



Episode 24: Embracing Life with a Disability

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Mindy: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association as part of the Quest Family of content. I'm your host, Mindy Henderson. Together we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities and those who love them. We are here for you to educate and inform, to demystify, to inspire and to entertain. We are here shining a light on all that makes you, you, whether you are one of us, love someone who is or are on another journey altogether, thanks for joining. Now, let's get started.

Lainie Ishbia and Estela Lugo are friends, business partners and advocates, and I am excited to get to speak with them today. Both ladies live with CMT Charcot-Marie-Tooth disease. Both are moms, both have backgrounds in fashion and both are TEDx speakers. They both have a lot going on separately, but together they host the Embrace It Podcast and lead Embrace It workshops where the overarching mission is to empower and create progress for individuals living with disabilities. We have a ton to dig into. So I am going to get started.

You guys, I am so excited that you're here. You two are both clearly incredible people all on your own as individual people, but together you are forced to be reckoned with. I mean, do places just spontaneously combust when you get together? Do crazy things happen when you guys get together?

Estela: I don't know about crazy. I think, yeah, we definitely have a unique chemistry and I think we just compliment each other really well, so thank you.

Lainie: And we have that brunette thing locked.

Mindy: You do.

Lainie: We'll be really in trouble if as Estela, well not me, I'll never go blonde, but if Estela ever does, we're done, we're finished, but we got the the whole brunette thing.

Mindy: You do. You look like you could be sisters. So how did you two meet?

Estela: Oh wow. And so I think I worked for the Hereditary Neuropathy Foundation. So I think we are always on the lookout with the Google CMT Google alerts and people pop up on our radar that are doing things within the community. And then just one day, a few years ago, Lainie popped up on our radar with this amazing adaptive fashion blog for people that wear leg braces. And we were like, "Whoa, pump the brakes. We need to figure out who this woman is. We need to reach out to her." And that's how it all got started.

Lainie: And it was really cool. This was exactly five years ago because Trend-Able was launched five years ago. And when I launched it, I had a wonderful support from family and friends and people in general. But what was so cool is that the people from HNF, these women who I know that you already said Charcot-Marie-Tooth, I had met people other than my own family and older people with Charcot-Marie-Tooth.

So to see these faces that were like me, people who I could relate to, who got it from the perspective of being active people, not necessarily home-bodied people who are in support groups where they're complaining, these women were thriving and living with CMT the same way I was. So it was an instant connection and it turned out, unfortunately, my mom passed away three weeks after I launched this website. And the people at HNF and Estela, especially, they sent me a beautiful note and a plant and it that was so incredibly thoughtful and they became instant family and friends. And then we went on to really do a lot of partnership stuff together for CMT people and Estela and I, as you know then, formed this connection and started doing what we do at with Embrace It.

Mindy: I love it. I love it. And Trend-Able, I just have to throw it out there, I absolutely love it. I was doing some research and looking through all of your stuff last night and the product recommendations and things on Trend-Able are so good. I'm wheelchair user, but I don't use leg braces, but so many of the recommendations and things that you talk about are just pure gold. So everybody needs to go check it out.

Lainie: Thank you. And actually the MDA did a wonderful article on Trend-Able.

Mindy: It's true.

Lainie: Yeah, actually they've done a couple. But MDA was also extremely supportive with Trend-Able. And what we do with Trend-Able is really look for... There's only so many products right now, the same things that people have always seen, the zip pull, the reacher, the same stuff. All stuff is solid and obviously people need, what I look for is really products that may not be specifically for people with disabilities, but can improve your life if you have fine motor weakness or mobility issues, things that are outside of the box to make your life better.

Mindy: Exactly. And it's interesting that you say that. We just did a holiday gift and giving guide that you can see on mdaquest.org as well. And it was really interesting to me. We got our ambassadors involved and looked for a lot of different products that are tried and true from the community. And it was interesting to me because so many of the product recommendations, or I should say, so few of the product recommendations were actually things that were designed to be adaptive. Most of the product recommendations were just things that people have come across that for one specific reason or another are easy and conducive to their needs. So that was really interesting to me.

But yeah, you guys do an absolutely amazing... I have such a shopping list of things that I want that I found on your website. So I'm going to turn the tide just a little bit and get a little bit serious for a second. There's so much to talk about with you two ladies, but I want to talk a little bit about your CMT journey. So Lainie, if you don't mind kicking us off, would you tell us a little bit about your diagnosis journey and what living with CMT is like?

