Understanding the Impact of Dual Sensory Loss in Children with CMV, in partnership with Midwestern University and Phoenix Children's Hospital

Presenter: Mimi Pruniski, OTR/L; Patrice Jung, MA

- [Christy] It's my pleasure to welcome two wonderful presenters today, they'll be presenting to us on the Impact of Dual Sensory Hearing Loss in Children, those who have contracted congenital CMV. This course is in partnership with Midwestern University and Phoenix Children's Hospital. If you'd like to learn more about either presenters, you can read their bio on the course registration page, and at this time, I'll hand the mic over to you, Mimi.

- Thank you very much. We are really happy to be with you this morning, or I think the beginning of this afternoon with some of you. I would like to let you know that I am an occupational therapist and I have been practicing for 40 some odd years with children with dual sensory impairment, and Pat is an educator that is a certified for children with hearing loss and with vision loss. So what we are hoping that you'll come away with after this course is that you'll be able to define what dual sensory loss is, you'll be able to identify the characteristics of cortical visual impairment, and that you'll be able to list three major identifiable values of early intervention for children with dual sensory loss.

- Good morning. One of the reasons that we are talking about dual sensory loss is that many children born with CMV have some amount of vision and or hearing loss. And so it's important that we understand how the two work together. So the definition of dual sensory loss is a person who has a degree of loss in both sight and hearing, the combination of which results in significant difficulties in accessing information, the information that we need to learn about our environment, communication and everything that goes on. During the first three years of a child's life, major neural networks are being formed in the brain. Much of this development comes from the distance senses, such as vision and hearing, and this allows us to know about things and people in the world around us even if we are not in physical contact with them.

So if someone walks by and you just happen to look out the window, you know that there's somebody there, you might be able to hear them, but a child with dual sensory loss may not. After the first three years, development of these neural networks becomes slower, skills that may be gained in early intervention cannot be made as quickly when the child is older, and about 80% have some degree of usable vision and or hearing. They may even have unilateral hearing or unilateral vision loss, and specific strategies are used in working with children who have a dual sensory loss. It's important to remember that it's not just a vision and hearing loss, but it's a vision times hearing loss, the effects are multiplicative.

We use different terminologies to discuss the population, the most common include but are not limited to, deaf-blind, combined vision and hearing loss, dual sensory loss, dual sensory impairment, coexisting co-occurring vision and hearing loss, and sordociegos, which is Spanish for deaf-blind. So the term cortical visual impairment or CVI is used to describe a visual impairment caused by brain damage of some kind or conditions that affect the back part of the brain where the visual system is located. Individuals with CVI often have healthy eyes and may obtain normal results on eye exams because it is the processing centers of the brain. Oops, sorry, sorry about that. It's the processing centers and the visual pathways in the brain that are atypical.

CVI does not have an impact on visual acuity, contrast sensitivity or many other symptoms of ocular impairments, but it can coexist with other ocular forms of vision loss. CVI cannot be corrected with glasses. It's important to know that children and youth with CVI can be expected to make progress in their visual function over time if provided with appropriate early screening, assessment and early intervention. CVI requires a very different approach to instructional supports and environmental and material adaptations as compared with ocular vision loss. Cortical blindness, well, few doctors will use this term anymore in this country because it would refer to total blindness where there is usually some light perception. However, for insurance purposes, oftentimes this term may be used on paperwork.

Often, cortical visual impairment and cerebral visual impairment are used interchangeably, which is more common lately. While they both involve the brain and how the eyes interpret vision, they're different, and for this session we'll be referring only to cortical visual impairment. However, the term cerebral visual impairment is commonly used in Europe. I also wanted to touch on the fact that there are many ophthalmologists that will not use or give CVI as a diagnosis. We're not quite sure why, but we think while the condition may improve with proper early intervention from a certified teacher of the visually impaired, some ophthalmologists do not have a clear understanding of the importance of the diagnosis at an early age to obtain these services where they're unfamiliar with all the characteristics.

