

Episode 70 –
A Woman with Duchenne: Steffni Randle's Journey from Rare Diagnosis to Social Media Star

November 10, 2026

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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. 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.

What happens when you spend your life defying expectations and then you build an audience of hundreds of thousands who want to hear your story? Meet Steffni Randle, a woman living with Duchenne muscular dystrophy, a condition rarely diagnosed in females. Despite navigating complex health challenges, Steffni has become a social media sensation using her voice to challenge assumptions and connect with people around the world. Today, we're talking about her journey, the power of representation, and what it means to make your voice heard. Steffni, thank you so much for being here.

Steffni Randle: Yes, ma'am. Thank you for having me.

Mindy Henderson: Absolutely. I've got 9,000 questions for you. So let's start just talking about Duchenne. Like I mentioned, it's rare for a woman to be diagnosed with Duchenne. So I know that you were young, you were really young when you were diagnosed, but could you take us back to that time in your life, whether it's your own memories or information you've been told, and share what your journey was like for you and your family?

Steffni Randle: Yes, ma'am. So I was around, I want to say two and a half when my mom started noticing that I was falling a lot and I wasn't catching myself completely with my hands. So I was falling face first. And so she took me to the doctor and the first doctor had said I would grow out of it. It was a phase. And then over a couple of months, she said it got worse. So she took me to get a second opinion with my pediatrician that was my pediatrician from three till I was 18. And she seen me and she spot on told my mom, "This is definitely a form of muscular dystrophy." So she sent my parents off to Dallas, to Texas Scottish Rite, and they did a biopsy of my thigh, and that's when they took tissues out of my thigh and tested it, and I had Duchennes.

Mindy Henderson: Interesting. I mean, did she even suspect, given that it's typically a condition that you see in boys, that that was the one?

Steffni Randle: No, she didn't actually. And my parents said that when I was born, and you know how they do all the testing and stuff, nothing came back suspicious or anything, so it was very shocking to them.

Mindy Henderson: Wow. So growing up with a condition that even many healthcare professionals rarely encountering girls must have brought some unique experiences. What has the experience been like for you, particularly as a woman in the Duchenne community, and how did that shape your understanding of your own diagnosis?

Steffni Randle: I think growing up it was a little different because I didn't completely understand, hey, this is something that is rare. I don't think it really hit me until I was older, but something that my doctors did tell my parents when I was diagnosed is that they didn't expect me to live past seven because everything would be affected, but they didn't tell me that. So I guess I've always been this happy kid growing up, so I really don't think it hit me until I maybe reached my teen years when they wanted to put the halo on. And that's when everything started coming clear because I wasn't able to have spinal surgery due to the muscular dystrophy. So that's when the halo became something more permanent.

Mindy Henderson: I see. I'm sure that it's something that was difficult to go through. Has it been sort of a source of empowerment for you?

Steffni Randle: It definitely has because it's just something that worked for me and not a lot of people will really rarely, they get their halos and then they get their spinal

surgery a couple of months after. Mine is just something that's been continuous with the halo.

Mindy Henderson: Can I ask how long you've had the halo now?

Steffni Randle: 17 years.

Mindy Henderson: Really?

Steffni Randle: Yes.

Mindy Henderson: Incredible. So it's probably just become part of your life, I would guess.

Steffni Randle: Yeah, it's just a piece of me.

Mindy Henderson: Yeah. Interesting. Have you connected with a lot of people in the Duchenne community?

Steffni Randle: I haven't because growing up here in Lubbock, Texas, there's really not anyone here and they closed our MDA down here in Lubbock specifically. So no, I haven't, which I have connected a lot now with my TikTok. A lot of parents reach out.

Mindy Henderson: Oh, interesting.

Steffni Randle: With their kids having muscular dystrophy, different types and things like that. So it's more of younger kids, but their parents are reaching out.

