## Seizing Life, episode 118 The Caregiver Journey: A Father's Story Guest: Bud Hager (Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by

CURE Epilepsy.

Kelly Cervantes: Today I'm happy to welcome Bud Hager to the podcast. Bud's daughter Emma

began displaying signs of infantile spasms when she was six months old. Following a series of medical tests, Emma was diagnosed with pachygyria, a devastating and rare condition that affects 1000 people in the United States. As the father of a medically complex child and a licensed therapist, Bud is here today to share his experiences, insights, and advice about the caregiver's

journey.

Kelly Cervantes: Bud, thank you so much for joining us today. I am so excited for this

conversation. This just feels like such a treat because you and I have been friends for years now, first meeting through social media and eventually getting to meet in person at Epilepsy Awareness Day at Disneyland. In fact, I have to call

out. I'm wearing my Wonder Woman t-shirt today.

Kelly Cervantes: Years ago, I started a hashtag Wonder Woman Wednesday for my daughter

Adelaide and Bud, you have been amazing in keeping that tradition on with your

daughter, Emma, and it means the world to me to see those posts on

Wednesdays. So that everyone else can get to know your incredible vivacious,

sassy Emma a little bit better. Why don't you tell us about her?

Bud Hager: Yeah. Well, Kelly, first off, a true, true honor to be here. I've been watching the

podcast for a long time, and one of those I dreamed I'll be on it one of these days, and it's happening. So thank you and the team at CURE so, so much for having me on. I mean, really, you took the words out of my mouth. She is vivacious and she is sassy, and today we added a little extra flare. She lost her

first tooth, so now she is vivacious, sassy, and toothless.

Bud Hager: So real exciting day for us. But Emma is six years old and some change. As far as

her as a person, like you said, I mean vivacious and sassy. She is willful. She is powerful. There are moments where I wish her energy was a little less, like at two in the morning. But for the most part, that fighting spirit has been just so comforting for us, knowing that she is not going quietly into that good night. That is something that pushes us forward. Outside of the poetry, she loves classic rock music. We actually on... and now I realize this is not classic rock.

Bud Hager: But we're on a big Stevie Wonder kick recently. The songs in the Key of Life

album is one of our favorites. So we're doing that. Walks outside. She loves looking at trees. She absolutely adores her mom. I'm not sure who loves who

more in that. So that's Emma as a person. Then as you know, Emma is

diagnosed with something called pachygyria, which comes with it a whole host of just a fun box of diagnoses and conditions, and one of the most serious being

epilepsy.

Kelly Cervantes: Now, you received Emma's diagnosis when she was six months old. What were

some of the indications leading up to that?

Bud Hager: I'd like to say that I knew something was off from the beginning because her

particular diagnosis is congenital, so it's something that has been there some... before she was born. But I think I was just sort of in that happy bliss phase of just like, "No, she's fine." Maggie, on the other [inaudible 00:03:52], Maggie, my wife, got the sense right around three months or so where she was like, "Mmm,

something feels different."

Bud Hager: And then, around four or five months, we started seeing what we now know are

infantile spasms, movements that the jerking of the head, the jackknife positioning of the arms. So that happened right around the beginning of her... five months old or so, and we were told it was colic. We were told it was gas. And actually, there was a very heavy conversation with her pediatrician where she was having these motions in the office, and Maggie was not taking no for an

answer. She said, "This is not gas. You can't tell me this is gas."

Bud Hager: And so the pediatrician called the hospital. We set up a one-hour EEG for the

next day, and straight from that one-hour EEG, we got admitted into the hospital straight from there. As you know, you don't catch a lot on a one-hour EEG, but obviously, it was plain enough that from that they knew something was happening. Outside of that, developmentally, there was a lot that, again, looking

back, she wasn't quite hitting those milestones.

Bud Hager: She was always very happy and smiley, so we weren't concerned about that

part. But eye contact wasn't there a lot. She wasn't rolling. She wasn't sitting. So all of those, again, these are sort of puzzle pieces put together after the fact. Or

like, "Oh yeah, all of that also wasn't happening." So between the

developmental and then the presentation of the spasms, that's where we knew. And, like I said, that was right around the fifth month or so. And then we got

into the hospital.

Kelly Cervantes: And so you get into the hospital. She's diagnosed with infantile spasms. They do

an MRI and is that when you got the... Now, how do I pronounce it again?

Bud Hager: Pachygyria.

