CMV and the Medical Home, in partnership with Midwestern University and Phoenix Children's Hospital

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- [Harold] Hi, this is Harold Magalnick and Kathleen have the Presenter Disclosures noted on the slide. This event does not focus exclusively on any specific product or service and this course is presented in partnership as was discussed previously with Midwest University and Phoenix Children's Hospital. I'm Harold Magalnick and I'm a pediatrician, and I have been a pediatrician for over 50 years and have had the pleasure of helping children and families who are experiencing significant illnesses. And congenital CMV and it's sequelae have been some of the issues that I've had to deal with. I currently work for the Division of Developmental Disability as a contracted physician where I do medical reviews. The learning outcomes from this presentation, hopefully you'll be able to describe the incidents, prevalence and complications that can present with a congenital CMV infection.

Name the diagnostic criteria for the Division of Developmental Disabilities and DDD is under the Department of Economic Security, and you'll see who could be eligible and how to maintain your DDD eligibility and what that actually does for you. And we will then discuss CMV advocacy and the importance of that advocacy across the United States. CMV is known as a human herpes five virus, it is a member of the herpes virus family and the beta herpes virus subfamily and the cytomegalovirus genus, the viral genome contains double stranded DNA and is the largest of the human herpes virus genomes. CMV is highly species specific and only human CMV has been shown to infect humans and cause disease. The virus is ubiquitous and CMV strains exhibit extensive genetic diversity, transmission occurs horizontally by direct person to person contact with virus containing secretions, vertically from mother to infant before, during and after birth, and via transfusions of blood products, platelets and white blood cells.

And when we take a look at the issue of horizontal transmission, it is probably the result of exposure to saliva, urine and genital secretions from infected individuals, spread of CMV in households in childcare centers is well-documented. Excretion rates from urine or saliva in children, one to three years of age who attend childcare centers

usually range from 30 to 40%, that can be as high as 70%. In addition, children who attend childcare frequently excrete large quantities of virus for prolonged periods. In the U.S. nearly one in three children are already infected with cytomegalovirus by five years of age, over half of adults have been infected with CMV by the age of 40. One CMV is in a person's body, it stays there for life and can reactivate, a person can be reinfected with a different strain.

Most people with CMV infections have no symptoms and aren't aware that they've been infected, about one out every 200 infants is born with congenital CMV infections and around one in five babies born with congenital CMV and infections will have long-term health problems. A pregnant woman can pass CMV to her fetus following primary infection, re-infection with a different CMV strain or re-activation of a previous infection. Risk of transmissions for a primary infection is 30 to 40% in the first and second trimester and 40 to 70% in the third trimester, the risk of transmission following non-primary infection is much lower at only 3%. The risk of complications to the fetus is greatest if a primary infection occurs during the first trimester, babies born with CMV can have brain, liver, spleen, lung and growth problems.

The most common long-term health problems in babies born with congenital CMV infection is hearing loss, which may be detected soon after birth or may develop later in childhood. About 10% of infants with congenital CMV infections are symptomatic at birth, which include rash, jaundice, microcephaly, which is small head, low birth weight, intrauterine growth retardation with IUGR hepatosplenomegaly, seizures and retinitis. About 40 to 60% of infants born with signs of congenital CMV disease at birth will have long-term health conditions, 90% of infants was asymptomatic congenital CMV infection and 10 to 15% will develop a long-term disabilities. Congenital CMV infection is the leading non-genetic cause of sensory neuro hearing loss in children in the United States, approximately 20% of all hearing loss at birth and 25% of all hearing loss at four years of age is attributable to congenital CMV infections.

Sensory neuro hearing loss is the most common sequelae following congenital CMV infection, with sensory neuro hearing loss occurring in up to 50% of children with congenital infections that are symptomatic at birth and up to 15% of those with asymptomatic infections, between 55% and 75% of symptomatic and asymptomatic children respectively ultimately developed congenital CMV associated sensory neuro hearing loss will not have hearing loss detectable within the first month of life. This illustrates the increased incidents of late onset sensory neuro hearing loss in these populations and for this reason, targeted CMV testing of infants who fail their newborn hearing screen will not detect the majority of infants who are at risk of CMV associated hearing loss, especially in infants with asymptomatic congenital CMV infections.

