

Episode 28: There is No Such Thing as Normal April 14, 2023

(Music playing)

Mindy Henderson:

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. Whether you are one of us, love someone who is or are on another journey altogether, thanks for joining. Now let's get started.

All right, well, hello everybody. We are so excited that you are here to join us for this podcast episode with Megan Dejarnett. Megan is an author, speaker, disability DEI educator and inclusion advocate. Megan lives with spinal muscular atrophy and is the organizational founder of No Such Thing, a company with a mission to help others redefine purpose by removing defining labels. Author of the children's books, No Such Thing As Normal and Lovely As Can Be. Megan teaches children the ways in which everyone is unique and that our differences are what actually make us special. Megan, thank you so much for joining us today.

Megan Dejarnett:

Thank you so much for having me. I'm so excited to be here and chat with you.

Mindy Henderson:

We are so excited that you are here. I've been looking forward to talking to you. I feel like I've seen your face everywhere. I follow you on Instagram. I've seen you in that fantastic music video with James Ian, and so I feel like I know you a little bit, but even though this is the first time that we're actually speaking, so thanks again for being here.

Megan Dejarnett: Yes. That's the beauty of social media, right? We're friends before we even

knew it.

Mindy Henderson: You share very beautifully that your passion is motivating others to approach

life with an I can do this attitude. Where did that attitude come from?

Megan Dejarnett: Honestly, I would have to really give the credit back to my parents as they raised

me and when they first got my diagnosis, it was a whole new world, which I know is a very similar case to a lot of families. They had zero experience with children with disabilities. They had no idea what spine muscular atrophy was, and so they really just dove in and started learning and started joining groups and not to give my age away or anything, but that was over 30 years ago. And so times have definitely changed, but I would say that they just had this outlook. They really didn't know what the future was going to look like, but they knew that they had control of the present moment and so they were going to raise me and my siblings to do everything and anything that we wanted and could do.

Obviously we had to do things differently than other families, but I think the beauty of it was that we were creative and we did all the things other families were doing. We just did it differently. And so I think just having that as a young child, never being felt like I was held back from anything. I was pushed in a good way to experience life and education and all the different things. And so I think that just naturally is part of who I am. I might see an obstacle or might see something that seems difficult and I'm going to figure out a way to do it if it's

something I really want.

Mindy Henderson: So good. So let's go back to your childhood a little bit. What did you want to be

when you grew up or did you know that you always wanted to write and speak

and be an advocate?

Megan Dejarnett: Sure. Well, here's the thing. When I was really, really little, I was I would say

your very typical little girl, and I was playing house and I was playing mommy, and I was doing all those things. And I think in my head I never thought that was not a possibility. I always had the dreams of getting married and having a family. I don't think I thought of what the realities or what that would actually look like until I got older. So little girl, those were definitely on my that's just what I'm going to do. Every little girl has different dreams and that was definitely part of mine. As far as the career path of writing and speaking, I always knew I loved storytelling and I loved sharing my personal life experience, both with people who have similar disabilities or diagnosis as being, and those who have no

experience with disabilities.

I just love it. I love being able to show all the abilities that we really do have despite what we're walking through in life. When I was in high school, I really felt the urge to get into public speaking, but I hated it. I hated being in front of people. I would get so nervous, I would cry, but I knew that was the path I was going to go down. And so I forced myself to sign up for a public speaking class, and it was one of those where I was kicking myself every day, why did I do this?

But at the same time, it's like I knew I wanted even just that little bit of training. And as I've gotten older, I've signed up for more of that. And again, I'm like, right before I speak or do something, I'm looking at my husband, why am I doing this? And then afterwards I'm like, this is the best thing ever. I love this so much. A double edge thing there.

And then as far as the book, I really didn't think I would... I never had a huge dream to be an author until I became a parent and I saw a gap in stories that I was reading my kids and I figured if my kids had questions, I'm sure other parents' children had questions too. So that's where that journey started. And then as far as other things I have on the horizon that we'll see, I don't know.