Kelly Cervantes: Yeah. Pachygyria. I can never remember which [inaudible 00:05:55] goes on.

Bud Hager: Yeah.

Kelly Cervantes: But the other way around. So it was the MRI that diagnosed that. Explain what

that diagnosis actually means.

Bud Hager: Yeah. So pachygyria and I'll probably just call it pachy from here on out.

Kelly Cervantes: Perfect, love that.

Bud Hager: Because A, yeah, it's easier, and it sounds sort of fun and quirky, and it makes

me feel a little bit better about the heaviness that it is. So pachy is a cortical malformation, so that means that the brain is shaped differently. It's a different shaping of the cortices, which is that part that looks like a pink walnut that's on top of the brain. So pachy literally means big or wide gyri. Think of Pachyderm is

another term for an elephant. It means big.

Bud Hager: So pachygyria is wide gyri. So what that looks like on an MRI is those bumps that

I just mentioned. They're really thick and broad. As opposed to having a bunch of these grooves, she has almost none. So it is... Still to this day, it's diagnosed mostly on a visual confirmation through the MRI. So they take the MRI, you get a picture of the brain, and from that, there's a couple of different types of cortical malformations that go into it. So pachy is a subtype of a broader category called lissencephaly. Now lissencephaly is one that more people have

heard of.

Bud Hager: But [inaudible 00:07:24] same is these are both just descriptive diagnoses. All

they're doing is saying what the brain looks like. So they come with the MRI, and then they confirmed it later with the different... with a slew of genetic testing. Now there are several different genes that could lead to a lissencephalic-type disorder. She happens to have one. It's called KIF2A. She has a genetic mutation that didn't allow her neurons to fold back on themselves when they were

growing. So what happens, your neurons spread out when they hit your skull.

Bud Hager: When you're in utero, they turn back and fold on themselves. That's how you

get those folds. Hers just went and stopped. So what you see is what you get. And that is how now we know that it is a congenital disorder is that this happens right around day 28 after conception. This is first trimester. This neuronal migration is happening. And so, that was something that brought us peace later, knowing that there was really nothing we could have done to even know that this was happening until there was some symptomatic expression like

infantile spasms.

Kelly Cervantes: So you receive this diagnosis in the hospital, and what are you told in terms of

what to expect for her life and for prognosis, I guess, in general?

Bud Hager: Yeah. It's interesting because it's still so... Misunderstood isn't the right word.

It's just not understood. There's not that we have wrong information. It's that

we don't have enough information about it.

Kelly Cervantes: There's fewer than a thousand cases in the United States that we know of.

Bud Hager: Yeah. And that's... So those numbers, as you know, with any rare disorder, I

mean, they get updated and changed as soon as a new one comes in because it changes the rate. It's so rare that you get one new diagnosis, and it changes the

percentage amount in the total population. That's how little there is. So when the doctor sat us down to say, "Hey, this is what she has." And we did the same thing you did. "It's called what. How do you say it again?"

**Bud Hager:** 

And the prognosis he gave us was, as far as lifespan, it could be anywhere from six months to 60 years. We just really don't know. And that's a really broad prognosis to give is six months to 60 years. So then our question is, "Well, how do we prepare for this? If it could happen in six months or it could happen decades later, what are we doing now?" And that's when he got into the developmental delays and that sort of...

Bud Hager:

So what he had told us was, "Between now and whenever she happens to pass, what she's going to need are things like aggressive therapy regimes because she will have global developmental delays, cognitive delays, behavioral delays, neurological delays, physical delays. Everything is not going to progress, not even just at a speed, but to the level that most other children would experience. Everything will be so far back on that scale for you guys."

Brandon:

Hi, this is Brandon from CURE Epilepsy. Since 1998, CURE Epilepsy has raised over 90 million to fund more than 280 epilepsy research grants in 17 countries. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes:

So with such a wide prognosis, you don't really know what to expect. There's no... It's so rare you don't have a roadmap. How did you and Maggie decide to move forward with treatment, with goals, with parenting?

Bud Hager:

It's interesting that you bring this up now. Is that at our most recent EEG, we just had a complete shift in how we view that exact question? Recently, Emma just got put on palliative care, and that is a shift in how you view things like goals directly. So at the time, we get the diagnosis, Maggie and I both work in healthcare. Maggie is a nurse. I am a therapist.

