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Please stand by for realtime captions.

>> Before Robbin starts recording in the room, I want to remind everybody on tonight that your phones will be muted and if they are not muted, you can press star six to mute your phone. Then, we don't hear background noise at your house. I want to remind you, again, that the presentation tonight is going to be recorded and it will be archived and available on our website. When you type in the chat box, in the lower right-hand corner, all of the information that you put in will be archived and available as part of the webinar recording. Be mindful of that, in terms of entering private information or things like that. I think that is everything I need to remind people of, Robbin. Is there anything else? Otherwise, we can start recording.

>> This meeting is now being recorded.

>> I will officially welcome everyone to the webinar. We are so glad you could join us tonight. My name is Lisa Weir and I'm the Vice President of the CHARGE Syndrome Foundation and I want to welcome you all here on behalf of everyone at the foundation. Tonight's webinar is different. We will have a number of presenters talking about different aspects of the conference for people who, perhaps, want to little more information and have never been to a conference and want to know a little bit more. I want to thank the donors and everyone who does fundraising because those are the people who keep the programs like this running. I'm going to click to the next slide and introduce everyone and run through the agenda. Remember, as we are going, if you have questions, type them in the chat box on the right and I will collect those questions all through the webinar and we will leave lots of time at the end for questions. If you have a question, type it in before you forget. This is how we are going through the webinar tonight. We will start with Minnie Lambert and Pam Ryan, also Board Members at the foundation and they will talk about scholarships that are available and funding. Basically, how you can get funding to get to conference and we will the director of administration, Jody Wolfe, talk about the registration process and she will give you information about the hotel and about the camp. There is a lot there and it's a separate process and it will be really good for you, if it is your first conference. I will come in and talk about the program and I am also the program chair and I will talk about the program and the sessions you will see at the conference and run you through the day today have scheduled activities. Karin Dagley, board member will talk about nearby attractions and things that are around the hotel in Orlando. Finally, our director of outreach, Sheri Stanger will give closing thoughts and after that, we will do questions and answers and everybody will just kind of chime in, depending on what the to dose depending on the question, whoever is in charge of that section will jump in. I will click to the next slide and turn off my camera so that Minnie and Pam can turn on their cameras and talk about scholarships and funding.

>> I will go first. Hello, this is Minnie. Scholarships and funding, the CHARGE Syndrome Foundation has three scholarship families can apply for your help with finances. The first is the trend 23 scholarship and the second is the DFIC scholarship and the CHARGE for Connor scholarship. How do you apply? How do you apply, Pam?

>> First-come you have to be a member. How do you get to be a member? It's easy to be a member. You go to our website, [www.CHARGE Syndrome.org](http://www.CHARGE Syndrome.org) and click on the get involved button. Follow it down and then you will see become a member and click again in the form of pop up will be there for you to become on your way to become a member of the charge foundation. You will see a list of membership levels from a yearly membership at \$30 to a lifetime diamond, \$10,000. Shoes, obviously obviously, what is best for your family and it's important to remember that you have to be a member at any level by April 1, 2017, an order to apply for a scholarship. If you need help with the membership, make sure to let us know because we will see what we can do for you. How do we know -- the next slide is how do I know which scholarship to apply for? Well, as Minnie said, we have three different scholarships and starting with the Norbury scholarship, that is explicitly for first-time conference attendees and it covers registration costs. If this is the first time you are going to conference, this is what you might want to start with. This scholarship is named for and in tribute to Lee Norbury and is for Lee and Marion Norbury. Marion started the foundation and her husband supported her work and this scholarship is in their name and was very important to them. Then, there is the CIF C conference and if you have been to the website, people are starting their own CIFC campaign to raise money for our scholarship and foundation, and general and this one is supported by the campaign and covers registration costs. It's important to know that preference for this particular scholarship will be for those that are participating in CIFC in the past and had their own campaigns going and they would be given preference for this particular scholarship. The third scholarship is a charge for Connor. They are in memory and tribute to Connor Logsdon. This particular scholarship was set up by his family and supports families that may need help with hotel costs at conference time and it's very important to pay attention to what these are and start to apply for them. This year, the online application is new. The application is new for online this year and you will find all you need to know when you go to the website. Does that seem clear? Minnie, how about the funding?

>> There she is.

>> We want to see everyone be able to attend the CHARGE Syndrome Foundation conference and we are aware about concerns of being able to afford the full cost of attending the conference. In response to these concerns, the board has taken the Internet to get sources for funding you might be able to tap into to fund the trip. We've identified a number of organizations that offer grants to individuals and families of children with developmental disabilities.

>> Okay.

>> The next slide, Minnie?

