CATHY WURZER: Our next guest is an Alexandria, Minnesota woman who's turned her passion for inclusion into a huge social media presence. She has half a million followers on TikTok and a new children's book. It's called *the ABCs of Inclusion*. Beth Leipholtz is on the line right now. Beth, welcome to Minnesota Now.

BETH

Hi. Thank you so much for having me. I'm excited to be here.

LEIPHOLTZ:

CATHY

I'm excited to have you here too. I want to begin by talking about your child Cooper. You are the hearing mom of a deaf child. Tell us Cooper's story.

BETH LEIPHOLTZ:

WURZER:

You'll hear me say a lot like he's been a surprise from the very beginning. My husband and I got engaged in January of 2019, and like 36 hours later, I found out I was pregnant. Total surprise, we were not trying. And so from there, he just kept the surprises coming. I had to just kind of wrap my head around becoming a mom when he was born.

And he was born in September. He did not pass his newborn screening in the hospital, which is like a mandatory screening they do before you go home. And didn't think much of it. We were just kind of told it could be fluid in the ears, which is pretty normal. And so we left the hospital thinking that's all it would be. And it was kind of in the back of our minds, but not at the forefront. And kind of settled into life at home.

And Cooper was born with a big white swash of hair. The rest of his hair was dark, which was kind of unique. And I had mentioned that on like a Facebook group I was in, and somebody brought up that it could be an indicator of Warrensburg syndrome, which I had never heard of. And so started to dive into that a little bit, and it was-- a lot of things aligned with him. And so ultimately, that did end up being his diagnosis. And we learned that he was deaf.

CATHY

BETH

A streak of white hair. I've never heard of that before.

WURZER:

LEIPHOLTZ:

So when I started doing kind of that Google research or whatever on my own, I would say he was about three weeks old. And at that point, I just kind of knew. I mean, there was no way around it. He fit to many of the criteria. And so going into his, it's called a sedated ABR, auditory brainstem response, he was six weeks old when we did that.

And I had a feeling that would be the outcome, but it was still really hard to process and work through. I think I was like holding on to hoping like maybe he could hear a little bit out of one year or just not thinking that he was going to be like totally completely deaf. So it was a lot to work through, and my husband and I process things very differently. So he was just a little quieter and taking it in, and I was upset and crying and just kind of scared because we didn't know what the future would look like. And this was never part of the plan.

CATHY WURZER: Yes, exactly. It never is when something like this comes up. And I'm not surprised that you started to Google and do research because you're a former journalist, which then brings me to the book. You had a lot of collaboration for this book. You have the stories of Cooper but also 25 other kids. How did the idea for the book come about?

BETH

LEIPHOLTZ:

The idea for the basing it on real kids stories just kind of came from that social media presence that we have built. And I had realized the people that were following me were more so parents of any sort of children with special needs. And so I was like, you know what? Why don't I tell all of their stories and Cooper's, but make it child friendly and actually base the illustrations on the real children? And so it just spiraled from there.

CATHY WURZER: Do you find that the special needs community has to deal with and battle a lot of stereotypes and misperceptions?

BETH

LEIPHOLTZ:

Yeah, I think there's a big divide on whether to even call it special needs. I mean, it's so down to the particular person what they prefer, and I think that's something that I've learned along this journey. Is that there is no one size fits all when it comes to inclusion. Some people consider being deaf a disability and others don't at all. And so that's something I've had to sort of walk through, and I'm even careful when I use the phrase special needs for that reason, because I think it makes people feel like they fall into one category when really there's so many shades of gray in there.

CATHY WURZER: What do you hope folks take away from reading the book? Are the lessons intended for kids or for parents or for both?

BETH

LEIPHOLTZ:

Yeah, obviously it's written for kids kind of seven and under, but every adult that has read it has said to me like, Wow, I actually learned something. The diagnoses that are covered are some of your more common or more heard of ones. It covers obviously being deaf with Cooper and then Down's syndrome, anxiety, OCD. Like I wanted the visible and non-visible to be included. Autism, that's another big one that I've had a lot of people ask about.

There's also other ones that are maybe a little bit lesser known or less talked about: Fragile X syndrome is in there, epilepsy is in there. I don't feel like a lot of kids know a lot about epilepsy and seizures. Really I think anybody that reads the entire book will take something away from it. I learned so much when I was writing it. And it's probably the hardest thing I've ever written because you're taking these super complex diagnoses and topics and trying to not only write them very short and succinct but bring it to a level that kids can understand.

CATHY WURZER: Say, I thought we need to hear this. This is Cooper's reaction to the book on TikTok. You posted it. Let's listen to a little of that.

