Date: 12-5-12
Adobe Cochlear Implants in Children with Vision Impairment and Multiple Disabilities: Results of a Nationwide Study
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>> Cathy: Hello, Melissa, this is Cathy. I'm checking my audio. Thank you. I can see the audio is working. Welcome to today's course. We begin in 1 minute. I appreciate your patience. Hello, everyone, and welcome to today's presentation. Just one second. I think we have a bit of an echo. I'm going to wait one second. I think that one other person with a microphone on and they need to mute. Excellent. So now we are truly beginning. Hello, everyone, and welcome to Cochlear Americas HOPE presentation tied titled Cochlear Implants in Children with Vision Impairment and Multiple Disabilities: Results of a

Nationwide Study my name is Cathy Luckoski and I'm a HOPE specialist. Today is in two part series in the topic of deaf-blindness. Both today and one scheduled January 15th are led by Susan Bashinski and Charlotte Ruder. Now, during the presentation your comments and questions are welcome. There's a Q-and-A box in the upper right hand corner. The file box holds hands-outs for today's presentation. To download these to your computer, select one which will highlight it and then save to my computer. Today's presentation is part of the HOPE Cochlear program to chief personal best with a hearing device. HOPE resources are on the web page with 100 recorded courses in the archive. There are also articles on a range of topics related to hearing rehabilitation in the reading room and listening tools with interactive exercises to develop schools for skills list being on the telephone, listening to music and listening to learn and talk. After today's presentation please visit Hope Online to see what's new and see what's next for our next online event. Now, it is my pleasure to introduce our guest presenters. Dr. Susan Bashinski and Charlotte Ruder are distinguished speakers nationally and internationally on topics related to multiple disabilities and cochlear implants in children. In particular those that experience low incidence disabilities such as deaf-blindness. Dr. Bashinski is in Department of Special Education Foundations and

Research at East Carolina University in North Carolina. In addition to authoring numerous has grants on disabilities and acted as site instigator for research projects for learners that experience deaf-blindness and received a cochlear implant. Charlotte Ruder is speech-language pathologist at Cincinnati Children Hospital Medical Center in Ohio. Her professional focus is on the development of speech language and listening on chirp with hearing loss. She has been investigator on everyone are topics with topics that include language that experience deaf-blindness and use a cochlear implant. I'm excited to have both Susan and Charlotte today, and I will turn the microphone over to them now for the presentation.

>> Susan: Hello, I'm going to get us started today, and I want to thank you all for your interest in cochlear implants with somewhat different group of children than those with whom you might typically work. Both Charlotte and I love the picture on the introductory HOPE slide of kids that have received cochlear implants, but we wanted to show you a couple of our guys and gals. You're seeing them now. These are two of the children that participated in our cochlear implant research with children who have vision and hearing loss, so we wanted to introduce you to some of our folks as well. We will introduce you to the background and don't know what the individual

