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>> Good evening, everyone. For those of you who do not know me, I'm David Wolfe, the president of the foundation. Welcome to our webinar on Issues with Pain in CHARGE. This is our first foundation webinar. We were thrilled with the response to this webinar. For future webinars, we will continue to get the first opportunity to sign up to members. I hope that if you enjoy this webinar, and I'm sure you will, and you want to see the foundation continue to do these types of webinars, that you'll join us and become members. You can easily go to the website, and then join. Before we begin the seminar, a couple quick thank you to. First two Randy Klumph, without Randy, without NCDDB we wouldn't have been able to pull this off. Special thanks to Lori Swanson and Kathy McHulty, the -- the cochairs of our education committee. Thank you for reporting this together. They've told me I'm supposed to talk a little bit about the chat box. Everything seems to be fine on that. And so we should be good to go. Everyone seems to be working it without a problem, judging from the corner there on the screen. For those of you who don't know how to work it, go ahead and any time you have questions, type in there. It's being monitored throughout the presentation. Tim and Kasee will leave time at the end of the presentation to answer questions.

>> With that I want to introduce our two speakers. First of all, a man who needs very little introduction, Tim Hartshorne. Tim has been a friend of the foundation since the very beginning in 1993. He's been a regular presenter at our conferences. He is a professor of psychology at Central Michigan University and a grant holder for the Michigan State deaf blind project. Tim has a particular interest in understanding the challenging behavior exhibited by many individuals with CHARGE syndrome. He is an author on CHARGE, a researcher on CHARGE and a father of a wonderful young adult CHARGE. Our next presenter will be Kasee Stratton. She is completing her pre-doctoral internship in the pediatric development disorder disability climate at the Kennedy Krieger Institute. For those of you who don't know, that's the other John Hawkins at University school of medicine -- medicine. Many of you may recognize her from her very well received presentation at our 2011 CHARGE conference. She has been researching CHARGE pain and challenging behaviors for more than six years. She's the pride -- and has created a CHARGE nonvocal pain assessment. With these two wonderful presenters I'm going to turn it right over to them. Tim? Take it away.

>> Thank you very much, David. I add my thanks to the foundation for putting this webinar together. I'm honored to be able to participate. Thank you very, very much for both Kasee and I being invited to this. For the structure for this evening, I will begin and talk generally about the problems -- I'm getting echo here -- I hope that's not everywhere. Anyway, talked generally about where pain improves in CHARGE, and why pain and behavior may be related. And then Kasee is going to take it over and talk about her

research, specifically on development of the measure of pain in CHARGE, and then of course, if you're typing your questions down below come those will be monitored and we'll try to answer questions towards the end.

>> This is Randy. I hate to interrupt your flow at the moment. Could you start your WebCam?

>> How do you want it?

>> Can you -- up in the left corner, click start my WebCam.

>> Sorry.

>> There we go.

>> Is that better?

>> Perfect. And feel free to interrupt again if I screw up here.

>> So we'll begin with pain and behavior. The reason Kasee and I got interested in pain was because having looked at the issues related to behavior over the years, trying to understand the unique challenging behavior that individuals with CHARGE demonstrate, we were impressed with how often the pain may well be related to that. Seeing the ability to identify pain was really significant as a first response to challenging behavior.

>> I've told this story before and many of you have heard it, but it really influenced me a great deal. When Jacob -- when Jacob stop sleeping, it was a gradual process. He took a couple hours to fall a sleep at night and then more hours to fall as the night. I know many of you are familiar with the problem of trying to set up with a kid and how that works for you. Nancy to Jacob to the doctor, nothing wrong with them, the wax in the here. Jacob didn't sleep at all the next night, and we got very concerned, call Dr. back. He said let's try some psychotropic medication to help him through whatever he's going through. I said no, this is not a problem of psychotropic medication. This is not a problem of emotional impairment, this is challenging behavior because of something wrong. And we need to know what's wrong. Dr. discovered the wax in the year was not wax, there was a foreign object embedded in eardrum, it was rubbing against his eardrum when he moved. We had went to the emergency room and had that pulled out, it was badly infected. Once it was out, he went right to sleep. This is the issue that I think we are confronted with is very difficult with some of our children to know when they're in pain, and many children who are able to communicate don't let us know. So that's kind of the focus of tonight's discussion.

>> There may be many, many sources of pain related to CHARGE as you think about that. Think about all the surgeries that individuals with CHARGE may undergo. My first study about a quarter of the participants said their child -- more than 12 surgeries had. I know in of the research I've done that people can have as many as 30, 35 surgeries over a number of years. Our kids know about surgery. I know Jacob when we go to the hospital gets very, very hurt nervous even if it's not for surgery. He's familiar with where we are and what might be up in front of him in surgery. Rarely does not involve

pain. There may be paying more after the surgery, but there's a lot of pain involved. Many procedures that are kids undergo is well. Many trips to the doctor, where they may be poked and prodded and injected. Jacob gets shots now, lots of reasons why our experienced -- kids experienced discomfort. And then more one of my CHARGE related pain, pain kids have because of some of these problems are significant in CHARGE.

>> I'll start with your infections. We know that many children get your infections but they tend to outgrow them. However, individuals with CHARGE typically do not outgrow them. I don't know if you've got your your infections. I suffered from them when I was a child which is why we are hearing aids today. I can recall and I have -- occasionally we'll still get one. Very, very painful things. Very hard to endure, very sharp, continuous pain that doesn't fade right in eardrum. Why do kids with CHARGE gets so many ear infections? Due to the ear anomalies we have, including the small eustachian tubes and also [Indiscernible -- poor audio] rather than draining back into the back of the throat, hold liquid inside of them and cause -- causes the build up and you get your infections. Your infections can be treated but they have to be identified that they have an ear infection. Sometimes our kids don't let us know that the year hurts, although speaking of behavior, Jacob will often take a sharp object, any kind of poise he has that has edges on it, stick it into his neck and ranch his neck against it. That's generally a pretty good indication that Jacob is in pain with an ear infection.

>> Migraines, I've been thinking a lot about headaches recently and how they are very common in CHARGE, although we don't really know. I'm thinking this is an area someone should be doing researchon.. Although sometimes it's hard for people to describe when they have a headache. How do you demonstrate nonverbally that your head hurts? Migraines of course are very, very painful. I get one every 10 years about. I know [Indiscernible -- poor audio] in terms of why kids with CHARGE might get migraines, we really don't know. We have thought about the TMJ headaches that people get through the trigeminal nerve , cranial nerve V, when Kim Blake and I did our review of cranial nerve manifestations in CHARGE syndrome, she had asked to try to indicate when individuals with CHARGE might have problems with cranial nerves. The trigeminal nerve brings sensation all around the face, especially the jaw. That's why when you click your jaw, the jaw is mal- aligned, you can get the TMJ headaches. They can also [Indiscernible -- poor audio] so that's really the sinus pain, the palette which we know can be a problem. The lips, it also seems to have a role with chewing and swallowing. And with the different cranial nerve, a couple of doses, you can add on the chewing, or dating the chewing with the swallowing. That seems to be cranial nerve five. And because that's a problem with kids with CHARGE, we wonder whether they might be experiencing TMJ headaches. Because the CN V nurse isn't working well anyway, it makes a certain amount of sense that they might get the TMJ headaches. That's treated by mouth appliances that people sleep with, which is very difficult for many kids to cooperate with. Could be a difficult thing to try to help with. I think we need a lot more work on seeing whether headaches are very common in CHARGE. If they are, we should be thinking about how we can help kids to let us know when they have a headache but also what we can do to help them through that.