And in speaking with local ophthalmologists that know a lot about cortical visual impairment, they were saying that this is not really talked about in medical school, a lot of time is not spent on this, so it's important for us to be knowledgeable about the characteristics which we'll be talking about soon. Eye muscle issues or strabismus is a disorder in which the eyes don't look in exactly the same direction at the same time possibly due to poor muscle control. While there are other eye conditions that may be related to CMV, such as optic atrophy, retinopathy, or Chorioretinitis, the conditions mentioned on the slide are the most prevalent. The point being is that early intervention and identification is so important, we can't stress that enough.

So vision screening obviously is paramount. Birth through the first month, a baby begins to focus on lights, faces, and objects, 8 to 15 inches away from the face. So within hours, a newborn can show preference for a mother's face over that of strangers. Even at six to eight weeks of age, babies can have good eye control and eye contact with other people and may smile back at a smiling face. By two to three months, that may have intense eye contact, and by four months they may be interested in looking at themselves in a mirror. How cool is that? Babies begin to follow slowly moving light, faces, and objects set near. We need to be looking if they have an atypical blink reflex when tapped at the bridge of the nose.

So just a easy tap right over there. This can be done in the NICU by anybody, you don't need a professional, mom can do it, anybody can do that, don't need special equipment. There should be a blink reflex, it may be delayed, it may not exist, but we need to know that. And the sooner we know that, it sends up a red flag. And they may have atypical visual threat response in children older than six months so that if something's coming at them, they should blink. It may be delayed, but we need to know that. And parents obviously are the closest to the children and they have a lot of information that we need to interview and get the correct responses so that we can forward that onto either pediatricians or ophthalmologist.

So the parent interview is so important. While there are many vision screenings available, and we'll mention two of them in our resources slide, parents' observations are just critical. There's a screening done in Europe, and I was just at an early intervention conference last week. It's called NAVEG, and it's Neonatal Assessment Visual, and it's the European Grid, and it's used to identify brain-based visual impairment and it's slowly being used in some states, but vision teachers need to be trained in using this assessment as do others. But it's nice that there's something that's being used to detect this CVI earlier, earlier, and earlier. There's also a program called the InfantSEE program, which allows for free eye exams by certain providers for six to twelve month old babies.

And this is available in most states, you just need to Google and find out where and who is doing that. So this is all a quote from Dr. Christine Roman-Lantzy, who is one of the pioneers of assessing cortical visual impairment. "When attempting to determine the cause of a child's visual disability, CVI should be considered when the child has a normal or near normal eye exam that cannot explain the child's impaired vision." So the parent or someone feels that there's just something not correct. If the child has a history or presence of neurological problems, in the presence of behavioral responses to visual stimuli that are unique to CVI. So in talking about neurological problems, so any trauma at birth, cerebral palsy, prematurity, brain bleed, stroke, et cetera, those are all red flags.

So we're going to talk about the characteristics of CVI. And there are many unique visual behaviors that are characteristics of CVI, and the more you use them, the more you have children that you work with that have CVI, the more it'll become natural to you. These characteristics may not be present to the same degree or severity in each child, and the characteristics may change and improve over time. Typically, the degree of change and the amount of time it takes for improvement is based on early intervention. A teacher of the visually impaired knows how to assess this and how to work with children with CVI. The assessment that is typically used is called the CVI Range, and that was developed by Dr. Christine Roman-Lantzy.

And there's basically two parts. The basic assessment is used to establish a score that shows the overall extent to which CVI is interfering with the child's vision, and the second part looks at the degree in which each characteristic is affecting the child. The range uses a 10 point scale, zero represents no functional vision, and ten represents near typical or typically functioning vision. However, we've noticed that even in adults who've had CVI that looks like it's cleared up on occasion, especially with mobility, oftentimes these characteristics or some of them creep into their daily lives. So the three phases of CVI that represent the level of severity, one to three on the range is where we work on building visual behaviors, getting some purposeful visual attention.