Up to 65% of children with CMV associated sensory neuro hearing loss continue to have further deterioration of their hearing loss over time. As such, the children with symptomatic or asymptomatic congenital CMV infections should be evaluated at regular intervals for early detection of hearing loss or progression and for implementation of appropriate interventions like hearing aids. When we take a look at a child who has congenital CMV, whether it's symptomatic or asymptomatic and we find out that they do indeed need progressive long-term follow-up for their issues, they might need referral to subspecialists and different agencies. What we have developed within pediatrics is the idea of the medical home. This slide helps us to show how we build the process of the medical home to help our families navigate the issues that they have to deal with when dealing with a child with a special healthcare need.

At the bottom, the foundation for all of this is the primary care provider and then you can see how we believe in pediatrics that family-centered care is a way to go utilizing parents or caregivers as integral parts of the building blocks for the house, they're the center of this entire house and you can see all the areas that we need to incorporate in the pediatric medical home. If a child has a significant issue that needs to be evaluated

and requires special services. In the United States, Medicaid is the primary payer for home and community-based services and plays a significant role in providing children with special healthcare needs. The long-term services and supports, LTSS that they need to live at home with their families, the main issue for us is to look at the issue of family-centered care.

Medicaid CHIP, which is Children's Health Insurance plan, covers almost half of all US children with special healthcare needs. Although the share varies state by state, it's a federal program, but it's individually implemented by each state. A child might have certain services in one state, they move to another state and they have to reapply for some of those services. The individuals with Disabilities Education Act or IDEA Part C covers early intervention services, which help eligible infants and toddlers younger than three years of age with developmental delays in disabilities and their families to support children's development. Early intervention focuses on helping infants and toddlers learn the skills that children typically develop during the first three years of life.

In some states, CMV is considered an eligible at risk diagnosis and referral for early intervention services is therefore available just by the diagnosis for the issue of getting it in the state of Arizona, we call it AZEIP, Arizona Early Intervention Services, and anybody can apply for AZEIP and can go through the evaluation through the AZEIP care team, which is sent out to the home to evaluate the child. To qualify for AZEIP services, the client has to demonstrate a significant developmental delay based on performance and developmental testing. The testing must be norm referenced or criteria referenced and culturally appropriate, testing must demonstrate a 50% delay in one developmental domain or a 25% delay in two or more developmental domains and that domains are physical in their fine motor, gross motor vision or hearing cognitive abilities, communication or social emotional or self-help.

When we take a look at the issues with congenital CMV, some kids are identified in the newborn nursery and come into the office into the primary care office already diagnosed. And it's important that we get the medical records to establish the medical home for those records, especially hearing testing and that we realize that repeat testing and follow up is needed. If the infants is in need of services, help with coordination of their important appointments becomes quite important. In our office, we usually get the families established with one referral coordinator so that they have one person to help them in coordinating their referrals and future appointments. We also make sure that they get involved with and enrolled with Arizona Early Intervention Program.

Children can continue with AZEIP services until three years of age when they must transfer to a developmental preschool for continued services, OT, speech, PT and developmental health. Even if they are enrolled with AZEIP, they can still apply for the division of developmental disability, which is DDD and again, DDD is a division under the Department of Economic Security. In order to qualify for DDD, an individual must be diagnosed with one of five DDD qualifying diagnosis in our state. They are cerebral palsy, epilepsy, autism, cognitive intellectual disability or down syndrome. For children younger than six years of age, they can be DDD eligible if they are considered to be at risk for one of the DDD eligible diagnosis.

Anyone can apply for DDD eligibility, but not all who apply, qualify for the full range of DDD services. In order to qualify for the full range of services, you must have substantial functional limitations in three of seven major life activities. If a child is younger than six years of age, they can be considered at risk and if they can show the same way as they did for AZEIP, a 50% delay in one developmental domain or a 25% delay in two or more developmental domains, they can qualify for DDD and they do not have to show significant functional limitations in any area until the age of six, at age of six and at age of 18, they have to re-qualify for DDD.

When we take a look at SFL, Substantial Functional Limitations, those are seven are listed below. A Substantial Functional Limitation is a limitation so severe that extraordinary assistance from other people, programs, services or mechanical devices is required to assist the person in performing a appropriate major life activities. When we take a look at self-care, self-care exists when a person requires significant assistance in performing, eating, hygiene, grooming or healthcare skills, or when the time required for a person perform these skills is so extraordinary as to impair the ability to retain employment or to conduct other activities of daily living. When we look at the issue of receptive and expressive language, an SFL occurs when a person is unable to communicate with others or is unable to communicate effectively without the aid of a third person, a person with special skills or without a mechanical device, a communication board.

