>> Amanda Devereaux: Okay, we're going to get started. I think we're going to start with a video, so I'm going to do that first.

>> There were things happening with the ultrasound.

>> I assumed we have this problem and it cleared up and it wasn't a big of a deal.

>> I felt a little bit let down. -- [captioner can't hear video]

>> A hearing aid on the left side.

>> She doesn't see those kind of dividing lines that we see. Everybody is her friend. It does not matter, they are all her friends and she is so open and so happy and she will give anybody a hug. When she grows up, she wants to bake cookies and give them to people and that is just Kaitlin.

>> Nobody knew what it was. I wish we were given more information.

>> It is hard. It does take a little bit of a shift and intentional behavior, but you do that when you're pregnant anyways. You understand the importance. I think moms are willing to do anything to protect their kids, as long as they know about it.

>> Amanda Devereaux: Thank you to the Hill family. They always give me permission to share that video. Some day, Kaitlin might say no. We're always thankful. I'm going to cover CMV basics, I'm not going to be able to cover everything in 25 minutes, but I'm hoping to give a foundation for those who don't know the basics of CMV.

We're going to talk about ways pregnant persons can reduce their risks, supports for a CMV diagnosis. I'm Pippa's mom, so Pippa is our case study today. We needed a little help getting pregnant. no -- no one mentioned CMV to us. At the time we were told we could terminate or do nothing. We were told there was nothing we could do. Those who know me, I'm not a do nothing type of person, so we did reach on our own. We received experiential treatment during the pregnancy.

Pippa looked typical, no small head size, no rash, nothing that you think of when you think of CMV. She was born with CMV in her blood, our win and saliva. She received Valcyte for 180 days. Her follow-ups included hearing, vision, early access that is what we called it in Iowa, early intervention. She went to a development alkalinic for a while, infectious disease, PT, OT, SLP, feeding therapy. She got this because we knee she was CMV. When her brain was forming, it did not form typically. I had a primary infection during my first trimester. She has intellectual delay, epilepsy, nonverbal.

What is CMV in general? It's a virus. It is a common virus, been around for a long time, most people have had it, most people don't know they have it. Infections are usually "silent." Most adults have been exposed by the age of 40 and healthy children are shedding the virus at any time. It is out there. It is everywhere. In a certain sense, you can't avoid it in a sense it is out there. There are things that can be done to reduce your risk, but you will run into it.

What is congenital cytomegalovirus? We're going to use cCMV during the rest of the presentation, when a mother catches cCMV, it can cross the placenta and infect the baby. When a baby is born with the virus, it is called cCMV. One in 200 infants are born with cCMV. It is the most common form of birth defects. What about transmission? The risk of casual transmission, is pretty small. You have to be in contact with someone's body fluid. It is thought to be transmitted from saliva toddlerlers are hot zones for cCMV. They don't teach their germs to themselves. They are teething, drooling, they put everything in their mouth. Spread easily in daycares.

It can be transmitted during pregnancy, which is what we're talking about and common cause is in children in less than 3. Pregnant people who contract cCMV, one in three will pass it to the baby. What is the impact? One in 200 babies, we're talking 20,000 plus babies in the United States. Most are asymptomatic at birth, but 90% of significants with symptomatic CMV are not identified. This is a study out of Canada and their symptoms are subtle enough they are missed on all newborn exam. One out of five babies will have a permanent health condition and this can show up months or years later. So it is birth defects or permanent health conditions for year.

There is a paper looking at asymptomatic children and they may not always be symptomatic. About half of children in a study with asymptomatic with CMV had a gaze or balance disorder. I don't think we know the full impact on children who are deemed asymptomatic. Black and multi-racial significants are at increased risk, again, that is something we need more information on. That's just one study by Karen Fowler.

In a study of 20,000 significants -- infants at University of Minnesota, second born significants had higher risk of CMV. That was very interesting. Working for the National CMV Foundation, I have anecdotally see that. I do know people who have had a first born baby with CMV, but it seems it is second or subsequent baby. It could be the toddlers in daycare or toddlers in general that could be sharing the disease. That is not conclusive. It is just a thought.

Here is a spectrum of symptoms. This is from our website. There are babies born without symptoms and will never have symptoms and most babies are in that category, which is great. That is what we want. But we go all the way to very symptomatic children and, actually you know, some children are going to die from ramifications of the virus. About 400 deaths annually. there are some studies that 15% of the stillborn babies in the study had congenital CMV. That is an area we need more research in.

Then we have everything in between, we have children with hearing loss, children who are deaf, children who have visual disorders, cognitive delays, cerebral palsy, all of these things and some of these babies are very fragile, failure to thrive, in and out of the hospital a lot, those types of things. Again, we've got a whole range of symptoms.