Phase two to three is all about integrating vision and function, and phase three is about refinement of remaining CVI characteristics. So now we're gonna talk a little bit about each of the characteristics. So color preference. Some children just have a strong preference for a particular color. Often it's red or yellow, but it could be green or some other bright color that can be easily seen. What's important is that when we're working with the child, even if we're in an, wherever we're we are, that we present a single item. It may be yellow, and if it's red, can you easily see that? Maybe not, maybe need to have a different background, maybe we need to have a white background.

Need for movement. To initiate or sustained visual attention, often the object viewed or the child needs to be moving. So you know, we talk about kids getting their wiggles out, but that might be the only way they can see something. So this has like a movement quality, you don't even have to move it. Mylar, Mylar has a movement quality, you don't even have to move it. And using, you know, talking about colors, child might have a preference for green. Here's just a piece of material, but it's sequined and it has a movement quality to it. So all these things are things that we use, they don't cost a lot, it's not a fancy toy, but it's great for the kids to get their attention.

Latency. Often it takes the child a few seconds or minutes to respond to an object being presented. Child needs more time to coordinate the vision along with the brain. It's important to be quiet during this processing time and it's tempting to cheer the child on, but this can be distracting. So we're gonna talk about this a lot and I know Mimi's gonna talk about this a lot. Parents and all of us in the field are great cheerleaders, we want the best for our kids, but we have to remember that it takes the child time to process the information. So they may have to wait for them to latch onto something visually and then respond. Field preferences.

Lower field loss is common. The child may have certain areas in his or her visual field that work best when presenting an object. Oftentimes the child might have an object right in front of you, but the child kind of looks like this. But just remember, if you're gonna present something down low, there may be a lower field loss. Complexity. When an object is being presented that is complex, it's gonna make it difficult for the child to see. So we want to eliminate that and make sure that the environment is calm for the child. For example, here's a beautiful little quilted rug that grandma made. Well, even if we're putting our favorite yellow ball in the middle of it, it still might be hard for the child to see, or this is his favorite cup, which is a little on the busy side, if we want the child to find the cup in this busy blanket, it's gonna be difficult.

So if you've ever noticed sign language interpreters are usually wearing a black background or shirt or dark gray or blue. Why? Because we wanna make it easier for people to see their hands. So the need for light. The child may need light to be paired with the object to view the target. Additionally, there may be a lot of light gazing and non purposeful gazing. So oftentimes you'll see what we call, often people call it stemming where they're just playing with light, they're, you know, creating a little slide show for themselves, they're entertaining themselves. Or they're just staring at a light or even a ceiling fan that may not even be on, but it's reflecting some light.

Difficulty with distance viewing. The child has difficulty looking at a target that is beyond a certain distance. Especially when they're young, their viewing distance is maybe 8 to 10 inches, but with CVI, it still takes a longer time for distance vision to develop. We talked a little bit about atypical visual reflexes, the blink reflex is absent or delayed. I can't stress this enough. A little girl was just diagnosed last year with meningitis, and of course the first thing that, you know, everyone was worried about her immediate medical health, but when she got home, no one ever paid any attention to her vision. She got hearing aids because she lost her hearing, but once I got to the house and I just did this, there was nothing, there was no reflex.

And we started working on CVI activities and mom finally got her diagnosed and then she was able to get a teacher of the visually impaired in the house. Visual novelty. So familiar toys, objects and targets are easier for the child to visually explore. There may be a lack of visual curiosity for new objects. Well, if the child likes the yellow ball, here's the movement quality, so that's attracting the child. What? And then we introduce this brand new beautiful toy, the child's not interested. Well, it's hard for the child to make that connection. So we try and find a toy that has similar qualities. So maybe introduce another yellow toy that has the similar qualities. Absence of visually guided reach.

So the ability to look at and touch and object at the same time may be difficult. Sometimes the child may need to look at something for a few seconds, then look away, rest, process, then look back and attempt to reach it. Remember no cheering during this process and the child may need to start over if we do the cheering thing. So the one thing Mimi and I are going to really talk about besides wait time and cheering time, is stressing these two things. I could say it 101 times, and we're all guilty of not waiting enough, but this is a problem. If a child looks at an object and then looks away, he's processing that information, it takes time.