Bud Hager:

So we're used to that sort of language of things like goals and assessments and that sort of stuff. That part wasn't as foreign to us, which I believe helped because we were able to get into that mindset. When you have a child, say, a neurotypical child, and you're not thinking immediately, "What are my goals for this child?" But when you have an atypical child who needs help, then, right then, you do have to think like that.

Bud Hager:

And so the doctor, like I said, recommended an aggressive regime of therapies, medications that we'd be starting right away, and we sort of fell in step with that. Like, "Yeah, we will do what you recommend. Obviously, I mean, you are the expert on this. You're the epileptologist at this level for epilepsy center on the West Coast. We're new to this. I know what epilepsy is, but I don't know what this is."

Bud Hager:

And so we went forward with his recommendations on what to do for therapy and medications. We were fortunate that the medication that we chose to go with seemed to work pretty much right away. There are a couple of different that you can do with infantile spasms. ACTH is usually a frontline one, or Vigabatrin is another one. Those are both medications. And we went with Vigabatrin, which the side effects are a little bit less scary than ACTH.

**Bud Hager:** 

So we started with that medication, and this is sort of the... Just the double-edged sword of this is that it looked like the medication was working and that we weren't seeing the spasms. We thought we saw a little bit of developmental progress, especially coupled with the therapies. And then, just recently, last year, we found out those spasms had been still happening all along. They had just not been as visual to us. They were sub-clinical sub-graphical on the EEG. She had some movements, but we thought, "Nah, that's just her brain. She's going to have odd movements just like we had at the very beginning."

**Bud Hager:** 

So it's this odd sort of recapitulation. This sort of eternal recurrence of this same thing over and over again. And that brings you back to the palliative care. And so our ideas of goals now are much less about getting her to a place, having her do therapy so that she can walk, that she can talk. It's sort of shifted from that, that sort of projection type of a goal into her right now. So how is she feeling now? It's more about her comfort. Still thinking about the future. But our goals are not six months, a year down the road. The goals are right now with it. So that was our sort of shift with that is what are we doing for Emma right now?

**Kelly Cervantes:** 

Yeah. What she has and what Adelaide are entirely different. That said, so much of what you are talking about, be it the symptoms or be it the decisions that you're having to make, I can relate to 100%. I mean almost to the T. I mean, regardless of the diagnosis, what we both went through are going through is rare and unique in and of itself for the most part. Where did you find that support? Because we all need it. We cannot navigate medically complex parenting alone. So where did you find that support?

**Bud Hager:** 

In just all of the places, which sounds weird, and I'll qualify that in a second. Just what you mentioned, Adelaide's diagnosis and Emma's diagnosis are so... are worlds apart really, especially when you get down to how complex the human body is. They really... I mean, they would never be on the same chart. But the needs and the pain and the fear that we have as parents and they as children are so similar that you can find this support.

**Bud Hager:** 

Like I said, Maggie and I are both in healthcare and so we know. We've been trained on how to read research articles. We know where to find them. Through my job as a professor, I have access to scientific journals that a lot of people don't have just due to the nature of my work. So exactly like the doctor told us not to do, we went to Google, and we went straight into pachygyria, and there's just so little there that very quickly you're into other diagnoses, you're into other worlds because it's like this... pachygyria is related to lissencephaly.

Bud Hager:

Okay. So we've already moved up. Lissencephaly is part of a broader range of neurological disorders, including something like cerebral palsy. Okay. So now we're out to another ring, and in each one of these areas, you can find people hurting. You can find people with passion for this. You can find people who will sit there with you in that and go through it. So we went pretty quickly from the clinical side. Like you said, you can get so wrapped up in that. So wrapped up in that stochastic nature of it, the statistics and the numbers. And then we went to social media because we're like, "We need people. The numbers are great, but I can't talk to a statistic. I can talk with people."

**Bud Hager:** 

So type in hashtag pachygyria, and there's like two or three accounts. We were able to connect with one of them and then found out that they live in the same state as us, which was mind-blowing. [inaudible 00:17:09] like, "Oh." I mean, it's still... California is a pretty big state. So they're still a country away from us, but they were our first family that we found. We're still friends with them to this day. And then, like I said, on social media, you have to do the same thing. From pachygyria, you get into epilepsy, and then you get into other communities, and that's where we connected.

