

Please stand by for realtime captions.

>>There is an attendee whose number starts with 617 and ends in 29 and ends in 2920. If that is you, if you can use the number*and the sixth and mute your found. Your phone is not muted. I can't muted. Thank you so much. Great.

>> Someone is asking a question about connecting with the phone. I will let you do that. I will give a few reminders to everyone. Before we start the recording, I want to remind you that all of your phones are automatically or usually automatically muted. I want you to be mindful of that. I also want to remind you that this webinar is going to be archived and available online, so be mindful when you frame your questions in the chat box not to include names or too much personal information. Just a quick note about the questions, we will start with some of the questions that got sent in in advance. David will start with those. People can type questions in the chat box. I will be collecting them and we will get to as many of them as we can throughout the evening. Just a reminder, again, about the questions. David will take questions on a wide variety of topics that are more general education development in nature behavior questions like how can I stop my son from biting. That requires a lot of data gathering and reflection to provide any real useful information so we can't really fit those kind of behavior questions into the time or format this evening. So with that, Robin, we can go ahead and start the recording.

>> Hello. My name is Lee so we're -- Lisa Weir. I am the vice president of the CHARGE Syndrome Foundation. I want to welcome everyone to the webinar and thank you the donors for keeping this webinar running. I will take a few minutes to introduce our speaker for many of us needs no introduction. David Brown has been involved in the specialist field of deaf blind education since 1983 in the UK and the United States. He has done trainings and made presentations all over the world related to CHARGE and among the many recognitions he's received, he was awarded our stars in charge award from the CHARGE Syndrome Foundation in 2005 for his significant and long-standing work toward increasing the understanding, management, and treatment of CHARGE. He truly has dedicated so much of his time in life to making this world a better place for people with CHARGE. He spends most of its time to time circling the growth training others, he is extremely generous with his time with a variety of online CHARGE support groups and is known in many of those circles as the CHARGE guru. We are fortunate to have some time this evening to: his expertise it during this Q&A webinar. With that, I will welcome you, David, and hand things over to you.

>> Thank you very much, Lisa. Good evening, everyone. It is only 4:00 in the afternoon here, so I am aware that some of you have already had your dinner and maybe having problems staying tuned in for the next 90 minutes. I have to thank Lisa and the CHARGE Syndrome Foundation for inviting me to do this webinar. It's a new format for us. It is based on feedback from family members and they wanted webinars that were literally ask the S Burke -- expert structure. There was practically no structure and this will be a first in a whole series of this kind of webinar. I also have to think Robin Bull on the national Center on deaf blindness who last Thursday did a lot to calm down my anxieties about technology and she has done the same thing again today as we have been building up to this. I am very worried that my computer will crack up on my phone will go dead or something will go wrong. But I am relying on the fact that Robin is there and very competent to carry me through.

>> It's an interesting idea. This kind of webinar is very much an experiment, and I really hope it works. I'm particularly anxious that it is being recorded so I am mindful that people may be looking and listening to this webinar in a year or three years or five years time. I really hope that we can come up with some useful information. I wasn't totally comfortable with just being a talking head for 90 minutes. And because we had some questions, not a lot, but we had some questions that came in in advance, I put together a slide show to accompany my responses to those initial questions, and I will be doing that first. And then we will move on to questions that are coming in from you in the chat box as this webinar is proceeding.

>> CHARGE is a very complex [Indiscernible] and the more time passes the more complex it turns out to be. In 90 minutes there is a limit to how far anybody can cover things with any great useful outcome. Plus of course I am just one person, and you can [Indiscernible] deaf blindness you can line to teachers up like me and get two different opinions. You can put two different psychologist together and get different opinions, to pediatricians and get different opinions. So what you are getting is very much my views and my opinions. But also, what you are getting is a lot of stuff off the top of my head because the question has been asked and I can't say I will go away and think about that which is my normal response. Some of the things I say might not come out very clear because I am talking about complex ideas, that you are very free to ask for more clarification or ask me to go back and say more about something at some point.

>> Before I do begin with the questions, I want to talk a little bit about resources and literature. There is now a surprising amount of information available about CHARGE syndrome. When I go back 10 years there was much much less. What is available is increasing all the time, and I think if you are involved with someone with CHARGE it is good to know about these resources. The CHARGE Syndrome Foundation, who are hosting us tonight, of course, are the key organization and if you go to their website, there is a vast amount of information there. I have listed things like a professional packet the entire AJMG addition that came out in 2005 and was completely devoted to CHARGE syndrome. There is the ASHA video and the parent manual and all of the archives of CHARGE accounts and that is the newsletter of the foundation. There is a collection of webinars and also some links and there are other things there as well such as proceedings and presentations that were given at various conferences. Lisa, just for me that the CHARGE Syndrome Foundation website is being completely restructured this year and she suggested we watch this space in the summer. So it will be very interesting to see how they managed to reorganize all these materials because there is a lot there. Perkins School for the Blind in Massachusetts have lots of information on their website, but in particular, it has a collection of short webcasts about charge syndrome and there are various presenters and I am one of the presenters but there is a whole range of people being filmed giving these short talks and I think for a lot of people, especially professionals who may be involved with your child, it is often easier for them to watch a 10 or 15 minute video than it is for them to read the tour three-page article. And then there is the charge lab at Central Michigan University I will say more about that in a moment. The national Center for deaf blindness who are providing all the technical facilities and support for this webinar, if you go to their website, their library is vast and there is so much information there. This is on various aspects of deaf blindness including a whole section of charge syndrome which is growing all the time. Their library and is

very good at spotting anything about CHARGE that comes out and getting it in their library. The Texas school for the blind and visually impaired also has all sorts of interesting material on its website. My old agency. California deaf blind services has a lot of information including, I don't know, six or eight or 10 articles that have been written, many of which are about CHARGE syndrome. My previous former agency sends in the UK issued a charge information packet two years ago and it is quite large. It is downloadable free, so if you go to the sense UK website you will find that information packet. It's well organized and there is a hope don't host of different writers and contributors. There are four books available about CHARGE. One is from the USA and one is from the CHARGE Association of Australasia. That is Australia and New Zealand. And their art from Germany, what does one of which is only in German but one of which and it is a different book is all in English. And if you put those three English-language books together, it makes it very comprehensive and what was state-of-the-art with the syndrome when the books were published. I am on six different CHARGE syndrome Facebook pages which I think I have learned more about CHARGE since I have been on Facebook than I have learned in all my years of working directly with children with CHARGE. If you are not on Facebook and you think you are not a Facebook kind of person, I would ask you to think again because if you have questions, whether you are a professional or family member, if you have questions on specific issues in mind like some of the things that of common is questions to me, if you post those questions on a CHARGE Facebook page, you can often get massive stuff and really good practical feedback information from especially parents and sometimes from professionals about their experiences and what worked and what didn't work and what was the breakthrough and all of that kind of thing. So those resources are there to be used.