Could take 15 seconds, it may take a minute, but then he may look back at it and then reach for it. If we cheer him on or repeat what we said, then the whole process has to start again. So what you may see a classic characteristic of CVI is that a child might glance at something like a toy, look away, then reach for the object. Like I just say, visually guided reach. The same thing if they're in the booth and they're looking at your toy or a birdie or a red light or something, they look at it, look away, they may go back to it. Need for more processing time, wait time, delayed response when looking, please give them the time, count to a hundred if you have to, but just give them that time, every child is different, every person is different.

Preference for toys of a specific color that light up or move, stare at light or sun coming through windows, staring at ceiling fans. Now oftentimes it's hard, you put a child down and all they're doing is looking out the window. And so activities around that would have to be developed, but that's just a red flag. Feeling that the child is looking through you rather than at you. This is a really common comment that parents report, and we need to pay attention to that. Another important thing is that the environment and physiological factors may affect the child's visual responses. So as soon as you change the child's environment, people think that his vision changes. Well, the vision doesn't change, it's the environment that's changing.

Even one more person coming into the room changes the environment, the smell of the room, like going to a doctor's office, they, you know, has a certain smell. Anything, how the child is feeling, if the child is tired, any of these things. So more information related to CVI. It's not always easy to diagnose basically because doctors don't have the experience, we talked about parents are often the best observers and reporters. They don't always know what they're seeing or why they're seeing it, it's just that they know something is not right. We don't wanna wait for a diagnosis to implement intervention. And we'll talk about the Deaf-Blind Project a little later, but they can help you with implementing intervention if you see this and you can't get a diagnosis from an ophthalmologist.

And early diagnosis and intervention is critical because of neuroplasticity. Visual efficiency varies according to environment, health and sleep. How the child is feeling, what their stress level is, their fatigue, positioning, the amount of light in the room, new surroundings, new people, the smell, all these things affect how the child is seeing on a given day, and that could change from day to day to day. And due to various reasons, many children with CVI go undiagnosed or receive a late diagnosis. Specialists in the eyecare field, pediatricians and various providers are unaware of CVI and the appropriate methods that can be used to diagnose it. So many of you are audiologists, so we're not gonna spend a whole lot of time talking about audiological considerations, plus, there were other talks about this previously, but I think it's important to mention for those that are not audiologists, there's a range of possibilities for hearing loss with many having sensory neural loss.

The loss can be unilateral or bilateral, and it's possible for a child with cCMV to pass the newborn screening and then later develop a hearing loss. It's very important to have regular hearing testing with an audiologist. Many parents feel, "Okay, we're good, my child passed the hearing screening and he's good to go." And then we find out sometimes even in elementary school, there's a problem. So the various devices listed below are things that we are seeing in the school, behind the ear aid, BAHAs and cochlear implants. But I just wanted to throw in here, I do a training, a presentation for beginner, first year audiologist, and we put them under occlusion, take away their vision and their hearing for activities even going in the booth, and what they're feeling and experiencing is just amazing. When you take away a child vision and hearing, the responses are different. And so just to make you aware of that, please, please think of the CVI or the vision considerations. Mimi, you're muted.

- Thank you. Now that you have a good understanding of CVI, which is the primary diagnosis that you'll see with children with CMV, the primary vision diagnosis, I wanna talk a little bit about the value of early intervention. So first of all, when a child gets a diagnosis of CMV early on, a lot of times the first thing that they look at is hearing, but they don't look at the vision, because as Pat spoke about, that's much more complicated to diagnosis, especially at a very young age. So it's really vital that as audiologists and hearing specialists, which I'm thinking many of you are, that you are aware of many of the characteristics of CVI and that you help the parents as you are seeing them, to look at those things when you are seeing them, because hopefully they are being supported in getting regular hearing screenings, even if they are not being diagnosed with a hearing loss during that initial newborn screening.

