Will Eiserman:

Welcome to EarWorm: Dialogues on Hearing Health You Can't Stop Thinking About. EarWorm is brought to you by the National Center for Hearing Assessment and Management at Utah State University known as NCHAM. I'm Will Eiserman and I'm the Associate Director of NCHAM and I'm your host today.

Pregnant women are commonly educated about a variety of ways they should take care of themselves to have a healthy pregnancy and a healthy baby. Some of the most widely known precautions women are advised about during pregnancy are actually quite rare. While one of the greatest risks to the health of the developing fetus remains largely undisclosed to women, cytomegalovirus or CMV, which is the leading cause of birth defects. The fact that CMV is left out of most conversations healthcare providers have with pregnant women is especially surprising given that there are relatively simple things pregnant women can do to significantly reduce the risk of their baby contracting it during pregnancy.

CMV is a disease infants can be tested for at birth and if they're found to have it, there is a medication that can reduce, if not prevent altogether, the potential profound effects CMV can have on a child's development. And yet this testing is not done as a matter of standard practice either.

In this episode of EarWorm, we'll be talking with Author, Megan Nix, who is the mother of five children, one of whom was born with CMV or what is called congenital CMV, and who as a result is profoundly deaf. Megan is the author of the book, Remedies for Sorrow: An Extraordinary Child, a Secret Kept from Pregnant Women, and a Mother's Pursuit of the Truth, published in 2023. Megan is a self-described fierce advocate for educating women and their healthcare providers about CMV and all that can be done to prevent and minimize its impact.

Megan, welcome to EarWorm. I'm confident your story is one that will give our listeners a lot to think about.

Megan Nix:

Thank you so much for having me. I hope so. I hope they think about it.

Will Eiserman:

So start out Megan, let's make sure we're all on the same page. Tell us what cytomegalovirus or CMV is and why it's so important for pregnant women in particular to be educated about this.

Megan Nix:

Yes. I like to talk about there being two types of CMV. So there's CMV infection, which is pretty ubiquitous and common in the world. So about 50 to 80% of the population has had a cytomegalovirus infection by the time they're 40 years old. Most people don't even know that they've had it. They've not heard of it, they've not felt it. It can be asymptomatic, it can manifest like mono or a common cold sometimes, but generally it is asymptomatic. It is very prevalent in toddlers and in daycare centers. For example, kids in daycare, 80% of them will have had a CMV infection in their first two years in daycare. And really, it's harmless. It passes through the system. For some reason it stays in toddlers for years. But in an adult, it'll pass through the system in a couple of weeks. It is dangerous if you are severely immunosuppressed, so if you are undergoing an organ transplant.

It is also dangerous if you are pregnant. And so if you catch it when you are pregnant and it crosses the placenta and it reaches the fetus, that is the other type of CMV, which is congenital CMV. Congenital means from birth. And if you catch it during pregnancy, it can pose a lot of issues for the developing fetus. And these are things that emerge sometimes at birth, sometimes years after birth. So CMV can cause progressive issues. It can cause deafness, blindness, cerebral palsy, epilepsy, autism, stillbirth, early infant death, and it's the leading cause of birth defects. And so it really is this huge issue that we have this prevalent disease in the world and pregnant women are not aware that this is a high-risk situation.

Will Eiserman:

Let me ask you to clarify something. You said CMV is the leading cause of birth defects. Do you mean the leading cause of non-genetic birth defects?

Megan Nix:

Well, it's interesting you ask that because I always say it's the leading cause of birth defects, and I actually asked this very knowledgeable pediatric infectious disease doctor at the recent public health and policy conference around CMV, "Am I correct to say it's the leading cause of birth defects?" And he said, "Yes, you are."

Will Eiserman:

So you're saying that about 50% of pregnant women, give or take, may have never been exposed to CMV, but we're not only concerned about the risk to them, we're also concerned about re-infection of women who were already exposed to CMV earlier in their lives?