Lainie: Sure. Yes. Well, so I have CMT type 1A, which is the most common type of CMT. In fact, when I was diagnosed, which was childhood, I think there was only a couple kinds. Now there's so many different ones. I can't really speak to that. So it's hereditary. My mom had CMT, one of my children has CMT. I have a sister who has CMT. And as you know, with all muscular dystrophy type diseases, everyone has different abilities, different strains, different types. It's all, it looks different on everyone. For me, it has progressed fairly slowly. As a child, the typical thing like gym class sucked. I couldn't run, I mean, before I had my ankles fused, which was later on in life, I think I ran. But I always looked funny doing it.

I didn't have great hand grip to be able to do the things that in the eighties you had to do in these Presidential Fitness Tests that were a nightmare. And so I avoided most of that, which wasn't necessarily the best decision, but it's what I did. And I just avoided things that I felt uncomfortable doing

back then. And putting that out there and being last picked for dodge ball was not high on my list of things I wanted to be a part of, so I avoided them.

Fast forward, I didn't go into leg braces until my late twenties. I, at the time, with living in Chicago post, I had a master's in social work and was living and working in Chicago and I just started falling. And I hadn't fallen before. I mean, I had occasionally fallen, but I was just tripping over my own feet. And that was because of the drop foot and it was becoming more significant. And back then, actually, the Muscular Dystrophy Association, that was who I called. I mean that was where I went because they gave free braces at the time for people who had some form of muscular dystrophy. I don't even know if that's still done, but I went to a muscular dystrophy clinic and I wasn't ready for full AFOs. So I started with ones that came up to my ankles. But if anybody's out there who knows CMT, that doesn't really do shit. It did not do anything.

So then I was given my first pair of braces, AFOs that came up to my knees and they were the hard plastic kind. And there was no option. That's what I got. And I hated them. I put them on the shelf, took them out, put them on the shelf, really felt like it affected my self-esteem because I was always into clothes and shoes and I was miserable with those braces, but at the same time, I really needed them. And I guess the rest from there is really about how Trend-Able formed. But my CMT now affects my hands. I have very poor fine motor. I'm strong because I work out all the time, so I have bicep strength that accommodates for a lot of things, but if you don't have a pincher grip, you don't have a pincher grip. So I couldn't pick up a penny off the ground. It would take an hour, a few hours, maybe.

Mindy: A penny is not worth much anymore anyway.

Lainie: Buttons, stuff like that. And my foot drop really with wearing, which I now wear very lightweight carbon fiber AFOs, they allow me to do everything. I can walk for miles and miles and miles. And I would say I have a pretty severe form of CMT, but if you looked at me, you wouldn't even know there is anything.

Mindy: Gotcha. Okay. And how old were you when you were diagnosed?

Lainie: Well, because my mom had it, so in elementary school when you started to run and do stuff, I think that's when I officially went through the nerve conduction tests and stuff as a young child.

Mindy: Okay, okay. And Estela, do you mind telling us a little bit about your journey and is it similar, is it dissimilar? How old were you when you were diagnosed?

Estela: In some ways. I started my journey a little earlier. I was diagnosed at about three and a half years old. I was the oldest of two daughters. So my parents started noticing I was tripping a lot and walking with floppy feet. So looking back, I'm amazed that I was able to be diagnosed in the early eighties at three and a half years old because there's still people today that are misdiagnosed or can't get a confirmed diagnosis in 2022. They really had no idea. Unlike Lainie, mine was a spontaneous mutation. So there was no family history. My parents had no idea what CMT was, what to expect. The only reference they had was Jerry Lewis telethon.

Mindy: Yeah, back in the day.

Estela: Oh yeah. So yeah, that started our journey. And then as I was being diagnosed, my mother was pregnant with my sister and less than two years when she started walking, they were more aware of what the symptoms and what the signs were. And she was diagnosed as well. So it was very devastating for them. They didn't know what to expect. They were just going off of what the doctors were telling them. We were both wearing leg braces in kindergarten and that was our norm. So we didn't really know anything different.