Mindy Henderson: Interesting. Yeah, unfortunately over COVID, the local offices really were challenged to stay open, but I'm glad if you found some other connections and that people have felt like they could reach out to you. I think that's part of the beauty of what you do is you put a face to a condition and people feel like they can come to you for information or advice. I'm sure that must feel really good.

Steffni Randle: Yes, because I always told myself if I was going to be known, it would be specifically for being able to be a voice for other younger people or older people or just people in similar, maybe not muscular dystrophy, but just other thing. And they can just see we're still normal people. We can get through it.

Mindy Henderson: Oh, sure. I didn't actually realize you were in Lubbock. I'm a Texas girl.

Steffni Randle: Oh, really?

Mindy Henderson: I'm actually down in Austin, just south of you. Yeah, we've got Texas in common.

Steffni Randle: Yes, ma'am.

Mindy Henderson: In addition to Duchenne, you manage a few other significant health conditions. What does navigating all of that just in your everyday life look like? And what have you learned about advocating for yourself the older that you've gotten and making sure that your healthcare needs are provided and understood?

Steffni Randle: It was really challenging over the COVID years, I would say. That's when I focused more on my health. It's more so when everything, I went from, hey, taking one medicine to taking 15 over the year and everything popping up as I got older. Living here in Lubbock as well, there's not a lot of muscular dystrophy doctors here. My doctors are in Dallas. So going to hospitals and stuff, it is difficult because it's something rare. So they're questioning you and then you're kind of like, "Oh, hey, I'm here because I'm sick," but you're questioning me. So it has been very important that I know everything that I'm dealing with and all my medicines and everything because it's just a lot. And I understand the doctors too. It's something they've never seen before, so as long as we can work together.

Mindy Henderson: Yeah, for sure. What was it like for you transitioning from a child to an adult who was responsible for your own medical care? Was that sort of a gradual transition or did it happen overnight where all of a sudden you were in the driver's seat?

Steffni Randle: I think I've always been so aware of everything since I was younger, so it really wasn't that big of a change because I've always kept up with my medicines and what I need since I was younger. So it wasn't a really big change. It was just more so having to deal with, okay, this is my life now. This is what we have to do. This is what we have to take.

Mindy Henderson: Yeah. No, that's great. And it's a testament to how you were raised and clearly you were raised to have a voice, and I love that. It's exactly how it should be. Now, sometimes when people see someone with a visible disability, they focus so much on the medical condition that they miss the person behind it. What's something about Steffni that people might never guess from even watching your videos or hearing about your diagnosis?

Steffni Randle: I do depend a lot on help and things, but there's a lot of things that I'm very independent in. I'm very strong-minded and I don't like to let any of my illnesses or disability define the person that I am because my personality, I was raised very well by my mother, and my personality is one of my biggest traits that a lot of people don't give time to get to know and see, because of course you go in the store and they're judging you. They're like, "Oh, something's wrong with her." I've had people think, "Okay, she can't talk because of the way that she looks." And then I start laughing and having a full conversation with my mom and they're like, "Oh, wow." And then in my head I'm like, "Yeah, that's what you give for judging. I was raised, you don't judge people by their looks and things like that." So it's been a lot of my character.

Mindy Henderson: Yeah. Because I know me personally, I live with spinal muscular atrophy, and that was something that bothered me a lot growing up. I hated the staring and how people would speak to the people who were with me but wouldn't speak to me. And it was kind of a constant source of frustration for me. What would you say to any young people, even teenagers maybe, who could be listening and are working through that themselves right now?

Steffni Randle: Be your voice. Be a voice in the world. Do not let anyone knock you down. You know who you are and you know what you're capable of. And like I said with my mom, it's still to this day where people will speak to her instead of me, like you said, because they think... And then my mom is like, "Don't ask me. She can speak. She speaks for herself." So it's very important to keep your voice and voice your opinion because it's your body, your life, and that's what's most important. Nobody knows us like we know ourselves.