repertoire experience is on kids with deaf-blindness and I'm sure this will be old hat for some of you. For inexperienced folks you might say deaf-blind mean the child hears nothing, sees nothing, and that is absolutely not true. That is not the case. When we use the label of deaf-blindness or in order for a learner to qualify for that label of deaf-blindness, we are simply saying in consistent with Federal Law, we are simply saying that the learner experiences concurrent losses in vision and hearing. It might be cortical vision impairment and hearing loss, it might be field visual impairment and CAPD. It is any combination of any type of vision loss and any type of hearing loss. Regardless what the combination is, deaf-blindness does impose many, many limitations that affect the internal understanding the world. A lot of what we are trying to teach is the world is organized, world is safe place to be. For some of the kids with near total blindness and profound hearing loss, just to even teach them there's a world out there which they can learn to trust and it does vary in terms of what the kids needs are individually dependent upon what a particular child can hear and see and touch. I think the very last point on this slide is important. Just under 90% or for all intense and purposes, 90% the children and youth to 22 years of age who have this label of deaf-blindness nationwide have other additional disabilities. Motor and or cognitive and or medical and or behavior and or social and when Charlotte is presenting the demographic information she will go into detail about some of those with you. Deaf-blindness does affect all areas of development. Basically the biggest challenge for learners with this label is access. Kids who have concurrent hearing and vision loss do require thoughtful, well planned input because they have such seriously limited opportunities to interact with other people, to interact with objects in the world. They're inability to see and hear may limit motivation. So they really are dependent on other people to label activities, objects, experiences, people, places, things using multi-sensory input. As you might expect when we say that deaf-blindness affects all areas of development, we could look at those general commonly recognized developmental areas of cognitive skills which includes memory and concept development, social skills. Again, very cultural the link here but just how you interact with other people, greet, have relationships, come into contact with other people, gross motor skills, fine motor skills, lots of things going on. The way we see this manifest most commonly certainly not across the board with every individual learner but most commonly, many, many of the kids with deaf-blindness particularly at young age lack skills of functional object use. And you will hear us say that again later today because many of the participants in our studies did lack functional object use. And then finally the major area of development that's most central to our discussion today is whole area of communication. Communication and language skills and with our kids with less cognitive limitation vocabulary skills, articulation skills, all of those in the speech and language areas. Another point that Charlotte and I had ask you to bear in mind, and you will hear from us again today, is that many of our participants when they entered our study were nonsymbolic. Many, many of them lacked a good repertoire of prelinguistic skills. Some of them lacked almost the entirety of prelinguistic skills. They showed very little pretend play, they used few vocalizations and in particular their gestural development was very, very delayed or nonexistent when they joined our research effort. And that's very significant to those of you that are familiar with communication development how gestures are really a bridge to symbolic communication. We thought you might be interested in just a tiny bit of incidence information. All of these data are taken from the 2011 national child count for children who are deaf-blind. There's a national consortium on deaf-blindness that operates out of Western Oregon University. They conduct, manage a count of all the children, adults, birth through 22 years of age across the country, and keep data. They have amazing database about all aspects of these children and young adults, so we thought we would extract some key information from 2011 child count and share with you. In last year's census a total of 9,387 kids and young adults birth through 22 years of age were identified as eligible for label of deaf-blind. Again to repeat for you just under 90% of this population have other disabilities in addition to deaf-blindness, and we think you might be interested and perhaps surprised to realize over 42% of the population of children and youth with deaf-blindness experience four or more additional disabilities, so these kids are really challenged with access to the world and information and people in it. Of this total group of children and young adults who have a label of deaf-blindness, 4,354 of that group have a moderately severe, severe or profound sensorineural hearing loss. We have extracted this figure for you because it is this portion of the national population with deaf-blindness who might be considered eligible for cochlear implantation. And if you do the math, it comes to 46.4 or just under half of the entire population of learners with deaf-blindness in our country who might be eligible for a CI. In 2005 was the first year the national consortium asked the states to report the number of kids on the census who had received a cochlear implant. That first year was reported at 167 and last year's census 695 learners nationwide who have a label deaf-blind were reported to have one or more implants, and as we say here, increasing numbers of kids with deaf-blindness are receiving bilateral implants. The last thing that I will mention before I turn this over to Charlotte, the research questions we have had a series of two back-to-back Federal research grants. The numbers are listed on the slide. We were fortunate to receive these under technology stepping tone invasion. Those of you familiar with the stepping stone competition, wait a minute, longest funding you can get three years. That's right. Each year we were able to get a no cost extension and had money for the Federal Government eight years and been working at this the last eight years. We were not taking a position of trying to advocate for families to get, seek cochlear implants for their children, nor were we taking a position obviously of discouraging them. What we were trying to do as shown on your screen right now, we were just trying to compile a database. On outcomes, related factors so that families of kids could make informed decisions about whether or not they wanted to seek implants for their child with deaf-blindness. We wanted to identify factors correlated with more positive learner outcomes, long-term objectives for progress. The reason we started thinking of this in the first place was as we were talking with families who are participants in deaf-blindness and those kids had already received implants, parents were telling us when they went to clinics, went to physicians, went to CI surgeons offices to seek an implant, the only thing that those clinics and offices could share with them were data collected with kids who were only deaf and had received cochlear implants. Progress data, predictive data, that kind of thing, and there just was nothing that had. Compiled with learners of deaf-blindness that families could try to use to help them make informed decisions, so that was the goal, just establishment of a database for families to consult when they were confronted or seeking out information about a possible implant for their child with deaf-blindness. And with that I will turn it over to my colleague.