Mindy Henderson: That's amazing. I love what you said about being in high school and taking a

public speaking course. I think public speaking is such a fear for so many people, and I'm really impressed that at that young age that you had the foresight to push yourself out of your comfort zone and to do that, given that it was a bit of

a fear of yours.

Megan Dejarnett: Oh yeah. Like I said, I hated it. Even just reading my papers in class, I was like,

this is terrible. But there was something bigger in me that was just do it and

you'll be glad you did later.

Mindy Henderson: So amazing. I love that you did that. So you've mentioned that you're a mother,

you're a mother of two. And of course that's an important role in your life. You mentioned that you grew up knowing that you wanted to be a parent. Is that

true?

Megan Dejarnett: I did. I was just telling someone the other day, they were asking me when did

you know you wanted to be a mom. And I think since I was super little, I have memories of being sitting on the floor in my parents' living room, being under five, I would say under five years old. And I would stuff a pillow in my shirt and pretend like I was pregnant. And I would tell my mommy, Mom, look, the baby's moving. The baby's moving. And obviously I was watching my mom. I have two other siblings younger than me. Something just naturally in me always wanted to be a mother. And it wasn't until I was obviously in a relationship I was older that I was like, okay, I need to figure out what that realistically looks like for me. But yes, as far as wanting, having that desire to have a family that has been in

me forever.

Mindy Henderson: That's awesome. And I also live with SMA and I'm a mother. My story is very

similar to yours in a lot of ways, but there was some distinct differences. I became a mother through adoption, and you mentioned age. I am a bit older than you. When I was looking at becoming a parent, the mindset of the doctors was still very much that it was inadvisable for someone with SMA to give birth biologically and all of that. And I know that nowadays a lot of people do it and self included and it's fabulous. But did making the decision or the decision to start a family, did your diagnosis impact your thoughts and what [inaudible

00:09:28]? There may be people listening who want to be parents but haven't decided yet how they want to make it for themselves.

Megan Dejarnett:

Yeah, I will definitely say that when my husband and I were open to the let's grow our family topic, we really didn't know. We did not know what route we were going to go. And so we had settled, whether that's adoption, whether that's surrogacy, whether that's I get to carry my own children naturally, whatever route that was going to be safest for me and for the child. We were okay with that. And so I love that you have that of adoption, that story, because my best friend adopted her daughter and I just think it's beautiful. And so weren't like, this has to be the way it's going to go. We went into it openhanded saying we found a specialist. She had never had a patient with SMA. However, she was a high risk doctor. And so we presented it all. She was very good at just listening and learning about my body.

She did some research and we did not make a decision right there and then. We actually came back a few months later and she gave me the green light where she felt comfortable with my body carrying a child. And so that's the path we went down. But definitely it was something we considered and we were very, I say this obviously every person's body is different, and so you can't just look at my diagnosis and say, oh, well I have the same thing. I'm good to go. Obviously you need a medical professional to give you that green light, but we had our different specialists that were just ready on hand. Knew my care. I was seen every couple of weeks. Actually, I was seen very frequently just to monitor things. But other than that, everything went extremely smooth.

Mindy Henderson:

That's amazing. And I'm very happy to hear that and that it was a good experience for you. What about after giving birth and adapting to the physical aspect of taking care of a baby? Again, with my situation, we adopted a five year old, and so the way she was out of diapers and didn't have to pick her up when she was crying, we didn't have to her fingers away from electrical outlets, things like that. How did you adapt to those sorts of things?

Megan Dejarnett:

Yeah, well, I think parenthood in general, I think especially bringing home a newborn, you don't know what to expect. There's parenting classes, but until you are in that position, nobody can prepare you 100%. And so a lot of it was just learning as we went. I think when they were super tiny, a lot of it was adapting and figuring out what those roles looked like for my husband and I, what were the things that I could do and what were the things that I could not and he obviously had to do? I could not pick the child up out of the crib to soothe them, but he could pick the baby up and hand it to me. And we had different positionings and different pillows and gear, all the different things we had that made it work for me, certain feedings and certain things.