So, if we just look at viral causes of congenital -- I can't read that word up there. Viral causes of congenital health conditions, people have heard of the Zika virus a lot. During that time, it was a difficult thing to see all the coverage on Zika and everybody has heard of that, but nobody has heard of congenital CMV. This is a slide out of Arizona. She made a wonderful slide looking at Zika, rubella and CMV and by no way to mean to minimize children who are infected by Zika or rubella, but rubella is almost extinct due to vaccinations.

2018, Zika, a few hundred birth defects and if we look at CMV, and she uses a different study, but we're talking about thousands of birth defects every year, year-over-year. It is important to keep in mind, we have heard of these other things that cause less difficult than congenital CMV.

This is our awareness of congenital conditions. When we look at the number of children who are disabled by the condition, those are the orange dots. So, if we look at congenital CMV, she is using the number 6,000 and we can look at Down Syndrome, about the same, 6,000 disabilities every year due to Down Syndrome. But most people have heard of Down Syndrome, that is the blue bar. The awareness of down syndrome is high, along with it being a significant cause of disabilities, a common cause of disabilities. If we look at congenital CMV, it is 9% of women who have heard of the condition. We call that the awareness gap, the space between the awareness level and the ones who know the cause. How do we help with that? I'm hoping all of you will help with that.

Congenital CMV has been called a "silent global burden." I think CMV is a public health crisis and I don't think people are paying attention to it. I have had people tell me they have never seen a kid with CMV. I tell them, have you seen all kid with Down Syndrome? It is 1:1. This is a public health issue. Why is attention to CMV so low? Well, most of the time it is asymptomatic. I had physicians say they never delivered a baby with CMV, and I will say how many babies have you delivered, because you have delivered one with CMV. They were just asymptomatic or had symptoms that were subtle enough that they weren't obvious. By the time they showed symptoms, if they did, it is too late to go back and determine that is the cause.

Maternal and newborn infections are usually asymptomatic, if there are consequences from the virus and usually it is too late to tie it back to the disease. So, a lot of times I will hear people say, if you have had CMV before, you're in the leer. You -- clear. You don't have to worry about it anymore. Two-thirds of babies born with CMV are born to moms who had the virus before they were pregnant with them. So, it's not completely protective to have been exposed to the virus before, and that is why we recommend the same risk reduction techniques for everybody, no matter if they had CMV before or not.

How can we reduce the risk? Per the CDC, pregnant women may be able to lessen the risk of acquiring CMV during pregnancy. However, there is a sense from certain people that it is unavoidable or we're going to stress pregnant women out more if we talk about CMV. However, there have been studies indicating the hygienic measures can reduce seroconversion during pregnancy. Some states, so it is important to look at your state, have laws mandating that pregnant women be given CMV preventing materials. In 2015, the American college of obstetrics pregnancy bulletin called prevention measures impractical or burdensome. It is not recommended to council all pregnant women about CMV. However, prethey at education is recommended by the college of on streetics and gynecologists in Canada. Both of the groups gave evidence for the risk reduction a high rating.

In recent studies, participants expressed a strong desire to receive the information, so that is what we think we should be guided by. We also think it is important to give the information in the right way. We're not trying to scare anybody at all, and we think we can provide this information in a way that is empowering for people to protect their babies.

So, I get this question a lot from early interventionists, so I thought I should put this in here. Soul you avoid children with a cCMV diagnosis? Most kids with congenital CMV show no signs of infection, people who work with children and planning a pregnancy or are pregnant should follow the same precautions for all children. Adults are at a higher risk of acquiring CMV from their own children than children they work with professionally. The CDC and AAP do not recommend treating children with cCMV than any other children. It is hard to shed the virus being asymptomatic. For me, I don't want workers to put their guard up that they know has CMV, and the next child who walks into the room and could be shedding it, lets their guard down.

I will say, myself personally, and a lot of the families we work with have been told, I won't work with your children anymore. We were at the hospital once and they would not let my daughter go to the playroom, and they said, we have pregnant workers on this floor. I said you need to check your policy. The kid next door could be shedding it and she is 4 years old. She was born with it 4 years ago. You have no clue if she is still shedding the virus. It is important to note that all children pose a risk of having CMV.

So, here are the five simple tips to reduce your risk. We say I cans them on the top of the head, don't put a pacifier in your mouth, don't share utensils, drinks or straws, don't share a toothbrush a, wash your hands, especially after changing your diaper. People are like, these are common sense. When you're a busy mom, you're pregnant, and you're doing all of these things, I think it is easy to forget these things and sometimes you have a good intention.

I remember when I was pregnant, I had a toddler in daycare and he wouldn't finish his breakfast. I said, I am not going to throw that food away. What a waste to throw it in the garbage. I had no idea I was putting my baby at risk, and I was. And that is what happened. I do think that I had the right to have that information, and I was never given that information.