>> Charlotte: Hi, this is Charlotte Ruder, and this topic is near and dear to our heart, and we obviously have been working on for quite a few years. The number of states that were involved in our research study, because I will be talking about demographics, the testing that we did and the outcomes, and so we had 27 states in the District of Columbus that had children who were evaluated by our evaluators. These were people, speech-language pathologist like myself, or specialist in deaf-blindness like Susan from around the country and part of the deaf-blind projects who gave a battery of assessments to the children that were in the study.

The state of Ohio Children's Hospital, we had, for example, 10% of the population, but they -- the children came from all over the country, and there were various individuals who were trained to use the test assessment battery and we compiled data over a period of time so some of the children had multiple assessments. I had show that slide in a minute, but it was a longitudinal study, both parts of A and B, and here is our participant assessment data. You will see that we have 109 total children that were enrolled in the study that we have assessment data on. Looking at the post cochlear implant only, these are the 69 children that we have only post data on and how many assessments we have. Then we had group of pre-post children. There were 23 of those and so we have data before they were implanted and longitudinal data after implantation, so that slide will be really telling when I get to it, and also 17 children that enrolled in the study initially, but for whatever reason did not receive a cochlear implant, so leads to our total of 109 children and as Susan mentioned earlier, a significant number of our children, 24, but when we finished the study were bilaterally implanted. The etiology of the deaf-blindness are many. We have the largest portion of our population, which is kind of surprising -- was surprising to us. Almost 30% of the population of 109 children were children with CHARGE, which is a multiple -- multiple complex syndrome that leads to multiple complex children, and won't go specifically into the CHARGE results today, but this group did benefit from the implant. Complications of prematurity, infections such as CMV, meningitis and encephalitis and we had a number of children that were other and about 12% of the children were no etiology was reported on our demographic form and sometimes we don't know the etiologies. As you know working with children with implants, we don't know what the cause of hearing loss is. This is also true for children with deaf-blindness. As Susan alluded to, deaf-blindness does not mean totally deaf -- I mean totally blind. So looking at our percentages, we had 28% that were -- that qualifies on the basis of the legal definition of blindness. Some children with low vision, some with cortical vision impairment which can improve over time. Variations of visual feel, meaning some parts of the visual feel were not functional. The total blindness, which was only 7.3% of the children and then similar group of children that had light perception only and few children that had progressive vision loss as we know children with progressive hearing loss. Susan also alluded to 42% of children with deaf-blindness have additional disabilities and this is the breakdown for the children in our study, so we had children with many complex health needs. Physical disabilities, children who have difficulty keeping implants in their heads because of problems with wheelchairs and so on, children with cognitive disabilities and then children with autism and other behavioral issues. We had more males than females, which is typical of the disabled popular children with multiple issues, children with issues, period. The breakdown on ethnicity is in front of you and, of course, the larger portion was Caucasian and some not reported. The age of implantation ranged from just under 12 months of age to 84 months of age or seven years and 1 month. A few children were implanted before 12 months. I think three were six months, eight months, ten months and then three and 11 months and then remainder of 15.3% were children who were at 12 months of age. The major -- major portion were children between three months and three months of age and older children implanted and I will share all of those results with you. Looking at population and their time in sound, younger children, pre-post children I will talk to you about in a moment that had a limited amount of time and sound. As minimal as three months before they were ending at their last assessment for post testing because the study ended. So we have a lot of variability in the range of time and sound as well as age as well as vision impairment. Hearing loss seems to be the most consistent variable, they were severe to profound. Susan talked about there were two consecutive longitudinal studies, and we are reporting on the total of the 109. The first grant was over a couple of years, and we looked at just assessment, assessing children 12 months to 13 years of age at various times during that study's three-year period, and at the extension we had -- we only tested children up to eight years of age, and we look more at children who were pre-implant preparing to receive an implant, and then testing -- following them post-implant. The study A question what effect does age at implant and hearing age have on child outcomes? We used battery of assessments that were individually administered by the group of individuals in those 27 states in the District of Columbus and we also then concluded with the third portion of the study which is more recent where we looked at treatment. So we are reporting today on the assessment results of last assessment of children of three portions of the study and grants one and two. The assessment instrument we used were communication symbolic, behavior language skills, only use the caregiver questionnaire. For