The other thing is that we are encouraging children, babies that get this diagnosis to immediately be referred to the early intervention system in their state. Every system has, I mean, every state has a little bit of a different eligibility, but it's very important to begin that referral system. And the reason that you want early intervention as soon as possible is that having someone in the home helps those families to navigate a pretty complicated social and medical system. It helps them to understand the diagnosis and the implications of that diagnosis in their everyday life. Typically, because audiology is a medical based service and many of the services that children with CMV are associated with at the beginning are medically based, it is in a clinical setting, it is not in a home setting.

And early intervention happens in the home. So this is an opportunity for families to develop a relationship with someone that is coming into their home on a regular basis, and they can begin to hear things repeatedly and hear things at their pace when they are ready to hear and understand them. So what what I have heard as an early interventionist is parents ask questions, and I don't wanna say understand, but begin to really comprehend and understand what those answers are when they are ready to hear them. So they may ask them repeatedly. And having access to someone who can help support them in that when they are ready to hear them in the home, is much easier than when they don't have access to their doctor, their audiologist, those professionals, but on an interval that is happening at the hospital when they have appointments.

So that's a really important piece of the puzzle when you're having intervention that's happening in the home. The other thing is that early intervention helps the family with strategies that will help that child move forward in their everyday routines. So whatever's happening with the child, it is occurring in the home on an everyday basis. Now, an early intervention team is typically comprised of occupational, physical, speech therapy, if a child has a vision impairment, a teacher of the visually impaired, if they have a hearing impairment, a hearing specialist, possibly a social worker. So any combination of those people, that child's family will have access to. The national concept for early intervention is a coaching model, and so it's not that all of those interventionists are going into the home every week to provide support for the child, but that a primary person is, and the child's team has access to all those people.

So if a child has been diagnosed as deaf-blind, then they will have access to that hearing specialist, to that teacher of the visually impaired, to that OTPT, whatever, to help support them. And with the coaching model, they are providing that family with strategies embedded into that child's routine that is going to advance their skills on an everyday basis. The belief is that the parent is the first and best teacher of that child. And so if we can help support them in providing strategies for how to set up the environment in that child's home, for allowing them to see that toy in the best possible way, for allowing them to change the environment, for accessing their hearing in the best possible way, then that child is going to advance their skills.

And that is the concept of early intervention and that is what we are trying to achieve. So therefore, it just makes sense that the sooner the child is referred, the better the outcome and that that will help that child gain their skills and help them to be more functional both educationally and then being more productive members of society. So there are some key guidelines when working with dual sensory loss. And this was from a seminar that I went to from she was an occupational therapist that works with a clinic for CVI out of Cincinnati Children's Hospital. Her name's Karen Harpster, and she referenced an article from 2023 from R.F. Pilling. And the article is, "Make it Easier.

Three word Strategies to Help Children With CVI use their vision more effectively." He has 10 of them, and these are just three, I mean, these are just four, I do know how to count. These are four of the ten. This is an easy way to try and give parents just some cues for how to set up their environment, I use it with teachers, with parents. I'm doing early intervention at this point, but to give them ideas for how to address how to make vision, how to set up the environment so that this is the most opportune way to help their child with their vision. First of all, is just one thing. I'm reinforcing what Pat said, but I just don't, I can't tell you how important this is and this is an easy way to remember it.

Present one item at a time and make it simple, clear the clutter. There's a couple ways that you can do this. Families love to set up the playroom so that there are shelves and the toys are on their shelves and they want their kids to be able to go over and choose the toys. Those are great choices for children and we want them to make choices and we want them to be independent in those choices, but a lot of times the clutter is just too difficult for our children with dual sensory impairment to handle, especially if the CVI is a significant CVI. So one of the things that I'll do is just say, "Just put a a sheet over those cubicles, or have just one of them available, or put bins in them and just have one toy available for them to look at."

