**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 MomLearning to Communicate

**Madeline Cheney:** I think, like, definitely the most like, exciting moment, um, before he turned three, in that zero to three section, um, was his communication. When he, he kind of like, we were up against a brick wall for a lot of months, of him just not making any progress as far as language.

And you know that was already, it felt really overwhelming, since he had both the vision loss, and the hearing loss. And we were trying to do signs before we found out he also was blind. But then we were, we like we kept at it because we're like, well, I think he can kind of see like when we do the motions and stuff. So, we're trying that.

And it was just really discouraging, because there was like zero, zero um like progression. Even just like the sounds he was making, the types of sounds.

And then, there was one month where we decided to, to go, you know, to do more signs than we were doing before, and just to go all in. I was like, I’m really gonna do all the signs I can do um all the time. And so again, again that was kind of that intrinsic motivation. It was like me being like, that's it. I'm gonna do as much as I can. I want to communicate with him at this point. I think he was, he was one, and there was nothing even close to like, I mean he had milk. I think that was it. But he wasn't anywhere near spoken language, but especially not even sign.

And so when we got to that, when I started like, really doing it, within one month he went from two signs to twenty-five signs that he was using regularly. And so that was just incredible, and just being able to celebrate that with our providers um, and to see how happy he was to be able to communicate finally, and I kind of felt like one of those barriers that we had, you know, in bonding um. That I kind of felt like it's just so much harder to feel like that, you know that traditional closeness as a parent, when he can't communicate with me.

But when he was able to do that, and the next month he had fifty, and it was just this explosion of language. And it eventually switched, he switched over to spoken language.

But it was like, it was just, it was one of those moments I was like, okay, everything we were doing actually was worth it. Cause it kind of was feeling like if we’re not making any progress why are we even doing all this.

But to see how happy he was, and how excited he was, and we were so excited, and that kind of built on it. And so, he was just learning more and more and more.

It felt like when they would come, I’d know that we have a visit. I'd be like, oh, my gosh! I'm so excited to tell them what he's done this week. And so that definitely shifted the like, the attitude I had of them coming over. Before it's like, I'll just tell them again like nothing new. I kind of did what you told me to, but I also struggled with it, you know, and kind of feeling that discouragement and kind of seeing a little bit of discouragement in them. I think they tried to cover it up, but being like you know they, they're kind of like, hey, why, why is it, why is there this brick wall? Why can't we get past this?

Before it to shift over into like, I just can't wait to tell them what Kimball did this week. It was so cute when he said this, this, and this.

He's always so excited about them, too. I think that's the best part, is seeing how happy he is to learn new things and master it. That's just, it's so wonderful to see, because you know, you get used to seeing them struggle and be frustrated.

But it's so great to see like, when they do have, like, you know, progress or improvement, or they're just excited about a skill they've learned. It's so fun.

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**[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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