Megan Nix:

So there are thousands of different strains of CMV. So while it does protect you in some way to have had the virus before, you could always catch a different strain. So in cases where it's not a primary infection, a first-time infection, those babies are less likely to be impacted by the virus. However, there are still globally just as many babies with congenital CMV. There are more from reinfection than there are from a primary case. So it is of risk to all pregnant women that they could potentially catch a strain of CMV.

Will Eiserman:

We know that about one out of every 200 babies is born with CMV, which is what we mean by congenital CMV.

Megan Nix:

Of those one in 200, one in five will have permanent delays. The majority of babies born with CMV are asymptomatic. And so this poses some problems because most of these babies, because it's really not on doctor's radars and it's not routinely screened for at birth, most of these babies will then go home, they seem fine, but all of those babies are at risk if they have congenital CMV for progressive hearing loss. And so really I'm an advocate for testing all babies for CMV because all of them potentially could go on to lose their hearing and their families wouldn't know until that has manifested at the age of two or three.

Will Eiserman:

There's a distinction, isn't there, between children who test positive for CMV at birth and already display signs that could be attributable to CMV and those who also have congenital CMV but whom are asymptomatic at birth? In other words, show no signs of any apparent impacts of the virus?

Megan Nix:

One of the issues with CMV is really identifying it in these children who are symptomatic at birth, who you already see that the virus has made changes to their system. So like my daughter, she was born small for gestational age. She had microcephaly and she was in fact profoundly deaf, we think, at birth because she did not pass her initial hearing tests. So those differences that CMV had wrought into her had happened potentially progressively in utero. I'm not really sure if they were taken away right away when she contracted the virus or if it was progressive in a fast way during her gestation.

And then after birth, yeah, I do think there are some things that CMV has not yet touched in some children. A lot of times children who have an initial hearing difference, like they might have moderate hearing loss in one ear and severe in the other, these children sometimes overnight go to profound hearing loss.

Will Eiserman:

And what about treatment once you know a child has congenital CMV?

Megan Nix:

The of it is really to stop that progression of the virus in the brain because we do know that CMV continues to work in the body, the viral load of the virus. So the concentration in the body has to be reduced for those impacts to be reduced in infancy. And so the treatment, which is an antiviral, reduces the strength of the virus and therefore reduces the impact that it's having in the body.

Will Eiserman:

Okay, that's an interesting prelude to our conversation about CMV and your story. Now, you didn't have the benefit of the information we just discussed in advance, did you? You learned about CMV through your own experience of it when it touched your family directly?

Megan Nix:

Yeah. So just to touch on what you just said, I think almost all couples that I know and mothers that I know who have a child with CMV learn about it through their own experience.

Will Eiserman:

As opposed to being educated about CMV like they are educated about so many other things during pregnancy?

Megan Nix:

So I was pregnant with Anna in 2014 and she was born in June of 2015. During pregnancy, I knew intuitively that something was different. I was measuring small. The doctors just sort of dismissed that as this margin of error being wide when they do the measurement with the tape over a year bump. And when she was born though, she was born totally silent and the midwife held her above me and she just stared at me and I was just totally taken aback by the focus of her gaze and her silence and her smallness. I could tell looking at her because she was my second. Like most moms with kids who have CMV, I had a toddler at home.

And so I had this comparative thinking like, "My older daughter screamed and she looked bigger." And it just was a different electricity in that moment. And so the midwife handed her to me and I held her against my chest, and I just felt this internal alarm ringing in her silence and in my silence and of course this profound love, but it was definitely supercharged with intuitive worry. And the oncology came and they got a scream out of her in the corner, but they said she's just five pounds. And then we went to recovery and to the mom baby unit, and that's where the hearing test was rolled into the room.

Will Eiserman:

You wrote in your book, Remedies for Sorrow, about how when you saw the hearing test coming, you somehow knew instinctively she wouldn't pass.

Megan Nix:

I just knew. With my firstborn, her name is Zaley, I just knew she would. Not with certainty. It was more of just a passive, "We're hearing." This is just one of those boxes you check at the hospital. But interestingly with Anna, it was just this out-of-body knowledge that this was not an apparatus for her, that this was not going to apply to her. Yeah. So she did not pass. And the hearing technician said, "Oh, she's small. It's probably just birth fluid. We'll test again tomorrow and if she doesn't pass that one, we'll test again in a week." And I just was thinking, "She's not going to pass those either."