Big, bright, and bold, we've talked about that. And the last thing is, give me time. Now you guys think I just forgot what I was trying to say. Nope, I wasn't. That was only 15 seconds, that was 15 seconds of wait time. Most of our kids need thirty seconds to two minutes. We are going to hit this probably another four or five times during this presentation because I cannot tell you how important it is. We had another guest lecture with one of the seminars from the Deaf-Blind Group of, I think it was in May, he's in California right now, that talked about this also. Giving kids time to respond is absolutely essential. And when you give them time, if you wait that 15 seconds and go, "Johnny, I know you can do it, I know you know the answer," then you start that clock all over again.

So remember not to do the encouragement that you know that you in your heart you wanna do, just say it in your bed and keep letting that clock run out. Strategies and interventions. Positioning is important. Many of our kids that have CMV and have a dual sensory impairment have multiple disabilities, have physical challenges also, and the first thing that you wanna do before you're asking them and challenging them in their vision and challenging them with their hearing is to make sure that they are not only comfortable in their position, but that they are in a position that is not challenging with their body so that they don't have to work so much on their trunk and their head control, that they can just concentrate on using their vision, that they can just concentrate on working on listening and attending.

Because if they have to do all of that at the same time, something is going to be lost. And depending on what you want to work on, they can't do all of that at the same time. So I'm not trying to say set your expectations too low, I'm saying start with just working on one thing, and if they can handle more, great, but let's work from the standpoint of giving them the support that they need and then backing off. Make things clear and simple, use color contrast. As Pat had said, colors do matter, the color preferences tend to be red and yellow, but it is not always that way. Use solid backgrounds. Both of us at different points in our career have worked at Foundation for Blind Children, and at one point they were giving out lots of T-shirts and the T-shirts all had beautiful logos on the front, and at one point someone said, "Maybe we should put those logos and all the text on the back of the shirt instead of on the front of the shirt."

So I mean, even the professionals were not thinking things through well, those were the marketing people, weren't thinking things through when they were considering what we needed to do. Eliminating glare. I am working with a little one in their home on feeding, and one of the things, and she's a little one with a diagnosis of CMV and one of the things that we have to do is we have to move her chair actually out of the dining room and into the kitchen because the glare from the window makes such a big difference on how she can visually attend. And that has to do with experimenting with light too. The other thing that we do when we have introduced a new food is I use a flashlight, just a little pen light, and I'll kind of shake it to use a movement quality to get her attention to it because she will not eat a new food until she touches it and she won't touch it if she doesn't attend to it visually.

So you have to do some of those kinds of things with kiddos to get them to understand what is going on. I'm running through some of these so that we're not doing too much repetition. Movement is vitally important and as an OT, you know, incorporating vestibular into that movement is important visually, but also movement to get the child activated, remembering that you want them calm and attentive, but also alert and awake. And then repeat, repeat, repeat. Repetition is really important, but to do that in a way so that the child has lots of opportunities to learn the task that they're doing. Make changes slowly. So novelty is not always a good thing. We think that especially with young children, that change is good, that you bring something new and exciting and that that's a positive, but many of our children, what that does is that that is actually overstimulating.

So you wanna look at their behaviors and see what happens. So we'll have kids that some of their behaviors will be that, you know, they're closing their eyes or they're blinking. That's not always a sign that there's something wrong with their eyes, a lot of times that may be just visual fatigue and that, you know, that is what's going on. I have another little one that, she always brings her face really close to, oh, sorry, really close to whatever's going on. And she has a diagnosis of CVI and I sent her back to the ophthalmologist and she has glasses because I thought it was an acuity problem. After the CVI workshop that I went to with Karen, what she was talking about is that, and they have a very busy home, is that what she was doing is she was blocking out the clutter, that the home was so busy that she was bringing things close to her face to block out the rest of the environment so she could actually visually attend to something and see what was happening.

So a lot of times we need to look at our kids' behaviors and see what is happening. So again, during an audiological evaluation or if the kids are in the sound booth or things like that, looking at their behavior to see if some of the times, it's not that they are not trained to attend auditorily, but because some of the things that are happening with their vision is affecting what is going on. And then I think, I remember Pat mentioning this, but if they're looking away, not only can it be that they might have peripheral vision, but that the task is too challenging and they're just looking away because it's just too much for them to handle or they're overstimulated.

