>> DONNA: Good afternoon, everyone, this is Donna Sorkin from Cochlear America’s HOPE program. We’re going to begin our program very, very soon. In the meantime I really want to encourage everyone to download the handouts for today and they're in the file share area of your screen on the left side. They're is both a feedback form and the handout is the PowerPoint that Kris will be using today. We will be offering CEUs as
always from both the American Academy of Audiology and ASHA and you will get a prompt for that a few hours after the settling is over today. We will be offering captioning today and if you do wish to use that please go ahead and get connected with the website right now so you'll be ready to go. We are asking everybody if you would answer a few questions today before we begin. We would like to know if you're a parent of a child with a cochlear implant. And if that is the case please answer the survey right here.

We've got -- we would also like to remind you that there are other materials up for parents in the HOPE area of the website, which is www.cochlear.com/HOPE if you would just tell us if you're a parent with a child with a hearing loss go ahead and note for us if we know that you are.

And if -- I'll give you a little bit more time. Okay, and if you're a professional who is working with children with hearing loss we've got a little questionnaire for you there. If you would go ahead and vote that would be really great. Okay. And my third question is are you using the captioning today? And that's really important for us to know because we want to be sure to address people's needs

Okay, that's great. I think that is -- I think that is really helpful. So I think we're ready to begin our session today. Back to the opening slide. And there is the captioning link for those that have not gotten it yet.

Okay, so our talk today is on facing deafness in our children, the professional impact, and our speaker is Kris English who is at the
University of Akron.

This is -- this program is part of Cochlear’s lifetime commitment to our recipients and the professionals who serve our recipients. We have with this program and one that we had a couple of weeks ago began a series of programs for parents and adult recipients and that goes right alongside of the program that we've been offering for some time for professional whose support our recipient community. We're really pleased to be able to do these in collaborate with all the best people in the field in order to bring this information to you to allow you to support your recipients or your children or yourself.

So with that I think we'll just launch right into our talk today. Our speaker is Kris English. She is an audiologist. She's also the in-coming President of the American academy of audiology. She's an Associate Professor at the University of Akron and she's a very well-known expert on audiology counseling with over 100 presentations around the world on this topic so we really are honored and pleased that she's going to be with us today for this -- not only this talk which has really a parent voice but two more on this same subject, one for professionals and telling you how to council the family that you work with and one for adults with hearing loss as well. So with that I think we'll just turn the floor over to Kris and I'll be back with you at the end of the program. Thanks so much for being with us today.

>> KRIS: Donna I appreciate the invitation to be here and I hope you can hear me because I'm not hearing myself but I think we're fine. I noticed from the survey at the beginning only a handful of parents are with
us. I really hope to hear from you throughout the session that we have today. And as you are inspired to if you could post questions on the bottom there, I'll address them as we go along.

Also, just curious about the remaining part of the audios. Could you who are audiologists click on the hands-up button, the blue button on the left-hand side of your screen so I know who is in our audience. About 12 of us. And Melissa I'm going to actually ask those who might be teachers of the hearing-impaired to click on the thumbs up button.

So that probably -- oh, there we go. That probably accounts for the most -- most of our professionals who are in our audience.

I wanted to indicate to the parents who are here that under no conditions would I presume to say that I understand how things are going. I'm a witness, an observer to a process that families work their way through, an outsider at best, sometimes welcomed in but certainly not -- I'm not you. I'm not a parent and I wouldn't ever say I have that kind of expertise. So what I will be trying to do throughout our hour together is report back to parents what audiologists bring to their work, what they bring in terms of their concerns, are we helping as best as we can. We know that families are on a journey, and our task we see is to try to help the journey make some sense to familiar lis and also help families to support it as they go along. So input from families would be appreciated.

Before we look at the title that we have on our presentation today, facing deafness in children, the emotional impact, there are some things
that happen before we get started at the beginning then take a look at some shared experiences along the way and then which of these experiences are unique to hearing loss. We'll start at something that is almost so tried and trite is now a cliche but just as a starting point, we know that when individuals are coming across something very unexpected that really throws their life into another direction. A lot of times people apply what is called the classic at this point grief cycle developed by Kubler-Ross in 1969. She was observing in the greatest sense of loss in terms of facing one's death or losing a family member or a loved one and she started to describe the process in a secular fashion that there is denial. She did not mention shock initially but we're going to spend some time here talking about shock. Once the shock is over she would suggest the rest of these stages to include anger and then depression because it starts to sing in and become real and then a bit of depression perhaps after that and detachment. Sometimes people call it bargaining away to kind of get out of it. And then ultimately acceptance or growth. That is classic to the point where people can hardly stand looking at it to be honest. It is just so familiar. So since then people have been thinking that maybe there are ways to define it differently and maybe we should talk to people who experience the loss themselves. Another model that we would be taking a look eights the transformation cycle and these websites are all here just to help you find them.