BETH

You're going to read it. Isla was born with Down's syndrome. Can you say Down's syndrome?

LEIPHOLTZ:

BABY:

Down's syndrome.

BETH

Yeah. Can you say chromosome?

LEIPHOLTZ:

BABY:

Chromosome.

BETH

He likes when things vibrate like this-- [VIBRATING NOISE] like a vacuum.

LEIPHOLTZ:

BABY:

There's Coop right there.

BETH

There's Coop right there. Can you say achondroplasia?

LEIPHOLTZ:

BABY:

No.

[LAUGHS]

BETH

OK there.

LEIPHOLTZ:

BABY:

Look at that owie.

BETH

It's not an owie. It's a machine. It helps him. And then he knows when to take his special medicine.

LEIPHOLTZ:

CATHY

Aww! Cooper uses cochlear implants, is that right?

WURZER:

ВЕТН

Yes, we use cochlear implants and also American Sign Language.

LEIPHOLTZ:

CATHY WURZER: Some people do not understand them at all. And I know some in the deaf community are against the idea of using cochlear implants. How do you deal with that?

BETH

LEIPHOLTZ:

Yeah, and that was something, again, like I did not even know about before starting this journey. And then obviously putting ourselves out there as much as we do opens us up to a lot of criticism and unwarranted and unwanted comments from people. So I always like to preface this by saying I'm speaking obviously as a hearing mother who has learned about this the last three years. But I think the divide comes from the fact that people who are very immersed in deaf culture and use only American Sign Language are very proud of that; having their own language and their own culture.

And I think there's that fear that medical devices are going to continue to evolve and eventually make that obsolete. But then there's also the aspect of, Oh, well, by choosing to have children implanted, you are taking away their consent. You should wait until they're 18. But on the flip side, being a parent is making decisions every single day, and children who are implanted before 18 months of age have much better outcomes when it comes to spoken language than waiting 18 years.

That's something that's-- it's still hard when I see like a really rude comment or somebody just assuming that we don't give him any access to deaf culture or American Sign Language because he uses spoken language. But I think I've also come to realize like I'm very confident in the decisions that we've made and the languages that we've given him access to, and that's all that matters.

CATHY

It's so hard to deal with the negative comments though. It really is. They're hurtful, no matter how you slice it.

WURZER:

BETH

LEIPHOLTZ:

Oh, yeah, yeah, for sure. And I feel like I've grown a pretty thick skin, but if somebody says something that's like mean towards him, that's when I get very like obviously mama bear, but it's a harder thing to balance to when your child is also being put out there. And that's something that we are mindful of and going to continue being mindful of as he gets older.

CATHY

And you didn't have to put him out there. Why did you decide to do that?

WURZER:

BETH LEIPHOLTZ: Obviously I didn't know that I was going to have more than a million people following on this journey across platforms when I started sharing at the beginning. That was not my plan. I think it really goes back to-- so when I was in college, I actually got sober when I was 20. I stopped drinking.

And through that journey, I started sharing and writing a lot and blogging, putting it out there on social media.

And I found that it really helped me process everything, but also there were people reaching out back to me and saying like reading this really helped me. I appreciate it. I needed this at the beginning.

And so it was kind of that same process honestly when we learned that he was deaf. Like writing it and sharing it was really therapeutic for me, and then it started that same kind of full circle moments where I would have new moms coming to me and saying, I read this thing that you wrote when you got Cooper's diagnosis, and it literally like picked me up off the floor and helped me get through this.

And so that, I think, is really what keeps me going, being able to connect with people. Social media is amazing. It obviously has its downfalls, but I have met so many of my really good friends via Instagram, via Facebook; people who are walking this same journey that I wouldn't have met in rural Minnesota.

CATHY

BETH

Good. Say, where you think this is going to go? Do you have any idea?

WURZER:

LEIPHOLTZ:

I never know how to answer that. I would like to think there will be a second book. I kind of want this one to just ride out for a little bit because it's blowing my mind already. It's fun to see the community continue to grow across social media. I would say 99.9% of people are kind and welcoming and want to learn. And I think that's really what keeps me there. Is that if I can impact this one person who meets a child like Cooper or even Cooper himself and like remember something from a video or knows a sign, like that is worth it to me.

CATHY WURZER: All right. We wish you all the best. You, Cooper, and the whole family, really. Thank you so much, and we'll have to keep following your progress.

BETH

Thank you. I appreciate that.

LEIPHOLTZ:

CATHY

WURZER:

Beth Leipholtz is the author of the ABCs of Inclusion which is out today. You can order the book at bethandcoop.com, or follow her on TikTok @beth--coop.