>> Thank you. Are primary source of information is wonder baby newsletter published by the Perkins School for the Blind. In the second link gives tips on how to go about getting a sponsor advocate and

writing a successful proposal letter to request financial aid for attending a conference. Using this Article as a guide, we have developed a sample letter specifically focusing on obtaining funding to attend the CHARGE conference. We hope you will find it a good starting place at writing your own letter and we also created a sample chart to document your family's travel, conference calls and to create a document to attach to your letter that shows your detailed, categorized conference related expenses.

>> This funding guide might become one of your best friends, in terms of how to get some money and have your family supported to go to conference. It will take some time and it is all worked out for you. Going to the guide online will be very helpful to you, I think. Then, there is the CHARGE incentive program and you see the slide in front of you. If you raise \$2500, you earn one free conference registration, T-shirt and that sweatshirt and for each additional \$2500 raised, you earn additional registrations up to a maximum of four and if you raise \$1000, you get a free conference T-shirt and sweatshirt and if you raise \$500 on your CIFIC campaign, you get a free conference T-shirt. You will note that there is a limit of one T-shirt and one sweatshirt per fundraiser. These are important things to know and you can be raising money for the foundation and also benefit yourself. Where can we find this information? All of it is on the CHARGE Syndrome website and it's not quite there, yet. It will be there early in 2017. Give us time to put this up. Check in every now and then at [www.CHARGESyndrome.org](http://www.CHARGESyndrome.org) and click on the taking CHARGE in Orlando icon. It will direct you to the conference pages and everything you need to know, you will find there. Anything else? Let's go back to membership. Minnie?

>> As we all know, members are the lifeblood of our foundation. By working together, we can create a world does a better world for all of those individuals with CHARGE ski, whether an annual member or one of the four lifetime levels, every membership shows that you support the largest organized, dedicated -- excuse me -- organization dedicated solely to CHARGE syndrome. You can increase awareness, educate others and encourage research. The membership levels, as Pam said earlier, \$10,000 level, we have the lifetime membership with \$5000 level and we have lifetime platinum membership at \$1000 and the lifetime gold membership. At \$250, the lifetime silver membership and the annual membership rate is \$30. We look forward to helping you get ready for the conference and also, seeing you in Orlando.

>> Thanks, everybody. Now, we will move to Jody talking about online registration and when it will open. Take it away, Jody.

>> Hello, everybody. I think I just clicked one too many times. Online registrations will open in early 2017 and we don't have the exact date. We will release it as Pam and Minnie stated, just like with scholarships, around the same timeframe. If you aren't connected to our e-news, please go on our website and in the upper right-hand corner, there is a button to get all our blasts so you will be updated as to when the registration opens. The rates are as follows, everybody with individuals that charge are always free for conference. The rates for the children are 12 and under, if you are over 13, you are considered the adult rate. They all have to be paid by June 1st and you can see on the slide, and for those who may not see the slides, if you are only on audio, the presentation will be posted on our website after the end of this webinar. You will go back to reference it, as well and there will be late fees if you pay after June 1st. An extra \$50 until July 15 and after July 15, an extra \$100 per person. As

Minnie and Pam mentioned, becoming a member is important for scholarships. As well, for discounts on registration. And a lifetime member will receive a 10% discount off their registration for the immediate family. Immediate family includes parents, guardians, and any siblings. It does not include grandparents or any caregivers or aunts or uncles. If they wanted 10% discount off their registration, they have to become a lifetime member. Other important things about registration -- when you register, and it will be online registration, you need to register one family unit per registration form. Again, mother, father and children is considered one family unit and anybody else coming to help you, caregivers, nurses or other relatives, must register separately. We do offer many different payment methods. We have the for partial payment, which is nice for those who want to pay as you go. And, we also have an option to pay later if you are waiting for scholarships or funding. You don't have to pay when you register. Full refunds are available prior to June 1 and there will be a cancellation fee if you've already made payments. We will apply a cancellation fee toward your payment. A little about the hotel, it's the Rosen Shingle Creek and the hotel room reservations are available now. There is no reason -- if you are considering going to conference -- go ahead and book your hotel room. Rates are \$149. Tell them you are coming for the CHARGE Syndrome Foundation conference and I believe you can do it online, as well. Or, you can call them and we have extended dates if you want to come early or stay a little bit longer. Those rates will apply. If you have any special requests or upgrades, call the hotel directly and make sure they know you are with the CHARGE Syndrome Foundation conference. All the hotel staff will attend training, directly from the foundation and they will know what to expect -- will know what to expect. This is our second time at the hotel and some may be familiar with our families. Again, the hotel is a great hotel and Karin, in a few minutes, will go through some of the amenities that are close to the hotel but you all know there is Orlando, Disney and obviously, Universal and Sea world and a lot of things at the hotel, fun things where you don't have to go off the hotel. There's four different pools, tennis courts and volleyball and a game room. It was important for me to know, last time, that there were laundry facilities on-site. You don't have to worry about how many clothes you bring. Obviously, if you don't want to do laundry on vacation, but know that it is available and there is complementary Wi-Fi available. Let me talk about camp. Campus offered on Friday all day ends Saturday all day and a half day on Sunday. Two camp options and they are the same options if you've gone to conference before or if you haven't -- these are camp discovery and camp Explorer, two camps located in the same area and the hotel, they are a slightly different staff to camper ratios. Camp discovery has a higher staff to camper ratio and camp Explorer is a little more structured with a lower staff to camper ratio. Some of the activities they do art together and some are separate. We do also offer a combing sensory room for those individuals who might need that during camp and don't want to, necessarily, participate in all the activities. Are camp is run by corporate kids events. I mention the registration form for conference. They require a separate registration form. When you register for conference, at that point in time, corporate kids events will have a link to register with them. They asked specific questions about your child and what their needs are, as well. Corporate kids events offers one to one supervision for an additional fee and that is something we have not gotten information about the cost. It will come out a little closer to conference - - a little closer to registration, I should say. That is something you will pay directly to Corporate Kids Events, not through the foundation. The camp does not handle any medical issues, feeding, suctioning -- there is one nurse available for emergencies for the camp but if your child has medical needs, you need a nurse or caregiver with them in the camp that is totally fine and they must be over the age of 18 and