>> Abdominal migraine is something I really hadn't heard about, so Kim Blake started talking about how she felt it was only common in CHARGE. Typically, the people get abdominal migraines, children ages 5 to 9 and there's no reason to think his with CHARGE would be exempt. We wonder whether kids with

CHARGE might be more susceptible. If you have abdominal migraines as a child, you're likely to have adult migraines in the head, when you are an adult. It really evidently feels very much like a migraine headache, except it's in the stomach area. It can last from 1 to 72 hours, 72 hours is a long time to supposed to -- suffer through something like this. Acute stomach pain with nausea, vomiting, light sensitivity, diarrhea, and loss of appetite. Those headache migraines are often accompanied by nodding, vomiting, loss of the and diarrhea. I never thought about eating with mine.

>> Fairly, this is something we did find out more about. When you see a kid who really is intensely in pain and holding their stomach, there can be so many things with CHARGE, one of the things we don't want to rule out is abdominal migraines.

>> The next one, gastroesophageal reflux disease, GERD. We know this is common in CHARGE, projectile vomit, especially in kids that are younger. Belching, coughing or wheezing, swallowing is often how it's diagnosed. Someone has to be able to say, I'm having trouble swallowing. Horrible heartburn -- pain in the chest, when you lie down but you're not feeling well or eating gets worse, more frequent or worse at night, GERD in general is worse at night, getting relieved by antacids. You can also be diagnosed with hoarseness or changes in voice. Not in vomiting, you wonder whether it is GERD or abdominal migraine, symptoms might be similar. Regurgitation of food, sore throat, [Indiscernible -- poor audio] vomiting blood, but that can happen.

>> I know Jacob has gas because you can smell it. I often go over to his house and it's clear he's been suffering from this. You can see -- you can hear him passing gas sometimes with -- the abdominal bloating you can see sometimes, because he's so thin. Abdominal pain, belching is associated with gas. Not everyone with gas experiences symptoms. If you've had a gas attack, how extremely painful that is. How much gas does the body produce? How much does it weigh down your fatty acids, how much absorbed and how sensitive you are to gas in the large intestine? There is sensitivity to it that my guess is that because of all our problems with swallowing and digestion in CHARGE, that our kids are experiencing a lot of gas. [Indiscernible -- poor audio] my wife and I -- because we can smell that Jacob is passing gas.

>> Constipation. We've all experienced [Indiscernible -- poor audio] it's not a very pleasant thing to go through. But the thing you really worry about is the fecal impaction. That happened to us with Jacob actually back in 1996, when we were over in Australia for the Australian conference. Jacob was there and while we were there, he stopped having bowel movements. We were using PediaSure with fiber, and I think we added Metamucil, made a disgusting mess but didn't really relieve the constipation. What happened was the colon got bigger and bigger and bigger. And then you have this impaction just doesn't move, you get liquid stuff that will pass around it and come out, but [Indiscernible -- poor audio] I know Jacob goes back and forth to school, we sent back and forth a book and one of the first things we check is if there was an owl movement that day. Were very concerned to make sure that he doesn't come here regular -- become irregular. Very effective over the years taking medication. But there is still always a concern because we know there's -- and one of those other painful experiences that does take a long time for the intestines come back down to its normal size. That's part of the problem is [Indiscernible -- poor audio] if you can't keep things moving through.

>> Muscle pain, I don't know if people talk about that much in CHARGE, but it occurs to me our kids would very likely have some problems with their muscles related to typically tension overuse or muscle injury. In the case of CHARGE, we know it for currently occur -- includes a hypotonia. Floppy muscles. Is there any possibility that we're doing that, you experience a certain amount of discomfort. Then we have underused muscles and overused muscles. I know Jacob's legs seem to be incredibly strong because he uses those a lot. To push against things. But his arms, not so much. So when you have muscles that pull against one another, one does not used -- what is not used commonly, the other is overused, you can experience a certain amount of pain. Not my area of expertise, I don't know a lot about muscles but I think it's something we should think about because of the way they do have the hypotonia.

>> Tactile defensiveness. We talked about our kids are tactfully -- tactily defensive, not just wanting not to be touched in certain places but there's actually a pain reaction. The pain can vary from individual to individual. And my guess is that a lot of us who do not have CHARGE syndrome do have some tactile the fences in certain places. I've noticed this with certain people having problems with foods. I know a person come of the idea of putting a cherry in her mouth was very disgusting because she couldn't stand it. The feel of something like a cherry in her mouth. Another person couldn't eat pizza because the texture didn't work. It can vary from person to person, what they experience. I've got a list here of a variety of things that may cause -- may be defensive about certain kinds of textures. We try to guess with Jacob what kind of textures you would like. Others he pushes away and will have nothing to do with them. He loves of vibrating stuffed what gets defensive about vibrations.

>> He refuses to wear shoes and socks. Just those want to do it. His house, his floors seem to be so cold and his feet start turning blue. Whoever's working within tries to put them back on. He will not keep them on. I suspect that's somewhat of a defensive issue. We've also experienced problems with our kids touching grass or sand and not being able to walk and those kinds of places barefoot. I know David Brown talked about a person he observed, just people walking by them in the classroom kind of wind blowing on them, that was trading some behavioral issues. We already are thinking about the [Indiscernible -- poor audio]

>> One other that I thought about because Jacob used to have -- and how difficult that stoma site is. We thought we were doing such a good job, clean it regularly, but over the years -- I don't want to say it ever got as bad as the slide on the right that you see, but within certain limits it wasn't so different from that. I got really the feeling as Jacob got older and we took out his -- when he was 14 -- the doctor said don't take it out and we took it out. He said, oh, it fell out. We could do it back in. We felt like this was really bothering him. Wouldn't have to surgically remove and fill up the whole -- back to the kidney or liver's or something. As he grew, the whole site shifted and cited -- shifted inside him. Not just from the side that the whole [Indiscernible -- poor audio] and of course in the same area where he has gas, abdominal migraines, GID, so it's hard for them to different surely detect what it is asked -- actually that's causing the pain in the stomach area, Astrid that so area. When you think about all these things. We need to be training our physicians to understand that all of these things can be related so we don't just get silly diagnoses.