When we take a look at the issue of learning, learning means the ability to acquire, retain and apply information and skills. And SFL occurs when cognitive factors or other factors related to the acquisition and processing of new information are impaired to the extent that the person is unable to participate in age appropriate learning activities without utilization of additional resources. When we take a look at mobility, mobility means the skill necessary to move safely and efficiently from one location to another with the person's home, neighborhood and community. And SFL occurs when fine or gross motor skills are impaired to the extent that the assistance of another person or mechanical devices required for movement from place to place, or when the effort required to move from place to place is so extraordinary as to impair ability to retain employment and conduct other activities of daily living.

When we take a look at self-direction of functional limitation regarding self-direction occurs when a person requires assistance in managing personal finances, protecting self-interest, or making independent decisions, which may affect wellbeing,

self-direction means the ability to manage one's life. Examples of managing one's life include setting goals, making and implementing plans to achieve these goals, making decisions and understanding the consequences of these decisions, managing personal finances, recognizing the need for medical assistance behaving in a way that does not cause injury to self or others and recognizing and avoiding safety hazard. Obviously this is all age related, we don't expect certain issues to be seen in younger children. When we take a look at the capacity for independent living, a functional limitation regarding the capacity for independent living occurs for a person's own safety or wellbeing supervision or assistance is needed at least on a daily basis in the performance of health, maintenance and housekeeping.

When we look at the issue for economic self-sufficiency, a functional limitation regarding economic self-sufficiency occurs when a person is unable to perform the tasks necessary for regular employment or is limited in productive capacity to the extent that earned annual income, other extraordinary expenses occasioned by the disability is below the poverty level, so this gives you an idea about substantial functional limitations that DDD uses. So again, you can be DDD eligible but not acquire the full service because you do not have the significant functional limitations and you have to have three of seven. Again, under the age of six, children may be eligible for services if there is a strongly demonstrated potential that the child is or will have a developmental disability as determined by the appropriate tests.

In the absence of other qualifying circumstances, children with the following conditions are not eligible for services for DDD in the state of Arizona. These include congenital heart disease, muscular dystrophy, orthopedic disorders, speech delay involving only intelligibility, significant auditory impairments or significant visual impairments. Arizona long-term care, once you have been determined to be DDD eligible, you can apply for Arizona long-term care. Having DDD eligibility, but not having ALTCS limits the client to just have coordination of care benefit services from DDD and you saw that coordination

of benefit services is a needed compliment of the medical home. If the client qualifies for ALTCS, that opens up many service opportunities beyond what might be available from their primary insurance, primary insurance is always the first insurance utilized to acquire services.

When a denial comes into our office from the primary insurance, the secondary insurance, which becomes the ALTCS insurance, comes into play to acquire the services. If the client is not DDD eligible, they might be ALTCS eligible through a different program called the Elderly and Physically Disabled or EPD, this gives a client all text eligibility even when they don't have or at risk for one of the five DDD criteria. After three years of age, the child transfers from AZEIP to the Department of Education or DOE from many of their service needs. The medical home can help with the transition process to make sure that what is educationally required gets paid through DOE dollars and not through their medical dollars and individual educational plan is written every year to show what services a child will be receiving for the year and what can be expected as far as their educational progress.

The full evaluation to see what they qualify for in special educational services must be done every three years. So every three years have to re-qualify to see if they still require special educational services, but every year a new service agreement is written up to show what gains they hope the students will acquire over the year with continued services, coordination of services between the educational community and the medical community should be facilitated through the child's medical home. I've attended a lot of IEP meetings during my years as a pediatrician, it is always gratifying to be at the table and to explain why I think a child requires a service as an educational service in the school.

Those kids who are being homeschooled, their parents are still paying taxes in their school districts and you can still acquire services from the district even if they're not

receiving education through the district. At six years of age and 18 years of age, as we talked about before, a child must be re-evaluated to see that they still qualify for DDD services. The child's medical home can help to make sure that the child receives the evaluations required so that services do not get interrupted. Very often, you have to show that evaluations are up to date in order to continue qualifying for services. Now I will turn over the presentation to Dr. Kathleen Muldoon, who will continue looking at the issue of advocacy.