they need to be registered for the conference. If your child needs G-tube feeding, you are able to leave the session or during a break, you can certainly go into camp and feed your child. Sorry about my dog in the background. [dog barking] sorry about this. I apologize. Siblings can attend a fun half-day workshop and you can see pictures on the screen. It is geared toward siblings ages 8-13. Again, this is another reason you want to be a member of the foundation, because priority is given to members of the foundation. It fills up very quickly and you can sign up on the conference registration form, as well. And is in the registration form come out, they will ask of you want to attend a trend 24. Of the child is attending camp, they will pull them out of camp for that three-hour period and they will go to the Sibshop room and then they go back to camp. If you are over age 13, if the sibling is 14-18, you can act as a junior leader. It means you are a helper during the Sibshops and it's really a fun experience for siblings to be together and talk and do fun activities. In a few minutes I will talk about sign language interpretation and then I will handed over to Lisa, in a minute, to talk about the program. There is sign language interpretation offered during conference sessions and this is something on the conference -- on the conference registration form that you will indicate. You will fill out this for your child, as far as what type of sign language interpretation needs they have. Then, all those wonderful people you see on the screen and black, they will be floating around the different sessions to interpret for those individuals with CHARGE who need interpretation. Is no interpretation at camp, though. If you need an interpreter, that is not a place that we offer that service. There will be interpreters roaming the camp to help, but there is not an option in each camp room to have interpreters. There may be some volunteers who know some sign language and can help, but, again, we don't offer interpreters in the camp rooms. Lisa? I think you are up, next.

>> Okay. I turned off my mute button. You've learned a little about funding options and a little bit about the hotel. You learned what the kids do, the Sibshops. Now, I want to talk about the program. Well we have a lot of fun activities for the kids and things are happening, people are there to learn, as well. When we look at putting the conference program together, most of the proposals that will come to the program committee fall under these four general areas, behavior, education, adult issues and medical. As you all know if you are attending this session, if you are of a parent of a child with CHARGE Syndrome, you know there can be a huge array of issues, depending on the age and what parts of CHARGE you may be dealing with. There is a wide range of presentations and there is something for everyone at conference. We really are mindful when we put the conference programs together, that during each time slot, there is something for everyone. We are not scheduling two adult sessions at the same time, for example. We really try to spread it out so everybody will have something that will be of interest and be useful to them during each time slot. What will happen, is the program is being put together right now and we've sent out a call for presentations and they will come in and get evaluated by a committee and then, we will decide which will be put in the program and contact all of those people and ask them for their handouts by a certain date. That is important. We do not give you a great big thick book full of paper with all of the handouts, anymore. We are very green at the foundation and what we do, is make the handouts available online ahead of time, which is wonderful. I remember going to my first conference and I did not have anything before hand, I just got a big book when I got there and was very overwhelmed trying to think about which sessions I would go to and which would be best for me. Doing it this way, in addition to being more green, it gives you a chance several weeks before the