>> I'm going to turn this over temporarily to Kasee to talk about the next slide, because this comes from research and maybe some indication of how often these things might be occurring.

>> I'll turn it over to Kasee. Get her picture up.

>> Okay. I believe -- good evening, everyone. Can you hear me okay I hope? Real quick, I just want to say, jump in on the slide here because this is actually based from the research that we did in our first study. To keep in mind that this [Indiscernible -- poor audio] CHARGE Syndrome. So the [Indiscernible -- multiple speakers] Can you start your WebCam please?

>> I thought it was started. There we start -- there we go.

>> Are we good? Perfect.

>> Good evening. Like I was mentioning, in the first three columns we have the intensity of pain, the mean, the average duration and then the range. The last column would have days -- days per year the child was in pain. These characteristics to just mentioned and the characteristics that US parents have also mentioned were indicative of pain. You notice the ones that are highlighted in red. Abdominal migraines, constipation, gastroesophageal reflux, breathing issues, hip and back pain, muscle pain and difficulty swallowing. Those all occur over 50 days a year to over 170 days a year. Gastroesophageal reflux, parents on average said their child had almost 170 days a year of issues related to that. Not only are these children experiencing pain, it's a very chronic issue we're seeing. You also look at the pain intensity column, if you notice the range, we had parents rate from 0 to 4, four being the highest pain intensity how painful that experience was for them. Also very high rating. If you look at some of the highest ones, migraine is something that many of you parents actually commented here in the chat box that your child didn't even know they had this experience. The abdominal migraines, constipation, all playing really high rolls down to the difficulty swallowing. This provides us some data to share with your physicians as well as these are chronic issues and they are, and across the large population of individuals with CHARGE. So with that being said, I'll turn his back over to Tim.

>>> All right. I'm back. Thanks, Kasee. Kasee will be back in just a little bit actually.

>> So does pain affect behavior? This is kind of critical to what we're trying to do and understand and use. There is some research, and actually the research has been increasing in recent years, which we're really happy to see, we did see, some ideas or evidence of pain associated behavior problem in typical children with early research about headbanging associated with your infections, I don't think I ever banged my head when I had an ear infection but I probably wanted to. Dr. tantrums along with upper respiratory infections. -- Temper tantrums. Behavior problems in children with disabilities. Some earlier studies here from the 90s, it's really picked up. That's very exciting. It's interesting, self injury and ear infections seem to be associated with behavior problems in children with disabilities. Number of sick days that the chick -- and their behaviors, the more sick days out, the worse behavior was. Constipation and difficulty of your. Allergies, difficult behavior. Then aggressive behavior, destructive behavior, self

injury along with pain, elevated pain related to elevated self injury. And then some suggestion from Olander and Simon, quality of life may be compromising people with disabilities due to the amount of pain they may be experiencing. For us it's just something we need to pay attention to.

>> Why would pain affect behavior? Again, the role of behavior -- painting in behavior isn't extremely well understood because it's a new area of research. Some studies -- show a decrease with medical intervention but others don't find a decrease in behavior with medical intervention, is it pain, is it not pain? Others have suggested maybe not just [Indiscernible -- poor audio] but how much pain. Not every illness that a person has getting medical intervention for has a great deal of pain. So you have a cold and if you're attending, but you may even take some cold medication but it may not be painful as having the flu or having a migraine headache. So it's not just the individual being sick, it's how much pain is involved along with that illness. Assessing pain is difficult with [Indiscernible -- poor audio] difficulties so that's one reason why the researchers are taking so long to begin. At one time, the literature actually people with disabilities really did experience a lot of pain so you really didn't have to worry about it. There were kids undergoing surgeries without anesthesia, 50, 60 years ago because they obviously don't experience much pain. We know that's not true. So my simple -- the error there, Payne leads to disequilibrium and feeling upset, which leads to problem behavior. -- pain. Think about when you're in pain, do you whine, complain, look at the cartoon -- he's complaining of chest pain, shortness of breath, cramps and dizziness. Do you sell earplugs? I'm perfect when I'm in pain, but I know a lot of people aren't. Seek attention, make demands, certainly act out, and I've heard that this was more husbands and wives because wives can't afford to do all that. We won't put up with it. But certainly I know I engage in some of those activities.

>> I want to spend a few minutes thinking about the self-regulation model. Some of you have heard me talking about self regulation. Know that this is something I'm thinking more and more about, its role in behavior. The basic model here, the Dunn Conceptual model looks more complex than it is. Basically the left column is the most important part . Really acts to -- different levels -- for some people, the level of whatever we're reacting to, let's say it's a sound can be very, very low level and still we notice it on the it bugs us. The noise of a fan in your room, just driving you crazy, somebody tapping a pencil behind you, -- there was a guy when I was trying to study once back in my Masters program was tapping his pencil in the library and I really want to shoot a guy. But I was good. I didn't. Very low-level on the continuum. On the other hand you may have a very high level which means it takes a lot for you to notice something. And so until the noise gets very loud, you really aren't paying attention to it. Maybe actually when one of our children's [Indiscernible -- poor audio] that's just a silly example. The middle column talks about if you have a low threshold to be very sensitive to the stimuli. If you have a very high threshold, you're going to have very poor registration, it's going to take a lot to get you to ask -- to act upon it . the third column, how an individual might respond to counteract the threshold. So it's very, very low, highly sensitive, what can I do to avoid sensation? I could have actually -- have you ever seen your kid crawl into a corner or under a table in a busy room, two seemingly try to get away from all the noise and activity going on around them? Very high threshold, you may respond to counteract by a lot of sensation seeking behavior, maybe running around the room knocking and people, you may be self stimulating very kind -- various kinds of ways. Trying to get your brain up and get yourself reacting to what's going

on around you. That's the basic model. Let me try -- this is new, it's not refined. The way I'm thinking about this in terms of pain, first of all, I don't want to talk about pain as having a high versus low threshold. I'm talking about pain as having a high versus low tolerance. I think this is an important distinction because threshold implies that certain people don't really experience pain because they have a high threshold, what I'm suggesting instead is that some people don't react to pain because they have a great deal of tolerance. So at certain times, we may have a very low level of tolerance for pain and be very, very sensitive to it. We know for example that in the evening, particularly at nighttime, Payne tends to be more intense in people and probably one of the main reasons for that is because we have fewer distractions. What do you do when you're very sensitive to pain at the moment? Click over to the right column, we engage in various kinds of pain avoidance, so I try to avoid the pain by distracting myself. I might watch TV, listen to music, I remember years ago with headaches I would put on Emerson Lake and Palmer's album of brain salad surgery. Something about the music in that thing that used to mask all the pain I was experiencing. That was kind of a weird behavior, and that's my point. Some of the weird behavior, unusual behavior we see in our kids may be to engage in pain avoidance, until they're very sensitive to pain, they may engage in some of the sets of compulsive behind the play -- that gives him focus. They may be running around the room because that helps them run away from the pain. They may be engaging in a lot of annoying kinds of behaviors and interaction with you to get some kind of interaction going, which helps them to avoid focusing in on the pain they're experiencing. I suspect Jacob, in putting sharp objects in his neck and wrenching his neck on it is getting a pain which is easier to deal with than the pain -- particularly sensitive to. At the other end with very high tolerance, why would a person have high tolerance to pain? I have gotten older and now I'm getting a lot older, I've noticed that certain things that would cause me pain a number of years ago are just nuisances, just annoying. Paper cuts that we get once in a while, when I was a child, certainly that kind of thing would have me crying and upset. Today, I barely notice it. It's like, why does that have to happen? I tolerate it and forget about it right away. It would take much more -- I'd have to cut my finger off in order to have that register in a way that I would acknowledge.