our language assessment we used Reynell-Zinkin For Visually Handicapped Children, used MacArthur-Bates Communication Developmental Scales and we use both the words and gestures and the words and sentences portions -- I mean scales. We used the Infant-Toddler Meaningful Auditory Integration Scale and speech intelligibility rating measure that was used on older children that had more extensive complex language. This is -- the Reynell-Zinkin has two parts, and this instrument was developed in England -- or -- yes, in England for children with blindness, so we adapted this for children who were deaf-blind. It consists of two parts, receptive language portion and the expressive language portion. The receptive language portion starts with detection to understanding words and phrases to word identification to following simple directions and then lastly following more complex longer directions. On the expressive side the Reynell-Zinkin looks at vocalizations as subset and words, expressive jargon, so we are looking at what kinds of sounds, what combination of consonant vowels, production of simple sentences and more complex portion of the expressive language measure that looks at complex sentences, so we are looking primarily at grammatical structure here, past tense, future tense, longer and more complex sentences. The research findings I will share with you now. So the general findings were kind of surprising to us. There, of course, was grade variability and outcomes of children who are deaf-blind with cochlear implants and that was not surprising to us, but the data was -- did not support our assumption that severity of any disabilities -- additional disabilities and degree of vision impairment did not seem to be predictive of who was going to make progress with their cochlear implants. This was very surprising because we thought it would be along the lines kids with more severe -- more disabilities and more visual impairment would be performed more poorly. But the Reynell-Zinkin with participants at the last session of those that were 92 showed that age of implant was not a significant variable but duration of the implant was a significant variable for expressive language and the longer you had the implant the better your language outcomes were. This was also significant. And developmental english age or cognitive ability also was our most significant variable. If we look at the pre-post data and I will show you some really nice slides in a second. Look at the change data for both receptive and expressive language skills for children who were tested before implantation and following implantation was very significant. Summary the findings are that there's a relationship with receptive language outcomes. There's a weak relationship at age of implant, so if you get an implant and you're older and you have deaf-blindness, there's a slight relationship, but it is not a strong significant one, but what was significant -- what showed a significant correlation was time and sound. How much time you had with the implant. The age at assessment, so how long you're implanted, time and sound and how much opportunity you had to learn language, your developmental level was also significant correlation as I mentioned. So the conclusion is receptive language does improve significantly from pre to post implant and overtime post implant with cochlear implants in children who experience deaf-blindness. This is just -- was just really heartening to go through this and to find that these children do benefit from cochlear implants. Okay. On the expressive side there's a relationship with expressive language outcomes. There was no again relationship with age and implant but correlation with time and sound, age at last assessment and developmental level, and we can conclude expressive level does improve significantly from pre to post implant and post-implant for some but not all the children in the study and just thinking, okay, this is really contrary to what we know about children who receive implants. The younger children implanted around 12 months of age do better than those at two and three and so on, but if you consider if you are -- you have limitations in both your vision and your hearing and that you improve one of those systems, your hearing, that you can make progress, even if you are not implanted at age one or age two or age three. These are the levels of -- average levels of rate of progress for our children -- for the 92 children so this being at the last assessment. You can see that some children even made -- were able to produce complex sentences but again, we had variability in developmental skills. And on the expressive side, this is a summary of how these 92 children averaged as far as producing sound, using jargon, using single words, single sentences and complex sentences. This is the slide that shows how our population pre-post population in which we had 23 children that were tested before they were implanted. Some several times. And those -- and then several times post-implant -- post implantation so that you would see these children made nice gains in receptive language. This skill change and I mention the numbers previously, skill change was significant -- highly significant at the .001 level of confidence. Looking at the excessive side, we also see some nice gains this these children. Now, these -- the expressive skills were only -- were significant but at the .005 level of significance. So again, given these children were deaf and blind and acquired some hearing, yes, it takes lots of training and lots of adaptations and so on, and Susan will mention these shortly, but these kids did make nice progress with their cochlear implant. Again, most -- or some but not all. The pre-post group shows really nice progress, and some of these children were not implanted for very long. Now, Susan is going to talk to you about the family survey that she completed about children who had been implanted. Susan, take it away.