Mindy Henderson: I love that. And I know that there are a lot of parents who listen to the podcast, and I love the point that you just made about them saying, "Ask her. I don't know. I don't know what she feels like eating right now. Ask her. You're exactly right." And I think that the people that you surround yourself with is really important, and knowing that they've got your back and that they're going to empower you when other people aren't getting it.

Steffni Randle: Yes. It's very, very important who you surround yourself with.

Mindy Henderson: Yeah. Yeah. You have built, like I said, an extraordinary... How many followers do you have on TikTok right now?

Steffni Randle: I have 623,000 right now.

Mindy Henderson: Okay. That's amazing, first of all.

Steffni Randle: Thank you.

Mindy Henderson: It feels like sort of a constant moving target. I've followed you for a while and I'll look, and it was like 400,000, then it was 500,000. Yeah, it's been incredible to see you grow this platform. What made you first want to start sharing your story, and was there a moment when you realized that your voice was reaching far beyond your own little daily circle?

Steffni Randle: So for the beginning of it started with my niece. Her name is Trisha, and she encouraged me. She was like, "Hey, Amy, let's do this TikTok and just post it." And so she pushed me because before I started, I was scared of the world, scared of what they would say.

Mindy Henderson: Did you resist it? Were you-

Steffni Randle: At first, I was, and she was like, "Come on, just do it. What's the worst that could happen?" And overnight, it took off. And then like I said, I always told myself, "Hey, if I'm going to be known, it's going to be because of my story and my journey." So we just kind of flipped it around and it took off from there just sharing my story.

Mindy Henderson: I love it. I think given what I do every day with Quest Media for MBA, I am a firm believer that I don't think there's much more powerful that a person can do than share their story. What do you think make people so interested in you and your story?

Steffni Randle: I would honestly have to say is the fact that I'm so independent. A lot of people love seeing me do my makeup and they love seeing how I can cook. So it's things of being different, but being able to do the same thing that a lot of people can do.

Mindy Henderson: I love it. Your makeup looks fabulous, by the way.

Steffni Randle: Thank you.

Mindy Henderson: Yeah. So for younger people in the neuromuscular disease community who might be interested in becoming content creators themselves, what are a couple of practical tips that you would give them for getting started and building an audience?

Steffni Randle: Do it. If you want to do it, go for it. There's going to be negative people. There's going to be positive people. You're going to get negative whether you're doing good or not. I realize you could be doing the best thing in the world and someone's still going to have something negative to say and bring you down. It comes with a lot of positivity from a lot of people. Do what you want to do because we're all here on borrow time at the end of the day. We all have to answer to one person, and why dwell on things that you can't change? Because if we sit there and we dwell and we are sad for ourselves, we're not living life. So go on the limb and do what you can and pursue whatever you want to do.

Mindy Henderson: You kind of read my mind actually, because the next question I wanted to ask you was putting your life on social media means opening yourself up to the curiosity, the assumptions, and sometimes the criticism from complete strangers like you were talking about, what's been maybe the most surprising part of building such a large audience?

Steffni Randle: The negativity. I didn't know that the world could be so cruel at different points and different videos and things that they've sent. I just didn't know people though so negative of other people. So that is something that really took me by surprise.

Mindy Henderson: Yeah. I don't know. Is there kind of a number one strategy? When you see something that's just mean or that someone has the audacity to judge or say something critical about your life, do you have anything that sort of stands out in your mind about how you manage to just let it go or dismiss it?

Steffni Randle: I've grown over the years. I've been doing it for about four years, and I do struggle from anxiety and depression. And so having to juggle that in the beginning, there would be days where I would just lay in my bed and I'm like, "Wow, these people hate me for what?" And then over the years, it's like they're not in your shoes. They don't know what you go through on a day-to-day basis. They're looking at you from the outside.