This model, I'm going to forward to help you show what we're talking about, it looks quite curley q and each stage is a cycle that goes around and around but each process does have an end point. Now, I would take exception to this when we're talking about families who are raising a child
with a hearing loss. There really is no end point, there is? As long as the child is in the family there is work to be done.

This model kind of loops around. It makes me kind of laugh because it looks a little bit odd but I just wanted to mention how we do have these different models in place. These are the cycles that you're talking about if you are saying this there is this stage of normal functions, the status quo, that is important to remember.

There was a situation or a life that was lived and then some news was delivered or an event occurred and then a bit of a tumbling down in terms of psychological states of -- and also kind of hitting if you think about the nadder of the whole situation being depression and then finally a recovery of sorts, returning back to a meaningful life.

This might also look semi familiar. It is what they're trying to get at. It is not a cycle. I think they really do want to emphasize the downness of it and then the upness of it.

Again, not particularly meaningful to a great many people, and parents in particular report that there is no cycle at all. And more often than not I have heard the metaphor of a rollercoaster. I have to report that in fact I have experienced it in my own family life. I have a child and his spouse trying to start a family and fertility is not quite within reach and the steps that they have had to go through to have and conceive a child and things not work out I'll hearing the word rollercoaster a lot. It looks like it is going to work out and it doesn't and heart brake ensues and I know
everybody in this room knows what that is like as well. Ultimately we all know we have good days and bad days and on the good days we're strong and able to manage the challenges and face them and sometimes it is not possible and hardly worth explaining to one's self at the end of the day.

One of my favorite currently woven my favorite models that makes the most sense to me is that within the process of adjusting to big changes there are periods of being disorganized and then we reorganize because that is who we are. That is what we're designed to do. We're designed to be ultimately making some sense out of it and then work with what we've got. Then there will be subsequent periods of feeling disorganized as new events occur in our life or new stages in one's life occurs and we work kind inform a tizzy around it and then eventually reorganize again.

One issue we bring up most frequently when we chat with parents about this is the idea that the fact that there is no end point as a cycle might imply but it is actually a chronic state. The child is a baby at first but turns to be a toddler, kindergartner and all the way through the lifespan and with each new life stage comes new surprises, new opportunities to celebrate certainly. But new reminders that this is going to be a long road ahead of us. And that is something I want to talk a great -- to some length on today.

What does it mean to be an experiencer of chronic grief, not the kind that you can somewhat rebound to or accept. For instance, a death if it is in the family and somewhat expected as a -- an end result of a long illness there is a natural grief that you work your way through but it doesn't catch
you by surprise and is natural. You do know that people are going to not make it for a while. (audio out) forever but the words are there. We're talking about stability as that starting off point, the status quo then an event happens and our emotional responses are up and down depending not only on the circumstance and our stages but how we are handling each day at a time.

Our website is there as well and the horizontal time we're talking about the axis in the middle there.

What I particularly enjoy about this model is the notion of immobilization. That is another way of describing shock, I would say. And we'll take a look at that concept in a second here.

So when one moves from stability to shock or when people's feet are kind of rooted to the ground because something very unexpected occurs we have all been there. I can speak for the experience of those who are residents of the United States. We have a very common experience of shock related to 9/11. I can report being on the East Coast watching it live on CNN and when tower 1 fell down, the words that came out of my mouth were -- that did not happen because it could not possibly happen. It was so unexpected first of all and also unprecedented. So my mind is telling me you did see it. But my reaction was saying it could not possibly have happened. So that would have been my immobilization stage at that point.

Parents also report that they are thunder-struck even if they have had a few inclinations there might be a diagnosis of hearing loss. When it
is finally confirmed they're almost paralyzed because they just don't quite
know how to react. It is a threat to one's status quote and nervous system
as well.

This is a clip or a segment pulled out from an article written by an
audiologist and temp of the heard impaired in England and she said this is
probably what it is like based on parent report that the audiologist or
sometimes the pediatrician just starts talking. I'm sorry, Mr. And
Mrs. Jones but I'm afraid our results show that Anne has a significant
hearing loss. In other words, she's a little bit deaf. The cause of this is
probably that she was born prematurely and as you can imagine it is blah,
blah, blah, blah, blah from the parents' point of view as the words are going
into the ears but not making sense because the big word of deaf or hearing
loss or hearing impairment literally stops the ability to listen further. And
we really have to be aware of that situation because first of all, our
tendency is to be uncomfortable. I'm speaking from the audiologist's point
of view right now -- is to be uncomfortable with this moment and then to
continue the talk time with more and more words just as this person does
in this slide.

The point of it being, of course, from the recipient's perspective is
that none of those words are making any sense and it is just a lot of noise
in a very meaningful way. I'll ask you all in a minute and those that are
audiologists if you have talked to parents about in retrospect what they
remember and many of them remember and parents will remember that
the audiologist had a spot of mustard on his tie. And that there was some
interesting music on the elevator that they will never forget on their way
down to the car. They can tell you the weather when they got to the car whether it was sunny and hot or rainy. Those moments, those images are burned in their brain.

