TED & CEC Collaboration Podcast Special Series: Interview with Lacey Henderson

Unknown Welcome to a special series of the TED and CEC Collaboration Podcast. In this series, we hear the stories of families, educators, and researchers who may be impacted by changes to the Department of Education, IDEA funding, and Medicaid. Lacey Henderson is mother to six-year-old Estella, who was born with alternating hemiplegia of childhood, or AHC. AHC is an ultra-rare neurological disorder that affects one in one million people and causes episodes of paralysis and dystonia that can last for days at a time. It is known as the mother of all neurological diseases and is described as having seven neurological disorders in one. Autism, Parkinson's, Alzheimer's, ADHD, epilepsy, stroke, and cerebral palsy. Lacey and her husband, Stephen, are very active in the AHC community and have dedicated themselves to research, raising awareness, and are actively fundraising for a cure. Lacey is a registered nurse and lives with her husband, Stephen, and their five children. Welcome, Lacey. Thank you so much for having me. We're really glad to have you today and to just hear your story. So start off and just tell us a little bit about you and why this topic is important to you. Yeah, so um, like you did your wonderful introduction of me. My name is Lacey and um, my husband and I have five children and our fourth child was, uh, very unexpectedly born with an ultra rare neurological disorder. Um, she was developing normally. Um, we had no idea anything was wrong with her until four and a half months old when she had her first What we now know is an episode of AHC. But it took, it was a very long path to get the correct diagnosis. We were misdiagnosed two times. And once we did get the correct diagnosis, we quickly learned we were in way over our heads and we were thrown into this world of what we knew would be she would have special needs and she would be severely disabled. We had no clue. Our older three children were perfectly, um, what I'm going to call normal and, you know, developing typically, and we, we just, um, had, had no idea this was coming for us, so. This has now become a topic that is very important to us and very near and dear to our hearts as these things usually do once you're affected. Before we were affected, we I mean, I, embarrassingly enough, um, I didn't pay much attention to it. I wasn't impacted in any way, shape, or form, but now that we are, it's, it's a very important topic to us. I think that's an important, um, just an important point to make that sometimes when we don't know, you know, it's hard to understand and so until you live something like that so. Um, you know, I'm blessed to be able to know you and Steven a little bit, um, more than maybe some of our other guests that I've been able to interview. And so just being able to Talk with Stephen occasionally about, you know, your guys' life. It's just always, um, inspiring to me all that you do for this community. And so I, I think again, We don't know what that life is like. So just walk us through a day for you. So what's it like to be Lacey Henderson? Well, um, there are no two days that are exactly alike, um, and no matter how much I try to plan something, it doesn't mean that it is going to happen that way. So we have what we call good days and bad days. Um, and we don't know how a day is going to be until it's over. Because it's so unpredictable. So I will walk you through today just as an example. So today, um. Yeah, Estella got up, she's waiting for her clock to turn green at six o'clock in the morning, and she jumps out of bed and tries to open her door, um, and, you know, She this morning was great, so we did our normal routine. She does take medication. We do have to feed her. She doesn't feed herself, so we feed her her breakfast. Give her her medication. We have to dress her, do her hair, and brush her teeth. We have to do all of that for her to go to kindergarten. Um, and then she goes off to school, um, uh, What we call her van comes to get her and it's a driver and her associate rides out here and picks her up to school and then she's off to school today. But as you know, we were supposed to have a nurse today meet her off of the bus and um, our nurses She is sick. So she called off. And so, um, whatever I had planned for the day is now over. And we had to adjust times for this too. Um, so we'll come home from school and she will likely be in an episode today. So, um, what an episode looks like is she loses all control of her body. So it can be triggered by things that We call life being a trigger. So, um, too much sun, wind, heat, cold, water, excitement, overexertion. And overexertion means like walking too far. Um, not, you know, like running a mile. Those are all triggers for her. So when she does have an episode, she will either become paralyzed in part of her body or her entire body. And then she also gets dystonia. And dystonia is our worst symptom. It's incredibly painful for her. We just, I mean, we don't know what it feels like, but, um, because she can't tell us, she's essentially nonverbal, but she will get, um, a muscle, it's like a charley horse in your leg, you know, that sometimes wakes you up in the night. But it can be her entire body. And I kind of describe it too. It kind of seems like a labor contraction where, you know, this is the nurse coming out in me. But, um, where, you know, it kind of, it starts to come and then it builds and it builds and it climaxes. Sometimes at that climax she'll actually pass out because the pain is so horrible. And then it'll come back down and that can last for um, days at a time. So Her longest episode is somewhere around twelve days where she's just unable to function. She'll lose her ability to swallow so she can't eat or drink. Sometimes she can't hold her head up, but it also waxes and wanes. So, um, sleep aborts