>> Susan: Thanks, CeeCee, I appreciate that. The last

major set of data that Charlotte and I wanted to share with you today before we tried to summarize this and we entertain the questions has to do with a survey we conducted with the families, parents, guardians of the children and our first grant study who had received a cochlear implant. It was actually initiated -- the survey was initiated in the fall of 2009. We finally wound this thing up early summer of 2010, I think. So the data are a couple of years old, and I will try to explain to you how the numbers might have morphed a little bit as we added more children to our study group. We provided the survey online or in paper copy. We let the families choose which way, which mode they wanted to respond to us. It was a relatively short survey. It consisted of 30 Likert scale item, five-point response, we will show you those several results in a few minutes, six multiple choice and two short answer questions that had to do with the identification of their child's level of vision loss and some other personal experience when they were seeking an implant. The result of which were most proud and I think that Linn's credibility to the kinds of things that Charlotte and I can share with you, achieved a 84.5 response rate to the survey, which was unbelievable. At the time it was distributed to the 60 folks who were enrolled at the time we did the survey, and as Charlotte was explaining to you, by the time we ended the second grant there were 109 kids and their families, but at the time we end -- time that we ended, it was 84.5% response rate from those 60 families, and as you see as we go through it, most all 60 families answered all questions. There are three questions that we are choosing to share results with you today that a couple of people didn't respond, so if you add the numbers, you will go 58, that's not 60, but we had a blank question, and because those parts of the survey were anonymous, we go back and pick them up, so I hope that makes sense. So that was consent of the survey? We wanted information about the decision to seek a cochlear implant for their child. As I mentioned identifying a child's level of vision loss because we had anticipated that would be a significant correlate of progress and it was not but we anticipated it would. We are glad we had the information because it didn't seem to make the difference. We asked about the pre-implants experiences, post-implant experiences, good, bad and ugly to tell you the truth. Asked information about wearing patterns, the kind of services their child received at school or private therapy and information about their child's outcomes with the implant. So here are a few of the items. As you can see, the response scale was five-point Likert from strongly agree, agree, neither, neutral middle category, disagree or strongly disagree. On this particular slide we had 60 responses to each of the questions. I think the thing that is in my opinion most significant on this slide is the first item. We asked parents to respond to whether or not they had noticed their child attending to common sounds in the home. Water running, filling up the bathtub, microwave, appliance, dogs barking, phones ringing, this kind of response to environmental sound, and as you can see, there are 44 of the families said oh, yes, they agreed or strongly agreed with the statement. This might be a good place to take a real quick aside and tell you that for many of the families through just anecdotal conversations with them, this was their ultimate goal for their child, whereas with kids that don't experience a lot of different disabilities and significant vision loss, many, many families will tell you their goal is for their child to understand spoken language and develop speech. With the participation of our participants, there were a fairly significant subgroup of the families who never held that out as a goal. Certainly if the child developed expressive speech, they would love it, they would be thrilled, they would take that result, of course, but that wasn't the expectation. We had several families report to us they just wanted their child to be able to be more aware of sounds in the environment from a safety standpoint to be able to hear traffic, lawn mowers, animals, different kinds of things or just to be able to attend to environmental sound to glean more enjoyment through the world through another sensory modality and indeed 44 of the 60 families agreed or strongly agreed with the statement. As you can see the responses were pretty strong that the children were responding to feelings expressed through vocal inflexion only, not words that I'll angry but that I am angry or I am upset that kids responded to those vocal inflexions to much greater extent than they did before. Since receiving implant the children entertaining themselves by listening to music, watching TV, playing video games. Again, pretty significant response. Far more than last. The last one is a little bit interesting. My child's overall behavior has improved since receiving the implant. Split just about half said yes, they agreed with that, but there's a hugely neutral portion, neutral group on that particular response. This next slide -- again, we randomly pulled -- it is not true. I shouldn't say randomly. We have selectively chosen some of the responses from the survey to share with you, the ones they thought were most significant. The first item that's highlighted on this slide is in Charlotte and my opinion exceptionally important. Progress during the first few months after their child received the implant seemed to be very slow. And you see that two-thirds the families agreed or strongly agreed with that statement. 