The words that the audiologist said had no mean what so ever and, so, what about shock? What happens here.

We actually know from neuroscience research done in the 90s. You might remember that the 90s were described as the decade of the brain among the areas of interest or areas of specialties occurred is what happened when shocking news reaches the brain, when the listener is hearing news that something is very unpredicted and very upsetting as well. That the amygdala which are two almond shaped organs or either side of the corpus callosum it immediately kicks into gear. It provides the system or the human being a set of hormones to start reacting and a primitive sense that there is a threat and we're familiar with the response of being a -- to fight or flight responses. What happened during that response, during that hormonal response to the threat of the immediate moment (audio out).

>> KRIS: Such as fear. So there is an interesting difference about those hormonal responses that I want to just mention the sideline because I have mentioned before that flight or fight response it is classic. People consider it the usual responses among all species or members of our species. Interestingly some grad students in UCLA were taking a look at some similar articles about those study its, taking a look when it happens to the brain when something is shocking to the human system. And triggers fear or a sense of threat. And they realized that those studies
included only men. It is really hard to explain it at this point why that happened that would never be done now. But if they were thinking, you know, if it is a hormonal response might it be different when women have a threat to their sense of safety and security and they replicated the studies and sure enough women unlike men don't tend to have a flight or fight response. Their responses are to tend or befriend. Tending means to seek out the vulnerable. Children, older persons or persons with disabilities because that is just kind of the natural tendency and other rule of befriending is to reach out to the people who we know in terms of our social networks and communicate with them, make sure that they know what is going on with regard to the community or one's self. I'm not going to ask how many women and how many men are in this group but you probably recognize that there is going to be differences here. It is important -- I think that is important to highlight because our family members take on different roles sometimes and they are feeling this need to fight or flight. A fight is not going to be your fists up ready to punch somebody but to argue or blame or be very upset. Whereas women might have a different response. Not always. Not that generalized.

Let's see, a comment that was made by Taylor who was the leader of the studies wrote a book called "The Tending Instinct." She expands that notion of befriending. Families may not think about the need to reach out to other families as they proceed in their journey in raising their child with a hearing loss. She strongly -- the research is showing that support of social ties really do reduce the response of threat or stress. So something more to think about as we council families. So two families again we're talk from the stage of mobilization up to denial and I want to emphasize
this because it is -- it tends to be perceived as a stage in which we would rather -- that families shouldn't be too far along but in fact to spend too much time in but in fact denial actually serves a really special purpose and is one to be respected and honored. Primarily it buys time. Denial allows the family to find the inner strength that they need to cope with this challenge that they were not expecting.

Certainly they are going to need information in order to make decisions down the road and that requires a certain amount of time.

There is also a psychological state of readiness. Before any decisions are made you have to be ready to make the decision. That is both strength and information to be at your disposal as you move forward. And it is described by psychologists as a truly legitimate coping strategy and I highlight this because professionals feel a sense of urgency and wonder if families are in the same track of feeling that same kind of urgency. Families who might be attending this presentation today are already aware that there is -- there is this notion of getting children identified as quickly as possible, amplified or implanted as soon as possible and then in early intervention as soon as possible. Well, families are necessarily aware of course of that urgency that it is all new them. New terrain and it is going to take some time.

What we found is that when given some time they don't ask families are not asking for the moon, right? They just want enough time to get things organized or their duck in a row as it were and then they move forward. Hold on just a second if you don't mind.
When we talk about denial we might see these kinds of reactions from families, for instance, those tests have got to be wrong. What worries me is when we see families being argued with by professionals when they might be trying to convey to families that our tests are legitimate. You can trust us. We know what we're doing. This is a choice we have to think about in terms of our practices that this is not a time to be arguing. Our task is to try to establish a trust. A relationship. Keeping in mind that in fact families are very much caught by surprise with these results. Even if they suspect it and early identification processes were not finding the hearing loss. It is still a surprise and families are going to struggle here. We might be not working together. We may not be in step.

These are the risks of actually creating a -- what could be called a communication mismatch. The risk is fairly high. Goleman wrote a book called "Merely Intelligence," and why it might matter more than I.Q. It was quite the best seller and I would recommend if anyone has not read it to pick it up. It is really quite breathtaking in some of its summary of the research that we know about brain function. He talks about how the brain is both thinking and feeling at the same time. We tend to think that the brain only thinks. As we mentioned before with regard to the function of the amygdala there is that notion of how to feel as well and from Greek days on the Greeks would suggest that we are -- our feeling mind was very primitive. Our thinking mind was quite to be respected and have the higher priority and we should try to squelch that as much as possible.