>> If you think about that and how often we may build up certain amount of pain, maybe you've got a need that's bothering you, maybe you've got a cut on your elbow and maybe you've got a mild headache coming on, all of that is not a big deal because we've learned to tolerate those kinds of things. So we ignore it. But you get one additional pain added on, and suddenly it all falls apart. I was reading part of an e-mail I got just last week I think it was, where a mother was actually responding -- she wanted to know what is we want her pain survey. I said probably not at this point. That research is done. She was very apologetic. What she said was, I was trying to find a time when my daughter was in pain. And then suddenly it hit me, this is what she said, now that I think about it, it seems likely she hasn't experienced pain for months and months and months we've been hurrying -- holding onto the survey materials waiting for pain. She's been suffering long-term with edema in legs and feet. Breakthrough Mr. Bleeding on and off for more than a month. And all kinds of issues with her fingers were she has chewed on the cuticles, picked at her skin, bit her nails to the quick, et cetera. She still buys her fingers, very hard indeed, in frustration. But if she has any kind of real injury, we have to be vigilant in order to prevent her from making it into a large wound. She had a spot on her outer thigh that she picked for a

year until we were able to get it healed. I feel sad regarding many of its is the pain she endured as a common and constant part of her life. She's such a trooper about it.

>> So she's showing either through her behaviors, the pain avoidance behaviors, maybe it made sense to some of the pain but she may all the -- also be showing high degree of tolerance because she's so used to having pain. I think many of our children especially through chronic pain, which Kasee will address, they developed a tolerance to this chronic pain because there's no point in coping with it. However, when you get that one additional pain added on and you lose at that point, all ability to control yourself, that's when I think some of the severe self injury is big -- injurious behavior will occur. Then there's the straw that breaks the camel back. I've got one more insult to my body, and I could no longer handle it. And now it's fighting, head banging, whatever it is, but I'm over that edge. It took me a long time to get there. Kasee and I really are concerned about describing pain in CHARGE has a high threshold, people just don't have a lot of pain -- because that -- they can cope with so much of it. We think about tolerance, we tolerate and tolerate until we can't tolerate anymore. That's when some of the more severe behavior occurs. Some of the minor difficult behavior, I think, I have to keep thinking through this model as we go forward but may be related to certain kinds of pain, maybe really a cute Payne, which can lead to -- acute pain which can lead to sticking sharp objects in your neck.

>> All behavior is to medication. Some of you have heard me say that for many years. Think about Jacob here. Not going to sleep, communicate in -- I'm not saying all behavior communication -- all behavior is intentional communication, but we need to learn to read our child or young adult behavior as what is it telling me? What is it communicating to me? If we're seeing changes in behavior, that's particularly important for us to pick up on, because that's -- that suggests something new is going on and again, I always begin by saying, let's check out Payne. -- pain. If we can rule out Payne -- pain something going on in the family, neighborhood, whatever it might be, let's roulette pain at the beginning -- rule out pain. That's when we're really in good shape moving forward.

>> At this point, I'm going to turn it on over to Casey, who will -- Kasee who will talk about her research. Kasee, get yourself on.

>> All right. I should be popping up. Good evening again. Real quick before I jump right into the presentation I also want to thank the foundation for holding this and for all the support everyone has provided to make this happen. It quickly became a large number of people, much more than we expected. The e-mails have been coming in all week from around the world saying, I can't get in. Can I still see the presentation? This goes to show that US parents keep telling us this is an area we need to look at and we're going to continue to look at that.

>> As Tim had mentioned, there are multiple sources of pain, and we also have the issue of not being able to identify it. So that was my research study, how do we identify this pain. Unfortunately for children with development of disabilities, this is a very new area of research. They haven't done a lot, because your kids feel pain differently, which we don't agree with. They express it differently, but we feel that they feel it just the same and really have to tolerate a lot of it. As we move forward, we look to how do we identify this pain and particularly non-vocally from a kid?

>> As Tim had mentioned, challenging behavior plays a role with pain too. I saw this on one of my favorite websites, one day this pain will make sense to. Man, wouldn't it be great if I could figure out this pain in CHARGE and it would make sense to me and then it would make sense to the parents. And then finally maybe a physician would believe you that your kid has pain because that seems to be another issue. Then I thought, maybe if we switch it and put challenging behavior, it will make sense to us. If we look at that behavior, we're more likely to see the pain coming through and we'll talk about that in a little bit more detail.

>> Why is it so difficult to measure pain in CHARGE? First of all, many of our children have many different communication strategies. If you go to the doctor, often enough they will tell you, I -- on a 0 to 10 scale, where is your pain at? I don't know if you're like me, but I'm ready to just hit them in the face at that point. My pain is here, I'm at the emergency room. That's why we're here. Could you fix it? I think that's the situation many children are in because their tolerance is so high at that point. Because most of our children can use vocal communication, that limits how well they can research this pain for children with developmental delays, partly for CHARGE, I have other concerns about how they find out and learn about pain. As we look at these social communicative justices -- there was an article where they talked about observational learning. If you know anything about child development, your children learn based on their interactions with the environment. If a toddler looks at another toddler, fall down, he starts crying and gets up and runs to his mom, he might learn, every time I fall down, I get up and run to my mom. If you think about the multi-sense impairment with CHARGE, that makes this challenging because they're not able to see those interactions. They're not able to hear those interactions, which makes what we learn about observations challenging for pain, because they're not actually observing anybody in pain. That's going to be much more an issue for our children who have more severe visual impairment. Also, this development, there's a social referencing deficit. This has been noted with children who are blind that you know when your child falls down and they look back at you, this is when my favorite things to observe with parents, the child falls down, they've hurt themselves, and they look back and it's whether you respond with fright or whether you respond calmly how they're going to respond. If we run over and panic, they more likely cry and let out a big wail. If you don't let that out, they're going to move on from what they've been doing. Your children aren't going to be able to have that referencing, particularly given vision and hearing impairments. This has been a great line of research for children with visceral and parents, they have been included across multisensory issues. Those are issues why showing that pain and the social cues that we look for is going to be a little bit different for individuals with CHARGE, which means, how the heck to become about measuring it when they're not learning it the same way?