Will Eiserman:

So what were you thinking and feeling at that point?

Megan Nix:

It felt very diminishing for them, each tester and each pediatrician who rotated to not say, "If she doesn't pass, here is what things might look like. You might have a deaf child, you might have a child with hearing loss." And that was never vocalized and neither was the potential that she had a disease that is in fact the leading cause of hearing loss if it's non-genetic. And that continues to recur in all these families that I talked to whose children do not pass the hearing test. There is one disease globally that is non-genetic that causes hearing loss and that is CMV. And these babies are not being tested for it in the hospital.

Will Eiserman:

So when a child doesn't pass a hearing screening, one thing that could be done is a test for CMV, but that's not standard practice being tested for CMV?

Megan Nix:

We weren't. Went to the pediatrician at 10 days of age and he said, "I want to test her for a common but little known virus, and it's called CMV." And that was the first I had heard of it. So of course he does the test. It's a urine test.

Will Eiserman:

You've got the positive diagnosis of congenital CMV, and then what?

Megan Nix:

Our family's very complicated. We live on a remote island in Alaska during the summer, and she was born in the summertime. So my husband was not in Colorado for her birth, and she was tested in Denver at a big pediatric office. But I said, "I'm flying to Alaska tomorrow with my toddler and this baby and my mom. Can we still go up there and absorb the diagnosis up there?" At the time I'm sitting in the pediatric office, so I had not Googled it yet. And the pediatrician who's awesome, his name's Dr. Bryan Kono, he said, "I think it's important to be with your husband and yes, you should go and a pediatrician up there can direct her care." So I flew to Alaska the next day with my mom and these two little girls, and when Dr. Kono called, he said, "Take her in tomorrow. You have to get her on this antiviral."

So I called the pediatrician in town. There's a couple of them actually, but we landed with this excellent doctor there too. His name's Dr. David Vastola, and he's a veteran pediatrician with grown kids, and he was validating. We brought her in and he said, "She looks good. And actually, I probably would not have tested her." He was very humble, very open with his own fallibility, which I found very wise ironically. And he said, "The one thing that we need to do, because I'm going to have to research this more from home, is we have to get her on this treatment and it's going to be a challenge because she needs to start it within the first month of life and it's going to have to get here from the Midwest on a small plane without the temperature of the medication changing." And I was just like, "Oh my gosh, I can't even believe this perfect storm of events that has imploded my life in Alaska into this whole new challenge." It has always been a challenge for me to live there. And then it was just like, "Wow."

Will Eiserman:

And in your book, which we hope everyone will read, you tell this gripping story of what it took to ultimately get that medication in hand and which you did in fact get in time. Tell us why that medication is so important.

Megan Nix:

Yeah, I think it's really the only proven treatment for congenital CMV. There has not been a successful treatment proven in pregnancy. And so really the chance that these kids have to really... And a ton of kids don't have the opportunity to take this treatment. So I always approach this with sensitivity because I think there is a lot of retroactive pain for these families who did not have the opportunity to treat their children. But it can stop and even reverse progressive hearing loss.

Will Eiserman:

If CMV is identified and treated within the first month of age, right?

Megan Nix:

Right. I think so. Yeah. All of the studies are done on children who have started treatment the first month of life. The doctor needs to order it and the child really... This is the kicker. They really need to be identified during that first month of age. Early identification is both important to the family's pathway and obtaining that medication that has proven to not only potentially stop hearing loss but also stop the progression in the brain. And for us, that was very important that we wanted to do everything we could to protect her brain from further impact from the virus.

Will Eiserman:

So just to reiterate, the real risk of CMV to infants is contracting the virus in utero before being born?

Megan Nix:

Any healthy baby who catches CMV even on day one of life, they're fine. It's totally fine. It really is an in utero risk.

Will Eiserman:

And do we know if there are points during pregnancy when the risk is greater than at other points?