Research is showing we think and feel at the same time and
proportions might change based on the circumstances but my guess when I first started reading about all this material back in the day my -- I suspected that I knew -- I was a product of my training which was to say we were rationale clinicians that only used our thinking mind. Then I started working with families and I thought I have a feeling we're not on the same page. We seem to be struggling a little bit. Parents might not be using their thinking mind right now and, therefore, might we be at this idea of a communication mismatch? Is it likely? Well, I've been able to prove it a couple of times and this is just one study I want to highlight for you to in fact we may be at odds. I had heard, picked up from clinic over the years statements that I thought surely were highly effective, highly reflective of an affective or thinking -- excuse me -- feeling mind. Comments including from a Mom who said my family blames -- my family says Ashley was born deaf because they worked to the last week of pregnancy. I hope you might hear about that that was the guilt this Mom might be experiencing the extra stress from the family about making a decision to work. I also would hear an audiologist say with full confidence well there is no evidence to support that. You're working till the last week of pregnancy had nothing to do with Ashley's hearing. I thought this sounds like a mismatch. Parents speak from a feeling mind. Audiologists speaking from a thinking mind. I had more (audio has gone out.) I had two colleagues of mine rate those responses and they were all mixed up. They didn't know who said what or when they said them. If it was highly technical or highly data driven, highly databased response that would be given a one. But if the responses were sensitive to the affect and in other words hearing that there was a feeling mind comment and trying to respond in a feeling mind way, then that -- those scores or responses would be graded a five. Well, the reliability
among the raters was 82% so that was real encouraging and definitely a green light to keep going and we came up with these results. This is a summary of the first two bars that would describe the control group. Their sets of responses before the semester and then after the semester were very technical. 1.73, 1.6 meaning if they heard the affect of those comments, they certainly didn't match it. They created a communication mismatch by their responses. Before the semester and afterwards which is what I expected because they weren't in a counseling course. They were in something entirely very technical.

This is the group who I approached before the semester started comparable to the control group. Their responses were a mismatch. Their responses were very technical. Again on that scale of here one high-five would be up here and 1 being way down here and technical.

This is the same group who participated in the project before this semester started. This time their responses were very effective. Meaning they heard the response and they tried to match the responses accordingly. Always that risk by virtue of participating in the project before the semester and that could influence how they responded here. But here is the group who didn't have that presemester experience. Their responses were as equally sensitive to the affect as the other groups so as an instructor I could celebrate and say hurrah. People can actually learn how to listen to the affect that we would hear from patients and parents and then change our responses accordingly. But it does confirm the fact that we're likely to have a communication mismatch. If we are not sensitive to the risk of it.
Well, how to help parents discover for themselves when they are struggling to make themselves understood and communicate with family when is they are saying I don't think that there is a hearing loss. I actually would change your test results and in fact I think your test results are wrong. Rather than argue back and forth on what we know versus what they think and what they perceive what families would perceive and audiologists are using what I consider to be a real gold standard tool. The early listening function evaluation or tool developed by Karen Anderson who was very much talking to families and recognizing that it was hard to believe because you cannot see that there is a hearing loss in their perfectly looking baby. And this tool is available on her website. What she asks is for families to use these questions that she would talk children or talk parents through to say if you hold your child, check out what happens when a sound is loud or soft. When it is near or far. Or if it is a high pitch like Mommy's voice or a deeper pitch like perhaps Dad's voice and what would happen? Here what is should happen if the hearing is perfectly fine. That is the age dependency part. Here what is might be happening with your little kiddo. That helps a family start to discover for themselves that, in fact, there is something going on with the hearing that is not as expected. I wonder if I could ask family members to click on the hands up feature and click on the blue hand to indicate that yes you have use they'd before. I'm encouraged to see that because we have few family members here and one person says no not yet. I don't know how to erase this. Melissa, perhaps you can?

Now I'll ask audiologists have you used this with families as well?
Click yes or no. Thumbs up or thumbs down. The majority say no. I hope if you are a pediatric cardiologist you may consider helping families if you find yourself in a bit of a tank gel with your communication with families and they're finding it hard to see or get to that acceptance stage because the evidence that they're working with does not support the test results. In other words, they do see their baby respond. Of course they might if there is just a moderate or mild hearing loss. Conditions would help that baby hear to some extent. So things are not adding up.

So moving along when we think about that rollercoaster that we were talking about what we might see in the different stages in kind of a broader sense of things during that anger stage we might see frustration. We might see -- it is difficult to learn and accept when in fact it doesn't all make sense to you. Then the bargaining stage is looking for a way out. This might explain several families who -- if you have been in this situation, family members, where you might have gone to more than one audiologist to find a confirmation to the diagnosis makes perfect sense. Don't we all seek second opinions or third opinions when in fact not all the evidence is quite wrapping up and aligning itself in what we would recognize.

Depression is not the clinical depression that we are familiar with when it -- when it is -- the discussion is about anti-depressant drugs and all the rest of it. It is just a marl progression of things when it starts to -- the realization starts to sing in.

And then the testing stage is something new, different from Kubler-Ross’ model and if this is where we are at how do we find realistic
solutions and how do I find the information I actually do need?