And then as the seasons changed, as a parent, seasons change constantly. And so as we would enter different seasons that changed. The things that I could do changed. And now my kids are seven and nine now, and we're at a really fun age because we can run into a store together, just the two of us, and we can take on

the day. It's totally different. But what I think is also very similar to able-bodied parents is that those beginning years are hard. They're just hard in general. And so we just had to get creative really was what it was. And it's okay to ask for help and it's okay to identify what those roles are between you and your partner. All of that I think was just a very helpful thing for us.

Mindy Henderson:

Well, and I think it speaks to back to that I can do this attitude and mentality that you talk about and clearly live by and teach other people to live by. And you make a really good point, I think no matter how you splice it, challenges abound with parenting.

Megan Dejarnett:

Absolutely.

Mindy Henderson:

We all regardless of what those challenges are have things to figure out. And so I love hearing your answer on that.

Megan Dejarnett:

And that's where I see that heart I have for motivating people. It's not just for others that are in wheelchairs or other people that are living a very similar lifestyle as me. It's for anyone, because parenting is hard. I've had ones who are not disabled who are like, oh my goodness, I don't have the mental capacity right now. I'm so exhausted. It's like, okay, here's some tools, whatever, here's some resources or here's what I did or here's what. And so I hope to be an encouragement really to anybody and not just in the exact scenario as I'm in. However, I do hope to encourage those who do live with SMA who want to have a child, and it's good for them, their body, they've got the green light from the doctor. I want to be an encouragement to them because it's the greatest gift I have right now is raising my family.

Mindy Henderson:

I love that. I love that. So you've also shared that your oldest also lives with a disability, and that was a key motivation in teaching children the [inaudible 00:15:09] being unique and that there's no such thing as normal. Can you share more with us about what your oldest taught you and how that philosophy came to light?

Megan Dejarnett:

So my oldest son was later diagnosed with cerebral palsy, and so a lot of assumptions are made that he has the same condition as me, which he does not. He was tested for all the things. He does not have SMA. And so it was a whole different path that I had to learn to go down because it was different than my personal experience. And when you come at this as a mother now, it's different. Oh my gosh. It opened my eyes to a whole different world. And I was always, like I had mentioned, I was always passionate about public speaking, about motivating, storytelling, all these things. However, it wasn't until I became a parent to a child with a disability that I was like, I've got to do something about this. What is my role in the world when it comes to disability and inclusion and all these things?

And that is when I decided to write my first children's book. It really came out of just this, like I mentioned before, this personal need that my own household had of answering those tough questions. I don't know about you, but I have

been in public places and my children have asked questions that make me want to crawl into a hole. And typically they have the best intention. They're just curious and we have to equip them well with what do we do in those scenarios. And so that's really what my book is about. There's some discussion questions in the back, there's different tips and prompts, but honestly, it started as my own personal, I needed my own resource. And so that's what I did.

Mindy Henderson:

And I love the title No Such Thing As Normal, and it speaks the truth. My daughter, we adopted from China, and so one of her concerns growing up was looking different than my husband and me. And we had a lot of the same conversations with her about the things that made her different, made her special and unique and all of that. And so I think that you're giving people such a gift by teaching children this life lesson who may not otherwise have the opportunity to learn it. So you've got two books, if I'm not mistaken. You've got some coloring books.

Megan Dejarnett:

Well, and I did want to just mention this because what you were saying, my book is not only about disability, it's also about just differences in general. So the first couple pages actually, it talks just about kids who look different. One of the scenes is they're in a library and they're noticing kids that are all together that look different than her. One girl has red hair, one boy has black curly hair. And so my hope is to just show in general, my book can't touch on every single disability and topic, but it touches on so many general differences that my hope was that children could at least correlate it to their story. So to answer your question, yes, I have the hard cover book, No Such Thing As Normal. And then we decided to do a coloring book. I wanted some kind of fun activity that had representation in it.