Megan Nix:

Yeah, it's much greater risk during first trimester because the development is so fragile and so important at that time. Babies who are impacted during second trimester, there's usually not as much organ involvement. There's more of the hearing involvement. And then babies who contract it during third trimester usually are so developed that they are asymptomatic. And any of these babies can still be asymptomatic at birth.

Will Eiserman:

Let's talk now about prevention. You didn't know about CMV and most women don't. What do you think women need to be told and why aren't they being told that?

Megan Nix:

Yeah. So the first answer is very easy. The second answer is why I wrote a book. The first answer is that during pregnancy, all women should know to avoid the saliva and urine of toddlers. Now on first hearing that people are like, "That is totally impossible, kids sneeze on you." And really the idea is to not fear-monger this because CMV has always existed. So your risk is not higher for knowing that it exists because your fear is higher. You actually are much less likely to contract it just knowing that it lives in the saliva and fluids of toddlers, so you can not finish their meals when you're pregnant. This is just during pregnancy. Totally fine to the rest of the time. To not kiss them on the lips during pregnancy. You can kiss them on the top of the head, you can give them a lot of hugs.

All these surveys that have been done after childbearing, age women have heard about this, people are willing to do these and they do not feel that it impacts maternal bonding. And I certainly didn't. I had three kids after Anna and I did this during all three of those pregnancies, and I was no less close to my little kids during those pregnancies. And then anything else that if you change a diaper, to wash your hands vigorously, it's very small changes. And post COVID, these are things that we're more used to anyways, like much better hand hygiene, much more awareness that if somebody in your house has something, you really don't want to be eating the same thing as them. And it's not airborne. I always have my husband follow these rules too, because you're both ingesting the same saliva. If you're both eating your toddler's food and then you kiss your husband, there's risk of transmission there.

Will Eiserman:

We're not really only talking about mother and child. We're also talking about risks related to people like childcare workers who may be pregnant, who are working with other people's toddlers. That's another context, isn't it, in which CMV risks are present?

Megan Nix:

Yeah, especially daycare workers, in-home daycare centers where toys and surfaces are covered in the fluids of children who are statistically very likely to be carrying this disease. And often these women who do go on to get pregnant, they have children who are impacted very symptomatically by CMV because they're contracting it over and over again from first trimester forward, not knowing that disease is all over everything in their practices.

Will Eiserman:

So the first thing we want to do is educate pregnant women about CMV risks. And then that second question, why isn't this happening more often?

Megan Nix:

I think the big stopper is that the obstetrical world is not on-board yet with educating women. Some individual OBs are, but in general... So the American Congress of Obstetricians and Gynecologists says in this document that guides all OBs in the US, "We recommend not counseling pregnant women about CMV because these hygienic measures would be impractical and burdensome."

Will Eiserman:

So they actually recommend not informing women about this risk?

Megan Nix:

Which to me reads as total paternalism. That is not their choice to make. This is known information that has a critical impact on the development and lives of our children. To withhold that information is something called benevolent deception. Omitting information deceptively under the guise of care, under benevolence, is actually prohibited by the American Medical Association. So we have a very unethical standard here saying, "Doctors can handle this information, women cannot." And that's not fair. If we give women this education, they can do with it what they please. They can say, "I don't think I'm very high risk for that," which would be inaccurate. But people can believe that and they can go on and live their lives with their toddlers however they want to. But in these surveys, both in the US and abroad, 97% of women say they want to know about CMV. They even want to know more about CMV after the initial five-minute discussion that they're given in these studies.

And they will go on to do what they can to mitigate their risk of contracting it during pregnancy. And these smaller studies have shown that these measures reduce the risk of contracting CMV by about 80%. So yes, there's always the potential that even knowing about CMV, you will have a child who has congenital CMV, and this is just the world. Pregnancy is not a zero risk endeavor. You cannot prevent every possible thing from affecting your pregnancy. I think its name gets in the way. Nobody remembers cytomegalovirus. I say it sounds like like a dinosaur. Even the acronym is not great. CMV has always been here. It's usually asymptomatic at birth. There's just a lot of complexity to the virus physically too. Virologically, it's not as easy to prevent as something like measles. And so yeah, it's sort of this perfect storm that CMV can continue to fly under the radar.