Acceptance, the testing part a little bit more to say on that. Parents are really seeking information. We know how the Internet is so available and so helpful but sometimes conflicting. And I imagine pediatric audiologists think long and hard about the information stream they want to make available to families and thinking about new situations as every life stage occurs. I was just talking to a Mom on Monday about her 11-year-old daughter who has two cochlear implants and she is recognizing that as an 11-year-old there is a point where there is -- a need to start planning for the autonomy that teenagers start to seek and how to start preparing for that. How to help her talk to her peers rather than to family because it is just kind of the natural way of things. And yet there were few peers regionally that this young lady could talk to who have implants. So we were putting our heads together on how that might be worked out. That would be kind of again coming around Mom would do or actually say for a while she was depressed because she could not -- she realized that there was a new stage and she didn't have any resources or solutions and she started to draw on her inner strength and her circle of friends and asking around how might I start testing? How can I start finding ways to address this next stage?

I've heard many times from family members and I appreciate hearing from those that are here today the word acceptance as typically described in the Kubler-Ross model is maybe a word that doesn't mean enough. One Mom said if you just give me credit for managing I would really appreciate that. Or that I'm coping. That I'm handling it. But acceptance
sometimes infers or implies that I'm now embracing this with all my strength and all is well when it and if truth be told challenge I would rather it was not the case but it is what it is so I'm coping and I'm managing. To talk a little bit about coping strategies there are some legitimate ones out there that you probably have found yourself saying on the tough day where is it is just too hard to handle. Thinking about it later is often reminds us of Scarlet O'Hara. I'll deal with this tomorrow. It is often called cognitive avoidance, perfectly reasonable on some of our tougher days or tougher decisions.

I was talking to a Mom who's -- I have worked with her a long time with her little boy that had a cochlear implant and I was supervising her little boy's development of his listening skills. She once mentioned one morning she said to me I met in the waiting room a Mom whose little boy was blind and I had thought there was nothing harder than having a little boy who is deaf. And then I realized this is even harder. I realized to her she was reframing it that this deafness is part of a challenge for her. She had limited resources in terms of family support. But still she could handle it and thought that maybe she couldn't have handled blindness so I was saying to myself she's reframing it and we -- when I -- what I want to always think about only family members can refrain. Audiologists and other professionals are not in a position to say to families at least it is not leukemia or at least it is not life threatening. That is family's work to get to that point in terms of developing and adjusting.

Then another coping strategy of course is seeking support. Some families don't have ready support. Some people are overwhelmed by
support and probably recognize that they're lucky in that regard.

More about the impact. The fact that rollercoasters are exhausting. We mentioned already the motion of chronic grief. It is related also to chronic stress. All families, excuse me, I'll say all parents experience stress. As soon as they put a baby in your arms you're a new person with regards to the amount of stress that you now experience. And we are now eternally vigilant to what is going on with regard to our child's safety, the friends that they're hanging around, with the decisions that they make and how we communicate. But when there is a hearing loss overlaying that condition, describe it as hyper-vigilence and chronic stress because there is immediately more to be involved and again it doesn't go way. Every day it is there.]

I remember once reading an article written by his first or last name was Oswalt. But as he was adjusting to the reality he said everyday he would wake up and say oh, yes. Today, Dorothy is still deaf. And I was thinking that is chronic stress every morning to remember and adjust and then eventually it starts to diminish of course.

With the stress of course comes fatigue. I suspect that most family members would imagine that most other people don't imagine the degree of fatigue that is involved as well as self-doubt because you wonder -- you wonder am I really making the right decisions who can I bounce this off of and who will understand? A sense of feeling underappreciated or even isolation. And then ultimately with the amount of support because there is this notion and counseling that with the supportive environment people do
grow, they do choose growth. And they're stronger for that experience.

My goodness so much energy, right?

All the feelings that parents go through are part of the stress package and here are some that I just picked up as I read David Luterman's classic books on but counseling and families and I started jotting down the adjective that he would glean from family reports and all of them were very demanding on the psyche and I just picked up guilt because it is the number one things that parents feel.

Here is an example of it -- of a situation of guilt that really struck me. It was out from left field. This was a book written by a forest -- a person who works for the forest service in Maine. She works as a chaplain. The book is called "Here If You Need Me," and I was just reading it out of curiosity but she was talking to a family member, parents, whose little girl had wandered off and they were desperately afraid and didn't know where she was. She was out in the deep woods. The forest rangers were looking for her and the chaplain is staying with the family. The Mother said (audio is out). And that is the guilt that we carry that we think there is this expectation that this is what parents are or should have been able to do and of course it is not possible. We don't have that kind of control and we don't have that kind of immunity from the things that happen. But it reminded me of more than one and I think it tend to be Mom that maybe mention that to me but a statement along those lines that a good Mother would have known this. And I just -- there is nothing to say there except to know that that is the burden that they're carrying.
Another word a parent said let's put acceptance aside and think about somehow I'm going to rise above it and deal with it. It won't be easy but transcendence is another quite inspiring word. It does bring to mind that notion from Carl Rogers who would say we are genetically disposed toward growth as long as we have the safe environment we know we’re surrounded by people that trust us and hold us in their goodwill that. We will be faced with challenges. That is the nature of life. But we will also choose growth. Some strategies that support group are to lean on others. I'm sure after you parent in this audience, you're already doing so and also focusing on deciding on what are our desired outcomes and focusing on them.