>> The CHARGE Syndrome Foundation sponsors a growing body of research, and I have taken this from my website. Their research grant program for this year, they announced the availability of research grants up to \$50,000 and they described the purpose of the grants as to promote new biomedical research into the etiology, genetic, and Malec killer mechanisms and treatment of Tran knowing -- CHARGE syndrome and new research into clinical and medical diagnosis and treatment of CHARGE syndrome.

>> The CHARGE Syndrome Foundation also recommends areas for future research, and this is their current list. I will read spread quickly, behavioral issues, cochlear implants, control of access salivary secretions, and your recess, genetics, growth bone cartilage and muscle development, immunology, hormones and fertility, lifecycle issues, neurological issues, and sleep disturbance.

>> CHARGE lab at Central Michigan University, this is the current lab all posing nicely for a photograph. In the back row you will see Tim Hart song who is as well as being a lead and professional in the field of CHARGE syndrome is also the parent of a son with CHARGE syndrome. Around him are his psychology students, who are undertaking research projects involved with CHARGE. I asked him for a list of their current research and I was surprised how much came up.

>> I will read through this. The effects of a fun she video and sleep and emotional self-regulation and children with charge syndrome, interventions for sleep problems in CHARGE syndrome, the development of social play, a measure of severity, anxiety, and I would say we've never had a

satisfactory way of measuring severity in CHARGE. Is such a complex syndrome, people sometimes talk about a child having major CHARGE or minor CHARGE or severe CHARGE or mild, and when you invest to Kate this it isn't a very good way of describing them. There are children who have lots of receptive and expressive language for following an academic curriculum, but they have major medical supports, both in terms of medication and equipment and nursing and are still in diapers at the age of seven or 10 or 15. So to say they have mild CHARGE is quite misleading. And I know children who are now adults who have never really developed much in the way of language receptively or expressively but breast-fed normally and whenever aspirated and was the feeding development was more or less on time all the way through their childhood. They had described as having severe CHARGE but how can it be severe if they have made this kind of progress when feeding is so often a major major issue for this population. The next topic is anxiety in charge syndrome, recreational choices and opportunities in CHARGE syndrome, headaches in CHARGE syndrome, decision-making in the removal of gastrostomy tubes in charge, peculiar behavior, inclusion of children with CHARGE syndrome, the effects of psychotropic medication on children with CHARGE syndrome, and finally parents finding connections to support themselves raising their child with CHARGE syndrome.

>> We now have a second lab. This is the bulldog charge lab and the long -- young lady with the blond hair in the picture is one of Tim Hart songs graduate students. She is now an associate professor in Mississippi and she set up the bulldog charge lab. Their research, again, it is a psychology section, they are currently researching CHARGE in CHARGE syndrome . Charge and family demographics Arjun issues of sexuality and differences between CHARGE and autism.

>> I should also mention when you go to the CHARGE foundation website there is a database. It is created and run by Meg [Indiscernible] of the foundation and I just want to publicize it because I think a lot more parents could contribute information to that database to make it more comprehensive and more effective. The more we have this information and the more we know, the more likely we are to develop our insights into the syndrome. That is my rather long introduction. I am going to start, this sounds very first, but I am doing the webinar, so I suppose I can make these decisions. No one send me questions yet about dental issues. But it is something that concerns me a lot.

>> I want to talk a little bit about dental issues and CHARGE. They can be very serious and they can be very disruptive and they can lead to all kinds of related health problems and they can certainly contribute to a lot of behavioral issues in CHARGE. The list that I have made, which I think is very comprehensive, it is the cutting of teeth which is usually delayed but sometimes abnormally early. The children often grind their teeth and I will talk a lot about sensory issues and self stimulation. There is often very persistent and quite severe grinding of the teeth. This happens for a variety of reasons, but obviously it has that implications for healthy teeth. We believe that dental enamel and many people with CHARGE is of poor quality, so that they develop cavities even if they have quite good dental care. Children after pouch foods like hamsters. They save their food in the side of the cheek, sometimes for many hours. This again, long-term, can have a lot of negative impacts on the state of the teeth. There are medications that children have for other reasons, which are not particularly healthy for the teeth. Persistent reflux and vomiting, those stomach acid coming up again and again are going to have a negative impact, not just on the tissue in the gums but also on the teeth as well. And then facial

questing is likely to lead to serious physical disorganization of the jaws and of the teeth. Facial palsy can create those problems. And even when those problems are there, the teeth may be misaligned, so that as the teeth grow, instead of growing next to each other, they grow into each other and you get this kind of impacting, which can be a major source of pain in children. So regular dental visits to keep an eye on things are really recommended. I have a picture from one of the German books showing and after cleft pallet that has been surgically repaired this is was -- was the state of the teeth. Once it was reconstructed into the facial work you then need a very skilled dental surgeon to come in and start trying to put the situation right. These are for the reasons I already mentioned.