And so we collected 31 stories of real children and developed a coloring book. And so the coloring book has their picture, obviously, but then it also has a little bit about their story, who they are. Things that would make them similar to other kids. Maybe they like dinosaurs or they like coloring or they like playing doctor, but then also tells about their story of what makes them a little different. And the purpose behind that was to not only highlight, well, I'm different than everybody, but actually to highlight, well, we probably have similarities within us because I'm a human and I'm a kid and I like things you like too. And then at the bottom there's some vocabulary words that help answer those questions when your kid says, well, what's down syndrome? Well, there's a little tiny blurb in there, obviously doesn't go into great detail.

And then in the back there's actually some websites that have some more resources. And then the last book collection that we have is called Lovely As Can Be. And that one is actually a four book set. So it has four different books and every book's a different topic from how you look is lovely to what you need is lovely, whether that's a wheelchair or a feeding tube. And then it talks, the third book talks about how we communicate different, and the last one talks about how we all express our emotions differently. And so I just get these creative

ideas and really it comes from, okay, I need something that can speak to this family or this parent, and then we just run with it.

Mindy Henderson:

That's amazing. I feel compelled to ask you with the work that you do and these themes and philosophies that you talk so much about, how do you feel like we're doing in today's day and age in terms of representation of people with disabilities? Do you feel like we've made progress? Do you feel like there's a long way? How do you feel about it?

Megan Dejarnett:

Yeah. Well, I say this all the time. I say we have come a long way, but we have a long way to go in the sense of, I love seeing advertisements and billboards and things in Target, and there's so many, I'm in a really cool space with so many different authors that are inclusive children's book authors, and I'm proud of that. I'm proud of the headway that we've started and we've made, and it's taken a lot of people standing up and saying, hey, we got to make changes in this area. But I do think we have a long way to go. I just recently got certified in DEI because I have a passion to start implementing that in companies and organizations because I think we want to do it, we don't know how to do it is one side of it. And then there's the other side of it that does it because they're checking a box because they don't want to be accused of anything versus doing it out of the understanding that it is actually beneficial for everybody, for the company down to finances, everything.

It's actually beneficial to truly have a diverse group. And as far as representation, I think we're getting there and I think it's an interesting mix. I don't like to feel like disability inclusion representation, that those are buzzwords and that they're just going to fade away and not be trendy one day. But I do think we're at a pretty cool pinnacle right now. But I just hope it just keeps claiming and that we see more change with things, especially, personally, especially when it comes to education, when it comes to political things, insurance, there's just so much work that needs to get done. But I think if everyone does their part in some manner, we'll see more really good changes, especially for the next generations.

Mindy Henderson:

Very well said. Very well said. Let's talk about your nonprofit, because if I haven't mentioned that already, you also have a company called by the same name as your book.

Megan Dejarnett: No Such Thing.

Mindy Henderson: Is it, I'm sorry, No Such Thing or No Such Thing As Normal the organization?

Megan Dejarnett: So the book is No Such Thing As Normal, and my company as a whole is No Such

Thing Co. It's actually a for-profit. It's not a nonprofit.

Mindy Henderson: Oh, gotcha.

Megan Dejarnett: Yeah. But one thing that we do within No Such Thing is we love giving back to

other organizations. So with every purchase that is made of our books or our t-

shirts or anything from our shops, whether it's online or in person, we pick an organization for the month and we give 20% back, which 20% is a pretty good chunk.

Mindy Henderson: That's a sizable amount.

Megan Dejarnett: But it's been so rewarding because we've seen, actually, the way we've had it

laid out is that we actually let families pick who they want to donate to. So every month is a little bit different, but last month we did this really big campaign for World Down Syndrome Day and we gave back to the Lucky Few Foundation, and

they're a foundation that I'm passionate about because they're big on storytelling and representation and changing the narrative behind down syndrome. And so we rallied together and sold as many books as we could, and we're getting to donate \$1,200 to their organization and from one small

business to another it's just so fun to see the impact that you can make, not just in your little sphere, but also in someone else's company. And so that's one of

the fun things that we get to do every month is give back.

Mindy Henderson: That's beautiful. I really, really love that. What's your most proud

accomplishment? You've done so much.

Megan Dejarnett: Oh man, that's a hard one.