>> As we move ahead, I quickly learned we were going to have to come up with our own in study and own investigational scale. There are two very well known [Indiscernible -- poor audio] not communicating -- not communicating pain checklist and the pain profile. Both of them are wonderful and have been a huge help. Unfortunately when we use them in the first study, think you two are parents who have participated in both of those and received my massive packet in the mail, when we used those skills in our first study we found that many of the behaviors didn't change across writings of no pain and ratings of pain. We found a difference because we were looking for the items, they were things that you figure

kids do all the time anyway. So we knew we had to eliminate those items because they were going to show us a new behaviors. In that study we also asked parents for their input, and that led to the creation of a we call the CHARGE nonvocal pain assessment. I'm sure many of you were able to download this from the website. If you weren't, e-mail to remind you about the webinar include a link on there so you can get that item. It's about 30 items that are all based on behaviors. We look at vocal behaviors, facial behaviors, we looked at challenging behaviors as we've noted is -- those increases in pain and we also looked at physiological changes. The sample items would be your child would be less active, there was an increase in OCD like symptoms when they were in pain. They guarded a part of their body more often than usual and grinding teeth was also an item in there. When we ran the study, what actually found a much more significant difference in the item between no pain and pain, showing that our scales really identify behaviors that are quite different from your child on a typical day. And then for about 40% of our sample we actually had physicians that were able to confirm a diagnosis of pain, which led us to have some real validity in our scale of pain, saying that the items parents are endorsing increase and that the physician is able to say, your kid has an ear infection, sinus infection. There was a surgery and this is what is producing the pain. For the remainder of our study, individuals who were higher functioning with vocabulary were able to vocalize their pain experience, so parents did the writing and then ask them about pain and they were able to say they were experiencing pain. Or they showed physiological symptoms like a fever or a bruise. And lastly, parents who are really cute into the pain experience who been involved for a while said, I just know when my kid is in pain. This is behavior that are typical for them, and that's how we knew pain was occurring.

>> As we look at this scale, I think some of the items that stood out was the dramatic difference, many you're describing, many of the be -- the behaviors that are challenging. We had parents rate on the CNVPA scale when they did or didn't express pain. There was a one-point difference between those showing these behaviors either increased or decreased. So children became less cheerful less sociable and responsive and less active when they were in pain. I've seen many of your children with CHARGE at multiple conferences, that's not a typical kid with CHARGE. Their social, they want to be there and cheerful and active. Those are dramatic difference is when they're in pain. Also, the aggression, as I was watching you guys [Indiscernible -- poor audio] at a lot of chat about self-interested behavior, pulling hair out, aggression towards you, those are things we noticed to have a really high increase in pain. For her brow, frustrating look, also a high number to be one of the first indicators that pain could be occurring. And then if we look at the next focus, they .9 difference between those two scales, children were reckless and agitated, engaged in specific behaviors to indicate their pain, they were less cooperative or they exhibited a change in color. First when I looked at this, I remember chatting and going, I'm going to have to cross the hall into Tim's office and tell him there was a change in eating, I don't know why that would occur. I look at my first study, gastroesophageal reflux, abdominal migraines, most chronic conditions. Of course there's going to be a change in eating. These are going to be are key factors in behaviors to queue us into pain out of those 30 items. I see the one point offenses are pretty high, and the challenging behaviors kick in there to indicate there's pain.

>> We also wanted to develop a skill that was useful for parents, and then hopefully we can expand the scale to be useful for teachers and for physicians or nurses following surgery. There's a whole lot of

research to be done, but certainly parents are our first primary target. So we asked parents, do you find the scale to be relevant to identify your child's pain? 85% of you said yes, which was fabulous. We were really excited by that number. Then I thought, I was really thinking it might be a little bit higher. Of those 15% who said they didn't find the scale relevant, the child could vocalize pain, they had a higher option vocabulary. They tolerated it for ways to identify pain on their own, so they have been cute into their child behavior. The one that concerns me is they never complained or tolerated -- which is a great example of the e-mail tinge just read to you. Certainly, I think that there identifying that pain on their own and finding ways to communicate it to you, we're just not that great -- not great at identifying that it yet. As we look ahead into the different ages that I use on the scale were going to see that that changes over time of what behaviors were most relevant. And so maybe what used to be a pain behavior is now transferring it something else.

>> We did find some changes on the scale with age and I would love to do another study where we can expand our population and include this. In our study we had birth up to 42 was the oldest individual who participated. And we had a good chunk of individuals based on age groups, so we split that up. Our youngest age was birth to age 5. And then the biggest differences were a change in eating, they became less active and a change in color. That's not very surprising because as parents, those are things we look for in toddlers who are not able to communicate that pain. That seems realistic to follow through with the same sense for CHARGE. As we look into our older age group, 26 years out and up, we noticed more facial changes. Their eyes would be more frustrated, more of that for a brow, there was more disturbed sleep, they were resisting being moved. They were [Indiscernible -- poor audio] actually, and that behavior I think the tolerance level had hit its peak and then we see more self injury. You're also talking a lot of time with chronic pain here. Were as far as teenagers, we noticed more -- and grinding teeth. This was one that surprised me because I feel many of the e-mails that come in from parents indicated their child is becoming aggressive and having Morse -- more self injury behavior in the early teens. We're not sure how those changes are occurring, but that's something we certainly want to spend more time looking at him a because our goal would be based on the age of the child, we could have a much more -- smaller scale than 30 items, maybe 10 items you could use, and that could be cute into page on that -- pin on the same page. With that in mind, all children with CHARGE are going to experience an exhibit that pain differently, so those are things that we have to keep in mind as we look ahead.

>> So what Tim had mentioned, challenging behavior plays a huge role. That's what got us started in this area to begin with. On a -- for working at Hopkins to completing my internship, my goal is to identify in every child I work with was nonvocal but the purpose of their behavior? Why are they behaving this way? How can I help parents deal with that? It's always interesting to me that our training always includes is its attention seeking? Do they want something from you that you're not giving them? For many children, we give them the most attention when they're doing something we don't want them to be doing. Rather than when their client -- quietly painting, we give them the least amount of attention and I think that changes daily we -- Piggly with CHARGE him of their need for attention is going to be almost a chronic issue, they constantly need that. Sometimes I go away from that when. The next when they train us to look at is access to preferred items or activities. Are they angry that you took away their favored position? Most of your children have that prize item. They want it back. Are they trying to

escape doing something? This is when all the e-mails coming from the teachers, I think we have a few of those in the group tonight. They're trying to escape a task, to challenging, I'm over stimulated, this is far too much. I think we see that a lot for children with CHARGE, the need to escape . And in the fourth when we look at as behavioral psychologists and individuals who work with children is stimulatory behaviors, very prevalent for children with CHARGE , that [Indiscernible -- poor audio] is happening jumping up and down, lying on the floor, hand slapping, those are all things that just help to fuel them, and David Brown will be giving some presentations on that as well. They're very worthwhile to the understanding. The last thing that no one ever considers is pain. It was always the first thing I big parents to think about. Date teachers and nurtured -- nurse at the hospital think about. Is there pain involved? Before we start considering any other reason for that pain. Or for that behavior because the function of that challenging behavior of that strange look on the face, the weird position they just place the body and, very likely pain related. Given for 170 days out of the year you have things like gastroesophageal reflux, migraine headaches, you have things like abdominal headaches. Those are all big behaviors that are chronic in nature and something we'd pay attention to. So speaking first about pain before we jump to all those other areas. I think that something as professionals we need to always consider that US parents the pick up on this a little bit faster. -- You as parents. Might be helpful to share with your classroom teachers.