>> I will return to the questions that have come in, and I'm sorry this has to be quick, that we are running out of time. I have are ready had 20 minutes. We only have 90 in total. The first question is from Tina [Indiscernible] and she is not happy with her daughter's school. She says in the courses for my daughter can use computers, she has letter a's. In her grade 9 English class she is feeling but the teacher lectures and that use technology. I've asked for a notetaker and asked for an educational assistant and I've asked for copies of the lessons and no cooperation. And stead of taking an issue with my failures -- my daughter's failures they want to keep lowering her level. If they keep lowering her level they won't be able to go to college. I can't let the school do this and how do I maintain a functional relationship with teachers were unwilling to change their teaching strategies to accommodate my daughter? This is a question I get asked surprisingly often, unfortunately, and I can only say off the top of my head, I think this -- my answer revolves around assessment and around the IEPs . I think if the assessments are not up to date or they aren't in-depth, like there hasn't been an assistive technology assessment or documented education assessment than that is obviously the first at. If those assessments come up as it seems pretty obvious they will with the need for computer use in all classes, or with the need for notetaker or an educational assistant, or advanced copies of the lessons, then all of that kind of thing is going to the IEPs and then you are in a much stronger position to get the school to provide these things. Your question is how do I maintain a functional relationship with teachers, that is a tricky one, because even when right is on your side and when you get all of this evidence and you have the authority of the law behind you, it often can be quite damaging to the relationship with the school and with the students teachers. That is a tough one. But I do think assessment and then letting the assessment feed into the IEPs and possibly change what is in the IEPs is the way to go.

>> The next question that came in is actually two questions from Linda Daughtry. The first question is my daughter is seven years old. We've been trying to potty train her on and off for years. I collected data showed records and motivators etc. She will not void in the 20. She has no problem with entering the bathroom and taking down her pants and sitting. She will finish but does not go in the toilet. She will then have an accident a little while after she. School is been very supportive also. They regard to the potty often but she doesn't go in the toilet there either. Ottawa get this child potty trained? That is a big one. Again, it is a question I am asked all the time. I can't give you very satisfactory answer because this depends very much on your daughter but it also depends on you and the school setting and what is available and how people think about this issue. We do know in CHARGE that control of the bladder and bowels is it usually delayed. Sometimes it's very delayed and nonexistent into adulthood. We think there are neurological reasons for that. It doesn't relate to cognitive levels. It is not that the children are not

smart enough to understand this, but they are simply not in terms of sensory channels, they aren't getting the information from the bowel and the bladder that the brain needs in order to know that there is an issue and there is about to be a bowel motion or bladder opening. So that is one issue. Then there are other issues like balance problems and problems with sitting on the toilet and proper physical supports. There are major issues with their whole digestive tract. Great from the face and the mouth to the peen and pain ends. Constipation which is your other question, constipation is a very common issue. I think if the child has had all kinds of negative with their digestive tract, and discomfort and maybe even surgical intervention, that is going to give them a lot of negative emotional feelings about the whole business of guillotine. It is very complicated and I have made some notes to say first of all, the best known name in the CHARGE field for pivoting is Lori Danell. She is based in Massachusetts. She wrote a chapter in the American CHARGE book on toileting and if you do a search on Lori LE a UR letter I E space DEMNO. Name all,. There is also a summary does Laurie Denno. there is also a presentation she gave on toileting about five or six years ago. The other resource is on Facebook. It isn't unusual for parents to go on Facebook asking specifically this question. There you will get a lot of responses from parents who have been through this successfully and or unsuccessfully and very few of them have been through it successfully right from the get go. So there is usually quite a long history of difficulties and false starts. What you actually asked me Linda, isn't unusual and isn't surprising and I know that cold comfort. But I just want you to know, it is very unlikely that you have been missing things are doing things wrong. Your other question is about constipation. We deal with constipation a lot. She has been on my Rolex for years my relaxed. Sometimes she cries from gasping. Any suggestions on helping us to the constipation. I remember her wearing a button at the Chicago conference that said ask me about: massage. There is the button. Can you go over that? These buttons I think were her idea and we were able to tell her what we wanted and she very nicely came up with relevant artwork and I wore this throughout the Chicago conference and it got a lot of laughs. And even about four or five people talk seriously about what it meant I am surprised colon massage is not better known. I trained in massage many years ago and one of the aspects of that was colon massage. I want to talk just a little bit about it. They laugh because people assume this is done internally somehow. It is actually done entirely externally to the child's body. I have a picture of this. This is looking directly at the person's abdomen. So the colon if you are massaging on the left of this picture would actually be the right ascending colon of the child. You start at the bottom down near the groin around near where the appendix are. The idea is you move up with deep pressure and it's easy to find the child especially in a child was constipated because you can feel it as quite a hard line or two. You start there and you make firm circular movements gently up the colon and you are trying to shift what is in the colon and move it forward. Once you get up to the bottom of the rib cage, it is time to go across from the right side to the left side, and then when you reach the same point on the right side, you come down the descending colon and do the same kind of thing. If the child is very severely constipated, starting at the lower right won't work very well and you may need to go almost to the lower left. And just try to shift at the end of the colon and work back. Keep working back until you end up going across and then down. And you end up back. All the time, you are trying to move stuff, a small amount at a time, in the right direction. So it's really important to work from lower right up to the rib cage and across and down to the lower left. It's important to use firm pressure. Clearly, you need to work on the child accepting this and tolerating this. If the child is resistant and you use very light pressure, it's likely to make them tickle and make them even more aversive. A good time is

after a bath because they are probably naked and drying them off and hopefully more relaxed from being in the warm water and as part of drying them, you may be able to do this. It helps if they are flat on their back because that assist you in using will equip pressure. That is it really. I have been in massage classes were one of the people in the class is a volunteered and they laid on the massage table and the teacher starts the colon massage and twice I have seen those people go very suddenly jump up and run to the bathroom because the colon massage is working so effectively. That is colon massage. If you search for it on the Internet, you will find lots of information . Much of it is commercialized a.m. when they are trying to sell food additives and essential oils and things. But really I think for our purposes you need to stick to the colon massage first until you get used to it. And until the child is accepting of it.