conference to really look over the presentations that are going to be happening at the conference. I put a sample on the screen where you can see that this is from the 2015 conference, and when I put the handbooks together, there is a page that tells you the information about where and when the session will happen and some things about the presenters and a little abstract that tells you what you will learn about during the session. You can take that and look at the program schedule and kind of map out where you are going to go. It will be a little easier on you when you go to conference if you've had the opportunity to review these materials. You can download them onto your phone, tablet, or computer. Some people still prefer to print them and that is fine. You will get a little program book when you get to conference. It does not contain all of the handouts. The PowerPoint presentations, the slides from the presenters will be online and you will get the conference program schedule and the presentation abstract, those pages, in that book. Again, I highlighted it and put bold at the bottom. It's really important. I recommend, especially if it is your first time coming to conference, go through these before hand so that when you are trying to get your family settled and into a hotel and dealing with everything and figuring out where to go, you won't have to worry about where you are going for the program. You will already know and will have made your decisions about which sessions you want to attend. You do not need to tell us in advance that I am going to this or that session. If you change your mind, you end up going to a session and it's not for you are not what you wanted, you can change. We are very flexible that way. I just wanted to talk a minute about general and breakout sessions because I remember, way back, many years ago when I went to my first conference, I really didn't know what this breakout session thing meant. We start each day with general sessions. You will see in this picture, there are many, many people and we are all together in one big room. A general sessions, there will be awards one day, a keynote speaker on the first day, on Sunday, we have a popular adult panel where young adults or adults with CHARGE Syndrome get up and give some speeches and take some questions from the crowd. We also do some other foundation news and things during those times. We all gathered together each day to start the day in a general session and if there's housekeeping items, typically, David Wolfe, our President, will provide that information to everybody, at that time. Then, we go to what is called breakout sessions. I was a little bit surprised at my first conference. I had not been to a lot of big conferences before and I didn't realize things would happen at the same time. It's important to know that after general session in the morning, we have up to six breakout sessions happening at the same time and it's another reason why you really want to be thinking about where you want to go ahead of time and not trying to decide on the fly. So, there will be one group of breakout sessions with one group of up to six sessions before lunch and three in the afternoon and as I mentioned, if you get into one and it's not what you thought or you think this really doesn't apply to my son or daughter, it is fine to slip out the back and go to another one. I put a note at the bottom that some families choose the divide and conquer method. You may go with your spouse or you and grandma are together or a caregiver who works with your son or daughter and you both noticed there are two sessions at the same time and you really want the information. Some families, the husband will go to one and the wife will go to another one and they will get the information and come back together to talk about things after. Some choose to stay together the whole time and that is completely up to you. Do whatever is comfortable for you. All right. I thought what would be good is to run through the days and give you an overall look at what each day will look like at conference. Thursday is the day when everyone arrives and at the last conference, we started a semi-new thing about having a welcome reception in the afternoon. People get together to

meet other families and for new people, to meet people who have been to other conferences and ask some questions, to start making some of those connections. Is such an important part of conference and we have that in a big ballroom in Chicago, which was wonderful and lovely. Let's face it, we are in Orlando. This year, our welcome reception in the afternoon on Thursday will be a pool party. We've got four beautiful pools. Why not make use of them? Information will be provided about where to go and which pool will be for the pool party. It's very informal and there will be snacks available. In the evening, Thursday night, it's the official welcome grand opening kickoff and that is -- you can see if picture from Chicago -- we had a drumming group at the opening reception last time and it was a lot of fun and there's going to be a light dinner served that night and we hope everyone will be able to make that. It's a lot of fun and there are raffles and we break up into different groups. In the past, we broke -- we broken up into groups based on geography and I think we will try something new. Be sure to see that and be there for that. Friday, -- sorry -- getting ahead of myself -- also, on Thursday, there will be information about the professional day and this will be the fifth professional day that happens on Thursday before conference and what happened in the past, was all the professionals would get together informally on Thursday, to talk about studies they were working on or the work they were doing in the field of charred ski. Five conferences ago, this became a more formalized professional day with keynote speakers, plenary sessions, breakout sessions. It's really designed for the professionals working in the field to share information with each other. That being said, anybody can attend this. There is an additional fee to attend, as he said at the bottom, \$175. People are welcome to attend, but the presentations that are happening during that they are not geared for everyday audiences or parents. They may be using different lingo that is more professional or technical in nature. Keep that in mind that you can attend but it is really about professionals sharing on that day and it wouldn't be the type of session where you could raise your hand and asked the question specific about your child. For example, if they were talking about gastrostomy tubes, it wouldn't be where you could ask about your child's G-tube, or something like that. Friday, we have welcomed you and have had a big reception kickoff on Thursday and Friday is the day where everything is full on. We start, as we learned about a minute ago, a big general session first thing in the morning after breakfast. Make sure you go down and get breakfast, it's very delicious and then we meet promptly at 9:00 for general sessions and after that, the breakouts will go the full day until 5:00. The camp program happens all day and then you have the breakfast and take your son or daughter to camp, if applicable, and go to the general session. On Friday, there will be an exhibitor fair and I've included a picture to the right where there will be set up Swiss and information from a wide variety of exhibitors. In between going from breakfast to the sessions or when there is a break, you have the opportunity to visit with the exhibitors to see what kind of information and things they have available. Also, on Friday, we have a poster presentation session and something called information Central. That is the time where professionals set up posters about their work and you will have access to go in and talk to professionals who are there presenting at conference. That is a long session at the end of the day on Friday. On Friday, there will be breakfast, lunch, dinner and snacks. You will be eating all day, it's wonderful. [Laughter] also, on Friday night, you people that are here for this webinar are the first to hear this news of a very special event happening on Friday night. We are having Rachel Coleman, the Texas CHARGE group is sponsoring this activity for us and Rachel Coleman will be there to do a show and stay afterward for autographs and things and that is pretty exciting. We are happy to have her. She was at the conference in Chicago in 2009, I believe. She was a huge hit and fun for everybody, young and