**Bud Hager:** 

So eventually, this comes full circle back to you. And then through that, like I said, going to the epilepsy conference and going to other various conferences where you get to connect with real people through her doctors. When we got the diagnosis, and in every meeting since, we tell all of her doctors, "Hey, if there are families who are going through this, please give them our information. Give them... Here's my email. Here is my cell number. They can call, email, whenever they want to, whenever they're ready for it."

Bud Hager:

But that is, I think, how you build this community because that's really what you have to do is you will find people, but then you build that community. There is no sort of ready-made community for this. The diagnoses are so rare that you have to sort of build this on your own. And that's sort of what this is that we have these sort of concentric circles of various communities that all help us and support us in various ways.

Kelly Cervantes:

Well, I have to let everyone know what a phenomenal writer you are and point them to your social media as well as you've written a couple of posts for me on my Inchstones blog, and they are just so beautiful and really speak to a lot of the emotional, philosophical aspects that we run into as parents to medically complex children.

**Kelly Cervantes:** 

And I think that you're... the way that you see Emma and the way that you process grief and acceptance, in particular, is just so incredible. How did you get to this place of understanding that grief would be a part of your life in this capacity and the acceptance and the continued acceptance of Emma's life not looking like what you thought it would?

Bud Hager:

Oh. Well, first off, I kind of have to blame you for the writing thing. When you say, "How do we get to this place?" And this is something that I did talk, I

believe, in one of the Inchstone guest posts is I don't think that we're at that place because I don't think it's a place really. Like you said, it's this continuance. It's this continuing acceptance. So how we get to this understanding of what something like acceptance is is not by arriving, by getting to the destination?

Bud Hager:

It is by continually arriving. There is no sort of place to be. It's a way that you live, and it's something that we have to choose every day. And it's not that you... Acceptance to me is you're not making a choice. Acceptance is choice. It's not like a thing you decide to do. It is decision itself. It's this process, this mode of existence that you inhabit in the world. And in a really twisted roundabout way, this is something that everybody has to do.

Bud Hager:

But having Emma and having her diagnosis is something that makes it so forefront for us. It's not a back burner. I'll decide the kind of person I want to be. It's something that every day it's right there. I have to decide every day the kind of person I'm going to be because her life might depend on it.

**Kelly Cervantes:** 

So, Bud, I love this idea of it being this ongoing journey, that acceptance, and the grief. None of these are destinations. It is not a place. This is something that we are constantly working on and through day in and day out, or hour by hour, as the case may be. Because I think we both know that sometimes a day is just way too much to process. So what does that look like for you in a specific moment? How... In what ways are you continuing to find acceptance or to live with the grief?

**Bud Hager:** 

Yeah. So I mean, you hit it right on the head of the idea that sometimes even a day is too much to process. It's that, due to her condition, she's so dependent on us physically that everything she does I have to do for her, even if it's as simple as scratching her nose. I've sort of learned how to read her signs that I know, "Oh, that's the nose itch face." And so I can scratch her nose. And so it really is this moment-to-moment process of, "Okay, I need to go roll her over. I need to go scratch her back. I need to go do this."

**Bud Hager:** 

And it is a way for me to also better understand myself because I will see Emma laying there on the couch or in the bed, and I have to think, "Okay. If I had been in that position for half an hour, what would I want? Would I want... I would probably roll over." And so it's, "Okay, I have to make decisions for her based off of how I would feel." And then she lets me know if it was the wrong choice. She's very, very, very clear. We talked about the sass earlier, very clear if I did something wrong like, "Nope, it was not... That's not what I wanted. I wanted this."

Bud Hager:

But that's really what Emma's life is for us. It's so moment-to-moment that we have to make those decisions just physically. And that's not even talking about the larger medical decisions. I disagree with the sort of mentality that I don't have any other choice that I'm doing this because there's nothing else for me to do. I'm not doing this because I have no choice. I'm doing this because I have nothing but choice. And the choice is always going... for me so far has always

been for Emma, and that's something that I have to constantly remind myself is that at any moment, this is something that I could choose not to do.

**Bud Hager:** 

And there have been moments. I mentioned her willfulness at two in the morning. There's moments where I'm like, "I'm staying in bed." But then I have to remember, "Okay. If I were the one in the bed, and I was coughing and I needed to roll over, would I want Emma to come help me?" And so there is this sort of reciprocity back and forth with that coupled the fact that I just love her so dang much. So that makes those decisions easier. It doesn't take away the choice. It makes those choices clearer to me. So like I said, on that day-to-day life, like you said, it really is down to the moment to moment.