>> The next question. I don't have a name, but the question is related to my granddaughter who is five years old and was diagnosed with CHARGE when she was six months. She currently resides in the Washington DC area with her mom and my son, her dad. My son is the oldest of five boys, and all of the uncles and I would like to know how we could be supportive in particular with communication. We don't see her very often, but we would like to maximize the quality of our interactions when we do see her. She finds a bit but has limited vision and is a happy and loving child. Thanks in large part to her parents. It's possible she will go to the Kendall school at [Indiscernible] in the fall if she is admitted. I was actually in Washington DC last week and I went to the Kendall school and saw a very good program there for students with CHARGE and I think I may have met this little girl . I did a home visit. I'm pretty sure this is probably the same child. I think this is really an issue about how do you get information accessible to people about what works for a child in terms of their communication and language program. I am going to talk a little bit about an idea called personal passports. I wrote an article many years ago called knowing the child and it is about personal passports. It's an idea that you find all over that people have developed and we developed it and called personal passports in England more than 20 years ago. It is about thinking about if you were writing a book about your granddaughter or if your son and his wife are making a book about this little girl, how could you convey to people the best way to communicate with her or the best way to understand the behaviors and what she is doing. This is if they were there to help explain it. I have some examples -- I have some examples of two real personal passports where I have talked to families about this approach and they have gone ahead and made one. I will go through these very quick we.

>> These are some pages from one this is about a little boy I met in another state. This was many years ago now. It's also a little bit -- it has a picture with his name and a nice portrait of him and it says something like hi this is me and this book is to help you get to know me. Tells you a little bit of background information about him and his syndrome and then there is a page on communication and I especially like at the bottom showing pictures showing facial expressions demonstrating he is happy you're not happy or content or nervous. I especially like the nervous picture because it is very communicative.

>> There is a picture about his sensory issues and his difficulties with touch, but the fact that he dislikes cold objects but he loves light and they don't think he can smell but he does seem to enjoy music especially if it is quite loud.

>> There is a page about his hearing and is cochlear implant. There is a page about his vision and his vision issues. There are other pages as well. It is a long passport. I also have as a follow-up passport after about 43 years. His parents realized that this passport was out of date and he had developed, plus the parents had developed a deeper understanding of Pam. He developed more expressive behaviors, and they updated the personal passport. This is the first one which is now different. Some of the information carried over but it has been updated. I know children whose families often with the school have made one of these passports every year, and they filed them away as 2009 and 2010 and 2011, because when you go back through them, they give a nice view of the child's progress. I have been known when a parent is a little down the child isn't making progress or development, I've been known that they suggest they get their personal passports out and go back to her for years or five years and see what she was like then and they are often quite surprised. This idea could just focus on communication and language, if that is what you wanted. I think sometimes parents run away with the idea and they make this huge book. I have seen some with like 50 pages. That is really not going to be very accessible to people. I have seen very good ones with just three pages. It just depends really on the content. But they are all written in the first person so it gives the feeling that this is the child's -- child telling you about themselves and this is a young lady I know. This is Stephanie down in Australia. This is her very first personal passport. She was actively involved in creating the passport with her mom. She had a lot of say in the design of the passport. She had a lot of ideas about what she wanted to be included and not included. And she also dictated which pictures were to be used. Her mom told me that, for example, she wanted nice baby pictures and cute pictures. But Stephanie wanted these kinds of pictures. If you look at the top, you see her in a medical centime -- setting wired up. If the lower picture showing the scars in the but never G-tube. Stephanie herself wannabes in the book. She was very very focused on where she had come from and what she had come through. I think that in itself is a revelation to the family. I -- there are pages about her feeding and about her hearing and balance and subsequently about vision.

>> Finally, this came up on Facebook recently and I contacted the stories mom and asked if there was any way I could use these photographs tonight and the webinar and she gave me permission. They have done this as a trifold brochure. It is the same idea, but it is the ultimate inaccessibility, really. It has his name on the top and a nice picture and a little about me. On the left there is a list of medical stuff that helps a stranger understand what he has been through and why certain things are happening or not happening and why they are happening in a particular way maybe.

>> On the inside there is a list of important things to know about me. There is a list that says what works for me, and there is a section on vision for him with some nice pictures. Again, these are just outlines of ideas for getting that information that you are requesting about your granddaughter to you. Another possibility, of course, is video. These days, parents tend to be a lot younger than me and a lot more technically able and sophisticated. I think if you are up to it, looking at that information on the Internet about video portfolios, specifically to look at communication and language systems and signing and adapted idiosyncratic signs and so on, that could all be helpful.

>> I have two more sets of questions. There is a doctor in Washington DC and she sent me three questions. I must admit, they have quite a heavy medical bias, which scared me off a bit because I don't know that vestibular nuclei neurons as a teacher. Maybe I should but I don't. They are good questions

and I will deal with them. I have quite a lot of slides for this, and I will go through them. Just mention that many of you have seen the slides before over and over again actually. CHARGE is the most multisensory impaired of all the syndromes. I have listed others as well but I think these are the main ones -- main ones to think about. There are two senses that people often don't know about which is and 14 and the vestibular sense. In CHARGE also senses tend to be affected and impaired. That has a huge impact on the way the children develop on their postures and the movement patterns they adopt. But on a whole range of other things as well. I do a lot of talking about the senses. The CHARGE foundation on its website has a webinar I did about five or six years ago just about these two senses. I call them the forgotten senses. I won't say much about them today but I will talk specifically because I did get these questions about the vestibular in children with CHARGE.

>> This is what you should see in the inner ear if everything is developed normally. At the top you have anything like a snail shell which is the cochlea and below that you have the vestibular apparatus, there are two bulbs and pre-curved semicircular canals and just like the cochlea the vestibular apparatus is made up of hollow structures, which are filled with fluid and lined with nerve hairs. We do know that in CHARGE and because it is scanning, we know there is often significant damage and malformation to their vestibular apparatus and to the cochlea, not surprisingly. Often, there are -- there are two bulbs are intact but the semicircular canals are damaged or missing completely. There are also children when the scans show have everything looking anatomically correct and just the way it should be. What we see though when we observe those children if they have very very significant vestibular problems. So even though it looks as though the vestibular apparatus is all present and correct, from a neurological point of view it is not working. It's almost as if it isn't plugged in or it isn't connected. Whatever that system is doing, that information is not getting through to the brain the way it is meant to be.

>> Dr. George Williams wrote in the parents manual about vestibular function and said it is a very important sense and it detects head motion and detects in response to gravity and is the main sense that helps us know which way is up and how to resist gravity. To provide stability during body movement and helps us to locate our body parts and develop a good body schema or good body image. It has a huge influence on muscle tone and posture. Usually muscle tone these children tend to be very floppy and they like to melt down into the floor because gravity is a challenge to them and such a problem.