>> As we move ahead and try to understand pain in CHARGE and know that we need much more research and would help to refine our scale and improve that with the larger population, I hope to see all of you in Arizona where we can make this happen at the next conference. We do need to consider what do children with CHARGE know about pain? Do they -- can they predict when it's going to stop? If you stop and think about when you have a really bad backache, you know that you can take your muscle relaxer and your pain meds and it's going to disappear soon. Many of our kids might not know that that medication is going to take about four hours and then kick in. They try to find ways to resolve that pain but can they predict when it will end? That might be another part of the problem with the challenging behaviors. Also the intensity of the experience is likely going to increase the intensity of the challenging behaviors. So I would bet that following a major surgery, your challenging behaviors aren't likely to be the first few days while still recovering on meds and hospital. It's going to be the next few days while the pain is much more intense, similar things with the chronic issues. Your infection and it wasn't until they adjust something in the year that you knew that. Obviously the intensity is really increased for them. Lastly, I believe we really need to teach specific coping strategies to identify pain and how to control that pain. This is something we're going to have to spend quite a bit of time dealing with for CHARGE, because everybody is going to experiencing that pain for me and that tactile defensiveness from children, what might be a coping strategy, one will not be a coping strategy for another. With some children it might be really great to hold on tight until they falsely. With other children they might not do those things with the pain. It's really going to be something at parents do with the child and how their communicating with them.

>> As we conclude here, as Tim had mentioned, all behavior is really communication. And it's not always to get your attention, it's not always to escape something. When you think about it, we really need to consider pain first. And with adaptive behaviors, we know our children are already behind on those day-

to-day activities, challenging communication, social skills are challenging and all of those things are going to help even more impact when there's pain involve. There's research to show that all of the adaptive behaviors drop, so if you think about your child -- they can tell you there in pain but then it dropped the adaptive level and ability to do that you may still need to look at the behaviors on the scale to help you identify the pain is really the issue. So with that being said, that's going to conclude Tim and my portion of the presentation, and I thank you so much for being in attendance. We're also going to open it up now for questions, which I believe they've been trying to follow along with your items so we can try to answer as many questions as possible with the time we have left.

>> Do we have anyone who moderated that portion?

>> Kasee, can you hear me now?

>> I certain they can.

>> This is Kathy McNulty, you're absolutely right. There's been great conversations going on in the chat ox with lots of questions. So with your permission, I will do my best to highlight those and to organize them in some way. Tim, I'm going to start with you. There was some questions early on -- I'm going to clump these together for you, around grinding teeth and, Kasee, I know you mentioned that as one of the indicators of pain. There were two or three questions of grinding teeth. How do you know when it's pain and how do you know when it is sensory seeking? If you could comment a little bit more about that

>> That's a really great question. The answer is -- I don't know, this is really good. -- Really tough. For me looking at the teeth grinding is -- I hear that from parents all the time, and not just the CHARGE of course I've had several other of my children that ground their teeth from time to time. So it's not that unusual a behavior. It's a very frustrating one and it's hard for parents to know what to do because a lot of the then full recommendations don't work terribly well with our kids because it includes -- but to know whether it's pain or not, I think a plug for [Indiscernible -- poor audio] is it a combination of behaviors, if the only behavior you're seeing is teeth grinding, my guess is that is probably not pain, although we would know for sure. I think that -- I had a friend, she worked with adult individuals with disabilities for many, many years, especially autism. This one-man that the whole institution -- where this guy was living was focused on his headbanging, which was really her and this and getting worse all the time. Every intervention they tried, had no impact on the rate of headbanging whatsoever. One day, they took all the people living at this institution to some free dental clinic and discovered he had very badly impacted, infected teeth. And once those teeth were fixed, and remove probably, the headbanging reduced. At this point in time, the headbanging was so well-established, it made it all together, you could reduce it some. So I think that it's worth -- worse with teeth grinding, all our kids need to have dental care. I know with Jacob it's so hard because the only way to have them tried other ways, is to put him under anesthesia, so he's asleep. We don't like to do that very often. We do get delays and -- he hasn't had any cavities, I believe. It's been like two years between cleaning. We do need to get the kids in there. Teeth grinding may just be a habit. Many children engage in it. It's one we would like to reduce, but it could be pain when I felt like other behaviors going along with it.

>> That's good advice. Question came up in the chat box about medication. Very often, the medication will work, but it can have side effects. I believe the person mentioned depacote, if I'm pronouncing it correctly. I guess there are side effects to that. So your thoughts on yes, it works, but the side effects are there and can you justify using it? I think that was the intent of the question.

>> First of all, let me say that I know the medication can be lifesaving for the parent and for the family and sometimes for the child as well. Sticking on the theme about behavior communication, if I'm behaving a certain way and that behavior I'm engaging in means something, not necessarily intentional again, but it still can be understood when that behavior occurs. We use medication to get rid of that behavior. What have you lost? You've lost a major way that the child has to communicate something. So rather than medicating it away, it makes more sense in general to try to find out what the source of the behavior is. The problem with that of course is that behavior is multiply caused. Tonight saying lookout for pain, pain, pain. That's not the only thing. Also behaviors are learned over time. So maybe the behavior develops when they are in for -- in first grade in school, and at that time, it meant some discomfort, but they've learned the behavior gets a lot of attention as well as a way of coping with the discomfort. And so ultimately, many different things sustained the behavior. If it gets worse and worse and worse, it quickly -- it could be possible that the medication could reduce that. We have a site not -- psychiatric diagnoses, autism, compulsive disorder, rats, people who know me -- Tourette's, people who know me know -- it sometimes leads to inappropriate intervention rather than what would be most effective with CHARGE. But until -- the way interventions are used with CHARGE, I would never take the position I've actually never used psychotropics. They will always, always have side effects. There's no medication you take that doesn't have side effects. Some can be worse than the behavior they're designed to address. Sometimes what happens is the parents go back to the psychiatrist and say, now they're behaving this way. The guy says, let's add a second psychotropic to try to control that. Then their behavior start getting shaky because that's often a side effect. Then they get another medication to stop the shakiness. Pretty soon they are on four or five different topics. -- Psychotropic. I would be very concerned about having in medication after medication, rather than trying to understand what the behavior is due to, what it's communicating and seeing if we can try one, it's low does and doesn't seem to be effective, take that off and try different one. I am very concerned about side effects.

