

CMV and Congenital CMV: Part 2

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SPEAKERS

Gina, Priscilla W., Narrator, Amanda

Narrator 00:02

Welcome to Inclusion Matters, a podcast about children's development from the Center for Inclusive Child Care.

Priscilla W. 00:20

Welcome to Inclusion Matters a podcast from the Center for Inclusive Child Care. I'm Priscilla Weigel, the Executive Director and I'm back again for part two of our conversation with the folks that are experts on something called CMV. And I'm joined by Gina livre seed from the Minnesota Department of Health. She's the CMV, nurse specialist. And we're also here with Amanda Devereaux, who is Program Director of the National CMV Foundation. And so since this is a two part series, Amanda, can you just kind of catch up our listeners who maybe didn't fully get the first part, but just tell folks an overview of information about what is CMV?

Amanda 01:00

Sure, yes, so CMV Cytomegalovirus is a very common virus that most people will get in their lifetime, most of the time, they won't even know that they had it, because it resolves on its own. And the symptoms can be pretty mild. However, it can be particularly dangerous for those who are pregnant because they can pass it to their baby. And when a baby is infected before birth, that is called Congenital CMV. And it's actually the most common virus that infants are born with. And it's the most common infectious cause of birth defects. So it can be very serious. And so that's why it's important. And again, it's it's something that's pretty common.

Priscilla W. 01:40

Yeah. And in part one you talked about truly, it's, it can be quite a spectrum of how it plays out in a child's system. And so I think that just getting more information out there to folks is so important, and especially how, how is the support? What does the support look like to families who maybe do have a child with that diagnosis?

Amanda 02:04

Yea, this can be a really challenging diagnosis for families. And I guess I would start by just normalizing that, because families aren't going to know about this, they're not going to have heard of it before, they're not going to get an exact roadmap of this is exactly what your child is going to look like. So there's a lot of unknown and a lot of things that are going to be up in the air. So we definitely understand that this is a challenging diagnosis for families. So we at the National CMD foundation want to provide support. We we connect families with other families in their area, we answer questions, we try and help people find CMD experts, if they're not getting, you know, the medical care that they're really looking for, we try and do all those things. We also refer to other disability and, you know, hearing difference organizations, you know, Hands and Voices being a great example, other disability organizations, the National Center for Deaf and Blindness, things like that, that can also provide some support, that isn't necessarily CMV specific, but can be very, very related to the symptoms that they can see in their children. So we definitely try to connect people with the resources that they need.

Priscilla W. 03:15

That's so important. And I love to that you connect them with other families who have are going through the same process. That's, I think that when you're going through something that is scary and unknown, and because you can't give a clear, this is how it's going to play out. It can be really daunting, and it's easy to pull kind of into yourself, but you're giving the folks an opportunity to really build social connections with folks who are going through it. So that's so important and so helpful. I'm sure they appreciate that. And the wonderful resource of your national organization. And I think to just to toot Minnesota's horn again, in our earlier episode, we talked about the fact that Minnesota is really on the forefront of getting the word out more about this. And Gina, can you just toot the horn of Minnesota Department of Health and the process that's that's happening here in Minnesota, about CMV.

Gina 04:08

And, I'll even go a step before that and toot the horn of all the parents in Minnesota who really started our activities. So our activities really began following the passage of legislation at the end of the 2021 legislative session. And that legislation was really brought by a grassroots effort of Minnesota parents, who knew it was important to increase awareness and to identify more kids with Congenital CMV. And so that the law was passed in Minnesota and it's known as the Vivien Act. And that really led to our two major activities which we have touched on. So screening of all newborns for Congenital CMV, which began about a year ago in February 2023. And then all of our outreach and awareness activities that we're doing with health care professionals and with the general public are all directed by this Vivian Act legislation.

Priscilla W. 05:04

Fantastic and more. I mean, it's so exciting to hear stories like that, that families who have experienced challenges, they rally together and bring forward, you know, tools and resources that will hopefully not create situations that other families will have to find out in the way that they found out about it. And so being proactive, and that's so exciting that Minnesota is such a proactive state, and there's so many resources available to that. So when you think about so there's, there's a lot of activities, Amanda that are happening, not just in Minnesota, but across the nation, because you're a national organization. So that's very exciting.

Amanda 05:47

Yeah, we're, we're super excited. And actually, we're about to have our 10 year anniversary, and it's been 10 years, since the first CMV law was passed in the United States. So the first, the first state to pass a CMV law was Utah. And since then we've seen 20 states pass some type of CMV legislation, and it's all been driven by parents with the support of of medical professionals who also want to see changes regarding CMV. But we're very excited, we've got bills pending again, this year, we have we're always seeing more states trying to take this up. And we're also really looking at a federal push, we've got interest from federal legislature legislators for some national CMV legislation that would hopefully provide more resources, for states for education for research that's needed. And for more screening.

Priscilla W. 06:39

Yeah, oh, and those preventative measures can really make a difference in the on the front end of things, and not just emotionally for families and for the folks who are impacted, but hopefully, as a true preventative measure that children won't be left to just have this found out at a later point, you know, the more we know, we're all about early intervention and how important that is. And so you know, if they are going to be delays or concerns in the pathway of their development earlier on finding that out and starting off on that track of providing the the necessary interventions, it's going to be a more positive outcome long term. So as you think about our listeners, Gina, who primarily are folks who are spending time with the kids who are spitting in their faces, slobbering all over the place, sneezing and coughing, and they're changing their diapers, and, you know, they're together all day long. And there's not just one, there might be 10 of them in one group. Why is it important for providers, childcare providers to know about this information?