all episodes and it might only abort it for thirty seconds, but it might be three hours or it might then be over. We never know until it's over. So anyways, back to my day. Um, she's gonna come home from school. I think she's probably gonna be in an episode because yesterday she was an episode off and on all day. Um, but then my other kids are gonna come home from school too, and so I'm gonna have to try to balance, um, being mom to four other kids and mom to Estella, um, and being a wife. And you know, I still am expected to have supper on the table and not, I should back up. You maybe came out wrong. But like that, I figure that is my role. That is something that I enjoy to do. Um, not that anyone forces me. But so, um, like, I made supper this morning because I knew I wouldn't be able to do it tonight. Um, and then, yeah, we will... We'll take Estella on walks. We will do anything to keep her calm and quiet. The really hard and frustrating part of HC is that She's mentally completely aware of what is going on. So she's, she's trapped in her body when she's paralyzed. So maybe, um, you know, she might be hungry but she can't swallow and she can't tell me she's hungry because she's, she is trapped. So that's the hardest part. So we just do, like, we do silly things and we, I try to make her laugh and we, um, watch her favorite shows and we rock, you know, just things to keep her happy and then. She'll go to bed and then we can breathe for the night and know that today was either a good day or a bad day and we wait until tomorrow again. So you've talked about, you know, what that day looks like for you. How does that impact your other kids? How does that impact her siblings? Yeah, that's a really good question. Um, we thought that they were not so affected. We, we thought that we were doing a really good job of really shielding them from the, the negativity of AHC. When she starts to scream in that dystonic pain, we take her away from the other kids. So we'll go into her room because it's dark and it's quiet and she can relax and calm down in there. And then the other kids just kind of play. But what we're learning is that that's not the case. They are actually severely impacted by AHC. And so we're just doing our best now just to try to really pour into them when we can. And so we do have nurses, which is amazing. And one of the biggest reasons we have nurses is to spend time with our other kids because Estella requires 100% one-on-one attention at all times. And so this allows us to be with them. So when we do have a nurse here, which is, we do have good, we have amazing nurses and we do have pretty good coverage. We, um, typically are with our other kids and so, you know, we, uh, we'll take them away from maybe the noise of AHC. Um, but yeah, we're, we're just doing our best trying to navigate how they are impacted in there. You know, there's four of them and they're all impacted differently. And so our youngest just last night. He's three. And Estella was in an episode and she gets high flow oxygen when she's in a dystonic episode. And so I was sitting in her room and typically I'll take her back there or my husband will. We'll close the door and then he just plays with everybody else. But he came in last night and he saw her getting hurt. She has an oxygen mask with a bag underneath of it, a reservoir. And he's never seen that before. And so he came in. His eyes were just as big as saucers. And he's like, what is Estella doing? Yeah. So, and my husband came in too and he's like, What do you mean? And he's like, what is, what is that attached to her face? And we had no idea that he, he'd never seen that before because we had shielded him from it. But, I mean, he knows that she has episodes and stuff, but... So that was, I mean, every day it's eye-opening how they're impacted. Absolutely. Yeah. Well, and, you know, I was thinking, too, about, like, how do you balance... The, um, I don't want to say the guilt because I don't ever, I don't think that that's always the right word, but maybe that's how you feel at certain times of Spending time with your older kids and prioritizing or and the little guy too, uh, but, but prioritizing that time when you know Estella needs so much and. You know, as a, as a mom, I think sometimes my own experience has been, you know, when my child is sick, I want to be that person with them. I feel like that's my job, my responsibility. They want me, um. So how do you balance that for yourself to, again, prioritize kids, prioritize your own well-being when You know, I'm sure that is exhausting if those episodes last hours or days and then, you know, just life outside of family too, like being able to work or do something for yourself. Um, that is a really great question. Um, and I definitely don't have the correct answers. Um, I have what is maybe... What we are doing and maybe not necessarily working for us, but what we are doing. I think those can be two different things. But, um, when Estella was first diagnosed, she, she was like almost nine months old when she was officially diagnosed. And from nine months until about age three, I would not let anyone else be with her during an episode. So I was home. She was mine. And if she was in an episode, like, no, that was all me. Nobody else was good enough in my book. Um, but then, um, we had her little brother and I can't, or I couldn't be everything to both of them. And obviously when you have a newborn baby, you have to kind of extinguish some of that control of your husband. And so that was kind of a page turner there. And then we also made the really, really tough but important decision to send her to school. Um, when she was three. She did early intervention and that was something we actually weren't going to do. We were going, we were planning on homeschooling her because I just couldn't imagine anyone else being with her during an episode. And we decided