>> Okay. Thank you.

>> Do you mind if I chime in real quick?

>> Absolutely, Kasee, there's an interesting conversation going on in the chat box. I was going to ask for you to respond to that. Go ahead.

>> Tim and I are very on the same page about how we feel with concerns about medication. Having worked in the pediatric facility for seven months, I have even more concerns about the large amount of drugs that the children are placed on to deal with behavior. With that in mind, if you are near somewhere where there's a development of clinic or a behavioral-based psychology department, I think that that would be a huge advantage to help you have an assessment to try to rule out some of those

more significant behaviors, especially if you are having high rates of self injury or aggression, those would be a really good resource to get involved with.

>> Now, in our little chat box, what was the latest question we had a concern about?

>> Kasee, I just wanted to share with everyone, because she responded to one of the participants, and I think it was around teaching coping strategies and getting information around some behaviors, and you had written that you would be able to help that person, and I just wanted for to know that if people weren't following along that that information is available.

>> Yes. And I believe Tim is going to be on the same page as me on that. Please feel free to e-mail us at anytime when you have questions or concerns to describe some of the behaviors you're experiencing. We're not there, so it's hard to really identify the exact behavior from a phone call but we can offer some good recommendations and where to go to get some of those resources.

>> We get e-mails all the time, and I really enjoy the e-mails, because it really helps me to think more through the issues as I try to figure out ways to respond to often very, very difficult questions. Do not ever hesitate to contact either one of us.

>> Great. Great. Lori, do you want to -- I'm going to keep looking at my notes. Did you have some questions that you would want to ask on behalf of the group to either Tim or Kasee Lori, you will have to hit star six to unmute yourself.

>> Okay. Now can you hear me?

>> Yes.

>> Okay. There was an interesting question by Laura. Ask, do any of your children eat quickly and swallow food without chewing much? There was a lot of discussion in the chat box about possible medications that might help the situation. Do you have any suggestions for Laura?

>> [Indiscernible -- poor audio] not mine. Kasee, do you have some experience with that?

>> I know that there is various clinics within this country, which is a huge downfall for our kids know should at Krieger, we have a wonderful feeding clinic that works with chewing and swallowing but many behavioral psychologists can also apply the same principles to assist with that. My concern is with CHARGE, there's so many other medical competition that play a role that you need to consider these things. I haven't heard from many parents in e-mails or at conferences about a fast chewing and swallowing kind of thing. I would say maybe it could be a sensory texture-based issue, it's just uncomfortable to be in the mouth. I have witnessed many children gored -- gorge their mouth full and then make attempts to swallow as if they could really feel it in their mouth. Those might be some things to consider. I guess I'm not very familiar with a fast eating -- being a common characteristic.

>> Thank you. Those are good suggestions. Another question that occurred early in the presentation is, why is constipation common in CHARGE?

>> Oh, my goodness. I can't answer that, except that the motility, the body's ability to move things along its system, seems to have been impacted, even one of the reasons for the aspiration pneumonia can be because of the liver cells and in the trachea -- supposed to move back up may not be fully functioning. We may have problems with sensory canals. It may just be in general that within CHARGE, the various physiological -- pathways we use for moving substances through our body may be impaired. Certainly from the swallowing down through the soft gage and through the intestines, things may not move as normally as they do as in other people. That's an issue that we've had a few chats about, but I haven't seen anybody really look at that. I don't know how you do look at it.

>> I think it's worth looking at. Kasee I was also thinking too, I know I've read some research, not CHARGE related specifically about poor muscle tone and how that may impact passing. I'm not sure if our hypotonic kids with CHARGE, if that makes a difference in the ability to pass through all the organs of the -- organs in the system. That may be something we have to do some more research on.

>> Thank you. There was another very interesting question asked by Jessica. She said, my son has a trach; does anyone else's child complained of throat pain from its? She says that when you look in the child's mouth, it's red and swollen. She was told by the doctor that this is common in children with CHARGE.

>> Oh, that's a new one for me. I can't imagine that having a trach would not involve pain. It's got to be uncomfortable. And I would guess because of dry throat that you would get some your Tatian back there. It's not something I have any particular expertise on. I think -- I'm not aware of the diagnosis about CHARGE, I'm not saying it's not true, I just don't know anything about that.

>> We have had e-mails on that Tim and I went over over the years that where kids pull out the trach; we've had concerns about pain being related to that. It sounds like it's a little too large, based on where it's heading -- I was trying to keep up with your quote, I believe it was Lori. I think that's something that maybe you need to see another specialist in the area, because I think it's -- a second opinion on that would be worthwhile.

>> Thank you. Cathy?

>> Yes. Tim and Kasee there, there is some chat in the box, just around touch and whether or not the children like it. One of the questions came. Is it common for children with CHARGE to dislike being hugged? Would either be respond to that?

>> I would tell you -- yes, absolutely. I think that the general sensitivity -- going back to the whole idea of self-regulation, when you're born come you've got all sorts of aspects of your system that need to be regulated, eating, sleeping, mood states. Then also just keeping a calm physiological -- physiological presence throughout your body and skin. I think that since the defensiveness -- which I would generalize a great deal in terms of ball door -- all of the body can make us uncomfortable to experience touch. It may come from kids being poked and prodded when their infants. They take a lot of fluids, hook them up to also to machines and tubes and things, and maybe that's part of it. I think it's also related to general self-regulation issues. I think it can be overcome. My experience tells me that kids with CHARGE

prefer firm pressure. Light touch is much harder for them. People have big bear hugs, some people with the tap on the shoulder, doesn't work for a well with a kid with CHARGE. When I go in and hugged Jacob and put his arm around me because I make him do it -- it's a very tight hug. He doesn't push me away. Heap which is other people way, but not his dad.

>> [Laughter] -- He pushes other people away, but not his dad.

>> You don't know what's coming at you if sensory impaired, you may be resistant to hug. The best way to overcome that is gradually increasing the amount of time that you are hugging somebody. Make sure it's firm. Kasee, do you have some other ideas?

>> I would agree with that, Tim.

>> Okay. The next question -- I can't remember exactly if there was a question per se, but there was some chat about the use of Botox. Can adjust be used one-time? Is it something that needs to be used more than once? I was just wondering if either of you would want to comment on Botox as part of a treatment.

>> Not for the parent.

>> -- Not for the parent, huh? [Laughter]

>> The person to comment on that is Tim Blake. She's used Botox -- in excess saliva. I don't know if she's had to repeat it or not. I can't recall. Conversations with her, whether that's something she's had to have several times or not. Kasee, do you recall?