old. Saturday is almost the same as Friday. You will have breakfast, take your kids to camp and go to the general session and go to the breakout sessions that you've chosen and then, Saturday night is the big party called CHARGE-A-Palooza. There is a dance, a silent auction that you can see in the picture at the bottom and there's all kinds of carnival games and photo booths, lots of fun things happening and if things are too stimulating or overwhelming there will be a space outside to take your son or daughter to if they need a break or if the parents need a break, let's face it. That is happening on Saturday. Sunday is a little bit different. Sunday, we have our breakfast and the kids go to camp but we all stay together for the morning and the general session. We stay in one big room on Sunday. There are no breakouts on the presentations run from 9:00 until noon and then we have an adult panel. You see Aubrey, one of our young adults from the last conference, giving her presentation. I'm excited to announce that David Browne has agreed to come and do deep thoughts. If you are unfamiliar with David Browne, he is a very frequent presenter and well loved professional who works in the field of deafblindness and has a very special place in his heart for people with CHARGE Syndrome and working for Pamela -- working with families who have a child with CHARGE. He has traditionally done closing deep thoughts talks for us that a number of conferences and took a break from the last conference but is coming back, this time. Camp program, everything ends at noon on Sunday and when things are over, you will go back and pick up your sons or daughters from camp and then breakfast is included and things will be over at noon and you are on your own, after that. That is a brief rundown of each day at camp and at sessions and what is happening in the evenings. I am going to now turn my camera off and turn things over to Karin who will share about what's available around Orlando.

>> Karin, you are on mute.

>> I was talking and no one could hear me.

>> In Orlando, this year, everyone knows it is a hot vacation spot on top of being a place for our conference. Some people may want to stick around and go to Disney or Universal. Hotel is a universal affiliated hotel and they offer some discounted multiple day passes from the hotel that you can purchase and it's right there at the guest services desk. They do not offer any tickets to Disney, so you have to get those on your own. Anything having to do with Disney is separate from the hotel. If you are going to Disney, there is a transportation service you can call. From the hotel, it is an approximation about \$18 per person in the vehicle for transportation to Disney from the hotel. The hotel offers complementary shuttle service to Universal and Aquatica and Sea world. If you're traveling from their ports, in Orlando, to the hotel, there are several options available. You can take a shuttle, a taxi, and one of the tips is that if you take a shuttle to the airport to the hotel, it's about \$20 per person and the other option is taking a taxi, about \$46, roughly and don't quote me -- but roughly \$46 per ride and for -- four to five people per ride. You can see what option works best for you. The numbers and the names for the shuttles and the taxi services are on the Rosen Shingle Creek hotel website. There are people that they work with, in particular and if you are renting a car, there is a parking fee at the hotel, \$18 for self parking and \$26 for overnight valet parking and we do get a discount, being with the conference. You can speak with the hotel directly about that. If you want to rent a car while you are staying at the hotel and you want to go on an excursion or go someplace, there is an enterprise rental car right at the hotel and you don't have to leave to figure out how to get a car when you are there. Also, nearby, there is a

public store, it's a grocery store across the hotel that is a long entrance at the hotel, it's a decent walk to Publix, 10-15 minute walk. It will be the end of July, beginning of August and very hot. Keep that in mind that it will be hot. Make sure you have sunscreen and anything to do to keep cool while outside. There's not a pharmacy and that particular store. Up the road about four minutes, driving or walking, there is a Walgreens and Universal Boulevard, as well. There's a wonderful hospital in Orlando that is roughly eight miles from the hotel, the Arnold Palmer Hospital for children. An excellent hospital if you should need those services. There are urgent care facilities if you need something. You can get the information of the concierge desk at the hotel or look it up online before you go to see which one may work best for you. Now, I will turn it over to Sheri Stanger, our director of outreach to give a little more information. Thank you.