Will Eiserman:

We can clearly see then the need for women to be educated so that prevention measures can be taken. But then there's more. What do we need to do when a child is born with symptoms that may be attributable to congenital CMV?

Megan Nix:

And the symptomatic babies who manifest with these things at birth, 75% of those babies will go on to have hearing loss. So the really big issue is to get those babies tested for CMV and then to get that child in with an infectious disease team so that they can start treatment if the family decides to use the antiviral. Then they will have routine audiological checkups throughout early childhood to see if their hearing is sliding. They need ophthalmology appointments to see if there's evidence of vision loss.

Will Eiserman:

And if there are delays?

Megan Nix:

A huge aspect of treatment is enrolling that child in early intervention so that they have PT, OT and in-home team that is really guiding the family through some of these differences that are most likely pretty foreign territory. It's not all to fix the hearing, that's not the goal. It's to have a deep knowledge of the child that they need intervention, be it hearing aids for a family that decides to pursue spoken language or ASL for a family that is going to go with the sign language route.

Will Eiserman:

So from a public health standpoint, what would be ideal would be if all children could be screened for CMV at birth when they're getting their hearing screening, not only those children who don't pass, but all children. Is that what you're thinking?

Megan Nix:

Yeah.

Will Eiserman:

Do you see it that way?

Megan Nix:

Yes. But again, this is CMV, so nothing is easy. So right now, there are a number of states who are piloting a program to test all their infants for CMV. Up until very recently, like last year, this was not possible except for a doctor named Mark Schleiss in Minnesota, he was thinking about this like 20 years ago. So every infant is tested through their blood for a variety of diseases and inheritable disorders at birth, and that test is called the newborn dried blood spot. They poke the baby's heel and they stamp the blood on a card. Those blood spots are then sent to a lab and they're tested for these diseases. Well, in the seventies and eighties, I think that test was not... that assay, it's called, was not very effective at picking up CMV in the blood. It was like 30% effective.

Well, Dr. Mark Schleiss said, "Okay, that assay has gotten more advanced as time has gone on. We need to look at that assay and see how effective it is now." Because all the doctors who knew about CMV were like, "We don't have a captive test that families are already getting in the hospital on their newborns that could possibly pick up CMV. It's just too expensive to introduce the other ways that you can test for CMV, which are urine and saliva, and they require a lot of nursing protocols and they're just not built into the system. And they also require an educated parent to ask for them most of the time. And we need a test that is affordable, that's already being done, and that doesn't require prior knowledge. And so the DBS, the newborn dried blood spot, is that test." So they looked at the newborn dried blood spot for like two years to see if it was more adequately picking up CMV, and they would confirm that with either urine or saliva, I can't remember right now which one.

And it came to the results and they saw that it was actually effective about 85% of the time. And so that's not perfect. And Dr. Mark Schleiss, when I interviewed him for my book, he said, "There's a lot of naysayers who say it's still not accurate enough." And he says, "We cannot let the perfect be the enemy of the good. We have this test right now and in 10 years we'll have something better, but we should be using it to catch these kids who would otherwise be totally undiagnosed. Their parents will never know what they have. They're starting to miss milestones, progressive losses, and they're just totally bewildered in these unknowns." And so he passed a bill in Minnesota to test all newborns there for CMV through the dried blood spot. And that has begun, and they don't have the initial data back, but he's hopeful that this is going to show that this is in fact a worthy way to test babies for it.

They also have a pilot program in New York where they're testing babies for a year to see, because New York is a very high population state, so there's 220,000 born in New York every year, and they're going to test all those babies for CMV this year. Connecticut has a program where they're starting to test in 2025, universally. That's what it's called, universal screening. And Maine is shortly to follow. I think they have a work group that's pretty devoted, and I think they'll see it through. And then there's a lot of states, including Colorado where I live, where... Actually it's not mandated in Colorado, but three-fourths of the birthing hospitals are doing targeted testing. So if a baby is small for gestational age, microcephalic or does not pass their hearing tests, they are testing those babies for CMV. However, because most are born asymptomatic, 43% of those babies who are not tested because there's no red flag, there's no target, those babies will go on to be at risk for progressive hearing loss.