>> He goes on and says it helps you develop good bilateral development across the midline and it obviously has an impact on motor control motor coordination and sequencing of movements. It plays a big part in auditory and visual perception. People usually don't know that and don't understand that. Very importantly, it helps modulate arousal and alertness for attention and calming. And other words, the ability to self regulate depends on an intact vestibular sensory system, and it's not surprising that the group of children we know where vestibular damage is the most common, which is CHARGE syndrome, is also the group of children with the most significant difficulties with self-regulation. And I'm sure there's a very very direct link between those two things.

>> I will skip forward now through the slides because these are available in articles I have written. I was going to talk about aspects of CHARGE but I am aware of time passing. Why might movement be difficult for children with CHARGE especially with vestibular problems? There are orthopedic issues like

skeletal malformations and problems with the muscles in the tendons and brain issues such as cerebral palsy but a whole range of possible brain malformations. We think that in some of these children the connective tissue that binds their joints is of poor quality so the joints tend to be hyper elastic and they bend far too much and it's difficult for the child to flex and extend these joints and keep in control. There is a whole range of sensory issues that contribute to movement problems like blindness and deafness and vestibular issues and proprioceptive issues and tactile issues. Drugs and medication, which often make the children quite drowsy and kind of dump down. Their awareness. There is seizure disorder, which is not statistically very prominent in CHARGE, but it is definitely there in some CHARGE anomalies. There are breathing problems which will have a big impact on movement and may well -- the children may find it much easier to breathe rather than to breathe and move. They may feel that they have a choice of reading or moving. And obviously, they will go with breathing in most cases. There are nutrition issues, of full range of feeding problems and poor absorption of food and this leads to low energy and poor bone growth and muscle growth.

>> There is stress and there may be depression and a lot of fear about resisting gravity. The child themselves may have low expectations and they may have low expectations of effective movement and there is often poor awareness and poor motivation of the environment around them because of the children's multisensory issues. They may be very distractible and they may -- there may be a vicious circle where all of these things cause movement problems but also movement problems can compound all those bullet points that I just read through.

>> I think most children with CHARGE are not in touch with their bodies and don't feel their bodies it very well. We know why that would be the case because of the significant multisensory issues. We see our bodies and know where our bodies are because of our sensory systems. If those systems are missing or not working properly, the brain has a much less idea of where the body is and what it is doing. One look at the way children with CHARGE self stimulate, we look at the postures they adopt, often they are trying to exaggerate sensory information in order to get better contact with their body. I think when working with a child with CHARGE, my first priority is to try to work out how does their brain communicate with their body? Is it working well or are there problems and how can I help their brain feel where their body is more effectively through movement or pressure or massage or tactile input or visual markers or whatever? Then we need to think about how does the child communicate with the immediate environment and then we think about extending communication out. But I think we need to keep going back to that very first kind of communication between the brain and the body.

>>> There are a lot of CHARGE postures and self stimulation and they are a way of locating the head in my opinion. Where is my head? If the vestibular sense is not working and if there is low vision, it is very hard to know where your head is. We see head leaning and we see head binding with a tight head or a sweatband pulled over the head or a scarf for string binding the head. We see a lot of head holding and tapping and rubbing. We see head banging and especially, I have many pictures of kids who are not yet standing independently, and they are not yet walking, but they do head banging with great facility to get that pressure going through the head and all through the spine so that their brain has a better idea of where everything is. There is jaw clenching and that helps give an idea of where the head is. Teeth grinding plays a huge role in keeping the brain in touch with ahead and also the biting and chewing. I'm

giving a presentation at the German charge conference in a months time and I will be talking about this specifically about posture and movement as a form of self stimulation. I haven't photos into this yet. I think it is important to remember that everything that children with CHARGE do has meaning and the first obligation on the teacher is to work out what that meaning is or at least come up with a good guess rather than to dismiss it.

>> Why is walking -- I am talking about the vestibular sense here. Why is walking such a problem? Bone malformations and loose joints and low muscle tone and other sensory issues and breathing problems and possible cerebral palsy and so on.

>> What helps? Lots of physical jerks as I call it and poor's writing and swimming and Jim type activities the kind of things and adaptive PE teacher will come up with. Deep pressure or binding or pressure clothing and good physical support an appropriate postures for efficient functioning. Rest periods and regular movement and controlled environment and self-taught and taught strategy varies -- strategies. We are trying to get the brain and better contact with the body and postural security. We are trying to prepare the children for attending and learning and to stabilize the visual field and inputting self-regulation and we are aware of the importance of sensory inputs positioning and posture.

>> Back to the question. -- Balance or equilibrium depends on these three sensory systems. The vision the vestibular and the proprioception. Back to the question, I will deal with these as they come. The first question is not strictly about this. In the focus of children with CHARGE I noticed that their eyes are not coordinated . What treatments are available to produce conjugate eye movements. Yes, this is implanted with young children and CHARGE and often the better I or the functional I is patched to try and force the other I work and to improve the connection between the eye and the brain. So the idea is that eventually that I will become a functional one and will start to work in coordination with the other stronger I. Good people to contact our optometrists and a vision therapist. It's quite common on the Facebook pages for parents to say we have been asked to patch and how to do that because the child usually doesn't like it. The next question is I can't find any studies of the brain stem this tubular nuclei and I really can't answer that question. It's beyond my competence. But then the third question, there are two sub questions. Our children with CHARGE syndrome aware of feeling dizzy and the conditions causing dizziness --? In many cases know they are not. They never get busy mostly because they don't have a functional or vestibular sense. Dizziness is when the vestibular system is overstimulated and if it's not there or it's hard the -- hardly working it can't be overstimulated. I've written an article about the vestibular sense and I believe I talk about assessment and that. But traditionally, for example, if you put a person in a chair and spin them around, and then stopped suddenly, normally if the vestibular senses working the eyes continue to move for a while. This is what we call nystagmus. The vestibular apparatus in the fluid and there is still moving even though the head is not moving. The eyes are trying to cope with the sense of movement coming into the vestibular system. Many children with CHARGE, if you put them in that chair and spin them, when they stop there is no nystagmus. The eyes are stable because the vestibular sense has not hope -- been overstimulated. The other question. Our children with CHARGE syndrome aware of their spatial or -- when their eyes are closed? It's a good question. If you look at the slide, if the eyes are closed, so you take away vision, most of these children have some kind of problem with their vestibular sense and they also don't feel their bodies through the proprioception.