>> Just starting my webcam. Hello, everyone. This is Sheri Stanger and I'm your director of outreach with the CHARGE Syndrome Foundation. As you can see, that is a picture of me at one of our conferences. It may not be my favorite picture of all time, of myself, but as you can see, we are all having a lot of fun and that is what I'm here to talk to you about tonight. To offer you some insight into the field of the conference, itself and how it may feel to you when you arrive. First, let me tell you that no one experiences conference in the same way. You may be new to the world of CHARGE or you may have been involved in it for 30 years. There is still something that attracts people to this particular conference and I, personally believe, it is the feel of the conference. The feelings of hope that it brings to families and the knowledge that your family and your child are accepted at this conference with no questions asked, no stairs, no judgment. I think you will understand what I'm saying. As you've just heard from Lisa and everybody, there are general sessions and breakout sessions, social events, activities and childcare. There is even downtime built into the conference so that families can spend some time together in an unstructured way. It's a lot to ask of a conference to do all of these things. Somehow, we do manage to achieve it. We always, always, strive to do better at each conference and make sure it's meaningful to all of our families and the professionals that are in attendance. The reality is that not every event is for everyone. You shouldn't feel like you need to do everything. You can pick and choose what you need to do and what you need to hear. If anything becomes too overwhelming for you or your child, it's okay to take a break. This conference is for you and it is why we try to offer so much in only a few days time. As a new parent, or not so new, but a first-time attendee or a person with CHARGE Syndrome, or a professional attending for the first time, you will certainly be feeling some hesitation prior to conference and no doubt, you will hear lots of chatter on Facebook about this conference and hear how excited everybody is to attend. It's true they really are excited and I'm sure you want to know why all this excitement over a conference. What I think, is that people genuinely love to spend time together at our charge -- are CHARGE conferences. Our kids, no matter what age, are celebrated at these conferences. We see potential in our kids despite all of their challenges and it's not just the kids with CHARGE Syndrome that are celebrated, our entire families are celebrated. It reminds us that we are important in our lives. It reminds us how special siblings are, too. There needs and the role they play in our families, and it reminds us that parents also need to take care of themselves. We remind people of how critical it is to stay involved and to stay informed, to stay connected to the foundation and two other families that understand our day to day life. We also are reminded of critical roles that professionals play. There will be manner -- many medical, educational and therapeutic professionals at this conference, as Lisa

pointed out, previously. They are part of the CHARGE family, as well and are there to present and also there to learn. They want to speak with you and if you are a professional attending for the first time, our families love to talk about our kids. We do. So, if you are on this webinar tonight and you are a professional, do not be afraid to ask questions. We want people to learn more about CHARGE Syndrome. I'm also going to tell you a little bit about myself. I'm your director of outreach and I'm also a parent and I have a 23-year-old daughter with CHARGE Syndrome. I will tell you a bit about my first experience. My first conference was the second international CHARGE Syndrome conference in Portland, Oregon, in 1995 my border -- the daughter was born a month after the first conference and she was almost two years old at the time and we had no idea what to expect. This was before social media and even email wasn't so great and we knew the agenda, we knew there would be childcare and we would stay in college dorms. Think about that. We've come a long way from dorms to a resort, but I will never, ever, forget my first conference and it will always be my favorite, in many ways, despite the heat wave in Portland that summer and the dorm rooms that did not have air conditioning. It holds special memories for me because it was the first time I was with so many people in one place that had a child with CHARGE Syndrome and I will never forget my conversation with a family that had a 15-year-old son with CHARGE. I saw him sitting with other kids, reading a textbook and saw how well he was doing. I remember him holding my daughter and cooing and talking to her. He spoke with us, as well and at that moment, I knew things were going to be okay. Not easy, but okay and there was hope for us. I have to admit it was also the first time that I met David Brown and also, Rob Last, another wonderful professional in the field. I want you to know that the conference can be an emotional roller coaster. You will feel lifted up one moment and sometimes you are going to be in tears but that's okay. It's a part of the experience and you may be overwhelmed, at times and you may also feel energized and armed with new information and support systems at the ready. The foundation has really come a long way with conference planning. While the conferences have certainly grown in size, over the years, we still try to maintain that intimate family feel. It may seem, as a new person coming into a conference, that everybody knows each other. Many people do. But, there are always many new families at conference and I want you to know that so you are not going to be alone and board members and the state parent liaisons in attendance, they will be available to help you navigate the conference. We will also help connect you to other families, even prior to the conference, if you wish. Soon, you will be chatting with new friends and planning to attend the next conference, as well. I want to thank you all for your time tonight. Please know that I'm always available to talk with you about conference and assist you with any resources, information and family connections that you may need. I look forward to meeting you all at conference and, now, we will open the meeting to questions from the audience tonight. Thank you.