And at that, you need to look and wait and say, "Okay, maybe we need a break from this visually." Remember that kids that have deaf-blindness, that it's multiplicative. It's not just that they have a vision impairment and a hearing impairment, it's exponentially much more difficult for them to learn, and that's what we need to keep in mind. So now I'm gonna run through these really quickly. These are just some examples of things that are good, bad, or indifferent. So the quilt, individually, these are good high contrast examples of what we want our kids to do, all together, that can be a little bit overstimulating. Again, I don't think you can see me, I'm pointing to the book, the Little Feet Love on the top left.

That is an example of a good picture with high contrast, I mean, a good picture with high contrast. If you look to the left side, that's very busy and hard for a child to see. We use invisboards. Any child that has a vision impairment is eligible for a registry called American Printing House for the Blind, APH, and they can get some services through their state registry. So this board on the bottom left, it's just a trifold board that has kind of a felt back. You can create that on your own, families can, and it's recommended. On the right hand side is just an example of some PVC pipe with a black sheet. That is another good background to try and make it easy for kiddos to see.

Kids with vision impairments also need boundaries. On the bottom left, there's a yellow APH board that has boundaries that we do for sensory play or for writing activities, just depending on what level the child is or what kind of activity. But you can also use bins or you can use cookie sheets that have a border on it, any of those things are good boundaries. These are good toys that are simple, high contrast toys and material. Clifford, it's all red, it's a single color, it's bright, Elmo, Cookie Monster, again, single colors, bright. Big Bird. The toy on the bottom left is a toy that I really like because it's got the black and white, it's easy for babies to hold and it changes color if you hit it or shake it.

These other toys, again, they are multiple colors, but they're bright, single colors. The ring stack and the shape sorter, you can take and only do a few of them at a time for kiddos. With the shape sorter with kids that I'm using that have a vision impairment, I have parents outline the shapes with a black magic marker, or, no, permanent marker, so that it's easier for the kids to see high contrast. These are a couple books that we look at for early learning strategies. It's shapes, and as you see the pictures, they're easy to see and not very busy, high contrast. Tactile books. These are a couple examples of tactile books. Again, they're easy to see.

These are shapes. There's some books that I've seen at Costco that I really like, you can get 'em at other places, by Rosie Greening and Stuart Lynch. It's called "Never Touch a Monster," "Never Touch a Dinosaur," I think there's one about trucks also, but on every page there's a different texture. These are really good for kids that don't have a vision impairment, but they're particularly good for kids that have a vision impairment. And then these are homemade books that Pat had made, they're multisensory, they should be like three dimensional and they can be books that are of high interest to the child. So if it's a topic related, one is a Halloween book and the other's at Christmas time, so they can be topical and just of high interest to the child.

- So if you have any questions, you know, you think in your mind you're seeing something, talk to the parent and refer, refer, refer, call your local pediatric ophthalmologist, or have the parent contact the pediatrician or audiologist. And here are just some places for you to get more information as well, early intervention services, you can refer a child, Arizona Deaf-Blind Project, and the National Center on Deaf-Blindness. And to be considered deaf-blind, a child can have a unilateral hearing loss and a unilateral vision loss and they're still eligible to receive services from the Deaf-Blind Project in your state. There is one in every state, and any child from birth to 22 with a vision and hearing loss is eligible to receive services from your state Deaf-Blind Project.

There's one in every state, they may be called something different, but you can even go to that National Center on Deaf-Blindness and CDB and find out where the Deaf-Blind Project is in your state. The projects are funded through a federal grant and offer free services to families. I can't stress that enough, free, free, free, and there's very little paperwork that has to be done, once the child is registered, that's pretty much it. Services are free to families, providers, teachers of children and youth with the combined vision and hearing loss. As a reminder, the term deaf-blind can be very misleading. Families we serve have children with a wide range of learning styles and communication preferences, and most, all of them have some degree of vision and some hearing.