Mindy Henderson: Being a parent obviously is your number one accomplishment. But after maybe

being a mom [inaudible 00:25:02]

Megan Dejarnett: That's hard because I feel like, and a lot of this is just personality, I'm very much

like, okay, cool, we hit that goal. Let's move on to the next thing that sometimes I have a hard time celebrating in the win. But I think one of the coolest things is that when I started this, I had mentioned that I did that public speaking class in high school, and that's high school, you're only going to learn so much there with when it comes to the professional world. I think just being willing to tackle things and rolling with the punches and taking the curve balls as they come. When I writing this book and I self-published it, and so everything financially was coming out of our pocket and we dumped everything we had into this

project and I was so proud of it.

And I had signed up to be Miss Milter Tennessee with the purpose and the goal of getting better at public speaking. And I did it again with that thought of why the heck did I do this? But I signed up for it with the goal of I wanted to get better and I wanted coaching and public speaking and then I won. And part of it was, you're going to go and make appearances and speak and do all these things. And it was great. And I was super proud of that. That I won it and I was launching my book only a few months later and a big grand plan was go into schools and start speaking and do it as Miss Milter Tennessee and all these, I had all these ideas. Well, I launched my business and my book two weeks before

the world pandemic that we had no idea was coming.

Mindy Henderson: Oh my gosh.

Megan Dejarnett:

So it was very disappointing too. I had a book release party planned. I had all these grand ideas and I could have just quit everything. And I was like, we're going to pivot and we're going to figure this out. And we were all in lockdown and we decided, hey, everyone's on their phones, everyone's on social media. Let's go down that route. And it was sad because I wanted to be in person. I love in person, I love conversations like this, but we were going to make it work. So that was 2020, and we've sold around 7,000 copies of our products all through social media. And I think that is a pretty cool accomplishment because I once had someone who was partnering with us and in really early stages, I knew nothing about writing. And so I was trying to figure out do I go a publisher?

But I had no idea how to do that. And so I had someone tell me, you got to just do it because you love it. And I'm like, that's cool, but I am a goal setter. And so I'm like that I got to have something a little more than that. And he had said, well, you got to do it for the love of it because a self-publisher, an average book sells 250 copies in its lifespan. And I was like, I am not doing all of this work to only put it in front of 250 people. Within the first few months we had sold over 3000 copies. I was just so dang proud of that. And it's not because my book is the best book in the world. It is because there were people who had a desire to help their children or their classroom or their clients understand the beauty of everyone. And so they grabbed a copy of our book and have a resource. And so I would say I'm proud of that. Second to raising my family, that's probably my best accomplishment. I don't know.

Mindy Henderson:

Be proud of that too. I think that's really, really impressive. What an awesome story and testament to you, and again your determination and this can-do attitude, it all keeps circling back to philosophy. So there are a lot of people out there who have aspirations to be public speakers, to be professional speakers. What's your best advice for someone who's listening that wants to go that route?

Megan Dejarnett:

I would say prepare as though you already have your dream job. And that has been something that obviously from the little stories I've told, I try really hard to implement. It's not going to fall in your lap as much as we wish that would happen. But I think if you can be prepared so that when that door opens you are ready to knock it down, then I think you can be entrusted with more that way. And I always say, because there's some taboo things in the disability world about storytelling and being an inspiration, and I have my own opinions on some of that. But if somebody can look at your story and can make a positive change in their life, then you have a story worth telling. And I think if you want to be an inspiration to someone, then you go be an inspiration to someone.

And so I've had different people come to me, I've done some coaching for authors who are like, hey, I have this idea, what do I do with it? And we create a plan and we do some things. I've done coaching in social media because we've had some success in that, but my hope is just to equip other people to go chase down their dreams. And so whether that's public speaking or whether that's being an author or whether that's being a parent, cling onto people who are

willing to share the goal that they have or the advice they have and then run with it. Go and go do your thing.

Mindy Henderson:

Love it. That's great. So what about publishing a book? You've referenced the fact that you self-published and there are a few different ways that a person can publish a book nowadays, and I know that self-publishing has become more and more widely done and you I think self-published both of your books. Is that correct?

Megan Dejarnett:

Yes.

