CMV.

>> Is a virus that is acquired by a pregnant woman and transferred then subsequently to her unborn child. And as a matter of fact, CMV is the leading viral cause of hearing loss in children and statistics show that upwards of 80% of individuals by the time they are 40 years old, will have experienced or been exposed to CMV at

some point in their life.

Cytomegalovirus, the way that it affects fetal growth is it attacks the development of the brain. And the vital organs. There's a very broad range from absolutely no signs, symptoms, effect of the infection. All the way to unfortunately death. And almost everything and anything in between. So Parker's brain had been impacted. Parker unfortunately had that acute illness when he was born however Parker has global developmental delay. Parker has sensory integration challenges. Parker has cerebral palsy. Parker wears glasses.

He did not walk until he was about three years old. After extensive therapy and we still undergo extensive therapy today.

And the biggest thing that I want our communities, Oklahomans, providers and anybody listening to this message is to know what your risks are of CMV and that any pregnant woman has the potential of being exposed to the virus and acquiring the virus and transferring that virus to her unborn child. Especially if she is around other young children ages one to three.

>> At that two-month appointment we got our results back that it was cytomegalovirus and there was basically -- he just told me there was nothing they could do. He said, here is her diagnosis. We don't really know what her outcome is going to be. You're just going to have to take your time and wait.

>> We were more worried about the outcome. What the -- if she was going to survive the pregnancy.

>> And at first we thought, a lot of times it doesn't affect your child. So it's okay.

And then we read when it does affect your child. And it just tore our world apart.

>> By the time he was maybe like ten months old, you know, he wasn't meeting the milestones that she wanted him to meet and we got an MRI. I remember that day, it was very dreadful day. We got the phone call from her. And she said it was abnormal.

>> She was diagnosed with epilepsy at three or four months old.

>> It was anemia, microcephaly.

>> But I have a mild case of cerebral palsy on my right side.

>> So I mean really it's not minor that your child can't hear. But that's kind of where, as a CMV mommy that I now am, that's where our lives are. That's minor. If that's the worst case scenario, we are so happy.

>> Absolutely nothing compares when you see those moms losing their babies.

>> Speak with your provider. It's essential that you talk to your provider about your risk and to get more information.

>> ALYSON WARD: What a powerful video, Cara, I'm going to move to opening up the Q&A box. And please feel free to enter in questions in the chat box here. And Cara will move to start answering some of your questions.

Cara.

>> CARA GLUCK: Yes.

>> ALYSON WARD: Why don't you go ahead and keep moving forward with your

PowerPoint and as questions start to roll in, we will move to answering some questions.

>> CARA GLUCK: Okay. I'm actually seeing several questions now.

>> ALYSON WARD: Okay.

>> CARA GLUCK: My PowerPoint really -- so on moving forward really what I'm wanting to do, my overarching goal is continually increasing awareness and educating women of childbearing years about congenital CMV. I would like to see legislation within the state of Oklahoma when we're in an environment that that would be beneficial.

The National CMV Foundation has submitted information to the recommended universal screening panel. And really I would like to see universal screening. That really is my ultimate thing that I want to see in my lifetime is that all babies are when they are born that they are screened for congenital CMV because we know that early intervention is essential. And can be a significant positive thing within a child's life for their overall outcome.

And then I would like obviously statewide adoption of that.

>> ALYSON WARD: Great.

>> CARA GLUCK: And I'm seeing --

>> ALYSON WARD: Yeah we have several questions that have rolled in so I will just voice the questions for you and you can verbally answer them and then everybody in the audience can hear your response. So the first question is, when you talked with legislators were they receptive to you and your recommendations? If yes, what is the main hindrance preventing legislation from passing?

>> CARA GLUCK: So when I've gone and spoken at the capitol I have taken basic information and provided them basic information. I have actually not started the conversation about pass legislation just yet because I'm trying to develop the relationships. And the reason I haven't is because the climate in Oklahoma, we have had a -- we've kind of been on a roller coaster in regards to our economic climate within the state. And when we are in a time of cuts across the board and deficits, I didn't want to bring up something that would potentially cost money so when I get legislation I'm really pushing for the universal screening piece and I want to make sure all of the pieces are in the right spot before I do that. So I haven't made that jump yet to actually see about passing.

I'm just now working on awareness at this point.

>> ALYSON WARD: Great. So the next question is, I am in Minnesota. Is there a brochure available to share in other states?