And like people have said, misery loves company. So you have to really think about, hey, they could be going through something worse or a family member and they just don't know how to tell you, "Hey, you're doing great." So they come at you with anger and things because they want to maybe pursue content like I am, but they can't. So I just take it as like, "Hey, you don't know what I'm doing. I get up every day and I do this, so your opinion is irrelevant."

Mindy Henderson: You know what? I really love your perspective on this because it's one thing, and I think that I look at people like you who have this crazy success, and then the haters that come after you and say the most unimaginable things, and I think about it from the perspective of what makes you think that you know anything about Steffni or anybody else, but I love what you said kind of in the opposite direction of you don't know them and what's making them or what's contributing to that kind of negativity or ugliness. And it's a really generous perspective, I think, to have, and a really healthy one, honestly. How do you decide then which parts of your life you are comfortable and willing to share and how do you decide maybe this is private, nobody else gets to see this?

Steffni Randle: I noticed that a lot of people, well, there's really not a lot of people that share their story on Duchennes muscular disease. So to me, it's very important to be raw and very authentic with it because there are people that really do care and want to know, "Hey, how do you get in your car? How do you go outside? How do you go to store?" So I think over the years I was very closed off, of course, because of the negativity. But as I've grown, there's a lot of people that really do support me and they really do care about how things are done.

So that's what, from the beginning, I said if I was going to do this and put my story out, I was going to be very raw with it and show people. When I leave this world, I want people or younger people to be like, "Hey, I got motivation because Steffni showed me this, so now mom, let's go and try this. Maybe it'll work for me." So it's very, very important that I share a lot of things.

Mindy Henderson: Yeah, I love that. And your story has also attracted attention beyond social media. We're talking a lot about social media, but it doesn't even stop there. There was a video feature about your life. So I have two questions to that end.

The first question is, what do you hope that people outside of the disability community take away from seeing your story? Let's start there.

Steffni Randle: That nothing is impossible until you make it impossible. Everything is literally possible. As long as you try, it's very important that you just say, "Hey, if it didn't work, at least I tried it and it didn't work." Everybody just needs to try. And sometimes we have negative fallbacks, sometimes we have positive, so you won't know unless you try.

Mindy Henderson: Oh, I love that. So then my next question is, what do you hope that people within the neuromuscular community or the broader disability community take away from seeing your story?

Steffni Randle: That we all go through very tough parts in our life, and we are all kind of the same in our little disability area because there are a lot of people that aren't like us. So I say reach out to other people in our community and talk amongst them and hey, we could figure out things that work for us that work together. And it's very important for them to know that not every day is going to be perfect. We all have bad days. We all have good days, and that's where my saying comes. It's just a bad day, not a bad life, is what I tell myself when I'm having my bad days.

Mindy Henderson: I love that saying. So apart from reminding yourself of that, what do you do on those bad days, those hard days to make yourself feel better or to pull you out of maybe some more negative feelings that we all, of course, have?

Steffni Randle: Little screenshots of when people have reached out and said the most wonderful things, and I will go back when I'm feeling down and I'm laying there and I go back and read those and I'm like, "My story is touching somebody." I have people tell me just running across your video, "You saved me today. You saved my mental." And those things really mean the world because that's all I've wanted to do since I was little. I literally used to tell my mom, "I'm going to be known around the world before I leave for being an inspiration." And now it's like my dreams have come true.

Mindy Henderson: Yeah, you're doing exactly that.

Steffni Randle: Yes, ma'am.

Mindy Henderson: I love that. And I have to circle back to what you said about connection and community, because I've said it before, I'll say it again. I don't think there's any better community than the neuromuscular community. It's such a supportive part of the world to be a member of. Yes, ma'am. It's not always fun to live with a neuromuscular disease, but some of the most supportive, kind people, and it just seems like everybody wants to help everybody. And so I think you're exactly right. I love that you said that.

Steffni Randle: Yes, ma'am.