This set of outcomes was reported by a Mom who had heard speak at a key -- as a keynote speech while I was in Colorado. She just described her family's journey and her little girl had not been identified with a hearing loss until she was about age 3 because it was before early newborn screening. And they decided after -- while the dust was settling they decided here what is we're going to do as a family. They wrote it down. They had a big family powwow. They wrote it down and summarized it all on a 3 X 5 index card. That 3 X 5 index card came to every IEP meeting and was placed in the center of the table because they didn't want to lose track. They didn't want to lose focus of the desired outcomes. And for their family they came up with these six. Our child will become an adult who has positive self-esteem. Who values hers and is not afraid. Our child is responsible. In other words, assumes responsibility for her decisions with guidance as the child gets older. Our child will be
self-sufficient and independent. And by that what they meant is she will get a job and she will pay her own taxes and she will live as anybody else is expected to do in the United States. This was a family value that she would be a lifelong learner because that is what the family valued. She will be a problem solver. Which means now when we start scheming out how to help her reach those desired outcome that she will acquire and we will make sure that she develops problem solving skills and kind of thinking bigger, you know, outside of the box a little bit she will have friends. She won't be isolated and living only within our family's tent. But she will have the usual social skills that kiddos need to develop friends.

And then when they sat back they were -- the parents reported that they realized this was not unique to the little girl who had a hearing loss. It was exactly what they expected of all the children in the family. It happened to be a big family. And they said this is -- there is this extra wrinkle. She has a hearing loss but this is exactly what we're shooting for all of our friends -- excuse me -- all of our children. I really enjoyed learning this lesson from families who said we actually thought about this long and hard up-front. What I appreciate is that families regardless of whether there is a hearing loss involved or not it is a miracle that one gets through the day, isn't it, that life is so complicated and schedules are so tight and so many demands on energy that it is very hard to think about when my child is 18 or 21 or 25. Because we can barely get lunch made. But at the same time how helpful it is to think long-term. I currently have a passion to help audiologists think about not the long-term but the mid-range term k we help families think about preliteracy skills? It has all to do with listening of course and that means optimum amplification and all
the duck in a row that child is ready to read when he or she attends first or second -- excuse me even kindergarten and first grade. That is a reasonable -- a highly expected goal actually isn't it for people in the United States?

So this is one of my favorite quotes with regard to families. And parenting. That it is somewhat related to rollercoasters. I couldn't quite tie this together. This is more about a little girl spinning around and around rather than families going up and down but the quote is this you don't really understand human nature unless you know why a child on a merry-go-round will wave at his parents every time around -- and why his parents will always wave back. Thanks to everyone. Now I would be glad to take some questions.

>> DONNA: What we would like you to do at this point is everyone type your questions to Kris and you can just do that in the question and answer area. Of the screen and Kris will get back to those for you and meantime what I would like to do as you're typing the questions is just go through our events for HOPE Online. On October 7th we will be back with Ashley Garber for part 2 of you lead the way and Ashley did Part I already. If you miss that and you want to see it, it is archived and in the hope area of the website. That is www.cochlear.com/HOPE and that is where these are always listed so she'll be doing that one and then October 14th we ave Lisa Christensen from Arkansas Children's Hospital and she'll be talking about pediatric use of the BAHA. And looking at it from SoftBand to implementaion in a child. And then on October 23rd, we're going to click or kickoff our adult HOPE Online session. This is the beginning of four programs that are on adult rehabilitation. This is a new emphasis for us for
HOPE and those are you that are professionals and work with adults or want to work with adults or have adult patients, I really hope that you will share information about this or come and join us yourself. I'll be doing that one with Nancy Shank and Nancy is an auditory-verbal therapist and audiologist and a teacher of the deaf and that is a two part series with this first one being on the wants and why for rehabilitation of an adult after a cochlear implant. Then part two is focusing in on particular in or on working with a professional and who that professional might be. I encourage you to join us for those that are interesting to you.

I also just want to remind everyone that this session will be recorded. All of our sessions actually have been recorded and we have over 60 HOPE Online seminars that are up on the website. These have actually been organized into learning modules so you can pick a topic that is interesting to you. If you're interested for example in mainstream fog a child we have that as a module. We have a number on auditory learning and we also have a module that is just for parents and we selected our HOPE Online courses that we feel word useful to parents. I encourage you to check those out.