- [Kathleen] Thank you Dr. Magalnick, for that introduction and I'm just going to expand why we're we're doing this together and that is that I am a professor at Midwestern University and I teach in multiple programs there as a medical educator and I'm also the co-founder and co-director in Arizona, our CMV advocacy group and collaboration, which is called STOP CMV AZ in English and ALTO CMV AZ in Spanish and we have materials available in both of those languages. And the reason why I became passionate about this subject and involved with these efforts in Arizona and also nationally, I'm the former scientific chair of the Scientific advisory Committee at the National CMV Foundation, is because I did not know about CMV until it affected my family directly.

So I'm also speaking as a parent of a child who is disabled because of a congenital CMV diagnosis. So I'm going to speak from my perspective as an educator and as a parent and having to take questions along those lines as well. So what we're looking at on this slide is the current map that's maintained by the National CMV Foundation, which is our national advocacy group for raising awareness of congenital CMV and interacting with healthcare providers to educate not only providers, but also families and their patients through those providers. And there is a very recent history of growth in the advocacy movement around this diagnosis in the USA and it didn't really begin until 2013. Prior to 2013, there were some local state groups that had been working

towards increased awareness and maybe using the legislative system to increase awareness in various states.

But the collaboration nationally did not come together until 2013 or until 2015 after Utah passed the first CMV public education and hearing targeted congenital CMV testing law, which required not only education of women in childbearing years, which we'll talk about in just a moment, but also for those children who refer from their newborn hearing screen for those children to be offered as strongly recommended to have a congenital CMV screen, so we'll talk about that some more in the next slide. In 2015 is when the national CMV Foundation was founded by six mothers and partnering ENTs and audiologists and infectious disease doctors. So these are the people who are most invested in increasing knowledge and really the partners that form the medical home for kids who have the CMV diagnosis.

Very recently, there has been more states that have passed very similar laws to the Utah law, but in 2021, Minnesota passed the Vivian Act for CMV public or healthcare professional education and universal testing, so that all children born in the state of Minnesota are now offered a CMV test as part of their newborn health screening program, which will catch a lot more kids with this diagnosis and present those kids to the medical home. As of right now, CMV legislation has passed in 18 states and others are pending, including states to establish a health commission to investigate what is the impact of CMV on public education and testing and what that impact is on on our medical system as a whole.

So, you know my point is that more children, because of these laws and because of the awareness that's been happening over the last decade or so, more children are being diagnosed with congenital CMV early, which is a great thing to know as Dr. Magalnick explained, you know what the complications might be and how to manage that care and direct families towards resources, but what are the implications for

healthcare management? So along those lines, I'm just going to reiterate in a slightly different form what Dr. Magalnick has already said, and that babies born with congenital CMV may or may not have lifelong disabilities, but the fact of the matter is based on clinical suspicion alone, it's difficult to predict which of the children are going to leave or need what level of care.

So this is a slide from the National CMV Foundation website, you are happy to go or I refer you to that website or to your handout to get a copy of the slide, or I'm happy to talk more about it. But what it represents is, as we know now, is that many diagnoses that children are born with or congenital diagnoses are a spectrum and they can range from, you know no apparent developmental differences or disabilities to very complex needs. So in the case of CMV, I'm gonna first start with the top of the slide here where as Dr. Magalnick pointed out that babies can be born, what we call symptomatic symptoms of being sick. And of those children, 10% of those babies are going to be born infected with congenital CMV will have symptoms at birth and of those babies, about 75% will develop a long-term disability.

But most babies are actually born with no symptoms of being sick, so they would not be suspected based on clinical suspicion alone and this is 90% of the babies born with cCMV, but even of those babies that are born asymptomatic, 10 to 15% of those will go on to develop a long-term disability. So it's really important to catch all of those kids and know what the prognosis is or at least have appropriate monitoring in place. So if you go down to the blue bar is down here, then you can see that the spectrum does correlate with whether the baby is born, symptomatic or asymptomatic. So kids that are born with symptomatic presentations have more complex outcomes and you know it can range from death and forms of miscarriage and stillbirth or early infant or child loss, which is typically due to kids that have really significant liver involvement.

Through medically complex kids, so kids that have CP seizures, failure to thrive hearing and vision differences often. So it's those comorbidities really make the primary diagnoses of CP a little more complex to manage and then all the way through to the other side where some kids have have developmental delays, learning difficulties, again with vision and hearing differences. But as Dr. Magalnick pointed out, that the most common outcome from a congenital CMV diagnosis is a hearing difference and that can be a minor difference in thresholds or it can be deafness and that occurs across the spectrum and is very common. So CMV as Dr. Magalnick said, is the leading non-genetic cause of hearing loss, which is why it's really important to be partnering with AudiologyOnline to bring awareness to this issue.