>> Thank you, Sheri. It is Lisa and I will put my camera on. Jodi is back, too. I want to put my camera on because I think we can only get two at once. I've kept track of the questions and prepared some answers and links but I will let you go ahead, Jody.

>> Lisa, Rob and thought we could all get on, at the end, unless I am wrong.

>> You are right. I will adjust the screen just a moment.

>> Okay.

>> Thanks, Jody. Let's see -- I will turn mine on. If it is all right with you, Jody and Sheri, I will go through the questions and if you want to add anything, jump in. Is that okay?

>> Sounds good.

>> The first question was typed out, Joanne asked when will scholarships and applications of the available? I think we answered that on the next slide but I wanted to double check with Joanne that it was okay and they will be available on the website early in 2017. I can't say the exact date but keep checking and just to reiterate, I think was Jody, who mentioned that if you are not getting our e-news from the foundation, we don't send out a ton of emails but sometimes every week or every other week, there is an announcement about the webinar, for example. If you are not getting those, make sure we have you signed up with for e-news because then you will get email blast about when things are updated and available for conference. Joanne, if you have further questions, or anybody, just type it in the box.

>> The second question was from Denitra. She said how can we tell if we are a member or a renewed membership. Great question. Denitra, I will copy and paste into the box, a website that is linked to our membership recognition page on the dose on our website and all of our current members are listed. If you became a member in the last week or two, it is updated about once a month, so check back if it just became a member very recently. It is updated about once each month with new members for that month.

>> Lisa, this is Sheri and I also want to add that if, for any reason, you are still not sure when you go to the website, you can always get in touch with me and call me at my toll-free number. I can put it in the chat box in a moment, or you can email me at [sheri@chargesyndrome.org](mailto:sheri@chargesyndrome.org) and I can look you up in the database to see if you are a member. Our annual membership follows the calendar year. You become a member as of January 1 and the end is January 31. If you are a yearly member, you need to renew at the beginning of the year as of January 1. Of course, if you signed up as a lifetime member, you never have to remember to renew your membership.

>> Very wonderful. [Laughter]

>> The next question was from Heather and she asked, can we find CHARGE Syndrome Foundation tax ID information on the website and the CIFC links? In terms of the tax ID number, you can email the foundation for that if you need it, Heather. It's [its@info@charge-syndrome.org](mailto:its@info@charge-syndrome.org) and I will type that in the window so you can easily copy and paste that. I will hop back to the PowerPoint for amendment -- for a minute and go back. Asked about the link for the main page. I have a little picture and I made a lot of slides. I went right by it. If you go to [CHARGE Syndrome.org](http://charge-syndrome.org), you will see on the main page a picture that looks like this one on the slide, charge it for CHARGE and that will take you there if you click on the link. The next question was from Michelle. My daughter has CHARGE and she would be free for registration. Does the registration include the camp or is that an additional charge and separate registration process? Great question, Michelle. When we say individuals with CHARGE have no fee, there is no fee and everything is included. When you see our registration fees, it includes camp and the meals and all of the activities. The only part that is different is that you still need to register your daughter for the camp.

They need that specialized, specific information about your daughter so they need that information before she comes to camp. And we say it is free for individuals with CHARGE, it is free and hopefully that clarifies that a little bit. It is a little confusing with two registrations but it's a good thing because camp is very thorough, in terms of getting the information they need to make camp be the best experience possible for your child, your son or daughter.

>> I want to add one more thing. This is Jody and I think I mentioned the only additional charge would be if you would want a one to one caregiver for your child and this is something that Corporate Kids Events would hire directly for an additional fee. Otherwise, no additional charge.

>> Great. Okay. The next question -- I'm sorry -- it said my son will be 18 months and we aren't certain if it is best for us to attend, as he will still be the age where he needs a lot of direct supervision and care from my husband and I. Is there any age that you recommend coming to conference? I will start and I have a feeling some of the other gals will jump in. It's absolutely a personal decision, as to whether or not you decide to bring your son with you. I will tell you, personally, the first few conferences I went to, I did not bring my daughter. I'm coming from Canada and there were medical and insurance issues and things like that, as well. You know, there are kids of all ages at the conference. It might be a situation where you choose to bring your own nurse or caregiver to look after your son or a grandmother or older sibling over the age of 18 who can go to camp. Again, there is no real age that I recommend. We have seen little babies. Everyone is well taken care of. It's really just you and your comfort zone and what you are comfortable with for your family and I will let you go because it looks like you want to talk.

[Laughter]

>> I must have covered everything.