40 out of 60 said yes, it seemed very slow. And this is consistent with the fact that kids with deaf-blindness and other disabilities, they need more response time. They tend to be much slower than other children in terms of responding because they have more to process, less -- fewer channels to access information and need more time. This will impact what we are going to share with you on the summary about auditory-verbal therapy, so please bear this in mind the family said progress seemed very slow. About 24 of the families said progress after the implant exceeded their expectations. Just over 20 said they agreed with that statement. We were pleased to see that more than 40, more than two-thirds of the family said that the process of getting an implant was no more intrusive in the family life than they expected to be, and these last two items on your screen right now are two of those questions that only 58 folks responded, and as I said, don't know why the numbers are correct. We didn't misadd, just we didn't get 60 responses to those two questions. Again, three more items we wanted to share with you. The first one is very, very interesting to us in light of what our dataset from direct observation showed us. The families 36 of the 60 families reported they were confident the child's school knew how to meet their child's needs for learning how to use the implant. Our findings, not data solicited from the families themselves agreed. Our findings showed almost the opposite of this as we talked to folks in the school and in clinics people were saying they honestly didn't know what to do to most effectively reach kids with deaf-blindness who had received an implant, so that is a very interesting point of discussion. Small numbers of families worried child might not be receiving support services he or she needed. Last one is interesting because you will say I will contradict that in five minutes and I will try to plain. The families at this point, 42 of the 60 families reported they agreed or agreed -- pardon me. I apologize. Agreed or strongly agreed that after the child's implant was aggravated the family received direct training to teach them how to help their child learn to use the implant. And this was the final summative question that we think speaks to all of us who are interested in therapy and helping learners with deaf-blindness develop effective communication skills. The families were asked if they knew what they know now tet they were deciding whether to proceed with implantation with their child would they make the same decision again, and 48 -- here it is 48 out of 58 families said yes they absolutely would make the same decision. 32 out of 58 said they strongly agreed with that statement, and three are neutral, so only seven the families weren't sure they would make the decision, and we think that's very, very important. So what do we think we have learned in terms of general adaptations for learners that have deaf-blindness and receive cochlear implants? It is essential to remember as we said child's response time is generally slower. Perhaps the child will need as much as 20 seconds more or 30 seconds more than typically developing child or child who experiences only hearing loss will need. And as we all know when we are waiting for something, and I think commuters teach us impatience, if something doesn't happen in two or three seconds it seems like eternity and waiting for the child to respond 30 seconds is quite a long time, but many of our kiddos needed that much time. It is very critical to present information consistently to kids with deaf-blindness. Waiting consistent with the first point that if their response time is slower, we need to wait. We need to wait for reactions that indicate understanding our at times wait for reactions that will indicate at least that the child perceived or received a stimulus. Folks that work with learners with deaf-blindness learn to develop keen observation skills. They need to be great observers, whether it be practitioners, family members, anybody interacting with the children. The first point on this particular slide each and every one of you could state Charlotte and I know we are not sharing a new discovery with you that if kids are going to make progress, they must wear their implants. We encountered several families that say they give them a break after at school all day long and take off the implants. Yikes. If kids are going to make optimal progress, they need to wear the implant all the time. With some of the kids in the study, this was exceptionally tricky because as Charlotte noted some of the children have physical challenges, they will go into extension motor patterns, they will go into various ADNR reflex patterns and if equipped with equipment it will knock things off and other children it is a behavior issue and they throw it off and protest and it is going to be a challenge but wearing time is very important. The last three points on the slide have to do with what Charlotte and I will call our modified auditory sandwich. We hope this doesn't oven anybody because we are using that term auditory sandwich and changing it a little bit to suit our purposes with kids with deaf-blindness, and that's the notion, of course, that you have speech but in the middle might provide tactile support, kinesthetic stimuli, visual support, might provide visual and tactile support. Whatever that child needs, and that's going to be dependent on his or her own profile of vision disability and then again to close the sandwich with spoken language again after the other modality cues are provided. The limitations what we believe as we have examined our entire database from the two research studies, limitations to progress that children made as we said as we began this webinar, many of our participants did not demonstrate prelinguistic communication skills at first assessment. Many of them did not demonstrate strong prelinguistic skills at final assessment, and those children showed slower progress. Again, to just reiterate that could be pretend play, vocalization, but in particular gestural use. Many participants did not have skills of functional object use as I just tried to explain some of the kids did not wear their implants consistently. Some