And among those that spectrum, there are kids that are classified as severe or moderate or mild, but I will kind of put a caveat on that and say objectively these are true, but also as experienced by the families, they may be a child that has their primary disability as a hearing difference, may also experience that as very severe for the family. So it's important to keep in mind that these are fairly subjective terms, but do have implications for the way that we manage it. So because 90% of kids are born with no symptoms, this is why the push in advocacy has been towards a newborn screen for congenital CMV. So it's important to kind of review where we're at and where we hope to go with the hearing screen and how that relates to congenital CMV.

So the current newborn hearing screen, which is the graph at the top, is hearing targeted HT for cCMV and it's added on in some states and that's legislated for, so for example, in the first state that had the law, Utah. So in this case, all newborns are born and all newborns undergo a physiological screening for a hearing difference and if those children's fail or refer from that test, then that kicks off a suite of testing that includes genetic testing or may include genetic testing. Those kids and families may be offered testing for congenital CMV, which is often - the gold standard is a saliva or a urine test 'cause that has the highest level of viral load in it.

It may include a blood test or even going back to the blood spot if hearing loss is detected a little bit later in life or there might be some other evaluation, so I'm happy to answer any questions about how that that testing actually looks. But this is our current state, so there has to be a demonstration of a hearing difference, before CMV is recommended in most states and what is proposed, because as you can imagine, if not all children are going to present with hearing loss, although they might develop it. So there are gonna be some children who their diagnosis is not detected in an appropriate timeframe to get appropriate monitoring in place and so what is proposed as a way to catch more kids is a comprehensive newborn hearing screens or universal testing for congenital CMV.

And in this model, which is shown at the bottom of the screen, all newborns would receive in this case as recommended by shear et al in 2019 physiological screening. So the typical newborn screening as well as the the health screen of babies at birth genetic screening, which is the controversial part of this universal proposal in this paper, published in 2019 and congenital CMV screening less so because it's more financially feasible, it's covered by insurance and then it would give you a sense of whether or not that child needs additional hearing monitoring in their early years. So it's important to think about that because as it relates to congenital CMV management and the medical home, we need to just, I mean I'm gonna repeat this many, many times, but congenital CMV is a leading cause of deafness even in babies born without symptoms and hearing differences that relate or caused by cytomegalovirus present differently than other kinds of hearing loss.

And so it's important to characterize what that looks like and why we're talking about this in the context of medical management in the medical home. So hearing differences or deafness, they may be present at birth and if they are, then they will be detected by the newborn hearing screen. But kind of the special case of congenital CMV hearing

loss is that it's often not present at birth and has a late onset, so hearing thresholds can change later in childhood. So even if there's no hearing loss present, but you have the congenital CMV diagnosis, it's really important to get appropriate ideological monitoring in place and it's recommended to occur every three to six months, especially in the early years, because of that late onset and ability for the hearing loss to change dramatically.

Hearing thresholds may also be asymmetric, you may have hearing loss in one side and not the other, or different thresholds in either ear, so it's important to have that bilateral monitoring. Babies with congenital CMV may have hearing differences in one ear, so they may be unilaterally deaf or hard of hearing or have hearing loss in both ears or have bilateral hearing differences and this also may progress at different rates, although children who are born with unilateral hearing difference often progress to a bilateral difference. And that time difference between when that happens is an area of study, but it often can happen in the order of five to 10 years later. Children born with congenital CMV with or without a hearing difference, therefore strongly benefit from services and monitoring by a healthcare team that centers the patient, the pediatrician and the audiologist.

So again, we're coming back to that medical home model where all of these parties are involved in that close monitoring. So special consideration, so I'm sorry I went a little bit too far. Special considerations for congenital CMV and the medical management of hearing differences and really centering that role of the audiologist is that congenital CMV is a central neural hearing loss that initially presents typically as unilateral and progress to bilateral hearing loss. So it's not a middle ear hearing loss, it's an inner ear hearing loss, it's a virus that attacks especially the viral ganglia and the Organ of Corti and even in the semicircular canals and that's an important part to manage or to understand, because of the way that hearing loss presents.