Bud Hager:

Every single decision I make, like scheduling this interview, I had to schedule around, "Okay, this will be a time where I know Emma can be doing X, Y, and Z so that I can do this." My professional career. I schedule it around what Emma can do and so on and so forth. So it's really what's helped me is just being so present, that constant presence of Emma. Like I said, doesn't make the choices easier. Makes them clearer. Makes my understanding of what I need to do that much more focused.

**Kelly Cervantes:** 

I love that so much because it is... it feels empowering. I think there is so much in being sort of an informal carer to our children or to a spouse or to any loved one where we feel so powerless and we are at the whim of their condition and its symptoms. But just the simple mindset shift of, "This isn't something that I have to do. It's something that I want to do because I love them, and that this is a choice that I get to make." That is so empowering in just that simple mindset shift.

**Kelly Cervantes:** 

And I think that's so much of what you have written about that I have connected to is those simple mindset shifts. And you wrote on one of my Inchstone's guest blog posts, "Are we finding light in the dark places, is there joy to make the pain worth it, and are we settled into our new normal? Have we reached acceptance?" And then you answered these questions with, "Yes. But also a sonorous no." It's so emotionally messy, but when you write it, it feels so much clearer. Can you sort of elaborate on that a little bit?

**Bud Hager:** 

Sure. I mean, it's messy. It's clouded. It's convoluted. But I mean, if you take a look around at nature, take around at life, everything is squiggly. There are no straight lines in that. And so I don't feel that it's any more messy than any other part of nature. It's just that it doesn't fit in with how we would want things to be. And I think that's the hardest part about this are we there yet type of mentality is that it isn't this direct line from A to B. It's all over the place.

Bud Hager:

So when I say, have... I posed a question to myself, which is a great writer's trick to make you sound fantastic, is you give yourself a question, then answer it. When I say, "Yes. But also a sonorous, no." Yeah, we have acceptance, but no, in that I've spoke before, it's not a place that you reach. It's this way that you live.

It's this constant choice you make to accept. As I said, it's not like a choice. It is choice itself. It's not that I have a purpose to help Emma.

Bud Hager:

It's that I have purpose, purpose itself, and that is something that is going to drive and push me is the fact that I am just imbued with this purpose. The hard part about that is that there is no book about my purpose or your purpose. That's something that you only get by living this purpose, by living this acceptance. It would be fantastic if I could write a blog post and say, "Here's five things you need to do in order to accept your child's rare diagnosis."

Bud Hager:

That would be five lies that I would be telling you is that that's not how it works. It's not that you do these things and then you're done. It's not a goals-based understanding. It's a values-based understanding in that you decide what you value, and then you live those values. I happen to really value Emma, and so I'm living in that space with her.

Kelly Cervantes:

You talked about having your own purpose, and sort of we still have to have our own identities outside of being the caregiver for our loved one. And so how have you been able to find that balance between being Bud, the therapist, and the husband, and also the caregiver, and making a way for that all to work together?

Bud Hager:

This is something that I struggled with from the beginning, and still, to this day, it's something that I still have a hard time balancing. How I put it is that once Emma was in the picture, she was in all the pictures. And so it was difficult for me in the beginning to see anything sort of outside that. I mean, I did work, but it was always, "I got to get through this day so I can get home for Emma."

**Bud Hager:** 

So it's finding that balance is I have to remind myself that I can't just be all about Emma because then what am I giving to Emma? She already is Emma. So I'm reminding myself that being able to give yourself for a person means being a whole person yourself. And so finding a way to fully understand and who I am, and that includes making time for my hobbies, making time for things that I'm interested in so that I can wrap those up and then bring those back to her.

Bud Hager:

For example, reading. I love to read. I am a painfully slow reader. Partially I think due to the types of books that I like to read and just the fact that I just am a slow reader. But what I love doing is I will spend time, I will be able to have time with just me in the book, and then that's what I can bring back to Emma. So it's not so much finding a break from Emma as it is, "Okay, be a person so that you can be a person for her."

Bud Hager:

So I have to realize that spending time with myself, spending time by myself, isn't abandoning Emma. It's being a whole person. And that includes being that person for Emma as well as people like Maggie and my work. It's something that I have to do to fill myself so that I can help other people, if that makes sense.

Kelly Cervantes:

It makes perfect sense. And you are a wealth of advice. So Bud, as both a father to a medically complex child and also a mental health therapist, you sort of are in a unique position to give advice to parents who are in a similar position. And what advice would you give them?