of the participants did not have their implants mapped frequently and possibly accurately. Charlotte has stories from the audiologist with whom she works at Cincinnati Children's who's just an artful mapper if I may say it that way, and he has helped us all appreciate how very challenging it is to map correctly an implant for a learner with deaf-blindness, and as -- we talk about for a minute or two right now, the auditory-verbal therapy programming provided for the kids in study post-implant were not individualized, and in fact, many of our participants were dropped from those programs due to, quote, lack of progress. And this is one point that really is of great concern to both Charlotte and me and we hope that it is something that might give you pause for reflection. If you remember what Charlotte shared with you about our research findings, statistically significant research findings, post-implant even over time the kids continued to show more and more progress the older they got and more time they got to have to access input have the world and speech and language from other people, and their progress is typically slower, and if they didn't show accelerated progress like many of the AV therapist, at least in our areas where we were working, they have come to expect very -- pretty rapid progress from the participants who are enrolled, and kids with deaf-blindness aren't going to be able to keep pace and they were dropped. Families reported not being taught effective strategies that could be used at home, and I hope you're going wait a minute, wait a minute, wait a minute. That doesn't match, Susan, what you told us from the family survey on slide 45, and that is true. That is something that changed. Remember, the family survey was conducted with first 60 families. As we have increased the number in our sample, our participant sample up to 109, we are getting more reports from families to say they weren't taught effective strategies that could be used at home to help their children learn to use their implants. Optimal outcomes, we are guessing -- Charlotte and I are guessing you guys could write these yourselves. Wearing the implant during all waking hours, having their implant map frequently, being positioned for maximum access and monitoring, and that is really more unique to the population and learners that experienced deaf-blindness. Their bodies, especially if they have physical challenges, need to be supported, need adapted equipment so they are not fatiguing themselves just by trying to hold their trunk in place or hold their heads up because of their vision loss to have low glare, high contrast in the room, so they are not fatiguing themselves trying to protect their vision or use their vision, and I might say what does that have anything to do with using a cochlear implant effectively, but it does if the energy that a child must channel to try to keep vision in focus and not be obstructed by glare or lack of contrast or they have to work so dang hard to hold their bodies in place, it does detract from the energy that they're able to channel to learn to use their implants. So it really is important. And then to consistently receive communication services for years following implant activation. Real quick story since we are doing okay on time. The young man from our study, he was standing in the doorway on the slide which we opened the presentation, I was very fortunate to be able to be present on the very first day. I was doing assessment with him in his school, and I hand to be there on the very first day that his family or his teacher noticed him responding to his spoken name, and his momma has said that I may share the story with you. His name is Lance, and he was walking down the hallway, and he experiences CHARGE syndrome, as you might have been able to tell from the photo, and he was walking down the hallway with his back to his teacher and me, and the teacher called out to him fairly loudly, Lance, stop. He stopped but that's not the -- that could have been coincidental, and he turned around, looked over his shoulder, looked back at the teacher and me, and that was the first time he had ever responded to his spoken name that anyone observed, and here is the kicker. It was more than six years after he had received his implant. That was the first time, so kids need as much as, kid needs support for a very, very long time. Granted, he had significant vision loss, lots of physical problems, lots of health problems, lots of cognitive issues, six years later he responded to his name for the first time. As a group as Charlotte very clearly explained, our kids with deaf-blindness did show significant receptive and expressive language benefits from cochlear implants. Their individual results varied, but they really did significantly achieve important life outcomes, important communication outcomes, so it is very important. I think the results suggest the need for agencies and service providers to entertain the idea of implanting kids with deaf-blindness to be more knowledgeable regarding proactive strategies for meeting the needs with kids with deaf-blindness and other disabilities that receive implants and embrace them with open arms. Simply getting an implant doesn't guarantee increased communication or increase participation. So we have to systematically teach families, teach service providers, speech-language pathologist, with service providers to teach children how to learn to use the implant, and as Cathy mentioned when she introduced the webinar, Charlotte and I will be another presentation in January where we will be sharing with you results of a sub-study from these grants where we went into families' homes and tried to teach strategies to parents for working with their children to learn to use their cochlear implants. So if this has been interesting or helpful, please consider joining us then. I think that concludes our prepared remarks. Charlotte, if you want to join us, Melissa, Cathy, if we have questions.