A rapid progression of sensory neuro hearing loss is likely with a congenital CMV in diagnosis and if it's seen unilaterally detected at first, the ear with the greatest hearing difference may progress earlier and more quickly than the ear with hearing in typical ranges. So again, really important to have that in your back pocket when you're thinking about how to monitor these children. Because CMV is a sensor neural hearing loss, we know that the inner ear includes the cochlea and the semicircular canals and therefore it can affect the vestibular system as well as the auditory system. And what has come about in with more research in this area and long-term monitoring is that there can be a significant effect on mobility and balance in kids with congenital CMV even without a diagnosis of cerebral palsy.

So it's strictly a vestibular function to the impact on balance, so balance should be monitored and audiologists should be screening for a vestibular function. So for example, that can include monitoring movement and physical development milestones at each follow-up visits and if concerns are identified, those children should refer to specialized care and those specialists include people who are experts in vestibular function, so those could be otolaryngologists or ENTs. There are branches of audiology now that specialize in vestibular function and therapies and of course physical therapists as well, so that's all part of the medical management of congenital CMV related hearing differences. So that brings us back to really thinking about what does the patient-centered medical home look like for a child born with congenital CMV?

And it's tricky and in fact, in some ways cCMV is unique in this way and other ways that it's not right. We know that most of the diagnoses now are complex and of course each individual and each individual family is going to experience the diagnosis differently. But the thing about congenital CMV is that it doesn't have a consistent or uniform long-term outcome, some kids may have no significant or present disabilities or maybe a learning difference or a slight hearing difference and others may be extremely medically complex, so the care team should be individualized to meet each

patient and families unique needs. Babysitter diagnosed with symptomatic congenital CMV at are higher risk of developing more severe sequelae and as a result of their infection may need larger care teams due to the medical needs.

So it's important to keep in mind that it's not just the medical home but for medical needs. But that if you do have a family that has, or caregivers that have multiple children, if there's a child that has mobility issues or has needs specialized medical support, these are all things to keep in mind when developing that individualized plan and directing people to the resources that they need, so what does the patient-centered medical home look like? And because we can't predict what the outcomes will be for each individual, it's important to get, referrals in place and offer the possibilities to the families of what they they might need. So again, we're just rebuilding the house that Dr.

Magalnick introduced at the beginning of this presentation and at the base of the home supporting the family, 'cause the family is really the center is the primary care provider, which is typically a pediatrician with the onset of a congenital diagnosis. But the audiologist is also really in partnership with that primary care provider and pediatrician to be the primary person monitoring those changes in the hearing differences. And you know, from there is where we branch out and involve the medical specialist who will be able to support and get baseline readings and levels for the child, especially at the beginning. And you know, some of these specialties may drop out and that would be fine, but at least knowing what you know, where the starting point is, so that if a diagnosis presents as a late onset or there's a significant difference in a health status, that data is present.

So typically with an onset, the first medical specialist to be brought on board is infectious disease with a symptomatic presentation at birth. So a child that is born and is able to be detected based on clinical suspicion of their congenital diagnosis. It is

now standard treatment for the child to receive six months of valganciclovir, which is a antiviral treatment, which is known to decrease viral loads and increase hearing outcomes. So that's recommended at this point only for kids who are born with symptomatic presentations and not at this point for asymptomatic presentations. And I'm happy to answer some questions about this, but whether or not hearing loss alone is considered as symptomatic or an asymptomatic presentation is actually a point of controversy.

So children that only have hearing loss at birth, and you know I say that with an asterisk like only that's still a significant difference, especially when the parents are hearing are not recommended for valganciclovir at this time, but again it's an area of study. It's also to good to have, because of the risk of hearing differences to have to pull in the otolaryngologist or ENT vision loss often also accompanies or vision differences. It may be in the form of an actual difference in how the child sees, but also how the brain processes the images, so cortical visual impairment can affect a child and their ability to take in information. So it's important to bring in ophthalmology and as well as neurology for the risk of CVI, but also the risk of seizures, developmental pediatrics to make sure that the child is meeting their developmental milestones as well as physical medicine and rehabilitation or physiatrists to monitor for the development of mobility differences or cerebral palsy.

It's also important to bring in not just the strictly medical specialists, but also the Allied Healthcare providers, specialists and related services that help support the child as well as their family. So these are the services that are typically coordinated and offered by in Arizona, it's the, you know all techs and development division of developmental disabilities. But every state has their form of the part C of IDEA or early intervention as Dr. Magalnick mentioned. So Allied Health Services that can support a family and a child with congenital CMV include physical therapy, occupational therapy, so physical therapy for gross and mild skills, occupational therapy for fine motor and activities of

daily living orientation and mobility to help children navigate space if they have, especially if they have hearing and vision differences.