>> CARA GLUCK: So I have the brochure that the state of Oklahoma developed. I am willing to share that with anybody who is interested. If they just want to send me an email. And I have my email address here on the last slide, if you want to just send me an email, I can share those brochures with you. But those are developed and distributed within the state of Oklahoma.

>> ALYSON WARD: Okay, excellent and you know what we could also do, Cara, is

as we go to post the slide deck and the webinar on our websites on the infant hearing.org and CMV.usu.edu we can have accompanying documents and the videos that you shared as well as your brochure in the same location if people are interested.

So if you're okay with that, I think that might help facilitate dissemination.

>> CARA GLUCK: Absolutely.

>> ALYSON WARD: The next question is do you have anything that can help tell women about precautions that they can take and can get --

>> CARA GLUCK: You know, OBs are really, really hard to get through to, I will say. I will tell you the foundation is working really hard to try and get ACOG on board. And I think it's really just going and talking to that individual. And getting them to hear your story. And then expressing to them how common it is. And then providing them information that they could do their own research. Because while you -- your story might catch their ear, if they want to go back and find that those medical journals and that information, so that's how I would recommend moving forward with them.

>> ALYSON WARD: Okay. Great. So one of the questions we already answered was posting the videos. And then another question is, are your awareness videos being played through social media?

>> CARA GLUCK: Yes. They have been shared by the Oklahoma State Department of Health. If you go to the state -- you can go to YouTube and search Oklahoma State Department of Health. And then within the Oklahoma State Department of Health's channels type in CMV and you can find those or even on the website that I provided. They also have been shared on Facebook.

>> ALYSON WARD: Okay. Sorry about that, I was on mute. I'm trying to be careful to mute my line every time I'm not speaking.

So the next question, Cara, is, what's the greatest challenge to get state officials to mandate CMV universal screening.

>> CARA GLUCK: I think really the biggest hurdle right now is that it's not recommended and there's not a national mandate. And so I certainly want that mandate. But then also just getting them to understand the importance and looking at the benefits of the -- the cost-benefit analysis per se. How much it costs to actually do the test versus the benefit that the family or the child would have by doing the test. And actually knowing if that child does have congenital CMV or not.

>> ALYSON WARD: Okay. Great.

So another question, this is kind of along that same thread so can CMV be detected in toddler stem cells taken at birth? So I'm assuming the question is if she has a toddler now if maybe there were stem cells taken at birth if they would be able to detect the CMV through those stem cells? I'm not --

>> CARA GLUCK: I would think so. However, I am not a medical doctor. Nor am I an expert on stem cells. So I would recommend reaching out to your medical provider and/or the stem cell organization and see if they could provide you that information.

>> ALYSON WARD: Okay excellent. The next question is, as a parent advocate,

do you recommend parents who may have an interest in pursuing future legislative activity in their state reach out to their state EHDI program or their Early Hearing Detection and Intervention program to gauge the climate in their state?

>> CARA GLUCK: Absolutely. And I would recommend reaching out to them just to build and foster a collaborative environment of education. Even if the political climate may or may not be right, that relationship really can go a long way.

>> ALYSON WARD: Yeah, agreed. And if you are looking at trying to get ahold of the coordinator for Early Hearing Detection and Intervention in your state please contact us go to infanthearing.org we have a contact us link and we'll be able to connect you with the coordinator in your state.

So we have time for one more question.

The last one is I am a Service Coordinator in Nashville. My first encounter and knowledge of CMV was when I was about seven or eight months pregnant with one of my families. I was a quite -- it was a scary experience. So I'm just kind of skimming down to the question.

Do you have direct connections for Tennessee that I can be put in contact regarding CMV and linking with providing more information to my district?

>> CARA GLUCK: I do not, but I would just recommend looking at your county health department or your State Department of Health website and seeing if you can identify contact information for either your local director or that EHDI coordinator or just you know I don't know if there's just a basic -- I mean, you could easily make the phone call and say you wanted to speak to somebody in health education.

>> ALYSON WARD: Okay. Excellent. And then I'm going to go ahead and stop the recording. One more time I just want to remind you about the CMV Public Health & Policy Conference to save the date August 22nd through 24th in 2021 to join us in Ottawa if you are looking to get a certificate of attendance please click on this purple link on the screen that you see right here. It will take you to a short evaluation of the webinar as well as finish you off with getting your certificate of attendance.

We appreciate you coming today. And tomorrow we will be having our next CMV webinar talking about different screening procedures in five Minnesota hospitals. It will also start at 10 Mountain. 12 Eastern. We hope to see you then. In the meantime, have an excellent Tuesday.

>> CARA GLUCK: Thanks, everybody.