Mindy Henderson:

And I know that there are a lot of people in our community who have written books or essays about themselves or their experience. Can you share a little bit about self-publishing specifically and some of your big takeaways or advice?

Megan Dejarnett:

Yeah. I would start with, for any writer out there, don't wait for perfection. Just get your stuff out there and do it well. But I think we can hold ourself back. I definitely struggle with this. I have missed opportunities because I was too afraid to be vulnerable, to put something out that I didn't think was perfect, and there's no such thing as that. And so I think go put it out there, whether it's an article or start a blog or go submit it to different places that are taking inquiry. There's so many cool places that you can publish your stuff depending on what kind of writing you're doing. I will say I jumped into self-publishing not knowing a dang thing. I just did it and started researching. And I had a friend who sat with me and was like, hey, let's learn about this and let's go this route.

If you're familiar with the music industry, my husband's a musician, so I relate it to this back in the day I'll say getting signed to a label was the way you had to go to make anything of your music. But nowadays, being an indie artist, there's so many freedoms with it and with social media and the different platforms that we have, you can reach just as many people. You just have to be consistent with what your passions are and then going after it. So I would say don't feel like I'm in this funny boat because I'm going to be writing what I call my big girl book, so not a children's book, and I think I want to go down the route of actually getting published, but there's a lot of technicalities that publishing houses look at from how many sales do you have to how many followers do you have?

They're looking at numbers. And so I also don't want that to hold me back. So I think I'm going to just start with it and roll with it and just see what happens. But that would be my advice for anyone is just start the process. Write as much as you can because you can have, it's easier to pull when you have a lot more to pull from. You can throw away the things you don't like and then do some research and find out where you want to go print and publish and God bless the internet because you can find anything there.

Mindy Henderson:

Amazing. That's exciting. Well, I can't wait to read your big girl book, and that's exciting to hear. I was about to ask you what else is on the horizon for you? We've got an audience of people who I'm guessing also have some questions for

you, but apart from writing another book, is there anything else you've got planned and coming next?

Megan Dejarnett:

Obviously I love the speaking aspect of things, and so that is my big focus, my big goal, I'd like to get into schools and I love sitting with kids and allowing kids to ask questions. And I love being a physical representation of what does someone that is different than you look like. And so some of my goals are getting in schools and being able to do some school assemblies and readings and author visits. I had mentioned, I really hope to get into more of the corporate space of teaching DEI specifically disability and just seeing what doors that opens. I'm here hands open wide going, okay, what are we doing next?

Mindy Henderson:

Sky is the limit. Sounds like. Well, awesome. Well, like I said, I want to give a few other people a chance to ask some questions. I think we've got a few minutes left. So if you are in our audience and you have a question for Megan if you look at the bottom of your screen, you should see an icon that looks like a hand. If you can just hit that button and we'll take questions in the order they come to us and get through as many as we can.

Megan Dejarnett:

Yeah, no question is a bad question. I'm a pretty open book, and so if you're curious about something, please ask away.

Mindy Henderson:

Fantastic. Rebecca, it looks like we have a question from Rebecca.

Rebecca:

Hi. I absolutely love your concept for your coloring book and that you featured with the children's individual stories, and I love that you featured what makes them similar to others in addition to what makes them stand out. This sounds like a fantastic resource for classrooms as well as parents. In thinking about classrooms what advice would you give to teachers just in general for increasing inclusion and empowering their students?

Megan Dejarnett:

I love that. I always say start with, and this is really the same concept for at home so if you homeschool or your kids aren't in school yet, but start with literature because it's a safe space for them to ask questions when you're sitting down and reading. And so fill those libraries there. Obviously I have my books, but there are so many great books out there right now that have representation in it. And my concept with it and why I even did my board books for the even younger ages is I don't think there's too young of a person to start introducing disability and differences too. The more that we can expose them and represent and show things and allow them to ask questions and appropriately be curious, I think the more, the easier it is as they get older, to not have to unlearn habits and perceptions and ideas around people that are different.