Speech therapy for communication as well as if there's a child that has a demonstrated hearing difference or is at high risk of it, having a teacher of the deaf and hard of hearing and introducing ASL along with any equipment that might amplify a hearing difference if the family chooses, making those available to the families early on. And part of the psychosocial model, which is the current model of healthcare in the us also offering and knowing about family support and community resources, especially because we know that most children who are born with hearing differences are born to hearing parents and that's certainly the case for CMV and so many states have their own family support and community resources to be aware of.

So for example, in Arizona we are separate from but kind of a ranch of the national CMV Foundation and that is STOP CMV AZ, ALTO CMV AZ for Spanish speaking families to have resources specific to our state and also that we coordinate a patient or family registries so we can connect with each other and have gatherings and just offer that support. We actually have a fairly tight-knit community here, and I believe that's true in most states, the national CMV Foundation can connect you with resources in the different states. They have a program called the Community Chair Alliance where there are families that are interested in raising awareness in their states, maybe moving towards legislation, but certainly in connecting with other families to have gatherings every year.

There is a service referral program in every state in Arizona, it's Raising Special Kids. You can find your state referral program to community resources through Family Voices and they will give, you know some help in gathering communities together, but also in and where to find and access resources, especially for different diagnoses. Hands and Voices is a great organization that's national and they definitely have chapters in every

state, but they also have programs such as Guide By Your Side to help introduce total communication approach, which honors families that choose to intervene medically with a hearing difference, but also offering ASL and you know just even navigating those choices, especially when your kid is young with every family.

And then you know something that I've become very involved in are the ways in which social media can create online communities of support. So even if you don't have somebody nearby, if you live in a rural part of your state or you know can't connect for other reasons. Our communities online have been very, very strong and I welcome you to refer any family to, for example, the Facebook group is called CMV Mommies or reach out to myself or to the National CMV Foundation to help you find those online communities. And so all of these ways are you know kind of building up the whole home, so that people can navigate this new diagnoses that, you know can seem very scary at the very beginning, especially when you don't know where your kid's gonna land on that spectrum.

So we offer at STOP CMV AZ a parent guide for care core coordination and what that might look like, CMV Canada has something very similar. National CMV is developing one, so that is very specific to CMV and the kinds of of care that parents should seek out and that to bring to their pediatrician and their audiologist to help coordinate. There is also a national academy for state health policy, which lists ways in which you can coordinate standards for children with special healthcare needs or who are at risk for special healthcare needs and so they are a national organization that can help you find the resources in your state. And then I've just placed there the link that you can grab from your handout to handout to any anybody which has basically a standard for how do you approach a diagnosis when you're presented with this at a young age for your kid.

So, you know it is important to keep in mind and hopefully you can tune into some of the recorded or if maybe you've already looked at some of our earlier presentations in this webinar series. But congenital CMV is a really important diagnosis to be aware of and it's important to keep in mind that it is a virus and like all viruses that can affect your pregnancy, it is preventable if you are aware of it. It's a virus that can survive on objects such as and objects include hands, faces, toys, pacifiers, teething rings, food plates, cups, straws, forks, spoons and eyes. Anything that, you know the term that maybe we've all become more familiar with over Covid is fomites.

But anything that is a surface can CMV can survive on it up to, you know 15 minutes. So that's long enough to be transmitted between people by touching services and it's important to keep in mind that when you take actions while pregnant, when you are aware, then you can protect your baby from all germs including congenital CMV. And those actions are washing your hands often with soap and water, especially after changing diapers and wiping faces or touching services in which have been drooled on 'cause saliva is a common bodily fluid that contains high levels of viral CMV when a child is shedding. Faces often have drool and spit and mucus all over them for young kids and so it's really important that, you know you give kisses and hugs, you give hugs and then kisses on the forehead or top of head to avoid drool when you are pregnant.

Cleaning and disinfecting services and objects such as toys very often because CMV can live on a surface for to 15 minutes so long enough between a child or if you're a childcare worker or an audiologist or somebody who has any equipment in your office, in your clinic, a healthcare provider that when you pick it up, you may be transferring that CMV to your hand and then you could inadvertently transfer it to your mouth eating only your food and drink your own food and drink while you're pregnant and the same thing for using your own cup plate and utensils. And again, using your own

toothbrush while you're pregnant will prevent transfer of the virus to you while you're pregnant.