**Bud Hager:** 

I've been hesitant to give advice. I'm happy that you're sort of giving me this space for this. That's one of the things that I struggle with a bit on social media is that I'm very, very into everybody's lives are their own lives. And so coming out with, "You must do this." Or, "All parents feel this way." I'm really, really hesitant about that. It's something that I struggle with.

**Bud Hager:** 

It's something that I'm not... I don't feel qualified or prepared to do. But there are a few things that I would say that, again, advice or not, this is what we did, and it was helpful for us. So I got two really sort of two parts to it. The first one is the tagline is find your people. Is that this life... I mean, scientifically speaking, it is isolative just in the fact that nobody else has your child's diagnosis or very few other people do.

**Bud Hager:** 

So it's isolated that way. But then, it doesn't have to be. As we spoke earlier, it doesn't have to be socially because pain is pain, struggle is struggle. This sort of continuum of, "I'm grieving more than you are" is not really a thing. I mean, it feels that way. But [inaudible 00:32:09], grief is grief, and you can connect with another person's grief by recognizing that they're grieving as well. So find your people. In the beginning, though, one of the best things to do is buy your diagnosis because you might have more connections that way.

**Bud Hager:** 

At the very least, you'll have an icebreaker of like, "Hey, your kid has this, my kid has this." But also something that we got stuck with a bit is you don't have to stay with that. There seems to be this idea that, "Well, if your child has epilepsy, my child has epilepsy, we have to be friends, right. We have to be this." And you don't have to. You don't have to force a friendship just based off a medical diagnosis, just like you don't have to force friendships outside of medical diagnosis.

Bud Hager:

So in your process of finding your people, get to know those people more than just a diagnosis. Get to know the kids more than just a diagnosis. Get to know yourself more than just your child's diagnosis, and then you will find people that you can connect with. A community is more than just shared experiences. It's those shared values. And so getting to know that is what's going to help you find your people. That's advice one.

Kelly Cervantes:

Okay.

**Bud Hager:** 

Advice two, I would say, is information might be power, but information is not peace. And especially in a world that pushes information so much. There's so much right at your fingertips. More than anyone, as far as we know in the

history of civilization, you have access to so much information. But in our experience, that constant need for more information was not bringing us peace.

Bud Hager: And especially in the rare community, it's not even really going to give you much

direction. And so, at some point in the journey, you will have to decide, "Do I need more in order to make a decision, or do I not have to have this constant voracious devouring of information? Can I set that aside so that I can have peace and be with my child?" So the information is not peace. I'm not saying to

not look, but that's probably not where you're going to find rest.

Bud Hager: That's probably not where you're going to find peace because as wonderful as

social media is, as wonderful as science is and what we can do with it, your child doesn't live in a journal. Your child doesn't live in an academic paper. They live right here. They live right now. You don't live on social media. You are living here. And so being able to balance that information, I think, is going to be very meaningful for a lot of people. That idea that I can get information, but it's not a

compulsion. It's not the thing that is going to bring me peace.

Kelly Cervantes: Well, and you can have all the information in the world, and that doesn't

necessarily equate to answers.

Bud Hager: Oh, absolutely. Absolutely.

Kelly Cervantes: Bud, you are a wealth of information. I will... am obsessed with the women in

your life.

Bud Hager: Me too, me too.

Kelly Cervantes: You have to make sure you give them all the hugs to your wonder women, and

I'm just so grateful to have had this opportunity to share this space with you and

hopefully give people a new way of looking at their life with medical complexities and what grief and hope and acceptance can look like.

Bud Hager: Yeah. Kelly, I really, for somebody who prides themselves on being a word nerd,

I cannot find any words to thank you, not just for this opportunity today but for everything you've done for my family. I mean, it's unfathomable. Always a

treasure to talk with you, Kelly. Absolutely.

Kelly Cervantes: Oh, thank you so much. Thank you, Bud, for sharing your experiences and

insights as father and caregiver to Emma. For 25 years, CURE Epilepsy has been

funding patient-focused epilepsy research with the goal of finding a cure.

Kelly Cervantes: Progress has been made, but there's still work to be done to lead us to that

cure. If you would like to help us achieve our goal of a world without epilepsy,

please visit cureepilepsy.org/donate. CURE Epilepsy, inspiring hope and

delivering impact. Thank you.

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