>> Cathy: Excellent, thank you. Thank you, Susan, and thank you, Charlotte. That was -- that was a wonderful presentation, and we have a few minutes remaining now for questions. So I'm going to refer to the very last couple slides that are in the handout while questions are being typed in for both Charlotte and Susan. As Susan mentioned, on January 15th as the next in the series on this topic, and you can register for that presentation at cochlear.com within the hope web page. You will also find another event that we have scheduled for Monday, December 10th at 3:00 p.m. eastern with Jane Madell and Carol Flexor, managing the complexity of acoustic accessibility. Today's presentation is approved for continuing education credit, and you can find all of that the information at the

Audiology Online website. If you would like a certificate of participation from today complete the feedback form and send to hope@cochlear.com or hopefeedback@cochlear.com. Now we have a couple minutes still for questions. I'm going to mute my microphone and see if there are questions that are typed in, and we will come back online. Susan and Charlotte, I have one question and that is what are your thoughts on why some of the children in the study improved but not all children improved significantly with their expressive language pre-implant to post-implant.

>> Charlotte: One of the reasons I alluded to is some of the children in the study were not implanted for very long when the study ended, so some of the data is over young children that were in the process of acquiring language. We had a significant range of cognitive skills if you recall back to the one slide, so I believe that some of that had to do with some differences in who learned and who didn't and some of the things Susan just alluded to, some of the children did not receive, the parents were not trained, the children were not wearing the implants consistently and one of the -- one of the parts of -- third part of the study went into the schools after and completed the training with the families and I was told by the school quite frankly that was not a priority for them to have that child wear the implant, and they estimated it was on the child for maybe 25% of the

time. So it was all of those variables that I think Susan discussed that led to some children not making progress, although many of our children and referred to many of them significant, many did make progress. Susan, do you have something to add to that?

>> Susan: One moment.

>> Cathy: I think Susan is trying to come back online. Susan, are you still there? Unfortunately Susan is still with us but her microphone won't un-mute. We are at the top of the hour. I appreciate the response to the question, Charlotte, and I look forward to the next presentation on January 15th where we can explore this topic more closely.

>> Susan: Can you hear me now? One important quick point. I think one other additional thing to what Charlotte said was it is very difficult to find instruments that are appropriate for kids with multiple disabilities and vision and hearing loss, and I don't think our expressive language assessment instrument was sensitive as it might have been to those earliest achievements in terms of expressive language, particularly what we have talked about with prelinguistic skills. I'm not sure that if there had been some child change the assessment instruments were sufficiently sensitive to capture those. That was all I have been trying to type. I'm sorry.

>> Cathy: That's excellent. Just as a lead off of that, is there a plan then for additional studies or investigation

into what other types of instruments might be more sensitive?

>> Susan: I think where we are right now, Charlotte chime in here, those of us that worked on the grants are incredibly invested and not letting the research line drop, but we both have other jobs and as you can tell from, you know, Charlotte explained, we had to work across 27 states, and we had to either travel a lot on our own or solicit help from other people, so we had to re-compensate them in some way, and without additional funding, we just can't pick it back up right now. We want to. We have talked about writing for more grant funding. I think we hope to do that, but at this point there's nothing that's right on the horizon. Charlotte, anything else?

>> Cathy: This was an amazing undertaking. Thank you for sharing the results and coming back on January 15th. I noticed a few people raised their hands are in the audience, and although we are at the top of the hour, I want to remind you, if you have a question, you can type it into the Q-and-A box, the very small field at the bottom next to the balloon and that will send the question out to us so that we can see what your question is. In any case, thank you Susan and Charlotte for joining us today. This was an excellent presentation. As I said before, I'm looking forward to January 15th, and as long as no other questions come

in, I'm going to go ahead and close the session. Thank you all for joining us today, and remember Hope Online and all resources are available at cochlear.com. Thank you.