And then much like yourself, Mindy, my parents submitted my photo to MDA for a poster child call when I was seven. And I ended up being the poster child for Long Island for about, I don't know, five years. And then my sister was as well. So our childhood was very much in the spotlight. Every weekend we were going to MDA fundraisers, we were on TG, we were volunteering. Our family was very heavily involved in the chapters and the telethons and that became our life. So in a way, it was very positive. My parents were very proactive. I think it made it a lot easier. We didn't feel like we had all hide our disability. We went to the MDA summer camps, which was-

Mindy: Yeah. Did both of you go to those camps? I'm sorry to interrupt you.

Estela: Lainie didn't, right?

Lainie: No, literally very different. Estela was taught really wonderful, empowering things about her disability. Obviously, my mom is deceased and she did her best, but it was more just like, you have this, deal with it, move on. And we didn't really talk about, it just was what it was.

Mindy: Okay. Okay. I'm sorry, Estela. Keep going.

Estela: Yeah, I mean, so I have a lot of great memories with MDA and just all those things that they provided. And I think it really laid the foundation for a life and advocacy. Much like Lainie, I wasn't really able to contribute or participate in sports. So I leaned towards the arts and the creative world, and I pursued a career in design and loved interior design, fashion design,

things like that. There was always a way to navigate where I had to and adapt to where I had to.

I have two beautiful children now who do not have CMT because of the type that we have is recessive and spontaneous. But yeah, it's been a journey. I still wear leg braces. It is progressive. I've lost more mobility, hand function. It does affect my vocal cords now. So that's been over the past few years, just my voice has gotten weaker and I get more fatigued, things of that nature, but yeah, it's a very wide spectrum of severity and we're just part of this big family, and it's really a pleasure to be speaking with you today and sharing our story.

Mindy: Thank you. Thank you. Absolutely. And it's really interesting to listen to you both talk and the nuances of your stories and Lainie, like you said, the different ways that you grew up and yet you come together and you've got this common bond and we can all help each other through it.

So I think, if I'm not mistaken, both of you have kids. I don't know who wants to grab this one first, but can you talk just a little bit about how parenting is affected by your CMT, or is it?

Lainie: Oh, Deep breaths when you mentioned kids.

Mindy: Full disclosure, this is after Thanksgiving. They were home and mine are both in college and you're so excited to have them come home. I'm counting down the minutes until they got home and then literally they're home for an hour, I'm counting down the minutes.

Talk to me a little bit about parenting with some physical limitations. We've probably got a lot of listeners out there who are parents, are about to be parents or thinking about being parents. What was that like for you and how did you navigate it?

Estela: Yeah, I mean there's a lot of anxiety with just becoming a parent in general in a healthy body. But then of course, when you had disability to that, it just adds another layer to all the potential challenges that someone can face. I think for me, it just started with the whole genetics of it and still not knowing whether or not this was the type of CMT that I could pass on. So once we crossed that bridge, I could take a little bit of a breath, but it's almost like there's really no part of parenting that disability doesn't affect in a lot of ways. I feel like it's woven into the whole experience of being a parent and like anyone else, it's an opportunity for growth and, for me, it really shifted my perspective on what I wanted to do with my life.

It also had a good positive impact on making sure that I was going to stay as healthy as possible so that I could be as active and present with them as I possibly could. So I started working out more and started eating better and just being more aware of how I was taking care of myself as well. But

there's that guilt that comes along with it. I couldn't run around and throw a catch with my kids or run on the beach with them or go skiing for the first time or even put my daughter's hair and pigtails because of my hand weakness. Anything from those day-to-day things that I think probably almost everyone takes for granted can be really exhausting. And if we don't check in with ourselves and make an agreement with ourselves that we're not going to internalize that guilt and our limitations as us being bad parents, then I think we can get through those moments, but it's hard. There's a lot of guilt that we have to navigate.

Mindy: Yes. So true. Lainie, any other perspective things to add?

Lainie: Yeah. Well, I get a lot of people writing me through Trend-Able pages asking about my experience and knowing my type of CMT is hereditary. And so a lot of people have asked, "Well, how did you make the decision? Weren't you worried? A lot of people choose not to have children nowadays." And my sister chose this route of having in vitro and being able to separate the CMT... There's got to be a better word than infected, but CMT, whatever. And my personal feeling is that yeah, you can get rid of that, but then you could get something worse or you're playing with whatever. And my mom, even though she didn't do the best job of talking about CMT or empowering me about CMT, what she did do is showed me that you just live.