>> I don't recall either. I think --contactingg Kim would be the best option. At the last conference, she was continuing one for studies in that, so there's may be more data we're not aware of.

>> Okay. Kasee, this question I have is for you. There was discussion during your presentation about just acknowledging that doctors and folks in the medical field don't always do it. They just don't understand a lot of what's going on. Someone wrote in and asked, is there an introduction letter from the CNVPA for the doctors, something saying, here it is, this is how you use it? Is there something like that available for the parents?

>> Sure. We haven't used the scale in a hospital-based setting yet, which is something we would like to expand on, because we want to first make sure that physicians are able to complete this. Like parents are because you know your child so well and that physicians sealed -- sees your child for such a small period of time. I will be writing a little bit to put in the CHARGE foundation newsletter that comes out, and that can gladly be shared. There will be a copy of the scale on that as well.

>> Great. Lori, did you have any other questions?

>> Well, Jessica wrote in and said that her son was reprimanded for hitting himself at school by the teacher. This upset her because she felt her son was communicating pain, and she said that this happens quite often, every year when her son has a new teacher. Do you have suggestions for Jessica?

>> It specifically happens with a new teacher?

>> Teachers don't get it. I think that's a --

>> Right.

>> So frustrating, and actually I usually start my presentation if I'm in charge, -- 101, David sent me about a teacher who's complaining about [Indiscernible -- poor audio] wouldn't pay attention, all these really negative characteristics. What we just basically no is typical of CHARGE. If you're just sensory impaired, trying to attend in the classroom, how long would you last? Not very long, I don't think. Hitting oneself in the head is something that's a behavior we see as CHARGE, something uncommon in CHARGE. Not because the kid is being bad or hating themselves, it's not going to change, because they're punished for it. Just looking for it. That's not going to change the behavior. They may not understand what the behavior is. I don't know how we reach teachers. I'll put in a shameless plug for the book, because the idea in writing the book CHARGE Syndrome, something you can take to doctors, maybe doctors can look at certain chapters and get a little education about what CHARGE is all about. It's so frustrating when they just won't listen to the parent and think that they know, this is a child misbehaving when it's not misbehavior as much as it is this communication.

>> And unfortunately, I think they're going to have to be the person who takes the reins on that. Each new teacher that comes in, you say, before school starts we need to sit down and have a conference about my child's behavior and about CHARGE Syndrome because they need to understand it. Unfortunately, it seems that the teacher doesn't see an academic file, that your child has CHARGE, and it typically doesn't happen. So unfortunate, you have to take the reins and teach them about that. There's a lot of great articles that are very near -- easy for teachers to comprehend. If you have a copy of this presentation, sharing it with them without even hearing this is enough for them to gain some additional information about the pain.

>> I want to have a little bit more to that. It's very unsettling -- very upsetting to me when children get blamed for behavior which is related to a condition that they have. It's also upsetting to me that parents get blamed for the child's behavior, which is related to the syndrome. I know many of us as parents, I'm included in this, people have said, Tim and Nancy must be doing something wrong with Jacob because he's sticking sharp object in his neck. That kind of thing is so unfair and takes us so far way from understanding what's going on inside the child that's leading to the kind of behavior they're experiencing. So I share your frustration, if there's anything I can do, I spoke to teachers, I'm happy to speak with teachers again to help them better understand what's going on here. And also have them watch the webinar.

>> Thank you very much. There was one other question about a teacher, I believe, who has a student that only uses two signs, manual signs. And unfortunately, this student is engaging in self abusive behavior. And the teacher wanted to know how you might protect the child to give her an outlet for her frustration.

>> Certainly, communication is likely exacerbating that behavior, because if I can only say that two things, that really makes that difficult. I would also look into a picture exchange system, because maybe signs is not the best mitigation tool for that child. It's really hard to give a recommendation on exactly what to do when that behavior occurs. We do need to look at the functions or behaviors that I have a slide on -- if the child is doing it and you're letting them escape doing work, of course I'm going to keep engaging in that behavior so I can get out of doing work. There might be other factors inside that. Maybe I just need a break and the work isn't that challenging, but I'm overstimulated and this has been too much. That can be a huge problem for kids with CHARGE. I think we need to know a little bit more about that and I'm hesitant to give a quick recommendation when we don't know what the purpose of that might be.

>> White right. We do want to look at the environment and the communicative environment in particular, because if you were sitting in a chair for long periods of time in a very boring environment, I'm not saying this teachers invited is boring, but if that were the case -- this teachers environment was boring, if this child has significant problems kicking in, this behavior is the result of that, we need to figure out what kind of environment best works with the child. We too often want to make the kid for the environment as opposed to getting the environment meeting the needs of the child.

>> If that behavior is impacting our academic progress, which it has to be at this point, we really need to have a behavior intervention plan at your school. And that you can request in writing, give it to the principal and say, you want a functional behavioral assessment in place, that will be added on to the -- that many of you already have.

>> Thank you. I'll hand it back to Cathy.

>> Tim and Kasee, I'm looking at the time and I think we were scheduled to go from 7 to 8:30, and we're already a little over. I'm wondering if Lori and I compile the questions that have not been asked and got them to you, if there would be some way that your answers or comments could be posted on the CHARGE listserv, would that be possible?

>> Certainly.

>> All right. Just as you were speaking, there was another run of really good conversation going on around coping strategies, a variety of new things. And we are running a little bit out of time. I see Ann is clarifying that situation about the teacher and the signs, so we'd need to get that both to you, Tim and Kasee so that the -- you could give her some more accurate information.

>> So, Lori, I think that probably is going to conclude our Q&A time for right now. But I just want to give assurances to everyone who has taken the time to write in their questions, Lori and I are going to do our very best to get them to Kasee and Tim, and if you would check on the listserv for that -- and also, I would take -- Tim and Kasee at their word, if you contact them directly in their e-mail, they will also assist you with that. Okay?

>> There's a question, where is the listserv? I'm going to send that back to David. David, if you could unmute and maybe help -- helpful with that, where the listserv is? Lisa, we will just put it in the chat box. There's a link there. Okay.

>> Lisa just put in, so I'm off the hook.

>> It -- yes, you are. Thank you, Lisa.

>> At this point in time, I have to thank Tim and Kasey -- Kasee. It was a fantastic webinar, it was our first one, and it's hard to believe that anyone is going to outdo these two, but I'm sure our next ones will give it their best shot. I would encourage all of you if you have comments, questions, ideas for additional webinars that you would like to see, please let me know. You can e-mail me directly, e-mail Sheri Sanger, our director of outreach. E-mail Tim and Kasee your questions. We all do our best to provide as much information as we can. I hope you will join us, and I look forward to seeing each and everyone of you in Arizona. Next year. So thanks again, Tim and Kasee. Fantastic.

>> Thank you.

>> Good job.

>> Good night, everyone.

>> Good night.

>> Good night. [event concluded]