It's not unusual for kids who are work -- walking quite well in light to have big problems going into darkness. They often drop to the floor or grab at someone and want to hold onto somebody. They often see better when it's bright because of this triangle because their vision senses compensating for the missing proprioception and vestibular. I think often visually they use strong vertical markers in the room and I think the cornice or the door posts with a picture frame for the window frames, all of these visual markers give them an idea of which way is up. I think their brains use that visual information to help them to compensate for the vestibular dysfunction. If they go outside the building, into open space, they have lost those strong vertical visual markers, and their postural control and their mobility falls away very dramatically. Sometimes there are specific behavioral issues where people don't understand this and they are trying to make the child go outside say, during recess at school, and they are getting the negative responses from the child.

>> I hope that was helpful. I am very aware I am talking far too much. Walking, I have some points about CHARGE walking. I will not move on to the last question. This is from Maureen and Jason. They say my husband and I saw David [Indiscernible] percent last fall. You ran out of time before he could cover self soothing or self-regulation. I'm interested in what his thoughts are on self-regulation for children with CHARGE and what are some approaches for help self-regulation? With our 1 1/2-year-old do we let it quite --. I it out? Does the up changes the kids get older? Well, this is a very big challenge for the children and for their families and then for the professionals involved. I had a vote here on the slide, a definition of self-regulation. It is defined as the capacity to manage one's thoughts feelings and actions in adaptive and flexible ways across a range of contexts. I think for schools this may be the biggest challenge of all in trying to educate the child with CHARGE. How can we help the student to recognize and deal with excessive levels of over arousal or under arousal in socially acceptable ways? If it's difficult can they learn ways of asking for help? I know for example the staff that [Indiscernible] school for the blind where they have quite a number of students with CHARGE have done a lot of work on this. This is a ladder of arousal, which people may like to look at when they subsequently to an end to this webinar. I talk a lot when I am visiting schools about children going up and down this ladder and how can we help them understand what they are going through. How can we help them know where they are on the ladder and where do they need to be and how can they get there.

>> There are various strategies, again, which I won't talk about too much today. Tim Hart song in Michigan has led various teams and produced a series of articles about this, self-regulation in CHARGE syndrome for deaf blind international. Those articles are available from him and they are available from me if you are interested. The last one just came out a few weeks ago. It's an interesting way of starting to think about self-regulation. I think back to what Maureen and Jason's question was, if your daughter it was 1 1/2 years old, I think letting her cry it out, I don't know her, but I will risk saying that is probably not the best approach. I think possibly some deep pressure and maybe some really controlled rhythmic movements might be quite effective in bringing that arousal level down. But of course, instance with CHARGE cry for all sorts of reasons and there are all sorts of issues that deal with pain and physical discomfort. So it is very complicated.

>> I am going through these slide soap cleat, but here is my last slide. We think there are big problems with executive functioning in CHARGE with organizing and priority and with initiating and activities with initiating communication in getting started. Children

>> Good levels of language have good vocabulary receptively maybe free speech &, that initiating is hard for them. They might express very well with words or signs if you go over and start them off or ask them a question. Problems with sustaining and shifting attention or problems with managing alertness which is the self-regulation issue and managing their frustrations. There is a whole range of difficulties, which many of us are talking about more and more and hoping to research. My last slide, before we move on to the questions, this is my email address. I don't get back to people very quickly when I get swamped. But if you want to contact me with specific questions, this is my email. The questions do need to be kind of contained. As Lisa said, if you ask me how can I stop my son biting? I don't have a clue because I need a lot of information. I don't even know biting what. Is that other people or objects with the cat? There is a need for a lot of information to deal with those kind of questions but I am particularly good at pointing people the resources and that information. As I say, I have Tim Hart songs -- I don't have the last one which I contributed to but I have the others and I will get the last one. And you can have a look at those. So I am sorry that way longer than I was expecting but I always talk to much. So now I am up for what questions have come in. I have not looked at the chat box so I will rely on Lisa let me know what questions have come up I hope.

>> Okay. This is Robin. Lisa just sent me a message where her phone died. I think she will probably try to get in on a different phone. Let's go back.

>> I can scrollbar. -- Scroll back. I see lots of people that -- say their child never gets dizzy which is not a surprise at all. It's very hard for me to go back up.

>> Let me start at the first question when they first started coming in. This one indicates and says my son is 30 and we have a new ENT says because of scar tissue due to repeated [Indiscernible] he will not do any more tubes. My son has had about one ear infection a month since this visit. Is vestibular -- his vestibular system is affected more so. One thing that help was an evening allergy pill but still his infections continue. Advice please.

>> I'm not sure I totally understand that.

>> David, this is Lisa. I am back. My phone died. What they are saying is that is a lot of scar tissue because he has many sets of May ergotamine tubes. But yet he won't do anymore and he's had lots of ear infections once a month and has left a system is affected more so because of all of this. One thing that used to help was he took an evening allergy pill that the infections are still continuing so they are looking for any advice on that.

>> Well, again, like so much in CHARGE, what you are describing is a very familiar picture. This is with younger children and also with adults. I think one of the CHARGE things I haven't talked about is this supposed immune system -- suppressed immune system. I think -- all I can suggest is thinking about infections and I am sure you are doing all of this already but think about infections and limit the

possibilities of picking up infections and thinking about diet and many parents report that once they take their child off dairy, for example, major improvement in -- and reduction in secretions and blockages and that may be a way forward. Part -- posture is important. One of the difficulties with children with CHARGE with vestibular issues, which is most of them, they often like to be flat or horizontal and on their back. That isn't good for drainage of fluids. There eustachian tubes, if they are there and open enough. They have to be upright for them to drain effectively. So trying to keep them more upright, if they like to be horizontal or reclined much of the time, it's very hard for me to guess anything else, I'm afraid. This is without knowing him. But it is a very common issue. That is all I can say really.