to send her to school and just, and she got the most amazing associate, the most amazing preschool teacher. And even as far as like the person who drove her back and forth to school, we were all just amazing. And so that was a really important step for me to see, wait, other people actually can Do this. And other people actually want to do this. Yeah, they care about your kid. Yes, exactly. And so that was amazing and a really important thing that we did. And so just kind of that realization that I don't have to be the only one. And so, yes, we started sending her to school. We then also got nursing services approved and got some nurses hired. And that was a, I would say, a one-year transition to Where she would allow someone else to take care of her while I was still home. And that's still something that we struggle with is that when she's in an episode and I'm here, she wants me. And that's not, sometimes that works and sometimes it's like, no, it's not like you with your nurse right now because I've. You know, I prioritize myself in other ways. Um, so that is just what we have done. That is what is working for us. Now she goes to school. She goes to kindergarten. She's there all day. And the, um, the school there, I can never say enough good things about the school district that she is in and her teachers, but kind of just having other people to share that load with. Has been really. Life-changing over the last, she's six and a half, it's been life-changing over six and a half years. That's great to hear that you feel that, just that connection with the people who can provide that additional care and That appreciation because, you know, not every family has that where they have that level of trust, um, in others and so I'm glad you, you guys were able to find that. So, um. Um, would you speak a little bit about some of the services that Estella receives? So maybe like services that she gets at school through her IEP? And then maybe services that she gets, um, outside of school that your family has explored and that sort of thing. So at school, it started with the early intervention program. Like I said, she started school when she was three. Actually, two months before she turned three, she started school. And she started with getting physical therapy, occupational therapy, and speech therapy at school. And her IEP also allowed for a one-on-one associate because she does need that one-on-one help. And that also, um, gives her, someone picks her up with the associate and drives her back home. They come to our house and do all of that. And, um, Her IEP also allows for her to eat when she can at school, which is really, actually a real, it sounds so insignificant, but it's actually really important for Estella because Like today, if she was in an episode over lunchtime, she wasn't able to eat. But if maybe she slept a little bit and if she's awake right now, she might be able to swallow for a few minutes. And so that gives them the flexibility to, hey, Estella gets to go eat right now. And then it also allows for her to nap at school. So sleep is a really important thing. It's actually like called the miracle drug of AHC because it does abort episodes. So she can sleep whenever she requests to sleep. They let her sleep. So those are the things that she's getting at school, um, specifically. And then they, they modify the curriculum to work for her. She is delayed. So she's six and a half. She's a kindergartner, but mentally she's not six and a half. And I don't, I don't dare say how old she is, but I would guess maybe like a four-year-old mentally. But they modify that curriculum for her to work for her. Her hands do not work very well. Um, she had a bad episode when she was twelve months old and it It permanently disabled her right hand. So she struggles a lot with her fine motor with her right hand. Her left hand is better but still not that great and so they modify things and her IEP allows for all For all of that and things that I don't even understand because that's their world and I just, and we trust them completely. We know they have Estella's best interests in mind. So we just... They run things by us and we say, yep, if that's what you think is best, we are on board. Um, so those are school services that she gets. And then, and I should add too, she has the best cheerleading team at school. They're just amazing. Outside of school, um, we do Physical therapy, we do occupational therapy, we do speech therapy, we do hippotherapy, which is horseback riding. Um, and I think that's it that we do outside of school for services. Okay. So thinking about any changes that could be coming, um, and we'll kind of get into maybe some of the research side of things. I know you, your family is very involved in that as well, but If there were changes to the Department of Education and IDEA, so that special education law, um, that would potentially Shift, um, special education services under health and human services where then we maybe don't have that educational oversight. Do you have concerns about that and the type of services that Estella might receive at school? Yeah, I do have concerns about it. The shifting of it from the Department of Education to the Health and Human Services is the first thing that I'm concerned about. Because anytime you have education oversight from someone without an educational background, Is a little scary. Um, they don't know necessarily what the priorities are. They don't know, um, you know, kind of the ins and outs of and why things exist the way that they do. And so that part is, it is. Concerning to me. Um, the other part that's concerning to me is that she would lose services that she gets. You know, everything In the disability world is a fight. And in our experience, everything has been a fight with the exception of school services. Again, our school system is incredible. And that has never been a fight. And