So I was worried while I was pregnant about things that were out of my control. What if my little boy is going to run away from me? Everyone says that they do at the mall and I wouldn't put my kid on a leash, but I can't when people do that, so all that stuff. But I personally feel like you get what you can handle and your kid, even as babies, pick up on the things you need and what you need and what they need safety wise and what they need from you. One of my kids has CMT, one of them doesn't. The one who has CMT, it's extremely mild. They don't wear leg braces yet.

But my son, who does not have CMT is a total sports boy. He is active, he is busy, he is like a stereotypical boy. But he never left my side. Never. I would say "Blake, sit here." He'd sit. And having a disability gives your kids gifts that are priceless. So I believe that because of my disability, both my kids are much more empathetic to others. They understand things that most adults who do not have disabilities aren't sensitive to. They think about people and what they may or may not be able to do before making assumptions. They're really intuitive and both of my kids have really good emotional intelligence. And I think that comes from having a parent with disabilities.

Mindy: Absolutely. And I'm a mom also. We actually made the choice to adopt and adopted our daughter when she was five. And so it's interesting, you've got three moms here with different stories and different

experiences, but I think that between the three of us, what I'm hearing and what I'm picking out of the conversation is that you work it out. It's cliché, but where there's a will, there's a way. And I think Lainie, what you said about kids picking up on what you need is so true. And from such a young age, kids are so trainable. And I think that they really understand a lot more than we give them credit for. And it's a two-way street where they're picking up on what we need, what our limitations are, how we're going to work together to make all of these things happen. And kids are amazingly resilient. And I could not agree more that I think growing up in a family with a family member with a disability creates such a sensitivity and such an empathy in kids that they grow up with and really positions them to go on in the world.

Lainie: I'm laughing because as you're talking, I'm thinking about my dogs. I'm way more concerned about losing my dogs and what happens when they get away.

Mindy: Yeah. Dogs don't get it.

Lainie: But then I think they got a warm house, they have a cushiony mattress, they have all the best. Estela knows I spoil them rotten. They might go away, but they'd probably come back.

Mindy: Yeah.

Lainie: They're like, "Why would I want to go out here?":

Mindy: I know.

Lainie: So I mean, you can't worry about what you don't know. And honestly, it's a personal choice. A lot of people choose the genetic route and whatever and is doing all that. And that's totally an individual decision. But I will say that not having children or making the choice because of my CMT was never even a thought. I was like, "Well, yeah, I mean, knock and wood, for the most part, CMT is not fatal for the most part." My mother actually passed away because of CMT's influence, but she passed away from pulmonary issues related to having a weak diaphragm. And so you learn from that too. My mom was not into exercise. My mom sat around a lot and was very social, very, very social, but she didn't prioritize weightlifting and the things that may have prevented that. You just feel as you deal. And with children, none of us would've had children if we would've known what they're like as actual teenagers.

Mindy: What happens to them when they turn 13? It's like aliens take over their bodies. But I digress. But I don't know if you guys follow Marie Forleo, but the phrase everything is figureoutable is coming to mind. I think that that's so true when it comes to parenting. You get creative and you figure it out. So it sounds like you both grew up very differently, but where did your

empowered outlook and mission in life come from? Estela, let's start with you.

Estela: I think, again, going back, having that foundation that was so strong all of those years growing up around a community and people that were selfless and wanted to move forward and had a purpose, that was the groundwork. But then circling back after I had my children and had a career, I still felt like something was missing. And I didn't really make the connection until I came across the documentary called Bernadette, that the foundation that I work for now actually funded and it's going to be the 10-year anniversary, actually, next year.

Mindy: Oh wow. We'll have to put that link in the show notes.

Estela: Yeah, it's on Amazon Prime. It's an amazing documentary. And it just brought home within just a really powerful moment of just almost remembering who I was, why I was here, that there was something bigger. And just remembering that there was people outside of just me and my sister living with CMT and almost planting this seed and this question, how can I use my skills and my talents and then combine them with this bigger purpose? And that's how it started again for me.

And I started volunteering for the foundation. I just wanted to be part of it again. But this time, I was bringing my creative services and my creativity to the table so it looked different. And I could see how that could impact fundraising, how that could impact spreading the word about genetic testing and helping people get educational resources and webinars and things that would actually really make a difference. All of these things that I wish I had growing up, models, adaptive fashion, all of these things that can make us feel so isolated growing up, that if we would've just seen ourselves represented differently or had those resources, or even known where to find those pair shoes when we were going back to school shopping, how that could have impacted us. So I came back full circle and was like, "Oh, now it all makes sense, now my experience, my education, and I can make something new from it."