So the younger you can do it. So I would say fill those libraries with inclusive children's books. Allow them the space to ask questions. Be okay to say you don't know an answer. I think so many times as parents, I am guilty of this that we don't want to leave our child hanging with and we make up an answer, but if you don't know, it's okay to say, I'm not sure, and maybe go figure it out and then come back and tell them. Or if you're in a public space or maybe there's a

kid in your classroom who's different, maybe they use a wheelchair, maybe they're deaf, seeing if the parents are comfortable coming in and talking about it or letting the child and the parent or just the child. That was one of the most empowering things I did as a kid, is I would take the first couple days or the first week of being in school after kids have acclimated and just letting them ask me questions or sharing what I wanted to share.

I was a teacher's assistant for a couple years right out of high school, and I would take my kindergartners and first graders that first week and I'd say, okay, you can ask me any question as long as you're polite and I will do my best to answer. And I think that it broke down some of those awkward barriers for them. And it was fun. It was actually honestly really fun, and it helped equip me on how do you answer those really hard questions because kids ask everything.

Mindy Henderson: That's a good question.

Rebecca: I love that. Thank you.

Mindy Henderson: Okay. It looks like we have a question from Holly.

Holly: Hello. You are absolutely amazing. Your story is just tremendous. My question

to you is how would you advise someone to get over, like you had an issue with your public speaking and if they have an issue with public speaking or whatever they may be doing. I know you have a lot of internal fortitude, but how do you advise someone to get out there and help the way that you've helped so many

people?

Megan Dejarnett: Yeah. Well, that's a great question. I think if you have a desire to help and make

a change, or whether it's a book or whether it's, maybe you don't know how that helping looks like, I think the best thing is to partner and find allies within the disability community. So joining groups or supporting groups, asking them, hey, here's my role in my career. What's something I could do that would be beneficial? And maybe they might say, hey, actually, can you talk to your whatever principal of your school or whatever, and see if I can come in? Maybe you don't have to be the words, but maybe you can be the vessel that will allow someone else to come in. And that is just as important. Everybody can take a role in something. As far as that personal overcoming I'm not just this powerhouse of I can do anything. I definitely have my moments that I'm in

tears. I'm like, I can't do this.

And my husband's like, you're doing this, or whoever that support system is that you can rally around you to say, hey, here's my goal. I want to be an author, I want to be a speaker, whatever. And being able to be honest. And when you have those hard moments, being able to go back to them, say, hey, I want to quit everything right now. I have had those moments. I have a really good friend. She knows the ins and outs of my business. And there are times when I text her and I'm like, I'm quitting everything I'm doing. And she's just there just to remind me, don't you dare do that. You have made so much progress. You're doing great. And just those words of encouragement helps. I think that I was

taught we need encouragement in our life because encouragement is simply to just put courage back in you. And so if you're scared of public speaking, you need a little bit of courage put back in you. So surround yourself with people who will encourage you in that area.

Holly: Thank you so much.

Mindy Henderson: Thanks, Holly. That was a great question. Awesome. Well, I hate to say it, but I

think that we're out of time. Do you have any final words of wisdom or advice

that you just want to leave us with today?

Megan Dejarnett: Thinking of possibly who could be listening to this, one of my token things I say

all the time is I've had to learn to adapt to a non-adaptive world, unfortunately, and when you ask the progress that we've made in this world, I think we've, like I said, we've come a long way. We have a long way to go. But don't be scared to figure it out how you are going to do it. It's going to look different, and that's okay, but don't let your circumstances hold you back from the things that you really want to accomplish in life. And you can do it. I believe in you, whoever

you are.

Mindy Henderson: Oh, so good. I can't think of a better set of words to leave us on. That was

wonderful. Megan, thank you so much for being here with us today. And to those of you who joined us in the audience, we appreciate you being here, and I

hope that you'll come back Megan.

Megan Dejarnett: I would love to. Thank you so much. It was such a pleasure chatting with you

today.

Mindy Henderson: Have a good one.

Megan Dejarnett: You too. Bye everyone.

Mindy Henderson: 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 keep bringing you great content and maybe share it with a friend or two. Thanks everyone. Until

next time, go be the light we all need in this w