but, but I know the fight of every other aspect of her life. And so my concern is, is that going to also become a fight? Am I going to have to fight for her to have an associate? Am I going to have to fight for her to get picked up not on a regular school bus? Am I going to have to fight for her to receive speech therapy at school? And I don't want to. And I don't think that we should have to. But those are my two biggest concerns. I think those are really valid concerns. And You said it so well that everything I'm sure has been a fight in terms of, um, just types of nursing care, potentially medications. Um, would you talk about that a little bit? Just kind of what has that been like in terms of insurance? You know, that's always a big one that, um, I, I mean, you know, for Even just a family who maybe doesn't have a child with a disability or anything like, you know, there's always insurance problems, right? So I can't imagine the fight that you've had potentially with that. Could you speak about that a little bit? Yeah, so the insurance thing has been, um, I think an interesting experience for me. Because I did not know Medicaid existed for kids like Estella. So when she was born, um, and then we suspected that things were wrong with her, Um, we were told that she should have genetic testing done. And we said, great, like, let's do genetic testing. And then her neurologist kind of backtracked and he's like, well... It can be very expensive and insurance likely won't cover it. And we, and to give this context, we had been in the emergency room. We had been inpatient in the hospital. For days and days. Like, this was not just like, yeah, we should do this. It was like, we are at our wit's end. We do not know what's going on. Um, we need help. So we're like, yes, let's do genetic testing. And again, he said, you know, it'll probably cost, cost you out of pocket. And we said, well, like, we don't care about how much. And he said, probably $15,000 We're like, well, we don't exactly have $15,000 just to give to a genetic test. But again, we're desperate. We don't care. And so we did the genetic test and it cost us zero dollars. We had already met her insurance deductible and we didn't have to pay anything for it. So that was just kind of the first like, well, there was just such a disconnect there between what we were told and what the reality was. And if we had not done that genetic test. We would not have gotten a diagnosis as quickly as we did. Um, typically, we got diagnosed around nine months old. Um, typically kids are not diagnosed for anywhere twelve to twenty-four months is pretty normal for AHC kids because it is so rare the doctors have never seen it before. So anyways, um, we went through the first two years of her life just with, um, her being on my husband's insurance through his employer, which in my opinion is great insurance. Um, and we didn't know that anything else existed. And then I don't even remember who somebody said, well, is she on Medicaid? I'm like, well, no, we, like, we have jobs. We don't, we don't qualify for Medicaid because that was my perception. Mm-hmm. And they were like, no, you should call. And so I called and oh yeah, there's Medicaid for kids with special needs. Here's a packet to fill out and she qualified. And so from that point forward, it was like this door opened up and we're like, wow, we don't have to pay. For all of these things out of pocket anymore that we had been. And so Medicaid for our family has been such a blessing. And just the things I did not realize. Were the services that are not covered from our regular insurance. Again, this is through my husband's employer. I think it's great insurance for your normal family. They don't cover a wheelchair for Estella. Well, she's six and a half years old and can't walk sometimes. She has to have a wheelchair. Those costs, her wheelchair costs $8,500 Oh my gosh. So, and it's just a regular wheelchair. It's nothing special. It's a pediatric wheelchair, but it's so, so primary insurance said, no, we don't, we don't cover that. But Medicaid says, oh yeah, we do. So Medicaid picked up that tab. Whereas otherwise we would have had to pick up that $8,500 tab. Um, her, her AFOs, her leg braces, she has to get new leg braces about every twelve months. Those are $1,700. And primary insurance does not pay for that. Medicaid does. Um, the biggest thing though is her nursing services. Her, her primary insurance, they do not cover in-home nursing. Medicaid does. Um, our Nursing services are billed at $250 an hour. So, you know, if for someone, obviously the nurse doesn't get paid $250 an hour. But, you know, for them to have, you know, benefits and insurance and, you know, it goes to a corporation. Um, so if we were to pay for that out of pocket, it would cost us about $700,000 a year. Oh my gosh. Again, her insurance doesn't cover that. But Medicaid does. And so that is something that I don't I did not know before Estella, and I'm guessing most people don't know, but it's still not perfect. There are things, um, That medicaid is not covering that I really need them to cover so again here comes the fighting um But you know just the things that they have covered though. We are we are so grateful and I cannot imagine A world where they're not, where those things aren't covered because it's not, it's not practical. It's not feasible. It's not possible for a normal family like us to come up with. Yeah, and you mentioned how, you know, you both had jobs, and so it was, you had jobs, you had insurance, you were a two-income family, and so even with that, those types of costs are not sustainable. Um, for even a family, you know, when sometimes people are like, well, but, but you're working, right? But that isn't always the case. And so, um, I'm going to be really honest. I don't know, um, I don't know the Medicaid proposed changes like I know maybe the education