Mindy: I love it. And you're problem-solving, you're filling the void that existed for you growing up. And I think some people are just natural problem solvers. Lainie, does that describe you as well? Where did your empowered outlook come from?

Lainie: Yeah, one of my skillsets has always been to just find workarounds for everything, not only because of disabilities, but just in general. I'm the person who finds things like, "Oh, you're looking for something, I'll find it." I figure things out and the cliché, you can do anything you want. No, you can't do anything with a disability, but there is a way to do it differently if you want to do it. So that's how I lived. And I mean, there's a lot of things I

don't even care about doing. Like Estela said, skiing. I've never, obviously, been skiing. That is something I cannot do. And I don't even have a need to figure out a way to do it. I have no desire to do it. I don't want to be in snow or on snow or have anything to do with snow.

Mindy: We're going to get letters from people giving links to adaptive skiing for you, right?

Lainie: Oh, there is. And I could, but see that's the example. I don't even want to.

Mindy: Yeah, of course.

Lainie: Just because you can't, doesn't mean you want to, right? I don't know. So yeah, I am all about using your best assets and that's what you bring to the table. And I mentioned that I have a background as a social worker and I did a lot of work with teenagers and women in my professional career before Trend-Able and Embrace It with self-esteem and body image issues. And I had a lot of body image issues growing up. And a lot of it probably stems from the fact that my family wasn't open and there was a perfectionism ideal of what I wanted to look like and what I felt like was ideal and acceptable. And I hid my disabilities truly most of my life. No one really even knew. I'd lie and make up excuses. So now I'm all about doing what works for you.

So I wrote an article on Trend-Able a while ago called Leg Braces: To Show or Not To Show. That is a question. And it doesn't make you more confident. Just because Estela choose with maybe to show her leg braces. And I, on an everyday basis, do not, that's all good. What I encourage people to do is really to do what feels good. If you feel like hiding your leg braces is hiding who you are, then don't hide them. I don't feel like my leg braces are who I am. I don't feel a need. And frankly, I care about what I'm wearing more than telling people I have a disability. I don't need to tell everybody and I don't care to. That's all individual. So I just blabbed on as usual.

Mindy: No, no, no, no. That's all so good. And I think that it's something that we can all learn from and because self-esteem all of that, particularly for women, is such a prevalent thing. And so I love the way that you framed all of that. I want to talk about your podcast and your workshop. Both are called Embrace It and I think they are fantastic. In fact, I think I may or may not be showing up in an episode of Embrace It Podcast.

Lainie: Yeah, it's a good one.

Mindy: You're so nice. But yeah, tell us a little bit and we're running out of time and I have 9,000 more questions I would love to ask you, but if one of you could talk a little bit about the podcast and the workshop and how they came to be and what your mission is with those two things.

Estela: Yeah, I think they happened both really organically. I think Lainie and I were just so excited at the chemistry that we both had because we felt like, well, how could we share this with other people who maybe doesn't have that close friend that they could talk to about disability openly and who really gets it? So we were having all these great conversations between the two of us and with Lainie's background in social work, she had more of a framework on how to talk about these issues around disability, how to be more assertive and the different types of communication. And it really set a different tone on what our role is as people with disabilities, how we can communicate with the world better, how we can get a better outcome, how just by using humor or using different tools or seeing things differently or rethinking a situation, how we can have a better outcome.

And so our first workshop was at an HNF summit. It was so much fun and that was really different. It wasn't like you're a typical traditional support group where unfortunately they have a lot of bad rap and people are crying, which is needed as well. But this was fun. It was role-playing, it was experimenting on how we can have these interactions in a better way and it gave power back to the people with disabilities. And so we felt less like the victims.

And then at the same time, we started having these conversations on the podcast, just the two of us. And then we slowly started bringing in guests and then we started going outside of the CMT community and just thinking bigger about disability, that there's so many other common threads no matter what kind of disability you have, whether it's vision, hearing, amputee, it's such a huge demographic. And I think it only empowers us even more as this huge group in the world to know how many people out there really have different disabilities and learn from their journeys. Everyone has such a unique perspective and the amazing gems that they can share. And that's what we're doing.