Just a word about an upcoming live event. On October 21st we will be collaborating with the nutrient with an evening event supporting environments for children with cochlear implant and so the night before as you're -- is for parents and the day time one is for professionals in educational settings. Our featured speaker is Sheryl Johnson who is a wonderful educational audiologist who has really a long career in this area.
So there is information there about going to the registration online site or you can go to the HOPE area on the website.

If you have additional information after this, Kris has very kindly (audio out) saw on the screen and send that back to HOPE feedback for professionals who need that who are continuing education credits. The feedback form is another mechanism in addition to the CEUs in the American Academy of Audiology and ASHA that you can seek from us. With that I'm going to turn the floor back to Kris. Looks like we have got some good questions there. And so we'll get to that part of the program.

>> KRIS: Okay, thank you, Donna. First of all I'm looking at some of these questions and realize I had not tapped into all the professionals who might be here. I apologize for not asking about attendance from SLPs and others. I just kind of froze up on that part and forgot. One of the first questions that came up is from a parent who says I feel like I experienced a mini version of the rollercoaster with every transition. For instance starting preschool, kindergartener garden and so on. Have you heard this from other parents with hearing-impaired kids? Yes, in a nutshell. Every parent goes through the rollercoaster when there is a change. The preschool years can be -- everything is under control. You know where your child is. You are pretty much under a certain sense of maybe delusional but you do have a sense of control over the situation. And then you put your child into a classroom and you walk away and it is pretty devastating.

Now -- then you adjust, don't you? And then what occurs to me when I talk to parents is when their child has a hearing loss it is like
rollercoaster plus. There is the usual rollercoaster we all experience with the new life changes and then there is this extra level that heightens the intensity of the rollercoaster and to be honest once I talked to a Mom who said there are days I just want off of this rollercoaster because the intensity is so powerful. I'm not necessarily ready for it on a regular bases. So to your answer, to your question rather, I would absolutely agree that this is a very common experience to all parenthood and then there is the extra level of drama or intensity or pain or anxiety that occur when is there is something extra or additional to think about with your child's situation.

I'm just going to pick these at random. It is all overwhelming at first to parents. Is there any model about how to help parents?

My only model that comes to mind is simply to be there. Parents appreciate from what I understand from reports is that there is a sense of support. There is a sense of trust that parents can and will make good decisions. They may feel insecure and on occasion wish that someone else could take this away from them because they're not preparedness but they make good decisions throughout the rest of their life and they will here.

The model that I talked about with my friends about this is can we think about a side-by-side. We're on this journey together. Shoulder to shoulder. I'm not dragging you along or pushing you to make decisions you're not quite ready to make but at any time you can look to your side and there is someone there for you. There is a professional all colors who understands and it is there and waiting for you. I hope that answers a little
bit your eye of a model. Let's see, what do you see or what -- what do you see is the roller of the SLP or audiologist with helping families move along the grief rollercoaster and not remain stuck in one stage? That is a really interesting question because there is no definitive time frame to say okay we can expect this to happen and then things will evolve but there is a gut reaction when in fact you know that things are not moving forward like they should. I am very comfortable at this stage in my life and have to acknowledge I was not comfortable with it when I was younger but now I'm very comfortable in saying I am actually concerned that we are not moving forward. There is a sense of urgency and I know you feel it and we talked about it and it could actually paralyze or frighten parents to where they're not comfortable to making any decisions. Is there anything to do to help? Sometimes that kind of breaks the ice enough to say well here what is on my mind. I haven't been able to articulate it before or aye some deep seeded worries and sometimes it is a notion it would be helpful to talk with other families or be helpful to talk to really a professional counselor, some hospitals for instance have social workers that are skilled to have families talk their way through it and recognize that they have thrown up some barriers that are not in anybody's best interest but they don't even understand them. That is what I tend to notice at first. Initially. So what we may say as being stuck a family may not say is being stuck but there is a sense of things need to be accomplished in somewhat of a timely fashion. Here is a truism that I hold on to what I'm wondering. When I'm wondering about things. Here is what we know about human nature. If I push you, you push back. People don't like to be pushed. So one of the first things I would do is ask myself am I pushing? That would explain a lot. That would explain why a family is pushing back. So I need to ask
myself and then I have gone to families to say have I gone too far? Have I been pushy? Has that border you is that what might be accounting for some of the worrying that are on your mind now? I don't know until I ask.