>> I will share my experience. My son had a tracheotomy and we chose -- we didn't have a caregiver come with us when he was -- I think our first conference was in Miami, many, many years ago and my husband and I chose to switch off and go to camp with him and one of us would be in camp with him and the other would be at questions and that -- at question -- at sessions and then we would switch off. He had a tracheotomy so I felt more comfortable having someone attend to medical issues that he needed. That is what we did and what worked for us. Again, every situation is different. That is how we handled it at our first conference and down the road, we did end up bringing our own nurse with us to have him in camp with him. Again, it was because he had medical issues that he needed a one to one caregiver with him at all times.

>> Another personal note, when my daughter started coming to conference, she had a G-tube and would have different times in the day where she was fed and has Jody mentioned earlier, we would just go down on the break or figure out when we needed to go down and give her that feeding and make sure everything was all good and then went back to the sessions and people are very understanding if you need to go in and out of a session and sneak out to do something like that and then come back. People are very understanding. This is the one time in your life you don't have to explain anything to anybody. Is everybody good on the panel for that question?

>> One more point that people should know, as well. F's -- if at any point you need to bring your child into a session with you, we have had people bring young children into session. It is a family conference and all we ask, is that you are mindful of the noise and respect everybody else in the session, that they are listening and if your child is crying or making a lot of noise, just step out for a little bit. People should know that we don't encourage everybody to bring their kids to the session. If you need to, for something, it can be done. We are a family conference.

>> Okay. Go ahead, Pam.

>> You are on mute, honey.

>> Sometimes, the rest of us like having a little one around so that we can hold them, too. Just saying.  
[Laughter]

>> Okay.

>> The next question, what is the age limit for camp. My son will just be turning 19. Again, great question. We don't really have an age limit for camp. We are aware that there are older individuals who still require support and would benefit from being in the camp typesetting. So, if your son will be turning 19, you will discuss with the camp company, his needs and with most of the kids, they will have you fill something out and there may be a phone call to clarify things, as well, but your son will be able to go to camp. Jody, anything to add?

>> No. I agree. For a typical child, not one with CHARGE Syndrome, we do have a recommendation around the age of 12, is when kids usually like -- if you have a sibling -- one that is coming -- sometimes, if they are in their teenage years, they go to Sibshops or hang out at the pool with other siblings. Some of them attend sessions with the parents and if they are over 18, they can go to camp and be a caregiver. For a typical child, not with CHARGE Syndrome, we recommend the age over 13, that there are specific situations where someone may be 13 or 14 and want to attend camp, that's perfectly fine. That's our recommendation for the typical child.

>> There is a scholarship question. For the scholarship, I went to the Houston conference in 2003, 1999. I was there with you, I think. That is the only one because it was in Texas and I haven't been to a conference since. Can I still apply for the Norbury Scholarship? It's absolutely only for very first time conference attendees. If you have been to a conference, even a long time ago, you would apply for the other scholarships likely charge it for charge the, or charge it for Connor, but not Norbury. Anybody else have anything to add?

>> That was correct.

>> I think I captured all of the questions. I know that Neil is on the line with us. Neil Stanger is online with us. If anybody has any questions, or if Neil wants to jump in, feel free. Other than that, we are ending early, folks. [Laughter] I will give it another minute in the chat box window because I see some people are typing and I will wait just a minute.

>> This is Neil. I don't have anything to add, but if anyone has questions I can answer, I don't think -- if there's anything you need, shout for me.

>> I just typed Neil's email in the chat box window. The dates of the conference are July 27-July 30. It is at the Rosen Shingle Creek in Orlando next summer and again, I can't stress enough to keep up with the website and check back on the website for the latest information. It will be posted there. Next-door you get the emails from [info@chargesyndrome.org](mailto:info@chargesyndrome.org). Put us in your address book so we don't end up in your dreaded spam folder and you miss something important. Sign up for our e-news to get the information and if you are on FIS -- if you are on Facebook, we repost any of the information. The CHARGE Syndrome Foundation has its own page, Twitter, Instagram and you can follow us everywhere to see links to the information we send through e-news. Pam?

>> I want to remind people that when we talk about memberships, just because you are an active person on the Facebook page doesn't mean you are a member of the charge foundation. They are two separate things and I want to remind you of that, thanks.

>> That is really important. Sometimes, there is a little bit of confusion between the groups. Thank you for that clarification. I would like to thank everybody who helped with the presentation and I would like to thank Robbin and everybody at NCDB who helped make the webinar is possible and do all the tech support in the background, which we appreciate. Thank you, Robbin. We hope that you have more information about the conference and we really hope that we will be seeing you next summer in Orlando.

>> Lisa? I just want to add one quick thing. If anybody thinks of questions that they had and maybe thought about tonight or tomorrow, they can always email one of us by going on the foundation website. All our email addresses are on the website. Or, you can email [info@chargesyndrome.org](mailto:info@chargesyndrome.org) if you have a question that you didn't think of, tonight.

>> Thank you, Jody and thank you everyone and have a great night.

>> [Event concluded]