Gina 07:49

Right! Well, for a lot of the reasons you just mentioned, they are, your providers are at a higher risk of getting CMV, because they do work closely with young children. And as we've talked about, we know that young children are a common source of CMV. So it's really important for child care providers to be aware of CMV and have those risk reduction tips that can help them reduce their chance of getting CMV. And again, this is especially important if

they're pregnant or thinking about becoming pregnant. I think the other way that childcare providers, why it's important for them to know, is because we know they're an important source of trusted information for parents. So these parents, these parents who have kiddos who are being identified with Congenital CMV, the vast majority have never heard of CMV. And now they're being told their child has Congenital CMV. And so childcare providers really have that opportunity to pass on the information to parents to help them improve their awareness and knowledge about CMV. And the same risk reduction tips are important for parents to know because these kids come home from childcare. And these parents are at risk of a CMV infection from their own kids. So I think childcare providers can be an important partner on the work that we're doing.

Priscilla W. 09:05

That's fantastic. And I'm thinking too, you know, a lot of things over the pandemic, some of the common occurrences of that information sharing maybe changed for childcare. There used to be, you know, parent nights or family gatherings. And so I think a lot of sites are starting to get back to that. And opportunities for information sharing about this very thing. That's an ideal avenue because, and even I don't know if this is something that you all provide, but if an educator who is planning to do an informational night, I think in the earlier episode you mentioned, you know, going out to conferences or presenting there I'm sure if folks reached out to they would be able to get more information about how to best disperse the information, whether it's just a packet of written materials, or maybe it would be someone from your team coming out and sharing with families answering questions, those types of things.

Gina 10:03

Absolutely, we're very willing to go out and reach folks out in the field like that. And then we also have the materials on our website. If you'd like additional materials, we have some, you know, cute fun things like swag type materials to help promote our messaging as well that we're very happy to share with people who would be in that kind of environment. And then to the national CMV Foundation has lots of great information, that's printable, as well. So either place is a great place to look, but they can always reach out to the Department of Health if they want additional support or materials.

Priscilla W. 10:39

That's fantastic. And so when you think about even so let's say this, the child with CMV, who has the diagnosis and may have some of those needs that you listed in in part one, Amanda. How can childcare support that child in their care and education and communication with their peers?

Amanda 11:06

Well, I think first of all, I would say to be really inclusive of children who who get this diagnosis. First of all, you're

not going to know every child that has this diagnosis, and the parents do not have to provide you with that information that that information is not required to be shared. But you may end up finding out that some children in your care have CMV. And I think one of the most important things is just treat that child the way you treat any other child. So sometimes we do hear of folks wanting to avoid children, or avoid working with children who have this diagnosis. And our big message is that that child poses no greater risk to you, if you are a childcare worker, and you're planning a pregnancy than any other child, because a lot of children are shedding this virus at any given time. So if you avoid the newborn who has the diagnosis, and then you work with a different baby or toddler that's six months old or two years old, they're just as likely to be shedding it as that baby with the that has the diagnosis. So we want to make sure that people aren't excluding any children. And nobody recommends excluding these children, the AAP, you know, CDC, nobody is saying that these children should be treated any differently. So I think that that's the big one. And then just understanding that these children may need, you know, maybe having appointments and getting pulled in and out to kind of do all these checkups and follow ups and just make sure that that they're developing, typically, and if they're not that they can get the help that they need. And so I think just communicating with the parents and letting them know, if if you notice something, that might be a concern, that would be another way, I think, to support these families.

Priscilla W. 12:48

Definitely, I think, and I will, just as we were tooting horns, our listeners are amazing folks doing this work every day. And I think that your reminder is so important. And when you think about early childhood, and those critical years birth to five, and the dedication of the folks providing that care. And really, you know, it's all about the attitude of saying any child in my care could have some sort of unique need throughout those years of early childhood. And they may have a diagnosis, they may not, but they're still going to need me as that educator to help them out when those bumps come up along the road. And every child has a different developmental path. And so I think that that's the beauty of early childhood education is, you know, the professionals in the field are ideally in tune to that very thing. And so they're looking at their group all the time seeing and thinking, how can I support? Oh, this one looks like this child looks like they need they're not really connecting socially, oh, how can I help them communicate with their peers in a way that's going to create positive play interactions, all of those things. So it's great that I'm so glad to hear also that you straightforward leaps, you know, pointed out, any child could be shedding this virus. And the more that we do to truly be inclusive, the better off all kids in our care will be. And then the very important piece that you noted, Amanda, supporting those families. I think that that's something that we see a lot of in our work, especially with exclusion or expulsion, and suspension of children that might have some unique needs at any given time. When a family is really connected to that educator and and you have that deep relationship, you're going to have greater success, because you care about each other, and you so we are constantly advocating for open communication and I think, you know, your organization and Gina's team at MDH, all of the resources and so I'm going to ask that Gina,

you want to share those contacts again so that as we close out this conversation, folks can have that fresh. And we'll also put the links in the, on our website when these podcasts go live so that people can just click on those as well. But would you bring those forward again?

Gina 15:09

Sure, so we have the Minnesota Department of Health and our CMV information is located at health.mn.gov forward slash CMV. Amanda's organization, the National CVD foundation is nationalcmv.org. And then again, we encourage folks to have this conversation with their health care provider. Bring your questions about CMV and testing options to your next appointment.

Priscilla W. 15:34

And again congratulations on 10 years for the national organization.

Amanda 15:41

We're excited we're hoping to have a little party

Priscilla W. 15:46

Well deserved. You certainly should have a party. And I love that I love that you shared that their swag. Swag is always really nice. People love swag, so reach out to either Gina or Amanda. They're here to help and to make sure that all of our listeners have what they need to be better informed about CMV. Thank you so much for being with us on Inclusion Matters. Thank you, thank you

Narrator 16:19

Thanks for listening. For more resources, visit us at inclusivechildcare.org