I think we maybe have a little more. I see my friend Jane and I'm going to take her question. No preference here but do you have a reference for the gender differences that you described? Yes. If you look and Jane I can send you some more information on it but the classic information is quoted in Taylor's books that went on the tending instinct. Her citations in the back of the book will get you into the deep background what she came up with in terms of measuring. I really had a -- like a little laboratory experience in my own home. I mentioned 9/11 just a while ago. On 9/13 my daughter who is in her mid twee called me and said Mom I made a decision. I'm going to buy some property and build a house and I'm going to be a foster Mother for say six kids. And I was speechless because you don't know my daughter of course but my daughter has no maternal instinct in her entire being. She's never baby-sat. She's never -- she would laugh to hear this story she doesn't even remember doing this. But it was this need to tend and be definitely a need to tend. She had the instinct to somehow preserve humanity perhaps but she had to say let's wait on that. My son who was Mr. Piece nick himself he had a job delivering office supplies at the time and he was driving around his truck with a gun under the seat of his car because we didn't know if we were under attack or not. So he was fighting. My daughter was tending. Neither of them not their natural reaction but understandable to stress at this point. So I -- it helps a lot doesn't it to understand human nature and I'm thinking depending on which clock we have two minutes or we don't.
I'm going to ask for guidance. Donna what would you recommend? Okay I'm getting the two minute. Excellent. One more question just randomly selected. The biggest gap I have experienced in my new journey is getting in contact with other families with a deaf or hard of hearing child. Any suggestions? I don't know what state you're living in, Tracinda, one of my favorite groups of all time is Hands and Voices. It is an organization designed for families not dedicated to any communication mode but to help families communicate with each other and connect with each other and of course I imagine Cochlear Americas has an organization or some supports as well. That is not my area of expertise to speak on. But if you were to go to Hands and Voices, all one word, dot org you can click on your state and find out if there is a state chapter. Also, A.G. Bell, agbell.org. And if you go to their state chapter they can help you get direction as well. Even then it might not be helpful -- the Mom I mentioned talking to on Monday she needs something in Akron and there is things in Columbus but that is three hours away and Cleveland is an hour away. I know that it is not simple.

>> DONNA: One thing just to add to that, we are (audio has gone out) and contact them if they so desire. So that should be really up and launched in maybe a month or so. So that would be another great way if -- if your child has a cochlear implant. It is really for families that have children with cochlear implants or adults with cochlear implants.

>> KRIS: Thank you. That was good to know. I had a feeling there was going to be an update on that. The first person that sent in a note, let me get to that one. What would be an example of how you would respond to a parent who voices concerns that their child is being teased? One of the rules of thumb in counseling is to simply be a good listener. There is
nothing that you really can do about the teasing part. I do know of one Mom who taught me a very important lesson. She had talked to her child early on that there is going to be moments in the child's life where there would be teasing. And she's told her -- the little boy whose name is Ryan and she told Ryan you actually have a choice on how you can react. You can be embarrassed. You can be angry. Or you can decide this person really doesn't know what they're talking about and that is not my problem. And I -- that sounds like a very sophisticated conversation that you would have with a teenager but she actually started talking with him about that before he started school anticipating looking down the road at the things that might happen that might really throw him for a loop. She called it bumps in the road. They would talk about what kind of bumps in the road might there be? There was this anticipation of like how to develop a wise child I would think of this way to describe it. I happened to be with them -- this is how he learned about it in the back door. We were standing in line in McDonald's waiting to place an order and this is back when colorful ear molds were quite new. This shows you how old I am I suppose. At one point a child turn around and says as clear as a bell everyone in the restaurant could hear look Mommy he has bubblegum in his ears. My first reaction as a Mom who would know how my child would react is gosh this is going to be devastating and instead he looks to his Mom and his Mom looks at him and they both nod. That was it. And I couldn't stand it. So later on I said so how come Ryan -- what was with the nod and how come Ryan wasn't upset? And she said here is what we had cued ourselves to do. If he was thinking this is a bump in the road look at me, and I will nod to let you know yes you're right. This is a bump in the road. He nodded and said okay many she was deciding not to let this bother him and he
truly shrugged that off. I said that is so remarkable. I wish I knew that when I was raising my own children to anticipate that people are probably going to hurt your feelings. Let's we're going to give them -- be generous, give them the benefit of the doubt even if they're mean to everybody that is their problem, isn't it? In fact it is simply ignorance because they don't know better. That is their problem. I'm doing my best to be a kind and thoughtful and generous person and probably can't manage that. So that is all I can provide in terms of advice and again it is from a parent who lived the life, walked the journey to say here is how we handled teasing. We knew it was going to happen. We talked about it beforehand when it happened we talked about it afterwards to say it is going to happen. And we have choices in how we react.

I think what I will do is we do have some time I'm getting the note from Melissa we can keep going if we choose to. What I'll do is agree to say we can do one more. Let's see. The rollercoaster model does it eventually lead to a circular model where coping settles into a cycle and becomes available to the parents as new challenges present? That is a very good question and my answer or my hunch would be yes. If you start developing coping strategies that work for you you're going to return to them. If you find, you know, you attempt a coping strategy that is not particularly helpful you probably will put them by the wayside. That is a good idea. That is a good way to visualize it there is going to be this return this, cycling event because you have tested them and you have confirmed that in fact they have been helpful to you after all.

Well, I do want to thank everyone for your attendance. Do take use
of my e-mail I would love to hear from you all, your follow-up and thoughts on this. It takes a while for the -- for the questions to percolate up. I'm that kind of a thinker myself. Thank you.

>> DONNA: Thank you very much, Kris and we'll see you again soon.

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