Will Eiserman:

Megan, in the absence of a state program or special CMV initiative, can an individual pediatrician write an order for a CMV test out of an abundance of caution? Can a parent request that and most likely get it?

Megan Nix:

Totally. Well, yes to the first, not exactly to the second. So yes, my pediatrician put in the order, "We should test this baby for CMV." And the turnaround was pretty fast. They did a urine test, she peed in the little bag and it went to the lab. Urine is the most accurate, it's the most sensitive. Saliva is a little trickier. So some hospitals do use saliva, however, there's a little trickiness there with breast milk can contain CMV, so the mom needs to have not nursed for a couple of hours before they swab the infant's cheek for their saliva to contain CMV. But it is easier to capture than the urine test because you don't have to wait for the baby to pee. So yeah, for sure, any parent can just say, "I had a toddler at home during this pregnancy. I want to test this child for CMV. Do a saliva swab after I've nursed," or whatever the hospital has available.

"I want to do a urine catch." Or they can request that newborn dried blood spot. I've not gone through that process. I don't think it's as simple as it might be. You have to go back into the archives to get the DBS in a lot of cases, and that can be a pretty circuitous process, but it is possible. I think there's definitely pushback from doctors because this is a new ask and the systems aren't always designed for them to just come up with a test that is not generally requested, but it's imperative that they do. If a parent asks, it needs to be seen through.

Will Eiserman:

Yeah, my understanding is that most insurance companies will in fact cover a CMV test performed at a parent request.

Megan Nix:

Yeah. And I think with insurance it's like a $4 test, and without, it's like $17.

Will Eiserman:

We do have another EarWorm episode in which we focus on recent progress in the development of a CMV vaccine for pregnant women. I won't ask you to comment on that, Megan, but it's something worth noting here that we should all keep an eye on over time. So before we end, tell us about Anna and how she's doing.

Megan Nix:

Anna is awesome. She's our most emphatic child probably. It's so interesting. She was born the most silent, and she is by far the loudest in our house. She's pretty mildly affected by CMV. She has profound hearing loss. But yeah, she's just super outgoing. She has cochlear implants, as I mentioned, and we took sign language for about six years and really grew to love the deaf community and have some close friends who are deaf. And so we learned sign language, but because she has cochlear implants, we've not used sign language as much as we envisioned and as we want to. So it's one of those things that we're constantly trying to pursue. So she understands sign language, but she usually speaks back to us. She's pretty articulate and she's really tiny, but it never gets in her way. She is just the type of child who is just accepting of herself. She knows that she's different, but she's very matter of fact about it. And yeah, she's just a joy.

Will Eiserman:

Do you have a final message that you'd like to give to healthcare providers, early interventionists and other professionals who are in the presence of women and their partners as they prepare for the arrival of a child? What do you want them to think about and put into action?

Megan Nix:

Yeah, that's a big question. It's a great question. I think we have the right to know about CMV and our world has the benefit of learning from our children who have congenital CMV, and that everybody who knows somebody who's going to be pregnant or have a child, which is everyone in the world, should know what this is, and we should know what we can do to prevent it, and we should embrace these children as a powerful example of the diversity of life from pregnancy forward.

Will Eiserman:

Thank you so much, Megan. We really appreciate your time with us. And also, thank you for all that you've done to share your personal story with the goal of improving outcomes for all children and families.

That was Megan Nix. You can learn more about her family's story by reading her book, Remedies for Sorrow: An Extraordinary Child, a Secret Kept from Pregnant Women, and a Mother's Pursuit of the Truth, published in 2023.

I'm Will Eiserman from the National Center for Hearing Assessment and Management at Utah State University. Check out EarWormpodcast.org for other episodes of EarWorm: Dialogues on Hearing Health You Can't Stop Thinking About.

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