>> Great. We will move on to the next question. My son has excellent receptive ASO and appears to lip read to the extent that he can often pass hearing. But he is struggling to develop expressive sign language any ideas on how to assist?

>> As soon as you said my son has pretty good receptive I thought this is going to be about initiation. I'm glad I talked about executive function disorder and I will go back to that slide. It's the first one. Activation, this is a very common problem, and as I said, children could have pretty good receptive vocabulary. Sometimes they have good expressive vocabulary but they can't start, so someone has to go over and say are you all right and what are you doing or is that your picture or something like that. Sometimes the language comes out fairly spontaneously, but they can't initiate spontaneously and we don't really know why. We need really good neurological investigations of this allied with neuropsychology to look at behavioral outcomes. I think one of the pieces I wrote a long time ago, I talk about the need or the recommendation in which you use a concrete communication system. In other words, in the sense that speech & are not concrete. They are temporary limited and -- using some kind of concrete system like photographs picture cards or symbols or symbolic books or vocabulary books that have written words or braille the words sometimes it's easier for the child to use that concrete system even if they have good receptive understanding of the more abstract forms of speech porcine or both. -- sign Or both. I have seen children who don't use the book very often but it goes everywhere they go because they don't want to be without it. And then if there is the need for really skilled teachers to find ways of supporting the child and giving them the confidence to initiate with a lot of the scaffolding and support so that you have made it as easy as possible to show them what to say or what to sign and how to do it. Again, I'm talking in a very abstract way because I don't know him, but I think again this is a very common problem and it's very much to this executive function disorder that we are seeing in the children.

>> Great. Thank you, David. The next question is about is there a significant correlation with postmeal pain such as Gaster bloating -- gas or bloating?

>> Yes. I mentioned huge complications with the whole digestive system from the mouth all the way through. We are discovering more and more issues with the digestive tract. There are anatomical problems where things are tied in knots or there are holes in them or they don't go to the right places or things are closed off when they should be open. There are all of those kind of issues and difficulties with the tissue itself which may be poor quality. You know about the tracheal piece of facial fistula for

example where the esophagus and the [Indiscernible] are connected together. Even if the child can coordinate swallowing, many children can't because of cranial nerve damage, but even if they can swallow effectively cover aspirate anyway because the food goes down the right way but then goes through the whole and down to the lungs. That needs urgent repair, surgical repair. A lot of information on the Facebook pages relates to diet and how food is presented and many of these children have the G-tube mainly because of poorly correlated breathing and swallowing because of the cranium nerve damage and more and more parents now are moving off formula feeding on to blended diet, so it is regular food and often what the family is having for the meal and is just blended down with the powerful blender so that it can be passed through the tube safely and effectively. Parents are reporting all kinds of benefits for the children once they come off formula and go on the blended diet. It's a lot of work, but it's really paying off for more and more children. If I can name names, Wendy [Indiscernible] is a parent who is very active on Facebook and she and her husband organized the second ever charge foundation conference which is my first. I worked with Wendy is apparent and she has very interesting ideas on the whole idea of the digestive tract and that got in charge of being a source of major issues. They take note of them and deal with them. Again, I am talking in very broad terms, but I do think that whole business of gas and bloating relates as well the constipation and it relates to food absorption and good posture. All those things are going to be involved and often if you can get children upright and moving after a meal it helps, but having said that, every so often a child is getting up right after meal. You don't want them on their back. It's about experimenting and seeing. Again, if I were a parent and that was an issue, I would get on to the Facebook page for parents of infants and toddlers and I would post the question or CHARGE syndrome page of the foundation. Pose the question and see what parents have to share and you may be amazed at the amount of practical information that comes forward.

>> Can I jump in because I have just seen a question? Is that okay?

>> That is fine.

>> It is from Dan and Nicole and they say is it too late to ask the question why is it so hard for my daughter to gain weight? Again, this is a very common question. I think it's a little bit beyond my purview as a teacher. As I sit looking at getting a neurologist involved and looking at diet and there are problems with food absorption, especially with hypocalcemia where calcium isn't absorbed properly. This contributes to growth issues. There are questions about growth hormone deficiencies and lots of hormonal involvement, which is why an endocrine specialist should be involved with children with CHARGE and we are lucky to have Dr. Jeremy Kirk who is like the CHARGE endocrine specialist as far as we know, all over the world. And there are problems with hypoglycemia or low blood sugar. There are lots of issues around growth which relate to diet and that is about all I can say really.

>> Well that's interesting, David because our next question is there a correlation with low pressure -- blood sugar and CHARGE .

>> Yes there definitely is.

>> Are 12-year-old daughter spends much time on our computer and iPad that only wants to learn on her own. If we try to discuss topics of interest, she tells us to go away. Is there another way to promote her -- is there any way to promote her to share her interests with us?

>> My first question would be what issue like at school? Because you don't want for being like that in school. I am just wondering if she is relating to other people and learning with an alongside other people at school, maybe she just doesn't want to do that at home, at least at the moment.

>> That is just off the top of my head.

>> I know mine like to come home and be alone after a full day of school and they are done.

>> Yes. Absolutely.

>> He asks our son is seven years old love school and is answering more simple questions especially at home. But in school if you ask him what is a circle or a square, he doesn't answer and he knows all of these. He does answer some questions but not academic. Hence, we are stuck in our education. How can we get him to answer academic bastions?