Mindy Henderson: You also said, and I'm getting a glimpse of this, and just in talking to you, you're such a positive person, you've said that one of your biggest dreams is to become a motivational speaker. What message, I mean, you've already brought us some really good messages that could last for the whole next year, but what messages do you most want to bring to the world? And when you think about the next chapter of your life, what are you the most excited to pursue?

Steffni Randle: Last month, I had a very big opportunity to be a part of the Disability Comic-Con that took place in Houston.

Mindy Henderson: Really?

Steffni Randle: I was invited, and so that was my first big influencer project, and I was there for a motivational speaker, and I just really want to bring light to people's darkness. There is light at the end of the tunnel, and I'm excited to continue not only to share my story, but to share others. I mean, I want to be there if someone is scared to share their story with the world and they're like, "Hey, Steph, can you help me with bringing my story out?" I would love to do those things. I would love to... One thing that I do say is that I've grown enough to handle being bullied on the internet, and if a person could come and bully me and not go to the next person that's probably on their last straw, bring it to me. Come on.

Mindy Henderson: Oh my gosh, that hit me right in the heart. That is so sweet.

Steffni Randle: Yes, ma'am.

Mindy Henderson: Wow, that's incredible. Now I've got goosebumps, and what a kind thing to say. Are there any other projects coming up that you're allowed to talk about or anything that you can give us some sneak peeks into that you're going to be spending your time on?

Steffni Randle: So we have a lot of little podcasts lined up with different people coming up within the next couple of months, and hopefully I'll be transitioning to live in Houston coming up. So we're going to be doing a lot of little things out there and collabing.

Mindy Henderson: Amazing. Houston's a big, big city. That's a big move.

Steffni Randle: Yeah, there's not a lot of content creators here or anything like that in Lubbock, so I'm ready for my journey to expand.

Mindy Henderson: Is there anyone that comes to mind that would be your dream person to work with? Let's put it out there in the universe.

Steffni Randle: Honestly, I would love to work with... You know how Selena Gomez has her makeup line?

Mindy Henderson: Yes.

Steffni Randle: But her story behind her illness and everything that she goes through really inspired me. And also Demi Lovato with all of her things, her challenges that she's overcome and things like that. I really love how they've strived and how they've overcome their things. And so I just feel like we kind of are similar in ways, and those are two people that I really look up to and I've always looked up to.

Mindy Henderson: Yeah. Well, you would definitely enrich their lives and their work that they do. So Selena, Demi, you heard it here first. Call Steffni.

Steffni Randle: Thank you.

Mindy Henderson: My last question, and I could talk to you for all afternoon, but you've built your platform, you said it just a little while ago, around this message that a bad day doesn't mean a bad life. For someone listening who maybe is having one of those particularly difficult days today, what would you want them to hear from you?

Steffni Randle: Don't let it define your day. We don't like to say it, but there's worse situations, people in worse situations than what we're going through now. And so don't take time for granted. Don't take life for granted because with me being able to do my makeup every day, there's people that can't even use their arms or anything. So that is something that I really think about on my bad days. Like, hey, there's someone out there that's worse than me that's going through it. Get up and continue.

Mindy Henderson: Yeah. Well said. I can't think of a better note to end on. You are absolutely incredible. You are everything that I knew you would be when we scheduled this interview. So I just thank you for your time and for your willingness to share your story and your desire to help other people.

Steffni Randle: Yes, ma'am.

Mindy Henderson: It's really a good-

Steffni Randle: I really, really appreciate this opportunity to get to share my intake on DMV and things like that.

Mindy Henderson: Yeah. Well, you're doing amazing things for the world, and I know that it's only going to continue to get bigger and better. So I am going to keep watching your journey, and I hope you'll come back. I would love to talk to you again.

Steffni Randle: Of course. Yes, ma'am. Any opportunities, just give me a call.

Mindy Henderson: Absolutely. Well, thank you so much, Steffni.

Steffni Randle: Thank you.

Mindy Henderson: Enjoy the rest of your day.

Steffni Randle: You too.

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 world.