Lainie: So our workshops and the podcast, the parts that are geared for people with disabilities cover everything from how to communicate with someone about your disability, how to disclose your disability, so very practical but fun everyday thing. You go to work every day, how to talk to your coworkers, how to tell them what you have or not, how to get a pedicure and explain that you can't do this or can't do that, little things. And we give scenarios, we give tips. We want people to really walk away with concrete steps that can change their lives. And separately from that, as Estela alluded to, we work with companies and businesses and we talk to them about how to talk to people about disabilities. So just make an assumption with one out of four people having an adult having a disability that you have people who haven't disclosed. How can you make your workplace safer? What's the communication that you should and could use in your

workplace to empower people with and without disabilities to be their authentic selves? And it makes the workplace stronger.

Mindy: Yeah, that's so good and so needed in this world. Leading up to this interview, I asked you ladies to send me your top three aha moments from 2022 from your podcast and one of the ones that you mentioned and all three of these we could have a whole podcast about. But one of them you said there's still so much harmful stigma and discrimination of disability. And when I read that and I started ruminating on it, air travel and employment come to mind first and foremost before anything else. I'm sure there are tons of other things that we could talk about, but those two things, in particular, the inequity and the dehumanization that related to these two things alone in 2022, the idea that we can't drive a wheelchair onto an airplane or that only about 28% of individuals with disabilities who are available to work actually do blows my mind in 2022. What needs to happen? I mean, this is a big question, but what needs to happen to turn this around? And this dovetails into your podcasts and the work that you do in your workshops.

Lainie: From my perspective, I'm sorry, it dovetails into the TEDx that hopefully will be released by the time this podcast airs.

Mindy: Yes, both of you have done TEDx talks.

Lainie: Yes. And the one I just did it was all about invisible disabilities and realizing, of course, that this audience may have visible and visible disabilities. But what I think needs to happen truthfully is that if people can relate to you, they're that much closer to reducing the stigma. So we need more people to basically be advocates for themselves, to share and tell people, "Yeah, I have this. This is how I am." And do it in a very matter-of-fact way, not in this big production of this is my long list of medications I take, life sucks, blah, blah, blah. Not that, but just as a matter of introduction, like, "Yep, I'm Lainie. I have CMT. Oh, you want to know what CMT is? This is what it is." That is what is going to help, but so many of us don't tell anybody, we struggle alone, we don't say anything and so how can people relate if they don't even know anybody who has a disability?

Mindy: Yeah, it's so true. It's such a good point because I do a lot of speaking to companies and I'm always surprised at how many people tell me that they don't have a disabled person in their life. And so as a result, because they haven't been exposed to disability at least that they know of, they don't know how to act and how to speak to somebody and all of these things. And you're so very right. I think that the issues and the topics and just people in general living with disabilities need to be more in our line of sight every day. I think there's almost like a desensitization that needs to

happen to normalize all of this so that we can embrace it. Ha, see what I did there?

Lainie: You did it. We love it.

Mindy: And incorporate it into more equity in the world. So I'm on my soapbox, but one of the other aha moments that you sent me was that the sheer spectrum of disability is so much larger than we realize. Estela, can you hit on this one just for a second and talk a little bit about what we can do with this piece of information?

Estela: Yeah, no, I think it really ties into what we've been saying is that we need to have these conversations more in the open. We need to feel more comfortable speaking about... We need to rebrand disability and we need to really highlight not just the extreme ends of disability. You have a completely fully able body person and then you have a person who is very much obviously disabled, but there's this whole spectrum in the middle. For example, we've interviewed guests with vision impairment and when we think of somebody in the blind community, our mind right away goes to, "Oh, they only see completely blackout." That's what blind is. We can't see anything at all. Or if someone's deaf, they can't hear anything at all. But really the majority of these types of disabilities are everything from have a limited vision to more severe vision loss.

So I think we need to have more of these conversations with people that are on these different parts of the spectrum to really understand all of the ways in which disability affects us and all the types of accommodations that are necessary in order for us to thrive. And a lot of these accommodations are not huge expensive changes, a lot of them are just being more mindful of that these disabilities even exist, like someone sitting next to you at your office every day, has colorblindness and can't decipher red or green on a spreadsheet. That's a disability. So I think just rebranding what disability is and being more specific about what falls under the umbrella of disability.