>> Good question. Again this is a very common issue. I saw families last week in their home and the boy is -- the mother is showing him a series of cards. He had never seen these cards before and he is signing the names of all sorts of items of clothing and parts of the body. His mother was amazed at how clean he was doing this and how much he loved these cards being randomly presented. She went into school and told them and said he has never signed at school. So clearly this is about environment and I think the child's confidence in their own expectations of themselves. If I were the advisory teacher being brought in, I would want to talk to the school about how they are structuring things and how they are playing. I can't talk about the school so I don't want to be accused of being unfair to the school, but I have been to schools for children get smiley faces and frowning faces if they get academics correct or incorrect. For children with CHARGE the frown face can be disastrous because of their executive functioning issue. If you look at the slide on the screen, you will see that the fourth on down is problems emotionally with managing frustrations in modulating emotions and was keeping a good emotional perspective. These children -- I have seen children very smart and following the academic curriculum and they accidentally knock the pencil off the desk or there he racer am that old world ends. It's like the worst possible thing that could happen just happened. And sometimes they need five or 10 or 30 minutes to calm down again and it all relates to this kind of pattern of executive function disorder. So I would want to know how the school is handling success and lack of success with the academics and what pressure they are putting on him. I would want to know what the environments are like and I wonder if it is a case of the school environment has too many distractions may be and the child is overstimulated and maybe is even going into a bit of a shutdown mode where home they are a lot more comfortable and able to focus more. Maybe, I am just putting out possibilities.

>> Okay. Great. I typed a little bit. I know there is other talk in the window as well. People should scroll down there and look at some things as well. We have time for maybe one or two more. Our son, age one has had a few episodes where he becomes pale and cold and clammy and nonresponsive when

sleeping. He becomes totally limp and we can't wake him up. Each time he is snapped out of it after about an hour. His breathing becomes fast and shallow but his oxygen saturation and heart rate are fine throughout. He has Ajit nieces of the corpus colostrum also. We wonder if these are some type of non-convulsive seizures. Has anyone else ever talked about experiencing this?

>> Yes. Again, this kind of pattern is described on Facebook. This is occasionally. It is not every -- always frequent but it does pop up. The obvious thing to think about is seizures and sleep apnea and hypoglycemia, which I just mentioned, low blood sugar. There may be others but as a nonmedical specialist those of the three things that come up in my mind to investigate. It sounds like you are investigating those things. I don't know if you are looking at all of them. They are the most likely issues and again this is part of the CHARGE spectrum of development and behavior. This is not out of the ordinary.

>> Great. And the second part of this question was our son becomes very irritable at the end of a long day sometimes and acts like he can't get comfortable. If you sit him up, he wants to flop backward and if you provide down backward he wants to set up. How do we help them get comfortable and settle down. He's too young for things like sensory swings and hammocks.

>> He is one-year-old?

>> Correct.

>> Okay. Will that depends on a lot of things, but this is a population of children who often don't do very well as the day goes on. They often need that chill out time at school but they certainly need it when they get home and they are interesting because sometimes they need to chill out literally by laying down and just relaxing. Other times they have to go running and jumping and swinging and being very active, and both of those approaches are ways of reorganizing their sensory systems, which have become overstimulated and they are probably low in energy and in focus. If you look at that slide again, you will see all of these come up in the executive functioning agenda. I think deep pressure is also effective. I think a one-year-old could go, if it is appropriate, in a Hammack or a Jamon type swing maybe. So that kind of rhythmic movement may help but I certainly think deep pressure and I think deep pressure with rhythmic movement. Like you do with any baby holding them tighter than usual and very close to you and doing or side to side or your rocking back and forth and see of those things work. I think if you provide a child like that with a residence aboard and if you don't know what they are there is an article I wrote in the national Center of deaf blindness website and so you will find it there. But the resonance board is on to maybe self occupied and also with the Lily Nelson -- Lily Nelson. If you search that on the Internet and look up little room. It's a box, a play box for children. That might help. Trying to create an environment where the child is attracted by the environment, via media and environment, less focused on the fact that they are overstimulated or exhausted or maybe even physically uncomfortable and because of this overstimulation.

>> I think we have time for one more. We will squeeze one in. Children with CHARGE are very bright but our school is hung up on him having intellectual delays. How do we convince them that he is very smart?

>> You could quote me. I am not joking. I really think one of the things -- one of my goals for decades -- has been to get away from the idea that people with CHARGE syndrome tend to have significant cognitive disabilities. Some do and some tend to have autism. But most I am convinced don't have autism and most of them I don't think have inherent cognitive disabilities. But they have so many sensory impairments and so many other issues associated with all this medical stuff that it's very hard for them to focus and tend and learn in the way that prelate does regularly developed in does developing infants learn. I am trying to write things and other people write things where we all contribute to the growth of literature and it says that children with CHARGE do things that often look -- I use the word mentally retarded because even if people don't say it, I think that is what they are thinking very often. They often do things that look crazy or look like a very significant cognitive disabilities, but if you understand why they are doing it, you often find it is adaptive functional behaviors. I have written about that and Tim Hart song talks about it all the time and I have been working for two years on an article about self stimulation in children with CHARGE and what it means. What it means very often is ways of functioning because they have all of these difficulties with their sensory systems. It isn't unusual to see a really smart older child with CHARGE following an academic curriculum with lots of language expressively and receptively developing very well but secondly, they will get up and jump up and down in the air and hyperventilate and blow raspberries or they will lay on the floor and shake their arms up and down rhythmically and then they get up and set up a desk and they carry on working. People automatically think that's cognitive, but I think it is very often a multi sensory impairment issue. It's just the student hasn't had anyone take them on board to think about that and to get them other ways of reorganizing their sensory systems or waking themselves up or ringing their arousal level down by getting to stressed or two hyper. So I think -- I worry when people evaluate significant cognitive issues and people with CHARGE. I often happen in schools and I will say something of the child with CHARGE and the staff will say well with this level of cognitive difficulty blah blah blah. I always say, oh what the level of cognitive disability? Of course, there isn't a level because no one has assessed it because no one has the ability to do that. It's very difficult. So it is an assumption that people fall back on because they don't understand this syndrome. It is not surprising they don't understand it because it is very low incidence and it is incredibly complicated but we have a job to do in helping them acquire that understanding.

>> Great. Well, I think we got through most of the questions, David. I want to thank you so much again for the wealth of information you have shared with us tonight. I would like to thank all of the attendees and of course, I would like to remind everyone that this webinar will be available on the foundation website and I encourage all of you to become a member or think of us when you are thinking about fundraising or donations so programs like this can continue. With that, I will sign off for tonight and thank you again, David.

>> Thank you. Goodbye.

>> Thanks, David. [Event concluded]