And so it's really important to know not only how to prevent CMV, but also you know how to manage it when the kids come to your clinic with them. So you can prevent CMV from affecting someone you love by practicing health, pregnancy tips to avoid all germs, but now you also know how to refer those parents to the appropriate services for their child when they come to you with a diagnosis. So I think that's really important in building the medical home and to strengthen those partnerships, promote healthier pregnancies and to empower families and so I thank you guys for listening. I think our community partners, I've put my contact information up there with a picture of the cutest kid I know who was born with CMV, my son there from a couple of years ago, Gideon and you can find out more about our story by visiting any of these websites or googling me or looking me up on social media. So I think we want to say thank you, on behalf of myself and Dr. Magalnick and we are happy to take any questions that you might have.

- [Narrator] Thank you so much Dr. Muldoon and Dr. Magalnick, we're gonna go ahead and open up the floor for any comments or questions, we do have a few minutes left for the conclusion of the webinar. Okay, we do have a question here. A attendee asked, "What age does a child no longer qualify as at risk per the DDD?"

- [Harold] I guess that goes to me. This is Dr. Magalnick, and now that's the child can be at risk up to age six. At age six they have to qualify for one of the five DDD diagnostic criteria and then again, remember they have to have three of seven of the significant functional limitations attributable to that diagnosis.

- [Harold] Thank you, Dr. Magalnick, any other questions? Feel free to type them in, the attendee said thank you for the clarification.

- [Kathleen] Okay, we have another question. Dr. Magalnick, what is the awareness of pediatricians of cCMV?

- [Harold] Pediatricians are quite aware about the complications for congenital cytomegalovirus infection. I have a feeling that the issue of the medical home and it's a utilization the closer that a pediatrician is to a university center where all these services are available, the probability is that they will utilize it and supply the medical home as a concept. But the American Academy of Pediatrics puts it as one of the tenants of pediatric care, so pediatricians per se are very knowledgeable. I'm an old pediatrician, I'm knowledgeable, but I know a lot of the younger pediatricians were brought up with this whole issue of care of children with complex healthcare needs and the issue of the medical home.

- [Kathleen] Great, we have another question or this was actually a comment. The series has been really informative and helpful thank you to all who coordinated and presented this far, which was from Kimberly, lovely. Okay, we have another question also, Dr. Magalnick you mentioned primary infections and re-infections and different strains of cCMV. What's the difference between a primary infection and a reinfection and are there some strains of cCMV which causes greater handicaps for the children than others?

- [Harold] Definitely, I didn't know if you wanted to get into this, but obviously primary infection is the one that produces the most severe results as far as a newborn is concerned. So that re-infections produce much less of the issues because there is circulating antibodies present in the mother. When you take a look at primary infections, this is a first time infection. The issue is that if it occurs during the first trimester, it produces more serious effects because obviously it's in a developing fetus later onset or later acquisition of the primary infection produces less severe issues and

then with re-infections, only 3% present with significant sequelae. So the other issue here is also if a mother is breastfeeding and acquires an infection, she can pass it on to the newborn.

Usually this does not produce much of a problem if it's a full term newborn, but if it's a premature newborn less or a low birth weight individual, it can have serious consequences. So screening all blood products are screened in the United States for cytomegalovirus so that they are cytomegalovirus free and breast milk has to be monitored.

- [Kathleen] Great.

- [Harold] Hopefully not, if you have anything more to add to that.

- [Kathleen] Yeah, I'll just reiterate that breast milk is considered a environmental infection, typically not a congenital infection, except as Dr. Magalnick said in cases of extreme prematurity. So the neurodevelopmental outcomes that we've been speaking about are typically ones that are acquired, you know in utero when the organ systems are developing. And the only other thing I would add is that with an early trimester infection, it is if the infection is passed to the embryo or the fetus, then the outcomes tend to be more significant, but it's not always passed because of the state of development of the placenta. And so there have been also cases where, you know there we have to monitor, you know all children depending on no matter when the trimester of infection has occurred and just pointing out also, we don't typically have that information because of lack of screening. So all areas that promote more significant screening for kids, for pregnancies even with congenital CMV risk, so thank you for that question.

- [Narrator] Thank you so much again, Dr. Muldoon and Dr. Magalnick we're gonna go ahead, close the classroom. Thank you so much for joining us today, AudiologyOnline. We hope you enjoyed this presentation, have great day everyone.

- [Harold] Thank you.