**Parent Perspective: Madeline Cheney Part 1 Descriptive Transcript**

**[Visual Description]** A baby who is deafblind sits on a blanket and looks up toward the camera. He smiles happily.

**[On-Screen Text]**
Parent Perspective: Madeline Cheney
Kimball’s Mom
Learning the Diagnosis

**Madeline Cheney:** So, we finally got that tested when he was like, I think he was four months old, maybe five months old. We brought him in to an ophthalmologist. And you know he, he told us that he was partially blind.

It was hard to know exactly how much he was seeing. But just from what the functionality, I mean, it seemed that he could see the bright lights, and that was about it. And so, um, that's when we realized that kind of made, you know, so that I guess, was the second half of the deafblind diagnosis.

I have to say, I think that was probably the hardest one to receive. I think, just because, even though he has like life-threatening, you know, different parts of a syndrome, and those are really, really, hard obviously because we were really afraid for his life. But I think that, that deafblind diagnosis was just on top of everything else that we'd already received, and so it, we already felt like we couldn't handle everything as it was so, having that on top of it was just, it just was, it just floored us.

Like I said, I kind of knew deep down inside that there was something to it like it was kind of that mommy gut like this feels like something's definitely off with his vision. And I was being reassured over and over again.

But I just like, like I'm not being reassured right now. Like I know somethings up with that. And so, when we got that official diagnosis, it was kind of like, well, what else could be wrong. Like, this is like, worst case scenario. Like he can't even see us. He can't hear us, like. So, I think that's, you know, and I think partially, because those are like such a huge way that a lot of parents connect with their children, and that's a huge way that I was connecting with my older daughter Wendy, you know, with visually smiling at each other. And you know the eye contact and things like that.

And then, you know, talking to her, and you know, singing to her and things like that. And so, just being like this child cannot hear me, he cannot see me. You know and so, it was kind of like this, there definitely was a lot of, I felt like there was kind of a barrier that I felt between us.

And not that I didn't love him just as much as my other child, like there, there was all the love there, but I feel like there, there was just like this barrier and when I was trying to connect with him because those huge sensory inputs were not there. And he did have, he was, he's not, he's not profoundly deaf, so he does have some hearing with his hearing aids.

Um, but at the time we weren't, we weren't, putting his aids in all the time, because we had so much going on medically. And so, um, it really just felt like I was kind of like, well, how do I even connect with him? And how could things get worse than this? This is just the worst thing I could ever think of. And so, like for me, I mean it, for me, it was just, I was just, totally overwhelmed with grief, like just completely like everything I was doing like that whole time period of like the first year. It was just dark like this heavy cloud on me. It was just so, I was so sad about it. It's really hard to see your child suffer.

And then it's also just sad, and then you're also sad for yourself, you know, like I thought it shouldn’t be like this. I thought he'd be able to do this and this. And you know I'm bitter that I have to have the therapies and all that kind of thing. But I think, like, you know also, in interviewing a lot of parents in, in my own scenario.

A lot of that grief does evolve. If not, I don't want to say it goes away because I think I will always feel really sad that he had to go through everything he went through. That’s just sad.

Um, but, I think there's, also like, when you see the joy, and you see the things that they that they love, and that like, makes them who they are. So, seeing their personality and getting to know them. I think that's what makes the grief become way less just like heavy and sad, and it becomes like, oh, I'm so sad that you had to go through this because I love you.

But I'm like, I also see that your life isn't just sad like your life is great. You love Buzz Lightyear, and running around, and you know, hugging your dad and just seeing all the things that make them human. Um, I think, is what makes it all like much more bearable and just like oh no, like life’s actually really great, too. It's not just sad. It's not just overwhelming. It's also like, like there's moments of like just pure joy, just like it would be with my daughter, you know, but just everything more intense, like the, the triumphs, and, like seeing him happy, feel just like you would never be able to feel that amount of like satisfaction or contentment, and seeing someone happy if you didn't see them miserable at other points or think they would never be happy.

Um, and so, I think you know what I like to describe as, there's just so much more depth. There's so much more depth to this type of parenting because there's so much more joy, and like not, I don't want to say more joy, but that joy is just so much deeper.

**[Visual Description]** A baby who is deafblind sits on a blanket and looks up toward the camera. He smiles happily.

**[On-Screen Text]** To learn more about Madeline and Kimball Cheney and what it is like being a parent of a medically-complex child, listen and subscribe to “The Rare Life” podcast at therarelifepodcast.com.

**[On Screen text]**
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