Mindy: I love what you just said and rebranding disability is brilliant. I'm creating a hashtag and that's happening. Just to round it out, and I think we've talked about this one quite a bit over the course of our conversation, but the third aha that you sent me from 2022 for you is that real conversations matter and are vital for real change. And Estela, I think that you just talked about that brilliantly. So I'm going to wrap by asking you both the same question, whoever wants to start, but we are at the end of a year and we're going into a new year and a lot of people are thinking about what they want for themselves in the new year. They're setting goals, things like that. What is the one piece of advice, I'm sure you have lots of advice you could give, but one piece of advice that comes to mind that you could give to

someone listening about how to start off the new year as empowered as possible?

Lainie: I would say just start. A lot of times people just are like... You and I talked, Mindy, someone asked me yesterday, someone literally was like, "I want to do a TED Talk, whatever, I've been looking them." And I'm like, "Just apply." That's what it comes down to. If you want to have more friends, then go do stuff.

Mindy: Leave your house.

Lainie: If you want to lose weight, then start writing down what you're eating. You just have to start. So you start and don't be hard on yourselves because it's not always linear. Everyone has days where things aren't exactly how you intended them to go. And then just start again. I just do and that's what I recommend for people is get out of your head. Stop planning to do, just start doing.

Mindy: That's so good. I love that because you're absolutely right and I am guilty of getting stuck in the planning to start phase. And it doesn't matter if the first step is the right step. It's a step. I love that. I love that. Estela, what about you?

Estela: Yeah, I think really understanding your why even before you start taking action is super vital because a lot of people are taking action based on someone else's expectations or they're comparing themselves to others, someone else or I should be doing that, or I don't know what to do with my life, or I don't know what to do with my career. All of those things that I think... We are most successful when we're aligned with our purpose, when we're aligned with what brings us joy, authentically brings us joy. And then from there, we have much more momentum to move forward and we're less likely to burn out. We work our asses off, Lainie and I, but we love what we do. And if we didn't, we wouldn't still be doing it because it takes a lot of work and effort.

So I think first, it's just really reflecting on if money was not an issue, what would you be doing? Maybe it's around your disability, maybe you're a mom of a child with autism and you see a need for some kind of toy that's not out there or some kind of program that would benefit your child and other children. Start there. Start with the need, start testing out what that would look like. Start talking to people about it as well because that'll get you help people support you and get ideas and learning about what that is that brings you joy. And it'll slowly begin to develop. I think a lot of people expect to have all the answers and to be able to execute immediately, but I think there's a lot in that development stage that can be underestimated as well.

Mindy: That's really good. I think a lot of us get caught up in shoulds and we do something because we think we should, and you're so right. I think really understanding your motivation behind something, it's the thing that's going to keep you going. Because accomplishing something, going after a goal is hard. And at some point, you're going to get tired and you are going to want to throw in the towel. But you're right, if you understand why you started in the first place, that's the thing that you can revisit that's going to keep you going. You guys are so smart. I'm pretty sure that we became best friends during this conversation and I'm just so excited to have had this conversation with you and to continue to watch your journey and all of the amazing things you're putting out in the world.

Speaker 4: Thank you, Mindy.

Lainie: We loved being with you. Estela's been listening to you on Audible. I had a meet with you on my own. So we truly are girlfriends and it's really, really nice to meet another person affiliated with muscular dystrophy and who is living the best they can and thriving. We appreciate you having us so much.

Mindy: Thank you so much. It's been pleasure.

Estela: If you have not read Mindy's book, please pick it up. And I am halfway through it. I'm just zooming through it because your personality is just so contagious and I think it's such a wonderful read for anyone and it's not just somebody with a disability, that's how you see the world through your disability and how you navigate each of the things that suck. But I think it's so relatable to everyone and really, I'm loving listening to it,

Lainie: Mindy, obviously Estela is available as a publicist, but I get a-

Mindy: I was going to say, I'm going to have to send you a check.

Lainie: Honestly, I feel like I need a commission from her publicity. She does the word and I'll get the payment. She's been raving about it. So I definitely need to put it on my list.

Mindy: Well, I appreciate it.

Lainie: Thank you so much for having us. I got to get mammogram.

Mindy: Thank you for being here. It's been a pleasure. Thanks guys. Thank you for listening. For more information about the guests you heard from today, go check them out at mda.org/podcast. And to learn more about the Muscular Dystrophy Association, the services we provide, how you can get involved and to subscribe to Quest Magazine or to Quest Newsletter, please go to mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review, go ahead and hit that subscribe button so we can

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Thanks everyone. Until next time, go be the light we all need in this world.