proposed changes. Are there anything, any conversations happening right now in the Medicaid world that you're concerned about? Yeah, and I don't know all the ins and outs either, to be honest, right back with you, but I do know that there are proposed cuts over the next ten years to cut billions from the Medicaid budget. And that is just, it's concerning because of how much we rely on it. And, you know, we know from experience that typically services are cut to the most vulnerable people. Yeah. And we are the most vulnerable people. And, you know, Estella's disease in specific, it can be so, um, Misunderstood because you, if we have someone from, you know, let's say insurance would come and do An assessment on Estella. Because I'm claiming that she, you know, goes paralyzed and she can't swallow and she has these horrible dystonic attacks and she stops breathing sometimes and I can tell you that, but maybe insurance would come to assess her on a good day. And on a good day, you're gonna see a six-year-old who's laughing, having fun, talking a little bit as, you know, to the extent that she can. Walking, eating, and you're gonna say that that woman is crazy and she is trying to get things from insurance that, that Aren't, aren't for her. And so that is where, um, I get specifically very concerned is that those cuts are going to happen. They're going to impact us. First hand and that we will see the negative impacts of that with the care that we require for her. Which could be really scary for your family, you know, so I think in other conversations I've had with folks that's just kind of that fear that is settling in and Not knowing what's coming, which, you know, just from talking with you, that's probably a day-to-day, you know, feeling you have anyway, just um. What is it that, what challenge might be in front of you today, you know? And so, um, and just that fear of, of Estella's well-being, you know, I think, you know, your husband and I, Steven, have talked a lot about In the world of special education, sometimes we're so focused on the can'ts. What can't this child do? They're not able to do that. And so you want all of those good days for Estella and you want the days where she can be, you know, feel like a typical six-year-old where she gets to play with her friends or her siblings and be outside and so. Um, I'm sure that's really difficult to, to balance, again, the, the potential fear of what if and what might happen with Enjoying those moments where you get to see her be her most lively self. And so, um, I'm sure that's just a feeling that that comes to you often. And so I want to give you an opportunity because I know You and Steven are really involved in the AHC community and you've done a ton of work, um, raising awareness for AHC, um, and in the foundation. Could you speak a little bit about that part of your life? Yeah, so when Estella was first diagnosed, um, we had never heard of AHC. And we, um, you know, obviously didn't know anybody with the disorder. And it's a one in a million disease. And there are right now six kids in the state of Iowa that have AHC. And so we, honestly, we took the first year or so that she was diagnosed and we just, we just kept to ourselves. We, you know, we told our family, we told our close friends, but otherwise we didn't, we didn't talk about it. We just mourned. Just with, without the public knowing all the things. But then after about a year, um, As you know, Steven, he had to get involved. And he reached out to one of the foundations for AHC and he said, hey, I want to help. And he ended up just kind of throwing himself into the The AHC community and specifically focusing on research. And we ended up that every year the AHC community has an international symposium where Researchers, doctors, um, clinicians, family from all over the world meet and we went in the year, um, let me think, 20... 2022, um, we went and, uh, to that symposium in Scotland and Steve ended up meeting Some of the, I'm going to call powerhouse families of AHC. Just the hyper-involved, really making changes. Absolutely incredible people. And he, we met them and Steve just, um. Yeah, really got involved with the research side. And so we decided that we need to do more. So we ended up, um, starting a foundation for Estella, Estella's Wish, and And we are raising money through awareness. Um, we have found that we can describe AHC as much as we want to. I can tell you that she gets paralyzed. I can tell you that she gets dystonic. But unless if you actually see what that looks like, you don't actually know what I'm talking about, right? Like, a lot of my friends, truthfully, they thought that Estella, when she was paralyzed, laid on the couch and watched TV all day. Oh. Because like, we hadn't really told that much about it and like, oh my goodness, if that's what my, the closest people to me think. There is such a misconception of what, how horrific this disease actually is. And so we decided that in conjunction with starting Estella's Wish, we would also start an Instagram page. That would, we would show videos of, of what an episode looks like just to raise awareness, to raise funds. And, um, so that's where we're at right now is we are just still in that process. We are, um, Working on a cure with the AHC community, um, there is no treatment for AHC, there is no cure. Because it, I mean, it is so small, it's such a little orphan disease. So we, um, as a community, we have, um, some research projects going. We have three different pathways towards a cure and they're all Really showing promising results, so we are so hopeful that this will lead to a treatment and a cure for Estella, but also knowing that Sometimes we have to remember that maybe we're not working for Estella. Maybe we're working for the kids that are going to be born in five years that have AHC too. But obviously she's our... She's our biggest reason