Where are we at with vaccine development? I would love to see a vaccine. Immunity does reduce transmission to the baby, and we do still think it reduces the severity of disease. I don't know. There may be some emerging research that may not be the case, but that is still the thought here. So, the thought is, if we eradicated rubella with a vaccine, we should be able to do the same with CMV. However, they have been in development, vaccines for decades and we do not have a licensed CMV vaccine. Institution of medicine gave development a vaccine the highest priority rating, I will say that was before COVID. At the time, this is from Mark Schelss' paper. I'm putting COVID to the side.

What about treatment? Just to note the treatments in pregnancy are not standard treatments. They are not, in general, recommended unless you are part of a research study. However, there are still people getting experimental treatment in pregnancy, with immuno globulin or oral Valaciclovir. If for some reason they found out the pregnant person has been exposed and they don't think it has gotten to the baby, they can reduce transmission occurring. More work on pregnancies that would be the take-home messages. We need more money invested in treatments during pregnancy.

After birth, we have to note babies are not going to get treated if we don't know they have the virus. And we at the National CMV Foundation really like to, not focus treatment only on medicine. To us, treatment is more than just a drug that we give a prescription for. So, infants should have regular follow-up, including hearing, vision, development, etc. It is an automatic qualifier for early intervention in many states, my state included. So, we're just monitoring the kids, intervening early if they show any consequences. There was a paper where infants received antiviral therapy with improved outcomes. It is a six-month oral therapy regimen, it needs to be importanted be someone who is familiar with the drug. We're not saying all infants born with CMV should be treated. They should be seen by someone familiar with the treatment who can help the family in making that decision.

So, what is a typical family experience? These circles are not to scale. It is just trying to drive home the message that some people will experience miscarriage or stillbirth, some people will find out during the pregnancy, that is less common, some people will find out during the nigh yo fatal period, again, less common or later. We do have families that have found out by going back and checking their blood spot or someone had kept their baby's umbilical cord stump, and they sent it off and that found out that is what it is. Most will not receive a CMV diagnosis, I think it is 90%. Can you give me a time update? Five, okay.

So, this is from a paper out of the UK and it was a nice qualitative study. We don't have a ton on the impact on families, but families experience a diagnostic Odyssey. They experience feeling let down, loss of a dream, dismissal by the medical community. They are frustrated by the lack of awareness even in the medical community. They are angry. They are not happy. They feel really unhappy that they missed opportunities to reduce their risk of this happening to their baby or to have early intervention diagnosis treatment whatever the case may be. And the number one thing I hear, why didn't anyone tell me about this? Why is the thirst first time I'm hearing about this when my baby is really sick or I'm pregnant and there is something on ultra sound that doesn't look right?

A brief story. This is Ryder. He was born in a state that has hearing targeted screening. He passed on his third try. At age 1, he had hearing loss and they did an MRI and he had anomalialties. His family feels like they got the diagnosis, because they pushed and pushed. And they got it. He missed out on possible antiviral treatment, follow-up hearing testing and early intervention and he is bilaterally cochlear implanted.

Where are we at screening? I'm not going to have time to go into this too much, but early identification can allow for evaluation, treatment and monitoring. Most infants are not identified, several states have mandated laws related to screening. We're going the hear from Minnesota next. We were given a list of questions that they would like us to bring back to them with answers so, we're working on that. This would be more common than anything else we're screening for. Research has indicated parents want to know this information. Parents are happy to know this even if their children never develop symptoms.

These are the different ways you can screen. The dried blood spot sensitivity, that is from Mark's paper. That is average sensitivity there. Interventions, we have nice materials on our website and I think Christen is going to talk about that. And I have one minute, so I'm happy to have questions or if someone wants to e-mail me, please let me know. And there are all of my references.

 time" information and education. So, the biggest thing, we will recommend urine CMV PCR by 21 days of age. We're not encouraging saliva.

And then we will fax the newborn screening report and informational sheet to to provider and that will include information that they can give to the families as they go for that information test. We will continue to follow to obtain the diagnostic results. We may get them from the PCP via fax or phone or do have chart extraction at some facilities, so we may use that if access exists. And really trying to minimize the impact on to providers by doing as much as we can on the Department of Health side.

So, the outcomes of the blood spot screening, again, false positive. We expect them to be minimum and no further follow-up would be needed, unless there are clinical concern. The true positives will be -- that is distracting, isn't it? The true positives would require additional evaluations. I will talk about that on the next slide. If they're symptomatic at birth, an ID consult will be encouraged, if they are asymptomatic at birth, then they are followed up by their primary care provider, again, this is new, so we will see if we make adjustments as we go or not.

All confirmed cases receive additional tracking and longitudinal follow-up. Sorry. Okay, so these are the additional testing that we are recommending or follow-up that we're recommending for all confirmed cases. Laboratory testing, pediatric diagnostic, audiology appointments even if they passed the newborn screening test and continued regular audiologic monitoring. We are requesting that the audiologic evaluation happens within one month of their timeframe of their confirmation. Cage ultrasound if they need it an MRI and early intervention.