Having a combined vision and hearing loss impacts the way the child communicates, as well as the way they develop concepts and learn skills. The child will need family, friends, teachers, therapists, medical personnel, various other providers and community members equipped with specialized strategies to support their learning and development, and the Deaf-Blind Project can help with that. So since the child is eligible from birth through 22, we can go into the home early on, we can go to a doctor's office, we can do virtual or in-home consultation, we can provide training for your child's medical, educational and therapy providers. So if a child is having difficulty in an audiology clinic and they're distracted, you can call us in.

And there's, like I said, you don't have to do any paperwork, you just call us, email us and say, "Hey, I've got a kid coming in and he's deaf-blind and we just need some help with the environment." We can do that for you. We help make connections to other families through hosted events and workshops and drop-ins, we can assist the families with attending workshops and conferences, and we help guide them through different transitional period. So at the end of early intervention, when they turn three, then what? They're so close with their families, with their early interventionists, now what? So if we're involved we can help them into the next stage, into school, preschool or into the next stage, elementary school or whatever, we can go to the meetings that they need to attend, once again, go to doctor's offices and help them understand what the doctor's saying.

I mean, I don't know, when I go to a doctor's office, if they're saying a bunch of stuff, I remember about three out of five things, while the parents are typically overwhelmed with all the medical terminology, especially if it's vision and hearing, we can go with them to help explain that once we're out of the room. We also work with children transitioning into adulthood. So there are programs, there's even a national center, Helen Keller National Center where children or young adults actually can go and be trained in some future life skills, vocational skills and we can help with that.

- So we just provided you with a couple slides that have some different resources on 'em. These are some apps that we use with kids that are visually impaired and or hearing impaired, and then these are some resources and references that we used that we wanted you to have access to. Lastly, this is a quote about the importance of early intervention from Temple Grandin, that the treatment method, why can I not see this? "The treatment method or educational method that will work with one child may not work with another child, but the common denominator is that all young children with all young children is that early intervention will work." And so, we really value the need for early intervention and do think that it's essential. Thank you so much for your time. Sorry we went right up to the end.

- [Wendy] That was such a great presentation. If there's any questions, please put them in the chat, I'm sorry, put them in the Q and A. I have a question to get us rolling, and Pat, you may have mentioned this, but, is CVI the most common type of visual loss that children with cCMV have?

- Yes, simple answer, yes.

- Okay, great. My next question is, "this was a lot of great information, but as an audiologist I'm feeling a bit overwhelmed right now. If we see a child who is blind or has some sorts of degree of visual impairment and we know they have some sort of hearing loss, where should we begin? What should we start to think about? I know you gave whole bunch of stuff, but again, I'm just a bit overwhelmed. How should we start to look at evaluating this child to get more information about their degree of hearing loss?"

- Well, you wonderful audiologists have all your information at hand from all your testing, but I would contact the Deaf-Blind Project in your state to see how their hearing is going to be functional in the environment in which they live and go to school and all of that. And they can help you not necessarily do the tests, but create the right environment so that you're getting the information you need to make the child successful in school. 'Cause oftentimes we'll have a child in the classroom with hearing aid or cochlear implant, and either the child is, you know, flicking them off or whatever. We go back to the audiologist and they say, "Well, you know, the child just doesn't wanna wear it."

Well, you know, our first thing is maybe it's, you know, too high or not high enough or whatever. Maybe the environment is just too distracting, maybe the child just being overstimulated and taking the hearing aid off or the processor off. So those are just all things I would just contact the Deaf-Blind Project in your state and they can give you some basic information, come out and observe the child. And obviously, you know, talking with the parent and finding out what's going on in the home is really important as well, how the child is functioning with their vision and hearing loss.

- Okay, that makes sense. Well, it looks like there are no other questions, so we're going to wrap it up. Mimi and Pat, thank you so much for this presentation, I really learned a lot and I'm sure everyone else did also. Thank you.

- Thank you.

- Thank you so much.