that we're doing this, of course, but. So that's kind of like the. Really highlight of what we're doing. Um, I could get down in the weeds about it and talk to you for a really long time about research and genetic therapies and all of that, but I won't. I wouldn't understand it, but I'm sure it would be fascinating. I can't, I can't claim to understand it totally either. But, um, it's just amazing the people that we have working for AHC and what they're coming up with. Just how promising a cure and a treatment is for her. That's so exciting. And I know just I should probably let our listeners know that your husband is a colleague and friend. I consider friend as well. So, you know, just, um, for their context, they won't get it now till the end of the episode, but, uh, but I think, you know, that piece of being able to have those conversations and so, um, Once I knew about your Instagram page, you know, that's where I went to and that's where I see videos of Estella and I like you said, you know, you don't really know what that's like until you see it and Um, you know, she's been, she's been to work with him or I think maybe you brought her by one day. And so, you know, when she walked in and was able to sign and all of those things, you know, She does appear to be just a typical little kiddo. Um, and so she just walked right in and, um, so I think, like you said, there are just these pieces that Are misunderstood. And so on a day like that, people, you know, don't know what she might be experiencing at another part in her day and maybe not long after that happened. Um, and so I think that that's just, you know, an important distinction. So, um, what, you know, I just want to give another opportunity for you to share a little bit about like, what do you suggest, um, How do you suggest, I guess, families get involved? So when we talk about advocacy and awareness, how can families do that? While trying to balance some of this, um, I have a child who needs me all the time or I have a job or, um, Um, I have other children like what are some steps they could take maybe to enter into that world for their own child? Yeah, I, I think that's something really important um, to do is just remember that you're doing this for your child. When Estella was born, I didn't have social media. I didn't have Facebook. I didn't even, like, I'd never been on Instagram. I didn't know. I didn't know anything and I love that. Um, I'm not a social media person. And, um, I would say my husband and I, we live pretty, like, Surprisingly, maybe to people that don't know us, but we live pretty private lives and we, the thought of putting our life online. Was revolting to me. And actually, I'd had people suggest it for a couple of years before I did it. And I was like, oh, that sounds, I don't want No, I don't want to do that. Um, it's scary and um, so honestly, I, you know, I just told you that I do an Instagram page. I've never told anyone that I do an Instagram page. People have just found out. Um, through people or, you know, it gets recommended or whatever, but I don't tell anyone that I do that. Well, now you have a whole audience that knows that you do this. Yeah. Just because it is so scary to put, to put that online. Um, it's scary to put her episodes online. I get a lot of, um, nasty comments about like, how dare you put her on? And in some ways I get that. I totally get that. Um, But in the same breath, if I don't put her online in those episode moments, how am I going to save her life? AHC is life-limiting. And so she, AHC is going to kill her if we do not get a treatment for her. And so every time that I think, oh, I can't post this, I think, Why not? Like, this is literally how, once, one way that I can try to save her. So, I think for parents, um, just to get over yourself, I guess, is probably the big, the big thing. Um. The other thing too to get involved is just try to find a community Of that diagnosis, we have an AHC community online and those parents are honestly some of our closest people. Not in distance because it's so few and far between, but the people that we feel the most connected with, the people that actually get it, Are the people that have kids with this disorder too. And so just finding that community has been huge for us. Um, and then also just you, you don't have to. You don't have to do a ton. My husband does a ton. Yes, he does. There are parents that do way more than he does in our AHC community. There are parents that don't do anything. And I understand all levels because we're all just trying to do our best and it is super hard to balance with A disabled child, with a medically complex child, with a child who was fine literally five seconds ago and now is choking because she can't swallow. So just... Man, I don't know. That is such a hard question because everybody's capabilities are different and seasons change. Um, and you know, we are at a season where we are able to do these things. Um. But maybe that will change and and I don't post as much as I used to even because I don't have recently it seems like I don't have the brain space to come up with content to post. And so I haven't been as much and I'm like, you know what? That's okay. That's okay. There's a season for it and it'll come back. Hmm. That's very good advice. I think just biting off a little bit at a time and taking it one step at a time is such good advice because like you said, those, you know, capacity will change depending on the season and I think, I think that's so important. Um, you mentioned your community and, and I know we want to wrap up here in a couple of minutes. I don't want to take too much of your time, but um, because I've heard about Estella and her journey. When you talked about your community not necessarily being close in distance and only six kiddos in the state, you have to travel a really far way to see a doctor for Estella, correct? Yes.

Correct. And where do you have to go to be able to get care for her? So we live in Iowa and we have to travel to Duke University, which is in North Carolina. So, um, it is a... Plane ride or like a 16-hour car ride just to get her to a doctor that knows anything about her disease. And we do. Oh, go ahead. Do we? Well, we do have a doctor in Iowa um, just because we have to um, and he's, he's great, we love him, but he's not an AHC specialist and so Um, Estella was his first and only patient with AHC until, um, last year one of the other Iowa families, um, joined with him, so now he has a whopping two patients with AHC. But yeah, that's where we have to go for care is all the way on the East Coast. And so, you know, I think that's That's something that not all of us think about and maybe some days we take for granted, you know, when we think about having access to health care. Um, you know, sometimes I complain about having to drive thirty minutes or forty-five minutes to, um, an appointment because I don't have it in my town and so really putting that into perspective I think is important, so. Lacey, I want to honor our time and I want to give you one last opportunity to share anything about Estella or your family, something you'd like our listeners to know or any last thoughts. Oh, that's like the question I'm not prepared for. I don't, I mean, I think we've covered so much. Um, thank you for having me. It's been, it's been good. It's been fun. Um, I just think it's important to know that changes are Changes to Medicaid, changes to the Department of Education, changes to the Individuals with Disabilities Education Act, those changes could, could, can negatively impact Real families, real kids that are already like, I read a quote and it said, um, you know, each morning these families get up and they are pushing a boulder uphill all day long. And so, um, It just feels kind of like adding a bigger boulder with these proposed possible changes. And so just realizing that these things impact real people is important to know. I don't think I could have said it better myself. So we'll leave everyone with that thought. And Lacey, thank you again so much for joining me today. Yes, thank you.

Jamie Nelson Thank you for tuning in to this episode of the TED and CEC Collaboration Podcast. We hope you found our discussion enlightening and inspiring. Remember, change begins with awareness and advocacy is the catalyst for progress in education. Keep exploring, keep advocating, and keep pushing boundaries to create a brighter future for exceptional learners everywhere. Join us next time as we continue our journey of discovery and action in education. Until then, stay informed, stay engaged, and keep advocating for what matters most. We want to take a moment to express our gratitude to the incredible individuals who have contributed to the TED and CEC collaboration podcast. First and foremost, a big thank you to the TED organization and CEC for their collaboration and support in making this podcast possible. Your commitment to special education advocacy and policy is truly inspiring. We also extend our heartfelt appreciation to our guests for sharing their expertise, insights, and passion with us. Your perspective has enriched our conversations and inspired action. A special thanks to our production team Danielle A. Waterfield, University of Virginia. Caitlin Criss, Georgia Southern University. Nancy Welsh-Young, PhD. Allison Curley, University of Alabama. And Jamie Nelson, William Penn University. For their dedication and hard work behind the scenes. From researching topics to editing episodes, your contributions ensure that each podcast episode is informative and engaging. Additionally, we want to acknowledge the contribution of the production equipment and software provided by William Penn University. Without the tools and technology that enable us to record, edit, and distribute this podcast, none of this would be possible. And finally, we want to express our gratitude to you, our listeners. Thank you for tuning in, for your support, and for being advocates for positive change in education. Remember, the work doesn't end here. Let's continue to collaborate, innovate, and advocate for a brighter future in education.